

## **Supplementary Material**

### **Normal or diseased? Navigating indeterminate gut behaviour**

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## **Interview topic guide Gut symptom investigation Te Waipounamu – diagnosis**

Just a reminder about why we are doing this study – Te Waipounamu/the South Island has high rates of gut cancers and other types of gut disease so we are trying to better understand how best to do something about that.

When we talk about the gut and bowel we just mean the whole system from your throat right down to your bottom so where you swallow, your stomach, your bowel and the organs that are connected to your gut like the liver and pancreas.

One of the things we learned while we were preparing for these interviews was that people sometimes have different ways of talking about parts of the body that we need to understand better.

Can you first tell me how you talk about the different parts of the gut in your family and what kinds of words you use?

Prompt with: “what about this part” with your hand on your upper chest and near your throat, then move down to stomach area, then lower down to the lower abdomen.

We were told you have a diagnosis of \_\_\_\_\_

How might you describe your \_\_\_\_\_ if you had to explain it to someone who didn't know anything about the condition?

What made you think you had something wrong with your gut that led you to go and see a doctor?

- **Try to tease out what words people used to describe their symptoms e.g can you tell us a bit more about what you mean by .... whatever words they use?**
- Who did you first talk to about that, if you talked to anyone?
- How long was it going on for?
- Leave plenty of time for participant to flesh this out

How did you feel about going to see someone with those symptoms?

Can you tell us if you had any issues getting help for your condition?

- Prompt with: what about getting an appointment; cost; time off work; transport etc

What parts of the health care system have you used for your condition - like GPs, hospital specialists, dietitian, counsellor, social worker?

- Anyone else?
- How have you found each of these?
- What are your positive experiences with health care and health care providers?
- What about negative ones?

What other kinds of things do you know about what can go wrong with the gut?

Is there anything you wish you had known about your condition earlier?

- If appropriate ask participant to expand

If you were giving advice to someone else about symptoms to be concerned about related to your condition what would that advice be?

Just before we finish, is there anything else you'd like to add?

### **Interview topic guide Gut symptom investigation Te Waipounamu – no diagnosis**

Just a reminder about why we are doing this study – Te Waipounamu/the South Island has high rates of gut cancers and other types of gut disease so we are trying to better understand how best to manage that.

When we talk about the gut and bowel we just mean the whole system from your throat right down to your bottom so where you swallow, your stomach, your bowel and the organs that are connected to your gut like the liver and pancreas.

One of the things we learned while we were preparing for these interviews was that people sometimes have different ways of talking about parts of the body.

Can you first tell me how you talk about the different parts of the gut in your family and what kinds of words you use?

- Prompt with: “what about this part” with your hand on your upper chest and near your throat, then move down to stomach area, then lower down to the lower abdomen.

What kinds of things do you know of that can go wrong with the gut?

- Prompt with: “Do you know anyone with any type of gut disease?” If so, tell us what you understand of their condition.

What might make you think you had something wrong with your gut?

- May differentiate into upper and lower simply by indicating with your hands to prompt more specific reflection.

How might you describe that if you had to explain it to someone else?

- Leave plenty of time for participant to respond but could prompt with: “Do you use terms like heartburn, reflux, indigestion, the runs, being bunged up..... and get them to explain what they mean by whatever terms they come up with

What might make you go to see the doctor?

What do you think the doctor might do about that problem

Do you think you would have any issues with getting your problem seen to?

- Prompt with: what about getting an appointment; cost; time off work; transport etc

Just before we finish, is there anything else you'd like to add?

**If participant discusses having any of the following ‘alarm’ symptoms, please strongly suggest they see their GP:**

- **Bleeding from the bowel; rectal bleeding**

- **Change in bowel habits that has been going on for a while – particularly looser motions than usual.**
- **Abdominal pain**