Ipsos MORI
Social Research Institute

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DH birth injury compensation policy research

Contents

1 Introduction

1.1 Background and objectives

Safety in the NHS has generated a great deal of interest over recent years; high profile cases and enquiries, such as Morecambe Bay in 2015, where a series of failures resulted in the deaths of several babies and a mother; the public enquiry led by Robert Francis QC into poor care and high mortality rates at Mid Staffordshire NHS Foundation Trust in 2013; and National Maternity Review (Better Births) in 2016, have heightened the focus placed on both the safety of maternity services and standards of maternity care.

Furthermore, evidence in the NHS Litigation Authority (NHSLA)'s 2015/16 report and accounts highlighted that, while the number of maternity cerebral palsy / brain damage claims had not increased in the two years prior to that, the costs of these cases had. The report outlined that, these claims accounted for over a third of expenditure on claims in 2014/15. In addition, the periodical payments linked to these cases posed an ongoing cost[1]. Such evidence suggests that the cost of litigation for the NHS, particularly in negligent cases of birth injury, is likely to increase further in the future.

In light of the recent focus on maternity safety highlighted in the maternity review *Better Births*[2], the Department of Health (DH) are looking at options for a new non-adversarial, administrative compensation scheme for severe brain injuries during birth. The scheme would have the main aims of:

- Reducing the number of severe avoidable birth injuries by encouraging a learning culture;
- Improving the experience of families and clinicians when harm has occurred; and

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[1] NHS Litigation Authority, *Report and Accounts 2014/15. Fair Resolution.* NHS Litigation Authority, London. http://www.nhsla.com/aboutus/Documents/NHS%20LA%20Annual%20Report%20and%20Accounts%202014-15.pdf

[2] NHS England (2016) *Better births. Improving outcomes of maternity services in England* https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf

- Making more effective use of NHS resources.

More specifically, the scheme aims to introduce standardised, independent investigations of potentially avoidable instances of neurological birth injury. This will be supported by analysis of maternity and claims data across the country, in order to better understand the common causes of avoidable harm and share learning to drive future harm reduction. The scheme also aims to provide early access to counselling and support in accessing state services, facilitated by a dedicated case manager. Once eligibility is established a compensation package would be provided for the current and future needs of the injured individual, including regular assessments of need.

As such, the scheme should offer a supportive alternative to court for families who have experienced a severe avoidable birth injury. It is important to note that the scheme is proposed as a voluntary alternative to the courts, and the option to pursue a legal claim would remain available to families at all stages.

As part of the design of the scheme, DH have carried out exploratory work reviewing the current evidence; listening to the concerns of families, clinicians, lawyers and others about the current system; and considering and developing the proposal outlined in Better Births. They have also modelled the potential costs and benefits for different policy designs, which will be further tested through a consultation exercise. However, very little is currently understood about the experience and views of those involved in negligent cases relating to severe birth injury to help inform scheme design. To get input from a wider range of views and experiences DH therefore commissioned Ipsos MORI to undertake qualitative research to explore the experiences of families and establish the motivations to pursue litigation in negligent birth injury cases.

More specifically the research aimed to understand:

- The 'journey' of parents who have a child that has experienced a birth injury;
- The factors influencing parents' decision making, why they litigate and how they chose to fund care following a birth injury; and
- What parents think of the potential policy options and proposed care arrangements.

Findings have been reported back to DH on an ongoing basis, and this document brings together all aspects of the research in a final thematic report.

1.2 Research approach and methodology

A qualitative approach was adopted in order to provide in-depth insight into the views and experiences of those taking part. Four different audiences were included in the research to gain a broader understanding of the journey parents with a child who experiences a brain injury during birth go on, and a wide range of perceptions of the potential new scheme.

The research included:

- Interviews with **seven parents/families** who had experienced brain injury during birth;
- Eleven stakeholder interviews including **solicitors – claimant and defendant**, a **case manager**, the **NHSLA**, and **charity representatives**[3];
- **Four clinicians** with an understanding of cases of brain injury during birth, such as Heads of Midwifery; and
- **Four general public discussion groups** with around eight parents, each with at least one child under four years old.

The seven families who had experience of a brain injury or suspected brain injury were at varying stages in their journey and the litigation process following the injury as shown in the table on the next page.

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[3] All charities were patient support and advice charities and did not provide legal advice. nor represent the legal profession.

Profile of the litigation process for each family

	Litigation started	Length of litigation process	Compensation outcome
Family 1	2.5 years after birth	8 years	Unsuccessful
Family 2	9-10 months after birth	8 years[4]	Lump sum
Family 3	3 years after birth	7 years	Lump sum and PPO[5]
Family 4	In the first few weeks after birth	Ongoing: three years to-date	Received 1 interim payment of £50k to date
Family 5	In the first few weeks after birth	8.5 years	Lump sum
Family 6	Around 4 months after birth[6]	Considering litigation	N/A
Family 7	1.5 years after birth	Ongoing: less than a year to-date	Nothing to-date

Fieldwork took place between May and October 2016, and participants were recruited through a mixture of recruitment channels. Greater detail on the approach to recruitment is appended to this report.

Group discussions and interviews followed a discussion guide, designed in collaboration with DH. A draft guide for the general public sessions was tested in a pilot in-depth-interview[7] with two parents who had not experienced brain injury during birth to help with the design for these sessions. This involved going through the guide with parents to test out reactions to personal and potentially upsetting questions, including testing fictional case studies to ensure that sensitive issues were being explained and dealt with appropriately. Materials were refined after the first interviews and groups with each audience, the final discussion guide for each audience is appended to this report.

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[4] Settled earlier than solicitor's recommendation, due to stress.

[5] Periodical Payment Order: compensation is paid to claimants at regular intervals, rather than in a single lump sum award.

[6] Participant has only discussed their case with a solicitor and has not started litigation proceedings.

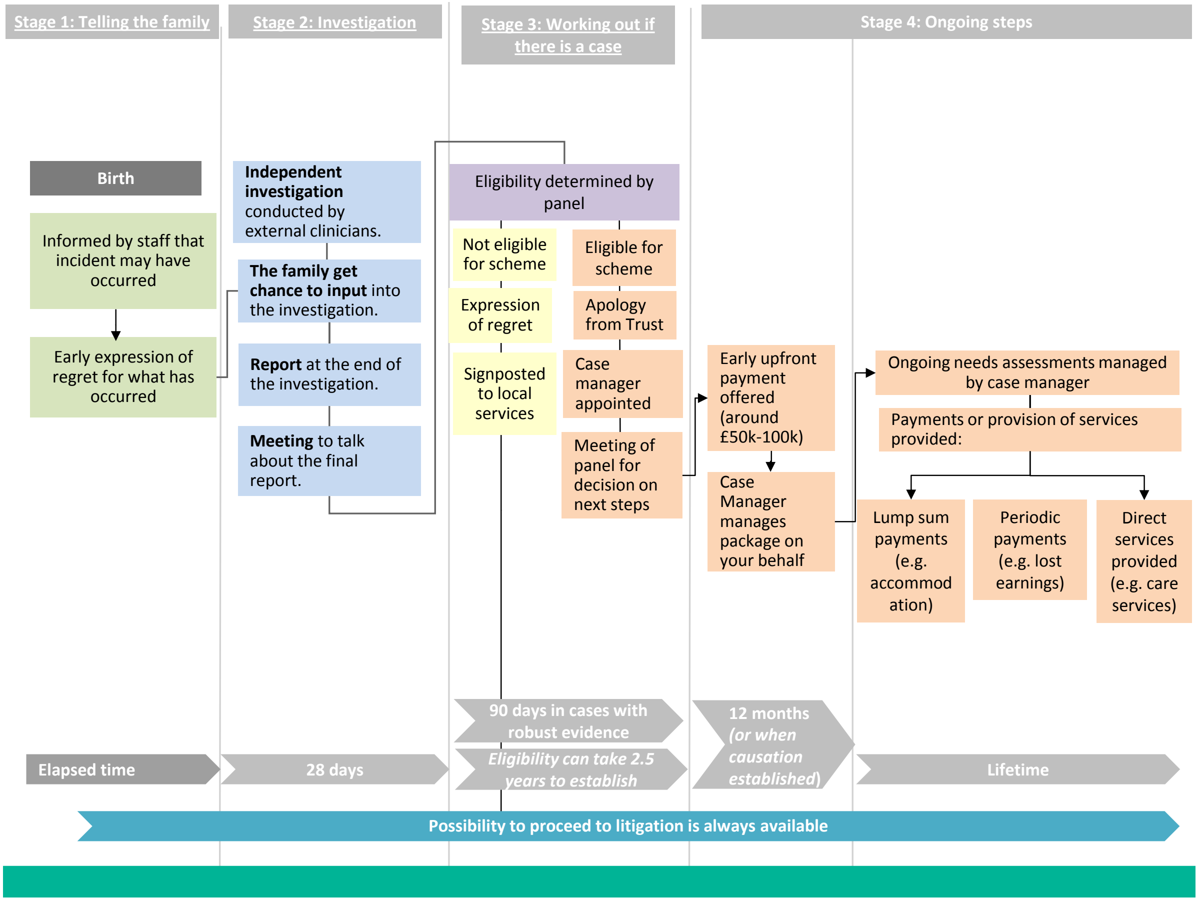
[7] This was an interview conducted to test the materials and did not contribute to the findings.

The interviews focused on the overall journey experienced by parents and the decision-making process, both of which were mapped and the influencers around decision-making were explored in more detail. The questions acted as a guide only for the depth interviews; researchers adapted the conversation to suit the participant, taking into account the parents’ unique situation and the sensitivity of the subject matter, and the differing roles of stakeholders and clinicians interviewed.

Fictional case studies were used in the groups with the general public to stimulate discussion, given that this audience had not personally experienced a birth injury. Since the subject areas (litigation and birth injury) were complex, a deliberative technique was also used with this audience. This involved providing participants with detailed information at various stages to build knowledge and facilitate debate. Their expectations of and reactions to current arrangements, where improvements could be made to the current system, and reactions to the potential new scheme were all explored using this approach.

At the time the research was commissioned, DH had established an initial scope for a new scheme based on their preliminary exploratory work. For ease of research, this design was split into four stages. Stages one and two introduce standardised, independent investigations of potentially avoidable instances of neurological birth injury; stages three and four aim to provide an improved service to families, reduce the current need for litigation as the default for fair compensation and appropriate care, and compensation package for the current and future needs in eligible cases. Each stage is shown in the chart below, and this chart was used to explore the options for a new scheme with participants.

In the months in which this research was conducted, some aspects of the policy design were adjusted – such as the time needed for the investigation phase – and, at present, DH are continuing to refine the design of the potential scheme in order that it best meets the needs of families and will be operationally feasible. The next stages are for DH to consult more widely on the potential scheme.



1.3 Presentation and interpretation of the data

It is important to note that qualitative research is used to explore why people hold particular views, rather than to estimate or quantify how many people hold those views. Such research is intended to be illustrative rather than statistically representative of a wider population and, as such, does not permit conclusions to be drawn about the extent to which findings can be generalised to the wider population. With this in mind, when interpreting the findings from this research, it should be remembered that the results are not based on quantitative statistical evidence but, like all qualitative research, on a small number of people who have discussed the relevant issues in depth. The views stated here are not facts; rather they are the participants' perceptions and the truth as they see it.

Verbatim comments from the interviews have been included within this report to provide evidence of participants' views. Quotations should not be interpreted as defining the views of all participants, but have been selected to provide insight into a particular issue or topic expressed at a particular point in time.

1.4 Structure of this report

The report is shaped around the key stages of the journey for families experiencing brain injury during birth.

Chapter 2 looks at the early stages of the journey following an incident at birth, including experiences of the first few days and weeks after the birth through to investigating what happened.

Chapter 3 explores the decision-making process parents go through when considering litigation and the experiences of the litigation process itself.

Chapter 4 looks at how parents meet the ongoing needs of the child, both putting an appropriate care package in place and funding it. How each stage relates to the potential design for a new scheme for birth injuries is discussed throughout.

1.5 Acknowledgments

Ipsos MORI would like to thank all of the participants who took part in this research across audiences, and, in particular, the parents who shared their stories and journeys with us.

2 Experiences of the early stages

This chapter explores the early stages in the journey for parents and families. It moves from experiences immediately after birth, through to investigating what happened in cases of brain injury, and highlights many of the key themes evidenced throughout the research and across all stages of the journey.

The first section explores the complex nature of the injuries themselves and the dual uncertainty – about what had happened during the birth, and how the child would develop – that comes with these experiences in the very early stages. The impact on the families beginning this journey – and the professionals that come into contact with them – is also explored.

The second section looks at collecting evidence and investigating what happened. What this means for the new scheme – in particular the design of the investigation process – is explored throughout.

2.1 Brain injury during birth

Across audiences, participants acknowledged that giving birth in any scenario is likely to be an emotional and sometimes difficult experience. During discussions with parents in the general public groups, examples from their own experiences of birth or those of family and friends were used to highlight the feelings of uncertainty and worry that could come with a birth, even where no injury had been sustained.

Those who had experienced a brain injury during birth described the feelings they had at this stage as strikingly different to anything they had ever encountered before. Many knew or felt that 'something had gone wrong' during the birth, and therefore the survival of their child was the most immediate concern before coming to terms with anything else.

Stakeholders told us that, quite often, parents can be so immersed in worrying about their child that they do not realise the mother has also sustained injuries during the birth, and are rarely immediately thinking about litigation or whether negligence had occurred.

Parents in the general public group could also appreciate they would feel this way if they were to be in this situation, acknowledging the 'emotional rollercoaster' and tribulations they would encounter, their core focus being their child's survival.

> *'You're not necessarily thinking in a logical frame of mind. It's very emotional. Your only real focus is your child and if they are okay.'*
>
> Parent, general public, London

Experiences of brain injury during birth were also said to be both varied and complex – again as seen in the variety of cases for families included in this research. Stakeholders said that the nature and extent of a brain injury is not always clear-cut at this early stage; while there may be indicators – such as potential deprivation of oxygen during birth – establishing whether there has been any damage, and the consequences of that damage, takes time. This meant a broad scale of injuries was outlined, with even the most catastrophic and severe not being completely clear-cut at this stage in the journey.

> *'Obviously it depends if it's a scaled operation or a different, more catastrophic, brain injury. It's a huge range of scale of injury when it comes to birth injuries.'*
>
> Stakeholder, claimant solicitor

Solicitors said that damage is normally established with an MRI scan once the child had missed expected developmental milestones. (The need to sedate a baby to carry out an MRI scan was identified as the reason why it is often not appropriate to carry out the scan straight after the birth).

While there may be an awareness that 'something had gone wrong' during birth, whether this was due to negligence or natural 'bad luck' was also often unclear. The dual uncertainty – about what had happened and how the child would develop – not only characterised these stages, but also affected the experience for all involved.

This uncertainty was said to make discussions around the birth difficult for the healthcare professionals involved, given they are not able to provide definitive answers to parents, who are having to deal with traumatic and devastating experiences.

> *'And it's usually the most devastating news possible, for a family to learn that something's wrong with their baby. And the healthcare professionals, they've got a very difficult job, of*

> *course, in breaking it to them, and they do it with varying degrees of success. Sometimes it's kind of softly, softly, it's look, we think there might be a problem, we're not quite sure yet, but your baby's got to go to intensive care.'*
>
> Stakeholder, claimant solicitor

Solicitors and clinicians spoke about the 'Duty of Candour' healthcare professionals have, often outlined in the codes of conduct for the profession to which they are registered and reinforced in NHSLA guidance[8]. This means that health providers have a legal duty to inform and apologise to patients if there have been mistakes in their care that have led to significant harm. However, the dual uncertainty and complexities around these cases often means the level of harm and mistake – if any – are not clear. Stakeholders highlighted that this could impact on whether a conversation happens and, where is does, how difficult it could be for those involved.

However, clinicians said that they often felt they were taking all the steps they could to involve the family, and yet this was not reflected in the experiences of families themselves. Instead, parents who had experienced brain injury during birth described feeling distanced from staff. Some parents spoke of staff not wanting to look at them when they were in the room or answer their questions, making the whole process more worrying and isolating for the family. As such, the relationship between Trusts and families was sometimes described as adversarial, even in these early stages, with a lack of communication reinforcing this.

> *'When we tried to ask questions about what happened we were pushed away, and in terms of those very initial days, that was really, we were just so isolated is all I can say.'*
>
> Parent, experience of a birth injury

Case study: communication in the hospital

Francesca gave birth to her second child, David, prematurely. David was diagnosed with cerebral palsy at around one years old, a diagnosis Francesca now believes was caused by bleeding on the brain during birth.

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[8] NHS Litigation Authority, Duty of Candour: http://www.nhsla.com/OtherServices/Documents/NHS%20LA%20-%20Duty%20of%20Candour%202014%20-%20Slides.pdf

During the birth, Francesca did not feel she was getting the help she needed. Because David was so premature, hospital staff did not believe her when she said she was going into labour; she felt that because she was a young mother the midwives were not taking her seriously. David also had a high heart rate during the birth – something Francesca's mother, Sara, pointed out as abnormal, but this was not picked up by the midwife. Throughout, Francesca felt assistance was not provided at the right times.

After David was born, he had to be taken away to be stabilised. Sara went with him, and noted that he had a bruised face from the trauma of the birth. By this point, the trust had not communicated with the family about why the birth had been so traumatic, however a doctor mentioned to Sara that David may not be 'unscathed'; she also overheard staff talking about bleeding on the brain.

In the following weeks, Francesca and David were in a specialist hospital as well as the hospital in which she gave birth. During this time Francesca sought answers about the birth, as well as advice to care for David, but neither were forthcoming.

Therefore, parents and stakeholders alike highlighted that one of the primary things most people who have traumatic births want is an explanation or to be able to discuss their concerns. As one charity representative conveyed, if the family were able to see how distressed clinical staff were and the actions they were consequently taking as a result of the incident, this could dramatically reduce families' feelings of alienation and isolation. As noted earlier, various stakeholders stated that clinical staff do take the cases very seriously, but this is rarely relayed back or communicated to parents.

In light of this, the inclusion of an early 'expression of regret' as part of a new scheme was seen positively. All audiences thought that more needs to be done to acknowledge that a potential birth injury has taken place, regardless of whether clinical negligence is a factor. They felt this would make the experience – though complicated – more transparent and provided a chance to reduce the isolation and distress parents could feel.

> *'That is so necessary and it never happened with us, we were left believing that, yes, he'd been through a traumatic birth but we weren't told there was any permanent damage or that there might be permanent damage, we were told nothing. And that is important.'*
>
> Parent, experience of a birth injury

However, this issue was seen to be more complicated than simply opening up communication channels. Stakeholders said that all the uncertainties also created a situation in which staff were fearful of litigation, and this offered some explanation as to why they may not have communicated with parents in the way parents wanted.

> *'Within a hospital, as soon as there are grounds for a case, the legal department are on the case like a shot saying be careful what you say, don't say anything, don't admit anything.'*
>
> Stakeholder, patient charity

In several cases, affected parents mentioned how they felt clinical staff did not want to acknowledge the incident *because they wanted to avoid admissions of responsibility*. One participant said that some of the nurses in the hospital had given 'clues' – such as suggesting the parent writes down what happened – while also saying they were 'not allowed to say more' to the parents. Another had a similar experience of being advised 'off the record' that they may want to look into what happened further. Therefore, while openness and transparency were valued, participants recognised that an expression of regret was one step in a longer process. They thought that the level of cultural change needed was great, because the fear of litigation was so ingrained and normalised in working culture; staff would need to be supported not only in expressing regret, but also in talking about the uncertainty inherent in these cases without fear of repercussions. As is discussed in section 3.3, involving parents in an investigation process could facilitate this by ensuring parents understand the concerns and actions of the staff.

2.2 Experiences after leaving hospital

The research found that the uncertainty and isolation experienced by parents continued to have an impact after they left the hospital or unit and began caring for their child. As noted earlier, the variety and complexity of cases means that parents may leave the hospital not fully understanding what has happened, which means that the early stages were characterised by a 'creeping' realisation of the situation or impact.

> *'Sadly it is not at all unusual for parents to leave hospital with their baby with cerebral palsy, and it's been diagnosed, and they've only got the thinnest understanding of what the full implications are going to be.'*
>
> Stakeholder, claimant solicitor

Parents and stakeholders told us that this stage can feel particularly devastating and chaotic. It was described as 'immeasurable', with no two families reacting or being affected in the same way. The grieving process was said to be unique, and one parents themselves found difficult to put into words during interviews.

> *'I think it's a different type of grieving process that parents go through with birthing injuries than any other injury – because you're not losing somebody you know, you're losing the dream of somebody you've never met yet which is very different and hard to compare with any other claim.'*
>
> Stakeholder, claimant solicitor

In these cases, grief was accompanied by worry and anxiety. For some, this stage was also characterised by the post-partum depression they were experiencing. This level of distress and worry resonated strongly with parents in the general public, despite them not personally encountering this situation. They could still recognise that birth injuries were unique, which shaped the grief and long-term anxiety likely to come with it.

> *'Worry is a good point. The difficulty is likely to be that [a brain injury is] not abundantly obvious in a new-born. So it's quite a long stretch of worry before you find out if there is brain damage. You won't know what it is straight away so there's long-term anxiety.'*
>
> Parent, general public, London

For one participant, the range of emotions experienced during this stage was even more varied and shaped by the amount of questioning directed at them, as it was initially suspected that the brain injury was a result of a child protection issue, before it was clarified that it happened during birth.

Parents who had experienced a brain injury during birth also described feeling completely unsupported – both emotionally and practically – after they left hospital. All parents who took part in the research gave examples where they were not given the information, advice or support they felt they needed to come to terms with the incident and care for a disabled child. They felt they only received the support they needed when they pushed for it.

> *'And it just illustrates how little thought goes into preparing parents and actually sharing best practice or best ideas or best care options with parents…we just could not believe that no one would tell us that. There's a whole team of medical experts who know about feeding pumps, that they're so routine we now know, but as new parents we had no idea.'*
>
> Parent, experience of a birth injury

As such, many described these early stages of care provision as one in which grief translated to determination and they were focussed on 'just coping'. Chapter 4 explores the ongoing care needs in cases of a brain injury during birth in more detail. However, the research suggests that, alongside an expression of regret, a new scheme needs to provide or signpost advice and support even in the very early stages, if feelings of isolation are to be minimised.

2.3 Gathering evidence

Where it is felt that clinical indicators suggest the birth did not go as planned, trusts – as employers – are encouraged to carry out their own investigations to establish what happened.

Learning from individual trusts can be fed back into processes to improve the delivery of care. For example, processes could be adapted or the employer could enforce a programme of training for the clinician.

If a clinician's fitness to practise is called into question, there are also various different regulatory mechanisms that would be triggered as the result of an investigation. The possible consequence of this would be a clinician being removed from their professional register, and therefore not being allowed to practise anymore.

Finally, evidence from any investigation work could be used as evidence in a litigation process if one is raised.

Clinicians in this research said that investigation processes and mechanisms triggered straight after the birth in the setting they worked in were robust and comprehensive. They could typically involve one or more of the following: a root cause analysis; an action plan; a weekly review of all incidents by a panel; multi-disciplinary risk management meetings; and other formal governance processes.

Case study: Stephen, midwife in a large hospital

Stephen has been a midwife for over 10 years, and has worked in his current setting for a great deal of that time. He feels that the processes the trust had in place were robust and clear. He said that the trust has an obstetric ‘trigger list’ that he and his midwifery colleagues were fully aware of and used as a basis to decide whether to use the clinical incident reporting system.

He explained that the midwives cross-examine the maternity service’s IT system at the end of each month to check that all of the cases that should have been on the trigger list are. If not, they retrospectively report them on to the incident reporting system. Stephen and his colleagues use this system to analyse the trends and themes prevalent across the cases.

Stephen stated that each incident is fully investigated through an initial local investigation, and if there are further learning points that they have been unable to unpick through these means, they will be flagged to their clinic issues group, a multidisciplinary group, which looks at more complex, or high-risk incidents that have occurred.

Stephen pointed out that there would then be a case note review, which will be presented back to the group to pick out whether there are any learning points, changes in practice, or changes in their trust guidelines that need to happen on the back of those.

Although clinicians themselves had a lot of trust in their internal processes, they and other stakeholders suggested that there is little or no consistency across trusts.

> *‘If there's been an adverse incident then a report has to be done, but if there's a full investigation very much depends on the trust. There's no consistency across trusts - some are much better at this than others.’*
>
> Stakeholder, claimant solicitor

This lack of consistency was borne out in the experiences of families included in the research. Indeed, there were mixed experiences of the investigation process. As described earlier, many felt that the trust ‘closed its doors’ and was not forthcoming with information. It was only once litigation had started that some families began to get answers from the trust– normally in the form of medical notes – and even in these cases, it could take years to obtain these.

In some cases, however, parents said that trusts were very forthcoming with information and notes, once they were requested.

> *'The hospital then did a review which I was really pleased they were open about that...so we saw a report and went into hospital and had a meeting.'*
>
> Parent, experience of a birth injury

When the notes were thorough and detailed, and reflected parents' own version of events, this represented a crucial stage in helping parents understand what had happened during the birth and speeding up the compensation process. Where parents felt that the notes they received were incomplete or adapted, and did not reflect their own experience, this could cause suspicion and reinforce the need for litigation.

> *'Sometimes what really gets people is that they have an initial interview and it's really clear that what's in the notes isn't what happened - or there's been some retrospective writing up of notes or deviation in the notes. That always gets parents wholly suspicious. Most hospitals will light touch the fault and spin the unavoidable.'*
>
> Stakeholder, patient charity

Standardising investigations across trusts and involving families were both seen as strengths of the potential scheme. In doing this, it was felt that families would have a greater understanding of how their case was being dealt with and have the opportunity to share their versions of events. Overall, a collaborative, open and consistent approach was valued, and thought to be one way of supporting families in the difficult early stages, while also creating learning and therefore potentially reducing future cases.

> *'If there was a proper process in place for recording this mistake, or inadequate care, or breaches of duty where injury had occurred...if there was a learning opportunity from that that was then rolled out across the NHS, I think that would have a huge impact on, well, just preventing incidences occurring again.'*
>
> Stakeholder, claimant solicitor

However, as one clinician pointed out, in standardising it will be important to build on what currently works and not force changes to hospitals or trusts that already have effective investigation procedures in place.

> *'I'm worried that we've got hotspots that are not doing investigations really very well and there are other places that are doing it really well, and so changing something where it's*

> *working well in some areas, is my worry…it's not reinventing the wheel for the whole bus when actually there's only a spare wheel that needs changing.'*
>
> Clinician

In addition, stakeholders also agreed that the process of investigating an incident took time and this would also need to be considered in the new design. Among other things, time was needed to ensure the right experts were involved in the process, given the time pressures faced by senior consultant obstetricians and gynaecologists overall. Therefore, stakeholders said that any new policy would need to account for this beyond the 28-day period suggested in the early design of the scheme.

This was particularly relevant as the involvement of experts was valued across audiences. Parents – both those who had experienced birth injury and those who had not – highlighted the importance of independence in expert input. Indeed, ensuring independence in the investigation overall was seen as vital for reassuring parents that their case was being taken seriously and being dealt with fairly – particularly among a group of people who may have lost trust in the NHS. The importance of ensuring trust and distance from the NHS in the new scheme was a consistent theme across the different stages and journeys for those who had experienced a birth injury, and is discussed more throughout this report. For some, this meant an independent body, much like the Independent Police Complaints Commission (IPCC), should exist to oversee the investigations and instil confidence in their findings.

> *'There would have to be a completely separate arm looking at this. It couldn't be someone in the trust doing the investigation. It would have to be independent.'*
>
> Stakeholder, claimant solicitor

However, on the whole, independence in the context of the investigation meant independence from the incident or trust in which the incident occurred, rather than the NHS itself. Avoiding conflicts of interests, while also benefitting from the expertise of a multi-disciplinary team of people including legal and medical experts was the focus.

3 Establishing liability

This chapter focusses on the steps families take following a birth injury to receive answers and compensation from the NHS. While chapter 2 covered findings on the current investigation processes trusts have in place, this chapter looks more specifically at the decision-making processes around litigation for parents, and their experiences of the litigation process.

In doing so, it also presents early findings on the potential inclusion of a panel to replace the current role of the solicitor in establishing clinical negligence and the appointment of a case manager if avoidable harm is established.

3.1 The journey to litigation

Often, contacting a solicitor and beginning litigation proceedings was not an immediate thought straight after the birth for parents. Solicitors told us that it was typical in these cases for parents to only start to understand the implications of the experiences during birth once the child began missing development milestones, and therefore many contact them a few years after the birth. However, they also said that earlier diagnosis of brain injuries, and greater awareness and monitoring of a baby's developmental milestones, mean that parents are now contacting them earlier than they once did to establish if litigation is an option. Indeed, the parents included in this research had contacted solicitors at varying points in time, or were waiting to do so.

> *'Parents used to come to us when they were 3 or 4 years old. I think that families come to us much earlier now - their babies are still pretty young…diagnoses are coming a lot earlier but also they have perhaps had comments made from doctors that they should perhaps look into how they're going to provide for their child/see a lawyer.'*
>
> Stakeholder, claimant solicitor

This suggests that better knowledge and understanding of brain injuries could impact on whether or not a parent chooses to litigate in the future, and provides a further indication about why clinicians may be worried about discussing cases with parents in the early stages for fear of leading them towards litigation.

Stakeholders also pointed out the families who currently litigate tend to work in professional roles and have relatively high incomes. They said that they are more likely to have a social network to draw on for guidance on the litigation process, and recommendations of solicitors. This was borne out in the journeys parents described, with family contacts and their own roles in the legal sector both being mentioned as facilitators.

> *'It was only because of(?) my job, I deal with litigation, that's my area. It was only because of that that I realised that we had to get in really quickly. So although we wouldn't necessarily have chosen to do it that early, we did it almost immediately because we had to.'*
>
> Parent, experience of a birth injury

Therefore, stakeholders raised questions about a new scheme creating awareness among those who may have experienced clinical negligence, but would not have gone down the litigation route. While it was seen as positive that support would be made available to a wider pool of people, the possible cost implications of this to the NHS were highlighted.

These concerns were furthered when participants discussed the basis of eligibility for the potential new scheme. One option would be for eligibility to be based on avoidable harm alongside clinical negligence. This potentially means that not only cases where harm was caused because something *should have* been done differently would be eligible, but also cases where something *could have* been done differently. This was not covered extensively in this research, but where it was discussed, participants were worried about the cost implications of an unknown pool of people becoming eligible. Ultimately, however, even professionals working in litigation, found it difficult to explore this concept in more detail.

Despite concerns about potential increased appeal and reach of a new scheme, the research found that litigation against the NHS was not an easy decision for parents to make. In fact, stakeholders said that one reason parents choose not to litigate is that they feel ideologically opposed to suing the NHS.

> *'I've got a case at the moment where the father really doesn't want to sue the NHS, and it's quite clear that there has been some negligence, so [the mother] persuaded him to have a meeting to discuss the way forward, but he was very reluctant. When you get all this press about taking money out of the NHS, it becomes socially unacceptable to sue.'*
>
> Stakeholder, claimant solicitor

Participants in the general public groups acknowledged that the financial burden on the NHS would be a factor for them in deciding whether to litigate. Ultimately, participants said that they did not want to confront the NHS – an institution they said that they admired. The pride people feel in the NHS is well evidenced; for example, in 2014 Ipsos MORI conducted research with the general public on behalf of the Kings Fund, in which the NHS topped a list of things that make the public proud to be British[9].

However, the parents who had experienced brain injury during birth felt that they had no choice but to seek compensation, despite any reluctance. Their main motivation was securing financial stability and continuity of care for their child. Indeed, in the time after the birth, as parents began to understand the types of therapies and care that their child would need, they also realised that they were going to need substantial financial support to fund this.

> *'Then I realised I couldn't go back to my job obviously, and then financial worries start to dawn on you, because suddenly I knew my maternity would come to an end, at the point where I was going to go back, four days a week, and I realised there was no way I could do that… and then suddenly you've got this financial worry on top of you as well, OK, not only does this mean our lives have very much changed, but are we going to be able to pay the mortgage now?'*
>
> Stakeholder and parent with experience of birth injury

With this growing understanding of care needs, came a realisation that needs may change and the child could need increasing support as they get older. These parents outlined that, with the life expectancy of people with brain injury now being higher than it was in the past, they wanted to have a guarantee that the support would be provided if they died before their child.

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[9] More than half (52%) said the NHS is what makes them proudest to be British, placing it above the armed forces (47%), the Royal Family (33%), Team GB (26%) and the BBC (22%) - *Maintaining pride in the NHS: The challenges facing the new NHS Chief Exec.*
Ipsos MORI, Base: Adults aged 15+ in England (978) March 2014

> *'One of my big worries was what is going to happen when we're not here. And I think like any parent would be like that, I think that's the biggest...it's the future unknown, that I die, I was really, really concerned about, but now I know he's going to be sorted.'*
>
> Parent, experience of a birth injury

Case study: funding Elijah's care

While Elijah has received an upfront payment as part of the litigation process, his parents did not feel this was enough and are still struggling with the challenge of funding his care and support. Elijah's parents feel the state care he is receiving is insufficient and they have been reluctant to arrange the more expensive treatments until they have the stability of further compensation.

The family have found that getting extra care and support through a charity has been useful in coordinating this, and they believe it is important to have one 'go-to' person through whom different care needs can be organised.

Overall, Elijah's family hope the litigation process will result in periodic payments to pay for care. While they see lump sums as valuable for things like accommodation, they believe periodic payments carry less risk and offer the stability they wanted to provide for Elijah's care throughout his lifetime.

Therefore, there is an important role for any new scheme in providing reassurance about the child's future, and how the panel decision would provide this in the way that litigation does. Participants' views on whether they felt the potential new scheme would sufficiently meet care needs are discussed in chapter 4.

Furthermore, although not necessarily motivated by anger at individuals, parents also wanted to litigate to get the answers they needed from a system in which they had lost some trust.

> *'It became really apparent that something really different had happened to us than anybody else, and we just wanted to know. It wasn't anger really...'*
>
> Parent, experience of a birth injury

The NHS being able to learn from what happened was also a motivator for litigation, but less so than the need for answers and financial stability. Nonetheless, solicitors noted that parents were less likely to litigate in cases where their child had died from a brain injury, as they did not feel that they needed the compensation for this. However, they might still get in touch with a solicitor, as they were keen to ensure that the trust had put into place the correct systems to learn from their mistakes.

> *'In cases where people have lost their child, sometimes they haven't pursued litigation because they've lost their child and nothing can bring them back…It's more about well was there an acceptance of what's happened and were there measures put in place to prevent it happening again?'*
>
> Stakeholder, claimant solicitor

Given that the panel in the proposed new scheme would be responsible for establishing eligibility and providing access to the financial stability that parents were most motivated by, it was seen to have an important role. Parents would need to trust the panel to provide a fair and transparent decision on the outcome, and trust them to have the child's welfare as a primary concern, above and beyond any negative impact on the NHS if clinical negligence is found. Therefore, the idea of an NHS-led panel making a decision about eligibility represented a conflict of interest, or was at odds with the need for families to regain trust in a system they may have lost some trust in, regardless of how much they admired or were proud of the NHS overall. In contrast, a solicitor was seen as having an important symbolic role in being distanced from the NHS and the associated impartiality. Parents overall questioned whether they would be able to equally put their trust in the same decisions being made by a panel of NHS employees and would be more reassured if it was led by other experts – such as legal experts – with a focus on transparency and impartiality.

> *'It'd have to be completely external from the NHS if it was like that because if they're all being paid by the NHS surely they're going to do what the NHS tells them to do, you're going to do what the person tells you because that's who pays you.'*
>
> Parent, general public, London

Therefore, participants wanted an independent panel removed from or led from outside the institution of the NHS altogether, ideally meaning a separate government department with a legal or complaint focus. This has clear implications for how any new policy or scheme is positioned, as it will be important for parents to trust in the decisions on negligence and the future care needs to avoid the appeal of starting a litigation process at the same time.

3.2 Experiences of litigation

Once the decision to litigate had been made, the actual process was invariably described as an arduous and traumatic experience for parents; something that adds to the distress they are already experiencing caring for a disabled child. Solicitors mentioned the commitment needed from parents to engage in the process, and parents described the experience as a 'battle' they had to commit to.

> *'Oh it was quite traumatic all the way through, and the different things, but we just had to say put on our suit of armour and go and battle the next battle.'*
>
> Parent, experience of a birth injury

In particular, it was the experience of having to re-live the trauma of birth over and over again, years after it had happened, that parents found particularly distressing. Litigation required them to provide details of the incident to solicitors and other experts, which meant that their ability to move on and get on with their lives was delayed, sometimes for a prolonged period of time.

> *'You look at this [letter] box every few weeks...every letter was traumatic to read. It may only be three or four pages on a letter but there's thousands of letters in there so it was a constant...reminder. You're just trying to cope with a new regime, even three, four years down the line, and then you suddenly get a report that then goes back [to the birth].'*
>
> Parent, experience of a birth injury

All participants with experience of birth injuries, both parents and stakeholders, noted the extensive length of time litigation takes (in most cases it takes years) as it relies both on clinical negligence being established and the full impact of injuries also being understood. In general, participants often associated the length of time with the trust itself, with the perception that the trust was unwilling to be open and transparent with parents about what had happened, thus delaying any response. Solicitors suggested that admittance of liability and disclosure of information could happen straightaway but often does not.

> *'There is often a significant delay in disclosing the Serious Incident Investigation Report to the patient and his/her family. This arouses suspicion and some patients feel there is a*

> *cover up. Investigation Reports should be disclosed as soon as they are available and the patient should be involved in the investigation process. They should be but they are not.'*
>
> Stakeholder, defendant solicitor

Stakeholders believed that this delay was due to clinical staff taking on additional investigatory duties on top of their clinical roles. It was suggested that both the quality and speed of investigations would dramatically improve if staff could work specifically on investigations, rather than in addition to their clinical priorities.

> *"Often the lead investigator conducting the investigation is not appropriately qualified and fails to get to the root of the problem. A significant problem with the current system is that those that do have the skills to investigate do not have the time as they have to conduct the investigation in addition to their clinical/nursing priorities".*
>
> Stakeholder, defendant solicitor

Solicitors also outlined that in cases where trusts admitted liability early on, they can secure an early interim payment for the family, making it easier for them to cope financially in the short term. Whereas if the trust did not admit liability, it was likely to be a much longer and difficult process.

> *'The main thing that affects how the process works is whether or not liability is admitted and how long that takes – that's likely to be the biggest difference between any two cases. Whether there's a fight on.'*
>
> Stakeholder, claimant solicitor

One solicitor suggested that an additional reason it takes so long for a trust to admit liability is because of clinicians' concerns about implicating themselves and being blamed. Instead, the focus should be on acknowledging that something has gone wrong.

> *'There are other [cases] where it's hard to tell why it isn't resolved early. I think sometimes I think perhaps those involved from the medical profession on the defendant's side feel that they're being blamed when really negligence claims…are not about the individual blame so much as to the extent something bad has happened and it shouldn't have.'*
>
> Stakeholder, claimant solicitor

Therefore, the new scheme's focus on providing a less adversarial approach could be seen as an important change, assisting cases to be resolved more quickly, improving the experience for parents and ultimately reducing the costs associated with this time. Indeed, at the moment the length of time needed to establish liability was also said to impact on legal fees for both sides, something of concern to solicitors and stakeholders alike. They felt that the money and time spent proving and disproving claims could be better spent elsewhere.

> *'Really part of what distressed me was just the amount of money that was then spent…independently to prove everything that they'd admitted to in their response to our complaint…I don't want NHS money wasted on legal fees.'*
>
> Stakeholder and parent with experience of a birth injury

Solicitors recommended that more needs be done to acknowledge a breach of duty and admit liability earlier, for the benefit of both the claimant and the NHS. Although one solicitor suggested this was in the process of changing.

The potential new scheme was therefore seen as likely to be more appealing if it was shown to avoid the adversarial and expensive experience of litigation that parents went through in the current system, as well as provide more certainty early on.

However, even when liability was established early on, parents described a lack of closure because of the ongoing uncertainty of the case; it can take years as they work out the long term implications of the injury. During this time, families don't know what decision will be made, and whether they will be successful at the end.

> *'You may have to wait until developmental milestones to see how they're affected…they could have to go through puberty to tell how much care is required so it might take a long time to establish their needs. It's not a straightforward question I'm afraid.'*
>
> Stakeholder, claimant solicitor

Case study: experience of litigation

Aalia gave birth to her first son nine years ago. During the birth, several incidents occurred that meant he was born with severe brain damage. Aalia began litigation proceedings in the first year after the birth.

It took three years for the trust to admit liability; however, this preceded five years' worth of assessments to decide the final amount of compensation. Aalia described these assessments as distressing for both herself and her son Luka. Aalia spoke about having to relive the traumatic details of the birth. She felt there should have been some way for her to feed back on the conduct of the expert witness, as well as comment on the reports they produced, which she felt were sometimes inaccurate.

It took a long time for the final amount to be resolved, which the family described as profoundly frustrating; feeling that the case might be resolved before further delays pushed a decision back. They settled when Luka was eight years old, despite solicitors recommending that they keep going until Luka reached teenage years when the full impact of the injury might be known. The distress – particularly the intrusiveness of the litigation process - meant they didn't want to continue with the case. The case went to court as a formality, however this was something the family appreciated as the judge was able to 'sum up' the case for them, making them feel like their suffering had been acknowledged.

Parents also wanted a scheme, therefore, that focusses on putting the right support in place for a child and their families, allowing them to thrive. This is explored in more detail in chapter 4.

> *'The Department of Health should seek to support families in order to maximise the injured child's opportunities to develop and thrive.'*
>
> Parent, experience of a birth injury

The current system provides a mechanism for participants to feel supported: having an impartial advocate in the form of a solicitor to advise and support them through the process. Families saw their solicitor as a valuable asset, providing essential expertise and guidance. They reported strong relationships with their solicitor, who they saw as a vital contact; able to update them and explain what was happening.

> *'She was very approachable, she would sit and talk to us as friends basically…She'd come into your house and you could chat to her about anything…Even if nothing has been going on we had letters saying that, you know, we're still waiting, they kept us informed all the time.'*
>
> Parent, experience of a birth injury

Playing an advocacy role could be central for the case manager in the new scheme, and might go some way towards alleviating the perceived gap left by removing the need for a claimant solicitor.

One case manager explained that it is a key aspect of the role to act with the client's best interests at heart, and stand up for what is best for the families they look after. The roles of the case manager and solicitor in the current system are explored in more depth in the next chapter.

> *'We're the piggy in the middle – the insurers, therapy team, family all get at the case manager. You have to be robust and have a sense of integrity – do things in the client's interest. Advocate of the client and not the NHS LA.'*
>
> Stakeholder, case manager

Therefore, while the new scheme would offer an alternative to the litigation route, demonstrating that parents will still receive independent and ongoing support as eligibility is established and the outcomes of the injury are explored will be important. Ensuring parents believe in and trust this support in the same way they do solicitors will also be important in increasing the appeal away from the litigation route.

4 Meeting the ongoing needs of the child

This chapter explores the ongoing needs of the child, both getting the appropriate care in place and funding it.

Therefore, the first section of this chapter looks at early care support needs, outlining parent priorities, their information and support needs, and access to finances early on. What this meant for their views of the case manager and early payments is also explored.

The second section outlines findings on the ongoing assessment of needs; exploring what participants thought this would involve and how it related to experiences of the litigation process, as well as outlining perceptions of lump sums and periodical payments in relation to this.

4.1 Early care and support

4.1.1 Immediate priorities

When reflecting on their journey, parents were clear that getting early support and care for their child was of great importance. This was so for three main reasons: to ensure the most immediate needs of the child were met; to ensure the wellbeing of the whole family; and to improve the long-term health prospects of the child.

Alongside a focus on the therapeutic care and treatment needs (discussed more below), practical adaptations – such as moving to or building suitable accommodation, or getting a larger car to allow carriage of a wheelchair – were cited as vital in helping parents manage caring for their child.

> *'Because we were getting to the point then where life was becoming very difficult. He was 11 years old and I was still carrying him upstairs to bath him and put him to bed.'*
>
> Parent, experience of birth injury

Being able to manage the care of their child also meant the wellbeing of the whole family was considered. For example, one participant spoke about the need to adapt their vehicle because, although their current vehicle could fit the wheelchair and equipment that they needed, when this was being carried there was little room for their other children in the car. As such, they needed a larger vehicle to care for their child and ensure minimal impact on the rest of the family. Being able to spend time with other family members, having respite care, and family holidays were also cited as being important to families overall. They wanted to be a parent to their disabled child rather than carer, and do the same for their other children; in short, they wanted to be able to minimise the change that came with caring for a child with a brain injury.

> *'We need to move from a position where we're her professional full time carers to a position to where we actually have outside support to help provide the care that she needs, so that we can go back to being parents to Lilly and also give more time to our [other] daughter.'*
>
> Parent, experience of birth injury

Participants also emphasised the importance of being able to implement a care plan as soon as possible. Families described a myriad of care arrangements that their child required, many needing round the clock care. They spoke about their child needing various treatments and therapies – such as physiotherapy and speech and language therapy. Other forms of therapy that they wanted financial support for included horse riding to help with core strength and technology to support learning and development.

The early implementation of these therapies and treatments was important to parents. They agreed that early interventions would improve the long-term prospects of the disabled child, as well as relieving themselves of the burden of care. Early intervention could also make vital savings later on by removing the need for longer-term care for the disabled person. However, it was agreed that the current system, whereby litigation and admittance of liability can take years, did not necessarily allow these early interventions to be made.

> *'If you deliver the right physio and speech and language therapy in the first 18 months, then that child may have much reduced care needs later on in life, and so there's such a tangible and obvious benefit and saving if you give the child the right support in the critical early stages.'*
>
> Parent, experience of birth injury

4.1.2 Access to information and support

Alongside early access to care, parents said that part of being able to get the treatment their child needed was getting the right information as early as possible. They said that the main information sources they had used were their GP, friends, internet searches or forums, schools, and other parents with experience of a birth injury. However, families felt that they were often not informed in the early stages, because of the uncertainties that come with brain injury cases and the perceived lack of information provided by trusts. They explained that this meant they could not get therapies in place in a timely way. Therefore, as noted, in chapter 2, they felt there was a clear need for better signposting to services, and more support offered to families to understand the care needs of their child and what is available.

> *'There were lots of examples…[where] we weren't given the medical terms or the physios or the speech and language therapists. They didn't share with us options in terms of treatment, equipment, care approaches.'*
>
> Parent, experience of birth injury

Participants spontaneously talked about the importance of having an allocated, named contact to support them through the process, following an incident at birth. This could provide reassurances to the family that a case is being taken seriously and is progressing, as well as supporting families in their decisions around the kinds of equipment and care their child needs.

Some claimant families were already experiencing positive aspects of case management as a result of litigation – for example, through a social worker or assigned specialist case manager. As discussed in chapter 3, solicitors were also playing the role of supporting families to navigate the system and identify different therapies, and the question was therefore raised about whether the case manager in the new scheme would have sufficient knowledge to provide *both the legal and medical support* families require.

> *'Would that person have sufficient legal knowledge and care knowledge to do both the job that the care manager does now and the job of solicitors?'*
>
> Parent, experience of birth injury

Independence was again an important issue to participants. Many agreed that a case manager's independence from the NHS, or at least from the trust where the injury happened, would be important to ensure the parents had trust in them. This was also thought to be important to ensure case managers could act in the families' best interests and be accountable for their own professional input.

> *'If the case manager is perceived to be the foot soldier of the NHS LA you can't build up that trust – the family will just see you as cutting costs. We have to be really clear that we're not from the insurance company. If there's no independence, then they may as well be a social worker from the Local Authority.'*
>
> Stakeholder, case manager

Alongside sufficient expertise and independence, parents described other characteristics that they felt a case manager would need to have in the new scheme. These included having the understanding and compassion to deal with sensitivities around their case, being available and responsive to the child's needs, and being able to play a project management role over the child's care.

> *'They could be trained, so then their role becomes like a project manager appointing the physiotherapist, appointing the speech and language therapist, checking in with the therapist and the family and making sure that that's running, and the plan for that child for the next 12 months.'*
>
> Parent, experience of birth injury

Case study: the role of a case manager

Graham has been a case manager for over 30 years, and now works for a private company carrying out this role. His role involves managing the care needs of children who have suffered from a birth injury, as well as people who have experienced a personal injury.

He explained that one of the biggest challenges families faced was overseeing the practical requirements of hiring and employing caring staff, as well as tolerating new people in their homes for long periods of the day. Managing contracts as well as personalities can be difficult for families, and it is the case manager's job to take on this role and alleviate any tensions that arise from this.

Graham said to work at the company he works for, case managers all need at least six years' experience in health or care, in areas such as physiotherapy, social work or nursing. He said there is a particular need to have a community background and understand how care is managed in the community. In terms of personal qualities, he feels that their attitude and personality is key; for him, a good case manager is focussed and goal oriented, timely and efficient, empathetic and, above all, they have to be the advocate of the family they are working for. They also need to understand how care is funded and how this differs from other roles.

'[Newly recruited case managers] don't understand the legal system or money because they're so used to working with a statutory budget. We can think more blue sky.'

4.1.3 Paying for care needs

Alongside the case manager, the potential new scheme has two other functions that are intended to support families who are eligible for the scheme early on: an early payment for general damages and an initial lump sum intended for the most immediate needs, such as suitable accommodation.

Under the new scheme, it is proposed that an early upfront payment (potentially of around £50,000 to £100,000) would be provided to eligible claimants early on. This would be to cover general damages – or pain and suffering – which at the moment may be agreed once liability had been established, but parents may have to wait until the final settlement to receive it.

In light of this, the upfront payment was seen as a welcome addition to the scheme, both as an early acknowledgement from the NHS of the pain and suffering families had been through, and to facilitate earlier implementation of the care priorities discussed above.

> *'I would like to have some sort of closure at an earlier point which says "this happened, we were negligent..." and if you're awarded it now, that would mean that you can kind of close that bit.'*
>
> Parent, experience of birth injury

Parents across the research were asked what amount of money was most appropriate for the early payment. Many people found it difficult to establish what would be a suitable amount of money early on; it was hard for people to put an amount on pain and suffering – and the value of their injured child. However, the findings reveal that establishing how to position and talk about the upfront payment will be important. For example, one family said that £50,000 to 100,000 sounded 'quite a lot', but at the same time when they spoke about the amount they had received for general damages through litigation, they suggested it being titled general damages was 'hideous' and the amount felt 'quite brutal', despite being around £250,000 more than the suggestion in the new scheme. This contrast highlights the value people saw in getting the payment early on to begin caring for their child.

Parents who would be eligible for the new scheme would also receive payments based on ongoing needs assessments. In the design discussed with participants, this included an earlier lump sum payment to pay for needs such as new accommodation, and periodical payments based on the ongoing assessment of need and for other aspects such as loss of earnings.

As outlined in chapter 3, having reassurance that their child's future is secure was the main motivator for litigation, and immediate priorities including new housing, were in turn also seen as a good investment. Therefore, when discussing the possibility of a lump sum against periodical payments, a lump sum offered the chance to invest, providing reassurance that there was money there to be used as and when it would be needed. For parents who had received a lump sum payment following a litigation process, it had been vital in enabling them to put a care package in place for their child, and make essential changes to their accommodation, or pay for carers. Families who had successfully litigated also felt the money enabled them to make improvements to their quality of life; e.g. buy a bigger car that allowed a wheelchair, take their family on holiday. These things were possible because of the flexibility the lump sum provided.

> *'I've been able to take time off work [and] become his carer. It's also meant that we've been able to move house, have accommodation that we're all comfortable in, accommodation that allows Jimmy to be looked after safely and far more easily. Also means that we can have holidays with him…they're not easy but they're easier.'*
>
> Parent, experience of birth injury

4.2 Ongoing care over the lifetime

The ongoing assessment of needs and payments or service provision linked to this was an aspect of the potential new scheme discussed with participants. Parents recognised that assessing a child's needs throughout their life would have the benefit of being responsive to a claimant's needs, which they valued. This had clear benefits in comparison with making a final decision about a child's care and funding at an early age in order to receive a final settlement; the current litigation route in brain injuries during birth carried the risk of unforeseen future changes to the child's needs not being accounted for.

> *'I thought it was odd that everything was decided and a line was drawn in the sand, aged six or seven. Why wouldn't you just continue to assess the child and continue to make available the services or the treatments that that child needs throughout their life?'*

Parent, experience of birth injury

The ongoing assessments also offered the prospect of avoiding the negotiation phase in the current litigation model, involving various experts from the claimant and defendant side assessing the child. This experience was seen as time-consuming and costly, as well as profoundly traumatising for the claimant.

> *'[The ongoing assessments] would be a big time saving, money saving, stress saving, and everything, whereas we went through this thing where we had to have that side visit and that side visit, and those two argue.'*

Parent, experience of birth injury

In order for the ongoing assessments to be an appealing option, however, it was agreed that parents would need to be reassured that these are thorough and fair. Participants thought a number of experts should be involved in conducting the assessments, as well having input from people involved in the child's day-to-day care who could provide a longer-term, more intimate view on the child's needs.

'The hardest thing to understand is that you've got these specialists coming out to see him for an hour and they are determining what he's going to need for the next 20, 30, 40 years. That was really hard to get my head round because how can you possibly understand a very complex child? ...They need to talk to people who have day to day contact with him other than his parents.'

Parent, experience of birth injury

Participants questioned what the criteria used for the assessments would be; for example, they wanted to know if the differences they perceived between state care and private care would be taken into account. One stakeholder highlighted that a benefit of the current system is that the claimant solicitor acts solely with the claimant's interests in mind, whereas they questioned who would make the ongoing assessment decisions, and whether they would be able to approve private care over state care or whether they would also have to consider NHS finances.

In some ways, the periodical payments linked to ongoing assessment were valued, because they meant parents would not have to manage a lump sum; stakeholders reported that managing a lump sum could be difficult and stressful for parents who have to make decisions about how they spend the money over the course of the child's life. They said parents have the dual responsibility of ensuring the money does not run out, as well as providing regular proof that the money is being spent appropriately. They said that the skill of managing such a large sum of money was one that many parents had to learn quickly once they received a lump sum.

> *'It will be stressful - managing a large amount of money that has to last for life, so the parents have that 'should I be buying this, should I be saving for this, is the money going to run out?'; so litigation is over but there are still pressures on them.'*
>
> Stakeholder, claimant solicitor

Case study: managing finances

Riya has been managing her daughter's lump sum pay out for over a decade. She says that this has been somewhat challenging, largely because of, what she describes as, the bureaucracy it involves.

Providing receipts and proof of purchases was something she initially found difficult to get used to. For example, they bought a tricycle for her daughter that allows her wheelchair to be fitted on the front. They initially saw this at a mobility roadshow, had to explain what it is and ask permission to buy it, before returning to the company to order it while organising the solicitors to pay for it. This process will typically take around three months; 'it's not just a case of going and seeing it and saying 'yes we want one''. For everyday things, Riya will use her own money to pay for things, and then get receipts so that she can claim back expenses at the end of each month.

This approach took Riya some time to adjust to, but for her the challenges do not outweigh the benefits of knowing there is money there to pay for things, such as equipment, that her daughter needs.

This challenge was recognised by parents in the general public groups who had no experience themselves of managing such large sums of money. These participants felt that periodical payments would be easier to manage and would relieve families of this pressure. It was also pointed out that lump sums could be wasted and misspent, a risk that is mitigated with periodical payments, which would last over the course of the child's life.

> *'I think having that coming in every so often is, yeah, it really depends on every family, it's probably easier to manage, personally it'd be easier to manage for me if I knew that was coming in regularly.'*
>
> Parent, general public, Leeds

This also resonated with findings in earlier Ipsos MORI work in 2013 looking at personal injury cases for the Ministry of Justice (MoJ). Stakeholders in this research (including solicitors and professional deputies) said that claimants who were minors or vulnerable were more likely to accept periodical payments as part of their settlement than other personal injury claimants. These tended to be cases where a claimant had lacked capacity as a result of the accident, where the claimant was a minor and a long life expectancy was predicted, and/or also where the accident had been 'catastrophic' and care costs were high, and therefore ongoing management of the money was more pressing as an issue.

However, despite these acknowledged benefits, claimants who had received compensation themselves still felt they would potentially want access to a full lump sum under a new scheme. They identified a series of risks in relying on periodical payments and service provision based on ongoing needs assessments. The ongoing assessments were linked to potential ongoing intrusion and worry for parents, rather than reassurance that care would be adapted. A lump sum 'drew a line' for them and gave them independence and control over their finances. This was not something participants felt the new scheme explicitly offered; instead, they felt they would have continuous assessments and potential changes to their circumstances.

> *'If they say…we don't want to pay to have four nurses to come in, full 24-hour cover, we want to put your child into a care home. Because what you do by giving someone a huge lump sum of money is you give them full control over their future.'*
>
> Stakeholder, claimant solicitor

In the work carried out by Ipsos MORI in 2013 on personal injury claims, it was also found that many claimants intuitively valued lump sums over periodical payments, because of the perceived flexibility to spend the money as and when they chose. This allowed them to retain the independence they had before their accident. This financial independence was coupled with emotional closure on a litigation process that had been stressful and difficult.

Similarly, families and solicitors in this research thought that the ongoing assessments could be perceived in this light and, ultimately, seen as intrusive, offering little or no closure for the parents. The assessments were likened to the expert assessments made throughout the litigation process, which were described as stressful and invasive, and could deter families from choosing the new scheme.

> *‘What they don't like is having lots of intrusions in their lives - lots of experts…what I think is a problem [with the new scheme] is [that] it looks like they continue to be assessed…but with the current scheme once it’s done and dusted it’s done and dusted…with this scheme they would be more present for the rest of the lives.’*
>
> Stakeholder, claimant solicitor

A new scheme will therefore need to highlight the value in ongoing assessments, and allay fears about ongoing intrusions in the families’ lives. It will also be important for the scheme to allow parents to still draw a line under their experience, and take confidence in being able to secure their child’s future.

One of the main barriers for the scheme in doing this relates to perceptions of the risk associated with state care – which would be provided as part of the ongoing assessments – and the lack of trust in the scheme this may translate to.

Firstly, state care overall was seen as changeable and linked to the political climate. Stakeholders highlighted that stories in the news reinforced this perception, and, ultimately, they said parents would see ongoing provision as risky in light of this.

> *‘As a claimant, my concern is that political will changes…so from a claimant’s perspective there’s more security in having this lump sum model, you know what you’ve got.’*
>
> Parent, experience of birth injury

There was also a perceived risk with quality of state care overall based on wider experiences. For example, one participant said their friends had experienced a lack of integrated care in state services, and they felt that private care would offer their child more continuity of care. Another used the example of his mother who is a carer for another relative, highlighting that when they needed to rely on carers provided by the state when his mother was not available, the quality dropped a great deal, because they did not have the time to provide the level of care his relative needed.

> *'What we need is continuity, now the only way to get that is paying good wages and employing somebody who is going to actually love the job. And you're not going to get that through a state company, are you?'*
>
> Parent, experience of birth injury

One stakeholder highlighted the difference in levels of care that the current litigation route creates at the moment: those receiving a settlement are able to access private care and technologies, which people see as the 'gold standard', while others with the same conditions – but not caused by negligence – only have access to state care.

Indeed, overall, participants highlighted that state care would always need to be provided within the realms of what is financially possible for the government, and ultimately this may not fund the kind of care and support participants wanted for their child or wider family. Participants felt that through the lump sum compensation they had received, they had been able to afford a level of continuity in care and quality of care – including access to newer technologies – that would not currently be available from the state.

> *'There's so much more out there…the bicycles and stuff that are out there, the toys with the specialist switches and stuff…they're seen as a nicety by the state but actually when you've got your own pot of money there, you can afford them and you can make life easier with them.'*
>
> Parent, experience of birth injury

It was suggested that people were becoming more informed about what the 'best' care would look like through greater access to information via the internet, and this might encourage parents to still litigate rather than use the scheme. A family of a claimant with severe cerebral palsy, who had not been successful in litigating against the NHS, was in fact happy with the care provided by the NHS and social services. However, the state care they received was heavily supplemented by care funded by the family themselves through fundraising for expensive equipment that they felt was essential, but was not currently provided by the state.

> *'When we say we need something then they're quite good. He needed a new bed and that took over 2 years, in the end we started a trust for him and one lady paid the £10k for the bed…The fire brigade funded his wheelchair…The Make a Wish Foundation has got him a Trek Buggy.'*
>
> Parent, experience of birth injury

This suggests that perceptions about the inadequacies of state care might act as a deterrent to taking up the scheme, with families believing that they will secure a better future for their child through litigation and subsequently privately funded care. As one stakeholder suggested, a negative experience of state care might force people to look into other options at this stage, such as litigation. The scheme will need to reassure parents that this is not the case, highlighting the value in care and ongoing assessment of need.

> *'[Parents] have already been through the mill and even after a year they've had enough. The carers turn up late, aren't trained, change too much. You only have to go through it once and you know that if you had the chance to do something different you'd leap at it.'*
>
> Stakeholder, case manager

Appendices

Appendix A: summary of recruitment approach

Solicitors, charities, case manager and clinicians:

Participants were identified through Ipsos MORI and DH's existing contacts, snowballing and desk research. They were recruited using a joint-branded letter or email and a follow-up telephone call.

Parents who experienced a birth injury:

Parents were recruited with the assistance of charities and other gatekeepers, such as solicitors, advertising on online discussion forums, and snowballing.

Participants were given an incentive of £50, as a thank you for each participant's time.

Parents (general public):

Participants were recruited using a 'free-find' technique, meaning they were approached and invited to take part in the workshops on the street, as opposed to being selected from a list of people who have registered their interest in taking part in research projects.

All recruitment was handled by Ipsos MORI's in-house recruitment team. Participants received a £40 cash incentive to thank them for their time and contribution. Participants were recruited to ensure that a range of demographic characteristics were represented within each group of interest including gender, age, and social grade. Groups were carried out in London and Leeds.

For all groups, recruitment screeners, participant information leaflets, and consent forms were provided to participants where appropriate, and were developed alongside Ipsos MORI's Ethics committee to ensure they were suitable and appropriate for the target audience.

Appendix B: Discussion guide for solicitor and charity interviews

DH: Rapid Resolution and Redress (RRR) Policy Research
Discussion Guide: Stakeholder strand: solicitors and charities_220416 v3

This discussion guide is for use in the interviews with relevant stakeholders (solicitors/ charities) who support families with clinical negligence cases. The interviews will last between 45 mins and one hour; we have provided an indication of timings.

The key objectives for the research are as follows:

- ***What is the 'journey' of parents faced with deciding how to proceed after a birth injury*** – e.g. what are the key steps, what does a typical case look like?
- ***What factors influence parents' decision making in choosing how to fund care following a birth injury?*** From experience dealing with a number of cases, what are the key things that motivate parents to pursue litigation? To what extent is this route able to meet these expectations?
- ***What do parents think of the 'no blame' policy options/ potential care packages?*** What do professional's think of the alternative proposed? What could be improved? Why would parents choose this option and what would prevent them from choosing it?

The questions suggested below are to act as a *guide only* for the interviews; researchers will be expected to adapt and tailor the conversation to suit the role of the stakeholder being interviewed, and their level of experience. For example, charities may be more qualified to discuss one or two stages while solicitors may be able to talk in more detail about each stage.

1. Introduction	5 mins
• Thank participant for taking part • Introduce self and Ipsos MORI • **Purpose of research:** The research is being conducted on behalf of DH; DH is currently looking at the feasibility of a new compensatory scheme and want to hear from a range of experts and stakeholders to feed into the design of this new scheme. We are talking to them as experts in this area or people who understand the journey parents go on in more detail. We are also talking to families who have experienced birth injury to ensure their experiences are considered in the design. • Reassure that all opinions are valid/ no right or wrong answers. • Explain confidentiality and MRS guidelines.	This section will introduce the research, and orientate the participant to ensure they are comfortable with the approach.

• Level of attribution: can we quote them directly, their organisation or do they want total anonymity? We can confirm this at the end. • Get permission to digitally record – transcribe for quotes, no detailed attribution and not passed on to DH.	
2. Background	**5 mins**
I'd like to start by learning a little about you and the work you do. **Can you start by telling me a little bit about your organisation and its relationship with clinical negligence/birth injury work?** • What kind of role do you play? • What are your main responsibilities? • How much do clinical negligence/birth injury cases feature in your work? • What kinds of people do you represent/ support? • Which types of people do you regularly deal with/ support? • How many people are involved in this type of work in your organisation? ESTABLISH HOW SPECIALISED/PARTICIPANT IS IN BIRTH INJURY COMPENSATION	The purpose of this section is to provides contextual background information about the interviewee and their role.
3. Experiences of negligence cases	**15mins**
We are keen to understand more about the key stages of the parent's journey after learning of a birth injury. **How would you describe what the experience is like for parents who have been through a birth injury?** - How does this change over time? How does it vary for different people? **Can you talk me though the main stages parents generally go through, as you can see them?** • What are the first steps parents typically take when deciding how to proceed after a birth injury? • Who might they come into contact with? • At what stage in the process do you become involved? Does this vary ever? Why might this be? • Is there a referral process? Who refers them? • How long would you typically be involved with the case for? • How long can cases take? **What options do parents face at this early stage?** • What options aside from litigation are there?	This section will gather useful information on the parent's journey and reasons for pursuing litigation (or otherwise). It will also be used to explore the expectations and experiences of parents under the current scheme, including strengths and weaknesses. This can then be drawn upon when thinking about the proposed alternative scheme. Solicitors may be able to talk in more detail about these different stages of the parent's journey.

- As far as you know, what proportion of parents decide to go down a litigation route?

Thinking about the parents who do litigate, what is your understanding of how claimants experience the process of making a clinical negligence claim?

- Who advises and supports them during these stages?
- Is the process always broadly the same? Are there any exceptions and can you describe them?
- How do you think they feel over this process? What impacts this?
- What is the role of others? E.g. family members/charities/solicitors?

Overall, what do you see as parent's motivations for pursuing litigation?
PROMPT:

- To find out cause of injury
- To prevent it happening in future
- To ensure that their child has access services they need
- To provide financially for their child
- To "punish" perceived offenders
- Family pressures to pursue route

Of these, which do you think are the most important reasons for parents to pursue litigation? Why?

As far as you know, how is it established whether cases are eligible for litigation?

- Who is involved in establishing eligibility?
- What process does the hospital go through?

(If applicable) Can you tell me a bit more about how the final settlement is decided?

- How is it agreed?
- How are the heads of loss decided on?
- From a claimant's perspective, what are the most important considerations for the final settlement (refer to the 14 heads of losses)?
- Who makes the decision regarding a lump sum or Periodical Payment Order (PPO)?
- What advice do you offer your client about the final settlement?
- How involved in the process are they? How does this differ for the various stages of making a claim? PROBE on different stages including; putting in the claim, establishing losses, the negotiation process, agreeing the settlement, the court process (if involved), receiving the settlement and after the settlement.

And what outcomes do parents achieve through litigation? • Are their expectations mentioned above (e.g. finding out cause) met through litigation? • What are the main benefits of pursuing a litigation route? • What are the main drawbacks? **And are you ever involved in cases where the threshold for negligence is not met?** • Why were these cases not eligible? • What happens in these cases? • What options are there for these parents? • What role do you play in these cases? **Are you familiar with the concept of 'avoidable harm'?** *Avoidable harm describes a situation in which an incident could have been avoided if an optimal course of action had been pursued.* • Would any cases you're aware of be classed as 'avoidable harm' according to this definition? **Are you involved in cases where parents choose <u>not to litigate</u>?** • What are the main reasons parents choose not to litigate? • What advice or support do they receive? • Is the process always broadly the same? Are there any exceptions and can you describe them? • What are the main benefits of going down an alternative route? • What are the main drawbacks?	
4. Care needs	**5mins**
When thinking about a child's care, what are the most important things to parents? - Can you provide any examples? **What factors do parents take into account when deciding how to fund future care?** - Refer to the 14 heads of losses: what is the most important consideration for parents? - Out of the heads of loss which are the most important elements to parents? - What do you advise them? **What do you feel is the most important to parents?** • Do their care priorities change over time? Why? • In your initial discussions with parents what are their priorities?	This section will explore care needs in more detail, to help understand what parent's priorities are and when (if not already covered above).

• How do parents organise the care for their child? How does this change over time?	
5. Alternative routes	**15mins**
DH are currently developing a new scheme to improve the current system so that it better meets the needs of parents, reduces risks, and improves experiences in future. **If you could modify the current system, what are the most important things you would change? Why?** • What are the biggest issues/challenges from a parent's perspective? • What are the biggest issues/challenges from your perspective? Is there anything that doesn't work well? **What would you keep? Why?** • What are the biggest benefits from a claimant's perspective? • What works well? **What do you think the main objective of any new scheme should be?** **DH is looking to develop a scheme with the overall aims of improving the experience for families and clinicians when things go wrong, and ensuring the system benefits from any learning from each case. They want to design a scheme that:** - Encourages the hospital and family to work together towards a resolution, whatever the outcome. - Makes sure the hospital can keep learning from cases and focuses on system improvements rather than individual blame. - Standardises the process more – in particular, making sure the early investigation happens the same way. - Gathers evidence pertaining to the incident early on. - Provides support to the family through regular and ongoing assessments of the claimant's needs and signposting to support. **What are your impressions of this?** GO THROUGH EACH: - Are these the right aims? If you worked for DH what would you put in place to ensure this happens? ***Describe the new policy using a flow chart as stimulus (if face to face). Explain that it will be an alternative to litigation, but these routes will still be available.***	This section will explore reactions to the new policy. This will allow participants to use their experience and expertise to evaluate the policy.

What are your first impressions of this?

- Do you think this scheme will achieve DH’s key aims? Why? Why not?

From your perspective what is good and bad about it?

And from the claimant/parent’s perspective what do you think they will like/ not like about it?

Go through the proposed scheme stage by stage:

- Stage 1: family informed by staff and expression of regret
- Stage 2: independent investigation conducted
- Stage 3: working out if there is a case: eligibility panel to determine if the case is eligible for compensation
- Stage 3a: not eligible; referred to CCG for support
- Stage 3b: eligible
  i. Apology from Trust
  ii. Case manager appointed
- Stage 4: Ongoing steps
  i. General damages granted
  ii. Clinical review and support from case manager: ongoing
  iii. Payments or service provision via lump sum, PPO or direct services.

For each stage:

- What do you think about this stage?
- Can you identify any issues about this stage?
- What would you change?
- What would you keep?
- What is important to families?

Specific questions for each stage:

Stage 2: Independent investigation

- Who should be involved? Clinicians? The family? Solicitors?
- What needs to happen as part of the investigation?
- What needs to happen to ensure investigations promote learning?

Stage 3: Working out if there is a case/Eligibility

- Who should be involved in establishing causation?
- What system would you like to see put in place?
- What are your views on avoidable harm vs. clinical negligence?
- Have you seen any cases/examples where avoidable harm would have been relevant?
- What do you think the impact on families will be?

• Which route do you think DH should go down? What makes you say that? Stage 3bii: Case manager • Who is best placed to carry out this role? • What kind of role should they play? Stage 4bi: Upfront general damages payment: • How do you feel about this upfront payment? • At what point in the journey would you expect parents need to receive this? • What do you think of the amount? Stage 4biii: Payments or service provision: go through each heads of loss • What are your views on lump sums/PPOs/direct care? • What do you typically advise your clients? • What's good about this? • Can you identify any issues with this? **Thinking about the scheme overall:** • For it to work what do you think is essential? • And what would it be good to have? • What do you think should be changed? **Overall, to what extent do you think parents will follow a route like this?** **What might lead parents to reject this route and pursue litigation instead?** **What might lead parents to accept this route, but then to pursue litigation at a later stage?**	
6. Wrap up	**5 mins**
What do you think is the most important thing for DH to consider in the design of an alternative scheme? **Is there anything else that you feel is relevant but we haven't had a chance to discuss?** DH is aware your organisation was approached as part of this research, and is itself engaging with stakeholders. To help avoid unnecessary duplication, are you happy for your name to be passed on to DH? Happy to say organisation took part?	The final section will summarise the key parts of the discussion, and allow time for the participants to ask any questions.

Level of attribution. Thank participant for their time. Reassure about what happens to the data.	

Appendix C: Discussion guide for clinician interviews

Department of Health (DH): Rapid Resolution and Redress (RRR) Policy Research
Discussion Guide: Stakeholder strand: clinicians – 28.04.2016 v2

This discussion guide is for use in the interviews with relevant stakeholders (clinicians including nurses and midwives) who have experience or knowledge of clinical negligence cases (they may not have been directly involved in one).

The interviews will last between 45 mins and one hour; we have provided an indication of timings.

The key objectives for the research are as follows:

- ***What is the 'journey' of parents faced with deciding how to proceed after a birth injury*** – e.g. what are the key steps, what does a typical case look like?
- ***What factors influence parents' decision making in choosing how to fund care following a birth injury?*** From experience dealing with a number of cases, what are the key things that motivate parents to pursue litigation? To what extent is this route able to meet these expectations?
- ***What do parents think of the 'no blame' policy options/ potential care packages?*** What do professional's think of the alternative proposed? What could be improved? Why would parents choose this option and what would prevent them from choosing it?

For this strand of the research, we are also interested in understanding **what clinicians think the impact of the scheme could be on openness and learning in the NHS in general**.

The questions suggested below are to act as a *guide only* for the interviews; researchers will be expected to adapt and tailor the conversation to suit the role of the stakeholder being interviewed, and their level of experience.

1. Introduction	**2-3 mins**
• Thank participant for taking part • Introduce self and Ipsos MORI • **Purpose of research:** The research is being conducted on behalf of DH; DH is currently looking at the feasibility of a new compensatory scheme and want to hear from a range of experts and stakeholders to feed into an understanding of a potential scheme. We are talking to you as someone who understands the journey parents go on, and what the impact of a potential scheme could be in a clinical setting, in more detail. We are also talking to families who have experienced birth injury to ensure their experiences are considered in the design.	This section will introduce the research, and orientate the participant to ensure they are comfortable with the approach.

• Reassure that all opinions are valid/ no right or wrong answers. • Explain confidentiality and MRS guidelines. • Level of attribution: can we quote them directly, their organisation or do they want total anonymity? We can confirm this at the end. • Get permission to digitally record – transcribe for quotes, no detailed attribution and not passed on to DH.	
2. Background	**5 mins**
I'd like to start by learning a little about you and the work you do. **Can you start by telling me a little bit about your role?** • What are your main responsibilities? • How long have you worked in this role? • What does a typical day look like for you? **As you know we're here to talk about clinical negligence and birth injuries.** **How much experience do you have of clinical negligence/birth injury cases?** [REASSURE PARTICIPANTS ABOUT CONFIDENTIALITY IF NEEDED – SUGGEST BROAD EXAMPLES AND NOT NAMES ETC] • What do you know about birth injury cases? • Can you provide any examples? **What kind of work do you do in this area?** • What role do you play in clinical negligence/birth injury cases? • Is that typical of someone in your role?	The purpose of this section is to provide contextual background information about the interviewee and their role.
3. Mapping the processes in birth injury	**8-10mins**
We are keen to understand more about what happens after the occurrence of a birth injury. **I'd like to map the process as it typically happens to understand the key stages each of the parties (clinicians/the hospital (or centre) / the Trust) would go through after a birth injury.** **MAP AND TALK THROUGH EACH STAGE ESTABLISHING KEY FEATURES – SUCH AS WHO IS INVOLVED AND WHAT HAPPENS AS STANDARD.** - What are the first actions the hospital would take?	This section will gather useful information on the main stages following a birth injury from the clinical / Trust perspective.

- What processes are there? Are these always the same? - At what stages in the process would you/hospital be involved? Does this vary ever? Why might this be? - How long would the clinicians involved / the hospital / the Trust typically be involved in the case for? - Who is involved from the hospital perspective? - Who else is involved? Who else in the Trust? - How long can cases take? Why? - Do you have any examples? **IF NOT COVERED ALREADY: Thinking about the investigation…** **Can you describe what happens at this stage?** - Who is involved? From the hospital? From the Trust? **As far as you know, how is it established whether cases are eligible for litigation?** - Who is involved in establishing eligibility? - What process does the hospital go through? **And beyond eligibility, what role do clinicians / the hospital / the Trust play in the litigation process?** - Who is involved? - At what point are people involved? **And what happens in a non-litigation route?** - What role do you/the hospital play in these cases?	
4. The experience in more detail	**10mins**
I'd now like to talk briefly about the experience in more detail for those involved. **<u>The experience - clinicians</u>** **REFER BACK TO STAGES ON THE MAP** **Firstly, thinking about the clinicians, hospital and Trust…** **Can you describe what the experience is like for the clinicians involved?** • How does this change over each of the stages? • What support do you have throughout this process? **What are the priorities for the hospital or Trust at each stage?** • PROBE: supporting the families/establishing causation/learning from mistakes/embedding learning • Do these change when litigation does or does not happen? **What are the main challenges faced after a birth injury?**	This section will explore the expectations and experiences of clinicians and the hospital under the current scheme, including strengths and weaknesses, and processes for learning. This can then be drawn upon when thinking about the proposed alternative scheme. In addition, we can understand the journey of parents from the perspective of clinicians a little too.

- What are the biggest barriers clinicians / the hospital/ the Trust come up against?
- What would you like to change about the process you/the hospital goes through?

What impact does litigation have on clinicians of different levels/the hospital?

- Are there any benefits of the litigation process?
- Are there any drawbacks?
- To what extent does it affect the hospital’s ability to be open and honest about an incident?

Thinking about birth injuries overall, are there processes in place to ‘learn’ from these?

- What do these normally look like? For example, do you analyse data? What other tools or mechanisms are used?

How effective would you say these are?

- What is good / bad?
- Any barriers or changes needed?
- How does this learning translate to practice?

<u>The experience - parents</u>

From your experience, how would you describe what the experience is like for parents who have been through a birth injury?

- How does this change over time? How does it vary for different people?
- What support is available to parents?

What options do parents face when they have been through a birth injury?

- What options aside from litigation are there?
- As far as you know, what proportion of parents decide to go down a litigation route?

From your experience, what do you see as the parent’s motivations for pursuing litigation?

PROMPT:

- To find out cause of injury
- To prevent it happening in future
- To ensure that their child has access services they need
- To provide financially for their child
- To “punish” perceived offenders
- Family pressures to pursue route

From your experience, what outcomes do parents achieve through litigation?

• Are their expectations mentioned above (e.g. finding out cause) met through litigation? • What are the main benefits of pursuing a litigation route? • What are the main drawbacks?	
5. Alternative routes	**15mins**
DH are currently developing a new scheme to improve the current system so that it better meets the needs of parents, reduces risks, and improves experiences in future. **If you could modify the current system, what are the most important things you would change? Why?** - What are the biggest issues/challenges from a parent's perspective? - What are the biggest issues/challenges from your/the hospital's perspective? Is there anything that doesn't work well? **What would you keep? Why?** - What are the biggest benefits from a claimant's perspective? - What works well? **What do you think the main objective of any new scheme should be?** **DH is looking to develop a scheme with the overall aims of improving the experience for families and clinicians when things go wrong, and ensuring the system benefits from any learning from each case. They want to design a scheme that:** - Encourages the hospital and family to work together towards a resolution, whatever the outcome. - Makes sure the hospital can keep learning from cases and focuses on system improvements rather than individual blame. - Standardises the process more – in particular, making sure the early investigation happens the same way. - Gathers evidence pertaining to the incident early on. - Provides support to the family through regular and ongoing assessments of the claimant's needs and signposting to support. **What are your impressions of this?** GO THROUGH EACH: - Are these the right aims? If you worked for DH what would you put in place to ensure this happens?	This section will explore reactions to the new policy. This will allow participants to use their experience and expertise to evaluate the policy.

Describe the new policy using a flow chart as stimulus (if face to face). Explain that it will be an alternative to litigation, but these routes will still be available.

What are your first impressions of this?

- Do you think this scheme will achieve DH’s key aims? Why? Why not?

From your perspective what is good and bad about it?

And from the claimant/parent’s perspective what do you think they will like/ not like about it?

Go through the proposed scheme stage by stage:

- Stage 1: family informed by staff and expression of regret
- Stage 2: independent investigation conducted
- Stage 3: working out if there is a case: eligibility panel to determine if the case is eligible for compensation
- Stage 3a: not eligible; referred to CCG for support
- Stage 3b: eligible
    - i. Apology from Trust
    - ii. Case manager appointed
- Stage 4: Ongoing steps
    - i. General damages granted
    - ii. Clinical review and support from case manager: ongoing
    - iii. Payments or service provision via lump sum, PPO or direct services.

For each stage:

- What do you think about this stage?
- Can you identify any issues about this stage?
- What would you change?
- What would you keep?

Specific questions for each stage:

Stage 2: Independent investigation

- Who should be involved? Clinicians? The family? Solicitors?
- What needs to happen as part of the investigation?
- What needs to happen to ensure investigations promote learning?

Stage 3: Working out if there is a case/Eligibility

- Who should be involved in establishing causation?
- What system would you like to see put in place?
- What are your views on **avoidable harm** vs. clinical negligence?

- Have you seen any cases/examples where avoidable harm would have been relevant? - What do you think the impact on hospitals/clinicians will be? - What do you think the impact on families will be? - Which route do you think DH should go down? What makes you say that? Stage 3bii: Case manager - Who is best placed to carry out this role? - What kind of role should they play? Stage 4bi: Upfront general damages payment: - How do you feel about this upfront payment? - At what point in the journey would you expect parents need to receive this? - What do you think of the amount? **Thinking about the scheme overall…** **Overall, to what extent do you think parents will follow a route like this?** **What might lead parents to reject this route and pursue litigation instead?** **What might lead parents to accept this route, but then to pursue litigation at a later stage?** **And thinking about it from the perspective of clinicians or the hospital or the Trust…** [REFER BACK TO DISCUSSIONS ON LEARNING] **What impact do you think a scheme like this would have on learning among clinicians from birth injuries?** • How about across the Trust? • Or nationally? **What impact do you think it would have on openness?** • What makes you say that? **What impact do you think it would have on those involved in cases overall?**	
• **Wrap up**	**2-3 mins**
What do you think is the most important thing for DH to consider in the design of an alternative scheme?	The final section will summarise the key parts of the discussion, and allow

Is there anything else that you feel is relevant but we haven't had a chance to discuss? Happy to say organisation took part? Level of attribution. Thank participant for their time. Reassure about what happens to the data.	time for the participants to ask any questions.

Appendix D: Discussion guide for family interviews

16-022785-01 Department of Health (DH): Rapid Resolution and Redress (RRR) Policy Research Discussion Guide outline: Family strand
08.06.16 FINAL

This document outlines the broad themes and question areas we will cover in the depth interviews with parents of children who experienced an injury at birth. The interviews will last one hour and a half, and we have provided an indication of timings.

The key objectives for the research are as follows:

- ***What is the 'journey' of parents faced with deciding how to proceed after a birth injury*** – for example, what happens to them initially, who do they speak to (professional/ private interactions), where do they come into contact with statutory services (Trusts and social care providers)?
- ***What factors influence parents' decision making in choosing how to fund care following a birth injury?*** This would cover which issues are most important to them, such bringing a conclusion to the situation so that the family can move on, or the amount of time the settlement takes.
- ***What do parents think of the 'no blame' policy options/ potential care packages?*** This would cover how parents would respond to the proposed policy options.

The questions suggested below are to act as a *guide only* for the interviews; researchers will be expected to adapt and tailor the conversation to suit the person being interviewed, particularly taking the sensitivity of the subject matter into account.

1. Introduction:	***5 mins***
• Thank participant for taking part • Introduce self and Ipsos MORI • **Background:** Refer to information sheet This research being conducted on behalf of DH. DH is at the early stages of considering a new compensatory scheme for birth injuries, and want to hear from families so that they can understand their experiences better. The information they collect will help inform policy decisions. We're here to talk about your experiences of a birth injury so that any policy can be developed to meet parent's needs, reduce risks, and improve experiences in future. • Answer any questions. • Reassure that all opinions are valid/ no right or wrong answers. • Explain confidentiality and MRS guidelines. • Get permission to digitally record – transcribe for quotes, no detailed attribution and not passed on to DH. • Timings : 1.5 hours	*This section will introduce the research, and orientate the participant to ensure they are comfortable with the approach.*
1. Building rapport	***5 mins***
To begin with, I'd like to understand a little bit more about you and your family. **Can you tell me about a typical day?**	*The purpose of this section is to build on the introduction and*

Who do you live with? [*Get names and, if participant is happy use to reference back throughout the interview*]

What do you enjoy doing as a family?

ensure the participant feels comfortable talking to the interviewer.

2. Mapping the journey — *30 mins*

As you know we're here to talk about your experience of a birth injury.

First of all, in your own words can you tell me a bit about your experience?

- What words spring to mind?
- Invite parent to show photos

I'd now like to go through your experience in a bit more detail.

Introduce the mapping document: **this will help us understand your experience from the initial incident through to the present day.**

MAP EACH STAGE OF THE JOURNEY:

Can you tell about when you first found out that something had happened during birth?

- How did you find out?
- Who told you?

What happened immediately after your child was born?

- How long were you in hospital?
- When did you take him/her home?

What was the initial impact on you?

- Health/ relationships/ finances/ quality of life

What happened next?

- What were the initial steps you took?

At what point did you start thinking about compensation?

- What options did you know about?
- How did you find out about litigation?
- What did you know about it?

QUESTIONS FOR EACH STAGE (IF RELEVANT):

How did you feel at this point?

Who else was involved at this stage?

- What was their role?

What support did you have around you?

- Family/friends?
- Services?
- Charities?

How well did you understand what was going on?

- Did you need any more information at this stage?

What information did you have about what was going on?

- What advice did you receive/was offered?
- Who/what services were you in contact with?
- Did you trust this information/advice? Why/why not?

And what other key challenges you were facing at this point?

The first part of this section asks parents to discuss their experience quite broadly. This is to put them at ease and allow them space to talk about sensitive aspects before moving on to the process in more detail.

We will then go into the journey in more detail, exploring key stages of the process they went through. We will build the map in different stages (although they are likely to be built simultaneously) so the maps will outline what happened, who was involved and when, but also the drivers of behaviour such as capability (e.g. having the knowledge needed), social context such as input of family members etc.

- When did you make a decision whether or not to litigate?	- How did you overcome these challenges? **What were your priorities at this stage?** **Looking back now, would you have done anything differently at this stage?**	
3. Path to litigation		***20 mins***
BEEN THROUGH OR STARTED LITIGATION: **Can you talk me through your decision to litigate?** - How easy/difficult was it to make a decision? - Was it something that felt familiar? Comfortable? **What factors made you want to litigate?** - What did you know about your other options at this point? - What encouraged you early on? E.g. friends or family/ advice received **What were your expectations of the litigation process?** - What did you hope to get out of it? - What were your expectations of the compensation at this point? What impact did you think the compensation would have on your family/on your child? - What alternatives were available to you aside from litigation? How did you feel about these options? **NOT BEEN THROUGH OR STARTED LITIGATION:** **Can you talk me through your decision not to litigate?** - How easy/difficult was it to make a decision? - Was it something that felt familiar? Comfortable? **What factors made you choose against litigation?** - What did you know about your other options at this point? - What influenced your decision? E.g. friends or family/ advice received **What did you do instead?** - Why did you decide to do this? **ASK ALL – PROBES ON EACH BEHAVIOURAL FRAMEWORK AREA:** **Did this change over time?** *[Refer to other stages of the journey map]* - What did you know about your other options? - Looking back now, would you have done anything differently? **Who did you need help from at this point? Did you know how to engage with them?** - How easy or difficult was it finding/contacting these people? - What advice/support did you receive? - Was there any advice/support you needed at this point that you didn't have? - Who did you trust to offer the advice/support you needed? Why? **Did you know how to access information sources?** - What questions did you have? - What information did you need? - Were you able to find the information you needed? How?		*This section will continue the journey mapping exercise but focus specifically on the participant's decision to litigate or not. This will give us both insight into what participants understood about the process they were going through, and crucially what was driving their decision making and behaviour.*

Was there anything that provided a barrier or challenge?

- E.g. anything in your life that was happening at the same time?
- Was there anything that helped you at this time?

Can you tell me about the role of other people in your decision making?

- Who played a role in your decision? E.g. family/friends etc.
- Did you think about what others would think?

4. Thinking about care

15 mins

Here we will explore more on the final settlement itself (if relevant), and the priorities for funding care.

Can you explain a little bit about what your child's care arrangements are at the moment?

- Who is responsible for their care?
- How is it funded?
- How do you feel about how this care is organised/funded?
- (if relevant) If you didn't have compensation, what do you think your child's care would look like? How would it be funded?

When thinking about your child's care, what are the most important things for you?

- What's most important to your child (if relevant)?
- What is essential in terms of their care package?

How did you decide on the care package for your child?

- What were your priorities?
- What are your perceptions of state care? How did this impact your decision?
- How did you decide on the care package for your child? What advice did you receive? E.g. Clinicians/internet/other parents

Has this changed over time? Why? *[Refer back to the journey map]*

What were the most important considerations for you when thinking about future provision (e.g. care) for your child? *(Ask all participants even if litigation route was not taken)*

- What sorts of things did you consider? (refer to different care/financial needs. i.e. the heads of losses)
    - General damages for pain, suffering and loss of amenity
    - Past loss
    - Loss of earnings
    - Treatment and therapies
    - Travel and transport
    - Aids and equipment
    - Education
    - Accommodation
    - IT
    - Holidays
    - Deputyship
    - Care, health and case management
    - Miscellaneous
- What were your priorities when thinking about the settlement?
- Did your priorities change at all? *REFER BACK TO THE JOURNEY AND ESTABLISH ANY CHANGE*
- Out of the heads of loss which are the most important elements? Has this changed as your child has got older?

(If litigation route was taken) What do you think about the final amount you received (if relevant)?
- How was this settlement finally agreed?

Was it awarded as a lump sum or PPO?
- How was this decided?
- Did you have a preference?
- Were you offered a choice?
- What are the pros/cons of each?

Looking back, would you have done anything differently?

If someone like you was experiencing a birth injury, what advice would you give them?

Is there anything that you wish you had known when this whole process started?

5. The potential new scheme

15 mins

This section will explore reactions to the new policy. This will allow participants to use their experience and expertise to evaluate the policy, and reflect on how this might have changed their own decision making process.

As discussed DH is exploring the feasibility of an alternative scheme for compensating and supporting parents who have experienced a birth injury resulting in their child being brain damaged.

What do you think the main objective of an alternative scheme should be?

DH is looking to develop a scheme with the overall aims of improving the experience for families and clinicians when things go wrong, and ensuring the system benefits from any learning from each case. They want to design a scheme that:
- Encourages the hospital and family to work together towards a resolution, whatever the outcome.
- Makes sure the hospital can keep learning from cases and focuses on system improvements rather than individual blame.
- Standardises the process more – in particular, making sure the early investigation happens the same way.
- Gathers evidence pertaining to the incident early on.
- Provides support to the family through regular and ongoing assessments of the claimant's needs and signposting to support.

What are your impressions of this?
GO THROUGH EACH:
- Are these the right aims?

If you worked for DH what would you put in place to ensure this happens?

TALK THROUGH FLOW CHART. DH at the early stages of considering/looking at the feasibility of a new scheme to investigate and compensate birth injuries. It will be an alternative to litigation, but these routes will still be available.

What are your first impressions of this?
- How does this relate to your own experience?
- What stands out? Why?

- What is good/bad?

Go through each stage:

- What do you think about this stage?
- How does this compare to your own experience? How would this have changed your own experience?
- What's good about this stage?
- Can you identify any issues about this stage?
- What questions do you have about this part of the process?
- What would you change? What would you keep?
- What is important to families?

Specific questions for each stage:

Stage 2: Investigation

- Who should be involved in the investigation? Who would you trust to conduct an investigation?
- What does 'independent' mean to you? E.g. external body. How important is this?
- How should the family be involved in the investigation? How important is this?

Stage 3: Working out if there is a case/Eligibility
[go through definitions in detail, in interviewer notes]

- What are your views on avoidable harm vs. clinical negligence?
- What would this mean for your case?
- Which route do you think DH should go down? What makes you say that?

Stage 3bii: Case manager

- Who is best placed to carry out this role?
- What kind of role should they play?

Stage 4bi: Upfront general damages payment:

- How do you feel about this upfront payment?
- At what point in the journey would you expect to receive this?
- What do you think of the amount?

Stage 4iiiv: Payments or service provision: go through each heads of loss

- This scheme would be likely to provide a greater proportion of the overall payment as PPO (i.e. guaranteed staged payments at appropriate intervals across the life-course).
  How would you feel about structuring the payment in this way?

Go through each heads of loss:

- How do you feel about this being paid as a lump sum/PPO/direct care?
- What's good about this?
- Can you identify any issues with this?

State provision of care:

- How do you feel about some services being provided by the state? Do you see any problems with this?
- How would this impact your decision if you were offered this as an alternative to litigation?

6. Wrap up	*10 mins*
If this route was available to you now, would it have changed anything about your decisions? (Refer back to key milestones and decisions) *INTERVIEWER NOTE: DH is in the very early stages of considering whether it would be feasible to introduce a scheme like this; it is not open to families at the moment.* - What do you like about this scheme? What don't you like about the scheme? - Why might parents choose to use this scheme rather than litigating? - What would make parents decide to litigate instead of using this scheme? - What does this scheme need to do to encourage parents to choose this over litigation? **What questions would you have about this potential policy?** **Given everything we've talked about, what do you think DH's priorities should be in dealing with families after an injury like the one your family have experienced?** **Is there anything else that you feel is relevant but we haven't had a chance to discuss?** Thank participant for their time. Reassure about what happens to the data.	*The final section will summarise the key parts of the discussion, and allow time for the participants to ask any questions.*

Appendix E: Discussion guide for the general public focus groups

16-022785-01 Department of Health (DH): Rapid Resolution and Redress (RRR) Policy Research
Discussion Guide outline: General Public- Parents: focus groups
16.06.2016_v6_READY

This document outlines the broad themes and question areas we will cover in the discussion groups with parents. The discussions will last one hour and a half, and we have provided an indication of timings.

The key objective of this element is:

- ***What do parents think of the 'policy options/ potential care packages?*** This would cover how parents would respond to the proposed policy options.

The questions suggested below are to act as a *guide only* for the interviews; researchers will be expected to adapt and tailor the discussion accordingly.

Introduction:	***5 mins***
- Thank participants for taking part - Introduce self and Ipsos MORI **Background:** - This research is being conducted by the Department of Health (DH). DH is at the early stages of considering a new compensatory scheme for personal injuries. - We're going to discuss different aspects of health care and law and we're interested in your expert views as parents. - There will be times we ask for your views, and we'll spend some time explaining things. Throughout it all there are no right or wrong answers – every view is valid. - Feel free to ask questions - if there is something you're not sure what we mean, we can explain a bit more so don't worry about asking what things mean along the way. There might be some things that we don't know the answers to though. We do not work in law or in a hospital or other healthcare job so we have asked lots of questions as we've been learning more, so you can do the same! - If you feel uncomfortable at any point, then please feel free to take some time out. - Explain discussion group ground rules: -respect each other -ask not to talk over one another -might need to move the conversation on - Explain confidentiality and MRS guidelines. - Get permission to digitally record – transcribe for quotes, no detailed attribution and not passed on to DH. - Answer any questions - Timings: 2 hours	*This section will introduce the research, and orientate the participant to ensure they are comfortable with the approach.* MATERIALS: DIGI FLIPCHART AND PENS

7. Warm up	***5 mins***
Before we get going, spend a couple of minutes talking to the person next to you to find a bit out about them. What is their name? Have they had to travel far? What do they like doing? What is there favourite food, or drink or film or book? **In a minute we'll go around and tell everyone else a bit about what you've learnt.** ALLOW PARTICIPANTS TIME TO INTRODUCE THEMSELVES TO EACH OTHER AND FEEDBACK TO THE GROUP ONE BY ONE, WITH MODERATOR ASKING QUESTIONS, NOTING NAMES ETC.	*The purpose of this section is to build on the introduction and ensure the participants feel comfortable talking to the group.*
8. Claiming for injuries	***10 mins***
We're going to be talking in more detail about some cases when people might make a claim for compensation money because they have been hurt in some kind of way. These are called personal injury claims. **To start with I'd like to get some of your top of mind views on this with a couple of quick fire exercises. Remember there are no right and wrong answers.** **When I say <u>personal injury claim</u>, what does this make you think of?** ENCOURAGE PARTICIPANTS TO SHOUT OUT WHAT COMES TO MIND AND WRITE ON FLIPCHART / GROUP THEMES - Had you heard about them before today? What type of thing had you heard? - What does it mean? What does it include? - What kind of things might people claim for? - Who do you think people might want to claim money because of an injury? **There might be lots of different people involved in a personal injury claim, including a solicitor.** **What comes to mind when I say '<u>solicitor</u>'?** ENCOURAGE PARTICIPANTS TO SHOUT OUT WHAT COMES TO MIND AND WRITE ON FLIPCHART / GROUP THEMES - What does it make you think? - What words and images do you think of? **What do you think a solicitor might do as part of a personal injury claim?** - What different tasks would they do? - How long do you think it would take? - Does it differ for different types of claim? **What do you think people might use compensation money for?**	*Top of mind exercise to understand early perceptions of claims, and introduce participants to some actors in the process.* <u>MATERIALS</u> FLIPCHART AND PENS
9. Current cases where there is a brain injury during birth	***50 mins***
There are lot of different types of personal injury claims. For example: • **Sometimes people might ask a solicitor to help them for things like injuring themselves in a public space because the shopkeeper had not made sure the shop was safe.** • **After they've had a road accident – small or more serious –people might make a claim against an insurance company.**	*This section builds knowledge about the current system and some key topic areas to help discuss the new scheme.*

Cases could be for smaller amounts of money or for lots of money when it is a very serious case.

In all of these cases, the compensation money can include:

- **Some money because the person has experienced pain or suffering;**
- **Money to pay for any treatment or care they may need because of the injury; and**
- **Money to cover changes to their lives because of the injury. For example, an injury might mean somebody can no longer do their job and so they cannot rely on that wage any more.**

ASK IF THERE ARE ANY QUESTIONS ABOUT THIS

As you know, we've asked you here today to talk about one particular type of serious personal injury for which people might be due compensation money. This is when a child is injured during birth and, in particular, when they suffer a brain injury. At times when this happens the NHS pays compensation to the child – often through the parents – because this injury happened during birth.

Introduce the case study

- **We're going to think about one particular example case today – it is not a real case but it is very similar to lots of serious cases like this.**
- **We'll talk through what happened stage by stage, and we have some questions to discuss with you at each part of the case study.**
- **It's important to remember that no case is typical and this is just one example. We'll talk through other examples as we go through.**

PRESENTATION SLIDE 1:
STAGE 1– BACKGROUND TO THE INJURY
IN PAIRS: WHAT KEY QUESTIONS WOULD YOU HAVE AS A PARENT?

FEEDBACK TO THE GROUP

What are your first thoughts when you hear about this incident?

Can you tell me what kind of things you think happens when something like this goes wrong?

- What should happen next?
- Who might be involved? What would their role be?

If you were David's parents, who would you expect to have told you about the incident?

- How would you expect them to tell you?
- What information would you want at this point? What questions would you have?
- What help and support would you expect would be available to parents at this point? Where would you get this support from?
- What do you think the hospital should be doing at this point? Who should they involve? What should their priorities be?

It also establishes expectations for the process and experiences to feed into the design of the new scheme.

The case study helps explain the system as it is, so parents can understand how it currently works at the moment, and be able to compare to when they are thinking about the new scheme.

MATERIALS

STAGE 1 HANDOUTS FOR PARTICIPANTS TO READ

WALL CHART/FLIPCHART

CASE STUDY STAGE CARDS TO PUT ON WALL CHART

CURRENT SYSTEM STAGE CARDS TO PUT ON WALL CHART

LISTS OF HEADS OF LOSS

If you weren't told that there had been an incident – how do you think you would feel?

We're going to talk through some of the different stages in more detail and map out what happens at the moment.

PRESENTATION SLIDE 2:

STAGE 2: investigation and contacting a solicitor

If there was an official investigation by the hospital, what do you think this would look like?

- How long would you expect the investigation to take?
- Who would you expect would be leading the investigation? Who else might be involved?
- How frequently would you expect to be updated?

What would you expect the hospital in David's case to do in an investigation?

- Who do you think should be involved?

What do you think the parent's concerns would be at this point?

- How do you think they would be feeling?
- If you were in this situation, what would you want to happen?

Why do you think David's parents contacted a solicitor?

- Why do you think they decided to litigate?
- What do you think they're hoping to get out of litigation?

FLIPCHART: WHAT ARE THE KEY IMPROVEMENTS YOU WOULD MAKE TO THIS PROCESS SO FAR?

PRESENTATION SLIDE 3&4:

STAGE 3: the process of deciding the final amount and compensation

What do you think about the £300,000 for pain and suffering?

- What do you think of this amount?

What challenges do you think parents experience during this process?

- What do you imagine they would be feeling during this process?
- What support do you think they would need?

FLIPCHART: WHAT ARE THE KEY IMPROVEMENTS YOU WOULD MAKE TO THESE FINAL STAGES OF THE PROCESS?

PRESENTATION SLIDE 5:

STAGE 3: the final amount

Thinking about David's case, what things do you would want to spend the money on first?

- What would be most important to you? Why?
- Would it be the same for everyone?

Would you want to receive the money in one go or over different points in time?

What would work best? Why?
Does it vary for different things you would want to spend the money on?

How would you feel if you were David's parents working out how to use the money?

What kind of support would you want?

- Who do you think could help?
- What information would you need?

FLIPCHART: WHAT ARE THE KEY IMPROVEMENTS YOU WOULD MAKE TO THESE FINAL STAGES OF THE PROCESS?

REVIEW OVERALL *(REFER BACK TO THE IMPROVEMENTS OUTLINED ON THE FLIPCHART)*
Thinking about the system overall…

- Do you see any issues with this current system?
- If you were in this situation what do you think the main challenges would be as a parent? What do you think you would want to change about the current system?

If you were helping families in this position what would you do? How would you improve this process?

FLIPCHART: ARE THERE THINGS WE'D LIKE TO ADD TO OUR LIST OF IMPROVEMENTS?

BREAK ***5 mins***

10. The potential new scheme ***35mins***

Now we've gone through the current system and what might happen in cases like David's, we're going to think about a possible alternative for parents.

DH is exploring the feasibility of an alternative scheme for compensating and supporting parents who have experienced a birth injury resulting in their child being brain damaged. As parents, DH would like your views on this potential scheme.

PRESENTATION SLIDE: DH'S AIMS
DH is looking to develop a scheme with the overall aims of improving the experience for families and clinicians when things go wrong, and ensuring the system benefits from any learning from each case. They want to design a scheme that:

- Encourages the hospital and family to work together towards a resolution, whatever the outcome.
- Makes sure the hospital can keep learning from cases and focuses on system improvements rather than individual blame.
- Standardises the process more – in particular, making sure the early investigation happens the same way.
- Gathers evidence pertaining to the incident early on.
- Provides support to the family through regular and ongoing assessments of the claimant's needs and signposting to support.

What are your impressions of this?

This section explores perceptions of key features of the potential new scheme.

Expectations will be mapped back on to

MATERIALS
CARDS WITH NEW SCHEME DESCRIPTION

SHOWCARDS

Are these the right aims?

Let’s compare it with our list of improvements, do you think these aims cover everything we wanted to improve?

PRESENTATION SLIDES AND HAND-OUT: THE NEW SCHEME

INTRODUCE POTENTIAL SCHEME STAGE-BY-STAGE (STAGE 1 AND 2 TOGETHER AND THEN 3 AND 4 TOGETHER)

PRESENT STAGE ONE AND TWO

- What do you think about these stages?
- What’s good about them?
- Can you identify any issues about these stages?
- How is this different to what David and his family experienced? Is anything better? Is anything worse?
- What questions do you have about this part of the process?
- What would you change? What would you keep?
- What else should be happening at these stages?

WORKING OUT WHAT HAPPENED (INVESTIGATION)

- Who should be involved? Clinicians? The family? Solicitors?
- What needs to happen as part of the investigation?
- What needs to happen to ensure investigations promote learning?
- Who would you trust to conduct an investigation?
- What does ‘independent’ mean to you? E.g. external body. How important is this?
- How should the family be involved in the investigation? How important is this?

PRESENT STAGE THREE AND FOUR

- What do you think about these stages?
- What’s good about them?
- Can you identify any issues about these stages?
- How is this different to what David and his family experienced? Is anything better? Is anything worse?
- What questions do you have about this part of the process?
- What would you change? What would you keep?
- What else should be happening at these stages?

WORKING OUT IF THERE IS A CASE

- What system would you like to see put in place?
- What happens if it’s not clear that something went wrong?

ONGOING STEPS

Case manager:

- Who is best placed to carry out this role?
- What kind of role should they play?

Upfront general damages payment:

- How do you feel about this upfront payment?

- At what point in the journey do you think parents should receive this?
- What do you think of the amount?

Payments or service provision: refer back to some of the heads of losses:
- This scheme would be likely to provide a greater proportion of the overall payment as PPO (i.e. guaranteed staged payments at appropriate intervals across the life of the injured person).
  What do you think about structuring the payment in this way?
- The scheme will also provide a care package rather than just a one-off payment. What do you think of this? What are the benefits? What are the drawbacks?

State provision of care:
- How do you feel about some services being provided by the state? Do you see any problems with this?
- How would this impact your decision if you were offered this as an alternative to litigation?

OVERVIEW

Is there anything missing from the scheme we've not covered?

Given everything we've talked about, what would be the main thing you would focus on if you were designing the potential new scheme?

Given everything we've talked about, what would be the main things you would want if you were going through this scheme? Why do you say that?

FINALLY

If you were David's parents and this scheme had existed, which route do you think you would have gone down? Why? Why not?

Would there be any point you think the current route would be more appealing to use? Why? Why not?

11. Wrap up

10 mins

Is there anything else that you feel is relevant but we haven't had a chance to discuss?

Do you have any final messages for DH if they do design a scheme like this?

THANK PARTICIPANT
OUTLINE NEXT STEPS
REASSURE ABOUT DATA
HAND OUT INCENTIVES WITH INFORMATION ON SERVICES SHEET

The final section will summarise the key parts of the discussion, and allow time for the participants to ask any questions.

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About Ipsos MORI's Social Research Institute

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