Personal health record (PHR) case study

St Mark’s Hospital
Acknowledgements

This case study was informed by discussions with:

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> Lloyd Humphreys, vice president of business development, Patients Know Best® (PKB)

It is also based on a review of published PKB reports, information provided on the PKB website (see references), responses to an online survey and information from three other trusts, to provide a wider perspective.

Many thanks to all for their help.

Overview

St Mark’s Hospital (St Mark’s), in Harrow, is a national and international referral centre for intestinal and colorectal disorders. Simon Gabe became aware of the Patients Know Best® (PKB) personal health record (PHR) in 2011 from colleagues in Great Ormond Street Hospital (GOSH) who were also using it. He was particularly interested in using the PHR as it would support continuity of care when patients transitioned to St Mark’s from GOSH.

PKB allows patients to obtain a copy of their health/care information from different sources, and collate it in one place to share with whomever they choose. The sources of the data can be clinician/patient entered or via system interfaces with existing clinical record systems. The system enables interactions with a patient’s health network, remote consultations, active self-management through shared care plans, and at-home health monitoring via integration with medical devices. Other functionalities include the ability to store genetic information, track symptoms with alerts, take surveys, provide or integrate with patient registries, and read/write to other electronic medical record systems.

Key recommendations

The following key recommendations have been identified from the case study:

> It is important to demonstrate benefits to clinicians and patients in order to engage them.
> Information in PHRs needs to be understandable to patients but robust enough to be useful to clinicians.
> Open Application Programming Interfaces (APIs) are essential for integration with other electronic systems.
> Appropriate information governance and security measures must be in place to protect patient data.
> There needs to be functionality for information to be shared without patient consent in exceptional circumstances (eg patient unconscious or lacks capacity).
> Patients should be encouraged to contact teams rather than individuals to avoid clinician burden.
> Measures need to be implemented to prevent potentially worrying results being shared before clinicians are able to discuss the results with patients.
> Automation of information sharing between electronic patient records (EPR) and PHRs is needed to reduce pressure on administrators.

Methods and lessons learnt

Implementation

It has taken the hospital a few years to implement PKB. Initially, test results were entered manually, but after the first year interfaces to trust systems were implemented, which enabled results to be transferred automatically.

User recruitment and registration

In order to encourage adoption, posters about the PHR were displayed in the hospital. Clinicians also explained the system to patients and gave them hands-on demonstrations. In the early stages of implementation, a PKB staff member was available in the hospital to set up patients and train them how to use it. Patients enrol for the PHR, either in clinic, or on discharge from hospital. Their identity is verified at this point and they are provided with login details.

Information sharing

Where PKB is used by multiple care providers, they each transfer information into the PHR, where the patient can access records from all care providers. For example, a young adult who has transferred from GOSH to St Mark’s would have records from both hospitals available. Patients can control which individual healthcare professionals can access their records. For example, following transition from GOSH to St Mark’s, they may elect to share with clinicians at St Mark’s, but remove access from GOSH clinicians.

The PHR is segmented by different types of information, eg medical records, sexual health, mental health and social care. Patients can elect to share either their full record or only segments of their record with individual healthcare professionals.
Within PKB there is a ‘break glass’ functionality, ie consent can be broken in exceptional circumstances (eg the patient is unconscious, or lacks capacity). In this circumstance, the patient is made aware by email and the Caldicott Guardian of the organisation that broke consent is also notified.

As users control who can access their records, there is a need to handle situations where a court places a requirement on an organisation to remove access to an individual (eg a court order in a child protection case to remove access to the PHR from a parent). This is addressed by providing the organisation with the ability to amend access where there is a requirement to do so.

**User perspectives**

St Mark’s found that not all patients want a PHR (Simon Gabe estimated that around 70% of his patients have registered for PKB), and of those that register not all patients are regular users (Simon Gabe estimated that around 20% use it regularly). The frequency of use varies between individuals, with some using PKB much more than others. The main uses at St Mark’s are to view results and to contact clinicians.

St Mark’s found that PKB was used by a wide range of patients, not just a particular group, although individuals use PKB differently based on their needs. Other sites have used PKB with specific patient groups, mainly those with long-term conditions where there is specific need, eg getting test results quickly.

St Mark’s Hospital Foundation conducted a patient satisfaction survey with patients on home parenteral nutrition in 2014 (see appendix). Over a period of 18 months, 119 patients were registered for PKB. This resulted in the recording of 5,015 unique electronic conversations which would have otherwise been telephone conversations. A survey was distributed to all registered patients, of which 58 responded.

The survey found:

- 88% of respondents felt at least ‘somewhat confident’ working online with their healthcare team
- 26% found it “extremely helpful” having access to their results and 29% found it ‘very helpful’
- 52% used PKB a few times a month, 7% a few times a week and 41% used it less frequently
- 32% were ‘extremely likely’ to recommend PKB to others
- 43% were ‘very satisfied’ with PKB.

The survey demonstrated that many respondents found PKB useful to manage their long-term condition. Similarly, other trusts have found that the use of PKB has improved patient satisfaction, patient empowerment and their ability to self-manage.

‘Very few doctors properly understand my condition so going to an unfamiliar medical team can be terrifying. I can have a severe and potentially life-threatening reaction to everyday drugs. With PKB, it’s very reassuring that I can reach my entire medical team anywhere in the world – this makes me feel far more independent. Through PKB, I’m effectively carrying my entire medical history with me wherever I go in the world – and that’s very reassuring’ – a patient being cared for at St Mark’s expressing the benefits of using PKB

St Mark’s has not yet carried out a benefits evaluation as yet, but the following types of benefits have been identified:

- Viewing test results and messaging clinicians, including sending photos and videos to obtain clinical opinions, saves time for patients, as they do not need to phone or visit the hospital.
- Viewing test results quickly also reduces patient anxiety, as does being able to monitor trends in results over time.
- Being able to view information across care providers helps patients share information with clinicians when they transition or move between hospitals.

‘It saves patients time and reduces their anxiety, for example, where a patient has a tunnel catheter or stoma and a possible infection or swelling, they can upload a photo for me to look at and I can provide advice without them having to come in’ – Simon Gabe, consultant gastroenterologist
Although St Mark’s don’t actively promote the self-management functions in PKB, they have found a small number of patients use PKB to monitor their health (eg weight, blood pressure, urine output). Some add their own medical correspondence too.

An innovation at Luton and Dunstable Hospital to introduce remote monitoring of stable inflammatory bowel disease patients reported estimated reductions of 1,200 outpatient appointments per year. PKB was used by patients to undertake routine monitoring (eg blood pressure, weight, etc), symptomatic assessments, with tailored advice being provided, to obtain test results and communicate with their clinical teams.

‘Not only does it save patients having to come into hospital, but also allows us to see that if these patients flare up, we can see them within 48 hours rather than generated clinic appointments’ – Matthew Johnson, lead gastroenterology consultant, Luton and Dunstable Hospital

Health and care professional perspectives

St Mark’s and other PKB implementations illustrate the need for enthusiastic clinical champions to lead implementation and get other team members on board. They also indicate the need for clinicians, as well as patients, to see the value of a PHR and to have their concerns heard and addressed.

Initially, some clinicians expressed anxiety that patients would know test results before the doctors had viewed them and this could make them anxious if the result was abnormal. St Mark’s has not found this to be a problem. However, it may depend on the patient group, as the patients at St Mark’s are using intravenous nutrition and so tend to be an expert patient group in many respects.

A benefit of patients seeing results in their PHR is that results don’t get missed, as patients will see them even if they are missed by a clinician. A particular concern expressed by clinicians was the risk of patients viewing potentially worrying results before the clinician was able to discuss the result with them. This can be handled by switching on automated delays for results with text, such as ‘possibility of cancer’, which gives the clinician a chance to discuss the result with the patient.

Some clinicians were also concerned that the use of PKB would increase their workload, however this has not been found to be the case. The perception is that messaging by patients has replaced other forms of communication, such as phone calls, and so has not increased workload. In addition, it has the benefit of previous communications and clinician responses being recorded on the PHR and so available to both the patient and the clinical team.

Patients are encouraged to contact teams rather than individuals in order to avoid burden on any one clinician. St Mark’s also sets realistic expectations, for example, that messaging should not be used for urgent matters. Clinicians can also set up out-of-office alerts when away so patients are aware there will be a delay in response.
**Technical perspectives**

PKB acts as a single secure PHR, whereby all stakeholders are connected, with the patient in control at the centre (see figure 1).

**Integration with other systems**

PKB can integrate with existing health/care systems via Open Application Programming Interfaces (APIs). All of the APIs in PKB are HL7 compliant but other systems need to be configured to allow them to connect with PKB.

**Security**

It is important that patients are aware that their information on PKB is secure to reassure them when using the tool. PKB is hosted securely on the NHS N3 network, with all data encrypted on transport and in storage. PKB complies with the Information Governance Statement of Compliance (IG SoC).

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**Figure 1**

Without PKB:

[Diagram showing integration without PKB]

With PKB:

[Diagram showing integration with PKB]
References