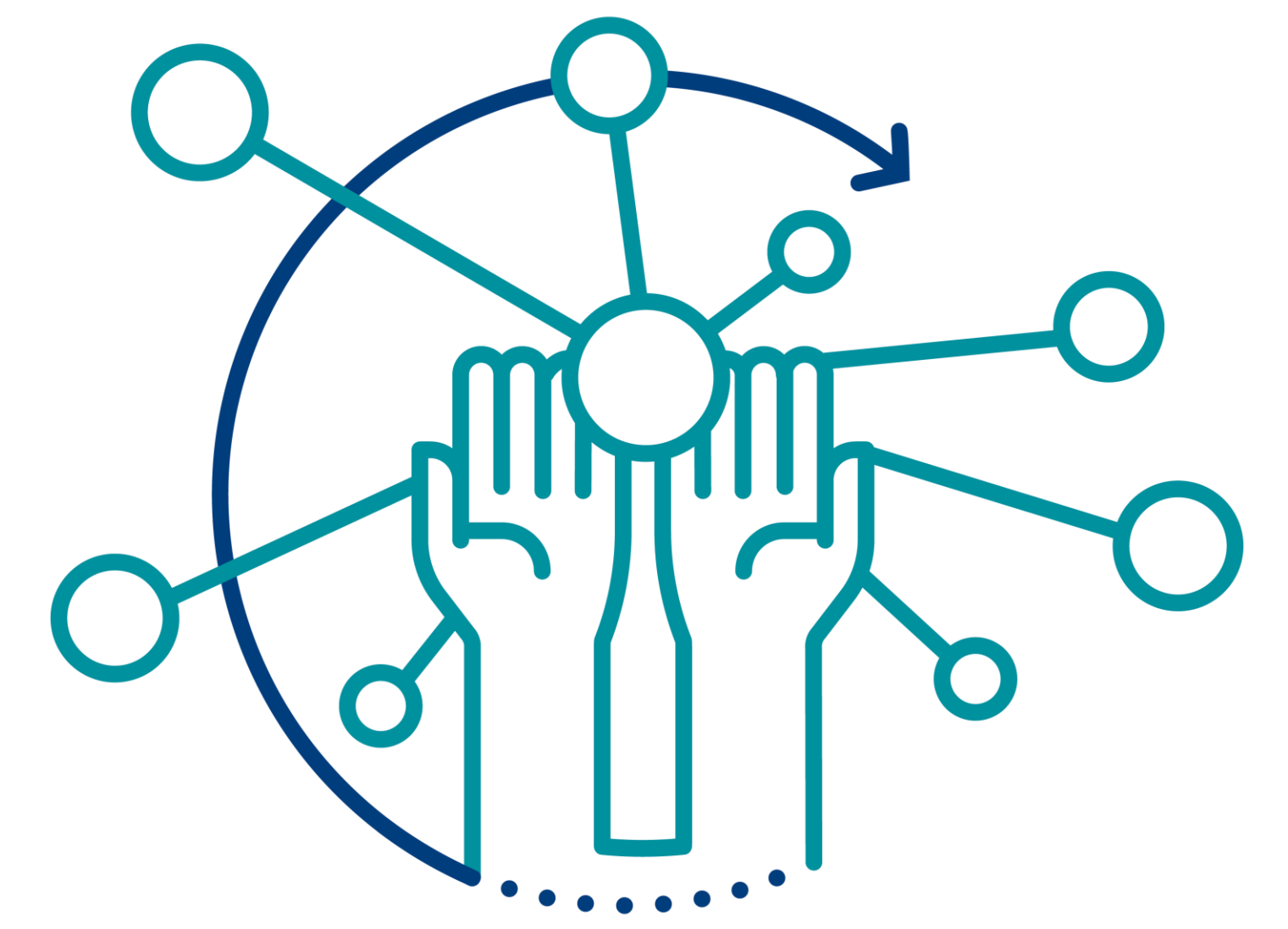


Understanding cancer risk-factor and symptom awareness among people with learning disabilities, paid and unpaid carers, & healthcare practitioners.



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Cancer Care

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Background

Adults with learning disabilities are at an increased risk of developing cancer at a younger age than the general population, including specific types such as gastrointestinal, breast and reproductive cancers.

They experience marked difficulties in navigating healthcare systems and often present with cancers at an advanced stage. This means that survival rates are significantly poorer than average.

Methods

In line with Arksey and O'Malley's (2005) framework for scoping reviews, five incremental stages were followed:

1. identify research question,
 2. identifying relevant studies,
 3. study selection,
 4. extracting and charting of data,
 5. collating, summarizing, and reporting results.
- Findings reported according to Preferred Reporting Items for Systematic Reviews & Meta-analyses extension for scoping reviews, PRISMA-Scr.

Risk-Factors

Results

Symptom Awareness

Lack of clear guidance on how to support and empower people with learning disabilities to participate in their own health by giving them the right tools and autonomy to make decisions

Increased risk for obesity and other lifestyle related factors that can increase cancer risk.

Low engagement with preventative services

Reliance on Carers to facilitate cancer awareness, while a dearth in education, training and support for caregivers and HCPs means they are lacking the skills to do this.

Lack of accessible public health messaging, information and interventions to improve risk-factor and symptom awareness

Carers may display a tendency to 'shield'

Conclusion

- Cancer risk-factor & symptom awareness is low among adults with learning disabilities, paid and unpaid carers and HCPs.
- Theoretically underpinned and co-designed tools and interventions are lacking.
- Uncertainty on how to best support people with learning disabilities in raising cancer awareness.
- Lack of consensus on how adults with learning disabilities can be empowered to make informed decisions and participate in their own healthcare.
- Breast cancer awareness studies predominate in this area. Research focussing on other cancers is needed to build a complete picture of risk-factor and symptom awareness among adults with learning disabilities, paid and unpaid carers, and both specialist and non-specialist HCPs.