

42 U.S. Code § 285a-11

Pediatric cancer research, awareness, and survivorship

(a) Children's cancer biorepositories

(1) Award

The Secretary, acting through the Director of NIH, may make awards to an entity or entities described in paragraph (4) to build upon existing research efforts to collect biospecimens and clinical and demographic information of children, adolescents, and young adults with selected cancer subtypes (and their recurrences) for which current treatments are least effective, in order to achieve a better understanding of the causes of such cancer subtypes (and their recurrences), and the effects and outcomes of treatments for such cancers.

(2) Use of funds

Amounts received under an award under paragraph (1) may be used to carry out the following:

- (A) Collect and store high-quality, donated biospecimens and associated clinical and demographic information on children, adolescents, and young adults diagnosed with cancer in the United States, focusing on children, adolescents, and young adults with cancer enrolled in clinical trials for whom current treatments are least effective. Activities under this subparagraph may include storage of biospecimens and associated clinical and demographic data at existing biorepositories supported by the National Cancer Institute, such as collected samples of both solid tumor cancer and paired samples.
- (B) Maintain an interoperable, secure, and searchable database on stored biospecimens and associated clinical and demographic data from children, adolescents, and young adults with cancer for the purposes of research by scientists and qualified health care professionals.
- (C) Establish and implement procedures for evaluating applications for access to such biospecimens and clinical and demographic data from researchers and other qualified health care professionals.
- (D) Provide access to biospecimens and clinical and demographic data from children, adolescents, and young adults with cancer to researchers and qualified health care professionals for peer-reviewed research
 - (i) consistent with the procedures established pursuant to subparagraph (C);
 - (ii) only to the extent permitted by applicable Federal and State law; and
 - (iii) in a manner that protects personal privacy to the extent required by applicable Federal and State privacy law, at minimum.

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