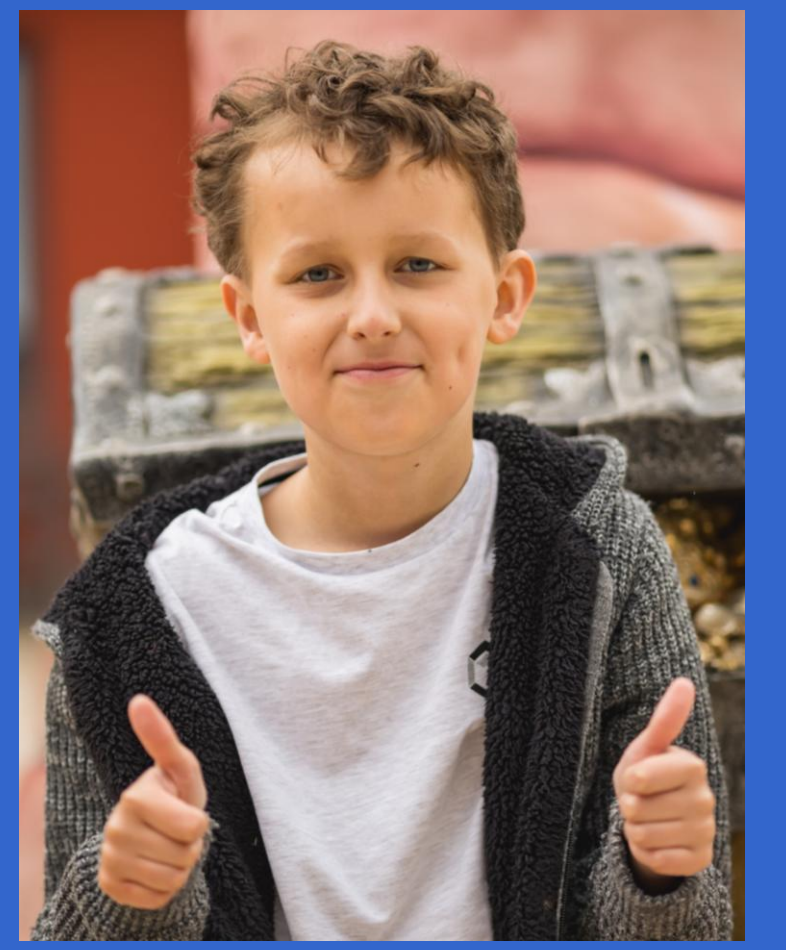


Who are the Children?

Point Prevalence Survey to understand who needs Children's Palliative Care



Introduction

Point prevalence surveys have been conducted effectively in recent years to inform development and resourcing of services for children with life-threatening and life-limiting conditions.

Our surveys in a UK region in 2022 and 2023 involved hospital, community and children's hospice services, and reviewed 1801 (2022) and 2619 (2023) babies, children and young people (BCYP).

In this paper we compare previous years with our 2024 survey and make recommendations.

Method

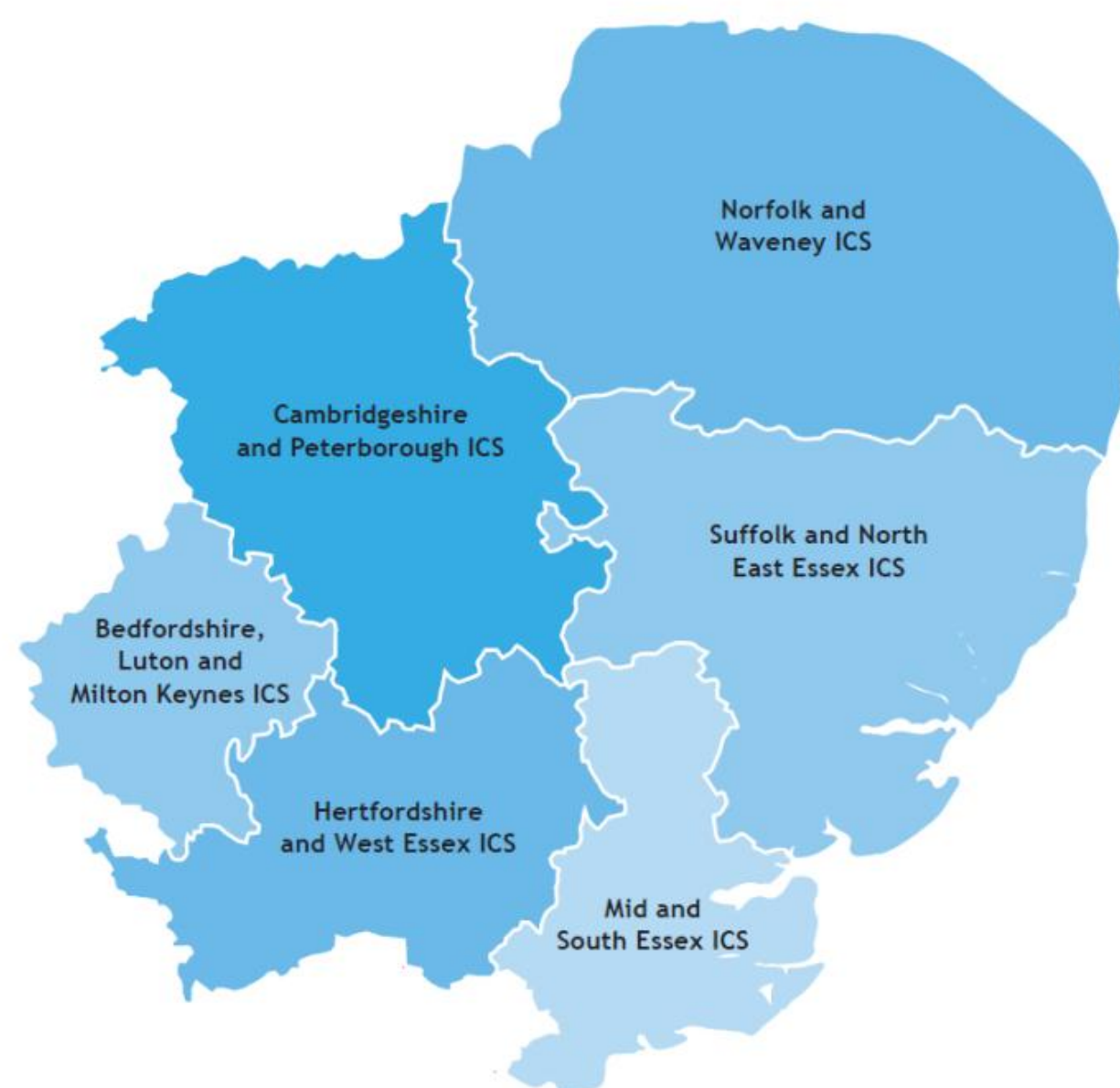
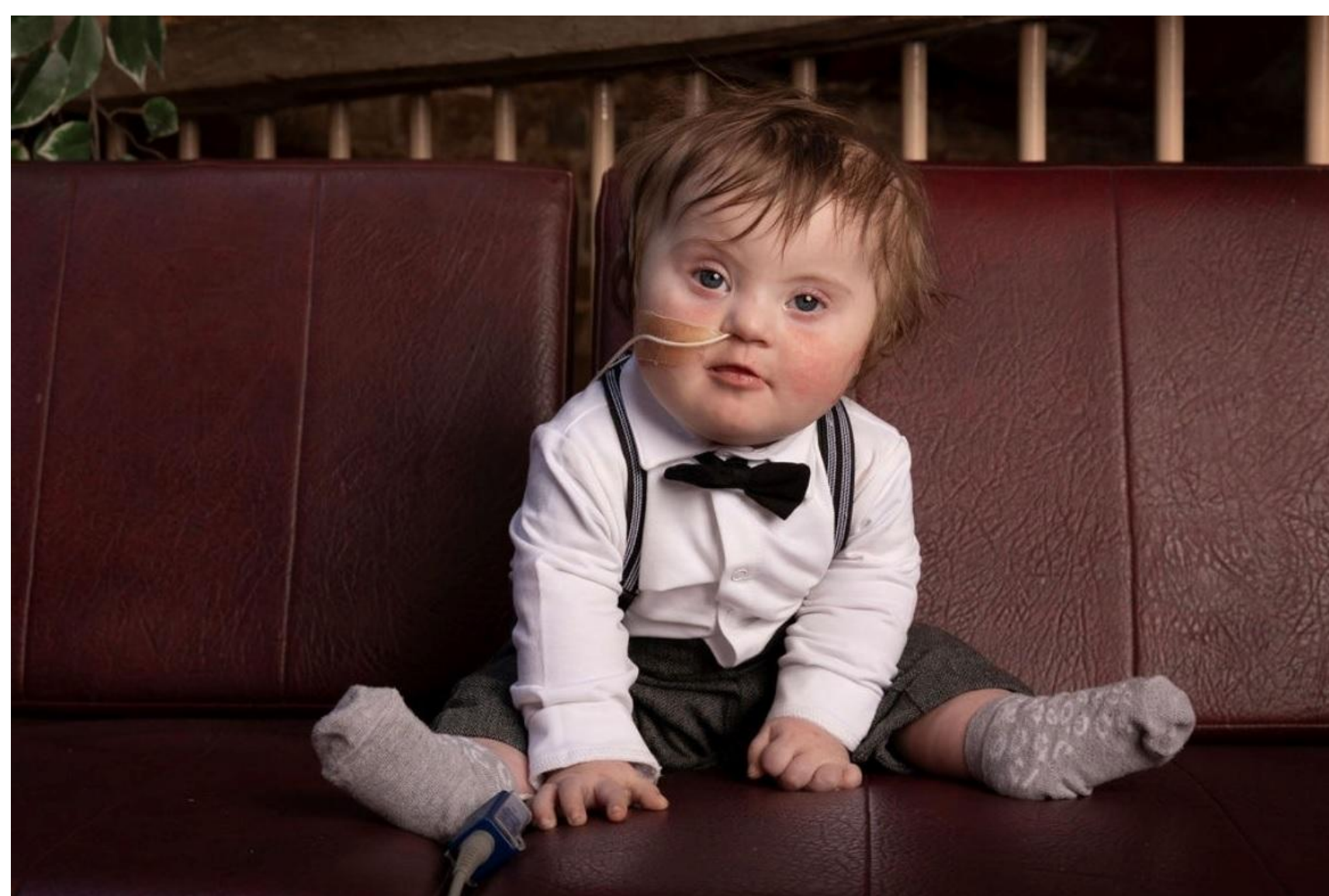
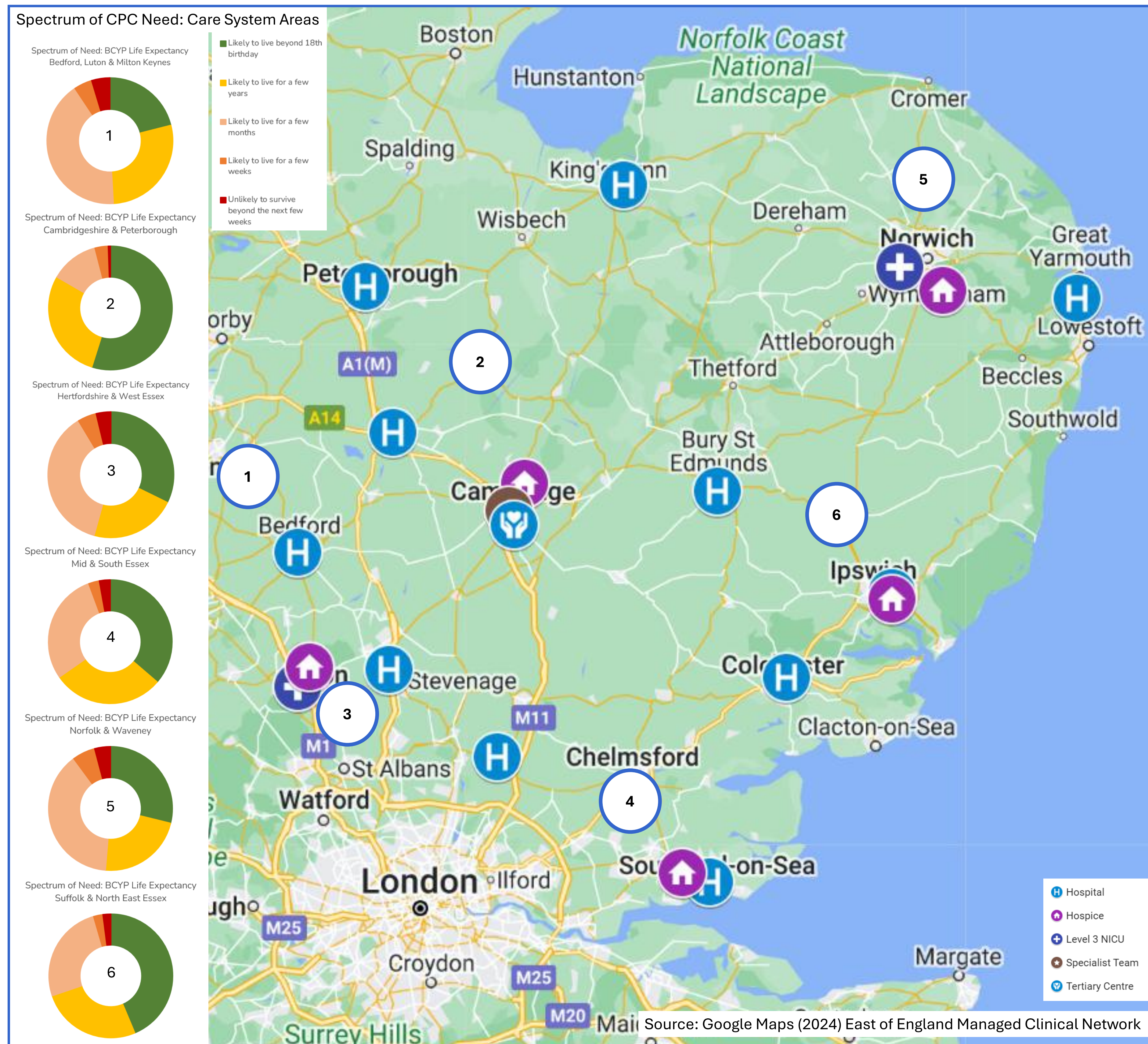
The Spectrum of Children's Palliative Care Needs, a prognosis-based framework using the 'would you be surprised if...' question was used with demographic data:

Gender; Age category; Diagnosis category; Partial postcode; Partial NHS number

Data collected by palliative care nurse specialists with professionals from children's hospices (n=5), hospitals (n=13), and community nursing teams (n=11).

Information governance maintained via regional Managed Clinical Network process.

Spectrum of CPC Need: All BCYP			
	Y1 (2022) n=1801	Y2 (2023) n=2619	Y (2024) n=2309
Would you be surprised if this child eventually died due to their underlying condition?	YES BCYP = 760 (42%)	BCYP = 1207 (46%)	BCYP = 839 (36%)
NO			
Would you be surprised if this child died before their 18th birthday?	YES BCYP = 460 (26%)	BCYP = 583 (22%)	BCYP = 562 (24%)
NO			
Would you be surprised if this child died in the next few years?	YES BCYP = 245 (14%)	BCYP = 363 (14%)	BCYP = 385 (17%)
NO			
Would you be surprised if this child died in the next few months?	YES BCYP = 259 (14%)	BCYP = 345 (13%)	BCYP = 423 (18%)
NO			
Would you be surprised if the child was still alive in the next few weeks?	NO BCYP = 57 (3%)	BCYP = 99 (4%)	BCYP = 59 (3%)
YES			
Critical illness / Survival is not expected beyond the next few weeks	BCYP = 20 (1%)	BCYP = 22 (1%)	BCYP = 41 (2%)



Prevalence compared with Fraser (2020) estimates showed our survey sample represented 8-26% of expected cases based on population estimates in six health care system areas.

(Fraser, L.K. et al. (2020) Make Every Child Count. Together for Short Lives.

Integrated Care System (ICS)	2023 Census Estimate of total population (Source: ONS)	2023 Census Estimate of child population (0-18 years) (Source: ONS)	(A) Estimated prevalence of BCYP with life-limiting conditions (Fraser, 2020)	(B) 2024 Survey No. BCYP identified as likely to die	2024 Survey BCYP identified (B) comparison with estimate (A)	2023 Survey BCYP identified with estimate (A)
Bedford, Luton & Milton Keynes	1,015,380	251,715	1661	171	10%	10%
Cambridgeshire & Peterborough	927,342	206,077	1360	348	26%	20%
Hertfordshire & West Essex	1,506,036	355,123	2344	186	8%	10%
Mid & South Essex	1,209,480	275,371	1817	247	14%	17%
Norfolk & Waveney	1,041,932	200,711	1325	267	20%	15%
Suffolk & North East Essex	997,767	206,050	1360	245	18%	17%

Conclusions

Our surveys provide essential information about those known to services at a given time. They do not identify all who could benefit from care as there will be those not in contact during data collection periods.

Data supports service development but must be used alongside patient outcomes and baby, child and young person and family stories to provide a holistic narrative.

Read me too:



L.Maynard¹, D. Vickers^{2,3}, C.Cannon³, E.Cattaneo^{4,1}

¹Cambridge University Hospitals NHS Trust, Children's Palliative Care, Cambridge, United Kingdom. ²Cambridgeshire Community Services NHS Trust, Community Paediatrics, Cambridge, United Kingdom ³East Anglia's Children's Hospices (EACH), Children's Hospice Service, Cambridge, United Kingdom. ⁴East Suffolk and North Essex NHS Foundation Trust, Paediatrics, Colchester, United Kingdom.

