An evaluation of staff member's perceptions and factors affecting the use of Procedural Distress Plans on a Paediatric Cardiology Ward (Ward 51)

Jovita Valuckaite

Commissioned by Dr Kat Bilbrough, Principle Clinical Psychologist

Table of Contents

Introduction3
Service evaluation context
Literature review
Aims5
Methodology
Design 5
Survey and interview schedule development6
Participants and sampling7
Ethical considerations
Procedure
Data collection process and analysis8
Quality check
Results
Description of the sample10
Aim 1: Current perception of the PDPs11
(a) What do staff perceive to be the aims of PDPs and are PDPs seen as relevant to them? 11
(b) Who is perceived to have the responsibility for implementing PDPs?
Aim 2: Factors affecting implementation of PDPs13
(a) Dissemination of the PDPs13
(b) PDP content and format15
(c) Staff identified barriers to implementation19
(d) Ideas of improvement23
Discussion
Aim 1: What are the staff teams' current perception of the PDPs?
Perceived PDP relevance, implementation responsibilities, and aims
Aim 2: What factors might be affecting the implementation of the PDPs?
Dissemination of the PDPs26
Format and content of PDPs 26
Staff identified barriers to implementation: External and internal factors
Limitations of the SEP
Service Recommendations
Dissemination
Conclusions
References

Appendices	35
Appendix A - Staff Survey	35
Appendix B -Semi-structured Interview schedule	43
Appendix C - Service evaluation project introduction page	47
Appendix D - Staff survey participant information sheet	48
Appendix E - Semi-structured interview participant information sheet	50
Appendix F - Pre-written email used to advertise the service evaluation project	53
Appendix G -Semi-structured interview consent form	54
Appendix H - Example Content Analysis table: What do staff perceive to be the aims of PDPs?	55

Introduction

Service evaluation context

Leeds Children's Hospital, a part of Leeds Teaching Hospitals NHS Trust (LTHT) based at the Leeds General Infirmary, offers a variety of specialist children's services. One of the specialist services includes the Paediatric Cardiac Congenital service. The team offers diagnoses and treatments for arrhythmias, and congenital and acquired heart disease for patients from birth to adulthood (LTHT, n.d.). The multi-disciplinary team (MDT) is comprised of a variety of professionals including Paediatric Cardiology Consultants and Surgeons, Cardiac Nurse Specialists, Dieticians, Sonographers (Leeds Congenital Hearts, n.d.), Junior Doctors, and Healthcare Assistants.

As part of the initial contact with the cardiology service, patients and families meet with the 'surgical team' comprised of a Paediatric Cardiac Surgeon, Cardiac Nurse Specialist, and a Clinical Psychologist to discuss their condition and treatments. The Clinical Psychologist in this appointment may offer some families and patients that are 16 or under a separate appointment on the Surgical Preparation Pathway (SPP) with a Clinical Psychologist, Assistant Clinical Psychologist, and / or a Play Specialist.

Clinical work in the SPP includes creating a Procedural Distress Plan (PDP). A PDP details how to support the patient through the procedures upon admission to the Paediatric Cardiology Ward (Ward 51). The plan may include important previous experiences of hospitalisation, the patient's preferences on how interventions are completed, and signs of distress and how to respond. PDPs are a locally developed tool within the service, meaning there is limited empirical evidence on their effectiveness. However, relevant literature and theoretical underpinnings that support the use of PDPs are discussed in the literature review.

It has not been possible to gather empirical data on if and how PDPs are being implemented during a patient's admission to the ward however, informal observations from professionals and reports from families and patients suggests variability in the ward staff utilising patients' PDPs when delivering care. The aim of this Service Evaluation Project (SEP) was to use a survey and qualitative interviews with the ward staff to capture the teams' current perceptions of PDPs and what may be affecting PDP implementation. The outcome of the

3

SEP will be used to recommend possible ways to support the professionals on the SPP pathway and Paediatric Cardiology Ward professionals to more frequently utilise and implement PDPs.

Literature review

The National Institute for Cardiovascular Outcomes Research (NICOR) states that around 1% of new-born babies have a congenital heart problem (NICOR, n.d.). Possible interventions include surgical procedures such as open-heart surgery, cardiac catheterisation (NCHDA, 2022), pacemaker implantation as well as some non-surgical interventions such as blood tests and canular drains from areas of the body including the neck, stomach, and heart. In 2020/2021 a total of 6,727 congenital heart procedures were completed in the UK on children and young people under the age of 16 (NCHDA, 2022).

Congenital heart disease (CHD) has been linked with negative psychosocial outcomes for patients and families. A scoping review recognised that parents of children with CHD can experience stress, anxiety, depression, and Post-Traumatic Stress Disorder symptoms (Franck et al., 2010; Franck et al., 2015; Kolaitis et al., 2017). Children and young people with a CHD are also more likely to experience anxiety and depression (Freitas et al., 2013; Gonzalez et al., 2021), and lower quality of life (Ernst et al., 2018; Latal et al., 2009; So et al., 2019; Uzark et al., 2008).

Marino et al. (2015) used the Pediatric Cardiac Quality of Life Inventory on sample of n=572 young people aged 12-15 years and found that lower quality-of-life was significantly associated with undergoing greater number of operations and admission to Intensive Care Units (p<0.01). Although these factors did not explain the full variance seen in the quality-of-life measure, and it is important to note that association is not causation, the results suggest links between the experience of hospital admissions and negative psychological wellbeing of patients (and families).

Children with heart conditions that are admitted to hospital for surgical and non-surgical interventions face painful and invasive procedures, which can results in psychological distress and trauma (Lerwick, 2016). This can impact a young person's ability to engage and cooperate with the medical interventions they require, highlighting the need for psychologically informed paediatric care.

4

Lerwick (2016) suggested that one of the key principles to supporting patients emotionally in these settings was choice. For instance, allowing patients to have 'small' choices such as which arm is used to measure blood pressure, or the order in which procedures happen. These choices can communicate care to the patient, and provide psychological safety and a sense of empowerment (Lerwick, 2016) by reducing patient's experiences of helplessness (DeMaso & Snell, 2013; Li & Lopez, 2004; Wolfer & Visintainer, 1975), and increasing their sense of self-efficacy (Bandura, 1977). This is in line with choice being key factor for delivering trauma-informed healthcare (Menschner & Maul, 2016).

PDPs are one example of a psychological intervention that aims to increase choice, control, and predictability for the patient that potentially reduces acute and longer-term distress and improves patient engagement. As such, it is important to understand what factors may be affecting whether PDPs are implemented on the ward. This is explored in this SEP.

<u>Aims</u>

Dr Kat Billorough, a Clinical Psychologist working within the cardiology department, commissioned this project to:

- Develop an understanding of the current perception of the PDPs by the Paediatric Cardiology Ward staff team.
- (2) Develop an understanding of the factors that might be affecting the implementation of the PDPs by the Paediatric Cardiology Ward staff team and how implementation of PDPs may be improved.

Methodology

<u>Design</u>

The aim was to use a mixed methods design using a survey and a semi-structured interview. It was anticipated that due to the demanding nature of the ward environment, interviews may be more difficult for staff to engage in, and the time-efficient nature of the survey would be preferred. The survey and interview schedule mirrored each other to ensure that if few interviews were conducted, the data from both methodologies would be complementary.

Survey and interview schedule development

The researcher, commissioner, and a Senior Play Specialist within the SPP co-created the survey (Appendix A) and interview schedule (Appendix B). The survey gathered demographic information from the sample such as their role and the length of time they have occupied this role (questions 1-3 in the survey). The aims of the SEP as stated above were then deconstructed and used to develop the survey and interview schedule.

The aim of (1) developing an understanding of the current perception of the PDPs, was deconstructed to include: questions on staff perceived the aims of the PDPs, the perceived relevance of the PDPs to their roles, and who staff believed held the responsibility for implementing the PDPs (questions 5-7 in the survey).

The aim of (2) developing an understanding of what factors that might be affecting the implementation of the PDPs and how implementation may be improved, was deconstructed to include: how the plans were disseminated to the wider team (questions 8-11 in survey), evaluation of content and formatting of PDPs (questions 12-15), perceived external barriers such as the business of the ward (question 16), and perceived internal barriers such as personal confidence and skill in using the plans (question 17). The survey responders were also able to offer their ideas on how to improve PDPs and processes around them (questions 19 and 20).

During the survey development process it was identified that some staff members would not be able to participate due to the small number and irregular creation of PDPs. This is because not all patient and families are offered or choose to accept input from the SPP. The service was not able to capture comprehensive empirical data on this, but it was estimated that around 15-25 PDPs were created from January 2021 to December 2021. The responders were able to 'skip' questions that required prior awareness of the PDPs (such as perceived aims, dissemination, etc) given the PDP infrequency. These questions were grouped into Section 2 of the survey. Thus, instead of excluding participants, this 'skip' design allowed the SEP to maximise the number of professionals being able to participate in the SEP and thus, supports the representativeness of the data gathered.

The 'skip' function allowed responders to move to Section 3 of the survey where they evaluated two typical examples PDPs. The two example PDPs were shared by the

commissioner and described as representative of the content and formatting of a 'typical' PDPs. The first example PDP (called 'Olivia's plan') used a structured table and brief bullet points. The seconds example PDP (called 'Liam's plan') used in-text headings and fuller sentences. The example plans were real PDPs created for patients' that had previously been admitted to the ward. Effort was made to anonymise the PDPs by changing the client's name, NHS number and the gender pronouns used in one of the plans. The use of real PDPs that had contrasting formatting styles supported the survey to reflect and gain feedback on real clinical practice.

Participants and sampling

The target population were all professionals working within the Paediatric Cardiology Ward. The staff group was made up of a variety of professionals including medical professionals (as identified in the Service Evaluation Context section) and allied health professionals (AHPs), such as Counsellors, Clinical Psychologists, and Play Specialists. The estimated total number of professionals working on the Paediatric Cardiology Ward was around 90 although this was difficult to ascertain due to factors such as some professionals often moving to different clinical areas (e.g., junior doctors).

An opportunistic sampling technique was used as the SEP was advertised via work emails to all relevant professionals as identified by the ward manager.

Ethical considerations

Ethical approval was granted by the Doctorate in Clinical Psychology Research Ethics Committee at the University of Leeds (Application Reference: DClinREC 21-018).

All potential participants were given contextual information about the SEP (Appendix C), and participant information for the survey (Appendix D) via Online Surveys. An interview participant sheet (Appendix E) was provided as needed to gain informed consent.

Obtaining informed consent was important given that PDPs relate to painful and invasive procedures, which can be distressing for patients, families, and staff alike. This was further managed through the survey and interview focusing on factors affecting the use of the PDPs rather than personally difficult experiences. Effort was also made to ensure confidentiality and anonymity by grouping job roles together where there were fewer positions. Participants were also given the option to not disclose demographic information in the survey. This was especially important given that the project had scope to capture clinical practice where PDPs were not used. The survey method was entirely anonymous meaning that any disclosed sensitive information is not traceable back to the participant with the aim of mitigating the impact of social desirability, and thus improving the validity of the findings.

There was also a recognition of the importance of creating a project that was time-efficient (and therefore ethical) given the considerable pressure that NHS services and healthcare staff are currently under (The King's Fund, 2022).

Procedure

The ward manager used work emails to advertise the SEP to the relevant population (see Appendix F for pre-written email). The email included a link to an Online Surveys page providing an overview of the SEP aims, how they could get involved (Appendix C) and the option to proceed to the survey. Consent to complete the survey was indicted by participants proceeding through the question and submitting their answers at the end.

Participants were able to share their email address with the researcher using an embedded link in the introduction page. The researcher then emailed them the interview participant information sheet (Appendix E) and a blank consent form (Appendix G). A suitable date and time would have been arranged if the participant wanted to proceed with an interview.

Recruitment was supported by SPP professionals and the ward manager via informal verbal reminders. A portable electronic tablet was also placed on the ward to support staff to access to SEP introduction page.

Data collection process and analysis

It was not possible to conduct any interviews. Recruitment appeared to be affected by high clinical load and complexity in the fast-paced ward environment.

Microsoft Excel was used to generate descriptive statistics from the survey data. Qualitative data gained through the open text boxes was analysed using qualitative Content Analysis (CA). There are multiple types of CA (Roller, 2019) with a common one being 'conventional'

(Hsieh & Shannon, 2005) or 'category' CA. Luo (2022) noted this process involves counting the frequency with which words, phrases or concepts appear in the text to be analysed. This is the method used in this SEP.

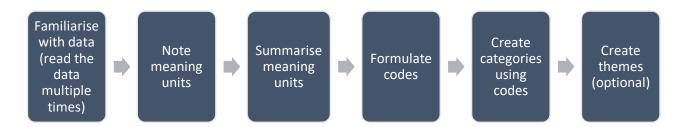
Category CA can be used to remain close to the data and reduce the volume of data while allowing the researcher to make sense of it (Bengtsson, 2016). It can also be used to limit the impact of the researcher pre-conceived ideas (Humble & Mozelius, 2022) through its data-driven, inductive approach.

Thematic Analysis (Braun & Clarke, 2006) was considered as a possible alternative to CA as it can result in a deeper understanding of the data being analysed (Humble & Mozelius, 2022). However, given that the data being analysed were brief responses from open text boxes where there was no opportunity for clarification, a less interpretative qualitative method such as CA was more appropriate.

The process of CA used for this SEP is depicted in Figure 1.

Figure 1

The process of CA as described by Erlingsson and Brysiewicz (2017)



Quality check

A Trainee Clinical Psychologist reviewed the themes, sub-themes, and quote analysis tables to act as a credibility check. This process resulted in refinement of some sub-themes.

Results

The results are divided according to the SEP aims. Aim (1) is around understanding current perceptions of the PDPs including data on (a) perceived aims of the plans and perceived relevance of plans and (b) who is responsible for their implementation.

This is followed by aim (2) which focused on understanding factors that affect the PDP implementation. This is sub-divided into (a) dissemination, (b) content and formatting of PDPs, (c) staff-identified barriers to implementation, which is further separated into (I) external and (II) internal factors. This is then followed by (d) staff ideas for improvement.

Description of the sample

A total of 25 staff members completed the survey. Table 1 offers an overview of the sample demographics collected. The range for the length of time working in Paediatric cardiology and specifically on Ward 51 ranged from less than a month to 27 years.

Table 1

Summary of demographic information of survey sample (N=25) including number of respondents, time (in years) working in Paediatric cardiology and time (in years) working on the Paediatric Cardiology Ward 51

Job Title	Number of responders
Consultants	5
Registrar / Junior doctor	4
Ward staff (including ward nurses, nurse specialist, clinical support worker / apprentice)	11
Allied health professional (psychology team, play specialist / leader)	5
Length of time (in years) working in the	Number of responders
clinical area of Paediatric Cardiology	
≤1 year	6
2-9 years	10
≥10 years	9
Length of time (in years) working in	Number of responders
Paediatric Cardiology Ward 51	
≤1 year	6

2-9 years	11
≥10 years	8

Aim 1: Current perception of the PDPs

Of the 25 responders, 22 professionals reported that they were aware of the PDPs.

(a) What do staff perceive to be the aims of PDPs and are PDPs seen as relevant to them? All 22 responders agreed that PDPs were relevant to their roles. The responders then described their perceived aims of PDPs. This data was analysed using CA (see Figure 2).

The largest main theme generated by the CA was **support the patient and family**. Within this theme, sub-themes mainly focussed on immediate patient outcomes while on the ward apart from one sub-theme addressing the PDP aim to *reduce negative long-term impact of procedural distress (N=1)*.

The other main theme was **supporting the team**, which included the sub-theme of **preparing the team to support the client (N=4).** It must be noted that this sub-theme is still somewhat patient-focused with only a few comments suggesting that **the plans support the team (N=2)** directly.

Please see Appendix H for an example CA analysis table with quotes as illustrations for each sub-theme.

In summary, results indicated that PDPs are seen as relevant to the team and that PDPs primarily perceived to be aimed at supporting the patient and family.

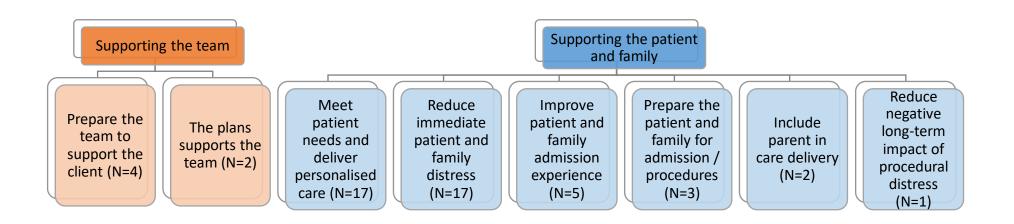
(b) Who is perceived to have the responsibility for implementing PDPs?

The survey results identified multiple clinicians as responsible for implementation including consultants (17/22), registrars / junior doctors (18/22), ward staff (19/22), the psychology team (18/22), and play specialist (18/22). Of the 22 responders, 17 chose to use an open text box to explain their answers further. They reiterated that there is not a single profession responsible for PDP implementation as 15 out of 17 respondents made references to *"everyone"* or *"anyone"* who is involved in the care of a patient and family needing to be aware of the PDPs and implement them.

Figure 2

Summary of CA themes, sub-themes and frequencies relating to perceived aim of the PDPs

What do staff perceive to be the aims of PDPs?



Aim 2: Factors affecting implementation of PDPs

(a) Dissemination of the PDPs

The survey showed that the majority 'strongly agreed' or 'agreed' (19/22) that how the PDPs are shared impacted implementation, and the majority 'strongly agreed' or 'agreed' (13/22) that the PDPs were currently being shared consistently.

The most common way that staff members found out about PDPs was through PPM, the online patient clinical note system (13/21), or email (4/21). One responder was excluded from this section because they do not implement PDPs.

All participants identified PPM (12/22) as the most useful way to share the PDPs. CA on optional text box responses noted several responders (N=7) suggested it would be beneficial to use multiple methods to share PDPs such as *"patient folder and on PPM"*, *"*[PPM and] *a hard copy that the family bring in"* and *"Email initially, note in the diary, then uploaded to PPM"*. See Figure 3 for details.

CA results echoed some of the closed question results. The main theme of **how PDPs are disseminated** included several high frequency sub-themes such as *Email (N=7)*, *PPM (N=6)*, and *multiple methods are used together (N=6)*. The latter sub-theme included comments such as *"We communicate any specific issues, initially in the diary, then on our handover sheet"*.

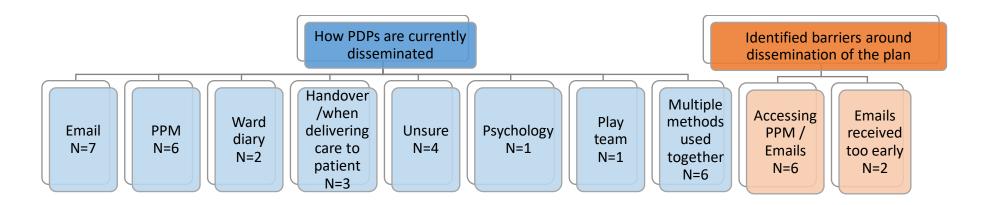
The other main theme was **identified barrier around dissemination**. The most frequent subtheme was **accessing PPM / Emails (N=6)**. Example comments included: "Not everyone looks at PPM" and that staff may not access "emails daily... [because they] have a lot of other responsibilities that take priority".

In summary, results indicated that PPM is the most common way the PDPs are found and that the majority agreed that this is the most useful way to share them. However, results also indicated that methods alongside PPM, such as emails and ward diary, may overcome identified barriers around PPM not being accessible to all professionals.

Figure 3

Summary of the CA themes, sub-themes and frequencies relating to the process PDP dissemination and staff identified barriers regarding dissemination of the PDPs

Dissemination of PDPs: How do staff become aware that a PDP is in place?



Note: The frequency of the sub-theme 'Multiple methods used together' includes responses that identified two or more methods of PDP dissemination. Frequencies were also double counted if the text being analysed referred to other relevant sub-themes (e.g., if comment says PDPs are diseminated using 'emails and PPM', this was captured in the sub-themes of 'Email', 'PPM' and 'Mulitple methods used together').

(b) PDP content and format

All 25 responders were asked to use a 7-point Likert scale from 'strongly agree' to 'strongly disagree' to respond to statements on formatting and content of the two example PDPs. The statements were either positively framed (e.g., 'the plan is concise') or negative framed (e.g., 'the plan is too long'). Results are presented in Figure 4.

In relation to 'Olivia's PDP', the responders largely agreed with the positively framed statements and largely disagreed with the negatively framed statements. The evaluation of 'Liam's PDP' followed a similar pattern although more responders chose 'neutral' across all statements. Most responders (15/25) preferred 'Olivia's PDP' to 'Liam's PDP' (10/25).

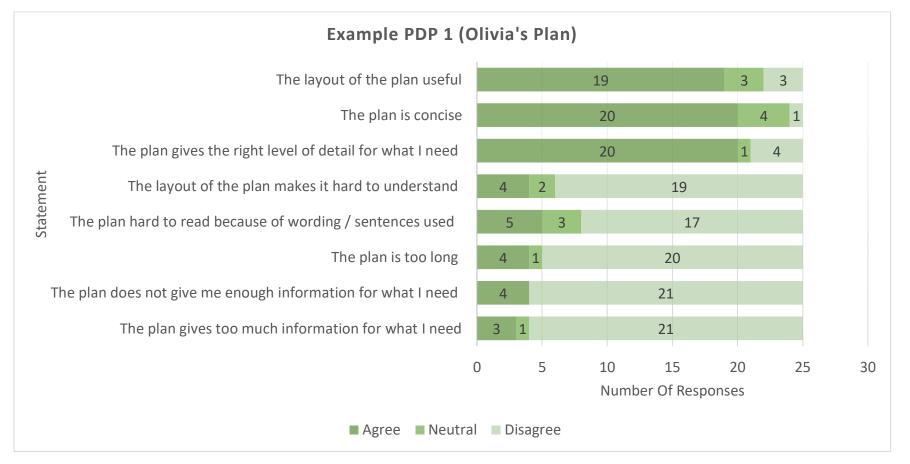
The CA regarding 'Olivia's PDP' included a main theme of **content**. This consisted of the subtheme around the plan being *concise and easy to read (N=6)*. Within the main theme of **format**, a common sub-theme was the staff members being able to *easily find information (N=4)* and that the *table layout is helpful (N=5)*. The latter sub-theme included comments such the table layout being *"much easier to read and digest"* in comparison to 'Liam's PDP'.

As depicted in Figure 4, the sub-themes under the main themes of **content** for both the PDPs, may suggest that different professionals may prefer different PDPs. For instance, 'Liam's plan' may be **useful for anaesthesiology (N=1)**, perhaps due to content of the plan relating to anaesthetic procedures, and **less useful for ward staff (N=1)**. It must be noted that sub-theme frequencies were low within this theme, so this result is tentative only.

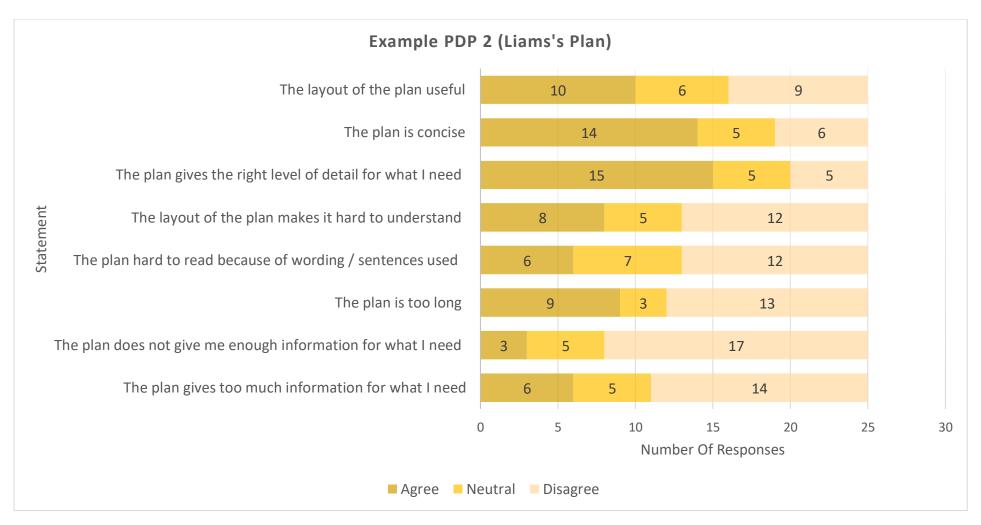
In summary, results indicated that most responders preferred 'Olivia's PDP' in comparison to 'Liam's PDP's due to its format, conciseness, the ease of finding information and the tabular format.

Figure 4

Summary graphs of staff evaluation for example PDP 1 (Olivia's plan) and example PDP 2 (Liam's plan) from 7-point Likert scale ratings; Summary of CA themes, sub-themes, and frequencies for staff evaluation for example PDP 1 (Olivia's plan) and example PDP 2 (Liam's plan) from open text box responses

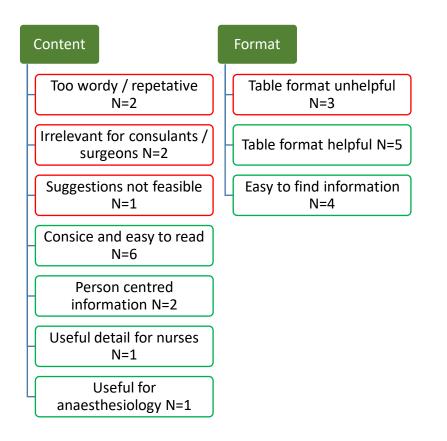


Note: 'Agree' key includes responses of 'Agree' and 'Strongly Agree'; 'Disagree' key includes responses of 'Disagree' and 'Strongly Disagree'

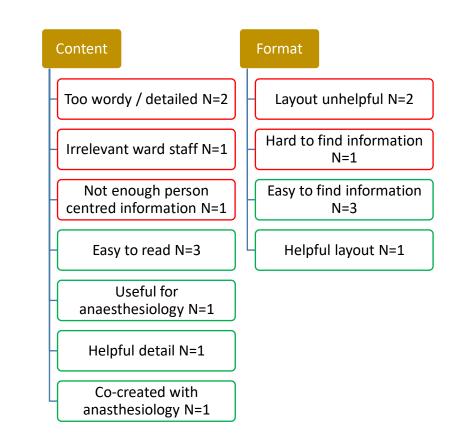


Note: 'Agree' key includes responses of 'Agree' and 'Strongly Agree'; 'Disagree' key includes responses of 'Disagree' and 'Strongly Disagree'

Content Analysis for example PDP 1 (Olivia's plan)



Content Analysis for example PDP 2 (Liam's plan)



(c) Staff identified barriers to implementation

Staff used a 7-point Likert scale from 'strongly agree' to 'strongly disagree' to respond to statements on possible barriers to PDP implementation. These have been divided into external factors (such as events on the ward) and internal factors (such as staff confidence in implementing PDPs) and are presented in Figure 5.

I. <u>External Factors</u>

Likert-scale results indicated that a possible important barrier to PDP implementation was unplanned emergency clinical tasks. As depicted in Figure 5, this mirrors the CA main theme of **lack of recourse** which included sub-themes such as **lack of time and high workload on the team (N=11)**. High workload may be further compounded by **staff shortages (N=7)**.

Likert-scale results suggested that the implementation of PDPs could be impeeded by other professionals not being available at the time of intervention. This is echoed in the CA (Figure 5) in the sub-theme *unavailbaility of the play team (N=6)* under the theme of **lack of resource.**

The main theme of **lack of resources** included a sub-theme of **lack of equipment and space** (*N=4*). This included comments identifying lack of "side rooms" and "PCs" as barriers to implementating and accessing PDPs, respectively.

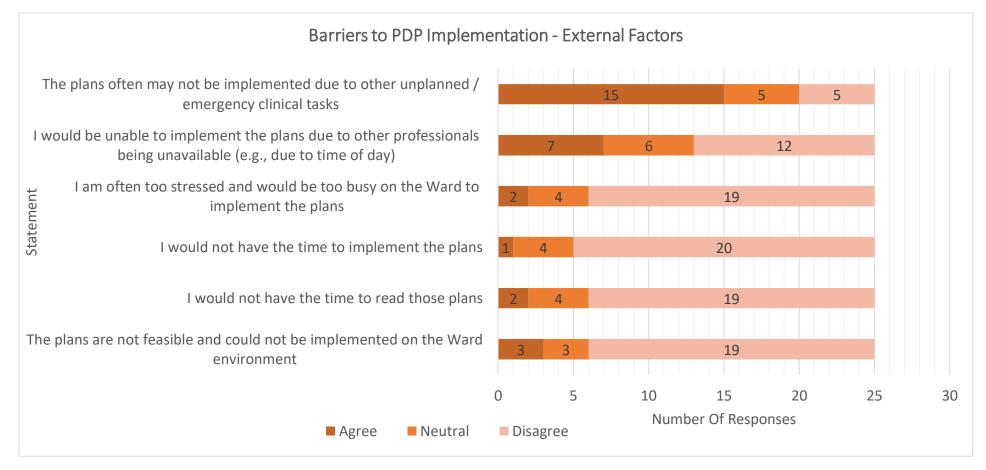
II. Internal factors

Likert-scale results showed responders generally 'agreed' (23/25) that the plans are useful for their role, supported them to adapt their work and that they felt confident and skilled enough to use them. The majority 'disagreed' (15/25) with the PDPs being more relevant for the patient and family.

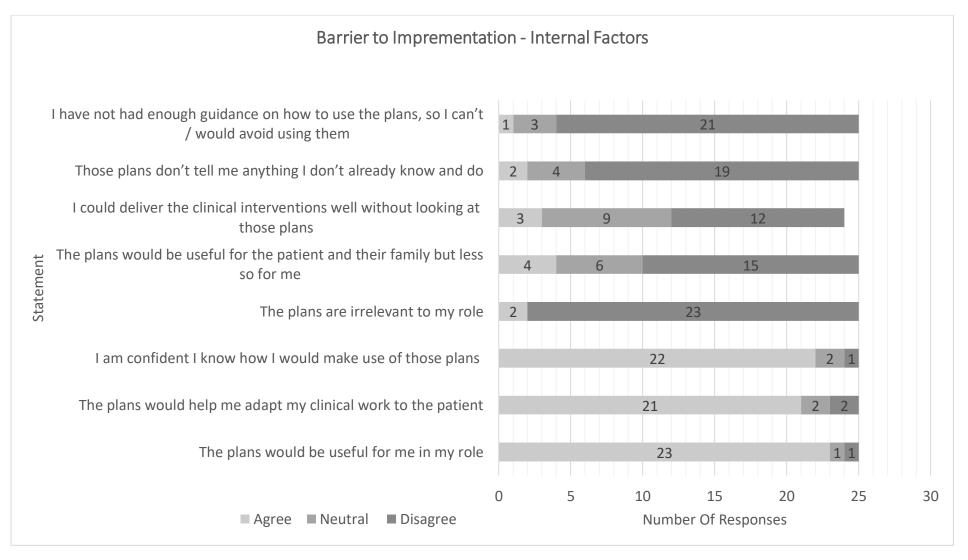
As noted in Figure 5, CA generated a main theme of **Team-related factors** as possible bariers to implementation. Within this theme, the most common sub-theme was staff **being unaware of the PDPs (N=9)**. This sub-theme included comments such needing to "ensure [that] staff are aware of the plans" and how PDPs can be "drawn up without the input from the people are who are expected to implement them".

Figure 5

Summary of staff perceived barriers to implementation of PDPs divided into external (e.g., events on the Ward, environment) and internal factors (e.g., personal confidence and skill) from the from 7-point Likert scale ratings; Summary of CA themes, sub-themes, and frequencies of staff perceived barriers to implementation of PDPs from open text-box responses

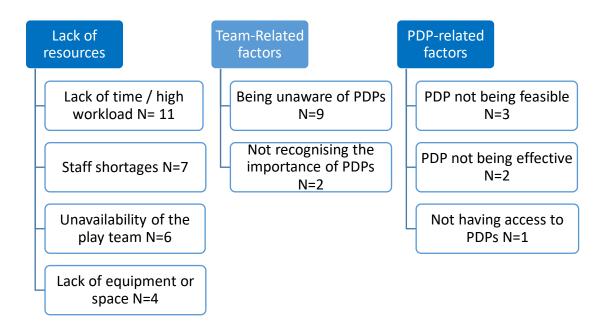


Note: 'Agree' key includes responses of 'Agree' and 'Strongly Agree'; 'Disagree' key includes responses of 'Disagree' and 'Strongly Disagree'



Note: 'Agree' key includes responses of 'Agree' and 'Strongly Agree'; 'Disagree' key includes responses of 'Disagree' and 'Strongly Disagree'

Barriers to PDP Implementation – Content Analysis



The main theme of **PDP-related factors** that may act as possible barriers included subthemes such as *feasibility (N=3)*. This referred to situations where a PDP cannot be implemented due to a disconnect between wishes of patient (as detailed in the PDP) and what is medically possible.

In summary, external barriers that may affect PDP implementation included the team having to respond to emergency clinical tasks, high workload, and staff shortages. Other external barriers to consider also included the unavailability of resources such as computers to access PDPs, private spaces to implement procedures in line with PDPs and the lack of support from AHPs (e.g., outside of hours). Internal barriers that may affect PDP implementation included the team being unaware of PDPs and the mismatch between the plan set out in a PDP and its medical feasiblity.

(d) Ideas of improvement

The staff ideas around areas of improvement and current needs are summarised in Figure 6.

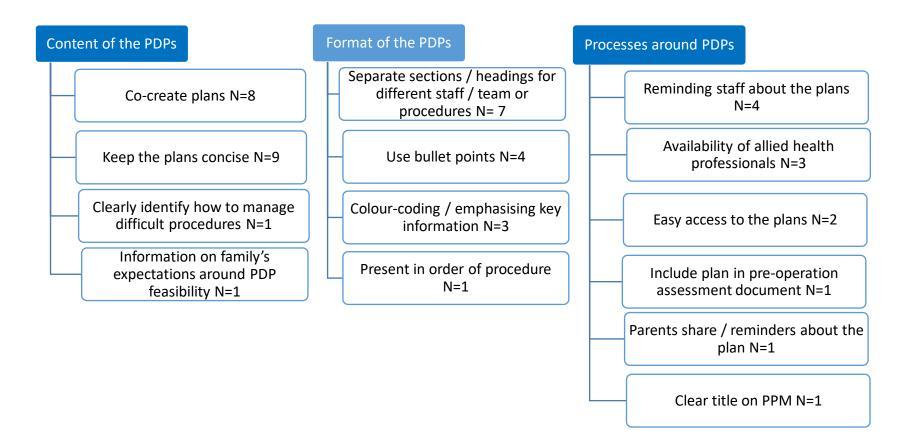
Within the main theme of **content of the PDPs**, there were key sub-themes of needing to ensure the plans are kept **concise (N=9)** and to **co-create plan (N=8)**. The latter sub-theme included comments such as *"The best plans are where the medical staff are equally on board with the plans and we can all work together"*.

The main theme of **format of the PDPs** included sub-themes such as **separate sections** / **headings for different staff** / **team or procedures** (N=7), with example comments such as "Maybe make separate paragraphs dedicated to different staff roles". Further suggestions for formatting improvements included using bullet point (N=4), and colour-coding / **emphasising key information** (N=3) such as by using "bold or red if something is particularly important".

Staff suggestions for improvement also generated the main theme of **processes around PDPs**. This theme included a sub-theme around *reminding staff about the plans (N=4)*. Another sub-theme was the *availability of allied health professionals (N=3)* such as "psychology" to support PDP implementation.

Figure 6

Summary of CA themes, sub-themes, and frequencies of staff ideas for improvement of PDP and processes around PDPs



The responders were given the opportunity to share any unmet needs around PDPs. Of those that chose to respond, CA showed that *training (N=5)* and *raising awaress of PDPs (N=4)* were the most common suggestions.

In summary, staff ideas around PDP improvement included ensuring the plans are concise and co-created with professionals on the SPP, patients and families. Other suggestions included ways that staff could be supported to process key information within the PDPs (e.g., using sub-sections, highlighting important information). There was also some suggestion that PDP implementation could be improved with increased availability of AHPs and that there was a need to raise awareness of PDPs on the ward though reminders and training opportunities.

Discussion

This SEP aimed to (1) capture Paediatric Cardiology Ward team current perceptions of PDPs and (2) explore what factors may be affecting PDP implementation and how it could be improved. This section will summarise the key findings, address limitations and suggest recommendations for the service.

Aim 1: What are the staff teams' current perception of the PDPs?

Perceived PDP relevance, implementation responsibilities, and aims

The results highlighted that all responders agreed that PDPs were relevant to their role and that all professionals involved in a patients' care held responsibility for PDP implementation. This mirrors the multi-disciplinary and collaborative nature of working within specialist (physical) health services and paediatric care (Leeds Congenital Hearts, n.d.).

The CA on open text box responses suggested that PDPs are perceived to primarily support the patient and family through their admission on the ward. While this is in line with the service aims to deliver quality person-centred treatment, there was less recognition that the PDPs aim to support the clinicians themselves. This finding may suggests that healthcare services are more focused on patient-outcomes in comparison to workforce wellbeing, despite the links between the two (West et al., 2015). There has been a recent shift within healthcare settings to address staff well-being, especially since COVID-19 (Dochert, 2020). It may be possible to raise awareness of staff-related benefits of PDPs, such as mitigating the impact that distressed patients and families have on the staff team. This could increase the perceived value of PDPs and improve rates of implementation.

The CA noted that only one response acknowledged that PDPs aim to reduce and mitigate the negative long-term impact of procedural distress on patients, such as a patient experiencing a trauma response (Lerwick, 2016). It must be noted that a lack of responses around this possible benefit of PDPs does not necessarily equate to professionals being unaware of it however, it is possible that this is less readily recognised by the team. As such, there may be scope to raise awareness of the longer-term impact of procedural distress and so the value of implementing PDPs.

Aim 2: What factors might be affecting the implementation of the PDPs?

Dissemination of the PDPs

The results highlighted that PPM is the main and preferred method of sharing PDPs. The results indicated that a variety of other methods are used alongside PPM (e.g., ward diary, email) and that this use of mixed methods may address some barriers around dissemination. The results indicated that staff do not always have the time or ability to access PPM. This preference for a mixture of methods to disseminate may reflect the challenges and complexities that arise when working with a variety of professions and their individual practices.

Format and content of PDPs

The responders were asked to evaluate two example PDPs. The first example PDP (Olivia's) utilises more headings, and presents the information more succinctly (e.g., short sentences, bullet points) in comparison to the second example PDP (Liam's). The results indicated there was a preference of the first example PDP for its layout, length, conciseness, wording, and the level of detail included in the plan.

The preference for conciseness may be driven by staff members needing to quickly locate and process information within the demanding ward environment. This interpretation is supported by one of the proposed ideas for improving the PDPs format suggesting the need to ensure PDPs are concise, use bullet points and visually emphasise key information with colour or font. The results from the CA suggested possible differing views on which plan had more relevant content. This appeared to be related to the profession of the responders. For example, 'Liam's plan' perhaps being seen as more useful for anaesthesiologists than ward staff such as nursing. It must be noted that the frequencies for the CA were low, meaning conclusions can only be tentative. It may also be reflecting that the content of PDPs varies based on patient need (e.g., what procedure that they might find more difficult during their time on the ward). This is in line with staff noting that clear headings or separating the PDPs via professional or procedure may support them to locate key information as needed.

Staff identified barriers to implementation: External and internal factors

The results identified external barriers around implementation to include high workload, reduced staffing numbers and unplanned emergency clinical tasks. Research by Savelsbergh et al. (2012) indicated that stressed and overloaded teams were less likely to engage in 'learning behaviours' such as the ability to take on different perspectives, share errors, and reflect on work outcomes and processes, which consequently affected team performance. Although the authors did not explore this within healthcare teams, it is possible to suggest that a pressured environment may impact on the team's ability to hold PDPs in mind. The teams may be operating in a reactive way, rather than the reflective or proactive mode required for PDPs. These identified external barriers may be indicative of a wider NHS systems issue as services attempt to manage high demand with limited resources (The King's Fund, 2022). This likely means that implementation of PDPs is affected by the need to balance 'best practice' with what is feasible given the available resources.

Another external barrier, and an area of improvement, was around the unavailability of AHPs on the ward. Continuing to co-create plans will provide informal opportunities to explore and discuss what skills staff have or could develop to support PDPs implementation when inevitably AHPs are unavailable on the ward. It likely that this process will involve SPP professionals utilising their existing working relationships to have open discussions about PDPs. Compassionate inter-personal relationship will also likely support to mitigate some of the anxiety that can arise when learning new skills and ideas. Continuing to take an MDT approach to creating the plans may also support the team to continue to take ownership (alongside the patient and family) of PDP implementation.

27

A key internal barrier to implementing PDPs was staff awareness. This partly linked to dissemination barriers, as discussed above. It is possible that awareness of PDPs could also be increased by the SPP professionals continuing to co-create the plans with the wider MDT. Collaboration will also continue to ensure medical feasibility of the PDPs.

Limitations of the SEP

There were several limitations of this SEP. Firstly, the brief nature of the survey is unlikely to have captured the possible complex team dynamics, interplays of power between professionals, or provide an in-depth exploration of personal attitudes and skills in relation to PDPs. Moreover, the pre-determined nature of the survey method has likely affected the validity of the data collected as it likely primed the participants to engage with the survey in a certain way with little option for unrestricted exploration and reflection. Future research around PDPs would benefit from qualitative semi-structured interviews to capture further complexity and richness and allow the research to adopt a more explorative stance. The process of gaining interviews may have been supported through the researcher allocating time to be present on the ward to build rapport needed for good quality interviews and offer the participants the flexibility to engage in the short interviews on an ad-hoc basis given the changeable nature of the ward.

Second, the sample that completed the surveys is relatively small in relation to the full size of the target population, which may have impacted the representativeness and validity of the results. For instance, it is possible the survey captured responders that predominantly have had positive experiences utilising PDPs, those already more aware of PDPs and their use, and those who work regularly alongside professionals on the SPP. Future research could consider using incentives (e.g., prizes, vouchers) to encourage participation.

Service Recommendations

See Table 2 for an overview of the service-related recommendations.

Table 2

Summary of recommendations for service / commissioner divided by area of recommendation

Area of	Recommendation
recommendation	
Processes around PDPs	 The SPP professionals to continue to use a variety of methods to disseminate the PDPs to meet the needs, preferences, and different ways of working of the staff team (e.g., clearly labelled PPM title, hard copies in the ward communication book, and emails around the time of patient admission). For the SPP to continue to work alongside patients, families, and the wider staff team when creating PDPs to: Continue to increase staff awareness of the PDP and psychological ways of thinking. Continue to ensure that the PDPs are medically feasible. Continue to assess the support that the wider team may need to deliver psychologically informed care (e.g., when AHPs are unavailable).
Formatting and content of PDPs	 To consider the layout of PDPs to ensure they are accessible and support staff to process information easily. This may include the use of: Tables. Clear headings / titles. Visually emphasising key information (e.g., colour coding, using bold text, <u>underlining).</u> Separating the PDPs via information most relevant to different professions and / or procedures. To consider the amount of information that is included in the PDPs based on the aimed target audience. This might include having a lengthier version for family / patient and a concise version for the ward staff (as outlined in the above point).

	During the process of the SEP, the service was noted to be person-
	centred and flexible which often resulted in PDPs having a variety of
	other names including 'Procedure Plans', 'Preparation Plans',
	'Surgical Preparation Procedure Plans', and 'Admission Plans', as well
	as a variation of layouts.
	The service could consider creating a uniform presentation (name or
	title, format, use of colour or images) to support staff to easily
	recognise the plans, especially since PDPs can appear infrequently in
	clinical work.
External and	To continue to consider what equipment and space may be required
internal factors	to implement individual PDPs, such as accessing side-rooms (and how
regarding PDP	this can be planned out where possible).
implementation	To consider the role of expanding and increasing awareness of staff
	perceived aim of PDPs to include:
	• The longer-term benefits of using PDPs on patient outcomes.
	• The benefit of using and implementing PDPs on them as
	individual clinicians.
	A possible way to approach this is via an in-depth case example or
	direct feedback from patients and families (see future research
	recommendation).

Future Research	To consider capturing the perspective of the patients and families as
	they are the only persons that are present throughout the ward
	admission and situations where PDPs would be implemented. This
	would provide a more holistic understanding of PDPs and their use.
	This could be achieved through using an existing follow-up
	mechanism at week-six post intervention. During this follow up,
	standardised feedback can be gathered on patient and family
	experiences of admission and the use of the PDPs during that time.
	This contact could also be used as an opportunity to gain consent
	from patients and families about being contacted in the future for
	evaluation purposes, which could form a future SEP.

Dissemination

The results from this SEP were shared during the SEP conference on 28th October 2022 via presentation and a research poster. They will also be shared with the commissioner and at a Clinical Governance meeting as requested by the commissioner.

Conclusions

The SEP results have captured some of the key current perceptions of PDPs and possible factors that may be affecting their implementation. Despite several methodological limitations of the project, the results can be used by professionals on the SPP to continue to foster engagement with PDPs within the team and may be used as a foundation for further improvement on PDP and their use on the Paediatric Cardiology Ward.

References

- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review*, *84*((2), 191–215. <u>https://doi.org/10.1037/0033-295X.84.2.191</u>
- Bengtsson, M. (2016). How to plan and perform a qualitative study using content analysis *NursingPlus Open, 2*, 8-14. <u>https://doi.org/10.1016/j.npls.2016.01.001</u>
- Braun, V., & Clarke, V. (2006, 2006/01/01). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. <u>https://doi.org/10.1191/1478088706qp0630a</u>
- DeMaso, D. R., & Snell, C. (2013). Promoting coping in children facing pediatric surgery. *Seminars in Pediatric Surgery*, 22(3). <u>https://doi.org/10.1053/j.sempedsurg.2013.04.004</u>
- Dochert, M. (2020). What has Covid-19 taught us about supporting workforce mental health and wellbeing? The King's Fund. <u>https://www.kingsfund.org.uk/blog/2020/06/covid-19-supporting-workforce-mental-health</u>
- Erlingsson, C., & Brysiewicz, P. (2017). A hands-on guide to doing content analysis. *African Journal of Emergency Medicine*, 7, 93-99. <u>https://doi.org/10.1016/j.afjem.2017.08.001</u>
- Ernst, M. M., Marino, B. S., Cassedy, A., Piazza-Waggoner, C., Franklin, R. C., Brown, K., & Wray, J. (2018). Biopsychosocial Predictors of Quality of Life Outcomes in Pediatric Congenital Heart Disease. *Pediatric cardiology*, 39(1), 79–88. <u>https://doi.org/10.1007/s00246-017-1730-6</u>
- Franck, L. S., McQuillan, A., Wray, J., Grocott, M. P. W., & Goldman, A. (2010, 2010/10/01). Parent Stress Levels During Children's Hospital Recovery After Congenital Heart Surgery. *Pediatric cardiology*, 31(7), 961-968. <u>https://doi.org/10.1007/s00246-010-9726-5</u>
- Franck, L. S., Wray, J., Gay, C., Dearmun, A. K., Lee, K., & Cooper, B. A. (2015). Predictors of parent post-traumatic stress symptoms after child hospitalization on general pediatric wards: a prospective cohort study. *International journal of nursing studies, 52*(1), 10-21. <u>https://doi.org/10.1016/j.ijnurstu.2014.06.011</u>
- Freitas, I. R., Castro, M., Sarmento, S. L., Moura, C., Viana, V., Areias, J. C., & Areias, M. E. G. (2013). A cohort study on psychosocial adjustment and psychopathology in adolescents and young adults with congenital heart disease. *BMJ Open*, 3(1). <u>https://doi.org/10.1136/bmjopen-2012-001138</u>
- Gonzalez, V. J., Kimbro, R. T., Cutitta, K. E., Shabosky, J. C., Bilal, M. F., Penny, D. J., & Lopez, K. N. (2021). Mental health disorders in children with congenital heart disease. *Paediatrics*, 147(2). <u>https://doi.org/10.1542/peds.2020-1693</u>

- Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches toqualitative content analysis. *Qualitative Health Research*, *15*(9). <u>https://doi.org/10.1177/1049732305276687</u>
- Humble, N., & Mozelius, P. (2022). Content analysis or thematic analysis Similarities, differences and applications in qualitative research 21st European Conference on Research Methodology for Business and Management Studies (ECRM 2022), University of Aveiro, Portugal.
 https://www.researchgate.net/publication/361063562 Content analysis or thematic anal ysis Similarities differences and applications in qualitative research
- Kolaitis, G. A., Meentken, M. G., & Utens, E. M. W. J. (2017). Mental health problems in parents of children with congenital heart disease. *Frontiers in Pediatrics 5*(102), 1-7. <u>https://doi.org/10.3389/fped.2017.00102</u>
- Latal, B., Helfricht S Fau Fischer, J. E., Fischer Je Fau Bauersfeld, U., Bauersfeld U Fau Landolt, M.
 A., & Landolt, M. A. (2009). Psychological adjustment and quality of life in children and adolescents following open-heart surgery for congenital heart disease: a systematic review.
 BMC Pediatrics, 9(6). <u>https://doi.org/10.1186/1471-2431-9-6</u>

Leeds Congenital Hearts. (n.d.). Meet the team https://leedscongenitalhearts.com/child/team

- Lerwick, J. L. (2016). Minimizing pediatric healthcare-induced anxiety and trauma. *World Journal of Clinical Padiatrics, 5*(2), 143-150. <u>https://doi.org/10.5409/wjcp.v5.i2.143</u>
- Li, W. H. C., & Lopez, K. N. (2004). Chinese translation and validation of the Nowicki-Strickland locus of control scale for children. *International journal of nursing studies, 41,* 463–469. <u>https://doi.org/10.1016/j.ijnurstu.2003.12.001</u>
- LTHT. (n.d.). *Children's Congenital Heart Unit*. <u>https://www.leedsth.nhs.uk/a-z-of-services/leeds-</u> <u>congenital-heart-unit/</u>
- Luo, A. (2022). Content Analysis / A Step-by-Step Guide with Examples. Scribbr. https://www.scribbr.co.uk/research-methods/content-analysis-explained/
- Marino, B., Cassedy, A., Brown, K., Cvetkovic, M., Costello, J., Franklin, R., Gaynor, J., Laker, S., Levinson, K., MacGloin, H., Mahony, L., McQuillan, A., Mussatto, K., O'Shea, D., Newburger, J., Sykes, M., Teele, S., Wernovsky, G., Drotar, D., & Wray, J. (2015, 03/01). THE IMPACT OF DEMOGRAPHIC, SURGICAL AND INTENSIVE CARE UNIT FACTORS ON LONG-TERM QUALITY OF LIFE IN CONGENITAL HEART DISEASE SURGICAL SURVIVORS. *Journal of the American College of Cardiology, 65*, A544. <u>https://doi.org/10.1016/S0735-1097(15)60544-7</u>

Menschner, C., & Maul, A. (2016). *Key ingredients for successful trauma-informed care implementation*. C. f. H. C. Strategies. <u>https://www.samhsa.gov/sites/default/files/programs_campaigns/childrens_mental_health</u> <u>/atc-whitepaper-040616.pdf</u>

- NCHDA. (2022). National congenital heart disease audit (nchda): 2022 Summary report. https://www.nicor.org.uk/wp-content/uploads/2022/06/NICOR-NCHDA_2022-FINAL.pdf
- NICOR. (n.d.). Congenital Heart Disease in Children and Adults (Congenital audit). https://www.nicor.org.uk/congenital-heart-disease-in-children-and-adults-congenital-audit/
- Roller, M. R. (2019). A quality approach to qualitative content analysis: Similarities and differences compared to other qualitative methods. *Forum: Qualitative Social Research, 20*(3). <u>https://doi.org/10.17169/fqs-20.3.3385</u>
- Rozensky, R. H., & Janicke, D. M. (2012). Commentary: Healthcare reform and psychology's workforce: Preparing for the future of pediatric psychology. *Journal of Pediatric Psychology, 37*(4), 359–368. <u>https://doi.org/10.1093/jpepsy/jsr111</u>
- Savelsbergh, C., Gevers, J. M. P., Heijden, B. I. J. M. v. d., & Poell, R. F. (2012). Team role stress: Relationships with team learning and performance in project teams. *Group & Organization Management, 37*(1), 67–100. <u>https://doi.org/10.1177/1059601111431977</u>
- So, S. C. Y., Li, W. H. C., & Ho, K. Y. (2019). The impact of congenital heart disease on the psychological well-being and quality of life of Hong Kong Chinese adolescents: Acrosssectional study. *Journal of Clinical Nursing*, 28(3), 1-10. <u>https://doi.org/10.1111/jocn.14864</u>
- The King's Fund. (2022). *NHS funding: our position*. The King's Fund. <u>https://www.kingsfund.org.uk/projects/positions/nhs-funding</u>
- Uzark, K., Jones K Fau Slusher, J., Slusher J Fau Limbers, C. A., Limbers Ca Fau Burwinkle, T. M., Burwinkle Tm Fau - Varni, J. W., & Varni, J. W. (2008). Quality of life in children with heart disease as perceived by children and parents. *Pediatrics*, *121*(5), 1060–1067. <u>https://doi.org/10.1542/peds.2006-3778</u>
- West, M., Armit, K., Loewenthal, L., Eckert, R., West, T., & Lee, A. (2015). Leadership in health care: A summary of the evidence base. K. s. Fund. <u>https://www.kingsfund.org.uk/sites/default/files/field/field_publication_summary/leadership-in-health-care-apr15.pdf</u>
- Wolfer, J. A., & Visintainer, M. A. (1975). Ediatric surgical patients' and parents' stress responses and adjustment as a function of psychologic preparation and stress-point nursing care. *Nursing Research*, 24(4), 244-255. <u>https://doi.org/10.1097/00006199-197507000-00002</u>

Appendices

Appendix A - Staff Survey

Section 1: About you and your role

1. Please select which best describes your role:

Consultant

Registrar / Junior doctor (including associate practitioner) Ward staff (including ward nurses, nurse specialist, clinical support worker / apprentice) Allied health professional (psychology team, play specialist / leader) Prefer not to say Other (OPEN BOX)

2. How long have you been working within the area of paediatric cardiology? (e.g., 6 months, 2 years and 8 months, 8 years, etc.)

OPEN BOX

3. How long have you been working on Ward 51? (e.g., 6 months, 2 years and 8 months, 8 years, etc.)

OPEN BOX

Section 2: Current use of Procedure Plans

4. Have you heard of Procedure Plans before?

Yes – goes to Q5 No – goes to Section 3 Q12

5. In your opinion, what is the aim of Procedure Plans?

OPEN BOX

6. Do you see Procedure Plans to be relevant to your role?

No Yes Unsure

(A): Please explain your answer (optional)

OPEN BOX

7. Who has the responsibility to ensure Procedure Plans are implemented? (you can pick multiple options if needed)

Consultant

Registrar / Junior doctor (including associate practitioner) Ward staff (including ward nurses, nurse specialist, clinical support worker / apprentice) Psychology team Play specialist / leader Patient and their families Unsure Other (OPEN BOX)

(A): Please explain your answer (optional):

OPEN BOX

8. What is the most common way you find out a Procedure Plan is in place?

PPM Email Communication's book Member of the psychology team or play specialist Another member of the team (not psychology or play specialist) Other I don't know where to find the procedure plans

9. Procedure Plans are shared using a consistent method

Strongly agree – Agree – Neutral – Disagree – Strongly Disagree – Unsure

(A): Please explain your answer (optional)

OPEN BOX

10. The way Procedure Plans are shared with the team affects whether they get used

Strongly agree – Agree – Neutral – Disagree – Strongly Disagree – Unsure

(A): Please explain your answer

OPEN BOX

11. What do you think is the *most* useful way to share Procedure Plans?

PPM Email Communication's book Member of the psychology team or play specialist Other

(A): Please explain your answer (optional)

OPEN BOX

Section 3: Your thoughts on two example Procedure Plans

"As mentioned before, one of the roles of the psychology team and play specialist is to collaborate with the patient and their families to create Procedure Plans that can be used when the patient is admitted.

You will now be shown two example Procedure Plans. After each example, you will be asked questions about the way they are presented (such as their formatting and wording).

Then, you will be asked some questions about content of both the plans (such as whether you see them as useful and feasible.). You can continue to go back to the example plans so don't worry about having to remember the content of the plans."

Example Procedure Plan 1 (Olivia)

Olivia Brown			
CONCERNS (<u>what</u> will be a challenge) WHAT IS THEIR	 Olivia struggles with procedures and has had to be restrained before Olivia will have a hospital passport Olivia understands that she needs to come to 		
UNDERSTANDING	 Onvia understands that she needs to come to hospital to fix her poorly heart and she needs to stay on ward 51. Doesn't have good understanding of procedure, timings etc 		
WHAT INTERVENTIONS WORKED BEFORE			
HOW DOES CHILD COMMUNICATE	 Olivia is developmentally 2 ½ - 3 years old and it is best to explain things as simply as possible It is best not to prewarn Olivia about procedures as this will upset her 		
INTERVENTION (what we have done to prepare them)	 Katie Bear book Explored ways of managing procedures Ward visit with family 		
SENSORY NEEDS	 Running water sounds such as toilet flushing Doesn't like hair being washed Current investigations around autism 		
HOME	 Olivia lives with her mum and dad Mum and Dad will be staying with Olivia while she is on the <u>Ward</u> but Dad will have to return to work 		
ADMISSION (<u>what</u> would help on admission)	 Olivia will need a <u>premed</u> and is going to try the tablet 		
PICU HDU (<u>what</u> may be difficult in PICU/HDU)	Olivia may find it difficult to communicate pain		
WARD 51 (<u>what</u> may be difficult on Ward 51) POST DISCHARGE	 A side room would be preferable as Olivia will find it hard fasting and she also wakes early (3am usually) and don't want to disturb other patients 		
PLAN FOR PROCEDURE (bloods etc)	 Prior to cannulation/bloods Olivia would like to use 'magic' cream and she has a prescription for this If play specialists are helpful for distraction this may be used, however family have been encouraged to bring distractions. Olivia will go to sleep with a gas mask Olivia would like appeal for sticky dressings/plasters 		

Individual Procedure Plan

12. Please rate following based on Procedure Plan 1 (Olivia)

Strongly agree – Agree – Neutral – Disagree – Strongly Disagree

The plan gives too much information for what I need

The plan does not give me enough information for what I need

The plan gives the right level of detail for what I need

The plan is concise

The plan is too long

The plan hard to read because of wording / sentences used

The layout of the plan useful

The layout of the plan makes it hard to understand

(A): Do you have any additional thoughts / comments that are not captured in the ratings above? (optional)

OPEN BOX

Example Procedure Plan 2 (Liam)

Admission Plan:

Name: Liam Smith

NHS number: 123456789

Background:

Concerns around this procedure:

- Liam finds procedures distressing and has previously been pinned to allow cannulas, COVID swabs etc, to be completed. He is hypervigilant and wary of healthcare staff and equipment and can hit and kick out during procedures.
- Liam has a fear of needles due to pain and blood. He also does not like plasters being removed as he finds this painful.
- To help Liam manage his anxiety, he has previously been provided with a pre-med, but he has spat this out. Liam's mum has also tried to support him in numerous ways during procedures (e.g. giving him a hug, distracting him with a tablet), but has not found this to work.

In surgical prep:

 Liam engaged very well with silly play in surgical prep but was not able to let his choices be known in relation to procedures. He was initially wary of staff and equipment, but later engaged <u>really well</u> with the play team.

Plan for the day:

- Liam would benefit from taking Clonidine (which is tasteless) with his favourite squash, prior to the procedure. As highlighted above, he has previously spat out pre-meds with a bitter taste.
- Mum has made the decision for Clonidine to be covertly put in Liam's juice for his best interests. Mum feels that if we tell him about the medication, he won't drink it.
- After taking Clonidine, the anaesthetist team recommend that Liam is transported in his ward L51 bed to the cath lab, so that he isn't disturbed.
- Liam would benefit from input from the play team to distract him while he is being put into a special sleep. He enjoys silly play and messy play (e.g. sand art, play doh, etc).
- Cannula induction would be preferable to a mask as Liam does not like things on his face. Mum has made this decision as Liam has not been able to.
- Induction being completed in the smaller anaesthetic room would be preferable, and for staff
 presence to be minimised at this point. Liam is hyperalert and is likely to find a lot of
 equipment and staff intimidating.
- Liam likes for plasters to be removed using magic creams.

Plan for preparing Liam at home:

- For mum and Liam to bring his favourite juice in on the day and drinking bottle.
- For Liam to bring in toys and treats that will help distract him (e.g. his doctor's kit, sweeties).
- For Liam to practice with masks, cannulas, and plasters at home with his family in preparation for the day.

13. Please rate following based on Procedure Plan 2 (Liam)

Strongly agree – Agree – Neutral – Disagree – Strongly Disagree

The plan gives too much information for what I need

The plan does not give me enough information for what I need

The plan gives the right level of detail for what I need

The plan is concise

The plan is too long

The plan hard to read because of wording / sentences used

The layout of the plan useful

The layout of the plan makes it hard to understand

(A): Do you have any additional thoughts / comments that are not captured in the ratings? (optional) OPEN BOX

14. Which Procedure Plan format do you prefer?

Example 1 (Olivia) Example 2 (Liam) I like both equally I don't like either of them

> A: Please explain your answer (optional) OPEN BOX

15. What ideas for improvement do you have about the way the Procedure Plans could be written and presented / laid out?

OPEN BOX

The aim of the following questions is for you to use your experience of working on Ward 51 to inform what might make it easier or get in the way of the Procedure Plans (such as the two example plans you have just seen) being used on the Ward.

One of the things that might affect the use of the plans include the environment, and events or situations that happen on the Ward.

16. With this in mind, please rate the following:

Strongly agree – Agree – Neutral – Disagree – Strongly Disagree

The plans are not feasible and could not be implemented on the Ward environment I would not have the time to read those plans I would not have the time to implement the plans I am often too stressed and would be too busy on the Ward to implement the plans I would be unable to implement the plans due to other professionals being unavailable (e.g., due to time of day)

The plans often may not be implemented due to other unplanned / emergency clinical tasks

(A): Do you have any additional thoughts / comments that are not captured in the ratings above?

OPEN BOX

There might also be things happening for us as professionals that might affect if and how the Procedure Plans may get used on the Ward. This could include our confidence in our own skills or what thoughts we have about the plans (e.g., whether we think they are useful, etc.).

17. With this in mind, please rate the following:

Strongly agree – Agree – Neutral – Disagree – Strongly Disagree

The plans would be useful for me in my role		
The plans would be useful for the patient and their family but less so for me		
The plans would help me adapt my clinical work to the patient		
The plans are irrelevant to my role		
I could deliver the clinical interventions well without looking at those plans		
Those plans don't tell me anything I don't already know and do		
I am confident I know how I would make use of those plans		
I have not had enough guidance on how to use the plans, so I can't / would avoid using		
them		

(A): Do you have any additional thoughts / comments that are not captured in the ratings above? OPEN BOX

18. Are there any other reasons / barriers that might get in the way of the plans being used on the Ward?

OPEN BOX

19. What changes or improvements would you make to the procedure plans that we have not covered? OPEN BOX Part of the aim of the project is to highlight any further areas of support / professional development around the use of the Procedure Plans that can be shared with the psychology team, play specialist, and ward management. As such...

20. In relation to Procedure Plans, has this survey highlighted an unmet professional need? (e.g., specific training, peer support opportunities, line management support)

OPEN BOX

21. Any final comments about Procedure Plans and their use? (optional)

OPEN BOX

Section 4: Thank you!

Your time on this is really appreciated!

If you have any questions or comments, please get in touch with Jovita, the lead researcher via email: <u>umjv@leeds.ac.uk</u>

Appendix B -Semi-structured Interview schedule

Introduction

Ensure that the consent form has been completed and if not, complete this verbally. Check if they have completed the survey.

KEY: Question with* = mirrors the question / themes asked in the survey

Section 1: About you and your role

- *How long have you worked within the area of paediatric cardiology?
- *How long how have you worked on Ward 51?
- *What is your job title?
- Can you give me a brief description of your role on the Ward?

Section 2: Current use of Procedure Plans

1. *Have you heard of Procedure Plans before? (Yes/No)

If YES, proceed with Q2 in Section 2

If NO, proceed with Section 3

2. *Can you tell me a little about what you think the aim of the Procedure Plans are and how related to your role?

Possible prompts:

- *Do you see Procedure Plans as relevant to your role? How / why?
- 3. Can you tell me a bit about who is responsible for implementing the plans? <u>Possible prompts:</u>
- * Why that person / professional(s)?
- 4. Can you tell me about the way you might find out a patient has a Procedure Plan in place?

Possible prompts:

- *Do you know where to find procedure plans?
- *What is the *most* common way you might find out a Procedure Plan is in place?
- *Are the procedure plans shared using a consistent method?

5. *Can you tell me about any links between the way the plans are shared and whether they get used?

Possible prompts:

- Why?
- *What do you think would be the most useful way to share procedure plans?

Section 3: Your thoughts on two example Procedure Plans

"As mentioned before, one of the roles of the psychology team and play specialist is to collaborate with the patient and their families to create Procedure Plans that can be used when the patient is admitted.

You will now be shown two example Procedure Plans. After each example, I'll ask you some questions about the way they are presented (such as their formatting and wording).

Then, I'll ask you some questions about content of both the plans (such as whether you see them as useful and feasible). I can reshow you plans as many times as you need so don't worry about remembering the content."

Show example 1 (Olivia's plan) followed by example 2 (Liam's plan) via screen share.

After each example plan, ask Q6 and Q7 (and then move onto Q8):

- 6. Can you tell me what you think about the <u>layout</u> of the plan? <u>Possible prompts:</u>
- *Can you tell me about the layout and how it might affect the usefulness of the plan?
- *Can you tell me about how the layout affects your ability to understand the plan?
- Are there any links between the layout and how the plan might be accessed or used on the Ward?
- 7. Can you tell me what you think about the way the plan is <u>written</u>? <u>Possible prompts:</u>
- *What do you think of the wording and sentences used? Why? How might this affect the use of the plans on the Ward?
- *What do you think about the level of information and detail included in the plan?
 Why? How might this affect the use of the plans on the Ward?
- 8. *Now, having seen both the plans, do you prefer one plan over the other and why? <u>Possible prompts</u>
- Why? What do you mean by X?

9. *What improvement ideas do you have about the way the plans could be written and presented?

Possible prompts:

- How might this affect the way they are used?

"The aim of the following questions is for you to use your experience of working on Ward 51 to inform what might make it easier or get in the way of the Procedure Plans (such as the two example plans you have just seen) being used on the Ward.

One of the things that might affect the use of the plans include the environment, and events or situations that happen on the Ward."

- 10. Can you tell me about the way the Ward environment or events on the Ward might make it more challenging for the plans to be implemented? Possible prompts:
- *What might make the use of the plans <u>less</u> feasible on the Ward?
- What might be happening on the Ward?
- *Might there be any links between the plans being used and the time of day? How does this link to use of the plans?
- *Might there be any links between the plans being used and your workload? How does this link to use of the plans?
- 11. Can you tell me about the way the Ward environment or events on the Ward might make it <u>easier</u> for the plans to be implemented? <u>Possible prompts:</u>
- *What might make the use of the plans <u>more</u> feasible on the Ward? What might be happening on the Ward?

"There might also be things happening for us as professionals that might affect if and how the Procedure Plans may get used on the Ward. This could include our confidence in our own skills or what we might think about a plan (e.g., whether we think they are useful, etc.). So, having seen the example plans..."

12. *Can you tell me about the usefulness of these plans?

Possible prompts:

- *How might they be useful / relevant? If not, why?
- Would they be useful to your <u>colleagues</u>? <u>Patient and their families</u>? Why?
- What might make the plans more useful for you? Your colleagues?

13. *If you did follow these plans, would your clinical practice change?

Possible prompts:

- How? If not, why?
- *Would the change be significant when compared to what you already do in your clinical practice?
- 14. *Can you tell me about your confidence and skills in using these the Procedure Plans to inform your work?

Possible prompts:

- *What factors might affect your confidence and skills in being to use them in your work?
- What about your colleague's confidence and skills?
- 15. * Are there any other reasons / barriers that might get in the way of the plans being used on the Ward that we have not mentioned?
- 16. *What changes or improvements would you make to the procedure plans that we have not covered? Possible prompts:
- How would these changes impact on if / how the plans are used by you / the team?
- What do you think would help staff to engage more with the plans?

"Part of the aim of the project is to highlight any further areas of support / professional development around the use of the Procedure Plans that can be shared with the psychology team, play specialist and ward management. As such..."

- 17. *In relation to Procedure Plans, has this interview highlighted an unmet professional need? (e.g., specific training, peer support opportunities, line management support)
- 18. *Any final comments about Procedure Plans and their use?

Thank you so much for sharing your thoughts with me.

19. Do you have any questions for me?

Appendix C - Service evaluation project introduction page

Exploring the use and perceptions of Procedure Plans on a paediatric cardiology ward (Ward 51)

As you are aware, one of the roles of the psychologists and the play specialists is to cocreate Procedure Plans with some of the patients and their families before admission to hospital. The plan might include the patient's needs and preferences for the various clinical procedures and events that might need to take place during their stay in hospital.

This project aims this Service Evaluation Project (SEP) is gain some valuable feedback on these Procedure Plans from the perspective of the professionals on Ward 51.

As such, all professionals working on Ward 51 are invited to participate. You can do this in <u>one</u> of two ways:

A short survey (10-15 minutes)

Or

A short interview (15-20 minutes)

To go to the survey, click 'NEXT' at the bottom of the page.

If you are interested in completing a short interview, you can provide your email address to the lead researcher (Jovita) who will then email you further information about the interview. You can then decide whether you want to participate. To provide your email address, follow this link: <u>https://leeds.onlinesurveys.ac.uk/w51-interviews</u>

If you're interested in participating but have additional factors that might affect your ability to engage (dyslexia, visual impairment), please get in touch with Jovita to discuss this via email: umjv@leeds.ac.uk

<u>Staff Survey Participant Information: Exploring the use and perceptions of Procedure Plans</u> on a paediatric cardiology ward (Ward 51)

Please take time to read the following information and discuss it with others if you wish.

What is the purpose of the project?

The aim of this project is to gather Ward 51 staff perception of the Procedure Plans and what might affect their use. This will provide valuable feedback for the psychologists and play specialists that co-create the plans with patients and families.

Who is conducting the project?

The lead researcher is Jovita Valuckaite (Clinical Psychologist in Training at the University of Leeds). The project was commissioned by Kat Bilbrough (Principal Clinical Psychologist, Congenital Cardiology Leeds Children's Hospital).

The project is also a part of the Clinical Psychology Doctorate at the University of Leeds and is being supervised by Kat Bilbrough and Ciara Masterson (Academic Tutor at the University of Leeds).

Ethical approval has been given by the Doctorate in Clinical Psychology Research Ethics Committee at the University of Leeds (Application Reference: DClinREC 21-018).

How long will the survey take to complete?

Approximately 10-15 minutes.

Do I have to participate?

No. You participation is voluntary.

Can I withdraw my data?

You can also withdraw at any time while you are completing the survey by either not clicking the 'Finish' button at the end of the survey or closing the webpage.

Can I withdraw my data after I have clicked 'Finish'?

As all data is collected anonymously, it is not possible to withdraw contributions made after clicking the finish button at the end.

Are my answers anonymous?

Yes. We have tried to ensure people are not identified by their job titles by grouping professionals together. You can also choose to not disclose demographic information.

Take care to not include identifiable information for yourself or others (professionals or patients) in the open text responses.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for participating in the project, it is hoped that this work will allow to evaluate the Procedure Plans and understand what factors might affect their use. We also hope that you may find participating an interesting experience!

What are the possible disadvantages and risks of taking part?

It is possible that thinking about your use and perceptions of the Procedure Plans could be distressing, especially when there are you continuing to hold a demanding clinical role.

You can discuss any such worries with Jovita (the lead researcher). You are also able to contact support available through line management, your employer (Occupational Health services) and your GP.

Who will see my data?

Data collected from this survey will be analysed by the lead researcher only. Individual data will not be shared with other people.

Quotes from the survey may be used in the final SEP report but all identifiable information will be removed.

The University of Leeds, the NHS trust and other regulatory bodies might need to see data collected as part of this project to ensure the project was carried out appropriately. However, data that might be shared in this instance will be anonymous.

What will happen to the results of the study?

Survey responses will be collated and analysed by Jovita. Information will be written up into a report and will be used as part of the Jovita's academic assessment on the Clinical Psychology Programme. Overall findings may also be presented at a student conference to other trainees, commissioners, and course staff.

Overall results of the study will be shared back with the commissioner, your team, and any other relevant places such as clinical meetings / conferences.

Will my taking part in the study be kept confidential?

Yes. Data from the survey will be handled in confidence and all transmissions and storage of data will comply with current relevant University of Leeds security standards. More information on the University guidelines can be found here: https://dataprotection.leeds.ac.uk/research-participant-privacy-notice/

Upon completion of the project, data will be securely kept for 3 years. After 3 years, data will be secure disposed of.

Researchers contact information

If you have any questions or comments, please get in touch with either:

Jovita Valuckaite (Clinical Psychologist in Training): umjv@leeds.ac.uk

Ciara Masterson (Project Supervisor): C.Masterson@leeds.ac.uk

Kat Bilborough (Principal Clinical Psychologist, SEP commissioners): k.bilbrough@nhs.net

By proceeding through the survey questions and submitting your answers, you are indicating that you understand the above information and are consenting to the process.

Appendix E - Semi-structured interview participant information sheet

1st May 2022 Version 1

Exploring the use and perceptions of procedure plans on a paediatric cardiology (Ward 51)

Please take time to read the following information and discuss it with others if you wish.

What is the purpose of the project?

The aim of this project is to gather Ward 51 staff perception of the Procedure Plans and what might affect their use. This will provide valuable feedback for the psychologist and play specialists that co-create the plans with patients and families.

Who is conducting the project?

The lead researcher is Jovita Valuckaite (Clinical Psychologist in training at the University of Leeds). The project was commissioned by Kat Bilbrough (Principal Clinical Psychologist, Congenital Cardiology Leeds Children's Hospital).

The project is also a part of the Clinical Psychology Doctorate at the University of Leeds and being supervised by Kat and Ciara Masterson (Academic Tutor at the University of Leeds).

Ethical approval has been given by the Doctorate in Clinical Psychology Research Ethics Committee at the University of Leeds (Application Reference: DClinREC 21-018).

How long will the interview take to complete?

Approximately 15-20 minutes.

How many will be completed?

We are looking to conduct a maximum of 10 interviews.

Do I have to participate?

No. You participation is voluntary. You can also withdraw from the interview at any times without providing a reason.

Can I withdraw my data after I have finished the interview?

You will be able to withdraw your data for up to a week following the interview. After this time, the analysis of the data might have already begun meaning removing your data from the collated analysis might not be possible. You would not have to provide a reason for why you want to withdraw your data.

Will my data be anonymous?

Yes. Personally identifiable information (such as names, job titles in a way that identifies you, etc.) will be anonymised throughout the process. Consent forms and data from the interviews will be kept in separate encrypted electronic areas.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for participating in the project, it is hoped that this work will allow to evaluate the Procedure Plans and understand what factors might affect their use. We also hope that you may find participating an interesting experience!

What are the possible disadvantages and risks of taking part?

It is possible that talking about your use and perceptions of the Procedure Plans could be distressing, especially when you are continuing to hold a demanding clinical role.

You can discuss any such worries with the Clinical Psychologist in Training. You are also able to contact support available through line management, your employer (Occupational Health services) and your GP.

Will I be recorded and how will the recorded media be used?

The interview will be recorded (audio-only or audio-and-video depending on your preference) using Microsoft Teams.

The recording will be saved on the password protected device on the Microsoft Teams account. The recording will then be transferred from the device to University of Leeds software, in line with data protection guidance.

Jovita will then listen and analyse the interviews and ensure that identifiable information (names, places, etc.) are removed and / or anonymised. Only Jovita will have access to the original recordings.

If you do not want to be recorder at all, it may be possible to participate without being recorded.

What will happen if I take part?

If you decide to take part, you will be asked to sign a consent form (electronically) and send this back to Jovita. Then, a convenient time / date for the interview will be agreed.

Before the interview you will be given the opportunity to ask any further questions and verbal consent will be gained. You will then be asked whether you consent to being recorded and given the option to be only-audio recorded or audio-and-video recorded. Only then will the recording begin.

The interviews will be semi-structured and will involve being asked about your broad views and experiences of the Procedure Plans. You will then be asked to review and discuss two example Procedure Plans and talk about what might affect the use of the plans on the Ward. You will be able to share as little or as much as you wish.

You will need access to a device with Microsoft Teams and have a quiet and private space to take part in the interview. To ensure that you are able to see the example plans clearly, please think about how you might be able to use an electronic device with a larger screen (computers / laptops, portable tablets on the Ward, etc.).

Who will see my data?

Data collected from this interview will be analysed by the lead researcher only. Individual data will not be shared with other people.

Quotes from the interview may be used in the final SEP report but all identifiable information will be removed.

The University of Leeds, the NHS trust and other regulatory bodies might need to see data collected as part of this project to ensure the project was carried out appropriately. However, data that might be shared in this instance will be anonymous.

What will happen to the results of the study?

Interview data will be collated, analysed, and written up into a report that will be used as part of Jovita's academic assessment on the Clinical Psychology Programme. The trainee might also present overall findings at a student conference to other trainees, commissioners, and course staff.

Overall results of the study will be shared back with the commissioner, your team, and any other relevant places such as clinical meetings / conferences.

Will my taking part in the study be kept confidential?

Yes. Data from the survey will be handled in confidence and all transmissions and storage of data will comply with current relevant University of Leeds security standards. More information on the University guidelines can be found here: https://dataprotection.leeds.ac.uk/research-participant-privacy-notice/

Upon completion of the project, data will be securely kept for 3 years. After 3 years, data will be secure disposed of.

Your data may be shared with other if there are any concerns about yours / someone else's practice being unethical and / or unprofessional or if there are risk of harm to yourself or other people. If such concerns arise, Jovita will discuss this with you in a transparent manner where this is possible to plan out next steps with you.

Researchers contact information

If you have any questions or comments, please get in touch with either:

Jovita Valuckaite (Clinical Psychologist in Training): umjv@leeds.ac.uk

Ciara Masterson (Project Supervisor): C.Masterson@leeds.ac.uk

Kat Bilborough (Principal Clinical Psychologist, SEP commissioners): k.bilbrough@nhs.net

Thank you for reading this information sheet. Your time and thoughts would be valuable, and I hope that you will take part!

Appendix F - Pre-written email used to advertise the service evaluation project

Email subject: Evaluation of Procedure Plans on Ward 51

Hi,

I am Jovita, a second-year Clinical Psychologist in Training. In the recent months I have been working alongside the psychology team and play specialists to co-create a service evaluation project (SEP).

The project aims to gain some valuable feedback on Procedure Plans (plans created with patients and families before admission to Ward 51 alongside the psychology team and play specialist).

<u>All</u> professionals working on Ward 51 are invited to participate and you can get involved in two ways – either a short survey or a short interview.

For more information, please follow this link: *LINK*

I really hope you consider participating and please don't hesitate to get in touch if you have any questions or comments!

Thank you all in advance,

Jovita Valuckaite (she/her)

Clinical Psychologist in Training

umjv@leeds.ac.uk

j.valuckaite@nhs.net



Appendix G -Semi-structured interview consent form

Version 1	
Staff Interviews	
SEP Consent Form: Exploring the use and perceptions of procedure plans on a paediatric cardiology (Ward 51)	initials next to the statement if you agree
I confirm that I have read and understand the information sheet dated 1 st May 2022 explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw at anytime during the interview without a reason. After the interview is completed, I understand I can still withdraw my data for up to a week without giving a reason. I understand my withdrawal will have no negative consequences. In addition, should I not wish to answer any question, I am free to decline.	
To discuss withdrawal, get in touch with the lead researcher (Jovita Valuckaite) via email: <u>umjv@leeds.ac.uk</u>	
I understand that members of the research team may have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the reports or any quotes used as part of the research.	
I understand that the data collected (such as audio or audio-and-visual recordings of me) may be stored and used only for the purpose of this project.	
I understand that relevant sections of the data collected during the study, may be looked at by individuals from the University of Leeds or from regulatory authorities where it is relevant to my taking part in this research.	
I understand the above information and agree to take part in the research project	

Name of participant	
Date	
Email address	

Appendix H - Example Content Analysis table: What do staff perceive to be the aims of PDPs?

Theme	Categorised Code (N=number of codes)	Quotes
Supporting the team	Prepare the team to support client (N=4)	"prepare nurses with strategies" "make staff aware of the best way to help and undertake patients when undergoing procedures" "inform staff of what measures need to be done for medical procedures on the ward, investigations and their cardiac procedure" "prepare staff caring for a child what may make things easier/smoother during their admission"
	The plans supports the team (N=2)	"assist the ward/ theatre staff during procedures" "make life easier for the staff"
	Prepare the patient and family for admission / procedures (N=3)	"prepare patients and there families for procedures that will happen on the ward" "Set out a clear plan of care" "prepare a patient for what they are likely to experience in hospital"
Supporting the patient and family	Meet patient needs and deliver personalised care (N=17)	"understand and carry out the procedure in the best way possible" "highlight any specific requirements of patients that have been highlighted by the child/ parent prior to admission" "give insight into the patients needs" "help support the patient having surgery on ward 51" "helps them [patient] to have their say about what they want to happen before the procedure starts happening" "ward staff are aware of any requirements/adaptations needed for patients coming into the ward" "May include instruction on how to best interact/communicate with the child and family" "Often being the person carrying out the procedure it is helpful to have a plan in place that has been made in advance so I can try to do the procedure in the best way possible" "Often the one carrying out interventions on the ward such as cannulas or bloods" "It's part of my role to ensure each child/ parent gets the right support." "I would look at a procedural plan when looking after a patient if there was one"

Reduce immediate patient and family distress (N= 17)	"They are essential for our role as they give relevant information regarding the patient who we are directly involved in supporting." "I always refer to procedure plans when working with a patient, if I'm aware that the patient has one, as it helps the procedure to go more smoothly." "They are extremely relevant as working directly patient facing and carrying out various different procedures means they can be utilised withing my role." " it helps increase the psychological mindedness of the MDT and smooth the care received by patients" "It's useful to know if children have pre agreed some things they prefer or the way things are done." "It important for nurses to support the child and family" "ensure that the child's needs are met in regards to procedural anxieties they may have" "bespoke plan for how to put the patient at ease and minimise distress for when they come into hospital" "minimise the child and parental anxiety" "help them [patient] cope with going through a procedure" "reduce the child/ families distress" "help the patient and family manage their worries before coming into surgery" "reduce the stress and anxiety caused by the admission and associated procedures on children and their family" "support the child through a potentially traumatic experience and to reduce the worry, stress and anxiety for future procedures" "Minimise distress of the child" "To allow parents to feel listened to" "Yes, as a nurse we have a huge responsibility to minimise distress to the child." "As part of preventative interventions to support mental well being" "It is a good starting point to know why and what all patients are concerned/ apprehensive about or indeed don't understand. Our job, as clinicians is to be clinically effective utilising the most acceptable means to the patient" "Many patients have anxiety regarding invasive mercedures"
Improve patient and family admission experience (N=5)	procedures" "To improve patient experience" "To ensure children have a more comfortable experience on I51" "to make the admission easier" "Make medical procedures easier for children"

	"mamise [maximise] patient experience" "make things easier/smoother during their admission"
Include parent in care delivery (N=2)	"To allow parents to have some input in the care delivery of their child." "I will be contributing towards them and liaising with the families"
Reduce negative long- term impact of procedural distress (N=1)	"minimise the long term effects of procedures in hospital on children and teenagers"