

**Guidance Document:  
Consent for Continued Participation in a Research Study  
By a Young Adult Who Has Reached Age 18**

Pediatric subjects who participate in research at the DF/HCC must provide consent to continue in the research when they reach the age of 18 – the age of majority in the Commonwealth of Massachusetts.

- Subjects who assented may be re-consented with either:
  - (1) The currently approved version of the informed consent form, using the participant consent signature section, rather than the assent signature section; or
  - (2) The generic informed consent form entitled “Consent for Continued Participation in a Research Study by a Young Adult Who Has Reached Age 18” that is posted to the OHRS website.
- A waiver of re-consent may be requested of the IRB by the study team where it is highly unlikely that the study team will have any contact with the subject at the time that they reach the age of 18.

This new informed consent form (Consent for Continued Participation in a Research Study by a Young Adult Who Has Reached Age 18) will allow former pediatric participants who were not able to provide consent, to now provide consent. This generic informed consent form briefly touches upon the general interventions outlined in the original consent document and requests that study participants indicate: 1) If they consent to continue participation or withdraw; or 2) If they wish to consent to continued use of their samples for research or do not agree to have their samples stored for future research. Participants will be given a copy of the original consent documents signed by their parent or legally authorized representative as well as the new consent form.

Dana-Farber/Harvard Cancer Center requires that the document used to re-consent participants who have reached the age of 18 be kept in the research files and that the re-consent should be noted in the medical records.

**Please note** that if study participants were enrolled onto a pediatric study prior to 2004 their original consent document may not contain the most recent HIPPA language. For these participants we recommend that they are consented using the generic pediatric consent form.