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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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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-

31   registry#home/registrationdetails/6246bfeeeaaed6001f08dadc/.

Introduction

Despite major reductions in acute COVID-19 hospitalisation and mortality,[1] the persistence

of symptoms over one year later is notable in the 45% of the 1.5 million individuals who had

symptoms four weeks post-COVID in the UK.[2-4] Unlike some long-term conditions

(LTCs), individuals with Long COVID (i.e. those with post-COVID symptoms >12 weeks)

may still fully recover. However, new care pathways for Long COVID attempt to manage it

akin to a LTC, given the increasing recognition of chronic symptoms.[4, 5]

Care pathways for LTCs have tended to be disease- or specialty-specific, an approach which

fails to accommodate the heterogeneity of symptoms occurring in Long COVID. ICPs are

structured, multi-disciplinary plans of the whole care pathway from primary care to specialist

services and rehabilitation services, which may be better suited to Long COVID.[6-8] They

offer coordination of investigation, treatment and rehabilitation, as well as opportunities for

real-time iterative improvements in service design and delivery, quality and access to care,

patient experience and satisfaction, while reducing complications and non-elective admission

rates.[9-11] Evolution of integrated care systems (ICSs) in the UK provide opportunities to

improve care across LTCs, multi-morbidity or multiple health conditions,[12] and Long

COVID.

Long COVID encompasses a broad array of symptoms and symptom clusters. It is unlikely to

reflect a single condition or pathology; rather it reflects a multi-faceted condition with

numerous contributory factors: some identifiable, and others not yet understood.[13]

Trajectory and recovery after SARS-CoV-2 infection are poorly defined and there is overlap

with medically not yet explained symptoms (MNYES), referring to symptoms which do not

represent a known medical condition, yet contribute significantly to lesser quality of life and

treatment need.[14] Multi-organ complications,[13, 15-18] including neuropsychiatric

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**

Model	Example condition(s)	Recovery time	Managed by	Approach
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 ≤ 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**

Early deliverables	Early read out and contact with stakeholders (NHS England, the Royal College of GPs, AHSNs, other Royal Colleges, RCP, RCPsych, patient groups and NICE)		
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?			
Final deliverable	Contact with stakeholders (NHS England, the Royal College of GPs, AHSNs, other Royal Colleges, RCP, RCPsych, patient groups and NICE)		
Outputs	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.

Authors' Contributions

Conceptualisation and methodology: CFC, JS, GA, EA, MG, AB, STIMULATE-ICP team.

Funding acquisition: all authors. Ethics: CFC, AB, PM. Project administration: CFC. Original

manuscript drafting and preparation: CFC, JS. Review and editing of manuscript: all authors.

Patient and public involvement: LH, EA. All authors approved the final version of the article.

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 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-

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-

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-

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-

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/conditionsanddiseas

446   es/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/3march2

447   022.

448   8. Campbell H, Hotchkiss R, Bradshaw N, Porteous M. Integrated care pathways. British Medical

449   Journal. 1998;316(7125):133-7.

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

455   Research. 2018;6(29).

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: l6964.

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   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, Denneny 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-

500   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-

511   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-

541   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-

543   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-

547   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-

551   policy/respiratory-disease/.

552   53. EQ-5D. EQ-5D-5L User Guide, 2019 2019 [Available from: https://euroqol.org/publications/user-

553   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, Yarlas 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, USA2020.

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

SCIENCE DATASETS ANALYSIS

To understand clinical outcomes depending on Long COVID Illness profiles

To understand effectiveness of current Long COVID care on physical and mental health outcomes

Goal: explore impact in terms of functioning, physical and mental health outcomes on course of Long COVID:
of cardiac, neuropsychiatric and mast cell activation symptom profile of LTC comorbidity including mental disorders

Key Deliverables
Data analysis of existing indicators; Inform Delphi study (below)
Publications

EVIDENCE RCT
To evaluate integrated care vs current care
To understand outcomes depending on Long COVID illness profiles

Goal:
RCT explore effect of intervention on physical, functioning, quality of life and mental health Long COVID outcomes

Key Deliverables
Inform Delphi (below)
Publication

To evaluate potential treatments
Explore outcomes in treatment effect (depression, anxiety, cognition, functioning, QoL)

CARE Qualitative study
To evaluate interventions to reduce the inequalities in Long COVID care
CARE Delphi
To assess transferability of components of integrated care pathways (ICPs)
to other long-term conditions

Goal - exploration of inequalities

Goal – evaluate differences in uptake, adherence of ICPs in Long COVID and LTCs

Explore if any inequalities exist in ICPs for other LTCs as well and suggest improvements

Key Deliverables
Survey and interviews among patient participants in trials, Long COVID clinics and the community
Survey among HCPs in Long COVID and other LTCs
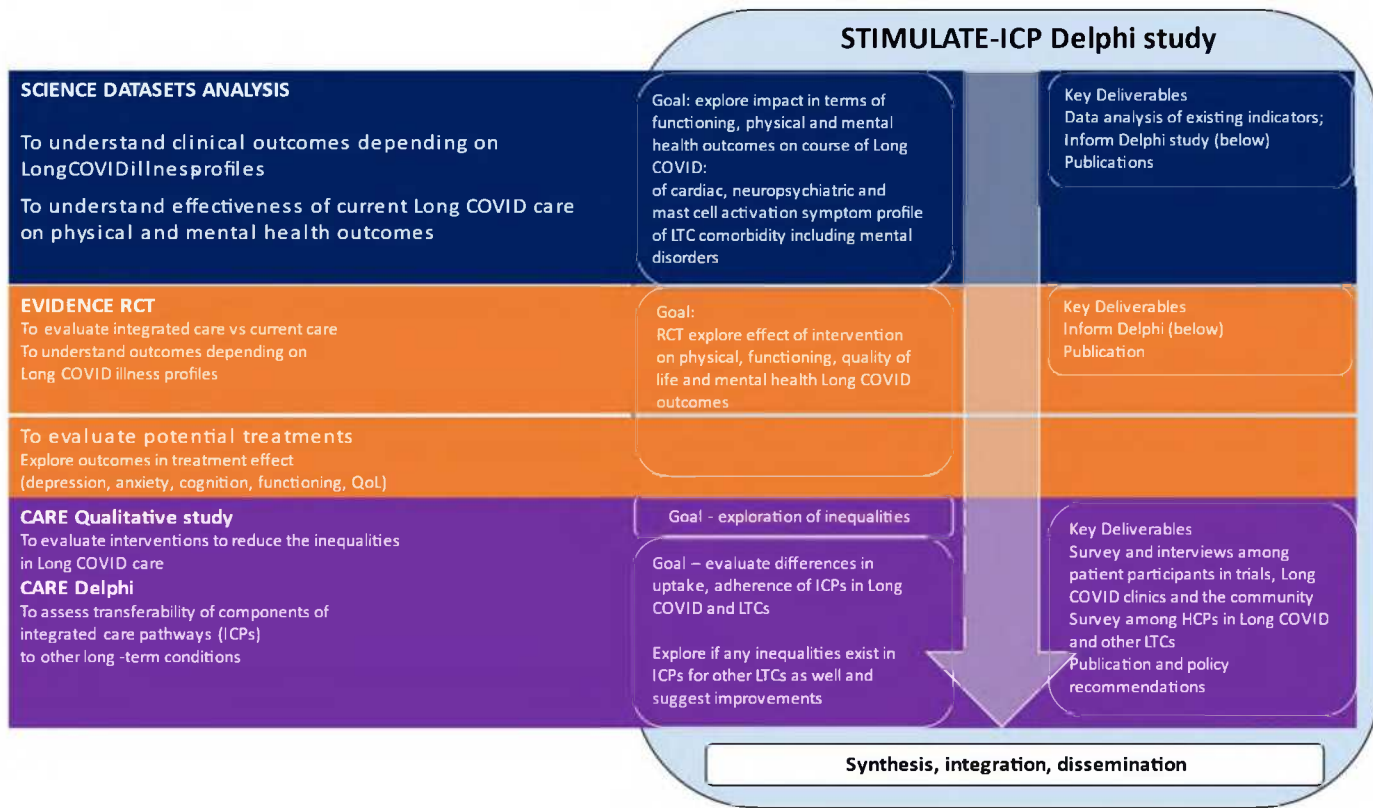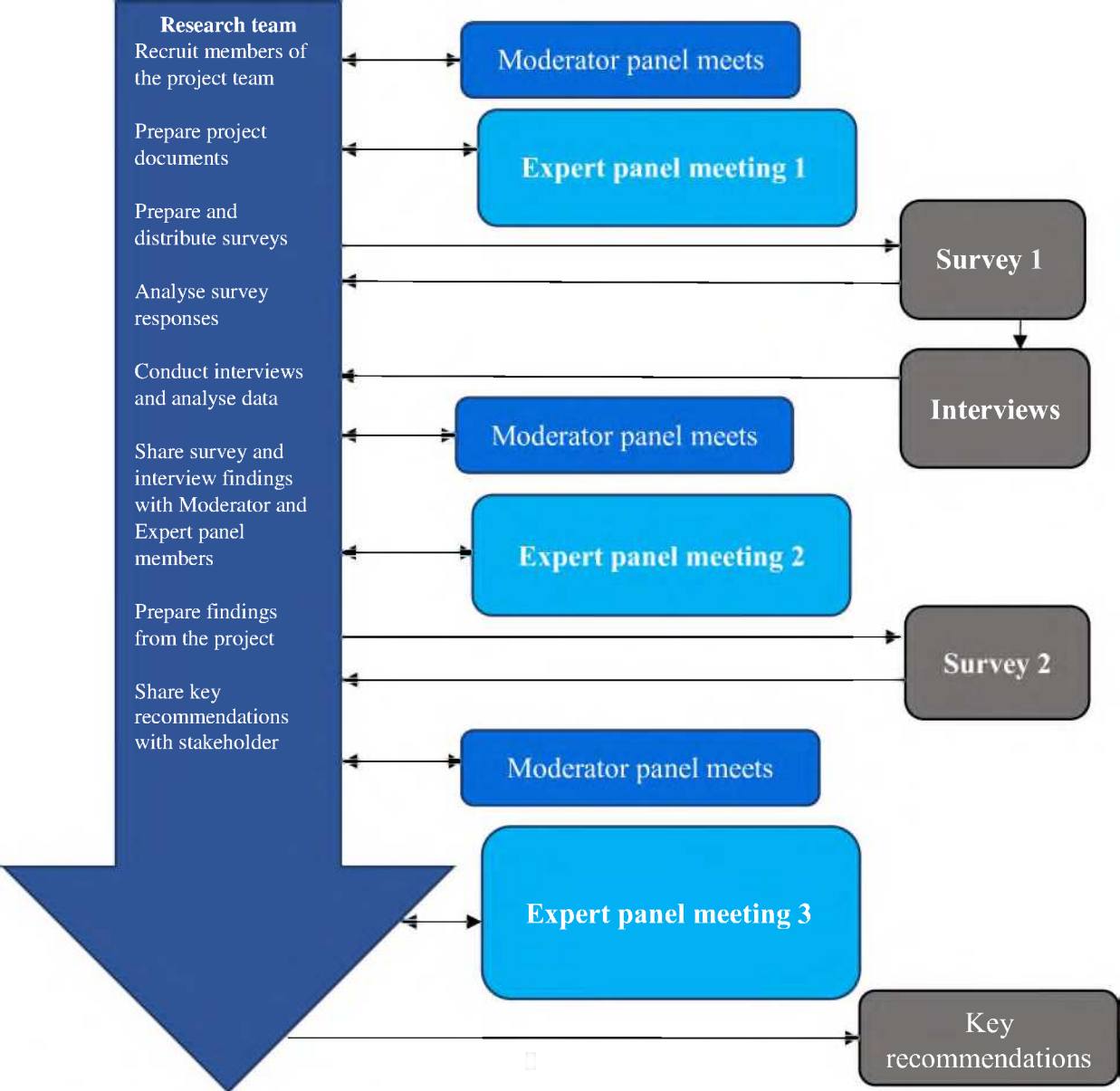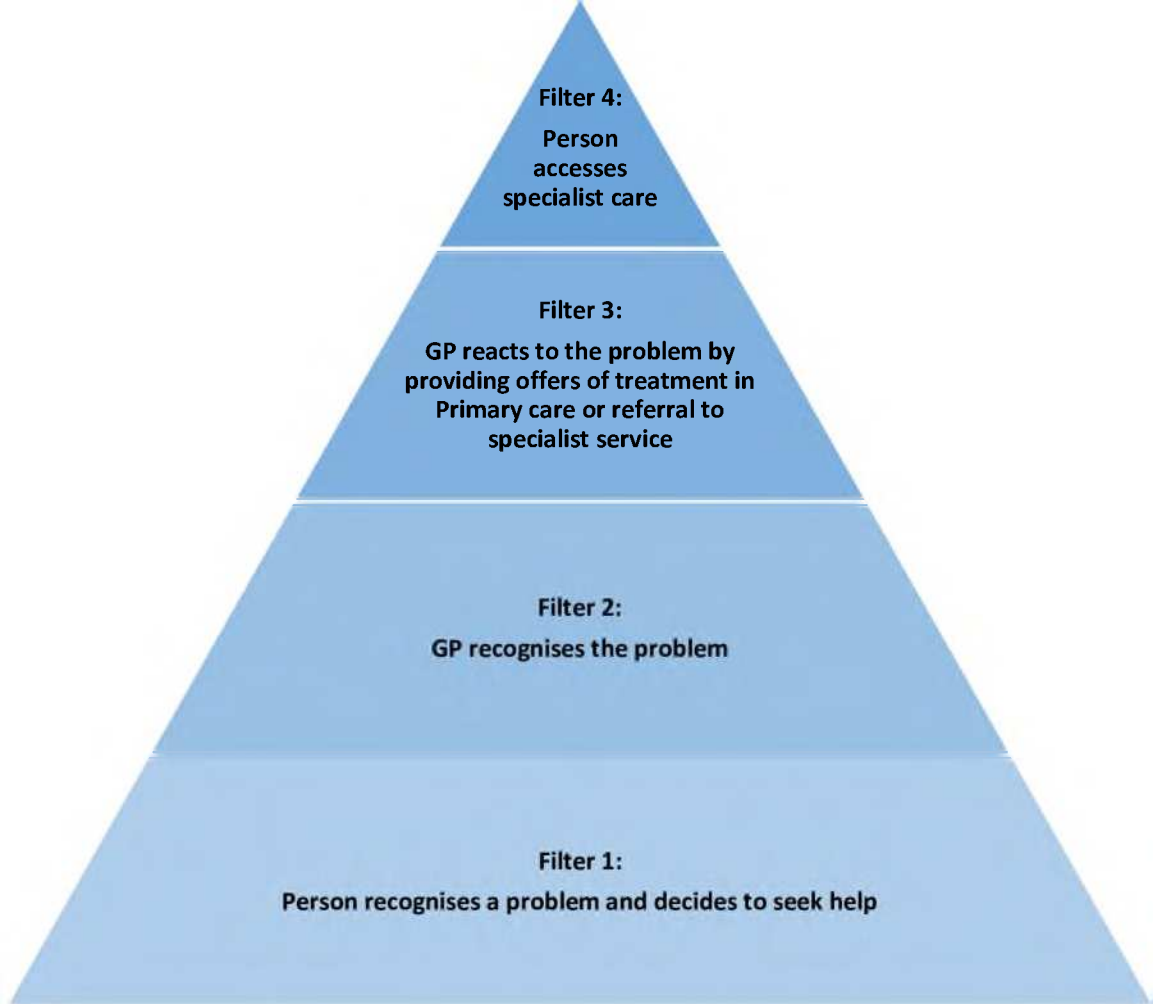Publication and policy recommendations

Synthesis, integration, dissemination

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.