The Great North Care Record: Integrating data in Newcastle

Nick Booth and Louise Wilson
Bringing together health and care data in the North East and North Cumbria
• One of four regions in the Connected Health Cities (CHC) programme
• Greater Manchester, Yorkshire and the Humber and the North West coast
• CHC **safely and securely combine population data** and technology to address disease burdens and reduce early mortality across the North
• It’s a **socio-technical programme** to implement a regional integrated care record
North East and North Cumbria: Care pathway projects

CHC NENC funds three research programmes:

- **Durham**: planned and unplanned care
- **SILVER**: working with vulnerable families
- **Palliative care plan**: information sharing for patients receiving palliative care

The **knowledge** and **insight** from these programmes is informing the next stage of the **Great North Care Record**.
Durham care pathway

CHC NENC funds three research programmes:

1. Urgent and unplanned care
2. Healthy New Towns
3. E-obs/Early Warning Scores

Developing the Regional “ARK” in the National Innovation Centre
SILVER: working with vulnerable families

CHC NENC funds three research programmes:

- Research on permission to share family records
- Access to GP record by lead social care professional
- Multi-agency data sharing to improve service design and delivery
Palliative care plan: information sharing in end of life care

CHC NENC funds three research programmes:

• Building an innovative shared care plan
• Using a comprehensive standard SNOMED CT coded dataset
• Accessing and analysing data in ARCHIE
Our vision

Building a vision for a population health legacy for the North East and North Cumbria
ARCHIE proof of concept

Other Sources of Data

Bilateral policy decision making

NHS Publication Servers and Hosts

Non-NHS Publication Servers and Hosts

XDS-HIE

ARC

Internal Publications

External Publications

Research Domains

Research Participation Brokerage Service

MIG/GP Connect feed

HIE Federation Hub

other CHC domains

Primary Care gateway

GP

GP

GP

GP

Patient Portal

Single point of policy decision making
The social: Professionals

- Professional network
- Discourse
- Informatics in the Pub
- Caffe Informatica
- Amy’s Page workshops
- Time In Time Out
- Blogs
- Social media
The social: Professionals

53 different participant roles

plus 18 who didn’t say
The social: Professionals

Amy’s Page workshops

9

53 different participant roles

plus 18 who didn’t say
The social: Professionals

9 Amy’s Page workshops

3 personas & scenarios

53 different participant roles

plus 18 who didn’t say
The social: Professionals

9 Amy’s Page workshops

3 personas & scenarios

123 participants

53 different participant roles

plus 18 who didn’t say
The social: Professionals

Over 470 GNCR Network members
The social: Professionals

Over 470 GNCR Network members

1500 Twitter followers
The social: Professionals

Over 470 GNCR Network members

350 event attendees

1500 Twitter followers
The social: Public

- Focus groups and workshops with around 500 participants
- YouGov poll
- Citizen groups informing the development of the privacy preference tool
- Public panel to approve data releases
What we want in the end

A permanent North East and North Cumbria Trusted Research Environment:

• Associated with a permanent home for health and care analytics
• Where NHS, social care and university data experts:
  • Work together
  • Teach each other
  • Go back to their organisations
  • Expert in multiple traditional and innovative analytics methods
  • Transform health and care in the UK for the 21\textsuperscript{st} century
Contact us

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CHC North East and North Cumbria
Thank you
The Great North Care Record makes information appropriately accessible for individual healthcare, service planning and research.
The technical

Great North Care Record

2016 - 2018

Phase one

100% of GPs using the Information Sharing Gateway
Read only view of GP record in emergency, out of hours, mental health, 111 and ambulance services
The technical

Phase one

100% of GPs using the Information Sharing Gateway
Read only view of GP record in emergency, out of hours, mental health, 111 and ambulance services

Phase two

2016 - 2018

2018 - 2020

Develop prototype for a regional Trusted Research Environment (TRE) and Health Information Exchange (HIE)
Capture regional privacy preferences
The technical

Phase one
100% of GPs using the Information Sharing Gateway. Read only view of GP record in emergency, out of hours, mental health, 111 and ambulance services.

Phase two
Develop prototype for a regional Trusted Research Environment (TRE) and Health Information Exchange (HIE). Capture regional privacy preferences.

Phase three
Create a fully shared health and care record; and a learning health system.

2016 - 2018
2017 - 2020
2019 - 2022
The technical

Phase one
100% of GPs using the Information Sharing Gateway
Read only view of GP record in emergency, out of hours, mental health, 111 and ambulance services

Phase two
Develop prototype for a regional Trusted Research Environment (TRE) and Health Information Exchange (HIE)
Capture regional privacy preferences

Phase three
Create a longitudinal care record and a learning health system

Phase four
Consent rich research environment

2016 - 2018
2018 - 2020
2020 - 2022
2021 onwards