

Online Patient Portals

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What is 'Patients Know Best'

- PKB is a patient held electronic record
 - Online program that the patient owns and has control over
- Patients can enter their own symptoms and feelings and have it all stored in one place that they have direct access to
- Patients give a verbal consent if they wish to use the program
- CLL team registers the patients with an email address and they complete an online consent once they register to the program
- CLL team have direct access to the patients PKB account once they have registered but otherwise patients have to invite people to use PKB, e.g. GP, family members etc.

How can PKB be used?

Patients can use PKB to:

- Keep up to date lists of medication, particularly new medication prescribed in the community. This can be printed/ uploaded to the patients NHS record
- Keep a track of symptoms and any drug side effects
- View blood results
- Keep a personal journal
- Complete a Consultation Document to assess CLL symptoms before each F2F clinic/ telephone appointments which we hope will keep a better track of symptoms over time

How can PKB be used? (2)

- Communicate with the CLL team
- Communicate with other health professionals, e.g., GP's/ other specialists can also use the record, which we hope will help to improve communication between the teams
- Access patient information leaflets in the library section
- It can connect it to a wearable activity device such as a FitBit!

PKB is not to be used as an emergency service but as a Patient Record

Advantages of Online Patient Portals- PKB

- Puts the patient in control of their own medical records
- Helps to improve communication between health professionals and communication with the medical team is secure- (NHS N3 Network firewall)
- Clearer/ accurate documentation of drug related side effects (not to be used for clinical trial patients) and captures patient reported outcomes
- It can be used within **telephone clinics** and can help to reduce time for patients and the CLL team

Advantages of Online Patient Portals- PKB (2)

- Reduces number of F2F clinic appointments for well patients which helps to reduce stress, hospital out patient waiting times, time taken off work for appointments etc
- Through the Consultation documents there is still clear documentation of patients symptoms even if medical notes are unavailable, particularly as many patients are on long term medication/ are well but need regular f/u
- Patients can have up to date information before clinic appointments, e.g. information on the next patient support groups

Disadvantages of Online Patient Portals

- Change in culture for staff and patients
- Staff need to believe in it before patients will use it
- Difficult during already busy clinics
- Lack of admin support
- Patients may prefer telephone calls/ F2F appointments to discuss any addition issues that may not otherwise be brought to the attention of the team (e.g. benefit advice)
- Can often be easier to talk over the phone/ in clinic
- Will GP's/ Health professionals sign up to PKB?!
- Patients need to be able to use/ have access to the internet
- Cost of the programme
- Does it do enough to make a difference to patients and our practice.....

How we manage PKB in Oxford

- We went live with PKB for CLL patients in November 2015. It was funded by Janssen until July 2016.
- Initially we also required a paper consent form
- Ideally patients should be given the PIS when they check in for their OPA
- Initial focus was to see if patients registered to PKB/ messaged via PKB rather than email
- Patients are now encouraged to complete the Consultation documents prior to all OPA/ Telephone clinic appointments
- Blood results are posted on PKB
- Aiming to upload clinic letters direct to PKB
- Communicate with patients via the 'message section'

PKB in Oxford

From November 2015- April 2017:

- Total number of patients with a record created with an email address: 102
- Total number of patients that have registered onto PKB: 84
- Total number of symptoms tracked: 514
- Total number of messages sent on PKB: 837 (some of these messages will have been about initial PKB communication)
- Look to do a patient satisfaction audit, Spring 2018

Welcome Anna Schuh

Add patient



Search

ID

NHS number

DoB (YYYY MM DD)

Name

From

YYYY	MM
DD	

My list

Go

Notifications

- | | | |
|--|------------|------------------------|
| You received a message about CMV | Today | View → |
| You received a message about PKB | 8 Apr 2016 | View → |

Discussions ?

Send message



Start consultation



Call patient



November

December

January

February

March

April

29-
Feb-
2016



Blood Test - Online communication

General health

3

08-
Feb-
2016



Valganciclovir - Online communication

General health

3

27-
Jan-
2016



Diarrhoea - Online communication

General health

1

20-
Jan-
2016



Idelatasib - Online communication

General health

6

14-
Dec-
2015



PKB Communication - Online communication

Started By: Lianne Palmer [CLL Advanced Nurse Practitioner in Oxford Cancer and Haematology Centre Oxford University Hospitals]
- Latest: Lianne Palmer [CLL Advanced Nurse Practitioner in Oxford Cancer and Haematology Centre Oxford University Hospitals]

General health

3

PKB CLL Symptom Chart

CLL Symptom chart

Chronic Lymphocytic Leukemia Team

We would be grateful if you could please answer the below questions a few days prior to your outpatient or telephone appointment. The symptom chart will then be reviewed during your next clinic appointment. Please get in touch with the hospital if you have any concerns before this. Lianne Palmer's telephone number is 01865 235284. Many thanks.

Please select both Dr. Anna Schuh and Lianne Palmer when submitting this consultation to the team.

In the last 6 months have you had difficulty or a worsening of the following symptoms:

Q1. General Fatigue (weariness, tiredness)

Yes

No

Q2. Please tick the box that best describes how your fatigue is relieved.

a) Is the fatigued relieved by rest?

Yes

No

b) Is the fatigue not relieved by rest and it limits your day to day activities?

Yes

No

c) Fatigue not relieved by rest, limiting self-care and day to day activities (for example: struggling to get dressed/ showered)

Yes

No

d) How often do you experience fatigue?

Q3. Night sweats with no evidence of infection? (for example needing to change the bed sheets or nightwear)

Yes

No

Q4. Fever (> 37.5 oC)

Yes

No

Q5. Required anti-biotics in the last 6 months for infections?

Yes

No

Q6. What infection(s) have you received anti-biotics for?

Q7. How many times have you required anti-biotics in the last 6 months?

0-1

>2

Q8. Change in appetite/unintentional weight loss in past 6 months?

Yes

No

Amount of weight loss (kg)

Q10. Abdominal pain (and discomfort)

- Yes
- No

Q11. Filling up quickly when you eat (early satiety)

- Yes
- No

Q12. Itching that prevents sleeping? (pruritus)

- Yes
- No

Q13. Have you noticed any new lymph nodes (lumps and bumps) or any existing lymph nodes that have got bigger since the last appointment?

- Yes
- No

Q14. Please rate your Quality of Life with 0 being poor and 10 being excellent

Q14. Are you a current smoker?

- Yes
- No

Q15. Have you received the annual Flu jab?

- Yes
- No

Are you up to date with your vaccinations against: meningococcus, pneumococcus and haemophilus influenza? These need to be repeated every five years. You should not receive any live vaccinations.

- Yes
- No

Any other comments:

Cancel

Submit

PKB Case Study- 1

- 69-year-old gentleman
- Works full-time
- 15 weeks into Ibrutinib treatment, the patient called the CNS office describing a persistent rash over 4 weeks. Not itchy, brown in colour to the arms/ thighs but not widespread
- Pictures of the rash uploaded onto PKB for consultant review
- Consultant Dermatologist invited to the site and reviewed the rash-recommended treatment for discoid eczema
- Patient contacted GP

PKB Case Study- 1

Results:

- Involvement of two consultants and a CNS without the patient leaving his home. Prompt treatment and expert advice. Well documented for the GP to view.
- Reduction in outpatient time and GP appointments
- We do need to look at how we are going to capture this activity going forward.

PKB Case Study- 2

- 57 year old gentleman
- Stage A CLL
- Referred to telephone clinic for 6 monthly f/u
- Full telephone clinic done via PKB
 - Consultant document showed no B symptoms
 - Blood counts stable
- Advantages: no hospital visits, time efficient for the patient

Any questions?

CLL Nurse Forum
