Children and Young People Refinement

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Contents

Background

Introduction

During the Children and Young People's Survey (CYP) Pilot in 2020, it was found that the number of mobile phone records provided by each trust varied considerably. Some trusts provided mobile phone numbers for almost all sample records, whilst nine of the nineteen trusts taking part in the pilot provided mobile numbers for 11% or fewer of their patients (with six of these providing no mobile numbers at all). Follow up conversations with trusts established that low mobile numbers were due to trusts being unable to differentiate between mobile numbers of children/young people and mobile numbers of parents/guardians. As a result, trusts did not feel able to include these numbers in their sample without clarity on who the mobile number belonged to, as the SMS reminders going to the parent/guardian was a requirement of the sampling instructions and Section 251 application.

The provision of mobile phone numbers had a significant impact on response rate during the pilot. Those trusts providing a higher proportion of numbers achieving far higher response rates than those trusts with lower proportion.

Although the results of the pilot were promising, they clearly illustrated the need for high levels of mobile phone numbers to make a move to a mixed method approach viable. For those trusts where more than 50% of the sample had mobile phone numbers (seven of the nineteen), a comparable response rate to the current approach was achieved with just three mailings (24.8% in the control group and 25.5% in the experiment group). However, for those trusts with lower levels of mobile phone numbers, four mailings were required to achieve a comparable response rate, and this would have a large impact on costs.

Approach to the project

From the data provided, there were several options available if the decision was made to move to a mixed mode approach. These could include asking trusts not to share numbers where it was unclear, asking trusts to share numbers where it was unclear but not where it was clear it belonged to the paediatric patient themselves, or asking trusts to share mobile numbers, regardless of who it belonged to.

However, before a decision could be made, it was important to consider how many trusts would be affected and how large the impact would be. It was also important to collect feedback from national experts, paediatric patients and their families, and trust staff, to understand any implications, including potential benefits and concerns. These findings could then be drawn together to make a decision, and ensure that this decision was communicated clearly, comprehensively, and in a useful format.

The findings of these stages of the research are detailed throughout the rest of the report.

Data provided alongside the CYP 2020 Mainstage

Method of this stage

The first stage of this project consisted of collecting data from all participating trusts in the next CYP mainstage, to assess how common the issues identified in the pilot trusts were among all eligible trusts. Therefore, alongside their CYP 2020 sample, trusts were asked to provide detail on:

- The proportion of patients supplied in their sample with:

    - A mobile number that definitely belonged to the parent/guardian;

    - A mobile number where it was unclear whether it belonged to the parent/guardian or the child; and,

    - No mobile number, or a number that definitely did not belong to the parent/guardian.

- The opinion of the trust's Caldicott Guardian on providing mobile numbers as part of the sample where:

    - it was unclear whether or not it belonged to the parent/guardian or the child; or,

    - it was certain that the number belonged to the child.

These questions were designed to understand the scale of the issue, as it would identify where numbers were not able to be identified, and concern about sharing these numbers where identification was not possible.

Availability and identification of mobile numbers

Individual trusts varied widely on the number of mobile numbers they collected and the proportion they were able to identify the owner of.

On average, trusts had a valid mobile number for 83% of their patients, and were unable to identify who the mobile numbers belonged to for 39% of records (47% of valid numbers).

However, this level was not consistent across trusts. Of the 113 trusts who provided data:

- **Labelling of numbers was highly polarised:** More than half (56) could identify who the mobile number belonged to in all cases that had a mobile number, but around a third (39) had 80% to 100% of cases where they mobile numbers but did not know who they were attached to.

- **Most missing mobile numbers were clustered in a small number of trusts:** Nearly 6 in 10 (65) trusts had a valid mobile number for at least 90% of cases. However, a sizeable minority (20 trusts) were missing any valid mobile number for between 40% and 64% of their cases.

In total, more than half of the trusts who provided details (59 of the 113) would not have a valid mobile number that definitely belonged to the parent/guardian for at least 50% of patients. This matters as this

was the threshold identified within the pilot as the boundary where there was a significant impact on the response rate. Of those trusts, the majority (49) would not be able to provide a valid mobile number that definitely belonged to the parent or guardian for more than 20% of patients. This reflects that these trusts were often unable to collect who mobile numbers belonged to on their system at all.

For the vast majority of cases where trusts are struggling to provide valid mobile numbers, this is normally due to not knowing who the mobile number belongs to, rather than issues with collecting a mobile number at all. Only 11 trusts had not collected any valid mobile number for at least 50% of their patients, and all but two had collected them for at least 40% of their patients. As the levels of mobile number collection are increasing over time, the availability of mobile numbers at all would not be enough of a concern to impact the transition to a mixed mode approach.

Willingness to share mobile numbers

Responses from Caldicott Guardians on providing mobile numbers where the mobile belonged to a child or was unclear who it belonged to were generally concerned. Of the 74 trusts that provided opinions from their Caldicott Guardian:

- 18 said they were willing to share these numbers;

- 14 provided a mixed response or said they needed more information; and,

- 42 said they were unwilling to share these numbers.

Where Caldicott Guardians were unwilling, this was mainly related to concerns about capacity for the child to consent, safeguarding in case of trauma associated with their stay, and worries that if it is not known who the number belongs to, it could be sent to someone inappropriate. These respondents felt the benefits of the survey were outweighed by the risks involved.

By contrast, Caldicott Guardians who were willing to share these numbers emphasised that they would not expect a child's number to be provided unless the child was competent enough to receive this type of information. Therefore, they were not concerned about the child's number being used.

Where a mixed response was provided, Caldicott Guardians generally wanted to know more about the age of the child, whether a clinician would be involved in assessing the capacity of the child to receive this information and more information about opt-out processes and how frequently reminders would be sent to these numbers.

Key findings from this stage of the research

In order to ensure trusts are able to provide enough mobile numbers to avoid raising costs on the survey by adding additional reminders, the key area of concern is numbers where it is unclear whether the mobile number belonged to the patient or their parent/guardian.

In addition, as the majority of Caldicott Guardians raised concerns about using these numbers, it will be important to ensure that if a decision is made to use these numbers in the future, engagement and communications activities with these audiences will need to be clear and contain enough information to reassure.

Interviews with Ethics, CAG and the UK Caldicott Guardian Council

Method of this stage

Following the analysis of the data provided alongside the CYP mainstage, the decision was made to pre-emptively contact the survey programme's Ethics Board, and the Confidentiality Advisory Group (CAG), as both of these entities review and approve the survey before it goes into field. Therefore, it was important to ensure that any concerns they had about the potential of using mobile numbers belonging to children or young people, or where the number was unknown, were addressed prior to the survey being designed. It was also agreed to discuss the prospective changes with the UK Caldicott Guardian Council, to ensure any feedback provided from the central body could be incorporated alongside findings from individual trusts.

The programme's Ethics Board contains three members, appointed due to their skills and knowledge of ethics and non-clinical patient research, practical applications of patient research and patient perspective. The board reviews the surveys and the associated methods they are using and ensure the interests of participants come first. CAG is coordinated by the Health Research Association and are responsible for reviewing the survey to ensure that sample is able to be provided without consent (via Section 251). The UK Caldicott Guardian Council provide a central point of advice, information, and guidance for Caldicott Guardians across the UK.

A qualitative depth interview was conducted with the Head of the Ethics board (Mark Sheehan) and separately with the Chairman of the UK Caldicott Guardian Council (Chris Bunch). These were done informally, with members of both the CQC and Ipsos team.

Conversations with the CAG Confidentiality Advisor and members of the committee who had reviewed the application for the CYP Pilot in 2020 happened via email.

Feedback from Ethics

The response from the Ethics chair was that overall, they were not concerned about the mobile numbers being used if they belonged to the child, or where it was unclear who the mobile number belonged to. They felt that where children have the authority to make decisions, this should be respected, and therefore if their number had been provided, it had been done because they were the most appropriate person to contact. However, it was flagged that this would not be everyone's view, and therefore it would be important to reassure other stakeholders (such as Caldicott Guardians) that this was being considered in an ethical context.

The chair suggested the following changes be made to the survey materials:

- **Letters:** The letters should include clarification that SMS reminders would be sent to the number attached to the child's medical record, ensuring the SMS message is not surprise and linking to the parent's authority in providing this number.

- **SMS:** The SMS should include something explaining that this number is being used because it is the number provided alongside the child's record.

- **Online script:** The online survey, linked to from the SMS, should include a question at the front asking if the person accessing the survey is the child or their parent/guardian, and should include the parent's survey first to ensure that they have given their consent to the survey taking place.

- **Sampling instructions:** It was felt this document did not need to include a detailed rationale for the inclusion of these numbers. However, it was suggested it should link to an external document, where this rationale could be covered in detail if concerns were raised.

Feedback from CAG

The response from CAG was also confirmed they did not think providing the mobile number of the child or where it was unclear who it belonged to would raise confidentiality issues.

The CAG Alternate Vice Chair confirmed that the number was very likely to be the parent's, considering the scope of the survey, and was reassured that if the number of the child had been given, that the child was "sufficiently competent to receive messages from the Trust".

Therefore, they were happy to support amending the previous application to specify that permission was granted to receive the mobile number attached to the child's record (either the child's or the parents), and that this could be used to support future applications. The updated letter is embedded below:

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Feedback from UK Caldicott Guardian Council

The UK Caldicott Guardian representative was particularly focussed on three key elements:

- **Is the purpose of the work a surprise?** As feedback is a common reason for the NHS to contact patients and their families, this wasn't considered a major concern for the proposal, particularly with communications happening in advance of the research in the form of posters. As participants could also opt-out directly during the survey period, or simply choose not to take part, this was also considered appropriate.

- **Is the information provided clear enough?** It was highlighted that it was important that any contact that could be provided directly to a child is understandable to an average 10-11 year old reading level, and was clear that the parents or guardians should be notified.

- **What happens if the mobile number is incorrect?** This was the main concern raised, as this was considered to be particularly risky, as the pandemic had made it less likely that details had been rechecked at every contact, and, due to the population, the chances were higher that the number could belong to a parent who no longer has access to the child, or who is not the main care provider following a relationship breakdown.

  As the data was considered to be minimal if provided to someone unrelated to the child in question, the main concern was the implications if a feedback request was sent to a former partner of the main of the main caregiver, especially if there was a safeguarding concern. Therefore, it will be important that any approach considers the implications for this and any mitigations possible (such as including the number to be contacted within the letter itself).

Key findings from this stage of the research

Both Ethics and CAG were not concerned about updating the instructions to ensure that the valid number attached to the patient record is provided, regardless of who the number belongs to. However, it was flagged that some changes would need to be made to the survey, to ensure that appropriate consents were collected, as those under 16 require consent from a parent or guardian before taking part in research activity.

The UK Caldicott Guardian Council were not concerned about the possibility of under 16s being contacted where that number had been provided, as that number was provided as the contact point. However, concerns were raised about the possibility of the wrong number being included, either due to an error, or out-of-date details where a relationship between the parents or guardians had broken down. Therefore, it will be important that guidance includes an understanding of what to do in these cases, and any steps that could be taken to mitigate the risk.

Interviews with children and young people and their parents or guardians

Method of this stage

Following the findings from the trust data analysis and interviews with CAG and ethics, the next priority was engaging with the eligible patient population, to understand their perspective on the mobile numbers of children and young people being used to ask for feedback. It was agreed that these interviews should focus on those most likely to be impacted. This was identified as children and young people aged 8-15 who had had an overnight stay in hospital in the last six months, who had their own mobile phone that could be used for calls, and the parents or carers who took them to hospital.

A qualitative approach was adopted to provide in-depth insight into the views and experiences of those taking part. In total, eleven interviews were conducted with the target group. Paired depths were conducted with the parent or carer and child or young person together, to allow for an exploration of both perspectives as well as the dynamics when it came to decisions about the mobile number being provided. Interviews were conducted by trained Ipsos MORI qualitative researchers and took place by telephone or over video conferencing software. An incentive of £50 was provided each family who participated.

In order to ensure the interviews covered a range of perspectives and experiences, quotas were set on gender of both the parent or carer and child or young person, the ethnicity and attitude towards the child's number being shared of the parent or carer, and the age and long-term condition status of the child or young person. **Error! Reference source not found.** details the achieved quotas for these interviews.

Table 1: Achieved quotas for interviews with children and young people and their parents or carers

Area	Category	Number of interviews
Parent or carer's gender	Male	3
	Female	8
Parent or carer's ethnicity	Ethnic minority background	5
	White British background	6
Parent or carer comfort level with sharing child's number for providing feedback to the NHS	Comfortable	7
	Not comfortable	4
Child or young person's gender	Male	5
	Female	6
Child or young person's age	8-11	6
	12-15	5
Child or young person's long-term condition status	Has long-term condition	7
	Has no long-term condition	4

The interviews followed a discussion guide designed in collaboration with the CQC (a copy can be found in the appendix). The interviews focussed on the child or young person's experience of providing feedback, communications with the hospital and using the child's mobile number to ask for feedback on

their hospital experience. The discussion guide acted as a guide only for the depth interviews; researchers adapted the conversation to suit the participant, considering their unique situation and the sensitivity of the subject matter. Participants were assured of anonymity, and were given the freedom to opt out of the research at any time.

Qualitative research is illustrative, detailed and exploratory. It offers insight into the perceptions, feelings, and behaviours of people rather than quantifiable conclusions from a statistically representative sample. Owing to the small sample size and the purposive nature with which it was drawn, findings from this research cannot be considered representative of the views of all parents and carers or children and young people. However, the design of the sample should allow for a depth of understanding of why participants hold specific views.

It is also worth noting that this report is based on participants' perceptions. It is important to remember that even though some perceptions may not be factually accurate, they represent 'the truth' to the participants and as such, are vital in understanding their attitudes and views.

Experience giving feedback in general

The children and young people had varying levels of experience being asked for and providing feedback.

Most feedback was requested via the parents or carers. This included school, play centre, sports and after-school activities, and providing feedback on purchases as well as following GP appointments and hospital visits. These requests used a variety of methods, including post, SMS, telephone, email, and Whatsapp groups.

> "It's always me. [I've been asked for feedback recently on behalf of my child] when we've been to the hospital, when we've been to the doctors, school and then when we've been to a play centre." – Female parent/carer of a female child aged 8-11

Where children were asked for feedback directly, this was normally face-to-face during the activity. However, many also mentioned being asked to complete feedback surveys from school via homework portals, without going through the parent or carer (although the parent or carer still had access to the portal so could review if they wanted to).

Older children were more experienced at providing feedback directly. These children mentioned receiving links to online surveys after online shopping or when using an app. They were more comfortable dealing with these requests independently.

> "[I've been asked to give feedback] When you buy something and then it asks you to give a survey on what the company could be better … I don't mind [giving feedback]." – Female child aged 12-15

Parents or carers were the key decision makers when sharing contact details, for any scenario where feedback might be requested. Many families discussed agreed approaches if the child received a call or message from a number they didn't recognise, or that didn't belong to a known friend, family member, and approved contact (such as a sports coach). This normally involved either deleting or ignoring the message, or bringing it to their parent or carer for review.

This was due to a range of concerns including:

- **Weblinks**: Parents and carers in particular were concerned about the potential safety implications of links, and the risks of viruses, scams or identity fraud, which children and young people were perceived as less likely to be able to identify. This was echoed by the children and young people themselves.

    > "I am scared of things leaking. It takes one person to hack a number and then they can get all sorts of text messages." – Female parent/carer of a female child aged 8-11

- **Abuse**: Concerns were also raised about who might have access to the details and whether they would be able to use them to contact the child directly, risking grooming. This concern was particularly highlighted by parents and carers of daughters. In these cases, an automated text was seen as more reassuring than a text that appeared to come from an individual.

- **Reliability**: Parents and carers also highlighted concerns that messages may be missed if they went to the child or young person, as they might not realise how important they are, forget to mention them, or not pass them on.

    > "Kids don't pass on any messages. Can't rely on them." – Female parent/carer of a female child aged 12-15

Where parents mentioned they would be comfortable sharing their child or young person's number, this was for older children who were more independent and where there was a specific purpose, such as for schools to communicate about homework during the pandemic for home-schooling periods. They were also described consistently as in addition to, rather than instead of, the parent or carer, with the parent or carer remaining the key contact.

In these circumstances, where parents or carers could see a benefit of the child being contacted directly, these were:

- **Convenience**: This was particularly referenced in regards to school homework. For example, one family mentioned that links and online instructions were provided via SMS during pandemic lockdown. Therefore, for that period, the child's number was provided to the school, as it was considered more convenient for the child to complete the homework on their own phone than for the parent to hand over their phone for extended periods of time.

- **Empowering the child**: Where children were older, the importance of empowering the child in their life was discussed as a potential benefit. Therefore, giving them small opportunities to be an additional contact was considered a potential steppingstone as they transitioned into adulthood.

    > "As a parent, I'm always looking for ways to help [my child] mature and become more grown up and more independent, so it's a quite nice concept that she starts realising her opinion is valued." – Male parent/carer of a female child aged 12-15

- **Allowing the child to feedback about their own experience**: Specifically regarding feedback, it was mentioned that experiences and perceptions could vary between the parent or carer and child regarding the same occasion. On these occasions, it was mentioned ensuring feedback was able to be collected from both parent or carer and child, and the child being contacted directly was mentioned as a tool to facilitate that.

Communications with the hospital

Families had received different levels of contact with the hospital that had provided the child or young person's care. Some families had received no contact at all and some had received information about follow-up appointments. Requests for feedback, or responses to complaints, were also received by some families.

All contact from the hospital post-discharge described was via the parents or carers. Families mentioned receiving letters, SMS messages and phone calls. For one child with a long-term condition that required repeated inpatient stays, notifications about their on-going care were received via an online portal.

As mentioned above, parents and carers were the key decision makers regarding the contact details provided, and universally provided their own details, rather than the child or young person. In addition to the risks specified in section 2, there were particular concerns about providing the child's number to the hospital, in case it was used regarding the child's medical treatment. This was considered a risk in case:

- The child received notification of a test result that could be scary or confusing;

- The child was reminded of the potentially traumatic experience of being in hospital;

- An important health appointment was missed, as the child did not pass on the information to the parent or carer who would need to organise the visit; or

- Information was provided that was too confusing for the child to understand.

    "It's also [a parents number] in case something goes wrong. [The hospital] might say they've already sent a message, and as a child, he may not forward that message to the parents." – Male parent/carer of a male child, aged 8-11

Parents and carers mentioned that they would consider providing their child's number when the child was judged to be old enough to deal with their own care. This age was considered between 16 and 18.

    "Probably 16 and above would be okay." – Female parent/carer of a male child aged 12-15

When talking about the administration of providing contact details to the trust, several parents or carers mentioned that the parent contact details were specifically requested when on-boarding with the trust. No family mentioned being asked for the child's details by a hospital trust, and even those who would have been comfortable providing the child's number would want reassurance of exactly how it was going to be used and to provide them as supplementary for that purpose.

It was also mentioned that contact details might stay as the parents without being reviewed on each visit. For example, a family with a child with a long-term condition mentioned that because they had been interacting with the same trust for a long time, the contact details had been supplied when the child was in primary school, and continued to be used. Therefore, although the child was older now and might have more capacity to take ownership of interactions with the hospital, the family had not reviewed which contact details were used in several years.

Use of child's mobile number for feedback purposes from the NHS

Where participants expressed concern about the child's phone number being used for the purpose, it was normally regarding the number being collected at all. This followed similar themes to that expressed above, around safety, security and whether the child would actually respond.

However, when it came to feedback about the NHS specifically, some of the parents and carers of younger children also mentioned concerns that the child's feedback alone might not be enough to accurately access the service as they would not know what they should expect.

> "I don't agree with sending [a survey] to someone of [my child's] age as I don't think it is a reflection of the service – I don't think she would understand." – Female parent/carer of a female child aged 8-11

This also came through from some of the younger children and young people themselves, who mentioned concerns that they might not be able to answer the questions as well as their parents.

> "I am quite happy about [the message going to my father] because my father has a far broader knowledge on medical than me and if I got it, I mostly would have forgotten about it and deleted it." – Male child aged 8-11

Where participants were particularly positive about the number going to the child or young person, this was normally because they felt the child had a unique experience to share.

> "I think it would be good [to receive the text directly]. It happened to me so I could tell them what I thought." – Male child aged 12-15

Some participants also described this as a welcome change in attitude to assuming that parents know best about the experiences of children.

> "I think it's quite an old fashioned thing where young people aren't asked for their opinion – it's almost like they don't have one" – Male parent/carer of a female child aged 12-15

Due to concerns about legitimacy, parents and carers said they would be reassured by an advance letter that highlighted that an SMS would be sent. Children and young people generally said they would check links with their parents before using, to ensure it was legitimate.

> "I would have to check it with my mum in case it was a scam." – Male child aged 12-15

Key findings from this stage of the research

Feedback from families reinforces that a child's mobile number is unlikely to be the main contact, unless it has been agreed with their parent or carer that they are ready to take ownership of their care. Where families were concerned about the child's mobile number being used, they were clear they would not provide it.

For reassurance, parents and carers mentioned some adjustments that would help reassure them if their child was contacted directly:

- **An advance letter**, to legitimise the survey link, particularly if it highlighted that the SMS would be sent to the mobile number associated with the record.

- **Timing the SMS reminders after school**, when the parent or carer and child could complete the survey together.

- **Assurance that the SMS is automated**, to reassure them that no child is being contacted independently by an individual.

Interviews with trust staff

Method of this stage

Following the findings from the previous stages of the research, the next priority was engaging with trusts to understand any concerns they had about using the paediatric mobile numbers for this purpose and how this would differ, if at all, from their trust's current approach for contacting this population.

A qualitative approach was adopted to provide in-depth insight into the views and experiences of those taking part. In total, eleven interviews were conducted with the target group. Interviews were conducted by trained Ipsos qualitative researchers and took place by telephone or over video conferencing software.

In order to ensure the interviews covered a range of perspectives and experiences, quotas were set based on data provided during the previous CYP mainstage on whether or not trusts were willing to share paediatric mobile numbers, as well as whether the trust would meet the 50% minimum mobile numbers if these numbers were only shared where it was clear it belonged to the parent. It was also agreed to speak to at least one trust from each region. As trusts who had already participated in the CYP pilot had previously been contacted to discuss this issue, the interviews were exclusively conducted with trusts who had not participated in the pilots. Table 2 details the achieved quotas for these interviews.

Table 2: Achieved quotas for interviews with trust staff

Area	Category	Number of interviews
Opinion expressed by Caldicott Guardian during CYP2020 engagement	Willing to share	1
	Mixed	5
	Unwilling to share	5
Whether or not the trust would meet the 50% minimum of mobile numbers according to CYP2020 engagement if paediatric numbers where it was unclear who they belonged to were removed	Would meet 50%	6
	Would not meet 50%	5
Region	East of England Commissioning Region	3
	London Commissioning Region	1
	Midlands Commissioning Region	3
	North East and Yorkshire Commissioning Region	1
	North West Commissioning Region	1
	South East Commissioning Region	1
	South West Commissioning Region	1

The interviews followed a discussion guide designed in collaboration with the CQC (a copy can be found in the appendix). The interviews focussed on how trusts currently communicate with paediatric patients, how trusts capture and use mobile numbers, and perceptions and concerns about using mobile numbers where it is possible they belong to a paediatric patient for the purposes of the CYP survey. The discussion guide acted as a guide only for the depth interviews; researchers adapted the conversation to suit the participant, considering their particular role and the focus of any concerns. Participants were assured of anonymity, and given the freedom to opt out of the research at any time.

Qualitative research is illustrative, detailed and exploratory. It offers insight into the perceptions, feelings, and behaviours of people rather than quantifiable conclusions from a statistically representative sample. Owing to the small sample size and the purposive nature with which it was drawn, findings from this research cannot be considered representative of the views of all trust staff. However, the design of the sample should allow for a depth of understanding of why participants hold specific views.

It is also worth noting that this report is based on participants' perceptions. It is important to remember that even though some perceptions may not be factually accurate, they represent 'the truth' to the participants and as such, are vital in understanding their attitudes and views.

Communication strategies with paediatric patients in general

Trusts mentioned different approaches to collection of contact details for paediatric patients, which impacted how they engaged with this population. These included trusts that collect one main number for a paediatric patient, with variation in whether the trust captured who this belonged to, and cases where there are different numbers collected specifically for the patient and then for their parent or guardian.

Methods of communication with this population included:
- Letters;
- SMS; and,
- Online portals.

Where participants were familiar with the specific details of their paediatric communications policies, these generally prioritised parents as the main contact. However, the way these numbers were used varied between trusts.

Although parent numbers were normally preferred, there were a few specific examples mentioned where children's mobile numbers were purposely used. These were where there were specific portals to access medical information that children were given access to (although some trusts restricted this to parents, and all allowed parent access as well). The other example mentioned was sexual health services, where parents may not be aware that children had accessed the service. In that case, the texts were deliberately sent to the child and were non-specific to avoid breaching confidentiality (only saying "Your result is negative" or "Your result is positive", without any other context).

In trusts where it was unclear who the number belonged to, some trusts mentioned that they had deliberately avoided SMS contact with this population to avoid contacting children instead of parents. This was designed to minimise the risk of complaints and concerns about capacity to consent. Others mentioned that the main number, regardless of who it belonged to, was used for standard trust SMS communications for these populations, including Friends and Family Test (FFT) invitations and appointment reminders.

Use of mobile numbers as part of communication with patients in general

Participants described SMS communication as a standard form of communication with patients from trusts. This was particularly for appointment reminders and for feedback invitations for the Friends and Family Test.

However, participants described some specific challenges related to the use of mobile numbers. These were:

- Risk of mobile numbers going out-of-date, with people changing numbers with new phones;

- Numbers for carers, next-of-kin and family members changing as relationships changed (for example, the risk of a number for an ex-spouse or partner being used incorrectly, if it had not been updated since a divorce or separation);

- Lack of specific consent for mobile numbers being used for the purposes of surveys, rather than for medical care;

- Lack of clarity as to whether numbers belong to patients themselves, or to carers or family members; and,

- Problems with labelling of phone fields requiring compiling and cleaning of multiple fields to identify mobile numbers, making the collection of mobile numbers more time intensive.

These issues were identified regardless of the age of the patient, but could be more concerning in the case of a child. They would therefore need to be factored into the practicalities of any SMS contact approach for the purposes of feedback collection, and would need particular review in this case.

Use of paediatric mobile numbers for the CYP survey

When asked about using the mobile numbers associated with paediatric patients, trusts raised several concerns they would like to see addressed.

For Caldicott Guardians, the main concern was the potential for a data breach if the personal details about the young person were shared with the wrong person, for example if the mobile number used had an error. However, as the purpose was to send an invitation to the survey, and no medical or safeguarding details about the child would be included in the message, this was not considered a major risk. To reduce this risk even further, it was considered important to minimise the amount of personal data included in the message, or within the introduction to the survey.

Particular concern was also raised about text messages being sent to younger children (e.g. those in primary school or under 13s) and whether a cut-off should be used to ensure that SMS reminders would not go to children under this age group. This was due to the concern that the patient may not be old enough to understand, or may be distressed by a reminder of what could have been a highly traumatic experience. However, this age varied between individuals and where it is unclear who a mobile number belongs to, the youngest age groups are least likely to include the number for the child themselves. Therefore, this would need to be reviewed in detail, as part of the sample guidance.

Trusts also talked about the importance of ensuring parents remained engaged with the feedback process, to ensure they were given the opportunity to make decisions about their child's life. This was seen as a potential challenge to the trust's relationship with the family, if parents felt that contact was being made with their child in a way that was deliberately excluding them. Trusts also mentioned that parents sometimes provided feedback on different areas than their children, which was also useful to inform quality improvement. To address this, it was highlighted that it would be helpful to ensure there was reference to the mobile number being used in any messages or materials to parents in advance of the SMS, and for the SMS text to be clear that the parent should be involved in the decision to take part.

However, trusts were also able to see the potential benefits of engaging with paediatric patients directly, using their own numbers. Participants mentioned that parents and young people themselves often had different expectations and perceptions of care received, and may have different priorities about what

good care looks like. Therefore, by contacting the child directly, it could help ensure the child was involved in the feedback process, and ensure their feedback is captured in their own words.

Views were mixed as to whether participants thought using the child's number would boost the response rate compared to the parent (as young people were perceived to be more likely to be on their phone), or whether the child or young person was more likely to ignore or delete the message, lowering the response rate. However, this was considered a practical consideration, and would not be the deciding factor as to whether the numbers should or should not be shared.

Overall, participants would prefer the decision to be made centrally on which mobile numbers should be used, and for this to be communicated in a central document that could be shared with parents in the case of a complaint. They recommended this included:

- Details of what the decision entails and the reasoning behind it;

- An opinion from key decision makers (e.g. CAG, Ethics, Caldicott Guardian Council);

- A summary of the feedback collection process and its findings (including engagement with parents, children and young people); and,

- FAQs that could be provided to parents who raised queries.

Key findings from this stage of the research

Overall, participants were reassured that if the decision was made centrally and could be communicated clearly to trusts and to members of the public, that using the main number attached to the paediatric record was feasible. In order to minimise issues, the following elements were highlighted for consideration:

▪ **A centralised, public facing document would be needed**, highlighting clearly and succinctly why the decision was made, what engagement was done, and including support from key stakeholders (such as HRA CAG, the ethics group and the Caldicott Guardian Council). It was recommended this could include standard FAQs that could be used by trusts.

▪ **The SMS reminders should be mentioned on the posters, advance letters and any other pre-notification materials**, to inform parents in advance and give them the opportunity to opt-out.

▪ **Personal details within the SMS reminders should be kept to a minimum**. This is to minimise the risk of data leaks, particularly for this potentially vulnerable population.

▪ **Clarity would need to be included in the guidance where there was more than one number for a paediatric patient.** Where trusts can clearly identify between parent and child numbers, the sampling guidance should specify which number should be given priority.

▪ **Where decisions are made not to implement any suggested interventions, such as age cut-off, discussion of why this decision was made should be included in any published documents.** This should be included alongside the reasoning behind a decision on the approach where parent and child numbers are recorded separately.

Conclusions and next steps

Overall, across all the research, it is clear that if the survey is to move to mixed methods, it will require an approach to be agreed for those numbers where it is unclear whether it belongs to the paediatric patient themselves, or a parent or guardian.

From the discussions with all the groups, it seems like it will be possible to move to these numbers being provided, alongside the Ethics and CAG guidance. However, specific changes would need to be made to materials and the introduction to the survey, to ensure that there is enough information for a child to deal with the invitation and ensure that the parent or guardian is involved and still able to provide consent in advance of the survey being completed. Detailed information will also need to be provided to trusts, both to reassure their own concerns, and to support with handling any complaints or queries from parents.

In terms of next steps:

- CQC will need to confirm the approach going forwards, which will inform the commissioning decisions for the next CYP mainstage;

- Communications will need to be written for trusts, including information for parents who raise any complaints or concerns. These will need to be made available in advance of the next CYP mainstage; and,

- As part of a future mixed methods CYP mainstage, the questionnaire and materials would need to be reviewed, to ensure they were appropriate if a child were contacted. The sampling guidance would also need to ensure it detailed how to approach cases where it was clear who the number belonged to, as well as where this was unclear, and any approaches to mitigate potential safeguarding concerns where the number belonged to a former-care giver, who was considered a safeguarding risk.

Appendix

1. Discussion guide for paired depth interviews with children and young people with their parent or carer

Introduction (FOR ALL)	2-3 minutes
- Ipsos is conducting this research for the Care Quality Commission, which is the organisation that makes sure that hospitals provide you with good and safe care. - The Care Quality Commission and Ipsos are designing a survey that will measure the experiences of children and young people who have stayed in hospital overnight. CHECK RESPONDENT'S UNDERSTANDING OF 'SURVEY' – EXPLAIN IF NECESSARY. - We want to understand the best ways of telling children and young people about the survey. To help with this, we would really like to hear about your views. - We won't tell anyone that you've taken part in this research, and we'll make sure that no one can see the answers that you give us. - The interview should last about 30 minutes depending on your answers. - You don't have to take part if you don't want to, and you can stop at any time. You can choose not the answer any questions if you don't want to. - Are you happy for us to record the interview? We will just record the sound, not the video. This is so that we can remember what you've told us. - Do you have any questions before we begin? - WHEN RECORDER ON: Can I check that you are happy to take part in the research? ENSURE THAT BOTH PARENT AND CYP CONSENT.	*Welcomes and prepares the participant. Informs them about key aspects of the interview, including those we are required to include under MRS guidelines and GDPR.*
Experience giving feedback (ASK ALL)	**8-10 minutes**
To start, I would like you to think about any times that [CYP] has been asked to give feedback. **What has [CYP] been asked to give feedback about in the past?** PROBE: Sports, school, apps, activities. **And was [CYP] asked directly for feedback, or was [PARENT] approached first?** PROBE IF NECESSARY: have you ever been in a situation where [CYP] was approached directly for feedback? - What about? - How did you feel about this? - Is this the best way of asking for feedback from [CYP]? Why?/Why not? **How was [CYP/PARENT] invited to give feedback?** PROBE: In person, by email, by phone? **Was this using [PARENT'S] OR [CYP's] email address/phone number?** - Does CYP have email/phone number? IF CYP's email/phone number: - Do you remember giving CYP's contact details? If so, why did you provide [CYP's] details rather than [PARENT's]?	*Aim to understand previous experiences of giving feedback and parent/CYP attitudes towards CYP being approached directly for feedback.*

o How did you feel about [CYP's] email address/phone number being used to ask [CYP] directly for feedback? Why?

IF PARENT's email/phone number

o Do you remember giving CYP's contact details? If so, why did you provide [CYP's] details rather than [PARENT's]?

o How would you have felt if [CYP's] email address/phone number was used to ask [CYP] for feedback? Why?

o Would that have been better or worse than asking [PARENT], why?

Communications with the hospital	8-10 minutes
I'd now like you to think about the communications that you both have/had with the hospital about [CYP's] care. • **What sort of things does/did the hospital get in touch with you about?** • **How does/did the hospital usually get in touch with you?** PROBE: Letter, email, text, phone? • **And are those communications usually sent to [PARENT] or [CYP]?** PROBE: Letters, emails, text, mobile phone, home phone? PROBE: Whose email address / mobile phone number is used? • **Do you remember deciding whose contact details to provide to the hospital?** o Why did you decide to provide [PARENT's]/[CYP's] contact details? o Were you both happy about this or not? Why? o Are there any situations when it would be best that the hospital contacted either [PARENT] or [CYP]? What are these? Why?	*Try to get insight on their perception of being asked for contact details and what the NHS did with them. Also explore if the child's direct contact details were provided and what happened. If not, initial perceptions of that request by the parent/guardian.*
Contacting the child using a mobile phone	3-5 minutes
I'd now like to talk specifically about communicating with the hospital by SMS/text message. • **Does [CYP]'s mobile phone have a phone number/sim card, or just internet access?** o IF HAVE PHONE: What does [CYP] use it for? PROBE: social media, education, messaging, apps, games? Anything else? o IF HAVE PHONE NUMBER: Who, if anyone, has [CYP's] phone number? PROBE: Friends/family, school, clubs/activities, who else? o Who do you feel comfortable having [CYP's] phone number? What do you feel comfortable for [CYP's] phone number to be used for?	

- **How would you feel if [CYP] received an SMS from the NHS to ask about their experience of going to hospital?**

    o What would be good about this?

    o What would be bad about this?

- **What would you want to know in order to feel happy to give feedback to the NHS?**

    o What sort of information would [CYP] want?

    o What sort of information would [PARENT] want?

    o What time of day would you by appropriate for [CYP]?

    o What if there was a letter sent in advance that mentioned that you might receive an SMS?

    o What if the feedback request included questions for [PARENT] as well as [CYP]?

- **Overall, in your opinion, would it be better if the SMS asking for feedback was sent to [PARENT] or to [CYP]?**

    o Why do you think this?

    o IF PARENT: What if the hospital only had [CYP's] phone number. Should they send the SMS to [CYP], or is it better that they don't send the SMS at all? Why?

Summary & wrap-up	Do at/just after the 30' mark
Thank you so much for your time today. Before you go: • Thinking about all the issues we talked about, is there anything else you'd like to say? • Is there anything else you would like to add or discuss? Thank and close.	*An opportunity for final reflections.* .

2. Discussion guide for interviews with trust staff

- Thank participant for taking part; introduce self and Ipsos

- **Explain the project:** The Care Quality Commission is trying to find ways of improving how captures feedback from patients that have received care at NHS hospitals. We are interested in exploring the experience and perspectives of those working at NHS trusts on the use of SMS reminders to collecting patient experience data from under 16s.

- All responses are confidential and anonymous

- **Recording:** get permission to digitally record

- **Length:** 30 mins

GDPR added consent (once the recorder is on)

Ipsos's legal basis for processing your data is your consent to take part in this research. Your participation is voluntary. You can withdraw your consent for your data to be used at any point before, during or after the interview.

Can I check that you are happy to proceed?

Introduction: Overview of their role	5 minutes

- Briefly, could you please tell us about your role and your main responsibilities? What is your involvement in data/feedback collection? PROBE: What experience or training do you have in data protection? What experience or training in dealing with data for under 16s?

- Are you familiar with the National Patient Survey Programme? What do you know about the programme? What about the Children and Young People's Survey?

IF NOT FAMILIAR:

The National Patient Survey Programme is a collection of five patient experience surveys, coordinated by a coordination centre on behalf of the Care Quality Commission, that each run on an annual or biennial basis. This includes the Children and Young People's Survey. Each trust commissions their own contractor to deliver the fieldwork, or does the survey in-house, and provides their own sample according to standardised rules.

The Children and Young People's NHS Patient Experience Survey is a survey about the hospital experiences of children aged 0-15. As part of the survey, we collect feedback from children aged 8-15 and their parents. Parents of children aged 0-7 answer on their behalf.

To access the sample, the survey gets Section 251 approval from the HRA's Confidentiality Advisory Group (CAG). The survey is exempt from the national data opt-out. During the sample months, posters are put up by trusts to let patients and their parents/guardians know that the survey is taking place and that they may be contacted. This includes a process for them to opt-out of the survey in advance. Before the first and third mailings, DBS checks are conducted to ensure any patients who have passed away are not contacted, and prior to the second mailing, trusts are encouraged to either check against their own records, or conduct another DBS check.

Contacting paediatric patients by mobile	8 minutes

- Do you currently use SMS contact or reminders with paediatric patients aged under 16 at your trust?

  - If so, what are they used for (e.g. appointment reminders, FFT etc.)? Who do these go to?

  - What are the processes around that? [PROBE: Language used, any consent structures, complaints procedures – do they have any policies they can share?]

- Do you keep records of who the mobile numbers attached to paediatric patient records belong to? Who's number would you normally record? [PROBE – do they have any policies they can share?]

- When do you think your trust might capture the mobile number of the paediatric patient themselves, rather than a parent or guardian?

- What are your opinions on contacting paediatric patients by SMS where their numbers have been provided, rather than a parent or guardian?

Using paediatric patient mobile numbers for the CYP survey	12 minutes

- For the Children and young People's survey, we currently send paper invitations that are addressed to the parent or guardian of the child. However, as part of moving the survey online, we are likely to be using SMS reminders in future waves, which will use the number associated with their record. In some cases, it may be unclear in the records who this number belongs to, and in a small number of cases, this number may belong to the paediatric patient themselves.

- What, if any, concerns do you have about this? What could be done to address these concerns? Do these concerns vary by age of the child?

- What do you think the benefits of using this number might be? What do you think could be done to emphasise these benefits?

- PROBES:

  - What information should be included on the poster or letter?

  - What information should the text message include?

  - Any advice on language to use?

  - Any advice on times of day for contact (normally between 9am and 9pm)?

Summary & wrap-up	5 mins

Thank you so much for your time today. Before you go: .

- Thinking about all the issues we talked about, is there anything else that you think the Care Quality Commission should know?

- Is there anything else you would like to discuss?

Thank and close.

Our standards and accreditations

Ipsos' standards and accreditations provide our clients with the peace of mind that they can always depend on us to deliver reliable, sustainable findings. Our focus on quality and continuous improvement means we have embedded a "right first time" approach throughout our organisation.

ISO 20252

This is the international market research specific standard that supersedes BS 7911/MRQSA and incorporates IQCS (Interviewer Quality Control Scheme). It covers the five stages of a Market Research project. Ipsos was the first company in the world to gain this accreditation.

Market Research Society (MRS) Company Partnership

By being an MRS Company Partner, Ipsos endorses and supports the core MRS brand values of professionalism, research excellence and business effectiveness, and commits to comply with the MRS Code of Conduct throughout the organisation. We were the first company to sign up to the requirements and self-regulation of the MRS Code. More than 350 companies have followed our lead.

ISO 9001

This is the international general company standard with a focus on continual improvement through quality management systems. In 1994, we became one of the early adopters of the ISO 9001 business standard.

ISO 27001

This is the international standard for information security, designed to ensure the selection of adequate and proportionate security controls. Ipsos was the first research company in the UK to be awarded this in August 2008.

The UK General Data Protection Regulation (GDPR) and the UK Data Protection Act (DPA) 2018

Ipsos is required to comply with the UK GDPR and the UK DPA. It covers the processing of personal data and the protection of privacy.

HMG Cyber Essentials

This is a government-backed scheme and a key deliverable of the UK's National Cyber Security Programme. Ipsos was assessment-validated for Cyber Essentials certification in 2016. Cyber Essentials defines a set of controls which, when properly implemented, provide organisations with basic protection from the most prevalent forms of threat coming from the internet.

Fair Data

Ipsos is signed up as a "Fair Data" company, agreeing to adhere to 10 core principles. The principles support and complement other standards such as ISOs, and the requirements of Data Protection legislation.

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