

THE ASTHMA AND COPD PATIENTS' DIGITAL JOURNEY IN EUROPE



DIGIT QUESTIONNAIRE

DIG-IT The digital asthma and COPD patient in Europe

Final Master – Questionnaire

Country:

- Belgium 1
- Czech Republic 2
- Ireland 3
- Norway 4
- Spain 5

Three-digit screener number to be entered

__' __' __

Recruitment source:

- Physician 1
 - Other HCP 2
 - Social media group 3
 - Referral of patient 4
 - Support group 5
 - Data base 6
 - Other 7
- (Please specify: _____)
- _____

A. SCREENING DATA:

Hello, my name is from..., an independent market research company. We are currently conducting a study related to COPD and Asthma for EFA, the European Federation of Allergy and Airways Diseases Patients' Associations. The study assesses a number of aspects that influence the disease management of people living with COPD/Asthma. Please note that your individual responses and personal information will be kept strictly confidential.

First, I would like to ask you a few questions to see if you meet the study criteria. If yes, the actual telephone study will last 20-25 minutes, and you will receive an incentive of ... Euro.

1. Gender (do not ask – Single answer)

- Male 1
- Female 2
- Diverse 3

2. "How old are you?" (Please record exact age and then circle the appropriate age category)

Years

- Below 18 years 1 Terminate
- 18-29 years 2
- 30-39 years 3
- 40-49 years 4
- 50-59 years 5
- 60-69 years 6

70-79 years 7
80 years and older 8 Terminate

3. "Please tell me if you suffer and are diagnosed with one the following diseases? (multiple answer)

Asthma 1
COPD 2
Other (please specify) 3

3a: INTERVIEWER Please select for which condition the participant is being interviewed: (single answer, **if both COPD and asthma are mentioned choose one option**)

Asthma (only possible if mentioned at Q3) 1 Go to Q 4
COPD (only possible if mentioned at Q3) 2 Go to Q 5

→ VERSION ASTHMA OR COPD

→ If only Asthma OR only COPD is selected at Q3, only allow the selected option at 3a

IF ASTHMA AT Q3a

4. "What level of severity has been most recently diagnosed?*"1 – (READ OUT - single answer)

Mild 1
Moderate 2
Severe 3
Don't know 4 TERMINATE

*1) If needed: disease levels for Asthma are: **FEV = Forced Expiratory Volume**

- **mild**= intermittent or persistently mild (symptoms less than daily / night-time awakenings: less than 5 nights per month / none or minor interference with normal activity / FEV >80 of predicted FEV
- **moderate** = persistently moderate (symptoms daily / night-time awakenings: not nightly, but more than once a week / some interference with normal activity / FEV >60 of predicted FEV
- **severe**= persistently severe (symptoms throughout the day / night-time awakenings: often every night / extreme interference with normal activity / FEV < 60 of predicted FEV

IF COPD AT Q3a

5. "What level of severity has been most recently diagnosed?*"2 - (READ OUT - single answer)

Mild 1
Moderate 2
Severe 3
Don't know 4 TERMINATE

*2) If needed: disease levels for COPD are: **PFT=Peak Expiratory Flow**

- **mild=** shortness of breath when running across level surfaces or when walking on a slight incline / coughing several days a week, but most days are good / not more than one exacerbation per year and without hospitalization / results of PFT >80 of predicted PFT
- **moderate=** shortness of breath, cough and sputum on most days and daily routine needs to be adjusted / frequent stops to catch breath / not more than one exacerbation per year and without hospitalization / results of PFT >50 and <80 of predicted PFT
- **severe=** shortness of breath, cough and sputum on most days and daily routine needs to be adjusted / flares and exacerbations worse than at moderate stage / exercise becomes more difficult and fatigue increased / More than one exacerbation per year with hospitalization/ results of PFT >30 and <50 of predicted PFT

6. "Please indicate which of the following symptoms do you experience? (READ OUT – multiple answers)

Wheezing	1
Breathlessness	2
Chronic cough	3
Exacerbations.....	4
Other (please specify_____)	5
None.....	6

7. "In what kind of area do you live? (READ OUT – single answer)

Rural	1
Suburban.....	2
Urban	3

8. "What is the highest educational qualification you achieved?" (single answer)

No qualification.....	1
Primary education / Lower secondary.....	2
Secondary education / high school diploma.....	3
A-levels/ IB	4
University (diploma, BA, MA)/ Postgraduate	5
Prefer not to say	6

9. "What is the monthly household net income (after tax)?" (READ OUT - single answer)

→ Categories will differ by country

Below 1.000,- Euro.....	1
1.000 to 1.999 Euro.....	2
2.000 to 2.999 Euro.....	3
3.000 Euro and more	4
Prefer not to say	5

B. QUESTIONNAIRE

Section 1: ACCESS TO digital HEALTHCARE

10. Do you have internet access? (single answer)

1. Yes → Go to Q11
2. No → Go to Q12

11. How good would you rate your internet connection? Is it... (READ OUT – single answer)

1. Very poor
2. Rather poor
3. Rather good
4. Very good

12. Which of the following devices do you own, or can you use at any time? (READ OUT– multiple answers)

1. Computer and/or laptop
2. Smartphone
3. Tablet computer
4. Wearables (like Smartwatch, Fitness tracker, etc.)
5. Mobile phone (no Smartphone)
6. Landline phone
7. Smart TV

13. Which of the following digital services and tools do you use, or have you used within the past 12 months?
(READ OUT – multiple answers)

1. Internet
2. Apps from Appstore(s)
3. Tracking Apps (Sports, diet, GPS, etc.)
4. Social Media (e.g. Facebook, Instagram, Twitter, etc.)
5. Streaming services (e.g. Netflix, Amazon Prime)
6. Online shopping
7. Video Telephony (like FaceTime, WhatsApp, etc.)
8. Video Conferencing (like Zoom, MS Teams, etc.)
9. Fitness wearables (Smartwatches, Wristbands, etc.)
10. E-health/M-health Care Services*
11. Digital access to physical services (e.g. online physiotherapy, online fitness courses)
12. Other (Please specify_____)

13. None of these

*) if needed: eHealth is the umbrella term for all (digital) technologies that somehow use information and communication technology to deliver health services. mHealth is a subset of eHealth activities and systems that are delivered on mobile devices. Examples are: Tele-monitoring, home-monitoring (e.g. use of digitally connected medical devices like oxygen, inhaler, spirometer, etc.), digital communication (emails, apps, etc.), digital appointment scheduling, electronic patient records, Information via internet portals, etc.).

→ ONLY SHOW ITEMS SELECTED AT Q13 (used within past 12 months)

14. For all that you use, how would you describe your familiarity with it on a 1-10 scale, where 1 is 'I am not very familiar and 10 is 'I am very familiar with it'? (READ OUT – single answer)

1. Internet
2. Apps from Appstore(s)
3. Tracking Apps (Sports, diet, GPS, etc.)
4. Social Media (e.g. Facebook, Instagram, Twitter, etc.)
5. Streaming services (e.g. Netflix, Amazon Prime)
6. Online shopping
7. Video Telephony (like FaceTime, WhatsApp, etc.)
8. Video Conferencing (like Zoom, MS Teams, etc.)
9. Fitness wearables (Smartwatches, Wristbands, etc.)
10. E-health/M-health Care Services*
11. Digital access to physical services (e.g. online physiotherapy, online fitness courses)
12. Other (taken from Q13/12)

*) Examples for eHealth/mHealth: Tele-monitoring, home-monitoring (e.g. use of digitally connected medical devices like oxygen, inhaler, spirometer, etc.), digital communication (emails, apps, etc.), digital appointment scheduling, electronic patient records, Information via internet portals, etc.).

15. Has your attitude towards digital devices and services changed in the last 12 months, due to the Corona pandemic? (READ OUT – single answer)

1. No, it has not changed
2. Yes, I am more negative about it.
3. Yes, I am a bit more positive about it
4. Yes, I am much more positive about it.

15a. In case your usage of digital devices and services has increased during the Corona pandemic. What usage. has specifically increased? More.... (READ OUT – multiple answer)

→ ONLY SHOW ITEMS SELECTED AT Q13 (used within past 12 months)

1. Internet
2. Apps from Appstore(s)
3. Tracking Apps (Sports, diet, GPS, etc.)

4. Social Media (e.g. Facebook, Instagram, Twitter, etc.)
5. Streaming services (e.g. Netflix, Amazon Prime)
6. Online shopping
7. Video Telephony (like FaceTime, WhatsApp, etc.)
8. Video Conferencing (like Zoom, MS Teams, etc.)
9. Fitness wearables (Smartwatches, Wristbands, etc.)
10. E-health/M-health Care Services* → ask 15b
11. Digital access to physical services (e.g. online physiotherapy, online fitness courses)
12. Other (taken from Q13/12)
13. Usage has not increased

*) Examples for eHealth/mHealth: Tele-monitoring, home-monitoring (e.g. use of digitally connected medical devices like oxygen, inhaler, spirometer, etc.), digital communication (emails, apps, etc.), digital appointment scheduling, electronic patient records, Information via internet portals, etc.).

→ ONLY SHOW, if usage of E-health/M-health has increased at Q15a (answer 10)

15b. You have indicated that you have used more e-health/m-health services*. Please indicate what exactly you have used more (or started using) during the Corona pandemic. Please be as specific as possible. (probe intensively)

*) Examples for eHealth/mHealth: Tele-monitoring, home-monitoring (e.g. use of digitally connected medical devices like oxygen, inhaler, spirometer, etc.), digital communication (emails, apps, etc.), digital appointment scheduling, electronic patient records, Information via internet portals, etc.).

16. Which of the following health care services do you use either digitally or physically or both? (READ OUT - single answer)

	Digitally	Physically	Both	Not used at all
1. Consultations				
2. Treatment plan				
3. Prescriptions				
4. Examinations / Diagnostics				

5. Disease monitoring / management				
6. Medical record				
7. Booking appointments				

17. Which of the following healthcare providers do you deal with regarding your ASTHMA/COPD? (READ OUT – multiple answers)

1. GP/family doctor
2. Specialist (like pulmonologist, etc.)
3. Hospital
4. Specialized nurses / consultants
5. Medical Care Centres / Health Offices
6. Physiotherapist
7. Other (Please specify_____)
8. None

→ **ONLY SHOW ITEMS SELECTED AT Q17 (healthcare providers)**

18. Which of these offer digital health care services? (READ OUT)

→ Answer categories yes/no/dk

1. GP/family doctor
2. Specialist (like pulmonologist, etc.)
3. Hospital
4. Specialized nurses / consultants
5. Medical Care Centres / Health Offices
6. Physiotherapist
7. Other (taken from Q17/7)

19. In general, how open are you to using digital services and tools in the context of your ASTHMA/COPD condition? (READ OUT, single answer)

1. Very open
2. Somewhat open
3. Somewhat sceptical
4. Very sceptical

20. For you personally, what speaks against using digital health services and tools? What would you like to share in this regard? (probe intensively)

21. And, for you personally, what speaks in favour of using digital health services and tools? (probe intensively)

Section 2: DIAGNOSIS

22. Now, I have a list of different digital tools and services that could potentially be used for **diagnostics** regarding Asthma/COPD disease. Please tell me:

- a. Which ones are you aware of? (READ OUT)
- b. All they are aware of (from a): Which of these are offered or accessible for you, regardless, if you use them or not? (READ OUT)
- c. All that are offered or accessible (from b): Do you use them and if yes, how often do you use them? (READ OUT)
- d. Only for aspects 4/5/6/7/8: if used (from c): Do you have to pay for this service fully out of your own pocket, with partial re-imburement or does it get fully reimbursed? (READ OUT)
- e. All that are used (from c): How satisfied are you with the tools you have used? Please use a 1-10 scale, where 1 means "I am not satisfied at all" and 10 "I am extremely satisfied" (READ OUT)

ROTATE ORDER 1-8	a) Yes/no	b) Yes/no	c) Not used/use occasionally/use frequently	d) Fully out of own pocket/partially re-imbursed/fully re-imbursed	e) Satisfaction 1-10
1. Online search (Google, etc.) for diagnostics					
2. Social media search/exchange for diagnostics					
3. Digital interaction via support group(s)/patient organisation(s) for diagnostics					
4. Digital diary / Apps to collect values and conditions					
5. Online booking for medical appointments (for diagnostics)					

6. Online/video consultations for diagnostics					
7. Digital spirometry (at home)					
8. Other digital diagnostic devices used at home (digital peak-flow, etc.)					
9. Other (please specify)					

23. Still thinking about diagnostics, where do you feel digital options are specifically useful when it comes to **diagnostics** for ASTHMA/COPD? Please use a 1-4 scale, where 1 means “not useful at all” and 4 means “very useful” (READ OUT)

→ (ROTATE ORDER 1-7)

→ Answer categories: 1-4 scale and DK

1. Online search (Google, etc.) for diagnostics
2. Social media search or exchange for diagnostics
3. Digital interaction via support group(s)/patient organisation(s) for diagnostics
4. Digital diary / Apps to collect values and conditions
5. Online booking for medical appointments (for diagnostics)
6. Online/video consultations for diagnostics
7. Digital spirometry (at home)
8. Other digital diagnostics used at home (e.g. digital peak flow, etc.)
9. Other (please specify)

Section 3: TREATMENT

24. Now, I have a list of different digital tools and services that could potentially be used for **the treatment of** your Asthma/COPD disease. Could you please tell me which ones you have used so far and how often?
- Which ones are you aware of? (READ OUT)
 - All they are aware of (from a): Which of these are offered or accessible for you (regardless, if you use them or not)? (READ OUT)
 - All that are offered or accessible (from b): Do you use them and if yes, how often do you use them? (READ OUT)
 - Only for aspects 3/4/5/6/7/8/9/10: if used (from c): Do you have to pay for this service fully out of your own pocket, with partial re-imburement or does it get fully reimbursed? (READ OUT)
 - All that are used (at least occasionally) (from c): How satisfied are you with the tools you have used? Please use a 1-10 scale, where 1 means "I am not satisfied at all" and 10 "I am extremely satisfied" (READ OUT)

ROTATE ORDER 1-9	a) Yes/no	b) Yes/no	c) Not used/use occasionally/use frequently	d) Fully out of own pocket/partially re- imbursed/fully re- imbursed	e) Satisfaction 1-10
1. Online search (Google, etc.) for treatment					
2. Social media search or exchange for treatment					
3. Digital (treatment) diary / Apps to manage and follow up on treatment					
4. Online/video consultations for treatment					
5. Digital treatment plan from physician					

6. E-prescriptions (via email, website of physician, etc.)					
7. Participation in ASTHMA/COPD register(s)					
8. Participation in clinical trials (e-documentation)					
9. Smart inhalers with feedback option					
10. Other related to treatments (Please specify_____)					

25. Thinking about treatment, where do you feel digital options are specifically useful when it comes to the **treatment of** ASTHMA/COPD? Please use a 1-4 scale, where 1 means “not useful at all” and 4 means “very useful” (READ OUT)

→ (ROTATE ORDER 1-9)

→ Answer categories: 1-4 scale and DK

1. Online search for treatment
2. Social media search or exchange for treatment
3. Digital (treatment) diary / Apps to manage and follow up on treatment
4. Online/video consultations for treatment
5. Digital treatment plan from physician
6. E-prescriptions (via email, website of physician, etc.)
7. Participation/registration in ASTHMA/COPD register
8. Participation in clinical trials (e-documentation)
9. Smart inhalers with feedback option
10. Other related to treatments (please specify)

Section 4: CARE

26. Now I have a list of different digital tools and services that could potentially be used for **the care of your Asthma/COPD disease**. Could you please tell me which ones you have used so far and how often?
- Which ones are you aware of? (READ OUT)
 - All they are aware of (from a): Which of these are offered or accessible for you (regardless, if you use them or not)? (READ OUT)
 - All that are offered or accessible (from b): Do you use them and if yes, how often do you use them? (READ OUT)
 - All that are used (from c): Do you have to pay for this service fully out of your own pocket, with partial re-imburement or does it get fully reimbursed? (READ OUT)
 - All that are used (at least occasionally) (from c): How satisfied are you with the tools you have used? Please use a 1-10 scale, where 1 means "I am not satisfied at all" and 10 "I am extremely satisfied" (READ OUT)

ROTATE ORDER 1-9	a) Yes/no	b) Yes/no	c) Not used/use occasionally/use frequently	d) Fully out of own pocket/partially re- imbursed/fully re-imbursed	e) Satisfaction 1-10
1. Apps for general disease self-management / electronic diaries					
2. Digital devices like oxygen, inhaler, peak-flow, spirometer, etc.					
3. Tele-monitoring (sharing data with physician for monitoring purposes)					
4. Apps to manage other aspects of health that beneficially					

affect your ASTHMA/COPD (exercise, diet, sleep, etc.)					
5. Wearables for monitoring like chest patch, SmartShir, etc.)					
6. Tools to monitor air quality					
7. Regular E- Consultations with physicians or nurses					
8. Social Media interaction with other ASTHMA/COPD patients					
9. Digital interaction via support group(s)/patient organisation(s)					
10. Other related to care (Please specify_____)					

27. Thinking about care, where do you feel digital options are specifically useful when it comes to **care** for ASTHMA/COPD? Please use a 1-4 scale, where 1 means “not useful at all” and 4 means “very useful” (READ OUT)

→ (ROTATE ORDER 1-9)

→ Answer categories: 1-4 scale and DK

1. Apps for general disease self-management / electronic diaries
2. Digital devices like oxygen, inhaler, peak-flow, spirometer, etc
3. Tele-monitoring (sharing data with physician for monitoring purposes)

4. Apps to manage other aspects of health that beneficially affect your ASTHMA/COPD (exercise, diet, sleep, etc.)
5. Wearables for monitoring like chest patch SmartShirt, etc.
6. Tools to monitor air quality
7. Regular E-Consultations with physicians or nurses
8. Social Media interaction with other ASTHMA/COPD patients
9. Digital interaction via support group/patient organisation
10. Other related to care (please specify)

Section 2-4: DIAGNOSES, TREATMENT, CARE

28. What are the main reasons for not using any or more digital services or tools for **diagnostics, treatment and care?** (probe intensively)

29. Here is a list of reasons that might hinder the (increased) usage of digital services/devices. Please select all reasons that apply to you: (READ OUT, multiple answers)

→ Rotate order 1-15

1. Too expensive/no reimbursement
2. Insecurity / missing digital knowledge/competence
3. Data security concerns
4. Distrust towards digital technologies
5. Prefer personal contact
6. Not offered
7. No access
8. Not needed
9. Missing interest
10. Too elaborate/too time-consuming
11. Concerns that AI, algorithms (based on big data) are replacing human aspects.
12. Risk to provide too much (private/sensitive) data, more data than needed.
13. Digital health services are too intrusive/fear of losing control
14. Don't know who receives the data and what it is used for
15. Misuse of data for commercial purposes/advertising
16. Other (Please specify_____)
17. Don't see any barriers

30. In general, what could trigger or increase your usage of digital health services? (READ OUT, multiple answers)

/ contact details, etc.)										
2. General health data (diagnoses / height / weight / my condition etc.)										
3. Sports tracking data (steps, activities, GPS tracking)										
4. Specific health data (diary data, test results, monitoring data)										
5. Treatment data (medication, drugs, treatment plan, etc.)										
6. Other personal information (age, hobbies, likes, diet, etc.)										

32. How do you feel about digitally sharing health and personal data? (READ OUT, single answer)

1. Very concerned
2. Rather concerned
3. Somewhat comfortable
4. Very comfortable

33. And how do you feel about digitally sharing **anonymized health data**? (READ OUT, single answer)

1. Very concerned
2. Rather concerned
3. Somewhat comfortable
4. Very comfortable

34. Here, I have a list of potential recipients of your data. Please tell me with whom, if anyone, you would share your **data digitally**.

- i. Firstly, with whom would you share **both** health and personal data? (READ OUT, multiple answers)
- ii. And with whom would you share anonymized health data? (READ OUT, multiple answers)

1. Physician/nurse
2. Hospital / Medical care centre
3. Other patients (e.g., social media)
4. Pharmaceutical company/Medical device company
5. Any health-related register
6. Patient organization/support group
7. App provider
8. Health insurance (Statutory and/or private)
9. State/public healthcare system (part of social insurance, citizens' insurance, etc.)
10. Other (Please specify _____)
11. None of these

35. How important are the following aspects to you when it comes to sharing data digitally? Please use a 1-4 scale where 1 means 'This aspect is not important at all' and 4 means "This aspect is very important". (READ OUT)

→ Answer categories 1-4 and DK

→ Rotate order 1-12

1. General Data Protection Regulation (compliance /consent)
2. Anonymity
3. Privacy
4. To keep data ownership
5. Ability to withdraw data
6. Transparency
7. Data stored in my country
8. Data stored in EU (→ DO NOT ASK IN NORWAY)
9. Data security / Data encryption/certificates
10. Feedback on the results of the use of my data

11. Data used for common good/for better health outcomes
12. Trust towards the data operator
13. Other (Please specify_____)

36. Which of the following aspects **justify** the sharing of your data digitally? (READ OUT, multiple answers)

→ Rotate order 1-11

1. Ability to manage my ASTHMA/COPD more efficiently
2. Ability to manage my ASTHMA/COPD more independently
3. To stabilize my condition
4. To improve my condition
5. To help researchers to understand the disease/cause of disease better
6. To contribute to public health
7. To ease the work of my physician/nurse
8. Early warnings of deterioration
9. Development of new drugs and therapies
10. Disease prevention in future generations
11. Less costs for the healthcare system
12. Other (Please specify_____)
13. None

Section 6: EMPOWERMENT

37. Overall, how satisfied are you with your current disease management? Would you say... (READ OUT, single answer)

1. Very satisfied
2. Satisfied
3. Neither satisfied nor dissatisfied
4. Dissatisfied
5. Very dissatisfied

38. Would you say that the usage of digital services and tools has overall impacted your health condition...? (READ OUT, single answer)

1. Very positively
2. Positively
3. Neither positively nor negatively
4. Negatively
5. Very negatively
6. Does not apply / digital services not used at all

39. How involved do you personally feel in the disease management of your ASTHMA/COPD? (READ OUT, single answer)

1. Not at all
2. Rather not

3. Somewhat
4. Very much

40. Do you think that digital solutions might increase your personal involvement in your disease management?

Would you say....(READ OUT, single answer)

1. Not at all
2. Rather not
3. Somewhat
4. Very much

41. What are you missing regarding your disease management (including diagnostics, treatment and care) that could be handled digitally: (probe intensively)

42. In case someone supports/supported your use of digital tools, who did/does? (READ OUT, multiple answers)

1. Family members/partners
2. Friends
3. Colleagues
4. Visited courses/trainings
5. Health care staff (e.g., nurses)
6. Patient organisations
7. Other (Please specify_____)
8. Nobody

43. Would you be willing to be trained on the usage of digital tools? If yes, by whom? (READ OUT, multiple answers)

1. Family members/partners
2. Friends
3. Colleagues
4. Visit courses/trainings
5. Health care staff (e.g., nurses)
6. Patient organisations
7. Other (Please specify_____)
8. No, not willing to / not needed

44. Do you participate in any disease related online communities? (READ OUT, single answer)

1. Yes

2. No

45. When it comes to maintenance costs for digital health services, such as upgrades, updates, devices and repairs. What are acceptable costs per year for you to ensure the usage of digital health services? (READ OUT, single answer)

1. None, no costs should occur
2. 1-10 Euro
3. 11-50 Euro
4. 51-100 Euro
5. 101-250 Euro
6. 251 – 500 Euro
7. 501 – 1000 Euro
8. 1.001,- Euro or more

46. And finally, do you think that the establishment of digital services and tools for the management of ASTHMA/COPD will change personal disease management prospectively...(READ OUT, single answer)

1. Very positively
2. Positively
3. Neither positively nor negatively
4. Negatively
5. Very negatively
6. Don't know

Section 6: ADDITIONAL DEMOGRAPHICS

47. Size of household: do you live in a ...? (single answer)

1. One-person household
2. Two-person household
3. Household with three or more people

48. Are you ...? (single answer)

1. working (full/part time)
2. a student
3. in vocational training
4. a housewife/house husband
5. on disability/sick leave
6. retired
7. out of work (unemployed, seeking work)
8. Prefer not to say

49. What kind of health insurance do you have? (READ OUT, single answer)

1. Public/statutory health insurance WITHOUT private supplementary insurance
2. Public/statutory health insurance WITH private supplementary insurance
3. Private health insurance

4. No health insurance

50. Is there anything else you would like to share with us on this topic?

Thank you and close!



European Federation of Allergy and Airways
Diseases Patients' Associations

#EFAPatientsDigital

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SCAN ME

