

BMJ Open Patients' perspectives on the medical primary–secondary care interface: systematic review and synthesis of qualitative research

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ABSTRACT

Objectives: To synthesise the published literature on the patient experience of the medical primary–secondary care interface and to determine priorities for future work in this field aimed at improving clinical outcomes.

Design: Systematic review and metaethnographic synthesis of primary studies that used qualitative methods to explore patients' perspectives of the medical primary–secondary care interface.

Setting: International primary–secondary care interface.

Data sources: EMBASE, MEDLINE, CINAHL Plus with Full text, PsycINFO, Psychology and Behavioural Sciences Collection, Health Business Elite, Biomedical Reference Collection: Comprehensive Library, Information Science & Technology Abstracts, eBook Collection, Web of Science Core Collection: Citation Indexes and Social Sciences Citation Index, and grey literature.

Eligibility criteria for selecting studies: Studies were eligible for inclusion if they were full research papers employing qualitative methodology to explore patients' perspectives of the medical primary–secondary care interface.

Review methods: The 7-step metaethnographic approach described by Noblit and Hare, which involves cross-interpretation between studies while preserving the context of the primary data.

Results: The search identified 690 articles, of which 39 were selected for full-text review. 20 articles were included in the systematic review that encompassed a total of 689 patients from 10 countries. 4 important areas specific to the primary–secondary care interface from the patients' perspective emerged: barriers to care, communication, coordination, and 'relationships and personal value'.

Conclusions and implications of key findings: Patients should be the focus of any transfer of care between primary and secondary systems. From their perspective, areas for improvement may be classified into four domains that should usefully guide future work aimed at improving quality at this important interface.

Trial registration number: PROSPERO CRD42014009486.

Strengths and limitations of this study

- This review employed rigorous and established methodology specific to qualitative studies throughout.
- The quality of the included studies was assessed using a published framework (Critical Appraisal Skills Programme, CASP) and found to be uniformly high.
- The independent analysis of full articles by two researchers generated themes, concordant between reviewers, in a transparent and reproducible manner and was considered helpful in maintaining a coding balance.
- Given reciprocal translational analysis provides summaries in terms that may have already been used in the original literature, there is acknowledgement that the synthesis will tend towards the privileging of a priori over in vivo codes.
- Patient preferences and experiences were synthesised from varying primary–secondary care interfaces in differing healthcare systems serving different populations, but are gleaned only from the published literature. Study findings may therefore not be generalisable to all situations.

INTRODUCTION

In numerous countries, primary care is the usual first point of professional contact for patients with a medical complaint. Many conditions are managed in primary care though some require more specialised medical expertise or treatment, necessitating access across the primary–secondary care interface to specialist attention, usually in hospitals as inpatients or outpatients.^{1 2} For patients who frequently transit the primary–secondary care interface, such as those with chronic conditions, coordination between the different disciplines is essential for the delivery of quality care.³ Since primary and secondary care clinicians often have different perspectives and can act in separate 'professional tribes', it is important that any

inconsistencies across the primary–secondary care interface do not impact on the effectiveness and safety of patient transitions.⁴

Although manifestations of the primary–secondary care interface across the world are diverse and the disciplines involved differ, similarities can be identified in most healthcare systems.^{5–7} In countries where general practice (or family medicine) is well developed, there are many similarities in the functions and characteristics of the primary–secondary care interface-based system, with general practitioners (GPs (or primary care physicians—PCPs)) usually acting as ‘gatekeepers’ to secondary care.^{2 5} In many nations, primary care is largely delivered by non-medically qualified practitioners, with less formal access to secondary care, and in others there is direct access to primary medical care provided by specialists, such as paediatricians, gynaecologists, specialists in internal medicine and cardiologists.^{2 5 8–11}

In countries with ‘gatekeeping’ primary care systems, there has been increased focus on the interface between primary and secondary care,^{12–17} highlighting the importance of better relationships between hospital and community, and between specialist and PCP, for the benefit of patient care.²

Qualitative studies describing experience at the interface have highlighted the importance of good access to patient-centred care (ie, that which is respectful of and responsive to individual patient preferences, needs and values),^{18 19} but the amount of patient-focused work is limited.

AIMS

Using a metaethnographic approach (a method for synthesising qualitative research studies) described by Noblit and Hare,²⁰ this study aimed to identify what patients perceive as important markers of care quality at the primary–secondary care interface. Such an approach may generate greater understanding than a single empirical study and may be helpful in determining the direction of future work to improve clinical outcomes.^{21 22}

METHODS

Study registration

The study was registered with the PROSPERO database, registration number CRD42014009486.

The seven-step model of metaethnography described by Noblit and Hare²⁰ was used. The first step involved *a clear statement of the specific research question* (What do patients perceive as important markers of care quality around the primary–secondary care interface?) and the contribution it will make to the field (to generate new insights, achieve greater understanding of the issues facing patients at the primary–secondary care interface than with a single empirical study, and determining targets for future research with the aim of improving patient outcomes). In step 2, a *search strategy* was devised to retrieve articles related to this aim. The search was

focused to locate primary studies that met the following criteria.

Eligibility criteria for study inclusion

Studies were eligible for inclusion if they met all of the following criteria:

- ▶ Employed qualitative methodology (focus groups or interviews);
- ▶ Explored patients’ perspectives;
- ▶ Targeted the medical primary–secondary care interface (ie, at the interface between PCP and secondary care hospital specialist);
- ▶ Full research papers (ie, not an editorial, conference poster or abstract).

Study exclusion criteria

Studies were excluded if any of the following were present:

- ▶ Non-qualitative methodology;
- ▶ Did not explore patients’ perspectives;
- ▶ Did not focus on the medical primary–secondary care interface (eg, studies focusing on the interface between social care and tertiary care would not be included);^{23–27}
- ▶ Not full research papers (ie, an editorial, conference poster or abstract).

Information sources and search strategy

Electronic databases were searched using database-specific terms and validated methods for retrieving qualitative studies (EMBASE (OVID 1974 to 30 July 2014), MEDLINE (OVID MEDLINE 1946 to 30 July 2014 with daily update), CINAHL Plus with Full text (EBSCO host accessed 30 July 2014), PsycINFO, Psychology and Behavioural Sciences Collection, Health Business Elite, Biomedica Reference Collection: Comprehensive Library, Information Science & Technology Abstracts, eBook Collection (EBSCO host, last accessed 30 July 2014), Web of Science Core Collection: Citation Indexes and Social Sciences Citation Index (database inception to 30 July 2014), and grey literature sources ((Open SIGLE (opensigle.inist.fr), last accessed 7 August 2014), (Health Management Information Consortium 1979 to May 2014 incorporating Kings Fund Information and Library service), (National Technical Information Service <http://www.ntis.gov/>, last accessed 7 August 2014) and (PsycEXTRA <http://www.apa.org/psycextra/>, last accessed 7 August 2014)) to identify literature using qualitative methods (focus groups or interviews) exploring patients’ perspectives of the primary–secondary care interface.^{23–27} No language or date of publication limits was applied to the search. Refer online supplementary appendix 1 ‘Search terms’ for specific detail of search used for each database. Authors of included studies were contacted to determine any key papers in the field of interest not identified by our own search strategy.

Study selection

One author (RS) examined titles and abstracts of all retrieved citations for eligibility according to the above criteria. The full-text articles of any abstracts classified as definitely or potentially suitable for inclusion were retrieved and analysed independently by two authors (RS and JC) against predefined inclusion and exclusion criteria with differences resolved by consensus.²⁸ See online supplementary appendix 2 'Excluded studies' for details of and reasons for study exclusion. Reference lists of all included studies were scrutinised for eligibility according to inclusion/exclusion criteria. Main authors of all included papers were contacted to explore the potential for any studies considered important to them that may have been missed in our search strategy.

No quality filters were applied prior to inclusion of studies in the systematic review. However, the Critical Appraisal Skills Programme (CASP) tool for assessing qualitative research²⁹ was applied postinclusion giving insights into the methods used for data collection and analysis (see online supplementary appendix 3 CASP review).

Data extraction

Step 3 of the metaethnographic synthesis involved reading the studies. Two authors (RS and JC) read and re-read the included studies, and independently listed the main themes from each article including both first-order (views of the participants) and second-order interpretations (views of authors). Where patients were interviewed with another healthcare professional, the analysis was restricted to the views of the patient where possible. Data were abstracted into standard fields, such as study aims, design, methods, setting and participants (see online supplementary appendix 4 'Data extraction template'),³⁰ and entered into QSR International's NVivo V.10 software to assist qualitative analysis and synthesis.³¹

Data synthesis

In step 4, two of the authors (RS and JC) *determined how the studies were related* to each other by comparing individual study findings, and derived key concepts that reflected the main findings of all included studies. Subsequently (step 5; studies were *translated into each other*) each study was re-examined and assessed for its relevance to these key concepts. In the same way that primary study moves from descriptive to explanatory analysis, these translations were then synthesised (step 6) to develop third-order interpretations (higher levels of abstraction) to represent the overarching perspective of patients at the primary–secondary care interface. Members of the research team (RS/RB/PW) developed this third-order interpretation or 'line of argument' synthesis by listing the translated themes and subthemes (derived from first-order and second-order constructs reported in the primary studies), then review and discussion.

The final step involved expressing the results of the synthesis using tables, figures and text in accordance with the 'Enhancing transparency in reporting the synthesis of qualitative research' (ENTREQ) statement (see online supplementary appendix 5 'ENTREQ statement').³²

FINDINGS

The electronic database search returned 690 citations, leaving 654 after removal of duplicates (see figure 1).

A further 618 articles were excluded after scrutiny of the title or abstract for using non-qualitative methodology (n=226), involving participants other than patients (n=195) or because they did not concern the experience of patients at the medical primary–secondary care interface (n=197).

The full texts of all remaining 36 articles were retrieved and evaluated independently by two authors (RS/JC) against predefined criteria, leading to the inclusion of 20 papers (table 1). See online supplementary appendix 2 'Excluded Studies' for details of, and reasons for, study exclusion.

Included studies originated from 10 countries and comprised a total of 689 patients (range 7–53 per study). Two studies used focus groups alone, 10 utilised solely individual patient interviews and 8 used both methods. The overall quality of the 20 included studies was high, with all articles meeting the majority of CASP criteria. One common weakness was around whether ethical issues had been taken into consideration (not clear in 5 of the 20 studies).^{34 37–39 47} The other common limitation was a lack of evidence demonstrating that the relationship between researcher and participants had been adequately considered; particularly whether the researcher(s) had critically examined their own role and potential for bias in formulation of topic guides, data collection, recruitment, study location, and whether they considered the implications of any changes in the research design (not reported in 17 of the 20 studies).^{35 37 38 40–42 44–50}

Translation of included studies

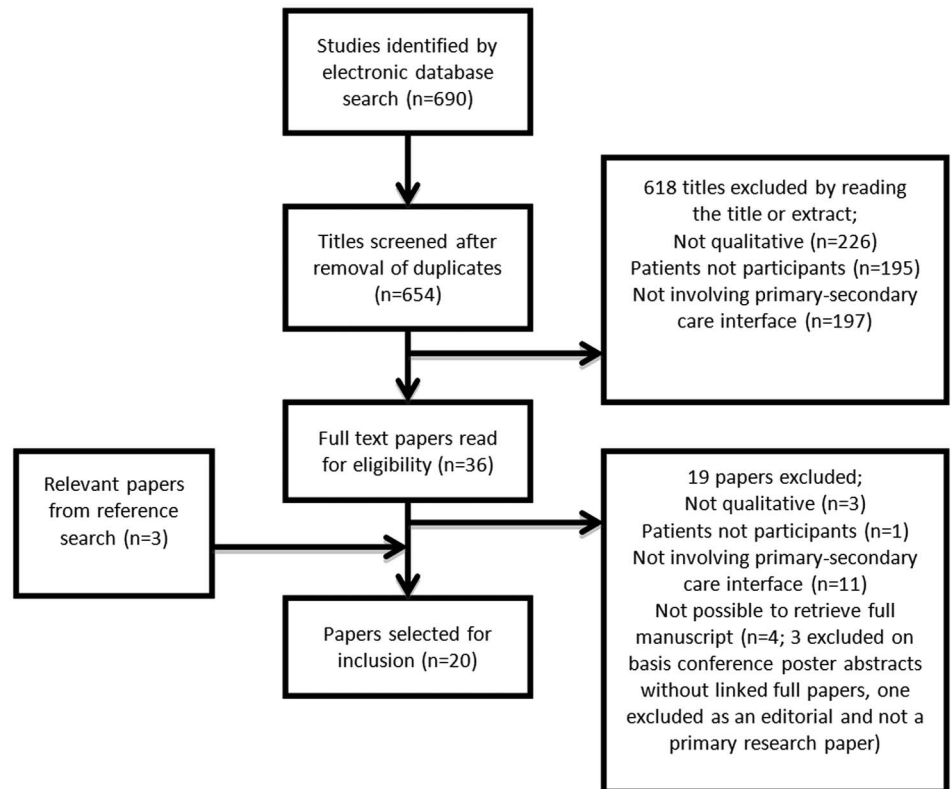
Four key concepts that reflected the principal findings of all included studies were determined: barriers to care, communication, coordination, and relationships and personal value (table 2). Within each key concept, subthemes arose that are highlighted in bold.

Barriers to care

There was a strong patient perception that **lack of PCP knowledge** could be an obstacle to the delivery of good clinical care; "If it's of a serious nature, I certainly wouldn't take the GP's word for it."^{33 46–48} Conversely for some patients, this apparent knowledge deficiency was not a practical problem, as their PCP referred them on.³³

Some patients described the **PCP acting as a barrier** (the one who controls your entry into the system) they

Figure 1 Flow diagram of search.



had to be overcome; “I was lucky, I didn’t have to go to my GP because I collapsed in church.”^{34 35 46}

Access to the PCP was also perceived as an impediment; “you can be on the phone for hours trying to ring a doctor and you don’t get anywhere. So I ring now for the paramedics.”^{35 36}

Further **system problems** were identified, such as perceived delays to specialist clinic appointments, postponements and cancellations. When at specialist clinics, patients described long waiting times, frequent consultation interruptions and a lack of time with clinicians.^{38–40 46} Patients spoke of being disempowered by system complexity,⁴⁸ bureaucracy resulting in disjointed care (“*There is a distance between the hospital and primary care. Each part protects his own territory*”⁴) and personal stress.³³

Some patients reported that scheduled specialist follow-up was often unnecessary when they were well and described frustration at having to organise their lives around superfluous appointments.⁴³

Communication

There were conflicting patient views of the **effectiveness of communication** across the interface. Some informants were satisfied, while others cited that inadequate communication between specialist and PCP could lead to provision of contradictory information by healthcare professionals, causing patient confusion.^{33 35 37 38 45 47} Use of **informal routes of communication** was mentioned as effective means of overcoming fragmentation in care.³³

Patients believe **good communication** with their doctor requires time; established trust, understandable information and good clinician interpersonal skills.^{18 35 37 39 40 45 46 48} Conversely, patient stress, inadequate information or a sense of not being listened to increased the perception of **poor communication**.^{37 38 40 44 47}

Certain patients responded to poor communication by becoming more proactive (eg, involving family members to act on their behalf, preparing lists of questions or quarrelling with clinical staff), while others became more anxious and uncertain.^{18 40} However, patients did not lay all responsibility for poor communication on healthcare professionals.³⁸ Some perceived that their own lack of personal knowledge, lower comparative social status (eg, when attending a hospital specialist) or physical condition at time of consultation inhibited their ability to communicate with clinicians.^{18 37 38 47}

Problems with the **transfer of information** at the interface were considered a significant cause of three major concerns:

- Delays in care delivery: “considerable numbers of patients were dissatisfied with the length of time it took for the GP to be given word from the specialist”;³⁸
- Frustration: “Separate clinics don’t talk to each other or ring each other. I find the whole thing incredible the length of time it takes; it’s just been horrendous, waiting weeks to see a consultant to be told ‘I don’t know why you’ve been referred to me’...it can make you feel very insignificant”;¹⁸

Table 1 Characteristics of included studies

First author (reference)	Objective	Data collection	Participants (n)	Qualitative methodology/ analysis	Country	Year of publication
Admi ³³	To gain insight into the hospital community interface from the point of view of patients with cancer, their families and healthcare providers on both sides of the interface, that is, the community and hospital settings	Individual and focus group interviews	Thirty-seven patients with cancer, their family members and 40 multidisciplinary healthcare providers. Twelve participants were interviewed individually and 65 took part in 10 focus groups	Based on the grounded theory approach, theoretical sampling and constant comparative analyses were used	Israel	2013
Bain ³⁴	To explore the perspectives of patients receiving treatment for CRC and compare priorities and attitudes in rural and urban areas	Focus groups	Patients at various stages of treatment for CRC and 10 of their relatives from different locations of Northeast Scotland and Shetland (22)	Thematic	UK (Scotland)	2000
Bain ³⁵	To explore how patients with CRC perceive their care	Focus groups and individual interviews	Patients and relatives of patients with CRC in the North, Northeast and Northern Isles, Scotland (95)	Emerging themes were identified inductively from the interviews, and divergent perspectives between rural and urban participants were noted	UK (Scotland)	2002
Beech ³⁶	To explore the perspectives of patients receiving treatment for CRC and compare priorities and attitudes in rural and urban areas	Individual interviews	Patients with one of three conditions (COPD, stroke or falls) (18)	Constant comparative method of grounded theory	UK (England)	2013
Berendsen ³⁷	To (1) explore experiences and preferences of patients regarding the transition between primary and secondary care, (2) study informational resources on illness/treatment desired by patients and (3) determine how information supplied could make it easier for the patient to choose between different options for care (hospital or specialist)	Semistructured focus group interviews	Patients referred for various indications in the North and West of the Netherlands (71)	Framework analysis	The Netherlands	2009
Burkey ³⁸	To discover the views of patients about their discharge from outpatient clinics, to detect any change in these perceptions over time, and explore how the discharge process might be improved for the patient	Individual semistructured interviews	Forty-five patients who had attended outpatient clinics on three or more occasions	Thematic analysis	UK (England)	1997
Davies ³⁹	To improve the knowledge and understanding of patients' perspectives about their participation in handover	Semistructured individual interviews	Thirty-three consecutive patients referred for endoscopy and subsequently diagnosed with CRC were identified prospectively from histology and surgical records	Framework analysis	UK (England)	2006
Flink ⁴⁰	To improve the knowledge and understanding of patients' perspectives about their participation in handover	Individual semistructured interviews	Patients with chronic diseases who presented to ER with an acute condition or an exacerbation of their chronic condition, and who were subsequently hospitalised in an emergency ward (23)	Inductive qualitative content analysis	Sweden	2013

Continued



Table 1 Continued

First author (reference)	Objective	Data collection	Participants (n)	Qualitative methodology/ analysis	Country	Year of publication
Göbel ⁴¹	To apply a microsystem lens to gain insights into gaps in the handover process from the hospital to the community, and to develop recommendations for improving handovers between (local) primary and secondary care	Individual interviews	Patients admitted to two hospitals in the Netherlands (7)	Qualitative thematic analysis according to the 'social science queries' technique	The Netherlands	2012
Hesselink ⁴	To explore aspects of organisational culture to develop a deeper understanding of the discharge process	Individual and focus group interviews	In five European Union countries, 192 individual and 25 focus group interviews were conducted with patients and relatives, hospital physicians, hospital nurses, GPs, and community nurses	Grounded theory approach	The Netherlands, Spain, Poland, Sweden and Italy	2013
Hesselink ⁴²	To explore the barriers and facilitators to patient-centred care in the hospital discharge process	Individual and focus group interviews	One hundred ninety-two individual and 26 focus group interviews with patients and relatives, specialists, nurses, GPs and community nurses. Individual interviews were conducted with 53 patients and/or caregivers	Modified grounded theory	The Netherlands, Spain, Poland, Sweden and Italy	2012
Kemp ⁴³	To explore patients' needs, preferences and views of follow-up care	Individual semistructured interviews	Patients with IBD were selected from a gastroenterology clinic in a UK Hospital (24)	Framework analysis	UK (England)	2013
McHugh ⁴⁴	To explore within primary care the experiences of management and care of individuals with end-stage lower limb osteoarthritis that are on the waiting list for joint replacement	Semistructured interviews	Patients with osteoarthritis (21)	Framework	UK (England)	2007
Pascoe ⁴⁵	This study aimed to explore Australian patients' perspectives of the referral pathway when they first receive the diagnosis of CRC, and to describe their expectations regarding referral to specialist services in order to improve the patient pathway	Individual and focus group interviews	Twenty-nine patients participated in four focus groups. Seven additional individual interviews supplemented the sample. In total there were 22 female and 14 male participants. In the South Australian focus group, three of the four patients were privately insured; in the NSW focus group all patients were privately insured; in the Qld focus groups five of the seven participants were privately insured (n=36)	The analysis was thematic, based on a social constructionist epistemology	Australia	2013
Pollard ⁴⁶	To assess the perceived barriers that prevents the provision of seamless integrated care across the primary and secondary healthcare sectors by assessing the varying perspectives of patients, carers, specialists and GPs	Focus groups and face-to-face interviews	Patients, carers, specialist medical and nursing outpatient staff and GPs working in or attending three hospitals and three PCTs (79)	Content and discourse analysis	UK (England)	2011

Continued

Table 1 Continued

First author (reference)	Objective	Data collection	Participants (n)	Qualitative methodology/ analysis	Country	Year of publication
Preston ¹⁸	To discover the views of patients about their experiences across the interface between primary and secondary healthcare, including referral from GPs, outpatient and inpatient care, discharge, and aftercare	Individual and focus group interviews	Thirty-three patients who had attended at least one outpatient appointment or had been an inpatient between 2 and 4 months previously	Constant comparative method	UK (England)	1999
Somerset ⁴⁷	To explore understandings concerning referral to and reattendance at outpatients, and to elicit detailed descriptions of the complexities of the outpatient experience for both providers and recipients of care at the primary/secondary interface, given the policy commitment to a 'primary care-led National Health Service'	Semistructured individual interviews	Patients newly referred from primary care to hospital outpatient specialties of general surgery, general medicine, gynaecology, ENT and paediatrics (9)	Negative case analysis	UK (England)	1999
Walton ⁴⁸	To explore New Zealand service users' experiences of the pathway to lung cancer diagnosis, identify factors contributing to delay and provide advice for service improvement	Semistructured individual and focus group interviews	Patients who presented to a hospital emergency department with suspicious symptoms (n=19) were interviewed individually. Those with confirmed lung cancer (n=20) took part in a focus group	Thematic	New Zealand	2013
Wilkes ⁴⁹	To explore the perceptions and attitudes of patients and health professionals to open access hysterosalpingography for the initial management of infertile couples in general practice	Nested qualitative study using in-depth interviews	Infertile couples ((nine interviewed with their partner) 13)	Thematic	UK (England)	2009
Wright ⁵⁰	To explore the views of people with severe mental illness and health professionals from primary care and CMHTs on how best to deliver services providing primary prevention	In-depth interviews	Patients with severe mental illness (31)	Framework	UK (England)	2006

CMHT, community mental health team; COPD, chronic obstructive pulmonary disease; CRC, colorectal cancer; ER, emergency room; GP, general practitioner; IBD, inflammatory bowel disease; NSW, New South Wales; PCT, primary care trust.

C. Inaccuracy, for example, incomplete hospital discharge information. In addition, lost referrals, professional schedule inflexibility, poorly communicated processes and resourcing issues highlighted complex difficulties.^{18 37 40 45 47 48}

Coordination

Some patients preferred their PCP to coordinate care since they could see the ‘whole picture’^{33 35 37 39 45} and others described increased confidence about discharge from hospital when they believed their PCP managed the ‘gatekeeping’ role well and would be willing to refer or re-refer when necessary; “I’ve every faith in him...Any problems I’ve got I just pick up the phone. He’s a very good doctor. He gets down to it you know and if he’s not sure he says ‘Right, hospital!’”³⁸

Where formal care coordination roles were not clear, patients and family members often assumed this role in either a **proactive** or **passive** fashion.³³ Proactivity was associated with provision of medication lists, a felt need to be assertive, initiation of PCP follow-up postdischarge and intentional modification of personal behaviour and clinical information disclosure to facilitate progression through the system; “I have to ‘play act’ when I see a GP. So I have to pretend that I am really ill and about to die before anything actually happens...I don’t have a lot of faith in them.”^{37 40 44 46}

Patients appreciated being involved in clinical decisions^{46 47} and regularly felt they took a level of **responsibility** for coordination of their own care,^{33 47 48} even when things went wrong.⁴¹

Coordination of patient care could be influenced by the **role of their family or carer**; “I wasn’t sure I was going to agree to the hospital tests. It was the family that changed my mind,”^{35 48} and the level of **information** provided; “lack of information perpetuated patients’ feelings of an imbalance in status and power, and reduced their sense of being involved in their own care.”^{18 37 45 48}

Specialist nurses and those with *specific care-coordinator roles* were valued by patients in terms of access, liaison with specialist and PCP, thoroughness, and acting as a point of continuity within the hospital system.^{33 36 37 43 46 48}

Relationships and personal value

Patients appreciated sympathetic ongoing **relationships** with their PCP; “He tries to help me, he is a really understanding doctor. He understands how I feel. I can really talk to him. He knows how I feel. I tell him where I am having the pain. I relate to him.”^{38 45 46} Good relationships with PCPs based on trust and understanding increased patient confidence to progress through the system^{18 45} and was thought central to help seeking. In particular, continuity of PCP was considered essential to build relationships in which patients felt safe to disclose concerns.⁴⁸ Conversely, patients were less confident when the relationship with their PCP was

poor or they were unable to see their usual PCP.¹⁸ Informal patient relationships with clinicians were sometimes used to facilitate progress through the system; “A patient with cancer must have connections, otherwise he gets lost in fairyland: go there, come back, wait, and so on.”³³

Patients’ personal perceptions of hospital care were related to the quality and consistency of their relationships with secondary healthcare professionals.^{39 43} Patients can sense they are not **valued** with predictable consequences; “I think you feel a bit like an accessory, you’ve got this great big medical system and you’re not really part of it, the system rolls on whether you’re there or not...as a patient I thought the system was there because of you, not you there because of the system. It’s this great big wheel of medicine going round and round and you’re an insignificant speck.”¹⁸ **Attitudes** of staff in practices and outpatient clinics can make patients feel ‘in the way’ and powerless to challenge failures in the system.¹⁸

Patients also noticed tensions in the relationships between primary and secondary care, some expressing the view that PCPs and hospital doctors were not working together; “Is there maybe problems that the doctors are frightened to refer people to the hospitals-you know, they are the small fry and the hospital the big fry?”^{4 34 44}

Third-order interpretations and ‘the line of argument’

Barriers to care

Many patients perceived low levels of PCP knowledge as being a barrier. Access to the PCP was highlighted as a difficulty. Once in the system, clinician and staff attitudes were described as obstacles. Patients identified organisational and system problems as hindering progress.

Communication

Clinicians on both sides of the interface require good interpersonal skills and a patient-centred approach in order to communicate effectively. The effect of poor communication with patients (patient uncertainty, anxiety, unwillingness to communicate and the potential for quarrelling with clinicians) should not be underestimated.

Coordination

Some patients feel able to take on an active coordinating role in order to progress within the primary–secondary care interface. Patients value those healthcare workers with formal care coordinator roles (eg, specialist nurses).

Relationships and personal value

Good relationships with clinicians and staff, described as sympathetic, understanding and trusting promote patients’ sense of being valued and influenced disclosure of concerns, help seeking, compliance and confidence about referral and progress in the system. Patients

sometimes used informal relationships with clinicians in order to advance through the system.

DISCUSSION

This systematic review, to our knowledge the first attempt to synthesise the qualitative literature exploring the patient experience at the medical primary–secondary care interface, has led to a broader description and fuller understanding of the range of challenges that exist at this critical point in care delivery.

Patients encounter multifaceted dynamics at the interface including barriers to care, communication, coordination of care issues and the impact of relationships and personal value.

Comparison with other research

Barriers to care

Patients in several studies perceived low levels of PCP knowledge as a barrier to care, one specific example being the patient experiencing a delayed diagnosis of lung cancer which they specifically related to a lack of PCP knowledge.⁴⁸ They contrasted the knowledge of the PCP and specialist, seeing the consultant as the ‘expert able to delve deeper’, in contrast to the PCP; “You need specialist input for some things, I don’t think that GPs have enough knowledge.”⁴⁷ This subtle negative view of PCP knowledge base perhaps belies a lack of understanding of differing roles of PCPs and specialists in a ‘gate-keeping’ interface context. There may be potential for further clarification of this phenomenon, perhaps including a triangulated approach involving patient and peer assessment of PCP knowledge. Clinicians have a professional responsibility to maintain up to date knowledge and skills throughout their working career, and to regularly take part in educational activities that maintain and further develop competence and performance.⁵¹

Systems need to be improved, so patients (and their information) can travel seamlessly across the interface between primary and secondary care. Medical notes should be complete, accurate and accessible to all relevant care providers.⁵² However, ‘information shared between GPs and hospitals when a patient moves between services is often patchy, incomplete and not shared quickly enough’.⁵³ PCPs frequently receive hospital discharge summaries with deficient or inaccurate medicines information and delay in transmission of such information from secondary to primary may adversely affect patients.^{53–56} For example, in one study, PCPs felt it may have been important to carry out a follow-up home visit had they known that the patient had been discharged from hospital.⁵⁶ The quality of patient information provided by PCPs to hospitals can also be substandard with regard to previous drug reactions, comorbidities and allergies.⁵³ There certainly remains room for improvement^{54 57–69} and a need to develop

and evaluate interventions to develop the content and speed of information sharing between primary and secondary care.⁷⁰

Communication

The effect of poor communication skills on patients on both sides of the interface should not be underestimated: poor communication is an increasingly frequent reason for complaint⁷¹ when patients feel ‘disempowered and disengaged’ and patronised by clinicians.⁷² Inadequate time spent by clinicians with patients is associated with increased likelihood of malpractice litigation, largely due to poor communication.^{73 74} Cultural factors and educational background may influence clinician communication abilities.⁷⁵ The question of how factors such as age and communication skills training impact on the doctor–patient relationship is interesting, and may merit further research.

Coordination

Patients vary in their ability to take on an active coordinating role of their progress within the primary–secondary care interface and value professionals adopting formal roles in this sphere. Though there has been some confusion about terminology,^{76 77} the clinical nurse specialist (CNS) is generally in a unique position with access to both PCP and specialist, as well as being available to the patient.^{78 79} This role is probably most developed and researched in patients with cancer where the CNS can improve quality of care, positively impact management, and improve understanding of treatment options and prognosis.⁸⁰ Such roles may offer good value for money, reducing emergency admissions, length of hospital stay, follow-up appointments and providing support to enable end of life care in a place of the patient’s choice.^{81 82} However, further research may be needed before firm recommendations can be made on the widespread value of CNSs in other chronic diseases.⁸³

Relationships and personal value

Good relationships with clinicians were important to patients, influencing disclosure of concerns, help seeking, compliance, and overall confidence about referral and progress in the system.

Some patients reported tensions between primary and secondary care, expressing the view that PCPs and hospital doctors were not working together.^{4 34 44} The influences on this relationship are complex and include political restructuring, patient demands and advances in medical knowledge.⁸⁴ Professional ‘tribalism’, acknowledged on both sides, has the potential to undermine the effectiveness and safety of patient transitions,⁴ though good evidence supports that professionalism and desire for best clinical care can overcome these obstacles⁸⁴ and lead to positive patient outcomes across the interface.^{84–86}

Table 2 Translations between studies using first-order and second-order interpretations and their relation to key concepts

First author	Barriers to care	Communicating	Coordinating	Relationships and personal value
Admi	"An issue that was raised by the some of the patients was that the PCP's knowledge about oncology diseases was inadequate"	Patients accorded great importance to maintaining continuity of care and communication between providers on both sides of the interface	Most patients interviewed expressed a desire for their family doctor to take on the role of an integrator of care. One woman explained the rationale behind this: "My expectations from my family doctor are that she will be an integrator for the disease. There's an oncologist, a haematologist, a pain specialist. From my side, it's totally acceptable that she (my family doctor) should tell me that this is something she does not know. She knows me not only in regard to the illness, but also from my personality. She sees the whole picture. She sees me as a whole human being." FG 5, Community, Patient 4	In a number of instances, patients succeeded in advancing their care through the use of personal relations, either by relying on acquaintances within the system or by establishing a good personal rapport with a provider. In the words of one patient: "A patient with cancer must have connections, otherwise he gets lost in fairyland: go there, come back, wait, and so on." FG 5, Community, Patient 5
Bain	Tensions were perceived at the interface between primary and secondary care... there was a feeling among some participants that GPs and hospital doctors were, on the whole, not working together	A great deal of heightened anxiety was mentioned around the reporting of test results. "I was sent for a liver scan and I never got the result. That was a bad thing... The GP said he would find out for me, but I never heard...It was when I was back at the clinic I got the result then, 6 weeks later." (male/60 s/urban)	"I find my doctor is feart (afraid) o' the clout of the hospital coming back on him. He hedges round the question and he waits for the hospital to give him the answer. He won't actually come out and say anything." (male/40s/urban)	–
Bain	For some patients, the GP was an advocate and they spoke highly of his representation on their behalf. Others viewed the GP as a 'barrier' to overcome and a hurdle to be negotiated, or 'the one who controls your entry into the system'	They were unhappy about the use of euphemisms such as 'suspicious cells', 'rogue cells' or 'a growth'. Others found direct communication difficult to cope with. No one style of communicating bad news was ideal for all patients	Some did everything they could to speed their progress through the system. These were usually urban residents, who were experienced at 'fighting' to the front of the queue like 'an ant in an ant hill' and were intolerant of any delays; "Because my wife agitated and agitated I got in (main cancer centre) a month earlier." (No. 21/male/60 s/urban)	For communication to be tailored to individuals, both good knowledge of the patient (usually the domain of the GP) and full understanding of the cancer and possible treatments (usually the domain of the specialist) appear to be needed
Beech	Other patients who required extended periods of rehabilitation encountered bottlenecks in access to bedded rehabilitation with the choice of discharge destination appearing to be driven by the availability of community hospital and intermediate care beds	Communication between professionals, particularly across organisational boundaries, remained problematic	In some cases, decision-making about ongoing care following an acute attendance or admission resulted in timely transfer and patient satisfaction with the process...a respiratory rapid response team assessed Mrs I after receipt of a referral from the hospital's	The patient journeys demonstrated the important role that family and friends play in providing follow-up care. For instance, one woman who lived alone received help from her son and friends for 2 days until a rehabilitation bed became available. However, such

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Table 2 Continued

First author	Barriers to care	Communicating	Coordinating	Relationships and personal value
Berendsen	When asked directly, many patients said they found it either too difficult or felt too ill to make their own choices	All patients felt, however, that improvement is needed for the communication between GP and specialist. Information needs to be conveyed more rapidly, more completely, and, for the patient, the information should be more accessible	observation ward, arranging immediate community follow-up after her brief admission. I just couldn't believe it. It all sort of clicked into place. I thought this is actually going to happen...I came home and I just couldn't believe it, the phone rang and they said 'We'll be here in half an hour'—and they were. Mrs I, Site 2 Almost all patients found it important that the GP referred them quickly and appropriately. They appreciated it when the GP was able to shorten the time span between the referral and the first consultation with the specialist, and when their GP stayed in contact with them after the referral	requests could put considerable pressure on informal carers Many patients liked receiving information from nurses during their hospital stay or at the clinic. Reasons for this included clarity of the instructions, more extensive information, easy access to information and the thoroughness of nurses. Nurses can also help in communicating with the specialist
Burkey	Some patients were discouraged from asking questions because they felt rushed or that the doctors were very busy	Where patients had tried to discuss discharge opportunistically during consultations, they were often disappointed because letters from the hospital had not yet arrived or their GPs claimed not to have received this information. Patients did not know where responsibility for poor communication lay	They (patients) felt more confident about the discharge when they believed their GP managed the 'gatekeeping' role well and would be willing to refer or re-refer them when necessary. "I've every faith in him...Any problems I've got I just pick up the phone. He's a very good doctor. He gets down to it you know and if he's not sure he says 'Right, hospital!'"	Most patients talked positively about the quality of the relationship with their GP. They felt their family doctor knew them as a person and cared about them. However, a few had more difficult relationships. The attitude of the individual GP seemed to shape patients' views more than the size of a practice or way it was organised
Davies	"Everything takes so long to arrange. You arrange the tests, gap, you have the tests, you go back to the clinic. The gaps are always so big." Case 20, 33 years old, male	However, there were a few cases where patients felt improvements could have been made to the approach, timing and privacy. "The only place that was empty was the cleaning cupboard, so we ended up sort of leaning against a wall in the cleaning cupboard while he told me how bad he thought it was." Case 20, 33 years old, male	"She (PCP) did all she could. She sent me to one (specialist), it wasn't right. I went back and told her. She was annoyed; she sent me somewhere else. She didn't waste time." Case 7, 52 years old, male	"No-one got in touch with me from whom I could sit down and seek advice from. It would have put my mind at rest. It was only after going to talk to the cancer specialist nurse it was only then that she told me that this cancer is a slow-growing cancer, a few days won't matter, a few weeks won't matter. You just need that information." Case 7, 52 years old, male
Flink	"When the doctors are on their rounds, it's terrible. They come into the room, often with a lot of students, and then at first the doctor talks with the students for	Clinical rounds during the hospital stay and formal discharge encounters were seen both as a facilitator and a barrier to patient communication.	Some patients indicated they had not given much thought to their participation in the handover process. These patients either trusted the handover system and	—

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Table 2 Continued

First author	Barriers to care	Communicating	Coordinating	Relationships and personal value
	15 min, teaching them; well, but I want to have a word with the doctor! So, this really distracts you.” (Man, 68 years)	A positive bedside manner, including the healthcare providers sitting down by/on the bed and talking to the patient in a relaxed manner, was seen as a facilitator	the healthcare providers’ performance or they did not consider participation in handovers a reasonable patient task	
Gobel	By contrast, the patient in the second case study viewed himself as an integral part of the handover, and felt responsible for the miscommunication: “I forgot to ask for a letter from my discharge physician for my GP” (quote 25)	The GP in the first case study reported she could not reach the patient after receiving a letter that the patient had been discharged home (quote 1), when in reality, the patient had been transferred to a nursing home (quote 20). The GP phoned the patient several times at home and, not being able to reach him, assumed he was staying at his daughter’s house. The GP later learned (quote 3) that her patient had been transferred to a nursing home for rehabilitation. In addition, the GP believed her patient had been transferred to a certain nursing home, while the interview with the nurse revealed that the patient had been transferred to a different nursing home (quotes 3, 20 and 26)	The GP (and the patient) does need a summary of the hospital stay and what should or may happen next, could benefit from the anticipatory guidance, and how best to respond if these symptoms or outcomes change (‘what if?’). Understanding these mind sets may facilitate anticipatory management —‘if this happens, then do that’	Other studies have also found that the most effective measures to support GP and specialist cooperation is to allow for easy telephone access (for patients and healthcare professionals), increase the timeliness of discharge letters, and create feedback between professionals through frequent meetings
Hesselink	Our findings indicate that hospital and primary care providers, both members of the same virtual ‘handover organisation’, have separate ‘professional tribes’ and have different, often incompatible values and beliefs that threaten to undermine the effectiveness and safety of patient transitions	—	—	Our findings also highlight weaknesses in the relationships of shared goals, shared knowledge and mutual respect between hospital and community-based healthcare providers. These ‘relational dynamics’ are associated with a lack of frequent, timely, accurate and problem-solving communication, in turn predicting low levels of quality and efficiency
Hesselink	Hospital nurses, patients and GPs mentioned difficulties in identifying and contacting the physician or nurse who treated them in the hospital. Patients are often advised to contact their GP, while GPs are not always up-to-date with the treatment that was provided and the	Patient: So, the cardiologist stood next to me and said all sorts of things in Latin. (...) I do not speak Latin!	Discharges on weekends; patient: At Friday they told me that I could go home the next day. But the offices are closed on Saturdays and they could not give me all the proper discharge information and equipment. (...) That was not	Community care providers’ role in monitoring patients after discharge; patient: To be honest I did not receive any calls from my GP and I would have appreciated it

Continued

Table 2 Continued

First author	Barriers to care	Communicating	Coordinating	Relationships and personal value
Kemp	<p>follow-up that was advised during the hospitalisation</p> <p>Many patients reported that the lack of confidence in their GP and their GP's lack of knowledge of IBD, often acknowledged by the GP, was a barrier to seeking their help.</p> <p>"He said to me 'well actually you know more than me about this'...that's what my GP said to me."(P005)</p>	<p>They wanted to be listened to by a confident and knowledgeable practitioner, asked about how their illness was affecting them, and provided with a plan of action and goals.</p> <p>"I suppose you need two minutes to pour your soul." (P020)</p>	<p>pleasant. (...) So I did the medication and all other things on my own</p> <p>All patients valued the IBD nurse, who was central to the IBD team, a liaison and a constant identity in the hospital system. The patients were asked about the proposal for an IBD outreach nurse at the interface of primary/secondary care and were strongly in favour of this</p>	<p>The personal value of follow-up care was based on the relationship the patient had with their nurse and consultant, and the confidence they had in their knowledge of IBD.</p> <p>"Continuity, that's what it is all about for me, my nurse, my doctor, they know me, they look out for me. I would have moved away from here but for them." (P021)</p>
McHugh	<p>Participants reported little active management by health professionals in both primary and secondary care while on the waiting list and there was no reassessment of their symptoms</p>	—	—	—
Pascoe	<p>Patients also need more information about the referral service and surgeon to whom they are being referred. Unfortunately, such information is often unavailable to the GP in a form that might help them make decisions about to whom to refer to</p>	<p>Communication between patient and surgeon and the quality of information provided were important in determining patient satisfaction with treatment. These factors also influenced how confidently patients made decisions about which treatment to accept. Poor communication was associated with poor satisfaction with treatment</p>	<p>Positive experiences were associated with information exchange between GP and patient during treatment and planning the involvement of other members of a multidisciplinary team. Information exchange was a specific strategy identified by patients to improve care. Anticipatory and preparatory information was perceived to be crucial to effective care and good outcomes</p>	<p>Given outcomes vary according to the patients' place of residence and clinician variables, the findings regarding the importance of the patients relationship with their GP has significant implications for care coordination and psychosocial care across the total interval. This may improve outcomes for patients by decreasing delays and improving satisfaction, perception of choice and shared decision-making</p>
Pollard	<p>Many (21/37) expressed criticisms about GPs' perceived lack of knowledge of RA and its up-to-date treatment (9/37)</p>	<p>Patients felt more comfortable discussing matters with specialist nurses, who both understood their concerns and had more time (7/37)</p>	<p>Patients emphasised the importance of immediate help and support during times of flare of their RA and/or emotional stress (14/37). They tend to approach rheumatology nurses first to gain access to specialists during flare-ups</p>	<p>"My GP, I have...I think I have lost respect...he hasn't really served me particularly well. I have to 'play act' when I see a GP. So I have to pretend that I am really ill and about to die before anything actually happens...I don't have a lot of faith in them." (Patient 24)</p>
Preston	<p>The attitudes of reception staff in practices and outpatient clinics were often identified as presenting barriers, the consequences of which made patients feel 'in the way' or 'a nuisance'</p>	<p>They (patients) could experience feelings of discomfort and uncertainty which were exacerbated by lack of information or failures of continuity:</p> <p>"I had some further tests in early June and I have still not heard anything.</p>	<p>The coordination of different services, and the degree to which care continued across interfaces, were important preconditions for the smooth progress of patients through the system. Services which patients expected to be arranged</p>	<p>Relationships with GPs were often built up over a period of time, and, consequently, respondents often felt they had access to information and had some degree of participation in decisions about their care. In</p>

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Table 2 Continued

First author	Barriers to care	Communicating	Coordinating	Relationships and personal value
		I think that is one of the worst things... you are just left in mid air”	were sometimes not provided or were delayed. Sometimes GPs were not informed of outcomes of their patients’ treatment or care: “Separate clinics don’t talk to each other or ring each other. I find the whole thing incredible the length of time it takes; it’s just been horrendous, waiting weeks to see a consultant to be told ‘I don’t know why you’ve been referred to me’...It can make you feel very insignificant.” (Patient)	comparison, relationships with hospital doctors tended to be viewed as more impersonal, interactions being of limited duration and presenting fewer opportunities for sharing information and participating in decisions about care
Somerset	“a lot of the GPs have said, when I’ve gone up to ask about things, they’ve said they don’t have the knowledge and they’ll have to ring up and find out things” (P:R2) “Hopefully the consultant will tell me what I can do and what I can’t do” (P:N1)	“they say it is not active but then why am I getting these hellish pains? ... they’ve never really explained it to me” (P:R1)	When considering the extent to which they were able to influence events during their outpatient attendances, some patients maintained that they would actively seek information if they were left in any doubt about their care following discharge to general practice	–
Walton	Timely GP referral to specialist care for investigation of symptoms suspicious of lung cancer was hindered by limitations in GP knowledge about interpreting symptoms and accessing the appropriate pathway	–	In the context of lung cancer, given evidence of delay within the primary-secondary care interface, locating care coordinators within specialist respiratory services and encouraging strong links with primary care and cancer services seem sensible	Participants’ overwhelming feeling was that they had trusted and relied on GP guidance. Many attributed this to prior successful treatments for other conditions and on a longstanding relationship. GP treated me for 6 months what she believed was the flu and my asthma. Put me on antibiotics, steroids, inhaler...No chest x-ray, no specialist appointment until it was all too late. Maybe she didn’t have the right knowledge; maybe I should’ve pushed harder but I’ve been with her for years. I trusted her. (Interview, Auckland)
Wilkes	Other infertile couples felt that these skills may not exist within general practice: “It is always nice to see the clinical consultants, these people specialise in this particular subject, therefore would you get the tyres for your cars changed at McDonalds?” (F6)	–	All couples who experienced open access HSG assessment were surprised to learn that this was a service that not all GPs might offer. They felt that this should fall within their professional remit. The majority of couples who did not experience open access HSG felt that it was within the	–

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Table 2 Continued

First author	Barriers to care	Communicating	Coordinating	Relationships and personal value
Wright	"I feel happier coming here to talk about my problems...my mental health problems...with a specialist, rather than going to a GP, who's fine but firstly they're not a specialist and secondly they haven't really got much time." (Service User 14)	Such interventions need to straddle primary and secondary care services, be flexible and accessible, and provide effective communication and liaison between relevant health professionals	capabilities of the GP, but a minority would prefer direct referral to a specialist, to 'someone who knows what they are doing' One or more individuals need to take responsibility for this role and we are currently developing and testing the feasibility and acceptability of a dedicated nurse facilitator who will monitor screening, encourage screening in either primary or secondary care and provide it him/herself if neither option succeeds	Preference for a service for the primary prevention of CHD in secondary care services was mentioned more frequently by people with SMI, often because they felt more comfortable engaging with mental health staff

CHD, coronary heart disease; GP, general practitioner; HSG, hysterosalpingography; IBD, inflammatory bowel disease; PCP, primary care physician; RA, rheumatoid arthritis; SMI, severe mental illness.

Strengths and limitations

This review employed rigorous and established methodology specific to qualitative studies throughout. The search strategy (see online supplementary appendix 1) validated combinations of qualitative search terms to optimise the list of citations returned,^{27–30} was extensive to ensure inclusion of relevant articles in the sociology or psychology literature,³¹ and broad in order to retrieve all articles with important information on the primary–secondary care interface, even if the stated focus was not from a patient perspective. Further, there was no language restriction, and translations of potentially relevant titles and articles were obtained. Given reciprocal translational analysis provides summaries in terms that may have already been used in the original literature, there is acknowledgement that the synthesis will tend towards the privileging of a priori over in vivo codes.²⁰ Further, the quality of the included studies was assessed using a published framework (CASP) and found to be uniformly high.

The independent analysis of full articles by two researchers generated themes, concordant between reviewers, in a transparent and reproducible manner and was considered helpful in maintaining a coding balance.

Patient preferences and experiences were synthesised from varying primary–secondary care interfaces in differing healthcare systems serving different populations,^{4 37} but are gleaned only from the published literature. Study findings may therefore not be generalisable to all situations.^{4 37 44} However, the countries represented in the synthesis do reflect a broad range of organisational and funding systems that, while not proportionally representative of the global picture, nonetheless provide findings relevant to individual national healthcare approaches.

Several studies highlighted limitations in the research participant population (either in numbers or representativeness),³³ which may also restrict transfer of findings to all patient groups and settings.^{40 41 44 50} Further, individual studies highlighted potential problems with the distinct participant characteristics of focus groups (eg, that views of quieter participants may have been lost), and the setting for group discussions.^{34 87 88} Other potential sources of bias were highlighted in individual studies including interviewer bias,⁴⁹ recall bias⁴¹ and selection bias.⁴⁰

Though the results represent the real-life pragmatic challenges faced by patients at the primary–secondary care interface, the clinician perspective also requires consideration.

CONCLUSIONS

The key areas for patients in the primary–secondary care interface may be classified into four domains: barriers to care, communication, coordination, and relationships and personal value. These findings highlight

the separate but inter-relating areas of patient experience that require intervention with the aim of improving patient care. There will not be a 'one size fits all' remedy but the domains that have emerged from this review give useful targets to guide the development of interventions that will assist and improve the provision of care to patients across the primary–secondary care interface. Further research may focus on the clinician experience of the interface, and from their perspective how this impacts on patient care.

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Contributors RS designed the study, undertook the systematic review, carried out the data extraction, analysis and interpretation, and wrote the manuscript. RB provided guidance on qualitative research methods and reviewed the manuscript. JC participated in the analysis and interpretation of results and reviewed the manuscript. PW participated in the design of the review, analysis and interpretation of results, and critical review of the manuscript. RP provided assistance in developing an appropriate search strategy and reviewed the manuscript. All authors had full access to all of the data (including tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis. RS is the guarantor.

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