

# Living matters now

Improving transitional care for young people with complex and life-limiting conditions



## Background

- An increasing number of children and young people in the UK are living with life-limiting or life-threatening conditions<sup>1</sup>
- These young people are living longer than in the past
- Needs and preferences change over time
- Young people face a process of transition from children's to adult hospice<sup>2</sup>
- This process can be difficult and concerning



## Methods

- Adopted a quality improvement approach to implementation, with a focus on continuous learning
- Engaged with professionals and young people with lived experience of transition
- Led and developed a national network for Transition Co-ordinators using ECHO methodology
- Supported three regional ECHO hubs
- Produced online resources for professionals supporting young peoples' transition



## Recommendations

1. Harness the expert voice of experience to improve transitional care
2. Encourage and support adult hospices to do more to support young people through transition
3. Discover more about who is missing out on care so that we can tackle unequal access
4. Continue the work of the Transition ECHO hubs and National Transition Network to realise their full potential
5. Make sure that local health and care systems consider the needs of young people in transition to adult services



### Authors:

Susanna Shouls, Carrie James, Angela Horsley, Hannah Hodgson, Tom Hardwick, Anita Hayes<sup>1</sup>, Melanie Hodson, Catherine Hodge. **Illustrations** by Becki Ward

### References:

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2. Chambers L. Stepping Up: Transition Pathway. Together for Short Lives. Bristol. 2023.

### Acknowledgements:

This programme was made possible due to the generous support of the DD McPhail Charitable Settlement.