Connected Health Cities Programme: Evaluation

Final research report

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Executive summary

The Connected Health Cities (CHC) programme is a Northern Health Science Alliance (NHSA) led programme delivered by a consortium of academia, NHS organisations and industry partners across four regions in the North of England. Each of the four regions has been tasked with establishing a Learning Healthcare System (LHS), using patient data to create and test innovative improvements for a variety of clinical pathways.

This report provides an independent evaluation of the CHC programme, including how the CHC programme has progressed towards the Department of Health and Social Care (DHSC) seven deliverables, as well as emerging benefits, additionality, and key challenges. Recommendations are provided for future programmes of work. This draws upon 59 interviews with staff and key stakeholders, a staff survey and documentary review across all four CHC regions and the central CHC hub.

The DHSC is to be commended in funding a high risk and innovative digital programme of work across the North of England; a programme of work which is beginning to tackle health inequalities that disproportionally affects this population. The multidisciplinary approach has brought together highly skilled and knowledgeable staff across academia, the NHS and industry, resulting greater staff exposure to research, addressing real issues in clinical practice and breaking down silo-based working practices.

Regional activities and care pathways are beginning to address health inequalities across the health and care system in the North of England to reduce unjustified variations in health outcomes. The investment made by DHSC has contributed to the building of I.T and health informatics infrastructure in NHS organisations across the North of England, allowing the flow of data to identify key health issues within local populations. Each region has developed its own infrastructure for clinical research and medical innovation through the creation of Arks and employment of skilled staff.

Furthermore, the CHC programme has created regional partnerships across the North of England between NHS Trusts, academia and industry with governance structures and commercialisation protocols in place that protect patient data confidentiality that could be utilised by the DHSC in driving innovation and digital change with NHS suppliers both nationally and internationally.

Several challenges were faced by the CHC programme. In particular, the length of time taken to gain the necessary approvals from NHS Digital, NHS England and Research Ethics Committees, the cost of data and the installation of IT infrastructure across the North of England has added significant delays and additional costs to delivery. The level of resources and staffing also far exceeded the initial DHSC investment, with the majority of staff working above and beyond their allocated time commitments to the activities and many partners offering services in kind to ensure output delivery. There is a lot of goodwill attached to the CHC programme in terms of time, costs and additional work that was not charged for.

Despite the many challenges experienced across all CHC regions in deploying their programmes of work, the evaluation has found that all CHC regions are undertaking a large number of initiatives and activities, some of which went beyond the original bid as collaborations led to discoveries of other areas in which partners could work together. Some of these are ready for rollout across the NHS, whilst others could be harnessed for commercialisation in the international healthcare arena.

Patients and members of the public have had an increased level of involvement, with branding guidelines and use of the #datasaveslives hashtag helping to create a project ‘brand’ that has assisted in linking all the work regional patient and public involvement (PPI) work together under the CHC programme. The hashtag is now widely used both national and internationally to bring about further awareness of the benefits of using health informatics to drive improvements in patient treatment and care.

Building on the successes, challenges and key transferable lessons previously identified, the following are key recommendations arising from the evaluation findings:

Recommendations for the CHC programme

- There is a need to put in place clear organisational structures to support regions and pathways. Organisational structures should allow for variations at the regional level, but these should be clearly defined and set out at the start of future programmes of work.

- Further consideration needs to be given to the involvement of industry within the regional and pathway activities, with a focus on the replication of pathways between regions with funds allocated specifically for cross-regional collaborations.
- Communication strategies should be reviewed and consulted within the CHC partnership with a view to improving lines of communication amongst all staff at all levels.

Recommendations for the DHSC

- Reporting of project deliverables and finances needs to be standardised and to remain unchanged throughout the duration of a research programme with templates agreed and fixed at the start of the programme. DHSC should consider a flexible approach to how funds are spent by programmes.
- Consideration should be given to having a longer study period that is fully funded. A minimum five-year study period is required to account for time taken for relationship building between stakeholders, construction of data infrastructure, gaining relevant approvals, signing of data sharing agreements and delivery of data.
- DHSC should consider streamlining and standardising Information Governance (IG) requirements for future health data projects, with clearly defined pathways and timescales for researchers to apply for and receive data. Standardised IG would reduce anxieties amongst local NHS data providers and facilitate future health informatics research.
- Whilst it is acknowledged that there is a cost attributed to storing and delivering data, transparency is needed in the breakdown of costs to ensure fair pricing of data for research purposes.

Disclaimer

The views expressed in this report are not necessarily those of the Department for Health and Social Care or any other government department, the NHS, the Northern Health Science Alliance or any organisations taking part in the CHC programme.

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Abbreviations

AHSN	Academic Health Science Network
CCG	Clinical Commissioning Group
CHC	Connected Health Cities
CY	Connected Yorkshire
DHSC	Department of Health and Social Care
GDPR	General Data Protection Regulation
GM	Greater Manchester
HEI	Higher Education Institute
HRA	Health Research Authority
IG	Information Governance
I.T	Information Technology
LHS	Learning Healthcare System
NENC	North East North Cumbria
NHS	National Health Service
NHSA	Northern Health Science Alliance
NWC	North West Coast
PPI	Patient and Public Involvement
REC	Research Ethics Committee
R&D	Research and Development
TRE	Trusted Research Environment

Section 1: Introduction

Background

The use of routinely collected health and social care data has the potential to drive forward improvements in health outcomes. This is especially important in the UK where an ageing population, increases in life expectancy and rapidly changing patterns of chronic disease have led to an increased demand in health and social care services. At the same time, the amount of health data being collected and stored is vast, whilst the technology and analytic tools needed to analyse 'big data' has been developed.

The 'learning healthcare systems' (LHS) has been proposed to deliver better outcomes for patients and communities by analysing routinely captured health information and feeding back results to clinical staff. The Connected Health Cities (CHC) programme aims to create LHS across the North of England and has been funded by the Department of Health and Social Care (DHSC). The programme covers four regions: Greater Manchester (GM), North West Coast (NWC), Yorkshire (CY) and the North East and North Cumbria (NENC). Each region was tasked with creating a LHS to enable the re-use of healthcare data in a trusted research environment using efficient data preparation and big data analytics, the results of which will be implemented and actioned back in the NHS (Figure 1).

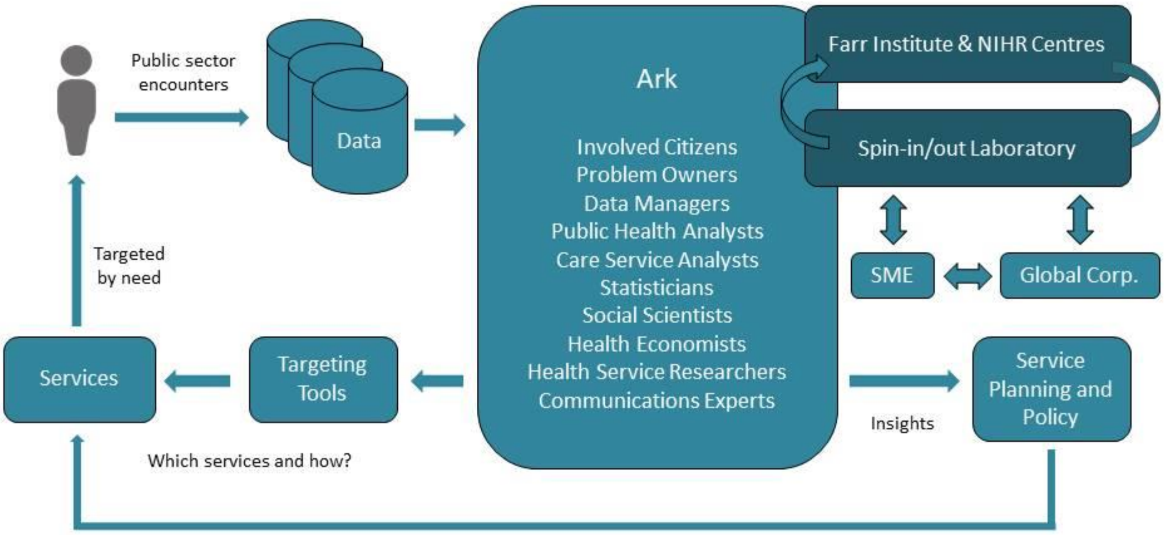

Figure 1: The Connected Health Cities Ark model

Furthermore, the CHC programme has over sixteen care pathways in the process of delivery. Initially, this evaluation focused on eight care pathways as per the criteria outlined in the pilot study tender. However, during the Summer of 2018, the DHSC changed the evaluation criteria, shifting the emphasis onto the following seven deliverables: establishment of data sharing strategy and agreements for each region; establishment and delivery of governance arrangements for the sharing and usage of data for each region; workforce arrangements optimised and CPD requirements identified; creation of Arks as analytical platforms; pathway analysis, variation assessment and improvements identifications; frameworks and integration with R&D partners; and the production of a business model suitable for scaling and sustainable for delivery in the NHS (see Appendix B for a full description of each deliverable).

This report provides an independent evaluation of the CHC programme, including how the CHC programme has progressed towards the DHSC seven deliverables, as well as emerging benefits, additionality, and key challenges. Recommendations have been produced for future programmes of work. This draws upon the discussions with staff, key stakeholders, a staff survey and documentary review across all for CHC regions and the central CHC hub. The findings of this evaluation cover the period February 2018 until December 2018.

The following two sections set out the aims, objectives and methodology for the evaluation. Sections 4 to 7 set out key evaluation findings and the final sections set out transferable lessons and recommendations for future programmes of work, both for the CHC programme and for DHSC. Appendices include a review of the evaluation methodology, a full description of each of the seven deliverables, the logic model developed for this evaluation and descriptions of the eight care pathways included in this evaluation.

Section 2: Aims and objectives of the evaluation

The overall aim of the evaluation was to provide an independent assessment of the CHC programme in relation to progress towards the following seven deliverables (see Appendix B for a full description of each deliverable):

- **Deliverable 1:** Establishment of data sharing strategy and agreements for each region
- **Deliverable 2:** Establishment and delivery of governance arrangements for the sharing and usage of data for each region
- **Deliverable 3:** Workforce arrangements optimised and CPD requirements identified
- **Deliverable 4:** Creation of Arks as analytical platforms
- **Deliverable 5:** Pathway analysis, variation assessment and improvements identification
- **Deliverable 6:** Frameworks and integration with R&D partners
- **Deliverable 7:** Production of a business model suitable for scaling and sustainable for delivery in the NHS

The individual evaluation objectives for the CHC programme are summarised below:

- To evaluate progress and early impact of each CHC region against the seven DHSC deliverables
- To identify the benefits, additionality and added value of the CHC programme
- To identify the challenges of implementing a LHS in four regions in the North of England and how these have been overcome
- To assess the level of input required from staff, resources and approvals (such as information governance) to create each regional Ark and care pathway

Section 3: Methodology

The evaluation was undertaken in seven main fieldwork stages as outlined below. The CHC programme evaluation took place between February 2018 and December 2018.

Stage 1: Inception, project steering, desk review, and development of research tools

This included an inception meeting with the evaluation lead, review of key project documentation and submission of the research tools for ethical review at the University of Manchester. Ethical review was granted in May 2018 (Ref: 2018-3923-6106).

Stage 2: Informational interviews with key stakeholders

Semi-structured informational interviews were conducted with key CHC staff from each of the pathways and the central CHC hub in mid-February to late April 2018. A total of 28 key staff participated in these interviews. The aim of these initial informational interviews was to establish which two pathways would be put forward for evaluation; what they considered to be the greatest challenges; any issues they foresaw; successes and unintentional outcomes of the CHC and a consideration of future challenges with regards to the CHC programme deliverables.

Stage 3: Documentary review of programme documentation for each region

Documentation from each of the care pathways was reviewed against the programme deliverables to provide an initial assessment between the proposed and actual programme of implementation.

Stage 4: Research with key CHC regional and pathway staff

Research with staff in each pathway had two elements - quantitative and qualitative - as follows:

Quantitative research: In May 2018, lead pathway and regional partners were sent an e-survey to be cascaded to staff working on the CHC programme. This was to gain a broad understanding of CHC staff experiences across the different pathways in relation to the programme deliverables, as well as their views on the challenges, benefits, impact and successes. A reminder was sent out four weeks after the original mailing, with pathway leads reminding staff to complete the e-survey. The survey proved a valuable source of information that informed the evaluation recommendations. However, the numbers involved in the survey are quite small and therefore the results should be treated with caution.

Qualitative research: Qualitative research was undertaken with a selection of CHC staff for each pathway and region. In late May 2018, initial semi-structured confidential interviews were conducted. Detailed discussions with a cross section of pathway and regional staff enabled the development of a balanced narrative of key achievements and challenges across the CHC programme. These were then used to inform recommendations and the development of case studies. A total of 59 individuals were involved in this stage of the research. Interviews were carried out until October 2018.

Stage 5: Discussions with other stakeholders

In order to consider the wider benefits and challenges of the CHC programme within each region, interviews were also conducted with a number of stakeholders who sit within the CHC programme but were not directly involved in activities in the eight care pathways or regional activities.

Stage 6: Preliminary results discussed with all CHC staff

In September 2018, an ‘All hands’ meeting was planned where CHC staff from across all four regions attended. This was to present the preliminary findings of the overall CHC evaluation and draft recommendations, as well as provide an opportunity for all regional staff to reflect and respond to their regional preliminary results. All CHC staff were encouraged to complete the feedback surveys, available both online and during the event to provide further updates on pathway and regional work, as well as comments on the overall CHC programme draft recommendations.

Stage 7: Analysis and reporting

Our data analysis utilised a thematic approach where data from the documentary review, survey and interview data were triangulated to quantify progress towards the CHC programme outcomes. This is because no baseline data was available for the CHC programme. Our analysis strategy used an iterative process, whereby data collection and data analysis were conducted concurrently. For data collected through our documentary review and interviews, a thematic analysis using our logic model as a framework was used to assess progress against the CHC programme outcomes and to identify recommendations to support future programme decision-making. Descriptive analysis of the online survey data was used to inform actionable recommendations, which in turn will aid the future development and refinement of the CHC programme and care pathways.

The two major outputs from the evaluation are an article published in a scientific journal and this final report. In addition, each CHC region has received its own report based on the evaluation findings.

A more detailed review of the evaluation methodology can be found in Appendix A.

Section 4: Meeting the CHC programme deliverables

Key findings:

- In the majority of cases, all CHC regions had either met the seven DHSC deliverables by December 2018 or had put in plans to do so by March 2019. All CHC regions had recorded activities that went beyond the original seven deliverables.

- All CHC regions have established governance arrangements, including the creation and acceptance of data sharing agreements between stakeholders, the setting up of working groups and gaining care pathway specific approvals. At the time of evaluation, all approvals required to share data had been obtained.

- The CHC programme has brought together highly skilled staff to each CHC region from the private, public, NHS, academia and social care sectors. Some regions are developing their own training programmes to meet the needs of the wider health and social care workforce.

- Each of the CHC regions has either established or is progressing towards the establishment of an Ark. Data that has been deposited includes patients data from GP practices, audit data, EPR data, A&E data and CPRD data.

- At the time of evaluation, there are more than sixteen care pathways in delivery across the North of England. Each care pathway has developed its own analytical framework.

- All CHC regions have established patient and public involvement (PPI) groups, exceeding what was required as a deliverable. The Central Hub has also delivered a range of PPI activities to engage with the wider general public.

- All CHC regions are working with industry partners to deliver aspects of care pathways. All regions have noted interest from local, national and international organisations in the CHC activities.

- The Central Hub is working towards the development of a CHC Kite Mark that will allow CHC products and other companies with an opportunity to develop and validate products for the health care market.

- All CHC regions, at the time of evaluation, are developing strategies to ensure that work completed can be continued and sustained. This includes applying for future funding from a range of sources. Furthermore, the Central Hub is developing a business strategy around the CHC LHS method that could be scaled up nationally and potentially internationally.

Introduction

The CHC programme had seven key deliverables that must be satisfied by the end of the project time period. Each of the CHC regions had a choice as to how these were delivered, with all regions undertaking a large number of initiatives and activities, some of which went beyond the original deliverables as collaborations led to discoveries of other areas in which partners could work together. This meant that all regions undertook activities that were not originally envisaged and therefore of fell outside the expectations of the core CHC deliverables. These are referred to in Sections 5 and 6.

This section of the report details the findings of the evaluation in relation to the seven CHC programme deliverables: establishment of data sharing strategy and agreements for each region; establishment and delivery of governance arrangements for the sharing and usage of data for each region; workforce arrangements optimised and CPD requirements identified; creation of Arks as analytical platforms; pathway analysis, variation assessment and improvements identifications; frameworks and integration with R&D partners; and the production of a business model suitable for scaling and sustainable for delivery in the NHS.

This draws upon the discussions with staff, key stakeholders, a staff survey and documentary review across all for CHC regions and the central CHC hub.

Deliverable 1: Establishment of data sharing strategy and agreements for each region

All CHC regions have produced templates for data sharing agreements that can be used in any future work by the CHC programme and other research projects. Data sharing agreements have been agreed in all CHC regions by regional partners of the CHC programme, NHS organisations, commercial data providers and Universities. In addition, the data sharing agreements allow for data providers to share and deposit data in regional Arks and/or Trusted Research Environments. This includes linking in data from GP practices, NHS Trusts and other data providers. Furthermore, each of care pathways has developed its own data sharing agreements, with some developing other forms of protocols, such as a Privacy Impact Assessment.

To further enhance and facilitate the creation of data sharing agreements, some regions have employed an Information Governance (IG) manager or are using the services of an IG expert to oversee adherence to all IG standards, data sharing protocols and GDPR, whilst providing IG support to CHC staff and stakeholders in CHC regions.

Deliverable 2: Establishment and delivery of governance arrangements for the sharing and usage of data for each region

All regions have IG arrangements in place for the sharing and use of data. As the CHC regional partnerships were new, none had previously established the formal arrangements expected to facilitate the sharing and usage of data. All regions commented that arrangements had taken longer than anticipated to finalise, in part due to the different interpretations of guidance provided by NHS England and NHS Digital. All regions established work streams involving senior staff from across all partner organisations, although for some staff turnover was an issue that reduced efficiency as new members of staff were brought up to speed and often interpreted existing guidance differently, resulting in further discussions to change pre-agreed arrangements.

Some regions have established or are in the process of establishing an Information Governance Working (IGW) Group or committee to review current and planned data projects, as well as reviewing project documentation. Some regions have appointed members of the public to sit on their IGW committee to assist in these processes.

Furthermore, each care pathway has developed and produced its own data sharing agreements, which have been agreed by all stakeholders involved in each pathway project, as well as obtaining the necessary approvals from the appropriate Ethical Research Committees (REC) (for example, university ethics approval, R&D and HRA).

Deliverable 3: Workforce arrangements optimised and CPD requirements identified

All regions have employed a range of highly skilled staff to work on the CHC programme. This includes data analysts, statisticians, software engineers, qualitative researchers, clinicians and specialist researchers from health and social care practice. Staff employed on the CHC programme bring a wealth of experience from the private, public, higher education institutes (HEI), NHS and social care sectors. However, several regions found it difficult to recruit staff to particular roles due to the low pay and short term contracts offered by HEIs.

Three regions have PhD students employed in the design and delivery of their programme of work. This includes eight fully funded PhD students, one partially funded student and one externally funded PhD student. Feedback from staff suggests that there was confusion as to whether regions could fund PhD scholarships as some regions would have liked to have offered more doctorate studentships through the CHC programme.

At the time of evaluation, some regions are developing and implementing their own training programmes to meet the needs of the wider health and social care workforce. This includes training NHS and social care staff (including clinicians, nurses and social workers) in the use of statistics and health informatics. As this is beyond the requirements of this deliverable, further information will be presented in Section 6. All CHC programme staff have had access to continuing professional development courses through their own organisations of employment.

Deliverable 4: Creation of Arks as analytical platforms

Ark infrastructure has been established or is in progression of being established in each of the CHC regions, which allows the re-use of patient data under appropriate governance controls and NHS Trust frameworks. Each of the regional Arks vary in structure, from a regional cloud-based system created in NWC, to a Health Information Exchange that will link up three Trusted Research Environments (TRE) in NENC. The range of Arks is a reflection of the challenges each region has faced in building local health informatics infrastructure, the local population and information governance requirements.

In addition, some regions have created their own TRE as a first step to creating a regional Ark. This has provided users with analytical tools and datasets to conduct population based health informatics analysis whilst regional Arks are set up. Some of the security features of these TREs include a 2-Factor authentication for authorised access, a remote desktop interface and AES256 encryption for data. Researchers using the regional Arks and TREs must complete all required training materials prior to accessing the data. Where needed, researchers are supervised by Ark staff to further ensure data security.

Data that has been deposited in the Arks includes: patient data from GP practices, audit data, demographic data, clinical observations, electronic health record data and A&E data. In some regions, this includes regional wide data, such as in CY where one pathway is linking de-identified routine NHS data to describe a detailed profile of patient demand across both prehospital, primary care and hospital emergency and urgent care settings in Yorkshire. Progression is being made to include social care data; however, challenges around service user consent and outdated infrastructure remain key issues.

Platforms for analysing care pathways have included the creation of statistical models, apps, DataLabs and dashboards. Some regions are progressing towards an e-version analytical platform for some of its pathways; however it is important to note that financial, staffing and technological infrastructure restraints have resulted in a variety of feedback tools to practitioners, service managers and guideline developers. These range from creating reports, organising monthly meetings and creating centralised contact points to facilitate feedback from end users of platforms for further improvements. CHC staff are to be commended on using their initiative to create alternative cyclical feedback mechanisms.

Deliverable 5: Pathway analysis, variation assessment and improvements identifications

Although eight pathways were required as part of this deliverable (see Appendix D for a description of each pathway included in the evaluation), the programme exceeded this number. There are over sixteen care pathways being deployed across the CHC programme. All regions reported that they have a minimum of two care pathways in delivery; however some regions have been able to use the CHC pilot programme money to fund additional pathways and pathfinder studies. Each pathway has a dedicated academic lead, with some academic leads also having a split role due to continuing clinical practice.

Furthermore, each care pathway has developed its own analytical framework, based on the availability of a regional Ark or a Trusted Research Environment (TRE) to house data. At this point in the evaluation, not all care pathways have been redesigned due to the length of time taken to put in data infrastructure and obtain approvals. The different elements of each clinical pathway are predominantly in the early stage of piloting. Similarly, it is too early to evaluate the health impact of each pathway. This is because the short project timeframe of the CHC programme has been focused on building the necessary infrastructure to facilitate the linking of data into a regional Ark or TRE.

All CHC regions have established patient and public involvement (PPI) groups with many care pathways establishing their own patient groups from the start of the programme. All CHC staff noted the importance of involving patients, members of the public and engaging with local populations as a whole in the use of patient data for health research. Care pathway staff in particular noted how patient groups have helped drive the CHC programme of work forward and have provided vital input into study design.

In some regions, patients and members of the public have been asked to sit on regional IG boards to further ensure that the voice of the patient is heard in future programmes of work. As the level of patient and public involvement exceeds that of what was required in this deliverable, further information will be presented in Section 6.

Deliverable 6: Frameworks and integration with R&D partners

All CHC regions are working with industry partners as part of their care pathway projects to deliver aspects of their pathway, such as specific software, analytical tools or technology development.

Some regions have been formulated a strategy for industry engagement, such as the creation of 'Spin in' or 'DataLabs' which will provide companies with an opportunity to develop and validate products for the health care market. All regions have noted interest from local, national and international organisations in the CHC programme activities. For example, some care pathways and regions are in discussion with regards to care pathway re-design for product development that have either commercial viability or could be replicated and used in the NHS across the U.K.

In addition, the CHC programme is progressing in the development of a CHC Kite Mark group which is identifying the requirements for effective, successful transfer and adoption of projects across the CHC regions for both CHC outputs and future commercial products.

Deliverable 7: The production of a business model suitable for scaling and sustainable for delivery in the NHS

Whilst this deliverable is for the overall CHC programme only, all CHC regions are working towards the production of strategies to ensure that facets of work completed can be continued and sustained. At present, some regions are implementing evaluations to evaluate the efficacy and utility of care pathways that have been completed to produce scalable and sustainable business models. In addition, a series of 'spin off' projects have been created within some regions to further develop elements of some of the clinical pathways, such as the Stroke project in GM and predictive modelling tools in NENC.

All care pathways, as well as all regions have applied for further funding from a range of funding organisations (such as CLARHC, NIHR, MRC), as well as securing funding as CHC regions, most notably from the Local Health and Care Record Exemplar (LHCRE) bids. Funding applications have further enhanced the relationship between HEIs, industry and NHS Trusts, with all funding applications drawing upon CHC regional and cross-regional collaborations.

In moving the CHC programme forward into future iterations of work, the Central Hub have been refining the LHS method that has been central to the CHC programme of work and this is now being developed into a business strategy moving forward. At a national level, it has been noted that the impact of the CHC programme has changed the way funders think about health informatics, who appear keen to engage more with the CHC programme of work (for example, the success of two regions obtaining LHCRE funding). Progress is being made with industry to develop a long term CHC programme strategy that will be more sustainable. However, it is important to note that the current funding landscape means that ambitions to fully realise the CHC programme across the North of England as part of the DHSC digital revolution remains at risk of failing without immediate further investment.

Section 5: The benefits of the CHC programme

Key findings

- The multidisciplinary approach utilised in all pathways and regions resulted in a greater exposure to new research, theoretical concepts and ways of working. Most pathways are demonstrating that multidisciplinary approaches have brought considerable benefits in better understanding health issues.

- All CHC staff interviewed confirmed that they had benefited from their involvement in the programme, including being directly involved in care pathway and strategic level decision-making.

- Patients and members of the public had an increased level of involvement in the delivery of regional activities, with some involvement in the design of care pathways. Other initiatives are in place to involve patients and members of the public in future programmes of work to ensure their voice is heard.

- It was too early to identify impact on patient outcomes from CHC programme activities. Impact will become clearer later as care pathways progress further. All CHC staff interviewed believed that the CHC programme of work will benefit patients as well as clinicians.

Introduction

This section of the report details the benefits of the CHC programme activities to partners in the CHC programme and patients. This draws upon the discussions with staff, key stakeholders, survey and documentary review across all CHC regions. It is important to note that an independent evaluation was conducted with members of the CHC patient and public involvement groups. These are presented in a separate document.

Main benefits for partners involved in CHC programme

Staff interviews and surveys confirmed that the CHC programme has provided HEIs, industry and NHS organisations with the opportunity to collaborate. It created opportunities to develop a new and innovative programme of work that puts the needs of the patients and clinicians centrally. Being part of the CHC programme has resulted in a greater influence on tackling health inequalities within local populations in the North of England through the design, implementation and governance arrangements. All NHS and industry partners agreed that they had developed closer links/relationships with regional HEIs, including the development of staff involved in split research and clinical/industry roles.

The multidisciplinary approach utilised in all pathways and regions has resulted in a greater exposure to new research, theoretical concepts and ways of working. Nearly all staff have taken advantage of this opportunity, resulting in a greater awareness of the problems faced in clinical practice and the potential use of health informatics in redesigning patient pathways:

> *"It's opened my eyes a little bit to the different methods, analytical methods and technologies in terms of how you would analyse large routine data sets and what you can do with them…I'm learning about what's possible making connections with people whom I would not have had interactions with."*

Furthermore, CHC funding has allowed partnerships to explore innovative ways of working with data without the constraints associated with traditional funding streams. As one academic reflected:

> *"It has allowed us to explore the possibilities more freely than what we would have been able to do. I think that having the funding there to do this has been fantastic, because it would be hard to find someone to fund something like this…you know, I don't think NIHR would have funded it."*

The evaluation found that there are more diverse opportunities for staff training and networking both within and across the CHC regions, as well as much greater access to coordinated events within each region. Whilst some regions struggled initially in their regional partnerships owing to sector and personality differences, they have all risen to the challenge. There was a perceptible sense of pride amongst all staff that they were involved in the CHC programme that was at the forefront of utilising routinely collected patient data in the North of England to make a difference to patients in their local population. Senior staff highlighted the benefits this has had on staff motivation.

Main benefits for patients of CHC programme activities

In relation to the CHC programme deliverables, the CHC regions needed to include the involvement of patients as part of the re-design of care pathways in order to facilitate feedback on patient care. Across all CHC regions, as well as the CHC programme as a whole, patients and members of the public have had an increased level of involvement.

Care pathway staff noted how useful and beneficial it was to have insights from patients, members of the public, and health and social care staff in their projects. In some cases, the patient voice was key to pushing forward a piece of work when an NHS Trust might have been hesitant. In one care pathway, local families have been involved throughout the pathway design and delivery stages.

In other pathways, gathering patient and public views and engagement were seen as being critical elements of the CHC programme, to the extent that some regions have a specialist PPI role within their partnerships to enable the voice of patients to be heard. As one member of staff observed:

> *"I think that there should be an emphasis on patient and public involvement, especially when you're talking about data and information that belongs to patients…people talk about data within organisations, but that data belongs to patients and if you don't engage properly with them then you end up in trouble…and I think NHS England have been there before with a top-down [approach], but I feel that CHC are doing this much better."*

At this point in the evaluation, it is too early to identify impact on patient outcomes from all CHC programme activities. Changes to care pathways are still in progression, with many delayed due to waiting for IG, GDPR and REC approvals. Some care pathways are already having a positive impact on patients, either directly or indirectly. All staff interviewed to date believe that the CHC programme will demonstrate benefit patients and health and social care staff in the long term. As one clinician noted:

> *"We just analysed the preliminary data last week and we can see straight away the 100s of patients that shouldn't be here, and the impact we can potentially can have with this innovation…and then with CHC we will be able to measure it in the future to see the impacts, and we have another piece of evidence then to move us forwards."*

Section 6: Additionality and value for money

Key findings

- There was strong evidence of partnership working, including the formation of joint strategic regional activities to tackle population health inequalities.

- All CHC regions identified a range of activities and outcomes beyond those contained in the seven deliverables that had been made possible by the CHC programme and the funding attached to it.

- CHC staff noted how the CHC programme has increased the speed of research being implemented in clinical practice compared to non-CHC programmes of work.

- In assessing the initial £20 million pound investment in the North of England to tackle health inequalities, the CHC programme has represented good value for money. Furthermore, the CHC programme is contributing to delivering the DHSC priorities across the North of England.

- It is too early to assess if the CHC programme has represented value for money from a health economist point of view. Similarly, it is too early in the delivery of care pathways to make a full assessment of impact on patient care.

Additionality

Funding of the CHC programme has allowed existing activity in care pathways and regions across the North of England to become more focused. Evidence from the evaluation points to a shift in tackling health inequalities using a regional rather than silo-based approaches to the benefit of both patients and NHS organisations. In addition, the CHC programme has provided an opportunity for developing regional strategies in establishing data infrastructure and using health informatics, forcing partners to progress things much more quickly than they might have done without the CHC programme.

There is strong evidence of partnership working including the sharing of knowledge, skills and information both within and across the CHC regions. Most CHC staff who were interviewed noted that the current regional and cross-regional partnerships would not have formed without the CHC programme due to the silo-based approach that is used within NHS Trusts and HEIs.

The partnership approach also facilitated the faster roll-out of research into clinical pathways, with pathway staff noting the accelerated rate of conducting research, testing outputs and running small pilot studies compared to non-CHC funded programmes. Several of these CHC pathway outputs have reached a stage there they could be shared and applied in other regions (e.g. data sharing agreements, analytical tools). As one clinician commented:

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

The issue of additionality and what would not have taken place with the CHC programme was addressed specifically by senior CHC staff across all four regions. Each of the regions stated that without CHC funding, the current partnerships and joint strategic regional activities combining the knowledge and expertise of multidisciplinary staff would not have happened. Furthermore, each of the regions have identified a range of activities and outputs beyond those contained in the original bid that had been made possible by the CHC programme and the funding attached to it.

In one region, the CHC programme has been attributed as bringing together all the NHS Trusts, Mental Health Trusts and HEIs in the region. Increased partnership working and commitments to engage in jointly funded initiatives in the future would not have happened within the CHC programme stimulus. Across all four regions, silos were perceived to be breaking down across the different partners and between clinical and academic staff.

Elsewhere, the majority of staff were enthusiastic about the role of the programme, not only because they enjoyed the work, but also because it felt worthwhile in terms of what they could bring to the team to make a difference to the lives of patients whilst the project was still in delivery. As summarised by one member of staff:

> *"I really enjoy where I am and my job, it's a different world compared to being in a lab and you can't see your significant finding making it to the clinical face for another 20 years whereas here, it will have an impact and I will see that impact whilst I am still on the project, so yeah, it's exciting."*

Across all four regions and the Central hub, there have been a variety of activities delivered to both patients and members of the public to engage with the CHC programme. Branding guidelines and use of the #datasaveslives hashtag have helped to create a project 'brand' that has assisted in linking all the work regional patient and public involvement (PPI) work together under the CHC programme. The hashtag is now widely used both national and internationally to bring about further awareness of the benefits of using health informatics to drive improvements in patient treatments and care forwards.

Value for money

Reflecting on the £20 million pound investment in the North of England, all senior staff and regional partners felt that the CHC programme had represented value for money for DHSC. In particular, the input of staff and partners has far exceeded the money provided with the majority of staff working above and beyond their allocated time commitments to the activities, and many partners offering services in kind to ensure output delivery. There was a lot of goodwill attached to the CHC programme in terms of travel time, travel costs and additional work that was not charged for.

It is too early to say if the CHC programme has represented value for money from a health economist's point of view. At the time of evaluation it was also too early to make a full assessment of impact on patient care and clinical care pathways as the progress made in delivering the CHC programme outputs by December 2018 were predominantly more process and infrastructure focused, with many pathways still delivering outputs. Furthermore, patient and clinical care pathways require a longer lead time to impact, compared to the short time period of the CHC programme. Furthermore, it is important to note that no baseline data was captured at the start of the CHC programme, nor any monitoring measures implemented with regards to capturing information to conduct a health economist evaluation.

At an early stage in the evaluation, the evaluator saw signs that the CHC programme was beginning to contribute towards the 2018-2019 priorities set by the DHSC. By the end of the evaluation period (December 2018) these signs were confirmed and are presented in

Table 1. The CHC programme is to be commended in delivering value for money in delivering a programme of work across the North of England that also contributes to the current priorities of the DHSC.

Table 1: Added value identified from CHC programme activities that contribute to the delivery of the DHSC 2018-19 priorities

DHSC Priority	Added value
Keep people healthy and support economic productivity and sustainable public services	Regional and care pathways are beginning to address health inequalities across the health and care system in the North of England to reduce unjustified variations in health outcomes. The creation of analytical platforms and statistical models has the potential to be applied throughout the U.K to assist DHSC in improving the health of the population.
Transform primary, community and social care to keep people living more independent, healthier lives for longer in their community	The CHC programme has established the foundational infrastructure across the North of England to improve health and care through better use of digital, data and technology. The knowledge and skills of CHC staff and partnerships could be leveraged as part of the wider DHSC digital revolution.
Support the NHS to deliver high quality, safe and sustainable hospital care and secure the right workforce	The collaborative and multidisciplinary approach of the CHC programme has allowed innovation in the creation and piloting of prediction models that can highlight resource and staffing gaps during period of high demand, which could be applied across the U.K. Some care pathways are testing a more targeted approach to solving health inequalities, enabling clinicians to learn from and evolve patient pathways in a shorter period of time.
Support research and innovation to maximise health and economic productivity	CHC programme funding has contributed to the building of I.T and health informatics infrastructure in NHS organisations across the North of England, allowing the flow of data to identify key health issues within local populations. Each region has developed its own infrastructure for clinical research and medical innovation through the creation of Arks and employment of skilled staff.
Ensure accountability of the health and care system to Parliament and the taxpayer; and create an efficient and effective DHSC	There are a number of areas where CHC programme outputs could be shared and applied across the U.K. For example, the creation of regional governance structures to facilitate the use of routinely collected patient data in research, data sharing agreements and creation of patient and public involvement groups.
Create value (reduced costs and growing income) by promoting better awareness and adoption of good commercial practice across the DHSC and our arm's length bodies	The CHC programme has created regional partnerships across the North of England between NHS Trusts, HEIs and industry with governance structures and commercialisation protocols in place that protect patient data confidentiality that could be utilised by the DHSC in driving innovation and digital change with NHS suppliers both nationally and internationally.

Section 7: Challenges faced by the CHC Programme and how they have been overcome

Key findings:

- All partners across each CHC region mentioned the time constraints to achieve the ambitions of the CHC programme. This meant for some that they were very much in the early stages of delivering care pathways and will require another year to fully realise the planned delivery of work.

- Gaining approvals from the relevant organisations, including NHS Digital and Research Ethics Committees took longer than expected. In some cases, approvals were taking up to two years to clear.

- A number of issues were reported to gaining access to data, receiving data and data quality. Those that paid for data noted disparities in costs between different data providers, with regions questioning why a DHSC funded programme was being charged by NHS Digital for data.

- There is a clear need for a CHC staff communication strategy to be central to the programme right from the bidding stage, including a clearly communicated vision and online space for CHC staff to discuss issues and future collaborations.

- Tensions between different partners work was noted in all CHC regions, with different paces of work, strong personalities and some activities not prioritised identified as key issues.

- All staff noted concerns with the long term sustainability of the CHC programme in the North of England. There was concern of losing the richness of knowledge and experience of staff, the infrastructure and innovative approaches adopted in regions to deliver the CHC programme.

Introduction

This section of the report considers the challenges faced by the care pathways and CHC programme as a whole and, where possible, how they have been overcome. It covers: time constraints in delivering the CHC programme within two years; communications and commitment to the CHC programme; budget and financial management; issues with data; differences in working cultures and priorities and long term sustainability of the CHC programme.

Time constraints

The timescales for the CHC programme were tight, with notification of the successful bid issued in the Spring budget of 2015. However, delays in the signing off from Government and the sign off of regional contracts, allocation of funds and putting staff in place meant that activities began to really get underway in January 2016, which gave the CHC programme considerably less time to implement the full programme of work.

This was reflected in staff interviews where all staff noted the time constraints of trying to achieve an ambitious and innovative programme of work within two years. This meant that for some they were still very much in the early stages of implementation and needed at least another year to fully realise changes to care pathways.

Several staff stated that the programme as a whole had under-estimated the scale of the challenge in getting NHS Trusts and HEIs with very different set-ups, approaches, resources and starting points to all get the degree of harmonisation and staffing necessary to implement all that they wanted to do and this had led to delays in delivering outputs. Several staff commented that what had been written in the bids had needed more thought in order to bring the ideas into reality and some of the timescales they originally envisaged were underestimates of how long things could take.

Gaining the necessary approvals for the sharing of data had impacted all regions and caused significant delays. The time taken for sign off on data sharing agreements and applications to NHS Digital, as well as HEI research ethics approval should not be underestimated. One region had taken nearly two years to obtain approval from NHS Digital to allow a doctoral student to access data as part of their PhD study that was part of the CHC programme. This time frame is simply unacceptable. Staff are to be commended on their perseverance in gaining the necessary approvals to conduct CHC programme activities, particularly with the additional challenge of the implementation of GDPR in the middle of the study period.

Communication and commitment to the CHC programme

There did not appear to be a consistent theme in relation to the level of commitment from some partners within the CHC programme, though geography did appear to be an issue. Where meetings were consistently held in one location, this meant that partners located further away geographically always had to allow for travel time and additional travel costs. One region had been particularly affected by this with some partners not attending as many meetings as had been expected. Despite the use of alternatives to face-to-face meetings, the frequency of meetings was noted as an additional demand on staff time. With care pathway staff, meetings were often perceived to be arranged at the last minute, however, this was found to be caused by the lack of internal cascading of information from regional leads to all regional staff.

The main challenge for each CHC region was to ensure that the partnership involved the right senior people in order to ensure commitment and direction at a high level. Each of the regions utilised a different governance structure, with mixed results. Only one region was successful from the start in fully implementing its governance structure, with senior staff in clearly defined roles, a clear regional vision and operational staff, including dedicated project managers for each care pathway, had resulted in quicker progress made.

Key issues that affected the other regions were a lack of clear vision and agreed set of regional objectives. Some staff noted that trying to get everyone to work out what was the common ground and then develop and implement strategies that would work for all was very time consuming. Most CHC staff felt that the CHC model required rethinking, particularly the overall structure. Regions with dedicated project managers noted the important contribution that they made to pushing forward the delivery of care pathways. It is also important to identify ‘blockers’ (i.e. people who challenge everything and can take up a lot of meeting time in debate) and work with them outside the meeting.

Internal communication was a challenge across the CHC programme. Getting all regions to communicate and cascade information had been especially difficult to achieve in some regions or within individual partner organisations. There was a clear need for a CHC communication strategy to be central to the programme right from the bidding stage to ensure all staff and partners felt part of a wider programme of work, including the CHC programme ‘story’ and how the regions and pathways fit into this.

Many staff felt ‘disconnected’ to the wider CHC programme, with a perceived lack of leadership shown from the Central hub and communication blockages appearing both within regions as well as overall as a programme. As several members of staff commented, *“we don’t seem to have the connected element of the ‘Connected Health Cities’ project”.* As a result, some staff, particularly pathway staff, felt isolated from both the regional and overall CHC programmes of work. In some cases staff were not aware of the vision of the CHC programme. Whilst some of the communication blockages have been addressed at this point in the evaluation, future programmes of work will need to consider having an improved communication strategy.

Budget and financial management

Nearly all staff commented on the financial management of the CHC programme. This was the first time that CHC staff had to provide financial report to a Government department and the constant change in reporting was a challenge identified by all staff that had financial reporting as part of their role.

Further concerns were raised by nearly all staff in the way budgets were allocated at the start of the programme and the issue around managing underspend have caused difficulties for most regions, with many pathways working on reduced budgets due to loss of finances at the start of the programme. This meant that regions were still having to deliver their original outputs but with a reduced budget.

Across the CHC regions, staff commented on how the initial budgets had not been enough, particularly when it became apparent that costs for installing data infrastructure within some NHS Trusts would need to take place, placing an additional and unaccountable cost onto an already stretched budget. Paying for data from NHS Digital and Clinical Practice Research Datalink became an additional unexpected cost for pathways, with many questioning why a DHSC funded programme would be required to pay for data from its own organisations.

It should be noted that all CHC staff are dedicated to the programme and have worked above and beyond their contract hours to ensure delivery of outputs. Partners from all regions noted that some work had been carried out 'in kind' to make up for the shortfall in budget, whilst some care pathways have had to apply for additional funding through research bids to ensure delivery.

Data

All staff reported challenges in getting access to, receiving data and data quality. In three regions, some of the data required for the CHC programme was not available in an electronic format, being stored in paper format in filing cabinets and in some cases, the paper files consisted of carbon copies of the original files. Staff working in care pathways with paper files were very frustrated with the additional time, budget and resources required to extract patient data from non-electronic formats.

Two regions noted that data they had paid for had not yet been delivered. One region spent nearly 12 months chasing the data supplier for paid data before having to use a different data supplier, reconfiguring their pathway to meet the new data specifications. Where regions had been able to gain deliveries of data, these were always late and not all data requests were delivered. Several staff reported that some NHS Trusts were reluctant to put data in the Arks, despite all the necessary approvals having been granted, as there were still concerns about data security, despite CHC Ark systems exceeding security features of NHS organisations.

Staff working with data expressed concerns about the data quality, highlighting the following specific issues: missing data, incorrectly coded data and duplicated data. Criticisms were expressed that the data was paid for and in some cases, the data itself came from NHS Digital, and therefore, paid for data should be of better quality and standardised.

Different working cultures and priorities

Conflicts in the way different partners work was noted in all regions. In particular, the different pace of work and changing funding landscape between academia, the NHS and industry created tensions within regions. Some of this was often due to the differences in language used by each partner, as one member of staff commented:

> *"We talk in different languages sometimes...but I think we've worked through that really…I remember we had a big discussion once about what a gate keeper was…and you think you're a [type of researcher] so you know what a gate keeper is, but it took us a long time to work out what a gate keeper is to other people…it's not impossible to understand it if you put it in the right language."*

Most non-academic staff interviewed have felt that the pace of delivery is too slow, with too much of a focus on writing academic journal articles. Some staff raised concerns that academia cannot keep up with the fast pace of delivery required by industry and other organisations (i.e. CCGs, NHS trusts). However, industry and NHS organisations have appreciated the difficulties of the HEI working environment in terms of having to have information governance and HEI ethical approvals in place prior to receiving data into Arks and TREs.

Long term sustainability of the CHC programme

All staff were concerned with the long-term sustainability of the CHC programme outputs once the project finished without further funding being in place. Whilst some regions and pathways are seeking funding from other sources to continue the work established in the

CHC programme, others are devising plans for shutting down pathways between December 2018 and March 2019, whilst also having plans in place for if further CHC funding is secured.

All staff and external stakeholders that have been interviewed are concerned that all work completed to date will have been for short term gain rather than a long term investment in the North of England, particularly in developing and installing the data infrastructure for TREs and Arks. External stakeholders also noted the lack of secure data repositories for research purposes in the North of England besides the CHC programme and that DHSC needs to invest more in the North of England to reduce health inequalities.

The short term nature of the CHC programme also affected staffing in all regions. Short term contracts and not being able to offer competitive salaries in line with industry and other sectors have resulted in staffing shortages. At this point in the evaluation, it is important to note that all regions are starting to see staff leave their posts due to uncertainty in future CHC funding from the DHSC. It is estimated that by the end of December 2018, nearly 40% of staff employed on the CHC programme will have left their posts due to the end of funding. This is resulting in some work being prioritised on what can be achieved with a skeletal team of staff.

Section 8: Key transferable lessons

Evaluator Overview

The evaluator was tasked with the objective of evaluating progress and early impact in each of the four regions against the seven CHC programme deliverables, including identifying factors that have helped or hindered progress and achievement of the care pathways and regional outputs. However, at the time of evaluation it was too early to make a full assessment of impact on patient care and clinical care pathways as the progress made in delivering the CHC programme outputs by December 2018 were more process and infrastructure focused, with a long lead time to impact. For example, nearly all regions have had to set up the infrastructure to facilitate the flow of data, including the switch from paper-based records to electronic health record systems. As a result, some clinical pathways have started only to implement changes based on the data analysis, but evaluation of these pathways will not be conducted until late 2019.

This evaluation has monitored progress towards each of the seven deliverables, including identifying factors that help of hinder progress and achievement of these deliverables. This evaluation objective has been a major part of the evaluation activity. The evidence is covered in detail in Sections 4 and 7 of the report in particular. One clear area of success is the establishment of each of the four CHC regional partnerships and completing a significant amount of work in a short time frame which has been largely achieved by the end of December 2018.

Section 6 of the report reviews the question of additionality and value for money and concludes that it is too early to say if the CHC programme has represented value for money from a health economist point of view. There was clear additionality and first impressions were that, in all regions, there is a new way of thinking and a new spirit and the programme had changed the way the local HEIs and health and social care stakeholders operate, with more awareness of the need to collaborate in tackling health inequalities within the local population.

The evaluator believes that each of the regions, as well as the overall CHC programme has achieved a lot in a short time including: the establishment of data sharing protocols and agreements, establishing governance structures and working groups to review and develop both regional and overall work stream areas and activities, installing data infrastructure and Ark infrastructure, recruiting highly skilled staff, and building partnerships and establishing agreements with industry for the potential commercialisation of some outputs.

The scale of collaborative working is significant across all CHC regions and the CHC programme as a whole, with a large number of meetings, working groups and liaison between partners. Whilst some partners in each of the CHC regions had worked together on specific areas previously, many commented that the breadth, scope and strategic nature of the CHC programme were of a different magnitude and scale. The amount of work and effort required by all staff to deliver this innovative and complex programme of work effectively should not be underestimated. Being able to commit this amount of effort and resource, on top of existing heavy work commitments is commendable.

In addition, the evaluator noted a step change in behaviour and working culture in the CHC regions and with (and within) the involved partnerships this is evidence, although in some case it has been a difficult journey to get to this point and for some it is still ongoing. The HEIs, in particular, have had to work at an unfamiliar pace compared to their NHS and industry counterparts, whilst becoming more responsive to the needs of the programme to facilitate the delivery of outputs.

A third objective of the evaluation was to assess the level of input required from staff, resources and approvals (such as information governance) to create each regional Ark and care pathway. Comparison across the four delivery models is difficult because of the very different circumstances within which each of the four CHC regions are operating. For example, devolution in Greater Manchester had created a very unique and different health and social care environment to the other regions. What is clear from the evaluation is that CHC staff went above and beyond their allocated time commitments, with additional costs that were not charged for, to ensure the CHC programme was implemented in each region.

Those with dedicated regional operational or programme managers enabled them to make faster progress that those who did not have someone in that position or did so belatedly. Similarly, clinical care pathways with a dedicated project manager also enable faster progress compared with those that did not have someone in that position. The overall experience of the CHC programme was that it is important that the operational/programme/project manager is seen to be working for the benefit of all concerned.

The involvement of patients and members of the public in each region and throughout the CHC programme as a whole has been strong. In addition to the lasting legacy of the #datasaveslives hashtag, there are two other examples that stand out in respect of the innovative involvement of patients and members of the public. The first are the Citizen's Jury's, where public concerns regarding the use of data, commercial gain and privacy were explored. These juries were held in 2017, with 36 citizens representing a demographic mix were chosen from over 400 applicants from across the North of England. Over four days, the citizens heard from and asked questions of expert witnesses, and carried out group exercises to explore the jury questions. They reached conclusions together, and were polled on their individual views at the start and end of the jury process. The second is the SILVER pathway (NENC) which has put local families at the centre of project development, design and decision making with the specific aim of ensuring that work produced is user led. Other programmes of work can learn a lot from the CHC approach to working in collaboration with the local population and patients.

As the CHC programme draws to a close, it is envisaged that many of these challenges will be minimised in future iterations of health informatics type research projects. As a result, a set of key transferable lessons emerged and are presented next.

Key transferable lessons

The key transferable lessons from the evaluation evidence are:

Time for relationship building – it takes time for partners to build relationships and trust with one another and should not be rushed.

Governance structures – it has worked well where there is a clear governance structure in place with operational groups reporting to a board that is involved in development and delivery. This ensures top level commitment to programme activities whilst the practical elements are pursued by 'front line' staff.

Communication – the importance of a clear communication strategy (from the outset) with partners and all project staff, as well as key external stakeholders.

Project Manager – a dedicated project manager plays a vital role in underpinning partnership activities by co-ordinating meetings, acting as a channel for communications, co-ordinating contract and data sharing agreement requests.

Multidisciplinary team – the benefits of having a range of highly skilled staff including clinicians, qualitative researchers, software engineers and statisticians working together provided a range of expertise and knowledge that was utilised to great effect.

Patient and Public involvement – the benefits of having patients and members of the public involved in the design and delivery of research and care pathways using patient data cannot be underestimated.

Awareness of the different pace and language between stakeholders – HEIs, NHS Trusts and Industry operate at difference paces and use different languages to communicate. This is to be expected within multi-stakeholder partnerships and time in future programmes of work needs to be allowed for to establish working patterns and languages for key concepts to ensure clarity.

Section 9: Recommendations

Building on the successes, challenges and key transferable lessons identified, the following are the key recommendations arising from the evaluation findings.

Recommendations for the CHC programme

- There is a need to put in place clear leadership and organisational structures to support regions and pathways. Organisational structures should allow for variations at the regional level, but these should be clearly defined and set out at the start of future programmes of work.

- Milestones with measureable outcomes to demonstrate both progression and impact towards deliverables should be agreed with DHSC at the start of future programmes of work. The CHC programme should consider how existing and new programmes of work will be monitored and evaluated throughout the study period to demonstrate impact.

- Regional objectives and outputs should be agreed at the start of future projects to ensure all CHC programme outputs are delivered in addition to pathway projects. There should be a clear understanding and acknowledgement of different languages and working practices. This should be in the form of a contract held between all stakeholders involved to ensure accountability and transparency.

- Future projects should consider employing a health economist who could evaluate the economic impact of the CHC programme across all regions.

- Further consideration needs to be given to the involvement of industry within the regional and pathway activities. This should consider the anticipated benefits of potentially up-scaling and/or commercialisation of outputs to ensure programme sustainability.

- Future projects should consider including NHS Digital, NHS England or DHSE as a project partner.

- CHC programme bidders need to be realistic about the scope of achievements indicated in bids; in other words what they could sensibly achieve with the resources and time available.

- Future projects should consider focusing on the replication of pathways between regions with funds allocated specifically for cross-regional collaborations.

- Consideration should be given to having a longer study period that is fully funded. A minimum five-year study period is required to account for time taken for relationship building between stakeholders, construction of data infrastructure, gaining relevant approvals, signing of data sharing agreements and delivery of data.

- It is clear that the composition of personnel is prone to significant change, particularly towards the end of the project period. It is suggested that cross-organisational briefing of roles and responsibilities is critical in order to avoid delays. This also reinforces the need for an adequate induction process to be developed for new individuals replacing existing staff, with succession planning put in place during interim phases.

- Communication strategies should be reviewed and consulted within the CHC partnership with a view to improving lines of communication amongst all staff at all levels. Strategies should consider having a dedicated 'all staff' mailing list rather that depending on regional leads to forward on email communication.

- An internal CHC programme staff website might consider including the following functions to promote cohesion and inclusion in the CHC programme:

    - An area with documents related to the working groups, minutes of meetings, etc.

    - A 'chat room' facility for staff to post questions for problem solving or solution sharing, as well as researcher specific areas (e.g. PhD student, qualitative researcher, data analyst).

    - Staff list with short biographies, expertise and contact information.

  - An online area with the latest announcements to ensure all staff are aware of up and coming events.

Recommendations for the DHSC

- Milestones with measureable outcomes to demonstrate both progression and impact towards deliverables should be agreed at the start of future programmes of work.
- Reporting of project deliverables and finances need to be standardised and remain unchanged throughout the duration of a research programme, with templates agreed and fixed at the start of the programme.
- Consideration should be given to having a longer study period that is fully funded. A minimum five-year study period is required to account for time taken for relationship building between stakeholders, construction of data infrastructure, gaining relevant approvals, signing of data sharing agreements and delivery of data.
- It was raised that funding decisions were not helpfully timed to the pathway and programme timelines. Delays in funding being allocated were frequently reported, resulting in project delays and monies not being able to be carried over to compensate for these delays. DHSC should consider a flexible approach to how funds are spent by programmes if they are not able to meet project timelines outlined in bids.
- From interviews, it was clear that that the composition of personnel in DHSC is prone to significant change throughout the bidding and delivery phases. It is suggested that cross-DHSC briefing of roles and responsibilities is critical in order to avoid future delays. This also reinforces the need for an adequate induction process to be developed for new individuals replacing existing staff, with succession planning put in place during interim phases.
- DHSC should consider the inclusion of NHS Digital, NHS England or DHSC itself as a project partner in future health informatics projects.

- DHSC should consider streamlining and standardising Information Governance (IG) requirements for future health data projects, with clearly defined pathways and timescales for researchers to apply for and receive data. Standardised IG would reduce anxieties amongst local NHS data providers and facilitate future health informatics research.
- Interview and survey participants have reported paying NHS Digital and the Clinical Practice Research Datalinks for datasets. However, it was noted that prices for datasets ranged from £24,000 to over £100,000 (while similar data from e.g. the Welsh SAIL databank cost £7,000). Whilst it is acknowledged that there is a cost attributed to storing and delivering data, transparency is needed in the breakdown of the direct costs to ensure fair pricing of data for research purposes.

Appendix A: Overview of evaluation methodology

To assess progress in the delivery of the CHC programme pilot study, a researcher was appointed to carry out an independent evaluation over the period of eleven months. The overarching guidelines adopted to scope and inform the research design to meet the objectives were:

- Consideration of research ethics, including ensuring informed consent and safety of all research participants and the management of confidential data.
- A sufficiently in-depth methodology to meet the objectives, but light touch where possible to avoid placing an undue burden on participants to reduce potential survey and interview fatigue.
- Carefully considered risk identification and mitigation.
- The contractual requirements of the CHC pilot phase programme.

The evaluation was undertaken in seven stages as follows:

- Stage 1: Inception, project steering, desk review, and development of research tools
- Stage 2: Informational interviews with key stakeholders
- Stage 3: Documentary review of programme documentation for each region
- Stage 4: Research with key regional and pathway CHC staff
- Stage 5: Discussions with other stakeholders
- Stage 6: Preliminary results discussed with all CHC staff
- Stage 7: Analysis and reporting

Below is a summary of activities in each of these phases.

Stage 1: Inception, project steering, desk review, and development of research tools

Inception meeting and project steering

An inception meeting was held on 1st February 2018. At this meeting discussion took place around elements of the original tender and a review of activities completed to date. Informational discussions were held with other leadership staff over a three week period to gain further information of the key deliverables. Following the inception meeting, an Evaluation Protocol was prepared and circulated to all regional leads for comments. An overview of the research activities and evaluation timetable was presented at the CHC Leadership Group Meeting on 20th March 2018.

Desk review and development of research tools

Following the inception meeting, researcher reviewed the full tender submission and any other relevant project documents in order to:

- Develop an initial overview of the CHC programme, the four regional partners and an initial comparison of their care pathways.
- Develop an initial understanding of where the CHC pilot study 'sits' within the overall CHC programme.
- Identify the contractual deliverables and develop a set of outcome indicators to assist in assessing progress towards each of the deliverables.
- Map the wider issues within the CHC programme and differentiate which issues are programme specific or are external factors that cannot be controlled at present.
- Utilise theories of change to develop a logic model to ensure equal emphasis of the evaluation is placed on both the processes involved and the contracted outcomes.

This led to the development of the research design strategy and the data collection tools. An application was made to the University of Manchester Research Ethics Committee to ensure the research design followed ethical guidelines. Ethical approval was granted in May 2018 (Ref: 2018-3923-6106).

Stage 2: Informational interviews with key stakeholders

Semi-structured informational interviews were conducted with key CHC staff from each of the pathways and the central CHC hub in mid-February to late April 2018. A total of 28 key staff participated in these interviews. The aim of these initial informational interviews was to establish which two pathways would be put forward for evaluation; what they considered to be the greatest challenges; any issues they foresaw; successes and unintentional outcomes of the CHC and a consideration of future challenges with regards to the CHC programme deliverables.

Stage 3: Documentary review of programme documentation for each region

A documentary review was undertaken throughout the duration of the evaluation period. In doing so, the researcher was able to review pre-existing and new documentation to determine any differences between the proposed CHC programme and the actual programme of implementation. In doing so, the documentary review highlighted issues that could be missed through other means of data collection.

To evaluate progress towards the CHC programme deliverables, documents from different time points in the project were used to identify the structures and procedures used to deliver each care pathway, as well as the overall CHC programme. This included monthly project reports, meeting documentation, internal evaluation reports, marketing materials and other project reports.

Stage 4: Research with key regional and pathway CHC staff

Research with staff in each pathway had two elements - quantitative and qualitative - as follows:

Quantitative research: We conducted an online survey that was offered to all CHC staff to complete. This was to gain a broad understanding of CHC staff experiences across the different pathways in relation to the programme outcomes. The questions were developed using the logic model and CHC programme outcomes as a guide to ensure questions were relevant to the evaluation. The questionnaire included the following sections:

- Approaches to creating regional learning health systems and pathways
- Challenges experienced and/or managed
- Unintended outcomes from being involved on the CHC programme
- Recommendations for facilitating future learning health systems and pathways

The questionnaire had substantial sections for free text to all staff to describe their experiences in the CHC programme and care pathways in more detail. These sections were transcribed for qualitative data analysis. In May, a link to the questionnaire was emailed to all 210 staff across the CHC programme. In addition to the online survey, staff could also request a paper-based copy of the survey, or to complete the survey over the telephone. Data from responses were exported from the survey handler and securely stored in Microsoft Excel for initial data cleaning and then to SPSS for data analysis.

The survey proved a valuable source of information that informed the evaluation recommendations and the development of case studies. However, the numbers involved in the survey are quite small and therefore the results should be treated with caution.

Qualitative research: Qualitative research was undertaken with a selection of CHC staff for each pathway and region. In late April 2018, initial semi-structured confidential interviews were conducted. The aim of the interview was to develop a clearer understanding of staff experiences in the design and delivery of the CHC programme and pathways. A topic guide was developed using the logic model and initial results from the documentary review as a framework in which to formulate interview questions. Key areas that were explored during the interview include:

- The perceived benefits and challenges of the CHC programme
- CHC programme deliverables
- Using data in care pathways
- Patient and public involvement
- Creating a skilled workforce
- Working with industry

Using a semi-structured interview methodology allowed the researcher to explore emerging issues during the interview. The interviews took place at the place of work of the participant. All interviews were audiotaped. Due to costings, interviews were minuted rather than transcribed verbatim. Interview data was anonymised to remove any traceable information that could identify the respondent to the transcript (e.g. names of people or place names). Each respondent was assigned a project code and this will be used in place of real names on all collected data. The ‘project key code’ linking project codes to identifiable respondent data was kept electronically on a password protected secure server. Digital recordings of interviews were stored on a password protected secure server, while hard copies of field notes were kept in a locked filing cabinet, in a locked room.

These were then used to inform recommendations and the development of case studies. A total of 59 individuals were involved in this stage of the research. Interviews were carried out until late September 2018.

Stage 5: Discussions with other stakeholders

In order to consider the wider benefits and challenges of the CHC programme within each region, interviews were also conducted with a number of stakeholders who sit within the CHC programme but were not directly involved in activities in the eight care pathways or regional activities.

Stage 6: Preliminary results discussed with all CHC staff

In September 2018, an ‘All hands’ meeting was planned where CHC staff from across all four regions attended. This was to present the preliminary findings of the overall CHC evaluation and draft recommendations, as well as provide an opportunity for regional staff to reflect and respond to their regional preliminary results. All CHC staff were encouraged to complete the feedback surveys, available both online and during the event to provide further updates on pathway and regional work, as well as comments on the overall CHC programme draft recommendations.

Stage 7: Analysis and reporting

Our data analysis utilised a thematic approach where data from the documentary review, survey and interview data were triangulated to quantify progress towards the CHC programme outcomes. This is because no baseline data was available for the CHC programme. Our analysis strategy used an iterative process, whereby data collection and data analysis were conducted concurrently. For data collected through our documentary review and interviews, a thematic analysis using our logic model as a framework was used to assess progress against the CHC programme outcomes and to identify recommendations to support future programme decision-making. Descriptive analysis of the online survey data was used to inform actionable recommendations, which in turn will aid the future development and refinement of the CHC programme and care pathways.

Outputs

The project outputs of the CHC evaluation were:

- One journal article.
- An interim report by end of June 2018.
- Presentation of preliminary findings and recommendations to each region for feedback in early September 2018.
- Final report by the end of December 2018.
- Four regional reports by the end of December 2018.

Appendix B: Connected Health Cities (CHC) Programme outcomes

Table 2: CHC programme deliverables, with criteria, which formed the evaluation criteria

Outcome	Criteria
Establishment of data sharing strategy and agreements for each region	• Development of local and autonomous information strategy and objectives. • Data sharing agreements established between the Arks and linked-data providers.
Establishment and delivery of governance arrangements for the sharing and usage of data for each region	• The agreement of oversight and governance arrangements between the CHCs, NHSA, NHS organisations and R&D partners.
Workforce arrangements optimised and CPD requirements identified	• Physical co-location of expertise in each CHC, with a workforce possessing the informatics skills to interrogate big data to analyse and assess health care pathways, with CPD mechanism established.
Creation of Arks as analytical platforms	• Delivery of secure data-analysis facilities which analyses, at least, local GP, hospital admissions/discharge, hospital laboratory and social care data, integrated and searchable at patient-level against care pathways. • The creation of a successful platform for analysing care pathways which, via feedback loops established with practitioners, can identify the variations from guideline-indicated care. • Development of a platform which can be used for researching variations in care to a greater extent than currently possible, including (antimicrobial) prescribing vs. diagnosis, across heterogeneous populations synchronously.
Pathway analysis, variation assessment and improvements identification	• Establishment of single analytical pipeline under an accountable lead for each CHC, which outlines areas for investigation for the CHC Arks. • Positive feedback loops with patients who are involved in their own care, accompanied by positive responses from patients on their involvement and access. • Care pathways redesigned using new intelligence across a number of health economies, in such a scale that the conclusions are robust, valuable and meaningful.
Frameworks and integration with R&D partners	• Processes created for co-developing care pathway optimisation tools with industry, whilst preserving patient privacy. • Increased R&D partnerships with private sector organisations e.g. UKTI LSIO partnerships.
Production of a business model suitable for scaling and sustainable for delivery in the NHS	• Production of a business model suitable for scaling and sustainable for delivery in the NHS.

Appendix C: Logic Model

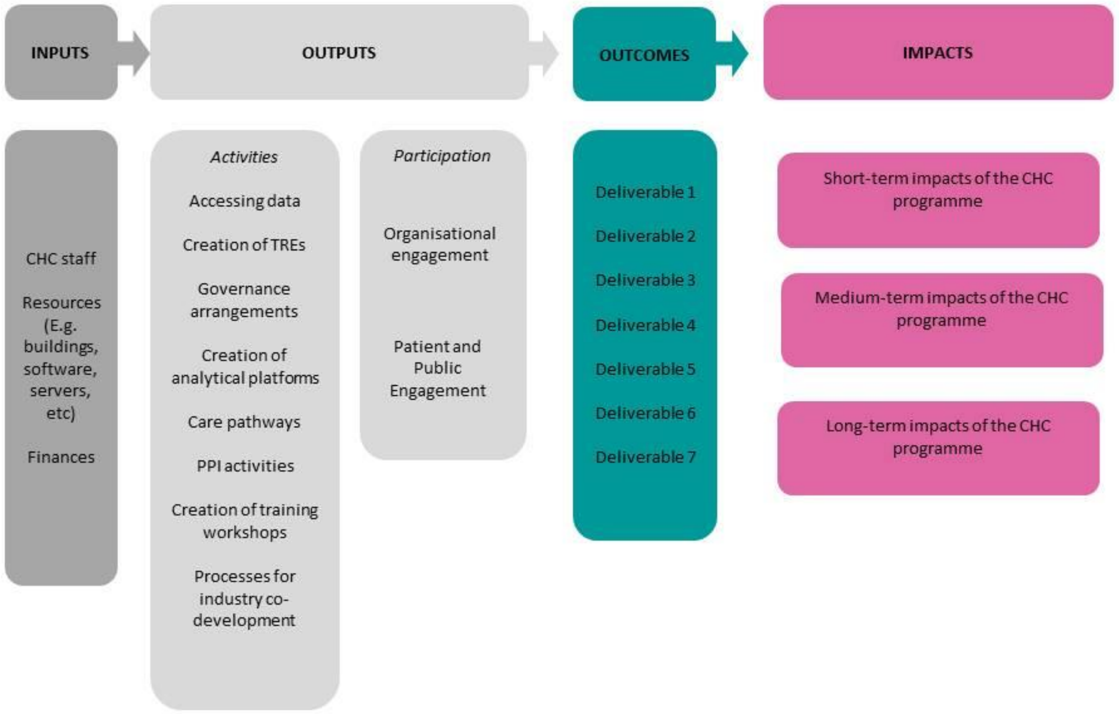

Figure 2: Logic Model for Connected Health Cities (CHC) Programme Evaluation

Appendix D: Description of care pathways being evaluated by region.

Table 3: Description of care pathways being evaluated by region.

CHC Region	Title of Care Pathway	Objectives of Care Pathway	Description of Care Pathway
Connected Yorkshire	Supporting community care and reducing demand on A&E services	• To link de-identified routine NHS data to describe a detailed profile of patient demand across both prehospital, primary care and hospital emergency and urgent care settings in Yorkshire.	To collect routine NHS data from a number of emergency and urgent care (EUC) providers and link the data to provide a coherent picture of EUC demand.
	Safer Prescribing for Frailty	• To reduce inappropriate polypharmacy for people with frailty.	To work with GPs to change behaviours related to deprescribing for older people with moderate or severe frailty as identified by electronic Frailty Index scores. This includes developing interventions using which apply evidenced tools to support deprescribing.
Greater Manchester	BRIT – Using data to tackle antibiotic resistance	• To provide the NHS and clinical care teams with better information on what is happening and who is getting antibiotics. • To assist in determining whether the use of antibiotics is reasonable given local resistance patterns to antibiotics	Analysis of patient records from GPs for effectiveness of antibiotic prescribing in general practices. This includes the development of a Data Lab feeding back advanced analytics to clinical staff and policy makers and the evaluation of interventions to optimise prescribing.
	Using technology and data to improve the diagnosis and treatment of stroke	• Improve the recognition of stroke by paramedics to maximise the proportion of acute stroke patients taken directly to a specialist stroke centre for timely expert care and minimising the number of non-stroke patients entering the stroke pathway. • Provide timely and focused referral to neurosurgery for patients in Greater Manchester with stroke caused by a brain haemorrhage. • Ensure that all patients get all the right treatments that they need to reduce the risk of another stroke when they are discharged from hospital.	To improve stroke recognition by paramedics by linking ambulance data to data at Salford Royal; using primary and secondary care data to create a large cohort of stroke and TIA patients for creating a predictive model of patients who are at high risk of stroke; and using acute trust data to identify predictive factors of early deterioration and death.
North East North Cumbria	Predictive modelling for unplanned care	• To develop predictive modelling tools for unplanned care forecasting to support demand management and service planning in relevant health and social care services.	To produce statistical models that can be used by health/local authority/other analytics teams to produce daily forecasts up to six months in advance with the pertinent associated uncertainties and variations in urgent and emergency care.
	SILVER: Smart Interventions for Local Vulnerable Families	• To develop data sharing agreements to allow the linking of existing health data across multiple health agencies via one platform that provides recommendations to key workers.	To link data across multiple agencies including health (physical and mental), social care, criminal justice, housing and education to develop a more complete Learning Health System.
North West Coast	Development of a learning system for alcohol	• To be able to inform health professionals about local clinical care. • To define best care or treatments, implement and demonstrate benefits.	Improving the way information is collected, analysed and shared between agencies and service users to bring opportunities for news was to respond collectively.
	Development of a learning system for unplanned care	• To improve how data is used to enhance patient care admitted to hospital for emergency care.	Linking NHS data with social services data to improve the care pathway for patients with COPD and epilepsy.