# What do people do in the aftermath of healthcare-related harm? A qualitative study on experiences and factors influencing decision-making

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## ABSTRACT

**Objectives** To capture experiences of people self-reporting harm and contrast responses and actions between those who do or do not take formal action.

**Design** Semi-structured qualitative interview study.

**Setting** People self-reporting harm experienced in the National Health Service (NHS) or their family/friends identified from a general Great British population survey.

**Participants** 49 participants.

**Results** There were commonalities in experiences after harm whether formal action (including making a formal complaint or litigation) was taken or not. Many participants reported raising concerns informally with NHS staff, trying to access explanations or support, but were usually unsuccessful. Decision-making on action was complex. There were multiple reasons for not pursuing formal action, including fears of damaging relationships with clinicians, being occupied coping with the consequences of the harm or not wanting to take action against the NHS. NHS advocacy services were not regarded as helpful. Knowledge of how to proceed and feeling entitled to do so, along with proactive social networks, could facilitate action, but often only after people were spurred on by anger and frustration about not receiving an explanation, apology or support for recovery from the NHS. Those from marginalised groups were more likely to feel disempowered to act or be discouraged by family or social contacts, which could lead to self-distancing and reduced trust in services.

**Conclusions** People actively seek resolution and recovery after harm but often face multiple barriers in having their needs for explanations, apologies and support addressed. Open and compassionate engagement, especially with those from more marginalised communities, plus tailored support to address needs, could promote recovery, decrease compounded harm and reduce use of grievance services where other provision may be more helpful.

### WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Current knowledge of responses and actions after National Health Service (NHS) harm in Britain is mainly based on experiences of people who complain formally or litigate and does not include the perspective of those who do not take this route.

### WHAT THIS STUDY ADDS

- ⇒ Most people initially seek support from healthcare providers or advocacy services, and when this is not forthcoming, their decisions about whether to take formal actions are influenced by complex multiple factors (eg, lack of knowledge of the complaints system, feeling disempowered, not wishing to raise a grievance).
- ⇒ Anger and frustration related to the lack of explanations, apologies or support can tip a minority to act, but the majority are left dealing on their own with consequences which can compound harm and reduce trust in the healthcare system.

## BACKGROUND

Healthcare's remit is to relieve suffering for those who use its services; however, our recent survey of the British public found 9.7% self-reported harm through National Health Service (NHS) treatment or care or lack of access to it.[1] When outcomes are poor and expectations of relief are not met or suffering is exacerbated, the negative experience can be further amplified by insensitive responses from healthcare organisations.[2–4] Impacts go beyond the physical impact, also affecting psychological health, social roles and financial status.[5] Emotional consequences of harm tend to be overlooked and downgraded as less

**HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY**

- ⇒ There is a gap (beyond traditional complaints and legal services) in the provision of holistic support for those reporting healthcare-related harm from a wide range of causes.
- ⇒ Open and compassionate communication and tailored patient-centred and inclusive support would facilitate resolution and recovery and complement other patient-centred safety initiatives in the NHS.

important than physical impacts by the health service.[6] However, many people experience disturbing memories, distress, disappointment and anxiety after harm, and some develop depression or post-traumatic stress disorder.[7–10] The experience of harm can have long-term effects not only on health and well-being but trust in healthcare service use into the future.[2–5]

The international literature on the impact of healthcare-related harm and peoples' interactions with healthcare systems afterwards highlights the frequency of poor experiences.[2 4] Those affected and their families seek acknowledgement of what has happened, understandable explanations and support to mitigate impacts. However, clinical teams and mediation and grievance services often demonstrate defensive behaviour which limits listening and empathy, provides vague or obtuse explanations, disingenuous apologies and little exploration of support needs.[2 3 11 12] To date, understanding of peoples' responses after harm in the British NHS mainly comes from studying the minority of people who take formal action, which encompasses either lodging a written complaint or a legal claim for compensation.[13 14] Such actions are often instigated as a last resort in order to gain explanations or apologies, support for recovery, to ensure accountability or prevent the same thing happening to others. Financial compensation is often not the main concern.[13] Formal grievance processes are a mechanism for delivering accountability and, in some cases, learning and change for organisations, and it is important these processes are accessible to patients and families in cases where accountability or financial redress are key priorities. However, patients may also have other priorities. Our survey of patients harmed in the NHS highlighted that 44% wanted treatment or care to redress harm, with only 20% wanting an investigation into causes and 10% disciplinary action.[1] High levels of dissatisfaction among harmed patients and families with grievance services indicate a limited ability to meet wider needs for recovery and, in some cases, a potential to cause further harm.[15–19] The NHS Patient Advocacy and Liaison Services (PALS) was introduced across British hospitals to address a gap in provision of advice, information and assistance to those experiencing harm, but capacity has been limited.[20] Levels of access and satisfaction remain low.[1]

Relatively little is known about decision-making, motivations and actions in the majority of people who do not take formal action after harm. Physical and psychological harms experienced by patients in the NHS result from a much wider range of causes than clinical error and encompass complications of treatment, failures in care coordination or lack of access to treatment or care. Formal grievance services or PALS may not represent a comprehensive enough approach to ensuring that different types of harm and their impacts are addressed by the NHS.

This study aims to explore the experiences of people self-reporting harm as a result of NHS treatment or care or lack of access to such care who have or have not sought formal redress. We will contrast decision-making after harm in both groups to identify factors influencing capability, opportunity and motivation to action.[21] This comparison will draw out key barriers and facilitators to the use of grievance services, alongside highlighting unmet needs for patients and families, thus helping to inform the design of services that support resolution and recovery after harm.

## METHODS

### Study design and context

Semi-structured qualitative interviews were conducted with people who had self-reported experiences of harm in the NHS, or family members or friends who provided care and support to someone who was harmed, identified via a survey (reported elsewhere[1]) that ran in 2021 and 2022.

### Sampling and selection criteria

The survey collected information on physical and/or emotional healthcare-related harm in the last 3 years, its location, impact, peoples' responses and desired reactions from healthcare providers. The survey was administered as part of a telephone-based omnibus survey by Ipsos, using quota sampling to ensure a nationally representative sample. A total of 10 082 members of the general public across Great Britain completed the survey, with 9.7% (n=988) reporting harm and 12% (n=119) agreeing to be contacted for a qualitative interview and providing contact details. Potential interview participants were purposively selected from this 12% based on their responses to the survey to ensure a distribution of participants with physical and/or emotional harm, a range of harm severity and whether they took formal action or not (figure 1). For the purposes of the study, we defined 'formal action' as a self-reported submission of either a verbal or written complaint to a healthcare provider/service or the legal filing of a claim for compensation. The harm had to have developed within 5 years of the study. Those with a claim in progress (n=1) were excluded due to the possibility of the interviewer being

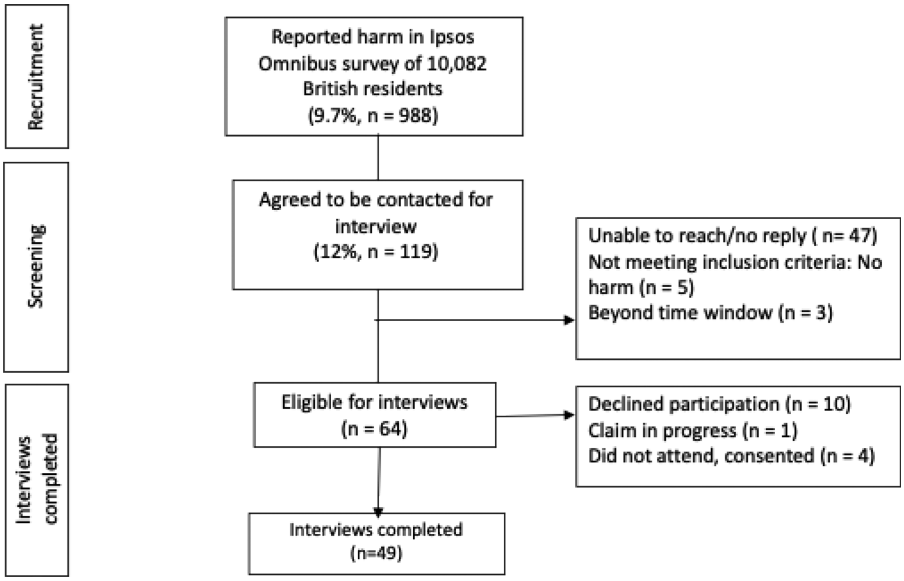

**Figure 1** Participant recruitment flow chart.

called to give evidence in court. Contacting an advice or advocacy service such as the NHS PALS was not considered formal action. Potential participants were contacted by phone or email. 47 who could not be contacted were excluded.

### Data collection

Remote in-depth narrative-style interviews lasting between 60 and 120 min were conducted by two researchers (LT and HC). Participants could have a family member present if they wished, but the majority chose to be interviewed alone. They were also free to terminate the interview at any point or reschedule if emotionally overwhelmed. Participants were given the opportunity to narrate their experiences without interruption from the interviewer, following which a topic guide was used to facilitate further exploration of the harm experience as well as factors influencing responses to harm (online supplemental box S1). The topic guide was developed by the research team based on the literature, input from academic experts and an Expert Advisory Group (EAG) consisting of patient and public involvement members, representatives from safety advocacy groups, clinicians and legal professionals. Participants were provided with a leaflet listing a range of sources of advice and support at the end of the interview.

### Analysis

The interviews were transcribed verbatim and inductively analysed by the first author (LT) using a systematic approach adapted from constructivist grounded theory.[22] This approach was particularly relevant to the exploration of complex experiences and sense-making from the participants' perspective.[23]

Analysis proceeded in two stages. For stage 1, close reading and initial line-by-line coding of transcripts accompanied by constant comparison of the data within and between interviews generated focused codes which represented experiences across all participants. Focused codes were developed into categories capturing collective aspects of peoples' journeys after harm based on the data and its variations. The frequency of categories and their relationships was mapped. If particular areas were not adequately explored, then questioning in subsequent interviews was adapted until there was a 'sufficient' level of confidence that the elements of each of the categories were consistently generated among a substantive number of participants.

In stage 2, a deductive approach was applied to the inductively collected data. Findings emerging from across participants who had taken formal action and those who had not were mapped against the Capability, Opportunity, Motivation–Behaviour (COM-B) model of behaviour change constructs: capability (an individual's psychological and physical capacity to engage in the behaviour concerned), opportunity (factors that lie outside the individual that make the behaviour possible or prompt it) and motivation (brain processes that energise and direct behaviour including goals and conscious decision-making and also habits and emotional prompts).[21]

### Credibility checks and reflexive practice

The codes generated from the analysis and a subsample of transcripts were reviewed by the study team (LT, CP, HC, HH, MP), following which the developing findings were discussed and 'blind spots' explored through further data collection and analyses. Interim findings were also presented for feedback to both the EAG and wider study team which included subject and methodological experts.

## FINDINGS

### Participants

42 people (coded P in quotes) with self-reported experiences of harm and seven family members or friends (coded F in quotes) who provided care and support to someone who was harmed participated (table 1). 37 (72%) were female, 60% white British, living in various regions of Great Britain and with a range of socioeconomic circumstances. Harm was described across a range of severity with moderate emotional impact (45.1%) and/or moderate physical impact (35.3%) reported most frequently. The harm resulted from a single event or several incidences of poor care and could be due to an error, omission, poor coordination or the failure to access treatment or care with failures in both the technical and relational aspects of care represented (see table 2 for examples of harm). 29 participants who did not take formal action were compared and contrasted with 20 who did.

### The journey after harm

There were many commonalities, but also some differences, in participants' descriptions of their experiences after NHS-related harm independent of whether or not formal action was pursued. For most, the journey after harm was a longer-term rather than short-term process. When the harm occurred in close proximity to an event, individuals often described an initial state of disbelief usually followed by distress. For others, where the evolution of harm was slower, the distress accumulated over time. Many had difficulty making sense of their situation. Discussions with family, friends or colleagues or searching information on websites or social media led to a realisation that their treatment or care might have caused harm.

> Like even my daughter said, "No, there's something wrong there mum, no, there's definitely something wrong there." I said, "Yeah." P003

In some cases, a healthcare professional (HCP) who witnessed the event provided confirmation, particularly by coming forward and expressing empathy in the immediate aftermath. Socially isolated individuals or those who took longer to share their concerns with others seemed to find the processing of their harm experience more challenging.

In the early period after harm, many described at least one informal attempt to raise concerns, primarily with health service staff where the harm had occurred. Only a few felt confident to communicate with a senior doctor; others sought out nurses, managers or receptionists. Rarely would staff initiate discussion about what had happened or offer an explanation and support. If initial concerns were dismissed, some participants made further attempts to raise the issue with other team members or their primary care physician. Participants were seeking a better understanding of what had happened and why, access to advice as to

**Table 1** Sample characteristics (n=49)

| | Frequency (n) | % |
|---|---|---|
| Sex | | |
| Female | 36 | 73.4 |
| Male | 13 | 26.5 |
| Age | | |
| 18–24 | 8 | 16.3 |
| 25–34 | 9 | 18.4 |
| 35–44 | 6 | 12.3 |
| 45–54 | 7 | 14.3 |
| 55–59 | 5 | 10.2 |
| 60–64 | 7 | 14.3 |
| 65+ | 7 | 14.3 |
| Ethnicity | | |
| Asian Chinese/British Chinese | 3 | 6.1 |
| Asian Indian/Pakistani/British Indian/Pakistani | 7 | 14.3 |
| Black Caribbean/black British/black other | 2 | 4.1 |
| Mixed background | 4 | 8.2 |
| White British/Irish | 29 | 59.2 |
| White other | 2 | 4.1 |
| Declined to answer | 2 | 4.1 |
| Social grade* | | |
| A | 1 | 2.0 |
| B | 10 | 20.4 |
| C1 | 23 | 47.9 |
| C2 | 2 | 4.1 |
| D | 2 | 4.1 |
| E | 6 | 12.3 |
| Unknown | 5 | 10.2 |
| Employment | | |
| Full-time paid work | 10 | 20.4 |
| Part-time paid work | 6 | 12.3 |
| Self-employed | 7 | 14.3 |
| Not working due to long-term illness or disability | 10 | 20.4 |
| Seeking work | 3 | 6.1 |
| Retired | 11 | 22.4 |
| Full-time student | 2 | 4.1 |
| Geographical region | | |
| East Midlands | 3 | 6.1 |
| Eastern | 2 | 4.1 |
| London | 11 | 22.4 |
| North East | 2 | 4.1 |
| North West | 3 | 6.1 |
| Scotland | 3 | 6.1 |
| South East | 11 | 22.4 |
| South West | 4 | 8.2 |
| Wales | 2 | 4.1 |
| West Midlands | 4 | 8.2 |
| Yorkshire And Humberside | 4 | 8.2 |
| Physical harm | | |
| No impact | 7 | 14.3 |
| Mild | 9 | 18.4 |
| Moderate | 19 | 38.8 |

Continued

**Table 1** Continued

| | Frequency (n) | % |
|---|---|---|
| Severe | 13 | 26.5 |
| Don't know | 1 | 2.0 |
| Psychological harm | | |
| No impact | 1 | 2.0 |
| Mild | 7 | 14.3 |
| Moderate | 22 | 44.9 |
| Severe | 18 | 36.7 |
| Declined to answer | 1 | 2.0 |
| Did not take formal action (DnTFA) | 29 | 59.2 |
| No claim made or informal complaint only | 22 | 44.9 |
| Sought formal advice but no formal action taken | 7 | 14.3 |
| Took formal action (TFA) | 20 | 40.8 |
| Made a formal complaint | 14 | 28.6 |
| Legal action taken | 6 | 12.3 |

*Social grade: National Readership Survey Classification: A-Higher managerial, admintrative and professional, B: Intermediate managerial, administrative and professional, C1: Supervisory, clerical and junior managerial, administrative and professional, C2: Skilled manual workers, D: Semi-skilled and unskilled manual workers, E: State pensioners, casual and lowest grade workers, unemployed with state benefits. https://nrs.co.uk/nrs-print/lifestyle-and-classification-data/social-grade/

what to do next or support for physical or emotional impacts. Some commented on how emotionally healing it was when a member of NHS staff took the time to listen to them. However, few participants secured adequate explanations or assurances that their case would be followed up, it was far more common to feel ignored, disregarded or have the veracity of concerns questioned.

> There was no, "Are you all right? We'll put it on your record," or anything like that. It was, "The doctor is very busy at the moment, can't talk to you, please put your query in an email." P022

At times, participants went along with their provider's view of events rather than their own, in order to access the needed symptom relief or support. Others, distressed over the prospect of returning to the provider where the harm happened, looked for help outside of the NHS including alternative and private providers.

> And so [daughter] was kind of like, she thought this isn't, what he's saying to me isn't right. But then she was thinking, "Well this is the only help I'm going to get because there isn't another case worker, so I have to kind of like play along to get the help." F003

Recognising the full emotional or physical impact of the harm usually happened over time and was often accompanied by feelings of anger, disappointment, exhaustion and sometimes helplessness. Participants frequently expressed high levels of anxiety centred on getting back to work, fulfilling family roles or managing health in the long term. Continued dismissal or rebuttal from a HCP heightened feelings of rejection and abandonment.

### Factors influencing the decision to take formal action or not after harm

Most participants had at some point considered the option of taking formal action, even if only fleetingly. Only a small minority reported receiving an explanation, an apology or support and thus never considered the need for further action. Multiple factors were described as influencing decisions around formal action, and these have been categorised under the COM-B model constructs of capability, opportunity and motivation (table 3). This approach necessarily simplifies the detail in people's accounts to enable the teasing out of individual factors under each construct and downplays their complex interactions. Some factors influenced behaviour across a spectrum, at one end acting as a barrier and at the other, as a facilitator to taking formal action. In addition, some factors applied to more than one COM-B construct, influencing behaviour through differing mechanisms.

### Factors affecting capability

The construct of capability relates to barriers and enablers associated with a participant's sense of ability to take a certain action, in this instance whether to take formal action or not. Participants who did not take formal action described uncertainty about how to make a complaint or difficulties filling out forms with sometimes unsuitable prespecified sections. Some were unsure whether or not their harm would or could be dealt with by complaints or legal systems, especially as to whether it would be regarded as serious enough. Participants who had migrated to Great Britain from other countries were most likely to be influenced by these beliefs. Additionally, low confidence in voicing concerns and in self-advocacy affected capacity to act.

> To be honest at that time I didn't know that you could, like there is a—I don't know you could complain somewhere, or you could have mentioned [it to someone], I never knew about it. P040

In contrast, those who took formal action were more aware of their right to complain, the complaints system and the possibility of seeking a solicitor's opinion. This knowledge came not only from experiences within the health service but also from other areas of life such as consumer rights or employment practices. Taking this action required self-confidence, and participants found it easier if they already had experience of speaking up to authority, accompanied by having a greater sense of control over their lives. Being in a more recovered health state was also important when assessing the ability to cope with the anticipated pressures of formal action.

**Table 2** Examples of the types of harm experienced among participants

| | Severity (self-reported) | | |
|---|---|---|---|
| | **Mild** | **Moderate** | **Severe** |
| Physical impact | n=9 | n=19 | n=13 |
| | Prolonged, untreated abdominal pain experienced in NHS walk in clinic. P021<br>Lack of follow-up from GP practice led to prolonged period with discomfort due to undiagnosed hernia. P022 | Dismissal of patient's advice and problematic sedation led to traumatic catheter insertion and subsequent infection with impact on the management of other longstanding conditions. P013<br>Middle grade doctor ignored mother's expression of concern about her child's deteriorating condition and neurological disturbance, which caused delays in treatment and further deterioration resulting in admission to critical care. F002<br>Worsening bladder symptoms left untreated due to lengthy delayed access to consultation and treatment. P028 | Deterioration on ward following multiple failures to identify postoperative organ damage and development of sepsis. Led to prolonged hospital stay. P033<br>Midiagnosis and failure to monitor risk of stroke, despite family member's warning that patient had previously had stroke. Carer found mother in a 'catatonic state' on ward with hip and arm injuries and in a state of undress. Recovery from injuries took several months as an inpatient and was followed by at home support. F005 |
| Psychological impact | n=7 | n=22 | n=18 |
| | In pain and delays securing appointment. Appointment cancelled last minute. P029<br>Poor experience with mental health services, without continuity of case with same therapist. Offered little meaningful support. P018 | Colposcopy examination undertaken without due attention to patient's anxiety which led to a panic attack during the procedure.Intense anxiety in the aftermath led to self-medication of non-prescription drugs to cope with further gynaecological investigations. P004<br>Long wait after 'arduous' referral and assessment process to get individual talking treatment only to be offered group therapy at inconvenient times. Patient left feeling hopeless and in despair with increased stress and sense of uncertainty about getting sustained support. Reluctant to seek help for mental health in the future. P042 | Mismanagement of long-standing condition during hospital stay led to pain and physical long term impacts. Developed post-traumatic stress disorder and intense anxiety at thought of engaging with healthcare in the future. F002<br>Male anaesthetist questioned and berated patient's refusal to take a pregnancy test despite being in menopause. Altercation resulted in fear and vulnerability and feeling unsafe prior to having to undergo surgery with the same anaesthetist. P014<br>Offered therapy for panic attacks which left her feeling significantly worse. Was asked to perform exposure tasks which involved revisiting areas of previous attack. Therapy was abruptly stopped without needed support. P041 |

GP, general practitioner; NHS, National Health Service.

### Factors affecting opportunity

Opportunity encompasses factors external to the individual that enable, prompt, or inhibit, a behaviour. Fragmented and disjointed NHS services made it difficult to know where or to whom a grievance should be directed. Hospital-based PALS offices were difficult to access due to limited office hours. It was also not obvious where to direct complaints about community-based services or care that spanned community and hospital services. For some, the opportunity to act was further reduced due to having distanced themselves from health services after harm.

> I'm not even back to square one yet. Square one just being just a mutual [belief that] 'I would go to my doctor if I had a problem'. P014

Those who took formal action acknowledged the importance of friends and family, and other social networks in developing a sense of agency towards exploring the opportunity to act. Belonging to social self-advocacy groups such as disability rights groups with collective knowledge of rights to complain and mechanisms to do so could make action seem less daunting. The backing of an independent impartial source, such as a local politician, could strengthen the sense that taking formal action was a legitimate way to get concerns heard and secure help. Those who did not take formal action often highlighted lack of social support as a barrier. Despite PALS' advocacy role, many reported that the service response was unhelpful.

Among those considering legal action, media adverts for legal firms suggesting legal fees would only result if a case was won could act as a prompt to investigate this option. Once prompted, a process of 'testing the water' often followed, ascertaining the initial response of a solicitor before committing further.

### Factors affecting motivation

Multiple factors impacted the degree of motivation participants had for taking formal action or not. Barriers to action fell under four main themes: emotional state; negative influence of social networks; fear of consequences; and attitudes towards the NHS.

**Table 3** Capability, opportunity and motivational factors associated with the decision to take or not to take formal action (some factors apply to more than one COM-B construct)

| COM-B construct | Factors associated with not taking formal action | Factors associated with taking formal action |
|---|---|---|
| Capability: an individual's psychological and physical capacity to engage in the behaviour concerned | Low knowledge of complaints and legal systems<br>Limited ability to complete complaint forms<br>Limited English language proficiency<br>Lower confidence<br>Limited experience in self-advocacy<br>Limited energy as still in recovery from physical or emotional impacts | Higher knowledge of right to complain<br>Previous experience of complaints or legal systems<br>Higher self-confidence<br>More experience in speaking up to authority<br>Greater sense of self-efficacy<br>More energy having recovered from the physical or emotional harm |
| Opportunity: the factors that lie outside the individual that make the behaviour possible or prompt it | None or limited family, friends or community support<br>More difficulty pinpointing where or to whom a complaint should go due to fragmentation of the health service<br>Voluntary distancing from health service following harm | More support for action from friends, family and colleagues<br>More support from specific support groups, politicians, advocacy services, mental health counsellors, etc<br>Advertising by legal firms that imply no fee is payable unless the case is won |
| Motivation: all the brain processes that energise and direct behaviour | Other issues having higher priority than taking formal action such as returning to work or family role or maintaining health<br>Perception that complaints or legal action will be complex, difficult or have financial implications<br>More feelings of despondency, abandonment and disempowerment after harm<br>Limited trust in the healthcare system<br>More uncertainty as to whether their case can be proved<br>More uncertainty of the likelihood of getting a fair hearing<br>More pessimism about power to change things<br>More fear of retribution from HCP or organisations<br>More likely to be influenced by family/ community reluctance to challenge authority or promotion of stoicism<br>Successfully accessing an explanation, apology and/or support<br>Less desire to sue the NHS as indebted for care or not wishing to drain funds from NHS | More frustration and anger in response to unresolved issues<br>Less fear of the consequences of action on future care and relationships<br>Receipt of a disingenuous apology<br>Stronger belief that formal action is the only way to get validation, an explanation or support<br>Stronger wish to hold individuals or services to account or to protect others from harm<br>More desire for financial support |

COM-B, Capability, Opportunity, Motivation–Behaviour; HCP, healthcare professional; NHS, National Health Service.

Dealing with the mental or physical impacts of the harm led to deprioritisation of pursuing matters further. Many described their consuming need to conserve limited energy to meet the demands of daily routines. Being met with continued dismissal or denial of concerns compounded emotional harm, heightening despondency and pessimism and increased distrust in the health service. Some participants doubted from early on whether their accounts would be believed or whether they would get a fair hearing, especially if they or their families had previous poor experience of the complaints system.

> And I just thought well at the end of the day do I have the time and energy to go through court proceedings and I think also another thing is that would they take me seriously? P010

Negative attitudes to NHS grievance processes among family, friends or the wider community could reinforce participants' beliefs that these processes were complicated and difficult to navigate, or costly in terms of time or finances. Motivation could be further dampened by family or community opposition to taking formal action. Participants, especially those from ethnic minority groups, described how family members' discomfort with challenging authority or the questioning of HCPs reinforced their silence.

Others worried that formal action might damage their relationship with HCPs and result in being labelled as 'troublesome'. A few participants reported being pressurised by a HCP not to take formal action, which was upsetting and intimidating and reduced motivation to act.

> …it felt a bit hollow as though he's—I think he, himself, is sorry, but really, it should be coming from Dr [name], not from him.… So I'm not impressed with that and it feels very much like, 'Please drop it. Come on. Right, are you going to drop it now?' P013

An additional minority indicated that they would never consider making a complaint or claim against the NHS, feeling indebted to the staff and services. Some did not want to drain funds from an already underfunded NHS.

In contrast, for those who took formal action, strong and sustained feelings of anger or frustration could act as powerful motivators. Participants described how the strength of these emotions moved them past fearing the consequences on future relationships with HCPs or services.

Others described their desire for acknowledgement of the harm and its impact, an explanation, someone to be held accountable, or to see changes made to services to prevent similar harm to others as being key enablers to action. Fewer indicated that their action was prompted by the need for financial support.

> I understand people who take the NHS to Court and who sue for hundreds of thousands of pounds and at the end of that they say, "It wasn't about the money." I can understand that because it's the only way you get an answer from them is go to court and when they answer there. P006

Taking formal action could also engender strong feelings of guilt.

> I felt like God's sent me a message saying 'why are you taking advantage?' You already got more than what you asked for—a pacemaker—why do you want compensation for? P044

### Evolution of decisions to act

For most participants, harm and its impact developed over time. It could also take time to link poor outcomes to care received, especially where initial concerns were dismissed rather than engaged with by HCPs. Family, friends and work colleagues were often consulted for their opinions, and sometimes multiple avenues were explored to acquire acknowledgement, explanations or support. Decisions on action evolved over time, often circling round in the mind of the affected individual and influenced by their context, responses from HCPs to previous actions and attitudes of family and friends around them. Many reasons were put forward as barriers to not pursuing formal action, ranging from not feeling this route would bring resolution or support for recovery, not having the time or energy to do so, feeling disempowered to take this step, not wishing to raise a grievance against the NHS or believing the harm was not suitable to report (eg, harm thought too mild or predominantly psychological). Participants who did not take formal action expressed one or more of these reasons, and each could have different degrees of dominance over time. Indecision over taking formal action could last for many years, with the distress and frustration over unresolved issues persisting.

Although those who took formal action usually had more knowledge of their right to complain and were more confident to raise concerns, considering such action also relied on having adequate personal energy and social support. Despite these factors being in place, participants described also needing to reach a tipping point at which taking formal action was perceived as the only way to resolve issues and address needs. Support from family and friends could be a decisive factor in moving beyond this point.

> I think my mum and my granddad both said, "Go back down,[to the surgery] but keep pushing." I think my mum said, "I'll come back down with you" P001

A few participants described how a HCP proactively suggested taking formal action.

Anger and frustration with the way initial concerns were handled by the treating team or PALS, particularly where responses denied or devalued experiences, or took the form of a poor or insincere apology, could provide the final push to action by lessening fear of potential negative impacts on future care.

> That's what [PALS] told me, they said, "You're unlikely to get an apology and they won't admit guilt." P032

Not being able to stand back because the same thing might happen to others acted as a powerful motivator for many. It could take months or years to reach the tipping point, except where harm happened suddenly and had severely debilitating impacts including loss of earnings and potentially lifelong medical or care expenses. For these participants, thoughts of taking formal action came early, especially in instances where HCPs acknowledged that a mistake had been made.

## DISCUSSION

Our study confirms international findings that patient experiences after healthcare-related harm resulting from a wide range of causes and across care settings are generally poor and that there are more commonalities than differences, whether or not formal action is taken. Most of those harmed were active in trying to make sense of what had happened and in looking for support but were rarely provided with the acknowledgement, explanations or help that they desired from healthcare services. Many described not being listened to, being dismissed or not believed. Although some of this is known internationally, there is limited literature on responses to healthcare-related harm in Britain, much of which is based on those making complaints or claims for financial compensation.[10 14 24 25]

This study took a wide, patient and family-centred lens when conceptualising harm which includes a wider range of harms than those who are due to errors in care[6 26] and captures the emotional and social harms that are less, if at all, visible to HCPs. HCPs negative attitudes to patients reporting harm may reflect their fear of the blame culture frequently reported to exist in the NHS, an unwillingness to take responsibility for harms related to system failure or perceptions that such reports threaten their competence or are motivated by the negative intentions of the complainants.[27 28] It is not surprising then that only a small number of participants reported getting their needs met, and most had thought about making a complaint or taking legal action at some stage and sometimes for years.

Teasing out the specific factors that are linked to decision-making after harm across the constructs of capability, opportunity and motivation identified important barriers to action including uncertainty about how to access formal systems and how they work, not feeling this action would bring benefits, lack of social support or not wanting to damage their relationship with HCPs, all of which resonate with previous studies.[29–33] Our approach to dichotomising participants to highlight differences in COM-B constructs could suggest that removing barriers to formal action would mean that more people might take such action. However, our findings support previous research indicating that decision-making after harm is complex and non-linear.[16 34] Different influences interact over time, and outcomes of previous actions can unpredictably influence next steps. Therefore, it becomes difficult to predict at an individual level which behaviours are likely to tip the balance towards formal action. As found elsewhere, people often feel forced to take formal action as a last resort to gain acknowledgement of their harm and suffering, more information on what went wrong and support that has previously been unavailable.[13 14 16 34 35] Those who did not take formal action often recognise that this route will not bring them the help they desire, with negative attitudes to these processes often reinforced by previous experiences of themselves, family or community members. Some would never feel comfortable making a formal complaint or litigating against the NHS, which was echoed in our survey of NHS patients.[1] Grievance services are poorly equipped to provide holistic, person-centred and inclusive support or deal with harm resulting from poor quality care, system failures and lack of access to care. Poor responses, as a result, can compound suffering and delay recovery.[2 35 36]

Inequities exist in the distribution of healthcare-related harm, with socioeconomically deprived and minoritised groups impacted most.[37 38] Our findings suggest that these groups may also be more vulnerable to poor experiences after harm and face reduced prospects for resolution. Social isolation was associated with more difficulty in making sense of what has happened and reduced the support for action provided by social networks, thus potentially limiting the opportunities for meaningful recovery. Social status and cultural norms with regards to questioning authority within families and minoritised groups also reduced the likelihood of action, as indicated in previous research.[39 40] Power imbalances between patients and providers are more likely to exacerbate fears of retribution if concerns are raised.[41] Other studies have similarly found people's sense of powerlessness stopped a formal response.[42] One consequence of unresolved emotional impacts of harm is loss of trust in HCPs and services. This distrust can drive people to change their clinician or distance themselves from services.[43–45] In the long term, disengagement will impact on people's health and their quality of life and generate hidden additional costs to health services in treating avoidable or exacerbated conditions.[46–48] Services that might have a role in better supporting marginalised groups to resolve issues, such as PALS, did not seem to function well in this role.

### What can be done to support patients harmed by healthcare?

Reducing barriers and inequities to engaging with formal grievance processes, where applicable, would seem an important element of a just and caring health service.[49] Where harm has resulted from an avoidable error, engaging with formal action to ensure accountability and financial compensation as needed would be appropriate, both for the individual and their families' sake, and to ensure organisational learning and improvement. Efforts to improve access to NHS complaints systems in Britain have included actions such as making information available in a range of formats, better signposting to independent advocacy and striving for openness and transparency in communication.[50] However, further insight is needed into how inequities in access to such services for disadvantaged and marginalised groups are best addressed. Despite often significant physical and psychological impacts, most people experiencing a wide range of NHS harms will never seek redress through formal action. Difficulty in accessing PALS and suspicion as to its levels of independence have curtailed the effectiveness of this service in providing support to these patients and families.[20] Our findings indicate that harmed patients frequently make informal attempts at gaining support for recovery in the aftermath of harm. Therefore, an understanding, supportive and sincerely apologetic health service could go a long way to addressing the needs of patients who do not wish to or don't feel able to pursue the burden and cost of formal action. Important opportunities to transform the service lie in improving the quality of informal interactions between patients and HCPs after harm occurs.

Despite recognition that genuine compassionate listening to concerns and trust in the veracity of peoples' accounts, particularly the impact on lives, promotes healing,[51 52] it is clear that an 'empathy gap' exists between patients and families and HCPs.[53] Many barriers exist for HCPs to improving these early interactions, including reticence to discuss difficult issues, personal feelings of failure, poor training and fear of litigation.[29 54] International initiatives that take a more patient and family-centric approach after harm, such as Communication and Resolution Programmes in the US and restorative programmes in New Zealand, prioritise compassionate receipt of patient and family testimony, acknowledgement of harm and its impacts and ongoing engagement with patients and families, and have also built in support for HCPs within the process.[36 55 56] These programmes aim to replace harmful adversarial grievance processes with systems that provide early, tangible and personalised support for recovery and maximise the opportunities for learning and improvement within health services. When implemented with fidelity, they appear to improve patient experiences[51 56–58] and are being mirrored through the development of more patient and family-centred approaches to patient safety incident investigation in England.[59 60] Marginalised populations also want improvements in communication after adverse events, and HCPs indicate that they sometimes feel ill-equipped and uncertain in these interactions.[61 62] As part of addressing inequities in patient safety, HCPs could actively explore patient and families' experiences of care and outcomes with these groups as part of maintaining open channels of communication and trust and building a more inclusive health service. Open communication can facilitate assessment of physical, psychological, social or financial needs after harm and promote access to support for recovery. Such holistic provision would not only benefit the individual and their family, address the deficit in compassion faced by many complainants but also provide the health service with the opportunity to learn from a wider pool of harm, much of which remains hidden from view.[63] This change might seem a low priority for health services in resource-constrained times, but it could help reduce the hidden costs of treating exacerbated long-standing conditions or harm sequelae into the future.

### Strengths and limitations

The in-depth, narrative style interviews facilitated the collection of authentic accounts of harm experiences and the factors determining responses in the participants' own words and from their unique vantage point. Drawing our sample from a national survey enabled us to explore a wide range of experiences of harm, including both patients who took further action and those who did not, and to contact people whose harm may not have been recorded or previously detected.

Accounts were retrospective in nature, which leads to the potential for some recall bias, although we accounted for this by limiting harm experiences to the relatively recent past. In addition, people who may be particularly disturbed by their experiences or are still dealing with unresolved issues have stronger emotional responses and might feel more inclined to consent to an interview than others who reached resolution or accessed support through other means. Our sample may, therefore, be more representative of such experiences than of those who have been successful in getting their voice heard.

## CONCLUSIONS

Many people actively seek resolution and recovery in the aftermath of NHS-related harm, often through raising concerns via informal channels before considering formal action. Over time, a lack of explanations, apologies and support for recovery, together with access to social support and feeling empowered enough, can tip some people into formal action, although this remains a minority. Most others have multiple interacting reasons for not pursuing formal actions, including barriers that go beyond the harm, such as being from a marginalised community. Our findings suggest that many people do not get the support for recovery after harm that they need or want, and that people need to be provided with options beyond current grievance services to help them in recovering after harm. Provision of open, inclusive and compassionate engagement and tailored support for those experiencing healthcare-related harm from a range of causes could promote recovery, restore trust and decrease compounded harm, as well as complementing current patient-centred improvements to NHS patient safety incident investigation.

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