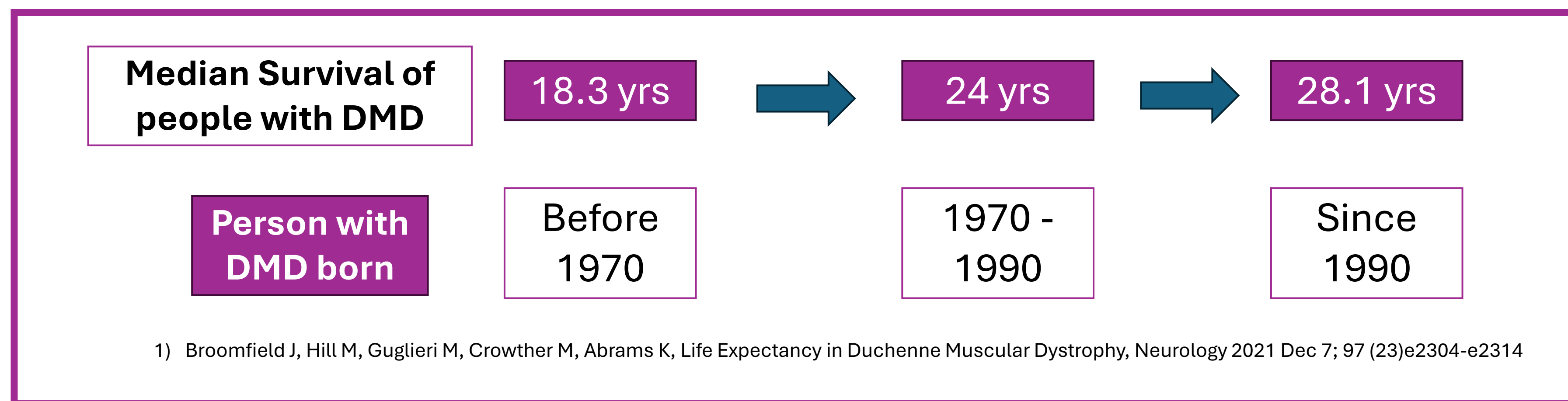


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BACKGROUND:

Duchenne Muscular Dystrophy (DMD) is a progressive muscle-wasting condition associated with a reduced life-span. A systematic review in 2021 demonstrated increasing survival rates¹



What is the potential impact of this shift in disease trajectory and hospice provision?

METHODS:

Step 1) We surveyed 207 hospices in England regarding admission criteria, services available, and specifically DMD care provision.

Step 2) A focussed view of admission criteria - including age limits - for children and young persons (CYP) hospices was obtained via HospiceUK's online 'Hospice Care Finder'² selecting 'Care for Children' and limiting to 'England'. Results were cross-checked against a list of hospices in the UK held by DMD Care UK Palliative Care Working Group. Websites were accessed and referral criteria including age limits recorded.

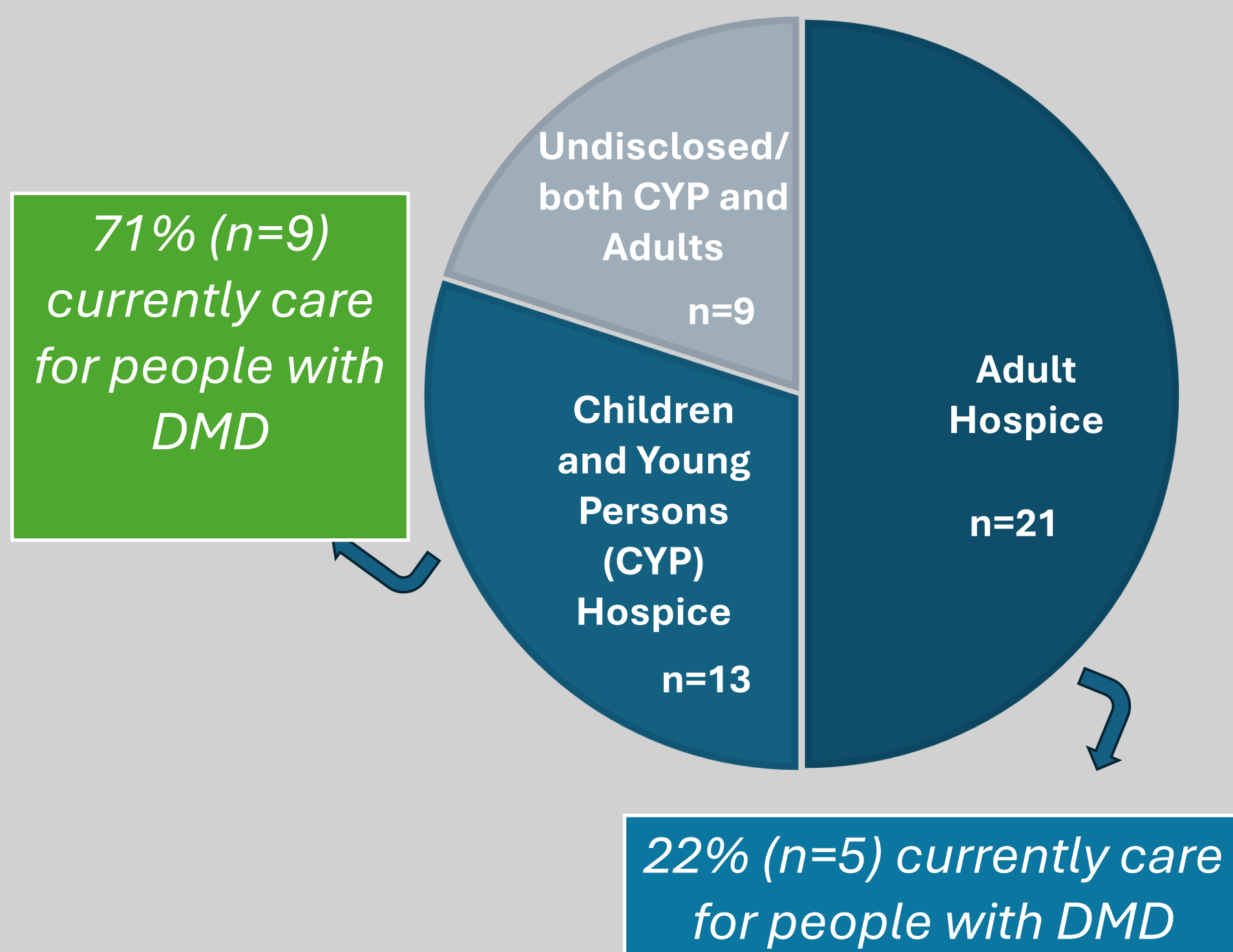
Inclusion Criteria: Children services, young adult services, hospice services, palliative care services.
Exclusion Criteria: Adult-Only services, services limited to bereavement support, non-registered services.

What does the current hospice provision for people with DMD look like?

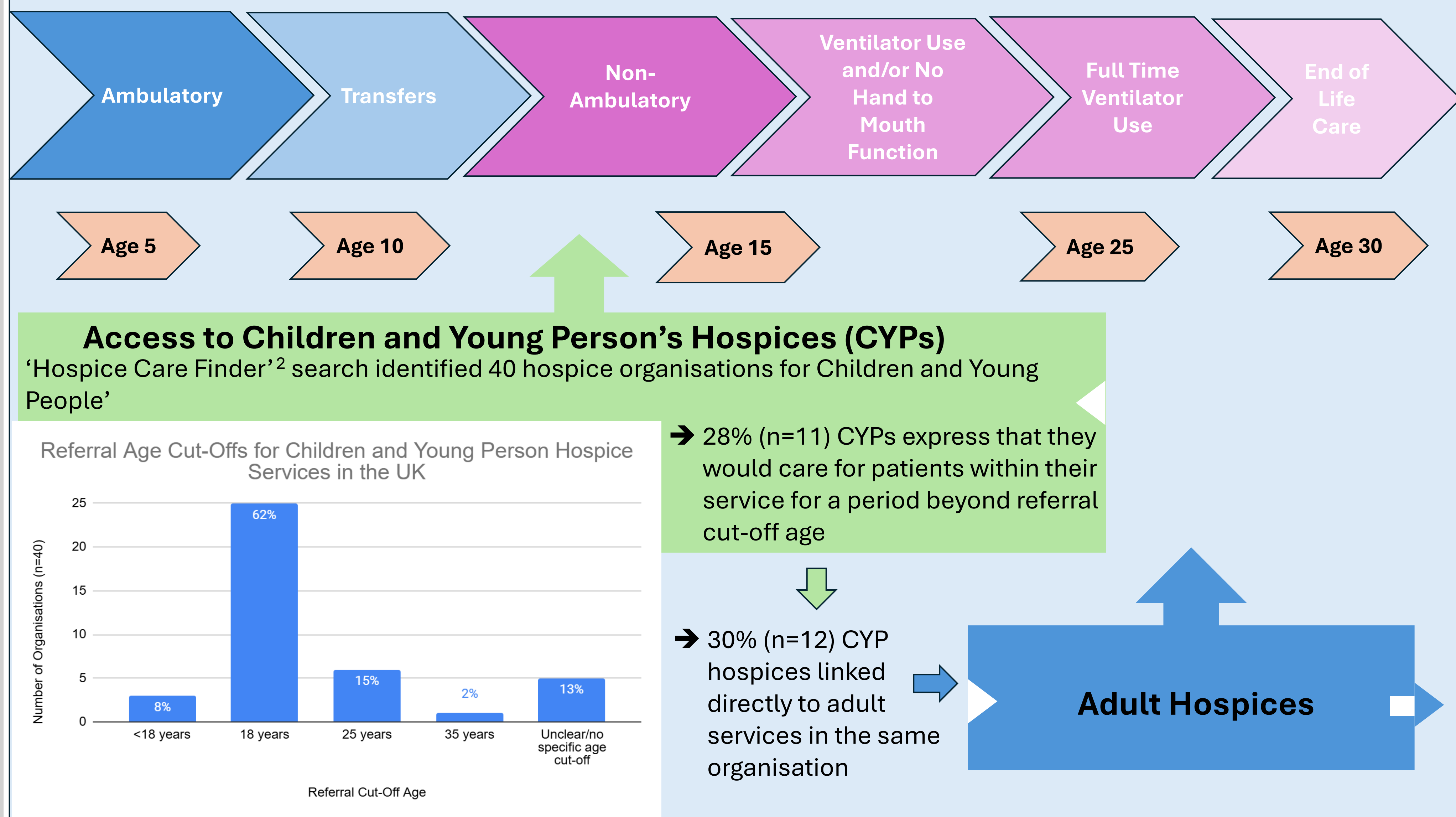
RESULTS: Step 1)

43 Hospices responded to our survey (20.7% response rate) → ALL said that they **could** provide services to people with DMD, a greater percentage of Children and Young Persons hospices reported caring for people with DMD

SURVEY RESPONDENTS N=43



Step 2)



²Step 2' Image developed using data from: (3) Broomfield, J., Hill, M., Chandler, F. et al. Correction: Developing a Natural History Model for Duchenne Muscular Dystrophy. *PharmacoEconomics Open* 8, 643 (2024)

What is the experience of people with DMD as they transition from CYP services to adult services? Do they get the support they need?

CONCLUSION:

With average age of needing ventilatory support at 20 years⁴, and the current median survival of 30 years¹ we highlight the risk of loss of care continuity for people with DMD as they transition from palliative services for children and young people to those for adults. Currently the transition coincides with the time at which symptoms escalate and they approach maximal support needs as they enter the final phases of their illness. With this increasing life expectancy, it may be that by the time some people with DMD need palliative support they no longer meet criteria for CYP services, meaning adult hospice services may be their first exposure to palliative care.

Do adult palliative services have the knowledge, skills and resources to support people with DMD given it has previously been regarded as a paediatric condition?

REFERENCES:

1) Broomfield J, Hill M, Guglieri M, Crowther M, Abrams K, Life Expectancy in Duchenne Muscular Dystrophy, Neurology 2021 Dec 7; 97 (23) e2304-e2314
2) Hospice Care Finder, HospiceUK, <https://www.hospiceuk.org/hospice-care-finder> accessed 15/10/2024
3) Broomfield, J., Hill, M., Chandler, F. et al. Correction: Developing a Natural History Model for Duchenne Muscular Dystrophy. *PharmacoEconomics Open* 8, 643 (2024)
4) Mercuri, E., Bonnemann, C. G. & Muntoni, F. Muscular dystrophies, Comprehensive overview of the clinical and genetic aspects of muscular dystrophies. *Lancet*, 2019, **394**, 2025–2038