The Queen Elizabeth Hospital King's Lynn
NHS Foundation Trust

Meeting:	Board of Directors (in Public)		
Meeting Date:	1 September 2020	**Agenda item:**	2b
Report Title:	Update on the Patient Story		
Author:	Edmund Tabay, Deputy Chief Nurse		
Executive Sponsor:	Dr April Brown, Chief Nurse		

Implications

Link to key strategic objectives

KSO1	KSO2	KSO3	KSO4	KSO5	KSO6
Safe and compassionate care	*Modernise hospital and estate*	*Staff engagement*	*Partnership working, clinical and financial sustainability*	*Healthy lives staff and patients*	*Investing in our staff*

Board assurance framework	Patient experience supports the delivery of safe and compassionate effective care as set out in KSO1.	
Significant risk register	None	
	Y/N	If Yes state impact/ implications and mitigation
Quality	Yes	Patient experience is a key element of quality, alongside providing clinical excellence and safer care.
Legal and regulatory	No	
Financial	No	

Assurance route

Previously considered by:	None

Executive summary

Action required: *[highlight **one** only]*	Approval	**Information**	Discussion	Assurance	Review

Purpose of the report:	To update the Trust Board on actions taken following the patient story at the Trust Board meeting on 4 August 2020.
Summary of Key issues:	The patient story at the Trust Board meeting in August 2020 was presented by Jennie Turner, mother of late Bonita 'Bonnie' Turner who was born with complex health needs and died in 2019. Our Paediatric Team had the privilege of caring for Bonnie for most of her life and provided individualised end of life care in Bonnie's home. Bonnie's family recognised that at some point she would be transitioning to adult care and the thought of that was a source of concern, leaving a multi-disciplinary team that knew and appreciated their daughter's clinical needs and moving to an unknown adult team or teams and the risk of fragmented care provision.
Recommendation:	The Trust Board is requested to note the actions taken following the patient story.
Acronyms	QEHKL- The Queen Elizabeth Hospital King's Lynn CCNT-Children's Community Nursing Team CCG - Clinical Commissioning Group

Patient Story Update from 4 August 2020

1. Introduction

Jennie Turner, mother of the late Bonita "Bonnie" Turner who was born with complex health needs and died in 2019, shared her reflections of the care Bonnie received whilst under the care of the Paediatric team at the QEH at the Trust Board meeting on 4 August 2020.

2. Summary

- Bonnie was cared for by the Paediatric Team for the majority of her life. Bonnie's parents, Jenny and Marcus have always trusted the staff at our Trust, leaving their child with the Team knowing that her needs will be met.
- The Paediatricians and Paediatric Community Team were able to provide individualised end of life care in Bonnie's home and she died surrounded by her family. The strong relationships between the family and our staff were evident when the family opened their home following Bonnie's death, inviting some of the staff based on Rudham Ward to say goodbye to Bonnie.
- For Bonnie's family, as with all families with children with complex needs the thought of transitioning to adult care is a concern, leaving a multi-disciplinary team that know their child's clinical needs causes concern for families.

3. Update on Our Actions Following Trust Board on 4 August 2020

- Following the story, it was recognised locally that the transition of care for adolescents from the paediatric services to adult services especially for children with complex needs or long-term conditions always pose a challenge and uncertainty for parents.
- Standards for ongoing health needs states that there must be a designated person responsible for ensuring that developmentally appropriate transitional care is provided and coordinated by both child and adult services.
- As part of the Children's Community Nursing Team (CCNT) expansion plan, the Trust is anticipating that one of the posts for the additional staff would focus on transitional care. Currently, the work for phase 2 of the CCNT development was paused at the height of the COVID-19 pandemic. This work is being restarted in conjunction with the Norfolk Clinical Commissioning Group (CCG) as the CCG will be providing the funding.
- There is also work commencing across Norfolk and Waveney Strategic Partnership focussing on transition into adult services and our Paediatric Team is in conversation with the service leads to scope out and enable joint working to improve transition and engage with the GPs and community services.

Edmund Tabay, Deputy Chief Nurse
25 August 2020