



Liverpool City Region Health Informatics Research Strategy 2017-2022

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Executive summary

A joined-up approach to health data is essential to improving healthcare and to supporting research. With the appropriate safeguards this will improve health outcomes for patients and communities, improve service delivery and efficiency, and lead to new scientific discoveries.

This strategy document outlines the steps that are needed to create a trustworthy approach to enable the use of personal health data, that are already routinely collected, for research purposes. Our aim is to work in partnership to create a learning healthcare system for the Liverpool City Region (LCR), and the wider Cheshire and Merseyside regions, where research findings can be swiftly implemented into practice. This has the potential to transform healthcare delivery and population health, as well as bringing investment into our region.

This is already happening in other parts of the UK, and it is important that we are not left behind. Indeed, the potential of using personal health data to improve health and the need for investment in infrastructure has been highlighted by the Medical Research Council, The Wellcome Trust, and the Chief Medical Officer.





There are 5 vital elements to this strategy:

1. Building a vibrant and effective network

We propose to work in partnership and build upon the excellent talent and leadership within the LCR: we benefit from a vibrant digital economy, and within the healthcare sector there has been significant investment from local and national sources. National funding includes four 'Global Digital Exemplars' at the following NHS Trusts: Alder Hey Children's NHS Foundation Trust, The Royal Liverpool and Broadgreen University Hospitals NHS Trust, Mersey Care NHS Foundation Trust and Wirral University Teaching Hospitals NHS Foundation Trust. Local initiatives include the Merseyside Digital Roadmap and the iLINKS project. Whilst these initiatives will impact on IT systems, local care delivery and the flow of information, research is not an integral part of their remit.

This document describes the strategy for building a research infrastructure integrated into these initiatives. We will expand to include other stakeholders. working in partnership with NHS Trusts, the University of Liverpool, Liverpool John Moores University and other local digital partners. This builds on our experience with the Department of Health funded North West Coast (NWC) Connected Health Cities (CHC) programme and we will also work with experts across the UK, to ensure we are working to the highest possible standards.

2. Working with the public

We are committed to communicating and working with the citizens in our region. We will explore how personal health data may be used for research, the potential benefits, and safeguards that permit personal health data sets to be anonymised in any analysis without identifying individuals. We also need to identify which uses of data are acceptable to our local population. Public engagement work has already started via some of the initiatives mentioned above, and we are committed to strengthening and widening this engagement.

3. Establishing and rolling out a model of consent

Some uses of data require consent, which in turn requires processes and systems that meet national standards. Gaining consent is complex as people need to identify which data they are happy to share and with whom. A system that records consent needs to take into account that the public interacts with the NHS at various sites, and that the public must have the ability to change their consent.

4. Creating a secure facility for data analysis

We require a data facility that can anonymise and store data from a range of NHS and non-NHS organisations (e.g. universities) that meets national regulatory governance standards. This will need the facility to link datasets in a secure way, and allow trusted researchers access to the data in an environment where they have the tools to analyse it.

5. Identify the resources required and bring investment in to the LCR digital economy

Delivering this strategy will require significant investment into the local digital health economy. In the first instance this will need to come from the local health economy but we must position ourselves, working with the Local Enterprise Partnership (LEP) and others, to attract further national and international investment in infrastructure and manpower.

In conclusion, we generate a huge amount of personal health data in our healthcare system, but are not using it to its fullest extent. The Chief Medical Officer, Professor Dame Sally Davies recently stated, "Personal data must always be stored securely, but using it responsibly can bring huge benefits to patients and improve diagnosis and treatment across the world". Our strategy is consistent with this, and outlines our vision to effectively utilise locally-generated personal data, with the public's consent, to improve the health and prosperity of our city and wider regions.

Professor Andrew Morris
Director of Health Data Research UK

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Professor Sir Munir Pirmohamed Executive Director, LHP

Professor Tony Marson

Professor of Neurology, The Walton Centre NHS Foundation Trust Integration across the LCR and the wider Cheshire and Merseyside regions

In order to ensure integration and linkage across the LCR and the wider Cheshire and Merseyside regional networks ("our region")*, a Strategy Implementation Group will be convened with cross representation, including a representative from the Cheshire and Merseyside Sustainability and Transformation Partnership's (STP) Digital Group and a Patient and Public Involvement and Engagement (PPIE) representative. The Strategy Implementation Group will report to the LHP Board on a quarterly basis. The Terms of Reference will be agreed at the first meeting of the group. Reciprocally, a representative from the Strategy Implementation Group will sit on the Clinical Informatics Advisory Group.

Timeline
January 2018 to December 2018
January 2018 to December 2020
January 2018 to December 2018
From December 2018
First wave of pathways from June 2018 Second wave from June 2019
From June 2018
From June 2018
From June 2018

*For the purpose of this document, "our region" denotes the LCR, working in partnership with the wider Cheshire and Merseyside STP footprint.



Mission, vision and objectives

Our mission

Our mission is to make our region a world leader in health informatics research.

Our vision

Our vision for health informatics research is to put the people of our region at the forefront to revolutionise healthcare delivery and transform our ability to make new scientific discoveries.

Our objectives

- Work with the public to identify appropriate uses of health data for research and gain consent.
- Create an infrastructure that links information systems, stores data securely, and enables a learning health system across our region, linking in with wider networks (e.g. the STP and other Universities across Cheshire and Merseyside).
- Bring together and add value to on-going initiatives and clinical systems within our region by developing a research infrastructure.
- Undertake analyses of data that will improve health, the delivery of services, and make new discoveries in both clinical and non-clinical research.
- Create jobs and attract investment into our region.
- To work with organisations to build training programmes and expand the health informatics

Example – Northern England amongst worst for multiple health and social needs

Examining the relationship between multiple different metrics of health and wellbeing using clustering methods, researchers from Liverpool John Moores University identified 5 distinct clusters of public health need. Despite accounting for only 13% of all local authorities mapped, Northern England accounted for over 60% of local authorities in the worst cluster. Examination of health outcomes data on a smaller geographical area would allow us to pinpoint the areas of most need in the North West for the appropriate targeting of interventions and services.



Introduction

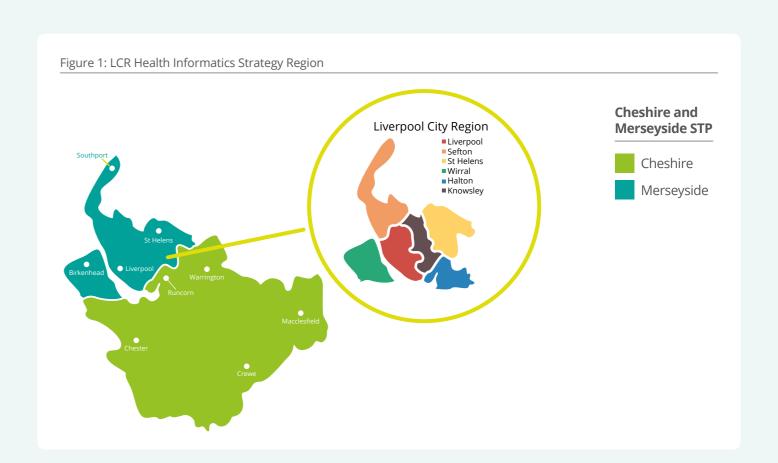
2.1. Why do we need a health informatics research strategy?

This is a crucial time for the LCR and the Cheshire and Merseyside STP (see Figure 1), as resources for health and social care are squeezed, whilst demand for access to services increases. At the same time power is being devolved from central Government with the establishment of the Combined Authority, coterminous with the LEP boundary, creating a functional economic geography that includes a critical mass of research bodies and innovation assets.

The formalised devolution agreement with the Government includes the creation of a £458 million Single Investment Fund, a Single Growth Strategy and now an elected Metro Mayor.

We are one of only 3 City Regions in England to have all of these developments, meaning that we have greater freedom to make major decisions that affect all of our lives, including those about health and investment in technologies. Health is a key concern for people in our region, and in order for it to thrive, improving the health of individuals, children, families and communities is essential. We have a proud and long tradition of working together with our universities, the local NHS, city and local councils and voluntary sectors to improve health.

Additionally, there are wider networks across our region that have already carried out a significant amount of work in data sharing (e.g. Health Information Exchanges and the Cheshire Care Record). Ensuring that the wide range of systems that influence health outcomes in our region can deliver the best possible health for everyone depends fundamentally on research (see Figure 2). This research depends on access to and timely use of highquality data.



Whilst there are a number of ongoing local digital and informatics initiatives, the main focus of most initiatives is on creating clinical systems. Crucially there is no overarching strategy for research, including non-clinical research, which is a threat to our future health and prosperity. People's health is influenced by political, social, economic, environmental and cultural factors. (Figure 3).

The greatest influences on our health and wellbeing are factors such as poverty, education and employment, housing and the extent to which our community facilitates healthy habits and social connection.

These determinants of health are, to some extent, under the influence of local organisations, but in the current climate many are struggling with budget cuts and increased responsibilities.

More than ever, organisations need to know what works best to inform targeting of increasingly scarce resources. In order to understand and improve the health of people in our region, it is necessary to make better use of the data we collect to understand factors that influence health over the course of people's lives.

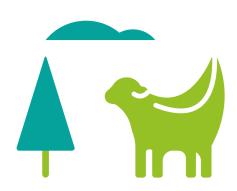


Figure 2: The stages of research

This is a schematic of the full research and adoption pathway, covering the whole spectrum from research design (which includes discovery and early phase research), research delivery (including recruiting patients into trials), adoption of research into practice (including implementation) and diffusion of best practice into the NHS.

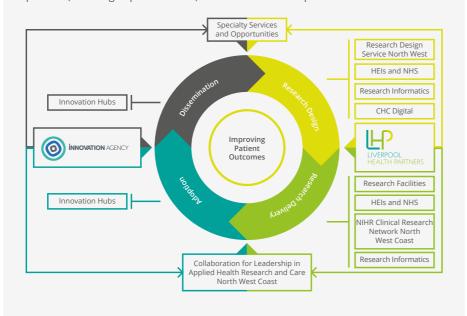


Figure 3: The factors that influence health in Liverpool

This figure illustrates the social determinants of health starting with the individual and their lifestyle and including social and community networks and general socioeconomic, cultural and environmental conditions.



2.2. The poor health in our region and the stark health inequalities

The LCR serves a population of nearly 1.5 million and includes some of the highest levels of deprivation and poverty across the country with some of its mortality rates 76% higher than the European average.

A baby girl in Liverpool can expect to live 15 fewer years in good health than a baby girl in Richmond, London. Similarly, adult health in the LCR is significantly worse than the England average for early deaths due to cancer and cardiovascular disease deaths; alcohol-related hospital stays; rates of hip fractures; sexually transmitted infections and people killed and seriously injured on roads. Figure 4 illustrates how life expectancy changes dramatically between areas in our region.

Liverpool Clinical Commissioning Group (LCCG) highlight that 30% of people in the city live with one or more long-term conditions, with Liverpool having one of the highest cancer mortality rates in England. In addition, LCCG state there are 93,000 people affected by mental health problems, and by 2021 there will be a 10.7% increase in the number of people living with dementia (Healthy Liverpool Blueprint, 2015).

This is a critical time for health in our region: health services, the city council and local voluntary agencies are under considerable pressure for resources. The Five Year Forward View is part of the health service response to this agenda. Key themes in the plan include supporting people to live better quality lives by working together with partners in local government and the voluntary sector to develop more joined up models of care; standardising quality of care and reducing unwarranted variation, and using the latest technology to support people in their own homes.





2.3. Harnessing data to respond to these challenges to improve health

There is international recognition of the potential for better use of data for research to improve the delivery of services at local levels, improve population health, and make new discoveries that can drive development and investment. Harnessing the rich data routinely collected within our region offers the opportunity to improve the lives of people now, and to establish an essential data resource for future research. For example, research using routinely collected data can help identify:

- Whether services are working effectively and inform service improvements.
- · Whether new technologies are being implemented and having an impact.
- Variation in mortality and associated causes.
- Previously unknown side effects (or beneficial effects) of treatments.
- · Causes of diseases.
- Genetic causes and determinants of diseases or response to treatments.

Using routinely collected data in this way will require the creation of a skilled workforce, including information technology experts, researchers, clinicians and managers, bringing investment and boosting employment.

The Welsh Secure Anonymised Information Linkage (SAIL) Databank is a population level data linkage system for Wales, established by Swansea University with funding from the Welsh Government. It now holds over 15 billion anonymised records of 4-5 million people. There is much learning that we can take from SAIL, including the collaborations required, the development of a robust governance framework.

SAIL began as a pilot in 2007, linking an extract of hospital and GP records, and social services data from a local authority area. SAIL now holds anonymised data from 80% of Welsh GP practices and large number of national datasets including: in-patient and outpatient records, emergency care, ONS births and deaths, screening services, Welsh Cancer Intelligence Surveillance Unit, Congenital Anomaly Register and Information

The SAIL databank has been the basis for over 160 research papers, spanning a wide range of topics, including:

- Evaluation of a housing programme offering early help to reduce demand on other services such as health and social services.
- Establishing a national multiple sclerosis registry hosted and linked to the SAIL databank.
- Clinical trials using routinely collected outcome data.
- The establishment of the Welsh Electronic Cohort of Children, which tracks over a million children born in Wales across health, education and social care.



2.4 This strategy

This strategy aims to put the people of our region at the forefront of the advanced analytics and health informatics research agenda, improving health and bringing in investment.

Huge amounts of data are generated and the volume and variety of data generated increases every year. Each visit to a GP, a hospital, or services provided by local councils (e.g. by schools or social care services) generates data. However, although a great deal of work has already gone into data sharing frameworks across our region, we do not currently have the infrastructure or systems in place to readily access and analyse these data for research purposes. This is to the detriment of our local population and is impeding our ability to deliver efficient services, monitor them, make discoveries, and attract investment into our digital economy.

To deliver this strategy we will need to overcome some significant challenges. There are clearly a number of technical, ethical and governance issues to address. However, the greatest initial challenge may be to encourage more local organisations to work together. Generally speaking there are major technical or governance problems preventing organisations from sharing data with one another; and there are barriers such as a lack of standardisation among data sets, and a lack of digital maturity across providers.

We desperately need to respond to the criticism and external view, that the health economy in our region is too fragmented; a view that has previously deterred investment.

Working with the public is also key to this strategy. We need to ensure the public are reassured about the security of their personal health data and the potential uses of it to facilitate research. However, at the same time, we must not let this impede their decision to consent to the sharing of their data among healthcare professionals providing direct care.

We need to ensure that privacy concerns are addressed, particularly given the lessons from Care.data, and also learn from the successes of health information exchanges nationally (e.g. Southampton and Leeds). We want to enable access to data for research that is in the interest of people in our region, at the same time as maintaining confidentiality and the highest standards for using data safely.

Action:

Appoint a Chief Officer to oversee the development and delivery of an implementation

Establish a board to oversee the delivery of the strategy and implementation plan.

Example – Co-location of GP at A&E reduces waiting times and hospital admissions

When Alder Hey Children's NHS Foundation Trust decided to introduce a GP on site, next to their emergency department, there was an opportunity for researchers to see whether this initiative had an impact on waiting times, hospital admissions and antibiotic prescriptions. Of over 5,000 children deemed appropriate to be seen by the GP, and after taking account of other factors that may explain some of the differences, children seen by the GP had shorter waiting times, were less than half as likely to be admitted to hospital, but were prescribed more antibiotics. This research would not have been possible if GP and hospital data were not available in a linked form.



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Learning healthcare systems

A primary goal of this strategy is to develop a learning healthcare system that uses information effectively, rapidly and intelligently to inform prioritisation, underpin improvements in the quality and efficiency of services, and enable innovation and scientific discovery. Whilst at a first glance this might seem an easy and obvious thing to do, it will require significant effort to bring our organisations and the public together. It will also require major investment in analytic and research capacity, ulitmately generating wealth and bringing investment in to our region.

Importantly we must 'close the loop' and ensure that analyses of data really do impact on health care. That is, we need to put research into practice effectively and efficiently for the benefit of our population.

Figure 5 illustrates the cycle of a learning healthcare system, starting with identifying a problem, designing and then implementing an intervention, evaluating that intervention, making necessary adjustments and wider dissemination. Through this process we will work with multiple stakeholders (e.g. the public, primary and secondary healthcare, public health, universities). Recent local examples include improving access to seizure clinics after presenting to the Emergency Department, or improving vaccine uptake rates.

From the perspective of this strategy, steps four and five evaluation and adjustment - are crucial. Evaluation will require analysis of a range of routinely collected datasets, the range of which is illustrated in Figure 6. In the first instance analyses may focus on Hospital Episode Statistics (HES) or primary care data such as those held by Egton Medical Information Systems (EMIS). To enable those analyses we require investment in infratructure, and staff creating a data storage facility, which will include a 'trusted researcher environment', as well as public consultation and the development of data governance processes.

Figure 5: A Learning Heathcare System This figure illustrates the cycle of a learning healthcare system, starting with identifying a problem, designing and then implementing an intervention, evaluating that intervention, making necessary adjustments and wider dissemination. Internal **External Evaluate** nalvse results to sho what works and what Internal and External Scan dentify problems and potentially innovative solutions. **Implement** evaluation based or control settings. (Figure adapted from Learning Health Care Systems and Justice (Ruth R. Faden, Tom L. Beauchamp, Nancy E. Kass). Hastings Center Report, Volume 41(4), July-August 2011) To be useful, those analyses must be timely. That requires mimimal time-lag between data being collected and being made available for analyses. Otherwise mutiple cycles of evaluation and adjustment will take many years, to the detriment of patients and services. At present, for example, there is a 3 month lag between HES data being collected and being made available by NHS Digital. We will deliver a local solution that enables real-time analytics. Similarly any analyses will need to be swift and presented in a way that is useful and accessible to clinical and managing teams.

Scientific discovery will come from further analyses of datasets held, which can harness the power of major assets in our region such as the Hartree Centre and IBM's Watson. The possiblities might include discovery of risk factors for disease, identification of unanticipated harms or benefits of treatments (e.g. drug repurposing). The most useful analyses will likely come from those that link various datasets held by different parts of the health service and other parties, enabling a broader view and better targeting of services for the population, and more rapid development of innovative solutions to the growing health problems within our region. Linking datasets and delivering these analyses poses significant challenges including the roll out of a consent model as well as major technical challenges. Analyses of linked datasets will be addressed in the latter phases of this strategy.

It is important to highlight that health data takes many forms and is often stored in such a way as to make it very difficult for researchers to access and analyse. To enable timely and efficient analyses of data, it is fundamental to our strategy to create a data storage facility with robust governance process that meet national standards, as described in the following sections.

Action:

Identify datasets for inclusion in the data ark, building on existing programs of work including the Global Digital Exemplar NHS Trusts, iLINKS, Informatics Merseyside, and NWC Connected Health Cities.

Example – ensuring appropriate pathways for people presenting with seizure

Following a national audit which highlighted variation in treatment for people presenting with seizure, researchers from the NWC have implemented a pathway to streamline referrals from the emergency department or medical assessment unit to neurology / seizure clinics. Data are fed back to trusts via reports and an interactive dashboard allow benchmarking of local services, creating a learning health system. Improvements in the number of admissions referred to outpatient clinics has already increased by over 50% since its introduction in

Figure 6: The Wheel of Data

This figure illustrates the range of datasets that are already routinely collected, starting with GP and hospital records, and including other health and social care records, and a range of non health datasets.





Regional data storage and access facility

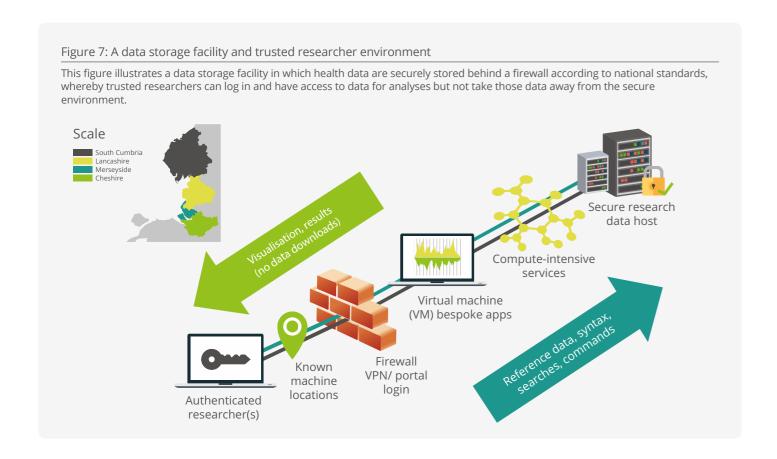
A key element of this strategy is the creation of a data storage facility that can collate and store data from a range of sources, and allow analyses by 'trusted researchers'. Whilst there are a range of NHS informatics initiatives in our region that underpin or link clinical services and data, none allow for the storage and use of data for research; the primary objective of this strategy.

The creation of a data storage and access facility requires significant technical know-how and a complex governance structure that meets the requirements of legislation as well as those of our local population. It also requires investment in infrastructure and the workforce.

We can learn from, and adopt, best practice from similar projects elsewhere in the UK that are more advanced in their development. For example, A Charter for Safe Havens in Scotland (2015) details a baseline set of principles for ethical uses of data that are in the public interest, which are scientifically sound, and have patient identity and privacy appropriately protected.

We plan to create what is currently being called a Trustworthy Research Environment' (TRE) that allows authenticated researchers access to data in order to undertake analyses. One model that is being used is in Genomics England's 100,000 Genomes project. The TRE is configured such that only outputs of analyses (but not the source data) can be taken away (exported).

This way of working influenced the Phase 1 design for data access in the North West Coast Connected Health Cities (CHC) (a partnership between the Innovation Agency (Academic Health Science Network for the North West Coast), Universities of Liverpool and Lancaster, and AIMES Grid Services) project which currently holds anonymised (no patient identifiable data) hospital episode statistics data and is visualised in Figure 7 below.



4.1 Architecture and Infrastructure

Table 1 summarises a number of relevant and ambitious initiatives addressing aspects of health informatics research. When developing our plans for a regionally-scalable data storage and access facility, it is imperative that we are clear in what we want to achieve. In the CHC design, it has been recognised that the power of health informatics for radically improving research performance falls into a series of practice domains or use cases (green boxes, below). This demarcation is useful because each application area could share technology/infrastructure with subtle differentiating factors in deployment. This efficiency will be key to delivery and the risk of fragmentation of solutions must be strongly avoided.

Public Health

Clinical Research/Discovery Science

Citizen-Driven Health

Personalised/Precision Medicine

Action:

Identify the requirements and best provider of a data ark/ repository and commission its development.

Table 1 – Shortlist of digital strategies, initiatives and recommendations guiding development of the Regional-scale Data Storage and Access (TRE) Facility

Liverpool iLINKS Strategy (2014-2017) http://www.imerseyside. nhs.uk/Library/innovations_and_developments/ilinks_informatics_ transformation_strategy_2014_2017.pdf

Merseyside Digital Roadmap http://www.ilinksmersey.nhs.uk/ media/1554/the_merseyside_digital_roadmap.pdf

Intra-Region Digital Exemplar strategies e.g. for the Global Digital Exemplar Trusts: The Royal Liverpool and Broadgreen University Hospitals NHS Trust, Alder Hey Children's NHS Foundation Trust, Wirral University Teaching Hospital NHS Trust, Mersey Care NHS Foundation Trust and the Fast Followers programme.

A Charter for Safe Havens in Scotland (2015) http://www.gov.scot/ Publications/2015/11/4783/4

The Digital Economy Act (2017) is now in force and provides a UK regulatory framework for the use of data for research in an effective, safe and secure manner; see Chapter 5: Sharing for Research Purposes http://www.legislation.gov.uk/ukpga/2017/30/contents/enacted

Liverpool PRIME: Precision in Medicine proposals (details available from LHP)

The Wachter Report https://www.england.nhs.uk/digitaltechnology/inforevolution/wachter-review/

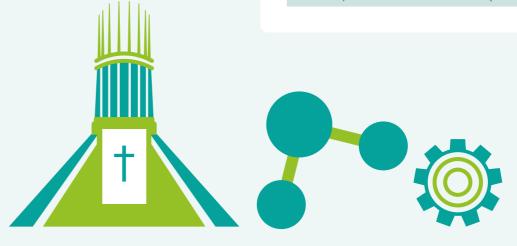
UCL Partners Health Informatics Strategy (2014-2017) http:// uclpstorneuprod.blob.core.windows.net/cmsassets/UCLP%20 Informatics%20Strategy

NHS England Target Architecture for Learning Health Systems

The National Data Guardian https://www.gov.uk/government/ organisations/national-data-guardian

NHS system supplier expertise and technologies e.g. EMIS Web, Cerner, Tiani Spirit, InterSystems, Endeavour Health, Patients Like Me, Patients

Expertise in national and international informatics initiatives e.g. NHS Digital, Regional CSUs, The Farr Institute for Health Informatics Research, Health Data Research UK (HDR UK), GA4GH, BRCs, HL7 UK etc.



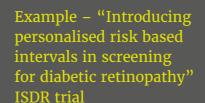
Patient and public involvement and engagement

Patient and public involvement and engagement (PPIE) is key to this strategy. It is vital that we clearly and effectively communicate the potential benefits to the health and wealth of our population in terms of using personal health data for research. It is also paramount that we consult and work with our population to identify ways of using data that are acceptable and to reassure them of the use of their data for research, whilst not impacting on their consent to share data for clinical purposes.

To achieve this, we need to develop an effective dialogue with people in our region, enlisting trust and active involvement, about how we would like to use their data across a range of agencies, both within the NHS and beyond, including partnering with industry (as appropriate) to achieve breakthrough research objectives. Learning from other successful organisations, such as those in Manchester, Leeds and Southampton, and working with colleagues within the patient engagement teams across the Cheshire and Merseyside STP footprint, will be imperative to our success.

We will achieve our PPIE objectives by a multifaceted approach, through identifying and developing a relationship with key citizen engagement and public involvement groups within our region. This engagement will be facilitated by using social media and creating digital areas for dialogue blogs, web areas, social media, events and twitter chats.

We will also work with other organisations and stakeholders, such as Cheshire and Merseyside STP, SMEs, Healthwatch, Health North and technology partners, industry and universities, to enhance partnership and collaborative working. The aim being to ensure involvement from diverse groups, including those that are hard to reach, and to avoid duplication with other initiatives.



One of many complications seen in people with diabetes is diabetic retinopathy – damage to the retina (the back of the eye) which can cause blindness if not diagnosed and treated. Current recommendations in England suggest screening every 12 months but the evidence behind this is very limited, with potential for better targeting of services. The University of Liverpool and The Royal Liverpool and Broadgreen University Hospitals NHS Trust are running the ISDR trial, which is integrating diagnostic data from hospitals, demographic data from GP practices and imaging data from eye-clinics to calculate an individual's risk of developing retinopathy. Based on this they will be called back for screening at either 6, 12 or 24 months. This study has necessitated the creation of bespoke data sharing systems as mechanisms to link these different sources of data are not presently available in our health data architecture.



5.1. Benefits

Our PPIE will help to inform the development of the programme of work and help gain trust from the public in the data sharing model. Data will, for the most part, be used in an anonymised form, but should data be required to be used in a patient identifiable format additional consent will be sought and safeguards put in place.

Engagement with our community will help assist in the development and implementation of a "Model for Consent". Citizens will be able to view the extent and degree of their consent to data sharing and to have control over it.



Obtaining consent from patients to use their personal health data for clinical research is a fundamental step in the success of this strategy. We need to understand what motivates patients to provide this consent and, more importantly, to establish what barriers may present and how they can best be tackled. In the development of this strategy, some PPIE work has already taken place.

In collaboration with several organisations from within LHP, a series of 'vox pop' interviews from a number of pre-selected locations around Liverpool were conducted. We were able to gather the opinions of members of the public through asking them the following questions:

- **Q1.** Do you think it is important to support clinical research in the NHS? Why is that?
- **Q2.** When you visit your doctor or nurse you share personal health data, would you be happy if this data was shared with clinical researchers in the NHS?
- **Q3.** Do you have any concerns about the sharing of your personal health data?
- Q4. If your personal health data could be made anonymous when shared would you still have any concerns?
- Q5. Would you be happy if we shared personal health data with other researchers in life science companies that may be outside the NHS?

The video of responses can be viewed here: http://www. liverpoolhealthpartners.org.uk/

We recognise that this initial PPIE work provides only a snapshot of opinion and much more detailed engagement will be required in the next steps of this strategy.

Action:

Undertake a programme of work on public engagement to describe the benefits of data use for research and identify uses that are acceptable to the population of our region.

Example – University of Liverpool researchers have developed a data linkage at small area level

The Integrated Longitudinal Research Resource (ILRR) allows researchers to extract, manage, and link data from diverse, datasets for policy relevant analytics, including consumer, finance and welfare datasets not routinely used in applied public health research. Through a collaboration between the NIHR CLAHRC North West Coast, the ESRC funded Consumer Research Data Centre and 10 local authorities across the North West we have established an Integrated Longitudinal Research Resource (ILRR) of linked neighbourhood datasets, enabling the tracking of the determinants of health and health outcomes within neighbourhoods.



Permissions and consent governance

There is a complex range of legislation and permission required for the use of health data for research, which largely depend upon the type of data and the intended use. It is essential that we work with the public, as described above, to navigate these processes when we create our learning health system.

In England, some uses of anonymised data (data are considered anonymised if they do not include information that allow an individual to be identified, such as date of birth or NHS number) do not require individual patient consent (e.g. in public health, audit, NHS service improvement and some research studies). In the early phases of this strategy the focus will be on the use of these data given the complexities of setting up systems to manage patient consent, as described below.

Other uses of data do require individual patient consent, such as uses that require linkage of records from a number of systems. In this circumstance, the NHS number is commonly used as a unique identifier to link data. Data linkage can be undertaken by a trusted third party who then removes patient identifiers to provide researchers with anonymised data. One example of a linked system in our region is the Healthy Wirral Care Record (WCR), which links data from primary care, Wirral University Teaching Hospital NHS Foundation Trust, community, mental health and social care etc. In the WCR, consent for use of data is managed with the GP record as a central point.

It is important to realise that consent is multi-layered (Figure 8). For example, patients may choose to share anonymous data with some parties (e.g. other health service organisations) but not others (e.g. industry), may want to restrict which data are shared, and will need the ability to change those permissions. In the WCR, if a patient opts out of sharing of the record there is a Read Code set on the primary care system (EMIS). This code prevents data held in EMIS for that patient being shared, and also prevents sharing of data from other sources. In addition, national standards exist that exclude the sharing of certain data items, for those that do not opt out of sharing.

Facilitating patients to opt in or out of sharing their personal information, for reasons other than their individual care and treatment, is the subject of an English national development by NHS Digital that is proposed for operation from late 2017. It follows on from the National Data Guardian's (NDG) review of data security and consent of July 2016. The patient opt out preferences will be stored in a central repository and systems will be made available so that it can be securely accessed and applied when personal information is being shared between organisations for purposes.

The General Data Protection Regulation (GDPR, https://ico. org.uk/for-organisations/dataprotection-reform/overview-of-thegdpr/), which becomes effective in May 2018, identifies additional and more sophisticated requirements to capture and manage patient permissions for research. For example, the ability to include or exclude specific episodes of care, and the need for interoperability of systems.

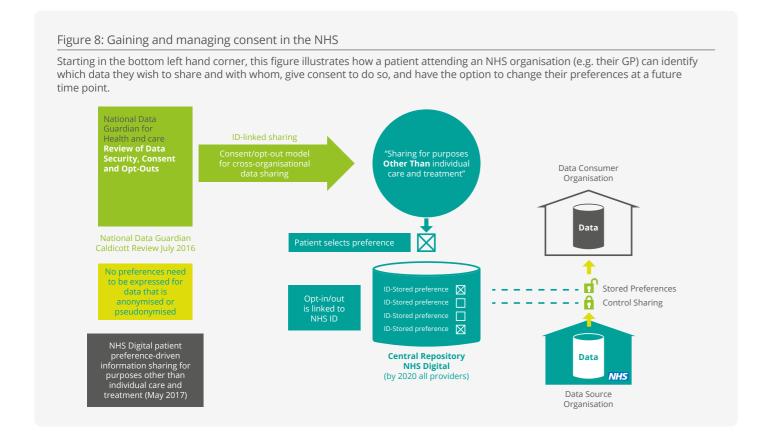
We need to work towards creating an infrastructure that meets all of these requirements and enables the people in our region to contribute their data and to participate in research. Whilst the text in this section has focussed on information technology, the importance of working with the public and integrating this into the day to day working of our health services must be emphasised. This can only work if seamless processes are put in place to capture consent and permissions at time points where patients interact with health services.

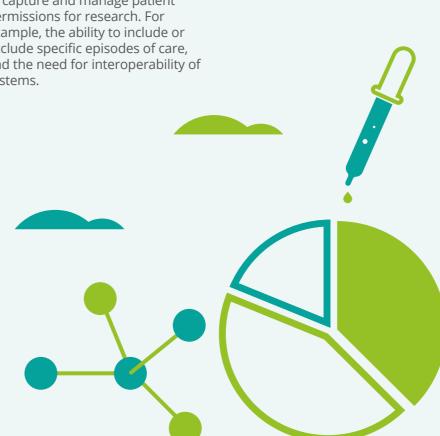
Action:

Identify the best model for gaining consent to share data for research in keeping with national governance standards.

Example – UK birth cohort shows impact of transition into poverty

Using a specially conducted study – the Millennium cohort study – which collected information on children from across the UK born between 2000 and 2002, researchers from the University of Liverpool were able to show that transitioning into poverty was associated with an increase in childhood social and behavioural problems. This study collected data directly from participants (socioemotional behaviour) and also used data from government agencies including the Department of Work and Pensions (benefits) and the Department for Education (educational achievement). We plan to create a similar anonymised population level child health and development dataset for all children in Liverpool from existing data sources to allow researchers and policy makers to improve child health in our region.





Current local and regional initiatives

LHP serves to ensure close collaborative healthcare research through University of Liverpool and Liverpool John Moores University working together with local NHS organisations.

This complements the ongoing digital initiatives locally and regionally, including our region's hosting of four of the NHS's Global Digital Exemplar Trusts (GDEs); and we are the only area in the UK that has such a concentration of GDEs. These initiatives (Table 2) underpin this strategy and place our region in a strong position to succeed.

We are creating a sharing environment that enlists the trust, and active involvement, of NWC citizens.

Table 2. Local and Regional Digital Initiatives				
Initiative	Lead organisation	Brief description	Project ambitions / objectives	Further information
The Merseyside Digital Roadmap	Liverpool CCG	A strategic plan in response to the NHS Five Year Forward View requirement to improve health and care services by the increased and improved use of information and technology.	 Digitally empowered individuals A connected health and social care economy Exploiting the digital revolution 	http://www. ilinksmersey.nhs.uk
EMIS Health	EMIS Health	Leading supplier in connected healthcare software and services in the UK. EMIS Health and the LCR have enjoyed a long and successful relationship with Liverpool CCG and Informatics Merseyside being key strategic partners through the EMIS Pathfinder Programme.	 Deployment of EMIS Web in Walk-in Centres Electronic Patient Record (EPR) Viewer Mobile working 	https://www. emishealth.com/ home/
FARSITE	NWeHealth	A powerful search and patient administration tool that allows the rapid identification of, and easy communication with cohorts of patients drawn from primary care information systems for the purposes of research and population health management.	 To recruit over 90% of GP practices in Liverpool and surrounding environs to use FARSITE. To develop relationships with Industry to mount large scale trials that can test new drugs, devices or models of care quickly. Population health management interventions to be designed and implemented to achieve meaningful and lasting improvements in the health and wellbeing of patients in our health economy. 	http://nweh.co.uk/ products/farsite
NWC Connected Health Cities (CHC)	Innovation Agency (Academic Health Science Network for the North West Coast)	NWC CHC is funded by the Department of Health and brings together the Universities of Liverpool and Lancaster, the Innovation Agency (Academic Health Science Network for the North West Coast) and AIMES Grid services. The programme is creating learning healthcare systems.	 Making information available to front-line staff in timely ways that enable them to better plan and review the care they offer; and develop new and more effective pathways. Harness the power of data and data analytics by collecting, linking and collating data from health and social care and eventually from a wide range of other sources – finding new ways to use data to transform care. Support industry and academia and others in using data to conduct research that both improves understanding of health care efficiency and effectiveness and enables new techniques, ideas and organisational forms to be tested. Create a sharing environment that enlists the trust and active involvement of North West Coast citizens. 	http://www. connected healthcities.org/ connected-health- cities/north-west- coast/

Initiative	Lead organisation	Brief description	Project ambitions / objectives	Further information
iLINKS Informatics Transformation Programme	Liverpool CCG	A shared vision of Liverpool CCG, South Sefton and Southport and Formby CCGs, to improve health and social care by providing professionals with the information they need to work and share collectively around the individual.	 Create and deliver an information exchange across health and social care. To ensure informatics system-wide coherence and strategic leadership across health and social care. To exploit the benefits and investment of existing future technologies and processes. 	http://www. ilinksmersey.nhs. uk/
		Global Digital Exen	nplars (GDEs)	
Alder Hey Children's NHS Foundation Trust (AHCH)	AHCH	NHS England's only specialist children's GDE.	 Paperless medical record Web portal for patients and families. Web portal for healthcare professionals. Patient 'app' platform. Collaboration with Hartree Centre and IBM Watson to create the UKs first 'Cognitive' hospital. 	http://www. alderhey.nhs.uk/
The Royal Liverpool and Broadgreen University Hospitals NHS Trust (RLBUHT)	RLBUHT	'Digital Liverpool' is RLBUHT's digital vision and strategy underpinned by it's GDE programme. With health and social care partners across the city, RLBUHT, through its GDE, will revolutionise patient and staff experience, transform quality and safety of its services and produce better health for the population.	 Digital Innovation New Royal Digital Transformation Electronic Patient Record 	http://www.rlbuht. nhs.uk/
Mersey Care NHS Foundation Trust (MCT)	MCT	One of seven Mental Health GDEs in England.	 Flip the Clinic Digitisation is about people, not just technology. 	http://www. merseycare.nhs.uk/
Wirral University Teaching Hospital NHS Foundation Trust (WUTH)	WUTH	WUTH is leading a programme of work in Wirral as part of the GDE programme. As well as developing the digital platform in the hospital, the community of provider organisations in Wirral are working to create a new shared Wirral Care Record (WCR). This will support clinicians/carers on the 'front-line' of care delivery as well as the system as a whole as it works to manage the health of the population.	 Organisation level electronic patient records – based on the very mature GP records in the EMIS system in primary care WCR will also contain data from the other providers as shown above. Thus the content of the individual systems is a basic building block. Creating a single population long term record – as data flows from EPRs into the WCR, it goes through a series of algorithms to create a single unified view of the data which dedpiulicates and normalises the data to make more sense of it to the end user and also make it easier to analyse. Registries / Care Plans – the data allows us to target specific disease groups and link the data from the various organisations to provide a single view of the patient, in a set of wellness and condition based registries. These assist clinicians to identify what has been done for the patient already and also those things that have not yet been achieved for each patient. Analytics – by bringing together all of the health issues and identifying the resources deployed in each sector to deliver care, WCR is a rich source of data to understand how to manage population health and where best to apply scare resource. Future – in future we would expect the patient to be more involved digitally in this process and for example services like puffel.com will be linked to the WCR. 	http://www.wuth. nhs.uk/patients- and-visitors/

Table 3. Informatics strengths within our local Universities

University

Summary of informatics strengths

University of Liverpool (UoL) Ranked in the top 1% of higher education institutions worldwide, the University of Liverpool (UoL) is a comprehensive university of global reach with campuses in China and Singapore.

In collaboration with its partners, UoL has developed an ambitious programme of health and biomedical informatics research, tackling important global challenges at scale, initiating new business links, influencing policy, and improving health and social environments. Over 50 academics across UoL carry out interdisciplinary health and biomedical informatics research. The UoL Healthcare Data Laboratory, established as part of the Connected Health Cities programme.

UoL uses novel informatics approaches to answer important clinical and public health questions. It supports industry, academia and others to conduct research in its theme areas to improve understanding of health care efficiency, the benefits of treatments and minimizes risk, and also enabling new techniques, ideas and organisational forms to be tested.

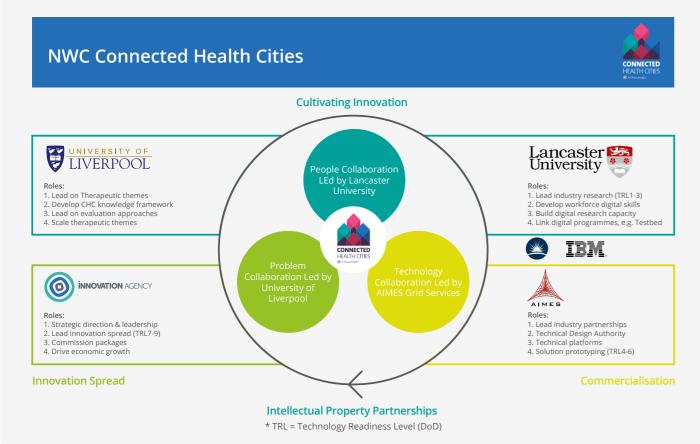
Liverpool John **Moores University** (LJMU)

LJMU is a modern civic university with a long history of applied teaching and research responding to the needs of external stakeholders including the NHS. LJMU won the 2017 Educate North University of the Year award, and has the highest number mainstream journal published articles co-authored by international collaborators of any University in the UK.

LJMU offers degree apprenticeships working alongside employers to enable students to develop practical skills within the workplace. Health research, scholarship and knowledge exchange within LJMU is embedded within the Institute for Health Research (IHR) which has a portfolio of cross disciplinary expertise and facilities including digital health, applied health informatics and health service delivery needs analysis.

Figure 9: North West Coast Connected Health Cities

This figure shows the partners in this programme and what they plan to deliver.



Generating wealth

The LCR has a population of 1.5m and a £28.3bn economy. This is a crucial and exciting time as power is being devolved to the region from the central Government, with a Devolution Deal agreed with Government in 2015, the LCR Combined Authority established and the election of a first ever LCR Metro Mayor (Steve Rotherham) in May 2017.

Devolution provides an opportunity for LCR to direct its economic future, to build on recent success and to address the challenges, in particular those relating to inequalities mentioned above.

The LCR Growth Strategy (published June 2016) provides a 25-year strategic approach to how growth will be driven forward across the City Region via three pillars of Productivity, People and Place, and building on LCR's unique strengths and assets. The Growth Strategy, through consultations with the City Region's partners and key stakeholders, has identified a framework for devolution and the achievement of long-term sustainable economic growth. Key to implementation of the Growth Strategy is the attraction and focused allocation of investment. The Single Investment Fund (SIF) has been established to fund delivery of the Growth Strategy. Over the next five years the SIF will invest £458 million. This resource will help leverage private sector and external investment opportunities as they become available.

Initiatives aligned to the Growth Strategy/SIF will:

- Build on key assets: including LCR's role as a unique global port and a world-leading centre for innovation and achievement in science, culture and civic life.
- Focus on growth sectors: investment will be maximised by strategically focusing on those sectors with the greatest potential.
- Respond to challenges: including long-established challenges regarding levels of health, business, jobs, worklessness, productivity, skills and spatially concentrated deprivation.

The outcomes that the Growth Strategy will deliver across its three pillars by 2040 can be summarised as:

- 100,000 additional jobs
- A net increase of 20,000 businesses
- An additional 50,000 people living in the City Region
- An increase in the City Region's economy to around £50bn.

The ambition of the Growth Strategy is for each sector to become a beacon of excellence, productivity and accelerated growth through investment in facilities, infrastructure, networks, people and innovation, creating more and higher skilled jobs and more growth businesses. Sector based interventions will focus particularly on those activities that accelerate growth, apply innovation commercially and deliver increased productivity.

Sectors identified in the LCR Growth Strategy include Digital and "Health and Life Sciences", which clearly align with the development of the LCR Health Informatics Research Strategy. In addition, the LCR has been recognised through the Government's Science and Innovation Audit (SIA) process as having world leading capabilities in infectious diseases, materials chemistry and high performance/ cognitive computing, with further commercial programmes in these areas under development.



Colleagues responding to the recent Government Industrial Strategy Green Paper also highlighted the need to ensure that new informatics and digital health approaches are established across the UK to unlock NHS data for research and innovation.

The LCR LEP and Combined Authority work together to deliver the Growth Strategy for the City Region. The LEP provides strategic advice and guidance on economic development priorities while the Combined Authority brings democratic accountability and oversight for the City Region.

In addition, the LEP provides links into large companies and SMEs active in the health, life science and digital sectors, and supports inward investment with partners, including Invest Liverpool (http://www. investliverpool.com/). Furthermore, organisations such as the Innovation Agency (Academic Health Science Network for the North West Coast) (http://www.innovationagencynwc. nhs.uk/) support the deployment of digital innovations from companies into the healthcare system and groups such as the eHealth Cluster (http://www.ehealthcluster.org.uk/) provide a network of technology and health sector organisations. The LCR Health Informatics Research Strategy clearly supports the LCR economic policy to grow and develop sectors/ businesses, to increase prosperity.

Action:

Identify workforce research health informatics training needs locally and develop and strengthen education programs for that workforce.

Example – identifying and targeting groups to increase access to vaccines

Vaccines are amongst the

most cost-effective tools for improving health and can provide benefits crossing social and deprivation boundaries. Combining data from local CCGs (Liverpool, Sefton, Wirral, Knowlsey, St Helens), hospital episode statistics and vaccine delivery records researchers from University of Liverpool, PHE North West, Liverpool CCG and the local council have studied uptake of vaccines across Merseyside, the burden of rotavirus and influenza vaccine-preventable disease and the association with deprivation. Vaccines prevent more disease per dose delivered in the most deprived groups, yet the same sectors of society have the poorest coverage. The results have led to work to provide education and ways of improving vaccine access amongst the most deprived and least engaged groups of the Merseyside population.



Phased approach

This document outlines an ambitious health informatics research strategy for the LCR. Whilst planning the implementation and delivery of this strategy is beyond the scope of this document, it is clear that the operationalisation of the strategy will require a phased approach and careful planning (Figure 10).

Additionally, the parts of our region that will become involved in this initiative will need to follow a phased approach; the work will initially start in Liverpool, and then across the wider LCR, and with partnership working within the different parts of Cheshire and Merseyside, spread to the whole local STP footprint. Ultimately, we will link with initiatives throughout the whole of the North West Coast, working in partnership with the wide range of academic and healthcare institutions, in addition to the Innovation Agency (Academic Health Science Network for the North West Coast).

Action:

Develop a programme of work in phases, initially identifying key clinical pathways/services for data analyses, but building it up to encompass the whole healthcare economy, utilising the significant expertise and experience already present in our region.

Figure 10: A phased approach

This figure illustrates the phased approach that the implementation and delivery of this strategy will require, starting with local initiatives and exemplars, progressing to more complex structure and analyses, and to wider involvement across the region over time.

Public engagement and consultation	Consent for health service data use Anonymous level data Linked data (NHS number)	Consent for research use Health service and university / public sector	Consent for third party
Clinical and research examples	Prioritise clinical pathways / research exemplars	Second wave	Wider use
Regional-scale Data Storage and Access Facility	TRE Phase 1: anonymised, retrospective dataset access	TRE Phase 2: Prioritised clinical domain dataset access	TRE Phase 3: Learning cycle actionable data; near real-time
Trusted researcher environment and data analyses	HES – anonymous	Linked datasets (HES and others linked by say super output	Linked datasets (HES and GP prescribing linked by NHS number)
Wealth generation and capacity development	Consolidate	Public sector grants	Industry

Appendix A

As a key initiative of LHP across the LCR, and working with the wider Merseyside and Cheshire regions, in order to develop and produce this strategy, LHP established both a Health Informatics Research Strategy Steering Group and Task and Finish Group with broad representation from organisations across the region.

LHP would like to thank all organisations involved on this project, and will continue to work in partnership across our region in implementing the strategy.

LHP, a strategic partnership of 9 NHS organisations and 3 universities, encompasses the following organisations (all represented on LHP Board):

Aintree University Hospital NHS Foundation Trust

Alder Hey Children's NHS Foundation Trust

Clatterbridge Cancer Centre NHS Foundation Trust

Liverpool Clinical Commissioning Group

Liverpool Heart and Chest NHS Foundation Trust

Liverpool John Moores University

Liverpool School of Tropical Medicine

Liverpool Women's NHS Foundation Trust

Mersey Care NHS Foundation Trust

The Royal Liverpool and Broadgreen University Hospitals NHS Trust

The Walton Centre NHS Foundation Trust

University of Liverpool

Additionally, for the purposes of this project, LHP also worked in partnership with the following groups and organisations:

LCR Health Informatics Research Strategy Steering Group

Members:

Professor Sir Munir Pirmohamed (Chair) – Executive Director, LHP

Dr Keith Bodger - Senior Lecturer, Department of Biostatistics, University of Liverpool

Paul Charnley - Chief Information Officer at Wirral Teaching Hospitals **NHS Foundation Trust**

Dr Ed Conley – Chief Scientific Officer, AIMES

Dr Alan Davies – Digital Associate, Innovation Agency (Academic Health Science Network for the North West Coast)

Paul Davis - Head of Commissioning, Primary Care and Commissioning, **EMIS**

Dr Kate Fleming - Senior lecturer in Public Health Intelligence and Statistics, Liverpool John Moores University

Professor Christiane Hertz-Fowler – Centre Manager, Centre for Genomic Research Functional and Comparative Genomics, University of Liverpool

Jim Hughes – Director of Informatics and Performance Improvement and Chief Operating Officer - Corporate Division, Mersey Care NHS Foundation Trust

Mark Jackson – Liverpool Heart and Chest Hospital NHS Foundation Trust

Professor Tony Marson – Professor of Neurology, Molecular and Clinical Pharmacology, University of Liverpool and Clinical Lead for Connected Health Cities, Liverpool.

Professor Simon Maskell - Professor of Autonomous Systems, University of Liverpool

Professor David Taylor-Robinson – Public Health and Policy, University of Liverpool

David Walliker - Chief Information Officer at Liverpool Women's Hospital NHS Foundation Trust and The Royal Liverpool and Broadgreen University Hospitals NHS Trust

Kate Warriner – Healthy Liverpool Digital Lead and Royal Liverpool Global Digital Exemplar Programme Director

Rosalind Way - Director of Operations, LHP

John Whaling - Strategic Investment Lead - Superport & Innovation for Liverpool Local Enterprise Partnership

Sarah Wright - Strategic Projects Manager, LHP

Peter Young - Chief Information Officer at Alder Hey Children's Hospital **NHS Foundation Trust**

Appendix A

LCR Health Informatics Research Strategy Task and Finish Group

Members:

Professor Tony Marson (Chair) – Professor of Neurology Molecular and Clinical Pharmacology, University of Liverpool and Clinical Lead for Connected Health Cities, Liverpool

Paul Charnley - Chief Information Officer at Wirral Teaching Hospitals NHS **Foundation Trust**

Dr Ed Conley - Chief Scientific Officer, AIMES

Graham Downhill - Product Manager, EMIS

Professor Christiane Hertz-Fowler – Centre Manager, Centre for Genomic Research Functional and Comparative Genomics, University of Liverpool

Professor Neil French - Clinical Academic Lead for Infection, LHP

Dr Kate Fleming - Senior lecturer in Public Health Intelligence and Statistics, Liverpool John Moores University.

Dave Horsfield - Digital Innovation and Research Lead, Liverpool CCG

Jim Hughes – Director of Informatics and Performance Improvement and Chief Operating Officer - Corporate Division, Mersey Care NHS **Foundation Trust**

Professor Simon Maskell – Professor of Autonomous Systems, University of Liverpool

Debbie Parkinson – Public Involvement Lead, Innovation Agency (Academic Health Science Network for the North West Coast)

Professor David Taylor-Robinson – Public Health and Policy, University of Liverpool

David Walliker – Chief Information Officer at Liverpool Women's NHS Foundation Trust and The Royal Liverpool and Broadgreen University Hospitals NHS Trust

Rosalind Way - Director of Operations, LHP

Professor Paula Williamson - Professor of Medical Statistics, University of Liverpool

Sarah Wright - Strategic Projects Manager, LHP

Peter Young - Chief Information Officer at Alder Hey Children's NHS **Foundation Trust**

Other groups / organisations / key individuals:

Professor Andrew Morris, Director of Health Data Research UK

LHP Board

Innovation Agency (Academic Health Science Network for the North West Coast)

Informatics Merseyside

Cheshire and Merseyside STP

Cheshire and Merseyside STP Digital Group

Cheshire and Merseyside Clinical Informatics Advisory Group

NIHR Clinical Research Network North West Coast

NWeHealth

Key linked publications:

Healthy Liverpool Blueprint

The Merseyside Digital Roadmap (2016-2021)

iLINKS Informatics Transformation Strategy (2014-2017)

Partnership Working



Global Digital Exemplar Trusts:





























