Developing a Regional Specialist Children's Palliative Care Service: Analysis of Caseload and Consultant in Paediatric Palliative Care Activity between 2010 and 2020

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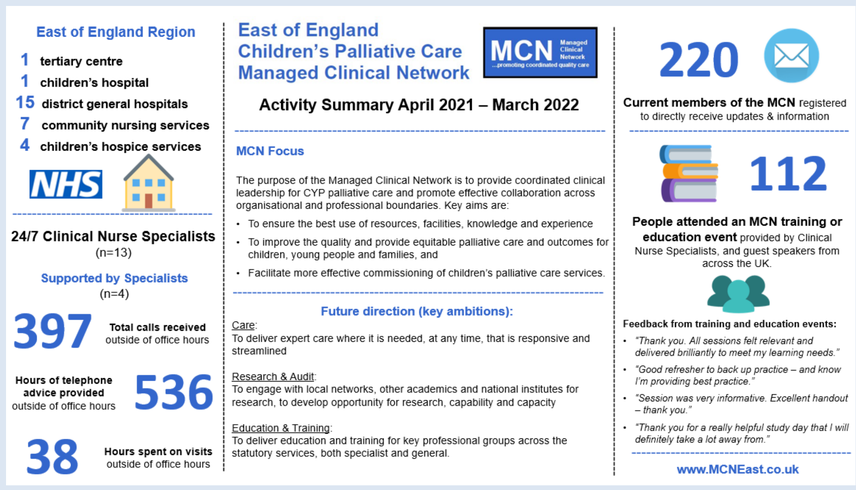
Background

- East of England Child Population (aged 0-19 years) 1.4 million
- Children with life-limiting conditions est. 8,989 (61.1 per 10,000)[1]
- Low numbers of children with high level of need
- Not every child needs level 4 Consultant in Paediatric Palliative Medicine (PPM) input but needs timely access to this support if required
- Provision across wider area is more efficient and sustainable
- The Specialist Palliative Care team works in partnership with core services and with local paediatricians and teams
- Activity and caseload of a part time Consultant in Paediatric Palliative Care (PPC) gathered during 10 years of service.

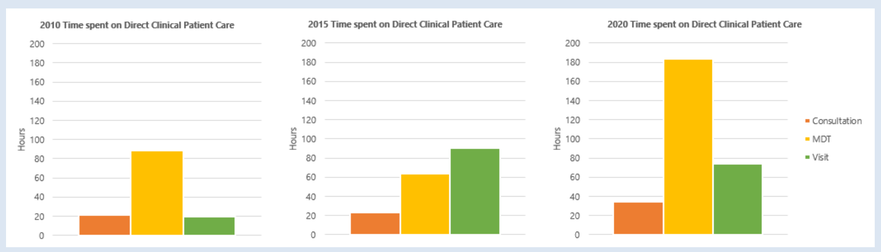


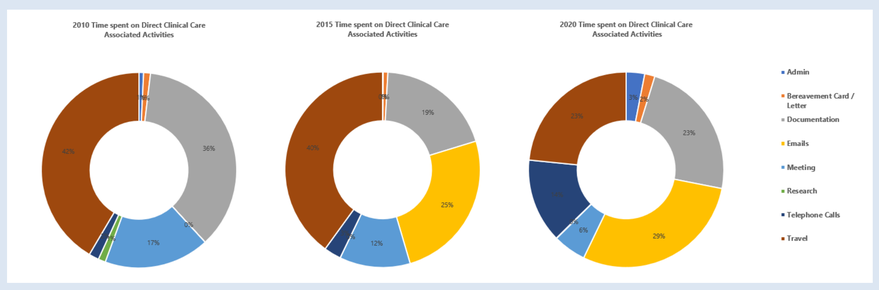
Method

Data analysed in 5 year intervals: 01 January 2010 to 31 December 2020. Children (CYP) referred to PPC Consultant were logged.
Caseload analysed by year, diagnostic category, treatment location, age at death.
Diary (time spent) of activities classified as 'Direct Clinical Care' or 'Supporting Activity' with sub categories.

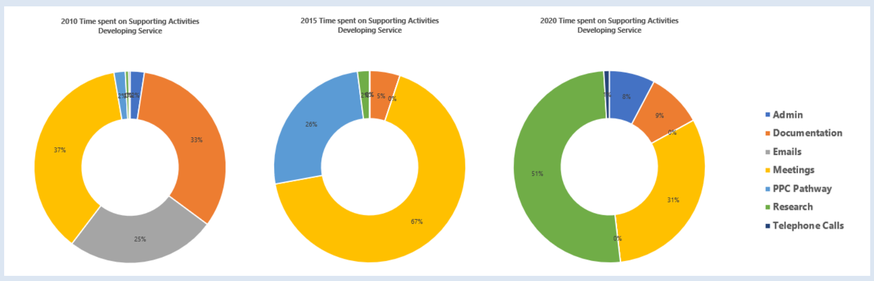
Results: Activity

Total activity hours consistent at three time points and with employment terms.
Direct Clinical Care 25% of available time in 2010, 63% (2015), 86% (2020); this included leading Multi-Disciplinary Team (MDT) meetings (69%, 36%, 63% of time spent on Direct Clinical Care).



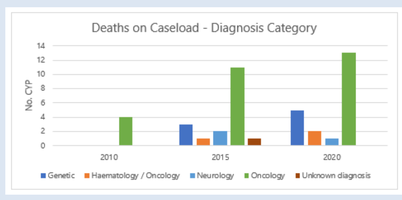


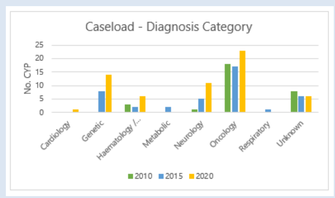
Time spent on developing the service as a proportion of all 'Supporting Activities': 60% (2010); 12% (2015); 23% (2020)

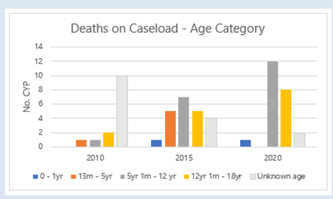


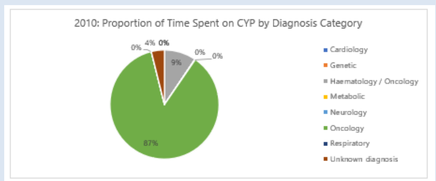
Results: Caseload

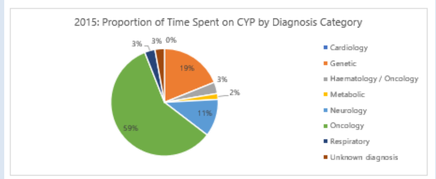
Caseload doubled 2010 to 2020 (n=30; n=62).
CYP with cancer largest proportion of patients each year (87%, 59%, 62%) & aligned with PPC Consultant speciality.
Other diagnostic categories increased over time.
Focus on caseload local to PPC Consultant base in 2010, caseload included all diagnostic categories across region in 2015 & 2020.
End of life care increased: oncology only deaths 2010 (n=4). Deaths in all categories in 2015 (n=18); 2020 (n=21).
Age at death >13 months in 2010 & 2015. 1 infant death in 2020.

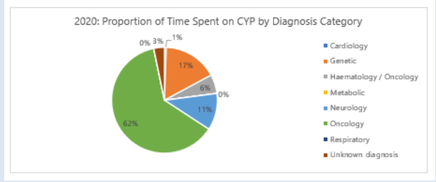












Discussion

There was increased reach over time (caseload size; diagnosis; geographical distribution) which shows regional development and efficient use of scarce resource.
Age at death and location of death were not aligned with regional data and suggests gaps in referrals from PICU, NICU.
The MDT meeting is a key intervention and vehicle for Consultant role: PPM expertise, leadership, oversight, planning, coordinating care, support and teaching for clinical teams.

Conclusions

Expert Paediatric Palliative Medicine leadership is a requirement in the current UK Service Specification (2021)[2].
These data can help influence service strategy across one region and support the development of the new specialist Children's Palliative Care Team.

References

1 Fraser, L.K. Gibson-Smith, D. Jarvis, S. Norman, P. Parslow, R. (2020) 'Make Every Child Count' Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom.
2 NHS (2021) Children's & Young People's Palliative & End of Life Care: Service model for a comprehensive approach to delivering palliative care from identification of need through to end of life.

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