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1.

Introduction and Background

The Cumbrian Centre for Health Technologies (CaCHeT) developed the Stakeholder Empowered Adoption Model (StEAM) as a framework for digital health (e-health, telemedicine, telehealth) adoption studies. Our remit is to evaluate the PKB Personal Health Record system using the StEAM Model developed by CaCHeT at the University of Cumbria and work with stakeholders to support continued or widened implementation. The StEAM model identifies 4 stakeholder groups. These are the 'economic' stakeholders – the healthcare organisation (providers, but also commissioners as appropriate) and technology supplier(s) – and the 'user' stakeholders – the patients (including carers) and health professionals. Whilst it is important to recognise that the decision makers are the economic stakeholders, who need to define what evidence is required to make the decisions, it is essential to recognise that user stakeholders are critically important in influencing those decisions and indeed their views and values form part of the evidence. The impact on professional staff and the implications to their roles, workflows and relationships is often of critical importance.

The purpose of this study is to:

   i.   Identify the barriers to and benefits from using the 'Patients Know Best' Personal Health Record system from the viewpoint of stakeholders at the Gastroenterology Department of Luton and Dunstable University Hospital Trust (LDUH), and
   ii. Share these findings with the aim of facilitating wider adoption of the technology.

2. **Summary of work plan and status update**

The study effectively commenced on 17th November 2014 with a visit by the researchers to the Luton and Dunstable Hospital (LDUH) at which we clarified the terms of reference with Dr Matt Johnson (MJ) and his team, received an orientation and introduction to the Inflammatory Bowel Disease Supported, Self-Help and Management Programme (IBD-SSHAMP) programme and how the team were using the PKB software. Data collection was continued to the end of February.

The following tasks have been completed within the study:

- Detailed protocol and study design finalised with MJ and PKB;
- Protocol sign off and permission obtained from LDUH as a service evaluation;
- Structured interviews with
    o One consultant Gastroenterologist at LDUH

- o   Two IBD Nurse Specialists at LDUH
- o   One ward manager, IBD Nurse Specialist at Torbay Hospital
- o   One representative of Luton Clinical Commissioning Group
- Distribution and analysis of the patient survey, email opened by 323 patients;
- Full literature review and desk research.

We were given referrals to two other consultant gastroenterologists at LDUH. One declined to be interviewed as he did not feel he could contribute, but indicated that "the patients seem to like it". The other has been away in January and we have still not been able to make contact. Further interviews were planned with a Luton GP, a consultant gastroenterologist at Torbay (where PKB software has also been licensed), and possible follow up with the CCG and LDUH business managers. However, to date we have not been able to make contact with any of the above. The final report includes the analysis of the patient survey and literature review. It is important to remember in viewing patient responses that many of them are not comparing IBD-SSHAMP with the previous system, as they were not necessarily a patient before the introduction of IBD-SSHAMP. They may therefore simply assume that this is how it has always been done. Due to limitations in access to stakeholders, this study has focused mostly on the 'user' stakeholders in the StEAM model, with very minimal attention to the views of the 'economic' stakeholders. However, there are some significant findings and further work to cover gaps is possible in the future.
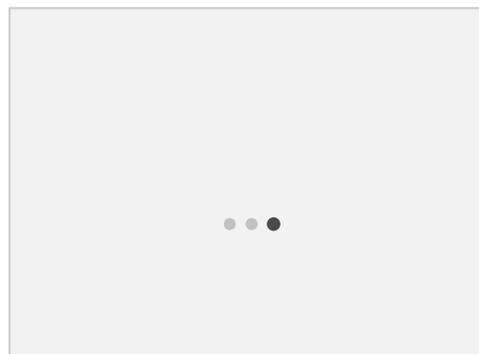
Detailed data analysis is included in the appendices. Appendix 1 presents qualitative data of the semi-structured interviews with clinical users. Appendix 2 presents the patient survey data.

3. **Key features of PKB and their usage**

The PKB software has been introduced at LDUH alongside other innovations, to form the IBD-SSHAMP service as an integrated package aimed at improving clinical outcomes for stable IBD patients through supported self-management. It has therefore been difficult at times for the nurses and other staff to separate the benefits of PKB from those of the other changes. We summarise here what we have inferred to be the key features that pertain directly to PKB, rather than to IBD-SSHAMP more generally.

3.1. Traffic Light System for patient monitoring and hospital alerts.

One of the elements that was cited to us as most significant is the use of automatic alerts from patient-entered data. The LDUH have designed a traffic light system for IBD patients, which they have used

successfully. Patients are prompted to upload symptoms twice yearly but patients can and do upload symptoms when feeling unwell, thus giving them either reassurance or pro-active support. A red score sets off an alert at the hospital and prompts a telephone call from an IBD nurse specialist, who might also send out blood and 'faecal calprotectin' tests. This replaces a process that would previously have involved one or more hospital visits. Staff at LDUH feel the scoring system for the alerts is set relatively low so as to optimize the prevention of flare-ups, but note that their scoring system has not been validated. Thus far however, a red alert usually results in a change of management of the patient symptoms:

> *"If it's active inflammation we optimize the treatment but actually, if it's all psychological, Irritable Bowel Syndrome symptoms we have to deal with that, we can't just leave them; we manage that through IBS type drugs, management therapy or psychologists".*

This means that patients have access to more immediate specialist assistance, with the assumption that this reduces unplanned admissions and GP consultations. One patient commented

> *"I had a response within days when I started to flare and this really helped get the required medication in place relatively quickly".*

Although highly significant to the Trust and a key component of the business case, patients did not cite the alerting system as being important to them. This is possibly because they may not have experienced the 'old system' and therefore do not realise that a change has occurred. Many simply use PKB when asked to enter data twice yearly. In the majority of cases, the rating is 'green' so no further action is taken, beyond a simple message and reference to educational materials:

> *"They get a colour co-ordinated bar chart for this and the next thing is they get some information depending on their overall score they get some instant information pinged back to them depending on their score and if they get a red then we get alerted and the IBD nurses can call".*

> *"If the information that's gone back to them on the green is things look stable however if you feel you're doing badly and you have a lot of symptoms and you scored badly in certain areas then maybe you need to look at and we've listed various dietary things and also the information leaflets that we have in the library. That's on the site and so they're guided to where to look".*

Quantitative impacts require analysis of the full cohort and some comparison with the status quo before the introduction of IBD-SSHAMP. This analysis is being undertaken as part of Dr Matt Johnson's funded research project with the University of Hertfordshire. These results will be available towards the end of 2015.

A comprehensive study of the literature for shared patient health records has not revealed any other systems that provide automated analysis of patient entered data. This suggests that PKB is innovative in this respect. Within telehealth systems (telemonitoring), the use of automated analysis is more common. An example is the Whole System Demonstrator using the Tunstall system for COPD and CHF patients, in which an automated red/green/amber system was monitored by a nurse-call centre [1]. There are other examples, but relatively little analysis of the value to patients or the hospital. The Whole Systems Demonstrator evaluation was striking in its neutrality in this respect – no strong statement has been found to demonstrate the economic or clinical value.

3.2. Direct portal of access to hospital specialists
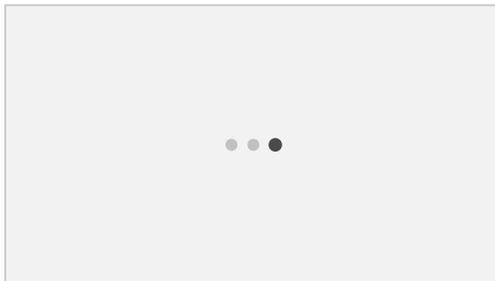
Patients are able to email or send messages to specialist IBD nurses directly at any time. This facility was considered to have benefitted clinicians and patients alike and fears that it might lead to an overwhelming increase in communications were not well-founded. Whether the facility to email had resulted in less time spent on communications was unclear, although all agreed that patients were more frank and to the point in emails.

Anecdotal evidence suggested that the facility to email had enabled patients to take holidays abroad, whereas once they feared to go far from home. Examples given to us included those of a patient contacting them from a cruise in the Mediterranean Sea and another from a hospital in Lithuania. Another stated benefit was that patients are able to attach photographs of their stools, which nurses have found to be valuable to give a swift diagnosis and appropriate advice.
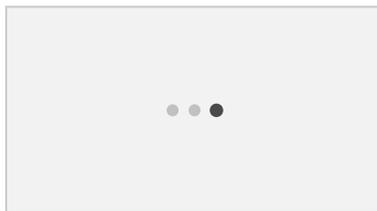
The patient survey gave a mixed response, with a number of respondents reporting that they were unaware of this facility. However, others were clear that they did use the system to contact nurses and indicated that they valued it. Two patients indicated that their use was higher when they were in active disease mode or when undergoing tests and changes to treatment.

Amongst those who are using this facility regularly, there are several different reasons given as to why they value it – convenience, privacy, faster diagnosis.

"[I] use it to ask for results rather than getting answer phone and waiting for ring back"

"Recently had a flare up so needed to contact specialists and prefer not to us the phone for this, especially if I'm at work, as it gives me more privacy"

"Communicating with professionals was a godsend during a period of having hospital tests and getting a diagnosis."

This finding is mirrored in studies of patient health records elsewhere. In the USA there are two major implementations of shared electronic health record systems by health insurance companies Kaiser Permanente and the American Veterans Association. A large scale study [2] of the Kaiser Permanente system looked at both physician and patient attitudes to virtual consultations via secure messaging and found that on the whole attitudes were favourable. They also noted a tendency for this practice to reduce patient attendances (in the USA this is seen as a negative outcome, but the paper discusses reimbursement issues to offset this). A second study using Kaiser Permanente [3] with HIV patients noted that patients mostly used it for communicating with physicians, booking appointments and ordering prescriptions, rather than using the facilities to enter their own data. A qualitative study [4] of around 40 patients using the Veterans Association system indicated that patients find the sharing of data useful, but largely to check accuracy of verbal instructions rather than to proactively control the record with their own data. There are a number of other studies of HER/PHR systems in Australia, Estonia, France and Germany, either fully available nationally or partially available as part of a gradual rollout. Although other features are provided to patients in many cases, the main uses cited are booking appointments, getting prescriptions and emailing/messaging doctors (or other clinical professionals).

There is evidence that patients of higher socio-economic status and with higher levels of education are more likely to use electronic health systems [5]. This is an important factor in planning services, but at least gives the opportunity to reduce resource consumption by this group to hopefully enable resources to be focused on those less able to access care. Related to this point, in the patient survey we undertook, 66% of respondents said they were 'very familiar' with computers and internet technology. This may simply be a matter of understanding better how PKB can be targeted and recognising that even removal of a segment of the patient cohort from outpatient clinics is helpful and can free up clinical time for those patients who may need more attention.

3.3. Patient education from libraries of information

PKB has the facility to provide an extensive library of patient education resources and links. This means patients have constant access wherever they are, stored and relevant to them. The expectation is that this will improve self-care and reduce pressure on all parts of the system. There was little comment from patients on this aspect of the system, but 24 of the respondents indicated that had used it, of which 11 used the libraries once a month or more. The libraries are important in developing an 'IBD-specific implementation' of PKB and potentially transferable (with permission of MJ and LDUH) to other customers. However, in this information-saturated age it is possible that patients do not value it specifically. Some may not even remember where they read particular information. Others come to PKB with significant prior knowledge. One patient noted that PKB had not enhanced understanding of his/her health condition because "I have done extensive research on the web". Others had "researched it thoroughly when originally diagnosed" and "got more

information from the charity Crohns and Colitis UK". This is a difficult feature therefore to use as a differentiator for PKB. If patients are already information-literate they are unlikely to value it, but others may use it as their primary source. A significant 26% of respondents said that the PKB website had given them a greater understanding of their health condition.

It is also likely that some patients may be reluctant to learn more about their condition as they are feeling negative about the impact it will have on their lives, although we have not specifically collected any data to explore this issue.

3.4. Sharing and access to multiple users

A particularly powerful feature of the PKB system is that patients may invite other professionals or non-professional carers or family to share access to their own individual PKB 'website'. Nurses are not specifically aware of how much use has been made of this facility, as they do not have full access to patient spaces. Anecdotally they are aware that some patients have asked a family member who is perhaps more IT literate to help them, but not necessarily through a separate login.

The patient survey showed that this is an under-used (and under-appreciated) feature. Over 50% of respondents were unaware that they could do it. Of those aware, only 4 patients (16.7%) reported that they had shared it. Even these may have misunderstood, as 2 reported that they had shared it with the IBD nurse. One patient reported having shared their PKB website with a GP.

Even within the two clinical teams we surveyed it has proved difficult to extend the use of PKB more widely. At LDUH, we are only aware that one consultant is actively using it and usage has not been extended to dieticians or psychologists, who have an important role in supporting IBD patients to self-manage. The same issue around professional uptake was reported at Torbay, where use is limited to two consultants.

> *"We've got six gastroenterologists here, top gastroenterologists and only two of them were willing to add their name and so unless everybody was will to sign up it was always a really difficult thing to, you know, challenge" (TOR1).*

This is a common finding with similar innovations in digital health. It is often the case that innovations are championed and driven by a single individual, who struggles to influence colleagues particularly if they are from different clinical professions. This is an issue that cannot easily be solved without high level management input, but with wider uptake PKB would become a much more attractive proposition to the patient.
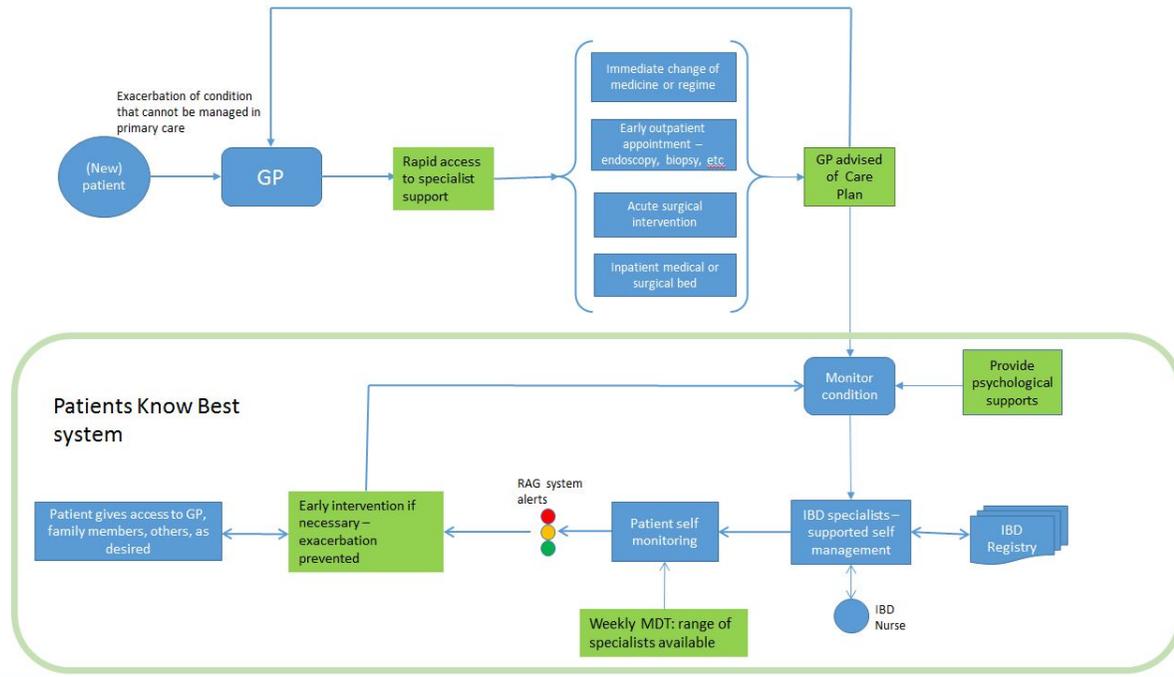
4. **Key Benefits**

As already stated, benefits cannot be easily ascribed directly to PKB in the clinical context due to the complex nature of the service and the limitations of data collection and metrics in place. However, it is an important cog in a wheel that supports patient empowerment and ultimately should reduce pressures on the system, enabling resources to be deployed more effectively and reduce waiting times in other parts of the system. We have started to demonstrate a) that PKB supports patient empowerment and self-management and b) that self-management does make care of long term conditions patients more efficient and free up resources.

The Health Foundation published a review of the evidence of the value of supported self-management in 2011 [6]. The diagram below (Figure 1), taken from this report, indicates the importance of different strategies. Patient held records is recognised as improving self-efficacy and information provision. To effectively support behaviour change, more active measures including self-monitoring and goal setting are considered important.

Figure 1: Continuum strategies to support self-management – from Health Foundation 2011

The IBD Standard [7] outlines the preferred procedure for supporting IBD patients with long term conditions, represented diagrammatically in Fig 2a below.

Figure 2a: Representation of pathway recommended by IBD Standard

The clear recommendation of the standard is for patients to be supported to self-manage, with specific sources of support outlined and including acute specialist services. The IBD-SSHAMP project, with PKB, enables the recommendations, as shown in Fig 2b.

Figure 2b: How PKB is being used at Luton and Dunstable within IBD-SSHAMP

For PKB to really affect self-management, it needs to be used in full by its stakeholders, taking advantage of all the design features available. In particular, proper virtualisation of the multi-disciplinary team (sharing of records with GPs, dieticians and all involved in patient care) are a critical requirement to patient engagement and ultimately their self-management. This aspiration is limited by the professional cultures within healthcare (professionals operate in their own distinct 'siloes') and piecemeal attitudes to innovation (each pilot is separately funded and evaluated), but may come as new generations are educated and enter the workforce.

Figure 2c: How IBD-SSHAMP would be enhanced if expanded across professional groups

The work being undertaken at LDUH is shortly to be improved significantly by integration of the PKB system to the IBD Registry, giving each patient access to their full medical record. This may drive usage and create interest from both patients and professionals.

Next we review the core value proposition for PKB, separating it from the IBD context. A summary of the statements of benefits is shown diagrammatically below and on the next page. Figure 3 shows how PKB may benefit patients and Figure 4 shows a similar representation for the healthcare system.

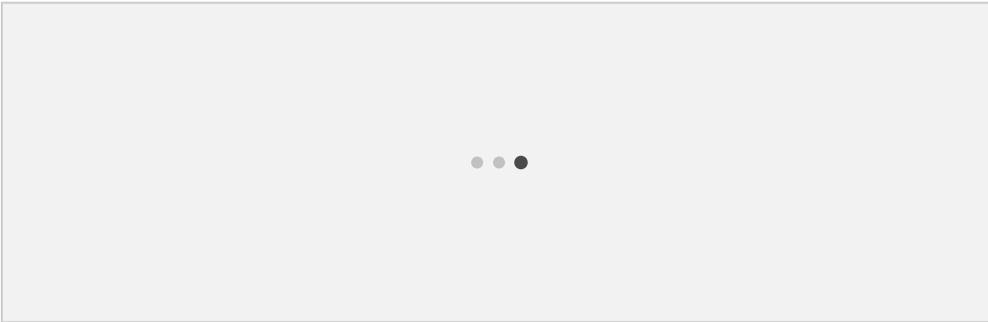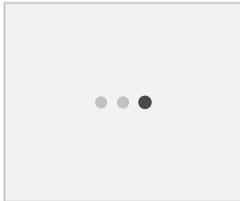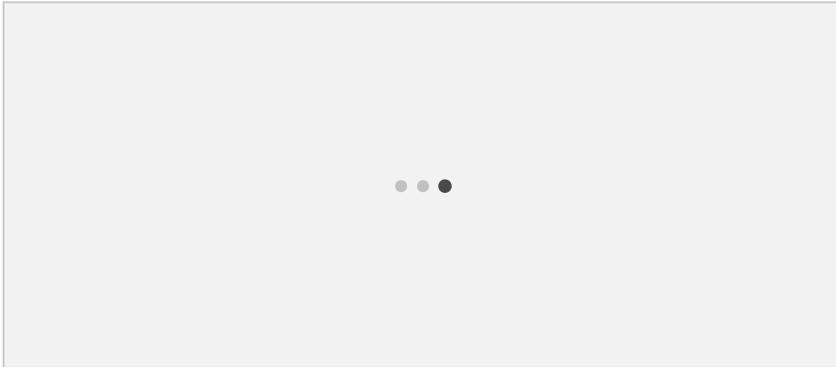FIGURE 3: The key benefits of PKB to patients

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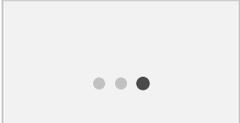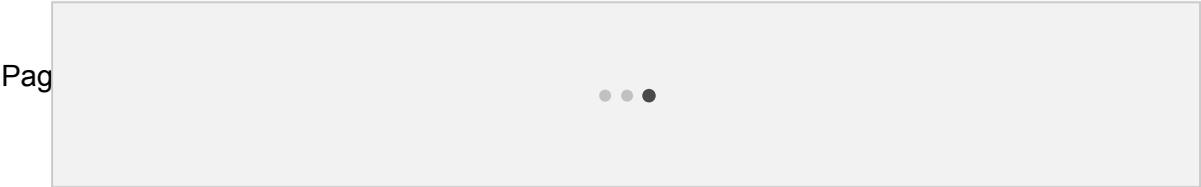
FIGURE 2: The key benefits of PKB to the healthcare organisation

5. **Barriers to implementation of PKB**

Our investigations have also highlighted some concerns and barriers from users. In the patient survey two themes were apparent, the first related to awareness of the system and of how to use it: a number of patients reported being unaware of what PKB could do. The second related to the lack of personal information on the system, patients wanted this and some had stopped using PKB because they could not get it.

In the qualitative interviews, clinical user stakeholders also identified barriers and concerns. Some of these have been successfully overcome at LDUH, but we make recommendations that may be useful in short-circuiting this process with later adopters of PKB. Others may need further considerations. See Table 1 below for a summary of the barriers.

A less tractable issue is the impact of implementing IBD-SSHAMP on the wider health economy. We have not been able to explore this in any depth, beyond an initial consultation with the manager with this responsibility at Luton CCG. This person was new in post when we spoke to her and the CCG had also very recently agreed a contract for community care services. The contract with LDUH for gastroenterology is in review leading up to the new financial year and it is therefore a difficult time to get the attention of either CCG or LDUH managers.

Table 1: Perceived barriers to implementation of PKB by users

	Chief Concern(s)	How Overcome	Recommendation to PKB
Information Governance			
	Security of personal information	Evidence and information from PKB	Prioritise and stress system security in Marketing
		Evidence from Government Assessment	Reiterate security credentials within the website for patients
		Passing trust's information governance	
Getting others on board (The Hospital Trust, Hospital IT departments, Colleagues)			
	Cost of implementation	External Funding for implementation	Minimalize input needed from economic stakeholders
	Increased workload	Development done externally (PKB)	Assist in identifying and applying for funding
	Time implications	Individual clinicians driving it forward	Development and provision of disease specific libraries/ information templates
			Provision of support and resources for 'Champions'
			Enlist support of satisfied user stakeholders (especially senior clinicians)
Patient engagement			
	Patient fear of taking control	Reassurance rather than pressure	Improved patient area on website
	Appropriateness to different patient groups –uptake influenced by:-	Patient nights - perspectives of peers using system	● Stress security
	● Status of IBD (active/stable)		● Patient stories
	● Lifestyle factors (utility to patients)		● Sample patient record
	● Geography (proximity to clinic)		
Integration with existent information systems			

	Delays with integration:-	Not overcome	Prioritise integration before going live.
	Caused Frustration for champions		
	Lessened utility for patient users		
	Reduced patient usage		

The implementation of IBD-SSHAMP (including the IBD registry, PKB software and the calprotectin self-test) have been accomplished by ceasing to discharge patients to community care. This may give a better clinical service to patients but it is perceived as an expensive option by the CCG and to reduce the valued link with the GP and community nursing teams. In the recent period, there has not been a viable community nursing service, but the preference of the CCG is that the specialist nursing input to IBD-SSHAMP is managed by the new community care provider currently being contracted. This may not significantly affect the IBD-SSHAMP working arrangements, but will have implications for the business model.

This may be a more important issue for PKB elsewhere, for instance if PKB software was used for a more prevalent condition, such as COPD. If the patient numbers were greater, it may be viable for a community nursing team to be structured differently and to operate more independently from the consultant team. The beauty of a virtual system is that such an arrangement can be accommodated successfully if the multiple user facility is used fully.

If patients are experiencing fewer exacerbations and flare ups, it can be surmised that they may be using GP services less. We do not have a way to prove this currently. However, the CCG will hold data that may be helpful if we can get their interest in exploring this topic.

Torbay have used PKB software very differently from LDUH, focusing on highly acute patients rather than more stable ones. They have also been hampered by PKB not yet being integrated into their hospital IT system, which limits its usefulness. Their experience highlights the dependence on a lead consultant or champion, which is a common theme in digital health adoption studies. There is no easy solution to this, except to seek influence at all levels up to policy makers. NHS England recently published the very comprehensive and helpful Guidance on Technology Enabled Care Services [8], which could be used to influence and develop a model with CCGs and Trusts. Our own work elsewhere has also highlighted the need for partnership working between different providers and stakeholders in the health economy. Our Telehealth Readiness Tool (see www.ready4telehealth.com) could be applied to explore the problem with specific groups.

Finally, we note a number of specific suggestions by patients on the design of the user interface of the PKB website. These are listed in full in Appendix 2.

6. **Outline recommendations**

- PKB is a useful tool in the arsenal to support self-management of long term conditions. There is strong evidence to support its role theoretically and some good case study material that can be used in marketing.

- Continue to develop IBD as a specialist area and to target other departments and consultants through the profession. LDUH have pioneered a strong implementation for IBD patients, linked to the published IBD Standard. In partnership with Dr Matt Johnson, consider developing 'turnkey'

systems, to include guidance and manuals for gastroenterology staff and patients.

- Data security and privacy issues have emerged as major concerns of patients as well as of organisational customers. PKB have excellent credentials, but the need to keep stating them cannot be overestimated. Strengthen communications to all customers.

- Recognise that patients need direct communication to be enabled to take full advantage of the system. Provide direct targeted emails and perhaps an online tutorial of all the benefits of PKB to the patient.

- Consider promoting PKB directly to patients, even as a consumer product. The benefits to patients are significant and many will have co-morbidities meaning they can be strong advocates across different clinical specialisms.

- Seek to discuss in further detail with Luton CCG and to obtain a better understanding of their views on the appropriate level of community nursing (generic and specialist) to be provided.

- Continue to engage with CCGs and NHS England to influence commissioning decisions at all levels.

7. **Further work**

We outline below a number of possible projects.

a. Larger scale patient study (ethics approval would be required) to consider how patients are using PKB and how this may change over time? How has their ability to self-manage their condition been supported?
   - Patient interviews and observation (with them) of their PKB record.
   - If we can get access to emails (through staff records?), we could do a qualitative analysis of emails – code for categories of use, eg. urgent request for advice, request for access to leaflet, request for clinical advice etc.
   - Group work with patients, asking for their ideas on how the system could work better for them

b. Test our findings with other PKB customer implementations, in particular within other areas where PKB is operational for IBD patients and obtain comparative data from other sites about patient usage, improvements in compliance and patient condition, leading to consequent benefits in

productivity. We could also apply the approach to explore other specialist areas such as Diabetes care (e.g. in responding to hypoglycaemic attacks in diabetes), or COPD exacerbations.

c. A study specifically looking at the use of patient recorded data for automatic alerts. Where else has this been used and how successful has it been? First assessments would suggest that this is relatively innovative – alerts systems are used, but rarely with patient entered data.

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