

Express check-in: developing a personal health record for patients admitted to hospital with medical emergencies: a mixed-method feasibility study

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European Pressure Ulcer Advisory Panel Review

DOI:
[10.1093/intqhc/mzab121](https://doi.org/10.1093/intqhc/mzab121)

Published: 01/01/2021

Peer reviewed version

[Cyswllt i'r cyhoeddiad / Link to publication](#)

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):
Subbe, C. P., Tomos, H., Jones, G. M., & Barach, P. (2021). Express check-in: developing a personal health record for patients admitted to hospital with medical emergencies: a mixed-method feasibility study. *European Pressure Ulcer Advisory Panel Review*, 33(3).
<https://doi.org/10.1093/intqhc/mzab121>

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Abstract

Background

Patient participation is increasingly recognized as a key component in the redesign of health care processes and is advocated as a means to improve patient safety. We explored the usage of participatory engagement in patient-created and co-designed medical records for emergency admission to hospital.

Methods

Design: Prospective iterative development and feasibility testing of personal health records.

Setting : An Acute Medical Unit in a University affiliated hospital.

Participants: Patients admitted to hospital for medical emergencies.

Interventions: We used a design-led development of personal health record prototypes and feasibility testing of records completed by patients during the process of emergency admission. 'Express-check-in' records contained items of social history, screening questions for sepsis and acute kidney injury, in addition to the patients' ideas, concerns and expectations.

Main outcomes measures: The outcome metrics focused on feasibility and a selection of quality-domains: Effectiveness of recording relevant history, time-efficiency of documentation process, patient centredness of resulting records, staff and patient feedback.

The incidence of sepsis and acute kidney injury were used as surrogate measures for assessing the safety impact.

Results

The medical record prototypes were developed in an iterative fashion and tested with 100 patients in which 39 patients were 70 or older, and 25 patients were classified as clinically frail. 96% of the data items were completed by patients with no or minimal help from healthcare professionals. The completeness of these patient records was superior to that of the corresponding medical records in that they contained deeply held beliefs and fears, whereas concerns and expectations recorded by patients were only mirrored in a small proportion of the formal clinical records. The sepsis self-screening tool identified 68% of patients requiring treatment with antibiotics. The intervention was feasible independent of the level of formal education and effective in frail and elderly patients with support from family and staff. The prototyped records were well received and felt to be practical by patients and staff. The staff indicated that reading the patients' documentation led to significant changes in their clinical management.

Conclusions

Medical record accessibility to patients during hospital care contributes to the co-management of personal health care and might add critical information over and above the records compiled by healthcare professionals.

Keywords

Emergency admission, personal health record, co-production, patient-centred

INTRODUCTION

Policy makers have expressed the belief that health care needs to shift from a model where the patient is seen as a passive spectator in his or her own healing process, to a participatory model in which Personal Health Records (PHRs) could empower patients while making health care professionals more aware of the underlying patients safety risks(1).

The admission process to hospital is a key, anxiety provoking moment in the patient's journey and a focus of intense training for medical and nursing trainees. Documentation is exclusively done by healthcare staff and comes at a measurable expense of working time(2).

PHRs promote meaningful engagement and might improve key aspects of care (3). PHRs have been used in primary care and long-term disease management but evidence for hospital usage remains limited and knowledge about the safety impact of PHRs is largely confined to medication safety(4). Previous work by our group demonstrated that patients are able to participate in their own safety management in acute care settings even while admitted for emergency treatment in hospital(5).

We report the results from the Express-Check-in patient engagement project aimed at developing and testing novel documentation formats to support patient contribution to their own health records during emergency hospital admissions. In particular we aimed to

1. determine the feasibility of patients contributing to their health records in this setting.
2. measure patient satisfaction, and
3. record the healthcare worker's impressions on the value of patient contributions to the work of health care workers.

METHODS

Study Design and Settings

We conducted a prospective mixed-method study in the Acute Medical Unit (AMU) of a university-affiliated District General Hospital in Wales, UK. AMUs receive patients with medical emergencies who are referred to hospital either directly from General Practitioners or after self-presentation to the Emergency Department to establish an underlying condition, initiate treatment where required and monitor patient progress. Severity of illness of attending patients is variable with 5 to 10% suffering from a potentially life-threatening condition (6,7). The study AMU consisted of an assessment area with 5 trolleys, an ambulatory care area with 3 trolleys and a bedded area with 23 beds.

Participants

Inclusion criteria: Adult patients aged 18 years or older referred to the AMU for assessment due to a medical emergency from General Practice. Patients who were critically ill as indicated by a value of the National Early Warning Score (NEWS) of more than 6 and patients receiving end-of-life care were excluded.

Development of the intervention

Prototype Development

The Personal Health Record prototype was developed and tested through an iterative design process involving ethnographic observations and a series of workshops over a 12-months period (Figure 1).

- a. *A residential two-day workshop* was held at the Pontio Innovation Lab(8) at Bangor University in 2018. The workshop was facilitated by a team trained in improvement science and human-centred design. The workshop included equal participation from clinicians and patient representatives. The workshop identified transfer of information

between patients and clinicians as a uniquely problematic design challenge and suggested potential interventions including a personal health ‘passport’ containing safety-critical information. The proceedings from the workshop have been submitted for publication elsewhere (under review and available upon request).

- b. *Ethnographic observations* (9,10) were conducted over a five day period in March 2019 and focused on patients’ experiences in the AMU. Four researchers (MD, BE, BJ, BS) used predominantly a ‘fly-on-the-wall’ technique⁽¹¹⁾ by passively observing patients and staff. Direct observation discerned that communication between patients and clinical teams tended to commonly be a one-way process (“talking at the patient”) or task-based (“your test is at 10:00”). In the presence of medical staff very few patients were seen to ask questions or talk about things that worried them. The observers noted that patients spent extensive time waiting and preparing to be seen by their medical team and that this period of time constituted a potential opportunity for patients to actively contribute to their care by documenting their concerns and questions. Confirmative interviews were conducted with patients, doctors and nurses. The observations and reflections were collated daily in a semi-structured debriefing with one of the authors (CPS).
- c. *Development of prototype*: This information was utilised during rapid-design workshops, facilitated by faculty trained in human-centred design (HT) to ideate and develop concepts.
- d. Concepts were prototyped by the team and subsequently iterated and pilot tested on a group of patients.
- e. The improved proto-type was used for the feasibility testing.
- f. The final iteration of the Personal Health Record was implemented into clinical practice (Appendix 1).

The Intervention

The study intervention was informed by recommendations about data fields of UK clinical records from the Royal College of Physicians Health informatics Unit(12). The product was cross-referenced with data items collected from existing clinical documentation and good practice for consultation including with questions about the patient's condition, social history, ideas about the nature of their admission, concerns about their health and hospital stay and expectations(13). The social history was identified as an area of high importance for care planning(14).

Items related to sepsis and acute kidney injury were included as surrogates for potential safety impact: The sepsis screening questions were developed in a previous study(15) as indicative of sepsis: *'Do you think you have an infection?'* and *'In the past week, have you experienced any fever, chills or abnormal sweating?'* A coloured and numbered chart based on the NHS Wales KidneySafeBracelet (5) (Figure 2) was used to identify potential acute kidney injury: numbers 1 to 3 correspond to more dilute urine and numbers 4 to 6 represent more concentrated urine. The number 7 is red, indicating haematuria. Data items readily available from other sources were excluded (previous medical history from primary care record, medication history from electronic record, vital signs from care records).

Feasibility testing of the intervention

A convenience sample of patients presenting to the AMU during office hours was recruited. The patient participants were screened after an initial assessment by a triaging nurse. The patients were given information sheets about the study and all study subjects gave written consent. The patients filled out their study records, and these were filed with their clinical records. The patient participants were followed up in the hospital on the day after

recruitment for interventions related to sepsis (antibiotic prescription) and acute kidney injury (intravenous fluid prescription).

Study of the Intervention

We conducted iterative testing of the intervention during two, four-week periods in March/April and May/June 2019. The results of the intervention were compared to the documentation in clinical records by healthcare professionals. No formal sample size calculation or assessment of bias were undertaken.

Measurement

The intervention was assessed using validated metrics of quality(16) including effectiveness, efficiency, patient satisfaction and staff satisfaction, and defined as follows:

- i. **Effectiveness of the intervention:** *'Are patients able to complete the records?'* For the purpose of the study, the patients were assessed at time of their presentation. Relatives, friends, formal or informal carers with the patient were permitted to assist patients in completing their medical records. Additionally the response to patient reported indicators of sepsis and acute kidney injury was reviewed.
- ii. **Efficiency:** The duration of time required to complete the record was measured in a convenience sample of the patients recruited.
- iii. **Patient-centredness:** Patient documented their ideas, concerns and expectations in relation to the care episode. Clinical records by medical staff including the documentation of the admitting doctor and the first encounter with the admitting consultant were screened manually for any evidence that ideas, concerns and expectations of patients were referenced and addressed during the subsequent clinical encounters.
- iv. **Patient satisfaction:** The feedback from patients was collected within 24 hours of completion of the record using five tailored statements related to the experience of

completing records, a comparison to past experience of the admission process and views on future preferences. The replies were graded with 5-point Likert scales ranging from 'strongly agree' to 'strongly disagree.' (Appendix 2)

- v. **Staff satisfaction:** Feedback from staff was collected through a bespoke survey on the acceptability and usability of the patient record (Appendix 3). The staff were interviewed within 24 hours of completion of the record and asked to rate the unique value of the patient documentation on a scale from 1 to 10 and to confirm their awareness of patient concerns. The staff feedback forms were linked to specific patient participant numbers in order to assess potential association with patient characteristics.

Data Analysis

Qualitative and quantitative data were collected and analysed. The differences between groups were assessed using independent T-testing for normally distributed variables and Mann-Whitney U tests were used for non-normally distributed variables. Chi-square or Fisher's exact test were used for the categorical variables. Analyses were performed using SPSS software (SPSS version 22.0, IBM, Armonk, NY, USA). P-values of less than 0.05 were as regarded as significant.

Sub-group analysis were performed in order to understand the variation within the data: The patient-participants were characterized by age, gender, level of formal educational, frailty using the Clinical Frailty Scale(17), severity of acute illness using the National Early Warning Score (NEWS) (18) and whether they presented alone in order to understand the contextual elements that might contribute to the success, failure and cost of their care.

The Completeness of data was calculated as a percentage of data entry fields completed by patient participants. The accuracy of data was evaluated through a close comparison with nursing and medical records.

The qualitative data was used to inform our deeper understanding about patient and staff communication, acceptance of the intervention, and any feedback about the medical record design and effectiveness but was not formally analysed.

Ethical considerations

The ethics approval was granted for this study by the Research Ethics Committee, Bangor [18/WA/0110]. None of the authors reported conflicts of interest in relation to the study.

The reporting followed the revised Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0)(19).

RESULTS

Recruitment

A total of 162 patients were screened and 100 patients were included for further analysis during two two-week periods in 2019. Of the patients screened 27 were excluded based on criteria stated above, and 30 declined due to feeling unwell, tiredness, concern of not understanding the questions, inability to write due to hand pain, inability to see the questions due to poor eyesight or lack of interest; 5 patients were lost to follow-up.

Participants

The characteristics of the patient population are summarized (Table 1). Thirty-nine patients were 70 years old or older, 25 patients were classified as frail and 33 patients needed assistance from a partner or family member to complete the questionnaire. Of the 25 patients who were classified as frail, 18 had limited formal education ($p < 0.000$), 10 required help with a walking aid ($p < 0.000$) and 20 (80%) received help completing the questionnaire.

Measures of Quality

i. Effectiveness

The completeness of record documentation for social history and warning signs for acute kidney injury and sepsis were assessed.

Social history: The rate of completion for data items of the social history by patients was 96% (SD 6%) and all but 5 patients completed more than 90%. Completion rate was not affected by the level of frailty, severity of illness or educational status (Chi-Square test n.s.). The rate of completion by admitting doctors was 59% (SD 23%) and was much lower than patient record completions (Wilcoxon Signed Ranks-test ($p < 0.000$)).

Screening for sepsis and Acute Kidney Injury: 96 patients completed the sepsis self-screen questionnaire. 31 patients received antibiotics. Each affirmative answer to the two screening questions was scored with one point: A high proportion of patients who subsequently received antibiotics scored two points on the self-screen i.e. 21 of 25 (84%) who scored two, 7 of 22 (32%) who scored one and 2 of 49 (4%) who scored zero points (Chi-Square test $p < 0.000$). A score of two points identified 68% of patients requiring treatment with antibiotic. No differences were noted in the number of patients receiving intravenous fluids. Ninety-four patients completed the Acute Kidney Injury self-screening question: The 28 patients with concentrated urine (4 or above on a scale from 0 to 9) were more likely to receive intravenous fluid (12 patients, $p < 0.005$) but not more likely to be diagnosed with Acute Kidney Injury (4 patients, $p = .83$) than those patients with more dilute urine.

ii. Efficiency

The time required to complete the records was measured in a sample of 53 patients. The completion took a mean of 7 minutes (standard deviation 3.5 minutes). There was no differences in the times taken between patients who were frail and those who were not frail

($p=.92$) and between patients who received help and those who completed the questionnaire on their own ($p=.48$).

iii. Patient centredness

Seventy-five patients documented ideas about their health condition, 72 recorded concerns and 85 specified expectations they wanted met (Table 2: sample quotations). Of ideas expressed by patients, 65% matched those documented by doctors as part of their differential-diagnosis. In only 12 of the 75 patients, were the documented patient concerns explicitly addressed subsequently in the medical or nursing records.

iv. Patient Satisfaction

A total of 41 feedback-cards were collected from patients, 14 of these patients were frail. To the question '*I enjoyed writing in my hospital notes*' 38 (93%) agreed or strongly agreed. 28 patients (68%) agreed or strongly agreed that they would like to contribute more to their hospital documentation. When asked to compare their experience to their experience of a previous hospitalization, where applicable, 23 patients (64%) preferred to contribute to their documents. Preferences were unrelated to degree of frailty ($p=.217$; Chi-square test).

Patients commented on the level of effort required to complete the record: "*That was easy enough*", "*It gives me something to do whilst I wait*". Patients appreciated the opportunity to document their views but were worried about adverse consequences of omitting important features:

"If I'm being honest, I like the idea, and thank you for inviting us to help, but I get forgetful. I'm scared that I'll forget to write important medical information. I don't know what's important to write down and what's not".

v. Staff Satisfaction

Twenty-four staff feedback forms were collected: 10 from nurses, 10 from doctors, three from senior medical students and one by another member of the clinical team. Eleven cards (46%) related to frail patients: Twenty staff (83%) rated the value of patient documentation for their work 6 or higher on the 10-point rating scale. The rating was unrelated to professional group. Staff were only partially aware or totally unaware of concerns of 9/11 (82%) frail patients and 3/13 (23%) of non-frail patients. The staff indicated that reading the patient's documentation led to a significant change in their clinical management (8 patients) or partial change in patient management (10 patients). Medical staff commented that "*this makes patients more engaged*". Another doctor stated that "*I would be more likely to look in this rather than the nursing notes, because I can never find anything in the nursing notes!*".

DISCUSSION

Statement of principal findings

We demonstrated that records can be competently completed by a significant proportion of patients even in emergency settings, including frail patients when supported by carers assisting them, and that these add significant value to clinical decision making as assessed by physicians and nurses. Completion rates for the social history were higher for patients than for clinicians. The use of patient generated medical records was related to several dimensions of quality: it was time-efficient for patients and patients and staff widely praised the study records acceptability.

Strength and limitations

Our study has significant limitations: First, the present study has the inherent challenges of being conducted in a single centre. From the experience of the authors of working in over 30 hospitals on four continents it would appear that the processes that we

observed might still be representative of the ways that patients are assessed on admission to hospital in many settings both in the United Kingdom and further afield. Our iterative approach could hence be applied in comparable settings. Second, patients with serious physiological instability and those receiving end of -life-care were excluded because of concerns about the validity of the consent process in this patient population. It is possible that a proportion of these excluded patients and/or their carers might have been able to contribute to their care. Third, it is perceivable that paper documentation might have been more suitable for our comparatively elderly patient cohort who might have struggled with digital technology(20). Integration of patient generated records into an existing documentation system or indeed an electronic health record was not tested in this study but was in a subsequent study(21). Finally, we did not formally assess the cost of implementing our intervention.

Interpretation within the context of the wider literature

The discrepancy between ideas, concerns and expectations voiced by patients and the lack of their documentation in clinical records is concerning. While a patient-centric approach is advocated in training guidelines and by policy makers, it is not consistent with the way healthcare systems including medical documentation systems are set up. Key patient social information, which can impact patient's needs, is all too often as documented in our study, unidentified, undocumented and overlooked by clinicians (22,23).

Several studies have compared the completeness of the history obtained by patient-completed documentation as compared with healthcare professional entries into medical notes in primary care(24), orthopaedic surgery outpatients(25), emergency medicine(26) and surgical emergency admissions presenting with a single symptom (abdominal pain)(27). Hershey(24) and Boissonnault(25) found that less complex and closed questions improved completion rates and accuracy of patient-completed documents. Renggli(26) and

Saravanan(27) reported, similar findings to our study, in which patients completed their relevant items at a much higher rate of completion than that completed by their healthcare professionals.

Implications for policy, practice and research

The cost of documentation in clinical care is determined by the cost of the recording system(28) and the time for data entry and retrieval as well as changes to work-efficiency by having access to the right information in the right place at the right time(29). Documentation consumes a quarter of the working time of nurses and doctors (2) and constitutes up to 40% of working time required for the admission of new patients(2,30): Implementing self-documentation by patients represents a major opportunity for redesign of clinical workflows and could serve the dual purpose of reducing workload of health care staff, whilst promoting better patient engagement and safety. The establishment of Express-check-in and Express-check-out facilities in hotels and airports served as inspiration for this project and is reflected in its name. We appreciate that the effects of transferring tasks from staff to patients might affect their relationship and work satisfaction of staff and this requires further research.

Conclusions

Personal Health Records are increasingly used in primary care and chronic disease programs. A comparable approach appears achievable and inevitable for documentation during emergency hospital admission. We demonstrated the feasibility, efficiency and efficacy of a patient-delivered record and its potential to contribute to patient-centred hospital documentation. The evidence for impact on clinical outcomes will require larger studies. We demonstrated improved completeness of records even in patients who were frail, elderly, or had limited formal education.

Further investigation is required to measure the impact of the approach on safety outcomes and formal measures of work-flow and health economics as part of an integrated health record systems study.

Contributorship

CPS and PB conceived the concept for this study. HT, GJ, MD, BE, BJ and BS developed the intervention around principles of human centred design, GJ, MD, BE, BJ and BS collected the data and undertook the primary analysis. CPS and PB wrote the initial manuscript and undertook further analysis. All authors contributed to further versions of the manuscript and approved the final version.

Ethics and other permissions

The ethics approval was granted for this study by the Research Ethics Committee, Bangor [18/WA/0110].

Funding

Funding was provided through an Improvement Science Fellowship for the corresponding author and by Cardiff University through students contributing to the study as part of their Student Selected Component. The funding organizations did not participate in the design, implementation, interpretation, and reporting of the study.

Conflict of interests

None of the authors reports any conflict of interest in relation to this manuscript.

Acknowledgments

The authors are indebted to Mari Davies, Buddug Eckley, Bethan Johnson and Bethan Stacey from Cardiff University for their contribution as researchers on this project.

Data availability statement

The data underlying this article cannot be shared publicly due to reasons of the privacy of individuals that participated in the study. The data will be shared on reasonable request to the corresponding author.

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Table 1: Characteristics of Patient Participants (n=100)

Category	Median / N
Age (years)	Median age 60 years (IQR 40-70)
Gender	53 female, 47 male
Frailty as measured by the Clinical Frailty Scale (CFS)	Median CFS 3 ('managing well') (IQR 2-5)
Use of a walking aid or help required with walking	16 patients
Educational status	
General Certificate of Secondary Education or equivalent	41 patients
A-levels or equivalent	55 patients
No educational qualification	4 patients
National Early Warning Score on admission	Median score 1 (IQR 0-2)

IQR: Interquartile range

Table 2: Quotes from the Patient Recorded Documentation

I. Do have any ideas about what’s causing your current symptoms? If so, what are they?
<i>“Bleed in gut. Black stools.” (Medical diagnosis: Upper gastro-intestinal bleed)</i>
<i>“Self-inflicted stupidity - drugs.” (Medical diagnosis: Groin abscess after drug injection)</i>
<i>“Fluid on the lung or chest infection.” (Medical diagnosis: Community acquired pneumonia with pleural effusion)</i>
II. What are your worries or fears currently (if any)?
<i>“To end my life in peace without too much pain.”</i>
<i>“That I’ll be in a wheelchair forever.”</i>
<i>“Taking blood or anything needle-related.”</i>
<i>“I’ve been suffering with panic attacks since the number of infections I get is increasing”.</i>
III. Is there anything specifically you were expecting or hoping the hospital staff could do for you during this visit?
<i>“To get mobile again and enjoy life to the full.”</i>
<i>“Allocated to a more permanent ward, not moved around.”</i>
<i>“Reassurance and help with pain.”</i>

Figure 1: A conceptual framework/flow chart provides a visual representation of the iterative development process of the personal health record prototype for usage by patients admitted with medical emergencies. The prototypes were developed during an innovation lab (a) in 2018. Ethnographic observations in March 2019 led to modifications of the prototype with further changes during subsequent Plan-Do-Study-Act (PDSA) cycles, a four-stage rapid cycle improvement model used for improving a process or carrying out change in March/April 2019. Clinical testing (e) was undertaken in April, May and June 2019.

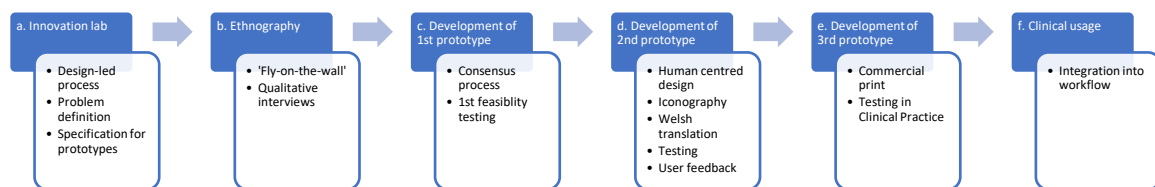
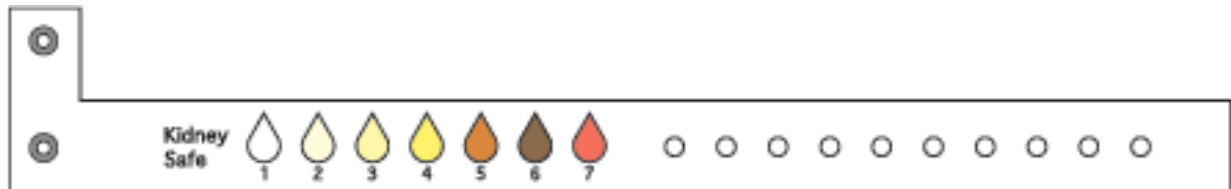


Figure 2





KidneySafeBracelet: patients are requested to inform their clinical team of the colour of their urine as compared to the colours on the bracelet. Bracelets are single patient-use only .



Supplementary material

APPENDIX 1

Sample pages from the EXPRESS-Check-in document. The original is A4 sized. The document was developed in iterative cycles. The sample is from the final version and shows the lay-out and key topics. The use of icons structured the content, and a large font was chosen to help visually impaired patients.

<h3> Your thoughts</h3> <p>Your ideas about your health are important to us and we want to hear your thoughts. The following questions can help your medical team understand what is important to you.</p> <p>Do you have any ideas about what's causing your current symptoms? If so, what are they?</p> <p><input type="text"/> <input type="text"/> <input type="text"/></p> <p>What are your worries or fears currently (if any)?</p> <p><input type="text"/> <input type="text"/> <input type="text"/></p> <p>Is there anything specifically you were expecting or hoping the hospital staff could do for you during this visit?</p> <p><input type="text"/> <input type="text"/> <input type="text"/></p>	<h3>Infection </h3> <p>The following questions can help us to identify a serious infection or sepsis and treat it sooner.</p> <p>Do you think you have an infection?</p> <p><input type="radio"/> <input type="radio"/></p> <p>In the past week, have you experienced any fever, chills or abnormal sweating?</p> <p><input type="radio"/> <input type="radio"/></p> <hr/> <h3>Your kidneys </h3> <p>The colour of your urine can help us to identify any issues with your kidneys and, if necessary, get you treatment quickly.</p> <p>Please tick the option that best corresponds to the colour of your urine today:</p> <p><input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> 
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Your home

The following questions help us to better understand your needs.

Where do you currently live?

- House Supported living
- Bungalow Nursing / care home
- Flat / apartment

Who do you currently live with?

- Spouse / partner Alone
- Family Other



Activities

Which of these activities can you normally do without help?

- Washing Cooking
- Using the toilet Shopping
- Dressing

Family, friends and carers



Do you have any carers come to your home?



If yes, please specify e.g. how many times a day?

Do you rely on your friends or family for help?



If yes, what do they help with?

Thank you for filling in this form.
Please show this to your doctor when they see you next.

APPENDIX 2

Patient feedback questionnaire. The questionnaire was handed to a sample of patients subsequently to completing their records

V1.1 09-Jun-19

We would be grateful if you could answer the following questions about writing in your own notes

1) Overall, I enjoyed writing in my own notes

Strongly Agree Agree Unsure Disagree Strongly Disagree

2) The questions were easy to follow

Strongly Agree Agree Unsure Disagree Strongly Disagree

3) Answering the questions did not take up too much of my time

Strongly Agree Agree Unsure Disagree Strongly Disagree

4) I would like to contribute more to my hospital notes in the future

Strongly Agree Agree Unsure Disagree Strongly Disagree

5) If you have been to hospital before, how would you compare this time (being able to write in your hospital notes) to the last time when the staff wrote all the notes?

N/A


Much better Better Unsure Worse Much Worse

We're listening..



APPENDIX 3

Staff feedback survey. The survey was disseminated to staff including doctors and nurses after admission of a patient who had completed a personal health record.

Do patient filled notes help you in your work? 

Please tick the appropriate box -
I am a : Doctor Nurse Student Other

Please rate the value of self-documentation by patients to your dally work.

1- not valuable at all 10 - very valuable

1 2 3 4 5 6 7 8 9 10

Were you aware of the patient's concerns before reading the notes they made?

Yes No Partly

Did having notes written by the patient change the way you managed the patient?

Yes No Partly

Notes :