Introduction to the Electronic Personal Child Health Record (ePCHR)

October 2013
The PCHR (Personal Child Health Record) – often called the ‘Redbook’ – is a record of a child’s health, growth and development kept by the child’s parent or guardian, with contributions from various health professionals.

The Redbook supports the Healthy Child Programme, recording details of screening tests, immunisations and reviews as well as signposting to relevant information.

It is a ’personal’ health record, held by the parent or guardian on behalf of the child, and should not be confused with the clinical records kept by midwives, GPs or Health Visitors as part of their consultations with the family.
What is an ePCHR?

• An ePCHR -Electronic Personal Child Health Record – is the same record of a child’s health, growth and development but kept electronically in a secure system so that a child’s parent or guardian can have the convenience of managing the child’s care online.

• An ePCHR will contain the same material as the paper Redbook but will also have the additional benefits of modern online applications:
  • Fast, easy access wherever the parent is located
  • Prompting for scheduling appointments and checking up on test results
  • Feeds and links to rich sources of NHS-approved information on caring for children
  • Ability to share or communicate the record with health professionals and flag up areas of concern.
What is the eRedbook?

• The eRedbook is a prototype ePCHR developed by Sitekit Labs, in conjunction with Harlow Printing Ltd, who print the current paper Redbook.

• The development has been funded by Microsoft, the Technology Strategy Board, Sitekit and economic development funding from Highlands and Islands Enterprise board (HIE).

• The RCPCH is working with Sitekit Labs to evaluate the usability and benefits of the eRedbook prototype.

• The prototype is being trialled by two NHS partner organisations: Liverpool Community Health, and NHS South Warwickshire.

• Those interested in knowing more, can find information on the eRedbook at http://eredbook.org.uk/
The eRedbook is currently available as a prototype version.

Those NHS organisations interested in looking at the prototype should contact Sitekit Labs at http://eredbook.org.uk/

The RCPCH will commission a formal evaluation of the prototype in early 2014.

A successful evaluation will mean that the eRedbook becomes more widely available within the NHS.
eRedbook Timeline

• Edition 1 (parent-entered data only) was released to NHS partner organisations in February 2013 for evaluation with mothers and parents.
• A mobile phone application of Edition 1 was released in March 2013 and was a featured application at the Healthcare Innovation Expo in March 2013.
• Edition 2 of the eRedbook – which enables health professionals to log-in and enter and review information – was released September 2013.
• Edition 3 of the eRedbook will become available in December 2013
### Development

**How the eRedbook is being developed**

<table>
<thead>
<tr>
<th>Edition</th>
<th>Features</th>
</tr>
</thead>
</table>
| **Parental Engagement**  | • Appointment Reminder System  
                           | • Immunisation Reminder System  
                           | • Parental Guidance  
                           | • Parental Growth Charts  
                           | • Parental Notes  
                           | • Parental PreAssessment Forms |
| **App Edition**          | • Mobile/Touch interfaces                                                |
| **Health Professional**  | • HP Login  
                           | • HP Core Screening and Review  
                           | • HP Growth Charts |
| **HP Connected Edition** | • Inbound API for Health Professional push data |
| (E3)                     |                                                                          |
| (E2)                     |                                                                          |
| (A1)                     |                                                                          |
| Live 2013                |                                                                          |
Why is the RCPCH involved?

• The eRedbook project is aligned with the RCPCH values: to transform child health through knowledge, innovation and expertise.

• Personal health records (PHRs) – of which the eRedbook is a leading example - are increasingly being viewed as a tool in improving outcomes in health.

• The DoH Information Strategy, The Power of Information, advocates existing patient-held records, such as the Redbook be made electronic and accessible to patients online.

• The RCPCH currently hosts the multi-disciplinary PCHR committee which oversees the current content of the Redbook. It therefore has an interest in how effectively the current content of the Redbook is made available in digital format.
The RCPCH has produced a set of standards for software development to provide a framework for suppliers interested in providing an electronic version of the record.

These standards are available here: http://www.rcpch.ac.uk/PCHR

The RCPCH is working through a specially convened Clinical Advisory Group and the inter-collegiate Personal Child Health Record Committee to assure these standards are met by the prototype eRedbook.
Clinical Advisory Group

Dr David Low – Paediatrics
National Clinical Lead for Paediatrics & Child Health
Department of Health
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

Dave Munday – CPHVA Representative

Dan Moulin - Project Director eRedbook Sitekit

Chris Eckl – Chief Technology Officer
Sitekit

Dr Libby Morris – GP Representative
eHealth Clinical Lead
NHS Lothian

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

Catherine Powell – HV Representative

RCPCH Officers

Alison Golightly and Shona Golightly
Project Managers
RCPCH

Dan Bayley - Project Manager eRedbook Sitekit
The eRedbook Prototype

- Designed for parents and guardians to easily enter information and check their child’s health status
- Available in a mobile version for smartphones
- Designed for health professionals to contribute their observations quickly and easily
- Provides connectivity through electronic carbon copies using ITK standards based messages with EDT (docman) and EMIS. These connections automate information flows and reduce information rekeying.
- CSE Rio and Euroking connectors are anticipated early 2014.
NHS No. 222 222 2222
Age: 5 days
Gender: Female
Born: 16/10/2013

Most Recent Weight: 2.00kg
15/10/2013

Photos of Year

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

Contacts
Use this space to save important clinical contacts.
You have not yet added any contacts. Add contacts

Year
Switch child

Add to Year's eRedbook
Add to health record
Add growth measurements
Add appointment

Next Appointment
There are no appointments scheduled.

Questions
17 October 2013 Added by Daniel Moulin
is this right?

Add
Length measurement
Weight measurement
Head circumference measurement

Close
Some degree of weight loss is common after birth. Calculating the percentage weight loss is a useful way to identify babies who need extra support.
Primary Course Immunisations

<table>
<thead>
<tr>
<th>Antigen</th>
<th>Date (dd/mm/yyyy)</th>
<th>Batch No.</th>
<th>Site</th>
<th>Immuniser</th>
<th>Venue</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

<table>
<thead>
<tr>
<th>Antigen</th>
<th>Date (dd/mm/yyyy)</th>
<th>Batch No.</th>
<th>Site</th>
<th>Immuniser</th>
<th>Venue</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 2nd Immunisation?  
- Totally
- Partially
- Not at all

<table>
<thead>
<tr>
<th>Antigen</th>
<th>Date (dd/mm/yyyy)</th>
<th>Batch No.</th>
<th>Site</th>
<th>Immuniser</th>
<th>Venue</th>
</tr>
</thead>
<tbody>
<tr>
<td>DTaP/IPV/Hib</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MenC</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Mobile Version
Understanding PHRs

• An ePCHR or the eRedbook is an example of a Personal Health Record or PHR.

• These are online records owned by the patient in which they enter their own health information, access and use information contributed by health professionals and share this record with any organisation or individual they choose.

• PHRs are a relatively new development in the UK and shouldn’t be confused with organisation clinical records, often called EPRs (Electronic Patient Records) or EHRs (Electronic Health Records), which are owned by healthcare organisations.

• PHRs will not replace EPRs or EHRs, they are supplementary to them. A failsafe mechanism.
Why are PHRs necessary?

‘Indications overall are that where we find increased patient involvement in personal healthcare, so we expect to find better health outcomes alongside lower service costs’
– Personal Health Records: putting patients in control?
(2020health.org)

• There are potentially long term benefits – both economic and in health gain - in having patients use PHRs.

• They provide a platform for patients to access their health records, something to which they have a legal entitlement even where such records are owned – as currently – by the Secretary of State.

• These benefits and entitlements are now being recognised as essential by government who in the new Information Strategy advocate existing patient-held records, such as the Redbook be made electronic and accessible to patients online
What are the benefits of PHRs?

• Enfranchises the patient as an equal partner in their care
• Promotes collaboration with healthcare professionals
• Shares information – with the consent of the patient – to all professionals involved in care
• An ePCHR could become a key enabler of information sharing across the parental/professional boundaries in exactly the same way as the physical Redbook – it promotes communication.
• Has the potential to substantially improve cross-care setting information sharing, that is, between primary, community, acute (maternity) and social care. (Information sharing and hand over of key information is known to be very weak in some areas)
• Developing patient access to and management of their own health records will lead to new communication models and healthcare delivery models within the NHS
A move from this...

Current System: information silos with no automated communication

Red Book used to flow information round system on paper
A collaborative way of flowing health information round the system with the patient’s consent. Supplements existing clinical systems.
Person centred care
Data in the prototype eRedbook resides in Microsoft HealthVault.

HealthVault is a specially built platform enhanced for privacy and security.

The HealthVault service sends all communications, except email, using encryption.

The data is housed in UK data centres, it is not held offshore.

The UK instance of HealthVault is hosted by Attenda, a provider of NHS data services including hosting the nhs.uk portal.

As a user of HealthVault you can always view a history of access and actions to your health record. The record cannot be accessed without your permission.
• Users of a personal health record, decide who has access to their information: they are the ‘custodian’ of the record.
• Users explicitly give consent to the use of each data item: there is no implicit consent and no global (unspecific or umbrella) consent.
• As a custodian, users decide what level of access to grant others, for example, ‘view-only access’ (time-limited access), ‘view-and-modify access’ (time-limited access) or ‘custodian access’ (no time limit).
• HealthVault creates a fixed list of each access or change by other users, so there is a full history of the record. Users can examine the history of access and changes to the record.
• Microsoft do not use data outside of the rights the individual grants them in using HealthVault and they do not ‘sell’ data onto others. The Privacy Statement comprehensively describes this position.
Further information

• For further information on the project from the RCPCH please contact Jacqueline Fitzgerald, Director of Research and Policy.
• For more information or to get involved with the eRedbook project please email: info@eredbook.org
• For more information about Personal Health Records, we recommend the following paper: Personal Health Records - Putting patients in control?