Uncovering the Value of Real-World Data for Blood Cancer

The Future of PROMs and Clinical Data Collection in Irish Health Care Report

Contents

I. Overview

The roundtable meeting, *Uncovering the Value of Real-World Data for Blood Cancer* [i] brought together thought leaders on data, cancer and haematology, patient representatives and decision-makers in order to foster new ideas and build partnerships on the access and use of cancer data in Ireland.

Blood cancer care is evolving rapidly due to improved understanding of the disease and the development of new therapies. With the advent of new technologies, health data is increasingly available from a wide range of sources. This explosion of information offers new opportunities but also highlights old challenges, such as the fragmentation and concerns around data privacy and security.

Given the potential of data to improve population outcomes and health system sustainability, these challenges must be overcome. The vision of a 'learning healthcare system' based on electronic health records and routinely collected healthcare data such as PROMs, would allow real-world data to be continuously fed into the system, ensuring that with every new patient treated, we would know more about the overall practice of medicine.

However, by comparison with our peers, Ireland fares poorly in the routine collection of real-world data. Better data will allow for more tailored patient-centred treatment plans for individual patients as well as providing a view on broader trends as to how patients respond to care.

The objective of the meeting was to make recommendations on how to improve data infrastructure to capture real-world evidence and to make Ireland more attractive for clinical research; to discuss the importance of quality of life data for patient outcomes and clinical decision-making; and to drive the debate on electronic data collection and innovative technological solutions.

Collaboration is crucial in achieving these objectives and the event organisers intended that the discussion and recommendations emerging from the meeting will drive the issue further up the agenda of all the stakeholder groups. This, in turn, should lead to tangible progress in improving the collection and use of real-world data to better improve patient outcomes in both the near and long-term future.

[i] *Uncovering the Value of Real World Data for Blood Cancer roundtable meeting was held in Royal College of Surgeons on 14th October 2019. Full details on the event can be found in section IV and V below.*

L–R: Mary Kelly, Chair, Multiple Myeloma Ireland; Donal Buggy, Head of Services and Strategic Implementation, Irish Cancer Society; Laurent de Saint Sernin, General Manager, Commercial Operations, Janssen Sciences Ireland; Jessica Walsh, Clinical Trial Network Coordinator, Blood Cancer Network Ireland; Anne Marie Murphy, Patient Advocate, CLL Ireland; and Jan Rynne, Co-Founder, CLL Ireland.

II. Roundtable Outcomes

Participants noted the need for policy action to deliver on the potential of health data for better care. Based on the day's discussions, this report highlights the challenges and recommended areas for action, as the output from the meeting.

The recommended areas for action emerging from this roundtable should help guide policymakers on a national plan for better data in cancer and provide a starting point for further action.

Summary

1. **Cancer Data:** Most current cancer data sources in Ireland lack scale, robustness and detail to support decision-making for policy and planning.
2. **Clinical Decision-Making:** When it comes to the feedback of patient data into clinical care in cancer, Ireland is behind the curve internationally.
3. **Clinical Research:** Lack of cancer data collection and usage reduce Ireland's attractiveness as a location for cancer trials and research.
4. **Health Information Infrastructure:** Deficiencies in Ireland's health information system make it inefficient to capture useable data for both hospital databases and population registries.
5. **Link Existing Data:** Strategically, the Irish health service should take 'small steps' to link up and integrate existing data collections.
6. **Interoperability and Standards:** Solutions exist that can help standardise existing health data collections, such as hospital records, and make them useful for secondary purposes.
7. **Secondary Use of Patient Data:** A new data policy, informed by patients and data users, is required around patient consent and secondary use of data.
8. **Education and Communication:** There is a need to communicate the benefits of data for better cancer care to health professionals and patients.
9. **Patient Quality of Life (QoL) Data:** Capturing patient experience and quality of life data will be essential to the future of cancer treatment and personalised care.
10. **Frontier Technology:** Ireland can become a leader in the use of new digital technologies, such as natural language processing and artificial intelligence, to collect and code data in clinical settings.

L–R: Dr Jayne Galinsky, Health Services Research Manager, Myeloma UK; Dr Cicely Kerr Senior Outcomes Research Manager, Janssen UK; and Lee-Ann Farrell, Government Affairs Manager, Janssen UK

III. Discussions at the Roundtable

The roundtable highlighted the obvious gaps in what is known about the care needs of patients living with, or after, a blood cancer diagnosis in Ireland. Cancer care in Ireland is behind the curve internationally when it comes to collection and use of data to improve patient care.

It is particularly inefficient to capture clinical and patient data in the current context, characterised by an absence of a national electronic health record scheme, a lack of integration between primary and secondary care data and the persistence of paper-based patient records across care settings.

The first section of this report, 'The Cancer Data Landscape in Ireland' summarises the problems identified in the cancer data environment in Ireland and the value better data could bring in these settings.

The second section 'Recommended Areas for Action' summarises the concrete recommendations that emerged for how to improve the collection and use of real-world cancer data across the Irish health service.

Setting the Scene: The Cancer Data Landscape in Ireland

Attendees identified three general areas where Ireland could benefit from better collection and use of real-world data in cancer: cancer policy making and service planning; clinical decision-making and patient care; clinical trials and research.

1. Better Data for Policy Making and Service Planning

Most current cancer data sources in Ireland lack scale, robustness and detail to support decision-making for policy and planning.

Collection of data on cancer in Ireland has historically been through patient registries, especially the National Cancer Registry of Ireland which is an invaluable resource, allowing for the monitoring and comparison of trends in incidence, mortality and survival across time and across regions.

The National Cancer Registry of Ireland is in a unique position within the cancer data environment, in that it has permission to collect clinical data (i.e. without individual patient consent) at a population level, underpinned on a legislative basis. This central role in the collection of data to monitor outcomes, allows us to benchmark our performance internationally in terms of mortality and survivorship.

> ***"Further data is needed to get a more complete picture of the care needs of everyone in Ireland living with or after a cancer diagnosis"***
>
> Dr Conan Donnelly, Research Manager,
> National Cancer Registry Ireland

However, attendees spoke about the shortage of richer information on cancer at a population level, beyond incidence, mortality and survival.

As **Dr Conan Donnelly,** Research Manager, National Cancer Registry Ireland, described, *"The National Cancer Registry of Ireland is in a fortuitous position with regards to our ability to collect and interrogate data. However, the collection of cancer incidence and treatment data has not kept pace with innovations in data management or with regard to developments in cancer control and associated policy. For example we only report on cancer care up until the end of the first diagnosis.*

We cannot capture important outcome information in the registry, such as minimal residual disease or relapse free survival. Patient related outcomes are not captured 'routinely' on a population level."

This puts Ireland at a disadvantage in terms of providing a basis for research and evidence-based decision-making in policy and service planning.

"When we look to Europe, we see that there is health information infrastructure in most countries that allows data around more complex outcomes, and the comprehensive treatment of patients, to be collected.

This is becoming increasingly important as survival improves. Further data is needed to get a more complete picture of the care needs of everyone in Ireland living with or after a cancer diagnosis. Because of continued improvements in treatment and care, these needs are also likely to change over time.

Benefits of real-world data to the stakeholder groups

Governments:

- Enables a better understanding of the healthcare context and treatment patterns to improve the quality of care and overall resource allocation.

Clinicians:

- Gives a clearer view on treatment patterns and on the real-world clinical value of interventions.
- Leads to more informed, individualised prescribing.

Patients:

- Patient Reported Outcome Measures (PROMs) provide an understanding of the impact blood cancer has on individuals – this data is helping improve outcomes.

Industry:

- Improves efficiency of trials.
- Supports discussions with health authorities.
- Helps with meeting post-approval requirements.

Health Service:

- Demonstrates the impact of expenditure.
- Enables innovative pricing mechanisms.
- Increases insight into the patient experience of their disease, treatment and wellbeing.

Research:

- More routinely banked electronic data equals more material to inform clinical and academic research.

A key recommendation from our recent research is to begin to regularly collect important information about the needs of cancer survivors directly from survivors."[1]

While patient health records are digitalising in Ireland, especially in primary care, such data are regularly not 'linked', missing important opportunities for evidence generation.

Darrin Morrisey, CEO, Health Research Board, spoke about the role of the Health Research Board in managing and funding a number of existing databases, encompassing data from disability services, psychiatric inpatient data and alcohol related deaths, *"The HSE uses these databases a lot for the delivery of care. However, they don't use them for long-term strategic decision-making. And they don't link them to demographic, social and patient outcome data. It is in linking up what's there that we need to improve."*

Strategic planning for service delivery is not traditionally something which registries generally focused on. At present, the rich data collected from registries cannot be fed back into planning in local service delivery:

Dr Donnelly explained, *"Registries have traditionally been thought of as the purpose of research. They're not solely for research but for infrastructure which is there to support service planning."*

2.Better Data for Clinical Decision-Making and Patient Care

From the point of view of care teams working in hospitals, attendees discussed deficiencies in the availability and usage of health data across secondary and tertiary care for decision-making on treatment pathways and patient care in cancer.

L–R: Dr Conan Donnelly, Research Manager, National Cancer Registry Ireland; Donal Buggy, Head of Services and Strategic Implementation, Irish Cancer Society; Kevin McGowan, Ireland Strategy & Integration Executive, IBM; and Darrin Morrissey, CEO, Health Research Board.

into clinical care in cancer, Ireland is behind the curve internationally. The continued reliance on paper-based records in hospitals is a frustration for health care workers as well as a source of systematic inefficiency.

As **Donal Buggy,** Head of Services and Strategic Implementation, Irish Cancer Society, explained, *"When it comes to the integration of data on patient experience in clinical care, Ireland has a long way to go to catch up with our peer countries across Europe, North America, Australia and New Zealand.*

This is due to a lack of health information systems in secondary care units. Cancer clinicians are frustrated with the hand-written, paper-based record making environment within which they currently work.

Moreover, the heavy workload caused by existing methods of note taking adds to the challenge of getting data collection on clinicians' agenda. However, it will also become increasingly unsustainable as cancer incidence among the population rises."

Mary Kelly, Chair, Multiple Myeloma Ireland, said that, in her experience, better data collection has begun to have a positive impact on patient care in blood cancer, but the process for collecting data from patients and feeding it back into clinical decision-making is inefficient and burdensome, *"On a positive note, better collection of data has influenced how we do our work today. However, to be sustainable, data collection must help address patients' concerns and it has to be meaningful to them."*

3. Better Data for Clinical Trials and Research

Finally, some attendees mentioned the data infrastructure as a barrier to a more 'research-active' health service. Ireland fares unfavourably with other healthcare systems on several metrics for cancer research, including our low spend on cancer research and low numbers of patients enrolled on clinical trials.[2]

While the ambition in the National Cancer Strategy 2017-2026 is to double the number of people with cancer enrolled on cancer trials from 3% to 6% by 2020, recent evidence presented by Cancer Trials Ireland, suggest that only 1.5% of cancer patients were enrolled on clinical trials in 2018.[3]

Dr Fionnuala Keane, Chief Operating Officer, HRB CRCI, pointed out that deficiencies in our health information systems reduce Ireland's attractiveness as a location for trials and research, *"We're trying to make Ireland a more attractive location for clinical research and we're out talking to industry and commercial organisations about why Ireland is a good location for research.*

But we're constantly hit with companies saying we don't have electronic patient health records as the data source which they use in other jurisdictions. Ireland is compared to Denmark all the time. We have a similar population, but they have multiple times the number of clinical trials to Ireland. We need to enable our doctors and nurses to deliver clinical research by integrating it into our healthcare system."

Many attendees made the point that investment in background data infrastructure, including clinical data registries, will be essential to reversing this trend and in bringing more clinical trials to Ireland.

Jessica Walsh, Clinical Trial Network Coordinator, Blood Cancer Network Ireland explained, *"Most clinical trials are industry-led and capturing patient experience data is not a priority for these organisations. There are pockets of people collecting data about different things in Ireland for their own databases. But it's not being coordinated in pathways that it should be. This is one area of great potential in Ireland which is not yet being tapped".*

> ***"To be sustainable, data collection must help address patients' concerns and it has to be meaningful to them"***
>
> Mary Kelly, Chair, Multiple Myeloma Ireland

4. Health Information Infrastructure

One of the key themes discussed by participants was the absence of an integrated health information system, as one of the main barriers to improving the collection of meaningful cancer data in Ireland.

A general view shared was that the deficiencies in Ireland's health information system make it inefficient to capture useable data for both hospital databases and population registries.

Broadly speaking, five major deficiencies were identified with the current health information system, primarily related to the absence of an individual health identifier and electronic health record:

- Lack of integration, interoperability and linkage between data systems in primary and secondary care, across secondary care and between health and social care data collections;
- Reliance on paper based records in hospital settings;
- Limited patient access to own data in electronic format;
- No central body to coordinate data collections, including registries, which leads to lack of strategic planning and collaboration, data gaps and/or duplication of data collection;
- Uncertainty about the ownership of data and patient consent over secondary use of data.

Contributors compared Ireland's health information system with that of our peers.

As **Dr Donnelly** explained, *"In Ireland it is particularly inefficient to capture oncology data in the current setting. A key differentiator is that countries, such as Finland and Norway, have unique health identifiers and electronic patient records to systematically capture patient related data."*

Some attendees pointed out that the implementation of the individual health identifiers across the health service, will significantly enhance the ability to capture real-world data across cancer.[4] For instance, due to the roll-out of individual health identifier, the NCRI is embarking on a new strategy to improve the way data is captured in cancer care with less burden on clinicians and patients.

Looking Ahead: Recommended Areas for Action

Participants noted the need for policy action to deliver on the potential of health data, and a national plan that could help provide this. Sláintecare reforms in the health service over the next five years represents an opportunity for progressing the e-Health and national cancer strategies.

The recommended actions emerging from this roundtable should help guide policymakers on how cancer data could be addressed as part of this national plan and provide a starting point for further action.

Recommendation one: Strategically, the Irish health service should take ‘small steps’ to link up and integrate existing data collections

Attendees were confident that progress can be made in improving the cancer data environment despite missing key elements of a health information infrastructure, such as individual patient identifiers or electronic health records.

A strategic recommendation that emerged is that we should not wait to have all the elements of the e-health strategy embedded before we begin to improve our cancer data collection and usage across the health service.

There are ‘pockets of excellence’ across regions, in registries and in hospitals and it may be possible to link these with existing demographic, social and patient outcomes data, using customised data solutions.

Kevin McGowan, Ireland Strategy & Integration Executive, IBM, said the implementation of the electronic health record is a distant prospect. However, this should not be considered the sole, or even primary solution, to data collection and usage problems in the health service, *“We need to reconsider our e-health strategy and whether or not the electronic health record is the ‘landing spot’ we should be aiming for. Building the electronic health record is not actually a solution to our myriad problems. Rather we need a health data platform, particularly if we want to leverage existing data points housed in existing registries. Instead, what we need is a healthcare data platform that would allow us to normalise, standardise and to start to use the data we already have.”*

Customised health data platforms and safe-haven databases are ‘small step’ approaches that could be employed to leverage data points, housed in existing registries and clinical records.

Federated data models were suggested as a means of overcoming differences in data interoperability across care providers, such as electronic patient records in hospitals.

This would mean different health providers can progress at a different pace, but still feed into a national database.

As **Lee-Ann Farrell,** Government Affairs Manager, Janssen UK, advised, *“This is particularly useful if your aim is to get some of the existing information back to patients on site in a meaningful way, who are contributing their health data for their care as well for research.”*

Darrin Morrissey described efforts underway by the Health Research Board in their data access sharing storage and linkage programme (DASSL), *“The DASSL model aims to develop a proof of concept for technical infrastructure that will inform a national solution for the safe and controlled access, storage, sharing and linkage of research data and routinely collected health and social care datasets.*

It is primarily a data safe haven mechanism, based on similar models used by the Central Statistics Office for economic and social datasets.

While we’ve a long way to go, we have several pieces of the data infrastructure ‘puzzle’ already in place.’

> ***“What we need is a healthcare data platform that would allow us to normalise, standardise and to start to use the data we already have.””***

Kevin McGowan, Ireland Strategy & Integration Executive, IBM

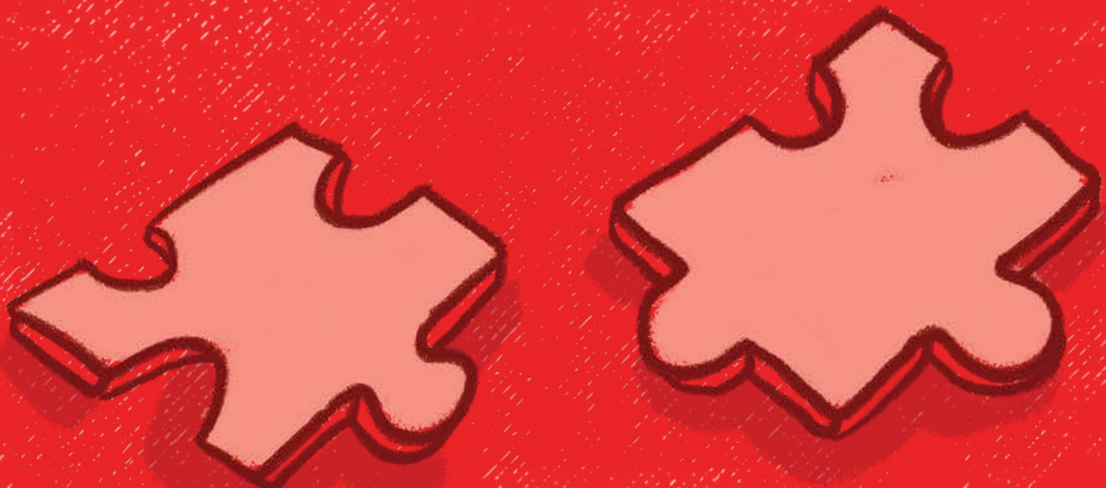
Recommendation two: Solutions exist that can help standardise existing health data collections, such as hospital records, and make them useful for secondary purpose

In relation to Ireland’s health information infrastructure, a repeated recommendation made by attendees was ‘don’t wait for perfect’.

Building customised data models to standardise cancer data that already exists, is seen as a potential ‘bottom up’ approach by some attendees.

Kevin McGowan commented, *“We need to build data models that will enable us to understand the data we have, try to normalise it and use it, via a health data platform. This is a better, more fruitful approach than ‘working towards nirvana’ with the electronic health records, which will not be the answer in and of itself.”*

The pieces of the **PUZZLE** are **on the table**, we just need to use them better.



Darrin Morrissey
CEO
Health Research Board

Dr Cicely Kerr, Senior Outcomes Research Manager, Janssen UK, concurred on the potential of building customised data models to fit the data that already exists,*"In terms of not waiting for perfect, there are different ways of coming at existing data and dealing with the issue of accessing this data.*

In many cases, it may be possible to map or structure the existing data 'where it sits' locally, in hospitals or registries by using a common data model.

If it is possible to move notes and paper-based patient records into an electronic format, then there are some approaches of federated analysis which can work with common data models. This can mean that everyone does not have to be using the same system or collecting all the data in the same place."

Health data models may be able to standardise storage of data across different systems, *"There are some approaches that we've been working on, where it's possible to create an interface locally, where the data sits, such as in hospitals. In an imperfect environment, lacking unified health information systems, this is a useful 'second-best solution'.*

Health providers can move at a different pace, but still feed into a national database."

> ***"The HSE should not wait until they have the full infrastructure in place or try to build something brand new from scratch"***
>
> Lee-Ann Farrell, Government Affairs Manager, Janssen UK

Lee Ann Farrell, discussed learnings from Wales, where different data systems lacking interoperability were integrated to construct the Welsh Haematological Malignancy Database, a best-in-class outcomes database for blood cancers, *"In the Welsh NHS, we needed a new database that could critically analyse what was happening to people with blood cancers.*

The key learning is that the HSE should not wait until they have the full infrastructure in place or try to build something brand new from scratch.

Rather, if you can pull together a health data platform that can collect the best of what's currently available, you can 'nail on' richer data when that becomes available. That was the most effective way for us in Wales to get something started, to stimulate momentum around data capture for all diseases. This project is now being expanded to all cancers."


L–R: Dr Fionnula Keane, Chief Operating Officer, HRB CRCI; Kelan Daly, Healthcare Consulting Director, KPMG; and Dr Derick Mitchell, Chief Executive, IPPOSI

> **PROMs**
>
> are a ***real-time capture*** of how patients are feeling in the short-term, that ***shapes their conversation*** in the consultation, and their ***treatment*** and ***therapeutic relationship.***
>
> ***But it also adds to the longer term***
>
> *reservoir of information*
>
> **TO IMPROVE OUTCOMES**
>
> ***FOR EVERYONE***

Lee-Ann Farrell
Senior Health Economy Liaison Manager
Janssen UK

Recommendation three: A new data policy is required around patient consent and secondary use of data

Several attendees pointed out that the policies in Ireland around consent are lacking in clarity. This can lead to a higher burden on patients, due to the need to seek re-consent for secondary data use purposes.

A new data policy is required around both patient consent and the secondary use of data, underpinned by the principle that data should be 'collected once and used many times'.

Enhanced access to data depends on the confidence of patients to securely share their sensitive data, but also on increased interoperability, which needs appropriate infrastructure and data standardisation.

Dr Donnelly said, *"Information is no good if it's not used. While there are challenges around the collection of data, including consent, it's essential to make sure information is available to support research."*

> *"There's a certain level of education that needs to be provided to patients and also the clinical community"*
>
> Mary Kelly, Chair, Multiple Myeloma Ireland

There is a need to educate patients on the value of data and on making the link between good quality data and improved health services and outcomes. Trust and consent are seen as key issues that require a stronger legislative foundation. However, a shift in culture is also required and must be informed by deliberation with patients.

Dr Derick Mitchell, Chief Executive, IPPOSI, recommended the establishment of a national patient forum to deliberate on the issue of patient trust and consent, *"A public conversation about what's most important to patients in Ireland needs to take place in order todrive a change mechanism in terms of how we collect, store and share data with trusted third parties."*

Many attendees recommended that patients and clinical teams also need to see a short-term benefit of data collection on the ground. Otherwise, there is a high risk of patient dissatisfaction with patient related outcome surveys, especially if patients do not see the results of data collection.

Donal Buggy, observed that, *"Quite a lot of research is already looking at the collection of quality of life data across treatment. But patients aren't seeing the benefit clinically of the information they're providing".*

Recommendation four: There is a need to communicate the benefits of data for better cancer care to healthcare professionals

A key theme reiterated by attendees was on the need to communicate the value of better data for cancer care, especially its importance for future treatment pathways.

Meaningful health data at scale (such as electronic health records, genomic data, imaging data and digital health tools) can lead to better and more personalised healthcare, improved diagnosis and treatment. High-quality real-world cancer data can also be used to inform regulatory, reimbursement and health policy decisions.

However, these benefits are not well communicated to healthcare professionals working on the ground. Most data collection is seen as 'in addition' to routine clinical care, rather than as an integral part of it.

Mary Kelly spoke about the importance of educating nurses about PROMs and their importance for patient care as being essential to gaining support for better data in the health service, *"There's a lot of good work happening, but the communication of that to people on the ground is not good.*

When you speak to nurses in chemotherapy clinics, the challenge for them will be to explain to patients about PROMs.

There's a certain level of education that needs to be provided to patients and the clinical community as well."

L–R: Mary Kelly, Chair, Multiple Myeloma Ireland; Siobhan Kelleher, Board Member, Multiple Myeloma Ireland; and Karl Haslam, Senior Scientist, Genomics Ireland

> The barriers to data collection are often
> *two-legged*
> *rather than technological*
> The people charged with collecting information can be hesitant, based on
> **FEAR**

Dr Derick Mitchell
Chief Executive
IPPOSI

Recommendation five: Capturing patient experience and quality of life data will be essential to the future of cancer treatment and care

Many attendees spoke about the increasing importance of capturing patient experience and quality of life data for cancer care.

Donal Buggy spoke about the need to find out what's important to patients and what they want in relation to data collection and usage, *"Patients want to know what you're going to do with their information. Currently patients may not be able to see the clinical benefit, or the effect of the data being collected, and this is something that's important to them."*

There is a high risk of patient and clinical burnout in patient data collection, especially if they do not see the results of the data analysis.

Patients and clinicians must be involved in the design phase of any new data collection to ensure there's a mix of incentives and an understanding of the long-term value of better data to patient care.

Patient reported experience measure surveys are also increasingly used in health care systems to measure patient experience of service.[5]

According to **Dr Mitchell,** these surveys are not routine in the Irish health service, *"This way of collecting data based on irregular patient reported experience measure surveys is not sustainable. It's a snapshot of one time in the year. If you want real performance data, you must do that on a continual basis."*

A key recommendation from experts, such as **Dr Jayne Galinsky**, Health Services Research Manager, Myeloma UK, was that the patient related outcome surveys that work best, and are the most sustainable are 'service-driven' rather than purely research focused, where the data captured is also used to inform clinical practice and provide feedback to patients, *"Time, training and resources around PROMs for healthcare professionals are some of the main issues. Even where the infrastructure and resources aren't in place, doctors and nurses are making it work. They are creating local solutions that work for them, developing their own systems for PROMs data collection to inform clinical practice. These are far from perfect, but they work.*

The PROMs that work best are service-driven. If patients get 'high scores', they are using this as a way to decide upon referral to other services. They are healthcare practitioner driven rather than purely research focused and data capture is used to inform clinical practice."

Recommendation six: Ireland can become a leader in the use of new digital technologies to collect and code data in clinical settings

Many interesting recommendations were made on how innovative digital technologies can help scale clinical data collection and make it more useful for secondary purposes.

A key attribute of a learning health care system is the ability to collect and analyse routinely collected clinical data in order to quickly generate new clinical evidence, and to monitor the quality of the care provided.
To achieve this vision, clinical data must be easy to extract and store in computer readable formats. Although highly desirable, a learning healthcare system does not automatically emerge from the implementation of electronic health records.

Unstructured data, such as free-text, is frequently used to capture patient information using clinical notes, operative reports, and discharge summaries. This needs to be coded for meaningful analysis. However, one of the risks of additional electronic data input and collection of patient data is that it can disrupt clinical workflows and lead to 'clinical burnout', among nurses especially.

> ***"How do we take speech and put it into text, code it and make it meaningful for both the clinician and patient?"***
>
> Kevin McGowan, Ireland Strategy & Integration Executive, IBM

Kevin McGowan spoke about dealing with unstructured data, *"We need to think about how to ingest and deal with unstructured data. Speech is our most natural language in human interaction. How do we take speech and put it into text, code it and make it meaningful for both the clinician and patient?"*

It was noted that in the US, where electronic health records are advanced, clinics employ specific people to code 'unstructured data' captured by clinician's in real time. However, manual coding on this scale is unlikely to be affordable in the Irish health service.

Attendees discussed how innovative methods to improve the structured capture of clinical data are needed to facilitate the use of routinely collected clinical data for patient phenotyping.

Dr Joao Bettencourt-Silva, Research Scientist, IBM, described how emerging technologies such as natural language processing and other artificial intelligence applications might be harnessed to capture unstructured data, such as notes in a free-text format, and avoid clinical burnout, *"Technology-enabled abstraction of unstructured data from electronic health records, combined with rigorous quality control, is a possible way to extract meaningful information. Quality and reliability, particularly of routinely collected data, remain challenging for this technology.*

I believe that both structured and unstructured data may be combined, using existing technology, and that we can mine this data to figure out what is of relevance in specific areas. In IBM, our research has shown that we can identify key elements in a body of text and figure out which of these elements are relevant to different healthcare professionals. Using similar techniques we may, for example, summarise the most relevant keywords in pathology reports in a structured fashion.

Assuming that we have established techniques for mining such text, the key question will be how to build a data model that best represents blood cancer data. How do we structure it? And how do we make it comparable across different pathology reports, clinicians and organisations in Ireland?

Both the technology and knowledge to tackle these questions exist. The challenge will be to tailor it to specific diseases across multiple organisations with varying degrees of data quality and availability."

Dr Donnelly, said that this ability would be very valuable in the National Cancer Registry Ireland, *"The only way we'll be able to expand on our capture — and find solutions to patient issues from the data — is by being able to continually capture data from the diagnosis through multiple treatments and beyond.*

"With survivorship rates increasing, it's an additional challenge for the registry so we really need to move in this direction."

Dr Mitchell cautioned that although the potential benefits from the use of artificial intelligence in healthcare are significant, these data-driven technologies should be designed and used in ways that respect and protect the privacy, rights and choices of patients and the public, *"There are concerns coming to us by individual patients or patient organisations approached by technology-based solutions, where their endorsement for a particular product is being sought.*

There is little transparency about how algorithms have been developed and whether they might discriminate on certain attributes.

On these new technologies, such as artificial intelligence, there's a certain level of education that needs to be provided around data collection and use, not just for the patient organisations, but for the clinical community."

However, according to **Dr Mitchell**, Ireland could gain an advantage in the use of new technologies, such as artificial intelligence, *"We can't compete with the US or China on the development of the artificial intelligence tech, but we can compete on the use. A great example is Finland, which has taken the approach of educating staff, state agencies, companies and health providers on the use of artificial intelligence within their context. They designed educational programmes, that provide a minimum level of understanding of what artificial intelligence is.*

They are betting that within five to ten years, artificial intelligence will be in use in multiple areas that they never thought possible. And they combine that with a national conversation on the use.

From a national perspective, if we can't compete on time or money, then maybe the best thing to do is to compete on the use through education.

If we don't do this, we're just not going to get there."

"We can't compete with the US or China on the development of the artificial intelligence tech, but we can compete on the use"

Dr Derick Mitchell, Chief Executive, IPPOSI

IV. Participants

Jonathan McCrea, meeting chair

Anne Marie Murphy, Patient Advocate, CLL Ireland

Bernard Mallee, Director of Communications and Advocacy, IPHA

Brita O'Reilly Head of Market Access, Janssen Sciences Ireland

Dr Cicely Kerr, Senior Outcomes Research Manager, Janssen UK

Darrin Morrissey, CEO, Health Research Board (HRB)

Donal Buggy, Head of Services and Strategic Implementation, Irish Cancer Society

Dr Avril Kennan, CEO, Health Research Charities Ireland (HRCI)

Dr Conan Donnelly, Research Manager, National Cancer Registry Ireland (NCRI)

Dr Derick Mitchell, Chief Executive, IPPOSI

Dr Fionnuala Keane, Chief Operating Officer, HRB CRCI

Dr Jayne Galinsky, Health Services Research Manager, Myeloma UK

Jan Rynne, Co-Founder, CLL Ireland

Jess Walsh, Clinical Trial Network Coordinator, Blood Cancer Network Ireland (BCNI)

Dr Joao Bettencourt-Silva, Research Scientist, IBM

Karl Haslam, Senior Scientist, Genomics Ireland

Kelan Daly, Healthcare Consulting Director, KPMG

Kevin McGowan, Ireland Strategy & Integration Executive, IBM

Laurent de Saint Sernin, General Manager, Commercial Operations, Janssen Sciences Ireland

Lee-Ann Farrell, Government Affairs Manager, Janssen UK

Mary Kelly, Chair, Multiple Myeloma Ireland

Sarah Freeman, Health Data Analyst, Department of Health

Also, in attendance

Dr Féaron Cassidy, Programme Manager, Blood Cancer Network Ireland

Hilda O'Shea, Patient Engagement Manager, Janssen Sciences Ireland

Iris Cribbin, Head of External Affairs, Janssen Sciences Ireland

Marc Nolan, Senior Clinical Data Manager, Cancer Trials Ireland

Mark Canavan, Government Affairs Manager, Janssen Sciences Ireland

Siobhan Kelleher, Board Member, Multiple Myeloma Ireland

Attendance at the meeting was not an endorsement of the report recommendations.

Suggested actions, outlined in the report, may not reflect the opinions of those who attended.

Reference

[1] NCRI, 2019. National Cancer Survivorship Needs Assessment: The Unmet Needs of Cancer Survivors in Ireland: A Scoping Review 2019

[2] Morrissey, D. Statement at Oireachtas J. Health Committee Hearing on National Cancer Strategy, 13 March 2019

[3] Mulroe, E. Statement at Oireachtas J. Health Committee Hearing on National Cancer Strategy, 13 March 2019.

[4] While the Health Identifiers Act was signed into law in 2014, progress on the implementation of the IHI into data systems has been slow and intermittent.

[5] Patient Reported Experience Measures (PREMs): A patient's perception of their experience of the health system.

V. Roundtable Agenda and Guiding Questions

10:00 Introductory comments from MC Jonathan McCrea

10:05 Setting the scene

Laurent de Saint Sernin, General Manager, Commercial Operations, Janssen

10:15 Session 1: Real-world data infrastructure in Irish cancer care

Chaired by Jonathan McCrea

Discussion topics:

- How does Ireland compare in the capture of real-world data in clinical settings?
- What barriers exist to building and scaling data solutions that can capture clinical outcomes in Irish healthcare?
- How can we develop clinical data infrastructure to make Ireland more attractive for cancer research?

Key deliverable: Make recommendations on how to improve data infrastructure to make Ireland more attractive for clinical research.

10:45 Session 2: Patient quality of life

Chaired by Jonathan McCrea

Discussion Topics:

- How does the Irish health service compare to other countries on the integration of patient experience into clinical care?
- Can we improve the routine collection of PROMs in our health service?
- What are the barriers to the routine collection of PROMs and PREMs in clinical settings in Ireland?

Key deliverable: Make recommendations how to better integrate patient experience into clinical decision making in Ireland.

11:15 Session 3: Innovative digital solutions

Chaired by Jonathan McCrea

Discussion Topics:

- One of the barriers that restricts the scaling of registries is the cost of manual data collection, are there ways to automate these processes?
- Can we implement innovative methods to improve the extraction or the structured capture of clinical data in a computable format?
- Are there innovative methods of data capture that do not disrupt clinical workflows?

Key deliverable: Make recommendations on innovative digital technologies and data solutions that can help scale clinical data collection and make it more useful for secondary purposes.

11:45 Closing remarks

Donal Buggy, Head of Services and Advocacy, Irish Cancer Society

12:00 Meeting ends

To read a copy of the Patient Perspectives on Blood Cancer, visit janssen.ie

To watch a series of support videos for people living with blood cancer, visit the @JanssenIreland YouTube channel.

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