UK Health Security Agency

Paper 7

English Surveillance Programme for Antimicrobial Utilisation and Resistance (ESPAUR) Oversight Group

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Personal Health Records
Presented by: Fran Husson

PURPOSE OF THE PAPER

The purpose of the paper is to present to the ESPAUR Oversight Group the latest developments on Personal Health Records [PHRs] across the UK.

RECOMMENDATION

The Oversight Group is asked to NOTE the potential for AMR and AMS.

Fran Husson
ESPAUR Public Partner
May 2022

1.0 Personal Health Records [PHR] Brief History

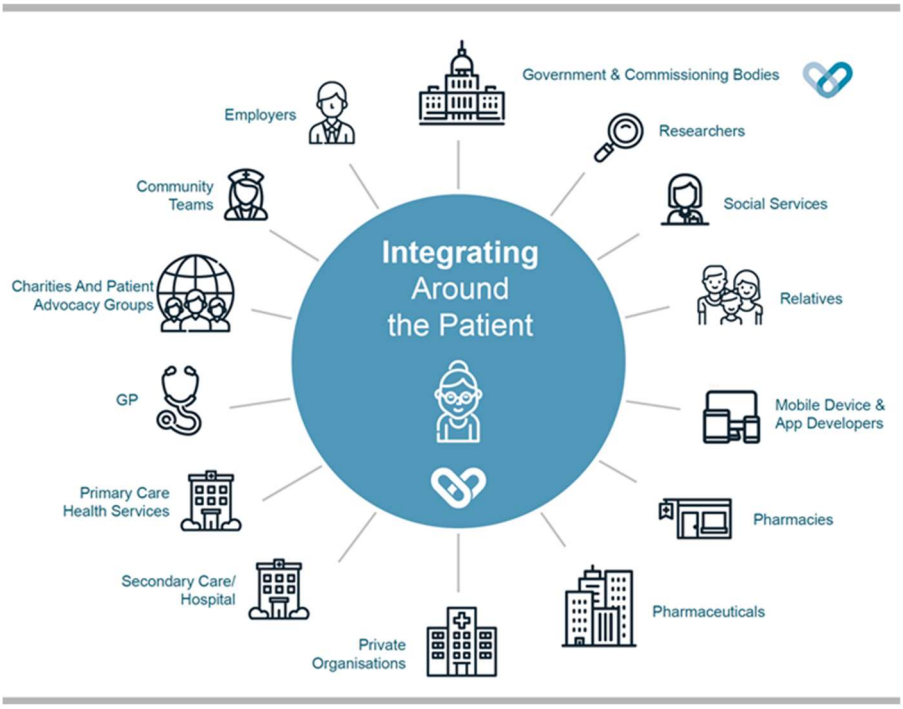
The concept of a Personal Health Record [PHR] is not new. The first product was developed by Microsoft at the turn of the century and called “My Health Vault” which was a good descriptive to cover all the bits and pieces that patients, particularly those affected by serious and chronic medical conditions, want and need to keep. But adoption was weak, and MS withdrew the product a few years ago.

The UK saw its first PHR offering in 2008 with the launch of “Patients Know Best” [PKB] and the start of a second one in 2012 with MyMedical Record [MyMR] led by University Southampton Hospital NHS Foundation Trust and South West Commissioning Support Unit, which took inspiration from My Health Vault.

For the NHS a record is a PHR if:

- it's secure, usable and online
- it's managed by the person who the record is about and they can add information to their PHR
- it stores information about that person’s health, care and wellbeing
- health and care sources can add information to the PHR

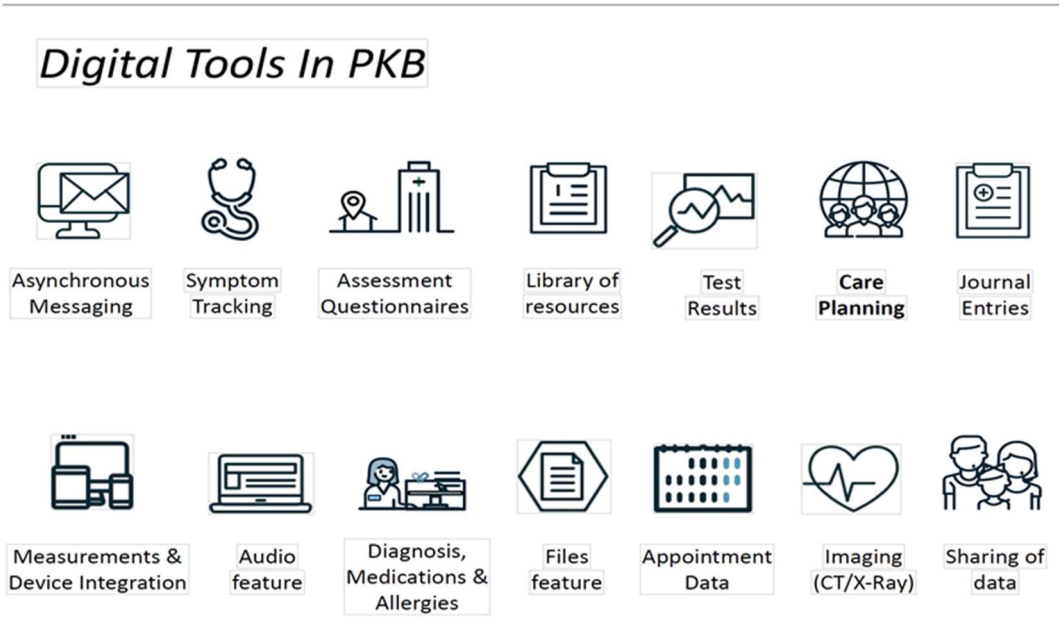
A true PHR also needs to be untethered, i.e. not linked to a specific care setting [e.g. a hospital patient portal is not a PHR] to be fully portable and usable anywhere on the planet.



2.0 What is new?

PHRs are not new but what is is a health and care landscape that witnessed a significant acceleration in the adoption and scaling of digital health technologies and processes during the Sars-CoV-2 pandemic leading to a rapid transformation of many services.
One significant development was the integration of PHRs with the NHS login and the NHS app, which took place in March 2020. I will focus on PKB because it is the most widespread across the UK and also because I have been using it since 2017. Contact details for MyMR can be found in the list of references at the end of this paper.
PKB a few facts:

- PKB is a social enterprise and technology platform, designed to bring together patient data from health and social care.
- Patients can login to access everything, from appointment letters and test results, to their multi-disciplinary care plans. To be able to play an active role in their health and wellbeing, they can also use specially designed tools to monitor and track their health condition [wearables, hypertension monitoring via smart phones etc…].



They can also decide which part of their data they want to share with carers, family and other health care professionals anywhere in the world by selecting between general health, mental health, sexual health and social care in their record.

"*Patient controlled data sharing is the right way to join up health and social care and to consent patients to contribute data for research*".
Dr Sanjay Gautama, Caldicott Guardian and Chief Clinical Information Officer,
Imperial College Healthcare NHS Trust

At the time of writing, PKB has 1,5 mn active users in the UK, links to 27 mn patient records and is averaging 3,000 new registrations per day.

Its procurement process is aligned with its mission to see every person:

- Own a copy of all their health information
- Understand what this information means
- Use this understanding to make shared decisions with carers, relatives and healthcare professionals.

Procurement / contracting can take place with a region [ICS, for instance], a specific hospital trust, a group of GP practices, a community service [such as social care agency] or a medical charity [e.g., the UK Kidney Association]. This translates into a rich geographical map of users but also into an ecosystem which is challenging to research and quantify!

Secondary care systems such as hospital trusts can select PKB functionalities and features according to their different and multi specialties. Even within defined specialties and departments, clinicians can personalise the record to achieve the best outcomes for their patients or to research specific topics.

3. WHAT ABOUT AMR/AMS?

In general, the use of antimicrobials still takes place without patient active involvement and engagement.

A tool is needed to activate patient agency. Awareness of drug resistant infections, through public health campaigns and good media reports, alas, is not enough to see patients develop automatic reactions and question whether a new prescription is appropriate or not.

PKB's Medication List [ML] offers a tool which is worth considering to assess the potential benefits of having patients manage and control their medications. An important feature is that both clinicians and patients can enter a new medication in the list. What this means practically:

- Patient can use the free text box available for each ML item to report whether a delayed prescription has been collected and self-administered or not, and why

- Patient with rescue packs can record various data points: date of issuance, date of expiry, info to use as aide [eg a medication dose of 30 mg in 6 tablets of 5mg each - often a factor of confusion for older patients], self-administration problems, adverse reactions, reason a medicine has been stopped etc…

- The date of expiry is important as the item will automatically transfer to the Past Medicines section in the ML, enabling the clinician [or any other HCP who has access

to the ML] to see how patients cope with flare ups, when infections may be self-limiting and thus not require use of the home stand-by anti-microbials [and steroids]. And it is also very useful to assess whether a vaccination [eg flu] is past its active period.

- Drug-Drug Interaction [DDI]: the reality is that only the patient knows what s/he self-administers every day [or not...]: prescribed meds, OTCs, supplements … Professionals need visibility of all these substances not only for antimicrobial stewardship but also to try and reduce problematic polypharmacy. Patients need to manage all aspects of their meds and find ways to comply and conform to regimen which are often a very heavy burden [eg use of antimicrobials for NTM patients]. Compiling, managing, updating, enriching their ML also produce positive mental health outcomes of being in control, of self-managing difficult LTCs, of self-esteem.

- Because the Medication List is part of an integrated single-sign-on tool it does not require any specific effort to consult or use it for adding a new item.

- ML design updating: professional and patient feedback [eg UK Kidney Association] have led to the introduction of attachment functionality for each item [PIL, prescription from non UK care setting, or any other document or image the patient, or the professional, wants to link to an entry].

FURTHER INFORMATION

For the sake of brevity, I have left out of this paper PKB's Information Governance compliance certificates and documents. For further information please contact me at:

franhusson@btnternet.com

REFERENCES

A. LINKS:

https://patientsknowbest.com/
https://patientsknowbest.com/nhs/

https://digital.nhs.uk/services/personal-health-records-adoption-service

MyMR : https://mymedicalrecord.uhs.nhs.uk/
https://www.digitalhealth.net/2019/03/university-hospital-southampton-mymr-expansion/
contact : mymedicalrecord@uhs.nhs.uk

B. PAPERS

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Humphreys L, Al-Ubaydli M, “Digital patient-controlled records in end of life care. “ International Journal of Integrated Care. 2014;14(8): DOI: http://doi.org/10.5334/ijic.1801

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