

# INTRODUCTION

*The same month that my mum was diagnosed with Alzheimer's and dementia, my employer asked me to relocate down south. I thought, I can't really do that, she's in her hour of need, so I'll take redundancy. That was probably ten or eleven years ago now. I was 42 then. She didn't want to go in a care home, so I said, I'll do as much as I can to prevent that. When she was diagnosed, I was disappointed with the service she got from the NHS. It was a case of, right, there's your diagnosis, you've got mixed dementia, Alzheimer's and vascular dementia, here's some tablets, come back in twelve months, and that's it. This is a massive, life-changing thing for her and for her family. We didn't know what to expect. (James, in Chapter 7)*

## SECTION 1 INTRODUCTION

Ill health is a burden. For many of us, when it comes, it is a passing inconvenience and the burden is light. But ill health can also come as a devastating bolt from the blue, like a stroke or cancer or COVID-19, or as a life-defining or life-limiting chronic condition. At its worst, the experience of ill health is measured out in pain, fear, anxiety, depression, exhaustion, confusion and much more besides.

No healthcare system can eliminate these bad experiences, which are inherent features of illness. Nor can it remove the intrusiveness of treatment and procedures: the worry of tests, the pain of surgery, the hassle of getting to the hospital, the side effects of medications, the labour of caring for loved ones. But healthcare can do much to make the experiences better, or worse.

## 2 ORGANISING CARE AROUND PATIENTS

In its millions of daily encounters with patients and their families, the NHS saves lives, relieves suffering and helps people manage, on a massive scale. But it also creates bad experiences. Patients wait too long, struggle to get information and wear themselves out navigating bureaucracy. Their medical notes get lost, the different professionals looking after them don't talk to each other, and sometimes it feels as though no one is taking responsibility. Countless acts of kindness and compassion are offset by the occasions when staff are impatient, dismissive, high-handed or worse. Massive reorganising designed for the general good – such as the changes the NHS had to make during the COVID-19 pandemic – might have a devastating impact on individuals. Not all care is safe and sometimes it causes harm.

### *Why this book?*

The NHS has long declared its commitment to “patient-centred care”, but a large gap remains between the fine words and the reality. Care often feels as if it is designed for the convenience of the organisations that deliver it, and not enough around patients and their families, or even around the frontline staff who provide it. Why does this happen? What does it feel like? And, most importantly, what can be done about it?

This book aims to stimulate reflection on these questions by listening closely to those at the frontline. It provides accounts from patients, carers and healthcare professionals who are patients about what it's like when services get it right and wrong, from birth up to the end of life. Quite simply, we want to draw on the power of storytelling – increasingly valued as a tool for learning – to help practitioners understand how to deliver better care.

There is a growing literature of first-person accounts both from patients and from healthcare professionals. This book differs by providing a collection of narratives, from a variety of viewpoints and stages in life, to paint a rich and varied picture. Alongside these narratives we provide some context: an overview of the history, theory and evidential underpinnings of moves towards a more patient-centred approach to care. We present some of the theory and practice of storytelling in the context of healthcare. And we seek to help the reader to draw out the practical learnings from the individual accounts.

This book is primarily focussed on England. Our storytellers relate experiences of the NHS in England, and our policy and historical scene-setting is also mostly from an English perspective. The English healthcare system is by far the largest in the UK and one of the largest

among high-income countries. It is grappling with problems, many of which are global in nature, such as the need to adapt healthcare to the growing populations of people with multiple long-term conditions. We are confident therefore that the themes and learnings that we draw out in the book, while reflecting English particularities, will also have broader resonance.

### *Who is this book for?*

This book is aimed primarily at undergraduate, postgraduate and research students in the healthcare professions, and students and scholars interested in management, health and social policy, and leadership. We believe it will also be of interest to policymakers, NHS managers, healthcare professionals, the voluntary sector operating in the health space, and a broader reading public who care about the NHS and want to understand it better.

### *How to read this book*

This introductory chapter sets the scene and is structured as follows. Section 2 explains what we mean by organising care around patients and our alternative term “patient-centred care”. We set out the key characteristics of patient-centred care and explain why it is important. Section 3 provides a brief history of developments in patient-centred care, in policy, attitudes and practice. Section 4 reviews, in light of this history, whether and to what extent the NHS can be viewed as patient-centred and the obstacles to further progress in this direction. Section 5 explains our approach to storytelling as a means of eliciting important truths about patient-centred care. It explains how we found the storytellers, the ethical and methodological issues we encountered, and what we learned from the process of listening to the stories. Finally, Section 6 summarises the structure of the rest of the book and suggests how the reader might engage with and learn from the stories it contains.

## **SECTION 2 ORGANISING CARE AROUND PATIENTS: WHAT IS IT AND WHY DOES IT MATTER?**

“Organising care around patients” is not a technical term, nor is it a single thing. We think of it as a family of attitudes, practices and behaviours. Here are some of the ways it is most commonly framed:

## 4 ORGANISING CARE AROUND PATIENTS

- **Understanding and valuing what matters to patients** (and doing something about it). This is exemplified by the NHS commitment to measuring key domains of patient experience, such as access to care, physical comfort and emotional support, as described in the NHS Patient Experience Framework (Department of Health, 2011).
- **Seeing the whole person.** The approach often described as person-centred has been well-summarised by the think tank the Health Foundation as care which treats people with dignity, compassion and respect and which is personalised, coordinated and empowering (Health Foundation, 2016). It is an approach often contrasted with the all-too-common experience of being seen as a “case”, disease or body part and finding oneself battling powerlessly against a technocratic and bureaucratic system. It is an approach which also values the relational as well as the technical aspects of care: listening to the patient, treating them as a person, being kind and compassionate. It values “what matters to you?” as much as “what’s the matter with you?”
- **Respecting people’s rights and autonomy.** This ensures that they have as much choice, voice and control as possible in decisions about their own care – and that of their loved ones – and in what happens more generally in their health services, as a matter of right. A rights-based approach also prioritises equality, diversity and inclusion, opposing discrimination on grounds of race, ethnicity, gender, stigmatised condition or other factors.
- **Being “customer focussed”.** Patients are not the same as shoppers, but there are nonetheless aspects of customer service that patients value and which make a difference to their experience of care (and often also to the safety and effectiveness of the care). These include speed and efficiency, convenience, the availability of meaningful choices, and how well staff relate and communicate. “If only the NHS were better at customer care” is something you often hear when there is a discussion about the difficulties of getting an appointment, of the NHS’s outdated attachment to snail mail or of unfriendly receptionists.

### *Getting the terminology right*

These different perspectives on “organising care around patients” overlap to an extent: they are facets of an overall approach that could be summarised as “be kind, be efficient, treat me as a person” and which

is often termed patient-centred care. In fact, there is no definitive terminology in this territory, partly reflecting the variety of perspectives and approaches. Thus some commentators prefer “person-centred”, objecting to the word “patient” as narrow and demeaning. “Patient” emphasises one’s lack of agency and control: as a sick person my role is to wait “patiently” while others do things to me. “Patient” can also be seen to exclude people who are of vital importance to the patient, such as their family, friends and informal carers.

Others prefer “people” to “person” because they want to emphasise the collective: we live in communities which have a powerful impact on our health and which have agency in their own right. Even “centred” is contested by those who think it lacks ambition and who would prefer a “patient-led” NHS. Others will take the view that patient-centredness is something of a distraction when the NHS has a relatively minor impact on health compared with the wider social and economic factors: social class, income, ethnicity, housing and employment, for example. Some activists would rather be working to promote healthier communities than risk being co-opted into tokenistic activities by the box-ticking NHS managers.

It is as well to be aware of these linguistic debates because they indicate where different philosophies of health and care come into conflict with each other. For our purposes, we will stick with “patient-centred” because – for all its semantic drawbacks – it is a sufficiently explanatory and well-understood term in the context of a book about the NHS.

### *Why is patient-centred care important?*

Just as patient-centred care is not a single thing, so there is not a single rationale for it. Rather there are several arguments, reflecting the different perspectives considered above, and which draw upon different kinds of world view, theory or evidence. They partly overlap and together they can be seen as a compelling case for patient-centred care.

- **The moral case.** There is a straightforward moral case for patient-centredness: that it is simply the right thing to do.
- **The clinical case.** This makes the case that patient-centred care leads to better outcomes from healthcare. It cites a body of evidence showing that patients who have agency – who are actively engaged in decisions about their health and care – are more likely to cope well, have a good experience of care and report good outcomes of healthcare.

## 6 ORGANISING CARE AROUND PATIENTS

- **The person-centred case.** This argues for the need to correct the dehumanising and alienating features of modern, science-based healthcare. It stresses the importance to patients of being seen as and treated as a whole person. It argues for holistic, seamless, joined-up care which overcomes professional and organisational silos such as the separate approaches to physical and mental ill health and to health and social care.
- **The justice case.** This makes access to patient-centred care a question of human rights and social justice. It has inspired generations of activists – for example, those who have campaigned for the rights of disabled people and those detained under the Mental Health Act. It sees the more equal distribution of power as fundamental to healthcare and insists on “no decision about me without me”. The justice case draws attention to the fact that those with the worst health and the worst outcomes of healthcare are often those with the least voice in decisions that affect both. It insists that a patient-centred approach must also be tailored to the circumstances, needs and preferences of different groups and communities in order to reduce health inequalities and promote greater equality and inclusion.
- **The economic case.** This claims that patient-centred care is more economically efficient because an approach that encourages individual agency (people doing more for themselves to stay well) is less reliant on expensive interventions. A notable expression of the economic case was the Wanless Review (Wanless, 2002), which deployed economic modelling to argue that the rate of increase in required resources for the NHS would be lower in the “fully engaged scenario” in which people took active responsibility for their own health.
- **The organisational case.** This can be summarised as “happy staff deliver good care”, and there is evidence of a positive association – for example in Care Quality Commission reports – between staff satisfaction and patient experience in NHS organisations. In fact, the relationship is unlikely to be just one way. It is likely that there are common factors that nurture both good working conditions and excellent care. The organisational case also draws on the lessons from successive investigations into failures of care, such as in the Mid Staffordshire NHS Foundation Trust; Winterbourne View Hospital, Morecambe Bay Hospital, Gosport Memorial Hospital and Shrewsbury and Telford Hospital NHS Trust. These investigations revealed some common features of organisations

that had delivered poor care, such as autocratic leadership, a lack of focus on quality of care, dysfunctional staff relationships and a failure to listen to the concerns of patients, families and frontline staff.

### SECTION 3 A BRIEF HISTORY OF PATIENT-CENTRED CARE

Because the creation of the NHS in 1948 was such an important advance in social welfare, it took decades for a progressive critique of it to gather force. Universal healthcare, available according to need, not means, was – and is – a massive good. But it was not perfect. As Britain moved away from post-war austerity and Edwardian social attitudes, and as healthcare provision expanded and became more technocratic, people began to chafe at medical paternalism, the dominance of “producer” interests and bureaucratic indifference to people’s rights.

**The 1960s and 1970s.** An early turning point was the movement to close down the old asylums and re-provide care for people with mental illness and learning disabilities in the community. As part of broader reorganisations of public services, the 1970s saw the creation of Community Health Councils, which provided a statutory consumer voice in the organisation and delivery of local NHS services.

**The 1980s and 1990s.** The decades of the Thatcher and Major governments saw a growth in consumerism and a concomitant growing interest in patients having voice, choice and redress when things went wrong. The Griffiths Report (Department of Health and Social Security, 1983), which advised the government on the introduction of modern management into the NHS, argued that the NHS had to recognise and respond to the needs of its “customers”. The White Paper “Working for Patients” (Department of Health, 1989) set out the government’s intention to introduce market mechanisms into the NHS and cast recipients of healthcare as consumers in an economic sense. The Patient’s Charter (Department of Health, 1991), and associated initiatives such as the publication of hospital league tables, further entrenched the view of patients as consumers.

**The 2000s.** The Blair and Brown governments, initially focussed on increasing investment in the NHS after years of spending restraint, further entrenched patient-centred care in policy, law, guidance and practice. The NHS Plan (Department of Health, 2000) noted that the

NHS ran on an increasingly outdated 1940s model which, among other things, left patients disempowered. It set out a raft of measures, including new patient surveys and hospital-based patient advocates, under which patients would “have a real say in the NHS”.

Patient and public engagement or involvement became recognised NHS functions, reflected in job titles. There was growing acknowledgement of the fact that people were living longer and that increasing numbers had to manage long-term conditions, which required a different approach to traditional “patch and mend” medicine. Interest correspondingly grew in models of care for long-term conditions, such as the Wagner Chronic Care Model (Wagner, 2001). The Department of Health launched the Expert Patient Programme (Tidy, 2015). Patient experience was recognised as a key dimension of care quality and started to be systematically surveyed. Meanwhile, many health charities, representing the interests of people with different diseases and conditions, grew in prominence and impact during this time.

The New Labour governments also continued the Conservatives’ attachment to market mechanisms and to a view of patients as consumers – reflected, for example, in policies to enable patients to have a choice of hospital. The accumulated advances in patient-centred care were captured in and symbolised by the NHS Constitution, launched in 2009 and updated in 2012, 2015 and 2021 (Department of Health and Social Care, 2021).

**The 2010s to present day.** The Conservative-led governments from 2010 presided over a much more constrained budget for the NHS. They continued to build patient-centred approaches into law, policy and guidance. The health secretary Andrew Lansley announced his 2010 reform plans with the mantra “no decision about me without me”. (This was a borrowing from the disability rights movement and it is debatable whether the policies lived up to this billing.) The Francis Reports into the failures of care in Mid Staffordshire highlighted the importance of NHS organisations listening to patients. The 2014 NHS *Five Year Forward View* (NHS, 2014) heralded the intention of having “a new relationship with patients and communities”. The NHS increasingly borrowed empowerment approaches from the more person-centred social care world – for example by encouraging the spread of personal health budgets. And social media provided a fresh fillip to patient-centred activists. But actual empowerment proved more elusive, and in these years the gross inequalities in health highlighted in the seminal 2010 Marmot Review, updated ten years later, continue to provide a grim background to the ever-changing NHS policy scene (Marmot, 2010; Marmot et al., 2020).



*A brief review of patient-centred care in other developed countries*

Parallel moves towards patient-centred care have occurred in other developed countries. Each country has taken a different path, shaped by the characteristics of how their separate healthcare systems are organised and funded. In Europe the principle of universal coverage holds, which is that all citizens can access healthcare without suffering financial hardship. This is achieved either by giving a strong role to independent health insurance organisations, as in Germany, France and the Netherlands – the “Bismarck” approach – or with governments taking a more central role in both funding and organising healthcare, as in the UK, Italy and Sweden – the “Beveridge” approach.

There is some evidence that Bismarck countries are more patient-centred than Beveridge countries (Health Consumer Powerhouse, 2019). For example, the UK scores well on patient rights and information but poorly on accessibility (waiting times for treatment) and “amber” on outcomes. The Netherlands, on the other hand, score even better on patient rights and information than the UK, and also well on accessibility and outcomes (Health Consumer Powerhouse, 2019).

The Picker Institute notes how Bismarck countries have embedded patient rights in statute. Germany issued a Charter of Rights for People in Need of Long-Term Care and Assistance in 2003. Its Patients’ Rights Act of 2013 gives patients explicit rights to choose physicians, hospitals and treatment types, request a second opinion and obtain timely face-to-face information about a proposed treatment. The Dutch have entrenched seven patient rights, similar to those in Germany, with the additional right to coordination between healthcare providers (Paparella, 2016). The NHS in England does have its Constitution, referred to earlier, although the commitments to patients’ rights are more modest and less explicit, and balanced by a section on patients’ responsibilities.

Uniquely among high-income countries, until recently (with the advent of Obamacare and the Affordable Care Act), there was no attempt at universal coverage in the US. Coverage continues to be offered either through private employment insurance schemes with high levels of co-payments, or through a public safety net for the very poorest and for older people, which leaves millions with inadequate or no cover. Not surprisingly, and despite spending far more overall on healthcare than all other comparable countries, the US scores badly on measures of patient-centred care. In a study comparing eleven high-income countries carried out by the Commonwealth Fund (Schneider et al., 2017) the US comes last on access and equity. Its

system has been described as “islands of excellence in a sea of misery” (Pollock, 2011).

Despite the sea of misery, the islands of US excellence do offer examples to other countries and opportunities for them to learn. Being often at the cutting edge of high-tech healthcare, the US has fostered a lively discourse about the downsides of modern medicine and what to do about them. For example, Michael Betz and Lenahan O’Connell (2003) write about the growth of professionalisation, specialisation, bureaucracy and population mobility, and how these have intruded into doctor/patient relationships and left patients feeling powerless and disaffected. Richard Bohmer (2009) argues that patient care has become the domain and responsibility not just of the individual practitioner, but of the whole organisation.

The US has also been at the forefront of practical moves to develop integrated and patient-centred care (for example, within health maintenance organisations such as the Veterans’ Administration and Kaiser Permanente); to advance shared decision-making (for instance, through provisions in the Affordable Care Act) and to integrate patients into quality-improvement initiatives (such as through the work of the internationally respected Institute for Health Improvement).

The American discourse has tended to emphasise the importance of patients having greater choice, control and agency, along the lines of Sherry Arnstein’s classic ladder of citizen participation in planning processes (Arnstein, 1969), which we cover in more detail later in this chapter (see Section 4, pp. 15–16). These are important dimensions of patient-centred care but, as this book shows, far from being the only ones.

## SECTION 4 HOW PATIENT-CENTRED IS CARE NOW?

Is the NHS more patient-centred now than in 1948? In some respects, almost certainly yes, but the question is not straightforward to answer. There is no single measure of the quality of healthcare. It is measured and assessed in a variety of ways, all of which have methodological strengths and weaknesses, but which, looked at together, paint a picture. Overall, there is evidence that the quality and outcomes of healthcare have improved over recent years, both in the UK and other high-income countries. For example, the Euro Health Consumer Index 2018 reported improvements across Western Europe in the previous twelve-year period, including in the UK, against a basket of measures (Health Consumer Powerhouse, 2018). COVID-19 might subsequently be shown to have slowed or reversed that trend.

When it comes to patient-centred care, the picture is more nuanced. As discussed earlier, patient-centred care is not a single, easily defined thing, but a basket of approaches. Assessing it depends to a great extent on the measures chosen and on how we uncover and interpret people's subjective experiences.

### *Advances in policy*

Certainly, there have been significant advances in legislation, policy, service organisation and professional attitudes, alongside broader societal changes. For example:

- **The case for engaging patients** in decisions about, and the management of their own care is now well established. In part this is because advances in public health and medicine have resulted in many more people living longer but with chronic conditions. Patient engagement is particularly relevant to people living with long-term conditions. The NHS's "comprehensive model of personalised care", which brings together a menu of approaches such as shared decision-making, personalised care planning, supported self-management, social prescribing and personal health budgets, is an example of how patient-centred care is moving into the mainstream (NHS, 2019).
- **The patient point of view** is now recognised as a legitimate and important source of data for monitoring and improving services. Patient and carer experiences are seen as indicators of the extent and quality of patient-centred care. Patient views and experiences are routinely collected in the form of national surveys and local feedback mechanisms. Digital platforms have extended the reach of feedback. For example, the website Care Opinion allows patients and carers to post stories about their experiences and elicit responses from providers. Care Opinion has been adopted as a universal engagement platform by the NHS in Scotland.
- **The active involvement of patients** in the design and delivery of services is now seen as a valuable and legitimate endeavour. This is reflected in the various discourses and models of co-design and co-production – for example, the experience-based co-design toolkit offered by the Point of Care Foundation (n.d.).
- **Social mobilising** has been an emerging strand, with social media providing new platforms on which patient activists can organise. Perhaps the best-known example is offered by the

doctor-turned-terminally-ill cancer patient Kate Granger, who in 2013 was dismayed to encounter healthcare staff who failed to introduce themselves to her when she was being treated in hospital. She launched the #HelloMyNameIs campaign to encourage staff always to introduce themselves.

- **A wider role for citizens in health matters** is built into NHS legislation – for example, the duty of commissioners to consult the public on major service changes – and into governance – for example, the role of governors and members of Foundation Trusts, and lay members of clinical commissioning groups. The local public watchdog role once performed by Community Health Councils is now exercised by a network of local Healthwatch organisations.
- **There was a marked “Mid Staffs” effect** as a result of the two inquiries by Robert Francis into poor care at Mid Staffordshire NHS Foundation Trust between 2005 and 2009. The first report (Mid Staffordshire NHS Foundation Trust Public Inquiry, 2010) highlighted multiple failures in a Stafford hospital to attend to the safety and quality of care for patients, and to listen to patients and their families. The second report (Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013) exposed wider systemic failures which enabled that scandal and which made the NHS vulnerable to other similar situations in the future.

The inquiries prompted soul-searching in the health community about patient focus, patient safety, organisational culture and the importance of accountable and compassionate leadership. The second inquiry gave rise to a significant policy response from the coalition government, with an initial document called “Putting Patients First”. Subsequent measures included: a renewal of the inspection and regulation regime under a revamped Care Quality Commission (CQC), the creation of the NHS Leadership Academy, a new duty of candour (in the event of harm suffered by patients or near misses) and a fresh emphasis on listening to patients – symbolised by the introduction of the NHS feedback tool, the “Friends and Family Test”. Naomi Chambers and colleagues (Chambers et al., 2018) found that in response to Francis there had been mostly positive (though variable) improvements in the behaviour of boards of NHS organisations.

### *Advances in practice*

How far have these developments in thinking and policy been reflected in healthcare practice and in people’s experiences of care? The stories

we share in this book present a mix of both good and bad experiences of care. Official data and assessments paint a similar, varied picture. The annual State of Care report published by the health and care regulator the Care Quality Commission is a case in point. In its report for 2019/2020 (CQC, 2020a) the Care Quality Commission assesses most of the care it sees in England as of good quality but also highlights a number of continuing concerns that predate the COVID-19 pandemic:

- The poorer quality of care that is harder to plan for
- The need for care to be delivered in a more joined-up way
- The continued fragility of adult social care provision
- The struggles of the poorest services to make any improvement
- Significant gaps in access to good-quality care, especially mental healthcare
- Persistent inequalities in some aspects of care

In addition the Care Quality Commission notes that while overall quality has been maintained, there was no overall improvement compared with the previous year. It also points out that the pandemic has put further strain on the system and magnified pre-existing inequalities. There is a good deal of continuity between one Care Quality Commission annual report and the next. In its previous report, for 2018/2019, the Care Quality Commission drew attention to problems including widespread difficulties in getting appointments and access to care; a lack of suitable, community-based services, especially for people with a learning disability, autism or mental illness; and people having to fight and “chase” to get the care they need. These can, among other things, be fairly read as deficiencies in patient-centredness. They partly reflect financial pressures and workforce shortages faced by the NHS, but culture, leadership and management also play a part.

The website Quality Watch keeps track of more than 200 indicators of quality of care, including patient experience measures that are relevant to patient-centred care. A similar mixed picture of good and bad emerges in relation to whether patients are informed about medication side effects, feel involved in decisions about their care, feel supported to manage their long-term condition, or report an overall good experience. The typical picture is that the majority report good experiences, but a significant minority do not; the patterns have remained broadly stable over several years but have shown a deterioration more recently. For example, the 2018 adult inpatient survey reported decreased patient experience scores compared with the previous year, in nineteen of the twenty questions asked (NHS, 2019). The 2019 adult inpatient survey

(CQC, 2020b) showed a mixture of improvement and decline against key measures of patient experience.

The charity coalition National Voices published an overview of the state of person-centred care in 2017, drawing on a range of data sources and focussing on a small number of key ingredients of person-centred care: how people experienced information, communication, participation in decisions, care planning and care coordination. It also looked at families and carers. Again, the results were mixed and the report notes that for some aspects of person-centredness – for example, coordination of care – there were no adequate measures (National Voices, 2017).

National Voices also looked at the variations in experience. People's experiences vary depending on time, place and many other factors, but survey data also show some broader patterns in the variability of experience based on demographic group and health status. For example, in the 2018 adult inpatient survey (NHS England, 2019), people with a long-standing health condition had significantly lower experience scores than those with no long-standing condition, and people from certain ethnic groups: for example, Indian, Pakistani, White and Black Caribbean, had significantly lower scores than the White British group (conversely, White Irish and African patients overall had more positive experiences). A 2016 thematic review by the Care Quality Commission (CQC, 2016) highlighted concerns that certain groups were less likely to be sufficiently involved in choices and decisions about their care and treatment – including people with long-term conditions, people over 75, people with dementia, young people with complex health needs, people with a learning disability and people detained under the Mental Health Act or experiencing a mental health crisis.

While it is important to attend to the groups who report worse experiences, there is also learning from what works well. For example, a 2017 report by the Care Quality Commission provides case studies of services that they rated “outstanding” and notes some common characteristics:

Good leadership is a central part of improvement – services that improve tend to have leaders who are visible and accountable to staff, promote an open and positive organisational culture, and engage effectively with partners. Improvements in the quality of care people are receiving are happening despite tight financial constraints and increased demand across the sectors. Also important is the way that care services in an area work together. (CQC, 2017: 5)

*Why isn't the NHS more patient-centred?*

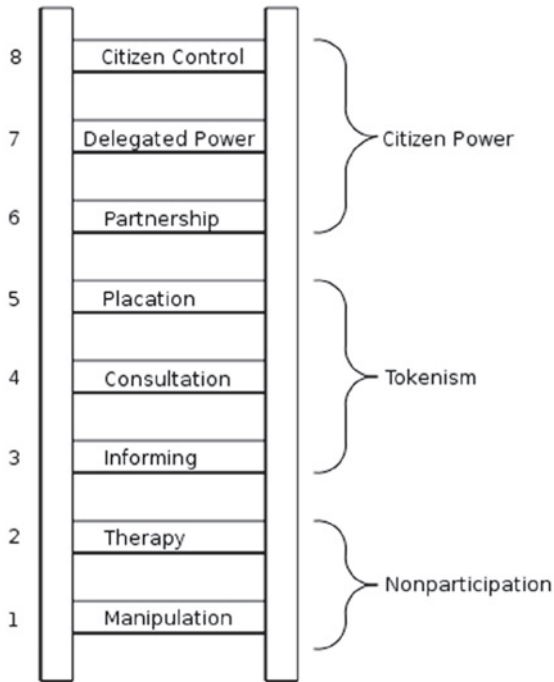
After many years of policy designed to make healthcare more patient-centred, the evidence would bear the conclusion that practice lags behind the good intentions. Why is this? A principal reason is that patient-centred care is hard to do, especially hard to do well, and that there are obstacles in the way.

One obstacle is that of capacity. Patient-centred care requires people, money, kit and expertise. A fully patient-centred NHS would, for example, have enough people and resources to devote sufficient time to patients; would train healthcare professionals in shared decision-making and health coaching; have IT systems that allowed patient records to be shared between different hospitals; have simple, effective and welcoming complaints and feedback systems; have the organisational nous to be able to coordinate services seamlessly across a large geography, and so forth. In reality, people, money and kit are always in short supply. So is the expertise needed to run the large and highly complex system which is the NHS. Translating high-level policy into practice challenges even the ablest. And highly able managers and leaders are a strictly finite resource.

Another obstacle is power. Patient-centred care demands a bigger say for patients. In this respect it challenges the current distribution of power and that challenge is to an extent resisted. Power lies predominantly with the government, the managerial senior leadership of the NHS and the health professional elites. The policies and activities of the NHS reflect the priorities of the powerful. These priorities certainly reflect and overlap with the priorities of patients and the public. But they are not the same. In this analysis, the powerful have a strong incentive to maintain their power and are reluctant to share it, so that processes and mechanisms designed to share power are prevented from realising their full radical potential.

The result is that patients – and also frontline staff – can often feel powerless. They can experience engagement efforts as tokenistic or paternalistic: the doctor who is not really listening, the public consultation designed to rubber-stamp decisions already made behind closed doors. In terms of an analysis of power (and how far it is shared with the citizenry), the charge is that the NHS remains stuck at best on the middle (“tokenism”) rungs of Arnstein’s famous ladder of participation (Arnstein, 1969).

While those with power can choose to share it, they can also wrest it back. In that sense, without more radical change, patient-centredness remains provisional. During the COVID-19 pandemic, a number of



**Figure 1.1** Arnstein's ladder of participation

patient organisations noted that major changes were made to the way in which the NHS was organised, with little or no involvement of communities and public representatives. When the going gets tough, patient and public engagement can be seen as a “nice to have”, rather than an essential ingredient of informed decision-making.

This power imbalance cannot be fully understood unless also viewed through the lens of equality, diversity and inclusion. In important respects those at the top of the NHS do not represent the communities they serve, and from which the broader NHS workforce is drawn. Ethnicity is the most visible (though far from the only) point of difference. The report on the “snowy white peaks” of the NHS (Kline, 2014) highlighted the persistent lack of ethnic diversity in the upper echelons of NHS management and explored the connections between this lack of diversity; the experiences of inequality and discrimination among Black, Asian and minority ethnic staff; and shortcomings in patient care. Race inequality was further highlighted in 2020 as a result of the unequal



impacts of the COVID-19 pandemic, and because of the worldwide Black Lives Matters protests following the murder of George Floyd in the US. There is growing debate about such concepts as unconscious bias, white privilege and intersectionality, and their applicability in the healthcare context. In the longer run, for example through the application of the NHS Workforce Race Equality Standard, it is to be hoped that an NHS leadership which better reflects the communities it serves might also better hear those communities.

A further obstacle is that of NHS organisational culture. Commentators and academics such as Professor Michael West have highlighted enduring features of NHS culture that are likely to stand in the way of achieving patient-centred care (West, 2017). A top-down, authoritarian style of management is seen as widespread: one that focusses more on managing performance and hitting targets than on engagement and improvement, and which can stifle innovation and the adoption and spread of good practice. The aforementioned Francis Inquiries into the poor care at Mid Staffordshire NHS Foundation Trust (Mid Staffordshire NHS Foundation Trust Public Inquiry, 2010 and 2013) shone a light on the impact of this management style, sparking a wider discourse about NHS culture at its most dysfunctional, where forceful management veers into bullying, intimidation and victimisation, a failure to listen to patients and frontline staff, and with failures of care denied and covered up.

It goes without saying that such authoritarian cultures are conducive neither to patient-centred care nor to staff empowerment. Disempowered and disaffected staff are not in the best position to provide good care. Nor are they well placed to act as respected and supported champions for change and improvement. In an adverse culture which is potentially or actually harmful to patients, staff have limited options. They can speak up, but that is risky for them. The whistleblowing option is frequently a career-ending one. They can keep their heads down and do their jobs as best they can. They can give up trying to make things better, even within their direct sphere of influence, and adopt a stance of “learned helplessness”. Or they can quit.

A key response to problems of NHS culture has been to seek improvements in the quality of NHS leadership. This was a significant motivation for the creation of the NHS Leadership Academy in 2013, with its emphasis on nurturing a new cadre of open, engaging, collaborative and compassionate NHS leaders.

The annual NHS staff survey provides some evidence that NHS culture and leadership are improving. The results of the 2019 survey show a slowly improving trend on many of the measures, but with some

areas of continuing concern. Thus there has been a significant rise in the proportion of staff who would recommend their organisation as a place to work, but more than a third (37 per cent) still would not. There has been a small rise in the proportion of staff who say that they would feel secure reporting concerns about unsafe clinical practice, but 28 per cent say they would not (NHS England, 2020).

Open and compassionate local NHS leaders may find themselves in conflict with national NHS bosses. The dictates of quality may, for example, be in tension with the dictates of financial management. To this extent, the perspectives of culture and power intermingle. The top-down, target-driven NHS management culture is very much an outcome of priorities set by government ministers, and how hard these priorities are driven. The imposition of power from Whitehall can foster powerlessness on the wards and in the clinics.

Conversely, the perspectives of capacity, power and culture offer hope. The NHS is shaped by powerful political and economic forces but it is also the cumulative effort of millions of staff. To differing extents, everyone in the NHS has the scope to improve their capacity to be patient-centred, to confront or share power and to improve the culture of their teams and organisations. The stories in this book illustrate some of the possibilities.

## SECTION 5 STORYTELLING: THE APPROACH WE TAKE IN THIS BOOK

There is no way to understand the human world without stories. Stories are everywhere. Stories are us. (Storr, 2019: 2)

This book is based on stories. Storytelling draws on lay wisdom to generate new understandings. It complements and enriches the knowledge that comes from science and data. Storytelling is as old as humanity. In the forms of myths, legends and fables it was the means by which groups and societies transmitted their histories, identities, moralities and cultural meanings. The words “story” and “history” are closely related and, in some languages (for example French and German), identical (*histoire*, *Geschichte*).

While in contemporary culture we often associate story with entertainment, it has always served a serious purpose too. Stories have power. They create an immersive experience for listeners and readers which can be more compelling and memorable than factual information (Mar and Oatley, 2008). Artur Lugmayr and colleagues (2016: 15709 and

15715) discuss the concept of “serious storytelling” in which the power of narrative – conveying experience, triggering emotional responses and reshaping understandings – is used to achieve serious goals. Organisations are formed and reformed in part by the stories which members tell about their collective selves, values, victories and challenges (Seely-Brown et al., 2005).

Stories can be a call to action, part of social mobilising for change. Marshall Ganz, who heavily influenced Barack Obama, and has also worked with the NHS, wrote:

A story is like a poem. It moves not by how long it is, nor how eloquent or complicated. It moves by offering an experience or moment through which we grasp the feeling or insight the poet communicates. The more specific the details we choose to recount, the more we can move our listeners, the more powerfully we can articulate our values. (Ganz, 2008)

### *Storytelling in healthcare and in the NHS*

The Victorian physician Sir William Osler, an early enthusiast for hearing the patient story, stressed the centrality of history-taking: “Just listen to your patient, he is telling you the diagnosis.” He helped influence the course of undergraduate and postgraduate medical education (Bliss, 1999). Michael Balint talks about the “flash of understanding” that arises in medical consultations as a result of close listening and probing questioning of the patient (Balint, 1967). Stories are increasingly a feature in modern healthcare. This reflects the rise of service user and survivor movements and a growing interest in patient-centred care. It could also reflect an impulse to restore the human into what some see as an emotionally distant and over-technocratic culture in modern healthcare. Patient stories are appear more often in healthcare literature, such as the growing “single testimony” literature by frontline clinicians – for example, Henry Marsh (2014), Adam Kay (2017), Christie Watson (2018) and Rachel Clarke (2020) – and in books on dying by Atul Gawande (2015) and Kathryn Mannix (2017), and on mental ill health by Linda Gask (2015) and Suzanne O’Sullivan (2015).

Storytelling can be a teaching instrument (Rossiter, 2002). Organisations like Healthtalk ([www.healthtalk.org](http://www.healthtalk.org)) and Patient Voices ([www.patientvoices.org.uk](http://www.patientvoices.org.uk)) use stories to help patients understand their conditions and to support organisations to change their cultures and behaviours in light of people’s experiences. Enza Gucciardi and colleagues

(2016) discuss how stories can be used to encourage behaviour change and support people to manage their long-term health conditions. Mark Exworthy (2011) examines how health service managers can come to change their professional understandings and practices as a result of recounting and reflecting on their own personal experiences of illness and healthcare. It is now considered good practice to start board meetings of NHS organisations with a patient or staff story in order to keep discussion grounded in what matters at the frontline and to focus minds on care quality. Making use of new media platforms, TEDxNHS ([www.tedxnhhs.com](http://www.tedxnhhs.com)) was founded in 2016 as a volunteer movement to allow the voices of everyday NHS staff and patients to be heard on a national stage. It aims to break down the walls that can exist between professions, organisations and cultures and to share learning in a new and engaging way.

In short, storytelling has secured a well-recognised place in health and sickness discourses – a status analogous to that of oral history in relation to academic history. In parallel, and in the form of “narrative research”, storytelling has established legitimacy as a social science research method, as argued by Trish Greenhalgh and Tom Wengraf (2008), for instance. There is a standing critique of the narrative method as “anecdotal” and thus insufficiently scientific (Exworthy, 2011), but this is changing. For example, Rachel Rose and colleagues (2015), synthesising a large body of evidence, showed that patient stories had the potential to facilitate culture change, more patient-centred practices and greater humanism in healthcare.

### *Finding stories: Problems of ethics and methodology*

In Chapters 2 to 7 of this book we present stories that we have collected, curated and then presented in ways that are intended to promote reflection and learning. The Appendix at the very end of the book has the complete anonymised list of interviewees, including background details. This method is distinct from the “single testimony” accounts we have described above. The storytellers did not approach and use us as a vehicle for disseminating their story. Rather, we initiated and controlled the process. As authors we are intermediaries between the people with stories and the people who might learn from these stories. This process raises a number of considerations which are both ethical and methodological.

There is first the question of selection bias. For example, in finding people to tell their stories it is relatively easy to draw upon a pool of

actively engaged people with strong links into professional circles and thus to exclude voices from poorer, disadvantaged, more diverse and marginalised communities. Further bias is possible in how the authors translate people's experiences into text on a page. Some people have a clear story that they want to tell, but for others it is more a case of responding to an invitation to share their experience, which is then turned into a story through the processes of interview, transcription and editing.

Stories are inherently biased to the extent that they embody the storytellers' values, the limitations of their memories, and their judgements about what is important and what it means. Storytellers select some things, present them in particular ways and exclude other things. There is a risk that authors of a book like this introduce further bias through their active involvement in creating and presenting the stories. At best we are neutral brokers between storyteller and audience, but we risk distorting or misrepresenting our volunteers and at worst exploiting them.

A third issue is the risk that storytellers suffer in the process of telling their story. Though recounting a difficult or traumatic experience can be therapeutic, the opposite can also be true. Inviting people to reveal their private thoughts and feelings, as distinct from a more "public account" can be challenging (Cornwell, 1984). Putting a traumatic experience into words is not always possible or helpful (Van der Kolk, 2014; Hooper, 2019). Patients sometimes express frustration that they have told their story repeatedly but nothing has changed as a result (whether in the context of research or in service improvement). It can be argued that hearing a patient story confers a moral obligation to act in light of it.

These ethical risks informed our methodological approach, including our consent process. To minimise selection bias and maximise diversity, we reached out in a variety of different ways and sought individuals of varying ages, backgrounds and health issues. We found it relatively straightforward to achieve a spread of ages, a gender balance and a degree of ethnic diversity. It took more effort to compensate for the bias towards people from middle-class, professional circles (for example, those who are well connected with the health world, and those with whom the authors had a personal connection). It was hardest of all to find people who were not already in some way engaged, either as health volunteers (such as chairing a GP patient participation group) or more broadly active in their communities. As a reminder, a table summarising our storytellers and some of their characteristics, appropriately anonymised, is shown in the Appendix.

We used a variant of Wengraf's (2001) biographic narrative method – essentially asking people to tell their story in the way they wanted to, which was often “from the beginning”, wherever that was, with only minimal prompts from us along the way. Our stories were gathered through a mixture of face-to-face and telephone interviews. The interviews were recorded. As listeners, we were sensitive to the possibility that storytellers become emotionally distressed in their recounting and were always ready to pause or end the interview. (This did not happen.)

The listening process was constantly interesting for us as interviewers. There were various aspects that on reflection we thought were of wider relevance to the art of listening to patients in the NHS:

- Our storytellers spoke freely. They had as much time as they needed (on average about an hour), and as listeners we had no agenda, other than to attend to their account and occasionally nudge it along through our questions and reactions. These are very different conditions from those which characterise typical clinical and other NHS encounters, in which professional listening is for a defined purpose (e.g. diagnosis), is geared towards determining action (e.g. referral) and is under time pressure. We realised that it was a privilege to be able to listen free of the responsibility to do something immediately. It enabled us to give our full attention.
- We were surprised that it was relatively easy to elicit personal accounts over the phone, despite the absence of eye contact and body language.
- Not having to take notes was a further liberation for the listener. It was also experienced by at least one interviewee as more respectful: the professional who is constantly clacking away at a computer or head down in a notebook can often be a source of irritation in a therapeutic context.
- Some tales were fragmented, raw, unvarnished or impressionistic; others were polished narratives. This variation partly reflected the extent to which people had told their story previously. It is also the case that some people are naturally gifted storytellers and others much less so. We realised that all the stories contained important learning, regardless of the communication skills of the interviewee. It reminded us that in the clamour of voices, there lies the risk of paying undue attention to the eloquent and persuasive, to the detriment of the halting and inarticulate.

## SECTION 6 HOW TO READ THIS BOOK

There are twenty-five stories in this book, of varying length, divided across six chapters. The chapters group the stories around the major stages of the life-course, from birth to death, and around some of the key categories of ill health. A concluding chapter draws together some of the key issues raised by the stories. Each story chapter begins with a brief introduction to the connecting theme, presents the stories, and then concludes with a short set of questions designed to encourage reflection on the implications of the stories for practice. The stories do not lend themselves to a conventional textbook format in which a body of knowledge is progressively laid out and then translated into key facts, tips and actions. The principal demands that the stories make of the reader are: engage and reflect. It follows that the reader is free to read as few or as many of the chapters as desired, and in any order.

Chapter 2 is about pregnancy and childbirth. **Cathy** is a healthcare professional who recently gave birth. **James** is an older new father.

Chapter 3 is about children and young people. **Dan** is a normally healthy teenager who became acutely ill. His father Jonathan tells the story. **Jim** was a severely disabled young man from birth until his death aged 36. His parents Lucinda and Justin tell his story. **Eve** remembers how as a child she came to be diagnosed with Type 1 diabetes. **Finbar** is a teenage boy with a diagnosis of scoliosis. His mother Eileen tells the story of being his carer.

Chapter 4 is about managing long-term health conditions. **Katie** has had Type 1 diabetes for about twenty-five years. **Tim** is a young man living with epilepsy. **Joanna** has various long-term conditions, including a rare condition. **Jasmin** waited four years to get a diagnosis of lupus. **Venetia** lives with chronic fatigue syndrome.

Chapter 5 is about adult acute care and cancer. **Jill** suffered a major knee injury. **Andrea** had an operation to remove her gallbladder. **Lucy** was hospitalised with sepsis. **Shona** experienced breast cancer.

Chapter 6 is about mental illness. **Audrey** describes her quest to find services for a family member. **Stanley** describes his breakdown and subsequent years of contact with mental health services. **Alan** has been living with bipolar disorder for over twenty years. **Nathan** is a teenager with various mental health issues. **Lucy** is a retired hospital psychiatrist with a severe and enduring mental illness.

Chapter 7 is about older age and end of life. **Robert** is in his 80s with a heart condition and stomach and joint problems. **Rabiya** cares for her mother who has dementia. **James** looked after his mother who had

dementia. **Sheila** cares for her husband who has dementia. **Kauri's** dad died of pancreatic cancer.

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