eRedbook
The UK’s electronic Personal Child Health Record

Dan Moulin – Director and eRedbook Project Director, Sitekit
Dan Bayley – Strategic Project Manager, Sitekit

@sitekit  @eRedbook

innovators in digital health + care
PHRs and Shared Records
What is the ‘red book’?

Ethos: National Personal Health Record/National Standard
- Partnership between health professionals and parents
- Communication between health professionals and parents
- Parental understanding of their child’s health and development
- Involvement of care-givers in the management of child health and development leading to better health outcomes for children

Helen Bedford UCL Institute of Child Health. Chair, PCHR Working Group
Walton et al. Millennium Cohort Study Child Health Group. Use of personal child health records in the UK: findings from the millennium cohort study. BMJ. 2006 Feb 4;332(7536):269-70
What is the ‘red book’?

- Parents record health & developmental firsts & issues to discuss with Health Professionals
- Record examinations, screening tests, immunisations, etc.
- Essential support for Healthy Child Programme 0-5
- Used well for first 1-2 years

Research shows:
- Less use by
  - Disadvantaged mothers
  - Mothers with more children
  - Younger mothers and lone parents
  - GP & Hospital doctors
- Perceived as belonging to Health Visitor, not parent
- The record isn’t always available when parents visit a health professional

Helen Bedford UCL Institute of Child Health. Chair, PCHR Working Group
Walton et al. Millennium Cohort Study Child Health Group. Use of personal child health records in the UK: findings from the millennium cohort study. BMJ. 2006 Feb 4;332(7536):269-70
Journey so far

- Initial funding from Microsoft 2011
- Co-designed and developed with industry and the NHS
- Part of Department of Business Funded UK dallas project
  - Liverpool Community Health NHS Trust
  - Harlow
  - Microsoft
  - RCPCH
What is the Redbook?

Ethos: National Personal Health Record/National Standard

• Partnership between health professionals and parents
• Communication between health professionals and parents
• Parental understanding of their child’s health and development
• Involvement of care-givers in the management of child health and development leading to better health outcomes for children

The online version of your personal child health record

eRedbook is launching soon

Keep me up to date with the latest eRedbook developments

Notify me
Collaboration – eRedbook clinical advisory group

Dr David Low – Paediatrics
Clinical Informatics Adviser, NHS England
Chair Informatics for Quality
Royal College of Paediatrics and Child Health

Dr Helen Bedford – Chair of Personal Child Health Record
Senior Lecturer In Children’s Health
Director, MSc Paediatrics and Child Health
Centre for Epidemiology and Biostatistics
UCL Institute of Child Health

Dr David Elliman - Paediatrics
Community Paediatrician
Royal College of Paediatrics and Child Health

Catherine Powell – Health Visitor, CPHVA Representative
Health Visitor
NHS South Staffordshire

Dan Moulin - Project Director eRedbook
Sitekit

Dr Libby Morris – RCGP Representative
eHealth Clinical Lead
NHS Lothian

Mervi Jokinen – RCM Representative
Practice and Standards Professional Adviser
Midwifery Directorate
The Royal College of Midwives

Dave Munday - Policy Officer
Community Practitioners and Health Visitors Association (CPHVA)

Sara Neill – RCN Representative
Associate Professor in Children’s Nursing
University of Northampton

dallas NHS Partner representation
Jane Banks, Year Zero Project Manager, Liverpool Community Health NHS Trust

RCPCH Standards

Clinical Safety Case

RCPCH & CPHVA Endorsement
Existing CHIS Structure

1. Lots of paper
2. Information silos
3. No automated communication

Paper Red Book used to flow information round systems
A collaborative way of flowing health information round the system with the patient’s consent.
NHS Alignment

- Putting Patients First
- NHS Constitution
- The NHS Mandate
- Liberating the NHS
- Paperless by 2018
- Five Year Forward View
- Personalising Health and Care 2020
- Policy shift to digital channels
- Policy shift to self-care
- Policy shift to embracing more innovation
- Policy shift embracing SME’s

**Tim Kelsey, National Informatics Director**, said: “New mothers will now be able to carry their red book around with them on their smart phone and tablet as the NHS moves towards offering digital Personal Child Health Records. This will put an end to worrying about leaving your child’s information at home when going for a review, vaccination, or emergency treatment.”

- October 2009 - Healthy Child Programme ‘The PCHR is the main system for collecting and recording HCP data’
- March 2013 - NHS Commissioning Board - IT operating model for Child Health Information includes the PCHR
The requirements:

“CHISCC038 The system must integrate with an electronic health record (e.g. Personal Child Health Record, eRed Book and GP systems), which all parties, (including parents and adolescents) would collaborate to maintain.”

CHISOP013 CHIS systems should support extensive system interoperability to deliver the critical linkages between child health delivery systems, maternity records, the personal child health record (PCHR), the eRed Book, national screening systems, laboratories and GP practice systems in terms of communication of records and provision of failsafe processes.

Heathy Child Programme

“The PCHR is the main system for collecting and recording HCP data. At the same time, it promotes greater personal ownership and guardianship of the health and illness biography of each child. The PCHR should be the same in appearance and core content as advised by the national PCHR group, to ensure consistency and continuity into the school years.”


<table>
<thead>
<tr>
<th>Age (wks)</th>
<th>Event</th>
<th>Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>0d</td>
<td>Bloodspot</td>
<td>Midwives, HVs / Lab Systems, Bloodspot Failsafe, CHIS</td>
</tr>
</tbody>
</table>
| 5d        | Hearing | Screeners/
|           | New Baby Review | Health Visitors/CHIS |
| 7w        | 6-8 Week Exam | GP/Primary Care Systems |
| 9w        | 8/12/16 wk Imms | Practice Nurse/Primary Care Systems |
| 12m       | 12 mth Review | Health Visitors/CHIS |
| 13m       | 12/13 mth Imms | Practice Nurse/Primary Care Systems |
| 24m       | 2/2.5 yr Integ Review | Health Visitors or EYP/CHIS or LA Systems |
| 40m       | 3yr 4mth Imms | Practice Nurse/Primary Care Systems |
| 4y        | 4-5yr eyesight check | School Nurses/CHIS, paper, LA systems |
|           | School Entry Chk | School Nurses/CHIS, paper, LA systems |

Healthy Child Programme: Providers of service/ Source system for information
Birth registration and NHS Number (Initiation)

Newborn Hearing Screening (Hearing Screening)

New baby review (Health Visitor)

6-8 Week review (GP)

1 year review (Heath Visitor)

2. year review (Heath Visitor)

Antenatal

Newborn Exam. (Midwives, Junior Doctor (or GP))

Blood spot taken (Community midwife)

Primary course of immunisations (GP / practice nurse)

MMR immunisation Second dose (GP / practice nurse)

Health review(s) (Heath Visitor)

School Entry review (School Nurse)

Legend

Antenatal  Midwifery  Hearing  GP  Health visiting  School Nurse
Connectivity

Reuse of standards based messaging to connect local systems and services
“Only patients can unlock the potential of electronic record.”
“A digital “Redbook”– is a great place to start”.
Lord Ara Darzi
Service delivery

**Liverpool** – 15.2% minority ethnic groups
5900 births pa

**Sefton** – 3.5 % minority ethnic groups
2800 birth pa

Health Visiting workforce
Current 170.6 on trajectory to reach 180.2 for HV
Implementation plan
Vision for a child’s journey across the health & social care economy in Merseyside enabling shared records and a PCHR

Author: Jane Banks v 3.1 29/08/14
Parents Views

**Positives:**
- General acceptance of shift away from paper
- Some like the paper version as a keepsake
- Generally easy to use
- Want to be able to share their child’s record as needed and particularly developmental firsts and growth

**Challenges:**
- Cost of phone credit for some parents

**Story**
Signed on through NHS Choices & loaded her baby & photos in 20 mins
Professional Views

Health Visitors

**Positives:**
- Growth charts and automatic plotting, especially for prem births
- Access to Health Promotion guidance
- Future potential for more timely and accurate information

**Challenges:**
- Concern about additional work
  - Dual process – choice for paper/electronic version
- Wifi or 3G access in some venues

GP’s and Community Paediatricians

**Positive** about potential for improved information sharing
Parental Feedback

How frequently parents use eRedbook

<table>
<thead>
<tr>
<th>How often</th>
<th>Responses</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Every few days</td>
<td>5.0</td>
<td>3.5</td>
</tr>
<tr>
<td>Never</td>
<td>27.0</td>
<td>18.9</td>
</tr>
<tr>
<td>Once a month</td>
<td>41.0</td>
<td>28.7</td>
</tr>
<tr>
<td>Once a week</td>
<td>19.0</td>
<td>13.3</td>
</tr>
<tr>
<td>Only when I visit the clinic</td>
<td>50.0</td>
<td>35.0</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td><strong>142</strong></td>
<td></td>
</tr>
</tbody>
</table>

Preference of eRedbook or paper

<table>
<thead>
<tr>
<th>Preference</th>
<th>Responses</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>eRedbook</td>
<td>85.0</td>
<td>59.4</td>
</tr>
<tr>
<td>Paper based record</td>
<td>57.0</td>
<td>39.9</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td><strong>142</strong></td>
<td></td>
</tr>
</tbody>
</table>

Source: Innovate UK, dallas, Year Zero survey – April 2015
Parental Feedback

Preferences of how parents would like to receive information

<table>
<thead>
<tr>
<th>Preference</th>
<th>Responses</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>I only want paper</td>
<td>2</td>
<td>7.4</td>
</tr>
<tr>
<td>I’d like it electronically but would also want paper copies</td>
<td>13</td>
<td>48.1</td>
</tr>
<tr>
<td>I’d prefer it all to be electronic and paperless</td>
<td>12</td>
<td>44.4</td>
</tr>
<tr>
<td>Grand Total</td>
<td>27</td>
<td></td>
</tr>
</tbody>
</table>

Would parents recommend to a friend?

<table>
<thead>
<tr>
<th>Recommend</th>
<th>Responses</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>11</td>
<td>40.7</td>
</tr>
<tr>
<td>Yes</td>
<td>16</td>
<td>59.3</td>
</tr>
<tr>
<td>Grand Total</td>
<td>27</td>
<td></td>
</tr>
</tbody>
</table>

Source: Innovate UK, dallas, Year Zero survey – April 2015
eRedbook London - Project Overview

- Commissioned by NHS England London
- Support Trusts in **delivering** the eRedbook CQUIN and CHIS OBS
- Map out information flows and **implement connectivity** with CHIS
- Develop a wider **understanding** of digital “perception” and the needs of the wider stakeholder group in relation to eRedbook
- Feeding into the Digital CHIS Strategy.
NHS Trusts & Suppliers

• Commissioned to move forward 3 to 4 Trusts.
• 7 currently in flight
  – Your healthcare CIC
  – Oxleas
  – Barts
  – Croydon
  – CLCH
  – Sutton & Merton
  – East London FT

• 4 CHIS Suppliers
  – EMIS, Advanced Health and Care, Serverlec (Rio), TPP (System One)
**Progress**

<table>
<thead>
<tr>
<th></th>
<th>Engagement</th>
<th>IT</th>
<th>IG</th>
<th>CHIS</th>
<th>eRedbook Setup</th>
<th>Training</th>
<th>Comms</th>
<th>Go-live</th>
<th>Signups</th>
</tr>
</thead>
<tbody>
<tr>
<td>East London</td>
<td>AAD</td>
<td>Approved</td>
<td>Served</td>
<td>Parent + Prof access</td>
<td>Attended, Need to Cascade</td>
<td>Progressing</td>
<td>Parental go live in Jan</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>CLCH</td>
<td>AAD</td>
<td>Approved in principle</td>
<td>TPP, but using data warehouse</td>
<td>Parent + prof access</td>
<td>Attended, Need to Cascade</td>
<td>Progressing</td>
<td>Parent go live Jan Feb go live with immrs</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Oxleas</td>
<td>AAD Scheduled</td>
<td>Progressing</td>
<td>Served</td>
<td>Parent access</td>
<td>Attended, Need to Cascade</td>
<td>Progressing</td>
<td>Parental go live in Jan</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Barts</td>
<td>AAD TBC??</td>
<td>Approved in principle</td>
<td>EMIS</td>
<td>Scheduled</td>
<td></td>
<td></td>
<td></td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Croydon*</td>
<td></td>
<td></td>
<td>EMIS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Your Healthcare</td>
<td></td>
<td></td>
<td>Approved, in principle</td>
<td>Advanced Health &amp; Care</td>
<td></td>
<td></td>
<td></td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Sutton</td>
<td>Re-engaged recently</td>
<td>Served</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

* Croydon are running 2 months behind to allow for local CHIS procurement
**Emma**  
NHS No. 123 456 8799

Age: 12 weeks  
Gender: Female  
Born: 25/08/2013

**Summary & Appointments**
- Screening & Routine Reviews
- Immunisations
- Notes
- Firsts & Growth Charts

**Recent Developmental Firsts**  
See all

**People**
- Emma Usually sleeps through the night aged 3 mths
- Emma Moves eyes to watch you aged 1 mths

**Moving**
- There are no developmental firsts in this category recorded in your eRadbook.

**Hands**
- There are no developmental firsts in this category recorded in your eRadbook.

**Words**
- Emma Laughs aged 2 mths
- Emma Smiles aged 1 mths

**Recent Immunisations**  
See all

- 18 November 2013  
  DTaP/IPV/Hib
- 18 November 2013  
  Rota

**Recent Health Reviews**  
See all

- Primary Course Immunisations  
  18 November 2013  
  Added by Rob Day

- 6-8 week review, Health Professional  
  18 November 2013  
  Added by Rob Day

**Recent Notes/Questions**  
See all

- “Is cradle cap usual at this age?”  
  18/11/2013  
  Added by Anna Martin

**Contacts**
- Family doctor  
  Dr David McDonald  
  0151 7089370
- Health visitors  
  G Emmanuel  
  0151 708 9370
- Dentist  
  Paul Sherman  
  0151 639 5799
Engagement

“Parents’ access to information needs to be easier to navigate”

“Parents’ pre-consultation information seeking was dominated by the internet, albeit with limited success.”

“When consulting a healthcare professional, parents liked to be given information to refer to later, although the information received varied”.

“our findings indicate a need for easy access to clearly signposted, professionally validated resources”

“Parents find it increasingly difficult to determine whether a child requires urgent care, as reflected in the 42% increase in children’s emergency department attendances in the last decade”

Sara Neill, Associate Professor in Children’s Nursing
Information guidance for this form

What immunisations will be offered to my baby?
by NHS Choices

What vaccinations will my child be given at a year?
by NHS Choices

Your child will be offered the following immunisations

<table>
<thead>
<tr>
<th>Age Due</th>
<th>Immunisation</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 weeks</td>
<td>Primary course of immunisations, 1st set</td>
<td>Go to form</td>
</tr>
<tr>
<td>12 weeks</td>
<td>Primary course of immunisations, 2nd set</td>
<td>Go to form</td>
</tr>
<tr>
<td>16 weeks</td>
<td>Primary course of immunisations, 3rd set</td>
<td>Go to form</td>
</tr>
<tr>
<td>Between 12 and 13 months of age (i.e. within a month of the first birthday)</td>
<td>12 month immunisations</td>
<td>Go to form</td>
</tr>
<tr>
<td>3 years 4 months</td>
<td>2nd dose MMR vaccine (can be given earlier) and pre-school booster immunisations</td>
<td>Go to form</td>
</tr>
</tbody>
</table>
### Immunisations

**Your child will be offered the following immunisations**

<table>
<thead>
<tr>
<th>Age Due</th>
<th>Immunisation</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 weeks</td>
<td>Primary course of immunisations, 1st set</td>
<td>Go to form</td>
</tr>
<tr>
<td>12 weeks</td>
<td>Primary course of immunisations, 2nd set</td>
<td>Go to form</td>
</tr>
<tr>
<td>16 weeks</td>
<td>Primary course of immunisations, 3rd set</td>
<td>Go to form</td>
</tr>
<tr>
<td>Between 12 and 13 months of age (i.e. within a month of the first birthday)</td>
<td>12 month immunisations</td>
<td>Go to form</td>
</tr>
<tr>
<td>3 years 4 months</td>
<td>2nd dose MMR vaccine (can be given earlier) and pre-school booster immunisations</td>
<td>Go to form</td>
</tr>
</tbody>
</table>
Hi Slondon Test

We hope that you'll find the following articles of interest for Steve Test:

**How will my baby develop?**
by NHS Choices

**What vaccinations will my child be given at a year?**
by NHS Choices

**What is involved in the two year review with my health visitor?**
by NHS Choices
Immunisations

When did Anna last have her Tetanus Immunisation?
# Received messages

<table>
<thead>
<tr>
<th>Message name</th>
<th>Date Received</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hep B, adolescent</td>
<td>11/11/2015</td>
<td>Read</td>
</tr>
</tbody>
</table>

- **Age:** 1 y 9 months
- **Gestation:** 40 weeks
- **Gender:** Male
- **Born:** 30/01/2014
- **Recent Weight:** 12.00kg

- **Preterm**
- **Growth Chart**
Nathan
NHS No. 885 533 1191
Age: 1 y 10 months
Gestation: 40 weeks
Gender: Male
Born: 30/01/2014

Primary Course Immunisations

Information guidance for Primary Course Immunisations
What vaccinations will my child be given at a year?
by NHS Choices
Relevant from 0-2 years
What immunisations will be offered to my baby?
by NHS Choices
Relevant from 0-2 years

8 Weeks

<table>
<thead>
<tr>
<th>Antigen</th>
<th>Date (DD-Mmm-YYYY)</th>
<th>Batch No.</th>
<th>Site</th>
<th>Immuniser</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>DTaP/IPV/Hib</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PCV</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Breastfeeding at 1st Immunisation?
Totally  Partially  Not at all
Life pathway

Everyone is on a health pathway

‘The NHS will provide a comprehensive system of social insurance from cradle to grave’.
William Beveridge, December 1942.

Notes:
• Baby born today 1/12/2015.
• Life expectancy 86 years.
• Financial allocation £1,994 in 2013/14.
• Inflation 2.5% per annum.
• Average cost £350k
Opportunity

For Parents?
- Increased parental engagement
- Additional accessibility

For Health Professionals?
- Reduced administration
- Improved data accuracy

For the Health System?
- Activated patients
- Clean data
- Reconciliation of vaccinations

Value of engaging 750,000 new parents each year is £314m for every year they are engaged, £4.7bn over 5 years

Patients with higher activation scores can cost health systems 21% less
### Business case development

<table>
<thead>
<tr>
<th>Who sees the benefit</th>
<th>What type of benefit is it; cash releasing, efficiency, etc.</th>
<th>The benefit “story” – how the person will benefit</th>
<th>The relative priority of the benefit in terms of when it should be achieved..</th>
</tr>
</thead>
</table>

| What area of the eRedbook is it applicable to. | The term to realise the benefit - short, medium or long | What value will be realised from the benefit | Challenges in achieving the benefit. |
Challenges?

- Culture
  - Digital Confidence
  - Digital Inclusion
  - Information Governance

- Mobile working
  - Devices
  - IT Infrastructure

- Connectivity with clinical systems

- Commissioning model for services that include PHRs

- Wider understanding of PHR’s which are ‘Untethered’ and connected to EPR’s with Open APIs (not patient views of EPR’s or Portal’s)
Thank you

www.eredbook.org