TRAJECTORY

Understanding Patients' Experiences of Referrals

A report for the General Medical Council

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Trajectory is a consumer insight, futures and forecasting business. London based and founded in 2008, Trajectory builds on the 70+ years combined experience of the three founding partners, covering qualitative and quantitative research techniques, scenario planning, advanced statistical analyses, forecasting and more. Trajectory works across multiple sectors including leisure, travel, technology and financial services. Trajectory clients include; the BBC, the British Council, HSBC, National Lottery Community Fund, O2, Royal London and The V&A.

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1. Executive Summary

Background and objectives

Previous research into referrals found that a significant source of pressure for doctors is unnecessary referrals being made to them. At the same time, research has found that doctors report they are making defensive or unnecessary referrals as a tactic to help cope with their own high workload.[1] Overall, the evidence suggests more doctors are making more referrals.

These changes may be impacting on patients' experiences, patient safety and potentially patient outcomes. For this reason, the GMC wanted to understand these issues better and explore the experience of referrals from the point of view of the patient. Specifically, the key questions for this research were:

- Is there a typical patient experience of referral?
- To what extent do patients who have been referred several times deem their referrals to be necessary?
- What is the impact of being referred?
- What are patients' views on referral more generally?
- What is the impact of multiple referrals on groups who are more likely to be adversely affected?

Research Method

To answer these objectives, a mixed methods research approach was designed. First, to both size the proportion of unnecessary or unsatisfactory referrals and to inform later stages, a quantitative survey of patients who had had a referral in the last two years was commissioned.

Following this, 35 in-depth interviews took place with patients who had a range of experiences, including those who were satisfied with their referral and those who were either unhappy or perceived their referral to be unnecessary. The interviews took place either face-to-face or over the phone with a sample of people drawn from across the UK and a range of backgrounds.

[1] *Adapting, Coping, Compromising (2018)*

Quantitative findings

The quantitative survey found that the vast majority (83%) of patients that have had a referral in the last two years are satisfied with how it was handled.

- Overall, 6% were unsatisfied with their referral
- 10% felt their referral was unnecessary
- Almost all of those that had an unnecessary referral were satisfied with it; i.e. they thought it was the right thing to do, even if it was not necessary

Qualitative findings

In the qualitative research, patients were divided into two broad groups; those that were satisfied with their referral experience and those that were either unsatisfied or felt their referral had been unnecessary. There were notable differences in experience between these groups.

Among satisfied patients, the logistics and practicalities of the referral went smoothly. They were seen by the right people at the right time and did not experience delays or cancellations. Additionally, they reported positively about their interactions with doctors and the overall quality of communication and explanation they had about the referral process.

However, among unsatisfied patients these experiences were quite different. This group were more likely to experience delays and cancellations in their journey, or to arrive at an appointment to see a doctor who was not expecting them or familiar with their case. In some cases, the referral got 'lost' entirely. Equally, this group were far less likely to report positively about their experiences with doctors; some commented on the manner and rudeness of individual doctors, while others felt they needed clearer communication and better explanation about what the referral process would involve.

Despite these very different experiences there are some commonalities between the two groups. One is the speed of the overall process – frustration with the length of time between appointments is a criticism expressed by both groups. Another is the firm belief in and support for both the NHS overall and individual doctors. Despite their criticisms and dissatisfaction, patients have sympathy for doctors and the challenges that come with their workload.

Conclusions

The research and analysis has produced a number of conclusions on the patient experience of referrals.

- **The scale of dissatisfactory and unnecessary referrals is small**: overall only 1 in 10 patients perceive their referral to be unnecessary, and only 6% are dissatisfied with their referral
- **Patient expectations of GPs are high**: patients do not always recognise that diagnosis is an iterative process and that this may involve multiple referrals (particularly when this has not been explained). It is entirely appropriate for the GP to act as a gatekeeper that refers patients on, but this occasionally falls short of expectations
- **Minor problems can have big impacts on patients' lives**: living with symptoms or in pain can affect a patients' ability to work, sleep or live their normal lives. The feeling that they are being bounced around the system can lead to patients feeling like the condition, rather than the patient, is being treated.
- **Problematic referrals have practical impacts on patients**: for many patients it is not easy to fit multiple appointments around other commitments.
- **The deferential patient**: patients are deferential to doctors and do not typically assert themselves as they might in other walks of life.
- **The myth of the litigious patient**: although doctors themselves might be referring more because of concerns regarding medico-legal risks there was no evidence of litigious patients in our research.
- **Patients can be satisfied regardless of outcome**: in both groups there were some patients who had experienced long term issues as a result of their condition, and in some cases, conditions the patients perceived to have been exacerbated by the actions of doctors. Ultimately, the patients' perspective on their referral experience does not appear to be directly correlated with their health outcome.
- **Patient experience can depend on individual expectations:** individual expectations of care and service affect referral experience. In the fieldwork, what amounted to an unacceptable delay or doctor communication for one patient would have been acceptable to another.

2. Background

Previous research into Referrals

In 2018 the GMC commissioned research called 'Adapting, Coping, Compromising' (ACC)[2]. This research, conducted with doctors, aimed to explore the approaches and tactics doctors were applying in working in a health system under pressure. It found that a significant source of pressure for doctors is unnecessary referrals being made to them.

At the same time, doctors also reported that they sometimes referred patients to other doctors even when not strictly necessary when they did not have time to deal with their issues themselves. They report that this was often a tactic to help cope with their own high workload.

Referrals of this nature might alleviate immediate pressures but build up longer term pressures for doctors and their colleagues further down the line.

In particular, the findings showed that a significant number of doctors are making more referrals and, as gatekeepers, GPs are particularly likely to be making more referrals.[3]

- A third (33%) of doctors agreed somewhat or strongly that they are making more referrals now due to the higher workload pressures
- 31% agreed that they refer patients more readily than they used to, even when they feel it may not be strictly necessary
- Half (51%) of the surveyed GPs agreed that they refer more than two years previously due to workload pressures. This is around 20-25% more than each of the other types of doctors
- GPs agreed most strongly that they are referring patients more readily now than two years ago - even if they sometimes feel it may not be necessary
- Over half (53%) of the surveyed doctors agreed that they refer more now owing to increased concerns regarding medico-legal risks and less than one in five (18%) disagreed. Again, GPs were most likely to agree with this.

[2] See chapter 3 of *State of medical education and practise 2018* (SoMEP).
[3] Ibid

Wider Context

The role of GPs

Diagnosis is an iterative process. It may take several consultations and procedures until a condition is diagnosed – with some conditions being ruled out before one is definitively ruled in.

Within this, the role of the GP is changing; rather than acting as diagnosticians they are often the gatekeepers to the wider health system, referring patients based on a brief consultation. This may occasionally jar with patients' expectations of GP care: they may expect their GP appointment answer their queries and provide a quick diagnosis.

Furthermore, with GPs the most common starting point for patients they are also likely to feature heavily in terms of referral experiences.

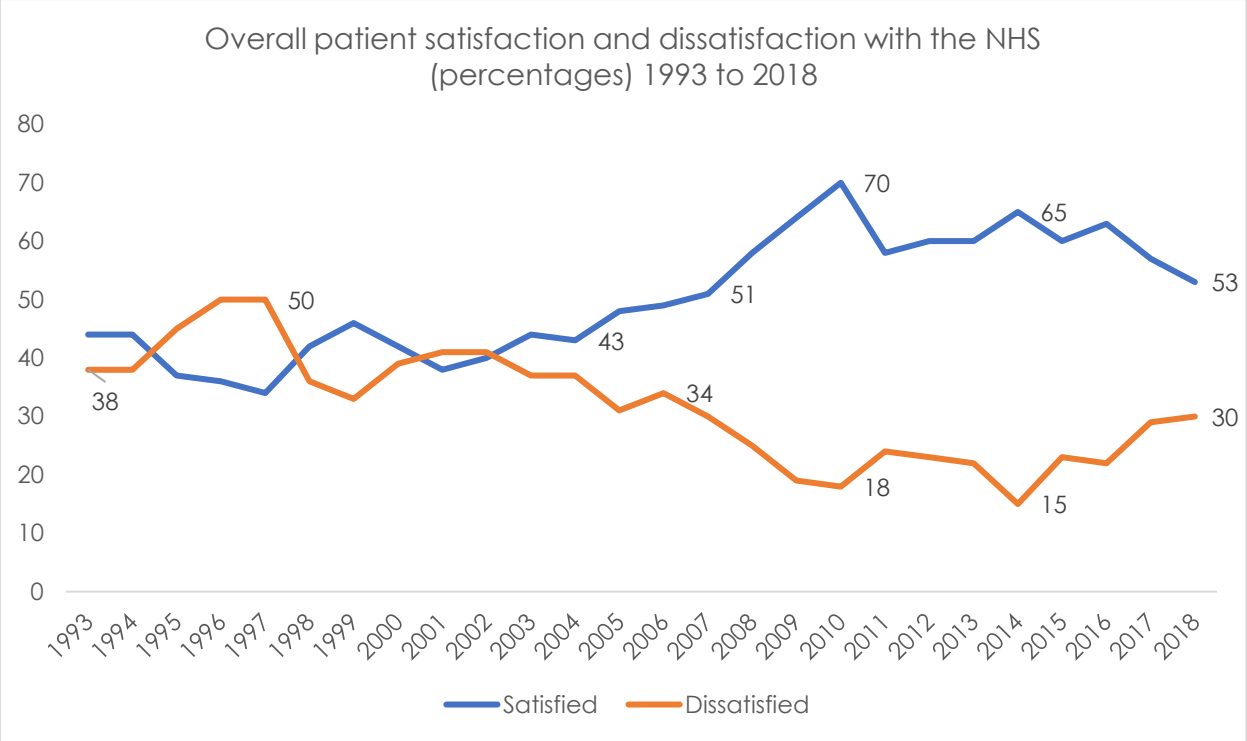
Public satisfaction with the NHS

Although there is no annual measure of patients experience of unnecessary referrals, we do have a robust indicator of overall public satisfaction with the NHS.

Since 1983 British Social Attitudes has asked questions about public trust in the NHS. The BSA survey is conducted the same way every year where a randomly selected sample of the public are interviewed face to face. The data provides rich trends with a depth and context that no other measure of NHS satisfaction provides.

Public satisfaction with the NHS has fallen over the last decade. Overall satisfaction in 2018 was 53 per cent – a 3 percentage point drop from 2017 and the lowest level since 2008[4].

[4] The Kings' Fund (2019) Public satisfaction with the NHS and Social 2018. Found at https://www.kingsfund.org.uk/publications/public-satisfaction-nhs-social-care-2018



Source: BSA2018 Final data tables

The main reasons people gave for being satisfied with the NHS overall were:

- the quality of care
- the NHS being free at the point of use
- the range of services and treatments available
- and the attitudes and behaviour of NHS staff.

The four main reasons people gave for being dissatisfied with the NHS were:

- long waiting times
- staff shortages
- a lack of funding
- money being wasted.

A huge system under strain

The NHS is a huge operation. In 2018/19 around £126bn is budgeted to be spent on the NHS in England[5] - around £2,892 per head[6]. It is also meeting the

[5] The Kings' Fund, Nuffield Trust and the Health Foundation. Autumn Budget 2017: what it means for health and social care https://www.health.org.uk/sites/default/files/AutumnBudgetWhatItMeans.pdf#page=3

[6] Reality Check. Does UK spend half as much on health as US? 6 Feb 2018. https://www.bbc.co.uk/news/uk-42950587

challenges of a growing and ageing population and a proliferation in the range of treatments, interventions and drugs available.

As an employer it will also be affected by the impact of the decision to leave the EU on its workforce; and the wider effects of austerity on the NHS[7], cuts in public services on people's health[8] and their likelihood to turn to the NHS in crisis.

In the year ending March 2019 there were 21.46 million first outpatient attendances (up from 20.68m the year before). At the end of March 2019, 1 million patients were waiting for a diagnostic test (a like-for-like 2.4% increase on the previous year). Overall providers failed to achieve the waiting time standard for 13 out of the 15 key diagnostic tests meaning more patients waited longer than 6 weeks.

At the same point in time, the waiting list for NHS providers was 4.0 million, a 9.7% increase compared to a year previously (like-for-like and excluding providers that have restarted reporting this year). The number of patients waiting more than 52 weeks in NHS only providers was 1,117. There were 5.7 million attendances at NHS A&E departments, an increase of 7.0% compared to the same quarter the year before[9].

The research into patients' experiences of referrals

Changing referral behaviours may be negatively impacting on patients' experiences (and potentially outcomes) and patient safety. If more doctors are referring more patients then the pressures on the system increase.

For this reason, the GMC wanted to understand these issues better so that it could engage with them appropriately.

For a rounded picture on the referral experience, the GMC wanted to explore this issue from the patient perspective. Key questions included:

1. Is there a typical patient experience of referrals? If not, what do the range of experiences look like?

    - How well is the purpose of referral communicated?
    - Are patients able to ask questions?
    - How 'joined up' is the healthcare system, e.g. are notes transferred properly, is 'whole person' seen rather than individual conditions treated?

[7] https://www.kingsfund.org.uk/publications/understanding-nhs-financial-pressures
[8] https://www.ohchr.org/Documents/Issues/EPoverty/UnitedKingdom/2018/Academics/University_of_Liverpool_Department_of_Public_Helath_and_Policy.pdf

- Are patients given an option of where to be transferred to, or other options about their referral, e.g. dates or times of appointments?

2. To what extent do patients who have been referred several times for a single issue deem that their referrals were necessary?
    - Have they pushed for referral themselves?
    - Have they been given any indication they may have been referred for a non-medical reason, e.g. lack of capacity?

3. What is the impact of being referred, particularly if the patient has already been referred many times for a single condition (including time off work, delays with treatment, missed appointments, emotional impact, e.g. worry and/or stress, or relief?)

4. What are patients' views on referral more generally, including their awareness and understanding of unnecessary referrals or those resulting from defensive practice?

    - What's the impact of this on patients' perceptions of healthcare professionals and the wider NHS?

5. What is the impact of multiple referrals on groups who are more likely to be adversely affected, e.g. disabled or elderly people?
    - What are the specific challenges/impacts on these groups?
    - Which groups are at greatest risk of negative impacts?

This research was designed to explore the experience and perception of referrals in the eyes of patients: what are their perceptions of necessary or unnecessary referrals and their wider experience of the health system when being referred. Within this, the research also explored patients' expectations of diagnosis and treatment.

In May 2019, Trajectory were commissioned to carry out this research with patients for the GMC.

3. Research Method

The approach used was principally qualitative because this lends itself best to exploring patient experiences and views. However, we also included an early quantitative stage for two reasons.

Although there is a robust measure of overall public satisfaction and dissatisfaction with the NHS, there is no equivalent measure of satisfaction or dissatisfaction with referrals or the proportion of people who believe that their referral was unnecessary. We know from the literature that there are over 21m first outpatient appointments each year in England alone, but we had no insight into patients' experience of these (or indeed other types of referrals to healthcare professionals) or if different types of patients were more likely to be dissatisfied than others.

A quantitative stage was included to give insight into the scale of unnecessary referrals and identify whether some groups of patients were more affected than others. Secondly, the data from the quantitative stage would provide data to inform the sampling approach for the qualitative research.

Summary of research approach

1. A **quantitative online survey of 527** patients

A five minute, 15 question survey (see Appendix 1) was designed to identify individuals who had experienced a referral in the previous two years (this was deemed to be a period over which respondents would have good recall of what happened).

The survey had three main objectives:

- Understand the scale of unnecessary referrals in the eyes of patients
- Understand the wider experiences of patients when being referred
- Provide contacts for recruitment into the qualitative phase (by asking respondents if they'd be willing to take part in the second stage of the research)

A 'permission to recontact' question was included so that we could identify individuals who indicated that they had experienced a dissatisfactory or

unnecessary referral and could screen them later to see if they were suitable to be interviewed for the qualitative stage of the research.

Data were collected between 24th and 28th May 2019.

2. **35 qualitative in-depth interviews with patients across the UK**

The qualitative phase involved face to face and telephone interviews with both:

- Patients who were dissatisfied with their referral experience, or who believe they had experienced an unnecessary referral. There were 25 in-depth interviews with these patients and all interviews took place face to face, usually in the participant's home.
- Patients who were satisfied with their referral experience. There were ten in-depth interviews with these patients, all taking place by phone.

Sample Frame

Using the results of the online survey, a sample frame for the in-depth interviews was drawn up to explore the research questions over a broad range of patients. As we were unable to recruit the necessary numbers for some sub-groups in the sample frame, we used free-find techniques to identify these individuals.

The sample frame was not designed to reflect the population. We weighted the sample towards those that felt their referral was unnecessary, or were dissatisfied with their experience as we felt these experiences would provide us with more insight into the challenges placed on the system by changes to referral practice.

We also built the sample so that there was a range of ages, an even break of men and women, good representation of patients from different ethnic backgrounds and those with a long-term impairment or disability. Potential interviewees were then screened to ensure that that they met the recruitment criteria for the study before they were invited to take part.

Interviews were clustered whenever possible. Interviews took place in inner and outer Cardiff, Edinburgh, Belfast and London areas as well as Coventry, Preston, Dorchester, Southampton, Mid-Wales, Northumberland and Colchester. This spread included urban, rural and semi-rural settings and with interviewees that had attended referrals in large university teaching hospitals though to local outreach clinics in small towns.

Discussion Guide

The discussion guide was designed with feedback and input from GMC staff to explore:

1. The interviewees' background (age, living and working situation, interests and hobbies, general health)
2. A brief medical history
3. An in-depth exploration of the condition that had led to a referral, what had happened at each stage of that journey and their satisfaction and dissatisfaction at each stage
4. Their views on the referral experience overall
5. Their views on what might be done to improve referrals

Table: Breakdown of sample

	Number
Gender	
Male	18
Female	17
Total	**35**
Age	
Under 18	1
18 to 34	7
35 to 54	17
55 to 69	8
Over 70	2
Total	**35**
With a disability/Long term chronic condition	9
Ethnicity	
Black	1
Asian	3
White	29
Mixed race	2
	35
Location	
Scotland	6
Northern Ireland	5
Wales	5
England	
North East/West	4
Midlands (Incl. East of England)	3
South	2

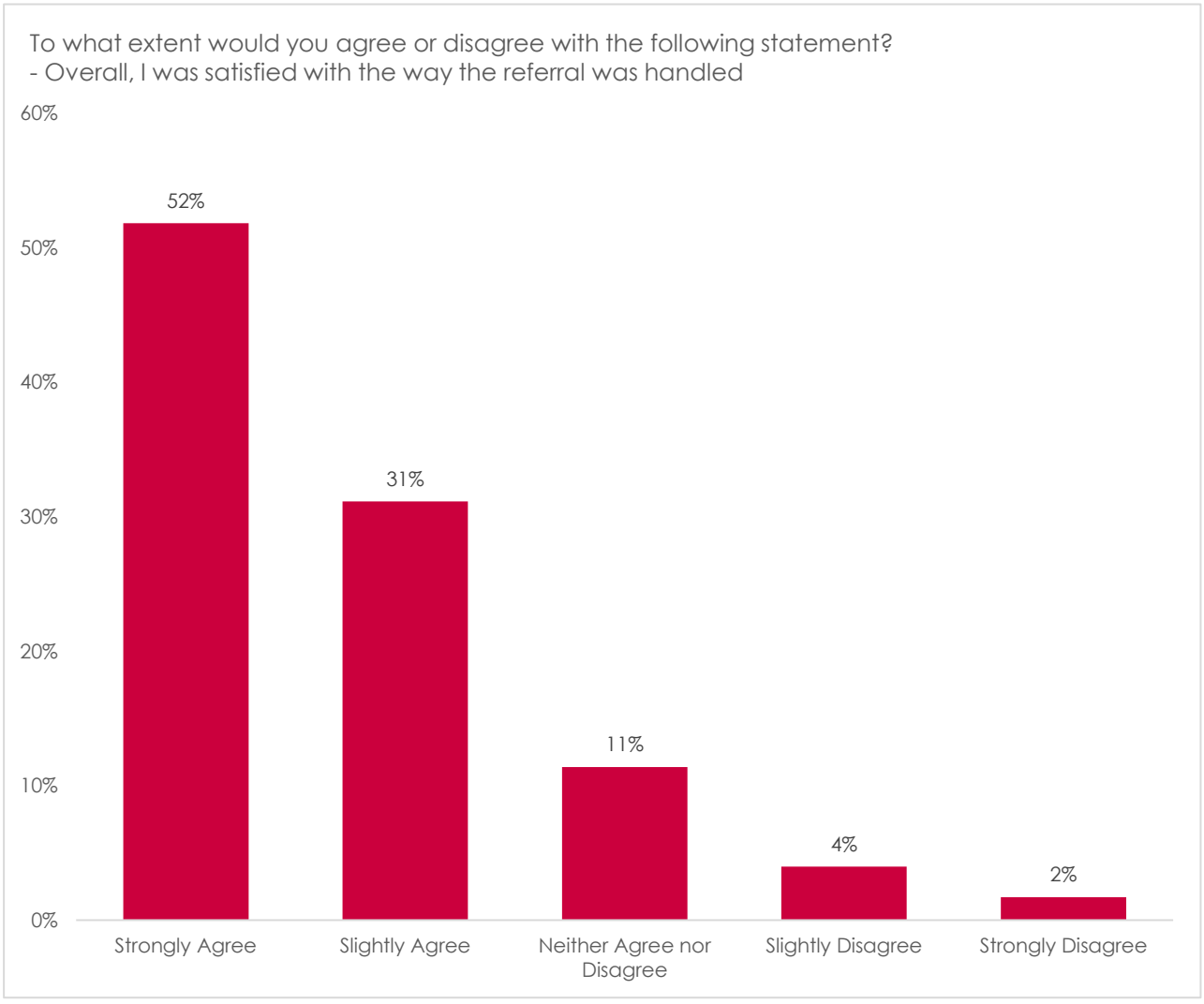
South East (Inc. London)	7
South West	3
Total	**35**

4. Key Findings from the Quantitative Research

The majority of patients are satisfied

A large majority of patients (83%) were satisfied with the way their referral was handled – only 6% express dissatisfaction. Similarly, only a small number (10%) felt their referral was unnecessary.

Chart: Satisfaction with referral



Base: 527 (all respondents)

Interestingly, there is very little overlap between the 6% who are dissatisfied and those who feel their referral was unnecessary. Only 8% of those who felt their referral was unnecessary (less than 1% of patients overall) were dissatisfied with it; the overwhelming majority are happy with their experience, despite perceiving their referral to be unnecessary. Overall, 15% of patients had a

problematic referral; that is, they were either dissatisfied with the experience or felt it was unnecessary.

Satisfaction and perceptions of how necessary the referral was varied slightly by patient type.

- Younger patients were more likely to think their referral was unnecessary or were dissatisfied with it (25% of 18-24s and 20% of 25-34s, compared to 12% of 55-64s and 8% of 65+)[10]
- Men were slightly more likely to be dissatisfied or think their referral was unnecessary (18%, compared to 14% of women)[11]
- Non-white patients were more likely to be dissatisfied or think their referral was unnecessary (25%, compared to 14% of white patients)[12]

GPs make the most referrals

Unsurprisingly, the quantitative survey found that the most common source of referrals are GPs. As the gatekeepers of the system they are typically the first port of call for patients.

Nearly three-quarters (72%) of patients said their most recent referral was made by a GP. By contrast, 18% of referrals were made by specialist doctors, 2% by A&E doctors and 7% by another healthcare professional.

That GPs make the most referrals also means they are the most likely to be perceived to have made unnecessary referrals. Two-thirds (66%) of unnecessary referrals came from GPs.

Views on their experience – positive sentiments

The majority of patients in the online survey reported positively about their referral experience.

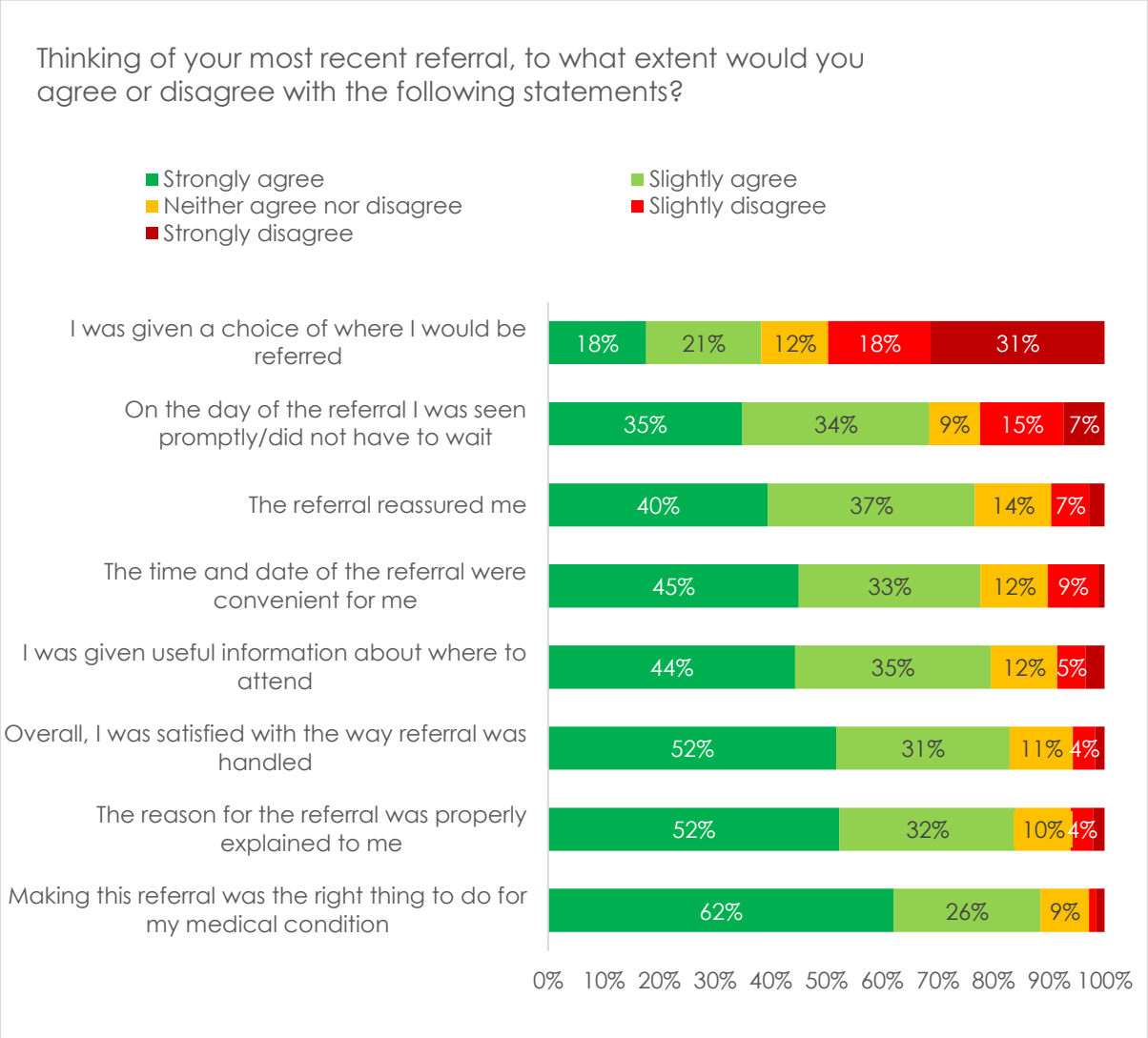
- 88% agreed that making the referral was the right thing to do for their medical condition
- 84% agreed that the reason for the referral was properly explained
- 80% said they were given useful information about where to attend

[10] Base: 18-24= 36, 25-34=92, 35-44=100, 45-54=94, 55-64=103, 65+=102

[11] Base: Men=194, Women=333

[12] Base: White = 464, Non-white=63

Chart: Views on referral – positive statements



Base: 527 (all respondents)

However, the minority (15%, or 79 respondents of the total 527) who had a 'problematic' referral of some kind (either they felt the referral was unnecessary or were dissatisfied with it) are consistently less likely to agree with these statements.

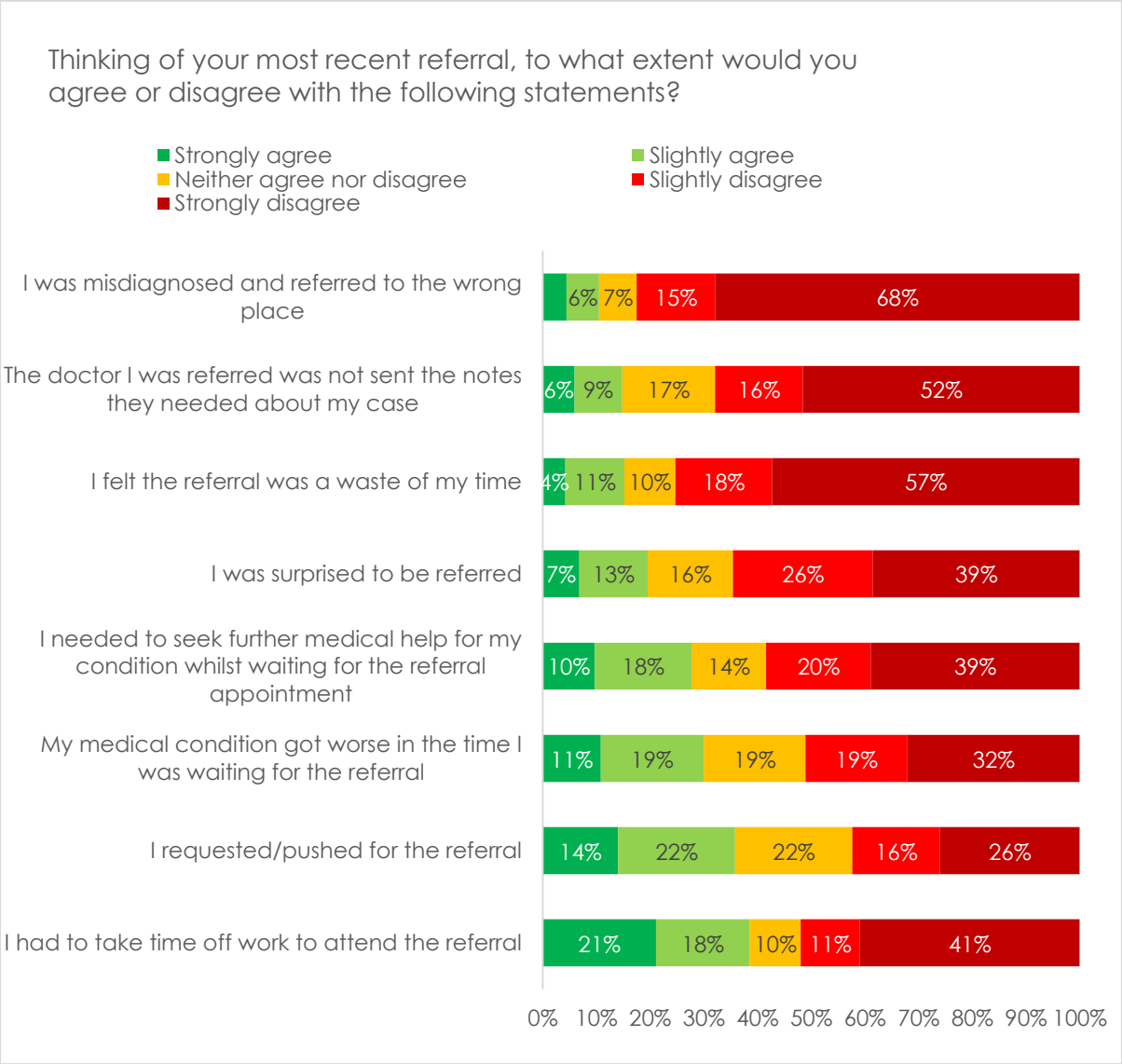
For example, only 66% agree that the reason for the referral was properly explained to them (compared to 84% of the total sample) and only 51% were reassured by the referral (compared to 81% of the total sample).

Views on their experience – negative sentiments

In keeping with the generally positive experience most patients had, only a minority identified concerns about their referral experience. These concerns were varied, including:

- 39% who said they had to take time off work to attend the referral appointment
- 36% of respondents who said they needed to push for/request the referral
- 30% of respondents who said their medical condition deteriorated while waiting for the referral appointment

Chart: Views on referral – negative statements



Base: 527 (all respondents)

As with positive sentiments, the minority with problematic experiences report differently to the overall sample, which is dominated by those that are satisfied with their referral and believe it was necessary. Here, for example: those that were either dissatisfied with their referral or perceive it to have been unnecessary are more likely to:

- Agree that the doctor they were referred to was not sent the notes they needed about their case – 34% of those with a 'problematic' referral agree with this, compared with 15% of all patients
- Have pushed for, or requested, the referral themselves – 52% agree with this, compared to 36% of respondents overall

5. Key findings from the Qualitative Research

Summary of Key Findings

Across the 35 qualitative in-depth interviews we encountered a wide array of experiences – including positive and negative, problematic and straightforward. Generally, patients who were satisfied with their referral experienced the health service differently to those that were unsatisfied, although there were some common themes in both groups.

A key difference is **whether the practicalities of the referral worked** or not. Typically, satisfied interviewees did not experience postponed or cancelled referral appointments and their notes did not get lost. Generally – and unlike the unsatisfied group – the basic logistics of the referral worked: they saw the right person at the right time.

Another notable difference in experiences is patients' views on the **quality of their interaction with the doctors they see**. For example, communication or sometimes, interpersonal issues, were a frequent concern of patients who were unsatisfied with their experience. Often, dissatisfied patients would complain about the manner with which they were spoken to, indicating that they felt brushed off, or not listened to. Although not all satisfied patients were completely happy with all doctors they had seen they generally felt listened to.

Additionally, patients who are satisfied with their experience are also likely to be positive about **the quality of communication and explanation about the referral process**. Unsatisfied patients were often bewildered by the process or unsure about what each appointment was for. This was much less likely to be the case for satisfied patients, many of whom knew exactly what their next appointment was for and who it was with.

However, in some areas, both satisfied and dissatisfied patients expressed very similar points of view. One such area is the **firm belief in and support for the NHS and doctors in general**. Support for the NHS is very strong and patients are sympathetic to the challenges that those working in it face. They are generally reluctant to criticise the institution or individual doctors.

Despite this, **the speed of referrals was a common criticism** from both satisfied and dissatisfied patients. While some satisfied patients accepted a wait of several weeks others wished it could be quicker. In this respect they voiced similar concerns to dissatisfied patients, although the latter group were also more likely to be encumbered by other process issues and disruptions (e.g. lost notes).

Very **few patients perceived their referral to have been unnecessary**; for the most part, patients were happy to take the recommendation of doctors. However, where patients did feel their referral had been unnecessary it often overlapped with other complaints, such as not feeling listened to in the initial appointment (and being referred without proper examination) or not feeling the purpose of the referral had been communicated clearly enough.

The referral journey

For most, despite having different conditions and needs – and ultimately, different perspectives on their referral experience – most patients' journeys through the health service followed the same pattern:

1. A GP appointment (or in some cases, a referral from another doctor)
2. A wait between this appointment and the referral appointment
3. The referral appointment itself

1. The initial appointment

For most patients in the qualitative research, their referral journey started with a GP appointment. For satisfied patients, this was usually very straightforward – this group often commented positively on the experience, the explanation given by the GP and the manner in which the appointment was conducted; they typically felt listened to and that they had had sufficient time to discuss their condition or symptoms.

For dissatisfied patients, their GP appointment could be more problematic. For several respondents, the issues began before the appointment itself as they needed to wait either several weeks or months to get an appointment, others struggled to see the same GP as previously, and felt their continuity of care was affected as a result.

When the appointment was made, complaints from this group of dissatisfied patients centred on two themes:

- The brevity of the appointment – not having enough time to discuss things in detail
- The quality of interaction between doctor and patient – some dissatisfied patients do not feel 'listened to', and some feel dismissed

The combination of these can lead to patients being referred when they feel they don't need to be, and not getting a referral when they want one.

Appointment length

Patients are aware of and sympathetic about the time pressures their GPs are under and the difficulty of trying to have a thorough discussion in their short appointment. Some interviewees are full of praise for their GPs who do provide empathetic care despite time constraints and pressures.

In most cases, satisfied patients had no complaints about the length of time they had with the GP. Among dissatisfied patients, however, not having enough time to fully discuss their condition or symptoms is a key factor in their experience. For some, this leads to a quick referral when they consider there is more the GP could have done.

Some patients were unhappy that doctors referred them on rather than dealing with the issue themselves. Examples included dietary advice for diabetes, exercises for an injured knee, what to do while waiting to see consultant or specialist, providing more information about an illness or condition. This dissatisfaction is exacerbated when the wait time for a referral is very long.

> "*I went in wanting information not a referral*" - Male, 57, London (dissatisfied patient)

> "*No 'come back and see me in the meantime'…it was 'go away and wait' …He was very matter of fact. He offered no words of advice, support or encouragement to come in again. I was disappointed. I expected that he would have counselled or said come back in*" - Woman, 50s, South West (mum of self-harming teen, dissatisfied patient)

> "*He doesn't talk to you, just refers you. Didn't examine [my arm] just referred me.*" - Female, 65, London (dissatisfied patient)

In other cases, patients perceive that the lack of time in appointments contributes to not getting the referral they would want.

> "*I knew they [GP] were going to send me away. He didn't believe me. I'd had lumps on my neck but they had gone*" - Female, 43, London (dissatisfied patient)

In some cases, patients who wanted a referral – but did not get one the first time they visited the GP – made subsequent appointments in order to push for one.

> "*This time, we only got the referral because my daughter was there, was pushing for it, saying 'look, she's lost three stone, this isn't right'*" - Female, 65, London (dissatisfied patient)

Some respondents felt that the delay in getting a referral had serious consequences for their condition – there were two patients in our sample who had suffered significant hearing loss while their GPs treated them for wax build up and possible ear infections.

Doctor-patient interactions

Satisfied patients are generally happy with the discussions they have with their GPs and report positively about them.

Dissatisfied respondents, however, were more likely to report challenges with interpersonal communication and interaction, for example feeling that the GP was abrupt, brusque, didn't look them in the eye and typed throughout the consultation.

Not being listened to properly and taken seriously was often the most frequent source of dissatisfaction when a patient thought they needed a referral. This was particularly common among female patients, who were more likely to say doctors were rude and they often felt talked down to, disbelieved, made to feel stupid or dismissed by doctors.

> "*He made me feel like I was making it up. The way he spoke to me was horrible. I'd tell him a symptom and he'd screw his face up.*" - Female, 28, Northern Ireland (dissatisfied patient)
>
> "*He [GP] dismissed the diagnosis [from a large teaching hospital].*" - Female, 38, Dorset (dissatisfied patient)

One interviewee was the mother of a teenager with mental health problems. Although she understood perfectly the need for patient confidentiality (she worked in the NHS herself), she believed that it was unsatisfactory that as a parent of a teenager (her daughter was 15 when first referred), she had no communication or involvement with her daughter's treatment or even feedback on progress.

Case Study: dissatisfaction with quality of interaction

Megan is a schoolteacher in her 50s and lives in Wales. For eight months she has suffered from steadily increasing and now excruciating pain in her groin.

After three visits to her GP she was given a referral to see a consultant. She was disappointed with the consultant visit. He did not introduce himself, told her to take her trousers down, felt her groin - said he had no idea what it was, but he was only a general consultant and that she had better have a scan. He left the room before even saying what sort of scan she would be having.

She was with him for 90 seconds. The nurse had to tell her she was free to go.

The scan results were meant to be back after two weeks but she did not hear anything from the hospital, so she went back to see her GP who managed to access the scan results. The results indicated a tumour on her appendix and she now has a consultant appointment to discuss this further.

A&E referrals

In contrast to some patients' experience of GP referrals, respondents were generally very satisfied with the treatment they received in A&E. A few reported that when they presented to A&E with a condition for which they were waiting for a referral, their A&E attendance fast tracked an appointment.

> *"He [A&E doctor] said 'has anyone ever mentioned mitochondrial disease? You fit the criteria. Did your neurologist mention it? It's flagged on your notes."* – Woman, 28, Northern Ireland (dissatisfied patient)

Those that went to A&E often got a diagnosis faster than the GP route – from a patient perspective it was because the doctors listened to them, read their case notes and diagnostic tests were done there and then.

However, not all patients who presented at A&E were positive about their experience. Two patients who, overall, were satisfied with their referral were unhappy with the treatment at A&E. One (outlined in the case study below) believes the lack of referral at A&E led to a misdiagnosis.

Case Study: A&E Referral

Tim is the director of a charity and lives in Wales. Working at home on the laptop one evening his fingers on one hand suddenly felt very strange – he rested a moment and then tried again, but the same thing happened. Later that evening he had a seizure which lasted about 30 minutes – when he came round, his wife had called the paramedics and he was being taken to hospital.

At the local A&E he was initially misdiagnosed. The first consultant who examined him diagnosed a fit, despite the fact Tim was having a focal seizure while being examined. He was discharged but he and his wife were convinced something neurological was going on, so they insisted on a scan.

"While the A&E doctor was assessing me, I was having a focal seizure. He was assessing me while it was happening… he just dismissed me and sent me home."

Eventually A&E relented and send him for a scan, which showed a large, growing mass in his brain. He was told it was possibly a tumour and he would be referred to a specialist unit at Stoke.

On arrival at Stoke he was told to disregard everything he had been told at the previous hospital. They rescanned and diagnosed a cyst, rather than a tumour, which was aspirated. After a long period of follow up care Tim is getting better, but long term issues with dexterity and mobility remain, which Tim believes could have been avoided if he had been diagnosed more quickly.

"Overall, looking at the care I've had from the NHS, I am pleased. I'm not dead!... Once I'd got into the right place and had the right diagnostic tests it was all really really good."

Ultimately, there aspects of Tim's care that he is very unhappy with. However, the referral worked well – it got him into the right hands and led to the right diagnosis.

2. Between appointments

An inevitable part of the referral experience is a period of time between the first doctor making the referral and the referral appointment itself.

For satisfied respondents, this process was typically uncomplicated. They knew when and where the referral appointment would take place, when they would be notified of the appointment and what the referral appointment would be for. As the quantitative research suggests, the majority of patients are satisfied with their experience and are likely to have experienced a process that, in terms of the logistics, worked well.

For other patients, the period between appointments could be a source of dissatisfaction. This was typically the result of one (or more) of four factors:

- The referral not happening quickly enough
- Lack of choice on when and where the referral takes place
- The patient not feeling they had enough information on what the next steps would be
- The referral being disrupted in some way – for example, through the referral getting 'lost' in the system

Time between appointments

Many satisfied respondents are pleased (and sometimes pleasantly surprised) by how quickly the referral appointment takes place. For example, one

interviewee was very pleased to be put on a two-week pathway that ensured she was seen by the consultant just a couple of weeks later.

Case Study: Satisfied with speed of referral

Fiona has two children and lives in Norfolk. In 2017 she found a lump in her breast and went to see her GP. The GP told her it was just a cyst, and nothing to worry about.

At the start of 2019 (two years after the first GP appointment) she felt increasing pain coming from the same place and became anxious. She went to a new GP (as she had moved in the last year) who told her it was probably a cyst but made a referral so she could have further checks. She was referred to the breast cancer clinic at the local hospital on a two-week pathway.

"*There's a two week pathway if they think it might be breast cancer, which is really good…*"

She was very pleased by how quickly she got the appointment, the quality of the interactions with the doctors at the hospital and the care she received. The consultant she saw was expecting her and she felt she had time to discuss the issue with him. He also arranged an ultrasound on the same day to confirm that it was a cyst. The examination and ultrasound were within three hours of each other – minimising the inconvenience.

"*Initial consultant did an examination and said he didn't think there was anything there, but arranged an ultrasound as well… he said he could push for [the ultrasound] to be done today, to put my mind at rest.*"

Others, experienced longer waits but have either had their expectations managed by doctors or know from experience what to expect. For others, however, the possibility of a longer wait is a cause of dissatisfaction and even an impetus for patients to look at alternative options. Dissatisfaction with the time between appointments is a criticism of both satisfied and dissatisfied patients.

Examples include:

- A patient arranging a private chiropractor appointment after being warned of a six-week wait for physio on her knee
- The mother of a daughter who fainted on the tube arranged a private consultation after GP said it might take two months to arrange a specialist appointment

- A woman who suspected her new medication was causing severe headaches, so arranged a consultation with a specialist through a personal connection

Patients were often sympathetic regarding delays between appointments. For many, it met their expectations of a health service under strain.

> *"All the appointments are very far apart – it seems it's OK, normal. I don't understand it. Everything seems so slow"* - Female, 43, London (dissatisfied patient)

Other patients experienced a delay in hearing from the hospital or healthcare provider after a referral was made. They often expect the system to be slow so allow for a long wait. When the delay is prolonged and the patient eventually chases it and sometimes discovers that the referral hasn't been received or is 'lost in the system' they frequently blame themselves for not following it up earlier.

> *"I chased up after six months of nothing. They (Child and Adolescent Mental Health Services) had lost the referral. We then waited three months for an appointment for triage…I blame myself, I should have chased earlier."* - Female, 50s, Dorset (mother of a teen, dissatisfied patient)

> *"I know that they're a busy practice. I don't want the GP running around to cover my arse. They've got sick people to deal with."* Male, 53, Scotland (dissatisfied patient)

Lack of choice of where and when referral takes place

The NHS Choice Framework outlines that patients have the right to choose where to go when referred to see a consultant or specialist.[13] Not all patients expected a choice of where the referral would take place and for many the appointment time and location they were given was suitable for them.

However, for some patients the lack of choice or flexibility around the timing and location of appointments caused inconvenience. For example:

- A patient in Wales who has had around 20 different hospital appointments and referrals since he fell and injured his head. Has never been offered any choice of appointment time. Quite often he has waited between one-two hours at the location of the referral for his appointments.

[13] https://www.gov.uk/government/publications/the-nhs-choice-framework/the-nhs-choice-framework-what-choices-are-available-to-me-in-the-nhs

- A teenager accessing mental health services had all her appointments and therapy sessions during school time. There appeared to be no attempt to schedule appointments after school or allowance made for her sitting GCSEs and A Levels. Her mother believed that having to excuse herself from class and telling the school why she needed to leave added to her anxieties.

There appeared to be more choice around services that were provided by allied healthcare professions such as physiotherapists or hearing assessments. Some interviewees were prepared to travel further to get an early appointment. Some services were offered on a walk-in basis – convenient to some but less convenient to those with mobility problems or dependent on public transport.

Patients having information about the process

Patients having a clear idea about the referral process – including how long it would take to get the referral appointment – appeared to affect their overall experience of the process and the time between appointments.

For example, one patient in Edinburgh who has multiple health conditions, including reflux, has been to see his GP regularly over the last five years. The appointments can sometimes result in a referral for a nasal endoscopy, and the patient knows what to expect.

> "*Takes about 8 weeks for the letter to come through. Feels about average. It doesn't bother me.*" – Male, 70s, Edinburgh (satisfied patient)

In this example the patient is informed more because of previous experience of referrals. In other cases, patients reported that their doctor had given them some indication of how long the referral would take, managing their expectations. Generally, satisfied patients had clarity about their referral journey – knowing when they would be seen, by who and what for.

Dissatisfied patients were less likely to feel they had clarity over the referral process, feeling that the referring doctor had not given them enough information about what the referral appointment would involve.

For example, some patients arrived at what they expected to be a consultant appointment to find that it was a screening appointment. These patients felt the referring doctor (in all cases, a GP) had not explained this clearly enough.

> *"I met a physio who further assessed me and said he'd refer me for physio. I explained that I thought this was a physio appointment. He said I had to be assessed by a physio for physio. I had to wait another*

five weeks for an appointment. I won't say it's a delaying tactic. It's like yeah, we've got him on the radar. I wasn't best pleased. It's only getting worse" - Male, 58, North West (dissatisfied patient)

Other patients described being confused by the process more generally – for example, one (satisfied) respondent from Northern Ireland was referred for a scan in a Bupa clinic – he had not requested a private consultation and was surprised to find himself there. Even for satisfied patients for whom the referral journey has generally worked well there are parts of the system that remain opaque.

System process and admin issues

Another common source of dissatisfaction was around patient notes – either getting lost or mixed up with another patient. These issues only affected dissatisfied patients; those satisfied with their referral typically experienced a process that worked smoothly.

Some participants were very dissatisfied that their notes, scan results or diagnostic results got lost or that information does not get shared effectively among healthcare professionals.

"One department doesn't seem to know what the other department is doing. They don't provide information back to your GP. But your GP tends to be your first point of contact. They need the information so that they can tell you."- Male, 57, Edinburgh (dissatisfied patient)

The effect of lost notes can be very distressing. Examples include:

- An interviewee who moved across the country but her notes did not transfer with her when she registered with a new GP. Without them, she reported that her new GP refused to believe her condition (osteoarthritis).
- Another patient was reluctant to change her physiotherapy treatment to a hospital nearer to home because the further hospital seemed more organised and her local hospital had lost her referral previously
- One interviewee believed that confusion over her notes and hospital records compounded by doctors not listening and dismissing her, resulted in an unnecessary surgical procedure.

"I was miffed……. I try not to get cross. They don't have a lot of time. It's frustrating. I'm going around in circles" – Female, 38, South West (dissatisfied patient)

Case Study: System Process and Admin Issues

Ann is in her 60s and was working full time before she had to retire on the grounds of being unfit for work post-surgery. In late 2013 she had a hysterectomy and expected to be off work for three months.

Two months after surgery she asked her GP to refer her back to the surgeon due to continued pain. He thought it was unnecessary and referred her to physiotherapy. After ten sessions she was referred to a Senior Physiotherapist who concluded that physiotherapy was exacerbating the pain and that Ann should be referred back to the gynaecologist.

Ann's GP referred her for an MRI scan on her lower back. After a 14 week wait, the consultant said she had 'adhesions' and would need further surgery to release them. Ann was perplexed – no one had ever mentioned adhesions. She had no idea how this had been diagnosed. She discussed this with her GP who had no idea either. She eventually received a hospital letter with a date for surgery and the instruction to take the medication as discussed in the consultation. No medication had been prescribed or discussed in her consultation.

Ann suspected that there was a problem with her notes. She turned to her GP who advised her to either not attend or go for the surgery, speak to the consultant beforehand and phone the medical secretary about the medication mentioned in the letter. However, she made no headway doing this, and the surgery went ahead.

After surgery, the consultant came to speak to her. He said he was surprised that there weren't any serious adhesions but 'if you get anymore problems with your bowels, we'll get you referred for a colonoscopy'". Ann had never had a problem with her bowels.

Advised by her GP, Ann wrote to PALS. It transpired that Ann's hunch was right and there were three hospital numbers associated with Ann's records. She's had numerous referrals to pain clinics, scans and X rays but the cause of her pain hasn't been found.

She had to retire from the police force as she couldn't work in such pain and knew she would not pass the fitness test. She'd just been promoted and had loved her job.

3. The referral appointment

As shown by the quantitative research, the majority of patients are satisfied with the referral appointment itself. In the qualitative research, satisfied patients echoed this: they were generally seen promptly by the right people.

Among this group, there were no examples of notes getting lost or mixed up, or the referral doctor not expecting to see them. For most satisfied patients there was no surprise at this – it seemed unremarkable – this is how they expect the system to work.

Dissatisfied patients were more likely to encounter issues at the referral appointment itself. These could be:

- Long waiting times at the appointment, and feeling hurried in the appointment itself
- Doctor's acquaintance with the case not meeting their expectations
- Involvement of other healthcare professionals (for example, imaging technicians offering a diagnosis)
- Feeling the referral was unnecessary or a waste of time

Waiting times and duration of the appointment

Interviewees experiences were mixed. Sometimes things run on time, sometimes they run extremely late; some interviewees had experienced delays of up to three hours and some experienced hospital appointments that were very rushed. In some cases, patients felt they had experienced a 'rushed' appointment, after months of waiting.

Examples of this include:

- One interviewee who pushed her GP for a referral back to the consultant for post-operative acute pain. After a 14 week wait for an appointment and a two and half hour wait at the hospital she was "in and out in under three minutes". She was very dissatisfied that she was not examined or asked about the pain.
- One interviewee who felt that there was no time in the consultation to discuss the implications of surgery which would leave him unable to pursue his walking hobbies. He tried to question the consultant but felt the consultant "did not want to discuss it further" and he left the hospital. In the car park felt unhappy and tried to go back in but they would not see him.

> *"Nothing is properly explained – they should take time to explain even if you are referred to a nurse. Give people [information] sheets. Explain things better."* - Female, 30s, Dorset (dissatisfied patient)

In contrast, patients satisfied with their referral were unlikely to report these kinds of issues. In fact, several were pleased with the speed with which they were seen when they arrived for their appointment, and the flexibility shown by registrars when arranging multiple different appointments at the same hospital.

Doctor's acquaintance with the case

In the interviews with satisfied patients we did not encounter any examples of doctors not having read the notes or expecting to see the patient when they arrived. This is in line with broader expectations; once the referral is made, patients expect the referral doctor to be transferred the relevant information.

Among dissatisfied patients, however, many interviewees said that their notes were not read by doctors. They felt this was bad practice as it was a waste of time and resources.

Those referred from one speciality to another for the same condition were very frustrated having to 'start all over again' with each person. For them it seemed that no one was reading their notes to see what the issue was and what had happened before.

> *"They ask the same questions over and over again. They don't care … they don't check what I've had done. Repeating tests…I'm fed up with telling every doctor from the very beginning. If they read the notes it would be there in black and white. Can they not see all that in their systems and notes?"* - Female, 28, Northern Ireland (dissatisfied patient)

Although medical practitioners might have good reason for asking patients about their case history and symptoms as different practitioners are looking for different things, patients do not always feel this is explained clearly. Without this explanation, patients see it as wasteful and evidence that the system is not linked up.

Understanding and appreciation of other professional's roles

In some cases, patients encountered more than one doctor or healthcare professional during their referral appointment(s). Patients do not always understand what these professions or roles are and/or have a perception that they are doing something that their own doctor should be able to cover (for example, specialist dietary advice, physiotherapy, psychologists).

> *"Surely my doctor, having taken an examination, is good enough. He's sent me for X Rays, he's got all the evidence to decide if I need physio. I don't know if he's qualified to say 'here is some exercises to do while you're waiting'. He has to wait for the physio to say 'here's some exercises"* - Male, 58, North West (dissatisfied patient)

Nonetheless, we found evidence of some patients being very positive with the treatment they received from other healthcare professionals (even if they were unsure about their role).

> *"I didn't have much expectation from [a mental health support worker] but she was brilliant." - Female*, 50s, South West (dissatisfied patient)

One interview was distressed and shocked after a hearing test carried out by a technician. He told her that she had severe hearing loss diagnosis and would need hearing aids. She had lots of questions that he could not answer

> *"I was hit with big news. He had no bedside manner. There was no support offered…. I had to go to the internet to seek out information."* Female, 20s, Lancashire (dissatisfied patient)

Feeling the referral was unnecessary

According to our quantitative research, only 10% of patients who received at least one referral deemed at least one of them to be unnecessary. Qualitative exploration has shed some light on why this might be. Patients tend to be deferential to the decisions of their doctor – if their GP thinks it is worth a referral, they are unlikely to disagree – and typically adopt a better 'safe than sorry' approach.

However, some patients do feel their referral is either unnecessary or inappropriate. This can be a source of immense frustration. For example, one interview received a letter for an appointment with a consultant that she did not think her GP had mentioned. Because the reason for the referral had not been made clear she decided not to attend. Other patients wanted to be referred back to their original surgeon or consultant but instead were referred to physiotherapy and pain clinics.

Referrals that are not properly explained to patients result in them judging them as unnecessary. This also causes huge frustration, dissatisfaction, a belief that doctors are not listening or a sense of impotence when the patient has a clear idea of what they want or need.

Additionally, patients can be frustrated when a problem is picked up by a healthcare specialist but the patient has to go back to their GP for a hospital referral. Equally, patients are frustrated when they have a reoccurrence of a

problem but had to start the process all over again. In these circumstances they would like to take the GP out of the process to simplify things. This was a particular issue for patients with long term or chronic conditions; after several years, these individuals can feel like experts in their own condition (especially in how it affects them) and would like to go directly to the specialist for consultation.

Case Study: Unnecessary Referral

Jim is in his 70s and lives on his own in Edinburgh. He needed a scan on his lungs, following sore throat and was referred to his GP local hospital for a scan. He then met a specialist at another hospital in Edinburgh who examined him using a tube/camera up his nose.

Jim was then sent to Ear Nose and Throat department at St John's hospital in Livingston. He wasn't entirely sure why he was going but expected a biopsy, because was told that he shouldn't eat for several hours beforehand. The hospital is two bus journeys' away. He phoned the department to say that he wouldn't be able to get there in time for the morning clinic; and they suggested that he come and stay in a bed the night before.

He made the two-bus journey and stayed the night. He stopped eating, as instructed. After two hours, he spoke to a nurse, thinking maybe he'd been forgotten. The nurse checked and said: there's been a change of plan; you're not going to the theatre; you might as well put your clothes back on; the theatre administrator and doctor will come to speak to you.

He waited another two hours. The administrator and doctor came and said he couldn't go into theatre because of his COPD/breathing difficulties. They had only realised this just before he was due to go into theatre. But he would have hoped that they would look at his records in advance and know about his medical condition.

Impact of the referral experience

The qualitative research also found that outside of specific touchpoints with the health system, patients' experiences of referrals can affect their lives and views of the NHS more widely.

Practical implications of problematic referrals

Interviewees were asked about more practical and financial impacts of any referrals that they might have found unnecessary or dissatisfactory. Apart from elderly people or people with mobility problems who find it transport or walking challenging, the practical, time and cost implications of referrals are almost accepted as a given.

Some patients mentioned the downside of having to take time off work or take annual leave to attend appointments. Because of long waiting times at appointments, people are unable to make up the time so have to book leave to attend.

> *"I've had to take lots of time off work. Probably 15 days of holiday"* - Female, 28, Northern Ireland (dissatisfied patient)

Undermining trust in the NHS

Belief in the NHS runs deep. All the patients that we interviewed wanted to trust the NHS and particularly doctors and other healthcare professionals. But while most retain a broadly positive view, negative experiences can dent this trust.

> *"It made me not want to go back. It makes you not want to go to the doctors if all they do is give you pain relief. It would have to be something seriously wrong before I'd consider the GP"* - Male, 40s, Northern Ireland (dissatisfied patient)

> *"I held the NHS in high regard but I've met incredible arrogance by male consultants. They've belittled and been dismissive of the research I showed them. It was peer reviewed by the BMJ not a page of Women's Own!"* - Female, 45, South (dissatisfied patient)

Seeking resolution outside the NHS

Patients that feel in some way let down or frustrated by the system can occasionally take matters into their own hands. This can involve using the internet to research symptoms or conditions, opting for private scans or appointments, or in a handful of cases, making a complaint. Very few

interviewees mentioned using the internet and where it had been used interviewees were very clear of the downsides of using it. Some interviewees said they tried to steer clear of the internet as it fuels anxiety preferring to see to a doctor. It was often the 'physician of last resort' when they can't get a diagnosis, treatment isn't working or if there is an information gap post diagnosis.

> *"I had to go to the internet to get information but Doctor Google is not the best idea. I wanted to speak to someone knowledgeable"* - Female, 28, North West (dissatisfied patient)

As mentioned earlier, private healthcare was considered by a small number of people experiencing long waiting times in both the satisfied and dissatisfied groups.

> *"My Dad said to the neurologist, can we go private and do this? He (the consultant) wasn't too happy about that."* - Female, 20s, Northern Ireland (dissatisfied patient)

Case Study: seeking resolution outside the NHS

Amal works for a human rights charity. On a recent trip to Spain she hurt her knee while exercising. When she returned home she was still in pain so went to see her local hospital which sent her home with painkillers.

Two weeks later she was still in pain so went to her GP, who referred her to a physio but warned it could take six weeks for the appointment to come through. Dismayed by the waiting time, Amal booked a private chiropractor – however, this session made her knee much worse, setting back her recovery.

Amal blames herself for this, saying she 'did a stupid thing' by disrupting the process and going to a private chiropractor. Having been able to gingerly walk before this appointment she was back on crutches and painkillers afterwards.

The physio (referred by GP) started about ten weeks after the GP appointment and about three months after the initial injury. It is going well; her knee is back to about 80% fitness. Logistically the physio is working well too – it is convenient for her to attend (she is senior at work so can arrange appointments around it).

Overall, she is happy with her treatment if frustrated with both the speed of the NHS referral and her own decision to book a private chiropractor.

Although some patients sought resolution outside the NHS, most were very reluctant to complain – even when they received treatment that was

dissatisfactory and fell far short of the expected standard of care. When things have gone very wrong, often all they want is for their situation to be resolved. They also want the system to be changed so that other people don't have to experience what they did.

Some disgruntled interviewees experienced what they saw as 'back covering' and a reluctance to criticise other medical colleagues.

> *"It worries me that if I have a problem it will take a long time to get sorted. If you don't trust it you end up going for private health. 'Your health is your wealth'. But plenty of people can't do that."* - Male, 29, Northern Ireland (dissatisfied patient)

Improvements that all interviewees would like to see

Interviewees were also asked what improvements they would like to see in the way referrals are handled. Many of their answers are antidotes to the issues illustrated above. They include:

- **Communication**: better communication between different parts of the NHS; doctors listening to patients better
- **Treating patients as people and equals**: understanding that a minor medical problem is having huge effects on a person's life; doctors displaying more empathy; doctors showing more compassion and understanding; doctors believing patients; honesty; not talking down to patients; not being defensive
- **Clarity about the referral process and reason**: more explanation about the referral process and timings; what to expect; how diagnosis works; more explanations about scans and tests
- **Doctors being able to refer directly when a condition reoccurs**: some patients are frustrated when the GP is brought back into the process – they would like to be referred directly, without GP involvement.
- **Consistency of care**: seeing the same doctor; not being bounced around the system
- **Notes**: more accurate note taking; doctors reading notes; patients not having to start all over again with every doctor they encounter
- **Appointments**: longer appointments; appointments running to time; appointments in the early morning, evenings and weekends;
- **A holistic approach**: treating patients as a whole person not a series of different conditions; treating the cause and not just the symptoms; having an independent medically trained case manager who reviews the situation when a patient is going around the system;
- **Speed**: Above and beyond everything was the speed of the referral process. Patients would like the whole system to work faster than it does

The majority of the interviews in the fieldwork focussed on the minority experience – patients who were dissatisfied with their referral experience. However, many of the same issues – particularly around the speed of the service – were echoed by those patients who were satisfied with their experience.

From the patient perspective the current referral process is often very slow and inefficient. They also recognise that in addition to inconveniencing them, this inefficiency creates a cost to the NHS. For patients there is a cost too – time off work, using large amounts of annual leave, loss of income, loss of lifestyle, negative impact on mental health and wellbeing, effect on family life and relationships, living with pain and a loss of trust in the NHS and doctors.

How doctors speak to and behave with patients has a huge bearing on patient satisfaction. A good approach can change how a patient perceives an unsatisfactory outcome of a referral.

6. Conclusions

The scale of dissatisfactory and unnecessary referrals

This research has been exploratory: designed to understand in more detail the range and breadth of patient experiences of the referral process. However, our online study gives us some indication of the scale of unnecessary or unsatisfactory referrals.

The online survey carried out for this study suggests that a minority of patients (c10%) thought their referral was unnecessary, around one in five (20%) were surprised to be referred and around 6% were dissatisfied with their referral. This insight suggests that in the context of the millions of referrals[14] that take place within the NHS each year only a small minority (6%) are dissatisfied with their referral and only 10% think their referral was unnecessary.

But even relatively small percentages of unnecessary appointments (though it is important to note this is from a patient not clinical perspective) translate into a significant volume for the NHS and its staff when dealing with millions of patients. If, for example, doctors' workloads could be alleviated by anything like a corresponding 10% (the percentage of respondents who thought that their referral was unnecessary), this might be a significant improvement in their working lives as well as save money.

Role of the modern GP vs expectations

Patients have high expectations of the standards of care and the breadth of service they expect from their GP. This may be unrealistic and the patient expectation of their GP as their all-round healthcare provider or omnipotent physician does not reflect the reality of the modern GP's role or NHS commissioning.

However, the perception applies to both satisfied and unsatisfied patients. In the satisfied group, some patients were pleased with their referral because they felt it would progress them away from a GP that was not treating their concerns seriously enough, or with enough attention, while others observed a change in the nature of GP consultations over the decades.

[14] In England alone there are 1.3m completed pathways for consultant led treatment per month (c60,000 per working day) and a waiting list of 4.34m in March 2019 (House of Commons Library. Briefing Paper, No 7281. May 2019. NHS Key Statistics. May 2019) found at https://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7281#fullreport

Some of the patients interviewed thought that their GP should have been able to offer more advice, be able to diagnose and manage the condition themselves and provide more support for them and the condition they presented. There was little awareness that modern medicine is highly specialised and it is entirely appropriate for a GP to act as a gatekeeper that refers patients on to other healthcare professionals. The way in which this is communicated can make patients experience an unsatisfactory appointment.

Minor problems, big effects

In this study, one of the loudest sources of dissatisfaction with referrals was from people with musculoskeletal problems, chronic pain, foot complaints, skin conditions and mobility problems.

Those with damaged knees, pulled tendons and bad backs often experienced long waits (months) for referrals to physiotherapy. Many thought physiotherapy was pointless (as they'd had it before) and were frustrated that they had to exhaust the physiotherapy route before they could be referred on for more diagnosis (often a scan) and see a specialist. This is even more the case when it is a reoccurring condition – these patients know what they want and want to fast track a slow referral system.

These are huge effects on people's mood, mental health, sleep, ability to work, exercise, relationships and quality of life. They are frustrated and dissatisfied that they have to jump through the different hoops of the referral process.

Feeling that they are bounced around the system from doctor to doctor looking for a diagnosis or appropriate treatment can often mean that the overall effect on the patient's life gets lost. They can perceive that the physician is looking at the condition not them as a person and the huge effect the problem is having on many aspects of their life.

Typically, but not universally, satisfied patients had experienced fewer disruptions of this nature. Where they had, they did not place the blame on the referral – they either accepted that this was how it was or, in one case, blamed themselves for arranging private chiropody while waiting for a physio referral appointment.

Practical impacts of problematic referrals

Older, disabled and less mobile patients found getting to appointments a struggle – particularly if this involved public transport. Often these patients were poorer and could not afford taxis.

However, overall, patients rarely dwelt on childcare, driving distances, parking fees, or the need to take a family member or friend with them as issues.

Referrals during working hours are problematic for working people and young people at school/college and especially for those who needed lots of referrals. Many interviewees talked about having to take time of work and use annual leave – and the impracticality of being able to make up time (as they could, for example, for a dental appointment) because waiting times mean that it took at least half a day. Working interviewees often mentioned that they'd welcome referrals available out of hours and on weekends.

Demise of the deferential patient

In other walks of life our interviewees are consumers. When acting as consumers they are confident, assertive and savvy. However, although there was some evidence of consumer-like behaviour in our interviewees' approach to doctors this was not the universal approach.

As patients, our interviewees were not consistently deferential – they frequently objected to the tone that doctors used with them and their comments about not feeling listened to could apply in any aspect of customer service. Patients have more choice in other areas of life, they expect more. They don't expect to be spoken down to, their views dismissed. Universally doctors were respected but patients do not expect to be deferential and they expect to be listened to and treated well.

This was particularly evident among younger and more educated or assertive patients in this sample – and particularly those who worked in public facing roles themselves. They expected more out of doctors who they were more like to see as equals.

However, two factors hold them back from truly acting as consumers in this area. One is the lack of expertise in medicine or diagnosis – they are reliant on the doctors they see or are referred to and their primary goal is to get a diagnosis or treatment, to get their life back on track or end their pain. Some interviewees defy this – patients who have lived with a chronic condition may

not be experts in the clinical science of the condition but are experts in how they feel with it and how it affects their life.

The second factor – already discussed in this report – is the firm belief in the NHS and the general high levels of trust in doctors. With some exceptions, interviewees were reluctant to criticise individuals and more likely to lay any blame at the door of the 'system'.

The myth of the litigious patient?

One of the reasons for this research was that there was evidence that doctors, and particularly GPs, were referring more because of increased concerns regarding medico-legal risks.

None of our interviewees talked about pursing a course of legal action. Indeed, they were highly unlikely to make a complaint against an individual doctor. Their primary objective is simply to get better.

Although interviewees had high expectations of professional behaviour and standards of care, they were reluctant to challenge or complain when it fell short. Some felt intimidated by doctors.

If doctors are referring more because they are worried about litigation and professional misconduct, there was no evidence of resorting to this course of action from our sample. Many respondents see doctors as human and trying to do their best under circumstances that they understand as challenging. They just want to be diagnosed and treated in a timely, effective and respectful way.

Patients can be satisfied regardless of outcome

Many of the dissatisfied patients felt mistakes had been made with their care that had – in their view – had long term consequences or led to poor outcomes. Many of the dissatisfied patients we spoke to had conditions that were unresolved. Some had conditions that would be life-changing; on a few occasions they attributed some of this to the nature of their care and the role of the referral specifically.

The same was true of satisfied patients; some had ongoing conditions that were easily managed, while others had had a referral that had resulted in no clinical diagnosis (e.g. a breast cancer exam that ruled out breast cancer). However, several participants in this sample did have significant, ongoing

conditions (e.g. cancer, neurological disorder), in a couple of cases ones that they attributed to the care they had received.

These patients are not satisfied with all aspects of their care – far from it. However, they are satisfied with their referral because this acted as a route out of the problematic area of the health service they were experiencing. In one case this is a GP that diagnosed hypothyroid for what turned out to be a brain tumour, and in another (at A&E) a cyst in the brain that was initially dismissed as a one-off fit. For these patients, the referral was positive because it progressed their treatment and led to a diagnosis.

Ultimately, the patients' perspective on their referral experience does not appear to be directly correlated with their health outcome.

Patient experience can depend on their individual expectations

Patients' individual expectations of care and service do appear to be an important factor in their perception of their referral experience.

Each patient is different and will carry different expectations of service and care into the consultation. We encountered a range of different attitudes, including patients who are happy to wait eight-ten weeks for a referral, in contrast to patients for whom a six week referral is an impetus to booking a private appointment.

Similarly, while some patients were frustrated at not having enough time to discuss all their conditions in one GP appointment, another was happy to make two appointments, describing himself as 'pushing my luck' when he tried to raise a fourth issue.

Patients bring their own expectations and levels of tolerance with them to the GP appointment or specialist consultation. What is acceptable for some will be unacceptable for others: this divergence is a major challenge for doctors and the health service. In some cases, greater transparency or information about the referral may lead to more positive experiences – for example, a doctor spending a couple of minutes describing the possible referral journey or providing a leaflet with some information.

Appendix 1: Quantitative Questionnaire

Standard Demographic information will be collected as follows:

- Age
- Gender
- SEG
- Region/Nation
- Ethnicity
- Disability

Q1. In the last two years, have you received a 'referral' from a doctor?

A referral occurs when a doctor makes an appointment for you to see a different doctor or health professional. For example, this might be for tests, to see a physiotherapist or to see a specialist in hospital. Referrals are most commonly made by GPs, but can also be made by doctors who work in hospitals. ***Please do <u>not</u> include referrals within a GP practice (e.g. from a GP to a practice nurse) or referrals from A&E to another part of the hospital when answering this question.***

1. Yes, I have received a referral in the last two years, and I have attended an appointment (GO TO Q2)
2. Yes, I have received a referral in the last two years, an appointment was made but I did not attend (GO TO Q2)
3. Yes, I have received a referral in the last two years, but the appointment has not yet taken place (CLOSE – CAPTURE DATA FOR ANALYSIS)
4. No, I have NOT received a referral in the last two years (CLOSE - CAPTURE DATA FOR ANALYIS)
5. Don't Know (CLOSE - CAPTURE DATA FOR ANALYSIS)

Q2. How many referrals have you received in the last two years?

1. 1
2. 2
3. 3-5
4. 6-9
5. 10+

Q3a. Which of the following types of medical professional have you received a **<u>referral</u> <u>from</u>** in the last two years?

Q3b. Which of the following types of medical professional was your **most recent <u>referral</u> <u>from</u>**?

1. A GP
2. A specialist doctor
3. An A&E doctor
4. Another healthcare professional/service
5. Other: please specify
6. Don't know

Q4a. Which of the following types of medical professional have you been **referred to** in the last two years?

Q4b. Which of the following types of medical professional were you **referred to** for your **most recent referral**?

1. A GP
2. A specialist doctor
3. An A&E doctor
4. Another healthcare professional/service (e.g. a physiotherapist, for an x-ray etc)
5. Other: please specify
6. Don't know

Q5. Thinking of your **most recent referral,** to what extent would you agree or disagree with the following statements

1. Strongly agree
2. Slightly agree
3. Neither agree nor disagree
4. Slightly disagree
5. Strongly disagree

ROTATE ORDER – APART FROM P WHICH SHOULD ALWAYS BE LAST ON THE LIST

A. The reason for the referral was properly explained to me
B. I requested/pushed for the referral
C. I was surprised to be referred
D. I was given useful information about where to attend
E. The doctor I was referred was not sent the notes they needed about my case
F. The referral reassured me
G. I was misdiagnosed and referred to the wrong place
H. I felt the referral was a waste of my time
I. I needed to seek further medical help for my condition whilst waiting for the referral appointment
J. I had to take time off work to attend the referral
K. The time and date of the referral were convenient for me
L. I was given a choice of where I would be referred
M. My medical condition got worse in the time I was waiting for the referral
N. On the day of the referral I was seen promptly/did not have to wait
O. Making this referral was the right thing to do for my medical condition
P. Overall, I was satisfied with the way referral was handled

Q6. Thinking of your most recent referral, did you feel the referral was necessary?

1. Yes (GO TO Q8 OR CLOSE IF CODE 1 AT Q2)
2. No (GO TO Q7)
3. Don't know (GO TO Q8 OR CLOSE IF CODE 1 AT Q2)

Q7. You mentioned you felt that your most recent referral was NOT necessary, why was this? (MULTI CODE)

A. I felt the doctor referred me because they did not have enough time to see me properly themselves
B. I felt the doctor referred me because they were not confident enough to give me a diagnosis
C. I knew my symptoms did not require a referral
D. I think my doctor may have referred me mainly because they knew that I wanted a referral
E. I felt the healthcare professional/service I was referred to was not the right one to help me
F. The medical professional I was referred to said that my referral was unnecessary
G. Other: Please specify
H. Don't know

(ONLY ASK Q8 AND Q9 FOR THOSE WHO ANSWER 2 TO 5 AT Q2)

Q8. Do you feel that any of your other referrals in the last two years were unnecessary?

1. Yes (GO TO Q9)
2. No (CLOSE)
3. Don't know (CLOSE)

Q9. You mentioned you felt you have received an unnecessary referral in the last two years, why was this? (MULTI CODE: GO TO Q10)

A. I felt the doctor referred me because they did not have enough time to see me properly themselves
B. I felt the doctor referred me because they were not confident in their ability to give me a diagnosis
C. I knew my symptoms did not require a referral
D. I think my doctor may have referred me mainly because they knew that I wanted a referral
E. I felt the healthcare professional/service I was referred to was not the right one to help me
F. The medical professional I was referred to said that my referral was unnecessary
G. Other: Please specify
H. Don't know

Q10. For which condition(s) did you receive a referral that you felt was unnecessary? (MULTI CODE)

1. Allergies
2. Alzheimer's
3. Arthritis
4. Asthma
5. Cancer
6. Cholesterol

7. Chronic Pain
8. Cold & Flu
9. Depression
10. Diabetes
11. Disease Prevention
12. Eyesight
13. Heart
14. Hepatitis
15. High Blood Pressure
16. HIV
17. Infectious Diseases
18. Liver
19. Lungs
20. Menopause
21. Men's Health
22. Mental Health
23. Migraine
24. Osteoporosis
25. Rheumatoid Arthritis
26. Skin
27. Sleep
28. Thyroid
29. Urology
30. Weight Loss & Management
31. Women's Health
32. Other: Please specify
33. Would rather not say

Appendix 2: Qualitative Discussion Guide

1. Moderator Introduction (2 Mins)

Explain that:

- this research is being conducted by Trajectory, an independent market research agency on behalf of the General Medical Council

- The GMC is the regulatory body for doctors that exists to protect, promote and maintain the health and safety of the public by ensuring proper standards in the practice of medicine

- We are speaking to you today because the GMC is keen to understand more about patients' experience of the referral process

    - (*As appropriate) A referral occurs when a doctor makes an appointment for you to see a different doctor or health professional. For example, this might be for tests, to see a physiotherapist or to see a specialist in hospital. Referrals are most commonly made by GPs, but can also be made by doctors who work in hospitals.* ***Please do <u>not</u> include referrals within a GP practice (e.g. from a GP to a practice nurse) or referrals from A&E to another part of the hospital when answering my questions.***

- We understand that you have recent experience (within the last 2 years) of a referral or referrals and we would like to talk to you about that/those experience(s)

- All your responses will remain anonymous – so no one at the GMC and no doctor will be able to link you personally to any comments you make

- NOTE FOR MODERATORS – if you suspect any respondent may have cause to instigate a fitness to practice investigation, please advise them in line with the MRS Code of Conduct

OBTAIN SIGNED CONSENT TO TAKE PART IN THE SURVEY

2. Respondent introduction (5 mins)

These questions are about you – things such your job, living arrangements and lifestyle because might help to explain your responses to our questions about referrals. We'll also ask a few questions about why you were referred and your general health. Would you mind telling me…

1. Who, if anyone, do you live with?

2. Your marital status

3. Do you have children?

   If yes, do they still live at home?

4. Are you currently in employment, retired, etc? What do you do?

5. Can you give me a brief employment history?

6. Do you have any hobbies or leisure interests?

7. How is your health generally?

8. Can you give me a brief medical history and why you were referred?

3. Referral summary overview (2 to 5 mins)

As I mentioned at the beginning, we are speaking to you today because you have had a referral (or referrals) in the last two years and you were dissatisfied with what happened or felt it was a waste of time? Can you give me the basic details surrounding your referral(s) as follows…?

9. How many referrals have you had?
10. What was the medical condition?
11. When did the medical condition start?
12. Which type of doctor (GP or other) made the referral?
13. Which type of medical professional were you referred to?
14. Where did the various consultations take place?
15. How far was this from where you live? How do you travel to your appointment(s)?

Repeat as appropriate for those who have had more than one referral

Referral number	What was the medical condition?	When did it start?	Who made the referral?	Who were you referred to?	To where (e.g. hosp)	How far away?	How did you get there?
1							
2							

3							

4. Referral journey in detail (5 to 10 minutes)

In your own words, starting with you feeling the symptoms, can you talk me through your referral process step by step from beginning to end/today (if on-going).

(Moderator to make a note of each key event for later reference)

5. Views on their referral experience (20 to 25 mins mins)

(Unprompted response) Thinking of the whole referral journey:

16. What, if anything, worked well in the process?
17. What, if anything, did not work well?
18. Was there anything surprising or unexpected about the referral?

(Moderator prompt for good and bad aspects of the key events as noted in section 4 above. Check for satisfaction/dissatisfaction with each stage of the journey)

Then prompt specifically for:

19. How was the consultation that led to the referral?
20. Did you have enough time with the doctor that referred you?
21. Did you feel you were able to tell the doctor everything you wanted to tell them?
22. Did you feel that that doctor who made the referral listened to you properly?

23. Communication – was the purpose of the referral made clear? Was this important to you?
24. Were you able to ask questions about the referral process? Was this important to you?
25. Did you feel you got to see the right medical professional on each occasion? Was the diagnosis of the first doctor accurate?
26. Was the medical professional prepared for the referral, did they have the right notes? Had they read them in advance?
27. Were you given any choice about where to go for your referral? Did they/would you have welcomed choice?
28. Were you given any choice of appointment time/date? Would you have welcomed this choice?
29. Was the appointment rebooked or postponed?
30. Speed of the referral – were you seen quickly enough? Why/why not?
31. Did your medical condition deteriorate during their referral process? Did you have to seek alternative treatment (e.g. go to A&E) in this time?
32. Did you not attend/ miss any referral appointments? If yes, why?
33. Whilst at the appointment did you have to wait to be seen?
34. Did the appointment cause you any inconvenience?
    - Time off work
    - Childcare or other care issues
    - Getting there – travel challenges, arranging lifts, etc
    - Finding a friend or family member to go with you
    - Cost of travel
    - Car park charges
35. Did the referral cause you any worry? Could this have been avoided or was it a necessary part of the process?

36. Did the referral provide you with any reassurance? (e.g. felt they were making progress towards a diagnosis, getting the problem sorted, reassurance of seeing a specialist, feeling in safer hands etc)
37. Did you ask for/push for the referral?
38. Was there any sign that the referral took place because the doctor was too busy?
39. Was there any sign that the referral took place because the doctor was unsure about diagnosis, did not feel able to give a diagnosis?
40. Was the (any) referral unnecessary? If yes, explain why
41. Was any part of the (any) referral unnecessary?
42. Was the (any) referral inappropriate? If yes, explain why
43. Was any part of the (any) referral inappropriate?
44. Did your experience in anyway undermine your trust in the medical profession/NHS?

6. Making referrals better (5 mins)

44. Reflecting on all the above, what if anything, could improve the referral experience from your point of view?

In particular, we are interested in improvements in the role played by the doctor rather than the NHS system (e.g. individual doctors cannot reduce waiting times for referrals)

45. For any of the things that you felt might have gone better around your referral, can you think of solutions?

46. What would your priorities be for making these changes? Which would be most important to you?

47. If there was one thing you could change about your referral experience, what would it be?

Thank respondent and close

If not being paid by Panel Provider, pay incentive fee and ask for a signature to confirm receipt of payment.