



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.

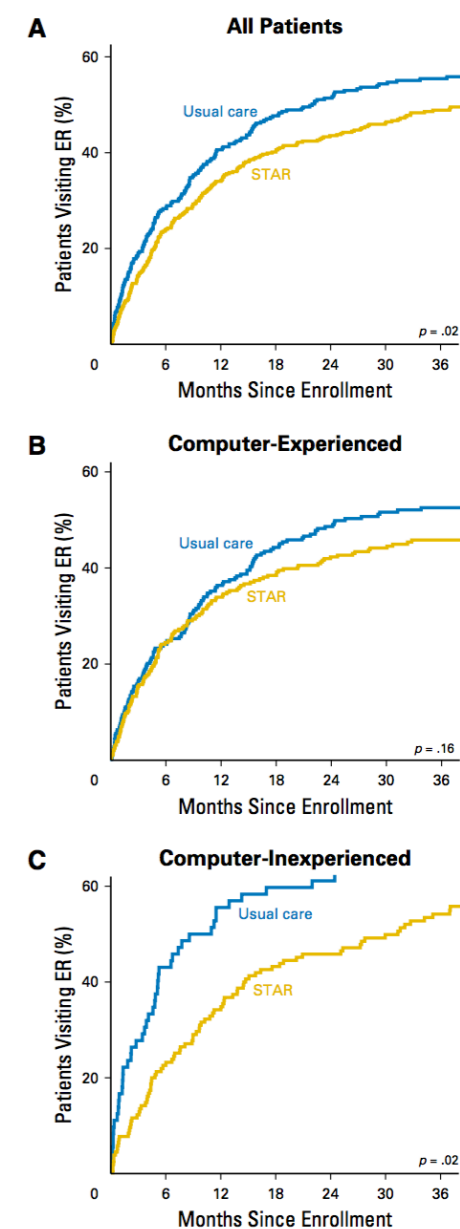
J Clin Oncol 33. © 2015 by American Society of Clinical Oncology

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}

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 but it is not known if 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 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



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.

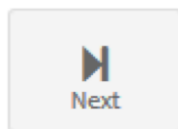
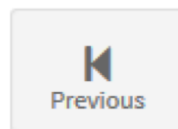
During the past week:

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



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 dietician 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](#)

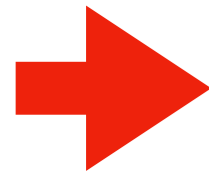


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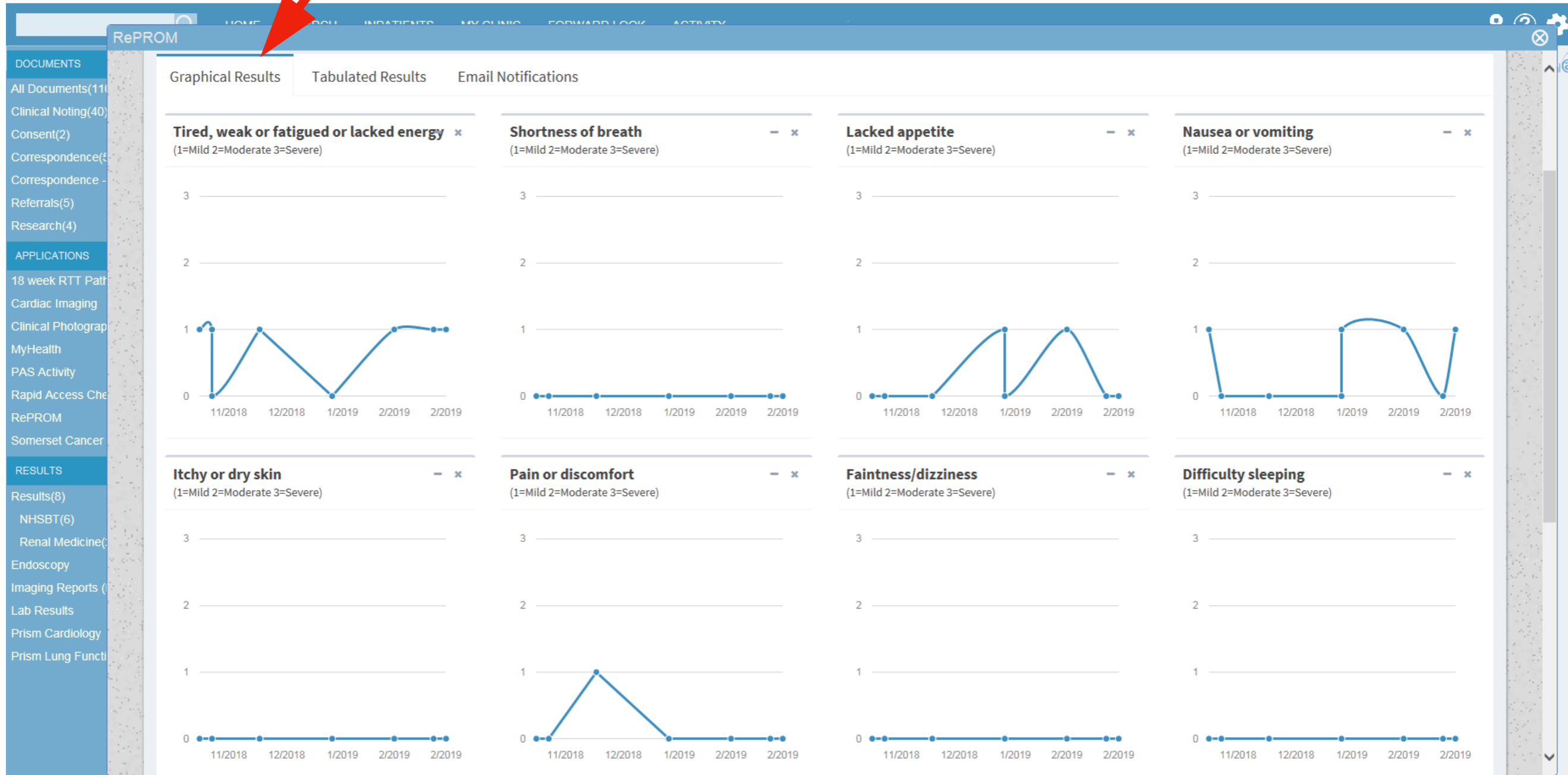
Viewing longitudinal RePROM data in clinic

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



The screenshot displays a clinical portal interface. At the top, there is a navigation bar with links for HOME, SEARCH, INPATIENTS, MY CLINIC, FORWARD LOOK, and ACTIVITY. A search bar is located on the left side of this bar. The main content area is titled 'Dashboard - Patient Search - Patient Details:'. It shows patient information including NHS Number, Date of Birth, and Gender (Female). Below this, there are several tabs: Overview, PICS, Dictation, PACS, Document Import, My Health, and Print Wrist Band. A central card displays '55 years old' with a female icon. To the right, a 'Recent Visits by Patient' table is visible, with columns for Appointment Date, Visit Type, and Visit Detail. Below the central card is a 'Demographics' section with fields for NHS No, Title (Mrs), Date of Birth, Address, Surname at Birth, Place of Birth, Marital Status, Ethnic Group, Telephone, Mobile, Religion, and MyHealth Reg Date. At the bottom of the main content area is a 'GP' section with fields for GP, GP ID, Address, Telephone, Practice ID, and PCG. On the left side, there is a sidebar menu with categories: 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), and RESULTS (Results(8), NHSBT(6), Renal Medicine(2), Endoscopy, Imaging Reports (RMS), Lab Results, Prism Cardiology, Prism Lung Function). A red arrow points to the 'RePROM' link in the APPLICATIONS section. The footer contains copyright information: '© 2019. University Hospitals Birmingham NHS Foundation Trust. All rights reserved.' and the date/time: '13/03/2019 10:12:33'.

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



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13/03/2019 10:12:33

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.



RePROM

DOCUMENTS

All Documents(11)

Clinical Noting(40)

Consent(2)

Correspondence(5)

Correspondence - Referrals(5)

Research(4)

APPLICATIONS

18 week RTT Path

Cardiac Imaging

Clinical Photograph

MyHealth

PAS Activity

Rapid Access Chem

RePROM

Somerset Cancer

RESULTS

Results(8)

NHSBT(6)

Renal Medicine(

Endoscopy

Imaging Reports (

Lab Results

Prism Cardiology

Prism Lung Functi

Graphical Results | **Tabulated Results** | Email Notifications

| 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 | No | No | No | 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 | No | No | No | No | No | No | No |
| Problems with Fistula? (Yes / No) | NA | NA | NA | NA | NA | NA | NA | 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 | NA | NA | NA | NA | NA | NA | NA |
| Difficulty sleeping (1=Mild 2=Moderate 3=Severe) | NA | NA | NA | NA | NA | NA | NA | NA | NA | NA | NA |
| Restless legs or difficulty keeping legs still (1=Mild 2=Moderate 3=Severe) | NA | NA | NA | NA | NA | NA | NA | NA | NA | NA | NA |
| Diarrhoea (1=Mild 2=Moderate 3=Severe) | NA | NA | NA | NA | NA | NA | NA | NA | NA | NA | NA |
| Ankle swelling (1=Mild 2=Moderate 3=Severe) | NA | NA | NA | NA | NA | NA | NA | NA | NA | NA | NA |
| Other symptoms | | | | | | | | | | | |

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

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

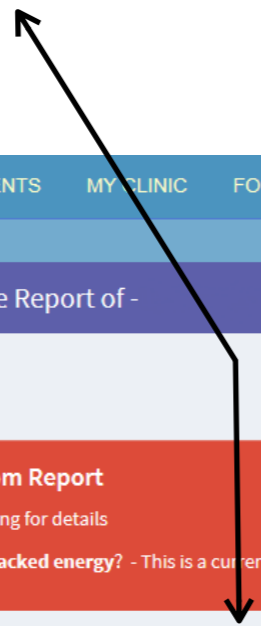
Patients Primary Telephone Number:

[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.



HOME SEARCH INPATIENTS MY CLINIC FORWARD LOOK ACTIVITY

DOCUMENTS RePROM

Data Collector | RePROM Questionnaire Report of -

RePROM Symptom Report

Latest Notification for RePROM Symptom Report
Notification : 28/12/2018 17:05:20 - See clinical noting for details

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

Graphical Results Tabulated Results **Email Notifications**

| 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 me • Have you experienced itchy or dry skin? - This is a current problem for me • Apart 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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Real RePROM patient data.





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