Patient Notification Document for the Cancer Survivorship Studies

Main aim

To set-up a system to monitor the risks of side-effects of cancer and its treatment among survivors of childhood, teenage, and young adult cancer in Britain using two national studies: the British Childhood Cancer Survivor Study (BCCSS) and the Teenage and Young Adult Cancer Survivor study (TYACSS).

Why are we doing this study and why have you been included?

There is no current system to monitor the health of the entire population of survivors of childhood, teenage and young adult cancer in Britain.

Our aim is to extend two existing studies the BCCSS and the TYACSS to understand the risks of all side-effects of cancer and its treatment among all British survivors of childhood, teenage and young adult cancer.

It is likely that by 2030 there will be 4 million individuals living after treatment for cancer. So far there has been little research to understand risks of side-effects of cancer and its treatment and how the risk might be reduced or prevented in the future.

In recent years there have been several detailed consultations involving cancer survivors, their families and friends and the health care professionals. The reason for the consultations was to identify the research priorities as rated by survivors, their family and friends and health care professionals.

One consultation relating to teenagers and young adults with cancer reported their top 10 research priorities. Of these top 10 research priorities, 5 are addressed by the research reported here.

https://www.jla.nihr.ac.uk/priority-setting-partnerships/teenage-and-young-adult-cancer#tab-28621

Another consultation involving a UK-wide survey resulted in 1500 responses from those diagnosed with cancer over the age of 16 years and their health carers. Again a top-10 list of research priorities was produced and of these 7 are addressed by the research reported here.

https://www.jla.nihr.ac.uk/priority-setting-partnerships/living-with-and-beyond-cancer#tab-27506

The British Childhood Cancer Survivor Study (BCCSS) includes 35000 individuals who were diagnosed with cancer under the age of 15 years, between 1940 and 2006, in England, Wales or Scotland and who survived at least 5 years from diagnosis of their cancer.

The Teenage and Young Adult Cancer Survivor Study (TYACSS) includes 200,000 individuals diagnosed with cancer when aged 15 to 39 years, between 1971 and 2006, in England or Wales, and who survived at least 5 years from diagnosis of their cancer.

The results produced are likely to change both clinical practice and health policy in the following ways

- By providing evidence to inform and empower survivors
- By providing evidence to develop clinical follow-up guidelines
- By providing evidence to help prepare “survivorship care plans” after end of treatment
- By providing educational material for health care professionals including GPs
- By providing evidence to assess both risks and benefits of particular treatments
- By providing evidence to national health authorities concerning the levels of risk different groups of survivors are likely to experience
- By identifying survivors of low risk for whom hospital follow-up may not be necessary

Proven impact of our previous research

Our research has previously investigated the long-term risk of the total burden of serious illness experienced by cancer survivors. This resulted in identification of which groups of survivors were at high, medium and low risk of serious illness. NHS England has used this information to update its Service Specifications. In future every survivor of childhood, teenage and young adult cancer will be assessed in relation to their long-term risk of serious illness using our findings:

https://www.engage.england.nhs.uk/consultation/childrens-cancer-services/user_uploads/service-specification-childrens-networks-and-principle-treatment-centres.pdf

https://www.engage.england.nhs.uk/consultation/teenager-and-young-adults-cancer-services/user_uploads/service-specification-tya-principal-treatment-centres-and-networks.pdf

What will happen to the information included about you?

We have obtained details relating to your cancer from the national cancer registration systems in England, Wales and Scotland. We shall use your details to undertake individual patient electronic record linkage between each of the BCCSS and TYACSS cohorts and several national health registers and databases including:

- the national cancer registers – to identify new primary cancers experienced more than 5 years after the original cancer diagnosis
- hospitalisation for any disease after 5-year survival using the national Hospital Episode Statistics database
- hospitalisation for a cardiovascular condition after 5-year survival using the National Institute of Cardiovascular Outcomes Research (NICOR)
- the national NHS GP prescriptions database to identify the GP prescriptions received by survivors
- Use the Mental Health Services Dataset to identify the mental health services in the community used by survivors

- Use all of the above to estimate the total burden of illness experienced by 5-year survivors of childhood, teenage and young adult cancer
- the national death registers – to identify causes of death experienced by survivors who die more than 5 years after cancer diagnosis

Ethical and Consent considerations

The work has been assessed by a national NHS Research Ethics Committee and they were happy for the research to be done from the ethical perspective.

The Health Research Authority, on the advice from the Confidentiality Advisory Group, an advisory body which provides independent expert advice on the use of confidential patient information without consent in England and Wales, has provided support for the research described here to be undertaken. This provides the legal basis for the research to proceed without individual informed consent.

What are the potential benefits of including information about you?

As outlined above these national studies provide evidence which identifies those at low, medium and high risk of serious illness. It is used by NHS England as a basis for assessing the level of intensity of clinic follow-up needed for specific groups of cancer survivors. The information will also be available to individual survivors and health care professionals.

What if I do not wish to take part?

Under Article 17 of the GDPR individuals have the right to have personal data erased. However, removing information limit the ability to conduct research. Cohort members can opt out from the use of their data for research and or planning purposes.

Further information on this national data opt-out can be found at: https://digital.nhs.uk/services/national-data-opt-out.

Cohort members that would like to opt-out of use of their health-care records by the Study Centre have two options. Identifiable information (including name, NHS number, date of birth) will only be used for linking of electronic health care databases, not for analysis purposes; names or other identifiable information will never be published or appear in the public domain. However, if cohort members wish that their electronic health care records are no longer processed by the Study Centre then the Study Centre can be contacted with the preferable opt-out option:

1. Opt-out with remaining access to existing data: the Study Centre will no longer prospectively link their databases to other datasets that may have information on your health, but you do give the Study Centre permission to continue using the data they currently hold.

2. Complete opt-out: the Study Centre will completely remove any records relating to you from our databases and your records will not be used for medical research at the Study Centre.

The Study Centre can be notified of an opt-out decision by:

emailing at: colmds-c-pcsf-support@bham.ac.uk
by telephoning a free-phone number (**0800 328 9419**)
or by writing to the Study Centre at:

Centre for Childhood Cancer Survivor Studies
Robert Aitken Institute for Clinical Research
University of Birmingham
Edgbaston
Birmingham
B15 2TY
UK

What will happen to the results of the study?

- Results will be published in international peer-reviewed journals and an up-to-date list of such publications is always available on the study website. https://www.birmingham.ac.uk/research/activity/mds/projects/haps/pheb/cccss
- We intend to establish a section of the study website to provide accessible summaries of the research in the form of newsletters.