# *Table of Contents*

# Co-designing improved communication to parents of newborn bloodspot screening results

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## *Abstract*

**Background:** Each year in England, almost 10,000 parents are informed of their child's positive newborn bloodspot screening result around 2-8 weeks after birth, depending on the condition. Communication of positive newborn bloodspot screening results is a subtle and skilful task, which demands thought, preparation and evidence to minimise potentially harmful negative sequelae. Evidence exists of variability in the content and the way the result is currently communicated which has the potential to lead to increased parental anxiety and distress.

**Objective:** The main objective was to co-design interventions to improve delivery of positive newborn bloodspot screening results to families.

**Methods:** The principles of Experience-based Co-design were used with seventeen health care professionals employed in three National Health Service Trusts in England and 21 parents; 13 mothers and 8 fathers of 14 children recruited from the same three National Health Service Trusts. Staff experiences were gathered via semi-structured interviews. Filmed, narrative interviews with parents were developed into a composite film. These data were used to identify priorities for improving communication of positive newborn bloodspot screening results to parents during firstly, separate parent and heath care professionals feedback events followed by joint parent and heath care professionals feedback events. Following this, parents and heath care professionals worked together via online co-design working groups to develop co-designed solutions and additions to existing processes.

**Results:** Themes identified from the parent's interviews included: impact of initial communication; parental reactions; attending the first clinic appointment; impact of staff communication strategies and skills; impact of diagnosis on family and friends; improvements to the communication of positive NBS results; and parents views of NBS. Themes identified from the staff interviews included: communication between health care professionals; process of communicating with the family; parent and family- centred care; availability of resources and challenges to effective communication. Three online co-design working groups were developed, each attended by 12-18 participants who had taken part in the parental or health care professionals' interviews. The priorities included: changes to the NBS card; standardised laboratory proformas; standardised communication checklists; and an email / letter for providing reliable up to date condition specific information for parents following

communication of the positive NBS result.

**Conclusions:** Variation in communication practices for positive NBS results continues to exist. This was influenced by many factors and has the potential to lead to negative sequelae from a parental perspective. Parents and health care professionals were able to successfully work together to identify priorities and develop potential solutions to improve communication of positive NBS results to parents. The adaptation of EBCD to include virtual methods could reduce costs associated with this methodology while also enabling the approach to be more responsive to health care professionals' and patients'/parents' busy schedules. Clinical Trial: ISRCTN 15330120

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# Original Manuscript

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# Abstract (450 words)

## Background

Each year in England, almost 10,000 parents are informed of their child's positive newborn bloodspot screening (NBS) result. This occurs around 2-8 weeks after birth, depending on the condition. Communication of positive NBS results is a subtle and skilful task, demanding thought, preparation and evidence to minimise potentially harmful negative sequelae. Evidence of variability in the content and the way the result is currently communicated has the potential to lead to increased parental anxiety and distress.

## Objective

The research focused on the development of co-designed interventions to improve experiences of parents, receiving positive NBS results for their child and enhance communication between healthcare professionals and parents.

## Methods

An Experience-based Co-design (EBCD) approach was employed to explore experiences and co-design solutions, with 17 health professionals employed in three National Health Service (NHS) Trusts in England and 21 parents; 13 mothers and 8 fathers of 14 children recruited from the same three NHS Trusts. Experiences of existing services were gathered via semi-structured interviews with health professionals. Filmed, narrative interviews with parents were developed into a composite film. The co-design process identified priorities for improving communication of positive NBS results through separate parent and health professional feedback events followed by joint feedback events. Four interventions were then co-designed between the participants through an online platform.

## Results

Parents and health professionals provided positive feedback regarding the process of gathering experiences and identifying priorities. Themes identified from the parent's interviews included: impact of initial communication; parental reactions; attending the first clinic appointment; impact of health professionals' communication strategies and skills; impact of diagnosis on family and friends; improvements to the communication of positive NBS results; and parents views of NBS. Themes identified from the health professionals' interviews included: communication between health professionals; process of communicating with the family; parent and family- centred care; availability of resources and challenges to effective communication. In response to these themes 4 interventions were co-designed: changes to the NBS card; standardised laboratory proformas; standardised communication checklists; and an email/letter for providing reliable up to date condition specific information for parents following communication of the positive NBS result.

## Conclusions

Parents and health professionals were able to successfully work together to identify priorities and develop co-designed interventions to improve communication of positive NBS results to parents. The resulting co-designed interventions address communication at different stages of the communication pathway to improve the experiences of parents, receiving positive NBS results for their child.

## Introduction

Newborn bloodspot screening (NBS) in England involves collecting a small sample of blood on a special card from a baby's heel on day five of their life. This is then sent to a NBS laboratory to be analysed. Positive NBS results are reported to relevant clinical teams, often using locally developed proformas [1], who then communicate the result to the family, Each year in England, almost 10,000 parents are informed of their child's positive NBS result around 2-8 weeks after birth, depending on the condition [2,3]. The purpose of NBS is identification of pre-symptomatic babies affected by one of nine conditions currently screened for, to enable treatment to be initiated early to improve outcomes for the child. The conditions are sickle cell disease (SCD); cystic fibrosis (CF); congenital hypothyroidism (CHT); phenylketonuria (PKU); medium-chain acyl-CoA dehydrogenase deficiency (MCADD); maple syrup urine disease (MSUD); isovaleric acidaemia (IVA); glutaric aciduria type 1 (GA1) and homocystinuria (HCU) (pyridoxine unresponsive) – the latter six collectively referred to as inherited metabolic diseases (IMDs). The clinical spectrum in screen positive cases varies enormously and consequently the message to parents needs to be carefully crafted to prepare for a range of outcomes.

Communication of positive NBS results is a subtle and skilful task, which demands thought, preparation and evidence to minimise potentially harmful negative sequelae [4-8]. For instance, perceived lack of knowledge of the person communicating the NBS result rather than the actual result *per se* has been linked with parental distress [4]. Poor, or inappropriate, communication strategies for positive NBS results can also influence parental outcomes in the short term [4-7,9,10] but may also have a longer-term impact on children and families [8]. Evidence suggests the distress caused can manifest in several ways including arguments between couples including apportioning of blame [4,6,11], alteration of life plans and inability to conduct tasks of daily living such as going to work or socialising [4], long-term alterations in parent-child relationships [8] and mistrust and lack of confidence affecting ongoing relationships with healthcare staff [6]. There is also evidence of increased parental concern resulting in parents reducing their child's interaction with others, particularly in the case of CF [4]. Parents also experience poor intra and interpersonal relationships within their family system and more widely [12].

This supports the importance of ensuring the initial communication of positive NBS results is handled sensitively, and considers individual parent characteristics, to minimise parental distress and consequences of this distress as well as the knowledge and experience of the person imparting the result. The choice of approach is to some extent influenced by the seriousness of the condition identified, and the need for an immediate or less immediate response. In one study, parents who had received the screening result from a CF Specialist were more satisfied than those who had received the screening result from the maternity ward [13]. In another study, information received by telephone was less satisfactory to parents of children diagnosed with CF (OR 2.23, p=0.044), or parents of younger infants (OR 0.93 per day older, p=0.001) [10]. Results delivered over the phone, by staff not known to the families or without condition specific knowledge were viewed less favourably and contributed to parental dissatisfaction, anxiety and distress [9].

Recognising the need to work with parents and health professionals to improve this communication, the '*Rethinking Strategies for Positive Newborn Bloodspot Screening Result Delivery: a process evaluation of co-designed interventions*' (ReSPoND) project sought to develop, implement and evaluate new interventions to improve delivery of initial positive NBS results to parents. The mixed method study comprised three main phases. Phase 1 involved a national survey using telephone interviews to explore current approaches to the communication of positive NBS results [14] and

inform selection of two study sites for the remaining phases. The second phase employed the principles of Experience-based Co-design (EBCD) to explore health professionals' and parents' experiences of receiving and delivering a positive NBS result respectively. Findings from interviews with health professionals have been published [1]; sections of this paper related specifically to these, have been reproduced from BMJ Open under licence CC-BY-4.0. In addition, EBCD was used to develop interventions for communicating positive NBS results to parents. In phase 3 the interventions were evaluated in two selected case study sites (two NBS laboratories that served three National Health Service (NHS) Trusts in England) [15].

The aim of the research reported here was to describe the use of a modified version of EBCD during phase 2 in order to develop co-designed interventions to improve the experiences of parents, receiving positive NBS results for their child and enhance the communication between healthcare professionals and parents.

## Methods

This formative study was underpinned by Family Systems Theory (FST) [16] because of the potential vulnerability of family relationships if the initial positive NBS result information is not shared as effectively and empathetically as possible [17]. In FST all components of the family are regarded as interdependent; what happens to one member, will affect all other members of the family directly and indirectly. FST postulates that family functioning has the potential to be affected by an event such as the communication of the initial positive NBS result and subsequently, facilitating the coping mechanisms used and adaptation of families to the NBS result is paramount.

The co-design process was informed by the EBCD Toolkit [18]. EBCD was selected due to its focus on service users and health professionals working in partnership to develop and improve health services. This was felt to be particularly appropriate since family centred care, which includes working in partnership with the family, is the principal philosophy of paediatric care in many countries throughout the world [19]. EBCD is an approach to improving healthcare services that draws on participatory design and user experience to bring about quality improvements in healthcare organisations [20]. It involves focussing on and designing patient/carer experiences rather than just systems and processes [21-23]. The co-design process enables staff, patients and carers to reflect on their shared experiences of a service and then work together to identify improvement priorities, devise and implement changes, and then jointly reflect on their achievements. EBCD was piloted in an English head and neck cancer service in 2005 [21]. After a subsequent project in an integrated cancer unit, an online toolkit [18] was developed as a free guide to implement the approach. A recent systematic review identified 20 studies that had used EBCD in mainly mental health and cancer services in the UK. This review highlighted variations in the use of EBCD with many of the studies eliminating or modifying some of the EBCD stages; it has been recognised that the disadvantages of EBCD include it being time consuming and expensive. Until recently, EBCD had mainly been used with adult service users and/or their carers or family members. The use of EBCD with parents +/- children is still quite novel having only been explored more recently and with adaptations to the process [24-26]. This work therefore also builds on knowledge of using this method with parents.

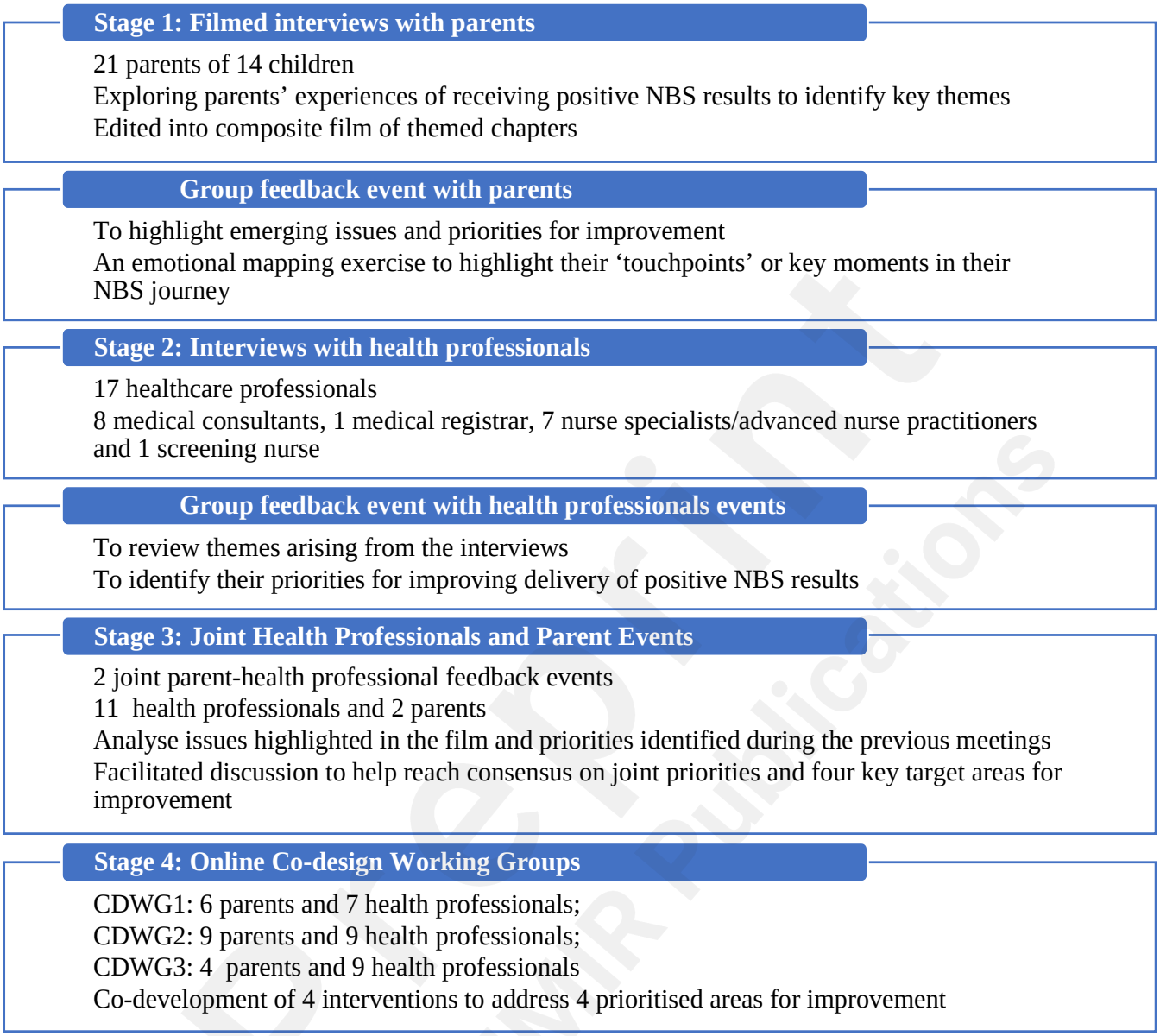
The EBCD process was modified to gather parent and health professionals' experiences and agree areas for improvement for the communication of positive NBS results to families. It followed 4 stages (see Figure 1).

1. engaging health professionals and gathering experiences (the findings from health professionals' interviews have been published elsewhere [1])
2. engaging patients and gathering their experiences
3. bringing parents and health professionals together to share experiences and identify priorities for improvement
4. online co-design activities

## Patient and Public Involvement (PPI)

PPI was instrumental in the design and conduct of this study. Eight parents of babies who had received a positive NBS screening result for one of the nine screened conditions formed a PPI group who met every six months for the duration of the study. Their suggestions were incorporated into the study design, data collection tools, data analysis and dissemination. The PPI group were presented with data from the annual reports of the NBS Programmes and made suggestions as to which sites should be used during the co-design process. In addition, views of representatives from charities for the screened conditions including Metabolic Support UK, the British Thyroid Foundation, the CF Trust and the Sickle Cell Society were also incorporated.

***Figure 1: Adapted EBCD approach followed***




## Study sites and sampling

Study sites consisted of three NHS provider organisations (Trusts) in England served by two NBS Laboratories (NBSLs) (study sites) that process comparable numbers of positive NBS reports annually for each of the nine conditions currently included in the NBS programme. These consisted of two Trusts in Greater London served by one NBSL and one NBSL in the West Midlands that processed 128 positive NBS results and 129 positive NBS results respectively in 2017/2018.

Informed by previous successful EBCD projects [20,22,27], we recruited a purposeful sample of parents across the two study sites. This ensured participation of parents who had a) received a positive NBS result for their child b) in the previous 3-36 months and c) representation of all screened conditions. Parents were identified by health professionals communicating positive NBS results as potential participants. During a routine hospital appointment, health professionals asked parent(s) if they would be willing to talk to a member of the research team about the study. If the parent(s) agreed, a member of the research team, met with them, explained the study and provided a

participant information sheet. Parent(s) were asked if they would be willing to share their contact details so that a member of the research team could contact them the following week to answer any questions they might have about the study. During the follow-up contact, if parents were agreeable, an appointment was made to undertake the filmed interview at a convenient time and location of the parents choosing (all parents chose to be interviewed at home).

A two-stage sampling approach was employed to recruit health professionals involved in communicating positive NBS results in the preceding six months in the two study sites. Participants were first sampled purposively based on their experience of reporting or communicating positive NBS results, followed by a second stage of snowball sampling. Members of relevant clinical teams (medical consultants; general paediatricians; nurse specialists; specialist screening nurses) were initially identified through individual Trust websites and contacted via email and invited to participate. If no response was received, a follow up email was sent after one week. Health professionals who responded were asked if there were any other members of their clinical teams that the research team should contact to ensure views were representative.

Sample sizes for both parents and health professionals were influenced by previous EBCD projects and the EBCD toolkit [18]. All potential participants were given the choice to participate or not and were reminded of their right to withdraw from the study at any time. Written informed consent was obtained from all participants. This study is part of a larger programme of work [28] and was approved by the London Stanmore ethics committee (17/LO/2102).

## Stage 1: Engaging Parents and Gathering Experiences

**Participants:** Filmed interviews were undertaken with 21 parents; 13 mothers and 8 fathers of 14 children recruited from three NHS Trusts in England served by two NBSLs. Of the 21 parents, eighteen identified as White British, one identified as White European, one identified as Asian British, and one identified as Black British. Their ages ranged from 25-44 years (median 37 years). Of the 14 children, four had CF, three MCADD, two PKU, one MSUD, one CHT, one SCD, one had been designated CF screen positive, inconclusive diagnosis and one had received a false positive result for CF. Seven of the children had older siblings, only one of whom had also been diagnosed with a condition (CF) via NBS, two of the children were twins (both had CF), five of the children did not have any siblings. At the time of the interview the age of the children ranged from 10-107 weeks (median 43 weeks).

**Data Collection:** We undertook filmed, narrative interviews with parents across the two study sites between September 2018 and March 2019 exploring parents' experiences of receiving positive NBS results to identify key themes (touch points). Interview questions were guided by the principles of FST [16,17] and focussed on the impact of receiving a positive NBS result on the family, their relationships with each other, with their child and also their wider support network including their friends. Interviews lasted between 14.5 to 47.4 minutes (median 26.4 minutes). Parents were asked to talk about their experience of receiving their child's positive NBS result both in terms of the process and any emotions or feelings this had caused and why.

**Data Analysis:** FST [16,17] informed the development of themes identified from parental interviews. This included consideration of parental reactions to receiving the positive NBS result and consideration of how this had impacted on them as parents, individuals and partners as well as the impact of the diagnosis on family and friends; reflecting the tenets of holism and interdependence which are fundamental to FST. Themes identified from parental interviews were developed into a composite film during April 2019. The film was used to capture parents' experiences of receiving

their child's positive NBS result and provide rich information to guide the development of the co-designed interventions.

Following the interviews, parents at each study site were invited to a parent feedback event (one in the West Midlands and one in London) to enable them to watch the composite film and discuss key priorities to improve communication of positive NBS results to families. These events were guided by the online EBCD toolkit [18] and accompanying online resources including the invitation, the agenda and the feedback templates. Parents were invited to view the composite film of thei interviews to ensure it was a fair and valid representation of their shared experiences. This was used to inform a facilitated group discussion that lasted approximately 3 hours to highlight emerging issues and priorities for improvement. Also, an emotional mapping exercise to highlight their 'touchpoints' or emotionally charged or key moments in their NBS journey. During this discussion, parents were asked to work together to consider four key questions (see Table 1):

***Table 1. Prompts for the parent feedback event***

Touch points were gathered from the composite film and the emotional mapping exercise to highlight priorities to share with health professionals.

## Stage 2: Engaging Health Professionals and Gathering Experiences

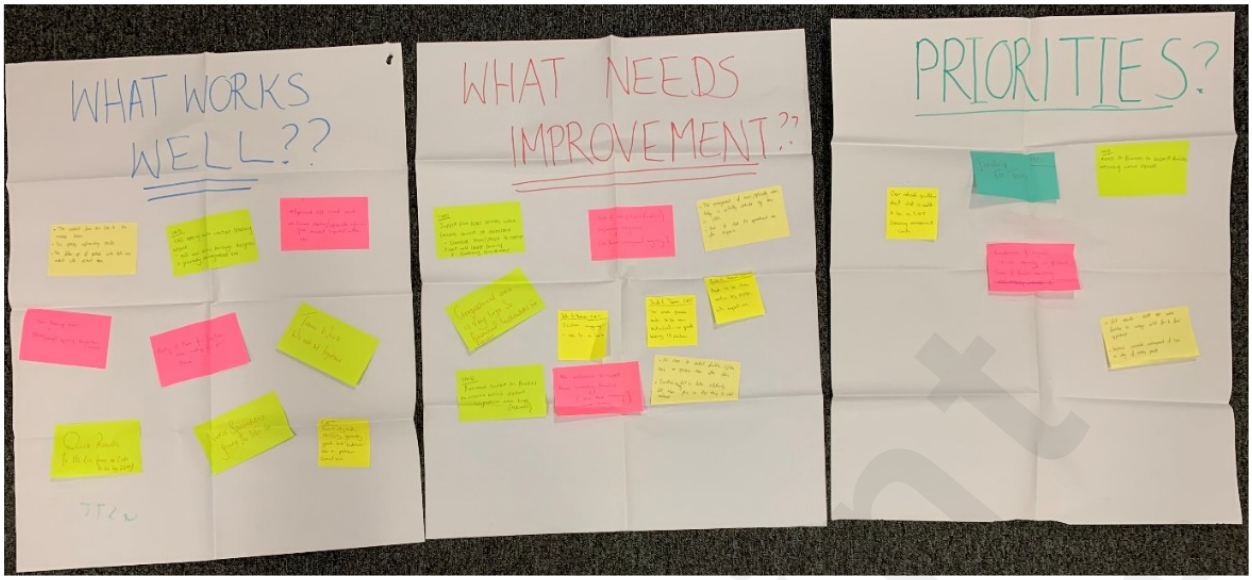
**Participants:** Health professionals were recruited from the same three NHS Trusts in England served by two NBSLs. In total, 20 health professionals involved in communicating positive NBS results in the preceding 6 months were emailed and invited to participate. Two did not respond to the invitation and one did not communicate the initial positive screening result and was therefore ineligible. In line with the EBCD approach [18], sixteen face-to-face interviews were conducted with 17 health professionals (two requested to be interviewed together); 8 were from the one of the NBSLs and the remaining 9 were split across the two Greater London Trusts served by the other NBSL. Participants with experience of all nine screened conditions were included. The sample consisted of eight medical consultants, one medical registrar, seven nurse specialists/advanced nurse practitioners and one screening nurse. Length of experience with NBS ranged from 2 to 38 years (median 8 years). Interviews lasted on average 37 minutes (range 19 to 58 minutes) [1].

**Data collection:** Semi-structured telephone interviews comprising closed and open-ended questions were conducted between September 2018 and February 2019 to identify the approaches used to communicate positive NBS results from NBSLs to health professionals. Data collected included: the mode of communication strategy (face-to-face; letter; telephone; e-mail); the resources involved in each communication strategy; who provides the information and their role; location (co-located or alternative site) of relevant services for each condition.

After the interviews, health professionals at each site were invited to attend a health professionals' event to review themes arising from the interviews and identify their priorities for improving delivery of positive NBS results (one in the West Midlands and two in London). These events were guided by the online EBCD toolkit [18] and the accompanying online resources including the invitation and the agenda template. The findings of the health professionals' interviews were presented via a PowerPoint presentation using direct quotes to illustrate points made. Participants were encouraged to reflect on what they considered to be working well, what they thought required

improvement and from these, key priorities to improve communication of positive NBS results to families. Health professionals were asked to record their thoughts on flip chart paper so it could be shared with the whole group (Figure 2).

***Figure 2 Illustrative flipcharts from health professionals' workshops***




**Data Analysis:** Interviews were analysed thematically; an inductive method of data analysis was used and themes generated using a latent approach. This provided a deeper understanding of approaches used to communicate positive NBS results to families [29]. Two members of the research team (JC and HC) coded one interview transcript separately. These codes were then compared to inform and align code development [30] and a code book was developed [31]. A further four transcripts were then coded separately by the same two members of the research team using the code book. These separately coded transcripts were then compared; inter- coder reliability was 84%. Following this, the same two members of the research team coded the remainder of the transcripts using the code book. Once this initial coding had been completed, data for each code were compared to ensure consistency in coding and to enable the codes to be collapsed into themes. All quotes for each theme were collated to inform theme development. This was an ongoing, iterative process; new codes were developed, and the definition of codes refined as analysis progressed [1].

## Stage 3: Bringing Health Professionals and Patients/Carers Together

**Participants:** Health professionals and parents who had taken part in the previous events were invited to take part in one of two joint parent-health professional feedback event; one in the West Midlands and one in London. Six health professionals and one parent joined the event in the West Midlands and five health professionals, and one parent joined the London event.

**Data Collection:** Mixed health professional and parent events [32] were held in each of the study sites. These events were face-to-face and took approximately 2-3 hours. These events were guided by the online EBCD toolkit [18] and the accompanying online resources including the invitation and the agenda template. During these events, a parent representative (discussed and agreed prior to the meeting) was invited to introduce and share the composite film with health professionals. An unstructured discussion followed to analyse issues highlighted in the film and priorities identified during the separate health professional and parent meetings. This was followed by a facilitated discussion to help reach consensus on joint priorities. Four key target areas for improving delivery of positive NBS results [20,27,33] were agreed to be the focus of the co-design activities over the

following 8 weeks (July and August 2019).

**Analysis:** During the joint health professional/parent feedback event, participants were asked to write on post it notes placed on flip chart paper: what they currently considered to be working well; what areas they thought needed improvement and priorities. These were shared with the group and following a facilitated group discussion, shared priorities were agreed, and key target areas were identified for improvement of communication of positive NBS results to parents.

## Stage 4: Co-design Working Groups (CDWGs)

**Participants:** Three co-design working groups (CDWG) were run, each attended by 12-18 (see Figure 1) participants. Participants were permitted to be part of more than one CDWG if they wished.

**Data collection:** The CWDGs took place during July and August 2019. EBCD is typically undertaken through face to face events [18]. It was modified here as health professionals and parents requested that the CDWGs were held online. The rationale for this was to offer more flexibility to share resources but also to facilitate communication and negotiation between health professionals and parents regarding the proposed co-designed interventions.

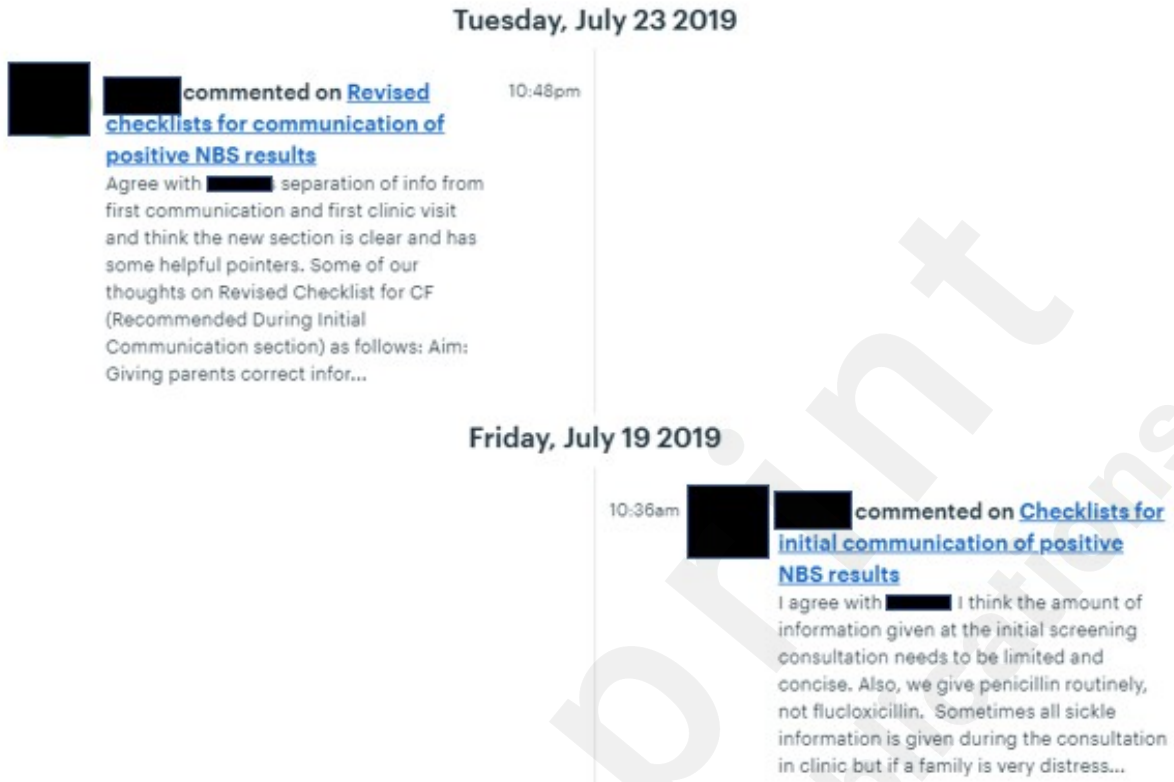
The online platform Basecamp[34] was used to host the online CDWGs. Each CDWG was set up as a different group; those who had indicated they would be interested in a particular CDWG were invited via email to participate.

Ground rules were jointly agreed at the outset and posted online. The ‘Message Board’ was used to invite participants (a mixture of health professionals and parents in each CDWG) and remind them of the purpose of the groups. The composite film, as well as PowerPoint presentations and priorities from the separate and joint parent and health professional events were made available. . Example interventions based on discussions held during the separate and joint parent and health professional feedback events were also shared and members of the CDWGs were asked to provide feedback and comments. The ‘Campfire’ function was used for discussion related to iterations of all documents. Each time new documents were uploaded; a message was sent to members of the relevant CDWG via the ‘To-dos’ function.

Participants were asked, over a period of eight weeks during July-August 2019 to post comments on documents and files that were uploaded. Members of each group were sent a message approximately weekly or when new/revised documentation was uploaded to the online portal asking them to review the information and provide feedback. They also used the online discussion board to communicate with each other and develop the co-designed interventions. An example of communication between parents and health professionals via this platform can be seen in Figure 3. Versions of relevant documents were updated in light of health professionals’ and parents’ comments until consensus was reached regarding the suitability of the proposed interventions. Both parents and health professionals engaged effectively in the online CDWGs. Comments and feedback were left at all times of the day and night indicating that using the online forum enabled participants to contribute to the CDWGs at times that were convenient to them. Conducting the CDWGs online also appeared to mitigate against any potential imbalance in terms of perceived power hierarchies between patients and health professionals [35] with both contributing and replying to each other’s comments. Furthermore, being able to monitor which participants had contributed comments/feedback meant it was easier to direct questions to participants who had been less forthcoming in discussions and encourage their

involvement in a non-confrontational manner.

***Figure 3 Redacted example of communication during CDWGs***




# Results

## Experiences and views

Five themes were identified from the interviews with health professionals: communication between health professionals; process of communicating with the family; parent and family- centred care; availability of resources and challenges to effective communication. Data from the interviews with health professionals have been published in full elsewhere [1].

Themes identified from the interviews with parents included: impact of initial communication; parental reactions; attending the first clinic appointment; impact of health professionals' communication strategies and skills; impact of diagnosis on family and friends; improvements to the communication of positive NBS results; and parents views of NBS. The findings were presented as a composite film (available via the study blog [36]) to capture and illustrate parents' experiences of receiving their child's positive NBS result and provide rich information to guide the co-design activities. The film is presented in seven sections that reflect stages of parental experiences and their journeys through screening. The common experiences or 'touchpoints' for parents that were reflected in each section of the film are summarised in Table 2.

Table 2. Touchpoints from the composite film

| Section of Film | Touchpoints |
|---|---|
| Section 1: Initial communication | • Various methods of communication were used including face to face, telephone and text. |

| | |
|---|---|
| | • Characteristics of the person communicating the NBS result was important<br>• The person communicating the NBS result was not always knowledgeable about the condition and could be viewed as unreliable<br>• Mothers frequently communicated the result to their partners<br>• The NBS result was perceived to be delivered as 'bad news' which contributed to their initial feelings of fear and pain (see below) |
| Section 2: Parents reactions | • Common feelings: shock; fear; confusion; pain; disbelief.<br>• The positive NBS result was: traumatic; upsetting; devastating. |
| Section 3: Attending the first clinic appointment | • The wait between the initial communication and the first clinic appointment was difficult (this was normally less than 24 hours)<br>• Practical arrangements had to be made at short notice e.g. travel (which could be expensive) and childcare for other children<br>• The initial clinic appointment was exhausting. |
| Section 4: Health professionals' communication | • Condition specific specialists were found to be: positive; supportive; knowledgeable; empathetic; reassuring and credible. |
| Section 5: Impact of diagnosis on family and friends | • Some parents reported that the positive NBS result had brought them closer together.<br>• Some felt it had created a strain on their relationship.<br>• Some felt it had affected their relationship with their baby in terms of bonding and attachment.<br>• Parents felt responsible for telling family and friends. |
| Section 6: Improvements to the communication of positive NBS results | • Those involved should be knowledgeable about the conditions and the process when communicating positive NBS results.<br>• Partners should be informed at the same time as mothers.<br>• A text alert (or similar) could help prepare parents to receive the positive NBS result.<br>• The NBS result should be communicated to parents by a condition specific specialist.<br>• Information should be provided immediately after the child's positive NBS result is relayed. |
| Section 7: Parents views of NBS | • The NBS programme was viewed very favourably.<br>• New parents should be encouraged to participate in the NBS programme<br>• Midwives should be familiar with the conditions included in NBS |

## Priorities for improving communication

During a facilitated discussion after watching the film of parental experiences, the feedback from parents and health professionals was narrowed down to a shortlist of priorities for them to explore together to improve communication. These are summarised below in .

***Table 3 Summary of participant priorities to improve communication***

| Parents' priorities | Health professional priorities |
|---|---|
| **Changes to NBS card** | |

| | |
|---|---|
| • How the parent would like to be contacted<br>• Significant other's contact details on the card (as well as the mother)<br>• Whether a translator is needed<br>• Email address of parent(s) | • Inclusion of a question on the NBS card asking the parents how they would like to be contacted: Skype, telephone, email<br>• Addition of a parental email address to the NBS card |
| **Initial communication** | |
| • Being told by the same person you will see at the first clinic appointment<br>• If being told over the telephone, to co-ordinate care so the parent(s) can speak to a health visitor (registered nurses or midwives who have undertaken additional training and work mainly with children from birth to 5 years and their families)/midwife after for support (they do not need to have knowledge of the condition).<br>• Parents to be told who they can/should bring to the first clinic appointment | • Templates for communication to clinical teams and initial communication to families which should be condition specific<br>• Information for families about who should attend the initial clinical appointment |
| **Follow-up communication** | |
| • Parents to be emailed details of the first clinic appointment.<br>• Information for family and friends<br>• Being signposted at this stage to trustworthy and reliable resources/websites. | • Email parents following delivering the positive NBS result by phone with appointment letter, directions and condition specific leaflet. This can be done by administrators or the Clinical Nurse Specialist (CNS).<br>• Information resources for families and extended families |
| **Service provision** | |
| • Financial support for families to attend the initial clinic appointment | • A centralised system for CHT<br>• Formulation of diagnostic services especially out of hours (so laboratories can conduct confirmatory testing over the weekend)<br>• Financial support for families to attend the initial clinic appointment<br>• |

## Co-designed working groups and interventions

During the joint parent and health professional groups, participants reduced the initial priorities in Table 3. Through discussion and shared expertise of the potential causes of communication issues they decided on the focus of each of the co-design working groups. This is summarized below in Table 4.

***Table 4 Co-design working groups (CDWGs)***

| Group | Proposed Intervention | Need |
|---|---|---|

| | | |
|---|---|---|
| CDWG1 | Changes to the NBS card completed during the heel-prick test by the midwife | To ensure health professionals have all the required information to make rapid contact and parents are contacted in their preferred way |
| | Standardised laboratory proformas for use in the NBS Labs | To ensure required information is consistently transferred from the laboratories to clinical teams |
| CDWG2 | Standardised communication checklists for healthcare professionals | To ensure required information is relayed consistently to families during initial communication |
| CDWG3 | A template email / letter to parents | To provide reliable up to date condition specific information for parents following communication of the positive NBS result |

Participants agreed that changes to the NBS card (completed during the heel-prick test by the midwife) was required in order to address the challenge of having all the information necessary to contact the family a) in a timely (condition specific) manner and b) according to parental preferences.

There was also a focus on standardised laboratory proformas for use in the NBS laboratories. This focus emerged from a need for consistent and thorough information to be relayed to clinical teams to facilitate making contact with the child's family following a positive NBS result.

Parents recognised inconsistent communication approaches. It was agreed that standardised communication checklists for healthcare professionals would guide conversations throughout the screening journey and support health professionals with less condition specific knowledge and/or experience.

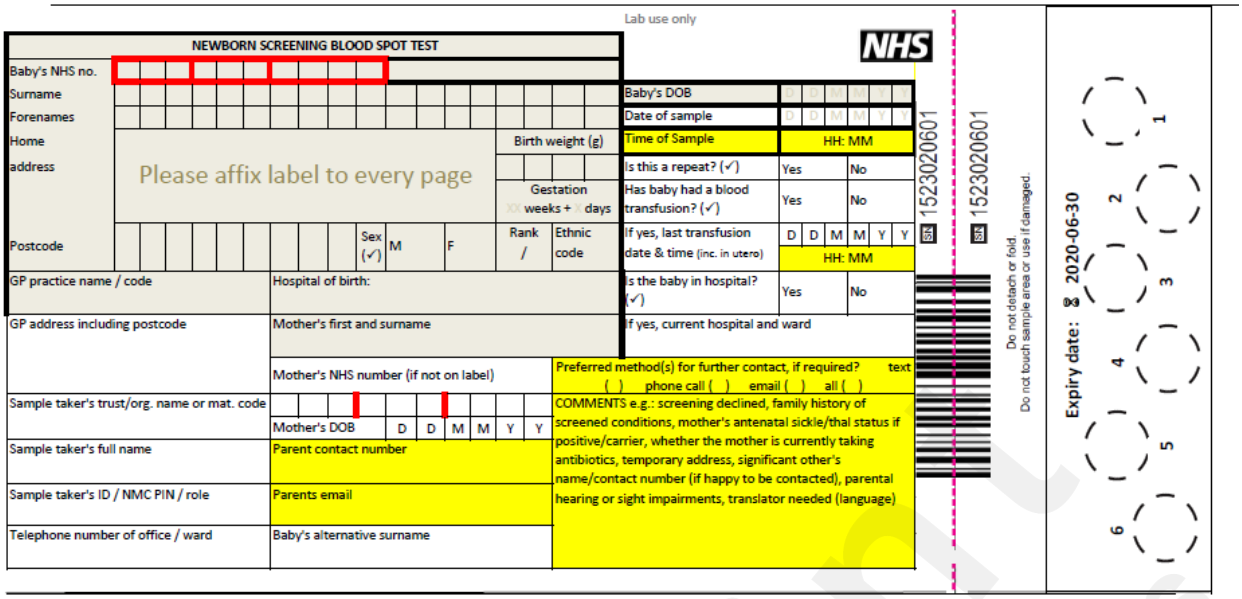
A template email / letter to parents was proposed as the fourth intervention. This would be sent by the clinical team after the initial communication with the parents. The purpose would be to provide reliable up to date condition specific information for parents following communication of the positive NBS result.

Through the co-design process, ideas and documentation was reviewed and iterated through the Basecamp platform until consensus was reached regarding the suitability of the proposed interventions. Overall, there were six iterations of the NBS card, five iterations of the laboratory proformas, eight iterations of the communication checklists and six iterations of the email/letter for providing information for parents following communication of the positive NBS result. Examples of the final versions are outlined below.

## The NBS Card

The final version of the proposed NBS card included the addition of parents preferred method of contact. This aimed to prompt the conversation between midwives and parents at the time the NBS sample was taken regarding the possibility of them being contacted in the future if the result were positive. Also, to ensure parents were involved in the decision about how they might be contacted. Alternative contact details of a significant other were also added to act as a second line of contact should a clinician be unable to reach the mother following the NBS result. The parents' email address was added to aid future communication and contact. Finally, the option to add information related to any hearing or sight impairments or language needs that might hinder future communication with parents was added to the NBS card. The changes and additions are highlighted below in Figure 4.

***Figure 4 New NBS Card***




## Standard laboratory proformas

The standard laboratory proformas built upon those developed by the Department of Clinical Chemistry and Newborn Screening at Sheffield Children's NHS Foundation Trust. The proformas are condition specific and included a front page that was mainly intended for completion by the NBSL, and a section for completion by the clinicians to be fed back to the NBSL. On the reverse side a reminder of current referral guidelines, more information about the child's NBS result and a checklist focused on steps in the referral process. Additions as a result of the co-design process included information related to recommended actions following a positive NBS result for each condition and a comments section to allow clinicians to record suggested condition specific relevant information. (Figure 5).

***Figure 5 Example co-designed laboratory proforma for CF***

| **NOTIFICATION OF PRESUMPTIVE POSITIVE FROM NEWBORN SCREENING – CYSTIC FIBROSIS**<br>**CONFIDENTIAL – PATIENT INFORMATION** | | |
|---|---|---|
| Referred by (name and designation): | Date: | Case/ laboratory ID: |
| Tel: | E-mail: | |
| Referred to (name and designation): | | Location: |
| Tel: | E-mail: | |
| Resources e.g. parent leaflet, communication, diagnostic and treatment guidelines available at: https://www.gov.uk/government/collections/newborn-blood-spot-screening-programme-supporting-publications#cystic-fibrosis-(cf) | | |
| **PATIENT DETAILS** | | |
| NHS Number: | Date of birth: | Gestation: |
| Name: | Gender: | Location: Home/Hospital |
| Gestation: | Birth weight (g) | |
| Address:<br>Post Code: | Telephone number(s): | |
| Mother's Name: | Mother's date of birth: | |
| Mother's NHS number: | | |
| | | |
| **TEST RESULTS:** | | |
| **Initial sample:** | **Date:** DD/MM/YY | **IRT (ng/mL whole blood):** **(cut off = )** |
| **Mutation analysis:**<br>**(Including legacy names)** | | |
| **Second sample:** | **Date:** DD/MM/YY | **IRT (ng/mL whole blood):** **(cut off = )** |
| **Disorders from the other eight newborn screening tests** (PKU, MCADD, IVA, GA1, MSUD, HCU, CHT and SCD) were: ****Not Suspected / In Progress** (Please pass information to parents).<br>**COMMENTS:** | | |
| **GP (address and phone number):** | **Consultant:** | |
| **Disorders from the other eight newborn screening tests** (CHT,PKU, MCADD, IVA, GA1, MSUD, HCU, and sickle cell disease) were:<br>****Not Suspected / In Progress** (Please pass information on to parents).<br>**COMMENTS:** | | |

**REQUIRED ACTION please complete and return by secure e-mail to INSERTEMAIL@nhs.net**

**Acknowledge receipt of referral (name and designation):**

**Date of planned clinic appointment for PP (ideally day after referral):**

| **Parents informed by (name and designation):** | **Date** DD/MM/YY |
|---|---|

**Recommended action as per CF Screening Programme Guidelines for Clinical Referral (available from www.newbornbloodspot.screening.nhs.uk/cf):**

- unless the primary care team has significant concerns, only inform the family of a positive screening result on a Monday, Tuesday or Wednesday. This avoids the diagnostic assessment being undertaken on a Friday or the family waiting over a weekend for the assessment
- offer parents an appointment for the diagnostic assessment the following morning
- the baby must be seen within **five working days** of the Regional CF Centre being informed of a positive result
- a sweat test is essential and should occur at the diagnostic assessment visit if possible. This should include measurement of sweat chloride and be undertaken according to ACB standards (www.rcpch.ac.uk/improving-child-health/clinical-guidelines-and-standards/endorsed-and-supported/inherited-metabolic). If unsuccessful at the first visit, repeat the sweat test at a later stage
- if a sweat test is not undertaken at the diagnostic assessment, or insufficient sweat is collected, organise repeat *CFTR* gene analysis at the diagnostic assessment. This can be undertaken on a blood sample or buccal (mouth) swab
- the diagnostic assessment should include a clinical assessment of the infant

**Case / laboratory ID:**

**TEST RESULTS**

| | | | | |
|---|---|---|---|---|
| **Initial sample:** | Date: | Age: | Mean: IRT (ng/mL): **(cut off = )** | |
| | DNA 4 mut: | | Further mut analysis: | |
| | **Second sample required:** Yes / No | | **Reason:** N/+ / above action limit 2 | |
| **Repeat sample:** | Date: | Age: | IRT (ng/mL):……. / ……. | Mean: |

**PRESUMPTIVE POSITIVE (PP) (e-mail notification to clinical team)**

Referred to (name and designation):

Email and telephone number:

**PAPERWORK**

| | |
|---|---|
| DNA report received: • | Consultant informed (name and contact number): |

| | |
|---|---|
| CF team informed • | E-mail notification of PP form: • |
| Copy of card attached to referral: • | Result uploaded to CHIS: • |
| **COMMENTS e.g. siblings with same condition, inpatient location, has baby had penicillin, has baby had any immunisations:** | |

## Communication checklist

The communication checklists were initially intended to focus on the initial communication of the positive NBS result. However, during the CDWGs, participants indicated they would like checklists for each stage of the families' NBS journey to include: the initial communication (see Figure 6), the initial clinic visit and subsequent clinic visits. It was thought that this would enable all information about the child and family's NBS journey to be recorded in one place This would also act as an aide memoir for subsequent clinicians when seeing the child and family and mitigate the need for parents to recount their story to different clinicians. The initial communication checklists were built on those developed by the CF teams at Sheffield Children's Hospital and King's College Hospital and the Newborn Screening Team at Birmingham Children's Hospital to include more detailed condition specific information and optional information that could be included if deemed appropriate. The checklists for subsequent clinic visits were developed with clinical teams and parents during the co-design process.

***Figure 6 Example communication checklist for a child with suspected CF by NBS***

| | | | |
|---|---|---|---|
| Name of child: | | | |
| Name and profession of person giving result: | Sign Print | | |
| | Consultant ☐ Nurse ☐ GP ☐ HV ☐ Other_____ | | |
| Method of communication: | Home visit ☐ Telephone ☐ Other_____ | | |
| **RECOMMENDED WHEN COMMUNICATING INITIAL POSITIVE NBS RESULT** | | | |
| | | Date | Initial |
| **Introduction** | Who you are and where you're from (if two parents present, speak to both) | DD/MM/YY | |
| **Check who you are speaking to** | Confirm you are speaking to the parents /legal guardians of the baby | DD/MM/YY | |
| **Check correct baby** | Name<br>DoB DD/MM/YY | DD/MM/YY | |
| **Reason for visit / call** | Remind parents baby had 'heel prick' when 5 days old | DD/MM/YY | |
| | One of the results has come back suggesting one of the conditions is **suspected** | DD/MM/YY | |
| | Name of the condition | DD/MM/YY | |
| | Not diagnostic, a screening test | DD/MM/YY | |
| | **Need more tests to confirm the result** | DD/MM/YY | |
| | Give date and time of first clinic appointment<br>**Date: DD/MM/YY Time HH: MM** | DD/MM/YY | |
| **Initial information** | Explain that there is a DNA result and this is an inherited condition | DD/MM/YY | |
| | Ask if they know of any family history | DD/MM/YY | |
| | If have friends or family with CF, advise parents not to have contact with them before seeing the clinical team | DD/MM/YY | |
| | Not caused by anything the parents did before or during pregnancy | DD/MM/YY | |
| | Reassure parents that their baby is well and it is safe to wait until they are seen by clinical team | DD/MM/YY | |
| | Advise parents to write down any questions they think of so they can ask these at their clinic appointment | DD/MM/YY | |
| | If face-to-face, give information sources and appointment details | DD/MM/YY | |
| | Suggest parents to come together or bring someone with them to the appointment | DD/MM/YY | |

| | | | |
|---|---|---|---|
| | Give contact name and number of member of clinical team | DD/MM/YY | |
| | Give PHE ‘suspected’ leaflet | DD/MM/YY | |
| | Discuss suitable websites if appropriate | DD/MM/YY | |
| **Afterwards** | If not face-to-face, send email with appointment details, contact information and information sources | DD/MM/YY | |
| **Optional information (If confident and qualified to discuss *and* if parents are interested in hearing more)** | Abnormal protein from abnormal gene | DD/MM/YY | |
| | Results in altered movement of salt | DD/MM/YY | |
| | Leads to production of abnormal secretions | DD/MM/YY | |
| | May also affect digestion – so a stool sample will be collected and sent away | DD/MM/YY | |
| | Lifelong condition | DD/MM/YY | |
| | In the UK, around one in every 2500 newborn babies have CF | | |
| **Comments** | | DD/MM/YY | |

### Email / letter template

The email/letter template was intended to be sent to parents immediately after the initial communication of the positive NBS result. These built upon those developed by the Paediatric Metabolic Clinical Nurse Specialists at St Thomas Hospital. The purpose was to congratulate parents on the birth of their baby, reiterate why they had been contacted about the NBS test and provide details regarding what would happen next including details of when and where they needed to take their baby for confirmatory testing. It was also recommended that reliable condition specific links to information sources were included. The text was drafted and revised with input from the CDWG until they agreed that the language and style of communication was appropriate and all information for all nine conditions currently screened for was included.

### EBCD Process

Participants were asked to reflect and feedback on their experience of the EBCD process using the template provided by the EBCD Toolkit [18]. This included a five-point Likert-type scale ranging from 'excellent' to 'very poor'. All parents rated viewing the composite film of parents' experiences as 'excellent', their experience of being filmed as 'good' or 'excellent', meeting other parents and talking about their experiences as 'excellent' and the emotional mapping exercise as 'good' or 'excellent'. They felt the priorities agreed at the end of the parent event reflected their own experiences of what needed to be improved. Five health professionals provided feedback and indicated that their overall impression of the health professional feedback event was 'excellent' and an 'excellent' way to reflect on experiences at work.

## Discussion

Uncertainty has been described as the single common challenge faced by patients who receive healthcare and health professionals who provide it [37]. NBS, by definition, is not diagnostic and as such uncertainty, in terms of clinical and prognostic outcomes, is inevitable when communicating the initial NBS result [38]. In this study, parents and health professionals were able to successfully work together to identify priorities and develop co-designed interventions to improve communication of positive NBS results using a modified EBCD approach.

### Parents' experiences of receiving the NBS result

Consistent with previous research [9,10,13,39-42] parents in this study reported receiving the NBS result in a range of ways including face to face, via telephone and text from a variety of clinicians including nurses, doctors and health visitors. The method used is to some extent influenced by the seriousness of the condition identified and the need for an immediate or less immediate response; MSUD and sickle cell carrier status would, for instance, be expected to be treated very differently in relation to the approach adopted. Furthermore, the content of the communication was less well defined and was, to some extent, determined by the person delivering the result. Current UK guidance states that the health professional delivering the news should be 'appropriately trained' [43,44]. This is important since, like previous research [4,9,13,39,45] knowledge of the person communicating the result in the present study, was considered to be important to provide reassurance and allay parental fears.

In addition, parents in the present study expressed the importance of the personal and professional attributes of the person delivering the news. In terms of personal attributes this included being kind,

empathetic, supportive (physically and verbally), and possessing effective communication skills which allowed them to appropriately pace and tailor information given and take the necessary time to explain the condition and answer parental questions. In terms of professional attributes, this included, being perceived as a specialist, being credible and working in an organisation recognised as a centre of excellence. The importance placed on knowledge and attributes of the person communicating the positive NBS result to families provides further support for the widespread use of specialist screening nurses who not only have knowledge of all conditions included in NBS but have also undergone relevant training related to breaking bad news and possibly even counselling skills.

As previously reported [13,39] the positive NBS result was associated with negative parental reactions including feeling nauseous, shock, disbelief, fear and sadness. Previous research has reported the impact on parents [4,6,11] parental and child [8] and family relationships [46,47]. This was reflected in the results of the present study as parents talked about the impact on their relationship with the affected child including being scared to bond with their child and fear of being overprotective. In the present study, the impact of the diagnosis on parental relationships ranged from bringing them closer together to causing a strain on the parental relationship. Parents also talked about the impact of sharing the news with family and friends; associated with this were feelings of responsibility, guilt and a lack of understanding.

## Health professionals' experiences of delivering the NBS result

The experiences of health professionals delivering the positive NBS result has been published elsewhere[1]. In summary, health professionals invested a lot of time and energy ensuring communicating positive NBS result to families was parent and family-centred, but this could be influenced by challenges they experienced including inadequate information on the NBS card and parental reactions. As mentioned, a variety of methods have been reported previously for the delivery of positive NBS results [9,10,13,39-42] which are often determined by the seriousness of the condition. In the present study, it became apparent this was also, to some extent, dependent on local arrangements. The COVID-19 pandemic meant that telemedicine rapidly and unexpectedly became the medium for health consultations that had previously taken place face-to-face. Other research has indicated that staff found the use of telemedicine for the delivery of NBS results during the COVID-19 pandemic safe and effective[48] and recipients also considered it an acceptable alternative to face-to-face communication. Therefore, going forward this may be an acceptable means of delivering positive NBS results to families which could be time saving and therefore cost-effective if the content is well considered and the person delivering the result is knowledgeable about the relevant condition.

In addition to parental experiences, this study furthers our understanding of health professionals' experiences of communicating positive NBS results to families. Health professionals involved in communicating positive NBS results are passionate about making sure that although the message is distressing for parents, it is done well. Variation in communication practices continue to exist and are influenced by many factors including resources available but also the lack of clear guidance. This impacted on the methods used to communicate positive NBS results but also the content of the communication to parents. This is supported by previous research, conducted both nationally and

internationally [4,6,41,49], suggesting that further guidance may be needed to ensure a more cohesive approach which meets the needs of parents' and health professionals while being sensitive to the subtleties of each condition. However, the issue of finite resources and the need to prioritise these also needs careful consideration. Nevertheless, with clear evidence of the deleterious effects of poor communication practices on parents [4-12], this variability is not reasonable nor conducive to building a positive rapport with families. This is vital to ensure concordance with treatment regimens and trust in health professionals to maximise outcomes for the child.

## Co-designed Interventions

To respond to the experiences and issues raised by parents and health professionals, EBCD, an established technique for gathering experiences and for co-design, was employed [20-22,27,33,50-52]. It has been applied for the first time here to explore parents and health professionals' experiences of the communication of positive NBS results. The process has enabled the prioritisation of stakeholder requirements and identification of co-designed solutions and additions to existing processes.

The co-designed interventions (changes to the NBS card; condition specific, standardised laboratory proformas; condition specific communication checklists; and an email/letter template to provide information to families following communication of a positive NBS result) tackled different stages of the screening journey and areas where participants felt that communication could be improved to minimise anxiety and uncertainty experienced. These tools have been tailored to guide health professional communication with the aim of providing a more consistent experience. The interventions have subsequently been piloted in two sites; findings from this have been published elsewhere[15].

EBCD can be time consuming and logistically challenging [27]; modifying the process has been shown to reduce costs [27].The ReSPoND project has been delivered during the COVID-19 pandemic, this has presented challenges in terms of bringing parents and health professionals together; a challenge that may continue for some time globally. We have adapted to these circumstances by employing Basecamp as a collaborative tool enabling online EBCD outside of the healthcare setting.

## Strengths and Limitations

This is the first known study that has explored communication pathways for positive NBS results from the laboratory to parents via clinical teams. Health professionals were recruited from clinical teams involved in managing all the conditions currently included in the NBS programme. This increases the transferability of the study findings as previous work has mainly focussed on CF and SCD. It is the only known study that has used EBCD to bring stakeholders together to develop co-designed interventions to improve communication of positive NBS results.

In terms of limitations, health professionals were recruited via email; those with a pre-existing interest in this topic may have been more likely to self-select into the study. These may communicate results differently than providers who did not participate in the study which may have biased the

findings. However, health professionals were recruited from clinical teams involved in managing all the conditions currently included in the NBS programme which would have contributed to both the depth and breadth of data collected. The researchers are experienced in this field which may have biased data collection and analysis. Most parental participants were white British; this may limit the transferability of the findings.

## Implementation and further research

COVID-19 has meant that virtual consultations via platforms such as Microsoft Teams and Zoom were being used to communicate with families about their child's positive NBS result. These have been described as an approximation of face-to-face interaction and are considered a "visual upgrade" of telephone consultations [53]. Initial studies that have explored these as a means of communicating positive NBS to families suggest they could be a safe and effective method for the delivery of positive NBS results to families[15,48]. Evidence suggests that video consultations (often referred to as telemedicine) have been viewed more favourably than telephone consultations[54]. The benefits of building rapport prior to using online approaches were found during teleconsultations in primary care during lockdown[55]. The opportunities for using these virtual methods in NBS requires further exploration to ensure they are used appropriately, that the content of the message continues tobe carefully crafted and that people involved are knowledgeable about the specific condition. However, a hybrid approach could act as a potential solution to address parental preferences, in particular, face-to-face communication with their significant other present, via a condition specific expert, and the clinical need for timely provision of results.

As well as the delivery of healthcare remotely, the pandemic has required online research and development. The adaptation of EBCD to include virtual methods could reduce costs whilst being easier to schedule. Adopting an online approach also has the potential to mitigate against the imbalance of perceived power hierarchies [35] when patients and health professionals work together, or conversely make it challenging to build a rapport. Here we benefitted from the early stages of the process being run face to face enabling relationships to develop. It is likely that a blended approach including face-to-face and online methods would help build effective relationships while offering flexibility and adaptation to the needs of patients/parents (e.g., childcare needs) and health professionals (e.g., busy schedules). We argue as hybrid or blended ways of working are of increasing focus, the consideration and evaluation of different models of delivery for application in healthcare design would be beneficial.

## Conclusion

Staff involved in communicating positive NBS results are passionate about making sure that although the message is distressing for parents, it is done well. Despite this, variation in communication practices continues to exist. This is influenced by many factors including resources available but also the current lack of clear guidance. Parents and health professionals were able to successfully work together to share experiences, identify priorities and develop potential solutions to improve communication of positive NBS results to parents. The resulting co-designed interventions address communication at different stages of the communication pathway to improve the experiences of parents, receiving positive NBS results for their child. Adopting a hybrid approach to EBCD that incorporates online CDWGs could enhance the success of future EBCD projects.

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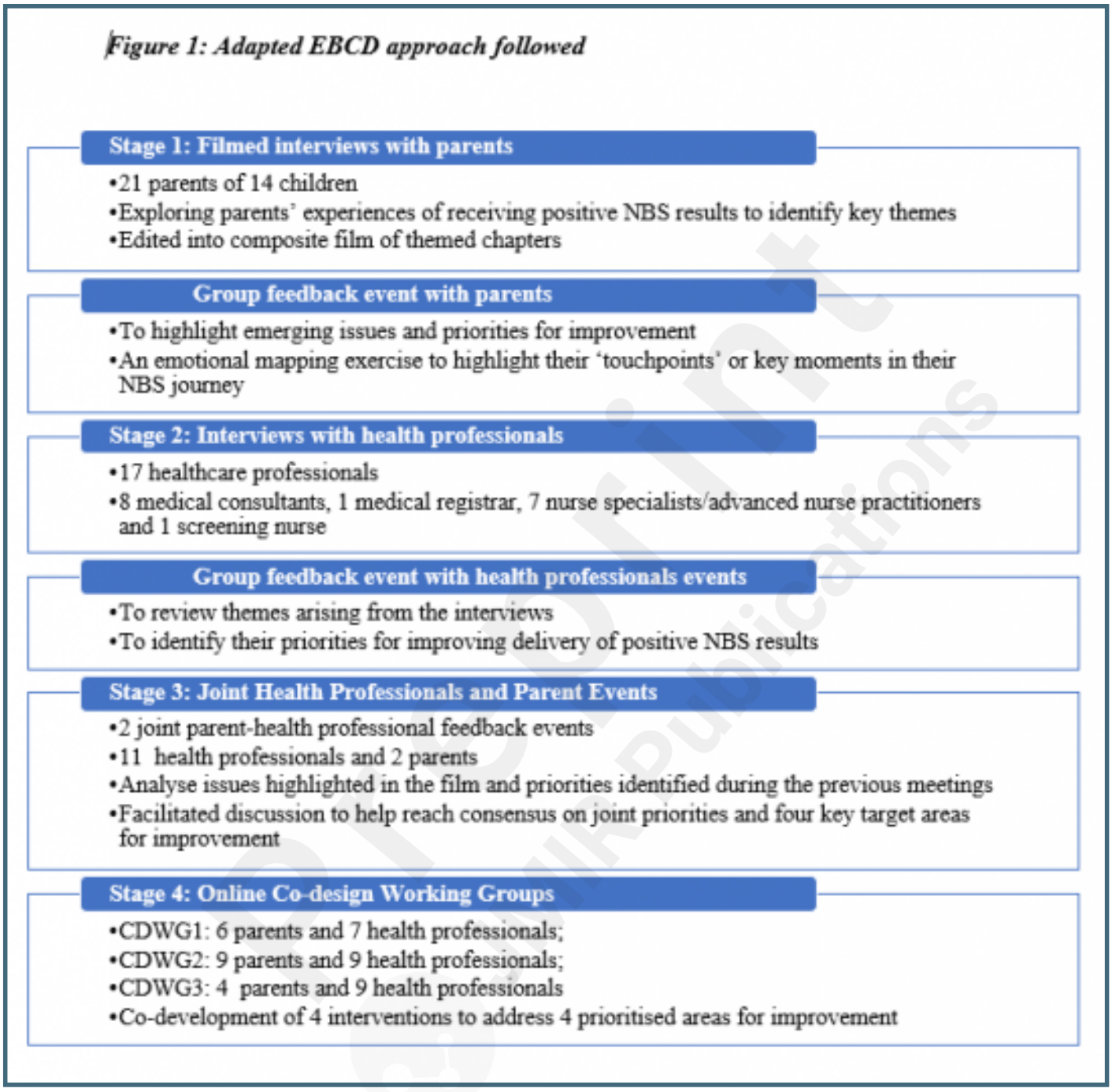
# Supplementary Files

# Figures

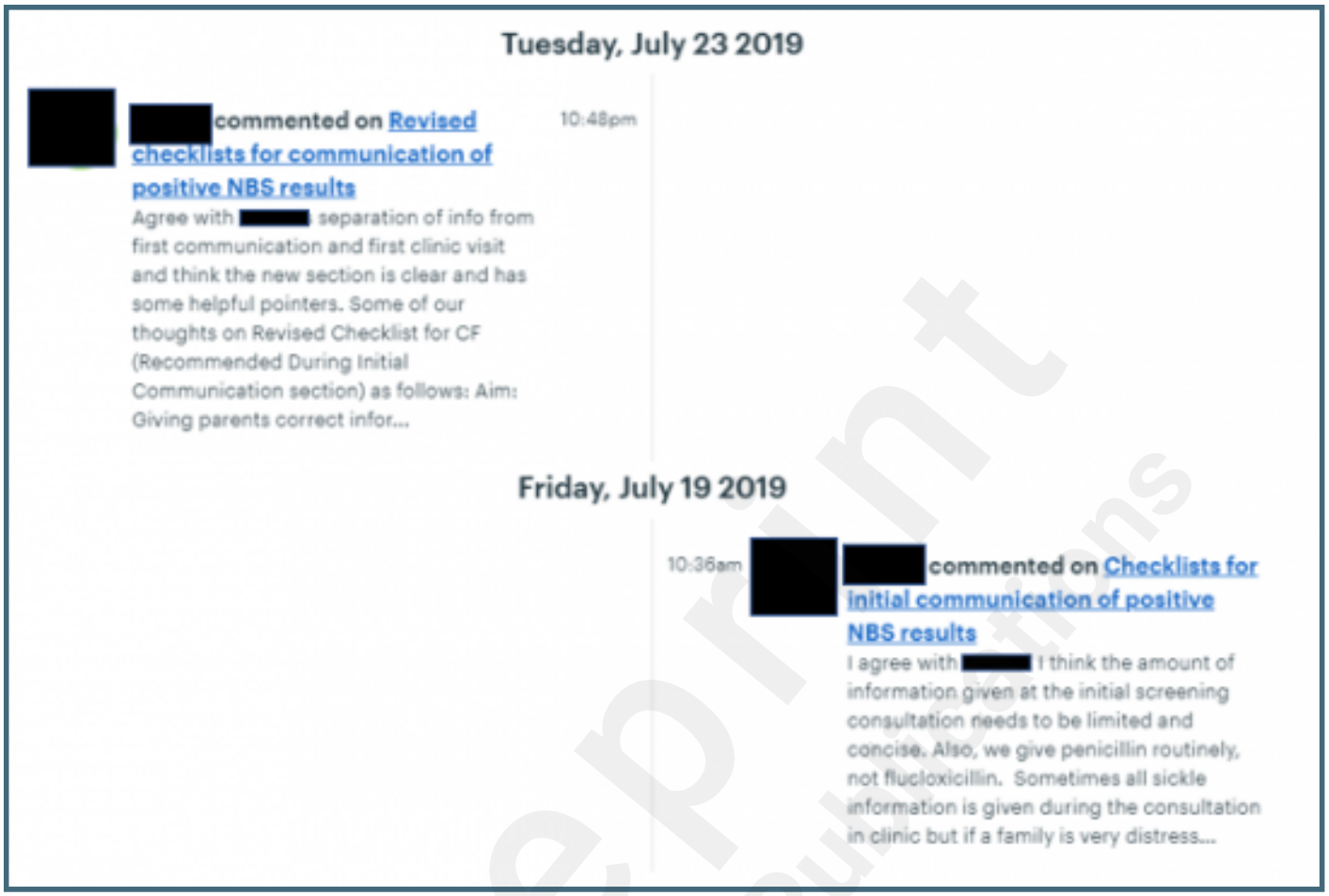
Adapted EBCD approach followed.

*Figure 1: Adapted EBCD approach followed*

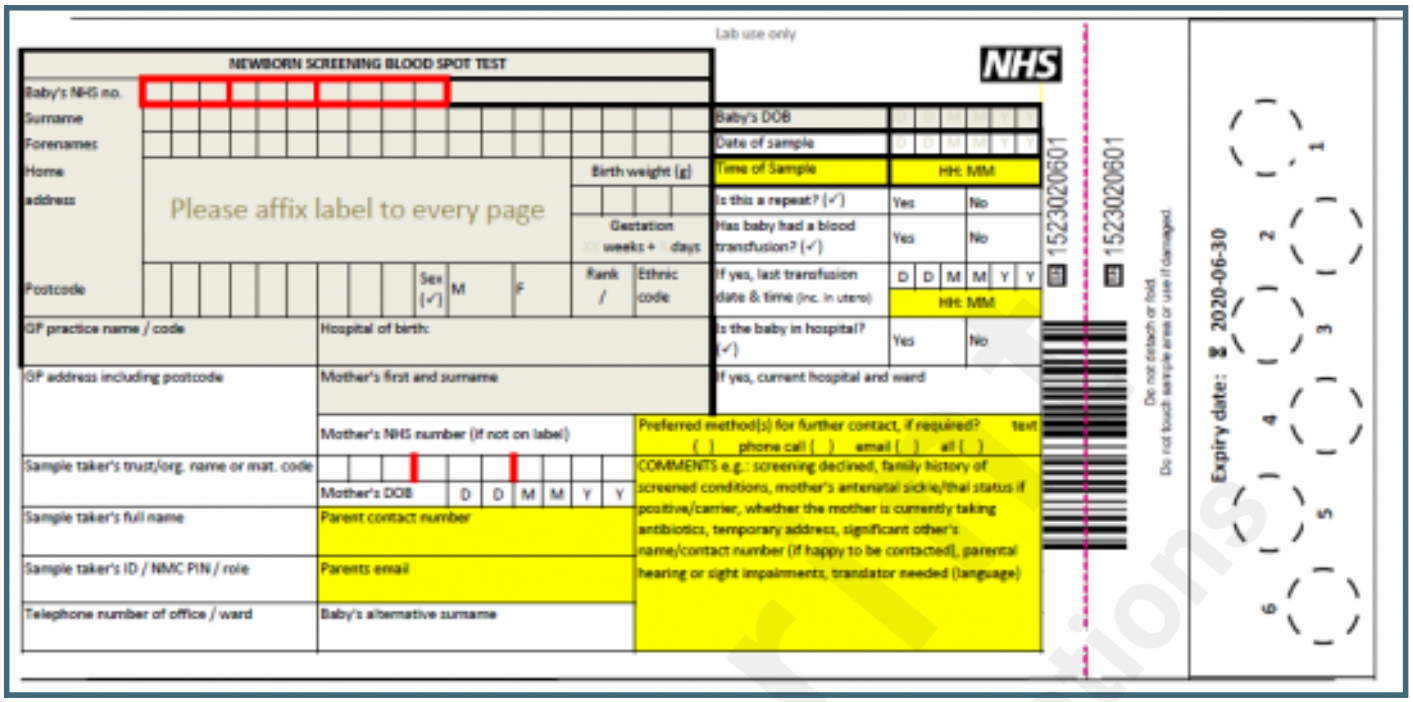


Illustrative flipcharts from health professionals' workshops.

Redacted example of communication during co-design working groups.



Newborn bloodspot screening card.



Example laboratory proforma for cystic fibrosis.

Name of Lab:
Contact details/Phone number:

*Figure 6 Example Laboratory Proforma for CF*

**NOTIFICATION OF CONDITION SUSPECTED FROM NEWBORN SCREENING – CYSTIC FIBROSIS**

**CONFIDENTIAL – PATIENT INFORMATION**

| | | |
|---|---|---|
| Referred by (name and designation): | Date: | Case/ laboratory ID: |
| Tel: | E-mail: | |
| Referred to (name and designation): | | Location: |
| Tel: | E-mail: | |

Resources e.g. parent leaflet, communication, diagnostic and treatment guidelines available at: https://www.gov.uk/government/collections/newborn-blood-spot-screening-programme-supporting-publications#cystic-fibrosis-(cf)

**PATIENT DETAILS**

| | | |
|---|---|---|
| NHS Number: | Date of birth: | Gestation: |
| Name: | Gender: | Location: Home/Hospital |
| Gestation: | Birth weight (g) | |
| Address:<br><br>Post Code: | Telephone number(s): | |
| Mother's Name: | Mother's date of birth: | |
| Mother's NHS number: | | |

**TEST RESULTS:**

| | | |
|---|---|---|
| Initial sample: | Date: DD/MM/YY | IRT (ng/mL whole blood): (cut off = ) |
| Mutation analysis: (Including legacy names) | | |
| Second sample: | Date: DD/MM/YY | IRT (ng/mL whole blood): (cut off = ) |

**Disorders from the other eight newborn screening tests** (PKU, MCADD, IVA, GA1, MSUD, HCU, CHT and SCD) were: ****Not Suspected / In Progress** (Please pass information to parents).
**COMMENTS:**

| | |
|---|---|
| GP (address and phone number): | Consultant: |

**Disorders from the other eight newborn screening tests** (CHT,PKU, MCADD, IVA, GA1, MSUD, HCU, and sickle cell disease) were: ****Not Suspected / In Progress** (Please pass information on to parents).
**COMMENTS:**

**REQUIRED ACTION please complete and return by secure e-mail to INSERTEMAIL@nhs.net**

**Acknowledge receipt of referral (name and designation):**

**Date of planned clinic appointment for PP (ideally day after referral):**

Example communication checklist for a child with suspected cystic fibrosis.

*Figure 7 Example communication checklist for a child with suspected CF by NBS*

| | | | |
|---|---|---|---|
| Name of child: | | | |
| Name of person communicating result: | Sign Print | | |
| Profession of person communicating result: | Consultant ☐ Nurse ☐ GP ☐ HV ☐ Other_____ | | |
| Method of communication: | Home visit ☐ Telephone ☐ Other_____ | | |
| **RECOMMENDED DURING INITIAL COMMUNICATION OF POSITIVE NBS RESULT** | | | |
| | | Date | Initial |
| **Introduction** | Who you are and where you're from (if two parents present, speak to both) | DD/MM/YY | |
| **Check who you are speaking to** | Confirm you are speaking to the parents /legal guardians of the baby | DD/MM/YY | |
| **Check correct baby** | Name<br>DoB DD/MM/YY | DD/MM/YY | |
| **Reason for visit / call** | Remind parents baby had 'heel prick' when 5 days old | DD/MM/YY | |
| | One of the results has come back suggesting one of the conditions is **suspected** | DD/MM/YY | |
| | Name of the condition | DD/MM/YY | |
| | Not diagnostic, a screening test | DD/MM/YY | |
| | **Need more tests to confirm the result** | DD/MM/YY | |
| | Give date and time of first clinic appointment<br>Date: DD/MM/YY Time HH: MM | DD/MM/YY | |
| **Initial information** | Explain that there is a DNA result and this is an inherited condition | DD/MM/YY | |
| | Ask if they know of any family history | DD/MM/YY | |
| | Not caused by anything the parents did before or during pregnancy | DD/MM/YY | |
| | Reassure parents that their baby is well and it is safe to wait until they are seen by clinical team | DD/MM/YY | |
| | Advise parents to write down any questions they think of so they can ask these at their clinic appointment | DD/MM/YY | |
| | If face-to-face, give information sources and appointment details | DD/MM/YY | |
| | Suggest parents to come together or bring someone with them to the appointment | DD/MM/YY | |
| | Give contact name and number of member of clinical team | DD/MM/YY | |
| | Give PHE 'suspected' leaflet | DD/MM/YY | |
| | Discuss suitable websites if appropriate | DD/MM/YY | |
| **Afterwards** | If not face-to-face, send email with appointment details, contact information and information sources | DD/MM/YY | |
| **Optional information (If confident and qualified to discuss *and* if** | Abnormal protein from abnormal gene | DD/MM/YY | |
| | Results in altered movement of salt | DD/MM/YY | |
| | Leads to production of abnormal secretions | DD/MM/YY | |