Experience of long COVID in the Irish population

* Required

Why is this study being run?

You are being invited to participate in this research study because you have had COVID-19, or suspected COVID-19 infection and are still suffering or suffered symptoms for longer than 1 week and you are 18 years of age or older.

This is a voluntary questionnaire and data collected is anonymous. No personal identifiers will be collected or stored. The questionnaire consists of 30 questions and will take approximately 10-15 minutes to complete.

We appreciate your time to help us characterise the experience of people living with long COVID in Ireland.

Study Procedure

After reading this participant information leaflet, if you decide to take part in the study you will be asked to tick the "yes" box at the end of the leaflet. By ticking this box you will have consented to taking part in this study. If you tick the "no" box you will not be consented into the study and you will not have to do anything else.

Participation involves the completion of one anonymous online questionnaire. The questionaire will assess your experience of COVID-19 infection, ongoing symptoms, impact of ongoing symptoms on health and your experience of access to care and supports nationally. Information regarding your medical history and current medical status will be requested and we will be relying solely on the information you provide to us. No medical records/files will be requested or looked at for the purposes of this questionnaire.

What is my involvement in the study?

Participation only involves completing one online questionnaire. Length of time to complete the questionnaire will be approx. 10-15 minutes.

What are the benefits?

This questionnaire will aid in expanding our understanding of the experience of COVID-19 and long COVID in Ireland. Findings from this study may help inform planning for services, care pathways and supports for patients affected by COVID-19 in Ireland.

What are the risks?

There is no data risk involved with this online questionnaire. The online questionnaire will be set up using Microsoft Office 365 Forms, approved under the UCC cyber security framework. The data collected will be stored securely on the Office 365 cloud storage platform, with only the individuals directly involved in the project having contact to the data set. IP addresses will not be linked and therefore there will be no connection of information between participants and the information they provide when filling out the questionnaire. All data collected will be anonymous and there will be no way of identifying you.

What happens if I do not want to complete the online questionnaire?

You do not have to take part in this study, participation is entirely voluntary. Refusal to participate will involve no penalty and will not affect the healthcare you receive.

Participation in this study is voluntary

This research study involving an online questionnaire has been fully explained to me. I am aware that participation is voluntary. I am aware that my decision not to participate will not restrict my access to health care services normally available to me. Confidentiality of data concerning my involvement in this study will be maintained in an appropriate manner.

I hereby consent to participate in the above described study to complete an online questionnaire conducted at APC Microbiome Ireland, University College Cork. I understand that if I have any questions concerning this research, I can contact the Investigators listed above. If I have further queries concerning my rights in connection with the research I can contact the Clinical Research Ethics Committee of the Cork Teaching Hospitals, Lancaster Hall, 6 Little Hanover Street, Cork.

Analyses of all data collected will occur at APC Microbiome Ireland, University College Cork. I am aware that this online questionnaire is anonymous and there is no way to trace the information I provide back to me.

Results of this online questionnaire will be utilised to document the experience of COVID-19 and long COVID in Ireland. Findings from this study may help inform planning for services, care pathways and supports for patients affected by COVID-19 in Ireland.

Confidentiality

The online questionnaire will be set up with an in-house server and will be completed using Microsoft Office 365 Forms which is approved under the UCC cyber security framework and by data controllers. The questionnaire will be completed anonymously, with no personal identifiers attached to the data collected. The data collected will be stored securely on the Office 365 cloud storage platform, with only the individuals directly involved in the project having contact to the data set.

If you have any questions about this questionnaire you can contact:

Dr Corinna Sadlier, Department of Infectious Diseases, Cork University Hospital, Tel 021 492 2795

Prof Liam O' Mahony, Principal Investigator at APC Microbiome Ireland & Professor of Immunology, University College Cork. Tel: 021 490 1316

After reading the entire consent form, please answer the following:

1. I consent to taking part in this study by completing the online questionnaire *

   Mark only one oval.

   - ◯ Yes
   - ◯ No

Experience of long COVID in Ireland

2. 1. Age (year of birth)

   _____

3. 2. Gender assigned at birth

   Mark only one oval.

   - ◯ Male
   - ◯ Female
   - ◯ Prefer not to say

4. 3. Ethnic group

   Mark only one oval.

   - ◯ Asian
   - ◯ African
   - ◯ Hispanic
   - ◯ White
   - ◯ Other

5. 4. County in which you live:

Mark only one oval.

- Carlow
- Cavan
- Clare
- Cork
- Donegal
- Dublin
- Galway
- Kerry
- Kildare
- Kilkenny
- Laois
- Leitrim
- Limerick
- Longford
- Louth
- Mayo
- Meath
- Monaghan
- Offaly
- Roscommon
- Sligo
- Tipperary
- Waterford
- Westmeath
- Wexford
- Wicklow
- Antrim
- Armagh
- Derry
- Down
- Fermanagh
- Tyrone

6. 5. Highest level of education attained – please tick most appropriate

Mark only one oval.

- Completed secondary school or less
- Certificate/diploma
- Undergraduate university degree
- Postgraduate / higher university degree

7. 6-A: Height in feet e.g 5 ft 2 in

8. 6-B: Weight in stones e.g 10 st 2 ozs

9. 7. Pre-existing comorbid illness

Check all that apply.

- [ ] Asthma
- [ ] COPD
- [ ] Allergies
- [ ] High blood pressure
- [ ] Chronic heart disease
- [ ] Chronic kidney disease
- [ ] Rheumatic disease
- [ ] Autoimmune disease
- [ ] Diabetes mellitus
- [ ] Immunosuppression
- [ ] Current or prior smoker
- [ ] Mood disorder (e.g., Anxiety or depression)
- [ ] Trauma and stressor-related disorders (e.g., adjustment disorder or PTSD)
- [ ] Migraines
- [ ] Fibromyalgia
- [ ] Chronic fatigue
- [ ] Cancer
- [ ] Neuromuscular disease
- [ ] None of these

Acute/Short COVID (initial 2 weeks of illness)

10. 8. Date of acute COVID illness (best estimate)

Example: January 7, 2019

11. 9. Was your acute COVID illness

Mark only one oval.

- ◯ Confirmed by PCR testing
- ◯ Confirmed by antibody testing
- ◯ Suspected

10. Symptoms during ACUTE COVID illness - Please tick all relevant

12. Systemic symptoms:

Check all that apply.

- [ ] Fever
- [ ] Fatigue
- [ ] Post-exertional malaise and/or poor endurance. (Post-exertional malaise (PEM) is the worsening of symptoms following even minor physical mental exertion, with symptoms typically worsening 12 to 48 hours after activity and lasting for days or even weeks).

13. Respiratory symptoms:

Check all that apply.

- [ ] Cough
- [ ] Shortness of breath
- [ ] Sore throat
- [ ] Hoarse voice
- [ ] Sinus pain
- [ ] Runny nose

14. Cardiovascular symptoms:

Check all that apply.

- [ ] Chest pain
- [ ] Palpitations

15. GI symptoms:

Check all that apply.

- [ ] Stomach upset/nausea
- [ ] Skipped meals
- [ ] Diarrhoea
- [ ] Abdominal pain

16. Neuropsychiatric symptoms:

Check all that apply.

- [ ] Concentration problems
- [ ] Memory problems, “Brain fog”
- [ ] Sleep problems
- [ ] Headache
- [ ] Dizziness/light-headedness
- [ ] Mood changes
- [ ] Pins and needles (Paresthesia)
- [ ] Disturbed taste
- [ ] Disturbed smell

17. Musculoskeletal symptoms:

Check all that apply.

- [ ] Joint pain (Arthralgia)
- [ ] Muscle pain (Myalgia)

18. Other

Check all that apply.

- [ ] New allergies
- [ ] Rash (e.g., urticaria)
- [ ] Mouth ulcers
- [ ] Tinnitus
- [ ] Ear ache
- [ ] Menstrual abnormalities
- [ ] Sexual dysfunction

19. Other symptoms during ACUTE COVID illness

20. 11. Self-assessment of severity of ACUTE COVID illness

Mark only one oval.

- ◯ No symptoms
- ◯ Mild impact on general well being
- ◯ Moderate impact on general well being
- ◯ Severe impact on general well being

21. 12. Treatment sought or received for ACUTE COVID illness

Mark only one oval.

- ◯ No medical attention sought
- ◯ Sought medical attention from pharmacist/ GP by phone
- ◯ Visited GP or COVID assessment hub
- ◯ Attended the Emergency Department
- ◯ Admitted to hospital

22. 13. Level of care in hospital (if relevant)

Mark only one oval.

- ◯ Hospitalised requiring medical treatment/observation
- ◯ Hospitalised requiring oxygen
- ◯ Hospitalised requiring non-invasive ventilation or high flow oxygen
- ◯ Hospitalised requiring critical care or ICU

23. 13. (i) Duration of Hospital admission (days)

_____

3. Long COVID

24. 14. Have you returned to usual health following acute COVID illness?

Mark only one oval.

- ◯ Yes
- ◯ No

25. 15. If yes, how long (months) following acute COVID illness did it take for you to return to usual health?

_____

16. If you have ongoing symptoms following acute COVID illness - Please tick all that apply

26. Systemic symptoms:

Check all that apply.

- ☐ Fever
- ☐ Fatigue
- ☐ Post-exertional malaise and/or poor endurance. Post-exertional malaise (PEM) is the worsening of symptoms following even minor physical o mental exertion, with symptoms typically worsening 12 to 48 hours after activity and lasting for days or even weeks.

27. Respiratory symptoms:

Check all that apply.

- ☐ Cough
- ☐ Shortness of breath
- ☐ Sore throat
- ☐ Hoarse voice
- ☐ Sinus pain
- ☐ Runny nose

28. Cardiovascular symptoms:

Check all that apply.

- ☐ Chest pain
- ☐ Palpitations

29. GI symptoms:

Check all that apply.

- ☐ Stomach upset/nausea
- ☐ Skipped meals
- ☐ Diarrhoea
- ☐ Abdominal pain

30. Neuropsychiatric symptoms:

Check all that apply.

- [ ] Concentration problems
- [ ] Memory problems, “Brain fog,”
- [ ] Sleep problems
- [ ] Headache
- [ ] Dizziness/lightheadness
- [ ] Mood changes
- [ ] Pins and needles (Paresthesia)
- [ ] Disturbed taste
- [ ] Disturbed smell

31. Musculoskeletal symptoms:

Check all that apply.

- [ ] Joint pain (Arthralgia)
- [ ] Muscle pain (Myalgia)

32. Other:

Check all that apply.

- [ ] New allergies
- [ ] Rash (e.g., urticaria)
- [ ] Mouth ulcers
- [ ] Tinnitus
- [ ] Ear ache
- [ ] Menstrual abnormalities
- [ ] Sexual dysfunction

33. Other ongoing symptoms

_____

_____

_____

_____

_____

17. Under each heading, please tick the ONE box that best describes your health TODAY

34. Mobility

Mark only one oval.

- ◯ I have no problems in walking about
- ◯ I have slight problems in walking about
- ◯ I have moderate problems in walking about
- ◯ I have severe problems in walking about
- ◯ I am unable to walk about

35. Self-Care

Mark only one oval.

- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

36. Usual Activities (e.g. work, study, housework, family or leisure activities)

Mark only one oval.

- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

37. Pain/Discomfort

Mark only one oval.

- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

38. Anxiety/Depression

Mark only one oval.

- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed

39. We would like to know how good or bad your health is TODAY

Mark only one oval.

	1	2	3	4	5	6	7	8	9	10	
The worst health you can imagine											The best health you can imagine

40. 18-A: During the past 4 weeks, how much have you been bothered by any of the following problems?

Mark only one oval per row.

	Not Bothered at all	Bothered a little	Bothered a lot
Stomach Pain			
Back Pain			
Pain in your arms, legs, or joints (knees, hips, etc.)			
Menstrual cramps or other problems with your periods			
Headaches			
Chest pain			
Dizziness			
Fainting spells			
Feeling your heart pound or race			
Shortness of breath			
Pain or problems during sexual intercourse			
Constipation, loose bowels or diarrhea			
Nausea, gas or indigestion			
Feeling tired or having low energy			
Trouble sleeping			

41. 18-B: Over the last 2 weeks, how often have you been bothered by any of the following problems?

Mark only one oval per row.

	Not at all	Several days	More than half the days	Nearly every day
Feeling nervous, anxious or “on edge”				
Not being able to stop or control worrying				
Worrying too much about different things				
Trouble relaxing				
Being so restless that it is hard to sit still				
Becoming easily annoyed or irritable				
Feeling afraid as if something awful might happen				

42. 18-C: Questions about anxiety attacks

Mark only one oval per row.

	Yes	No
In the last 4 weeks, have you had an anxiety attack — suddenly feeling fear or panic?		
Has this ever happened before?		
Do some of these attacks come suddenly out of the blue – that is, in situations where you don't expect to be nervous or uncomfortable?		
Do these attacks bother you a lot or are you worried about having another attack?		
During your last bad anxiety attack, did you have symptoms like shortness of breath, sweating or your heart racing, pounding or skipping?		

43. 18-D: Over the last 2 weeks, how often have you been bothered by any of the following problems?

Mark only one oval per row.

	Not at all	Several Days	More than half the days	Nearly every day
Little interest or pleasure in doing things				
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 or watching TV				
Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual				
Thoughts that you would be better off dead or of hurting yourself in some way				

44. 18-E: If you checked off any problems on this questionnaire, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Mark only one oval.

- ◯ Not difficult at all
- ◯ Somewhat difficult
- ◯ Very Difficult
- ◯ Extremely difficult

45. 19: We would like to know more about any problems you have had with feeling tired, weak or lacking in energy in the last month.

Mark only one oval per row.

	Less than usual	No more than usual	More than usual	Much more than usual
Do you have problems with tiredness?	◯	◯	◯	◯
Do you need to rest more?	◯	◯	◯	◯
Do you feel sleepy or drowsy?	◯	◯	◯	◯
Do you have problems starting things?	◯	◯	◯	◯
Do you lack energy?	◯	◯	◯	◯
Do you have less strength in your muscles?	◯	◯	◯	◯
Do you feel weak?	◯	◯	◯	◯
Do you have difficulties concentrating?	◯	◯	◯	◯
Do you make slips of the tongue when speaking?	◯	◯	◯	◯
Do you find it more difficult to find the right word?	◯	◯	◯	◯

46. How is your memory?

Mark only one oval.

- ◯ Better than usual
- ◯ No worse than usual
- ◯ Worse than usual
- ◯ Much worse than usual

47. 20. Please tick most appropriate description of your long COVID illness

Mark only one oval.

- ◯ Symptoms are persistent
- ◯ Symptoms are relapsing
- ◯ Symptoms are worsening over time
- ◯ Symptoms are improving over time

48. 21. Self-assessment of impact of long COVID illness on general well being

Mark only one oval.

- ◯ Mild impact on general well being
- ◯ Moderate impact on general well being
- ◯ Severe impact on general well being

49. 22. Self-assessment of impact on long COVID illness on ability to work

Mark only one oval.

- ◯ Mild impact on ability to work
- ◯ Moderate impact on ability to work
- ◯ Severe impact on ability to work

50. 23-A: Have you been absent from work as a result of long COVID?

Mark only one oval.

- ◯ Yes
- ◯ No

51. 23-B: How much time (days) have you missed / been absent from work due to long COVID?

_____

52. 24-A: Have you previously been in receipt of social welfare supports or PUP payment while off work DUE TO long COVID?

Mark only one oval.

- ◯ Yes
- ◯ No

53. 24-B: Are you currently in receipt of social welfare supports or PUP payment DUE TO long COVID.

Mark only one oval.

- ◯ Yes
- ◯ No

Long COVID management

54. 25-A: Have you seen your GP for symptoms of long COVID?

Check all that apply.

- ☐ Yes
- ☐ No

55. 25-B: Consultation with the GP for long COVID was helpful

Mark only one oval.

	1	2	3	4	5	
Strongly Agree	◯	◯	◯	◯	◯	Strongly Disagree

56. 25-C: Has your GP formally diagnosed you as having long COVID

Mark only one oval.

- ◯ Yes
- ◯ No

57. 26-A: Have you seen a consultant/specialist for long COVID?

Mark only one oval.

- ◯ Yes
- ◯ No

58. 26-B: Consultation with the Consultant for long COVID was helpful

Mark only one oval.

	1	2	3	4	5	
Strongly agree	◯	◯	◯	◯	◯	strongly disagree

59. 27-A: Have you seen an Occupational Health physician while off work for long COVID?

Mark only one oval.

- ◯ Yes
- ◯ No

60. 27-B: Consultation with the Occupational Health physician for long COVID was helpful

Mark only one oval.

- ◯ Yes
- ◯ No

61. 27-C: Has the Occupational Health physician formally diagnosed you as having long COVID

Mark only one oval.

- ◯ Yes
- ◯ No

62. 28. Accessing and navigating services for long COVID has been difficult

Mark only one oval.

	1	2	3	4	5	
Strongly agree	◯	◯	◯	◯	◯	Strongly disagree

63. 29-A: Are you on a waiting list for a specialist long COVID clinic?

Mark only one oval.

- ◯ Yes
- ◯ No

64. 29-B: If yes how many months have you been waiting to see a consultant or long COVID specialist?

_____

65. 30. Is there anything else you would like to share about your experience of long COVID?

_____

_____

_____

_____

_____