

# Specialist paediatric care in the home

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## The stakeholder group

- The group meet every three months and comprises parents, paediatric surgeons, paediatricians, specialist children's nurses and dieticians from the acute, community and palliative sectors from the Oxford Academic Health Science Network (AHSN) region.

## Objectives

- The programme focuses on improving safety of technologically dependent children with complex medical needs who are cared for in the community.
- Foster closer collaborations between different stakeholders from the point of initial referral to surgical management of gastrostomy insertion and subsequent follow-up and long-term care in the community including transitional care to adulthood.

## Gastrostomy workstreams (Clinical lead: Mr Alex Lee, Consultant Paediatric Surgeon)

### Workstream 1: Empowering parents and carers

- Co-production of training information materials for parents/carers of children needing surgical enteral feeding (via PEG tube, gastrostomy button, etc) to support them with safer care in the home. For use in both hospital teams and by community children's nurses.

### Workstream 2: Upskilling regional specialists

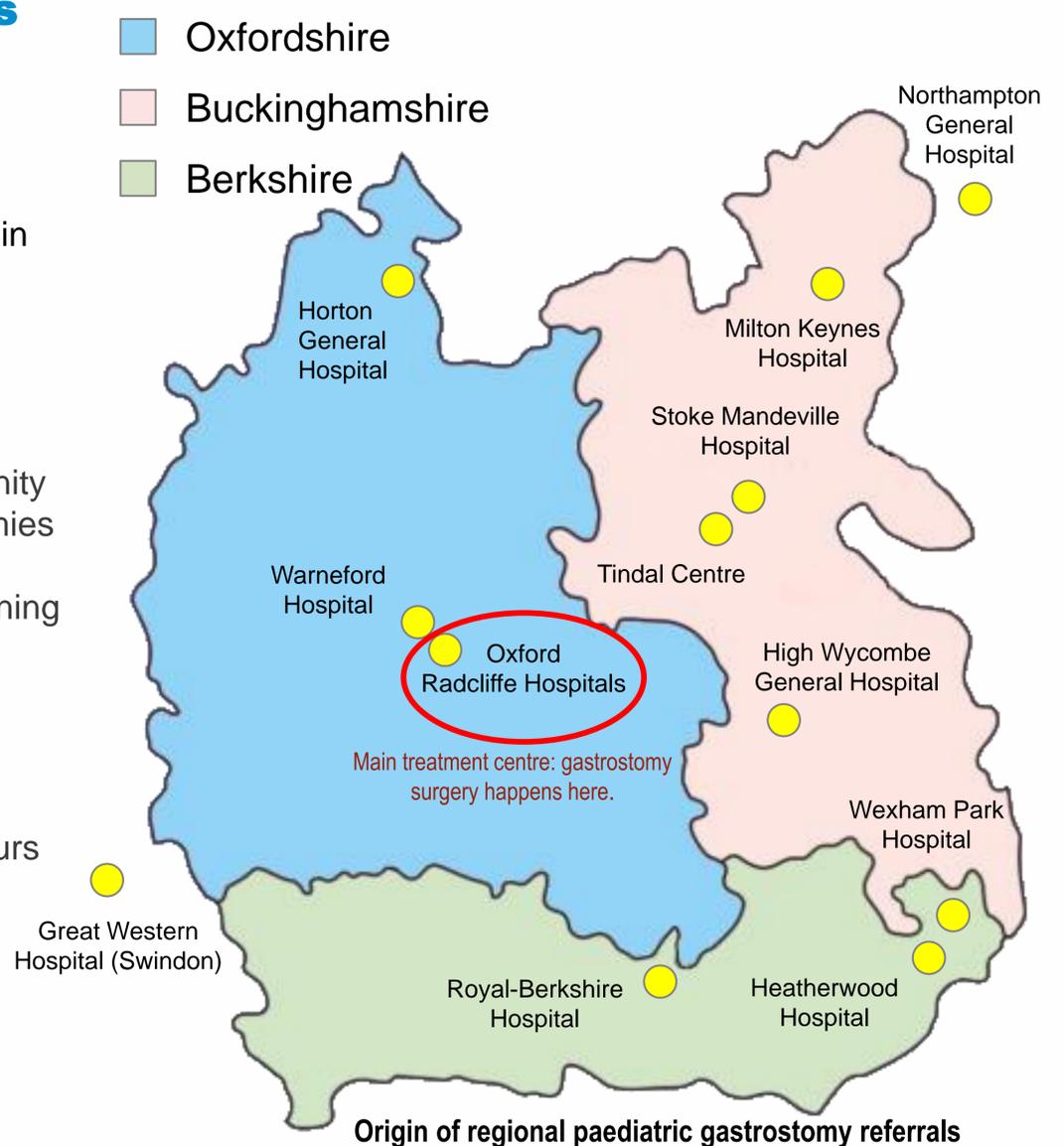
- Training and shared learning for specialist community staff supporting parents of children with gastrostomies in the community.
- Regional multidisciplinary training and shared-learning event in October 2018.

### Workstream 3: Awareness training for non-specialists

- Provide gastrostomy awareness training for non-specialist clinical staff receiving referrals out-of-hours e.g. emergency departments and GP practices.

### Workstream 4: Communication

- Connect together the specialist healthcare professionals caring for children within the region to share practice, learning and experience.
- Patient passport: to improve communication across the whole patient pathway.



## Long-term ventilation (Medical lead: Dr Emily Harrop, Consultant in Paediatric Palliative Care)

- A new programme has recently been added looking at improving safety for children who are totally dependent on a mechanical aid to breath (level 3 ventilation). These children require complex care after discharge.
- The aims are:
  - To empower parents to care for their children safely at home so that they are able to lead as normal a family life as possible.
  - To increase access to education and other enrichment activities.
  - To ensure competency of community healthcare professionals who support parents.
  - To reduce unscheduled hospital re-admissions for LTV children.