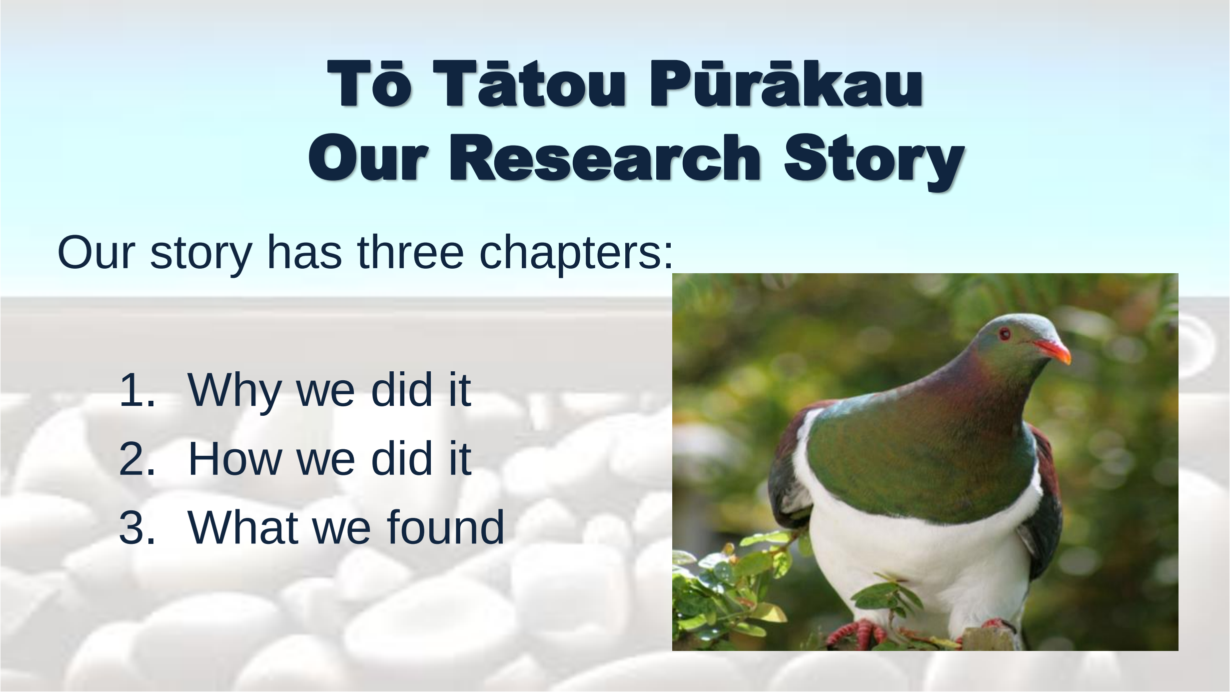
HE KĀHUI KŌRERO
CANCER STORIES FROM MĀORI

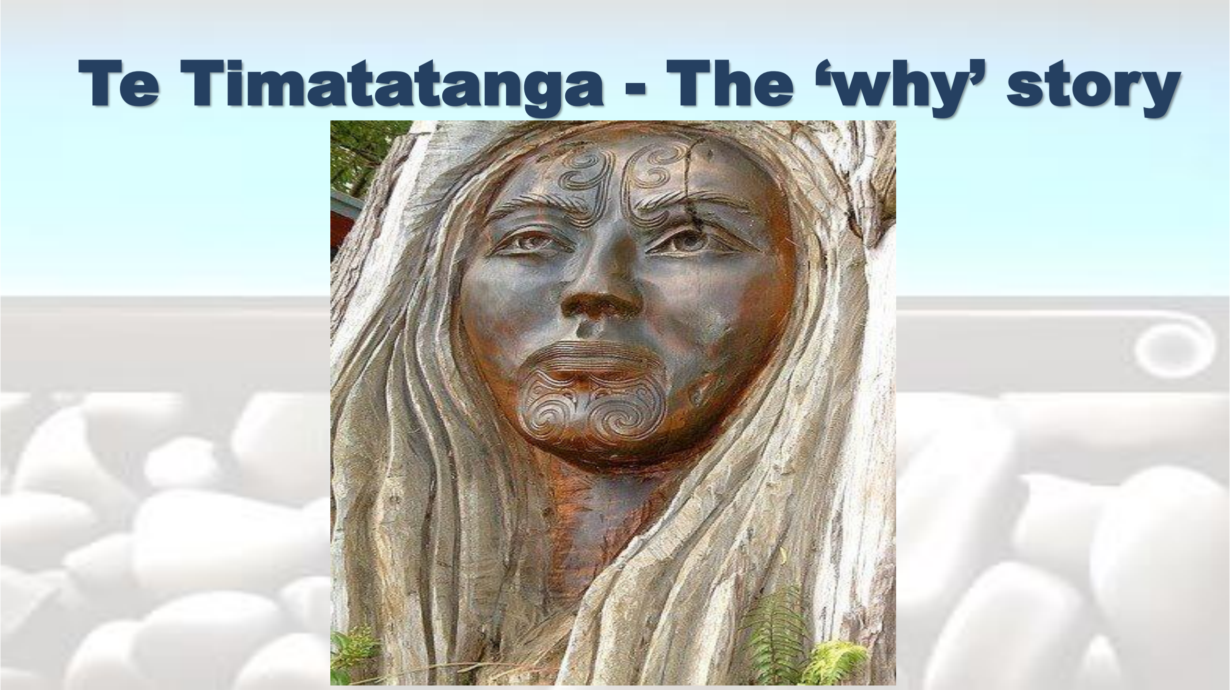
Tira Albert
World Indigenous Cancer Conference
Connecting Communicating Collaborating
April 2016



Tō Tātou Pūrākau
Our Research Story

Our story has three chapters:

1. Why we did it
2. How we did it
3. What we found



Te Timatatanga - The ‘why’ story

Pehea te Mahi

The “how” story

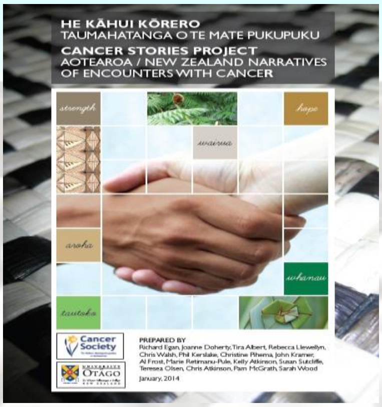
Ma Wai? - Who told their story?

- 27 females -11 males
- 13 primary cancer types
- Ages 18 years – 88 years

Ma Wai? - Who told their story?

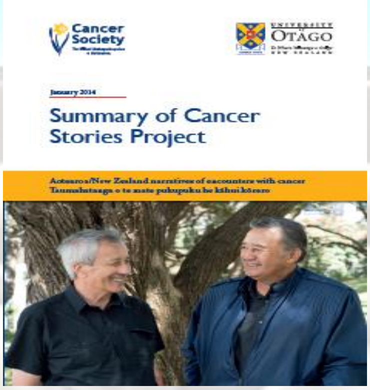
Ngā Kōrero – What we found

Full Report


HE KĀHUI KŌRERO
TAUMAHATANGA O TE MATE PUKUPUKU
CANCER STORIES PROJECT
AOTEAROA / NEW ZEALAND NARRATIVES
OF ENCOUNTERS WITH CANCER

PREPARED BY
Richard Egan, Joanne Doherty, Tira Albert, Rebecca Llewellyn, Chris Walsh, Phil Kerslake, Christine Pihema, John Kramer, Al Frost, Marie Retimanu-Pule, Kelly Atkinson, Susan Sutcliffe, Teresea Olsen, Chris Atkinson, Pam McGrath, Sarah Wood
January, 2014

Plain English Summary



January 2014

Summary of Cancer Stories Project

Aotearoa/New Zealand narratives of encounters with cancer
Taumahatanga o te mate pukupuku he kāhui kōrero

Empowerment

Attitude

‘Having a clear goal at the end helped me and kept me positive’

‘It’s about what’s best for you’

‘I kept very positive, focussed on the birth of my first grandchild’

‘Focus on what you need to focus on – imagine you are in a boat and if its not worth keeping, throw it overboard, you can come back for it later

Māori whānau experience

‘I visited a Māori healer - healing my wairua was important as your spirit can be crushed - you need your spirit to heal your body and be strong to overcome the cancer and the treatment.

‘Be Maori – be yourself’

‘Karakia - Rongoa - Mirimiri
Call on your tipuna’

‘I know my own body so I choose Maori healing and Goji juice – the dr said Goji juice was dear – cheaper than a coffin I told him!”

‘There’s nothing quite like those who love you being there for you – nothing, nothing’

‘Whanau and aroha – close family support is very important - we rang all the whanau and asked them to come around’

Family Whānau Friends

‘Be involved walk towards the person not away from the person’

Whanaungatanga – Connecting with family got me through and becoming an advocate in our rural community for Māori men

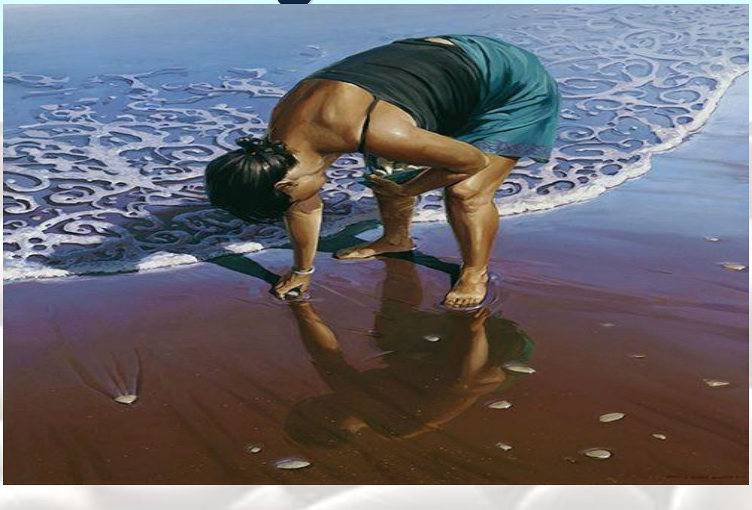
‘Knowing my children were all good
Knowing they understood
Taking them on the journey with you’

“Go to the river – karakia call on your ancestors its about remembering those things”

‘Telling everyone back home was terrible – I just couldn't do it in the end – to my sisters in particular

Health Care Professionals and Services

Looking for what's missing!



'They didn't really use a lot of strange words around me.

Basically 'you've got a tumour-it needs to come out' - nice and simple plain English.'

'Grade 3 cells – the surgeon said they were more lion than pussy cat – I found this useful language to explain to friends'

‘No consideration of the rest of me - wairua, hinengaro….. no suggestion of cultural support ‘

‘The doctor said “You’ve got to project manage this thing. This is gonna be your job for twelve months and you’ve gotta manage it like a job and just put your head down and get through it.”
So any time I felt like giving up, I thought about what he’d said.
Um, that was probably the best thing he could’ve said to me, if I’d had too much sympathy and too much softness then I would have probably crumbled, but, he was, just get on and do this thing.’

‘They didn’t call it cancer for a long time’

‘When the doctor told me it was grade 3 - I said oh that’s good, does it go up to ten and he said no grade 4 is terminal. I sat there like a stunned mullet then cried and cried in the car park.’

‘My oncologist always made herself available when I needed her – gave me her number so I could text her’

‘Take time, be good at answering questions, make the patient know you are interested in them and their wellbeing’

‘Be compassionate and kind’

Sources of Support

‘I was referred to a social worker who wanted to talk about my feelings. I didn’t want to talk about my feelings, I wanted to talk about someone mopping my floors!”

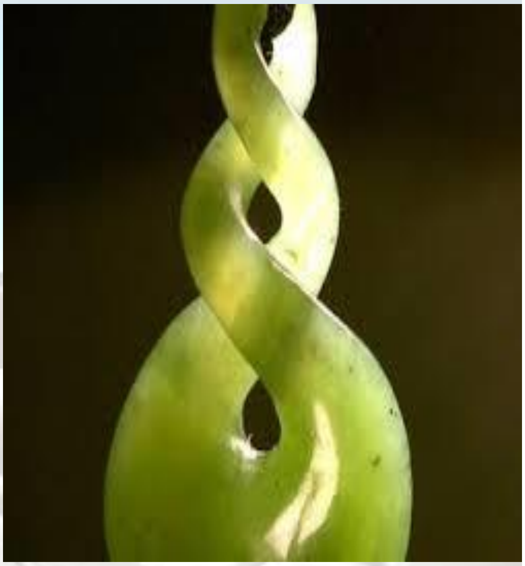
‘Have support at appointments - to listen or ask hard questions’

‘Keep a health diary – to remember and go back to’
‘Access information - ask questions’

‘It becomes a spiritual journey – there’s a lot of time for reflection’

‘My nan had passed away but she was still here helping me through’

‘Take care of your emotional and spiritual side too...know that being sick can be spiritual...take time for karakia, waiata, meditation music and song may all be of use”



Find out about Kia Ora - E Te Iwi where you live – ask the Cancer Society'

'It was soul sucking -sank me into a deep depression - I could have paid a lot more attention seeking help'

'*I didn't want to be labelled as a cancer patient – but after 4-5 panic attacks I thought it might be good to talk to someone so I rang the Cancer Society'*

'I felt like my cancer wasn't bad enough'

Employment

'Work said' - take all the time you need, we'll help you out and there'll be a job for you when you come back…..I'm extremely grateful to them.'

'Work was this pocket of my life where I could do normal things'

'My employer let my colleagues donate their sick leave as I needed so much'

'It was good to still contribute to the household and a reminder I had a life after this'

Change

I've always spoken from a positive place about it – it was a rough time but ultimately a blessing – it slowed my life down a bit, taught me what was important and you know brought my whanau closer together'

'I have a different perspective on life"

'I am more positive and thankful for what I have"

'My glass is half full now"

I live in the moment a lot more

My body is different, I have a lot of health issues but I don't have cancer, I am alive and I can go for a walk every day – I'm feeling more fit and healthy every day so it's positive.'

'I've got a voice….cancer has been a whole other kaupapa…having cancer is the best thing that's ever happened to me'

Ngā Mihi ki ngā Whānau