Shine 2012 final report

Listening to You

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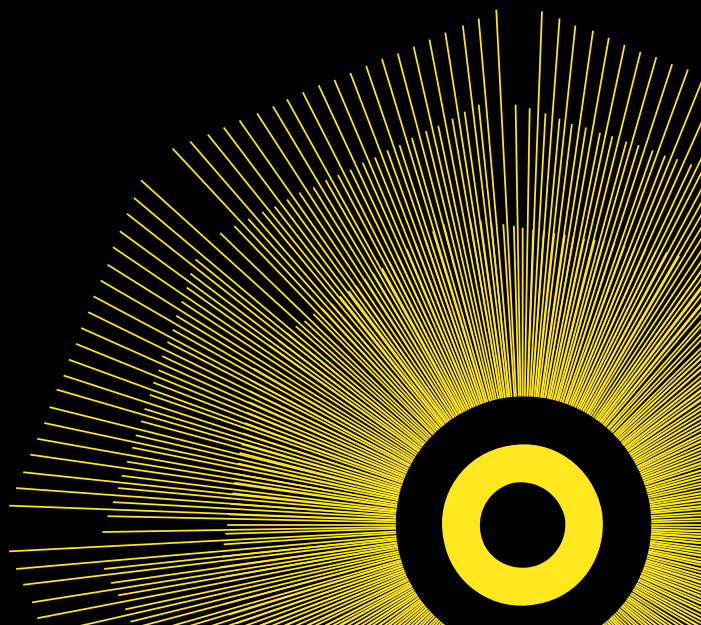
Birmingham Children's Hospital

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Part 1. Abstract

Project title: Listening to You

Lead organisation: Birmingham Children's Hospital

Partner organisation: None

Lead Clinician: Hermione Montgomery

Abstract

At Birmingham Children's Hospital, we recognise the importance and value in working in partnership with children and their families in identifying and understanding the subtle changes in a child's health. We appreciate that different parents, families and carers voice their concerns in different ways and at different times. The 'Listening to You' project aimed to formulate an intervention, through the development of a tool, that would acknowledge and act on parental/carer concerns in a structured and unified approach. This would enable parents' concerns to be used to help manage the children's healthcare needs and plan accordingly. Previously, sometimes the way parents/carers raised their concerns, and the way in which these were heard by us varied. Therefore there was an inconsistency in the ways these were acted on resulting in poor patient experiences and occasional failures to escalate concerns. We wanted to empower parents to communicate these concerns and differences (from their child's normal), for their child (especially those with learning difficulties), in a way that was appropriate for them and in a way that could be documented and escalated.

We approached the formulation of the tool based on our findings of current practices in other paediatric settings (through a telephone survey and a literature review) and through information gathering during interviews with 10 BCH parents and 13 staff. This led to the development of a parental communication bundle comprising of three elements:

- A leaflet for *parents/carers* including topics such as how to have a more effective conversation and a diagram to help pinpoint what "just isn't right".
- A leaflet for *staff* on their role in the Listening to You project,
- A 'Planning Care Together' form which allows parents and staff to share, discuss and document parental concerns. This is one way that parental concerns can be monitored on a continual basis, where necessary and any deterioration can be identified in a timely way.

Phase 1: Scoping

The project started with a scoping phase completed by a team of healthcare researchers and included:

- An in-depth literature search to identify current practice relating to the management and escalation of parental concerns
- A national telephone survey of other national acute child healthcare providers.
- Qualitative interviews with parents, nurses and doctors. The interviews provided the project team with an understanding of how parents would like to escalate their concerns and what would help them to communicate effectively with staff.

This provided information on current practice in this area in other hospitals (none) and ensured that the design of the tool would reflect the need of parents and staff.

Phase 2: Design and refinement of the Communication Bundle
The design of the tool was strongly influenced by key stakeholders – parents, staff and young people, who worked together with the project team. The communication bundle was taken to bedsides, feedback forums and a Young Persons Advisory Group meeting to be discussed and the comments were used to refine it. This led to the development of the final communication bundle for parents to use when sharing their concerns with staff, either verbally or in writing.

Phase 3: Pilot phase and evaluation
The communication bundle was piloted for a month in five clinical areas. The use , spread and success was evaluated on a daily basis (see Part 2 – Quality impact: outcomes). The main method of evaluation was through qualitative questionnaires aimed at parents and staff. It was challenging to evaluate the success of the intervention during such a short pilot phase as many parents were unaware of the intervention and therefore the success could not be measured. However, the limited evaluation remained valuable as it helped our understanding of how parents/staff access the information, how we can improve the project's visibility and therefore use.

What went well?
By developing a more responsive approach to parental concerns, we have aided communication between professionals and parents/carers, therefore ensuring that parents are active partners in the decision-making process whilst their child is in our care. We are open to listening to families and acknowledging their fears which enables us to act on the subtle changes that a parent recognises in their child that perhaps we may not witness, despite our regular assessments (using Paediatric Early Warning Score (PEWS) observations) and monitoring equipment.
This work is exploratory; the project has continually evolved since the initial proposal. However, it has achieved the original aim of: developing an intervention to improve communication of parental concerns and appropriate escalation of care. There have been some examples of positive changes in care, such as a long-stay family who managed to resolve a communication breakdown using the Planning Care Together form and now continue to feel comfortable communicating with nursing and medical staff in a meaningful and effective way.

Challenges
Changes to the project personnel and delay from the research team initially put the project behind schedule. The impact of this was to limit the pilot phase which increased the challenges surrounding staff buy-in and dissemination of the information to parents (see Part 4: Learning from your project). There was also some initial resistance to the new intervention before staff could clearly understand the benefits. Dissemination of information to parents has been reassessed and the parent and staff leaflets will be replaced with a more accessible, and sustainable, format in the future (see Part 5 – Plans for sustainability and spread).

General comments

The intention of the original proposal was to develop a parental concern framework which comprised of a parental concern tool to measure, monitor and to quantify the level of parental concern and to incorporate this data into our handover process. The original concept of bid being that parental concern could be quantified and included into our other escalation processes.

The original bid by implication made assumptions about what parents would want to communicate to us, how they would like to communicate and what they needed to make communication more effective. The changes to the project team brought with it a style of participatory working with parents which impacted positively upon the project outcomes. The outcomes are still very similar to the original bid but the approach and delivery are different. We have future plans to use parental concerns that we identify and incorporate these into the new electronic clinical handover and i-phone escalation process. As yet these are still developmental within the organisation and are not ready to consider how to incorporate parental concerns.

We now have a communications bundle which was designed by parents and a group of staff who have reflected upon why communications breakdown and appreciate how we can improve upon this position. The resources will empower parents to understand that is acceptable to ask questions or make comments about the child's care and that we welcome these.

Part 2: Quality impact: outcomes

We wanted to deliver a process whereby parents were included in the clinical assessment of their child, taking on board and believing the phrase 'Parents know their children best'. Past serious incidents, formal complaints and PALS contacts told us that sometimes parents felt unheard when they tried to escalate their concerns about their child's condition. They said that sometimes they found this difficult to do and that in a few instances a failure to listen had contributed to significant harm occurring. The parents focus groups echoed this and also reminded us of the organisational power imbalance for example parents worried about the care their child would receive if they were perceived to be difficult parents.

The trial showed us that we were correct in an assumption that most communications was effective. A majority of parents while they appreciated the potential need for the communication bundle said that they probably would not need to use it.
. The Planning Together Form successfully aids those who do not feel comfortable raising concerns verbally. Whilst parent numbers are small (5), it is very important that they are still heard in a way which is valuable to them.

Context:
The project was piloted on five wards that host a range of specialities such as cardiac (including surgery), oncology, respiratory and long term conditions (Cystic Fibrosis and Diabetes). Patients age ranged from neonates to young adults and some had learning disabilities. The pilot was widened to include parents with children on Paediatric Intensive Care Unit (PICU) as staff identified these parents had a definite need and would benefit from the communication bundle.

Metrics and Outcomes and Evaluation
We are unable to ascertain the exact number of communication bundles given to parents as these were given out on admission by the pilot ward staff. However the quality impact has been that parents who have used the communication bundle have gone on to have effective dialogue with staff as was demonstrated in PICU with one family restoring their faith and relationship with the staff there.. A parent in the cardiac area said that the Planning Together Form helped her to write down question to address with staff

Questionnaires
The daily questionnaire was the most informative way to measure the success of the intervention and 51 parents and 49 staff took part in the evaluation.

Parents
- Have you seen the Listening to You information? (two separate questions – poster/leaflet) *2 parents said that the information gave them more confidence.*
- Have you used the information to have more effective communication with staff? *6 parents said that had verbally interacted with staff.*
- Have you used the Planning Care Together form, and if so then the nature of the concerns raised. *3 parents said that they had used the form and staff confirmed that this was mainly for feeding queries and reassurance.*

Staff
- Have you found the staff information easy to use? Out of the 38 staff who knew about the project 22 felt that this would help the improve their confidence and this was embraced by student nurses and newly qualified staff
- Has it increased your workload? And if so is it manageable/acceptable*? 35 staff said no increase in workload, 1 too early to tell and 2 may increase workload initially*
- What types of concerns have parents have raised using the Planning Care Together forms? *Feeding issues and 1 parent said useful to write down questions.*

Anecdotal
Due to the sensitive nature of PICU, evaluation was not carried out in the same way and was largely based on anecdotal information. PICU Family Liaison nurses regularly reported to the project team on the effectiveness of the intervention and in particular, highlighted one family who greatly benefitted from the Planning Care Together form to then restore verbal communication. Evaluating in this way has been very successful as the Liaison nurses have a good rapport with the families on PICU and have been receptive to the project.

Quantitative
The Project Team also collected information from the Governance Department relating to the number of serious incidents, formal complaints and PALS queries regarding parental concerns and the escalation of concerns. This was pre-dated to June 2013. A monthly report identifies complaints based around a number of keywords and themes:
- Mum
- Dad
- Mother
- Father
- Family
- Parents
- Difficulty in obtaining clinical assistance
- Communication

Only 2 incidents relate to staff not listening to the concerns of parents before the project commenced and none since December.

Patient Experience
The Patient Experience Team has provided the Project Team with data from the hospital's feedback app, the friends and family forms and the patient experience feedback cards. The app has proven popular as it provides parents an opportunity to make comments that are visible to the public on the Trust's website in real time, and ward/department managers are asked to respond within 24 hours so it was interesting to see if there were any relevant concerns on here. The comments for the trial wards have been extracted from these three channels and any comments relating to parental concerns and escalation of care have been filtered out.

PEWS Charts
Our innovative PEWS (Paediatric Early Warning System) was introduced in 2008 and the observation charts have a box for nurses to complete with a yes/no answer as to whether parents have concerns. We have not provided staff with a standard operating procedure to use when completing the parental concern box. It was interesting to monitor the frequency of their completion. On two cardiac wards reviewed, 81% of the parental/nurse concern boxes were completed and of the completed boxes, only 4% documented a parental concern which is positive.

This table demonstrates the validity and reliability of the information sourced

What	Source/Ease of access	Validity	Reliability
Daily evaluation questionnaires	Verbally collected feedback from staff and parents by Project Leads	If parents had seen the information then this was a valid way to gather feedback on its use. However, some parents hadn't seen the information so it was hard to find out if it was useful. However, it identified the barriers in dissemination	Potentially some bias if staff/parents feedback what they think we would like to hear rather than their honest opinion
Anecdotal/verbal feedback	Verbal feedback from various staff/parents to either Project Leads. Collected on the wards, at meetings and through third parties such as PICU Family Liaisons	Useful for gathering feedback that isn't addressed by a specific question on the questionnaire	This can sometimes be more valid/less biased than the questionnaires as parents/staff are volunteering information. They therefore do not feel under pressure to say "the right thing"
Serious Incidents Requiring Investigation	Governance Department sends monthly reports	Measures the number of Serious Incidents Requiring Investigation relating to parental concerns and escalation of concerns – a very low number as only serious incidents	There is a certain degree of subjectivity as although reports are based on keywords they are not all relevant to parents concerns/escalation of concerns – filtered for relevance by Project Leads
BCH Feedback App	Patient Experience team sends app comments relating to the trial wards to Project Leads who extract those relevant to Listening to You	Measures the number of comments that come through on the feedback app relating to parental concerns	Degree of subjectivity as to whether comments relate to parental concerns/escalation of care as they are filtered for suitability by Project Leads
Friends and family form	Patient experience team sends Project Leads data from the Friends and Family form database, Project Leads then filters this information for comments relating to parental concerns/escalation of care	Measures the number of comments that are noted on the (CQUIN) Friends and Family form in the "need to improve" section	Degree of subjectivity as to whether comments relate to parental concerns/escalation of care as they are filtered for suitability by Project Leads

PEWS Parental concerns box	Project Leads spent time on two wards looking at the completion of their PEWS parental concerns boxes	Measures the number of completed boxes - if complete, shows that nurses are asking about parental concerns. This is good as it can reflect that parents/carers are comfortable enough to raise concerns verbally – thus not necessarily needing the planning care together form	Not very reliable measure of whether there are/are not parental concerns if the boxes are left blank

Part 3: Cost impact

The original plan did not include a cost impact prediction, the fundamental premise of this work was to prevent the very occasional care deficit which parents had tried to escalate to us but had not been heard by us.

There has been a limited time frame to identify whether the intervention had a cost benefit we have however, looked at some cost impact measures. The main measure has been the impact on staff workload, the daily evaluation questionnaires has shown that the workload of frontline staff has not increased since introducing the intervention.

We have not been able to quantify any saving as a result of our innovation.

It may be possible in the future to extrapolate cost benefit. For example following Trust-wide adoption of the 'Listening to You' communication bundle there may be a corresponding drop in PALS contacts or formal complaints. This may then allow us to find staffing cost savings.

Part 4: Learning from your project

As the project has evolved it has faced an array of challenges that have been overcome and that have provided learning points for future implementation of a similar project

Project Personnel and its effects
There were significant changes to key Project personnel. the original Project Lead moved roles and the original Project Manager left the trust in September 2013. This would have had a significant impact on continuity had the Executive and senior management commitment not remained constant. The need for a new team was responded to and the new project team brought with them a broad variety of skills. During the changeover phase the organisation communicated and updated the Health Foundation.

The changes in personnel contributed to the fall behind schedule, along with the long scoping phase. Therefore the pilot phase was conducted at a busy time in the hospital, when winter bed pressures were felt. This, combined with the Christmas period and a disruption to routine, was not the most effective time to pilot. However, The Project Team were eager to start the pilot as soon as the communication bundle was created.

Staff buy-in and project spread
Staff resistance has been one of the challenges that the project team has faced as some staff have been resistant to new ideas and their current culture has needed to be challenged specifically in relation to empowerment of parents..
This could have been anticipated had a robust stakeholder analysis been completed at the beginning of the project. We should have anticipated that by encouraging parents to be more vocal about their concerns that staff would feel the impact of this. Empowering parents and children and young people is positively promoted within the organisation but personal beliefs about how patients should be i.e. 'patient role' may over power this. These resources have challenged the status quo in some settings and as on organisation we need to support this challenge in order spread and sustain the innovation.

In the areas where we have found staff buy-in challenging it has been interesting to learn how to overcome this. A successful strategy has been through the use of examples. On wards where Ward Managers could use an example of a situation where the intervention would have been valuable it has been easier to engage staff with the project. This reinforces the fact that only a few parents may need the communication bundle. Especially valuable are examples where staff have struggled to escalate concerns to other teams and would have found the intervention empowering by using the staff tool and having the backing of the Executive Team. The project also aids staff to use the power of the parent voice to escalate their concerns.

The value of advocates of the project has been highly recognised. Whilst the Project Team approached the ward managers on each trial ward to help launch the project in their areas there have been certain other individuals that have approached the team. Project spread was particularly helped by these "champions" who have helped keep momentum going throughout the pilot phase and been very supportive. By having staff that are comfortable with explaining the project to parents and encouraging them to use the Planning Care Together form i(f necessary) this initiates the interventions use as if parents complete the form, it is then the responsibility of their bedside nurse for that day to acknowledge, act on, and sign off the form.

Dissemination of the information and accessibility for parents

A challenge that appeared during the pilot phase was embedding the practice of informing parents of the intervention into nurses' communications. Often there was a barrier to disseminating the information from staff to parents/carers and patients. As the new information had only been in place for a month, at the end of the pilot phase, when effectiveness was first evaluated, there were a number of parents and staff who were unaware of the project and communication bundle. The difficulty in educating all staff in a pilot area was increased by the shift patterns the nursing staff worked and the pilot phase being conducted over the Christmas period which made it difficult for the project team to speak to all the staff on the pilot wards. This highlighted to the team the importance of the timing of the pilot phase and the importance of a robust pilot phase.

The impact of the project was hard to evaluate when some staff and parents were unaware of it. Therefore we will continue to educate staff on wards about the project both through formal sessions and informal conversations; this will include an increase in structured training sessions, some of which have recently started on a weekly basis on the oncology ward. The project team will also be more represented at staff handovers, where they can educate about the project to staff.

User friendly interventions

The project team identified that the intervention needs to be made more accessible to parents in a variety of ways and not just rely on nurses disseminating the information. Therefore, since the trial, new methods of communication have been developed (see Part 5: Plans for sustainability and spread).

In order to encourage the parents to take an active role the Listening to You project posters have been modified to include encouragement of parents to ask staff for Planning Care Together forms if they need them. This positive action by parents can prompt discussions and further increase nurse awareness of the project.

On the oncology ward the Clinical Support Worker's offer a tea round for parents in the morning. They use this opportunity to offer parents Planning Care Together forms. On PICU they have Feedback Friday's in the parents room, where parents can talk to the Family Liaison nurses about any concerns and they can provide Listening to You information and Planning Care Together forms to those who need it. The Play Facilitators on each ward are also aware of the Listening to You project and can provide parents with leaflets and Planning Care Together forms.

These strategies will help to reduce the pressure of relying on Ward Managers to disseminate information to their staff. A future communication plan will also inform the wider team of the resources.

Involving the PACE Team

The PACE (Paediatric Assessment Clinical Intervention and Education) Team originally wanted to launch their parent activated phone line at the same time as the Listening to You information was introduced. However, their direction has changed and they now realise that they would like the Listening to You project to be well-embedded with staff and parents before they launch the phone line. This will assist them in reducing the number of unnecessary calls as well as the spread of the project as they will ask whether the parents were provided with Listening to You information and whether they had documented their concerns on a Planning Care Together form, and what the response was, prior to using the phone line. This will act as a reminder for parents and staff that the information is available and to use Planning Care Together forms where necessary.

Part 5: Plans for sustainability and spread

In order to ensure sustainability and spread of this new intervention across BCH we have planned dissemination in the following ways:

Internal dissemination of the communication bundle
- Presentation at the Chief Executive Briefing:
- Informative piece about the resources on the intranet
- Engaging with the ACMO Safety Team to identify the most effective way of dissemination to the medical staff
- Targeted email to the Heads of Nursing, Lead Nurses and Ward Managers
- Verbal communications to key areas e.g. the PACE team
- Presentations to ward teams

Engagement by all staff
-
- A staged plan for use of the communication bundle in all ward areas starting with the surgical areas
- Use of some staff of the pilot wards to act as role models new staff using the communication bundle
- The use of staff to develop networks around the hospital who will then act as Champions e.g. Safety Link Workers and Play Staff.

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Ensuring that the communication bundle is accessibility
- The communication bundle is being incorporated into the new bedside folders which will be accessible by all parents providing consistent standardised information.
- Insertion of the communication bundle into the "pre-admission" pages on the hospitals website which is often used by parents before coming into hospital.
- The staff information will be made into a card that can be inserted as an extra page into the Safety Manual handbooks carried by all nurses, both on the main site and by the Children and Young People Mental Health Service (CAMHS) nurses. This is an easily accessible and visually appealing handbook that is kept in nurses' pockets and contains important information.
- The Planning Care Together forms will be kept in an easily accessible location on each ward (such as parents' rooms) so that parents can use them on a needs basis.
- Linking the Listening to You work to the Electronic Clinical Handover project is being explored. An electronic system has been developed which collects all valid parent information in preparation for handover. The electronic page has been "future-proofed" with a space/tab for parental concern. It is hoped that the Listening to You communication bundle will clarify parental concerns and empower them to participate in the handover of their child's medical/nursing care...
- Adapting the bundle for young people. Whilst the phase used to formulate the tool involved lots of input from young people – on the wards, at feedback forums and discussions with the trust's Young Persons Advisory Group, the tool itself is currently aimed at parents. A future project will be to design a more versatile tool to appeal to both young people (patients) as well as their parents/carers.

External dissemination of the communication bundle

- The project will be presented at a Paediatric Safety Conference and at the next National Paediatric Nursing Conference
- The communication bundle will be presented at various paediatric networking events
- Co-working with another paediatric health provider on a project to expand the communication bundle is being explored.

Appendix 2: Resources from the project

Quotes from parent's pre and post use of communication bundle

Pre use

 "I didn't feel that I was given credence"
"Maybe there could be a very general pathway for knowing who to go to if you are concerned

- your nurse, your ward manager"

"There could be something that says if you see your child going through any of these, these are the steps you could take"
"Write down any concerns, if you can, as and when they happen"

Post use

 "Although we haven't needed to use these ourselves because we know the staff, we can

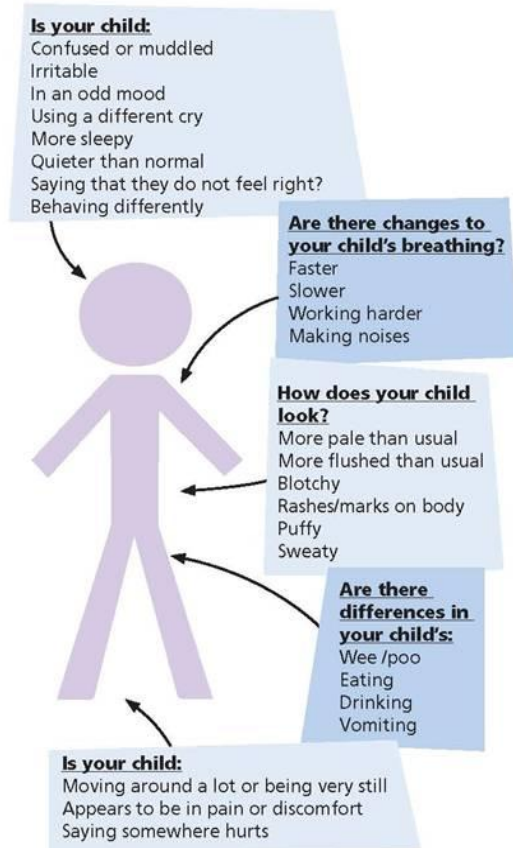see the value of it and how it will benefit new parents to the ward"

"The written form would be useful to remind me to ask particular questions of staff"

"We used the Planning Care Together forms with one long-stay family where it was identified

that there had been a communication breakdown. Through using the forms a couple of times

verbal communication was successfully restored" (Family Liaison Nurse).

Appendix 3: Communication Bundle for Parents

Look at your child
Use this diagram as a guide to help you describe what is making you worried.

Is your child:
Confused or muddled
Irritable
In an odd mood
Using a different cry
More sleepy
Quieter than normal
Saying that they do not feel right?
Behaving differently

Are there changes to your child's breathing?
Faster
Slower
Working harder
Making noises

How does your child look?
More pale than usual
More flushed than usual
Blotchy
Rashes/marks on body
Puffy
Sweaty

Are there differences in your child's:
Wee /poo
Eating
Drinking
Vomiting

Is your child:
Moving around a lot or being very still
Appears to be in pain or discomfort
Saying somewhere hurts

These are just examples; if you see any other signs please tell us what they are, talk to your nurse or doctor.

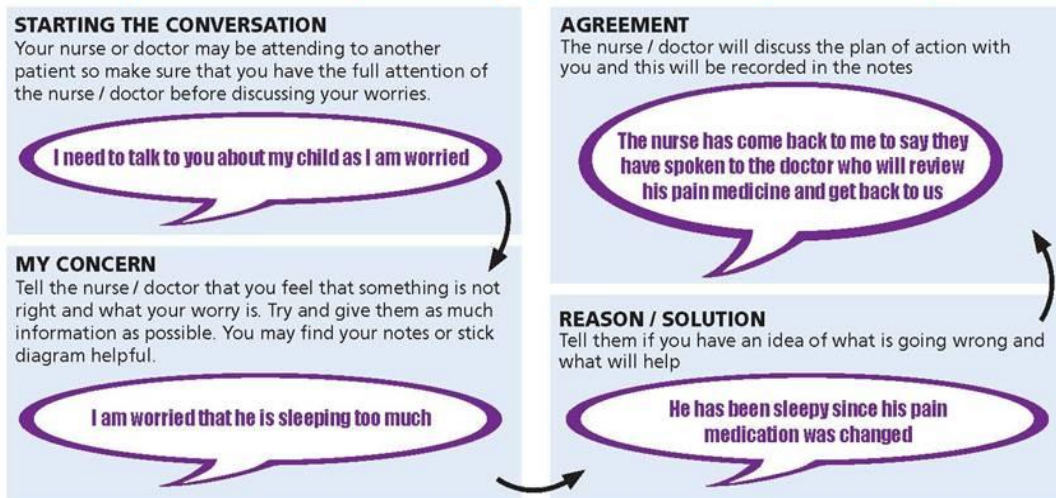## What to do next, you may not need to progress any further than step 1.

Step 1 Talk to your nurse

We will:
Assess your child
Do observations
Record on PEWS chart

We will:
Escalate your concern

We will:
Keep you informed and involved in any decisions

Step 2 Talk to the nurse in charge

Step 3 Talk to a doctor on a ward round or ask a nurse to call a doctor

Definitions:

PEWS = Paediatric Early Warning Signs - the coloured chart that the nurses write the observations on

Escalate your concern - raise your worry to get your child re-assessed by a senior member of staff.

You may use these tips to help you describe your worry to staff

STARTING THE CONVERSATION
Your nurse or doctor may be attending to another patient so make sure that you have the full attention of the nurse / doctor before discussing your worries.

I need to talk to you about my child as I am worried

MY CONCERN
Tell the nurse / doctor that you feel that something is not right and what your worry is. Try and give them as much information as possible. You may find your notes or stick diagram helpful.

I am worried that he is sleeping too much

AGREEMENT
The nurse / doctor will discuss the plan of action with you and this will be recorded in the notes

The nurse has come back to me to say they have spoken to the doctor who will review his pain medicine and get back to us

REASON / SOLUTION
Tell them if you have an idea of what is going wrong and what will help

He has been sleepy since his pain medication was changed

Talking to staff about your worries:
Planning care together

Birmingham Children's Hospital **NHS**
NHS Foundation Trust

IF YOU FEEL THIS IS AN EMERGENCY PLEASE CALL FOR IMMEDIATE HELP FROM ANY MEMBER OF STAFF

My child's name is:

Today's date:

What I would like you to know:
Sharing my worries, concerns or observations...

What I would like us to do next:
Planning the journey together...

You can share this information with staff if you wish. This information has been shared with the:

☐ Bedside Nurse: Name _____   Signed _____   Date ___ / ___ / ___
☐ Medical Team: Name _____   Signed _____   Date ___ / ___ / ___

Please file with the PEWS charts. To be used in conjunction with the **"Listening to You"** project

Appendix 4: Planning Care Together Form