Supplementary File 1

Welcome to the Danish Symptom Cohort – a survey about health, symptoms and healthcare-seeking

The questionnaire was not available in hard copy, but for illustrative purposes it has been reproduced in this appendix.
In order to address sex specific items with minimal disturbance to respondents, the questionnaire was distributed in two different versions; one for males and another for females. In this appendix questions from both versions are included, and each of the sex specific questions i marked with explanatory captions in italic.
The web-based questionnaire contains several leaps based on answers provide by the respondents (marked with explanatory captions in italic).

We appreciate that you will take the time to complete the questionnaire.

The questionnaire is to be used for the identification of a number of bodily sensations, symptom experiences and discomfort. You may find that some of the questions are similar. It is important that you answer them all anyway. You can also answer the questions, even if you feel perfectly healthy. There is a commentary box at the end of the questionnaire, in which you can note any additional remarks.

Should you get disrupted while answering the questionnaire, you can always log on again. The system automatically saves your answers. Simply use your personal logon information again, and you can continue the survey.

When completing the questionnaire, it is also possible to return to previously answered questions.

If you have any questions or experience problems while filling in the questionnaire, please feel free to contact us by e-mail: dask@health.sdu.dk or by phone: 29 71 44 24 weekdays between the hours 10:00-15:00 and 19:00-21:00.

For further information about the survey, please visit our website www.sdu.dk/dask. Here you will also find answers to some frequently asked questions.

Completing the questionnaire will take approximately 20-30 min.

Participant acceptance:
I accept that my answers can be used for research, and I herby give consent to obtain information from health records and medical records for research purposes. All my answers will be treated with the strictest confidence and used solely for research purposes. The responses will be used only in anonymous form. It is of course voluntary to participate, and I may at any time withdraw this consent.
The study was approved by the Danish Data Protection Agency, Science Ethics Committee and the Danish Health and Medicines Authority, and thus complies with current legal and ethical regulations.

- ❑ **I accept the above**

We are interested to hear if you have experienced any bodily sensations, symptoms or discomfort within the last four weeks. Later you will be asked when you first experienced these, and how you reacted with regard to these experiences.

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

- ❑ Abdominal pain
- ❑ Nausea
- ❑ Repeated vomiting
- ❑ Blood in vomit
- ❑ Difficulty swallowing

- ❑ Abdominal bloating
- ❑ Increased waist circumference (trousers tighter than normal)
- ❑ Change in stool texture (i.e. having hard or lumpy stools, althouth you usually tend to have loose or watery stools or vice versa)
- ❑ Change in frequency of bowel movements (i.e. passing stools more or less frequently than usual)

- ❑ Rectal bleeding/Blood in stool
- ❑ Black shiny stools
- ❑ Frequent, loose or watery stools
- ❑ Hard and lumpy stools

- ❑ Tiredness
- ❑ Lack of energy
- ❑ Feeling unwell or sick
- ❑ Memory problems
- ❑ Concentration problems
- ❑ Weight loss of more than 2 kg without making an effort

- ❑ Coughing
- ❑ Coughing up blood
- ❑ Shortness of breath
- ❑ Hoarseness

- ❑ Dizziness
- ❑ Headache
- ❑ Back pain
- ❑ Swollen legs
- ❑ Loss of appetite
- ❑ Lump/swollen lymph node
- ❑ Fever

- ❑ That you need to urinate more often than usual
- ❑ That you have to get up to urinate at night
- ❑ Difficulty emptying the bladder completely when urinating

- ❑ Pain or burning sensation when urinating
- ❑ Urge to urinate 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)
- ❑ Blood in urine

Only for women:

The next questions are about sexual relations. Some of the questions may seem private, but your response may contribute to a greater understanding of whether there is a correlation between sexual relations and symptoms or discomfort from the lower abdomen. If there are questions you do not wish to answer, simply tick the category "do not wish to answer."

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

Pelvic pain

- ❑ Yes
- ❑ No
- ❑ I don't wish to answer

Vaginal bleeding after menopause (i.e. absence of menstrual periods for more than 12 months.)

- ❑ Not relevant, as I have not yet reached menopause
- ❑ Yes
- ❑ No
- ❑ I don't wish to answer

Vaginal bleeding during or after sexual intercourse

- ❑ Not relevant, as I am not sexually active
- ❑ Yes
- ❑ No
- ❑ I don't wish to answer

Pelvic pain during intercourse

- ❑ Not relevant, as I am not sexually active
- ❑ Yes
- ❑ No
- ❑ I don't wish to answer

The next question may seem private, but your response may contribute to a greater understanding of the prevalence of symptoms or discomfort in the population. If you do not wish to answer the question, simply tick the category "Do not wish to answer."

Only for men:

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

- ❑ Erectile dysfunction
- ❑ Blood in the semen
- ❑ None of the above
- ❑ I don't wish to answer

Only for women, and only if stated that they had not yet reached the menopause:

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

- ❑ Yes
- ❑ No
- ❑ I don't know/ I don't wish to answer

Only for women

How many sexual relationships have you had altogether from your sexual debut and until now?

- ❑ Have not yet had my sexual debut
- ❑ 1-5
- ❑ 6-10
- ❑ 11-15
- ❑ 16-20
- ❑ 21-25
- ❑ More than 26
- ❑ I don't wish to answer

How many sexual relationships have you had within the last year?

- ❑ 0
- ❑ 1-5
- ❑ 6-10
- ❑ 11-15
- ❑ 16-20
- ❑ 21-25
- ❑ Mere end 26
- ❑ I don't wish to answer

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 sensations, 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
Abdominal pain Etc…	❑	❑	❑	❑

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
Abdominal Pain Etc…	❑	❑	❑	❑	❑

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
Abdominal Pain Etc…	❑	❑	❑	❑	❑

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 questions concerning who you have talked to about the symptoms or discomfort you experienced **in the last 4 weeks**.

Have you contacted your general practitioner with any of the following symptoms or discomfort? (Through appointment, by telephone or by email)

- ❑ Yes
- ❑ 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

You have 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, **before** contacting your general practitioner? (You may tick more than one box)

		Yes	No
Abdominal pain Etc.	I would be too embarrassed	❑	❑
	I would be worried about wasting the doctor's time	❑	❑
	I would be worried about what the doctor might find	❑	❑
	I would be too busy to make time to go to the doctor	❑	❑
	Other considerations [box for free text commentaries]		

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

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? (You may tick more than one box)

		Yes	No
Abdominal pain Etc.	I would be too embarrassed	❑	❑
	I would be worried about wasting the doctor's time	❑	❑
	I would be worried about what the doctor might find	❑	❑
	I would be too busy to make time to go to the doctor	❑	❑
	Other considerations [box for free text commentaries]		

Which of the following other health care professionals or therapists have you talked to/consulted regarding the symptoms or discomforts listed below (through appointment, by telephone or by email)? (you may tick more than one box)

Abdominal pain Etc.	❑ None ❑ Another doctor (practicing specialist, out-of-hours physician or hospital physician) ❑ Physiotherapist/chiropractor ❑ Home help/district nurse ❑ Pharmacy staff ❑ Alternative therapist (e.g. homeopath, healer, reflexologist) ❑ Other

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)

Abdominal pain Etc.	❑ None ❑ Spouse/partner ❑ Children ❑ Parents ❑ Colleague /classmate ❑ Friend ❑ Neighbour ❑ Other

We will proceed to another category of questions regarding abdominal pain. Furthermore we ask questions regarding various factors that may have impact on abdominal pain and discomfort. Because we use several different questionnaires you might experience that some of the questions appear similar. There are however nuances in the items that are important for the survey.

In **the last 3 months**, how often did you have acid regurgitation or heartburn (a burning epigastric discomfort or burning pain in your chest)?

- ❑ Never
- ❑ Less than one day a month
- ❑ One day a month
- ❑ Two to three days a month
- ❑ One day a week
- ❑ More than one day a week
- ❑ Everyday

The next three questions are skipped if the answer is "never" in the above-mentioned questions.

When you experience acid regurgitation or heartburn (a burning epigastric discomfort or burning pain in your chest), how severe are your discomforts?

- ❑ Very mild
- ❑ Mild
- ❑ Moderately
- ❑ Severe
- ❑ Very severe

To what extent does your acid regurgitation or heartburn (a burning epigastric discomfort or burning pain in your chest) affect your sleep?

- ❑ My sleep is not affected
- ❑ My sleep is affected to some extent
- ❑ My sleep is affected to a great extent

To what extent does your acid regurgitation or heartburn (a burning epigastric discomfort or burning pain in your chest) affect your everyday activities?

- ❑ Not at all
- ❑ Slightly
- ❑ Moderately
- ❑ Quite a bit
- ❑ Extremely

The following questions concern abdominal pain and bowel habits.

The next questions are related to the Rome 3 criteria for IBS: IF the symptoms are experienced less than two to three days a month, the rest of the questions for IBS are skipped

In **the last 3 months**, how often did you have discomfort or pain anywhere in your abdomen?

- ❑ Never
- ❑ Less than one day a month
- ❑ One day a month
- ❑ Two to three days a month
- ❑ One day a week
- ❑ More than one day a week
- ❑ Every day

For women: Did this discomfort or pain occur only during your menstrual bleeding and not at other times?

- ❑ No
- ❑ Yes
- ❑ Does not apply because I have had the change in life (menopause) or I am a male

Have you had this discomfort or pain **6 months or longer**?

- ❑ No
- ❑ Yes

How often did this discomfort or pain get better or stop after you had a bowel movement?

- ❑ Never or rarely
- ❑ Sometimes
- ❑ Often
- ❑ Most of the time
- ❑ Always

When this discomfort or pain started, did you have more frequent bowel movements?

- ❑ Never or rarely
- ❑ Sometimes
- ❑ Often
- ❑ Most of the time
- ❑ Always

When this discomfort or pain started, did you have less frequent bowel movements?

- ❑ Never or rarely
- ❑ Sometimes
- ❑ Often
- ❑ Most of the time
- ❑ Always

When this discomfort or pain

- ❑ Never or rarely

started, were your stools (bowel movements) looser?	❑ Sometimes ❑ Often ❑ Most of the time ❑ Always
When this discomfort or pain started, how often did you have harder stools?	❑ Never or rarely ❑ Sometimes ❑ Often ❑ Most of the time ❑ Always
In the **last 3 months**, how often did you have hard or lumpy stools?	❑ Never or rarely ❑ About 25% of the time ❑ About 50% of the time ❑ About 75% of the time ❑ Always, 100% of the time
In the **last 3 months**, how often did you have loose, mushy or watery stools?	❑ Never or rarely ❑ About 25% of the time ❑ About 50% of the time ❑ About 75% of the time ❑ Always, 100% of the time

The following questions concern feeling of fullness after meals and pain or burning sensation in the stomach.

The next questions are related to the Rome 3 criteria for functional dyspepsia

In the **last 3 months**, how often did you feel uncomfortably full after a regular- sized meal?

- ❑ Never
- ❑ Less than one day a month
- ❑ One day a month
- ❑ Two to three days a month
- ❑ One day a week
- ❑ More than one day a week
- ❑ Every day

The next questions only appeared if symptoms are experienced for one day a week or more

Have you had this uncomfortable fullness after meals **6 months or longer**?

- ❑ No
- ❑ Yes

In the **last 3 months**, how often were you unable to finish a regular size meal?

- ❑ Never
- ❑ Less than one day a month
- ❑ One day a month
- ❑ Two to three days a month
- ❑ One day a week
- ❑ More than one day a week
- ❑ Every day

Have you had this inability to finish regular size meals **6 months or longer**?

- ❑ No
- ❑ Yes

In the **last 3 months**, how often did you have pain or burning in the middle of your abdomen, above your belly button but not in your chest?

- ❑ Never
- ❑ Less than one day a month
- ❑ One day a month
- ❑ Two to three days a month
- ❑ One day a week
- ❑ More than one day a week
- ❑ Every day

Have you had this pain or burning **6 months or longer**?

- ❑ No
- ❑ Yes

We now proceed to the next category of questions that concern symptoms or discomforts from many parts of the body and how this affects your everyday life.

Have you within **the last 4 weeks** experienced any of the following symptoms or discomforts? (You may tick more than one box)

- ❑ Palpitations/heart pounding?
- ❑ Precordial discomfort?
- ❑ Breathlessness without exertion?
- ❑ Hot or cold sweats?
- ❑ Dry mouth?
- ❑ None of the above

To what extent did you experience that the following symptoms or discomfort interfered with your usual daily activities?

- ❑ Not relevant, as I did not experience any of the above symptoms or discomforts
- ❑ Not at all
- ❑ Slightly
- ❑ Moderately
- ❑ Quite a bit
- ❑ Extremely

Have you within the **last 4 weeks** experienced any of the following symptoms or discomforts? (You may tick more than one box)

- ❑ Pains in arms or legs?
- ❑ Muscular aches or pains?
- ❑ Pains in the joints?
- ❑ Feeling of paresis or localized weakness?
- ❑ Pain moving from one place to another?
- ❑ Unpleasant numbness or tingling sensations?
- ❑ None of the above

To what extent did you experience that the following symptoms or discomfort interfered with your usual daily activities?

- ❑ Not relevant, as I did not experience any of the above symptoms or discomforts
- ❑ Not at all
- ❑ Slightly
- ❑ Moderately
- ❑ Quite a bit
- ❑ Extremely

The following questions concern trembling of the hands and trembling of other parts of the body. Your answers may contribute to a larger understanding of what part trembling plays for the quality of life and for health in general.

Do you have problems with your hands trembling when you have to drink a cup or a glass or pour it?

- ❑ Yes
- ❑ No

Do you often experience that your hands, arms or the voice tremble and quiver without you being able to control it?

- ❑ Yes
- ❑ No

Has a doctor diagnosed you with:

- ❑ Familial tremor or essential tremor
- ❑ Parkinson's disease
- ❑ None of the above

Does anyone in your family have or have had the same type of trembling as you?

- ❑ Yes
- ❑ No
- ❑ I don't know

How many of your relatives suffer from a similar trembling?

- ❑ None
- ❑ 1
- ❑ 2
- ❑ 3
- ❑ More than 3
- ❑ I don't know

Consumption of alcohol can alter certain types of trembling. When you drink alcohol, do you then experience that you trembling:

- ❑ Decreases
- ❑ Worsens
- ❑ Remains unchanged
- ❑ I don't know, because I don't drink alcohol

How old were you when your trembling began?

_____ years

Within **the last week:** If you sit at the table, do you have problems with drinking liquid from a glass?

- ❑ I haven´t had problems drinking from the glass
- ❑ I can drink from the glass with one hand, but if I must avoid spilling, there may not be much liquid in the glass.
- ❑ I cannot drink from the glass with only one hand, but must use both hands.
- ❑ I cannot drink from the glass even if I use both hands, but must use a straw.

Has a doctor diagnosed one of the following causes for your trembling?

- ❑ I have not been diagnosed
- ❑ Stroke
- ❑ Dystonia
- ❑ Medication
- ❑ Other

We have now finished asking about specific symptoms and discomforts. The next questions are of a general nature and concern your own perception of your health, your lifestyle, your management of problems and your worry about disease.

In general, would you say your health is:

- ❑ Excellent
- ❑ Very good
- ❑ Good
- ❑ Fair
- ❑ Poor

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

- ❑ Yes, mostly
- ❑ Yes, sometimes
- ❑ No, almost never
- ❑ I don't know

The following questions are about physical activity, smoking and alcohol habits.

How do you rate your physical fitness?

- ❑ Very good
- ❑ Good
- ❑ Fair
- ❑ Not so good
- ❑ Poor

Do you smoke?

- ❑ Yes, every day
- ❑ Yes, at least once a week
- ❑ Yes, less than once a week
- ❑ No, I have stopped
- ❑ No, I have never smoked

How often do you drink anything containing alcohol?

- ❑ Never
- ❑ Once a month at the most
- ❑ 2-4 times a month
- ❑ 2-3 times a week
- ❑ 4 times a week or more

The following questions only appeared in relation to a positive expression of smoking and/or alcohol intake - by a leap strucure in the electronic survey

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

- ❑ 1-7 units/week
- ❑ 8-14 units/week
- ❑ 15-21 units/week
- ❑ 22-28 units/week
- ❑ More than 29 units/week

For how many years have you smoked?

I have smoked for approximately

_____years (State the number of years in whole numbers)

How much do/did you smoke on average a day?

On average I smoke approximately

_____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)

The following questions are about your height and weight.

How tall are you (without shoes)?

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

_____cm

How much do you weigh (without clothes)?

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

_____kg

The next 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
- ❑ Slightly
- ❑ Moderately
- ❑ Quite a bit
- ❑ Extremely

Has a doctor expressed concern about your current health?

- ❑ Yes
- ❑ No
- ❑ 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 your experiences with your own disease or in your social network.

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

- ❑ Yes
- ❑ No
- ❑ I don't know

Have people in your immediate family (siblings, children, spouse, parents) had a serious illness?

- ❑ Yes
- ❑ No
- ❑ I don't know

Have people in your social network (friends, neighbours etc.) had a serious illness?

The following questions are about your contact with other people

How often are you in contact with friends, acquaintances or family that you do not live with? By contact is meant that you are together, talking with each other on the phone, writing to each other etc.

- ❑ Daily or almost daily
- ❑ 1-2 times a week
- ❑ 1 or more times a month
- ❑ Less than once a month
- ❑ Never
- ❑ I don't know

If you become ill and need help with practical things, can you count on help from others? (By others is meant people you do not live with)

- ❑ Yes, definitely
- ❑ Yes, maybe
- ❑ No

Does it ever happen that you are alone, even if you want to be in the company of others?

- ❑ Yes, often
- ❑ Yes, once in a while
- ❑ Yes, but rarely
- ❑ No, never or almost never

Do you have someone to talk to if you have problems or need support?

- ❑ Yes, often
- ❑ Yes, mostly
- ❑ Yes, sometimes
- ❑ No, never or almost never

The questions on this page deal with how you usually act in relation to problems and disease. For each item, place a tick in the box that best fits what you think about yourself just now. The questions are written in 'I' form, and you place your tick depending on how much you agree/disagree.

	Agree completely	Tend to agree	Yes and no	Tend to disagree	Disagree completely
I say so if I am angry or sad.	❑	❑	❑	❑	❑
I like to talk with few chosen people when things get too much for me.	❑	❑	❑	❑	❑
I make an active effort to find a solution to my problems.	❑	❑	❑	❑	❑
Physical exercise is important to me.	❑	❑	❑	❑	❑
I think something positive could come out of my complaints/problems.	❑	❑	❑	❑	❑
I firmly believe that my problems will decrease (and my situation improves).	❑	❑	❑	❑	❑
I try to forget my problems.	❑	❑	❑	❑	❑
I put my problems behind me by concentrating on something else.	❑	❑	❑	❑	❑
I bury myself in work to keep my problems at a distance.	❑	❑	❑	❑	❑
I often find it difficult to do something new.	❑	❑	❑	❑	❑
I am well on the way towards feeling I have given up.	❑	❑	❑	❑	❑
I withdraw from other people when things get difficult.	❑	❑	❑	❑	❑

The last group of questions concern your attitude to risk and your satisfaction with your life in general

Imagine that you unexpectedly inherited DKK 10,000 (approximately USD 2,000) from a distant relative. Subsequently you have the possibility of participating in a lottery with an equal chance of doubling the money or losing the money. That means that there is a 50% chance of you winning DKK 20,000 and a 50% chance of losing the DKK 10,000.

What do you choose?

- ❑ I choose to participate in the lottery
- ❑ I choose not to participate in the lottery
- ❑ I don't know

How do you normally react in relation to health and disease. Please tick one box for each statements to show how much you agree/disagree.

	Completely agree	Tend to agree	Yes and no	Tend to disagree	Completely disagree
I focus a lot on having a healthy behaviour and prefer to avoid risks that can affect my health.	❑	❑	❑	❑	❑
If I experience symptoms, I generally count on it passing.	❑	❑	❑	❑	❑
I do not like to take chances regarding my health and prefer to see my GP once too often than once too little.	❑	❑	❑	❑	❑

In the following we will inform you how old people at your age on average can expect to become.
If you do not want the information, please tick the box.

How old are you?

_____Year

- ❑ I don't want the information

Men, your age can expect to live, on average, until they are

_____Year

Women, your age can expect to live, on average, until they are

_____Year

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

- ❑ Longer than the average person
- ❑ Like the average person
- ❑ Shorter than the average person
- ❑ I don't know

On a scale from 0 till 10, where 0 means that you are very dissatisfied and 10 means that you are completely satisfied, how satisfied are you with your life in general.

	0	1	2	3	4	5	6	7	8	9	10	
Dissatisfied	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	Completely satisfied

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

You have now finished the questionnaire.
Thank you very much for your reply.
If any of the questions have made you concerned about your health, we recommend that you contact your general practitioner.
Press exit to close the window