CANCER DATA- MOVING FORWARD

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Introduction

Robin Swann launched a 10 year Cancer Strategy in March 2022. Much of what is planned is predicated on having sufficient data to help direct appropriate commissioning and funding cycles. This document describes why the data needed to design secure sustainable services is not in place. We do not yet sufficiently understand the impact of cancer on citizens, staff, families or the wider economy. If we do not have a plan to accurately measure the outcomes of care, then we are building on inadequate foundations. The Cancer Strategy cannot be achieved without detailed consideration of the data requirements interwoven with its aspirations.

This document recommends we plan to commission the data foundations we need to build an achievable and sustainable long-term plan for cancer care in Northern Ireland. The encompass programme will make things better in the longer term but will lead to some short-term immediate problems that need urgent solutions.

The citizens in Northern Ireland deserve to know more about our services and their place within it. They need better information on cancer outcomes, waiting times for care, access to support services and how to navigate a life that is interrupted by cancer. It is not enough to focus on the clinical systems and technology solutions, we need to understand the real-life journeys our citizen's experience as they receive treatment. For example, the burden of metastatic and progressive cancer is complex to record and report from on current systems; therefore, we need to design innovative solutions to solve this problem. This is an uncomfortable space for a Health Service struggling with demand and staff retention, and yet transparency in understanding problems can be the basis for change.

This document argues for the urgent creation of a Department of Health led steering group for cancer data to direct the appropriate agencies to deliver the necessary data infrastructure changes necessary to make the Cancer Strategy achievable. The team in DHCNI have developed a National Data and Digital Strategy which includes the creation of a Health and Social Care Data Institute (HSCDI) to co-ordinate, and action, all data related problems in HSC. This initiative is the key foundation stone in our solution for cancer data.

The citizens of Northern Ireland need an agency to **own** this problem, and to be **responsible** for delivering a solution. There are some **immediate** issues regarding the necessary **engineering** and infrastructure needed that DHCNI are uniquely placed to deliver on and in doing so they can create a reusable **platform** for the wider HSCNI. This response must be **inclusive** of citizens, enabling a greater inclusion of their lived experiences of cancer. To achieve all of this will require **funding**; however, given that the Cancer Strategy will be unachievable without the required data to drive its vison, deliverables and statutory obligations, it is important to have these funding discussions now. The exposure to new potential **research** treatments for cancer, through better data awareness, is also a key consideration. Our citizens deserve access to the best care - we need to acknowledge that access to data is a large part of delivering that.

I am grateful to the Department of Health for being asked to undertake this Independent Review of cancer data. The Department's vision and aspiration is for Northern Ireland to become one of the highest performing cancer healthcare systems internationally. Developing a reputation for delivering timely and high-quality cancer care, novel diagnostics and treatments that encouraging innovative practice. The department wants to deliver patient survival rates which compare favorably with similar populations and to develop a collective approach to leadership that is committed to providing compassionate care for patients.

The Cancer Strategy comes with 4 themes and 60 actions. Cancer can affect all aspects of a person's life, therefore the information we collect is crucial to understanding how the delivery of services can be improved for the future.

While HSC currently collects a huge amount of data using a myriad of both manual and electronic formats; using this data is problematic, cumbersome and administratively difficult. Northern Ireland lags behind other UK nations in the range of cancer data it collects. We are severely limited in both access to data and in the way we can use that data when it is collected and as a result we are limiting our healthcare systems ability to care for citizens with cancer. This situation leads to widespread frustration and dissatisfaction with the inability to link routinely collected information from all of the disparate systems.

Accurate data is vital to underpin all decisions including:

- core service delivery
- patient outcomes and satisfaction
- commissioning
- service improvement and development
- performance management
- future planning

The core priority is that common data sets are developed, agreed and used uniformly across the service.

This review specifically addresses actions 57 band 58.

Action 57: Review the data required for the effective delivery of cancer services in alignment with Encompass.

Action 58: Develop a cancer data framework to inform and improve cancer services and facilitate research.

In addition it touches on other cancer strategy actions relating to a research strategy, clinic trials, the review of the cancer registry and patient outcomes.

In earlier work, we have reviewed the current information systems that provide data for the delivery of cancer care in Northern Ireland. This document outlines a potential methodology for bringing this information together over the next 5 years.

This work has been reviewed by an expert panel: Prof Suneil Jain, Prof Mark Lawler, Prof Gerry Hanna and Prof Helen Coleman. All are leading experts in cancer care, specialising in service delivery and research in Northern Ireland. The Northern Ireland Cancer Registry (NICR) have also been kind enough to review the document and make suggestions. I would like to thank Dr Damien Bennett and Dr Deirdre

Fitzpatrick. Together; colleagues have challenged me to keep this document citizen centric and yet focused on the most achievable and significant outcomes possible.

During routine clinical work clinicians often meet acutely unwell medical patients who present with a new diagnosis of cancer or with a complication of a known cancer. The care we deliver is 'safe' but it is often not an optimal service for either patients or staff. Trying to provide timely, specialized care is a challenge for every healthcare system. Our system is under so much stress, such that demand continually exceeds supply, and we encounter very difficult circumstances for both patients and their care givers.

My experience of the care delivered is not always what we would want for our families, and yet we have come to accept it as normal. Like most of us, I have had family members with cancer diagnoses, and we have been through the anxiety of trying to get clear and usable information on what that means and what will happen in the future. Whilst I am always amazed by the resilience of citizens living with cancer; trying to negotiate their way through a confusing system is the last thing they need. Understanding their lived experience and journeys - through clinical and other cancer-relevant data - is what this document is all about.

This paper is not written to simply sit on a shelf; it outlines a series of options to achieve meaningful and positive change when using data related to cancer care in Health and Social Care Northern Ireland (HSCNI). The 'do' part of this document will be a challenge for some, there are potential risks involved and the intermediate periods will inevitably be a compromised position which many would prefer to skip - that just reflects Northern Ireland's position at the present. Over-emphasising the positives distracts us from understanding the real problems that we are currently experiencing; this document will focus on delineating these problems and also suggesting appropriate solutions.

This document will also be citizen-focused – the best care pathways are built around patients, their families and the professionals who deliver the care. There is often far too much reliance on individual practitioners going beyond the expected to achieve excellent care for their patients – almost, despite the system. The system should expect to deliver excellent care every time, regardless of who is 'on' that day or where the care is being delivered – only by measuring real world outcomes and lived experiences in a timely fashion, can we begin to get to the level of understanding we need to design better care.

The measurements and metrification of the cancer care process should be a natural co-process of care delivery - never the focus. This is a challenge in NI, trying to demonstrate outcomes in an unmeasured environment will always be disappointing and I do not envy commissioners nor the Department of Health (DoH) in their choices. As a nation, we should choose to discuss this complicated situation more transparently and not pretend to understand greater detail than what the data we have tells us. Fixing a problem first requires acknowledging that it exists. This requires data intelligence to identify the problem and its scale, resulting in better data-driven solutions. Fundamentally, the current data architecture for cancer care is not fit for purpose. The focus of this document is to explain how we could start to fix that problem.

A word on data transparency.

As a population, we need to become more comfortable about data and its use. The sad truth is that in the commercial world we are usually confused by data. Experts are often ignored and the detail (which is usually messy and hard to understand) glossed over. In advertising and politics, numbers are used to influence thought and direction. In medicine, we try and bypass these biases by being transparent. Not only do we try and have independent review of research findings, but we also insist on the data being openly published and made available. Transparency is the partial antidote to biases, inviting everyone and anyone to review the data that we hold about them.

Realistically, Northern Ireland healthcare delivery is slowly failing. This is not a criticism of anyone involved, but an objective assessment of the facts. Year-on-year, we are delivering lower quality care on an aggregate level. Individuals may still receive amazing care, but lots won't - there is no point in pretending otherwise. What we lack is actionable data, highlighting the problems but also directing us to possible solutions. We need to openly talk about that. We need accurate, timely and effective data to direct us to the right answers and to check if the interventions that we have made are working. We would like to believe that we are a data-driven healthcare system and economy; ironically, there is little evidence to support that.

Northern Ireland has some of the most innovative and imaginative data businesses and Start-ups, but there is disconnect between how these businesses support corporate NI. We find it difficult to integrate their innovation with our day to day work. We do not suggest a data 'free-for-all', but a recognition that we need to reimagine the clinical data ecosystem in NI. As we allow wider access to clinical information (e.g. doctors notes, aggregated data and patient journeys), we need skilled people to unlock the positive health and well-being influence of this information. Those 'data people' also need the systems help to allow them to explain what the data means – we will not be successful in our quest for an optimal cancer data ecosystem without everyone working together. Perhaps a data-commons for NI would be the logical outcome eventually, but this is well beyond the remit of this paper. The core argument is that a quality cancer data ecosystem is important, and like tax, pensions and high blood pressure it needs constant time and attention to detail to understand. However, without transparent access to the correct and relevant data, appropriately analysed in safe environments, we cannot provide the best services for our patients. Data saves lives, and in cancer we have a particular opportunity to enhance health and well-being and reduce mortality in one of the greatest challenges to human health.

The language in this paper is direct and focused on delivering the optimal outcome. This does not in any way dilute commitment to the protection of patient data, or the controllers of that data in any way. Ultimately, this is citizen data, produced and ultimately owned by them. However, this work will always emphasise our duty to routinely use data to help both current cancer patients and citizens who will develop cancer in the future. Covid-19 has given us the best example yet of how we can use data for direct care, in real-time. We must deploy the same approach to address the challenges we face in cancer, which after all has killed far more patients in NI than the Covid pandemic.

Summary recommendations

The Northern Ireland cancer strategy is ambitious and requires us to become proficient at using data efficiently to help improve how we deliver care. This section summarises what changes are needed to allow routinely collected clinical data to be better used to provide better cancer care for the citizens of Northern Ireland.

This summary outlines the main recommendations – for those interested in the 'why,' the remainder of the document articulates some of the reasoning, but for many readers this summary of required actions may be sufficient to both understand the problems and agree the potential solutions.

1. **Ownership:** The most important initial task is to identify a body which is responsible for the delivery of a NI Cancer Data Strategy. Currently, there is no one agency accountable for managing the delivery of the information needed for the high quality clinical, population and administrative data needed for our network of cancer providers. The Northern Ireland Cancer Network (NICaN) does not have dedicated informatics support. This paper argues that this work should be led and coordinated by the newly created Northern Ireland Health and Social Care Data Institute (HSCDI) working collaboratively with Clinicians, DoH, Northern Ireland Cancer Network (NICaN), Trusts, PHA, charities and the Northern Ireland Cancer Registry (NICR). This is such an important piece of work that it represents the perfect opportunity to create an exemplar of how the HSCDI will work moving forward - in all aspects of clinical data provision. HSCDI will be responsible for coordinating the collection, cataloging, and hosting of relevant data sets for use by cancer teams in clinical practice, research, and for citizens needing information. Without a prioritisation of this data infrastructure, led by one responsible agency, the wider cancer strategy will be unachievable.

2. **Delivery:** To ensure the HSCDI can meet the defined needs of the NI Cancer Strategy, we recommend the creation of a Data Steering Group within DoH, to monitor the work of HSCDI against the data requirements of the Cancer Strategy – this group needs to have a detailed understanding of both the technical and strategic aspects of this document and to be able to hold HSCDI accountable for the spend needed to achieve desired outcomes. Once commissioned and funding agreed, the HSCDI will be responsible for the timely access to required datasets for cotemporaneous audit – prioritizing direct clinical care and secondarily focusing on how research can support more effective and timely care delivery. The HSCDI must have the resources, governance support and mandate to prioritise data access to support clinical outcomes above all other priorities. Central to this argument is the need to rationalise data ownership across the HSCNI - we all agree the data is citizen-owned - but we need a collective agreement as to which Northern Ireland body supervises the seamless process of data use for public good. It is no longer acceptable to use data governance concerns to prevent direct comparison of cancer care outcomes in Northern Ireland to those in wider UK. This limits comparison and expectation in care delivery; prevents innovation and frustrates clinicians and patients. Lack of secondary use legislation is no longer a barrier to safe sharing of data, and we should proceed to a default prioritisation of citizen outcomes. We were able to access and use

Covid data during the pandemic – this provides the precedent for timely, responsible and effective collection and use of cancer data. The Goldacre report (Better, broader, safer: using health data for research and analysis - GOV.UK (www.gov.uk) and the citizens-focused and approved use of cancer data by DATA-CAN, the UK's Health Data Hub for Cancer, should become our North Star when safely accessing and deploying patient data, and our robust guide regarding the governance processes. If on balance, safely accessing and using data can deliver better clinical outcomes, then it is our duty to employ data safely, effectively and in a timely way.

3. **Immediacy:** The short-term focus of the HSCDI should be to design a way to create the HSCNI equivalent of the UK COSD dataset Cancer Outcomes and Services Dataset (COSD) (ncin.org.uk) – allowing access to detailed, timely and focused outcomes for citizens with a cancer diagnosis. It is also critical that data is made available in near real-time, so as to ensure its timeliness in informing clinical decision-making and policy change. There needs to be close working relationships between the NICR, QUB and HSCDI to supercharge the functionality of the NICR to deliver directly from HSCNI datasets. NICR has been crucial to both assessing national data (including the impact of Covid-19 and the pandemic on cancer patients and services) but also contributing cancer data to international efforts including the International Cancer Benchmarking Partnership (ICBP), allowing us to benchmark our performance against other countries and this should be continued and enhanced through a super charged functionality. For HSCDI to understand cancer care appropriately, it needs to have access to the smartest, most committed workforce who live and breathe cancer data. That expertise lives within the NICR, and this document argues that the NICR should become a core part of the HSCNI (Health and Social Care Northern Ireland), accessing the same datasets in real time. This would reduce duplication, protect data more effectively, limit sharing requirements and consolidate expertise. The relationship between the QUB staff in NICR and the HSCDI should be strengthened through a shared governance model. Our inability to collect and report accurate information on progressive and metastatic cancer needs immediate attention. Whilst some of the technical solutions outlined in this document will address this issue in the longer-term, we need to immediately fund the NICR to collect and report on metastatic disease as part of its core function.

4. **Engineering:** Attempts to provide the data needed to deliver our equivalent of a COSD dataset will quickly highlight the complexity of our problem. There is no straightforward way to accelerate the delivery of an accurately coded clinical dataset to document the burden of primary, secondary and metastatic cancer diagnoses in HSCNI. This information, if available, mostly exists in disconnected systems and is not routinely brought together for coding purposes anywhere outside of the Northern Ireland Cancer Registry (NICR). The *encompass* programme (The encompass Programme - a digital integrated care record for NI (hscni.net)) offers the best solution to this problem, but even with full implementation of the Epic software multiple gaps will persist. These gaps are significant; the main cancer information system in HSCNI, the Regional Information System in Oncology and Hematology (RISOH) (software by Varian Software | Varian) is still not yet fully implemented and there are no explicitly defined timelines or published plans for *encompass* to replace or augment that functionality. The Radiotherapy system (ARIA), also provided by Varian, is implemented but in separate instances and siloed. Consequently, information regarding multidisciplinary meetings and cancer diagnoses will remain separated, from a data perspective, for many years to come. Primary Care data remains

largely siloed, although the General Practice Intelligence Platform (GPIP) promises to safely transform this and will be a significant information asset for population health delivery in cancer care. The fact that many of these systems are separate and their data siloed is no longer acceptable and will severely compromise the delivery of cancer care, research and innovation. We have an unrivalled opportunity to reimagine cancer care and research and innovation, through a data-driven prism and we must grasp this unique opportunity to ensure an intelligence driven, citizens-focused cancer control system for the citizens of NI.

The *encompass* programme is working hard to allow all the siloed systems highlighted above to interoperate for clinical practice, but I think more considered thought should be given to accelerating cancer functionality (Beacon [Software | Epic](#)) into the encompass programme. As we will see, the alternative work arounds are laborious, incomplete, and duplicative. Whilst encompass is a complex programme and is approaching its implementation phase this is a time sensitive issue and if we proceed as is, the methodology of reconciling datasets will become ever more complex.

5. **Platform:** Regardless of how we proceed, the HSCDI will need access to world class technology to work effectively. There must be a continued move to a flexible cloud architecture for the collection, analysis, and secure storage of data sets related to cancer. This is as safe as on-premises storage solutions and inherently more flexible and will deliver greater benefits. It is the default methodology employed throughout the highest achieving healthcare economies. This must be a clinically-focused and not merely a technological decision - whatever technology offers the greatest utility of data access that can be used to drive better clinical outcomes, should be identified and deployed. These decisions should be clinically, and service led, and not subordinate to perceived technical risks without objective evidence. There is a direct connection between the technology employed and the clinical outcome – this needs to be understood. A combined model of on-premises and cloud infrastructure will be prevalent for some years and the HSCDI should be given the time and budget to outline a preferred target architecture, using the provisioning of a solution for data-enhanced cancer care delivery as a template. This is a complicated arena, too complex for this document to cover in detail, however the HSCDI must find a balance between dealing with the complexities of hosting data from legacy systems and managing the new requirements of the encompass programme. To accelerate delivery timelines, HSCNI must embrace shared working with commercial, charitable, and academic partners to achieve innovative solutions that deliver better citizen outcomes. Cancer represents a perfect use case for this approach with a broad range of local SME's and academic colleagues keen to help deliver a working model - The Belfast Region City and Growth Deal provides an excellent opportunity for an intersectoral digital health approach - working together to deliver the optimal cancer data solution that addresses the clinical, research and innovation and socio-economic challenges for NI.

6. **Inclusion:** Cancer is not just experienced in hospital settings; it is with patients and families at home and involves many parts of everyday life. There are currently over 50,000 cancer survivors in NI. We currently make minimal effort to routinely collect information about how citizens are affected by cancer in their normal day-to-day life. We do not measure their experience effectively, nor do we continuously measure how symptoms interfere with normal life. In all other aspects of life, companies ask for real-time feedback and obsess about how we rate their service. Why is that missing in medicine – are we afraid of the response? I think it is more likely

that we do not have the tools to record, collect and analyze these data. To gain a better understanding, we need to focus on patient experienced outcomes as part of our data requirements for a 21st century cancer service. These experiences should become part of the clinical record and be deployed cumulatively to indicate where to focus to achieve best outcomes for those living beyond a cancer diagnosis. *Encompass* has the technologies to record, archive and reach out to citizens living with cancer. MyChart [MyChart | Powered by Epic.](MyChart) will be available on roll-out and should be extensively promoted for use. A citizen inclusion roadmap is needed for cancer care, detailing how these services will operate. As with all aspects of care delivery, there also needs to be consideration of non-digital users in service design.

7. **Funding:** If we proceed as our current timeline suggests and defer the implementation of native *encompass* cancer functionality until after nationwide role out of Epic, we will need to reconcile multiple data sources to provide an accurate understanding of cancer's impact on the service and on our citizens. Data from RISOH, (Aria) Radiotherapy, PAS, Radiology Systems, Primary Care, CaPPS, Encompass, Laboratories (both new and old systems) and citizen facing applications will need to be merged and be integrated to provide the accuracy that we require. There are multiple requirements to achieve the data access, archiving and data repurposing, all of which are required to reimagine and deliver a flexible data repository system for Northern Ireland. The budget required for such work is extensive; however, it will greatly reduce cancer healthcare costs in the longer term - this is the perfect time to act. We can build the infrastructure we require now and flexibly design solutions to current problems but also future problems as we move forward. Northern Ireland is in the action phase of healthcare re-design, and this is the core part of that solution. The HSCDI will need a large workforce and implementation budget to achieve the work outlined just for the NI Cancer Strategy. In preparation for this work, we estimated that investment to be in the region of £ 15-18 million over 5 years – with at least 5 million of that being upfront in infrastructure costs. This infrastructure can then be reused for other diseases and other areas of the Health Service. This is exactly the type of vexing problem that the HSCDI has been envisioned to solve.

8. **Research is not optional:** Health services are bound by financial limits and often research is seen as a "nice to have" extra. This is emphatically not the case. The best health economies understand that research is a must have – a necessity, not a luxury. Research drives better outcomes, makes recruitment of the best talent easier, encourages investment, challenges the status quo and enhances the quality of health systems. In short – it makes the care we deliver better and challenges us to prove it. Northern Ireland has a legacy of exceptional cancer research, and the underlying benefits of its data ecosystem are yet to be effectively used for the benefit of its citizens. NICR remains a highlight of what can be achieved on a modest budget with vision and purpose. The Belfast City and Growth Deal [Belfast Region City Deal (belfastcity.gov.uk)](Belfast) investments and the ongoing excellence of our two local universities emphasise the need for the creation of a new partnership between these entities and HSCNI to deliver a state of the art cancer data ecosystem and platform that underpins optimal cancer control for our citizens. We have a unique opportunity to digitally link tissue (NI Biobank), clinical and social care data in cancer; this would be world leading and offers opportunities for delivery of citizen centric clinical trials and real world evidence studies. This ecosystem also has a marketable value – an investment that we could use to make our services better and deliver fair value to our citizens.

What can we hope to achieve?

This document suggests practical things that we can do to make cancer care delivery better, using data. That is always reliant on funding and a commitment to the technology needed. The problem is that these aspirations can end up being unachievable due to budget. The reality of Northern Ireland's public services makes me pragmatic about what we can hope to achieve and yet the recent investment in encompass is truly remarkable and I can't help remaining profoundly optimistic. For many regions of the UK, the procurement of Epic as a software provider across acute and community care would be unimaginable - due to cost and inability to leverage scale and to ultimately see the benefits in the longer term. In contrast, within NI, we have secured the largest implementation of an integrated electronic medical record across Europe. The fact that this is a challenge is unquestionable, however; a relentless focus on patient safety benefits, population health understanding and effective service delivery levers, will be transformative. Our learning from Covid 19 has allowed us to reconsider how we approach data and to ask better questions –

How can we turn the new focus and drive for actionable data into creating better cancer services?

Firstly, we must deliver as we design, rather than over-engineering a process that cannot work in the real world, or one that has too many dependencies on things that we cannot control. Waiting is no longer an option. Many aspects of our service are declining - we need to consider the actions we can take now, with the limited resources we have, to achieve better outcomes. We have a duty to see past the limitations in commissioning, in politics and long-term funding arrangements and start deploying data to deliver now, whilst trying to build towards a longer-term solution. That does not mean this document accepts the funding envelope for cancer data within current budgets, on the contrary, it will strongly argue that to improve efficiency in delivery, data is a key asset currently under utilisied and we need investment to unlock its potential.

Part of the conversation will be the use of data in commercial clinical trials and the way that data can be safely used to create an income stream for cancer care in NI. This is a controversial area; however detailed assessment across the UK, Europe and the US demonstrates it is both safe and a key lever to unlocking funding for cancer care delivery and societal benefit. As I said earlier, this document is citizen and outcomes focused. We live in a world where some people die from cancer when a service delivered differently might allow some of them to live longer or to even be cured. Given these lived realities, we all need to be open to effective solutions and any useful revenue streams – we cannot avoid these discussions.

Fundamental to Northern Ireland's ability to respond to the cancer challenge is a precise understanding of the information needed to provide better care for our citizens who are living with this disease. In today's world the term information is becoming increasingly equivalent to data. But they are not the same; data requires insight, knowledge and understanding to become usable information.

Turning data into usable information

We need to think about what data we collect, share and analyse, to allow us to provide better services. Without an infrastructure for sharing and integrating these data, we risk building even more data silos and missing important opportunities to provide care in a different and more connected way.

It would be helpful if all these data sets were "born interoperable". That is, regardless of which system collected them, they could be reused by other systems or approved individuals, for whatever purposes are required to provide better care. In Northern Ireland this is simply not the case, legacy systems are commonplace and data from these systems is siloed in safe, but largely unhelpful technical environments. We need a cancer data system that is integrated and part of a wider Data Institute for Northern Ireland – HSC Data Institute (HSCDI).

What is the HSCDI?

Implementing and unifying these new resources and the underlying data science infrastructure for Northern Ireland is the role of the newly envisioned Data Institute (HSCDI). Managing the cancer data requirements of Northern Ireland should be its first commission. By building the technical capabilities and making appropriate changes to governance models, longstanding challenges such as access and governance become subordinate to the singular outcome of delivering better care for cancer patients. We should always remember we are a provider of care, not a technology or insurance company.

The HSCDI is described in the following way by its architects:

'The HSCDI brings opportunity to change the way we look and think about our data at HSC. For example, across HSC different teams favour different systems for a specific utility and are therefore biased in assessing the benefit the system brings to HSC as a whole. These biases exacerbate our silos and therefore a responsible body is required for the archiving, storing, deleting or proofing of digital health and care systems. The Data Institute and DHCNI - informed by our people throughout the system - must choose what to do with legacy systems and their data, leveraging new technologies rather than maintaining redundant systems. This can only happen if we create an environment which has that collaborative and inclusive working approach established from the start. The Data Institute is designed to bring people and different agencies together. It must be funded and managed differently. We propose that the Data Institute be established as a joint venture between key stakeholder organisations, much like DHCNI, reporting ultimately to the CDIO and CMO.'

The many existing repositories of data are not always easy to find and are inconsistent with each other (e.g., use different coding, data models, and definitions), making it difficult to integrate and analyze multiple datasets. In addition, they are not easily accessible via application program interfaces (APIs) and often reside within institutional boundaries. This creates a significant barrier to progressing a data-driven digital health agenda for diseases like cancer.

A variety of cultural, technical, and policy issues make data sharing difficult for both researchers and patients. As a result, when clinicians and researchers attempt to share data, they are faced with multiple databases and multiple formats, and they do not necessarily have the expertise to proceed. Likewise, patients who may want to share their medical records are faced with the challenge of access, multiple sources of records, and the lack of an appropriate process. In addition, patients may have concerns

related to privacy, potential downstream consequences of sharing their data, and lack of control over how their data is used. In many cases, citizens may feel so disconnected from the process that they do not want to be involved. We need to move towards a more citizen-centered approach, where citizens and patients are active participants.

In addition to facilitating the sharing and ease of use of multiple existing data resources, the goal of the HSCDI must be to allow coordinated contributions from different teams/stakeholders across Northern Ireland and to provide a common data dictionary and appropriate tooling that promotes better usage. The current lack of agreed- ontologies, vocabularies, and data models severely impacts analysis across multiple datasets.

The HSCDI will provide the data science infrastructure necessary to connect repositories, analytical tools, and knowledge bases. The data from cancer care delivery could enable the creation and evolution of new cancer treatment models, help initiate new clinical trials and RWE (real world evidence) studies, and improve the overall quality of care for cancer patients.

Northern Ireland should provide the citizen-centric data environment to enable patients and healthy individuals to directly contribute their data for scientific research (eg https://www.usemydata.org) , for the greater good of all citizens. Providing patients with useful knowledge and understanding of their options as they move through the cancer journey, such as understanding the prevalence of their disease and clinical presentation, understanding their standard of care, and the availability of clinical trials should become the norm.

Why now?

This work is taking place in response to the recently released (but yet to be implemented) cancer strategy. Data and their application are a key component of the strategy It is important to be clear of the size of the task ahead. A paragraph from the strategy highlights the issue:

Although cancer survival in Northern Ireland has improved over the years, it still lags behind other comparable countries both in Europe and internationally. The International Cancer Benchmarking Partnership (ICBP) Module 1 report showed cancer survival in Northern Ireland to be behind other parts of the UK, Australia, Canada, Denmark, the Republic of Ireland, New Zealand and Norway. Northern Ireland consistently ranked between 8th and 10th out of the 12 jurisdictions involved.

The Cancer strategy has 60 actions; on review almost all of them have a data component and requirement. Reviewing the strategy indicates the huge task ahead to join these information sources/assets together. There is a lack of consideration given to the complexity of that task with regard to cancer data. There is an assumption in the document that the data needed to help achieve these 60 actions is readily available, for many of the actions envisaged that is unfortunately not the case.

Like many healthcare plans, the cancer strategy is based on the quadruple aim of healthcare delivery. The diagram below comes from DHCNI's data strategy and clearly articulates the benefits to be achieved from sharing data across the healthcare economy. The HSCDI will seek to leverage data to achieve these goals for all conditions in NI. The Data Strategy, written by DHCNI, outlines the many ways that they envision data as the key facilitator to achieve many of NI's healthcare goals. Cancer is the perfect place to begin this journey in NI, as it represents a difficult challenge that must be overcome for many of our

technical data deficiencies to be successful. If we can achieve a working data methodology for cancer care, it will be possible to adapt it in many other healthcare settings.
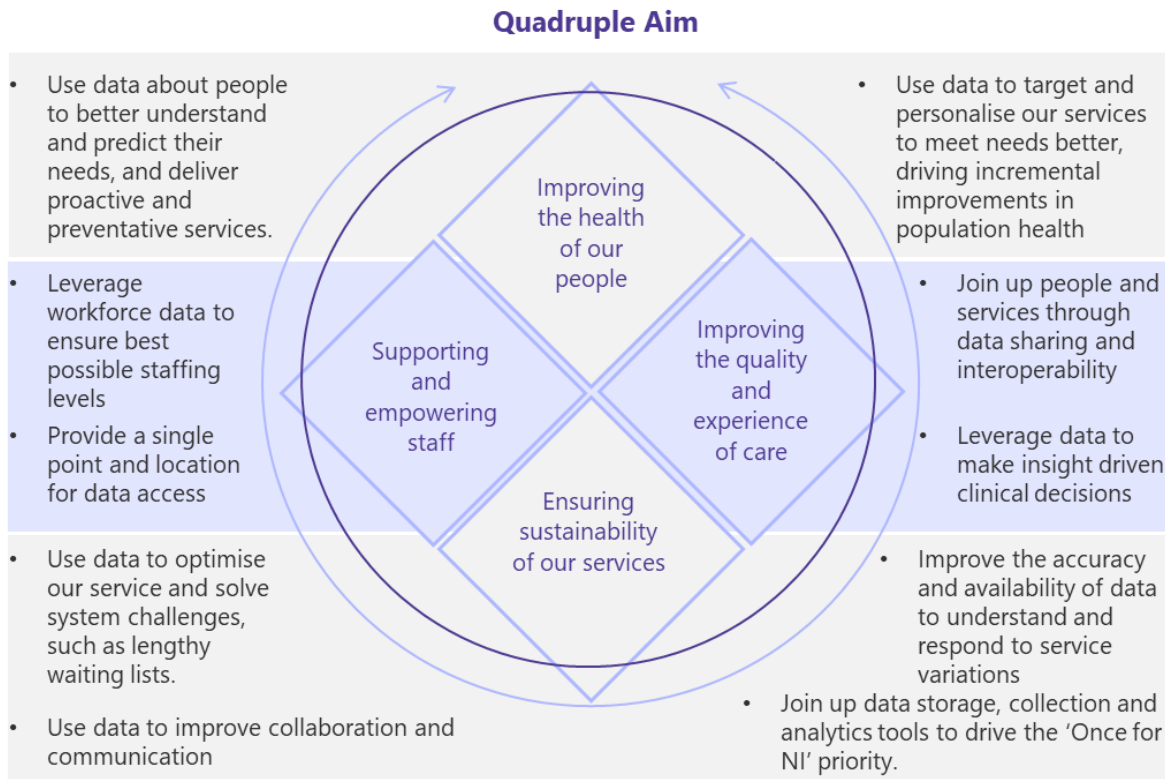

Quadruple Aim

- Use data about people to better understand and predict their needs, and deliver proactive and preventative services.

- Leverage workforce data to ensure best possible staffing levels
- Provide a single point and location for data access

- Use data to optimise our service and solve system challenges, such as lengthy waiting lists.

- Use data to improve collaboration and communication

Improving the health of our people

Supporting and empowering staff

Improving the quality and experience of care

Ensuring sustainability of our services

- Use data to target and personalise our services to meet needs better, driving incremental improvements in population health

- Join up people and services through data sharing and interoperability
- Leverage data to make insight driven clinical decisions

- Improve the accuracy and availability of data to understand and respond to service variations
- Join up data storage, collection and analytics tools to drive the 'Once for NI' priority.

Figure 1. Quadruple aim in healthcare and how data can help achieve it, as outlined in DHCNI data strategy.

Encompass is not a panacea!

Whilst *encompass* is progressing, it alone will not fill all the information gaps we have in cancer care delivery. We need to be careful not to assume that a single software programme can correct so many of the legacy data issues that have persisted in NI for so long. *Encompass* will be the largest, most challenging but ultimately the most impactful of all the programmes across all the health technology landscape in HSCNI – it is truly transformational in its scope, and it will provide the data needed to drive improvement in care delivery in Northern Ireland for the next 20 years. However, it is important to realise that *encompass* cannot fix what has passed, it will not collate and collect older datasets and make that data reusable. Rather, it will dramatically improve the quality and timeliness of data from the time it is implemented. Put in a more pragmatic way, *encompass* immediately makes the data more accurate and will incrementally improve NI data quality over the coming years. Perhaps, what is more reassuring is that *encompass* will more rapidly create linked clinical pathways than is currently possible, so that direct care immediately becomes more transparent, and patients can have greater oversight and involvement.

The *encompass* programme is a critical part of the Digital Future of Health and Social Care; it has the potential to make so much more possible in secondary care, mental and social services. This diagram below explains its functional scope and highlights areas where other systems will need to be integrated.
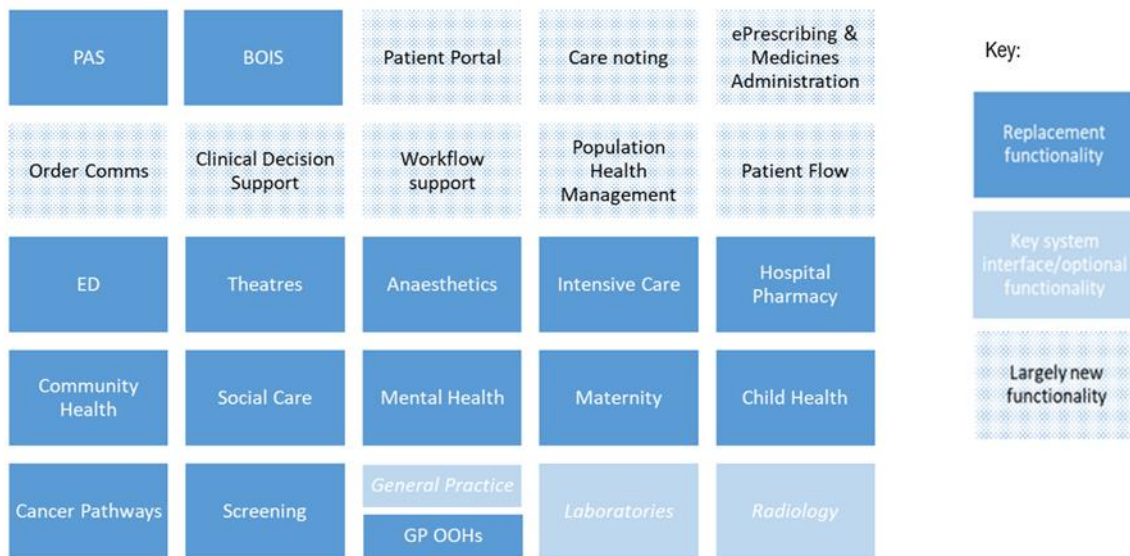

Figure 2. Encompass' functional scope replaces core legacy systems and adds digital noting, digital prescribing, national order comms and tracking, workflow control and importantly an integrated patient portal.

Encompass' functional scope replaces core legacy systems and adds digital noting, digital prescribing, national order comms and tracking, workflow control and importantly an integrated patient portal.

Encompass will replace many of the disparate system in place today and will add greater functionality. Importantly it uses clinical coding terminology, and every clinical interaction is coded in real-time by the care provider (specialist verification by coding teams continues in support of this).

Information Gaps

At present we have a large number of gaps in the information we collect about our citizens affected by cancer. These gaps exist in both clinical and non-clinical systems and we need to understand these areas urgently.

One of the most pressing issues is the tracking of cancer patients across our service. The box above labelled Cancer Pathways refers to - CaPPS - Cancer Patient Pathway System. This system was commissioned by DoH in 2008 to provide an orchestration role in cancer care delivery, in particular ensuring red flag referrals are appropriately assessed. Whilst this box is blue (functionality to be replaced by *encompass*) – in this circumstance that can only happen when the co-ordination of all cancer care is managed by Epic, there is no date for this level of functionality.

CaPPS is currently routinely used by all Trusts in Northern Ireland to:

Facilitate 45+ weekly and five monthly Multi-Disciplinary Meetings (MDM) held in NI by

- capturing cancer datasets for all new cancer patients including staging.
- recording the results of diagnostic pathology and imaging investigations.
- recording MDM treatment plan decisions.
- recording details of cancer relapse/progression and treatment and management decisions following relapse/progression.

CaPPS helps navigate patients through their cancer pathway, from referral through diagnosis, staging, and treatment. In addition, it provides oversight in monitoring cancer waiting times, alerting cancer patient navigators if waiting time targets are missed. It is important to remember CaPPS is not automated or driven by algorithms, it is completely human-operated and therefore prone to human error.

CaPPS has been iteratively developed to collect pertinent information on cancer presentation, staging and care delivery. The input of data from clinical MDM is supported by data administrators and data trackers. The need for data trackers will persist for as long as a manual monitoring system such as CaPPS exists.
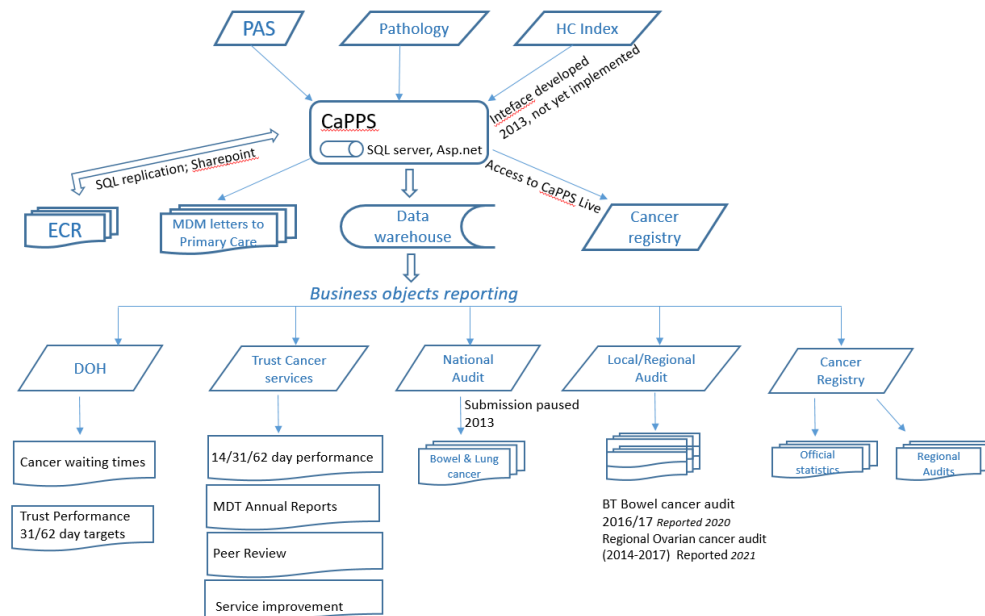
Figure 3. CaPPS schematic (kindly provided by Dr Lisa Ranaghan) – demonstrates collection and orchestration of data within CaPPS system.

There is some variation in how the system is used by clinical staff. In some disease areas, consultants complete the minimum data set, including TNM (**T**umour, **N**ode, **M**etastasis) staging and treatment plans, including detailed ancillary collection fields for co-morbidity and relevant clinical features. In other areas, these details are filled in by non-clinical staff.

The lack of defined standardisation in this approach leads to gaps in information accuracy when reviewed. The MDM record itself is recorded by data administrators and follow-up letters to care delivery teams and primary care are automated. The booking of follow-up treatment is manual via PAS systems and call/recall remains largely a manual process managed by clinical trackers. CaPPS offers Northern Ireland's main source of data regarding cancer journeys and effectively acts a minimum dataset for citizens. Its largely manual operating approach is not sustainable or desirable in the world of digital health.

Managing outpatients and in-patients with cancer - today and tomorrow

Outpatients' functionality will, in general, move to *encompass* – specialised cancer care is currently less clear-cut. Outpatient events are recorded in the Hospital Trusts' Patient Administration Systems (PAS), these will all be replaced by Epic. However, within cancer care, the Regional Information Systems in Oncology and Haematology (RISOH), is widely used in outpatient and inpatient settings, and this allows digital recording of diagnosis, planning of therapy (chemotherapy and radiotherapy), along with progress note recording, and it introduces physician-entered digital coding in secondary care. The entered coding within RISOH could be considered more accurate, as it is physician-entered, however it is variably used and there is little auditable information confirming its accuracy.

RISOH uses Varian Software – which is also used in Radiation Oncology treatment (Aria). The codified delivery of treatment in cancer is recorded in Varian systems - the level of standardisation in recording of treatment is again hard to quantify and is heavily dependent on training. RISOH has also released a patient portal service which augments the citizens ability to interact with their treatment and provide feedback on the care delivered Noona | Varian. This is being rolled-out in a few specific disease areas in oncology.

Getting usable, timely information from RISOH has proven difficult. There is a detailed system data schema, provided by the system vendor, and a coding system in place – extracting and easily visualising this data is difficult. There is a new query tool – Insightive – which may improve the data extraction/visualisation, in the interim clinical staff find the process of data entry and meaningful retrieval challenging. InSightive | Varian

The RISOH programme is still not complete, particularly in Haematology. Clinical staff describe varying degrees of satisfaction, and dissatisfaction, with the system. A review of the level of service satisfaction, usage, and quality of data entry or recording was not readily available. This leaves some uncertainty regarding the ultimate usefulness of data that can be made available.

All in-patient care will be recorded in the *encompass* system. Therefore, as and when in-patients need to have cancer care, their information will need to travel with them between systems. At present, the practicalities of this are being designed but there is no clear methodology outlined to link the important data from current oncology and haematology systems with all the remaining healthcare information that will exist in *encompass*. This is particularly complicated when we consider that all inpatient prescribing will be digital and held on Epic, and yet chemotherapy and radiotherapy data will persist on Varian.

Work is thankfully already well underway to link the clinical pathways within Epic and Varian. Epic have a long history of successful integrations with Varian systems in Haematology, Medical and Radiation Oncology. This practical solution to booking appointments across systems, allowing views of relevant clinical information which will make clinical practice better is being designed. However, this will not create an integrated data solution for cancer data. Inadvertently, we could find ourselves no further forward towards a longitudinal data record of cancer care that we so desperately need. As *encompass* is not currently planning to replace the functionality or data collection methodologies within oncology or haematology systems, we need to think about the data quality issues that will lead to.

Inpatient stays, day procedures and surgery.

When a person is admitted to hospital or has a day-procedure (e.g. endoscopy), paper notes are usually used, and on discharge this episode of care is given a list of diagnostic codes. These codes are created by coding experts who interpret the clinical notes and apply a digital code which is stored on the Hospitals PAS. These codes are often added some time after discharge (usually 1-3 months - but can be longer) and are consolidated in Northern Ireland Data Warehouse (DW) in the Business Services Organisation (BSO). This timing is different across Hospital Trusts and is different for speciality areas, e.g. endoscopy vs inpatient Acute Medicine.

There are 8 PAS systems in Northern Ireland, and they are not routinely linked for outcomes. Almost all medicines prescribing is on paper, apart from some small areas in critical care, renal medicine and chemotherapy in cancer care. This data is not systematically digitized and therefore not matched to citizens.

Laboratory Information Sytems (LIMS), host laboratory data including pathology specimen reports, and the Northern Ireland Picture Archiving Systems (NIPACS) stores images from radiology systems. There are multiple radiology systems, which again are entering a consolidation phase.

For clinical practice, all these myriads of systems are viewable as an integrated single record through a portal system called Northern Ireland Electronic Care Record (**NIECR**).

The NIECR contains information from existing electronic record systems from hospitals and clinics throughout Northern Ireland, as well as some information which is recorded directly in the system, where this is helpful to care.

This information includes:

lab tests
radiology results including x-rays
referrals
investigation requests
appointments
encounter and discharge letters from various HSC systems

NIECR makes all of this complexity clinical useable as we care for citizens. Importantly, however; NIECR does not improve the data we collect from other systems, nor does it make them any more usable to inform future delivery or system design. The data are not accessible for secondary uses nor will they be migrated to Epic.

In practical terms – all of the above systems will be replaced and improved by a combination of *encompass,* the new Laboratory information system programme (NIPIMS) and by a new radiology system (NIPCS+). These new programmes will, in many circumstances, provide digitally-codified information linked to an individual's central record. We need to consider in detail how these pathology and radiology systems can contribute data to a central usable cancer data repository, not just for immediate care, but for service planning and research. These data are as patient-centric as clinical notes or medicines.

The main systems detailed above contain a wealth of information regarding care delivery for patients with cancer. However, the codified information collected is not routinely combined and used for further analysis relating to the overall care delivery processes in HSCNI. The systems are not used to the maximum benefit, or in effective secondary ways, to advance service design and delivery in real-time.

HSCNI is overly dependent on CaPPS in each Hospital Trust to co-ordinate care, this will likely slowly be replaced by encompass functionality, but only as each Hospital Trust transitions. The obvious issue is the dual running of each system during the transition and the requirements for MDMs to be facilitated on both systems. The biggest question remains, where will the definitive code of care be recorded and

stored and when will that be defined and outlined? Without clarity on that process, replicating the COSD dataset remains aspirational.

Sometimes these issues can seem abstract. By way of example consider prostate cancer – in England the National Prostate Cancer Audit (npca.org.uk) is collated to assess the performance of cancer centers in the management of this condition. The data for prostate cancer comes from multiple systems; labs, PAS, radiology and radiotherapy. Together these systems facilitate care; however, our inability to link the data relating to the outcome of that care prevents us from comparing ourselves to other parts of the UK. Technology exists to overcome these barriers but there is a lack of combined will to achieve that goal. Clinical staff need to be set free from administrative burdens to investigate if the care that they deliver compares to best in the UK – this is about quality of care, citizens survival and opportunities to learn to be better - the stakes could not be higher. We simply must do better!

Medicines Management.

There are specialist teams in secondary and tertiary cancer units managing complex chemotherapy, and these staff are supported by community and high street pharmacists, who holistically help manage patients' care pathways. Pharmacists are particularly important in identifying compliance with treatment and noticing adverse effects of medicines. The cycle of medicine management, from procurement to dispensing, is complicated and can be greatly aided by technology.

Today, there are obvious gaps with this process as paper prescribing remains predominant in secondary care. Even within cancer speciality services usage of digital prescribing within RISOH varies between unit and speciality team. This will be improved by encompass in relation to non-cancer regimes but will be unchanged for cancer drugs. The lack of timely (non-paper or email based) update of medicines between primary and secondary care remains a most vexing problem. The requirement for humans-in-the-loop means the prescribing data is replicated in multiple systems and not consolidated anywhere. We lack the ability to scan population records for adverse events in prescribing, to look for relationships between effects of treatment on need for other medicines like anxiolytics, antidepressants or cardiovascular agents. Everything exists as if the episodes are disconnected when in the patients experience, they are an interconnected journey.

The experience of pharmacy staff to identify areas of excellence and formulate a regional approach to digitisation of prescribing will be critical to encompass' success. In particular there needs to be robust planning and continency arrangements for the period of dual-prescribing which will exist as encompass and RISOH interoperate to facilitate cancer care delivery. This process is being mapped out as part of the encompass programme and input from regional cancer services, facilitated by NICaN, will help this process. The DoH needs to consider the policy position regarding medicines prescribing interoperability between systems and take a clear position on plans to consolidate pharmacy data for audit, research and operational delivery.

Community service, Clinical Specialist Nursing teams and Hospices.

The data collected from community delivery of cancer care is probably the most complex. Hospital Trusts often use different community systems that do not produce standardised coding outputs which are measured. The information is collated in proprietary systems and stored securely but in a siloed manner. My experience with Deprivation of Liberty paperwork, and working on wards with social workers trying to place citizens in the community, suggests a system that seeks to replicate paper forms with digital forms. None of the systems record, code and describe in a searchable and machine-readable way an accurate record of what is actually happening.

District nursing and specialist Clinical Nurse Specialist (CNS) services, such as Macmillan or Hospice nursing, may collect information on paper, primary care systems or indeed some community systems. The Hospice services do not yet have an electronic patient record (although that is in planning), nor do they have a locally-agreed information sharing system. In the main, clinical processes are made possible by NIECR, primary care and community systems and the amazing commitment of clinical staff from all areas. Again, none of this information is coded or collected at a central searchable source.

Given the close relationship between citizens living with cancer and these community clinical staff, it is perhaps here that we have the most need for better data to learn how to deliver care more effectively. My hope is that *encompass* will be leveraged as much as possible throughout the care continuum and extended to follow the patient, regardless of where their care is delivered. This will ensure that we collect all the relevant information related to the patient journey – allowing us to "learn as we care". There will be reluctance to cede control of 'work-flow' to a new system, but that hesitancy must be overcome by understanding that the patient-centric record provided by *encompass*, will in time become the most accurate view of the patient journey.

Northern Ireland comparisons

Northern Ireland is a small place, and we can learn from what the nations who have better cancer outcomes have done to make data work better for their patients. We are part of the UK, yet our cancer outcomes are worse than a similar population in England – is data delivery and its use part of that inequality? The Covid pandemic has seen NHS England pivot to become a data-focused organisation. The need to deliver PPE, vaccinations and manage ICU capacity accelerated co-operation with commercial entities to ensure deliverable solutions. HSCNI, through DHCNI, made the same choices and delivered effective solutions with small and large businesses in application development and service delivery. The procurement of Epic software (as part of the *encompass* programme) is the clearest example yet that to achieve more for our population, we need to accept that Northern Ireland must learn from the world's best, accelerating gains based on the success that they have already achieved. By implementing *encompass*, we can learn from everyone who has implemented or iterated over Epic previously, from Harvard to University College London and by moving to a modern data environment we learn from what has worked at scale across the world – the risk is not in changing, the real risk is in standing still.

UK NHS and the Cancer data services have already understood this move and reacted by asking HDRUK to work in conjunction with academics, big data companies (AWS, Microsoft, Palantir and Google) and analytic specialists to accelerate access to usable data now. DATA-CAN has shown the power of data, particularly in identifying the impact of Covid on cancer services and cancer patients and developing intelligence-informed approach to mitigate the adverse impacts. Northern Ireland has tried to develop on the back of these advances but is limited by resource and anxiety regarding change and people. The NI cancer strategy is based on the need to rapidly accelerate care delivery for our population – this is not possible without up-to-date data – to profoundly enhance cancer care, we need to base decisions on what we know from the data.

In England it is relatively simple to review up-to-date cancer data on:
https://www.cancerdata.nhs.uk

This system allows timely access to detailed England information on Cancer provided by National Cancer and Analysis Service (NCRAS)
- Incidence and Mortality / Cancer type specified by age group
- Survival
- Prevalence
- Route to diagnosis
- Presentation Method
- Stage at diagnosis
- Treatment – Surgery, Chemotherapy, Radiotherapy
- Median Treatment Pathway efficiency

We must aspire to produce the same kind of data that NHS England has access to. NICR has provided some of these solutions but it is under-resourced. The use of collected population data to drive better outcomes has focused on the minimal dataset needed to understand the collection of diseases that make up cancer. As an absolute priority we need a line of sight to this outcome in Northern Ireland.

http://www.ncin.org.uk/collecting_and_using_data/data_collection/cosd

NHS England has merged its **Digital** and **X** verticals back into a unified NHS England service, largely to streamline this competitive tension between those whose want to deliver through business process modification and those who want to deliver through innovation. There is no doubt merit in both, but in a health service under pressure the need for actionable data is immense and NHS England discovered this the hard way during Covid 19.

NHS England has responded by doubling down on using cloud data technologies to drive service delivery. Envisaging cloud platforms combined with federated data access as the answer to this problem, the next Federated Data Platform procurement is the clearest sign yet of the direction of travel. In NI we need to ask - if it is good enough for our primary funder, is the same methodology not good enough for us?

The NHS procurement contains provisions for: https://www.find-tender.service.gov.uk/Notice/008755-2022

- Data management services
- Platform interconnectivity software package
- Database software package
- Software package and information systems
- Medical information systems
- Electronic data management (EDM)

The Northern Ireland Data Strategy confirms a further move towards a data architecture in-line with the commercial models utilised by many commercial data businesses throughout the world. We need these platforms to empower NI to understand the information that we collect and to ensure that we respond to patient's needs.

You cannot separate this from research

It is not possible to separate the delivery of a national cancer strategy from the parallel aim of having a world class research programme in cancer. The two goals are intertwined, and we must work hard to ensure they focus on the same goal of better care delivery and are not competing with each other. Data offers a core resource that can be used for both care delivery and research and innovation and NI is in a perfect position to exploit both opportunities.

The reality is that cancer research has so many aspects; basic science, cellular genetics, interventional biology, clinical trials etc. There are almost too many fields to list and yet they all require some basic connection to the clinical environment in which their research is based. Collaboration is key in research delivery, and we need simplified ways to allow our data to be shared and combined with colleagues across the UK and globally. NI has a legacy of discovery science, translational research and trial-based cancer research and the NICR has a long history of detailed analysis of disease trends. Northern Ireland has some of the most detailed pre-malignant registries in the World Northern Ireland Cancer Registry | N. Ireland Cancer Registry (qub.ac.uk). How do we use data to bring these areas together into a unifying data environment which protects information and yet simultaneously allows effective sharing and innovative use of informative and potentially lifesaving data?

Northern Ireland has an active research network which utilises routinely-collected data to advance understanding regarding cancer diagnosis, treatment outcomes and related factors which may affect how citizens receive cancer care. As an example, the Routes to Diagnosis work Routes to Diagnosis Report - Main Report Jan 2020.pdf (hscni.net), performed in combination with NICR, QUB and Honest Broker Service Honest Broker Service (hscni.net). This is a comprehensive piece of research that brought expertise from QUB, NICR together with HBS and BSO warehouse experts to investigate how citizens presented with cancer to the health service over a number of years. For relatively modest funding, the team established a longitudinal study of real interest to service providers – this work has initiated a process which could ultimately map out important trends in cancer presentation, allowing a more agile and reactive service. This sort of work requires sustained funding, now, to bring expertise and data together in useable way for HSCNI.

The Northern Ireland Cancer Registry (NICR) is located in the Centre for Public Health, Queen's University Belfast and is funded by the Public Health Agency for Northern Ireland. The Department of Health established the Northern Ireland Cancer Registry in 1994 and, via the PHA, provides a funding stream. The registry produces the annual Official Statistics on cancer incidence, prevalence and survival in Northern Ireland and provides evidence to help inform decision making about cancer services. Northern Ireland Cancer Registry | HSC Public Health Agency (hscni.net)

The aim of NICR is summarised below. Given their funding envelope they have achieved significant insight on cancer incidence, survival and mortality, but their access to data is limited in timeliness and ease of sharing information, and the lack of appropriate funding is challenging. The NICR has been limited by its lack of access to live HSCNI data and by the separate nature of its technological infrastructure. This type of enhanced security is no-longer dependent on the entire separation of NICR and real-time clinical systems and working with the Data Institute we need to provide the NICR with the resource to work hand-in-hand with our clinical services. The words in bold below are the key advances required to unlock improvements in service delivery and they cannot exist outside the structures of the health service that needs support.

*Collect, analyse and confidentially store accurate, **timely** and **comprehensive** data on cancer.*
*Uphold patient and carer **confidentiality**.*
Promote, facilitate and undertake research into cancer causes, prevention, treatments and outcomes.
__Facilitate planning__ of cancer services for prevention, diagnosis, cure and care.
Undertake and assist audits of cancer treatments, services and outcomes, and recommend improvements in cancer services where appropriate.
*Provide **appropriate information** on cancer for ad hoc queries.*
Promote professional and public awareness about cancer.
Publish scientific reports and papers relating to cancer.
*Link **nationally and internationally** to promote cancer registration and increase understanding and control of cancer.*

The NICR has a long legacy of substantive work and yet as an arms-length body is separated from the data it heavily relies on. Residing in QUB and funded by PHA, it has a complex system of data retrieval, matching and analysis; all separate from the health service delivery units. Given the *encompass* programme and the HSCNI's aspiration to collect information once, reduce duplication and share effectively, the NICR may be better served - for data access - by being much closer to the HSCNI. This centralises technology, security resources needed to leverage value from clinical data and adds the expertise of NICR to HSCNI's attributes. This can be achieved virtually without dramatic changes to organisations working practices, in this circumstance technology can accelerate working collaboration and practices.

The data collected in care does not just relate to the cancer diagnosis. Lab results, tissue pathology and imaging are all relevant to what we need to do. The Northern Ireland biobank facilitates and governs access to tissues samples from citizens with cancer [The Northern Ireland Biobank | Precision Medicine Centre | Queen's University Belfast (qub.ac.uk)](#). Wider service us of this unique resource should be considered as we move forward delivering better services and outcomes for citizens with cancer.

Throughout this paper, I have commented on the timeliness to access data. NICR, like other population-based cancer registries, produces complete, accurate, reliable and trusted data on cancer incidence, prevalence and survival. Processing and quality assurance of cancer registry data mean it may not be as timely as rapid cancer data sets, but this type of data is crucial to allow assessment of trends over time, to facilitate valid comparisons and benchmarking with other regions or countries, when assessing rare cancers or when investigating cancers in small or specific geographic areas (e.g. suspected cancer clusters). This consistent approach needs augmented by rapid data delivery for service needs. Covid 19 changed that approach in many aspects of health.

Rapid data analysis during lockdown demonstrated reduction in service provision and uptake. In this work, Prof Mark Lawler [DATA-CAN's Scientific Director wins prestigious award for outstanding contribution to cancer research and care — DATA-CAN (data-can.org.uk)](#), along with colleagues in DATA-CAN, the UK's Health Data Research Hub for Cancer, showed that we can use routine data to quickly gain insight and use it to inform decision making
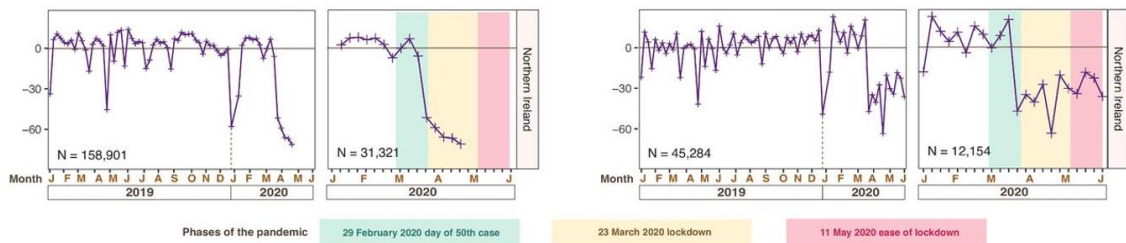
Alvina G Lai et al. BMJ Open 2020;10:e043828

Figure 4. DATA-CAN, impact of lockdown on referral and chemotherapy treatment.

His team's work, summarised in Figure above, demonstrated the remarkable drop off in urgent referrals (left panel) and Chemotherapy delivery (right panel) during the pandemic. This was using local data more aggressively collected and displayed. This leads to the obvious question - Why don't we do this all the time?

DATA-CAN is a critical pillar of the activities of Health Data Research UK (HDR UK) Home - HDR UK , the UKs Health Data Science Institute. DATA-CAN led research that measured the impact of COVID-19 on cancer services and cancer patients, employing near real-time sharing of aggregated data for Two Week Wait referrals, (known in Northern Ireland as Red Flag referrals) for suspicion of cancer (testing the adverse impact on urgent referral/diagnostic pathway), and chemotherapy unit attendances (testing the adverse impact on the cancer treatment pathway), for all five Trusts here in Northern Ireland and across seven other UK sites. It also provided crucial data intelligence that underpinned national policy-making efforts around the need to prioritise the restart of cancer services and informed patients and the public about the significant impact of the pandemic.

DATA-CAN could help support the establishment of a "Real-Time Data Network" for cancer in NI. With research support we are progressing continuation of this work through the HBS. Arguably, it should be core HSCNI business and not a research exercise.

Once again, NI can learn from others. North America has established numerous programmes aimed at combining and safely storing and reusing real-world clinical data for research purposes. These repositories make it their mission to integrate complex cancer systems data into a useable form for researchers and clinical staff. These resources are nationally sponsored but receive support from academic and business teams interested in working together to achieve better outcomes for US citizens with cancer. NI needs to develop a coordinated way of working with academic and industry partners for the betterment of our society. These US programmes have equivalents in England and many EU Nations – we need to build out, or more likely, realise partnerships to achieve the same in NI; without this aspect of delivery, it will be difficult for the Cancer Strategy to succeed.

https://datascience.cancer.gov
https://www.cancerimagingarchive.net
https://isb-cgc.appspot.com

Patient held records

At present, access to timely data is slow and cumbersome. This is largely due to the intricacies of ownership and guardianship of data storage. This contrasts with the repeated assurance of health services that claim to offer a patient-centered design and delivery approach. Health services want to be patient-centered but find delivery a challenge and the result is delay and a perception of being unhelpful, when in reality, both sides (patients and staff) are just struggling with demand.

If for example a patient has a rare genetically inherited cancer which company 'X' feels it can develop a treatment for with appropriate access to test results and historical records, and they are willing to remunerate the patient or dependents to access these data, should we intervene? Many would argue that bar some administrative costs we should have little input into what a patient wants to do with their own data. Their data – their choice – as long as the decision is an informed one - HSC has only a facilitator role. In practical terms however, allowing citizen access to their own personal data is much more complicated. The complications are technological, administrative and educational. The era of personalised medicine is here and yet we make it exceedingly difficult for our own citizens to control or manage their own personal health records. There is lip service paid to the idea, but when notes are requested or details sought, administrative barriers arise. This is no longer excusable in a digital world and with the introduction of *encompass* we will have a system which can democratise access to clinical data for whatever purposes citizens want. In some parts of the US, patients use Epic software to review all the clinical notes and results pertinent to their care, providing reassurance and added control of their illness. There will be individual differences in how patients and citizens may wish to use this sort of innovation, but those decisions should be for the data owners (the patients) and not for the system delivering care. https://www.opennotes.org/

The Cancer strategy refers to The European Cancer Patient's Bill of Rights mandate, 'The right of every European citizen to receive the most accurate information and to be proactively involved in his/her care' https://ecpc.org/. To achieve this, we must make records, citizen-centric, shared with clinical staff for care but ultimately ownable by citizens; there is already precedent in paper maternity records, this should be no different for all clinical records. If citizens don't want this accessibility, then we can continue to act as guardians. This understanding frees clinical and managerial staff from an abstract feeling of false paternalism, a protectionism which is well meant but inappropriately applied.

The Macmillan Recovery Package already alludes to this personalised journey approach to patient records, highlighting the benefits of holistic assessment of needs and access to a summary record of care delivered and planned. Cancer removes control from people's lives; allowing access to data and records can restore some of that control.

https://www.macmillan.org.uk/healthcare-professionals/innovation-in-cancer-care/personalised-care
https://www.macmillan.org.uk/documents/aboutus/health_professionals/macvoice/sharinggoodpractice_therecoverypackage.pdf

In a previous document, I suggested some of information areas Northern Ireland would need to understand, to have a detailed view of the true overall burden of cancer in our country.
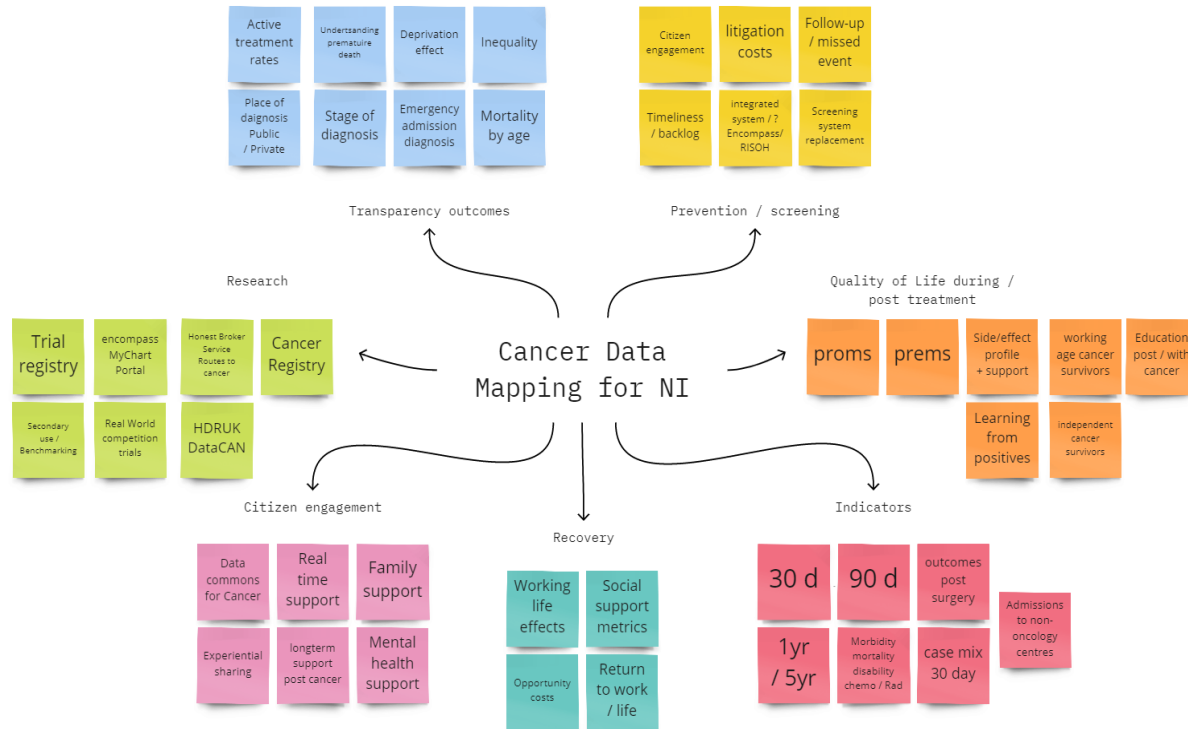
Figure 5. Cancer data map for NI users.

Looking at the diagram after publication of the cancer strategy, it is obvious that we have a lot of work to do to start bringing together a way of understanding the journeys of our citizens with cancer. Whilst the types of data we need are broad, their totality become useful to a patient diagnosed with or living with cancer. Where can citizens and agencies go to have their questions answered? At present, there is no centralised source of truth for Northern Ireland, there are committed charities, high quality research publications and government reports all based on similar datasets. The NICR registry is the default source of data, but it lacks the funding and rapid datasets to be able to answer the broad range of questions citizens, government and charities need answered and to contribute both to policy and cancer control going forward.

Considering the rapid advance of technologies, particularly video and voice systems, we must think about improving communication with our citizens to help understand disease trends and its societal impact. Medical systems collect important information, but we need better understanding of how this disease changes people's lives. Citizen journeys can be self-curated and HSCNI must develop ways in which we can on-board these stories to help us design better services.

As an example, partnering with Start-ups, QUB is helping develop software to record and learn from these stories - this allows citizens different ways to express themselves and yet simultaneously adds to HSCNI's knowledge base. The stories can be converted to valuable, searchable data and we believe we can create a tool that can add this to a digital patient record. Citizens need to be able to tell their stories and healthcare systems can use that patient information to learn how to deliver better services, more quickly. Given the state of care delivery in NI this more radical approach can complement the NHS systems approach and enfranchise citizens with cancer who may feel the system has not had time to

listen. Importantly, if the pilot is successful, this system relies on computers to do the heavy lifting and can be done in a citizen's own time. We need strategic Proof of Concept (POC) funding for work like this to bring citizens and the service closer together. The initial POC would need access to a small group of citizens willing to record and upload videos for feedback and analysis – all results will be shared in real time with citizens and the data is, as always, theirs. This also potentially leads to interesting and outcomes for the DoH concerning the validity of video as a method of inputting population health record information into a healthcare economy in a cost effective and citizen friendly way. This is a massively scalable and asynchronous methodology which can reach out to lots of citizens without taking up too much staff and citizen time.

As part of such research we could assess citizen satisfaction with the methodology, to include potential for Patient Related Outcome Measures recording. We also want to explore the potential to automate the connection between the machine readable, codified, output of those recordings with a living medical record (for test purposes only). The cost for progressing this with a group of citizens affected by cancer, and an SME specialized in video onboarding, within a sprint methodology is estimated at a subsidized budget of approx. 50K – the approximate timeline would be 3 months and. Funding is currently being sought.

Making use of what we have built

General Practice Intelligence Platform (GPIP)

The General Practice Intelligence Platform is a unique asset for NI. The foresight demonstrated in its design by Dr Brendan O'Brien, CCIO at HSCB at the time and implementation By Dr Margaret O'Brien, head of Primary Care at HSCB, is now beginning to bear fruit. GPIP is complicated, a warehouse of secure primary care data held separately within a warehouse of wider healthcare data. The innovation is the ability to match individuals based on their healthcare number, whilst at the same time preserving their privacy and the primary care team's data controllership. This has remarkable utility in helping primary care providers understand disease epidemiology within their populations and identifying ways to improve delivery of service.

On a wider population level GPIP is potentially transformative. As an example, consider the vexing issues of understanding metastatic disease prevalence in cancer care. When cancer spreads through the body from the primary site to another site it is said to have become metastatic. At present, we cannot access a population dataset to understand the current, real-time burden of metastatic cancer on the population of NI. In time, the NICR will be able to collate and collect some of these datapoints, but in the short-term we cannot collect and cross reference systems quickly enough, and with enough certainty, to deliver an estimate of disease burden. We could use radiology systems and innovative technology to extract information. Currently, our lack of data means an inability to plan, commission and deliver services for a population of our most in need citizens. Using GPIP as a potential reference point (GPs often receive the most up-to-date letter, radiology and diagnostic information – which they then code onto their clinical system) we can consider using data from multiple sources to estimate population burden of metastatic cancer, underpinning a better understanding of pain points and trends. This will need resource and support from HSCDI and will require focused funding for the GPIP team to expand their remit. However, this type of work exemplifies how collecting cancer patient relevant data and using it safely and effectively could help improve services rapidly, this is service development based on patient need, facilitated by better data – exactly the purpose of HSCDI.

Delivering for citizens with metastatic disease

Recording of metastatic disease and cancer recurrence will be of increasing importance as life expectancy increases and more people are living longer following their diagnosis of cancer. Furthermore, improved diagnostic and screening programs mean cancer is being diagnosed at an earlier stage, while better cancer treatments mean more people are living longer with cancer. However, this also means that more people will experience progression of their primary cancer. The recording of cancer progression (recurrence, metastasis) is currently the focus of international discussion and NICR staff are leading on the development of consensus guidelines on the classification and recording of cancer progression. The recording of metastatic disease has recently been highlighted in England with the planned introduction of a metastatic breast cancer audit which will be carried out by Royal College of Surgeons.

However, as with many population-based cancer registries, the NICR Cancer Intelligence Officers have expertise in the standardised recording of metastatic disease/recurrences, but do not routinely do so as the NICR is funded to record and report on the incidence, prevalence, and survival of primary cancers

rather than metastatic or recurrent cancers. Furthermore, the current IT platform used to register cancers by NICR was developed with primary cancers in mind and does not allow recording of cancer progression (recurrence, metastatic disease) although a system is being developed with the ability to record this

It is important we start funding the NICR to start recording and reporting on metastatic cancer. A better funded NICR, closer to the service will achieve this more quickly. It is unlikely citizens living with cancer think a great deal about where the actual data is stored, whether in primary care, secondary care, on a radiology system or in a lab. What I think most citizens would want is for that data to be used to help them, and everyone else suffering from this disease. The HSCDI and its partners need to focus on the cancer information problem as a timebound challenge that must solved – GPIP and other systems are part of the answer and they must be cherished and funded to take their place as part of the solution.

Northern Ireland Health Analytics Platform (NIHAP)

NIHAP - The Northern Ireland Health Analytics Platform, is proposed as a key tool for data analytics at HSC. This platform was originally developed during the pandemic and was a crucial component of the DHCNI and PHA response to COVID-19.

Moving forward, I propose further development and iteration of this platform and broader usage. Our current systems have been built with the primary goal of secure data storage – rather than ease of access for service use cases. *Encompass* will deliver so much of what we need; however, the greatest benefit to HSC comes from adding that rich source of data to multiple other pieces of disparate information to inform the comprehensive delivery of data-driven cancer care.

NIHAP (potential scope - the yellow rectangle below) presents an opportunity to collate data – e.g. from GPIP and encompass - into a centralised and secure location, from which it can be matched to a longitudinal care record and analysed in combination with additional data resources.

This is a central aspiration of the HSCDI, leveraging data to drive our ultimate goal - to deliver better care.

Why do we need NIHAP?

• *Consistent and continuous updates with no demand on limited HSC resources.*
• *Adoption of cutting edge cloud based technology to provide safe secure infrastructure for the housing and analysis of data.*
• *Convergence of data from a wide range of sources, securely enabling users to analyse core datasets with the most appropriate tools.*
• *Secure, flexible and scalable infrastructure which enables growth and scale of the platform and its users*
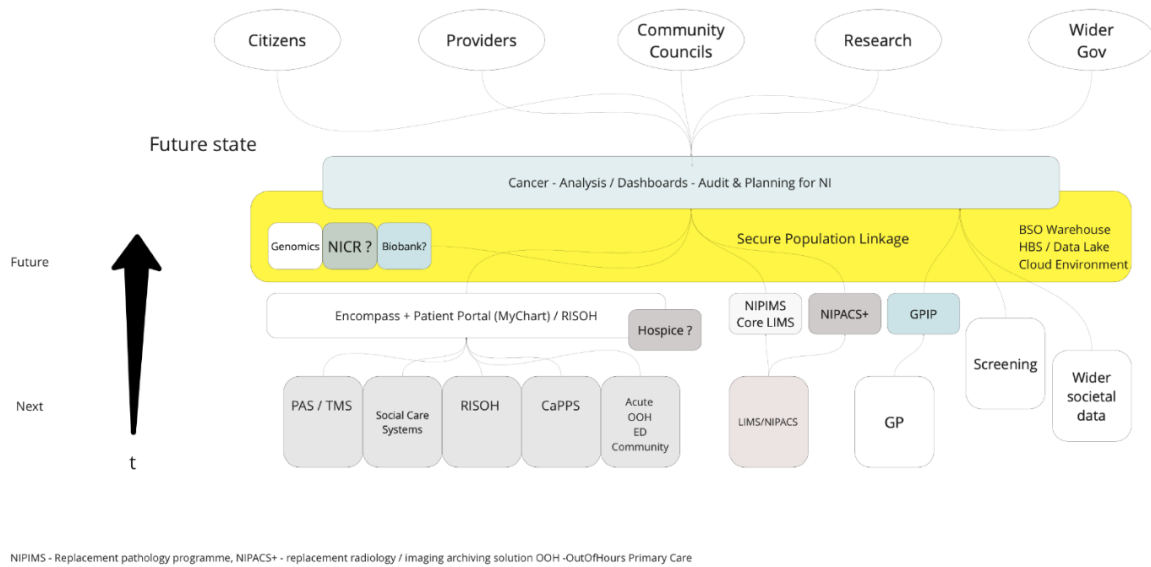
Figure 6. A potential starting point for cancer data infrastructure.

NIHAP has the potential to ingest self-reported patient related outcome measures (PROMs) in addition to those recorded by MyChart or other patient portals. Combined with other sources of public and governmentally-held records, we have a chance to proactively seek to help those in greatest need, without waiting for those citizens to ask – we can try and personalise aspects of our care for citizens based on what we already know about them from a data intelligence perspective. A particular paragraph on page 77 of the Cancer Strategy was interesting,

'The HSC is committed to a person-centred approach which aims to put the public, patients, their carers and staff at the heart of cancer services and empower managers and health care professionals to commission, plan, monitor and deliver effective and efficient services of the highest quality. No two people are the same, either in their cancer or their health and care needs. When care is truly person-centred, individuals are treated as individuals, with compassion, dignity and respect. The impact of cancer extends beyond the physical effects of the disease to include psychological, social, economic and spiritual consequences for people living with cancer and their carers. There needs to be a sustained focus in enabling, supporting and empowering people to make informed decisions about their treatment and care and supporting them to self- manage in the longer term.'

The cancer strategy outlines the need for greater knowledge in many aspects of cancer patients lives. At the core of this document is a way to create a dataset that allows us to do what is articulated above. Unless we understand how people differ – based on their data – how can we respond differently to individual patient needs? Given this commitment we must accept that data is core, underpinning reference upon which everything else must be built.

Screening.

The current cancer screening systems are old and due for replacement. There has been on-going discussion regarding the best approach to take and PHA have been leading with BSO on specifications and procurement plans. *Encompass*, although not a defined screening system, has much of the functionality to allow this to be designed and implemented within the Epic software. This has many advantages; primarily, being directly part of the medical record and leveraging Epic's logistical applications to link episodes to outcome. The most important aspect to consider from a data perspective is the ability to link the episode of screening with the longer-term record of care in real-time. This seems straightforward, but it is complex to build in a system without having an underlying linked data infrastructure. The process will be further complicated by the ongoing renewal of citizen identification systems. Fundamentally a national screening system must be linked to the outcome in question to assess the effectiveness of the programme. *Encompass* makes this considerably easier by linking the record. The fact that screening endoscopy, follow-up colposcopy and all associated care records will be recorded in *encompass*, leads to a compelling offer that we must accept and nurture.

Considering our financial constraints, it is difficult to find the perfect answer to every question, and no doubt screening will be a compromised solution based on cost, timing and parallel priorities. The key priority seems to be easily accessible, transparent data to allow better screening targeting, attendance and pick-up rates. A flexible data architecture is of central importance and those involved in screening solutions will no doubt have that high on their priority list. An example may be newly introduced screening services. New advances in Lung Cancer screening with CT scanning will focus minds and budgets, and having comprehensive data on at risk individuals will make future changes to screening policies more achievable.

Conclusion.

Northern Ireland needs to gather together a multi-disciplinary team to take the lead in bringing the wealth of data collected from our citizens together into a cancer learning environment that can serve as the driver of enhanced cancer care for our citizens. Better understanding will bring better plans for care delivery and, in time, better care. Given the recent strategic work by DHCNI, the HSC Data Institute has been designed to fulfil that role. Working in collaboration with PHA, DoH Hospital Trusts and academic institutions, it can provide the focus of expertise to allow NI to move forward rapidly.

This work should be focused on care outcomes primarily – given our waiting lists, previously reported clinical outcomes and the current difficult financial circumstances it would be easy to prioritise only clinical actions on waiting lists and acute service pressures. Data collection, measurement and understanding can seem like secondary, less important considerations. We need to pursue both with equal passion - we must always ask ourselves after we act – did that work? Only data and recorded outcomes can answer that question.

To put this in context, we have only a handful of data scientists in a service with an operating budget approaching 6 billion. We may pay lip service to the importance of data, but our real-world budget allocations more accurately reflect how we feel about its relevance. This must change.

Cancer will touch every one of us on our life journey. We must do all we can to make sure that the experience of those difficult episodes for each citizen leads to a better or easier journey for the next. Data is a clinical resource, and one we must cherish. Understanding and unlocking the potential of data in cancer care will create a template that can be reused throughout the HSC. HSCDI is a necessary investment to create a platform to help us rebuild our services, it will require commitment, investment and above all collaboration. Cancer services need better data; the strategy cannot be a success without it!

Appendix

CANCER STRATEGY RECOMMENDATIONS - quick data responses

Action 1. Increase public awareness of cancer-related risk factors through specific strategies on tobacco, substance use, skin cancer prevention, and overweight and obesity – including diet and physical exercise. *To be effective this will require a targeted approach to those in society based on known factors – risk stratification – requiring co-ordinated data platforms across society, and agile methods of contacting these populations.*

Action 2. Support the development and delivery of strategies to improve public health. *This is broad statement - this is the specific role of PHA and again requires complex data structures to facilitate.*

Action 3. Develop a co-ordinated approach towards chemoprevention in line with NICE recommendations. *Will require database of at risk of exposure based on occupational and discovered risk.*

Action 4. All people diagnosed with cancer must be offered appropriate and targeted information and support to live well. *This assumes a searchable, targetable list of everyone with cancer that can be used to reach out and supported effected individuals – this does not exist in current form and requires an options list for contacts and signposting – again a huge task and one that will rely on digital and human resources.*

Action 5. Establish routes to diagnosis reporting and analysis on a regular basis to monitor changes to help improve diagnostic pathways and outcomes for patients. *The routes to cancer work described should be persistently funded and part of normal service – we should not be relying on research to describe basics functions of our health service – this work should be prioritised now.*

Action 6. Deliver regular, effective, targeted evidence-based 'Be Cancer Aware' campaigns harnessing the expertise in the community and voluntary sector. *To deliver awareness campaigns requires understanding of the needs of population and a marketing approach to delivery – we are effectively motivating citizens to help diagnose their cancer earlier. This is best delivered digitally in social media and other mediums – data plays a huge role here and we should learn from our commercial partners about implementing such campaigns.*

Action 7. Reduce sensitivity levels and extend the age range for the bowel screening programme. *encompass offers the best chance to collate and action the information requirements needed to achieve this.*

Action 8. Implement HPV testing in the cervical screening programme. *Requires a target population base.*

Action 9. Increase uptake of all cancer screening programmes. *(Again, requires HSCNI to adopt a sales and gamification approach to citizen engagement – this can be facilitated by the information collected in encompass and other HSCNI population data sources).*

Action 10. Implement all UK National Screening Committee recommendations. *No action*

Action 11. Create surveillance systems for conditions where there is clear evidence regarding the pre-malignant potential of a particular condition to ensure people are not lost to follow up. *This action requires the co-ordination and capture of registry data in an actionable HSCNI environment where it can be combined with a workflow within a clinical system like encompass. It reflects why we must permit information transfer between NICR and HSCNI in real-time.*

Action 12. Implement NICE guidance including NG12 and, in the future, the most current NICE referral guidelines. *This action potentially directly interrupts the workflow between primary and secondary care - this can be built into the workflows of encompass but given the timelines this will have uncertain effect. Allowing GPs access to greater diagnostic testing – eg CT etc – is an obvious decision and requires technological support to allow it to be co-ordinated.*

Action 13. A 28-day standard will be introduced to track the time for all people from first referral for suspected cancer to confirmation of a cancer diagnosis, which includes all diagnostic and staging investigations. *This action outlines a challenge for HSCNI – as we implement encompass there will need to be a hybrid approach with a default back-up to ensure capture across the system – I am uncertain as to whether CaPPS can manage this effectively.*

Action 14. Review current targets to ensure equity across the pathway. *Requires a timely measure of outcome on which to base the equity judgement, which is currently hard to facilitate – also a view on equity requires detailed information on the target population to allow assessment of equity, which is currently not collected in a place to allow the analysis.*

Action 15. Develop new pathways and diagnostic services to improve diagnosis. *This will be configurable within the encompass programme – but will require significant work arounds until fully implemented across all trusts.*

Action 16. Develop a specialist integrated haematological diagnostics service for Northern Ireland. *This is again a logistics and resource problem requiring data on scan and service availability – MRI is particularly complex and difficult to organise. Once encompass and Grand Central in Epic are functional this will improve, but for many people, this will be years.*

Action 17. Develop and implement pre-habilitation and rehabilitation services on a regional basis for all those who will benefit. *To be able to identify patients needing rehabilitation services, requires an integrated longitudinal record, this will be available in encompass but again until that system is up and running some contingencies will need to be in place.*

Action 18. Reconfigure cancer surgical services alongside any future recommendations for the delivery of emergency and elective surgery. *Essentially this is logistic problem and needs to be matched with both physical and digital infrastructure - as technology advances there will be a greater need to integrate complex data from different systems such as genomics robotics, molecular or cellular pathology. Therefore, this will need seamlessly integrated with a data repository within Northern Ireland he able to provide such additional information.*

Action 19. Implement Enhanced Recovery After Surgery programmes on a regional basis for all appropriate major cancer surgery. *This requires a national database with enough granularity to identify which patients can be referred to which programmes, and encompass represents the only sensible way that this can be implemented over the coming decade and again will rely on the integration of our current cancer system with that programme.*

Action 20. Introduce and implement new radiotherapy techniques and technology in line with national guidance including staffing and associated training. *Radiotherapy is perhaps the most data intensive treatment modality in cancer care. The current system is limited in its integration with a wider patient record and with generalised logistics. This will be overcome gradually with the implementation of encompass but in the interim, like in medical oncology, there is a requirement to produce robust and accessible data sets to allow the analysis of outcomes on a national and international level. there is no current identified plan for this, and it should form part of the initial programme of work around cancer for the data institute.*

Action 21. Implement in full the recommendations of the Oncology Service Transformation Project and the Oncology Haematology stabilisation plan. *The implementation of encompass includes a digital prescribing system which increases safety and reduces error. Prescribing specifically for cancer will continue on RISOH, and as such there will be dual prescription of cancer and non-cancer meds across HSCNI for a period. Encompass are trying to clarify how that will work in practice, but it remains an unresolved is for medication audit, cancer outcome data presentation and needs urgently resolved.*

Action 22. Ensure timely treatment where services cannot be provided in Northern Ireland due to specialist nature of services, technology constraints or low number of patients. Continue to monitor the viability of providing these services locally including CAR-T. *Would benefit from electronic transfer of data in encompass or through patient held electronic records like MyChart.*

Action 23. Develop near-to-home phlebotomy services. *This is possible to deliver through encompass but will require temporary solution until the system is implemented. It will also*

require a delivery team with logistical support in workflows and delivery – these will require a data feed to work from.

Action 24. Review the model of delivery for Systemic Anti-Cancer Treatment services including the delivery of near/close-to home SACT. *(As for 23)*

Action 25. Develop a 24/7 metastatic spinal cord compression service with rapid access to imaging and treatment. *Regional ordering is a core feature of encompass but that does not necessarily improve access to MRI in the first instance. There needs to be combined work on the resource utilisation of radiology services based on area need and timeliness. This work will be possible in the HSCNI DI, with co-hosting of relevant datasets. This will permit some resource utilisation planning before encompass goes live everywhere.*

Action 26. Extend the acute oncology service across all Trusts to seven day working. *Encompass can help achieve this goal but over extended period of rollout. But this is primarily a staff and logistics issue which can be better informed by detailed data on Acute Oncology services delivered on medical and surgical wards.*

Action 27. Deliver genetic and genomic testing in cancer pathways in line with NICE recommendations. *Personalised – precision - medicine requires detailed understanding of many aspects of a citizen's life to allow a tailored approach for a specific disease. This needs a lot of relevant data and the integration of clinical data which genetic, tissue and digital assets. This is an enormous task based on having better data available on all of our population in a safe a usable way.*

Action 28. Develop ambulatory care haematology units in each of the Trusts and establish near-to-home treatment services for suitable patients. *Can be facilitated digitally by encompass, but dependent on staffing and capital funding.*

Action 29. Implement a safe and robust electronic prescribing system for all Systemic Anti-Cancer Treatment regimes. *See earlier discussion in document. The complexity of prescribing will be a significant issue moving forward.*

Action 30. Develop appropriate pathways and accessible services for older people with cancer, adults with learning disabilities, communication needs and chronic mental health problems, rarer cancers and metastatic cancer. *This is an enormous challenge within one sentence. It assumes an ability to identify, flag and then implement tailored cancer care pathways in these citizen subgroups. To allow this to be scalable, dependable and robust we need methods of stratifying populations who meet this criteria and then subsequently develop a cancer diagnosis. Currently this is entirely human triggered approach – encompass and a population health approach could automate a number of these roles.*

Action 31. Every child, young person and adult diagnosed with cancer, and their careers, will have access to staff with the specialist knowledge and skills to provide developmentally

appropriate, person-centered care. *From an information perspective these staff will need detailed, inclusive notes and systems to provide that care, encompass and RISOH co-ordination will accelerate this.*

Action 32. Increase collaboration between Northern Ireland, Great Britain and the Republic of Ireland in the provision of children's oncology services. *The HSCDI will accelerate this ability by promoting interoperability between areas, particularly with in the introduction of encompass.*

Action 33. Review the provision of services for teenage and young adults in Northern Ireland including transition arrangements, age-appropriate environments, psychological support and long-term follow up. *Requires integrated inclusive record and ability to add social care and an understanding of personal and background of each citizen – this is as yet uncaptured.*

Action 34. An effective Multi-disciplinary Team meeting will be held for all people diagnosed with cancer including cancer of unknown primary and metastatic disease. *Like all MDMs this will require detailed understanding of those being considered and their identification – which in the case of metastatic and unknown cancer remains incomplete. There needs to be considerable thought given to the way to collate information from various systems into one unified and clinically usable system.*

Action 35. Develop a person-centered model of care that builds on learning from COVID-19 with increasing use of telehealth and technology. *The person-centered comment is a legacy of design and at present no system in NI is designed around the citizen. Encompass gives citizens access to greater information and control and if used correctly will allow citizen data to be used to create personalised treatments plans – all of this is built on a patient centric data model which is currently missing.*

Action 36. Offer all people a holistic needs assessment, an appropriate care plan and provide signposts to relevant sources of help and support. *Once again this requires detailed information regarding what each of us need and more importantly and way to connect that information to the services available. That work is dependent on appropriate flow of data across the health economy.*

Action 37. Develop a comprehensive treatment summary record for all people diagnosed with cancer. *Currently this is NIECR. Given this document's contents, where will this record live, how will it be accessed and what primary source systems will provide the summary information? Encompass/RISOH and primary care systems are the obvious answer but the process of linking and connecting the workflows to achieve a comprehensive record needs a description that is currently lacking.*

Action 38. All people who have completed cancer treatment will be assessed and risk stratified to appropriate follow-up pathways. *Again, this makes perfect sense but where and how will this be actioned to ensure that the workflow is complete? Stratification suggests a risk approach based on data and yet as this document articulates, linking these datasets remains unplanned.*

Action 39. All patients, including children and young people, diagnosed with cancer will have access to a Clinical Nurse Specialist throughout the entire care pathway. *This is a logistics and demand problem which could be improved with better understanding of service use.*

Action 40. In alignment with the mental health strategy develop a model to promote good mental health and wellbeing for people affected by cancer and develop pathways to ensure that all people with cancer have access to mental health support in line with their needs. *This requires a registry of citizens with cancer cross referenced by self-reported of recorded mental health requirements. Epic will facilitate this work but is likely to further evidence the lack of available workforce to meet demand.*

Action 41. All people with a cancer diagnosis will be referred to a Cancer Information and Support Service at diagnosis. *Will require an incidence registry with automated referral, link to service, given dual system running this will require careful planning to ensure equity of delivery*.

Action 42. Timely and appropriate access to therapeutic and practical support services for people affected by cancer targeting emotional, physical, spiritual and social needs will be provided. *An appropriate registry will be necessary with an ability to ensure referral and delivery of services – encompass can help but allocation of resources will remain the key issue.*

Action 43. All people starting cancer treatment will have their health status assessed and recorded and a plan developed to mitigate potential late effects and consequences of their treatment. *This should be a standard feature of an integrated record on encompass; the effects of siloed noting and cancer service delivery on RISOH are hard to predict.*

Action 44. Develop a regional, multidisciplinary approach to the identification and management of all people at risk of late effects and consequences of their cancer treatment. *This requires the creation and constant active management of a longitudinal registry of all cancer patients cross referenced by treatment and ultimate outcome. This one sentence is an enormous task and does not identify who is responsible for its delivery?*

Action 45. Identify people deemed to be at highest risk for late cardiovascular effects and enroll them in a follow-up programme. *As for 46, this assumes detailed individual knowledge of all CVS illnesses for everyone cross-referenced with cancer status and treatment regimes, it is an ambitious task only deliverable with a population health approach to care delivery.*

Action 46. Screen children to detect early, subtle cardiac abnormalities that might be treated, or may be reversible. In addition, where children are treated with anthracyclines or cardiac radiation they will have lifelong screening. *This will need a registry, call and recall system with seamless integration to cardiac imaging and review processes – encompass can do all of this if appropriately configured.*

Action 47. Deliver integrated, coordinated and personalised palliative and end-of-life care to people with non-curative cancer when and where they need it. *Requires access to detailed and comprehensive medical records in all areas of care – home, hospital, community and hospice. This requires the broadest possible implementation of encompass across NI and in clinical areas dealing with palliative care patients.*

Action 49. Extend palliative and end-of-life support and continuity of care to seven-day working for all people with non-curative cancer. *As above for 47.*

Action 50. Increase awareness and uptake of advance care planning for all people with non-curative cancer. *This would benefit from digital records viewable by all care givers and family, allowing discussion and timely decision making. Encompass can facilitate if the data is available to express.*

Action 51. All people living with non-curative cancer, and those important to them will have access to the bereavement, psychosocial and counselling support appropriate to their needs and preferences before and after death. *No action*

Action 52. Develop a regional, multi-professional cancer workforce strategy and implementation plan. This will be underpinned by a training plan to ensure there are appropriately skilled staff to deliver services for the future. *This needs a detailed understanding of the work needing to be delivered and the needs of the staff delivering this work. Digital systems allow collation of this data and protect staff from unreasonable expectations, which can lead to over delivery and burn-out. Covid has made understanding this problem more acute and as services are under pressure we need a wider understanding of the problems before it becomes unresolvable.*

Action 53. All healthcare professionals who are expected to carry out sensitive communication must complete an advanced communication skills training programme. *No data action.*

Action 54. Measure the experience of all people with cancer on an ongoing basis to inform service improvement and redesign. *Patient related outcome and experience measures have been underutilised in cancer care delivery across NI. This needs to be a routine part of what we do, and clinical staff need to be open to the transparency of care delivered in difficult circumstances so we can learn ways to make it better. Only through collecting these data points can we assure ourselves and our patients that what we have delivered has been effective.*

Action 55. Develop a cancer research strategy for Northern Ireland in partnership with key stakeholders. *This has a separate but linked data requirement and is a significant piece of work.*

Action 56. Increase the number of people taking part in clinical trials, including children and young people. *This requires support of research as an important goal, within cancer care delivery. It needs funding to encourage oncologists and haematologists to consider research as*

a viable and exciting career. It requires public campaigns to explain the need and benefit of clinical trials. We also need a system to seamlessly and easily recruit citizens into clinical trials – this is a core functionality of MyChart in encompass and this should be understood at the highest levels.

Action 57. Review the data required for the effective delivery of cancer services in alignment with Encompass. *This work has highlighted potential solutions and ways forward.*

Action 58. Develop a cancer data framework to inform and improve cancer services and facilitate research. *This is a potential commission to be considered to follow this review, linking cancer data aspirations with those of the HSCDI.*

Action 59. Review the Northern Ireland Cancer Registry. *This work is underway.*

Action 60. Make provisions to allow secondary use of data to allow benchmarking of Northern Ireland cancer outcomes across the UK. *This work is underway by DHCNI.*

With thanks to Daniel Quinn for image formatting and document configuration support.