

The Patients Know Best Solution

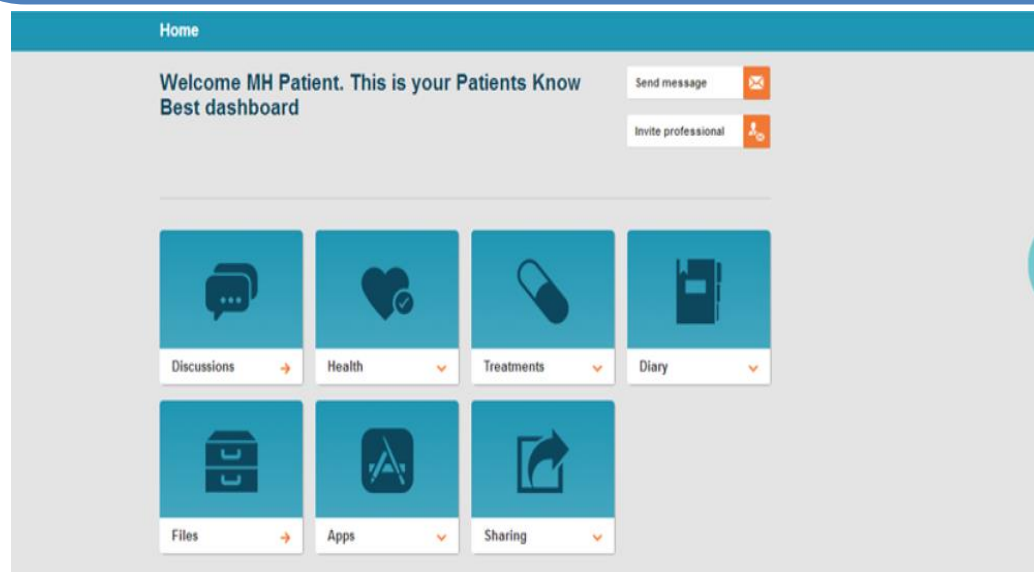
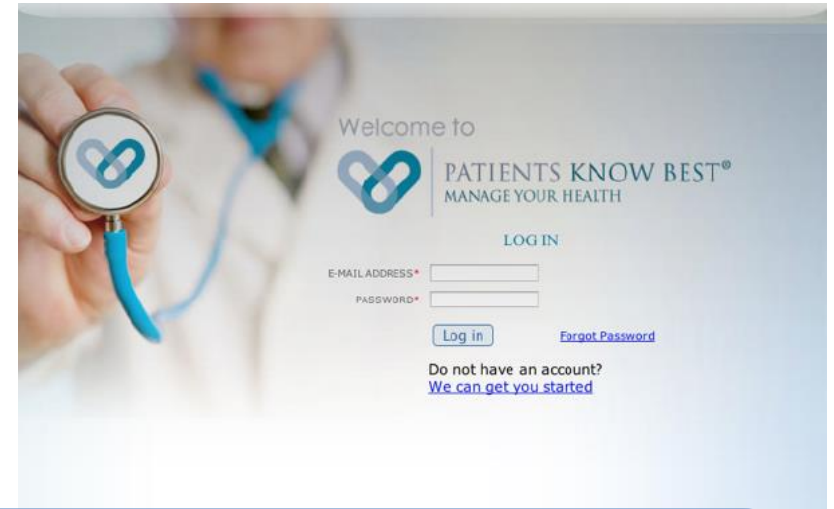
StEAM Adoption Study - Identifying and communicating benefits to aid adoption of patient controlled health records using the Patients Know Best solution.

The Patients Know Best (PKB) personal health record system

- Had been used with Inflammatory Bowel Disease (IBD) patients as part of a supported self-management programme.
- Progression from a successful pilot to mainstream adoption required engagement with managers and commissioners to understand the contractual and organisational implications of such a change.

Our remit

- To understand, from the viewpoint of various stakeholders, what were the barriers to and benefits from using the PKB Personal Health Record system with the aim of aiding wider adoption of the technology



PKB is internet based and can be accessed via mobile devices and personal computers; it offers patients a secure and safe personalised web site which enables worldwide access to:

- Instant IBD symptomatic assessment
- Instant management advice
- Direct alert system to the IBD Team
- Library of advice leaflets
- Direct portal of access to hospital specialists
- Integration with the National IBD Registry
- Integration with hospital results system
- Facility to share health record with others (e.g. family, GP).

PKB was celebrated by **Clinical Stakeholders**; they identified:-

Key Patient Benefits of PKB:

PKB enabled improved accessibility and facilitated a single, rationalised pathway for stable IBD patients to access information and pro-active support – an 'umbilical cord'

Leading to:

Patient Empowerment

- Increased patient confidence – not alone
- Increased ownership of condition
- Increased self-management
- Increased compliance with medication regimes

Which leads to

- Reduced emergency admissions
 - Reduced attendance at outpatients appointments
 - Less inconvenience and savings in time and money for patients
- Which facilitates the living of 'normal lives'

Key Organisational Benefits of PKB:

PKB has enabled a new way of managing stable patients. This has facilitated

- More optimal use of outpatient appointments
- More optimal use of consultants' time
- Clinical and cost effective use of specialist nurses
- Improved two-way communication

Leading to:

- Increased and improved access to specialist clinical advice
- Prevention of flares
- Reduction in emergency appointments and admissions
- Reduction in waiting times within the service
- Potential to reduce pressures elsewhere in the system

Patients' views of PKB:

- Some patients were not aware of the range of features available on PKB.
- Some were enthusiastic, particularly about the ability to contact IBD nurses at any time.
- Patients were largely not aware of the benefits of the automatic alerting, either because they had not (yet) used it, or because it seemed like something they were doing in response to a request from the IBD nurse.
- Patients were not sharing records with others
- Patients (and some staff) noted limitations in the system due to delayed integration with hospital medical records at LDUH.

Summary Findings:-

- PKB is a useful tool to support the self-management of long term conditions.
- First assessments would suggest the Instant IBD symptomatic assessment tool to be relatively innovative - alerts systems are used, but rarely with patient entered data.
- In relation to IBD, PKB can be used to support and improve the pathway recommended by IBD Standard 7 (see additional poster)
- Data security and privacy issues have emerged as major concerns of patients as well as of organisational customers.
- Patients need direct communication and support to be enabled to take full advantage of the system.

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The IBD Standard [7] outlines the preferred procedure for supporting IBD patients with long term conditions, represented diagrammatically in Fig 1:

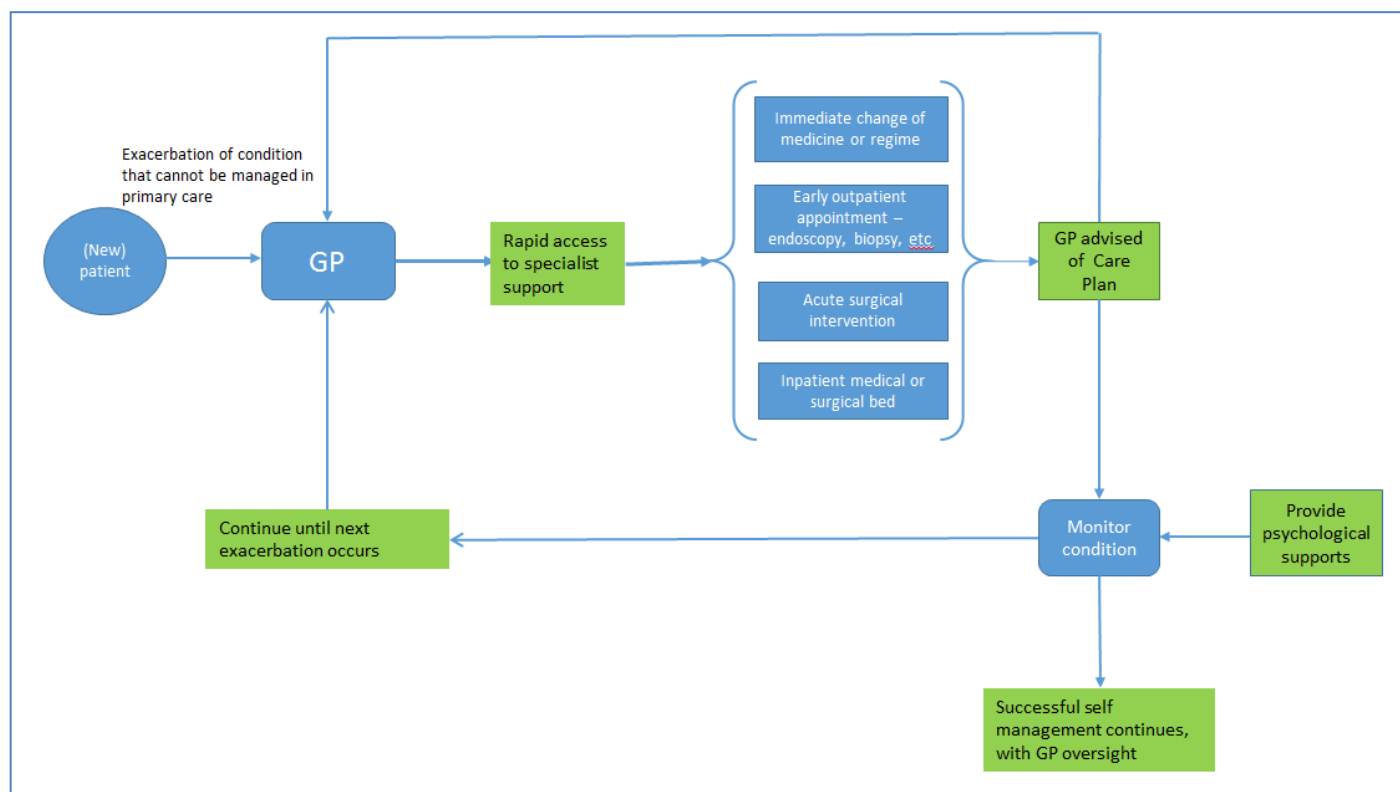


Figure 1: Representation of pathway recommended by IBD Standard

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 2.

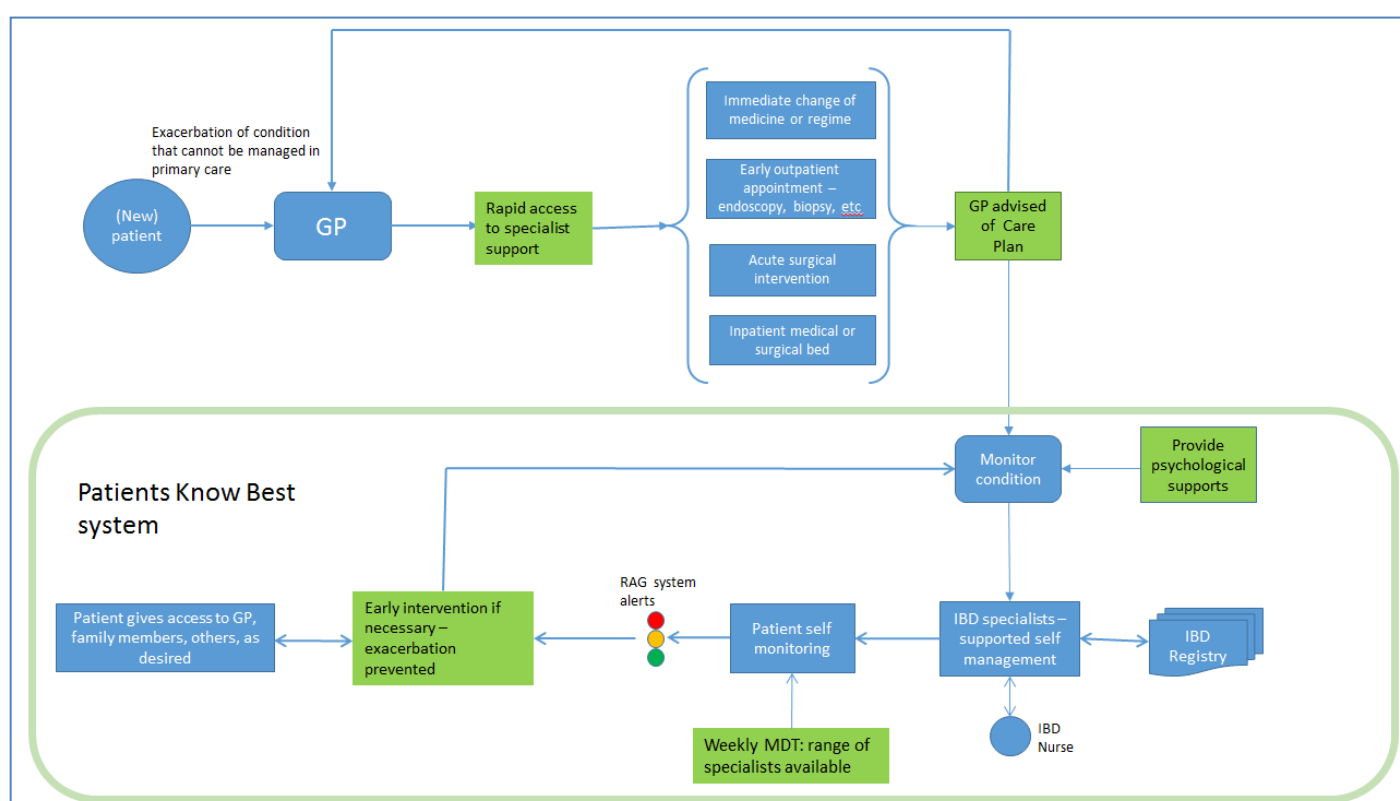


Figure 2: How PKB is being used at Luton and Dunstable within IBD-SSHAMP

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.

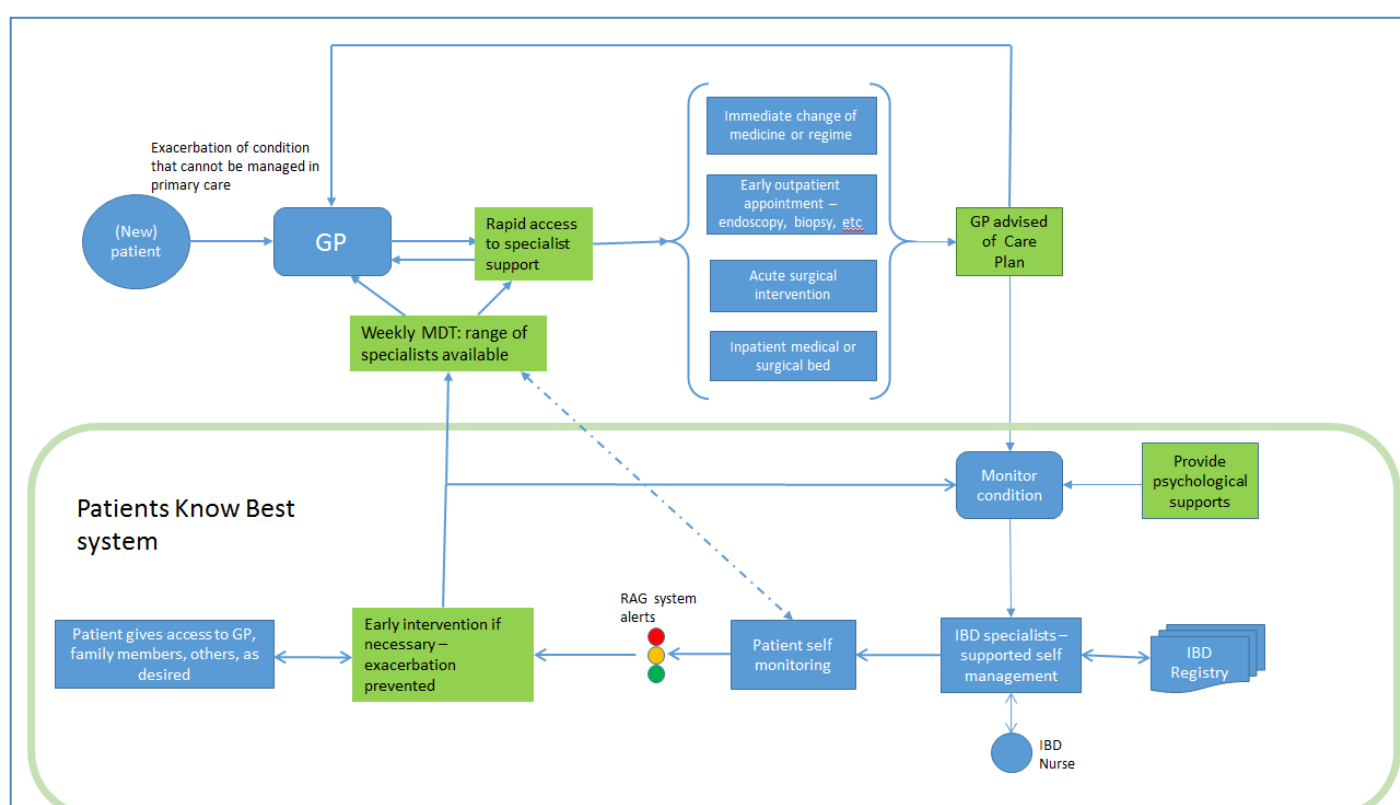


Figure 2c: How IBD-SSHAMP would be enhanced if expanded across professional groups

