BMJ Open

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (http://bmjopen.bmj.com).

If you have any questions on BMJ Open's open peer review process please email editorial.bmjopen@bmj.com

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open

Patient safety in primary care: where next for research and practice? A James Lind Alliance Priority Setting Partnership

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-020870
Article Type:	Research
Date Submitted by the Author:	28-Nov-2017
Complete List of Authors:	Morris, Rebecca L.; University of Manchester, NIHR Greater Manchester Patient Safety Translational Research Centre Stocks, Susan; University of Manchester, NIHR Greater Manchester Patient Safety Translational Research Centre Alam, Rahul; University of Manchester, NIHR Greater Manchester Patient Safety Translational Research Centre Taylor, Sian; University of Manchester, NIHR Greater Manchester Patient Safety Translational Research Centre Rolfe, Carly; University of Manchester, NIHR Greater Manchester Patient Safety Translational Research Centre Glover, Steve; Manchester University NHS Foundation , Trust library service Whitcombe, Joanne; Manchester University NHS Foundation , Trust library service Campbell, Stephen; University of Manchester, Centre for Primary Care
Primary Subject Heading:	Health services research
Secondary Subject Heading:	General practice / Family practice
Keywords:	James Lind Alliance, Patient safety, PRIMARY CARE, pharmacy, general practice

SCHOLARONE™
Manuscripts

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Title: Patient safety in primary care: where next for research and practice? A James Lind Alliance Priority Setting Partnership

Authors

Dr Rebecca Lauren Morris*, NIHR Greater Manchester Patient Safety Translational Research Centre, Centre for Primary Care, University of Manchester, 6th Floor Williamson Building, Oxford Road, Manchester, M13 9PL, UK. Email: Rebecca.morris@manchester.ac.uk. Telephone: 0161 27 50748.

*Corresponding author

Dr Jill Stocks, NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester, Manchester, UK

Dr Rahul Alam, NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester, Manchester, UK

Dr Sian Taylor, NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester, Manchester, UK

Ms Carly Rolfe, NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester, Manchester, UK

Mr Steve Glover, Trust library service, Manchester University NHS Foundation Trust, Manchester, UK

Ms Joanne Whitcombe Trust library service, Manchester University NHS Foundation Trust, Manchester, UK

Professor Stephen Campbell, NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester, Manchester, UK

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Abstract

Objectives: to identify the top 10 unanswered research questions for primary care patient safety research.

Design: a modified nominal group technique.

Setting: UK

Participants: Anyone with experience of primary care including: patients, carers and healthcare professionals. 341 patients and 86 healthcare professionals submitted questions.

Main outcomes: A top 10, and top 30, future research questions for primary care patient safety

Results: 443 research questions were submitted by 341 patients and 86 healthcare professionals, through a national survey. After checking for relevance and rephrasing, a total of 173 questions were collated into themes. The themes were largely focused on communication, team and system working, interfaces across primary and secondary care, medication, self-management support and technology. The questions were then prioritised through a national survey, the top 30 questions were taken forward to the final prioritisation workshop. The top 10 research questions focused on the most vulnerable in society, holistic whole-person care, safer communication and co-ordination between care providers, work intensity, continuity of care, suicide risk, complex care at home, and confidentiality.

Conclusions: This study was the first national prioritisation exercise to identify patient and health care professional priorities for primary care patient safety research. The research priorities identified a range of important gaps in the existing evidence to inform everyday practice to address primary care patient safety.

Key words: patient safety; primary care; James Lind Alliance; pharmacy; general practice

Strengths and limitations of this study

- This is the first national research prioritisation exercise to identify primary care patient safety research priorities.

For peer review only

- The study adheres to the James Lind Alliance process and principles of being patient- and health care professional-centric.
- The top 10 research uncertainties for primary care patient safety research were identified in the process.
- While the process identifies the top 10, and top 30, research priorities for future research it is not guaranteed that this will be funded.
- The process identified new areas of research focus as well as understanding how existing clinical concepts might be understood from a patient safety perspective.

INTRODUCTION

Patient safety in healthcare is a policy priority at international, national, regional and local levels and is important to, and the responsibility of, everyone. Globally the majority of patient contacts with healthcare occur out of hospitals in primary care, family medicine and transitional settings between providers, yet patient safety research has been done mostly in hospital settings [1]. Patient safety can be defined as "the avoidance, prevention, and amelioration of adverse outcomes or injuries stemming from the processes of healthcare" [2]. The knowledge base to inform safer care and clinical decision making needs to be expanded to address questions that are needed in everyday clinical practice and potential strategies for system-wide improvement of care safety need to be prioritised [3]. Primary care includes a number of healthcare areas including general practice, community pharmacies, dentistry, high street optometrists and others working in community settings. The nature of much of the clinical work in primary care centres on treatment uncertainties, which are often complex and not necessarily acute in nature, and co-ordination across services, which poses many challenges to patient safety [4,5].

Clinical research aims to improve the evidence upon which decisions are made about prevention, treatment, care, management and cure whilst avoiding a waste of research resources [6]. In the last ten years there has been a growth in primary care patient safety research [1], which has focused mostly on medication safety and errors. As there is limited time and resources available for research it is important that priority is given to areas of patient and healthcare professional priority to address issues that affect everyday practice [7]. There is an increasing recognition of the role of

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

patients and healthcare professionals in co-setting the research agenda and the research community has been challenged to prioritise and fund research questions that are of relevance to a diverse range of stakeholders, including patients and healthcare professionals [8]. The James Lind Alliance (JLA) priority setting partnership (PSP) approach works with patients, carers and healthcare professionals to identify the priorities that are most important for research to address [9]. There have been over 60 JLA PSPs investigating a range of treatment uncertainties, which focus on discrete clinical topics such as asthma, endometrial cancer, schizophrenia and vitiligo [10-13]. This approach addresses the possible divergence between clinical research and patient priorities, which brings about the largest improvements in our knowledge of disease and service delivery [8].

Involving a wider set of stakeholders in prioritising research questions may identify key areas that have not been prioritised previously by funding bodies [10]. In the UK, the Department of Health funds health and care research through the National Institute for Health Research (NIHR) [14]. The NIHR aims to improve health through research and supports the active involvement of the public to achieve this aim. The JLA is overseen by the NIHR to support the research priorities identified through the partnerships so that they can feed directly in to national funding priorities [14, 15]. The Primary Care Patient Safety PSP pushed the boundaries of the JLA process by looking at unanswered questions in the diverse area of primary care, as opposed to a single clinical topic [4, 16]. The aim of the Primary Care Patient Safety PSP was to identify unanswered research questions in the field of primary care patient safety research and to identify the top research priorities for primary care patient safety from patients, carers, and primary care healthcare professionals.

METHOD

This study followed the JLA methodology [9]. This project was led and funded by the NIHR Greater Manchester Primary Care Patient Safety Translational Research Centre (Greater Manchester PSTRC) which is a partnership between Salford Royal National Health Service (NHS) Foundation Trust and The University of Manchester working with clinical and patient partner organisations. Partner organisations included representatives from the Royal College of General Practitioners, Royal College of Nursing, British Dental Association, Healthwatch Manchester, Carers UK, The Patients Association, Pharmacy Voice, NHS Salford Clinical Commissioning Group, Royal Pharmaceutical Society, and the Lesbian, Gay, Bisexual and Trans (LGBT) Foundation. The JLA provided an independent chair, advised on methodology and facilitated the final prioritisation setting workshop [9].

For peer review only

The University of Manchester Research Ethics Committee approved the study (REC reference: 16141)

Stage 1: Initiation

The first stage involved identifying potential partner organisations to be members of the steering group to direct the project as well as having access to a wide range of potential participants to submit questions and reflected the diversity of people who work and/or use primary care services. The steering group was responsible for from agreeing the initial focus, publicising the PSP, overseeing and collating the priorities as well as taking the final priorities to research funders [9]. Anyone living in the UK who uses primary care services, carers, or who are healthcare professionals in primary care were eligible to participate in the identification and prioritisation of uncertainties. Non-clinical researchers and employees of pharmaceutical or medical devices companies were excluded from the survey [9]. A website was created (http://research.bmh.manchester.ac.uk/PatientSafetyPSP) to advertise the partnership and the online survey.

Stage 2: Gathering 'uncertainties'

The first consultation was conducted via an electronic questionnaire with paper copies available on request. Participants were asked "What are your questions about primary care (general practice, pharmacy, dentistry) patient safety?" and a short demographic survey available through the PSP website (the full survey is available as online supplementary material). The questionnaire was open from 1st June to 13th July, 2016. Participants were recruited via a range of convenience sampling in line with the aim of the JLA approach which promotes that the process is as inclusive as possible of patient and healthcare professional views [9]. The steering group members and the Greater Manchester PSTRC promoted the survey through a range of newsletters to members, social media, and through professional and patient networks.

Stage 3: Analysis and verification of uncertainties

The submitted questions were grouped into key themes. Questions were then analysed to identify duplicates and indicative questions were created when there were multiple questions submitted

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

that asked similar questions. Duplicate questions, comments or questions outside the scope of the PSP were removed. RM led the identification of the indicative questions with initial discussion with SC and JS. The steering group then reviewed the indicative questions, and questions identified as duplicate or out of scope which had been removed, alongside the initial submitted questions to confirm the final question set maintained the intent of the initial submitted questions. Every question was then searched against the existing literature. The literature was searched by an independent group of health information specialists led by SG and JW from Trust library service, Manchester University NHS Foundation Trust used a pre-defined systematic criteria. Analysis of the search results was completed by RM and RA. A question was considered to have met the certainty criteria if a recent (within 5 years) systematic review concluded that there was sufficient evidence to answer the question [11,17].

Stage 4: interim prioritisation

The steering group ranked the questions via an online survey where questions were presented to each member in a random order to reduce bias. The top 60 questions were then taken to a second national survey. The second survey was open from 13th January to 24th January, 2017. Patients, carers and healthcare providers were invited to rank the importance of each of the questions for primary care patient safety research from 'very important' to 'very unimportant.' To reduce bias questions were presented in a random order to each participant.

Stage 5: Final Prioritisation workshop

The top 30 questions ranked as the most important were taken forward to a final prioritisation workshop which was a face-to-face consensus meeting held on the 16th March, 2017. Steering group members, volunteers from partner organisations, patients and carers were recruited through networks to take part in the final workshop. Attendees were divided into 3 equal sized groups with a mix of healthcare professionals, patients and carers. The groups were asked to rank the questions through guided discussion facilitated by three independent JLA advisors. The rankings were then collated and the groups mixed and then ranked the questions a second time. The aggregate ranking from the small group exercise was then taken forward to a whole group discussion where the final order of question priority was agreed. The final top ten most important unanswered questions in primary care patient safety were agreed by the full group (Figure 1).

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Patient Involvement

Patients were involved in the study as members of the steering group as representatives of patient groups. Patient steering group members, along with other steering group members, directed the study, develop and agree the scope of the PSP, recruitment of patients as representatives of patient groups, reviewing and agreeing indicative questions, ranking of questions and in all stages of the prioritisation and dissemination processes through advertising the survey and its results to their networks.

For peer review only

RESULTS

Question gathering

448 participants answered all or part of the initial national free text survey with 237 people submitting 443 questions (see Figure 1). 341 questions were submitted by patients or carers (Table 1). The initial survey yielded 9124 views. 182 submissions either did not include a question or stated that they did not have a question about primary care patient safety (n=144) or did not understand the question (n=38). From the remaining 270 submissions, 443 individual research questions were identified.

Table 1: Participant demographics

Participant characteristic	First survey	Second survey
Patient or carer	341	373
Healthcare professional	86	51
Preferred not to say	3	1
Other	3	19
Left blank	5	3
Age		
16 to 24 years	4	5
25 to 34 years	25	43
35 to 44 years	38	45

45 to 54 years	62	86
55 to 64 years	87	117
65 to 74 years	75	115
75 and over	20	30
Prefer not to say	1	3
Left blank	6	3
Ethnicity		
Arab	1	1
Asian or Asian British: Indian	7	5
Asian or Asian British: Chinese	3	0
Asian or Asian British: Other	1	1
Asian or Asian British: Pakistani	2	3
Black or Black British: Caribbean	4	1
Black or Black British: African	2	0
Black or Black British: Other	1	0
Prefer not to say	7	8
Scottish	0	1
White	411	412
White English	0	1
White and Asian	1	3
White and Black African	1	2
White and Black Caribbean	1	2
White and North African	0	1
White British	0	1
Other	2	0
Missing	2	5
Gender		
Female	225	237
Male	218	202
In another way	1	0
Prefer not to say	0	5
Left blank	4	3
Gender same as at birth		
No	3	1

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Yes	427	434
Prefer not to say	0	5
Left blank	7	7
Did not understand the question	1	0

Analysis and verification of uncertainties

46 questions were excluded as outside of the scope of the PSP; for example a request for research in stem cell research. The remaining 397 questions were then grouped into themes. The key themes identified were medication (n=50), diabetes care (n=46), access (n=32), education and training (n=29), communication (n=28), patient records (n=14), workforce and capacity (n=13), continuity of care (n=10), governance (n=9), multimorbidity (n=7), foot care (n=7), reception (n=6), harm (n=6), out of hours care (n=6), patient awareness of patient safety (n=6), hygiene (n=6) (for all topic themes see table 2).

Table 2: Topic themes of submitted questions

Topic theme	Number of questions submitted
Medication	50
Diabetes care	46
Access	32
Education and training	29
Communication	28
Patient records	14
Workforce and capacity	13
Continuity of care	10
Governance	9
Multimorbidity	7
Foot care	7
Reception	6
Harm	6
Out of hours care	6
Patient awareness of patient safety	6
Hygiene	6
Interface	5
Blood tests	5
Diagnosis	5
Treatment	5
NICE guidance	4
Dispensing	4
Appointment time	3

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Disability	3
Information	3
Long term condition management	3
Pain	3
Risk assessment	3
Multidisciplinary teams	2
Holistic views of patients	2
Understanding patient safety	2
Implementation of research or guidelines	2
Co-ordination of care	2
Confidentiality	2
Cost of safety	2
Intervention development	2
Knowledge	2
Mental health	2
Annual follow-up	2
Patient experience	2
Medical errors	2
Identifying people at risk of suicide	1
Care Quality Commission	1
Definition of patient safety	1
Dementia	1
Diet	1
NHS changes	1
Dental infection	1
Condition awareness	1
Consultation	1
Contextual approaches to safety	1
Errors	1
Geographical differences	1
Health and social care development	1
Impact of patient safety awareness	1
Integrated approach to safety	1
Locum doctors	1
Minor injuries	1
Models of care	1
Obesity	1
Patient engagement with healthcare	1
Palliative care	1
Patient role in safety	1
Physical safety	1
Polypharmacy	1
Population versus personalised care	1
Patient and public involvement	1
Prescription	1
Prevention of issues	1
Priorities	1
Quality improvement	1
Referrals	1
Regional care	1

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Resources	1
Review appointments	1
Safety boundaries	1
Safety causing other issues	1
Safer care at home	1
Service changes	1
Technology	1
Test results	1
Transferability of patient safety initiatives	1
Violent patient management	1
Yellow Card scheme	1

Questions focused on primary care broadly (n=240), General Practice (n=95), patient level self-management (n=30), pharmacy (n=14), out of hours care (n=6), patient and public involvement in research (n=2), and physiotherapy (n=1).

Indicative questions were created from duplicate entries and narrative submissions so that they kept the original meaning of the submission, leaving 216 questions to be verified against the existing literature evidence. All indicative questions were agreed by the steering group. In total, 173 questions were considered unanswered by research.

Interim prioritisation

The 60 most important unanswered research questions were then prioritised by a second national online survey completed by 447 people, including 374 patients or carers. The top 30 questions that were ranked as most important were taken forwards to the final consensus meeting (see table 3 for ranking by patients and healthcare professionals).

Table 3: Ranking of Top 30 questions (final and pre-workshop)

Question	Final rank post workshop	Overall rank (pre final workshop)	Rank pre workshop (by patients or carers)	Rank pre workshop by healthcare professionals
How can patient safety be assured for the most vulnerable in society (e.g. people who are frail, have mental health problems or cognitive impairments)?	1	3	3	5

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

How can we make sure that the whole patient is treated, not just one condition and with mental health and physical health both being treated together?	2	1	1	4
How can we improve safe communication and co-ordination of care between primary and secondary care?	3	10	15	1
In what ways does work intensity, hours worked & staffing levels affect patient safety/near misses?	4	7	9	3
How does continuity of care influence patient safety?	5	11	11	22
How well do patients understand the information that has been conveyed to them during the consultation?	6	9	8	6
What can primary care do to identify and support people who may be at risk of suicide?	7	5	6	8
Which type of practitioner (GP, advanced nurse practitioner, practice nurse) is safest to see which types of patients (acute illnesses, acute on chronic multi-morbid)?	8	22	21	29
How can information within patient medical records be made available to patients and care providers in a way that protects privacy and improves safety and quality of care?	9	30	30	19
How can risks be mitigated to allow for safe complex care at home?	10	29	29	20
Are difficulties in contacting doctors and/or making appointments associated with more delays or errors in diagnosis or other failures of care?	11	15	13	27
How many patients actually know what medication they are taking, what for and what the potential side effects are?	12	20	25	18
What can be done to improve access to GP surgery for someone with mental health problems?	13	8	7	13
How can communication between healthcare professionals be improved for people with multiple long term conditions?	14	2	2	2
How safe is treatment in out of hours care if patient notes are not available?	15	4	5	7
What do patients understand about when they should or shouldn't contact a GP and who they should see instead?	16	25	27	24
How can we encourage patients and clinicians to be more open about patient safety incidents within a culture of learning rather than blame?	17	28	32	14
What steps can be taken to improve patient safety in out of hours care?	18	12	12	17
What is the role of the receptionist in patient		26	24	42

For peer review only

safety i.e. facilitating access to urgent appointments?	19			
How well trained are receptionists as acting as gatekeepers to GPs and prioritising patients?	20	24	22	33
How can GP practices appointment systems (e.g. telephone, online) be improved?	21	13	10	47
What types of prescribing errors are occurring in GP prescribing practice and how often are they occurring?	22	27	31	11
How do GPs inform their patients of the side effects and potential risks when prescribing a new medication?	23	21	19	35
How are medical errors in primary care prevented and recorded?	24	18	20	21
Do GP practices keep patient records up to date to ensure safety when a patient is seen by a different GP?	25	6	4	26
Why is there such a time lag between seeing the hospital consultant and the GP getting information about a medication change?	26	16	17	25
How frequent are the misdiagnosis of symptoms by GPs resulting in patient safety incidents?	27	14	14	23
Do GPs and other healthcare professionals record patients who are vulnerable/at risk in the patient notes?	28	17	16	36
Does seeing a named GP who knows an individual have safer care than seeing a GP who doesn't know me?	29	19	18	45
Do the actions of receptionists have potential ramifications for patient safety?	30	23	23	28

Final prioritisation

A mixed group of 22 stakeholders discussed and ranked the final 30 questions at a final face-to-face meeting (13 patients or carers, 3 GPs, 5 pharmacists and 1 nurse). The discussions were facilitated by independent JLA facilitators [9]. The top 10 questions were agreed by all stakeholders as the most important unanswered questions (see table 4).

Table 4: Top 10 research priorities

1	How can patient safety be assured for the most vulnerable in society (e.g. people who are frail, have mental health problems or cognitive impairments)?

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

2	How can we make sure that the whole patient is treated, not just one condition and with mental health and physical health both being treated together?
3	How can we improve safe communication and co-ordination of care between primary and secondary care?
4	In what ways does work intensity, hours worked and staffing levels affect patient safety/near misses?
5	How does continuity of care influence patient safety?
6	How well do patients understand the information that has been conveyed to them during the consultation?
7	What can primary care do to identify and support people who may be at risk of suicide?
8	Which type of practitioner (GP, advanced nurse practitioner, practice nurse) is safest to see which types of patients (acute illnesses, acute or chronic multi-morbid)?
9	How can information within patient medical records be made available to patients and care providers in a way that protects privacy and improves safety and quality of care?
10	How can risks be mitigated to allow for safe complex care at home?

For peer review only

DISCUSSION

This study has identified the limited evidence available currently to address some key questions and priorities about patient safety in primary care. Of 270 questions submitted, 173 unique questions were identified for prioritisation. The top 10 research priorities (see table 4) included how patient safety can be assured for the most vulnerable in society, taking holistic approaches to care, transitions and communication of care between primary and secondary care, staffing issues, continuity of care, communication between patients and care providers, identifying and support people at risk of suicide, the appropriateness of different practitioners for different types of clinical work, accessing patient medical records and safe care at home. The questions incorporated understanding existing concepts and challenges (e.g. continuity of care, holistic care and communication) with emerging issues and widening the focus of patient safety priorities (e.g. safer care at home or patients accessing their medical records) [18-21]. These results will be used by funders and researchers to identify future research priorities that are most relevance to patients and

healthcare professionals in an attempt to address this lack of evidence to support patient and healthcare professional everyday questions about patient safety in primary care and research activity.

The limited evidence to support patients and healthcare professionals to inform primary care service design and delivery is important given the growing priority of patient safety both nationally and internationally [22]. Whilst the focus of this PSP was within the UK, the top 10 uncertainties reflect many universal commonalities addressing patient safety in care delivery and management (such as staffing issues, communications, and transitions between care settings) that are of relevance internationally and for which there are limited tools or strategies to measure, monitor and improve patient safety; for example, diagnostics and transitions of care [1]. The fact that the number one priority was about understanding patient safety for the most vulnerable in society is particularly relevant given that this includes people where there has traditionally received less research focus [23]. Furthermore, the recognition of treating the patient as a whole person, rather than focusing on individual conditions, is of particular relevance given that many of the guidelines and support available has focused on individual conditions (for example, in the UK the National Institute for Health and Care Excellence [24]) and do not address the everyday decisions and prioritisations that patients and healthcare professionals must make when faced with multiple conditions and treatment options [25,26].

Communication and care co-ordination was a focus of many questions that were submitted, despite the fact that there is a large body of research in these areas and these issues. In addition, a focus on holistic care is not a new priority with personal and holistic care having been advocated for many years [27], suggesting that in an ever more complex and digital era of medicine, personal care remains of importance. It suggests also that there remains a gap between rhetoric and reality [28]. It is still not understood clearly how these issues are conceptualised and understood from a patient safety perspective; for example, continuity of care [29]. This suggests that there remain unanswered questions about how to implement research into practice and potentially the impact, or awareness, of research to inform policy, commissioning and clinical practice [8, 22, 30]. Whilst research exists in part to address some of these questions [31], there remains an imbalance of research evidence across primary care professions that responds to the context in which decisions are being made by

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

different professionals (e.g. dentists, pharmacists, practice nurses) and a lack of strong evidence, improvement studies or replication studies to support these decisions [32].

Strengths and limitations of the study

This was a large national prioritisation exercise with 341 patients and/or carers, and 94 healthcare professionals submitting questions and the priorities identified unanswered question which are of relevance across the UK. The imbalance of submissions between patients and healthcare professional was noticeable given the targeted approach by representatives of primary healthcare professional groups and professional networks. Adverts were sent to members of various organisations including patient support groups, members of professional organisations as well as through Twitter and other non-specific targeted adverts. Although this process is unlikely to be representative given that certain groups maybe more active and more likely to submit questions, this is mitigated by the process of creating indicative questions for similar submissions and the prioritisation exercises meaning that the final top 10 questions were from the full range of submissions reflecting patient and health care professional priorities. The breadth of different key stakeholders throughout the process was a strength, which ensured the credibility and relevance of the top 10 throughout the process [11, 33, 34]. However, the JLA procedure excludes non-clinical researchers, whilst including clinical researchers [9], assumes healthcare professional researchers are able to remove their research bias whereas non-clinical researchers (who may be users of primary care services as either patients or carers) are not. One potential limitation of this process is the breadth of questions that were submitted, as primary care is a broad and diverse service area and some questions suggested large programmes of research (for example: "*At what level can patient safety interventions in primary care be applied, e.g. nationally, regionally, clinical commissioning groups, practice cluster, practice, individual clinician, patient?*"). These questions were deliberately kept broad in order to ensure that questions kept the original intent of the submitted question in align with the JLA process. Rephrasing and indicative question were checked by the steering group to ensure that the original intent of the questions were maintained but it was difficult in some circumstances to be able to focus the question to fit within a searchable criteria. The questions are generally broad, potential programmes of work which reflects the broad nature of the question focusing on a core component of service delivery rather than a specific disease focus. In these instances, we were as open and inclusive in the literature searching and reviewing as possible. Another strength of this approach was that the areas of priority from the initial open survey were reflected in the top 10 final priorities: communication, team and system working,

For peer review only

interfaces across primary and secondary care, medication, self-management support and technology. One limitation of this study is that the majority of patients who completed the first survey were white (92%) and over 55 (58%) despite broad promotional activities. A consultation process like this will be more likely to reach people who were more engaged with research and this is a similar critique to the evaluations of other patient and public involvement activities who were more likely to involve white, older people [23]. Engaging with black and minority ethnic groups across a range of ages is an important component of future work.

Future work

This project will inform the development of future research priorities and funding applications. It is important that research in primary care patient safety prioritises questions that address practical issues to support care delivery and use. Future research could focus on understanding the priorities for particular communities, such as black and minority ethnic groups, who have often not participated in traditional research and patient and public involvement.

Conclusions

The top 10 primary care patient safety research priorities were generated using an established transparent and systematic approach. The research priorities covered a range of areas of priority for patients, carers and healthcare professionals; how patient safety can be assured for the most vulnerable in society, taking holistic approaches to care, transitions and communication of care between primary and secondary care, staffing issues, continuity of care, communication between patients and care providers, identifying and support people at risk of suicide, the appropriateness of different practitioners for different types of clinical work, accessing patient medical records and safe care at home. These findings will be used to address these issues to set the research agenda to support patients, carers and healthcare professionals and to maximise the utility and impact of patient safety research in primary care.

What is already known on this topic

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Patient safety in healthcare is an international priority for research and practice but despite the majority of patient contacts occurring in primary care the majority of research to inform practice has occurred in secondary care.

What this study adds

The top priorities for primary care patient safety research for healthcare professionals and patients focused on the most vulnerable in society, holistic whole-person care, safer communication and co-ordination between care providers, work intensity and continuity of care.

Acknowledgements

The authors would like to thank all the participants who took part in the study and everyone who promoted the surveys. We would like to thank our JLA advisor, Richard Morley, for his guidance and advice and the JLA advisors who facilitated the final workshop. We would like to thank all of the steering group members for their support to steer and promote the PSP (in alphabetical order): Rose Gallagher, Royal College of Nursing; Barry Kinshuck, British Dental Association; Alison Lea, Royal College of General Practitioners; Mike Molete, Healthwatch Manchester and Carers UK; Katherine Murphy, the Patients Association; Janice Perkins, Pharmacy Voice; Claire Vaughan, National Health Service Salford Clinical Commissioning Group; Mags Watson, Royal Pharmaceutical Society; and Laurence Webb, Lesbian, Gay, Bisexual and Trans Foundation. We would also like to thank the following information specialists for their help in running searches of the literature: Stephen Woods and Olivia Schaff from University Hospital of South Manchester library, and Elham Aalai and Michelle Dutton from Central Manchester Foundation Trust library.

Funding Acknowledgement

The National Institute for Health Research Greater Manchester Primary Care Patient Safety Translational Research Centre (NIHR Greater Manchester PSTRC) funded this study. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR, or the Department of Health.

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Competing interests declaration

We have read and understood BMJ policy on declaration of interests and declare that we have no competing interests

Details of author contributions

SC and ST designed the study and convened the steering group. RM led the study, carried out data collection, analysis, and interpretation of data. CR was responsible for promoting the surveys and co-ordinating members of the steering group. RA and JS were involved in the data collection and interpretation. SG and JW led the literature searching. RM drafted the initial manuscript and all authors have been involved in revising the manuscript and have given final approval of the version to be published. RM is the guarantor.

All authors, external and internal, had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Identifiable patient information

No identifiable patient information has been included in the manuscript.

Data sharing statement

Data sharing: no additional data available

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

For peer review only

REFERENCES

1. Spencer R, Campbell SM. Tools for primary care: a narrative review. BMC Fam Pract. 2014. 15: 166
2. Vincent C, Burnett S, Carthey J. The Measurement and Monitoring of Safety. 2013, Available from; http://www.health.org.uk/publications/the-measurement-and-monitoring-of-safety/.
3. Liberati A. Need to realign patient-oriented and commercial and academic research. Lancet 2011; 378: 1777–1778
4. Wilson T, Pringle M, Sheikh A. Promoting patient safety in primary care. 2001; 323: 583.
5. KingsFund. Improving the quality of care in general practice. 2011. https://www.kingsfund.org.uk/sites/files/kf/field/field_related_document/gp-inquiry-report-evolving-role-nature-2mar11.pdf
6. Moher D, Glasziou P, Chalmers I et al. Increasing value and reducing waste in biomedical research: who's listening? Lancet. 2016; 10027: 1573-1586
7. Tallon D, Chard J, Dieppe P. Relation between agendas of the research community and the research consumer. Lancet. 2000; 355: 9220, 2037-2040
8. Crowe S, Giles C. Making patient relevant research a reality. BMJ 2016; 355.
9. NETSCC & Cowan K. The James Lind Alliance Guidebook. 2016. Available from http://www.jla.nihr.ac.uk/jla-guidebook/downloads/JLA-Guidebook-Version-6-February-2016.pdf
10. Elwyn G, Crowe S, Fenton MA, et al. Identifying and prioritizing uncertainties: patient and clinician engagement in the identification of research questions. J Eval Clin Pract. 2010: 16: 3; 627-631
11. Wan Y L, Beverley-Stevenson R, Carlisle D et al. Working together to shape the endometrial cancer research agenda: The top ten unanswered research questions. Gynecol Oncol, 2016; 143: 287-293

12. Lloyd K, Rose D, Fenton M, Identifying uncertainties about the effects of treatments for schizophrenia. J Ment Health. 2006; 15: 3, 263-268.
13. Eleftheriadou V, Whitton ME, Gawkrodger DJ et al. Future research into the treatment of vitiligo: where should our priorities lie? Results of the vitiligo priority setting partnership. B J Dermatol, 2011; 164: 3, 530-536.
14. NIHR. National Research Context. 2017. Available from: https://www.nihr.ac.uk/about-us/our-purpose/national-research-context/
15. INVOLVE. Exploring the Impact of Public Involvement on the Quality of Research: Examples. Eastleigh, UK: INVOLVE, 2013
16. Chalmers I, Atkinson P, Fenton M et al. Tackling treatment uncertainties together: the evolution of the James Lind Initiative, 2003 - 2013. *Journal of the Royal Society of Medicine*, 2013; 106: 12, 482-491
17. Howick I, Chalmers P, Glasziou T, et al. Explanation of the 2011 Oxford Centre for Evidence-Based Medicine (OCEBM) levels of evidence. 2011. Available from: http://www.cebm.net/wp-content/uploads/2014/06/CEBM-Levels-of-Evidence-Background-Document-2.1.pdf
18. NHS England. 2017. Available from: http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/what_to_do.aspx
19. NHS England. 2014. Available from: https://www.england.nhs.uk/2014/12/patient-online-increase/
20. Patients Association. 2017. Available from: https://www.patients-association.org.uk/wp-content/uploads/2017/08/Seeing-your-medical-records.-1.pdf
21. ABPI. 2017. Available from: http://www.abpi.org.uk/media-centre/newsreleases/2017/Pages/New-partnership-set-to-help-%E2%80%98transform%E2%80%99-access-to-medicines-for-patients-in-Greater-Manchester-24.02.17.aspx
22. Chalmers I, Glasziou P. Avoidable waste in the production and reporting of research evidence. Lancet. 2009 4;374(9683):86-9
23. Redwood S, Gill PS. Under-representation of minority ethnic groups in research — call for action. Br J Gen Pract. 2013; 63(612): 342–343.
24. NICE. 2017. Available from: https://www.nice.org.uk/
25. Moffat K, Mercer, SW. Challenges of managing people with multimorbidity in today's healthcare systems. BMC Family Practice. 2015; 16:129
26. Morris RL, Sanders C, Kennedy AP et al. Shifting priorities in multimorbidity: a longitudinal qualitative study of patient's prioritization of multiple conditions. Chronic Illn 2011; 7(2):147-161.
27. Tarrant C, Windridge K, Boulton M et al. Qualitative study of the meaning of personal care in general practice. BMJ. 2003: 326
28. Wilson T, Roland M, Ham C. The contribution of general practice and the general practitioner to NHS patients. J R Soc Med. 2006. 99:1
29. Rhodes P, McDonald R, Campbell S et al. Sensemaking and the co-production of safety: a qualitative study of primary medical care patients. Sociol Health Illn. 2016; 38: 2: 270-285
30. Grimshaw JM, Eccles MP, Lavins JN. Knowledge translation of research findings. Implement Sci. 2012; 7: 50.
31. Panesar SS, deSilva D, Carson-Stevens A et al. How safe is primary care? A systematic review. BMJ Qual Saf. 2016; 25:544-553
32. Wynia MK, Classen DC. Improving ambulatory patient safety: learning from the last decade, moving ahead in the next. JAMA. 2011; 14; 306:2504-5

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

33. Bryant J, Sanson-Fisher R, Walsh et al. Health research priority setting in selected high income countries: a narrative review of methods used and recommendations for future practice, Cost Eff. Resour. Alloc. 2014; 12: 23
34. Sibbald SL, Singer PA, Upshur R et al. Priority setting: what constitutes success? A conceptual framework for successful priority setting. BMC Health Serv Res. 2009; 9: 43.

FIGURE LEGEND

Figure 1: Summary of the James Lind Alliance Priority Setting Partnership

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

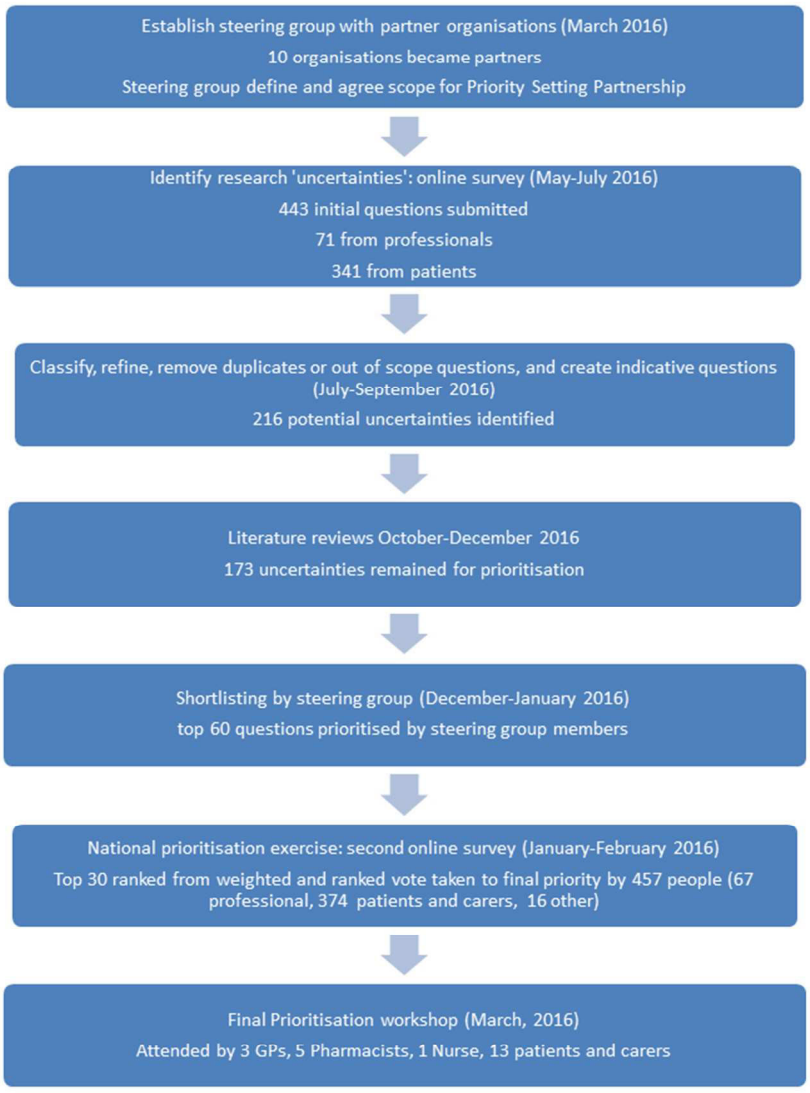

Figure 1: Summary of the James Lind Alliance Priority Setting Partnership

190x254mm (96 x 96 DPI)

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open

Patient safety in primary care: where next for research and practice? A James Lind Alliance Priority Setting Partnership

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-020870.R1
Article Type:	Research
Date Submitted by the Author:	22-Dec-2017
Complete List of Authors:	Morris, Rebecca L.; University of Manchester, NIHR Greater Manchester Patient Safety Translational Research Centre Stocks, Susan; University of Manchester, NIHR Greater Manchester Patient Safety Translational Research Centre Alam, Rahul; University of Manchester, NIHR Greater Manchester Patient Safety Translational Research Centre Taylor, Sian; University of Manchester, NIHR Greater Manchester Patient Safety Translational Research Centre Rolfe, Carly; University of Manchester, NIHR Greater Manchester Patient Safety Translational Research Centre Glover, Steven; Manchester University NHS Foundation , Trust library service Whitcombe, Joanne; Manchester University NHS Foundation , Trust library service Campbell, Stephen; University of Manchester, Centre for Primary Care
Primary Subject Heading:	Health services research
Secondary Subject Heading:	General practice / Family practice
Keywords:	James Lind Alliance, Patient safety, PRIMARY CARE, pharmacy, general practice

SCHOLARONE™
Manuscripts

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Title: Patient safety in primary care: where next for research and practice? A James Lind Alliance Priority Setting Partnership

Authors

Dr Rebecca Lauren Morris*, NIHR Greater Manchester Patient Safety Translational Research Centre, Centre for Primary Care, University of Manchester, 6th Floor Williamson Building, Oxford Road, Manchester, M13 9PL, UK. Email: Rebecca.morris@manchester.ac.uk. Telephone: 0161 27 50748.

*Corresponding author

Dr Jill Stocks, NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester, Manchester, UK

Dr Rahul Alam, NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester, Manchester, UK

Dr Sian Taylor, NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester, Manchester, UK

Ms Carly Rolfe, NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester, Manchester, UK

Mr Steven William Glover, Trust library service, Manchester University NHS Foundation Trust, Manchester, UK

Ms Joanne Whitcombe Trust library service, Manchester University NHS Foundation Trust, Manchester, UK

Professor Stephen Campbell, NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester, Manchester, UK

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Abstract

Objectives: to identify the top 10 unanswered research questions for primary care patient safety research.

Design: a modified nominal group technique.

Setting: UK

Participants: Anyone with experience of primary care including: patients, carers and healthcare professionals. 341 patients and 86 healthcare professionals submitted questions.

Main outcomes: A top 10, and top 30, future research questions for primary care patient safety

Results: 443 research questions were submitted by 341 patients and 86 healthcare professionals, through a national survey. After checking for relevance and rephrasing, a total of 173 questions were collated into themes. The themes were largely focused on communication, team and system working, interfaces across primary and secondary care, medication, self-management support and technology. The questions were then prioritised through a national survey, the top 30 questions were taken forward to the final prioritisation workshop. The top 10 research questions focused on the most vulnerable in society, holistic whole-person care, safer communication and co-ordination between care providers, work intensity, continuity of care, suicide risk, complex care at home, and confidentiality.

Conclusions: This study was the first national prioritisation exercise to identify patient and health care professional priorities for primary care patient safety research. The research priorities identified a range of important gaps in the existing evidence to inform everyday practice to address primary care patient safety.

Key words: patient safety; primary care; James Lind Alliance; pharmacy; general practice

Strengths and limitations of this study

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

- This is the first national research prioritisation exercise to identify primary care patient safety research priorities.
- The study adheres to the James Lind Alliance process and principles of being patient- and health care professional-centric.
- The top 10 research uncertainties for primary care patient safety research were identified in the process.
- While the process identifies the top 10, and top 30, research priorities for future research it is not guaranteed that this will be funded.
- The process identified new areas of research focus as well as understanding how existing clinical concepts might be understood from a patient safety perspective.

INTRODUCTION

Patient safety in healthcare is a policy priority at international, national, regional and local levels and is important to, and the responsibility of, everyone. Globally the majority of patient contacts with healthcare occur out of hospitals in primary care, family medicine and transitional settings between providers, yet patient safety research has been done mostly in hospital settings [1]. Patient safety can be defined as "the avoidance, prevention, and amelioration of adverse outcomes or injuries stemming from the processes of healthcare" [2]. The knowledge base to inform safer care and clinical decision making needs to be expanded to address questions that are needed in everyday clinical practice and potential strategies for system-wide improvement of care safety need to be prioritised [3]. Primary care includes a number of healthcare areas including general practice, community pharmacies, dentistry, high street optometrists and others working in community settings. The nature of much of the clinical work in primary care centres on treatment uncertainties, which are often complex and not necessarily acute in nature, and co-ordination across services, which poses many challenges to patient safety [4,5].

Clinical research aims to improve the evidence upon which decisions are made about prevention, treatment, care, management and cure whilst avoiding a waste of research resources [6]. In the last ten years there has been a growth in primary care patient safety research [1], which has focused mostly on medication safety and errors. As there is limited time and resources available for research

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

it is important that priority is given to areas of patient and healthcare professional priority to address issues that affect everyday practice [7]. There is an increasing recognition of the role of patients and healthcare professionals in co-setting the research agenda and the research community has been challenged to prioritise and fund research questions that are of relevance to a diverse range of stakeholders, including patients and healthcare professionals [8]. The James Lind Alliance (JLA) priority setting partnership (PSP) approach works with patients, carers and healthcare professionals to identify the priorities that are most important for research to address [9]. There have been over 60 JLA PSPs investigating a range of treatment uncertainties, which focus on discrete clinical topics such as asthma, endometrial cancer, schizophrenia and vitiligo [10-13]. This approach addresses the possible divergence between clinical research and patient priorities, which brings about the largest improvements in our knowledge of disease and service delivery [8].

Involving a wider set of stakeholders in prioritising research questions may identify key areas that have not been prioritised previously by funding bodies [10]. In the UK, the Department of Health funds health and care research through the National Institute for Health Research (NIHR) [14]. The NIHR aims to improve health through research and supports the active involvement of the public to achieve this aim. The JLA is overseen by the NIHR to support the research priorities identified through the partnerships so that they can feed directly in to national funding priorities [14, 15]. The Primary Care Patient Safety PSP pushed the boundaries of the JLA process by looking at unanswered questions in the diverse area of primary care, as opposed to a single clinical topic [4, 16]. The aim of the Primary Care Patient Safety PSP was to identify unanswered research questions in the field of primary care patient safety research and to identify the top research priorities for primary care patient safety from patients, carers, and primary care healthcare professionals.

METHOD

This study followed the JLA methodology [9]. This project was led and funded by the NIHR Greater Manchester Primary Care Patient Safety Translational Research Centre (Greater Manchester PSTRC) which is a partnership between Salford Royal National Health Service (NHS) Foundation Trust and The University of Manchester working with clinical and patient partner organisations. Partner organisations included representatives from the Royal College of General Practitioners, Royal College of Nursing, British Dental Association, Healthwatch Manchester, Carers UK, The Patients Association, Pharmacy Voice, NHS Salford Clinical Commissioning Group, Royal Pharmaceutical Society, and the

For peer review only

Lesbian, Gay, Bisexual and Trans (LGBT) Foundation. The JLA provided an independent chair, advised on methodology and facilitated the final prioritisation setting workshop [9].

The University of Manchester Research Ethics Committee approved the study (REC reference: 16141)

Stage 1: Initiation

Steering group set up

The first stage involved identifying potential partner organisations to be members of the steering group to direct the project as well as having access to a wide range of potential participants to submit questions and reflected the diversity of people who work and/or use primary care services. The steering group included representatives from the Royal College of Nursing; the British Dental Association; the Royal College of General Practitioners; Healthwatch Manchester; Carers UK; the Patients Association; Pharmacy Voice; National Health Service Salford Clinical Commissioning Group; Royal Pharmaceutical Society; and Lesbian, Gay, Bisexual and Trans Foundation The steering group was responsible for from agreeing the initial focus, publicising the PSP, overseeing and collating the priorities as well as taking the final priorities to research funders [9].

Project initiation and eligibility

Anyone living in the UK who uses primary care services, carers, or who are healthcare professionals in primary care were eligible to participate in the identification and prioritisation of uncertainties. Non-clinical researchers and employees of pharmaceutical or medical devices companies were excluded from the survey [9]. A website was created (http://research.bmh.manchester.ac.uk/PatientSafetyPSP) to advertise the partnership and the online survey.

Stage 2: Gathering 'uncertainties'

The first consultation was conducted via an electronic questionnaire with paper copies available on request (online supplementary material 1). Participants were asked "What are your questions about primary care (general practice, pharmacy, dentistry) patient safety?" and a short demographic

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

survey available through the PSP website (the full survey is available as online supplementary material). The questionnaire was open from 1st June to 13th July, 2016. Participants were recruited via a range of convenience sampling in line with the aim of the JLA approach which promotes that the process is as inclusive as possible of patient and healthcare professional views [9]. The steering group members and the Greater Manchester PSTRC promoted the survey through a range of newsletters to members, social media, and through professional and patient networks.

Stage 3: Analysis and verification of uncertainties

The submitted questions were grouped into key themes. Questions were then analysed to identify duplicates and indicative questions were created when there were multiple questions submitted that asked similar questions. Duplicate questions, comments or questions outside the scope of the PSP were removed. RM led the identification of the indicative questions with initial discussion with SC and JS. The steering group then reviewed the indicative questions, and questions identified as duplicate or out of scope which had been removed, alongside the initial submitted questions to confirm the final question set maintained the intent of the initial submitted questions. Every question was then searched against the existing literature. The literature was searched by an independent group of health information specialists led by SG and JW from Trust library service, Manchester University NHS Foundation Trust used a pre-defined systematic criteria. Analysis of the search results was completed by RM and RA. A question was considered to have met the certainty criteria if a recent (within 5 years) systematic review concluded that there was sufficient evidence to answer the question [11,17].

Stage 4: interim prioritisation

The steering group ranked the questions via an online survey where questions were presented to each member in a random order to reduce bias. The top 60 questions were then taken to a second national survey. The second survey was open from 13th January to 24th January, 2017. Patients, carers and healthcare providers were invited to rank the importance of each of the questions for primary care patient safety research from 'very important' to 'very unimportant.' To reduce bias questions were presented in a random order to each participant.

Stage 5: Final Prioritisation workshop

For peer review only

The top 30 questions ranked as the most important were taken forward to a final prioritisation workshop which was a face-to-face consensus meeting held on the 16th March, 2017. Steering group members, volunteers from partner organisations, patients and carers were recruited through networks to take part in the final workshop. Attendees were divided into 3 equal sized groups with a mix of healthcare professionals, patients and carers. The groups were asked to rank the questions through guided discussion facilitated by three independent JLA advisors. The rankings were then collated and the groups mixed and then ranked the questions a second time. The aggregate ranking from the small group exercise was then taken forward to a whole group discussion where the final order of question priority was agreed. The final top ten most important unanswered questions in primary care patient safety were agreed by the full group (Figure 1).

Patient Involvement

Patients were involved in the study as members of the steering group as representatives of patient groups. Patient steering group members, along with other steering group members, directed the study, develop and agree the scope of the PSP, recruitment of patients as representatives of patient groups, reviewing and agreeing indicative questions, ranking of questions and in all stages of the prioritisation and dissemination processes through advertising the survey and its results to their networks.

RESULTS

Question gathering

448 participants answered all or part of the initial national free text survey with 237 people submitting 443 questions (see Figure 1). 341 questions were submitted by patients or carers (Table 1). The initial survey yielded 9124 views. 182 submissions either did not include a question or stated that they did not have a question about primary care patient safety (n=144) or did not understand the question (n=38). From the remaining 270 submissions, 443 individual research questions were identified.

Table 1: Participant demographics

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Participant characteristic	First survey	Second survey
Patient or carer	341	373
Healthcare professional	86	51
Preferred not to say	3	1
Other	3	19
Left blank	5	3
Age		
16 to 24 years	4	5
25 to 34 years	25	43
35 to 44 years	38	45
45 to 54 years	62	86
55 to 64 years	87	117
65 to 74 years	75	115
75 and over	20	30
Prefer not to say	1	3
Left blank	6	3
Ethnicity		
Arab	1	1
Asian or Asian British: Indian	7	5
Asian or Asian British: Chinese	3	0
Asian or Asian British: Other	1	1
Asian or Asian British: Pakistani	2	3
Black or Black British: Caribbean	4	1
Black or Black British: African	2	0
Black or Black British: Other	1	0
Prefer not to say	7	8
Scottish	0	1
White	411	412
White English	0	1
White and Asian	1	3
White and Black African	1	2
White and Black Caribbean	1	2
White and North African	0	1
White British	0	1
Other	2	0

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Missing	2	5
Gender		
Female	225	237
Male	218	202
In another way	1	0
Prefer not to say	0	5
Left blank	4	3
Gender same as at birth		
No	3	1
Yes	427	434
Prefer not to say	0	5
Left blank	7	7
Did not understand the question	1	0
Sexual orientation		
Lesbian or Gay	13	Unknown
Bisexual	6	Unknown
Heterosexual	392	Unknown
Other	3	Unknown
Prefer not to say	15	Unknown
Left blank	19	Unknown

Analysis and verification of uncertainties

46 questions were excluded as outside of the scope of the PSP; for example a request for research in stem cell research. The remaining 397 questions were then grouped into themes. The key themes identified were medication (n=50), diabetes care (n=46), access (n=32), education and training (n=29), communication (n=28), patient records (n=14), workforce and capacity (n=13), continuity of care (n=10), governance (n=9), multimorbidity (n=7), foot care (n=7), reception (n=6), harm (n=6), out of hours care (n=6), patient awareness of patient safety (n=6), hygiene (n=6) (for all topic themes see table 2).

Table 2: Topic themes of submitted questions

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Topic theme	Number of questions submitted
Medication	50
Diabetes care	46
Access	32
Education and training	29
Communication	28
Patient records	14
Workforce and capacity	13
Continuity of care	10
Governance	9
Multimorbidity	7
Foot care	7
Reception	6
Harm	6
Out of hours care	6
Patient awareness of patient safety	6
Hygiene	6
Interface	5
Blood tests	5
Diagnosis	5
Treatment	5
NICE guidance	4
Dispensing	4
Appointment time	3
Disability	3
Information	3
Long term condition management	3
Pain	3
Risk assessment	3
Multidisciplinary teams	2
Holistic views of patients	2
Understanding patient safety	2
Implementation of research or guidelines	2
Co-ordination of care	2
Confidentiality	2
Cost of safety	2
Intervention development	2
Knowledge	2
Mental health	2
Annual follow-up	2
Patient experience	2
Medical errors	2
Identifying people at risk of suicide	1
Care Quality Commission	1
Definition of patient safety	1
Dementia	1
Diet	1
NHS changes	1
Dental infection	1
Condition awareness	1

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Consultation	1
Contextual approaches to safety	1
Errors	1
Geographical differences	1
Health and social care development	1
Impact of patient safety awareness	1
Integrated approach to safety	1
Locum doctors	1
Minor injuries	1
Models of care	1
Obesity	1
Patient engagement with healthcare	1
Palliative care	1
Patient role in safety	1
Physical safety	1
Polypharmacy	1
Population versus personalised care	1
Patient and public involvement	1
Prescription	1
Prevention of issues	1
Priorities	1
Quality improvement	1
Referrals	1
Regional care	1
Resources	1
Review appointments	1
Safety boundaries	1
Safety causing other issues	1
Safer care at home	1
Service changes	1
Technology	1
Test results	1
Transferability of patient safety initiatives	1
Violent patient management	1
Yellow Card scheme	1

Questions focused on primary care broadly (n=240), General Practice (n=95), patient level self-management (n=30), pharmacy (n=14), out of hours care (n=6), patient and public involvement in research (n=2), and physiotherapy (n=1).

Indicative questions were created from duplicate entries and narrative submissions so that they kept the original meaning of the submission, leaving 216 questions to be verified against the existing literature evidence. All indicative questions were agreed by the steering group. In total, 173 questions were considered unanswered by research.

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Interim prioritisation

The 60 most important unanswered research questions were then prioritised by a second national online survey completed by 447 people, including 374 patients or carers (online supplementary material 2). The top 30 questions that were ranked as most important were taken forwards to the final consensus meeting (see table 3 for ranking by patients and healthcare professionals).

Table 3: Ranking of Top 30 questions (final and pre-workshop)

Question	Final rank post workshop	Overall rank (pre final workshop)	Rank pre workshop (by patients or carers)	Rank pre workshop by healthcare professionals
How can patient safety be assured for the most vulnerable in society (e.g. people who are frail, have mental health problems or cognitive impairments)?	1	3	3	5
How can we make sure that the whole patient is treated, not just one condition and with mental health and physical health both being treated together?	2	1	1	4
How can we improve safe communication and co-ordination of care between primary and secondary care?	3	10	15	1
In what ways does work intensity, hours worked & staffing levels affect patient safety/near misses?	4	7	9	3
How does continuity of care influence patient safety?	5	11	11	22
How well do patients understand the information that has been conveyed to them during the consultation?	6	9	8	6
What can primary care do to identify and support people who may be at risk of suicide?	7	5	6	8
Which type of practitioner (GP, advanced nurse practitioner, practice nurse) is safest to see which types of patients (acute illnesses, acute on chronic multi-morbid)?	8	22	21	29
How can information within patient medical records be made available to patients and care providers in a way that protects privacy and improves safety and quality of care?	9	30	30	19
How can risks be mitigated to allow for safe complex care at home?	10	29	29	20

For peer review only

Are difficulties in contacting doctors and/or making appointments associated with more delays or errors in diagnosis or other failures of care?	11	15	13	27
How many patients actually know what medication they are taking, what for and what the potential side effects are?	12	20	25	18
What can be done to improve access to GP surgery for someone with mental health problems?	13	8	7	13
How can communication between healthcare professionals be improved for people with multiple long term conditions?	14	2	2	2
How safe is treatment in out of hours care if patient notes are not available?	15	4	5	7
What do patients understand about when they should or shouldn't contact a GP and who they should see instead?	16	25	27	24
How can we encourage patients and clinicians to be more open about patient safety incidents within a culture of learning rather than blame?	17	28	32	14
What steps can be taken to improve patient safety in out of hours care?	18	12	12	17
What is the role of the receptionist in patient safety i.e. facilitating access to urgent appointments?	19	26	24	42
How well trained are receptionists as acting as gatekeepers to GPs and prioritising patients?	20	24	22	33
How can GP practices appointment systems (e.g. telephone, online) be improved?	21	13	10	47
What types of prescribing errors are occurring in GP prescribing practice and how often are they occurring?	22	27	31	11
How do GPs inform their patients of the side effects and potential risks when prescribing a new medication?	23	21	19	35
How are medical errors in primary care prevented and recorded?	24	18	20	21
Do GP practices keep patient records up to date to ensure safety when a patient is seen by a different GP?	25	6	4	26
Why is there such a time lag between seeing the hospital consultant and the GP getting information about a medication change?	26	16	17	25
How frequent are the misdiagnosis of symptoms by GPs resulting in patient safety incidents?	27	14	14	23
Do GPs and other healthcare professionals record patients who are vulnerable/at risk in the patient notes?	28	17	16	36
Does seeing a named GP who knows an		19	18	45

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

individual have safer care than seeing a GP who doesn't know me?	29			
Do the actions of receptionists have potential ramifications for patient safety?	30	23	23	28

Final prioritisation

A mixed group of 22 stakeholders discussed and ranked the final 30 questions at a final face-to-face meeting (13 patients or carers, 3 GPs, 5 pharmacists and 1 nurse). The discussions were facilitated by independent JLA facilitators [9]. The top 10 questions were agreed by all stakeholders as the most important unanswered questions (see table 4).

Table 4: Top 10 research priorities

1	How can patient safety be assured for the most vulnerable in society (e.g. people who are frail, have mental health problems or cognitive impairments)?
2	How can we make sure that the whole patient is treated, not just one condition and with mental health and physical health both being treated together?
3	How can we improve safe communication and co-ordination of care between primary and secondary care?
4	In what ways does work intensity, hours worked and staffing levels affect patient safety/near misses?
5	How does continuity of care influence patient safety?
6	How well do patients understand the information that has been conveyed to them during the consultation?
7	What can primary care do to identify and support people who may be at risk of suicide?
8	Which type of practitioner (GP, advanced nurse practitioner, practice nurse) is safest to see which types of patients (acute illnesses, acute or chronic multi-morbid)?
9	How can information within patient medical records be made available to patients and care providers in a way that protects privacy and improves safety and quality of care?
10	How can risks be mitigated to allow for safe complex care at home?

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

DISCUSSION

This study has identified the limited evidence available currently to address some key questions and priorities about patient safety in primary care. Of 270 questions submitted, 173 unique questions were identified for prioritisation. The top 10 research priorities (see table 4) included how patient safety can be assured for the most vulnerable in society, taking holistic approaches to care, transitions and communication of care between primary and secondary care, staffing issues, continuity of care, communication between patients and care providers, identifying and support people at risk of suicide, the appropriateness of different practitioners for different types of clinical work, accessing patient medical records and safe care at home. The questions incorporated understanding existing concepts and challenges (e.g. continuity of care, holistic care and communication) with emerging issues and widening the focus of patient safety priorities (e.g. safer care at home or patients accessing their medical records) [18-21]. These results will be used by funders and researchers to identify future research priorities that are most relevance to patients and healthcare professionals in an attempt to address this lack of evidence to support patient and healthcare professional everyday questions about patient safety in primary care and research activity.

The limited evidence to support patients and healthcare professionals to inform primary care service design and delivery is important given the growing priority of patient safety both nationally and internationally [22]. Whilst the focus of this PSP was within the UK, the top 10 uncertainties reflect many universal commonalities addressing patient safety in care delivery and management (such as staffing issues, communications, and transitions between care settings) that are of relevance internationally and for which there are limited tools or strategies to measure, monitor and improve patient safety; for example, diagnostics and transitions of care [1]. The fact that the number one priority was about understanding patient safety for the most vulnerable in society is particularly relevant given that this includes people where there has traditionally received less research focus [23]. Furthermore, the recognition of treating the patient as a whole person, rather than focusing on individual conditions, is of particular relevance given that many of the guidelines and support available has focused on individual conditions (for example, in the UK the National Institute for Health and Care Excellence [24]) and do not address the everyday decisions and prioritisations that

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

patients and healthcare professionals must make when faced with multiple conditions and treatment options [25,26].

Communication and care co-ordination was a focus of many questions that were submitted, despite the fact that there is a large body of research in these areas and these issues. In addition, a focus on holistic care is not a new priority with personal and holistic care having been advocated for many years [27], suggesting that in an ever more complex and digital era of medicine, personal care remains of importance. It suggests also that there remains a gap between rhetoric and reality [28]. It is still not understood clearly how these issues are conceptualised and understood from a patient safety perspective; for example, continuity of care [29]. This suggests that there remain unanswered questions about how to implement research into practice and potentially the impact, or awareness, of research to inform policy, commissioning and clinical practice [8, 22, 30]. Whilst research exists in part to address some of these questions [31], there remains an imbalance of research evidence across primary care professions that responds to the context in which decisions are being made by different professionals (e.g. dentists, pharmacists, practice nurses) and a lack of strong evidence, improvement studies or replication studies to support these decisions [32].

Strengths and limitations of the study

This was a large national prioritisation exercise with 341 patients and/or carers, and 94 healthcare professionals submitting questions and the priorities identified unanswered question which are of relevance across the UK. The imbalance of submissions between patients and healthcare professional was noticeable given the targeted approach by representatives of primary healthcare professional groups and professional networks. Adverts were sent to members of various organisations including patient support groups, members of professional organisations as well as through Twitter and other non-specific targeted adverts. However, there was limited involvement by some health care professional groups, such as ophthalmologists, care homes and social work sectors as there were no organisations representing this group on the steering group as membership of the steering group was a balance between being inclusive whilst being a manageable size. Further PSPs could work with members from these communities to examine in detail patient safety within these diverse settings. Furthermore, despite working with the LGBT foundation there were fewer questions submitted by members of this community. Although this process is unlikely to be representative given that certain groups maybe more active and more likely to submit questions,

this is mitigated by the process of creating indicative questions for similar submissions and the prioritisation exercises meaning that the final top 10 questions were from the full range of submissions reflecting patient and health care professional priorities. Furthermore, while participants were asked to identify if they lived in the UK we did not ask which region they were located in and it is possible that one geographical location (for example) Manchester was over represented despite the engagement with national organisations to attempt to overcome this but from the demographic data collected we are unable to identify this. The breadth of different key stakeholders throughout the process was a strength, which ensured the credibility and relevance of the top 10 throughout the process [11, 33, 34]. However, the JLA procedure excludes non-clinical researchers, whilst including clinical researchers [9], assumes healthcare professional researchers are able to remove their research bias whereas non-clinical researchers (who may be users of primary care services as either patients or carers) are not. This approach has been adopted, and supported by the NIHR, as it aims to redress the imbalance in setting the research agenda where wider voices have traditionally not been included (i.e. patients and health care professionals) and whilst potentially all citizens are eligible to be users of primary care services it was deemed appropriate to exclude those who may already influence priority setting through funding applications, research projects and other mechanisms.

One potential limitation of this process is the breadth of questions that were submitted, as primary care is a broad and diverse service area and some questions suggested large programmes of research (for example: "*At what level can patient safety interventions in primary care be applied, e.g. nationally, regionally, clinical commissioning groups, practice cluster, practice, individual clinician, patient?*"). These questions were deliberately kept broad in order to ensure that questions kept the original intent of the submitted question in align with the JLA process. Rephrasing of indicative question were checked by the steering group to ensure that the original intent of the questions were maintained but it was difficult in some circumstances to be able to focus the question to fit within a searchable criteria. The questions are generally broad, potential programmes of work which reflects the broad nature of the question focusing on a core component of service delivery rather than a specific disease focus. In these instances, we were as open and inclusive in the literature searching and reviewing as possible. Another strength of this approach was that the areas of priority from the initial open survey were reflected in the top 10 final priorities: communication, team and system working, interfaces across primary and secondary care, medication, self-management support and technology. One limitation of this study is that the majority of patients who completed the first survey were white (92%) and over 55 (58%) despite broad promotional activities. Information about

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

sexual orientation was only collected at the first survey as it was not going to be used for analysis of the prioritisation results and in consultation with the steering group it was decided not to collect the additional information to encourage engagement with the longer second survey. A consultation process like this will be more likely to reach people who were more engaged with research and this is a similar critique to the evaluations of other patient and public involvement activities who were more likely to involve white, older people [23]. Engaging with black and minority ethnic groups across a range of ages is an important component of future work. Additionally, there was little engagement from younger adults and younger parents, as well as members from black and minority ethnic groups which was a limit of this work. Future work may need to use targeted engagement and involvement approaches to work with members of these groups and future PSPs could focus on identifying priorities for these communities.

Future work

This project will inform the development of future research priorities and funding applications. It is important that research in primary care patient safety prioritises questions that address practical issues to support care delivery and use. Future research could focus on understanding the priorities for particular communities, such as black and minority ethnic groups, who have often not participated in traditional research and patient and public involvement.

Conclusions

The top 10 primary care patient safety research priorities were generated using an established transparent and systematic approach. The research priorities covered a range of areas of priority for patients, carers and healthcare professionals; how patient safety can be assured for the most vulnerable in society, taking holistic approaches to care, transitions and communication of care between primary and secondary care, staffing issues, continuity of care, communication between patients and care providers, identifying and support people at risk of suicide, the appropriateness of different practitioners for different types of clinical work, accessing patient medical records and safe care at home. These findings will be used to address these issues to set the research agenda to support patients, carers and healthcare professionals and to maximise the utility and impact of patient safety research in primary care.

For peer review only

What is already known on this topic

Patient safety in healthcare is an international priority for research and practice but despite the majority of patient contacts occurring in primary care the majority of research to inform practice has occurred in secondary care.

What this study adds

The top priorities for primary care patient safety research for healthcare professionals and patients focused on the most vulnerable in society, holistic whole-person care, safer communication and co-ordination between care providers, work intensity and continuity of care.

Acknowledgements

The authors would like to thank all the participants who took part in the study and everyone who promoted the surveys. We would like to thank our JLA advisor, Richard Morley, for his guidance and advice and the JLA advisors who facilitated the final workshop. We would like to thank all of the steering group members for their support to steer and promote the PSP (in alphabetical order): Rose Gallagher, Royal College of Nursing; Barry Kinshuck, British Dental Association; Alison Lea, Royal College of General Practitioners; Mike Molete, Healthwatch Manchester and Carers UK; Katherine Murphy, the Patients Association; Janice Perkins, Pharmacy Voice; Claire Vaughan, National Health Service Salford Clinical Commissioning Group; Mags Watson, Royal Pharmaceutical Society; and Laurence Webb, Lesbian, Gay, Bisexual and Trans Foundation. We would also like to thank the following information specialists for their help in running searches of the literature: Stephen Woods and Olivia Schaff from University Hospital of South Manchester library, and Elham Aalai and Michelle Dutton from Central Manchester Foundation Trust library.

Funding Acknowledgement

The National Institute for Health Research Greater Manchester Primary Care Patient Safety Translational Research Centre (NIHR Greater Manchester PSTRC) funded this study. The views

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

expressed are those of the author(s) and not necessarily those of the NHS, the NIHR, or the Department of Health.

Competing interests declaration

We have read and understood BMJ policy on declaration of interests and declare that we have no competing interests

Details of author contributions

SC and ST designed the study and convened the steering group. RM led the study, carried out data collection, analysis, and interpretation of data. CR was responsible for promoting the surveys and co-ordinating members of the steering group. RA and JS were involved in the data collection and interpretation. SG and JW led the literature searching. RM drafted the initial manuscript and all authors have been involved in revising the manuscript and have given final approval of the version to be published. RM is the guarantor.

All authors, external and internal, had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Identifiable patient information

No identifiable patient information has been included in the manuscript.

Data sharing statement

Data sharing: no additional data available

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

For peer review only

REFERENCES

1. Spencer R, Campbell SM. Tools for primary care: a narrative review. BMC Fam Pract. 2014. 15: 166
2. Vincent C, Burnett S, Carthey J. The Measurement and Monitoring of Safety. 2013, Available from; http://www.health.org.uk/publications/the-measurement-and-monitoring-of-safety/.
3. Liberati A. Need to realign patient-oriented and commercial and academic research. Lancet 2011; 378: 1777–1778
4. Wilson T, Pringle M, Sheikh A. Promoting patient safety in primary care. 2001; 323: 583.
5. KingsFund. Improving the quality of care in general practice. 2011. https://www.kingsfund.org.uk/sites/files/kf/field/field_related_document/gp-inquiry-report-evolving-role-nature-2mar11.pdf
6. Moher D, Glasziou P, Chalmers I et al. Increasing value and reducing waste in biomedical research: who's listening? Lancet. 2016; 10027: 1573-1586
7. Tallon D, Chard J, Dieppe P. Relation between agendas of the research community and the research consumer. Lancet. 2000; 355: 9220, 2037-2040
8. Crowe S, Giles C. Making patient relevant research a reality. BMJ 2016; 355.
9. NETSCC & Cowan K. The James Lind Alliance Guidebook. 2016. Available from http://www.jla.nihr.ac.uk/jla-guidebook/downloads/JLA-Guidebook-Version-6-February-2016.pdf

10. Elwyn G, Crowe S, Fenton MA, et al. Identifying and prioritizing uncertainties: patient and clinician engagement in the identification of research questions. J Eval Clin Pract. 2010: 16: 3; 627-631
11. Wan Y L, Beverley-Stevenson R, Carlisle D et al. Working together to shape the endometrial cancer research agenda: The top ten unanswered research questions. Gynecol Oncol, 2016; 143: 287-293
12. Lloyd K, Rose D, Fenton M, Identifying uncertainties about the effects of treatments for schizophrenia. J Ment Health. 2006; 15: 3, 263-268.
13. Eleftheriadou V, Whitton ME, Gawkrodger DJ et al. Future research into the treatment of vitiligo: where should our priorities lie? Results of the vitiligo priority setting partnership. B J Dermatol, 2011; 164: 3, 530-536.
14. NIHR. National Research Context. 2017. Available from: https://www.nihr.ac.uk/about-us/our-purpose/national-research-context/
15. INVOLVE. Exploring the Impact of Public Involvement on the Quality of Research: Examples. Eastleigh, UK: INVOLVE, 2013
16. Chalmers I, Atkinson P, Fenton M et al. Tackling treatment uncertainties together: the evolution of the James Lind Initiative, 2003 - 2013. *Journal of the Royal Society of Medicine*, 2013; 106: 12, 482-491
17. Howick I, Chalmers P, Glasziou T, et al. Explanation of the 2011 Oxford Centre for Evidence-Based Medicine (OCEBM) levels of evidence. 2011. Available from: http://www.cebm.net/wp-content/uploads/2014/06/CEBM-Levels-of-Evidence-Background-Document-2.1.pdf
18. NHS England. 2017. Available from: http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/what_to_do.aspx
19. NHS England. 2014. Available from: https://www.england.nhs.uk/2014/12/patient-online-increase/
20. Patients Association. 2017. Available from: https://www.patients-association.org.uk/wp-content/uploads/2017/08/Seeing-your-medical-records.-1.pdf
21. ABPI. 2017. Available from: http://www.abpi.org.uk/media-centre/newsreleases/2017/Pages/New-partnership-set-to-help-%E2%80%98transform%E2%80%99-access-to-medicines-for-patients-in-Greater-Manchester-24.02.17.aspx
22. Chalmers I, Glasziou P. Avoidable waste in the production and reporting of research evidence. Lancet. 2009 4;374(9683):86-9
23. Redwood S, Gill PS. Under-representation of minority ethnic groups in research — call for action. Br J Gen Pract. 2013; 63(612): 342–343.
24. NICE. 2017. Available from: https://www.nice.org.uk/
25. Moffat K, Mercer, SW. Challenges of managing people with multimorbidity in today's healthcare systems. BMC Family Practice. 2015; 16:129
26. Morris RL, Sanders C, Kennedy AP et al. Shifting priorities in multimorbidity: a longitudinal qualitative study of patient's prioritization of multiple conditions. Chronic Illn 2011; 7(2):147-161.
27. Tarrant C, Windridge K, Boulton M et al. Qualitative study of the meaning of personal care in general practice. BMJ. 2003: 326
28. Wilson T, Roland M, Ham C. The contribution of general practice and the general practitioner to NHS patients. J R Soc Med. 2006. 99:1
29. Rhodes P, McDonald R, Campbell S et al. Sensemaking and the co-production of safety: a qualitative study of primary medical care patients. Sociol Health Illn. 2016; 38: 2: 270-285

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

30. Grimshaw JM, Eccles MP, Lavins JN. Knowledge translation of research findings. Implement Sci. 2012; 7: 50.
31. Panesar SS, deSilva D, Carson-Stevens A et al. How safe is primary care? A systematic review. BMJ Qual Saf. 2016; 25:544-553
32. Wynia MK, Classen DC. Improving ambulatory patient safety: learning from the last decade, moving ahead in the next. JAMA. 2011; 14; 306:2504-5
33. Bryant J, Sanson-Fisher R, Walsh et al. Health research priority setting in selected high income countries: a narrative review of methods used and recommendations for future practice, Cost Eff. Resour. Alloc. 2014; 12: 23
34. Sibbald SL, Singer PA, Upshur R et al. Priority setting: what constitutes success? A conceptual framework for successful priority setting. BMC Health Serv Res. 2009; 9: 43.

FIGURE LEGEND

Figure 1: Summary of the James Lind Alliance Priority Setting Partnership

ONLINE SUPPLEMENTARY FILE LEGEND

Online supplementary file 1: Questionnaire

Online supplementary file 2: Top 60 research questions

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

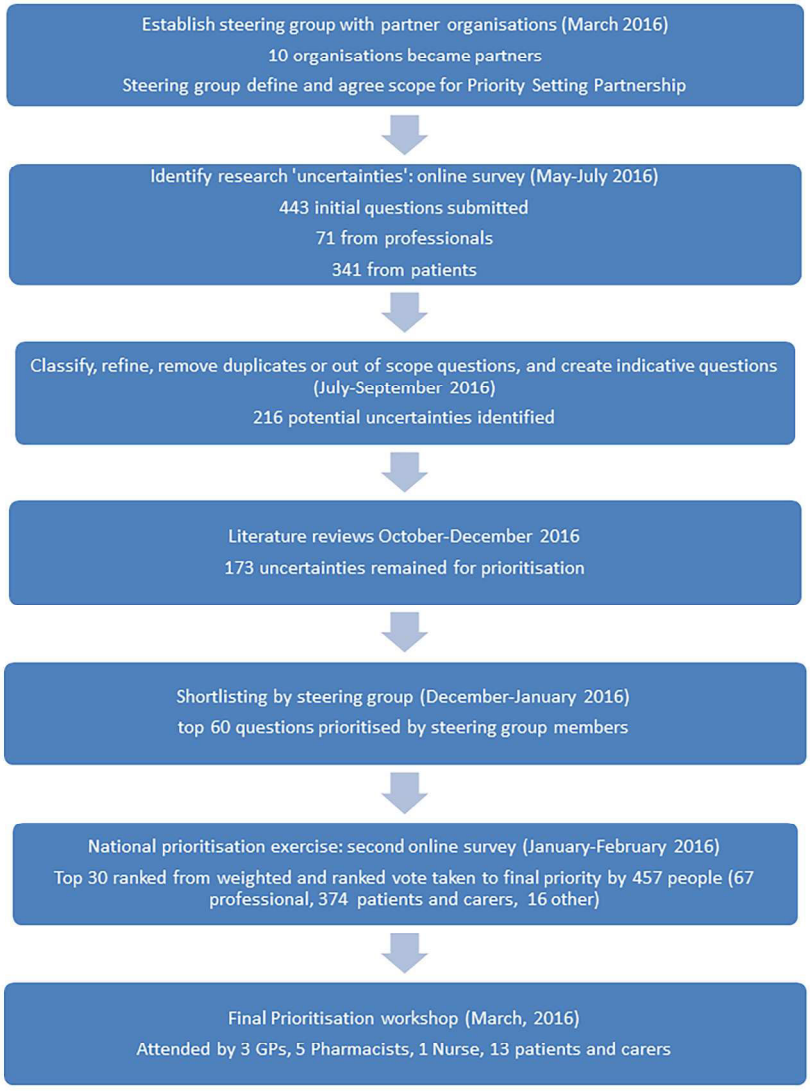

Figure 1: Summary of the James Lind Alliance Priority Setting Partnership

190x254mm (300 x 300 DPI)

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

James Lind Alliance Priority Setting Partnership on primary care patient safety

Page 1

James Lind Alliance Priority Setting Partnership on primary care patient safety

1. The NIHR Greater Manchester PSTRC is working with the James Lind Alliance to identify and prioritise the most important issues for research in primary care patient safety. If you have important unanswered questions about patient safety in primary care please describe them below.

   For more information and the participant information sheet Read the Information Sheet

   We are seeking to identify priorities for research about safety in primary care. Primary care includes your GP surgery, dental surgery, pharmacy, out of hours care, walk in clinic, community or district nursing, ambulance and opticians.

   Only complete this survey if you are over 16 years of age. If you are 16 or 17 years old please tick below to show that you consent to take part in this survey.

   - ○ I am aged 16 or 17 and consent to take part in this survey

2. **What are your questions for researchers to answer about patient safety in primary care?**

   If you have more than one question for researchers to answer please list all questions with numbers to clearly indicate each new question.

3. If you did not answer the question above asking you to suggest questions for researchers to answer about patient safety in primary care, is this because

   - ○ you have no questions about primary care for researchers to answer
   - ○ you did not understand the question
   - ○ Other, please specify

4. The following questions are all optional.

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

How old are you?

- 16 to 24 years
- 25 to 34 years
- 35 to 44 years
- 45 to 54 years
- 55 to 64 years
- 65 to 74 years
- 75 and over
- Prefer not to say

5. Do you live in England, Wales, Scotland or Northern Ireland?

- Yes
- No
- Prefer not to say
- If yes, please enter the first 2 letters of your postcode below

6. What is your highest level of education?

- No qualifications
- 1 to 4 GCSEs or equivalent
- 5 or more GCSEs or equivalent
- Apprenticeship
- 2 or more A levels or equivalent
- Degree level or above
- Other qualifications
- Prefer not to say
- Other, please specify

7. What is your ethnic group? Choose one option that best describes your ethnic group or background

- White
- Asian or Asian British: Indian
- Asian or Asian British: Pakistani
- Asian or Asian British: Bangladeshi
- Asian or Asian British: Chinese
- Asian or Asian British: Other
- Black or Black British: African
- Black or Black British: Caribbean
- Black or Black British: Other
- White and Black Caribbean
- White and Black African
- White and Asian
- Arab
- Prefer not to say
- Other, specify (optional)

8. Do you, personally, work as a Healthcare Professional in any capacity? For example, a doctor/nurse/therapist/pharmacist/health service researcher/other NHS staff, etc. (if retired answer for your previous work)

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

- Yes
- No
- Don't know
- Prefer not to say

9. How do you describe your gender?

- Female
- Male
- In another way
- Prefer not to say

10. Is your gender identity the same as the gender you were given at birth?

- Yes
- No
- Do not understand the question
- Prefer not to say

11. Which best describes you?

- Lesbian/Gay
- Bisexual
- Heterosexual/Straight
- Other
- Prefer not to say

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Online supplementary file 2: the top 60 research priorities

1	What is the role of the receptionist in patient safety; i.e. facilitating access to urgent appointments?
2	Do GP practices keep patient records up to date to ensure safety when a patient is seen by a different GP?
3	Do patients have thoughts on what is safe and unsafe practice and would they know how and where to escalate any concerns?
4	Does seeing a named GP who knows an individual have safer care than seeing a GP who doesn't know me?
5	How does continuity of care influence patient safety?
6	How is patient safety and patient harm monitored in primary care?
7	How many patients actually know what medication they are taking; what for and what the potential side effects are?
8	What can be done to make polypharmacy safer?
9	What is the impact of pharmacy input in the GP surgery?
10	Do GPs and other health care professionals record patients who are vulnerable/at risk in the patient notes?
11	Do patients referred to their community pharmacist by their hospital pharmacist for post-discharge support with their medicines have improved levels of medicines safety and medicines adherence?
12	How can patient safety be assured for the most vulnerable in society (e.g. people who are frail; have mental health problems; cognitive impairments; learning difficulties; disabilities; and poor health literacy)?
13	How frequent are the misdiagnosis of symptoms by GPs resulting in patient safety incidents?
14	How safe are phone consultations compared to face to face with one's GP?
15	How well trained are receptionists as acting as gatekeepers to GPs and prioritising patients?
16	In what ways does work intensity; hours worked & staffing levels affect patient safety/near misses?
17	What can be done to improve access to GP surgery for someone with mental health problems?
18	What can Primary Care do to identify and support people who may be at risk of suicide?

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

19	What do patients understand about when they should or shouldn't contact a GP; and who they should see instead?
20	What team working methods/cultures promote a safer approach?
21	What types of prescribing errors are occurring in GP prescribing practice and how often are they occurring?
22	Would a co-ordinated / holistic / overview approach to individual patients and families improve patient safety?
23	How can we encourage a culture that learns from patient safety incidents?
24	How can we encourage patients and clinicians to be more open about patient safety incidents; within a culture of learning rather than blame?
25	What tools could help practitioners balance safety/costs/workload/accessibility/quality?
26	Are difficulties in contacting doctors and/or making appointments associated with more delays or errors in diagnosis; or other failures of care?
27	Do clinicians ask patients if they understand the questions they are being asked and if they feel safe?
28	Do the actions of receptionists have potential ramifications for patient safety?
29	Does safety consciousness lead to anxiety and over compensation i.e. too much risk averseness?
30	Does the provision of detailed blood test data to patients lead to them managing their condition better?
31	How can communication between health care professionals be improved for people with multiple long term conditions?
32	How can information within patient medical records be made available to patients and care providers in a way that protects privacy and improves safety and quality of care?
33	How can patient safety reporting be made simple and action on reporting made effective?
34	How can patients best be informed about GPs with special interests in the practice they attend; in order to direct them to the most suitable doctor or nurse for consultation?
35	How can risks be mitigated to allow for safe; complex care at home?

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

36	How can we enable individual Practices to share their significant event audits and outcomes with each other in a way which promotes patient safer care?
37	How can we improve safe communication and co-ordination of care between Primary and Secondary care?
38	How can we make sure that the whole patient is treated; not just one condition and with mental health and physical health both being treated together?
39	How do GPs inform their patients of the side effects and potential risks when prescribing a new medication?
40	How well do patients understand the information that has been conveyed to them during the consultation?
41	In the backdrop of health and social care devolution; what are the risks to patient safety as services transform and the system transitions?
42	Is lack of continuity of care by a single doctor in a joint practice associated with more delays or errors in diagnosis?
43	Is there a clear understanding of patient safety in general practice?
44	What are the diagnostic success rates of GPs when compared to their final diagnosis for a patient?
45	What are the safe frequencies of medication review?
46	What can be done to help GPs or nurse practitioners decide when the use of antibiotics is necessary?
47	What kinds; seriousness; and frequency; of harms happen to patients in primary care?
48	What proportion of national guidelines and National Institute for Health and Care Excellence recommendations are followed and monitored?
49	What proportion of patients tell their GPs about anything else they may be taking (e.g. homeopathy; cannabis etc.) that may conflict with medications?
50	What steps can be taken to improve patient safety in out of hours care?
51	Which type practitioner (GP; advanced nurse practitioner; practice nurse; etc.) is safest to see which types of patients (acute illnesses; acute on chronic; multi-morbid; long-term illness)?
52	Why do some patients not engage with their healthcare and so not attend all/some of their health checks?
53	Why is it that doctors do not listen to carer's concerns?

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

54	Why is there such a time lag between seeing the hospital consultant and the GP getting information about a medication change?
55	Are patients with a disability particularly vulnerable to unsafe primary care and; if so; how can this be improved?
56	Are their harmful outcomes form excessive attention to safety?
57	How are medical errors in primary care prevented and recorded?
58	How can GP practices appointment systems (e.g. telephone; online) be improved?
59	How often do GPs report side effects; what is the level of under-reporting and how can it be improved?
60	How safe is treatment in out of hours care if patient notes are not available?

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open

Identifying primary care patient safety research priorities in the UK: a James Lind Alliance Priority Setting Partnership

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2017-020870.R2
Article Type:	Research
Date Submitted by the Author:	12-Jan-2018
Complete List of Authors:	Morris, Rebecca L.; University of Manchester, NIHR Greater Manchester Patient Safety Translational Research Centre Stocks, Susan; University of Manchester, NIHR Greater Manchester Patient Safety Translational Research Centre Alam, Rahul; University of Manchester, NIHR Greater Manchester Patient Safety Translational Research Centre Taylor, Sian; University of Manchester, NIHR Greater Manchester Patient Safety Translational Research Centre Rolfe, Carly; University of Manchester, NIHR Greater Manchester Patient Safety Translational Research Centre Glover, Steven; Manchester University NHS Foundation , Trust library service Whitcombe, Joanne; Manchester University NHS Foundation , Trust library service Campbell, Stephen; University of Manchester, Centre for Primary Care
Primary Subject Heading:	Health services research
Secondary Subject Heading:	General practice / Family practice
Keywords:	James Lind Alliance, Patient safety, PRIMARY CARE, pharmacy, general practice

SCHOLARONE™
Manuscripts

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Title: Identifying primary care patient safety research priorities in the UK: a James Lind Alliance Priority Setting Partnership

Authors

Dr Rebecca Lauren Morris*, NIHR Greater Manchester Patient Safety Translational Research Centre, Centre for Primary Care, University of Manchester, 6th Floor Williamson Building, Oxford Road, Manchester, M13 9PL, UK. Email: Rebecca.morris@manchester.ac.uk. Telephone: 0161 27 50748.

*Corresponding author

Dr Jill Stocks, NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester, Manchester, UK

Dr Rahul Alam, NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester, Manchester, UK

Dr Sian Taylor, NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester, Manchester, UK

Ms Carly Rolfe, NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester, Manchester, UK

Mr Steven William Glover, Trust library service, Manchester University NHS Foundation Trust, Manchester, UK

Ms Joanne Whitcombe Trust library service, Manchester University NHS Foundation Trust, Manchester, UK

Professor Stephen Campbell, NIHR Greater Manchester Patient Safety Translational Research Centre, University of Manchester, Manchester, UK

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Abstract

Objectives: to identify the top 10 unanswered research questions for primary care patient safety research.

Design: a modified nominal group technique.

Setting: UK

Participants: Anyone with experience of primary care including: patients, carers and healthcare professionals. 341 patients and 86 healthcare professionals submitted questions.

Main outcomes: A top 10, and top 30, future research questions for primary care patient safety

Results: 443 research questions were submitted by 341 patients and 86 healthcare professionals, through a national survey. After checking for relevance and rephrasing, a total of 173 questions were collated into themes. The themes were largely focused on communication, team and system working, interfaces across primary and secondary care, medication, self-management support and technology. The questions were then prioritised through a national survey, the top 30 questions were taken forward to the final prioritisation workshop. The top 10 research questions focused on the most vulnerable in society, holistic whole-person care, safer communication and co-ordination between care providers, work intensity, continuity of care, suicide risk, complex care at home, and confidentiality.

Conclusions: This study was the first national prioritisation exercise to identify patient and health care professional priorities for primary care patient safety research. The research priorities identified a range of important gaps in the existing evidence to inform everyday practice to address primary care patient safety.

Key words: patient safety; primary care; James Lind Alliance; pharmacy; general practice

Strengths and limitations of this study

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

- This is the first national research prioritisation exercise to identify primary care patient safety research priorities.
- More patients and/or carers submitted questions than healthcare professionals.
- The majority of questions were submitted by people over 55 and who were Caucasian despite broad promotional activities.
- The broad range of questions submitted would like require large programmes of research to address them.
- An inclusive approach to literature search and reviewing was used.
-

INTRODUCTION

Patient safety in healthcare is a policy priority at international, national, regional and local levels and is important to, and the responsibility of, everyone. Globally the majority of patient contacts with healthcare occur out of hospitals in primary care, family medicine and transitional settings between providers, yet patient safety research has been done mostly in hospital settings [1]. Patient safety can be defined as "the avoidance, prevention, and amelioration of adverse outcomes or injuries stemming from the processes of healthcare" [2]. The knowledge base to inform safer care and clinical decision making needs to be expanded to address questions that are needed in everyday clinical practice and potential strategies for system-wide improvement of care safety need to be prioritised [3]. Primary care includes a number of healthcare areas including general practice, community pharmacies, dentistry, high street optometrists and others working in community settings. The nature of much of the clinical work in primary care centres on treatment uncertainties, which are often complex and not necessarily acute in nature, and co-ordination across services, which poses many challenges to patient safety [4,5].

Clinical research aims to improve the evidence upon which decisions are made about prevention, treatment, care, management and cure whilst avoiding a waste of research resources [6]. In the last ten years there has been a growth in primary care patient safety research [1], which has focused mostly on medication safety and errors. As there is limited time and resources available for research it is important that priority is given to areas of patient and healthcare professional priority to

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

address issues that affect everyday practice [7]. There is an increasing recognition of the role of patients and healthcare professionals in co-setting the research agenda and the research community has been challenged to prioritise and fund research questions that are of relevance to a diverse range of stakeholders, including patients and healthcare professionals [8]. The James Lind Alliance (JLA) priority setting partnership (PSP) approach works with patients, carers and healthcare professionals to identify the priorities that are most important for research to address [9]. There have been over 60 JLA PSPs investigating a range of treatment uncertainties, which focus on discrete clinical topics such as asthma, endometrial cancer, schizophrenia and vitiligo [10-13]. This approach addresses the possible divergence between clinical research and patient priorities, which brings about the largest improvements in our knowledge of disease and service delivery [8].

Involving a wider set of stakeholders in prioritising research questions may identify key areas that have not been prioritised previously by funding bodies [10]. In the UK, the Department of Health funds health and care research through the National Institute for Health Research (NIHR) [14]. The NIHR aims to improve health through research and supports the active involvement of the public to achieve this aim. The JLA is overseen by the NIHR to support the research priorities identified through the partnerships so that they can feed directly in to national funding priorities [14, 15]. The Primary Care Patient Safety PSP pushed the boundaries of the JLA process by looking at unanswered questions in the diverse area of primary care, as opposed to a single clinical topic [4, 16]. The aim of the Primary Care Patient Safety PSP was to identify unanswered research questions in the field of primary care patient safety research and to identify the top research priorities for primary care patient safety from patients, carers, and primary care healthcare professionals.

METHOD

This study followed the JLA methodology [9]. This project was led and funded by the NIHR Greater Manchester Primary Care Patient Safety Translational Research Centre (Greater Manchester PSTRC) which is a partnership between Salford Royal National Health Service (NHS) Foundation Trust and The University of Manchester working with clinical and patient partner organisations. Partner organisations included representatives from the Royal College of General Practitioners, Royal College of Nursing, British Dental Association, Healthwatch Manchester, Carers UK, The Patients Association, Pharmacy Voice, NHS Salford Clinical Commissioning Group, Royal Pharmaceutical Society, and the

For peer review only

Lesbian, Gay, Bisexual and Trans (LGBT) Foundation. The JLA provided an independent chair, advised on methodology and facilitated the final prioritisation setting workshop [9].

The University of Manchester Research Ethics Committee approved the study (REC reference: 16141)

Stage 1: Initiation

Steering group set up

The first stage involved identifying potential partner organisations to be members of the steering group to direct the project as well as having access to a wide range of potential participants to submit questions and reflected the diversity of people who work and/or use primary care services. The steering group included representatives from the Royal College of Nursing; the British Dental Association; the Royal College of General Practitioners; Healthwatch Manchester; Carers UK; the Patients Association; Pharmacy Voice; National Health Service Salford Clinical Commissioning Group; Royal Pharmaceutical Society; and Lesbian, Gay, Bisexual and Trans Foundation The steering group was responsible for from agreeing the initial focus, publicising the PSP, overseeing and collating the priorities as well as taking the final priorities to research funders [9].

Project initiation and eligibility

Anyone living in the UK who uses primary care services, carers, or who are healthcare professionals in primary care were eligible to participate in the identification and prioritisation of uncertainties. Non-clinical researchers and employees of pharmaceutical or medical devices companies were excluded from the survey [9]. A website was created (http://research.bmh.manchester.ac.uk/PatientSafetyPSP) to advertise the partnership and the online survey.

Stage 2: Gathering 'uncertainties'

The first consultation was conducted via an electronic questionnaire with paper copies available on request (online supplementary material 1). Participants were asked "What are your questions about primary care (general practice, pharmacy, dentistry) patient safety?" and a short demographic

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

survey available through the PSP website (the full survey is available as online supplementary material). The questionnaire was open from 1st June to 13th July, 2016. Participants were recruited via a range of convenience sampling in line with the aim of the JLA approach which promotes that the process is as inclusive as possible of patient and healthcare professional views [9]. The steering group members and the Greater Manchester PSTRC promoted the survey through a range of newsletters to members, social media, and through professional and patient networks.

Stage 3: Analysis and verification of uncertainties

The submitted questions were grouped into key themes. Questions were then analysed to identify duplicates and indicative questions were created when there were multiple questions submitted that asked similar questions. Duplicate questions, comments or questions outside the scope of the PSP were removed. RM led the identification of the indicative questions with initial discussion with SC and JS. The steering group then reviewed the indicative questions, and questions identified as duplicate or out of scope which had been removed, alongside the initial submitted questions to confirm the final question set maintained the intent of the initial submitted questions. Every question was then searched against the existing literature. The literature was searched by an independent group of health information specialists led by SG and JW from Trust library service, Manchester University NHS Foundation Trust used a pre-defined systematic criteria. Analysis of the search results was completed by RM and RA. A question was considered to have met the certainty criteria if a recent (within 5 years) systematic review concluded that there was sufficient evidence to answer the question [11,17].

Stage 4: interim prioritisation

The steering group ranked the questions via an online survey where questions were presented to each member in a random order to reduce bias. The top 60 questions were then taken to a second national survey. The second survey was open from 13th January to 24th January, 2017. Patients, carers and healthcare providers were invited to rank the importance of each of the questions for primary care patient safety research from 'very important' to 'very unimportant.' To reduce bias questions were presented in a random order to each participant.

Stage 5: Final Prioritisation workshop

For peer review only

The top 30 questions ranked as the most important were taken forward to a final prioritisation workshop which was a face-to-face consensus meeting held on the 16th March, 2017. Steering group members, volunteers from partner organisations, patients and carers were recruited through networks to take part in the final workshop. Attendees were divided into 3 equal sized groups with a mix of healthcare professionals, patients and carers. The groups were asked to rank the questions through guided discussion facilitated by three independent JLA advisors. The rankings were then collated and the groups mixed and then ranked the questions a second time. The aggregate ranking from the small group exercise was then taken forward to a whole group discussion where the final order of question priority was agreed. The final top ten most important unanswered questions in primary care patient safety were agreed by the full group (Figure 1).

Patient Involvement

Patients were involved in the study as members of the steering group as representatives of patient groups. Patient steering group members, along with other steering group members, directed the study, develop and agree the scope of the PSP, recruitment of patients as representatives of patient groups, reviewing and agreeing indicative questions, ranking of questions and in all stages of the prioritisation and dissemination processes through advertising the survey and its results to their networks.

RESULTS

Question gathering

448 participants answered all or part of the initial national free text survey with 237 people submitting 443 questions (see Figure 1). 341 questions were submitted by patients or carers (Table 1). The initial survey yielded 9124 views. 182 submissions either did not include a question or stated that they did not have a question about primary care patient safety (n=144) or did not understand the question (n=38). From the remaining 270 submissions, 443 individual research questions were identified.

Table 1: Participant demographics

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Participant characteristic	First survey	Second survey
Patient or carer	341	373
Healthcare professional	86	51
Preferred not to say	3	1
Other	3	19
Left blank	5	3
Age		
16 to 24 years	4	5
25 to 34 years	25	43
35 to 44 years	38	45
45 to 54 years	62	86
55 to 64 years	87	117
65 to 74 years	75	115
75 and over	20	30
Prefer not to say	1	3
Left blank	6	3
Ethnicity		
Arab	1	1
Asian or Asian British: Indian	7	5
Asian or Asian British: Chinese	3	0
Asian or Asian British: Other	1	1
Asian or Asian British: Pakistani	2	3
Black or Black British: Caribbean	4	1
Black or Black British: African	2	0
Black or Black British: Other	1	0
Prefer not to say	7	8
Scottish	0	1
White	411	412
White English	0	1
White and Asian	1	3
White and Black African	1	2
White and Black Caribbean	1	2
White and North African	0	1
White British	0	1
Other	2	0

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Missing	2	5
Gender		
Female	225	237
Male	218	202
In another way	1	0
Prefer not to say	0	5
Left blank	4	3
Gender same as at birth		
No	3	1
Yes	427	434
Prefer not to say	0	5
Left blank	7	7
Did not understand the question	1	0
Sexual orientation		
Lesbian or Gay	13	Unknown
Bisexual	6	Unknown
Heterosexual	392	Unknown
Other	3	Unknown
Prefer not to say	15	Unknown
Left blank	19	Unknown

Analysis and verification of uncertainties

46 questions were excluded as outside of the scope of the PSP; for example a request for research in stem cell research. The remaining 397 questions were then grouped into themes. The key themes identified were medication (n=50), diabetes care (n=46), access (n=32), education and training (n=29), communication (n=28), patient records (n=14), workforce and capacity (n=13), continuity of care (n=10), governance (n=9), multimorbidity (n=7), foot care (n=7), reception (n=6), harm (n=6), out of hours care (n=6), patient awareness of patient safety (n=6), hygiene (n=6) (for all topic themes see table 2).

Table 2: Topic themes of submitted questions

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Topic theme	Number of questions submitted
Medication	50
Diabetes care	46
Access	32
Education and training	29
Communication	28
Patient records	14
Workforce and capacity	13
Continuity of care	10
Governance	9
Multimorbidity	7
Foot care	7
Reception	6
Harm	6
Out of hours care	6
Patient awareness of patient safety	6
Hygiene	6
Interface	5
Blood tests	5
Diagnosis	5
Treatment	5
NICE guidance	4
Dispensing	4
Appointment time	3
Disability	3
Information	3
Long term condition management	3
Pain	3
Risk assessment	3
Multidisciplinary teams	2
Holistic views of patients	2
Understanding patient safety	2
Implementation of research or guidelines	2
Co-ordination of care	2
Confidentiality	2
Cost of safety	2
Intervention development	2
Knowledge	2
Mental health	2
Annual follow-up	2
Patient experience	2
Medical errors	2
Identifying people at risk of suicide	1
Care Quality Commission	1
Definition of patient safety	1
Dementia	1
Diet	1
NHS changes	1
Dental infection	1
Condition awareness	1

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Consultation	1
Contextual approaches to safety	1
Errors	1
Geographical differences	1
Health and social care development	1
Impact of patient safety awareness	1
Integrated approach to safety	1
Locum doctors	1
Minor injuries	1
Models of care	1
Obesity	1
Patient engagement with healthcare	1
Palliative care	1
Patient role in safety	1
Physical safety	1
Polypharmacy	1
Population versus personalised care	1
Patient and public involvement	1
Prescription	1
Prevention of issues	1
Priorities	1
Quality improvement	1
Referrals	1
Regional care	1
Resources	1
Review appointments	1
Safety boundaries	1
Safety causing other issues	1
Safer care at home	1
Service changes	1
Technology	1
Test results	1
Transferability of patient safety initiatives	1
Violent patient management	1
Yellow Card scheme	1

Questions focused on primary care broadly (n=240), General Practice (n=95), patient level self-management (n=30), pharmacy (n=14), out of hours care (n=6), patient and public involvement in research (n=2), and physiotherapy (n=1).

Indicative questions were created from duplicate entries and narrative submissions so that they kept the original meaning of the submission, leaving 216 questions to be verified against the existing literature evidence. All indicative questions were agreed by the steering group. In total, 173 questions were considered unanswered by research.

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Interim prioritisation

The 60 most important unanswered research questions were then prioritised by a second national online survey completed by 447 people, including 374 patients or carers (online supplementary material 2). The top 30 questions that were ranked as most important were taken forwards to the final consensus meeting (see table 3 for ranking by patients and healthcare professionals).

Table 3: Ranking of Top 30 questions (final and pre-workshop)

Question	Final rank post workshop	Overall rank (pre final workshop)	Rank pre workshop (by patients or carers)	Rank pre workshop by healthcare professionals
How can patient safety be assured for the most vulnerable in society (e.g. people who are frail, have mental health problems or cognitive impairments)?	1	3	3	5
How can we make sure that the whole patient is treated, not just one condition and with mental health and physical health both being treated together?	2	1	1	4
How can we improve safe communication and co-ordination of care between primary and secondary care?	3	10	15	1
In what ways does work intensity, hours worked & staffing levels affect patient safety/near misses?	4	7	9	3
How does continuity of care influence patient safety?	5	11	11	22
How well do patients understand the information that has been conveyed to them during the consultation?	6	9	8	6
What can primary care do to identify and support people who may be at risk of suicide?	7	5	6	8
Which type of practitioner (GP, advanced nurse practitioner, practice nurse) is safest to see which types of patients (acute illnesses, acute on chronic multi-morbid)?	8	22	21	29
How can information within patient medical records be made available to patients and care providers in a way that protects privacy and improves safety and quality of care?	9	30	30	19
How can risks be mitigated to allow for safe complex care at home?	10	29	29	20

For peer review only

Are difficulties in contacting doctors and/or making appointments associated with more delays or errors in diagnosis or other failures of care?	11	15	13	27
How many patients actually know what medication they are taking, what for and what the potential side effects are?	12	20	25	18
What can be done to improve access to GP surgery for someone with mental health problems?	13	8	7	13
How can communication between healthcare professionals be improved for people with multiple long term conditions?	14	2	2	2
How safe is treatment in out of hours care if patient notes are not available?	15	4	5	7
What do patients understand about when they should or shouldn't contact a GP and who they should see instead?	16	25	27	24
How can we encourage patients and clinicians to be more open about patient safety incidents within a culture of learning rather than blame?	17	28	32	14
What steps can be taken to improve patient safety in out of hours care?	18	12	12	17
What is the role of the receptionist in patient safety i.e. facilitating access to urgent appointments?	19	26	24	42
How well trained are receptionists as acting as gatekeepers to GPs and prioritising patients?	20	24	22	33
How can GP practices appointment systems (e.g. telephone, online) be improved?	21	13	10	47
What types of prescribing errors are occurring in GP prescribing practice and how often are they occurring?	22	27	31	11
How do GPs inform their patients of the side effects and potential risks when prescribing a new medication?	23	21	19	35
How are medical errors in primary care prevented and recorded?	24	18	20	21
Do GP practices keep patient records up to date to ensure safety when a patient is seen by a different GP?	25	6	4	26
Why is there such a time lag between seeing the hospital consultant and the GP getting information about a medication change?	26	16	17	25
How frequent are the misdiagnosis of symptoms by GPs resulting in patient safety incidents?	27	14	14	23
Do GPs and other healthcare professionals record patients who are vulnerable/at risk in the patient notes?	28	17	16	36
Does seeing a named GP who knows an		19	18	45

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

individual have safer care than seeing a GP who doesn't know me?	29			
Do the actions of receptionists have potential ramifications for patient safety?	30	23	23	28

Final prioritisation

A mixed group of 22 stakeholders discussed and ranked the final 30 questions at a final face-to-face meeting (13 patients or carers, 3 GPs, 5 pharmacists and 1 nurse). The discussions were facilitated by independent JLA facilitators [9]. The top 10 questions were agreed by all stakeholders as the most important unanswered questions (see table 4).

Table 4: Top 10 research priorities

1	How can patient safety be assured for the most vulnerable in society (e.g. people who are frail, have mental health problems or cognitive impairments)?
2	How can we make sure that the whole patient is treated, not just one condition and with mental health and physical health both being treated together?
3	How can we improve safe communication and co-ordination of care between primary and secondary care?
4	In what ways does work intensity, hours worked and staffing levels affect patient safety/near misses?
5	How does continuity of care influence patient safety?
6	How well do patients understand the information that has been conveyed to them during the consultation?
7	What can primary care do to identify and support people who may be at risk of suicide?
8	Which type of practitioner (GP, advanced nurse practitioner, practice nurse) is safest to see which types of patients (acute illnesses, acute or chronic multi-morbid)?
9	How can information within patient medical records be made available to patients and care providers in a way that protects privacy and improves safety and quality of care?
10	How can risks be mitigated to allow for safe complex care at home?

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

DISCUSSION

This study has identified the limited evidence available currently to address some key questions and priorities about patient safety in primary care. Of 270 questions submitted, 173 unique questions were identified for prioritisation. The top 10 research priorities (see table 4) included how patient safety can be assured for the most vulnerable in society, taking holistic approaches to care, transitions and communication of care between primary and secondary care, staffing issues, continuity of care, communication between patients and care providers, identifying and support people at risk of suicide, the appropriateness of different practitioners for different types of clinical work, accessing patient medical records and safe care at home. The questions incorporated understanding existing concepts and challenges (e.g. continuity of care, holistic care and communication) with emerging issues and widening the focus of patient safety priorities (e.g. safer care at home or patients accessing their medical records) [18-21]. These results will be used by funders and researchers to identify future research priorities that are most relevance to patients and healthcare professionals in an attempt to address this lack of evidence to support patient and healthcare professional everyday questions about patient safety in primary care and research activity.

The limited evidence to support patients and healthcare professionals to inform primary care service design and delivery is important given the growing priority of patient safety both nationally and internationally [22]. Whilst the focus of this PSP was within the UK, the top 10 uncertainties reflect many universal commonalities addressing patient safety in care delivery and management (such as staffing issues, communications, and transitions between care settings) that are of relevance internationally and for which there are limited tools or strategies to measure, monitor and improve patient safety; for example, diagnostics and transitions of care [1]. The fact that the number one priority was about understanding patient safety for the most vulnerable in society is particularly relevant given that this includes people where there has traditionally received less research focus [23]. Furthermore, the recognition of treating the patient as a whole person, rather than focusing on individual conditions, is of particular relevance given that many of the guidelines and support available has focused on individual conditions (for example, in the UK the National Institute for Health and Care Excellence [24]) and do not address the everyday decisions and prioritisations that

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

patients and healthcare professionals must make when faced with multiple conditions and treatment options [25,26].

Communication and care co-ordination was a focus of many questions that were submitted, despite the fact that there is a large body of research in these areas and these issues. In addition, a focus on holistic care is not a new priority with personal and holistic care having been advocated for many years [27], suggesting that in an ever more complex and digital era of medicine, personal care remains of importance. It suggests also that there remains a gap between rhetoric and reality [28]. It is still not understood clearly how these issues are conceptualised and understood from a patient safety perspective; for example, continuity of care [29]. This suggests that there remain unanswered questions about how to implement research into practice and potentially the impact, or awareness, of research to inform policy, commissioning and clinical practice [8, 22, 30]. Whilst research exists in part to address some of these questions [31], there remains an imbalance of research evidence across primary care professions that responds to the context in which decisions are being made by different professionals (e.g. dentists, pharmacists, practice nurses) and a lack of strong evidence, improvement studies or replication studies to support these decisions [32].

Strengths and limitations of the study

This was a large national prioritisation exercise with 341 patients and/or carers, and 94 healthcare professionals submitting questions and the priorities identified unanswered question which are of relevance across the UK. The imbalance of submissions between patients and healthcare professional was noticeable given the targeted approach by representatives of primary healthcare professional groups and professional networks. Adverts were sent to members of various organisations including patient support groups, members of professional organisations as well as through Twitter and other non-specific targeted adverts. However, there was limited involvement by some health care professional groups, such as ophthalmologists, care homes and social work sectors as there were no organisations representing this group on the steering group as membership of the steering group was a balance between being inclusive whilst being a manageable size. Further PSPs could work with members from these communities to examine in detail patient safety within these diverse settings. Furthermore, despite working with the LGBT foundation there were fewer questions submitted by members of this community. Although this process is unlikely to be representative given that certain groups maybe more active and more likely to submit questions,

this is mitigated by the process of creating indicative questions for similar submissions and the prioritisation exercises meaning that the final top 10 questions were from the full range of submissions reflecting patient and health care professional priorities. Furthermore, while participants were asked to identify if they lived in the UK we did not ask which region they were located in and it is possible that one geographical location (for example) Manchester was over represented despite the engagement with national organisations to attempt to overcome this but from the demographic data collected we are unable to identify this. The breadth of different key stakeholders throughout the process was a strength, which ensured the credibility and relevance of the top 10 throughout the process [11, 33, 34]. However, the JLA procedure excludes non-clinical researchers, whilst including clinical researchers [9], assumes healthcare professional researchers are able to remove their research bias whereas non-clinical researchers (who may be users of primary care services as either patients or carers) are not. This approach has been adopted, and supported by the NIHR, as it aims to redress the imbalance in setting the research agenda where wider voices have traditionally not been included (i.e. patients and health care professionals) and whilst potentially all citizens are eligible to be users of primary care services it was deemed appropriate to exclude those who may already influence priority setting through funding applications, research projects and other mechanisms.

One potential limitation of this process is the breadth of questions that were submitted, as primary care is a broad and diverse service area and some questions suggested large programmes of research (for example: "*At what level can patient safety interventions in primary care be applied, e.g. nationally, regionally, clinical commissioning groups, practice cluster, practice, individual clinician, patient?*"). These questions were deliberately kept broad in order to ensure that questions kept the original intent of the submitted question in align with the JLA process. Rephrasing of indicative question were checked by the steering group to ensure that the original intent of the questions were maintained but it was difficult in some circumstances to be able to focus the question to fit within a searchable criteria. The questions are generally broad, potential programmes of work which reflects the broad nature of the question focusing on a core component of service delivery rather than a specific disease focus. In these instances, we were as open and inclusive in the literature searching and reviewing as possible. Another strength of this approach was that the areas of priority from the initial open survey were reflected in the top 10 final priorities: communication, team and system working, interfaces across primary and secondary care, medication, self-management support and technology. One limitation of this study is that the majority of patients who completed the first survey were white (92%) and over 55 (58%) despite broad promotional activities. Information about

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

sexual orientation was only collected at the first survey as it was not going to be used for analysis of the prioritisation results and in consultation with the steering group it was decided not to collect the additional information to encourage engagement with the longer second survey. A consultation process like this will be more likely to reach people who were more engaged with research and this is a similar critique to the evaluations of other patient and public involvement activities who were more likely to involve white, older people [23]. Engaging with black and minority ethnic groups across a range of ages is an important component of future work. Additionally, there was little engagement from younger adults and younger parents, as well as members from black and minority ethnic groups which was a limit of this work. Future work may need to use targeted engagement and involvement approaches to work with members of these groups and future PSPs could focus on identifying priorities for these communities.

Future work

This project will inform the development of future research priorities and funding applications. It is important that research in primary care patient safety prioritises questions that address practical issues to support care delivery and use. Future research could focus on understanding the priorities for particular communities, such as black and minority ethnic groups, who have often not participated in traditional research and patient and public involvement.

Conclusions

The top 10 primary care patient safety research priorities were generated using an established transparent and systematic approach. The research priorities covered a range of areas of priority for patients, carers and healthcare professionals; how patient safety can be assured for the most vulnerable in society, taking holistic approaches to care, transitions and communication of care between primary and secondary care, staffing issues, continuity of care, communication between patients and care providers, identifying and support people at risk of suicide, the appropriateness of different practitioners for different types of clinical work, accessing patient medical records and safe care at home. These findings will be used to address these issues to set the research agenda to support patients, carers and healthcare professionals and to maximise the utility and impact of patient safety research in primary care.

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Acknowledgements

The authors would like to thank all the participants who took part in the study and everyone who promoted the surveys. We would like to thank our JLA advisor, Richard Morley, for his guidance and advice and the JLA advisors who facilitated the final workshop. We would like to thank all of the steering group members for their support to steer and promote the PSP (in alphabetical order): Rose Gallagher, Royal College of Nursing; Barry Kinshuck, British Dental Association; Alison Lea, Royal College of General Practitioners; Mike Molete, Healthwatch Manchester and Carers UK; Katherine Murphy, the Patients Association; Janice Perkins, Pharmacy Voice; Claire Vaughan, National Health Service Salford Clinical Commissioning Group; Mags Watson, Royal Pharmaceutical Society; and Laurence Webb, Lesbian, Gay, Bisexual and Trans Foundation. We would also like to thank the following information specialists for their help in running searches of the literature: Stephen Woods and Olivia Schaff from University Hospital of South Manchester library, and Elham Aalai and Michelle Dutton from Central Manchester Foundation Trust library.

Funding Acknowledgement

The National Institute for Health Research Greater Manchester Primary Care Patient Safety Translational Research Centre (NIHR Greater Manchester PSTRC) funded this study. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR, or the Department of Health.

Competing interests declaration

We have read and understood BMJ policy on declaration of interests and declare that we have no competing interests

Details of author contributions

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

SC and ST designed the study and convened the steering group. RM led the study, carried out data collection, analysis, and interpretation of data. CR was responsible for promoting the surveys and co-ordinating members of the steering group. RA and JS were involved in the data collection and interpretation. SG and JW led the literature searching. RM drafted the initial manuscript and all authors have been involved in revising the manuscript and have given final approval of the version to be published. RM is the guarantor.

All authors, external and internal, had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Identifiable patient information

No identifiable patient information has been included in the manuscript.

Data sharing statement

Data sharing: no additional data available

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

REFERENCES

1. Spencer R, Campbell SM. Tools for primary care: a narrative review. BMC Fam Pract. 2014. 15: 166
2. Vincent C, Burnett S, Carthey J. The Measurement and Monitoring of Safety. 2013, Available from; http://www.health.org.uk/publications/the-measurement-and-monitoring-of-safety/.
3. Liberati A. Need to realign patient-oriented and commercial and academic research. Lancet 2011; 378: 1777–1778
4. Wilson T, Pringle M, Sheikh A. Promoting patient safety in primary care. 2001; 323: 583.
5. KingsFund. Improving the quality of care in general practice. 2011. https://www.kingsfund.org.uk/sites/files/kf/field/field_related_document/gp-inquiry-report-evolving-role-nature-2mar11.pdf
6. Moher D, Glasziou P, Chalmers I et al. Increasing value and reducing waste in biomedical research: who's listening? Lancet. 2016; 10027: 1573-1586
7. Tallon D, Chard J, Dieppe P. Relation between agendas of the research community and the research consumer. Lancet. 2000; 355: 9220, 2037-2040
8. Crowe S, Giles C. Making patient relevant research a reality. BMJ 2016; 355.
9. NETSCC & Cowan K. The James Lind Alliance Guidebook. 2016. Available from http://www.jla.nihr.ac.uk/jla-guidebook/downloads/JLA-Guidebook-Version-6-February-2016.pdf
10. Elwyn G, Crowe S, Fenton MA, et al. Identifying and prioritizing uncertainties: patient and clinician engagement in the identification of research questions. J Eval Clin Pract. 2010: 16: 3; 627-631
11. Wan Y L, Beverley-Stevenson R, Carlisle D et al. Working together to shape the endometrial cancer research agenda: The top ten unanswered research questions. Gynecol Oncol, 2016; 143: 287-293
12. Lloyd K, Rose D, Fenton M, Identifying uncertainties about the effects of treatments for schizophrenia. J Ment Health. 2006; 15: 3, 263-268.
13. Eleftheriadou V, Whitton ME, Gawkrodger DJ et al. Future research into the treatment of vitiligo: where should our priorities lie? Results of the vitiligo priority setting partnership. B J Dermatol, 2011; 164: 3, 530-536.
14. NIHR. National Research Context. 2017. Available from: https://www.nihr.ac.uk/about-us/our-purpose/national-research-context/
15. INVOLVE. Exploring the Impact of Public Involvement on the Quality of Research: Examples. Eastleigh, UK: INVOLVE, 2013

For peer review only

16. Chalmers I, Atkinson P, Fenton M et al. Tackling treatment uncertainties together: the evolution of the James Lind Initiative, 2003 - 2013. *Journal of the Royal Society of Medicine*, 2013; 106: 12, 482-491
17. Howick I, Chalmers P, Glasziou T, et al. Explanation of the 2011 Oxford Centre for Evidence-Based Medicine (OCEBM) levels of evidence. 2011. Available from: http://www.cebm.net/wp-content/uploads/2014/06/CEBM-Levels-of-Evidence-Background-Document-2.1.pdf
18. NHS England. 2017. Available from: http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/what_to_do.aspx
19. NHS England. 2014. Available from: https://www.england.nhs.uk/2014/12/patient-online-increase/
20. Patients Association. 2017. Available from: https://www.patients-association.org.uk/wp-content/uploads/2017/08/Seeing-your-medical-records.-1.pdf
21. ABPI. 2017. Available from: http://www.abpi.org.uk/media-centre/newsreleases/2017/Pages/New-partnership-set-to-help-%E2%80%98transform%E2%80%99-access-to-medicines-for-patients-in-Greater-Manchester-24.02.17.aspx
22. Chalmers I, Glasziou P. Avoidable waste in the production and reporting of research evidence. Lancet. 2009 4;374(9683):86-9
23. Redwood S, Gill PS. Under-representation of minority ethnic groups in research — call for action. Br J Gen Pract. 2013; 63(612): 342–343.
24. NICE. 2017. Available from: https://www.nice.org.uk/
25. Moffat K, Mercer, SW. Challenges of managing people with multimorbidity in today's healthcare systems. BMC Family Practice. 2015; 16:129
26. Morris RL, Sanders C, Kennedy AP et al. Shifting priorities in multimorbidity: a longitudinal qualitative study of patient's prioritization of multiple conditions. Chronic Illn 2011; 7(2):147-161.
27. Tarrant C, Windridge K, Boulton M et al. Qualitative study of the meaning of personal care in general practice. BMJ. 2003: 326
28. Wilson T, Roland M, Ham C. The contribution of general practice and the general practitioner to NHS patients. J R Soc Med. 2006. 99:1
29. Rhodes P, McDonald R, Campbell S et al. Sensemaking and the co-production of safety: a qualitative study of primary medical care patients. Sociol Health Illn. 2016; 38: 2: 270-285
30. Grimshaw JM, Eccles MP, Lavins JN. Knowledge translation of research findings. Implement Sci. 2012; 7: 50.
31. Panesar SS, deSilva D, Carson-Stevens A et al. How safe is primary care? A systematic review. BMJ Qual Saf. 2016; 25:544-553
32. Wynia MK, Classen DC. Improving ambulatory patient safety: learning from the last decade, moving ahead in the next. JAMA. 2011; 14; 306:2504-5
33. Bryant J, Sanson-Fisher R, Walsh et al. Health research priority setting in selected high income countries: a narrative review of methods used and recommendations for future practice, Cost Eff. Resour. Alloc. 2014; 12: 23
34. Sibbald SL, Singer PA, Upshur R et al. Priority setting: what constitutes success? A conceptual framework for successful priority setting. BMC Health Serv Res. 2009; 9: 43.

FIGURE LEGEND

Figure 1: Summary of the James Lind Alliance Priority Setting Partnership

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

ONLINE SUPPLEMENTARY FILE LEGEND

Online supplementary file 1: Questionnaire

Online supplementary file 2: Top 60 research questions

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

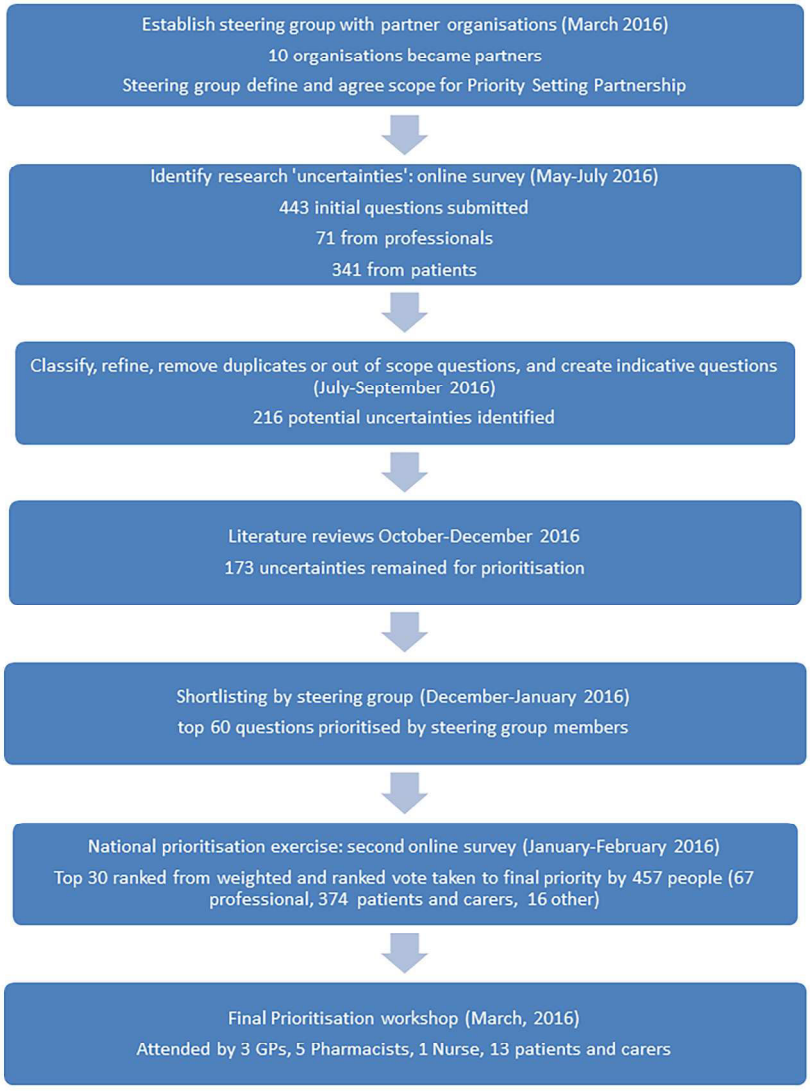

Figure 1: Summary of the James Lind Alliance Priority Setting Partnership

190x254mm (300 x 300 DPI)

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

James Lind Alliance Priority Setting Partnership on primary care patient safety

Page 1

James Lind Alliance Priority Setting Partnership on primary care patient safety

1. The NIHR Greater Manchester PSTRC is working with the James Lind Alliance to identify and prioritise the most important issues for research in primary care patient safety. If you have important unanswered questions about patient safety in primary care please describe them below.

   For more information and the participant information sheet Read the Information Sheet

   We are seeking to identify priorities for research about safety in primary care. Primary care includes your GP surgery, dental surgery, pharmacy, out of hours care, walk in clinic, community or district nursing, ambulance and opticians.

   Only complete this survey if you are over 16 years of age. If you are 16 or 17 years old please tick below to show that you consent to take part in this survey.

   - ○ I am aged 16 or 17 and consent to take part in this survey

2. **What are your questions for researchers to answer about patient safety in primary care?**

   If you have more than one question for researchers to answer please list all questions with numbers to clearly indicate each new question.

3. If you did not answer the question above asking you to suggest questions for researchers to answer about patient safety in primary care, is this because

   - ○ you have no questions about primary care for researchers to answer
   - ○ you did not understand the question
   - ○ Other, please specify

4. The following questions are all optional.

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

How old are you?

- 16 to 24 years
- 25 to 34 years
- 35 to 44 years
- 45 to 54 years
- 55 to 64 years
- 65 to 74 years
- 75 and over
- Prefer not to say

5. Do you live in England, Wales, Scotland or Northern Ireland?

- Yes
- No
- Prefer not to say
- If yes, please enter the first 2 letters of your postcode below

6. What is your highest level of education?

- No qualifications
- 1 to 4 GCSEs or equivalent
- 5 or more GCSEs or equivalent
- Apprenticeship
- 2 or more A levels or equivalent
- Degree level or above
- Other qualifications
- Prefer not to say
- Other, please specify

7. What is your ethnic group? Choose one option that best describes your ethnic group or background

- White
- Asian or Asian British: Indian
- Asian or Asian British: Pakistani
- Asian or Asian British: Bangladeshi
- Asian or Asian British: Chinese
- Asian or Asian British: Other
- Black or Black British: African
- Black or Black British: Caribbean
- Black or Black British: Other
- White and Black Caribbean
- White and Black African
- White and Asian
- Arab
- Prefer not to say
- Other, specify (optional)

8. Do you, personally, work as a Healthcare Professional in any capacity? For example, a doctor/nurse/therapist/pharmacist/health service researcher/other NHS staff, etc. (if retired answer for your previous work)

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

- Yes
- No
- Don't know
- Prefer not to say

9. How do you describe your gender?

- Female
- Male
- In another way
- Prefer not to say

10. Is your gender identity the same as the gender you were given at birth?

- Yes
- No
- Do not understand the question
- Prefer not to say

11. Which best describes you?

- Lesbian/Gay
- Bisexual
- Heterosexual/Straight
- Other
- Prefer not to say

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

Online supplementary file 2: the top 60 research priorities

1	What is the role of the receptionist in patient safety; i.e. facilitating access to urgent appointments?
2	Do GP practices keep patient records up to date to ensure safety when a patient is seen by a different GP?
3	Do patients have thoughts on what is safe and unsafe practice and would they know how and where to escalate any concerns?
4	Does seeing a named GP who knows an individual have safer care than seeing a GP who doesn't know me?
5	How does continuity of care influence patient safety?
6	How is patient safety and patient harm monitored in primary care?
7	How many patients actually know what medication they are taking; what for and what the potential side effects are?
8	What can be done to make polypharmacy safer?
9	What is the impact of pharmacy input in the GP surgery?
10	Do GPs and other health care professionals record patients who are vulnerable/at risk in the patient notes?
11	Do patients referred to their community pharmacist by their hospital pharmacist for post-discharge support with their medicines have improved levels of medicines safety and medicines adherence?
12	How can patient safety be assured for the most vulnerable in society (e.g. people who are frail; have mental health problems; cognitive impairments; learning difficulties; disabilities; and poor health literacy)?
13	How frequent are the misdiagnosis of symptoms by GPs resulting in patient safety incidents?
14	How safe are phone consultations compared to face to face with one's GP?
15	How well trained are receptionists as acting as gatekeepers to GPs and prioritising patients?
16	In what ways does work intensity; hours worked & staffing levels affect patient safety/near misses?
17	What can be done to improve access to GP surgery for someone with mental health problems?
18	What can Primary Care do to identify and support people who may be at risk of suicide?

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

19	What do patients understand about when they should or shouldn't contact a GP; and who they should see instead?
20	What team working methods/cultures promote a safer approach?
21	What types of prescribing errors are occurring in GP prescribing practice and how often are they occurring?
22	Would a co-ordinated / holistic / overview approach to individual patients and families improve patient safety?
23	How can we encourage a culture that learns from patient safety incidents?
24	How can we encourage patients and clinicians to be more open about patient safety incidents; within a culture of learning rather than blame?
25	What tools could help practitioners balance safety/costs/workload/accessibility/quality?
26	Are difficulties in contacting doctors and/or making appointments associated with more delays or errors in diagnosis; or other failures of care?
27	Do clinicians ask patients if they understand the questions they are being asked and if they feel safe?
28	Do the actions of receptionists have potential ramifications for patient safety?
29	Does safety consciousness lead to anxiety and over compensation i.e. too much risk averseness?
30	Does the provision of detailed blood test data to patients lead to them managing their condition better?
31	How can communication between health care professionals be improved for people with multiple long term conditions?
32	How can information within patient medical records be made available to patients and care providers in a way that protects privacy and improves safety and quality of care?
33	How can patient safety reporting be made simple and action on reporting made effective?
34	How can patients best be informed about GPs with special interests in the practice they attend; in order to direct them to the most suitable doctor or nurse for consultation?
35	How can risks be mitigated to allow for safe; complex care at home?

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

36	How can we enable individual Practices to share their significant event audits and outcomes with each other in a way which promotes patient safer care?
37	How can we improve safe communication and co-ordination of care between Primary and Secondary care?
38	How can we make sure that the whole patient is treated; not just one condition and with mental health and physical health both being treated together?
39	How do GPs inform their patients of the side effects and potential risks when prescribing a new medication?
40	How well do patients understand the information that has been conveyed to them during the consultation?
41	In the backdrop of health and social care devolution; what are the risks to patient safety as services transform and the system transitions?
42	Is lack of continuity of care by a single doctor in a joint practice associated with more delays or errors in diagnosis?
43	Is there a clear understanding of patient safety in general practice?
44	What are the diagnostic success rates of GPs when compared to their final diagnosis for a patient?
45	What are the safe frequencies of medication review?
46	What can be done to help GPs or nurse practitioners decide when the use of antibiotics is necessary?
47	What kinds; seriousness; and frequency; of harms happen to patients in primary care?
48	What proportion of national guidelines and National Institute for Health and Care Excellence recommendations are followed and monitored?
49	What proportion of patients tell their GPs about anything else they may be taking (e.g. homeopathy; cannabis etc.) that may conflict with medications?
50	What steps can be taken to improve patient safety in out of hours care?
51	Which type practitioner (GP; advanced nurse practitioner; practice nurse; etc.) is safest to see which types of patients (acute illnesses; acute on chronic; multi-morbid; long-term illness)?
52	Why do some patients not engage with their healthcare and so not attend all/some of their health checks?
53	Why is it that doctors do not listen to carer's concerns?

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.

54	Why is there such a time lag between seeing the hospital consultant and the GP getting information about a medication change?
55	Are patients with a disability particularly vulnerable to unsafe primary care and; if so; how can this be improved?
56	Are their harmful outcomes form excessive attention to safety?
57	How are medical errors in primary care prevented and recorded?
58	How can GP practices appointment systems (e.g. telephone; online) be improved?
59	How often do GPs report side effects; what is the level of under-reporting and how can it be improved?
60	How safe is treatment in out of hours care if patient notes are not available?

For peer review only

BMJ Open: first published as 10.1136/bmjopen-2017-020870 on 28 February 2018. Downloaded from http://bmjopen.bmj.com/ on June 30, 2024 by guest. Protected by copyright.