



RePROM

Renal Electronic Patient Reported Outcome Measures

What is RePROM and how do I use the system?

What is RePROM?

- **RePROM** is a 2-arm pilot trial recruiting patients with advanced CKD (trial definition: eGFR ≥ 6 & ≤ 15 mL/min/1.73m² OR Tangri 2-year risk of progression to ESRF $\geq 20\%$)
- **Intervention:** monthly ePROM (electronic Patient-Reported Outcome Measure) symptom reporting + usual care
- **Comparator:** usual care
- **Primary outcome:** feasibility
- **Target sample size:** n=66
- **Recruitment:** 12 months
- **Follow-up:** 12 months

ePROM Evidence

- Oncology research has shown regular ePROM reporting is associated with:
 - Significant improvements in quality of life
 - Reduced A&E visits and hospitalisations
 - Better treatment adherence
 - Improved survival
 - Enhanced benefits for computer-inexperienced patients
- RePROM is looking to see if these findings may apply to the renal population

JOURNAL OF CLINICAL ONCOLOGY ORIGINAL REPORT

Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial

Ethan Basch, Allison M. Deal, Mark G. Kris, Howard I. Scher, Clifford A. Hudis, Paul Sabbatini, Lauren Rogak, Antonia V. Bennett, Amylou C. Dueck, Thomas M. Atkinson, Joanne F. Chou, Dorothy Dulko, Laura Sit, Allison Barz, Paul Novotny, Michael Fruscione, Jeff A. Sloan, and Deborah Schrag

ABSTRACT

Purpose

There is growing interest to enhance symptom monitoring during routine cancer care using patient-reported outcomes, but evidence of impact on clinical outcomes is limited.

Methods

We randomly assigned patients receiving routine outpatient chemotherapy for advanced solid tumors at Memorial Sloan Kettering Cancer Center to report 12 common symptoms via tablet computers or to receive usual care consisting of symptom monitoring at the discretion of clinicians. Those with home computers received weekly e-mail prompts to report between visits. Treating physicians received symptom printouts at visits, and nurses received e-mail alerts when participants reported severe or worsening symptoms. The primary outcome was change in health-related quality of life (HRQL) at 6 months compared with baseline, measured by the EuroQol EQ-5D Index. Secondary endpoints included emergency room (ER) visits, hospitalizations, and survival.

Results

Among 766 patients allocated, HRQL improved among more participants in the intervention group than usual care (34% v 18%) and worsened among fewer (38% v 53%; $P < .001$). Overall, mean HRQL declined by less in the intervention group than usual care (1.4- v 7.1-point drop; $P < .001$). Patients receiving intervention were less frequently admitted to the ER (34% v 41%; $P = .02$) or hospitalized (45% v 49%; $P = .08$) and remained on chemotherapy longer (mean, 8.2 v 6.3 months; $P = .002$). Although 75% of the intervention group was alive at 1 year, 69% with usual care survived the year ($P = .05$), with differences also seen in quality-adjusted survival (mean of 8.7 v 8.0 months; $P = .004$). Benefits were greater for participants lacking prior computer experience. Most patients receiving intervention (63%) reported severe symptoms during the study. Nurses frequently initiated clinical actions in response to e-mail alerts.

Conclusion

Clinical benefits were associated with symptom self-reporting during cancer care.

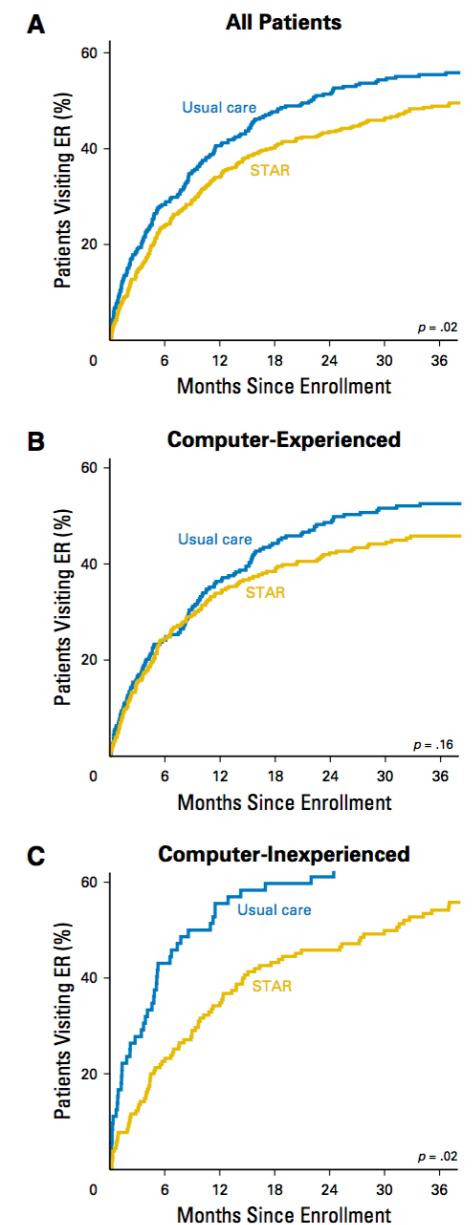
J Clin Oncol 33. © 2015 by American Society of Clinical Oncology

INTRODUCTION

Symptoms are common among patients receiving treatment of advanced cancers^{1,2} and often go undetected.³⁻⁶ Systematic collection of symptom information using patient-reported outcome (PRO) standardized questionnaires has been suggested as an approach to improve symptom control.^{7,8} Several web-based systems exist^{9,10} and have been shown to prompt clinicians to

clinician communication, patient satisfaction, and well-being.¹⁶⁻²² Most patients are willing and able to self-report via the web, even close to the end of life.²³

The effects of symptom self-reporting on clinical outcomes are not established, leaving open the question of whether the benefits of systems to elicit PRO self-reports outweigh their added cost and burden.^{9,16,17} Symptoms precipitate emergency room (ER) visits and hospital admissions.²⁴ In addition to the burden of such visits are





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ePROM System Overview

Patients randomised to the ePROM arm will access the system via myHealth@QEHB

myHealth@QEHB
unlocking your own health records

Queen Elizabeth Hospital Birmingham Charity

Queen Elizabeth Hospital Birmingham NHS Part of University Hospitals Birmingham NHS Foundation Trust

Register Log in Help

“ myHealth@QEHB has given me the opportunity to get involved with and manage my healthcare more easily. ”

Introduction

myHealth@QEHB allows you to view your healthcare information online. All data is stored securely so your records can only be viewed using your login

Video guides

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Renal Electronic Patient Reported Outcome Measures

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BCTU
Birmingham Clinical Trials Unit

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CPROR
CENTRE FOR PATIENT REPORTED OUTCOMES RESEARCH

Patients will be asked to complete monthly* ePROM reports addressing the following symptoms

Question No.	Questionnaire Domain/Item
1	Fatigue (1=mild 2=moderate 3=severe)
2	Shortness of Breath (1=mild 2=moderate 3=severe)
3	Appetite (1=mild 2=moderate 3=severe)
4	Nausea (1=mild 2=moderate 3=severe)
5	Itchy/Dry Skin (1=mild 2=moderate 3=severe)
6	Fistula Pain/Swelling/Numbness/Other Problems (Yes/No)
7	Pain (1=mild 2=moderate 3=severe)
8	Other symptoms (Matrix): Faintness/Dizziness; Difficulty sleeping; Restless legs or difficulty keeping legs still; Diarrhoea; Ankle Swelling (1=mild 2=moderate 3=severe)
9	Other problems (Free-text Box)

***Note: patients may submit ePROM reports more frequently, all data is captured by the system**

Here is an example question around nausea/vomiting

RePROM Symptom Questionnaire Saved but not submitted yet.

During the past week:

Have you experienced **Nausea** (feeling like you are going to be sick) or **vomiting** (being sick)?

*

- No
- I had mild nausea/vomiting
- I had moderate nausea/vomiting and I had difficulty doing some of the things I normally do (e.g. household chores, shopping)
- I had severe nausea/vomiting and I was not able to care for myself (e.g. getting out of bed, bathing, dressing)

Is this a current problem or has it now improved?

*

- This is a current problem for me
- I have experienced this problem in the last 7 days but it has now improved

◀ Previous

Next ▶

Page 6 of 11

Save to edit later

Submit

Cancel

After completing the ePROM, patients will receive automated advice on next steps

RePROM Symptom Questionnaire This is new questionnaire

NEXT STEPS

Thank you for completing the questionnaire. The answers you have given will help us plan your care.

You have said you have mild or moderate problems in one or more areas. This is normal for patients with Chronic Kidney Disease.

The results of this questionnaire have been added to your healthcare record ready for your next kidney clinic appointment.

If there is any change in your symptoms, you can let us know by:

- Speaking to the kidney care team at your next outpatient visit.
- Submitting another ePROM report at any time.

Have you experienced **itchy or dry skin?**
I had moderate itchiness/dry skin

The causes of a persistent itch can include high levels of certain minerals in your blood. Your doctor, nurse or dietitian may advise you to modify your diet to address this.

See below for more information about diet:

- Diet in CKD
- Eating right for CKD

Find out more about CKD treatment options at [NHS Choices](#)

Also see the US National Institutes for Health – [Managing CKD](#)

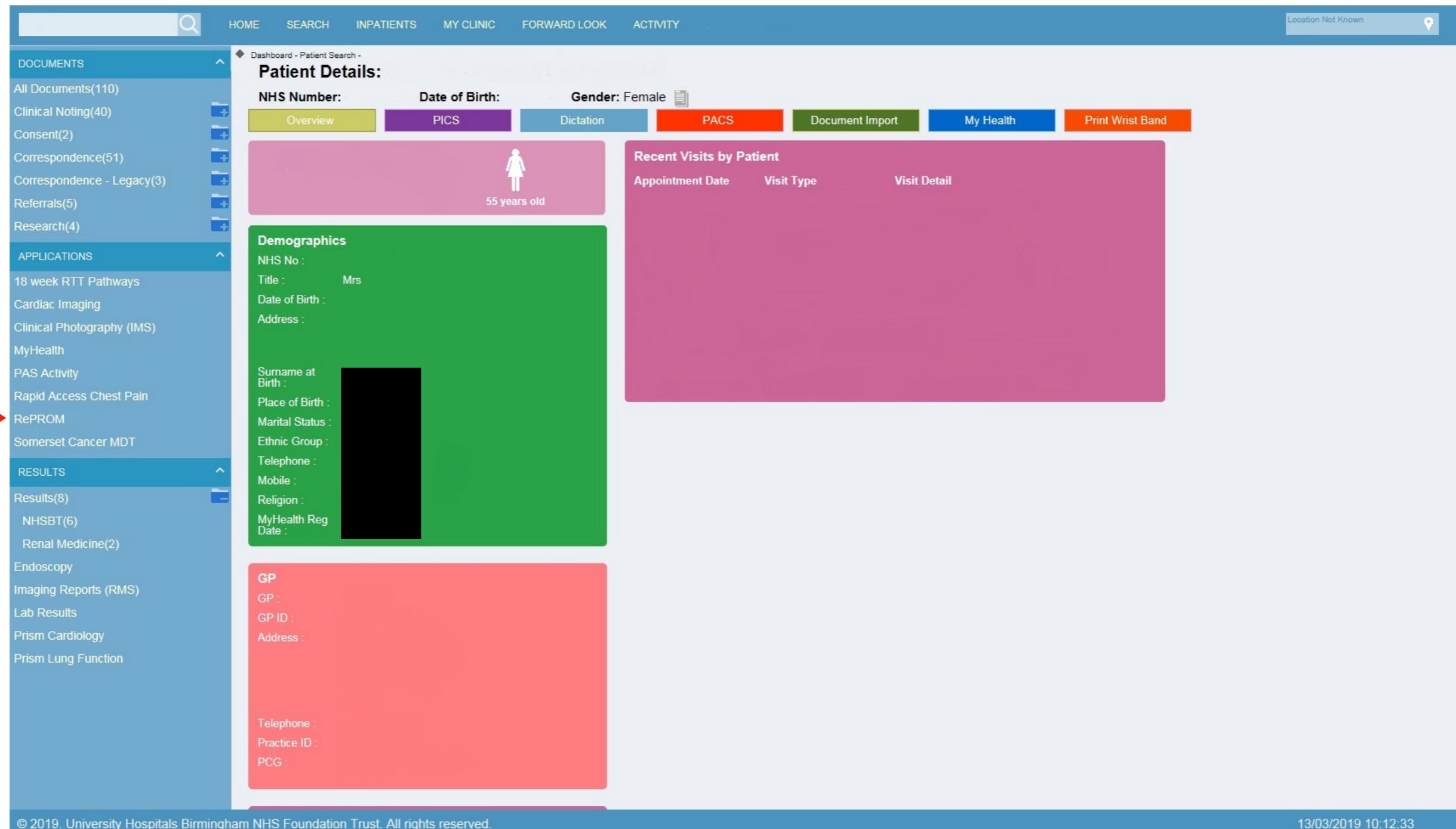


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Viewing longitudinal RePROM data in clinic

Patient RePROM symptom data can be accessed via clinical portal as shown below



The screenshot displays a clinical portal interface with a sidebar on the left and a main content area on the right.

Left Sidebar (Blue):

- DOCUMENTS**
 - All Documents(110)
 - Clinical Noting(40)
 - Consent(2)
 - Correspondence(51)
 - Correspondence - Legacy(3)
 - Referrals(5)
 - Research(4)
- APPLICATIONS**
 - 18 week RTT Pathways
 - Cardiac Imaging
 - Clinical Photography (IMS)
 - MyHealth
 - PAS Activity
 - Rapid Access Chest Pain
 - RePROM
 - Somerset Cancer MDT
- RESULTS**
 - Results(8)
 - NHSBT(6)
 - Renal Medicine(2)
 - Endoscopy
 - Imaging Reports (RMS)
 - Lab Results
 - Prism Cardiology
 - Prism Lung Function

Red Arrow: Points to the 'RePROM' link in the Applications section of the sidebar.

Top Navigation Bar:

- HOME
- SEARCH
- INPATIENTS
- MY CLINIC
- FORWARD LOOK
- ACTIVITY
- Location Not Known

Main Content Area:

Patient Details:

- NHS Number: [Redacted]
- Date of Birth: [Redacted]
- Gender: Female

Buttons: Overview (yellow), PICS (purple), Dictation (blue), PACS (orange), Document Import (green), My Health (blue), Print Wrist Band (orange).

Demographics:

- NHS No : [Redacted]
- Title : Mrs
- Date of Birth : [Redacted]
- Address : [Redacted]
- Surname at Birth : [Redacted]
- Place of Birth : [Redacted]
- Marital Status : [Redacted]
- Ethnic Group : [Redacted]
- Telephone : [Redacted]
- Mobile : [Redacted]
- Religion : [Redacted]
- MyHealth Reg Date : [Redacted]

Recent Visits by Patient:

Appointment Date	Visit Type	Visit Detail
[Redacted]	[Redacted]	[Redacted]

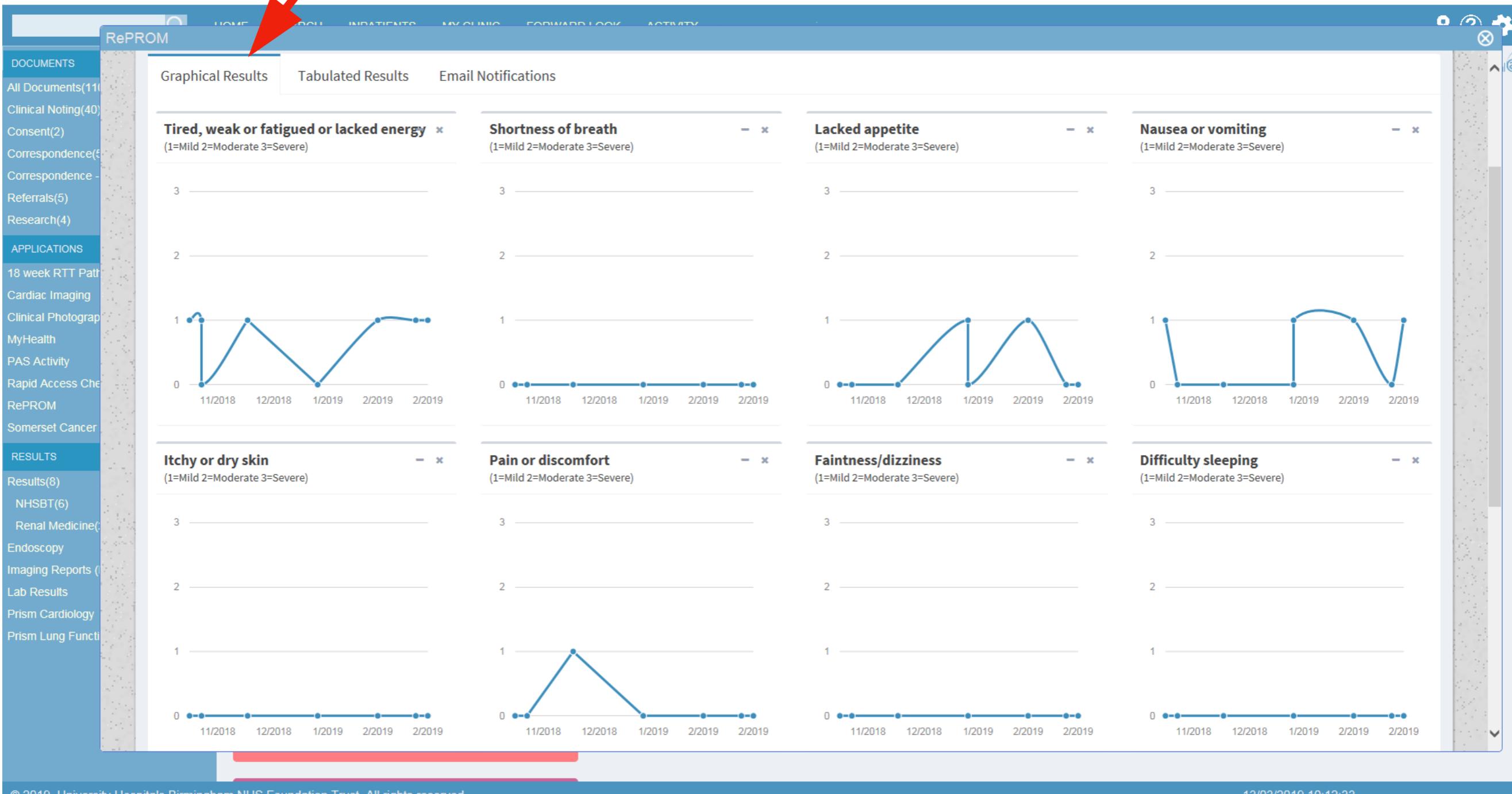
GP:

- GP : [Redacted]
- GP ID : [Redacted]
- Address : [Redacted]
- Telephone : [Redacted]
- Practice ID : [Redacted]
- PCG : [Redacted]

Bottom Footer:

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Longitudinal RePROM symptom data can be viewed in two ways. The default 'Graphical Results' tab displays a separate line graph for each symptom.



Real RePROM patient data. 0 = no symptoms.
1, 2 and 3 represent self-reported 'mild', 'moderate' and 'severe' symptoms respectively.

The 'Tabulated Results' tab displays the raw data, with the most recent report in the left-hand column.



The screenshot shows the RePROM application interface. On the left, a vertical sidebar lists 'DOCUMENTS' (All Documents(11), Clinical Noting(40), Consent(2), Correspondence(1), Correspondence - Referrals(5), Research(4)), 'APPLICATIONS' (18 week RTT Path, Cardiac Imaging, Clinical Photography, MyHealth, PAS Activity, Rapid Access Clinics, RePROM, Somerset Cancer), and 'RESULTS' (Results(8), NHSBT(6), Renal Medicine(1), Endoscopy, Imaging Reports(1), Lab Results, Prism Cardiology, Prism Lung Function). The main content area is titled 'RePROM' and shows a 'Tabulated Results' table. The table has a header row with dates: 26/02/2019, 20/02/2019, 01/02/2019, 02/01/2019, 02/01/2019, 28/11/2018, 28/11/2018, 28/11/2018, 05/11/2018, 05/11/2018, 30/10/2018. The table lists various symptoms and their presence or absence across these dates. For example, 'Tired, weak or fatigued or lacked energy' is present on 26/02/2019, 20/02/2019, 01/02/2019, and 02/01/2019. The table continues with other symptoms like 'Shortness of breath', 'Lacked appetite', 'Nausea or vomiting', etc.

Symptom	26/02/2019	20/02/2019	01/02/2019	02/01/2019	02/01/2019	28/11/2018	28/11/2018	28/11/2018	05/11/2018	05/11/2018	30/10/2018
Tired, weak or fatigued or lacked energy (1=Mild 2=Moderate 3=Severe)	1	1	1	No	No	1	1	1	No	1	1
Shortness of breath (1=Mild 2=Moderate 3=Severe)	No	No	No	No							
Lacked appetite (1=Mild 2=Moderate 3=Severe)	No	No	1	No	1	No	No	No	No	No	No
Nausea or vomiting (1=Mild 2=Moderate 3=Severe)	1	No	1	1	No	No	No	No	No	No	1
Itchy or dry skin (1=Mild 2=Moderate 3=Severe)	No	No	No	No							
Problems with Fistula? (Yes / No)	NA	NA	NA	NA							
Pain or discomfort (1=Mild 2=Moderate 3=Severe)	No	No	No	No	No	1	1 - legs	1 - in legs	No	No	No
Faintness/dizziness (1=Mild 2=Moderate 3=Severe)	NA	NA	NA	NA							
Difficulty sleeping (1=Mild 2=Moderate 3=Severe)	NA	NA	NA	NA							
Restless legs or difficulty keeping legs still (1=Mild 2=Moderate 3=Severe)	NA	NA	NA	NA							
Diarrhoea (1=Mild 2=Moderate 3=Severe)	NA	NA	NA	NA							
Ankle swelling (1=Mild 2=Moderate 3=Severe)	NA	NA	NA	NA							
Other symptoms											

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13/03/2019 10:12:33,

Real RePROM patient data. This view will display any free text comments the patient has submitted.



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ePROM Notifications

When a patient submits an ePROM report highlighting one or more symptoms that are both **severe AND current, this triggers a ‘notification’.**

Two things then occur, both aimed at facilitating appropriate follow-up.

RePROM Symptom Questionnaire Saved but not submitted yet.

During the past week:

Have you experienced **Nausea** (feeling like you are going to be sick) or **vomiting** (being sick)? *

No
 I had mild nausea/vomiting
 I had moderate nausea/vomiting and I had difficulty doing some of the things I normally do (e.g. household chores, shopping)
 I had severe nausea/vomiting and I was not able to care for myself (e.g. getting out of bed, bathing, dressing)

Is this a current problem or has it now improved? *

This is a current problem for me
 I have experienced this problem in the last 7 days but it has now improved

◀ Previous Next ▶ Page 6 of 11 Progress bar: 60%

Save to edit later Submit Cancel

(1) The patient sees the following pop-up message

NEXT STEPS

You have indicated problems that require follow-up.

We recommend that you contact the hospital as soon as you can to discuss your symptoms with the kidney nursing team.

During office hours, **Monday to Friday 09.00 - 17.00hrs**, please call: **0121 371 8761**.

Outside of these hours, if you feel that your problem cannot wait until the kidney nursing team are back in the office, you can either ring NHS 111 or contact the on-call renal medical registrar at QEHB by ringing 0121 6272000.

Tell the registrar that you are participating in the **RePROM** study and explain the problem that you are currently experiencing, they will then be able to provide you with medical advice.

(1) The patient sees the following pop-up message

NEXT STEPS

You have indicated problems that require follow-up.

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Tell the registrar that you are participating in the **RePROM** study and explain the problem that you are currently experiencing, they will then be able to provide you with medical advice.

(2) An automated notification email is sent to the kidney nursing team

DataCollector@QEHB – ePROM Notification

From "DataCollector@QEHB" <DataCollector@uhb.nhs.uk>
To [REDACTED]

The following patient has triggered an RePROM notification for symptoms questions listed below.

Symptom Questions

Have you felt **tired, weak or fatigued or lacked energy?** - This is a current problem for me

Hospital Number: K010918

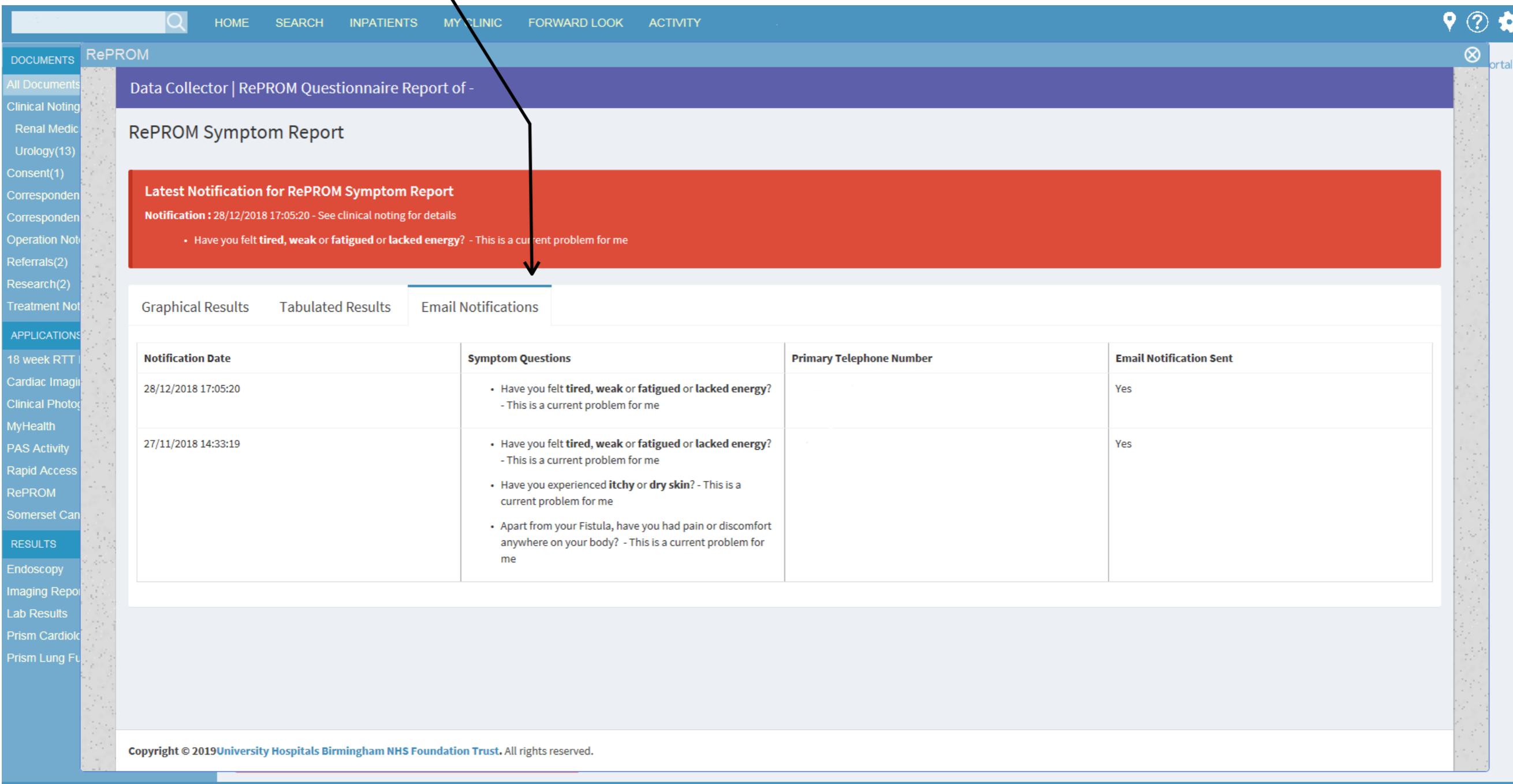
Patients Primary Telephone Number:

[Please click here to view report](#)

Thank you,

RePROM team

In clinic, the 'Email Notifications' tab displays the details of all notifications triggered by the patient.



The screenshot shows a clinical software interface for RePROM. At the top, a navigation bar includes links for HOME, SEARCH, INPATIENTS, MY CLINIC, FORWARD LOOK, and ACTIVITY. A search icon is also present. The main content area is titled 'RePROM' and shows a 'Data Collector | RePROM Questionnaire Report of -'. Below this, a 'RePROM Symptom Report' is displayed. A red box highlights the 'Latest Notification for RePROM Symptom Report' with the date '28/12/2018 17:05:20'. The notification content includes: 'Have you felt **tired, weak or fatigued or lacked energy?** - This is a current problem for me'. Below this, there are three tabs: 'Graphical Results', 'Tabulated Results', and 'Email Notifications'. The 'Email Notifications' tab is selected, showing a table with the following data:

Notification Date	Symptom Questions	Primary Telephone Number	Email Notification Sent
28/12/2018 17:05:20	<ul style="list-style-type: none">Have you felt tired, weak or fatigued or lacked energy? - This is a current problem for me		Yes
27/11/2018 14:33:19	<ul style="list-style-type: none">Have you felt tired, weak or fatigued or lacked energy? - This is a current problem for meHave you experienced itchy or dry skin? - This is a current problem for meApart from your Fistula, have you had pain or discomfort anywhere on your body? - This is a current problem for me		Yes

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