

NSW & ACT Hereditary Cancer Registry

Registration form

Registration with the Hereditary Cancer Registry (HCR) is for people at risk of hereditary cancer syndromes.

Registration is voluntary but is strongly encouraged.

Please use this form for the first notification of your patient to the HCR.

Please complete all requested information and attach copies of the family pedigree, relevant pathology and genetic test reports, and clinic letters.

The inclusion of an individual on the HCR requires a **signed consent form**. This can be found on the second page of the registration form.

Please send completed registration forms to:

Cancer Institute NSW
NSW & ACT Hereditary Cancer Registry
Locked Bag 2011
St Leonards NSW 1590

If you have any questions about these forms or the HCR, please contact us:

T: 1800 505 644
F: (02) 8374 3617
E: cinsw-hcr@health.nsw.gov.au
W: cancer.nsw.gov.au

The HCR currently focuses on hereditary bowel cancer syndromes, including:

- Lynch Syndrome
- Familial Adenomatous Polyposis
- MUTYH-associated Polyposis
- Peutz-Jeghers Syndrome
- Juvenile Polyposis
- Serrated Polyposis Syndrome
- Hereditary Mixed Polyposis Syndrome
- NTHL1-associated Polyposis
- PTEN-associated syndromes
- CHEK2-associated syndromes



NSW & ACT Hereditary Cancer Registry – Registration form (continued)

Person being registered

Title	Male	Female	Maiden name
Surname	Mother's maiden name		
Given names			
Date of birth	Phone	Email	
Address			

Reason for registration (Please tick this individual's current status)

Lynch Syndrome	Proven	Suspected	At risk due to family history
Familial Adenomatous Polyposis	Proven	Suspected	At risk due to family history
MUTYH-associated Polyposis	Proven	Suspected	At risk due to family history
Other polyposis syndrome (give details below)	Proven	Suspected	At risk due to family history

Genetic testing

Has the family gene mutation been identified?	Yes	No
Has this person had blood collected for genetic testing?	Yes	No
If 'Yes' to the above, is this person:	Mutation positive	No mutation found
	Mutation negative	Results pending

If a causative mutation is known, please provide details:

Surveillance plans

We will be offering our **screening reminder service** unless requested otherwise. If you are not the treating clinician, please give details of the clinician to whom screening reminders should be sent.

Doctor	Next screening due
Address	

Details of registering clinician

Title	Name
Address	
Signature	Date

In order to complete registration for the above person, please attach copies of:

- Family pedigree
- Pathology and genetic test reports
- Clinic letter with screening recommendations

NSW & ACT Hereditary Cancer Registry – Consent form

If you (or your child/dependant) would like to be included on the Hereditary Cancer Registry, you will need to read through this form with your doctor or treating clinician. If you agree with its contents, please sign it and send it to:

Cancer Institute NSW
NSW & ACT Hereditary Cancer Registry
Locked Bag 2011, St Leonards NSW 1590

I consent to be included on the Hereditary Cancer Registry (HCR) on the understanding that:

1. The HCR will only obtain information about me (or my child/dependant) and my family that is necessary to:
 - verify relevant health details from my doctor
 - record an accurate family history
 - identify other family members who have a high risk of developing cancer, and assist me or my doctor to inform them of their increased risk and their treatment options
 - accurately record the details of my regular screening check-ups and gene test results (if applicable)
 - keep the information recorded about me on the HCR up to date.

2. I (or my child/dependant) understand the HCR Screening Reminder Service involves:
 - receiving a letter reminding me that I am (or my child/dependant is) due for a follow-up examination
 - allows the HCR to obtain relevant follow-up information from my doctor regarding my (or my child/dependant's) hereditary cancer condition.
3. I understand I can opt off the screening reminder service at any time.
4. I (or my child/dependant) may be asked to assist with research into hereditary cancer which would require a separate consent. I have the right to decline to participate in any research studies, and this decision will not in any way affect the services my family and I receive from the HCR.
5. My (or my child/dependant's) information will be kept confidential and will not be released in a form that could identify me (or my child/dependant), except when needed by a doctor, accredited genetic testing laboratory, family cancer clinic or another hereditary cancer register to assist in my care or the care of other members of my family. Any information identified with me (or my child/dependant) will not be passed on to any members of my family without my consent.

I, *(PRINT your full name)*

Date of birth

Address

have read and understood the above information and agree to be included on the NSW & ACT Hereditary Cancer Registry.

Your signature

Date

OR, if signing on behalf of your child or dependant who is under 16 years of age:

I, *(PRINT your full name)*

have read and understood the above information and agree for my child/dependant

(PRINT his/her full name)

Your child/dependant's date of birth

Address

Your signature

Date

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