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Evaluation of My Medication Passport: a patient-completed aide memoire designed by patients, for patients, to help towards medicines optimisation.

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Evaluation of My Medication Passport: a patient-completed *aide memoire* designed by patients, for patients, to help towards medicines optimisation.

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Susan Barber led the evaluation, developed the protocol, supervised data collation from all sources, the analysis and writing of the original report.

2. Kandarp Thakkar, Deputy Chief Pharmacist Clinical Services, Royal National Orthopaedic Hospital NHS Trust.

Kandarp Thakkar led the original project that resulted in the patient development of the My Medication Passport and the App, its promotion and spread, assisted with data evaluation and writing of the manuscript.

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Participated in the collation and evaluation of the data, promotion of the My Medication Passport, prepared and edited the manuscript for submission.

4. Derek Bell, Professor of Acute Medicine, Chelsea and Westminster Hospital NHS Foundation Trust

Derek Bell as Director for NIHR CLAHRC for NW London directs the programme of work including development of the My Medication Passport, promotion and spread through partner organisations. Contributed to the evaluation and editing of the manuscript for publication.

Acknowledgements

Bryony Dean Franklin contributed to the development of the protocol, supervised data collection at Imperial College Healthcare NHS Trust and assisted with analysis and writing of the evaluation report.

Sara Garfield, Shirley Kuo conducted interviews and assisted in the writing of the evaluation report.

Sabrina Amer, Saadi Jamil, Seetal Jheeta conducted patient interviews.

Sylvia Chalkley of Chalkley Survey Design & Statistical Analysis Ltd. Structured the Survey questionnaire.

Other members of the ImPE Supergroup were key to the development, promotion and spread of the My Medication Passport and co-ordinating the evaluation: Stella Barnes, Iñaki Bovill, Louise Collins, Edward Dickinson, Beverly Hall, Fran Husson, Ann Jacklin, Nick Jones, Colin Mitchell, Sue Newton, Sam Oliver, Ganesh Sathyamoorthy, John Soong, Margaret Turley and Tom Woodcock.

Sponsorship

The sponsor of the study was the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) for North West London, which is hosted by Chelsea and Westminster Hospital NHS Foundation Trust, in partnership with Imperial College London.

Funding NIHR CLAHRC for North West London funded the evaluation. The passport has been produced with support from AstraZeneca under a joint working agreement.

Data Protection The project was conducted according to the principles of the Data Protection Act, 1984, 1998. No patient identifiable data is held in the evaluation database nor will this information be released outside the NHS.

Ethics The protocol for the study was sent to the London Harrow Research Ethics Committee for their guidance who classified it as a service evaluation. Ethics approval was therefore not necessary.

Consent Information about the purpose of MMP and the aims of the evaluation was given to patients, along with consent forms which were completed prior to surveys being conducted.

Key words: Medication aid, concordance, adherence, medicines optimisation, passport, patient engagement.

Competing interests: None

Extra data is available by emailing: susan.barber@thh.nhs.uk

ABSTRACT

Background: A passport-sized booklet designed by patients for patients to record details about their medicines, has been introduced to North West London Hospitals as part of a group of wider improvement projects focussing on medicines optimisation in older people (‘ImPE’). After finalising the style and content of the booklet we undertook an evaluation of ‘My Medication Passport’.

Methods: We recruited patients from a cohort who had been given a passport as part of the medicines management improvement projects at one of four sites. A structured telephone questionnaire was conducted and responses collated.

Results: Over 200 patients were recruited and 66% (131 patients) completed the questionnaire. More than half of respondents had found their medication passport useful and/or helpful in managing their medicines; 42% through sharing details from it with others (most frequently family, carer or doctor) or using it as a platform for conversations with health professionals. One third of those questioned carried the passport with them at all times. We found that for 27%, English was not their first language and 10% were partially sighted or blind, presenting challenges for further improvement and patient engagement.

Conclusions: My Medication Passport has been positively evaluated; we have a better understanding of how patients use them, what medication details are being recorded and how they can be an aid to dialogue about medicines with family, carers and health care professionals.

Article Summary

Strengths and limitations of this study

- Patients’ own opinions were sought following their 4-6 week period of use of a personally issued My Medication Passport
- Patients valued MMP as an aid to communicating about medicines in their own way writing in it what they choose
- As a self-completed list of medications and notes, it complements any other documentation about medicines produced by health care professionals whether from GP (e.g. repeats slip), hospital (e.g. discharge summary or dose reminder chart)
- We were only able to recruit patients who were well enough to be contacted by telephone during a specific period of time. This selection process may be biased in favour of patients who are better able to manage their medicines with or without a MMP

- We did not look at what was written in the MMPs to check for accuracy of content or legibility. This may be the focus of a further study

BACKGROUND

My Medication Passport (MMP) is a pocket-sized booklet designed for patients' personal use, to record details of their current medication and related information and thereby keep track of their past and current medicines use. It is hoped that the use of MMP might improve communications about medications across organisational boundaries and support patients in managing conversations about their medicines when they are talking to health care professionals (HCP) and to carers, friends and family. It was developed originally as part of a collaborative project in North West London,[1] to improve prescribing and medicines management in the elderly (ImPE) and has spread to other age groups and geographical areas.

It is recognised that communication about medicines needs to improve between medical professionals from different disciplines, and between professionals and patients/carers. There is evidence that gaps in communication and incomplete documentation, particularly concerning the elderly and medicines at discharge from hospital, contribute to re-admissions.[2] Closing this gap is likely to result in health benefits, including a reduction in adverse drug events.[3]

It is estimated that among patients with long-term conditions, as many as 30-50% do not take their medicines as intended[4] and intervention to improve adherence may have a greater impact on the health of the population than improvements in specific medical treatments.[5] Part of the solution is to encourage self-management of health problems with HCP providing, for example, compliance aids and portable records in support.[6,7]

The purpose of this study was to evaluate the use of MMP by a cohort of patients with the intention of gaining a better understanding of its value. In particular we wanted to find out if MMP helped to foster good communication between patients and HCPs; improved their confidence about what medicines they take in order to help in adhering to medication regimens.

METHODS

Research setting and sample

The study involved four sites:

- Hillingdon Hospitals NHS Foundation Trust;
- Imperial College Healthcare NHS Trust;
- Chelsea and Westminster Hospital NHS Foundation Trust
- Marylebone Health Care Centre

To elicit a map of MMP use, a short structured telephone survey was carried out. The purpose was to find out if patients had used their passport and if they had shared it with a HCP, family member or friend.

To elicit a better understanding of how useful the passport had been and to gain insights into the strengths, weaknesses and any perceived obstacles to the use of MMP, each study site was asked to conduct 10 longer surveys. Information about the purpose of MMP and the aims of the evaluation was given to patients, along with consent forms which were completed prior to surveys being conducted.

Data collection procedures

Patients who were contacted to complete the short telephone survey were systematically sampled from a database of those who had given their consent until at least 30 short and 10 longer telephone surveys had been completed from each of the four settings. Patients were contacted up to 3 times each to elicit a survey. The intention was to reach the target number of patients and conduct surveys within a defined timescale of 4-6 weeks from first issue.

Data elements collected

The survey questionnaire forms were designed, generated, scanned and verified using TELE*form*©. TELE*form*© is a software package comprising four separate programmes that combine to create forms that can be printed out with automatic individual serial identity numbering, scanned after data entry, all data identified and validated, then exported to one or more selected databases ready for reporting and/or statistical analysis. When a form is designed using TELE*form*©, the questions are designated as 'choice fields', 'constrained print fields' or 'image zones'. In the image zones, the software is able to identify hand-written text. After the completed Survey questionnaires were scanned, the verification of the data using the TELE*form*© software provided double data entry. The data were exported simultaneously to populate databases generated in SPSSv20© and Excel.

Data quality and analysis

The content of the survey questionnaires was based on consultations previously carried out with a sample of stakeholders (including patients, carers, and hospital staff).

The survey questionnaires were designed to answer the overarching evaluation questions about patients' use of their personal MMP in communications and adherence. Each study site collected the same data, and used the same methods, and data collected by staff in each study setting were forwarded to the Evaluation Lead and specialist survey designer for analysis.

RESULTS

In total, 202 patients were recruited to the study and 133 completed one or both surveys (66% response rate). Ninety participants (majority male) completed the short survey only and 43 also completed the longer survey (13 men, 29 women and one participant for whom gender was not recorded). The majority of patients were in the 71-80 year old age group. Demographic data are summarised in Figure 1. The majority of patients answered "No" to questions identifying any additional needs in relation to communication. However, 10% were partially sighted or blind; 19.5% had some degree of difficulty hearing, and English was not their first language for 27% of respondents (see Table 1).

Table 1: Characteristics of Patients Participating in the Survey

	Yes		No		Not Stated	
	N	%	N	%	N	%
Hard of hearing or deaf	26	*19*	94	*71*	13	*10*
Partially sighted/blind	13	*10*	104	*78*	16	*12*
Require an interpreter	2	*1*	113	*85*	18	*13*
Any learning difficulty	5	*4*	115	*86*	13	*10*
Require an advocate	5	*4*	114	*86*	14	*10*
English is first language	82	*62*	36	*27*	15	*11*

From the 36 patients for whom English was not their first language, three telephone surveys were carried out with an interpreter (in Cantonese, Punjabi and Bengali). In addition, the languages summarised in Table 2 were mentioned as the 'first' language of patients who also spoke English fluently.

Of those respondents who indicated that they were hard of hearing, visually impaired, had a learning difficulty, required an advocate or interpreter, only 12% recorded this information about themselves in their MMP.

Table 2: First Language of Fluent English Speakers

Language	**N**
Punjabi	4
Gujarati	4
Hindi/Urdu	2
Turkish	1
Arabic	1
French	2
Philippino	2
Swahili	2
Farsi	1

Gaelic	1
German	1
Italian	1
Spanish	1

How MMPs are used

Fifty-two percent of patients had used their passport in some way since receiving it and 58 of the 133 questioned (42%) had 'shared' it with someone, most frequently this was a family member, as shown in Table 3. Thirty-two had 'shared' their MMP with one or more health care professionals; most frequently cited were GP and a hospital doctor.

Some respondents commented that they thought the passport was for their use only and didn't feel the need to take it with them to HCP visits/appointments. However, of the 32 patients that did, 22 (69%) reported that it improved their confidence in talking to the HCP about their medicines. A further two were 'not sure'.

Thirty-three percent carried their MMP at all times and 37% responded 'sometimes'. When asked "Will you take your passport with you when you see your HCP in the future?" 81.4% said yes, they would.

Table 3: 'Sharing' of MMP

	Number	
	Yes	**No**
GP	24	47
Hospital Doctor	24	46
Other Hospital Staff	13	53
Pharmacist (community)	8	60
Community Nurse	7	59
Pharmacist (hospital)	3	63
Voluntary Sector Organisation	3	64
Dentist	2	65

Optician	2	64
Care Home	0	65
Mental Health Services	0	66
Family Member	57	18
Friend	17	48
Other	6	49

Patients responding to the longer survey were asked about medication changes (within 6 weeks of owning an MMP). Sixty seven percent of respondents reported that they recorded details in their MMP. Their recorded reason for the change, most commonly side-effects, are given in Table 4. None reported that a HCP wrote in their passport; they completed this themselves or a carer or family member helped.

Overall, the majority of patients indicated that they were pleased to have a passport in which they themselves or their carer document changes (76%). However, 14% would like a HCP to do this.

Table 4: Patients' Comments on Why Their Medicines Were Changed

Reason Given	Frequency
Side Effects	4
Legs swollen	3
Help heart rate	1
Prior to operation	1
New style inhaler	1
Prostate enlarged	1
Sodium levels too high	1
Heart palpitations	1
Medication not working, started chemotherapy	1
Shared decision, but not happy with change	1
Not sure	1
Total	16

Eighty-six percent of respondents reported 'yes' they would recommend MMP to friends or family', and one was 'not sure'.

Further positive comments given by patient (or carer where indicated) were:

"My GP thought that the passport is a really good idea and said that I should carry it with me and keep it up to date".

"They said it was a good idea. First one they've seen. Yes. It helped communication with them".

"Very easy. Was more accurate than GP record. Eased communication. Facilitated dialogue".

"It was very useful. I see so many different doctors now. One document [for medicnes] and all of them can see the same information".

(Carer) "Helpful – as it makes it easier for [patient] as she doesn't speak English. MMP makes it easier for family member too because they can just hand it over to the professional to see".

"It was fine [sharing MMP]. She [HCP] didn't really look at it as she said she had a list. Dermatologist didn't really look. However, my carer found it useful and it helps the communication between them and me with HCPs".

"Very helpful to be on top of new medicines, and view MMP prior to sharing with GP".

"[Spouse] became ill recently. MMP useful to remind myself [carer]. Helpful to talk to GP".

"Really useful to her [patient] and me as carer. Helps to have conversations about medicines and keep track of things. Will order another MMP for my mother in law. My sister and wife use this too (they are additional carers)".

Negative comments included:

One respondent had concerns over 'identity theft' and one about 'accuracy'. Another suggested that the MMP duplicates what the GP already does and a further two thought it was better to use the 'pharmacy' list. Comments included:

"No easy way of writing in the changes to give a clear view of the latest date/entry. I have 10 medicines. Maybe one changes for a week. Then changes back. It could get messy quite quickly".

"My medicines change so often. I'd be updating the passport too often. I prefer to use the slips/information from the pharmacy. They have a good system. It works well. I can see that MMP will work well for someone who does not have a good system already".

Suggestions for Improvements

Several suggestions for improvement to the MMP were elicited from respondents who had used, or attempted to use their MMP. These are listed in Table 5.

Table 5: Suggestions for Improvement of MMP

PATIENT'S COMMENTS	Number of respondents
NONE NEEDED	23
ADD LIST OF MEDICATION SIDE EFFECTS	20
RECORD ALLERGIES, INFECTIONS, HOSPITAL VISITS, RESULTS, IMMUNISATIONS, TRAVEL VACCINATIONS, PAST HISTORY, BLOOD TYPE, SCREENING, CONTACT IN EMERGENCY	8
BIT SMALLER FOR MEN TO PUT IN POCKET	5
MORE PAGES AT BACK , EITHER BLANK OR LABELLED: a. CURRENT MED, b. MED CHANGES	4
NEED BETTER COVER, MORE LIKE DIARY	3
NEED BIGGER PRINT, DIFFICULT TO READ	2
WOULD LIKE OWN LANGUAGE VERSION	1
SEPARATE LISTINGS OF SHORT AND LONG TERM MEDICATIONS	1
PREFER TYPE OF CREDIT CARD TO BE SCANNED BY DR OR AMBULANCE DRIVER	1
NO RESPONSE/DON'T KNOW	24

Twenty respondents suggested the need for a space to record medicine side effects. (Nb. This was provided as an example by the interviewer).

"Sometimes the Chemists have given me something that disagrees with me. I will use the passport to record that and tell the pharmacy".

Eight respondents suggested the addition of a space to record a variety of specific things: allergies, health conditions, hospital visits/appointments, medical test results, screening, vaccinations, past history of operations etc., and blood type.

Five patients suggested a smaller format (especially that men would like something to put in their pocket). Further comments included:

"… far too big for pocket. Needs to be much smaller. Would like an e-system but does not have an android phone. Liked the idea of an App."

"The book is written in English. If it was translated in Bengali then the patient could themselves understand and write something themselves. The book would be better if it was a smaller size".

DISCUSSION

'Passports' as tools enabling patients to better manage their medicines, have been used in targeted patient groups with reported evidence of success. For example in palliative care,[8] diabetes,[9] inflammatory bowel disease[6] and glucocorticoid replacement therapy.[7] Medication passports may be regarded as a support to self-management and a decision aid if used in communications with the doctor when considering a new therapy.[10]

Most respondents to our questionnaire reported positive results; they felt their MMP was useful, that it facilitated dialogue about medicines and that a patient held, patient-filled portable document was 'a good idea'.

Less than 20% of patients had discussed their passport with their GP; we had anticipated that more patients would have done so within the 4-6 week time period between being given MMP and participating in the survey. The majority reported the intention to do so at future consultations. However there appeared to be a strong feeling among respondents that this was not their perceived use for the passport; it was for their personal recording and though it might be used to facilitate discussions about medicines with doctors, it was more important as an *aide-memoire* for the user.

For those respondents who had shared their passport with someone else, family members ranked highest. Several mentioned how useful it was to both patients and carers. The majority affirmed that MMP is useful in aiding communication between themselves and HCPs. Carers too liked MMP and found that it provided them with a point of reference when the need arose to talk to either the patient, or the patient's HCP.

The majority of respondents saw MMP as helpful in managing their medicines despite some reservations from patients whose medicines change frequently. Side effects recording seems important to users. This finding is perhaps expected as patients phoning our medicines information helpline ask most frequently about side effects of medicines than any other category of query, [11] and patients' experience surveys consistently suggest not enough is given in plain language.[12]

Limitations

The use of MMP is not obligatory, or 'prescribed'. Its users are usually introduced to it by a clinician and they are chosen because they take multiple medicines. It is free of charge, but the choice of whether to use it or not is the recipient's. For these reasons, recruitment of patient participants in this evaluation should be understood to have been ‘self-selected’.

It is recognised that those less able to be recruited to this study might be the more vulnerable patients with a greater need for assistance with managing their medicines. They remain the more difficult to assess and the more in need of tools such as a passports and compliance aids in general.

MMP is being used by different cohorts of patients across the sites included in the study. Many people who take multiple medicines are elderly and/or have co-morbidities. It was recognised and acknowledged from the outset that the present study is ‘formative’ and it may be necessary to carry out a further, larger and/or more in-depth study to gain a deeper understanding of potential changes that may be needed to evaluate MMP use by different types of patient.

Recommendations and conclusion

Although based on small numbers, it would appear that availability of MMP in different languages or with bi-lingual text/headings would be an asset.

Space for recording of side effects in particular would be useful as well as more specific space for changes to medication (or perhaps continuation sheets). This should be followed by further evaluation of MMP in particular user groups; we suggest in frail patients: those with particular long-term conditions; and perhaps homeless patients or patients who move frequently (for example students and some new immigrants).

Further analysis of the number of men and women who had used their MMP or shared it with a HCP is suggested, to help us to understand the gender differences in response rate found in the evaluation.

This evaluation was not structured to find out *what* patients write in their MMP; it may be valuable to do this in a further study. Rather, we set out to gain an understanding of *how* what was written by the patient was used and this has, with limitations, been achieved.

NIHR CLAHRC for NW London has since rolled-out the MMP across London and the wider community through other hospitals, community pharmacies and GP surgeries and successfully launched an ‘App’ version, now available to download onto smart phones and devices. We have communicated through several media with over 45,000 copies distributed and over 2400 ‘app’ downloads to date.

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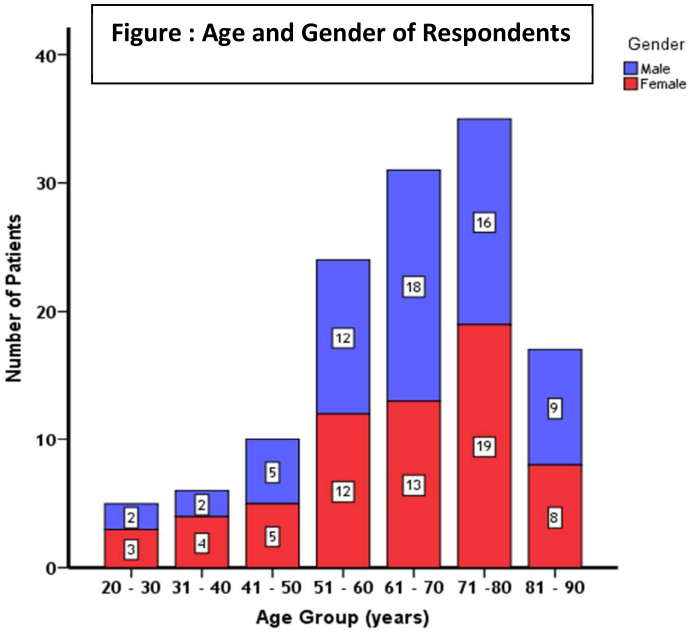
Figure : Age and Gender of Respondents

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding
		(*b*) Describe any methods used to examine subgroups and interactions
		(*c*) Explain how missing data were addressed
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses

Continued on next page

Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time
		Case-control study—Report numbers in each exposure category, or summary measures of exposure
		Cross-sectional study—Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses
Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Sara Garfield, Shirley Kuo, Sabrina Amer, Saadi Jamil, Seetal Jheeta, Sylvia Chalkley, Stella Barnes, Iñaki Bovill, Louise Collins, Edward Dickinson, Beverly Hall, Fran Husson, Ann Jacklin, Nick Jones, Colin Mitchell, Sue Newton, Sam Oliver, Karen Phekoo, Ganesh Sathyamoorthy, John Soong, Margaret Turley and Tom Woodcock.

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Consent Information about the purpose of My Medication Passport and the aims of the evaluation was given to patients, along with consent forms which were completed prior to surveys being conducted.

Key words: Medication aid, concordance, adherence, medicines optimisation, passport, patient engagement.

ABSTRACT

Objectives: A passport-sized booklet designed by patients for patients to record details about their medicines, has been developed as part of a wider project focussing on improving prescribing in the elderly (‘ImPE’). We undertook an evaluation of ‘My Medication Passport’ to gain an understanding of its value to patients and how it may be used in communications about medicines.

Setting: The Passport was launched in secondary care with the initial users being older people discharged home after an admission to one of the four North West London participating Trusts. The uptake subsequently spread to other (community) locations and other age groups.

Participants: We recruited more than 200 patients from a cohort who had been given a passport as part of the improvement projects at one of four sites. Sixty six percent (133) completed the structured telephone questionnaire including 27% for whom English was not their first language. Approximately half of respondents were male and 40% were over 70 years old.

Results: More than half of respondents had found their medication passport useful or helpful in some way; 42% through sharing details from it with others (most frequently family, carer or doctor) or using it as a platform for conversations with health care professionals. One third of those questioned carried the passport with them at all times.

Conclusions: My Medication Passport has been positively evaluated; we have a better understanding of how it is used by patients, what they are recording and how it can be an aid to dialogue about medicines with family, carers and health care professionals. Further development and spread is underway including an App for smartphones which will be subject to wider evaluation to include feedback from clinicians.

Article Summary

Strengths and limitations of this study

- Patients’ own opinions were sought following their 4-6 week period of use of a personally issued My Medication Passport
- Patients valued MMP as an aid to communicating about medicines in their own way writing in it what they choose
- As a self-completed list of medications and notes, it complements any other documentation about medicines produced by health care professionals whether from GP (e.g. repeats slip), hospital (e.g. discharge summary or dose reminder chart)

- We were only able to recruit patients who were well enough to be contacted by telephone during a specific period of time. This selection process may be biased in favour of patients who are better able to manage their medicines with or without a MMP
- We did not look at what was written in the MMPs to check for accuracy of content or legibility. This may be the focus of a further study

BACKGROUND

My Medication Passport (MMP) is a pocket-sized booklet designed for patients' personal use, to record details of their medication and related information and thereby keep track of their past and current medicines use. It is hoped that the use of MMP might improve communications about medications across organisational boundaries and support patients in managing conversations about their medicines when they are talking to health care professionals (HCP) and to carers, friends and family. It was developed originally as part of a collaborative project in North West London,[1] to improve prescribing and medicines management in the elderly (ImPE) and has spread to other age groups and geographical areas.

The MMP includes some general 'dos and don'ts' of medicines use and the following sections for completion by the patient:

- Allergies
- Medication aids (non-clic lock lids/large label fonts/blister packs/liquids/tablet cutter/other)
- Current medicines (including inhalers, eye/ear drops, patches, injections and alternative/herbal medicines) – date, name, dose, times and additional information
- Changes to my medicines (date, reason for change, by whom)
- Blank pages for notes (illnesses, vaccinations, screenings) and to record additional needs

It is recognised that communication about medicines needs to improve between medical professionals from different disciplines, and between professionals and patients/carers. There is evidence that gaps in communication and incomplete documentation, particularly concerning the elderly and medicines at discharge from hospital, contribute to re-admissions.[2] Closing this gap is likely to result in health benefits, including a reduction in adverse drug events.[3]

It is estimated that among patients with long-term conditions, as many as 30-50% do not take their medicines as intended[4] and intervention to improve adherence may have a greater impact on the health of the population than improvements in specific medical treatments.[5] Part of the solution is to encourage self-management of health problems with HCP providing, for example, compliance aids and portable records in support.[6,7]

The purpose of this study was to evaluate the use of MMP by a cohort of patients with the intention of gaining a better understanding of its value. In particular we wanted to find out if MMP helped to foster good communications between patients and HCPs; improved patients' confidence about what medicines they take and we also wanted to increase our understanding of whether or not changes to medicines are likely to be recorded in MMP and kept up to date.

METHODS

Research setting and sample

The study involved four sites:

- Hillingdon Hospitals NHS Foundation Trust;
- Imperial College Healthcare NHS Trust;
- Chelsea and Westminster Hospital NHS Foundation Trust
- Marylebone Health Care Centre

To elicit a map of MMP use, a short structured telephone survey was carried out. The purpose was to find out if patients had used their passport and if they had shared it with a HCP, family member or friend. In the context of the questionnaire, by 'shared' we explained that we mean: showed it to; talked about it with; used it to aid a conversation with [a friend, carer, family member, health care professional].

To elicit a better understanding of how useful the passport had been and to gain insights into the strengths, weaknesses and any perceived obstacles to the use of MMP, each study site was asked to conduct 10 longer surveys. Information about the purpose of MMP and the aims of the evaluation was given to patients (see Appendix 1), along with consent forms which were completed prior to surveys being conducted.

Data collection procedures

Patients who were contacted to complete the short telephone survey were systematically sampled from a database of those who had given their consent until at least 30 short and 10 longer telephone surveys had been completed from each of the four settings. Patients were contacted up to 3 times each to elicit a survey. The intention was to reach the target number of patients and conduct surveys within a defined timescale of 4-6 weeks from first issue.

Data elements collected

The survey questionnaire forms were designed, generated, scanned and verified using TELE*form*©. TELE*form*© is a software package comprising four separate programmes that combine to create forms that can be printed out with automatic individual serial identity numbering, scanned after data entry, all data identified and validated, then exported to one or more selected databases ready for reporting and/or statistical analysis. When a form is designed using TELE*form*©, the questions are designated as ‘choice fields’, ‘constrained print fields’ or ‘image zones’. In the image zones, the software is able to identify hand-written text. After the completed Survey questionnaires were scanned, the verification of the data using the TELE*form*© software provided double data entry. The data were exported simultaneously to populate databases generated in SPSSv20© and Excel.

Data quality and analysis

The content of the survey questionnaires was based on consultations previously carried out with a sample of stakeholders (including patients, carers, and hospital staff).

The survey questionnaires were designed to answer the overarching evaluation questions about patients’ use of their personal MMP in communications and adherence. Each study site collected the same data, and used the same methods, and data collected by staff in each study setting were forwarded to the Evaluation Lead and specialist survey designer for analysis.

RESULTS

In total, 202 patients were recruited to the study and 133 completed one or both surveys (66% response rate). Ninety participants (majority male) completed the short survey only and 43 also completed the longer survey (13 men, 29 women and one participant for whom gender was not recorded). The majority of patients were in the 71-80 year old age group. Demographic data are summarised in Figure 1. The majority of patients answered “No” to questions identifying any additional needs in relation to communication. However, 10% were partially sighted or blind; 19.5% had some degree of difficulty hearing, and English was not their first language for 27% of respondents (see Table 1).

Table 1: Characteristics of Patients Participating in the Survey (n=133)

	Yes		No		Not Stated	
	N	%	N	%	N	%
Hard of hearing or deaf	26	*19*	94	*71*	13	*10*
Partially sighted/blind	13	*10*	104	*78*	16	*12*
Require an interpreter	2	*1*	113	*85*	18	*13*
Any learning difficulty	5	*4*	115	*86*	13	*10*
Require an advocate	5	*4*	114	*86*	14	*10*
English is first language	82	*62*	36	*27*	15	*11*

From the 36 patients for whom English was not their first language, three telephone surveys were carried out with an interpreter (in Cantonese, Punjabi and Bengali). In addition, the languages summarised in Table 2 were mentioned as the 'first' language of patients who also spoke English fluently.

Of those respondents who indicated that they were hard of hearing, visually impaired, had a learning difficulty, required an advocate or interpreter, only 12% recorded this information about themselves in their MMP.

Table 2: First Language of Fluent English Speakers

Language	N
Punjabi	4
Gujarati	4
Hindi/Urdu	2
Turkish	1
Arabic	1
French	2
Philippino	2
Swahili	2
Farsi	1
Gaelic	1
German	1
Italian	1
Spanish	1

How MMPs are used

Fifty-two percent of patients had used their passport in some way since receiving it and 58 of the 133 questioned (42%) had 'shared' it with someone, most frequently this was a family member, as shown in Table 3. Thirty-two had 'shared' their MMP with one or more health care professionals; most frequently cited were GP and a hospital doctor.

Some respondents commented that they thought the passport was for their use only and didn't feel the need to take it with them to HCP visits/appointments. However, of the 32 patients that did, 22 (69%) reported that it improved their confidence in talking to the HCP about their medicines. A further two were 'not sure'.

Thirty-three percent carried their MMP at all times and 37% responded 'sometimes'. When asked "Will you take your passport with you when you see your HCP in the future?" 81.4% said yes, they would.

Table 3: 'Sharing' of MMP (n=133)

	Number	
	Yes	**No**
GP	24	47
Hospital Doctor	24	46
Other Hospital Staff	13	53
Pharmacist (community)	8	60
Community Nurse	7	59
Pharmacist (hospital)	3	63
Voluntary Sector Organisation	3	64
Dentist	2	65
Optician	2	64
Care Home	0	65
Mental Health Services	0	66
Family Member	57	18
Friend	17	48
Other	6	49

Patients responding to the longer survey were asked about medication changes (within 6 weeks of owning an MMP). Sixty seven percent of respondents reported that they recorded details in their MMP. Their recorded reason for the change, most commonly side-effects, are given in Table 4. None reported that a HCP wrote in their passport; they completed this themselves or a carer or family member helped.

Overall, the majority of patients indicated that they were pleased to have a passport in which they themselves or their carer document changes (76%). However, 14%

would like a HCP to do this.

Table 4: Patients' Comments on Why Their Medicines Were Changed (n=43)

Reason Given	Frequency
Side Effects	4
Legs swollen	3
Help heart rate	1
Prior to operation	1
New style inhaler	1
Prostate enlarged	1
Sodium levels too high	1
Heart palpitations	1
Medication not working, started chemotherapy	1
Shared decision, but not happy with change	1
Not sure	1
Total comments	16

Eighty-six percent of respondents (37 of the 43 people who completed the long survey) reported 'yes' they would recommend MMP to friends or family', and one was 'not sure'.

Further positive comments given by patient (or carer where indicated) were:

"My GP thought that the passport is a really good idea and said that I should carry it with me and keep it up to date".

"They said it was a good idea. First one they've seen. Yes. It helped communication with them".

"Very easy. Was more accurate than GP record. Eased communication. Facilitated dialogue".

"It was very useful. I see so many different doctors now. One document [for medicnes] and all of them can see the same information".

(Carer) "Helpful – as it makes it easier for [patient] as she doesn't speak English. MMP makes it easier for family member too because they can just hand it over to the professional to see".

"It was fine [sharing MMP]. She [HCP] didn't really look at it as she said she had a list. Dermatologist didn't really look. However, my carer found it useful and it helps the communication between them and me with HCPs".

"Very helpful to be on top of new medicines, and view MMP prior to sharing with GP".

"[Spouse] became ill recently. MMP useful to remind myself [carer]. Helpful to talk to GP".

"Really useful to her [patient] and me as carer. Helps to have conversations about medicines and keep track of things. Will order another MMP for my mother in law. My sister and wife use this too (they are additional carers)".

Negative comments included:

One respondent had concerns over 'identity theft' and one about 'accuracy'. Another suggested that the MMP duplicates what the GP already does and a further two thought it was better to use the 'pharmacy' list. Comments included:

"No easy way of writing in the changes to give a clear view of the latest date/entry. I have 10 medicines. Maybe one changes for a week. Then changes back. It could get messy quite quickly".

"My medicines change so often. I'd be updating the passport too often. I prefer to use the slips/information from the pharmacy. They have a good system. It works well. I can see that MMP will work well for someone who does not have a good system already".

Suggestions for Improvements

Several suggestions for improvement to the MMP were elicited from respondents who had used, or attempted to use their MMP. These are listed in Table 5.

Table 5: Suggestions for Improvement of MMP

PATIENT'S COMMENTS	Number of respondents
NONE NEEDED	23
ADD LIST OF MEDICATION SIDE EFFECTS	20

RECORD ALLERGIES, INFECTIONS, HOSPITAL VISITS, RESULTS, IMMUNISATIONS, TRAVEL VACCINATIONS, PAST HISTORY, BLOOD TYPE, SCREENING, CONTACT IN EMERGENCY	8
BIT SMALLER FOR MEN TO PUT IN POCKET	5
MORE PAGES AT BACK , EITHER BLANK OR LABELLED: a. CURRENT MED, b. MED CHANGES	4
NEED BETTER COVER, MORE LIKE DIARY	3
NEED BIGGER PRINT, DIFFICULT TO READ	2
WOULD LIKE OWN LANGUAGE VERSION	1
SEPARATE LISTINGS OF SHORT AND LONG TERM MEDICATIONS	1
PREFER TYPE OF CREDIT CARD TO BE SCANNED BY DR OR AMBULANCE DRIVER	1
NO RESPONSE/DON'T KNOW	24

Twenty respondents suggested the need for a space to record medicine side effects. (Nb. This was provided as an example by the interviewer).

"Sometimes the Chemists have given me something that disagrees with me. I will use the passport to record that and tell the pharmacy".

Eight respondents suggested the addition of a space to record a variety of specific things: allergies, health conditions, hospital visits/appointments, medical test results, screening, vaccinations, past history of operations etc., and blood type.

Five patients suggested a smaller format (especially that men would like something to put in their pocket). Further comments included:

"… far too big for pocket. Needs to be much smaller. Would like an e-system but does not have an android phone. Liked the idea of an App."

"The book is written in English. If it was translated in Bengali then the patient could themselves understand and write something themselves. The book would be better if it was a smaller size".

DISCUSSION

'Passports' as tools enabling patients to better manage their medicines, have been used in targeted patient groups with reported evidence of success. For example in palliative care,[8] diabetes,[9] inflammatory bowel disease[6] and glucocorticoid replacement therapy.[7] Medication passports may be regarded as a support to self-management and a decision aid if used in communications with the doctor when considering a new therapy.[10]

Most respondents to our questionnaire reported positive results; they felt their MMP was useful, that it facilitated dialogue about medicines and that a patient held, patient-filled portable document was ‘a good idea’.

Less than 20% of patients had discussed their passport with their GP; we had anticipated that more patients would have done so within the 4-6 week time period between being given MMP and participating in the survey. The majority reported the intention to do so at future consultations. However there appeared to be a strong feeling among respondents that this was not their perceived use for the passport; it was for their personal recording and though it might be used to facilitate discussions about medicines with doctors, it was more important as an *aide-memoire* for the user.

For those respondents who had shared their passport with someone else, family members ranked highest. Several mentioned how useful it was to both patients and carers. The majority affirmed that MMP is useful in aiding communication between themselves and HCPs. Carers too liked MMP and found that it provided them with a point of reference when the need arose to talk to either the patient, or the patient’s HCP.

The majority of respondents saw MMP as helpful in managing their medicines despite some reservations from patients whose medicines change frequently. Side effects recording seems important to users. This finding is perhaps expected as patients phoning our medicines information helpline ask most frequently about side effects of medicines than any other category of query, [11] and patients’ experience surveys consistently suggest not enough is given in plain language.[12]

Limitations

The use of MMP is not obligatory, or ‘prescribed’. Its users are usually introduced to it by a clinician and they are chosen because they take multiple medicines. It is free of charge, but the choice of whether to use it or not is the recipient’s. For these reasons, recruitment of patient participants in this evaluation should be understood to have been ‘self-selected’.

We were only able to recruit patients who were well enough to be contacted by telephone during a specific period of time and only 66% participated. It is recognised that those less able to be recruited to this study might be the more vulnerable patients with a greater need for assistance with managing their medicines. They remain the more difficult to assess and the more in need of tools such as a passports and compliance aids in general.

MMP is being used by different cohorts of patients across the sites included in the study. Many people who take multiple medicines are elderly and/or have co-morbidities. It was recognised and acknowledged from the outset that the present study is ‘formative’ and it may be necessary to carry out a further, larger and/or more in-depth study to gain a deeper understanding of potential changes that may be needed to evaluate MMP use by different types of patient.

Recommendations and conclusion

Although based on small numbers, it would appear that availability of MMP in different languages or with bi-lingual text/headings would be an asset.

Space for recording of side effects in particular would be useful as well as more specific space for changes to medication (or perhaps continuation sheets). This should be followed by further evaluation of MMP in particular user groups; we suggest in frail patients: those with particular long-term conditions; and perhaps homeless patients or patients who move frequently (for example students and some new immigrants).

Further analysis of the number of men and women who had used their MMP or shared it with a HCP is suggested, to help us to understand the gender differences in response rate found in the evaluation.

This evaluation was not structured to find out *what* patients write in their MMP; it may be valuable to do this in a further study. Rather, we set out to gain an understanding of *how* what was written by the patient was used and this has, with limitations, been achieved.

NIHR CLAHRC for NW London has since rolled-out the MMP across London and the wider community through other hospitals, community pharmacies and GP surgeries and successfully launched an ‘App’ version, now available to download onto smart phones and devices. We have communicated through several media with over 45,000 copies distributed and over 2400 ‘app’ downloads to date.

Contributorship statement

Susan Barber led the evaluation, developed the protocol, supervised data collation from all sources, the analysis and writing of the original report.

Kandarp Thakkar led the original project that resulted in the patient development of the My Medication Passport and the App, its promotion and spread, assisted with data evaluation and writing of the manuscript.

Vanessa Marvin participated in the collation and evaluation of the data, promotion of the My Medication Passport, prepared and edited the manuscript for submission.

Bryony Dean Franklin contributed to the development of the protocol, supervised data collection at Imperial College Healthcare NHS Trust and assisted with analysis and writing of the original evaluation report.

Derek Bell as Director for NIHR CLAHRC for NW London directs the programme of work including development of the My Medication Passport, promotion and spread through partner organisations. Contributed to the evaluation and editing of the manuscript for publication.

Sara Garfield, Shirley Kuo conducted interviews and assisted in the writing of the evaluation report.
Sabrina Amer, Saadi Jamil, Seetal Jheeta conducted patient interviews.
Sylvia Chalkley of Chalkley Survey Design & Statistical Analysis Ltd. Structured the Survey questionnaire.
Other members of the ImPE Supergroup were key to the development, promotion and spread of the My Medication Passport and co-ordinating the evaluation: Stella Barnes, Iñaki Bovill, Louise Collins, Edward Dickinson, Beverly Hall, Fran Husson, Ann Jacklin, Nick Jones, Colin Mitchell, Sue Newton, Sam Oliver, Karen Phekoo, Ganesh Sathyamoorthy, John Soong, Margaret Turley and Tom Woodcock.

Competing interests: None
Funding: NIHR CLAHRC for North West London funded the evaluation. The passport has been produced with support from AstraZeneca under a joint working agreement.

Data sharing: The following extra data are available:
The data split between the short and longer surveys completed by patients;
Patients' comments on why and when their medicines were changed and by whom (n=16).
Modified questionnaires (not included in this evaluation) completed by 5 health care professionals about the My Medication Passport;
The patient target sampling matrix;
Promotional material (posters and leaflets) for My Medication passport.
Available from the corresponding author:

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Evaluation of My Medication Passport: a patient-completed *aide memoire* designed by patients, for patients, to help towards medicines optimisation.

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Comment [MV1]: moved

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~~**Extra data is available** by emailing: susan.barber@thh.nhs.uk~~

Comment [MV2]: moved

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Results: More than half of respondents had found their medication passport useful or helpful in some way; 42% through sharing details from it with others (most frequently family, carer or doctor) or using it as a platform for conversations with health care professionals. One third of those questioned carried the passport with them at all times.

Conclusions: My Medication Passport has been positively evaluated; we have a better understanding of how it is used by patients, what they are recording and how it can be an aid to dialogue about medicines with family, carers and health care professionals. Further development and spread is underway including an App for smartphones which will be subject to wider evaluation to include feedback from clinicians.

~~**Background:** A passport-sized booklet designed by patients for patients to record details about their medicines, has been introduced to North West London Hospitals as part of a group of wider improvement projects focussing on medicines optimisation in older people (‘ImPE’). After finalising the style and content of the booklet we undertook an evaluation of ‘My Medication Passport’.~~

~~**Methods:** We recruited patients from a cohort who had been given a passport as part of the medicines management improvement projects at one of four sites. A structured telephone questionnaire was conducted and responses collated.~~

~~**Results:** Over 200 patients were recruited and 66% (131 patients) completed the~~

~~questionnaire. More than half of respondents had found their medication passport useful and/or helpful in managing their medicines; 42% through sharing details from it with others (most frequently family, carer or doctor) or using it as a platform for conversations with health professionals. One third of those questioned carried the passport with them at all times. We found that for 27%, English was not their first language and 10% were partially sighted or blind, presenting challenges for further improvement and patient engagement.~~

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- Changes to my medicines (date, reason for change, by whom)
- Blank pages for notes (illnesses, vaccinations, screenings) and to record additional needs

It is recognised that communication about medicines needs to improve between medical professionals from different disciplines, and between professionals and patients/carers. There is evidence that gaps in communication and incomplete documentation, particularly concerning the elderly and medicines at discharge from hospital, contribute to re-admissions.[2] Closing this gap is likely to result in health benefits, including a reduction in adverse drug events.[3]

It is estimated that among patients with long-term conditions, as many as 30-50% do not take their medicines as intended[4] and intervention to improve adherence may have a greater impact on the health of the population than improvements in specific medical treatments.[5] Part of the solution is to encourage self-management of health problems with HCP providing, for example, compliance aids and portable records in support.[6,7]

The purpose of this study was to evaluate the use of MMP by a cohort of patients with the intention of gaining a better understanding of its value. In particular we wanted to find out if MMP helped to foster good communications between patients and HCPs; improved patients' confidence about what medicines they take ~~in order to help in adhering to medication regimens.~~ and we also wanted to increase our understanding of whether or not changes to medicines are likely to be recorded in MMP and kept up to date.

METHODS

Research setting and sample

The study involved four sites:

- Hillingdon Hospitals NHS Foundation Trust;
- Imperial College Healthcare NHS Trust;
- Chelsea and Westminster Hospital NHS Foundation Trust
- Marylebone Health Care Centre

To elicit a map of MMP use, a short structured telephone survey was carried out.

The purpose was to find out if patients had used their passport and if they had shared it with a HCP, family member or friend. In the context of the questionnaire, by 'shared' we explained that we mean: showed it to; talked about it with; used it to aid a conversation with [a friend, carer, family member, health care professional].

To elicit a better understanding of how useful the passport had been and to gain insights into the strengths, weaknesses and any perceived obstacles to the use of MMP, each study site was asked to conduct 10 longer surveys. Information about the purpose of MMP and the aims of the evaluation was given to patients (see Appendix 1), along with consent forms which were completed prior to surveys being conducted.

Data collection procedures

Patients who were contacted to complete the short telephone survey were systematically sampled from a database of those who had given their consent until at least 30 short and 10 longer telephone surveys had been completed from each of the four settings. Patients were contacted up to 3 times each to elicit a survey. The intention was to reach the target number of patients and conduct surveys within a defined timescale of 4-6 weeks from first issue.

Data elements collected

The survey questionnaire forms were designed, generated, scanned and verified using TELE*form*©. TELE*form*© is a software package comprising four separate programmes that combine to create forms that can be printed out with automatic individual serial identity numbering, scanned after data entry, all data identified and validated, then exported to one or more selected databases ready for reporting and/or statistical analysis. When a form is designed using TELE*form*©, the questions are designated as 'choice fields', 'constrained print fields' or 'image zones'. In the image zones, the software is able to identify hand-written text. After the completed Survey questionnaires were scanned, the verification of the data using the TELE*form*© software provided double data entry. The data were exported simultaneously to populate databases generated in SPSSv20© and Excel.

Data quality and analysis

The content of the survey questionnaires was based on consultations previously carried out with a sample of stakeholders (including patients, carers, and hospital staff).

The survey questionnaires were designed to answer the overarching evaluation questions about patients' use of their personal MMP in communications and adherence. Each study site collected the same data, and used the same methods, and data collected by staff in each study setting were forwarded to the Evaluation Lead and specialist survey designer for analysis.

RESULTS

In total, 202 patients were recruited to the study and 133 completed one or both surveys (66% response rate). Ninety participants (majority male) completed the short survey only and 43 also completed the longer survey (13 men, 29 women and one participant for whom gender was not recorded). The majority of patients were in the 71-80 year old age group. Demographic data are summarised in Figure 1. The majority of patients answered “No” to questions identifying any additional needs in relation to communication. However, 10% were partially sighted or blind; 19.5% had some degree of difficulty hearing, and English was not their first language for 27% of respondents (see Table 1).

Table 1: Characteristics of Patients Participating in the Survey (n=133)

	Yes		No		Not Stated	
	N	%	N	%	N	%
Hard of hearing or deaf	26	*19*	94	*71*	13	*10*
Partially sighted/blind	13	*10*	104	*78*	16	*12*
Require an interpreter	2	*1*	113	*85*	18	*13*
Any learning difficulty	5	*4*	115	*86*	13	*10*
Require an advocate	5	*4*	114	*86*	14	*10*
English is first language	82	*62*	36	*27*	15	*11*

From the 36 patients for whom English was not their first language, three telephone surveys were carried out with an interpreter (in Cantonese, Punjabi and Bengali). In addition, the languages summarised in Table 2 were mentioned as the ‘first’ language of patients who also spoke English fluently.

Of those respondents who indicated that they were hard of hearing, visually impaired, had a learning difficulty, required an advocate or interpreter, only 12% recorded this information about themselves in their MMP.

Table 2: First Language of Fluent English Speakers

Language	N
Punjabi	4
Gujarati	4
Hindi/Urdu	2
Turkish	1
Arabic	1
French	2
Philippino	2
Swahili	2
Farsi	1
Gaelic	1
German	1
Italian	1
Spanish	1

How MMPs are used

Fifty-two percent of patients had used their passport in some way since receiving it and 58 of the 133 questioned (42%) had 'shared' it with someone, most frequently this was a family member, as shown in Table 3. Thirty-two had 'shared' their MMP with one or more health care professionals; most frequently cited were GP and a hospital doctor.

Some respondents commented that they thought the passport was for their use only and didn't feel the need to take it with them to HCP visits/appointments. However, of the 32 patients that did, 22 (69%) reported that it improved their confidence in talking to the HCP about their medicines. A further two were 'not sure'.

Thirty-three percent carried their MMP at all times and 37% responded 'sometimes'. When asked "Will you take your passport with you when you see your HCP in the future?" 81.4% said yes, they would.

Table 3: 'Sharing' of MMP (n=133)

	Number

	Yes	No
GP	24	47
Hospital Doctor	24	46
Other Hospital Staff	13	53
Pharmacist (community)	8	60
Community Nurse	7	59
Pharmacist (hospital)	3	63
Voluntary Sector Organisation	3	64
Dentist	2	65
Optician	2	64
Care Home	0	65
Mental Health Services	0	66
Family Member	57	18
Friend	17	48
Other	6	49

Patients responding to the longer survey were asked about medication changes (within 6 weeks of owning an MMP). Sixty seven percent of respondents reported that they recorded details in their MMP. Their recorded reason for the change, most commonly side-effects, are given in Table 4. None reported that a HCP wrote in their passport; they completed this themselves or a carer or family member helped.

Overall, the majority of patients indicated that they were pleased to have a passport in which they themselves or their carer document changes (76%). However, 14% would like a HCP to do this.

Table 4: Patients' Comments on Why Their Medicines Were Changed (n=43)

Reason Given	Frequency
Side Effects	4
Legs swollen	3
Help heart rate	1

Prior to operation	1
New style inhaler	1
Prostate enlarged	1
Sodium levels too high	1
Heart palpitations	1
Medication not working, started chemotherapy	1
Shared decision, but not happy with change	1
Not sure	1
Total comments	16

Eighty-six percent of respondents (37 of the 43 people who completed the long survey) reported 'yes' they would recommend MMP to friends or family', and one was 'not sure'.

Further positive comments given by patient (or carer where indicated) were:

"My GP thought that the passport is a really good idea and said that I should carry it with me and keep it up to date".

"They said it was a good idea. First one they've seen. Yes. It helped communication with them".

"Very easy. Was more accurate than GP record. Eased communication. Facilitated dialogue".

"It was very useful. I see so many different doctors now. One document [for medicnes] and all of them can see the same information".

(Carer) "Helpful – as it makes it easier for [patient] as she doesn't speak English. MMP makes it easier for family member too because they can just hand it over to the professional to see".

"It was fine [sharing MMP]. She [HCP] didn't really look at it as she said she had a list. Dermatologist didn't really look. However, my carer found it useful and it helps the communication between them and me with HCPs".

"Very helpful to be on top of new medicines, and view MMP prior to sharing with GP".

"[Spouse] became ill recently. MMP useful to remind myself [carer]. Helpful to talk to GP".

"Really useful to her [patient] and me as carer. Helps to have conversations about medicines and keep track of things. Will order another MMP for my mother in law. My sister and wife use this too (they are additional carers)".

Negative comments included:

One respondent had concerns over 'identity theft' and one about 'accuracy'. Another suggested that the MMP duplicates what the GP already does and a further two thought it was better to use the 'pharmacy' list. Comments included:

"No easy way of writing in the changes to give a clear view of the latest date/entry. I have 10 medicines. Maybe one changes for a week. Then changes back. It could get messy quite quickly".

"My medicines change so often. I'd be updating the passport too often. I prefer to use the slips/information from the pharmacy. They have a good system. It works well. I can see that MMP will work well for someone who does not have a good system already".

Suggestions for Improvements

Several suggestions for improvement to the MMP were elicited from respondents who had used, or attempted to use their MMP. These are listed in Table 5.

Table 5: Suggestions for Improvement of MMP

PATIENT'S COMMENTS	Number of respondents
NONE NEEDED	23
ADD LIST OF MEDICATION SIDE EFFECTS	20
RECORD ALLERGIES, INFECTIONS, HOSPITAL VISITS, RESULTS, IMMUNISATIONS, TRAVEL VACCINATIONS, PAST HISTORY, BLOOD TYPE, SCREENING, CONTACT IN EMERGENCY	8
BIT SMALLER FOR MEN TO PUT IN POCKET	5
MORE PAGES AT BACK , EITHER BLANK OR LABELLED: a. CURRENT MED, b. MED CHANGES	4
NEED BETTER COVER, MORE LIKE DIARY	3
NEED BIGGER PRINT, DIFFICULT TO READ	2

WOULD LIKE OWN LANGUAGE VERSION	1
SEPARATE LISTINGS OF SHORT AND LONG TERM MEDICATIONS	1
PREFER TYPE OF CREDIT CARD TO BE SCANNED BY DR OR AMBULANCE DRIVER	1
NO RESPONSE/DON'T KNOW	24

Twenty respondents suggested the need for a space to record medicine side effects. (Nb. This was provided as an example by the interviewer).

"Sometimes the Chemists have given me something that disagrees with me. I will use the passport to record that and tell the pharmacy".

Eight respondents suggested the addition of a space to record a variety of specific things: allergies, health conditions, hospital visits/appointments, medical test results, screening, vaccinations, past history of operations etc., and blood type.

Five patients suggested a smaller format (especially that men would like something to put in their pocket). Further comments included:

"… far too big for pocket. Needs to be much smaller. Would like an e-system but does not have an android phone. Liked the idea of an App."

"The book is written in English. If it was translated in Bengali then the patient could themselves understand and write something themselves. The book would be better if it was a smaller size".

DISCUSSION

'Passports' as tools enabling patients to better manage their medicines, have been used in targeted patient groups with reported evidence of success. For example in palliative care,[8] diabetes,[9] inflammatory bowel disease[6] and glucocorticoid replacement therapy.[7] Medication passports may be regarded as a support to self-management and a decision aid if used in communications with the doctor when considering a new therapy.[10]

Most respondents to our questionnaire reported positive results; they felt their MMP was useful, that it facilitated dialogue about medicines and that a patient held, patient-filled portable document was 'a good idea'.

Less than 20% of patients had discussed their passport with their GP; we had anticipated that more patients would have done so within the 4-6 week time period between being given MMP and participating in the survey. The majority reported the intention to do so at future consultations. However there appeared to be a strong feeling among respondents that this was not their perceived use for the passport; it was for their personal recording and though it might be used to facilitate discussions about medicines with doctors, it was more important as an *aide-memoire* for the user.

For those respondents who had shared their passport with someone else, family members ranked highest. Several mentioned how useful it was to both patients and carers. The majority affirmed that MMP is useful in aiding communication between themselves and HCPs. Carers too liked MMP and found that it provided them with a point of reference when the need arose to talk to either the patient, or the patient's HCP.

The majority of respondents saw MMP as helpful in managing their medicines despite some reservations from patients whose medicines change frequently. Side effects recording seems important to users. This finding is perhaps expected as patients phoning our medicines information helpline ask most frequently about side effects of medicines than any other category of query, [11] and patients' experience surveys consistently suggest not enough is given in plain language.[12]

Limitations

The use of MMP is not obligatory, or 'prescribed'. Its users are usually introduced to it by a clinician and they are chosen because they take multiple medicines. It is free of charge, but the choice of whether to use it or not is the recipient's. For these reasons, recruitment of patient participants in this evaluation should be understood to have been 'self-selected'.

We were only able to recruit patients who were well enough to be contacted by telephone during a specific period of time and only 66% participated. It is recognised that those less able to be recruited to this study might be the more vulnerable patients with a greater need for assistance with managing their medicines. They remain the more difficult to assess and the more in need of tools such as a passports and compliance aids in general.

MMP is being used by different cohorts of patients across the sites included in the study. Many people who take multiple medicines are elderly and/or have co-morbidities. It was recognised and acknowledged from the outset that the present study is 'formative' and it may be necessary to carry out a further, larger and/or more in-depth study to gain a deeper understanding of potential changes that may be needed to evaluate MMP use by different types of patient.

Recommendations and conclusion

Although based on small numbers, it would appear that availability of MMP in different languages or with bi-lingual text/headings would be an asset.

Space for recording of side effects in particular would be useful as well as more specific space for changes to medication (or perhaps continuation sheets). This should be followed by further evaluation of MMP in particular user groups; we suggest in frail patients: those with particular long-term conditions; and perhaps homeless patients or patients who move frequently (for example students and some new immigrants).

Further analysis of the number of men and women who had used their MMP or shared it with a HCP is suggested, to help us to understand the gender differences in response rate found in the evaluation.

This evaluation was not structured to find out *what* patients write in their MMP; it may be valuable to do this in a further study. Rather, we set out to gain an understanding of *how* what was written by the patient was used and this has, with limitations, been achieved.

NIHR CLAHRC for NW London has since rolled-out the MMP across London and the wider community through other hospitals, community pharmacies and GP surgeries and successfully launched an 'App' version, now available to download onto smart phones and devices. We have communicated through several media with over 45,000 copies distributed and over 2400 'app' downloads to date.

Contributorship statement

Susan Barber led the evaluation, developed the protocol, supervised data collation from all sources, the analysis and writing of the original report.
Kandarp Thakkar led the original project that resulted in the patient development of the My Medication Passport and the App, its promotion and spread, assisted with data evaluation and writing of the manuscript.
Vanessa Marvin participated in the collation and evaluation of the data, promotion of the My Medication Passport, prepared and edited the manuscript for submission.
Bryony Dean Franklin contributed to the development of the protocol, supervised data collection at Imperial College Healthcare NHS Trust and assisted with analysis and writing of the original evaluation report.
Derek Bell as Director for NIHR CLAHRC for NW London directs the programme of work including development of the My Medication Passport, promotion and spread through partner organisations. Contributed to the evaluation and editing of the manuscript for publication.
Sara Garfield, Shirley Kuo conducted interviews and assisted in the writing of the evaluation report.
Sabrina Amer, Saadi Jamil, Seetal Jheeta conducted patient interviews.
Sylvia Chalkley of Chalkley Survey Design & Statistical Analysis Ltd. Structured the Survey questionnaire.

Other members of the ImPE Supergroup were key to the development, promotion and spread of the My Medication Passport and co-ordinating the evaluation: Stella Barnes, Iñaki Bovill, Louise Collins, Edward Dickinson, Beverly Hall, Fran Husson, Ann Jacklin, Nick Jones, Colin Mitchell, Sue Newton, Sam Oliver, Karen Phekoo, Ganesh Sathyamoorthy, John Soong, Margaret Turley and Tom Woodcock.

Competing interests: None

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Data sharing: The following extra data are available:
The data split between the short and longer surveys completed by patients;
Patients' comments on why and when their medicines were changed and by whom (n=16).
Modified questionnaires (not included in this evaluation) completed by 5 health care professionals about the My Medication Passport;
The patient target sampling matrix;
Promotional material (posters and leaflets) for My Medication passport.
Available from the corresponding author:

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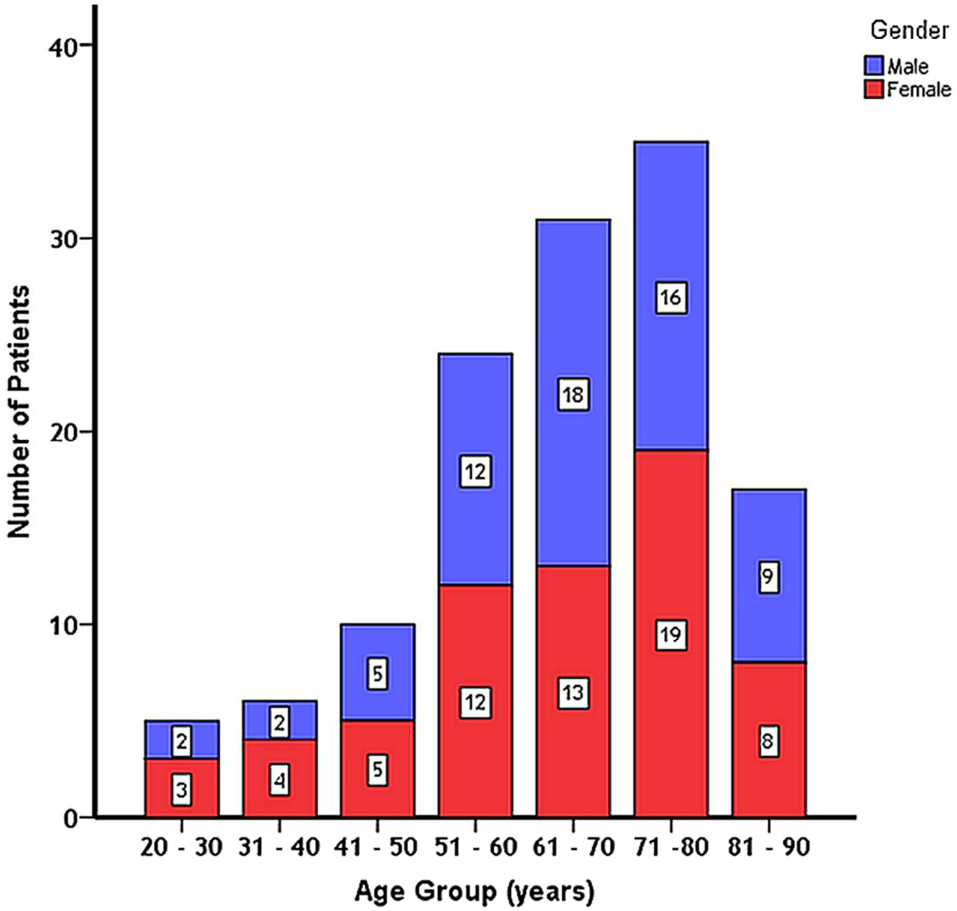

Age and gender of participants
73x73mm (300 x 300 DPI)

Appendix 1

Information Sheet for Patients'
Evaluation of the use of My Medication Passport

Introduction

This information sheet is for patients who have received `My Medication Passport' (MMP) from one of the following: Hillingdon Hospitals NHS Foundation Trust, Chelsea and Westminster NHS Foundation Trust, Imperial College Hospitals Health Care NHS Trust; Marylebone Health Centre, Boots London Fulham Road Pharmacy.

You will have been given a copy of the MMP by your Doctor/Pharmacist/Nurse or other health care professional and they will have talked to you about how to use it.

Aim of the evaluation

Three NHS Trusts in North West London, the Hillingdon Hospitals NHS Foundation Trust; Chelsea and Westminster NHS Foundation Trust and Imperial College Hospitals Healthcare NHS Trust have recently introduced "My Medication Passport". MMP is also being used by a number of community based health care providers such as GPs and pharmacists.

We want to understand how you use the passport, including if it helps to improve communication between you and your GP or dentist, optician or other health care professional.

We would also like to know if it improves your confidence in talking about your medicines, and if it is useful for you to share with other people that you are close to, e.g., your partner, family, carer or main friend.

With this in mind we are inviting you to take part in the formal evaluation of the project. You will be one of approximately 200 people across North West London taking part in the evaluation.

What will happen if I take part?

If you agree to take part in this evaluation, we ask that you agree for us to contact you 4-8 weeks after you receive your medication passport to carry out a short telephone survey to help us to understand how successful the use of the passport is. The survey will take no more than 10 minutes.

We may subsequently ask you to take part in a slightly longer telephone survey. We will contact a small number of patients (not everyone who participated in the short interview) to carry out the longer survey, taking about 30 minutes. If you do not speak good English we may be able to carry out the survey face-face, with a professional translator present. You will need to tell us if you require a translator by ticking the box where indicated on the consent form (attached). Any face-face survey could take place in your home or at one of the hospitals.

Will my information be confidential?

Yes. All data that is collected in order to evaluate the program will be anonymous (no name or other details which could be used to identify you will be recorded). For the purpose of the evaluation you will be identified only be a unique number.

What will happen to the information?

The anonymous information will be analysed by staff attached to one or more of the participating Trusts. A report will be written to record what we've found and shared by all three Trusts with the National Institute for Health Research, Collaboration for Leadership in Applied Health Research and Care. It is envisaged that whatever the findings of the evaluation, they will help to inform decisions about the use of the passport in the future.

Not sure about taking part in this evaluation?

It is up to you to decide whether you wish to participate in the evaluation of the passport. If you do not want to participate that is okay. You have the right to say no.

Is there any benefit for me?

The evaluation will not affect the services you receive now but we hope that it will contribute to the general development of services to support patients in the Trusts across North West London in the longer term. For further information see: http://www.clahrc-northwestlondon.nihr.ac.uk/research-projects/bespoke-projects/my-medication-passport

What if I am not happy?

If you have a concern about any aspect of this evaluation, you should ask to speak with the Project Lead who will do their best to answer your questions. Telephone Susan Barber on 01895 238282 extension 2428.

What do I do now?

We hope that this information is helpful to you and gives you a better understanding of why we want to evaluate the programme. Please take your time to think about whether you are happy to participate. Please complete the consent form if you are willing for us to contact you for interview and hand it to the member of staff who invited you to take part in the evaluation.

Appendix 2

Consent Form for Patients
Evaluation of the use of My Medication Passport

Introduction

This information sheet is for patients who have received `My Medication Passport' MMP from one of the following : Hillingdon Hospitals NHS Foundation Trust, Chelsea and Westminster NHS Foundation Trust, Imperial College Hospitals Health Care NHS Trust; Boots London Fulham Road Pharmacy.

You will have been given a copy of the MMP by your Doctor/Pharmacist/Nurse or other health care professional and they will have talked to you about how to use it.

Please tick the boxes

	Yes
I have read the information sheet and have had the opportunity to ask questions about it. I understand what is involved in taking part in the evaluation of My Medication Passport.	☐
I understand that the information I give will remain confidential.	☐
I understand that taking part is voluntary and I may withdraw my consent at any time without needing to give a reason.	☐
I understand that the services I receive will not be affected in any way if I decide not to take part or wish to withdraw from the study.	☐
I am willing to participate in this evaluation. My telephone number is: ……………………………………………………………	☐
I would require a translator to take part in this evaluation	☐

Signed: .... Date:..................................

My Medication Passport issued by: ……………………………………………………………………….

Signature: ……………... Date …………………….…........

Thank you for agreeing to participate in this evaluation.
Please hand your completed consent form back to the doctor, pharmacist or nurse who gave it to you.

A member of staff will contact you in 4-8 weeks to carry out an interview.

Appendix 3

Short structured telephone survey (patients).

Note to interviewer:

1. This questionnaire is to be used with at least 30 and no more than 50 patients from the list of up to 70 people recruited by:

- The Hillingdon Hospital
- Chelsea and Westminster Hospital
- Hospital(s) attached to Imperial College Health Care NHS Trust
- Marylebone Health Centre
- Boots London Fulham Road Pharmacy

Screener questions:	**Yes**	**No**	**Not sure**
Do any of the following apply to you?			
Do you have a learning difficulty?			
Do you require an advocate?			
Are you hard of hearing/deaf?			
Do you find it hard to see?/ Are you partially sighted/ blind?			
Do you require an interpreter?			
Is your first language English? [If not which language do you use? – and record which] Drop down list to go here			
If any of the above apply record answers and if necessary close the interview – e.g., an advocate or interpreter is required.			
If the answer to any of the above is yes, have you recorded this information in your passport?	Yes	No	Not sure
Are you male or female?	Male	Female	

In which age group are you?	Yes	No	
20-30 years old			
31-40 years old			
41-50 years old			
51-60 years old			
61-70 years old			
71-80 years old			
81-90 years old			
91 + years old			

TELEPHONE SURVEY: MAPPING PATIENT'S USE OF MMP

Q.No	**Question**	Yes	No	Not sure
1	Have you used your passport since you were given it?			
2	Have you shared it with anyone else?			
	If the answer to 1 and/or 2 is "yes" continue with the interview from question 3. **If the answer to 1 and 2 is "no" – "thank you" and close the interview.**			
3	Who have you shared it with?	Yes	No	
3.1	GP			
3.2	Pharmacist			
3.3	Community Nurse			
3.4	Dentist			
3.5	Optician			
3.6	Hospital Doctor			
3.7	Hospital pharmacist			

3.8	Other hospital staff			
3.9	Care Home			
3.10	Mental Health Services			
3.11	Voluntary Sector Organisation (e.g. Age UK) Add space to record which one(s)			
3.12	Family Member			
3.13	Friend			
3.14	Other			
3.15	Write in the contact details of the health care professional (s) that the patient has shared MMP with here:			

End of questionnaire.

Appendix 4

Longer telephone survey using questionnaire

Notes to interviewer:

1. This questionnaire is to be used with 10 patients from the list of up to 70 people recruited by:
    - The Hillingdon Hospital;
    - Chelsea and Westminster Hospital;
    - Hospital(s) attached to Imperial College Health Care NHS Trust;
    - Marylebone Health Centre
    - Brook Green Medical Centre, Hammersmith;
    - Boots London Fulham Road Pharmacy.

2. Respondents should be selected according to the criteria shown in the Table below:

Table 1 Criteria for Selection

Setting	**Each Acute Trust Site**	**Community Pharmacy**	**GP practice**
Age ≥70	≥5	≥5	≥5
Sex			
male	≥3	≥3	≥3
female	≥3	≥3	≥3
Long-Term condition	≥3	≥3	≥3
Learning disability	≥1	-	-
Presenting with confusion	≥1	-	-
English not first language	≥1	≥1	≥1

Screener questions:	**Yes**	**No**	**Not sure**
Do any of the following apply to you?			
Do you have a learning difficulty?			
Do you require an advocate?			
Are you hard of hearing/deaf?			
Do you find it hard to see?/ Are you partially sighted/ blind?			
Do you require an interpreter?			
Is your first language English? [If not which language do you use? – and record which] Drop down list to go here			
If any of the above apply record answers and if necessary close the interview – e.g., an advocate or interpreter is required.			
If the answer to any of the above is yes, have you recorded this information in your passport?	Yes	No	Not sure
Are you male or female?	Male	Female	
In which age group are you?	Yes	No	
20-30 years old			
31-40 years old			
41-50 years old			
51-60 years old			
61-70 years old			
71-80 years old			
81-90 years old			
91 + years old			

TELEPHONE SURVEY USING QUESTIONNAIRE : To elicit responses of patients about the usefulness of the passport, insights into its strengths and any perceived weaknesses or obstacles to its use.

Q.No	Question	Yes	No		Not sure
1	Have you used your passport since you were given it?				
2	Have you shared it with anyone else?				
	If the answer to 1 and/or 2 is "yes" continue with the interview from question 3. **If the answer to 1 and/or 2 are "no" – go to questions 4&5, then skip question 6 and continue from question 7.**				
3	Who have you shared the passport with?				
3.1	GP				
3.2	Pharmacist				
3.3	Community Nurse				
3.4	Dentist				
3.5	Optician				
3.6	Hospital Doctor				
3.7	Hospital Pharmacist				

3.8	Other hospital staff				
3.9	Care Home				
3.10	Mental Health Services				
3.11	Voluntary Sector Organisation (e.g, Age UK)				
3.12	Family Member				
3.13	Friend				
3.14	Other				
3.15	Write in the contact details of the health care professional (s) that the patient has shared MMP with here:				
4	Do you carry the passport with you when you go out?	Yes	No	Sometimes	Not sure
5	Are you still on the same medication that you were on when you were first issued your MMP?				
5.2	If you are not on the same medicines now: What was the change?	New Medicine	Re – started medicine previously stopped	Change of dose	Not sure
5.3	Who changed your medicines? [write in which type of HCP	Drop down list	---	---	

	here]				
5.3.a		GP			
5.3.b		Pharmacist			
5.3.c		Community Matron/Nurse			
5.3.d		Hospital Doctor			
5.3.e		Other			
5.4	When? Do you recall the date? Or approximate date?	Day	Month	Year	Not sure
5.5	Why? [write in why medicines were changed – patient's recall of symptoms and/or reactions, reasons HCP may have given]				
5.6	Was your passport updated?	Yes	No		Not sure
5.7	If the answer to 5.6 was yes – ask the respondent: Who updated the passport? **If the answer to 5.6 was no, go to question 6.**	Go to drop down list (5.7.a-e)			
5.7.a		GP			
5.7.b		Pharmacist			

5.7.c		Community Matron/Nurse			
5.7.d		Hospital Doctor			
5.7.e		Patient themselves			
5.7.f		Other			
6	You took your passport with you to show your GP/other HCP - did they look at it and did you discuss it?	Yes	No		Not Sure
6.1	How did you find the process of sharing your passport with your GP (or other HCP as indicated in Q3)? Prompt if necessary: Help communication or not?				
7	Do you think that you will take your passport with you to your GP or other HCP in future?				
8	Would you say you were more confident talking to your GP (or other HCP) because you had your medicines clearly written in the passport?				
9	Who would you like to record changes to your medication?	Self	Carer	HCP	
10	If your first language is not English how are you using the passport? E.g.,				
10.1	My first language is not English but I speak / read it				

	well				
10.2	An interpreter/translator helps me				
11	Are there any other sections you feel would be helpful to add to the passport? Prompts: Side effects?	Yes	No		
12	Aside from anything we've already mentioned, have you used your passport for any other purpose? [if yes, write in description of what else below]				
13	How do you think the passport could be improved (if at all)? [write response below]				
14	Would you recommend a passport to friends or family?				

Thank you. Close the interview.

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported
Objectives	3	State specific objectives, including any prespecified hypotheses
Methods		
Study design	4	Present key elements of study design early in the paper
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group
Bias	9	Describe any efforts to address potential sources of bias
Study size	10	Explain how the study size was arrived at
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding
		(*b*) Describe any methods used to examine subgroups and interactions
		(*c*) Explain how missing data were addressed
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy
		(*e*) Describe any sensitivity analyses

Continued on next page

Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed
		(b) Give reasons for non-participation at each stage
		(c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders
		(b) Indicate number of participants with missing data for each variable of interest
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time
		Case-control study—Report numbers in each exposure category, or summary measures of exposure
		Cross-sectional study—Report numbers of outcome events or summary measures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
		(*b*) Report category boundaries when continuous variables were categorized
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses
Discussion		
Key results	18	Summarise key results with reference to study objectives
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
Generalisability	21	Discuss the generalisability (external validity) of the study results
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.