

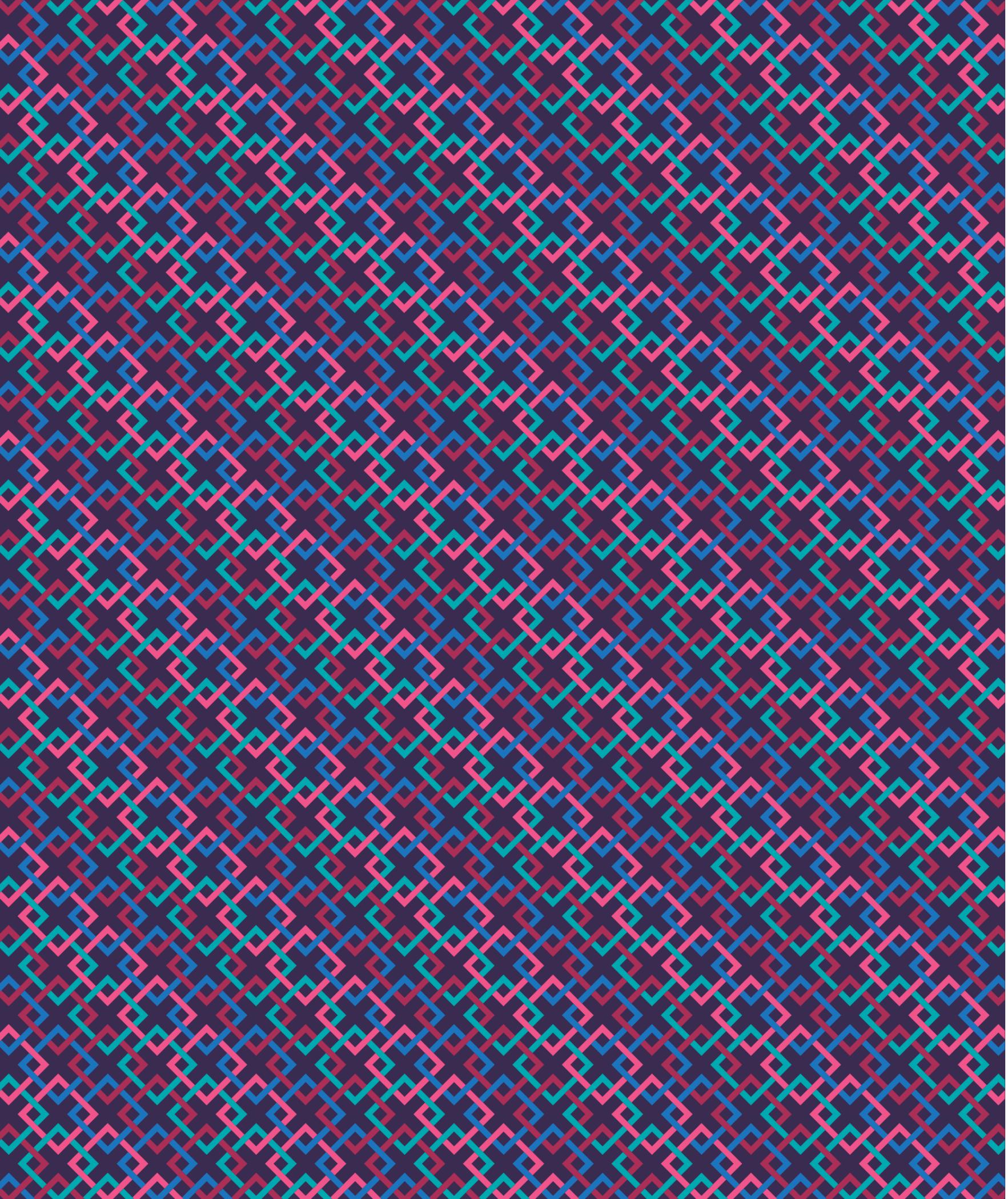


Connected Health Cities

IMPACT REPORT

2016-2020

Connected Health Cities was a Government funded programme that used information and technology to improve health and social care services for patients across the North of England.



Connected Health Cities

Impact Report

DELIVERING TRUSTWORTHY DATA
DRIVEN IMPROVEMENT IN CARE FOR
OUR PATIENT POPULATION

◆ Introduction

◆ CHC Hub

◆ North West Coast CHC

◆ Greater Manchester CHC

◆ Connected Yorkshire CHC

◆ North East and North Cumbria CHC

◆ References and Resources

“Connected Health Cities really set the bar for public and patient engagement in health data use. The programme showed not just that it was possible to talk to patients about complex health data topics, but also how vitally important that engagement is for building a trustworthy system for data.

CHC’s ethos of really listening to communities and working with them to create models of data use will continue to resonate through the patient data community for years to come.”

Dr Natalie Banner,
Lead for Understanding Patient Data

“I commend Connected Health Cities for its commitment to public engagement and its dedication to understanding what patients and the public truly think about the use of their health and care data.

Such meaningful engagement is vital if we are to gain people’s trust and win their support for the use of their information in initiatives that may see data being used in new and innovative ways.”

Dame Fiona Caldicott DBE,
National Data Guardian for Health and Social Care



An Introduction by Northern Health Science Alliance

THE CONNECTED HEALTH CITIES (CHC) PILOT PROGRAMME WAS DEVISED AND DELIVERED BY THE NORTHERN HEALTH SCIENCE ALLIANCE (NHSA) ACROSS THE NORTH OF ENGLAND AS A PARTNERSHIP OF OVER 20 ORGANISATIONS AND THE PEOPLE THEY SERVE.

The original vision for CHC was developed by Professor Iain Buchan and, as with all mass movements, it has been dependent on countless leaders and contributors: not least the Directors cited later in this section; the respective teams in the regions, the CHC Hub and the NHSA, who have helped shape and deliver it. We extend our thanks to all involved.

The programme demonstrated the NHSA's ability to mobilise, across our population of 15m people:

- ◆ Our world-class academic expertise in health data.
- ◆ Our sustained and meaningful discussions with our citizens.
- ◆ Our outstanding health and care system, to deploy the findings of the programme and create impact for the health and wealth of the region.

The £20m pilot Health North: Connected Health Cities was funded by the Department of Health in 2015. It recognised the potential value of health data, with appropriate care system and citizen engagement, to both drive improvement in the provision of care and to create an economic asset across the North of England that was understood and supported by its people.



by Dr Séamus O'Neill



Achievements and Impacts

Connected Health Cities has:

- ◆ Put the citizen at the heart of this work and produced an exemplar of involvement and consultation, building trust amongst our patient population and developing a learning health systems approach that can be replicated.
- ◆ Co-created the programmes through innovative engagement projects, including citizens' juries and the hugely successful social media campaign #DataSavesLives.
- ◆ Established Trustworthy Research Environments (TREs) within regional Data Arks to deliver a common governance and operational platform, allow data interrogation and research to meet all the required standards, and support data-driven innovation and improvement.
- ◆ Delivered 16 pathway projects which are continually improving care in the NHS - saving lives, money and capacity.

The impact of CHC includes:

- ◆ Over 10m people now have connected health and care records across the North of England.
- ◆ Over 40m consultations and episodes of care have been analysed: saving time, money and leading to better patient care and future care improvements.
- ◆ At least £30m of investment has been secured through CHC, new jobs created, and small businesses and industrial partners supported to develop products and services with the NHS.
- ◆ Early indications show an estimated £150m could be saved across the care system.
- ◆ 20 Acute NHS Trusts, 550 GP Practices and 10 universities have been brought together to innovate and improve care through joint working.
- ◆ The Great North Care Record was accessed 1.5m times in 2019 and is saving the North East's NHS at least £8m a year.

LEARNING TOGETHER AS A SYSTEM

The North of England is a vibrant life sciences cluster. The cluster includes leading academic and hospital expertise in digital health, some of the best care providers in the UK, engaged citizens, and innovative companies.

CHC's ground-breaking Learning Health System was created to put informed consensual use of citizens' health data at its heart. CHC developed, tested and implemented continuous improvement within the health and social care system of the North of England with measurable benefits for patients, their families and their communities.

Delivering a large-scale transformation and improvement programme across the whole of the North of England and a population of 15m was a challenge. The approach taken by the NHS enabled local ownership of change, adoption and impact. This coupled a facilitating central coordinating hub with regional centres for innovation around health and social care. As a result, we now see thriving engagement within and between regions and in the data-driven improvement they work on.

We used the footprints of the northern Academic Health Science Networks (AHSNs) to deliver the programme within four health and care economies:



Having CHC programmes designed and delivered in each region resulted in the local context being taken into consideration including the needs, aspirations and priorities of the people delivering frontline care. This was crucial, particularly for professional and citizen engagement.

CITIZENS AND DATA

Citizen engagement and approval for working with health data has often been neglected in the health data space, and yet without the conscious and consistent building of citizen trust, the potential for health data to improve lives will not be realised.

The Office for Life Sciences emphasises the role of transparency and the need to prioritise the benefits to the health and wellbeing of NHS patients for any use of data (1). CHC worked throughout the project to build connections with citizens, gain informed consent on the use of data, provide full transparency on the use of data and prioritise improvements in the health and welfare of NHS patients in line with the principles. The work of CHC has been held up by Baroness Dido Harding, Chair of NHS Improvement, as an exemplar of citizen engagement and building trust to realise the potential of health data (2).

Across over 3000 conversations with citizens on principles that should apply to the use of their data, five clear expectations emerged (3) around:

- ◆ Agency
- ◆ Reciprocity
- ◆ Fairness and lack of exploitation
- ◆ Privacy
- ◆ Transparency and trust

It is gratifying to see these principles becoming part of the national narrative (4).

THE DIAMETER OF TRUST

A key piece of learning has been that working supra-regionally with a population size of three to five million demonstrates reciprocity to people on how their data improves care within their communities. This size of target population is large enough for economy of scale and small enough for a conversation with professionals and citizens about data sharing and change. Because of this it is possible to develop systems that are scalable to local need rather than isolated academic research, with embedded capability for managing quality, sharing expertise, and data structure infrastructure for research and innovation.

DELIVERING NEW LEARNING HEALTH SYSTEMS

CHC has shown through its achievements the talents and capabilities that are in place to keep delivering successful and impactful projects, changing lives and the way we bring the advantages of digital technologies to health and social care. This is not just across the UK, but as a global leader too. There is much that can be shared with other UK programmes to ensure the success of those initiatives and retain the support of the public in mobilising their data.

The work and outcomes from CHC are reproducible and scalable; within the project itself we have acquired considerable expertise and know-how on scaling. With future investment we will make the North of England a global player in ethical use of data in healthcare and create a new paradigm of how industry engages with citizens on access to data.

THE UNIQUE VALUE TO THE WHOLE UK OF INVESTMENT IN THE NORTH

The UK's opportunity to lead globally in digital health relies on calling citizens and practitioners to arms in system-wide data and health tech innovation that involves all communities and delivers multi-dimensional value.

Connected Health Cities successfully delivered data sharing and digital innovation from deprived regions and represents a very high value opportunity for the UK. Innovative involvement of patients, publics and practitioners have been key to this success.

Citizen involvement and civic pride are key to harnessing whole system data and analytics without controversy. This approach is also key to equitable economic growth in the digital health sector, avoiding problems such as large tech company using personal data from deprived communities to train algorithms that generate net benefits in a wealthy community, thereby compounding inequalities.

The public understand this and media coverage of Connected Health Cities has been overwhelmingly positive with the #DataSavesLives movement spreading as far afield as Australia.

CREDIT TO OUR SPONSORS DHSC

The innovation in this programme went beyond the programme delivery side. We are indebted to our funders, the Department of Health and Social Care (DHSC), who led on the oversight, and to NHSX. Both were hugely constructive and supportive. The health data landscape is a very different place now thanks to both the investment received and the way in which we were supported to use the funds.

DHSC/NHSX took an enlightened approach to partnership within, and management of, the programme. They created an environment where we had the freedom to try new approaches, trusting us to lead while ensuring accountability. As a consequence, we were able to mobilise and empower practitioners and citizens to deliver something that is unique and which will have lasting societal and economic benefits as well as a transformative effect on the health and care system.

THE FUTURE

Connected Health Cities demonstrated that getting people involved and informed about their data use is integral to a successful system and that data quality, availability and interpretation improve with local involvement.

The North of England is well-placed within the UK to drive health data and tech innovation in major areas of need with the highest disease burdens, grave inequalities and the greatest need to economic growth. It does this in potentially the UK's most valuable data-generating communities and in a civic way that optimises implementation and sustains innovation.

The learning, capability, networks and organisational memory of Connected Health Cities should be sustained as an opportunity to embed the use of health data into the health and social care system. The approach has saved lives and money with an 8:1 return on investment. It has generated effective, exciting new ways to use health data with the citizen at its heart.

The original funding of £20m was intended as phase one; a three-year pilot and demonstrator. We now have an exceptional opportunity to deliver the next phase, Civic Data Co-operatives (CDCs) to scale-up and roll-out the value delivered and create a globally important asset in the North of England.

CIVIC DATA CO-OPERATIVES: BUILDING ON CONNECTED HEALTH CITIES

Civic Data Co-operatives linked in a supra-regional grid by national digital services are NHS's vision for phase 2 of Connected Health Cities across the North. Data is a currency for inclusive economic growth and service improvement. CHC demonstrates there is a diameter of trust within which the public and practitioners are comfortable sharing data as part of civic belonging and pride. For sustainable health data & tech innovation, this diameter needs to be large enough to have potent data yet small enough to have the social license of meaningful public involvement.

When the generators, stewards and consumers of data are in one civic system they can hold one another to account for good governance as a tangible social value chain. Data governance activities will be shaped by citizens and be accountable to the public through civic leaders (such as devolved administrations), within a diameter of trust. The CDCs will:

- ◆ Link to trustworthy national infrastructure wherever possible to link data while preserving individual privacy.
- ◆ Contribute as part of a national/international grid of regions that can borrow strength from larger numbers of data across the network (e.g. for studying rare diseases).
- ◆ Support the sharing of human analytic resource as civic systems are overwhelmed by requests for data analyses.
- ◆ Broker links between smaller/local and larger partner companies in creating inclusive economic growth through the co-development, evaluation and adoption of data-driven technologies.

The CDC grid will enable regional cooperatives to borrow strength from each other via shared digital resources, a common, continuously-improving operating model, and a united interface to other UK and international regions with similar needs.

In funding phase 2, Government will unlock the huge potential of the health data, digital capabilities and care intensity and excellence across the North.

This can help reposition England's health and social data strategy from a limited national hub-spokes model to an extensive network of regional cooperatives sustaining strong data science embedded in health and care systems with communities that trust, respect and nurture them.



Dr Séamus O'Neill
Chief Executive, Northern Health Science Alliance

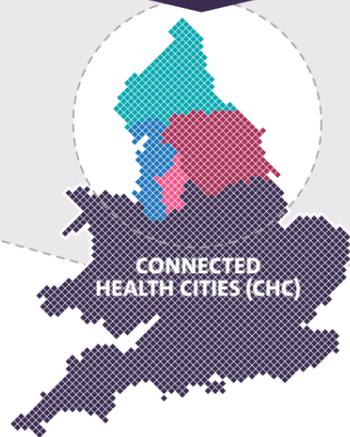
Connected Health Cities Programme in Numbers

In four years, **Connected Health Cities** has delivered outstanding results which have changed the North's health data landscape through driving trust in its patient population and using 'learning health systems' to improve care and save lives.

£20
MILLION
FUNDING

4
YEARS

4 GEOGRAPHICAL
BOUNDARIES
WITH
POPULATION
GROUPS
OF 3-5 MILLION



5

TEAMS
CHC Hub
GM CHC
NWC CHC
NENC CHC
CY CHC



200+

PEOPLE
worked on
CHC across
4 regions



20+

ACUTE NHS
Trusts were
involved in
CHC projects



550

GP PRACTICES
participating
or accessed
through
project



10+

UNIVERSITIES
participated
actively in
CHC projects



100+

**MULTI-
DISCIPLINARY
PARTNERS**
joined in
to support
delivery

CHC Programme Key Impacts

From early years to end of life care, 16 clinical pathway projects have been put in place using health data to improve patient care.

Early indications show an estimated **£150-200m PER ANNUM SAVING**, with multiple projects projecting an average eight-fold return on investment

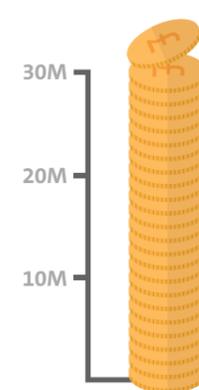


ANALYSIS OF OVER 40M CONSULTATIONS AND EPISODES OF CARE

across the UK through the development of apps and web-based platforms, including real time access for decision-support at point of care, service improvement and planning

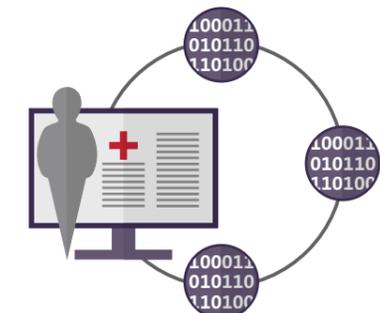


CHC has supported SMEs in creating new jobs and **HELPED SECURE INVESTMENT, INDUSTRY GROWTH AND WEALTH GENERATION IN THE NORTH OF ENGLAND OF OVER £30M**



RECORDS FOR A POPULATION OF 9.5M CAN BE ACCESSED

through three major linked datasets in the North of England. These are now working across primary and emergency care giving healthcare professionals and many patients direct access to care records.



Patients, Citizens and Impact

Over 30 million patient-level data and 20 million consultations from over 400 General Practices in England is used to reduce national and local burden of **ANTIMICROBIAL RESISTANCE (AMR)**.

THE GREAT NORTH CARE RECORD (GNCR) now gives care records access to 100% of General Practices across the North East and North Cumbria, involving 400 practices, 25 NHS and Local Authorities, and 12 CCGs saving at least **£8m** per year.

Working with schools to support children with potential **CHILDHOOD AUTISM SPECTRUM DISORDER (ASD)**, the initial project linked education and NHS data and used new algorithms to identify children requiring neurodevelopmental support. This resulted in new referrals for ASD diagnosis.

**313
BED
DAYS
SAVED**

In the first 12 months, **313 bed days were saved** for **CHILDHOOD ASTHMA-RELATED SYMPTOMS** with 45 General Practices supporting the new home-based care pathway.



THE SMART INTERVENTIONS FOR LOCAL VULNERABLE RESIDENTS (SILVER)

team created tailor-made, multi-partner data sharing agreements that met the needs of all stakeholders across **healthcare, social care, criminal justice, housing and education**. This ground breaking approach enables holistic, joined up support for vulnerable families.

The newly developed algorithms identified an extra **66%** of **EPILEPSY-RELATED ADMISSIONS** when compared to just using the primary diagnosis code, now capturing more accurate average length of stay.

New algorithms were developed to identify emergency admissions due to **CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)**. When compared with the national analysis, the NWC algorithm identified **58%** more admissions for people with COPD currently being provided with NHS care.

An extra 40% of cases of **ALCOHOL-RELATED LIVER DISEASE**

were detected using new algorithms when compared with standard approaches for capturing data on emergency admissions.



The Pre-Hospital Pathway Aid (PHPA) app resulted in ambulance staff being able **to take decisions within seconds** on the most appropriate and the nearest specialist care team for **PATIENTS WITH SUSPECTED STROKE**.



Whilst using the ABC care bundle for **PATIENTS WITH INTRACEREBRAL (BRAIN) HAEMORRHAGE (ICH)**, one Hyper Acute Stroke Unit observed a **reduction of around 22%** in the number of patient deaths within 30 days.

The **CYSTIC FIBROSIS (CF) HEALTH HUB** has reached more than 50% of adult UK's CF centres where direct patient care is being supported through real time access and analysis of data.

Identified 1 in 5 **ACUTE HOSPITAL ADMISSIONS** in Yorkshire and Humber are unnecessary, helping identify **£700m** which could be redeployed into other areas of health and social care.

Twice as many **PATIENTS IN THE END OF LIFE CARE PATHWAY** are benefitting from their Special Patient Notes being available to ambulance services in North Tyneside.



Connected Health Cities Directors' Statement

CONNECTED HEALTH CITIES WAS AN AMBITIOUS PROGRAMME THAT BROKE NEW GROUND.

Spanning the whole of North England and its population of fifteen million people, the aim was to address healthcare challenges that cross organisational boundaries where a collective and collaborative approach was required from disparate organisations. We set for ourselves three principal objectives: to test the learning health system methodology for data driven transformation of healthcare in the real world; to develop a social licence for the use of data driven transformation; and to develop new models of partnership with service providers, academia, industry and citizens.

The CHC programme was launched at a time when public trust in the reuse of healthcare data was at its lowest. CHC developed an innovative approach to public involvement that set a new benchmark and has been widely adopted. We have shown that data driven transformation of health services does not occur simply by making health data available for analytical purposes. It is essential that the people and organisations providing those services and generating the data are integral to the analytic work. A deep understanding of the local context, its complexity and the perspectives of those involved is crucial for success. Therefore, a holistic approach is required bringing together all stakeholders including patients, public, practitioners, providers, industry and academia. We have piloted multiple successful care pathway transformation projects across the Northern footprint with each delivering significant knowhow and system impact. However, the lasting legacy of CHC goes beyond our service transformation work; the development of an open innovation culture has enabled the building of quality foundations, both physical and relational, to co-create and spread solutions across a wider community of practice. The very fact that this has been delivered with citizens as our central partner is what has made CHC truly transformational.

Professor John Ainsworth, Dr Amanda Lamb, Dr Liz Mear, Professor Niels Peek, Professor John Wright, Professor Joe McDonald



Professor John Ainsworth



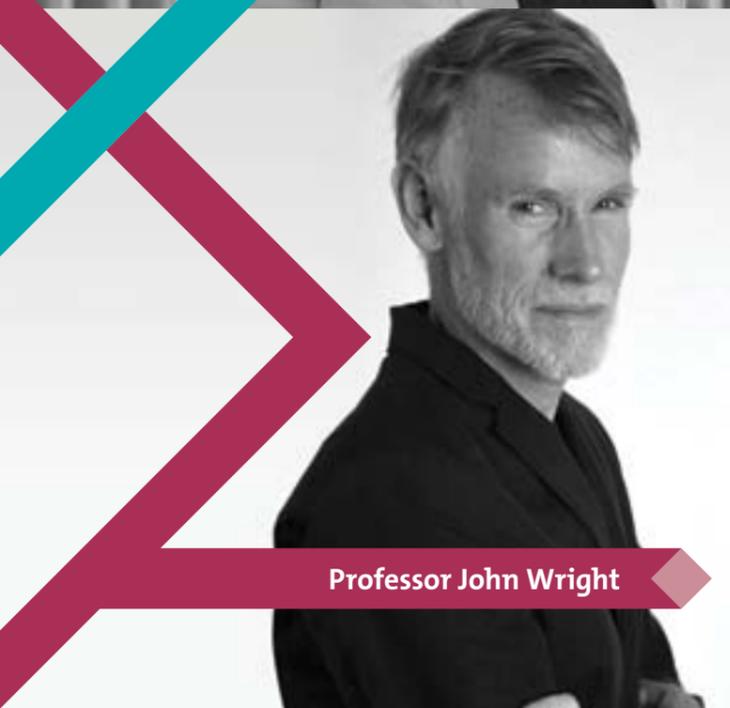
Dr Amanda Lamb



Dr Liz Mear



Professor Niels Peek



Professor John Wright



Professor Joe McDonald

Putting Connected Health Cities in Context

CONNECTED HEALTH CITIES ESTABLISHED EFFECTIVE PARTNERSHIPS LINKING UP NHS, SOCIAL CARE, PATIENT GROUPS, LOCAL CITIZENS, ACADEMIA AND INDUSTRY TO PUT IN PLACE ITS LEARNING HEALTH SYSTEM APPROACH TO IMPROVEMENT.

The approach taken by CHC enabled local ownership of change, adoption and impact coupled to a facilitatory central core that catalysed knowledge spread, scale-up and the amplification of quality foundations to support the learning health system and its critical mass of experts.

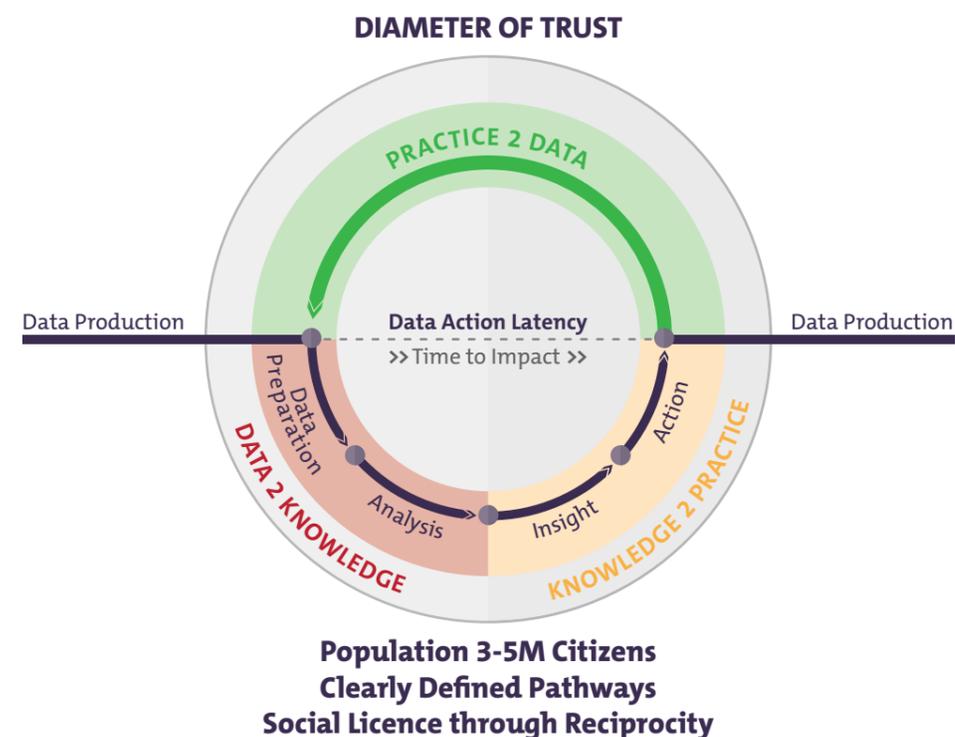
At the heart of CHC is what's called a learning health system (LHS). An LHS is defined as "science, informatics, incentives, and culture aligned for continuous improvement and innovation, with best practices seamlessly embedded in the delivery process and new knowledge captured as an integral by-product of the delivery experience" (5).

Based on the footprint of the four northern Academic Health Science Networks (AHSNs), regional CHC LHS projects were focussed on the need of the local system. Each project deeply understood the context, complexity and perspectives of those delivering frontline care and their requirements for change.

However, it was the size of population in which CHC operated that was critical for successful delivery. Change would impact service users, patients and local citizens. To truly involve the public in these changes in a meaningful manner, a 'diameter of trust' with an upper boundary of 5m people was set. This enabled changes and improvements to impact citizens, their families and their local communities: the reciprocity requirement that so clearly came out of our citizens' jury work.

Historically, a huge barrier to innovation in health has been the time between data becoming available and it being used in an actionable way; this is termed data-action latency (DAL). DAL is a measure of the maturity of a data system: the bigger the DAL the less mature the system.

CHC introduced DAL as a key metric of the LHS to monitor continuous data driven improvement. Significant reductions in DAL were observed; with one front-line innovator reporting a reduction down from 10 years to 18 months. Reductions were achieved by bringing together the right people with the right methods and right data; to deliver the best care for the right patients at the right time.



THE DIAMETER OF TRUST

Developing regional centres for sustainable impact and scalability to reinforce trustworthy use of data across a population of 3-5 million citizens

- ◆ Large enough for economy of scale and small enough for a conversation with the citizens about data sharing in a way that meets local needs and concerns.
- ◆ Designed to manage data quality, and share expertise and data infrastructure for research and innovation.
- ◆ Projects deliver reciprocity to the population providing the data, improving the health of their communities.

Embedding systematic approaches to system wide change required multiple supporting enrichment programmes. Each regional had specific workstreams focussed on public involvement, workforce development, robust and secure data analytics platforms, industry engagement, information governance, and consent or preference setting. Combined, this approach provided the framework to build reproducible and scalable solutions that made LHS tractable. Ultimately, the LHS made it easier for front-line innovators to safely use data to save lives.

Building System Change

Today in the North of England, mobilised teams of researchers, clinicians and partners are able to accelerate impact to patients and citizens through data driven improvement in a matter of months, where it would have previously taken years.

“[when you think about] how long it takes to roll it out, and it’s something like 17 years from starting a project to rollout compared to 18 months on this [CHC] pathway.”

CHC EVALUATION PARTICIPANT

“I was just amazed by the quality and breadth and amount of work that’s been done across the different regions.”

CLINICAL EVALUATOR

“It has been a real catalyst for change pulling Northern partners together. At a geopolitical level, it has been really crucial to have this investment”.

“Others have been there before with a top down approach but I feel CHC are doing this much better ...”

CHC EVALUATION PARTICIPANTS

PROGRAMME DELIVERABLES ACHIEVED

Establishment of data sharing strategy and agreements for each region	✓
Establishment and delivery of governance arrangements for the sharing and usage of data for each region	✓
Workforce arrangements optimised and Continued Professional Development requirements identified	✓
Creation of Arks as analytical platforms	✓
Pathway analysis, variation assessment and improvements identification	✓
Data frameworks and integration with R&D partners	✓
Production of suitable business models for scaling and sustainable delivery in the NHS	✓

DEMAND GENERATED USING REPLICABLE APPROACH

Funded for 8 pathways and delivered 16 diverse pathways	✓
100% coverage of data sharing agreements in local areas	✓
Up-skilled local workforce, built critical mass of experts and transformed working from silos to team	✓
Four locally owned Data Arks and six trusted research environments created	✓
Identified replicable approaches: what works, and where and the know-how to scale	✓
Connecting UK and global health systems & researchers	✓
Know-how commercialisation: immediate interest in “blueprint” & consultancy	✓
Future pathway project commercialisation potential for the benefit of NHS	✓
Export demand: interest from overseas health systems in 9 countries	✓

READY TO SCALE INNOVATION AND IMPROVEMENT

Enabled front-line innovators to improve care, reduce waste and unlock learning	✓
Shaped learning health systems to deliver policy objectives and influence policy	✓
Codified the knowledge and applied the know how to scale what works in different contexts	✓
Created online library and community for open sharing of applied resources and best practice	✓
Focussed on collaborative approach with existing projects as well as innovative new initiatives to achieve short-term gains with long-term impact in UK	✓

Meeting National Priorities

DHSC Priority	Added Value
Keep people healthy and support economic productivity and sustainable public services	Regional and care pathways are beginning to address health inequalities across the health and care system in the North of England to reduce unjustified variations in health outcomes. The creation of new algorithms and analytical platforms has the potential to be applied throughout the UK to assist DHSC in improving the health of the population.
Transform primary, community and social care to keep people living more independent, healthier lives for longer in their community	The CHC programme has established the foundational infrastructure across the North of England to improve health and care through better use of digital, data and technology. The knowledge and skills of CHC staff and partnerships could be leveraged as part of the wider DHSC digital revolution.
Support the NHS to deliver high quality, safe and sustainable hospital care and secure the right workforce	The collaborative and multidisciplinary approach of the CHC programme has allowed innovation in the creation and piloting of prediction models that can highlight resource and staffing gaps during periods of high demand, which could be applied across the UK. Some care pathways have tested a more targeted approach to solving health inequalities, enabling clinicians to learn from and evolve patient pathways in a shorter period of time.
Support research and innovation to maximise health and economic productivity	CHC programme funding has contributed to the building of technology and health informatics infrastructure in NHS organisations across the North of England, allowing the flow of data to identify key health issues within local populations. Each region has developed its own infrastructure for clinical research and medical innovation through the creation of Arks and employment of skilled staff.
Ensure accountability of the health and care system to Parliament and the taxpayer; and create an efficient and effective DHSC	There are a number of areas where CHC programme outputs could be shared and applied across the UK. For example, the creation of regional governance structures to facilitate the use of routinely collected patient data in research, data sharing agreements and creation of patient and public involvement groups.
Create value (reduced costs and growing income) by promoting better awareness and adoption of good commercial practice across the DHSC and our arm's length bodies	The CHC programme has created regional partnerships across the North of England between NHS Trusts, higher education institutions and industry with governance structures and commercialisation protocols in place that protect patient data confidentiality that could be utilised by the DHSC in driving innovation and digital change with NHS suppliers both nationally and internationally.

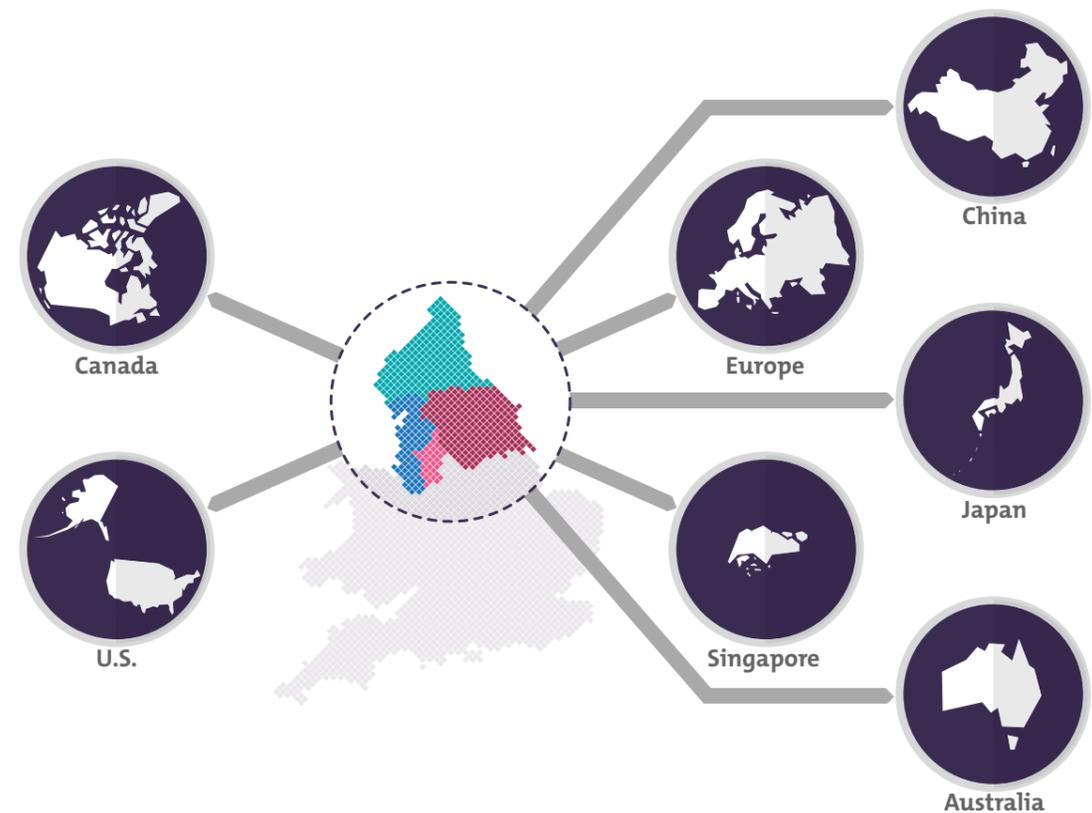
Connected Health Cities International

CHC has developed a pipeline of international routes for scale-up, sustainability and knowledge transfer.

This was supported by regular and repeated engagement with academic institutions, health organisations, government bodies and industry across the US, Canada, Australia, Singapore, China, Japan and Europe. Engagement was holistic: presenting the CHC programme at international conferences and symposia (e.g. Medical Informatics Europe, Hi.Tec Singapore 2019, BioJapan 2018), development of longer-term collaborations and replication of the methodology and projects, and meetings with senior leaders in governments and health authorities.

A wide range of health system leaders have explored collaboration including: the Singapore Ministry of Health; New South Wales Ministry of Health; South Australia Health and Medical Research Institute; Beijing University (PKU) National Institute for Health Data Science; China National Health Development Research Centre; Institute for Global Health Policy Research, and World Economic Forum (WEF) Centre for the Fourth Industrial Revolution, Japan.

As a result of this successful international relations programme, a community of practice has been agreed to promote sharing and access to a suite of online tools and software.





Meet the Team

From GPs to surgeons; from health psychologists to software architects; from data scientists to public engagement experts: CHC brought them all together. Meet some of the team who made CHC happen below and find out more at www.connectedhealthcities.org



Glossary

◆ A&E	Accident and Emergency
◆ AHSN	Academic Health Science Network
◆ AMR	Anti-microbial Resistance
◆ ARC	Applied Research Collaboration
◆ ARLD	Alcohol-related Liver Disease
◆ ASD	Autism Spectrum Disorder
◆ BiB	Born in Bradford
◆ CCG	Clinical Commissioning Group
◆ CCIO	Chief Clinical Information Officer
◆ CHC	Connected Health Cities
◆ CIO	Chief Information Officer
◆ CLAHRC	Collaboration for Leadership in Applied Health Research and Care
◆ COPD	Chronic Obstructive Pulmonary Disease
◆ CPM	Clinical Prediction Models
◆ CPRD	Clinical Practice Research Datalink
◆ CY	Connected Yorkshire
◆ DHSC	Department of Health and Social Care
◆ eFI	Electronic Frailty Index
◆ EPaCCS	Electronic Palliative Care Co-ordinating Systems
◆ GDPR	General Data Protection Regulation
◆ GM	Greater Manchester
◆ GNCR	Great North Care Record
◆ HIE	Health Information Exchange
◆ ICH	Intracerebral Haemorrhage
◆ IG	Information Governance
◆ IT	Information Technology
◆ LHS	Learning Health System
◆ MIG	Medical Interoperability Gateway
◆ NENC	North East and North Cumbria
◆ NHS	National Health Service
◆ NHSA	Northern Health Science Alliance
◆ NWC	North West Coast
◆ PCCC	Pre-Competitive Collaborative Consortium
◆ DAC	Data Access Consortium
◆ PPI	Patient and Public Involvement
◆ QI	Quality Improvement
◆ R&D	Research and Development
◆ SILVER	Smart Interventions for Local Vulnerable Residents
◆ SPCS	Shared Palliative Care Summary
◆ TRE	Trustworthy Research Environment

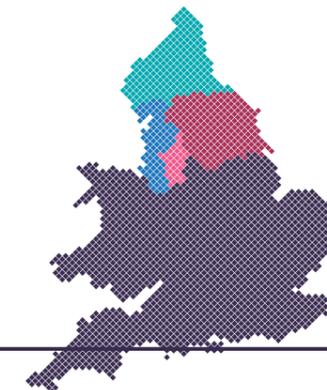
TECHNICAL TERM DEFINITIONS:

- ◆ **Algorithm:** An algorithm is a sequence of instructions for a computer to follow to undertake a calculation or solve a problem.
- ◆ **Anonymisation:** The process of rendering data into a form which does not identify individuals either directly or indirectly and where identification is not likely to take place by any means reasonably likely.
- ◆ **Care pathway:** A document agreed by all disciplines involved in the care of a specific group of patients (such as patients who have suffered a stroke), which outlines the agreed standards for treatment, based on the best available evidence. It makes clear what different tasks (interventions) need to be done by which professionals, when and where.
- ◆ **Citizens' Jury:** A Citizens' Jury is a method of deliberation where a small group of representative people come together to deliberate on an issue over a set period of time.
<https://www.involve.org.uk/resources/methods/citizens-jury>
- ◆ **Data-action latency:** The time between data becoming available and it being used in an actionable way.
- ◆ **Data Ark:** A structured system for key stakeholders to collaborate: bringing together involved citizens, problem owners, data managers, public health analysts, care service analysts, statisticians, informaticians, social scientists, health economists, health service researchers and communications experts.
- ◆ **Diameter of Trust:** A regionally based population of 3-5million: large enough for economy of scale and small enough for a conversation with professionals and citizens about data sharing and change.
- ◆ **Electronic Patient Record (EPR):** A platform or series of software applications which bring together key clinical and administrative data of a health service in a digital format in one place.
- ◆ **Learning Health System:** Learning health systems (LHS) are healthcare systems in which knowledge generation processes are embedded in daily practice to produce continual improve in care.
https://en.wikipedia.org/wiki/Learning_health_systems
- ◆ **Medical Interoperability Gateway:** A computer system that enables the sharing of specified datasets of patient information between healthcare providers.
<http://www.nottinghamnortheastccg.nhs.uk/wp-content/uploads/2015/05/What-is-MIG-information-document.pdf>
- ◆ **Trustworthy Research Environment:** A secure platform to analyse data which meets the needs of the data owners, citizens, and researchers and satisfies common data standards, information governance and legal requirements for the storage and use of data.



The Hub

Connected Health Cities



IN SUMMARY

- ◆ Public involvement and engagement: A clear public engagement strategy has been at the very heart of the entire CHC programme.
- ◆ Safe and trustworthy use of data: CHC dataflows were designed to cross organisational boundaries, including NHS, social care, education, police, academia and industry.
- ◆ Technical projects applying the CHC expertise: Building and applying a reference data architecture, CHC launched four data arks and six operational trustworthy research environments in 24 months across the North of England.
- ◆ Professional engagement, training and education: CHC initiated the development of a digital capabilities learning programme starting with the identified priority topics of evaluation, information governance and health economics.
- ◆ Industry partnerships: Two consortia were key in forming the foundation of active networks, consultation and collaboration to support wealth generation and industry partnership working.
- ◆ Scaling up real time Cystic Fibrosis care: The Cystic Fibrosis Health Hub formed a digital learning health system creating the research evidence to transform care for people with cystic fibrosis.



CHC Hub Director **Professor John Ainsworth**



CHC Hub Deputy Director **Dr Amanda Lamb**

In this section

Public Involvement and Engagement

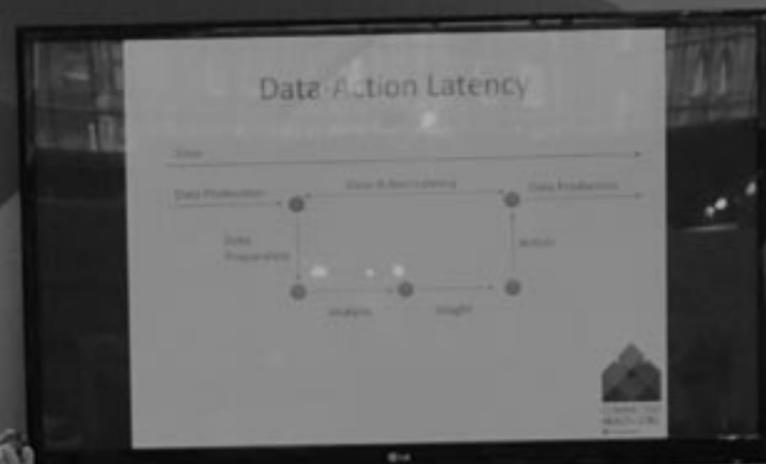
Safe and Trustworthy Use of Data

Technical Projects Applying the CHC Expertise

Professional Engagement, Training and Education

Industry Partnerships

Scaling up Real Time Cystic Fibrosis Care





Public Involvement and Engagement

A CLEAR PUBLIC ENGAGEMENT STRATEGY HAS BEEN AT THE VERY HEART OF THE ENTIRE CHC PROGRAMME.

The team used a range of complementary methods and approaches, with both citizens participating in core activities and outreach into communities. There was a variety of activities ranging from citizens' juries, focus groups and public debates, to immersive games and musical performances.



CITIZENS' JURIES

Citizens' juries are a method of deliberation where a small representative group of people come together to decide on a complex policy issue, in this case the use of patient health data. Three citizens' juries were held by the CHC Hub over 18 months. During the first two juries, the jurors decided that when patient health data is being used outside the NHS, the benefits of this usage must prioritise patients first, then the NHS, and only then commercial companies.

How CHC Hub delivered the programme

Two four-day citizens' juries were run: one in Manchester and one in York to investigate what informed citizens considered to be appropriate uses of health data and understand why they made those decisions. Jurors considered the acceptability of eight scenarios of anonymised health data use. The scenarios were either planned CHC initiatives to improve care pathways or possible commercial data uses that were as yet unplanned.

In general, scenarios leading to potentially positive health outcomes for patients were more acceptable than improved efficiency of services for the NHS, although the latter were also recognised to improve health. Jurors had concerns about whether efficiency improvements would lead to inequitable distribution or closure of services, based on their existing understanding from media reports. Many jurors accepted commercial gain if public benefit was achieved.

A third jury was run in partnership with the National Data Guardian office, recruiting 18 people from across Greater Manchester. This jury deliberated on defining the boundaries for "reasonable expectations" on data sharing, a yardstick used in court cases to decide whether there is a right to expect privacy in a particular set of circumstances. The jurors spent three days deliberating the levels of privacy a fictitious patient should reasonably expect in different scenarios and when it was reasonable to share identifiable data. As with other juries on other topics, the jurors became more supportive of data sharing the more they understood why it was needed.

They concluded that, in most of the scenarios they discussed, patients would reasonably expect that confidential patient data would be shared between healthcare professionals for the care of the patient, although that this did not necessarily mean that all data could be shared. Some but not all members of the jury were also supportive of the use of such data for altruistic reasons other than direct care, such as helping with the diagnosis of other patients for the 'greater good'. The National Data Guardian's office has worked with CHC Hub to implement findings from this citizens' jury in national initiatives.

The series of citizens' juries was of great interest to academia, policy makers, industry and government communities and was presented widely in the UK and internationally. The series has raised interest in the citizens' juries approach as a way of engaging with the public around complex topics and led to further collaboration between CHC and the National Data Guardian's office.

“The team has done much to ensure that the patient’s voice has had a prominent ‘place at the table’ during the delivery of their data sharing initiative – their work has made its mark both regionally and nationally.”

DAME FIONA CALDICOTT, DBE,
NATIONAL DATA GUARDIAN FOR HEALTH AND SOCIAL CARE.

INFORMING THE UK GENOMIC MEDICINE SERVICE

The NHS is positioned to be a “world-leading healthcare system in its use of cutting edge genomic technologies to predict and diagnose inherited and acquired disease, and to personalise treatments and interventions.” (6)

With a new Genomic Medicine Service in England (Spring 2020), the wider data sharing required within and between regions providing the service carries implications for privacy, consent processes and models of information governance. The CHC Hub worked with the regional genomic medicine services in the North of England to understand public values, interests and concerns in relation to sharing genomic data in the course of routine care within the NHS.

A total of 44 participants (16 patients; 28 members of the public) took part in six qualitative, deliberative focus groups in Sheffield and Manchester. The participants of the groups were provided with information and opportunities for reflection and group discussion, creating a greater level of engagement than that seen in standard focus groups. The patients and the public supported the creation of a collective resource of genomic data (like a database) that could be built up over time and drawn upon more widely within regional Genomic Medicine Services. The findings reiterate the need to consider the timing and delivery of information to patients about data sharing alongside any changes to these services. The findings of the focus groups were used to inform the design of the new NHS Genomic Medicine Service in the UK.

PUBLIC DEBATE ON USE OF MENTAL HEALTH DATA

The CHC Hub public engagement activities opened up discussions with citizens as to whether mental health data should be treated differently than physical health data. There is a known lack of parity in research funding between mental and physical health problems. The CHC Hub collaborated with the British Science Association bringing together four experts from across research, the NHS and mental health charities to publicly debate the question:

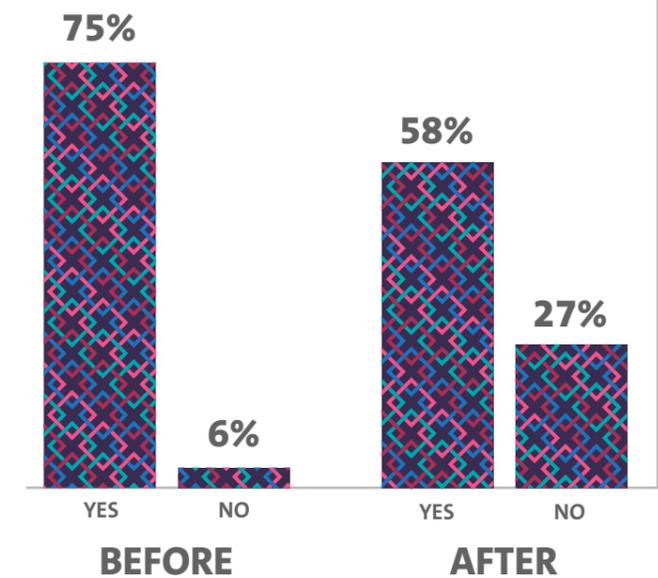
“Do you agree that mental health data is no more sensitive than physical health data and that both should be used equally in data linkage research?”

The discussions during the debate highlighted important nuances for the trustworthy use of mental health data, which informed our information materials and further public engagement work.

Engagement was high across the public debate participants

Consensus

I agree that mental health data is no more sensitive than physical health data and that both should be used equally in data linkage research



The experts debated a range of topics including: how current legislation applies to different types of health data, how research practice might change if mental health data were actually declared more sensitive than physical, whether the data we currently have access to is sufficient to produce meaningful results in mental health research, and how individuals would feel if their data were leaked. The debate sparked poignant and thought-provoking discussions between the speakers and the audience around mental health service provisions, stigma and how the use of data could improve the lives of those affected by mental illness.

The findings were used to inform local priority setting for the use of mental health data and projects within CHC.

“It is difficult to overstate the importance of the #datasaveslives campaign. It unites the public with research, industry, and the health & care sectors to demonstrate and drive the trustworthy and powerful use of health data for good.”

HARRY EVANS, SENIOR PROGRAMME MANAGER, NHS ENGLAND & NHS IMPROVEMENT

#DATASAVESLIVES ONLINE ENGAGEMENT

Twitter is used in healthcare with wide participation from patients, citizens and healthcare professionals. #DataSavesLives is a multi-platform campaign that regularly demonstrates the trustworthy re-use of health data and has kick-started thousands of online conversations. The hashtag #DataSavesLives was established in 2014 and has developed during the lifetime of CHC to become a global movement.

#DataSavesLives collates and shares examples of how health data from patient records and other sources could be used to create health benefits for the public. 4175 original tweets, 9,720 retweets and engagement from 3,649 unique Twitter users were observed in 12 months (2017). In total, 2,756 (66.0%) of original posts were retweeted at least once. Higher frequencies of tweets were observed during the weeks of prominent policy publications, popular conferences and public engagement events. Users span academia, health services and policy, charities and patient networks from the North of England.

Cluster analysis based on retweet relationships revealed an interconnected series of groups of #DataSavesLives users. Thematic analysis of tweets showed that #DataSavesLives was used for a broader range of purposes than its original goal, including event reporting, encouraging participation and action, and showing personal support for data sharing.

#DATASAVESLIVES ANIMATION

A three-minute animation was created in Spring 2018 in collaboration with The Farr Institute of Health Informatics Research and developed with patients and members of the public from across the UK. The animation was designed to answer common questions about health data sharing as well as increase public awareness of how routinely collected NHS data is safely and securely re-used by universities for health research. Since its release, the animation has been viewed online as well as being shown at events and conferences to large audiences. There have been over 4,000 unique views with coverage across the UK and globally from North America to the Middle East.

About the #DataSavesLives animation

The short film takes viewers on a journey to understand how patient data is created and shared, and its important role in research to improve the health of patients and populations.

Examples are highlighted with relevant case studies and the measures that universities undertake to ensure patient data is protected and accessed are explained.





“I have a greater understanding of health data science”

IMMERSIVE EARWORM GAME PLAYER

“Great way to interact with ideas around research and data”

IMMERSIVE EARWORM GAME PLAYER

ENGAGEMENT THROUGH FESTIVALS

The CHC team attended four festivals over two years engaging thousands of diverse groups of citizens on accessing and using health data.

Festivals can be a great way to start new and continue ongoing conversations with people on the use of health data. Health data was a surprise hit for CHC at a variety of public science events in the North: such as the Manchester Science Festival (2016), Bluedot Festival (2017, 2018) and Manchester Caribbean Festival (2017). Teams from CHC used these opportunities to have meaningful conversations on the use of people’s health data, with very broad and varied different groups of people in relaxed and informal settings. Festival attendees could take part in a suite of data-inspired activities aimed at a range of ages and interests such as data friendship bracelet making (each thread represented a different data set) and assembling a data jigsaw to reveal the #DataSavesLives message.

Voting at the festival

I would share my health record



Bluedot Festival



Manchester Caribbean Festival

IMMERSIVE EARWORM GAME

The Earworm Game is a citizen engagement tool on health-related data science concepts and use of patient data.

The game made its debut at the Bluedot Festival in 2018 and was then delivered at multiple further festivals thereafter. The game is immersive, with players working together to uncover the best treatment for a virus that attacks the brain over 5 minutes. The better they are at accessing patient data, putting data security in place and gaining public trust, the more likely they are to win.

The Earworm game takes players through the procedures and considerations inherent in health-data research and elegantly meshes them together, creating a picture of why access to patient data is necessary for successful research and how important data security and public trust are to this process; all while also providing a fast-paced, fun gaming environment.

PLAYING GAMES AT FESTIVALS

“A good demonstration of the importance of keeping data safe”

IMMERSIVE EARWORM GAME PLAYER

A survey with around 300 players:

- 79% said that they learned something new about health-related data science while playing the game.

Players gained 3 learning points:

- the importance of data security,
- the complexity inherent in the research process and
- the importance of sharing data for health research: which corresponded well with those intended.

How to play

Players are split into two teams, medical professional role or health researcher role. Both teams need to work collaboratively to successfully complete the game and gather sufficient information about the three possible treatments for a virus that attacks victims’ brains, leaving sufferers unable to shake Oasis’s Brit Pop classic, Wonderwall, from their heads.

The teams build up information on treatments by interacting with the data board – to uncover the best treatment, they collect samples in the form of beads. With gamification of the complex information and concepts that is used for health data access, citizens who would otherwise be less involved in these discussions were able to think about these concepts.



Image © Gavin Trafford

“ I never thought you could build a creative relationship between music and data. Well done! It was brilliant.”

“Each piece captured beautifully the dataset it represented. Could feel the patients and families in each piece.”

COMMENTS WRITTEN ON POSTCARDS BY THE AUDIENCE

PUBLIC ENGAGEMENT MUSIC PERFORMANCE

[#MusicSaysDataSavesLives](#)

**If you could hear your health data, what would it sound like?
Has patient data got (algo)rhythm?**

These were the tongue in cheek questions asked prior to a live performance of [#MusicSaysDataSavesLives](#), a suite of five short contemporary musical pieces by composers from the Royal Northern College of Music (RNCM) Centre for Practice and Research in Science and Music (PRISM). This was the final public engagement activity that marked the end of the CHC programme.

Composers worked with each of the four CHC regions in North East and North Cumbria, North West Coast, Greater Manchester and Connected Yorkshire as well as the CHC Hub to create five short musical pieces inspired by research projects that are using patient data to address the health priorities in those regions.

For example, the composer of the hub CHC piece, Zakiya Leeming, described how she developed discrete musical identities for each of the four and then showed how each region was influenced by the “learning” i.e. the pitches and rhythms from the other regions, leading to a final merge of the materials to musically depict the successful conclusion of the CHC project.

The pieces were performed by the Festivo Winds woodwind quintet and were interspersed with short conversations between each composer and a researcher on topics from the project that inspired them. Following the performance, a lively question and answer session continued the dialogue between composers, researchers and the public.

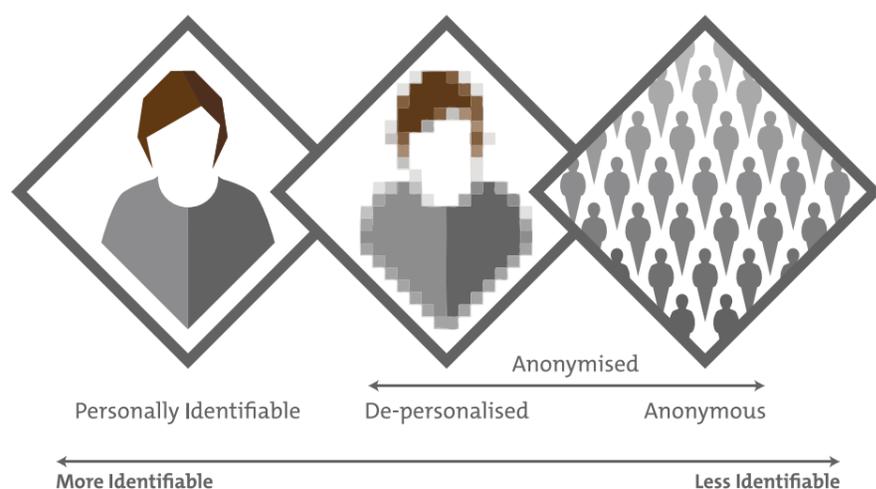


Safe and Trustworthy Use of Data

CHC DATAFLOWS WERE DESIGNED TO CROSS ORGANISATIONAL BOUNDARIES, INCLUDING NHS, SOCIAL CARE, EDUCATION, POLICE, ACADEMIA AND INDUSTRY.

Clear, consistent rules and practices for information governance (IG) are critical to the success of any project based on the sharing of data about an individual's health. The purposes for the data were often mixed, including research, service re-design, and direct care so being clear about how data is shared and used can be complex to describe. Creating a single approach to IG for all the CHC regions was important to ensure that they had the appropriate legal basis and permission for sharing and use of sensitive health data. The CHC Hub worked with all the CHC regions to establish an Information Governance working group to share expertise and develop a framework for managing the secure sharing of data in order to successfully deliver the CHC pathway projects.

Identifiability spectrum



Attribution: Understanding Patient Data

“By making additional information accessible for our ambulance clinicians, they will be able to make more informed decisions based on the patient’s medical history.”

MIKE JACKSON, CHIEF CONSULTANT PARAMEDIC, NORTH WEST AMBULANCE SERVICE NHS TRUST

The development of the unified approach for safeguards to protect data meant that all the CHC regions were able to work to the same standards, which had also been tested for acceptability with both the public and IG experts and their implementation monitored through the working group. This ensured that regions could be confident that their approach to privacy was sufficient for the purposes for use of the data.

Chaired by Clare Sanderson, a nationally recognised expert, this group met monthly over two years to highlight ongoing challenges and develop outputs for use within the regions, as well as support public engagement and local data access discussions.

Key outcomes from the IG working group

- ◆ Unified information sharing guidance and safeguards across all CHC partners.
- ◆ Templates for data sharing agreements for use of data in research which can be completed and accessed via an online Information Sharing Gateway.
- ◆ Privacy impact assessments completed for all CHC projects.
- ◆ Co-production of glossary of terms to create unified language across stakeholders.
- ◆ Development of consent models for CHC projects requiring consent directly from citizen.
- ◆ Preparing regions for GDPR regulations with new Data Protection Act of 2018.
- ◆ Development and delivery of IG best practice training for workforce development with two sessions with fifty attendees.

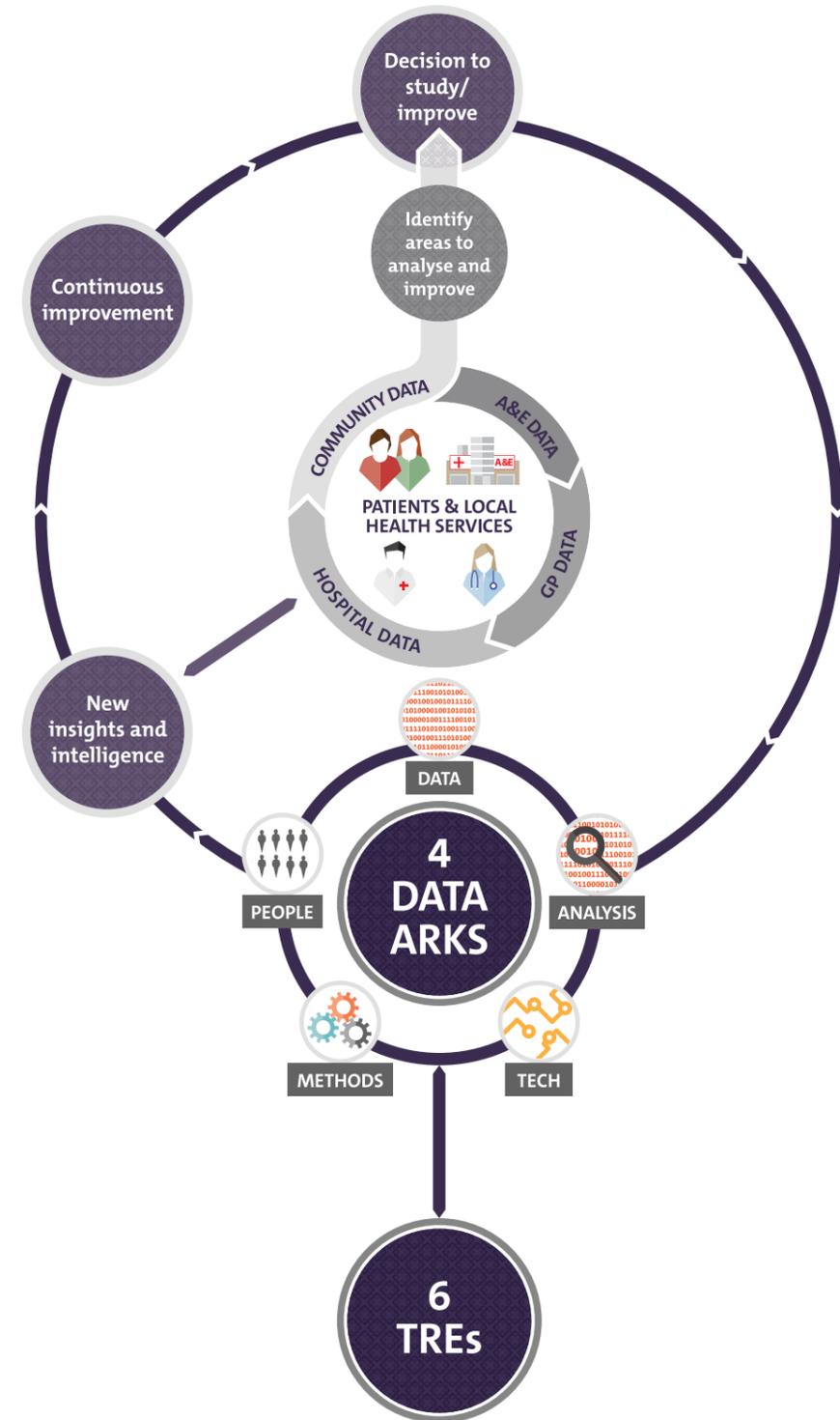
A comprehensive guide of IG learnings, based on the CHC guidance and safeguards, is now publicly available. This will provide information on the issues surrounding data sharing between organisations, such as how to identify the minimum, legal dataset to meet the objectives for a research study, how to assess the lawful basis for processing or using data, the types of approvals and documentation that are needed as well as advice on accessing national datasets. By having this information at the start of the design of a project it should be possible to minimise delays and create appropriate pipelines for data flows from multiple stakeholders.

Technical Projects Applying the CHC Expertise

BUILDING AND APPLYING A REFERENCE DATA ARCHITECTURE, CHC LAUNCHED FOUR DATA ARKS AND SIX OPERATIONAL TRUSTWORTHY RESEARCH ENVIRONMENTS IN 24 MONTHS ACROSS THE NORTH OF ENGLAND.

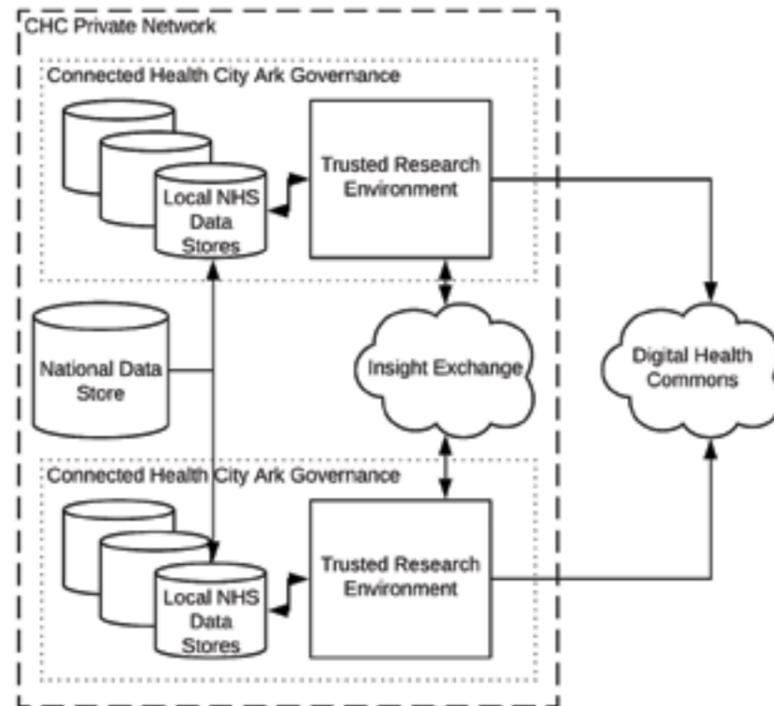
A Data Ark is a structured system for key stakeholders to collaborate, bringing together involved citizens, problem owners, data managers, public health analysts, care service analysts, statisticians, informaticians, social scientists, health economists, health service researchers and communications experts. Combining the people with the CHC methods, technologies, data and analysis, a Data Ark provides the underlying infrastructure on which Trustworthy Research Environments can be built.

CHC Learning Health System



Trusting the Research Environment

HIGH LEVEL CONNECTED HEALTH CITIES TECHNICAL INFRASTRUCTURE REQUIREMENTS



Trusted Research Environment

- ◆ Credential management
- ◆ Data quality management
- ◆ Data catalogue
- ◆ HPC
- ◆ Roles based access control
- ◆ Standard semantic layer
- ◆ ETL - Protected data
- ◆ ETL - Sheep dip
- ◆ Data stores
- ◆ Anonymisation services

Insight Exchange

- ◆ Federated querying
- ◆ Secure data linkage
- ◆ Credential management

Digital Health Commons

- ◆ Public research object sharing
- ◆ Best practice guidance
- ◆ Software and services
- ◆ Only data that has been approved for public release

“we need...something that is really useful to practitioners...easy for them to use and can integrate into what they already do and can see the benefit of.”

CHC EVALUATION PARTICIPANT

ESTABLISHING THE TRES

A Technical Working Group was established February 2017. This Group worked with the four regions to develop a common design for the essential features, or reference architecture, as a baseline for future implementation of local TREs.

The key features of a TRE were identified as being:

- ◆ A Data Safe Haven: A service to receive and store anonymous, patient-level data securely
- ◆ A Data Catalogue: A description of the datasets and projects within the TRE
- ◆ Security and Governance: Appropriate access controls, including encryption and limiting physical access to the network, with strong governance processes certified to ISO27001
- ◆ A Virtual Desktop Infrastructure for researchers: The software and tools to allow the researchers access to datasets to undertake the analysis in a secure environment
- ◆ Publication: The TRE service should also be able to securely publish applications and output from the researchers

Each of the TREs has been used to store a range of datasets that are available to local researchers. These include national datasets such as Secondary Uses Service hospital data, but also develop local datasets, such as the innovative linked health and social care data for the SILVER project (NENC CHC), developed in partnership with the local community of service users as well as medical and care professionals.

Examples of the anonymised data that are available in the TRE include:

- ◆ De-identified at source feeds of local GP records
- ◆ Ambulance service and A&E data feeds
- ◆ 111 and 999 call data
- ◆ National audit and other disease specific data
- ◆ Research specific datasets, e.g. geographical mapping of services

The concept of a Trustworthy Research Environment (TRE) is central to the work of Connected Health Cities. A TRE is a secure platform to analyse data which meets the needs of the data owners, citizens, and researchers. A TRE must be able to meet common data standards, information governance and legal requirements for the storage and use of health data. The development of the individual TREs within the CHC regions enabled local adaptation to governance, data, and research requirements while meeting these core design principles. CHC launched six operational TREs across the North of England, including 100% coverage across the NENC region, within twenty four months.

- ◆ Born in Bradford TRE
- ◆ Sheffield 111 TRE
- ◆ Leeds Institute for Data Analytics (LIDA) TRE
- ◆ University of Manchester TRE
- ◆ AIMES/NWC TRE
- ◆ AIMES/NENC TRE

Sustainability and shared resources

1. A new Maturity Index for digitally enabled Learning Health Systems

With the development of the reference architecture and the implementation of TREs, there is a need to understand the critical components for a successful, digitally enabled learning health system. Following indexes such as HIMSS and KLAS for understanding digital capability, CHC Hub is leading the development of a new maturity model specifically for Learning Health Systems.

This will enable any health system to understand how health data is currently used in research and if it is effective in improving the quality of care and outcomes. This will make it possible to understand the current capability of a whole pathway or region to act as an agile, digitally enabled ecosystem rather than in isolated silos.

The first version of this Maturity Index will be published in Spring 2020, along with new open source tools to enable new multi-stakeholder programmes to test and implement effective learning health systems.

2. Digital familial consent with Born in Bradford project

The question of consent for the use and re-use of health data was an essential question from the start of the CHC programme. Most CHC projects used anonymised data, accessed under appropriate legal purposes, but the general question of consent remained important. Two regions, NWC and NENC, both began the development of consent frameworks for data that was not anonymised and the CHC Hub supported this discussion through workshops, citizen engagement and the design of opt-out and data donorship concepts. It is through this work that Born in Bradford (BiB) partnered with CHC Hub to co-design the requirements for a digital solution for management of familial consent.

BiB is one of the largest research studies in the world tracking the lives of over 30,000 Bradfordians with requirements for consent processes to be maintained over many years for a multilingual population. As a birth cohort study, consent of the mother is required for children to be included from birth and is managed for the child by their mother or guardians until they reach competence. This created a complex challenge that was previously managed on paper but, in order to support the scaling of the study, they needed a new, digital solution. A review of existing consent tools showed that there were no existing software able to meet these needs and so a new consent application was developed. This supports integration with the existing maternity record system and provides a solution for managing consent over the decades of the study.

This consent application is now available as an open source solution and further development is taking place to extend the use of the system to support dynamic consent management by participants using an online portal.

3. Sustainability and Development

CHC Hub are working with Innovate UK and NICE on the Digital Health Technology Catalyst (DHTC) Round 4. With funding from the Industrial Strategy Challenge Fund, £4m of funding has been allocated to support a host of small and medium enterprise (SMEs) innovators to develop their exciting digital health solutions. The sixteen successfully funded project teams have been offered the use of the NICE DataLab services which is an innovative collaborative between NICE, the University of Manchester and CHC to bring together a wide range of expertise from across the NHS, academia and NICE on health data research. The SMEs are gaining an understanding of the health economics, the constraints and standards for the use and interoperability of health and research data, and robust evidence creation to enable a stronger and more mature route to market. Outcomes from this ongoing engagement includes the development of new recommendations on guidance for digital health interventions for NICE.

RECIPROCITY AND SUSTAINABILITY

The sharing and use of data through the Trustworthy Research Environments is based on the principles of anonymity, security and, importantly, reciprocity. Reciprocity is demonstrated through the research of local issues with the link to how services for the community providing the data can directly benefit. CHC TREs support the idea that data should be used for the benefit of all, while recognising the challenges that can arise from conflicting needs between stakeholders.

An example of this key principle of reciprocity and sustainability is the Great North Care Record, supported by the CHC programme.

“ The Great North Care Record (GNCR) connects 372 general practices with 11 acute trusts, 2 mental health trusts and one ambulance trust to deliver vital information to the point of care whenever it is needed... It will shortly be upgraded to include patient accounts where privacy preferences can be set including willingness to be contacted about relevant research trials, producing, we hope, the most consent rich research environment in the world.”

JOE McDONALD, CONSULTANT PSYCHIATRIST AND DIRECTOR, NENC CHC

The CHC Hub continues to work with cloud services providers, such as Google Cloud and Amazon Web Services, to understand how TRE environments can be utilised in the cloud. This is in response to the longer-term gains, including providing auditable trails of utilisation and versioning, reduced costs for maintaining secure data environments, and access to the latest services and tools, such as for machine learning. Cloud-based services can also enable easier collaboration between research groups, improving transparency and management of data flows.



Professional Engagement, Training and Education

CHC INITIATED THE DEVELOPMENT OF A DIGITAL CAPABILITIES LEARNING PROGRAMME STARTING WITH THE IDENTIFIED PRIORITY TOPICS OF EVALUATION, INFORMATION GOVERNANCE AND HEALTH ECONOMICS.

The need to increase informatics knowledge and skills in the health and social care setting is well documented. In response, the programme worked to gain an understanding of the current challenges involved in implementing a learning health system, and to provide an appropriate training framework and solution to overcome these challenges.

“CHC enabled individuals and teams to adapt to new ways of working by co-designing practical training to support the LHS model & create a continuous learning environment.”

GEORGINA MOULTON, PROFESSOR OF BIOHEALTH INFORMATICS AND EDUCATION, THE UNIVERSITY OF MANCHESTER

A three-stage qualitative study was undertaken to identify learning and training needs that could be translated to others working in a learning health system.

This work was carried out in three stages:

1. Review of current practice to understand how best to provide sustainable digital solutions;
2. Identification of key training needs through conducting 25 interviews across eight case-studies; and
3. Design of a 10-step short workshop programme.

Specific areas were highlighted as being the most important for implementing a successful learning health system project:

- ◆ Health economics and how to evidence impact and return on investment;
- ◆ Development of robust, relevant and up-to-date data sets;
- ◆ Knowing how to navigate information governance;
- ◆ Understanding how to engage with the public, when to do it and how to ensure continued transparency;
- ◆ Data analysis and gaining both valuable and actionable insights from the data;
- ◆ Evaluation of work and how to set baselines;
- ◆ Achieving sustainability and adoption in a scalable way.

A 10-day learning programme for building digital capabilities was proposed as part of the qualitative study building on the themes identified.

Topic areas for a 10-day learning programme to build digital capabilities:

1. What does it take to get the data for care pathway improvement?
2. The highs and lows of Information Governance in gaining access to health data
3. The human element in building networks and maintaining involvement
4. A clinician's guide to establishing a robust data set
5. A health professional's guide to using data sets
6. From data to improvement: Deriving insights from your data
7. Evaluation Masterclass
8. Evaluation SOS
9. Communication for effective diffusion and dissemination of digital innovations
10. How to evidence economic and societal impact in healthcare systems

In Spring 2018, CHC initiated the development of this learning programme with design, development and delivery of the curriculum for Evaluation SOS, Evaluation masterclass, Information Governance, and Health Economics. This curriculum has been implemented in parts of the North of England and has also formed the basis of postgraduate level training schemes developed to facilitate the implementation of learning health systems across England and internationally.



Industry Partnerships

TWO CONSORTIA WERE KEY IN FORMING THE FOUNDATION OF ACTIVE NETWORKS, CONSULTATION AND COLLABORATION TO SUPPORT WEALTH GENERATION AND PARTNERSHIP WORKING.

The Pre-Competitive Collaborative Consortium (PCCC) and the Data Access Consortium (DAC) created the framework for teams to tackle mutual challenges including new developments in areas such as procurement, delivery, adoption and sustainability of data and technology solutions. By engaging with start-ups and small businesses in the North of England, CHC were able to support wealth generation and business growth.

“Red Ninja collaborated with PCCC as a founding member of their industry advisory board. We gained experience of how academia and the NHS approach open innovation and connected with some fine health researchers to explore how we can work together to create an impact for society. We found the PCCC to be a pioneering concept and ambitious in leveraging data for research and a pan Northern footprint representing a market of 15m citizens. A lot can be learnt to iterate on the next version of how we leverage city data sets to improve population health and drive economic growth.”

LEE OMAR, CEO, RED NINJA STUDIOS

THE PRE-COMPETITIVE COLLABORATIVE CONSORTIUM (PCCC)

A collaborative, cross-sector innovation space for health system, industry and academic partners was developed and trialled as part of the CHC programme: the Pre-Competitive Collaborative Consortium.

The CHC Hub used an open innovation model across the public and private sectors for the PCCC.



The PCCC reached a membership of 22 technology companies, ranging from micro SMEs to multi-nationals, working with clinicians, researchers and change specialists from academia and NHS partners across the CHC footprint.

A true partnership between industry, NHS and academia, the PCCC ecosystem served as a trusted space for knowledge sharing; solution development, providing mentorship, network development and idea creation. The CHC hub provided the members with hands-on, creative and focused workshops.

The PCCC prioritised two workstreams and tackled two key industry challenges to successful innovation.

- ◆ **Sustainability: Championing change and adoption of innovation**
Working with NHS and academic change champions to define and promote success factors that embed innovations within the NHS.
- ◆ **Transferability: Evidencing the benefits of innovation**
Working with early adopter sites to capture marketable metrics of value: a 'kite-mark' of trustworthiness.

A PCCC CASE STUDY – ORCHA

Building on the relationship and mutual objectives identified by working together in the PCCC, a spin-off collaboration was developed between ORCHA and the CHC hub. Based in the North-West of England, ORCHA have pioneered the evaluation of health apps, and worked with the CHC hub team to create a unique partnership to design a skills development and career development intervention for young people.

Working in collaboration with school children, workshops revealed what 11-18 year olds need to understand to consider a career in the health tech and data science space. Building upon this insight, ORCHA & CHC Hub co-produced the ‘#DataSavesLives Careers Zone’. This careers information service was embedded into ORCHA’s Digital Healthy Schools (DHS) online programme in the 19/20 academic year. This is a space for young people and their teachers to access a bespoke module of information, signposting, tools and real-life examples of the diverse roles available in the sector, bringing these to life with inspiring case studies and videos.

“As a small northern-based digital health company, it has been really valuable to work with the Connected Health Cities programme. Together we have been able to develop a tool to support our young people to navigate a career in digital health and data science.”

LIZ ASHALL-PAYNE, CEO/FOUNDER, ORCHA

“The CHC hub team’s drive to promote diversity in health technology and data science has also had a notable impact on ORCHA. The CHC hub’s recognition and inclusion of work underrepresented groups in digital and health technology is demonstrated by supporting and promoting ORCHA and its employees. These efforts have impacted on ORCHA’s productivity and enabled myself and other staff to develop networking links across sectors and regions.”

LISA SIMMONS, CLINICAL IMPLEMENTATION MANAGER, ORCHA

DATA ACCESS CONSORTIUM (DAC)

As part of the programme of work on providing access to routinely collected data, four Data Arks were created by CHC. These formed the foundation for developing the Trustworthy Research Environments, establishing the secure analytics platforms used for data driven innovation and improvement. A multi-stakeholder group, the Data Access Consortium (DAC), was then established in 2018 to discuss the standards for acceptability of using this data beyond the initial set of projects.

The DAC stakeholder group included representation from patients, information governance expertise, industry, researchers and NHS organisations as direct members and feedback on draft documentations were included from the wider community.

The group developed principles of common access rules while recognising that each region has bespoke needs.

These included:

- ◆ Definitions of acceptable research use and organisations,
- ◆ The legal basis for using health data in research and
- ◆ Codes of practice for health information exchange, Arks and research.

This overarching code of practice for CHC was agreed by all four regions as key guidance for the ongoing strategic development of the TREs and has been published and available to be used by other project teams who do similar work in the UK and globally. This formed the basis for the programme of work undertaken by CHC across the North of England and in collaborations formed with stakeholders and industry.



CASE STUDY INDUSTRY ENGAGEMENT AND IMPACT - AIMES

As part of the CHC programme, AIMES acted as a technology partner for the development of the Data Ark infrastructure (Trustworthy Research Environment, TRE), initially for the North West Coast AHSN region (Innovation Agency) but subsequently extended to two other regions.

“ The Connected Health Cities programme was probably the single most important stimulus to the development of TRE architecture and infrastructure here at AIMES. As a result of this development we are now supporting transformative digital healthcare developments here in the UK in areas such as oncology, cardiology and mental health”.

PROFESSOR DENNIS KEHOE, CEO, AIMES

AIMES is a cloud computing and data science company specialising in healthcare data and is a spin-out from the University of Liverpool. The technology developed as part of CHC has now been deployed by a number of universities, NHS Trusts and important new research programmes across England including HDR UK, Cancer Research UK and SBRI.

In total it is estimated the expansion of the technology across England has generated additional financial value (GVA) of around £3m at AIMES and led directly to the creation of around 10 new high technology jobs in Liverpool.



Scaling up Real Time Cystic Fibrosis Care

CF HEALTH HUB (CFHH) IS A DIGITAL LEARNING HEALTH SYSTEM CREATING THE RESEARCH EVIDENCE TO TRANSFORM CARE FOR PEOPLE WITH CYSTIC FIBROSIS (CF).

Cystic Fibrosis (CF) is a long-term condition which affects every level of society and which is caused by a genetic defect carried by 1 in 25 of the population. Self-care is important in all long-term conditions and is particularly challenging in multi-morbid conditions requiring multi-modality treatment such as CF. As a care pathway, service is primarily delivered by a relatively small number of units across the UK with a UK CF registry available of nearly all the people diagnosed with CF.

CASE STUDY: CFHH WORKING FOR SALLY

Sally was finding it difficult to keep track of her nebuliser intake. She often couldn't remember what she had taken on a given day and this meant that she sometimes missed treatment.

Sally was provided with access to CFHH which meant that she automatically tracked the use of her nebuliser. The data collected was stored on a secure system where analytics could be applied to the data. A dashboard for clinicians and an app for patients were also created to present the analysed data in a colour coded system.

Having real time nebuliser data available on her smartphone provided timely feedback on a co-produced platform allowing Sally to clearly see the progress she was making in adhering to her new routine and this made her feel more confident and reduced her stress levels.

Sally also noticed a change when discussing her treatment with the CF team. The data provided unbiased evidence of Sally's treatment adherence, allowing for focused discussions on barriers to adherence and a more personalised approach to treatments.

Patients using the CF Health Hub (CFHH) platform owned their own data and are invited to share anonymised data at centre and national level. Using the Trials within Cohorts (TWICS) online platform, patients also consent to be controls in future trials allowing behavioural interventions to be tested. This digital consent process speeds up the potential for future randomised controlled trials (RCTs). CFHH implemented an online system that automatically records medication adherence and self-care data from patients across the system.

CFHH worked closely with the CHC Hub team and benefited from CHC's expertise in digital learning health systems. This enabled the scale up of the service funded by a £2.4m NIHR programme grant*. This project also leveraged around £5m from NHS England in a 6-year programme (CQUIN) to achieve implementation across 60% of adult CF units within 3 months of completing the research trial.



Detailed data to monitor and support CF care was invisible.



Applying the principles developed by CHC and working with staff with roles within CHC and CFHH, more than 50% of adult UK's CF centres are receiving support through real time access and analysis of data.



With new research opportunities using real time data, care can be improved for people with CF who find it harder to seek support.

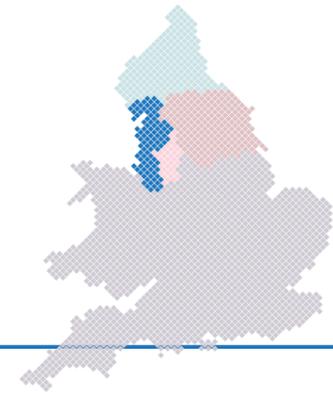
Preventative care for co-morbidities associated with CF will be in place with data driven intervention design and implementation.

CFHH maintains the real time online data service for use by clinicians and patients, and can now explore new research questions. 'Difficult to reach' populations require intensive and expensive self-care support, and CFHH will explore whether the increased investment required to reach these patients can improve care while reducing system costs. There is also the potential to design longer term preventative behavioural interventions such as for older CF patients who develop CF-related diabetes. CFHH can work with partners to explore how engaged patients can build new and maintain existing protective habits in the face of comorbidity.

* This work was funded by the National Institute of Health Research Programme grants for Applied Research [Grant Number RP/PG/1212/20015]. The views expressed regarding CFHH are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health and Social Care.



North West Coast Connected Health Cities



IN SUMMARY

- ◆ **Impacting on the care for people with Chronic Obstructive Pulmonary Disease (COPD):** New algorithms were developed to identify emergency admissions due to COPD. When compared with the national analysis, the NWC algorithm identified 58% more admissions for people with COPD currently being provided with NHS care.
- ◆ **Improving Services for Alcohol-Related Illness:** An extra 40% of cases of Alcohol-Related Liver Disease (ARLD) were detected when compared with standard approaches for capturing data on emergency admissions.
- ◆ **Epilepsy and Seizures Learning Health System:** The newly developed algorithms identified an extra 66% of epilepsy-related admissions when compared to just using the primary diagnosis code, now capturing more accurate average length of stay.
- ◆ **Professional engagement, training and education:** The NWC CHC team successfully developed and delivered new training modules and accredited courses and supported postgraduate level applied research studies in data science and data driven improvement.
- ◆ **Industry partnerships:** NWC CHC worked closely with small and large businesses, academia and healthcare professionals to deliver new programmes and develop partnerships.
- ◆ **Public involvement and engagement:** NWC CHC had an active public involvement and engagement senate. The role of the senate was to ensure that the patient voice is represented in the region's health improvement projects.

In this section

Impacting on Care for Chronic Obstructive Pulmonary Disease

Improving Services for Alcohol-Related Illness

Epilepsy and Seizures Learning Health System

Professional Engagement, Training and Education

Industry Partnerships

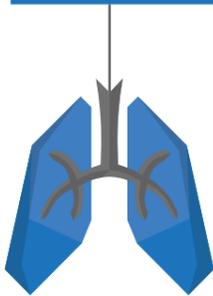
Public Involvement and Engagement

Safe and Trustworthy Use of Data



NWC CHC Director **Dr Liz Mear**

Impacting on Care for Chronic Obstructive Pulmonary Disease



New algorithms were developed to identify emergency admissions due to **CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)**. When compared with the national analysis, the NWC algorithm identified **58% more admissions for people with COPD** currently being provided with NHS care.

COPD is the second most common cause of an acute medical admission, and NICE guidelines suggest many of these cases could be prevented or managed outside hospital. COPD is slowly progressive and most admissions are from people who are breathless during mild or minimal exertion, 60 or older, and come from more deprived backgrounds.

NWC CHC identified the COPD patients from the Secondary Uses Service (SUS) dataset with a new algorithm that made use of more than just the primary diagnosis. This improved the detection of COPD admissions. The NWC CHC team then characterised the admissions, examined their prior and later history and mapped them to locate 'hotspots' of admissions. The algorithm identified a total of 52,389 emergency admissions due to COPD over 3 years across the 12 NWC trusts, compared to just 33,233 spells if only the first diagnosis code was considered. Therefore the algorithm identifies 19,156 additional COPD admissions (a 'missed' population of 58%). This missed population is more severe, older and from deprived areas, with three times higher hospital mortality and has much higher use of resources (e.g. 81% more bed days).

Planning based on the official statistics (which take into account some of the issues around coding of COPD admission), when the exclusion of these additional more severe patients are omitted, will significantly underestimate the impact of COPD and the staffing required to manage it.

Why we developed new algorithms to find more existing cases.

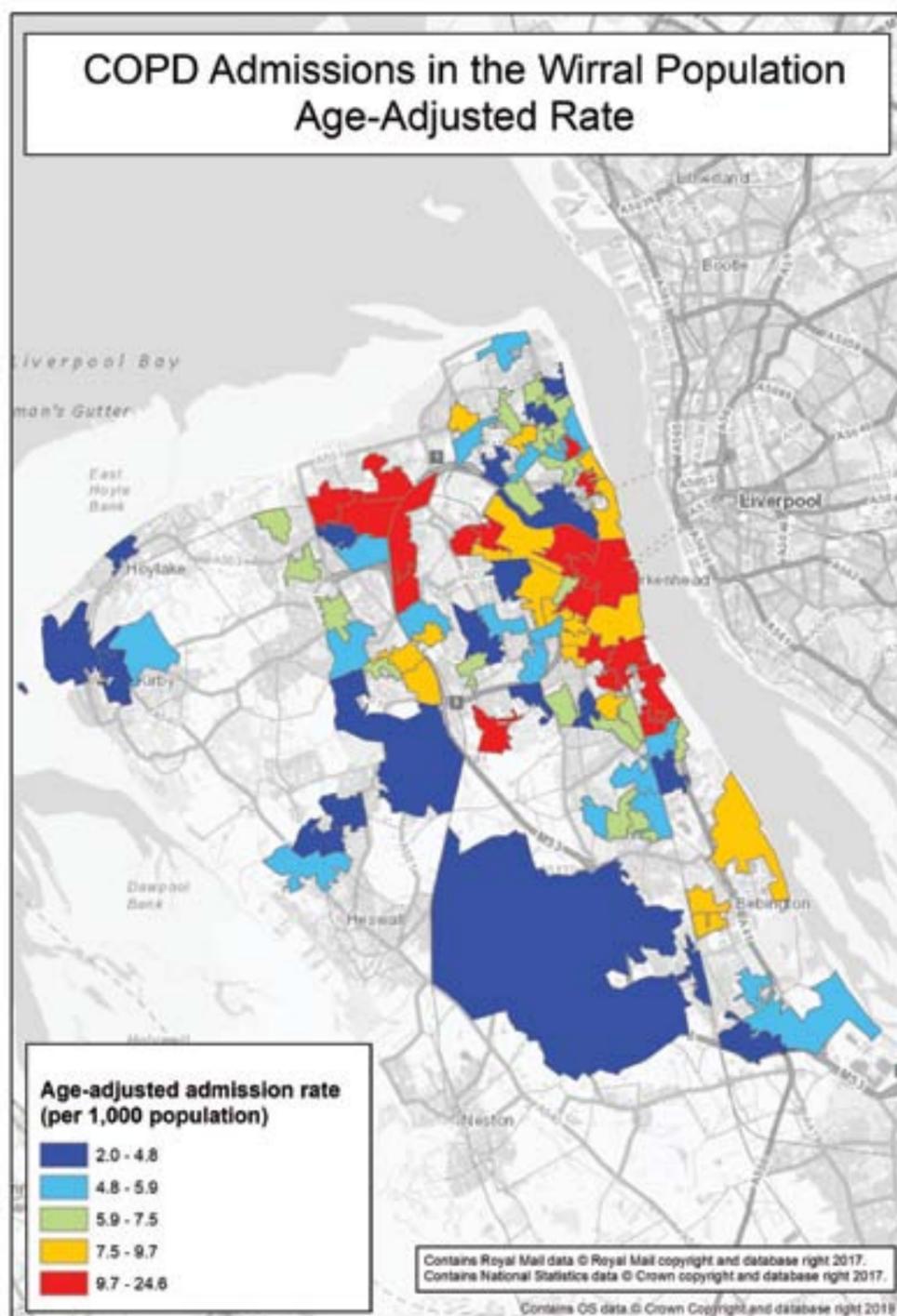
The North West Coast CHC project was concerned that many standard reports about clinical conditions were being disregarded by clinicians because the numbers within those reports did not match their clinical experience.

Most reports only use the first of many diagnostic codes recorded for each patient and so fail to take account of the additional information available.

In each of the disease areas, NWC CHC has developed algorithms using the wider information available to identify the cases that physicians can recognise, and in doing so, has found more cases, as well as cases with greater severity, which provides a very different assessment of workload and patient pathways.

As this is based on a clinical rather than just a statistical approach, the response from the clinical community to our reports has been uniformly favourable and we believe this offers a better way forward for future planning of, and assessing the effectiveness of, clinical care.

We describe the approach in three specific disease areas but the approach is taken equally applicable to many other areas within medicine.



“CHC enabled us to focus our efforts where they were needed. One of the actions we took as a result of the CHC data was to focus on GP practices and try to educate and upskill them on the management of COPD.”

DR PAUL MARSDEN, CONSULTANT IN RESPIRATORY MEDICINE, LANCASHIRE TEACHING HOSPITALS NHS FOUNDATION TRUST

Some of the applications from the COPD NWC CHC project outputs:

- ◆ Two CCGs in Central Lancashire have used the local area data to drive the early stages of their Elective Care Respiratory Quality Improvement Programme. This methodology enabled them to focus on the most challenged areas of their populations to improve the integrated care pathway for the biggest benefit at the lowest cost.
- ◆ As part of the wider local respiratory strategy, data and methodologies from NWC CHC were used to contribute to data sets made available to CCGs and respiratory teams across the Cheshire and Merseyside Network, informing resource allocation across the regions. A Physician Associate Scheme in the area was set up to review COPD patients more efficiently and get them 'winter-ready' as well as supporting hospital A&E departments in the colder months. The Learning Health System can evaluate the effectiveness of this approach.
- ◆ A COPD dashboard has been developed at Lancaster University so that healthcare professionals can access relevant information to improve service planning and delivery in their area.
- ◆ Government bodies intend to make use of these new algorithms in the future and the Innovation Agency has developed a respiratory theme and is incorporating outputs from the COPD Pathway developed by NWC CHC.

The image shows the COPD admissions in the Wirral population. This is adjusted for age and shown as per 1,000 population. A high admissions “hot spot” is shown in red, moving through to orange, green, light blue and with dark blue being the lowest rate.

Improving Services for Alcohol-Related Illness



An extra 40% of cases of **ALCOHOL-RELATED LIVER DISEASE (ARLD)** were detected when compared with standard approaches for capturing data on emergency admissions.

The North West region of England has one of the country's highest rates of alcohol-specific deaths. ARLD is the dominant cause. Early inpatient intervention has the potential to save lives, however reports show fewer than half of patients received 'good care' and mortality rates are high.

The detection of extra cases of ARLD resulted in improved knowledge of disease burden and better monitoring of inpatient and post-discharge outcomes.

There were four use cases for the alcohol pathway projects:

1. Development of a new experimental case mix-adjusted mortality measure using analysis from 3,887 admissions for ARLD, through working closely with the Advancing Quality Alliance (AQuA) ARLD Collaborative across seven hospitals. The new measure now informs analytics for service improvement.
2. Provision of hospitals with data reports for ARLD pathways in the first 90 days following an admission. Focusing on seven hospitals and covering a five year period, a benchmarking dashboard was created to compare activity levels for index admissions for ARLD, tracking pathways from admission through discharge and 90-day events, readmissions, A&E attendances and outpatient visits. The analytics were presented locally as benchmarking reports, comparing hospitals, and shared with hospital teams, gathering feedback to refine the content and methods. The teams were made aware of a 2-3-fold variation between hospitals in the proportion of patients attending an early hospital outpatient review following discharge from index admission with action being taken by the clinical teams to support service improvement.
3. Bespoke data outputs were developed with local clinicians in line with service priorities. One hospital team had undertaken retrospective case note reviews of all deaths from liver disease in response to an 'alert' on national metrics. Granular data confirmed case-mix differences from local trusts for that year. Whilst the hospital was an outlier using simple case-mix adjustment, the Trust team was provided with independent analysis showing that there was no significant signal of excess mortality when adjustments were made for additional clinical severity flags using the risk adjustment models.

4. Working with Hartree Data Science Centre, cohort identification and segmentation algorithms were transferred from test datasets into Liverpool CCG's data warehouse containing hospital, primary care and other data for routine service commissioning. This resulted in deployment into live systems containing richer datasets to exploit opportunities for near-real-time analytics to identify factors associated with readmission and to create models.

How the NWC CHC team worked

To improve the quality of care and identification of alcohol-related liver disease, the NWC CHC:

- ◆ Developed new algorithms and analytical tools to monitor outcomes of unplanned admissions and post-discharge events, identifying variation over time between hospitals and different localities.
- ◆ Mapped ARLD hotspots and services and linked these to use of emergency and other services generating new insights to help re-design pathways for alcohol patients.
- ◆ Worked closely with Advancing Quality Alliance (AQuA) to improve the reliability of clinical practice and to reduce variations in care for patients with alcohol-related liver disease.
- ◆ Moved from previously unavailable analytics to a live and ongoing QI programme, the experimental mortality metrics were added to our site-level benchmarking reports in 2019.

"...we linked, analysed and visualised data in ways that reflect the complexities of alcohol-related conditions and the wide variability in local service provision and organisation across the region – bringing local context to the interrogation of data."

DR KEITH BODGER, CLINICAL LEAD FOR ALCOHOL, NWC CHC

Epilepsy and Seizures Learning Health System



The NWC epilepsy pathway identified an extra **66%** of **EPILEPSY-RELATED ADMISSIONS** when compared to just using the primary diagnosis code, now capturing more accurate average length of stay.

Epilepsy and seizures are the most common neurological reason for emergency presentations at hospital. They account for 1.5% of emergency admissions, and a similar number are discharged from the emergency department without admission. Many seizure admissions are preventable and improvements in care are needed. NICE guidelines recommend that patients experiencing their first-ever seizure should be seen in a seizure clinic within two weeks but this is rarely the case.

What the NWC CHC team did:

- ◆ Developed a new algorithm to identify epilepsy-related seizure admissions, which went beyond the traditional approach of just using the primary diagnostic position. The NWC CHC used routinely collected hospital data to assess the impact of interventions such as the Walton Seizure Pathway and the Care After Presenting with Seizures (CAPS) Project and monitor the effect of these interventions on health inequalities.
- ◆ Geographical data was analysed to allow patterns of high admissions rates to be identified and fed back to CCGs within Cheshire and Merseyside; this led to the planning of community-based epilepsy clinics.
- ◆ Analysed routinely collected hospital data to identify unnecessary CT scans, highlighting inadequate coordination in care and leadership, wasted resources, and unnecessary exposure of patients to radiation.

CASE STUDY: NEW INVESTMENT WITH THE PED4PED PROJECT – PEOPLE WITH EPILEPSY SHARING DATA FOR CARE WITH PARAMEDICS AND THE EMERGENCY DEPARTMENT.

PED4PED connects patient information from GPs, hospitals and ambulance services in the North West Coast and makes it available to paramedics and A&E staff when they are called to epilepsy patients requiring urgent care.

It builds on the work by Connected Health Cities in the North West Coast, to transform health services by improving access to patient data.

Working together are the Innovation Agency, University of Liverpool, Liverpool Health Partners, North West Ambulance Service NHS Trust, The Walton Centre NHS Foundation Trust, Royal Liverpool and Broadgreen University Hospitals NHS Trust, Alder Hey Children's NHS Foundation Trust, Epilepsy Action and Forcare.

“By making additional information accessible for our ambulance clinicians, they will be able to make more informed decisions based on the patient's medical history. This means that if the patient could benefit more from care in the community, unnecessary A&E admissions can be avoided which in turn will free up vital emergency resources.”

MIKE JACKSON, CHIEF CONSULTANT PARAMEDIC,
NORTH WEST AMBULANCE SERVICE NHS TRUST

As a result of these activities, the NWC CHC achieved:

- ◆ Identification of an extra 66% of epilepsy-related admissions when compared to just using the primary diagnosis code. This cohort is more representative of the seizure population than those reported by other national groups, for instance, capturing a more accurate average length of stay.
- ◆ Analysis of data showed that since the instigation of the Walton Seizure Pathway, the odds of getting a neurology referral within 3 months of a seizure admission were increased by 28% for those already known to the service, and by 48% for those newly identified. A further increase in the odds was observed for hospitals where nurses were employed part-time to facilitate referrals (by 105% for newly identified cases).
- ◆ South Sefton CCG used geographical data relating to the source of epilepsy admissions to plan community-based epilepsy clinics, run in a local GP surgery by a Walton Centre neurologist.
- ◆ Adoption of the NWC CHC algorithm at a national level including by the National Neurology Advisory Group (NNAG), and the NHSE Epilepsy Specialist Commissioning Review.
- ◆ The GIRFT neurology group gained insights from the work undertaken by the NWC CHC team on using routine data to identify admissions and calculate referral rates, and now use the 3-month referral rate as a key metric on which to measure hospital performance.
- ◆ The epilepsy pathway work also led to the PED4PED project, funded by MRC/HDRUK, which aims to provide paramedics with access to epilepsy care records from secondary care in order to inform decisions about conveyance and immediate care.



Professional Engagement, Training and Education

THE NWC CHC TEAM SUCCESSFULLY DEVELOPED A RANGE OF EDUCATIONAL AND DEVELOPMENTAL OPPORTUNITIES LINKED TO CONNECTED HEALTH CITIES, BOTH FORMAL AND INFORMAL.

One of the key workstreams in the NWC was to support the development of a greater understanding of how data could be used to inform decisions within the workforce in health and social care. This was specifically focussed on enhancing the use of data, supporting the integration of digital health into service transformation and to develop a more advanced knowledge of data science. In collaboration with local organisations, the team successfully developed and delivered new training modules, four PhDs, accredited courses and a postgraduate level applied research studies in data science, as well as a number of informal learning opportunities.

How NWC CHC enhanced capacity in the region:

- ◆ Analysts at our infrastructure delivery partner, AIMEs, were developed and upskilled in their understanding of NHS data through their contact with the two universities and NWC CHC analysts.
- ◆ An NHS data analyst was seconded to the NWC CHC Data Laboratory at the University of Liverpool for the duration of the project.
- ◆ NHS Advancing Quality Alliance (AQuA) analysts worked closely with the data lab to understand how to evaluate their improvement work in alcohol using routinely collected data.
- ◆ Hartree Data Scientists worked with the NWC CHC Data Laboratory team in Liverpool to develop and deliver predictive models in health (ARLD) and build usable tools for front-line clinicians.
- ◆ Four PhD students studied applied research in data science and worked closely with NHS teams, and under supervision at Lancaster University.
- ◆ Clinical placements were developed for doctors to work with the data lab team at the University of Liverpool to learn how to apply data science techniques to analytics on care pathways.
- ◆ Training sessions from NWC CHC statisticians were delivered on several occasions at conferences and quarterly meetings to North West business informatics staff (attendance at each meeting was over 30 people).

“It’s opened my eyes a little bit to the different methods, analytical methods and technologies in terms of how you would analyse large routine data sets and what you can do with them...”

CHC EVALUATION PARTICIPANT

Training frameworks, training and accredited courses

- ◆ Working with the North West Skills Development Network, NWC CHC explored the skills and needs of analytics and informatics professionals in the NWC region and developed a Business Informatics Skills Framework (BISF). This framework was created to help healthcare informatics professionals develop and progress their careers.
- ◆ The Postgraduate Certificate in Professional Practice (Evidence-Based Commissioning) was created to provide accredited qualifications and delivered by Lancaster University’s Centre for Training and Development (CETAD). The year-long ‘Evidence Champions’ Programme was delivered to staff in a range of sectors and roles, including clinicians, data analysts, commissioners and quality leads from across the NWC. A number of staff attending the course went on to gain promotions as a result of their project work.
- ◆ A NWC CHC Intelligence Dissemination Survey was used to provide information on the nature of operational intelligence delivery and dissemination within health and care organisations. It also identified how NWC CHC can support staff working within those structures. These findings informed the direction for the tools being generated by the NWC CHC Data Laboratory Team. The NWC NIHR Applied Research Collaboration has now included a digital programme which will build on research themes developed in CHC.
- ◆ A six-month digital coaching programme was delivered by the Innovation Agency’s Coaching Academy to health and care professionals to enable better understanding and use of digital technologies in care delivery. The programme - ‘Using Data from Digital Technology to Improve Health’ - provided practical skills and tools for attendees who wanted to adopt and deploy digital technology for the benefit of their patients and clients. The programme was a mixture of action learning workshops, group coaching to support learning, reflection, resilience and personal growth.



Postgraduate Education

Four PhD students based at Lancaster University carried out applied research projects on clinical care pathways in the North West



Project 1.

Real-time mapping of COPD emergency admissions

Olatunji Johnson

- ◆ Investigated methods of data-linkage between HES and other relevant health data sources, for example, socio-demographic small-area indices, general practice prescribing patterns and weather station networks.
- ◆ Developed methods of visualising admissions data (socio-temporal analysis) to support decision-making at the point of care for COPD.
- ◆ Worked closely with a clinician at University Hospitals of Morecambe Bay NHS Foundation Trust and identified areas of high rate of presentation and characteristics of place and/or person that contribute to the risk of emergency COPD admission in this population.
- ◆ Developed a predictive statistical model using a combination of socio-economic and environmental variables to predict areas with likely high incidence of COPD emergency admission.



Project 2.

Understanding patient data coordination in alcohol care pathways

Nicola Platt

- ◆ Improved understanding of the multiple sources of data, how it is shared amongst the various teams throughout the patient's journey, and data coordination across the many health and social care interfaces within a pathway.
- ◆ Interviewed a range of care providers (including hospital and community workers), health information professionals (including IT specialists) and patients who manage and use patient data.
- ◆ Findings support the development of new approaches to ensure that healthcare professionals get the right information about the right patient in the right place at the right time.

“My knowledge has just improved and I feel more confident in talking to people who both process data and people, like patients, who have a stake in data...I'm enthusiastic in what we do.”

CHC EVALUATION PARTICIPANT



Project 3.

The role of data supported decision-making technology in respiratory care

Helena Tendedez

- ◆ Partnered with clinical staff and designed a new innovative system enabling clinicians to have a more meaningful view of clinical data on COPD patients through a dashboard.
- ◆ Designs were informed by research on the challenges of using data-driven support systems in practice, with a focus on a dashboard for COPD patients. The final design was for secondary care and community care staff, with emerging promising opportunities for primary care staff.
- ◆ The final dashboard has been released as a prototype with clinical teams exploring how to embed the system as part of daily working practice.



Project 4.

Consent and data permission management in health data infrastructures and systems

Victoria Neumann

- ◆ Explored designing secure systems for data sharing in relation to values of consent, such as privacy, trust, or patient/public attitudes.
- ◆ Areas of interest were the design of interoperable consent models and observing the development of the supporting technical frameworks in relation to specific biomedical research projects within NWC CHC.
- ◆ New insights were gained from research, industry and information governance perspectives through qualitative and quantitative research, closely aligned to topics such as trust, identity and privacy in future pervasive computing environments.
- ◆ Research supports the development of a set of design approaches, recommendations and develop tools to model and support consent for a variety of healthcare settings and systems.
- ◆ New research funding has been obtained through EPSRC funding in partnership with the University of Manchester to extend this theme at Lancaster University.



Industry Partnerships

NWC CHC WORKED CLOSELY WITH SMALL AND LARGE BUSINESSES, ACADEMIA AND HEALTHCARE PROFESSIONALS TO DELIVER NEW PROGRAMMES AND DEVELOP A REGIONAL ECOSYSTEM TO PROMOTE THE DEVELOPMENT OF PARTNERSHIPS.

Starting with a mapping exercise, key digital assets across a range of industry sectors in the North West were identified, to highlight availability of skillsets and activity in digital health innovation, data science and machine learning. Data from mapping informed the national AHSN Network Report Accelerating Artificial Intelligence in Health and Care. As well as allowing us to create an ecosystem of experts and innovators in data and AI, this allowed us to look at opportunities for partnerships and collaboration. It enabled us to review gaps in our skills and knowledge in industry to give us a greater insight into considering new opportunities.

NWC CHC worked closely with small and large businesses, academia and healthcare professionals to deliver new programmes and develop partnerships. A quarterly ECO system event to unite industry and the NHS was held throughout Cheshire, Merseyside, South Cumbria and Lancashire.

“... [we worked] on an organisational network basis, these sorts of things don't happen very much so it provided a basis for pulling Northern partners together which I think is really good.”

CHC EVALUATION PARTICIPANT

WORKING WITH INDUSTRY PARTNERS

Examples of joint working with local and national industry partners within CHC:

- ◆ AIMES was a partner in the CHC programme, providing the NWC infrastructure and went on to develop trusted research environments (TRES) throughout the UK. In addition, AIMES worked with Imosphere to support developing new techniques in data visualisation.
- ◆ The Hartree Centre Data Science team worked with NWC CHC Data Laboratory team at the University of Liverpool in developing a model of risk for emergency admissions for ARLD, to be embedded into clinical systems and used by clinicians.
- ◆ The Organisation for Reviews of Health Care Apps (ORCHA) worked with NWC CHC to develop the early stages of a patient consent app.
- ◆ Intelesant supported the pilot project of a consent app and provided the 'How Are You Today' COPD support app, which is used now across Lancashire.
- ◆ A jointly funded post with the Innovation Agency and Hartree continues to support the development of a digital cluster in the region.
- ◆ Building on the work of NWC CHC, Liverpool City Region has agreed to fund a multi-million pound Civic Data Trust, which will support the development of using health data to benefit patients, the public and local business.
- ◆ The Innovation Agency holds quarterly ECO events which aim to develop relationships between NHS, care and industry colleagues around specific themes. Several of these regular events focussed specifically on NWC CHC themes of alcohol, COPD, digital and workforce. A common element to all the ECO events is understanding and using data effectively to drive change.
- ◆ Two North West conferences were held at the Hilton Hotel and work on CHC was given a national showcase.

DEVELOPMENT OF A NORTH WEST COAST DIGITAL THINK-TANK

The Digital Think Tank was an example of a project bringing together healthcare professionals and industry partners to actively work through some of the barriers faced by healthcare practitioners who adopt data management innovations. This was led by the University of Cumbria working closely with the NWC CHC team at Lancaster University.

Activities included interviews with clinicians and structured dissemination sessions with industry partners and focus groups. Two workshops were held, firstly as an 'expert panel' with three companies and later as a larger workshop with six companies. Although healthcare professionals expressed a reluctance to share data for clinical purposes (due to data confidentiality and security concerns), they recognised that this was impacting on clinical care and were keen to engage with technology partners to improve the systems.

The Digital Think Tank developed formal processes and guidelines to enable improved engagement between industry, academia and health service organisations and processes for the efficient auditing, testing and assessing of new innovations and tools. Common standards were identified to simplify technical and cross-organisational interoperability. These guidelines and reports have been published for use across NHS and stakeholder organisations.



Public Involvement and Engagement

NWC CHC HAD AN ACTIVE PUBLIC INVOLVEMENT AND ENGAGEMENT SENATE. THE ROLE OF THE SENATE WAS TO ENSURE THAT THE PATIENT VOICE IS REPRESENTED IN THE REGION'S HEALTH IMPROVEMENT PROJECTS.

Stimulating debate with the wider public regarding consent and use of data, the NWC CHC team supported the completion of three main projects including a patient and public survey, co-development of voting polls and an app working closely with the Senate led by patients and citizens.

“Working with patients and members of the community has ensured that their voices were listened to at every step during the CHC process. The project started with the patient and public voice from the outset which is quite rare in most projects so our outcomes are a true reflection of what patients and the public think about data sharing and the wireframe app shows how patients and public members can have a real and practical input.”

DEBBIE PARKINSON, PATIENT AND PUBLIC INVOLVEMENT LEAD, NWC CHC

“By my data being shared electronically and in a more innovative way, this could turn hours into seconds, to get me the right treatment faster and uphold tighter confidentiality about my health.”

KENNY LAWLER, MEMBER OF THE PATIENT INVOLVEMENT AND ENGAGEMENT SENATE

PATIENT AND PUBLIC SURVEY

An online survey was developed focussing on gaining insights from citizens in the North of England and gained traction across the country through social media. Insights were acquired into how and what data patients would be prepared to share. Patients and members of the NWC Senate were asked what questions they would want to be asked in order to consent to share their data. The questions, written by the Senate, formed the basis of the survey and informed the production of an app for consent to share healthcare data.

The survey was used when engaging with patients and citizens at hospital clinics, GP surgeries, Breathe Easy groups and more public events such as iLinks Innovation Conference, NHS Expo and shopping centres. The survey took place over 3 months in 2018.

SOME OF THE FINDINGS FROM THE SURVEY

79% of those questioned had registered for access to their electronic records at their GP surgery, but of these, only 21% had used it and reported that it was simpler to order their prescription in the surgery or to ring for appointments. On explaining that both of these could be done online saving the constant redialling when trying to book an appointment, most said they would try and use it in the future.

There were differences observed between the views of patients with long-term health conditions and those of members of the public not currently accessing healthcare.

82% of those asked said they would readily share their healthcare record for research but would prefer to remain anonymous with only 18% refusing to consent to share their data. When asked if they would agree to be identified in research, this figure dropped to 70% agreeing to share their data.

When asked if they would share their data with commercial companies including dentists and opticians, only 61% said they would consent to share their data. When it was explained that companies may include professionals such as dentists prescribing antibiotics, most of the respondents changed their minds but stipulated that they did not want insurance companies or the police to have access to their data.

VOTING POLLS AT LARGE EVENTS

Coloured counters were used in events and conferences for 'Happy to share my data', 'Would not want to share my data' and 'Not sure if I want to share my data'. The voting polls were used in 21 events including universities, festivals, shopping centres, iLinks conference, NHS Expo, Blue Dot Festival, Innovation Agency events, as well as local health melas.

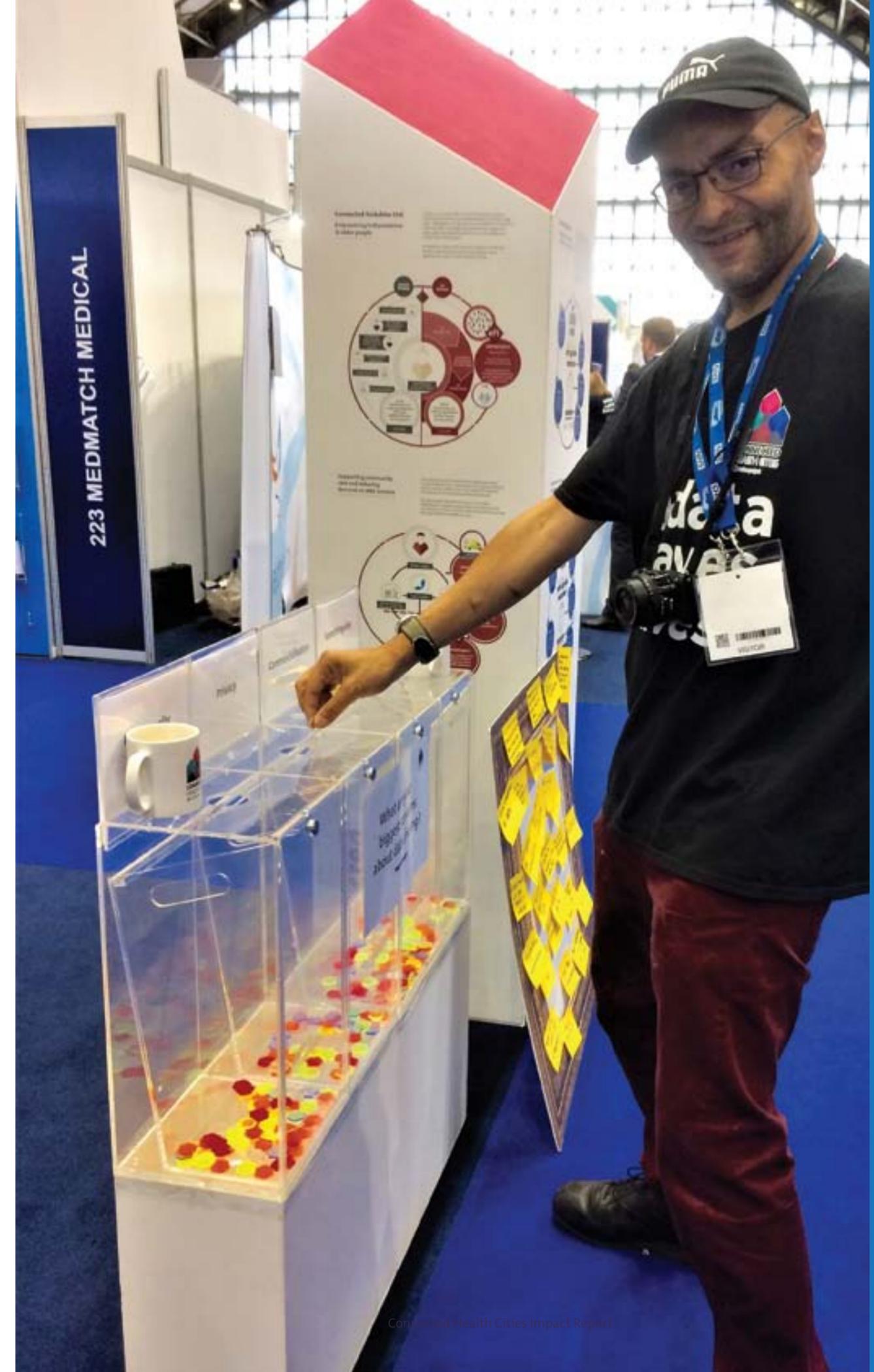
Based on the voting polls, 92% were willing to share their data, a higher proportion of people as compared with the online survey. It is important to note that there were discussions at the voting polls (before voting) on the use cases for shared data and the potential value as part of improving own and wider population health. This is aligned with the general CHC finding that it is imperative to hold conversations on what they are consenting to with both patients with long term conditions and members of the public.

DEVELOPING AN APP-BASED CONSENT TOOL

The Senate worked closely with ORCHA, an industry partner, and co-produced a wireframe, or 'wizard', for an app as part of gaining consent to share healthcare data for research and other uses. This is essentially a set of carefully curated questions with a guide on how it is presented (the wireframe) in any digital app used in healthcare which requires consent. Patients and members of the public will be able to easily complete the consent process by selecting the data they would like to share, how to share it and can also select or decline the companies with whom they wish to share their health data.

A series of workshops, meetings and working sessions were held with participation from the patients, citizens, healthcare professionals and stakeholders such as NHS Digital. The development phases and review points included the wireframes, early stage prototypes and trial versions.

Following successful completion of the project, the wizard has been adopted as part of the consent process for two regional projects with a view to further roll-out in the region. The Local Health and Care Record Exemplars (LHCRE) Programme, Share2Care in the North West Coast, is using this wireframe to trial consent in two areas including tele-dermatology and breast cancer post-operative patients. The Senate also contributed to early stage feedback on the NHS App. The wireframe is free for app companies and others to use as they work with researchers to gain consent for their projects.



Safe and Trustworthy Use of Data

NORTH WEST COAST CHC DELIVERED A RANGE OF SPECIALIST TECHNICAL OUTPUTS FOR THE PROGRAMME ACROSS TRUSTWORTHY DATA ENVIRONMENTS AND INFORMATION GOVERNANCE.

- ◇ Rolled out a data safeguarding implementation plan, with the CHC Hub, with approval from NHS Digital.
- ◇ Worked with our patient Senate to draft privacy agreements which were shared publicly.
- ◇ All researchers were required to pass MRC and NHS IG training.
- ◇ AIMES, an industry partner, has been named as the first data centre in Europe to be awarded with the new Data Centre Alliance certification. The AIMES research environment is recognised as highly secure with ISO27001 certification, accreditation as an NHS aggregator and externally audited as compliant with the UK Cyber Essentials scheme.
- ◇ Processes for routinely managing data quality and anonymising data have been developed with the local Data Services for Commissioners Regional Offices (DSCRO).

INFORMATION GOVERNANCE

IG and Security

Agreed Information Governance Templates for CHC member organisations	◇
Data centres have appropriate security certification, e.g. ISO27001, NHS IG Toolkit, CyberEssentials	◇
Data are encrypted	◇

Implementation

Public and Patient Involvement strategy	◇
Use of research output in routine care	■
Use of research output in commissioning and planning	◇
App development and roll out	◇

TRUSTWORTHY RESEARCH ENVIRONMENTS

Data Management

Secure analytics tools and platform	◇
Anonymisation processes	◇
Secure audit of data use	◇
Statistical disclosure control processes for data release	◇

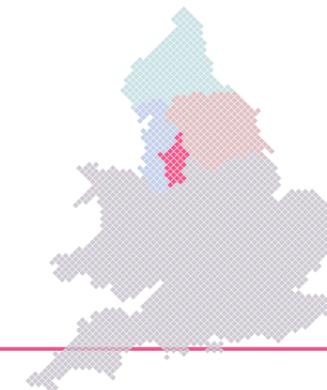
Data Availability

Hospital Episode Statistics/Secondary Uses Service	◇
Primary Care research data, eg. CPRD	◇
Primary (local) data sources, e.g. GPs, 2 ^o , 3 ^o services	◇
Real time data services	◇
Data quality processes	◇

Key

■	◇	◇
Not project priority	In current scope and achieved	In scope and reproducible/shareable

Greater Manchester Connected Health Cities



IN SUMMARY

- ◆ A Learning Health System for Stroke:
 - ◇ Whilst using the ABC care bundle for Patients with Intracerebral (brain) Haemorrhage (ICH), one Hyper Acute Stroke Unit observed a reduction of around 22% in the number of patient deaths within 30 days.
 - ◇ The Pre-Hospital Pathway Aid (PHPA) app resulted in ambulance staff being able to take decisions within seconds on the most appropriate and the nearest specialist care team for patients with suspected stroke.
- ◆ Building Rapid Interventions for Anti-Microbial Resistance: Over 30 million patient-level data and 20 million consultations from over 400 General Practices in England are used to reduce national and local burden of antimicrobial resistance (AMR).
- ◆ Pathfinder projects on Wound Care and Opioids: Pathfinder projects were early stage idea testing projects in wound care and opioids aimed at informing the next stages of development.
- ◆ Professional engagement, training and education: Education and training and increasing capabilities and capacity in big data and applications in health and care were focus areas for GM CHC.
- ◆ Industry partnerships: GM CHC has worked proactively with large industry and SMEs to accelerate business growth in the digital health sector for the benefit of the North of England.
- ◆ Public involvement and engagement: GM CHC have contributed to the development of public trust in the use of sharing health data for research purposes.

In this section

A Learning Health System for Stroke

Building Rapid Interventions
for Anti-Microbial Resistance

Pathfinder Projects on Wound Care and Opioids

Professional Engagement, Training
and Education

Industry Partnerships

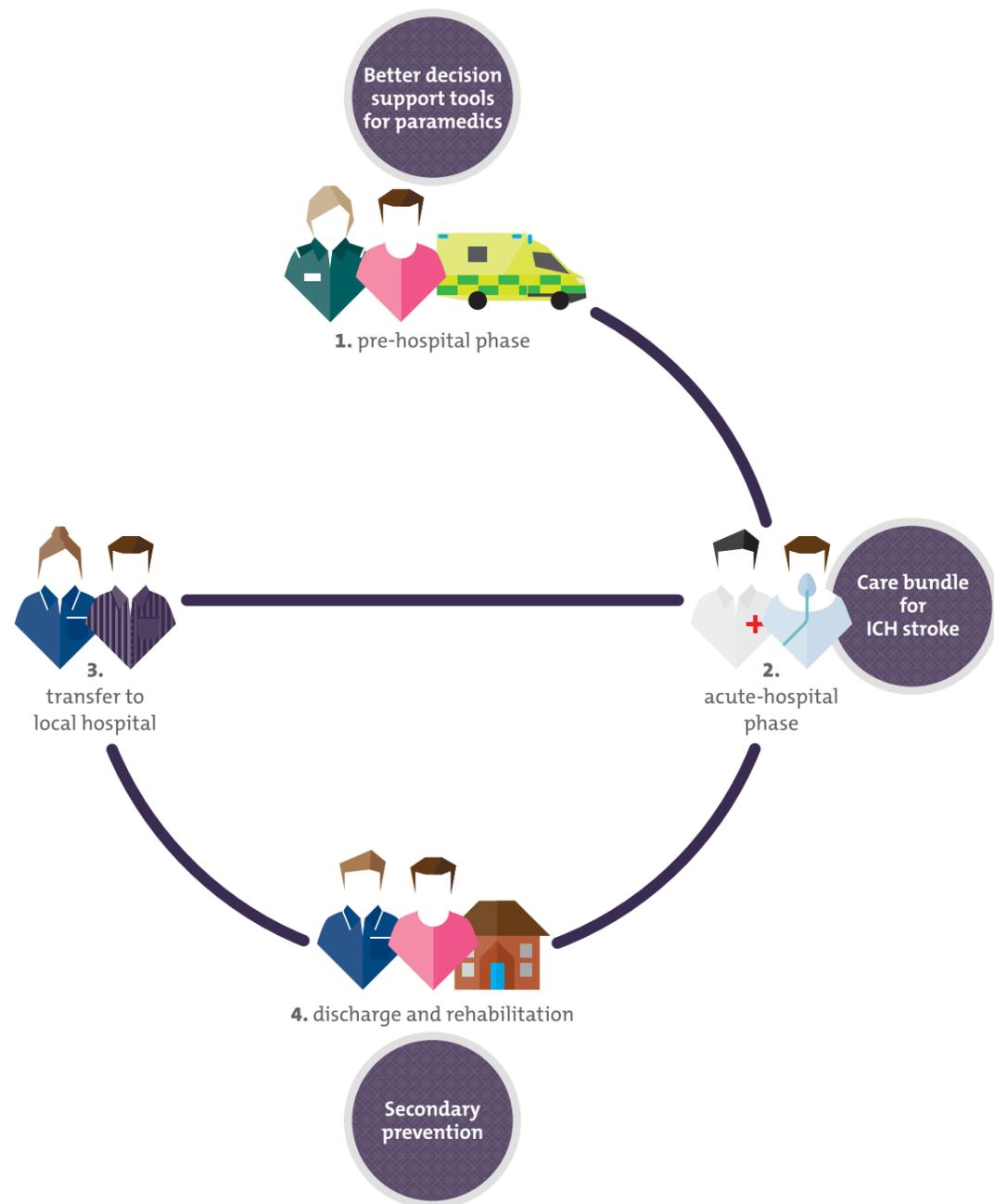
Public Involvement and Engagement

Safe and Trustworthy Use of Data



GM CHC Director **Professor Niels Peek**

A Learning Health System for Stroke



Part A • ABC - ICH Care Bundle

Whilst using the ABC care bundle for **PATIENTS WITH INTRACEREBRAL (BRAIN) HAEMORRHAGE (ICH)**, one Hyper Acute Stroke Unit observed a reduction of around 22% in the number of patient deaths within 30 days.



In order to help improve the care for patients who suffer the most serious type of stroke, caused by an Intracerebral (brain) haemorrhage (ICH), the ABC care bundle was developed in 2015-16 at Salford Royal Hospital NHS Foundation Trust. When the care bundle (ABC-ICH) was introduced to Salford Royal NHS Foundation Trust, one of the three Hyper Acute Stroke Units (HASUs) in Greater Manchester, the number of patients dying within 30 days was reduced by 35% in 2015 and 2016, an average of two lives saved per month.

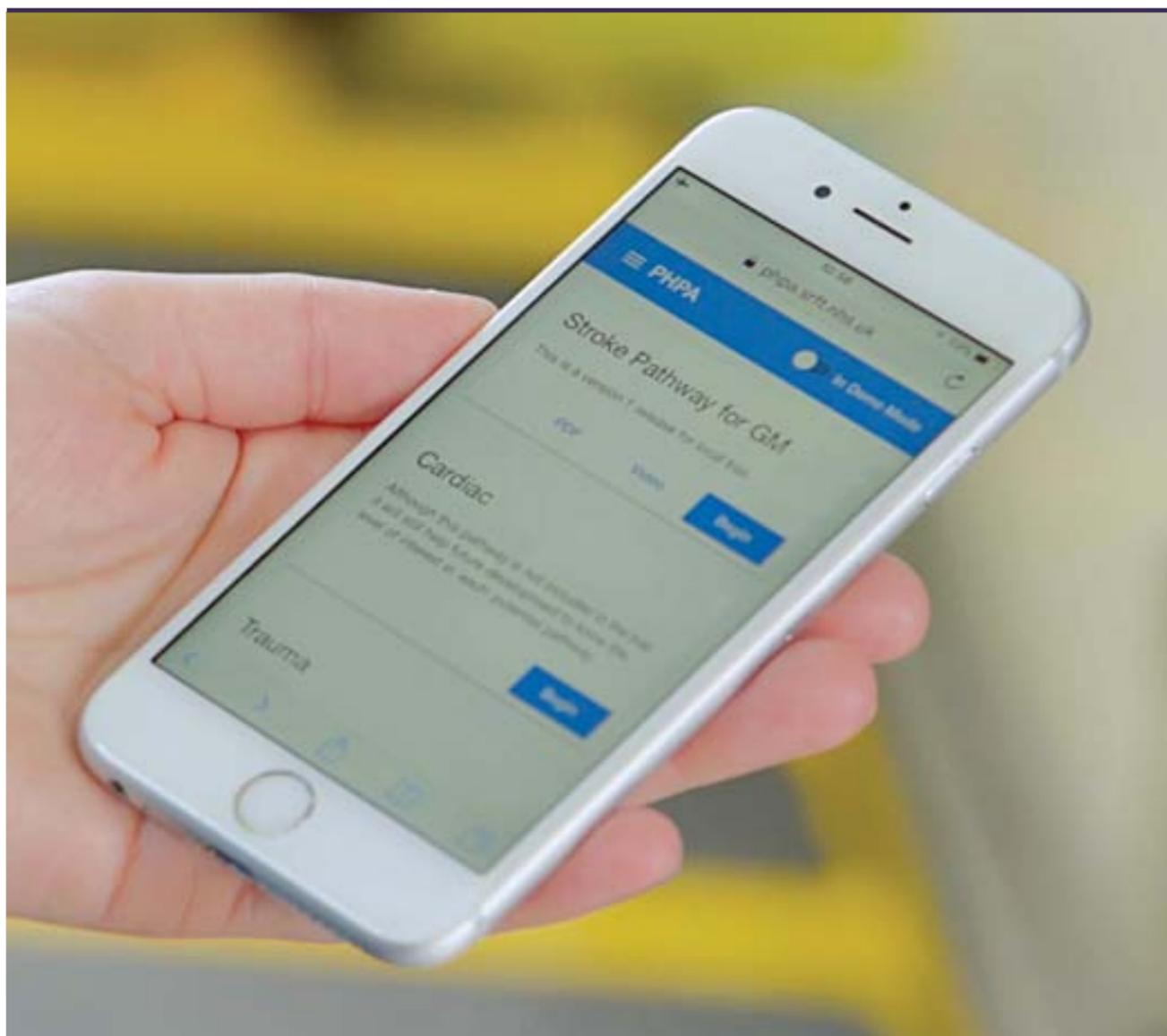
Through GM CHC, the ABC-ICH care bundle was also introduced into two other HASUs in Greater Manchester from April 2017 onwards and an easy-to-use app and supporting dashboard was developed. During the initial implementation phase, one HASU reduced the number of patient deaths within 30 days by around 22%. The HASU team also demonstrated marked improvements in the care process including a reduction in door-to-needle time for initiating treatment (anticoagulant reversal) by nearly half (from 134 minutes to 72 minutes). As a result of this workstream, a second version of the ABC-ICH app is being developed for scale up across the North of England including Newcastle, Middlesbrough, Hull, Sheffield, Liverpool, Preston with the support of the Academic Health Science Networks.

The ABC bundle consists of:

- ◆ 'A' – Rapid reversal of Anticoagulation;
- ◆ 'B' – Optimal delivery of intensive Blood Pressure lowering and;
- ◆ 'C' – Care pathway to ensure consistent and timely access to neurosurgery.

SCALING UP FOR IMPACT

- ◆ The care of ICH patients were monitored before the bundle was introduced and afterwards to compare the impact that it had on patient care and outcomes.
- ◆ The app was piloted at one of the HASUs with key staff being interviewed and observations carried out to find out how well the app was being received and used in the HASU setting.
- ◆ There were some clear benefits to patients from using the bundle in ICH care, such as less time taken for patients to receive the care and medication they needed and better management of patients' blood pressure.
- ◆ The user-centred factors of using a digital platform via a mobile app were also impacting on use of a digital platform through an app were also observed prior to designing the implementation programme.



“As ambulance clinicians working in a really busy ambulance, it is clear that we will often cross boundaries and areas that we don’t perhaps fully understand and work in very often, and that can be a real challenge, knowing what is right for patients, knowing the right destination... this app supports our clinicians to know where to take the patient.”

“... with the app, I can put a few clicks in and it will tell me where the patient needs to go to for the right stroke treatment... I had a gentleman who was false-positive [mimics] and I wanted to know where to take him.. and the app told me the nearest location which was not where I would have originally taken him.”

COMMENTS FROM USERS OF THE PHPA APP

Part B • Improving the pre-hospital recognition of strokes

The Pre-Hospital Pathway Aid (PHPA) app resulted in ambulance staff being able to **take decisions within seconds** on the most appropriate and the nearest specialist care team for **PATIENTS WITH SUSPECTED STROKE**.



Across Greater Manchester three specialist centres, known as Hyper Acute Stroke Units (HASUs), provide expert and urgent care for people who have a stroke or are suspected of having a stroke. The Greater Manchester Stroke Operational Delivery Network (GMSODN) found in 2015 that around half of suspected stroke patients taken to the HASUs turned out not to have strokes. Patients who present stroke-like symptoms could be experiencing seizures, sepsis, or migraines that can be confused with a stroke and these are sometimes called ‘stroke mimics’. The mimics workstream was developed to reduce the number of stroke mimics being transferred to HASUs, allowing HASU clinicians to focus on delivering specialist stroke care whilst also ensuring that patients with other conditions can receive care more quickly at the nearest Emergency Department.

Working with the GMSODN, the Collaboration for Leadership in Applied Health Research and Care Greater Manchester (CLAHRC GM), D2Digital and the North West Ambulance Service (NWAS), the GM CHC stroke team extracted data from a large, linked dataset of pre-hospital and hospital data for patients on the acute stroke pathway and identified how many false positive (mimics) and false negatives (missed strokes) were occurring within Greater Manchester. The Pre-Hospital Pathway Aid (PHPA) app was then developed to aid stroke recognition. The app follows the standard Face Arm Speech (FAST) assessment and the exclusion conditions as a flowchart in a user-friendly digital format.

The ambulance staff, who work across organisations with different stroke pathway protocols and procedures, are now supported in real time to identify the most appropriate and nearest location for treatment. During the pilot, around 43% of interactions with the PHPA app resulted in correct identification of a negative FAST test (mimics) within seconds followed by appropriate transfer to the emergency department and avoiding the HASU. The PHPA app is now being used across the NWAS service in Greater Manchester with additional use cases identified for the linked dataset developed as part of this project.

Building Rapid Interventions for Anti-Microbial Resistance



Over 30 million patient-level data and 20 million consultations from over 400 General Practices in England are used to reduce national and local burden of **ANTIMICROBIAL RESISTANCE (AMR)**.

Building Rapid Interventions to reduce antimicrobial resistance and over-prescribing of antibiotics: (BRIT). To complement NHS Antibiotic Medicines Optimisation strategies, the BRIT project has generated novel insights into the use of antibiotics within the primary care landscape in the UK. A national DataLab has been established, containing more than 30 million patient-level records for the treatment of common infections in primary care. These data contain information on the consultation, the antibiotic prescriptions and are linked to hospital admission outcomes. A national antibiotic dashboard has been launched where information from over 20 million consultations has been analysed and made available in the form of a new digital dashboard, providing policy makers with access to detailed results of patient-level outcomes.

For General Practices, BRIT has uniquely combined detailed analytics of very large national datasets (including anonymised data > 10 million patients) with deep analyses of the local practice data. This provides clinical teams with access to anonymised patient-level data that are analysed fortnightly with practice-specific results fed back to improve clinical outcomes in their practice. BRIT has been established in almost 100 general practices with the required secure IT infrastructure for data processing and practice-specific feedback to support clinical decision-making.

“When you hear about the other studies, you can see that they [CHC] are really making a difference during the lifetime of the projects rather than afterwards.”

CHC EVALUATION PARTICIPANT

Why reduce antimicrobial resistance?

- ◆ Around 32.5 million antibiotics are prescribed in England each year and antibiotic resistant infection costs the NHS £180m per year.
- ◆ Research has found that the current use of antibiotics is highly variable across the NHS, resulting in the ineffective targeting of patients who are a high risk of infection-related complications and emergency hospital admission. This has not improved within the past fifteen years.
- ◆ Majority of hot spots with high rates of antibiotic prescribing are located in the North of England and were also typically more deprived than their ‘cold spot’ counterparts, specifically when factors such as income, employment, education, crime and health were taken into account.
- ◆ Patients with frequent prior antibiotic use are more likely to suffer infection-related hospital admissions compared to those with limited prior antibiotic use. Suggesting repeated courses of antibiotics may have limited benefit and point toward adverse outcomes.

Starting in Autumn 2016, GM CHC in collaboration with the NHS and Public Health (North of England) designed a project to tackle variation and deliver advanced analytics to support the implementation of NHS antibiotic medicine optimisation strategies. New data driven insights into antibiotic prescribing patterns were published as part of the project such as prescribing non-opioid painkillers and benzodiazepines being strong indicators of the level of antibiotic prescribing within general practices.

The BRIT infrastructure allows close to real time analyses and feedback of the effectiveness of quality improvement activities in each practice. With these in place, the team have established several successful collaborations with

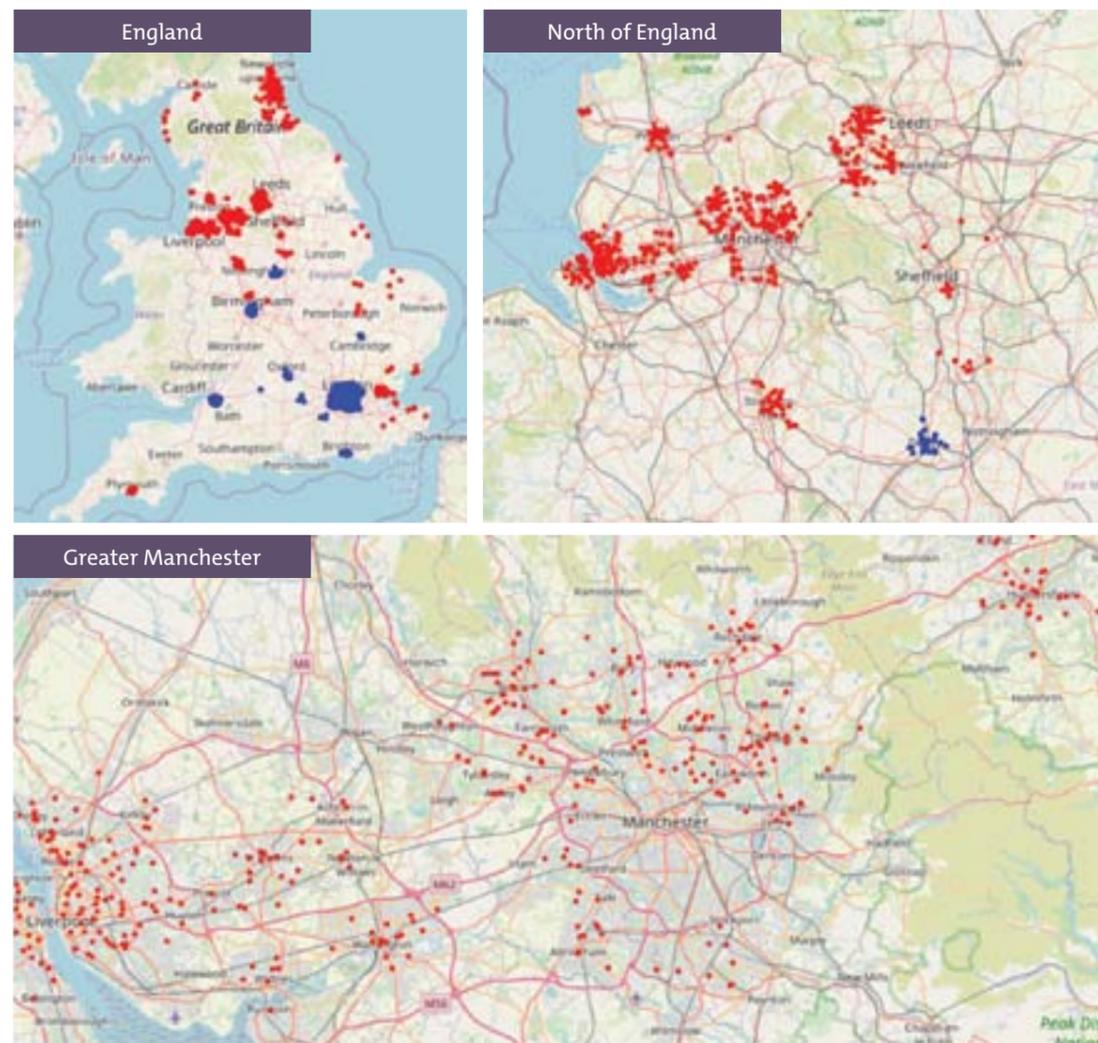
- ◆ First Databank to implement a decision support system,
- ◆ Imosphere to offer their advanced user-friendly data analytics software to NHS users,
- ◆ Apollo who deliver practice data securely into the TREs,
- ◆ NICE DataLab to show how the application of advanced healthcare analytics can help demonstrate effectiveness of interventions to improve health outcomes with guidelines.

Building Rapid Interventions for Anti-Microbial Resistance

NATIONAL ANTIBIOTIC PRESCRIBING DASHBOARD

The GM CHC team have developed a [National Antibiotic Prescribing Dashboard](#) which allows a range of health stakeholders, including policy makers, to better understand the factors that influence the UK's antibiotic prescribing profile.

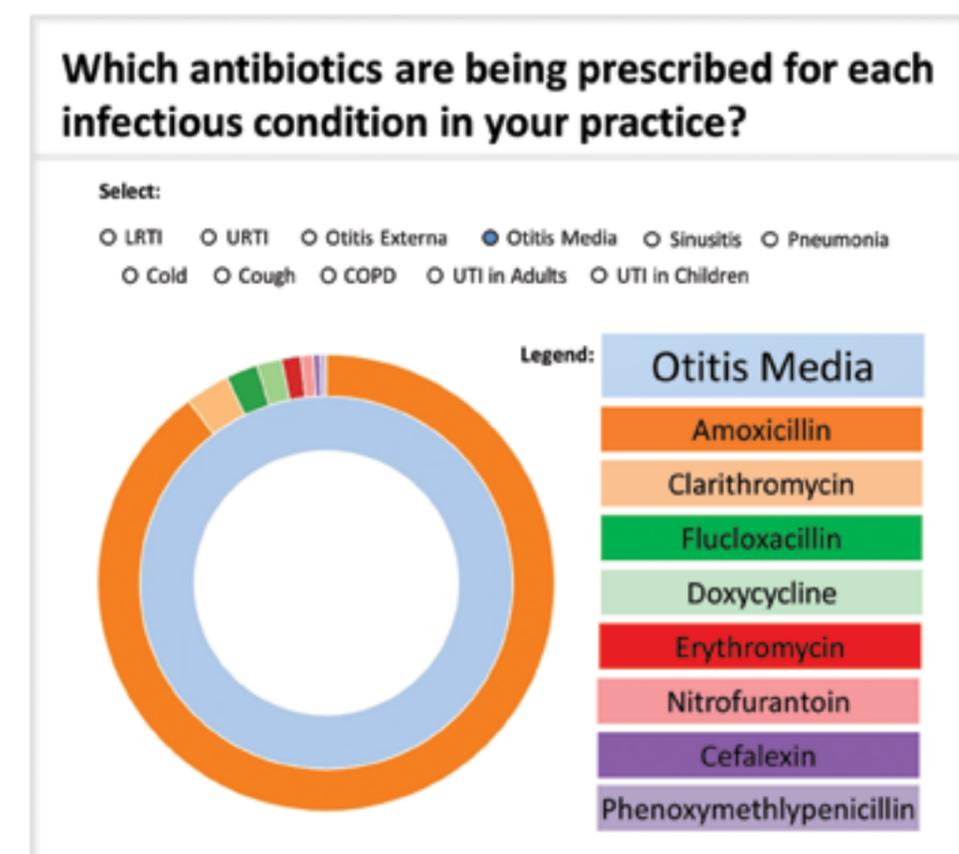
The dashboard is being used nationally in the UK and internationally, with users logging on from North America, Brazil, Australia, India, The Philippines, Japan and countries within the European Union to view the standards being set in England.



The analysis of all English practices shows that hot spots of antibiotic prescribing occur predominantly in the North and East of England, while a large cluster of cold spots occur in London. Available at www.britanalytics.uk/research

GP ANTIBIOTIC PRESCRIBING DASHBOARD

The GP dashboard uses anonymised health data to allow healthcare professionals in General Practice to compare their own antibiotic prescribing patterns with national and regional figures. Health care practitioners are also able to identify patients considered to be at high-risk of developing infection related complications, helping decisions on whether or not an antibiotic prescription is needed. Users get actionable insights into their practice based on advanced analytics, which summarise their own practice results and can be adapted to include further data analyses on request.



This sunburst plot is like a pie chart which can be filtered to see what antibiotic prescriptions were issued for each infectious condition. The outer ring indicates how frequently each antibiotic was prescribed (%) for that condition. Data is a summation of all cases prescribed an antibiotic in the last 12 months.

Pathfinder Projects on Wound Care and Opioids



PATHFINDER PROJECTS were early stage idea testing projects in wound care and opioids aimed at **informing the next stages of development.**

Two of these projects were carried out by the GM CHC team, on focussing digital technologies in the community as part of wound care for ulcers, and comparative risk of respiratory depression in patients treated with opioids for non-cancer pain.

1) Wound care in community nursing

Patients with venous leg ulcers and pressure ulcers often experience long healing times and numerous interactions with healthcare services before their condition improves. The care for these patients takes place in the community and support was given by GM CHC to explore the use of digital technologies for wound care in the community.

Research was conducted to assess the implementation of a 3D camera in the community for capturing wound images and recording the data into the electronic patient record.

The study showed that there were still a number of technical barriers in the community including integration issues between the camera software and the electronic patient record system and difficulties with internet connectivity whilst in patients' homes and the community.

Practical issues included the extent to which available lighting affected the quality of the photographs and therefore usefulness of the image for clinical care.

A consortium is using the insights from the research study to inform future innovation spread and adoption plan as part of supporting digital technologies in the community.

“...[CHC] has allowed us to explore the possibilities more freely than what we would have been able to do.”

CHC EVALUATION PARTICIPANT

2) Opioids

The most serious opioid-related adverse event is respiratory depression, which is potentially fatal. Assessing the comparative risk of respiratory depression in patients treated with opioids for non-cancer pain can support improved care pathways and ultimately contribute to reduction of unintentional overdoses.

- ◆ In the UK, opioid-related deaths have been increasing over the last few decades, it is of particular concern that the majority of deaths are unintentional. Opioids are also associated with serious side effects, the most serious being respiratory depression that usually precedes death.
- ◆ Respiratory depression is not captured in primary care records and often not coded in electronic patient records (EPR), therefore minimal data exist regarding comparative safety.
- ◆ GM CHC worked with Salford Royal Foundation Trust (SRFT), a Global Digital Exemplar site to measure Opioid 'exposure' using electronic prescribing data, with accurate information on not just if an opioid was prescribed by the physician but whether it was administered to the patient.
- ◆ A standardised governance process for accessing data from EHRs was established.
- ◆ Data on 33,341 opioid users admitted to hospital between 2014-2017 were accessed, analysed with extension of existing methods for processing medication data from EPRs, and examined for medication safety outcomes.
- ◆ The study showed that electronic vital signs that are measured in every patient as part of routine clinical care can be used to measure respiratory depression whilst on an opioid. Additional information collected in the EPR such as assessment of the patient's pre-hospital status, allowed better control for confounding by indication, giving a clearer picture of causal associations.



Professional Engagement, Training and Education

EDUCATION AND TRAINING AND INCREASING CAPABILITIES AND CAPACITY IN BIG DATA AND APPLICATIONS IN HEALTH AND CARE WERE FOCUS AREAS FOR GM CHC.

“...I’m learning about what’s possible, making connections with people whom I would not have had interactions with.”

CHC EVALUATION PARTICIPANT

Four applied doctoral research projects were initiated in 2017/18 supporting the clinical care pathways as well as the infrastructure required to increase access to health care data.

Two examples of applied research projects

1. Commercial organisations accessing health data for research purposes

- ◆ Given public concern about commercial organisations accessing health data for research purposes, there is a need to convey what patients, public and citizens would expect as part of rules for data access.
- ◆ This research builds on the safeguards devised by citizens’ juries and uses the existing research literature to identify what are acceptable and unacceptable options for citizens. Focus groups were held to find out which options for commercial access to health data in the UK are preferable.
- ◆ Future outputs will include the development of a social licence for commercial organisations accessing health data for research. Social licences outline the expectations of society regarding the conduct and activities of companies and organisations that go beyond the requirements of formal regulation. The recommendations can then be used in future projects where public and private organisations share health data for research purposes.

2. Dynamic prediction modelling in a learning health system

- ◆ Clinical prediction models (CPMs) are used to predict future outcomes for individuals, and thus have the potential to be used for effective targeting of resource.
- ◆ This project is developing methods within the dynamic modelling framework to help better predict patient outcomes and risks within healthcare.
- ◆ Starting with systematic review of dynamic prediction models will obtain an understanding of the current methods, different approaches will then be used to develop a prediction model for 30-day mortality following coronary heart disease intervention and compared to a current CPM used in clinical practice.
- ◆ Future outputs will include new methods to address some of the challenges with dynamic prediction models with potential impact illustrated through simulation studies.



Industry Partnerships

GM CHC WORKED PROACTIVELY WITH LARGE INDUSTRY AND SMES TO ACCELERATE BUSINESS GROWTH IN THE DIGITAL HEALTH SECTOR FOR THE BENEFIT OF THE NORTH OF ENGLAND.

As part of the clinical care pathways projects, partnerships were formed with national businesses that had specific innovations that could extend the scope of our projects:

- ◆ D2 Digital supported the development of the pre-hospitalisation pathway stroke app,
- ◆ MDSAS developed an integration application and platform to support national rollout of our ABC-ICH stroke project, and
- ◆ Imosphere integrated their Atmolytics tool for completing in-depth data exploration, visualisation, benchmarking and reporting within the primary care pathway outputs.

GM CHC developed a spin-in lab to support companies wishing to validate products for the healthcare market.

- ◆ The Spin-in Lab is an innovation environment to build tri-partite partnerships between industry, NHS, and researchers to accelerate the development of digital health technologies.
- ◆ This model enables companies to develop, test and validate digital health products and services using real-world health data and access to domain specific data analytics capabilities and expert advice on the design and development of their ideas.

“Programmes such as Connected Health Cities are an essential part of advancing the digital health agenda to ensure that technology really does transform the health and wellbeing of our citizens.”

PROFESSOR BEN BRIDGEWATER, CEO, HEALTH INNOVATION MANCHESTER

A SPIN-IN LAB CASE STUDY

The most recent Spin-in Lab project is a collaboration between Intelligent Medical Objects (IMO), Salford Royal NHS Foundation Trust (SRFT) and the University of Manchester to support a research and innovation project to advance the automation of coding diagnoses from digital clinical text.

Clinicians typically record brief free-text descriptions of symptoms, diagnoses and treatments in semi-structured letters, which require additional efforts in clinical coding (e.g. to ICD or SNOMED CT) to make such data accessible for both clinical care and research. IMO was developing support for clinicians to facilitate clinical coding either at the point of care (e.g. while recording diagnoses) or as a separate functionality (e.g. automated coding of descriptions in clinical letters).

The company already had three quarters of US hospitals connected to an on-line, organic clinical vocabulary that it maintains and this interface vocabulary is mapped to several standardised terminologies. Assessing the value of accurate clinical coding using their technology in the UK was however a challenge, given the sensitivity of accessing clinical services or letters by anyone outside the NHS. However, access to data is not necessarily needed if a trusted party (that has access to the data) can assist in developing the software by testing and validating the outcomes.

To support the project, which was funded by IMO, GM CHC established a multi-disciplinary team that acted as a trusted third party and facilitator. The team prepared and obtained all ethical approvals and monitored the entire process including the data extraction steps. They organised training and manual clinical coding of data by SRFT clinicians, installed and run the IMO software at SRFT (local access to data but making sure that the proper licences for running the software are in place), and collected and analysed the results.

The findings were then discussed with all partners and relevant conclusions reached, including, for example, that the quality of automated coding using the IMO's interface terminology was comparable to manual expert coding by clinicians. The results of the Spin-in lab have further led to subsequent clinical projects and future collaborations on new projects.



Public Involvement and Engagement

GM CHC CONTRIBUTED TO THE DEVELOPMENT OF PUBLIC TRUST IN THE USE OF SHARING HEALTH DATA FOR RESEARCH PURPOSES.

Working closely with the GM CHC Public Forum, which consists of members of the public recruited from across the ten local authority areas locally, GM CHC have contributed to the development of public trust in the use of sharing health data for research purposes.

These have included:

- ◆ Invigorated public debate about primary and secondary uses of health and care data - achieved via the CHC website, deliberative workshops, community events and science festivals.
- ◆ Stimulated learning and reflection about secondary use of health and care data and data linkage using public engagement materials and activities such as games, voting booths and leaflets at community events and science festivals.
- ◆ Influenced and informed public opinion about the sharing of health data beyond public institutions highlighting what organisations need to demonstrate in order to maximise public trustworthiness.

“The reason it’s gone so well is that they have a team that have a passion for making a difference to patients...”

CHC EVALUATION PARTICIPANT



Safe and Trustworthy Use of Data

GREATER MANCHESTER CHC DELIVERED A RANGE OF SPECIALIST TECHNICAL OUTPUTS FOR THE PROGRAMME ACROSS TRUSTWORTHY DATA ENVIRONMENTS AND INFORMATION GOVERNANCE.

- ◇ Designed information governance framework through multi-day focus groups with the public to create over two dozen project safeguards.
- ◇ Created template data sharing agreements, public information leaflets and privacy impact assessments, as well as a glossary of terms.
- ◇ Created workshops and training packages on research information governance that have been shared under an open licence.
- ◇ The GM Trustworthy Research Environment has hosted over a dozen projects across health and care, with approval from NHS Digital.
- ◇ Statistical disclosure controls ensure that no data can leave the trusted environment without independent checks to ensure it is safe to be moved.

INFORMATION GOVERNANCE

IG and Security	
Agreed Information Governance Templates for CHC member organisations	◇
Data centres have appropriate security certification, e.g. ISO27001, NHS IG Toolkit, CyberEssentials	◇
Data are encrypted	◇
Implementation	
Public and Patient Involvement strategy	◇
Use of research output in routine care	◇
Use of research output in commissioning and planning	■
App development and roll out	◇

TRUSTWORTHY RESEARCH ENVIRONMENTS

Data Management	
Secure analytics tools and platform	◇
Anonymisation processes	◇
Secure audit of data use	◇
Statistical disclosure control processes for data release	◇
Data Availability	
Hospital Episode Statistics/Secondary Uses Service	◇
Primary Care research data, eg. CPRD	◇
Primary (local) data sources, e.g. GPs, 2 ^o , 3 ^o services	◇
Real time data services	◇
Data quality processes	◇

Key		
■	◇	◇
Not project priority	In current scope and achieved	In scope and reproducible/shareable



Connected Yorkshire

Connected Health Cities



IN SUMMARY

- ◆ Reducing Demand on Emergency Care: CUREd (urgent and emergency care) project showed a potential to reduce the proportion of acute hospital admissions by 1 in 5 which is equivalent to a cost saving of £700m per year for the Yorkshire and Humber region alone.
- ◆ Connected Bradford: Linked datasets were used to establish a more comprehensive view of the needs of around 700,000 citizens. This has resulted in access to data for whole population analysis, tracking care as well as identifying opportunities for preventative care.
- ◆ Childhood Care Pathways:
 - ◇ In the first 12 months, 313 bed days were saved with childhood asthma related symptoms with 45 General Practices supporting the new home-based care pathway.
 - ◇ As part of the obesity and healthy child growth clinical pathway, the CY CHC team worked collaboratively to develop predictive tools for use in clinical settings.
 - ◇ Working with schools to support children with potential childhood Autism Spectrum Disorder (ASD), the project linked education and NHS data and used new algorithms to identify children requiring neurodevelopmental support. This resulted in new referrals for ASD diagnosis.
- ◆ Safer Prescribing for Frailty: A quality improvement approach resulted in a 6% reduction in average number of prescription items for people with frailty.
- ◆ ClearPath Pathway Models: In cancer care, ClearPath pathway models helped establish Leeds as a national centre for cancer data analytics research and establish a new doctoral training centre for using artificial intelligence (AI) in cancer diagnosis and care.
- ◆ Professional engagement, training and education: CY CHC helped provide a population data laboratory by linking data and creating unique opportunities for research and improvement projects.
- ◆ Industry partnerships: Working with data service providers and GP practices, CY CHC were able to open up new data for use in health service improvement and research including historical datasets.
- ◆ Public involvement and engagement: Patients, service users and citizens were involved at the early stages. They influenced the overall direction and focus areas for clinical pathways and improvements projects.



CY CHC Director **Professor John Wright**

In this section

- Reducing Demand on Emergency Care
- Connected Bradford
- Urgent Care for Childhood Asthma
- Healthy Child Growth
- Screening Pathway for Childhood Autism Spectrum Disorder
- Safer Prescribing for Frailty
- ClearPath Pathway Models
- Professional Engagement, Training and Education
- Industry Partnerships
- Public Involvement and Engagement
- Safe and Trustworthy Use of Data

Reducing Demand on Emergency Care



CUREd (URGENT AND EMERGENCY CARE) project showed a potential to reduce the proportion of acute hospital admissions by 1 in 5 which is equivalent to a cost saving of £700m per year for the Yorkshire and Humber region alone.

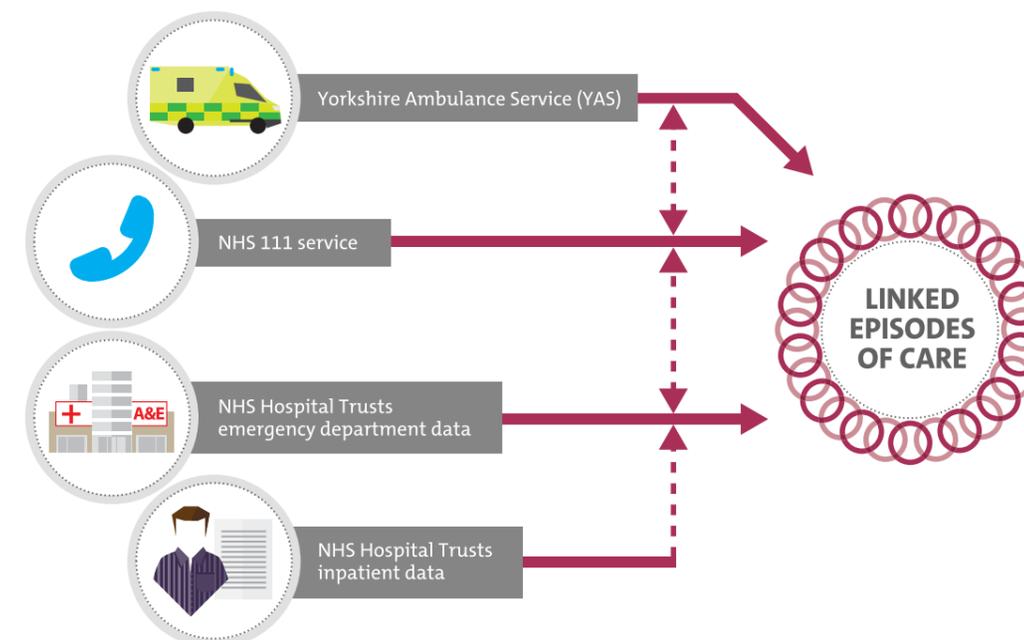
The CUREd (urgent and emergency care) dataset covers a population of 5.5 million (Yorkshire & Humber region, UK). Routinely collected anonymised data were linked from numerous providers across the Yorkshire and Humber region including Yorkshire Ambulance Service, NHS 111 and NHS Hospital Trusts.

There are over 15 million episodes of care in the dataset:

- ◆ Mixed rural and urban
- ◆ 1 Ambulance Service (999 and NHS 111 services)
- ◆ 13 acute hospital trusts
- ◆ 19 EDs (≈10% of England)

“We just analysed the preliminary data last week and we can see straight away the 100s of patients that shouldn't be here, and the impact we can potentially have...”

CHC EVALUATION PARTICIPANT



CUREd (urgent and emergency care) provides new insights into the utilisation of emergency departments and unscheduled care for vulnerable groups to inform data-driven improvements:

- ◆ The first ever study to link NHS 111 call data and ED attendance datasets demonstrated that 23% of people calling NHS 111 attend ED as well. Around 50% of these people are advised not to attend.
- ◆ Algorithmic approaches to identifying patients with an avoidable ED attendance. The dataset identified 23% adults and 30% children attend ED with an avoidable problem and could be managed in more appropriate care settings such as GP, pharmacy, or through self-care.
- ◆ Algorithms applied to ambulance service data demonstrated that 1 in 6 ambulance journeys with patients to emergency departments could be avoided.
- ◆ By understanding geographical variation between hospitals in acute hospital admission for older patients (rates vary 43-70%), especially with short stays (rates vary 23-48%), it is possible to identify the patients who would benefit from interventions to keep them at home, or access same day emergency care.

The project estimated savings that can be made through reducing the proportion of acute hospital admissions by 1 in 5 which is equivalent to a cost saving of £700m pa, reduced ambulance transfers (1 in 6) at a saving of £8m pa and emergency department attendances (1 in 5) at £35m pa for the Yorkshire and Humber region only.

Connected Bradford

Linked datasets were used to establish a more comprehensive view of the needs of around **700,000 citizens**. This has resulted in access to data for **WHOLE POPULATION ANALYSIS**, tracking care as well as identifying opportunities for preventative care.

Linking GP practice to hospital, and other healthcare data, empowered commissioners and providers across Bradford & Airedale to understand discrete events that impact groups of people within the GP, community and in the hospital. A data 'safe haven' was created by the CY CHC team to hold anonymised data from the GP practices.



This image shows the aim for Connected Bradford to be a single population health management system to improve health and wellbeing of patients across the Bradford and Airedale region.



This image shows the sources of the de-identified, longitudinal, near to real time data from different organisations for around 700,000 citizens. Acknowledgements: Bradford Institute for Health Research and Bradford Teaching Hospitals NHS Foundation Trust.

- Born in Bradford 30,000 cohort
13,500 children Health Records
- Genomics
 - Surveys
 - Metabolomics
 - BioBank

Urgent Care for Childhood Asthma



In the first 12 months, 313 bed days were saved with **CHILDHOOD ASTHMA RELATED SYMPTOMS** with 45 General Practices supporting the new home-based care pathway.

The ACE (Ambulatory Care Experience) Service provided an alternative to hospital referral or admission for children and young people with common acute illnesses. With safety assessments in place, the wheezy child pathway was the first ACE clinical service launched by Bradford Teaching Hospitals NHS Foundation Trust in 2017 in collaboration with GPs and the CCG.

The ACE services are delivered by fully trained nurses in the patient's own home. After assessment, short and long-term management plans are put in place. The nurses are supported by the on-call consultant paediatrician based in the hospital who takes full clinical responsibility for patients in a 'virtual ward'. Cases can be referred to the service from Primary Care, as well as the A&E and Children's Clinical Decision Area from the hospital.

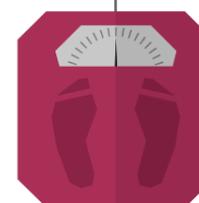
In the first 12 months, 273 referrals were accepted and 313 bed days were saved with primary care referring the majority of cases (61%) from 45 different GP practices for asthma-related symptoms.

Within 18 months, the service has managed 515 referrals including for the wheezy child and gastroenteritis pathways and the croup service with expansion to new clinical pathways including jaundice and bronchiolitis.

- ◆ [ACE gastroenteritis pathway care bundle](#)
- ◆ [ACE wheezy child pathway care bundle](#)
- ◆ [ACE croupy child pathway care bundle](#)
- ◆ [ACE jaundice pathway care bundle](#)
- ◆ [ACE bronchiolitis pathway care bundle](#)

The ACE service is now informing developments in the newly formed West Yorkshire Paediatric Ambulatory Care Network.

Healthy Child Growth



As part of the **OBESITY AND HEALTHY CHILD GROWTH** clinical pathway, the CY CHC team worked collaboratively to develop predictive tools for use in clinical settings.

The CY CHC team supported the obesity and healthy child growth clinical pathway on the use of their predictive tools based on algorithms applied to linked datasets.

The first predictive tool developed before the start of the CHC programme, the Healthy Weight app, was developed to predict the likelihood of obesity by the age of 2 years. This was applied to young children attending monitoring visits between the ages of 7 and 9 months. This proof of concept was shown to have good discrimination and was acceptable for use in a clinical setting.

As part of the CY CHC programme, support was given to develop a second predictive tool. This was completed in collaboration with health visitors who were interested in using additional routine data to automatically predict obesity in children at an older age and send an automatic referral to their support service for at-risk children. Given that the age at which parents are routinely invited to have their children measured is 5 years old and there is poor uptake of the routine measurement appointment at two years, there was a request to investigate the use of the tool for 5 year olds. In response to these requests, the team investigated the ability of this new tool to predict obesity at five years in children aged 2 years. It was found that predictive ability was insufficient for use in a clinical setting for the second tool, predominantly because diet and physical activity are important factors at this age. This is information that is not readily available and is time-consuming to collect.

The learning from these projects were published and Connected Bradford data will be used to validate the first risk tool across the city and work with TPP, an electronic clinical records system used across primary care, to integrate the algorithms as part of the routine workflow for the health visitors.

“The challenges of developing a simple predictive model for the risk of obesity in young children reflects the complex interaction between genetics and the obesogenic environment.”

GILLIAN SANTORELL, PRINCIPAL STATISTICIAN, CY CHC

Screening pathway for Childhood Autism Spectrum Disorder



Working with schools to support children with potential **CHILDHOOD AUTISM SPECTRUM DISORDER (ASD)**, the initial project linked education and NHS data and used **new algorithms to identify children requiring neurodevelopmental support**. This resulted in new referrals for ASD diagnosis.

The diagnosis for children with ASD process is lengthy and parents and children have to wait for sometimes 3 to 4 years to receive a diagnosis. This is in part due to the late identification/formal diagnosis of children which then leads to delay in appropriate support and interventions for families.

Using linked datasets, the CY CHC team segmented population health data to identify children that had received a diagnosis of Child ASD. Linking health care data to educational and socio economic datasets, it was found that there is late diagnosis of autism in families with low income, ethnic minorities and families with low education. Working at the intersection of health and education gave an opportunity to explore how fast track assessment and subsequent early interventions could be developed in Bradford.

The CY CHC completed a pilot project across 10 schools in Bradford with early indications that children with potential ASD are accessing interventions earlier and that there is a potential to reduce inequity in provision of assessment at each intervention. The pilot project was delivered in collaboration with schools, educational psychologists from the Local Authority, psychiatrists and the CAMHS team (including support from the medical director of the local care trust) from Bradford, Leeds and York.

Using the dataset and algorithms developed by CY CHC, from a cohort of 600 children, 35 children were assessed and all were identified as requiring neurodevelopmental support with 9 as being at risk of ASD diagnosis. The local CCGs are currently reviewing external funding options for developing this project to a larger cohort of students potentially across 60 schools.

“... [the project] has emphasised the gains for a family, a diagnostic processes are enhanced through the leadership of school staff as shown through assessments being carried out in schools and the results immediately leading to school-based support.”

DAVID SIMS, MEDICAL DIRECTOR, BRADFORD DISTRICT CARE TRUST

“We embedded different clinical healthcare professionals, the CAMHS team from multiple locations, educational psychologists at the local authorities and the schools. This is a fascinating project that has been completed with a new way of working.”

CONNECTED BRADFORD PROGRAMME MANAGER

Safer Prescribing for Frailty



A quality improvement approach resulted in a **6% reduction** in average number of **PRESCRIPTION ITEMS FOR PEOPLE WITH FRAILITY.**

Connected Yorkshire CHC contributed to a series of learning workshops led by the Yorkshire and Humber AHSN Quality Improvement Academy and the Medicines Optimisation Programme. In this collaborative project funded by the Health Foundation, the electronic frailty index was used to identify patients taking a large number of medicines and begin to provide evidenced-based tools to support deprescribing.

Working in collaboration with clinical pharmacists to support deprescribing, the electronic frailty index (eFI) was used to identify eligible patients within primary care. GPs and primary care professionals attended the workshops and implemented the quality improvement (QI) approach in their Practices based on the Institute for Healthcare Improvement (IHI) QI model. The improvement measure was a reduction in the number of prescribed items for identifiable clinical reasons.

This resulted in case-based medication and polypharmacy reviews being implemented by GPs across Practices in Yorkshire and Humber resulting in a 6% reduction in average number of prescriptions per person. With eFI being accessible to 90% of England through electronic patient record systems, an expansion through the medicines optimisation programmes nationally could deliver savings and service improvement at scale.

“In a short period of time, there was a significant amount of work done to stop unnecessary prescriptions.”

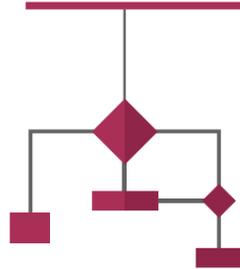
GP ATTENDING THE WORKSHOP

The eFI is automatically populated with routine primary care electronic health record (EHR) data and has been validated using data from 900,000 UK primary care patients. It has been implemented into the SystemOne EHR, which is used by 100% of practices in Bradford and around 70% of practices in Yorkshire & Humber.

The eFI has now also been implemented into the EMIS Web EHR as part of the Yorkshire & Humber AHSN Improvement Academy Healthy Ageing Collaborative, enabling availability to the large majority of GPs across Yorkshire & Humber, and around 90% of GPs across the UK.



ClearPath Pathway Models



In cancer care, **CLEARPATH PATHWAY MODELS** exemplify Leeds as a national centre for cancer data analytics research and as a centre for doctoral training using artificial intelligence (AI) in cancer diagnosis and care.

The ClearPath project has had a significant impact on at least seven care pathways in the Yorkshire region and nationally. ClearPath is an approach that produces actionable intelligence from care pathway visualisations designed to support operational decision-making.

The ClearPath approach has been used across a wide variety of settings:

- ◆ In social care, ClearPath produced a decision model to support earlier detection of childhood autism in Bradford schools.
- ◆ In primary care, models were created for hazardous prescribing patterns in Manchester and pathways for urinary tract infection for NHS England.
- ◆ In elderly care, the team modelled the progression of frailty and correlation with polypharmacy and falls.
- ◆ In urgent and emergency care, ClearPath produced “what if” models for the introduction of a Children’s Clinical Decision Area (CCDA) for the paediatric ambulatory care pathway at Bradford Royal Infirmary, new models of triage at Doncaster and Bassetlaw NHS Trust, a proposed Urgent Care Hub for Leeds city commissioners and a city region model for the city of Bradford.
- ◆ In secondary care, the pathways for complex conditions for Giant Cell Arteritis and Functional Neurological Disorder were modelled and are informing national debate.
- ◆ An innovative software developer, ADI of Shipley, was supported to refine its MyPathway product for musculoskeletal care.
- ◆ In cancer care, pathway models were developed which exemplify Leeds as a national centre for cancer data analytics research and as a centre for doctoral training for using AI in cancer diagnosis and care.

“Modelling pathways with NETIMIS has proved fast and fun, ClearPath has made care improvements visible.”

OWEN JOHNSON, SENIOR FELLOW, UNIVERSITY OF LEEDS

The ClearPath Method combines data from disparate sources with qualitative investigation methods to produce care pathway models. These can be run as simulations of current care and “what if” improvement scenarios. ClearPath uses the [NETIMIS care pathway simulation tool](#) which was developed by University of Leeds spin-out X-Lab Ltd and made available to CHC. The approach was to train undergraduate, masters and PhD students in the ClearPath method and tools and then support them working with local NHS stakeholders through to the completion of a successful pathway improvement. In the replicator project, University of Liverpool used the ClearPath Method to model data on alcohol related emergency admissions to demonstrate the ease with which ClearPath could add value to collaborative partners. Highly effective pathway models were produced within several months by embedding a University of Leeds student within the Liverpool team on just a one day a week basis. The analytical approaches used by the Clearpath team have proved very successful and have had a strong impact on the careers of over a dozen young people including some who have now taken leadership roles in the NHS and health industry.

ClearPath has introduced scientific methods from process analytics to the understanding of care pathways. The team at Leeds forms one of the largest research groups in care pathway data and process mining worldwide and is linked to other international centres in Europe, Chile and Australia. ClearPath [case studies](#) from the North of England have been presented in the UK, Europe and worldwide.

Professional Engagement, Training and Education

CY CHC HELPED PROVIDE A POPULATION DATA LABORATORY BY LINKING DATA AND CREATING UNIQUE OPPORTUNITIES FOR RESEARCH AND IMPROVEMENT PROJECTS.

“We are always overwhelmed with the amazing response from our BiB families; the rich data that our BiB families share with us allows us to work with decision makers and communities across the district to make real improvements to the health of families within our city.”

PROFESSOR ROSIE MCEACHAN, DIRECTOR, BORN IN BRADFORD

The team used the Born in Bradford birth cohort study and the region-wide linked health and wellbeing datasets. Locally, Bradford is the 6th largest city in the UK and holds unique connected data and informatics potential.

In recent years Bradford has collaborated closely with academic partners from the University of Leeds and the University of York to establish data linkage across primary and secondary care and local government. Nearly 30,000 mothers, fathers and children in the Born in Bradford birth cohort study data have had their records linked and extensively validated across primary care, hospital, community (health visitors and school nurses), laboratory, radiology and more recently education records. This was built on their experience in the £50 million Better Start Bradford programme to expand coverage to 50,000 Bradfordians and test how data linkage can support tailored and effective interventions in early childhood.

Focussing on linked health and wellbeing datasets, significant professional stakeholder engagement was carried out involving 86 GP practices, three CCGs, three Trusts, two local authorities, and charity organisations in the Bradford area. Active liaison and engagement activities were carried out with the clinicians, and general practitioners, the Local Medical Committee (LMC), senior management as well as other key professionals. A number of steps were followed to ensure that there were regular feedback processes as the draft data sharing agreement was reviewed and updated. This included setting up a governance group with representation from each of the data providers, citizen representation and the CCG Data Protection Officer. In addition, discussions on the data sharing agreement took place with the ICO to inform them of the projects that were underway.

The organisations involved in addition to the GP practices are Bradford City & Districts and Airedale Wharfedale & Craven CCGs, Bradford Teaching Hospitals, Airedale Hospitals, Bradford District Community Trust, Bradford Council, North Yorkshire County Council, Sue Ryder and Marie Curie. All the organisations consented to share pseudonymised data for the programme. This resulted in 100% of the individual data sharing agreements being signed by all the 86 GP Practices.

“We have been taken aback by the fantastic level of support for our Connected Health Cities programme in Bradford and Airedale. All 86 general practices covering over half a million patients have now signed up. We will be working with clinicians and patients to develop cutting edge approaches to how linked data can improve the quality and safety of health care we provide in the NHS.”

PROFESSOR JOHN WRIGHT, DIRECTOR, CY CHC



Industry Partnerships

WORKING WITH DATA SERVICE PROVIDERS AND GP PRACTICES, CY CHC WERE ABLE TO OPEN UP NEW DATA FOR USE IN HEALTH SERVICE IMPROVEMENT AND RESEARCH INCLUDING HISTORICAL DATASETS.

The CY CHC team worked closely with industry partners and GP Practices to understand the main barriers to implementation of learning health systems.

With a focus on information governance, the team was supported by a number of stakeholders including the CHC Hub Information Governance team and the ICO to put into place new data sharing agreements. The team worked closely with The Phoenix Partnership (TPP) and Apollo Medical Software Solutions as data providers for GP Practices. The comprehensive work across a number of stakeholders resulted in approval being given by the relevant ethics committees including for the linking of healthcare data with education data.

The extensive work carried out by the CY CHC team resulted in rapid access to GP Practice data for specific projects such as for people aged over 65 years old for the frailty project, and for families as part of the childhood ASD project. There are now two major datasets available in the region including the BiB and the GP Practice-led health and wellbeing datasets. Access has now been gained for historical datasets for up to 30 years for use as part of research, improvement and innovation projects.

“This is an exciting collaboration as it is the first feasibility test for using app technology to collect real-time data.”

KIRSTY CROSSLEY, RESEARCH FELLOW,
BRADFORD TEACHING HOSPITALS NHS FOUNDATION TRUST

“The close collaboration between Bradford and Craven District health and social care partners with Apollo and the adoption of innovative automated data processing services, has successfully facilitated new evidence based research that supports improvement of health and care for the local population.”

TONY MEGAW, MANAGING DIRECTOR, APOLLO

CASE STUDY WITH THE PHOENIX PARTNERSHIP (TPP)

BiB have been collaborating with The Phoenix Partnership (TPP) for the development of an app called ‘Airmid’ which is designed to allow patients to take control of their own healthcare. The app includes functions like being able to view and contribute data to their SystmOne medical record (such as allergies and medications); book and manage appointments; import data from health apps; monitor pollution locally; and sign up to research projects, including the Digital BiB research study. This creates a platform for BiB to disseminate surveys to collect measures like monthly mental wellbeing and daily mood scale that can be done at anytime and anywhere.

CASE STUDY WITH APOLLO MEDICAL SOFTWARE SOLUTIONS

The CY CHC team engaged with Apollo Medical Software Solutions to support the secure automated harnessing and collation of GP practice data, including historical data with scheduled regular data updates. Apollo has successfully implemented the service in all GP Practices across the Bradford and Craven district and provided the Connected Bradford team with primary care datasets that can be linked to secondary care data.

Building on this experience, a pseudonymised linked dataset is held on a digital platform developed by Bradford Teaching Hospitals NHS Foundation Trust that links primary care data, community care, secondary care, social care data presented from a population of approximately 600,000 patients across the Bradford & Airedale region.

Public Involvement and Engagement

PATIENTS, SERVICE USERS AND CITIZENS WERE INVOLVED AT THE EARLY STAGES AND INFLUENCED THE OVERALL DIRECTION AND FOCUS AREAS FOR CLINICAL PATHWAYS AND IMPROVEMENTS PROJECTS.

The CY CHC team worked closely with individuals and families as part of designing and delivering the projects. There were interactive conversations with patients and citizens exploring the general topics of service improvement, opportunities for change and where routine data could play a role.

The team focussed on understanding more about the lives of the people who use the services, the types of services they use in the wider communities, and the outcomes that they themselves identified as being important.

The projects were developed using their experiences and their questions about the services and the care that they received. This engagement took place at a very early stage of the project and continued throughout the duration of the projects. The CY CHC team carried out this work through workshops and informal drop-in sessions, as well as engagement with the citizens. Examples of these activities included attending local events including the Bradford Science Festival in July 2017, 2018 and 2019 and hosting patient/citizen panels. Networks of patient groups from existing research and healthcare projects were also involved in the engagement activities coordinated by CY CHC.

“Very inspirational and insightful getting to know the work being done behind the scenes, and honoured to partake in helping to streamline the complex system currently in place.”

RABIA SHAH, CONNECTED BRADFORD PPI GROUP



Examples of the leaflets/poster distributed across GP surgeries. The leaflet provided more information about the ways in which Connected Yorkshire were planning to use health information to improve health services.

The conversations with individuals and families resulted in new insights about priority areas and some of the questions that came up during the engagement activities were:

- ◆ 'why is my data not connected'
- ◆ 'why do I keep repeating my information' and
- ◆ 'why is my school not being informed?'

In addition to the wider engagement activities, a patient and public involvement panel was formed to provide a governance structure for the projects. All the providers and participating organisations were provided with clear communications to use with their service users and citizens.

All the interactions with patients and citizens in the early stages led to changes in the way the projects were delivered and informed the overall direction of the project. One of the defining features of the engagement activities was the focus on driving changes for individuals and their families in their unique circumstances whilst delivering population wide impact.

Safe and Trustworthy Use of Data

CONNECTED YORKSHIRE CHC DELIVERED A RANGE OF SPECIALIST TECHNICAL OUTPUTS FOR THE PROGRAMME ACROSS TRUSTWORTHY DATA ENVIRONMENTS AND INFORMATION GOVERNANCE.

- ◇ The Bradford Institute for Health Research, at Bradford Teaching Hospitals NHS Foundation Trust, hosts the world renowned Born in Bradford (BiB) longitudinal cohort studies.
- ◇ To improve the ability of the data to support frontline healthcare professionals, providers and commissioners, this dataset has been extended as Connected Bradford, with ethical approval.
- ◇ Connected Bradford worked with CHC Hub Information Governance expertise to develop data sharing agreements and upskill local knowledge to provide improved posters, leaflets and public fair processing notices.
- ◇ Connected Yorkshire has developed Trustworthy Research Environments for the storage of the BiB and CureD datasets, so that there are appropriate governance controls and processes for researchers to be able to securely use the data.
- ◇ Bradford has developed a digital solution, with the CHC Hub, for digital consent management of participants in the longitudinal cohort study.

INFORMATION GOVERNANCE

IG and Security	
Agreed Information Governance Templates for CHC member organisations	◇
Data centres have appropriate security certification, e.g. ISO27001, NHS IG Toolkit, CyberEssentials	◇
Data are encrypted	◇
Implementation	
Public and Patient Involvement strategy	◇
Use of research output in routine care	◇
Use of research output in commissioning and planning	◇
App development and roll out	■

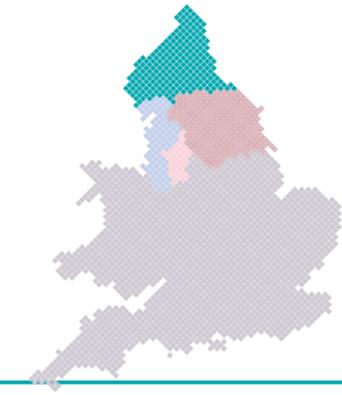
TRUSTWORTHY RESEARCH ENVIRONMENTS

Data Management	
Secure analytics tools and platform	◇
Anonymisation processes	◇
Secure audit of data use	◇
Statistical disclosure control processes for data release	◇
Data Availability	
Hospital Episode Statistics/Secondary Uses Service	◇
Primary Care research data, eg. CPRD	◇
Primary (local) data sources, e.g. GPs, 2 ^o , 3 ^o services	◇
Real time data services	◇
Data quality processes	◇

Key		
■	◇	◇
Not project priority	In current scope and achieved	In scope and reproducible/shareable



North East and North Cumbria Connected Health Cities



IN SUMMARY

- ◆ Great North Care Record: GNCR now gives access to GP records to hospitals, mental health, ambulance and out of hours. The programme works with General Practices across the North East and North Cumbria, involving 400 practices, 25 NHS Trusts and Local Authorities, and 12 CCGs saving at least £8m per year.
- ◆ Predictive modelling for planned and unplanned care: Two proof of concept apps have been developed, one supporting unplanned care for emergency departments, and the other supporting clusters of General Practices with long term planning.
- ◆ The Smart Interventions for Local Vulnerable Residents (SILVER): The team created tailor-made, multi-partner data sharing agreements that met the needs of all stakeholders across healthcare, social care, criminal justice, housing and education. This ground breaking approach enables holistic, joined up support for vulnerable families.
- ◆ Palliative care plan project: Twice as many patients in the end of life care pathway are benefitting from their Special Patient Notes being available to ambulance services in North Tyneside.
- ◆ Professional engagement, training and education: The NENC CHC team developed and expanded networks to enable regional data sharing and engage a wider audience in data driven improvement and innovation.
- ◆ Industry partnerships: One of the undoubted successes of NENC CHC has been the extent to which it has helped us to forge and take forward strong links between the project team, affiliated researchers and key commercial partners.
- ◆ Public involvement and engagement: A patient preferences tool programme continues to explore enabling members of the public to take control of their data sharing preferences.

In this section

Great North Care Record

Predictive Modelling for Planned and Unplanned Care

Smart Interventions for Local Vulnerable Residents (SILVER)

Palliative Care Plan Project

Professional Engagement, Training and Education

Industry Partnerships

Public Involvement and Engagement

Safe and Trustworthy Use of Data



NENC CHC Director **Professor Joe McDonald**

Great North Care Record



THE GREAT NORTH CARE RECORD (GNCR) now gives access to GP records to hospitals, mental health, ambulance and out of hours. The programme works with General Practices across the North East and North Cumbria, involving 400 practices, 25 NHS Trusts and Local Authorities, and 12 CCGs **saving at least £8m per year.**

GNCR used the Medical Interoperability Gateway (MIG) to create one shared care record for patients across the North East and North Cumbria.

“In a recent GP consultation, an elderly lady presented new confusion and an urgent CT scan request was made. Although the CT was normal, the MIG entry of a recent head injury helped expedite care and narrow down the diagnosis to infection as the likely cause of confusion.”

DR PHIL STAMP, ACCIDENT AND EMERGENCY CONSULTANT,
NORTHUMBRIA HEALTHCARE NHS FOUNDATION TRUST

Starting in late 2016, GNCR made 96% of GP records (369 GP Surgeries) available to emergency care, out of hours and mental health within 12 months and scaling fast to 100%. Records are viewed for the purposes of care provision over 130,000 times per month across the North East and North Cumbria. The programme aims to become the most connected and consented healthcare economy in order to become the go-to place for research and innovation.

Background information

- ◆ The care records system has been rolled out to 14 partner organisations to use the information for data driven improvements and innovations including North East Ambulance Service and 111 service, eight foundation trusts, two mental health trusts and three GP out of hours care providers.
- ◆ There is an estimated saving of £8m reflected by the figures of 1,000 views per month, saving 20 minutes of clinical time at £5.00 per time.
- ◆ Once consent has been provided by the patient, health and social care practitioners can use the Detailed Care Record (DCR) service to view real time extracts of information from the patient’s GP record.
- ◆ Benefits recorded from the GNCR include: accessing real time extracts of information to inform patient care; providing faster care where previously accessed by telephone or fax; and reducing the potential for medication errors and duplication of tests and investigations. This has helped to increase the accuracy of care and reduced duplicate testing.

“Sometimes the caller won’t remember which medication they are taking. The MIG provides a list of the patient’s medication (current and past), which saves time and ensures safe decisions are made. Nurses say this is one of the most helpful things with the MIG.”

PAUL NICHOLSON, ASSISTANT DIRECTOR OF IM&T,
NORTH EAST AMBULANCE SERVICE NHS FOUNDATION TRUST

“Historically, care records are like a jigsaw puzzle – with small bits of information held at the GP surgery, in A&E, on the ward but they don’t all work together. We have done lots of research with patients and many are surprised that this information is not already easily shared between organisations. The Great North Care Record makes everything come together to complete the picture for better patient care.”

PROFESSOR JOE McDONALD, CONSULTANT PSYCHIATRIST AND DIRECTOR,
NENC CHC

The Great North Care Record is a way of sharing patient information with health and care staff. It covers the 3.6m people living in the North East and North Cumbria (NENC). It allows information recorded about people’s health and care such as diagnoses and treatments to be shared with different healthcare services.

There were two phases to the implementation of GNCR

Phase One:

Accident and emergency departments, out of hours, ambulance, mental health and 111-services were given access to the GP record. This was the first step in the process towards creating an integrated care record. This was vital to get information sharing agreements set up and for the region to adopt data sharing. Much of the work that has been about building a conducive culture, developing trust, encouraging collaboration, and setting up the networks and teams necessary to implement the next stage of the project. Finally, it was about learning how we bring different sectors and agencies together to work towards a shared vision.

Phase Two:

Currently being implemented and comprising three components/modules

1. A regional Health Information Exchange (HIE) to allow health and care professionals to see information about an individual from across the system.
2. A Patient Engagement Platform (PEP) to let individuals themselves see their own information, set their data sharing preferences and interact with services using the GNCR app, whilst offering the option to opt out of their information being shared within the NHS.
3. A Public Health Management (PHM) system to allow the data collected to be used and analysed in new ways to help manage the health of people across the NENC regions.

“...its [CHC] ability to bring data together and sort out all those horrendous data sharing agreements...just being able to do that is such an amazing feat...”

CHC EVALUATION PARTICIPANT



Predictive Modelling for Planned and Unplanned Care



TWO PROOF OF CONCEPT APPS have been developed, one supporting unplanned care for emergency departments, and the other supporting clusters of General Practices with long term planning.

Through collaboration with practice managers, NHS analysts and IG specialists, practical modelling, planning and decision-support tools have been built and made available to key NHS stakeholders across the North East of England.

The NENC CHC team partnered with Durham University who achieved success in two distinct areas; one modelling approach was developed for Accident and Emergency (A&E) Admissions at key acute Hospitals in the region 'Unplanned care', and a second for Practice Managers and GPs within General Practice settings 'Planned care'. The team has gained momentum and is currently working with additional partners with further investment such as the NENC ARC on exemplar projects.

“We are using new tools and data analysis techniques from the academic world and applying them to real life examples such as in A&E departments, which is helping to inform their planning.”

DR IAN BRIGGS, CONSULTANT, DURHAM CARE PATHWAY PROJECT

Unplanned care

A&E admissions data were received from several regional NHS Trusts. This was analysed to produce a meaningful predictive model of future A&E attendances. This model was developed in consultation with the NHS Trust analysts to ensure it addressed practical needs in planning and could be easily installed and used on site.

The app was useful in detecting patterns and peaks in demand and can be used to support planning decisions which were previously based on anecdotal beliefs relating to service demand. The app was adopted by a trust outside of the project.

Planned care

Darlington was a pathfinder site in a national NHSE initiative, 'Healthy New Towns' (HNT), which reviewed health provision and design in sites planned for extensive housing developments. As part of this programme, the Durham University team, funded by CHC developed a planning support tool that could allow demand and activity changes in population workforce and house building programmes to be modelled.

This tool, co-developed with several GP practices and local authorities at 2 sites within the HNT programme, allows managers to model different scenarios and ways of working. As well as modelling the impact of large scale house building on GP practices, managers can also model impacts such as GP retirements, changes to appointment lengths or number of sessions, with visual representations of key targets. This has the potential to lead to efficiencies in delivery.

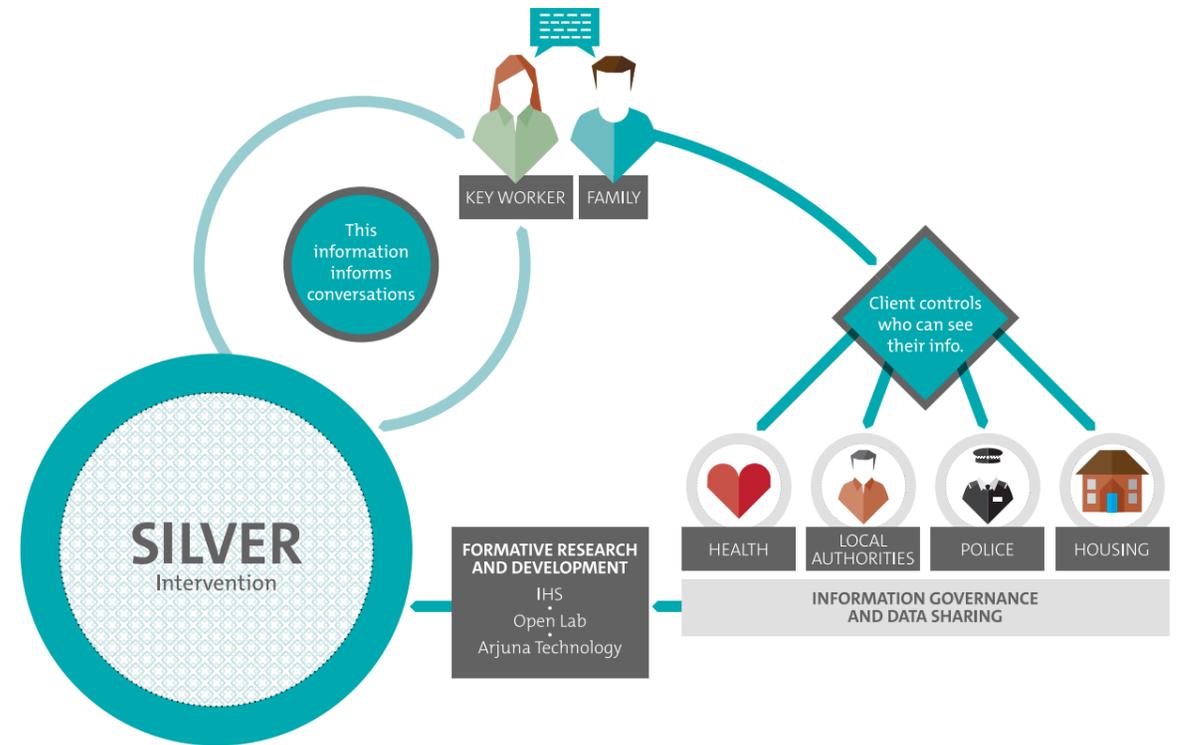
The planning app allows users to better understand current levels of activity and to investigate how different scenarios are likely to affect their practice. For example, one practice manager involved in the programme noticed a significant number of GP and nurse appointments allocated to women aged in their thirties – more so than any other age group. This insight enabled the practice to plan their clinics to meet this demand in a more efficient way.

Smart Interventions for Local Vulnerable Residents (SILVER)



THE SMART INTERVENTIONS FOR LOCAL VULNERABLE RESIDENTS (SILVER) team created tailor-made, multi-partner data sharing agreements that met the needs of all stakeholders across **healthcare, social care, criminal justice, housing and education.** This ground breaking approach enables holistic, joined up support for vulnerable families.

The SILVER programme linked data from multiple agencies including healthcare, social care, criminal justice, housing and education. It explored issues around gaining consent and how agencies can develop sustainable interventions. By creating a secure corridor for data from different agencies to flow through via one platform, this provided social workers with the latest up to date information on their service users. Despite the additional complexities of the introduction of the EU General Data Protection Regulation (GDPR), the SILVER team delivered a ground breaking approach enabling holistic, joined up support for vulnerable families.



The image shows the flow of information for the SILVER project.

“...this [CHC] has been a way for the North of England to capitalise on what it does well which is data linkage from the data side, but also target the underlying issue of health inequalities...”

CHC EVALUATION PARTICIPANT

Based on initial findings, a data sharing system was developed that would allow early care practitioners access to family members' medical records via the Medical Interoperability Gateway (MIG), a system already used to share GP records in emergency and out of hours settings. A consent portal was designed to ensure that data sharing operated within the relevant legal frameworks and that families knew what they are agreeing to before access was enabled. Practitioner requirements were taken into consideration so that information would be relevant, readable and filterable.

To meet information governance requirements, SILVER produced a detailed care record agreement outlining which data would be provided, to be agreed by the GP practice and local authority, as well as a data sharing agreement outlining the purpose for which the local authority would use the data. The project was also required to demonstrate compliance with Clinical Risk Management standards DCB0129 and DCB0160 prior to the authorisation of data sharing agreements. These requirements were met alongside gaining consensus amongst specialists on the appropriate legal basis for information sharing in this setting, given that early help provision sits outside of statutory social care intervention.

Why this is important

- ◆ An estimated 400,000 families in England and Wales have multiple and complex needs, including mental and physical health problems, involvement in criminal and anti-social behaviour, truancy, unemployment and domestic abuse.
- ◆ These families often receive care from multiple agencies such as healthcare professionals, social services and the criminal justice system.
- ◆ The national framework for responding to the needs of vulnerable families, referred to as the Troubled Families Programme, aims to identify and provide effective early help by way of joined up local support.
- ◆ Evaluation of the programme, however, has shown that the failure to share information between agencies is a significant barrier to providing better services.

“By bringing together data from health, criminal justice and social care, key workers can better support families that are at risk due to significant poverty, parental chronic illness or disability, unemployed or mental health problems.”

DR LINGAM, PRINCIPAL INVESTIGATOR, SILVER PROJECT

How SILVER was delivered

Newcastle University brought together leads from five regional local authorities, academics/researchers, IT specialists, local families and other key stakeholders to explore how health and social care data can be shared, with the aim of improving care for vulnerable families by establishing an appropriate data sharing system: the SILVER clinical pathway.

Phase 1. Semi structured interviews, focus groups and surveys were completed on the barriers and facilitators to information sharing between professional organisations. This involved parents in receipt of local authority early help support and close family members providing direct care to children, young people (aged 14-17) and practitioners from local authorities (e.g. education, health visitors, housing).

Phase 2. Three co-design workshops were held with parents, children and practitioners using activities such as card-sorting, storyboarding and scenario discussion to inform the development of the SILVER user interface. In addition, surveys with early help practitioners identified the information type of greatest priority to them.

In Phase 3. The SILVER data sharing system was demonstrated to early help practitioners from Gateshead Council and Newcastle Council using test data and views on user interface, functionality and usefulness were gathered.

Palliative Care Plan Project



Twice as many **PATIENTS IN THE END OF LIFE CARE PATHWAY** are benefitting from their Special Patient Notes being available to ambulance services in North Tyneside.

There is increased awareness of the need to support people who are dying to have more control over their end of life experience through documenting their care preferences. Few eligible patients are registered on electronic systems and not all professionals use them.

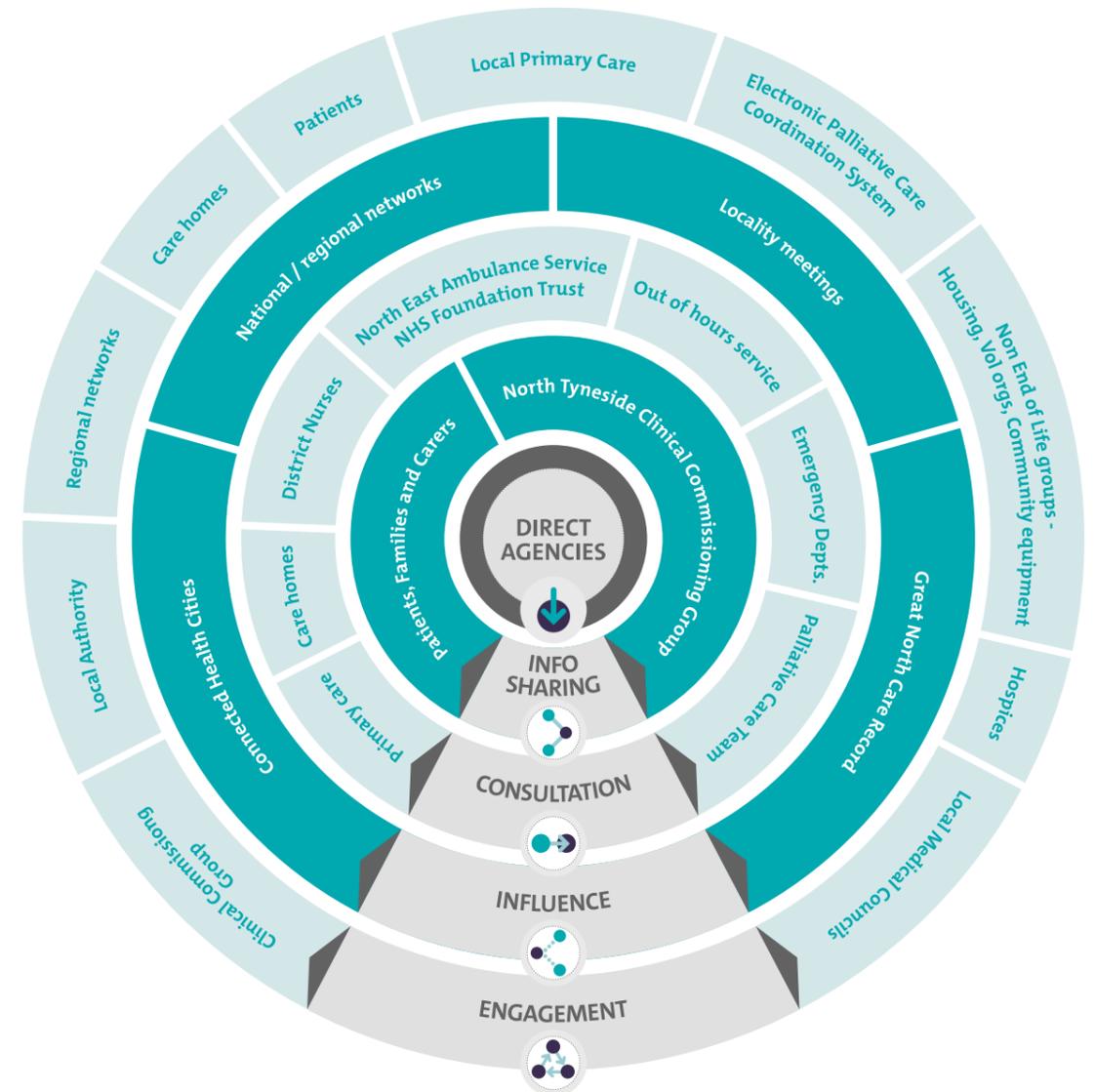
The Electronic Palliative Care Co-ordinating Systems (EPaCCS) was developed using a multi-organisational mode, the Shared Palliative Care Summary (SPCS), and went live in North Tyneside in spring 2019. In partnership with Black Pear, SPCS is a scalable integrated electronic care plan for patients on the Palliative Care Plan Register. With joint agreement on a reporting format in place for all CCGs across the North of England, the way forward for a regional approach has been secured.

EPaCCS were developed to capture patient wishes and preferred place of death, and to improve co-ordination of care in real time by enabling the sharing of information across hospital, primary and community services in and out of hours. Information presented through EPaCCS gives greater control over end of life experience. This information has the potential, when managed efficiently, to reduce anxiety and depression resulting in a positive impact on the patient and their surrounding family and friends. In practice, managing this information this has proven challenging and access to key health information is often limited for many health and social care professionals.

Using an established regional palliative care network, the CHC team supported activities which led to improvements in data collection and wider voluntary data sharing agreements. Interviews and focus groups were conducted with health and social care professionals, patients and bereaved family members to inform implementation. The project generated actionable insights into training needs, technical issues, information governance and clinical safety risk issues at the cutting edge of current developments.

“We found a way to share the patient’s information effectively, efficiently and in detail, with the patient’s story, the patient’s narratives and the patient’s choices across all services that might be involved in the patient’s care.”

CHC EVALUATION PARTICIPANT



The image shows the organisations, systems and stakeholders involved in the project and how they were involved in the main stages of engagement, influence, consultation and information sharing.



Professional Engagement, Training and Education

THE NENC CHC TEAM DEVELOPED AND EXPANDED NETWORKS TO ENABLE REGIONAL DATA SHARING AND ENGAGE A WIDER AUDIENCE IN DATA DRIVEN IMPROVEMENT AND INNOVATION.

Existing organisations were included in workforce development where possible (e.g. Chief Information Officer community), while new ones were created where gaps existed (e.g. Chief Clinical Information Officer (CCIO) network). The team were active online including accessible platforms such as Twitter to reach relevant and interested audiences. The result today is a 850+ strong (and growing) online and face-to-face Practitioner network linking health and care professionals across the region with an interest in data sharing.

“I think it has been a real catalyst for change.”

CHC EVALUATION PARTICIPANT



Informatics in the Pub events, a community of practice where practitioners meet monthly to forge connections, share knowledge and build capacity for digital leadership.

Some examples of network activities include:

- ◆ 12 Amy’s Page workshops, in which fictional clinical scenarios are used to bring professionals together to consider practitioners’ attitudes and insights on information sharing. The results have been successfully presented to multiple audiences of over 250 people.
- ◆ 25 *Informatics in the Pub* events, a community of practice where practitioners meet monthly to forge connections, share knowledge and build capacity for digital leadership. Since NENC CHC support ended in May 2019, the group has been adopted and continued by a local medical consultant.
- ◆ Extensive use of discussions and webinars as online platforms to enable conversations, networking and collaborative work. Over 700 practitioners joined Discourse to July 2019, generating 366 topics, 1,700 messages and 7,100 user visits.
- ◆ The @GreatNorthCare Twitter channel with almost 2,600 followers and an average of 40,000 impressions per month as of February 2020.



Industry Partnerships

ONE OF THE UNDOUBTED SUCCESSES OF NENC CHC HAS BEEN THE EXTENT TO WHICH IT HAS HELPED US TO FORGE AND TAKE FORWARD STRONG LINKS BETWEEN THE PROJECT TEAM, AFFILIATED RESEARCHERS AND KEY COMMERCIAL PARTNERS.

The NENC CHC team have worked with a number of industry partners, and here are some examples:

- ◆ GE-Healthcare-Finnamore supported the publication of a strategic report setting out key principles for the development of GNCR and guiding the translation into healthcare settings. This involved a series of discussion sessions involving members of the NENC CHC team, key players from other CHC regional teams, and other third parties.
- ◆ Close links were developed with AIMEs Technology (Liverpool) and Arjuna Technologies (Newcastle). Starting with the collaborative working on the TREs, these relationships have matured into active on-going collaborations including joint funding bids development and future product development projects.
- ◆ Black Pear and Inhealthcare provided expertise to design and build several key elements of the infrastructure and systems for the care pathway projects and continue to work with the GNCR team in future developments.

There is now a replicable approach in place for collaboration with industry partners and making this pivotal to future strategy for developing health care informatics in the North East. The LHCRE bid was closely linked to the strong capabilities for developing successful industry partnerships with endorsement of the health and care organisations in the North of England.





Public Involvement and Engagement

A PATIENT PREFERENCES TOOL PROGRAMME CONTINUES TO EXPLORE ENABLING MEMBERS OF THE PUBLIC TO TAKE CONTROL OF THEIR DATA SHARING PREFERENCES.

Establishing GNCR, and creating one shared care record for patients across the North East and North Cumbria, relied heavily on engaging citizens in project development to making sure it was acceptable and met the needs of all citizens. This work has provided both the impetus and evidence needed to guarantee that citizens co-produce and co-design the GNCR. The obligation was met that all systems and practices are transparent, fair and commensurate with citizens' expectations, and that the overall project enjoys their ongoing support.

“The Connected Health Cities team not only ensured they correctly captured the views of the regional population, they listened to them too and that is evident in the five key values reported.”

MICHELLE THOMPSON, CEO, HEALTHWATCH DARLINGTON

Multiple approaches were used to reach into different communities and understand people's views and perspectives across a variety of settings.

Teesside University, Newcastle University and Healthwatch Darlington collaborated on the collection and analysis of data through an initial series of 23 focus groups conducted across the region and designed to explore attitudes towards sharing healthcare records. Participants expressed clear values and expectations about sharing health data relating to them. Fundamental to these values was an expectation of respect. Analysis identified five key values developers of the GNCR now know what they must observe: reciprocity, fairness, agency/control, privacy and transparency/trust.

The focus groups were followed by an online YouGov poll in which over 800 people across the region were asked for their views about the aims of the GNCR. The majority of those surveyed were in favour of data sharing, but 86% also believed it was important for them to control their own privacy settings so they could choose who they share information with. Over half said they would share their identifiable data on a secure database with approved researchers.

Researchers from Newcastle University then considered a key finding from the focus groups: that participants often reflected on how the GNCR might affect people other than themselves. Using a variety of ethnographic approaches, the team engaged with nine groups and organisations in the Teesside region working directly with marginalised communities. The findings highlighted how members of some social groups have deep seated concerns about presenting to a doctor or allowing their personal information to be shared. Anxiety about doctor-patient confidentiality or doubting that personal information will be held in strict confidence was shown to push people away from accessing healthcare. Moreover, improved systems for sharing health and care data are not a replacement for engaging fully with individuals each time they are in contact with health service providers.

Finally, a patient preferences tool programme (the Leadgate project) continues to explore what questions and technology would need to be developed to allow members of the public to take control of their data sharing preferences. Trialled initially in County Durham and Darlington NHS Foundation Trust, this work has yielded positive results with around 80 per cent of respondents signing up to be contacted to participate in clinical trials. Leadgate project in particular looked at whether it was possible to collect the communication and data sharing preferences of people at one GP practice in County Durham. The project was co-funded by NENC CHC and the National Institute of Health Research NENC. The response was positive, with considerable insight coming back from the practice patients.

The learning from this has informed the future development of the Great North Care Record patient preferences tool and provided insight into appetite within the region for individuals to sign up to clinical trials.

Safe and Trustworthy Use of Data

NORTH EAST AND NORTH CUMBRIA CHC DELIVERED A RANGE OF SPECIALIST TECHNICAL OUTPUTS FOR THE PROGRAMME ACROSS TRUSTWORTHY DATA ENVIRONMENTS AND INFORMATION GOVERNANCE.

- ◇ A cornerstone to successful, sustained data sharing across the region was the successful mobilisation, delivery and monitoring of citizen engagement.
- ◇ A regional information governance group was established to act as a cross-agency forum, called the SIGN group. This allowed a standardised approach for processes and documentation across health and social care.
- ◇ A consent and preferences app was trialled within Durham to collect public feedback on preferences. This was developed in partnership with Healthy New Towns and industry collaborators.
- ◇ The Medical Interoperability Gateway (MIG) and the Information Sharing Gateway (ISG) were keystones for enabling sharing of data for the Great North Care Record. This enabled access to GP records for out of hours and emergency care, not just within the scope of research. This foundation enabled accelerated rollout of data sharing agreements across the region and the creation of a trusted research environment with AIMES as partners.
- ◇ Ongoing development of the open source [DataSHIELD project](#), including integration with the AIMES research environment.
- ◇ The SILVER project worked with vulnerable families to co-design a secure data corridor across services. By bringing together data from health, criminal justice and social care, the SILVER project will help key workers better support those families that are at risk due to significant poverty, parental chronic illness or disability, unemployment or mental health problems by working with those families to share data about them.

INFORMATION GOVERNANCE

IG and Security	
Agreed Information Governance Templates for CHC member organisations	◇
Data centres have appropriate security certification, e.g. ISO27001, NHS IG Toolkit, CyberEssentials	◇
Data are encrypted	◇
Implementation	
Public and Patient Involvement strategy	◇
Use of research output in routine care	◇
Use of research output in commissioning and planning	◇
App development and roll out	■

TRUSTWORTHY RESEARCH ENVIRONMENTS

Data Management	
Secure analytics tools and platform	◇
Anonymisation processes	◇
Secure audit of data use	◇
Statistical disclosure control processes for data release	◇
Data Availability	
Hospital Episode Statistics/Secondary Uses Service	◇
Primary Care research data, eg. CPRD	◇
Primary (local) data sources, e.g. GPs, 2 ^o , 3 ^o services	◇
Real time data services	◇
Data quality processes	◇

Key		
■	◇	◇
Not project priority	In current scope and achieved	In scope and reproducible/shareable

References and Resources

- ◆ **For a full list of references, see**
<https://www.chc-impact-report.co.uk/references>

- ◆ **CHC Online Resources**

- ◇ CHC programme website
<https://www.connectedhealthcities.org>
- ◇ CHC community of practice and final reporting documents
<https://connectedhealthcities.github.io/>
- ◇ CHC code and resources repository
<https://github.com/connectedhealthcities>
- ◇ Co-produced glossary of terms used to create a unified language across stakeholders
<https://www.connectedhealthcities.org/community/glossary-data-use/>
- ◇ CHC Impact Report, summary document and full references list
<https://www.chc-impact-report.co.uk/>

- ◆ **Page 9**

1. Office of Life Sciences 2019, 'Creating the right framework to realise the benefits of patients and the NHS where data underpins innovation' <https://www.gov.uk/government/publications/creating-the-right-framework-to-realise-the-benefits-of-health-data/creating-the-right-framework-to-realise-the-benefits-for-patients-and-the-nhs-where-data-underpins-innovation>
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3. Mulrine et al 2018, 'Great North Care Record Public Engagement Report' <https://www.greatnorthcarerecord.org.uk/wp-content/uploads/2018/09/GNCR-public-engagement-report-FINAL.pdf>
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5. Institute of Medicine (2012), 'Best Care at Lower Cost: The Path to Continuously Learning Health Care in America' <https://www.ncbi.nlm.nih.gov/books/NBK207218/>

- ◆ **Page 32**

6. NHS England 2020, 'Genomics' <https://www.england.nhs.uk/genomics/>

In this section

References and resources

Supporting organisations

Thank yous

#DATA
SAVES
LIVES



Supporting and Collaborating Organisations

The Connected Health Cities programme has been devised and delivered by the Northern Health Science Alliance in collaboration with over 50 organisations. We would like to take this opportunity to recognise the diverse network of NHS, academic and partner organisations who, working with industry, made this project happen. Here are some of the supporting organisations:

Advancing Quality Network (AQuA)	Healthier Lancashire & South Cumbria Integrated Care System	North Tyneside Clinical Commissioning Group	Teesside University
AgeUK	Healthwatch Darlington (working with other Healthwatch organisations in NENC)	North Tyneside Community and Health Care Forum	The Farr Institute of Health Informatics Research
AHSN North East and North Cumbria	Hull University Teaching Hospitals NHS Trust	North Tyneside Council	The Health Foundation
Bradford Teaching Hospitals NHS Foundation Trust	Innovation Agency, AHSN for the North West Coast	North West Ambulance Service NHS Trust	The Leeds Teaching Hospitals NHS Trust
Champs Public Health Collaborative	Lancashire and South Cumbria Clinical Commissioning Groups	North West Coast CLAHRC	The Newcastle Upon Tyne Hospitals NHS Foundation Trust
Clinical Commissioning Groups (CCGs) in Cheshire and Merseyside	Lancashire Teaching Hospitals NHS Foundation Trust	Northern Doctors Urgent Care	The Royal Liverpool and Broadgreen University Hospitals NHS Trust (now Liverpool University Hospitals NHS Foundation Trust)
County Durham and Darlington NHS Foundation Trust	Lancaster University	Northumberland County Council	The Royal Northern College of Music Centre for Practice & Research in Science & Music
Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust	Manchester University NHS Foundation Trust	Northumbria Healthcare NHS Foundation Trust	The University of Manchester
Cystic Fibrosis Health Hub	National Data Guardian	Northumbria University	The University of Sheffield
D2Digital	National Institute for Health and Care Excellence (NICE)	Primary Healthcare Darlington	Understanding Patient Data
Darlington Borough Council	Newcastle City Council	Public Health England	University of Cumbria
Durham University	Newcastle University	Salford Royal NHS Foundation Trust	University of Leeds
Gateshead Council	NHS 111	Share2Care	University of Liverpool
Gateshead Health NHS Foundation Trust	NHS Digital	Sheffield Teaching Hospitals NHS Foundation Trust	University of York
Getting It Right First Time (GIRFT)	NHS England & NHS Improvement	South Tees Hospitals NHS Foundation Trust	Vocare
Greater Manchester NIHR CLAHRC	NHS Health Call	South Tyneside and Sunderland NHS Foundation Trust	Yorkshire Ambulance Service NHS Trust
Greater Manchester NIHR Patient Safety Translational Research Centre	NHS RightCare	South Tyneside Council	Yorkshire and Humber AHSN
Hartree Data Science Centre	North East Ambulance Service NHS Foundation Trust	St Benedict's Hospice and Centre for Specialist Palliative Care	
Health Innovation Manchester	North of England Commissioning Support Unit (NECS)	St Luke's Sheffield Hospice	



Thank you

This work uses data provided by patients and collected by the NHS as part of their care and support. Using patient data is vital to improve health and care for everyone. There is huge potential to make better use of information from people's patient records, to understand more about disease, develop new treatments, monitor safety, and plan NHS services. Patient data should be kept safe and secure, to protect everyone's privacy, and it's important that there are safeguards to make sure that it is stored and used responsibly. Everyone should be able to find out about how patient data is used.

The CHC programme is a Northern Health Science Alliance led programme. It was funded by the Department of Health and Social Care and delivered by a consortium of academics and NHS organisations across the North of England. We would like to extend our thanks to the team at DHSC, the Treasury and the Office of Life Sciences.

We are grateful to the CHC teams and close partners who have worked hard and shown commitment to make the programme a success with a high level of engagement and collaboration.



About the NHSA

The Northern Health Science Alliance is a pan regional health partnership established by the leading Universities, NHS Teaching Trusts and Northern Academic Health Science Networks.

The NHSA works across a population of 15m people bringing together research, health science innovation and commercialisation for the benefit of patients. The NHSA also led the £20m Department of Health funded Health North: Connected Health Cities programme.

Cite as: NHSA (2020) Connected Health Cities Impact Report. Northern Health Sciences Alliance, Newcastle

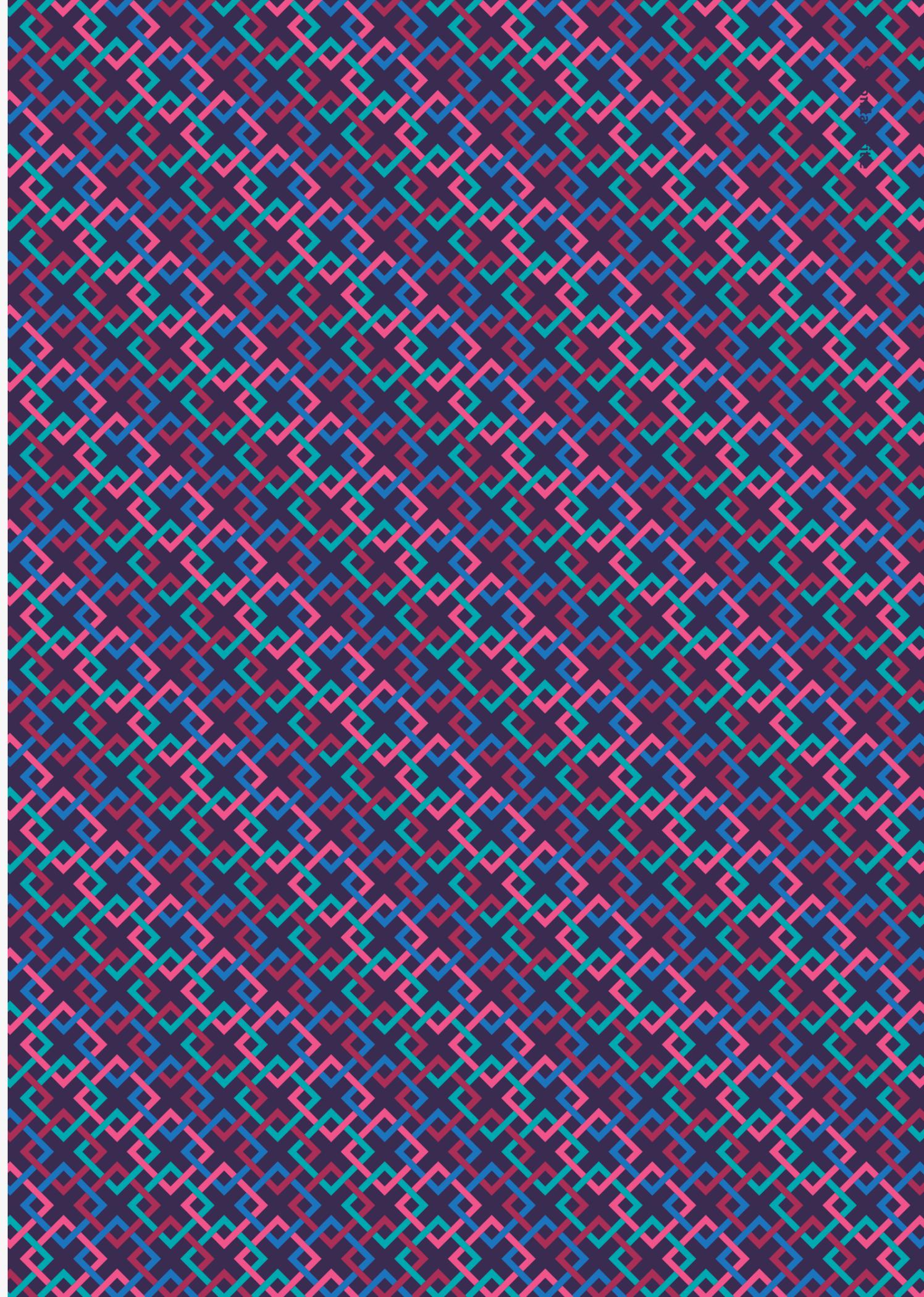
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Disclaimer

The views expressed in this report are not necessarily those of the Department for Health and Social Care or any other government department or wider partner organisations taking part in Connected Health Cities.



**Follow the ongoing work of the projects
created within CHC and resources/tools**

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