



Hospital logo

## CHILDREN'S CANCER INSTITUTE

### MINIMUM RESIDUAL DISEASE TESTING AND BANKING OF SPECIMENS FOR FUTURE RESEARCH

#### PATIENT INFORMATION STATEMENT

Your doctor or clinical trials centre has requested that Children's Cancer Institute performs some tests to measure minimum residual disease (MRD). MRD is a research test based on the identification of unique features known as markers that are present in leukaemic or lymphoma cells but that are not usually present in normal cells. Once they have been identified, these markers can be measured in a sample collected from the same patient after treatment. MRD testing is usually done on bone marrow samples but blood and other tissues can also be tested. MRD testing is used mainly in clinical trials to identify patients at higher or lower risk of relapse. **We will not provide any test results to you directly. The results of MRD testing will be sent to your doctor and the clinical trials centre if applicable, and your doctor has the responsibility for interpreting these results for you.**

**We would like your permission to keep any leftover sample (DNA and/or cells) for research.** If you agree, the sample(s) will be kept frozen in our Tissue Bank at the Lowy Cancer Research Centre, UNSW, Randwick, NSW, 2031 for an unknown amount of time. Sometimes doctors request additional diagnostic tests for a patient using their stored samples. Stored left over samples may also be used in medical research which has approval from a Human Research Ethics Committee (HREC). Most research will not show results for a considerable period and there will be no direct medical value to you. The use of your sample(s) could however benefit other patients in the future. All research using banked tissue requires approval by an HREC and the Management Committee of the Children's Cancer Institute Tissue bank. The results of the research may be published provided that patients cannot be identified. The choice to let us keep your samples for future testing or research is up to you. If you decide to let us keep leftover sample (cells and/or DNA), you may change your mind at any time and we will destroy any remaining sample(s).

In the event that incidental/unexpected information relevant or useful to you, your child or your community becomes available, the researchers who have been given your sample have agreed to provide the results to the Tumour Bank Management Committee. If information becomes available, you will be informed of this information by your treating doctor or GP who is listed on your medical records charts. You can choose to be notified of these findings by ticking the appropriate box on the consent form.

**Researchers who use your samples in the future may need up-to-date information on your health.** If you give consent, then Children's Cancer Institute staff from the MRD group or Tissue Bank may request your health information from your doctor or hospital or clinical trial co-ordinator. Only these staff will have access to your name and other personal details. Your health information will be coded to preserve your privacy. In rare cases, more information may be needed from you for a research project, but this will only happen if you have given specific consent.

Your sample(s) will not be sold and will only be used for: 1) tests that your doctor requests including MRD testing, 2) quality control purposes or 3) cancer research. Although research conducted using your samples may result in the development of new medical products or treatments you will not receive money or other forms of compensation.

**If you have questions at any time your doctor will be happy to answer them.**

**If you have specific questions about the Tissue Bank at the Children's Cancer Institute, you may contact Ms Kiri Collins [fbmgmt@ccia.unsw.edu.au](mailto:fbmgmt@ccia.unsw.edu.au) ; phone 02 9385 2085.**

**CHILDREN'S CANCER INSTITUTE**  
**MINIMUM RESIDUAL DISEASE TESTING**  
**AND BANKING OF SPECIMENS FOR FUTURE RESEARCH**

**PATIENT CONSENT FORM**

~ I understand that MRD testing will be performed at the Children's Cancer Institute. I understand MRD test results will be provided to my doctor who is responsible for their interpretation.

**I freely consent to MRD testing.** Yes  No

~ I understand that any samples left over after testing will be stored in the CCIA Tissue Bank for future testing if requested by my doctor or for future research approved by an ethics committee. This applies to all specimens collected from the date of my first admission documented below.

**I freely consent to storage of my samples and their use in research.** Yes  No

~ I understand that information on aspects of my health may be useful for future research; that any information will be kept confidential and may be updated in the future.

**I freely consent to the provision of information about my health.** Yes  No

**I agree to be informed of any new information that may benefit or reduce the risk to me, my family or my community resulting from research on my sample.** Yes  No

**I freely consent to being contacted by the medical staff in the future.** Yes  No

\_\_\_\_\_  
**Name** \_\_\_\_\_  
**Date of first admission**

\_\_\_\_\_  
**Medical Record Number** \_\_\_\_\_  
**Hospital**

\_\_\_\_\_  
**Signature of Patient** \_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Signature of Witness** \_\_\_\_\_ \_\_\_\_\_  
**Name of Witness** \_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Signature of Interpreter** \_\_\_\_\_ \_\_\_\_\_  
**(if needed)** \_\_\_\_\_  
**Name of Interpreter** \_\_\_\_\_  
**Date**

**CHILDREN'S CANCER INSTITUTE**  
**MINIMAL RESIDUAL DISEASE TESTING AND**  
**BANKING OF SPECIMENS FOR FUTURE RESEARCH**  
**REVOCAION OF CONSENT**

I hereby WITHDRAW my consent for future research on samples collected from me. I understand that such withdrawal WILL NOT make any difference to my relationship with the hospital or medical attendants.

**Name of Patient:** \_\_\_\_\_

**Date of Birth:** \_\_\_\_\_

\_\_\_\_\_  
*Signature of Patient*

\_\_\_\_\_  
*Date*

**The section for Revocation of Consent can be given to your doctor for forwarding to**

**The Scientific Services Manager,  
Children's Cancer Institute,  
C25 Lowy Cancer Research Centre, UNSW,  
PO Box 81, Randwick, NSW 2031, Australia.  
Fax 02 9662 6584**