Introduction

- Increasing prevalence CYP - severe disability, complex health needs, life limiting conditions
- Community, disability, palliative care services working together
- 2 models – Nottingham & Manchester

Nottingham

- Community neurodisability paediatricians
- Nottingham Children's Hospital
- CDT -multi disciplinary assessment & support
- Lead professional role to coordinate TAC
- On going medical care

- Commissioned - community palliative care

Teams

- CYP, parents and carers
- Child development team – physios, OT, SALT
- Community respiratory physios
- Neuromuscular & LTV services
- Community nurses - incl. 24/7 EoL care
- Family support, bereavement teams, hospice

- No specialist PPC team in the region

Continuity of care

- Child Development Centre
- Special schools
- In-reach to hospital - NNU, wards & PICU
- Joint neurology clinics
- Complex disability / palliative care clinic
- End of life care at home

- On a journey with child and family from recognition to transition or death
- Familiar, trusted professional
- In depth knowledge of child
- Awareness of medical, social, cultural, economic factors - how to tailor support to that child and family
- Parallel planning Better quality care

Enablers

- Relationships - community, acute & tertiary services

- Multi professional teams

- Shared digital records – remote access

- Funded PAs for community palliative care

  Complex disability clinic – extended appts.

  Community palliative care team meetings

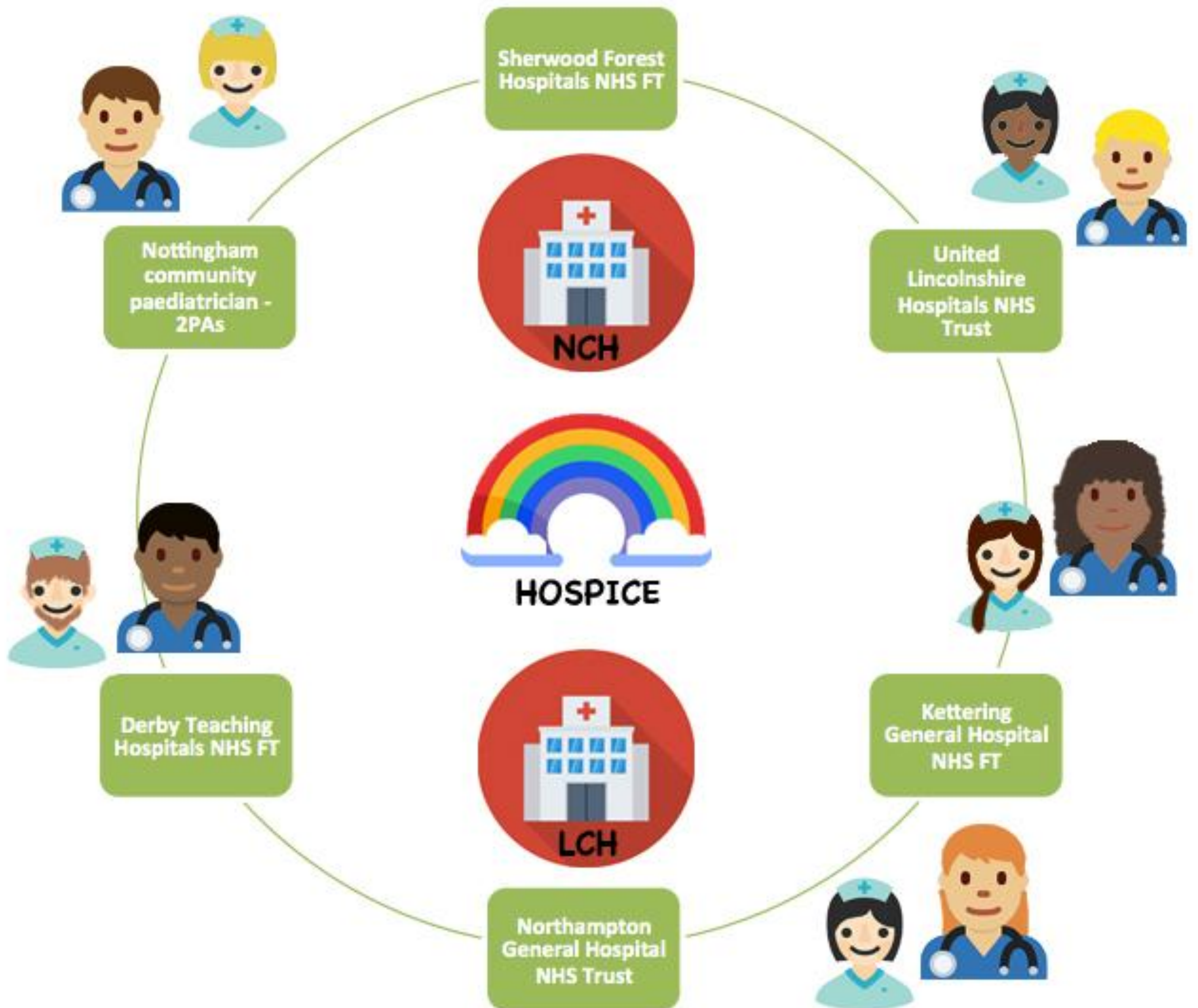
  OOHs service for end of life care

Service developments

- QIP 2018   Data – gaps, admissions, costs

- Regional Managed Palliative Care Network

- Specialist PPC team in each children's hospital
- Network coordinator
- Paediatricians with expertise in each district


Sherwood Forest Hospitals NHS FT
United Lincolnshire Hospitals NHS Trust
Kettering General Hospital NHS FT
Northampton General Hospital NHS Trust
Derby Teaching Hospitals NHS FT
Nottingham community paediatrician - 2PAs
NCH
HOSPICE
LCH

Safe and High Quality Care

- Governance arrangements to allow working across boundaries
- Shared information systems
- Joint clinics and peer review
- Training and support for paediatricians to develop expertise in end of life care
- SPIN

Manchester

- Commissioned Community Children's Palliative Care team
  - Nurses, support workers, family support worker, counselling, paediatrician
  - Working very closely with Continuing Care team and with Special School nursing team, all within CCNT
- No PPC team in the tertiary centre, but 2PAs paediatrician with expertise
- Paediatrician embedded in community paediatric department, palliative care team and hospital.
- Developing NW regional model on very similar lines

What else makes it work?

- It’s all about the professionals’ approach
  - It’s all about the communication; especially listening
  - Comfortable with not making children better
  - Comfortable talking about dying with children and families
  - Comfortable working with families, and sometimes agreeing to a decision that you don’t necessarily feel is the best one

What makes it work even better?

- Those skills across the child and family journey
- Access to support for those professionals who find it harder
- Commitment across the health economy