Connected Health Cities

End of Project Report

WP4: Workforce Development

Business Informatics Workshop

(barriers and enablers of innovation)

CONTENTS

ABSTRACT

One of the core challenges the Connected Health Cities Project (CHC)[1] set for itself was to work with the Health Service Business Analytics community to understand how they support the wider service in generating and utilising data.

Working closely with that community, CHC sought to identify the nature of the cultural, technical, financial and governance challenges that prevent the efficient integration of complex analysis algorithms, or general business intelligence outputs generated by data specialists within healthcare, academia or the private sector, into local, operational NHS information reporting platforms.

That work has taken the form of a range of structured activities in partnership with the NW Informatics Skills Development Network (ISDN), a healthcare community of staff at all levels of seniority that are involved in Business Analytics function in the North West Health Service.

This report details the activities undertaken, initial findings and headline recommendations that have resulted from that work.

INTRODUCTION

Connected Health Cities' central aim is to increase the strategic use of relevant data in informing decisions in health and social care.

The role of the Health Service's Business Analytics community in creating, curating and disseminating that data, driving insight and helping move forward to a proactive and preventative system of delivery, is a key factor in achieving that aim.

Work with the NW Skills Development Network (ISDN)* has been ongoing throughout the CHC project.

The project team has worked closely with the ISDN at several levels: as a member of the Business Informatics Special Interest Group and supporting and attending the ISD Senior Analyst Developer Network and Senior Information Leads meetings.

In addition to representing CHC in these groups, the collaboration included undertaking three key pieces of collaborative work.

The first piece of work was an 'Information Dissemination Survey' of senior information leads across the NWC region and the second and third were the subsequent dissemination of those survey findings to the ISD community through two of their Senior Information Analyst Network Days (October 2019 and February 2019).

Those pieces of work and the resulting conclusions and recommendations form the core of this report.

* Formed in 2011, the ISDN is part of the North West Skills Development Network and is funded by North West Health Service Organisations through a membership subscription. The network supports information specialists across the NW region through the provision of networking opportunities and the development of learning programmes, which aim to raise the professional profile and skill levels of informatics staff generally. The ISD has been a key support for informatics in the NW region for some time and is highly valued by many senior information managers within the region. https://www.skillsdevelopmentnetwork.com/home

METHODS

SURVEY OF BUSINESS INFORMATICS TEAMS

Undertaken from February to April 2018, this activity was structured to help develop a better understanding of:

1) The nature of operational intelligence delivery and dissemination within NWC Health and Care organisations
2) Common challenges faced by NWC information teams in disseminating intelligence across their organisations and externally
3) Successes that have been driven by effective delivery of intelligence within, and across, organisations
4) How best practice in any one area might be shared and adopted in another area

The survey was distributed online during February 2019, with the last response collected in late March and the survey remaining 'live' and available until the end of April.

The survey was marketed through networks and groups dedicated to intelligence professionals within healthcare.

The Skills Development Network and the Association of Professional Healthcare Analysts (AphA: https://www.aphanalysts.org/) circulated the survey weblink* https://www.research.net/r/CHC_IntelligenceDissemination to their members through mailshots and newsletters.

The CHC team also promoted the survey through direct links with professional colleagues and at a range of intelligence leader events. Sixteen complete responses were collected during the 'live' collection phase.

SENIOR INFORMATION ANALYST NETWORK DAY (23/10/2018)

The meeting was held in Liverpool. The CHC team presented an update on the progress of the Intelligence Dissemination work Workshops to understand the barriers were convened.

Participants: The meeting was attended by 45 health analytics professionals representing eight CCGs and 21 NHS Trusts from across the North West.

Key challenge areas: Barriers faced by health service organisations in the adoption of analytics algorithms developed by third parties such as the CHC Data Laboratory Team are related to **Cultural, Technical, Governance and Commercial issues.**

SENIOR INFORMATION ANALYST NETWORK DAY (27/02/2019)

This second meeting took place at Lancaster University. The CHC Team presented the analysis of the collated comments provided previously re the four challenge areas.

A set of key thematic areas that are undermining the effective dissemination of best practice business intelligence processes and practices were discussed.

Participants: The meeting was attended by 41 health analytics professionals representing seven CCGs and 18 NHS Trusts from across the North West.

RESULTS

SURVEY OF BUSINESS INFORMATICS TEAMS

A series of key headline messages were drawn from survey responses, primarily that business intelligence teams, regardless of their organisation type, are navigating complex data environments and are doing so with less than ideal resources.

The survey highlighted:

- Over 90% of information teams were dealing with over 11 internal data source systems
- Over two-thirds of Intelligence Teams contain 11 or more staff, with only one team reporting less than five full-time employees
- All intelligence teams reported having a wide base of intelligence consumers, each with specific needs and requirements
- Only one team supported the information delivery needs of their organisation completely using internal resources.
- Over 75% of responding organisations require a combination of internal and external data infrastructure resources
- All organisations are required to deliver many local, regional and national indicators
- A shortage of staff and particularly staff with highly specialist skills was a common issue
- The sharing of best practice in intelligence service delivery is generally informal and lacks formal platforms and processes to support it
- Collaboration with private providers of business intelligence is limited, but most organisations do work with public sector partners in some capacity
- Speed of access to data, the complexity of Information governance and a lack of standardisation around reporting specifications were key common issues shared by the majority of information teams
- All responders would like to see investment in their services to enable them to deliver improved outcomes.

SENIOR INFORMATION ANALYST NETWORK DAYS

The Networking days enabled the CHC team to ask four questions on barriers and obstacles to Intelligence Dissemination across the North West.

The individual list of proposed actions is summarised below.

1) **Investigate in partnership with ISD and AphA the potential for developing a one-stop portal for information leaders that would signpost users to:**

    - Relevant training and development resources
    - Useful Case Studies and contacts covering best practice in intelligence output development and delivery

2) **Templates and guidance documents covering new approaches to:**

    - Technical delivery of intelligence products
    - Common approaches to applying Information governance Standards
    - New models for developing contracts and finance agreements

3) **Contact directories for engaging with external resources:**

    - Academics and academia
    - Industry Partners specialising in Intelligence Products
    - Patient and Public Engagement Teams

4) **A regional Community of Practice Hub allowing Information Specialists to communicate easily on common issues affecting all.**

CONCLUSION AND FUTURE PLANS

From a CHC perspective, the survey responses clarified the need for the CHC team to consider very carefully how the intelligence outputs and algorithms being developed by the programme could be delivered back to health and social care organisations.

There was a clearly stated preference for any indicator or algorithm, developed by the CHC programme, to be delivered into organisations using their own internal business intelligence platforms and approaches. Creating an additional external Business intelligence portal to deliver the CHC outputs was not an option supported by the majority of information leads.

There was, however, a clear sense that NHS information specialists are keen to engage with projects like CHC and academic and other partners to improve intelligence delivery and dissemination in the future, although the logistics of doing this and the time to do it is challenging.

The CHC team identified the need to work with local intelligence teams to consider how a clear and consistent model framework could be developed that would mitigate the obstacles and barriers to intelligence dissemination across the region and provide the opportunity for optimizing some of the outputs of CHC with these teams. This model would need to be constructed around a generic design that could accommodate internal business intelligence platforms, and data architectures, within individual organisations and which could provide support in addressing the technical and cultural barriers to effective intelligence dissemination. In Liverpool CCG, the alcohol pathway team has successfully implemented the algorithm into the pathway to give a risk score for readmission which is visible to clinicians seeing the patients. The CCG is using a Power BI analysis platform.

All of these projects can be engaged with voluntarily and at a level of commitment relevant to each organisation. The CHC team can facilitate the initiation of many of these tasks, but longer-term, the goal would be to transfer ownership of this approach to the information community through their network organisations as with the Liverpool CCG example, which took some support from the BI teams. The survey demonstrated that BI teams do not always have this capacity.

We need to ensure our outputs can spark a longer-term sustainable approach to collaborative partnerships, owned by intelligence leaders. This needs to be developed in the future from an early stage to improve the potential of innovative new intelligence products developed by third parties, to be sustainably embedded into local organisations.

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APPENDIX 1

WORKSHOP OUTPUTS

The following sections look at the responses to each of the presented challenges in turn. The four groups undertook their discussions with a scribe recording the group's responses onto a flipchart. At the end of the discussion, the flipcharts were collected and collated by the CHC team for this report.

What are the cultural barriers to intelligence dissemination and adoption?

- Organisational resistance to change
    - Executive resistance
    - Clinical resistance
    - General staff resistance
- Variation in the interpretation of Information Governance requirements
- Organisational resource constraints
    - Time to implement change
    - Primary focus on business as usual and immediate challenges
    - Financial priorities
- Protectionism / Localism / Competition
    - Local organisational structures
    - Local architectures and processes
    - Competition concerns
    - Conflicting local priorities

These common themes came out very strongly from the responses captured in the workshop and each poses a unique set of challenges that many NHS organisations struggle to address internally. However, there is a range of potential mitigating actions that could be developed by more strategic organisations, such as the CHC with its broader remit to investigate these issues that could support local information leaders in tackling these issues within their organisations.

Organisational resistance to change

Many NHS organisations struggle to balance their operational management challenges effectively with keeping pace with technological innovations and data science developments that could help them in increasing their efficiency, while simultaneously improving clinical and performance outcomes. Introducing new processes and technology into their organisations involves the investment of already stretched finance and staff resources without strong evidence bases that can articulate the potential returns on that investment.

As a result, changes that have the potential to provide innovative and sustainable solutions to organisational pressures are seen as risky by executive and clinical teams and demoted down their internal priority lists. Internal teams may not have the capacity, evidence or skillset necessary to build strong business cases for investment and the opportunities for improvement are missed.

To address this issue, there is a need for innovators to provide local teams with more robust evidence on the potential impact of implementing improvement within organisations, while keeping implementation costs to a minimum. This evidence needs to focus on highlighting the possible improvements across multiple domains to address the concerns of the different audiences who contribute to green-lighting investments within NHS organisations.

In particular, these business cases need to illustrate:

- How the improvement will impact on clinical pathways and outcomes in a manner that is acceptable to clinicians
- How the improvement will support performance management indicators for an organisation in a manner that is appropriate for executive management teams
- How the improvement will provide a return on investment in a language that is acceptable for finance leaders
- How the improvement can be implemented efficiently within an organisation's technical infrastructure in a manner acceptable to Information Technology leaders
- How the governance of the innovation complies with statutory and ethical standards to accommodate governance leaders

To construct business cases containing each of these elements requires support from a range of subject matter specialists to ensure the language used in each section is appropriate and designed to meet the needs of each specific audience.

There is potential for a business case framework model to be constructed that would support internal innovators in constructing business cases for investment that highlights the steps required to provide evidence within a business case to address the priorities of all of these individual groups.

Variation in the interpretation of Information Governance requirements

The second theme outlined in this section of the workshop highlighted the challenges information leaders have to address to comply with the varied interpretation of information governance and privacy regulations. The recent introduction of the General Data Protection Regulation (GDPR) has added to an already complex area and increased the barriers to effective information sharing.

This should not necessarily be the case and if the governance rules around appropriate data sharing were understood and applied consistently, effective information sharing within and across organisations could, in reality, be simplified.

The broader CHC programme contains additional workstreams that are looking at the barriers to effective data sharing across the region, specifically working with patient groups to understand patient views around consent to data sharing and investigating technical solutions that could address common challenges around the capturing of explicit and informed patient consent for data sharing, maintaining accurate timely registers of captured patient consent and providing assurance around mechanisms for the electronic authentication of patient identity.

In parallel, the CHC programme has gained a lot of experience in addressing common information governance issues related to the secondary use of pseudonymised and anonymised patient data.

The workshop has highlighted this issue as a common barrier to successful data sharing and there is an opportunity for the CHC specialists to work with local information governance leads and Caldicott guardians to try and develop an agreed common approach to the application of information governance protections that could be applied to the most frequent the data sharing use cases.

Organisational Resource Constraints

The groups highlighted that a lack of resources, in terms of financial support, staff time and capacity were common barriers to implementing new intelligence outputs and systems. These concerns were also highlighted by the survey results.

Tackling these resourcing issues is difficult when public sector organisational funding is under stress through a combination of rising demand for services and decreasing national allocations and capacity. When staff are facing increasing workloads merely to maintain safety, efficiency and financial stability in operational practice it is practically impossible to make time for innovation and strategic horizon scanning.

Within informatics, in particular, the rate of change in the development of data management tools, big data analytics, data science, data governance and IT infrastructure is exponential and keeping pace with all of the latest developments is practically impossible. Releasing small volumes of capacity to make incremental improvements is potentially the best internal informatics leaders can be expected to achieve, and there is often a lack of understanding from external developers, and even internal management teams, on the constraints that information leaders are dealing with.

The CHC team tried to understand how the CHC analysis team's work could be implemented within local organisations without adding further to these burdens and this thought process has highlighted that there is need for external developers of informatics tools to take more consideration of the way they present their tools to organisations and also how they construct those tools in a form that can more easily be integrated into local systems and processes.

Particularly, with the dissemination of new business intelligence tools, algorithms and measures, the traditional approach of providing access to these algorithms through standalone external platforms only increases the burden of local information teams by creating additional access points to an already complex intelligence landscape.

The outputs of the survey, coupled with this highlighting of resource challenges, lead the CHC team to propose that new mechanisms for the delivery of external intelligence tools to NHS organisations need to be considered and developed if necessary if we are to ensure that innovative new work developed in the academia, the private sector or elsewhere can be incorporated into local NHS organisations.

Protectionism | Localism | Competition

The final overarching theme illuminated by the question of cultural barriers related to the tendency of some NHS organisations to resist data sharing approaches, or the implementation of products developed elsewhere, due to an internal protectionist viewpoint within the organisation overall, or selective departments within it.

This issue shares many characteristics with the broader resistance to change element of the

work outlined earlier and should benefit from the CHC action to develop improved business case models. Protectionism is often an element of a broader resistance to change and addressing it involves justifying implementing the change that illustrates that any collaboration with partners will not impact negatively on the organisation's reputation, performance or its unique intellectual property.

These concerns would need to be considered when making a case for investment, partnership or collaboration within the executive management, clinical and financial sections of an effective business case.

What are the technical barriers to intelligence dissemination and adoption?

Question 2 of the workshop asked for a specific focus on the technical barriers to intelligence dissemination. The four groups recorded their views as before and the responses have been collated under the following common themes:

- Variable skill-mix and capability within intelligence teams, particularly relating to specialist skills
- Variation in underpinning data architectures across organisations
- Inconsistent data dictionaries and data standards
- Capacity issues, both in terms of staff or infrastructure
- Data quality

These issues are returned every time a discussion on the barriers to data sharing and innovation adoption across NHS organisations takes place and not unexpected or new. The challenge now is to consider whether a traditional approach to resolving them is practical or feasible in the current climate.

The likelihood of significant additional funding being made available to NHS information teams to address staffing levels and training needs as identified here is low, and wholescale changes to, or investment in, existing IT infrastructures are unlikely, so alternative solutions need to be considered if the impact of these issues is to be mitigated or overcome.

Variable skill-mix and capability within intelligence teams, particularly relating to specialist skills

The issue of variable skill mixes and capability within organisations is not new and has been an issue that organisations like the ISD Network and AphA have identified and been working to address for some time.

The problem has become more acute for information departments as new technologies drive new demands for more complex datasets, integrated data management structures and analyses. The introduction of 'big data', cloud data services, open data, data visualisation and the development of new types of analysis tools all add to the complexity of the intelligence marketplace.

Maintaining staff training to ensure that an information team is fully up-to-date with the latest trends in data management and provision is almost impossible and early adoption of the next big thing is not always appropriate for the NHS in any case, given the need for consistency, stability and confidentiality when dealing with health data and patient records. Also, training and development budgets are often hit hardest in times of austerity as they are not typically seen as an immediate 'core' operational priority.

To address this in times of constraint requires organisations, and employees themselves, to consider a more creative approach to training to supplement the traditional focus on formal courses and professional accreditation. The ISD Network and AphA already provide links to subsidised training courses for information specialists, but there is also a wide range of new alternative training and development resources that can be accessed for little or no cost.

A recent, unrelated project in Lancashire looked at developing an online training and development portal for innovators and entrepreneurs that brought together links to paid formal training courses but presented them alongside free online training resources such as those available online generally, or via specialist international training sites like the Khan Academy and Edx.

As well as creating a central resource where users could get signposted to training relevant to them and within a cost bracket amenable to their funding sources, the project also promoted the idea of a parallel 'community of practice' that would ensure that new resources could be trialled, rated and reviewed by peer review groups to ensure that poor quality resources were removed and highly rated material was easily recommended across the community.

The lessons learned from this project could potentially be adapted to provide access to alternative training and development resources that would support the upskilling of local information teams in areas of specialist need that they identify. The CHC team could facilitate this work, in partnership with ISD and AphA leads, to explore whether this approach could be harnessed using the online platforms of one, or both, of those organisations.

Variation in data architectures/data dictionaries across organisations

The results of the Intelligence Dissemination survey highlighted the volume, and range, of information systems currently in use across the North West and, for intelligence dissemination, in particular, most organisations reported using a combination of in-house developed and externally purchased tools to fully cover their reporting requirements.

Within local data management environments, organisations will naturally apply data models customised for their needs with data table structures, data field naming conventions and approaches to query development consistent with the infrastructure within the organisation and any legacy systems that may remain in place. Past attempts, like the National Programme for IT, to impose a standard approach to organisational data management have provided ample evidence that this approach is not practical and rarely successful.

A similar challenge arises when trying to direct organisations to change their data models to accommodate new data infrastructures. The complexity of data models that have been built up over time, incorporating new and legacy systems, can be so difficult to unpick that it is quicker to construct new workarounds in old systems or give up on certain functionalities in new ones.

Most organisations will, however, utilise the NHS Data Dictionary and messaging standards inherent in protocols like HL7 and FHiR to ensure data extracts, and messages, can be developed and transmitted across organisations.

As a consequence, external providers of business intelligence systems tend to operate by taking data extracts and presenting them back to organisations using proprietary platforms which only adds additional complexity to an already complicated approach to reporting delivery. Organisations need to purchase these platforms and absorb the added frustrations of additional passwords and unfamiliar user interfaces if they wish to avail of the functionality and copyrighted algorithms of the new provider systems.

This approach is not beneficial to either party and new models of intelligence delivery need to be considered that minimise disruption to both sides. There is the potential for the CHC team to facilitate conversations with private sector and academic partners to consider new models for delivery that would be more adaptable to local infrastructures, without adding additional costs to intelligence product providers.

There is also an opportunity to trial some alternative approaches to intelligence product delivery using the CHC analysis algorithms to ensure that alternative solutions can be tested in operational contexts. This work would look to understand the impact of the issues raised

in this workshop and aim to isolate approaches that can practically be used to resolve them.

Capacity issues, both in terms of staff or infrastructure

The response provided on the issue of organisational constraints, covered under the cultural barriers question, applies here also in terms of examining new and creative ways of addressing resourcing challenges whether they are in staff terms, financial terms or infrastructure-related.

The challenge of extracting better value from infrastructure is less straightforward, but collaboration and improved sharing of specialist tools and systems across information teams may be one way of offering increased value across the health economy. Currently, many teams face common challenges in reporting and each organisation will instigate internal work to address these challenges. However, if development work could be delegated and shared across the system, there are opportunities for the outcomes to be more than the sum of the parts for each organisation.

For example, if organisation A has developed excellent reporting tools focused on a single, clinical pathway, and organisation B has done the same for a different pathway, and they share the core elements of their learning, both organisations could essentially get two projects for the price of one.

However, in the intelligence dissemination survey, when asked if their organisation had a platform, or approach, to enable successful data-driven case studies to be shared externally with peer organisations and partners only 2 out of 11 organisations said they had. The workshop discussion confirmed this with many of the participants saying that it was difficult to find and share best practice, which meant resorting to recreating the work from scratch in each organisation.

Therefore, it may be possible to consider assessing whether there is potential for developing a process and platform that our regional information teams could use to provide case studies of their best practice for use by other organisations and to share learning from successful and unsuccessful intelligence development projects alike.

This work also the potential to be considered alongside the proposal in CHC – Action 5 in terms of creating a one-stop-shop platform for information specialists, in partnership with the ISD Network and AphA, where they could access training, build communities of practice and share learning and case studies that could remove duplication of effort and other inefficiencies in the intelligence development cycle.

Data quality

Data quality within organisations remains a key challenge for many information teams and there is no straightforward solution to this problem. Addressing data quality issues tends not necessarily to be a technical challenge, but one where rectification is only possible when the issue is addressed at source by those who input the data initially. As such it is often outside the remit of information teams, beyond highlighting the problem, to rectify.

All staff within an organisation will get mandatory training on Information Governance and Data Quality, but this training will generally focus on the consequences when statutory regulations around privacy and security are breached.

Deeper issues around the accuracy of administration data and clinical recording of activity, and codes, are often neglected somewhat in these sessions. Many ward clerks, receptionists and clinical coders never get to see or access the reports that emanate from their inputted data and as such do not get to fully understand the implications, from a reporting perspective, of what they are inputting into system.

This is not an issue that information functions alone can address, but potential actions and contributions can be made by information specialists to a broader audience to drive greater awareness of the consequences of poor data quality.

To address this issue, it would be beneficial to collect and record in more detail the key data quality issues that are impacting across the region, ideally with some root cause analysis to understand where these issues originate from. Once identified it will be possible to consider developing guidance packages to support data input teams in identifying how to address those problems and improving the understanding of the impact these issues can have across all professional groups within an organisation.

To initiate this work, it may be helpful to enlist the ISD Network and the AphA network to conduct an initial collection and assessment of common data quality issues being experienced by information teams. The CHC can contribute to this work by engaging with the CHC data management workstream to contribute their view from the data they have been working with. Once the initial collation work has completed, plans for addressing these issues can be developed by local information leaders through the network forums and disseminated across regional organisations through all available channels.

What are the governance barriers to intelligence dissemination and adoption?

Question 3 of the workshop asked for a specific focus on the technical barriers to intelligence dissemination. The four groups recorded their views as before and the responses have been collated under the following common themes:

- Variation in Information Governance interpretation and application
- Variation in the application of Consent
- Variations in application of IT Security / Cybersecurity
- Confidence in 3rd Parties

Having grouped the responses provided at the workshop into these four themes, it became clear that two overarching issues could be further summarised as:

- Developing Clarity around IG issues concerning data sharing
- Assuring that data security is managed correctly both internally and within external partners

Fortunately, there is a lot of work already being undertaken regionally and nationally around these areas of concern and the outcomes from those projects should provide strong roadmaps from addressing these issues for all organisations in the coming months.

Developing Clarity around IG issues in relation to data sharing

The recent introduction of GDPR, and the transfer of the NHS IG toolkit into the new national Data Security Protection Toolkit (DSPT) approach to organisational assurance, have created new challenges for local information governance teams with the development of revised data sharing processes across organisations and multi-disciplinary teams. However, while certain rights and regulations have been strengthened as a consequence of these changes, many of the underlying principles around data sharing and the protection of personal privacy remain unchanged.

Nonetheless, while our understanding of how the GDPR regulations, in particular, will impact organisations in practice is still developing, many organisations remain justifiably concerned about initiating data-sharing programmes even where there is a legitimate case for this and clear benefits to all parties involved. An individual organisation's view on the risks involved in these programmes can be determined by the advice of information governance specialists within the organisation and these are not necessarily consistent

across all organisations. This creates variability in the application of governance protections and was clearly seen as an issue by the attendees at the workshop.

This variability in approach to IG application can cause significant frustration but could be addressed if IG specialists came together to agree on a common approach to data sharing and the processes that would need to be in place to address any governance concerns that arise. There are several standard scenarios where robust data sharing processes are required, but many organisations have successfully delivered those projects and could offer advice and guidance to support others undertaking similar projects.

The CHC programme has encountered some key information governance challenges in building the Trusted Research Environment (TRE/Data ARK) for the North West Coast and has worked with local, regional and national specialist IG leads to overcome the obstacles it faced. A key output from that programme workstream is to develop guidance for other organisations and to present a step by step guide, potentially using a checklist and template approach, that other organisations could use if engaging in similar data-sharing projects.

The CHC scenario is one of the potential scenarios for data sharing but the guidance model outcome from that work could be adapted for use in other data sharing scenarios. It would be possible to collate a common set of data sharing scenarios, incorporating instances where identifiable data is needed, where pseudonymised data would suffice and where anonymous, aggregated data will serve the purpose, and to develop checklist and template guidance packages for each of those scenarios individually.

Having access to a collaboratively agreed set of standard processes would serve to reduce the variability in approach, and remove some of the effort involved, in setting up data sharing projects without undermining local customisation and need.

Assuring that data security is managed correctly both internally and within external partners

The rapid development in recent years of a wide range of digital health technologies such as telehealth/telecare tools, health and well-being apps, artificial intelligence tools, virtual reality tools and hardware like 3d printers have opened up new approaches to diagnosis, care management and treatment of health care conditions. It has also opened up the potential for more personal and rich data to be collected on patients, and citizens, that could drive more personalised diagnoses, treatments and richer research tools. However, the pace of development of these tools has been so rapid that the ability to assure communities that these tools are not harming rather than healing has fallen behind. This is an issue that has been recognised nationally and a range of projects are in place to address

the assurance challenge.

While the Medicines and Healthcare Regulatory Agency (MHRA) is in place to regulate medical devices to ensure that meet the standards necessary to be deployed within the NHS, many of the new tools do not yet have a national standard assurance process to provide similar confidence for them.

This is being addressed by the introduction of the NHS Digital 'Digital Assurance Questionnaire' (DAQ) process which is now into its second iteration and aims to provide an equivalent assurance process for health-related devices that do not come under the 'medical device' category. This process is developing an assurance process to ensure that digital health products can be validated against an agreed range of standards that cover:

- Data Security, storage and Management processes
- Data Transfer and encryption practices
- Clinical validity and safety
- User experience
- Value for money
- Interoperability with NHS systems

This work has involved the national teams engaging with a wide range of partners both within and outside the NHS and many of these partners are based within the North West region. Trials of these processes are underway across the country and as a consequence, it is potentially more beneficial to wait for the outputs from these projects to be finalised, rather than commencing local or regional projects to assure individual suppliers.

What are the commercial barriers to intelligence dissemination and adoption?

Question 4 of the workshop asked for a specific focus on the technical barriers to intelligence dissemination. The four groups recorded their views as before and the responses have been collated under the following common themes:

- Who funds or pays for new products?
- Who owns the Intellectual Property (IP)?
- Public perception and the media?
- Who is accountable for failure?

This final set of challenges is intrinsically linked to the new models for the technical delivery of intelligence products discussed under the technical challenges section of this paper.

There is no question that the current models for paying for new products are not always suitable for local organisations and that new models for funding the purchase and implementation of these tools are required. The opportunity to create new ways of commissioning these services runs in parallel with designing new methods of delivery.

Who funds or pays for new products?

When financial resources are limited, organisations naturally are reticent to invest in new tools, where the return on investment can be difficult to articulate. This impacts both commissioners, who will not get access to the benefits these tools can potentially bring, and the providers, who cannot get a foothold in the market for what may be an excellent tool. There is an incentive for both sides of that equation to consider new ways of funding innovation, development, implementation and maintenance to ensure that benefits can be realised for all parties.

Instead of traditional standard licensing approaches, organisations in other fields of expertise are investigating funding approaches that incorporate:

- Joint ownership arrangements
- Cost per use
- Profit-sharing
- Subscription
- Quid pro quo arrangements, (e.g. where academic analysis expertise is exchanged for the right to publish case studies and academic papers using the local analysis outputs)

The proposal from this report would be to add the task of assessing alternative funding approaches alongside the work proposed in CHC - Action 6. This would ensure that as new technical approaches to delivery are developed, new funding models appropriate to that approach is considered in parallel.

Who owns the Intellectual Property (IP)?

The ownership of Intellectual Property of innovations can be challenging for organisations who have not typically worked with others to co-produce new products, but it is a question which is becoming more common within the health care domain as private providers recognise that to truly build fit for purpose digital tools requires a multi-disciplinary

approach, and that co-development with clinicians and healthcare organisations can go a long way to assure the broader healthcare domain in the tools developed as a result.

Again, however, this issue is linked to the development of new delivery models and financial models and will need to be addressed in tandem with those questions. There should be a set of common approaches to the assignment of IP that are appropriate to the delivery and funding models utilised in each case.

Again, IP can be assigned in a number of ways:

- Owned by a single funder of the work
- Proportionally owned by multiple funders in line with their investment levels
- Proportionally owned by multiple parties in line with their development input
- Offered in lieu of financial input
- Offered in addition to financial and resource input

Matching the IP assignation to the product development, therefore, depends on how the product was developed and funded.

Public perception and the media?

The public perception around data sharing, often fanned by media reporting around specific individual projects, can be sensationalist and NHS organisations are often justifiably nervous when engaging in data sharing project, particularly with external private providers, as a consequence. The press furore around the implementation of Care.Data and the Royal Free's work with the Google DeepMind system, highlighted the risks if organisations do not undertake data-sharing programmes with strong public engagement and transparency within the project scope.

It does not need to be like this and a range of national and regional work on patient engagement, and specifically, their views on data sharing within the health service have highlighted that the vast majority of patients are more than willing to support innovative data-sharing programmes as long as those programmes are transparent and provide legitimate justification around the benefits and risks to the work.

The CHC Public and Patient engagement workstream has produced evidence, through its work with regional citizen's juries and local Public and Patient Involvement (PPI) teams; and has also built a strong network of patient liaison groups across the North West that could be harnessed to assist any local NHS teams considering the development of complex data-sharing projects. These groups will test that the relevant processes are in place and provide

effective protections around data security and privacy and will support those projects publicly once they are confident all of their concerns are addressed.

The key learning from this work has been that patients are incredibly supportive of training as long as they are well-informed about the nature of the project.

The challenge for local teams is understanding where these groups exist, how to communicate with them and how to engage them in the design and development stages of their projects. This information has been collected by the CHC PPI engagement team and could be made available to the information community via the portal proposed under CHC - Action 5.

This additional service would provide information leaders with access to groups of patient representatives who could assure local data-sharing project teams that their work was robust, appropriate and of benefit to patients and could also ensure that the risks of negative public perception and sensational media attention could be minimised, or eradicated.

Who is accountable for failure?

Accountability for failure resides with project ownership and in the case of data sharing projects, this would also apply.

The penalties for failure concerning the loss of personally sensitive information, or health system breaches, are rightly severe. These penalties apply only when all possible steps to prevent breaches 'that could reasonably be expected to be taken' are not taken. Organisations do not face such severe reprimands if they have put in place all of the processes and protections that they could reasonably have been expected to do.

With the use of outsourced services such as cloud service providers, the allocation of responsibility needs to be considered and managed through service level agreements and contracts. These contracts should allocate responsibility for failure with the entity in control of that particular point of failure.

While it will be difficult to put in place specific actions to tackle this concern, the range of actions that have been discussed throughout this report should ensure that all reasonable protections are in place in any data-sharing projects that engage with this process. The CHC team can ensure however that questions of ownership and responsibility are raised as a key part of any discussions that take place under the actions proposed around developing new product approaches and financial models.

APPENDIX 2

Recommended Actions

Action 1

Work with intelligence leaders and external partners across the NW to explore the concept of developing a template business case toolkit that contains the necessary elements required to support improved take-up and implementation of new innovative intelligence products and measures within organisations. This work would aim to provide a business case template for use by local information leaders when they are building internal business cases for investment that could provide guidance and tools to address the challenges in overcoming resistance to change within their organisations.

Action 2

Local information governance specialists to develop a commonly agreed approach to the application of information governance standards across a range of common data sharing use cases.

Action 3

Investigate potential alternative approaches that can deliver external intelligence tools into NHS organisations in a manner that minimises the local resource requirements for both the implementation and maintenance of these new intelligence tools and measures.

This work will also involve engaging with external intelligence providers to understand if they are amenable to delivering their tools in new ways, and work with regional NHS leads to ensure that can accept new models for delivery of these tools.

Action 4

Ensure that elements necessary to counteract protectionist viewpoints are included in the relevant sections of a Business Case Development framework.

Action 5

ISD and AphA leads to discuss the potential for a focused online training and development portal for information staff.

Action 6

Facilitate discussion with private and academic partners on the potential for new delivery models for intelligence products addressing the issues raised within the workshop.

Action 7
Work with local organisations to trial the embedding of new analyses within local systems.

Action 8
ISD Network and AphA leads set up a working group to undertake an initial collation of key data quality issues being experienced within the region and plan for potential solutions to address those issues collaboratively.

Action 9
IG leads and local counterparts, to assess whether the IG guidance work done to support the creation of the Data ARK could be adapted to create collaboratively produced guidance packs for common data sharing scenarios.

Action 10
To continue to monitor the development of national assurance standards development and communicate progress from these projects to local information teams via the ISD Network and AphA.

Action 11
Incorporate the development of new financial models into the work to investigate new technical delivery models.

Action 12
Incorporate the development of new IP assignation models into the work to investigate new technical delivery models.

Action 13
Patient and Public engagement teams are engaged in the development of any Intelligence Network development portal.

Action 14
The issue of ownership and responsibility are considered in discussions re future algorithms.