



# Patients' and consumers' perceptions of and involvement in safety and quality in Australian general practice

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### CONTENTS

Background	5
Emergence of safety and quality in health care	5
Patient involvement in safety and quality	5
Patients' views of safety in primary care	6
Patients' views of factors contributing to patient safety in primary care	7
Aims	7
Methods	8
Phase 1- Patients' views of safety	8
Recruitment and sample frame	8
Focus Group Interviews	8
Focus group protocol	9
Analysis	9
Phase 2 –Patients' views of factors contributing to safety	9
Semi- structured interview protocol	9
Analysis	9
Results	10
Phase 1- Patients' views of safety	10
Risk awareness	10
Trust	10
Vulnerability	10
A forgiving view of mistakes	11
Desire for an explanation and apology	11
Appreciation of general practitioner interpersonal skills over competence	11
Phase 2 –Patients' views of factors contributing to safety	13
Communication (doctor-patient)	13
Patient agency	13
Access	14
Primary-secondary interface	14
Continuity of care	14
Task performance (skill, competence)	14
Prescribing	15
Referrals	15
Time in the consultation	15
Expenses	15
Availability	16
Primary care system and structure	16
Coordination of care	16

Primary care culture	16
Decision making	16
Information flow	16
Teamwork	17
Practice layout	17
Waiting	17
Communication (other primary care staff)	17
Discussion	25
Recommendations for policy and practice	26
Recommendation 1	26
Recommendation 2	27
Recommendation 3	27
Recommendation 4	27
References	28
Appendix 1. Focus group and semi-structure interview questions and prompts	32
Appendix 2. Phase 1 participant demographic characteristics (n=26)	33
Appendix 3. Phase 2 participant demographic characteristics (n=34)	34

### **Background**

# EMERGENCE OF SAFETY AND QUALITY IN HEALTH CARE

Over the last decade there has been an increasing awareness of patient safety and quality as an important issue for health care providers, organisations, policy advisors and the public. Safety and quality in health care were primarily brought to attention by two landmark reports from the Institute of Medicine (IOM) in the US; *To Err is Human* <sup>1</sup> and *Crossing the Quality Chasm* <sup>2</sup>. While patient safety had been discussed in the literature in terms of medical errors, adverse events and patient harm for some time prior to these reports <sup>3-7</sup>, it was the release of information detailing the extent and effects of errors on patients which inspired investment into changing the way health care services were delivered on an international scale.

These two reports have stimulated great advancement in the science and practice of safety and quality in health care. Many have reported on the success stemming from these evolutionary health care improvement initiatives including the considerable increase in the amount of published literature on patient safety and research awards. Additionally, Leape & Berwick (2005) reported that the main outcome of these reports was the small spread of substantial efforts to improve safety in hospitals and other health care organisations. A recent overview on the progress made to patient safety over the last decade has revealed an obvious advancement in significant areas such as regulation and accreditation, reporting systems, malpractice accountability, research, organisational leadership and national and international interventions.

While there have been positive and effective examples of improvement since the introduction of the IOM's landmark reports and recommendations, some have declared that there is still much to be done by way of progressing patient safety and quality. Longo et al stated in 2005 that hospital safety was not meeting the IOM recommendations <sup>11</sup>, and others have said that translation of the many research studies on safety and quality into practice are unknown. Watcher (2010) asserts that key elements in health care systems such as health information and technology, workforce and training, payment systems, and importantly patient engagement and involvement require stronger focus. <sup>10</sup>

The importance of patient safety and quality research is renowned worldwide, but research outlining the interventions, intended outcomes, measurement and effectiveness are few and far between. 12-15 Most of the research surrounding patient safety has focused on measurement and identifying what constitutes a risk, analysing, evaluating and managing risks effectively. 14 Identifying practices and process of successful quality improvement can lead to effective results through greater understanding of the development, design and evaluation of complex interventions. 16 Davidoff & Batalden (2005) point out that health care safety and quality research adds to scientific discovery and experiential learning, and that disseminating knowledge leads to better performance. 17 However, there is still lack of relevant, timely, appropriate, accurate and transparent studies on this topic. 17-21

Research on safety in primary care is just beginning to emerge as much of the literature has focussed on secondary care settings. Furthermore, research involving patients and carers is in its infancy and there has been a call to engage and partner with patients more effectively to improve the safety and quality of care they receive.

# PATIENT INVOLVEMENT IN SAFETY AND QUALITY

Patients and carers have an important role to play when preventing errors and reducing harm. They have firsthand experience of their care, and are often able to provide detailed

information about the processes, systems and structures that have led to the occurrence of an adverse event. <sup>22, 23</sup> Although there are many well-recognised benefits for involving patients to improve the safety of their care, there are still some unresolved contentions regarding the effectiveness of interventions <sup>24</sup>, the roles and responsibilities for both patients and health professionals <sup>25</sup>, and the kind of health care culture and organisational governance required for patient involvement in safety to occur successfully. <sup>26</sup>

A systematic review of the effectiveness of interventions designed to improve the delivery of patient centred care has shown that there are some promising approaches.<sup>27</sup> This mainly includes improving patient education, health literacy, self-management skills, and capacity for making decisions, as well as developing partnerships with physicians, and contributing to safety and quality of care.<sup>28, 29</sup> There is also a growing evidence base centred on how health professionals can better support patient engagement in care.<sup>30, 31</sup> Patient involvement in health care has been proposed as a promising approach to achieving better quality of care, greater cost efficiency, and improved population health.<sup>32</sup>

Much of the literature on patient involvement in safety has focussed on partnering with patients to reduce harm in hospital settings. Hand hygiene interventions<sup>33</sup> and speaking up campaigns<sup>34</sup> dominate the evidence base in this area. However, research that has been conducted in general practice is scarce. A tool to measure patient involvement in decision making in general practice has been developed by Elwyn and collegues (2003)<sup>35</sup>, Sanders et al (2013) have found that interventions aiming to increase patient participation as a means to improve health outcomes in general practice are non-conclusive<sup>36</sup>, and Flink et al (2012) have investigated patient activation during handover between primary and secondary care.<sup>37</sup> Apart from these studies little else has been undertaken in this setting.

To the authors knowledge only one study conducted in Australian general practice found that patient directed questioning improved information provision by physicians and patient involvement in safety.<sup>38</sup>

While there are some examples of partnering with patients to improve the safety of primary care, there is no evidence of how patients and carers view safety. Having an in depth understanding of patients and carers perceptions of safety is the starting point for designing and implementing effective and appropriate interventions that can help to reduce harm in the primary care setting.

# PATIENTS' VIEWS OF SAFETY IN PRIMARY CARE

Engaging with patients to gain an in-depth understanding of their preferences, beliefs, values and contexts can facilitate delivery of safe and high-quality care.<sup>28</sup> The rationale is that positive patient experience through engagement in care is associated with improved patient satisfaction, clinical effectiveness, patient safety and health outcomes.<sup>39, 40</sup>

The Royal Australian College of General Practitioners have promoted the importance of obtaining patients' views about the health care they receive through the of standards for practice. <sup>41</sup> For accreditation to the standards, practices must regularly undertake patient feedback through surveys or other means, and they must also have a process for receiving and managing patient complaints. <sup>41</sup> While these surveys enable comparisons at a health system level they do not elucidate how patients think about safety and what the implications are for their involvement in safety. Furthermore, Pope et al (2002) suggested that qualitative methods could possibly uncover the complex and multi-faceted issues concerning patients' views of safety in health care. <sup>42</sup>

There has been ample research on patient preferences regarding quality of care in general practice in Australia<sup>43-48</sup>, but none has focused on patient perceptions of safety in general practice.<sup>49</sup> There has been some work to categorise the major incidences and causes of harm in this setting<sup>50</sup>, but the actual level of harm has been inferred from international

studies which indicate that diagnostic errors occur in approximately 1 in 20 cases <sup>51</sup>, likewise for medication errors. <sup>52</sup> Additionally, there has been some work on understanding what Australian patients know about problems and failures in health care <sup>53</sup>, and adverse event and incident disclosure. <sup>54</sup>

The Australian Commission for Safety and Quality in Health Care (ACSQHC) recently identified a number of gaps in the evidence base regarding Australian safety and quality research. They have stated that, little is known specifically about safety in general practice and the majority of the studies look at quantitative measures of safety and quality from a provider or organisational perspective. Little research has focused on patient values, experiences and satisfaction of safety with primary health care or exclusively within general practice. <sup>55</sup>

# PATIENTS' VIEWS OF FACTORS CONTRIBUTING TO PATIENT SAFETY IN PRIMARY CARE

As mentioned above evidence is growing which suggests that patients and consumers are willing and able to provide feedback on the safety and quality of health care.<sup>23</sup> Patients are uniquely placed to observe their care, treatment and physical environment throughout their journey in the health system. Patients' views and understanding of safety and quality are valuable as they can identify issues that contribute to creating safe environments that staff or others may not recognise.<sup>56</sup>

Patients' ability to identify factors which contribute to safety incidents has been proven to be successful in hospital settings in the United Kingdom. Patients were able to comment on a range of organisational and environmental factors which influenced safe care delivery. These included communication, patient/individual factors, the physical environment, staff training and education, lines of responsibility, management of staff and staffing levels/workload, equipment and supplies, supervision and leadership, team factors, and support from central functions. These contributory factors of safety were then developed into a patient feedback tool – the Patient Measure of Safety (PMOS) questionnaire. The patient feedback collected on the PMOS is then acted on by hospital ward staff to facilitate rapid and continuous safety improvement.

There is no such example in the literature which captures patients' views on the factors which contribute to creating safety in primary care in Australia. There have been some studies conducted internationally which investigate patient-focused typologies of medical errors and harms in primary care settings<sup>59</sup>, and others which detail the specific contributing factors of safety in primary care such as presence of a medical home<sup>60</sup> or the transition between primary and secondary care.<sup>37</sup> But none have provided a comprehensive review of all possible patient identified factors which contribute to safety in primary care.

The benefits of primary care organisations having access to patient reported sources of potential harm are numerous. It would allow organisations to proactively identify areas of strength and weakness of the practice, promote future learning, and intervene to prevent errors from occurring. This kind of innovative approach is required to actively engage patients in developing safe primary care environments.

### **AIMS**

Given the evidence gaps described above the aims of this study were:

- 1) To describe patients' and carers' views of safety in general practice
- 2) To describe patients' and carers' views of the factors contributing to safety in general practice.

This project is part of the APHCRI CRE in Primary Health Care Microsystem which is a collaboration between The University of Queensland, Flinders University, University of New South Wales, Greater Green Triangle University Dept. of Rural Health, Mater Health Services, and other stakeholders <a href="http://www.aphcricremicrosystems.org.au/about-usb">http://www.aphcricremicrosystems.org.au/about-usb</a>.

### **Methods**

### PHASE 1- PATIENTS' VIEWS OF SAFETY

We chose to conduct focus group interviews as they have to potential to gain a rich understanding of people's attitudes, beliefs and views about their lived health care experiences.<sup>61</sup>

The benefits of conducting focus groups is to explore the similarities and differences between group members, with the exchange of ideas being a prominent attribute of this practice. <sup>62</sup> Interaction between members allows the group dynamics and the conversations between them to become the focal point of analysis. Here complementary and argumentative interactions illustrate how knowledge, ideas and opinions are developed within a given setting, social circumstance or cultural context. <sup>63</sup>

### Recruitment and sample frame

The sampling strategy targeted rural and regional patients and carers from south-west Victoria who were frequent users of general practice, such as those with a chronic condition, on repeat medication, the elderly and mothers with children. These types of patients were selected as they were believed to have more experience with the general practice setting and therefore have greater insight into specific safety issues. Patients with high reliance and need for attending general practice have been shown to be more engaged in their care, have greater depth of knowledge and understanding regarding the particular aspects of their care and are more likely to have high levels of physical and psychological ill health. Additionally, patients at risk to errors or harms in primary care are likely to be people with multiple chronic diseases, the elderly, and those on repeat medication.

Participants were recruited through local community health or allied health organisations between August and November 2012. Recruitment sources comprised education and support group meetings for type 2 diabetes self-management, cardiac rehabilitation, group exercise, and a mothers' group. The principal researcher attended meetings and provided participant packs which included study material, information sheets and a consent form. Interested individuals self-selected into the study by contacting the principal researcher.

The Flinders University Social and Behavioural Research Ethics Committee granted ethics approval (project no.5667). Participants provided informed written consent and received a \$50 shopping voucher for their time and travel expenses.

### **Focus Group Interviews**

We conducted a series of focus group and each group contained three to ten participants. The focus groups were conducted over a period of four months from September to December 2012. They were recorded and transcribed verbatim. Notes were taken during the focus group and when participants disclosed further information after the audio recorder had been turned off.

Basic demographic information was obtained using a questionnaire that was administered prior to the start of the focus group.

### Focus group protocol

The semi-structured focus group interview protocol was developed to gain a broad understanding of patients' and carers' experiences of care (Appendix 1). Non-structured research questions are often employed during qualitative inquiry to allow in-depth exploration of a topic. An exploratory study like this required a flexible approach and use of general concepts which could be further refined and revised during data collection. Open ended and non-leading interview questions encourage unanticipated statements and stories to emerge from participants. The flexible approach allowed the focus group facilitator to adapt questions and expand with follow up questions to probe particular safety points of interest from previous focus groups, and to confirm or contest these issues.

### **Analysis**

Focus group data were analysed using a thematic and iterative approach to identify the safety issues evident in participants' narratives. Narrative analysis was used to explore and interpret the lived experience of individuals to understand their perspective as well as reveal the historical, cultural and interactional features of their experience. <sup>68</sup> Narrative analysis is the study and interpretation of human experience as described through storytelling. Studying narratives provides insight into understanding social life within a particular context at a certain time. Stories are usually constructed around a particular event. Analysing the content of the event, the contributory or explaining factors, as well as how the story was told are basic attributes of narrative analysis. <sup>68</sup>

The transcripts were reviewed by two researchers (AH and CW) and analysed using the constant comparative method to inductively generate a coding structure that outlined a series of themes and subthemes. After the researchers reached consensus on the coding structure, the codes were then applied to the entire set of interviews. The similarities and differences between patients' stories were noted and accounted for when interpreting the data. Discrepancies between researchers were resolved through discussion and constant comparison with the data. Nvivo 10 (QSR International Pty Ltd, 2013) was used to support the analysis.

# PHASE 2 -PATIENTS' VIEWS OF FACTORS CONTRIBUTING TO SAFETY

Interview participants for Phase 2 were recruited into the study in the same manner as described above for Phase 1.

### **Semi- structured interview protocol**

Semi-structure interviews with patients and carers were conducted between June and September 2013. They were recorded and transcribed verbatim.

The semi-structure interviews centred on patient experience with general practice and used the same interview protocol as outlined in Phase 1 (Appendix 1). The semi-structured interview schedule was adapted and expanded with follow up questions during data collection to include particular points of interest from previous interviews, and to confirm or contest these issues.

### **Analysis**

The analysis was undertaken using the Yorkshire Contributory Factors Framework as a coding framework (YCFF). The YCFF is a comprehensive taxonomy of the factors contributing to patient safety incidents in hospital settings and includes factors such as physical environment, communication, leadership and teamwork. These contributory factors and additional contributory factors specific for primary care safety not included in the YCFF were identified in the patients and carers accounts of general practice. The additional

primary care contributory factors were inductively generated and applied to the entire dataset. NVivo 10 (QSR International) was used to support the analysis.

### Results

### PHASE 1- PATIENTS' VIEWS OF SAFETY

During recruitment, 114 individuals were approached, with 32 providing consent. Twenty-six participants took part in one of four focus groups across the Victorian towns of Balmoral, Hamilton, Merino and Portland. Each group had three to ten participants. Reasons for not participating in the focus groups included being too ill to attend, not able to attend at the specified time and date, loss of interest, and failing to attend. Participants' demographic characteristics are provided in Appendix 2.

While those participants who had experienced some level of harm were able to comment more extensively on safety aspects of care, a number of themes related to safety were identified from the analysis of all participant narratives. Table 1 provides illustrative quotes associated with the key themes.

### Risk awareness

Although not explicitly recruited with these criteria in mind, there were two types of participants – those who had experienced harm and those who had not. Harm was experienced in two different settings, hospital care and general practice care with the former being more common in the participants' stories. The severity and seriousness of the circumstances which led to hospitalised care, and the errors that occurred during the participant journey created a heightened sense of awareness for safety in this setting. Compared with hospital care, experience of harm in the general practice setting was perceived differently by some participants. The continuing and trusting nature of the doctor-patient relationship alleyed their perceptions of risk to some extent. Here a forgiving view of mistakes, and appreciation of the general practitioners (GPs) interpersonal skills rather than competence influenced the development of safety perceptions and the importance placed on safety.

### **Trust**

Participants spoke of the characteristics of general practitioners that contributed to a sense of trust. These included the GP's confidence in their clinical competence, and having personal knowledge of the patient.

When participants had experienced harm in general practice their trust was compromised to some degree. Some patients took action to rebuild this trust, while others ended their relationship with that GP and sought care elsewhere. These actions were dependent on the patient context including factors such as access to services, choice of provider, and personal attitudes and beliefs.

Those participants who had not experienced harm relied heavily on their trust in provider. Some were forthcoming about their lack of knowledge or understanding of safety, and their limited ability to accurately identify when risks could occur. Experience and expertise of the GP were additional factors which promoted trust.

### **Vulnerability**

Participants described feelings of vulnerability in their experiences of care. They were vulnerable in the sense that many suffered from multiple chronic conditions and therefore considered themselves more at risk to harm in their care, whether these were clinical or psychological harms. Clinical harms that were reported included misdiagnosis, delays in treatment, not adhering to standard care procedures, and medication errors. Psychological harms that some participants' experienced included verbal abuse, name calling and other

disrespectful or dehumanising behaviours or practices such as lack of eye contact, and dismissive, rude or aggressive forms of interaction. Even participants who had not experienced harm emphasised their need to be treated with respect as an individual by the GP, demonstrating a collective sense of vulnerability faced by the general population of patients.

The power dynamics between the patient and the doctor also influence patient vulnerability. When participants attempted to voice their real or perceived fears about their health conditions to their GP, responses which highlighted the power imbalance between patient and provider led to feelings of embarrassment and foolishness, and further compounded this sense of vulnerability.

### A forgiving view of mistakes

In addition to experiencing vulnerability, some participants also considered mistakes or errors in their care as 'normal'. They expressed an understanding and sympathy towards the GPs situation and considered mistakes as part of being human. Mistakes were linked with a view about care, in that both patients and GPs are humans and therefore subject to human qualities such as the ability to make mistakes. Traditional 'god-like' perceptions were not evident in this sample with many viewing the GP as an ordinary person in their community.

The familiarity and continuing nature of the doctor-patient relationship in general practice may have exacerbated this forgiving view of mistakes, when compared with one-off and short encounters with health professionals in hospital settings. The sense of closeness experienced in a rural community may also account for the differential tolerance of hospital versus GP mistakes.

### Desire for an explanation and apology

Participants seemed to lack an appreciation of the systematic nature of medical error and as a result they placed responsibility for errors solely on the GP. In contrast to accountability for errors, participants described the barriers in the system that prevented GPs or other health care professionals from apologising and acknowledging patient harm. These barriers were understood to come from a medical culture that is fearful of litigation.

Nevertheless, they reported a need for an explanation of what went wrong and why, and they described apology as the most effective way for patients to recover and move on from an incident. Some participants described feelings of admiration for those clinicians that did apologise to patients when errors occurred despite the perceived threats of litigation.

### Appreciation of general practitioner interpersonal skills over competence

Some participants did not focus on the safety of their care but rather the interpersonal skills of the GP in the consultation. In these instances participants appeared to value the interaction and relationship with their GP more so than the GP's clinical competence. Some participants seemed unconcerned by the possibility of errors occurring, even though they could clearly identify issues with GP competence. A desire for a caring GP and other relational attributes were considered to be more important than safety of care for these participants.

Table 1. Participant quotes associated with safety themes

### **Risk Awareness**

If I know I'm being looked after I feel safe. Like if I know, alright they may not have all the answers but people are onto it... people are working together with me and then I feel safe. Whether it's like my current doctor who doesn't know anything much about my condition anyway, but he's working together with my cardiologist and they're working it out together and so I feel guite, far safer than I have in a very long time so. But not so with the hospital.

That's a different thing. (37 year old woman with a congenital chronic condition)

[Hospital acquired infections] are the things you see in the major hospitals that cause havoc. Where... what you end up with is worse than what you went in with. (83 year old man with multiple chronic conditions)

### Trust

The thing is ... when you don't have confidence in a doctor either a) because of something they've done or b) because you don't know them, it makes life even that more difficult. (69-year-old man with multiple chronic conditions and a carer)

Conversation between two participants:

P1: You don't know I don't reckon ... I'm just like "whatever" you know like I didn't want to be there so they kept coming and saying "oh we'll try this", and I'm like "yep whatever go for it", you know ... (27-year-old mother)

P2: You trust, yeah. (28-year-old mother)

P1: ... you just "OK", you're just in there, you know, emotional to say the least ... you have no idea what's about to happen ... Well they're doctors and they're nurses and they've probably done it 100 times before, they all know. You just go with it, like that's me and I'm one of those personalities to just say "yep, yep OK". I just trust that they know what they're doing.

### **Vulnerability**

... [we] told her that his bowel habits had got worse, they changed, he wasn't feeling that well and everything. And he said I wouldn't mind a colonoscopy and she's saying "you don't need it, I'll give you something else for your haemorrhoids". After she finished we were getting ready to leave and he said "I'd really like a colonoscopy" and I can still see her sitting there, she was kinda half turned her back to us with the computer and she looked over like that [over shoulder] and she said "I cannot send you for a colonoscopy like that for haemorrhoids" ... he felt really stupid for asking then ... We did feel rather foolish the way she spoke with us ... (64-year-old woman carer)

Conversation between two participants:

P1: You're vulnerable. You're vulnerable to them ... (37-year-old woman with a congenital chronic condition)

P2: Yeah, yeah. (73-year-old man with multiple chronic conditions)

P1: And you'd prefer if they don't abuse that ...

P2: We're pretty frail creatures, aren't we, when it comes to sickness?

### A forgiving view of mistakes

I felt that, ah, more should have been done when I went to doctor for a respiratory problem ... Not a sign of sounding me or doing anything like that, but he was busy and as I was told he was having a bad day, and the phone had gone out and a few things like that. Well OK, he's only human. (83-year-old man with multiple chronic conditions)

### Desire for explanation and apology

I'd prefer someone to say to me "look I've made a booboo", "yes you're right", "OK, we'll make sure that doesn't happen again". All over red rover. (73-year-old man with multiple chronic conditions)

Conversation between two participants:

P1: Like, I feel like you need an explanation and why everything went chaotic. I think they should explain this is what happened. They can't tell you at the time because it's all happening. (28-year-old mother)

P2: No, nobody was telling me anything. (35-year-old mother)

P1: But afterwards I think you definitely need a, your doctor should debrief you and say this is what is happening; this is why we did this and that.

### Appreciation of general practitioner interpersonal skills over competence

... so I went to there and, um, this fella was a lovely fellow but he had no idea about five of the illnesses that I had suffered from. He had no idea about what medications I ought to take. He still doesn't figured out what the blood tests I get for the leukaemia, and um, so you know, that's where, but he is a lovely fellow, and I love going to him because we have a good chat ... (70-year-old man with multiple chronic conditions)

# PHASE 2 -PATIENTS' VIEWS OF FACTORS CONTRIBUTING TO SAFETY

During recruitment approximately 114 individuals were approached, with 46 providing consent to participate. A total of 34 participants took part in four focus groups and eight semi-structured interviews. Reasons for not participating in either the focus groups or the semi-structured interviews included being too ill to attend, not able to attend at the specified time and date, loss of interest and failing to attend. The basic demographic profile of the participants is available in Appendix 3.

There were a total of 20 contributory factors to safety identified by participants. Of these, eight were similar to the YCFF and 12 emerged from the data. The contributory factors to safety are described below. The frequency of the contributory factor, the harm associated with the contributory factor and an illustrative quote from the patients and carers stories are outlined in Table 2.

### **Communication (doctor-patient)**

Doctor-patient communication was the most prominently discussed contributory factor to safety. Problems with communication mainly resulted from patients feeling that their doctor did not listen to their concerns. Active listening by the doctor was felt to better assist with appropriate and personalised treatment and care, increased accuracy of diagnosis, facilitated trust and reduced stress and anxiety. In some cases patients' reported inappropriate interaction with their doctor where they were subjected to verbal abuse and belittlement. These instances of communication breakdown occasioned a range of patient harms including misdiagnosis, delays in diagnosis and treatment, physical harm in the form of pain and suffering, and psychological harms including loss of trust, stress and anxiety, and feelings of vulnerability and intimidation.

### **Patient agency**

Patients and carers who took direct actions to intervene and prevent harm from occurring were considered to be actively involved in managing their own safety. Being able to identify particularly harmful situations or possessing the knowledge and understanding of the factors which could contribute to unsafe care were attributed to the patient or carers' personality, their past experiences with health care, their health status and the health care context. Actions to prevent harm included speaking up when dissatisfied, requesting second opinions, navigating timely access to care, taking responsibility for health and being informed about the risks and benefits of treatment and care. Fear and vulnerability were perceived as barriers which prevented patient agency from occurring. Furthermore, the culture and context surrounding the health care encounter influenced the extent to which patients felt they were able to voice concerns or whether these requests were welcomed and executed by primary care professionals.

### **Access**

Receiving timely access to primary care was important for preventing delays in diagnosis and treatment. Patients and carers who were unable to get an appointment with a doctor at a preferred time described the frustration, stress and anxiety that resulted from not knowing where to get help and how much worse their health condition could get before they received treatment. Patients were mindful of not wanting to burden emergency departments with things that could be more appropriately handled in primary care, so did not seek care from this source when access to primary care was limited. In some cases inability to access care led to physical harms such as exacerbated pain and suffering and unintended health outcomes such as permanent disability.

### Primary-secondary interface

The transition between primary and secondary care was perceived as an area where communication and information sharing was problematic. Often it was left to the patient and carer to manage this transition and be the person to relay information from one health care provider to another. A concern by participants was that patients may not have the capacity to be the primary information holder and sharer between primary and secondary care. In these instances accuracy of information, and ability to communicate specific medical procedures or activity was considered to be burdensome for patients with a disability, those who were in ill health, or had memory problems. When information was incorrect or not received to either primary or secondary care in a timely fashion this could potentially lead to delays in treatment and diagnosis, inappropriate or wrong treatment, and further pain and suffering.

### **Continuity of care**

Discontinuity of care was seen as both a strength and a weakness of general practice by participants. Those who saw it as a strength had positive experiences of receiving a second opinion from a different doctor who was able to correctly diagnose a health problem that had been ongoing for some time without effective treatment. Participants felt that in some instances prior knowledge of the patient clouded the doctor's ability to explore alternative opportunities of diagnosis and treatment. Some patients believed they were pigeon holed by their disease status and there was little possibility to investigate other options for treatment and care.

Conversely, participants who highly valued a continuous relationship with a doctor were frustrated and upset when they were unable to access the same GP on an ongoing basis. Availability of doctors and administration of the practice were cited as the main barriers to continuity of care. Those who were in a continuous relationship with their GP often spoke about the importance of trust and being able to have confidence in their provider. When these were compromised patients were psychologically harmed in that they were fearful of having to start all over again with a new doctor and were concerned about the safety of their care when beginning this new relationship. Prior knowledge of the patient was also mentioned as something that influenced accurate diagnosis and treatment. This contradicts what was said above by some participants and illustrates the complexity around factors contributing to safety in primary care.

### Task performance (skill, competence)

Patients were generally aware of when the doctor or nurse did not have the skill or competence to carry out a task during their consultation. This awareness was heightened for those who had previous experience where their safety had been compromised. In some cases task performance was recognised retrospectively when discussing a particular safety incident, or when other health professionals pointed out the error to the patient, or where other health professionals were able to accurately perform the task. When participants had

experienced harms due to lack of competence of a doctor or nurse they subsequently lost trust and confidence in that provider and were hesitant to seek care in the future.

Skill in diagnosis was the most frequently observed task that participants were able to comment on. This was followed by failure to appreciate severity/acuity of problem. Patients were discerning when doctors and nurses were interested in or fixated on other problems which did not seem to be the most urgent from their perspective.

### **Prescribing**

Medication interaction, wrong dosage and inappropriate prescribing were the main problems participants discussed regarding GP prescribing. Incorrect or interacting medications were identified by the pharmacist in most cases along with the patient. Patients were often able to identify when medications were the wrong dosage as many with multiple chronic illnesses kept up to date medication list. Furthermore, patients were able to determine which medication caused interaction or had contributed the observed side effects.

Some patients encountered difficulties when attempting to resolve these medication problems with their doctor. The main outcomes from incorrect or interacting medications were physical harm in the form of pain and suffering, although none were considered by participants to be serious harms. Generally, the patient intervened before serious medication harms occurred. This was either through obtaining a second opinion or discontinuing use of the incorrect medication.

Adherence was perceived to be an issue for those participants who were unable to get a repeat prescription for longer than 21 days. There were inconsistencies between participants' accounts where some pharmacies allowed repeat prescriptions to be collected within the 21 day period while others were not.

### Referrals

There was variation in participants' accounts of being able to get a timely and appropriate referral to secondary or specialist care. Many participants were able to get a referral to a reputable provider when requested. But some questioned whether GPs had a broad knowledge of all the available providers to refer to, which providers offered reduced or no out of pocket expenses, and also the timing of the referral in critical circumstances. Some participants considered GPs hesitant to refer patients on when care was needed. Overall patients were able to report when a referral was necessary, and the problems associated with delays in getting a referral, or not receiving one at all.

### Time in the consultation

All participants appreciated and valued having enough time in the consultation with the GP or nurse to communicate all their concerns. They believed that having enough time reduced unnecessary subsequent visits, out of pocket expenses, and further delays in access to care. Sufficient consultation time also facilitated patient engagement and GP understanding and knowledge of patient needs and their personal context. Moreover, patients recognised that having enough time allowed for accurate diagnosis and treatment, improved patient satisfaction, and generation and sustainment of the doctor-patient relationship.

### **Expenses**

Out of pocket expenses for medical care were considered a major barrier to seeking care by participants who were financially constrained such as pensioners or families on low income. Delays in diagnosis and treatment were the most often described consequence of not being able to afford medical care. Further to this some participants were also aware that if they did not access health care due to the cost that they were taking a risk with their life. Expenses for access to primary care were compounded by the ongoing cost of essential medications.

### **Availability**

Linked to access, patients considered availability and choice of primary care physicians as a contributing factor to safety. For those participants who lived in regional and rural areas there were limited number of practicing primary care doctors and nurses or these professionals were located some distance away – in some cases more than an hour's drive. Patients often made judgments and potentially compromised their safety when deciding to access care based on the travel time and availability of care.

### **Primary care system and structure**

Patients were conscious of the regulations primary care professionals were subjected to by the federal government Medicare system. Most were forgiving towards GPs who were perceived to be constrained by the short consultation times as directed by Medicare. The main issue patients identified in the Medicare system concerned the model of bulk billing. There were perceived inequities and inconsistencies for bulk billing. While there were concessions available for pensioners and low income families, there were still instances where it was left to the discretion of the GP whether or not to charge gap fees. This resulted in access barriers to receiving care from providers who were known to bulk bill as these GPs were popular among the patient population.

### **Coordination of care**

The GP was viewed as the central cog in the wheel of health care encounters. They were seen as the provider who coordinated their care with various other specialists and secondary care settings. The information flow between all these services was also understood to be the responsibility of the GP. Harms in care often resulted from issues of misinformation or communication breakdown between the GP and the other health care providers, or when patients did not have continuity of care with a GP to ensure all their information was centralised. Patients acknowledged a feeling of being safe when their GP coordinated their care. A sense of trust facilitated this feeling of safety.

### **Primary care culture**

Patients were aware of the influence of organisational culture on care delivery and the hierarchies evident within the organisation. Patients could identify the leaders in the practice and how other staff members interacted with them based on their role and responsibilities. When the organisational culture was perceived to be poor patients noted the intimidation and constraints staff members were subjected to. In some cases the inability of staff to speak up about safety concerns when necessary resulted in patient harm.

### **Decision making**

Opportunities to be involved in decisions about care and treatment were highly valued by participants. Having knowledge of the risks and benefits, and weighing these options up were considered to be important in ensuring care is tailored for patients needs and is the safest option for their circumstances. Engaging with patients to make decisions was seen to prevent unnecessary, unwanted or invasive treatment from transpiring. Sharing in decisions also facilitated greater trust and communication between patient and provider and reduced feelings of stress or anxiety.

### Information flow

Similar to care coordination, sharing accurate and up to date information was vital to ensure smooth and seamless transitions between primary and secondary care and within primary care. Communicating and sharing information between the patient and the primary care provider was also viewed as important to engaging patients in care, fostering patient education and knowledge about their health condition, and reducing patient stress and anxiety. There were some instances reported where patient test results were delayed or

poorly managed. Furthermore, patients realised when information was not being transferred efficiently and were in need of solutions to manage information sharing between providers.

### **Teamwork**

Working collaboratively was seen to occur in two domains. Firstly, teamwork between the patient and the primary care provider, and secondly teamwork between staff members within the practice. Patients wanted to feel like they were part of a team with their doctor or nurse, and that teamwork extended to specialists and secondary care providers. This sense of teamwork was seen to enable patient involvement in care and increase satisfaction with the doctor-patient relationship. Teamwork between the GP and practice nurse was viewed as useful for picking up things that the other staff member may not have identified, and facilitated transparency of information sharing and coordination between team members.

### **Practice layout**

Most participants were satisfied with the layout and access to the practice and did not identify many potential safety risks. Infection control was mentioned by a few patients who were concerned about risks to health in the waiting room from other patients who were contagious with cold and flu symptoms.

### Waiting

Waiting to be seen by a GP or nurse at the practice was a safety concern for those patients who were seeking urgent care or were a carer for unwell family members. Although some recognised that primary care was inappropriate for emergency treatment, rural patients stated that there was no alternative option but to seek help from primary care in some areas.

### **Communication (other primary care staff)**

Poor communication with other staff members at the practice were low in frequency but still resulted in psychological harms for some patients who were belittled or upset by the interaction with reception staff. Consequently, patients did not seek care from the practice due to fear or being further upset or encounter poor communication again.

Table 2. Patient identified factors contributing to safety in primary care

Patient identified factor contributing to safety	Times domain identified	Outcome (type of harm)	Participant quote illustrating examples of factors contributing to safety
Communication (Doctor-patient)	48	Delay in diagnosis and treatment  Psychological harm (upset, belittled)  Physical harm (pain and suffering)	I just found that after I think 10 years or something with the same GP that I was being yelled at and all that kind of thing so I felt that that wasn't, I don't need that. Like I have, and it was because doctors didn't listen to me recently that I had to have eleven hours of surgery six months ago and I kept saying, and they said 'nah it's all in your head' and so I, and then I suffered a lot, like the specialists in Melbourne in the end said I suffered a lot longer than I needed to because GPs didn't listen. (37 year old woman with a congenital chronic condition)
Patient agency	46	Inadequate time with GP Delay in diagnosis and treatment Psychological harm (fear, vulnerability)	You know, I can go in there and say 'look how much time have you got?', 'well 5 minutes', I say 'well I can't do it in 5 minutes so we're wasting each other's time, so don't charge me', and walk out again. I can do that. Other people can't. Other people are so dependent that they need, they need that, um, and they're frightened. People are frightened to think that if they do speak up their treatment is going to be substandard. It's a real fear and that's why we don't get the complaints too because if I complain then next time I need to use the service something bad's going to happen to me, you know, this is the attitude of people I don't care about that because I'm strong enough to stand up for myself but some people are not. (55 year old woman carer and consumer representative)
Access	32	Delay in treatment Physical harm (pain and suffering) Psychological harm (stress and anxiety)	It's all very well to say you can see your doctor when you want to; you can't. My wife has dementia which is exacerbated by urinary tract infections. It gets exacerbated dramatically and traumatically I couldn't see a doctor to get antibiotics for her for three days. I couldn't see any doctor. Now I rang the clinic at 8.30 every morning and there was no doctor available. So to not have a doctor available for three days in a case of just skin and hair flying is ridiculous. (69-year-old man with multiple chronic conditions and a carer)
Primary – Secondary interface	29	Physical harm (pain and suffering)	He went through this [acquired brain injury]and he left hospital and of course he didn't know what he was doing so he went to the doctor over in the clinic and

		Psychological harm (stress, anxiety, depression)	said I'm not allowed to go back to work until you give me the all clear and he said 'oh well what's, what's been wrong?' He said 'I've had a hypo' and he goes 'oh right', so he tested his blood pressure, tested his sugar and said 'yes, you can go back to work'. He went back to work and the chap who was the boss out there where he worked said that he would help him, you know like [workmates would] say 'hand me the spanner' well he'd hand them the axe. He didn't have a clue what he was doing. And that was alright until that boss went on holidays three weeks later and the rest of the men decided they'd bully him because he couldn't remember what to do and how to do it. So they bullied him to the extent that he tried to commit suicide coming home from work. So then I stepped in and went to the doctors and the doctor said to me 'well what happened to him?' and I told him and so he looked it up on the [computer] and he said 'there's nothing here'. Now the hospital do not send their records to the doctors clinic; to your GP. They keep them at the hospital. And so [the GP] rang them and he struck the anaesthetist who put him on life support and he said 'that lad hasn't been working has he?' He said 'is he, is he alright?' He said 'we, three times during one night we had to resuscitate him, he nearly died'. We nearly lost him three times in one night Now he'd gone back to work, he had no idea that he should not He did not have a clue No memory. (71 year old woman with multiple chronic conditions and a carer)
Continuity of care	26	Psychological harm (Relationship effects – loss of trust)	you get attached to your GP, I mean, it's a personal thing, I mean he knows more about you, you know, than next to your wife or your partner what's wrong with you, how your reacting to certain things or what have you and you form a bond, a friendship, don't you? And to break away from that all of a sudden with this other bloke, I built up such a relationship with him. I even, you know, I painted, I do a bit of art, you know, and he happened to see one and I said 'oh I'll do you, I'll do you a thing', and it's probably still sitting, I don't know whether he's thrown it out or what he's done with it. But um, you know, I did an art thing for him he hung up in his waiting room or wherever it was and that's the sort of thing, how close you get and to be treated so offheadedly and saying well you know I couldn't care less really what you do. Um, it, it breaks you up and then you gotta start all over, and that's the hard part you gotta start all over again; now can I trust this bloke? (73-year-old man with multiple chronic conditions)

Task performance (skill, competence)	26	Delay in diagnosis and treatment  Failure to appreciate severity/acuity of problem  Psychological harm (loss of trust and confidence)	Conversation between two participants:  P1: I've had a bit of an experience with that organisation, and I don't do anything with it now I went in there with I'm a diabetic, and I had a heart a racing heart which was in de fib and it was running at 145 beats a minute. And they weren't concerned, they weren't concerned, they were more worried about why I didn't take a certain tablet. They focused on that rather than trying to help me find the problem so I just walked away. (63 year old man with multiple chronic conditions)  P2: It makes you feel like why do you want to go to your local GP because you're not getting the support and help you need. (59 year old woman carer)
Prescribing	19	Unnecessary medication/treatment Physical harm (medication side effects)	the doctor didn't find anything wrong but gave me antibiotics anyway without really telling 'yes, I'm quite sure this is viral and it needs antibiotics', it was just like 'oh no the antibiotics will clear it up' and I think a lot of the times, I don't know if it's a lot of the times but I've heard that they can do that just to sort of reassure the mother that 'oh yeah at least something's being done' cos with a viral thing you just normally, just let it run its course because [my child] ended up vomiting a bit of blood and so I was also doubly concerned about that. I took him to emergency and they said 'yeah nah it's probably the antibiotics just irritating his system because he doesn't even really need them'. (30 year old mother)
Referrals	19	Avoidable medical expense	I have very serious, I still have very serious problems with osteoporosis and I thought maybe a physio might help me. I was really bad at that stage so I went along to allied health and they were good they started treating me and it was costing me I don't know \$20 a session or something like that and one of [the allied health staff] said why don't you get referred by your GP and you can get it for a lot cheaper, and I thought that's a good thing I'll do that. And I came over here and to the clinic and saw a doctor and I asked him for a referral to the physio and he said 'you're not going along to those crack pots, you want to go to them you pay oughta your own bloody pocket mate'. (69-year-old man with multiple chronic conditions and a carer)
Time in the consultation	18	Delay in diagnosis and treatment	I sometimes have a few matters to discuss but my time is spot on the 20 minutes. When that magic time that my appointment is the allotted time, I'm

		Unnecessary repeat visits Psychological harm (stress, anxiety, frustration)	out the door, without so much as by your leave But however I have some, on occasion had serious matters I wanted to discuss with him but haven't had the opportunity so then I have to go back into the world about it again, make another appointment, try to discuss it with him and find myself out the door again it's very very unsatisfactory (69-year-old man with multiple chronic conditions and a carer)	
Expenses	17	Delay in diagnosis and treatment Psychological harm (stress, anxiety)	Conversation between participants:  Facilitator: Do you think not bulk billing is a big barrier [to accessing care]?  P1: Yes because they don't tell you beforehand that they want the money upfront (76 year old woman with multiple chronic conditions)  P2: It's like having Al Capone with the cannon in the hand; money or your life? (70 year old man with multiple chronic conditions)  P1: Yeah, no that's shocking.  P3: What happens if you can't afford that? (70 year old woman with multiple chronic conditions)  P2: Well they won't see you.  P4: You die. (74 year old man with multiple chronic conditions)	
Availability	16	Delay in diagnosis and treatment	It definitely makes you hold off for a bit longer like when [my child] was sick; he had a temp and like really crook and I was like 'ohh'. Like you sorta, if the doctor is five minutes I woulda taken him but I waited until 8 o'clock that night and I'm like 'yeah, nah you're sick', then we had to travel the hour; two hours round trip for a five minute doctor consult. (28 year old mother)	
Primary care system and structure	16	Inadequate time with GP	The poor buggers, they're only allowed what 10 minutes I think, this is through Medicare. [The GP] gets himself into all sorts of strife with Medicare or whoever they are in charge because he spends time with his patients and the reason he spends time with his patients is because of his caring I don't think it's always the GPs fault. Alright, the reason I say that is because the government, whoever governs these guys and gives them, pays them whatever they're paid, like through the government bodiesthey're the ones that are at fault, it's not so much the GP. It's the rules and regulations that the GPs are under as far	

			as allowing time with the patient. (73-year-old man with multiple chronic conditions)
Coordination of care	14		If I know I'm being looked after I feel safe. Like if I know, alright they may not have all the answers but people are onto it, kinda people are, you know, people are working together with me and then I feel safe. Whether it's like my current doctor who doesn't know anything much about my condition anyway, but he's working together with my cardiologist and they're working it out together and so I feel quite, far safer than I have in a very long time so. (37 year old woman with a congenital chronic condition)
GP culture	11	Physical harm (pain and suffering) Psychological harm (loss of trust)	I think some doctors are careful too cos when I had [my child] there was, like my doctor was looking after me and then I sorta got handed over to another higher up the ranks doctor and my doctor sorta got shoved aside. And I think they're too intimidated by the other doctors to actually say this should happen or like when I went back to my doctor he didn't actually say anything negative about [the harm], but obviously things went wrong. Yeah I think they're just too scared to, like the pecking order of the doctors (28 year old mother)
Decision making	9	Unnecessary treatment Psychological harm (stress, anxiety, discomfort)	And like the doctors say 'I want you to do this', and you don't really want to do it, you can say why you don't feel comfortable about doing it and then you maybe work around it. But at the moment there's no such thing because you're told to do things I was told when I come here 'oh you, you have to, to get this tablet, you have to pay for this tablet', but I wasn't asked 'did I want that tablet?' I was told it was going to be prescribed. (60 year old woman with multiple chronic conditions)
Information flow	9	Delay in diagnosis and treatment  Physical harm (pain and suffering)	I've got a friend, or a neighbour who has can't really walk cos he's in a wheelchair most of the time and in a lot of pain and he travels backwards and forwards to [metropolitan suburb] for pain management and they keep telling him that they don't know what's causing it and he has to carry the letters back to his GP, they don't talk to his GP they don't even talk to the Professor and the pain management doctor. They don't even talk to each other. And they're looking for some way, [someone] who can coordinate the information between the five or six people that he is dealing with so he can get an answer and get relief from the pain. (70-year-old man with multiple chronic

			conditions)
Teamwork	8	N/A	how I see it working in a team is for you and your doctor to understand each other number one. He can talk to me the way he wishes to explain my problem and I can respond back to him exactly the same way. And then he can refer me to who he thinks is going to be right. And then those two confer with each other about my problem. And also that specialist is given the freedom by my GP to be able to talk to me the same way. So in other words forming a teamwork where I consider my GP to be in charge, he's in number one, and then he's got these specialists that he's referred me to reporting back to him and then he in turn lets me know what's going on. Or if he prefers them to go direct to me and tell me what's going on. As long as I'm informed of my condition if I'm going to live, die, whatever I'm going to do, and whatever the conditions going to cause, ok I need to know then. Simple. (73-year-old man with multiple chronic conditions)
Practice layout	5	Infection	Conversation between two participants:
			P1: The only thing that worries me a lot you go there and you wait and sit in there for an hour or so with all these people coughing and sneezing everywhere (73 year old man with multiple chronic conditions)
			P2: But you can't do anything about it. It's the facilities there, well maybe I don't know, maybe the government should be looking at waiting facilities the doctors waiting rooms and the facilities in there for looking after patients. People with flu should maybe be made to wear masks, have masks in the waiting room for people to put on, I don't know. It's just a simple thing. (73 year old man with multiple chronic conditions)
Waiting	4	Psychological harm (stress, anxiety)	It's bad enough having to sit in the waiting room with my wife 'what are we doing here?' 'where are we?' 'why are we here?' and so on; continually. The thing is when I go and disappear and leave her in the waiting room and go into the doctors surgery [the GP] knows full well my wife has dementia and several times he's said 'excuse me a moment', he'll leave the room and he'll disappear for another hour and I'm sitting there in his office looking at the ceiling for an hour with my wife doing goodness knows what in the waiting room. Now this hasn't happened once, it's happened several times. (69-year-

			old man with multiple chronic conditions and a carer)
Communication (other primary care staff)	4	Psychological harm (upset, belittled) Delay in diagnosis and treatment	Well I have a problem to with the accounts department at the clinic My son, who is brain damaged he has no idea what sometimes about anything, like he'll, its good he'll talk to you, you'd say there's nothing wrong with him, but he got the bill and he just thought 'well they, oh no you don't pay them'. So I went up and fixed it up and there was a balance owing, and it was \$40 and I said 'no you must go back to your doctor'. I'm battling to get him to keep going back to the doctor and so he's going to his usual GP who bulk bills him, and um when he went there to say 'I've come to see my doctor', they said 'would you go to the accounts department'. And then he got dressed down by a girl who would have been 18 at the least and he's 43 years of age, and he was so confused, humiliated, he didn't know what to do. So he came home to me and said 'I couldn't go to the doctor'. (71 year old woman with multiple chronic conditions and a carer)

### **Discussion**

The findings from Phase 1 have found that patients and carers generally had an assumed sense of safety in general practice. Only those patients who had experienced some level of harm were able to adequately comment on safety issues in general practice. Furthermore, most of this harm had occurred in a secondary care so risk perception in setting was heightened compared with primary care.

This believed sense of safety was mediated by two factors prominent to the general practice context – trusting relationships and continuity of care. These two factors masked patients risk perception of potential safety issues. Trust is undoubtedly an important factor in creating and sustaining doctor-patient relationships and has been used to as a model to improve patient involvement in safety, but the effectiveness of these interventions have shown mixed results. Patients who rely on a default position of trust when they believe they do not have sufficient knowledge or skills, or are not in a position to adequately comment on safety is problematic for two reasons. Firstly, because patient awareness of and involvement in safety has been shown to improve clinical effectiveness, health outcomes and satisfaction with care. Secondly because primary care is often the first access point in the health care system, and is also characterised by high volume of repeat interactions; which consequently increases safety risks for patients.

Other safety related themes were also identified from patient stories during Phase 1 data analysis. Unique themes were discovered such as patients having feelings of vulnerability, preference for interpersonal skills over competence and desire for explanation and apology when harm had occurred. Effective communication between the GP and patient has been shown to reduce feelings of vulnerability which has been shown to be prominent in patients with chronic disease. This interaction style which enables patients to feel comfortable and confident has shown to vary widely therefore it is important for practitioners to be flexible, adaptable and responsive to patient needs. Disclosure of errors, which includes an apology and explanation of what went wrong, was also an essential component of providing safe care in primary care. However, there have been reported gaps in compliance and patient satisfaction with the disclosure process.

Patients having an assumed sense of safety in general practice is in direct contrast to what has been reported in the hospital setting. These studies found that patients who have experienced harms in hospital settings could accurately identify and report on safety incidents <sup>23, 74</sup> and make recommendations on improvements to safety. <sup>53</sup> These findings may not be applicable to the general practice setting, where issues of trust, vulnerability and preferences for interpersonal skills are prominent over safety.

While the findings from Phase 1 found that patients and carers did have an assumed sense of safety, Phase 2 findings revealed that patients can identify a range of organisational and environmental factors that contribute to safety in primary care. This may be contradictory in some sense but could also be a promising approach for all patients to provide feedback on safety to primary care practices, not just those who have experienced harms.

It was observed that all participants in Phase 2 could recognise a variety of factors which contributed to safety incidents or potentially harmful situations. Tackling patient safety using this indirect nature of patient reporting accords with a system view of health care which prospectively identifies the latent failures within organisations that represent the possible conditions for errors, and which also aims to address these before a serious event occurs. To Direct patient reporting mechanisms and tools once an incident has occurred are important but they not often used correctly, are poorly designed or have had little value in improving safety. Understanding the contributory factors of safety within an organisation can be used to proactively identify the causation for error and prevent harm to patients.

Patients providing feedback on these contributing factors to safety in a health care environment is necessary as they have unique knowledge and experiences that may not be

recognised by health care professionals, managers or policy advisors. Patient involvement in safety promotion in secondary care settings has been initiated by the Yorkshire Quality and Safety Research Group in the United Kingdom who have developed a Patient Measure of Safety (PMOS) questionnaire. The PMOS is the first tool to capture patients' views on the contributing factors to safety.<sup>57,58</sup> The patient feedback collected on this questionnaire is then acted on by ward staff through facilitated action planning cycles. The effectiveness of patient reporting on contributing factors to safety is currently being investigated with results expected in 2015.<sup>78</sup> Using a similar patient feedback tool to improve safety is a possible intervention that could be applied to the general practice setting.

The domains identified by patients in Phase 2 are similar to what has previously been reported in the literature <sup>59, 79-82</sup>; however these studies have focused on these themes from a quality lens. This study has considered these themes from a safety perspective and the implications these factors have on contributing to creating harm. This is the first study of its kind in Australia and has provided important evidence to the knowledge paradigm on patient safety and how it can be improved.

Finding methods to incorporate patient views on safety into practice is not without challenges. Lawton & Armitage in their thought paper from the Health Foundation have described the specific requirements of a safety intervention that includes patient involvement<sup>26</sup>:

- > Feedback tools need to be available to the broad population, taking account of different levels of literacy and different languages
- > Data collection process needs to be non-threatening to patients
- > The data collected needs to be linked in to other safety data (eg, staff incident reports, routinely collected data on falls, infections, etc.)
- > The intervention package is clear about how best to utilise the data to make a difference to safety (ie, links between causal factors and solutions)
- > There needs to be a process of connecting the intervention to current governance arrangements (eg, safety walkrounds) and the organisations membership group
- > The tools used to do make inappropriate comparisons across wards where clinical contexts may be very different

Furthermore, "the willingness and ability of patients to be involved, the blurring of accountability that comes with greater involvement, and the unease among some staff about this new role for patients and the potential for erosion of trust" are additional issues that will need to be considered prior to undertaking a patient involvement in safety intervention. These barriers can be overcome through careful planning in collaboration with staff and patients during the development of such interventions. <sup>26</sup>

The results from this study are novel in the Australian primary care research landscape and have added to the knowledge gap in the area of patient views of and their involvement in safety. The findings provide the contextual information required to further consider how to best incorporate the patient voice in practice. The recommendations for policy and practice are discussed below.

# RECOMMENDATIONS FOR POLICY AND PRACTICE

### **Recommendation 1**

It is essential for patients and carers to be involved in the prevention of harm in Australian primary care settings. We recommend that primary care organisations be receptive to patient feedback on the safety of the service they provide. Many practices already undertake routine data collection from patients (e.g. satisfaction surveys, patient focus groups etc.) and would have established systems for doing so, accordingly supplementing this with patient

feedback on safety would be beneficial to generate a holistic understanding of the practice and be practical to implement.

### **Recommendation 2**

We recommend that incorporating the patients' perspective of organisational and environmental factors that contribute to safety incidents would be the most feasible and appropriate approach in primary care. This is in contrast to patients directly reporting on safety incidents as only those who have experienced harm are able to adequately comment on safety and patients in general are able to comment on a range of features in the primary care organisation that influence safety.

### **Recommendation 3**

This could be achieved through the use of either qualitative and/or quantitative data collection techniques undertaken by primary care staff. The questions posed to patients would need to be reflective of things practice staff could take action on and be measurable to change. Further research on the best way to capture patients' views of factors contributing to safety for practice use is advocated.

### **Recommendation 4**

We recommend that primary care organisations adopt an action planning approach to implementing safety improvements based on patient feedback. The nature of this process is amenable to an already familiar and established quality improvement methodology in Australian primary care – the Australian Primary Care Collaboratives program. The Plan Do Study Act (PDSA) cycle which is the prominent and successful feature of the Collaboratives methodology could easily be applied to safety, as it has been for other waves such as access, diabetes care and coronary heart disease.

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# Appendix 1. Focus group and semi-structure interview questions and prompts

1. Can you describe what is involved in a normal visit to your general practitioner?

Prompts: Ringing to make an appointment, arriving at the clinic, waiting time

2. Can you describe your relationship with your GP?

Follow-up question: What makes a good relationship?

Prompts: Communication, trust, information provision

3. What other staff do you come across at the GP clinic?

Prompts: Reception staff, practice nurse, practice manager.

4. Is there anything about the clinic that influences you wanting to go there?

Prompts: Car parking, disability access, cleanliness

5. What is most important to you about the care you receive at your GP clinic?

Prompts: Patient-centred care, patient involvement in care

6. If you could improve something about the care you receive, what would it be?

Follow-up question: What do you do when things go wrong?

Prompts: Awareness of safety issues, risk perception

7. Can you tell me a little bit about what you do to be involved or active in the care you receive from the GP?

Prompts: Patients providing feedback through surveys, complaint systems or discussion groups, Patients participating in making decisions about their care, Patients being actively involved in the self-management of their health conditions, Utilising patient support materials such as brochures or information leaflets

8. How do you think patients could be more involved or active in their care in the future?

Prompts: Any other ideas different to the ones above

# Appendix 2. Phase 1 participant demographic characteristics (n=26)

	Number	%
Women	14	53.8
Pension card holder	18	69.2
Health care card holder	15	57.7
Married	16	61.5
Secondary Education (years 7 - 10)	10	38.5
Retired	15	57.7
Repeat prescription	18	69.2
Common health conditions:		
High blood pressure	11	42.3
High cholesterol	10	38.5
Arthritis	10	38.5
	n	mean (SE)
Age (range: 27-83 years)	26	59 (3.8)
Level of multimorbidity – number of health conditions	26	3 (0.6)
(range: 0-14 conditions)		
Number of visits to GP in previous year	26	12 (2.3)

SE: Standard Error

# Appendix 3. Phase 2 participant demographic characteristics (n=34)

	n (%)		
Female	19 (55.9)		
Pension card holder	22 (64.7)		
Health care card holder	17 (50)		
Married	24 (70.6)		
Secondary education (years 7–10)	15 (44.1)		
Retired	19 (55.9)		
Repeat prescriptions	24 (70.6)		
Common health conditions:	Common health conditions:		
High Blood pressure	13 (38.2)		
Arthritis	13 (38.2)		
High Cholesterol	11 (32.4)		
Heart disease	10 (29.4)		
	Mean (SE)	Range	
Age (years)	59 (3.1)	27-83 years	
Number of health conditions	3 (0.5)	0-14 conditions	
Number of GP visits per year	12 (1.8)	0-50 visits	

Pension card holder: Cardholders can access Australian Government health concessions and get help with the cost of living by reducing the cost of certain goods and services.

Health care card holder: Provides help with the cost of prescription medicine under Pharmaceutical Benefits Scheme, Australian government funded medical services, and access to state, territory and local government concessions.

SE: Standard error