Trust, temporality and systems: how do patients understand patient safety in primary care? A qualitative study

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Abstract

Introduction Patient safety research has tended to focus on hospital settings, although most clinical encounters occur in primary care, and to emphasize practitioner errors, rather than patients’ own understandings of safety.

Objective To explore patients’ understandings of safety in primary care.

Methods Qualitative interviews were conducted with patients recruited from general practices in northwest England. Participants were asked basic socio-demographic information; thereafter, topics were largely introduced by interviewees themselves. Transcripts were coded and analysed using NVivo10 (qualitative data software), following a process of constant comparison.

Results Thirty-eight people (14 men, 24 women) from 19 general practices in rural, small town and city locations were interviewed. Many of their concerns (about access, length of consultation, relationship continuity) have been discussed in terms of quality, but, in the interviews, were raised as matters of safety. Three broad themes were identified: (i) trust and psycho-social aspects of professional–patient relationships; (ii) choice, continuity, access, and the temporal underpinnings of safety; and (iii) organizational and systems-level tensions constraining safety.

Discussion Conceptualizations of safety included common reliance on a bureaucratic framework of accreditation, accountability, procedural rules and regulation, but were also individual and context-dependent. For patients, safety is not just a property of systems, but personal and contingent and is realized in the interaction between doctor and patient. However, it is the systems approach that has dominated safety thinking, and patients’ individualistic and relational conceptualizations are poorly accommodated within current service organization.
Introduction

The focus of patient safety research has tended to be on hospital settings, although most clinical encounters occur in primary care, where the diversity, scope, and variation in structure and infrastructure may offer more opportunity for error than more highly regulated and procedure-oriented hospital-based care. Risk factors include longer duration between visits, care coordination among multiple clinicians, complexity of medication regimens, stepwise approaches to diagnosis and treatment, and problems with access. Patient safety incidents detected in hospital may originate in primary care and incidents detected in primary care may originate in hospital. The narrow time frame within which most incidents are considered may be too short; with a time lag between an error and the detection of harm; harm may result from accumulated errors, poor decision making, or lack of timely access occurring over long periods; many ‘errors’ may be recognizable as errors only with hindsight.

Research efforts have concentrated on defining and classifying medical error, in recognition of the likelihood that primary care errors may differ from those occurring in hospital. However, there is little professional consensus about what constitutes error or harm, and studies investigating patients’ views reveal broader conceptions of both harm and the causes of harm than those of health professionals.

There is a growing recognition that patient safety cannot simply be equated with absence of error, not all errors cause harm and not all harms result from error. In this study, we explored lay understandings of patient safety in primary care and, rather than starting with a preconceived or formal definition, sought to elicit participants’ own conceptions. Ethical approval (reference: 12/LO/1588) was given by the National Research Ethics Service Committee London - City & East.

Methods

Recruitment

Participants were recruited through five general practices in two primary care trusts in northwest England. Letters of invitation were sent by the practice to members of the practice Patient Participation Group or handed to patients who expressed an interest, having seen a poster advertising the project in the practice waiting room. People who returned a reply slip or contacted the research team were sent additional information and a consent form. Further participants were recruited using snow-balling techniques, whereby participants already recruited suggest others who might be eligible. People with multiple morbidities were over-sampled, as this group is known to be vulnerable to safety incidents. The study aim, to explore patients’ understandings of safety in primary care, was reiterated at each stage of recruitment. Interviews, arranged at mutually convenient times and locations (usually participants’ homes), lasted 30–120 min, were digitally recorded and fully transcribed.

Sample

Thirty-eight people were interviewed (Table 1), fifteen recruited through practices, the remainder through snow-balling, registered with 19 practices in rural, small town and city locations across northwest England.

Interviews

All participants were asked basic socio-demographic details (age, marital status, the presence of long-term condition/s, length of time at practice, number of visits in past 12 months), thereafter interviews began with broad questions, for example:

If I mention patient safety in general practice, what do you think of?

I’m not sure whether it’s the safety of a patient when they’re in the practice, when they’re on NHS property, say, or whether it’s the safety of
the patient as in they’ve got to be cared for and looked after, which is a slightly different thing, isn’t it?

Yes. There’s no right answer. (F.31)

A topic guide was generated from pilot interviews, but, as this was an exploratory study, topics covered were largely introduced by interviewees themselves. Topics raised in early interviews were explored in later interviews; for example, as it became apparent that perceptions of quality and safety were often interlinked, later interviews sought to unpick the distinction. Where there was ambiguity, the interviewer sought clarification.

There was a delay in getting medication, would you say the problems were purely inconvenient or do you think there was a safety issue?

Oh, there was definitely a safety issue. (F.08)

Topics initiated by patients included access, continuity, privacy and doctors’ manner.

Analysis

Anonymized transcripts, with participants identified by number and gender (M or F), were coded sequentially, using the software package NVivo10, and following a process of constant comparison.18 This allows generation of new codes and refinement of the coding framework, development of key themes, and identification of unusual cases. The coding was carried out by one person (PR) to ensure consistency. Each author read selected transcripts. Extracts and emergent themes were discussed and refined at regular meetings.

Findings

Many of participants’ concerns (about access, length of consultation and relationship continuity, in particular) have been more generally discussed in terms of service quality rather than safety, but were raised by patients as matters of safety. Three main themes emerged: (i) trust and psycho-social aspects of professional–patient relationships; (ii) choice, continuity, access, and the temporal underpinnings of safety; (iii) organizational and systems-level tensions constraining safety.

Trust and psycho-social aspects of professional-patient relationships

The interviews revealed high levels of confidence in biomedicine and GPs’ competence to practice it as a professional group, guaranteed by the quality of medical education and ability of external regulation to monitor standards. Only one person expressed any real scepticism:

I don’t have a lot of faith in GPs because they’ve only got a tiny bit of knowledge about everything,
I don’t think they know necessarily as much as the patient themselves knows about what’s wrong with them. (F.05)

Trust was based on limited ability to assess clinical competence, given the disparity in medical knowledge between doctors and their patients. As one person said,

It’s really hard, isn’t it, to know what, on their side, they should be doing. (F.29)

However, trust in individual GPs, although initially stemming from generalized trust in doctors, derived from experience of ‘good care’ from the doctors in question and the absence of (in patients’ eyes) culpable error. One person, for example, remained loyal to a GP even after he had mistaken bowel cancer for piles.

‘Good care’ extended beyond clinical competence (the competent application of medical knowledge) to the manner in which it was exercised and the interpersonal relationship between doctor and patient. Clinical competence was considered a prerequisite for safety, but could not guarantee ‘feeling safe’ without concomitant trust in the doctor’s benevolence and goodwill. One person explained,

You may have confidence in their ability, you may not actually trust them necessarily… people expect the doctor to find out what is wrong with them; they may not necessarily trust that the doctor is their friend in sorting it out. (M.17)

Loss of confidence in individual GPs did not necessarily damage trust in GPs as a group. More damaging was the organization of care. Interviewees expressed fears about an increasingly bureaucratic and depersonalized service, in which patients are processed rather than treated as individuals, and efficiency (interpreted in terms of speed of patient throughput and numbers seen) overrides quality considerations, with services characterized by short consultations, few opportunities for longitudinal continuity, and impersonal and disengaged care.

They seem to almost not be registering you and they’re sort of on auto pilot…. they’re professional but…you don’t feel like you matter….. (I want to feel) safe in terms of they’ve got my welfare in mind when I’m there. (F.21)

Although doctors varied in their consultation styles, the problem was perceived to be systemic, as reflected in the use of factory metaphors: ‘assembly line’, ‘conveyor belt.’

…it was sort of the culture in the practice, it was just like an assembly line, you were just whisked through. (F.16)

Lack of confidence in the system by which care was delivered was associated with generalized loss of confidence in GPs as a group. ‘Feeling safe’ thus embraced psycho-social factors as well as a sense of safety concerning physical health (physical safety); as one person said,

…your care and approach is as much part of what you are expecting from a GP… as the actual medical judgement. (F.07)

To participants, ‘feeling safe’ meant having confidence that they would be listened to seriously, treated with respect and dignity, not unduly hurried, disbelieved, judged negatively, patronized, or have their concerns dismissed as trivial. It also included respecting privacy, not having confidential information passed to or overheard by others:

I wouldn’t want to think that the receptionist could be sitting there reading my file … I want to be satisfied that my info is secure. (M.01)

The term ‘psycho-social’ embraces the social elements of the interaction and their influence on people’s sense of identity as well as the purely psychological – what people think and feel.

For some people, psycho-social harm clearly constituted a separate category from physical harm: one patient, for example, described her distress on discovering that the only doctor available was one with whom she had had a previous unpleasant encounter:

It made me cry… the fact that I could only see him. (F12)

However, matters of psycho-social safety were more commonly raised in terms of their role
Patients worried that their concerns might not be taken seriously and/or the quality and safety of their care compromised, if doctors considered them to be malingerers, hypochondriacs or in some other way undeserving. One man, for example, was afraid to admit the true extent of his smoking and drinking:

...he'll think, ‘Oh, I won’t treat him here, he smokes too much, he drinks too much.’ (M33)

Some, especially those with a history of mental health problems, worried about diagnostic overshadowing – that accounts of physical symptoms would simply be attributed to their primary diagnosis without consideration of other possible explanations. One woman recalled:

(The GP) went in there thinking, ‘This woman’s got mental health issues, I’m going to completely discount anything she’s saying because it’s all in her head.’ And she let that get in the way of her consultation with me. (F26)

People who were anxious about how they might be received reported: delaying or avoiding seeking help; selectivity in the concerns for which they were prepared to seek help; and, within a consultation, unwillingness to be open about treatment adherence, lifestyle, circumstances and concerns. Examples included a man reluctant to consult about his smokers’ cough because it was self-inflicted, and another who had delayed re-visiting until he became dangerously hypertensive because he had not wanted to admit that he had not been taking the prescribed medication. These instances demonstrate that fear of psycho-social harm can outweigh fear of illness related harm.

According to participants, a sense of psycho-social safety promoted safer physical care by encouraging open communication, honesty and greater willingness to accept unpalatable messages or advice:

...there has to be a degree of honesty from the patient, without feeling I’m going to be criticised for being honest or whatever. (M.10)

And some of it is your feelings about how you trust this person...how you open up, which, I think, is quite personal. (M.30)

Conversely, fear of a hostile or dismissive reaction could inhibit communication:

It can freeze you so you don’t pass on all the necessary symptoms you need to be telling them about and things like that. (F.08)

Interviewees acknowledged that qualities and skills that promote psycho-social safety, such as empathy and listening skills, are not necessarily those required for technical competence. Technical skills were deemed more valuable in some contexts than others, and appreciation of GPs differing skills meant that some people felt ‘safer’ with a particular GP/s for some matters but ‘safer’ with another/others for others. As one person remarked, ‘Everybody’s got different skills.’ Similar considerations applied to nurses, especially in respect of technical skills, such as giving injections or taking blood. However, where trust in GPs’ clinical competence was underpinned by the institutional structure of medical education and professional regulation, confidence in their interpersonal skills was largely based on experience over time. It was primarily on the basis of their interpersonal skills that participants discriminated between GPs.

Choice, continuity, access, and the temporal underpinnings of safety

In choosing a GP, people sought to match the GP’s characteristics, skills and qualities to their perceived needs. Longitudinal continuity with a single GP was generally considered the safest option for ongoing problems, but less important for time-limited matters. There was thus an important temporal dimension to trust. A sustained relationship was valued: when people were consulting about sensitive and potentially stigmatizing matters, felt psychologically vulnerable, or had ongoing concerns or long-term conditions; where care involved intimate physical procedures; and, for non-English speakers, there was a shared language. Some participants feared an unsympathetic reception
from an unfamiliar GP. One, for example, commented,

> I suppose I fear, because GPs are under pressure, that they’ll run out of patience with me having to re-explain the problem or not having got on top of a problem. (F.25)

Participants believed that they were more likely to obtain prompt action and mistakes were less likely if the GP knew their full medical history.

> ...you’re less likely to get mistakes and you’re more likely to get action quickly if the person knows you and knows (your health history)... (F.18)

A minority who professed not to mind whom they consulted \((n = 4)\) relied on their patient record to provide information continuity between consultations.

> Any doctor in the practice can have access to my notes and the medications I’m on and so on, so it’s not like a complete unknown. (M.10)

Others felt safer seeing the same GP.

> If you go to the same person, they get to know you better, and know your history, and are more able to access you as a whole, rather than just dealing with one illness. (M.11)

In their view, holistic care included taking into account information unlikely to be recorded in the medical record.

> ...albeit the medical information will be there, a lot of the relevant non-medical background wouldn’t be there, so they couldn’t take it into account. (M.02)

As one person pointed out, ‘It isn’t just notes, you get a feel about patients’ (M.17). Part of this ‘feel’ was the ability to go beyond the immediate, superficial presentation.

> ...as a GP starts to know you a little bit personally, they start to pick up on... the sub-agenda that you may not even realise yourself you’ve gone in with. (F.24)

Reliance on patients to provide much of the information continuity between consultations was, from some participants’ perspective, a weak point in terms of safety.

> ...you’ve only got 5 minutes and you’ve got to get it out, you know. The number of times you come away and think, Oh no, I didn’t mention that part about it! (F.07)

> ...they’re hurried and rushed ... and I don’t think they can possibly update themselves with the notes adequately. (M.11)

People with complex needs valued relationship continuity because it enabled the GP to accumulate specialist knowledge of their condition/s, ensured that at least one doctor had knowledge of the full medical history, facilitated communication between different sectors of the service, helped them to negotiate transitions between primary and secondary care, and promoted partnership in ensuring safe care.

> If you’ve got a longstanding medical condition with a lot of complications, then it is important to build up a relationship over a period of time... because, otherwise, there is only one person who really knows your case and that’s you, and it does help if the person you’re talking to knows something about it and you’re not having to start forty years back. (F.18)

Lack of relationship continuity was associated with relationships between symptoms missed, communication failures, inconsistent and fragmented care, no coherent strategy in treating ongoing problems, misdiagnosis, and delayed referral to hospital. One person, for example, described how a succession of GPs had persistently misdiagnosed and mistreated an ear problem. Accounts of poor care attributed to lack of relationship continuity outweighed those in which continuity was implicated. The counterpoint to continuity with a preferred GP was the desire to avoid seeing a particular GP or GPs, with most people simply avoiding them.

Feeling safe was generally equated with being safe; however, a few people recognized that relationship continuity brought its own risks: a false sense of security, complacency.
and lack of vigilance on the part of both GP and patient.

They may know you well but they can be a bit blasé... I think it can work both ways sometimes. (F.18)

The benefits of relationship continuity were weighed against the lack of a fresh perspective or insight from another GP and risk that an initial failure to diagnose, mistake in diagnosis and/or treatment might be perpetuated. Even personal experience of serious, life-changing error did not necessarily deter people from seeking relationship continuity, but, rather, made them careful about whom they selected and more alert to the risks.

The ability to choose a GP for a specific purpose and opportunities to sustain relationship continuity when it was needed were important safety strategies, but neither was, in participants’ view, adequately supported by practice appointment systems. Same day access with a GP of choice was rarely an option and people had to compromise between an early appointment and waiting (sometimes weeks) to see a preferred GP. Barriers to timely access included: practice opening hours; getting through on the telephone and, once through, persuading reception staff of the urgency of their need; obtaining an appointment within an acceptable and (from patient’s perspective) safe time frame. Problems were exacerbated if people wanted to see or to avoid particular GPs, or could not be flexible in the times they could attend.

Interviewees did not accept that receptionists were qualified to make judgements about the urgency of requests and objected to being asked personal information. Unlike hospital accident and emergency departments, where patients determine their need to attend, GP practices operate some method of (formal or informal) triage.

If you ring up, they’ll say, ‘Oh, we’ve got an appointment in three weeks’ time... unless it is something that is really, really urgent.’ And, to be urgent, you have to fit into these different categories and, quite often, it is urgent to you but not to them. (F.05)

Important markers of safe care were prompt investigation and referral to hospital specialists, regardless of outcome, as demonstrated in the following instance where investigations proved negative:

I had very bad headache which... lasted for a couple of days... I saw the doctor... and he referred me straight away to the hospital... it was brilliant. (M.01)

No one mentioned unnecessary investigation as a cause for concern or seemed to be aware of the high error rates associated with testing. Conversely, markers of unsafe care included lack of or delayed investigation, as illustrated by this person’s very different experience:

I kept going to the GP about it (severe allergic reaction)... but they weren’t solving the problem... I would think, when it was covering 90 per cent of my body, that they could have taken it more seriously and not waited so much... The specialist certainly thought it was very serious, they got me into hospital the day after they’d seen me. (F.29)

The temporal question of when to order further investigation or refer on could become a source of tension between GP and patient, when each party holds different views about what constitutes safe care. In one instance, in which the GP insisted on treating the patient’s physical symptoms as psychosomatic in origin, the relationship seemed to have broken down irrevocably. ‘Safety,’ for this patient, meant avoiding seeing that particular GP again. In another case, the initiative for referral to a specialist had come, according to the patient’s account, from the patient rather than a doctor.

I kept going backwards and forwards... to the GP and they just kept giving me tablets... I knew there was a problem (and) I needed to go and see a specialist but that still didn’t happen.... I had to actually spell it out to them, that’s what I feel... It’s almost like I have to sort of lead them into it... (F.21)

Another patient with unexplained symptoms commented.

I feel like I’ve got to keep pushing to get referred to try and rule (things) out. (F.25)
Organizational and systems-level tensions constraining safety

Sites of tension where participants perceived a threat to safety coalesced around gate-keeping functions and differing interpretations of exigency (how to judge the urgency of appointment requests, when to order laboratory tests or refer on to specialist services), and were generally regarded as systemic problems underlain by financial pressures. One person commented:

You’ve still got a huge demand, and the demand is still growing, but your resources are dwindling, so you’re just having to eek them out. (F.16)

Difficulties obtaining an appointment (entry access) were similarly attributed to system-level weaknesses. Patients who were more assertive and adept at negotiating the appointment system and/or flexible in the times they could attend were more likely to obtain speedy access than others, despite similar need. The following comments from two people, both of whom were immune-suppressed, illustrate very different experiences:

...as soon as they pick the phone up, I say my name. The receptionist knows me, the admin team knows me, the secretary, everybody knows me, so it just gets done a bit faster. (M.13)

I’ve never been able to ring and get through and explain what’s the matter and they say, ‘Well, all the appointments have gone today, but, because of your circumstances, we’ll be able to fit you in.’ (M.10)

In the first instance, the patient had developed some relationship continuity with reception staff. In the second, realizing that the practice could not provide the safety net he needed, the patient had decided to bypass primary care altogether.

That’s when I contact the hospital or I call 999 if it’s serious enough... I realised I wasn’t going to change their system. (M.10)

The ten minutes consultation was another area where rule-driven practice was criticized from a safety perspective, on the grounds that there was often insufficient time for patients to mention all their problems or go through the relevant history; they felt unduly rushed; it precluded in-depth discussion, militated against the provision of holistic care and encouraged a superficial and less compassionate approach, with attention to physical problems at the expense of psychological.

You sort of feel like, you know, Should I mention this or shouldn’t I? Is it relevant? (F.07)

If there’re a few things wrong with you, by the time you finish your first one, they chuck you out of the surgery [laughs]. (M.33)

...If somebody presents with an apparently physical problem but there could be other issues that are more psychological, there is no time to explore that... (F.18)

Inflexible systems for ordering repeat prescriptions were another perceived threat to safety, as demonstrated in the following description of the contrasting approaches of different practices.

If you do ring outside the hours at my husband’s ex-practice, they would just fob you off and ask you to ring tomorrow, whereas (because I’m a bit disorganised with my own medication), if I ring outside nine till twelve and say, ‘I’m really sorry, I’ve run out,’ they will sort it out for you. (F.12)

In general, participants associated holistic and individualized care with enhanced safety and believed this could be threatened by rigid adherence to rule-driven practice. As one person said,

I think they do have a ‘one scenario fits everyone’ mentality... it is just not right that everyone is treated the same when they are clearly not the same. (F.08)

Patients often became aware of ‘back room’ safety procedures only when they were breached, for example lost test results or inaccurate prescriptions. Similarly, GPs’ failure to follow recommended procedures or care pathways might only become apparent if something goes wrong and the patient finds out what should have happened.
Most people seemed to have implicit trust in the safety of their care without really knowing in what ways that safety was secured. For others, such opacity could make them feel insecure, as demonstrated in the following example:

I’ve just started a drug now that’s quite a serious one, I have to keep a card in my purse to say that I’m on it… I’m not sure if that will be down on my GP’s list, because that’s from the hospital… if I go to the GP, will I remember to tell them? I’ve every good intention of making sure it’s on my records, but you often forget, don’t you?… Because, often, you go and they’re going through all the letters and they’re going through all your notes on the computer, and they’re searching through letters for things, so I don’t know if it’ll just be written on the notes, or whether it’ll be hidden in a letter somewhere. (F.29)

Discussion

Previous efforts to elicit patients’ views about safety in primary care have focussed on patients’ understanding of error and harm.12–14,20,21 In this study, we chose not to predefine safety or frame the research in terms of error in order to allow greater openness to alternative conceptions of safe care.

It was difficult for people to disentangle the various dimensions of safety from quality. Such confusion demonstrates that, although distinguishable at the conceptual level, at the experiential level, there is often no easy distinction: an aspect of care experienced much of the time in terms of quality can become a safety concern in a different context. Many of the concerns raised have been discussed in the literature previously; however, it is their inclusion within the ambit of safety and the ways in which this challenges professional understandings that is novel. The issues themselves may not be new, but they have not generally been included in safety agenda, and this omission has both political and resource implications.

The conceptualization of safety that emerged involved a broad and nuanced interpretation, encompassing issues unlikely to be captured in incident reports or recognized in terms of conventional understandings of error. Achieving safe care involved balancing priorities, weighing up the costs and benefits of different options, and flexible interpretation of ‘rules’.

A crucial dimension is trust. Patients rely on trust in the institutional structure when they consult an unfamiliar GP, and in the experiential, interpersonal trust invested in individuals when they opt for relationship continuity. However, speed of access and management continuity are prioritized over relationship continuity and trust is primarily grounded in ‘managerial relationships, accountability, and credibility’,22 leaving little scope for the sort of interpersonal trust developed over time in interactions between healthcare professionals and their patients.23

For patients, safe care was realized in the interaction between doctor and patient, and the skills and qualities required for its accomplishment were likely to be different in different encounters. This analysis chimes with that of a small, but growing, body of work,23–25 in which safety is portrayed as ‘an ongoing achievement not only of healthcare staff but also of patients… in interaction with healthcare staff.’23 The interviews reveal that patients are alert to the risks as well as benefits of different kinds of relationship and seek different types of relationship in different situations. They highlight some of the ways in which patients’ strategies may be blocked, hindered or facilitated by different types of service organization and policy objectives.

Previous studies have argued for a broadening of definitions of error to encompass psychological as well as physical harms.12,13 Our study also highlights the importance of the psychological dimensions of safety, not just as a category of harm, but as a mediator of physical safety, influencing how patients think about their problems, for what, when and with whom they consult, and how they interact within a consultation.

Psycho-social safety included a moral dimension. Patients were concerned to present themselves as people in genuine need of a doctor’s attention,26 not merely as ‘ethical consumers’,27 but because they feared a hos-
tile or dismissive reception from the GP and that the quality of their care might be compromised if they were perceived otherwise. Skilful negotiation of this ethical terrain had become a necessary strategy to ensure timely and safe care. Such anxieties, along with difficulties in obtaining access, acted as deterrents to consulting for ‘minor’ problems, but, although effective in limiting demand, may work against early detection of serious disease and discourage some patients who are in genuine need.

In the same way that doctors are now discouraged from ordering laboratory tests or making specialist referrals to rule out unlikely diagnostic hypotheses, patients are deterred from visiting the doctor ‘just in case it is something serious’. Both illustrate how the parameters of safe practice can change with the changing capacity of the service to meet demand.

Conceptualizations of safety included a common reliance on the apparatus of accreditation, accountability, procedural rules and regulation that formed a largely invisible and taken-for-granted framework to safe care, but were also individual and context-dependent: one person’s interpretation of what it means to be safe might be different from that of another and different in different contexts. According to this view, safety is not just a property of systems, but personal and contingent. However, it is the systems approach that has dominated safety thinking, and patients’ individualistic and relational conceptualizations are poorly accommodated within service organizations that discourage choice of GP, where GPs are considered equivalent, and management continuity, through common access to patient records, is thought to obviate need for relationship continuity. If patients’ views are to be taken seriously, choice and continuity are not simply matters of quality but intricately tied to safety in subtle and complex ways that fall outside the capacity of current regulatory systems.

The study did not uncover a single, coherent understanding of safety but a plurality of views that could change with changing circumstances and needs.

Limitations
As this was a small-scale study, the findings may not be representative of the views of primary care patients in general. Participants opted in to the study, and we have no information about those who chose not to take part. The sample was weighted in favour of people with long-term conditions and women outnumbered men. The findings, however, are consonant with those reported from previous studies.

Competing interests
The authors declare they have no competing interests.

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