Improving the Delivery of Different News to Families by Healthcare Professionals: The DDN Study 2 Report

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ABBREVIATIONS

CRN	Clinical Research Network
CST	Communication Skills Training
DN	Different News
DDN	Delivering Different News
HCPs	Healthcare Professionals
iHV	Institute of Health Visiting
NICE	National Institute for Health and Care Excellence
PHE	Public Health England
PI	Principle Investigator
PMH	Perinatal Mental Health
TDF	Theoretical Domains Framework

EXECUTIVE SUMMARY

SITUATION

The first 1001 days covering from pregnancy to the time that a child is two years old are critical for their physical, emotional and cognitive development. There is increased vulnerability for babies and their families during this period when congenital anomalies are identified. The diagnostic process has significant implications for parent and child emotional and mental wellbeing. In this study, we refer to this diagnostic process as delivering different news (DDN). Ineffective delivery of different news (DN) and the DN itself can result in chronic stress, depression, anxiety or other mental health conditions in parents. In the first 1001 days of life, this may impair parenting ability which potentially has a direct immediate and long-term impact on the infant's physical, cognitive, emotional and social development. Parents must receive DN from healthcare professionals (HCPs) with skills to deliver the news sensitively and compassionately. Currently, not every family has access to such HCPs due to a lack of standardised training or policy to guide professionals on how to effectively deliver DN. Providing communication skills training can potentially minimise the negative psychological impact of the news, maximise the psychological wellbeing of the whole family and reduce staff burnout.

In 2017 we conducted a study to test the feasibility and acceptability of this type of training with 26 HCPs involved in the prenatal and postnatal delivery of DN. Statistically significant increases in mean scores were observed in confidence as well as skills to deliver DN. HCPs reported feeling more confident in their ability to provide sensitive, responsive, balanced care to families. In 2019, we received additional funding from Health Education England working across Kent, Surrey and Sussex to test the findings of the exploratory feasibility study with a larger group of professionals involved in the first 1001 days of life. We also sought to understand the potential impact of the training on patient experiences as well as how to scale up the training in a sustainable way.

BACKGROUND

This study comprised four main phases:

1. The co-production of case studies covering a wider range of disabilities to supplement the existing training intervention through interviews with parents with lived experience.
2. The delivery of the training to DDN champions and the subsequent cascade training by these champions to HCP colleagues.

3. The mixed-methods evaluation of the training intervention to understand its value, impact and feasibility of the training delivery model.
4. The policy and dissemination related work involving stakeholders to facilitate the transfer of research findings into policy and practice.

ASSESSMENT

We used a pre-post intervention study design. 204 HCPs completed the Self-Efficacy Scale (SE-12), a validated questionnaire that evaluates communication skills training. Self-Efficacy is an individual's confidence in their own ability to successfully accomplish a specific task. We also used bespoke questions that measured changes in knowledge, skills and attitudes related to DDN. Participants responded to the combined questions before the training, immediately after the training and after a month. Changes in the SE-12 scale were examined at an item and scale level. The SE-12 was analysed using statistical methods to compare the mean response pre-and post-training, comparing differences within participants. We also statistically analysed individual items from the pre-and post-training questionnaires on knowledge, skills and attitudes. To understand more about the impact of the DDN training, we analysed our interviews with DDN-trained healthcare staff to investigate their self-reported changes in self-efficacy, knowledge, attitude and practices. We also explored how the training was being utilised to deliver DN; the barriers and facilitators to the transfer of knowledge gained from the training into daily practice and barriers and facilitators to the adoption of the training at a managerial level.

KEY FINDINGS

We trained 22 DDN champions from six NHS organisations across England through two separate virtual, interactive training days. Our DDN champions were from neonatal and foetal medicine, ultrasound and obstetrics. The DDN champions delivered 17 half-day cascade training sessions. Pre-training data were collected for 204 HCPs (champions and cascade trainees) who participated in the DDN training. We conducted 19 interviews with HCPs and four managers. They comprised: four health visitors, four sonographers, four midwives, one paediatrician, two obstetricians, two neonatologists and two neonatal nurses, and four managers (some managers also held clinical roles; two attended the training). We also interviewed seven parents during the co-production process and one parent after the training was delivered.

Although DDN was of fundamental importance to the interviewees, 80.5% (n=165) of the participants had not had any training in DDN. Practitioners across all professions had developed their skill base

through a combination of (unofficial) peer learning, personal experience and through reading academic or other relevant articles. There was a strong desire among the interviewees to improve services, reduce patient complaints, improve patient experience and help families understand and manage diagnoses in the best way for them.

Both the qualitative and the quantitative data indicated that the training had a significant impact on the knowledge and skills of the participants. There was a statistically significant improvement in self-efficacy to deliver DN post-training. We examined the quantitative data to understand if these changes were the same across the various trusts that participated in the study as well as across professions, trainees and champions. The data also showed that the training improved self-efficacy to deliver DN across the all professions, trainees and trusts although results for one of the NHS trusts in the North of England (Site E) were higher compared to the other trusts.

In addition, there was a statistically significant increase in self-reported confidence and skills to deliver DN after the training. Among other things, the training gave HCPs confidence and skills in the following areas: pacing the provision of information to the needs of the family, the use of the right language when DDN as well as provision of a structure for delivering the DN conversation using the READY mnemonic. This was also reflected in the quantitative data. On the SE-12 scale, the biggest improvement in mean score was seen on Question 6: "How certain are you that you are able to successfully structure the conversation with the patient?" . This is an important finding which suggests that the READY mnemonic potentially enables HCPs to have an evidenced-based format of how to structure and pace a DN conversation.

To this end, the READY framework was also to be used by other interviewees to make structural changes across the organisation. It was also considered as a useful framework for use beyond the congenital anomalies in the first 1001 days for example an HCP was able to use it after training in DDN about oncology results for an adolescent to their family. We also heard from the health visitor team about the application of the framework to community settings where it can support difficult public health or safeguarding conversations with families. Other researchers in Australia have applied the READY framework to DN conversations in critical care.

The results also suggest that the training supported HCP skills to engage families and make joint decisions about care with a statistically significant increase in the average score in response to SE-12 Q2: "How certain are you that you are able to successfully make an agenda/plan for the conversation with the patient?" after the training. There was also a statistically significant increase in the average

score in response to Q3 on the SE-12 score: "How certain are you that you are able to successfully urge the patient to expand his or her problem/worries?". These changes suggest that the training gave HCPs the skills and the knowledge to actively seek to engage the patient in the decision-making process and the care plan. This is an important aspect of ensuring patient agency and autonomy.

Parents contributed to the training as experts by experience. Their sessions emphasised the fact that parents retained such a strong image of how they received their DN as a film in their minds long after they had received the news. This was highly impactful for the interviewees with reports from HCPs about ensuring that they provided parents with more balanced information or simply took time to focus on the baby or babies which was quite different from how they had presented DN to parents in the past.

We sought to understand if the observed changes in Self-Efficacy were the same between HCPs trained by the iHV team (Champions) and those trained by the champions (cascade trainees). There was a statistically significant difference between DDN champions and non-champions. SE-12 scores were generally higher for champions and the improvement from pre-training was greater. Although the changes observed in the cascade trainees was lower than for the champions, the results are promising as there was still a statistically significant increase in overall means scores although this was modest as compared to the results from the iHV team.

It is important to bear in mind the challenging backdrop against which DDN champions delivered their cascade training particularly the Covid-19 pandemic an environmental factor that had an impact on both the training and the delivery of DN. DDN champions delivered the training amidst the pressures of social distancing measures, staff redeployment, staff members shielding, self-isolating, cancellation of non-essential training; having to learn to deliver training virtually, staff dealing with the secondary impact of the pandemic as well as the impact of the pandemic on staff emotional and mental wellbeing. Given this backdrop, we think it was a huge success that 5 out of the 6 sites were able to deliver the DDN as planned and produce the positive results that were observed. To build the capacity of DDN champions it would be important for them to continue to have opportunities to deliver the training so that they build their confidence and skills in delivering the training to enable them to have the same level of proficiency as the iHV team who have the advantage of several years of delivering related training to HCPs.

The HCPs were overwhelmingly positive about the training. Using virtual delivery was well received given the circumstances due to Covid 19, with some suggesting that this was convenient, but others

missing the opportunity to meet known and unknown colleagues, particularly from different disciplines, in person to have a better interaction. To support the effective delivery of DN, it would be important to address the organisational structure and culture in the NHS at the local and national level which had an impact on the uptake of the training as well as on the delivery of DN. Respondents discussed the impact of the persistent service pressures such as time, capacity and space on DDN. The skills that HCPs had developed for DDN could be undermined if a supportive environment is not created.

RECOMMENDATION

1. Scaling up DDN training through the cascade model

The findings illustrate that the DDN training is effective at improving the knowledge, skills, confidence and self-efficacy to deliver DN. This is a very important finding which is similar to our feasibility study findings. Implementation of the training coupled with policy and structural level changes that support effective delivery of DN may improve outcomes for families. We would recommend that the training be rolled out nationally and internationally given the interest in this work we have seen in the READY framework in Australia. With the imminent plans for using genomic medicine in the NHS as part of new born screening, this training is timely and crucial as a strategy for preventing generational mental ill health for families that receive different news. It is imperative for Health Education England to work with the iHV to secure funding to enable scaling up of the training nationally. We also recommend that the DDN training be used beyond the original scope of the first 1001 days as the data suggests that it has a much wider application for enabling delivery of DN in different settings.

2. Training Content

Although our co-production process allowed us to include a range of other experiences of receiving DN, feedback from participants showed that there was a need to further diversify the focus of the DN to reflect parents who received antenatal DN and a wider range of conditions or circumstances. It was felt that the DDN training and READY framework were applicable and useful for various other settings and including a wider range of conditions and circumstances would increase the training's relevance to various other HCPs and better support them in the reality of their role. There were also suggestions to include video role-plays to enable trainees to test out skills through role-plays.

3. Policy

Our feedback showed that practitioners overwhelming want to DDN well. However, they referred to persistent constraints which affected how well DN was delivered. These included lack of space, time,

shift patterns. These issues must be addressed alongside providing training to staff encouraging individual-level change to develop a more accommodating environment both for parents and for practitioners. This could include changes at the organisational/cultural/policy level to make lasting improvements for parents and practitioners. It is also important that the training enables HCPs to address these wider challenges that impact DDN well.

4. Research

It is important to note that the study has gathered information from a larger and more diverse group of HCPs and produced additional evidence of the value of the DDN training. The evidence base for the DDN training needs to continue to advance to ensure changes in policy and practice. Further research is required to understand the impact of delivering this type of training on the emotional and mental wellbeing outcomes of families who receive DN news from trained HCPs. Ideally, this would need to be answered through the use of a randomised control trial to compare outcomes with those who have news delivered by untrained HCPs. This would provide further evidence for the training and its potential impact on families that receive DN.

CONCLUSION

The DDN training aims to equip HCPs to demonstrate empathy; show compassion; utilise kind, simple and truthful language; offer sufficient time to answer questions and know where to refer families for further support. It utilises the READY framework. The significant improvements in confidence and skills reported by HCPs suggest that the training may be effective in equipping HCPs to minimise the psychological distress associated with receiving DN. This is a key aspect of the prevention of mental ill-health across the life course and contributes to the NHS Long term plan to improve understanding of the needs of people with learning disabilities and their families and to work with them to improve their health, wellbeing, and access to timely support. It is crucial that this training is rolled out nationally so that families that receive DN receive adequate support when they need it most.

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1. INTRODUCTION

The first 1001 days covering from pregnancy to the time that a child is two years old, are critical for their physical, emotional and cognitive development [1-3]. This is also a period of increased vulnerability for babies and their families particularly if their expected parenting journey is altered by the identification of congenital anomalies [2]. In 2018, it was estimated that 1 in 47 babies born in England had a congenital anomaly [4]. Congenital anomalies may be identified during pregnancy as part of the NHS Foetal Anomaly Screening Programme, at birth or during various stages of the child's life through developmental assessments and or tests [4].

The diagnostic process is pivotal for parents with significant implications for their emotional and mental wellbeing as well as that of their child [5, 6]. In this study, we refer to this process as delivering different news (DDN), which is the process of imparting information relating to a child being diagnosed with a congenital anomaly in the first 1001 days of life. Previous research reported that parents experienced various emotions after diagnosis including significant distress, shock, sadness, fear, grief, depression, anxiety and chronic stress [7-16].

Research also shows that positive experiences of receiving different news (DN) are associated with greater levels of acceptance of the child's condition, lower levels of stress, more effective coping strategies and more cooperation with HCPs [17, 18]. Consequently, there is evidence to suggest that effective delivery of DN can reduce stress, feelings of anxiety and uncertainty in patients [10, 13].

Ineffective communication can have adverse effects on parents, leaving them feeling anxious, uncertain and generally dissatisfied with their care [10, 13]. This is of particular importance in the first 1001 days of a child's life as parent experiences of chronic stress; depression, anxiety or other mental health conditions may affect foetal programming and the parent-foetus relationship – and post-birth this may affect the parent-infant relationship [19]. This, in turn, can impact the social-emotional, cognitive and physical development of children, increasing the risk of mood disorders in later life [20]. The experiences of adverse life events during pregnancy and the early years of a child's life have been associated with an increased risk of the development of mental health and behavioural problems in children which can last into adolescence [21]. Furthermore, maternal and paternal depression are also known predictors of poorer cognitive functioning, impaired adaptive functioning, increased risk of depression, anxiety and conduct disorders in some children exposed to this [22-24]. Perinatal mental health (PMH) problems cost approximately £8.1 billion per birth cohort, with 72% of costs being associated with the adverse impact on the child [25].

It is, therefore, crucial to ensure that every parent who receives DN in the first 1001 days of a child's life has access to an HCP who has the skills to deliver the news sensitively and compassionately. Currently, not every family has access to such an HCP when they need them due to a lack of standardised training or policy to guide professionals on how to effectively deliver DN [6, 7, 26]. To this end, there is significant variation in the way that DN is delivered by HCPs [6, 7].

However, clear compassionate communication remains a priority to families that receive DN. Providing evidence-based Communication Skills Training (CST) to HCPs could potentially minimise the negative psychological impact of the news, maximise the psychological wellbeing of the whole family and reduce staff burnout [18, 26]. CST has also been associated with improvement in HCPs ability to show empathy to families as well as increased patient satisfaction with services [27, 28]. Given that most patient complaints are related to poor communication as well as inability to demonstrate care towards patients, CST could benefit HCPs, their employers as well as families [17, 29]. Findings from a systematic review indicated that CST can improve HCP self-efficacy with regards to communication tasks including improved confidence to successfully deliver DN [30]. To this end, SE is a widely used measure for CST.

Providing HCPs with CST is consistent with the NHS Long term plan to improve understanding of the needs of people with learning disabilities and their families and to work with them to improve their health, wellbeing, and access to timely support [31]. It also resonates with the cross-government agenda to intervene more actively in the first 1001 days of life to reduce inequality, improve children's health, development and life chances [2, 3].

In 2017, our study team conducted a feasibility and acceptability study of this type of a CST to multi-professionals involved in the prenatal and postnatal delivery of DN [5]. We co-created the training intervention with parents and carers [5]. In addition, we integrated the voice of parents with lived experience in the training intervention. This aspect of the training was very well received and perceived as an integral part of the learning experience by HCPs.

We piloted the training intervention with a group of 26 HCPs including paediatricians, obstetricians, screening midwives and specialist neonatal nurses. Our training aimed 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; offer sufficient time to answer questions, and know when and where to refer families on to for further care and support [5]. These key aspects of DDN have also

been highlighted in other studies as crucial for minimising the negative impact of receiving DN on parents [7, 10-12, 15, 32].

We conducted a mixed-methods evaluation of the CST intervention. 26 HCPs self-completed pre-and post-training questionnaires on skills, knowledge, and attitudes related to DDN. Interviews were conducted with 8 HCPs. Quantitative data were analysed using descriptive statistics, and the paired t-test to compare the pre and post scores, estimate the difference between pre and post scores and the 95% confidence interval. Qualitative data were analysed using Framework guided by the Theoretical Domains Framework (TDF).

The training intervention was both feasible and acceptable. HCPs indicated that it enhanced or consolidated their knowledge and skills, covered topics relevant to their practice and that they would recommend it to colleagues. Participants particularly valued the integration of the voice of parents with lived experience in the training. Statistically significant increase in mean scores was observed in confidence to deliver DN (2.81, 95% CI 2.43 to 3.19; to 4.28 95% CI 4.09 to 4.47; $p<0.001$) and skills to DN (3.00, 95% CI 2.64 to 3.36 to 4.36, 95% CI 4.13 to 4.59; $p<0.001$) [5]. HCPs reported feeling more confident in their ability to provide sensitive, responsive, balanced care to families.

In 2019, we received additional funding from Health Education England working across Kent, Surrey and Sussex to conduct a larger study to test the findings of the exploratory feasibility study with a larger and more diverse group of professionals involved in the first 1001 days of life. In addition, we sought to understand the potential impact of the training on patient experiences as well as how to scale up the training to a larger cohort of healthcare professionals in a sustainable way.

2. STUDY AIMS AND OBJECTIVES

The aims of the study were:

- To test the initial findings of the DDN Study 1 by way of a larger scale cohort of HCPs from across the south of England.
- To demonstrate that the recommended intervention can be scaled up in a sustainable way that can meet the workforce needs or offer alternative sustainable interventions.
- To support the referral of this work to the NICE to scope, develop and potentially publish national guidelines.

- To develop and make freely available the first international evidence-based best practice guidance and education resource for staff to follow when providing DN.

The objectives of the study were:

- To further develop and co-produce the DDN training intervention based on the recommendations from the feasibility study.
- To create a DDN best practice guidance document to support multi-professionals who deliver DN to maximise the impact of the training.
- To conduct a pre and post-test study to measure the impact of the training on the self-efficacy, knowledge, attitudes, and practices of HCPs who receive the DDN training.
- To conduct qualitative exploration of the experiences of parents who receive DN from HCPs who have received DDN training.
- To conduct an in-depth qualitative exploration of the barriers and facilitators to the implementation of the training in practice from the perspective of HCPs and managers.
- To assess the sustainability and scalability of providing the DDN learning through a cascade model of training.
- To support the referral of this work to the National Institute for Clinical Excellence (NICE) to scope, develop and potentially publish national guidelines.

3. METHODS

DDN Study 2 comprised four main phases (Figure 1): the co-production of training materials to supplement the training intervention through interviews with parents; the delivery of training to designated DDN champions and the subsequent cascade training by these champions to their HCP colleagues; the mixed-methods evaluation of the training intervention to understand its value, impact and feasibility of delivery; and the policy and dissemination related work involving stakeholders to facilitate the transfer of research findings into policy and practice.

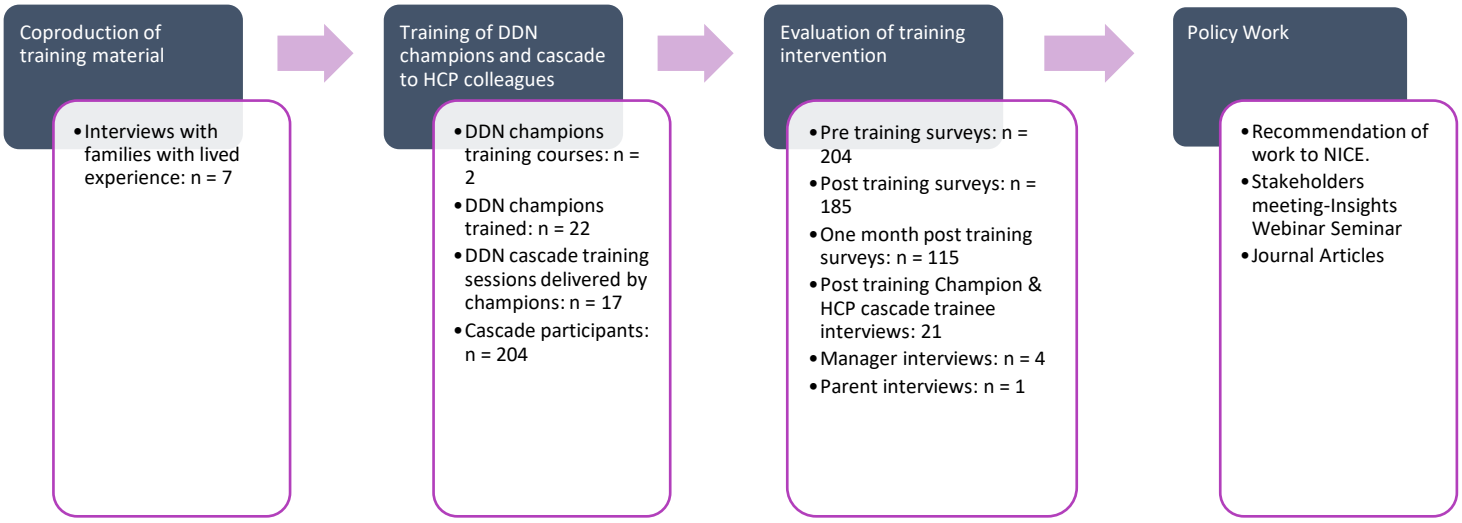


Figure 1: Overview of DDN study delivery and data collection stages

3.1 CO-PRODUCTION OF THE TRAINING INTERVENTION

We conducted seven parent interviews between March and July 2020 to further develop and co-produce the DDN training intervention which was originally developed during the feasibility study [5]. The interviews were used to develop additional case studies that looked at conditions other than Down Syndrome in order to have case studies of parents that receive DN beyond prenatal and immediately after birth. The case studies were used to emphasise the parent voice and experience of receiving DN. The parents recruited had received DN during pregnancy, at birth or after birth (up two years after the child was born). We worked with established links in local/national charities to identify parents of children with other disabilities diagnosed in the first 1001 days who were not represented in the feasibility study. The sample of parents included a father of a child with a disability and parents of children with a range of disabilities as per recommendations from the feasibility study [5]. Data collection was conducted during the first wave of the Covid-19 pandemic when stringent social

distancing measures were in place. As a result, all interviews were conducted via telephone and/or online virtual platforms, with appropriate consents recorded in advance. The interview guide explored the parents' experience of receiving DN, what went well and what could have gone better and their perceptions of training needs for HCPs. All interviews were audio-recorded. Summaries of the core lived experience discussed in the interviews were used to build case studies for discussion in the DDN training. These are not presented in this report but are included in the training package. Data analysed from the parent interviews has also been included in the write up of the results section in this report.

3.2 TRAINING OF DDN CHAMPIONS AND CASCADE TO HCP COLLEAGUES

3.2.1 NHS trust recruitment and training delivery

The Clinical Research Network (CRN) supported the recruitment of relevant NHS trust sites. Each of the recruited NHS trusts was asked to nominate at least three health care professionals (HCPs) with the clinical credibility, professional experience and confidence to teach their colleagues. These DDN Champions – received a one-day training to enable them to understand how to deliver DN and the expectations of their role as a DDN Champion (see Figure 2 for detail).

We recruited six NHS trusts. The first group (two NHS trusts in the South East of England which we refer to as Site A and Site B and one NHS Trust in West Midlands which we refer to as Site C) did the DDN Champion training in November 2020 and the second group (one NHS trust in the East of England- Site D, one in the North of England- Site E and one NHS trust in the West Midlands -Site F) were trained in February 2021. We trained a total of 22 DDN champions from a range of professional roles involved in the first 1001 days of a child's life (see Figure 3 for detail).

The DDN Champions are ambassadors for DDN within their local area, taking an active role in leading these very important agendas through:

- Cascading the training to colleagues: increasing awareness and knowledge of DDN within teams, enabling them to support families when they receive different news.
- Ensuring service users and those who are experts by experience are partners in the planning and shaping of local services.
- Being the voice of the child
- Making certain that services are inclusive and developed to meet the needs of its population with respect to diversity, equality, and equity.
- Empowering colleagues to raise parity of esteem for understanding the needs of families that receive DN and getting things right when DDN to families.
- Promoting evidence-based information at all levels
- Building community capacity through working in partnership with local citizens
- Dispelling myths and proactively working to challenge and reduce stigma.

Figure 2: DDN Champion role description

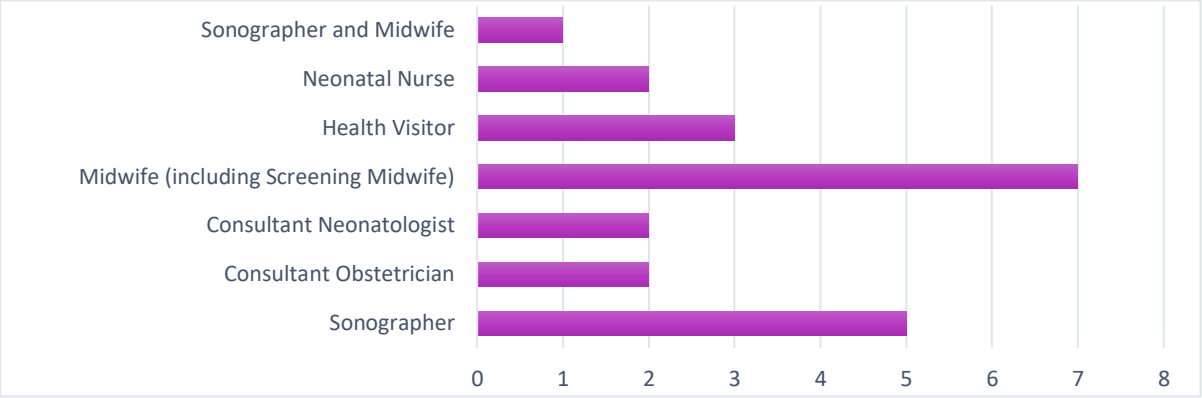


Figure 3: DDN Champions by role

3.2.2 THE DDN COMMUNICATION SKILLS TRAINING INTERVENTION

The DDN training was co-produced with the support of parents with the lived experience of receiving DN. It aims 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; offer sufficient time to answer questions; know when and where to refer families on to for further care and support [5]. These key aspects of DDN have also been highlighted in other studies as crucial for minimising the negative impact of receiving DN on parents [7, 10-12, 15, 32].

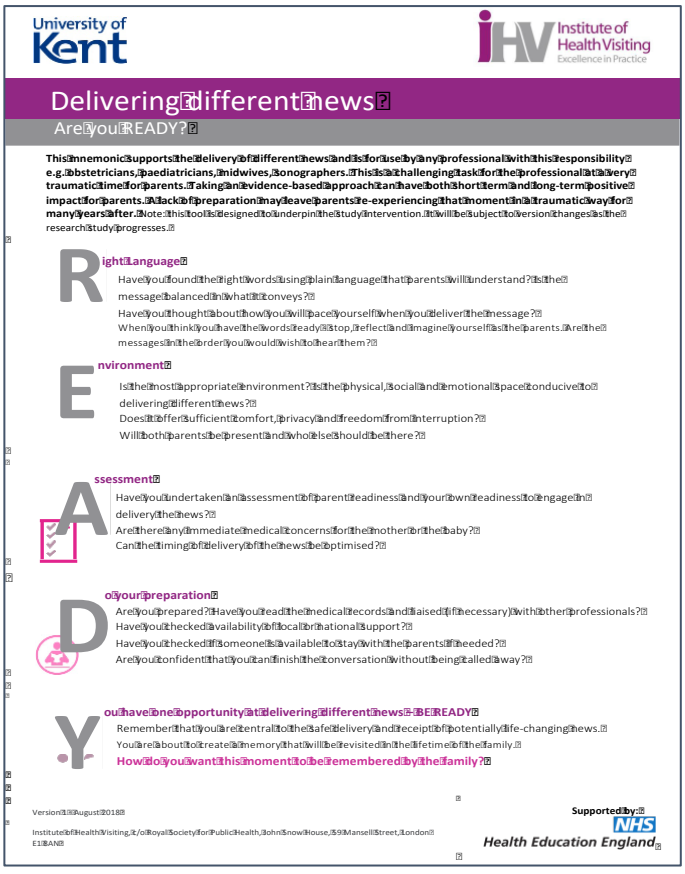
Prior to receiving this training, each champion received three pieces of 'pre-reading: a summary of the feasibility study [5], a journal article based on the feasibility study [18] and an article written from the parents' perspective exploring the impact of bias when delivering DN [33]. The training used didactic and experiential learning methodologies including an overview of the DDN study, an oral presentation by a parent with lived experience, discussion of case studies (informed by the parent interviews conducted during the feasibility study as well as the co-production process). The sessions that were included are in the training are in Table 1 below:

Table 1: Sessions for the Training

Session 1: Meaning of different news	Session 2: Components of effective delivery of DN	Session 3: Practical application of the learning	Session 4
• Discussion of the articles emailed to participants prior to the training. • Definition of different news. • The importance of the first 1001 days of life. • Impact, adjustment and coping with DN. • A brief discussion of perinatal mental health and infant mental health.	• Evidence from the feasibility study literature review • Example of lived experience from parents-positive and negative. • Practitioner resilience and wellbeing. Awareness and recognition and management of HCP emotional response.	• READY Protocol for communicating different news. • Use of READY protocol in case studies and role-playing how to improve on the negative scenarios. • Online completion of the post-training questionnaire.	• The role of a DDN champion. • Cascade planning tools. • Planning and delivering training • Working with parents to deliver training

Participants were also provided with a READY framework which is shown in figure 4 below.

Figure 4: READY FRAMEWORK



After the training, the DDN Champions were provided with an online set of the training materials, trainer resources and guidance and support from the research team to organise, plan and cascade the training. We asked each DDN champion to cascade half-day training to an additional 15 colleagues in relevant professions. The Champions then worked with managers (service managers, training managers, team managers) and/or PIs, as appropriate, to develop plans to deliver their half-day cascade training. How they did this varied according to their trust, their role and the professional groups of HCPs they were targeting for cascade training.

The training itself followed the same structure as the DDN champions training without the section on cascading the training. From April 2021, the 'live' parent experience session was replaced by a video presentation by the same parent and the Q&A session was replaced by a video of two parents with lived experience responding to frequently asked questions. This was in response to the need for greater flexibility by the DDN Champions, the concern raised by some DDN Champions that they may need to deliver multiple smaller sessions (due to the pandemic), and the need to develop a more sustainable training package.

3.3 MIXED-METHODS EVALUATION OF THE TRAINING INTERVENTION

3.3.1 QUANTITATIVE DATA COLLECTION

A. SAMPLE SIZE

Several issues governed the planned sample size, including the importance of:

1. recruiting various professionals involved in the first 1001 days of a child's life in order to see the applicability of the training to different types of services
2. recruiting enough HCPs and families to allow comparison between the outcomes of the training delivered by the research team and the outcomes of the training delivered by the DDN champions
3. keeping the training courses small enough to allow for effective teaching and discussion to occur
4. ensuring that data collection and analysis could be completed in the allocated timeframe for the study

Given the above factors, we initially planned to train a total of 240 HCPs (based on 15 DDN champions training 15 HCP colleagues). This was a much larger sample than we had in the DDN feasibility study, enabling us to answer more research questions and carry out more extensive data analysis. Based on

the sample size of 240 HCPs, the power to detect a difference of 5 points in the total SE-12 score, assuming a standard deviation of 20[2] and a significance level of 0.05 (95% confidence interval) was 97%. The minimum sample size required to attain 90% statistical power to detect a difference of this magnitude was 171 HCPs.

The Covid-19 pandemic impacted recruitment however due to staff absences and increased pressures on services. As a result, HEE agreed to the following: an extension to the timeframe from January 2021 closure to August 2021; an additional training session for DDN champions to increase the number of participating trusts and champions available for cascade training; and a reduction in the target number of HCPs to be trained to 200. We managed to recruit 204.

B. PRE AND POST-TRAINING DATA COLLECTION

Quantitative study data were collected using Qualtrics surveys completed online at three time-points: pre-training, post-training and 4 weeks (one month) after DDN training. Prior to the training, participants (DDN Champions before their training and HCP cascade trainees before theirs) were asked to complete an online pre-training survey to assess their knowledge, skills, and attitudes towards DDN. The survey link was emailed to each participant by the research team. The pre-training survey was based on the Self-Efficacy Questionnaire (SE-12) for communication which is a validated tool for measuring how HCPs demonstrate empathy skills and relationship building skills [34]. It also contained demographic, professional (background) and training-related questions. Each participant was allocated a 4-digit code to use in each survey so that data could be tracked anonymously.

The post-training surveys also included background questions, self-efficacy questions based on the SE-12 and questions asking participants to reflect on the training itself. The online survey links were sent directly to participants by email during the training session so that they could complete their feedback in the allocated time during the final session of the training. This method was planned to strengthen the response rate, however, some participants were not able to complete the survey at this point for a range of reasons, such as shift patterns or other work commitments, or access to electronic devices. In these cases, the research team and/or DDN champions followed up with the participant to encourage timely survey completion.

The final online survey was sent to participants after four weeks. It comprised background and self-efficacy questions based on the SE-12 but did not ask about the training in detail. 25 participants from the final three training courses were not sent this survey as data collection had closed by their +4 week

time-point. Participants who did not complete the survey were sent email reminders by the research team as well as their DDN champions to encourage responses.

3.3.2 PRE AND POST-TRAINING QUANTITATIVE DATA ANALYSIS

CSV files of the data were extracted from Qualtrics and imported to create Stata datasets before Statistical Analysis. Stata code was used for derivation of SE-12 scores and changes from baseline. The primary and secondary outcome measures are indicated in figure 5.

A. VARIABLES USED IN THIS ANALYSIS

The following outcomes were subject to statistical analysis:

- Self-Efficacy Questionnaire (SE-12)
- Demographic, professional, training data, SE-12 and individual items from the SE-12 as well as pre-and post-training questionnaires were summarised.

B. STATISTICAL METHODS

Stata/IC software version 16.1 was used to analyse the quantitative data. The proportion of missing data and patterns of missingness were examined for the primary and secondary outcomes. There was no evidence of systematic occurrences of missing data observed in the pre-and post-training data. Missing values were not estimated, only observed data were analysed.

SE-12 was analysed using analysis of variance (ANOVA) to compare the mean response pre-and post-training, comparing differences within participant. The model included fixed effects for the time, site (trust) and champion (DDN Champion or not). The differences between pre-and post-training SE-12 were estimated with 95% confidence intervals. Diagnostic tests and plots to assess the assumptions of normality were performed prior to analysis. There was some evidence of non-normality for SE-12, a sensitivity non-parametric analysis using the Wilcoxon signed rank test was

Primary outcomes:

Post-training Self-Efficacy Questionnaire (SE-12) [34].

Secondary outcomes:

1-month post-training SE-12 and change from baseline (pre-training) in SE-12 post-training

Individual items of the training questionnaires measured pre-and post-training:

- I know how to provide parents with meaningful support
- I know how to manage my own emotional response when giving news
- I feel confident delivering different news to expectant/new parents
- I have the skills to deliver different news
- I find delivering different news stressful
- I think it is important to signpost families to local or national resources for their immediate or long-term support
- It is important for me to deliver different news well
- I think it is important to share the responsibility of delivering different news

Figure 5: Primary and Secondary Study outcomes

performed in addition to the parametric analysis, and medians and interquartile range were presented in the plots. Individual items from the pre-and post-training questionnaires were analysed using the non-parametric Wilcoxon signed rank test.

Stepwise regression analysis was performed to model the relationship between demographic/professional factors and observed outcomes post-training for SE-12. A significance level of 0.1 was used to determine which factors are added and removed from the regression model. Factors included in this analysis are baseline SE-12, age, gender, profession, language spoken at home, length of employment in current position, prior training in DDN (Yes/No), prior training in communication skills (Yes/No), and trainer (champion or training team ID number or DDN champion). Summary statistics (mean, SD, median and interquartile range) were calculated and presented in tables. Summary data are presented graphically to illustrate the main findings from the statistical analysis.

3.3.3 QUALITATIVE DATA COLLECTION

A. POST-TRAINING PARENT INTERVIEW

After the training, we asked DDN champions to share a parent information sheet and invitation to take part in an interview with parents who had received DN from them. We hoped to recruit up to 10 parents through this method however the champions were not able to regularly share the information with families and we were able to conduct just one interview. We interviewed this parent using a semi-structured interview schedule to explore how the READY framework was utilised in the delivery of the DN. Prior to the interview, we ensured that this parent had sufficient study information, had provided consent and was aware of sources of support.

B. HEALTHCARE PROFESSIONAL AND MANAGER INTERVIEWS

HCPs were able to register their interest to take part in interviews via the online post-training survey. We interviewed 19 HCPs who were either champions or trainees using a semi-structured schedule that explored perceived changes in knowledge, attitude and practices after the training, the barriers and facilitators to transfer of knowledge into daily practice, and the strengths and limitations of the training. We also conducted interviews with four NHS managers from four different trusts to explore the barriers and facilitators to the adoption of the training in their trusts as well as the sustainability of the training. Managers were invited to interview by DDN champions and/or the PI and were provided with study information and consent. Two of these managers were also trainees who had

followed cascade training and therefore responded to both questions about the training and its feasibility. Interviews lasted between 25 and 45 minutes, were conducted by telephone due to Covid-19 social-distancing and lockdown restrictions and were audio-recorded then transcribed.

3.3.4 INTERVIEW DATA ANALYSIS

All qualitative interviews were transcribed from the audio-recording and organised using NVivo and analysed through Framework analysis [35] guided by the Theoretical Domains Framework (TDF) which is shown in Figure 6 [36, 37]. Framework analysis begins with familiarisation with the data, followed by the development of a thematic framework that is used for indexing the data [35]. This was followed by charting the data and then mapping and interpretation which allowed the development of descriptive and explanatory findings [35]. These were illustrated using various anonymised quotations. The seven interviews for co-production were also analysed as described above. The parent interview conducted after the training was analysed as a case study as we only managed to recruit one parent rather than the ten we had hoped to recruit.

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

Figure 6: Theoretical Domains Framework, with definitions and examples of each domain [37]

3.3 POLICY-RELATED WORK

The results of the current study as well as the feasibility study were used to lobby the NICE for the development of guidelines specific for this area of care. We made initial contact at the beginning of July 2021 once we had our final study findings. NICE indicated that new clinical guidelines needed to be formally referred to them by the NHS England's medical directorate. We went on to contact NHS England and NHS Improvement who have now referred this work to Public Health England (PHE) to review the need for clinical guidelines in this area. NHS England and NHS Improvement were able to do this on our behalf on the 13th of August. We are awaiting a formal response from PHE.

The iHV has also been able to contribute to the guidelines which are being developed by NICE for Children and young people with disabilities and severe complex needs based on our experience of the DDN study as well as other streams of work that involve co-production of training or projects with families and children with special and additional needs.

Nationally, the All Party Parliamentary Group (APPG) have expressed an interest in our study findings. We are awaiting confirmation of a date when we can present our study findings to the APPG.

We will be holding an Insights webinar in Spring 2022 for professionals and families as a method of disseminating our findings and to enable families to see the impact of their contribution to HCP training and to raise awareness for this training to HCPs.

After this final report is accepted by HEE, we will publish journal articles in peer-reviewed, open access journals and present findings at national practitioner conferences and patient forums. We are aiming to submit the following manuscripts by Spring 2022:

1. Building capacity to deliver DN in the context of the Covid-19 pandemic
2. Guidelines for delivering different news
3. Mixed methods evaluation of a multi-centre cascade model of communication skills training intervention to improve the delivery of DN by HCPs.

4. RESULTS

4.1 STUDY PARTICIPANTS

4.1.1 QUANTITATIVE STUDY PARTICIPANTS

In November 2020 and February 2021, we trained 22 DDN champions from six NHS organisations across England through two separate virtual, interactive training days. Our DDN champions were from neonatal and foetal medicine, health visiting, ultrasound and obstetrics. Between February and July 2021, the DDN champions delivered 17 half-day cascade training sessions. Pre-training data were collected for 204 HCPs (champions and cascade trainees) who participated in the DDN training. The mean age of participants was 44.8 years (SD 9.96), and most participants were female n=190 (94.1%). Table 2 summarises the characteristics of study participants.

Table 2: Quantitative participant characteristics

Age (years)		Mean	44.8
		SD	9.96
		Median	44
		25%ile	37.5
		75%ile	52.5
		N	204
Gender	Females	N (%)	190 (94.1)
	Males	N (%)	12 (5.9)
DDN Champion Profession		N (%)	20 (9.8)
	Health Visitor	N (%)	47 (22.9)
	Midwife (including screening midwife)	N (%)	28 (13.7)
	Neonatal Doctor	N (%)	10 (4.9)
	Nursery Nurse	N (%)	15 (7.3)
	Obstetrician or Obstetric Specialty Trainee	N (%)	2 (1.0)
	Paediatric Doctor/Trainee	N (%)	11 (5.4)
	Public Health Nurse	N (%)	7 (3.4)
	Sonographer	N (%)	52 (25.4)
	Specialist paediatric nurses OR Advanced Nurse Practitioners and/or Neonatal nurses	N (%)	21 (10.2)
	Other (please specify)	N (%)	12 (5.8)
Length of time employed in current position	Less than ½ year	N (%)	18 (8.8)
	½ year - less than 1 year	N (%)	16 (7.8)
	1 year – less than 2 years	N (%)	14 (6.8)
	2 years – less than 5 years	N (%)	33 (16.1)
	5 years – less than 10 years	N (%)	53 (25.9)
	More than 10 years	N (%)	71 (34.6)
	English	N (%)	180 (88.2)

Language spoken at home	Other	N (%)	24 (11.8)
Prior training in DDN to patients?	Yes	N (%)	40 (19.5)
	No	N (%)	165 (80.5)
Prior participation in communication skills training?	Yes	N (%)	117 (60.6)
	No	N (%)	76 (39.4)

4.1.2. QUALITATIVE INTERVIEW PARTICIPANTS

We conducted 19 interviews with HCPs and 4 managers. They comprised of four health visitors, four sonographers, four midwives, one paediatrician, two obstetricians, two neonatologists and two neonatal nurses, and four managers (some managers also held clinical roles; two attended the training). We also interviewed seven parents during the co-production process and one parent after the training was delivered. This sample allowed data saturation. The code and interview group of participants is in table 3 below. Due to the small sample size involved in the interviews, we have omitted the detailed description of participants to protect their anonymity and to ensure confidentiality.

Table 3: Qualitative participants: interviewees

CODE	INTERVIEW GROUP
POST-TRAINING PARENT1	Post Training Parent
CO-PRODUCTION PARENT1	Co-production Parent Interview
CO-PRODUCTION PARENT2	Co-production Parent Interview
CO-PRODUCTION PARENT3	Co-production Parent Interview
CO-PRODUCTION PARENT4	Co-production Parent Interview
CO-PRODUCTION PARENT5	Co-production Parent Interview
CO-PRODUCTION PARENT6	Co-production Parent Interview
CO-PRODUCTION PARENT7	Co-production Parent Interview
HCP1	HCP Interview
HCP2	HCP Interview
HCP3	HCP Interview
HCP4	HCP Interview
HCP5	HCP Interview
HCP6	HCP Interview
HCP7	HCP Interview
HCP8	HCP Interview
HCP9	HCP Interview
HCP10	HCP Interview
HCP11	HCP Interview
HCP12	HCP Interview
HCP13	HCP Interview
HCP14	HCP Interview
HCP15	HCP Interview

HCP16	HCP Interview
HCP17	HCP Interview
HCP18	HCP Interview
HCP19	HCP Interview
MANAGER1	Manager/Lead
MANAGER2	Manager/Lead
MANAGER3	Manager/Lead
MANAGER4	Manager/Lead

Our primary outcome measure was HCP scores on the Self-Efficacy Questionnaire (SE-12) [34]. Our secondary outcome measures were change from baseline (pre-training) in SE-12 post-training; individual items of the be-spoke questionnaires were measured pre-and post-training and at one month as well as 1-month post-training SE-12 scores. Self-Efficacy is an individual's confidence in their own ability to successfully accomplish a specific task. The concept is drawn from Bandura's Social Learning Theory [38]. To enable us to create a better understanding of the self-reported changes in knowledge, attitude and practices as they pertain to the delivery of DN, we used the TDF to explore how the training and READY framework were utilised in the delivery of DN; the barriers and facilitators to transfer of knowledge gained from the training into daily practice as well as barriers and facilitators to the adoption of the training at a managerial level. Our findings are categorised according to the relevant TDF domains that emerged from the qualitative data.

4.2 SOCIAL/PROFESSIONAL ROLE IDENTITY AND INTENTIONS

This section covers two TDF domains, social/professional role identity and intentions. We used this domain as a baseline to understand the motivations that participants had for taking part in the DDN training as well as the aspects of the HCPs, or their team's, practice that our interviewees were seeking to develop through participating in the DDN training.

DDN well was of fundamental importance to the interviewees both before and after the training as was reflected in the quantitative findings as shown in table 4 below:

Table 4: Pre and post-training scores on the importance of DDN well

It is important to me to deliver DN well	Time		
	Pre-training	Post-training	One month post-training
Strongly Disagree	1	1	0
Disagree	0	0	0
Neither Agree nor Disagree	0	0	0
Agree	47	26	18
Strongly Agree	139	160	91

Total	187	187	109
Wilcoxon signed rank test		0.0018	0.191

The response to this question was not statistically significant one-month post-training and this may well be because participants already felt that DDN was important as most of them indicated that they either agreed or strongly agreed that DDN well was important to them prior to the training.

In the qualitative interviews, there was an acknowledgement that '*no-one likes to tell someone difficult things*', for example, this interviewee noted that being able to '*make that better for somebody … (is) so important... (as) that initial contact sets the scene for everything else'* (HCP7).

There was a strong desire among the interviewees to improve services, reduce patient complaints, improve patient experience and help families understand and manage diagnoses in the best way for them. Developing DDN competency was viewed as a professional obligation: interviewees noted it was impossible to underestimate the importance of language and its impact, particularly since some were aware of the gaps in their skills and knowledge. The managers felt the training developed services and improved organisational culture. The cascade model was valued for its ability to share the learning across teams, multi-disciplinary teams in particular.

Among our DDN trainees were HCPs who had English as an additional language and for them, having the opportunity to develop stronger verbal and non-verbal communication in English, specific to DDN, was important for their confidence in delivery and care of parents and patients as this respondent explains:

> '*I have always really tried to improve my communication skills and being from a non-English speaking country, I've always thought well, whatever works in my favour, whatever can support me in my communication with parents, that would be great* (HCP12).

However, regardless of their first language, respondents welcomed the opportunity to develop skills, competencies and frameworks around communicating DN to parents so that they could both improve their practice, but also strengthen their capacity to cascade learning to colleagues to strengthen the team's practice. These motivations were important and closely linked to the domains of capabilities, skills and knowledge which were also measured as part of the study.

4.3 BELIEFS ABOUT CAPABILITIES, SKILLS AND KNOWLEDGE

The section brings three TDF domains: Beliefs about capabilities, Skills and Knowledge. The Beliefs about capabilities domain has constructs such as self-efficacy, self-confidence, empowerment and confidence. The Skills domain has constructs such as skills development and ability and the knowledge domain has constructs such as procedural knowledge and knowledge of tasks. We used these three domains to examine the status of respondents' perceived capacity prior to training, their explanations for this and the perceived changes after the training. Three factors were central to the narratives on beliefs about capabilities, skills and knowledge namely: the lack of standardised training, the confidence to deliver the news as well as the stress surrounding the delivery of DN.

4.3.1 LACK OF STANDARDISED TRAINING

Similar to our feasibility study, we found that central to interviewees' beliefs about their capabilities, skills and knowledge was the fact there is no standardised training in DDN across the various professions that were represented in this study. We found that 80.5% (n=165) of the participants had not had any training in DDN. Practitioners across all professions had developed their skill base through a combination of (unofficial) peer learning, personal experience and through reading academic or other relevant articles. Interviewees also noted that the skills they had often lacked a structured approach. The following quotes across obstetrics, sonography and midwifery illustrate this:

> *I haven't had any official training on stuff like this, it's all just picked up as we go along throughout our training. So, it's really nice to think there was something specifically designed to help us in this area because I think it's something we all struggle with* (HCP10)

> *As professionals, we've never been taught how to deliver, previously I would have said 'bad news' but now I say 'different news'… (earlier in my career), we were just expected to go ahead and do it and I didn't know whether I was doing it in the right way, the wrong way, was it acceptable to the patient, you know, nobody fed back to me* (HCP8)

> *My experience was just having training on the job, so being on hand during scanning. Really just paraphrasing what colleagues had said, and therefore learning from them* (HCP4)

Interviewees acknowledged a wide range of levels of experience, understanding and ability in the peers and senior professionals they worked with, with implications for the modelling of good practice.

4.3.2 CONFIDENCE TO DELIVER DN

The level of confidence and skills to deliver DN among respondents prior to training varied. Some respondents felt that they were almost overwhelmed by the prospect of DDN and were concerned about the impact on the parents as this interviewee explains:

> *It was hard, it was super hard that I actually, I usually struggle finding the correct words about how to discuss it with the parents or sometimes I try to avoid the discussion first or try to actually look for a doctor to do it for me and it takes a long time for a doctor to come in, and then what happens is that sometimes the parents just get frustrated because they've been waiting in there for the news to be delivered* (HCP17)

This was reiterated by a manager who noted that their trainees nearing the end of their course and those transitioning across from other specialities were often particularly worried about DDN (Manager 4). However, other respondents were more confident in their skills, gained through experience, relevant training (such as ARC training) and working with children with disabilities. They were aware of the importance of monitoring language for jargon and avoiding certain terms, such as 'risk' or 'bad news'. The training highlighted the need for ongoing pre-delivery planning and reflection on personal practice and exchanges with parents. This need for sensitive language cannot be overemphasised and was a particular need as highlighted by parents that helped us with the co-production of the intervention:

> *I think a couple of the nurses were probably a bit insensitive and a bit like they see this all day-in-day-out so they just are a bit, kind of saw that we were lucky because our child wasn't dying or wasn't like born three months early or something. But I think for every parent that's in that situation it's difficult, you don't compare yourself relatively to the other parents in there, you compare yourself to what you're expecting, which was a healthy child and going home with that child. So, I think probably some offhand comments, not from everyone, there was just the odd like generally the high up sisters that were just like "you need to like to be thankful for what you've got" kind of comments and I think you've got all those hormones rushing around so you're obviously feeling quite upset.* (Co-Production Parent 3)

4.3.3 STRESS RELATED TO THE PROCESS OF DDN

Despite their experience, DDN remained stressful for many practitioners often due to an appreciation of the fact that parents vary so widely in their responses. Respondents noted that they still took time to try to do their best in DDN, but that sometimes communication did not go well.

> *it's always been something that I've taken a lot of time to prepare for because even now, I still have to do that to calm myself down and think about how I'm going to say that and sometimes I write things down to*

help me because it's about getting the right terminology, pace and tone – so I know that I still find it a challenge (HCP13)

Although I might think I'm quite practised at it and quite good at it at times and think that hopefully, I support women quite well, I still get those experiences where I think, 'actually I didn't do a great job there' because somehow the way that I was with that woman didn't fit her, everyone's different… so yes, I still find it difficult and I'm still very aware that, you know, it's not a routine… it's never a case of 'oh well I can just say that because it doesn't work that way, everyone's different (HCP2)

The quotes above indicate that DDN may still be a challenging task despite training and experience largely because of an inert desire to get things right for families. It is possible that this may explain why there was very little change in the post-training responses to the question '**I find delivering different news stressful',** as shown in Table 5 below:

Table 5: Pre and post-training scores on DDN related stress

I find delivering different news stressful	Time		
	Pre-training	Post-training	One month post-training
Strongly Disagree	1	4	0
Disagree	7	17	14
Neither Agree nor Disagree	50	38	31
Agree	102	104	52
Strongly Agree	27	24	12
Total	187	187	109
Wilcoxon signed rank test		0.616	0.0033

4.3.4 LIMITED FEEDBACK FROM PARENTS

Some participants noted the absence of a structured way to collect feedback from families as a learning and service development strategy as it could seem inappropriate to ask, as this interviewee explains: '*they've got too much in their heads already and nobody would push one of those survey cards in front of them'* (HCP4). Therefore, parent feedback is limited to complaints or thank you cards/emails, though there are opportunities for practitioners to discuss cases at a team or small group level, both formally and informally. This was illustrated in our post-training parent interview where our parent discussed how she was supported emotionally and with information by a bereavement midwife in follow up to her baby's death, however, she was not asked specifically to

provide feedback about her experience of receiving this news as shown in the case study report in figure 7:

The parent who was interviewed was 34 years old. She and her husband have three more children.

After a smooth early pregnancy and early scans, she experienced some bleeding and her midwife referred her to a consultant. The consultant noted that the growth rate of her baby was less than expected and suggested a scan. He listened to the baby's heartbeat, checked her blood pressure and told them that the scan would provide more information and that the baby might need to be delivered a little early. The scan was booked for the following week. At the scan, the sonographer found that the baby had died and shared this news with the parents. The scan suggested that the baby might have died one to two weeks earlier. The parents were then supported by a bereavement midwife and counselled over how they wanted to end the pregnancy. They have questions over when their baby had died and why the scan was not booked sooner (within 72 hours) for them. They are receiving support from their local community midwife and the hospital-based bereavement midwife who is also providing updates, as appropriate, on the findings of the report from analysis of the placenta.

Figure 7: Parent Interview Background

It would be important to develop ways to systematically gather feedback from parents about the process of receiving DN sensitively.

4.4 BELIEFS ABOUT CONSEQUENCES OF THE TRAINING, SKILLS AND KNOWLEDGE

The following TDF domains present respondents' beliefs about the consequences of participating in the training in terms of their skills, knowledge and confidence in DDN. We also examined the content of the training and perceptions about how this would lead to expected changes in clinical practice.

4.4.1 CONFIDENCE

We measured participants' self-efficacy (confidence to complete the task of DDN) before and after the training using the SE-12. There were statistically significant differences between pre-and post-training SE-12 scores at both post-training time points. SE-12 was significantly higher post-training. The estimated difference post-training was 18.3 (95% confidence interval 15.7 to 20.9), and one-month post-training 16.9 (95% confidence interval 13.7 to 20.2). These comparisons were also significant using the non-parametric Wilcoxon signed rank test as shown in table 6 below:

Table 6: ANOVA estimates of pre-and post-training differences

	Outcome	Mean post	Mean Pre	Difference	95% CI	ANOVA P-value	Wilcoxon signed rank P-value
Post-training	SE-12	103.9	85.6	18.3	15.7 – 20.9	<0.001	<0.001
One month	SE-12	102.5	85.6	16.9	13.7 – 20.2	<0.001	<0.001

These changes were also reflected in the qualitative data. Interviewees described the impact of the training on their confidence:

> *I think the training has helped… however they react you know that you've got that knowledge base to act accordingly… I don't shy away from it, and I don't, I don't fear it as much … I would never look forward to it, but I think, I think if anybody has to give it, I want to be one of the people that give it, because I'd like to think that I have the knowledge base and the skills to give that news in the best way possible, rather than somebody else giving it* (HCP3)

Practitioners noted that the training had also given them the confidence to continue to sit with families across a range of their responses: '*it definitely made me feel that the next time I'm in that situation, I'm more skilled in how to go about dealing with that and more confident in the phrases and terminology'* (HCP18). There were also opportunities to reflect on situations where HCPs might have been questioned by colleagues for their actions on behalf of families – hearing from parents and the research was a welcome justification in some of these cases: '*I've always felt that I did the right thing, but the course really made me say, you did the right thing'* (HCP7).

We examined the quantitative data to understand if these changes were the same across the various trusts that participated in the study as well as across professions, trainees and champions. There were no statistically significant differences in the change from baseline in SE-12 between trusts, although overall SE-12 scores for the NHS trust in the North of England were higher compared to the other trusts. This is an important finding which suggests that self-efficacy to deliver DN increased across the board although there was some variation in the changes across the sites.

We examined the data to see if there was a difference in scores between HCPs who were trained by the iHV team and those trained by the champions (cascade trainees). There was a statistically significant difference between DDN champions and non-champions, SE-12 scores were generally higher for champions and the improvement from pre-training was greater. The difference from non-

champions in SE-12 change scores post-training was 7.81 (95% confidence interval 1.37-14.2) and 13.0 (95% confidence interval 3.10 – 22.9) one-month post-training (see figure 8 and 9 for details).

Figure 8: SE-12 Median and Interquartile range over time by Champion

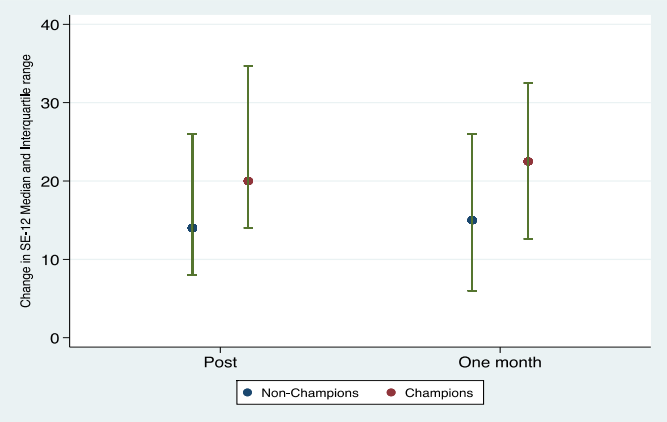
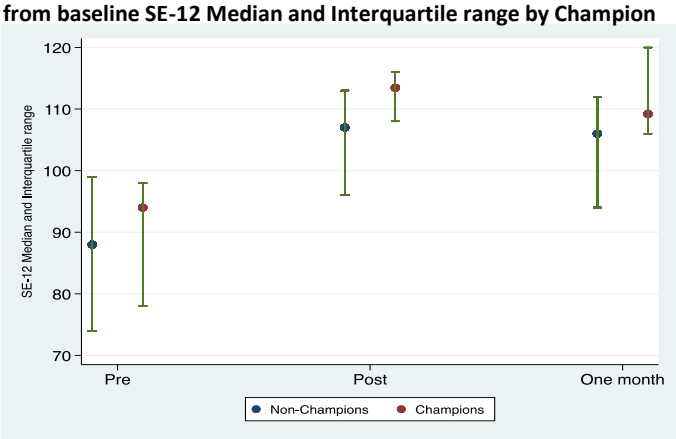


Figure 9*:* Change from baseline SE-12 Median and Interquartile range by Champion



4.4.2 KNOWLEDGE AND SKILLS

Both the qualitative and the quantitative data indicated that the training had an impact on the knowledge and skills of the participants. There was a statistically significant increase in the perception that HCPs were confident to deliver DN and that they had the skills to deliver DN after the training as shown in table 7 below:

Table 7: Pre and post-training scores on confidence and skills to deliver DN

I feel confident in delivering different news to expectant/new parents	Time		
	Pre-training	Post-training	One month post-training
Strongly Disagree	7	2	1
Disagree	41	2	1
Neither Agree nor Disagree	76	20	11

Agree	58	111	70
Strongly Agree	5	52	26
Total	187	187	109
Wilcoxon signed rank test		<0.001	<0.001
I have the skills to deliver different news	Time		
	Pre-training	Post-training	One month post-training
Strongly Disagree	2	1	1
Disagree	22	1	0
Neither Agree nor Disagree	89	13	4
Agree	69	111	79
Strongly Agree	5	61	25
Total	187	187	109
Wilcoxon signed rank test		<0.001	<0.001

Among other things, the training gave HCPs confidence and skills in the following areas: pacing the provision of information to the needs of the family, the use of the right language when DDN as well as provision of a structure for delivering the DN conversation using the READY mnemonic. We discuss these in detail below.

A. PACING THE PROVISION OF INFORMATION

In the interviews, HCPs indicated that the training afforded them with opportunities to rethink how parents managed information when experiencing shock and how the service or team could ensure parents had time, access to help and support bearing in mind that there is no failsafe mechanism for every parent. Interviewees said they were now more likely to provide a clearer route for families through the information they received, gauging their level of understanding and need for additional input. This is an important aspect of DDN which was also highlighted by parents when we developed the training intervention:

> *I needed 24 hours to come to grips with it and I needed somebody to either take the children or give me 24 hours just to get my head around it because it was such a bombshell...It wipes out everything that you never knew that you were thinking about, all their future that you never thought you were thinking about, but you didn't realise how much you had held onto that subconsciously in your head.* (Co-Production Parent 1)
>
> *I do think giving you all that information on the day…it's a lot to take in…so the only suggestion that I would make is to give the parents a couple of weeks or so to process the information, especially when it's a diagnosis like it's been in my son's case, then follow it up with a phone call or email the parent and say, when is a good time for me to give you a follow-up phone call and then give them all the resources*

but to give it on the day it's too much, it's just too much to take in because I misplaced half of what they gave me, I couldn't remember what's what, it was so overwhelming. (Co-Production Parent 6)

One respondent noted that a parent had phoned her after their initial DN conversation to ask for more information. She reflected that this could have been because she now more explicitly ensures parents know they can call her, though it was difficult to know what motivated this parent: 'she said,

'*I think we've already talked about this, but I can't remember so she asked another question. Whether that's coincidental or whether some of that is because they felt better supported I don't know, it's difficult to tell isn't it?*' (HCP2).

B. RIGHT LANGUAGE

Interviewees described a greater commitment to getting the language right for parents around diagnoses and testing, referring to 'chance' rather than risk and being more mindful (HCP5). While again, there was often an existing knowledge of the language shift, hearing the rationale behind that change from a parent was impactful:

'*listening to the parent contribute, listening to them very, kind of clearly repeat what they'd been told even though it's many years down the line and you know how jarring they found certain phrases, etc. these were things, the terminology that I was aware of, but I think it added a new, kind of, emphasis to things'* (HCP18).

Some practitioners in particular were fascinated by the learning and thinking around the impact of the first 1001 days. While they were aware of the importance of this time through their job, one person noted:

I had never connected that to how families were reacting with the news about disability and the importance of getting the parents in a more positive mindset from the start… and that helping them in terms of their acceptance and so on' (HCP1).

Respondents referred to using this kind of insight with their practical subtle skills to structure '*a more holistic picture of how it should be done rather than doing it haphazardly*' (HCP8).

C. STRUCTURING THE DN CONVERSATION

We heard that the structure of the READY mnemonic was providing a way for HCPs to organise themselves and relate their existing and new knowledge to the experiences of parents and the communication skills they, as parents, were advocating:

…it helped me a lot because at the moment I think more on how to discuss it. I think first on how I would discuss it, build a rapport… try to weigh things up… then I'm much more careful with my words. I'm much

more confident in doing things in a way and then I can compartmentalise what I feel… I just needed to first have like a structure. I think it's always a stressful job to deliver DN but I'm much more confident and secure now (HCP17)

In other interviews, participants also indicated that the READY mnemonic gave them a basis to make wider changes and to structure communication with parents. On the SE-12 scale, the biggest difference in pre and post-training responses for participants was seen on Question 6: "How certain are you that you are able to successfully structure the conversation with the patient?" The mean score changed from 6.33 to 8.37 a difference of 2.04, 95%CI (1.75-2.33; p<0.001) immediately after the training and 2.15, 95%CI (1.80-2.51; p<0.001) one month post-training. This is an important finding which suggests that the READY mnemonic potentially enabled HCPs to have an evidenced-based format of how to structure and pace a DN conversation. To this end, the READY mnemonic was also to be used by other interviewees to make structural changes across the organisation:

'*in the context of something that is unexpected… the strategies we possess and strategies to implement with, sort of, clear practical information that was given, that was really useful. And then, yeah, but I think still, you know, a lot of people use the term bad news, which I think one of the things that we'll be doing in our organisation is to slowly change that traditional approach'* (HCP9).

D. VARIATION IN IMPACT OF THE TRAINING ON KNOWLEDGE

Although there was an overall gain in skills and knowledge among participants, it is important to note that the impact of the training was variable. In the interviews, some participants felt that the knowledge gained by more experienced HCPs was not extensive and that the knowledge and skills uplift would have been greater in more newly qualified colleagues given the fact that some had significant experience on learning through practice and collaboration. This was also reflected in the quantitative data. Stepwise regression analysis to model the relationship between demographic/professional factors and post-training SE-12 (figure 10 and 11) showed statistically significant differences between those who had previously received DDN training and those who hadn't. Pre-training SE-12 scores were higher for the 40 participants who had received prior training in DDN, but the change from baseline was lower. The difference in the SE-12 change score between those who had received prior training and those who hadn't was -7.36 (95% CI -12.5 to -2.25). The one-month post-training scores were similar for both groups.

Figure 10: SE-12 Median and Interquartile range over time by prior DDN training

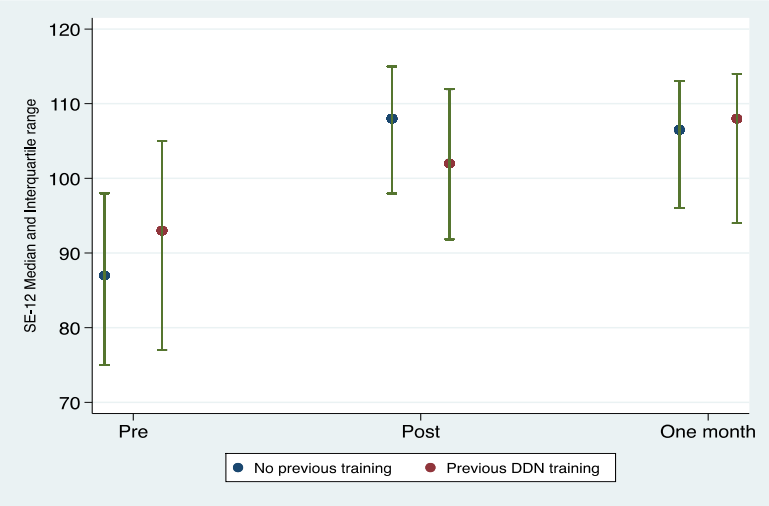
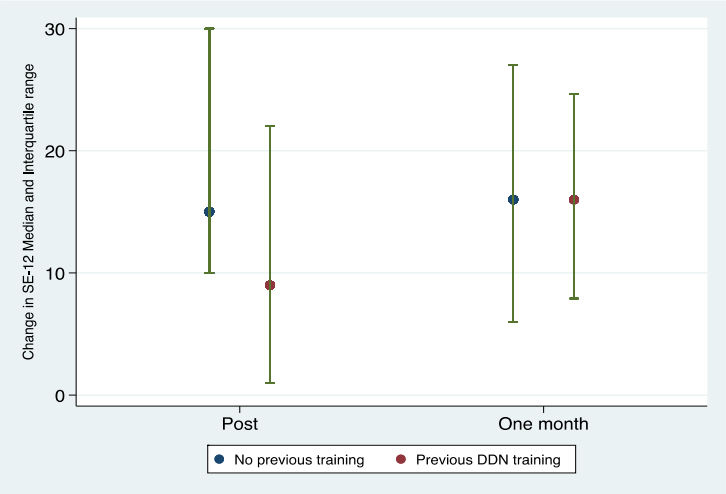


Figure 11: Change from baseline SE-12 Median and Interquartile range by prior DDN training



4.4.3 THE TRAINING DESIGN, DELIVERY AND CONTENT

The Champions were overwhelmingly positive about the training they had received on DDN noting how they valued that it was '*well structured, with well aware, well-informed trainers and parent involvement… very much in synch*' (HCP12) with a 'good flow' (HCP4). There was continuity in the responses across different professions who referred to the course as '*a really good day, it was the right length of time, it was long enough, we got enough in, but it was varied as well*' (HCP7) and having energy (HCP13).

Using virtual delivery was well received given the circumstances due to Covid 19, with some suggesting it was convenient this way, but others missing the opportunity to meet known and unknown colleagues, particularly from different disciplines, in-person to have a better interaction: 'o*bviously online is never the perfect arena… but it does actually mean that you have because you are not having to travel and book less of your day out, so it has benefits*' (HCP1).

Participants appreciated that the content was sensitive and noted that they felt '*held and looked after* by the trainers (HCP1), as well as '*part of it and welcome*' (HCP4).

A. PARENT CONTRIBUTION

The parent input was highly valued as '*powerful*' (HCP9), emotional and '*really useful*' (HCP19): '*it brings it alive really'* (HCP1). Participants felt that the tone was just right (HCP7). Others appreciated the lasting impact of parent input, the fact that it was possible then to '*carry those parent voices around in the back of my head*' as a guide (Manager 3), allowing them to '*hit home and really resonate*' (HCP10). Some champions wondered whether it would encourage a more open discussion if there had been an opportunity for the participants to reflect together on their learning from the parent contributor and how they wanted to relate her input to their practice.

The case studies from the initial parent interviews were also useful for generating discussion, with the opportunity for smaller-scale discussions in breakout spaces, though some of the situations described were quite shocking to participants. These worked best when instructions were clear and groups were diverse, however, there was some advice to develop more challenging scenarios and allocate more time for discussion for greater impact. Champions valued the opportunity to develop these case studies for the cascade training to reflect their work and fully anonymised cases of families they had worked with, keeping the parent and baby focus.

The pre-reading resource which explored bias [33] based on parents' lived experience gave the participants a strong 'eye-opening' insight in advance of the training and combined with the other opportunities to hear from parents, as this HCP reflected: '*actually seeing it put down in words, I think makes it hit home a bit harder, I think maybe really seeing, then hearing, I found it quite sad at some points, some of the journeys that people had been through and it set us up well for the day and what was expected…*' (HCP10). Access to this material was valued, particularly since there are few opportunities to hear from parents in a way that feels safe for the parents as part of the daily routine.

B. DOWN SYNDROME FOCUS

When interviewees reflected on their own work, some suggested that it would have been useful to have the opportunity to discuss or receive insights from a wider range of conditions, with parents who had received DN ante- as well as post-natally; they also suggested conversations with parents – or among practitioners – about less '*well-researched, well clinically well-defined*' conditions (HCP9) with less certainty for the family, or where the baby is dying or has died as an opportunity to learn from each other. However, in later discussions with champions post cascade delivery, some reflected that the parent video of the lived experience of receiving DN on Down Syndrome was so powerfully and clearly delivered that it lent itself to the wider discussion (e.g.: HCP1).

C. ROLEPLAY

Some champions and HCP trainees noted that they would have valued some role play examples to be able to then evaluate good and poor practice and try out delivering content, in a similar way to content is delivered in medical education: '*Some videos… some examples of good communication and some bad communication…. Like we do in the exams for medical school… then if we could have some kind of interaction'* (HCP8). This was also important for some participants who did not have English as their first language in order to support them in the appropriate word choice and delivery.

4.5 ENVIRONMENTAL CONTEXT AND RESOURCES

For the Environmental context and Resources or Environmental Stressors domain, we looked at the personal situations that encourage or discourage skills development; organisational culture as well as critical or salient events to examine the factors impacting access to and engagement with the DDN training and the delivery of DN more generally. Our data indicated that patient demographics; organisational culture; continuity of care and the Covid-19 pandemic were central to the narratives on effective delivery of DN as well as the training.

4.5.1 PATIENT DEMOGRAPHICS

Interviewees noted the broad variation in the patient (and parent) populations they worked with. It is important to acknowledge the degree of diversity and ensure messaging is understandable and meaningful to all parents. The skills gained from the training could be undermined by the factors such as parents who did not speak English, those with an additional need or those with lower literacy levels.

HCPs reflected on the difficulties faced when DDN to parents who did not speak English and they had to use the support of interpreters (sometimes over the phone) for such important news.

> *Because of the language barriers, some people would just say, there's no heartbeat but they wouldn't understand and after saying 'your baby has died' then they understand but it's not the way you wanted to deliver it* (HCP5)

> *Especially if English isn't the first language as well, that's another challenge… and again, you know you're then having to have your interpreter over the phone* (HCP7)

Ideally, a professional interpreter would be present for such conversations, however, it also seemed clear that sometimes there was no language support. In these circumstances, more subtleties were lost in trying to ensure the message was understood with potential impact on the quality and depth of delivery. It would be important to ensure language support is available to non-English speaking families when DN is delivered.

Other factors that could also limit HCPs ability to transfer the skills gained from the training into practice included parents having additional learning needs, lower literacy levels, deprivation or negative perceptions of HCPs connected with prior negative encounters and the power differential between practitioners and patients/parents. As well as considering how these factors influence how information is received or framed, interviewees also noted that there would be an impact on how that information is passed on to relevant others for example between family members and the need to ensure that DN is also delivered effectively for parents in these situations:

> *When you consider, some of the families work with are, you know they might have some sort of learning needs themselves, I'd not consider how they would then communicate that information* (HCP1)

> *You've got to try and maintain that relationship, but you need to be an advocate and, you know, we have to have really challenging conversations… (that are) really important for public health* (Manager 3)

4.5.2 ORGANISATIONAL CULTURE AT LOCAL AND NATIONAL LEVEL

The organisational structure and culture in the NHS at the local and national level had an impact on the uptake of the training as well as on the delivery of DN.

A. IMPACT ON THE TRAINING

At a local level, the ability to attend the training was perceived as a function of the flexibility associated with the role as well as the time dedicated to training for the role. Participants had to navigate attending the training within these confines. For example, the consultants who participated in the training had a level of flexibility in their roles which enabled them to arrange a time for training and teaching, e.g.: through their SPA time (Supporting Professional Activity time). In other professions (i.e.: staff who were not doctors) access to the training was generally facilitated by local team, service or training managers in line with the organisational policy/culture:

> *our line manager… she's pretty fair, to be honest, so we don't ever have any problem getting on training… I mean it's constantly changing in public health, so we need to do lots of training* (HCP19)

Some managers were able to arrange cover through organising agency staff, and other participants used their day off to attend (facilitated to an extent by the fact that the training was predominantly delivered virtually) or an admin day. At one trust, the training sessions were booked to coincide with audit days when only emergency scanning would take place on the unit. However, workload and work pressures remained in many cases with some participants needing to make up lost time/caseloads (which were already at capacity) on their return to work. Some trusts were able to pay practitioners to attend the training in their own time, however, this was not consistent across trusts, varied between the (smaller numbers on the) champion training and the (larger) cascade training, and was dependent on the availability of budget.

B. IMPACT ON DDN

Respondents discussed the impact of the persistent service pressures such as time, capacity and space on DDN. The skills that HCPs had developed to DDN could be affected by time and capacity issues:

> '*sometimes we cannot find the right words to express… because of the hectic workload. Every 20 minutes, for example, we have a new call and if it's sad news – we have to say there's no heartbeat today in your baby – so we have to tell straight away*' (HCP11).

I think anywhere you have a clinic booked, in that you can't step out, you can't step away from, you know, if you are the only person that can carry on with that scan list (you give the news, then it's almost) goodbye, my colleague will sort you out. It's just, it's really unsatisfactory' (HCP3).

The parent we interviewed after the training, also indicated that the news had been delivered to her quite quickly which potentially added to the shock of receiving the news as well as the parents' understanding of the news. Delivering the news early in the consultation may have allowed for time for the confirmatory check by a colleague and follow up discussion, however, it was difficult for the parent to hear the news so suddenly. This may have also been influenced by Covid-19 restrictions with practitioners being asked to keep talking to a minimum to reduce the chances of transmission, as discussed later in the section on Covid-19 /impact on DDN.

she just keeps on the thing on my tummy, and she nearly straightaway said… "Oh there is bad news, there is… like not good news," or "your baby heartbeat is no more." … I think maybe she could take a minute or something... maybe she can talk like, maybe a minute, you know? She just says very quickly everything, you know, so we said what happened like we couldn't understand. (Post Training Parent1)

Some suggested that a broader culture change was needed to bring about a more conducive environment for DDN, rather than focusing on individual-level change for staff who did not deliver news very well due to pressures on staff. Understanding the contributing factors to DN delivered under strain, respondents noted how practitioner tiredness could also negatively combine with parents' tiredness and emotional load as this respondent explains, '*if you've been on call every single night and it's been disturbed, everything shifts slightly – and I think if I'm here like this and you've got a woman who maybe hasn't slept for 36 hours, you know, the two of you together isn't a good combination'* (HCP13). Similarly, respondents said that appropriate spaces for DDN were not always available or appropriate meaning that DN was often shared in environments that are not supportive to the parents as this interviewee explains,

'*the room environment is really hard for us… in our unit, we do have a quiet room… but sometimes it is not available and then we discuss the news inside the wards and then there are other parents entering… I see that my parents would actually want to ask a lot more questions or have a lot of worries in their face, but they can't just verbalise it because there are other parents around*' (HCP17).

Whole system changes would be needed beyond the training to ensure that provision of space to deliver DN is a priority as per the READY framework used in the training.

4.5.3 NATIONAL POLICY DRIVERS

A. IMPACT ON THE TRAINING

At the national level, organisational changes and the adoption of care reforms and policies had an impact on the ability to engage with the DDN training. For example, changes in service delivery models such as a continuity model of midwifery (and the government pledge of every woman knowing their midwife within two years had an impact on HCPs ability to attend training. This was of particular concern to managers who had to implement changes but also ensure staff development: '*you're assigned a woman and you follow that woman, so you don't sit on a ward… it's new, there are no templates… we're learning lessons along the way. So, it's been challenging*' (Manager 1). This change has impacted staffing, leaving some services short-staffed at times and meant that that usual training had been cancelled within the trust, as well as new training including DDN: '*even though Covid-19 is moving on, we are nowhere near in the position to even get back to where we were before with the training because of our staffing and this continuity strategy*' (Manager 1).

B. IMPACT ON DDN

Respondents cited continuity of care as a highly valued aspect of delivering care. It reduced the need for families to repeat their stories, built trust between practitioners and parents and improved communication. In smaller teams, there was a greater capacity for this. Having this level of contact and continuity was clearly seen as an advantage both for being able to maintain contact with families after DDN but also in terms of providing context to DDN if the parent has already established a form of relationship with the team.

Our post-training parent interviewee explained how she had been allocated a bereavement midwife who has been able to maintain contact, provide support and updates and ensure information is being shared in the best way for the family. While this midwife was not involved in the initial DN delivery, she was allocated shortly afterwards.

> *she asked me, she text me, she just, you know, just give us the support, the emotional or like mental support, she just, she is very good as well, she asks me so many times like oh how you're feeling, you okay, you need any help or something, so it's like okay* (Post-training Parent 1)

This was also reiterated by parents that we interviewed when we co-produced our training intervention:

because I'd met her [the HCP] *and I knew kind of her manner [laughs], and I mean is there a nice way to deliver bad news, so I mean that you need to be honest without being brutal, don't you? You can't soften difficult news like that, but I think the most important thing for me was that I knew who it was that was ringing, and it was the same person, as opposed to how she delivered the news, I think.* (Co-Production Parent 2)

*She was very calm; she was very matter of fact. I think it really helped that she knew us well because she'd been treating ******* (child's name) *since day one that we went into the hospital. She knew a lot about our background and was able to reassure us of what it meant.* (Co-production Parent 4)

This parent was also able to speak first-hand about their experience with a lack of continuity in care, which led to a great deal of unnecessary frustration in their mind.

making sure the continuity of care is there, I think that's, the only thing that we've struggled with is, it's obviously when you have to go and explain it again and, when you've not heard of it before, which 99% of people are not going to have, explaining it every time takes a good five, ten minutes before they can process that and then actually move on with what you need to do and talk about. (Co-production Parent 4)

4.5.4 COVID-19

The Covid-19 pandemic is an environmental factor that had an impact on both the training and the delivery of DN.

A. IMPACT ON TRAINING

At the outset of Covid-19, there were concerns about redeployment among medical teams and how they would manage the process. This manager described the early changes and the impact on non-medical work:

at the beginning of the pandemic, there was a lot of concern that we may be redeployed and, you know, as things were just spiralling and we didn't know where we were going and then as things settled down and the service just started to, to just continue to deliver we were able to, I would say October/September last year we were really able to think about training again (Manager 3).

Whilst some specialities (e.g.: neonatal) were less impacted by the uplift in Covid-19 patient admissions to their wards, others such as sonography saw an increase in the demand for scanning. While mitigating actions were in place by the time the first DDN Champion training was delivered in November 2020, the lockdown which started in January 2021 due to another sharp rise in Covid-19

cases and hospitalisations altered the environment once more. This had an impact on the services and raised further questions over their capacity to release staff for cascade training. This team decided to go ahead but acknowledge the level of unpredictability:

> '*it's a challenging time… if there are emergencies on the day then we can cancel – I actually myself came out of the training to do some emergency scans because we had major cases – ideally, you want to be there and just concentrate but if you're working in this environment, we can't predict. So, I think that's one of the challenges*' (Manager 2).

Further, across all specialities, there were also several staff members shielding, self-isolating and taking sick leave for Covid-19 symptoms or the impact of stress throughout the project.

> *We have long-term sick, we're short of staff, so it has been a lot of things beyond our control* (Manager 2)

> *We were hoping to deliver the training at the end of January but because of the staff shortages we couldn't* (HCP12)

However, there were some positive impacts of Covid-19 on the training schedule. The necessary shift to online (Microsoft Teams and Zoom) training to reduce social contact has meant that this form of delivery has become normalised: '*I think as a service we have embraced new technologies… we won't go back now, and I think the reason we're able to open our training is through that, the digital platform*' (Manager 3). Despite an often 'clunky' start, the technology offer has improved through 'breakout rooms and Jamboards (digital whiteboards)' and it has enabled staff who are shielding to participate, reduced travel time and made training more accessible to some because it is less time consuming: a half-day training is just that, rather than half-day, plus travel, parking and associated costs:

> '*(before) it would take the whole day clinically… whereas the virtual training… people just log on, they do their training, then they log off and it seems to be a lot more effective, people value it*' (Manager 3).

> *I think we can offer people more; we can offer… people more training and more development if we do it like this*… (Manager 3)

B. IMPACT ON DDN

Respondents were consistent in their feeling that Covid-19 had had a great influence on DDN, and their parents' experience as stated by this participant, '*I think Covid-19 has had a massive impact, on women's experience particularly*' (HCP3).

The PPE worn by HCPs to reduce Covid-19 transmission impacted DDN. Respondents described how masks obstructed many non-verbal cues and while practitioners tried to adjust their communication to mitigate this, it was difficult. Similarly, social distancing meant that the opportunity to touch was removed with some respondents feeling this had the potential to increase parents' sense of isolation on receiving DN.

> *The mask, you know, PPE what we used, so maybe the person cannot see my actual emotion… I try to use my hands and body language, but I hope it helps… Social distance rules make it a bit difficult because we can't come close to them, like two metres distant and this kind of barrier, which is between us, I think it's also making difference to the patient, they feel like isolated sometimes, so it is difficult* (HCP11)

Similarly, Covid-19 guidance placed restrictions on the number of people permitted in a room to reduce the likelihood of transmission which meant that partners could not always be present. We heard a range of examples of individual parents receiving news, but also of HCPs seeking to secure support for them. Interviewees acknowledged how this affected parents receiving DN and the fact that it meant that some parents were angry and if they received DN, the parent would then need to go on to share the news with their partner.

> *They're angry they can't have partners, and it's having to deal with that side of it as well, which is something you would never normally have to deal with* (HCP3)

> *You had to take into account that person was on their own and they had to ring their partner and tell them what you just told, you know… the news they'd received… we couldn't let them in the department, and they were outside sitting in their car* (HCP4)

Our post-training parent interviewee told us that for her routine scans she had been told that she could bring one person in with her and that when she met the doctor to discuss her baby's growth and attended the follow-up scan, he had asked if she wanted to call her husband to join her if he was already in the hospital. She explained that she valued this for the support it gave: '*I was thinking like obviously the partner should be there, for support, yeah, because if you tell a lone person… you can't get support, you know?*' (Post Training Parent 1). However, while she did not have to pass on information to her husband, she explained how she had to share the information with her children who were waiting for her, providing some insight into the emotional load of sharing this information.

> *my other daughter, she was waiting in a car as well, my mind is like in two directions, you know, like what should I say to her, because we had just planned, my daughter was with me, so she said, 'Okay, well mum we, when we finish your scan so when we go to the shopping for the baby and everything,' because the kids*

were too as excited, you know because it's after ten years, I had this pregnancy, and the baby is growing up properly now, so they know that everything now, what's going on, and you know like they were preparing their selves as well, we want to do this, we want to do this… they went through the trauma as well, because they are waiting for the baby

The fact that sonographers did not have the flexibility to adapt their lists to spend time with parents, particularly those who were alone due to Covid-19 restrictions, was frustrating. Other alternatives such as asking parents to come in to discuss results rather than DDN over the telephone were also curtailed by the pandemic.

The day before Christmas Eve I had a lady who was all on her own. Obviously, her partner wasn't there and there was no heartbeat… and it's just, oh, no matter how much training you have, given that news… I think as long as you've got to carry on with that scan list… I'm going to be unsatisfied by that, by the way I give that news (HCP3)

Policies around partner admissions to scanning appointments seemed to vary according to the stage of the pandemic, the prevailing national social distancing measures that were being implemented. There was also variation between trusts and even between hospitals. Some teams had a greater level of flexibility to respond to parents and partners than others. This was related (in some cases) to having access to suitable spaces:

They allowed both parents at the moment here… but at (hospital name), they allowed only the patient, no partner, so everywhere is different rules at the moment – and I don't know what's going to change now after tomorrow (HCP11)

I tend to ignore those policies when it comes to people that are being given unexpected news… we've got a particular room… we don't have to go through any wards so they (the parents) literally can come upstairs and straight into that room, so I always tell them their partners can always come (HCP2)

While practitioners felt it was important that parents had the support they needed at the time of sharing different news, some also noted that having additional people in the room was highly stressful at a time of heightened anxiety about transmission. This anxiety felt by staff could be seen as detrimental to the communication in the scanning room.

'they've complained and now Public Health England wants partners to come in even though we are already in Tier 4 – so in the obstetric field only (for first and second-trimester scans) someone else is allowed in the room so with everything that's going on, you're anxious… thinking, oh my gosh, what if I get something you know… we're told you're not meant to talk a lot for spreading but the partners are asking so many questions

and then you have to concentrate… there are many factors now, unlike before when everyone was free and you could talk freely …. So, it makes it hard, but we're still trying you know, trying to make it the best we can' (HCP5)

The need to ensure that news is delivered well and that parents receive the support they need and are signposted accordingly was also reflected in the quantitative data with statistically significant improvement in the scores before and after the training as shown in table 8 below:

Table 8: Pre and post-training scores on the importance of signposting families

I think it is important to signpost families to local or national resources for their immediate or long term support	Time		
	Pre-training	Post-training	One month post-training
Strongly Disagree	2	2	0
Disagree	2	3	0
Neither Agree nor Disagree	11	5	6
Agree	92	43	36
Strongly Agree	80	134	67
Total	187	187	109
Wilcoxon signed rank test		<0.001	0.0058

4.6 BEHAVIOURAL REGULATION

This section presents examples provided by the interviewees of how they have regulated or changed their behaviour around DDN since taking part in the training in line with the Behavioural Regulation domain of the TDF. Overwhelmingly, interviewees discussed how the training had helped them to develop their practice in terms of their involving parents in the process more actively, their assumptions about the parental understanding of conditions and how they share information ensuring they provide balance, and how they look after themselves.

4.6.1 INVOLVING AND EMPOWERING PARENTS

Interviewees described how they wanted to involve and empower parents. One example of this is provided by an HCP who adapted their introduction to parents to ensure they are more involved in their scan appointment and better prepared. The HCP described their conversation with parents at the start of the appointment to 'set the scene' to provide both practitioner and parents with a clear pathway through the appointment.

> *I think (couples) think it's more of a social visit sometimes rather than a diagnostic view of their baby, so we have to sort of prepare them but in a nice way … so I've introduced that into my spiel because I feel that sort of sets them up to think, oh yes, you know, we're not just here to find out the sex of our baby… so I think from that point of view they're very attentive… I think it's had a dual purpose of engaging everybody in why they're here for the scan so that's really helped* (HCP4)

Another interviewee described how since the training, their team had worked with a woman and her baby who has Down Syndrome. The team's focus was on empowering the mother and ensuring the process has been led by her and marked what this respondent saw as a very conscious shift in their way of working.

> *Since the training, we have had a lady carry on the pregnancy with T21, and I think it just, I think the training just reinforced how it's to be led by her, I think we very much put it into her hands, you know, saying, 'We'll support you 100%.' And I think, again, we've made sure she has seen the same consultant each time. It's just given the continuity, yeah, so putting all the, taking all the comments from Angie, all the negative things from the case studies that were presented, I think it's, 'Right, well, we're not going to do that, we're going to do this.'* (HCP3)

The above experiences were also reflected in the quantitative findings. There was a statistically significant increase of 1.87 points (95% CI 1.59-2.16; $p<0.001$) in the average score in response to Q2 "How certain are you that you are able to successfully make an agenda/plan for the conversation with the patient?" on the SE-12 Scale. A lower but statistically significant increase was observed at one month 1.55 points increase (95% CI 1.21-1.90; $p<0.001$). There was also a statistically significant increase of 1.74 (95% CI 1.47 – 2.01; $p<0.001$) in the average score in response to Q3 on the SE-12 score: "How certain are you that you are able to successfully urge the patient to expand his or her problem/worries?". These changes suggest that the training gave HCPs the skills and the knowledge to actively seek to engage the patient in the decision-making process and the care plan. This is an important aspect of ensuring patient agency and autonomy.

We also found that the training was also applicable beyond the immediate target group as illustrated below:

> *At the weekend I had a girl with a new diagnosis of a probably oncological malignancy, she's 12, so not at all within the age range of the course, but… I was just really thinking… about the way I sat with the mother because it's Covid-19 so we can only have one parent down, trying to speak to the dad on speakerphone, so just trying, so things like that making, you know, being mindful about thinking about*

my choice of words, how I go into things, how I lead into things… I was very conscious of wanting to allow both parents to be involved in the discussion, which I think definitely came across from the course, the importance of not just giving information with one, I think mainly the mother and then there are scenarios on the course, and, you know, giving the mother the burden of then having to explain that to her partner or her, you know, the rest of her support mechanism.

I suggested early on that we facilitate the child going home quite early on so that the family could be together and that they would have support mechanisms rather than staying in hospital and being separated. This child is under my name, to see if there's anything specific that the family want, you know, made myself available to come back and answer further questions if the parents have. So, I think, again, that was something that was really emphasised in the course, is being available to go back and have subsequent discussions (HCP18)

4.6.2 PLANNING AND STRUCTURE

To translate the training into clinical practice, there was a need for HCPs to reflect on how to make the training applicable to their practice and clinical settings. For example, acknowledging their busy schedule, this HCP was keen to ensure they were was able to 'reset' between each appointment and start each session with parents with a good structure to ensure they had sufficiently planned to deliver information well to parents indicated below:

Transparency is everything… whereas before it might have come across as being a bit rushed, not now. No. so that's how I've changed. I start every single appointment, scan with the thoughts that this might not go the way we all want it so therefore what am I going to do? And what have I got on hand, who can I call on, etc., so yeah, I've just become more organised, I think. It's made me more methodical in the way I approach delivering the news, how I would like to hear it, you know if I had to...What is it, what it means (HCP4)

4.6.3 INFORMATION MANAGEMENT AND COMMUNICATION

Acknowledging the fact that parents have so much information to cope with and might struggle to order their thoughts and questions, another HCP explained how they were working to give parents more thinking time and opportunities for follow up. Another interviewee reflected on the confidence that they now had to manage the timing of information sharing based on optimising support for the parent/s:

On Friday at half-past four, I got a CVS result that showed a baby had Edward's syndrome. And I, you know, I just thought, no, I didn't give that result, you know, my colleagues gave it this morning (Monday) because

that lady, you know, she did not need to know that at half-past four on a Friday and then be left with nothing, nowhere to go over the weekend, no one to talk to. I think as a whole know, if something comes in past two o'clock on a Friday, we think right, we'll leave that till Monday - you know, unless the woman is desperately waiting for it, I think, yeah, there is no, there is no need to give it there and then (HCP3)

This is an important change to clinical practice which was also highlighted by parents during the co-production process with the need to not leave parents hanging with no one to speak to being emphasised: *the way we found out is we just got a letter through from the geneticist saying, '"your daughter has a genetic diagnosis, here's an appointment time" and it was like for three or four weeks away.* (Co-production Parent 3)

Moreover, parents during the co-production process emphasised the need for HCPs to listen to parents, to their concerns which relates very closely to patient empowerment:

> *I felt really dismissed by her when I had real concerns and bizarrely, afterwards, when we actually came back after the diagnosis, she said to me, "well how do they know he's blind?"* (Co-production Parent 1)

> *I said I don't think his eyes look right and the GP reassured me and said, it's fine. And then the health visitor, I mentioned some concerns to her, and she thought I was depressed and sent me on a parenting course.* (Co-production Parent 5)

Our quantitative data as shown in table 9 below, also indicated that HCPs generally felt that they were better able to support parents after the training as shown in the results below which were statistically significant immediately after the training as well as one month after the training:

Table 9: Pre and post-training scores on knowledge to provide meaningful support to parents

I know how to provide parents with meaningful support	Time		
	Pre-training	Post-training	One month post-training
Strongly Disagree	1	2	1
Disagree	17	1	1
Neither Agree nor Disagree	56	14	3
Agree	102	105	69
Strongly Agree	11	65	35
Total	187	187	109
Wilcoxon signed rank test		<0.001	<0.001

4.6.4 OPTIMISM AND BALANCE

The fact that the parent contributors retained such a strong image of they received their DN as a film in their mind long after they had received it was highly impactful for the interviewees. One HCP described how they are ensuring that they provided parents with more balanced information, or simply took time to focus on the baby or babies, noting this was a shift from how they would have previously presented information when the prognosis was poor. This is an important aspect of DDN which was highlighted by parents during the co-production process:

> *if we'd have found out that she had the heart condition and didn't have Downs Syndrome nobody was going to sit down with us and say, you know, your baby's got to have open-heart surgery when they're born and, you know, do you really want to put a baby through that, you know, do you think you might want to think about, you know, and there just wouldn't have been that discussion. But all of a sudden because [name] has Downs Syndrome there's, it's changed it in some way and it's, she's almost less of a person, less of a child.* (Co-production Parent 7)

We heard similar descriptions of more balanced and family-focused conversations from other practitioners, motivated by the 1001 days input, the fact that they had been given the 'green light' to present more positive information by families with lived experience and a focus on building the parent-baby relationship where possible.

> *So, I had a lady who came to my foetal medicine clinic, monochorionic monoamniotic twin pregnancy and the babies had multiple abnormalities… the prognosis was very, very poor. So obviously the way I spoke to the mother, first of all, I did mention to her that you've had a scan, you've got two lovely babies but there are things which is a bit different than I need to talk about. So, the mother said to me, is everything okay? So, I said, no, everything is not okay... So I looked at the positive first and said the babies are, the heartbeat is fine, they are moving and they're lovely babies, wriggling around and then I came onto that, but I did not give her all the information, I said that this is how much I would give you but if you want more information, there's a lot for you to take in, I am happy to go through it or if you want to have a cup of tea and come back then that's fine.*
>
> *In this Covid-19 situation we don't allow partners to come in but with her, I did allow the partner to come in to give the information and for them to sort of digest and they came back at the end of the clinic, I knew that day I didn't have anything in the afternoon, so they came back at the end of the clinic with a clearer picture and then I went through everything.* (HCP8)

4.6.5 SELF-CARE

Lastly, the training highlighted the emotional impact of DDN and the value of formalised supervisor support as well as informal peer support structures. This was also reflected in the quantitative data as shown in the table below with statistically significant changes in average scores to the questions on the importance of management of personal emotional response when delivering DN as shown in table 10 below:

Table 10: Pre and post-training scores on the personal emotional response when giving DN

I know how to manage my own emotional response when giving news	Time		
	Pre-training	Post-training	One month post-training
Strongly Disagree	1	3	1
Disagree	11	1	1
Neither Agree nor Disagree	55	15	3
Agree	104	111	65
Strongly Agree	16	57	39
Total	187	187	109
Wilcoxon signed rank test		<0.001	<0.001

Many of the respondents acknowledged that there was support available in different formats, but that they did not tend to access it. One participant also discussed how there was an expectation that consultants are better able to 'handle things, but that this was starting to change with the current generation of doctors better able to express emotion and those around them more likely to allow them that. This was also reflected in the quantitative data with a statistically significant increase in the scores for the importance of debriefing and accessing support from colleagues immediately after the training but not at one month after the training as shown in table 11 below:

Table 11: Pre and post-training scores on the importance of debriefing and accessing support

It is important for me to be able to debrief and get support from colleagues	Time		
	Pre-training	Post-training	One month post-training
Strongly Disagree	0	2	0
Disagree	0	0	1
Neither Agree nor Disagree	7	3	0

Agree	76	51	40
Strongly Agree	104	131	68
Total	187	187	109
Wilcoxon signed rank test		<0.001	0.105

Our qualitative interviews indicated that self-care was seen as particularly important given the pressures of the pandemic on top of existing service pressures: '*especially with what's happening in the NHS at the moment, I think people's resilience levels are rock bottom*' (HCP7)

> *It's made me think, yeah, it's holding, my approach is holding an awful lot in, and I do need to start talking to other people and getting that sort of support that is available in the team… it made me think about the emotional toll that it can have on you* (HCP1)

The training also gave participants an opportunity to reflect on the need for joint responsibility when DDN and accessing support from colleagues see table 12 below so that HCPs did not have to deliver DN when they were exhausted, stressed and not at their best. Table 12 shows statistically significant differences in scores immediately after the training and one month after the training

Table 12: Pre and post-training scores on sharing the responsibility for DDN

I think it is important to share the responsibility of delivering different news with other team members	Time		
	Pre-training	Post-training	One month post-training
Strongly Disagree	0	2	0
Disagree	3	6	1
Neither Agree nor Disagree	26	15	5
Agree	84	55	43
Strongly Agree	74	109	60
Total	187	187	109
Wilcoxon signed rank test		<0.001	<0.001

4.7 REINFORCEMENT

This section presents responses about the TDF domain Reinforcement – incentives that could increase the impact and sustainability of the DDN training.

4.7.1 ORGANISATIONAL AND TEAM CULTURE

Without mandatory DDN training, working towards a team culture around DDN can provide a strong 'safety net' which strengthens team capacity and addresses areas of concern. While this is already happening to an extent through team meetings, 'huddles' and informal conversations, the training has helped to build momentum and a more consistent approach via a more structured way to influence colleagues. Champions and trainees aligned themselves with building momentum around DDN through structured and non-structured mechanisms such as mentoring students in DDN, focusing on strengthening and sustaining the culture – the conversation – around DDN and incorporating the key DDN themes into other associated learning. This was shown in the comments across obstetrics, paediatrics and midwifery.

> *I think if we develop something, really good culture and a really good way of work and delivering different news, I think that will be passed on quite quickly* (HCP10)

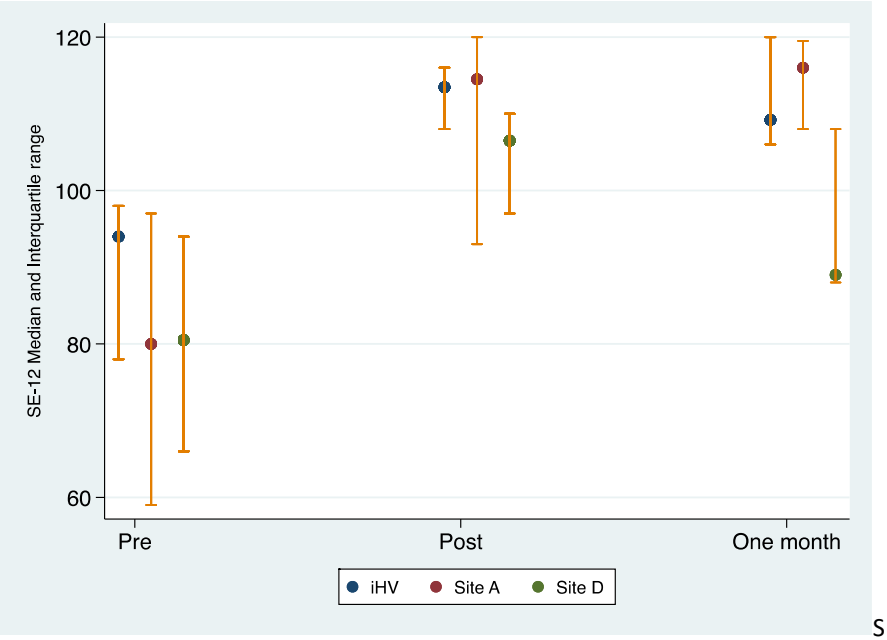
> *I'm thinking about how to incorporate it into either a sort of skills simulation, a communication skills-based simulation, or communication skills-based teaching… I think a number of my colleagues would be interested and I would certainly recommend the course to other people*. (HCP18)

> *I think taking the opportunity – if there's a student, take that student in with you. You know, because they will start to… almost students are more important than the trained staff in a way because they are at the beginning of their journey* (HCP7)

Managers were also motivated to support new members across departments to access the DDN training as part of their Continuous Professional Development, acknowledging that '*the whole department can run better if the communication is good – you get less complaints, usually most complaints are about communication'* (Manager 4). This sentiment was expressed across more than one trust: '*we've had some issues of patients leaving saying that you know, the way it's been delivered (requires improvement) … and so we're taking all that into consideration, so it was essential for her (the Champion) to get involved*' (Manager 2)

Our quantitative findings suggest that the cascade model of training is both feasible and acceptable. The percentage of DDN Champions who delivered one training to 15 HCPs (either individually or as part of a team of trainers) was 60%. Twelve of the champions delivered DDN training to 15 or more HCPs. Stepwise regression analysis showed statistically significant differences in SE-12 for participants who were trained by iHV and HCPs trained by champions in site A and site D but this was not seen for the other sites (see figure 12). Pre-training SE-12 scores were lower for those trained by site A and Site D champions, but post-training scores were similar to the DDN champions who were trained by the iHV team. This is an important finding which suggests that sufficient support, practice and training is required in order for the champions to produce the same results as the iHV team. This can make the DDN training sustainable in the long term.

Figure 12: SE-12 Median and Interquartile range over time by Trainer



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4.7.2 CONTRIBUTING TO MONITORING AND EVALUATION OUTCOMES

One manager described how she was at an early stage of discussing how to record data on conversations between HCPs and parents, suggesting it would be possible to use an existing facility, System One, to capture data on the conversation and the outcomes. The team had already been using System One to collect data connected to another research project and it was felt that there would be value in recording instances where DN is shared for monitoring, increased understanding and improvement.

This exploration of methods of data capture aligns with the high (and growing) number of documents that services are required to be compliant with (e.g.: CNST, Saving Babies Lives, MatNeo) and audited against with appropriate evidence. There could be potential here to assess where DDN training and outcomes could support departments or teams to evidence compliance with key documents.

4.7.3 PROMOTING THE READY FRAMEWORK MORE WIDELY

While the DDN framework was initially focused on DN regarding a congenital anomaly associated with a learning disability, the feedback from champions, managers and HCP trainees has confirmed that the READY mnemonic is more widely applicable and in fact, should be used for a greater range of scenarios to build a greater level of consistency in DN across teams.

Some practitioners were working with families who have received DN from a different team or department and felt that aligning the approach to DN would be valuable. For example, one of the HCPs referred to working with families struggling with the news they had received from outside of their service. These families faced similar issues which are covered in the DDN training such as too much information delivered without understanding checks, coupled with a lack of support.

> *we do an awful lot of picking up the pieces when the news has been delivered badly when parents have been given a diagnosis and sent away with no other explanation, and also sometimes parents, well mostly they go through some sort of grief reaction, they get told an awful lot of information only once, they're not in a place to take it in, they kind of turn in on themselves for some time, and then when they re-emerge there is nobody there because everybody thinks that they've told them what they need to know, but in reality, they just weren't in a place to take it in really* (HCP1)

Our post-training parent interviewee's experience emphasised the fact that DDN is a 'process, not an event which involves a range of practitioners with different roles delivering a package of care. This sentiment was also reflected by the parents we interviewed during the co-production process, emphasising the importance of a multi-disciplinary approach to the training:

> *a diagnosis isn't a discrete event, that there can be months and even years of getting little bits of information, so there was say a point where I knew that he was delayed but I didn't know it was a genetic condition... when I first went into the conversation with the ophthalmologist I didn't know, so when he said to me, when did he roll, when did he do this, when did he do that, he concluded he was delayed and that was actually a bit of a diagnosis, so there's been multiple happenings like that along the journey where lots of different people have given us bits of information, said not always that sensitively.* (Co-production Parent 5)

As well as having the news delivered that her baby had died by the ultrasound team, our post-training parent had conversations about taking medication to induce labour and her wishes with regards to her baby and investigation with two other practitioners. Prior to and following this, the family had met with a doctor who had booked the scan and discussed her follow up care. She also had follow up discussions about her baby's death with the bereavement midwife and, at home, with her community midwife.

Our interview showed that while she had some suggestions about making improvements to the way her DN was shared, she valued the continuity and support provided by the midwives in particular. Her main concern however which overshadowed this was a procedural one regarding how quickly her scan was organised after concerns were raised: '*we think like this thing need to be changed if the doctor is worried, and we are in hospital… there is the scan room, everything was there… so maybe this thing can change, you know? …maybe they shouldn't wait for the five days or, you know, like 72 hours, maybe they should say and send straightaway*?' (Post-training parent 1). This procedural issue emphasises that DDN is part of a wider package of care and that difficult conversations may be had in follow up to the delivery of the DN itself. One of our DDN champions noted that the DDN framework can be useful in discussion with parents where care has not gone as planned or where there are delays for example.

Interviewees also felt that the DDN framework was applicable to situations beyond the first 1001 days and to a range of health issues. Under the Behavioural regulation section, we presented a scenario where an HCP described the application of the READY framework and DDN learning in oncology, working with an adolescent and their family. We also heard about the application of the framework to community settings where it can support difficult public health or safeguarding conversations with families were '*you've got to try and maintain that relationship, but you need to be an advocate and, you know, we even have to have really challenging conversations* (Manager 3).

Discussing whether the training would need a high degree of adaptation to be relevant to these broader ranges of situations, this manager felt that the core should remain, with the opportunity to broaden the discussion through the case studies (as was the case by some of the champions).

> *I think, I think it is really relevant… that the training, not change it or adapt, but just to sort of make it relevant for other conversations, so really difficult conversations that you've got to have with that parent, and it could be down to even hygiene, the home environment, it could even be around things like obesity*

and diet. It really can morph itself into a lot of other situations that is, I think that's where we will take our sustainability (Manager 3)

This approach was taken by our DDN champions who developed a range of additional case studies to bolster the training to generate wider discussion around ante-natal care, neonatal care and health visitor/community care.

5. DISCUSSION

5.1 SUMMARY OF KEY FINDINGS

We trained 22 DDN champions from six NHS organisations across England through two separate virtual, interactive training days. Our DDN champions were from neonatal and foetal medicine, ultrasound and obstetrics. The DDN champions delivered 17 half-day cascade training sessions. Pre-training data were collected for 204 HCPs (champions and cascade trainees) who participated in the DDN training. We conducted 19 interviews with HCPs and 4 managers. They comprised: four health visitors, four sonographers, four midwives, one paediatrician, two obstetricians, two neonatologists and two neonatal nurses, and four managers (some managers also held clinical roles; two attended the training). We also interviewed seven parents during the co-production process and one parent after the training was delivered.

Although DDN well was of fundamental importance to the interviewees, 80.5% (n=165) of the participants had not had any training in DDN. This is similar to what we found in our feasibility study and has also been noted in other studies [5, 27]. Practitioners across all professions had developed their skill base through a combination of (unofficial) peer learning, personal experience and through reading academic or other relevant articles. There was a strong desire among the interviewees to improve services, reduce patient complaints, improve patient experience and help families understand and manage diagnoses in the best way for them.

Both the qualitative and the quantitative data indicated that the training had a significant impact on the knowledge and skills of the participants similar to what we found in our feasibility study [5]. We measured participants' self-efficacy (confidence to complete the task of DDN) before and after the training using the SE-12. There were statistically significant differences between pre-and post-training SE-12 scores at both post-training time points. SE-12 was significantly higher post-training. The estimated difference in mean scores post-training was 18.3 (95% confidence interval 15.7 to 20.9 p<

0.001), and one-month post-training 16.9 (95% confidence interval 13.7 to 20.2; p<0.001). Other studies have also reported that communication skills training has the potential to improve HCP self-efficacy as well as HCP-patient communication [27, 28].

We examined the quantitative data to understand if these changes were the same across the various trusts that participated in the study as well as across professions, trainees and champions. There were no statistically significant differences in the change from baseline in SE-12 between trusts, although overall SE-12 scores for one of the NHS Trusts in the north of England (Site E) were higher compared to the other trusts. This means the training improved confidence to deliver DN across the board although results for each site slightly varied. This is an important and promising finding for the DDN training intervention.

Overall, there was a statistically significant increase in self-reported confidence and skills to deliver DN after the training similar to our feasibility findings. Among other things, the training gave HCPs confidence and skills in the following areas: pacing the provision of information to the needs of the family, the use of the right language when DDN as well as provision of a structure for delivering the DN conversation using the READY mnemonic. These are very important aspects of the DDN process which have been documented in similar studies [39, 40].

These positive changes were also reflected in the quantitative data. On the SE-12 scale, the biggest difference in mean scores for the pre and post-training responses was seen on Question 6: "How certain are you that you are able to successfully structure the conversation with the patient?" The mean score changed from 6.33 to 8.37 a difference of 2.04, 95%CI (1.75-2.33; p<0.001) immediately after the training and 2.15, 95%CI (1.80-2.51; p<0.001) one month post-training. This is an important finding which suggests that the READY mnemonic potentially enables HCPs to have an evidenced-based format of how to structure and pace a DN conversation. To this end, the READY framework was also to be used by other interviewees to make structural changes across the organisation. It was also considered as a useful framework for use beyond the congenital anomalies in the first 1001 days for example an HCP was able to use it after training in DDN learning regarding oncology results for an adolescent to their family. We also heard from the health visitor team about the application of the framework to community settings where it can support difficult public health or safeguarding conversations with families. Indeed other researchers from Australia indicated that the READY framework could be used as a communication skills training intervention in critical care [41].

The results also suggest that the training supported HCP skills to engage families and make joint decisions about care. There was a statistically significant increase of 1.87 points (95% CI 1.59-2.16; p<0.001) in the average score in response to SE-12 Q2 "How certain are you that you are able to successfully make an agenda/plan for the conversation with the patient?" after the training. There was also a statistically significant increase of 1.74 (95% CI 1.47 – 2.01; p<0.001) in the average score in response to Q3 on the SE-12 score: "How certain are you that you are able to successfully urge the patient to expand his or her problem/worries?". These changes suggest that the training gave HCPs the skills and the knowledge to actively seek to engage the patient in the decision-making process and the care plan. This is an important aspect of ensuring patient agency and autonomy and evidence-based communication skills training for HCPs [30].

Parents contributed to the training as experts by experience. Their sessions emphasised the fact that parents retained such a strong image of how they received their DN as a film in their minds long after they had received it. This was highly impactful for the interviewees with reports from HCPs about ensuring that they provided parents with more balanced information or simply took time to focus on the baby or babies which was quite different from how they had presented DN to parents in the past when the news was different.

We sought to understand if the observed changes in Self-Efficacy were the same between HCPs trained by the iHV team (Champions) and those trained by the champions (cascade trainees). There was a statistically significant difference between DDN champions and non-champions, SE-12 scores were generally higher for champions and the improvement from pre-training was greater. The difference from non-champions in SE-12 change scores post-training was 7.81 (95% confidence interval 1.37-14.2; p<0.001) and 13.0 (95% confidence interval 3.10 – 22.9; p<0.001) one month post-training.

Although the changes observed in the HCPs to whom the training was cascaded is different from the champions, the results are promising as there was still a statistically significant increase in means scores although this was less than the changes observed in the HCPs trained by the iHV team. It is important to bear in mind the challenging backdrop against which DDN champions delivered their cascade training particularly the Covid-19 pandemic an environmental factor that had an impact on both the training and the delivery of DN. DDN champions delivered the training amidst the related pressures of social distancing measures, staff redeployment, staff members shielding, self-isolating, cancellation of non-essential training; staff dealing with the secondary impact of the pandemic as well

as the impact of the pandemic on staff emotional and mental wellbeing as reported elsewhere [42-45]. In most NHS trusts, research was either completely stopped in order to focus on clinical care or research was limited to Covid-19 studies which had significant implications for the setup and conduct of non-Covid-19 related studies such as the DDN study [46]. Given this backdrop, we think it was a huge success that 5 out of the 6 sites were able to deliver the DDN as planned and produce the positive results that were observed. To build the capacity of DDN champions it would be important for them to continue to have opportunities to deliver the training so that they build their confidence and skills in delivering the training to enable them to have the same level of proficiency as the iHV team who have the advantage of several years of delivering related training to HCPs.

The HCPs were overwhelmingly positive about the training. Using virtual delivery was well received given the circumstances due to Covid 19, with some suggesting it was convenient this way, but others missing the opportunity to meet known and unknown colleagues, particularly from different disciplines, in-person to have a better interaction. The organisational structure and culture in the NHS at the local and national level had an impact on the uptake of the training as well as on the delivery of DN. Respondents discussed the impact of the persistent service pressures such as time, capacity and space on DDN. The skills that HCPs had developed to DDN could be undermined by time and capacity issues

5.2 STUDY LIMITATIONS

This study was well designed to answer the research questions. The mixed-methods approach was useful for enabling the triangulation of quantitative data with qualitative data from four different participant groups: HCPs, co-production parents, the post-training parent and managers. The mixed-methods approach enabled the team to draw on expertise from different research disciplines which were represented in the research team. This strengthened the research work that was conducted by the team and reduced the biases related to each research method. The use of a mixed-methods approach meant that the limitations inherent in qualitative and quantitative studies were negated by the triangulation of data from different sources.

Despite these strengths of the research methods, the study has some limitations. Due to the time constraints on the study, we were unable to recruit families into the study or follow them up by collecting quantitative data to understand the impact of the support they received when the news was delivered on their emotional and mental wellbeing. Future research would need to investigate this in order to add to the evidence base. In addition, the study was originally supposed to be

completed in 12 months, it was not possible to conduct a randomised control trial to measure the effectiveness of the training intervention in this timeframe. Furthermore, a randomised control trial would have been costly. We, therefore, opted to conduct a pre-post study to evaluate the training intervention. This design has been used extensively to evaluate communication training interventions for healthcare professionals [40, 47-49].

A small number of participants (18 HCPs) completed the pre-training survey either during or after the DDN training workshop. Their pre-training outcomes were excluded from the statistical analysis and data summaries for these participants. Despite several reminders, more than 40% of participants did not complete the 1-month post-training follow-up survey. The results from both post-training surveys have been presented but should be interpreted bearing in mind that the groups may differ in important characteristics.

5.3 FACTORS INFLUENCING THE STUDY

5.3.1 IMPACT OF COVID-19 ON RECRUITMENT OF NHS ORGANISATIONS TO THE STUDY

In the early stages, the pressure of Covid-19 meant that many NHS trusts suspended approvals for non-Covid-19 related studies. Members of research departments had been redeployed and clinical teams were stretched. This delayed the recruitment of NHS trusts to the study. Some NHS trusts chose not to continue with the study as they felt they needed to prepare for future waves of the pandemic and did not have the capacity to participate in the study.

However, as the most severe phases of the pandemic subsided, it became possible to recruit a greater number of organisations as research departments were re-established and organisational confidence grew. The fact that the DDN study was an NIHR portfolio study but followed a simple design that did not require research nurses or departmental input beyond the approvals stage, was seen as positive. The practical, learning-focused design was also seen as interesting and beneficial to clinical leads making them more willing to take part. This is seen in the fact that we were able to recruit three additional trusts in January 2021 during the second lockdown as well as an additional DDN champion to one of our existing trusts.

5.3.2 IMPACT OF COVID 19 ON NHS STAFF ABILITY TO DELIVER THE STUDY

The Covid-19 pandemic has had an unprecedented negative impact on health, education and the UK economy. Like many other nations, one of the UK's primary response to COVID-19 was slowing the human-to-human transmission of the virus through the introduction of widespread population-level social distancing measures effected via a series of nationwide lockdown measures [50]. The pandemic also intensified workloads among NHS staff, who were already working at stretched capacity in some services prior to the pandemic [42, 43]. Some community services such as health visitors faced numerous challenges including redeployment of staff to support the Covid-19 workforce which resulted in increased caseloads at a time when face to face contact was limited with concerns that the needs of children would be missed. As the pandemic progressed and lockdown restrictions were slowly lifted, services faced pressures to catch up with hospital treatment waiting lists that had been stalled by the pandemic as well as the need to address other secondary health problems arising from Covid-19 [42, 43, 51].

Trust contacts reported greater levels of staff sickness and reduced capacity due to staff isolating or shielding, responding to family commitments in the UK and overseas. As the pandemic (and the study) progressed, study teams noted increasing levels of staff absence for mental health reasons as has been reported by other researchers [42, 43].

DDN champions also had to navigate their trust and local department policies designed to respond to the pandemic and capacity issues. Some non-essential training was cancelled or postponed, however, five of the six DDN teams were able to organise and deliver training, but this was done at a very challenging time nationally.

Additional pressures as a result of responding directly or indirectly to Covid-19 varied between teams. While some neonatal teams found that they were less impacted by the pandemic in terms of their caseload than others, there were additional pressures noted on sonography and midwifery departments in 2021 with very high service demand. This had implications in some teams for the organisation, local recruitment to and delivery of training. Champions found it harder to recruit certain professions, in particular from foetal medicine to the training due to their work pressures and capacity demands. Likewise, the implications of the non-Covid-19 related reorganisation in line with the government's midwifery continuity pledge had a particular impact on one trust with non-mandatory training cancelled.

5.4 LESSONS LEARNT

5.4.1 FACILITATING CASCADE TRAINING

Managerial/senior-level support for the training and/or professional role were good enablers to the champions being able to secure time to book training dates, plan the training, as well as recruitment of colleagues to attend. Consultants had a greater level of autonomy over their time, whereas nurses or sonographers, for example, did not have as much autonomy. It would be important to ensure that other professions with less autonomy have the managerial support to ensure the delivery of the training.

While online meetings have become commonplace during the Covid-19 pandemic, delivering virtual training without prior experience can be a daunting prospect. Putting 'tech support' (an iHV colleague who was able to set up the breakout spaces in real-time and respond to connectivity, AV or other related issues) in place gave some additional confidence to the champions.

The DDN champions used a range of methods to organise and deliver the cascade training. At one trust, it was decided to use audit days to deliver training to sonographers and a smaller number of associated colleagues. This had the benefit that sonographer lists were clear that day though in reality a small number of colleagues needed to be made available for scanning and were unable to attend. This may also be a strategy for other professions where securing a date to deliver the training is challenging.

Working with team and service managers, the champions were able to recruit HCP participants to the training with a range of methods in place to support and encourage participation (among those who are not consultants) from paid time/time in lieu offers, study time offers or arranging agency staff for cover. Not all participants were able to access these offers however with some completing training in their own (leave) time or making time to attend then working additional hours to catch up with their caseload afterwards.

Virtual delivery was beneficial when training colleagues across wide geographical areas, for example for community-based health visitors. However, some champions chose to deliver in the person finding that the discussions were richer and more productive. These sessions were dependent on having a suitable space for delivery within social distancing guidance and were of greater convenience to hospital-based teams already on site.

5.4.2 RECRUITING PARENTS FOR POST-TRAINING INTERVIEW

We struggled to recruit parents for post-training interviews. Our initial methodology was to ask (post-training) DDN champions to share a parent invitation letter and information leaflet with parents who they had delivered DN to about their baby's diagnosis of a learning disability. Champions were not obliged to recruit families, only share the letter and information as appropriate, this meant that we were relying on parents contacting the research team in follow up if they were interested in speaking with us. We later received ethical approval to broaden this cohort to parents receiving any kind of DN about their baby. DDN champions did not manage to share many of these letters, often stating that it was not appropriate at the time. We did not hear back from any parents directly through this method. We were able to recruit one parent who was in contact with the bereavement team at the hospital and who expressed an interest in talking with us through the team. Working through this longer-term, less immediate connection seemed to be a better way to approach families; it also supported this parent to make contact with the research team rather than just leaving her with a contact number.

5.5 RECOMMENDATIONS

5.5.1 SCALING UP DDN TRAINING THROUGH THE CASCADE MODEL

The findings illustrate that the DDN training is effective at improving the knowledge, skills, confidence and self-efficacy to deliver DN. Implementation of the training coupled with policy and structural level changes that support effective delivery of DN may improve outcomes for families. We would recommend that the training be rolled out nationally and internationally. The applicability of the READY framework in Australia [41] outside of the first 1001 days is encouraging and suggests that this training could have a significant impact on HCP communication skills in the UK and beyond. Going forward it would be imperative for Health Education England to work with the iHV to secure funding to enable the training and development of DDN champions with regional forums to provide support for champions to deliver the DDN training locally.

5.5.2 TRAINING CONTENT

The training was initially developed for working with families who were receiving news about their child's diagnosis of a congenital disorder associated with a learning disability. The materials were designed in consultation with families who had the experience of receiving this news. There were several case studies on Down Syndrome in the feasibility study and the co-production interviews with parents covered a wider range of conditions including Autism as well as other genetic conditions. Their

experiences were incorporated into the training materials through the case studies. However, the training somewhat had a Down Syndrome focus because the live or videoed 'lived experience sessions' were delivered by these parents whose children had been diagnosed with Down Syndrome. It would be important to have other live or videoed experiences of families with other conditions supporting the delivery of the training. The FAQ-style video developed to replace the Q&A section of the training could include feedback from parents with different experiences and it was also recommended that this video be shorter. As well as giving the option for these different videos to be used in training, they would also strengthen the resource package allowing for short videos to be viewed and discussed in follow up meetings or shorter input sessions.

Feedback from participants showed that there was a need to further diversify the focus of the DN to reflect parents who received antenatal DN and a wider range of conditions or circumstances. It was felt that the DDN training and READY framework were applicable and discussing this wider range would increase the training's relevance to various other HCPs and better support them in the reality of their role.

Giving DDN champions the flexibility to co-produce case study content with iHV meant that they were able to adapt the training and increase its relevance. Three trusts developed additional case studies which included community health visiting, neonatal team and sonographer scenarios to build scenarios that were more relevant to their teams. As well as generating discussion of learning disability, they covered talking with families about miscarriage, neurological impairment and developmental delay. As training teams diversify how content but maintaining fidelity to the intervention, having a range of online content (with user ideas/guidance) that can be used flexibly is increasingly practical and useful.

5.5.3 TRYING OUT DDN ROLE PLAYS

While the training contained feedback from parents who discussed their experiences of good and poor scenarios either through interview quotations or video, some respondents felt it would be useful to include video role plays which illustrated this as a means to discuss and a way of illustrating good practice more fully. Some also felt it could then be followed up with a session where trainees could test out their skills through role-playing. Arguably this may be easier to deliver in person than virtually and would need additional time to set up, deliver and sufficiently discuss.

5.5.4 TRAINING STRUCTURE AND TIMING

It was felt that the description of the DDN2 study could be somewhat reduced to a succinct summary of key findings connected to the prereading material provided. Some HCPs suggested the training could be shorter and others wanted a stronger focus on the opportunities to discuss using the READY framework through the case studies.

5.5.5 STRUCTURAL AND POLICY CHANGES TO SUPPORT EFFECTIVE DELIVERY OF DN

Our feedback showed that practitioners overwhelming want to DDN well. However, they referred to persistent constraints which influence how well DN is delivered in their units. Capacity, time, space, shift patterns, etc. – it was important to them that these issues were addressed alongside providing training to staff encouraging individual-level change in order to develop a more accommodating environment both for parents and for practitioners. This may need to be reflected in the training material and its discussion – for example in case studies where inappropriate scenarios are presented, to look at both the parent outcomes and how to make improvements to address this, but also the rationale for how this situation came about and what changes might need to be urged at a team/organisational/cultural/policy level to make lasting improvements for parents and practitioners.

5.5.6 LARGER RANDOMISED CONTROL TRIAL

It is important to note that the study has gathered information from a larger and more diverse group of HCPs and produced evidence of the value of the DDN training. Further research is required to understand the impact of delivering this type of training on the emotional and mental wellbeing outcomes of families who have news delivered to them by trained HCPs. Ideally, this would need to be answered through the use of a randomised control trial and the research team would need to look for additional funds to answer this important research question.

6. CONCLUSION

The DDN training aims 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; offer sufficient time to answer questions; know when and where to refer families on to for further care and support. The significant improvements in confidence and skills reported by HCPs suggest that the training may be effective in equipping HCPs to minimise the distress, anxiety, and depression associated with receiving DN. This represents a key aspect of the prevention of mental ill-health across

the life course. It is crucial to ensure that this training is rolled out nationally to support the NHS Long term Plan to improve our understanding of the needs of people with learning disabilities and their families and to work with them to improve their health, wellbeing, and access to timely support. Most importantly it means that families who receive DN receive the support they need when it matters the most.

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