Healthy Children: Transforming Child Health Information

From Strategy to Concept to Reality (and Beyond)

Phil Graham & Sarah Boyd

The King’s Fund - 10th July 2018
Why?

‘The future health of millions of children, the sustainability of the NHS, and the economic prosperity of Britain all now depend on a radical upgrade in prevention and public health.’

We have to do better. We have to be different.
The Vision

Keep children safe and well
‘Knowing where every child is and how healthy they are’

Enable co-ordinated, proactive care
‘Appropriate access to information for all involved in the care of children’

Start a generation that owns its own wellness
A shift from ‘us and them’ to ‘we’.
The Win

The first generation of digital record holders

Balance of need: people and organisation

A Generation that ‘own’ their wellness
Digital Redbooks

Sun safety for children

Exposing your child to too much sun may increase their risk of skin cancer later in life.

Sunburn can also cause considerable pain and discomfort in the short term.

That’s why babies and children need to have their skin protected between March and October in the UK.

Tips to keep you

This article was taken from NHS Choices on 2 May 2018 at 03:40
The Pilots

Lancashire & South Cumbria

London

Bristol & South Gloucestershire
The Future

Relationships

Technology

Data
Concept to Reality (and Beyond)
Phil Graham
What Lies Beneath

Beware the Appberg!

Why PHRS are just the tip of the iceberg and how Lancashire is planning for their introduction
What are we doing in L&SC?

- An exemplar for implementation of NHS England’s digital child health strategy, ‘Healthy Children: Transforming Child Health Information’

- Partnering with the national Digital Child Health programme to support the delivery of child health services by establishing an IT messaging framework and standards that will allow information to be exchanged securely between health professionals, parents/carers and public health
Project Scope: secure exchange of child health information to improve service delivery

Primary Care
National Failsafe & Events Management Service
London LEMS
Citizen Identity
Relationship Management
Local Events Management Service
Hub Registration Authority
Local Failsafe
Events Design Authority
National Screening Services
ePCHR
Other New Services
Public Health
Local Failsafe Events Management Service
London LEMS
Child Health Records
Maternity
School Nursing 5-19
Health Visitors 0-5
National Failsafe & Events Management Service
National Failsafe & Events Management Service
Why are we doing it?

- Introduce electronic Personal Child Health Records (ePCHR) for parents
  - Helping parents understand and access the preventative care available for their child
- Improve the uptake of the Healthy Child Programme (HCP)
  - Ensuring all parents in L&SC are offered preventative services for their child
- Improve delivery of the HCP
  - Helping health and care professionals to give the right care at the right time
- Improve decision making for children’s health
  - Parents, health visitors and GPs seeing the same care record for a child
- Improve the information available for population health management
  - Enable resources to be targeted to families who most need it
- Improve the value for money of child health services
  - Less costly administration, more time and money for care
The most mature model the NHS has for a PHR is the paper PCHR (redbook)

- Underpins delivery of Healthy Child Programme
- Access to/exchange of professional clinical records and personal health information between care settings and between parents and professionals
- Signposting to national standard health education information on the newborn period and local service information for parents and families.
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Tips to keep you...
Planning for the future – platforms not PHRs

We are not buying an ‘app’, we are planning a platform to have a sustained capability to link personal health information with professional clinical information and allow people and professionals to collaborate to create health and wellbeing.
Predictive analytics refers to using data mining techniques and statistical analysis of current and historical events to predict future outcomes.
• Tailored to the individual
• Integrated Information and mobile working
• Don’t forget the Governance!
• And into the future…………
The Circle of Life

Pre Conception

Antenatal
GP/Community/Home Hospital

Labour/Birth
Home/Hospital/MLU

Post Natal
Home/GP/Community

Children’s / Public Health
The Circle of Life
Funding and Benefits

Implementation

Specification

Procurement
Summary
With the benefit of hindsight...

The TEC change roadmap

1. Start with a clear and shared vision and purpose
2. Build understanding and support
3. Co-design and involve people end to end
4. Focus on the people: engagement, connectivity, leadership, roles, culture and values
5. Test, listen, learn and improve

TRUST & COMMITMENT
- Clarity of the who, what, when, why and how - a tailored narrative
- Systems leadership and Hacker in Chief approach
- Culture of collaboration and a hack mindset
- Connectivity and interoperability of systems, data, people, skills and resources
- Show and share examples of success and learning

A world-leading health and care system. Better for everyone.
More time, money and lives saved.
Improved quality and safety - less mistakes.
Less paperwork.
Clinicians and professionals with more time for those who need them.

This is Claire Cater and Social Kinetic’s work for NHS England
Change is what matters most

We need a new set of cultural norms – from:

**Me the expert**
Found the answer, invented the new solution, the successful organisation.

**Fear of failure**
And risk aversion.

**Competition**
We won because we succeeded where others didn’t.

**Innovation**
Is new and shiny and something never seen before.

**You’re either inside or outside**
The NHS family and anyone professing to be.

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**To the collective**
Working to a shared vision and purpose coming together to co-design the solutions to our shared challenges.

**Testing and learning**
From what didn’t work or could be better, identifying the benefits – a continuous cycle of designing, adapting and adopting.

**Collaboration and shared success**
This is critical in a new world of joined-up care and systems, STPs and accountable care organisations.

**Innovation is what works and delivers**
The vision and benefit in the beginning that could be joined electronic health and care records, and data within organisations and across systems.

**Partnership based on those who bring something to the table**
That’s needed who benefit to patients, clients, staff and the health and care system. TEC requires huge diversity of skills and investment that can’t all exist within the NHS.

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Also Claire Cater and The Social Kinetic
ADDITIONAL SLIDES
Out of the mouths of babes…

- Seeing your health information ‘to make it better’
- Do doctor’s share information, ‘yes, probably, doctors hand over to doctors about the same patient so they know what’s gone on in their life’
- ‘It matters to be healthy when you’re younger if you want to live when you’re older, you have to keep healthy’
- Don’t smoke, drink or do drugs
- What can the NHS do to help you? ‘Maybe just keep track of their patients’

Self Management

Information Sharing

Prevention

Public Health Education

Failsafe Management

‘the future health of millions of children, the sustainability of the NHS, and the economic prosperity of Britain all now depend on a radical upgrade in prevention and public health’
The Healthy Child Programme

The universal preventative service, providing families with a programme of screening, immunisation, health and development reviews, supplemented by advice around health, wellbeing and parenting.

‘The UK was one of the world leaders in improving children's health through the 20th century, and our public health system, our NHS and the research undertaken within them are the envy of many across the world’.

A NATIONAL standard service offered to all children. Although delivered locally, the interventions are mandated and it is the foundation for preventive healthcare in England, supporting the prevention and public health agenda’
Pre-Health & Social Care Act

Cohesive population

Public health services for children commissioned and delivered by one organisation

…your basic silo organisational health record
Post Health & Social Care Act

Different populations

Public health services provided by several different organisations

...and commissioned by different organisations

...record maintained by yet another set of organisations
Keeping it simple

Personal Health
- Info for use by: Parents, Children, Young People, Carers
- Info sharing controlled by: Parents, Children, Young People, Carers
- Info type: per child records with personal identifiers and personal data, shared by parents and young people and professionals
- Info grouped by: families, extended family, social groupings
- Info Systems in use: ICAP Health, Passport, iPatientBook, BABY Buddy, Patient Privacy: Best and many others

Professional Health
- Info for use by: professionals caring for parents, children and young people
- Info sharing controlled by: the organisation in which the care takes place, e.g. GP practice, hospital.
- Info type: groups of individual, identifiable health records e.g. consultations, medical notes, recorded by professionals
- Info grouped by: organisation providing the care
- Info Systems in use: CHERF, PAS, Maternity, MH Systems, GPR Systems, EOR, CDS, APE, Screening Systems and many others

Public Health
- Info for use by public health professionals and commissioners, providing care services to populations
- Info sharing controlled by: national and local agreements
- Info type: anonymous data, does not identify individual children, often aggregated or statistical, analysed rather than recorded.
- Info grouped by: national, regional, or local populations, consumption, by disease or condition
- Info Systems in use: Malaria and Cholera and Young People’s Database, Immunisation, Cancer reports, Screening, Key Performance Indicators and others

Multi-purpose interoperability

Clinical Encounter
- Each event will have one or more uses
- Each clinical encounter consists of one or more information events: smallest useful/usable chunks of information comprising that encounter
- Efficiency (savings in time and resource)

Information Events
- Parents need to see it/act on it
- Care Professionals need to see it/act on it
- It is an intervention actively tracked by Public Health & Commissioners
What people wanted

‘I want to be in control of decisions to share my information’

‘I want personalised care from professionals who know about my history’

‘I want to have accurate, up to date information when I need it’

‘I want to be alerted if there is a significant issue with a child under my care’

‘I want to have high quality, relevant, reliable information to assess the health of the population’

‘I want to be able to reach individuals in a population easily in the event of public health concerns’
Design Authority for Events

MDS

Clinical Encounters

&

Information Events

Healthy Child Programme
Pregnancy and the first five years of life

My personal child health record
**Test Assumptions**

- Healthy Child information
  - Q: Can events be standardized for exchange rapidly?
    - Yes Content Agreed
- Collaboration on standardization
  - Q: Can this standard be widely supported?
    - Yes
- Systems development
  - Q: Can systems be modified for interop
    - Yes

**Trial New Methods**

- Trial receipt of information (London)
- Events Catalogue for child health information created
- Events management service ready to go-live

**Deploy New Services**

- Potential to deploy PHRs with standard content in other regions
- Interoperability between CHIS, Maternity, GP systems and PHRs begins

**Dates**

- March 2017
- June 2017
- July 2018
- February 2019
Implementing the Strategy

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July 2018 – Digital Health and Care Congress
• To know where every child is
• And how healthy they are
• And what are we doing about it?
Joining up Health and Care – Digital Healthcare Congress

#CreateSomethingThatWorks

LIFE'S A JOURNEY
ENJOY THE RIDE

#CreateSomethingThatWorks
Personal Health

Info for use by: Parents, Children, Young People, Carers

Info sharing controlled by: Parents, Children, Young People, Carers

Info type: per child records with personal identifiers and personal data. Recorded by parents and young people and professionals

Info grouped by: families, extended family, social groupings

Info Systems in use: PCHR, Health Passports, eRedbook, Baby Buddy, Patient Knows Best and many others

Professional Health

Info for use by: professionals caring for parents, children and young people

Info sharing controlled by: the organisation in which the care takes place, e.g. GP practice, hospital.

Info type: groups of individual, identifiable health records e.g. caseloads, medical notes. Recorded by professionals

Info grouped by: organisation providing the care


Public Health

Info for use by public health professionals and commissioners providing care services to populations

Info sharing controlled by: national and local agreements

Info type: anonymized data, does not identify individual children. Often aggregated or statistical. Analysed rather than recorded.

Info grouped by: national, regional, or local populations. Sometimes by disease or condition

Info Systems in use: Maternity and Children and Young People’s Datasets, Immunisation Cover reports, Screening Key Performance Indicators and others
The diagram illustrates the integration of various health services and systems in England, managed by the NHS. It outlines key components such as Access Management Service, Failsafe Management, Events Management Service, and Dataset and API Definitions. The diagram connects these services with specific systems and repositories, emphasizing interoperability and access management for professionals, carers, and public health. The website www.england.nhs.uk is referenced at the bottom of the diagram.
Questions?
Implementing the Strategy

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July 2018 – International Healthcare Interoperability Conference