



Supporting Information

Participant interview questionnaire

This appendix was part of the submitted manuscript and has been peer reviewed. It is posted as supplied by the authors.

Appendix to: Wu D, Bampton TJ, Scott HS, et al. The clinical and genetic features of hereditary pancreatitis in South Australia. *Med J Aust* 2022; doi: 10.5694/mja2.51517.

1. Construction of a Family tree

Is it okay if we discuss your family tree?

- Ask patient to fill out family tree - inclusive of Aunts/Uncles, Children, Parents, Grandparents, cousins [as known]
- Important questions to ask
 - Medical diagnosis of pancreatitis
 - History of pancreatic cancer
 - Symptoms that have been suggestive of but not specifically diagnosed pancreatitis

2. Experience with pancreatitis

Is it okay if we now discuss your personal medical history?

Personal history of diagnosed pancreatitis

- Please describe your experiences with pancreatitis, from the beginning until now
 - Allow patient to tell their story, answering the questions as below. Ask closed questions to fill out the survey as necessary
- What age did you first suffer from pancreatitis? |__|
- What typical symptoms do you get during an attack?
 - Abdominal pain |__|
 - Pain radiating to back |__|
 - Pain worse after eating |__|
 - Fever |__|
 - Rapid pulse |__|
 - Nausea |__|
 - Vomiting |__|
 - Weight loss |__|
 - Bloating |__|
 - Bowel changes |__|
 - Other [note]
- Have you had any interventions for pancreatitis?
 - TPIAT procedure |__|
 - Endoscopic retrograde cholangiopancreatography (ERCP) |__|
 - Other surgical procedure [note]
- Have you had any medical imaging of your abdomen performed?
 - Ultrasound |__|
 - CT scan |__|
 - MRI |__|
- Did you ever have to take days off of school or work due to abdominal pain? Yes |__| / No |__|
- Can you estimate the days of work/school missed per month? |__|

- Have you ever been hospitalized due to abdominal pain? Yes / No
- Can you estimate how many times per year, and overall you have been hospitalized? Per year / Overall
- Has pancreatitis ever affected your bowel motions? Yes / No
 - Foul-smelling
 - Oily
 - Fatty
 - Floating
- We know that this condition can cause a lot of pain. Have you ever taken any medication to help with this? Yes / No
 - Anti-inflammatory [e.g. Nurofen] Yes / No
 - Drug name
 - Dose
 - How often per day
 - Only during attack
 - Regular medication
 - Paracetamol (e.g. Panadol) Yes / No
 - Drug name
 - Dose
 - How often per day
 - Only during attack
 - Regular medication
 - Opioids (e.g. Endone/Oxycodone) Yes / No
 - Drug name
 - Dose
 - How often per day
 - Only during attack
 - Regular medication
 - Other agents (e.g. pregabalin) Yes / No
 - Drug name
 - Dose
 - How often per day
 - Only during attack
 - Regular medication
 - If two or more of same class annotate as necessary
- Have you ever been diagnosed with gallstones? Yes / No
- Have you ever been diagnosed with diabetes [or in layman's terms, have you ever had problems with your blood sugar?] Yes / No

No personal history of diagnosed pancreatitis

- Have you ever had any symptoms that you feel are similar to **[name of affected family member]**? Yes / No
- Have you experienced severe abdominal pain? Yes / No
 - Have you ever had medical imaging done for this [if yes] Yes / No
 - Have you ever taken any pain relief for this? Yes / No
- Have you ever noticed changes to your bowel motions [similar to those of pancreatitis patients] Yes / No
 - These will specifically be noticing that your stools are floating, more foul-smelling than usual.
- If answers are suggestive of potentially undiagnosed pancreatitis; follow the script as per 'personal history of diagnosed pancreatitis'

3. Smoking/Alcohol history

Is it okay if we now discuss your history with alcohol and smoking? The reason we are asking about these are both things that can have an effect on the health of the pancreas.

Smoking

- Have you ever smoked cigarettes? Yes / No
- At what age did you first start smoking cigarettes daily?
- How cigarettes do you smoke each day? [Or if quit smoking; how many did you smoke per day when you smoked]
- Has this ever been significantly more or less?
 - Loosely define periods of increased/decreased smoking
 - I.e. How many cigarettes per day when you smoked the most?
 - How many years was this for?
 - How many cigarettes do you smoke currently

Alcohol

- Have you ever consumed alcohol? Yes / No
- On average, how often do you drink alcohol? [per week]
 - Every day
 - 5-6 times a week
 - 3-4 times a week
 - 1-2 times a week
 - 2-3 times a month
 - Less than monthly
 - Never
- On average, how many drinks do you have during a typical week? A standard drink means one glass of wine (140ml), one bottle of beer, one straight or mixed with drink with 43ml of liquor (~ 1 shot).

- During the last 12 months, how often did you have four or more drinks at the same sitting or occasion?
 - Every day |__|
 - 5-6 times a week |__|
 - 3-4 times a week |__|
 - 1-2 times a week |__|
 - 2-3 times a month |__|
 - Less than monthly |__|
 - Never |__|

4. Other medical conditions / medications

Do you have any other diagnosed medical conditions? Yes |__| / No |__|

- Annotate as necessary

Do you take any other prescribed medications? Yes |__| / No |__|

- Annotate as necessary

5. Quality of life questionnaire

SF-12 Health Survey

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. **Answer each question by choosing just one answer.** If you are unsure how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

1 Excellent 2 Very good 3 Good 4 Fair 5 Poor

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	YES, limited a lot	YES, limited a little	NO, not limited at all
2. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
3. Climbing several flights of stairs.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	YES	NO
4. Accomplished less than you would like.	<input type="checkbox"/> 1	<input type="checkbox"/> 2
5. Were limited in the kind of work or other activities.	<input type="checkbox"/> 1	<input type="checkbox"/> 2

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	YES	NO
6. Accomplished less than you would like.	<input type="checkbox"/> 1	<input type="checkbox"/> 2
7. Did work or activities less carefully than usual.	<input type="checkbox"/> 1	<input type="checkbox"/> 2

8. During the past 4 weeks, how much did pain interfere with your normal work (including work outside the home and housework)?

1 Not at all 2 A little bit 3 Moderately 4 Quite a bit 5 Extremely

These questions are about how you have been feeling during the past 4 weeks.

For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks...

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9. Have you felt calm & peaceful?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
10. Did you have a lot of energy?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
11. Have you felt down-hearted and blue?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

12. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

1 All of the time 2 Most of the time 3 Some of the time 4 A little of the time 5 None of the time

Patient name:	Date:	PCS:	MCS:
Visit type (circle one)			
Preop	6 week	3 month	6 month
		12 month	24 month
			Other: _____