Stop Researching Us Without Us

An opinion piece by Paula Ormsby

There is a saying that has stayed with me:

Until the lion learns to write, the hunter will always be glorified.

For generations, communities like mine have been the lion.

We have been researched, studied, interviewed, assessed, diagnosed and written about. Researchers have asked us about our trauma, our poverty, our homelessness, our addictions, our children, our involvement with gangs, our experiences with prisons, police, mental health services, state care and government agencies.

We have opened our lives to strangers.

We have told them things that hurt.

We have explained systems we have spent years navigating.

We have given them our stories.

Then something strange happens.

They write a report, publish an article, present at a conference or complete a thesis.

And suddenly they are the expert on us.

We are still the "participants".

I think it is time we had a serious conversation about that.

We are not just lived experience

I hear the words *lived experience* everywhere now.

Government agencies want lived experience.

Universities want lived experience.

Research projects want lived experience.

Advisory groups want lived experience.

But I sometimes wonder whether "lived experience" has become another polite way of saying:

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You tell us what happened, and we will decide what it means.

Why am I the person with “lived experience” while somebody who has interviewed people like me becomes the expert?

Why is what I know called a story until somebody with letters after their name puts it into a journal?

Why is my understanding anecdotal but their interpretation evidence?

I am not saying academic qualifications mean nothing. They matter. Research methodology matters. Ethics matter. Theory matters. Good academics bring skills and knowledge that can strengthen community research.

But a university degree does not magically give somebody a greater understanding of another person's life than the person who has actually lived it.

There are things you can learn from a book.

There are things you can learn at university.

And then there are things you can only learn by surviving them.

That is expertise too.

Tīhei Wāhine Ora demonstrates this in the experiences of wāhine from gang whānau. The research describes survival itself as producing expertise—knowledge of systems, law, patterns and people that becomes the basis of advocacy, leadership and community solutions.

We need to stop treating that knowledge as somehow intellectually inferior.

Who gets to decide what knowledge is?

There is an academic term for part of what I am talking about, hermeneutical injustice.

At its heart is a question of power.

Who gets to name our experiences?

Who gets to explain what happened to us?

Whose language becomes accepted?

Whose interpretation becomes policy?

Whose knowledge gets cited?

And whose knowledge gets dismissed?

A community can understand something for decades, but nobody in authority listens.

Then an academic arrives.

We explain it to them.

They record it.

They code it.

They put academic language around it.

They connect it to a theory.

They publish it.

Suddenly everybody listens.

Think about that.

The knowledge didn't necessarily change.

The person saying it changed.

That should make us uncomfortable.

Stop turning our survival into your discovery

This is probably the part some people will not like.

Sometimes researchers “discover” things our communities have known forever.

They discover that people do not trust services.

We could have told them that.

They discover that trauma travels through generations.

We knew that.

They discover that homelessness affects more than whether somebody has a roof.

We knew that.

They discover that people leaving prison need belonging, housing and support.

We knew that.

They discover that relationships matter.

We knew that too.

Our communities have often understood the problem long before somebody received funding to study it.

So instead of asking:

“How do we research these people?”

start asking:

“What would happen if we funded these people to research themselves?”

That one question could change the research landscape.

Trust matters

There is another thing researchers cannot manufacture, trust.

You cannot arrive in a community with a clipboard, consent form and ethics approval and assume people will tell you the truth about their lives.

Especially communities that have been harmed by institutions.

Our people know who they trust.

They know who will still answer their phone after the research grant ends.

They know who will turn up at the tangi.

They know who will come when someone is in trouble.

They know who has walked beside them.

That matters.

Tīhei Wāhine Ora recognises relationship as central to its methodology and acknowledges that established trust affected both access and the depth of what wāhine were prepared to share.

Yet when someone from inside the community conducts research, we sometimes hear the word bias.

They are “too close”.

I find that interesting.

Why do we interrogate closeness but rarely interrogate distance?

An outsider can misunderstand our language, our relationships, our humour, our silence, our whakapapa and the meaning underneath what somebody is saying.

That is a limitation too.

Being an outsider does not automatically make somebody objective.

And being an insider does not automatically make somebody incapable of rigorous research.

Follow the money

Then there is the conversation we really need to have.

Money.

There is money available to research marginalised communities.

People build careers researching our disadvantage.

There are salaries.

Research grants.

Conference presentations.

Publications.

Professional reputations.

Academic promotions.

Meanwhile, some of the communities providing the knowledge are fighting to keep their doors open.

Something is wrong with that picture.

Imagine giving communities even a portion of the resources spent repeatedly researching what is wrong with them.

Imagine funding us to investigate our own questions.

Imagine training community researchers.

Imagine providing access to academic mentors, statisticians and research infrastructure while leaving control of the kaupapa with the community.

Imagine research funding leaving behind permanent research capability instead of another PDF report.

Why shouldn't that happen?

Don't invite us in after everything has been decided

I also think we need to be careful with the word co-design.

Do not design the research question, secure the funding, determine the methodology, hire the researchers and then invite three community people into a room and call it community-led research.

That is consultation.

Real community-led research starts much earlier.

Ask us what needs researching.

Ask us what questions matter.

Ask whether there are people in our community capable of conducting the research.

Give us access to the funding.

Support us with methodology where we need it.

Help us navigate ethics.

Give us access to academic journals and statistical expertise.

But don't automatically assume that because you provide the academic infrastructure, you should own the research.

Sometimes universities need to lead.

Sometimes they should partner.

And sometimes their role should simply be to support and get out of the way.

Our stories still belong to us

We also need to talk about what happens after we tell our stories.

Who owns the interview?

Who owns the recording?

Who owns the transcript?

Who decides what gets published?

Who decides what our words mean?

Who can use those words five years later?

Tīhei Wāhine Ora offers a different way of thinking. Recordings were returned to participants as taonga, participants were involved in confirming themes, and dissemination was based on the principle that findings belonged first to the wāhine whose pūrākau created them.

I love the simplicity of that idea:

Our knowledge remains ours.

Research carries it.

Research does not own it.

I am not anti-academic

I want to make this very clear.

This is not an attack on academics.

There are incredible Māori and Indigenous academics who have spent their lives dismantling colonial ways of conducting research.

There are academics who understand that their job is not to speak over communities but to create space for community knowledge.

We need them.

We need their skills.

We need strong academic-community partnerships.

What I reject is the hierarchy that says:

You have the experience. We have the intelligence to explain it.

No.

You may know things I don't.

And I may know things you cannot know.

Put those forms of knowledge beside each other and something powerful can happen.

But do not place one automatically above the other.

Ask one simple question

I think every funding panel, university and research institution proposing research involving marginalised communities should have to answer one question:

Could the people in this community conduct this research themselves if they were given the same money, resources, training and institutional support?

If the answer is yes, then the next question should be:

Why aren't we funding them?

That question matters.

Because communities should not have to remain research subjects simply because someone else controls access to the research money.

The lion has learned to write

For generations, other people have written about communities like ours.

They have measured us.

Categorised us.

Diagnosed us.

Interpreted us.

Published us.

Our knowledge became their findings.

Our lives became their evidence.

Our trauma became their data.

And we remained the participants.

The hunter held the pen.

But the lion has learned to write.

We are researchers.

We are thinkers.

We are theorists.

We are knowledge holders.

We know what happens after the professionals leave.

We know who answers the phone at three in the morning.

We know who turns up when somebody is suicidal.

We know who finds somewhere for someone to sleep.

We know who sits beside the mother whose children have been removed.

We know who picks somebody up from prison.

We know who feeds the whānau when there is nothing left in the cupboard.

We know who carries the grief when another one of our people does not make it.

That knowledge may not have been learned in a university.

It may carry scars instead of qualifications.

It may be spoken around kitchen tables rather than conference tables.

But it is knowledge.

So don't just ask us to sit on your advisory group.

Don't just ask us to recruit our people.

Don't just ask us for our stories.

Don't take something our community has known for generations, translate it into academic language and return it to us as your discovery.

Give communities access to the resources.

Build our research capability.

Fund our organisations.

Recognise lived expertise.

Share academic infrastructure.

Publish with us.

Recognise us as authors.

And when the community has the knowledge, relationships and capability to lead—

let us lead.

Because we are not simply people waiting to be researched.

We are the experts on our own conditions.

Stop researching us without us.

The lion has learned to write.