

## **STIMULATE-ICP-Delphi (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways Delphi): Study protocol.**

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## **Metadata**

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### **Competing Interests statement**

EA is clinical lead in a Quality Improvement Support Team for Central Camden PCN. MG is funded in part by NIHR Applied Research Collaboration NWC. TH received travel and accommodation in UK to facilitate a talk for Multiple Sclerosis Debating Society and an honorarium payment related to the Acute and General Medicine Conference. GL is Consultant and speaker for BMS/Pfizer, Boehringer Ingelheim and Daiichi-Sankyo; no fees are received personally. HM has received funding from AstraZeneca related to use of monoclonal antibodies in acute COVID-19 treatment, from Millfield Medical in relation to the development of a new CPAP machine for use in hypoxic ventilatory failure, and from Axcella Health Inc about possible new therapeutics. He has delivered paid lectures to legal groups about Long Covid, received support to attend meetings as part of consultancy for AstraZeneca, participated on advisory boards for AstraZeneca and Axcella Health. HM has been involved as Chair, UK National Covid Critical Care Committee; Trustee, UK Intensive Care Society and has stock options with Millfield Medical Ltd. WDS has received research grants from AstraZeneca, Bayer, Novartis, Novo Nordisk and Takeda, and speaker and/or advisory board honoraria from AstraZeneca, Bayer, Boehringer Ingelheim, Bristol-Myers Squibb, Eli Lilly, Janssen, Merck, Mundi-Pharma, Napp, Novartis, Novo Nordisk, Pfizer, Sanofi Aventis, Servier and Takeda. DJC has received investigator-initiated research funding, conference and/or consultancy fees from NovoNordisk, Astra Zeneca and Ipsen. CW

has had recent involvement with nine UK-based grants, has contributed to five advisory boards and been involved with six project groups or committees in a leadership or fiduciary capacity. CW has been involved with six NIHR collaborations/projects, of which STIMULATE-ICP is one. NW is a member of NIHR HTA Programme Funding Committee (commissioned research). DGW is supported by an NIHR Advanced Fellowship; University of Liverpool receives an NHS hourly rate for his consultancy work with an NHS Advancing Quality Alliance programme; he has no conflicts of interest. All other authors have no conflicts of interest to report.

### **Data availability statement**

This article describes a study protocol and as such does not report data. The data availability policy is therefore not applicable to this article.

## 1 **Abstract**

2

## 3 **Introduction**

4 As mortality rates from COVID-19 disease fall, the high prevalence of long-term sequelae  
5 (Long COVID) is becoming increasingly widespread, challenging healthcare systems  
6 globally. Traditional pathways of care for Long Term Conditions (LTCs) have tended to be  
7 managed by disease-specific specialties, an approach that has been ineffective in delivering  
8 care for patients with multi-morbidity. The multi-system nature of Long COVID and its  
9 impact on physical and psychological health demands a more effective model of holistic,  
10 integrated care. The evolution of integrated care systems (ICSs) in the UK presents an  
11 important opportunity to explore areas of mutual benefit to LTC, multi-morbidity and Long  
12 COVID care. There may be benefits in comparing and contrasting ICPs for Long COVID  
13 with ICPs for other LTCs.

## 14 **Methods and analysis**

15 This study aims to evaluate health services requirements for ICPs for Long COVID and their  
16 applicability to other LTCs including multi-morbidity and the overlap with medically not yet  
17 explained symptoms (MNYES). The study will follow a Delphi design and involve an expert  
18 panel of stakeholders including people with lived experience, as well as clinicians with  
19 expertise in Long COVID and other LTCs. Study processes will include expert panel and  
20 moderator panel meetings, surveys, and interviews. The Delphi process is part of the overall  
21 STIMULATE-ICP programme, aimed at improving integrated care for people with Long  
22 COVID.

## 23 **Ethics and dissemination**

24 Ethical approval for this Delphi study has been obtained (Research Governance Board of the  
25 University of York) as have approvals for the other STIMULATE-ICP studies. Study

26 outcomes are likely to inform policy for ICPs across LTCs. Results will be disseminated  
27 through scientific publication, conference presentation and communications with patients and  
28 stakeholders involved in care of other LTCs and Long COVID.

29 **Registration**

30 Researchregistry: [https://www.researchregistry.com/browse-the-](https://www.researchregistry.com/browse-the-registry#home/registrationdetails/6246bfefeeaaed6001f08dad/)  
31 [registry#home/registrationdetails/6246bfefeeaaed6001f08dad/](https://www.researchregistry.com/browse-the-registry#home/registrationdetails/6246bfefeeaaed6001f08dad/).

## 32 **Introduction**

33 Despite major reductions in acute COVID-19 hospitalisation and mortality,[1] the persistence  
34 of symptoms over one year later is notable in the 45% of the 1.5 million individuals who had  
35 symptoms four weeks post-COVID in the UK.[2-4] Unlike some long-term conditions  
36 (LTCs), individuals with Long COVID (i.e. those with post-COVID symptoms >12 weeks)  
37 may still fully recover. However, new care pathways for Long COVID attempt to manage it  
38 akin to a LTC, given the increasing recognition of chronic symptoms.[4, 5]  
39 Care pathways for LTCs have tended to be disease- or specialty-specific, an approach which  
40 fails to accommodate the heterogeneity of symptoms occurring in Long COVID. ICPs are  
41 structured, multi-disciplinary plans of the whole care pathway from primary care to specialist  
42 services and rehabilitation services, which may be better suited to Long COVID.[6-8] They  
43 offer coordination of investigation, treatment and rehabilitation, as well as opportunities for  
44 real-time iterative improvements in service design and delivery, quality and access to care,  
45 patient experience and satisfaction, while reducing complications and non-elective admission  
46 rates.[9-11] Evolution of integrated care systems (ICSs) in the UK provide opportunities to  
47 improve care across LTCs, multi-morbidity or multiple health conditions,[12] and Long  
48 COVID.  
49 Long COVID encompasses a broad array of symptoms and symptom clusters. It is unlikely to  
50 reflect a single condition or pathology; rather it reflects a multi-faceted condition with  
51 numerous contributory factors: some identifiable, and others not yet understood.[13]  
52 Trajectory and recovery after SARS-CoV-2 infection are poorly defined and there is overlap  
53 with medically not yet explained symptoms (MNYES), referring to symptoms which do not  
54 represent a known medical condition, yet contribute significantly to lesser quality of life and  
55 treatment need.[14] Multi-organ complications,[13, 15-18] including neuropsychiatric  
56 sequelae (up to 20%), are well-documented.[19-24]

57 Table 1 shows current models that can potentially be applied to Long COVID ICPs.  
58 Depending on setting, expectations and provisions regarding treatment may differ. It can be  
59 argued that some current models for managing LTCs require improvement[25] as they cannot  
60 cover the whole range of patient presentations; episodic care is not appropriate for  
61 unpredictable exacerbating conditions, for example heart failure and COPD.[26, 27] An effort  
62 should be made to explore how to achieve integrated care from the perspective of individual  
63 conditions, but also from the perspective of how health services and settings can inform each  
64 other, and work together, to deliver optimal care for LTCs. The current pandemic and effort  
65 to set up Long COVID clinics[28] offers a unique opportunity to explore this from the  
66 perspective of Long COVID, and then to translate back to ICPs for other LTCs. For example,  
67 model 2 could also be based in primary care with better integration of GPs, primary care  
68 nurses and therapists. Model 3 could be more of a shared care arrangement between primary  
69 and secondary care with two-way data flow between these two sectors. In other words, one of  
70 the solutions for Long COVID care could be better working arrangements between  
71 community services, primary care and specialty care and ICSs might offer the perfect space  
72 for this in England.

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79 **Table 1: Potential models for ICPs managing recovery in Long COVID and other LTCs**

<b>Model</b>	<b>Example condition(s)</b>	<b>Recovery time</b>	<b>Managed by</b>	<b>Approach</b>
Model 1	Community Acquired Pneumonia (CAP)	This may take 6 months to fully recover in terms of fatigue (NICE guideline)[29]	Primary care teams and community General Practitioners (GPs). There is a NHS CAP CQUIN aiming to support discharge from the hospital and safe follow up of these patients. Follow up imaging is usually arranged by secondary care.	Currently there is no well-developed integrated care pathway but there could be a chance to identify how to identify CAP follow up better based upon Long COVID care experiences. They support the patient through their recovery with the length of complete recovery and the ramifications for work often underestimated.
Model 2	Post myocardial infarction, significant musculoskeletal injury	Taking a medium course to resolution, e.g., 1-2 years.	Multi-disciplinary team (MDT) driven and mostly provided in rehabilitation clinics.	Rehabilitation approach, personalised to the individual including a biopsychosocial approach to care, with physiotherapy and medical attention to address anxiety and depressive symptoms
Model 3	A chronic disease like type 2 diabetes or stroke	It is managed but often recovery is not complete.	Usually managed in primary or community care, by GPs and diabetes nurses, or in the hospital setting.	Escalation of a small proportion with complex needs being managed in a specialist setting[30]
Model 4	COPD Rheumatoid Arthritis	A chronic condition that may have high disability with tendency for relapses/exacerbations.	Limited care provision, mostly based in primary care with exacerbations increasingly managed in hospital in later stages. Growing emphasis on need to improve community diagnostics and	COPD is a condition that shares breathlessness as an important symptom with Long COVID, where pulmonary rehabilitation is a key evidence based treatment and supporting self-management is a key goal. Impact on function, breathlessness and psychological wellbeing as in Long COVID. Both conditions have a relapsing



			where pulmonary rehabilitation is a key evidence-based treatment.	course of symptoms that may benefit from prompt intervention.  There is growing emphasis on the need to improve community diagnostics.
Model 5	Comorbid mental disorders and other LTC.  For example, COPD in patients with mental disorders, often related to smoking.  Or, depression in diabetes patients.	These are in general chronic conditions with high disability.  There is an unmet clinical need here.	Mental disorders have case management, crisis teams, psychiatry follow up, but they do not identify physical health needs of their patients, such as respiratory issues. And clinics for somatic conditions can have short-term treatments available for psychological treatments but there is a lack of available long-term integrated treatment.	There are pilot playgrounds for dedicated respiratory clinics for patients with mental illness across the country.  Similar pilots exist for diabetes and depression - either community-based or hospital-based.
Model 6	Encompassing multi-morbidity (i.e. more than two LTCs) as well as a spectrum of symptoms that do not fit into a usual pattern for diagnosis of a single disease i.e. MNYES,[14] or both, crossing the mental health and physical health divide.	The perceived burden of disease is high.  These are conditions requiring a multisystem approach.	No current consistent pathway of care exists. Consultation, collaborative care and decision aids supporting health care providers to provide ICP would be possibilities to link primary, community and specialist health care settings	These patients are highly likely to benefit from an ICP. This would be best served with a flag up system approach which is for people who don't quite meet full diagnostic criteria in one condition but almost meet it in many conditions. This would be labelled as MNYES but disease burden is high and there is a need to integrate physical and psychological health care provision.

80

Acronyms: Community Acquired Pneumonia (CAP), National Institute for Health and Care Excellence (NICE), General Practitioner (GP), National Health Service (NHS), Commissioning for Quality and Innovation

81

(CQUIN), Multi-disciplinary team (MDT), Chronic Obstructive Pulmonary Disease (COPD), Long term condition (LTC), Integrated care pathway (ICP), Medically not yet explained symptoms (MNYES).

82 Even in well-defined entities such as community acquired pneumonia (CAP), symptoms such  
83 as fatigue[31] may take up to six months to resolve, even in young, physically fit people,  
84 fuelling fears that their symptoms will not abate, which may be biologically, psychologically,  
85 or socially driven, or depend on treatment setting. Learning from other LTCs, optimal Long  
86 COVID management may require a biopsychosocial model, rather than consideration of these  
87 components separately.[32]

88

### 89 **Research question**

90 What are effective ICPs for individuals with Long COVID and how can they be transferred to  
91 other LTCs including mental disorders, multi-morbidity and the interface between known  
92 medical disorders and MNYES[14] as well as newly developed conditions?

93

### 94 **Materials and Methods**

#### 95 *Aims*

96 In a Delphi study using a biopsychosocial approach, we will investigate:

- 97 1. (a) Key enabling elements for effective ICPs for individuals with long COVID, based on  
98 user experience, and (b) Strengths of existing ICPs for other LTCs.
- 99 2. Which (part of an) ICP model for Long COVID can be transferred to other LTCs for which  
100 care pathways were not yet developed sufficiently, and how.
- 101 3. Variations in uptake and adherence to treatment in Long COVID and LTCs.

102

#### 103 *Study design and setting*

104 This STIMULATE-ICP-DELPHI is a sub-study of the STIMULATE-ICP project (Symptoms,  
105 Trajectory, Inequalities and Management: Understanding Long COVID to Address and  
106 Transform Existing Integrated Care Pathways).[33] (**Figure 1**)

107

108

[ **Figure 1** ]

109

110 STIMULATE-ICP is funded by the National Institute for Health Research (NIHR: COV-LT2-  
111 0043)[34] and combines clinical epidemiological studies, a complex randomised trial exploring  
112 the benefit of an ICP for Long COVID (IRAS: 1004698), and mixed methods studies exploring  
113 inequalities of care and transferability of the ICP to other LTCs (IRAS: 303958).

114

115 The STIMULATE-ICP-DELPHI study will follow a Delphi process to establish consensus  
116 agreement on statements relating to ICPs and the transferability of ICP models between Long  
117 COVID and LTCs. The Delphi approach is a structured method for collecting opinions of  
118 experts concerning a subject of their expertise, reaching consensus over a number of  
119 rounds.[35] Since its development in the 1950s[36] a commonly used variation of the Delphi  
120 method is the *estimate-talk-estimate Delphi method* that combines assembling of expert  
121 opinions on an anonymous basis during surveys with open exchange during workshops  
122 moderated by a facilitator.[37] This Delphi method will be followed in this study,[38] aiming  
123 for stepwise consensus through three rounds of expert panel meetings involving exploration,  
124 prioritization, and as a final step attaining consensus(**Figure 2**).

125

126

[ **Figure 2** ]

127

128 The meetings will be interwoven by two online surveys, with addition of qualitative  
129 interviews. After a “knowledge check”, an information package based on the survey and  
130 interview outcomes will be provided to the panel. The expert panel will then discuss  
131 outcomes and provide policy recommendations in a final meeting.[39]

132

133 This study will depart from the theoretical framework of Goldberg and Huxley's filter-model  
134 of access to care[40, 41] that describes four filters; three of which a patient has to navigate to  
135 enter a primary care treatment pathway, and a fourth to access specialist treatment. This  
136 model was originally developed for access to care for mental disorders, but it would be a  
137 good fit for exploring barriers and facilitators to entering Long COVID services and other  
138 LTCs not only for psychological symptoms but for physical symptoms as well. This extended  
139 model spans multiple healthcare challenges and extends the existing inequalities in health  
140 such as limited access to healthcare, incomplete pathways across community and hospital  
141 care, inadequate research translation to practice, and overall insufficient healthcare resources  
142 **(Figure 3)**.

143

### **[Figure 3]**

144

145 People with Long COVID and those with LTCs frequently present to healthcare services with  
146 multiple symptoms.[42-44] Therefore, this study will take account of competing demands to  
147 determine how people seeking support prioritise their symptoms when seeking help, and how  
148 healthcare providers deal with multiple symptoms reported when making decisions about  
149 appropriate care.[45, 46]

150

### **151 Study management**

152 This work will involve a research team (n=3), a moderator panel (MP) (n=3) and an expert  
153 panel (EP)(n=25). The research team will prepare, distribute and analyse all information for  
154 the project. The MP will meet regularly, providing advice and guidance to the research team  
155 to ensure scientific quality. The EP will include people with expertise in academic and  
156 clinical research in addition to lived experience of Long COVID, other LTCs such as

157 cardiovascular disorders, type 2 diabetes, mental disorders and MNYES, or multi-morbidity;  
158 5 of each group with a minimum of 25.

159

160 EP members will be selected by the MP building on suggestions from the Royal College of  
161 General Practitioners and national charities following a snowballing method. Patients with  
162 illness experience of Long COVID and other LTCs will be identified by clinics, medical  
163 trusts, patient networks and charities following a snowballing method. As part of the  
164 invitation process, the research team will inform prospective EP members about their role  
165 within the study. The EP will provide information and advice relating to their experiences of  
166 living with, or supporting people with Long COVID or LTCs.

167

#### 168 *Sample size, participant characteristics, inclusion and exclusion criteria*

169 Recruitment for Survey 1 will involve collecting quantitative and qualitative data from two  
170 purposive samples selected from community, primary care, and specialist settings. Sampling  
171 will seek to achieve sufficient numbers (minimum of N = 50 per group) in order to have a  
172 representative sample. Sample 1: patients/carers and clinicians with experience of Long  
173 COVID and other post COVID morbidity across England. Sample 2: patients/carers and  
174 clinicians involved in other LTCs. Participants in both samples will be recruited via the study  
175 website, with support from relevant online forums, associations and charities. As personalised  
176 care is now a specific NHS workstream which is intended to touch on all the LTC pathways,  
177 we will seek the opinion of ICS stakeholders (commissioners and those involved in the  
178 clinical networks) as to how personalised care should be delivered.[47-52]

179

180 The selection of interviewees for the qualitative study will be nested in the surveys.

181 Participants from Survey 1, willing and able to provide informed consent, will be invited

182 (using a separate survey link) to express interest in participating in an interview to discuss  
183 their experiences of healthcare relating to Long COVID and/or LTCs. Using details from the  
184 expression of interest form, the research team will select a purposive sample of people  
185 (minimum N=10-15) to interview. Within those volunteers, a maximum variation approach to  
186 participant selection will be adopted to ensure a wide range of experiences are reflected  
187 (accounting for experience of Long COVID and/or LTC(s), patient/clinician). Sampling will  
188 stop once saturation is reached. Both patients and clinicians will be interviewed as to how  
189 they deal with multi-morbidity or multiple symptoms and competing demands when  
190 accessing or providing healthcare, and the barriers and facilitators to providing or receiving  
191 ICP.[53-60]

192

### 193 *Data saturation*

194 Interviews conducted for this research aim to supplement and provide context to the  
195 statements made by Survey 1 participants. For each group of interview participants  
196 (patients/clinicians with experience of Long COVID or LTCs), saturation will have been  
197 achieved when interviews stop providing new topics/themes which relate to ICPs.

198

### 199 *Patient and public involvement*

200 The parent study STIMULATE-ICP has been enriched by robust patient and public  
201 involvement (PPI) using multiple channels, including regular updates and webinars, surveys,  
202 social media. The STIMULATE-ICP DELPHI study has been informed by existing  
203 engagements with people with experience of Long COVID/ LTCs in research, and PPI co-  
204 applicants who will contribute to methods and outputs. In addition, people with relevant  
205 disease experience will be involved in the EP and will be involved in the selection of other  
206 LTCs for comparison. Public and patients will be involved as stakeholders for this project,

207 increasing awareness with relevant groups and promoting research activities. PPI will be  
208 involved in drafting the recommendations and their contributions through the EP and the  
209 wider STIMULATE-ICP team will shape our ultimate policy recommendations and the  
210 dissemination of this work. PPIE leads and co-applicants will contribute to the management  
211 and conduct of Delphi and qualitative interviews, the analysis plan and dissemination of the  
212 findings.

213

## 214 *Study processes*

### 215 *Round 1*

216 During the initial EP meeting, the scope of this work will be agreed. This work will focus on  
217 adults (18 and over); outcomes will include confirming the list of relevant LTCs and those  
218 considered out of scope. As an inclusive approach, a variety of LTCs including mental  
219 disorders, multi-morbidity and the interface with MNYES will be considered. Fatigue, as a  
220 symptom, will be in scope, myalgic encephalomyelitis or chronic fatigue syndrome  
221 (ME/CFS) will be considered out of scope for this survey. Cognitive limitations will be in  
222 scope, non-capacity will be out of scope for the survey. Following confirmation of the scope,  
223 EP members will discuss and agree on questions to ask in Survey 1. The survey will include  
224 questions about:

225 1) Demographic factors (age, gender, ethnicity), relevant disease experience as patient or  
226 clinician, and clinical and work functioning profile of participants.

227 2) Experiences of Long COVID which prompted help-seeking with a focus on the process of  
228 seeking treatment, referrals, treatment(s) offered and received and whether there were any  
229 barriers or facilitators to that.

230 3) Challenges and advances for clinical care, knowledge gaps and policies, possible  
231 improvements to services, transferability of care models to other conditions will be explored  
232 for Long COVID and for other LTC ICPs.

233

#### 234 *Survey 1*

235 This will be an anonymous, online survey (using the Qualtrics[61] platform) to establish  
236 demographic information and to explore the topics by open questions. Participants will also  
237 be invited to give a first indication of what their priorities to improve integrated care would  
238 be.

239

#### 240 *Round 1 Interviews*

241 Qualitative semi-structured interviews will be used to examine the experience, and needs for  
242 treatment, of people living with Long COVID and other LTCs.

243

244 Examples of good practice will also be sought. Interview topic guides will be developed with  
245 guidance from the MP. Interviews will be offered over the telephone or a secure video-  
246 conferencing platform (zoom). Interviews are expected to last 40-50 minutes, but no longer  
247 than one hour, to reduce participant burden. With consent, they will be audio-recorded to  
248 allow verbatim transcription.[62-64] Where respondents appear fatigued, they will be given  
249 the option for the interview to take place over two time-periods, to have a family member  
250 present, or to shorten the length of the interview. The researcher will stop the interview at any  
251 point if participants indicate discomfort or distress.

252

#### 253 *Round 2*

254 The EP will use data from Survey 1 and the interviews to create a list of statements about



255 1) Current Long-COVID clinics and future recommendations.

256 2) Current care models for LTCs.

257 Statements are likely to relate to how symptoms impact on general and social functioning and  
258 service use. Statements will also explore treatment and service need for people across  
259 different disease / condition profiles, in order to inform the recommendation phase.

260

261

262 *Survey 2*

263 There will be a second anonymous online survey seeking to explore for which statements  
264 consensus exists. Participants will review and respond to each of the statements using a 7-  
265 point scale (1. Totally disagree, 7, Totally agree).

266

267 *Round 3*

268 In a final meeting, the expert panel will use the findings to finalise a series of consensus-  
269 based recommendations about optimal care models for Long COVID and how these can be  
270 applied to other LTCs. These recommendations will be shared with healthcare professionals,  
271 policy makers and healthcare commissioners with the potential to influence future care.

272

273 ***Data analysis and outcomes***

274 Data analysis will provide descriptive statistics to outline the demographic characteristics of  
275 the two samples. Item response frequencies provide information about the current services  
276 offered. Open-ended questions will capture individual experiences of services and  
277 suggestions for future improvements. Responses will be organised into themes, with the  
278 research team adopting a pragmatic approach to provide feedback for the second expert panel  
279 meeting.

280

281 Thematic analysis will be conducted on data transcripts for round 1 interviews.[65] Theme  
282 development will be derived deductively from the topic guide. However, we will also allow  
283 for inductive theme development and will actively seek to identify new themes or topics  
284 within our data.[66] Following initial deductive and inductive coding, analysis will be set in  
285 the context of relevant theoretical concepts from the experience of chronic illness, such as,  
286 for example, the adapted Goldberg and Huxley's filter model;[40] competing demands in  
287 primary care;[46] biographical disruption;[67] and illness careers.[68] Emergent patterns and  
288 early analysis will be discussed at regular research and moderator panel meetings for  
289 comment. Data from Survey 1 and Interviews will be combined and presented to the EP for  
290 consideration during round 2 of this study.

291

292 Data analysis will collate responses to Survey 2. Then consensus of opinion about each  
293 statement will be assessed using interquartile deviations (IQD). For this calculation, at least  
294 50% of individuals will have responded using the same category.  $IQD \leq 1$  is considered to  
295 indicate consensus. Findings from survey 2 will be combined with an information pack based  
296 upon input from other STIMULATE-ICP sub studies as lined out in Figure 1, and shared with  
297 the EP members.

298

### 299 ***Data management plan***

300 This study will produce online survey data and qualitative interview data. Online surveys  
301 will be anonymous and therefore a survey ID code will be created for participants (for  
302 example, S146 would be the code given to Survey 1 participant number 46). Data will be  
303 downloaded from Qualtrics to Microsoft Excel. Qualitative interview data will be audio  
304 recorded via Zoom (for virtual interviews or telephone interviews). Participant ID codes will

305 be provided to all participants (for example, DI07 would be the code given to Delphi  
306 Interview participant number 7). A password-protected Microsoft Excel file will be used to  
307 track the status of data preparation for each interview; this document will contain participant  
308 names and ID codes. Audio recording will be transcribed verbatim into Microsoft Word  
309 documents. Transcripts will then be anonymised ready for analysis.

310

311 All data will be stored electronically on the University of York secure server with access  
312 restricted to the research team involved with this project. Analysis will be conducted in  
313 Microsoft Excel, SPSS and NVivo. Anonymous data (such as Survey 1 original responses)  
314 will be shared with MP and EP members to enable discussions and decisions about the  
315 organisation of data and the development of statements.

316

### 317 *Ethics*

318 This Delphi study was reviewed and approved by the University of York Department of  
319 Health Sciences Research Governance Committee in December 2021  
320 (HSRGC/2021/478/A:STIMULATE).

321

### 322 *Informed consent*

#### 323 SURVEY

324 Regarding the survey, following the presentation of participant information, consent for  
325 anonymous data to be collected, analysed and disseminated as part of this project will be  
326 required before survey questions are displayed for Surveys 1 and 2.

#### 327 INTERVIEW

328 Regarding the interview, a separate survey link will be embedded at the end of Survey 1 to  
329 enable participants to express an interest in participating in a subsequent qualitative interview

330 without linkage to their survey answers. All individuals who express an interest in being  
331 interviewed will be contacted to confirm whether they have been selected to contribute to the  
332 interviews. Individuals who are selected for interview will then receive full interview study  
333 information and will be required to provide consent if they wish to participate in an interview.

#### 334 *Data handling*

335 The study is compliant with the requirements of General Data Protection Regulation  
336 (2016/679) and the UK Data Protection Act (2018). All investigators involved in the study  
337 will comply with the requirements of the General Data Protection Regulation (2016/679) with  
338 regards to the collection, storage, processing and disclosure of personal information, and will  
339 uphold the Act's core principles. For this STIMULATE-ICP Delphi sub-study, survey data  
340 will be downloaded and stored/archived at the University of York. All interviews will be  
341 recorded. Interview data will be transcribed and coded by JS and will be identified and  
342 stored/archived at the University of York. Information provided to survey and interview  
343 participants will outline their right to withdraw at any point during this research. Data  
344 collected up to the point of withdrawal will be used unless there is an expressed request for  
345 withdrawal of all data.

#### 346 *Safety considerations*

347 There are not considered to be any safety concerns for participants involved with this project.  
348 EP and MP members will be informed of the project aims, the focus of their role and the  
349 project timescales prior to joining the study. These are voluntary roles and individuals can  
350 withdraw from the study at any time. Likewise, Survey participants' data will be shared  
351 anonymously with basic demographic details being collected to enable researchers to  
352 describe the sample. Survey participants will be able to ask questions to the research team,  
353 provide consent and withdraw at any point. Interview participants will provide contact  
354 details to the research team to enable interviews to be organised and conducted. Transcribed

355 data will be anonymised, and interview participants can stop or pause interviews at any point  
356 should they wish to. All data collected will be online, virtually or using the telephone to  
357 minimise any burden for participants. The anticipated time to complete each research activity  
358 will be shared with potential participants to enable them to make informed decisions about  
359 whether to participate in each element of the study.

360

### 361 *Status and study timeline*

362 Jan-Feb 2022 – Recruitment of Expert Panel members

363 March 2022 – Initial Expert Panel meeting

364 April 2022 – Survey 1 launched online

365 May 2022 – Interviews started

366 June 2022 – Survey 1 closed

367 July 2022 – Interviews completed, Survey 1 data cleaning and analysis

368 August 2022 – Survey 1 data analysis, Interview data transcription, small groups of Expert

369 Panel members discuss preliminary organisation of data from Survey 1

370 September 2022 – Second Expert panel meeting, Interview data analysis

371 October 2022 – Launch of Survey 2 online, Interview data analysis

372 November 2022 – Interview data analysis

373 December 2022 – Survey 2 closed, Interview data analysis

374 January 2023 – Survey 2 data cleaning and analysis

375 Feb/March 2023 – Final Expert Panel meeting

376 March 2023 – Key recommendations finalised and disseminated

377

### 378 **Discussion**

#### 379 *Dissemination*

380 We will publish the findings from this Delphi study in peer reviewed journals and will  
 381 present the findings during conferences. Table 2 provides an overview of the proposed  
 382 deliverables for stakeholders during the study.

383 **Table 2 Dissemination to stakeholders**

<b>Early deliverables</b>	<b>Early read out and contact with stakeholders (NHS England, the Royal College of GPs, AHSNs, other Royal Colleges, RCP, RCPsych, patient groups and NICE)</b>		
What should integrated care look like? What should be integrated for Long COVID, other LTCs and multimorbidity?			
How can ICPs integrate primary and specialty health care, as well as somatic and mental health care?			
Patient and clinician experiences in ICPs and variety in Long COVID and other LTCs regarding funding and structure of their care pathways.			
Inform care pathways for other LTCs that are unheard or under-served.			
What are facilitators and barriers to integrated care pathways?			
<b>Final deliverable</b>	<b>Contact with stakeholders (NHS England, the Royal College of GPs, AHSNs, other Royal Colleges, RCP, RCPsych, patient groups and NICE)</b>		
<b>Outputs</b>	Webinar contact with stakeholders	Report with summary of findings for stakeholders	Policy recommendations
Novel models of provision across sectors, addressing biological, psychological and social components as a matter of routine, new multi-disciplinary groups in settings such as primary care.			

384

385

386 ***Conclusions***

387 The pandemic and the legacy of Long COVID will alter the landscape of the UK NHS  
 388 forever, and possibly health care systems in other countries as well. This Delphi study can  
 389 support a novel way of developing integrated models of care. It will inform the beginning of

390 a change in NHS integrated care systems across diseases and the primary and specialty health  
391 care divide, while putting the patient first.

392 **Authors' Contributions**

393 Conceptualisation and methodology: CFC, JS, GA, EA, MG, AB, STIMULATE-ICP team.  
394 Funding acquisition: all authors. Ethics: CFC, AB, PM. Project administration: CFC. Original  
395 manuscript drafting and preparation: CFC, JS. Review and editing of manuscript: all authors.  
396 Patient and public involvement: LH, EA. All authors approved the final version of the article.  
397

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416 COVID Recovery; Professor Sir Mike Brady, Dr Rajarshi Banerjee, Dr Cat Kelly—



417    Perspectum. An up-to-date version of Consortium members can be  
418    found: <https://www.stimulate-icp.org/team>. STIMULATE-ICP can be contacted  
419    at: [info@stimulate-icp.org](mailto:info@stimulate-icp.org) Papiya Mazumdar contributed to obtaining ethics approval.

420

## 421    **References**

- 422    1. Gerotziafas GT, Catalano M, Theodorou Y, Van Dreden P, Marechal V, Spyropoulos AC, et al.  
423    The COVID-19 pandemic and the need for an integrated and equitable approach: an international  
424    expert consensus paper. *Thrombosis and Haemostasis*. 2021;121(08):992-1007.
- 425    2. The King's Fund. Long-term conditions and multi-morbidity 2022 [Available from:  
426    [https://www.kingsfund.org.uk/projects/time-think-differently/trends-disease-and-disability-long-](https://www.kingsfund.org.uk/projects/time-think-differently/trends-disease-and-disability-long-term-conditions-multi-morbidity#:~:text=Long%2Dterm%20conditions%20or%20chronic,pulmonary%20disease%2C%20arthritis%20and%20hypertension)  
427    term-conditions-multi-  
428    morbidity#:~:text=Long%2Dterm%20conditions%20or%20chronic,pulmonary%20disease%2C%2  
429    0arthritis%20and%20hypertension.
- 430    3. NICE. COVID-19 rapid guideline: managing the long-term effects of COVID-19 2022 [Available  
431    from: [https://www.nice.org.uk/guidance/ng188/resources/covid19-rapid-guideline-managing-the-](https://www.nice.org.uk/guidance/ng188/resources/covid19-rapid-guideline-managing-the-longterm-effects-of-covid19-pdf-51035515742)  
432    longterm-effects-of-covid19-pdf-51035515742.
- 433    4. World Health Organization. A clinical case definition of post COVID-19 condition by a Delphi  
434    consensus, 6 October 2021 2021 [Available from: [https://www.who.int/publications/i/item/WHO-](https://www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1)  
435    2019-nCoV-Post\_COVID-19\_condition-Clinical\_case\_definition-2021.1.
- 436    5. NHS England, NHS Improvement. National Guidance for post-COVID syndrome assessment  
437    clinics: NHS England and NHS Improvement; 2021 [updated 26.04.2021. Version 2:[Available  
438    from: [https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/11/C1248-](https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/11/C1248-national-guidance-post-covid-syndrome-assessment-clinics-v2.pdf)  
439    national-guidance-post-covid-syndrome-assessment-clinics-v2.pdf.
- 440    6. Evans RA, McAuley H, Harrison EM, Shikotra A, Singapuri A, Sereno M, et al. Physical,  
441    cognitive, and mental health impacts of COVID-19 after hospitalisation (PHOSP-COVID): a UK  
442    multicentre, prospective cohort study. *The Lancet Respiratory Medicine*. 2021;9(11):1275-87.

**STIMULATE-ICP Delphi (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways): Delphi Study Protocol.**

- 443 7. ONS. Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 3  
444 March 2022 2022 [Available from:  
445 <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/3march2022>.  
446  
447 022.
- 448 8. Campbell H, Hotchkiss R, Bradshaw N, Porteous M. Integrated care pathways. *British Medical Journal*. 1998;316(7125):133-7.  
449
- 450 9. Plishka CT, Rotter T, Penz ED, Hansia MR, Fraser S-KA, Marciniuk DD, et al. Effects of clinical  
451 pathways for COPD on patient, professional, and systems outcomes: a systematic review. *Chest*.  
452 2019;156(5):864-77.
- 453 10. Baxter S, Johnson M, Chambers D, Sutton A, Goyder E, Booth A. Understanding new models of  
454 integrated care in developed countries: a systematic review. *Health Services and Delivery Research*. 2018;6(29).  
455
- 456 11. Mitchell GK, Burridge L, Zhang J, Donald M, Scott IA, Dart J, et al. Systematic review of  
457 integrated models of health care delivered at the primary–secondary interface: how effective is it  
458 and what determines effectiveness? *Australian Journal of Primary Health*. 2015;21(4):391-408.
- 459 12. Whitty CJ, MacEwen C, Goddard A, Alderson D, Marshall M, Calderwood C, et al. Rising to the  
460 challenge of multimorbidity. *British Medical Journal*; 2020; 368: 16964.
- 461 13. Sykes DL, Holdsworth L, Jawad N, Gunasekera P, Morice AH, Crooks MG. Post-COVID-19  
462 symptom burden: what is long-COVID and how should we manage it? *Lung*. 2021;199(2):113-9.
- 463 14. James Lind Alliance. Medically Not Yet Explained Symptoms 2022 [Available from:  
464 <https://www.jla.nihr.ac.uk/priority-setting-partnerships/medically-not-yet-explained-symptoms/>.  
465
- 465 15. Stefano GB. Historical insight into infections and disorders associated with neurological and  
466 psychiatric sequelae similar to long COVID. *Medical Science Monitor*. 2021;27:e931447-1.

**STIMULATE-ICP Delphi (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways): Delphi Study Protocol.**

- 467 16. Miskowiak K, Johnsen S, Sattler S, Nielsen S, Kunalan K, Rungby J, et al. Cognitive impairments  
468 four months after COVID-19 hospital discharge: pattern, severity and association with illness  
469 variables. *European Neuropsychopharmacology*. 2021;46:39-48.
- 470 17. Theoharides TC, Cholevas C, Polyzoidis K, Politis A. Long-COVID syndrome-associated brain  
471 fog and chemofog: Luteolin to the rescue. *Biofactors*. 2021;47(2):232-41.
- 472 18. Graham EL, Clark JR, Orban ZS, Lim PH, Szymanski AL, Taylor C, et al. Persistent neurologic  
473 symptoms and cognitive dysfunction in non-hospitalized Covid-19 “long haulers”. *Annals of*  
474 *Clinical and Translational Neurology*. 2021;8(5):1073-85.
- 475 19. Varatharaj A, Thomas N, Ellul MA, Davies NW, Pollak TA, Tenorio EL, et al. Neurological and  
476 neuropsychiatric complications of COVID-19 in 153 patients: a UK-wide surveillance study. *The*  
477 *Lancet Psychiatry*. 2020;7(10):875-82.
- 478 20. Ellul MA, Benjamin L, Singh B, Lant S, Michael BD, Easton A, et al. Neurological associations of  
479 COVID-19. *The Lancet Neurology*. 2020;19(9):767-83.
- 480 21. Taquet M, Luciano S, Geddes JR, Harrison PJ. Bidirectional associations between COVID-19 and  
481 psychiatric disorder: retrospective cohort studies of 62 354 COVID-19 cases in the USA. *The*  
482 *Lancet Psychiatry*. 2021;8(2):130-40.
- 483 22. Khan S, Gomes J. Neuropathogenesis of SARS-CoV-2 infection. *Elife*. 2020;9:e59136.
- 484 23. Woo MS, Malsy J, Pöttgen J, Seddiq Zai S, Ufer F, Hadjilaou A, et al. Frequent neurocognitive  
485 deficits after recovery from mild COVID-19. *Brain Communications*. 2020;2(2):fcaa205.
- 486 24. Mandal S, Barnett J, Brill SE, Brown JS, Denny EK, Hare SS, et al. ‘Long-COVID’: a cross-  
487 sectional study of persisting symptoms, biomarker and imaging abnormalities following  
488 hospitalisation for COVID-19. *Thorax*. 2021;76(4):396-8.
- 489 25. Royal College of Physicians. Outpatients: the future - adding value through sustainability. London:  
490 RCP; 2018.

**STIMULATE-ICP Delphi (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways): Delphi Study Protocol.**

- 491 26. Martínez-González NA, Berchtold P, Ullman K, Busato A, Egger M. Integrated care programmes  
492 for adults with chronic conditions: a meta-review. *International Journal for Quality in Health Care*.  
493 2014;26(5):561-70.
- 494 27. Goodwin N, Smith J, Davies A, Perry C, Rosen R, Dixon A, et al. Integrated care for patients and  
495 populations: improving outcomes by working together. London: King's Fund. 2012.
- 496 28. NHS. Long COVID patients to get help at more than 60 clinics 2020 [Available from:  
497 <https://www.england.nhs.uk/2020/12/long-covid-patients-to-get-help-at-more-than-60-clinics/>].
- 498 29. NICE. Scenario: Community-acquired pneumonia 2021 [Available from:  
499 [https://cks.nice.org.uk/topics/chest-infections-adult/management/community-acquired-](https://cks.nice.org.uk/topics/chest-infections-adult/management/community-acquired-pneumonia/)  
500 [pneumonia/](https://cks.nice.org.uk/topics/chest-infections-adult/management/community-acquired-pneumonia/)].
- 501 30. Seidu S, Davies M, Farooqi A, Khunti K. Integrated primary care: is this the solution to the  
502 diabetes epidemic? *Diabetic Medicine*. 2017; 34(6):748-750.
- 503 31. Wootton DG, Dickinson L, Pertinez H, Eneje O, Keogan L, Macfarlane L, et al. A longitudinal  
504 modelling study estimates acute symptoms of community acquired pneumonia recover to baseline  
505 by 10 days. *European Respiratory Journal*. 2017;49(6).
- 506 32. Engel GL. The need for a new medical model: a challenge for biomedicine. *Science*.  
507 1977;196(4286):129-36.
- 508 33. STIMULATE-ICP. STIMULATE-ICP 2022 [Available from: <https://www.stimulate-icp.org/>].
- 509 34. NIHR. £19.6 million awarded to new research studies to help diagnose and treat long COVID  
510 2021 [Available from: [https://www.nihr.ac.uk/news/196-million-awarded-to-new-research-studies-](https://www.nihr.ac.uk/news/196-million-awarded-to-new-research-studies-to-help-diagnose-and-treat-long-covid/28205)  
511 [to-help-diagnose-and-treat-long-covid/28205](https://www.nihr.ac.uk/news/196-million-awarded-to-new-research-studies-to-help-diagnose-and-treat-long-covid/28205)].
- 512 35. Adler M, Ziglio E. Gazing into the oracle: The Delphi method and its application to social policy  
513 and public health: Jessica Kingsley Publishers; 1996.
- 514 36. Dalkey N, Helmer O. An experimental application of the Delphi method to the use of experts.  
515 *Management Science*. 1963;9(3):458-67.

**STIMULATE-ICP Delphi (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways): Delphi Study Protocol.**

- 516 37. Wykes T, Haro JM, Belli SR, Obradors-Tarragó C, Arango C, Ayuso-Mateos JL, et al. Mental  
517 health research priorities for Europe. *The Lancet Psychiatry*. 2015;2(11):1036-42.
- 518 38. Rowe G, Wright G. Expert opinions in forecasting: the role of the Delphi technique. *Principles of*  
519 *Forecasting*: Springer; 2001. p. 125-44.
- 520 39. de Meyrick J. The Delphi method and health research. *Health Education*. 2003.
- 521 40. Goldberg D, Huxley P. *Mental illness in the community: the pathway to psychiatric care* London.  
522 New York, Tavistock. 1980.
- 523 41. Simon GE. Improving the filter between primary and secondary care for mental disorders. *World*  
524 *Psychiatry*. 2003;2(3):158.
- 525 42. Scordo KA, Richmond MM, Munro N. Post-COVID-19 syndrome: theoretical basis,  
526 identification, and management. *AACN Advanced Critical Care*. 2021;32(2):188-94.
- 527 43. Fernández-de-Las-Peñas C, Palacios-Ceña D, Gómez-Mayordomo V, Florencio LL, Cuadrado  
528 ML, Plaza-Manzano G, et al. Prevalence of post-COVID-19 symptoms in hospitalized and non-  
529 hospitalized COVID-19 survivors: A systematic review and meta-analysis. *European Journal of*  
530 *Internal Medicine*. 2021;92:55-70.
- 531 44. Menchetti M, Murri MB, Bertakis K, Bortolotti B, Berardi D. Recognition and treatment of  
532 depression in primary care: effect of patients' presentation and frequency of consultation. *Journal*  
533 *of Psychosomatic Research*. 2009;66(4):335-41.
- 534 45. Nutting PA, Rost K, Dickinson M, Werner JJ, Dickinson P, Smith JL, et al. Barriers to initiating  
535 depression treatment in primary care practice. *Journal of General Internal Medicine*.  
536 2002;17(2):103-11.
- 537 46. Jaen CR, Stange KC, Nutting PA. Competing demands of primary care: a model for the delivery of  
538 clinical preventive services. *Journal of Family Practice*. 1994;38(2):166-74.
- 539 47. NHS England. Long COVID: the NHS plan for 2021/22 2021 [Available from:  
540 [https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2021/06/C1312-long-covid-](https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2021/06/C1312-long-covid-plan-june-2021.pdf)  
541 [plan-june-2021.pdf](https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2021/06/C1312-long-covid-plan-june-2021.pdf).

**STIMULATE-ICP Delphi (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways): Delphi Study Protocol.**

- 542 48.NHS. The NHS Long Term Plan 2019 [Available from: [https://www.longtermplan.nhs.uk/wp-](https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan-june-2019.pdf)
- 543 [content/uploads/2019/01/nhs-long-term-plan-june-2019.pdf](https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan-june-2019.pdf).
- 544 49.NHS. NHS England's work on stroke [Available from:
- 545 <https://www.england.nhs.uk/ourwork/clinical-policy/stroke/>.
- 546 50.NHS. Long term conditions 2022 [Available from: [https://www.england.nhs.uk/ourwork/clinical-](https://www.england.nhs.uk/ourwork/clinical-policy/ltc/)
- 547 [policy/ltc/](https://www.england.nhs.uk/ourwork/clinical-policy/ltc/).
- 548 51.NHS. Cardiovascular disease (CVD) [Available from:
- 549 <https://www.england.nhs.uk/ourwork/clinical-policy/cvd/>.
- 550 52.NHS. Respiratory disease [Available from: [https://www.england.nhs.uk/ourwork/clinical-](https://www.england.nhs.uk/ourwork/clinical-policy/respiratory-disease/)
- 551 [policy/respiratory-disease/](https://www.england.nhs.uk/ourwork/clinical-policy/respiratory-disease/).
- 552 53.EQ-5D. EQ-5D-5L User Guide, 2019 2019 [Available from: [https://euroqol.org/publications/user-](https://euroqol.org/publications/user-guides)
- 553 [guides](https://euroqol.org/publications/user-guides).
- 554 54.Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure.
- 555 *Journal of General Internal Medicine*. 2001;16(9):606-13.
- 556 55.Lam RW, Lamy F-X, Danchenko N, Yaras A, White MK, Rive B, et al. Psychometric validation
- 557 of the Perceived Deficits Questionnaire-Depression (PDQ-D) instrument in US and UK
- 558 respondents with major depressive disorder. *Neuropsychiatric Disease and Treatment*.
- 559 2018;14:2861.
- 560 56.Michielsen HJ, De Vries J, Van Heck GL. Psychometric qualities of a brief self-rated fatigue
- 561 measure: The Fatigue Assessment Scale. *Journal of Psychosomatic Research*. 2003;54(4):345-52.
- 562 57.Mundt JC, Marks IM, Shear MK, Greist JM. The Work and Social Adjustment Scale: a simple
- 563 measure of impairment in functioning. *The British Journal of Psychiatry*. 2002;180(5):461-4.
- 564 58.Spitzer RL, Kroenke K, Williams JB, Löwe B. A brief measure for assessing generalized anxiety
- 565 disorder: the GAD-7. *Archives of Internal Medicine*. 2006;166(10):1092-7.
- 566 59.Ware JE, Kosinski M, Turner-Bowker D, Gandek B. How to score version 2 of the SF-12 (r)
- 567 health survey. Lincoln, RI: Quality Metric. Inc, October. 2002.

## **STIMULATE-ICP Delphi (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways): Delphi Study Protocol.**

- 568 60. Broadbent DE, Cooper PF, FitzGerald P, Parkes KR. The cognitive failures questionnaire (CFQ)  
569 and its correlates. *British Journal of Clinical Psychology*. 1982;21(1):1-16.
- 570 61. Qualtrics. Qualtrics. Provo, Utah, USA 2020.
- 571 62. DiCicco-Bloom B, Crabtree BF. The qualitative research interview. *Medical Education*.  
572 2006;40(4):314-21.
- 573 63. Britten N. Qualitative research: qualitative interviews in medical research. *British Medical Journal*.  
574 1995;311(6999):251-3.
- 575 64. Archibald MM, Ambagtsheer RC, Casey MG, Lawless M. Using zoom videoconferencing for  
576 qualitative data collection: perceptions and experiences of researchers and participants.  
577 *International Journal of Qualitative Methods*. 2019;18:1609406919874596.
- 578 65. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*.  
579 2006;3(2):77-101.
- 580 66. Braun V, Clarke V, Hayfield N. 'A starting point for your journey, not a map': Nikki Hayfield in  
581 conversation with Virginia Braun and Victoria Clarke about thematic analysis. *Qualitative*  
582 *Research in Psychology*. 2019:1-22.
- 583 67. Williams S. Chronic illness as biographical disruption or biographical disruption as chronic  
584 illness? Reflections on a core concept. *Sociology of Health & Illness*. 2000;22(1):40-67.
- 585 68. Kelly MP, Field D. Medical sociology, chronic illness and the body. *Sociology of Health &*  
586 *Illness*. 1996;18(2):241-57.

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588

### **589 Figures**

590 Figure 1: Flow chart showing the integration of STIMULATE-ICP DELPHI within overall

591 STIMULATE-ICP

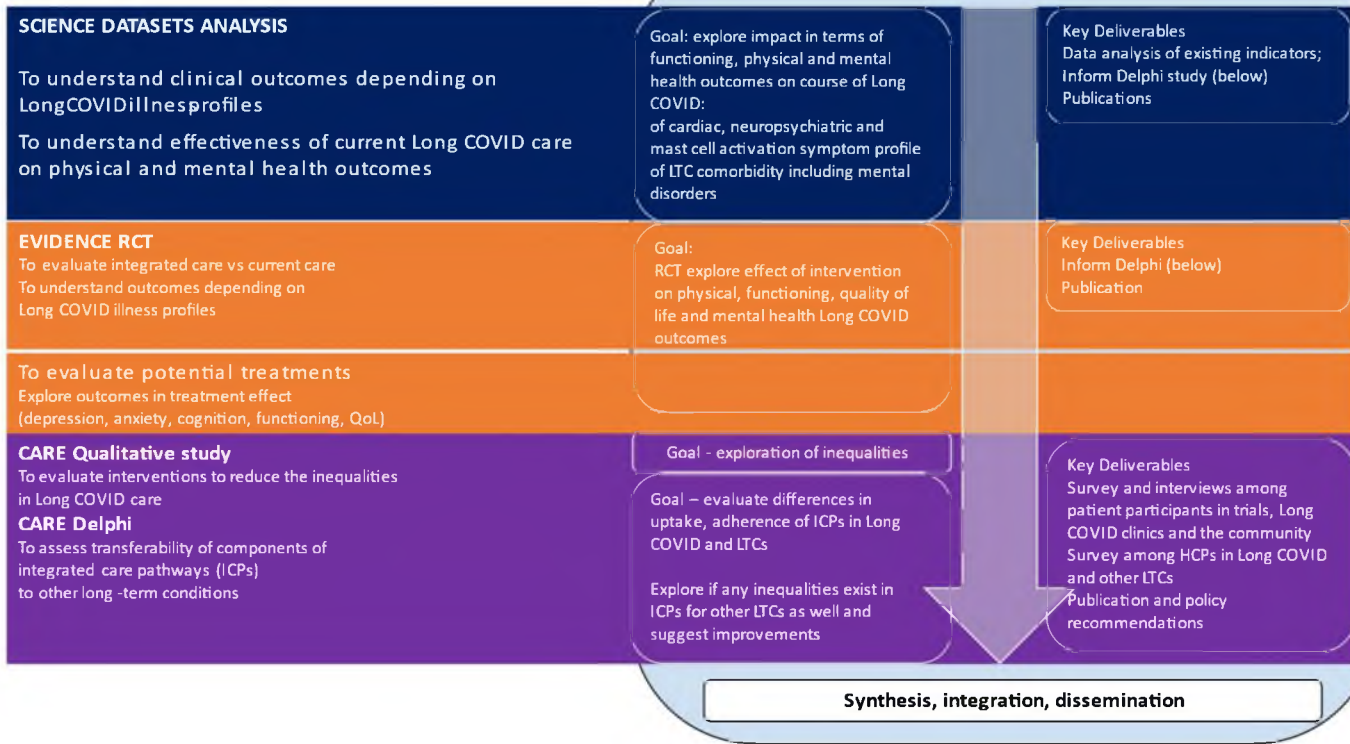
592 Figure 2: Outline of Delphi Process

**STIMULATE-ICP Delphi (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways): Delphi Study Protocol.**

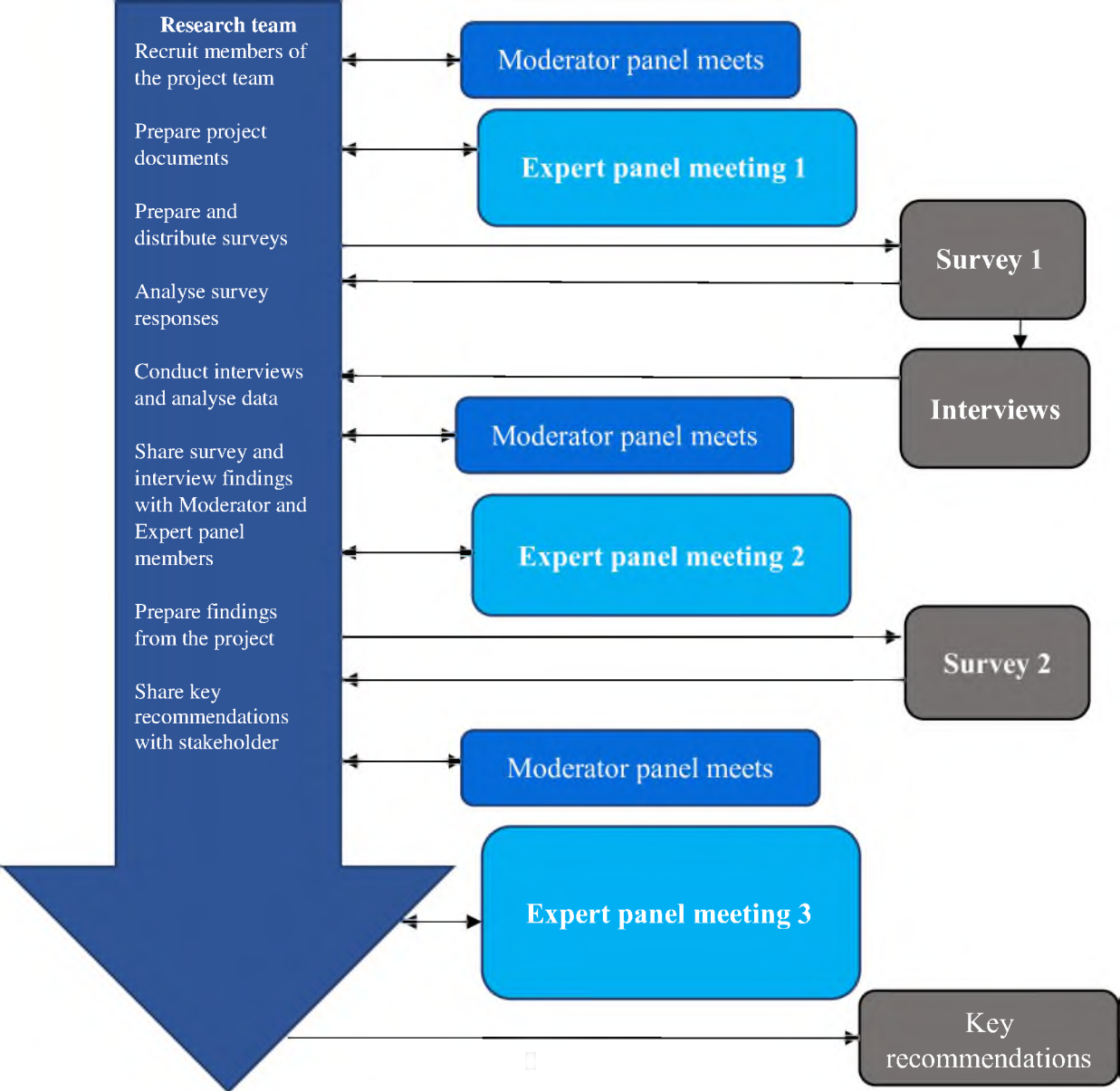
593 Figure 3: Filter model, expanded to conceptualise access to care for Long COVID or other  
594 long-term conditions (LTCs) including medically not yet explained symptoms (MNYES) and  
595 multi-morbidity



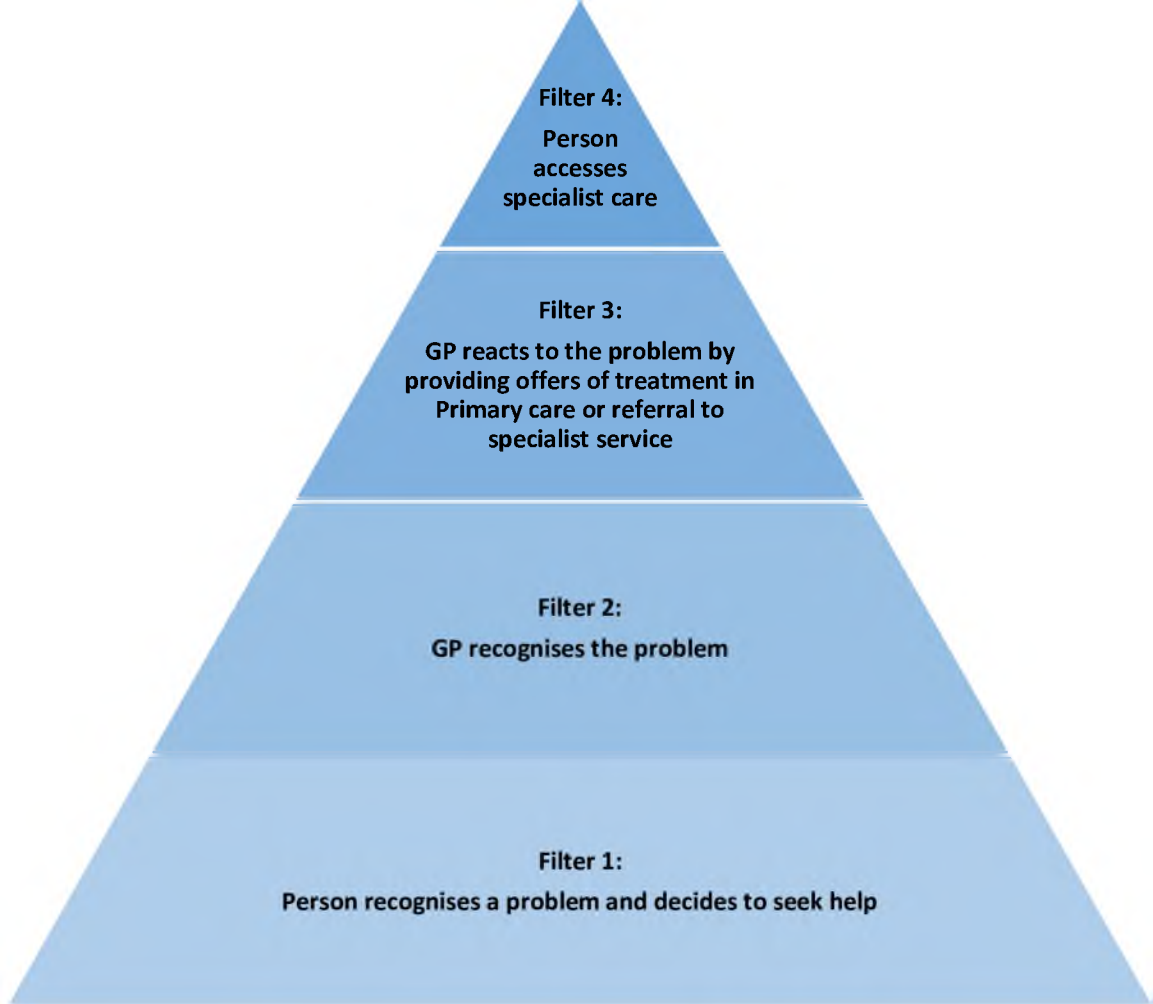
## STIMULATE-ICP Delphi study



**Figure 1: Flow chart showing the integration of STIMULATE-ICP DELPHI within overall STIMULATE-ICP**



**Figure 2: Outline of Delphi Process**



**Figure 3: Filter model, expanded to conceptualise access to care for Long COVID or other long-term conditions (LTCs) including medically not yet explained symptoms (MNYES) and multi-morbidity.**