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Response to Scottish Chief Scientist's Office consultation paper into their Health Research Strategy

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Introduction

Teenage Cancer Trust is the only UK charity dedicated to improving the quality of life and outcomes for the seven young people aged between 13 and 24 diagnosed with cancer every day. We fund and build specialist units in NHS hospitals and provide dedicated staff, bringing young people together so they can be treated by teenage cancer experts in the best place for them. Through education of young people about the signs of cancer and working with health professionals to improve their knowledge, we work to significantly improve their diagnosis experience.

There are around 2,500 young people diagnosed with cancer each year across the UK. In Scotland approximately 203 new patients in this age group will be diagnosed annually, while the same number again will continue to receive care for cancer or relapse¹. Patients aged 13-16 will be managed within the four children's hospitals in Scotland; the two Principal Treatment Centres for cancer in Glasgow and Edinburgh which have Teenage Cancer Trust units with Teenage and Young Adult Multi-Disciplinary Teams (TYAMDTs), Aberdeen and shared care in Dundee. Teenage Cancer Trust units at the Edinburgh Western General and Glasgow Beatson West of Scotland Cancer Centres are amongst the hospitals that provide care for 16-24 year olds, but care for this age group is more scattered.

Investment in research and medicines is important to young people with cancer, who know that access to clinical trials and developing best care and treatment can save lives². Teenagers and young adults get some of the rarest forms of cancer, and effective treatment for teenagers and young adults may differ from what works best for children or adults due to different cancer biology, different treatment protocols and different response to treatment.

Overarching comment

This consultation paper from the Chief Scientist's Office (CSO) is a welcome step in driving forward research within Scotland. We support the vision of the CSO to increase the level of high quality research conducted in Scotland for the benefit of the whole population, including teenagers and young adults with cancer. We further welcome the recent appointment of a cancer champion within the CSO as another encouraging step in the development of clinical trials and research for young people with cancer.

We note the barriers to research development and participation cited in the strategy, such as resources and clinician time. It is important to note that many other barriers exist and must be considered within the scope of this strategy. Currently young people with cancer face specific

¹ Information Services Division, NHS National Services Scotland (2013), *Cancer in Scotland (2011)*

² Teenage Cancer Trust (2012), *Young Voices: Transforming the lives of young people with cancer*

challenges in accessing research trials. There is a significant lack of trials for the types of cancers that affect teenagers and young adults, and where ones do exist, often the age criteria excludes patients in this age group. Not only this, but often when clinical trials are available for teenagers and young adults, information surrounding them is difficult to find, and therefore many patients do not know they exist.

The best way for young people with cancer to gain access to relevant clinical trials is for them to be discussed by the teenage and young adult multi-disciplinary teams (TYAMDT). In 2009-10 only 48% of 15-24 year olds with cancer in England were notified to Principal Treatment Centres for discussion at TYAMDTs³ and this is something Teenage Cancer Trust is working to change. The development of a national TYAMDT in Scotland should provide the opportunity to ensure that all young people who are eligible for a clinical trial be discussed and offered one. This national way of working also helps address the barriers of resources and clinician time for this cohort.

We strongly feel that these barriers of age, availability and access are why less than 20% of cancer patients aged 15-24 currently access clinical trials in the UK, compared with around 50-70% of children⁴. This in turn may have a direct impact on five-year survival rates for cancer as they continue to remain lower in teenagers than in children⁵.

Current strategies to drive research for young people with cancer in Scotland

It will be important for the CSO's strategy to complement and sit alongside other, similar, tools and levers for driving forward research in Scotland.

For example, the Managed Service Network for Children and Young People with Cancer published their Cancer Plan for Children and Young People⁶ in 2012. The plan stated that every child and young adult with cancer in Scotland should be enrolled into and treated on a clinical trial where one is available. It further aimed to speed up approval times, enable Scotland to act as a single research site, and improve training for relevant staff. It will be important for the CSO to encourage and support the fulfilment of these aims as these are not yet being met.

NHS Scotland published the Cancer Clinical Trials Quality Performance Indicator earlier this year, proposing to report on trial access by selected tumour types. It's imperative that data is available measuring access to clinical trials by age and tumour type in order to identify those groups with unequal access, and drive improvements. Producing and evaluating more and better data on access to research should be a priority for the CSO.

Furthermore, the Scottish Government published their Implementation Plan for Rare Diseases in July, committing to greater patient participation in planning and delivering services, including research. The CSO strategy will need to reflect the aims of this plan, particularly in how it seeks to deliver research opportunities for patients with rare diseases including young people with cancer. Research in Scotland is part of the European and International research context and documents like the Implementation Plan are important in recognising the need for such wider collaboration for small patient populations.

³ National Cancer Intelligence Network (2013), *Notifications of teenagers and young adults with cancer to a Principal Treatment Centre 2009-2010*

⁴ Cancer Research UK (2013), *Cancer Stats Report: Teenage and young adult cancer*

⁵ Ibid

⁶ Managed Service Network for Children and Young People with Cancer in Scotland (2012), *Cancer Plan for Children and Young People in Scotland 2012-15*

Specific comments on CSO's Research Strategy

Q2. CSO proposes to approve the functions of staff in R&D Offices; should CSO seek to standardise local R&D functions across Scotland, or is it preferable to allow local flexibility?

Q10. What proportion of CSO funding should be available for deployment in new research initiatives relevant to the NHS? In what areas should CSO seek to disinvest to free up resources?

In order to ensure sufficient resources for all patients, including those with less common illnesses or small patient populations, it might be appropriate for the functions and funding decisions of the CSO to reflect where patients are treated. To facilitate this, referral pathways for patients should be maintained and supported in order for patients to be able to access the research opportunities available at Principal Treatment Centres. For example, for young people with cancer it's imperative that teenagers and young adults are notified to the TYAMDTs – whether national or regional, to ensure they are informed of relevant clinical trials.

When considering the best use of resources by the CSO it should be noted that the number of life years lost to cancer in young people is currently estimated to rank second highest, behind breast cancer⁷. Yet 80% of young people diagnosed with cancer now live for five years or more⁸, and so with swift diagnosis, access to specialist care and treatment, including research and clinical trials, many young people with cancer can go on to lead long and productive lives, contributing to society and the economy.

Q8: Would a trial register be of benefit to patients seeking trials? Would it be an effective way to partner patients with researchers? Is there a danger that expectations of taking part could be unfairly raised?

We welcome any initiatives to increase the opportunities for young people with cancer to take part in clinical trials. We know that many rely on their oncologist to tell them about trials, yet there may not be a culture of referring patients to other oncologists who are running trials.

We also welcome the development of the Public Engagement Group outlined in the strategy, and its proposed role in increasing public awareness and understanding of clinical research. We know that young people with cancer consistently report worse experiences with regard to communication, particularly when explanations of treatments, condition and tests are not delivered in a way which recognises the lack of hospital experience many young people will have at the time they start treatment.⁹ It's important that information surrounding clinical research is provided in a patient-accessible format as to overcome misconceptions surrounding clinical trials, and lay involvement in the production of some of this information may help to address this.

Summary

There are significant arbitrary, commercial and legislative barriers which mean that only 20% of teenagers and young adults with cancer in the UK have access to clinical trials. Insufficient referrals to specialist services mean that many young people are not being informed of trials which might be suitable for them. And although legislation does not restrict access for this age group, the practice of trial protocol setting is often leaving them out.

⁷ CYP IOG Advisory Group Annex M (2010), *Children and young people with cancer 2015*

⁸ Cancer Research UK (2013), *Cancer Stats Report: Teenage and young adult cancer*

⁹ Department of Health (England) (2010, 2012 and 2013), *National Cancer Patient Experience Survey*

Increased investment and resources may help increase the amount of teenagers and young adults with cancer and other rare diseases taking part in clinical trials, along with increased notifications to specialist care and better provision of age-appropriate information.