eRedbook
The UK’s electronic Personal Child Health Record

Dan Moulin – Director and eRedbook Project Director, Sitekit

@sitekit  @eRedbook

innovators in digital health + care
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
What is the ‘red book’?

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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

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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 smartphone 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
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

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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)

Alison Golightly and Shona Golightly - Project Managers
RCPCH

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.
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
0-5 Pathway

- **Birth registration and NHS Number (Initiation)**
- **Newborn Hearing Screening (Hearing Screening)**
- **New baby review (Health Visitor)**
- **6-8 Week review (GP)**
- **1 year review (Health Visitor)**
- **2. year review (Health Visitor)**

**Legend**
- Antenatal
- Midwifery
- Hearing
- GP
- Health visiting
- School Nurse

- **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) (Health Visitor)**
- **School Entry review (School Nurse)**
Reuse of standards based messaging to connect local systems and services

Mobilisation of the market and ability to on-board new suppliers
“Only patients can unlock the potential of electronic record.”
“A digital “Redbook”– is a great place to start”.
Lord Ara Darzi
PHRs and Shared Records
Service delivery

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

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

Health Visiting workforce
Current 170.6 on trajectory to reach 180.2 for HV
Implementation plan
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>Grand Total</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>Grand Total</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>
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<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>

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Emmas digital health record

Emma
NHS No. 123 456 8799
Age: 12 weeks
Gender: Female
Born: 25/08/2013

Most Recent Weight: 6.30kg
17/11/2013
Photos of Emma

Summary & Appointments

Recent Developmental Firsts
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

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

Recent Health Reviews
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
"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

Appointments & Reminders

Future Appointments
M OnDAY 25 Doctor's appointment
10:00
### Immunisations

<table>
<thead>
<tr>
<th>Age</th>
<th>Immunisations</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 weeks</td>
<td>Primary course of immunisations, 1st set</td>
</tr>
<tr>
<td>12 weeks</td>
<td>Primary course of immunisations, 2nd set</td>
</tr>
<tr>
<td>16 weeks</td>
<td>Primary course of immunisations, 3rd set</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>
</tr>
<tr>
<td>3 years 4 months</td>
<td>2nd dose MMR vaccine (can be given earlier) and pre-school booster immunisations</td>
</tr>
<tr>
<td>12-13 years (girls only)</td>
<td>HPV vaccine</td>
</tr>
</tbody>
</table>
Immunisations

When did Anna last have her Tetanus Immunisation?
Understanding the value

For Parents?
- Increased parental engagement
- Personalisation
- Accessibility
- Improved participation

For Health Professionals?
- Improved collaboration and coordination
- Reduced administration
- Data accuracy
- Patient Safety & Quality

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

Patients with higher activation scores can cost health systems 21% less
Challenges?

• Funding

• Strategic Direction

• Culture
  • Digital Confidence
  • Digital Inclusion
  • Information Governance

• Mobile working
  • Devices
  • IT Infrastructure

• 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

Future of Personal Health Records
7th July, The King’s Fund
www.sitekit.net/events

innovators in digital health + care