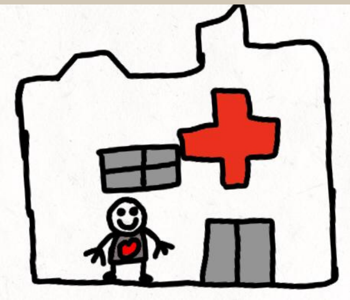


Edge Hill University

NHS
Manchester University
NHS Foundation Trust

NHS
Alder Hey Children's
NHS Foundation Trust

_______________'s
Visit to Hospital
A Guide for Children and Parents

This guide has been made by listening to what other children, young people, parents/carers and staff have told us has helped them. Write, or draw, or ask someone to help you fill in the pages.

APRIL 2022

Co-production of an evidenced-based child-centred toolkit to increase the use of positive behavioural support (PBS) and reduce the use of restrictive practices (RP) with children with Intellectual Disabilities (ID) and/or Autistic Spectrum Condition (ASC) attending hospital

Burdett Trust Final Report

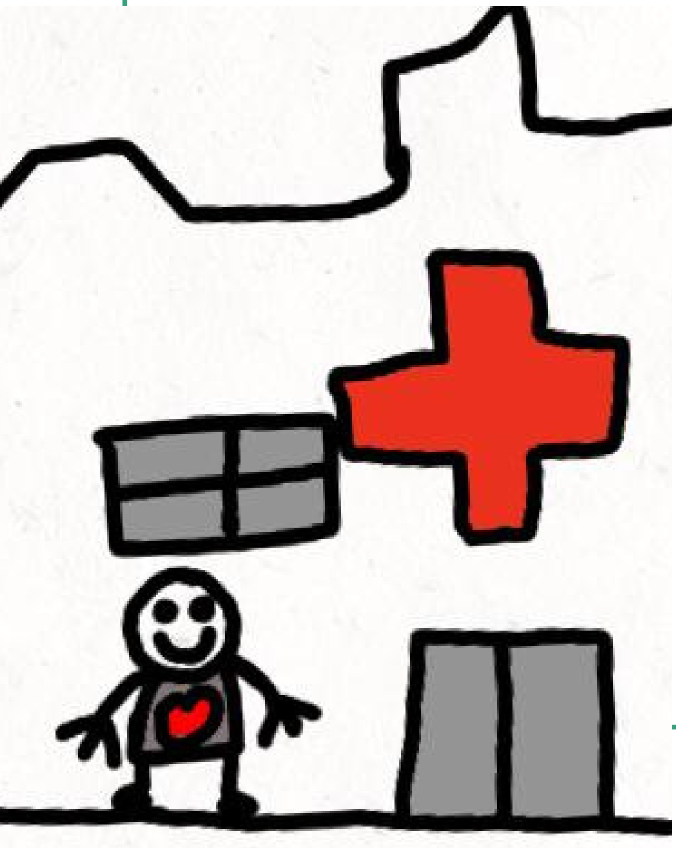
Dr Joann Kiernan,, Prof Lucy Bray, Samantha Miller, Jennie Craske, Dr Axel Kaehne, James Ridley, Anna Ostomeir- Brill, Dr Kate Oulton and Simon Nielson

INTRODUCTION AND CONTEXT

We are delighted to submit the final report which outlines the work conducted to develop the 'Evidenced-based child-centred toolkit to increase the use of positive behavioural support (PBS) and reduce the use of restrictive practices (RP) with children with Intellectual Disabilities (ID) and/or Autistic Spectrum Condition (ASC) attending hospital'.

The funding was awarded in April 2020.

The study was conducted during an extremely challenging time for the NHS and families and this did impact on recruitment and data collection.



PROJECT OVERVIEW

The aim of this study was to co-produce an evidenced-based child-centred toolkit to increase the use of positive behavioural support (PBS) and reduce the use of restrictive practices (RP) with children with ID/ASC attending hospital.

This was a mixed method multiple phase study working collaboratively with children and young people with intellectual disabilities and/or ASC, parent/carers and health professionals across multiple organisations.

THE PROJECT TEAM

Full team

Dr Joann Kiernan (PI- Edge Hill University, Alder Hey NHSFT), Prof Lucy Bray (Edge Hill University), Samantha Miller (Parent Advisor), Jennie Craske (Alder Hey NHSFT), Dr Axel Kaehne (Edge Hill University), James Ridley (Edge Hill University), Anna Ostomeir- Brill (Manchester Children's NHSFT), Dr Kate Oulton (Great Ormond Street Hospital). Simon Nielson (research assistant Edge Hill University).

The team was comprised of academics, nurses and parents, from Edge Hill University, Alder Hey Children's Hospital and Royal Manchester Children's Hospital.

The research team met virtually on a monthly basis to support updates, discussion, advice and review progress.

Thanks

We would like to thank all the children and young people, parents and professionals who shared their experiences, views and time with us, especially during such a challenging time.

We would also like to thank Jonny Glover for his creativity and endless patience in developing the resource.

EXPERT ADVISORS

We have worked with several expert parent advisors who have provided advice and guidance on all aspects of the study.

Parent advisors have been reimbursed for their time and expertise according to NIHR guidelines and as outlined in our application.

We have also received guidance from a small group of teachers from within a special education setting who have expertise working with children and young people with learning disabilities and autistic spectrum conditions.

CONSULTATION GROUPS

We have maintained our links with several very supportive forums including parents and carers of children with special education needs and disability (SEND) groups, a children and young peoples' forum and groups of young people with SEND from within a local authority.

Our consultation with these externally facilitated groups has been ongoing and they have been invaluable in informing all aspects of the original bid, design of the study and support for recruitment, data collection, and dissemination plans.

PROJECT BACKGROUND

Children with intellectual disabilities and or autistic spectrum conditions (ID/ASC) are frequent users of acute health care services (Johnson & Rodriguez 2013), have higher levels of health needs compared to the general population (Nocon 2006, CIPOLD 2013, LeDeR 2020) and often experience care inequitably (LeDeR 2020). Children with ID/ASC often require simple clinical procedures such as an X-ray, blood test or physical examination. It is not uncommon for these children to experience restrictive practices (RP) when they undergo these simple clinical procedures in response to displaying behaviours that are considered challenging and as a result of environmental, time and individual factors. The use of RP within this context can cause long-term psychological and physical harm to children with ID/ASC (Cigan 2018, Debbaudt 2009) and high levels of stress and anxiety to their parents/carers (Brown et al 2012, Kiernan et al 2017) and the health professionals involved. There is minimal research which have focused on children with ID/ASC undergoing these procedures and what supports or hinders their ability to cope and co-operate during such procedures. There is even less research which has investigated RP within these procedures. In many cases the use of RP within this context could be avoided or reduced (Pratt et al 2011) and evidence suggests that such interventions are being used too readily and are happening at a frequency that reflects a lack of planning or a focus on children's rights (Challenging Behaviour Foundation).

Despite some resources, tools and clinical guidelines existing which aim to support children with ID/ASC through a clinical procedure and reduce the use of RP in practice (autism society passport, Autism Speaks, individualised care pathways and passports, clinical guidelines, PBS training, RRN checklists) these are not routinely used by families and health care professionals and the child's voice is often lacking from their development. Evidence shows that there can be poor awareness of available interventions and resources (Johnson & Rodriguez 2013, Bray et al 2016) and they are often not adaptive enough to meet the individual needs of children with ID/ASC within an acute care setting (Oulton et al 2018). Our work in national policy development in the field of RP (Royal College of Nursing, Reducing Restraint Network) has highlighted the need for practice changes based on robust evidence and collaborative working. Our patient and public engagement work and years of clinical practice highlights the need for interventions to challenge and change practice to improve the care and access children receive. There is a need to co-produce a child-centred evidence-based toolkit to increase the use of preventative strategies (reasonable adjustments, PBS) and reduce the use of RP.

PROJECT TIMELINE

On the 17th April 2020 we received notification that we had been awarded the research grant.

Due to COVID-19 restrictions, it was agreed the project would start on the 1st of January 2021.

Pre-award we conducted patient and public involvement and engagement (PPIE) work with children, young people and families.

We received ethics approval for all aspects of the study from the Faculty of Health, Social Care and Medicine Research Ethics Committee in February 2021 (REC Reference: ETH2021-0038).

We received ethics approval from the Health Research Authority (HRA) on the 6th May 2021 (REC reference: 21/WA/0135). The application was praised by the HRA committee members for the levels of patient and public consultation and collaborative working.

The scoping review of the literature to inform the development of the toolkit was conducted in April-June 2021.

Phase 1 of the study (interviews with children, young people, parents/carers and health professionals from two hospital Trusts), was conducted between July-November 2021.

Design of the 'Visit to Hospital' booklet

Phase 2 of the study (workshops with children, young people, parents and health professionals to refine the toolkit) was conducted between December 2021-February 2022.

THE SCOPING REVIEW

The review focussed on interventions to prepare, familiarise or support children and young people with learning disabilities and or autistic spectrum condition for procedures.

This scoping review followed the approach advocated by Arksey and O'Malley (2005), We developed a broad search strategy, informed by consultation within a specific project steering group comprising health professionals, academics and experts by experience.

A total of 21 articles, published between 2001 and 2020, were included in this review. Publications were from the USA (n=10), the UK (n=7), Australia (n=2), France (n=1) and Canada (n=1). Articles comprised of empirical qualitative, quantitative and mixed-methods studies (n=7), intervention reports and evaluations (n=7), audits and change management reports (n=2), professional and public guidance to support families coming to hospital (n=2), an information article exploring challenges in the topic area (n=1), a case study (n=1) and a literature review (n=1).

The review identified a range of interventions, which used different mediums (storybooks, coping kits, hospital passports), were targeted at different audiences (children, parents, professionals) and were developed to be used at different timepoints in the procedural journey (before admission, during the visit)

The review findings have directly informed the development of the visit to hospital guide and we intend to submit the review for publication.

STUDY DESIGN

As this was an exploratory study, a naturalistic qualitative design was used. We used a mixed methods qualitative design over 3 data collection phases, based on 'Experience based co-design' (Point of Care Foundation) and guidance for the development of complex interventions (MRC) to ensure a ‘good fit’ to practice and relevance to children with ID/ASC, their parents/carers and health professionals working with them.

A qualitative approach aided the team in critically examining what works and what could be improved from the perspective of those involved. The qualitative research design and the use of multiple qualitative methods (activity books, remote interviews, stakeholder workshops) ensured that the investigation remained ‘open’ to understand the experiences, perceptions and opinions of children and young people with ID/ASC, their parents and health professionals.

PHASE 1

Methods and recruitment

The first phase of the study focussed on examining the experiences of children and young people with LD and/or ASC, their parents/carers and health professionals of having procedures in hospital and the use of restrictive interventions.

Children, young people with ID/ASC who were either due to attend for a planned outpatient appointment for a procedure (X-ray blood test, examination) or who had recently (within the last 6 months) attended hospital were identified by the specialist learning disability nurses based within each hospital trust.

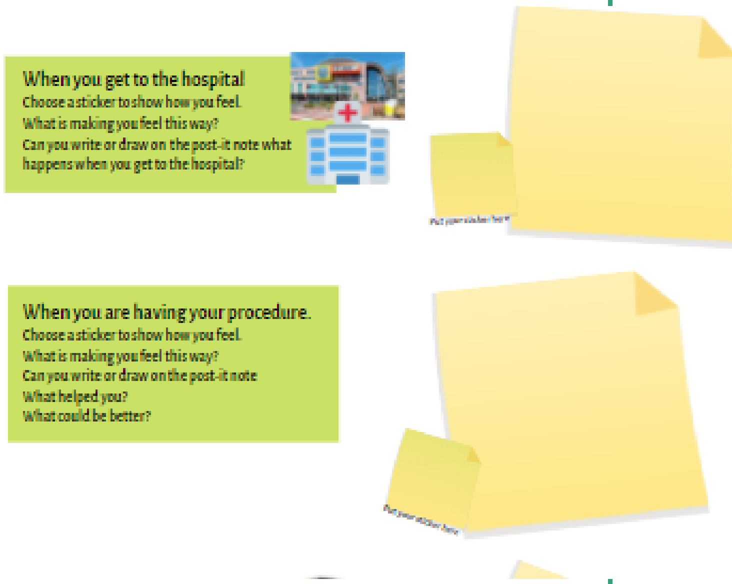
The short remote interviews with children and young people with ID/ASC were supported through the use of an activity book which included a journey map. The activity book aimed to foreground the abilities of children and young people with ID/ASC and help prompt consideration of specific events along the journey of procedure which either supported or negatively impact on a child.

Parent/carers were involved in short qualitative interviews conducted remotely over video platforms. These explored their experiences of accompanying their child for a procedural and what worked well and what could be improved.

Health professionals were involved in short focussed interviews conducted over the telephone or Teams and explored their views around what works well in procedural care for children and young people with ID/ASC and what could be improved.

PHASE 1

Participants and findings



When you get to the hospital
Choose a sticker to show how you feel.
What is making you feel this way?
Can you write or draw on the post-it note what happens when you get to the hospital?

When you are having your procedure.
Choose a sticker to show how you feel.
What is making you feel this way?
Can you write or draw on the post-it note
What helped you?
What could be better?

Children and young people (n=6; aged 8 to 15) participated in interviews. The children and young people had a range of diagnoses including autistic spectrum conditions and/or mild and moderate learning disabilities.

Parents/carers (n=6) had children with a range of diagnoses.

Health professionals (n=12) included nurses (n=5), liaison nurses (n=2), specialist nurses (n=3), a nurse manager (n=1) and a matron (n=1).

The key themes which were identified from the interviews were as follows:-

Children reported that; they get bored when they are waiting, there is no quiet space to wait, it can be too bright and noisy in the hospital, finding where to go can be hard, their parents can be worried about getting to the hospital, they see different staff each time, some which they like and some they do not.

Parents/Carers reported that; they worry about the appointment, they have to tell people what they need each time they come to hospital, some people don't ask them about their child, they do not know what help is available to them, their child gets bored and anxious waiting, there is no space to wait and waiting rooms are busy and noisy and they struggle to find where they need to go in the hospital.

Healthcare professionals reported that; they struggle to know what a child needs, often a family and child can be anxious, they have limited time with a child, a list would help them check what is needed for a child, it would be good if a child and family were ready and prepared for an appointment and that they don't like it when a child and family are unhappy at the hospital.

DESIGNING THE 'VISIT TO HOSPITAL' GUIDE

The work with the designers was an iterative process where we discussed the key findings from the scoping review and phase 1 interviews to help decide what the 'toolkit' should include and look like.

We also shared feedback from our consultation groups held with children and parents on what the resource should look like and include as well as what it should not be like.

There were also lengthy discussions focussed on the audience, the medium and the access to such a resource.

The aim of the initial drafting and consultation was to present more developed and detailed ideas at the phase 2 workshops to help refine the resource.

PHASE 2

Methods and recruitment

Phase 2 stakeholder workshops involved working alongside children, young people, parents and health professionals to examine the data collected from the Phase 1 interviews and the scoping review to develop and refine the content and format of the toolkit. The workshops followed a participatory design workshop (PDW) approach and were held remotely using video platforms.

The workshops examined which components could overcome the barriers which had been identified and enhance procedural practice.

Participants at the workshops were also shown and asked to critically review possible styles and content for the resource. This was helpful as providing some concrete examples towards the end of the workshops helped participants to provide focussed feedback whilst not constraining creativity and ideas in the beginning stages of the workshops.

Children, young people with ID/ASC were recruited from an established group of children and young people with Special Educational Needs and Disabilities (SEND) who meet regularly (currently online). This group is facilitated by qualified youth workers and the group are experienced in being consulted.

Parent/carers of children with ID/ASC were recruited from charitable organisations. We joined already timetabled online discussions.

Health professionals were recruited through professional networks and key contacts / local collaborators based at both hospital trusts. Health professionals were based either within specialist teams or outpatient departments who provide care to children with ID/ASC and families who may require additional support.

PHASE 2

Participants and findings

The children and young people involved in the workshops (n=5; aged 11 to 15) had a range of diagnoses including ASC and/or mild and moderate intellectual disabilities. Three workshops were facilitated by a Special Education Needs & Inclusion Team (n=2), and Youth Forum Leads (n=1).

Parent/carers who participated (n=6) had a child and/or siblings with a range of diagnoses including ASC and/or mild and moderate learning disabilities, anxiety disorder, attention deficit hyperactivity disorder, dyspraxia and dysphasia.

Health professionals (n=9) attended one of two workshops at one hospital Trust including nurses (n=6), liaison nurses (n=2) and a specialist nurse (n=1).

Parents as experts by experience (n=2) of boys and girls (n=4) with a diagnosis of ASC and/or mild/ moderate intellectual disabilities.

A workshop was facilitated for teachers (n=3) of boys and girls (primary) with a range of special educational needs, learning disabilities, autism and complex health needs.

These workshops identified the need for increased clarity around descriptions of 'sitting still', for the resource to remain 'clean' and not contain lots of bright colours, for there to be opportunities for children to 'interact and engage with the resource. For the resource to clearly identify that it had been developed with children and parents and for it to represent a journey through the hospital whilst not seeming like a 'story'. Professionals identified that they had a relatively short space of time to get to know a child and children and parents discussed how the set scripts some professionals used around a child's interests were unhelpful, this led to the 'this is me today' page.

PHASE 2

Participants and findings

Further workshops were conducted to refine the second draft of the toolkit.

Two workshops were facilitated by a Special Education Needs & Inclusion Team and special educational needs and disabilities teachers. Children and young people, (n=25; aged 11 to 16) attended with a range of diagnoses including autistic spectrum conditions and/or mild and moderate learning disabilities.

Expert advisors (n=9) attended one of two workshops and included members of a Special Education Needs & Inclusion Team (n=4), special educational needs and disabilities teachers (n=3) and parents as experts by experience (n=2).

Health professionals (n=3) from one hospital Trust including a specialist nurse (n=1), a nurse manager (n=1) and a matron (n=1) gave further feedback on the first draft.

The further workshops identified that the 'top tips' for health professionals should be detached from the family information as they were seen to be more impactful if they could be displayed within staff areas in a hospital. Participants struggled to think of a name for the resource, but were keen for it to be different to the hospital passport which was seen as long and unwieldy. There was overwhelming support for the 'This is Me Today' page which was perceived by all participants as the essence of the resource. There was a positive response to the 'Certificate of Attendance' rather than achievement to acknowledge that even if a procedure was not completed, a child had managed to attend the hospital and complete some part of the procedural journey.

_______________'s

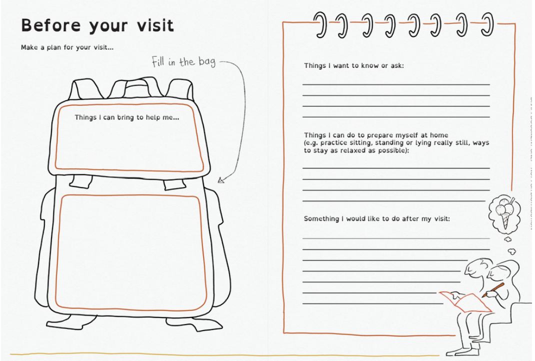
Visit to Hospital

A Guide for Children and Parents

Your name

Please colour in the pages

This guide has been made by listening to what other children, young people, parents/carers and staff have told us has helped them. Write, or draw, or ask someone to help you fill in the pages.



Before your visit

Make a plan for your visit...

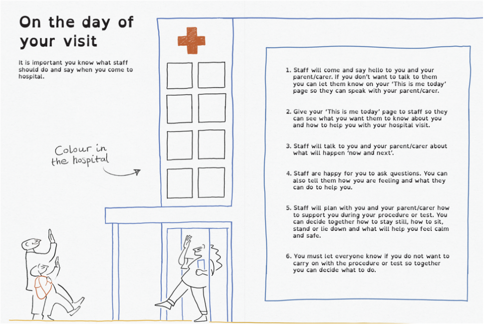
Fill in the bag

Things I can bring to help me...

Things I want to know or ask:

Things I can do to prepare myself at home (e.g. practice sitting, standing or lying really still, ways to stay as relaxed as possible):

Something I would like to do after my visit:

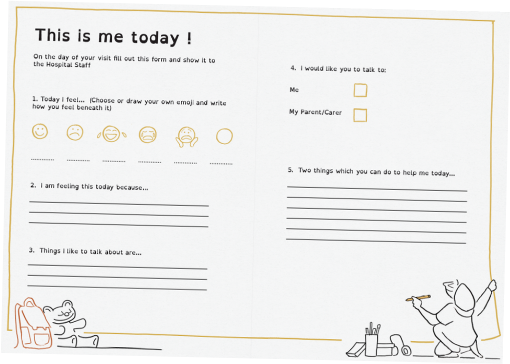


On the day of your visit

It is important you know what staff should do and say when you come to hospital.

Colour in the hospital

1. Staff will come and say hello to you and your parent/carer. If you don't want to talk to them you can let them know on your 'This is me today' page so they can speak with your parent/carer.
2. Give your 'This is me today' page to staff so they can see what you want them to know about you and how to help you with your hospital visit.
3. Staff will talk to you and your parent/carer about what will happen 'now and next'.
4. Staff are happy for you to ask questions. You can also tell them how you are feeling and what they can do to help you.
5. Staff will plan with you and your parent/carer how to support you during your procedure or test. You can decide together how to stay still, how to sit, stand or lie down and what will help you feel calm and safe.
6. You must let everyone know if you do not want to carry on with the procedure or test so together you can decide what to do.



This is me today !

On the day of your visit fill out this form and show it to the Hospital Staff

1. Today I feel... (Choose or draw your own emoji and write how you feel beneath it)

2. I am feeling this today because...

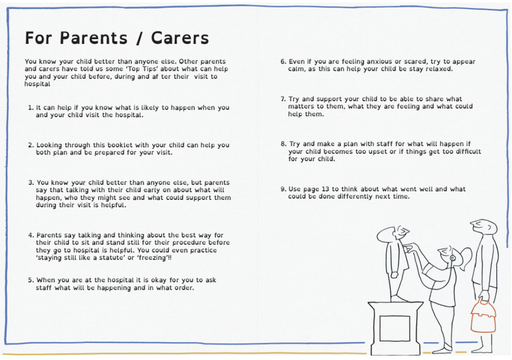
3. Things I like to talk about are...

4. I would like you to talk to:

Me ☐

My Parent/Carer ☐

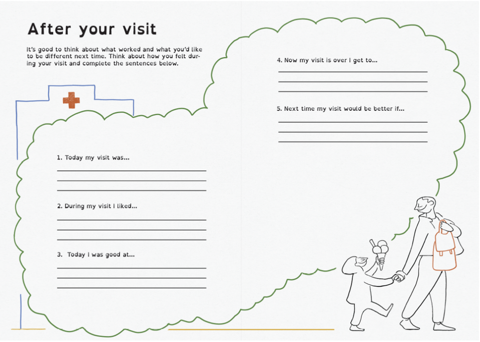
5. Two things which you can do to help me today...



For Parents / Carers

You know your child better than anyone else. Other parents and carers have told us some 'Top Tips' about what can help you and your child before, during and af ter their visit to hospital

1. It can help if you know what is likely to happen when you and your child visit the hospital.
2. Looking through this booklet with your child can help you both plan and be prepared for your visit.
3. You know your child better than anyone else, but parents say that talking with their child early on about what will happen, who they might see and what could support them during their visit is helpful.
4. Parents say talking and thinking about the best way for their child to sit and stand still for their procedure before they go to hospital is helpful. You could even practice 'staying still like a statute' or 'freezing'!!
5. When you are at the hospital it is okay for you to ask staff what will be happening and in what order.
6. Even if you are feeling anxious or scared, try to appear calm, as this can help your child be stay relaxed.
7. Try and support your child to be able to share what matters to them, what they are feeling and what could help them.
8. Try and make a plan with staff for what will happen if your child becomes too upset or if things get too difficult for your child.
9. Use page 13 to think about what went well and what could be done differently next time.



After your visit

It's good to think about what worked and what you'd like to be different next time. Think about how you felt during your visit and complete the sentences below.

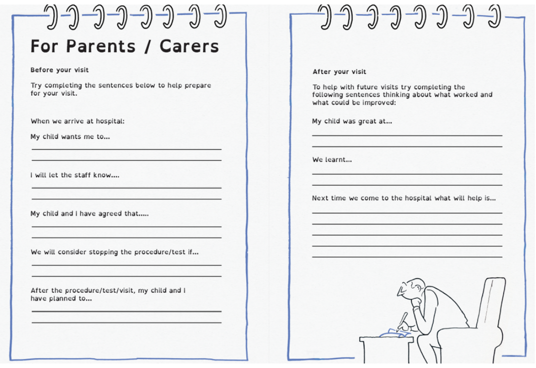
1. Today my visit was...
2. During my visit I liked...
3. Today I was good at...
4. Now my visit is over I get to...
5. Next time my visit would be better if...

CERTIFICATE OF ATTENDANCE

On ....

.... did really well during their hospital visit

Signed .... (Health professional)



For Parents / Carers

Before your visit

Try completing the sentences below to help prepare for your visit.

When we arrive at hospital:

My child wants me to...

I will let the staff know....

My child and I have agreed that.....

We will consider stopping the procedure/test if...

After the procedure/test/visit, my child and I have planned to...

After your visit

To help with future visits try completing the following sentences thinking about what worked and what could be improved:

My child was great at...

We learnt...

Next time we come to the hospital what will help is...

NEXT STEPS

PILOT TESTING THE GUIDE IN HOSPITAL

The team have encountered several factors which have limited the ability to pilot or test out the developed 'Guide to Hospital' in practice, The designer was delayed in issuing the final version due to illness and despite several families volunteering to pilot the resource they were not available before the ethics approval period expired.

The team are currently seeking additional funding through alternative sources to complete Phase 3 to pilot the resource. We then hope to conduct further evaluation and implementation work to develop robust evidence to underpin the use of the Guide to Hospital.

DISSEMINATION

The team have held several meetings with key members of the learning disability nurse network and also paediatric networks across the UK.

We are currently drafting a paper focussed around the scoping review and will begin to seek peer-reviewed gold open access to report the development process and the final resource.

We will establish a webpage within our institution to house the resource.