

## Supplement A: Interview Schedule

### Start

Entry, acquaintance, thanking for cooperation, provide opportunity to ask questions, informed consent, explain process, start interview ...

### General introductory

How do you experience living with the disease COPD?

### Person-related factors

#### *Knowledge of disease and medication*

To begin with, I would like to ask some questions about the disease COPD

- Can you explain what the disease COPD implies?
  - > What are the symptoms that occur in COPD?
    - > What symptoms do you experience yourself?
  - > To what extent does COPD limit you in your daily life?
  - > What do you think are the reasons that cause the disease COPD?
    - *Is smoking cited as a cause? Then:*
      - > Do you smoke?
      - > Did you smoke?
      - > Do people smoke in your vicinity?
      - *If smoke is not mentioned as a cause, ask later in the interview.*
  - > Do you think the disease can be cured?
  - > How serious is your illness?

#### Stimulation of knowledge and perception

Now that we talked about COPD, I would like to ask some questions about whether and how the doctor, pulmonary nurse or other health care provider has given information about the disease COPD.

- Who do you see as your main caregiver?
  - > Explain main caregiver if needed
- Did you receive information from your care provider about COPD, to gain knowledge about the disease?
  - > If so, how?
- Have you been explained what the treatment can do for you? How treatment can help?
  - > If so, how? Who gave you this information?
- Did you receive advice regarding a healthy lifestyle and was it fit for you?
  - > If yes, what advice have you received? And how did you fit this in?

#### *Depression*

Besides the above questions, now I would like to ask some general questions about how you feel lately.

- Did you suffer from gloomy or depressive feelings or even hopelessness, this last month?
- Did you experience loss of interest or pleasure in doing certain activities, this last month?
- Did you suffer from tiredness, last month?
  - > If yes:
    - Is that because of complaints that have to do with COPD?
    - Is it because you are worrying about, for example, the course of the disease?
    - Is it because you are afraid you will be short of breath at night or have fear of other symptoms that can occur with COPD?
- Are you more irritable lately, touchy or angry compared to before?

### *Physical performance*

- Can you remember things well or do you have the feeling sometimes that you forget things by mistake?

-> If yes:

You just mentioned that you accidentally forget things lately; does that affect the intake of medication?

### **Treatment Factors**

#### *Confidence in treatment and outcome*

Now that we have talked about COPD in general, whether and how the doctor, pulmonary nurse or other health care provider has given you information about COPD and how you feel lately, I would like to talk about the treatment and about the course of the disease.

- How do you experience the treatments you undergo?

-> Is it easy or difficult to live according to the prescribed treatment?

- What is easy / difficult?

- How many different types of treatments do you undergo?

-> Which of these treatments are easy to maintain? Why?

-> What treatments are more complicated? Why?

-> Is the combination of treatments easy to maintain?

- (Possibly: What is difficult for you?)

- Do you think that the treatment can prevent the sudden outbreaks?

- Do you think that the symptoms that you are experiencing may diminish?

-> Can this be due to the treatment that you follow?

- *Other factors?*

- Are you worried about the course of the disease and associated symptoms?

-> Does the treatment that you get (partly) take away your concerns?

#### *Acceptance of disease and treatment*

I would also like to know what your feelings are regarding COPD and its treatment.

- What kind of feeling do you experience suffering from COPD?

- Can you put up with the fact that you have COPD?

- Do you think it is therefore better to try to 'embrace' the disease by learning to cope with it?

- Do you agree with the prescribed treatment?

-> Do you have a say in the treatment you receive?

#### *Relationship between the patient and health care provider*

Regarding your treatment I would like to ask you some questions about the relationship between you and your health care provider

- How is the relationship between you and your health care provider?

-> Can you and dare you to discuss everything with your health care provider?

-> Do you feel that the caregiver knows you well and understands you?

-> Do you accept what the caregiver tells you and recommend you?

-> Can you work together with your health care provider; do you feel that your opinion also counts/is being considered?

## Medical factors

We talked earlier about the treatment of COPD in general. Now I would like to talk about one specific part of the treatment. The following questions are about the medication you use.

- Which medication do you take for the disease COPD?

*If the respondent knows this, then:*

-> Can you tell what effect does the medication have and what are they meant for?

*If the respondent does not know this:*

*Use*

- Could you show what medications you are taking?

-> How do you take this medication?

- *Do you have an idea whether the medication is used in a correct way?*

-> What do you think about your medication?

-Why?

-Are there any positive or negative effects?

-> How important is it to take the medication according to you? Why?

-> If yes / no:

-Why?

-> Have you received explanations about the medication that the caregiver has prescribed?

-> Do you know whether there are other medications for COPD? Or did you use other medicines in the past?

### *Frequency of use*

-> At what times do you take the medication?

- Do you experience the medication as something automatic, hence as a routine, or do you need to think about it carefully every time again to take the (different) medication in time and in the right way?

### *Difficulties inhaled medication*

We have just discussed all kinds of medication for COPD. Now I would like to talk for a moment about the inhaled medication. The following questions are about that.

- How do you experience the use of the inhaled medication?

-> Why?

- How do you know if you have used the correct dosage?

- How do you see whether the inhaler is empty?

- How could the use of inhaled medication be made easier?

### *Medications other disorders*

- Do you also use other medication for other conditions (diseases)?

-> If yes, how many other medications do you use daily?

-> How many times a day do you use this medication?

-> Can you use all these medications at the same fixed time? Or are there different times that you should use this medication?

We have now talked about the use of medications. With the medication there is always an insert and I would like to ask the following question about the insert.

- Do you read the package insert of your medications?
  - > If yes, what do you think of the instructions?
    - Are the letters big enough, or would you prefer that the letters would be something bigger?
    - Is the text understandable, or would it be better if the text could be simpler?
  - > If not, why not?

### ***Self-management***

So far we talked about the treatment and medication of COPD. Furthermore I would like to ask what you can do yourself to manage your illness in the right direction?

- How do you do that?
- Are you being guided in this by the caregiver?
- > If not:
  - Why not?
  - Do the caregivers try to stimulate you (to be able) to manage eventually?

### **Demographic data**

Besides the questions we have just asked you, we would also like to collect some basic information to get a better picture of the people who cooperated on this study.

1. You are man / woman
2. What's your birth year?
3. What is your highest level of education?
4. Are you still working? How many hours a week?
5. With how many people do you live together?
6. Do you get help collecting your medication?
7. Do you get help in taking your medication?

*Just ask these questions if the question has not been discussed in the section "person-related factors".*

2. In addition to your age, I would also like to ask whether you smoke?
  - > If not, have you smoked?
3. Do people smoke in your vicinity?



## Supplement B: Codingscheme

Coding scheme	1 <sup>st</sup> level	2 <sup>nd</sup> level
1. Identity	1.1 What encompasses COPD	1.1.1 Irreversible damage to the lungs (irreversible obstruction) 1.1.2 Emfysema 1.1.3 No idea 1.1.4 Losing participation in daily life
2. Timeline	1.2 Complaints/disease symptoms	1.2.1 Dyspnea
	2.1 Curability	2.1.1 Not curable 2.1.2 Maybe curable 2.1.3 I do not know if COPD is curable
	2.2 Experienced disease over time	2.2.1 Worse 2.2.2 Stable (no improvement) 2.2.3 Improvement/relief of complaints 2.2.4 Ups and downs
3. Cause	2.3 Expectations about the clinical course /future development of COPD	2.3.1 Positive: No worries about the clinical course 2.3.2 Negative: Worries about the clinical course 2.3.3 No idea about future development/clinical course 2.3.4 Hope for improvement
	3.1 Causes of COPD	3.1.1 Smoking 3.1.2 Genetic/Hereditiy 3.1.3 Unknowm 3.1.4 External factors (pollution, asbestos) 3.1.5 Unhealthy lifestyle

4. Consequences (personal impact)	4.1 Emotional complaints	4.1.1 Loss of joy /interest in Life 4.1.2 Gloomy, depressive feelings and hopelessness 4.1.3 Irritable, angry 4.1.4 Anxiety
	4.2 Emotional limitations	4.2.1 Have to quit smoking 4.2.2 Sadness about losing participation in daily life
	4.3 Physical complaints	4.3.1 Dyspnea, shortness of breath 4.3.2 Fatigue 4.3.3 Cough
	4.4 Physical limitations	4.4.1 Problems with every day activities
5. Control/Cure	5.1 Coping	5.1.1 Psychological adjustment to the disease (including acceptance) 5.1.2 Behavioral adjustment to the disease (use of (medical) aids, practical adjustments) 5.1.3 Seek social support
	5.2 Treatment	5.2.1 Acceptance of treatment 5.2.2 Problems with acceptance of treatment (non acceptance) 5.2.3 Influence memory on adherence
6. Treatment/Medication	6.1 Knowledge (on effect of) inhalation treatment	6.1.1 Knowledge on effect of inhalation treatment 6.1.2 No/wrong knowledge on effect of inhalation treatment
	6.2 Experience inhalation treatment	6.2.1 Positive effect (less complaints, less worries) 6.2.2 Side effects (negative effect) 6.2.3 No effect / no improvement 6.2.4 Dependency (fear of being out of medication)
	6.3 Knowledge inhalation device	6.3.1 Knowledge on correct use of device 6.3.2 No/wrong knowledge on correct use of device
	6.4 Experience inhalation device	6.4.1 Good experience / easy to use 6.4.2 Bad experience/ problems with use
	6.5 Routinely use of medication	6.5.1 Yes, routine (incl. knowledge correct dosing scheme) 6.5.2 No routine

**Supplementary table 1: Quotes for the topics emerged from the in-depth interviews.**

Topic	Quote (under- or overuse; patient number) (A=answer, Q=question)
Illness Identity	<p>A: Yes .. copd .. airway constriction .. small airways or something like that. In general. And regarding inflammation .. that .. according to me then. <b>under593</b>.</p> <p>A: It is a pulmonary emphysema. As a result of which the lung vesicles have broken. So it absorbs less oxygen into the blood. <b>under722</b></p> <p>A: Yes .. I'm always very short of breath. <b>over355</b></p> <p>A: Tightness of the chest. That is a very big complaint <b>under722</b></p>
Illness Timeline	<p>And we will not get better, we all know that. <b>under313</b></p> <p>It will only be getting worse, not better. <b>over767</b></p> <p>No, you can uuh... by using good medications .. you can keep it like this for a while, but you can't heal it. <b>over358</b></p> <p>Q: And do you think it could get better than it is now?</p> <p>A: Yes, perhaps there will be better medicine at some point. <b>over345</b></p> <p>Q: And do you think your COPD complaints can become less?</p> <p>A: Do hope so. <b>over355</b></p> <p>A: At the moment, it is quite stable. <b>under593</b>.</p> <p>A: Well .. I feel very well as it is. It stays a bit stable <b>over664</b></p> <p>A: Naah, it has become much less since I no longer smoke <b>under207</b></p> <p>A: Because my COPD category has greatly improved because I lost a lot of weight. <b>under501</b></p> <p>A: Yes. Not for the past years, but it happened that I've been so out of breath a couple of times at night.. that I think well .. what's the world coming to? <b>under593</b></p> <p>A: Nah, I'm not worried about it. If I worry, it won't help anyway. <b>over504</b></p> <p>A: Yes. I worry about that sometimes. <b>over664</b></p>
Illness	<b>Dyspnea</b>
Consequences	<p>During showering it is the worst. Then I'm completely out of breath <b>under207</b></p> <p>When I walk a few meters I'm already out of breath . <b>over355</b></p> <p>Well, it limits me in everything, I'm always wheezy. <b>over504</b></p> <p>Always short of breath. <b>over664</b></p> <p><b>Fatigue</b></p> <p>I'm exhausted. That's actually the case with everything I do. <b>under207</b></p>



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Yes, it is also tiring.. yes, of course. **over358**

**Cough**

A: Well, sometimes when I'm very short of breath and I have to cough a lot, then those lungs start to hurt so badly. **over345**

A: Yes, coughing. **over504**

**Problems with every day activities**

If you're somewhere ... ooh, you need to go one floor up .. then you will not just take the stairs. That doesn't work anymore. That is taboo. **under362**

For example, if I walk to the toilet, I can't even do that, that's hardly possible anymore ... **over355**

A: And I like gardening a lot. But if I'm busy for 5 minutes or 10 minutes then I'll sit down now and then. **over625**

If I for once want to do the dishes, I may have to lie down for an hour first. A couple of hours or so, sleep first. **over767**

And then my grandchildren, I can't do anything with them really. And then they ask: "Grandma, why can't you do anything?" ... That is SO hard ... **over355**

It restricts so much in your daily life, in your doings, in your existence. That is difficult sometimes. **over625**

Maybe you're somewhat eeuh .. Yes, somewhat more irritable, yes. That might be possible. **under207**

Q: And have you been a bit more irritated, annoyed or angry compared to before, lately?

A: Actually yes. Because I had a clash with my son recently. **over625**

You're so limited. At first, if you got it, in the beginning it was quite heavy. That was frightening. That's really frightening. Yes. **under362**

And because of that I also carry some of that anxiety with me ... Of being alone and being short of breath. **over625**

Q: The following questions are about how you have felt lately. Have you occasionally suffered from gloomy, depressive feelings or hopelessness, lately?

A: Yes .. yes .. yes .. for sure. **over345**

No .. Nooo .. That is not the case at all. No **over504**

**Smoking:**

Well, they told me it comes from smoking. Well, I guess it is.. **under313**

And if you also smoke, and you already have bad lungs.. I did not smoke much at all, but that's definitely the reason, the smoking.

That's bad. **over358**

**Hereditary:**

It will also be something hereditary. My father had it too. **under593**

It's hereditary. It's in the genes I think. **over710**

**Environment:**

I grew up in the Ruhr Area (Germany). Maybe also because of that air. **under362**

And particles in the air. At my work, my father had his own company, who was a car painter yes ... Without something in front of the mouth and when they blew their noses .. you had to see the shit that was in there. And you just inhale that. **over358**

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Illness Cause

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Illness Control/Cure	<p><b>Acceptance:</b> But I just accept it. I have no trouble with that. <b>under207</b> And it took a long time before I thought what a pity that I can't do things anymore. But I think now if I do something and get tired, then I'm going to sit down. <b>over625</b></p> <p><b>Non acceptance:</b> A: I just can't accept it. Just not. No, I could never sit still before. I still don't, I still have a lot of problems with that. <b>under460</b> Q: Can you cope with the fact that you have COPD or is it difficult? A: Well, that's hard, yes. I would prefer not to have it .. And that I can just do everything. <b>over664</b></p> <p><b>Practical coping:</b> Cycling is OK, but then, I have an electric bike. <b>under313</b> Every so often I will sit down for a while, where there is a possibility to sit. <b>under460</b> We love to ride a bike and an electric bike is nice. <b>over345</b> I cannot make an appointment for tomorrow, because tomorrow .. I have to wait for the morning first and then I can say, well.. I will do this or that. <b>over358</b> Because you are looking for shops where the shopping cart is very close to the parking lot. So if you have such a cart, it will be fine. <b>over750</b></p> <p><b>Support:</b> Q: And do you get help with collecting the medication? A: It will be delivered and if not my daughter-in-law will pick them up. <b>over504</b> Nobody smokes in this house and where I go to, no one else does too. <b>under362</b> I have a wonderful wife. She supports me in everything. <b>under460</b></p>
Necessity Pharmacological Treatment	<p>I am glad I have it, because if I do not use it, I'm a lot more breathless. And I have no problems with it. <b>under501</b> A: Yes, that's OK, I don't think it is that difficult either. If I don't do it, I'm getting breathless, right .. No, that's absolutely fine you know. <b>over345</b></p> <p><b>Non acceptance of necessity of treatment:</b> Q: What do you think about your medication? A: I think it's terrible.. <b>over664</b> A: Yes, it takes a lot of free time and yes, I'm getting tired of it. I am really fed up with it (...) A: Yes, it is very difficult. You have to take them, but I would rather throw them out of the window. Otherwise I would bring harm upon myself. <b>over767</b></p> <p><b>Reported underuse:</b> Actually four times, but because I take a double dose in the morning.. Of course I should not have too much of it. That's why I often do it three times. <b>under362</b></p>

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Treatment concerns	In the evening, I sometimes forget the inhaler because it is just going well, and I can permit myself to (..)
	A: And if I notice it's going less good, I'll use it more often again. <b>under501</b>
	A: Yes. meaning.. The pharmacy says to me: You need to use your inhalation more often, because you take too little. Well, that is just what I will not do then. <b>under690</b>
	Look, you should not take too much medicine. <b>under593</b>
	<b>Reported overuse:</b>
	I have puffers with me. Just in case. At times I take a puff more than is prescribed <b>under719</b>
	<b>Memory:</b>
	And does that also affect your medication intake for example? That you forget that by mistake?
	A: No, no. <b>under207</b>
	Q: Okay. Can you remember things well?
A: No. Not at all. I really don't. It's just a sieve. That is difficult yes.	
Q: Okay. Does this also affect the medication intake?	
A: Yes, of course. <b>under362</b>	
When I was still working, I forgot it sometimes. <b>under460</b>	
A: Nooo, I'll never forget that. I can't do without that. <b>over345</b>	
Q: Okay. And with the medication? Do you ever accidentally forget to use your medication?	
A: It happens every once in a while. That I think: "Did I take it, or not? <b>over625</b>	
<b>Side effects:</b>	
Getting hoarse. <b>under593</b>	
Like that Spiriva ... the disadvantage is that it irritates the throat immediately. <b>under719</b>	
Once I had a medicine that made me cough. <b>over358</b>	
<b>Medication dependence:</b>	
So I think I could not live without those medications anymore. <b>under501</b>	
Very important. Yes, very important. I couldn't live without those medications, I think. <b>over345</b>	
That medicine? Because you need it. If I go out and I notice that I do not have that thing, I panic. <b>over358</b>	
Yes, no but, especially those. I always have one in the car for that reason. But if I go out, I'll put it in my pocket, because you never know what will happen with the effort. <b>over668</b>	
It gives you some sense of safety when you have it with you. <b>over750</b>	
Inhaled medication use	<b>Correct knowledge:</b>
	I use medication to widen the airways and anti-inflammatory. <b>under460</b>
	And this is more for anti inflammatory, that's Seretide. <b>over345</b>
A: The medications are to keep it stable. <b>over625</b>	

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***Wrong knowledge:***

It was Ventolin and that was an inflammatory inhibitor **over625**

Q: And is one of that medication also for when you get out of breath that you can use it at that moment?

A: Yes, the Seretide. **over664**

A: The Spiriva every 3 to 4 hours really. **over664**

If I have a cold, I take an extra Seretide. Then I can cough better. **over710**

Q: But do you think that those exacerbations can be prevented by the treatment?

A: No, I do not think so. **under460**

Do you think the treatments can reduce the sudden exacerbations? That it will occur less often ..

A: No, I would not know how that would be possible. **under501**

***Positive experience:***

A: Yes, that is the relief of the tightness of the chest. It certainly does. **under460**

It gives a little relief; I get somewhat less short of breath. So I have some help from that. **under480**

Well, and then I take those medications, I have such an extension and you blow it in and you get air again. And that's really nice!

**over345**

Yes, you get a somewhat less short of breath and it gets lighter. **over504**

***Daily routine:***

A: Yes, that is automatic, but yes, I've been using those things for so many years now. Really, that just is automatic. **under719**

A: Yes, it's definitely a routine .. I do not have to think about it. **under313**

A: Yes, all goes automatic. **over664**

A: In the morning, I use them and that's always a fixed pattern. **over710**

***No routine:***

Q: At which times do you take the medication?

A: Well, that can be at any time of the day. **over504**

A: No. No fixed times. In the morning before I get out of bed I take this and that keeps on working around the clock and then at night it has stopped working sometimes and sometimes not. And then I will add this, but for the rest .. **over750**

***Discarding too early:***

Q: Do you see whether the inhaler is empty?

A: I can feel it .. when I think: he's going a little bit difficult. Then I spray once and then oh god, there are one or two left. I'll do that more often. Then it's empty. **over358**

A: Well, I see that with the Oxis, there's a little thing that indicates that. It shows a red signal: if it's at the top, then I can still take it a few more times, but if it's in the middle, I'll throw it away. Sometimes I think I throw it away too soon, but then I'm afraid I'm not getting enough. **over625**

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Inhalation devices

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If only very little is coming out, I just throw it away. And then I put a new one in. **over345**

***Discarding too late:***

A: Well, if nothing is coming out anymore then it's time to get a new one. **under719**

A: Yes, then I shake it and think well .. there could be nothing more in there.. I've also tried to weigh once, but that did not work .. with such a household weighing scale ... and that's not working, but I'll take a look and if something is still coming out then I know that it's still good. **under719**

***Knowledge device (when empty):***

A: If that piece turns red, it's empty **under207**

Q: And how do you see whether the inhaler is empty?

A: That is on the backside. There is a counter. **under501**

In the end, I think, "well, I don't think there's anything left...". I look at the number of times you have to use them, well that's just per month. Then I just write the date there ... Is the date due then I will throw them away and I take a new one. **under313**

A: Look, here it says: 5 more puffs. Do you see that? That is the Seretide..

Q: Yes ..

A: Well, then I can throw it away when it's empty and get a new one. **over345**

A: Well.. the Spiriva .. It will turn completely red .. Then you cannot turn anymore. **over345**

A: The Flixotide .. There I always write down when I start. **over625**

***Positive experience:***

Just easy to use yes. **under207**

No. No, no, but yes, because of years of medication use, especially in the field of COPD, it's just routine and it's not hard and there are no difficulties. **under460**

A: No, it's all very easy to use. **over345**

***Negative experience:***

I have that, but I only used that because the other one was one that I had to inhale.. I did not have the strength for that. **under313**

Well, I don't like such a spacer. **under719**

It just seemed like that thing was empty and then I will have used it a few times for nothing. That is very annoying. Then I spray it under the table, you know. There was nothing left anymore. A week ago or so I had tried that and then one still came out. That is very disadvantageous. **over767**

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