

PACYFIC study

- Follow-up patient questionnaire -

Instructions and additional information

Thank you for participating in the PACYFIC study patient questionnaire.

This questionnaire will evaluate how you, as a patient, experience cyst surveillance. The questionnaire also includes several questions regarding your background, lifestyle, and medical history. You will receive this questionnaire after each follow-up visit.

We expect it will take you 5 to 15 minutes to fill out the answers. Please read the instructions carefully before answering a question. We kindly ask you to fill out all questions, even if they seem unimportant or irrelevant to you. If you can skip a question, this will be explicitly mentioned.

There are no right or wrong answers. We are only interested in your personal opinion. Your answers will be handled and stored anonymously. We will never contact you regarding the answers you have given. If you have any questions or concerns, please don't hesitate to contact the study coordinator (see contact information on the front page of this questionnaire) or your treating physician.

We thank you for your cooperation,

The PACYFIC research team.

I. These first questions concern your personal background, lifestyle, and medical history.

Please fill out your details below.

1. Are you being treated for Diabetes?

- No **Continue to question 2**
 Yes **Continue to question 1a**

1a. Since what year? _____

1b. Do you use Insulin?

- No **Continue to question 2**
 Yes **Continue to question 1c**

1c. How many units of Insulin on average per day? _____ Units

2. Are you (or were you ever) treated for **inflammation** of the pancreas (pancreatitis)?

- No
 Yes If Yes, in what year? _____

3. Were you ever diagnosed with a **pancreatic cyst** before?

- No
 Yes If Yes, in what year? _____

4. Were you ever diagnosed with **pancreatic cancer** (pancreatic carcinoma)?

- No
 Yes If Yes, in what year? _____

5. Did you ever undergo **pancreatic surgery**?

- No
 Yes

6. Do you smoke?

- No **Continue to question 7**
 Yes **Continue to question 6a**
 Not anymore, but I used to **Continue to question 6a**

6a. How many years of your life did you smoke? _____ year(s)

6b. How many cigarettes on average per day? _____ cigarettes

7. Do you drink alcohol?

- No **Continue to question 8**
- Yes **Continue to question 7a**
- Not anymore, but I used to **Continue to question 7b**

7a. How many glasses on average per day? _____ glasses

7b. Did you ever drink more than 5 glasses on average per day?

- No
- Yes If Yes, for how many years? _____

8. Was any of your family members ever diagnosed with **inflammation** of the pancreas (pancreatitis)?

- No **Continue to question 9**
- Yes **Continue to question 8a**

8a. If yes, which member? (for example: father, niece) _____

8a. How old was this person at the time of diagnosis? _____ (years)

9. Was any of your family members ever diagnosed with **pancreatic cancer** (pancreatic carcinoma)?

- No **Continue to question 10**
- Yes **Continue to question 9a**

9a. If yes, which member? _____

9b. How old was this person at time of diagnosis? _____ (years)

10. Was any of your family members ever diagnosed with **breast cancer**?

- No **Continue to question 11**
- Yes **Continue to question 10a**

10a. If yes, which member? _____

10b. How old was this person at time of diagnosis? _____ (years)

11. Was any of your family members ever diagnosed with bowel cancer (colon carcinoma, cancer of the large intestine)?

No

Continue to question 12

Yes

Continue to question 11a

11a. If yes, which member? _____

11b. How old was this person at time of diagnosis? _____ (age in years)

II. The following questions are about your knowledge of your pancreatic cyst.

1. Do you know what type of pancreatic cyst you have?
 - Yes, a benign cyst (no cancer)
 - Yes, a benign cyst (no cancer) that has the potential to become a malignant cyst (cancer)
 - Yes, a malignant cyst (cancer)
 - I have been told, but do not remember
 - No, I have not been told

2. How large is, according to you, the chance that your cyst will progress to a malignant cyst (pancreatic cancer)?
 - Very small
 - Small
 - Average
 - Large
 - Very large

3. Have you searched for extra information on your pancreatic cyst?
 - No
 - Yes, through the internet
 - Yes, through my general practitioner
 - Yes, through friends and family
 - Yes, through books and/or magazines or scientific journals

III. The next questions concern undergoing regular follow-up of a pancreatic cyst.

1. Please specify to what extent you agree with each of the following statements:

a. Regular follow-up of my pancreatic cyst(s)...

	Strongly Agree	Agree	To some extent	Disagree	Totally disagree
a. Reduces my concerns about developing pancreatic cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Creates discomfort in my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Gives me a sense of certainty.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. May lead to unnecessary worries.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Is a good method to detect cancer in time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

b To what extent...

	Not at all	Somewhat	Rather	Very much
a. Do the follow-up visits convey you a sense of security?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Are you nervous before a follow-up visit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Are you reassured after the follow-up visit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Did you sleep less well in the week before follow-up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Did you postpone plans until after the follow-up visit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Do you find the regular follow-up burdensome?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Do the advantages of follow-up outweigh the disadvantages?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Would you be more worried about your cyst if it was not checked regularly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Do you dread the next follow-up visit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Would you prefer your cyst to be checked less frequently?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. How often would you prefer to have your cyst checked, if it was up to you?

- Every 3 months
- Every 6 months
- Every year
- Every 2 years
- Never, I would prefer to stop the follow-up
- Other, please specify _____

3. For how long would you prefer to undergo cyst follow-up?

- 2 years
- 5 years
- 10 years
- All my life, as long as I am fit to do so
- Other, please specify _____

4. Has your fear for the development of pancreatic cancer changed, since you started cyst follow-up?

- Yes, I worry less
- Yes, I worry more
- No, I am just as worried as before I started the follow-up
- No, I did not worry before, and I do not worry now
- Other, please specify _____

5. How would you feel if pancreatic cyst follow-up was no longer advised, because the risk of developing pancreatic cancer is too low?

- I would **not be worried** anymore and no longer wish to be checked
- I would **still be worried** and ask for follow-up
- I don't know

IV. MRI (Magnetic Resonance Imaging) and EUS (Endoscopic Ultrasound) are both used to visualize pancreatic cysts. The next questions are about your experience with these imaging studies.

Even if you did not undergo MRI or EUS (yet), we still ask you to answer the following questions.

6. How did you experience undergoing a MRI?

- Very uncomfortable
- Quite uncomfortable
- A little uncomfortable
- Not uncomfortable
- I did not undergo a MRI

7. Do you dread undergoing a MRI in the future?

- Not at all
- A little
- Quite
- Very much
- I don't know

8. How did you experience undergoing an EUS?

- Very uncomfortable
- Quite uncomfortable
- A little uncomfortable
- Not uncomfortable
- I did not undergo an EUS

9. Do you dread undergoing an EUS in the future?

- Not at all
- A little
- Quite
- Very much
- I don't know

10. Which investigation do you consider to be the most burdensome?

- MRI
- EUS
- Both equally
- I don't know

V. The following questions are meant to evaluate your mental state of mind.

Please read each item carefully and choose the answer that comes closest to how you have been feeling in the past week.

11. a. I feel tense or “wound up”.

- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

b. I still enjoy the things I used to enjoy.

- Definitely as much
- Not quite as much
- Only a little
- Not at all

c. I get a sort of anxious feeling, like something bad is about to happen.

- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

d. I can laugh and see the funny side of things.

- As much as I always could
- Not quite so much now
- Definitely not so much now
- Not at all

e. Worrying thoughts go through my mind.

- A great deal of the time
- A lot of the time
- From time to time, but not that often
- Only occasionally

f. I feel cheerful.

- Not at all
- Not often
- Sometimes
- Most of the times

g. I can sit at ease and feel relaxed.

- Definitely
- Usually
- Not often
- Not at all

h. I feel as if I am slowed down.

- Nearly all of the time
- Very often
- Sometimes
- Not at all

i. I get a sort of anxious feeling, like “butterflies in the stomach”.

- Not at all
- Occasionally
- Quite often
- Very often

j. I have lost interest in my appearance.

- Definitely
- I don't take so much care as I should
- I may not take quite as much care
- I take just as much care as ever

k. I feel restless, as if I have to be on the move.

- Very much indeed
- Quite a lot
- Not very much
- Not at all

l. I look forward with enjoyment to things.

- As much as I ever did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

m. I get sudden feelings of panic.

- Very often indeed
- Quite often indeed
- Not very often
- Not at all

n. I can enjoy a good book or radio or TV show.

- Often
- Sometimes
- Not often
- Very seldom

Thank you for filling out this questionnaire.

We will send you a link to the next questionnaire after your coming follow-up visit.

Yours sincerely,

The PACYFIC research team.