

LEAP: A Care Pathway for Long Term and Additional Needs Patients in Paediatric Critical Care Environments.

Patient Experience After One Year of Use.

D. Arambepola, S. Cuevas-Asturias, O. Banerji, T. Jerrom, J. Fraser, H. Cunningham & The LEAP Team

Introduction

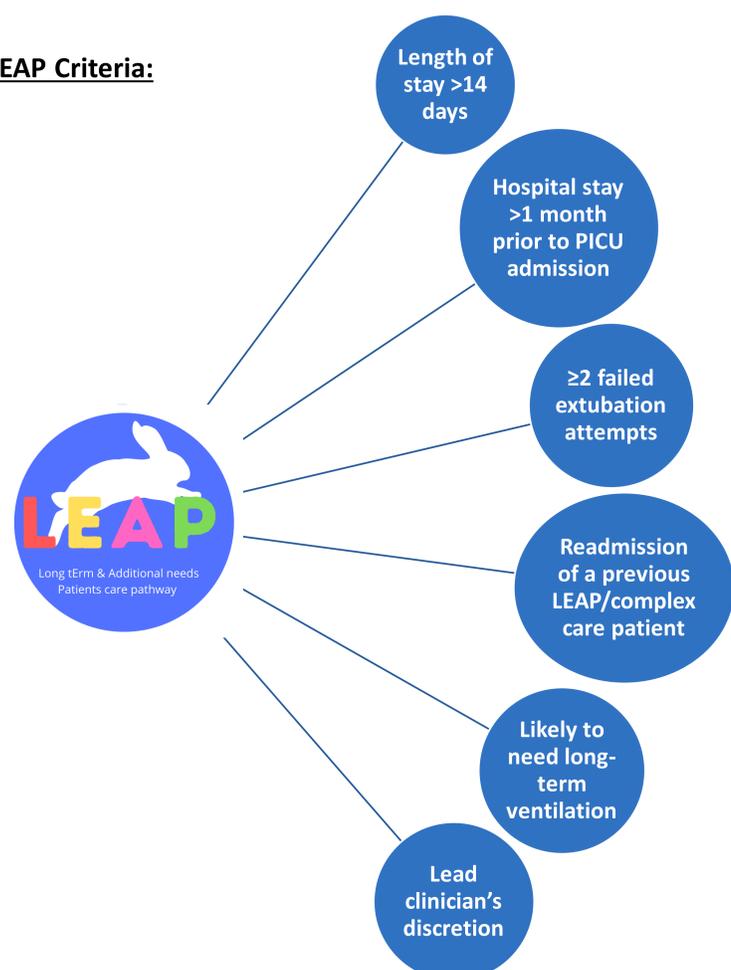
Children with chronic and complex conditions are a growing cohort presenting unique challenges.

We introduced the LEAP pathway to our PICU in May 2021:

- Engages a core multidisciplinary team around the child.
- Provides practical tools to address and monitor acute and longer-term needs, e.g. specific paperwork, bedside charts.

This survey sought to explore families' experiences in our PICU before and after the implementation of LEAP.

LEAP Criteria:



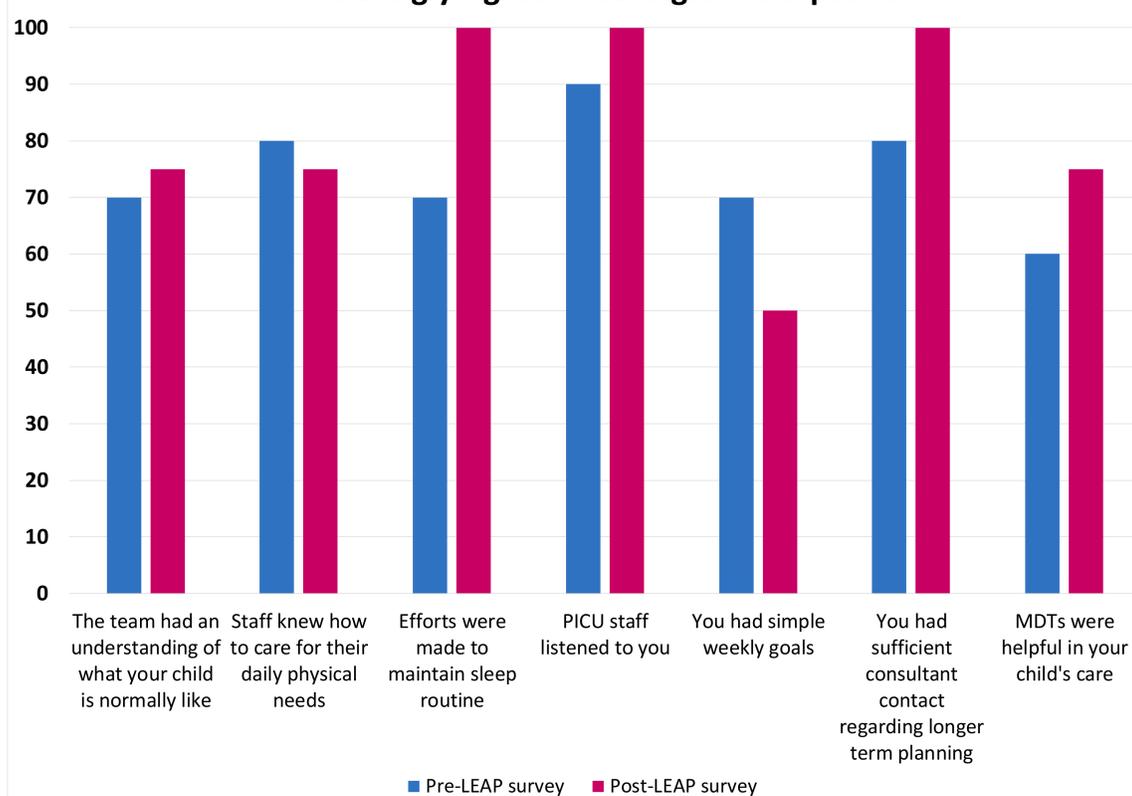
Results

Survey response rate: Pre-LEAP survey: 10/98 (10.2%)

Post-LEAP survey: 4/61 (6.6%)

Themes from free text answers: Pre-LEAP	Themes from free text answers: Post-LEAP
Sleep disturbance due to light & noise.	Being looked after by multiple different staff members made establishing routine difficult.
Suggestion of having a separate, dedicated area in the unit for LEAP patients.	Parents particularly liked bedside routine charts.
Need for earlier engagement of teams who will be involved post-discharge.	2/4 (50%) parents felt they did not fully understand what LEAP involved.

% of "Strongly Agree" and "Agree" Responses



Methods

- Pre-LEAP survey: Patients retrospectively identified from admissions in the 3-year period 2017-2020.
- Post-LEAP survey: Patients labelled as LEAP patients during admission from May 2021-May 2022.
- Letter sent to parents/carers containing a link to an online survey.
- Questions covering four main domains with Likert scale and free text questions.
 1. Knowing your child and their baseline
 2. Communication and leadership
 3. Progress in PICU
 4. Meetings and discharge planning

Discussion

- The pre-LEAP survey provided us with useful information to create and implement a new pathway for this patient cohort.
- Our conclusions and comparisons regarding the impact of LEAP are limited by the low survey response rate.
- The elements of LEAP that directly affect daily routine were well-received.
- However, parents are less aware of the broader LEAP pathway.

Next Steps

- Increase families' awareness of all elements of the pathway: review LEAP leaflets and explanations given to parents on admission.
- Explore ways to gather more information on patient experience of LEAP, e.g.
 - Survey at point of discharge from PICU
 - Focus groups
- Review and refine the pathway using feedback received.