

# Children's Services

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Trust Board paper C

## Purpose of report:

This paper is for:	Description	Select (X)
Decision	To formally receive a report and approve its recommendations OR a particular course of action	
Discussion	To discuss, in depth, a report noting its implications without formally approving a recommendation or action	X
Assurance	To assure the Board that systems and processes are in place, or to advise a gap along with treatment plan	
Noting	For noting without the need for discussion	

## Previous consideration:

Meeting	Date	Please clarify the purpose of the paper to that meeting using the categories above
CMG Board (specify which CMG)	October 2020	Discussion
PIPEAC	16.11.20	Discussion

## Executive Summary

In line with national guidance, visiting restrictions due to COVID-19 have been in place since April 2020. These restrictions are there to protect patients, visitors and staff, and although these restrictions are understandable, at times this is very difficult for families who cannot be together and for staff to maintain. Therefore each patient and family is viewed individually and staff have demonstrated compassion and flexibility in rising to this challenge.

This family story is about a child who required treatment in the Children's Hospital during the first wave of the pandemic and reflects the difficulties for parents and siblings being apart and how the clinical staff successfully balanced the needs for safety and family support at this difficult time. This story will be shared via a video recording, where the child's mother details their experience.

## Why has this patient story been selected for Trust Board?

This story is about a child who at six months old was diagnosed with Neuroblastoma, a cancer that forms in certain types of nerve tissue. The Neuroblastoma caused reduced movement in the child's legs and she was unable to weight bear or begin to crawl. Treatment was commenced at Nottingham University Hospitals, and was then transferred to Leicester Children's Hospital and care delivered on the oncology and haematology ward. Following appropriate treatment including a five month course of chemotherapy the child is now in remission and has regained the feeling and use of her legs, and is crawling. The family will receive ongoing surveillance with clinical review and imaging for the next five years. They will then transition into the Late Effects clinic for lifelong monitoring of growth and development to ensure there are no problems. The family will be provided with healthy lifestyle advice, education and support for any future issues.

This positive story illustrates how the clinical teams have delivered expert care and successful treatment while also adapting to the challenges of COVID-19 and the restrictions on visiting. The clinical team has been very supportive of the parents and family, acknowledging the times that it is

appropriate for the father and mother to be present together at appointments, to support each other when messages might be difficult.

**What are the key themes in the patient story and how applicable are they across the Trust?**

There are a number of learning points from this family's experience that are transferable across the Trust to reinforce the importance of this element of practice for all disciplines and specialties.

One of the main elements is how the mother details the ease with which the family have been able to access information and that they were able to call for help and advice at any time and were not made to feel that any of her questions were irrelevant. Also the flexibility in visiting as the child's father and mother were invited to attend clinic appointments together so they could discuss the baby's clinical condition or ongoing treatment, which enabled them to support one another through this difficult time.

Another key element that was very positive for the family was that during the time their baby was coming into Leicester Children's Hospital, staff were wearing face masks in line with the COVID-19 advice. The mother explains that due to the way that the staff members have interacted with her daughter, she has never been afraid and has always been happy and smiling.

**What are the key learning points to improve the quality of patients care/experience?**

Before COVID-19 the Children's Hospital welcomed both of a child's parents/guardians and also their siblings/extended family every day for prolonged visiting times. With the current national requirements to keep children in hospital safe from infection, families are not able to be together and therefore the usual support is not as easily available.

This family story is an illustration of the flexibility and compassion clinical staff are exhibiting every day to try and support families during this difficult time. The Children's Hospital recognises the need to keep children, young people and their families connected. For children and young people it is important that they can be with their parents or guardians while they are in hospital as they can be frightened and suffer with separation anxiety.

The Children's Hospital is also keen to continually hear from families and carers at this difficult time and a number of initiatives are taking place to seek feedback and engage with families. One of the most successful mechanisms to elicit feedback has been the introduction of an electronic survey specifically focused upon visiting and if families are feeling isolated or unsupported. This is available across the Children's Hospital and does include the Friends and Family Test score which has been 99% positive to date. The free text comments illustrate high levels of satisfaction from parents and families.

The Trust is continually reviewing the present restrictions for visitors and responding to the family and carers survey results in real time as well as looking at trends since July 2020 when the survey commenced.

**For Reference:**

**This report relates to the following UHL quality and supporting priorities:**

**1. Quality priorities**

Safe, surgery and procedures	Yes
Safely and timely discharge	No
Improved Cancer pathways	Yes
Streamlined emergency care	No
Better care pathways	Yes

Ward accreditation Yes

**2. Supporting priorities:**

People strategy implementation Not applicable  
 Estate investment and reconfiguration Not applicable  
 e-Hospital Yes  
 More embedded research Yes  
 Better corporate services Yes  
 Quality strategy development Yes

**3. Equality Impact Assessment and Patient and Public Involvement considerations:**

- What was the outcome of your Equality Impact Assessment (EIA)? This is a patient Story and therefore is one family’s experience of care
  
- Briefly describe the Patient and Public Involvement (PPI) activities undertaken in relation to this report, or confirm that none were required. This is a patient Story and therefore is one family’s experience of care, and has been chosen because it illustrates a patient feedback theme.
  
- How did the outcome of the EIA influence your Patient and Public Involvement ? N/A
  
- If an EIA was not carried out, what was the rationale for this decision? See above

**4. Risk and Assurance**

**Risk Reference:**

Does this paper reference a risk event?	Select (X)	Risk Description:
<b>Strategic:</b> Does this link to a <i>Principal Risk</i> on the BAF?		
<b>Organisational:</b> Does this link to an <i>Operational/Corporate Risk</i> on Datix Register		
<b>New Risk</b> identified in paper: What <i>type</i> and <i>description</i> ?		
<b>None</b>		

5. Scheduled date for the **next paper** on this topic: March 2021  
 6. Executive Summaries should not exceed **5 sides** My paper does comply