

STIMULATE-ICP Survey 1

Start of Block: Introduction

Q1 STIMULATE-ICP (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways) Delphi Project

You are invited to take part in a research study. Before you decide whether or not to take part, it is important to understand what the study is about and what it will involve. Please read this information and if you have any questions, please contact the person named at the end. Your participation is important to us but is entirely voluntary.

Background

As we learn more about COVID-19 and are better able to support people, it has become clear that many people experience long term symptoms relating to a COVID-19 infection (Long COVID). This is a challenge for healthcare. Traditionally, care pathways for long-term conditions are focused on single diseases; however, that approach is not effective at supporting people with more than one long-term condition or those with medically not yet explained symptoms. Long COVID usually presents with clusters of symptoms, which may change over time. Therefore, healthcare services have to take a broader approach to care focusing on more than one system (biological, psychological and social which together are called a biopsychosocial approach). This is called an integrated care pathway. Integrated care means more than patient-centred care which can be provided in one setting, integrated care involves the whole pathway from primary care to specialist services and rehabilitation services.

In the UK, integrated care pathways offer an opportunity to explore the benefits of an integrated approach to care for long COVID, long-term conditions and multiple long-term conditions. This Delphi study refers to the approaches for considering transferability of present long COVID integrated care pathway care models to other long-term conditions.

This study seeks to answer the broad research question: What are effective integrated care pathways for individuals with long COVID and how can they be transferred to other long-term conditions including mental health problems, multiple long-term conditions and the interface between known medical disorders and medically not yet explained symptoms as well as newly developed conditions?

This Delphi study using a biopsychosocial approach, will investigate:

1. (a) Key enabling elements for effective integrated care pathways for individuals with long COVID, based on user experience, and (b) Strengths of existing integrated care pathways for other long-term conditions.
2. Which (part of an) integrated care pathway model for long COVID can be transferred to other long-term conditions for which care pathways were not yet developed sufficiently, and how.
3. Variations in uptake and adherence to treatment in long COVID and long-term conditions.

Who is doing the study?

This study is part of the STIMULATE-ICP research (<https://www.stimulate-icp.org/>) and is funded by the National Institute of Health Research (NIHR), UK. The study team involves a wide range of researchers from many disciplines and people both with lived experiences of Long COVID, long-term conditions and clinicians who support these groups of people from a range of health service settings. This survey has been developed with input from all groups and is the result of this collaboration. It is being led by Prof. Christina Van Der Feltz-Cornelis, Department of Health Sciences, University of York, UK.

I have a question, who can I contact?

For any questions about this Delphi project, please contact Jenny Sweetman at jennifer.sweetman@york.ac.uk.

Please indicate below whether you would like further information, or if you consent to participate in this anonymous survey:

- I would like some more information about this project before I decide whether to take part (10)
- I would like to complete this survey and consent to my anonymous data being collected for this research (9)

Skip To: End of Block If STIMULATE-ICP (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Add... = I would like to complete this survey and consent to my anonymous data being collected for this research

Page Break

Display This Question:

If STIMULATE-ICP (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Add... = I would like some more information about this project before I decide whether to take part

Q210 STIMULATE-ICP (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways) Delphi Project

Thank you for your interest in this project. Some additional information about the project is outlined below. As previously stated, your participation is important to us but is entirely voluntary.

How does a Delphi project work?

A Delphi project is used in research to generate a level of agreement about a particular area of interest. In this case, we aim to provide healthcare commissioners and policy makers with some recommendations about the best model of care for long COVID and how this might be helpful for other long term conditions such as heart problems, COPD, diabetes and mental health problems. The project involves an expert panel; a diverse group of people with lived experience and professional experience of long COVID and long term conditions who will meet at set points during the project to make decisions.

This Delphi project will have three main phases:

1. An initial survey to learn about the people, services and treatments currently available for long COVID and other long term conditions. The questions included in this survey are deliberately broad to gain an understanding of a wide range of experiences. A small number of survey respondents, who would like to provide additional information about their experiences of the way healthcare for long COVID and/or long term conditions is coordinated, will be invited to participate in an interview. The findings from this survey and interviews will be reviewed by our expert panel to create a series of statements about current care.
2. A second survey will check whether people with personal and professional experience of long COVID and/or long term conditions agree with the statements created from the first survey.
3. The level of agreement with each of the statements will help the expert panel to form a set of Key Recommendations which will be sent to healthcare commissioners and policy makers.

What is the purpose of this survey?

This is the first survey in the project and focuses on long COVID and other long term conditions such as heart problems, COPD, diabetes and mental health problems. We aim to learn about the people who provide care and those seeking support, the related healthcare services and the treatments available for long COVID and other long term conditions.

Who can complete this survey?

We are looking for adults (18 years or older) who meet one or more of the following criteria:

- someone with lived experience of long COVID
- someone with lived experience of a long term condition (such as heart problems, COPD, diabetes and mental health problems)
- a healthcare professional working with people who experience long COVID
- a healthcare professional working with people who experience a long term condition (such as heart problems, COPD, diabetes and mental health problems)

How long will this survey take to complete?

We anticipate that this survey will take most people between 5 and 15 minutes to complete. If you need to take a break while completing this survey you can do this and return to where you left.

What will happen to my responses?

Once the survey closes, all of the responses will be downloaded and stored securely in an electronic folder on the University of York server. Only researchers working on this project will have access to the survey responses. The responses will be organised to provide an overview of the information generated by this survey and this will be discussed with our expert panel. Our expert panel will review the findings of this survey and create a list of statements based on the survey information which they believe reflect the experiences of people offering and accessing support for long COVID and long term conditions.

Will you know who I am?

All survey responses are completely anonymous; none of the information you provide can be traced back to you. We will, therefore, ask for some information about you so that we can describe the range of people who complete the survey. This information will be included in the findings of this study using phrases such as "On average, people completing the survey were X years old, Y% of respondents were male."

How can I find out more information about the interviews?

At the end of this survey there will be a link to a form for people who wish to express an interest in participating in an interview for this project. Creating a link to a separate form ensures that the responses for this survey are anonymous. We will try to conduct interviews with a diverse selection of people (based on demographics, experiences of healthcare and conditions, and geographical locations) to ensure that the findings from this stage of the project are relevant to as many people as possible. Because the researchers are not able to link your responses from the survey, the expression of interest form for interviews will ask you to repeat some of the general information you have provided in this survey. We will store your information securely in an electronic file on the University of York server and use it to select people to invite for interview. We will contact everyone who has expressed an interest in participating in an interview to confirm whether they have been selected or not.

Who is doing the study?

This study is part of the STIMULATE-ICP research (<https://www.stimulate-icp.org/>) and is funded by the National Institute of Health Research (NIHR), UK. The study team involves a wide range of researchers from many disciplines and people both with lived experiences of Long COVID, long-term conditions and clinicians who support these groups of people from a range of health service settings. This survey has been developed with input from all groups and is the result of this collaboration. It is being led by Prof. Christina Van Der Feltz-Cornelis, Department of Health Sciences, University of York, UK.

I have a question, who can I contact?

For any questions about this Delphi project, please contact Jenny Sweetman at jennifer.sweetman@york.ac.uk.

How can I take part?

Please select the option below to continue to the survey questions.

- I would like to complete this survey and consent to my anonymous data being collected for this research (1)

End of Block: Introduction

Start of Block: Filter

Q234 Thank you for agreeing to take part in this survey.

If you need to take a break you can do this and then return to where you left the survey.

Q3

Which of the following best describes you?

Please **select all that apply**.

- I have lived experience of long COVID (1)
- I have lived experience of a long-term condition (any health condition where symptoms have lasted longer than 12 months) (2)
- I am a healthcare professional providing care to people with long COVID (3)
- I am a healthcare professional providing care to people with one or more long-term conditions (4)

End of Block: Filter

Start of Block: Lived Experience LC

Q11 Thank you. This section of this survey focuses on your experience of living with long COVID and any contact with health services that you've had in relation to long COVID. The information you provide will help us to create recommendations to improve health services for people with long COVID. These recommendations may also be helpful for people with other long-term conditions.

All of the information you provide is completely anonymous.

Display This Question:

If Which of the following best describes you? Please select all that apply. = I have lived experience of long COVID

Q12 What is the main symptom of long COVID that affects you?

Display This Question:

If Which of the following best describes you? Please select all that apply. = I have lived experience of long COVID

Q47 How long have you been experiencing long COVID symptoms?

- Less than 3 months (19)
- 3- 6 months (20)
- 6-12 months (21)
- 12-18 months (22)
- More than 18 months (23)

Display This Question:

If Which of the following best describes you? Please select all that apply. = I have lived experience of long COVID

Q237 If there are other symptoms of long COVID which have a significant impact on your life that you would like to tell us about, you can list them in the box below:

Page Break

Q51 Did you seek advice from a healthcare professional about your long COVID symptom(s)?

- Yes (1)
- No (2)

Page Break

Display This Question:

If Did you seek advice from a healthcare professional about your long COVID symptom(s)? = Yes

Q52 Which healthcare professional did you approach?

Please **select all that apply**.

- Doctor (1)
 - Nurse (2)
 - Occupational therapist (5)
 - Physiotherapist (4)
 - Psychological therapist (6)
 - Another health professional (please specify) (3)
-

Display This Question:

If Did you seek advice from a healthcare professional about your long COVID symptom(s)? = Yes

Q54 If you experience more than one symptom, how did you deal with that when you were in contact with the clinician?

- Selected one symptom and talked about that (4)
 - Tried to cover all symptoms (5)
 - Not applicable, I experience one symptom (8)
-

Display This Question:

If Did you seek advice from a healthcare professional about your long COVID symptom(s)? = Yes

Q56 Did the health professional recognise your problem?

- Yes (1)
 - Unsure (2)
 - No (3)
 - Please select one of the options above and use this box if you would like to provide more information. (4) _____
-

Page Break

Display This Question:

If Did you seek advice from a healthcare professional about your long COVID symptom(s)? = Yes

Q61 Were you offered any of the following?

Please **select all that apply**

- Advice for self-care (1)
- Information about long COVID (2)
- Support from a website (7)
- Support from an app (8)
- Medical tests (please specify) (9) _____
- Treatment (please specify) (3) _____
- Referral to specialist service(s) (please specify) (4)

- Other (please describe) (5) _____
- No, I was not offered anything (6)

Skip To: Q195 If Were you offered any of the following? Please select all that apply = No, I was not offered anything

Display This Question:

If Were you offered any of the following? Please select all that apply = Referral to specialist service(s) (please specify)

Q63 Did you attend an appointment at the specialist service(s)?

- Yes (1)
 - No (2)
 - I am waiting for an appointment (3)
-

Display This Question:

If Did you seek advice from a healthcare professional about your long COVID symptom(s)? = Yes

Q76 Were your symptoms ever considered to relate to another health condition?

Yes (please specify) (1) _____

No (2)

Please select one of the options above and use this box if you would like to provide more information. (3) _____

Page Break

Display This Question:

If Did you seek advice from a healthcare professional about your long COVID symptom(s)? = Yes

Q71 Please think about the service that offered you support for long COVID.

What did they do that worked well?

1. (4) _____

2. (5) _____

3 (6) _____

Display This Question:

If Did you seek advice from a healthcare professional about your long COVID symptom(s)? = Yes

Q196

What do you think could have been improved?

1. (4) _____

2. (5) _____

3 (6) _____

Page Break

Q195 Overall, what are the most important things that healthcare services should prioritise when offering support to people with long COVID?

1. (4) _____

2. (5) _____

3 (6) _____

End of Block: Lived Experience LC

Start of Block: Lived Experience LTC

Q13 Thank you. This section of this survey focuses on your experience of living with one or more long-term conditions (any health condition where symptoms have lasted longer than 12 months) and any contact with health services that you've had in relation to your long term condition(s). The information you provide will help us to create recommendations to improve health services for people with long COVID and other long-term conditions.

All of the information you provide is completely anonymous.

Display This Question:

If Which of the following best describes you? Please select all that apply. = I have lived experience of a long-term condition (any health condition where symptoms have lasted longer than 12 months)

Q8 Which long-term condition(s) do you live with?

(A health condition where symptoms have lasted longer than 12 months)

(Please select all that apply)

Heart problem(s) (please describe) (1)

COPD (2)

Diabetes (3)

Mental health problem(s) (please describe) (4)

Other (please describe) (5) _____

Display This Question:

If Which of the following best describes you? Please select all that apply. = I have lived experience of a long-term condition (any health condition where symptoms have lasted longer than 12 months)

Q14 What is the main symptom that affects you?

Display This Question:

If Which of the following best describes you? Please select all that apply. = I have lived experience of a long-term condition (any health condition where symptoms have lasted longer than 12 months)

Q198 How long have you been experiencing symptoms?

- Less than 3 months (19)
 - 3- 6 months (20)
 - 6-12 months (21)
 - 12-18 months (22)
 - More than 18 months (23)
-

Display This Question:

If Which of the following best describes you? Please select all that apply. = I have lived experience of a long-term condition (any health condition where symptoms have lasted longer than 12 months)

Q238 If there are other symptoms of your long-term condition(s) which have a significant impact on your life that you would like to tell us about, you can list them in the box below:

Page Break

Q82 Did you seek advice from a healthcare professional about your symptom(s)?

- Yes (1)
 - No (2)
-

Page Break

Display This Question:

If Did you seek advice from a healthcare professional about your symptom(s)? = Yes

Q87 Which healthcare professional did you approach?

Please **select all** that apply.

- Doctor (1)
- Nurse (2)
- Occupational therapist (3)
- Physiotherapist (4)
- Psychological therapist (5)
- Another healthcare professional (please specify) (6)

Display This Question:

If Did you seek advice from a healthcare professional about your symptom(s)? = Yes

Q88 If you experience more than one symptom, how did you deal with that when you were in contact with the clinician?

- Selected one symptom and talked about that (4)
- Tried to cover all symptoms (5)
- Not applicable, I experience one symptom (7)

Display This Question:

If Did you seek advice from a healthcare professional about your symptom(s)? = Yes

Q89 Did the health professional recognise your problem?

- Yes (1)
- Unsure (2)
- No (3)
- Please select one of the options above and use this box if you would like to provide more information. (4)

Page Break

Display This Question:

If Did you seek advice from a healthcare professional about your symptom(s)? = Yes

Q93 Were you offered any of the following?

Please **select all that apply**

- Advice for self-care (1)
- Information about your long-term condition (2)
- Support from a website (7)
- Support from an app (8)
- Medical tests (please specify) (9) _____
- Treatment (please specify) (3) _____
- Referral to specialist service(s) (please specify) (4)

- Other (please describe) (5) _____
- No, I was not offered anything (6)

Skip To: Q201 If Were you offered any of the following? Please select all that apply = No, I was not offered anything

Display This Question:

If Were you offered any of the following? Please select all that apply = Referral to specialist service(s) (please specify)

Q98 Did you attend an appointment at the specialist service(s)?

- Yes (1)
- No (2)
- I am waiting for an appointment (3)

Display This Question:

If Did you seek advice from a healthcare professional about your symptom(s)? = Yes

Q106 Were your symptoms ever considered to relate to another health condition?

- Yes (please specify) (1) _____
- No (2)
- Please select one of the options above and use this box if you would like to provide more information. (3) _____

Display This Question:

If Did you seek advice from a healthcare professional about your symptom(s)? = Yes

Q199 Please think about the service that currently or previously has offered you support for your long-term condition(s).

What did they do that worked well?

- 1. (4) _____
 - 2. (5) _____
 - 3 (6) _____
-

Display This Question:

If Did you seek advice from a healthcare professional about your symptom(s)? = Yes

Q200

What do you think could have been improved?

- 1. (4) _____
 - 2. (5) _____
 - 3 (6) _____
-

Q201 Overall, what are the most important things that healthcare services should prioritise when offering support to people with long-term conditions?

- 1. (4) _____
- 2. (5) _____
- 3 (6) _____

End of Block: Lived Experience LTC

Start of Block: Lived Experience general questions

Q108 Do you have a preference about how appointments for diagnosis or treatment are offered?

- In person (1)
- Telephone (2)
- Online, video call (3)
- Other (please tell us your preference) (4)

End of Block: Lived Experience general questions

Start of Block: HCP LC

Q17 Thank you. This section of this survey focuses on your experience of providing healthcare to people experiencing long COVID. The information you provide will help us to create recommendations to improve health services for people with long COVID. These recommendations may also be helpful for people with other long-term conditions.

All of the information you provide is completely anonymous.

Q124 What is the standard response to someone with symptoms of long COVID who is referred to your service? Please indicate **all that apply**.

- Offer advice (1)
 - Provide information (2)
 - Support from a website (7)
 - Support from an app (8)
 - Request screening/diagnostic investigations (please specify) (3)

 - Offer treatment (please specify) (4)

 - Refer to another service (please specify) (5)

 - Other (please describe) (6) _____
-

Page Break

Q186 Please name three issues which should be addressed in integrated care for long COVID:

- 1. (1) _____
 - 2. (2) _____
 - 3. (3) _____
-

Q140 Please name three issues which should be addressed when patients present to your service with long COVID and other health condition(s)?

- 1. (4) _____
 - 2. (5) _____
 - 3. (6) _____
-

Q219 Are there aspects of long COVID care which may be useful for supporting people with other long-term conditions?

- Yes (4)
 - No (5)
-

Page Break

Q235 Please name three aspects of long COVID care which may be useful for supporting people with other long-term conditions:

- 1. (1) _____
- 2. (2) _____
- 3. (3) _____

End of Block: HCP LC

Start of Block: HCP LTC

Q18 Thank you. This section of this survey focuses on your experience of providing healthcare to people experiencing one or more long-term conditions (any health condition where symptoms last longer than 12 months). The information you provide will help us to create recommendations to improve health services for people with long COVID and other long-term conditions.

All of the information you provide is completely anonymous.

Q9 Please indicate the long-term condition(s) that you support people with:

Heart problems (please describe) (1)

COPD (2)

Diabetes (3)

Mental health problem(s) (please describe) (4)

Other (please describe) (5) _____

Q156 How do you respond to someone with symptoms of the long-term condition you provide support for? Please indicate **all that apply**.

Offer advice (1)

Provide information (2)

Support from a website (7)

Support from an app (8)

Request screening/diagnostic investigations (please specify) (3)

Offer treatment (please specify) (4)

Refer to another service (please specify) (5)

Other (please describe) (6) _____

Page Break

Q190 Please name three issues which should be addressed in integrated care for the long-term condition you support:

- 1. (1) _____
 - 2. (2) _____
 - 3. (3) _____
-

Q233 Please name three issues which should be addressed when patients present to your service with multiple long-term conditions:

- 1. (1) _____
- 2. (2) _____
- 3. (3) _____

End of Block: HCP LTC

Start of Block: HCP general questions

Q137 Please tell us about three things which work well in your service?

- 1. (1) _____
 - 2. (2) _____
 - 3. (3) _____
-

Q185 Please tell us about three things which could be improved in your service?

- 1. (1) _____
 - 2. (2) _____
 - 3. (3) _____
-

Page Break

Q143 Do patients present to your service with medically unexplained symptoms?

- Yes (1)
 - No (2)
-

Q144 What are the most important things to consider when people present with unexplained symptoms?

1. (4) _____

2. (5) _____

3. (6) _____

Q178 What do you do when people present with a mixture of explained and unexplained symptoms?

Page Break

Q131 What is your understanding of integrated care?

Q145 Do you feel that your service provides integrated care?

Yes (1)

Maybe (please explain) (2) _____

No (3)

Page Break

Display This Question:

If Do you feel that your service provides integrated care? = Yes

Q221 Concerning the digital divides between providers, have these have been overcome in your service?

Yes (how have these barriers been overcome?) (1)

No (what impact does that have on service provision?) (3)

Page Break

End of Block: HCP general questions

Start of Block: Demographics

Q182 Long COVID and long-term conditions often involve clusters of symptoms, which may change over time. Therefore, healthcare services have to take a broader approach to care focusing on more than one system (biological, psychological and social). This is called an integrated care pathway. Integrated care means more than patient-centred care which can be provided in one setting, integrated care involves the whole pathway from primary care to specialist services and rehabilitation services.

If a service would offer integrated support, combining physical, social and psychological support, what should that look like?

Display This Question:

If Which of the following best describes you? Please select all that apply. = I have lived experience of long COVID

Or Which of the following best describes you? Please select all that apply. = I have lived experience of a long-term condition (any health condition where symptoms have lasted longer than 12 months)

Q239 If you would like to tell us anything more about your symptoms and treatment experiences, please add that information in the box below:

Page Break

Q2

Thank you for providing information about your experiences.

This final set of questions ask for general information about you. The information you provide will help us to describe who has contributed to this stage in the Delphi project.

All of the information you provide is completely anonymous.

Q4 What is your gender?

- Male (1)
 - Female (2)
 - Non-binary / third gender / other (please describe) (3)
-

Prefer not to say (4)

Q5 What is your age in years?

Q6 Please enter the name of the closest city to your home where there is a hospital

Q7 What is your ethnicity?

- Asian or Asian British (1)
- Black, Black British, Caribbean or African (2)
- Mixed or multiple ethnic groups (3)
- White (4)
- Other ethnic group (please describe) (5) _____

Q183 Which of the following best describes your relationship status?

- Single (1)
- Co-habiting (2)
- In a relationship (3)
- Married (4)
- Divorced (5)
- Widowed (6)
- Other (please describe) (7) _____

Page Break

Q54 What is your work status?

- Full time employment (1)
- Part time employment (2)
- Self-employed/freelance (3)
- Student (4)
- Retired (5)
- Volunteer (6)
- Unemployed (7)
- Stay at home parent (8)
- Carer (9)
- Prefer not to answer (10)
- Other (please specify) (11) _____

End of Block: Demographics

Start of Block: Patient demographics

Q114 You have indicated that you have lived experience of long COVID and/or long-term condition(s). The following questions ask about your current well-being. Over the **past 2 weeks**, how often have you been bothered by the following problems?

| | Not at all (1) | Several days (2) | More than half the days (3) | Nearly every day (4) |
|--|-----------------------|-----------------------|-----------------------------|-----------------------|
| Feeling nervous, anxious or on edge (1) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Not being able to stop or control worrying (2) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Q119 Over the past 2 weeks, how often have you been bothered by any of the following problems?

| | Not at all (1) | Several days (2) | More than half the days (3) | Nearly every day (4) |
|---|-----------------------|-----------------------|-----------------------------|-----------------------|
| Little interest or pleasure in doing things (1) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Feeling down, depressed, or hopeless (2) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Q176 Do you experience brain fog (problems with memory and concentration)?

- Yes (what is your main symptom) (1) _____
- No (2)

End of Block: Patient demographics

Start of Block: HCP demographics

Q184

You have indicated that you are a healthcare professional working with people with long COVID and/or long-term condition(s).

What is your job title?

Q117 Please indicate the type of healthcare service you work in:

- Primary care (1)
- Secondary/specialty care (2)
- Acute care (3)
- Community care (5)
- Other (please describe) (4) _____

End of Block: HCP demographics

Start of Block: Thank you and Interview survey link

Q25

It's really helpful to understand how to reach people who might want to be involved in similar projects. Please tell us how you heard about this survey:

Page Break

Q10 Thank you for taking the time to complete this survey.

If you would like to help us understand your experiences in more detail, please follow the link to complete an expression of interest form to participate in an interview about the way healthcare for long COVID and/or long-term conditions is coordinated: [Expression of Interest](#) form.

Updates relating to this project, and other projects which are part of the STIMULATE-ICP research can be found at <https://www.stimulate-icp.org/>

Later this year we will launch a second survey to check whether people with personal or professional experience of long COVID and/or long-term conditions agree with the statements produced by this research. Responses to these statements will help us to understand which recommendations could improve health services for people with long COVID and other long-term conditions. We would value your responses to this second survey.

End of Block: Thank you and Interview survey link

STIMULATE-ICP Survey 2

Start of Block: Main survey

Q5 STIMULATE-ICP (Symptoms, Trajectory, Inequalities and Management:

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Background

This is the second survey being conducted as part of the STIMULATE-ICP project to learn more about Integrated care pathways for Long COVID and for other long-term conditions. Long COVID usually presents with clusters of symptoms, which may change over time. Therefore, healthcare services have to take a broader approach to care focusing on more than one organ system.

Integrated care means more than patient-centred care which can be provided in one setting; integrated care involves the whole pathway from primary care to specialist services and rehabilitation services. In the UK, integrated care pathways already exist for other long-term conditions such as for example diabetes or heart disease.

This study seeks to answer the broad research question: What are effective integrated care pathways for individuals with long COVID and how can they be transferred to other long-term conditions including mental health problems, multiple long-term conditions and the interface between known medical disorders and medically not yet explained symptoms as well as newly developed conditions?

Who is doing the study?

This study is part of the STIMULATE-ICP research (<https://www.stimulate-icp.org/>) that is led by Prof. Ami Banerjee, University College London, and is funded by the National Institute of Health Research (NIHR), UK. The STIMULATE-ICP team involves a wide range of researchers from many disciplines, people with lived experiences (PPI) of Long COVID and long-term conditions, and clinicians from a range of health service settings. This Delphi survey has been developed with input from all groups and is the result of this collaboration. It is being led by Prof. Christina Van Der Feltz-Cornelis, Department of Health Sciences, University of York, UK as academic lead, and co-leads Dr. Gail Allsopp, GP, Royal College of General Practitioners, Prof. Mark Gabbay, GP, Patient and Public involvement (PPI) leads Emily Attree, PPI and GP and Lyth Hishmeh, PPI.

What is the survey for?

In a first survey, important aspects of integrated care pathways have been identified and summarised in statements about what integrated care should look like. This second survey now provides the opportunity to indicate the level of agreement with each statement, and to rank them in terms of importance.

What will we do with your survey responses?

If you choose to take part in the survey, we will collate the answers you provided with all the other survey respondents. This will allow us to understand whether people agree with the proposed statements, and identify the statements that are most important to patients, healthcare professionals, carers and the general public. These will then be taken forward to inform a meeting with an expert panel involving patients and healthcare professionals where policy recommendations will be decided. The final step, in the future, will be for the STIMULATE-ICP team to provide policy recommendations for what integrated care should look like, for Long COVID as well as other long term conditions. These recommendations will be shared with healthcare providers and policymakers to influence the future care for Long COVID and other long term conditions.

What you can do to help?

We would like you to indicate whether you agree with the statements shown, and prioritise the statements which matter to you the most from the list that follows. This is an anonymous survey, but we will also ask for a little information about you so that we can understand who is responding and whether we're reaching as wide a range of people as possible. We won't be able to identify you in any of the survey results and we will keep the information you give us secure.

Please indicate below whether you consent to participate in this anonymous survey:

I give consent to participate in this survey (4)

I do not give consent to participate (5)

Skip To: End of Survey If STIMULATE-ICP (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Add... = I do not give consent to participate

Page Break

Q53 Have you accessed this survey through Prolific?

Yes (1)

No (2)

End of Block: Main survey

Start of Block: IC_LC



This symbol indicates the content of the following question has been presented in a random order.

Q44 The following questions relate to care for long COVID.

Please indicate the extent to which you agree or disagree with each of the statements.

Integrated care for long COVID should ...

| | Strongly agree (1) | Agree (2) | Do not agree or disagree (3) | Disagree (4) | Strongly disagree (5) |
|--|-----------------------|-----------------------|------------------------------|-----------------------|-----------------------|
| Offer timely, consistent and easy access to multi-disciplinary care (89) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Ensure the person is listened to, acknowledged, supported and believed, thus validating their experience and knowledge (90) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Provide appropriate diagnostic assessment which is person centred to rule out other conditions, aiming to confirm a diagnosis (91) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Offer personalised continuity of care (92) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Provide personalised evidence-based fatigue management (93) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Provide evidence-based treatment and recommendations (94) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Ensure all services offer a comprehensive biopsychosocial multi-system model of care (95) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Provide vocational rehabilitation with employment and welfare support (96) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Ensure services have sufficient and appropriate resources, including funding (97) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Provide self-management advice and support in line with individual needs and abilities (98) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Include long-term care with reviews of health, care provision, personalised care plans and provide a care coordinator (99) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Ensure clinicians and services provide knowledge and understanding of symptoms and services available to patients (100) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Offer opportunities for patient-led support and social prescribing (101) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Provide easy access to research studies where possible (102) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Share information between services (103) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |



This symbol indicates the content of the following question has been presented in a random order.

Q29 Please rank the following statements to indicate which you consider to be the most important (1= most important, 15= least important).

To do this, drag and drop the statements into your preferred order. To help you, numbers will appear once you move a statement in the list.

Integrated care for long COVID should...

- Offer timely, consistent and easy access to multi-disciplinary care (1)
- Ensure the person is listened to, acknowledged, supported and believed, thus validating their experience and knowledge (47)
- Provide appropriate diagnostic assessment which is person centred to rule out other conditions, aiming to confirm a diagnosis (48)
- Offer personalised continuity of care (49)
- Provide personalised evidence-based fatigue management (50)
- Provide evidence-based treatment and recommendations (51)
- Ensure all services offer a comprehensive biopsychosocial multi-system model of care (52)
- Provide vocational rehabilitation with employment and welfare support (53)
- Ensure services have sufficient and appropriate resources, including funding (54)
- Provide self-management advice and support in line with individual needs and abilities (55)
- Include long-term care with reviews of health, care provision, personalised care plans and provide a care coordinator (56)
- Ensure clinicians and services provide knowledge and understanding of symptoms and services available to patients (57)
- Offer opportunities for patient-led support and social prescribing (58)
- Provide easy access to research studies where possible (59)
- Share information between services (60)

End of Block: IC_LC

Start of Block: IC_LTC



This symbol indicates the content of the following question has been presented in a random order.

Q53 The following questions relate to care for long term conditions (any health condition where symptoms have lasted longer than 12 months).

Please indicate the extent to which you agree or disagree with each of the statements.
 Integrated care for long term conditions should ...

| | Strongly agree (1) | Agree (2) | Do not agree or disagree (3) | Disagree (4) | Strongly disagree (5) |
|--|-----------------------|-----------------------|---------------------------------|-----------------------|--------------------------|
| Offer timely, consistent and easy access to multi-disciplinary care (1) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Ensure the person is listened to, acknowledged, supported and believed, thus validating their experience and knowledge (47) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Provide appropriate diagnostic assessment which is person centred to rule out other conditions, aiming to confirm a diagnosis (48) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Offer personalised continuity of care (49) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Provide personalised evidence-based fatigue management (50) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Provide evidence-based treatment and recommendations (51) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Ensure all services offer a comprehensive biopsychosocial multi-system model of care (52) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Provide vocational rehabilitation with employment and welfare support (53) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Ensure services have sufficient and appropriate resources, including funding (54) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Provide self-management advice and support in line with individual needs and abilities (55) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Include long-term care with reviews of health, care provision, personalised care plans and provide a care coordinator (56) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Ensure clinicians and services provide knowledge and understanding of symptoms and services available to patients (57) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Offer opportunities for patient-led support and social prescribing (58) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Provide easy access to research studies where possible (59) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Share information between services (60) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |



This symbol indicates the content of the following question has been presented in a random order.

Q54 Please rank the following statements to indicate which you consider to be the most important (1= most important, 15= least important).

To do this, drag and drop the statements into your preferred order. To help you, numbers will appear once you move a statement in the list.

Integrated care for long term conditions should...

- _____ Offer timely, consistent and easy access to multi-disciplinary care (1)
- _____ Ensure the person is listened to, acknowledged, supported and believed, thus validating their experience and knowledge (47)
- _____ Provide appropriate diagnostic assessment which is person centred to rule out other conditions, aiming to confirm a diagnosis (48)
- _____ Offer personalised continuity of care (49)
- _____ Provide personalised evidence-based fatigue management (50)
- _____ Provide evidence-based treatment and recommendations (51)
- _____ Ensure all services offer a comprehensive biopsychosocial multi-system model of care (52)
- _____ Provide vocational rehabilitation with employment and welfare support (53)
- _____ Ensure services have sufficient and appropriate resources, including funding (54)
- _____ Provide self-management advice and support in line with individual needs and abilities (55)
- _____ Include long-term care with reviews of health, care provision, personalised care plans and provide a care coordinator (56)
- _____ Ensure clinicians and services provide knowledge and understanding of symptoms and services available to patients (57)
- _____ Offer opportunities for patient-led support and social prescribing (58)
- _____ Provide easy access to research studies where possible (59)
- _____ Share information between services (60)

End of Block: IC_LTC

Start of Block: Demographics

Q2

The following questions will help us understand who is responding to this survey and whether we're reaching as wide a range of people as possible.

All the questions in this section are optional. We won't be able to identify you in any of the survey results and we will keep the information you give us secure.

Q4 What is your gender?

- Male (1)
- Female (2)
- Non-binary / third gender / other (please describe) (3)

- Prefer not to say (4)

Page Break

Q5 What is your age in years?

Page Break

Q48

Which of the following best describes you?

Please **select all** that apply.

- I have no experience of long COVID or another long term health condition (6)
- I have lived experience of long COVID (1)
- I have lived experience of a long-term condition (any health condition where symptoms have lasted longer than 12 months) (2)
- I am a healthcare professional providing care to people with long COVID (3)
- I am a healthcare professional providing care to people with one or more long-term conditions (4)
- I am a carer for someone with one or more health conditions (7)

Page Break

Display This Question:

If Which of the following best describes you? Please select all that apply. = I have lived experience of a long-term condition (any health condition where symptoms have lasted longer than 12 months)

Q46

You indicated that you have lived experience of one or more long-term conditions. Which long-term condition(s) do you have experience of?

Page Break

Display This Question:

If Which of the following best describes you? Please select all that apply. = I have lived experience of a long-term condition (any health condition where symptoms have lasted longer than 12 months)

Q51

Do you have experience of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Yes (6)

No (7)

Page Break

Display This Question:

If Which of the following best describes you? Please select all that apply. = I am a healthcare professional providing care to people with long COVID

Or Which of the following best describes you? Please select all that apply. = I am a healthcare professional providing care to people with one or more long-term conditions

Q45

You indicated that you have professional experience of supporting people with one or more long-term conditions. Which long-term condition(s) do you support people with?

Page Break

Display This Question:

If Which of the following best describes you? Please select all that apply. = I am a carer for someone with one or more health conditions

Q52

You indicated that you are a carer. Which health condition(s) do the people you care for have?

- The person/people I care for do not have any health conditions (6)
- The person/people I care for have health condition(s) (please describe) (7)

Page Break

Q6 Please enter the name of the closest city to your home where there is a hospital

Page Break

Q7 What is your ethnicity?

- Asian or Asian British (1)
- Black, Black British, Caribbean or African (2)
- Mixed or multiple ethnic groups (3)
- White (4)
- Other ethnic group (please describe) (5) _____

Page Break

Q183 Which of the following best describes your relationship status?

- Single (1)
- Co-habiting (2)
- In a relationship (3)
- Married (4)
- Divorced (5)
- Widowed (6)
- Other (please describe) (7) _____

Page Break

Q54 What is your work status?

- Full time employment (1)
- Part time employment (2)
- Self-employed/freelance (3)
- Student (4)
- Retired (5)
- Volunteer (6)
- Unemployed (7)
- Stay at home parent (8)
- Carer (9)
- Prefer not to answer (10)
- Other (please specify) (11) _____

Page Break

Display This Question:

If Which of the following best describes you? Please select all that apply. = I am a healthcare professional providing care to people with long COVID

Or Which of the following best describes you? Please select all that apply. = I am a healthcare professional providing care to people with one or more long-term conditions

Q184

You have indicated that you are a healthcare professional working with people with long COVID and/or long-term condition(s).

What is your job title?

Page Break

Display This Question:

If Which of the following best describes you? Please select all that apply. = I am a healthcare professional providing care to people with long COVID

Or Which of the following best describes you? Please select all that apply. = I am a healthcare professional providing care to people with one or more long-term conditions

Q117 Please indicate the type of healthcare service you work in:

- Primary care (1)
- Secondary/specialty care (2)
- Acute care (3)
- Community care (5)
- Other (please describe) (4) _____

Page Break

Q10

Thank you for taking the time to complete this survey.

Updates relating to this project, and other projects which are part of the STIMULATE-ICP research can be found at <https://www.stimulate-icp.org/>

End of Block: Demographics
