

INTRODUCTION

You are invited to take part in a survey of patients attending Medical Oncology lung cancer clinic in Auckland. All patients attending this clinic are being invited to participate. The purpose of the survey is to better understand the lung cancer patient population, to help plan future research projects and to help guide possible changes to service delivery which may benefit others in the future. This survey will usually take around 5 minutes to complete

You already have a paper information booklet with information about the survey and contact details for the study team. There are also dedicated staff in clinic today if you need any help

Consent Form



Survey of Patient Engagement and Attitudes towards Research Priorities in Lung Cancer - korero tahi



Please tick to indicate you consent to the following

I have read the Participant Information Sheet, or have had it read to me in a language I understand, and I fully comprehend what it says.

I have been given sufficient time to consider whether or not to participate in this study.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.

I consent to the research staff collecting and processing my information, including information about my health.

I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.

I know who to contact if I have any questions about the study in general.

I wish to receive a summary of the results from the study. Yes No

Declaration by participant:

I hereby consent to take part in this study.

Participant's name:

Signature: **Date:**

Interpreter's name (If applicable):

Date:

Section 1: Ethnicity

1. Which ethnic group do you belong to? Select all that apply to you

- New Zealand European
- Māori
- Samoan
- Cook Islands Maori
- Tongan
- Niuean
- Chinese
- Indian
- Other, eg Dutch, Japanese, Tokelauan:

Section 2 : Biobanking

Biobanking is the process of collecting and storing donated patient tissue samples which are then made available to researchers for use in various ethically approved research projects. This could include research projects which are already underway (specified projects) and future projects which are in development or have not yet been proposed (future unspecified projects).

The samples used may be in the form of routine biopsies or blood tests which have already been done. Whilst in the biobank the samples are not linked to any information which could identify you. All information is stored in a secure database overseen by a kaitiaki rūpu. The donated tissue samples and associated clinical information act as important resources for scientists engaged in molecular research in order to develop better diagnostic tools and new drug therapies.

More information on biobanking can be found at: www.biobank.ac.nz



2. How concerned would you be about the following issues, if your tissue samples were used for biobanking?

	Very concerned	Some Concern	Not Concerned	Unsure
Privacy and data security	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being informed of study results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Care and disposal of tissue samples	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cultural concerns	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Faith or religious concerns	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other Concerns (biobanking):

3. Would you be happy for your hospital team to contact you in the future regarding biobanking of your tissue samples for research?

- Yes
- No
- Unsure

Section 3: Clinical Database

We would like to create a database of clinical information about lung cancer patients in the Auckland region. The database would be used to better understand the lung cancer patient population in our region, and would contribute to research projects which may help others in the future.

This data would be carefully safeguarded, meet all data sovereignty principles and would not include any information that identifies you.

4. How concerned would you be about the following issues if your health information was entered into a database?

	Very concerned	Some Concern	Not Concerned	Unsure
Understanding how data will be used	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ability to opt out	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Privacy and data security	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Access to data by other groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other Concerns (database):

5. If data is held securely and carefully guarded with no information that could identify you, would you support cancer related information being held in a database without a signed consent form from every included patient?

- Yes
- No
- Unsure

Section 4: Preferred Place of Treatment

One of our goals is to improve access to cancer care and treatment. This section will ask about your views on the best location to have your treatment.

6. Are you receiving IV cancer treatment (medicine given into a vein) such as immunotherapy or chemotherapy?

Yes - go to question 7 and 8

No - There are no more questions. Thank you for participating!

7. How long does it usually take to travel to Auckland City Hospital to your own home?

Less than 30mins

30mins to 1hour

1-2 hours

More than 2 hours

8. Imagine an ideal public healthcare system: How would you rate each of these options as a place to receive IV treatment?

	High preference for this option	Moderate preference for this option	Slight preference for this option	I do not like this option
Large public hospital eg Auckland City Hospital (the only current option)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My local hospital eg Middlemore, North Shore, Waitakere or Whangarei	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Selected local health centre or GP practice (not necessarily your own GP)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community Centre	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Marae	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A mobile unit (such as a cancer treatment bus)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your own home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>