Welcome to the Danish Symptom Cohort

Thank you for being willing to participate in our questionnaire survey.

In this project, we explore symptoms and healthcare-seeking in the Danish general population with the aim of contributing to a better and more accessible healthcare-system for everyone. We are interested in your symptoms and experiences although they may be explained be a known disease.

If you get interrupted while filling out the questionnaire, you can always resume later. The system automatically saves your responses. Simply click on the link in the invitation, or type in your personal code at <u>www.datafabrikken.dk</u> once again.

If you have difficulties or questions about the questionnaire, please feel free to contact us by email: <u>dask@health.sdu.dk</u> or by phone: 65 50 74 40 all weekdays from 11 am to 2 pm and 7-8 pm.

On average, it takes 15-20 min to complete the questionnaire, but it may vary from one person to another.

For some of the questions you will see a symbol. Click on the symbol to get an explanation of the question.

Thank you in advance. We appreciate you help.

Kind regards,

On behalf of the Danish Symptom Cohort

Dorte Ejg Jarbøl Professor, PhD, General Practitioner, and Head of Project

If you fill in the questionnaire by using your phone or tablet, we recommend that you turn the phone or your tablet, so the screen is as wide as possible.

Have you within the last 4 weeks experienced any of these? (You may tick more than one box)

We are interested to hear if you have **experienced any bodily sensations**, symptoms, or discomfort within **the last four weeks**.

- Coughing
- lacksquare Shortness of breath
- Coughing up blood
- Hoarseness
- Changes to a familiar cough (changes in strength, frequency, or sputum in a cough you normally have)
- None of the above
- Abdominal pain
- Nausea
- $\hfill\square$ Repeated vomiting without known cause
- $\hfill\square$ Blood in vomit
- □ Difficulty swallowing
- □ None of the above

□ Changes in stool texture (i.e., harder or lumpier stools than usual, or the opposite, looser and waterier stools than usual)

- Changes in bowel movement frequency (i.e., passing stools more often, or less often than usual)
- □ Rectal bleeding/blood in stool
- Black, shiny stools
- □ Frequent, loose, or watery stools
- □ Hard and lumpy stools
- None of the above
- □ Tiredness
- That you feel exhausted
- That you feel unwell or ill
- Fever
- □ That you have lost more than 2 kg without making an effort
- □ Loss of appetite
- □ None of the above
- Dizziness
- Headache
- Back pain
- None of the above
- Blood in urine
- $\hfill\square$ That you need to urinate more often than usual
- lacksquare That you have to urinate three or more times during the night
- Difficulty emptying the bladder
- That the urge to urinate is so strong that you cannot make it to the toilet in time
- □ Involuntary urination (incontinence) **during** exertion, e.g. coughing, sneezing, lifting and exercise
- □ Involuntary urination (incontinence) without exertion and urge (leakage)
- None of the above

Abdominal bloating
 Increased waist circumference (trousers tighter than normal)
 Pelvic pressure
 None of the above

The next questions may seem private. If you do not wish to answer the questions, simply tick the category "Do not wish to answer."

Only for men

Have you within the last 4 weeks experienced any of the following?

	Yes	No	Do not wish to answer
Blood in the semen	Ο	О	0
Erectile dysfunction	Ο	0	0

Only for women

Have you within the last 4 weeks experienced any of the following? Pelvic pain

- (1) **O** Yes
- (2) **O** No
- (3) O Do not wish to answer

Vaginal bleeding during or after sexual intercourse

- (1) O Not relevant, as I am not sexually active
- (2) **O** Yes
- (3) O No
- (4) O Do not wish to answer

Pelvic pain during or after sexual intercourse

- (4) O Not relevant, as I am not sexually active
- (1) **O** Yes

- (2) **O** No
- (3) O Do not wish to answer

Are you past menopause? You are past menopause if you have not had your period for one or more years. If you do not have a uterus, please answer "Not relevant". Please answer "No" if the absence of your period is due to pregnancy, recent childbirth, or your contraception prevents menstruation, e.g., if you have an intrauterine device.

- (1) **O** Yes
- (2) **O** No
- (3) O Not relevant

Only for women, and only if stated that they had reached the menopause (i.g. postmenopausal women):

Have you within the last 4 weeks experienced?

	Yes	No	Do not wish to answer
Vaginal bleeding	О	0	0

Only for women, and only if stated that they had not yet reached the menopause (i.e., premenopausal women):

Have you within the last 6 months experienced?

	Yes	No
Heavy and/or prolonged menstrual bleeding	0	0
Severe menstrual cramps	0	0
Irregular menstruation	0	0

Are you currently pregnant, or have you been pregnant within the last 6 months?

O Yes O No

The following questions only appeared in relation to a positive expression of one or more experienced symptom(s) - by a leap structure in the electronic survey to the symptom experience.

We will now ask you some elaborating questions, which deal with the symptoms or discomfort that you have just stated.

When did you experience these for the first time?

	Less than a month ago	1-3 months ago	3-6 months ago	More than 6 months ago
Coughing	Ο	0	0	0
Shortness of breath	О	0	0	0
Coughing up blood	0	0	0	0
Hoarseness	0	0	0	0
Changes to a familiar cough	0	0	0	0
Abdominal pain	О	0	0	0
Nausea	0	0	0	0
Repeated vomiting without known cause	0	О	О	О
Blood in vomit	0	0	0	0
Difficulty swallowing	О	0	0	0
Changes in stool texture	О	0	0	0
Changes in bowel movement frequency	0	О	О	О
Rectal bleeding/Blood in stool	0	0	0	0
Black shiny stools	0	0	0	0
Frequent, loose, or watery stools	0	О	О	О
Hard and lumpy stools	О	O	Ο	0
Tiredness	О	0	0	0
That you feel exhausted	О	0	0	0
That you feel unwell or ill	О	0	0	0
Fever	О	O	O	O

That you have lost more than 2 kg without making an effort	0	0	0	О
Loss of appetite	О	0	О	0
Dizziness	О	О	Ο	0
Headache	О	Ο	Ο	О
Back pain	О	О	Ο	O
Blood in urine	О	О	Ο	О
That you need to urinate more often than usual	0	О	0	О
That you have to urinate three or more times during the night	0	О	0	О
Difficulty emptying the bladder	0	0	О	0
That the urge to urinate is so strong that you cannot make it to the toilet in time	0	0	0	O
Involuntary urination (incontinence) during exertion, e.g. coughing, sneezing, lifting and exercise	O	0	0	O
Involuntary urination (incontinence) without exertion and urge (leakage)	0	0	0	0
Blood in semen/sædvæsken	0	О	О	0
Erectile dysfunction	О	О	О	0
Abdominal bloating	О	О	О	0
Increased waist circumference	О	О	О	0
Pelvic pressure	0	0	О	0
Pelvic pain	О	О	О	0
Vaginal bleeding during or after sexual intercourse	О	0	О	0
Pelvic pain during or after sexual intercourse	0	0	О	0

Vaginal bleeding after menopause	0	О	О	0
Heavy and/or prolonged menstrual bleeding	Ο	О	О	0
Severe menstrual cramps	О	0	Ο	О
Irregular menstruation	О	0	0	О

Within the last 4 weeks: To what extent did you experience that the following symptoms or discomfort interfered with your usual daily activities?

	Not at all	Slightly	Moderate	Quite a bit	Extremely
Coughing	Ο	О	О	0	О
Etc.	О	О	О	О	О

Within the last 4 weeks: To what extent were you concerned about the following symptoms or discomfort?

	Not at all	Slightly	Moderate	Quite a bit	Extremely	
Coughing	0	О	0	Ο	0	
Etc.	0	Ο	0	0	Ο	

Have you contacted your general practitioner about any of the following symptoms or discomfort (via telephone, email, video-consultation, or clinic visit)

	Yes	No
Coughing	0	0
Etc.	0	0

The following questions only appeared in relation to a positive indication of one or more experienced symtom(s) and negative indication of healthcare-seeking – by a leap structure in the electronic survey.

You have **not** been in contact with your general practitioner regarding the following symptoms and discomforts. We would now like to know, whether you had some of the following considerations, regarding contact to your general practitioner?

Coughing etc.

	Yes	No
I would be too embarrassed	0	0
I would be worried about wasting the doctor's time	Ο	Ο
I would be worried about what the doctor might find	0	Ο
I would be too busy to make time to go to the doctor	0	Ο
I knew what was causing the symptom	0	0
I expected the symptom to go away on its own	0	0
Other considerations	0	0

Other considerations [box for free text commentaries]:

We have just asked you about your contact to your general practitioner. The following questions concern which other healthcare professionals and therapists you have consulted. Afterwards, we ask about your contact to family and friends.

Which of the following other healthcare professionals or therapists have you talked to/consulted regarding the symptoms or discomforts listed below (via telephone, video consultation, email, or clinic visit). You may tick more than one box.

	None	Out-of- hours physician, hospital physician or another practicing specialist (e.g. gynaecologi st, ear, nose and throat specialist, etc)	Physiothera pist/chiropr actor	Alternative therapist (e.g. homeopath, healer, reflexologist)	Another doctor (please state which)(e.g. nurse and/or home care?)
Coughing					•
Etc.					•

Which of the following members of your family or social network have you talked to about the symptoms or discomforts listed below. You may tick more than one box

I

	None	Spouse/co- habitant/pa rtner	Children	Other family (parents, siblings, grandparent s, and others.)	Friends, colleagues and acquaintanc es
Coughing					
Etc.					

The following questions concern pain and general symptoms. There may be overlap with previous questions, but it is important for the survey that you reply to the questions. There will **not** be elaborating questions to these symptoms.

During the last four weeks, have you been bothered by:

	Not at all	Slightly	Moderate	Quite a bit	Extremely
Palpitations/heart pounding?	О	О	O	O	0
Precordial discomfort?	Ο	Ο	Ο	0	0
Breathlessness without exertion?	О	О	О	О	0
Hyperventilation?	Ο	Ο	Ο	0	0
Hot or cold sweats?	Ο	0	0	Ο	О
Dry mouth?	О	Ο	Ο	0	О

During the last four weeks, have you been bothered by:

	Not at all	Slightly	Moderate	Quite a bit	Extremely
Frequent loose bowel movements?	0	О	О	О	0
Abdominal pains?	0	0	0	0	0
Feeling bloated/full of gas/distended?	0	О	О	О	0
Diarrhoea?	0	0	0	0	0
Regurgitations?	О	0	0	0	0
Nausea?	0	0	0	0	0
Burning sensation of the chest or upper part of stomach/ Epigastrium?	0	0	О	0	O

During the last four weeks, have you been bothered by:

	Not at all	Slightly	Moderate	Quite a bit	Extremely
Pains in arm or legs	О	Ο	0	0	О
Muscular aches or pains?	0	Ο	Ο	0	О
Pains in the joints?	Ο	0	0	0	О
Feeling of paresis or localized weakness?	O	О	О	О	0
Backache?	О	0	0	0	О
Pain moving from one place to another?	0	О	О	О	О
Unpleasant numbness or tingling sensations?	O	О	0	0	0

During the last four weeks, have you been bothered by:

	Not at all	Slightly	Moderate	Quite a bit	Extremely
Concentration difficulties?	Ο	Ο	Ο	Ο	О
Excessive fatigue?	Ο	Ο	0	Ο	О
Headache?	0	0	0	0	О
Impairment of memory?	Ο	Ο	0	Ο	Ο
Dizziness?	Ο	0	0	0	О

We have now finished asking about specific symptoms and discomfort. The following questions refer to your experience with health, disease(s), and contact to the healthcare system. There may be questions that seem similar, yet answering each question is important to the overall understanding.

Please tick one box for each statement to show how much you agree/disagree

	Disagree completely	Disagree	Agree	Agree completely
I feel I have good information about health	0	Ο	0	О
I have at least one healthcare provider who knows me well	0	О	О	О
I can get access to serval people who understand and	0	0	0	О
When I feel ill, the people around me really understand	0	0	О	О
I have at least one healthcare provider I can discuss	0	0	О	O
I have enough information to help me deal with my	0	0	О	О
If I need help, I have plenty of people I rely on	0	О	О	О

Please tick one box for each statement to show how much you agree/disagree

	Disagree completely	Disagree	Agree	Agree completely
I am sure I have all the information I need to manage 	0	0	0	0
I have at least one person who can come to medical	0	0	0	О
I have the healthcare providers I need to help me work	0	0	0	О
I have strong support from family and friends	0	0	О	О
I can rely on at least one healthcare provider	O	0	0	О

I have all the information I	Ο	0	О	О
need to look after my health				

Please indicate how difficult or easy the following tasks are for you.

	Always difficult	Usually difficult	Sometimes difficult	Usually easy	Always easy
Make sure that healthcare providers understand your	0	0	0	0	O
Feel able to discuss your health concerns with a	0	0	0	О	0
Have good discussions about your health with doctors	0	0	0	0	O
Discuss things with healthcare providers until you understand	0	0	0	0	O
Ask healthcare providers questions to get the	О	О	О	О	О

How often do you seek information about symptoms?

	Almost daily	Weekly	Monthly	Yearly	Rarely (< yearly)	Never
On the internet? (e.g., search engines/Google, or specific webpages (Netdoktor, Patienthåndbogen))	O	0	0	0	O	0
In books, newspapers, and magazines?	0	0	0	0	0	О
By talking to family, friends, and acquaintances.	0	0	О	0	О	0

The following question is only asked as an in-depth question in the event of a positive indication of Internet usage (Almost daily, weekly, monthly, yearly) - as a leap structure in the electronic questionnaire.

You have stated that you searched for information about symptoms **on the Internet**.

Please tick one box for each statement to show how much you agree/disagree

	Completely disagree	Partly disagree	Partly agree	Completely agree	l don´t know
I generally find it easy to find information about symptoms on the Internet	O	O	0	O	0
I usually understand the information I find on the internet	О	0	0	O	0
When I look for information on the Internet, it is to find out if I should see a doctor	O	0	0	O	0
The information I find on the internet often influences whether I seek a doctor	O	O	О	0	0

The following question is only asked as an in-depth question, if there is a negative indication regarding using the internet (rarely or never) - as a leap-structure in the electronic questionnaire.

You have stated that you rarely or never search for information about symptoms on the internet.

Please tick one box for each statement to show how much you agree/disagree

	Completely disagree	Partly disagree	Partly agree	Completely agree	l don´t know
I don't need to search for information about symptoms	O	0	0	O	0
I don't trust the information that can be found on the internet about symptoms	O	0	0	O	0
I do not have access to the Internet on a daily basis.	0	0	О	O	О
I find it difficult to search for information on the Internet	О	0	0	О	0
I avoid searching the internet for information about symptoms because I start worrying that I have a serious illness	0	0	0	0	0

Other explanations for why I never or rarely search for information about my symptoms on the internet:

The following questions are about general considerations and experiences regarding your contact with your general practitioner.

Please tick one box for each statement to show how much you agree/disagree

	Completely disagree	Partly disagree	Partly agree	Completely agree	Not relevant
I find it difficult to talk to the secretary at the GP's office about my problems	O	0	О	0	O
I have difficulty getting an appointment with the doctor I want to see	0	0	О	0	0
I find it difficult to get in touch with my doctor	О	0	О	О	0
I am confident, that my doctor can help me	О	0	О	О	О
I would like to be seen by the same doctor I usually see	0	0	О	0	0
I have had bad experiences with doctor visits	O	O	О	0	O
I often experience, that the doctor has too little time for my consultation	O	O	0	0	O

The next questions are of a general nature and concern your own perception of your health, your lifestyle, and your worry about disease.

In general, would you say your health is:

- \mathbf{O} Excellent
- $\mathbf O$ Very good
- $\mathbf{O} \text{ Good}$
- **O** Fair
- $\mathbf{O} \text{ Poor}$

Do you feel well enough to do what you feel like doing?

O Yes, mostly

- ${\mathbf O}$ Yes, sometimes
- **O** No, almost never
- $\mathbf{O} \, \mathsf{I} \, \mathsf{don't} \, \mathsf{know}$

Do you think that you will live longer or shorter than the average person?

O Longer than the average person

- **O** Like the average person
- **O** Shorter than the average person
- \mathbf{O} I don't know

Do you have any chronic disease, long-term effects after injuries, disability, or other chronic disorder?

O Yes

- O No
- **O** I don't know

Do you smoke?

- ${f O}$ Yes, every day
- $\mathbf O$ Yes, at least once a week
- O Yes, less than once a week (e.g., social smoker)
- O No, I have stopped
- ${\bf O}$ No, I have never smoked

Please state for how many years you have smoked in total:

How much do you smoke on average a day?

Cigarettes State the approximate number of cigarettes in whole numbers	
Cheroots State the approximate number of cheroots in whole numbers	
Cigars State the approximate number of cigars in whole numbers	
Pipes State the approximate number of pipes in whole numbers	

When did you stop smoking (most recently)?

Year:

How many units do you drink per week on average? One unit corresponds to a normal beer (33 cl), a glass of wine (12cl), or spirits (4 cl)

O units/weeks
O 1-4 units/weeks
O 5-10 units/weeks
O 11-14 units/weeks
O More than 15 units/weeks

How often do you drink more than 4 units at the same occasion?

- **O** Almost daily
- **O** Weekly
- **O** Monthly
- **O** Rarely
- O Never

How tall are you (without shoes)?

State your heigh in whole numbers measured in cm (e.g., 172)

How much do you weigh in full kg (without clothes)?

State your weight in full kg (e.g., 67)

The following questions are about your own concerns about your current health, and whether other people have expressed concern about your current health.

To what extent are you concerned about your current health?

- Not at all
- **O** Slightly
- **O** Moderately
- \mathbf{O} Quite a bit
- **O** Extremely

Has a doctor expressed concern about your current health?

- O Yes
- O No
- O I don't know

Have people in your family or social network expressed concern about your current health?

Yes
No
I don't know

The following questions are about how you usually act in relation to problems and in difficult situations.

The questions are written in 'I' form, and you place your tick depending on how much you agree/disagree.

	Disagree completely	Tend to disagree	Yes and no	Tend to agree	Agree completely
l say so if I am angry or sad	О	О	О	О	0
I like to talk with few chosen people when things get too much for me	0	О	0	О	0
I make an active effort to find a solution to my problems	0	О	0	О	0
Physical exercise is important to me	O	О	O	О	О
I think something positive could come out of my complaints/problems	О	0	О	0	0
I firmly believe that my problems will decrease (and my situation improves)	0	О	0	О	0
I try to forget my problems	О	0	О	0	0

I put my problems behind me by cencentrating on something else	0	0	0	О	0
I bury myself in work to keep my problems at a distance	0	0	0	О	0
I often find it difficult to do something new	0	0	О	О	0
I am well on the way towards feeling I have given up	0	0	0	O	0
I withdraw from other people when things get difficult	0	0	O	O	0

The remaining questions are about your thoughts and experiences during the COVID-19 lockdown in March 2020. It might be difficult to remember that far back, but just answer the best you can.

Thinking back to the time during the COVID-19 lockdown in March 2020, did you need to contact your general practitioner concerning your health?

O Yes

O No

O I don't know

Thinking back to the time during the COVID-19 lockdown in March 2020, how much do you disagree or agree with the following statements?

	Completely disagree	Partly disagree	Partly agree	Completely agree	l don´t know
I was in doubt as to what I could contact the doctor with	O	C	0	0	0
I was worried I would catch the Corona virus if I went to the doctor's office.	O	O	О	0	0

I was worried about putting an unnecessary burden on the healthcare system	0	О	О	O	О
I found it difficult to discuss my symptoms over the phone, in an email, or during a video consultation	0	0	O	O	O
I considered it as an advantage, that more things could be handled over the phone, email, or video	0	0	O	O	O
I experienced that the reason I contacted the doctor was considered as less important	0	0	O	O	О
I experienced that I was examined less thoroughly due to the corona pandemic	0	0	O	O	O

Other considerations [box for free text commentaries]:

The next question is about your contact with your doctor now.

Which of the following statements best applies to you?

Compared with the time before the corona pandemic:

- ${\bf O}$ I generally wait longer before contacting my doctor
- ${\bf O}$ I am now generally quicker to contact my doctor
- **O** I have not changed when I contact my doctor

Other considerations [box for free text commentaries]:

You have now finished the questionnaire.

Thank you very much for your reply

Should you have any comments to the questionnaire, please feel free to list them here:

If any of the questions have made you concerned about your health, we recommend that you contact your general practitioner.

The results of the survey will be presented on our website: www.sdu.dk/dask.

On behalf of the Danish Symptom Cohort

Dorte Ejg Jarbøl Professor, PhD, General Practitioner, and Head of Project