

ASPERT

Bulletin | DECEMBER 2024



AOTEAROA AUSTRALIA PANCREATIC ENZYME REPLACEMENT THERAPY RESEARCH GROUP

FROM THE PRINCIPAL INVESTIGATOR

AMANDA LANDERS



Tēna koutou katoa,

As we come to the end of 2024 I would like to take the time to thank everyone in the ASPERT community; from fellow researchers, clinicians and allied health to patients and whānau/family who reached out to us throughout the year. We have had an enormously successful year with two publications, the launch of three new studies, reaching 100 followers on social media, and countless emails from interested people across Aotearoa NZ and Australia. We successfully ran a “Where is My Pancreas?” social media campaign during November alongside the Gut Cancer Foundation (see page 4), cementing our collaboration with the national advocacy group.

ASPERT has also created more formal collaborations with the UNSW Implementation science team, with two new publications looking at nutritional interventions due next year. We have also made links with the Gut Dysfunction Node at PaCCSC, with several collaborative grant applications in the pipeline focused on pancreatic exocrine insufficiency and a symptom scoring tool to help clinicians with diagnosis.

We are also venturing into the neuroendocrine tumour space, exploring the potential rates of malabsorption in this population. We may be able to use the enormous expertise in the ASPERT community to help with education and research.

Finally, the ASPERT team hopes you have some restful and rejuvenating holiday plans for Christmas. We all need the rest as there is much work to be done in 2025!

Merry Christmas and Happy New Year

Ngā mihi nui
Amanda

IN THIS ISSUE

Patient-reported registry update

Team news - Allison Love

Where Is My Pancreas?



PATIENT-REPORTED REGISTRY UPDATE

NIAMH FANNING

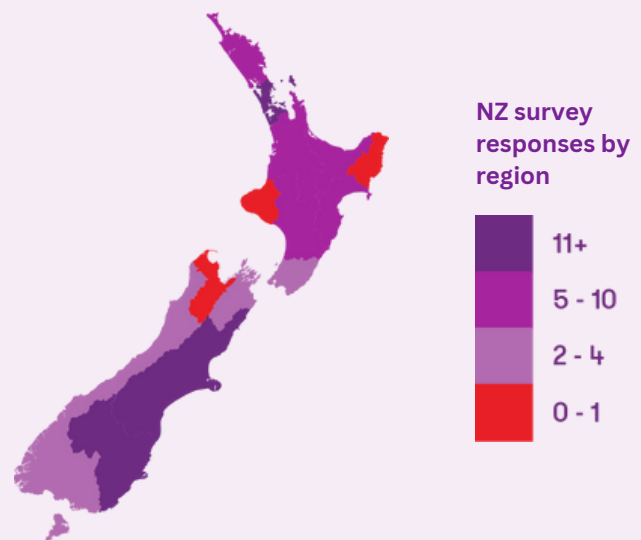
The patient-reported registry was launched in Aotearoa New Zealand (NZ) in June and in Australia in August. The purpose is to hear from as many people with pancreatic cancer (PC) as possible about their medical care and what they know about pancreatic enzyme replacement therapy (PERT).

To achieve this, we are using social media advertising and connecting with clinicians, dietitians and advocacy groups involved in PC.

So far, we have had 211 people respond to the survey, 119 from Aotearoa NZ and 92 from Australia.

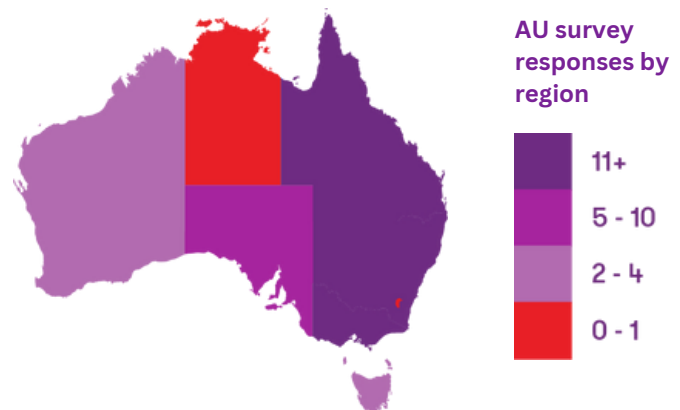
There are responses from all regions in Aotearoa NZ, with Auckland (24/92) and Canterbury (13/92) accounting for the highest numbers.

Some of the least populated regions (approx. 50k-60k) have the fewest responses: Gisborne (1), Nelson (1), Tasman (1) and Marlborough (2). Taranaki, with a population of 126k, has only 1 response. West Coast, with a population of only 33k, already has 4 responses.



Most Australian responses were from the most populous territory of New South Wales (29/92), or Queensland (22/92), the third most populous. Victoria, the second most populous territory, remains behind Queensland with 18/92 responses.

The remaining responses were from South Australia (6), Tasmania (4) and Western Australia (4). There have been no responses from Northern Territory and Australian Capital Territory.



In this bulletin we focus on three survey questions:

- 1) who gave you your diagnosis of PC?
- 2) have you seen a dietitian?
- 3) have you heard of PERT prior to this study?

Seventy-three of 119 (61%) Aotearoa NZ participants and 72 of 92 (78%) Australian participants responded to these questions.

A higher proportion of Australian participants (35%) were informed of their diagnosis by their GP compared to Aotearoa NZ participants (19%) (Figure 1).

In both countries most patients were informed by their surgeon, but the percentage was slightly higher in Aotearoa NZ (48%) vs Australia (43.0%).

Access to a dietitian was inadequate in both countries but worse in Aotearoa NZ (62%), compared with Australia (72%).

A similar proportion of participants from Aotearoa NZ (81%) and Australia (78%) had heard of PERT.

Overall, the results suggest some differences between Aotearoa NZ and Australia in the treatment of PC.

Interestingly, knowledge of PERT among survey respondents was relatively high, suggesting that the study may be reaching a highly engaged population. However, approximately 1 in 5 people with PC had not heard of PERT, indicating a continued need to raise awareness.

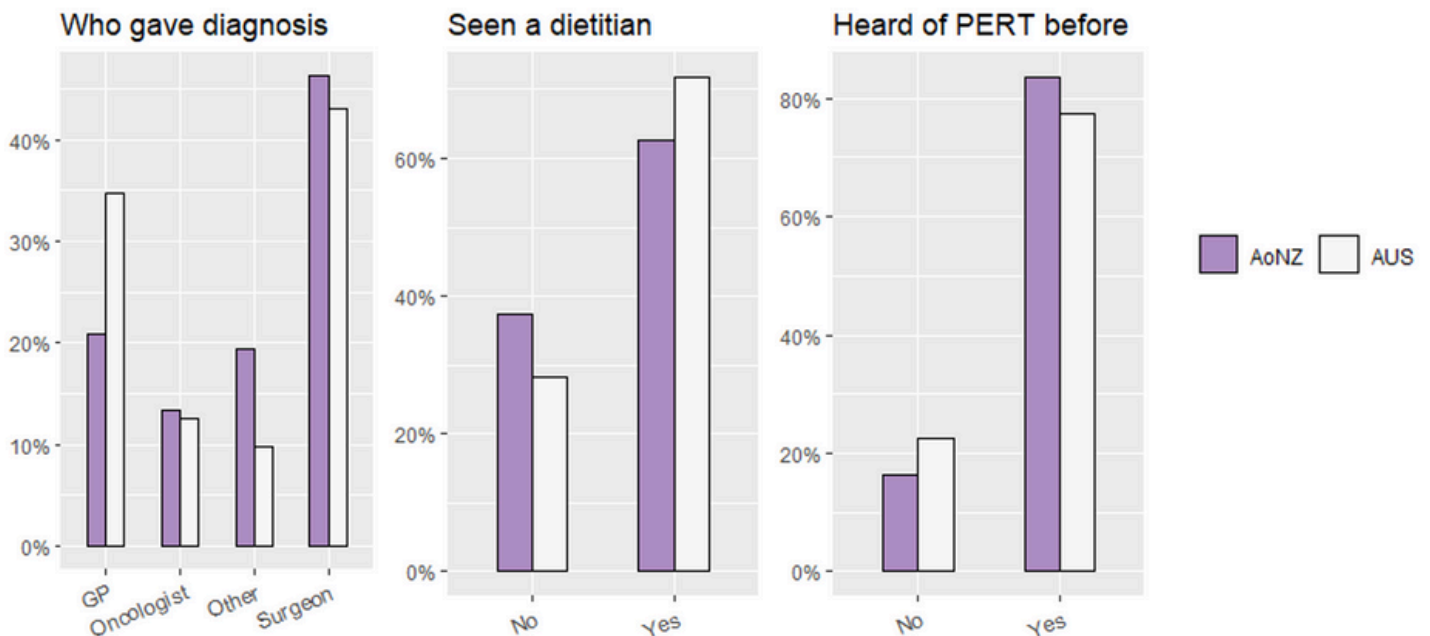


Figure 1. Survey results
Participants with missing responses for particular question were excluded.

WHERE IS MY PANCREAS?

ALLISON LOVE

Typically, the pancreas is tucked away behind the stomach, in front of the spine. But most people without a medical degree don't know that!

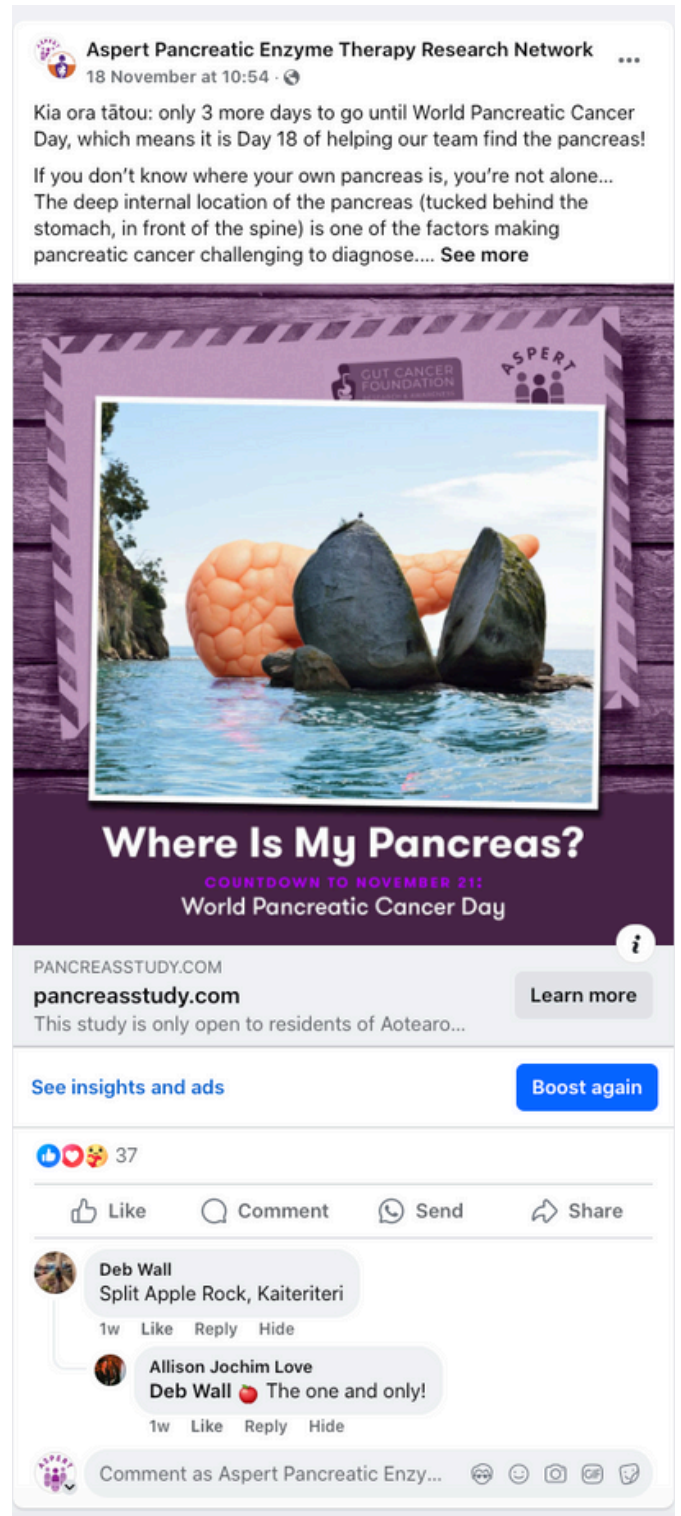
So, in collaboration with Gut Cancer Foundation, the ASPERT team created a 21-day social media awareness campaign called "Where is My Pancreas?".

Its goal was to highlight the deep internal location of the pancreas (one of the factors making pancreatic cancer challenging to diagnose), as well to encourage people with a diagnosis of pancreatic cancer to take part in the study at pancreasstudy.com.

From November 1 to November 21 (World Pancreatic Cancer Day 2024), ASPERT posted a daily image of a pancreas 'visiting' an iconic NZ place or artwork. Commenters identifying the correct location of the pancreas were entered into the prize draw.

Congratulations to our campaign winner, Hope Smith, who successfully identified 18/20 daily locations of the pancreas, including Hairy McClary's gate, Split Apple Rock, and the Switzers Museum & Bottle House, Waikaia.

For a quick snapshot of all locations visited by the ASPERT pancreas, visit instagram.com/aspertstudy.



TEAM NEWS

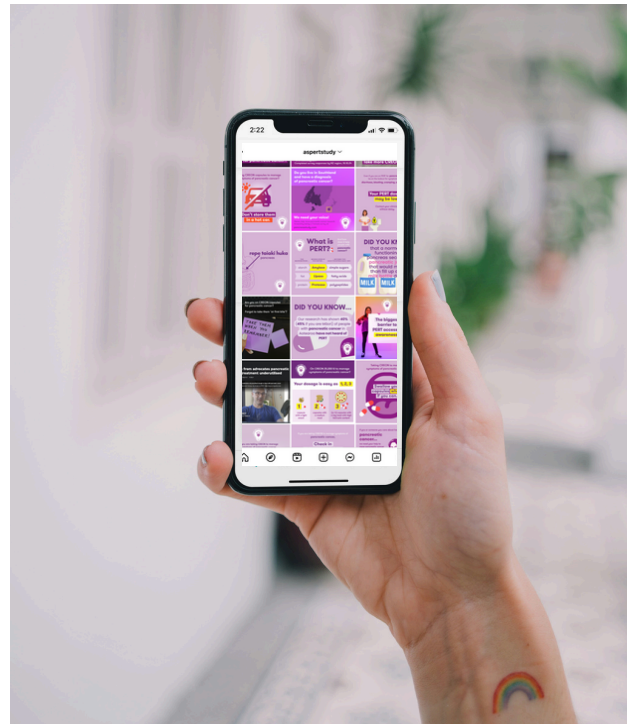
ALLISON LOVE



The team welcomes Allison Love, a Marketing Research Co-ordinator at the University of Otago Christchurch (UOC). She joined the team in May 2024 to help raise awareness of ASPERT's current patient-reported PERT study (pancreasstudy.com). She can be found creating marketing and design materials for ASPERT of all types!

Originally from the United States, Allison graduated from San Jose State University (California) in 2007 with a Bachelor of Fine Arts, Graphic Design. She has worked for a number of large and small companies, including Nike and Adidas in the USA, Tommy Hilfiger in Amsterdam, and Icebreaker in New Zealand (her favourite). Her experience also includes time working as a designer for the Martin Luther King Jr. Community Hospital, in southern Los Angeles.

In her free time Allison enjoys mystery novels, and spending time with her partner and two sons, ages six and three.



WE'RE ON SOCIAL MEDIA!

ASPERT has Facebook and Instagram profiles! Follow us to keep up to date with all things.

FACEBOOK: [@aspertresearch](https://www.facebook.com/aspertresearch)

INSTAGRAM: [@aspertstudy](https://www.instagram.com/aspertstudy)

LINKEDIN:

[linkedin.com/in/aspertregistry](https://www.linkedin.com/in/aspertregistry)



Subscribe or find out more by email to Amanda Landers

E: aspert@otago.ac.nz

W: uts.edu.au/aspert