Breath of Fresh Air

Providing integrated and coordinated care for children on invasive long term ventilation and their families

Erin Krisenthal, Laura Giblin, Shefali Jani & Daniel Flunt

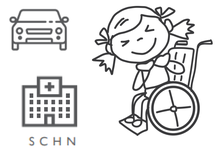
Sydney Children's Hospitals Network & EnableNSW

Case for change

24 children ventilated via tracheostomy - 22 reside in the community, 2 inpatients

Community management of these children described as "**frustrating**" and "**relentless**" by parents

Reside across NSW between 30 minutes and 8 hours drive from a SCHN hospital



Managed by **10-15 different** medical and allied health **teams after discharge**

Fractured health and community systems

Limited access to existing **ambulatory care** services due to their complexity

Parents are **isolated** and **overwhelmed**

Diagnostics

"Transport [to appointments] is tricky, you always need a carer or someone to go with you"

"Felt like hospital was washing their hands of us now we are discharged."

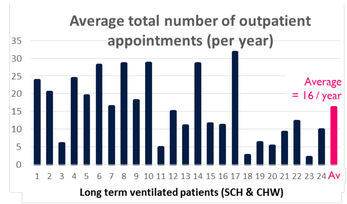
"I dread it, going to hospital"

"Sometimes you have to go [into the hospital for appointments] like four times in one month. Why can't I just go once?"

"My key frustration is the teams not communicating"

"You can never switch off. If you're tired you need to keep going. You make one wrong decision & she's dead"

Inpatient → Discharge planning → **Outpatient** → Re-admission



Ambulance Care Plans:
46% updated and completed
0% parental awareness

LTV Medical Lead:
Only 25% of children had a co-ordinating lead

Main themes uncovered

- Support after discharge
- Inpatient and community processes
- Governance structure
- Internal & external communication

Goal

To increase the support provided to children within the SCHN requiring invasive ventilation and their families after initial discharge.

Objectives

- 100% of parents of LTV patients will have reported awareness of emergency procedures to support their child after discharge by November 2018
- Reduce the number of days LTV patients attend outpatient appointments by 20% by July 2019
- 100% of children with long term ventilation needs will have an identified coordinating medical lead by December 2018.

Method

Diagnostic

- Parent interviews (n=6) – face to face
- Parent surveys (n=10)
- Multidisciplinary focus groups (n=4)
- Data analysis: Length of Stay, ED presentations, readmissions, other specialty involvement, outpatient appointments attended
- External engagement with EnableNSW, LHD Coordinators and Care Providers, Interstate Tertiary Paediatric Hospitals

Solution design

- Workshops (n=3) (site based and network medical and allied health care teams)
- Theming and prioritisation of ideas and feedback to the teams (n=3)
- Collation of an executive brief and business case

= Ambulatory care package to improve support after discharge

Results

Solution 1: Implementation of a governance structure for the Long Term Ventilation (LTV) Service	• Governance structure has been developed in consultation with clinical and executive leads, priority for 2018-2019 growth funding • Once achieved, 100% of children will have an identified medical lead
Solution 2: Enhance the utilisation of Kids GPS service (care coordination)	• 38% of LTV children are supported by Kids GPS, planned for 100% by July 2019 • We are continuously evaluating and refining the process based on parent and staff feedback
Solution 3: Development of emergency care plans	• 80% of LTV children have active Ambulance NSW Authorised Care Plans, up from 46% in April 2018. • 100% of parents who have plans now report awareness of how to use them.
Solution 4: More consistent utilisation of Hospital in The Home (HiTH) service	• Currently testing HiTH pathway with patients, families and staff to determine efficacy and usability
Solution 5: Utilising telehealth in outpatient appointments	• Currently partnering with the integrated care team to co-design telehealth solutions

One patient, 6 months, positive impact, big savings…

Sustaining change

Current ambulatory care protocols and guidelines are being reviewed in order to determine how they can be amended to incorporate children with long term ventilation needs.

Development and refinement of a new model of care for the long term ventilation patient cohort is needed to ensure that we meet the needs of the current and projected patient population by relying on documented processes instead of variable workforce relationships.

Conclusion

A coordinated approach to care for LTV children and their families aims to empower and support families throughout their community journey, minimise risk, build confidence and collaboratively manage care.

The review of the Long Term Ventilation services of the SCHN is a planned multi-year project for which this project is the first step. This project involved multiple disciplines, services, departments, processes and governance structures.

It is hoped that the processes used to incorporate the complexities and responsibilities of assisting this patient group through the implementation will pave the way for the inclusion of individualised coordination and support for other chronic and complex patients in the hospitals.

Acknowledgements

Parents and children from the Long Term Ventilation Service

Brad Ceely, Jackie Hiller and Sara Burrett Project Sponsors (SCHN & EnableNSW)

Christie Graham Redesign Leader (SCHN)

Tania Webb Patient Co-design Liaison (SCHN)

Joanne Ging & Nadine Shaw Ambulatory Care (SCHN)

Contact

Erin Krisenthal

Long Term Ventilation Coordinator

Sydney Children's Hospitals Network

Erin.Krisenthal@health.nsw.gov.au