

## Supplementary File One

### Survey design Aotearoa New Zealand

1. How did you hear about our survey?

*Social media*

*Word of mouth*

*Advertisement*

*Family member*

*Support group*

*Health Professional*

*Other (please specify)*

2. How old are you?

*20-29,*

*30-39,*

*40-49,*

*50-59,*

*60-69,*

*70-79,*

*80-89,*

*90 plus*

3. What is your gender?

*Male/female/Nonbinary/Other*

4. *What is your ethnicity?*

*NZ European*

*Māori*

*Iwi (free text)*

*Pacific Peoples*

*Samoan*

*Cook Island Maori*

*Tongan*

*Niuean*

*Tokelauan*

*Fijian*

*Other Pacific Peoples*

*Asian*

*Asian nfd*

*Southeast Asian*

*Chinese*

*Indian*

*Other Asian*

*Middle Eastern/Latin American/African*

*Middle Eastern*

*Latin American*

*African*

*Other (please specify)*

5. Which area do you live in?

*Northland, Auckland, Waikato, Bay of Plenty, Gisborne, Hawkes Bay, Taranaki, Manawatū, Wellington, Tasman, Nelson, Marlborough, West Coast, Canterbury, Otago, Southland*

6. What type of area do you live in?

*Major urban area (100,000 or more)*

*Large urban area (30,000- 99,999)*

*Medium urban area (10,000- 29,999)*

*Small urban area (1,000- 9,999)*

*Rural (300- 999)*

*Remote (<300)*

7. *How long ago were you diagnosed with pancreatic cancer?*

*Last week*

*Last month*

*The last 3 months*

*The last year*

8. Have you had surgery for your pancreatic cancer?

*Yes/No*

6a. Are you going to have surgery for your pancreatic cancer?

*Yes/No/Unsure*

9. Have you lost weight since the diagnosis of pancreatic cancer?

7a. If yes, how much (kg)?

*0-5*

*6-10*

*11-15*

*16-20*

*Over 20*

10. Have you seen a dietitian?

*Yes, No, Unsure*

11. Have you heard of pancreatic enzyme replacement (PERT) eg CREON?

*Yes, No*

If yes please answer the following questions about pancreatic enzyme replacement therapy (PERT)

12. How did you hear about PERT? (May have more than one answer)

*GP,*

*Oncologist,*

*Hospice doctor*

*Hospice nurse*

*Palliative care doctor*

*Palliative care nurse*

*Surgeon,*

*Dietitian,*

*Internet,*

*Friend,*

*Relative,*

*Support group*

*Other \_\_\_\_\_*

13. Who prescribed the PERT?

*Doctor,*

*Nurse practitioner,*

*Dietitian,*

*Unsure*

14. Did the clinician who prescribed the medication explain how PERT works?

*Yes, No*

*Free text*

15. Did the clinician who prescribed the medication explain when to take PERT?

*Yes, No*

*Free text*

16. Did the pharmacist who dispensed the medication explain how PERT works?

*Yes, No*

*Free text*

17. Did the pharmacist who dispensed the medication explain when to take PERT?

*Yes, No*

*Free text*

18. Were you given written information when PERT was first discussed with you?

*Yes, No*

*Free text*

19. Were you directed to any resources on PERT?

*Yes, no*

*Free text*

20. What dosage was recommended?

*10,000 units*

*25,000 units*

*Unsure*

21. What number of capsules were recommended?

*None,*

*One tablet with every meal,*

*One tablet with every meal and one with snack,*

*Two tablets with every meal,*

*Two tablets with every meal and one with snacks,*

*Two tablets with every meal and two with snacks,*

*Three tablets with every meal,*

*Three tablets with every meal and one with snacks,*

*Three tablets with every meal and two with snacks,*

*Choose dose yourself depending on what you are eating*

*Other (please specify)*

22. When were you told to take PERT?

*Unsure,*

*At the start of every meal,*

*At the start of every meal or snack,*

*At the end of every meal,*

*At the end of every meal or snack,*

*In the middle of the meal,*

*In the middle and at the end of the meal and with every snack,*

*Other (please specify)*

23. How often did you take PERT?

*Each time I ate,*

*With all meals and snacks,*

*With all meals, snacks and fluids not water,*

*Occasionally,*

*Rarely,*

*Never,*

*Other (please specify)*

24. When did you generally tend to take the capsules?

*At the start of every meal,*

*At the start of every meal or snack,*

*At the end of every meal,*

*At the end of every meal or snack,*

*In the middle of the meal,*

*At the start and in the middle of the meal and with every snack,*

*Other (please specify)*

25. Where there any barriers to getting the medication?

*Yes/no*

22a. If yes what were they?

*Could not afford the scripts,*

*Could not get transport to the pharmacy,*

*The pharmacy did not have the medication,*

*Wrong script,*

*Other (please specify)*

26. Did you have symptoms before PERT?

*Yes/no*

23a. If yes, which symptoms did you experience before PERT?

*Bloating,*

*Wind (belching or passing gas),*

*Abdominal pain,*

*Diarrhoea (loose bowels),*

*Reflux (burning sensation in the food pipe),*

*Nausea,*

*Floating bowel motions (hard to flush away),*

*Other (please specify)*

27. Did you notice any of these symptoms improving after the PERT?

*Bloating yes, no*

*Wind yes, no*

*Abdominal pain yes, no*

*Diarrhoea yes, no*

*Reflux yes, no*

*Nausea yes, no*

*Floating bowel motions yes, no*

*Other yes/no*

28. Did you have a change of dose from the initial starting dose?

*Yes,*

*No,*

*Not sure*

29. Who made this adjustment?

*Self,*

*GP,*

*Oncologist,*

*Surgeon,*

*Dietitian,*

*Other (please specify) \_\_\_\_\_*

30. Did anyone explain the reasons for changing the dose?



*Yes,*

*No,*

*Not needed,*

*Unsure*

31. Did you have any side effects from PERT?

*Yes/No*

28a. If yes, which ones

*Pain,*

*Cramps*

*Other*

32. What advice would you give a person with pancreatic cancer who is starting on PERT?

*Free text*

