

Cancer Care Post-COVID: **An All-Ireland Approach**

Event report—16th June 2021



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Introduction

The coronavirus pandemic has had a devastating impact on cancer prevention, detection, treatment and support services for patients and their families across the island of Ireland since March 2020, as the new ‘big C’ of COVID dominates health services and headlines.

On the 16th of June 2021, over 80 stakeholders including patient representatives, clinicians, politicians and industry, came together as part of an exploratory discussion, ‘Cancer Care Post-COVID: an All-Ireland Approach’.

The interactive roundtable discussion examined the impact of the pandemic on cancer care on the island of Ireland, and the expert panellists suggested a range of key actions that policymakers could take to support the recovery and future resilience of cancer services on both sides of the border. The session was sponsored and hosted by MSD Ireland and chaired by Priscilla Lynch, Clinical Editor at Medical Independent, and this resulting paper outlines the key points discussed, the views and experiences of the speakers, and the potential solutions recommended.



Welcoming guests to the online discussion, **Managing Director of MSD’s Human Health** operations in Ireland, **Mairéad McCaul**, emphasised how all attendees were on a united mission to extend and improve the lives of people with cancer, and highlighted the importance of collaboration to achieve a generation-defining moment and beat cancer.

Speaking about MSD’s role in this regard, she said: *“For us at MSD, we believe that the most important thing we make is a difference and we always aim to take a patient-centric approach in all that we do. We also try to challenge ourselves continuously to innovate for the betterment of patients, healthcare providers and the wider healthcare landscape.”*








Priscilla Lynch began the discussion by setting some context and illustrating the significant impact that the COVID pandemic has had on the island of Ireland. Priscilla presented data that showed that, at the time of the event there had been *“nearly 125,000 cases of COVID diagnosed in Northern Ireland and over 2,100 deaths¹, while in the Republic, we’ve seen 267,000 cases of COVID-19 and almost 5,000 deaths²”*, highlighting how the island of Ireland had nearly 400,000 more sick people than it normally would.

Furthermore, Priscilla stated that in the context of cancer, over 45,000 people are diagnosed each year with cancer in the Republic of Ireland with just over 9,000³ deaths, and 9,600 diagnosed in Northern Ireland with a further and 4,000 deaths⁴. Linking the pandemic to cancer cases, Priscilla stressed the importance of prioritising cancer care going forward in the context of delayed diagnosis on the island of Ireland because of the pandemic, and in the likely event of a future increase in cases as the public return to our doctors surgeries, hospitals and routine screening appointments. *“This event is about turning the focus back to the real ‘BIG C’ ... Cancer”*, stressing how we must not forget about this common disease.

However, this is not an insurmountable task and many great innovative approaches have emerged from the healthcare sector since the start of the pandemic in continuing to deliver care while dealing with this new reality. With the right plans, backing and support, the huge impact of COVID on cancer care can absolutely be successfully addressed. Ireland is not alone in the challenges it faces, thus learning from the lessons of the pandemic both at home and abroad, and collaborating further with Northern Ireland, the UK and Europe is essential to both recovering from the pandemic and future proofing cancer services for better patient care and outcomes in the future.

Context

- Cancer causes **30%** of all deaths in the Republic of Ireland⁵.
- Before the pandemic, cancer diagnoses were increasing at a rate of approximately **5%** per year.⁶
- On average, **44,753** cancers or related tumours were diagnosed in Ireland in 2020, including⁷:
 -  **Lung: 2,753**
 -  **Colorectal: 2,819**
 -  **Breast: 3,704**
 -  **Prostate: 3,890**
 -  **Melanoma: 1,197**
- Cancer services across all levels have been significantly impacted as a result of the pandemic – screening, early diagnosis, presentation with suspicious symptoms, cancer treatment, follow up and support services, and surveillance of those in remission were all negatively affected⁸.
- **Up to 2,000** invasive cancers may have been missed last year due to the impact of COVID, the HSE National Cancer Control Programme estimates⁹.
- UK figures from DATA-CAN, the UK's Health Data Research Hub for Cancer revealed that seven out of ten people with a suspicion of cancer were not getting access to cancer diagnostics services in a timely fashion during the pandemic, while four out of ten patients were not receiving their chemotherapy at the appropriate time¹⁰.
- Patients were delaying reporting cancer symptoms due to reluctance to visit their GP over coronavirus concerns¹¹.
- The number of patients recruited to clinical trials fell by **45%**¹².

Participants



Professor Seamus O'Reilly,
Consultant Medical Oncologist at Cork University Hospital and Associate Professor of Medicine at University College Cork & Vice Clinical Lead, Cancer Trials Ireland.



Professor Mark Lawler,
Associate Pro-Vice-Chancellor, Professor of Digital Health, and Chair in Translational Cancer Genomics, Queen's University Belfast.



Margaret Grayson,
Chair of the Northern Ireland Cancer Research Consumer Forum, and lay member of the All-Island Cancer Research Institute Steering Committee.



Conor O'Leary,
Manager of Purple House Cancer Support Centre in Bray, Co. Wicklow, and member of Irish Association of Counselling & Psychotherapy

Executive Summary/Key Themes:



1. The COVID Challenge:

- Delayed presentation for potential cancer cases
- Diagnostic delay
- Volume of patients being seen was reduced
- People who had a suspicion of cancer could not get access to cancer services in a timely manner
- Delays in research and clinical trials



2. Unseen Patient Impacts:

- People are fearing a COVID diagnosis more than a cancer diagnosis¹³
- Increased isolation for patients as a result of cocooning, absence of physical contact from friends and loved ones
- Many cancer patients are in poorer financial situations due to COVID with job loss or the inability to provide for themselves adequately due to the risk of catching COVID by leaving the home
- Physical services had to go online to try and support cancer patients, which caused anxiety for patients as they felt they were not being 'seen properly'
- Some people thought GP surgeries were closed
- Healthcare settings were encouraged to reduce the numbers attending to avoid close contact
- People had symptoms but did not want to bother doctors
- Some patients losing their hair through chemotherapy had to have a wig styled and fitted by video call
- Newly diagnosed cancer patients had limited access to physical supports in the healthcare system



3. Mental Wellbeing:

- Lifestyle Oncology refers to how individuals might treat their cancer outside of a medical setting, such as mental health, wellness and complimentary therapies, diet and exercise
- As a result of COVID, cancer patients have had to be more cautious about their isolation, which led to a spike in mental health and psychological issues
- Grief and bereavement have been impacted – by funeral numbers being limited and the lack of opportunity for loved ones to be with dying patients
- There has been a significant impact on children who have cancer or live with those who have cancer – suffering from anxiety as they have been stuck inside for many months and must be extra cautious about socialising



4. Importance of Data, Messaging and Communication:

- Being able to track and report on data has been key
- Data allows health systems to inform, adapt, pivot, react and address issues – and you can't manage what you can't measure
- Impact of Public Health messaging on patients who stayed away from hospitals to protect the NHS/ HSE – this could have led to many missed diagnoses



5. HSE Cyber-Attack:

- COVID caused massive issues for the island of Ireland's health system; the cyber-attack that occurred in May 2021 further impacted on this
- The timing of the cyber-attack couldn't have been worse for patients and for healthcare providers
- Health systems were already playing catch-up, which is now further delayed and compounded by the cyber-attack
- Patients returning to treatment faced considerable further delays as a result of the cyber-attack



6. Importance of Vaccination Roll-Out for Cancer Patients and Health Workers:

- Vaccination has the potential to be a game changer for patients
- People should no longer fear attending hospitals now staff and clinicians have been vaccinated

Panel discussion

key participant points

Professor Seamus O'Reilly,

Consultant Medical Oncologist at Cork University Hospital
and Associate Professor of Medicine at University College
Cork & Vice Clinical Lead, Cancer Trials Ireland.



“The COVID pandemic has been very challenging on multiple fronts for patients and their families. However, we must get used to COVID being with us yet for some time. Our health systems have to adapt and remain robust. We need to work in parallel with COVID and adjust our services accordingly.”

Prof Seamus O'Reilly directly discussed the impacts of COVID in terms of both interventional Oncology and Lifestyle Oncology in Ireland. *“The disruption that occurred in the first and second waves really led to delayed diagnosis for many, and also to a backlog in services, some of which have not been fully restored”* he said. *“The need for social distancing has also meant that the volume of patients being seen has also been significantly (contemporaneously) reduced.”*

Talking about Lifestyle Oncology and the unseen impacts of COVID, Prof O'Reilly highlighted the significant and detrimental impact the pandemic has had on cancer patients. From his experiences, Prof O'Reilly commented that if his patients' mental health dis-improved, it was more likely that their health outcomes will be worse as a result. This can be anything from the stresses of COVID on sleep, friendships and relationships, physical activity etc.

Highlighting the difficulty facing consultants in quantifying the impact COVID on cancer patients, Prof O'Reilly cited one piece of French research from the COVIPACT Trial, which was previously presented at the American Society for Clinical Oncology (ASCO) Congress, and which showed that *“20% of patients were at risk of post-traumatic stress disorder while under a lockdown¹⁴”*.

Commenting on the need for increased proactivity and messaging with patients, and the importance of resumption of cancer screening services Prof O'Reilly commented that: *“I think CervicalCheck has been very much at the vanguard of demonstrating a catch-up programme, public engagement, social media engagement, etc, which is needed really for our colorectal and breast cancer screening programmes also. Data suggests that colorectal could be the worst impacted, so I think if I were in a position of influence, I would look at frontloading diagnostics, endoscopy, and I would maximise endoscopy capacity, and radiology capacity in the country in the next couple of months to catch up.”*

Panel discussion — key participant points

Alongside the need for increased awareness campaigns, Prof O'Reilly also warned about the impact that COVID has had on health professionals and GPs over the past 18 months, with high levels of exhaustion and burnout being reported, and the need for robust systems.

"Access to care is an issue, even with the best will in the world. We've a world class general practitioner service in Ireland; they have been working incredibly hard, most of them would indicate that they have been working the hardest they have ever worked in their lives and there is very little relief for them in terms of locum cover and holiday relief. I mean, they are outstanding, but if a system is overwhelmed, it does not matter how outstanding the people are."

The final point made by Prof O'Reilly related to the significant importance of COVID vaccination and the rollout of vaccination services in Ireland. *"Nobody is safe until everybody is safe and the COVID gamma and delta variants that are affecting our healthcare system now are rising in countries with low vaccination rates. When I was vaccinated on New Year's Eve and I arrived home, my children were ecstatic. I had totally underestimated that they were terrified they would bring COVID home and that patients could potentially die as a result of their actions, and by passing something on to me. I suspect that many other healthcare workers would have children which would have seen or have concerns that may or may not be vocalised."*



HSE Cyber-Attack:

In addition to the significant impact that the COVID pandemic has had on cancer care on the island of Ireland, patients have been further impacted by the cyber-attack on the HSE which occurred in May 2021. Commenting directly on the impact of the cyber-attack on patients, Prof. O'Reilly said *"COVID was a speed-bump, and the cyber-attack was a mountain on the motorway"*.

Further compounding the impact of COVID on patients across Ireland, Prof. O'Reilly elaborated on the magnitude of the cyber-attack, which *"had not been fully reflected publicly, especially at a time when health services were already playing catch-up"* ...*We've recognised the fact that we already need catch-up programmes for patients, but now, we're right in the middle of a ransomware attack which has really magnified the difficulty for patients and for healthcare providers in coping."*

Since the start of the cyber-attack, patients have been impacted in several different ways. This was further brought to life by Prof O'Reilly: *"If patients were in the middle of radiotherapy for breast cancer, and you were in your first week of treatment, that treatment was frozen completely for two weeks. If you had a head and neck malignancy, or an aerodigestive malignancy that was about to obstruct, your care was transferred to another hospital. Your detailed planning, your radiology, all of that was frozen in a system which was inaccessible, your radiotherapy notes, your clinical records, all of that. If you were coming in for surgery, you might know what the operation was, but the anaesthetist had no records of the theatre list, no records of your pre-op bloods, the surgeon had no access to your pre-op radiology which indicated where your surgery was even supposed to be"*.

Panel discussion — key participant points

Prof Mark Lawler,

Associate Pro-Vice-Chancellor, Professor of Digital Health,
and Chair in Translational Cancer Genomics,
Queen's University Belfast.

“How can we work better together, cancer and COVID share no borders. We need to share expertise across the island of Ireland to resolve the key issues for patients. If we share our knowledge, bringing it all together means that we will be greater than the sum of all of our parts.”



Prof Lawler has a strong commitment to patient-centred research and care and to addressing cancer inequalities. His work on COVID and its impact on cancer services and patients has received both national and international attention and he co-chairs the European Cancer Organisation's Special Focussed Network on COVID and Cancer. The work also recently received the Royal College of Physicians Award for Excellence in Patient Care

During the webinar, he stressed the importance and role of high-quality data in assessing the impact of COVID on cancer services at all levels and enabling an evidence-based approach to address these issues so that policy makers can see what is needed and what works. In his opening remarks, Prof Mark Lawler shared an engagement he had with a Croatian colleague which sparked his concerns about the impact of COVID on Cancer. He said, that “people in Croatia were fearing a COVID diagnosis worse than a cancer diagnosis. And that really worried me, and it also got me thinking in terms of Northern Ireland and across the UK, do we have data to either support or refute this statement?”

On the back of this engagement, Prof Lawler and his team reached out to hospitals in the UK and Northern Ireland to gain better insights and identify data to determine the impact of the pandemic on cancer services and cancer patients. This work was done through DATA-CAN, the UK's Health Data Research Hub for Cancer¹⁵ (Prof Lawler is Scientific Director of DATA-CAN). Speaking about the results he said: “What we found was really worrying.”

According to Prof Lawler's research, it was discovered that: “When we looked for example at the cancer diagnostic pathway, the people who had a suspicion of cancer were not being seen by cancer specialists. So, seven out of ten people with a suspicion of cancer were not getting access to the cancer diagnostic services they needed in a timely fashion. And we then looked at the cancer treatment pathway. So, we looked, for example, at chemotherapy attendances for clinic, and in terms of chemotherapy treatment, we found that four out of ten people did not have a chemotherapy attendance as it was delayed due to COVID¹⁶.”

Panel discussion — key participant points

Highlighting the breadth of the impact the pandemic has had on cancer care, he explained that it is not isolated to just one part of the cancer care pathway but instead permeates into all areas of the patient's experience. COVID has impacted cancer screening, presentation, diagnosis, treatment, cancer clinical trials, cancer research and more¹⁷. He emphasised the important role that data sharing across borders can play in informing policy and decision-making processes, for the benefit of patients, and ensuring the best use of scarce resources.

Prof Lawler also highlighted how capturing real-time data was essential to making informed decisions and better understanding the realities of the situation faced by patients, hospitals and clinicians alike.

"If you are trying to use data that might be three or four months old, it would be like trying to combat cancer and COVID with one hand tied behind your back. We need real-time data to allow us to assess what the situation is, and then use that data intelligence to act appropriately."

Further, he commented that collaboration is key when it comes to data and urged the Republic and Northern Ireland as well as the UK and EU to make more data available and work together to have similar data gathering approaches, to enable easier pooling and sharing of data to ensure robust findings that can be acted on. *"If we share our knowledge, bringing it all together means that we will be greater than the sum of all of our parts,"* he commented, referencing better sharing of resources on the island of Ireland.

Finally, and in addition to data, Prof Lawler discussed the importance of the restoration of confidence in cancer services and the critical need to clear any backlog of patients awaiting access to cancer services.

According to Prof Lawler, based on a new study that he and his colleagues have just completed¹⁸, in the EU *"there are probably 1 million people yes, 1 million people walking around with a ticking time bomb that could be a cancer. So, the time to act is now. We need to get that message across to our politicians, and in information campaigns across to people to say yes, your GP services are safe to attend, your hospital services are safe to attend, and there's no time to waste."* Prof Lawler is fronting a pan-European campaign called Time to Act¹⁹, to highlight the need for immediate action on COVID and cancer²⁰.

During the discussion, Prof Lawler highlighted the European Cancer Organisation's Seven Point Plan to help address the calamitous impact of COVID on European citizens, patients, and services. In the seven-point plan, the European Cancer Organisation proposes the following urgent recommendations to national governments, the EU, WHO Europe and others to:

1. Urgently address the cancer backlog
2. Restore the confidence of European citizens and patients in cancer health services
3. Tackle medicines, products, and equipment shortages
4. Address cancer workforce gaps across the European continent
5. Employ innovative technologies and solutions to strengthen cancer systems and provide optimal care to cancer patients
6. Embed data collection and the rapid deployment of cancer intelligence to enhance policy delivery
7. Secure and sustain deeper long-term European health cooperation as a key learning from the crisis.²¹

More information on the Time to Act campaign is available at www.europeancancer.org/timetoact

Prof Lawler also highlighted the importance of patients being central to the conversations and actions that need to take place and highlighted how DATA-CAN have led the way in patient and public involvement and engagement (PPIE) which has been a vital part of the response to COVID²².

Panel discussion — key participant points

Margaret Grayson,

Chair of the Northern Ireland Cancer Research Consumer Forum and lay member of the All-Island Cancer Research Institute Steering Committee.



“Alongside collaboration, the numbers and the statistics – ‘actions’ are needed. Actions that will lead to decisions being made to help patients regarding cancer services. The voice of cancer patients and carers must be at that table when those decisions are made. Policymakers need to listen to concerns of staff and their ideas, and to the concerns and ideas from patients as well.”

Cancer survivor and patient advocate Margaret Grayson discussed how the pandemic had impacted patients on so many levels, many unseen and unquantified.

Building on other conversations about ‘Fear of COVID,’ Margaret elaborated on the importance of the message being communicated by policymakers and governments to the public and those most vulnerable. She said:

“Take last March, and we got a very strong public health message. It was very strong, because it came out 24/7. It was in newspapers, TV, social media, everywhere. And that message was to stay at home, protect the NHS. And it is a strong message that people took on board.”

As a result of the fear of COVID over cancer, Margaret said that *“People told me that they thought the GPs were not open, that they were closed for business. And in fact, they were open, but business was being done in a different way. So, I know people who had symptoms last year, but did not want to bother their GP because they thought that was not doable. And in fact, they were diagnosed quite recently with stage four cancer... what difference that might have been in relation to treatment plans and survival.”*

Every figure behind all the data is a real person with family and with friends, Margaret reminded the audience. *“When you walk in a room, and somebody says three words, ‘you have cancer,’ you walk in a person, and you come back out with a patient label which says you are a cancer statistic.”*

In the context of COVID, this experience became even more difficult, she noted. *“And now thinking, how difficult that must have been for people, not able to be with friends or family, not able to have that physical touch of a hug, not able to have all those support systems. The anxiety from the cancer diagnosis and treatment and the anxiety caused from COVID.”*

So many already emotional cancer experiences were compounded and made more difficult because of the COVID-related restrictions. *“But can you imagine walking in to have your chemotherapy done and losing your hair. There were no face-to-face appointments. So traumatic enough losing your hair, but you had to have your wigs styled and fitted by a video call. I can’t quite imagine what a difficult experience that must have been for patients.”*

Margaret also pointed out that it wasn’t just newly diagnosed patients or current cancer patients undergoing treatment who were affected by the restrictions and health service disruptions of the pandemic - patients in remission or under active surveillance were also very impacted and fearful that if their cancer came back, it wouldn’t be picked up in time, given that review scans and tests were delayed.

Margaret, a cancer survivor herself, said: *“I had my review appointment by telephone, and I accepted that and just was happy to be speaking to my consultant. But then a friend who was to see a breast cancer specialist could not cope with the fact that she hadn’t had a physical examination. And for her, mentally, it was what’s happening to my cancer because nobody’s actually seeing me.”*

She also stressed the need for patient involvement in putting together any plan to deal with the current cancer backlog and any future service disruptions and changes, for example, when considering moving services remotely.

Margaret finished by saying, *“Many things have had to change and be adapted. And I would just want to say thank you to the oncology teams, to the healthcare professionals who’ve looked after patients to try to make the best decisions through a very difficult time.”*

Panel discussion — key participant points

Conor O’Leary,

Manager at Purple House Cancer Support Centre and member of Irish Association of Counselling & Psychotherapy



“Patients have shown us what they’re willing to embrace under a new way of working remotely. We need to meet their expectations and collaborate. One all-island voice would be vital to ensuring the needs of cancer patients are met.”

Conor outlined how his service pivoted to provide online and practical support to cancer patients during the pandemic. He explained the isolation and fear felt by cancer patients who had to deal with the twin fears of COVID and cancer at the same time, while losing so much of their vital in-person support services and relationships, having to cocoon to protect themselves. *“The impact on children is massive, and they’ve been out of school, particularly children who are living with cancer, but then also may have a sibling or a parent with cancer, they have been severely impacted on issues such as anxiety, and social isolation, and fear, they are all coming to the fore now and we are starting to see here an increase in counselling services and the increase has been impacted with many containing their distress during the last year.”*

Conor outlined how his service provided practical care in the form of delivering groceries to vulnerable cancer patients. *“Because a patient was on chemotherapy or radiotherapy, they could not risk getting COVID, so they could not risk going to the supermarket to do the shopping”.*

While Conor noted that Purple House frequently sees cancer patients who are at risk of poverty, (through job losses, being lone parents, etc), the risk of contracting COVID meant many more vulnerable cancer patients had to give up work, further increasing their poverty risk.

Calling for more supports for community-based cancer support centres, Conor anticipates *“A tsunami of mental health and psychological issues”* because of the impact of COVID. *“...we fear, managing that increase in the mental health effects because of COVID over the number of weeks and months ahead is going to be a huge challenge I think for everyone across this country.”*

Panel discussion — key participant points

He finished by calling for a national funding model *“for community based and cancer support centres”*, to enable them to better meet the growing demand for their services. *“So, in Ireland today, community-based psycho-oncology services are broadly owned by charities which rely on fundraising to provide those services. And if we are to continue to be able to meet the demands and the increasing demands for the emotional and mental health aspects of cancer, there needs to be an adequate funding model, and to stop this reliance on fundraising. But if psycho-oncology is to be taken seriously, and psycho-oncology is mentioned in the National Cancer Strategy as an integrated part of patient’s overall cancer care, and adequate funding needs to follow”*.

Next steps and actions recommended by the panel:

1. Develop a dedicated, all-island funded action plan with key targets and timeframes to deal with the impact of COVID on cancer care and cancer patients. An all-Ireland committee or consortium should be established to own and manage this plan, as per the existing example of the Ireland – Northern Ireland NCI Cancer Consortium which has achieved so much in the last 21 years and which has recently been rejuvenated and re-signed²³. Ensure patients are at the centre of these plans.
2. Prioritise the types of cancer most impacted by the pandemic to address delayed diagnoses and develop a specific action plan for each cancer.
3. Build confidence among patients to attend hospitals, attend routine appointments and present with symptoms as soon as they appear, in both Northern Ireland and Republic of Ireland. Develop all-island awareness campaigns to encourage anyone with concerns or symptoms to present to their GP or healthcare professional urgently.
4. Invest in better data collection and research – create the necessary structures to allow for data to be collected in ‘real time’ and shared among relevant bodies throughout the island, EU and globally. Ensure data is used by policymakers for evidence-based solutions and that the patient voice is central to the data collection process. A recent report by the All. Can initiative, ‘Harnessing data for better cancer care’, provides insights into how this can be achieved and best practice examples from other countries²⁴.
5. Better integrate existing voluntary, private and national cancer health services. Build awareness of the services that are available to cancer patients and effectively communicate about them, rebuilding confidence in these services in the process and ensuring better value for money, avoiding duplication of existing resources.
6. Reinvigorate cancer clinical trials and research – multi-annual funding to allow for better planning and stability and increased awareness of what is available for patients.
7. Further collaboration between Ireland and Northern Ireland, UK and European cancer services. Continue to listen to the needs of the patients across the entire island of Ireland and ensure access to the supports they need in interventional oncology and lifestyle oncology.
8. Develop a national funding model for community-based psycho-oncology support centres.
9. Improve patient involvement in cancer service design – ensure that the patient voice is heard and at the heart of all decisions made.
10. Telemedicine – Develop all island, patient-centred policies on the use of telemedicine in cancer care. Involve patients in designing such services to ensure a flexible approach, where in-person care is available where needed or desired by the patient.

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