Care and Health Informatics theme (CHI) Strategy and progress

V3.0

Contents

Document purpose and audience

This document shows an updated set of aims and objectives for the CHI theme, and outlines progress towards meeting them. It is intended to be an open and accessible description of what we do, which is suitable for all ARC stakeholders.
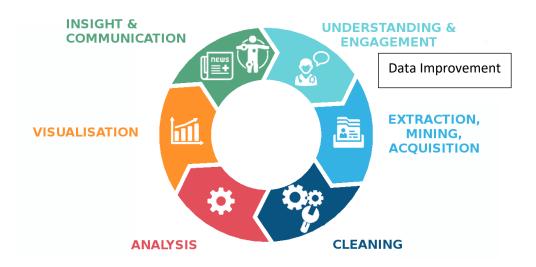
CHI theme vision

Poor integration of data sources, infrastructure and data scientists has impeded effective research and implementation in the North West Coast region. We will help to unlock this potential by bringing people and data together on infrastructure tailored to meet the needs of modern data usage.

Our ultimate vision is to link and utilise data within a databank system that is flexible and capable of being used by researchers to generate evidence to demonstrate changes in health and wellbeing. These changes are either as a direct result of policy (for example health service improvements) or indirectly, as a result of austerity followed by changing council and charitable provisions, for example, social and private housing repairs.

Delivering the vision

To achieve this, the Care and Health Informatics team (CHI) works across the whole care and health data lifecycle.

This will mean different things for different projects, but may include:

1. **Understanding & engagement**: We speak to patient facing staff and researchers to understand their research questions and identify where we can support ARC research with our expertise in software, tools, or data.

2. **Extraction, mining, acquisition**: We extract data from health records, generate datasets through techniques such as text mining and process local authority data. We also acquire additional datasets relevant to health from a variety of sources.

3. **Cleaning**: We spend A LOT of time assessing data quality and preparing data for use in research. This could include e.g. removing duplicate information, correcting any obvious errors, deciding what to do when large chunks of data are missing. We also may remove identifiable information or link to additional data sources.

4. **Analysis**: We look for trends and associations in data, aiming to generate robust evidence using appropriate data and methods.

5. **Visualisation**: We generate visualisations of data to help find and summarise information from it. This has included maps and virtual reality.

6. **Insight and communication**: Our outputs of our work feed into front line care, public communication, and academic journals.

In order to deliver the vision, have three overarching Aims with fourteen Objectives allied to one or more of them.

Aims

We have three main overarching aims in CHI with ***our ultimate vision of linking data within a system that is flexible and capable of generating evidence to improve health and wellbeing:***

1. Develop a network of linked data and a library of data methodologies.
2. Grow data science research capacity & capability in the region.
3. Deliver informatics research for care equity and health equality.

CHI is a new crosscutting theme (there wasn't a distinct similar theme in the NIHR CLARHC NWC) which supports the other themes. To do this, we need to operate directly with projects undertaken by themes in ARC NWC, as well as nurture/invest in new overarching infrastructure and data projects (both internal and external to the ARC) which will benefit the other themes in the future.

The fast-paced change of technology, data, legislation, and the organisational structure of health and social care means that CHI must be nimble to respond to external influences. This, in conjunction with the unknown nature of the projects the other themes may instigate, means that we need a broad skills base and good relationships with stakeholders.

Balancing the resource requirement between multiple short-term projects and long-term projects is key. The ARC project prioritisation process means that projects are engaged with CHI at an early development stage, ensuring that we can help shape the projects in a way to most effectively deploy CHI resources. The CHI public advisors and co-leads will also play a vital part in prioritising the projects we take forward and support.

Objectives

Short-term (1-2 years) (1/10/19 - 30/9/21)

Co-produce with Liverpool Health Partners (LHP), building on HDRUK gap analysis, a green paper sub-regional pilot recommending how to combine and refine digital infrastructure to improve data-uses for enhanced public benefit.

1. Build ARC member and Public Advisor-approved data governance processes into the CDC/CIPHA for nimbly addressing key public health challenges, improving care pathways and equity.
2. Co-develop CHI training and knowledge exchange between academics, Partners and Public Advisors.
3. Co-produce relevant clinically informed, longitudinal small-area indicators for targeting services, deploying care pathways and evaluating service redesign.
4. Secure additional funding to ensure core CHI team is well resourced.
5. Establish new collaborations at the local, regional and national level to foster the exchange of knowledge, align techniques/approaches and facilitate future collaborative grant applications.
6. Develop process for CHI project/resource prioritisation.
7. Develop FAIR/open science strategy for the ARC NWC.

Medium-term (3-4 years) (1/10/21 - 30/9/23)

1. Build on regional digital systems for effective local commissioning, co-developing a person-level digital cohort.
2. Publish a library of public metadata and documentation making CHI-Net data and analytic resources easy to find, access, interoperate, and re-use.
3. Submit at least two significant collective grant applications that test regionally generated algorithms on other regional or national population samples (e.g. Clinical Practice Research Datalink, CPRD); undertake all funded projects.
4. Create new visualisation and scenario planning tools for multi-disciplinary co-production of Learning Health System research questions with implementation solutions, tackling challenging areas such as alcohol care pathways, and building on our previous work (incorporating extensive P&CIEP).
5. Ensure data collection design aligns with the Health Equity Mainstreaming Strategy in partner organisations.

Long-term (5+ years) (1/10/23 - 30/9/24)

1. Produce an advanced library of population risk-stratification and clinical prediction methods for reducing multimorbidity in unscheduled care, and informing service re-design for integrated, equitable, community-focussed care of multimorbid frailty.

Note: We feel that the original long-term objective has a too narrow focus on multimorbidity, and we are considering updating it to something like:

Facilitate the implementation of a regional multi-purpose flexible data analytics system, enabling care and wider community data to be linked to evidence how to most effectively maintain well-being, and prevent ill health, while reducing inequities. While exchanging best knowledge of methods and approaches with NWC region and through national ARCs.

Aims and objectives update

Recruitment to the theme has given us additional expertise which was not present when the original grant application was submitted. In addition to this, the COVID pandemic helped to speed up the creation of some new routine data systems, while in general some PPI work has been slowed. With this in mind, we have updated our objectives from our original plans back in 2018/19 to revising them in 2021/22 to reflect the current landscape.

Strategy progress

Here we highlight areas we are working on to meet our objectives, these are aligned to the overarching aims. The objectives are numbered and prefixed with S/M/L to indicate their short/medium/long term nature.

Work stream 1. Develop a network and library of methodologies

Work stream 1. Develop a network and library of methodologies (objectives S1, S2, S6, S8, M1, M2) to develop research ready datasets suitable to evaluate multiple care, health and wellbeing initiatives.

Objectives aligned to Work stream 1:
S1: Co-produce with Liverpool Health Partners a green paper sub-regional pilot to improve data-uses for enhanced public benefit
S2: Build ARC member and Public Advisor-approved data governance processes
S6: Establish new collaborations at the local, regional and national levels
S8: Develop FAIR/open science strategy for the ARC
M1: Build on regional digital systems for effective local commissioning, co-developing a person-level digital cohort.
M2: Publish a library of public metadata and documentation

Engaging with data providers

As part of our original ARC objectives, we published a green paper on engagement of data providers for Learning Health System (LHS) implementation across a large part of the North West Coast (NWC), shaping digital and applied health research futures (National Grid of Civic Data Cooperatives for Health) (S1). We are building on the rapidly developed Combined Intelligence for Public Health Action (www.cipha.nhs.uk) programme [Iain Buchan], which has brought together stakeholders, data, and infrastructure in the Liverpool City Region under the remit of addressing the COVID emergency (S6). By working closely with the Civic Data Cooperative (CDC), we are mainstreaming this progress by ensuring that health equity data are core to its development, and that the data governance processes have public involvement.

Data governance

The COVID-19 pandemic has impacted on the timescale the objective of building ARC member and PA-approved data governance processes (S2), as the focus of the CDC and CIPHA has been primarily

on helping the region to manage and respond to the waves of infection and the health challenges face by both the NHS and the local population. The CDC director, Gary Leeming, gave a presentation at the April 2021 ARCFEST outlining to members, inducing PAs, what the CDC is and its aims. The hiring of Dawn Allen as the CHI theme's PA co-lead will also help us in achieving this aim as we move into the post-pandemic era (S2). Members of CHI are also coordinating PPI for the Health Foundation-led project.

Working with Health Data Research UK (HDR UK)

Since the beginning of the Applied Research Collaboration (ARC), we have been successful in joining HDR UK as part of the Northern Better Care Partnership [Sarah Rodgers, Iain Buchan, Olly Butters], which has brought in additional funding and established links with the wider national HDR UK community (S5, see Workstream 2). This is a successful strategic move to keep up to date with national data science endeavours, including placing metadata within the HDR UK Innovation Gateway. This, and the Place based Longitudinal Data Resource (PLDR) initiative (see below) meets our short-term objective (S8) in promoting our project data to be Findable, Accessible, Interoperable and Reusable (FAIR). We are currently advertising for a further staff member to specifically work on the HDR UK project (S6).

New databank initiatives

Our plans are to promote cross-organisational scaling-up of data linkage/governance, shared e-infrastructure, and data harmonisation. We are achieving this through the award of the CDC [Iain Buchan, Sarah Rodgers, £5.3 million funded by Liverpool Combined Region] (M1). We are bringing together community/expertise in the Liverpool City Region (as well as bringing in additional resources). We are working with the new Director of the CDC, Gary Leeming (University of Liverpool) and our Patient and Public Involvement (PPI) lead to embed public involvement into the design and governance of the CDC. Working with Liverpool Health Partners (LHP) we have consulted with Dr Andy Gibson (NIHR ARC West) to generate successful ideas for CDC PPI.

Household linkages

The CHI team are leading on technical developments that are essential to several NIHR funded projects. We are developing nationally leading data linkage initiatives through funded projects (NIHR Ways to Wellbeing, PI Ben Barr) with Liverpool CCG and the Commissioning Support Unit. We will apply techniques developed by Sarah Rodgers to enable anonymised linkage of data from multiple sources based on a household (Residential Anonymised Linking Fields). This technical implementation, along with the requisite knowledge exchange, enables a new facet of business intelligence currently unavailable. It will facilitate whole complex systems data linkage from health to social care (care homes as a special residence type) and to educational data (home to school modelling for child active travel routing). This will enable us to complete our medium-term objective of developing data linkage systems that enable creation of individual-level cohorts (M1) that will, importantly, include time changing residential environmental exposures as people tell their GP they have moved home.

Data access

Working with relevant stakeholders, we will explore different methods for researchers to access data that are held securely. Methods include leaving the identifiable data in situ (e.g., in NHS) allowing only special privacy-preserving algorithms to 'see' the data and not the researchers themselves. Or it could involve the need to anonymise the data – remove all the identifiers – and allowing trusted researchers access to the data within a safe haven. The CHI team have experience of both methods and are advising on the technical implementation of combinations of these. Following our PA consultations there may be recommendations to keep more sensitive data restricted to algorithms only, even once anonymised. (S8)

Exploring federated analysis methods

Scaling up analyses to include larger populations is possible using 'federated analysis' where data are secured in separate databanks but analysed as if they were in the same location. Software that CHI team members have developed called DataSHIELD (https://www.datashield.ac.uk) supports this: the same data items from several databanks are interrogated using algorithms and the results for people in different regions are combined, as if they were held in the same location. Where our expertise with DataSHIELD proves to be relevant, we will help with implementation. For example, in our northern ARC region several NHS Trusts (University Hospitals of Morecambe Bay NHS Foundation Trust, Blackpool Teaching Hospitals NHS Foundation Trust, and Lancashire Teaching Hospitals NHS Foundation Trust) are working with Jo Knight at University of Lancaster. We plan to do some preliminary work to gauge the reaction of information governance officers to DataSHIELD as a privacy preserving tool. The DataSHIELD tool sends the algorithms to the data, and because the researchers do not access the data, the data themselves do not need to have identifiers removed. This could remove the usual information governance 'barriers', helping to facilitate important epidemiological studies for large populations to make new discoveries about important determinants of health. (S8)

The Place based Longitudinal Data Resource (PLDR)

The PLDR (https://pldr.org/) is an ARC-funded resource that makes available small area health indicators generated from individual level hospital admissions data. Many indicators are openly accessible online to researchers and the public. Individual level hospital admission data are accessible currently to a database manager who supports research across ARC by creating project specific health indicators. Using our experience with the FAIR and open science agendas we will make our data FAIR, and where possible openly available via the PLDR (S8). We have successfully produced with the Improving Population Health (IPH) theme, several pandemic related vulnerability indices and are assigning identifiers to make these indicators accessible (S4, see workstream 3).

Method transparency

Additionally, we will work towards making ARC NWC-produced methodologies as open as possible. This will increase the transparency and reproducibility of our scientific results and allow more efficient uptake into policy and practice. A key starting point for this is to begin to collate source code into a publicly available version control repository. As we conduct more projects in the ARC,

the content of the repository will grow and the available source code will become more and more relevant to others to reuse e.g. NHS data analysts, local government, academics etc. (S8)

Discoverable outputs

Building on the work of Olly Butters and Becca Wilson (https://doi.org/10.12688/f1000research.25484.1), we will work to make scientific outputs from the ARC more findable, accessible and searchable to researchers, practitioners and the general public. We will achieve this by creating a web portal where users will be able to explore publications via subject area, title, author etc. This will enable users to quickly find relevant research and development happening in our ARC community in a way that is not easily done at present. This may in turn increase the citation of our outputs in the literature, the use of our work by practitioners, and increase the general awareness of our work by the public. Alongside this we will measure the impact of our outputs in the wider scientific community by collecting usage metrics (e.g. citations).

Work stream 2. Grow data science capacity & capability
Work stream 2. Grow data science capacity & capability (objectives S3, S5, S6, S7, M2, M3)

Objectives aligned to Workstream 2:
S3: Co-develop CHI training and knowledge exchange
S5: Secure additional funding to ensure core CHI team is well resourced
S6: Establish new collaborations at the local, regional and national levels
S7: Develop process for CHI project/resource prioritisation
M2: Publish a library of public metadata and documentation
M3: Submit external grant applications testing regional algorithms

Public Involvement

In March 2021 Dawn Allen was appointed as our Public Advisor Co-Lead to the CHI theme. With Dawn, we are co-developing plans to make our website material more accessible to all our ARC members. (S3)

At our December 2020 ARCFEST the CHI team introduced the theme and held an informative discussion with members, including public advisors. Since then, we have had feedback including:

"*The discussion really helped me to learn and appreciate what the CHI team can bring to the ARC in terms of using 'big data' to investigate inequalities in our health systems and more widely*" (S3).

"*The introduction of the team and what they do was very clear. The information about the data collection, data access, data governance was easy to understand*" (S3).

"*I heard about the ACMI project within the HDRUK Better Care North during the presentation which seemed to me very interesting, so I applied as a public contributor for the project and now I am appointed for that role*" (S3).

Staffing

In response to concerns about underfunding, Sarah Rodgers and Mark Gabbay (ARC NWC Director) agreed CHI staffing was a priority. Our decision was supported by the Senior Management Team and the CCG approved further funds to uplift two key posts in the CHI team. This resulted in attracting two strong candidates to the team (Becca Wilson and Olly Butters)– one of whom (Becca) brought a prestigious HDR UK innovation fellowship. This fellowship released funding, which (along with additional funding from the core ARC budget) has allowed an additional member of staff to be hired (Pete Dixon). Becca has now been offered a University of Liverpool tenure track fellowship, which means she will continue to contribute to the CHI theme going forward, but will not be substantively employed by the ARC. (S5)

Capacity Building

We will transform NWC health data science through co-investment in new capacity, and multi-disciplinary training (with Implementation and IPH Themes). One dimension of this involves hosting data science interns (S6). The CHI team is directly providing data handling and data privacy expertise to clinicians so they can handle databases with patient data more effectively to answer important clinical questions. This hands-on training directly returns expertise to our ARC member organisations, as well as improving our knowledge of their data and skills. A measure of success of this work will be the number of interns we host and potentially successful applications to further training awards from National Institute for Health Research (NIHR) or related organisations. We currently are hosting three interns from clinical and informatics backgrounds. The projects they are undertaking are titled:

1. What has been the impact over times of the Covid-19 pandemic on levels of demand and access to mental health services? (Peter Hall, Lancashire and South Cumbria NHS Foundation Trust),
2. Making UK Rehabilitation Outcomes Collaborative (UKROC) data at Rakehead Rehabilitation Centre (RRC) meaningful to staff and patients (Lee Hughes, East Lancashire Hospitals NHS Trust)
3. Using the Household Health Survey to inform discussions with the North Lancaster Community Action Network to assist with prioritisation of issues and provide evidence to support action addressing inequalities in health (Rachel Tyrrell-Smith, Lancaster City Council).

Our strategy to appoint doctoral students has successfully attracted five PhD students who are either associated with CHI directly or have a strong data science component to their research. The projects they are undertaking are as follows:

1. Core outcome sets through the healthcare ecosystem to inform value-based commissioning (Student: Anna Kearney. Supervisors: Susanna Dodd, Paula Williamson and Kerry Woolfall)
2. Artificial intelligence and inequalities in primary care (Student: Alexander d'Elia. Supervisors: Lucy Frith, Mark Gabbay, Sarah Rodgers. Associated ARC NWC Theme: P&CIEP)
3. Multimorbidity Clustering to Inform More Equitable Health and Social Care (Student: Sam Meredith. Supervisors: Jenny Downing, Tony Marson, Sarah Rodgers, Keith Bodger. Associated ARC NWC Theme: PCCC)

4. Public involvement & engagement of seldom heard voices in managing and organising big data research (Student: Piotr Teodorowski. Supervisors: Lucy Frith, Sarah Rodgers, Kate Fleming. Associated ARC NWC Theme: P&CIEP)
5. An evaluation of the impact and implementation of telemedicine in health visiting services in the North West Coast during the Covid-19 pandemic (Student: Bethany Gill. Supervisors: Soo Downe, Victoria Appleton, Rebecca Geary. Associated ARC NWC Theme: IMPaCT)

Students attend CHI theme meetings and contribute to our quarterly showcase events (ARCFESTs) by presenting their developing projects to the ARC community.

Data access

We are applying for our team to access key databanks across the NWC. Placement of data scientists in ARC member organisations will advance both skills development for both for CHI team and those in member organisation (S3). We will concentrate on documenting existing datasets and making accessible commonly used algorithms to provide transparency for researchers using these data (M2). For example, ethnicity is often incomplete nationally and we will investigate algorithms used to compile this variable, as well as the underlying methods of data collection. We will recommend solutions to reduce missingness and bias in datasets to allow for more equitable data analyses. This will initially be achieved through newly funded projects such as NIHR RESTORE, working with our co-investigators from a local Clinical Commissioning Group (CCG) and local authority organisations. This adds to the CHI networks and collaborations that began with the CIPHA collaboration (S6).

Wider determinants of health

Working across different data providing organisations will test cross-sectoral data linkages, enabling exposures from the wider environment (e.g., access to alcohol outlets from each home) to alcohol related harms for individuals (recorded in the hospital admission datasets). The CHI team have expertise in longitudinal analyses using these high resolution spatial and temporal data. Translating this expertise through working with member organisations will accelerate the ability of our ARC to complete complex whole system analyses that include care, health, educational and environmental exposures and outcomes. This is particularly important as we develop the CDC and similar data resources in our region.

As our network grows and our library of methodology matures, we will start to see a multiplicative effect where more people will be able to use more of our curated resources (health indicators, source code, procedures etc). These reusable assets will be used as business intelligence recipes/tools for Partners to implement or adapt to use with their data, helping to reduce their data curation burden and gain additional insight into their data.

The CHI team work closely with MIDAS and IMPaCT (the other cross-cutting themes) to review the resource needs of projects arising through the research themes and prioritised by the ARC members to show how CHI can offer support, guidance and build capacity across the ARC NWC including its member organisation staff wanting to make better use of their data and wider datasets (S7). This ensures we can strategically allocate our staff resources and expertise across the work of the ARC as well as our own theme research portfolio. For example, a new project has been formed out of the stroke network to use artificial intelligence to assess stroke outcomes based on routine audit data.

By using the resources (training, software licences, expertise) of Simon Maskell (a contributing academic at UoL) we will be able to deliver an analysis which has not been possible before. Moreover, by working with Simon in this way we are upskilling the CHI theme to be able to run similar analyses in the future.

External funding

Our methods and expertise add value to external bids arising from the ARC and associated with the ARC. In addition to the CDC and birth cohort funding (£10.5 million), we have worked with IPH to successfully obtain additional NIHR grants amounting to £1,220,217 (M3). We may thus build our team of data analysts and associated capacity development among the staff of the ARC member organisations working on these grants. Through working with our member organisations, we will identify technical skills needed to make data accessible without adding a burden to our member organisations.

In October 2021 the UK Prevention Research Partnership GroundsWell will officially begin with £7.1 million funding: https://ukprp.org/what-we-fund/groundswell/ Sarah Rodgers is one of 3 co-Directors in this Consortium spanning England, Northern Ireland and Scotland (S6). ARC public advisors (Neil Joseph, Peter Lloyd) provided invaluable advice during the development phase, with several ARC investigators becoming investigators, including Olly Butters (CHI) Selina Wallis (PPI), Ben Barr (IPH), and Rhiannon Corcoran (IPH). Sarah Rodgers will direct organisation of data for the whole consortium and liaise with holders of national databanks in NI and Scot. Our vision is to co-design urban green blue spaces and related interventions with communities, while developing systems to more easily implement changes in our cities, and evidence health and wellbeing benefits.

The external grants obtained by the theme and/or supported by the theme demonstrate that our ambitions are justified, and we can grow to meet demand:

Groundswell Consortium Development Grant	MRC UK PRP	£50,000
C-GULL – Children growing up in Liverpool.	Wellcome Trust	£5.2 million
CDC – Civic Data Cooperative	Liverpool Combined Authority	£5,278,534.82
HDR UK North

Project title: Development of a learning system to optimise anticholinergic medication prescribing for older people living with frailty. | HDR UK

Sarah is co-lead for one of 3 projects comprising HDR UK North. Olly Butters is providing valuable expertise in in data wrangling, working with the Leeds University statisticians. | £1,300,000 |
| BALANCES | Health Foundation | Not Funded |
| The Impact of COVID 19 policy changes on access to Early Medical Abortion in England and Wales: A health equity | NIHR | Not funded |

impact assessment and natural experiment.		
Ways to Wellbeing	NIHR Public Health Research	£727,703
RESTORE	NIHR	£492,514
GroundsWell UK Prevention Research Partnership Consortium: GroundsWell: Community and Data Led Systems Transformation of Urban Green and Blue Space for Population Health Co-Directors: Rodgers, Jepson and Hunter. £7.1 million. MRC: MR/V049704/1	MRC UK PRP Sarah is one of three co-Directors, along with Ruth Hunter (QuB) and Ruth Jepson (Edinburgh). Time contributed from ARC members, including Olly Butters, Selina Wallis, Ben Barr, Rhiannon Corcoran. All as investigators. With valuable design advice from PAs Neil Joseph and Peter Lloyd.	£7.1 million

Academic involvement

Staff across our regional universities and member organisations have been involved in the ARC CHI theme. Many are supervising ARC doctoral students, as detailed above (Kate Fleming, Keith Bodger and Tony Marson). Additionally, Jo Knight is leading the development of a northern data pilot project, consulting with Ben Barr and Sarah Rodgers as to how CHI team can help. Jonny Keville and his Liverpool City Council informatics team are partners in the NIHR RESTORE bid, a successful COVID-19 related bid. This has been funded by NIHR with IPH theme lead Ben Barr as PI, with Sarah Rodgers and Helen Duckworth as investigators. Although not specifically named in the CHI theme, Helen Duckworth and her LCCG Business Intelligence team are integral to several informatics projects and the development of CIPHA and its transformation into the CDC that was led by Iain Buchan. Rebecca Geary, a new lecturer at University of Liverpool, is now jointly supervising a student with colleagues at the University of Lancaster (Soo Downe). As Chief of Digital at Alderhey Hospital, Kate Warriner attended the first national Digital ARC meeting with Sarah Rodgers (Oxford, September 2019) and has been part of the CIPHA development.

We have shared the progress and ambitions of ARC NWC with John MacLeod, the national ARC Digital lead, who was particularly impressed with the progress of the CHI and IPH themes. As a result, we have been invited to host an ARC day for the observational research working group. This is to share nationally our learning of cross sectoral data linkages for observational research.

Work stream 3. Informatics research for care equity and health equality

Work stream 3. Informatics research for care equity and health equality (objectives S4, M4, L1)

Objectives aligned to Workstream 3:
S4: Co-produce relevant clinically informed, longitudinal small-area indicators
M4: Create new visualisation and scenario planning tools.
L1: Produce an advanced library of population risk-stratification and clinical prediction methods

The CHI team are leading on technical developments that are needed by ongoing funded research projects. We proactively contribute 'big data' methodologies to grants in development within the research themes, as appropriate for CHI as a cross-cutting theme.

Secondary Care data

With IPH theme we have co-produced a national level database for storing Emergency Hospital Admission data provided by NHS Digital, with the intention of developing bespoke aggregate indicators at the Lower Layer Super Output Area (LSOA) or GP practice (GPP) level (or higher geographies). These aggregate indicators are then used to investigate the impact on health care utilisation of risk factors, policies, and interventions. (S4)

We have co-produced, with the IPH theme, several pandemic related vulnerability indices. (e.g., Small Area Mental Health Index (SAMHI), https://pldr.org/dataset/2noyv and a Small Area Vulnerability Index (SAVI), https://pldr.org/dataset/e6kl0). These are being used to support public health responses to the pandemic and provide evidence of the inequalities that people are facing in the North West, West Midlands and North East regions of England. (S4).

The CHI team are working with the ARC public advisors to build the CDC so it is suitable for research purposes. We have several use cases that we are developing from our collective expertise to demonstrate to the public the value of their data, in an Understanding Patient Data format.

New databank initiatives

The CHI team are members of the CDC Development team to deliver a research data resource for Cheshire and Merseyside that is interoperable with other databanks nationally or internationally. We are currently testing access to the existing CIPHA databank, developed for COVID-19, applying for secondments for team members to assist in developing systems that allow the operational team to identify people living alone or in care homes. These groups have been particularly vulnerable during the pandemic, and it is important to investigate outcomes for those who may have been isolated or in housing that was susceptible to viral transmission.

Integrating with birth cohort data

We are leading on technical aspects using our expertise to establish best practice data collection and data linkage methods for the Wellcome funded birth cohort: Children Growing up in Liverpool.

Equity mainstreaming

As part of our ARC NWC 'mainstreaming health equity strategy' we are assessing the completeness of key demographic variables such as ethnicity and disability in routinely recorded data. Understanding how these data are generated and what may lead to missing data is the first step in encouraging improvement to enable more nuanced analyses in future.

Adding behaviour and wellbeing data

Part of our strategy is to augment routinely collected data with behaviour and wellbeing data. We intend to work with Equitable Place-based Health and Care (EPHC) theme to devise a strategy to assess if people who have already participated in a survey would consider linkage of their survey results to their electronic health record. Routine hospital admission indicators could be augmented

with survey participant responses from over 6000 region-wide households in two survey waves, providing details on behaviour and household circumstances unavailable through routinely collected data.

Team science

Our strategy is to work collaboratively with the data providers, public and with academics across the region and nationally. As our network grows, we will submit increasingly competitive grant applications on issues that are important to our communities and policy makers. The successful funding of these, and the cross-disciplinary dissemination/citation of our research findings, will be important markers of success. As will be the use and successful application of research using the routinely collected health and other data regionally, such as those to be held in the CDC and equivalent databanks regionally.

Through our HDR UK project we are aiming to reduce unscheduled care among multimorbid patients taking anticholinergic medications. The CHI team is advising on research that has important practitioner and policy-maker behaviours. Where data science perfects the accuracy of the information, the informatics research will maximise its actionability.

Glossary of acronyms

ARC NWC – Applied Research Collaboration North West Coast. A scheme which aims to improve outcomes for patients and the public; improve the quality, delivery and efficiency of health and care services; and increase the sustainability of the health and care system both locally and nationally.

CCG – Clinical Commissioning Group. Groups of general practices which come together in geographical areas to commission the best services for their patients and population.

CDC – Civic Data Cooperative. A publicly owned initiative to collect and make useful health and social care data in Liverpool City Region.

CHC – Connected Health Cities. A government-funded programme that used information and technology to improve health and social care services for patients across the North of England. The programme ended in March 2020.

CHI – Care and Health Informatics. One of the cross-cutting themes of ARC NWC.

CIPHA – Combined Intelligence for Public Health Action. A population health management platform, which was established in three months across Cheshire and Merseyside to help the health and care system manage the Coronavirus crisis and to drive its recovery.

CLAHRC NWC – Collaboration for Leadership in Applied Health Research and Care North West Coast. The forerunner to ARC NWC

CPRD – Clinical Practice Research Datalink. An observational and interventional research service that operates as part of the UK Department of Health that collects anonymised patient data from a network of GP practices across the UK.

EPHC – Equitable Place-based Health and Care. One of the research themes of ARC NWC.

FAIR – Findable, Accessible, Interoperable and Reusable. Principles that were defined in a March 2016 paper in the journal 'Scientific Data' by a consortium of scientists and organizations that emphasize machine-actionability (i.e., the capacity of computational systems to find, access, interoperate, and reuse data with none or minimal human intervention).

HDRUK – Health Data Research UK. The UK's national institute for health data science: their vision is that every health and care interaction and research endeavour will be enhanced by access to large scale data and advanced analytics.

IMPaCT – IMPlementation and Capacity building Team. One of the cross-cutting themes of ARC NWC.

IPH – Improving Population Health. One of the research themes of ARC NWC.

LHCRE – Local Health and Care Record Exemplar. A programme of NHS England that will enable the safe and secure sharing of an individual's health and care information as they move between different parts of the NHS and social care.

LHP – Liverpool Health Partners. A network of 12 organisations in Cheshire & Merseyside (including NHS Trusts and higher education institutes) who are working together to develop research to address the diverse and complex needs found across Cheshire & Merseyside.

LHS – Learning Health System. A system which continuously analyses data that is collected as part of routine care to monitor outcomes, identify improvements in care, and implement changes on the basis of evidence.

LSOA – Lower Layer Super Output Area. A geographical area designed by the Office for National Statistics to improve the reporting of small area statistics.

MIDAS – Methodological Innovation, Development, Adaptation & Support. One of the cross-cutting themes of ARC NWC.

MRC UK PRP – Medical Research Council UK Prevention Research Partnership. An initiative to support multidisciplinary research teams investigating the upstream and environmental determinants of health relevant to a range of non-communicable diseases.

NIHR – National Institute for Health Research. A UK government agency which funds research into health and care: it is the largest national clinical research funder in Europe.

P&CIEP – Public and Community Involvement, Engagement and Participation. This is central to ensuring that our ARC NWC programme is relevant to the needs of patients and the public in our diverse local communities within the North West Coast region.

PA – Public Advisor. A member of the public who collaborates in the work of the ARC NWC

PCCC – Person Centred Complex Care. One of the research themes of ARC NWC.

PLDR – Place based Longitudinal Data Resource. An ARC-funded resource that makes available small area health indicators generated from individual level hospital admissions data.

PPI – Patient and Public Involvement. Actively working in partnership with patients and members of the public to plan, manage, design and carry out research.

RRC – Rakehead Rehabilitation Centre. An inpatient unit based at Burnley General Teaching Hospital. It forms part of an integrated neuro rehabilitation service along with community and outpatient teams within the Blackburn with Darwen and East Lancashire commissioning areas.

SAMHI – Small Area Mental Health Index. A composite annual measure of population mental health for each LSOA in England. The SAMHI combines data on mental health from multiple sources (NHS-Mental health-related hospital attendances, Prescribing data – Antidepressants, QOF - depression, and DWP - Incapacity benefit and Employment support allowance for mental illness) into a single index.

SAVI – Small Area Vulnerability Index. An empirically-informed measure of COVID-19 vulnerability for each Middle Super Output Area (in England.

UKROC – UK Rehabilitation Outcomes Collaborative. A national database for collating case episodes for inpatient rehabilitation.

UoL – University of Liverpool

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