

# "It's not meant to be for life, but it carries on": A qualitative investigation into the psychosocial needs of young Retinoblastoma survivors



Nicola O'Donnell<sup>1</sup>, Bob Phillips<sup>2,3</sup>, Jess Morgan<sup>2</sup>, & Debra Howell<sup>1</sup>

<sup>1</sup>Epidemiology and Cancer Statistics Group, University of York

<sup>2</sup>Centre for Reviews and Dissemination, University of York

<sup>3</sup>The Hull York Medical School, University of York



nicola.odonnell@york.ac.uk



@nicolaod\_

## Background

Retinoblastoma (Rb) is a rare cancer of the retina that is diagnosed in approximately 40-50 children in the UK each year (Jenkinson, 2015). Although highly treatable, children can have long lasting effects such as reduced vision, facial changes, and some have increased risks of second cancers (Sethi et al., 2014; Temming et al., 2017).

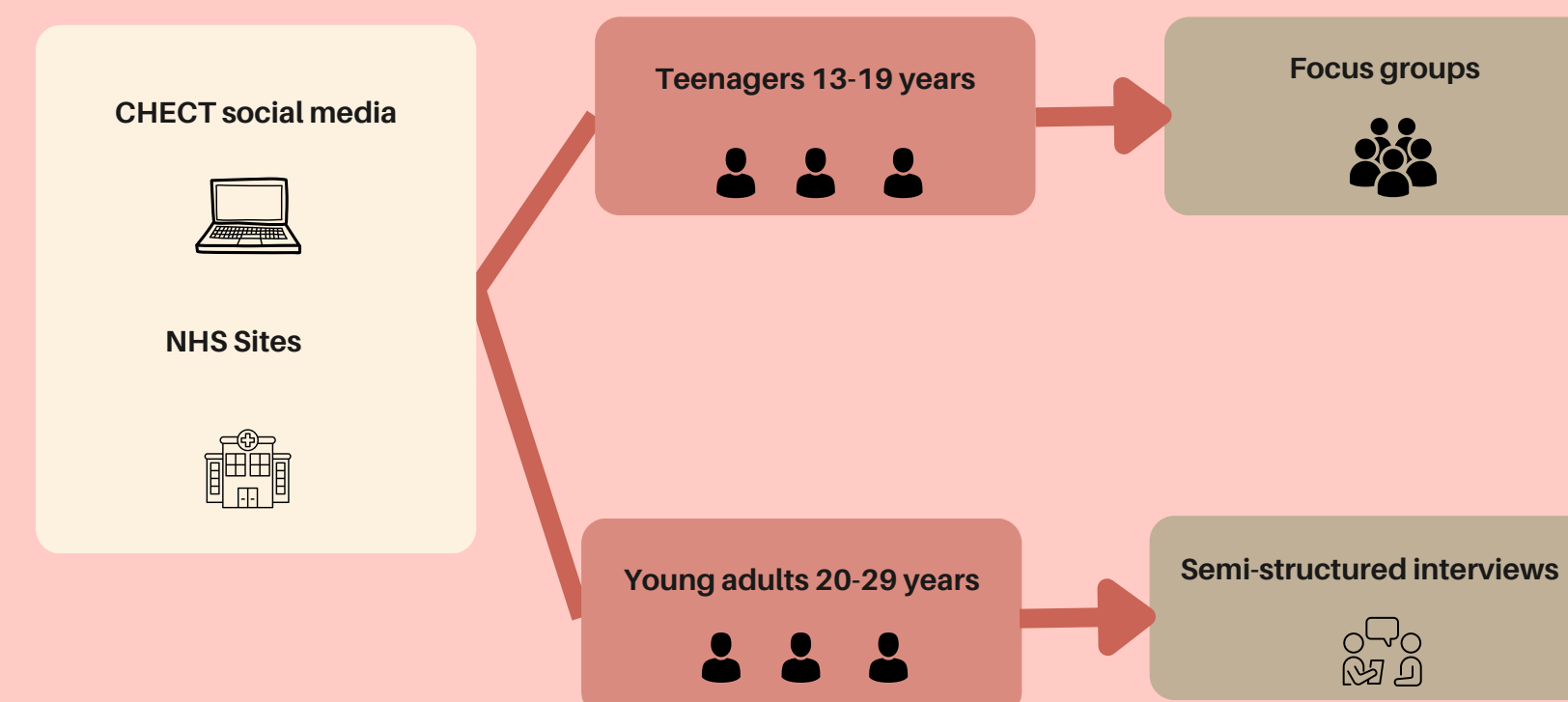
Little is known about the specific psychological challenges experienced by teenagers and young adults, who must manage the effects of Rb in a period of life when psychosocial support is crucial to the healthy development of identity (Zebrack, 2011).



## Aims & Methods

This research project involved a two-phase qualitative study: focus groups with teenagers (age 13-19 years) and individual interviews with young adults (age 20-29 years), all with a history of Rb.

The study explored individual's experiences of living beyond Rb and their views on challenges that they may have faced as a result. Participants were recruited from the two UK specialist Rb treatment centres (Royal London/Great Ormond Street Hospital and Birmingham Children's Hospital) and via the Childhood Eye Cancer Trust (CHECT) social media.



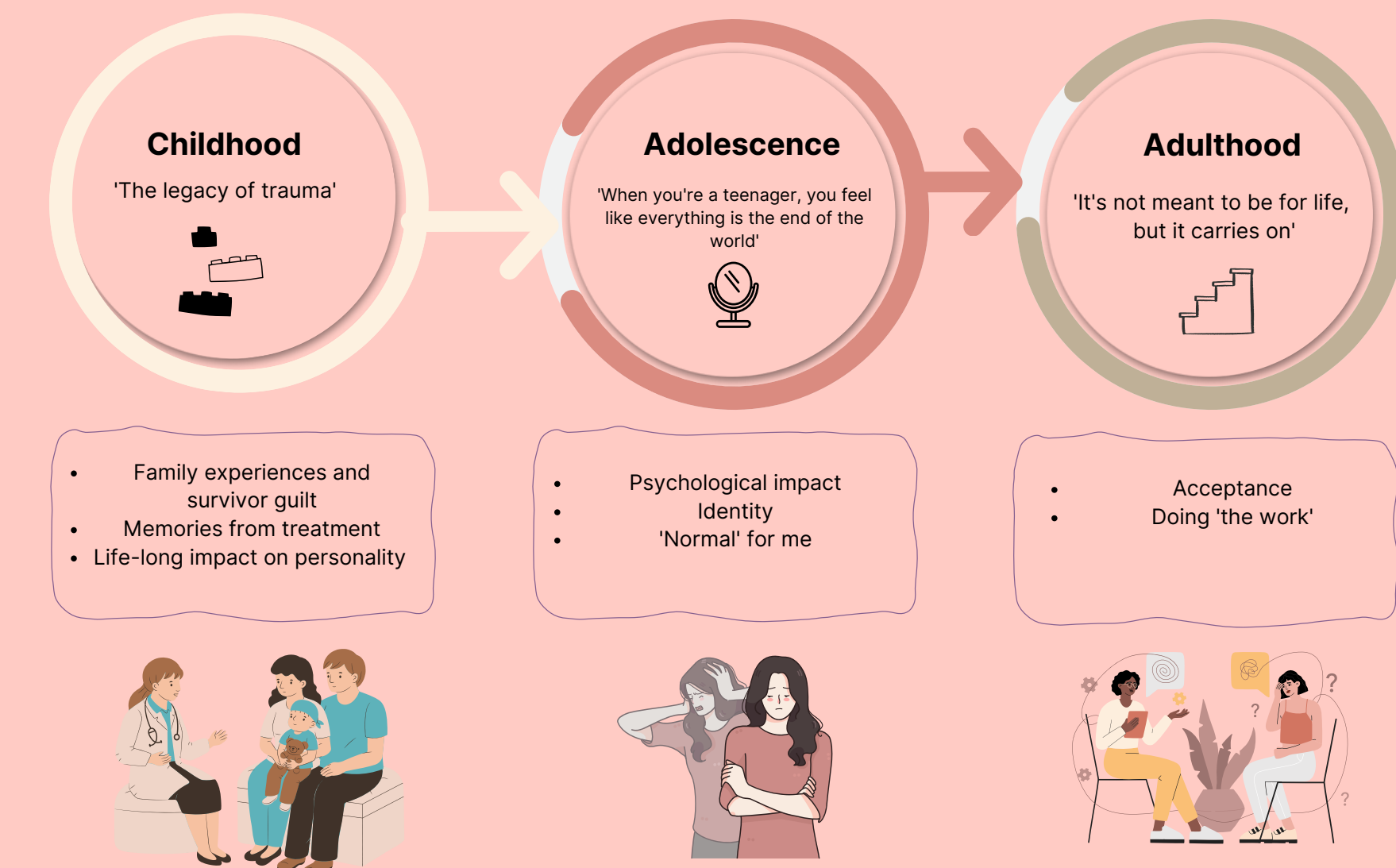
## References



## Analysis

32 young people (15 teenagers in 4 focus groups, and 17 young adults) took part. This included 20 females and 12 males, 20 with non-genetic Rb, 11 with genetic Rb, and 1 was unsure. 24 were impacted unilaterally and 8 bilaterally. 24 had been treated with enucleation and 8 had not.

Using Braun and Clarke's (2021) reflexive thematic analysis, three themes and eight subthemes were identified (see diagram). For further information about our findings please scan the QR code:



## Conclusions and Implications

Rb can have a huge impact on the psychological wellbeing of individuals long after treatment has ended. Existing research has highlighted the need for psychosocial support, yet we know this is not routinely offered and is under-researched. It is hoped that through the current study this can change, to support the wellbeing of individuals as they transition into adulthood and beyond. The findings of this qualitative study will be combined with wider research to co-design a novel psychoeducation intervention. For further insight into our work, scan the video QR code here:

You can also read our recent paper in BMJ Open: doi: 10.1136/bmjopen-2023-082779

