Using and loving the NHS

The previous chapters have sought to demonstrate the range of ways in which members of the British public interact with the NHS, shedding greater light on how donating time and money, and campaigning to protect or ‘save’ the NHS are important facets of societal engagement. In this chapter, I explore how the context of societal care for the NHS shapes experiences of service use. It is not always customary to understand the way patients use services a mode of participation in our healthcare system: it is often seen as private, and not public action. In a previous book (Stewart, 2016), I argued that separating out accounts of service use from accounts of citizen participation neglects the ways in which service use constitutes creative and tactical action, and risks missing out how swathes of the population exercise agency in healthcare, not through formalised ‘choice’ but by ‘playing the system’ to achieve an acceptable outcome. Several respected and valued colleagues told me that this was a step too far, over-extending the definition of participation and straying unhelpfully beyond disciplinary boundaries. This invokes a putative distinction between sociological study of people’s (private) experiences of healthcare, and political science or public policy study of how healthcare is organised and managed.

The consistent suggestion that not only can we separate out our roles as patient, and as citizen, within a health system, but that for analytic clarity we should do so, continues to strike me as misguided. In this chapter I present an analysis of how and when people providing online reviews of care received in the UK NHS talk about the NHS. Others have explored the way in which patient experience has come to be instrumentalised within healthcare systems and used as not just a barometer of quality of healthcare but as a mechanism for financial incentives within the system (Edwards, Staniszewska and Crichton, 2004; Montgomery et al, 2022). Existing research suggests that providing these online reviews – which a minority of patients do – has a specific function around caring for care:

Interviewees provided feedback because they cared about the NHS as a national resource, which, as citizens, they felt a sense of responsibility for. At the same time, many interviewees or their family members were receiving care from specific services and professionals. Thus, as patients, they had to navigate the power inequalities, vulnerabilities and dependencies implicit in care relations (Martin et al, 2015). These
two dimensions – caring for the NHS as a symbolic entity invested with emotional and ethical weight, whilst being dependent on care from NHS services and healthcare professionals – provides essential background for contextualising the practices of people providing online feedback about public healthcare services in the UK. (Mazanderani et al, 2021, p 5)

This analysis helpfully distinguishes the provision of feedback from a consumeristic act: acknowledging the complex and often hybrid roles that patients have within an NHS system (Clarke et al, 2007).

My determination to include a chapter on service use within this book on how Britain loves the NHS rests on two interlinked claims. One is empirical: I will argue that the way we feel and talk about actual experiences of healthcare in the UK is strongly filtered through the way we feel and talk about ‘the NHS’ as ‘symbolic entity invested with emotional and ethical weight’ (Mazanderani et al, 2021). The analysis that follows identifies recurring references to the NHS which, I suggest, support that claim. This makes large-scale comparisons of healthcare experience across different health systems – disentangling how members of the public feel about their own experiences of healthcare, current approaches to organising healthcare, and the institutional context of the healthcare system – extremely challenging (Larsen, 2020; Burlacu and Roescu, 2021).

The stronger claim is a normative one about how we should research and know healthcare. There is no lack of research published about people’s experiences of particular forms of care (Edwards, Staniszewska and Crichton, 2004). Especially within the sub-discipline of sociology of health and illness this work goes beyond Likert scale quantifications of patient satisfaction towards qualitative studies which are rich with meaning, exploring not merely whether healthcare ‘works’ (achieving its clinically-defined goals) but what difference it makes to the individual wellbeing and self-image of patients. This research does, though, intersect only lightly with research on the policy and organisation of healthcare systems. As General Practitioner and author Gavin Francis puts it: ‘Hospital is a place dedicated to the efficient processing of thousands of people; the hopes and anxieties of individuals tend to get drowned out in the crowd’ (Francis, 2015). There are of course exceptions in both healthcare practice and research: Edwards, Staniszewska and Crichton (2004) explicitly centre the question of whether and how patient reports of their experiences might be used as a barometer of quality of care. By contrast, when reading key accounts of the NHS as a healthcare system, and especially its historiography, the actual bodily, material, joyful and tragic interactions which constitute healthcare recede, in favour of viewpoints grounded in the experience, concerns and priorities of politicians, clinicians and managers.

My suggestion is both that sociology of health and illness requires more consistent engagement with the organisation and financing of healthcare (a
point already made by sociologists such as Davies, 2003), and that studies of healthcare organisation and health systems needs to engage more consistently with intimate and embodied experiences of patients as the crux of what is particular about the business of healthcare. As scholars, we need to find a register to discuss healthcare which neither neglects the critical, often life-altering significance of patient perspectives on a health system, nor delegitimises a broader perspective in which citizens might assess the merits of a particular system. Particularly in an NHS system where governmental responsibility for health security is broadly accepted, these standpoints are integrated in most people’s daily lives. When I attend hospital for an appointment, or navigate to the NHS website to assuage my worries about a poorly child, I do so as both patient and a member of society, aware that my service use is nested within a broader system of resources and priorities. Placing patient experiences of care at the centre of healthcare system research rejects the suggestion that we encounter the health system as either patient (with all its attendant vulnerabilities) or citizen (with all its association of power and agency), and foregrounds how we integrate both (Clarke et al, 2007).

**Care Opinion as a platform for feedback**

Formal structures have existed since the 1970s to offer some representation of patients and the public within health service decision-making (Newbigging, 2016 offers a helpful review). As well as varying over time, reflecting contemporaneous visions of what ‘good’ public and patient involvement might look like, these structures have differed in England, Northern Ireland, Scotland and Wales. Given these differences, there is no single organisation which represents patient and public views about the NHS across the UK. In this chapter, I rely instead on Care Opinion, a UK-wide platform for patient reviews, which has the added advantage of offering relatively unfiltered narratives of healthcare service use.

Practices of online reviewing of everything from restaurants to films to businesses are deeply entrenched into contemporary social life. They are also increasingly part of the context of health systems (Montgomery et al, 2022). Care Opinion is an online platform where members of the public can submit ‘stories’ of up to 1000 words, linking them to the different ‘provider’ organisations they interacted with during their care. Created in 2005, it was initially seen as part of the expansion of patient choice within the NHS in England (Appleby, Harrison and Devlin, 2003) but its role has evolved into a focus on collaborative quality improvement: as its founder described ‘turn[ing] the moving, thoughtful and reflective stories that people share into better health and social care services’ (Hodgkin, 2013). As a non-profit-making Community Interest Company, Care Opinion’s
business model is to sell subscriptions to health and social care organisations who can make use of the patient stories. In England these subscriptions are from specific provider organisations, but in Scotland and in Northern Ireland, Care Opinion has been contracted by the Scottish Government and Public Health Agency respectively (Care Opinion, 2022a). While Care Opinion therefore shares some similarities with private digital platforms which Lupton (2014) argues have commodified patient experience (see also Mazanderani and Powell, 2013), this is a non-profit-making platform which, through these contractual arrangements with NHS organisations, has become interwoven with the NHS. The idea of Care Opinion as a useful broker between patient experience and organisational improvement has been supported by research which has found that staff value the learning (Baines et al, 2021) and that reviews might capture safety incidents which have otherwise gone unreported through official channels (Gillespie and Reader, n.d.). The decision to submit a Care Opinion review is a voluntary one on the part of the service user. Patients are, though, encouraged to do so by subscriber organisations within the NHS, for example via posters and leaflets in waiting areas, so they can reply to stories directly.

My search filter aimed to capture reviews which did not simply describe an experience of care (whether negative or positive) but which specifically discussed the ‘NHS’ within the body text of the narrative. In order to create a manageable corpus, I searched only for stories tagged as being about emergency medicine. This specialism was chosen because it is one of the main ‘front doors’ to NHS care, and also because it is often a particularly visible pressure point in the broader healthcare system, especially given very public waiting time targets (Iacobucci, 2019; Thorlby, Gardner and Turton, 2019). However it also has other characteristics likely to change the way people express feedback: people are more likely than in other specialisms to have one-off experiences with an emergency department, and the process of triage is particularly uncertain, especially with heightened ‘right care’ campaigns about appropriate service use. I discuss how these dimensions of emergency care might influence the analysis later in the chapter. I applied text searching for any stories with ‘NHS’ in the body of the story, and manually removed stories where the reference was to, for example, a specific organisation (for example, NHS Lothian) rather than the NHS as a more general entity. This left 197 stories from 2019 (out of a total number of 352 emergency medicine stories) and 221 stories from 2021 (out of a total number of 634 emergency medicine stories).

Care Opinion does not collect reliable demographic data about stories, but one option to contextualise the nature of this corpus of stories, and its relationship to the broader body of patient stories, is to explore the criticality rating applied to each. Care Opinion moderators (that is, Care Opinion staff, rather than NHS staff) assign a criticality rating to each story shared,
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Table 6.1: Proportions of Care Opinion stories scored as having no critical comment

<table>
<thead>
<tr>
<th></th>
<th>2019</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency medicine stories with standalone mention of ‘NHS’</td>
<td>72% no critical comment</td>
<td>63% no critical comment</td>
</tr>
<tr>
<td>All emergency medicine stories</td>
<td>70% no critical comment</td>
<td>57% no critical comment</td>
</tr>
</tbody>
</table>

from 0 (not critical) to 5 (very critical) on the basis of reported emotional or physical harm to the patient in the story (Berry et al, 2022). Berry et al (2022) describe the role of moderators more fully and discuss the process of scoring. It is important to note that Care Opinion data cannot be used as a straightforward measure of the quality of patient care across the country. Highly critical stories are likely not to be submitted on Care Opinion (Berry et al, 2022), perhaps because anonymous feedback is not ‘actionable’, and formal complaints processes might be preferred (Locock et al, 2020; Speed, Davison and Gunnell, 2016). Additionally, there is longstanding evidence that patients may reinterpret their experiences in a positive light (Edwards, Staniszewska and Crichton, 2004). However, Table 6.1 offers two useful insights.

First, it shows that stories making standalone mention of ‘the’ or ‘our NHS’ are marginally less critical overall than the broader body of stories. Second, it shows a shift over time period: emergency medicine stories in 2021 were more critical than those submitted in 2019.

Understanding patient stories as NHS stories

Analysing hundreds of stories is a peculiar and emotional experience. While some are general and brief, many stories are highly affecting, containing personal details and fleeting mentions of moments of joy, relief, devastation and loss. Acknowledging this, Berry et al’s (2022) ethnographic research with Care Opinion moderators reports staff sharing positive stories between them to lighten the load of the more harrowing tales. The work of reading and coding them as a researcher can feel intrusive, even though consent for reuse for research is built into the platform (Munro, 2015). I returned often to Shapiro’s (2011) call for us to balance critical inquiry with ‘narrative humility’ when dealing with the stories patients choose to tell. Despite the very wide range of different conditions and services described, stories also, over time, begin to display repetitive elements. Sometimes this is about what is described; for example the recurrent weight attached to a timely cup of tea as a symbol of care. As a perplexed German colleague put it to
me, on analysing social media data on a different project, ‘what is it with this country and tea?’ More often it is about elements of narrative structure; recurrences in the way that stories begin, progress, and end. Through the thematic analysis I identified recurrent elements of how people’s described experiences of care were discursively connected to ‘the NHS’, and the ways in which this seemed to encourage particular descriptions of self and of organisational encounters.

**A credit to the NHS**

One feature of this analysis that surprised me was the relatively high number of very short stories, comprising only a few sentences, and often lacking much detail. The overwhelming purpose of such stories was not to communicate substantive, let alone actionable, feedback on details of care received but to express gratitude. The following is the whole story submitted by one patient: “I was recently in hospital at [location]. I cannot compliment the staff of A&E and Ward 2 enough. All were so kind and caring – real credits to our NHS!” (story from 2019, criticality rating 0).

As this example demonstrates, short and positive stories are often effusive, including exclamation marks. Descriptions of care are often accompanied by descriptions of staff as ‘angels’ or ‘real life superheroes’. Relatedly, in the absence of conventional signoffs (given the anonymity of the platform) many stories end with brief stock phrases, sometimes using a heart or thankyou emoticon: ‘Our wonderful NHS’, ‘proud of the NHS’, ‘keep up the good work!’ These can be understood as the ‘coda’ (Labov, 1997) of the story: it signals the end of a narrative and, as Labov (1997) puts it ‘puts off a question’ by ending on a positive note.

From a consumeristic perspective – in which feedback is given either to ‘voice’ an objection or to offer ammunition for other consumers to choose to ‘exit’ a failing provider (Needham, 2009) – such stories are bewildering. Even acknowledging that people are often short of time, the lack of substantive content makes the decision to offer a written review seem perplexing. However from the position of both invested stakeholder, and indeed a scared or suffering human grateful for human connection in a vulnerable moment, the prevalence of grateful, and somehow insubstantial stories makes much more sense. Mazanderani et al identified this in their interviews about online feedback:

> Feedback practices were shaped by both their embodied experiences of care (good and bad) and a strong moral commitment to, indeed a sense of responsibility toward, other patients and service users, healthcare professionals and services, as well as ‘the NHS’ as a highly symbolic national resource. (Mazanderani et al, 2021, p 6)
Many stories seem intended to find a public expression of gratitude, and as Mazanderani et al’s interviewees suggest, this was often explicitly in a context where the NHS was felt to be ‘knocked’ in public discourse. One interviewee in that study remarked: “I think doctors and nurses need to hear that we’re grateful and not just turn on the TV and see the NHS is crumbling around our knees” (female, 36). In this context, the recurrent codas – grateful expressions of thanks such as ‘thankyou NHS’ – function to leave the reader with an overall sense of things having gone well. In their analysis of patient comments on the NHS Choices website, Brookes et al (2022) suggest that codas to positive stories are intended for both other patients and for providers themselves to read, while codas to negative stories have a more restricted imagined audience of other patients. In grateful stories, the connection between the attribution of credit to individuals and to the entire healthcare system can be difficult to understand: “All in all we cannot thank the NHS enough for their excellent service, especially a great big thank you to Angela for calming us down and assuring us everything was fine” (story from 2021, criticality rating 0). The elision between ‘the NHS’ and the many staff who work within it is a familiar one from broader cultural representation of healthcare in the UK (Saunders, 2022). Note, for example, how Michael Rosen’s bestselling book about his experiences of healthcare during a life-threatening experience of COVID-19, filled with remarkably poignant letters from health professionals who cared for him, is “a story of life, death and the NHS” (Rosen, 2021).

Even in longer, more substantial stories, gratitude is very often the overall focus. The very common phrase ‘a credit to the NHS’ is frequently used to praise individual or groups of staff. ‘All the staff were outstanding but Maria was the pinnacle of what makes the NHS fabulous, Thank you!’ (story from 2019, criticality rating 0). This is interesting both in that ‘the NHS’ becomes not the experience being discussed but the yardstick or standard by which that experience might be measured. Furthermore, as in this story, the compliment of being a ‘credit to’ or even ‘the pinnacle’ of the NHS appears overwhelmingly to be attributed to acts of kindness and caring, rather than in reference to clinical aspects of care. Stories analysed were relatively quiet about clinical aspects of care received, let alone references to technology or sophisticated pathways. Likely reflecting a focus on thanking staff, stories are much more often focused on human aspects of care. These include holding a patient’s hand when they receive bad news (“held his hand when he was told about his brain tumour and reassured him. He told us he had a wee ‘greet’ since he knew the seriousness of it” [story from 2021, criticality rating 0]); using humour to lighten difficult moments (“everyone was amazing they even managed to get me laughing and totally took my mind off the situation” [story from 2019, criticality rating 0]); and careful reassurance
(“she listened to me and reassured me in my panicked state that everything was going to be ok” [story from 2019, criticality rating 0]). The intersection of care and vulnerability here is a powerful one: “I would like to say how wonderful each and every member of the team who I met were. They were caring, compassionate and professional and made me feel safe during a very overwhelming scary experience, where I felt at my most vulnerable” (story from 2021, criticality rating 0). As this excerpt suggests, critical moments in the narratives often combine a moment of (sometimes life-threatening) vulnerability and uncertainty for the patient; and the ability of a team of health professionals to temper the associated fear.

**The presentation of self in scene-setting**

Longer stories often display the classical structural components of narrative including abstract (summary), orientation in time and place, complicating action, evaluation, resolution and coda (Labov, 1997; Riessman, 2008). Many longer and more substantial patient stories begin with an orienting scene-setting paragraph, in which the writer explains where and when the care occurred. This is, at least in Labov’s view, a universal element of narrative structure. Distinctively though, in the pressured emergency medicine context of these narratives, the scene setting is also significantly focused on a favourable ‘presentation of self’. That is, writers provided details to reassure the imagined reader that they, or (if submitting a story of another person’s care) the patient in question, is legitimate, virtuous, or unusually vulnerable.

Efforts to present the visit to Accident & Emergency as appropriate drew on a number of different sources of legitimacy. Commonly, narratives refer to being instructed to seek emergency care by someone with medical knowledge or authority. Sometimes this is a phone call to either 999, a GP, or NHS 111, for example: “Have had to go to A&E three times within the last few days, due to covid complications. It was not my decision to go – I was taken twice by emergency ambulance and the other time, when no ambulances were available, by car” (story from 2021, criticality rating 3).

In another story, a patient describes the emotional toll of identifying the most appropriate route to care, contrasting her GP receptionist with a triage nurse:

‘The receptionist at my GP’s was very kind and concerned. This helped as I was scared. At A&E when I was triaged the nurse said “you’ll be here for hours you could still make your GP or pharmacist”. I asked if she thought I should go home, that this wasn’t serious. I also told her the GP advised me to come. I felt quite tearful and worried I was wasting NHS time.’ (Story from 2021, criticality rating 2)
Navigating routes into emergency care often seemed both difficult and worrying in people’s accounts of care. Patient stories often suggested that arriving at the hospital by ambulance (following a 999 call) was the most legitimate route to attending A&E, with triage by a paramedic providing reassurance of clinical need. “I appreciate you’ve got to be fairly tough to work in A&E, but to be shouted at by a doctor because you ‘shouldn’t be here’ (it was 999 who took me there, but never mind), & belittled for having medical conditions they hadn’t heard of” (story from 2021, criticality rating 3).

NHS 111 and informal referrals from primary care, by contrast, are a less reliable arbiter, in that many narratives recount taking advice to go to Accident & Emergency and there being treated as illegitimate:

‘The nurse asked me why I was in ED this evening. I attempted to answer the question but failed to do so as the nurse spoke over me every time and said “there’s nothing we can do for you here this evening you have a long term condition”! I advised her I knew that as did my GP who sent me to ED following a discussion with a Dr at the hospital.’ (Story from 2021, criticality rating 2)

Here, the spectre of timewasting (being a timewaster, being seen or treated as a timewaster, and, crucially, feeling reassured that everyone knows one is not a timewaster once triage has taken place) played a major role (Llanwarne et al, 2017):

‘Felt really nervous, and I hated that an ambulance had to come as I never like to pull on resources from the NHS as they’re so busy.’ (Story from 2021, criticality rating 0)

‘I came home and burst into tears feeling deflated and upset. I felt I was a burden on the NHS as it was a weekend, no beds and COVID and I would just have to await my turn.’ (Story from 2021, criticality rating 3)

People who had attended Accident & Emergency in the absence of an ambulance or formal medical advice often referred to broader structures of credentialed medical knowledge: a family member or colleague who was a health professional and who advised them to get urgent care.

Across the whole corpus of patient stories, examples of feeling that concerns had not been taken seriously, are common. In some cases such stories include a description of a ‘victory’ of the patient’s need for medical care having been proved legitimate after triage, sometimes with grim predictions for what might have happened if the patient had not persevered. These are, in common with earlier excerpts, depicted not only as a private
medical experience but as a public claim on medical help. One unusual example makes a formally-worded apology for using emergency care without a ‘legitimate’ reason:

‘I would like to apologise for having accessed A and E for what turned out to be a sprained ankle as I am aware this could have been dealt with elsewhere but I greatly appreciate the time and care taken by all staff to reassure me that this was not something more serious and to provide advice personal to me and my situation.’ (Story from 2019, criticality rating 1)

In contrast to stories of brusque or dismissive care for problems seen as illegitimate, this story expresses appreciation for staff providing reassurance and person-centred advice. The framing of the story is both grateful for kindness and advice received but fundamentally apologetic for having made what is perceived as an unnecessary request on this most pressured gateway to NHS care.

This overt apology relates to another facet of how story writers present themselves (sometimes co-existing with, and sometimes substituting for legitimacy); virtue. Here, descriptions of self focus not only on the described visit as a legitimate one, but on how little they ask from the NHS in general: “Was at A&E today, having been fortunate enough to have never needed a trip to hospital for last 20 years or so” (story from 2019, criticality rating 0), and: “Not having the requirement to attend A&E or a Hospital since I cannot remember when” (story from 2019, criticality rating 0).

Some of these go further, interweaving accounts of good fortune with aspects of their lifestyle that have reduced their healthcare needs: “I am back to my normal very active life, for which I will always be eternally grateful. I have been lucky and needed very little help from the NHS throughout my life” (story from 2021, criticality rating 0).

In one long and complex narrative, a description of general good health is offered to explain why the writer felt they should have been taken more seriously at triage:

‘At one point I mentioned that it was 20 years since I last was off work sick. I’d assumed this would indicate I’m not a person to ask for help often or if I don’t really need help. However, they interrupted to ask why that was relevant. I found that quite an astonishing question. I had already explained that I’m a self employed person and therefore not someone to be off work or asking for help or draw on resources if I don’t definitely need help.’ (Story from 2021, criticality rating 3)

Here, both good health and employment status are offered as evidence for the patient as someone to be treated respectfully, with an implied
comparison with those who might often ‘draw on resources’. The story goes on to describe staff resisting this evidence of virtue, and the patient being given pain medication and ‘sent home’: “I think they then said it was irrelevant when I’d last been off work sick and that the NHS is there to provide help when it’s needed – which I heartily agreed with of course” (story from 2021, criticality rating 3). This story is largely one of frustration and unhappiness, and the decision to include this exchange, especially the appeal to common-sense (‘of course’), are notable. The writer seems both committed to their starting point (that their broader lifestyle justifies being taken seriously) and particularly concerned to adhere to societal norms (that care is there when needed) as both patient and as narrator of patient experience.

A final, and often alternative route to presenting one’s narrative as that of a ‘worthy’ or ‘proper’ patient (Higashi et al, 2013) instead emphasises the heightened vulnerability of the patient. This was particularly prevalent where the writer was not the patient but their carer, and this was accentuated in the stories from 2021, where restrictions on access to hospital meant that carers could not always accompany vulnerable people as they might have usually. These narratives are sometimes written with a very purposeful effort to describe vulnerability in order to emphasise the importance of the narrative, for example: “Remember, she is alone, young and frightened” (story from 2019, criticality rating 0). This group of narratives often included the patient’s specific age (as opposed to simply the descriptor ‘elderly’): “My father is a 74-year-old man. He has had his health problems over the past few years including an abdominal aneurysm and a blood clot in his leg. He smoked for over 50 years and stopped abruptly 3 years ago and hasn’t smoked since” (story from 2019, criticality rating 2).

As with earlier examples, narratives sometimes interwove vulnerability with virtue, including where patients had themselves worked in the NHS: “Elderly mother with multiple medical problems called local practice requesting help for chest infection and did not get past reception staff – was not even put on call back list. My mother had COPD and had worked as an NHS nurse for 40 years!” (story from 2021, criticality rating 3). Occasionally the descriptions are of the patient’s own vulnerability: “My mother suffers from schizophrenia for the duration of my life and my father suffers from depression. I have told the doctors this. I need help. I’m not attention seeking. I have struggled for a very long time” (story from 2021, criticality rating 3). In this affecting example, intergenerational suffering is interwoven with descriptions of longstanding failures from the NHS to help.

It is worth emphasising that the Care Opinion platform doesn’t prompt writers to provide these kinds of context. The prompts in the online form’s free text box are simply ‘What happened? How did you feel?’ In my view, that so many stories provide context about how the patient accessed emergency care,
about ‘worthy patient’ aspects of their conduct, and about the extreme need and vulnerability of patients, responds not just to medical power or dominance, but to the NHS context. As in Mazanderani et al’s (2021) interviews on patient feedback: ‘Understandings of how online feedback might improve healthcare were premised on pre-existing embodied, emotive and, at times ambivalent, relationships with the NHS.’ Explicit and implicit logics of ‘appropriate’ or ‘legitimate’ service use held by both health professionals and patients are commonly identified in medical sociology studies (Hughes and Griffiths, 1997; Hillman, 2014; Llanwarne et al, 2017). It is significant, though, that in the narratives I analysed they are volunteered by patients and their carers. They suggest that, beyond a desire to be a ‘good’ patient in the face of medical power, patients seem to have an internalised awareness of attending A&E as drawing on a limited public resource. People explicitly referenced taking time, staff attention and beds ‘away from’ others in need. The ‘good patient’ is thus reconstructed as a good ‘citizen-patient’, and these details are repeatedly felt to be a necessary component of narratives of care.

*When things go wrong: cushioning the blow*

While gratitude was an overwhelming focus of the stories analysed, as several of these examples demonstrate, a range of narrative tactics were used in order to frame, cushion or justify negative descriptions within the stories. One key way people seemed to manage dissonance between their own experiences and a belief in the ‘good’ of the NHS is through blaming bad experiences on specific individuals rather than the NHS. This could at times conflict with the pervasive framing of NHS as ‘heroes’ or ‘angels’.

‘There was one doctor however who made the experience an unpleasant and upsetting one. Their bedside manner was poor and the way they talked to me and another patient across from me (whom I couldn’t help but hear the way they spoke to him) was rude and to be honest shocking. They came to give me the results of the tests I’d undergone, during which time they came across as uncompassionate, uncaring and dismissive, suggesting my symptoms were down to anxiety.’ (Story from 2021, criticality rating 3)

In stories such as this, where one health professional’s behaviour is suggested to have sullied a whole experience, writers are often keen to balance their criticism with explicit descriptions of how good or kind other health professionals were. This acts both to present the writer as reasonable (a reliable narrator), and to suggest that something has gone wrong with the individual (in that other staff members managed to behave properly).
‘Before I detail my concerns I must also state that throughout the past year I have experienced an incredible standard of care from the vast majority of the healthcare professionals I have come into contact with on my numerous journeys to and from hospital. Almost all of these people have treated me with huge amounts of empathy, kindness and delivered exemplary care with my comfort and dignity maintained as much as possible.’ (Story from 2021, criticality rating 3)

It is possible that this specific tactic is related to the one-off nature of (many) emergency care interactions, in that patients in ongoing longer-term care pathways might feel more able to extend their assessment across a whole ward, department or even organisation. However within the emergency care narratives analysed, focusing criticism very specifically on individual staff members acts to insulate the broader NHS from criticism.

An alternative route to a similar outcome was to describe failures in care but to excuse them with reference to the notion of ‘pressure’ experienced by the NHS. At times the ‘individual failure’ is linked to this pressure:

‘I include my long rambling story to illustrate the amazing machine the NHS is. So many pathways involved from start to finish during an incredibly pressurised time for the NHS. Only one example during my time of someone who was perhaps feeling the pressure and was a little uncaring. This is understandable. In 6 weeks I have gone from having pain to treatment and diagnosis. What a wonderful system.’ (Story from 2021, criticality rating 2)

Noticeably, the prevalence of references to ‘pressure’ or ‘pressures’ is fairly consistent between 2019 and 2021, with the shock of the COVID-19 pandemic simply substituting for what, two years earlier, would have been references to government failure, underfunding or understaffing. Some 2021 stories did, though, ramp up the description of pressure from the COVID-19 pandemic as new and unique: “The pressure the NHS is under just now it’s totally unprecedented and never in our lifetime has it ever been pushed to almost breaking point or never been so important to all of us. But break it didn’t and I for one think this is incredible” (story from 2021, criticality rating 0). The pandemic context was extreme and many aspects of NHS delivery will have been unprecedented. Stories reflect that by using heightened language of pressure. But, comparing across multiple years, the presence of an external problem for which the NHS is blameless is a consistent feature.

In other stories, the ‘pressure’ is used to explain equanimity in response to quite startling breakdowns in care:
‘He explained the theatres were backed up and it would be days before I’m seen … I decided I could either take up bed space and cost to NHS to pity myself in hospital or put myself at home where I was more comfortable. Unfortunately this means a long waiting time before I get the treatment I need, this could all be behind me. Ninety per cent of the staff I came across gave you their full attention. Nothing was too much bother. It’s so appreciated to have someone tell you that you aren’t being dramatic and that you’re suffering and they want to help. A few nurses were a little short tempered, but I suppose understandable with the pressure they’re under.’ (Story from 2021, criticality rating 1)

The longer story from which this is excerpt is taken, describes the painful exacerbation of a pre-existing problem requiring surgery. Despite the surgeons being willing to operate – ‘this could all be behind me’ – ‘pressure’ of capacity means that the patient decides to return home and await the surgical appointment for which they are already waiting. The alternative of taking up ‘bed space and cost to NHS to pity myself in hospital’ is rejected, and both this breakdown in sensible patient pathways and encounters with ‘short-tempered’ nurses is, somewhat reluctantly, attributed to ‘the pressure they’re under’. This story intrigues because the substantive content is of a frustrating, inefficient experience of the NHS, and yet the resolution is glowingly effusive about the staff encountered:

‘These outstanding individuals will never know my gratitude. They stepped up patient after patient. They work tirelessly. I cannot thank them enough for being there during a very vulnerable time for me. Despite the sheer amount of patients, the fact they’re under-funded as an institution and their physical exhaustion I was treated with the upmost care. Any problems were beyond their control and a result of the above issues.’ (Story from 2021, criticality rating 1)

In this example, as in many others, external ‘pressure’ (underfunding in 2019, and then the COVID-19 pandemic in 2021) functions to create space for stories of failure to be told without criticising the NHS or (most of) its staff. At times, writers explicitly disavow the notion of complaining (“My only negative comment is that all but one of my face-to-face physio appointments have been cancelled but I totally understand why and make no complaint” [story from 2021, criticality rating 2]).

This broader search for a comfortable register in which to share negative stories is also reflected in stories where writers apologise for complaining. Several stories, especially where the writer is a current or past NHS employee, describe the writers’ sadness at having to share negative experiences:
‘I am very upset and sad to be writing this as I worked in NHS for 21 yrs and was always proud to work for NHS and the values and culture we all encouraged and upheld until this evening.’ (Story from 2021, criticality rating 2)

‘I am a nurse myself and I have always been proud of my profession however this evening I am sitting at home very upset and sad to have received the care I did.’ (Story from 2021, criticality rating 2)

Each of these quotes emphasises the ambivalence of sharing negative feedback for the NHS, when one’s identity as staff member is bound up with it. Other stories explicitly – if light-heartedly – apologise for complaining: “But every one of them – except one auxiliary! Sorry! – was a credit to the NHS. I am so grateful and full of admiration for all the work these people do every day” (story from 2019, criticality rating 0).

In another story, a patient seeking help for a suspected heart attack reflects on why their wife’s requests for help weren’t acknowledged:

‘My wife had been out of cubicle a couple of times to try and get a doctor because I felt the heart attack coming on, I don’t know if this was normal but I would not want to go back to that accident and emergency again if I had another heart attack, sorry to say you were too busy to notice my wife shouts or it wasn’t your job I don’t know.’ (Story from 2019, criticality rating 2)

‘Sorry to say’ here is a sarcastic emphasis to this dangerous and upsetting experience, and even here, it is cushioned with the possible excuse that ‘it wasn’t your job’.

**Conclusion**

When analysing patient stories which invoke the NHS, I was struck by the recurrent phrasing ‘I cannot fault’ my care. As discussed, many of these stories are entirely positive, and ‘I cannot fault it’ is a colloquialism denoting everything being good, even perfect. However it also seems to speak to a broader discomfort of outright criticising care received in the NHS. It is important not to overstate this. Given the afore-mentioned particularities of Care Opinion, potentially actionable complaints are not likely to be featured in this corpus of data. Formal complaints, legal action and public inquiries into failures of care are all features of the UK system (Healthwatch, 2019; Department of Health, 2002; Ocloo, 2010). Despite many descriptions of problems within their care experiences, the authors of these stories had taken an active decision to take the time to write and share them. Rather than a
taboo against naming failure, a more positive interpretation instead is that cushioned criticism stems from an active, even politicised, desire to protect the NHS from criticism while still offering feedback.

The analysis of patient narratives described suggests a struggle between the desire on the one hand to protect and support the NHS, and on the other to share difficult, at times traumatic experiences of care in order to hopefully improve care and bring about positive change. This tension is also evident in interview accounts of why people post online feedback (Mazanderani et al, 2021). In the stories analysed, people give credit to the NHS for good care given by people working within it, and attribute blame for failures in care, even devastating ones, to anywhere but the NHS. But, as Mazanderani et al (2021) report (from an interviewee), offering patient feedback is often prompted by a frustrated desire to be heard in order to effect change: “I felt that the NHS was not listening, that there was no way for me to talk to the NHS. I can’t get the NHS in for a cup of coffee and say, ‘Now look here NHS’” (quoted in Mazanderani et al, 2021, p 6).

This somewhat awkward personification of the NHS speaks to a desire for humanised healthcare, in which problems can be discussed openly, but the suggestion of sitting down over a hot drink also suggests a parallel concern to care for the NHS through feedback. As so often in this book, the NHS is imagined informally and fondly: this is neither church nor garage. The focus on things that need improvement evokes the way one might discuss an errant family member who needs to change their ways.

Other kinds of stories of service use might have offered a different picture of how affection for the NHS is intertwined with the embodied experience of seeking care. A focus on different clinical areas, including those where the NHS has particularly failed, might have yielded a more critical take on service use (Ocloo, 2010). As well as the particular emphases yielded by a focus on emergency care, the platform of Care Opinion will have shaped the narratives outlined. Formal complaints are one obvious alternative where the ideas I posit about credit and blame might be writ large, or entirely disproved (Reader, Gillespie and Roberts, 2014; Martin, Chew and Dixon-Woods, 2021). Another might be ‘opting out’, where people turn to private healthcare provision, frustrated or, especially given soaring waiting lists since the COVID-19 pandemic, unable to continue to wait for an appointment (Centre for Health and the Public Interest, 2022). In 2022, polling by Ipsos MORI reported that 13 per cent of respondents already paid for private healthcare, and a further 23 per cent stated they would be likely to pay for it if needed (The Health Foundation and Ipsos, 2022b). Private routes to diagnosis are particularly likely to be employed in underserved clinical areas such as Attention Deficit Hyperactivity Disorder, where NHS services are uneven and can constitute a ‘postcode lottery’ (Young et al, 2021).
Broader debates rage over the veracity and reliability of patient narratives of healthcare (Edwards, Staniszewska and Crichton, 2004; Shapiro, 2011). Managerial logics which require the standardisation of patient experiences, including complaints, in order to render them amenable to aggregation and ‘action’ (Edwards, Staniszewska and Crichton, 2004; Reader et al, 2014), are ill-suited to the complexity and breadth of many patient stories. Such efforts misunderstand some of the work that storytelling does in making sense of the heightened experience of vulnerability that is innate in many healthcare interactions. Shapiro (2011) argues, simply, that ‘patients tell the stories they need to tell’. For the purposes of this book, I need no confirmation that these stories have a particular relationship to ‘what really happened’. This makes the task both simpler, and more expansive. Shapiro argues that ‘a patient’s story is rarely “just a story”’: ‘People do not simply pull their narratives out of the blue, but in fact are deeply constrained by the power of the dominant narrative conventions and meta-narratives that are most readily available to them as a result of their particular place in time, history, culture and society’ (Shapiro, 2011, p 69). Like all patient narratives, Care Opinion stories are ‘inseparable from their cultural context’ (Lucius-Hoene, Holmberg and Meyer, 2018). In this chapter I have explored the dominant meta-narratives evident in how we talk about our experiences of the NHS: gratitude, constructive criticism, and a concern with the legitimacy and reasonableness of our own claims on the system. My suggestion is that these tendencies in patient feedback are more than an unarticulated instinctive taboo for story writers as they respond to their socio-cultural context (Brookes et al, 2022). Rather, these are actively sought out opportunities to offer feedback as a gift to the NHS, and as such, are not merely cultural but also political acts.