

Oireachtas Special Committee on COVID-19 Response Submission



Executive Summary

COVID-19 has had a damaging impact on cancer patients and people anxiously awaiting important diagnostic tests and screening.

212 COVID-related deaths in cancer patients have been recorded to dateⁱ, but we have yet to see the full scale of its secondary impact on cancer mortality due to delayed diagnoses and treatment. However, as COVID-19 case numbers thankfully subside and society “re-opens”, urgent action is needed to prevent excess secondary cancer deaths as a result of restrictions.

Early indications from other countries suggest significant decreases in cancer survival in high-income countries could happen as a result of COVID-19, which would dwarf the number of deaths caused by COVID-19, and reverse hard-fought improvements in recent decadesⁱⁱⁱⁱ.

The Irish Cancer Society does not believe that this is inevitable, however. While the pandemic thrust a cruel psychological, social and economic burden upon already vulnerable patients, further anguish can be prevented.

The State must redouble its efforts to improve patient care, quality of life and survival, and implement a structured and funded recovery plan to support cancer patients and the thousands more awaiting a diagnosis.

This submission is informed by the Irish Cancer Society’s engagement with patients, people waiting for diagnostic tests and screening, clinicians and Government and public health officials, and below are a number of key recommendations we wish to see actioned by Government to prevent the worst predictions and build the best possible future for cancer patients.

Overview of Recommendations

1. Make ring-fenced funding available for a HSE recovery plan and publish contingency planning for a second wave of COVID-19, that prioritises continuity of cancer services;
2. Take urgent action on waiting lists by using short term interventions, including appropriate triaging, prioritisation based on clinical need and utilisation of all available capacity
3. Perform a rapid capacity review of cancer services to assess current capacity and demand;
4. Address reduction of capacity due to social distancing by making immediate investment in temporary builds while committing to overdue investment in oncology day wards, operating theatres, community diagnostics, elective-only hospitals and a comprehensive cancer centre;
5. Appropriately resource diagnostic, radiology and laboratory departments to allow timely access to investigations for both hospital doctors and GPs in the community;
6. Recruit and retain more doctors and healthcare professionals. There are now over 500 vacant consultant posts (not just cancer), while a comprehensive workforce plan for cancer services remains unpublished;

7. Clear communications campaigns are needed on the signs and symptoms of cancers, in light of drops in GP presentation and referral
8. Ensure appropriate diagnostic and treatment pathways are available to screening services upon resumption;
9. Future-proof health services by focusing on expedited delivery of the National Cancer Strategy and Sláintecare;
10. Expand national psycho-oncology service to match existing demand and cater for additional cases of distress caused by COVID;
11. Provide clearer communication to “extremely medically vulnerable” patients around protection measures and employment, and examine social protection supports for those still unable to return to work;
12. Maintain “community call” supports at local authority level.

Cancer Care under Coronavirus – a picture

1. With the introduction of restrictive measures to address the COVID-19 crisis, the healthcare system adapted quickly to new challenges in anticipation of a potentially disastrous scenario for our health services. However, this approach relied heavily on the redistribution of resources of non-COVID care, including cancer, alongside new arrangements with private hospitals. Though some measures have mitigated disruption in continuity of care, cancer care faces a range of new and complex challenges.
 - 1.1. COVID-19 highlighted the vulnerabilities and weaknesses in the public healthcare system.
 - 1.1.1. The healthcare system did not have enough capacity to address the COVID-19 situation; rather it redistributed already stretched resources and capacity from vital areas, such as screening and cancer services, to COVID-19 care.
 - 1.1.2. The fundamental weaknesses and under-resourcing of the public healthcare system must be addressed. The Irish Cancer Society has called and continues to call for increased investment in services to better cope with the backlog of screening, diagnostic services and the future treatment needs of those who may be diagnosed later without appropriate intervention.
 - 1.2. Weighing up the risks in responding to the COVID-19 crisis meant pausing screening services and surveillance procedures, and postponing many non-urgent services.
 - 1.3. COVID-19 is an unprecedented challenge for the healthcare system. Given the gravity of the situation, many aspects of the health system came to a halt to stop people dying in the short term from COVID-19. However, as a result of pausing many necessary screening and diagnostic procedures, there may be a wave of secondary deaths in addition to people who will become seriously ill.

Recommendation: To mitigate against negative impacts on cancer diagnosis and treatment if there is a second wave of COVID-19, the government, HSE and NPHET must publish and resource a contingency plan for the management of healthcare (patient flows, redirection of services from hospital to primary and community care and resumption/continuation of cancer care at non-COVID sites, among other measures).

2. There was concern among the public about accessing healthcare services due to COVID-19 restrictions, and this led to a drop in patient presentation to GPs and referrals for diagnostics. This has been observed across a number of other European countries, with a drop of 360,000 in regular referrals (not just cancer) by GPs in the Netherlands,^{iv} and falls in urgent referrals for early cancer diagnosis 60% in England,^v and by 70-89% at eight UK hospitals.^{vi}
 - 2.1. This largely centred on patient fears of contracting COVID-19 at GP clinics and the perception that their symptoms may be less important than those of COVID-19 and not wanting to “burden” GP services. The Irish Cancer Society, doctors’ representative bodies (IMO and ICGP) and the National Cancer Control Programme all urged patients to get signs and symptoms checked.
 - 2.2. Early GP referrals are vital in ensuring survivorship.^{vii} In May 2020, e-referrals by GPs for suspected breast cancers reduced by 55%, lung referrals dropped by 61%, prostate by 50% and pigmented skin lesions by 72.3% on pre-COVID figures.^{viii} This comes despite recent improvements in e-referrals across each of the aforementioned areas^x thanks to communications efforts, however the significant fall in referrals is very worrying.
- 2.3. It is likely that there will be a secondary effect of COVID-19 in which people who have experienced delays in getting a diagnosis for a serious illness, including cancer, will experience poorer outcomes and smaller chances of survival compared to cancers caught at an earlier stage.

Recommendation: While the referral numbers are improving since May it is important that public messaging is clear to ensure that the public understands the signs, symptoms of cancers and recognise that there are clear pathways to investigate and diagnose symptoms, and the National Cancer Control Programme must take steps to communicate this widely.

This must be supported, however, by available diagnostic services.

3. Waiting times for diagnostic procedures have grown exponentially.
 - 3.1. Wait times to access colonoscopy procedures have grown. Wait times for colonoscopies have already been a cause of concern with 11,953 people waiting over 3 months for a procedure in February 2020.^x However, COVID-19 has exacerbated an already existing problem, and as of 19 June 2020 a total of 2,627 people were waiting for an urgent colonoscopy. Of these people, 1,004 were waiting longer than 28 days, and 329 have been waiting longer than 90 days.
 - 3.2. Presently, urgent colonoscopies are highest priority and it remains to be seen when the circa 16,000 non-urgent cases waiting for tests will have a colonoscopy. Despite being classified as non-urgent, this includes people with cancer symptoms and some will ultimately face a cancer diagnosis.
 - 3.3. Significant investment is required across endoscopy services to clear backlogs. There is currently no clear plan as to how to address the backlog of colonoscopy wait times and, going forward, how to provide this procedure for the people in a timely manner.^{xi}
 - 3.4. The waiting times for elective procedures have inevitably grown, given that elective procedures were paused at the beginning of public health emergency response, the inpatient/day case waiting lists have risen by over 29% on pre-COVID figures to 87,238 people.
4. Some aspects of the health response to the COVID-19 supported cancer care.
 - 4.1. Where the use of private hospitals for cancer care worked well, it offered continuity of care for some existing public patients, though it may have proved somewhat disruptive to normal schedules.
 - 4.2. The National Cancer Control Programme and Cancer Policy Unit in the Department of Health made significant efforts to ensure that treatment continued for patients along with emergency and urgent diagnostics continuing for the most part.

Recommendation: The government was able to ensure additional capacity was available to deal with the COVID-19 emergency. It is clear that decisive action can be taken to ensure the best possible outcomes for public health can be achieved. It is now imperative that a recovery roadmap is promptly published and appropriately resourced to ensure that people waiting for diagnostic services and eventually cancer treatment can have swift access to services and care.

5. COVID-19 has had an impact on how we deal with the social, psychological and end-of-life care for cancer patients, particularly as many people need to be cared for in a community setting.
 - 5.1. The Irish Cancer Society experienced an increased demand (by 20%) for our Night Nursing services for patients choosing to die at home.^{xii} Our Night Nurse service provided over 1,000 nights of care for people in their home.

The Current Picture and impact on cancer patients

6. The overwhelming majority of cancer patients on active treatment have been deemed “extremely medically vulnerable”, while all cancer patients have been classified as “high risk” by the HSE. For those who are cocooning there is some confusion as to whether there is an end in sight and how

prescriptive measures will be under new phases. Cocooning has also had a significant impact on livelihoods and family life, and is a cause of social isolation, increased anxiety and diminished mental health.

- 6.1.** People cocooning are deemed medically vulnerable; therefore, their quality of life, and potentially that of their household, has been significantly altered as a result of COVID-19 and their need to restrict their movements and contacts.
- 6.2.** Of 1,389 cases of COVID-related deaths, where information was available on underlying conditions, patients with cancer accounted for more than 1 in 7 deaths and 1 in 8 COVID-related hospital admissions. Cancer patients are acutely aware of their risk and this contributes to anxiety and distress.
- 6.3.** The social and mental impact of cocooning and anxiety around COVID-19 is deleterious to those cancer patients deemed “extremely medically vulnerable”. This can be seen in the significant increase in calls to our Cancer Support Line since the start of the pandemic of 63%, and uptake of our new remote counselling service, launched in partnership with Cancer Care West and the National Cancer Control Programme, which has provided 121 referrals to date. This includes pathways for psychology services for those who are suffering distress, but is no replacement for a national psycho-oncology service, which is still very much in its infancy and in need of investment and infrastructure.
- 6.4.** In response to health, social and financial challenges and increased anxiety, the Irish Cancer Society has galvanised its frontline services through additional counselling, extending our Cancer Support Line to operate seven days a week, and providing new and additional benefits and entitlements advice. Demand for our Night Nursing service which provides vital end of life care has increased and we have recruited an additional 10 night nurses to meet demand.
- 6.5.** Although many aspects of social and economic life are restarting, COVID-19 is still a real threat for public health. Vulnerable people are in a precarious situation not only in terms of their health outcomes should they contract COVID-19, but may also be financially vulnerable.
- 6.6.** Around 40% of people diagnosed each year are of working age and many continue to work, even during treatment. Some of those who are deemed “extremely medically vulnerable” and have been advised to cocoon face huge workplace challenges. Those who are unable to work from home, for example, those in the retail or hospitality sectors, may be forced to put themselves at risk out of fear of large drops in income at a time when they’re already [financially vulnerable](#). A lack of access to new COVID Social Protection payments and targeted supports compounds this vulnerability.
- 6.7.** Thankfully, since March, the pausing of reviews of medical cards due for expiry by the HSE Primary Care Reimbursement Service (PCRS) has provided some financial respite for cancer patients with medical cards.
- 6.8.** Action by the HSE, following representations by the Irish Cancer Society, to extend the allowance for cancer patients to procure wigs and hairpieces by €80 to cover scarves and bandanas while wig fittings are not possible due to distancing restrictions is welcome.
- 6.9.** Community supports, such as the “Community Call” programme run by local authorities have proven vital for cancer patients at a time of significant social isolation.
- 6.10.** Vulnerable people must continue to cocoon, even as much social and economic activity is restarting in Ireland. While these measures are in place to protect medically vulnerable people, this has implications on quality of life for many people.

Recommendations:

- **It is important to expand national psycho-oncology service to match existing demand for cancer patients and cater for additional cases of distress caused by COVID-19. This will support those who most need it through this difficult time.**
 - **Provide clearer communication to “extremely medically vulnerable” patients around protection measures and employment, and examine social protection supports for those still unable to return to work.**
 - **“Community call” supports at local authority level should be maintained.**
7. There is still anxiety around timely access to cancer screening, diagnostics and care
- 7.1. Screening services (CervicalCheck, BreastCheck and BowelScreen) have been paused since 18 March 2020. Though dates have been announced for the resumption of services, there will be significant backlogs, which may take months to clear.
- 7.2. Resumption of services relies on a number of assumptions, including assurances that downstream services like diagnostics and treatment will be readily available, the movement of staff who were previously redeployed back to screening services and ensuring sufficient supply of faecal immunochemical test (FIT) for issue to those eligible for the BowelScreen programme, for example.
- 7.3. Combined with significant pressure on diagnostic tests, the limited capacity to perform both screening and diagnostics may lead to later identification of cancers and pre-cancers and result in delayed treatment for some patients.
- 7.4. In June 2020, the Irish Cancer Society highlighted the high number of people waiting for urgent colonoscopy, many of whom have been waiting for their procedure over 28 days, which is the recommended maximum time a person should wait for this diagnostic procedure.
- 7.4.1. As outlined under paragraph 3 on the previous page, waiting lists have continued to grow for some diagnostic procedures, including colonoscopy. COVID-19 restrictions have exacerbated an existing problem in which the health service was unable to keep pace with demand and key performance indicators for performing timely colonoscopy procedures. The current COVID-19 health crisis has contributed to a situation where reduced capacity in the system, and the need to adapt hygiene and cleaning practices mean it is unclear how the current backlog of colonoscopy procedures will be cleared in a prompt manner, and immediate action is required to allow for innovation to support the clearing of waiting lists.
- 7.4.2. Early diagnosis is vital. Cancers which are detected early, at stage 1, have a higher survival rate at 5 years than cancers detected at a later stage. For example, in Ireland, colorectal cancers diagnosed at Stage I have survival rates of 95.4% after five years, compared to a 10.5% survival rate for those diagnosed at stage IV.
- 7.4.3. In the case of endoscopy procedures, non-urgent cases will continue to wait until all urgent cases are cleared, leaving great uncertainty for some, including people who have already been waiting upwards of a year for diagnostic procedures
- 7.5. People waiting for diagnostic tests used as part of continued surveillance for patients who have had a prior cancer or pre-cancer will face indefinite delays to care as symptomatic cases are being prioritised above everything else

Recommendations:

- **Future-proof health services by focusing on expedited delivery of the National Cancer Strategy and Sláintecare.**

- **Appropriately resource diagnostic, radiology and laboratory departments to allow timely access to investigations for both hospital doctors and GPs in the community**
- **Recruit and retain more doctors and healthcare professionals. There are now over 500 vacant consultant posts (not just cancer), while a comprehensive workforce plan for cancer services remains unpublished**
- **Current capacity and demand in cancer services should be captured through a rapid capacity review.**
- **Under-resourced areas of the health service should have ring-fenced funding, such as the Endoscopy Services and the Endoscopy Action Plan.**
- **Address reduction of capacity due to social distancing by making immediate investment in temporary builds while committing to overdue investment in oncology day wards, operating theatres, community diagnostics, elective-only hospitals and a comprehensive cancer centre**
- **Ensure appropriate diagnostic and treatment pathways are available to screening services upon resumption.**
- **Urgent action on waiting lists is required. The problem can be helped by using short term interventions, including appropriate triaging, prioritisation based on clinical need and utilisation of all available capacity**

Lessons learned

8. The COVID-19 public health crisis was unprecedented, and called for exceptional responses to ensure that our healthcare system and staff could respond appropriately in the public health interests with the least possible loss of life. The bullet points below summarise some of the key lessons from this crisis, applicable to other areas of prevention and management of disease, namely cancer:
 - 8.1. Resourcing is key to responding to any public health crisis/disease management. This was demonstrated in the response to COVID-19. As we face an uncertain future, understanding the personal and wider economic risks to illness, it is important to consider adequate resourcing and planning to help prevent, manage and survive cancer.
 - 8.1.1. Investment in historically under resourced areas such as endoscopy must be prioritised
 - 8.1.2. Vacant posts must be filled without undue delay.
 - 8.1.3. Community and primary care should be adequately resourced and empowered to conduct community care and diagnostics.
 - 8.2. The use of additional private capacity supported the delivery of cancer care, treatment and surgery in safe, non-COVID settings and allowed for a welcome boost in capacity for diagnostics, though limited by hygiene restrictions.
 - 8.2.1. Moving forward clear and costed plans and roadmaps will be required to demonstrate how the public health service will respond to backlogs and long wait times for screening and diagnostics, as well as capacity constraints for inpatients due to social distancing measures.
 - 8.3. The resumption of use of non-COVID sites needs to be examined as part of cancer-specific continuity planning for a “second wave”
 - 8.4. The pandemic exposed longstanding frailties in the health system and speak to the need to “build back better”, through the implementation of Sláintecare, which will need to be supported by provision of a Sláintecare transition fund

8.5. Cancer and elective-specific facilities need to be developed to “pandemic-proof” cancer. This includes the establishment of a comprehensive cancer centre, elective only hospitals and community diagnostic facilities.

ⁱ Health Protection Surveillance Centre. 2020. “Underlying conditions in confirmed cases of COVID-19 in Ireland”. Available at:

<https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/surveillance/underlyingconditionsreports/Underlying%20conditions%20summary.pdf>

ⁱⁱ [Pre-published paper] Lai, A. G., Pasea, L., Banerjee, A., Denaxas, S., Katsoulis, M., Chang, W. H., Williams, B., Pillay, D., Moursadeghi, M., Linch, D., Hughes, D., Forster, M. D., Turnbull, C., Fitzpatrick, N. K., Boyd, K., Foster, G. R. DATA-CAN, Cooper, M., Jones, M., Pritchard-Jones, K., Sullivan, R., Hall, G., Davie, C., Laeler, M., Hemingway, H. 2020. “Estimating excess mortality in people with cancer and multimorbidity in the COVID-19 emergency.” Available at: https://www.researchgate.net/publication/340984562_Estimating_excess_mortality_in_people_with_cancer_and_multimorbidity_in_the_COVID-19_emergency

ⁱⁱⁱ Round, T., Gildea, C., Ashworth, M., & Moller, H. 2020.

ⁱⁱⁱ Editorial, Lancet Oncology. 2020. “Safeguarding cancer care in a post-COVID-19 world”

Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7252123/>

^{iv} De Jong, J., Kroneman, M., Groenewegen, P, & Paget, J. 2020. “Maintaining Essential Services.” *COVID-19 Health System Response Monitor*. Available at:

<https://www.covid19healthsystem.org/countries/netherlands/livinghit.aspx?Section=3.3%20Maintaining%20essential%20services&Type=Section>

^v Mahase, E., “Covid-19: Urgent cancer referrals fall by 60%, showing “brutal” impact of pandemic.” *BMJ* 2020;369:m2386.

Available at: <https://www.bmj.com/content/369/bmj.m2386>

^{vi} IBID.

^{vii} Round, T., Gildea, C., Ashworth, M., & Moller, H. 2020. “Association between use of urgent suspected cancer referral and mortality and stage at diagnosis: a 5-year national cohort study.” *British Journal of General Practice* 2020; 70 (695): e389-e398. Available at: <https://bjgp.org/content/70/695/e389>

^{viii} Irish Cancer Society. 2020. “Irish Cancer Society concerned about decline in cancer diagnosis during COVID-19.” Available at: <https://www.cancer.ie/about-us/news/irish-cancer-society-concerned-about-decline-in-cancer-diagnosis-during-covid-19>

^{ix} eHealth Ireland. 2020. “National Cancer Control Programme Referral Data: eReferrals data for Cancer Services Statistics.”

Available at: <https://www.ehealthireland.ie/A2I-HIDs-Programme/eReferral/Latest%20Data/NCCP%20Referral%20Data/>

^x The National Treatment Purchase Fund. 2020. “IPDC Active Colonoscopy Totals by Hospital and Wait Times as at 27/02/2020.”

^{xi} Irish Cancer Society. 2020. “More than 2,700 people waiting for urgent bowel cancer test.” Available at: <https://www.cancer.ie/about-us/news/more-than-2700-people-waiting-for-urgent-bowel-cancer-test>

^{xii} Irish Cancer Society. 2020. “Nurses urgently required for increased demand in end-of-life care at home.” Available at: <https://www.cancer.ie/about-us/news/irish-cancer-society-nurses-urgently-required-for-increased-demand-in-end-of-life-care-at-home>