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Understanding the role of community pharmacy in the support of people with long COVID

Submission date
14/11/2024

Recruitment status
No longer recruiting

Registration date
02/06/2025

Overall study status
Completed

Last Edited
16/07/2025

Condition category
Infections and Infestations

[_] Prospectively registered
[X] Protocol
[_] Statistical analysis plan
[_] Results
[_] Individual participant data
[_] Record updated in last year

Plain English summary of protocol

Background and study aims:
In the spring of 2020, it became clear that some people who had a COVID-19 infection continued to suffer from persistent or cyclical symptoms including (but not limited to) chest pain, palpitations, shortness of breath, muscle and joint aches and pains, headaches, cognitive impairment, neuropathy, paraesthesia (pins and needles), and fatigue. Various terms and definitions have been used to describe persistent symptoms following COVID-19 infection. 'Post COVID-19 syndrome' is an umbrella term for a complex, multisystem illness following an acute COVID-19 infection. The term 'long COVID' has been adopted by patient groups as people came together to share their experiences. The World Health Organisation (WHO), National Institute for Health and Care Excellence (NICE) and SNOMED International have all adopted the term 'post COVID-19 condition' for classification. The patient-preferred term 'long COVID' is used in this application and is intended to capture people with ongoing symptomatic COVID-19 (4-12 weeks after infection) or post-acute COVID-19 (12+ weeks), as defined by NICE.
More than two million people in the UK are currently living with long COVID. The Office for National Statistics (ONS) data indicates that fatigue is the most common symptom (reported by 71% of those with self-reported long COVID), difficulty concentrating (52%), shortness of breath (48%, and muscle ache (47%). People at higher risk of long COVID include females, people aged 35-69 years, those working in social care, people in more deprived areas, and people with another health condition or disability.
To date, the NHS response to long COVID has achieved mixed success. There have been barriers to accessing acceptable and responsive services. In December 2020, specific funding was announced to establish specialist clinics in England to support the management of people with long COVID, however, delivery of these clinics has since proved challenging to sustain due to high demand. The devolved nations have been slow to establish specialist services for people with long COVID; no services are offered in Wales or Scotland. People with long COVID commonly access support groups, particularly online, to share experiences and inform self-management strategies; engagement with these groups is often driven by a perceived lack of understanding and empathy from others, including healthcare professionals.
Community pharmacy is a key strand of primary care and could provide convenient and accessible support for people with Long Covid. Community pharmacy played a key role in supporting COVID vaccinations and supporting people during the pandemic. Pharmacists are increasingly viewed as referral options for people with Long Covid in primary care as part of

multi-agency support. The Royal Pharmaceutical Society (RPS) further acknowledge the role pharmacists have in supporting people with Long Covid; the Society recommends pharmacists should be engaged in research on Long Covid and have time protected to keep up to date with the latest evidence and learning resources on long COVID. Pharmacy staff are in an ideal position to advise on the use of over-the-counter medicines and complementary treatment, particularly when people are also being prescribed medications for other illnesses. The proposed research will help us to understand how best to do this.
This study aims to explore the role of community pharmacy in supporting the management of people with long COVID.

Who can participate?
People with long COVID and community pharmacy staff, both aged 18 years and over

What does the study involve?
Phase 1:
Interviews will be conducted with people with long COVID and community pharmacy staff to explore experiences of symptom management and engagement with community pharmacy (past /current/future). This approach will support an in-depth exploration of individual experiences and beliefs about long COVID and its management. Recognising and documenting researcher positionality through reflexivity will be critical in our approach to inquiry, as people with lived experience of long COVID will be involved in some of the data collection.

Phase 2:
A participatory co-design approach involving key stakeholders will inform the development of a novel fit-for-purpose online training resource. The primary aim of the online training will be to improve awareness and understanding of long COVID among community pharmacy staff; and furthermore, to enable community pharmacy staff to provide advice and appropriate signposting. The online training will also introduce learners to long COVID networks to facilitate ongoing learning and promote critical appraisal skills to assess the evidence as it emerges. A certificate of completion will be provided to learners, which can support evidence for revalidation or CPD requirements for example for the General Pharmaceutical Council (GPhC). The participatory co-design will adopt the Centre of Postgraduate Pharmacy Education's (CPPE) (University of Manchester) rigorous and well-established approach to training development, which is grounded in education theory and seeks to promote inclusion, person-centred care and positive change in practice – as demonstrated elsewhere. Self-efficacy theory and self-determination theory will be used to underpin the development of the training resource and guide behaviour change among learners by establishing understanding and the confidence to apply knowledge.
Two workshops are planned to support the co-design of training. Workshops will take place face-to-face, at Keele University or in a central location convenient for most participants, or online via MS Teams (or equivalent) if participants prefer. A hybrid approach will be made available to accommodate mixed preferences should this be required. Stakeholders will include up to 20 topic experts, people with lived experience of long COVID, primary care practitioners, pharmacy staff, and research team members. Stakeholders will be identified from the pool of qualitative participants (Phase 1), the PPIE group, the Clinical Advisory Group, and existing networks.

What are the possible benefits and risks of participating?:
There are no known risks to participating in this study. All participants will receive a £25 e-voucher for their time and contributions.

Where is the study run from?:
The study is hosted by Keele University School of Medicine, collaborating with Aston University,

the University of Kent, and the Centre of Postgraduate Pharmacy Education (UK). All interviews are conducted online, via Microsoft Teams, or by telephone. Face-to-face interviews may be possible, depending on the location.

When is the study starting and how long is it expected to run for?:
April 2024 to August 2025

Who is funding the study?:
National Institute for Health and Care Research (NIHR) (UK), Research for Patient Benefit, reference number NIHR205384

Who is the main contact?:
Dr Tom Kingstone, t.kingstone@keele.ac.uk

Contact information

Type(s)
Principal investigator

Contact name
Dr Tom Kingstone

Contact details
David Weatherall Building
Keele
United Kingdom
ST5 5BG
+44 (0)1782 738217
t.kingstone@keele.ac.uk

Type(s)
Public, Scientific

Contact name
Dr Tamsin Fisher

Contact details
David Weatherall Building
Keele
United Kingdom
ST5 5BG
+44 (0)1782 731794
t.e.fisher1@keele.ac.uk

Additional identifiers

National Institute for Health and Care Research (NIHR)
205384

Study information

Scientific Title
What role can community PHARMacy play in the support of people with Long Covid?

Acronym
PHARM-LC

Study objectives
Exploring the role of community pharmacy in supporting the management of people with long COVID.

Ethics approval required
Ethics approval required

Ethics approval(s)
Approved 01/05/2024, Keele University Research Ethics Committee (David Weatherall Building, Keele, ST5 5BG, United Kingdom; +44 (0) 1782 733937; research.governance@keele.ac.uk), ref: 0791

Primary study design
Observational

Study design
Qualitative research study including semi-structured interviews and focus groups

Study type(s)
Quality of life, Treatment

Health condition(s) or problem(s) studied
Long COVID

Interventions
Semi-structured interviews with people with Long COVID and community pharmacy staff.

Participatory co-design approach to develop a fit-for-purpose online training resource for community pharmacy staff to improve awareness and understanding of Long COVID among community pharmacy staff, and enable community pharmacy staff to provide advice and appropriate signposting.

Intervention Type
Other

Primary outcome(s)
1. Patient attitudes towards community pharmacy supporting the management and care of Long COVID
2. Community pharmacy staff attitudes towards supporting patients living with Long COVID
3. Patient and community pharmacy staff attitudes towards training for community pharmacy staff on Long COVID

Collected using interviews with community pharmacy staff and people with long COVID conducted between June 2024 and June 2025. The data will be analysed using a thematic analysis approach.

Key secondary outcome(s)
1. Identification of key topics to include in a training package on Long COVID for community pharmacy staff
2. Identification of design suggestions for a training package on Long COVID for community pharmacy staff

Collected using interviews with community pharmacy staff and people with long COVID conducted between June 2024 and June 2025. The data will be analysed using a thematic analysis approach.

Completion date
31/08/2025

Eligibility

Key inclusion criteria
Patient inclusion criteria:
1. 18 years or older
2. Lived experience of long COVID (symptoms of COVID for 4 weeks or more)
3. Living in the UK

Health professional (interviews and focus groups):
1. Any staff member currently working within a community pharmacy setting
2. 18 years or older
3. Living and working in the UK

Participant type(s)
Patient, Health professional

Healthy volunteers allowed
No

Age group
Adult

Lower age limit
18 Years

Sex
All

Key exclusion criteria
People with long COVID:
1. Under 18 years old
2. Living outside of the UK

Community pharmacy staff:
1. Under 18 years old
2. Living and/or working outside of the UK
3. Not currently working in a community pharmacy
4. Not community pharmacy staff (e.g. pharmacist based in GP surgery, or hospital)

Date of first enrolment
01/05/2024

Date of final enrolment
01/11/2025

Locations

Countries of recruitment
United Kingdom

England

Northern Ireland

Scotland

Wales

Study participating centre
School of Medicine
David Weatherall Building
Keele
United Kingdom
ST5 5BG

Study participating centre
Aston University
The Aston Triangle
Birmingham
United Kingdom
B4 7ET

Study participating centre
University of Kent
The Registry
Canterbury
United Kingdom
CT2 7NZ

Study participating centre
Centre for Pharmacy Postgraduate Education
Division of Pharmacy and Optometry
Faculty of Biology, Medicine and Health
1st Floor, Stopford Building
The University of Manchester
Oxford Road
Manchester
United Kingdom
M13 9PT

Sponsor information

Organisation
Keele University

ROR
https://ror.org/00340yn33

Funder(s)

Funder type
Government

Funder Name
Research for Patient Benefit Programme

Alternative Name(s)
NIHR Research for Patient Benefit Programme, Research for Patient Benefit (RfPB), The NIHR Research for Patient Benefit (RfPB), RfPB

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan

The datasets generated during and/or analysed during the current study may be available upon request from the study PI Dr Tom Kingstone (t.kingstone@keele.ac.uk).

IPD sharing plan summary

Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Protocol article			20/03/2025	Yes	No
Study website	Study website	11/11/2025	11/11/2025	No	Yes