What can data tell us about the long-term effects of surviving childhood or adolescent cancer?

Our childhood and teenage years are full of milestones and transitions that impact the rest of our lives. For children and adolescents who receive a cancer diagnosis, this important period can be severely disrupted, and the long-term effects of their disease and its treatment can stay with them their whole life. **Dr Paul Nathan** at **The Hospital for Sick Children** and the **University of Toronto** in Canada is using large datasets to gain a better understanding of these long-term effects, with the aim of improving outcomes and support for survivors of childhood and adolescent cancer.

Dr Paul Nathan

Director of the Aftercare Clinic and Head of the Solid Tumour Program, Division of Haematology/Oncology, The Hospital for Sick Children, Canada

Professor, Department of Paediatrics, Department of Health Policy, Management and Evaluation, University of Toronto, Canada

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Websites
lab.research.sickkids.ca/rocca
lab.research.sickkids.ca/nathan

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PROFILE

Talk like a ...

paediatric oncologist

Adolescence — the transitional phase of growth between childhood and adulthood

Chemotherapy — a treatment that uses drugs to kill cancer cells

Late effects — health problems that continue for months or years after cancer treatment has ended

Paediatric oncology — the study, diagnosis and treatment of childhood and adolescent cancer

Surveillance — the ongoing and repeated monitoring of a patient's health to make sure any issues are spotted as soon as possible

Life as a child or teenager can be like a high-speed rollercoaster, full of changes and new experiences, such as forming friendships, gaining qualifications and travelling to new places. Unfortunately, receiving a cancer diagnosis at this age can make these formative years challenging.

"Getting diagnosed with cancer during adolescence can derail all the important life transitions that are taking place at this time," says Dr Paul Nathan from The Hospital for Sick Children. "Puberty, dating, going to college or university, getting a job, moving out of the family home, and taking increasing responsibility for one's life are all important things that happen during this period." Over 80% of children and teenagers will survive cancer, but these survivors may face the effects of their cancer and the disruption it caused for the rest of their lives. Paul is working to understand more about these long-term effects, with the aim of improving care and support for survivors.

What are late effects of cancer?

"Late effects of cancer include the long-term side effects that can develop from the cancer itself, such as the destruction of healthy bone due to a bone tumour, or from the treatments such as chemotherapy, radiation, surgery and bone marrow

transplants," explains Paul. "Late effects can be physical, psychological or social, and some can be serious or even life-threatening."

A cancer diagnosis and the following treatment can also result in financial difficulties for patients and their families. In countries such as Canada and the UK, public health care systems help to cover some treatment costs; however, hidden costs can still create financial difficulties. In countries with weaker public health systems, the financial challenges inflicted by a cancer diagnosis can skyrocket. "In the US, survivors of childhood cancer are at elevated risk of debt and occasionally need to declare bankruptcy," says Paul. There are often hidden costs, such as travel to and from appointments, and parents may have to reduce their working hours or even leave their jobs so they have time to care for their child or teen with cancer. "Interruptions to schooling or work (and the transition from one to the other) can have long-term financial impacts," says Paul. "Because of their cancer or its late effects, adolescents may pursue a different education or employment path than they had hoped for."

Why is continued surveillance important?

Once someone has survived cancer, it is important that they attend regular appointments to undergo surveillance in case further health problems arise. Although the risk of the cancer returning begins to decrease after the first 5 years, the risk of late effects increases as survivors get older. For example, some cancer therapies put survivors at risk of developing new cancers, heart disease and even post-traumatic stress disorder, so continued surveillance is vital. However, many survivors fail to regularly attend their appointments. "Many survivors do not know what specific treatments they received, or the late effects that may result from these," says Paul. "This makes it harder for them to share this information with doctors, and harder for the doctors to provide appropriate care."

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What is the ROCCA programme?

Working with his colleagues, Dr Sumit Gupta, a paediatric oncologist, and Dr Petros Pechlivanoglou, a health economist, Paul has founded the Real-World Outcomes of Cancer in Children and Adolescents (ROCCA) research programme. In Canada, a wealth of data is collected within the public health system, including demographic data, such as sex and area of residence, and data about cancer, recording things like type of cancer, treatments and outcomes. "ROCCA takes advantage of these data to study a whole range of outcomes in children and adolescents who have had cancer," says Paul. "Because we capture the whole population, this gives us a unique perspective that we can't get just by looking at patients who participated in clinical trials."

Paul must ensure that patient anonymity is preserved throughout the research, so precautions are taken. "For all of this research, all personal identifiers such as name and date of birth are removed from the data so we are not able to identify individuals, but we can still study outcomes across the whole population."

What has Paul learnt?

Paul has been using the ROCCA data to answer a number of questions. "We have used these data to study different late effects, to explore the best places for teens with cancer to receive care and to understand which survivors are most at risk of missing their surveillance tests," says Paul. "This allows us to design interventions to try and improve adherence. For example, a new programme called ONloop is using administrative data to find out which survivors are not up-to-date with their surveillance. This allows us to reach out to them and their family doctors to make them aware of the surveillance they need and then to send them periodic reminders to ensure they stay up-to-date."

In future research, Paul is keen to learn more about the long-term financial impacts of cancer on patients and their families. "For example, if someone gets cancer aged 15, how does their education and financial situation change over time compared to their classmate who didn't get cancer?" says Paul. "To study this, we are linking data about patients in our Canadian paediatric cancer registry with their tax return and education data." As ROCCA uncovers more about the late effects of childhood and adolescent cancer, paediatric oncologists like Paul will be better equipped to support patients and their families.

About *paediatric oncology*

The field of paediatric oncology aims to improve outcomes for children and adolescents who have been diagnosed with all types and stages of cancer. Paediatric oncologists might work directly with patients on the ward or in outpatient clinics, they might conduct clinical trials and analyse data, or they might train and supervise other oncologists and healthcare providers. "The balance between all of these responsibilities varies from one oncologist to the next, but there is always good variety and lots of fascinating challenges," says Paul. "Many of us also spend time travelling to conferences where we learn about, or teach others about, the latest research."

Paul finds working in paediatric oncology incredibly rewarding. "The medicine is fascinating and the science is constantly evolving," he says. "Supporting the patients, their parents and their siblings through the psychosocial challenges of cancer treatment is tremendously rewarding. I really enjoy the blend of clinical care and research, and I am constantly learning from my patients which helps to generate new research ideas."

Despite the rewards, paediatric oncology can be a challenging field to work in. "Even with the much-improved survival rates, there are still patients who cannot be cured," says Paul. "The difference I can make is not always about curing a patient, but often about helping a child or teenager navigate their cancer diagnosis and trying to make their road through it a little easier, even if, ultimately, they do not survive. Having an excellent team that supports each other both professionally and emotionally is incredibly helpful." Paul splits his time between clinical work and research. This balance allows him to invest all of his emotional energy into helping patients and their families.

Pathway from school to *paediatric oncology*

At school, study biology, chemistry and physics to build a solid foundation for pursuing medicine and specialising in paediatric oncology. Developing skills in data analysis and programming will also be useful for further research in college, university or work as a paediatric oncologist.

"The journey to becoming a paediatric oncologist has many steps," says Paul. "In Canada and the US, you should start with an undergraduate degree with a science focus. Then, you must complete medical school followed by a paediatric residency and a fellowship in paediatric oncology. This pathway may be different in other countries."

While at university, get involved in the research projects being conducted in your department to gain direct experience of biomedical research.

"Try to get volunteer experience in a medical or hospital setting to find out if patient care or medicine is really something that you want to do," says Paul.

Explore careers in *paediatric oncology*

The American Society of Clinical Oncology (**asco.org**), the British Association for Cancer Research (**bacr.org.uk**) and the British Oncology Network for Undergraduate Students (**bonus-oncology.co.uk**) all have useful websites with information, resources and volunteering opportunities. You could even consider becoming a student member.

The University of Toronto runs a Youth Summer Programme where students can get together to learn about life sciences: **ysp.utoronto.ca/medysp**

The Hospital for Sick Children offers a Summer Research Programme that provides undergraduate students with professional and career development opportunities: **sickkids.ca/en/research/research-training-centre/summer-research-program**

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Meet *Paul*

As a teenager, I didn't know that I would be interested in medicine, although it was certainly on my radar. I liked math and science, but I also liked English and social studies. At university, I realised that I wanted to work with and help people, so medicine seemed like an ideal path.

I love the opportunity to work with and help kids, teenagers and their families. I can't imagine anything as challenging as having to face a cancer diagnosis. To be able to care for and support young people and their families through this huge challenge is immensely rewarding. It is a privilege to be part of their lives.

The science I work with is fascinating, constantly evolving, and always opening new opportunities to treat patients or help them deal with the short- and long-term side effects of their therapy. To be working at this cutting edge of knowledge is incredibly stimulating.

I get to work with a team of amazing, smart, compassionate colleagues. Paediatric oncology is hard, but having such an incredible group of colleagues to share this journey with is a real gift.

Being inquisitive and enjoying working with people has enabled me to lead a successful career. I'm also fascinated by science and discovery, and I love being able to make a difference to people's lives.

Oncology is hard — even when you do your best, some patients don't survive. Being able to process and cope with this loss is one of the job's big challenges. Separating your work life from your home, family and relationships is critical. I am blessed to have an amazing family and to really enjoy my life outside of work. This balance is key.

To unwind from work, I enjoy spending time with family and friends. This is simple, but so rewarding and rejuvenating. I also enjoy reading, mindfulness meditation and exercise.

Paul's *top tip*

Paediatric oncology is an immensely rewarding profession. But there are lots of rewarding professions, so be sure that this is something you are passionate about. It is a long road, so you have to enjoy the process and love learning, and you need to be happy living in the moment – you must enjoy the journey as well as the destination.