

Table S2 Questions asked during pulmonary fibrosis patient information meetings in the Netherlands and Germany

1	<i>[Everyone]</i> Are you a patient or a partner? <ol style="list-style-type: none">1. I am patient2. I am a partner	20	<i>[Patients]</i> I aspire active involvement in the development of clinical trials on pulmonary fibrosis <ol style="list-style-type: none">1. Yes2. No3. Maybe
2	<i>[Everyone]</i> Have you been to the patient information meeting in this center last year? <ol style="list-style-type: none">1. Yes2. No	21	<i>[Patients]</i> I would like to participate in medical trials because ... <ol style="list-style-type: none">1. I might get better of it2. It could help other people3. It gives my hope4. I do not want to participate in medical trials5. No opinion
3	<i>[Patients]</i> I mainly came for ... <ol style="list-style-type: none">1. More information2. To meet other people with pulmonary fibrosis3. The information market4. My nearest and dearest and/or partner5. Contact with the doctors and nurses outside the consultation room	22	<i>[Patients]</i> I find filling in questionnaires for research ... <ol style="list-style-type: none">1. Annoying2. Neutral3. Fine4. Nice5. I do not want to fill in questionnaires
4	<i>[Partners]</i> I mainly came for ... <ol style="list-style-type: none">1. More information2. To meet other people with pulmonary fibrosis3. The information market4. My nearest and dearest and/or partner5. Contact with the doctors and nurses outside the consultation room	23	<i>[Patients]</i> I would like to see and keep up with my own data online ... <ol style="list-style-type: none">1. Yes2. No3. Maybe
5	<i>[Patients]</i> How often do you feel misunderstood because people do not know what pulmonary fibrosis is? <ol style="list-style-type: none">1. Never2. Now and then3. Regularly4. Often5. Most of the time	24	<i>[Patients]</i> I would find an ILD specialist nurse, who would take care of me during the whole course of my disease, very helpful in addition to the pulmonologist's treatment ... <ol style="list-style-type: none">1. Yes2. No3. Unknown
6	<i>[Partners]</i> How often do you feel misunderstood because people do not know what pulmonary fibrosis is? <ol style="list-style-type: none">1. Never2. Now and then3. Regularly4. Often5. Most of the time	25	<i>[Partners]</i> I find a visit to an ILD specialist nurse, who cares for me my through the who disease course, a good addition to the general visit by the pulmonologist ... <ol style="list-style-type: none">1. Yes2. No3. Unknown
7	<i>[Patients]</i> How often in the past two weeks did you have problems to relax? <ol style="list-style-type: none">1. Never2. Some days3. More than halve of the days4. Almost every day	26	<i>[Patients]</i> During the past period, I found seeing an ILD specialist nurse in addition to the out clinic visit to the pulmonologist beneficial ... <ol style="list-style-type: none">1. Agree2. Disagree3. Neutral

8	<i>[Partners]</i> How often in the past two weeks did you have problems to relax? 1. Never 2. Some days 3. More than half of the days 4. Almost every day	27	<i>[Everyone]</i> I see the ILD specialist nurse mainly as someone who ... 1. Is accessible for questions on my disease 2. Helps me with my oxygen applies 3. Gives support 4. Does all the above mentioned 5. No idea
9	<i>[Everyone]</i> What is pulmonary fibrosis? 1. Inflammation of the lungs 2. Celluloses 3. Connective tissue 4. Thrombosis 5. It is unclear to me	28	<i>[Everyone]</i> I wish to see the ILD specialist nurse ... 1. Always when I visit the pulmonologist 2. Only when asked for 3. I only want to see the pulmonologist
10	<i>[Everyone]</i> What causes pulmonary fibrosis? 1. Exposure to harmful dusts 2. Underlying rheumatic diseases 3. Certain medication 4. Genetic predisposition 5. Unknown cause 6. All above mentioned causes 7. I have no idea	29	<i>[Patients]</i> Next to support for my physical problems, I would like to have support for my psychological problems 1. Yes 2. Yes, I think that is lacking in current care 3. No 4. I have no psychological problems, I do not need it
11	<i>[Patients]</i> What type of pulmonary fibrosis do you have? 1. Idiopathic Pulmonary Fibrosis (IPF) 2. Connective Tissue Disease associated Pulmonary Fibrosis (CTD-PF) 3. Exposure related pulmonary fibrosis 4. Lymphangioleiomyomatosis (LAM) 5. Sarcoidosis 6. Unknown	30	<i>[Partners]</i> Next to support for my physical problems, I would like to have support for my psychological problems 1. Yes 2. Yes, I think that is lacking in current care 3. No 4. I have no psychological problems, I do not need it
12	<i>[Patients]</i> Most occurring symptom ... 1. Breathlessness 2. Cough 3. Dullness 4. Physical limitations 5. Worries 6. Other symptoms	31	<i>[Patients]</i> After this meeting I feel ... 1. More secure 2. Less secure 3. Nothing changed 4. No opinion
13	<i>[Patients]</i> I desire treatment and follow-up by ... 1. A pulmonologist nearby 2. In an expertise center 3. A pulmonologist nearby and in an expertise center combined 4. A general practitioner and in an expertise center combined 5. A general practitioner and pulmonologist combined 6. No preference	32	<i>[Partners]</i> After this meeting I feel ... 1. More secure 2. Less secure 3. Nothing changed 4. No opinion
14	<i>[Patients]</i> In the care for my long fibrosis I mainly need ... 1. Access to an expertise center 2. Information on my disease 3. Contact with peers 4. Practical support (e.g. medical devices) 5. Emotional (psychological) support	33	<i>[Patients]</i> This meeting was ... 1. Very useful 2. Partly useful 3. Not useful 4. No opinion

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| <p>15 <i>[Partners]</i> In the care for my long fibrosis I mainly need ...</p> <ol style="list-style-type: none"> 1. Access to an expertise center 2. Information on my disease 3. Contact with peers 4. Practical support (e.g. medical devices) 5. Emotional (psychological) support | <p>34 <i>[Partners]</i> This meeting was ...</p> <ol style="list-style-type: none"> 1. Very useful 2. Partly useful 3. Not useful 4. No opinion |
| <p>16 <i>[Patients]</i> I would like to know everything about my disease and its prospects ...</p> <ol style="list-style-type: none"> 1. Yes 2. No 3. No opinion | <p>35 <i>[Patients]</i> I find current care ...</p> <ol style="list-style-type: none"> 1. Excellent 2. Good 3. Sufficient 4. moderate 5. Poor |
| <p>17 <i>[Partners]</i> I would like to know everything about the disease of my partner and its prospects ...</p> <ol style="list-style-type: none"> 1. Yes 2. No 3. No opinion | <p>36 <i>[Everyone]</i> I find seeing the response of the other participants ...</p> <ol style="list-style-type: none"> 1. Pleasant 2. Neutral 3. Bothersome 4. No opinion |
| <p>18 <i>[Patients]</i> I would prefer talking about matters concerning end-of-life in an early stage of my disease</p> <ol style="list-style-type: none"> 1. Yes 2. No 3. No opinion | <p>37 <i>[Everyone]</i> Do you find it informative to see the answers of the other participants on the screen?</p> <ol style="list-style-type: none"> 1. Yes 2. No 3. No opinion |
| <p>19 <i>[Partners]</i> I would like to have more care for partners of patients with pulmonary fibrosis</p> <ol style="list-style-type: none"> 1. Yes 2. No 3. Maybe | |

ILD, Interstitial Lung Disease