

YORKSHIRE SPECIALIST REGISTER OF CANCER IN CHILDREN AND YOUNG PEOPLE



What is the Yorkshire Register?

The Yorkshire Register is a collection of information on children and young people, aged 0 - 39 years, who are diagnosed with cancer whilst living in Yorkshire. It allows us to know how many children and young people are being diagnosed with cancer in this area. This information is shared with the National Health Service (NHS) National Cancer Registration and Analysis Service. The Register is held at the University of Leeds.

What is the purpose of the Yorkshire Register?

The Yorkshire Register exists to carry out research investigating long-term outcomes and addressing questions pertinent to the Yorkshire population.

Our current work covers the following topics:

- . Looking at patterns of cancers across Yorkshire.
- . Identifying possible causes of the disease.
- . Investigating the type of care given to patients.

How can I get further information?

Please contact:

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Tel: 0113 343 4842

Professor Adam Glaser

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Tel: 0113 392 8779

Or scan the QR code to go to our website: www.yrccyp.org.uk



Are you aware your data are helping other people?

What information do we hold?

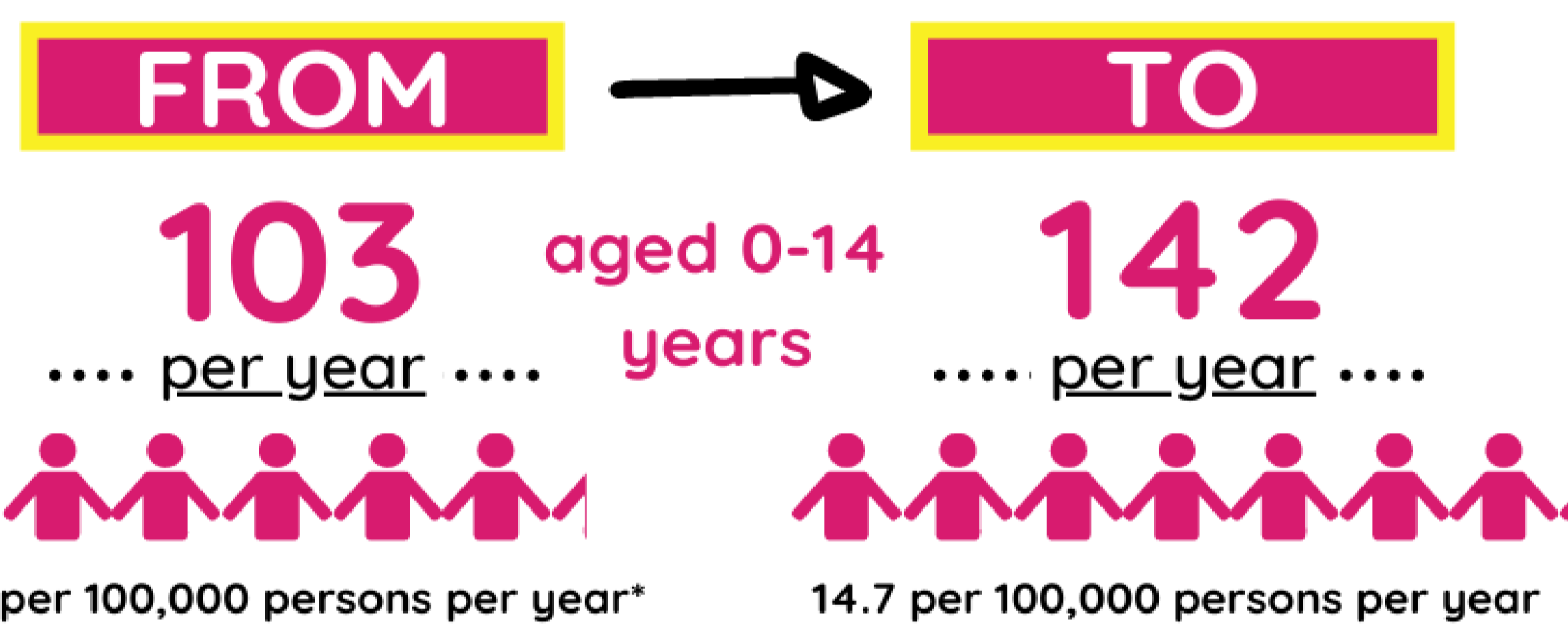
Information is held on approximately 12,000 individuals. For each person we hold information on their diagnosis, place of residence and age at the time of diagnosis, type of treatment received and their current health status. Every individual on the Register is followed-up through notifications from the National Cancer Registration and Analysis Service on any subsequent cancers, and causes of death.

What are our latest findings?

INCIDENCE OF CHILDHOOD AND YOUNG ADULT CANCER IN YORKSHIRE (BY AGE GROUP)

While a diagnosis of childhood/young adult (CYA) cancer is relatively rare, in Yorkshire, the incidence is increasing.

From 1990 to 2015, the average number of CYA cancer diagnoses increased



1990-1994 **2011-2015**

*Age standardised incidence rates (ASIR) (per 100,000 persons per year) 1990 vs 2015

Childhood and young adult (CYA) cancer survival is **INCREASING**

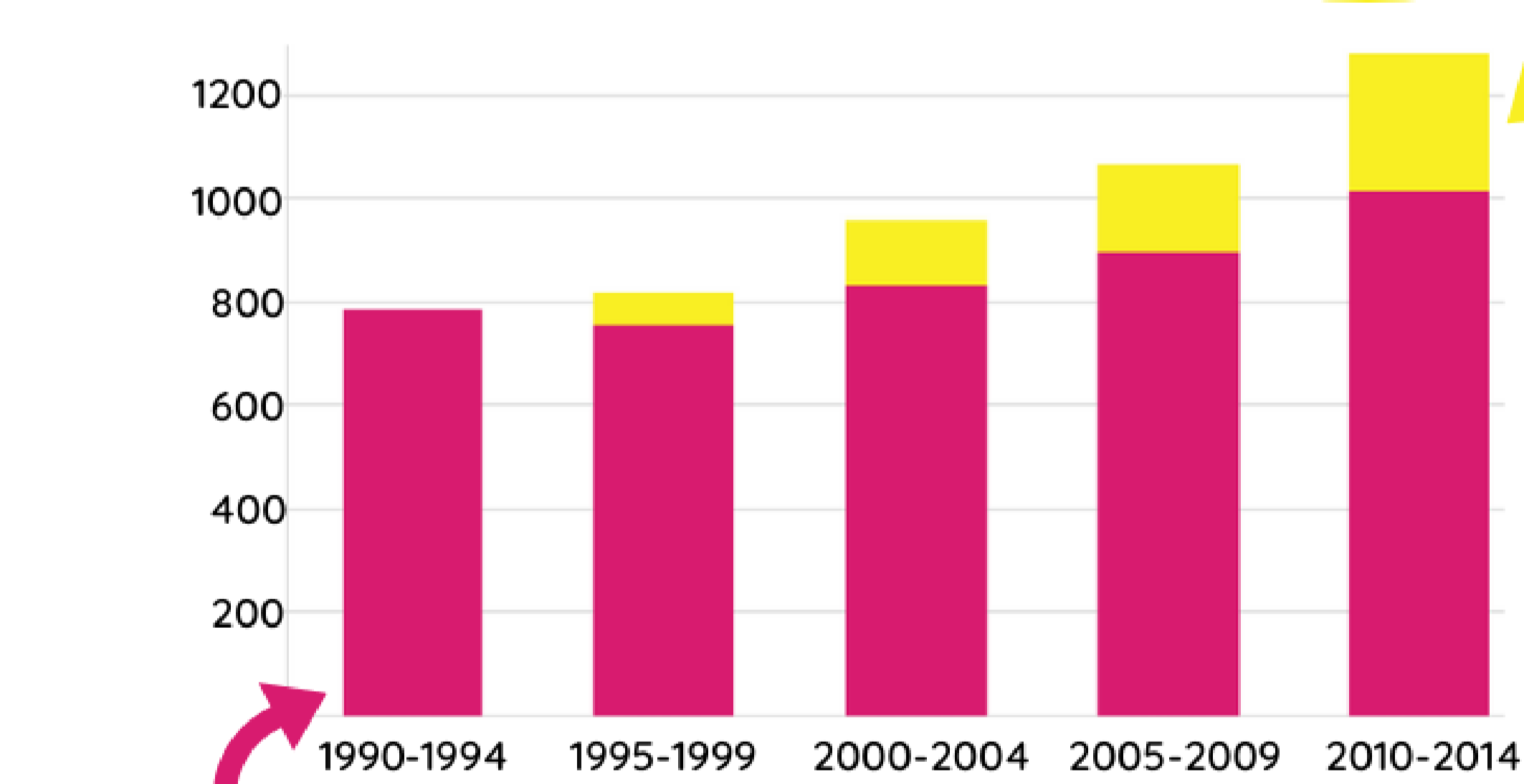
More children and young adults (aged 0-29) are alive ten years after their cancer diagnosis than ever before

CYA cancer survival has increased by almost 20% in the past 20 years

OVER 600 MORE 0-29 YEAR OLDS SURVIVED CANCER IN YORKSHIRE*

*Than would have done if survival had remained as it was in the early 1990s.

Additional lives saved thanks to research and improved treatments since 1990.



Number of lives saved if 1990 survival rate remained the same.

Based on children and young adults (aged 0-29) surviving cancer for 10 years or more in Yorkshire.

Do I need to give consent?

No, we have been granted support from the Health Research Authority under section 251 of the NHS Act 2006. This enables us to collect personal data without consent.

What if I don't want my details on the Register?

You have the right to control over the information we hold about you governed by two major UK laws—GDPR and section 251 of the NHS Act 2006. We therefore do offer the right to opt out, and doing so will not affect the care you or your child receives.

More information can be found on our website: www.yrccyp.org.uk (or scan the QR code above), including information about confidentiality and use of personal data.