

# Short Break/Respite Care For Young Adults During and After Transition in the UK: Research Findings From Young Adults, Parents, and Providers



## Dr Katherine Knighting - Edge Hill University

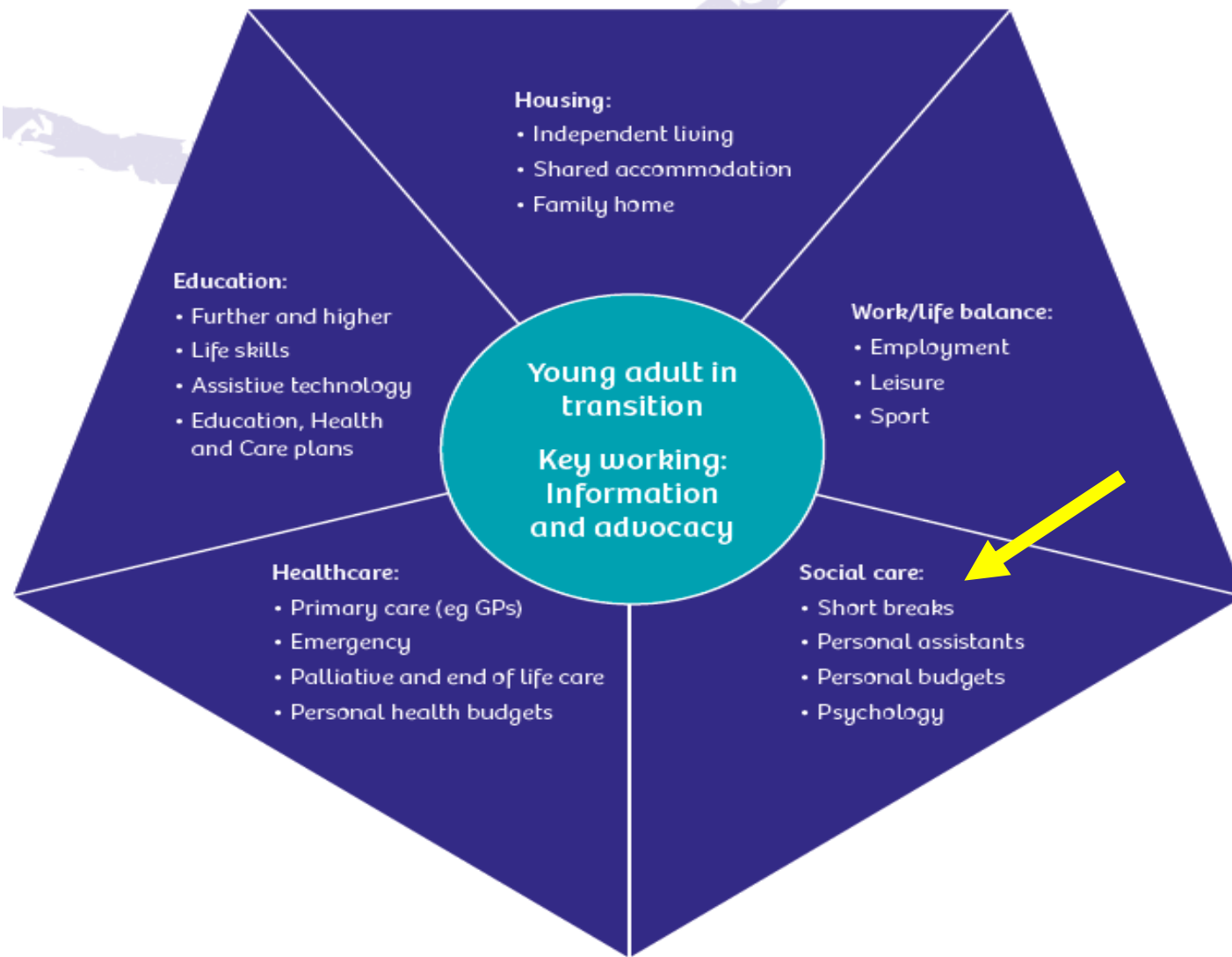
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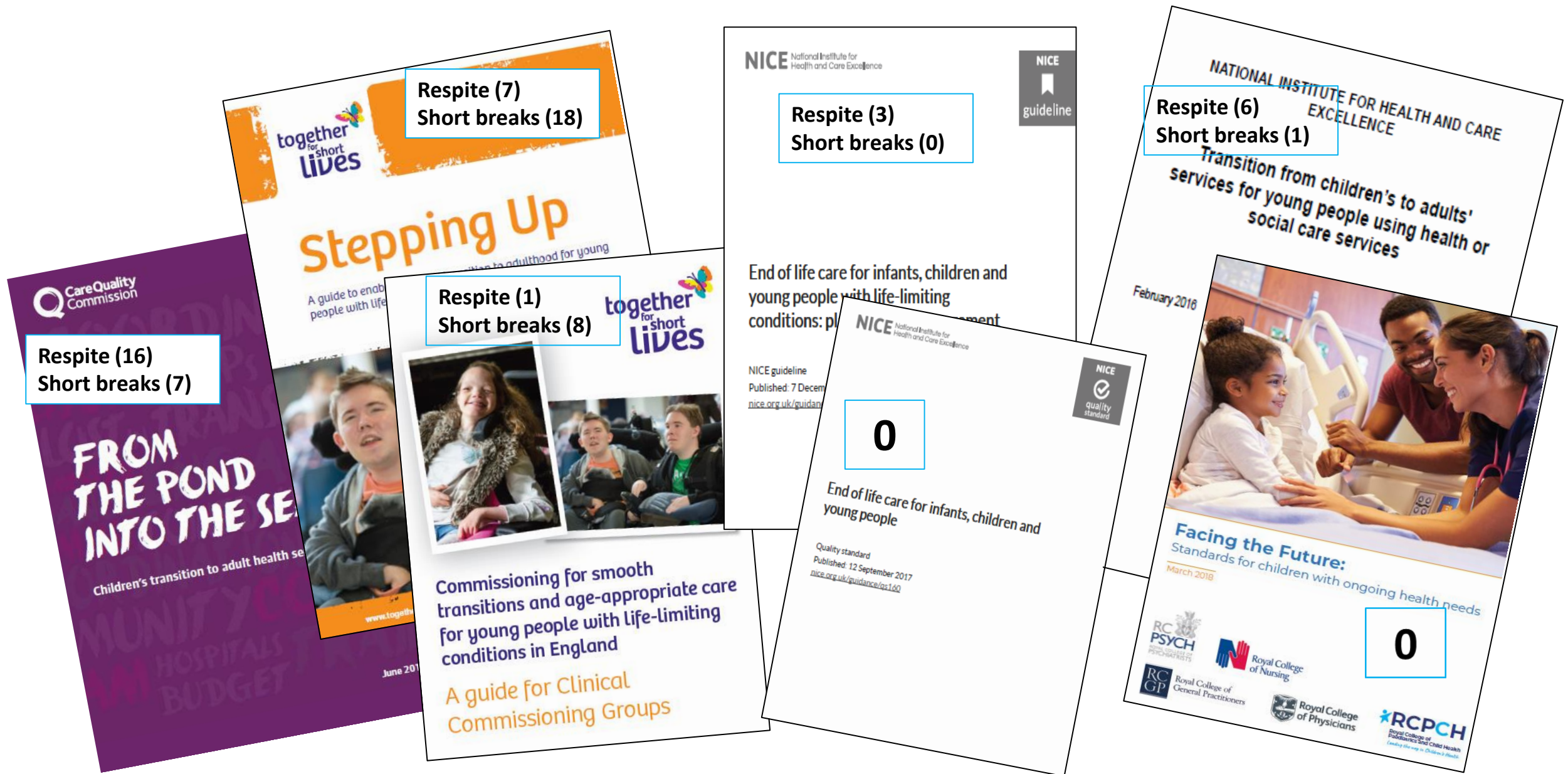
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# Transition – early enough? Holistic enough?



# Where does respite/short breaks fit into the narrative?





# Studies exploring short break/respite provision for young adults aged 18+ (Funded by Liverpool Clinical Commissioning Group)



## Hospice Surveys

- UK-wide
- Oct 2015-Feb 2016
- Online Survey
- Children's hospices (n=13, 25%)
- Adult hospices (n=63, 37%)

• Knighting et al. (in press) Meeting the needs of young adults with life-limiting conditions: A UK survey of current provision and future challenges for hospices. Journal of Advanced Nursing.



## Mapping of services

- North West region
- Feb-March 2017
- Online survey or telephone
- Providers (n=7)
- Interviews (n=3)

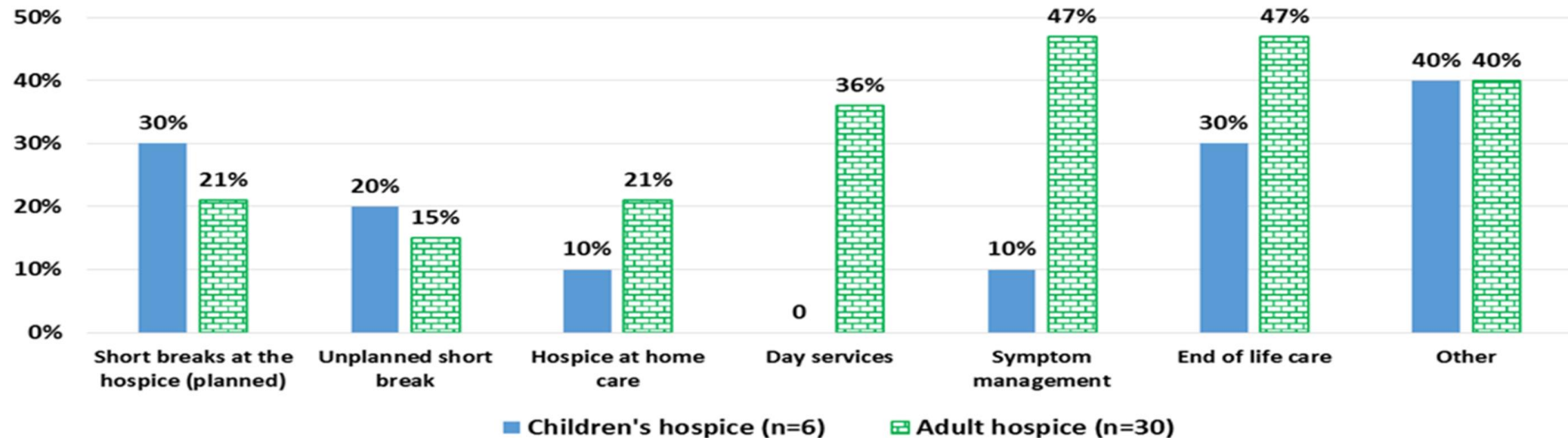


## Family Survey

- UK-wide
- June-August 2017
- Online survey or telephone
- Young adults (n=6)
- Parents (n=38)

# Hospice Survey – Highlights

- 76 hospices responded from across the UK; 13 children's hospices and 63 adult hospices (25% and 37% of UK hospices respectively).
- 4 children's hospices and 18 adult hospices did not provide any services for young adults.
- Provision varied by hospice type. 'Other' services including support with transition (e.g. counselling, social opportunities); independent living skills training; and on-call for symptom management and EoL care by children's hospices; and collaborative work to support transition, advance care planning or family support by adult hospices.



# Hospice Survey – Highlights

- **CHALLENGES**

- a lack of existing age/developmentally-appropriate adult respite services;
- the lack of funding and capacity to develop appropriate young adult services;
- a perceived lack of a skilled and confident workforce in adult hospices to support young adults with complex and different care needs to older adults;
- the need for better integrated working between children and adult hospices, along with other providers, to develop and improve access to appropriate services.

*“Our families and young people say - they want a service but they are often put off by the older persons accessing this type of care. They are wanting a bespoke service, often with children's [hospices] extending their remit. They want local, not travelling miles, to access care”*

*(Children's Hospice ID10)*

*“Meeting the expectations of the young person and their family/carers as they leave children's hospices is difficult as the equivalent service doesn't really exist in the adult world’*

*(Adult Hospice ID13)*

*“Ensuring an appropriately trained and skilled workforce ... there is a need for upskilling of their staff to ensure they can meet the needs of these young people who can present with a range of medical complexities”*

*(Adult Hospice ID22).*

# Hospice Survey – Highlights

## KEY CONCLUSIONS:

- Good collaborative working or expansion of services were reported.
- Some adult hospices saw no role for their services with the young adult population, unless individuals fit with their current provision and referral criteria.
- Disparity in access to appropriate services across UK.
- Key issues raised relating to the lack of alignment between C&A hospice transition categories, referral processes and eligibility criteria
- Despite educational interventions in recent years, perceived lack of a confident and skilled nursing workforce in adult hospices persists. Further development and spread of shared learning opportunities, joint transition planning and up-skilling interventions would help to support evolving practice.
- Integrated working and sustainability of new services is key, requiring services and commissioners to look at how best to utilise existing resources across the hospice, education and social care sectors to meet the demand for young adult services in their region.

# Family Survey – Highlights

- Before transition majority of young adults had accessed some form of respite or short break service.



## Value of Short Break and Respite Care before Transition

*‘Chance for him to socialise with other young people. We got chance to do the same, get rest and recovery in our own home. His teenage sibling also had the opportunity to have friends around as he wouldn't do so when his brother was present.’ (Parent 6)*

*‘I valued my time in the children’s hospice so much and hate that there is not a suitable service for me now, I enjoyed time away from my parents, making memories and meeting others who were in similar situations.’ (Young Adult 1)*



# Family Survey – Highlights

## Transition Planning

- Planning for short breaks and respite after moving to adult services was only included in the transition planning for **3** of the participants.
- Challenge of identifying appropriate services for their young adult to transition to due to the complexity of care required.

*‘Discussed but adult services have been unable to find a suitable placement that can deal with his complex needs! Really need respite though as I'm struggling to cope without.’ (Parent 8)*

*‘Transitioning to adult services is a challenge as not only do you have to get used to a new set of people, we have found that services seem large, more diverse and harder to navigate your way around compared to children's services.’ (Parent 14)*

# Family Survey – Highlights

## Challenges in Accessing Services

- \*Identifying appropriate services to meet their needs\*
- amount of paperwork and meetings involved;
- emotional impact of constantly fighting for support and access to services, including disappointment and unworthiness;
- social isolation for young adults and their families;
- high levels of stress; and
- physical impact on parents of caring 24 hours a day 7 days a week without a break.

# Family Survey – Highlights

## Challenges in Accessing Services

*‘The paper work, meetings, effort, disappointments, feelings of unworthiness of my precious daughter when finding continuing education for her.’ (Parent 1)*

*‘YP socially isolated, no respite provision. Carer has no breaks, unable to rest and recuperate.’ (Parent 5)*

*‘It has been a nightmare - social services have not been helpful and my son has been labelled as too complex, apparently there is nowhere that can deal with him though I am expected to do it on a daily basis.’ (Parent 17)*

# Family Survey – Highlights

## Challenges in Accessing Services

*‘There's a distinct lack of respite services, especially those like myself with complex needs. Many places cannot provide 1:1 ITU/Hickman line/TPN trained nurses. The Young Adult hospice we fought to get funding for is great, but it was so far away and it'd take months of planning for up to 5 days respite. ....Because I have very complex and specialist needs, it's hard to find places who can take me.’ (Young Adult 2)*

*‘I wish the CCG would see how vital it is for me to leave the house and enjoy days out, events and so on. The CCG say I never need to leave the house. I wish I had a more suitable care package and respite support to enable me to enjoy days out and things.’ (Young Adult 2)*

*‘Enormous challenges in identifying appropriate LA & CCG personnel to discuss the process. Obtaining sufficient hours, appropriate local placements, experienced staff.’ (Parent15)*



# Family Survey – Highlights

## Future Services

- 53% of parents responded 'Yes' their young adult would use an adult hospice for a short break or respite care.
- Similar standard to that received from children's hospices and correct nursing care.

*'The local adult hospice can't accommodate me, they can't do TPN and Hickman line care as they don't have staff who can do that. they said it's not the right environment for a young adult. However if they expanded a young adult service that could provide the high level of nursing I require then I would [use it]. (Young Adult 2)*

*'It would be good to meet other young adults going through similar things. It would also be good to just have fun with other people and be young adults.'* (Young Adult 1)

# The Future

Creativity

Confidence

Courage

Change

Compassion

Communication

*collaboration*



Pod  
Unimportant  
In  
or  
Sa



Excellent

Preferred

Valuable

Special



Top-drawer!

# Systematic Review

- Health Service & Delivery Research (HS&DR) funded
- Respite care and short breaks for young adults with complex healthcare needs due to a life-limiting condition and/or complex physical disability:  
Mixed-method systematic review and conceptual framework development
- Four streams:
  - clinical effectiveness
  - cost effectiveness
  - attitudes and beliefs (experience)
  - policy and guidelines
- 1<sup>st</sup> Feb 2018 – 31<sup>st</sup> July 2019
- PPI Advisory Group (PAG) of young adults and parents
- Young adult co-chair for steering group and PAG

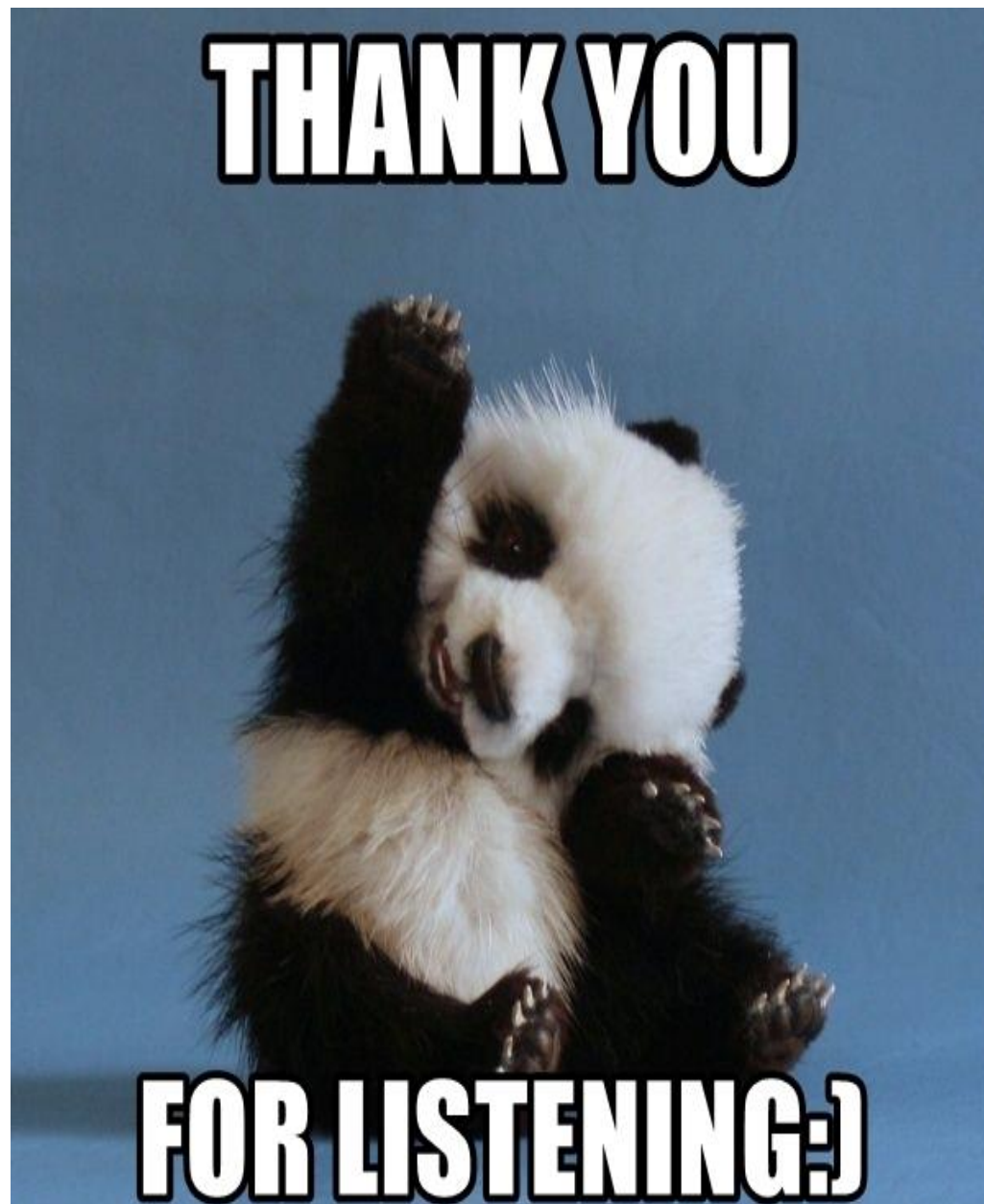


# Collaborators

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- Together for Short Lives
- Hospice UK
- CHAS
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