PATIENT PASSPORT APP

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

Secondary care in England
Emergency care in North Wales
Open Heart Surgery x 3
Several Cardiac Ablations
EMERGENCY ADMISSIONS - CONCERNS

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

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

Much of this waste can be eliminated

Failure to communicate with specialist teams at my request

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

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

19 patients enrolled

Only 7 used asthma services during the study

Paper based – main criticism was that it was forgotten
REDBOOK – CHILD HEALTH RECORD

- 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
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:
- * Aortic Dissection
- * Atrial Rupture
- * Collapsed Lung (Pneumothorax)
- * Ocular - Cerebral Sinus Venous 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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