

Paediatric Inflammatory Bowel Disease Nurses' Experiences of using the Paediatric Inflammatory Bowel Disease Patient Held Record in Clinical Practice.

by

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A thesis submitted in partial fulfilment for the requirements for the degree of Masters by Research
at the University of Central Lancashire

November 2014

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Abstract

The Paediatric Inflammatory Bowel Disease Patient Held Record (PIBDPHR) is a tool that was initially conceptualised to enhance the care and education of children attending a tertiary paediatric gastroenterology service in Liverpool. The concept was taken to a national paediatric Inflammatory Bowel Diseases (IBD) nurses meeting and adopted as a national project. No studies were identified on using a patient held record in paediatric Inflammatory Bowel Disease and the literature reflects a somewhat confused understanding of what is meant by the term patient held record. This study focuses on one aspect of the utilisation of the PIBDPHR. The study aimed to gain an understanding of how the PIBDPHR was used in practice from the perspective of paediatric IBD nurses.

The nurses who volunteered to participate in the launch of the PIBDPHR were invited to take part in a two phased study. A mixed methods design was adopted as data gathered in Phase 1 was required to inform Phase 2 of the study. Phase 1 consisted of an e-survey which was sent to all of the nurses identified, the nurses (n=12) who completed the e-survey were invited to self-select to participate in Phase 2. Phase 2 consisted of an interview with six nurses and focused on gaining a deeper understanding the responses given in Phase 1. Data were analysed using descriptive statistics and thematic analysis, as appropriate.

The findings of the study showed that the PIBDPHR was being used to: support transition from child to adult services; for patients with complex disease management; for patients who needed more education and with newly diagnosed patients. Four main themes were identified from analysis of both phases of the study: Theme 1 - Decision to introduce the PIBDPHR to patients; Theme 2 - Challenges due to professional resistance; Theme 3 - Organisational and pragmatic barriers; and Theme 4 - Promoting patient benefit through the PIBDPHR. Although many positive aspects were reported about the PIBDPHR, implementation of the tool and sustaining its use in practice were not without challenge.

The conclusions of this study reflect the challenges of implementing the PIBDPHR in practice. Proposed recommendations include the need to consider the embedding of an updated PIBDPHR within a multi-disciplinary pathway and stronger engagement of other professionals and families and consideration on an electronic app version. The evaluation of the patient experience of the PIBDPHR needs to be undertaken in future studies.

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Acknowledgements

I would like to take this opportunity to thank my husband Joe for all his love and support in helping me to achieve all my goals over the last 20 years. Especially over the last 2 years.....

I am eternally grateful to Bernie Carter, Rob Monks and Caroline Sanders for the hours they have given to me in order to complete this dissertation.

Thank you to Alder hey Children's NHS Foundation Hospital Trust for giving me the opportunity to continue my education and undertake this Masters by Research.

I also need to thank my colleagues at St Mark's Hospital who have given me so much support since I joined them in November 2013 to complete my dissertation.

Not forgetting my Mum and Dad, Jean, Matt and Freddie who have been so understanding when I have been distracted and Cathy with her red pen!

Without you all this would not have been possible

Thank you.

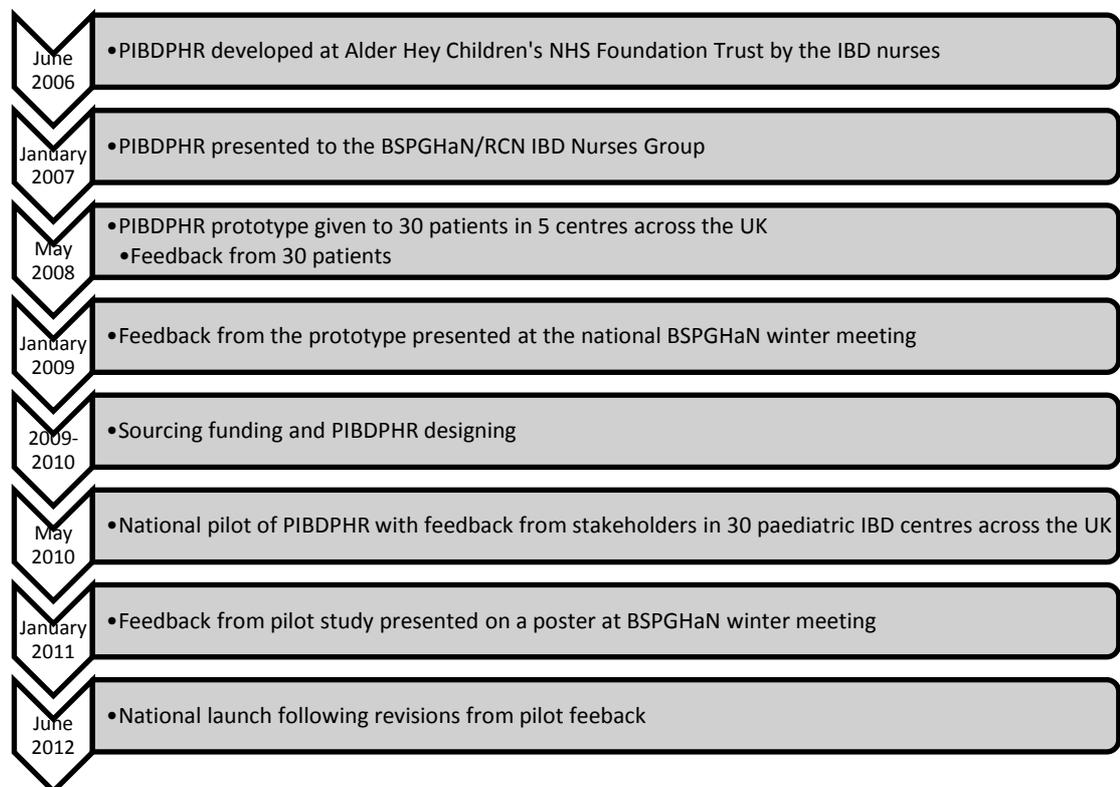
1. Introduction

The Paediatric Inflammatory Bowel Disease Patient Held Record (PIBDPHR) is a concept that was developed following interdisciplinary discussions within the gastroenterology team at Alder Hey Children's NHS Foundation Trust in 2005 when it was identified that Inflammatory Bowel Disease (IBD) patients and their families appeared frequently to demonstrate a lack of understanding of IBD. The team recognised the need for patient education and support prior to it being highlighted in the 2008 National Paediatric IBD Audit commissioned by professional groups, patient organisations and charities (Fitzgerald et al., 2013) several years later. While access to our professional team was implemented locally in line with the 2008 audit, the Alder Hey team ascertained during consultations that patients and parents were often unable to understand fully the condition in general and particularly why they needed regular blood monitoring for certain medications. In paediatrics, parents usually take the lead role in managing their son's/daughter's disease in discussion with the health care professionals. Therefore the PIBDPHR was developed for either for the young person (aged 11 years or older) to use themselves or for parents of younger patients to use until such time that their child matures. When the child starts to take more of an interest and control of their disease themselves it is anticipated they could use the PIBDPHR as an aspect of self-management. As Fishman, Houtman, van Groningen, Arnold, & Ziniel (2011) found medication knowledge is the first step towards self-management. As part of a strategy to improve education and blood-monitoring compliance, and to give patients ownership of undertaking blood monitoring, the first version of the PIBDPHR was developed. In addition to providing information and education, the record was also designed to be an on-going working document for the patient to maintain and utilise whilst under the care of the paediatric team and to aid the transition process into adult care.

The PIBDPHR is a small and easily transportable A5 folder containing patient information and local team/community contact details. A section is included for the

documentation of blood results and a list of investigations undertaken, with dates and other key information. The original design for the PIBDPHR was intended to be maintained and completed by patients aged 11 and over, parents or both parents and patients as previously described. The decision to aim the PIBDPHR at children aged 11 and over was to target the children when they move to high school and start the process towards becoming more independent. The concept of PIBDPHR was presented to the Royal College of Nursing (RCN)/British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHaN) National Forum for Paediatric IBD Nurses in January 2007, where initial reactions to the tool were very positive. The PIBDPHR was then further developed and modified to enable local personalisation (e.g. local IBD team information in Section One) and also to give standardised information to the patient and parents in Section Two (e.g. medication information). A flowchart of the journey of the PIBDPHR up to the point of this study being undertaken is demonstrated in Figure 1.1.

Figure 1.1: History of PIBDPHR prior to commencement of this study



The key focus for this study was to understand the paediatric IBD nurses' experiences of using the PIBDPHR in clinical practice. Since the determinants of its success were

unknown, the study needed to address several areas. The sub questions to be explored were the identification of the different ways in which the PIBDPHR was being utilised in clinical practice (e.g. to support transition from child to adult services, for patients with complex disease management, for patients who needed more education, for new patients to back up information given verbally at diagnosis). The study also aimed to assess any aspects of patient care which were perceived to have been changed by the use of the PIBDPHR and to consider any particular situations, settings or contexts where the PIBDPHR was deemed by PIBD nurses to be useful and/or problematic.

2. Literature review

Introduction

Patient held records (PHR) as a concept have been extensively cited for more than 40 years since Shenkin and Warner (1973) proposed the use of them to improve patient care. The intended purpose was, and continues to be, to develop patient education and knowledge (McCormick, Shapiro & Starfield, 1981; Daley, Rooney & Wallymahmed, 2008), improve patient care (Ayana, Pound, Lampe & Ebrahim, 2001), promote greater patient involvement (Lecouturier, Crack, Mannix, Hall & Bond, 2002) and increase the level of communication and information exchanged between patients and health care professionals (Gysels, Richardson & Higginson, 2007; Williams et al., 2001). However, a recent systematic review by Ko, Turner, Jones & Hill et al. (2010) found no clear benefits to the use of PHR in adults with chronic disease and recommended the need for more high quality studies.

At the time of commencing this literature review there were no studies of the use of a PHR in paediatrics that were identified as being directly aimed at the young person. Typically when a PHR is designed to improve paediatric care they are generally aimed at the parents rather than the patient. Within this literature review, unless otherwise indicated, the studies reviewed were aimed at adults rather than children. The PHR is used in many clinical areas including cancer services (Gysels et al., 2007; Hyne, 1999; Williams et al., 2001), childhood vaccination education and documentation (McCormick et al 1981; McEligott & Darden, 2010), diabetes care (Davis & Bridgford, 2001), mental health (Lester, Allan, Wilson, Jowett & Roberts, 2003), palliative care (Finlay, Jones, Wyatt & Neil, 1998; Komura et al, 2011) and, increasingly, in the intensive care arena (Hale, Parfitt & Rich, 2010). However, there is no unified definition of what constitutes a patient held record and therefore the interpretation of their measurements of success is varied. Liaw (1993) found that patients considered the patient held health record as a

personal document for reference, while the general practitioners perceived it as a management and communication tool.

Inflammatory Bowel Disease

Inflammatory Bowel Disease (IBD) is a term that collectively describes Crohn's disease and ulcerative colitis. Sartor (2006) describes them as chronic, relapsing, immunologically mediated disorders with no definite aetiology underlying the conditions and currently no cure. There are two phases of management - active treatments induce remission, and maintenance treatments aim to keep the condition in remission. There are a variety of treatments for each phase and many national guidelines (BSPGHaN, 2008; NICE Crohn's Guideline, 2012) and international guidelines (ECCO, 2012; ESPGHaN, 2011) support the treatment strategies. However, treatment is individualised to each patient due to the differing responses of patients.

Griffiths (2004) estimated that 25% of patients diagnosed with IBD were children. There are many differences between adult and paediatric disease due to the different effects of the symptoms. For example, in children, disease-related anorexia, nausea and vomiting can lead to malnutrition which in turn causes delays in growth and puberty (Kelsen & Baldassano, 2008). In adults, growth and puberty are not an issue. In paediatric IBD, parents play a major role in managing the disease therefore communication with the child or young person is often overlooked and they do not feel a part of the consultation (Beresford and Sloper, 2003; van Staa, 2011). The PIBDPHR has the potential to enhance the communication between the team caring for the young person and to improve their education regarding their condition, thus encouraging young person involvement in disease management.

Paediatric Inflammatory Bowel Disease Patient Held Record

An initial idea to give paediatric patients and parents a PIBDPHR in which to document their blood results and tests, and to keep all their hospital correspondence was further developed through the RCN/BSPGHaN paediatric IBD nurses group. The PIBDPHR was not designed to be a medical record, where health care professionals make documentation to enhance communication between each other but it was designed to be held by the parent/patient. It was seen as a personal and educational record, owned by the patient/parent, to empower and educate them.

The first section is for personalised information documentation of procedures, blood results, weight charts and medications, with the second section containing educational material and support group information. Although the PIBDPHR was given the title of patient held record, in its current format and at the time of the inception of the study, it informs self-management rather than acting as a shared medical record.

After extensive searching, no published research was found relating to the use of a standalone PHR in IBD. However, within the concept of self-care management of this chronic condition there is increasing evidence for the use of the 'patient passport' (Saibil, Lai, Hayward, Yip & Gilbert, 2008) or patient guide (Kennedy & Rogers, 2002) which are conceptually similar to the PIBDPHR but are used within an education pathway.

Aim

The initial aim of this literature review was to identify all papers relevant to PHR's or similar tools that related to them being used by children or young people with IBD or their parents. As indicated below this aim was extended to encompass all patients and disease areas because of the lack of any relevant papers to the initial search criteria.

Search strategy

A literature search was undertaken during March 2012 and repeated in May 2013 to ensure that all appropriate literature was included. The search engines Medline, CINHAL, BNI, and NCBI and also the Cochrane database were used to conduct the literature search. These databases were selected as they cover all nursing and medical literature. The limitations of selecting a medically- oriented search will be explored in the limitations section. The MeSH terms used were 'Inflammatory Bowel Disease', 'Crohn's Disease', 'Colitis', 'Ulcerative', 'Child#', 'Adolescen#'. Other search terms used were 'patient-held record', 'hand held record', 'log book', 'patient guide', 'patient diaries' and 'patient passport'. Boolean operators 'and' and 'not' were used when appropriate to focus the search. Initial searching did not produce many articles related to children, so this was extended to include all patients regardless of their age. The search was therefore re-run removing Child# and Adolescen#. The disease area was also widened to include any disease area. The inclusion and exclusion criteria were as follows:

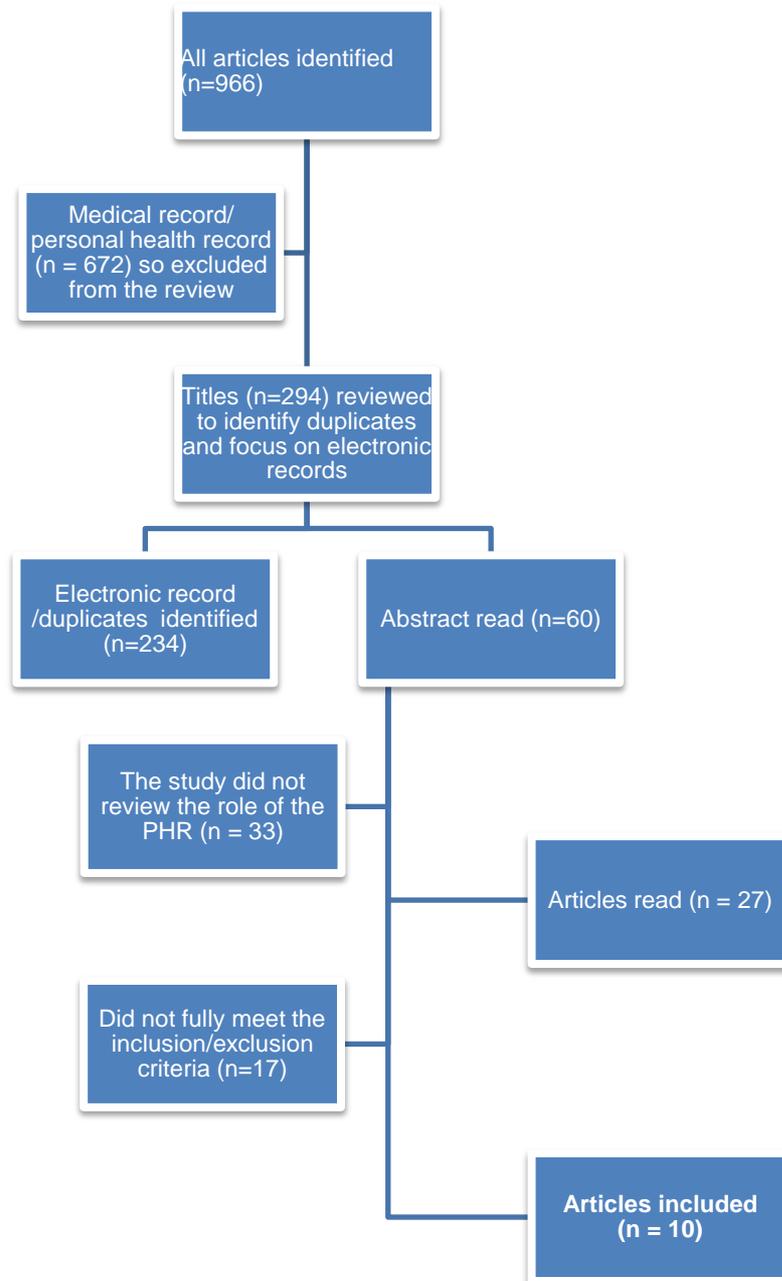
Inclusion criteria

- All articles published in English;
- The patient held record described had to be in a paper format, as there is potentially different usage for and engagement with computer/smart phone based patient held records; and
- Published up to May 2013

Exclusion criteria

- As the IBDPHR was not designed to be used by health care professionals, any articles that related to being shared between patients and health care professionals such as medical health records, shared care, personal health records or personal medical record were excluded; and
- Any studies which were designed to improve communication between health care professionals.

Figure 2.1: Flowchart of decision making re: inclusion/exclusion of studies



Patient held records

The literature search identified 966 articles relating to the search terms; initial review discarded 672 due to the PHR being a medical record that is held by the patient rather than a record of care that the patient maintains for their own use. This was further

reduced to 60 papers by excluding papers that related to electronic based records and duplicates. The abstracts of the 60 remaining articles were then reviewed and discarded if the article did not include an evaluation of the PHR; this reduced the number to 27. A further 17 articles were rejected after reading the full articles and identifying that they did not meet the inclusion criteria. This left ten studies that met the inclusion criteria (see Figure 2.1; Table 2.1) and these papers were reviewed using a critical appraisal approach to ensure that even though they met the inclusion criteria they also met quality criteria.

The appraisal tool that was initially used was the 10 step guide to reviewing an article as explained by Young and Solomon (2009); it was routinely used for reviewing papers in the researcher's departmental journal club. While this was not a recognised critical analysis tool such as CASP and was not specific to the type of study undertaken it incorporated the majority of the questions identified with CASP tools. Subsequently the ten articles identified by the literature search were appraised using the appropriate CASP tool, which was related to the methodological approach of the study. As there is no CASP tool to evaluate a survey this paper was not re-evaluated. This was undertaken as the researcher was not fully satisfied with the 10 step tool and she wanted to be as rigorous as possible. An example of completed CASP form is included in appendix 1. It is important to have a structured appraisal of any literature to avoid being misled into believing invalid results or findings of a study (Parkes, Hyde, Deeks, Milne, Pujol-Ribera, & Foz, 2001).

Before reviewing a paper it is imperative to screen it to ensure that there is a clear statement of the aims of the research and that the methodology is appropriate for the research that has been undertaken, if these two factors are not met then there are concerns regarding the rest of the paper and its credibility. Other considerations in the clinical field are how relevant the article is and whether it adds anything new. Once these criteria have been met then the researcher moved on to interrogating the paper using

more detailed critical appraisal questions. These questions examined how appropriate the research design and recruitment strategy were in meeting the aims of the research and if any bias had been addressed. The researcher also considered how the data were collected and if this was undertaken in accordance with the study protocol, and if any inconsistencies were identified, then again this would create suspicion that the data may not be accurate. Consideration was made about the relationship between researcher and participants, conflicts of interest and any ethical issues. The researcher also considered whether there was a detailed and rigorous analysis of the data with a clear statement of findings and conclusions. All of these stages were undertaken by the researcher for the literature review in this thesis.

The papers included in this literature review are wide-ranging and represent several different chronic conditions (e.g., diabetes and IBD), children's health records, paediatric immunisation, and palliative cancer care. The papers are now discussed within these topic areas. It was decided to review the papers by disease speciality to give the studies a context with the speciality area. Please note, where specified in the studies, the details of ages will be included.

Table 2.1: Overview of patient held record papers meeting study criteria

Study Authors (Year) & (Country)	Population & ages	Research Approach/Methods	Study Aim	Outcome	Limitations
Diabetes papers					
Daley et al (2008) (England)	50 newly diagnosed patients with Type 2 diabetes. Adults.	Qualitative study. Data collection by questionnaire and viewing the PHR. Entries in the PHR were coded.	Evaluation of a care pathway which includes an education folder/patient held record.	Care was more standardised with significant improvements in HbA1c levels, BMI and weight. Good levels of patient satisfaction 22/37 rated the education care pathway as very good.	There was no reference to who distributed the questionnaires and collected them giving concern for bias as the nurses delivering the education care pathway were actively involved in the participants regular care.
Davis & Bridgford (2001) (Australia)	885 diabetic patients and 400 health care professionals. Ages 12-98 (average age 63).	Quantitative study. Questionnaire distributed by a stratified randomised selection of patients from the Freemantle Diabetes Study database.	Evaluation of a pilot patient-held diabetes record (Databank) prior to general distribution.	Results corresponded with previously reported data. Very few changes were required to the patient held record – reference ranges for test results and improved explanations and terminology abbreviations removed.	There was no explanation why only 137 out of 620 patients using the databank were randomised to further evaluate.
Dijkstra et al (2005) (Netherlands)	769 diabetic patients from 9 general hospitals. Adults -mean age 58.	Quantitative study The study was clustered, randomised and controlled. Data collection was via a questionnaire to analyse the HbA1c and yearly examination results.	To investigate whether a comprehensive strategy involving patients and professionals with the introduction of a patient passport improves diabetes care.	Small improvements in HbA1c and blood pressure were found to have improved.	There were no data on how many patients had attended an educational session or what patients who had attended education sessions considered to be the biggest influence on improving their care.

Table 2.1: Overview of patient held record papers meeting study criteria

Study Authors (Year) & (Country)	Population & ages	Research Approach/Methods	Study Aim	Outcome	Limitations
Health Record papers					
Walton et al (2006) (UK)	18,503 Mothers of children aged 9 months born between 2000 and 2003.	Cross sectional survey within a Cohort Study Interviews. Production of the Personal Child Health Record.	Use of personal child health records in the UK: findings from the millennium cohort study.	Of the 16917 (93%) red books produced 15138 (85%) showed effective use with the child's last weight being recorded The number of red books produced in disadvantaged electoral wards decreased to 89% and down to 83% for lone parents.	The data collected did not allow for any further analysis of why the use was less in disadvantaged electoral wards or lone parents There was no indication of further analysis into these findings.
Immunisation papers					
McCormick et al (1981) (USA)	Parents of 4,980 infants at 1 year.	Quantitative study. Survey undertaken as part of a project looking at the regionalisation of perinatal care in the USA. Data coded for all sources of immunization information.	Correlation between the production of a vaccination record and completion of nationally recommended vaccination programme.	Improved vaccination uptake and vaccination history recall if the record was available.	Only the methodology for this element of the larger survey was presented.

Table 2.1: Overview of patient held record papers meeting study criteria

Study Authors (Year) & (Country)	Population & ages	Research Approach/Methods	Study Aim	Outcome	Limitations
McElligott & Darden (2010) (USA)	5,940 204 parents of infants 19-35 months old.	Quantitative study. Retrospective review of the public-use files of the 2004-2006 National Immunization Survey. Data analysis using a data management system.	Parental report of the presence of the child's vaccination record.	Improved vaccination uptake if the vaccination record was readily available.	As the data were extracted from a larger data set the outcomes were unable to be interrogated to assess causality. Only children with 'adequate' data were included therefore this may have created bias, even though this was intended to be calculated with the weighting of the analysis.
Inflammatory Bowel Disease Papers					
Kennedy & Rogers (2002) (UK)	259 patients with ulcerative colitis, 6 IBD specialists and 16 GP's. Over 16 years old.	Randomised Control Trial. Postal questionnaire/semi structured interviews which were thematically analysed.	The utility of using a guidebook to facilitate self-care in ulcerative colitis patients.	There were different views on the utility of using the guidebook between doctors and patients. Doctors were in favour of self-management but found it difficult to change traditional management strategies	Although 551 patients completed the RCT main study there is no explanation why only 259 were eligible to participate in this section of the study
Saibil et al (2008) (Canada)	IBD patients. Adults.	Literature review of 7 studies in self-management for IBD. Framework for self-management using an IBD passport.	Self-management. Patient passport.	Recommendation to use a passport type document in self-care.	Not original research. No criteria for the identification or selection of the literature reviewed. The framework for self-management is primarily based on little evidence apart from the authors own practice.

Table 2.1: Overview of patient held record papers meeting study criteria

Study Authors (Year) & (Country)	Population & ages	Research Approach/Methods	Study Aim	Outcome	Limitations
Palliative cancer care					
Finlay et al (1998) (UK)	50 palliative care patients attending a 'Marie Curie' day care centre. Adults.	Qualitative study. Retrospective review of entries in patient held record.	The use of an unstructured note book as a patient record.	Good medication record and prompted dialogue between patients and health care professionals.	Single centre review No discussion of data collection tool used or ethical approval.
Komura et al (2011) (Japan)	50 cancer patients attending 2 general hospitals in Japan. Adults.	Qualitative study. Semi structured interviews with content analysis.	Patient perceived usefulness of PHR.	The PHR was useful in facilitating communication and increased understanding of the condition and treatments.	Length of time the tool was used was only 3 months which did not allow time for it to be adapted into 'normal' practice.

Review of articles

Diabetes

The three studies identified within the field of adult diabetes relate to the use of the PHR within an education care pathway. Diabetes is a chronic condition on which there is an increasing emphasis on improving standards of care (Daley et al., 2008; Davis & Bridgford, 2001) and patient involvement to improve their care (Dijkstra et al., 2005). Davis and Bridgford (2001) conducted a study exploring patient and health care professional feedback from the Diabetes Databank which they introduced in Australia in 2000. The Diabetes Databank is a comprehensive patient held diabetes record consisting of personal and educational information. The study reported by Davis and Bridgford (2001) was Phase 2 of an on-going project evaluating the Diabetes Databank to ensure it was appropriate to patient needs. The Diabetes Databank was modified following Phase 1 of the study. There were 855 patients recruited from the Freemantle Diabetes Study (FDS) by stratified random selection using either country of birth or aboriginality as the grouping variable to receive a Diabetes Databank. The databank was mailed to the patients with instructions on how to use it. Both patients and health care professionals could enter data. After four months, 620 (70%) patients were using the databank regularly. One hundred and thirty seven were randomly selected to evaluate the tool in more detail, with 102 responding to the invitation. There was no rationale why only 137 patients were selected for evaluation of the tool in more depth. Although only 33% of patients felt that it had improved their control of their diabetes, 93% recommended it being used for all diabetic patients. Of the 400 health care professionals invited to take part, 134 responded of whom 100 (75%) had come into contact with the PHR. The majority of the health care professionals liked the PHR; although the exact figure was not expressed numerically it was demonstrated in a graph format. Forty three percent of health care professionals stated that the databank had helped in the management of their patients whereas 66% stated they would support it being used routinely for all diabetic patients.

The two other diabetes-related studies used objective data to evaluate the effectiveness of a diabetes pathway, which included a PHR. In Dijkstra et al.'s (2005) study in the Netherlands, the PHR is referred to as a patient passport. Dijkstra et al. (2005) recruited nine general hospitals to randomised intervention or control hospitals. Four hospitals were randomised to the intervention, which consisted of increased education sessions and the use of the diabetes passport. The five non-intervention hospitals continued their usual practice. The primary outcome measure was HbA1c levels. There was a reduction in HbA1c levels in the intervention group of 0.3 while the control group had an increase of 0.2; this result gave a p-value of 0.001. While this appears to be a modest change it was deemed to be significant in reducing the risks of complications in diabetes. It was also noted during multivariate analysis that there was a reduction in the diastolic blood pressure of the intervention group. These results were found to be similar to other diabetes care improvement projects. The potential effect of the educational sessions that all of the health care professionals attended was considered by the researchers. They were unable to evaluate whether this would have made a difference to the level of care that was given to the patients. However, although the patients were also offered the option of attending educational sessions there were no data on how many had attended a session. There was no evaluation on which intervention had the biggest influences on the improved care of patients who had attended education sessions.

Daley et al. (2005) evaluated their education care pathway, which included a patient held record along with an education folder and 2 ½ day education group sessions. They used the HbA1c, weight, body mass index (BMI) and diabetes knowledge as measures of efficacy. They enrolled 50 patients who were newly diagnosed with Type 2 diabetes onto the programme. Less than half of the patients (n=17) attended the education sessions although of those who did attend, 16 found it very beneficial. The authors found that there was an improvement in HbA1c, a decrease in weight and BMI all with a p-value of 0.05 for all the parameters. Knowledge levels had improved in all areas, which ranged from a 10% increase to 33% increase. Both studies by Dijkstra et al. (2005) and Daley et

al. (2005) were able to show an objective improvement in the level of patient education and care. These three studies all presented data on patient held records that were used as a main element of an education pathway. The PIBDPHR is a standalone document and has not been developed as part of an education pathway and, as such, the outcomes may not be transferable.

Health records

Walton, Bedford & Dezateux, (2006) used data from a cohort study to undertake a cross sectional survey, to review the use of personal child health records also known as the 'Red Book' in the United Kingdom. The natural parents of 18,503 first born (of multiple births) or singleton children were interviewed when the child was nine months old in relation to the 'Red Book'. The aim of the study was to determine how the Red Books were being used, and the team examined three factors: the number of Red Books that were produced; the proportion that had an up to date weight recorded; and the number of parents who used them effectively (defined as meeting the previous two questions). They found that majority of parents (16,917 or 93%) produced the Red Book and, of these, overall 85% of the parents showed effective use of the Red Book and had the child's last weight documented. Analysis of the parents who were unable to produce the books or had not recorded the last weight found several common factors: disadvantaged communities, large sized families, young maternal age, low maternal educational attainment and lone parents. The red book is given to parents when the child is born and its use is encouraged and supported by midwives, health care visitors and the medical profession. It is therefore seen as an accepted tool to be used and completed by both the parents and health care providers. This is evidenced by the large number of parents who use them effectively (Walton et al., 2006). The PIBDPHR has not been fully implemented for use with all paediatric IBD patients and it is therefore difficult to make any comparisons between the two although the PIBDPHR and the Red Book have the same basic concepts underpinning their design. However, this study does highlight that if

a PHR is used and supported effectively it could become an established part of a health care pathway.

Immunisation

Two paediatric studies were identified (McCormick et al., 1981; McElligott & Darden, 2009) both of which were carried out in the USA. Both studies compared the immunisation records stored by the vaccination providers with the presence of an up to date vaccination record held by parents. Despite the studies being undertaken nearly 30 years apart they have similar data collection strategies; the data were retrospectively analysed as part of a larger study. McCormick et al. (1981) analysed data collected within a study looking at the regionalisation of perinatal care in the USA. The data was collected from families randomly selected from eight regions in the USA to participate in a health interview regarding their child. The interviews were undertaken in home visits to 4,980 families with a one-year-old infant. The interviewer requested to look at the immunisation PHR and recorded the data from the record. McElligott and Darden (2009) reviewed data obtained from the public use files from the USA 2004-2006 National Immunisation Survey (NIS). The data collection methods are briefly outlined as 'national validated, stratified, random digit dialling telephone surveys of households with children aged 19-35 months' (McElligott & Darden, 2011 p.E468). The immunisation data are taken from parents and verified with the vaccination provider (McElligott & Darden, 2009). The main aim of both studies was to determine whether the vaccination record was associated with increased vaccination rates. Just under half of the parents in both studies were able to produce the PHR: 44% in McCormick et al.'s (1981) study and 40.8% in McElligott and Darden's (2009) study. Findings suggest that children who had a vaccination record were more likely to have an up to date vaccination history than those who could not produce the record and the presence of an immunisation PHR played a significant role in increasing the number of children who were up to date with their vaccinations (82.9% versus 66.1% McCormack et al., 1981; 83.9% versus 78.6% p <

.0001 McElligott & Darden, 2009). There are limitations to both studies as data were collected from a predefined data set and were unable to be scrutinised to elicit the reasons for the immunisation PHR not being used or to assess how the tool made a difference in the uptake of immunisation. These are accepted tools, within their health care systems in the USA. However they are not used as routinely as the red book in the UK which is a nationally accepted tool. A nationally distributed tool such as the Red Book appears to be utilised by a much larger proportion of the population, this may be because it is seen as the 'norm' and an expected part of childhood monitoring.

Inflammatory Bowel Disease (IBD)

Over the last decade there has been a move towards empowering patients with IBD through self-management programmes following a report by the Department of Health Expert Patient programme (2001). As part of their self-management programmes both Kennedy and Rogers (2002) and Saibil et al. (2007) reviewed their versions of a patient held record designed for adult IBD patients. While Kennedy and Rogers (2002) carried out a study to understand the patients' and health care professionals' views of using the patient guidebook to self-manage ulcerative colitis, Saibil et al. (2007) explain their concept of the patient passport designed for use with all IBD patients.

The trial undertaken by Kennedy and Rogers (2002) was part of a larger study into self-management in ulcerative colitis. The trial was undertaken through multicentre cluster randomisation with 19 hospitals in the northwest of England. Nine centres were randomised to be intervention sites and the IBD teams were trained to deliver patient centred care. The remaining ten centres continued with their current usual care. Patients had established ulcerative colitis and were over 16 years of age at enrolment. Each centre recruited the first 38 eligible patients following the commencement of the study.

The intervention comprised of four elements:

- A guidebook with information on ulcerative colitis self-management;
- A personal details section;

- A self-management plan which was put in the guidebook, a patient centred approach to care; and
- Direct access to the service for patients to self-refer.

Of 908 eligible patients, 635 completed the entrance questionnaire, (270 were in the intervention group). Data relating to hospital appointments and medication were taken from the medical notes, the patients were asked to complete two patient questionnaires – on enrolment and exit of the study measuring the patients' IBDQ (IBD Quality) scores. The results showed that hospital appointments were reduced by a third. Patients were satisfied with the intervention, and 75% wanted to continue on it following the end of the study. A randomised selection of patients, GP's and consultants were invited to give their opinions on the guidebook. Patients were sent a postal questionnaire while their GP's and consultants' views were elicited with face-to-face semi-structured interviews. The doctors in this study were receptive to patients being given more information to enable them to take more control of their condition. However there was a difference in opinion on the actual use of the guidebook. For patients it was seen as a being supportive and therapeutic while doctors saw it as a tool to improve compliance and encourage better use of their services. The doctors, despite saying they were in favour of the guidebook did not facilitate its use in practice. Patients welcomed the opportunity to evidence their self-management of their conditions.

Saibil et al. (2007) reviewed the concept of self-management for all people with IBD. Although this was not primary research it was included as it assisted with the identification of the variation of patient held records and helped to further understand these types of tools. The literature review identified articles on self-management in chronic disease and then focused further on self-management and IBD. They neither stated any inclusion or exclusion criteria nor the search terms used. They described the strategies that can be used to promote self-management in IBD and refer to the importance of using a patient passport that can be personalised to the patient's needs.

They concluded that the use of a patient passport can have benefits in several areas, such as reduced cost and burden of outpatient visits to both hospital and patient, empowering the patient and therefore encouraging compliance. One potential problem to this style of management that they identified is the loss of control that some health professionals may feel when the patients make their own decisions about managing their care without consultation. The use of a patient held record appears to be linked with self-management in IBD and is seen as part of an education pathway rather than as an individual tool to deliver information. This may have implications on how the PIBDPHR is viewed in paediatric IBD and therefore the PIBDPHR needs to be defined to enable all users to understand what the tool is designed to do. The PIBDPHR was not initially designed with any particular consideration to how or where it fits into the patient care pathway but as a practical tool to improve the patient journey.

Palliative cancer care

The two studies identified in adult palliative cancer care have very different formats of a PHR to the other PHRs examined. Finlay et al. (1998) evaluated an unstructured record which consisted of a notebook given to the patients with a sticker requesting that they document their medications and any changes made to their treatment/medication regimes. PHR usage was driven by the patients with input from the health care professionals when requested by the patient. Of the 50 notebooks that were analysed (there is no clarification whether this was the total amount allocated to patients) there were a total of 1207 entries; most entries were by patients and healthcare professionals with a small number of relatives also making entries. A similar number of patients (n=52), were recruited to a study by Komura et al. in 2011. This was a qualitative study designed to understand patients' perception of the usefulness of a specifically designed PHR for palliative cancer patients in Japan. The PHR consisted of several sections with patient-specific information (personal profile, medical history, current treatment) and an information section with details of end of life care and options. The study consisted of

semi-structured face-to-face interviews after the patients had used the PHR for over three months. Finlay et al. (1998) found that the entries in the unstructured PHR were predominantly related to medications and changes made to treatment and found that the PHR was an effective aide memoir for medication. Both studies found that the use of the PHR improved communication between patient and some health care professionals.

Komura et al. (2011) also identified improvements in communication with patients and their families and facilitated communication between patients who were able to identify each other by the PHR. In addition, Komura et al. (2011) also found that their version increased patients' understanding of their condition and facilitated end of life discussions. The negative aspects identified by Komura et al. (2011) were the lack of instruction on completing the PHR, the medical profession undervaluing the role of the PHR, an unwillingness to participate in making decisions, concerns about privacy, and the burdensome nature of self-reporting. Finlay et al. (1998) identified that the use of the PHR outside of their department was very limited and suggested that patients were unsure of asking other professionals to help them keep their PHR. There has long been a history of the use of patient held records in cancer care and this is where the initial idea for the PIBDPHR was developed. The researcher has first-hand knowledge of tools that are very similar to the PIBDPHR that have been and are being used in three paediatric hospitals in the UK within cancer care and also in two adult IBD services. However, there is no published literature related to the use of these particular tools. Indeed, as this literature review has shown there is very little documented research into the use of PHRs with children, young people and their parents.

Synthesis

The patient held record is referred to by several different names such as patient passport (Saibil et al., 2007), databank (Davis & Bridgford, 2001), notebook (Finlay et al., 1998) and guidebook (Kennedy & Rogers, 2002). The PHRs reviewed were generally

structured although one (Finlay et al., 1998) was unstructured in nature. The commonalities shared by these different approaches to a PHR are that they are the property of the patient and can be used to help the patient improve their communication with the health care professionals and with their families. The PHRs identified in these studies and the PIBDPHR are not intended to be used to improve communication between health care professionals. However, there are tools that aim to do this; these are also either called patient held records (e.g. Gysels et al., 2006; Ko, Turner, Jones & Hill, 2010), patient diaries (e.g. Johnston et al., 2013; Åkerma, Granberg-Axéll, Ersson, Fridlund, B & Bergbom, 2010) or shared care records (e.g. Warner, King, Blizard, McClenahan, & Tang, 2000).

Having completed this literature review the author proposes that a hand held record or patient held record that contains medical information should include medical in their title (e.g. Shared Medical Care Record or Patient Held Medical Record). The information recorded in a medical record requires a particular type of accuracy and if it is to be a means of informing other health care professionals, then the expectation should be that health care professionals have a responsibility to record information (Gysels et al., 2006). However, a non-medical PHR is intended to be a personal document for the patient's own use (Kennedy & Rogers, 2002), therefore the information documented should be in a language that the patient/family can understand or written in their own words. Health care professionals and family members can be invited to help the patient to complete the record. Non-medical patient held records have a large role to play in educating patients (Kennedy et al., 2004) and as a consequence of their improved knowledge, enable them to be more actively involved in their medical management (Lecouturier et al., 2002). As seen from the articles reviewed, a non-medical PHR is generally used in chronic disease within a self-management strategy.

The nationally distributed 'Red Book' (Walton et al., 2006) is used by many more parents than most patient held records. This may be due to the 'official' way they are given to

every mother at the birth of their baby and are widely accepted as a useful tool by the health care professionals who routinely come into contact with them such as health visitors.

Within the field of paediatric IBD there were no studies into the use of patient held records or self-management identified during the period covered by the inclusion criterion. Therefore this study will build on data already collected through the pilot study and will form an understanding of how the PIBDPHR is functioning in practice. The aim of the study is to explore how the PIBDPHR is being used by PIBD nurses in the UK and in the following chapter, details are presented on the methodology and methods used.

3. Methodology and Methods

Introduction

This chapter discusses in detail the methodology and methods used to conduct this research. The rationale for the theoretical framework and the choice of methods are provided. The aims and objectives and the sampling strategy are discussed and the inclusion and exclusion criteria presented. The phases of the study are discussed along with detailed explanation of the data collection tools used for each phase. The ethical issues that were considered and the ways in which the researcher ensured that the research was undertaken in an ethical manner are presented. Finally the various methods of data analysis that were used are explained followed by a conclusion.

Aims/Objectives

The aim of this study was to gain an understanding of how the PIBPHR was used in practice from the perspective of paediatric IBD nurses.

The specific objectives were to:

- Explore how the PIBDPHR is utilised in the clinical setting;
- Assess which, if any, aspects of patient care the PIBD nurses perceived to have changed by the use of the PIBDPHR; and
- Critically consider particular situations or settings or contexts, if any, where the PIBDPHR was deemed by PIBD nurses to be useful and/or problematic.

Methodological approach and research design

The methodological approach that was used for the study was a mixed methods design.

A general definition of mixed method research as defined by Johnson, Onwuegbuzie, and Turner (2007) is:

“.... the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration” (p.123).

A single method approach was considered unlikely to lead to opportunities to explore interesting avenues of study in relation to better understanding the context and application of the PIBDPHR within busy nursing practice. As such a mixed methods approach was used so as to allow breadth of opinion, depth of experience and a range of insights about the use of the PIBDPHR to be generated, explored, analysed and synthesised. Neither quantitative nor qualitative methodologies alone would have been able to robustly explore the aim of understanding how the PIBDPHR was used, this is a problem that is often found when undertaking nursing research due to the complexities of the question that is being investigated (Östlund, Kidd, Wengstrom, & Rowa-Dewar, 2010). Doyle, Brady & Byrne (2009) explain that a benefit of using mixed methods research is ‘illustration of data’ where using a qualitative approach to illustrate quantitative findings can help to paint a better picture of the phenomena under investigation. Fleming (2007) has identified that mixed methods research can enable nurses to develop an evidence base for nursing that is relevant to the nursing profession through integration of both quantitative and qualitative research methods. A mixed research method, such as the one used in this study, is being used more frequently in the development of nursing research as it enables the researcher to gain a more rounded and holistic understanding about the phenomena under investigation or completeness (Doyle et al., 2009; Hayes, Bonner & Douglas, 2013). Mixed methods

research also enables triangulation of the research by 'seeking corroboration between quantitative and qualitative data' (Doyle et al., 2009).

This study is best described as using a mixed method sequential explanatory strategy (Creswell, 2009). In brief, Phase 1 was quantitative and Phase 2 was qualitative.

The quantitative data gathered in Phase 1 were necessary to build a base level of knowledge (e.g., about the caseload and other such service data) from nurses using the PIBDPHR. This aimed to build a baseline understanding of the context in which the PIBDPHRs were being used in as many settings as possible. These data informed the second phase of the study where qualitative data were collected to generate a more in-depth understanding of the nurses' perspectives of actually using the PIBDPHR in practice. Doyle et al., (2009) refer to this as 'explanation of findings'.

These two phases required different approaches to their data generation. Phase 1 of this study used a survey to generate quantitative baseline data about the topic area. The findings from Phase 1 informed the second phase of the study enabling the researcher to develop interviews for Phase 2 with reference to data already collected from the participants and subjected to initial analysis. Phase 2 used semi-structured interviews to gather qualitative data to explore the rationale behind the nurses' utilisation of the PIBDPHR. Phase 2 also explored whether and in what settings the PIBDPHR may have been perceived to enhance patient care. These phases are presented in more detail later in the chapter.

Participants

The BSPGHaN/RCN Paediatric IBD Nurses Group consists of nurses who have an extended role in managing the care of children diagnosed with IBD within secondary and tertiary specialist gastroenterology services. The PIBDPHR was developed with the support and recommendations of the group through various iterations to its current

format (see Figure 1.1). Since only 500 copies of the PIBDPHR were printed, the number of copies available to be distributed to any one PIBD centre was rationed to a maximum of 20 PIBDPHRs per PIBD centre. In those centres where there was more than one nurse working within the paediatric IBD speciality, the centre still received a maximum of only 20 copies.

There were more stakeholders who could potentially have been included in this project such as the PIBD patients (who had been given copies of the PIBDPHR) and the wider PIBD multi-disciplinary gastroenterology teams which would have come into contact with the PIBDPHR. However, the constraints of the study period meant that the focus was on the PIBD nurses' views of using PIBDPHR in practice.

The professionals who were invited to participate in the study were identified from a defined population of nurses who requested copies of the PIBDPHR for use in their practice at the time of the launch in June 2012. This is classified as a purposive sample group. Purposive sampling describes the process where the members of the sample group are purposely selected as they are expected to be able to make the best contributions to answering the research question (Polit & Beck, 2010; Teddlie & Tashakkori, 2009). PIBD nurses were responsible for distributing the PIBDPHR and were therefore considered competent to share information about their experiences to enable the researcher to understand the aspects of how the PIBDPHR was being used in clinical practice. It is important to note that as part of the on-going development of the PIBDPHR all of the nurses who requested copies were aware that there would be evaluation of their use within a year of launch.

Inclusion criteria

Phase 1: Any PIBD nurse who was a member of the BSPGHaN/RCN Paediatric IBD Nurses' Group and who requested copies of the PIBDPHR at the launch in June 2012.

Phase 2: Any nurse who participated in Phase 1 and self-selected to be available to take part in Phase 2.

Exclusion criterion

Phases 1 and 2: Any BSPGHaN/RCN Paediatric IBD Nurses' Group members who had not requested copies of the PIBDPHR were not invited to participate in the study.

It is recognised on reflection that these criteria should have required the participant to have used the PIBDPHR in practice as this would have ensured that participants had actual experience to draw on. The assumption inherent in the first inclusion criterion was that if the PIBDPHRs had been requested they would have been used in practice.

However, the researcher was known to the respondents and did not want to deter the enthusiasm of any member of the BSPGHaN/RCN IBD nurses group who volunteered to participate in this research.

Phase 1

Phase 1 used a survey via email (e-survey) using Survey Monkey® software to generate quantitative baseline data. Andrew & Halcomb (2009), Cormack (2000) and Maltby, Williams, McGarry & Day (2010) explain that surveys can quickly get access to wide populations using limited resources and enable the study population to be described. McColl, Jacoby, Thomas, Soutter, Bamford, Steen, Thomas, Harvey, Garratt & Bond (2001) identified through a NICE Health Technology Appraisal that there are four areas that need to be considered when designing a questionnaire - the mode of administration is the first step. This is where the researcher needs to consider the best way to capture her target audience to generate the most data. In this study the rationale to choose an e-survey was due to the busy schedules of the PIBD nurses and the difficulty they have in finding time to participate in research. The evidence for this statement came from the RCN IBD nurse audit in 2011 (RCN, 2012) which showed that during a two week audit

analysing the diaries of IBD nurses, no time was allocated for research activity. Using email as a format to send a link to the survey also reduced cost and time delays in potential participants receiving their invitations. The decision to use Survey Monkey® as the data collection tool was influenced by the researcher's previous experience of using the basic level version for a different project. It was easy to use and data were ready to review as soon as the deadline for data entry had passed. However this did then exclude the use of other similar internet based tools, such as Zoomerang or Survey Gizmo, that are also available. While Survey Monkey® has many benefits there are some drawbacks, which were also considered and these are now presented. Survey Monkey® is a well-recognised tool that enables the researcher to design a survey specific to the research aims. There are different levels of access from basic and free use, to 'pro' accounts giving access to more complex survey designs and analysis. For the purpose of this study a pro account was used. Data submitted to Survey Monkey® is stored on a secure server where the data are anonymised. For a novice researcher being able to download data in various forms, including as an Excel® spreadsheet is a great benefit as there is reduced risk of human error in data entry, the data are presented in a manageable format which enables easier analysis of the data collected (Alessi & Martin, 2010; Mc Peake, Bateson, & O'Neill, 2014). Another benefit is that it also enables the researcher to begin analysis immediately (Tenforde, Sainani & Fredericson, 2010). The negative aspects of using a web based tool such as Survey Monkey® include the restrictions to changing the layout. The only personalisation of the layout is related to the colours on the pages therefore the basic layout looks the same for all Survey Monkey® questionnaires, this may cause potential respondents to become complacent as the use of this medium increase (Hunter, 2012). The formatting of the questions is limited and therefore you have to phrase questions within the Survey Monkey® format and are unable to fully personalise the survey. Concerns have been raised in the literature about whether the use of e-surveys can reduce the response rate (Chizawsky, Estabrooks & Sales, 2011; Mc Peake et al., 2014). However, with increased access to computers and smart phones this is a concern that is decreasing and several studies have

demonstrated that the contemporary response rate to e-surveys can be on a par or better than paper-based surveys (Tenforde et al., 2010; Sanchez-Fernandez, Munoz-Leiva & Montoro-Rios, 2012; Mc Peake et al., 2014).

Once the decision to use an e-survey had been made the questionnaire had to be developed. According to McColl et al., (2009) this forms the second and third steps where consideration is given to the wording and presentation of the survey.

Jones, Murphy, Edwards & James (2008) explain that by constructing a questionnaire for use in a survey the questions have to be more 'precise and focused' than those typically used in an interview. The use of a survey ensured that data accrued from Phase 1 arose from questions that were all phrased the same. The use of closed questions with predefined answers written by the researcher aims to gather as much high quality data as possible (Maltby et al., 2010). Closed questions can vary from Yes/No answers to more complex expressions of opinion. However, the main aim is to ensure comparability of answers and facilitate quantitative analysis of the responses (Polit & Beck, 2009). Like most structured surveys, all questions needed to be clear and unambiguous as there would be no facility for immediate clarification of the meaning of questions. The researcher understood that there would be no way to clarify responses made by participants (Andrew & Halcomb, 2009).

The aim of Phase 1 was to gather baseline data on how and in what settings the PIBDPHR was most commonly being used in practice, the method chosen to gather this information was through an e-survey. Twenty six PIBD nurses in the UK had requested copies of the PIBDPHR for use in their settings (from 5-20 per IBD centre) were invited by group email (see Appendix 1) to participate in the e-survey. As the lead clinician for the PIBDPHR project the researcher had access to a list of all the nurses who had requested copies of the PIBDPHR. All of these nurses were already colleagues that the researcher already knew before starting the study. While the group email was circulated to those who had previously requested a copy of the PIBDPHR the address and names

of the individual were embedded within a Bcc email message to promote confidentiality. Participants were given the opportunity to discuss their involvement in the study and any questions they had about the study through email, phone and face-to-face at meetings (as appropriate) with the researcher. The group email was sent three times to capture any participants on annual leave. There was no direct contact made to recruit participants on an individual basis as the potential participants were all known to the researcher this may have been perceived as coercion.

Survey Design

The survey primarily consisted of 11 closed questions (see Appendix 2). There was the opportunity for participants to document additional comments related to four of the questions, which allowed for the capture of some qualitative data within the quantitative instrument. There was only one completely open question that gave participants the opportunity to give more a detailed qualitative response. The survey was divided into three sections

Section 1: Clinical service demographics (including information about site, caseload, characteristics of the service) (4 questions).

In order to understand how the PIBDPHR was being used by the nurses in practice, it was important to understand the background of the nurses and their services. Therefore the first section in the survey was designed to gather demographic information. These questions required specific numerical data to be entered. The number of years working within paediatric IBD was required to understand how much experience the nurses had within this specialty. The next two questions asked how many hours the participant was working within PIBD and the size of the caseload, this information enabled the researcher to analyse the ratio of PIBDPHRs to the participants' population to see if this had any influence on how the nurses were able to use the PIBDPHR and their experiences of using it. The final question used a checklist and asked the participant to select how many PIBDPHRs they requested and how many were actually used in

practice. This question was designed to understand if the nurse was able to utilise all the PIBDPHRs that they had requested.

Section 2: Clinical use of the PIBDPHR (including information about the way it was being utilised, how widely was being used in the setting, whether the nurses perceived its use had changed practice) (4 questions).

The second section explored the actual clinical use of the PIBDPHR in the participants' practice. These questions were informed by the initial discussions by the PIBD nurses involved in the design phase of the PIBDPHR in 2006. The questions were generally checklists allowing the respondent to select all that applied. In the question focusing on the patients who were given the PIBDPHR, there were four types of patient groups pre-identified in the survey with an extra option for 'other'; if other was selected there was a default asking the participant to explain this option further. Similarly, the six areas identified as potentially benefiting from the use of the PIBDPHR were pre-identified from the original meetings; participants were also given the option to select 'other'. If 'other' was selected there was a mandatory field for free text qualitative comments. Data regarding the actual users of the PIBDPHR were gathered to understand whether there were any patient/parent or staff groups who used the tool more than others. The last question in this section was asked to better understand the impact of the limited supply of the PIBDPHR. This question aimed to evaluate whether the participant would have had a different rationale for using the PIBDPHR if there had been access to unlimited supplies.

Section 3: Benefits and challenges of use (including benefits accrued, barriers/challenges to implementation, solutions) (3 questions).

The final section was composed of three questions that were designed to receive feedback on the PIBDPHR. This section started with a question asking if there had been any perceived barriers encountered whilst using the PIBDPHR and, if so, what they were. There was a mandatory request for comments if the participant answered 'yes'. The participants' experience of using the PIBDPHR was one of the objectives of the

study, so the participants were requested to rate it on a 5 point Likert scale from 'very good' to 'very bad'. The Likert scale has been shown to be useful in gathering data because "it places very few cognitive demands on respondents" as it is easy to complete and it is also simple to score (Van Laerhoven, Van der Zaag-Loonen & Derkx, 2004). It was decided to use a 5 point Likert scale to give the participants choice while maintaining a strength of opinion (Johns, 2010). Although there is evidence that Likert scales become less accurate if the scale contains less than five or greater than seven options there does not appear to be any consensus as to the real difference between five and seven points (Dawes, 2008). It was decided to give the respondents the choice of a neutral midpoint which as Johns (2010) explains "avoids forcing respondents into expressing agreement or disagreement when they may lack such a clear opinion".

To ascertain if the participant would continue to use the PIBDPHR, the next question asked the participant to quantify the number that they would require initially and yearly if there was no limit. This question was split into the two elements to understand how the nurses would actually use it in practice and also to give insight into how many would be required for continued use in the future. The final question was an open-ended question that asked for any further comments, thus ensuring that the participants could provide feedback and allow them to present qualitative remarks, with the expectation that these would add context to and understanding of the closed questions.

Finally, participants were asked if they were willing to take part in Phase 2 of the study. It was expected that the survey would not take longer than ten minutes to complete, providing the respondent had ready access to some of the information such as caseload size.

The survey was piloted on two nurse work colleagues within the researcher's department. The aim of a pilot was to assess the clarity of the questions and to check the survey's ease of use within NHS systems. Although both of these colleagues had

little experience of IBD, they were able to clarify that they clearly understood the questions, the survey flowed appropriately and that, as an e-survey, it was manageable and accessible via an NHS computer platform. There were no changes required following the pilot.

Phase 1 analysis

Data from Phase 1 were analysed prior to the commencement of Phase 2. This enabled the researcher to tailor the scheduled interview questions to the individual participants by incorporating, where appropriate, the responses they had given in the e-survey i.e. you requested x number of PIBDPHR's why did you actually use y? This personalised the actual question without changing the meaning of the question.

The findings gained from Phase 1 enabled a matrix to be developed to allow purposeful sampling (Creswell, 2009 p.178), so as to explore different aspects of use of the PIBDPHR (see Table 3.1). (Note: although this matrix was developed, it was not used due to low numbers, as explained in the presentation of Phase 2).

There were five factors used in the sampling matrix which directed the selection of the participants, the factors chosen were all related to how the tool was being utilised in clinical practice:

1. Newly diagnosed children
2. Children approaching transition
3. Children who are on complex regimes of treatment
4. Given to a mixture of patients
5. Other uses

Table 3.1: Sampling matrix for Phase 2 based on clinical usage of Phase 1 (n=12) participants

	Newly diagnosed children	Children approaching transition	Children on complex treatment regimes	Mixture of patients	Other uses
Number of participants	3	2	3	2	2

Phase 2

Different qualitative methods were considered prior to the decision to use interviews.

These other methods are now briefly presented and the reasons for rejecting them are discussed.

The use of focus groups was considered as the participants meet on a regular basis.

Focus groups allow the researcher to gather large amounts of data from groups of people in a short amount of time (Kitzinger, 1995; Wilson, 2012), which can reduce the costs of individual interviews. As Kitzinger (1995) explains focus groups are not individual interviews conducted at the same time but participants are encouraged to interact between themselves and the researcher who uses open questions to guide the discussion. As with all methods of data collection there are positive and negative aspects to be considered. A positive aspect of a focus group is the use of personal anecdotes or experiences of participants which may trigger more group discussion and derive a greater depth of data than would have been generated through individual interviews. There are also a number of people who would feel intimidated speaking honestly in a one to one situation but feel more able to express their views in a group situation (Kitzinger, 1995). However, although they can generate lots of data some will be irrelevant to the issue under investigation and require a great deal of sifting of the transcribed data. The group dynamic can be pivotal to the richness of the data generated and often an experienced moderator can be invaluable. Negative issues can be the inclusion of participants with dominant personalities who may dominate the group discussion reducing the input of some less forthright participants (Wilson, 2012).

Telephone focus groups can offer the benefits of face to face focus groups but do not require all of the participants to be in the same room, this can be useful for participants who are unable to meet at the same venue (Allen, 2013). The difficulty of having this type of focus group is that it can be very difficult to moderate dominant participants and vital information may be missed by participants talking over each other.

Knowing the potential participants helped the researcher to consider the benefits and pitfalls of using a focus group for this study. There are several dominant personalities who may make it difficult for participants to put their true views across and they may therefore be more likely to agree with the dominant views feeling that their views were not as valid. It was therefore decided that this was not the most appropriate method to gather the data for this study.

Observation of the PIBDPHR in practice was also considered but due to the low numbers of PIBDPHR's in use in each centre it would be very difficult for the participant to arrange for the particular patients to attend clinic for the observational visit to be of any real benefit. Therefore this method of data collection was also discarded.

Interviews were then selected as the method to gather the data in Phase 2 as it was hoped they would enable the researcher to explore a sub-group of participants' views, enhance the richness and depth of the data generated and clarify elements of the findings from the Phase 1 survey (Polit & Beck, 2010; Andrew & Halcomb, 2009). Interviews allowed the researcher to explore the participants' responses in more detail than had been possible in the survey, encouraging participant experiences to be shared while also having the opportunity to explain what their response actually means. The participant was able to reflect on the questions and therefore their clinical practice. As there was allocated time for the interview the respondents had time for reflection which may not have been available to them when responding to the survey, and may result in different responses.

The researcher had planned to select nurses who had agreed to be included in the second phase from each group identified in the matrix to give a maximum of eight nurses. However, due to the small number of nurses who offered and subsequently consented to participate in Phase 2 (n = 6) and who represented a variety of identified uses of the PIBDPHR, the decision was taken to interview them all. The researcher

invited each of them to participate in a semi-structured interview. It was decided that as the researcher was known to the participants that the use of a semi structured interview would ensure that the interviews were consistent and would reduce the potential for any existing relationship, assumptions of knowledge or stance to sway the data generation. However it is acknowledged that the use of a schedule to guide the interview meant that the approach could be seen as not being fully qualitative.

While semi structured interviews enable specific topics to be covered, the nature of the exchange is that the participant can often share things that are unexpected and illuminating and it was hoped that this could help to unravel why they used the PIBDPHR in one circumstance and not another. It enables a deeper understanding of their thought processes that would not be possible from a questionnaire.

The interviews were conducted using both open and closed questions, (see Appendix 3) to elicit information on the nurses' rationale for how they had used the PIBDPHR in their own clinical setting. Questions explored any challenges they faced, the benefits they felt had accrued from the use of the PIBDPHR and any changes that had perceived to have occurred in practice. Again the researcher acknowledges that the use of some closed questions within a qualitative interview is not entirely consistent with a pure qualitative approach.

Development of interview schedule

As recommended by Creswell (2009) an interview schedule was designed. This was designed to ensure that all of the interviews were consistent. The decision to use a semi structured format to the interviews was discussed during supervision following discussion of the three different interview structures. Consideration was given to the use of an unstructured interview, however as Doody and Noonan (2012) explain, the use of an unstructured interview is often not appropriate for a novice researcher if they do not have the appropriate skills to actively listen to the information being shared. Much

irrelevant data can be gathered and this can make coding and analysis of the data difficult. The use of a structured interview was discarded because it would be too rigid and too similar to the survey from Phase 1. Therefore the decision was made to use a semi-structured interview guide to provide consistency, but not to restrict the spontaneity of the participants' perception of the phenomena under study.

The interview questions were directly related to the questions in Phase 1 of the study. Six questions were devised and these were personalised based on initial analysis of the responses that the participants had given in the survey during the interview.

The first question asked the participant to explain why they requested the number of PIBDPHR that they had in relation to the number of patients within their caseload and was personalised by the number of PIBDPHR's that they stated they requested in Phase 1. This gave a base to the participants' rationale for using the PIBDPHR and was then built upon as the participant was asked to explain their rationale for selecting the patients/parents to whom they gave a copy of the PIBDPHR. These initial questions enabled the researcher to gain an understanding of the participants' rationale for their use of the PIBDPHR. The third question asked the participant to discuss the effects of the PIBDPHR on local practice; this question was slightly rephrased from the survey. In the survey participants were asked 'Has the PIBDPHR had any effect on local practice?' Although a more detailed response could have been provided, this was a question that could be answered with a yes or no answer (as per the survey). By rephrasing the question the participant was encouraged to consider all aspects of using the PIBDPHR. The fourth question addressed the impact of the number of PIBDPHR's that were distributed and gathered more in-depth information about the impact that this had on the participant selection criteria. The next question asked the participant to explain any barriers or challenges that they had encountered while using the PIBDPHR. Although there was an opportunity for the participant to enter a comment on barriers and challenges in the e-survey, it was not a mandatory field; therefore this may not have been fully explored in the participants' survey responses. The final question was based on the participants' survey assessment of using the PIBDPHR and they were asked to

give any comments or suggestions or discuss their comments/suggestions in greater detail particularly with regards to use in practice.

To maintain the consistency across all interviews, the following structure was used to guide the researcher. This was helpful as this was the first time that the researcher had undertaken interviews for a research study and the structured approach to setting up and outlining the rules of engagement were done to ensure that no vital stage was missed out. Having this structure was also 'settling' for the novice researcher and enabled her to maintain a somewhat formal element to the interview. The respondents were very comfortable with the researcher as a colleague and utilise her for clinical supervision therefore it was important to be able to refer to the guide to bring discussion back to the interview. Although it looks somewhat regimented it was applied in an individual way and took account of the particular circumstances of each individual participant.

1. Prior to the interview starting the interviewer discussed the rationale for recording the interview as per the participant information sheet that was sent with the invitation email. Although the participant had consented to participate in Phase 2 of the study through the e-survey, consent was confirmed verbally prior to the start of the interview.
2. The participants were informed that they could stop the interview and withdraw their consent at any point and any recording would be deleted. Apart from this being good research practice, it was felt to be especially important in this study as the researcher was previously known to all the participants and remains in regular contact with them on a professional basis. Being transparent about the consent process meant that participants were adequately informed that they were taking part in a research study rather than entering a discussion on a professional matter or being contacted for advice.

3. Several minutes of preamble while checking that the non-digital, audio-recorder was functioning appropriately helped to make the participant feel more comfortable and the researcher more confident with the recording process. The researcher ensured that there was an explanation of the format of the interview and why the participant had been invited to be interviewed. The participant was informed about how long the interview was expected to take and given the opportunity to ask any questions prior to consent being taken.
4. The participant was then officially informed when the actual interview was to commence. It was imperative to both participant and interviewer to have an understanding when the conversation changed from general to specific to ensure awareness that the conversation had shifted.
5. The questions were written in a sequence although the interviewer altered the questions slightly depending on the participant's responses to the questions. For example, if in the response to one question the participant incorporated an answer to a different question this was not then repeated as a separate question. As needed, the researcher checked her understanding with the participant to ensure that she had effectively interpreted the meaning of the response.
6. The interviewer used prompts and probing techniques as appropriate. For example, the researcher referred to comments written by the participant in the survey to start a response, echoing the comments the participant had made in the interview and expanding on particular points to gain more detailed information.
7. Following the final answer, the interviewer concluded the interview thanking the participant for their time and summarising the next steps in the research process. The researcher offered to send the participant a copy of the final transcription of their interview if they wished to have a copy (although none of them accepted this invitation).

8. The audio recording of the interview was then transcribed by a medical secretary who was working for the paediatric gastroenterology department in the hospital where the study was undertaken and in keeping with ethical approval. The medical secretary was accustomed to dealing with confidential material as required in her daily role.
9. The researcher then checked the transcriptions against the audio-recording for accuracy and made any corrections necessary prior to undertaking analysis of the interviews.

Setting

The interviews were undertaken either face-to-face at the participants' hospital base or at a mutually agreed, pre-arranged venue (n=2), or remotely via telephone (n=4). The national aspect of the sample and the large geographical distances between the researcher and the participants meant that telephone interviews were used in four of the six interviews. All of the interviews were audio-recorded using a non-digital, audio-recorder as planned to increase accuracy of transcription.

Recruitment (Phases 1 & 2)

Phase 1

All the participants were contacted by email, with an introductory letter (see Appendix 1) explaining the rationale and outline of the study, along with the contact details of the researcher and their supervisor. The email addresses which had been used on request for the PIBDPHR were used once more to invite the nurses to participate in the study.

Phase 2

The participants from Phase 1 of the study self-selected to be contacted to participate in Phase 2 by submitting their contact details when they returned the survey via Survey

Monkey® (see Appendix 2, question 12). Participants were informed that by submitting contact details they were agreeing to be invited to participate in the interview

The participants who consented to be interviewed were initially contacted via email to identify a convenient time and location for the interview to take place. This was then reinforced with a telephone call to confirm the details which had been previously mutually agreed.

A sampling matrix was developed (see earlier section and Table 3.1) to support purposeful selection of nurses across the five factors that represented different uses of the PIBDPHR. However, due to only six nurses self-selecting to participate in Phase 2, the sampling matrix was not used.

Ethical issues

Ethical approval to undertake the study was sought from the University of Central Lancashire BuSH Research Ethics Committee (REC). Changes to the NHS Local Research Ethics Committee (LREC) guidelines state that as the participants were all NHS staff it was unnecessary to gain ethical approval from LREC (HRA 2011).

There were seven conditions and one recommendation in the initial response from BuSH. These related to clarification about funding of the study, data storage, the use of logos, the level of detail in the letter of invitation, password protection of the survey, an issue relating to consent and scope of the interviews. All of the conditions were either explained or amended and a response was submitted. Permission was then given to proceed with the study.

Data protection was ensured on the Survey Monkey® website through a variety of well-known online security seals such as Norton (previously known as VeriSign) TRUSTe and McAfee. Transcription was undertaken by a medical secretary to try to avoid any transcription bias. Transcribed data were stored on a password protected computer and the transcriptions of the audio-tapes were stored in a locked drawer in the researchers

secure office. The audio-tapes were stored separately from any identifying data. Audio tapes were destroyed once the data had been verified and any necessary changes made to the transcripts; this generally occurred where some participants' words had been mis-transcribed due to their accents.

Participants in the Phase 1 survey who were willing to be recruited to Phase 2 gave their email and telephone contact details and so their survey responses were therefore no longer anonymous. All other participants in Phase 1 remained anonymous. In the final report and in other aspects of dissemination, care has been taken in order to ensure that the settings and participants remain anonymous. Research codes of conduct have been adhered to in accordance with the University of Central Lancashire's Code of Conduct for Research and in line with National Research Ethics Service (NRES) guidance and governance.

By completing and submitting the e-survey all participants were deemed to have given their consent. Although the participants in Phase 2 had given their consent to be directly contacted by providing their contact details, consent to be interviewed was taken verbally prior to the interview starting. The participants were informed that they could withdraw from the study at any point and that any recording of the interview would be discarded.

The researcher was known to all of the participants and therefore had to ensure that all procedures were strictly adhered to regardless of having personal/professional relationships with each participant. The maintenance of anonymity of participants was essential. The possibility of bias in the presentation of the results was a factor the researcher took into consideration, therefore particular caution was applied to avoid over-interpretation of the responses and to add personal judgement as to what the participants intended to say rather than how they actually responded.

Data analysis

Phase 1 data were analysed using descriptive statistics along with thematic analysis of any free text data provided.

Data were exported from Survey Monkey® in the form of an excel spread sheet. In order to enable the easier management of the data each participant was allocated a number (1-12) this allowed for any free text comments to be attributed to a particular participant. The nurse identifier was continued into Phase 2 analysis and data reporting for the participants who had volunteered to be interviewed.

Initially participants' responses were reviewed individually and any free text comments read. This allowed the researcher to have an overview of the data. Subsequently each individual question was downloaded from Survey Monkey® in the form of a much smaller excel spread sheet this facilitated much easier analysis of the individual questions. Any statistics generated were then added onto the large spread sheet, for example, average length of time in post. As each question was analysed the researcher considered what the data was telling her and how best this should be presented i.e. pie chart, columns and comparison columns. Some of the graphs were viewed in several versions before the final ones were decided upon.

Due to the fact that there were only 12 participants, the mean and range of the caseloads has been presented in raw numbers and percentages. The small number of participants meant that only descriptive statistics could be used to present the data

The initial analysis from Phase 1 data informed the decision-making process in relation to Phase 2 as it allowed a sampling matrix to be created to guide participant selection for Phase 2. Due to the low number of potential participants who offered to participate in Phase 2 (n=6) and the varied indications for use, all were contacted to participate in the

interviews. This included the participant who had not received any of the PIBDPHR. The decision for the inclusion of this participant was made to compare the understanding of the concept between the nurses who had actually used the PIBDPHR and those who had expressed interest.

Phase 2 data were analysed using thematic analysis. This involved using six steps as identified by Creswell (2009 p185-189) as follows:

1. Organise and prepare the data for analysis
2. Read through the data to obtain a general sense of the data
3. Detailed analysis using a coding process
4. Use the coding process to generate a description of the setting and people as well as categories or themes for analysis
5. Advance how the description and themes will be represented
6. Make an interpretation or meaning from the data

The researcher found these steps useful as it helped to guide her in her analysis.

Once the data were transcribed, the transcriptions were read whilst listening to the audio tapes twice and then the transcripts were read again thoroughly several more times to gain an understanding of the data. The interviews were reviewed individually with notes made of general information that initially stood out to the researcher, for example, family centred care and resistance to changes in current practices. The next step involved coding the data; this was not a simple process and took many attempts before the researcher felt confident with how she had undertaken this element of the study.

Coding required the researcher to read each transcript very carefully and identify small codes such as words or phrases that seemed to be important and relevant to the aims of the study. These words and phrases were identified with various coloured highlighter pens. An example of the words and phrases that the researcher initially marked was 'appropriate patients' and 'information'. This process took a long time as initially the researcher was uncertain what to mark and what was relevant. However, as she gained confidence in marking sections of the text she started to apply labels (codes) that described the words/phrases. Examples of the codes include 'nurse perception', 'type of information' and 'medical engagement'. After these codes had been developed in the first transcript they were applied in the subsequent transcripts. The process was repetitive and the codes were refined and developed (for example, the initial code 'keeping track' was eventually refined to become 'remembering'). Other codes that initially seemed promising were discarded (for example, the code 'driving the bus' was eventually discarded as its meaning was not as evident to the supervisory team as it was to the researcher). All of this close engagement with the transcripts and thinking about the coding meant that the researcher came to know her data very well. Once the codes had been refined, these were then grouped into 'chunks' of similar codes and then clustered into topics or themes.

Examples of early ideas of themes included 'positive' and 'negative' although these ones do not appear in the final analysis as they were felt to not reflect the data as effectively as the final themes. The researcher kept checking within and across the transcripts to ensure that the codes and themes were robust. This iterative review occurred several times before the four main themes and sub-themes were identified and clear descriptions were created for each theme and sub-theme.

The researcher was very reflexive during this period asking herself many questions to ensure that she carefully thought through any initial assumptions she had about the use of the PIBDPHR, for example that the PIBDPHR had become a part of 'normal' patient

care and were being used in all patients. She wanted to be sure that she was examining the participants' views and rather than simply focusing on her own experience of using the PIBDPHR. The construction of the themes and subthemes were discussed and developed with the support of the supervisory team. This level of reflexivity was also discussed within supervision meetings. The supervisory team would question the researcher encouraging exploration of her interpretations as well as challenging and questioning the themes in order to enhance rigour within the study as well as support the researcher to develop greater critical appraisal and thinking skills.

Establishing Rigour

To establish trust or confidence in research, rigour (qualitative) and reliability (quantitative) methods can be used (Thomas & Magilvy, 2011). According to Holloway and Wheeler (2010 p.298) "...rigour indicates thoroughness and competence" while reliability relates to the dependability of the research. As there are different qualities required to ensure rigour in quantitative and qualitative research, they will now be appraised separately in order to reflect the nature of both the quantitative (survey) and qualitative (interviews) research methods within the study.

Appraising the quality of the quantitative element of the study

Quantitative research is 'measured' through reliability, validity, and generalisability (Parahoo, 2014).

Reliability refers to the degree of consistency of the data gathered using the tool that collected the measurable data (Andrew & Halcomb, 2009). As Polit & Beck (2010) explain reliability can be seen as encompassing four components – stability, internal consistency, equivalence and interpretation of reliability coefficients. However, due to the small scale nature of this survey and constraints such as the amount of time available, the researcher did not undertake full reliability testing. Thus, the researcher cannot claim

that the survey is reliable or that the results of the study are easily reproducible. In designing the survey the aim was to consider the reliability with which data could be collected with subjects who had a shared common practice and worked in similar environments with similar patient populations. The survey was developed to be clear and concise with questions that were appropriate to the subject that was being investigated. The survey was piloted on two paediatric nurses who had a basic knowledge of the subject area; this was done to ensure the questions were clear and the survey followed a logical structure. Internal consistency was not tested. However, care was taken to word the questions carefully and unambiguously and questions that explored the same concepts (i.e. challenges and barriers) were grouped together. The data in this study did not reveal any extreme abnormal results, there were no obvious misunderstandings and the responses were within the expected range. This suggests a level of consistency and it demonstrates good stability of the data collection tool and understanding of the questions by the participants. Furthermore, reliability was maintained through reference to the pertinent literature and regular supervision sessions to ensure that the researcher learnt and explored the research process and was able to understand and observe the correct procedures of the research process. Equivalence and reliability coefficients were not tested in the development of the survey.

Validity assesses that the instrument measures what it is designed to measure and that any inferences are accurate (Holloway & Wheeler, 2010). The researcher concluded that there was face validity of the survey due to the consistent responses from the respondents. The options field 'other' was rarely selected; therefore this suggests that the questions were representative of the thoughts and experiences of the participants.

Generalisability relates to the data gathered being representative of the whole population of the topic being researched (Andrew & Halcomb, 2009). The participants' responses were very similar despite there being a wide representation of demographics. As such,

similar responses highlight the likelihood of the generalizability to a wider population of nurses working in the field of paediatric IBD and the usefulness of the PIBDHR in clinical practice.

Appraising the quality of the qualitative element of the study

Qualitative rigour is characterised by dependability, credibility, confirmability and transferability (Lincoln & Guba, 1985).

Dependability is the ability to show that the findings are consistent and repeatable (Lincoln & Guba, 1985). This was undertaken by ensuring that there was an audit trail that included all documentation and decisions. The process of a transparent audit approach enabled the researcher to log and then discuss each step of the research process with her supervisors. By following a clear research process and by considering the methodology and methods in detail throughout the study, the researcher ensured that good research practice was followed; this in turn strengthened the credibility of the study. All the records of different phases and different versions of the study have been kept to allow for 'auditing' of the research process so as to enable others to judge the validity of the study (Holloway & Wheeler, 2010). These records are either in electronic or paper formats and stored as previously described in accordance with data protection guidelines and policy.

Credibility relates to the integrity and quality of the study (Lincoln & Guba, 1985). The researcher brought a degree of credibility to the study by the nature of her clinical practice and skills as she had been immersed in the subject area for 16 years. The years of clinical practice within different care settings and working with various clinical teams meant the researcher has a very good understanding of the application and utility of the PIBDPHR in clinical practice. Credibility in the data collection and reporting processes was important so the transcripts of all the interviews were checked thoroughly to confirm that they had been accurately transcribed (Tracy, 2010). The researcher

achieved this by listening to the audio recording of each interview whilst reading the transcripts. Working with the transcriptionist the researcher was able to ensure that all elements of the interview were captured including elements such as pauses and laughter as these add depth to the transcript. The various accents of the respondents and their local dialects, which were not known to the transcriptionist, accounted for most of the subsequent amendments. This dual approach to transcription ensured that assumptions made by the researcher, who knows the subject and the participants well, were not allowed to appear in the final transcript. The interviews were initially coded by the researcher, this was done to guarantee consistency and reliability in the coding across all the transcripts. Regular supervisory sessions with expert and experienced supervisors allowed exploration of the coded data and challenged the researcher's thinking while supporting her to stay focused within the boundaries of the study aims. The supervisors were able to suggest reading to guide the researcher in developing her understanding of specific areas of the research process where the researcher demonstrated deficiencies in her knowledge. Reading was undertaken and the subject area reviewed during supervision sessions. This learning and the opportunity to talk also enabled the researcher to question the data in different ways and not simply accepting the results at face value but to critically think about the elements that underpinned the themes as they emerged. Having a clear protocol for the study limited the variability of how the data were collected, sustained the focus and helped to maintain the consistency of the approach.

Confirmability ensures that there is integrity in the study and that the study represents the participants' views and is not biased by the researcher (Lincoln & Guba, 1985). The researcher used a reflexive approach to ensure that her opinions and influences had a limited effect on her interviewing techniques and subsequent interpretation or potential over-interpretation of the data. A difficulty that can be encountered when interviewing peers is the assumption by the interviewee that the interviewer knows what they mean

and therefore they may not fully expand on their thoughts (McDermid, Peter, Jackson & Daly, 2014). The researcher was very conscious that this might occur so she conducted each interview with this in mind and was careful to use probes and check her understanding.

Transferability examines the extent to which the findings can be transferred into other settings (Polit & Beck, 2010). Although this was a small sample it did enable the researcher to give a thick description of the research undertaken including the setting and participants. Although the sample was small and the study focused on a particular element, the PIBDPHR, the findings have the potential to be transferred into other settings, for example, they could have relevance to an adult IBD setting or a different speciality within a paediatric setting.

Conclusion

In this chapter the aims and objectives have been presented and a detailed explanation of the methodology and data collection techniques used to undertake this study has been explored. The rationale has been presented for utilising mixed methods framework was to develop quantitative base level data, in the form of an e-survey from which further qualitative interrogation of the actual experiences of nurses using the PIBDPHR was undertaken using interviews. The two different data collection tools were discussed showing how carefully the researcher considered that the most effective ways of collecting data from each phase of the study were used. The methods of data analysis for each phase of the study have been presented; Phase 1 was primarily analysed using descriptive statistics with some descriptive analysis of free text comments while Phase 2 data was analysed using thematic analysis. Within this chapter, careful consideration has been given to the ethical issues and appropriate guidelines have been referred to. The quality and reliability of the data collection process has been explored. The data analysed will be discussed in more detail in the following chapter.

4. Results

Introduction

This chapter will present an overview of the job characteristics of the nurses who participated in both phases of the study followed by the separate analysis of Phases 1 and 2 of the study. These analyses will then be summarised at the end of the chapter. Phase 1 analysis will be presented in line with the three sections of the survey using descriptive statistics (percentages) and raw numbers; tables and figures will be used to illustrate the text. The analysis of any free text from Phase 1 will be presented after the statistical analysis. Phase 2 findings will be presented using four themes and direct quotes will be used to illustrate the participants' responses.

Overview of Job Characteristics of Study Participants

Due to the small number of participants within the study and the specialist nature of their jobs, care has been taken in reporting the demographics of the sample. In order to protect the anonymity of respondents the decision was made not to report the gender of participants and participant characteristics are not reported on at an individual level. However, broad information in terms of mean and range of years of experience across the participants are presented. The job characteristics of the participants from both phases of the study groups are similar (see Table 4.1). More detailed presentation of these characteristics is presented in the following sections. Overall, the characteristics from both phases of the study were similar. The biggest difference between the two phases was the size of the patient caseload. This difference was due to the largest caseload of patients not being included in Phase 2 of the study. In this study a caseload was defined as the number of IBD patients that an IBD nurse was managing.

Table 4.1: Characteristics of study participants

Phase 1	Mean	Range
Time in current post	7 years 7 months	4 - 12 years
Hours spent on IBD/week	26.5 hours	15 – 45 hours
IBD Patients on caseload	191 patients	35 - 450 patients
Tertiary gastroenterology service	9 nurses	
Phase 2		
Time in current post	7 years 1 month	6 – 8 years
Hours spent on IBD/week	27.8 hours	15 - 45 hours
IBD patients on caseload	159 patients	35 – 300 patients
Tertiary gastroenterology service	3 nurses	

Phase 1 (Survey)

The Phase 1 survey results are presented by under the following headings: overview of usage; clinical uses of the PIBDPHR; and challenges, barriers and benefits.

Overview of Usage

Twenty six nurses had requested copies of the PIBDPHR; however, six nurses were not invited to participate in this study. The researcher conducting this study was excluded, while the remaining five nurses had left their posts since the PIBDPHRs had been distributed. Therefore 20 invitations were sent to nurses to participate in the study; 12 of the nurses consented to participate and completed the Phase 1 survey, giving an initial response rate of 60% (12/20). Table 4.2 shows an overview of the key uses of the PIBDPHR.

Table 4.2: Overview of the participants' key usage of the PIBDPHR

Participant	New Patients	Difficult to manage disease	Education tool	Transition	Other
1	√ (all)	x	x	x	x
2*	x	x	x	x	x
3	√	√	x	√	√
4	√	√	√	x	x
5	√	x	x	x	√ (all)
6	√	√	x	x	x
7	√ (all)	√	√	x	x
8	√	√	x	x	x
9	√ (all)	x	x	x	x
10	√	√	√	√	x
11	x	x	x	x	√(all)
12	x	√	√	√	x

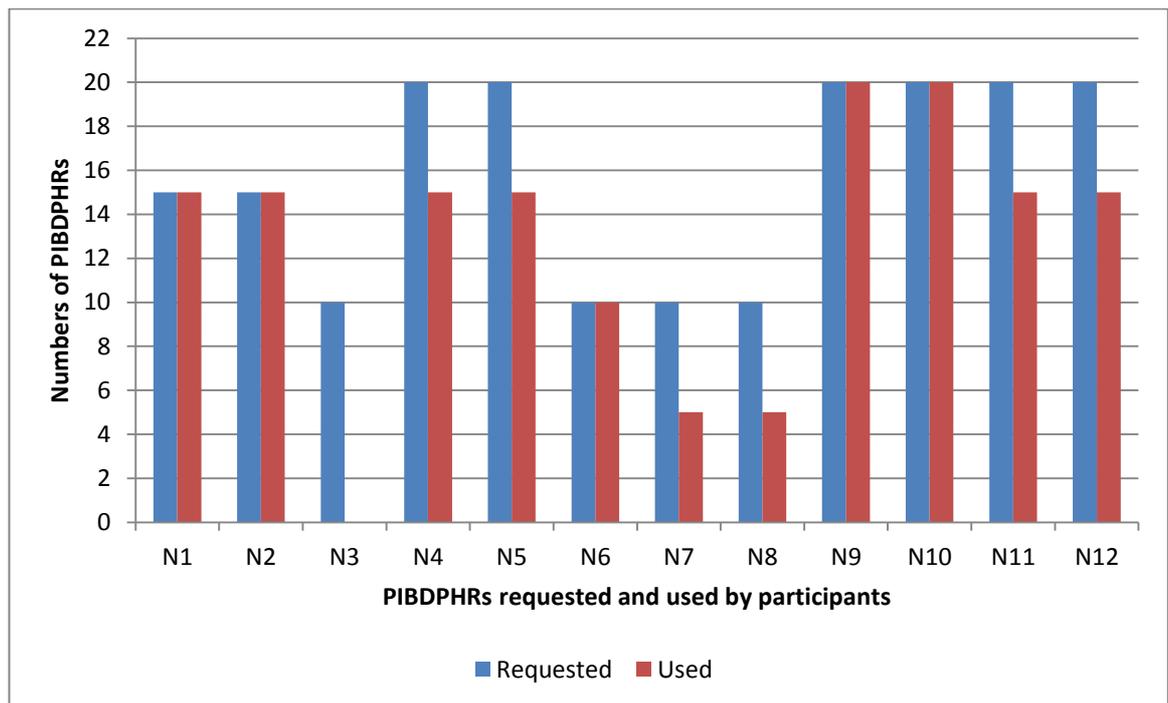
* Participant 2 did not receive any copies of the PIBDPHR

Note: 'all' indicates that the participants distributed the PIBDPHR to all patients in all categories.

Respondents had been in their current IBD role for an average of 7 years 7 months (range 4 - 12 years). Only two of the nurses were dedicated to caring for IBD patients in a full time capacity; the hours worked by the respondents solely with IBD patients were reported as ranging from 15 - 45 hours a week with an average of 26.5 hours. The numbers of patients on the IBD nurses' caseload was varied; the smallest caseload was 35 patients and the largest caseload was 450 patients (mean = 191 patients). This variation is explained by the fact that some of the nurses work in tertiary centres (n=9), while others are in gastroenterology specialist services in district general hospitals (n=3). Tertiary centres generally have a larger population of patients with IBD as a result of the specialist knowledge and skills that are available to manage patients with chronic and complex health care needs as a consequence of their IBD.

A total of 180 PIBDPHRs had been requested by the 12 nurses in the study (see Figure 4.1). Three nurses did not record how many they had actually used; therefore data were available only on the 110 PIBDPHRs that had been used in practice by eight nurses. It should be noted that one respondent did not receive any PIBDPHRs from the distributor despite several requests.

Figure 4.1: PIBDPHRs requested and actually used in practice (N=11)

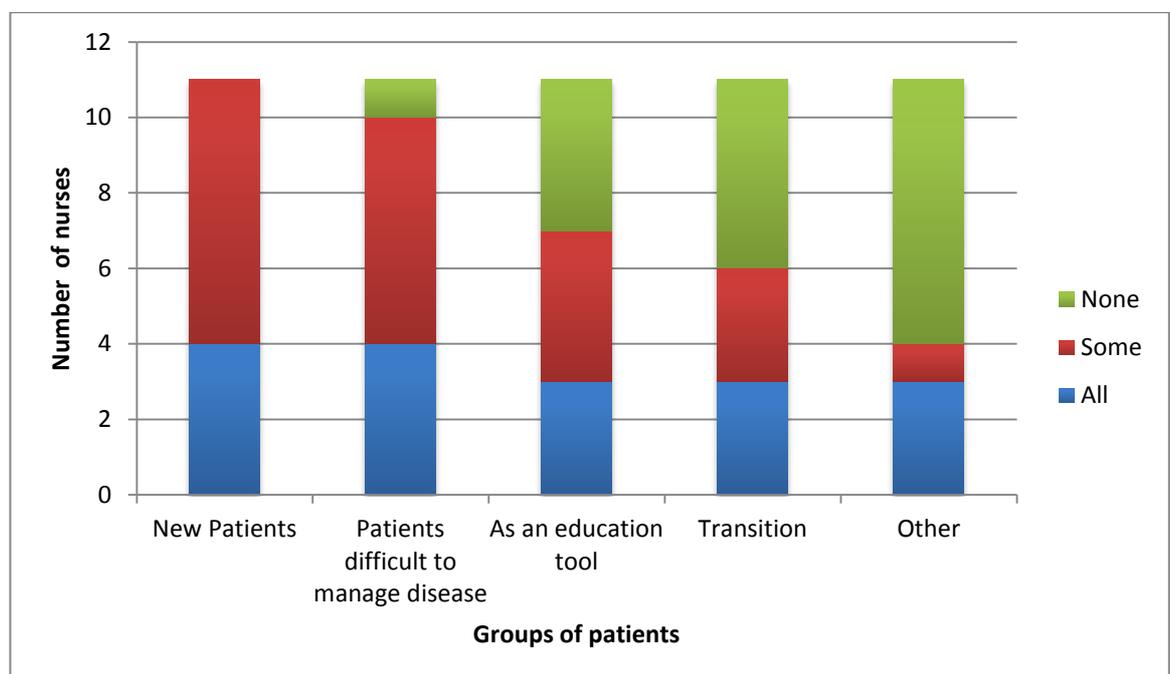


Clinical Uses of the PIBDPHR

All 11 respondents who received copies used them with at least some of their newly diagnosed patients. Five nurses used them with all of the new patients they had cared for after they had received copies of the PIBDPHR. Six nurses used them with patients who had difficult to manage disease and four used them as an educational tool for specific patients. The PIBDPHRs were used to facilitate transition to adult services by three nurses. Most of the nurses (n=10) were very selective about which patients they gave them to and used their own criteria for selection rather than giving them indiscriminately to all patients. Three nurses used the PIBDPHR in other groups of patients that were not listed, one nurse (Nurse 4) used them to help reduce patient and

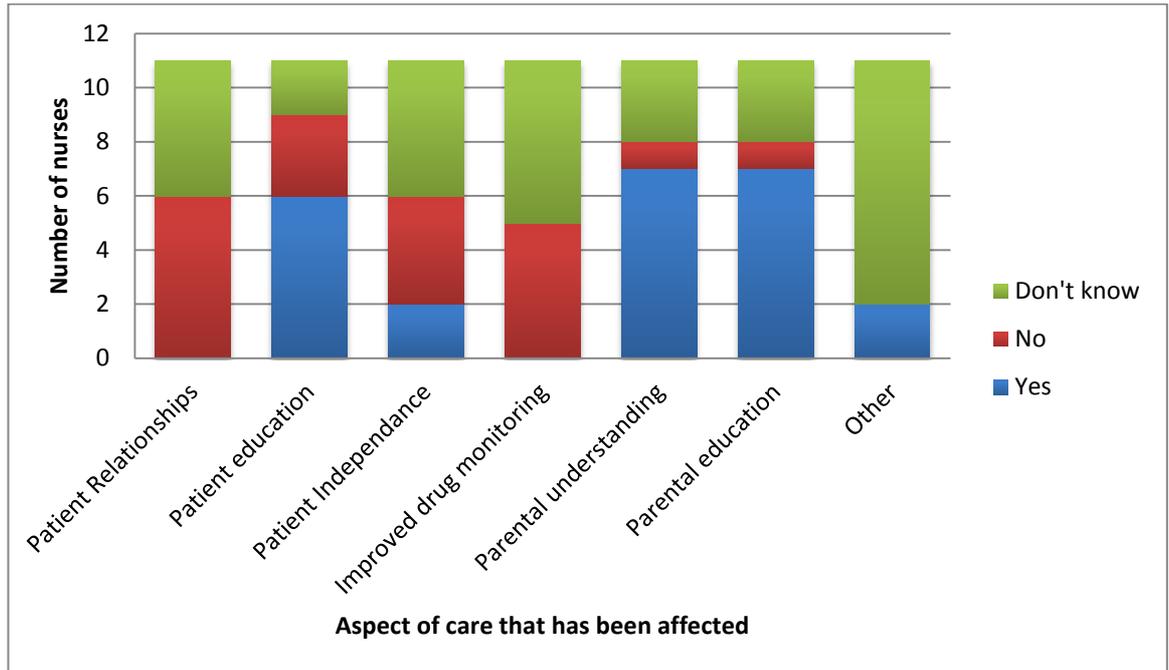
parental anxiety, Nurse 8 discussed the PIBDPHR with her patients and then gave them to patients who were interested in using them, while Nurse 7 used them with patients who already kept records. Figure 4.2 shows an overview of the different groups of patients selected by the participants to be given the PIBDPHR; in the figure the results are presented as ‘all’ (all patients in this category were given PIBDPHR), ‘some’ (some patients in this category were given PIBDPHR) or ‘none’ (no patients in this category were given PIBDPHR).

Figure 4.2: Groups of patients with which the PIBDPHR was used (N=11)



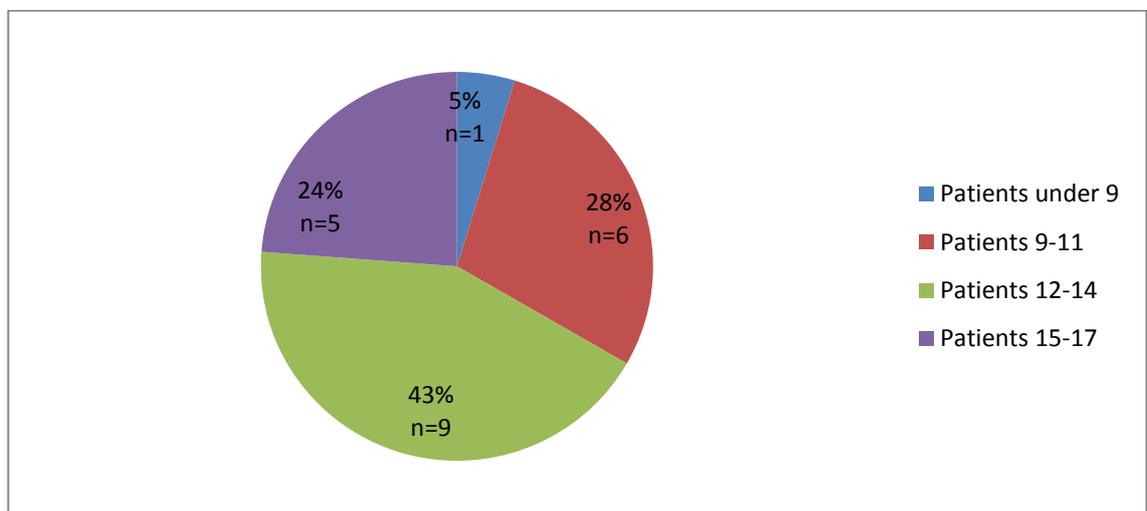
Having identified the patient groups who were given PIBDPHRs, the nurses were asked to identify which aspects (if any) of local practice they perceived had been affected by the use of the PIBDPHR (see Figure 4.3). Parental education was the area most respondents (n=7) felt had been affected. The next most frequent areas of improvements identified by six respondents were patient education and parental understanding. None of the respondents reported that it had improved either relationships between patients and health professionals or drug monitoring. Patient ownership of their disease and an increased sense of involvement in decision making were both aspects which the respondents commented had improved.

Figure 4.3: The effects of the PIBDPHR on local practice (N=11)



In response to the question asking respondents to identify more specific details about the patients and parents that the PIBDPHRs were used with, the majority of PIBDPHRs were used with the young teenage patients (see Figure 4.4). Four parents were reported as being the prime users of the PIBDPHR. The nurses noted that no other members of the MDT were involved in using the PIBDPHRs within their practice. Only four of the nurses had any direct input into the on-going use of the PIBDPHR within their services.

Figure 4.4: Ages of the patients who have used the PIBDPHR

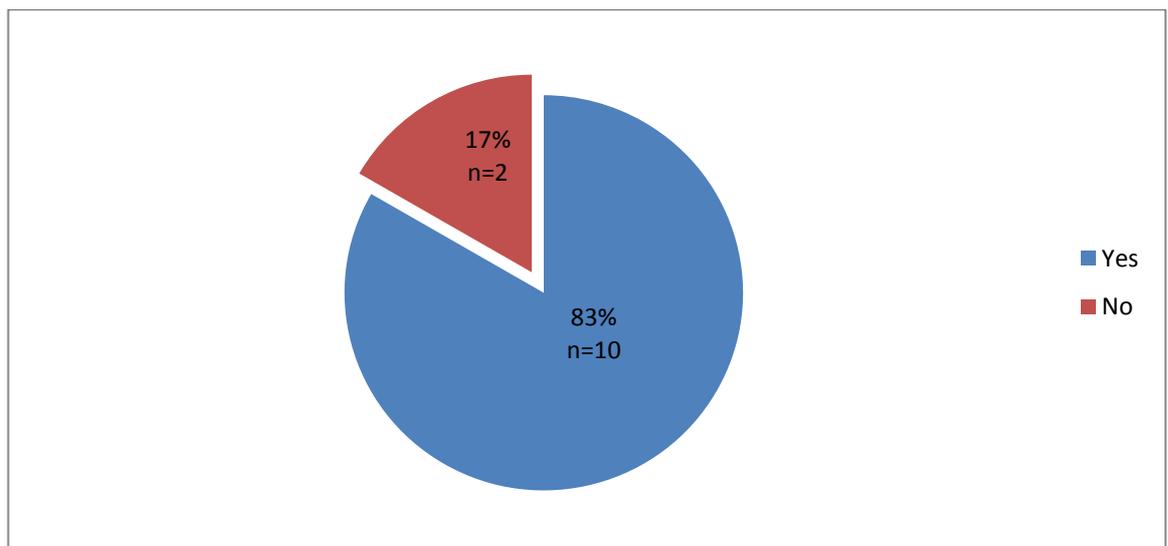


When asked if the limited availability of PIBDPHRs had affected their usage, five out of twelve of the respondents reported that it had, this included the one who did not receive any copies. There was the option to comment on this question. However, although no responses were documented at this point all five nurses did include it as a negative factor in their final comments.

Challenges, Barriers and Benefits

This section will present the results from the final section of the survey which concentrated on gathering more information on the challenges and barriers that the nurses encountered while implementing the PIBDPHRs. The respondents were given the opportunity to select Yes/No answers with mandatory free text responses if yes was selected. This section also rated the nurses' experiences of using the PIBDPHR with a 5-point Likert scale. To understand whether the respondents would use the PIBDPHR in the future the penultimate question asked how many PIBDPHRs would be required in an ideal world and how many a year would they need. Finally the respondents were given the opportunity to add any further comments on the PIBDPHR.

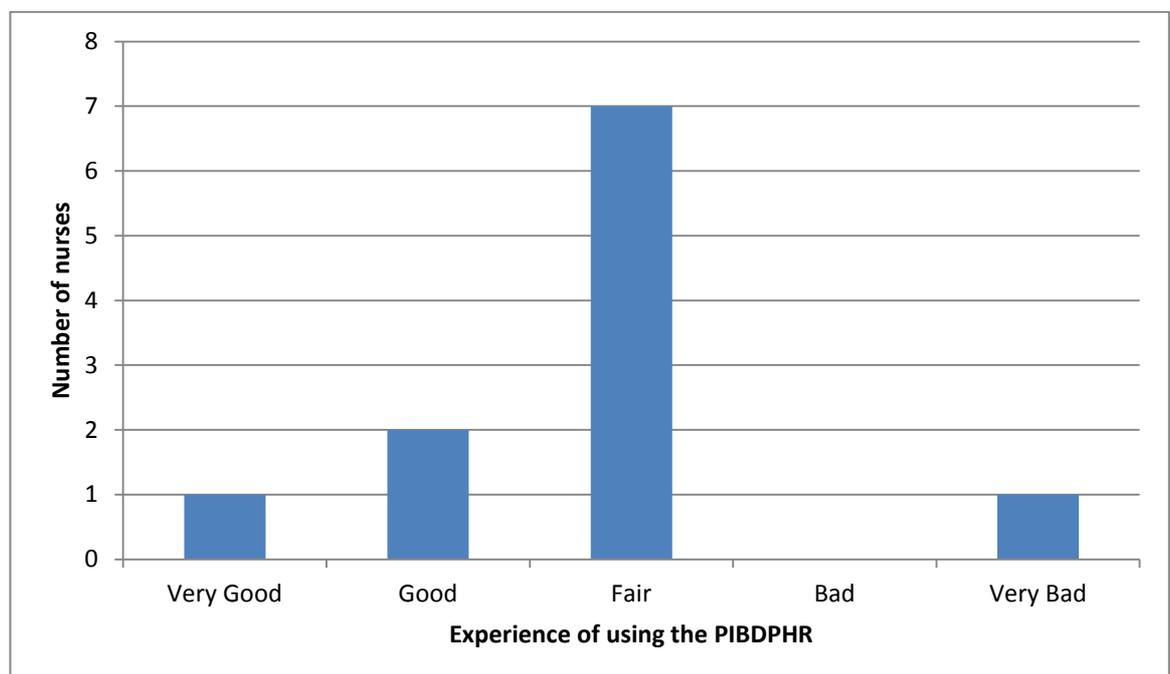
Figure 4.5: Have there been any challenges/barriers to implementing the PIBDPHR?



There were 10 respondents who felt that there had been barriers and challenges to implementing the PIBDPHR in their practice (figure 4.5). This included nurse 3 whose main barrier was not colleagues or patients but the practicality of not actually receiving copies of the PIBDPHR that had been requested. Another respondent ticked that they had no barriers or challenges but then used the free text comments to explain the problems they had implementing them. The main challenges identified in using the PIBDPHR were related to remembering to use the record (n = 6) and the time involved in using it (n = 4). The barriers included getting medical staff engaged in their use (n = 5) and failure to return the records to clinic routinely (n = 7).

The free text comments from the challenges, barriers and benefits section will be reviewed in detail together with the respondents' overall comments later in this chapter.

Figure 4.6: Overall experiences of the PIBDPHR (N=11)



The overall feedback for nurses' experiences of using the PIBDPHR, based on responses to the 5-point Likert scale showed that seven respondents (58%) reported their experience was 'fair' (see Figure 4.6). Only one respondent (Nurse 6) felt their

experience of using the PIBDPHR was 'very bad'. This was due to the poor buy-in from the patients and medical staff compared to other areas in which she had used a similar tool in (oncology and parental nutrition). She reported that this may have been due to the length in time between appointments when the patients with IBD are generally well and seen on a 3 monthly basis. The benefits were that the PIBDPHR was perceived as useful with certain patients and overall the experience of using them was positive.

The final question asked how many PIBDPHRs the nurses required to fully initiate them into their practice. Nurse 10 stated that ideally they would order enough to give a copy to all existing patients and then to all newly diagnosed patients. The rest of the nurses reported that they would order enough to give to some of their existing patients who met their specific criteria and then an on-going supply on a yearly basis to give to new patients.

Analysis - free text responses

The free text comments gathered from questions 10 and 11 were reviewed independently of the Phase 2 interviews. However, the themes that evolved did mirror the themes that were later identified following Phase 2 interviews. The responses are now reviewed.

Nurse 4 and Nurse 10 were both selective in the patients that they distributed the PIBDPHR to. Their selections were based on very different criteria with nurse 10 concerned about the level of knowledge that the PIBDPHR would give to their patients.

As Nurse 10 said

“...I had concerns that patients and parents (mostly parents) get too involved in filling in blood results, losing sight of the ethos behind a patient held record.”

Nurse 4 wanted to empower her patients to work towards “self-management” and selected patients that she felt would “benefit most”.

Time was also identified as a challenge for the nurses. The PIBDPHR was a new tool so this meant that the nurses had to take time to discuss the PIBDPHR with the patients and explain to them how to utilize it. This was a challenge due to the increasing time pressures, and, as Nurse 2 explained “The main problem is actually getting to meet up with the patient and having time to go through things (explaining the PIBDPHR and how to use it)”. Meanwhile, Nurse 8 considered that time was problematic in ensuring that the details entered into the PIBDPHRs were “...kept up to date and complete”.

Five respondents reported that a barrier that they encountered was the difficulty in getting engagement from the medical staff. Nurse 9 summed this up by stating that they had “...difficulty engaging doctors to use and remember to prompt patients in clinic to get it [PIBDPHR] out”. A key reason for “...[slow] buy in from medical staff” was reported to relate to time in busy clinics (n = 3) that include a variety of gastroenterology patients and not purely IBD patients (Nurse 6). Nurse 1 explained that the medical staff with whom he/she works were “...not keen to use them as they perceive them to be [too] time-consuming” to allow them to assist patients to use them effectively.

Nurse 9 explained the challenge related to remembering the PIBDPHR in detail, saying the challenge was “integrating it” [PIBDPHR] into her own practice, and remembering to “trigger patients to use it” either to use as a reference tool or to record medication. She was hopeful that this would “improve with time”. Another memory-related issue was the nurse having to remember which of their patients had been given a PIBDPHR. As Nurse 4 explained “It was difficult to remember who I've given them to”, however, she queried whether this was “a reflection of my poor data management” rather than the tool itself.

Another barrier arose when the patients and parents failed either to remember to bring the record or to refer to the PIBDPHR in their clinic appointment, which meant that the record was often not used in the clinic setting. Typical responses included “parents don't remember to bring them to clinic” (Nurse 6) and “patients forget to bring them to appointments” (Nurse 11). Nurse 12 reported that in her experience “initially patients thought (the tool was) useful but all have quickly disbanded [stopped] using it or bringing to clinic”.

Although as reported earlier, most respondents (n=7) reported that their usage of the PIBDPHR had not been affected by the limited number of PIBDPHRs available in their clinical setting, one respondent (Nurse 10) explained that the “limited number available affects commitment from professionals” as they had “to prioritise who to give it to”.

However there were perceived benefits identified in using the PIBDPHR with two respondents reporting positive comments on how patients were using the PIBDPHR in practice. Nurse 11 explained that on their caseload “patients appear to have them as a source of reference rather than anything else”. Another respondent, Nurse 12 had gained direct feedback from patients they used the record with, stating that their “patients have voice[d] usefulness of having information in booklet”, Nurse 9 felt that if the priority given to using the PIBDPHR changed to replicate the emphasis given to the ‘red book’ they could make a big improvement in the treatment of patients with IBD.

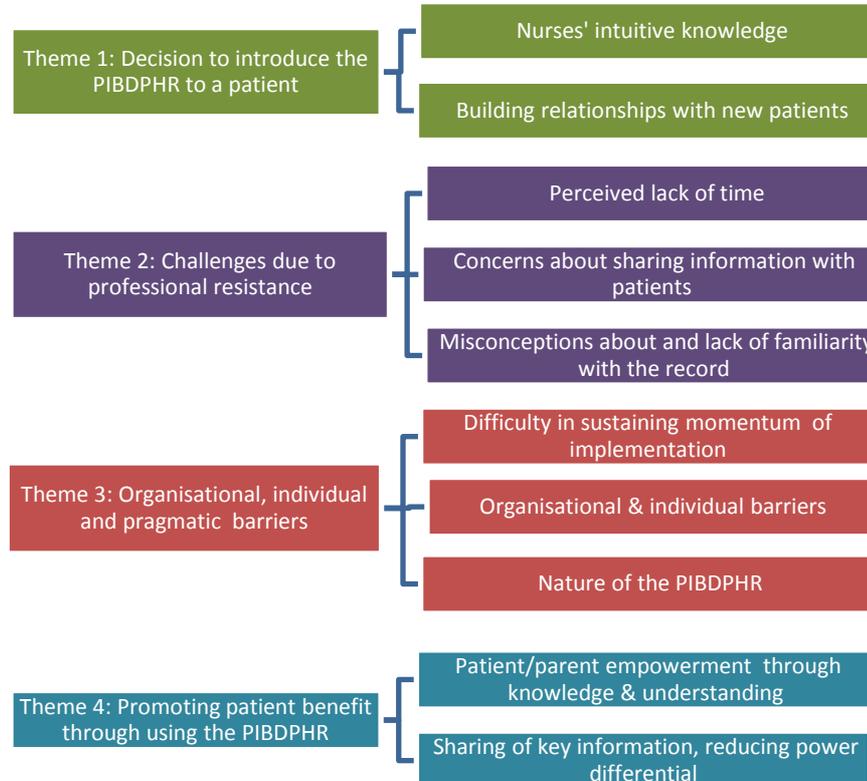
Phase 2 (Interview)

Theme identification

As previously described the interviews were reviewed using thematic analysis. Using this process enabled the researcher to build four themes and then identify sub themes (see Figure 4.7). The development of themes was a difficult process for the researcher whose initial ideas needed to be developed since these initial ideas made sense to her but the

sense, context and links were not apparent to her supervisors. There was much discussion and the researcher was challenged to take her initially fairly superficial and descriptive themes further and develop these into themes that had more depth. The aim was for the final themes to not only reflect the thoughts of the researcher but would also make sense to an outsider reading the thesis. There were some instances where the researcher revised the wording of a theme to make it better reflect the totality of the content of the theme. An example of this is the second theme 'Challenges due to professional resistance', this was changed from a very simplistic and potentially confrontational theme 'Negative views of health care professionals'. Each of the main themes contains sub themes that reflect the scope of the theme. The final themes as presented in Figure 4.7 represent a more conceptual consideration of the data than the initial analysis provided.

Figure 4.7: Phase 2 interview themes



The themes and sub themes are presented in more detail in the following sections.

Theme 1: Decision to introduce the PIBDPHR to a patient

The initial concept for using the PIBDPHR was that it could be a resource for all patients regardless of the IBD nurses' perceptions of who would be appropriate. However, in practice all of the patients were deliberately selected for a variety of reasons. As identified in Figure 4.7 there were two main sub themes that are discussed in the following section.

Nurses' intuitive knowledge of patients and their families

All of the nurses who used the PIBDPHR utilized their knowledge of the patients and their families to select appropriate candidates to receive copies of the PIBDPHR although none of the nurses had a clear and consistent rationale for whom they gave PIBDPHRs to. On questioning, the nurses used a variety of criteria in their selection process, for example:

“If they were older and they had been diagnosed for a while, it was because I knew them and had quite a good rapport with them or if they were newly diagnosed and a bit older, it was because I had sat down with them at length and discussed things and introduced the hand held record.” (Nurse 5)

The criteria for four of the participants changed over the period of time they were issuing the PIBDPHRs. The changes were mainly due to the nurse becoming more familiar and comfortable with using the PIBDPHR:

“.....in the end I was using them more, so used them with patients who were progressing onto different therapies.....I suppose I was getting more familiar with actually what was in the record.” (Nurse 2)

Some nurses (n = 3) used the PIBDPHRs with patients who had treatment escalation, as Nurse 2 explains above, so as to enhance their patients' education and knowledge of the new treatments they were receiving.

Nurses 1 and 2 consciously selected patients that they personally trusted to give “honest feedback” about the new tool and those they perceived would be “interested” and therefore engage in trialling a new information device. Both nurses also wanted feedback from their patients who had received information in both the department traditional information packs and the PIBDPHR to be able to make a comparison between the two different formats “...I wanted to use patients who could have something to gauge it against” (Nurse 1).

Nurse 3, who did not receive any copies, also saw the patient selection and subsequent feedback as an important factor in future planning for their department and planned to use them in a variety of patients to get an overview from all categories of patients. Another area of patient selection was to facilitate the transition to adult services for selected patients. Nurse 5 used them for transition process, so as to ensure patients were well informed and educated on their condition and medications:

“I thought it might be quite a good idea to get the young people who are going over to the adults to actually have a hand held record to discuss with the adult nurse.” (Nurse 5)

There was no consensus as to what age group the PIBDPHR should be used in. It was dependent on the individual nurse’s experience of their patient group. However, there was a perception from two of the nurses that age was an important factor in selecting patients to use the PIBDPHR. Nurse 6 explained that “older children will not be interested and do not want to carry around with them”, although Nurse 5 found that when used in older children, the PIBDPHR facilitated engagement in the transition process from paediatric to adult Services. When caring for younger children there was more parental involvement but as Nurse 4 explained:

“...for younger children I would give the PIBDPHR to them and encourage mum and dad to help them to fill them in.....to primary school children I say to get stickers and funk it up.”

Building relationships with new patients

New patients were the most frequently cited group of patients selected to be given the PIBDPHR to use, with four nurses targeting new patients. The rationale that Nurse 6 used was that the PIBDPHR was "... mainly used in the newer patients so that it was something they used from the beginning." The new patients were a diverse group because there was no previous history with the child and family. Nurse 1 felt that it was a positive way to start a relationship with a new patient and this was the direction their service would be taking for the future. If children were newly diagnosed and a bit older then the PIBDPHR created the opportunity to build a rapport as identified by nurse 5 who explained how the PIBDPHR was helpful "...because I had sat down at length and discussed things and introduced the patient held record"

The nurses reported that the patients who had an existing diagnosis felt it would have been "useful" to have been given a copy at diagnosis.

Theme 2: Challenges due to professional resistance

This theme considers the challenges to implementing the PIBDPHR by other professionals as perceived by the IBD nurses. These challenges were often spoken about passionately by the nurses and the level of frustration was audible in their interviews with the researcher. As the PIBDPHR is a 'nurse led' venture it is vital to address the issues related to professional resistance. The responses from the nurses in the interviews will help to enable the issues to be addressed in the future.

Perceived lack of time

There appeared to be a misconception from the medical staff that it would be time consuming to assist the patient in maintaining the PIBDPHR and increase their workload, for example:

"I think they felt they would be a good tool, but I don't think they wanted any additional work like filling in blood results." (Nurse 6)

Nurse 1 also talked of the perceived workload issues when stating

“I think the medical professionals thought it was too cumbersome and too much like hard work.”

For nurse 5 there was also the added pressures felt by the medical staff who do not run specific IBD clinics and had busy ‘gastroenterology’ clinics and just saw it as “another thing to do”. It was not only in relation to medical staff that there was concern regarding time, Nurse 8 felt that a barrier she encountered was “finding time” to ensure the PIBDPHR was completed to be useful. Nurse 6 also commented that:

“I think clinics were just so busy that ploughing through the paperwork was difficult (for the medical staff).”

This observation indicates that although there may not always have been explicit feedback from medical colleagues there was some discussion about how the PIBDPHR was working within the teams.

Concerns about sharing information with patients

All of the nurses who used the PIBDPHR felt that the PIBDPHRs were of benefit in keeping a record of blood monitoring although this was not verified by their responses to the Phase 1 survey. However, as already explained there was still a desire in paediatric IBD services to be ‘in control’ as exhibited by the IBD nurses’ decision making around which patients they believed were appropriate to have a copy of the PIBDPHR. In this situation, the nurse dictates who receives a copy and this may not correspond with the patient perspective. Patients who would appreciate having a PIBDPHR may not be given the chance to experience and benefit from it if they do not meet the selection criteria their nurse is using. Nurse 4 described this desire to be in control as the need to “drive the bus”.

This concern about suitability of patients was also demonstrated by Nurse 5 who explained how a consultant was concerned about abnormal blood results being available to patients and/or their parents:

“...we are opening ourselves up; if the bloods were abnormal they (the patients/parents) might question it.”

This nurse explained that she already talks to patients about abnormal blood results and gives them the information they need to help them to “...be more in control of their own disease”. She further explained that she perceived the use of the PIBDPHR as a way to enhance the information that she already gives to patients. She felt that the consultant assumed that the results would just be written down and the patient sent away with no education about them.

There was also concern that the PIBDPHRs “would not work for all patients” (Nurse 4) and this would create a two tier level of information giving. This was supported by the comments from Nurse 1 who reflected that this change to information giving and patients having more access to information would require more education of ward staff as they would also be involved in using the PIBDPHR

“...we would have to do teaching sessions with the ward staff indicating this is where they are, this is what we use...we are not using the NACC packs anymore.”

This then led to Nurse 1 considering the wider sphere of health workers who would need to be educated within their individual Trust to ensure an optimal implementation of the PIBDPHR “...everybody across the board within the team have to buy into it...”. Nurse 2 had some reservations that new patients would be given too much information too soon in their disease process:

“[I]...sometimes worry a little bit about giving it to them too early on ... you look at all the different information that's in there and make sure that it doesn't overwhelm them a bit.”

Misconceptions about and lack of familiarity with the record

The most frequent comment from four of the five nurses who had used the PIBDPHR in their own practice was the high level of difficulty in getting the medical staff to engage with the tool, as Nurse 1 explained:

“It’s hard to get the medical staff engaged with the tool because they are so used to their way of working.” (Nurse 1)

Other perceived problems associated with using the PBDPHR included the difficulty in changing the MDT perceptions of how information is delivered and the role they play in supporting patients’ education needs (Nurse 5). As the PIBDPHR is in a folder incorporating various sections it was also seen to be “too cumbersome” for some medical professionals (Nurse 4). However Nurse 6 explained:

“I found them quite small and wondered if the parents/young children would want them to be bigger. I also found locating information a bit fiddly...”

Nurse 1 felt that if it was incorporated as part of a pathway then people (MDT) would be more likely to use it, although there would need to be a much bigger consultation process. Part of this challenge was that not only did the clinicians need time to familiarise themselves with the PIBDPHR and how to complete it but that this would also mean that consultations with patients could potentially take longer initially. It was felt by Nurse 1 and Nurse 4 that the PIBDPHR should have a “proper launch” once there was the full backing of the paediatric IBD professional group – BSPGHaN. Nurse 1 felt that “it would seem more professional if the versions were numbered i.e. Version 1.2”. All of the nurses wanted to reform the working group with the aim to re-engaging investors and stakeholders and also involving patient focus groups in ensuring the PIBDPHR is able to deliver what the patients require.

Theme 3: Organisational, individual and pragmatic barriers

This theme addresses the barriers that were encountered at all levels. There are a variety of different aspects of where the barriers have arisen, from implementation, through to the current processes within the department and then the actual tool and its current format. These will be presented in more detail below.

Difficulty in sustaining momentum of implementation

Although all of the five nurses who received copies of the PIBDPHR felt there had not been any restriction in use due to the number of copies available there was an acknowledgement that they probably would have used them differently if there had been an endless supply;

“...I guess what we would do if we were to use them and that’s what we agreed to do full time, would be to send them out to everybody. “ (Nurse 1)

The five nurses who received copies reported that their colleagues initially expressed a lot of interest in the PIBDPHR and were very enthusiastic about them being used. However when it actually came to the implementation stage, the interest in them appeared to have waned. Although most (n = 5) nurses reported that initially there had been quite a good implementation and use of the PIBDPHR, they also explained that the “momentum kind of lapsed” (Nurse 5) over a period of time. Nurse 5 also reflected on whether there were disease specific differences in sustaining the use of the PIBDPHR over longer period of time, explaining:

“A lot of the kids are teenagers, maybe not that interested and the fact that they've got Crohn's and carrying something that reminds them that they've got a condition when they just want to be normal. Give them information and they ‘chuck’ it under their bed.... Whereas in oncology the kids tend to be younger and the parents are taking more ownership of it.” (Nurse 5)

The momentum also waned due to some patient-oriented reasons such as the “patients forgot to bring them to clinic” (Nurse 6) as mentioned in the Phase 1 responses.

Organisational and individual barriers

There are some organisational barriers that are outside of the PIBD nurses’ control such as clinics where not all IBD patients are seen in the same clinic. This required the nurse and their medical colleagues in the clinics to consider IBD patients and whether they have a PIBDPHR in a clinic setting where they will be seeing a large number of gastroenterology patients with a variety of other conditions. As none of the centres in the study had specific IBD clinics it was difficult for the nurse to ensure that the

PIBDPHR was considered when the patient was attending the clinic setting. There were some debates about how to get the patients to remember to bring them to clinic “they forgot, that is they simply forgot to bring it in” (Nurse 5), Nurse 1 felt that if they were made a unit wide development and fully adopted by the whole team they would be more likely to succeed.

Other organisational reasons that were highlighted perhaps reflected the working practices of the individual nurses; Nurse 4 explained; “I found keeping track of them is the main thing and quite difficult”. Overall, the nurses reported that enthusiasm for using the PIBDPHRs waned over time. Most of the nurses (n=5) did not think that the reduction in engagement with the PIBDPHRs was related to the small number of PIBDHRs that were allocated to each centre. Changing pathways of care to incorporate new practices such as introducing the use of PIBDPHRs was also seen as being challenging to Nurse 1 who explained:

“...it's hard to get the medical staff engaged with them because they are so used to their way of working and one particular information pack that it is entrenched in them, trying to get them to change their minds.... (Voice tailed off)”

Nature of the PIBDPHR

Two nurses reported feeling that some problems arose from the PIBDPHR being a ‘static’ booklet, which in this era of technology based living young people may find it difficult to relate to. As Nurse 4 explained, “...the mechanism of delivery may be outdated”.

There are several different mobile phone applications (apps) that are similar in concept to the PIBDPHR, that are accessible in the UK although they were developed in North America and Canada. Some of the nurses were aware of them and had used them with their patients. The current IBD apps are perceived to be useful in clinical practice in certain settings but are mainly related to symptom management and are used regularly with the adolescent patients by two nurses. The use of a mobile app was brought into the interviews by both Nurse 4 “I think a mobile app is the way forward” and Nurse 5

“...apps - they have always got phones and just being able to input data really quickly I think would be so much simpler and better”. The concept of developing a mobile app was then adopted as a question to the remaining four nurses.

When asked about developing an IBD app to replicate the PIBDPHR on mobile devices all the nurses reported that this would be a good way forward. However three out of the six nurses had not actually seen or used the current versions of the IBD applications that are available, although they thought it would be a good idea. Nurse 6 tried to think of other ways to engage the younger children such as developing a type of mobile game. The two nurses who currently use the apps felt that creating a UK IBD app would encourage better disease management for the patient rather than parents/family and would therefore benefit the older children/adolescents, as Nurse 6 explained:

“For the adolescent patients I would encourage them to use the IBD app and I have been using it a lot...at the moment it is a symptom control app and very Americanised...something pertinent to the UK would be good.”

There was a concern from three of the six nurses that there should still be access to a paper copy of the PIBDPHR as well for people who are not computer literate (parents) As nurse 2 explained “ they (parents) are not necessarily computer literate... for the kids themselves having the app is what they would use.”

Theme 4: Promoting patient benefit through using the PIBDPHR

Two themes emerged from the data that relate to patient benefit, which was one of the main reasons and rationale behind the initial development of the PIBDPHR.

Patient/parent empowerment through knowledge & understanding

The use of the PIBDPHR was perceived as having improved some aspects of patient care and education for the patients and their families. For example, Nurse 2 explained “I think their (patient and their family) understanding is better and it enables them to

question more as well". However, that view was not supported by all the nurses interviewed "I wouldn't say they made a difference with all the patients that used them" (Nurse 1). Nurse 1 went on to try to understand why they had an effect on certain patients and felt that it was probably due to the level of engagement the patients and their family had with using the tool.

Five out of the six nurses identified the need to empower patients as one of the reasons for using the PIBDPHR, and as one nurse explained "any resource that we have to empower the patients is vital to us" (Nurse 4). The need for more self-management in paediatric IBD was highlighted by Nurse 3 who did not receive any copies of the PIBDPHR who explained: "If we don't start doing it (self-management), when they go to adult services, it will come as more of a shock..."

All of the nurses agreed with the basic concept of the PIBDPHR as being "nursing focused, advocacy, empowering the patients" (Nurse 4).

Sharing of key information, reducing power differential

The PIBDPHR was reported to be a good record for blood monitoring and the information leaflets were useful and informative. Two nurses felt that the fundamental principle of the PIBDPHR was "...fantastic because it is nursing focused", and that this was the opportunity to develop a consistency of information giving, directed by the IBD nurses. Nurse 5 intended the PIBDPHR to be used to help the patients to understand the care plan that had been discussed in clinic and gave this example of how she had used it:

"...this is our plan, this is what we are going to do as it's about getting 'you' more and more motivated and more in control of your own disease, knowing if we are discussing that your bloods are out and you need to do x, y & z you know why."
(Nurse 5)

As most of the IBD nurses use information provided by the two IBD charities there was some discussion about revisiting the input that they initially had in allowing their

information to be incorporated into the PIBDPHR. They therefore should be included during any stakeholder involvement to ensure they would like to continue contributing their information for use in the PIBDPHR.

Conclusion

This chapter has identified that the nurses who were involved in this study could be perceived as being experienced in their management of paediatric IBD patients, in relation to their adult counterparts, with a wide range of caseloads in terms of size of caseload population. The results from Phase 1 and Phase 2 of the study have been analysed and four themes were identified with sub themes. The themes identified ranged from being directly related to the nurse and their relationship with the patient, to professional resistance by other people in their teams, and organisational barriers and finally the benefits that the PIBDPHR can bring to the patient. The findings from the survey were supported, for the most part, by the findings from the interviews in Phase 2. The next chapter will discuss these results in more detail.

5. Discussion

Introduction

In this chapter, the findings are discussed drawing on the key themes presented in the results chapter and linking these to the wider literature. The nurses who participated in the study were all experienced and interested in developing their practice but even with these two key characteristics they found the implementation of the PIBDPHR a challenge as often systems acted as a barrier to implementation. Some of these challenges were organisational; other challenges lay at an individual level.

Misconceptions about the nature and purpose of the PIBDPHR, the perceived time-burden and concerns about the effect of information sharing on patients were reasons why some professionals resisted the use of the PIBPHRs. However, set against these difficulties and some resistance, it was clear that the use of the PIBDPHRs had the potential to empower patients through promoting their knowledge and understanding and reducing the power differential between the patient/family and the health care professionals. Following the presentation of these themes, a synthesis and conclusion are presented. Recommendations for practice are also presented.

Perceived and actual benefits

There was a perception from the nurses involved in this study that the PIBDPHR would be useful in practice. The nurses within this study were all experienced nurses who were experts in their field of nursing who were looking at ways to improve the care of their patients. The need for patients to be informed and play a more active role in their management has been linked to improved adherence (Kennedy & Rogers, 2002; Hommel, Odell, Sander, Baldassano & Barg, 2011) and is therefore one of the key drivers for nurses in this study in utilizing the PIBDPHR. While the concept of the PIBDPHR appears to be appropriate there is some concern that it could appeal to more

patients if there was consideration given to the format in which it is produced. These areas will be discussed in more detail with reference to the literature.

A key driver for nurses to be involved in the use of the PIBDPHR is to empower the patients to be able to function as an integral member of the decision-making team regarding their health. Funnell, Anderson, Arnold, Barr, Donnelly, Johnson, Taylor-Moon & White (1991) define empowerment as:

“A process whereby patients have the knowledge, skills, attitudes and self-awareness necessary to influence their own behaviour and that of others in order to improve the quality of their lives”.

However some patients/families may still choose to defer some decisions to the health care professionals ‘who know best’ as, despite efforts to support their decision making, they may still feel unable to make certain decisions (Anderson and Funnell 2010, Sanders and Skevington, 2003). Being more informed can help patients and families to feel more confident about participating in treatment discussions, challenging views or opinions and participating in planning the care for their child (Panicker 2013). The information collected in the PIBDPHR such as the child’s history, blood monitoring medication list as well as the information leaflets regarding the condition, medications have been included to support the HCP’s to empower the patient and their family. There are also support groups identified to signpost the patient and their family to reputable information sources. Helping patients to gain the skills to manage their own health more effectively is one of the main points within the government’s policy on ‘Improving quality of life for people with long term conditions’ (DH, 2013). This policy is part of a whole range of documents designed to improve the lives of patients who have chronic conditions including the NHS Plan (DH 2000); The Expert Patient (DH 2001), Creating a Patient Led NHS (DH 2004), Supporting Patients with Long-Term Conditions (2005), Self-Care (DH 2005), National Service Framework (2005) and the NHS Mandate (DH 2012a). The NHS choices website (<http://www.nhs.uk/Pages/HomePage.aspx>) supports

a series of pages designed to empower patients with long term conditions, including information on how to be more involved in self-care. While empowerment is an essential element of self-care (Wilson, Kendal & Brooks, 2007), the PIBDPHR in its current format is not designed for self-care purposes. The Department of Health (2005) define self-care as:

“The actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital.” (p.1)

Kennedy et al (1999) identified that using a guidebook helped in empowering patients to participate in self-care practices in ulcerative colitis. However further research (Kennedy et al 2004) found that the guidebook functioned better as part of education package in the promotion of self-care in ulcerative colitis. Currently the PIBDPHR has not been developed to be part of a self-care management package but there is no reason why it could not form part of an education programme which supports this concept when the concept is more widely adopted within IBD. The differences in paediatric and adult IBD and different levels of treatments that are required in children due to their different presentations is also seen as another barrier to self-care being adopted in paediatric IBD (Turner et al., 2012) even though there appears to be a resurrection of the concept in adult IBD (BSG 2014). However it has been shown that empowerment and self-management can improve the outcomes of people with IBD (Holman & Lorig, 2004; Schaefer, Miller, Goldstein & Simmons., 2009).

There has long been reluctance in paediatrics and paediatric IBD to change from a paternalistic model of care towards shared care (Fiks & Jimenez, 2010; Hommell, et al., 2013) unlike other long term conditions such as diabetes (Valenzuela, Smith, Stafford, D’Agostino, Lawrence, Frazier, Seid & Dolan, 2014) and asthma (Kirk, Beatty, Callery,

Milnes & Prymachuk, 2012) where there has been considerable success in initiating shared care. The frequently cited rationale for this is due to the variable, unpredictable and episodic nature of the condition which requires wide variations of medical management (Robinson, 2004; Hommell et al., 2013). The PIBDPHR was used in patients who were in the process of transitioning to adult services where most emphasis is focused on empowering the patient to ask questions and to develop a greater understanding of their condition this is an important step in the transition process. Milnes, McGowan, Campbell & Callery (2013) identified that “young people need confirmation that their participation is welcomed” in a consultation, and the PIBDPHR is designed to support the patient to write their questions and thoughts in and is a prompt for HCP’s to ask the young person what questions they may have thereby encouraging them to participate and communicate more in consultations. This is in preparation for handover to adult services and reduction of parental involvement (<http://www.ibdtransition.org.uk>). This would then enable the children and their parents to be more receptive to the introduction of the concept of self-care that may be encountered in the adult services.

Several medications used in the management of IBD are classed as ‘Red, Amber or Green’ drugs and therefore require a shared care agreement between the initiating hospital service and the general practitioner (GP). This enables the patient to have appropriate local care on discharge from the hospital when they return home (NHS National Prescribing Centre (NPC) 2009). The concept of shared care is an aspect of the NHS plan for improving quality of life for people with long term conditions (DH, 2012b). Inconsistent communications between the two health care providers, as the researcher experienced within her patient cohort, can result in bloods being repeated. This increases costs and gives the patient a poor experience. There is increasing need for patients to have a blood monitoring records that can be shared by the patient with their health care providers – GP and specialist services. The NPC issued a five minute guide to shared care in 2009, with guidance on how to develop a shared care request and

shared care protocols before prescribing immunomodulators (i.e. Azathioprine and Mercaptopurine). However, the patient does not always have any kind of documentation to carry information between the two health care providers. The PIBDPHR has therefore got the potential to be incorporated as a consistent patient-held record for blood monitoring. The information leaflets contained within the PIBDPHR, as well as being useful and informative, could create national consistency for patients so wherever they are treated the team understands the information tool the patients are using. This need for improved consistency in patient care and the information given to patients is shown in the yearly IBDqip benchmarking tool (<http://www.ibdqip.co.uk>) that accompanies the national IBD audit (Fitzgerald et al 2013). There is a wealth of information on the website to help centres to meet the standards (e.g. age appropriate patient information leaflets), with the aim of bringing consistency to patient information.

PIBDPHR Format

There is some evidence that patients like to have new information given to them in paper format, Bernstein et al. (2011) found 75% of newly diagnosed adult patients would like to have a brochure or booklet with information on IBD and how to manage the condition. The PIBDPHR would therefore meet the needs of a vast majority of patients. However, as D'Auria and Kelly (2013) propose when presented with a diagnosis of IBD there are so many questions that it is inevitable that both patients and their parents will turn to the internet for support and answers. There is some question to the reliability of some websites that they may access (Benigeri & Pluye 2003).

The use of electronic resources helps patients to be more informed about their health (D'Auria & Kelly, 2013). The potential of electronic resources was also mentioned by all the nurses in the study who all embraced the concept of developing an English version mobile app; however, there was no consideration of the implications of implementing this information portal. There are increasing smartphone apps used in many different areas

of healthcare such as weight loss (Carter, Burley, Nykjaer, & Cade, 2013) and cancer services (Pandey, Hasan, Dubey & Sarangi, 2013), medication adherence (Dayer, Heldenbrand, Anderson, Gubbins, & Martin, 2013) which are shown to have some benefit to the patients such as increased compliance with treatment regimens (Carter et al., 2013).

Dennison, Morrison, Conway, and Yardley (2013) conducted a study identifying the challenges and opportunities in using smart phone applications; they highlighted many aspects that should be considered when developing an app. Within NHS trusts there are policies on how to use electronic tools in the delivery of health information. There are strict criteria to be met when developing electronic patient information (Alder Hey, 2007).

There are many aspects that need to be considered if developing a mobile app for the use of NHS patients. Confidentiality is a concern to patients (Dennison et al., 2013). What if the mobile phone was stolen with the patient's disease information stored on it? The loss or theft of the existing PIBDPHR could also result in information about the patient and their disease being available to people other than the patient and their family. While the PIBDPHR is trying to standardise information delivered to paediatric IBD patients any development of a mobile app should be consistent with the information in the PIBDPHR. This would ensure equity in information giving.

As identified by two nurses in the study the apps that are currently available for patients with IBD have been developed in North America and Canada. Therefore some of the names of medications they refer to are different to the medications used in the UK and Europe which can be confusing to patients. The apps related to IBD are mainly symptom trackers rather than apps which combine symptom tracking with information to educate the patients. If the PIBDPHR was adapted into a mobile app it would combine a combination of both types of information. If the aim of the PIBDPHR app is to encourage better disease management and empower the patient rather than parents/family, the app

should be simple to use and relevant to the patient (Hommel et al., 2013). There is evidence that using different information formats can improve the knowledge of adolescents as demonstrated by Boamah, Bohren, Pentiu, Baker, Yi, and Moyer (2010) who used a CD rom self-directed programme to improve adolescents' knowledge of their IBD. The PIBDPHR in its current form of a paper booklet is therefore a different format to the various websites and information leaflets that patients are given. Elkjaer, Shuhaibar, Burisch, Bailey, Scherfig, Laugesen, Avnstrom, Langholz, O'Morain, Lyng, & Munkholm (2010) found that a specific programme of e-learning with web site support resulted in all the patients that had this level of input taking better control of their ulcerative colitis when they had a relapse.

One of the benefits of the PIBDPHR, as identified by respondents, could also be seen as one of the problems. As the PIBDPHR has been developed by nurses it has been developed with a nursing focus and while the concept of this PHR is clear to the IBD nurses, it may not have been fully explained to the rest of the of the multi-disciplinary team (MDT) adequately. This may have an effect on the level of engagement from gastroenterology doctors. As the nurse specialist is an integral member of the MDT in managing patient care (Fitzgerald et al., 2012) they would be in a position to facilitate communication with the professional groups and patients if the PIBDPHR was more widely adopted. While the understanding of a concept by the whole team is integral to implementing it into practice and improving patient outcomes (Wensing, Wollersheim & Grol, 2006) the value of having a champion to drive forward change and implementation cannot be dismissed. Often in such circumstances the nurse embraces this role. As has previously been highlighted in the literature review, there are many examples of a PHR that is also a medical record (Ko et al., 2010). However, the concept behind the PHR according to Ko et al. (2010) is to "enable the continuity and quality of care". The PIBDPHR has not been developed to enable continuity and quality of care but to enhance patient understanding, therefore patients are in control of the content and dictate who looks at the tool. The PIBDPHR was not designed to be a partnership tool,

unless the patient wishes to invite professionals to utilize it. The data collected by patients should not be taken as if it were a medical record although it may give a good representation of the patient's thoughts and understanding of information that they have been given.

Barriers and resistance to the use of the PIBDPHR

The nurses encountered several barriers and challenges to integrating the PIBDPHR into their practice. This section will look at some of these incorporating the literature to analyse these barriers and challenges. Initially the resistance from the medical professionals which featured heavily in responses in both phases of the study will be looked at from two different perspectives of the skills required to deliver self-management and the potential differences between the medical and nursing aims and finally the difficulties within implementing new ideas.

There were many references to the challenges posed by introducing the PIBDPHR into practice and the resistance from other professionals. One of the main problems encountered appears to be related to differences in the perceptions of how patients should be cared for and how involved they should be in their own care. There has been increasing emphasis on patients with long term chronic conditions being more involved with their own care since the publication of the NHS plan (2000). Self-management is a model of care that focuses on educating and empowering patients and their families to manage a disease (Saibil et al, 2007). There are many reasons why this concept is a challenge. Robinson (2004), a gastroenterologist managing adult patients with IBD, identified that there may be a reluctance from clinicians to give control to their patients to change treatment strategies as this may also increase the need for urgent clinic appointments placing more pressure on clinics. Another barrier was identified by Fiks and Jimenez (2010) regarding the adequacy of clinicians' communication skills to enable patients and their families to undertake decision making, with the required emotional

support. The concept of self-management is starting to find its place in adult IBD but is less common in paediatric IBD, and as Cox, Smith, & Brown (2007) identified, families often have passive involvement in the care of their child.

There was a suggestion from some participants in this study that there was a lack of understanding of the role of the nurse from the perspective of the doctors within their MDT's. The lack of understanding in the roles of doctors and nurses undertake was highlighted back in 1975 by Hoekelman (1975) and continues today as demonstrated by Nurse 5's interaction with one of their consultants who did not understand that part of his/her nursing role was to educate patients. In 1991 Heenan found that nurses did not feel that doctors understood their work and more recently Ahmad (2011) recommended that doctors and nurses should learn more about each other's roles to improve care for their patients. Holyoake (2011) feels that the reluctance by doctors and nurses to understand each other's roles is part of the doctor-nurse game that was first identified by Stein (1967), where nursing is perceived as subservient to medicine, and Holyoake (2011) suggests that this still continues today. The reason for the division between nursing and medicine to persist may be related to the concept of 'clinical mindlines'. Clinical mindlines have been described by Gabbay & May (2004 p329) as:

“...collectively reinforced and internalised, tacit guidelines, which were informed by brief reading, but mainly by their interactions with each other and with opinion leaders, patients and pharmaceutical representatives and by other sources of largely tacit knowledge built on their early training and their own and their colleagues experiences”

This indicates that apparently outdated beliefs may subconsciously continue and therefore be difficult to change. It is therefore important to fully explain the concept of the PIBDPHR to all of the stakeholders to ensure that they are able to add it to their 'clinical mindlines'

Implementation

There were difficulties identified in implementing the PIBDPHR into every day practice. This cohort of paediatric nurses were all experienced paediatric IBD nurses specialists who all spend a large amount of time working with and have a good knowledge of their patients. Compared to a recent IBD nurse audit (RCN, 2012) they are generally more experienced than their colleagues who work with adult patients with IBD. However despite this expertise they faced challenges in the implementation of the PIBDPHR in this initial launch.

Implementation is an issue that is frequently seen in the literature and there are many different frameworks that have been developed to improve the implementation process (Wensing et al., 2006). Damschroder, Aron, Keith, Kirsh, Alexander, & Lowery (2009) developed a framework utilizing elements from many of the existing frameworks to devise the Consolidated Framework for Implementation Research (CFIR) (Appendix 5).

The CFIR consists of 5 components

1. Intervention characteristics
2. Outer setting
3. Inner setting
4. Characteristics of individuals
5. Process – Planning, engaging, executing, reflecting and evaluating

Although this is an American framework it has a resonance with UK practice, therefore the issues associated with the implementation of the PIBDPHR will be reviewed utilising the CFIR framework in the following discussion.

There was a suggestion that incorporating the PIBDPHR into a pathway may increase the acceptability of it into daily practice. There are several disease specific guidelines that have been published in the last few years (NICE: Crohn's Disease (CG152), 2012 and ulcerative colitis (CG166), 2013; ECCO-ESPGHaN Paediatric ulcerative colitis guidelines, 2012) that are in the process of being implemented. Pathways are often attached to new guidelines to try to assist in the acceptance and implementation of the

guideline (Turner et al 2012) bringing information into a more visual dimension such as National Institute of Clinical Excellence have introduced to accompany new guidelines (Nice Pathways 2011). Through adopting a multidisciplinary approach and pathway educational session, Deneckere, Euwema, Van Herck, Lodewijckx, Panella, Sermeus, & Vanhaecht (2010) demonstrated in their systematic review that pathways can lead to better teamwork and improve the care of patients, however to integrate the PIBDPHR into a national pathway will require a consultation process with all the stakeholders involved in paediatric inflammatory bowel disease. Including the PIBDPHR into a national pathway would give the PIBDPHR a level of quality and strength that, according to the CFIR, is the first step to implementation a new innovation. The evidence gained from this study and the previous stakeholder feedback will also give strength and a level of evidence to the use of the PIBDPHR. As has been shown in this study if there is no engagement from the rest of the MDT it is very difficult to make changes to an established patient journey.

There were several concerns regarding the amount of information and teaching that would be required to fully implement the PIBDPHR into daily practice for both the extended multidisciplinary team and the patient and family. As with any new innovation, there needs to be a teaching programme established (Kypsen, Nifong & Chitwood, 2004) for anyone coming into regular contact with the PIBDPHR. This will have an impact on the often scarce resource of time. However, without the whole of the MDT having adequate education there will be very little chance of the PIBDPHR becoming an established tool in the care of children with IBD (Damschroder et al., 2009). Although there are some reservations, from two of the nurses in the study, that patients will receive too much information too soon in their disease process with the introduction of the PIBDPHR, the information needs of patients and families are often underestimated and they utilize many different forms of information to supplement the information given to them by health professionals (D'Auria & Kelly, 2013). The PIBDPHR has been designed to allow the booklet to be personalised for the patient's needs by the nurse

who is introducing it to the patient; the use of a ring binder folder should enable the nurse to introduce information as the patient requires. This is an important component of the PIBDPHR, because, as Day et al. (2005) identified, patients and parents feel the need for on-going education from their health care professionals after initial diagnosis. Boamah et al. (2010) found that most adolescents have a low level of education regarding their IBD therefore any concerns regarding giving patients too much information in the PIBDPHR should be seen with this existing lack of information in mind. A more balanced approach to information given to the patient and their family at the appropriate time for them could be supported by the conscientious use of the PIBDPHR. Generally the PIBDPHR initially generated interest from members of the MDT and they were very enthusiastic about them being used. However, when it actually came to the implementation stage, the interest in them appeared to have waned and the momentum lapsed over a period of time. Lecouturier (2002) reported that they also found in their pilot study of a medical PHR that because it was not being used routinely in all patients, the interest in it reduced and it was not regularly used in consultations. These are concerns that sit within both the inner and outer settings of the CFIR framework which Damschroder et al. (2009) has acknowledged can happen (see Appendix 4).

The next step in the implementation process is considering the individuals involved (Damschroder et al., 2009). Unfortunately data were not gathered to understand whether the nurses in this study were working solely with IBD patients, working with IBD patients as part of a gastroenterology role with time allocated to IBD or as part of a team of nurses looking after the IBD patients. Therefore it was not possible to know if some of the challenges or barriers were related to pressures of workload or differences within the nursing team philosophy. All of the nurses were experienced in managing PIBD however their self-efficacy and position within their respective MDT's may be different creating a wide variety of levels of influence they have on implementing new processes (Edwards 2011; RCN 2012).

The final step in the implementation process according to the CFIR is the process of initiating the innovation into practice (Damschroder et al, 2009). There was only one reference to the process of the implementation of the PIBDPHR from the nurses in the study. This could indicate that generally the nurses thought the process of introducing and planning the introduction of the PIBDPHR was good, they had not considered that there should be a process of implementation or the questions asked did not generate these responses.

As has been shown there are many parts to the process that could have been improved upon. From the researcher's experience there was little consideration given to the implementation process when the PIBDPHR was introduced into practice. This may have contributed to the lack of engagement seen from other members of the MDT.

Reflections

There are some elements of reflexivity presented through the thesis. However, the researcher found it useful to reflect on the dissertation as a whole and these reflections will now be described in relation to each chapter of the dissertation.

Literature search

Despite all of the previous work that has been done on the PIBDPHR a literature review has not previously been published. I initially thought that there would be significant amounts of research as I was personally aware of PHRs being used in many different settings. I had copies of similar documents from adult IBD services and paediatric cancer services. Therefore it came as a shock when nothing came back from the initial searches. Although there was a plethora of literature related to medical patient held records, it was often difficult to decipher how the record was actually used. I then questioned how something that was being used so widely had no substantial evidence base. As a practitioner who tends to do reflection-in-practice more than reflection-on-

practice, this made me think and worry about how other aspects of my practice might be based on a flimsy evidence base. However, as I continued to think about this, I became even more determined to contribute to the literature through my research.

I felt I approached this study with a reasonably strong understanding of searching the literature however although some of my experience was useful I found I was on a steep learning curve. Although I had previous experience in using a critical appraisal tool I had only used it to prepare presentations for a journal club and had not really considered the structure involved or why it was being used. The main rationale for its use in journal club was to give structure to the actual presentation. However, using a structured critical appraisal tool helped me to sift through the potential articles more quickly than without it. Initially I found it difficult to keep to this structured approach, but my skills developed as I worked through more articles, as my initial anxiety reduced and my confidence increased it then became much easier to use a structured approach. Through undertaking the literature review I found myself becoming more conversant with different research methods and processes, and gaining more insight into different data collection and sampling methods. One of the benefits of learning the skill of critical appraisal has been adopting its use into my clinical practice. For example, when I am preparing a presentation I now ensure that the articles I use are of a high calibre; if they are flawed in some way then I highlight this to the audience and also when reviewing new research papers before adopting new practices.

Methods

One of the challenges I faced was undertaking interviews with people I knew quite well as colleagues and/or friends. A number of different strategies were put in place to ensure that this did not unduly influence the data. One of these strategies was the development of a fairly structured approach to doing the interviews. However, despite this, the interviews were interactive, engaging, flexible and in-depth. The decision to use such a

structured plan was made to provide support to me as a novice researcher. I felt this was essential in this study, as the participants are all known to me as either friends or colleagues. I was aware that I may find it difficult to keep both myself and my participants focused. During the interviews, having a guide enabled me to bring the discussion back to the questions when the focus of the participant veered away from the interview question. An example of this occurred during the interview with one participant who turned her response to question seven into a clinical question that she required help with, I explained

“Although this is a valid question that I can definitely help you with could we leave it until we finish the interview, we have done really well getting this far without veering off course, other interviews have got diverted before this! As you can see (showed the interview guide) there are only another couple of questions to finish, let’s write that down so we don’t forget it once we have finished the interview.”

My immediate response was to support my colleague and help with her problem but having the interview guide enabled me to focus the interview again without disregarding the participant’s question and allowed the interview to restart with both parties focused on generating relevant information regarding the PIBDPHR from the participant. Reflecting after the interview on how it felt to defer a clinical question, I initially found it uncomfortable. However, after considering the participant’s positive response I found I had acquired a useful skill that I used during subsequent interviews. This has also helped me when I am chairing meetings to bring discussions back to the agenda allocating time after to discuss important issues that are highlighted but not relevant to the agenda item.

Results

During the interviews I found it difficult not to intervene with some statements and bring my interpretation of the difficulties that the participants had with both, their own and their

colleagues perceptions of time required to implement the PIBDPHR into practice. One respondent who stated that doctors believed '...it is seen as something the nurses will use and it's not something I would use as it is too time consuming to fill in' did acknowledge that there should have been better communication with the MDT when they were introducing the PIBDPHR into their service. My own experience was that the PIBDPHR was a MDT service innovation and that all staff looking after children in my practice setting were involved in using the tool in clinic. This may have been because I developed the initial tool myself with the involvement of our MDT so there was a more personal connection. We had also unknowingly used an implementation process to establish it into our service which followed the process as outlined by Damschroder et al. (2009). There seemed to be a perception that as the PIBDPHR was devised by nurses that nurses had to be responsible for its continued use. This view was quite frustrating because I have the minutes from a meeting where we had discussed this issue and therefore did not expect the participants to have this belief. On reflection I feel that I should have added more interrogative questions, into both phases of the study, such as 'how did you introduce the tool to your team' to aid better understanding of these issues. However, this is one of the constraints of using an interview guide and being a novice interviewer; I did not feel able to start adding in questions after completing two interviews. I also thought I would remember to use different prompts and probes in the interviews but on reflection, I was very nervous about getting the interviews right and followed my guide very closely, so I do not think that I did use them often enough. In future research I will probably use an interview guide again but include different prompts and use it much more as a guide rather than a schedule that needs to be closely followed.

I had considered that as I undertake patient consultations on a regular basis research interviewing would not be too different; in practice and on reflection, it was very different as acknowledged by Hunt, Chan & Mehta (2011). The pressure to try to get as much information out of a question to generate data in a consistent fashion is different to

assessing a patient. When assessing patients you also ask the same generic questions but the consultation is adapted to the responses of the patient, there does not need to be any consistency of information gathered as the aim is to assess the patient as an individual and not evaluate the data that is generated during the clinic. This can be a difficult switch for health care practitioners as they migrate from a clinical world to a research world (Doody & Noonan, 2013).

Discussion

I found undertaking a study looking at the PIBDPHR - 'my baby' - with such scrutiny very difficult at times. I was and remain passionate about the need for the use of PIBDPHRs to support children and their families and this passionate belief had to be tempered during the study. Trying to acknowledge and accept criticisms of the tool and to examine these in a clear manner was not always easy. Sometimes I was frustrated by some of the reasons the nurses have for the problems experienced with the use of the PIBDPHRs as I felt that they could have been reasonably easily solved.

The lack of passion for the PIBDPHR in some people was also challenging. As the group of nurses that were invited to participate in the study knew me, it may have influenced on the low number of respondents who volunteered for Phase 2. I initially found the low number of respondents and the apparent lack of interest personally and professionally upsetting. The study was on the agenda of the BSPGHaN/RCN Paediatric IBD Nurses group meetings and also on the minutes of the meeting. I have considered why there was a low response rate and identified that during the data collection phase there were many issues going on for specialist nurses such as having to spend time on the ward, this resulted in many paediatric IBD nurses becoming demotivated and attendance to the group meetings was declining rapidly. The issue of the PIBDPHR was not high on most people's radar at that point and I did not want to be seen to be too pushy and overly

forceful in getting responses. However on reflection I now recognise that I may not have been as proactive as I could or should have been in recruiting participants for the study. I have also reflected on the fact that my MSc was one of the first undertaken within this group of nurses and there was little recognition of the importance of supporting each other. This experience has made me more proactive and supportive of other colleagues requesting the input of the group in studies and surveys resulting in much higher response rates for the last three surveys circulated by colleagues. There is also an increased response to general questions that are circulated. I have considered whether this general increase in group interaction would make a difference to the response rate if I was to undertake my data collection now. However I think that it would probably be the same as many of the nurses that used the PIBDPHR have left their posts. However there is interest in the project from new members of the group which is very encouraging for the future of 'my baby'.

Limitations

This is a small study with only 23% (6/26) of the initial users of the PIBDPHR participating in Phase 2 of the study despite 46% (12/26) responding to Phase 1. This meant that the proposed selection of participants for Phase 2 was changed to accommodate the reduced number of respondents for Phase 2. The researcher then did not feel able to reject any of the respondents despite one of them not actually using the PIBDPHR. It should also be noted that 19% (5/26) of the nurses who had used the PIBDPHR were no longer in post and therefore were not invited to participate in the study.

The researcher is well known to the participants and this may have had an influence on the number of participants who were willing to be involved in the research due to concerns of 'upsetting' the researcher with their views. This aspect was not considered prior to the study being undertaken by the novice researcher who considered that as this follow up was agreed at the launch of the PIBDPHR that all those involved would participate. The researcher was concerned that if she actively pursued nurses to

participate it may affect the results, on reflection this somewhat 'hands-off' approach may have contributed to the low participation rate in Phase 2.

The survey and interviews took place during a period that was very busy for clinical staff across the NHS, as was evident in the researcher's own practice setting which experienced considerable unpreventable workload pressures.

As the researcher is fairly new to research they were learning and acquiring research skills as they went which has meant that, on reflection, the survey design and undertaking of interviews could potentially have been improved.

Although the study design was followed there was overlap between the survey questions and the interview questions and although this was intentional this may have constrained the breadth of data collected. The opportunity to delve deeper into participants' responses in Phase 2 was not fully utilised due to the narrow range of questions.

The patients', parents' and healthcare workers' views of using the PIBDPHR were not sought in this study due to the time limitations associated with undertaking a part-time MSc and the researcher's clinical workload. The views of these stakeholders would add to the depth of understanding that has been gained through this research.

Recommendations

Based on the findings of the study, the following recommendations are presented:

1. The BSPGHaN/RCN IBD nurses group should reconvene the subgroup involved in developing the PIBDPHR to enable a full review. The review should be carried out using an implementation framework such as the Consolidated Framework for Implementation Research (Damschroder et al. 2009) to give a structure to the review.
2. The PIBDPHR should be reviewed to ensure that it remains compatible with current treatment recommendations following a plethora of recent publication of

national and international guidelines that have been published since the last revision of the PIBDPHR.

3. There should be an opportunity for all stakeholders to be involved in the review process to ensure that it is relevant not only to health care professionals but also to patients. There needs to be consideration on how to initiate patient focus groups with attention to costs for holding meetings.
4. Consideration should be given throughout the review period as to how the PIBDPHR could be integrated into a national pathway and the process to enable this to happen.
5. Any development towards a mobile app needs to consider who would ensure that the content of the app was maintained, to ensure that there was accurate, up to date information with relevance to the users.

6. Conclusion

This study has reviewed the literature surrounding patient held records and identified the differences between different types of patient held record which can be used for medical or personal information and used in a variety of ways with the two most common uses being to enhancing communication between the patient and health professionals and for educational or self-management support. The paediatric IBD nurses' experiences of using the PIBDPHR in current practice was evaluated and found to be useful in a variety of situations. The PIBDPHR was being used to: support transition from child to adult services; for patients with complex disease management; for patients who needed more education and with newly diagnosed patients. All of the nurses who had used the PIBDPHR felt that it has a place in paediatric IBD, including the nurse who rated it as a bad experience. There was not one particular way that the PIBDPHR was used but it was seen as an additional element to encourage patients/parents involvement in their condition.

However, it has become apparent that to be a success the PIBDPHR needs to be properly implemented with the consensus of all of the stakeholders who will come into contact with it. The current format also needs to be considered and patient/parent focus groups have been suggested as a way to gauge what the actual users would like.

The PIBDPHR has been found to assist with the transition process; although long term use of the tool was questioned. There has previously been interest in the PIBDPHR from adult colleagues who also felt it could be useful in transition. However this study has not really added to this assumption as the nurses in adult settings who took over the care of the transition patients were not included in this study.

Further research needs to be carried out to investigate the patient perception of using the PIBDPHR; however this would need to follow a re-launch to get the newer PIBD nurses involved and using the PIBDPHR.

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8. Appendices

Appendix 1

Example of how critical analysis of the literature was undertaken.

Critical Analysis
Dijkstra, R. F., Braspenning, J. C. C., Huijsmans, Z., Akkermans, R. P., van Ballegooye, E., ten Have, P., Casparie, T & Grol, R. P. T. M. (2005). Introduction of diabetes passports involving both patients and professionals to improve hospital outpatient diabetes care. <i>Diabetes Research and Clinical Practice</i> , 68(2), 126-134.

	Yes	No	Can't tell
(A) Are the results of the study valid?	X		
1. Did the study address a clearly focused issue?	X		
<ul style="list-style-type: none"> The goal of the research was to see if the introduction of a diabetes passport involving both patients and health care professionals improved the diabetes care of the patients. The researcher recognised the lack of random controlled trials looking at the use of patient held record in diabetes. The results of previous studies were variable as to the utility of the patient held record. It is relevant to my study because the passport gives general information about the disease and how to manage it, there is also a section for the patient to record personal information relevant to their disease – goals and results. 			
2. Was the assignment of patients to treatments randomised?	X		
<ul style="list-style-type: none"> Nine hospitals were recruited to be randomly allocated to introducing the intervention (diabetes passport) or control hospitals where standard treatment was continued. Randomisation was carried out by someone outside of the research group once the preintervention measurements had been carried out. By randomising the hospitals and inviting 150 consecutive newly diagnosed patients from each hospital to enter the study, ensured that the PHR was able to become part of the usual routine for the patients at that particular hospital. The randomisation was concealed from the researchers until the hospitals started to use the intervention. This is therefore a very acceptable way to recruit to assess a new intervention. To make it part of the hospital standard practice ensures that the whole team are using the intervention. 			
3. Were all of the patients who entered the trial properly accounted for at its conclusion?	X		
<ul style="list-style-type: none"> All of the patients were accounted for at the conclusion of the trial. The study questionnaire was conducted at the predefined time of pre study and 1 year and baseline data was repeated at 1 year. The data were analysed by intervention group versus control group. Pre and post intervention data were analysed for each group. 			

Is it worth continuing?	X		
4. Were patients, health workers and study personnel 'blind' to treatment?	X		
<ul style="list-style-type: none"> All were blind until the first patients were recruited at the hospital. Patients were blind because they had never had any other intervention aside from standard care and were introduced to the intervention at their first appointment after the trial started. 			
5. Were the groups similar at the start of the trial?	X		
<ul style="list-style-type: none"> There were no major differences between the two groups at the start of the trial. 			
6. Aside from the experimental intervention, were the groups treated equally?	X		
<ul style="list-style-type: none"> The groups were treated as per the Dutch national guidelines for management of diabetes which were updated during the trial period and disseminated to all hospitals in the Netherlands. 			
(B) What are the results?			
7. How large was the treatment effect?			
<ul style="list-style-type: none"> The main treatment outcomes were related to the effect measures taken from the evidence based Dutch guidelines on the treatment of diabetes and prevention of complications. The primary outcome measure of HbA1C showed a 0.3% improvement in the intervention group, in the control group it had deteriorated by 0.2%. Improvements in the treatment group were also seen in the number of patients who had their feet examined and were given advice on physical exercise and smoking. 			
8. How precise was the estimate of the treatment effect?			
<ul style="list-style-type: none"> The odds ratios were presented with confidence limit of 95% There was a p-value of <0.001 between the intervention group and the control group. 			
(C) Will the results help locally?			
9. Can the results be applied in your context? (or to the local population?)	X		
<ul style="list-style-type: none"> The results could be applied indirectly to the PIBDPHR, even though the parameters that are monitored in paediatric IBD are different and the personal behaviours of patients do not have such a direct relationship on the disease activity i.e. physical exercise. The discussion highlights some of the difficulties encountered in implementing a new intervention that have also been identified in the PIBDPHR study such as perceived lack of time by professionals to support the patient to use the passport. The results from this study concur with other intervention studies in diabetes which have shown that there is more impact on process outcomes i.e. information giving than on outcome measurements i.e. HbA1C 			
10. Were all clinically important issues considered?	X		
<ul style="list-style-type: none"> The study appears to have identified the main concerns in diabetes care and targeted the changes in them following the patients' use of the diabetes passport. I do not have sufficient knowledge of diabetes care to know whether there are other outcome measures that could have been considered. 			

Appendix 2

Participant Email Invitation to Study and Information Sheet

Dear

I would like to take this opportunity to invite you to participate in a study I am undertaking as part of my MSc. The study is called:

An Evaluation of Paediatric IBD Nurses' Experiences of Using the Paediatric Inflammatory Bowel Disease Patient Held Record (PIBDPHR) in Clinical Practice

You requested copies of the PIBDPHR when they went live in March (2012) and, as was discussed at that point, it is important to continue to evaluate them and their effectiveness. This study has been divided into two Phases. Phase 1 is being sent to all of the nurses who requested copies of the PIBDPHR, with Phase 2 participants being self identified by nurses who would like to continue to be involved in the study.

Phase 1 of this study will entail completion of an online survey to gain basic information about the use of the PIBDPHR. It is entirely anonymous (unless you release your contact details at the end of the survey) and consists of three sections. Section 1 focuses on demographic information about the different services. Section 2 focuses on the use of the PIBDPHRs in the clinical environment. Section 3 concentrates on any problems/benefits that you may have encountered. At the end of the survey you will be asked if you would like to participate in Phase 2. If you agree to this you will be required to give your contact details and therefore the survey will become identifiable. Due to the limits of this study there will be a limited number of people contacted to be involved in Phase 2. The exact method of selection will not be fully identified until the data from Phase 1 have undergone initial analysis.

Phase 2 will entail a one to one interview to discuss your responses in more detail and to gain a more in depth understanding of how the PIBDPHR is being used in your clinical practice. The researcher will arrange the interviews directly with each selected participant. The location of the interviews will be either at a location appropriate for both the participant and the interviewer or via telephone. All interviews will be audio-recorded (with the participant's permission) or notes will be taken to enable an accurate representation of the participant's views.

There is no obligation to participate in this study and you can withdraw from the study at any point. If you do not wish to take part, simply do not click the link to the survey. If after commencing the survey, you decide that you no longer want to be involved then simply exit the survey and do not save the previously entered data.

If after completing the survey, you do not want to participate in Phase 2 then do not proceed to the consenting process.

You can withdraw from Phase 2 at any point with no reason, please contact me by email to inform me and to cancel our appointment. If it is during or after the interview please inform me and I will terminate the interview and destroy any recordings that have been made.

If you would like to discuss the study in more detail then please contact Kay Crook at Kay.Crook@alderhey.nhs.uk or on 07903500826

If you would like to participate then please click on this link.....

Thank you

Kay

Appendix 3

Email Survey

Nurses experiences of using the Paediatric Inflammatory Bowel Disease

Nurses experiences of using the Paediatric IBD Patient Held Record in clini...

You have been invited to join in Phase 1 of a study that has been designed to evaluate the PIBDPHR to gain a deeper understanding of its effectiveness within clinical practice. As you requested copies of the PIBDPHR for use in your service we would like your thoughts.

We would be grateful for your comments and honest opinions to help us to evolve the PIBDPHR and build a body of knowledge on this subject.

There will also be an opportunity at the end of the survey for you to participate in Phase 2 where your experiences will be discussed in more detail in an interview.

Nurses experiences of using the Paediatric Inflammatory Bowel Disease

Demographics

The information from this part of the survey provides some very brief information about your experience and some key information about your service. This information will help us to understand if there are any similarities between services and outcomes.

1. About how long have you been in your current position?

Years	<input type="text"/>
Months	<input type="text"/>

2. Approximately how many hours do you spend on IBD related work a week?

*3. Approximately how many patients with Inflammatory Bowel Disease do you have in your service?

4. How many PIBDPHR did you.....

	1-5	6-10	11-15	16-20
request?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
actually use in practice?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Nurses experiences of using the Paediatric Inflammatory Bowel Disease

Clinical Use

The next 4 questions will enable us to understand how you have used the PIBDPHR in practice to understand if there are a variety of ways they can be utilized.

5. In what group of patients have you used the PIBDPHR?

	All	Some	None
New patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patients with difficult to manage disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
As an education tool	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

6. Has the PIBDPHR had any effect on local practice?

	Yes	No	Dont Know
Patient relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient education	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient independence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Improved drug monitoring	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parental understanding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parental education	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)Comments

7. Who has used the PIBDPHR

- Patients (under 9)
- Patients (9-11)
- Patients (12-14)
- Patients (15-17)
- Parents
- Multidisciplinary team
- IBD Nurse

Other (please specify)

Nurses experiences of using the Paediatric Inflammatory Bowel Disease

8. Did the number allocated influence your usage?

Yes

No

Comments

Nurses experiences of using the Paediatric Inflammatory Bowel Disease

Challenges/ Benefits/Solutions

The next 3 questions focus on any problems that you have encountered and how you have overcome them (or not)

9. Have there been any challenges/barriers to implementing the use of the PIBDPHR?

Yes

No

If Yes please explain further

10. What has your experience been of using the PIBDPHR?

Very Good

Good

Fair

Bad

Very Bad

Any comments

11. In an ideal world how many PIBDPHR's would you require?

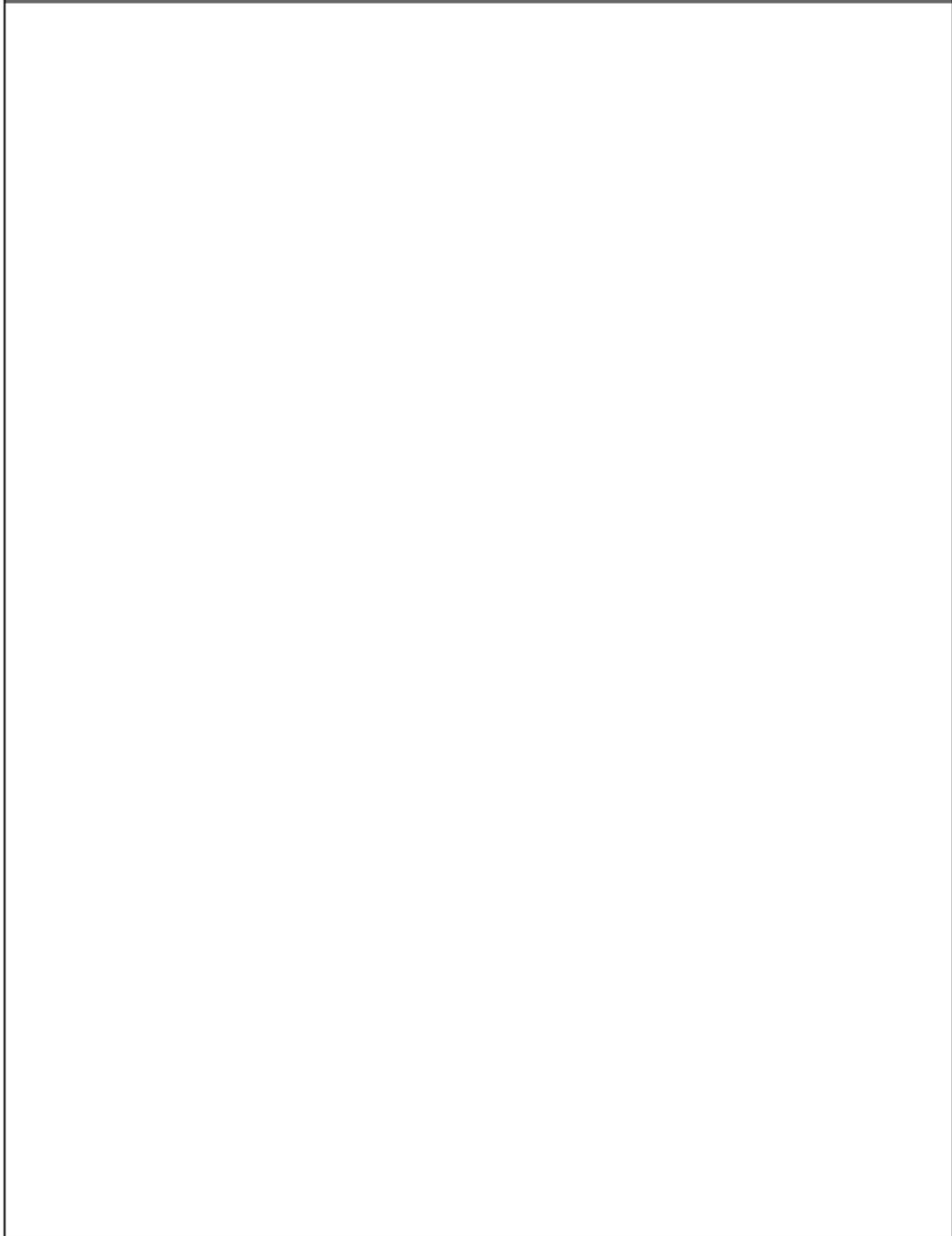
Initially

Yearly

12. Do you have any further comments on the PIBDPHR?

Nurses experiences of using the Paediatric Inflammatory Bowel Disease

Thank you for completing Phase 1 of this study



Nurses experiences of using the Paediatric Inflammatory Bowel Disease

Phase 2 information

Please read the following information regarding participation in Phase 2 of this study.

Phase 2 will entail a 1:1 interview to discuss your responses in more detail to gain a more in-depth understanding of how the PIBDPHR is being used in your clinical practice. The location of the interview will be arranged directly with you at an appropriate location for you or via telephone. The interview will be audio recorded and notes taken to enable an accurate representation of your views.

Nurses experiences of using the Paediatric Inflammatory Bowel Disease

Consent to be contacted

I am willing to be considered as a participant in Phase 2 of the study called Nurses' Experiences of Using the PIBDPHR. I understand that not all people who offer to take part will be selected to take part. I understand that by completing the online contact details I may be contacted to participate in Phase 2 of the study and that if I am not selected the researcher will inform me of this and they will destroy the form.
Prior to the interview taking place the researcher will go through the patient information sheet and then take written consent.

13. Please give your name and contact details

Name	<input type="text"/>
Email address	<input type="text"/>
Contact Number	<input type="text"/>

Appendix 4

Phase 2 Interview questions

The interview will take place with the participant's survey responses for reference and the questions are based on the participant's responses to the survey questions.

1. You requested copies of the PIBDPHR why did you actually use.....?
2. What influenced this use?
3. Can you explain your rationale for selecting specific patient populations
4. Can you explain in more detail the effects of the PIBDPHR on your local practice
5. Did this meet your initial expectations? If not why not
6. You say you would/wouldn't change your selection criteria if you had as many PIBDPHR's why?
7. You have said there were barriers/challenges to implementing the PIBDPHR can you discuss these further and any solutions that you found to overcome them.
8. You rated the PIBDPHR asdo you have /could we discuss any comments or suggestions on how to improve the PIBDPHR
9. Do you have any other comments?

Appendix 5

CFIR Constructs

Intervention Characteristics

Intervention Source
Evidence Strength & Quality
Relative Advantage
Adaptability
Triability
Complexity
Design Quality & Packaging
Cost

Outer Setting

Patient Needs & Resources
Cosmopolitanism
Peer Pressure
External Policies & Incentives

Inner Setting

Structural Characteristics
Networks & Communications
Culture
Implementation Climate
Tension for Change
Compatibility
Relative Priority
Organizational Incentives & Rewards
Goals & Feedback
Learning Climate
Readiness for Implementation
Leadership Engagement
Available Resources
Access to Knowledge & Information

Characteristics of Individuals

Knowledge & Beliefs about the Intervention
Self-efficacy
Individual Stage of Change
Individual Identification with Organization
Other Personal Attributes

Process

Planning
Engaging
Opinion Leaders
Formally Appointed Internal Implementation Leaders
Champions
External Change Agents
Executing
Reflecting & Evaluating

Adapted from Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: A consolidated framework for advancing implementation science. *Implementation Science: IS*, 4, 50-50. doi:10.1186/1748-5908-4-50