



**Comisiwn  
Bevan  
Commission**

# PATIENT PASSPORT APP

LOWRI SMITH – CONGENITAL HEART PATIENT AND PUBLIC  
GOVERNOR AT ALDER HEY



# MEDICAL HISTORY

A vertical timeline graphic on the left side of the slide. It consists of four horizontal orange lines, each followed by a text block. The background is a gradient from green at the top to blue at the bottom, with faint circular patterns and a scale on the right side.

**Secondary care in England**

**Emergency care in North Wales**

**Open Heart Surgery x 3**

**Several Cardiac Ablations**

# EMERGENCY ADMISSIONS - CONCERNS



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All patients arriving at A & E follow the same clinical pathway.

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For those who have a complex medical history and experience recurrent health crises' this is often a waste of time and a stressful experience.

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Much of this waste can be eliminated

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Failure to communicate with specialist teams at my request

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Lack of initiative and decision making



# PATIENT PASSPORTS – LITERATURE REVIEW

Scoping review identified only 12 studies involving patient passports since 2000

- Variable uses and intentions – health records vs patient information resources
- Focus on design rather than clinical impact
- Studies are almost universally small
- In many cases information is general – not patient specific

# PATIENT PASSPORTS IN ASTHMA

## Parental Perceptions Of The "Asthma Health Passport," A Tool Designed To Track Asthma Treatment In Acute And Maintenance Care Settings

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Rationale: Although asthma is a chronic illness, the clinical presentation is episodic, often requiring frequent visits to primary and acute care settings. While the primary care provider (PCP) should be and is usually the foremost prescriber of preventive controller medications, multiple studies note that PCPs do not always add these medications to the treatment regimens of asthmatics, even following an emergency department (ED) visit. This may be due to lack of access of the PCP to details of the frequency of their patient's visits to ED and other facilities in between health maintenance appointments. The aim of this study is to investigate the conceivable impact of a portable record, the Asthma Health Passport, on the continuity of asthma management. The passport is designed for parents to bring to visits for asthma treatment. Parents ask their child's provider to document on the passport, the date, location of the visit, as well as any medications that were used to treat or prescribed for the child's asthma during that visit. The study will explore the parent's perceptions on the use of the passport.

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Similar design – passports to be updated when a child attended ED/clinic for their asthma

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19 patients enrolled

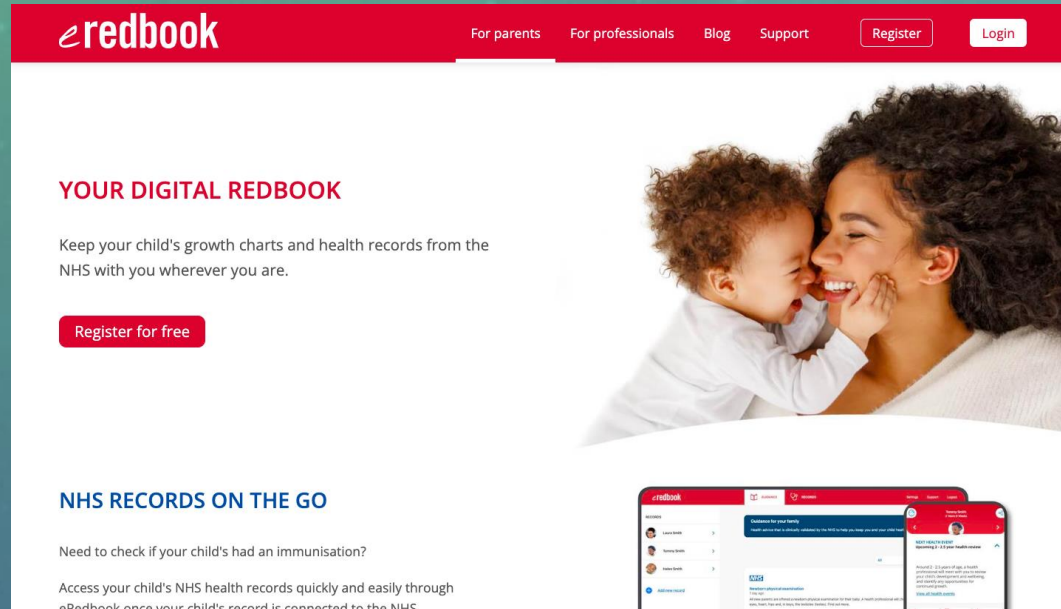
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Only 7 used asthma services during the study

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Paper based – main criticism was that it was forgotten

# REDBOOK – CHILD HEALTH RECORD



**eRedbook** For parents For professionals Blog Support Register Login

## YOUR DIGITAL REDBOOK

Keep your child's growth charts and health records from the NHS with you wherever you are.

[Register for free](#)

## NHS RECORDS ON THE GO

Need to check if your child's had an immunisation?

Access your child's NHS health records quickly and easily through eRedbook once your child's record is connected to the NHS.

- Compatible with NHS Login
- Partnership with Royal College of Paediatrics and Child Health
- Currently only available within London NHS Trusts
- Reminders of upcoming child health appts

# PATIENT PASSPORT APP



**Patient owned data  
– no complex GDPR  
issues**



**Separate sections  
completed by  
patient and doctor**



**Ability to upload  
photos of medical  
documents**



**Ability for cross-  
border and  
international use**



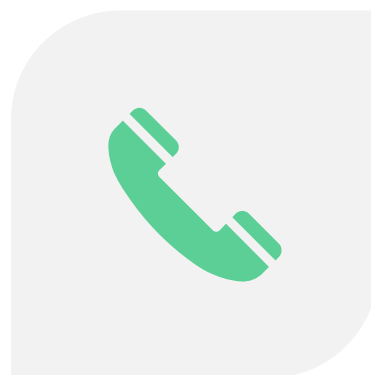
**Ability to send link  
to staff treating you**



# IS IT DIFFERENT TO THE NHS APP?



NOT JUST A LIST OF TEST  
RESULTS AND LETTERS



SPECIFIC INFORMATION, ADVICE  
AND CONTACT DETAILS FROM  
THE PATIENT'S RELEVANT TEAM



FOCUSED ON SECONDARY AND  
TERTIARY CARE

Tristan Batiste: Care & Respond

Condition Name

Vascular Ehlers-Danlos syndrome (vEDS)

Would you like to enter more information about this condition that may help others to support you?

- Yes
- Remind me later - We will send a reminder by email
- I do not want to enter further details about this condition

About my condition

Describe your condition

Inherited conditions that affects the blood vessels and internal organs, which means:  
\* My skin bruises very easily  
\* My blood vessels are very fragile so they may bulge or tear,

Key information about my rare condition

Medical Emergencies

Increased risk for emergencies involving the aorta, eyes, arteries, lungs, uterus, and hollow organs (like the intestinal tract).

Key things to look out for:

- \* Arterial Dissection
- \* Arterial Rupture
- \* Collapsed lung (Pneumothorax)
- \* Ocular - Carotid Cavernous Sinus Fistula formation (CCSF) may

Relevant Clinical Investigations / Procedures

Imaging in the case of an emergency should include: CT/CTA, MRA/MRI. Ultrasound, or Echocardiography to determine if the patient is experiencing an acute arterial, aortic, gastric, pulmonary, or obstetric

Medications / On-going Treatment

## FUTURE PLANS

- Approach patient charities/groups
- Promote our app at various medical/patient conferences
- Upscale the app to the whole of the UK
- Huge potential for a number of different patient groups e.g. oncology, transplant, dementia and paediatric

Any Questions?

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