

# CASE STUDY



## Transforming research methodology through lived experience

Lisa Briggs, Patient Research Advocate

### The work and its impact

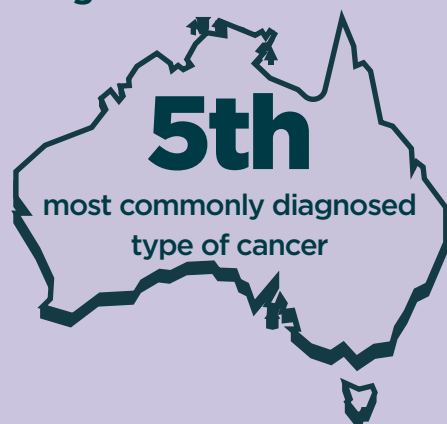
Lisa Briggs has been an investigator on multiple lung cancer research grants. She has lived experience of lung cancer and provides a valuable consumer perspective that ensures the research focuses on delivering impactful results for people with lung cancer.

An outstanding example of Lisa's advocacy is her work on the MRFF-funded grant: *Tissue Repository of Airway Cancers for Knowledge Expansion of Resistance (TRACKER)*. In this research, clinician-scientists collect blood and tissue samples from patients with advanced lung cancer throughout their cancer journey. The samples are stored in a secure facility called a biobank. The researchers study the samples in the **biobank** to look for characteristics called **biomarkers** that will help them develop treatments.

Taking a tissue sample from the lungs can sometimes require needles or incisions in the chest. Lisa has undergone multiple tissue biopsies, and knows through this experience how challenging they can be. As a result, she advocated for a less invasive procedure to be used in the TRACKER study. She connected the research team with a leading expert in a procedure called **liquid biopsy**, who now leads that aspect of the project. In this procedure, samples of blood are collected and examined for biomarkers. Liquid biopsy is quicker and less invasive than tissue biopsy, making it less painful and stressful for people with lung cancer. Samples can also be collected more often, making it easier to monitor the cancer over time.

It was Lisa's advocacy that led to the clinician-scientists to use liquid biopsies in the TRACKER study. This was only possible because Lisa was involved in the TRACKER study right from the earliest stages of research, where she could have the most input and impact. Lisa is the Chair of the TRACKER Consumer Committee. The Committee provides ongoing strategic direction to the research team and drive consumer-led initiatives. One of these initiatives was a multilingual animation video to help explain biobanking and the consent process.

#### Lung cancer in Australia



Lung cancer occurs when abnormal cells grow and multiply in the lungs, forming tumours that affect breathing and cause chest pain.<sup>1</sup> In Australia, lung cancer is the leading cause of cancer mortality and the fifth most commonly diagnosed type of cancer. The average age at diagnosis is 72 years old.<sup>2</sup> Lifestyle and occupational factors, like exposure to tobacco smoke and asbestos, can increase someone's risk of getting lung cancer. However, lung cancer can also occur in younger people and people with no known risk factors. Because lung cancer can affect anyone, it is essential that the people involved in research reflect the diverse backgrounds, ages, and life experiences of people living with lung cancer.

<sup>1</sup> [Overview - Lung Cancer - Lung Foundation Australia](#)

<sup>2</sup> [Lung cancer | Causes, Symptoms & Treatments | Cancer Council](#)



*Lisa was diagnosed with stage IV lung cancer (the most advanced form of the disease) at 32 years of age. Having always led an active lifestyle, never smoked a cigarette in her life, had no known risks factors and working in allied health, the diagnosis came as a massive shock.*

*Lisa generously gives her expertise and tireless work ethic to engage with a variety of organisations to advocate for change, promote the importance of consumer engagement in medical research, including consumer assessment in grant review, and reducing the stigma for people diagnosed with lung cancer.*





# Transforming research methodology through lived experience

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## Identifying and prioritising:

- Dr Tracy Leong approached Lisa about creating a study involving the collection and analysis of tissue samples to better understand treatment and resistance in lung cancer.
- Lisa suggested including liquid biopsies in this study and connected Dr Leong to a leader in the field.
- Lisa suggested and brought together a group of diverse consumers to help deliver the idea.

## Design

- The team of researchers and consumers met regularly for 2 years, continually bringing new ideas to the table.
- Every 6 months, the researchers shared a scientific presentation in plain language to ensure mutual understanding with the consumers.
- Consumers ensured the research was designed to minimise people with lung cancer undergoing invasive procedures and unnecessary burden.

## Developing the grant proposal

- Originally, the biobank was going to be based in Victoria only.
- Lisa advocated for the project to be a national initiative that could later become international.
- Lisa was named as a co-applicant on the grant as a result of her involvement.

## Analysing and interpreting research

- The 6-monthly plain language presentations are still ongoing where consumers can ask questions about the work and results.
- New projects are always presented to the consumer committee for verbal and written feedback at their earliest stage.
- Two consumers sit on the governance committee.

## Undertaking the research

- Lisa led the development of a strategic plan and terms of reference for consumer involvement throughout TRACKER. This plan took into account diversity, cultural inclusivity and succession planning.
- She developed consultative approaches to ensure community representation in the project, particularly with CALD communities and Aboriginal and Torres Strait Islander people.
- Lisa also set up partnerships between the research team and consumer organisations.

## Dissemination, implementation, monitoring and evaluation



- Consumers are involved in disseminating information about the research through the annual TRACKER Tales newsletter and as co-authors on abstracts.
- Receiving MRFF funding allowed implementation of the biobank that underwent 2 years of planning and design, and has led to many sub-projects.
- The impact of consumer involvement is monitored and evaluated against measurable goals as per the strategic plan.