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TITLE:

Collaborating with parents of children with chronic conditions and professionals to design, develop and pre-pilot PLAnT (the Parent Learning Needs and Preferences Assessment Tool)

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Abstract:

Purpose: This study aimed to design, develop and pre-pilot an assessment tool (PLAnT) to identify parents' learning needs and preferences when carrying out home-based clinical care for their child with a chronic condition.

Design and methods: A mixed methods, two-phased design was used. Phase 1: A total of 10 parents/carers and 13 professionals from six UK's children's kidney units participated in qualitative interviews. Interview data were used to develop the PLAnT. Eight of these participants subsequently took part in an online survey to refine the PLAnT. Phase 2: Thirteen parents were paired with one of nine professionals to undertake a pre-pilot evaluation of PLAnT. Data were analyzed using the Framework approach.

Results: A key emergent theme **Identifying parents' learning needs and preferences** was identified. The importance of professionals being aware of parents' learning needs and preferences was recognised. Participants discussed how parents' learning needs and preferences should be identified, including: the **purpose** for doing this, the **process** for doing this, and what would the **outcome** be of identifying parents' needs.

Conclusions: The evidence suggests that asking parents directly about their learning needs and preferences may be the most reliable way for professionals to ascertain how to support individual parents' learning when sharing management of their child's chronic condition.

Practice implications: With the increasing emphasis on parent-professional shared management of childhood chronic conditions, professionals can be guided by PLAnT in their assessment of parents' learning needs and preferences, based on identified barriers and facilitators to parental learning.

Keywords: child; parent; long-term; chronic illness; information; healthcare professionals

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CONFLICT OF INTERESTS

The last author, Professor Veronica Swallow, is a member of the JPN Editorial Board but neither of the other authors have any competing interests.

BACKGROUND:

Some parents of children and young people (children) with chronic/long-term conditions (chronic) readily accept the clinical care-giving role, and adapt to it by developing competent management styles that minimise the intrusiveness of conditions. However, other parents experience difficulties, and the condition remains an unwelcome focus of family life (Drotar, 2000; Knafl & Gilliss, 2002; V Swallow, Lambert, Clarke, Campbell, & Jacoby, 2008). The concept of health literacy helps to explain how health-care professionals (professionals) can empower parents to act appropriately in new and changing health-related circumstances through the use of advanced cognitive and social skills. Health literacy includes reading and numeracy skills, comprehension, the capacity to use information in health care decision-making, and successfully communicate with professionals. Optimum health literacy for parents of children with chronic conditions can potentially increase their health knowledge, reduce use of health care services and lead to them feeling more empowered (Speros, 2005).

There is also emerging evidence that from early in the trajectory, some parents are reluctant to acknowledge any learning or comprehension difficulties in case professionals judge them to be incompetent. Moreover, some parents find the relentless requirements of home-based clinical care-giving difficult to maintain (Macfadyen, Swallow, Santacroce, & Lambert, 2011; V Swallow et al., 2008; V. M. Swallow & Jacoby, 2001).

Often isolated and overwhelmed, parents may look to professionals for help with care, while professionals often fulfil a parent-educative role as well as meeting the child's clinical needs (Coffey, 2006). Studies of chronic disease management acknowledge the 'work' associated with parental care giving (Hexem, Bosk, & Feudtner, 2011), the ways families adjust (Aldridge, 2008), and the fact that fathers and mothers may have differing support needs (Sullivan-Bolyai, Rosenberg, & Bayard, 2006; V Swallow, Lambert, Santacroce, & Macfadyen, 2011; V. Swallow, Macfadyen, Santacroce, & Lambert, 2012). However, there is little research evidence on the ways parents actually learn to take responsibility for and deliver clinical care at home.

Parents increasingly "perform the vast majority of care-giving, including tasks that are complex and demanding" (DOH, 2006, p.13). If parents are unsure about aspects of care-giving they may not adhere to treatment regimens or may fail to recognise subtle clinical changes in their child (Coulthard & Crosier, 2002; Divertie, 2002), negative outcomes may occur. All of these carry significant emotional, physical and financial costs for families

(Drotar, 2000; V Swallow et al., 2008), and have financial implications for health services (DOH, 2006).

Delivery of high quality care for children with chronic conditions such as chronic kidney disease (CKD) (BRS, 2002; CMO, 2012) requires the sharing of skills and knowledge between multi-disciplinary teams (MDTs) and parents. Furthermore, parents need access to accurate and accessible information in order to make informed decisions in partnership with clinicians, and an agreed care plan that promotes the child's best possible quality of life (DOH, 2006).

Communication between parents and professionals is essential when parents of children with chronic conditions are learning to share expertise about clinical care; however, limited evidence exists on how they actually communicate. In previous qualitative research, with a convenience sample of 112 professionals within 12 of the 13 UK children's Kidney Units (clinical-psychologists, dietitians, doctors, nurses, pharmacists, play-workers, therapists and social-workers), exploring accounts of their parent-educative activity, a group including one of the current authors described the way expertise was distributed within and across teams (Swallow et al, 2014). Two different professional identifications also co-existed within MDTs, with participants using the term 'we' both as the intra-professional 'we' (relating to the professional identity) when describing expertise within a disciplinary group and the inter-professional 'we' (a 'team-identification'), when discussing expertise within the team. We concluded that the dual identifications implicit in 'being professional' in this context (to the team and to one's profession) as well as each person's unique role, contributes to children's care.

Next, in a focussed ethnographic study involving parents of six children with CKD, and 28 professionals at two tertiary, children's hospital-based units we identified two dimensions of parental expertise around their child (personal and clinical). Parents' and professionals' expertise about the child and their condition was acknowledged and exchanged as parents learned to share clinical-care with the MDT. Professionals acknowledged parents' need to understand aspects of each of the eight disciplinary knowledge bases (clinical-psychologists, dietitians, doctors, nurses, pharmacists, play-workers, social-workers and therapists), relating to the child's management; these professionals also recognised parents' expert knowledge of their child and wove parents' expertise into the management plan. Parents spoke of how their own expert knowledge of their child complemented professionals' clinical knowledge. However, there was ambivalence around expertise and this was evident as parents and professionals questioned what the expertise was, and who the actual expert was (Swallow et al., 2013).

The current emphasis on evidence-based health-care means that a robust, well developed and evaluated intervention is needed to help MDTs support parents to learn home-based clinical care (MRC, 2008). The study reported here, therefore, comprises the initial design, development and pre-pilot phase of the Medical Research Council complex interventions framework. As a precursor to this current study we also undertook a systematic review of the literature to (1) identify parents' learning needs and preferences when sharing the management of their child's chronic condition and (2) inform professional support provided to parents across the trajectory. In summary, 23 studies were reviewed and three themes emerged: (1) parents' learning needs and preferences (2) facilitators to parents' learning, and (3) barriers to parents' learning. The review, which is reported elsewhere (Nightingale, Friedl, & Swallow, 2015), concluded that asking parents directly about their learning needs and preferences may be the most reliable way for professionals to ascertain how to support them when sharing management of their child's chronic condition. However, no validated intervention exists for professionals to use when assessing parents' learning

needs and preferences in this context. Therefore, we used the evidence to inform the design and delivery of the study reported here.

METHODS:

Research design

A two phased study using an exploratory, mixed methods approach.

Research aim and objectives

The aim was to design, develop and pilot The Parent Learning Needs and Preferences Assessment Tool (PLAnT). The PLAnT would be a resource used by professionals to ascertain how to support parents' as they learn to share management of their child's chronic condition. The objectives were to:

1. Determine items for inclusion in PLAnT and the response format to be used.
2. Identify methodological issues associated with pre-piloting and future development of PLAnT.

Research context and participants

It was important to achieve maximum sampling variation and so having 11 of the 13 UK children's kidney units participate helped us to realise this aim. Our goal was to recruit a range of the renal disciplines, and parents from both English and South Asian backgrounds. We were able to recruit some parents from South Asian backgrounds; however, we were unsure why we were not able to recruit as many as we had aimed for. Local Principal Investigators (PIs) tended to identify parents whose child had been known to the team for several years, rather than parents of newly referred children; this may have been a result of PIs not wanting to 'burden' parents whose child was recently diagnosed and/or preferring to approach parents they had established relationships with. This pattern of having more 'experienced' participants was reflected in the professional sample also, especially as some disciplines (e.g. dietitians) are more likely to only employ professionals with significant experience to work in renal MDTs.

Phase 1: Initial design, development and refinement of PLAnT

To address objective 1 we established a virtual development group to identify potential PLAnT components. The group comprised members of the renal MDT, parents whose first language is English, and parents whose first language is not English. Data were collected via focus group and individual interviews.

Seven parents/carers were initially asked to discuss their experiences of obtaining information and learning to care for their child's condition and nine professionals discussed their role in this process. Participants were invited to suggest items for inclusion in PLAnT. This information was used to develop PLAnT v1, i.e. a list of questions to determine parents' learning needs and preferences.

When developing PLAnT, it was important for the items to reliably operationalise the key concepts identified in the literature and be relevant and acceptable to the target group. This helps ensure that parents and professionals share underlying assumptions about the language used in PLAnT, and that they interpret statement wording in a similar manner. Items and questions were included for their potential to assess typically important aspects of parents' learning needs/preferences and required the parent to respond to a series of questions, prompts or statements (Hertzog, 2008; Rattray & Jones, 2007). We also considered the order in which items were presented. For example, controversial or emotive

items were avoided at the beginning of PLaNT, while a combination of positively and negatively worded items were generated in an effort to minimize the possibility of acquiescent response bias. We avoided leading questions and those that include double negatives.

A further seven participants, (three parents and four professionals) were interviewed about their experiences of learning and teaching and asked to comment on PLaNT v1. This iterative process meant that developing and refining PLaNT was a collaborative activity. In total, ten parents/carers and 13 professionals from six of the UK's children's kidney units participated in qualitative interviews. Table 1 provides information about the participants. Of the 18 interviews conducted, 16 were individual, one with a mother and father jointly and one focus group comprising two mothers, one father and two professionals. For mutual convenience 11 interviews were carried out face to face at five different venues and seven telephone interviews were conducted.

[insert table 1 here]

A researcher-designed on-line survey asked participants for their views on PLaNT v1; 16 participants (seven parents and nine professionals detailed in Table 1) were invited and eight participated (see Table 2). By the end of phase 1 we had developed PLaNT v2 (Figure 1, supplementary material), for testing in phase 2.

[insert table 2 here]

Phase 2: Pre-pilot evaluation of PLaNT

To address objective 2 and because little consensus exists on the ideal sample size for pre-pilot studies (Ratray & Jones, 2007) we followed Hertzog's (Hertzog, 2008) recommendation for samples of ten or fewer at pre-pilot stage. Participating professionals each administered PLaNT to one/two of the participating parents. We then conducted individual interviews with participants to assess PLaNT for a range of factors such as item-wording, acceptability of formatting, ease of administration and how much time it takes to complete.

Nine children's kidney units participated in the pre-pilot evaluation; five of which had not participated in Phase 1. Due to the need to determine whether PLaNT is effective in assessing English and South Asian parents' learning preferences, our aim was to pilot it with six-ten English and six-ten South Asian parents, and also with six-ten MDT members to assess its acceptability in their practice. Thirteen parents participated and were paired with one of nine professionals to test out PLaNT (see Table 3). No participants had taken part in phase 1.

[insert table 3 here]

Phase 1 and 2 interviews were supported by topic guides and interpreters were available to assist with discussions and translation of items if required. Interviews were digitally-recorded, transcribed verbatim and lasted between 20-70 minutes. Interview/focus group data were analyzed using Framework (Ritchie & Lewis, 2003) which is systematic, thorough, grounded in the data and flexible, enabling easy data-retrieval to produce audit-trails. Framework is widely used in health-research. Framework is an explicit approach to analysis and sits in a thematic methodology. It provides transparent results, offers conclusions that can be related back to original data and may be undertaken both during and after data collection (Ritchie, Lewis, Nicholls, & Ormston, 2013). There is also the possibility for individual but linked studies to be analysed separately and then combined in

the final analysis to identify crossing themes. It allows for flexibility and the easy retrieval of data to show others how decisions were derived. The use of charting within Framework is regarded as a valuable for assisting transparency and team working (Dixon-Woods, 2011) and it enables investigators with competing responsibilities to stop the analysis and return later to continue where they left off (Ward, Furber, Tierney, & Swallow, 2013).

Approval was obtained from a National Health Service (NHS) Research Ethics Committee (reference: 13/NI/0197) and NHS Trust Research and Development (R & D) Departments. All study participants were volunteers and provided informed, written consent.

FINDINGS:

Phase 1 survey data:

Table 4 contains information gathered via the online survey; data was used to refine PLAnT v1 and resulted in PLAnT v2, which was tested in Phase 2.

[insert table 4]

Phases 1 and 2 interview data:

A key theme “Identifying parents’ learning needs and preferences” was identified. In line with the mixed-methods approach we adopted (Cresswell & Clark, 2011), the following section integrates data from qualitative interviews in phases 1 and 2 to most effectively illustrate this theme and the related sub-themes. An outline is presented in Figure 2.

[insert figure 2]

The importance of professionals being aware of parents’ learning needs and preferences was recognised. Both parents and professionals discussed how parents’ learning needs and preferences should be identified, including: the **purpose** for doing this, the **process** for doing this, and what the **outcome** would be of identifying parents’ needs. Each of these sub-themes is explored, using illustrative quotations from phase 1 and 2 qualitative interviews.

Purpose

Participants discussed what the purpose might be of asking parents about their learning needs and preferences.

- **A diagnostic tool and/or a way to gain feedback**

Both parents and professionals saw the value of PLAnT as a method by which professionals could gather information from a parent about their learning needs and preferences and potentially ‘diagnose’ a parent as a learning ‘type’ in advance of teaching them about their child’s condition and care. In addition, by asking parents directly, this could convey to parents that their views are important and that professionals viewed them as individuals:

...as well as be quite therapeutic filling it in with parents, because it conveys a sense of, we want to be as patient-person centred as we can be, we want to try and get it *right, because it is very complex information and we want to take on board what’s your [parents] view* (clinical psychologist)

Professionals and parents also saw value in using PLAnT to enable parents to give feedback as it could be used to adjust future information provision to more closely meet parents’ identified needs. It was recognised that PLAnT could have a dual purpose, both as a diagnostic and as a feedback tool:

'It's giving you an insight as to how parents want information, how they want to learn, or how happy they are with the information that they're given (parent)

- **Focus on need for information and/or support**

There was acknowledgement that parents received a vast amount of information, therefore, it would be important for professionals to find out how parents like to learn early in the child's trajectory:

Because a parent is as individual as a child's medical condition, so everything is individual. And if you don't know how that parent wants you to tell them things, and how they want to know things, you don't know that you're giving them the right amount of information' (play worker)

However, participants in phase 1 interviews, thought it would be useful for professionals to ask parents about their need for support as well as information; consequently a question regarding parents' support needs was introduced into PLAnT v2 (see Figure 1, Supplementary material, Question 9).

Participants could see the value of professionals asking parents directly about their support needs due to inconsistencies in how support was offered; for example whether parents should be proactive in asking for help or whether it was the professionals' responsibility to ask:

It would be nice to be asked 'how are you coping? How are you managing? Do you need any help?' Maybe the protocol is you wait 'til the parent says....I don't know how the system works...like I said, it's always about you, the onus on the parent to say, 'look, I need help here'. It would be good if they could do ...ask, 'how are you coping?', or, 'do you need any help?', because they know how the system works how to get the help. We only know how to ask for it. (parent)

Process

The process by which professionals identified parents' learning needs was discussed.

- **Asking parents directly**

There was debate about whether a tool was needed to ask parents directly; some thought professionals could make judgements at an intuitive level, others questioned whether parents' learning needs could be ascertained by professionals at a tacit level and there was some uncertainty about whether asking parents would yield more accurate information:

... having a tool may be good, but there will still be people who tell you what they think you want to hear, rather than give you a true answer. (nurse)

- **Validated questionnaire and/or discussion**

Some participants queried whether professionals should use a structured questionnaire to identify parents' learning needs or whether this information should be gathered as part of an informal discussion. A questionnaire was viewed as beneficial as it would support a more standardised approach across the MDT to identify parents' learning needs. It was also thought a questionnaire was more likely to benefit some parents as it could be easier to provide information and feedback using this method, than through an informal discussion:

...so I think sometimes having something like PLAnT will allow parents who maybe

don't feel as confident to ask the questions or to find that information. (parent)

However, some participants thought parents' learning needs were too complex and situation-specific to be understood via a questionnaire and found it difficult to answer some of the questions in PLAnT. Potentially due to this, some parent-professional pairings in phase 2, used PLAnT as part of a wider discussion, with parents' providing more information on why they had chosen a specific response. For some participants who used PLAnT in a structured way, there was a suggestion it would be more useful to have used PLAnT to facilitate a wider discussion:

I think there could have been a place for discussion, and reasons why some of the answers have been picked just to gather some more information. The fact that they were all tick ... *you had to pick an answer and maybe that wasn't actually the answer that you would have been giving had you been able to write a bit of qualitative information underneath. (nurse)*

- **Independently or with a professional**

Both parents and professionals discussed whether a parent should complete PLAnT independently or with professional support. It was suggested that a parent completing PLAnT independently might feel they have more time to reflect on the questions and potentially be more honest in their responses. However, it was recognised that if a parent was asked to complete PLAnT unaided, there was the potential it would not actually be completed as parents might not appreciate the value of doing it. Through completing PLAnT with a professional the parent would have the opportunity to discuss their learning needs, be able to provide more information and seek clarity if a question was unclear. As there were benefits associated with parents completing PLAnT on their own and with a professional, some participants concluded there should be the option for PLAnT to be administered in either way:

My inclination would be that it should be something that someone can just work out by themselves, have time to think and not feel like someone is watching the clock, *'have you filled it in yet?'* So everybody has their different ways. Some people are really *conscious about, 'what do you think I should do?'* And sometimes that works *better if you have a conversation saying, 'well, there really is an option here, you can choose whichever one',* and you can help them decide. (nurse)

- **Timing/repeat**

There were differing opinions about when a parent should be asked to complete PLAnT. Some participants discussed the value of asking a parent shortly after their child was diagnosed as it would mean the MDT would know from the start about the parents' learning needs and preferences:

Probably fairly close to the beginning. Give it a little while just to sink in [*child's diagnosis*] but, yeah, within the first week. *Everyone's different, aren't they? That's the importance of them probably answering this [PLAnT] (parent)*

However, others thought it was not a priority for parents shortly after diagnosis, as PLAnT could be viewed as an additional burden.

Whether PLAnT should be completed once only or be repeated was also discussed. There was some concern that if it was repeated it might feel irrelevant; however, there was also recognition that parents' learning needs and preferences could change over the disease course:

... if you repeat a process too often it becomes a, just a bit of rigmarole...*it's just a procedure* and it needs to be done more subtly than that. But yeah, because as you say, things change, and people...may feel they need ...more in-depth information (nurse)

Participants' discussions about the process used to identify parents' learning needs and preferences highlights the necessity for further research to explore how to identify these needs, who should be involved in this process, and when it should be done. It also emphasises that to be used in practice, PLAnT would need to be flexible so its use could be adapted to each family's situation.

Outcome

The final sub-theme was around what the outcome would be of identifying parents' learning needs and preferences; for example how could the information gathered through PLAnT be used by professionals.

• Useful

Participants recognised the value of using PLAnT to identify parents' learning needs and preferences and improve parental education, both in terms of the process and the information that it gathered:

It's very accessible and, well, it prompts the discussion... and would maybe allow people to think that they are entitled to more information or to, the level of information that suits them. (parent)

There was recognition that an assessment tool, like PLAnT could provide useful information to the MDT and be used to adjust professionals' information provision to match a parent's identified needs. However, some participants were concerned that it may not reflect the fact that a parent may want different information/teaching at different times:

It's just a path and things change all the time. I think it can be quite difficult to pin down what people want and when they want it and how much they want. 'Cause I'll go through weeks where I don't want to speak to anyone or think about anything and then I decide that I want a load more information. (parent)

• Sharing information

Some participants thought having a standardised, MDT assessment tool to identify parents' learning needs and preferences would be valuable; PLAnT could be stored in a child's file for professionals to access and could facilitate a consistent team approach when communicating with a parent:

...it's one way of documenting it and having it shared in a clear format. And everyone usually just flicks through and sees, 'oh, they're not so confident' or 'they're feeling very confident. Let's try them with this'. I'd just be aware of that when I ...talk to them. (nurse)

• Able and willing

The final sub-theme considered whether professionals would be able and willing to adjust their teaching and information provision in light of a parent's identified learning needs and preferences. Participants who believed there was value in using PLAnT appeared to demonstrate willingness to use the information obtained therein, and to adjust their practice

accordingly. There was recognition that some MDTs adopt a particular approach to information provision which may not be suitable for all parents:

...I think as MDT teams we, you fall into working patterns that you think work well, but you don't take necessarily into account, what, in that situation what is best for the whole family and that it is for the parents to decide that (clinical psychologist)

The above quotation raises the issue of 'who knows best?': should a parent be asked to identify their own learning needs and the MDT adjust its approach accordingly or should the MDT decide on an approach it thinks works well, and expect the parent to 'fit' into this approach? This issue was explored by some participants who pre-piloted PLAnT; for example where parents indicated they would like more information from the MDT than was being provided, would the MDT be able and willing to meet this parent's identified need. As the quotation below illustrates, professionals may sometimes experience difficulty providing parents with additional information due to uncertainty around the child's disease trajectory, but also the MDT focus tends to be on the short term:

...it's more short term scenarios which is the way the system works because they[professionals] just deal with what's ahead of them right now....'So what will happen after that?'. And they're like, 'we'll deal with this bit at the moment'. And that's normally the way that they work: 'we'll deal with this bit first. And then we'll see what happens after that', because there are so many different variables (play worker)

This suggests that professionals may be unwilling to meet parents' identified learning needs and preferences as they think they 'know what's best' for a parent. However, even professionals who would be willing to adjust their practice in light of information obtained from PLAnT could face barriers to doing this:

There are time pressures. *There's so much that you have to do that something like this can end up being seen as a 'nice to have' rather than a 'must have'. Whereas actually, if you get it right, you could improve treatment adherence if you're giving information and treatment in the way that means something to them [parents] (clinical psychologist)*

DISCUSSION:

We aimed to build on previous research to design, develop and pre-pilot a tool to promote a standardised MDT approach to assessing parents' learning needs and preferences at key points in the child's trajectory, for example at diagnosis and when the child's home-based clinical care changed. Supporting parents to share management of their child's clinical needs and deliver safe and appropriate care at home is identified as a priority in health policy and research literature. However, there is a lack of tools that have been rigorously developed and evaluated with parents and professionals to support this process.

Study design and methods

This mixed-methods, primary research study involving a multidisciplinary research team builds on our prior evidence synthesis (Nightingale et al., 2015) and forms part of a phased approach towards developing and evaluating a complex intervention (MRC, 2008; Richards & Hallberg, 2015).

Fulfilment of study objectives

To address objective 1 and building on our review findings we identified potential PLAnT components. To achieve this we established a virtual development group comprising

members of the disciplines represented in renal MDTs; and parents whose first language is or is not English. To ensure content validity, development of PLaNT required considerable work to define items for inclusion, determine its accessibility for English and non-English speaking users, assess flexibility and accessibility of delivery, refine wording, determine how/where/when/by whom it would be administered and decide whether it should include uni- and/or multidisciplinary items and responses.

To address objective 2 we identified:

- **Methodological strengths**

This multidisciplinary project involved all of the disciplines represented within the UK network of children's kidney units. The mixed-methods design meant that by collecting interview and survey data we were able to gain a greater understanding of our particular phenomenon. There was also considerable interest in the study in the UK children's kidney network; there were more interested participants than we were able to recruit within the timeframe.

Several Phase 2 professional participants explained that data they obtained from piloting PLaNT provided them with information they could use to alter their practice. For example, one professional noted that the parent who completed PLaNT with them highlighted for the first time a lack of confidence in their ability to manage their child's condition; therefore the professional allocated more time to discussing the child's treatment and supporting the parent. Another professional reported that when administering PLaNT the parent identified specific concerns regarding the child's management; with the parent's permission this was mentioned at the subsequent MDT meeting so a strategy could be developed to address the concerns with the parent.

- **Methodological challenges**

Sampling issues

Although we had the full support of 11 UK children's kidney units, attaining R & D approvals for each site was challenging so only six of the 11 sites participated in phase 1 as the remaining sites did not receive approval within the timeframes.

Having more experienced parents and professionals as participants potentially influenced our findings, as professionals had more experience of teaching parents, and parents more experience of learning. This is relevant to note, as we had hypothesised that a tool to assess parents learning needs and preferences may be of more use to newly qualified professionals, or those new to working in the renal MDT, and to parents who were at the start of their journey of learning to share management.

PLaNT administration issues

After considerable discussion the research team agreed that no specific instructions would be provided to participants about how PLaNT should be used as we were interested in learning how they used the tool. However, some participants found the lack of instruction a challenge, assuming they needed to follow the questions in the order in which they appeared in PLaNT, and only focus on the specific questions, when they would have preferred to explore some of the issues further via discussion.

Locating the study in the wider context

As well as ascertaining parents' learning needs the benefit of professionals asking parents directly was also discussed in terms of conveying to parents that their views and experiences are important and they are regarded as individuals. This finding corresponds with and extends work reporting initial development and testing of a tool to help paediatric

oncology professionals gauge patient/parent communication preferences (Sobo, 2004). Sobo's data demonstrated that nurses' perceptions of patient and parent communication preferences were frequently in error, so presenting the findings obtained using the tool to nurses was a crucial step towards developing their commitment to using the tool in practice.

In our systematic review (Nightingale et al., 2015) we noted that although parents received information from professionals (Patistea & Babatsikou, 2003), gaps in information provision existed including psychosocial issues (A Thon & Ullrich, 2009; Angelika Thon & Ullrich, 2010), the child's future (Collier, Pattison, Watson, & Sheard, 2001) and research into the condition (Patistea & Babatsikou, 2003). Our current data extend these findings; with parents sometimes emphasizing the way the onus was on them [the parent] to proactively seek information, help or support. Parents in our study, therefore, advocated a 'system' whereby professionals actively enquire how the parent is coping and whether they need any help. Parents observed that while professionals know how the health 'system' works and how to seek help, parents only know how to ask for help; therefore parents recommended that professionals have a responsibility to change their practice by actively enquiring about parents' information and support needs, in the way that a tool such as PLAnT can facilitate.

In contrast, some professional participants questioned the value of asking parents directly; believing that an understanding of parents' learning needs could be ascertained at an intuitive level. This finding is in contradiction with the literature in which professionals having the knowledge and skills to be able to teach was seen as central in facilitating parents' learning. The importance of tailoring information provision and teaching to individual parents' requirements (Henley & Hill, 1990) means professionals can be required to: elicit parents' individual concerns, learning needs and understanding on an ongoing basis (Hummelinck & Pollock, 2006); take into account parents' previous experiences and knowledge (Kelo, Eriksson, & Eriksson, 2013); and take an interest in the family's whole life situation (Nordfeldt, Ångarne-Lindberg, Nordwall, & Krevers, 2013). It may be that professionals who question the value of asking parents directly about their learning needs using an intervention such as PLAnT are anxious about standardised tools undermining or questioning their own knowledge and skills; this is an important area for further investigation.

Nevertheless, despite the reservations discussed above, some parents thought a structured questionnaire was more likely to benefit some parents as it could be easier to provide information and feedback using this method, than through informal discussion. This endorses our systematic review findings that questionnaires such as PLAnT may be easier for parents from ethnic minority and lower socio-economic groups to complete (Povlsen, Karlberg, & K C Ringsberg, 2008; Sobo, 2004), this issue warrants further investigation.

Overall, our data indicate that participants who believed there was value in using a tool appeared to demonstrate willingness to use the information and adjust their practice accordingly, as is illustrated by the following quotation:

I haven't seen anything like it before and I really like it. I really like how we can use it to support parents. I think that's really important in a child's care. (nurse)

RECOMMENDATIONS AND CONCLUSIONS:

Implications for practice and recommendations for further research

With the emphasis on parent-professional shared management of childhood chronic conditions, both pediatric nurses and MDT members can be guided by PLAnT in their assessment of parents' learning needs and preferences, based on identified barriers and facilitators to parental learning. PLAnT could help to ensure all aspects of a child's care are

being supported and optimise delivery of home-based care, thereby contributing to improved clinical outcomes for the child. In a context where parents may feel anxious about giving feedback, a professional administering PLAnT can help emphasise the importance of a collaborative learning alliance between parents and professionals. This approach helps to emphasise that professionals are ready to listen to parents' needs, and to facilitate individualised support.

Further research exploring the impact of 'external' factors such as the child's age, families' ethnicity and socio-economic status on parents' learning needs and preferences, as well as how parents' learning needs change over time, would be an important contribution to the evidence. Parents may be in shock at the initial point of their child's diagnosis, and have few questions or desire for detailed information. However, as they start to adjust to the reality of their child's condition the drive for more complex discussion may increase. This study reminds us of the need for reassessment of parents' needs, and PLAnT could potentially provide a standardised, yet flexible way to facilitate this discussion.

Future studies are needed that build on this initial development and pre-piloting work to further refine PLAnT, identify and finalise trial components and develop a protocol for a pilot feasibility study and a future UK wide, definitive trial of PLAnT. A future study would benefit from 'narrower' eligibility criteria e.g. parents whose child was recently diagnosed with CKD and professionals in their first year of working in a renal MDT.

Conclusions

This paper reports on a study that built on existing literature and worked with parents and health professionals to design, develop and pre-pilot PLAnT. This involved defining items for inclusion, determining PLAnT's accessibility for English and non-English speaking users, assessing flexibility and accessibility of delivery, refining wording, determining how/where/when/by whom it would be administered and deciding whether it should include uni- and/or multidisciplinary items and responses. With the current emphasis on parent-professional shared management of childhood chronic conditions, both pediatric nurses and MDT members can be guided by PLAnT in their assessment of parents' learning needs and preferences, based on identified barriers and facilitators to parental learning. Asking parents directly about their learning needs and preferences may be the most reliable way for professionals to ascertain how to support individual parents' learning when sharing management of their child's condition. Future studies are needed that build on this initial work to further refine PLAnT and inform a future UK-wide, definitive trial of PLAnT.

REFERENCES

- Aldridge, M. (2008). How Do Families Adjust to Having a Child with Chronic Kidney Failure? A Systematic Review. *Nephrology Nursing Journal*, 35(2), 157-162.
- BRS. (2002). The Renal Team, A Multi-Professional Renal Workforce Plan For Adults and Children with Renal Disease.
- CMO. (2012). Annual report of the Chief Medical Officer-Our children deserve better: Prevention pays London: Department of Health.
- Coffey, J. (2006). Parenting a Child with Chronic Illness: A Metasynthesis. *Pediatric nursing*, 32(1), 51.
- Collier, J., Pattison, H., Watson, A., & Sheard, C. (2001). Parental information needs in chronic renal failure and diabetes mellitus. *European Journal of Pediatrics*, 160(1), 31-36. doi: 10.1007/pl00008413
- Coulthard, M. G., & Crosier, J. (2002). Outcome of reaching end stage renal failure in children under 2 years of age. *Arch Dis Child*, 87(6), 511-517.

- Cresswell, J., & Clark, V. P. (2011). *Designing and conducting mixed methods research* (2nd ed.). London: Sage Publications.
- Divertie, V. (2002). Strategies to Promote Medication Adherence in Children With Asthma. *American Journal of Maternal Child Nursing*, 27(1), 10-18.
- Dixon-Woods, M. (2011). Using framework-based synthesis for conducting reviews of qualitative studies. *BMC Medicine*, 9(1), 39.
- DOH. (2006). *The National Service Framework for Renal Services: Working for Children and Young People*. London: Department of Health.
- Drotar, D. (2000). *Promoting adherence to medical treatment in chronic childhood illness*. London: Psychology Press.
- Henley, L. D., & Hill, I. D. (1990). Global and specific disease-related information needs of cystic fibrosis patients and their families. *Pediatrics*, 85(6), 1015-1021.
- Hertzog, M. A. (2008). Considerations in determining sample size for pilot studies. *Research in nursing & health*, 31(2), 180-191. doi: 10.1002/nur.20247
- Hexem, K., Bosk, A., & Feudtner, C. (2011). The dynamic system of parental work of care for children with special health care needs: A conceptual model to guide quality improvement efforts. *BMC Pediatrics*, 11(1), 95.
- Hummelink, A., & Pollock, K. (2006). Parents' information needs about the treatment of their chronically ill child: A qualitative study. *Patient Education and Counseling*, 62(2), 228-234.
- Kelo, M., Eriksson, E., & Eriksson, I. (2013). Perceptions of patient education during hospital visit—described by school-age children with a chronic illness and their parents. *Scandinavian Journal of Caring Sciences*, 27(4), 894-904.
- Knafel, K., & Gilliss, C. (2002). Families and Chronic Illness: a Synthesis of Current Research. *Journal of Family Nursing*, 8(3), 178-198.
- Macfadyen, A., Swallow, V., Santacroce, S., & Lambert, H. (2011). Involving fathers in research. *Journal for Specialists in Pediatric Nursing*.
- MRC. (2008). *Developing and evaluating complex interventions: new guidance*. London: Medical Research Council.
- Nightingale, R., Friedl, S., & Swallow, V. (2015). Parents' learning needs and preferences when sharing management of their child's long-term/chronic condition: A systematic review. *Patient Education and Counseling*, 98(11), 1329-1338. doi: 10.1016/j.pec.2015.05.002
- Nordfeldt, S., Ängarne-Lindberg, T., Nordwall, M., & Krevers, B. (2013). Parents of adolescents with type 1 diabetes-their views on information and communication needs and internet use. A qualitative study. *Plos One*, 8(4), e62096.
- Patistea, E., & Babatsikou, F. (2003). Parents' perceptions of the information provided to them about their child's leukaemia. *European Journal of Oncology Nursing*, 7(3), 172-181.
- Povlsen, L., Karlberg, I., & K C Ringsberg. (2008). Support and education of immigrants with chronically ill children: identified needs from a case study of Turkish and Kurdish families. *Health Education Journal*, 67(1), 35-44.
- Rattray, J., & Jones, M. C. (2007). Essential elements of questionnaire design and development. *Journal of Clinical Nursing*, 16(2), 234-243. doi: 10.1111/j.1365-2702.2006.01573.x
- Richards, D., & Hallberg, I. (Eds.). (2015). *Complex Interventions in Health: An Overview of Research Methods*. London: Routledge.
- Ritchie, J., & Lewis, J. (Eds.). (2003). *Qualitative Research Practice: A guide for Social Science Students and Researchers*. London: Sage Publications.
- Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (2013). *Qualitative research practice: A guide for social science students and researchers*: Sage.
- Sobo, E. (2004). Pediatric Nurses May Misjudge Parent Communication Preferences. *J Nurs Care Qual*, 19(3), 253-262.

- Speros, C. (2005). Health Literacy: Concept analysis. *J Adv Nurs*, 50(6), 633-640.
- Sullivan-Bolyai, S. D. C. N. S. R. N., Rosenberg, R., & Bayard, M. (2006). Fathers' Reflections on Parenting Young Children With Type 1 Diabetes. *MCN, American Journal of Maternal Child Nursing* January/February, 31(1), 24-31.
- Swallow, V., Lambert, H., Clarke, C., Campbell, S., & Jacoby, A. (2008). Childhood chronic-kidney-disease: A longitudinal-qualitative study of families learning to share management early in the trajectory. *Patient Education and Counseling*, 73, 354-362.
- Swallow, V., Lambert, H., Santacroce, S., & Macfadyen, A. (2011). Fathers and mothers developing skills in managing children's long-term medical conditions: how do their qualitative accounts compare? *Child: Care, Health & Development*, 37(4), 512-523.
- Swallow, V., Macfadyen, A., Santacroce, S. J., & Lambert, H. (2012). Fathers' contributions to the management of their child's long-term medical condition: A narrative review of the literature. *Health Expectations*, 15(2), 157-175. doi: 10.1111/j.1369-7625.2011.00674.x
- Swallow, V. M., & Jacoby, A. (2001). Mothers' evolving relationships with doctors and nurses during the chronic childhood illness trajectory. *Journal of advanced nursing*, 36(6), 755-764.
- Swallow, V. M., Nightingale, R., Williams, J., Lambert, H., Webb, N. J., Smith, T., . . . Allen, D. (2013). Multidisciplinary teams, and parents, negotiating common ground in shared-care of children with long-term conditions: A mixed methods study. *BMC Health Services Research*, 13(1). doi: 10.1186/1472-6963-13-264
- Thon, A., & Ullrich, G. (2009). Information needs in parents of children with a rheumatic disease. *Child: Care, Health and Development*, 35(1), 41-47.
- Thon, A., & Ullrich, G. (2010). Disease impact and disease-unrelated strain in parents of children with rheumatic disease: Is there an influence on disease-related information needs?*. *Disability & Rehabilitation*, 32(2), 134-141.
- Ward, D. J., Furber, C., Tierney, S., & Swallow, V. (2013). Using Framework Analysis in nursing research: a worked example. *Journal of advanced nursing*, 69(11), 2423-2431. doi: 10.1111/jan.12127

Table 1. Characteristics of participants who took part in phase 1 qualitative interviews

Parents/carers	Professionals
10 in total consisting of: <ul style="list-style-type: none">• 5 mothers• 3 fathers• 1 grandmother• representing 8 families• 4 of the parents were South Asian	13 in total consisting of: <ul style="list-style-type: none">• 1 clinical psychologist• 1 dietitian• 2 doctors• 7 nurses• 1 play specialist• 1 social worker

Table 2. Characteristics of respondents to Phase 1 online survey

Parents/carers	Professionals
4 parents/carers in total consisting of: <ul style="list-style-type: none">• 2 mothers• 1 father• 1 grandmother• representing 4 families• from 3 of the participating children's kidney units	4 professionals in total consisting of: <ul style="list-style-type: none">• 1 doctor• 2 nurses• 1 play specialist• from 3 of the participating children's kidney units

Table 3. Characteristics of phase 2 participants

Parents	Professionals
13 in total consisting of: <ul style="list-style-type: none">• 12 mothers• 1 father• representing 12 families• 3 parents were South Asian, 1 required an interpreter• 1 parent was Black African	9 in total consisting of: <ul style="list-style-type: none">• 1 clinical psychologist• 1 dietitian• 1 doctor• 4 nurses• 1 play specialist• 1 social worker

Table 4. Survey data

Question	Responses
Do you think the PLAnT would be easy to use?	1 of 8 respondents: 'Very easy' 7/8: 'Easy'
What do you think of the language used in the PLAnT?	2/8: 'Very clear' 5/8: 'Clear' 1/8: 'Unclear'
Do you think the PLAnT asks relevant questions?	8/8: 'Yes'
If you are a parent how would you feel about being asked these questions?	3/8: 'Very comfortable' 5/8: 'Comfortable'
If you are a professional how would you feel about asking parents to answer these questions?	2/5: 'Very comfortable' 3/5: 'Comfortable' 3 of the 8 respondents did not provide a response
What do you think of the length of the PLAnT?	5/6: 'Just right' 1/6: 'Too short' 2 of the 8 respondents did not provide a response
How easy is it to understand?	2/8: 'Very easy' 6/8: 'Easy'
Do you think the questions are in the right order?	7/7: 'Yes' 1 respondent did not provide a response
Please suggest the order you think they should be in.	No responses
Are there any other questions that you think would be useful to ask?	1 respondent suggested including an option to document who had recorded the answers, in recognition of the fact that some parents have reading/writing difficulties
Would you make any changes to the PLAnT?	<ul style="list-style-type: none">• To make it available in other languages• To include a 'comments' box for additional detail• To use pictures for non-English speakers• Instructions for professionals on how often PLAnT would be administered and updated

Figure 1. PLaNT v2

People differ in how much information and support they want around their child's kidney condition and care and how they like to receive the information. Your answers to these questions will help the staff in the children's kidney team to understand your needs. Your needs may change over time so you can update your answers later if you want to.

Name of child:

Name of parent/carer completing the form:

Relationship to the child:

Date:

1. Where do you currently get information about your child's kidney condition from?

Tick all which apply:

a. Children's kidney team	
• Dietician	
• Doctor	
• Nurse	
• Pharmacist	
• Play specialist/worker	
• Psychologist	
• Social Worker	
b. Other health professionals e.g. GP	
c. Family and friends	
d. Internet	
e. Reading	
f. Other (please list)	

2. How would you like to get information about your child's kidney condition and care?

Tick all which apply and which is most important (1 = most important, 6 = least important):

	✓	1-6
a. As part of a conversation with staff from the children's team		
b. Written down		
c. Visual methods e.g. pictures ,photos, videos, DVDs		
d. Being shown how to do something		
e. Being able to talk with other parents of children with kidney conditions		
f. Internet		

3. When you are being given information about your child’s kidney condition and care, what would you like best? Tick one:

a. To be told when I’m on my own	
b. To be with family/friends	
c. For my child to be present	
d. For my child not to be present	

4. When meeting with the children’s kidney team, what would you prefer? Tick one:

a. To meet with all the professionals at the same time in one room	
b. To meet each professional separately	

5. Which sentence best describes how much information you want about your child’s kidney condition and care? Tick the one you agree with:

a. I want the simplest information you can give me.	
b. I want more than the simplest information. But keep it in everyday terms.	
c. I want more than the simplest information. I also want help to understand things in depth.	
d. I want as much in-depth and detailed information as you can give to me.	

6. Compared to what you want, the information you get right now is: (circle one)

Too little

Just right

Too much

7. Which sentence best sums up how you would describe yourself? Tick one:

a. I wait and see what happens and then I deal with it	
b. I always want to know what to expect in the future, even if there is uncertainty.	
c. I am satisfied if staff just tell me what to do. I am not interested in medical details.	
d. I want staff to ‘tell it to me straight’ but only about the ‘here and now’. I don’t want to know what the future might hold.	

8. How confident do you feel about managing your child’s kidney condition and care?

Please circle one number:

1 2 3 4 5 6 7 8 9 10

**NOT SO
CONFIDENT**

**VERY
CONFIDENT**

9. Compared to what you want, the support you get right now is: (circle one)

Too little

Just right

Too much

10. Would you like an interpreter to be present when you talk with the children's kidney team?

Yes	<input type="checkbox"/>	If yes, which language?
No	<input type="checkbox"/>	

11. Would you like written information to be translated into a different language?

Yes	<input type="checkbox"/>	If yes, which language?
No	<input type="checkbox"/>	

Any other comments?

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Figure 2. Overview of study findings: identifying parents' learning needs and preferences

