# The value of compensation



Report

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### Context & approach

### Context

The essential purpose of compensation is to, as far as possible, enable the person who has suffered from negligent medical treatment to get back to a 'normal life', i.e. the position they were in prior to the negligence occurring. The impacts of negligence are wide-ranging and include job loss, poor physical health, financial troubles, relationship breakdowns and a loss of self-identity and self-worth.

Patients who have suffered negligent medical treatment may be able to take legal action against the NHS and claim compensation if it can be shown that the negligence has directly resulted in injury. Patients can take legal action on behalf of themselves or on behalf of their next of kin if that person doesn't have capacity to pursue action themselves or has died as a result of the negligence.

Examples of clinical negligence include the healthcare provider:

- Failing to diagnose a condition or making the wrong diagnosis
- Negligence during a procedure or operation
- Administering the wrong drug
- Failing to get informed consent for treatment
- Failing to warn about the risks of a particular treatment<sup>1</sup>

Compensation is split into three parts – general damages, that is compensation for pain, suffering and the detrimental effect on quality of life; special damages for past losses, that is compensation for upfront expenses related to the injury; and special damages for future loss, that is compensation for the loss of earnings in the future, or the loss of earning potential, and future care.

<sup>&</sup>lt;sup>1</sup> NHS organisations pay an annual premium to the Clinical Negligence Scheme for Trusts (CNST), an insurance scheme administered by NHS Resolution, to mitigate against the cost of clinical negligence claims. Typically, NHS Resolution represents the NHS when a patient takes legal action against the NHS and claims compensation. There are also other, more minor schemes which NHS organisations pay into to mitigate the cost of clinical negligence claims. See https://resolution.nhs.uk/services/claims-management/clinical-schemes/

At present *Judicial College Guidelines for the Assessment of General Damages in Personal Injury Cases* are used to determine the financial value of general damages. These guidelines place an upper limit on the amount of compensation that can be awarded for each type of claim. Every penny of special damages must be accounted for in a schedule of loss.

### Why this research was conducted

The Association of Personal Injury Lawyers (APIL) commissioned this research to better understand how financial compensation affects the lives of patients who have been injured as a result of NHS negligence.

In the NHS negligence compensation debate, too often the emphasis is placed on the cost to the NHS and not on the people who have suffered due to negligence. This human-centric research puts the spotlight back onto patients and provides a platform for them to talk about their experiences in an open and honest way.

Through a series of qualitative interviews, people were able to tell us about their stories of NHS negligence, their claims journeys and what receiving the compensation has meant for them and their families. Conversations were semi-structured and participant-led. In their own words, people were able to tell us about the things that mattered to them.

### Approach

**15 x 45-minute in-depth telephone / web conferencing interviews** were conducted with people who have received compensation because of NHS negligence within the last 15 years. Interviews were conducted in October 2020.

This research included people with different experiences of negligence and included:

- Those who had received compensation on behalf of themselves, a dependent or next of kin
- A mix of negligence types and award values
- A mix in length of time since the negligence claim

Interviews were conducted with people who lived across the UK and included a spread of age, gender and ethnicity. A profile of respondents can be found in the appendix.

The research, analysis and reporting were conducted by Opinium, an independent insight agency.

### **Executive summary**

Patients who have received compensation due to negligent care place high value on the compensation, from both a practical and emotional perspective. This executive summary highlights key findings from the research.

### 1. The consequences of NHS negligence are wideranging

NHS negligence causes significant disruption to patients' lives and to the lives of their family and friends. Peoples' physical, emotional and financial health can be seriously affected by the injury caused through negligent care.

With the help of compensation, some can recover from, or adapt to, the consequences of NHS negligence relatively quickly. However, compensation doesn't always stretch to help with the longer-term effects of negligence, which many suffer from for the rest of their lives.

When rapid recovery isn't possible, people can fall into a spiral of decline. Financially, they face mounting debt; psychologically the pain and suffering can result in poor mental health, including depression. In the cases with the most serious consequences, the negligent act can become embedded in the patient's sense of self-identity and self-worth. It's not possible for people to return to the life they previously enjoyed when they have lost relatives unexpectedly or when the negligence has caused acute impairment. In these circumstances some find it difficult to see themselves as 'more than' the victim of the negligence. The fight for justice can become an all-consuming process.

# 2. The injury caused by NHS negligence has both direct and indirect costs

Direct costs are commonly associated with:

- A reduction in household income
- Increased expenditure due to the need to travel to appointments
- Unexpected costs associated with increased living expenses
- Direct costs of home adaptations or mobility aids

Again, rapid recovery is key for mitigating against indirect costs associated with long-term unemployment and relationship breakdown. If patients are unable quickly to cope with financial

pressures, it can take a long time for their standard of living to return to 'normal'. Some may never have access to the same financial opportunities they had before the negligent event. This in turn has a negative effect on their quality of life.

### 3. Compensation helps people to rebuild their lives

The role of compensation is multifaceted and serves to help people who have suffered injury because of negligent care get their lives back on track.

Financially, it helps people to recoup expenses or loss associated with direct costs, and in doing so alleviates financial pressure. Functionally, it provides access to the private treatment or alternative therapies needed to aid physical recovery and mitigate against long term damage.

When physical recovery is not possible, compensation helps people adapt to their impairment and provides access to home adaptations and mobility aids. In doing so it helps people regain independence and freedom.

### 4. Private treatment is often a key factor in recovery

Private treatment aids recovery, both physically and mentally. It includes treatments such as physiotherapy and acupuncture, which contribute to better mobility and dexterity, and corrective surgery, which helps in the rehabilitation process and in improving the patient's condition. Having access to quality treatment quickly provides reassurance to those who feel like their life has been put on pause.

### 5. Compensation can be an effective acknowledgement of what can't be replaced

On an emotional level, compensation can be perceived by the patient and/or their next of kin to be recognition of the injustice experienced. Families experience avoidable pain, suffering and loss as a result of negligence and it is important to acknowledge, and be empathetic towards, the real-life consequences felt by individuals. In a top-down institution, some patients feel there is a tendency to lose sight of the people affected by negligence.

When a life has been lost, compensation can go some way towards honouring that person's contribution and acknowledging the opportunities missed. For families to feel any sense of justice for the deceased, it is important that the NHS is held accountable and recognises the loss of life.

# 6. Where negligence has caused uncertainty about the future, compensation offers reassurance

Especially in cases where children are involved (either directly or indirectly), the negligence causes particular anxiety around potential long-term implications for the patient and their family, especially in relation to on-going health problems and financial stability.

Compensation has a key role in providing a sense of security. Knowing that there are funds to fall back on for further treatment or to facilitate financial stability offers reassurance to patients living with unknown consequences. It is important for people to feel that they can protect their family against future disadvantage caused by the negligent act. From an emotional perspective, this is important as it allows people to feel they can move forward.

# 7. The compensation awarded is 'not life changing', it simply helps people get back on track

Patients place huge value on compensation because it helps them get back on track and recover from the negative fall-out that was caused by the negligence.

Compensation does not provide the means for people to elevate their standard of living. It simply facilitates a 'return to normal', or an adaption to a 'new normal', post the negligent event.

*"I think the most important thing to understand is that, if there has been a miscarriage of justice, people have been failed in their health…they're going to need… not just their wheelchairs and things, [and] adaptions around the home but maybe the loss of earnings for the rest of their life… We're not* 

# naming and shaming or anything like that, but someone is still at fault. It is your health, your life." **CS**, **48**<sub>2</sub>

Some don't think it goes far enough in acknowledging what they have gone through. A sizeable proportion of those that we spoke to felt that they had been treated in an unjust way when processing the complaint. Some call for a more compassionate and all-encompassing approach to claiming compensation.

"...there needs to be a bit more compassion ... don't put people under unnecessary stress for years. With my case, they turned around, they said, 'No.' I even went to the ombudsman and then, as soon as I got my MP involved, then they decided to open it again. Why should it have to be that?" HM, 36

# 8. Compensation isn't about shaming the NHS, but about recognition of wrongdoing

Many patients mention their admiration and respect for the NHS and the work that they do, and some mention not feeling particularly happy at having to take action against them. However, it is considered important that negligence and wrongdoing are recognised and equally that these experiences are not repeated for others.

<sup>&</sup>lt;sup>2</sup> In response to the final question asked in the interview, *'Thinking about all we have discussed, what would you say to someone who thought that compensation should be reduced?'* 

The value of compensation

# The impact of negligence on physical and mental health

# NHS negligence can leave patients with lifelong complications

### Physical impairment and disability

When the injury caused by NHS negligence leads to permanent disability and impairment, the patient's quality of life can be severely affected.

These individuals often struggle to complete daily tasks or even look after themselves. Those with the most severe disabilities struggle to move around their own home and access basic facilities. People live a limited life when they are not able to easily complete simple tasks, such as cooking or going to the toilet.

Some patients feel that they have lost their sense of self-identity. They find it difficult not to let their disability become part of their identity due to their dependence on others. This is especially true for those who have young children They find it hard not being able to care for them in the same way they had done previously.

Those who had led very active lives before the negligent event also struggle emotionally. A lack of socialisation leads to isolation, loneliness and poor mental health. Some living with acute consequences described how they had seen a change in their personality, going from outgoing and bubbly to quiet and reserved.

Even a short break from regular exercise and sport can lead to low moods. It's especially frustrating for those who lead an active life as for them, fitness is a tool for good physical and mental health; it has an important role in balancing their lifestyle.

#### Isolation and depression

Several patients we interviewed who are living with long-term conditions find it difficult to leave the house. For some this is due to mobility issues linked to a physical disability. For these individuals the inability to get out and about often results in low moods and poor mental health.

For others, the negligence experienced has caused a lack of confidence in themselves, where the injury has stopped them feeling 'normal' and 'themselves' again. This poor mental health results in reluctance to leave the house and speak to others. All those who were interviewed who had lost a child due to NHS negligence have battled depression. Some continue to do so. Similarly, those interviewed who have prematurely lost adult relatives struggle with low mood and a sense of hopelessness. A number experience guilt for not being able to 'do more' to prevent the death of their loved ones.

The impact of this depression is widespread and, in some cases, has affected every area of patients' lives. Depression has prevented people from returning to work, inhibited their integration into society and damaged relationships with family and friends. When people are depressed and house-bound it can be difficult to break the negative cycle and begin reintegration. The act of not leaving the house perpetuates feelings of isolation, as described by RP (who lost her 26-year-old sister-in law due to a failure to diagnose tuberculosis) and WL (who lost his son after repeated misdiagnoses):

"Our lifestyle has completely changed. It's taken our wellbeing away from us. Some weekends we can spend the entire weekend indoors just sitting in front of the television like a vegetable because we just don't want to interact with the world. We just feel so hurt and it's really, really difficult." **RP, 42** 

"When you've lost a child, it devastates your life...I became isolated. I was suffering with posttraumatic stress disorder, I was suicidal. Three days after Robbie's death, the post-mortem confirmed it was Addison's disease. Could you imagine how I felt after losing Robbie the way that we did? Finding out that the disease that he had was treatable? You can only imagine what that would do to any parent. It ruined my social life, it ruined my family life, it ruined my relationship with my other two sons because I was angry all the time...that grief is [exacerbated] by people who tell lies and cover up..."

WL, 67

### **Relationship breakdown**

Another impact of negligence is the breakdown of relationships. A few included in this research had separated from their partner due to the long-term consequences of their injuries. One person described how they had become disconnected from their husband after living with life-long impairment; they didn't want to become a 'burden' to their husband who had to take on a caring role.

# Compensation has an important role in rebuilding independence and freedom

Compensation has a vital role in supporting independent living and in some cases, giving people back their dignity. Those living with physical impairment use the compensation to make home adaptations or purchase mobility aids that significantly improve their quality of life.

Compensation allows patients to invest in a range of aids, such as banisters, hoists, chair lifts, wet rooms, wheelchairs and specialist mattresses – all of which serve to make patients' lives more comfortable and help rebuild their sense of freedom. KR suffered with a severe leg infection following negligence during an operation:

"I need my leg raised otherwise I find the pain too much. I've got a special kind of hoist on the bed where I can raise the leg and [I purchased] an extremely comfortable bed with a memory foam mattress. The comfort is really important when you're in pain with your legs. I have had to install a new bannister on both sides of the stairs." KR, 40

Compensation also provides access to private medical treatment, which many state is important in helping their physical and mental recovery. A sizeable proportion of people included in this research had undergone private physiotherapy or alternative therapies, for example.

- LB (who suffered nerve damage to her back following negligence while giving birth to her son) said she had spent around £2,000 on physiotherapy as a result of the nerve damage she suffered.
- CE (who had undiagnosed endometriosis) uses part of the compensation she received to get private scans - it enables her to monitor her condition more effectively. She also feels relieved that the funds are available for private operations in the future, if needed.

 RB (who claimed compensation on behalf of his son, who suffered internal burns following negligence for diabetic treatment) appreciates that the compensation will provide his son access to private corrective and plastic surgery if he needs it in the future.

Compensation allows injured patients access to private care which means they are seen quickly and so recovery is not hampered by lengthy delays. People also value the attentive care they receive.

"It has been really beneficial to have that physio and have all the advice about strengthening certain muscles and bones and actually having the hands-on therapy...It's not just a physical thing, it's mental. It's peace of mind that you know you are treating the problem... in a very all-encompassing way... when I come out of [a private healthcare appointment] I always feel great. I feel that I have been listened to, I feel like the person genuinely cares. And I feel that my anxiety is much less ... if I didn't have that there would be a lot more anxiety around this constant pain and limp that I have every day."

#### KR, 40

Some have used the compensation awarded to purchase a car. Having a car has helped patients 'get back to a normal life'. Being able to participate in everyday activities, such as dropping the children off at school or shopping, is empowering and is an important aid to recovery. It helps people to see themselves as more than ill or disabled. For some, it also gives the opportunity to create new memories with their family and friends. CS is disabled and living with terminal cancer following a misdiagnosis of bone cancer in his spine:

"They've [the amount given in compensation] allowed for a decent electric wheelchair which will give me great independence. They've allowed for care to come in and out the home when I need it before I go to a hospice... [It has given me freedom] because I can fill up my car with fuel every other day and go for a drive. At the moment I'm able to get into my car and get out to a shop 10 yards and back." **CS, 48** 

### Case study: HM, 36

#### **About HM**

HM is separated and lives with her 4 teenage children. Her relationship broke down following her life-changing illness, but her ex-husband still helps with living expenses.

HM lives with a severe and incurable lung condition that was caused by medication

HM wasn't given sufficient information about the potential side effects of the drugs and now lives with a number of conditions, the most serious of which is pulmonary hypertension. Her respiratory issues have led her to become severely disabled and she finds it difficult to move around her house.

"...even to go to the bathroom or to the kitchen, I'm out of breath..."

Losing her job triggered a sense of loss of freedom and put pressure on her relationship

HM was an active, sociable person before her injury and now leads an insular life.

"When I lost my job, I think that was the turning point for me. I felt like I lost my independence. And then that affected my married life a lot, because I felt like I was a burden."" When HM installed a downstairs wet room, it made her life much easier

Using compensation and money given to her by a charity, HM built a downstairs wet room. This alleviated anxieties about getting up and down the stairs and aided basic sanitary care.

"I struggled a lot. I struggled with the time that I used to take to get upstairs to go to the bathroom, even for a wee. I used to think, 'I'm going to wet myself.' But now, it's all nearby, so I don't have to worry... It's just the little things. Me getting in and out of the bath was a big one. And now, it's just a shower, and it's just so much easier."

# Purchasing a car let her do normal things with her children

HM wants to shield her children from the realities of her condition as much as possible. Whilst they know that she's unwell and they help with chores around the house, it's important for HM to build some normality into their lives.

"I bought a car as well because sometimes I need to take the kids to school, and we did some trips to see my mum. They saw a different side to me at that point. I don't really talk about my illnesses with them because I don't want it to affect their childhood."

### NHS negligence can create uncertainty in peoples' lives

### Insecurities around future health and ability

NHS negligence can cause insecurities about the patient's future health and ability to carry on with their lives as normal. In some cases the long-term complications of a condition are unknown. This type of news is difficult for all patients to manage, and parents are especially angry when there is uncertainty around the health and ability of their child to live their lives as normally as possible. The prospect of their child being disadvantaged in the future is difficult to accept.

# Compensation has a role in providing hope for the future

Compensation also provides access to treatment options for patients later in life. When there is uncertainty about what the injury will mean for people later down the line, knowing that patients can gain access to private treatment offers peace of mind.

### Case study: RB, 41

#### About RB

RB lives with his wife and two young boys. His oldest son suffered negligence when he was born.

#### RB's son was given treatment incorrectly

Due to RB's wife being diabetic, their son had to be given treatment for diabetes after his birth. Glucose is usually given through the belly button but was instead administered incorrectly through his arm. This resulted in deep tissue damage and third-degree burns.

## RB's son needed immediate treatment and will need treatment when he gets older

Due to the negligence, RB's son spent further time in hospital, where doctors spent hours trying to rectify the mistreatment by attempting to remove the glucose from his body. It wasn't enough, and his son now has third degree burns on his arm and his hand is weaker than it should be. RB had 10 further appointments with the care team and a plastic surgeon to understand further complications and treatments for his son.

"They didn't find it until we pointed out to them at...2 o'clock in the afternoon, so 4 hours of having intensive glucose put into his arm. They then spent another 3 hours doing irrigation on his arm, which is basically needle pricking the arm, filling it with saline solution to get the glucose out."

# The negligence makes RB worry about his son's future

The negligence has meant that RB son's hand is weaker than it should be, and he is likely to need a skin graft in future. Currently, doctors are unsure whether his son's condition will worsen but will know when he gets older. This altogether infuriates RB, as he worries that his son will have a disability that wasn't his fault.

"It scares the life out of me because at the end of the day, I don't want my son to have a disability that could affect his life that wasn't his fault... [but happened because] someone else hadn't done their job."

## Compensation has allowed RB set aside money for future treatments

RB has set aside the money received in compensation in case his son needs further treatment if his condition worsens in future, including skin grafts and other corrective surgery.

"Because it's quite a big scar he's got on his hand, and it'll only stretch as he grows, so they're saying there might be corrective surgery needed later on in life, but that's... why the figure of compensation's what we've got."

### Case study: CE, 40

#### About CE

CE lives with her husband and two young, adopted children.

### CE was diagnosed late with endometriosis which prevented her from receiving free IVF treatment on the NHS

NHS medical professionals failed to diagnose CE with endometriosis as a teenager and throughout her adult life. She continues to have ongoing health complications and may need a hysterectomy if her condition worsens further.

### Due to the delayed diagnosis, CE had felt forced to use private healthcare for surgery for endometriosis and for IVF treatment

Due to the delay in diagnosis, CE's condition had worsened and prevented her from getting IVF treatment from the NHS on time. Having a family had always been important to CE and she was distressed to learn that she had missed the cut-off for NHS funded IVF by a few months at her local trust. CE and her husband felt forced to have private treatment.

"I wasn't getting any younger, we couldn't wait 2 years to see a consultant and then get put on the waiting list to have these operations. We felt like we were forced to go privately because of the situation that we'd been put in." Significant finances were spent on the private healthcare, creating future financial uncertainty

If not for the delayed diagnosis, CE could have received treatment for her condition earlier and received IVF on the NHS. Instead, she had to spend huge sums of money on private surgery and private IVF. As well as the costs involved, this also created concern that she would not be able to support any potential children as they would have previously hoped.

"...it was about £40,000 that we'd spent. That's all their university education, that's a deposit for their house, all this money that we've worked really hard for and it was for nothing...."

#### CE went through a stressful, long process

A lack of recognition motivated CE to pursue the case.

"If they'd just given us 1 round of IVF or, in my view, acknowledged that they had done some things wrong and were prepared to learn from it, we would have both moved on from it, but they didn't. They [NHS] thought that we would be dismissed and moved on."

## CE felt relieved of the guilt when the compensation was received

The amount of money CE and her husband spent on her treatment made her feel incredibly guilty. When they received compensation, CE felt relieved that they now had recouped much of that money and can use it for private medical treatment in future.

### Financial implications of negligence

### NHS negligence disrupts household finances and can lead to financial turmoil

### **Financial insecurity**

There can be significant financial uncertainty about the future for those who cannot recover from the long-term impact of an injury caused by negligence. The path for those who are unable to return to work, and for those who return to work but in a lower-paid role, is very different from what it might have been had they not experienced the negligence. They may never be able to enjoy the same experiences or opportunities that they had been able to enjoy before their injuries and a few patients interviewed expressed concerns about the type of future they will be able to provide for their family.

Others expressed frustration over 'wasted' money – money that could have been used as a deposit for a house, or money that could have been used to fund their child's university education. The security that those savings provided has been eroded.

#### Loss of income

Loss of earnings is a significant cost associated with an injury caused by NHS negligence. Those who are self-employed and unable to work due to disability or impairment caused by the negligence feel the financial impact quickly. Being out of work immediately reduces their income and causes financial strain, even when the period of inactivity is relatively short. This can lead to a depletion in savings and can lead to the need to take out a loan to help bridge the gap.

Patient PL has his own roofing and cladding business. A misdiagnosis of and delayed treatment for appendicitis caused ongoing health complications which meant he couldn't work for 4 months. During this time, he lost his largest contract. He had fully expected the repeat client to commission his company again, but the client lost confidence and took his work to a competitor:

"We run on a tight budget, every penny counts and when you've got a hole of £30,000 from a contract that you expected to get, all of a sudden you've just got to balance things around. We had a shortfall of money and borrowed from the bank." PL, 42

Those in part-time or full-time employment are also significantly affected in the medium term. Once holiday allowance is exhausted people must manage a shortfall in salary and rely on, often statutory, sick pay. Making ends meet can be difficult and some borrow money to get by. In these circumstances, rapid recovery is key to mitigating against the longer-term effects of income loss. Those who are unable to return to work for prolonged periods of time suffer exponentially.

When the injured person has a longer-term impairment, sometimes a partner or family member will leave their employment or decrease their hours to take on caring responsibilities, further reducing the household's income. For both the family and the injured person, it can take a long time for their standard of living to return to 'normal'.

RP helped her brother claim compensation after his wife (her sister-in law) died following the failure to diagnose tuberculosis. The 26-year-old patient left a young daughter behind, and RP explained how the extended family had reduced their working hours to help with childcare responsibilities and wider support:

"My brother has had to change his working life completely. He has become a working-from-home dad. I have had to reduce my hours because now I'm having to take care of my niece and my mum." **RP, 42** 

Those who are unable to return to work indefinitely due to permanent disability or long-term mental health issues must readjust to a new way of life and eke out their living expenses on benefits. 'WL' was unable to return to work after suffering from severe depression following the death of his son due to NHS negligence. He has spent many years on benefits and accepts that he and his family have a lifestyle in which they are unable to live on anything but essentials as a result:

"People who live on benefits don't have luxuries. We're grateful for what we are given, and we survive on it."

WL, 67

#### Indirect costs associated with unemployment

Unemployment can have additional, sometimes less obvious, negative financial implications. When someone has been out of the workforce for a prolonged period, re-entry can be difficult. Some report an inability to handle stress in the same way as before. Others say they lack confidence in their ability to carry out the job, due to an erosion of their knowledge or skills.

Some people feel a need to retrain to fulfil a role like the one they had before the negligent event. The cost to individuals in these circumstances is two-fold: firstly, there is the cost of not being able to sustain employment and, therefore, income at the previous level; secondly there is the expense associated with learning and education.

#### Increased expenditure and unexpected expenses

Many have ongoing treatment to help resolve physical injury caused by NHS negligence. Costs associated with travel (petrol, public transport and parking) easily mount up and leave people out of pocket, sometimes by hundreds of pounds.

Patients are not always able to rely on someone else to take them to hospital due to mid-day appointments clashing with work schedules. In these situations, patients often find it easier to take taxis. Parents who must take their young children to repeat appointments describe the impact of having to make multiple trips and taking time away from productive work.

### "...the amount of time we spent away [from work], days of travelling to the hospital [in London] and back ...I am self-employed, my wife's self-employed ... it's had an impact on our business..." **RB**, **41**

Some experience an increase in living expenses as they deal with the repercussions of living with injury. Being out of work also means that patients are spending more time at home and bills can go up as result. This is especially true for those living with conditions that make them sensitive to temperature.

"My hands, they go blue and they go white because I've got Raynaud's now with this condition. I need to keep my hands and my feet warm a lot, so the heating needs to always be on. I realised that my bills were coming up unexpectedly high."

#### HM, 36

# "I wasn't able to go to work so it was a financial disaster, my bills were piling up ..." RL, 34

Others have expenses linked to sustenance. Working parents taking children to follow-up hospital appointments are especially time poor. Scheduling appointments around work/life demands is difficult and some find themselves relying more on takeaway and convenience foods to save time and energy.

In addition, there are costs following the death of a next of kin. The family must arrange and host a funeral, which can be an unforeseen expense when the deceased has died prematurely and without a pre-paid funeral plan. There can also be unexpected costs associated with the deceased's estate: one person was shocked to learn of her husband's significant debts following his death.

### Compensation has an important role in helping people get back on track financially

When NHS negligence has caused disruption to household finances, compensation goes some way to recouping financial loss and helping get patients back on track.

It takes a long time for compensation claims to be processed and for the money to be awarded. Because of this, people must make payments upfront and manage on a reduced income for a long time before they are able to retrieve costs. Often receipt of compensation is key for preventing a spiral of decline, particularly in cases where people have taken on debt to cover expenditure.

"Basically, the main factor was to pay back my loans. I borrowed some money from someone else and then I had to pay the bills and everything. Those are the main things, the money I borrowed and the financial difficulties I had, so [with the compensation] slowly I can recover." RL, 34

Compensation also has an important role in alleviating stress caused by financial concerns and in providing hope for the future. Compensation provides the opportunity for people to 'start again' from neutral ground, as opposed to fighting on from the back foot.

"...In an ideal world, I would have liked more [money] to have reflected the stress, time and impact that all of those things have had."

#### CE, 40

### Case study: RL, 34

#### About RL

RL lives by himself in shared accommodation. RL used to work in IT but currently works parttime as a shop assistant.

An incorrect diagnosis delayed access to treatment and prevented RL from returning to work for 6 months

RL had Lyme disease, the symptoms of which meant that he couldn't work.

Despite repeated appointments, it took the GP over 6 months to make the correct diagnosis. During this time RL had been taking the incorrect medication and had not been referred to hospital for a more detailed examination.

Whilst out of work RL struggled to cover his living expenses and borrowed money to cover bills.

"Initially, they apologised but that didn't resolve the financial problems. I had lots of problems... I wasn't able to go to work and it was a financial disaster, my bills were piling up..."

## The compensation RL received helped him move past the 'headache' of his debts

The compensation helped RL 'get back to normal life'. It relieved the financial pressure that RL felt from borrowing money.

"After getting the compensation, I was thinking, 'Okay, this can help me a little bit to survive by myself.' It was a little bit of a relief, it just kept me moving...basically the main factor was to pay back my loan.

It is really hard to explain sometimes. After getting the compensation, I just needed to get back my normal life."

## RL's experience has impacted his career confidence

RL feels unable to return to IT. In a fast-moving tech sector, 6 months is long enough for skills and knowledge to become obsolete.

"I used to work for an IT company...if you have a gap, the gap is really bad. Technology is getting updated very frequently, so yes, it had a bad impact on my job as well.

### Case study: LB, 32

#### About LB

LB is a single mum and lives with her 1-yearold and 9-year-old boys. She works full-time in customer service.

# Faulty equipment during pregnancy led to health complications

During the birth of her first child LB was placed in a broken bed. She was given an epidural. During labour, LB's foot dropped out of the stirrup and caused nerve damage to her back.

Once home with her new-born, she was bed bound and unable to move. She was readmitted to hospital and spent 1 month in hospital before returning home.

# LB's mobility was seriously affected and initially she was unable to return to work

After returning home LB was unable to walk or travel for a few months. Her life was confined to the living room.

"I couldn't walk, I couldn't climb the stairs... everyone needed to do everything for me."

## LB's mum took unpaid leave to care for her and her child

Her mum took 6 months off work to help care for LB and her son.

"[My mum's] sick leave had gone, her whatever they give you on top of that had gone. My mum had taken so much time off to look after me...she was just managing... she couldn't get benefits because technically she's got a job..."

# When LB had recovered enough to get around, she had to get her car back on the road

Because LB's car had been out of action there were costs associated with getting it road worthy again.

"When I was able to drive, my car had been out of [action and off the road] for ages, so I had to get it back on the road. I used it to get my car back on the road, the money was going towards that".

# It took a long time for the compensation to come through

LB had already paid for her car and for private acupuncture treatment to aid her recovery by the time the compensation came through, three years after the negligent care.

"The money came year 3. My son was 3 and a half. I had already had to pay for everything from my own personal funds.

### **Compensation can provide justice**

### Compensation provides recognition of wrongdoing

The fundamental value of compensation is to help people who have suffered negligence to get their lives back on track and enable them to live as normal a life as possible. However, it also has a big role in acknowledging the negligence experienced and in recognising that it has had serious consequences on the patient's life. In some cases, the award is perceived to be a sign of respect, symbolising that the NHS accepts accountability for causing injury. This is especially important for those who have had to fight hard to win their case. A few of the people interviewed reported feeling a sense of relief after receiving their compensation as it shows that they have been believed and that they were not to blame for what had happened.

### *"It was tremendous relief, because people had always been saying, 'No, it's not true, no, we don't want to know, you're talking rubbish' …"* **AE, 57**

Compensation also has a role in honouring someone's memory. Although life is priceless, when someone has died due to negligence, the compensation awarded can be perceived as recognition that the NHS values the loss of life.

"I was pleased that they'd acknowledged what had happened. I would have been very, very angry if they had not acknowledged that there had been faults. When my husband died, [the GP] sent me an email which I didn't respond to and I really felt that [in that] email [she] was trying to justify her position."

GL, 76

### The process of claiming

### The act of claiming compensation is very stressful

Claiming compensation is a very emotional time for people. Patients are frustrated and devastated by the fact that they are living with injury, pain or suffering that could have been avoided. The injustice of the situation is hard to digest, especially for those who have lost a loved one due to the negligence.

The approach taken by the NHS differs hugely for different patients. Some of those interviewed received an apology from medical staff for the negligence but many got a much less empathetic approach and agreed that the NHS could have shown more compassion. Some felt that the NHS failed to acknowledge them as people throughout the compensation process, others felt victimised for challenging treatment decisions and for pursuing their compensation claim.

# "To me, it felt like that I was just a case to them. I just felt like there was no empathy, there was no compassion."

#### HM, 36

Patients reported very different experiences with transparency in the NHS. A few said that the NHS had been very upfront about what had gone wrong and about the learnings that had emerged from the case, with consultants even recommending that the patient take legal action. However, most had a much less open experience. In the worst cases, NHS staff had tried to proactively cover up the errors that had been made and some reported that medical staff had lied about the events and even fabricated medical records. Those having to deal with a negative backlash of claiming and proving the credibility of their case felt betrayed by the NHS and found the process especially stressful.

"They basically said that I was lying or embellishing [it] ... in the end it was the other nurse that admitted it [that mistakes had been made]. They weren't helpful at all. It seemed to be all the proving and all the proof had to come from my end ... I had to prove everything to make them believe that they're the ones that caused my pain. They never offered an apology." LB, 32

The claims process is often lengthy and drawn out. It became an all-absorbing activity for some as they engaged in time-consuming research, learning about their condition, or the condition that had affected their child, to help them make sense of what had happened and form an argument for their case. Some speak of accepting the first offer presented to them as a means of bringing the experience to a close.

All in all, these factors compound to make it a difficult, and in some cases inhumane, experience.

## Appendix

### Profile of participants

Participant	Age	Working status	Ethnicity	Negligence type	Claimed on behalf of	Compensati on value	Compensati on awarded
AE	47	Working full time (30 or more hours per week)	White British	A healthcare provider failed to diagnose a condition or made the wrong diagnosis	Child who had died	£50,000 - £69,999	Within the last 15 years
CS	48	Not working	White British	A healthcare provider failed to diagnose a condition or made the wrong diagnosis	Himself	£90,000 - £199,999	Longer than 12 months ago but within the last 2 years
CE	40	Working part time (less than 8 hours a week)	White British	A healthcare provider failed to diagnose a condition or made the wrong diagnosis	Herself	£30,000 - £49,999	Longer than 2 years ago but within the last 3 years
GL	76	Working full time (30 or more hours per week)	White British	A healthcare provider made a mistake during a procedure or operation	Her husband who had died	£10,000 - £29,999	Longer than 3 years ago but within the last 5 years
HM	36	Not working	Asian / Asian British	A healthcare provider didn't give warning about the risks of a particular treatment	Herself	£1,000 - £4,999	Within the last 12 months
JH	60	Not working	White British	A healthcare provider gave the wrong drug	Himself	£10,000 - £29,999	Within the last 15 years
KR	40	Working full time (30 or more hours per week)	White British	A healthcare provider made a mistake during a procedure or operation	Himself	£10,000 - £29,999	Longer than 2 years ago but within the last 3 years
LB	32	Working full time (30 or more hours per week)	Black / African / Caribbean / Black British	A healthcare provider made a mistake during the birth of my baby	Herself	£1,000 - £4,999	Longer than 5 years ago but within the last 7 years
NA	26	Working full time (30 or more hours per week)	White and Black African British	A healthcare provider failed to diagnose a condition or made the	Herself	£50,000 - £69,000	Within the last year

				wrong			
PL	42	Working full time (30 or more hours per week)	White British	diagnosis A healthcare provider failed to diagnose a condition or made the wrong diagnosis	Himself	£10,000 - £29,000	Longer than 12 months ago but within the last 2 years
RL	34	Working part time (8 – 29 hours per week)	Asian / Asian British	A healthcare provider failed to diagnose a condition or made the wrong diagnosis	Himself	£1,000 - £4,999	Longer than 12 months ago but within the last 2 years
RB	41	Working full time (30 or more hours per week)	White British	A healthcare provider made a mistake during a procedure or operation	His child, who can't take action himself	£10,000 - £29,999	Within the last 12 months
RP	42	Working part time (8 – 29 hours per week)	Asian / Asian British	A healthcare provider failed to diagnose a condition or made the wrong diagnosis	Her sister in law, who had died	£70,000 - £89,999	Longer than 3 years ago but within the last 5 years
SY	40	Not working	White British	A healthcare provider made a mistake during a procedure or operation	Her child, who had died	£10,000 - £29,999	Within the last year
WL	67	Not working	White British	A healthcare provider failed to diagnose a condition or made the wrong diagnosis	His child, who had died	£300,000 - £399,999	Within the last 15 years

## **About Opinium**

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