Professional Standards Authority for Health and Social Care

The role of patients and service users in ensuring the safety of the care they receive

Research Report - March 2019

Prepared for:

Professional Standards Authority
for Health and Social Care

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TABLE OF CONTENTS

1. BACKGROUND AND OBJECTIVES

1.1 Introduction

The Professional Standards Authority for Health and Social Care (the Authority) raises standards of regulation and registration of people working in health and care to promote the health and wellbeing of patients, service users and the public.

The Authority oversees the work of nine statutory bodies that regulate health professionals in the UK and social workers in England. In addition, the Authority sets standards for organisations holding registers for people in unregulated health and care occupations and accredits those organisations that meet these standards.

1.2 Background and research context

The Authority has identified a number of agents who contribute to the safety and quality of patient care namely: regulators and systems, the employers of healthcare professionals, the law, the healthcare environment, health and safety legislation and the patients themselves.[1] The Authority believes that patients and service users can play a valuable and important role in the safety and quality of their care,[2] specifically in assessing risks and making appropriate choices. Whilst not proposing putting the responsibility for staying safe onto patients, the Authority suggests that patients can be effective partners in maintaining their safety.

The Authority's 2017 publication *Right-touch reform*[3] identified a need for further work to explore how people can be encouraged to engage with the safety and quality of their care. This reflects the work on the importance of trust in healthcare by Peters and Bilton,[4] who have observed that patients and service users can delegate responsibility for making decisions about their care to health professionals. Too much trust, they reflect, can be potentially dangerous, but conversely too little trust may deter patients from accessing the care they need.

Right-touch reform puts forward the idea of 'constructive distrust'. This involves encouraging and empowering patients to act on their instincts, question situations where they feel uncertain and take action when something does not look right. The Authority is keen to identify how people can be encouraged to be 'constructively distrustful'.

Right-touch reform also identifies the need to promote this concept with care. The Authority is aware that promoting the idea of distrust may be inherently problematic, with the potential to damage confidence in services, regulation and professionals, and may be seen to transfer unreasonable levels of responsibility to patients. The Authority is therefore aware that,

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[1] Professional Standards Authority, 2015, Right-touch regulation
[2] Professional Standards Authority, 2015, Right-touch regulation
[3] Professional Standards Authority, 2017, Right-touch reform
[4] Peters, S and Bilton, D. Right-touch trust: thoughts on trust in healthcare. In The Routledge Companion to Trust

however carefully done, the promotion of distrust in any sense risks undermining patients' confidence to the detriment of their care, particularly amongst vulnerable groups.

The Authority also notes that any exploration of the idea of 'constructive distrust' needs to be framed in the context of an ever-changing healthcare landscape where:

- Individuals have improved access to information on health matters and patients may therefore be more involved in decisions about their care.
- Greater numbers of people are living with long-term health conditions and have more regular contact with services; these individuals may be expert and in a better position to question the care they are receiving and spot errors.
- Advances in technology mean patients can monitor their conditions and self-care which may give them the confidence to challenge their care. Conversely technological advances might make patients feel more vulnerable if they don't understand the technology in their care.

1.3 Research objectives

The Authority commissioned qualitative research to explore:

- The role of patients, service users and the public in the safety of their care and how this fits with the role of other agents
    - In particular, identifying how people's view of their role changes in different situations, settings and with different professionals

- An exploration of how patient or service user vulnerability affects their inclination to be trustful and take a role in the safety of their care

- Identifying and exploring situations where people have identified an error, potential error or emerging risk to safety: in particular
    - Understanding the decision around whether to take action and what resulted from the decision
    - Discussing what might have resulted in a different outcome – specifically could they have been more actively encouraged to raise a concern earlier?

- Discussing the idea of 'constructive distrust':
    - Is it easily understood?
    - How comfortable are people with the concept?
    - Do people feel they display 'constructive distrust' currently and how does this vary based on the situation?
    - Is the concept seen as empowering or undermining and why?
    - Will promoting this concept likely result in a loss of or strengthening of confidence in health and care services?

2. METHOD AND SAMPLE

2.1 Summary

In summary, the approach was qualitative, due to the need to explore the complex concept of patient safety and ‘constructive distrust’.

A mixed methodology was adopted, with each element designed to facilitate access to the research for participants as well as to optimise data quality.

The sample comprised 86 respondents:

- 9 focus groups with patients and members of the public – 6 respondents, 1.5 hours
- 16 face-to-face depths with more vulnerable respondents who would find participating in a focus group difficult – individual or paired depths 1-1.5 hours
- 16 teledepths with those who have raised a more formal complaint about their care, 1 hour

The focus group and depth interview samples included a range of experience in terms of whether respondents had experienced ‘moments of doubt’ about their care. They included those who had never had occasion to worry about safety, those who had experienced slight doubts and those who had experienced several doubts over a longer period of time.

The fieldwork was conducted in England (Birmingham, Leeds, Norfolk and St Albans), Wales (Cardiff), Scotland (Glasgow) and Northern Ireland (Lisburn) weeks commencing 4th, 11th and 18th February 2019.

A full breakdown of the sample, recruitment criteria and recruitment method is appended at Appendix A.

2.2 Research materials

There were two topic guides drafted in collaboration with the research team at the Authority: one designed for focus group and face-to-face depth interview respondents; and one designed for teledepth respondents (which focussed on the respondent’s experience and, more specifically, what had prompted them to complain). Both are appended at Appendix B.

The stimulus materials (appended at Appendix C) were created by the Authority. They were designed to create a debate around hypothetical scenarios where patient/service user safety was in question. They included scenarios set in different health environments with different kinds of patients/service users: adult in primary care, adult in emergency care, vulnerable patient using an independent health practitioner, adult using an independent health practitioner, child and parent appointment with a consultant at an out-patient clinic. A member of the Authority's research team observed the first two focus group sessions and, after discussion, changes to the research materials were made.

2.3 A note on terms used in this report

'The Authority' refers to the Professional Standards Authority.

'Independent health practitioner' refers to individual practitioners providing private health services e.g. sports massage therapists, counsellors.

'BC1' or 'C1C2D' refers to the socioeconomic group to which the quoted respondent belongs.

These groups are based on the 'occupation of the head of the household', which respondents self-identify at the point of recruitment. The groupings are used to compare how people in differing socio-economic situations react to the same stimuli. The groups are most often defined as follows:

A- Higher managerial, administrative, professional e.g. Chief executive, senior civil servant, surgeon
B - Intermediate managerial, administrative, professional e.g. bank manager, teacher
C1- Supervisory, clerical, junior managerial e.g. shop floor supervisor, bank clerk, sales person
C2 - Skilled manual workers e.g. electrician, carpenter
D - Semi-skilled and unskilled manual workers e.g. assembly line worker, refuse collector, messenger
E - Casual labourers, pensioners without private pensions and anyone unemployed and living on basic benefits

3. MANAGEMENT SUMMARY

An exploration of the idea of 'constructive distrust' was a key objective of the research. This summary focusses on reactions to this idea. The conclusions to each of the other research objectives can be found in section 5.

3.1 Level of comfort with the concept

The two components of the phrase 'constructive distrust' reflect a belief that it is important to engage with health and care services positively, whilst reserving the right to question the safety of the care received.

Constructive

Respondents did not want their trust in health professionals undermined by anyone

Distrust

But they reserved the right to question the safety of the care they receive themselves

However, in a context of service users actively wanting to trust health professionals, certain words were perceived to be too negative, including 'distrust' as well as 'assertive' and 'sceptical'.

3.2 Do people feel they display 'constructive distrust' currently and how does it vary based on the situation?

Those remaining alert to the possibility of needing to question the safety of the care they receive tended to be more experienced users of health and social care. Ironically, these audiences may – in other contexts – be described as 'vulnerable' e.g. patients/service users with long-term conditions, older people with longer health histories, carers.

In this context, it may be less experienced users of health and social care who are more vulnerable e.g. general public or users of private providers (who had a tendency to perceive themselves as less at risk than those using NHS services).

3.3 Will promoting this concept likely result in a loss of or strengthening of confidence in health and care services?

In a context of service users actively wanting to trust health professionals, words such as 'distrust', 'assertive' and 'sceptical' were perceived to undermine confidence in health professionals and therefore health and care services. The language respondents preferred was relatively 'soft' when compared to 'constructive distrust'. Preferred phrases included: 'questioning', being 'open' and taking an 'active role'.

3.4 Is the concept seen as empowering or undermining and why?

Overall, the idea of creating a single phrase may not be sophisticated enough to empower patients and the public to raise their concerns, given the complexities of trust in a health and care situation. Feedback from respondents more experienced at actively taking responsibility for their safety in health and care settings included advice and tips on how to do so, which involved:

- **Adopting the right mindset -** regarding our duty of care to ourselves and trusting ourselves *as well as* health professionals
- **Knowing our patient rights**
- **Developing our skills as a user of health and care services e.g.**
    - Controlling the variables we can
    - Making sure we ask our questions
    - Creating an environment in which we feel comfortable and confident
    - Developing a language for challenging health professionals or expressing discomfort or dissatisfaction appropriately and effectively

The findings suggest that this recipe has the potential to empower patients and service users to adapt their approach to a range of situations in order to safeguard their health and care.

4. MAIN FINDINGS

4.1 What is the perceived role of patients, service users and the public in the safety of their care and how does it fit with the role of other agents?

At the beginning of each interview, respondents were asked to reflect on who they felt was responsible for their safety as a patient/service user. From the way that they responded, as described below, it was clear that this was not a question respondents had considered before.

4.1.1 Health professionals

Across the sample, health professionals were perceived as having most responsibility for patient safety:

"You're putting your trust in them to look after you. That's their responsibility. Everything goes on under their roof. They are fundamentally responsible." (General public, 35-55 years old, children aged 11+ years old, C1C2D)

"The individual you're seeing. It's their responsibility." (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)

"Ultimately, it's down to the person who is delivering the treatment." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

This response was largely driven by the experience of feeling safe when receiving health and care services (which respondents attributed to the care they receive directly from health professionals); as well as a general lack of awareness about the different elements that contribute to patient safety which are *not directly or visibly* related to *immediate* patient care. Anyone less directly or visibly involved in maintaining patient safety (e.g. employers, professional bodies, regulators) were not as top-of-mind as health professionals:

"They [regulators] aren't actually physically with the patient. It's the responsibility of the regulator to come in and check on the health professional." (General public, 35-55 years old, children aged 11+ years old, C1C2D)

"I'm trying to think whether the NHS would be more responsible for our safety than the doctor. No, I'd say 25% NHS, 25% patient and 50% doctor. The doctor makes the final decision." (Carer for a vulnerable user of health and social care services)

"The overall responsibility would lie with the hospital Trust, but you can't hold the Trust accountable for something that an individual staff member has missed, so the practitioner has quite a big part to play." (Vulnerable user of health services)

There was also a general lack of awareness about the different elements which contribute to patient safety which are *not directly or visibly* related to *immediate* patient care. Previous research has identified that patient safety is not typically top-of-mind for patients[5], who are therefore unlikely to reflect on different aspects of safety which, in combination, keep patients safe. At best, respondents vaguely referred to other aspects of safety associated with health and care services, as illustrated by the following examples of collective responses to the question *"Who do you think is responsible for your safety as a patient?"*:

"Premises … so there's the building …"
"The management of the practice."
"The professionals, the people who are delivering the care."
"Your family as well, having to be there for someone."
"There's the supply chain as well, because of the medicines that get supplied and whether they are safe and properly regulated."

General public, aged 35-55 years old, with children aged 11+ years old, C1C2D

"The receptionist who make the appointments."
"Whoever you're there to see."
"The NHS."
"If it's a private hospital, then BUPA for example."
"The nurses."

Patients who have experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D

"Every single person that works there."
"Some sort of regulatory body?"
"There must be some sort of health and safety department."
"The NHS Trust must be ultimately responsible I guess."

Patients who have experienced a free choice in their care, 35-55 years old, with children aged 11 + years old, BC1

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[5] RWL on behalf of CQC and DHSC

In fact, it was only a very small number amongst our sample who were clearly able to articulate the responsibilities of health professionals in relation to safety distinct from the responsibilities of other agents in health and social care settings:

"If you don't get the policies and procedures right then everything else becomes a mess, so that's when problems happen." (General public, 35-55 years old, children aged 11+ years old, C1C2D)

"The overall responsibility would lie with the hospital Trust because they employ the staff and ensure there's a safe environment. Then the doctors and nurses have their own level of responsibility as employees." (Vulnerable user of health services)

Without a clear understanding of the different aspects of safety which, in combination, keep patients safe, **respondents appeared to *confer* responsibility for safety *onto* health professionals.**

The qualitative evidence suggests that high degrees of trust in health professionals discouraged scrutiny of safety. There was also evidence to suggest that some respondents actively wanted to adopt a forgiving attitude towards NHS staff:

"The trouble is, sometimes with nurses, because they are overloaded, sometimes they aren't particularly in tune with somebody. It's almost like you're just part of that conveyor belt. I know they're snowed under." (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)

"They've got so many patients they can't cope. I've had the same doctor for 30 years, but she let me down recently when – even though I was in hospital – there was no call from my GP. It's not her fault though." (Vulnerable user of health and social care services)

Respondents not only trusted health professionals but *wanted* to trust health professionals in future (as discussed in section 4.5). Even those who had made complaints, both formal and informal, still retained a degree of trust in health professionals:

"I still do have a lot of respect for them. It's a really tough, hard job and they do have a lot of strain with lack of staff …" (Informal complainant)

"My husband pays an awful lot of tax and feels that he should get the right treatment from the NHS. Whereas I think the NHS is so overburdened, these people are slogging their guts out, working twice as hard as I do, so cut them some slack." (Informal complainant)

This finding suggests that whilst patients are willing to *question* the care they are receiving, they do not want to feel that their trust in health professionals is being undermined.

4.1.2 Family members

Family members - either in caring roles or in situations where patients are unable to safeguard their own interests (e.g. emergency care) - were also felt to have an important role in taking responsibility for patient safety.

The focus on family members was generated by personal experience: both as patients who needed trustworthy people to safeguard their own interests; and as carers taking responsibility for more vulnerable people e.g. children, older people or people with learning disabilities, physical or sensory impairments or mental health problems.

Respondents reported examples of when they felt that they had fulfilled an important safeguarding role on behalf of a close relative.

- A mother reported that an A&E doctor had accused her son of 'faking' his illness and wanted her to take him home at midnight: *"I had to fight for him. I got to see the consultant and I had to get an apology from them because I felt so strongly about it. I thought what happens to people that don't have people to fight for them?" (General public, 35-55 years old, children aged 11+ years old, C1C2D);*

- A son described feeling reticent to assert his influence when he was caring for his dad in A&E, but feeling glad that he had: *"He had a really bad headache, but there was this generational thing where he was saying it wasn't so bad. After half an hour the onus was on me, so I said 'that's not normal – you really need to see him now'. I insisted that they did a scan. After that it turned out he had a brain aneurysm." (General public, 35-55 years old, children aged 11+ years old, C1C2D);*

- A daughter reported how questioning her mum's drug dosage was critical: *"My mum had been very poorly in hospital and came out after 5 or 6 days. After 2 days she just wasn't waking up, she just kept sleeping. The GP asked me what I was giving to her, so I read the medication out to him and he stopped me in mid-flow. The hospital had given her 2mg instead of 0.2 mg. If I hadn't questioned it, I would have overdosed her. It was only because I took the initiative." (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)*

Although we have no way of verifying the accuracy of these reports, they illustrate that it was not difficult to recruit respondents who felt that they had played, and had needed to play, an active role as a carer in keeping a cared-for person safe.

The caring role helped individuals overcome any reticence they might otherwise feel about challenging health professionals. In this role, individuals already felt that they had taken responsibility for the cared-for person. Overall, there was less evidence of respondents taking this type of responsibility on their own behalf (as discussed in section 4.3.1).

4.1.3 Patients/service users

Those with more experience of using health and care services (e.g. those with long-term conditions) or complaining about health and care services were the most likely to feel that they had an active role to play in their own safety, and to identify this role spontaneously:

"You've got to look after yourself first." (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)

"I think you've got to share responsibility these days. I think we know a lot more than we ever did before. Now, you want to be more involved." (Patient with a long-term condition)

"Bad things happened to me years ago, but in the last few years I've been more open and putting myself forward." (Patient with a long-term condition)

As well as having experience of using health services, this group also had more knowledge about their own condition and care needs (as discussed in section 4.3.2).

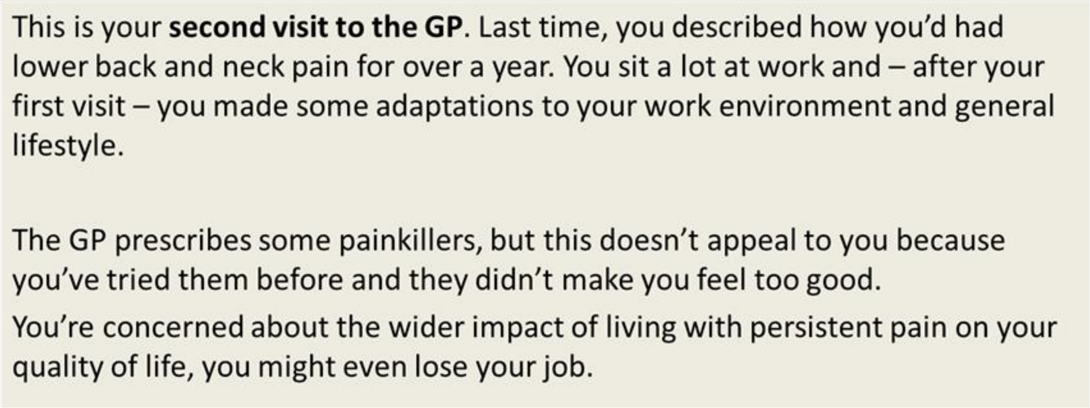
By comparison, other members of the sample only tended to identify themselves as having a role to play in patient safety after significant prompting. Amongst this group, the nature of the personal responsibility taken for patient safety was also felt to be limited. Respondents typically felt that they were responsible for correctly informing the health professional about their health, self-care and following health professional instruction.

Respondents from across the sample felt that taking personal responsibility for patient safety involved correctly informing the health professional about their health. However, even this responsibility was felt to be shared with health professionals, who were expected to ask the right questions in order to extract the appropriate information from patients:

"I will answer my doctor's questions to the best of my ability, but I expect them to keep me safe. The onus is on them to carry out their job." (General public, 35-55 years old, children aged 11+ years old, C1C2D)

"You need to make sure you tell them everything. As a parent, you're literally bombarding them with information. You need to tell them everything. You never know what might be important." (Patient who has not experienced any degree of choice in their care, 26-45 years old, with children aged under 11, C1C2D)

Respondents also felt that they needed to take responsibility for self-care (felt to be reflected in the idea of taking an 'active' role in one's health). For example, respondents felt that they needed to take responsibility for improving their own health in the scenario below, where back and neck pain is reported to be affecting the individual's lifestyle.



This is your **second visit to the GP**. Last time, you described how you'd had lower back and neck pain for over a year. You sit a lot at work and – after your first visit – you made some adaptations to your work environment and general lifestyle.

The GP prescribes some painkillers, but this doesn't appeal to you because you've tried them before and they didn't make you feel too good.

You're concerned about the wider impact of living with persistent pain on your quality of life, you might even lose your job.

"It's yourself that needs to take responsibility there, to try and make sure you're sitting right and making your work space right." (General public, 35-55 years old, children aged 11+ years old, C1C2D)

"That's down to me. Only you know how much pain you're in." (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)

"It's about you taking responsibility for your own lifestyle. I feel that we all have an active role in our own health and some illnesses are due to our lifestyles. So yes, people should be active in their own health – and understanding it." (Patient who has not experienced any degree of choice in their care, 65+ years old, C1C2D)

"I'm responsible primarily for what I put inside my body and my lifestyle." (Vulnerable user of health services)

Following instruction was also felt to be part of a patient's responsibility, particularly when instructed by a specialist:

"We've got the responsibility of doing as we are told, making sure we arrive at the appointments and doing the treatments we are asked to do. That is our responsibility." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

"When they give you exercises, it's up to you. So, if I'm not doing those and I don't get better, it's my fault." (Patient who has not experienced any degree of choice in their care, 26-45 years old, with children aged under 11, C1C2D)

"My friend had an injury to her shoulder and was supposed to rest for three weeks and didn't. Her shoulder got damaged and she didn't follow that advice. I blame her for that." (Vulnerable user of health services)

4.2 How does people’s view of their role change - in different situations, settings and with different professionals?

Moderators used scenario-based stimulus (as appended at Appendix C) to create a conversation about how respondents felt that their role varied in different scenarios, as discussed in section 2.2.

4.2.1 Variation in role between different types of service providers

Service users’ perceived roles in maintaining patient safety varied by setting, in particular: when using emergency care, private health services and independent health practitioners, as described below.

The findings also suggest that the degree to which service users will be willing to accept responsibility is likely to vary by service provider.

Very broadly speaking, it was easiest to ask users of NHS services to consider taking responsibility for their safety because of a general perception that the system is overburdened and therefore mistakes are more likely to occur.

By contrast, it was much harder to ask users of private services to consider taking responsibility for their safety because of a clear perception that paying for care meant paying for safety. This was largely the case for users of big private care providers, particularly amongst those paying insurance premiums.

Amongst users of private services, the exception were users of independent health practitioners. Although also providing private services, patients and service users felt that they were more vulnerable when choosing and using independent services compared to larger private care providers. However, many of the types of services provided were perceived to be lower risk (e.g. therapists of various kinds), particularly when compared to NHS medical services.

4.2.2 Emergency care

Respondents who had recent experience of using A&E services felt that they had less agency in terms of looking after their own patient safety. Although patients with experience of using A&E services still experienced 'moments of doubt', it was clear that carers were much more likely to question health professionals than patients in this situation (as described in 4.1.2).

For example, one A&E user explained how he doubted whether a healthcare assistant should be attempting a particular procedure, albeit supervised by a doctor. Although uncomfortable, this respondent reports, *“I trusted him because he was in the A&E department.”* This example illustrates how vulnerable individuals felt in emergency situations and therefore lacked the confidence to speak up on their own behalf. In this example, the respondent lacked confidence because he had lost a lot of blood and had been drinking *"so they assumed I was just drunk."*

4.2.3 Private care

Those with experience of using services paid for via insurance policies tended to *assume* that private services were safer than NHS services. This assumption was influenced by a belief that paying for a service would simply result in better quality of care (including safety).

The reported speed and efficiency of services delivered by private providers, particularly in terms of prompt appointments, clearly had a positive effect on levels of trust. These elements of good service made users of private services feel more cared for:

"You just feel more important." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

In practical terms, prompt appointments meant that patients were more focussed on discussing their health situation and therefore had more opportunity to make themselves comfortable with the suggested course of action:

"When you go to a private hospital for a first consultation, you'll have your bloods, scans, everything quickly so you automatically trust them more because it's all done quickly and you know you're going to get an answer quickly. You lose that trust when it takes forever." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

By contrast, waiting for NHS treatment – whether on a waiting list or in A&E - made patients feel less cared for and worse (both mentally and physically):

"In private, they make you feel it's happening for you and it's all so quick. If you have to wait a long time – like in the NHS – you could have had a complete decline in health by then." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

"They [the NHS] keep you waiting for months. They [the GP and the hospital] don't care… I had to go privately in the end and it was much quicker." (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)

In these circumstances, patients did not feel in control of their health. The NHS was perceived to dictate the terms of the interaction:

"When you're at your wits end, someone will come along, but then nothing happens and another two hours go by." (*General public, 35-55 years old, children aged 11+ years old, C1C2D)*

"My 15 year old plays rugby and constantly has injuries. One of his toes is permanently black and we regularly go to the hospital for toe injuries. This time, his toenail hadn't come off and his toe was throbbing. We went to the Minor Injuries [Unit] and they said, 'we don't touch toes'. I asked where I should go and they said 'A&E don't touch toes either'. The next morning, we went to the GP and he said we needed to see a chiropodist. I said, 'We've passed that level' and I asked to be referred privately. I was told it would take 10 days to get a referral note. I went straight to the clinic and they removed it there and then. I felt really out of control as a mum, everybody kept saying 'no'." (*General public, 35-55 years old, children aged 11+ years old, C1C2D)*

When challenged to consider safety issues when accessing private services, respondents were reticent to engage. They simply did not feel that safety issues were as prevalent in private services as they were in NHS services. For example, when asked to consider a hypothetical scenario where a doctor working for a private provider did not have access to patient notes, those with private medical insurance simply answered:

"They go through everything so thoroughly that would never happen." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

"They wouldn't want to see you if they hadn't got the history." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

If unsure or uncomfortable in a private setting, patients felt that they were more likely to seek a second opinion than challenge a health professional. This group of patients was therefore able to overcome barriers to challenging health professionals (discussed below in 4.4.2) by purchasing alternative advice:

"I'd still get a second opinion to see what other consultants are saying. You don't have to do what they tell you, it's your decision." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

4.2.4 Independent health practitioners

Respondents typically felt that they had most responsibility for safety when purchasing advice or treatment from independent health practitioners. There was a perception that independent health practitioners were not subject to as many checks as those working for employers such as the NHS and other private providers:

"You really want to be questioning who is dealing with you. If you go to the doctor's [i.e. a GP surgery), you know they have been through a university, you know that they have been trained to a certain level or standard." (General public, 35-55 years old, children aged 11+ years old, C1C2D)

"When it comes to your health, if you're not doing due diligence, it's your fault." *(General public, 35-55 years old, children aged 11+ years old, C1C2D)*

The nature of the responsibility patients needed to take was not only felt to involve responsibility for the choice of provider, but also some kind of 'due diligence':

"You should be looking for certificates, they should be asking about previous ailments and if they're not doing that and you proceed, then you've brought it on yourself." (General public, 35-55 years old, children aged 11+ years old, C1C2D)

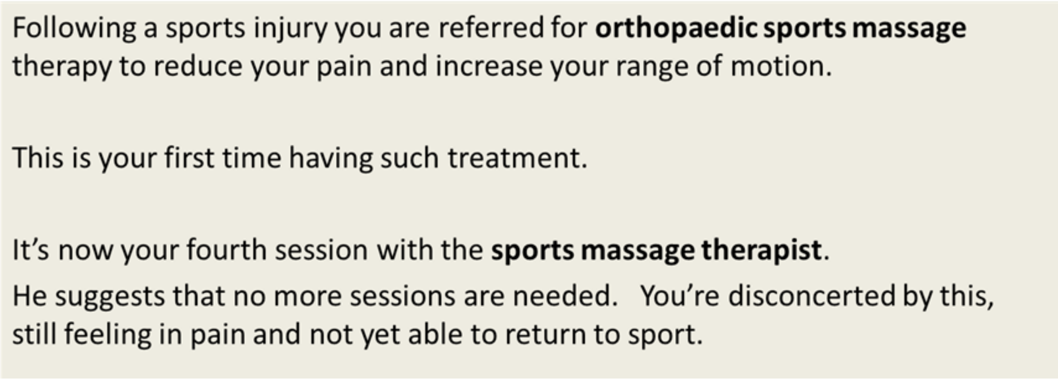
"When the chiropractor is suddenly wrestling your neck about, I suddenly start to worry about whether I should have done this kind of thing without checking it out." *(General public, 35-55 years old, children aged 11+ years old, C1C2D)*

It was clear that if respondents were referred to specific independent health practitioners by NHS health professionals, the safety of that choice was felt to be the responsibility of the referee:

"The clinic that's referred you should still be partly involved until it's all been properly moved over." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

Despite an increased sense of responsibility for safety when choosing an independent health practitioner, overall, these types of services were felt to be lower risk than primary or secondary care services.

However, if unsure or uncomfortable, once again (as described in 4.2.3, patients felt that they were more likely to seek an alternative provider than challenge the independent health practitioner directly. This was clearly evidenced by responses to the scenario below, which showed that respondents had little investment in challenging an independent health practitioner with whom they felt they had a very short and transactional relationship:



Following a sports injury you are referred for **orthopaedic sports massage** therapy to reduce your pain and increase your range of motion.

This is your first time having such treatment.

It's now your fourth session with the **sports massage therapist**.
He suggests that no more sessions are needed. You're disconcerted by this, still feeling in pain and not yet able to return to sport.

"You could just leave a bad review or something. There's no real follow up." (General public, 35-55 years old, children aged 11+ years old, C1C2D)

"It depends on how much pain you're in. If it's something you can live with, you probably wouldn't pursue it." (Patient who has not experienced any degree of choice in their care, 26-45 years old, with children aged under 11, C1C2D)

"It depends on whether I trust the person, in which case I'd feel comfortable to speak to them. If I feel dismissed, I'd find it more of a challenge and sometimes you go around them and find answers yourself." (Carer for a vulnerable user of health and care services)

4.3 How does patient or service user vulnerability affect their inclination to be trustful and take a role in the safety of their care?

Analysis of the responses from different groups within the sample identified clear differences in terms of patient/service user appetite to take a role in the safety of their care.

As described below, the key factors influencing individual respondents' propensity to become involved in the safety of care were caring status and experience.

Affluence also had a bearing on service use, which then had a bearing on the level of responsibility individuals expected to take. In short, those reliant on NHS services were more likely to realise that they needed to take some responsibility for their own patient safety; those who could choose to use private services were less likely to realise that this choice did not eliminate the need to take responsibility for their own patient safety (as described in section 4.2.3).

4.3.1 Caring status

As discussed in section 4.1.2, those caring for vulnerable patients simply felt that their role necessitated them taking an active part in the cared-for person's patient care. This group included those caring for adults with learning disabilities, physical and sensory impairments and mental health problems who needed considerable support to engage with health and social care services:

"We've not had the best experiences with my mum's diagnosis, so I take responsibility and make sure things are happening because I don't want to put my trust in somebody for whom my mum's just a number." (Carer for a vulnerable user of health and social care services)

"The hospital tried to organise a specialist wheelchair but there was a 3 month delay so they sent us back home with one of the hospital ones. When they dropped her off they tried to take the wheelchair back. I made it clear that either they left the chair or took her with it. No way could she could without it." (Carer for a vulnerable user of health and social care services)

"After she came back from theatre, a consultant came around and was pulling the covers down to check mum's dressing. He hadn't washed his hands since seeing the woman in the next bed. I had to ask him to do that … He looked a bit shocked and then went and got some gel. When he went, the nurse said, 'That's not very respectful speaking to a consultant like that.' I said, 'My mum has just lost her hip caused by an infection I don't know how she got'. (Patient with a long-term condition)

This caring role was felt to include helping health professionals to understand individual patients' needs e.g.

- **The need to address the patient, not the carer:** *"It annoys me when they talk to her [respondent's carer] instead of me." (Vulnerable user of health services)*

- **The need to read the patient's notes to understand the patient's personal situation.** In one example, a partially sighted respondent describes her experience of being treated by a health professional who has not read her notes: *"When you're asking me 'Can you see the light I'm shining?' and 'How many fingers am I holding up?', I feel like saying 'read my notes'." (Vulnerable user of health services).*

Responses to stimulus involving a scenario involving parents and a child revealed that **parents felt that it was easier to take a role in the safety of their children's care,** feeling that it was more socially acceptable to do so on their child's behalf than on their own behalf.

> Your daughter has been diagnosed with childhood arthritis. Although the arthritis is reasonably well controlled through a combination of drugs, she still feels generally unwell and is suffering bone loss (osteoporosis) too. You have been **referred to another clinic** which specialises in bones.
>
> The **bone specialist** prescribes a drug that your daughter will need to take for quite a while. You're uneasy about this, because she's already on some powerful drugs and hasn't really seemed herself since she's been taking them. Your daughter looks unhappy and is very quiet. The specialist is quite definite though that this is the way to go.

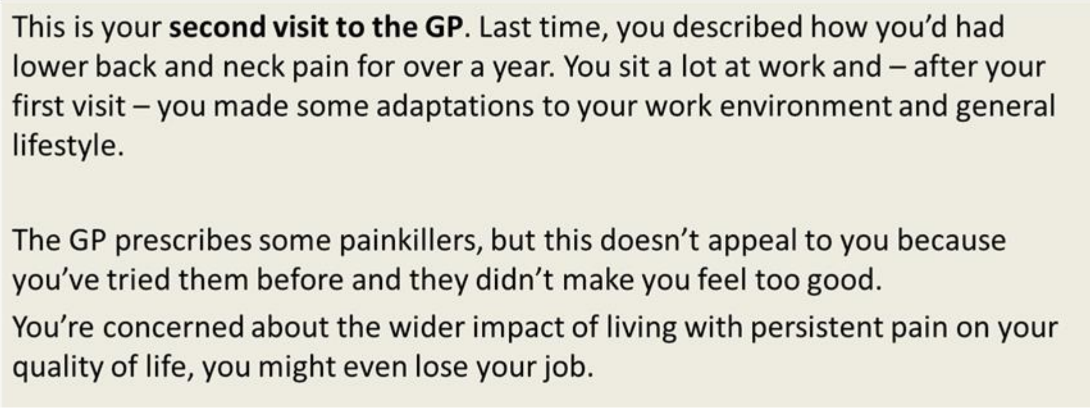
This scenario prompted respondents to say that they would be willing to take action to safeguard their child's care:

"For me, I'd just take it. But it's different when it's your baby." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

"The big thing I think, is that I'm a parent and I'm going to go on the internet and find out

everything I can because the doctor has trained for ages and I haven't." (General public, 35-55 years old, children aged 11+ years old, C1C2D)

In another scenario involving an adult, **respondents were comparatively more diffident about whether they would engage with the health professional.** Although several felt that they would seek a second opinion if they completely lost trust in this particular GP, the likelihood of challenging this GP directly was felt to depend on much more contingent factors such as the health professional's 'manner' and the individual patient's personality:



This is your **second visit to the GP**. Last time, you described how you'd had lower back and neck pain for over a year. You sit a lot at work and – after your first visit – you made some adaptations to your work environment and general lifestyle.

The GP prescribes some painkillers, but this doesn't appeal to you because you've tried them before and they didn't make you feel too good.
You're concerned about the wider impact of living with persistent pain on your quality of life, you might even lose your job.

"Not everyone is confident to open their mouth and some are in that doctor-patient relationship – who is the most dominant person in the room? (General public, 35-55 years old, children aged 11+ years old, C1C2D)

"Your mood on the day matters. We aren't always feeling 100%. If I've had a really rotten day, I might not want another confrontation." (General public, 35-55 years old, children aged 11+ years old, C1C2D)

Overall, a caring role gave many respondents the experience of taking responsibility for patient safety – albeit someone else's patient safety.

4.3.2 Experience

In many ways, the research evidence suggests that less experienced patients (e.g. general public) may be more vulnerable to potential lapses in safety because they lack the experience of engaging with health services and the attitude and skills more experienced patients have developed. More experienced patients included:

- **Those with long-term conditions** who tended to be more knowledgeable about their condition and how to care for it than health professionals.

- **Older respondents with longer medical histories,** although, in this sample, there was a difference in attitude between those aged 65+ who were more likely to take an active role in patient safety and those 75+ who were more likely to defer to the expertise of health professionals: *"My mum has always suffered from 'white coat syndrome'. She feels a bit like a burden, like they're up there and we're down here." (Patient who has not experienced any degree of choice in their care, 65+ years old, C1C2D)*

- **Those with negative experiences** whose behaviour and attitude had been changed by their previous experience: *"I think it depends what's happened to you in the past. I've had something happen to me and it puts me off. I'm always a bit wary now." (Patient who has not experienced any degree of choice in their care, 26-45 years old, with children aged under 11, C1C2D)*

- **Carers,** who tended to be heavy users of both health and social care services.

More experienced respondents had developed ways of engaging with health professionals:

"Some people are fearful of doctors, so it's a good idea to make a list. They might not hear what the doctor has to say because they're so in awe of the doctor. You've got to relax and realise that doctors are human beings." (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)

They had also learned about the limitations of NHS service and the implications for safety:

"The bed was wet with infection. We asked for someone to change the bed and they said they hadn't time. My daughter said she could do it if they would give her the dressings, but they said no. She had to go back to my house to get dressings to dress my leg so they could give her cleans sheets for the bed. She asked for blankets and was told they wouldn't have any until tomorrow." (Patient with a long-term condition)

Experienced respondents had rather different reactions to the scenarios which were shared with them.

For example, experience of not being 'heard' meant that more experienced respondents would assert themselves in the following situation:

This is your **second visit to the GP**. Last time, you described how you'd had lower back and neck pain for over a year. You sit a lot at work and – after your first visit – you made some adaptations to your work environment and general lifestyle.

The GP prescribes some painkillers, but this doesn't appeal to you because you've tried them before and they didn't make you feel too good.

You're concerned about the wider impact of living with persistent pain on your quality of life, you might even lose your job.

"I went in to see a locum doctor and I explained that I had a stiff neck and I'd been in bed for days. I couldn't move my neck at all. This was coming up to Valentine's Day. He said, 'Well, at least you'll be able to look lovingly into his eyes.' That was his attitude. After the MRI, they found I had 3 slipped discs. You have to become tough because you are protecting yourself." (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)

"Some GPs will listen to you, some GPs will give you a pill and push you out the door. It comes down to that person taking the time to listen and then exploring options with you. I'd be trying to make sure I was getting my point across to explain that I don't want to take the pills, so what else is there? There's always another option. Is there something else that has to be thought about here?" (Carer for a vulnerable user of health and care services)

The need to take control of interactions with health professionals was also illustrated by more experienced respondents' reactions to the following scenario:

You have taken an elderly friend for an appointment with the **chiropodist**. The appointment is at a local **private clinic**.

Your friend was diagnosed with diabetes almost a decade ago and suffers some cognitive impairment nowadays. The chiropodist will need to remove some painful, hard skin, as well as assess and treat problematic toe nails.

You wouldn't mind the chiropodist's thoughts on what the foot health of your friend says about her diabetes

Your friend has been seeing the same **chiropodist** for a while, but this time – unexpectedly - it's a new person and your friend seems worried by this. The practitioner approaches treatment in a different way and the equipment isn't even the same.

You can sense your friend is now becoming quite agitated, but the practitioner isn't picking up on this.

"You can avoid all this. You could speak to them the day before and say, 'Look, she's very nervous, can you make sure we have the same person because if we see someone different it's going to make her very upset." (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)

"My feet are my life. If it was me, I'd speak my mind and say, this is what needs to be done. You need to be straight. Some don't like it, but I just speak my mind." (Patient with a long-term condition)

"I would probably intervene and get some reassurance for my friend. I would say that this isn't the treatment she normally has and I would hope that they would have that conversation about the treatment and why it was different. Even when you're getting your hair done they explain what they're doing …" (Vulnerable user of health services)

Overall, the patients who we had described as 'vulnerable' (e.g. patients with mental health problems, learning difficulties, physical and sensory impairments) tended to be amongst the more experienced patients amongst our sample. The most vulnerable amongst this group tended to access services with the support of equally experienced carers. Through their experience of using services, this group had developed skills which less experienced patients and members of the general public lacked. This finding suggests that in this context, vulnerable respondents may be those who lack experience of using health and social care services.

4.4 Identifying and exploring situations where people have identified an error, potential error or emerging risk to safety

Respondents were given time within each interview to reflect on whether they had ever experienced a 'moment of doubt' whilst using health and care services. Respondents who had experienced such 'moments of doubt' were specifically included within both the focus groups and face-to-face depth interviews for this purpose. However, it transpired that respondents not specifically recruited as having had these experiences found it relatively easy to identify similar 'moments of doubt'.

4.4.1 Understanding the decision around whether to take action

Respondents who had acted on concerns that had arisen when using health and care services identified what *specifically* had motivated them to take action. These prompts included:

- **Pain or severity of health problem**:

  "I could see how much pain my husband was in. The painkillers weren't making much difference. Nobody should be in that much pain." (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)

"The paramedics gave her gas and air, but they couldn't leave it at the hospital with her. There they wouldn't let her have any pain relief. It was embarrassing and humiliating. I kept asking people for help and they kept saying she couldn't have anything or it wouldn't help." (Formal complainant)

Knowing that, if dissatisfied, returning for a second appointment would take time and that symptoms might increase during this time also motivated action:

"I think it's different if it's private because you've got their number. That happened to me and I was quickly given an alternative when the first drug didn't work. If you've got to wait 6 weeks for the next appointment, you're stuck." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

- **Not agreeing with the suggested course of action:**

  "I went to the doctor with a bad shoulder. I thought he'd refer me to have an MRI or physio, but he wanted to give me a cortisone injection. I came out and didn't feel comfortable with that so I asked around some other healthcare professionals in my family and they said that shouldn't be the first port-of-call. I went and had some physio which I paid for because it was quicker and within 4 weeks it was better." (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)

  "On the day of the operation I went in, got on the bed, and the anaesthetist came in. I said, 'The nerve is between toe 3 and 4 on my left foot, but he drew with his pen between toes 2 and 3. I wondered what he was doing. Then they started telling me about all the negative side effects of the operation, so I started to question whether I wanted to have it, because it had actually improved during my wait for the operation. I asked to see the consultant and he agreed that if I felt okay, I shouldn't do it. So I had lunch there and they sent me home!" (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)

  "My missus had post-natal depression and they kept throwing antidepressants at her, but we just refused all of that. If I've got prior experience of the drug, yes I would challenge it." (Patient who has not experienced any degree of choice in their care, 26-45 years old, with children aged under 11, C1C2D)

- **A *perceived* lack of competence:**

  "When we went for my wife's bad knee, we were sent to see a nurse practitioner who was looking it up on the internet. She didn't know what it was." (Patient who has not experienced any degree of choice in their care, 65+ years old, C1C2D)

"When I was at the hospital for my scan when I was pregnant, I was sent home with someone else's baby scan photo. When I phoned them, they didn't even seem bothered.

I stopped going there and went to a different hospital. I just didn't trust them. If you give me someone else's photo, are you going to give me someone else's baby?" (Patient who has not experienced any degree of choice in their care, 26-45 years old, with children aged under 11, C1C2D)

- **Knowing – rather than suspecting, as above - that something is inappropriate:**

  "I had a falling out with the consultant who was looking after my mum, who said, 'If I do explain it to you, you won't understand all the medical terms.' She belittled me, as if I couldn't possibly understand … I know they're busy, but your mum's very precious to you and I felt she was very patronising." (Patient with a long-term condition)

  "My mum had difficulty walking, but her emergency cord was on the other side of the room. I had to flag that up to the medical staff. Why has the bed been positioned here? (Carer for a vulnerable user of health and care services)

  The stimulus material also provided examples of when respondents felt that they would identify something inappropriate e.g. being asked about payment in advance of an appointment with an independent health practitioner or being asked to 'keep in touch' with an independent health practitioner. Interestingly, only some felt that the 'shabby' appearance of an independent health practitioner's premises would cause them concern:

  "If they can't look after their environment, what's their problem?" (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)

The findings suggest that patients needed to weigh up whether they felt taking action was justified in the circumstances, given a number of other considerations e.g. the pressure staff are perceived to be working under, how sure they felt that a mistake might have an unintended consequence.

4.4.2 Barriers to taking action when an error has been identified

There were a large number of reasons why respondents felt that it was difficult to take action in a health or social care context. Barriers included:

- **Not wanting to offend health professionals,** especially if there were concerns about how the patient's ongoing care might be affected, particularly for those dependent on NHS services:

  "I don't know if I'd necessarily say it to them in that meeting … I don't think it's polite to do it at the time." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

"You've got to keep on their good side." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

"There comes a stage where if you say something out of turn, they can refuse to see you." (Patient who has not experienced any degree of choice in their care, 26-45 years old, with children aged under 11, C1C2D)

"The time my leg was bad, I didn't say anything until my daughter came in. I wasn't well, I had a fever, I was in a really bad place. I wish I'd had more sense and wasn't scared to speak out. I was worried that they wouldn't give me the care I needed." (Patient with a long-term condition)

- **Not wanting to 'make a fuss' or avoid being perceived as a 'nuisance' or 'burden',** especially when health professionals are perceived to be overworked:

  "It's British nature. You get on with it." (Patient who has not experienced any degree of choice in their care, 26-45 years old, with children aged under 11, C1C2D)

  "Sometimes I feel like I'm being a nuisance." (Patient who has not experienced any degree of choice in their care, 65+ years old, C1C2D)

  "You're made to feel a nuisance if you ask question." (Patient with a long-term condition)

  "You don't want to be that person who is on their backs when they are trying to do a job." (Informal complainant)

- **Not knowing as much as health professionals:**

  "Being assertive is negative because they know more than you." (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)

  "Although we have parental responsibility, we're not experts. We're relying on the experts to give us advice, so we're in their hands really." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

- **Feeling vulnerable e.g. anxious, frightened:**

  "At the time it doesn't occur to you. You don't think to speak up." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

  "My dad had a district nurse coming in to dress his leg. He was crying in pain. She said it was phantom pain. This went on for 5 days. He was in floods of tears and my dad wasn't a man who showed his feelings usually. I phoned the doctor who said I needed to call an ambulance. We got to the hospital and the Senior Doctor said they needed to take him to

theatre to clean it out because he had got gangrene. It was so bad they had to take his leg." (Patient with a long-term condition)

- **Feeling intimidated by health professionals:**

  "A lot of doctors are very intimidating, speak quickly and want you out quickly. So, you freeze." (General public, 35-55 years old, children aged 11+ years old, C1C2D)

  "I would never take an active approach for a specialist, but I would for a GP. GPs are not experts. They're very intelligent, but ultimately, they're the gatekeepers to the specialists." (Patient who has not experienced any degree of choice in their care, 26-45 years old, with children aged under 11, C1C2D)

  "Whatever a doctor tells me, I will do. He knows better than me. If you don't trust your doctor, what's the point?" (Patient who has not experienced any degree of choice in their care, 65+ years old, C1C2D)

  It was noticeable that some of the most vulnerable users of health services preferred to speak to female members of staff rather than male members of staff.

- **A lack of time e.g. GP appointments:**

  "You're only allowed to go in with 2 problems. If you have more you have to make another appointment." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

- **Knowing the health professional well** e.g. in a small community:

  "People hear stuff, like local bad news about the doctors, especially in smaller communities." (General public, 35-55 years old, children aged 11+ years old, C1C2D)

  "With Dr X, if you annoy him, he really takes umbrage." (Patient who has not experienced any degree of choice in their care, 65+ years old, C1C2D)

- **A lack of continuity of care e.g. locums at GP surgery:**

  "*Some of them don't seem that confident and I just end up going back.*" (*General public, 35-55 years old, children aged 11+ years old, C1C2D)*

  "My doctor's a stranger… We've got eight doctors and I never see the same one twice." (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)

The research suggests that barriers to taking action are largely related to respondents' concern to protect their relationship with health professionals at a time when they feel vulnerable and reliant on health professionals to make them better (particularly for those without any other choice but to use NHS services).

4.4.3 Understanding what resulted from the decision

Amongst the non-complainant sample, respondents were most likely to have asserted themselves, either by taking action (e.g. choosing to be treated elsewhere, choosing not to be treated) or by directly challenging health professionals. **This group prioritised the need to resolve their immediate health situation, rather than making a complaint.**

The complainant sample differed in that they did not feel their health issue or experience had been satisfactorily resolved. They wanted to feel like they had achieved their desired outcome in terms of their:

- **Health situation** e.g. still not receiving the service or treatment felt to be required: *"When he [respondent's son] eventually did get referred to see a psychiatrist, the first person he was allocated got struck off for malpractice, the second was only a locum and the third, oh my goodness, she was dreadful." (Formal complainant)*

- **Experience** e.g. patients with poor ongoing experience of services that they wanted acknowledged and concluded: *"I just felt I was another number, just wait in line, keep quiet. My consultant didn't have time and I always felt I was just imagining my problems." (Formal complainant)*

It was clear that being offered an opportunity to feed back or encouraged to complain had an impact on respondents' decisions about whether to complain:

"I couldn't walk [after giving birth]. I pressed the buzzer asking for a wee and they eyerolled me. I was absolutely livid … Coming home gave me clarity of mind and when I got a feedback form from the hospital asking how the services were, I went to town on it." (Informal complainant)

"When I told him about her attitude [a nurse at an Out of Hours Service allegedly erroneously recommending Ibuprofen for a child under 12 in error], he [an A&E doctor] referred me to the complaints process." (Informal complainant)

Barriers to complaining were equally clear and included:

- **A lack of knowledge about how to complain:**

  "People still respect their GPs and the medical profession. Even though it's your body, you don't know enough to challenge it. I don't actually know what to do or how to go about

it.” (Formal complainant)

- **A lack of confidence and energy to pursue the complaint through formal channels:**

  “They make you feel like you’re in the wrong and complaining too much. They fob you off from one person to another.” (Informal complainant)

  “They tend to play everything down so you’re made to feel as if you’re being unreasonable.” (Formal complainant)

- **A lack of money for solicitors’ fees:**

  “In Northern Ireland they can’t do no-win no-fee, so it would cost me £5,000 for him to take it up.” (Formal complainant)

  “I keep getting letters saying we are investigating and it may take a few months, then another letter saying the same thing. It’s still not resolved, but I can’t afford to get a solicitor.” (Formal complainant)

Complainants supported the idea of service users trusting their own judgement:

“Just because they’re medically trained, it doesn’t mean they’re always right.” (Formal complainant)

“The GP is not always right. You know your body better than anybody else.” (Informal complainant)

“You know your body best and it’s your health, not the health professional, that is in question.” (Formal complainant)

They also supported the idea of service users becoming more skilled users of health and care services:

“People need to be honest with themselves. Make sure you know exactly how you are feeling and get that across to the doctor. They are not mind-readers.” (Informal complainant)

“You have to do it in the right way. You can be assertive and diplomatic – if you get it right.” (Formal complainant)

4.4.4 What might have resulted in a different outcome – specifically, could they have been more actively encouraged to raise a concern earlier?

Feedback from respondents more experienced at actively taking responsibility for their safety in health and care settings included advice and tips on how to do so.

The findings suggest that by promoting these ‘enabling factors’, there is potential to empower patients to adapt their approach to a range of situations in order to safeguard their health and care.

Below the advice and tips offered by more experienced patients/service users have been collated into a summary.

Mindset

- **You have a ‘duty of care’ to yourself,** as well as your loved ones. In practical terms, this means actively engaging the health professional in a conversation, asking questions and trusting yourself *as well as* health professionals

Knowledge/understanding of your patient rights

- **Know your patient rights!** For example, you always have the option to get a second opinion, you can change GP surgery, you can choose your hospital for elective care, you can access your health records, your options for feeding back/complaining

Develop your skills as a user of health and care services

- **Control the variables you can** e.g. book a double appointment, familiarize yourself with the health topic, make an appointment with a particular health professional whom you trust:
  “If you’ve seen the GP before, you open up a bit more. It’s familiarity.” (Patient who has not experienced any degree of choice in their care, 26-45 years old, with children aged under 11, C1C2D)

- **Make sure you ask the questions you want to ask** e.g. think about what you want to ask, write down key questions, check before you leave that you’ve asked them

- **Create an environment where you are feeling comfortable and confident** e.g. take someone with you:
  “I had a few appointments with a spinal specialist before I decided to go ahead with the operation and I asked someone to come with me so I could make sure I was taking it all in. I wanted someone else to hear it, to make notes, to ask questions that you might be too intimidated to say. Because it’s not happening to them, they’re less panicked and they’ve got more time to think about what to ask.” (General public, 35-55 years old, children aged 11+ years old, C1C2D)

- **Develop a language for challenging health professionals or expressing discomfort or dissatisfaction appropriately and effectively** e.g. *‘Do you have anything else you can suggest?’*
  “How you ask and the tone of your voice can change the conversation altogether.” (Patient who has not experienced any degree of choice in their care, 26-45 years old, with children aged under 11, C1C2D)
  “I don’t feel they’d mind you being direct and honest about what you needed help with.” (Patient who has not experienced any degree of choice in their care, 65+ years old, C1C2D)

The qualitative findings also suggest that imposing structure on a situation where patients may well be feeling unsafe would be reassuring, as illustrated by responses to the scenario below.

> You've been suffering from severe headaches for at least three days, which came on suddenly. On seeing your GP, she's concerned you may have a small bleed on the brain, which could be a precursor to something worse and potentially life threatening.
>
> You immediately **go to your nearest A&E**. You are capable of getting yourself there – you can still think and talk as normal. Having been through triage, spoken to a doctor and had initial blood tests and a CT scan, you're referred for a lumbar puncture – a procedure you've not heard of before.
>
> It's chaotic in A&E, it's been a long time since you saw your GP this morning.
>
> A hospital doctor working under supervision tries to insert a needle into the lower part of your spine for the lumbar puncture. After three unsuccessful attempts, you're feeling stressed. Worse, you've noticed a tingling sensation in your feet.

"They should have told you [about the potential side effects] before they started." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

"You'd want some reassurance that it was a totally normal reaction to what was being done." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

Respondents suggested that structure would give them confidence because it would put patients at ease and enable them to ask questions. Typically, patients and service users wanted health professionals to:

- Listen to the patient
- Explain what's going on (i.e. cause of symptoms)
- Give treatment options with pros/cons
- Invite questions
- Provide a way of contacting the health professional in between interactions to enable to patient to continue the discussion or ask further questions
- Provide an alternative way of providing feedback about care

"The man I saw yesterday, he really did give me confidence. Nobody has actually touched or looked at my knee apart from him. He immediately looked, felt round and had the scan results up on the screen. He was talking to me on a level. If I didn't understand something I felt I could ask and not be made to feel stupid. When I go back, I have to ask to see him. He specified that." (Patient with a long-term condition)

"People don't always speak up at that point, but if there was something where they can come back afterwards when they've had time to process their thoughts?" (Carer for a vulnerable user of health and care services)

4.5 Reactions to potential messaging

The last part of each interview and focus group involved asking respondents to review a range of words or phrases suggested by the research team. These words and phrases - 'sceptical', 'questioning', 'shared responsibility', 'active' and 'constructively distrustful' - were suggested as possible ways of empowering patients to take a more active role in patient safety. Two additional words/phrases - 'assertive' and 'being open' - were suggested by respondents themselves.

The potential use of any of the suggested words and phrases was felt to rely on the degree of trust individuals felt they had in health professionals. A discussion about trust therefore ensued, as described below.

4.5.1 Trust

Overall, respondents wanted to approach any interaction with health and care services positively. They wanted to trust their health professionals – at least, they wanted to trust their health professionals until the point at which their trust was undermined:

"You need to have a bit of trust to start with." (General public, 35-55 years old, children aged 11+ years old, C1C2D)

"Go in there with a nice attitude, but where you disagree with them, be a bit more assertive." (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)

"You've got to judge it on a case-by-case basis. You can't always go in with this predisposition of not believing what you're going to be hearing. We can't live our life like that. It's a combination of going in with your questions written down, having a constructive conversation and not being intimidated." (Patient who has experienced a free choice of care, 35-55 years old, children aged 11+ years old, BC1)

"If you're distrusting somebody, you're on the back foot straight away. I'd rather have it trustful. I want to trust that person that I'm telling about my health condition. I want them to trust me that I'm telling them the truth." (Patient who has not experienced any degree of choice in their care, 65+ years old, C1C2D)

"You can't be distrustful of everyone. There are some people you can trust and some you can't. You can't paint everyone with the same brush." (Patient with a long-term condition)

"It would cause chaos if you didn't trust health professionals." (Vulnerable user of health services)

The point at which trust had the potential to be undermined varied, but could be triggered by the patient not feeling that they are getting what they need out of the interaction, evidence of a perceived lack of professionalism – or pain (as discussed in section 4.4.1).

Typically, patients felt that they would need to have several reasons to lose confidence in a health professional. In any one interaction, the level of trust therefore had the potential to fluctuate, partly depending on the context and the content of the interaction itself, but also the degree of empathy demonstrated by each party for each other as well as the patient's degree of vulnerability.

It was noticeable that those who had complained tended to take their time to weigh up their experience, not only reflecting on the interaction itself, but also seeking advice from others. There is therefore evidence to suggest that complainers not only weigh up the extent to which their trust has been undermined, but also whether to take any action.

In a context of service users actively wanting to trust health professionals, certain phrases were perceived to be too negative e.g:

- **'Distrust' (however 'constructive')**

  "You're saying that the patient doesn't have trust in the staff. They're not going to want to do what they want them to do. If your patient doesn't trust you, it's not going to work." (Patient with a long-term condition)

  "I don't think it's a very good way to be. I just think that it would make it look like you weren't wanting to trust what they were saying. If I wasn't sure I would ask, but I think you've got to go in with a positive attitude." (Patient with a long-term condition)

  "There's too much distrust and blame in the culture as it is." (Vulnerable user of health services)

- **'Sceptical' (although 'healthy scepticism' was felt to be more appropriate)**

> *"Being sceptical could put a barrier between you and the person giving you the advice." (Patient who has not experienced any degree of choice in their care, 26-45 years old, with children aged under 11, C1C2D)*

- **'Assertive' (which was not well understood by all)**

> *"I think assertive is too strong a word. To me it can be a bit rude I suppose." (Patient who has not experienced any degree of choice in their care, 65+ years old, C1C2D)*
>
> *"Assertive is quite strong … Once you've sussed out how it is, maybe you could be a little bit more assertive, but I wouldn't go in instantly like that. I'd maybe start on friendly terms." (Patient with a long-term condition)*

These phrases were perceived to undermine confidence in health professionals and therefore health and care services.

4.5.2 'Constructive distrust'

The two components of the phrase 'constructive distrust' (i.e. 'constructive' and 'distrust') reflect respondents' belief that it is important to engage with health and care services positively (i.e. 'constructively') whilst reserving the right to change one's mind (i.e. by starting to feel a sense of 'distrust'). Respondents articulated this sense of balance in a positive way:

"I think it all boils down to you being in control of your treatment, with respect to the doctor and what he's advising. You're showing you're not a walk over." (Patient who has experienced a degree of choice in their care, 56+ years old, empty nester, C1C2D)

"You're not being aggressive, you're showing that you're willing to meet halfway and try to help as well as them with how you feel." (Patient with a long-term condition)

"It's about two-way dialogue and trust." (Vulnerable user of health services)

The language respondents preferred was perceived to be relatively 'soft' when compared to 'constructive distrust'. Preferred phrases included:

- **'Questioning' (felt to be more within most people's abilities than 'challenging')**

> *"That gives you the reassurance that the GP is not always right. You know your body better than anybody else." (Formal complainant)*
>
> *"It gives you permission. You would feel like it was a priority of theirs if you were encouraged to question." (Informal complainant)*

- **Being ‘open’**

  “If I was asked to be ‘open’ with staff, it would make me think at least they’re going to listen to what I’m going to say. I’m not going to be mistreated for being honest. It might give people more thought to be honest and open with people, to voice their opinion.” (Patient with a long-term condition)

  “It’s about being honest and telling the truth and not hesitating.” (Vulnerable user of health services)

- **Taking an ‘active’ role**

  “Active – that’s quite good. It’s encouraging you to be a bit more positive. I quite like to think that they would want you to be open and more involved.” (Patient with a long-term condition)

  “You have a say. It’s not asking you to question the care itself.” (Formal complainant)

Overall, the idea of creating a single phrase may not be sophisticated enough to empower patients and the public to raise their concerns, given the complexities of trust in a health and care situation.

5. CONCLUSIONS

Across the sample, health professionals were perceived as having most responsibility for patient safety. The research findings therefore reflect Peters and Bilton's[6] observation that *'patients and service users can delegate responsibility for making decisions about their care to professionals'.* The qualitative evidence from this study suggests that high degrees of trust discourages scrutiny of safety. There was also evidence to suggest that some respondents wanted to adopt a forgiving attitude towards NHS staff, due to the perceived difficulties of working in the NHS.

Respondents not only trusted health professionals, but *wanted* to trust health professionals in future. Even those who had made complaints (both formal and informal) still retained a degree of trust in health professionals. This finding suggests that whilst patients are willing to *question* the care they are receiving, they do not want to feel that their trust in health professionals is being undermined. In this way, respondents echoed Peters and Bilton's thought that '*too much trust … can be potentially dangerous, but conversely too little trust may deter patients from accessing the care they need'.*

The findings suggest that the degree to which service users will be willing to accept responsibility is likely to vary by setting:

- Respondents were more willing to accept a degree of responsibility when using NHS services because they perceived the system to be overburdened and therefore they felt vulnerable.
- Users of private services were less likely to accept a degree of responsibility for their patient safety due to an assumption that private care is somehow 'safer' than NHS care.
- Although respondents were typically more willing to accept a degree of responsibility when *choosing* independent health practitioners, they were less likely to perceive a need to assume this responsibility when using independent health practitioners, since these were typically perceived as 'low risk'.

The findings also suggest that awareness of the importance of taking responsibility for one's own patient safety varied across the sample.

Those with more experience of using or complaining about health and care services (i.e. those with long-term conditions, those with negative experiences, older people with longer medical histories and carers) were the most likely to feel that they had an active role to play in safety, and to identify this role spontaneously. This group agreed that putting too much trust in health professionals could be problematic.

In many ways, the research evidence suggests that less experienced patients (e.g. the public)

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[6] Peters, S and Bilton, D. Right-touch trust: thoughts on trust in healthcare. In The Routledge Companion to Trust

may be vulnerable to potential lapses in safety because they lack the experience of engaging with health services and the attitude and skills more experienced patients have developed. For example, less experienced respondents typically felt that their responsibility was limited to correctly informing the health professional about their health, self-care and following health professional instruction.

Caring roles helped individuals overcome any reticence they might feel about challenging health professionals. For example, parents felt that it was easier to take a role in the safety of their children's care, feeling that it was more socially acceptable to do so on their child's behalf than on their own behalf.

Amongst those who had taken action, respondents were most likely to have chosen to be treated elsewhere, chosen not to be treated or directly challenged health professionals. This group had prioritised the need to resolve their immediate health situation, motivated to take action by pain or the severity of the health situation, not agreeing with the course of action suggested by the health professional, a perceived lack of competence, or feeling confident that an error had been made. The findings suggest that patients needed to weigh up whether they felt taking action was justified in the circumstances, given a number of other considerations e.g. the pressure staff are perceived to be working under, how sure they felt that a mistake might have an unintended consequence.

The complainant sample differed in that even though they had attempted to raise their issue at the time, they did not feel their health issue or experience had been satisfactorily resolved and were still seeking a resolution. It was clear that being offered an opportunity to feed back or encouraged to complain had a positive impact on a respondent's decision to complain.

The two components of the phrase 'constructive distrust' (i.e. 'constructive' and 'distrust') reflected respondents' belief in the importance of engaging with health and care services positively (i.e. 'constructively') whilst reserving the right to question the safety of one's care (i.e. by starting to feel a sense of 'distrust').

In a context of service users actively wanting to trust health professionals, certain phrases were perceived to be too negative e.g: 'distrust', 'assertive', 'sceptical'. These phrases were perceived to undermine confidence in health professionals and therefore health and care services. The language respondents preferred was relatively 'soft' when compared to 'constructive distrust'. Preferred phrases included: 'questioning', being 'open' and taking an 'active role'.

Overall, the idea of creating a single phrase may not be sophisticated enough to empower patients and the public to raise their concerns, given the complexities of trust in a health and care situation. The research findings suggest that there is potential to empower patients to take action in a range of situations in order to safeguard their health and care by focussing on 'enablers'. These 'enablers' include: encouraging service users to change their mindset (i.e. to focus on their duty of care to themselves); increasing their knowledge of their patient rights; and improving their skills as users of health and care services.

APPENDIX A – METHOD, SAMPLE AND RECRUITMENT IN DETAIL

i) Focus group sample

The 9 focus group (6 respondents, 1.5 hours) sample was segmented as follows:

	England	**Wales**	**Scotland**	**N Ireland**	
Aged 18-30 without children	1				1 x Members of the public
Aged 26-45 with children under 11	2			1	1 x No choice care 2 x Degree of choice care
Aged 35-55 with children aged 11+	1		1		1 x Members of the public 1 x Free choice care
Empty nesters 56+	1	1			1 x Degree of choice care 1 x Free choice care
Retired 65+	1				1 x No choice care

- 'Free choice' defined as those who had experienced free choice of care e.g. private or unregulated care
- 'No choice' defined as those who had experienced emergency treatment (and included those who had attended emergency care settings with the patient e.g. carers)
- 'Degree of choice' defined as those who had experienced a degree of choice e.g. elective care
- 'Member of public' defined as those who had only experienced routine GP or dental appointments

Within this sample, a broad range of service use, both regulated and unregulated was achieved.

ii) Depth interview sample

16 individuals/paired depth interviews (1-1.5 hours) were conducted with those less likely to participate in a focus group:

- 6 interviews with those who have **long-term conditions** that might make participating in a focus group difficult
- 5 interviews with **social care users**, including some adult and some who are elderly (achieving a mix of residential & in-home care, provided by a mix of Local Authority & private providers)
- 5 interviews with **other vulnerable audiences** including:
    - 2 x mental health issues/learning difficulties

  - 2 x sensory/physical impairment
  - 1 x 75+ years old

Some of the interviews amongst social care users and vulnerable audiences were conducted as pairs, with the respondent accompanied by a relative or a friend.

iii) Telephone depth interview sample

16 telephone depth interviews (1 hour) were conducted with those who had with those who had complained about their care, either formally or informally:

- 8 had made formal complaints – through a formal complaints process or professional regulators fitness to practice process
- 8 had made informal – via an email, phone call or letter to their healthcare or service provider

Please note that those who had complained about their care were also included in the focus group and depth interview samples.

iv) Recruitment

Respondents were recruited via a network of Market Research Society (MRS) trained recruiters, with experience of free-finding those with specific health experiences or long-term conditions. The 'free-find' method involves recruiters approaching individuals face-to-face and asking them to participate in research. The strength of 'free-find' recruitment is that interviews can be clustered in localities, reducing the overall fieldwork burden and travel costs. MRS trained recruiters:

- engage respondents with the research process as they know the community/area and the importance of taking part i.e. 'having your say';
- gain genuinely informed consent through face-to-face recruitment;
- reassure participants about their rights (Data Protection Act, GDPR, MRS Code of Conduct) and maintain this reassurance throughout the research process;
- and support them to participate in the interview by offering interviews in venues that suit them.

The recruitment questionnaire, which is the protocol for screening potential participants and ensuring that they meet the recruitment criteria for the research, is available on request as a separate document.

All recruitment was managed by our in-house project support team, in accordance with Data Protection, GDPR and the Market Research Society Code of Conduct requirements.

Appendix B Topic guides – face-to-face and telephone discussions

PSA Patient Safety
Draft Discussion guide for Focus Groups and face-to-face depth interviews V2
Group discussions (6 respondents, 1.5hrs)
Face to face depths (1-2 respondents, 1.5 hours)

1. Introduction (5mins)

- Introduce self and RWL, an independent market research agency
- We have been commissioned by a public health body to explore views of the general public about some information on a particular topic
- Explain confidentiality (MRS Code of Conduct and Data Protection Act)
- Ask permission to record the session if relevant

Brief background and warm-up

- Name, family, working situation, any hobbies and interests

2. The role of patients in their safety (15 mins)

The purpose of this section is to identify how much responsibility respondents think they have for their (or the person they are caring for's) safety in relation to their healthcare and how this changes depending on the situation.

Explain that we are here to think about the idea of safety in relation to healthcare. So thinking about when you or someone you care for visits a GP, dentist, hospital or complementary therapy clinic, safety is ensuring the care is: appropriate (e.g. the right prescription, referral), follows health and safety rules, is professional and is undertaken by someone with the appropriate qualifications and registration.

- Thinking about visiting a healthcare provider of any sort (GP, dentist, hospital, complementary therapy clinic) who do you think is responsible for your safety as a patient in those circumstances?
- [As appropriate prompt] And anyone else? Are there any other organisations taking care of you?
- [As appropriate prompt] – have you also considered xxx may have a role to play in your safety? *Ensure the following are covered: me/the patient, health professionals/complementary therapists, regulator, service provider*

Note down all ideas on a prompt cards

Separate out those that say: Me, Health Professionals/Complementary Therapist, Regulator, Service provider

- Thinking about these four, who do you think has the most responsibility for patient safety? And who is least? Why is that?

Introduce Slide 1 of 3 selected healthcare scenarios in turn as headlines (rotate the 3 selected across the groups so all 5 are shown at least 3 times). For each Slide 1, ask:

- Imagine you are the patient/carer in this circumstance I have just described. Who is most responsible for your safety in this scenario?
- How responsible are you for your safety/ the safety of the person you are caring for? Why?
  - Are you more or less responsible for safety than in the previous scenario?
  - Are you more or less responsible for safety than in your original cake diagram? Why?
- *Listen out for mentions of trust or distrust in relation to health professionals and service providers and probe:*
  - What makes you feel trustful in that situation?
  - What might make you distrustful? Why?
  - *Probe: health professional actions, the environment, specific experiences*

3. Exploring barriers and enablers (25 minutes)

The purpose of this section is to identify what might prevent an individual speaking up in relation to patient safety and importantly what would encourage or enable them to do so.

Introduce the 3 healthcare scenarios again in turn and voice-over slide 2 of each. For each scenario, ask:

- I'd like you to imagine again that you are the patient/carer in this circumstance – what would you have done? Why?
- What are the barriers to you speaking up here?
- And what might have encouraged you to speak up?
- How trusting do you feel of the health professional/therapist in this situation? Why?
- And how does this differ if we adapt it slightly? [Voice over the possible adaptations] Would you be more or less likely to act or question the situation here? Would you feel more or less in control? Why? More or less trusting? Why?
  - *Probe: what is the tipping point between being trusting and starting to feel distrustful. What is a trigger to encourage them to speak up and take some control?*

Record barriers on 1 sheet of paper and enablers on another

4. Exploring ‘moments of doubt’ (15 minutes)

The purpose of this section is to explore incidences where respondents have identified an error, potential error or emerging risk to safety of themselves or others and explore why they did/didn’t act

- I’d like you to think about any time when as a patient or the carer of a patient you have thought something wasn’t quite right in a healthcare setting. This might be a slight or serious concern for your safety or the safety of the person you are caring for
- Please use the paper in front of you to note down some details of that circumstance and what you did and think about what action, if any, you took. If you didn’t take any action please think about what might have encouraged you, in that circumstance, to take action

Allow respondents 5 minutes of reflection time with refreshments

- Tell me about your experience? How did you feel? What was it that worried you? [*Moderator note: ensure anecdotes don’t take over – focus on why respondent did/didn’t act]*
- Tell me about the moment you noticed something wasn’t right. When was that? Who was there? What was the environment and situation like?
- Why did/didn’t you act or speak up at the time? What was the result?
- Thinking about that specific circumstance what could have encouraged you to act?
- What do others think? What would have encouraged you to speak up in this situation?
- *Probe any mentions of trust or distrust.* What made you trusting? What was the tipping point between trust and starting to feel distrustful?

Record barriers and enablers on previous sheets of paper

5. Discussion of the idea of ‘constructive distrust’ (30 minutes)

The purpose of this section is to explore a number of propositions to identify if these would encourage respondents to speak up or take action.

- We are going to spend the remainder of the discussion thinking about what might encourage you and patients/carers more widely to speak up and take action in relation to patient safety

- First, let's look at all of the detail we have captured so far on what might encourage you to take action [refer to enablers noted down]
- What words would you use to describe these?
- Is there any 1 phrase that would sum all of these up? *Capture these words on cards*

Split the group into pairs and hand each pair 2 cards. Each card contains 1 of these phrases. Add any others respondents have come up with themselves.

- **Sceptical**
- **Questioning**
- **Shared responsibility**
- **Active**
- **Constructively distrustful**
- **Assertive**

- In your pairs I would like you to imagine you are the patient in this scenario [utilise the most generic scenario from section 3 again]. How would you behave if you saw a message in the waiting room encouraging you to behave like the word on your card? E.g. to be sceptical, questioning etc.
- Using some paper note down how you might behave in your pairs and why?

Allow a couple of minutes for each pair to think through then ask them to share with the group

- Please tell the room what you understood by the phrase and how you would behave as a result of seeing the message?
- Why do you think you would behave like this?
- What about if you were sat in that same waiting room in 10/20/30 years' time with a long-term health condition and are very familiar with the centre you are in and the services you are receiving?
- And what about if you were sat in the same waiting room in 10 years' time and have the ability through advanced technology to monitor your own health and condition? How would this impact how you act?

- Thinking about the idea of 'constructive distrust' – what first sprung to mind when you saw this phrase? How comfortable does it feel as a phrase? What works about it/what doesn't work?
- [If necessary explain]. It's important to trust a healthcare professional/complementary therapist otherwise a patient may not go and get the care they need, but too much trust could mean a patient doesn't question when they should and this could be dangerous.

The idea of constructive distrust is that there would be a balance where a patient would trust the individual but not blindly

- What do you think now I have explained further? How does it make you feel? *[Probe if needed: empowered, undermined]*
- Do you think you have ever behaved in this way in a healthcare setting? Tell me about it?
- Imagine again that you saw this in the waiting room. How does it make you feel about the healthcare professional/complementary therapist you are about to see? Would you feel: confident, unsure, comfortable, uncomfortable, trusting?
- And how does it make you feel about the healthcare service more generally?

6. Summary

- Please take a notecard from the pile and write down 1 thing you think the healthcare service could do differently to encourage you to speak up and act when something doesn't look right

Thank respondents and close.

Telephone discussions

PSA Patient Safety
Draft Discussion guide for Telephone Depth interviews with those who have raised a complaint
Telephone discussions lasting up to 1 hour

1. Introduction (5mins)

- Introduce self and RWL, an independent market research agency
- We have been commissioned by a public health body to explore views of the general public about some information on a particular topic
- Explain confidentiality (MRS Code of Conduct and Data Protection Act)
- Ask permission to record the session if relevant

Brief background and warm-up

- Name, family, working situation, any hobbies and interests

2. The experience that led to an informal or formal complaint (25 minutes)

The purpose of this section is to explore the experience that led to the complaint. It will be vital to tap-into what prompted them to raise a complaint, why they felt able to do so, and what could have resulted in a different outcome.

- We want to talk today about the healthcare experience/complementary therapy experience you had/someone you care for had that led you to raise a complaint
- Tell me a bit about what happened?
    - What healthcare/complementary service were you accessing? Why?
    - When did you first notice something wasn't quite right? What did you notice? Where were you? Who was there? What was the environment like?
    - How did you feel when you first noticed something was wrong?
    - What was it that went wrong?
    - How did you feel at the time?
    - At what point did you act or speak up? Was it at the time or afterwards?
    - Tell me a bit about how trusting you felt of the health professional/therapist? *Probe: their 'trust journey' – different levels of trust at different points and why*
        - *Probe: what is the tipping point between being trusting and starting to feel distrustful*
- Tell me a bit about the complaint you raised? Was it informally or through a more formal channel? *[Probe: call, email to healthcare provider/complementary therapist vs. healthcare provider formal procedure vs. complaint to a regulator, MP or ombudsmen]*

For those that acted or spoke up at the time ask:

- Thinking back to the moment when you noticed something wasn't right, what was it that prompted you to speak up?
- What did you say and who did you speak to? How was it received?
- How did you feel speaking up? [Prompt: any sense of embarrassment, unease vs. empowerment and control]
- Was there anything particularly that enabled you to speak up?
- Is there anything that could encourage others to do the same as you in similar situations do you think?

For those who didn't act at the time ask:

- Thinking back to the moment when you first noticed something was wrong were you able to say anything at the time? Why not?
- What do you think prevented you from speaking up then? Anything else? Think about the situation you were in, the healthcare professional/complementary therapist, the environment?

- What would have resulted in a different outcome do you think? What could have been different about the situation/environment/who was present to result in a different outcome?
- What could have encouraged you to act and speak up earlier in the process?

3. Discussion of the idea of 'constructive distrust' (30 minutes)

The purpose of this section is to explore a number of propositions to identify if these would have encouraged respondents to speak up or take action.

- We are going to spend the remainder of the discussion thinking about what might encourage you and patients/carers more widely to speak up and take action in relation to patient safety
- I would like you to think back to your situation again. You are in the waiting room [change as appropriate] and you see a message encouraging you as a patient/carer to be:
    - **Sceptical**
    - **Questioning**
    - **Share responsibility**
    - **Active**
    - **Constructively distrustful**
    - **Assertive**

Rotate the order these are introduced across the telephone depth interviews

- How would you behave after seeing this message? Why?
- What do you understand about this phrase?
- Do you think you would have done anything differently based on this? Why/why not?
- Would any tweak/amendment to the phrase improve its likelihood to prompt action?
- What about if you were sat in that same waiting room in 10/20/30 years' time with a long-term health condition and are very familiar with the centre you are in and the services you are receiving?
- And what about if you were sat in the same waiting room in 10 years' time and have the ability through advanced technology to monitor your own health and condition? How would this impact how you act?

Ask the following additional prompts when discussing constructive distrust

- Thinking about the idea of ‘constructive distrust’ – what first sprung to mind when you saw this phrase? How comfortable does it feel as a phrase? What works about it/what doesn’t work?
- [If necessary explain]. It’s important to trust a healthcare professional/complementary therapist otherwise a patient may not go and get the care they need, but too much trust could mean a patient doesn’t question when they should and this could be dangerous. The idea of constructive distrust is that there would be a balance where a patient would trust the individual but not blindly
    - What do you think now I have explained further? How does it make you feel? *[Probe if needed: empowered, undermined]*
    - Do you think you have ever behaved in this way in a healthcare/complementary therapy setting? Tell me about it?
    - Imagine again that you saw this in a waiting room. How does it make you feel about the healthcare professional/complementary therapist you are about to see? Would you feel: confident, unsure, comfortable, uncomfortable, trusting?
    - And how does it make you feel about the healthcare/complementary therapy service more generally?

6. Summary

- Finally thinking back to your experience and everything we’ve discussed, what 1 thing do you think would make you more likely to speak up and act if you are ever in a similar situation again?

Thank respondents and close.

Appendix c

Stimulus material

You have taken an elderly friend for an appointment with the **chiropodist**. The appointment is at a local **private clinic**.

Your friend was diagnosed with diabetes almost a decade ago and suffers some cognitive impairment nowadays. The chiropodist will need to remove some painful, hard skin, as well as assess and treat problematic toe nails.

You wouldn't mind the chiropodist's thoughts on what the foot health of your friend says about her diabetes

Your friend has been seeing the same **chiropodist** for a while, but this time – unexpectedly - it's a new person and your friend seems worried by this. The practitioner approaches treatment in a different way and the equipment isn't even the same.

You can sense your friend is now becoming quite agitated, but the practitioner isn't picking up on this.

Verbal changes to Scenario 1. Please don't show to respondents

- You have had prior notice of the change of chiropodist and the chiropodist explained her approach at the start of the consultation
- The room looks untidy and very run down
- The chiropodist checked you'd paid at reception before starting the treatment (you normally pay afterwards)

You've been suffering from severe headaches for at least three days, which came on suddenly. On seeing your GP, she's concerned you may have a small bleed on the brain, which could be a precursor to something worse and potentially life threatening.

You immediately **go to your nearest A&E**. You are capable of getting yourself there – you can still think and talk as normal. Having been through triage, spoken to a doctor and had initial blood tests and a CT scan, you're referred for a lumbar puncture – a procedure you've not heard of before.

It's chaotic in A&E, it's been a long time since you saw your GP this morning.

A hospital doctor working under supervision tries to insert a needle into the lower part of your spine for the lumbar puncture. After three unsuccessful attempts, you're feeling stressed. Worse, you've noticed a tingling sensation in your feet.

Verbal changes to Scenario 2. Please don't show to respondents

- The doctor reassures you that it is normal for this procedure to be difficult
- A nurse is also close at hand and aware of the situation
- The same doctor had considerable difficulty taking a blood sample from you earlier
- You are on your own with the doctor

Following a sports injury you are referred for **orthopaedic sports massage** therapy to reduce your pain and increase your range of motion.

This is your first time having such treatment.

It's now your fourth session with the **sports massage therapist**.

He suggests that no more sessions are needed. You're disconcerted by this, still feeling in pain and not yet able to return to sport.

Verbal changes to Scenario 3. Please don't show to respondents

- Your GP referred you to the sports massage therapist
- Your friend had a successful outcome working with the sports massage therapist
- The sports massage therapist has shared details about his personal life. He suggests that you stay in touch and asks what your plans are for the weekend.

This is your **second visit to the GP**. Last time, you described how you'd had lower back and neck pain for over a year. You sit a lot at work and – after your first visit – you made some adaptations to your work environment and general lifestyle.

The GP prescribes some painkillers, but this doesn't appeal to you because you've tried them before and they didn't make you feel too good.

You're concerned about the wider impact of living with persistent pain on your quality of life, you might even lose your job.

Verbal changes to Scenario 4. Please don't show to respondents

- The GP has been an established partner in the practice for a long time
- There are a lot of patients in the waiting room and the GP is running behind
- You know the waiting list for another appointment is weeks

Your daughter has been diagnosed with childhood arthritis. Although the arthritis is reasonably well controlled through a combination of drugs, she still feels generally unwell and is suffering bone loss (osteoporosis) too. You have been **referred to another clinic** which specialises in bones.

The **bone specialist** prescribes a drug that your daughter will need to take for quite a while. You're uneasy about this, because she's already on some powerful drugs and hasn't really seemed herself since she's been taking them. Your daughter looks unhappy and is very quiet. The specialist is quite definite though that this is the way to go.

Verbal changes to Scenario 5. Please don't show to respondents

- The doctor doesn't seem to be aware of your daughters medical history and has visibly struggled to access test results on the computer system
- You have conducted research online into this drug and are aware that there isn't much evidence of its effectiveness in children
- You are offered access to a quick follow-up appointment if you have any concerns