The Royal Melbourne Hospital

Participant Information Sheet/Consent Form for Australian Rare Cancer Portal

Title	**WEHI Stafford Fox Rare Cancer Program:** Discovery of novel therapeutic targets within the biology of rare cancers
Project Sponsor	Walter and Eliza Hall Institute of Medical Research (WEHI)
Principal Investigator	Prof Clare Scott
Associate Investigator(s)	A/Prof Jayesh Desai, A/Prof Sumitra Ananda, Dr Damien Kee, A/Prof Alison Trainer
Site	The Royal Melbourne Hospital

Part 1 What does my participation involve?

1 INTRODUCTION

You are invited to take part in this research project (or research study) because you have been diagnosed with a type of rare cancer and your doctor would also like you to take part in the Australian Genomic Cancer Medicine Centre's Rare Cancer Portal (also called the Australian Rare Cancer Portal, or ARC Portal). You will also be given the option of donating blood, eyebrow hair and tumour tissue samples to be used for scientific research into rare cancers.

This Participant Information Sheet/Consent Form tells you about the ARC Portal and the research project, which is called the WEHI Stafford Fox Rare Cancer Program. It explains the tests and evaluations involved. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or your local doctor.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. You will receive the best possible care whether or not you take part.

If you decide you want to take part in the ARC Portal and the research project, you will be asked to sign the consent section. By signing it you are telling us that you:
• Understand what you have read
• Consent to take part in the ARC Portal and the research project
• Consent to the research processes that are described below
• Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

2 WHAT IS THE PURPOSE OF THIS RESEARCH STUDY?

Rare cancers are defined as those occurring in less than 6 out of 100,000 people per year.

The purpose of this research study is to collect clinical data and to use blood, eyebrow hair and tumour tissue samples from patients with rare cancers to study these types of cancers in detail.

Because these types of cancer occur so infrequently, there has been very little research into how rare cancers develop, and how best to treat them. Understanding this may be important because it may help doctors to better select appropriate treatment options.

In this research study, we will be looking closely at the following aspects of rare cancers:
Clinical Data
With clinical information obtained from patients with rare cancers, we will be able to learn more about how rare cancers behave, how patients respond to treatments and other aspects about their health, lifestyle and family history of cancer. If you choose to join this study, your clinical data may be linked with data from other people with a rare cancer from around the world, in a coded way, so that we have larger numbers of cases to study. With rare cancers this is an important way to provide new insights.

The Purpose of the Australian Rare Cancer Portal
The Australian Rare Cancer Portal (ARC Portal) is a new initiative funded by the Federal Government as part of the Australian Genomic Cancer Medicine Centre. It is designed to help your doctor to obtain advice from medical experts with experience in the treatment of your type of rare cancer.

The ARC Portal will collect data about the type of cancer you have, any testing performed on your cancer, the types of treatment you are recommended to have and other medical information including your family history of cancer. Your doctor and the ARC Portal specialists may stay in touch to see how you respond to the recommended treatment and continue to collect your information unless you withdraw your consent.

The ability to collect your clinical data is an important part of the ARC Portal and the research study. If you choose to join the ARC Portal and this study, your clinical data can be used in research to help improve our understanding of rare cancers. All other research mentioned in this consent form is optional.

Genetic Research - Optional
Genes are made of DNA – the chemical structure carrying your genetic information that determines many human characteristics such as the colour of your eyes or hair.

Researchers study genes in order to understand why some people develop certain conditions, such as a type of rare cancer, and why some people do not. Understanding a person's genes may also be able to explain why some people respond to a treatment, while others do not, or why some people experience a side effect and others do not. The DNA of your cancer cells contains genes that have changed, or mutated, from the genes in your normal cells, making them behave differently, and contributing to the growth and development of your cancer.

It is possible to identify changes, including mutations, in your cancer cells using a test called gene sequencing. Gene sequencing performs a detailed analysis of the DNA present in cancer to see if any of the genes have changed or mutated. Identifying changes in cancer cells can help researchers learn more about how your cancer formed, what kinds of treatments are likely to work, and what may not have any benefit.

New gene sequencing techniques make it possible to look for many hundreds of cancer genes at the same time.

Protein Research - Optional
Genes are responsible for making proteins. Proteins are responsible for a lot of things that your body does, including how your cells (including your cancer cells) function, how your cells (including your cancer cells) talk to each other, and how substances are moved around your body.

The researchers in this study want to study the proteins present in your cancer cells, for much the same reasons they want to study the genes present in your cancer cells – they think that

identifying changes in proteins can help researchers learn more about how your cancer formed, what kinds of treatments are likely to work, and what may not have any benefit.

Immune System Research - Optional
The immune system also plays an important role in cancer. Cancer cells can be recognised and destroyed by the immune system, but they can also avoid being "seen" or "detected" by the immune system, which allows the cancer cells to grow and spread**.** To help understand how changes are happening in your cancer the researchers may examine how your immune system works and will look for any changes present in the function of your immune system caused by the cancer.

Ongoing Research - Optional
We may also use your tissue to make "cell lines". A cell line consists of cells that are extracted from tissue samples and kept in the laboratory to allow researchers to study and perform research on them over a very long period of time. Because the cells in cell lines have been separated from the tissue samples they came from, they can be shared with other research groups, so different research can be performed and results compared to learn more about rare cancers in general.

3 WHAT DOES PARTICIPATION IN THIS RESEARCH INVOLVE?

If you agree to take part in this research study, firstly you will be asked to sign this consent form. By signing this form you agree to undertake the following procedures as part of participating in the study:

Collection of medical information
You agree to allow your cancer specialist to provide the study doctors with information about your health and medical conditions. Other health professionals, hospitals or laboratories outside this hospital may be contacted to release information for the purposes of this research project. This information is collected as part of the study for 3 reasons:

i) to enable your cancer details to be considered by the ARC Portal,
ii) to provide the study doctors with relevant medical information that will help them to discuss your case and provide information back to your doctor,
iii) to form a database of clinical data about rare cancers.

The information which will be collected about you will include:

- Your medical history including details about your cancer, when/how you were diagnosed, the kinds of cancer treatments you have received, and your progress on these treatments. This may include information on your medical file including results of past scans and any molecular or special testing previously performed on your cancer, including genetic tests.
- Other health problems you may have.
- We may ask you to give us health information about your relatives, relating to cancer or other genetic conditions which run in your family.
- Any complications that occur as a result of the optional blood tests which you may undergo as part of this study.

Collection of Blood, Eyebrow hair and Tumour tissue samples (optional)
You have the option to donate your blood or eyebrow hair or tissue samples for this program. We will use blood, eyebrow hair and tumour tissue samples for gene sequencing to find gene changes in your tumour. We will also use your blood, eyebrow hair and tumour tissue samples to understand how your immune system interacts with your tumour.

a) Research blood or eyebrow hair samples
If you consent to providing blood or eyebrow hair, you will be asked to provide blood or eyebrow hair samples for gene sequencing (30mls of blood, about 1.5 tablespoons each time; and/or eight eyebrow hairs). These blood or eyebrow hair samples will be used to determine the sequence of genes in normal tissue (germline), so that we can find any changes in your tumour (somatic). Your blood or eyebrow hair sample may also be examined to look for cells originating

from your cancer or immune system. You will be asked to provide up to three samples of blood each year that you are participating in this study and agreeable to this collection. You will be asked to provide eight eyebrow hairs at the start of the study. This is optional, you can still participate in this study without providing blood or eyebrow hairs.

b) Research tumour tissue samples

If you consent, you will be asked to provide tumour tissue samples for gene sequencing and analysis of proteins. By ticking the box for tissue sampling and signing this consent form, you consent to the collection of one or both of the following tumour tissue samples:

i) Retrieval of a previously obtained ("archival") tumour sample. This means you will give permission for the researchers in this study to retrieve a tumour sample that was collected from you prior to your participation in this study. This sample may be stored in a hospital or research laboratory or a tissue bank if you have previously agreed to storage of your tissue. This sample is optional, you can still participate in this study without providing a tumour sample.

ii) Providing a "fresh" (non-archival) tumour sample. Sometimes your cancer specialist may recommend surgery or biopsy as part of the treatment of your cancer. If this is the case, and the surgery or biopsy involves removing a tumour or part of a tumour, we can use samples of the tumour obtained at the time of your surgery for the purposes of this study. If you do not have a surgery scheduled as part of your standard of care treatment, a fresh tumour sample will not be collected. This sample is optional, you can still participate in this study without providing a fresh tumour sample.

Follow-up

After the collection of the medical information and samples, you may be contacted by your research doctor on a regular basis (every six-twelve months) to ask about your general health, if your disease has worsened, and if you have started any new anti-cancer treatments. You will also be able to contribute blood samples if you are agreeable to this collection. You may not need to be contacted if your medical information is available through your hospital record.

Completion of a Questionnaire

We will ask you to fill out a brief questionnaire that will ask you to what extent your cancer is interfering with your ability to perform your daily activities. People with a rare cancer face a lot of unknowns and it is important to understand how big a problem this is. This can be done if you visit the hospital or by mail.

Analysis and Interpretation of your gene sequencing results

Gene sequencing of tumour, eyebrow hair and blood samples can produce very complex results which require a wide range of experts to analyse and interpret these results. These may include scientists, bioinformaticians, specialists in genetics and oncologists. If your tumour, eyebrow hair and blood samples have undergone gene sequencing, where required your results will be analysed by a panel of experts (Molecular Tumour Board) associated with this study. All the experts and personnel involved with this study are bound by regulations to protect privacy of your personal health information including your results of gene sequencing in this study, so confidentiality will be maintained at all times.

During this analysis, it may be found that the results of the cancer sequencing test shows genetic abnormalities in your tumour which may suggest that a particular treatment or new drugs targeting these abnormalities may be useful treatment for your cancer. Although it is not the intention of this study to provide new treatment options for patients, if results of this type are found, they will be provided to your cancer specialist who will be able to discuss them with you.

4 DO I HAVE TO TAKE PART IN THIS RESEARCH PROJECT?

Participation in any research project is voluntary. If you do not wish to take part in the ARC Portal and this research study, you do not have to. If you do not wish to take part it will not be possible for your doctor to obtain advice from medical experts with experience in the treatment of your type of rare cancer through the ARC Portal. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you, nor will it impact your eligibility for any other research projects offered in the future. The ARC Portal is a new program and is not part of routine care. Your routine care will not suffer if you choose not to take part.

5 WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

There may be no direct benefit to you from taking part in this study although the information gained from our research may benefit patients in the future, by discovering the best way to use cancer gene sequencing tests.

As discussed above, the cancer gene sequencing test performed on your samples, if you choose to donate them, in this research study may find genetic abnormalities in your tumour which may suggest new treatment options, which your cancer specialist will discuss with you. However, as the gene sequencing performed on this study is for research purposes, your cancer specialist may advise further confirmatory tests in a standard laboratory before choosing to act on these results.

However, there are no guarantees that your gene sequencing results will change any of your cancer treatment options, as this is not the purpose of this study.

6 WHAT ARE THE POSSIBLE RISKS AND DISADVANTAGES OF TAKING PART?

Risks of Optional Blood Sampling

For most people, needle punctures for blood draws may be uncomfortable but do not cause any serious problems. However, they may cause bleeding, bruising, infections or pain at the needle site or dizziness at the time of blood draw.

Risks of Optional Eyebrow Hair Sampling

There are no risks or disadvantages associated with the collection of eyebrow hair samples.

Risks of Optional Genetic Testing

The gene changes in your cancer usually only occur in the cancer and are not passed from/to family members. However, when performing gene sequencing on your blood samples, on rare occasions we may identify a cancer gene abnormality that may be hereditary (runs in your family members). This may be significant for you and your blood relatives. This research project does not specifically look for these abnormalities but may find them co-incidentally. If these hereditary gene abnormalities are found, your cancer specialist will be informed of this by the research team and you will be referred to familial cancer specialists (doctors specialising in cancer conditions which run in families). The familial cancer specialists will be able to provide further tests to confirm the result found in our research study. They will provide further explanation of the implications of any hereditary genetic abnormality for you and will be able to inform and advise your family, with your permission. Any information you give us about you or your relatives as part of this process will be kept confidential. We will not contact your relatives without your permission.

It is important to understand that such results only suggest an increased *risk* of developing cancer; it does not necessarily mean that you (or your family members) will develop cancer.

Finding out about these hereditary gene abnormalities may have implications for you and your family. We advise you to think about these carefully. We would advise you not to donate your

blood or eyebrow hair or tumour tissue if you are not comfortable with the possibility of such findings. You can still be included in the study and have your clinical data collected, as this may be very helpful for research.

You need to also be aware that statutory or contractual duties may require you to disclose the results of genetic tests to third parties (for example, insurance companies), particularly where the results provide information about health prospects. If you have been informed that you have a hereditary genetic abnormality found by genetic testing, you may then be obliged to disclose this on any future application for insurance, should it be requested.

Your gene sequencing results from this research study are considered confidential research data and will not be released directly to yourself, or any other third parties, including your family members. You will only be able to receive them in consultation with a doctor.

7 WHAT ARE THE COSTS?

There are no financial costs associated with participating in this research project, nor will you be paid nor receive any reimbursements for your participation in this research project. Any medical tests, gene sequencing tests and medical care required as part of the research project will be provided to you free of charge.

8 WHAT WILL HAPPEN TO MY TEST SAMPLES?

Your blood, eyebrow hair and tumour samples, and any paperwork accompanying them, will be stored as re-identifiable specimen(s); this means that it will be labelled with a study unique identifier number (UIN) only, not with any personal details. However, the researchers in this study have the ability to re-identify your sample, by linking the UIN back to your clinical details in the study database, if this information is necessary for research. For example, genetic testing performed at a laboratory in the Victorian Comprehensive Cancer Centre (VCCC) precinct requires patient identifiers (your name, date of birth and hospital number or pathology specimen ID) on the samples (National Association of Testing Authorities Australia (NATA Australia) accredited laboratories); or if we need to identify the sample as yours (for instance if you have requested removal or destruction of the sample).

Any samples taken for the purposes of the genetic testing and any paperwork accompanying them will be transferred to the WEHI bank for long-term storage after processing. The purpose of banking is to answer research questions in the future, so we expect to keep your samples and information for a long time (indefinitely).

“Banking” is storing health information and/or blood, eyebrow hair and tissue for future research studies. A “bank” is the place where health information and/or blood, eyebrow hair and tumour tissue is stored. As part of this study, your unused blood, eyebrow hair and tumour samples and genetic testing results (genomic data) will be banked for use in future research. This future research will help doctors and scientists to learn more about the genetic information of cancers, with a goal to develop new treatments and improve the health of cancer patients. Any such future research projects will need to be reviewed by Human Research Ethics Committees (HREC) for the project to be granted approval, and for permission to be granted to use your samples for the newly approved research project. Approval will also be required from the study doctors before using your samples.

In the future, samples from the WEHI bank may be sent to other hospitals, research institutes, universities, international research groups or commercial organisations such as pharmaceutical companies, located within Australia or overseas for research purposes, should this be required for the purposes of this research. As this project involves novel research we will involve laboratories with expertise in the specific types of research being performed on your cancer type. If this is done, the samples will be labelled with their UIN, and all personal or identifying details will be removed before they leave the bank. This means that nobody outside of the research team will be able to identify you from your samples. The only exception to this will be if your samples are sent to a nationally accredited laboratory in the VCCC precinct which requires patient identifiers as explained above.

As discussed in Section 3, cells obtained from your blood or tissue may also be used to establish cell lines. The creation of these cell lines are for research purposes only. Neither you nor your doctor will be given the results of this research, nor will it be entered into your medical records or used to make treatment decisions. Once your cells have been extracted from your tissue samples, they will be stored long-term in the WEHI bank. Only researchers who have obtained special approval and have signed a special contract with the WEHI can use or perform research on these cell lines (either at the WEHI or at their own laboratory). This research may be genetic research, protein research, or any other type of research.

You may choose to have your samples, or the cell lines that came from your samples, removed from the bank or destroyed, by contacting the study doctor, Professor Clare Scott. If you do decide to do this, your samples/the cell lines that came from your samples will be removed/destroyed according to laboratory standard practise. However, the information resulting from research on your samples will not be destroyed, as it is needed to ensure the scientific integrity of this project.

9 WHAT IF NEW INFORMATION ARISES DURING THIS RESEARCH PROJECT?

Sometimes during the course of a research project, new information becomes available about the test that is being studied. If this happens, your study doctor will tell you about it and discuss with you whether you want to continue in the research project. If you decide to withdraw, your study doctor will make arrangements for your regular health care to continue. If you decide to continue in the research project you will be asked to sign an updated consent form.

Also, on receiving new information, your study doctor might consider it to be in your best interests to withdraw you from the research project. If this happens, he/ she will explain the reasons and arrange for your regular health care to continue.

10 WHAT IF I WITHDRAW FROM THIS RESEARCH PROJECT?

Your participation in this research study is voluntary, and you may choose to withdraw from the study at any time. If you are thinking about withdrawing from the study, you should talk to your cancer specialist before you make your final decision. If you decide to withdraw from the study, you will need to inform the study team. Your decision to withdraw from the study will not affect your medical care in any way.

If you do withdraw your consent during the research project, the study doctor and relevant study staff will not collect additional personal information from you, although personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want them to do this, you must tell them before you join the research project. When you withdraw from the study, you also have the option of withdrawing your tissue samples from the research bank or leaving it for use in future research.

Part 2 How is the research project being conducted?

11 WHAT WILL HAPPEN TO INFORMATION ABOUT ME?

By signing the consent form you consent to the study doctor and relevant research staff collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential.

Information about your participation in this research project may be recorded in your health records.

The researchers will need to collect personal information about you such as your name, date of birth, hospital record number, contact details (address, phone, email) and Medicare number. This information will have all identifiers removed and replaced with a unique identifier number (UIN). This UIN will be attached to the personal health information collected about you. Only

authorised persons who understand that this information must be kept confidential will be able to re-identify your information as yours using the UIN. Your study doctor and authorised research staff will be able to re-identify your personal health information.

Your coded personal data will be stored in a database hosted by BioGrid Australia and will be evaluated at the Walter and Eliza Hall Institute of Medical Research. BioGrid Australia is a data sharing technology company providing a secure infrastructure that advances health research by linking privacy-protected and ethically approved data.

By signing this consent, you agree that your coded personal data may be reviewed, processed and transferred, including transfer to other hospitals, research institutes, universities, international research groups, or commercial organisations such as pharmaceutical companies located within Australia or overseas, that are involved in rare cancer research. Any data, tissue samples or cell lines that are transferred will remain coded with the study UIN. The use of the data and the transfer process will be protected adequately under separate agreements.

Your health records and any information collected and stored by the study doctor during the research project may be reviewed for the purpose of verifying the procedures and the data. This review may be done by the ethics committee which approved this research project, regulatory authorities and authorised representatives of the Sponsor, the Walter and Eliza Hall Institute of Medical Research, the institution relevant to this PICF, the Royal Melbourne Hospital, Melbourne Health Human Research Ethics Committee or as required by law. By signing the consent form, you authorise release of, or access to, this confidential information as noted above.

In accordance with relevant Australian and/or Victorian State privacy and other relevant laws, you have the right to request access to your information collected and stored by the study team. You also have the right to request that any information with which you disagree be corrected. Please contact the study team member named at the end of this document if you would like to access your information.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission.

We will not use your coded personal health information for a different research project without the permission of a Human Research Ethics Committee. Your coded personal health information might be used or released for other purposes without asking you. Results of the research project may be presented in public talks or written articles but information will not be presented that identifies the participant.

12 COMPLAINTS AND COMPENSATION

If you suffer any injuries or complications as a result of this research project, you should contact the study team as soon as possible and you will be assisted with arranging appropriate medical treatment. If you are eligible for Medicare, you can receive any medical treatment required to treat the injury or complication, free of charge, as a public patient in any Australian public hospital.

13 WHO IS ORGANISING AND FUNDING THE RESEARCH?

This research has been initiated by the study doctor, Professor Clare Scott, and is funded by your hospital and the Walter and Eliza Hall Institute of Medical Research (WEHI).

By taking part in this research project you agree that samples of your blood or tissue (or data generated from analysis of these materials) may be provided to the WEHI. They, as the Sponsor of this trial, may directly or indirectly benefit financially from your samples or from knowledge acquired through analysis of your samples.

You will not benefit financially from your involvement in this research project even if, for

example, your samples (or knowledge acquired from analysis of your samples) prove to be of commercial value to the WEHI or to other research institutes, hospitals, universities, international research groups or commercial organisations such as pharmaceutical companies, from within Australia or overseas.

In addition, if knowledge acquired through this research leads to discoveries that are of commercial value to Melbourne Health, the study doctors or their institutions, there will be no financial benefit to you or your family from these discoveries.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

14 WHO HAS REVIEWED THE RESEARCH PROJECT?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of Melbourne Health.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007) (updated 2018)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

15 FURTHER INFORMATION AND WHO TO CONTACT

The person you may need to contact will depend on the nature of your query.
If you want any further information concerning this project or if you have any medical problems which may be related to your involvement in the project (for example, any side effects), you can contact the principal study doctor, Professor Clare Scott on (03) 9342 7000 or (03) 8559 5000, or any of the following people:

Any of the Associate Investigators on (03) 9342 7000 or (03) 8559 5000.

Clinical contact person

Name	Marita Black
Position	Stafford Fox Rare Cancer Program Associate Genetic Counsellor
Telephone	(03) 9342 2690
Email	contact@cart-wheel.org

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	Melbourne Health HREC
HREC Executive Officer	Ms Jessica Turner
Telephone	03 9342 8530

For matters relating to research at the site at which you are participating:

Local HREC Office contact (Single Site – Research Governance Officer)

Name	Director Research Governance and Ethics
Position	Complaints Manager
Telephone	(03) 9342 8530
Email	Research@mh.org.au

The Royal Melbourne Hospital

Consent for Participation

Title	**WEHI Stafford Fox Rare Cancer Program:** Discovery of novel therapeutic targets within the biology of rare cancers
Project Sponsor	Walter and Eliza Hall Institute of Medical Research (WEHI)
Principal Investigator	Prof Clare Scott
Associate Investigator(s)	A/Prof Jayesh Desai, A/Prof Sumitra Ananda, Dr Damien Kee, A/Prof Alison Trainer
Site	The Royal Melbourne Hospital

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in the ARC Portal and in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.

I understand that my health information will be stored and used in a coded way (without any personal identifying details) for this research project and future research projects that may or may not be related to this research project.

I give permission for my doctors, other health professionals, hospitals or laboratories outside this hospital to release information concerning my condition and treatment for the purposes of this research project. I understand that such information will remain confidential.

I understand that I can withdraw my consent to participate in this research project by telling the Study Doctor. If I withdraw from participating in the project, I can specify to have my blood, eyebrow hair and tumour samples which were collected and stored as part of this study, to be used for future research projects or destroyed.

I understand that I will be given a signed copy of this document to keep.

Optional *(please tick yes or no):*
I agree to provide blood samples up to three times per year.

☐ YES ☐ NO

Optional *(please tick yes or no):*
I agree to provide eight eyebrow hairs at the start of the study.

☐ YES ☐ NO

Optional *(please tick yes or no):*
I agree to the collection of a sample of my tumour/s from storage or from a future biopsy or surgery.

☐ YES ☐ NO

Name of Participant (please print) _____

Signature _____ Date _____

The Royal Melbourne Hospital

Form for Withdrawal of Participation

Title	**WEHI Stafford Fox Rare Cancer Program:** Discovery of novel therapeutic targets within the biology of rare cancers
Project Sponsor	Walter and Eliza Hall Institute of Medical Research (WEHI)
Principal Investigator	Prof Clare Scott
Associate Investigator(s)	A/Prof Jayesh Desai, A/Prof Sumitra Ananda, Dr Damien Kee, A/Prof Alison Trainer
Site	The Royal Melbourne Hospital

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine treatment or my relationship with those treating me.

With regards to my blood, eyebrow hair and tumour samples collected in this research project, I request for them to be: (*circle and initial as appropriate)*

stored and used for future research projects

Initial_____ Date_____

destroyed

Initial_____ Date_____

With regards to the cell lines that come from my blood and tumour samples collected in this research project, I request for them to be: (*circle and initial as appropriate)*

stored and used for future research projects

Initial_____ Date_____

destroyed

Initial_____ Date_____

Name of Participant (please print) _____

Signature _____ Date _____