



# ColiveVoice

BY LUXEMBOURG INSTITUTE OF HEALTH

## Questionnaires

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## Baseline characteristics

What is your mother tongue?	"Arabic", "Bengali", "Chinese (Mandarin, Wu...)", "English", "French", "German", "Hindi", "Italian", "Japanese", "Korean", "Luxembourgish", "Portuguese", "Russian", "Spanish"; "Other"
Age (years)	
Gender	"Male";"Female";"Other"
Weight (kg)	40-200
Have you - unintentionally - lost weight in the last 3 months?	"Yes";"No"
Height (cm)	120-220
What is the highest degree or level of education you have completed?	"Some High School or lower";"High School";"Bachelor's Degree";"Master's Degree";"PhD or higher";"Prefer not to say"
Which ethnic group would best represent you?	"White/Caucasian"; "Asian"; "Black/African/Caribbean"; "Arab"; "Mixed/Multiple ethnic group";"Other";"Don't know"
What is your blood type and rhesus?	"O+";"O-";"A+";"A-";"B+";"B-";"AB+";"AB-";"Don't know"
Do you currently smoke tobacco?	"Daily";"Less than daily";"Not at all"
Have you smoked tobacco daily in the past?	"Yes";"No"
In the past, have you smoked tobacco?	"Daily";"Less than daily";"Not at all"
On average, how many cigarettes (or pipes full of tobacco, cigars, cigarillos, kreteks, water pipe sessions) do you currently smoke each day?	
During the last 12 months :	
How often did you usually have any kind of drink containing alcohol? By a drink we mean 250mL of beer or cooler, a 125 mL glass of wine, or a drink containing 1 shot of liquor.	"Every day";"5 to 6 times a week";"3 to 4 times a week";"Twice a week";"Once a week";"2 to 3 times a month";"Once a month";"3 to 11 times in the past year";"1 or 2 times in the past year";"Never"
How many alcoholic drinks did you have on a typical day when you drank alcohol?	
How often did you have 5 or more (males) or 4 or more (females) drinks containing any kind of alcohol within a two-hour period?	"Every day";"5 to 6 days a week";"3 to 4 days a week";"Twice a week";"Once a week";"2 to 3 days a month";"Once a month";"3 to 11 days in the past year";"1 or 2 days in the past year";"Never"

## Symptoms

Please rate how much pain you have right now: from 0= no pain to 10=pain as bad as you can imagine	
Have you had any pain or discomfort in your chest today?	"Yes";"No"
Which of the following best describes your bowel movements?	"Normal";"Diarrhoea";"Constipation";"Alternating diarrhoea/constipation"
Do you have fever? (body temperature higher than 38°C or 100.4°F)	"Yes";"No"
Do you have regular headache or migraine?	"Yes";"No"
Do you have a sore throat?	"Yes";"No"
Do you have balance disorders or walking difficulties?	"Yes";"No"
Please mark all the emotions on the list that best represent how you are feeling at the moment.	"Love";"Joy";"Surprise";"Anger";"Sadness";"Fear";"Neutral";
Stress means a situation in which a person feels tense, restless, nervous or anxious or is unable to sleep at night because his/her mind is troubled all the time. Do you feel this kind of stress these days?	"Not at all";"Only a little";"To some extent";"Rather much";"Very much"
<b>Fatigue Severity Scale</b>	
My motivation is lower when I am fatigued.	"Strongly disagree";"Disagree";"Slightly disagree";"Neither agree nor disagree";"Slightly agree";"Agree";"Strongly agree"
Exercise brings on my fatigue	
I am easily fatigued	
Fatigue interferes with my physical functioning	
Fatigue causes frequent problems for me	
My fatigue prevents sustained physical functioning	
Fatigue interferes with carrying out certain duties and responsibilities	
Fatigue is among my three most disabling symptoms	
Fatigue interferes with my work, family, or social life.	
<b>WHO Well-Being Index</b>	
Over the last two weeks,	"All the time";"Most of the time";"More than half of the time";"Less than half of the time";"Some of the time";"At no time"
I have felt cheerful and in good spirits	
I have felt calm and relaxed	
I have felt active and vigorous	
I woke up feeling fresh and rested	
My daily life has been filled with things that interest me	
<b>PHQ-9 Questionnaire</b>	
How often have you been bothered by the following over the past 2 weeks?	

Little interest or pleasure in doing things?	"Not at all";"Several days";"More than half the days";"Nearly every day"
Feeling down, depressed, or hopeless	
Trouble falling or staying asleep, or sleeping too much?	
Feeling tired or having little energy?	
Poor appetite or overeating?	
Feeling bad about yourself — or that you are a failure or have let yourself or your family down?	
Trouble concentrating on things, such as reading the newspaper or watching television?	
Moving or speaking so slowly that other people could have noticed? Or so fidgety or restless that you have been moving a lot more than usual?	
Thoughts that you would be better off dead, or thoughts of hurting yourself in some way?	
Which of the following best describes your cough during daytime?	"No cough"; "Yes, transient cough occasionally during the daytime";"Yes, frequent cough mildly affecting daily life"; "Yes, frequent cough severely affecting daily life"
Which of the following best describes your cough during nighttime?	"No cough"; "Yes, transient cough before sleep or occasional cough during the night";"Yes, cough mildly affecting night sleep"; "Yes, cough severely affecting night sleep"
<b>VQ11 Respiratory Quality of Life Questionnaire</b>	
I suffer from my shortness of breath	"Not at all";"A little";"Moderately";"A lot";"Extremely"
I worry about my respiratory state	
I feel misunderstood by those around me	
My respiratory state prevents me from moving as I would like	
I'm sleepy during the day	
I feel incapable of carrying out my projects.	
I get tired quickly in the activities of daily living	
Physically I'm dissatisfied with what I can do	
My respiratory disease is disrupting my social life	
I feel sad	
My respiratory state limits my emotional life	
<b>REM Sleep Behavior Disorder Screening Questionnaire</b>	
I sometimes have very vivid dreams	"Yes";"No"

My dreams frequently have an aggressive or action-packed content	
The dream contents mostly match my nocturnal behaviour.	
I know that my arms or legs move when I sleep.	
It thereby happened that I (almost) hurt my bed partner or myself	
I have or had the following phenomena during my dreams: speaking, shouting, swearing, laughing loudly	
I have or had the following phenomena during my dreams: sudden limb movements, "fights"	
I have or had the following phenomena during my dreams: gestures, complex movements, that are useless during sleep, e.g., to wave, to salute, to frighten mosquitoes, falls off the bed	
I have or had the following phenomena during my dreams: things that fell down around the bed, e.g., bedside lamp, book, glasses	
It happens that my movements awake me.	
After awakening I mostly remember the content of my dreams well.	
My sleep is frequently disturbed.	
I have/had a disease of the nervous system (e.g., stroke, head trauma, parkinsonism, RLS, narcolepsy, depression, epilepsy, inflammatory disease of the brain)	

## Drugs

Are you taking any medications (excluding contraception) more than 3 times per week?	"Yes";"No"
<b>Are you currently taking:</b>	
Paracetamol	"Yes";"No"
Ibuprofen	
Codeine	
Morphine or morphine-derived drugs	
Medication for cholesterol	
Medication (tablets or insulin) for diabetes	
Medication for hypertension	
Angiotensin-converting enzyme medications	
Antibiotics	
Medication to treat anxiety or depression	
Anti-reflux medication	
Treatment for thyroid problems	
Corticosteroids such as prednisone or budesonide (Entocort EC)	
Muscle relaxants	
Decongestants	
Diuretics	
Antidiarrheal agents (ex. loperamide (Imodium A-D))	
Antihistamines	
Anticholinergics	
High doses of Vitamin C (greater than five grams per day)	
Anticoagulants	
Medication for throat pain	
Hormonal treatment (contraception, menopause...)	
Please precise the type of treatment	"Oestrogen treatment";"Oestrogen treatment";"Progestative treatment"

## List of diseases

Have you ever been diagnosed with one or several of the following diseases?	
Infarction/Heart attack	"Yes";"No"
Congestive heart failure	
Coronary heart disease	
Angina pectoris	
Hypertension	
Diabetes	
Thyroidic disease	
Chronic kidney disease	
Allergy (ex: mites, pollen, food, pets..)	
Emphysema	
Chronic bronchitis	
Chronic obstructive pulmonary disease (COPD)	
Asthma	
Cancer	
Influenza	
Malaria	
Tuberculosis	
Covid-19	
Zika	
Bronchitis or pneumonia	
Gout	
Hepatitis	
Crohn's disease	
Ulcerative colitis	
Rheumatoid Arthritis or Systemic Lupus (SLE)	
Multiple Sclerosis	
Epilepsy	
Amyotrophic Lat. Sclerosis (ALS)	
Narcolepsy	
Parkinson's disease	
Stroke	
Migraine	

Laryngitis	
Non cancerous vocal cord lesion (polyp, nodul, cyst)	
Laryngopharyngeal reflux	
Leukoplakia	
Depression	



## Cancer

Level 2 questionnaires (questionnaires displayed only if corresponding diseases are declared by the participant)

What kind of cancer was it?	"Bladder";"Blood";"Bone";"Brain";"Breast";"Cervix";"Colon";"Esophagus";"Gallbladder";"Kidney";"Larynx";"Leukemia";"Liver";"Lung";"Lymphoma";"Melanoma";"Mouth";"Nervous system";"Ovary";"Pancreas";"Prostate";"Rectum";"Skin (no melanoma)";"Softtissue";"Stomach";"Testis";"Thyroid";"Uterus";"Other"
How old were you when you have been diagnosed with cancer?	1-100
Are you currently undergoing cancer treatment?	"Yes";"No"
What was the type of cancer treatment you have received or are currently receiving? (multiple answers possible)	"Surgery"; "Chemotherapy"; "Immunotherapy"; "Radiotherapy"; "Other"
With which type of lung cancer were you diagnosed?	"Non-small cell lung cancer (NSCLC)";"Small cell lung cancer (SCLC)";"Not sure"
How long ago were you diagnosed with lung cancer?	"Less than 1 year ago";"1 year to 2 years ago";"2 years to 5 years ago";"More than 5 years ago";"I'm not sure"
At what stage were you diagnosed?	"NSCLC Stage I";"NSCLC Stage II";"NSCLC Stage III";"NSCLC Stage IV";"SCLC Limited Stage";"SCLC Extensive Stage";"Not sure"
Which of the following best describes your current condition?	"My stage has remained the same";"My stage has increased";"I am cancer free";"I'm not sure"

## Diabetes

**Level 2 questionnaires (questionnaires displayed only if corresponding diseases are declared by the participant)**

What type of diabetes do you have?	"Type 1 Diabetes";"Type 2 Diabetes";"Gestational Diabetes";"LADA";"MODY";"Other forms of diabetes";"Don't know"
How old were you when you have been diagnosed with diabetes?	1-100
Do you use tablets to treat your diabetes?	"Yes";"No"
Do you use insulin to treat your diabetes?	"Yes";"No"
How do you use insulin?	"I use an insulin pump";"I use an insulin pen";"Other"
What is your most recent HbA1c result (%)?	3-20
Do you use a continuous or flash glucose monitoring device?	"Yes";"No"
Can you please read your glucose level now and report the value here? (in mmol/l or mg/dl)	0-500
Can you please read your Glucose Management Indicator (GMI) - estimated HbA1c) now and report the value here? (%)	3-20
Can you please read your Time in Range (TIR between 70 to 180 mg/dl) now and report the value here? (%)	0-100
Does anyone in your family (parents, siblings, children) have diabetes?	"Yes";"No"
<b>PAID-20 Questionnaire</b>	
Which of the following diabetes issues are currently a problem for you?	
Not having clear and concrete goals for your diabetes care	"Not a problem";"Minor problem";"Moderate problem";"Somewhat serious problem";"Serious problem"
Feeling discouraged with your diabetes treatment plan	
Feeling scared when you think about living with diabetes	
Uncomfortable social situations related to your diabetes care (eg people telling you what to eat)	
Feelings of deprivation regarding food and meals	
Feeling depressed when you think about living with diabetes	

Not knowing if your mood or feelings are related to your diabetes	
Feeling overwhelmed by your diabetes	
Worrying about low blood sugar reactions	
Feeling angry when you think about living with diabetes	
Feeling constantly concerned about food and eating	
Worrying about the future and the possibility of serious diabetes complications	
Feelings of guilt or anxiety when you get off track with your diabetes management	
Not 'accepting' your diabetes	
Feeling unsatisfied with your diabetes physician	
Feeling that diabetes is taking up too much of your mental and physical energy every day	
Feeling alone with your diabetes	
Feeling that your friends and family are not supportive of your diabetes management efforts	
Coping with complications of diabetes	
Feeling 'burned out' by the constant effort needed to manage diabetes	

## Covid-19

**Level 2 questionnaires (questionnaires displayed only if corresponding diseases are declared by the participant)**

When have you been tested positive?	"In the last 7 days";"In the last three weeks";"More than three weeks ago"
Are you at home or hospitalized?	"At home";"Hospitalized";"Other"
How do you feel today?	"I feel well";"I'm tired";"I feel bad"
Do you sleep well?	"Yes";"No"
Do you have a strong reduction or a loss of taste and smell ?	
Do you have hand or limb tremors?	
Do you have ear pain?	
Do you have tingling / pins and needles / numbness sensations in the limbs or on the skin?	
Have you noticed a sudden onset of skin rashes on the hands or feet (for example frostbite, persistent redness that is sometimes painful, transient hives)?	
Have you noticed the appearance of conjunctivitis or pain in the eyes (persistent redness in the white of the eye, itching of the eyelids, tingling sensations, burning, frequent tearing)?	

## Multiple sclerosis

**Level 2 questionnaires (questionnaires displayed only if corresponding diseases are declared by the participant)**

How old were you when you have been diagnosed with multiple sclerosis?	1-100
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## Crohn's disease

**Level 2 questionnaires (questionnaires displayed only if corresponding diseases are declared by the participant)**

How old were you when you have been diagnosed with Crohn's disease?	1-100
<b>Short IBD Questionnaire</b>	
How often has the feeling of fatigue or being tired and worn out been a problem for you during the past 2 weeks?	"All of the time"; "Most of the time"; "A good bit of the time"; "Some of the time"; "A little of the time"; "Hardly any of the time"; "None of the time"
How often during the last 2 weeks have you delayed or canceled a social engagement because of your bowel problem?	
As a result of your bowel problems, how much difficulty did you experience doing leisure or sports activities during the past 2 weeks?	
How often during the past 2 weeks have you been troubled by pain in the abdomen?	
How often during the past 2 weeks have you felt depressed or discouraged?	
Overall, in the past 2 weeks, how much of a problem have you had with passing large amounts of gas?	
Overall, in the past 2 weeks, how much of a problem have you had maintaining or getting to the weight you would like to be?	
How often during the past 2 weeks have you felt relaxed and free of tension?	
How much of the time during the past 2 weeks have you been troubled by a feeling of having to go to the bathroom even though your bowels were empty?	
How often during the past 2 weeks have you felt angry as a result of your bowel problem?	
<b>Harvey-Bradshaw Index</b>	
How have you been feeling the last seven days?	"Well"; "Slightly below average"; "Poor"; "Very poor"; "Terrible"
How would you define the abdominal pain that was currently affecting you?	"None"; "Mild"; "Moderate"; "Severe"
During last week, how many liquid or soft stools have you had each day?	NA
Do you notice you have an abdominal mass?	"Yes"; "maybe"; "No"
Do you have any of these complications?	"Arthritis or arthralgia"; "Iritis or uveitis"; "Erythema"

	nodosum, pyoderma gangrenosum or aphthous stomatitis"; "Anal fissure, fistula or abscess"; "Other fistula"; "Temperature over 100 degrees F (37.8 degrees C) in the last week"
Are you currently taking other anti-inflammatory drugs such as aminosalicylates (sulfasalazine (Azulfidine) or mesalamine (Asacol HD, Delzicol)?	"Yes"; "No"
Are you currently taking immune system suppressors such as azathioprine (Azasan, Imuran) or mercaptopurine (Purinethol, Purixan)?	"Yes"; "No"
Are you currently taking other immune system suppressors such as methotrexate (Trexall)?	"Yes"; "No"
Are you currently taking biologic medication such as infliximab (Remicade), adalimumab (Humira), golimumab (Simponi) or vedolizumab (Entyvio)?	"Yes"; "No"
Are you currently taking antibiotics such as iprofloxacin (Cipro) and metronidazole (Flagyl)?	"Yes"; "No"

## Ulcerative colitis

**Level 2 questionnaires (questionnaires displayed only if corresponding diseases are declared by the participant)**

How old were you when you have been diagnosed with ulcerative colitis?	1-100
<b>Patient-modified Simple Clinical Colitis Activity Index (SCCAI)</b>	
On average per day (24 hours), how many times did you use the toilet for defecation during the previous week? Blood and slime discharge is also considered as defecation	"0 to 3 times"; "4 to 6 times"; "7 to 9 times"; "More than 9 times"
On average per night, how many times did you get out of bed to use the toilet for defecation during the previous week?	"Never"; "1 to 3 times"; "More than 3 times"
During the previous week, were you able to hold up your stool for 15 minutes or longer, when you felt the urge to use the toilet?	"Yes"; "No"; "I Don't know"
During the previous week, did you have to make adjustments to your activities, to ensure that there was a toilet nearby?	"Yes"; "No"; "I Don't know"
During the previous week, have you found stool in your underwear?	"Yes"; "No"; "I Don't know"
During the previous week, how many times did you see blood in your stool?	"Never"; "Much less than half of the times"; "A little less than half of the times"; "More than half of the times"
If you would have to rate your general well-being during the previous week by giving it a number, what number would you choose?	1 to 10. 1 = "very bad", 10 = "perfect"
During the previous week, did you have joint pain which was worse at rest than after activity?	"Yes"; "No"; "I Don't know"
During the previous week, were your joints red or swollen?	"Yes"; "No"; "I Don't know"
During the previous week, have you ever woken up from joint pain?	"Yes"; "No"; "I Don't know"
During the previous week, have you had a skin disorder that has been diagnosed as erythema nodosum by your treating specialist?	"Yes"; "No"; "I have a skin disorder but have not seen my specialist for it or do not know what the disorder is called"
During the previous week, have you had a skin disorder that has been diagnosed as pyoderma by your treating specialist?	"Yes"; "No"; "I have a skin disorder but have not seen my specialist for it or do not know what the disorder is called"



Do you momentarily have an eye infection, that you have seen an eye-specialist for and which your treating specialist diagnosed as uveitis?	"Yes";"No";"I have an eye infection but have not seen an eye specialist for it or do not know what the infection is called"
Are you currently taking aminosalicylates, such as sulfasalazine (Azulfidine) or Mesalamine, mesalamine (Asacol HD, Delzicol, others)?	"Yes";"No"
Are you currently taking balsalazide (Colazal)?	"Yes";"No"
Are you currently taking olsalazine (Dipentum)?	"Yes";"No"
Are you currently taking immunosuppressant drugs (Azathioprine, Infliximab, Methotrexate, Natalizumab, Ustekinumab)?	"Yes";"No"
Are you currently taking biologic medication (Infliximab (Remicade), adalimumab (Humira) and golimumab (Simponi). Vedolizumab (Entyvio)?	"Yes";"No"