

Patient Knows Best (PKB) User Survey of CLL Patients

September 2018

Introduction and discussion of survey design

The Patient Knows Best (PKB) platform was launched for OUH CLL patients in 2017.

Figures provided by PKB in April of 2018 indicated that as of the date of the report 210 patient records had been 'created.' However, data from PKB indicate that only a small proportion login to use the system on a regular basis, with a median of only 7.5 patient contacts per week over a two year period (range 0 – 23). This concurs with anecdotal evidence from the CLL team, who feel that the system is not widely used by those patients who signed up for it.

In addition to the data from PKB, we felt that we needed a better qualitative understanding of user experiences of PKB. We designed a questionnaire intended to indicate the ways in which people use PKB and to ask what obstacles might prevent people from engaging with the platform. The questionnaire asked 9 questions about PKB, inviting people to select options that best represented their experience, together with the opportunity to comment in free text. The intention of the questionnaire was not to be representative of all our PKB users, but rather to identify patterns or shared concerns, and to establish how people feel about using the platform.

To allow people to respond at a time to suit them, and to ensure that people could respond in confidence, we set up the survey using the online 'Survey Monkey' platform. The survey was given divisional governance approval in July 2018.

Number of respondents

Of the 210, 197 patients' email addresses were extracted from PKB. After identifying those patients who were deceased using hospital records, and after ruling out those patients who had declined permission to contact them via email or for research purposes, we were left with 86 potential respondents. Questionnaires were sent in September of 2018. 48 people completed the questionnaire.

Summary of results

Opinions about PKB are mixed. A very small number of respondents felt that the system offers nothing to enhance their experience, and a similarly small number were enthusiastic embracers of PKB and felt that it has great potential.

The majority of respondents have had a positive experience of PKB, are supportive in principle, and willing to engage. However, their use of the system is relatively limited. Most people reported using PKB once every 3 – 6 months, usually around clinic time, and usually to contact a health professional or check blood results. Less than a quarter of respondents reported that they use it to record symptoms.

Free text responses were rich indicators of the variety of experiences with PKB. They suggest that given more support, more information and improved integration with other health systems more people would engage with PKB more fully.

In spite of their enthusiasm, people experience frustrations with aspects of the PKB experience. These include a lack of knowledge about how to use it and lack of understanding about its potential.

Technical obstacles can be difficult to overcome. 4 people reported that they have attempted to communicate with the CLL team using PKB but without success.

The blood results interface in particular attracted comments suggesting that it has limitations, and respondents made suggestions about what could be included, what could be changed and what doesn't work. One person suggested that other people with CLL, perhaps at support groups, could provide training to other users. More information to help users interpret blood results would be welcome.

Only a small number of people completed the question aimed at people who have stopped using PKB. As such, the survey does not provide insight about users who have abandoned PKB altogether.

Discussion

It might be argued that a new approach to engaging with illness, information and the health care team needs a concerted and sustained effort to encourage potential users to see the worth of cultivating behaviours and using technologies that are new to them. At present, our team provide a letter of introduction to PKB with instructions about how to register. Beyond that point, however, there is little further PKB information provided by the CLL team unless patients explicitly ask for it. The patient must therefore rely on what is available on the PKB website, or help instructions built into the software. But, unless the patient is sufficiently persuaded of the merits of perseverance, there is a risk that people will disengage, particularly those who are not regular users of IT.

If the CLL team is committed to continued investment in PKB, then more needs to be done to ensure engagement that will make that investment worthwhile. Who is responsible for that promotional work – whether it should be the CLL team or the owners of PKB who have a commercial interest in its uptake – is a moot point.

But regardless of whose task this is, there are obstacles to promoting fuller engagement. PKB is designed to give the individual user full control over initiating communications. Unsolicited information to provide guidelines, prompts or suggestions for how to use PKB are prevented by the system's emphasis on user control. This is a good thing for protection of patient confidentiality and for limiting unwanted mail. But, it makes it difficult for anyone other than the individual to initiate learning about how to use PKB. If that individual is disinclined or discouraged, then the situation stalls.

As OUH intends to implement a new interface that will allow patients to view appointments, contact staff and – perhaps – look at test results, the CLL team will need to consider ongoing investment with PKB versus promoting engagement with the OUH interface instead.

Breakdown of questionnaire responses

The following summarises the individual responses to the questionnaire subject areas. The questions allowed individuals to select multiple responses to questions to indicate the differing ways in which they engage with PKB. Examples of free text responses to the different areas are provided under each summary.

Subject area

How do people rate the information provided about PKB?

- 28 people use the information on the PKB website and find it useful.
- 22 people felt they had all the information they needed.
- 9 people felt that the online information was not sufficient and difficult to use.
- 9 people would like more information from their nurse or doctor.

How frequently do people use PKB?

- 34 people (70%) use PKB every 3 – 6 months
- 2 people use it once a year
- 2 people have not used it since registering

Free text responses indicate that people typically use PKB to coincide with their regular appointments, or to contact the team with more urgent queries between appointments.

Reasons for not using or discontinuing use of PKB

- 2 people didn't want to think about their CLL unless they had to
- 4 people would prefer to contact the team via email or telephone

The fact that only 6 people completed this question indicates that the survey was more likely to be completed by

Example free-text responses

More information about using the system would be helpful or maybe simplifying some aspects of it would be ideal especially as some people are not as computer literate. I find it useful that I can access PKB at any time of day so not having restricted hours is great for me.

[I would like] Better explanation of how patients can use PKB for their own benefit and to benefit doctors/nurses.

I can understand the importance of confidentiality, but -perhaps I'm stupid or my computer has a sense of humour - PKB seems totally opaque. Can it be made more user-friendly. Or indeed, user-possible?

Have you thought of providing a buddy feature for those not familiar, and/or training at more local level e.g. At local support groups (Apologies I'm not a member of any currently so don't know if that already takes place)

those using PKB, and not by those who have stopped using it.

How do people use PKB?

- 33 patients use PKB to check blood results
- 24 patients use it to contact the nurse (13) or doctor (11)
- 10 patients use the symptoms questionnaire to report symptoms
- 5 respondents were unaware of the ability to report symptoms or upload information about their health.

Some respondents commented that PKB aided emotional support and reassurance, because of the ability to look at results before coming to clinic, or contacting someone with any queries. However, some people said that they failed to make contact because messages are not responded to.

Some responses indicate that people try to interest other doctors in PKB, and that the concept is attractive in principle. Several respondents raised better integration with other health information systems.

Looking at blood results

- 31 patients like having access to their blood results
- 10 people find the blood results difficult to understand or find the results screen difficult to use.
- Only 2 patients stated that the blood results make them feel worried.

Contrary to what health professionals feared about PKB, only two people expressed anxiety over access to blood results, and most people find it helpful to have access to this information. However, several users made comments about technical difficulties with blood results or made suggestions about how the blood results screen might be improved.

I don't really know what I can use PKB for apart from blood results. What happens to any information I put in - who is it read by? I haven't heard any doctors/nurses referring to it. I would like to see other results. There are buttons for imaging, genetics, measurements etc, but there is nothing there. It asks me to upload results, but I don't have any information!

I would be happy to use PKB more, but I need to understand what is wanted and how it would help the medical team. And there are so many buttons that are useless for me - asking me to upload results that I don't have! I thought the idea was that results of tests on me would be made available, but the only thing there is my blood results

Would like more context and information about each part of the test. What do acronyms mean? What, if anything is concerning/significant? Etc the graphs are not clear and difficult to interpret - tend to be misleading!

The Blood test results could be in a better format showing all results on one page perhaps

I like to see bloods, but whilst it has improved, the results are variable to see (several have no title, so I

Should the OUH CLL team continue to promote PKB?

- 32 patients feel that OUH should continue to promote PKB
- 14 patients feel that wider expansion should be subject to improvements.

That such a significant proportion of people support wider expansion would indicate that at least in principle patients are in favour of PKB. However, that enthusiasm must be weighed against reports of technical difficulty and lack of information about how to use it to its full potential. Those who are most enthusiastic feel that it could be much better, especially in better integrated with other health information systems.

have to guess what they are)

There is no explanation of results. Sometimes the system simply refuses to load.

It would be useful to have simple and clear explanations for each part of the blood test. I find that sometimes the graphs are misleading and can cause unnecessary anxiety because of the way in which data is displayed.

A direct reading of my lymphocyte count would be beneficial.

The beginnings of a very nice IT based system which could be expanded and improved and linked into other systems. For example was amazed to find that recent hip xrays I had taken were not digitally available to my GP let alone to myself. There is a long way to go and from my own now distant experience of real time engineering and artificial intelligence these projects can easily overspend and be poorly defined. Good luck with it

I agree in principle with giving patients access to test results and a vehicle for secure and private communications with their medical team. However, I do not find PKB user friendly in its current form. The results graphs used for blood tests could be made much clearer and easier to understand

I can see why for the less technically minded patients it might be daunting to use PKB and also they might feel they would slip through the net. But it is a really valuable tool and once patients realise that in actual fact it enables them to have direct contact with their medical team whenever they need it, they would see it as an enhancement. For the specialists, it could free up time to see more challenging cases while reassuring and monitoring patients with indolent or stable disease.

