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# Determine how best electronic personal health records (PHRs) should be designed and utilised to help patients get the full benefit of their prescribed medication

**Submission date**
04/06/2018

**Recruitment status**
No longer recruiting

**Registration date**
13/06/2018

**Overall study status**
Completed

**Last Edited**
18/10/2019

**Condition category**
Other

[X] Prospectively registered
[_] Protocol
[_] Statistical analysis plan
[_] Results
[_] Individual participant data
[_] Record updated in last year

## Plain English summary of protocol

Background and study aims
The annual NHS England spend on medication was £15.5 billion in 2015. Every year more and more medications are prescribed by NHS England. It is predicted that more than a third of all patients with a long term condition in the UK do not adhere to their medications. Medication non-adherence is related with a higher number of hospital admissions, adverse drug reactions, nursing home admissions and increase in health care and social costs.
Current NHS policy aims to aid patients to make the right choices and support clinicians by providing access to all the health-essential data and by helping them to make the most of the technology.
Personal Health records (PHRs) are useful for patients that have chronic conditions. PHRs give patients the ability to self-manage their health, empower them, increase access to care especially in remote areas and improve medication adherence. Some PHRs are connected to an electronic health record (EHR) that is held in a hospital or GP.
This study aims to determine how best computerised personal health records (PHRs) should be designed and utilised to help patients get the full benefit of their prescribed medication.

Who can participate?
Adults aged 18 years or above with at least one long term condition

What does the study involve?
Selected participants receive a 20-minute telephone or online interview, followed by a 10 to 15 minute online survey. The interview is recorded and transcribed by a professional service who work under a strict confidentiality contract.
Contact details are kept for one year after the study ends. No personal information is released from the interview, or disclosed outside of the research team, except with participants' clear consent. Interview recordings, survey answers and transcripts are securely stored on University of Portsmouth computers, accessible only to the research team. Information gained from the interviews is analysed to summaries patient views. The research team includes patient

representatives, who participate in the analysis but do not have access to any identifiable information.

What are the possible benefits and risks of participating?
It is not expected that there will be any direct benefits to participants; however, taking part in research is a valuable contribution to society.
When the interview and survey data is analysed, it is possible that the circumstances of a reported experience may reveal the participants' identity or that of a family member. Should this occur, they would be contacted again to see if they are still willing for their story to be included. It is possible that the study may lead participants to relate some distressing experience about themselves or someone else. Should that happen, the situation may be escalated to the responsible clinician or relevant healthcare regulator so that it can be addressed. The participant would be asked for consent to do this, but in unusual situations (such as the call being interrupted, or the participant becoming unwell) it might be escalated without specific permission. In rare circumstances, it may be recommended that participants discuss the situation with their general practitioner. They can also contact the Patient Advice and Liaison Service on 0800 917 6039.

Where is the study run from?
University of Portsmouth (UK)

When is the study starting and how long is it expected to run for?
Septmebr 2017 to August 2019

Who is funding the study?
University of Portsmouth (UK)

Who is the main contact?
Miss Elisavet Andrikopoulou (Scientific)

# Contact information

### Type(s)
Public

### Contact name
Miss Elisavet Andrikopoulou

### ORCID ID
https://orcid.org/0000-0002-4614-2907

### Contact details
Buckingham Building
Lion Terrace
Portsmouth
United Kingdom
PO1 3HE

### Type(s)
Scientific

**Contact name**
Miss Elisavet Andrikopoulou

**Contact details**
Buckingham Building
Lion Terrace
Portsmouth
United Kingdom
PO1 3HE

# Additional identifiers

**Protocol serial number**
1

# Study information

**Scientific Title**
A mixed methods realist evaluation of electronic personal health records design and use to help patients get the full benefit of their prescribed medication

**Acronym**
ePHRma

**Study objectives**
Aim: To determine how best computerised personal health records (PHRs) should be designed and utilised to help patients get the full benefit of their prescribed medication.
o What are the essential design features of PHRs to improve medication adherence in chronically ill adults?
o How do patient-specific factors (behaviour, socio-demographics) mediate the impact of PHRs?
o How do disease-specific factors (progression, severity, intervention type) mediate the impact of PHRs?
o How can we theoretically model the interaction between the PHR design features and the patient and disease specific factors, to help determine what works for whom in what circumstances?

**Ethics approval required**
Old ethics approval format

**Ethics approval(s)**
Approved 07/08/2018, NHS HRA North East - Newcastle & North Tyneside 2 Research Ethics Committee (NHSBT Newcastle Blood Donor Centre, Holland Drive, Newcastle upon Tyne, NE2 4NQ; 0207 104 8082; nrescommittee.northeast-newcastleandnorthtyneside2@nhs.net), ref: 18/NE/0253

**Study design**
Convergent mixed methods study

**Primary study design**
Observational

### Study type(s)
Other

### Health condition(s) or problem(s) studied
Any Long Term Condition

### Interventions
A purposive sample of approx. 30-40 volunteers will be recruited. Posters are displayed in GP surgeries, pharmacies, and Universities across Hampshire. A project website has been developed. Potential participants are asked to give basic demographic and chronic condition data (age group, gender, PHR use, chronic illness, job status) when agreeing to volunteer. Participants are recruited from a diverse mixture of demographic and chronic condition characteristics.
Both qualitative and quantitative data is gathered from the same population, during an online /telephone interview.
Qualitative dimensions of the concepts of the effectiveness of PHR design features with medication adherence are assessed with a semi-structured interview.
The socio-demographic information that we intend to gather is:
1. Age group;
2. Gender;
3. Ethnicity;
4. Education;
5. Financial status;
6. Marital status;
7. Employment.
Medication adherence is measured using the Medication adherence questionnaire (MAQ).
Quality of life is measured using the SF-36 scale, and personality traits are identified using the BFI questionnaire.
Mixed methods data analysis involves analyzing the quantitative and the qualitative data separately and then combine the two databases. The qualitative data is analyzed using the framework method and the quantitative data is analyzed using descriptive statistics. The integration of these databases is based on the convergent MM design, in which the two databases are merged after the initial and separate analyses of quantitative and the qualitative databases to form narratives and joint displays.

### Intervention Type
Not Specified

### Primary outcome(s)
Medication adherence is measured using the Medication adherence questionnaire (MAQ) at the interview

### Key secondary outcome(s))
1. Health related quality of life score is measured using the SF-36 scale at the interview
2. Personality traits are assessed using the BFI questionnaire at the interview

### Completion date
30/09/2019

## Eligibility

### Key inclusion criteria
1. Participant is willing and able to provide informed consent for participation in the study
2. Male or female, aged 18 years or above
3. Participant has at least one long term condition and is treated outside hospital
4. Participant can self-administer and manage his/her medication
5. Participant is frequently (at least once a week) using a PHR to manage in full or partially his /her medication
6. Participant is able to communicate freely

### Participant type(s)
Patient

### Healthy volunteers allowed
No

### Age group
Adult

### Lower age limit
18 years

### Sex
All

### Total final enrolment
42

### Key exclusion criteria
1. Participants that are pregnant or terminally ill or considered vulnerable adults and cancer patients
2. Adults with medically serious problems that are not classified as long term conditions
3. Patients require assistance with taking their medication
4. Patients unable to communicate or unable to self-manage their medication.
5. Inpatients or patients living in care homes

### Date of first enrolment
01/11/2018

### Date of final enrolment
01/09/2019

## Locations

### Countries of recruitment
United Kingdom

England

**Study participating centre**
**University of Portsmouth**
United Kingdom
PO1 2UP

# Sponsor information

**Organisation**
University of Portsmouth

**ROR**
https://ror.org/03ykbk197

# Funder(s)

**Funder type**
University/education

**Funder Name**
University of Portsmouth

**Alternative Name(s)**

**Funding Body Type**
Private sector organisation

**Funding Body Subtype**
Universities (academic only)

**Location**
United Kingdom

# Results and Publications

**Individual participant data (IPD) sharing plan**
The datasets generated during and/or analysed during the current study will be stored in a non-publically available repository.

**IPD sharing plan summary**
Stored in repository

**Study outputs**

| Output type | Details | Date created | Date added | Peer reviewed? | Patient-facing? |
|---|---|---|---|---|---|
| HRA research summary | | | 26/07/2023 | No | No |
| Participant information sheet | Participant information sheet | 11/11/2025 | 11/11/2025 | No | Yes |
| Study website | Study website | 11/11/2025 | 11/11/2025 | No | Yes |