

# Improving the Delivery of Different News to Families by Healthcare Professionals

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## ABBREVIATIONS

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BCW	Behaviour Change Wheel
COM-B	Capability, Opportunity, Motivation Behaviour model
DN	Different News
DDN	Delivering Different News
DS	Down's Syndrome
HCPs	Health care Professionals
HEE KSS	Health Education England working across Kent, Surrey and Sussex
iHV	Institute of Health Visiting
TDF	Theoretical Domains Framework

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## 1. BACKGROUND

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As part of the foetal anomaly screening programme, all eligible pregnant women in the United Kingdom are offered screening to assess the risk of their baby being born with Down's (Trisomy 21/T21), Edwards' (Trisomy 18/T18) and Patau's (Trisomy 13/T13) syndromes or other structural abnormalities [1]. Some congenital anomalies may be associated with a learning disability. This includes chromosomal disorders such as Down's Syndrome as well as other foetal structural anomalies such as complex congenital heart diseases [2, 3]. Antenatal screening identifies mothers with an increased chance of having a child with foetal anomalies and enables HCPs and the families to make a more informed decision about whether to proceed with definitive prenatal diagnostic tests [1]. It also enables HCPs and families to agree on appropriate plans for the delivery; treatment options if available and in some cases and have discussions on possible termination of the pregnancy.

While antenatal screening may identify some anomalies during pregnancy, some are not identified until after birth. When anomalies are identified, families are faced with the unexpected experience of receiving different news about their unborn or newly born child. The term "different news (DN)" is used in this study to describe the process of imparting and receiving information relating to an unborn or newly born child being diagnosed with a condition associated with a learning disability.

In previous studies, parents experienced a range of emotions immediately after DN was delivered including significant distress, fear, grief, depression, anxiety and chronic stress [4-6]. Chronic stress in parents may negatively affect parenting skills and may result in harsh reactive parenting which can impair the social-emotional, cognitive and physical development of children, increasing the risk of mood disorders in later life [7]. Maternal and paternal depression are also known predictors of poorer cognitive functioning, impaired adaptive functioning, increased risk of depression, anxiety and conduct disorders in children exposed to this [8-10]. It is imperative that HCPs who DDN are adequately trained to minimise the negative psychological impact of receiving DN on families.

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## 1.1 STUDY AIM

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### 1.1.1 Phase 1 Aim

- To develop a training intervention to improve the delivery of DN to families by HCPs.

### 1.1.2 Phase 2 Aim

- To conduct an evaluation of a training programme to assess its acceptability, feasibility and optimal intervention design for future roll-out of the training.

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## 1.2 STUDY OBJECTIVES

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### 1.2.1 PHASE 1 OBJECTIVES

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1. To describe and explain the lived experience of receiving DN from HCPs
2. To describe and explain the lived experience of DDN to families by HCPs.
3. To identify the barriers and facilitators to effective delivery of DN.
4. To identify training needs for HCPs who deliver DN.
5. To develop a DDN training intervention for HCPs.

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### 1.2.2 PHASE 2 OBJECTIVES

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1. To assess the acceptability and feasibility of implementing the training intervention for HCPs by assessing rate of uptake and course adherence and completion.
2. To establish barriers and facilitators to course attendance and participant views on course content and session delivery.
3. To determine proof of principle by gathering information about changes in knowledge, skills, attitudes from healthcare professionals pre-and post-intervention.

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## 1.3 STUDY OUTCOMES

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### 1.3.1 PHASE 1 OUTCOMES

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Phase 1 was primarily qualitative in nature due to the HCP survey having a very low response rate. The outcomes for Phase 1 were:

- Identification of the training needs for effectively delivering different news.

- Identification of barriers to effective delivery of different news.
- Identification of facilitators to the effective delivery of different news.

The main output from Phase 1 was the training intervention.

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### 1.3.2 PHASE 2 OUTCOMES

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#### A. Primary Outcomes

- The percentage of healthcare professionals who are offered and complete the training.
- The percentage of healthcare professionals reporting increased knowledge, skills and confidence after the training intervention is delivered.

#### B. Secondary Outcomes

- Acceptability of the training intervention.
- Acceptability and feasibility of delivering the same training intervention among various HCPs who deliver different news.

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## 1.4 REPORT STRUCTURE

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The report is divided into eight chapters. We describe the research methodology in chapter 2 and then detail our findings from the literature review in chapter 3. In chapter 4 we present the qualitative findings from Phase 1 and in chapter 5 we describe the training intervention and how we developed it. In chapter 6, we present the findings from Phase 2 and then in chapter 7, we present the discussion and in chapter 8 we present the conclusions from this study.

## 2. METHODOLOGY

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This was a prospective, mixed-methods, non-randomised study consisting of two phases.

### 2.1 METHODOLOGY FOR PHASE 1

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There were three components to Phase 1 data collection:

#### COMPONENT 1: LITERATURE REVIEW

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A literature and policy review exploring the process of DDN was conducted to:

- provide the context in which families receive DN in the UK.
- examine the impact of receiving DN on families.
- clarify good practice when DDN.
- Identify areas for further development for HCPs who deliver DN.
- identify the different types of training interventions to support the delivery of DN.
- clarify important factors to consider in the development of a training intervention.

A literature search<sup>1</sup> was performed in April 2017 by Surrey and Sussex Library and Knowledge Service in the following databases: CINAHL, HMIC, Medline, NICE Evidence, PsychINFO, Google Custom Search, Wiley Online Library. Only studies written in English were included. Conference proceedings were excluded from the review. The library team also searched grey literature for policy documents on DDN. One further search was undertaken by EM on the 23<sup>rd</sup> of October 2018 in PubMed and Web of Science to update the database of studies for the review. Only studies published between 2004 and 2018 were included to reflect current changes in practice in the delivery of different news. Studies were only included if they were conducted in the EU/EFTA, North America, New Zealand or Australia. The search included quantitative and qualitative evidence on DDN and had to report on:

- the lived experience of receiving DN during pregnancy or at birth.
- the process of DDN.

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<sup>1</sup>The search terms used were: breaking news, learning disability, prenatal, diagnostic techniques obstetrical, intellectual disability, postnatal care, disability, communication, news, breaking sad news, breaking bad news, informing parent, giving bad news, giving sad news, receiving bad news, receiving sad news, information preference, coping style, prenatal diagnosis, communication bad news, postnatal diagnosis, postnatal support, effect, impact, parental experiences, unborn child.

- the impact of receiving DN
- the impact of DDN on HCPs
- the services or support provided both prenatally and postnatally after receiving DN
- training interventions to improve DDN, their feasibility, acceptability, and effectiveness.

The library team initially screened all titles and abstracts for eligibility using the set criteria. Eligible studies were then passed on to the research team for full paper screening. This was done independently by EM and SG using a screening tool. A structured data extraction tool was developed to capture the required information from the included papers. Extracted data were summarised by EM and SG. Disagreements in interpretation were resolved through discussion between the team members. Quality of the eligible papers was appraised by EM using standard criteria (CONSORT and STROBE) to assess quantitative study quality [11, 12] and the Critical Appraisal Skills Programme (CASP) checklist [13] for the appraisal of qualitative evidence.

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## **COMPONENT 2: INTERVIEWS**

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We conducted nine in-depth interviews with families who have had the lived experience of receiving DN and conducted an additional 12 interviews with professionals who have delivered DN to families. The sample size for interviews was pragmatic and was large enough to allow for data [14]. HCPs were recruited from NHS Trusts supported by HEE KSS across Kent, Surrey and Sussex. Email invitations to participate in the interviews were sent out via HEE networks (such as Heads of Midwifery) to pass on to all eligible staff members who are involved in the delivery of DN to families. Interested participants contacted the research team directly and those who fulfilled inclusion criteria were recruited into the study.

Families were recruited from the Kent Community Health NHS Foundation Trust (KCHFT) - Health Visiting Service as well as from various charities namely Unique, 21&co, and the Cornwall Down's Syndrome Support Group. Families were recruited using flyers or the participant information sheet distributed during their usual meetings, usual communication updates or usual scheduled appointments by representatives from the charities or by the HCP. Families either contacted the study team directly to participate in the interviews or contacted the person who had distributed the flyer to register their interest in participating in the study.

Two interview guides were developed based on the literature review, one for families and the other

for HCPs. The interviews examined the process of receiving or DDN, what went well and what could have been improved on. They also identified perceived training needs and possible interventions to address the identified challenges. Interviews with HCPs were conducted over the phone while interviews with families were conducted face to face at a mutually convenient time and place. Both HCPs and family interviews lasted between 45 minutes and an hour.

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### **COMPONENT 3: DEVELOPMENT OF THE TRAINING INTERVENTION**

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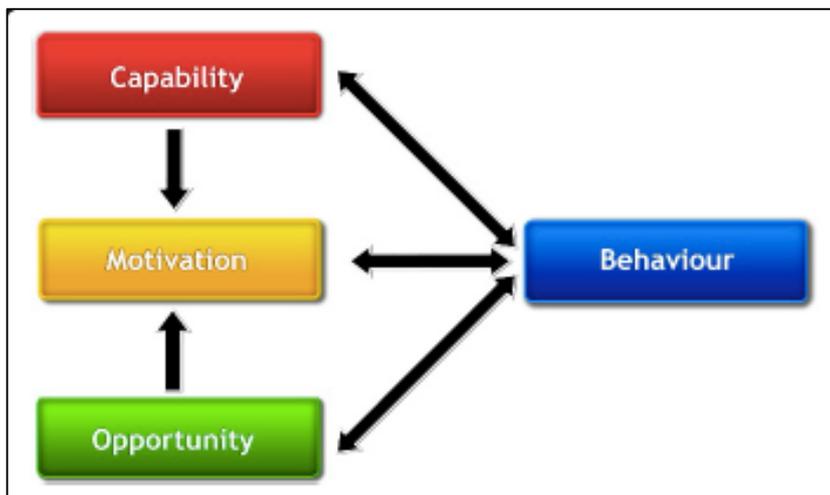
A training intervention to improve the delivery of DN represents a complex intervention as defined by the UK Medical Research Council (MRC). A complex intervention is one that has a number of separate elements which seem essential to the proper functioning of the intervention although the active ingredient of the intervention that is effective is difficult to specify [15]. Evaluating complex interventions requires a staged process as outlined in the MRC's Framework for the evaluation of complex interventions. A critical first step is to establish the evidence base for the proposed intervention and its underlying theoretical basis [15]. Second is to pilot and determine the acceptability and feasibility of both intervention delivery and the proposed evaluation methods. The process is iterative feedback into strengthening the intervention, its delivery and the evaluation process. The development of the intervention followed the above mentioned MRC guidance including:

- Qualitative data to ascertain the barriers and facilitators to the effective delivery of DN with parents as well as health care professionals.
- Extensive literature reviews to examine the factors affecting delivery of different news; the acceptability of various training interventions and to identify the core components of how to break DN sensitively and identification of suitable theory to underpin the intervention.
- Seeking consensus from research team members and experts in the field.

To mitigate the complexity inherent in developing an intervention aimed at changing clinical practice we followed a systematic four step approach to intervention development drawing on the behaviour change wheel [16]. Use of theory to understand the mechanisms of action of intervention strategies has been shown to improve their effectiveness [16]. The Behaviour Change Wheel (BCW) is a theoretically driven framework designed to enable the systematic development of interventions supporting the change of practice by HCPs and has been used extensively for this purpose [16-19]. It consists of multiple models of behaviour and is underpinned by the Capability, Opportunity,

Motivation-Behaviour (COM-B) model which posits that change in behaviour or practice is affected by capability, opportunity and motivation [16] as shown below in figure 1 below:

FIGURE 1: COM-B MODEL



Source [16]

The COM-B model can be subdivided into fourteen constructs within the Theoretical Domains Framework (TDF) [16, 20, 21]. Mapping barriers to change in practice onto the TDF is useful for identifying barriers and facilitators that need to be addressed to achieve behaviour change. The different domains are shown in figure 2. The COM-B provides support for appropriate intervention functions and behaviour techniques based on the behaviour change technique taxonomy [22].

FIGURE 2: THEORETICAL DOMAINS FRAMEWORK

Domain	Definition and example of a construct
Knowledge	An awareness of the existence of something, for example, procedural knowledge
Skill	An ability or proficiency acquired through practice, for example, competence
Social/professional role and identity	A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting, for example, professional confidence
Beliefs about capabilities	Acceptance of the truth, reality or validity about an ability, talent or facility that a person can put to constructive use, for example, self-confidence
Optimism	The confidence that things will happen for the best or that desired goals will be attained, for example, optimism, pessimism
Beliefs about consequences	Acceptance of the truth, reality or validity about outcomes of a behaviour in a given situation, for example, outcome expectancies
Reinforcement	Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus, for example, rewards
Intentions	A conscious decision to perform a behaviour or resolve to act in a certain way, for example, stability of intentions
Goals	Mental representations of outcomes or end states that an individual wants to achieve, for example, goal/target setting
Memory, attention and decision processes	The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives, for example, decision-making
Environmental context and resources	Any circumstances of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence and adaptive behavior, for example, resources
Social influences	Those interpersonal processes that can cause individuals to change their thoughts, feelings or behaviours, for example, social pressure
Emotion	A complex reaction pattern, involving experiential, behavioural and physiological elements, by which the individual attempts to deal with a personally significant matter or event, for example, anxiety
Behavioural regulation	Anything aimed at managing or changing objectively observed or measured actions, for example, self-monitoring

Source [20]

The training intervention was implemented in Phase 2 of the study. There were three components to Phase 2 data collection: delivery of the training intervention; administration of pre and post-training questionnaires and interviews with a small group of HCPs a month after attending the training.

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### **COMPONENT 1: DELIVERY OF THE TRAINING INTERVENTION**

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Invitations to participate in a half-day training workshop were sent out to staff who deliver DN in various NHS Trusts supported by HEE KSS. The training took place in Crawley and Canterbury. As this aspect of the study was a pilot, it was not powered to detect statistical significance. We recruited 26 HCPs in total. This sample size was pragmatic. Recommendations for pilot and feasibility studies propose examining changes in a group of 24 to 50 subjects in order to estimate parameters for a follow on randomised control trial [23-25].

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### **COMPONENT 2: QUESTIONNAIRES**

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All participants who took part in the training were asked to complete the pre and post-training questionnaires on skills, knowledge, and attitudes related to DDN. The post-training questionnaires also sought qualitative feedback on the strengths and possible improvements to the training.

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### **COMPONENT 3: INTERVIEWS**

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As part of the training, participants were asked to register their interest in participating in qualitative interviews a month after the training. Interviews aimed to explore perceived changes in knowledge, attitude, and practices after the training as well as to obtain additional feedback on the perceived strengths and limitations of the training. The telephone interviews were conducted using an interview guide and lasted between 25 and 45 minutes. The interviews were all audio-recorded, then transcribed.

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## **2.3 DATA ANALYSIS**

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All qualitative data were managed using NVivo and analysed using Framework analysis [26] guided by the Theoretical Domains Framework (TDF) [20, 21]. Framework analysis begins with familiarisation with the data, followed by the development of a thematic framework which will be used for indexing the data [26]. This will be followed by charting the data and then mapping and interpretation which allows the development of descriptive and explanatory findings [26]. These were illustrated using

various anonymised quotations. Pseudonyms were used to protect the identity of families that participated in the study.

The pilot training was not powered to determine the effectiveness of the intervention but was used to determine parameters such as acceptability and feasibility that are useful for a future larger study. Acceptability was assessed by the number of HCPs who attended the full training. Feasibility was measured by assessing the percentage of eligible HCPs who eventually enrolled in the training. All secondary outcome measures were summarised descriptively. Categorical data were described by counts and percentages as appropriate. All analyses were carried out in SPSS.

### 3. LITERATURE REVIEW

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#### 3.1 POLICY REVIEW: GUIDELINES ON THE DELIVERY OF DN

---

Our policy review aimed to summarise current guidelines, policies and or protocols around the delivery of DN in the UK. We found four guidelines published between January 2004 and February 2017. One was developed by a charity, another by a professional organisation and two were developed by NHS Trusts.

Contact a Family, published guidelines to assist HCPs working with families with a child with a disability in 2006 [27]. The guidelines focus on assisting HCPs to provide meaningful support to families following the diagnosis of a disability from pregnancy to pre-school age. The guidelines also provide brief suggestions on how to deliver DN [27]. As the resource was published 12 years ago, some of the information from the resource, for example, the sources of support cited are now outdated. Other guidelines were published in 2013 by the Royal College of Nursing (RCN) to support delivery of DN to parents by nurses, midwives and health visitors [6]. These guidelines outline the application of the RCN principles of nursing practice to DDN and suggest a framework for how this can be done using the SPIKE (setting, perception, invitation, knowledge, empathise) Protocol [28] and the ABCDE (advance preparation, build a therapeutic relationship, communicate well, deal with patient and family reactions, encourage and validate emotions) model [29]. The authors also acknowledged the importance of continuous professional development in communication skills for HCPs and how this can have a positive impact on families [6]. However, the guidelines whilst comprehensive, do not have a complementary training intervention to equip HCPs how to translate the guidelines into their everyday practice.

We retrieved local level guidelines for DDN from the Royal Cornwall NHS Trust (RCHT) and the Norfolk and Norwich University Hospital NHS Trust (NNUH) [30, 31]. RCHT have guidelines on DDN to children, young people, and their families based on some of the principles from the SPIKES protocol [28, 31]. NNUH guidelines are based on recommendations from the Right From the Start campaign which was aimed at supporting meeting the needs of disabled children and equipping professionals working with families with children with disabilities [30]. Both NHS trust guidelines provide suggestions on how to deliver DN including possible phrases that can be used by professionals. However, we were unable to find any data on training related to these guidelines or the possible effect of the guidelines on the self-efficacy of HCPs who deliver DN. The difference in the two guidelines also suggests that there may be variation in how DN is delivered between trusts.

### **3.2 RESULTS OF LITERATURE REVIEW**

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Over 1000<sup>2</sup> articles were retrieved from the initial search by the library. After removal of duplications and screening of titles and abstracts, 37 papers were identified as eligible for full paper screening through the initial search and the additional search by EM. Fourteen papers were excluded after full paper screening because they were not in English (n=2), were inappropriate publications (n=6), excluded populations (n=6). Figure 3 contains a flow chart of the study search and selection process. 23 studies were selected for inclusion in the literature review. These are described in table 1.

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<sup>2</sup> This number is an estimate is based on documents from the library on the search processes.

FIGURE 3: FLOW CHART OF THE STUDIES

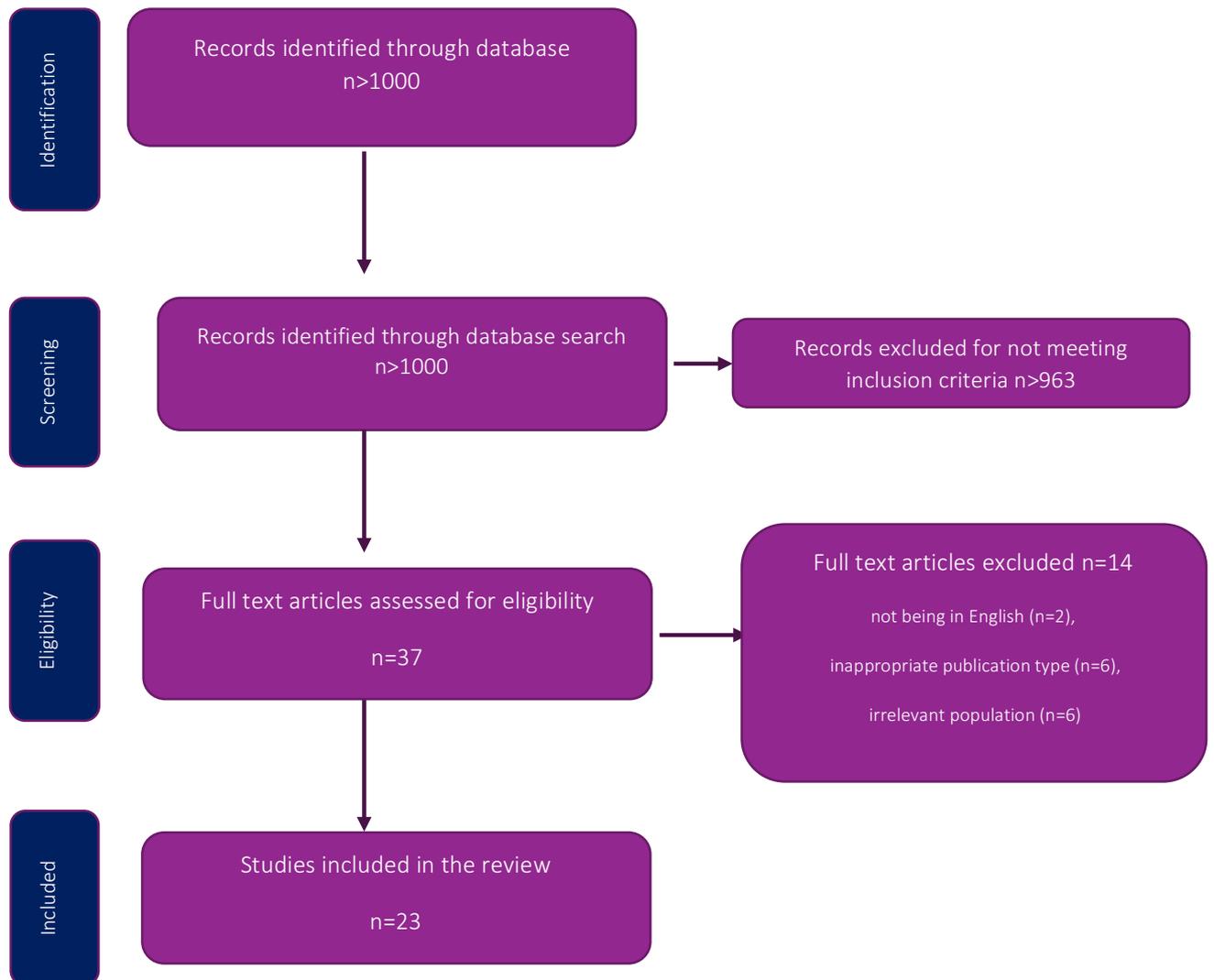


TABLE 1: DESCRIPTION OF STUDIES

Author	Year	Country	Objectives	Methods	Population	Main results
[32]	2018	Spain	To examine the healthcare provided to pregnant women whose fetuses have congenital anomalies and to facilitate the design of a more personalised health model.	Qualitative	22 obstetricians, 4 midwives, 3 nurses, 8 nursing assistants	HCPs acknowledged the need for sensitivity when DDN and tailoring information giving to the needs of the family. HCPs indicated a lack of training in communicating DN and how this was often learnt by observing other colleagues or standalone communication seminars.
[33]	2018	Norway	To explore obstetricians' experiences and views of the use of obstetric ultrasound in the clinical management of pregnancy.	Qualitative	20 obstetricians	DDN was described as a very difficult aspect of the obstetricians' work. Obstetricians had to balance the medical and social aspects of the ultrasound examination when delivering different news.
[5]	2017	Europe, USA, Australia	Explore the psychological effects of a prenatal diagnosis of a foetal anomaly on expectant parents.	Literature review	N/A	Impact of receiving DN on parents is discussed as well as experiences of HCPs.
[34]	2017	USA	To describe a train-the-educator workshop aimed to teach educators how to create and conduct workshops on facilitating difficult family conversations that target their own learners' needs.	Review and post-training evaluation	14 HCPs working in neonatology, general paediatrics, critical care, palliative care and other sub-specialties in paediatrics	The authors outlined how educators can develop workshops on DDN using simulation. 86% of attendants planned to use the skills from the workshop in the development of their own curriculum.
[35]	2016	USA	To outline the importance of providing up to date information to parents when they deliver DN on Down's Syndrome	Review	N/A	The anticipated outcomes of a condition can change significantly based on available social support, health care, and services hence it is important for clinicians to stay up-to-date about new developments and credible, medically reviewed information about Down syndrome and other genetic conditions.
[36]	2016	USA	To discuss the use of collaborative reflective training for breaking bad news.	Literature review	N/A.	Description of the collaborative reflective training and how this can be adopted by those developing training on delivering different news.

[37]	2016	USA	To explore effective techniques in the delivery of different news	RCT	42 participants	Both groups reported improvements in being able to deliver bad news with those who had debriefing instead of the lecture after simulation showing the greatest changes.
[38]	2015	Canada	To enhance care and quality of communication between staff and parents in a neonatal intensive care unit.	Literature review; Questionnaires and qualitative data.	Not stated	Incorporation of parent experiences of communication in the NICU is effective in addressing challenges associated with delivering different news.
[39]	2015	USA, Europe	To explore the link between information preference and coping style	Review	The number of papers included is not stated.	The information needs of parents when a foetal abnormality is identified on the ultrasound are discussed.
[40]	2015	USA	To provide a framework to break bad news of an anomalous fetus for physicians caring for pregnant women using the SPIKES protocol	Review	N/A	Shows how SPIKES protocol can be used as a framework to deliver DN to families following an ultrasound scan.
[41]	2015	Italy	Exploration of the use of films as a reflective learning tool for emotional awareness to aid the delivery of different news.	Qualitative	9 midwifery students	Participants identified good and poor practice in the delivery of different news. Reflection and use of simulation through the cinema were useful learning tools for delivering different news.
[42]	2014	USA	To evaluate a training on sharing of life-altering information (SLAI) in paediatrics.	Survey	159 pre-and post-surveys were completed.	The training improved self-efficacy in DDN. Medical trainees reported the greatest difference in all areas. Those with fewer than 16 years of experience had the most significant self-assessment increases.
[43]	2014	Netherlands	To analyse which dysmorphic features are most recognised in newborns with Down syndrome (DS)	Prospective Cohort	586 children with Down's Syndrome.	Appropriate communication with the parents of the message that their child has DS can be difficult. Guidelines can help to make counselling easier and more effective, which in turn may increase parental satisfaction.

<b>[44]</b>	2014	Portugal	To examine the psychological adjustment in parents of infants with congenital anomalies from the disclosure of the diagnosis to six months after the infant's birth.	Prospective cohort	43 mothers and 36 fathers	There was a significant reduction in psychological distress and a significant increase in physical quality of life over time, for both parents, regardless of the timing of diagnosis six months after diagnosis. However, some parents experienced adjustment difficulties and may need specialised counselling.
<b>[45]</b>	2013	Portugal	To examine parents' emotional reactions (high intensity vs. low intensity) and the intensity of each emotion when a prenatal or postnatal diagnosis of a congenital anomaly is disclosed.	Cross-sectional study	60 mothers and 50 fathers of 60 infants prenatally or postnatally diagnosed with a congenital anomaly.	Type of congenital anomaly, the timing of diagnosis, and parity were not found to be significantly associated with the patterns of emotional reactions.
<b>[46]</b>	2012	Portugal	To characterise the impact of the diagnosis on psychological distress and quality of life, in the early post-diagnosis stage.	Cross-sectional survey	84 couples: 42 infants with no congenital anomalies and 42 infants with a congenital anomaly	Parents with infant with congenital anomalies have higher levels of distress compared to parents of a healthy infant.
<b>[47]</b>	2012	USA	To improve the delivery of DN in a cross-cultural setting.	Qualitative interviews	14 Latin American women	Cultural differences in perception of DS can make the initial receipt of DN negative. HCPs need to be aware of these cultural differences when delivering different news.
<b>[48]</b>	2009	Europe & USA	To systematically review evidence regarding how physicians should approach the conversation in which they explain DS for the first time to new parent	Literature review.	19 articles, 3359 patients who received postnatal diagnosis of an infant with DS	Framework and guidelines on how to deliver news on DS based on the review were presented.
<b>[49]</b>	2007	United Kingdom	To explore women's experiences of encounters with caregivers after the diagnosis of a foetal anomaly at the routine second trimester ultrasound scan	Qualitative interviews	38 women	Negative experiences of initial receipt of DN were reported and suggestions of how this can be improved in the future were also made.

<b>[50]</b>	2006	USA	To propose a theoretical framework for the delivery of DN regarding Down Syndrome to new parents.	Review	N/A	A theoretical framework on how to deliver DN is presented to provide HCPs with guidelines on how to conduct an informing interview. Training of HCPs in DDN is recommended.
<b>[51]</b>	2005	USA	To describe communication techniques for delivering different news	Review	N/A	Several communication techniques with guidance on language; setting; and showing empathy are proposed.
<b>[52]</b>	2005	USA	To document the reflections of mothers in the USA whose children received diagnoses of Down's Syndrome.	Cross-sectional survey	985 women whose babies received a postnatal diagnosis of DS	Lived experience of receiving DN including factors which make initial diagnosis negative are described. Authors also suggest how DDN can be improved.
<b>[53]</b>	2005	Spain	To document the reflections of mothers in Spain who received a postnatal diagnosis of Down's Syndrome for their child.	Cross-sectional survey	467 women whose babies received a postnatal diagnosis of DS.	Lived experience of receiving DN including factors which make initial diagnosis negative are described. Authors also suggest how DDN can be improved.

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### 3.2.1 THE IMPACT OF RECEIVING DN

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Regardless of whether a diagnosis was made prenatally or postnatally, receiving DN was reported as distressing and unexpected with parents experiencing various emotions such as shock, denial, revolt, anger, guilt, sadness and depression [5, 33, 39, 44, 45, 47-50, 52]. Some studies have shown a clear correlation between maternal anxiety and the focus of the initial conversation when HCPs delivered DN, thus highlighting the importance of how DN is delivered [44, 48]. Previous studies indicated that DN was also often unexpected for the HCPs which contributed to delivering such news challenging [5, 50]. However, most parents adjusted to the news over time [44, 47]. A cross-sectional survey of parents found that over a period of six months, parents who were well supported and had access to appropriate information when they needed it, adjusted well to the diagnosis; showed patterns of resilience; had reduced symptoms of anxiety and depression and an improved quality of life [46].

Various studies showed that delivery of DN in the prenatal period had its own complications because parents were offered the opportunity to have additional diagnostic testing as well as the option to terminate a pregnancy. [32, 39]. Physicians reported providing a diagnosis in this context difficult due to the pressure to make the diagnosis; make a timely referral to foetal medicine and to discuss the option to terminate the pregnancy [32, 35, 39, 49]. Findings from a review suggest that parents found the decision to terminate a pregnancy based on foetal anomaly screening distressing [5, 32, 33, 39, 49]. In some instances, the decision to terminate was influenced by the potential challenges that the child would face and the perceived potential distress which siblings, as well as parents themselves would face [39]. The severity of the anomaly as well as religion were important factors in the decision to terminate a pregnancy and HCPs needed to be sensitive to these [39, 54]. The personal views of HCPs about terminating a pregnancy were reported as having a negative effect on how DN was delivered [39]. Some women reported a deterioration in the quality of their relationships with the HCPs after they decided to continue a pregnancy with a significant chance of physical or learning disability [39].

Whether the DN was delivered prenatally or postnatally, if the initial conversation was negative and parents were not given adequate support, the infant was at increased risk of poorer outcomes due to the poor mental health of the parent [46]. Chronic stress in parents can adversely affect parental functioning and the parent-infant relationship. Evidence shows it can result in parenting styles which

may impair the social-emotional, cognitive and physical development of children, which in turn, increases the risks of mental illness across the life-course. [7]. Maternal and paternal depression and anxiety are also known risks for poorer cognitive functioning, impaired adaptive functioning, and increased risk of depression, anxiety and conduct disorders in children. [8-10]. The effects are known to span from infancy into adolescence [8, 55]. In view of this, there is a need to ensure that HCPs are equipped with the skills to deliver DN effectively.

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### **3.2.2 IMPORTANT FACTORS FOR DDN EFFECTIVELY**

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Previous research has highlighted a number of factors which improve the initial receipt of DN [5]. One of the most critical things highlighted by the literature is the timing of the delivery of DN [43, 47, 50]. In various studies, parents indicated the importance of being given the diagnosis as early as possible to avoid overhearing HCPs discussing their child's diagnosis without them being directly informed [50]. However, this needed to be balanced as parents also indicated the importance of not delivering the news within seconds of the birth, particularly if the condition was not perceived as life threatening [52].

Closely related to timing, previous studies also showed the importance of ensuring that a significant other, such as a spouse was present to remove the burden on the parent who was first notified having to deliver the news to the parent who was absent at the initial conversation [5, 48-50, 52, 53]. One qualitative study found that mothers valued the discussion being delivered in a way that involved both them and their partner in the decision making about their child. Not involving parents in decision making was reported as exacerbating feelings of powerlessness, distress, and loss of control [39]. Furthermore, to give both parents the space they needed to process the diagnosis, express their emotions or to make decisions, it was important that the news was delivered privately.

The language used was of importance to the parents [39, 48-50, 52, 53]. Several studies reported that parents did not want HCPs to use language to suggest that the birth of their child was regrettable [39, 48-50, 52, 53]. In addition, parents did not want the language used to be overly technical, parents valued HCPs who ensured that their message was understood. This was sometimes a product of the HCP being available to answer questions during or after the diagnosis [5, 50, 51]. In addition, parents reported the importance of ensuring that the initial description was balanced and not overly negative [5, 39, 47-49, 52, 53]. For example, mothers from a large cross-sectional survey conducted in the USA

reported finding some information provided soon after birth, such as statistics about adult obesity, Alzheimer's disease, behavioural problems or predicting the level of independence that the child might have inappropriate [52]. While parents wanted information to be provided, HCPs needed to be able to gauge how much information parents could take as giving too much information, particularly if it was negative, exacerbated anxiety and or depression in parents [35, 48].

Several researchers have published frameworks and guidelines on how to deliver DN during pregnancy or the neonatal period based on primary research or literature reviews [39, 48-50, 52, 53]. The frameworks emphasise the factors highlighted above but also provide useful suggestions on when and how to break the news; the importance of verbal and non-verbal language when delivering different news; the importance of communicating in a respectful, sensitive and non-judgemental manner to parents; listening to parents and making joint decisions about care; being empathetic; the importance of providing timely supplementary written information and follow on support [39, 48-50, 52, 53]. Other authors have looked at the specific needs of ethnic minority women and provided recommendations on delivering news in the context of different religious and cultural beliefs.[47].

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### **3.2.3 TRAINING IN DDN**

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The literature search did not retrieve any studies on training to deliver DN specific to congenital anomalies associated with a learning disability prenatally or at birth. However, we were able to identify some studies on training to deliver DN in midwifery, paediatric and obstetric settings. We excluded studies that only reported on specific sub-specialties, for example, paediatric oncology and only included studies on training which were applicable across the specialities as these were more relevant to the development of the training intervention for this study.

There is recognition that DDN may be difficult and stressful for HCPs and that often HCPs lack the training to be able to deliver DDN news well [5, 34, 42]. Many HCPs have learnt DDN from the "see-one-do-one" approach that is limited because of the variation in the skills of the senior HCP observed by junior colleagues [32, 36]. Simulations, reflective practice, debriefing, and lectures have been used to teach HCPs how to deliver DN in the paediatric and obstetric settings [36-38, 41]. Simulations may take different forms including role plays and the use of narratives or videos of the lived experience of receiving DN to enable HCPs to identify with the emotions experienced by parents. In one study, the research team developed a training on DDN in paediatric populations by modifying the SPIKES

protocol to reflect the needs of their patient population and experiences of parents [42]. The training improved the self-efficacy of HCPs in DDN particularly those who had been practising for less than 16 years [42]. Similar findings were also reported in a randomised control trial comparing the effectiveness of simulation combined with lecture and simulation followed by debriefing on improving the DDN skills of HCPs [37]. The knowledge and skills improved for all participants but simulation followed by debriefing were superior to the lecture. A key point identified by the researchers was the importance of follow up of trainees in retaining the skills obtained from the training [37].

This approach was also advocated for by a group of researchers who developed a framework for communicating DN in the neonatal unit [38]. The training involved the use of videos, role plays, pictures and narratives from parents with the lived experience of receiving DN. The training was coupled with organisational changes such as the development of communication guidelines for HCPs to follow, regular follow-up of trainees; protocol and family meeting templates in which feedback from families was collected [38]. Although the training was very well received by the different types of HCPs working in the neonatal unit, there were no pre-and post-training data collected which would have been useful for understanding the effect of the training on self-efficacy of the trainees. However, the training content reflected some of the issues that have been identified in earlier sections as being important for the delivery of DN.

### **3.3 CONCLUSION**

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The literature indicates the significant impact of receiving DN on the emotional and mental wellbeing of parents. The process of DDN may be challenging for HCPs particularly as some may have limited training on how to deliver different news. A significant proportion of the recommendations on best practice for DDN were based on the experiences reported by families and only three studies reported the experiences of HCPs. There is need to gather more evidence from HCPs who deliver DN on their perceived training needs; what currently works well in practice; how this can be improved and the necessary organisational changes to support the effective delivery of DN. In addition, there seems to be a gap between evidenced-based guidelines on DDN and their implementation into policy and practice. This is also reflected in the fact that we only found publications from two NHS trusts which may suggest variation in the delivery of DN across NHS trusts. The review also suggests the importance of developing training which reflects the evidence available on best practice supplemented by primary

data from families and HCPs in the UK as we only found one UK study to include in this review. This approach would ensure that the training reflects the UK context. Training could involve the use of simulation so that HCPs to have a safe place to learn and practice DDN.

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## 4. PHASE 1 FINDINGS

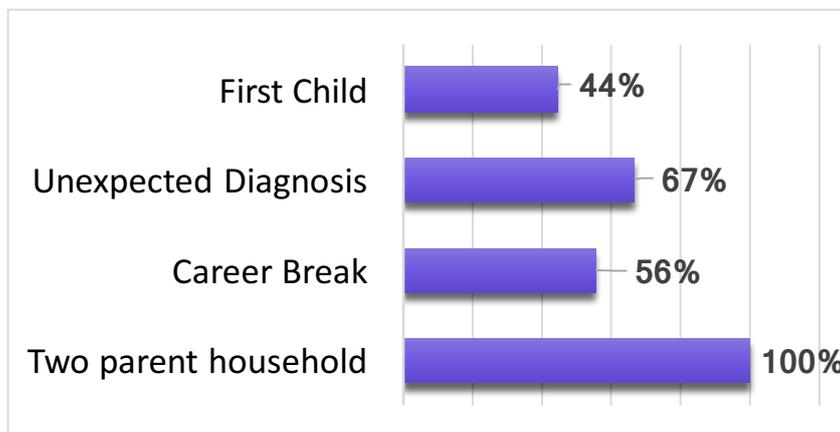
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### 4.1 DESCRIPTION OF PARTICIPANTS

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We conducted interviews with 12 HCPs who deliver DN on a regular basis and 9 parents of children who received DN during pregnancy or at birth. The professional background of the HCP's varied and included midwifery, nurses, registrars, and specialist consultants. 6 out of the 9 parents had children with Down's Syndrome and three had rare chromosomal disorders. A breakdown of the family characteristics of those parents (P) interviewed for this study is illustrated below figure 4 below:

FIGURE 4:CHARACTERISTICS OF THE FAMILIES



44% (n=4) of the parents indicated that it was their first child who had been diagnosed with a congenital anomaly but for others, it was the second or third pregnancy. 67% of parents (n=6) received the unexpected DN at birth. 56% of mothers (n=5) indicated that they had had to take career breaks to look after their children however some of the other mums were working flexibly including reduced hours or a mixture of working from home and in the workplace. All participants were in two-parent households. The analysis below highlights factors which both the HCPs and the families felt were important in DDN sensitively.

### 4.2 FACTORS TO CONSIDER WHEN DDN

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We used the TDF to identify barriers and facilitators to effectively DDN to determine what would need to be included in the training intervention so that HCPs could achieve the required change in clinical practice. Only those domains which are relevant to the study and which emerged in the data were included in the analysis. A description of the domains is in the methodology chapter. This chapter is

interspersed with recommendations for what should be included in the training as this was the main objective of the interviews.

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#### 4.2.1 SOCIAL/PROFESSIONAL ROLES

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This domain referred to the professional roles and boundaries of HCPs involved in DDN. Care for mothers during pregnancy and after birth was provided by multidisciplinary teams with each team member having specific roles and professional boundaries. In the context of DDN, sonographers identified concerns about a baby during ultrasound screening:

*So, she's (sonographer), like "Oh, I need to go and get a doctor", and there was a shadow, a black shadow, that's all there was.... ". (Parent 3)*

*She (sonographer) acted as usual and she didn't react, you know, like, oh, anything like that, but at the end she said, "I saw something that's not quite right, but I can't say anything, so I have to speak to the...to speak the doctor", I suppose the obstetrician, I can't remember um, "... and I'll let you know". So, she went out... and then she came back ....and then she said, "Yes, if you can come back at one o'clock or something". (Parent 4)*

Midwives identified concerns as part of the early baby check or if they worked as screening midwives this happened after they received the results of the combined screening test from the laboratory:

*So, I was in the middle of work and my phone went so I immediately answered it thinking that it was an [emergency], and it turned out to be somebody from the NHS, who wanted to speak to me about my test results. So, I stood outside the office to talk to them, and they immediately said, 'your test has come back with a one in twenty risk factor, we need you to come into the hospital as soon as possible', which did put me into a bit of [laughs] a panic! (Parent 9)*

In the case of the sonographers, when any anomalies were identified, professional boundaries meant that they referred the families to the doctor to discuss the findings and establish a diagnosis. When the results were delivered by the screening midwives over the phone, a follow up email was sent to the parents and they were invited to meet with the respective midwife at their earliest convenience to discuss the meaning of the screening results; receive referral to other relevant departments such as foetal medicine or to arrange for confirmatory tests or in some cases discuss the options of continuing or terminating the pregnancy.

Often, it was the consultant's responsibility to establish the diagnosis and communicate this to the parents either during pregnancy or shortly after birth. Parents indicated that confirmation of the diagnosis was given after the results of the karyotyping or other relevant investigations:

*You can't say, yes, your baby has Down's, until the chromosomal test is back and that's quite difficult because the parents want a definite and you can only say it's suspicious of and that sort of thing and I personally found that quite difficult. (HCP1)*

Several parents indicated that they respected the opinion of their HCPs and particularly held the consultants in high regard:

*When someone in a medical position like that tells you, you tend to believe them. (Parent 1)*

In view of this, parents who were unsure about terminating a pregnancy asked their HCPs about what they would do if they were in the same situation. It was therefore important for HCPs to use this positional power to support the parents no matter what they decided. It was not just what they said when they delivered the DN that parents felt was important but how they said the information as well as how they treated the parents if their decision was contrary to the clinicians' expectations.

Given that often the medical condition was new to most parents; parents relied on the HCPs for accurate up to date information about the medical condition in question. Participants felt that it was important for HCP's to demonstrate a level of professionalism by preparing adequately before communicating news about a condition to families. Both HCPs and parents felt that the informing clinician needed to be knowledgeable about the condition and if they were unfamiliar with the condition there was an expectation for them to have some basic level of self-education in anticipation of the questions which could be asked by parents rather than expecting them to find out answers on their own:

*He gave us a print-out of the diagnosis, which Ezekiel's is a duplication on part of his Chromosome-XXX, it hasn't got a brand name, it's just a lot of numbers and meant nothing to us basically. He said to us that he'd only had it through recently via fax, hadn't had a chance to look at the diagnosis really himself, didn't really know much about it, and gave us a leaflet of a charity ....and pretty much, we were left to google it. (Parent 2)*

*I think it's like you as a clinician, if you're prepared...before you see the patient, so you are, like you're able to answer their questions about like what's the meaning of chromosomes, erm, or like what's the mean... what investigations will they have to have or what, what complications does it mean. (HCP 3)*

It was clear in the data that consultants and other senior clinicians had the professional responsibility to provide junior staff with the opportunity to learn from their practice. However, there was some suggestion for this aspect of the professional role to be balanced with sensitivity to the needs of the families. For example, one parent felt that the incessant visits to examine them and their baby by the consultant and the medical students made them feel like they were a case study and they did not want to be one:

*She was doing the scan and then she was showing the students like, you know, this is my tummy, and she went like that [demonstrates to interviewer] and telling them, this is, you know, eyes or legs or, and she was describing my baby, it was my baby and she was speaking like, I don't know, an object there. And when I explained to the midwife, I said to her, "Look, I understand.... when it's a case you will study the case and it's interesting, but I'm not a case and my baby is not a case.... (Parent 4)*

In terms of social and professional roles, it would be important for the training intervention to support the fact that care is delivered by a multidisciplinary team and emphasise the value of the different professionals and their specific role in the delivery of DN. It would be important to also identify ways to improve each aspect of the process from the time that concerns are raised to the time that an official diagnosis is provided by recognising that these are not discrete events but are all part of the process of DDN.

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## **4.2.2 KNOWLEDGE, SKILLS AND BELIEFS ABOUT CAPABILITIES**

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This domain referred to the perceived knowledge and skills to deliver DN. Experience and competence were described by participants as factors which either enabled or hindered effective delivery of DN.

### **A. EXPERIENCE**

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A lack of experience was perceived as one of the main barriers to effectively conveying DN by HCPs:

*The more opportunities you have to break news like this, I think the more er, the more comfortable you become at changing your approach during the consultation, as a junior, you are, it's very easy to become tongue-tied because you just don't want to say the wrong thing... (HCP 10)*

*Reading the triggers, reading, because so much of it focusses on sort of watching and listening and observing, um, and just kind of picking up on cues which I guess only comes with experience. (HCP 12)*

The above discourses suggest that the more experience a HCP had at DDN the more likely it was that they improved their technique at this important aspect of their job. Although HCPs indicated that experience was an important aspect of being able to deliver DN effectively, the data also showed that even among the most experienced in terms of years of practice or clinical ranking, there was significant variation in how DN was delivered. Some senior clinicians were described as being very good at DDN well and others were described as needing to improve how they delivered DN.

### **B. COMPETENCE**

HCPs often indicated that they had received communication training either as part of their undergraduate or postgraduate training. This was often described as generic communication training with a small component of delivering difficult news. Only one participant indicated attending a DDN course which was offered as part of mandatory training by the deanery that was providing them with postgraduate training. Acquisition of knowledge and skills on DDN was generally based on observing more senior colleagues:

*We all do this based on, on experience, although there are breaking bad news courses, we don't encourage junior doctors to just do the consultation on their own, so what happens...the, the way the training works is they come with a consultant, so when we are doing the consultation they come with us and they observe us... (HCP 11)*

Although this is a common form of learning in clinical practice, it had limitations if the senior clinician was not perceived as being very good at DDN. This variation in the style of DDN by senior colleagues mentoring junior staff could be overcome by having standardised evidenced-based guidelines, policies or protocols. However, most HCPs were not aware of any locally developed policies or protocols specifically on DDN:

*I think there probably isn't a protocol, or if there is, it's certainly not even shown to anybody or talked about ever. (HCP 3)*

*I don't know, is there [both laugh], we have hundreds, we have [both laugh], we have, as you probably know we have frighteningly 150, 200 different protocols.....and I don't think I've seen that one there. But I'm not saying there isn't one. (HCP 6)*

*Not that I'm aware of, yeah..... I'm not aware that there's guidance in our trust. I think it's probably a good idea to have some guidance, yes. (HCP 1)*

No matter how skills or competence were acquired, all participants felt that it was important for HCPs who deliver DN to be adequately trained to do this sensitively and to also be able to provide effective support to parents and/or referral to appropriate services. Participants highlighted several skills which they perceived as important for DDN. These included being compassionate and being empathetic:

*You could tell that he (paediatrician) genuinely cared, he included Ezekiel in the conversations...I find that some paediatricians, weirdly, are not [pause] children friendly, strangely, erm, and will just talk about them, won't even really acknowledge them apart from when they're examining them. (Parent 2)*

*He sat down with both me and my husband and, and, he was really lovely and, he wasn't upset but you could tell that he, he really cared about our little boy .... he was the one who'd done, he'd done an echocardiogram on him so he knew that he was going to face some challenges and that he'd need, uh, a heart operation and he said that, you know "your lovely little boy is just going to need some extra help" and, um, he was, yeah, he was just really genuinely caring and, um, very kind in how he put, put the news. Because it is, it is a really hard thing to tell somebody that your child has been, that you kind of, also I think because we'd already other children and they were born without Down's syndrome and so you're kind, when you, when the next one arrives and you're not expecting it, it is more of a shock I think. So yeah, he was, he was really great. (Parent 7)*

*So she was kind of sat over a little bit, sort of bent forward and she was talking quite quietly to us and making sure that we understood what she was saying at all times actually.....so I think in that respect actually the way she went about it was quite, was quite good you know, she made sure we were sat down, that both me and my husband were there and that we were by where my son was as well so we were right by the incubator so we could see my son at the time (Parent 5).*

The above parents highlighted how the compassionate attitude of their HCPs which balanced being truthful and kind was important when they received their unexpected DN. Participants also highlighted the importance of the HCP being tactful in their choice of words as well as their non-verbal language which could be misinterpreted for blaming parents or making the birth of their children regrettable:

*And then the next day we had the main paediatrician .... one of the first things he did when he walked in the room, he came in with his hands behind his back which was just obviously his stature, how he walks, and he stood up straight and he looked at me and he looked me up and down, and then he said, "How old are you?" and I said, "Erm, well I'm 31 now, but I was, you know, I was, you know..." whatever age when I conceived or what... you know, I was sort of felt like I was having to justify like, and then he looked at my husband and said, and looked him up and down and he said, "And how old are you?" and then he looked at my daughter, and looked at her, and that, and I was like, "Oh," and then he said, erm, "And what was your score, what was your score for Down's Syndrome?" and I said, "I don't know, they didn't give me a score," I said, "that it was just high or low risk." (Parent 8)*

*The one thing, um, it wasn't giving bad news as such but talking about, um, this was a woman, a young woman, she was there with her mother and partner and she'd got a very small baby with Down's Syndrome and, um, so they had come to talk about further screening and I said, oh, you know, if you want another test to, um, you know, find out the risk of this happening again, and then of course, that was it, the consultation just pretty much ended there when the grandmother said, "Well, why are you saying the risk of this happening again? We wouldn't mind if it happened again, this would be absolutely fine." Um, and, you know, everything broke down at that point, I had to go and get someone else in because I'd said the wrong words... (HCP 12)*

*Instead of saying 'you have a one in a hundred risk of having a Down Syndrome baby', we're supposed to say, 'a one in a hundred chance' and that's come from a patient who has said that the word 'risk' has too many negative connotations, and I actually agree with that (HCP 3)*

The discourses above highlight how the use of inappropriate words or non-verbal language affected the HCP-patient relationship and in some instances resulted in the degeneration of the relationship. Several parents felt that having a child with DS should not be perceived as a negative regrettable experience although they acknowledged that it had its challenges. They also felt it was important to emphasise the joy that a child brought and not merely focus on the diagnosis.

The interviews also highlighted the importance of the HCP understanding the immediate psychological and emotional impact of receiving DN on parents. Parents reported having different emotions including acceptance, shock, guilt, shame and deep sorrow. These feelings could be fleeting but in some instances lasted beyond the hospital stay and even affected the couple relationship or relationships with various HCPs for a significant amount of time:

*Paul and me didn't really respond very much to each other for a long time, even talk to each other.....I had very severe postnatal depression...for probably two years.....Paul called it two years of hell ....Because every time he spoke to me I'd either be crying or shouting or crying, I had a baby that was covered in, you know, that I would have to change six, seven times a day because he was just sick all the time, and it was my fault because my body did it. (Parent 3)*

*So certainly for 24 hours we just didn't know what to do with ourselves, we were literally and then we were just like we want to announce that we've had a baby but like how... What do we say, how do we explain that to everybody? Um, my husband, my husband told or went to see my parents and told, told them and just felt awful, you know, he was like, oh I feel, I felt bad and I felt really guilty telling them this and we kind of... We kind of both felt like we'd done something wrong. (Parent 5)*

*It was like I was in a film and all these things were happening in front of me, very unreal and very painful. And when they say that, I started to cry and I say, "Oh, is it because of my age"....and so I realised later oh I was blaming myself, but I know now that it could happen to any woman. (Parent 4)*

*I think if I could have, if I could have physically run away at that point I would have but I obviously couldn't (laughs).... I think I just wanted to like get away from everything, but I don't think that was because of how she kind of told us it, I think actually she told us it in a very, in a very nice way. (Parent 6)*

Only one parent reported immediate acceptance after the news was delivered to her because she had known someone with a similar condition to their child who had done reasonably well in terms of their health, development and family life. All the other parents reported that the news had some kind of negative emotional impact on them shortly after receiving it. The above accounts highlight the importance of HCPs having a caring, compassionate attitude to minimise the negative impact and to enable parents to access ongoing support or referral to other appropriate support.

In terms of competence and experience, it would be important for the training intervention to include the lived experience of receiving DN as this would give HCPs an understanding of the impact of how DN is delivered as well as insight into the general impact of the news on a family. It would also be important to address health communication and sub-topics of value-based language and delivering the news in a balanced manner. Developing skills of empathy were also identified by parents as being crucial. Many of the parents interviewed noted that they did not want pity nor did they want a cold detached delivery of their child's condition, but rather a delivery which demonstrated a professional

level of understanding of what they were going through. It was also suggested by both HCP's and parents that future training included the opportunity for HCP's to practice what they are taught via role play or practical experience, therefore, allowing for a more tactile learning approach.

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### 4.2.3 ENVIRONMENTAL CONTEXT AND RESOURCES

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Privacy and time were highlighted as important factors for effectively DDN.

#### A. PRIVACY

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Certain scenarios in which DN was delivered by HCP's and/or received by parents was impacted by the limitations imposed by the health setting. For instance, a number of HCP's noted that hospitals did not have the physical space to accommodate the delivery of DN privately:

*There just isn't logistics of space within a busy NHS hospital to have the privacy to make those phone calls, that's something I find really difficult....one of the hardest things if I'm telling the parents their baby's got some condition and then someone will just storm into my office and, you know, make a cup of tea or something. If I was face-to-face with that couple in a little room, um, no-one would walk in and make a cup of tea in the background but no-one thinks twice about it when I'm on the phone. (HCP 12)*

*I think maybe, erm, if we'd been in a private room away from kind of being in the intensive care unit that might have helped in some respects because we would have been able to kind of you know, erm, cry or talk about it but because we were like ...in NICU, I felt I had to hold my emotions in, that I couldn't kind of just you know...I think you know, if, if I could go back and do it again I would have asked that we could have been moved, or we could have been in a room where we could have been left to just, to process ourselves rather than being in the intensive care unit. (Parent 6).*

*It's, unfortunately, it's not ideal cause we are really, we haven't got a lot of space on our unit, but unfortunately it all has to be done within the unit where there's still work going on.... (HCP 6)*

However, several participants reported that after the news was delivered postnatally, parents were often given their own space away from the other babies and sometimes looked after in the bereavement suite. Parents expressed mixed feelings about this. While in some instances this gave them the privacy to process their own emotions, being in a bereavement suite also reinforced the negative connotations of the birth of their child:

*So, erm, so, it's a bit of a double-edged sword. We were moved into a room by our self, which was good because me and my husband literally as soon as we got in that room we just cried and hugged each other, we literally just like cried, and just held each other tight and then we talked about things.....and then, my husband, the hospital allowed my husband to stay on a mattress on the floor in my room so that we were able to stay together, overnight, that was one good thing about being in the room. It did feel a little bit like we'd been, because they put us at the room right at the end of the corridor so it did feel like we'd been shoved right out of the way as well, like nobody really wanted to have to go past us or like speak to us at all, it did feel a little bit like that at times, like if we put them out of the way at the end of the corridor then we just don't have to kind of have the conversations with them, they can't just catch us as we go past, it did feel like that at times, like if we shove that problem out of the way it goes away, so it felt like that a little bit. (Parent 6)*

## B. TIME

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HCPs reported that they often had a significant number of patients they were looking after which sometimes hindered a more personal and patient centred approach:

*There are other babies which need delivery as well, so you are concentrating on other babies...so that is very challenging, and you just apologise to the patient .... "I am very sorry, I have to, go for an emergency, and will come back." (HCP 4)*

In the scenario above, it was beyond the HCP's control that they were needed for another emergency however, a protocol could have been in place for another HCP who knew the family to take over from them and respond to any questions the family had. Several narratives from the parents indicated that they thought it was important for the informing HCP to have time to answer questions after the diagnosis or to be available to answer the questions they may have as they processed the news they have received. Parents valued HCPs who made time for this especially if they had an ongoing relationship with them:

*And there might be a waiting room outside and you know that there are other people that are waiting but he always gives you the impression that he's got time, so nothing is rushed, he doesn't sit there looking at this watch. He doesn't keep like hurrying you along, he doesn't try and cut you off. (Parent 2)*

Time in this study not only referred to availability to discuss the prognosis with parents but the actual time at which the HCP decided to deliver the news:

*Is she ready to handle the news on 2 hours sleep without her husband here when her child is obviously being checked for things? (Parent 5)*

*I did feel that the doctor who delivered the news at XXX Hospital, that they felt that my baby had the signs of having Down's Syndrome, I felt that was done very sensitively and I was, I was happy with the way they did that, although I would have preferred that my husband was with me at the time and that I wasn't on my own [laughs] in the hospital having just given birth, feeling a bit isolated. (Parent 9)*

Both Parent 5 and Parent 9 reported that they would have preferred that the HCPs had delivered DN when they were not tired, alone and with their spouses absent. In another example, the HCP did not take into consideration both the need for a private space or the appropriateness of DDN within minutes of the child's birth:

*... maybe if she'd have waited a bit or gone out of the room and thought about it before she said what she said..... And just given us 20 minutes, or something.... but it was literally, if you can imagine, so you've got Zoe lifted up, shown she's a girl, said, "Do you want to tell your husband what it is?" so they then carry her off and I go, "It's a girl Zech, it's a girl," he burst into tears, happiness, and then I look around for someone's trying to get my attention, and she's like, "Oh, you know, your baby's got all its fingers and toes but I think she's got Down's Syndrome," and it's like it all happened, just like, and...Zoe's over there now with other people and I'm like, and there's just all these people looking at me that they're gonna get ready to stitch me up, and, you know ..... So, I'm still sort of like looking at everybody looking me, waiting for me to.... I don't know, do whatever they want me to do. (Parent 8)*

Parent 8, made the point that the news was given abruptly, there were no immediate medical emergencies which had to be addressed for the child and she felt that there was no need to tell her life changing information within minutes of her baby being born, in the presence of many other HCPs and most importantly before she had been given the opportunity to see and hold her baby for the first time, feed her daughter and bond with her. In a contrary scenario, the consultant noted some markers for Down's Syndrome however they dealt with the medical emergencies first and raised their concerns about Down's Syndrome when the baby was three days old:

*Um, so he was in the neonatal ward, bless him, and he was in an incubator because they were trying to keep him warm and they kept, um, and because his oxygen level kept dipping because he had this hole in his heart and so there was a lady, I think she was a locum, it wasn't one of the people that were generally on, on and she came in and she noticed that Chris had quite a flat sort of back, his back of his head was quite flat, um, and she was obviously kind of putting the pieces together and the heart, well*

*at that point we didn't quite know that he had a heart problem but the fact that he was struggling to keep himself warm and that his SATS were dropping and things like that. I think she noticed his almond shaped eyes and so she had her kind of concerns that, that Chris was born with Down's syndrome and it hadn't kind of been voiced, but I mean it was only three days into him being here, bless him, so, um, so she kind of, she said to us about it and said "I'd like to do a blood test... (Parent 7).*

It is important to note that medical concerns for the mum or baby created scenarios in which communication was abrupt or non-existent from HCP's in an attempt to deal with the emergency at hand. However, where there are no immediate life threatening emergencies for the mother or the babies, parents felt that it was important for the HCP to take time to prepare themselves to deliver the news by finding a private place to deliver the news; considering the most appropriate time of the day to deliver the news, bearing in mind the importance of including significant others such as a spouse and to have time to answer questions or identifying someone to take over if they knew that they would potentially be required to attend to other patients. Assessing the physical and social environment prior to DDN was perceived as a critical component to minimising the negative impact of receiving DN.

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#### 4.2.4 OPTIMISM

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Optimism referred to HCPs being able to reassure parents by providing a balanced description of congenital anomalies. All but two of the parents interviewed noted an unbalanced delivery of their child's condition by HCP's. It was important to parents and HCPs that the HCP had the skills to provide a balanced description of the medical condition as they felt it enabled them to have hope and a positive outlook on their children, to see past the diagnosis which their child had been given and to make an informed decision about continuing or terminating a pregnancy as indicated in the narratives below:

*We do need to be careful what we say, we do need to get that balance right, we do need to support the women in whichever choice they do] .....I think there is a movement around saying, making sure that women are aware that, actually, termination isn't the only option.... (HCP 2)*

*They were very, you know, "We recommend you terminate", not as in, "If he survives, he may have these problems", there wasn't any of that, it was, "We recommend you terminate and this is what happens", rather than, you know, "If he survives he may not be able to do this, this, this and this", it wasn't a balanced conversation. (Parent 3)*

*We've been really lucky to have a lot of positive sort of attitudes towards, our son and his Down's syndrome. So, I think, I think it's really important to kind of recognise the person first, not just the fact that they have Down's syndrome (Parent 7)*

*I can tell you so many families are the same, they just, you never forget what is said to you, and you over analyse everything because you're trying to work it all out, and if there's anything that makes you question yourself, you'll, you'll just play it over and over again and it's, it's really important that things aren't said in an excitable way, or a negative way, just, just that's this is what it is and, you know, it's gonna be okay, like, you know, you can get around it, we can, you know, there's things for you to, but it, it's not at the moment it's all quite doomy and gloomy. (Parent 8)*

While HCPs felt that it was important to be able to provide parents with information about the condition their child had been diagnosed with, it was important that this was given in stages as some parents mentioned being overwhelmed and unable to take in the large amount of information provided to them. It was very important to parents, that HCPs provided a balanced description of their child's diagnosis and its implications both in the short and long term future without an overemphasis of negative things which may or may not happen in the future such as developing Alzheimer's disease. Parents felt it was unfair to discuss such issues for children with DS for example and leave discussion of similar matters with parents of neurotypical children who could well have a family history of similar diseases and potentially have a genetic predisposition to this. Parents with lived experience stressed the need for the training intervention to highlight some of the challenges as well as the joys of having a child who was diagnosed with a congenital anomaly.

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#### **4.2.5 BELIEFS ABOUT CONSEQUENCES**

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We discussed in earlier sections the negative impact of receiving DN and how this could be exacerbated by the news being delivered inappropriately. Beliefs about consequences also referred to the impact of how DN was delivered on the HCP-family relationship. It is important to note that a number of parents in this study indicated that they had made formal complaints about how they were given the news:

*Yeah, I mean the first time I, I did actually make a complaint about the way the news was delivered to me, because I felt that nobody had asked what I was doing at the time or, you know.....if I was in a place that was... ..safe for me to be given that information, and I also felt that the way it was given*

*over the phone and erm the urgency that I had to come to the hospital as soon as possible, it, it put me into a bit of a panic which there was no need for. (Parent 9)*

*So, at that point, I was very upset, er, and eventually, it led me to make a complaint to the Patient Advice and Liaison Service at the hospital, and we were transferred to another paediatrician. We got an apology for the way that we had been treated, but it just makes you wonder how many other people have had that same experience? (Parent 2)*

*In fact, she made a formal complaint and she was then seen by a Consultant and that was sorted, most people don't, it's enough for them to talk to us, which actually doesn't help in the long run because I can complain, I can email and I've done it in the past, I've emailed Consultants saying 'this is what your doctor said to a patient' and nothing changes unless the patients complain, but they don't complain, they very rarely do complain, because they've talked to us and we've made them feel better. (HCP 3)*

Making formal complaints was motivated by the need to protect other parents from receiving a similar standard of care. It is therefore important for the training to highlight that the negative impact of DDN can also affect the HCP in question as well as the trust as a whole in the event of complaints being made about how DN was delivered.

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#### 4.2.6 EMOTION

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Several HCPs indicated that DDN on an ongoing basis affected them emotionally and that sometimes the effect of the conversations lingered for years after the event:

*I don't think you could ever not be erm affected by it, especially if you have the ability to be empathetic and put yourself in that, because you think 'oh my God, if that was my baby how would I feel', yeah... training to help people put themselves in other people's positions to think to themselves 'how would I feel if that was me or that was my daughter or my sister or my mother or', you know. (HCP 3)*

*I have gone into that woman's world completely unannounced and I've destroyed it...I have walked out of a feticide and absolutely broken my heart .... but it's part of the job, isn't it? (HCP 2)*

*It affects me, of course, ...but I have to accept that this is my job (HCP 4)*

While some NHS trusts were said to have facilities in place for team debriefing or counselling this was not a universal experience among the HCPs. It would be important for the training to support HCPs to identify ways to acknowledge and manage their own emotions about DDN. This aspect of managing

their own response and mental wellbeing is important in enabling HCPs to build emotional resilience so that they can effectively meet the demands of DDN and provide parents with good care.

### 4.3 SUMMARY OF PHASE 1 FINDINGS

How DN is delivered can impact upon the parent’s ability to cope, the parent-child relationship, the parent’s relationship with one another and the relationship between the family and professionals. For this reason, it is important that the training equips HCPs to demonstrate empathy, show compassion; learn to be flexible with time or plan around the demands of their ward; utilise kind, simple and truthful language; offer sufficient time to answer questions and ensure timely referral to relevant services as required by parents. The key components of DDN are detailed in table 2 below:

TABLE 2: KEY ASPECTS OF DDN

Key Aspects of the Training	Working Definition
Planning	Assessing the timing and setting in which the news is delivered
Professional Conduct	Demonstrating tact and a level of preparedness.
Balanced	Delivering a balanced description of the condition (i.e. need to ensure that women are aware that screening and termination are not the only options)
Language	Communicating with value based language.
Emotional & Mental Wellbeing	HCPs need to understand the impact of the news on families as well as the impact of how it is delivered on families. HCPs need to also be aware of their own emotions resulting from DDN and be able to manage these emotions constructively.
Identify Support Needs	HCP would need to provide ongoing support to families immediately after delivering DN and to provide referrals to appropriate local support which the families could access. HCPs need to also be able to identify times when they may need additional support from their team in DDN.

## 5. INTERVENTION DEVELOPMENT

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### 5.1 DEVELOPMENT OF THE TRAINING INTERVENTION

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Using findings from the literature review and interviews with HCPs and parents, we developed a training intervention for DDN. Drawing on the BCW and other previous studies [16, 17, 56], the following steps were taken to develop the intervention:

- Step 1: Delineating key intervention components. This involved an initial discussion of key intervention components based on findings from the literature review and specifications of the requirements from Health Education England working across Kent, Surrey and Sussex who were funding the study.
- Step 2: Mapping barriers to and enablers of the implementation of the intervention to the theoretical domains framework. Data from the parent interviews, HCP interviews, and the literature review were analysed with the intention of identifying the barriers to efficient delivery of DN and the enablers to this.
- Step 3: Identifying potential intervention components that can overcome modifiable barriers and enhance the enablers within a future intervention. This involved examination of the COM-B model and the Behaviour Change Taxonomy to identify the functions of the intervention required and the corresponding evidenced based behaviour change techniques which could achieve the required functions. This was then adapted to the context of DDN. The study team met to agree on the final content of the intervention.
- Step 4: Ensuring the viability of the intervention using APEASE (Acceptability, Practicability, Effectiveness/cost-effectiveness, Affordability, Safety/side-effects, Equity) [56]. The study team and the steering committee members met to determine if the intervention was robust and fulfilled relevant criteria and if this could be implemented.

Based on the above process, we outline the key components of the training intervention in table 3 below:

TABLE 3: INTERVENTION COMPONENTS

COM-B	Relevant TDF		Barriers which need to be addressed in the intervention.	Intervention functions	Behaviour Change Techniques	Intervention Components
			Facilitators which must be enhanced			
Capability	Physical Capability	Knowledge, Skills, Memory, attention and decision-making process	<ul style="list-style-type: none"> <li>• Lack of up to date information about the genetic condition.</li> <li>• Lack of knowledge of the positive lived experience of raising children with a condition associated with a learning disability.</li> <li>• Lack of Trust policy or guidelines on how to break news or support.</li> <li>• Unfamiliarity with the family</li> <li>• Lack of interpersonal skills</li> <li>• Lack of communication training.</li> <li>• Lack of skills on initiating the conversation.</li> <li>• Lack of experience in delivering different news.</li> <li>• Lack of skills to determine how much information to give parents and when.</li> <li>• Lack of knowledge about support available or appropriate signposting.</li> <li>• Insensitivity about parents' feelings or grief and using the child incessantly for teaching.</li> <li>• Good interpersonal skills</li> <li>• Good choice of words</li> <li>• Ability to learn new skills and retain the information</li> </ul>	<ul style="list-style-type: none"> <li>• Training</li> <li>• Education</li> <li>• Persuasion</li> <li>• Modelling</li> <li>• Enablement</li> </ul>	<p>5.1 Information on health consequences-</p> <p>4.1 Instruction on how to effectively DDN. Training needs to empower HCPs on appropriate language to use.</p> <p>5.2 Salience of consequences -HCP needs to be aware of the long term impact on the emotional response and mental health of parents of how DDN is delivered.</p> <p>5.4 Monitoring of emotional consequences of poor DDN.</p> <p>6.1 Demonstration of behaviour on how to deliver the news effectively.</p> <p>8.1 Behavioural practice or rehearsal including practising how to deliver the news sensitively.</p> <p>8.3 Habit formation- Encouraging HCP to use the skills on a regular</p>	<p><b>Within the training the following are important</b></p> <p><b>Language</b> - HCP needs to carefully choose words which:</p> <ul style="list-style-type: none"> <li>• indicate the unexpected nature of the news.</li> <li>• the current medical concerns that they have.</li> <li>• the medical procedures which need to be performed</li> <li>• Support available</li> <li>• Explain what diagnosis means</li> <li>• using language that values the child; validates the parents and makes a balanced informing interview.</li> <li>• Non-verbal language must be respectful.</li> <li>• Concrete examples of appropriate language.</li> </ul> <p><b>Professional conduct:</b> HCP needs to:</p> <ul style="list-style-type: none"> <li>• be empathetic and not sympathetic i.e. no pity or condoling</li> <li>• empowering -acknowledging concerns about the child but offering hope.</li> </ul>

					<p>basis in order for habit formation to occur.</p> <p>9.1 Credible Source-Involving parents who have had DN delivered well and then delivered inappropriately.</p>	<ul style="list-style-type: none"> <li>Supportive</li> </ul>
			<ul style="list-style-type: none"> <li>Competing demands-busy ward</li> <li>Short clinic times</li> <li>Lack of private place for delivering different news</li> <li>Medical emergencies for the mother or the baby.</li> <li>Breaking news in the absence of a partner</li> <li>Lack of policy or protocol to guide the course of action.</li> <li>Ability to link families with children with similar conditions who can support the new parents.</li> </ul>	<ul style="list-style-type: none"> <li>Restructuring of the environment.</li> <li>Education</li> </ul>	<p>1.2 Problem solve-Enable the HCP to be able to analyse the situation and select strategies to deliver the news well against the backdrop of competing demands.</p> <p>1.4 Action Planning- HCP needs to be able to plan their action and conversation before DDN.</p>	<p><b>Training needs to raise awareness about timing:</b> HCP would need to assess:</p> <ul style="list-style-type: none"> <li>Mothers physical and emotional state-Is this the best time to deliver the news?</li> <li>Baby's physical condition and any immediate medical needs which parents have to consent to before they can be conducted.</li> </ul>

Opportunity	Physical Opportunity	Environmental Context and Resources			<p>15.2 Mental Rehearsal of how to DDN sensitively.</p> <p>12.1 Restructuring the environment, for example, advising NHS Trusts on longer clinic time; development of policies and or protocols on how to DDN.</p> <p>12.5 Add objectives to the environment -Develop some short points to remember for HCPS. In addition to the usual clinical information given after diagnosis also give other books from the CDG to give to parents.</p>	<ul style="list-style-type: none"> <li>HCP needs to decide when to provide details about short term medical procedures which need to be performed and when and or how to discuss potential long term impact or medical need associated with the condition</li> <li>Training must enable HCPs to appreciate key factors that need to be considered when it comes to when to break the news including looking at the time of the day; presence or absence of a partner; availability of a room for privacy; presence of other HCPs; having sufficient time to provide the news and answer any questions?</li> </ul>
	Social Opportunity	Social influences	<ul style="list-style-type: none"> <li>Concerns about giving patients false hope.</li> <li>Need to follow Trust policies for example results only delivered over the phone.</li> <li>Ability to learn how to deliver news from modelling.</li> </ul>	<ul style="list-style-type: none"> <li>Education</li> <li>Training</li> </ul>	<p>12.5 Add objectives to the environment-Links to families with children with similar conditions. In addition to the usual clinical information given after diagnosis also give other books from the CDG to give to parents.</p>	<ul style="list-style-type: none"> <li>Training could also look at some of the positive experiences of parents who have received DN- from study findings or videos or parent voice so that they can provide a balanced informing interview which does not focus on all the things the child will be unable to do or the health problems they will have.</li> </ul>
		Social/Professional role	<ul style="list-style-type: none"> <li>HCPs may feel that it is unethical not to give full details about the condition.</li> <li>Good understanding of the condition and able to answer questions.</li> </ul>	<ul style="list-style-type: none"> <li>Education</li> <li>Training</li> <li>Modelling</li> </ul>	<p>13.1 Identification of self as role model-Trained HCP to be role model.</p>	<ul style="list-style-type: none"> <li>Training must address how to gauge when to discuss prognosis; parent readiness; considering giving information in stages, giving parents room to grieve if they want</li> </ul>

Motivation	Reflective Motivation		<ul style="list-style-type: none"> <li>Respecting patient autonomy</li> </ul>		<p>13.2-Reframing/Framing- Adoption of the perspective of how DDN will be replayed in the minds of parents.</p> <p>6.2 Social Comparison-Include examples of how other doctors deliver DN well- Examples from quotes or otherwise.</p>	to; being truthful but working with where the parents are.
		Beliefs about capabilities	<ul style="list-style-type: none"> <li>Inability to control the social environment in the event of emergencies.</li> <li>The desire to improve in this aspect of their work and undertake continuous relevant additional training.</li> <li>The perception that practice and training will improve DDN.</li> <li>Ability to value the life of the child.</li> </ul>	<ul style="list-style-type: none"> <li>Training</li> <li>Education</li> <li>Modelling</li> </ul>	4.1 Instruction on how to perform the behaviour-How to DDN sensitively.	<ul style="list-style-type: none"> <li>Training on how to do this well as detailed in the previous section.</li> </ul>
		Optimism	<ul style="list-style-type: none"> <li>Pessimistic about the condition.</li> <li>Unrealistic optimism.</li> </ul>	<ul style="list-style-type: none"> <li>Education</li> <li>Persuasion</li> </ul>	1.4 Action Planning-HCP needs to prepare to discuss their concerns with family having looked at national guidelines on a condition and current opinion; hospital policies etc. and not tell patient that they do not know about the condition.	<ul style="list-style-type: none"> <li>Training must encourage HCPS to keep up to date with information about various conditions so that they are able to respond to the questions parents must have.</li> <li>Training needs to emphasise the need for HCPs to be truthful but kind.</li> </ul>
		Beliefs about consequences	<ul style="list-style-type: none"> <li>Lack of understanding of the impact of the way DN is delivered impacts families.</li> <li>Large focus on the negative impact of the condition.</li> <li>Perceiving baby as a problem which needs to be fixed by termination.</li> <li>Enabling the family to see past the diagnosis and the enjoyable life they can have with the baby</li> </ul>	<ul style="list-style-type: none"> <li>Education</li> <li>Training</li> <li>Modelling</li> <li>Enablement</li> </ul>	<p>9.1 Credible Source- Having a parent discuss how the way DN was delivered to them impacted them.</p> <p>Having a well-known or respectable HCP discuss the impact of poorly delivered DN on family and child.</p>	<ul style="list-style-type: none"> <li>Training must include delivering a balanced interview discussing what is known and what may be unknown.</li> <li>Training must also look at the possible impact of the DN on the parent if the news is delivered well.</li> <li>Training needs to enable the HCP to put themselves in the place of the parent.</li> </ul>

		<ul style="list-style-type: none"> <li>Using clear plain language.</li> <li>Understanding the unexpected nature of news to the family.</li> </ul>		5.2 Salience of consequences- Using memorable ways for training to ensure that HCPs are aware of the consequences of poor DDN.	
	Behavioural regulation	<ul style="list-style-type: none"> <li>Feedback from colleagues to help improve practice.</li> <li>Obtaining training to prevent relapse to poor practice.</li> </ul>	<ul style="list-style-type: none"> <li>Education</li> <li>Modelling</li> </ul>	2.3 Self-monitoring  2.7 Feedback on outcomes	<ul style="list-style-type: none"> <li>Feedback- Training to emphasise how HCPs can monitor how well they are doing.</li> <li>HCP being able to obtain feedback from parents on how the news was delivered to them.</li> <li>HCP may also be able to obtain feedback from colleagues on how well they delivered DN as well as obtain restorative supervision.</li> </ul>
	Goals and Intentions	<ul style="list-style-type: none"> <li>Ability to plan the conversation with the parents before speaking to them.</li> <li>The desire to provide good care for patients.</li> </ul>	<ul style="list-style-type: none"> <li>Education</li> <li>Training</li> <li>Persuasion</li> </ul>	1.4 Goal planning.	<ul style="list-style-type: none"> <li>As discussed earlier.</li> </ul>
Automatic Motivation	Reinforcement	<ul style="list-style-type: none"> <li>Punishment in the form of complaints from parents if the news is delivered inappropriately.</li> <li>The inability for parents to provide feedback after diagnosis due to busy family schedules.</li> <li>Parents providing feedback on how DN was broken.</li> </ul>	<ul style="list-style-type: none"> <li>Education</li> <li>Modelling</li> </ul>	10.1 Future punishment	In addition to discussing the negative impact of poor DDN, training may also discuss issues of complaints etc.
	Emotion	<ul style="list-style-type: none"> <li>Lack of empathy</li> <li>The news is also unexpected to HCP.</li> <li>Tiredness, busyness, having a bad day.</li> <li>Grief, guilt, pain –the cycle of grief which parents may go through.</li> <li>Ability to be humane.</li> <li>Opportunity to debrief with colleagues performing a similar role.</li> </ul>	<ul style="list-style-type: none"> <li>Education</li> <li>Environmental restructuring</li> <li>Training</li> <li>Modelling</li> </ul>	11.2 Reduce negative emotions	<p>Training needs to emphasise the importance of <b>Support:</b> HCP needs to assess</p> <ul style="list-style-type: none"> <li>the family needs for support.</li> <li>their own needs for support and of debriefing.</li> <li>Provide links to resources if requested or suggest these without forcing.</li> <li>Be able to recognise when they need to debrief or additional support</li> </ul>

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## 5.2 TRAINING CONTENT

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### 5.2.1 TRAINING AIMS AND OBJECTIVES

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The training aimed to enable healthcare professionals to understand the short and long term significance of non-verbal and verbal communication for parents emotional and mental wellbeing when DN is delivered.

By the end of the training participants were expected to have:

- Recognised the importance of establishing the right physical, emotional, social and environmental space to deliver different news.
- Gained understanding of the importance of planning before DDN including identifying the appropriate time to deliver the news, choosing the appropriate language to use and the appropriate information to give at initial and follow up discussions with the family.
- Become aware of resources which may be available locally and nationally for parents which can help them process, understand and interpret the diagnosis.
- Recognised the importance of regular personal support and feedback on the delivery of DN and how this contributes to their own mental wellbeing and CPD.
- Gained an understanding of the importance of shared responsibility for the immediate and ongoing care and support of the family.

The training was aimed at:

- Paediatricians/Neonatologists or Specialty trainees in this field
- Obstetricians or Obstetric Specialty Trainees
- Midwives particularly Screening Midwives
- Specialist Paediatric nurses, Advanced Nurse Practitioners, and Neonatal nurses
- Sonographers

Table 4 shows the different sessions which were covered during the training.

TABLE 4: TRAINING CONTENT

Time	Activity	Facilitator
09:00 to 09:30	Session 1 Consent Introductions Pre-intervention questionnaires	EM
09:30 to 09:50	Session 2: Study Findings	EM
09:50 to 10:20	Session 3 Lived experience of receiving DN	AEJ (PPI)
10:20 to 10:45	Session 4 What could have gone better in Angie's story? Questions and Answers Key points from the study	AEJ (PPI)
10:45 to 11:00	Break	All
11:00 to 12:20	Session 5 Sharing and Learning from personal practice Case studies	MW
12:20 to 12:30	Session 6 Take home messages Quick points to remember tools	EM
12:30 to 13:00	Session 7 Post-training questionnaires	All

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### 5.2.2 DESCRIPTION OF THE SESSIONS IN DETAIL

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**Session 1:** This session detailed the pilot nature of the training and gave participants the opportunity to provide informed consent for taking part in the study. Participants were also given the opportunity to complete their pre-training questionnaires.

#### **Session 2 –Study Findings**

EM presented the study findings from Phase 1 and how these together with the literature review had been used to develop the training intervention. The findings highlighted current good practice when

delivering different news; practice which could be improved and suggestions of how this can be addressed.

### **Session 3- The Lived experience**

This session was facilitated by AEJ who is one of our Patient and Public Representatives and has lived experience of receiving DN. AEJ described her own journey of receiving different news, what went well and what could have gone better. AEJ gave a brief background on her family, described how DN was delivered to her as well as the immediate and long term impact of the news on her, her husband and her family.

### **Session 4: What could have gone better**

In this session, AEJ gave the HCPs an opportunity to examine her story and reflect on how the key requirements for DDN according to the study findings could have been used in her journey.

### **Session 5: Sharing and Learning from practice and Case studies**

This session was facilitated by MW. As the Mental Health Lead for the institute, MW has extensive experience in using case studies in training healthcare professionals on the iHV Perinatal and Infant Mental Health (PIMH) Champions Training programmes. Case studies are an excellent way for participants to evidence their learning. They offer the opportunity to: positively reinforce good practice; make explicit safe practice; address any areas of concern relating to practice; re-emphasise and consolidate the importance of communicating information effectively. All the case studies were based on actual real-life experiences which were shared by families during the interviews.

Participants were split into small groups. Using the power point slide which was hyperlinked to case scenarios, we asked each group in turn to pick a number, then reveal the case study behind that number. The whole group read the case study and had the opportunity for a 5 minutes' discussion within their small groups. After 5 minutes, **the group who chose the number** gave feedback to the whole group highlighting

- What they felt the key issues were
- What they would do

- What they would say or do differently based on the key components of DDN highlighted in the study findings.

Once the small group gave their feedback there was an opportunity for the rest of the group to share their thinking, positively challenge, reinforce good practice and make suggested alternatives.

### Session 6: Take home messages and Key Messages

EM gave all participants an opportunity to share their take home message from the training. They were also given a READY mnemonic (Figure 5 below) on key aspects of DDN.

FIGURE 5: READY MNEMONIC

**University of Kent** **iHV Institute of Health Visiting**  
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## Delivering different news

### Are you READY?

This mnemonic supports the delivery of different news and is for use by any professional with this responsibility e.g. obstetricians, paediatricians, midwives, sonographers. This is a challenging task for the professional at a very traumatic time for parents. Taking an evidence-based approach can have both short term and long-term positive impact for parents. A lack of preparation may leave parents re-experiencing that moment in a traumatic way for many years after. Note: this tool is designed to underpin the study intervention. It will be subject to version changes as the research study progresses.

**R**ight Language  
Have you found the right words using plain language that parents will understand? Is the message balanced in what it conveys?  
Have you thought about how you will pace yourself when you deliver the message?  
When you think you have the words ready - stop, reflect and imagine yourself as the parents. Are the messages in the order you would wish to hear them?

**E**nvironment  
Is the most appropriate environment? Is the physical, social and emotional space conducive to delivering different news?  
Does it offer sufficient comfort, privacy and freedom from interruption?  
Will both parents be present and who else should be there?

**A**ssessment  
Have you undertaken an assessment of parent readiness and your own readiness to engage in delivering the news?  
Are there any immediate medical concerns for the mother or the baby?  
Can the timing of delivery of the news be optimised?

**D**o your preparation  
Are you prepared? Have you read the medical records and liaised (if necessary) with other professionals?  
Have you checked availability of local or national support?  
Have you checked if someone is available to stay with the parents if needed?  
Are you confident that you can finish the conversation without being called away?

**Y**ou have one opportunity at delivering different news – BE READY  
Remember that you are central to the safe delivery and receipt of potentially life-changing news.  
You are about to create a memory that will be revisited in the lifetime of the family.  
**How do you want this moment to be remembered by the family?**

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### Session 7:

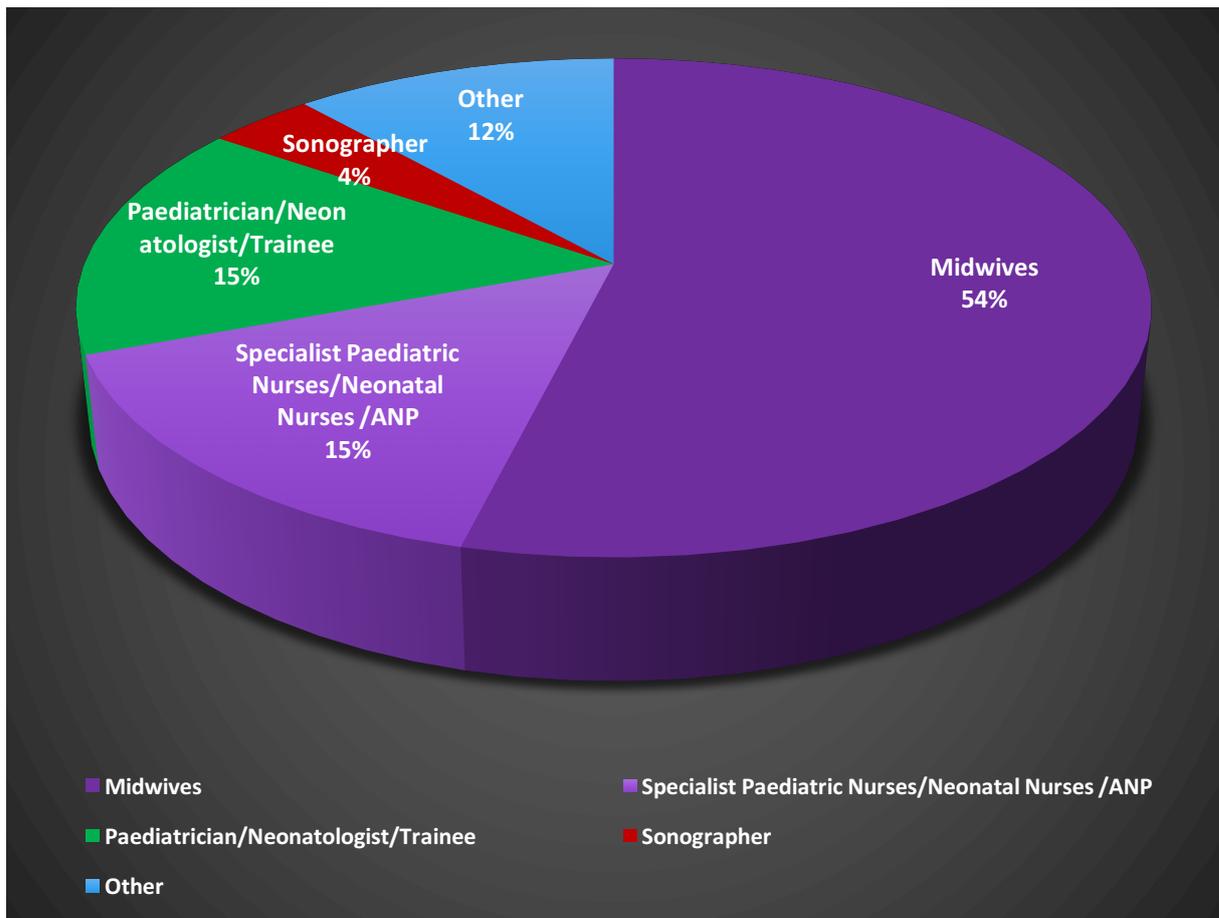
This training concluded with a summary of key points, a vote of thanks and completion of the post-training questionnaires by all participants.

## 6. PHASE 2 FINDINGS

### 6.1 DESCRIPTION OF PARTICIPANTS

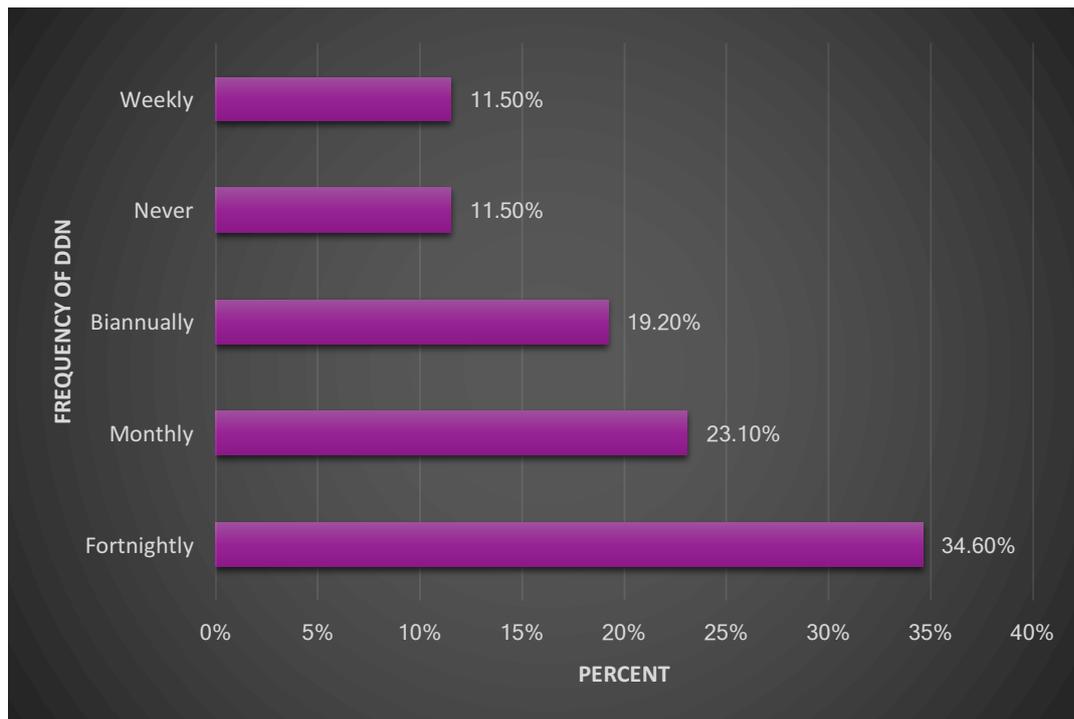
24 HCPs participated in the Phase 2 training. In addition, Rhona Westrip Programme Manager for Intellectual Disabilities HEE South Region and George Matuska Clinical Lead Intellectual Disabilities – HEE South of England Region also attended the training bringing the total of number of participants to 26. Feasibility of the training was assessed by the percentage of eligible participants who were eventually enrolled in the training. 37 participants had registered for the training and 26 participants attended (70.5%). There were various reasons for withdrawal such as illness, family emergencies and some unexplained. Acceptability was assessed by the percentage of HCPs who completed all aspects of the training as planned. All participants (100%) stayed for the duration of the training and completed all aspects of the training as planned. Their professions are indicated in figure 6 below.

FIGURE 6: DESCRIPTION OF PROFESSIONALS WHO ATTENDED THE TRAINING



Although some participants had not yet started DDN, they attended the training as this would be, a future integral part of their role. Participants completed pre and post-training questionnaires which assessed changes in their knowledge, attitudes, and skills in DDN as a result of the training. Of the 26 participants, 8 HCPs agreed to participate in semi-structured interviews four weeks after training. The frequency of DDN varied among participants as shown in figure 7 below:

FIGURE 7: FREQUENCY OF DDN BY HCPS



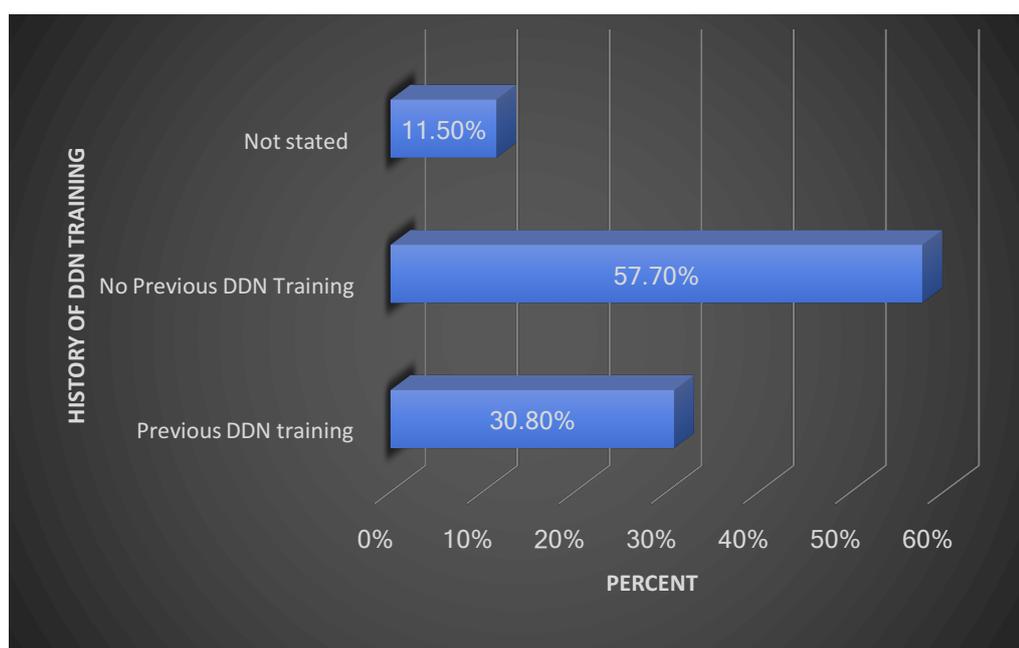
Most the training participants 34.6% (n=9) delivered DN on a fortnightly basis. The quantitative and qualitative phase 2 findings are presented under the TDF that were relevant to the study and which emerged from the data.

## 6.2 SOCIAL / PROFESSIONAL ROLES AND IDENTITY AND SOCIAL INFLUENCES

Most of the interview participants were midwives and many of them expressed their sense of privilege at being able to DDN to families. Often this aspect of their role was considered both challenging and rewarding given that they were involved in providing information to families to enable them to make difficult decisions when foetal anomalies were identified prenatally or helping them to understand, and adapt to, the implications of specific disabilities for their child and family life after birth. There

was also a clearly stated belief that all HCPs who DDN needed appropriate training because how they delivered DN was perceived as making a significant difference to how parents responded to their babies and adjusted to their infant in the early days. Only 30.8% (n=8) of the pilot training participants indicated that they had received some training in DDN. The majority 57.7% (n=15) stated that they had not received such training and data was missing for the rest of the participants 11.5% (n=3) as shown in figure 8 below:

FIGURE 8: PREVIOUS TRAINING IN DDN



The training aimed to give HCPs the opportunity to reflect on their professional role and how they could improve the experiences and outcomes for families that receive DN. The data suggest that the training was a useful social influence for changing clinical practice. Within the training, the most powerful interpersonal influences that seemed to affect the impact of the training and its subsequent implementation in practice were the parent testimony and case studies. The interactive nature of the training was also mentioned as providing opportunities for attendees to share ideas and experiences and to learn from each other:

*I think even just having the training, the training itself is part of the support process because you meet other people in other Trusts who, and other professions and you, you know, you learn from each other.*  
(HCP 4)

HCPs highlighted several issues which were perceived as challenging about their roles. For example, they highlighted that DN was often tailored to families' unique circumstances and perceived and actual expectations, beliefs, and capacity of individual parents. HCPs spoke about the difficulties of gauging what parents were ready to, or wanted to hear, or knowing how much information to share, or in what order it should be presented:

*It's very difficult to get the balance right and I've never understood for myself, I mean, I know that I operate differently in different situations and I will observe the way I'm working with a woman, with a couple, or with an extended family will change dramatically, and, for example, just the very basic thing about... do I put to them the option of continuing the pregnancy with the support that's there first, or do I put forward the option of ending the pregnancy, and how do I decide... and does that actually make a difference to what they end up doing, I'd be really interested to know. (HCP 5)*

These issues were raised in phase 1 and formed an integral part of the current training. There were several suggestions to strengthen the training. Several participants felt that it would be beneficial, although not always possible, to receive feedback from the families they worked with in order to continuously improve their practice. In addition, there were concerns expressed about the lack of support for families who opted to terminate a pregnancy and suggestions to incorporate this in future training:

*I'm sure that we say things to a lady who terminates, that resonates with them for the rest of their life as well, I'm sure that they, 20 years down the line still remember that midwife saying something that wasn't helpful, ...we're only concentrating on the ones who have chosen to keep their babies. So, I feel it's just as hard for those ladies, and I look after a lot of those ladies, and you know, that they have other issues as to why they don't want to keep their baby, that's down to them, but we are negatively impacting on them long-term by the things that we say and the behaviours that we have. (HCP 8)*

Similar to our phase 1 findings, HCPs spoke about learning from the good (and not so good) practice of others:

*I learnt everything I knew about DDN from colleagues, so fantastic colleagues, brilliant colleagues, but I learnt, that's where I learnt everything, by basically copying and learning from them. (HCP 8)*

In view of this prevailing style of learning among HCPs, the point was raised about the need to balance DDN and gauging the appropriate time to ask parents for permission to be able to teach more junior staff about the medical conditions which their children may be diagnosed with:

*So, we had the baby on the resuscitaire and obviously then had to discuss telling the parents because the Dad was coming over. So, myself and the paediatric doctor invited Dad over and congratulated him on the birth of his son, but it was the obstetrics doctor that then came over and said to the Dad 'well, obviously, you can see that there's something wrong with his head. So, it's very, very rare, I've never seen anything like this before, so I'd like to write a case study about your son. (HCP 6)*

In the scenario above, the junior HCP felt that the consultant could have waited and given the family time to process the DN before approaching them to make their child an interesting case study.

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### 6.3 KNOWLEDGE, SKILLS AND BELIEFS ABOUT CAPABILITIES

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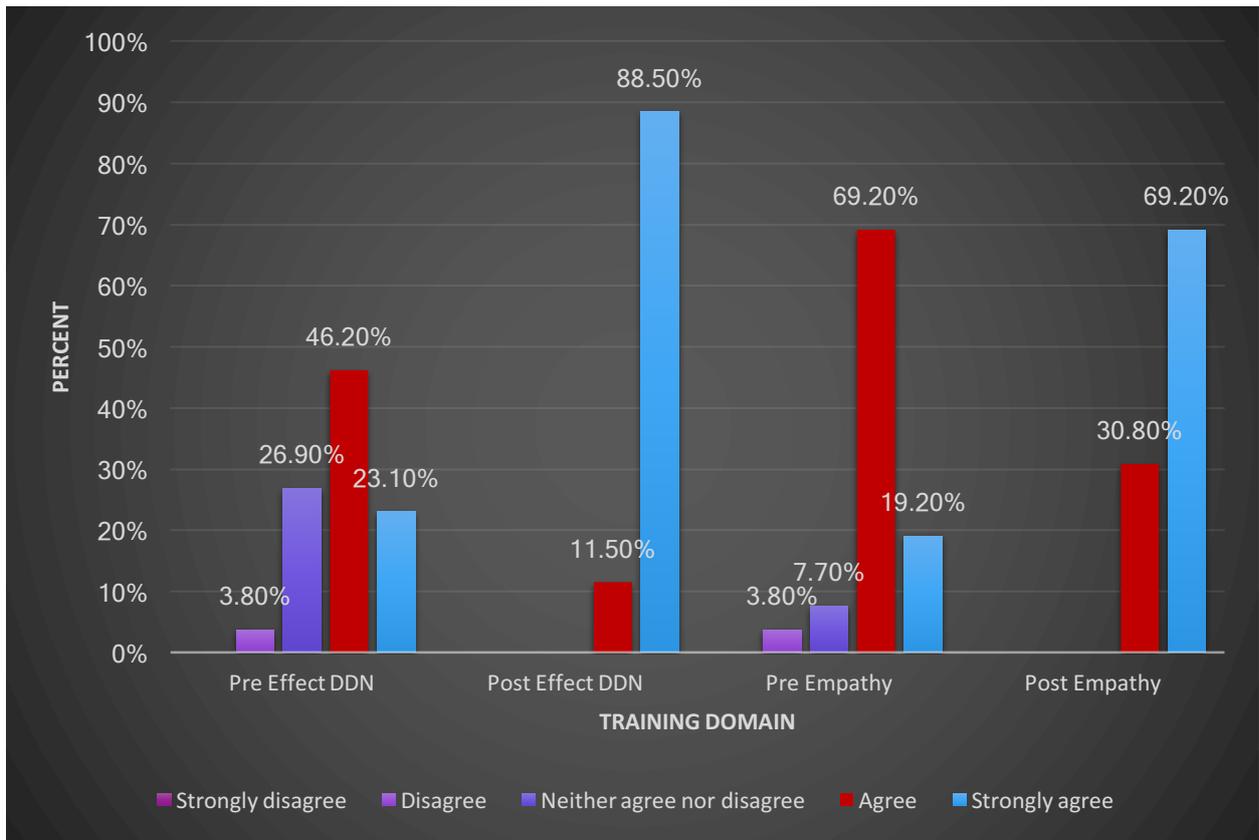
The training aimed to enable HCPs to recognise the importance of establishing the right physical, emotional, social and environmental space to deliver DN. It also aimed to enable HCPs to gain an understanding of the importance of planning before DDN including identifying the appropriate time to deliver the news, choosing the appropriate language to use and the appropriate information to give at initial and follow up discussions with the family. We assessed the knowledge and attitudes of participants with regards to the effect of DDN on families, the importance of empathy, the various communication styles and the HCPs confidence in DDN before and after the training. Following the training, all participants felt more confident in their ability to share DN in a compassionate, responsive and balanced way. Some regrets were expressed about the way they interacted with parents prior to attending the training:

*I think I feel kinder, I feel kinder giving the information, I feel, um, yes, I was kind before but I feel even kinder, there we are. (HCP 1)*

*...and then you get this sudden onset of guilt, because you start in your head you immediately start going through all these situations where you've said them things, and you've always said them with good intentions, so when we've had the debate I've said to the people I've spoken to, don't worry, I felt the same, I felt like, oh no, I've said that before, oh no, I shouldn't have said that, and oh my god, that lady's probably going to remember that for the rest of her life, she probably is, but there's nothing I can do about it now, all I can do now is change the language I use. (HCP 8)*

The quantitative data supported the qualitative findings and showed that there were improvements in knowledge about the effect of DN on families and the importance of empathy when communicating DN as shown in figure 9 below:

FIGURE 9: CHANGES AFTER TRAINING



The percentage of HCPs who stated that they agreed or strongly agreed that they understood the effect of DDN on families rose from 69.3% (n=18) before the training to 100% (n=26) after the training. There was already some understanding of the importance of empathy when DDN among the participants and this increased from 88.4% (n=23) to 100% (n=26) after the training. This was also reflected in the qualitative interviews in that some of the participants commented that the training affirmed that they were more or less doing the right thing. Nevertheless, there was an increase in the percentage of those who agreed or strongly agreed that they felt confident when DDN to parents from 26.9% (n=7) before the training to 96.1% (n=25). Whilst those who agreed or strongly agreed that they had the skills to deliver DDN increased from 34.5% (n=9) to 92.3% (n=24) after the training.

The training aimed to raise awareness about communication styles during the initial delivery of DN as well as the follow on discussions and this was one of the key messages shared from the lived experience and the case studies during the training. Nearly all the participants commented on the value of learning from a mother with lived experience and the importance of all aspects of

communication, including the words that are used, and the tone and way information was shared both in the qualitative interviews as well as the qualitative comments made as part of the post-training evaluation. Comments were made that emphasised the value of replacing the term 'bad news' with 'different news' and it was hoped that this would become the preferred term when talking to other professionals or running in-house teaching sessions:

*To put it really practically, is to not say bad news, and to not say I'm sorry before you say it, and to, yeah, not treat it as something that's wrong.....the other word is risk, we use risk a lot, and I'm trying, that's so hard, because all our paperwork and it is all our information, so and we're so used to saying it, so I'm trying really hard to move away from risk, but I can be honest with you and say that I've found it difficult. (HCP 8)*

*Change in language, use the term different or unexpected news avoid words like risk and not to apologise. Thinking about timing and environment. (HCP 9 Qualitative feedback from post-training evaluation form)*

The emphasis made by the parent with lived experience on the importance of working in partnership with families was also mentioned as a key take-home message and was reflected in the way that one participant subsequently engaged with families:

*You're stepping down from taking that hierarchical role of the professional who knows everything and this is how we're going to do it, and you kind of come down to the level of the service user and say to them, "How do you want...?", you know, you're including them, "How shall we do this, what can we do to improve things or help your understanding?", or whatever. (HCP 2)*

As part of the post-training evaluation, participants were also asked about how they would use the knowledge and skills from the training to change their practice. Most responses were around adjusting how to communicate with parents as well as supporting the dissemination of the content of training to other colleagues to support changes in their practice:

*To spread the news. Ensure if this training goes out as many key people as possible get to go on it. I work at 2 different trusts over different counties and will; push for a similar thing in XXX (HCP 10 Qualitative feedback from post-training evaluation form)*

*Speak to seniors on having departmental guidelines to follow. (HCP 11 Qualitative feedback from post-training evaluation form)*

*Using today's experience to improve the language and environment. (HCP 12 Qualitative feedback from post-training evaluation form)*

*I will organise teaching and training sessions for my junior doctors with my department. (HCP 13 Qualitative feedback from post-training evaluation form)*

Similar comments were made in the qualitative interviews about disseminating the training to ensure trust wide changes in practice. Other suggestions were about making other changes apart from face to face communication.

There were some immediate changes in practice which were reported by participants, for example, one participant reported going back to discuss with their colleagues about changing the standardised wording of follow-up emails sent to parents after they received a phone call explaining the results of their tests as well as updating leaflets given to parents.

*Actually, let's stop using that, let's use this one instead, so it just got us to talk about it rather than us going on just doing what we've been doing, so it freshened what we do, which has got to be good. (HCP 5)*

There were a number of suggestions to improve the training including making the training session longer and including the perspectives of other carers, such as fathers and grandparents so that HCPs also learn from these. These comments were raised in the post-training evaluation questionnaires. One participant also proposed that future training supports HCPs to encourage families to explore their options from the fundamental foundation of love for their baby and themselves.

*Yeah, I think, to me, the key point, the key message, that I come back to over and over again in those consultations is, if you make a decision based in love, you're not going too far wrong and it also enables you to live with that decision because when you look back, if the primary reason you made that decision, either to continue or to end the pregnancy, is out of love for that child and, indeed, love for yourself, and love for your other children, if you have any, then however difficult it is, you know you did it for the right reason. (HCP 5)*

Overall, interview participants reiterated a number of core components of DDN which were already covered in the current training and made suggestions which are highlighted in the recommendations section of this report.

## 6.4 ENVIRONMENTAL CONTEXT AND RESOURCES

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Included under this heading are aspects of the training environment that were considered by participants to enhance or impede their learning experience as well as resources that could be used in their workplace when DDN to families. Positive comments were made about the venue, the refreshments, the atmosphere, the other attendees, the facilitators, the mother with lived experience, the content of the training and the way it was delivered. This was also reflected in the quantitative data in that 96.2% of participants (n=25) agreed that the training covered topics relevant to their practice; that the content was well organised and easy to follow; that interaction and discussion were encouraged during the training. Data were missing for one participant. In the qualitative comments from the post-training evaluation and the interviews, participants valued the use of the case study approach; learning from a lived experience, and the fact that the training was relevant to multi-professionals and which allowed learning from others to occur. There were some conflicting comments about the length of the training:

*I think you always get quite a lot back from a service user's point of view, so the lady that spoke about her own case with her child, and I think, you know, as a professional I glean more from that than I do sometimes from the actual slides and the PowerPoints and everything else, because that's why I'm doing what I do, I want to make it right and as good as it can be for the patients. So, I think I got the most out of her input, actually. (HCP 2)*

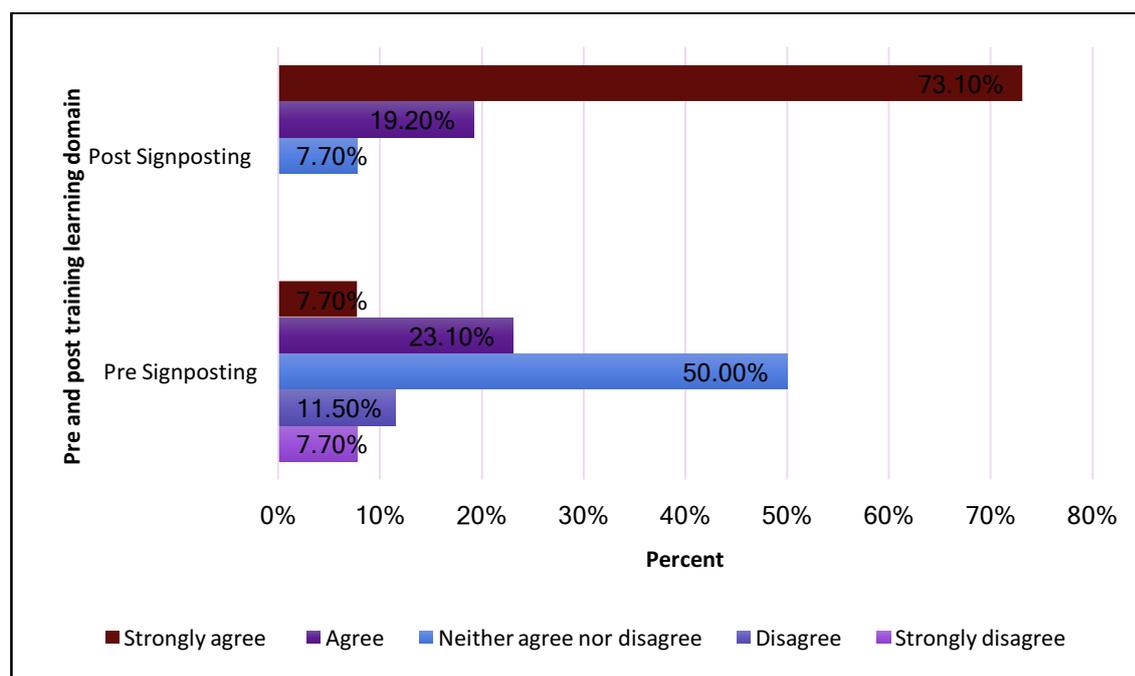
*The scenarios where we did go in groups, that was really nice as it wasn't particularly threatening in a sense of you have to answer it all because it was opened up to the real... the whole group, actually I really liked that and hearing different people's opinions was really good. (HCP 3)*

*I, well I like the fact there was such a cross-section of professionals, different professions, so I thought that was really good. Because often these events you have all midwives or all sonographers but there were doctors and someone from mental health services and it's just great when you get lots of different people together. (HCP 4)*

*I think to have a half day is really effective because people, well I felt like I could really focus for those few hours and then because I know sometimes if it's a full day of training you can get a little bit tired and then you, you know, after lunch, you find you lose a bit of focus. (HCP 7)*

The training aimed to raise the awareness of HCPs about resources available locally and nationally which could help parents process, understand and interpret the diagnosis. Participants were provided with various resources such as the “Looking Up” book, the “Tea at Grandma’s Book” and the “Going to school book”. These books were also spoken about in the lived experience. The changes in perceptions about the importance of signposting parents to local and national resources for their immediate and long term support needs after the training are shown in figure 10 below:

FIGURE 10: PRE AND POST-TRAINING UNDERSTANDING ABOUT SUPPORT



92.3% of participants (n=24) agreed or strongly agreed that it was important to signpost parents appropriately after the training. In the qualitative interviews, several participants also highlighted the value of learning about these resources:

*... it's particularly useful to sort of see physical resources that were around, you know, trying to find positive images of children with Down's Syndrome, for example, or people with Down's Syndrome, you know, the sort of standard national literature that we're given to use is so old fashioned and so negative, and it was, yeah, it was lovely to see some positive stuff. But also, once you got past the initial positive bit, it had realism there, you know, it wasn't sort of sugar-coated silliness. (HCP 5)*

In line with our findings from phase 1, the training aimed to provide an understanding of the importance of choosing the right environment for DDN in terms of the actual time of day when the

news is delivered; when after the baby is delivered the DN news is given; considering DDN at a time when significant others were present and the importance of ensuring privacy when DDN. There were a number of qualitative comments made by HCPs as part of their post-training evaluation on how HCPs intended to put this aspect of the training into practice:

*I have become more aware of what I'm saying when I say it and how I say it... (HCP 14 Qualitative feedback from post-training evaluation form)*

*Change in language, use the term different or unexpected news avoid words like risk and not to apologise. Thinking about timing and environment. (HCP 15 Qualitative feedback from post-training evaluation form)*

*I will have a discussion with the bereavement team. Hope to make conscious changes to my practice by being aware of environment, time allowance, language. (HCP 16 Qualitative feedback from post-training evaluation form)*

In the qualitative comments from the post-training evaluation, there were several comments from HCPs asking the study team to deliver similar DDN training in the trusts where participants were based. It was clear that participants felt that the training was valuable to their practice and useful for their colleagues. Most importantly participants had a genuine desire to improve outcomes for families and it was felt that the training enabled HCPs to do this and also gave those who were doing well confidence in their practice.

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## 6.5 OPTIMISM

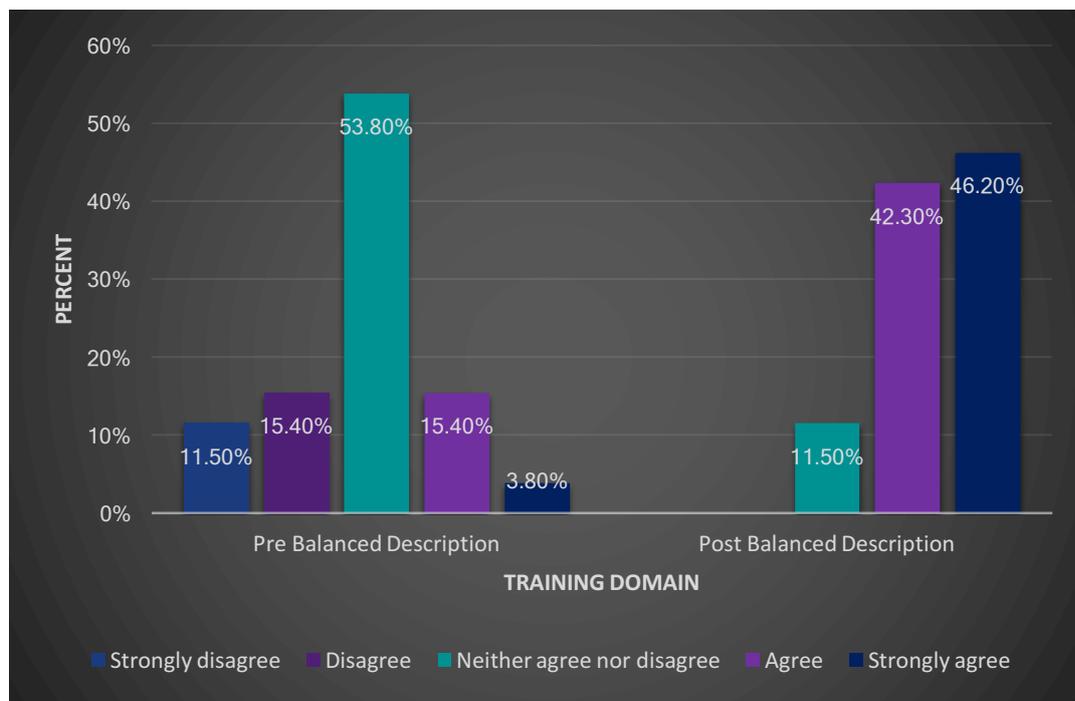
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In phase 1, optimism referred to HCPs being able to provide a balanced description of the congenital anomalies and maintaining a positive attitude about the medical condition by reassuring parents of the support that was available, what was known or unknown about the condition and not just limiting DDN to the negative aspects of condition or the things which their child would presumably never be able to do or the challenges they were likely to face.

The training aimed to help HCPs to understand the importance of providing a balanced description of congenital anomalies through case studies, provision of a research article on this and through lived experience. The training also aimed to support HCPs to empower families to see beyond the diagnosis which their child had been given and support them to build positive relationships with their children.

In the post-training questionnaires, significant changes were observed in the domain of understanding how to provide a balanced description of a condition to parents. Whilst only 19.2% (n=5) agreed or strongly agreed that they knew how to provide a balanced description of congenital conditions before the training, this increased to 86.5% (n=23) after the training as shown in figure 11 below:

FIGURE 11: CHANGES IN KNOWLEDGE ABOUT BALANCED DESCRIPTION



Hearing from a mother about the reality of looking after a child with a congenital anomaly was reported as helping HCPs to be more positive about that specific congenital anomaly and to have greater confidence about talking to mothers about their options. Seeing pictures of different children with Down’s syndrome for example from the resources which were provided and hearing about their lives were also mentioned as a useful way of appreciating individualism, the spectrum of ability and the need to focus on what children could do rather than what they would not be able to do:

*So, it’s really good to hear a parent’s perspective because when you hear actually that it’s, it was okay for her, it was really hard when, when women are really that honest about how difficult it was, that actually they’ve come through it and, um, you know, when they’re on the other side they, you know,*

*this is okay, tell parents it's going to be okay, you have the confidence to really believe in that when you tell parents. (HCP 4)*

*I didn't realise it, but I had some preconceived ideas before I read the article, so the article was fantastic, I got a real... I think that was such a good thing, because I did have some preconceived ideas that I didn't even realise I had until I read the article, it sparked a little debate, and it made me much better prepared for what we were going to come across, and it's made me start to think about my practice already, so when I have arrived at your training programme, I had already started thinking about the concepts that you wanted to talk about and how I, I always started to think, oh my god, I have said to someone, I've got some bad news for you, and I have said these things, and started to think about my practice, and how it's relevant, so on the day when you start to ask people, you've already had a think about them. So yeah, I'd say that was much, I found that very useful and I wish more of the study days I've been on had done that. (HCP 8)*

While a few HCPs were concerned about being over-optimistic and giving parents false hope, the resources shared at the training were perceived as useful in that they showed some of the challenging times that families went through but also showed some of their triumphs and ability to enjoy things which other families enjoyed which provided a balanced description of the raising a child with congenital anomalies. The main suggestion for enhancing this aspect of the training was to also include resources for various congenital anomalies.

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## 6.6 BELIEFS ABOUT CONSEQUENCES

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While in phase 1, beliefs about consequences were mainly to do with how DN impacted families, in phase 2, this was also about the potential positive impact of having trained HCPs deliver DN on the outcomes and experiences of families receiving DN:

*I thought it was really useful to understand how much of the conversation they remember, so knowing that the first sort of minute is the kind of, when they're really focused and if you give them any news that they weren't expecting that was different to what their expectations were then actually they might switch off after the first minute or so. And then also that they really remember sort of like the tone and the way in which they were spoken to, so to always go in and give them the respect that this might be one of the few interactions and they'll remember it longer than you ever will. (HCP 7)*

*It sent me away more determined to do pretty much what I'm doing anyway and to go on really weighing every word that I use with women and with families, because understanding how desperately important that is to them, and those words will be etched on their souls. (HCP 5)*

In terms of the consequences of the training, the expected outcomes related not only to the practice and impact of individual health professionals attending the training but also to the extent to which the training could be rolled out and embedded in the practice environments of the attendees and other HCPs in general. There were several suggestions about ensuring that the HCPs responsible for driving the agenda forward remained supported and motivated; that the infrastructure required for supporting the establishment of protocols and policies for effectively DDN were in place to ensure consistent, safe and balanced practice. There were suggestions about the development of a network of local trainers able to deliver informative, up-to-date DDN training:

*I think if there was some kind of like teaching package resources, that could be used at the local level, that would be really useful whether it's videos or, videos are really powerful and just easy to distribute. But it needs to be, in smaller bitesize chunks if you like that you can deliver... you know I can sneak, we have mandatory training for example that we have to deliver but you can sneak in ten minutes on another topic, so it's quite a good way of like feeding that in. (HCP 4)*

*...because you know you can't change the whole world by teaching every individual person separately, we're never going to get there, we've got to start changing cultures. I think we've actually done quite a lot and I'm quite positive about the way we've changed the use of language, to a very large extent from the use of the word risk to the word chance. (HCP 5)*

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## 6.7 EMOTION

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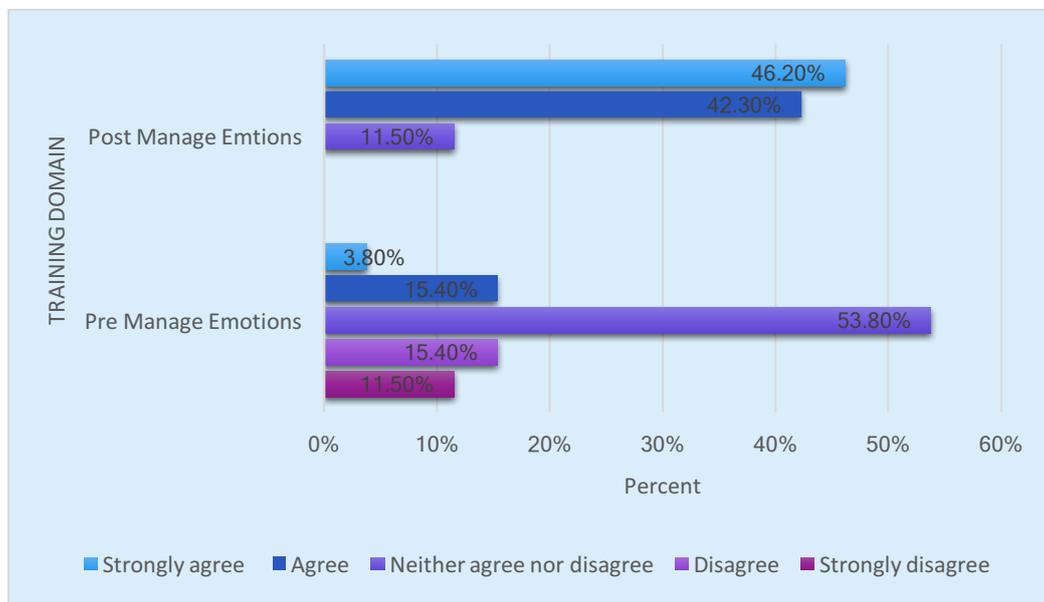
The training aimed to allow HCPs to recognise the importance of regular personal support and how this contributes to their own mental wellbeing. There was a unanimous acknowledgment by all the participants of the emotional challenges of supporting families facing difficult decisions or uncertain futures, especially when the decisions that some families made were difficult to reconcile with the HCPs own beliefs. The need for a supportive network in order to reduce stress and avoid burn-out was mentioned by several of the participants, so the session in the training programme on novel approaches to build practitioner resilience was also considered helpful.

*You know, they do play on your mind some of these lady's cases and you're just hoping...in the long run that you're...in the long run that the baby's forgiving you.... (HCP 1)*

*And I think we, I was... I've come back and certainly we discuss things much more like, erm, one of my colleagues had quite a, a difficult situation yesterday, so we spoke about it briefly yesterday, but I've actually just checked in with her again today and just said 'Actually, is that, are you okay with that?' (HCP 3)*

88.5% (n=23) of participants agreed or strongly agreed that they knew how to manage their own emotions after the training compared to 19.2% (n=5) participants prior to the training as shown in figure 12 below:

FIGURE 12: CHANGES IN MANAGING EMOTIONS



### 6.8 Summary of phase 2 qualitative findings

- All the participants in this study indicated that attendance at the half-day DDN training workshop enhanced or consolidated their knowledge and skills. On their return to their workplace participants felt better informed and more confident in their ability to provide sensitive, responsive, balanced care when supporting mothers and their families.
- Many positive comments were made about the structure, duration, and content of the training programme especially regarding the inclusion of lived experience. This presentation heightened awareness amongst the participants of the need to be mindful of the way that they present verbal

and written information to parents, not only in terms of the words that are used and the tone and manner in which they are shared, but also with regard to the way that evident or potential disabilities are perceived and described.

- Participants also acknowledged the emotional impact on HCPs of supporting families making difficult decisions and the need to have support from colleagues as well as awareness of strategies to support their own well-being.

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## 7. DISCUSSION

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### 7.1 KEY FINDINGS

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Our study findings indicate that receiving DN was a significant life event as such, parents remembered in vivid detail, how they received DN, including the tone of voice of the HCP, privacy afforded them when the news was delivered, the questions they were asked, the words used to describe their child; the care given to them, the posture taken by the HCPs; the time that the news was delivered and the level of preparation that the HCP had taken. How the news was delivered had a significant impact upon; the parent's ability to cope with the news, their emotional and mental wellbeing, the parent-child relationship, the parents' relationship with one another and the relationship between the family and the professionals as highlighted in previous studies [5, 33, 39, 44, 45, 47-52]. Two of these previous studies showed a clear correlation between maternal anxiety and the focus of the initial conversation when HCPs had delivered different news, thus highlighting the importance of how DN is delivered [44, 48]. These findings suggest that it is important for all HCPs involved in DDN to have training which reflects the needs of the families that have lived experience of receiving DN.

The process of DDN was sometimes challenging for HCPs particularly as some had limited experience and training to complement observing senior colleagues perform the task. Due to lack of standardised training on DDN as well as lack of policy to guide professionals on this, there was significant variation in the way that DN was delivered by HCPs. Other authors have also reported on this significant variation in how DN is delivered [5, 6]. Given the significant impact of how DN is delivered as well as the significance of the DN itself, parents and HCPs made important suggestions about the contents of a training intervention. These suggestions included training needs to equip HCPs to; demonstrate empathy, show compassion, be flexible with time or plan around the demands of their ward, utilise kind, simple and truthful language; provide a balanced description of the condition; offer sufficient

time to answer questions and know when and where to refer families on to for further care and support. These key aspects of DDN have also been highlighted in other studies as crucial for minimising the negative impact of receiving DN on parents [5, 47, 48, 50-52].

We drew on the BCW [16, 22] to develop the training intervention which incorporated the suggestions from families and HCPs. We piloted the intervention with a group of 26 HCPs. The training intervention was acceptable. Acceptability was measured by the percentage of HCPs who completed the course as planned. On both training days, all participants completed all aspects of the training and stayed for the duration of the training. We also found that it was feasible to recruit HCPs to attend the training via NHS trusts and HEE networks. Furthermore, it was both feasible and acceptable to make use of real life scenarios in the case studies alongside learning from the voice of parents with lived experience in session. These aspects of the training were very well received and perceived as an integral part of the learning experience by participants.

All participants indicated that attendance at the half-day DDN training workshop enhanced or consolidated their knowledge and skills, that it covered topics which were relevant to their current practice and that they would recommend the training to their colleagues. Participants could highlight specific ways that they could change their practice based on what they had learned from the training. On their return to their workplace participants felt better informed and more confident in their ability to provide sensitive, responsive, balanced care when supporting families. Several HCPs reported practical changes which they had already made in their daily practice as a result of the training. We found that the use of the BCW and specifically the use of the TDF in guiding the development of the intervention was useful in developing training which addressed some of the challenges and barriers to DDN effectively. The reported changes in practice suggest that theoretically driven interventions may be useful in changing clinical practice.

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## 7.2 LESSONS ABOUT DATA COLLECTION METHODS

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We conducted a two-phase study to develop and pilot a training intervention to improve the delivery of DN to families by HCPs. Phase 1 was qualitative in nature. Like other qualitative studies, this design allowed in-depth description of the lived experiences of parents and HCPs, however, the small sample size inherent in qualitative studies means that the findings from the study will be transferable to similar populations and not generalisable [14]. Phase 2 was not powered to detect statistical

significance however, we were able to assess the acceptability and feasibility of the training intervention as well as changes in knowledge, skills, and attitudes about DDN. Despite these limitations in the methods, the study was well designed, answered a number of significant questions on how to improve the delivery of DN by HCPs in the UK. The following lessons were learnt in the process of setting up the study and data collection:

- It was important to obtain local buy-in from service leads in the NHS trusts as their endorsement of the study had implications for the successful recruitment of HCPs and families into the study.
- We included two parents with lived experience in the research team to facilitate effective research design; optimise community sensitisation and engagement and to ensure that our study reflected the needs and experiences of families with the lived experience of receiving different news. The parents actively contributed to discussions on the feasibility of proposed designs and highlighted methods to refine the proposal, the interview guides, consent forms and participant information sheets for the families as well as recruitment of families into the study. The parents were from the Cornwall Down's Syndrome Support Group, a charity run by families affected by Down's Syndrome in Cornwall.
- The setup of the study including obtaining occupational health clearance for the NHS and completing DBS checks in order to have the necessary honorary contracts to allow our research team to conduct research within the NHS took longer than was anticipated. This delayed the study. Other researchers may find it helpful to be less optimistic about the timescales for such approvals to ensure that their studies run to time and budget.
- We had a slow start to the recruitment of families as NHS staff indicated that the families were hard to reach. We found it useful to also recruit families into the study via charities as well as local support groups.

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### 7.3 RECOMMENDATIONS

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The study findings suggest several potential research and training opportunities. It would be important to ensure that the voice of parents with lived experience remains part of these future opportunities so that training continues to reflect these lived experiences and the possible long term impact on families. In view of this, we make the following recommendations with regards to future research, the training content as well as rolling this out.

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### **7.3.1 FUTURE RESEARCH**

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We conducted a small study to assess the feasibility and acceptability of a training intervention to improve the delivery of different news to families. We recommend that HEE working across Kent, Surrey, and Sussex support the conduct of a larger definitive large-scale trial as an important next step. This study could look at the implementation of the training and its impact on family outcomes. The study could answer questions about how having HCPs who have been trained to deliver DDN might improve the emotional response and mental wellbeing of parents immediately after the news is delivered and in subsequent months.

Other studies have shown that parents may take six or more months to adjust to the news and to develop the emotional resilience to enable common family function [44]. A cross-sectional survey of parents found that over a period of six months, parents who were well supported and had access to appropriate information when they needed it, adjusted well to the diagnosis; showed patterns of resilience; had reduced symptoms of anxiety and depression and an improved quality of life [46]. It would be useful to compare if having supportive, DDN trained staff can shorten the length of time it takes parents to adjust to the news and mitigate the impact that this has on their emotional, mental and family wellbeing as well as the potential long term effects perinatal mental problems on both parents and children.

It would be important to ensure that families with lived experiences remain part of research teams that conduct these future studies as their insight on the study design and recruitment processes would be crucial for the success of the studies.

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### **7.3.2 TRAINING CONTENT**

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The current training emphasises the unique position which HCPs have in being able to shape how parents start their often unexpected journey. Based on the findings from Phase 2, we recommend that the training is strengthened by adding the following aspects:

- Including the lived experience of a father of a child with a disability; a young person with Down's Syndrome or other carers such as a grandparent;
- Including the perspectives of parents of children with a range of disabilities.

- Incorporate ways to support families that choose to terminate a pregnancy based on foetal anomaly screening.
- Exploring ways of seeking feedback from parents who have received DN regarding the best ways of improving service provision.
- Use of videos, audios on how other people deliver and receive DN.

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### **7.3.3 ESTABLISHMENT OF POLICIES AND PROTOCOLS ON DDN**

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In order to close the gap between evidence and practice, we recommend that HEE KSS uses the findings from this study and any follow on studies to lobby the development of complementary policy to ensure that DDN training becomes part of mandatory training for relevant NHS staff. This infrastructure would support large scale rolling out of the training to all staff.

We also recommend the establishment of local protocols and policies for effectively DDN in NHS trusts to ensure consistent, safe and balanced practice. These protocols and policies will address the variation in practice which was reported by various study participants.

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### **7.3.4 ROLLING OUT THE TRAINING**

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Following on from the larger definitive study, we recommend that the training is rolled out on a large scale in order to address the unmet need for training in DDN. The proposal to roll out the training to HCPs who DDN on a large scale was enthusiastically endorsed by parents and HCPs in both the phases of the study.

We recommend a cascade model of training which involves the appointment and development of local DDN champions to ensure that there is ongoing up-to-date evidenced based local support for HCPs who deliver different news. A similar model had been used by the iHV for its award-winning perinatal mental health training. This training has been running for 5 years and through its unique Champion cascade model, it has reached tens of thousands of practitioners, including, but not limited to; health visitors, midwives, psychiatrists, mental health nurses, social workers, general practitioners, and third sector practitioners. These professionals then implement their learning into everyday practice. The Institute has trained over 1650 multi-agency perinatal and infant mental health (PIMH) champions who, after attending the Institute training, go on to cascade it to their colleagues. The PIMH Champions receive continued support for their role as local leaders from the Institute via;

regional face to face forums, an annual conference and also through resources and national updates made available to them through the mental health section of the iHV website. The DDN training could use a similar model to develop a network of champions whose role would include cascading training to practitioners. These champions could be also be equipped with electronic teaching package/resources for rolling out the training including 'bite-size chunks' for those who may not be able to attend a half-day training.

We recommend that the parent voice remains a key aspect of the training as HCPs found learning from lived experiences as integral to them understanding the impact of DN on families as well as how it is delivered to families.

## 8. CONCLUSION

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The DDN training has the potential to provide essential skills to HCPs who deliver DN to parents. Equipping HCPs with the necessary skills to effectively deliver DN may reduce the negative impact of the news on parents, families, and HCPs. If delivered well, there is potential to minimise the distress, anxiety, and depression associated with receiving different news. The improved mental wellbeing and adjustment of parents will also affect the mental health of their children which represents a key aspect of the prevention of mental ill health across the life course. The significant improvements in confidence and skills reported by HCPs after the training suggest that the training may be effective in providing the aspects of DDN that parents shared as being essential for minimising the negative impact of the news. Given the paucity of this specific training for HCPs, the DDN training will fill a significant gap in training needs and provide support to HCPs to improve outcomes for families who receive DN.

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