Creating a Publicly-Led Long Covid Research Agenda

A mixed methods approach from Kenya and Malawi

November 2021
# Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgements</td>
<td>3</td>
</tr>
<tr>
<td>Foreword</td>
<td>4</td>
</tr>
<tr>
<td>Summary</td>
<td>5</td>
</tr>
<tr>
<td>Methodology</td>
<td>6</td>
</tr>
<tr>
<td>Study Approach</td>
<td>7</td>
</tr>
<tr>
<td>Prioritisation Methodology</td>
<td>11</td>
</tr>
<tr>
<td>Findings 1: Descriptive Statistics, Definition and Patient Journeys</td>
<td>12</td>
</tr>
<tr>
<td>Descriptive Statistics</td>
<td>13</td>
</tr>
<tr>
<td>Long Covid Definition and Patient Journeys</td>
<td>14</td>
</tr>
<tr>
<td>Findings 2: Research Agenda</td>
<td>18</td>
</tr>
<tr>
<td>Research Prioritisation</td>
<td>19</td>
</tr>
<tr>
<td>Chest Pain</td>
<td>20</td>
</tr>
<tr>
<td>Headache</td>
<td>22</td>
</tr>
<tr>
<td>Fatigue</td>
<td>24</td>
</tr>
<tr>
<td>Shortness of Breath</td>
<td>26</td>
</tr>
<tr>
<td>Fear</td>
<td>28</td>
</tr>
<tr>
<td>Stress</td>
<td>30</td>
</tr>
<tr>
<td>Depression</td>
<td>32</td>
</tr>
<tr>
<td>Anxiety</td>
<td>34</td>
</tr>
<tr>
<td>Cost of Care</td>
<td>36</td>
</tr>
<tr>
<td>Stigma</td>
<td>38</td>
</tr>
<tr>
<td>Discussion</td>
<td>40</td>
</tr>
<tr>
<td>References</td>
<td>43</td>
</tr>
<tr>
<td>Appendices</td>
<td>44</td>
</tr>
</tbody>
</table>
Acknowledgments

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Finally, we would like to thank each of the 1700+ research participants in Kenya and Malawi for generously giving their time to this project and sharing their experiences of Long Covid. Their contributions are the foundation for this publicly-led research agenda.

Wellcome

Wellcome is a politically and financially independent global charitable foundation, funded by a £29.1 billion investment portfolio. Wellcome supports science to solve the urgent health challenges facing everyone. We support discovery research into life, health and wellbeing, and we’re taking on three worldwide health challenges: mental health, infectious disease and climate. Wellcome believes that working with people who have lived experience of health challenges improves research, understanding and treatment.

Dalberg Design

Dalberg Design partners with leading organizations to bring people to the table so they can design solutions to the challenges and opportunities that affect their day to day lives. We use participatory processes to address inequities and drive positive social change with – not for – the communities we serve. Our global team brings together creative problem-solvers from a diverse set of backgrounds, including: qualitative research, behavioral science, various design disciplines, human rights and international development.

Dalberg Research

Dalberg Research provides research and analysis that offers clients actionable solutions to their problems. We are a full-service research agency answering questions about markets, consumers and lifestyles across more than 20 African countries via quantitative and qualitative studies. We specialize in the inventory, collection, and analysis of primary research data for businesses, NGOs, governments and other institutions. Dalberg Research has 21 years of experience in primary research and has a strong commitment to obtaining the information required to fuel sustainable and inclusive growth across Africa.

Dalberg Media

Dalberg Media is a mission-driven communications and experience consultancy aiming to empower and mobilize people to solve global development challenges through collective, sustained action. We design and deliver communication products to build awareness and push agendas. We invent and execute action-oriented experiences, such as global convenings, innovation labs and campaigns to equip people with the skills needed for developing impactful solutions. Through content creation, publications and social media, we disseminate compelling stories to fuel positive change.

As we near the two-year anniversary since the initial cluster of cases of Covid-19 were detected, we are sadly no closer to ensuring that our lifesaving vaccines and treatments are equitably distributed to every person who needs them. Without equitable access to these tools Covid-19 continues to remain a threat for many, and as now clearly shown, risks longer term health and socio-economic impacts that are only now being understood. Research has played a crucial role during Covid19, with research gaps initially prioritised by the launch of the WHO R&D Covid-19 Global Roadmap back in February 2020. Yet, we know all too well that regional and country-tailored research agendas that highlight national and local research priorities are often lacking.

In late 2020, there was a call for greater focus on Long Covid research, advocated by several patient groups and researchers. By December, the global consortium of research funders known as GLOPID-R, together with the clinical consortium group ISARIC, established the Long Covid Forum Group, which was made up of members of the research community, patient groups, global research funders, policy makers and public health representative. Following a research workshop, initial research gaps were highlighted which focused on the long-term impact of Covid19 in both adults and children.

During 2021, this publicly led prioritised research agenda was undertaken focusing on Kenya and Malawi, countries where the current double vaccinated rates stand at under 9% and 6% of adults, respectively. While vaccination rates remain low, in addition to the risk of developing severe disease, Long Covid will continue to remain a real threat to people’s health and livelihoods. Finally, we need research to be undertaken that is representative of all settings and communities, which remains a global gap as out of the 100 plus Long Covid research projects currently underway, only three are being conducted on the African continent.

The launch of this publicly led Long Covid research agenda will bring us one step close to improving our understanding of how Long Covid impacts patients, their carers and healthcare professionals. I encourage all to engage with this these research priorities, which represent public lived experiences. By focusing our investment and time on the most pressing issues, we can better understand and determine what management strategies could be used to impact global recovery, policymaking and the development of better therapeutics.

Dr. Josie Golding,
Epidemics Lead,
Wellcome Trust

What would we like you to do after reading this report?

1. Investigate or Fund the Research Questions: This report presents 52 specific research questions that support improved management and understanding of Long Covid or address key challenges identified by the public. We encourage both funders and researchers to use this work as a foundation for further study.

2. Leverage this Approach to Publicly-Led Agenda Setting: This study shares a tested process for incorporating patient, caregiver and health care professionals’ perspectives into research. We hope others will build from this methodology to create other publicly-led research agendas.

3. Explore the data: This project offers an evidence-base and publicly available data set which we hope researchers and policymakers explore in greater detail, elevating insights beyond our focus on research priorities.

The data from this project can be accessed here.
Summary

Long Covid impacts a significant number of patients following Covid-19 infection and is now a condition broadly recognized by the scientific community. However, there is no widely recognized definition, diagnosis or management and rehabilitation protocols. Additional research is required to ensure effective support for patients, carers and health care workers as they navigate this condition.

The aim of the research was to produce a publicly-led research agenda for Long Covid grounded in the experiences of patients, carers and health care professionals in Kenya and Malawi.

The study adopted a mixed methods approach, consisting of qualitative and quantitative data collection techniques paired with a clear dissemination strategy in order to:

1. Understand what frontline health care professionals, people affected by Long Covid 19 and their carers think the research priorities should be for this condition
2. Present findings as a research agenda that can be shared with key stakeholders including major global funders to influence what they choose to fund
3. Understand holistically how these priorities differ in the two countries and where there are shared priorities

The qualitative research captured the experiences of patients, carers and health care professionals as they navigated Long Covid, to understand their day-to-day management, the challenges and bright spots experienced across their journey and their perceptions of the areas of greatest need for support and further research. In total, 10 respondents were interviewed in each country: 4 patients living with Long Covid, 3 of their carers and 3 frontline health care professionals.

The quantitative survey captured responses from a total of 1691 respondents across Kenya and Malawi. The survey comprised of 4 sections, which were informed by the qualitative interviews (screening questions, demographic questions, Long Covid symptoms and symptom management strategies, socio-economic impact of Long Covid).

Analysis of the qualitative and quantitative data was used to identify a list of public-led priorities for Long Covid management research and associated socio-economic research priorities that address key barriers to effective Long Covid management.

In total, 52 self-reported symptoms were identified, and 8 of these were identified as high priority for research. The prioritisation was based on symptom prevalence, persistence, impact on life and difficulty to manage. The prioritisation surfaced that the psychological burden of Long Covid is as great as the physiological burden, with an equal number of each being deemed high priority. In addition, 2 socio-economic barriers were identified as priorities.

The resulting 10 research priorities are:

- Chest pain
- Headache
- Fatigue
- Shortness of breath
- Fear
- Stress
- Depression
- Anxiety
- Cost of care
- Stigma

Each of the priorities was then explored in greater detail through additional qualitative and quantitative analysis to identify future research questions, resulting in a comprehensive research agenda. A snapshot of more than 50 research questions can be found below (see blue box).

The study defined Long Covid management holistically, and as such, presents research questions across pharmaceutical therapeutics, diagnostics, supplements, traditional remedies, lifestyle changes, supportive care and socioeconomic strategies.

Snapshot: Publicly-led Research Questions*

- **Chest Pain:** What management strategies are effective in addressing pleuritic chest pain associated with Long Covid?
- **Headache:** Why are headaches associated with Long Covid resistant to common painkillers?
- **Fatigue:** Are oral Vitamin C supplements effective against fatigue associated with Long Covid?
- **Shortness of Breath:** Are traditional remedies, including onions, effective in managing shortness of breath associated with Long Covid?
- **Fear:** What approaches support the reduction of misinformation about the risk of death amongst Long Covid patients?
- **Stress:** How might policy or regulatory change protect Long Covid patients against loss of income?
- **Depression:** How might an understanding of the biological relationship between depression and Long Covid support the development of therapeutics for depression?
- **Anxiety:** What are the diagnostic criteria for Long Covid? How might Long Covid diagnosis be effectively communicated to patients in order to reduce anxiety?
- **Cost of Care:** How might policy or regulatory change reduce out-of-pocket costs associated with Long Covid?
- **Stigma:** What approaches equip carers with accurate information and protocols for the management of the risk of transmission by Long Covid patients at home?

*Additional research questions for each priority can be found in the full research agenda on pages (18-39)
Methodology
Study Design and Approach

Research objectives

The aim of the research was to produce a publicly-led research agenda for Long Covid that is grounded in the experience of patients, carers and health care professionals in Kenya and Malawi.

In order to achieve this outcome, the study had 3 primary objectives, namely:

1. Understand what frontline healthcare professionals, people affected by Long Covid 19 and their carers think the research priorities should be for this condition.
2. Present findings as a research agenda that can be shared with key stakeholders including major global funders to influence what they choose to fund.
3. Understand holistically how these priorities differ in the two countries, and where there are shared priorities.

Study setting

The study was conducted in 2 countries; Kenya and Malawi. The country selection was informed by the desire to have representation across South and East Africa and took into account how different countries responded to Covid-19 (6). The Covid-19 deprivation index (7) was used to ensure we had variability in Covid contexts.

The overall index (CCVI) is made up of seven themes: age, epidemiological factors, fragility, strength of health systems, population density, socioeconomic factors and access to transportation and housing.

Study approach

This study was conducted by Dalberg in close collaboration with the Wellcome Trust team. The research involved 3 Dalberg entities (Dalberg Design, Dalberg Research and Dalberg Media). The study adopted a mixed methods approach, consisting of qualitative and quantitative data collection techniques paired with a clear dissemination strategy. The qualitative data collection was led by Dalberg Design and the quantitative data collection was led by Dalberg Research through a population based survey. The dissemination strategy was developed and executed by Dalberg Media using a publicly-led framework.

The interviews and surveys were conducted in locally spoken languages in both countries. The languages of choice were English, Kiswahili and Chichewa.

Ethical consent and permission

Ethical approval to conduct this study was obtained from the National Health Sciences Research Committee of Malawi and AMREF Ethics and Scientific Review Committee (Kenya). Ref No: NCST/RTT/2/6) and (Ref No: P1012-2021) respectively.

<table>
<thead>
<tr>
<th>Country</th>
<th>Reported Covid cases as of 8/11/21</th>
<th>Cases per million population</th>
<th>Deaths per million population</th>
<th>CCVI Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kenya</td>
<td>253,833</td>
<td>4,616.35</td>
<td>96.61</td>
<td>0.23 (Lower vulnerability)</td>
</tr>
<tr>
<td>Malawi</td>
<td>61,815</td>
<td>3,146.17</td>
<td>117.16</td>
<td>0.63 (Higher vulnerability)</td>
</tr>
</tbody>
</table>

Reported Covid cases as of 8/11/21: 253,833 for Kenya and 61,815 for Malawi.
Inclusion Criteria

There is no consensus on the exact definition of Long Covid and its associated symptoms within the scientific community. For the purposes of the study, we aligned on a broad and inclusive definition, limiting data collection amongst patients to adults (over 18) who:

- Have had Covid-19 or suspected Covid-19, and have experienced or continue to experience symptoms for a duration of at least 8 weeks.

Through the analysis of the data collected during this study, we sought to develop a public-led definition of Long Covid to add to the growing Long Covid discourse, which can be found on page 14.

Diagnosis: We included patients who had:

- A positive diagnostic test (either PCR or rapid test)
- Diagnosis by health care workers without the use of a test
- Self-diagnosed based on their contact with those who had confirmed Covid-19
- Self-diagnosed based on their own assessment that their symptoms aligned with the Ministry of Health guidelines on common Covid-19 symptoms

This openness to different diagnoses is aligned with best practices established in other Long Covid studies (2) and was of particular importance in Kenya and Malawi given limited availability and access to Covid-19 tests. Accepting only tested respondents could cause bias in the geographical (urban vs rural) as well as the socioeconomic makeup of our sample. In each country, however, we aimed to reach a minimum of 50% of respondents who had a test-confirmed diagnosis.

Symptom duration: Existing large-scale Long Covid studies have varying duration thresholds from 28 days to 12 weeks (1,2). The study selected 8 weeks as the threshold for inclusion, aligned to best practices, and included patients who had experienced symptoms for any duration longer than 8 weeks.

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Table 1: Diagnosis and symptom duration of the sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>Kenya</th>
<th>Malawi</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N = number of respondents</strong></td>
<td>806</td>
<td>885</td>
<td>1691</td>
</tr>
<tr>
<td><strong>Diagnosis (% of respondents)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I took a Covid-19 test and the result was positive</td>
<td>58.6%</td>
<td>54.6%</td>
<td>56.5%</td>
</tr>
<tr>
<td>I talked to a healthcare practitioner who told me it was Covid after I described the symptoms I was experiencing</td>
<td>5.3%</td>
<td>4.0%</td>
<td>4.6%</td>
</tr>
<tr>
<td>I didn’t take a Covid test, but I know it’s covid because I was in contact with someone who took a Covid-19 test and tested positive</td>
<td>7.2%</td>
<td>6.1%</td>
<td>6.6%</td>
</tr>
<tr>
<td>I did not take a test, but I know it is Covid-19 as I have similar symptoms as identified/outlined by the Ministry of Health</td>
<td>28.9%</td>
<td>35.4%</td>
<td>32.3%</td>
</tr>
<tr>
<td><strong>Symptom Duration (% of respondents)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than 8 and less than 12 weeks (2-3 months)</td>
<td>75.6%</td>
<td>81.5%</td>
<td>78.7%</td>
</tr>
<tr>
<td>More than 12 and less than 24 weeks (3-6 months)</td>
<td>19.7%</td>
<td>17.0%</td>
<td>18.2%</td>
</tr>
<tr>
<td>More than 24 weeks (6 months+)</td>
<td>4.7%</td>
<td>1.6%</td>
<td>3.1%</td>
</tr>
</tbody>
</table>
Qualitative Data: Sampling, Collection & Analysis

Sampling
The qualitative sampling approach used purposive sampling to achieve diversity across geography, gender, age, symptom experiences (for patients and carers), type of care facility and healthcare worker role.

Data collection
Qualitative data collection consisted of: In-depth interviews with 10 respondents in each country, 4 patients living with Long Covid, 3 of their carers and 3 frontline healthcare professionals.

The respondents were recruited using a screening tool capturing demographic information (gender, location, profession, age). For patients, the screener also captured type of diagnosis, symptom duration, symptoms and pre-existing conditions.

The interviews were conducted using a hybrid in-person and remote methodology (by phone/video conferencing). In-person research assistants were available when needed to support participants to connect with the research team by phone/video conferencing.

Each qualitative interview was between 60-90 minutes in duration, exploring:
- The lived experiences of patients living with Long Covid, to understand their day-to-day management, the challenges and bright spots experienced across their journey, and their perceptions of the areas of greatest need for support and further research.
- The experiences of carers and frontline healthcare professionals who are providing care for people with Long Covid, to understand how the current health ecosystem responds to Long Covid and identify the areas of greatest need for research within the health system.

The interview guides were structured to holistically capture these experiences, with interactive activities embedded in the interviews. Activities included:
- **The patient's journey** which mapped the Patient’s experience from awareness of Long Covid to when they sought care. It surfaced the steps taken, their feelings, decisions, action points, pain points and long-term aspirations.
- **The ecosystem map** generated a detailed picture of the ecosystem (e.g. within households, communities, care facilities, health institutions). It highlighted the flows of information, resources, treatment services along with the enablers and barriers in patients’, carers’ and frontline healthcare workers’ networks of interaction, influence, and dependency.

Data analysis
All quotes from participants captured during the research were treated as individual data points and were analyzed using content analysis (08). Data points were manually coded based on shared themes, facts, or ideas. Themes identified in the data at the early stage of the analysis included i) understanding of Long Covid, ii) physical and psychological symptoms, iii) management strategies, iv) socioeconomic barriers, among others. Some data points fit within multiple themes and were reflected as such.

![Figure 1: Overview of the research methodology](image-url)
Quantitative Data: Sampling, Collection & Analysis

Sampling

Quantitative data was collected through a population based survey. The distribution of the sample size in each country is illustrated in Table 2 and 3.

Table 2: Kenya sample distribution (counties)

<table>
<thead>
<tr>
<th>County</th>
<th>Urban</th>
<th>Rural</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nairobi City</td>
<td>40</td>
<td>41</td>
<td>81</td>
</tr>
<tr>
<td>Mombasa</td>
<td>40</td>
<td>41</td>
<td>81</td>
</tr>
<tr>
<td>Kiambu</td>
<td>40</td>
<td>40</td>
<td>80</td>
</tr>
<tr>
<td>Nakuru</td>
<td>41</td>
<td>40</td>
<td>81</td>
</tr>
<tr>
<td>Uasin Gishu</td>
<td>40</td>
<td>40</td>
<td>80</td>
</tr>
<tr>
<td>Kisumu</td>
<td>40</td>
<td>40</td>
<td>80</td>
</tr>
<tr>
<td>Kiifi</td>
<td>43</td>
<td>39</td>
<td>82</td>
</tr>
<tr>
<td>Machakos</td>
<td>39</td>
<td>41</td>
<td>80</td>
</tr>
<tr>
<td>Busia</td>
<td>41</td>
<td>40</td>
<td>81</td>
</tr>
<tr>
<td>Kajiado</td>
<td>40</td>
<td>40</td>
<td>80</td>
</tr>
<tr>
<td>Total</td>
<td>404</td>
<td>402</td>
<td>806</td>
</tr>
</tbody>
</table>

Table 3: Malawi sample distribution (districts)

<table>
<thead>
<tr>
<th>District</th>
<th>Urban</th>
<th>Rural</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blantyre</td>
<td>66</td>
<td>61</td>
<td>127</td>
</tr>
<tr>
<td>Lilongwe</td>
<td>70</td>
<td>57</td>
<td>127</td>
</tr>
<tr>
<td>Kasungu</td>
<td>63</td>
<td>63</td>
<td>126</td>
</tr>
<tr>
<td>Mangochi</td>
<td>63</td>
<td>63</td>
<td>126</td>
</tr>
<tr>
<td>Zomba</td>
<td>66</td>
<td>63</td>
<td>129</td>
</tr>
<tr>
<td>Mzuzu</td>
<td>57</td>
<td>69</td>
<td>126</td>
</tr>
<tr>
<td>Mzimba</td>
<td>61</td>
<td>64</td>
<td>125</td>
</tr>
<tr>
<td>Total</td>
<td>446</td>
<td>439</td>
<td>885</td>
</tr>
</tbody>
</table>

The quantitative sampling approach utilised purposive and random systematic sampling.

Sample size determination

The quantitative sample size of 800 patients per country was calculated considering a population size of a projected 6,000,000 Covid-19 cases regionally, at 95% confidence ($Z_\alpha = 1.96$) and accounting for a 5% margin of error. The sample size was inflated to accommodate a 20% attrition/non-response rate and then rounded up to the nearest 100.

Sample frame determination

Primary Sampling Units (PSUs) were purposively selected from Covid “hotspots”, guided by available Covid prevalence data in each country. In Kenya, PSUs were guided by KEMRI prevalence data while in Malawi, the ministry of health dashboard indicated Covid-19 hotspots. In both countries, we picked the top 5 PSUs with the highest Covid-19 incidence and prevalence rates.

After identification of the PSUs, smaller administrative units were selected and categorised as urban or rural, guided by in-country population census data.

The sample was then evenly distributed within the identified urban and rural areas. Thereafter, systematic random sampling was used to identify and select the target households. Once an eligible household was selected, a screener was used to determine the participant eligibility.

Data collection

The survey

The survey was comprised of 4 sections and on average, took approximately 45 minutes to administer. The survey instrument was developed based on insights and identified areas of further research from the analysis of the qualitative data. The tool was designed to capture spontaneous participant responses, thereby reducing any chance of bias. This enhanced the validity and reliability of the data. The survey was administered in person and covered a number of topics:

- Demographics and self-reported medical history
- Understanding of Long Covid
- Physical and psychological symptoms
- Management strategies, including pharmaceutical and traditional therapies as well as other supportive measures, including lifestyle changes and other complementary practices
- Health-seeking behaviours and influencers in care
- Vaccination
- Socioeconomic challenges and systemic barriers that impacted access to care

The research assistants collected data electronically using mobile phones with Survey CTO software installed and in the language the survey participants preferred. This enabled the research assistants to capture responses digitally and for easier quality control of the data. The research assistants uploaded data into secure internal servers. Throughout data collection period, data clerks conducted high-frequency checks for data quality assurance purposes.

Interview completion rate

In Kenya, 40% of all identified participants terminated the survey before completion, whereas in Malawi 55% terminated.

Data analysis

After deployment and collection of the survey data, the data was cleaned by checking skip logic patterns, duplicate submissions, outliers, among other measures. To uncover Long Covid research priorities and research questions, a mix of exploratory analysis and statistical methods were used. Non-parametric tests like chi square (09) were used to test associations between variables at 95% level of confidence. Logistic regressions (10) were used to test strength of association between priority symptoms and other variables. One class machine learning algorithm (11) was used to test symptom effects on impact on life.
Research Prioritisation

The research prioritisation sought to identify publicly-led Long Covid research priorities.

The framework for symptom prioritisation and the associated variable selection was based on the aspects of Long Covid that were of greatest importance to participants in the qualitative research (persistence, impact on life, difficulty to manage) and a desire to prioritise symptoms that affect the greatest number of people (prevalence).

Prioritization methodology

To obtain the prioritized list, we used a mixed methods approach comprising of 3 key steps:

Step 1: Identifying priority symptoms

Through the qualitative research we identified that Long Covid has a wide range of associated symptoms. We sought to identify the highest priority symptoms for further research. In order to do this, the quantitative data was analysed and each symptom (physical and psychological) was given a score for each of the following 4 variables:

- **Prevalence**: Captures the frequency of self-reported physical and psychological symptoms, reported as a percentage of all patients.
- **Persistence**: Captures the symptoms that patients perceived they experienced for the longest duration, reported as the percentage of patients who believed each symptom was amongst the top 3 most persistent.
- **Impact on life**: A composite variable reflecting the frequency each symptom impacted the patient’s i) domestic duties, ii) social life, and iii) income generating activities. This was measured on a Likert score from “never” to “always”.
- **Symptoms that were difficult to manage or find relief from**: Captures the symptoms patients perceived to be most challenging to overcome, reported as the percentage patients who believed each symptom was the most challenging symptom to find relief from.

In the context of this study, the term “management” is used holistically to describe the full range of strategies that patient’s use to alleviate their symptoms. These ranged from pharmaceutical therapeutics, diagnostics, supplements, traditional remedies, lifestyle changes, supportive care, and socioeconomic strategies.

To obtain the top-ranked symptoms, for prevalence, persistence and difficulty to manage, we ranked symptoms based on the incidence of participants responding with each symptom across the 3 variables. Each symptom was allocated a score from 1 to 10 reflecting that incidence.

For the impact on life variable, to analyse the Likert scores a one class Survival Vector Machine learning algorithm (11) was used to assign weights, where higher weights denoted the symptoms that had the greatest impact across domestic duties, social life and income-generating activities. These weights were ranked, then allocated a score from 1 to 10.

Each symptom was then assigned a total score by adding the scores across the 4 variables (prevalence, persistence, difficulty to manage and impact on life) for a total possible score of 40. All of the symptoms were weighted equally across each variable.

Step 2: Identifying socio-economic barriers

We identified the most pressing socioeconomic challenges using content analysis of the qualitative research. This was then supported by test of association using the quantitative data to understand the extent to which each socioeconomic barrier impacted those with the prioritised symptoms. This mixed method approach allowed us to identify the barriers that have the greatest impact on the patient’s ability to access and use therapeutics and other management strategies.

Step 3: Surfacing specific research questions (pages 20-39)

Finally, once the priority themes (symptoms and socioeconomic strategies) were identified, we analysed associated symptoms and existing management strategies currently in use that are perceived to be effective. We then reviewed all the qualitative and quantitative findings to surface specific research questions for each priority theme.
Findings 1:
Descriptive Statistics, Long Covid Definition and Patient Journeys
Descriptive Statistics

The graphics below detail the descriptive statistics for gender, age, education level, relationship status, household size and occupation types by country (Kenya and Malawi). Charts for all descriptive statistics can be found in the appendices (pages 44-48).

**Gender**

- **Kenya**: 49% Female, 51% Male
- **Malawi**: 54% Female, 46% Male

The majority (60%) of the research participants were aged between 26 and 42 years of age. 14% were over 50.

**Age**

- **Kenya**: 51% Male
- **Malawi**: 46% Male

No respondents reported other genders

**Education**

- **Kenya**: 23% had achieved either complete or incomplete primary education, 36% secondary education, 24% tertiary education.
- **Malawi**: 37% had achieved either complete or incomplete primary education, 44% secondary education, 14% tertiary education.

**Relationship status**

- **Kenya**: The majority (56%) of the research participants were married in a monogamous relationship. 23% were single.
- **Malawi**: The majority (63%) of the research participants were married in a monogamous relationship. 17% were single.

**Household size**

- **Kenya**: The greatest proportion (38%) were in a household with 2-3 inhabitants. A further 27% were in 4-5 person households and 15% lived alone.
- **Malawi**: The greatest proportion (36%) were in a household with 4-5 inhabitants. A further 32% were in 2-3 person households, and 25% lived with more than 6 people and only 2% lived alone.

**Occupation**

- **Kenya**: 39% of the participants were self-employed while 21% were unemployed. Most participants work in wholesale and retail trade sectors.
- **Malawi**: 38% of the participants were self-employed while 34% were unemployed. Most participants work in agriculture, hunting, forestry, fishing and trade sectors.
With the evolution of the Covid-19 pandemic, there is a growing need to define the emerging condition following Covid-19 infection. At present, this is commonly called “Long Covid” but also labelled Long-haul COVID or Post Covid-19 condition by the World Health Organization (WHO). To date, there is ongoing research by WHO (1), Davis et al. (2), Carson (3), etc. to identify a comprehensive definition, establish a diagnosis and offer pathways for effective management that would support patients in their day-to-day experience.

At the beginning of this study in May 2021, our initial definition used for participants recruitment was: “Have had Covid-19 or suspected Covid-19, and have experienced or continue to experience symptoms for a duration of at least 8 weeks”.

This initial definition was validated by WHO in its clinical case definition of post COVID-19 condition by a Delphi consensus: “Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others* and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.” (Published on October 06 2021)

After completion of this study, we have developed the following public-led definition of Long Covid. This definition builds on the WHO definition, while specifying the additional symptoms most associated with Long Covid identified in this research. The following definition also addressed the mental health impact of Long Covid, which was reported as a significant aspect of the Long Covid experience.

**Publicly-led Long Covid definition**

Long Covid occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, with symptoms that last for at least 2 months, **including after a negative test**, and where symptoms cannot be explained by an alternative diagnosis.

Common physiological symptoms include headache, chest pain, fatigue, and shortness of breath. Long Covid also has a significant mental health impact, with psychological symptoms including fear, stress, anxiety and depression. Both physiological and psychological symptoms generally have an impact on everyday functioning.

Symptoms may be a new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.

**Diagnosis and care protocol**

Frontline healthcare professionals in Kenya and Malawi reported the absence of a Long Covid formal diagnosis or care protocol. They describe **practicing a diagnosis by exclusion**, meaning associating the lingering and/or new symptoms observed to Covid-19 after tests for other conditions were negative. In addition, they shared that no standard care protocol has been established to date. As a result, patients are treated symptomatically on a case-by-case basis.

> “We check everything, we cannot find any positive explanation of the symptoms and so eventually we tie it to Covid-19, even though they now are testing negative.”
> - HCW, Male, 35-44, Rural, Malawi

**Understanding of Long Covid**

Only 27% of the respondents had heard the term “Long Covid”: 20% in Kenya and 33% in Malawi. Moreover, those with lower levels of education were less likely to have heard the term. These statistics align with the narratives captured in the qualitative research where respondents described how they were navigating Long Covid on a day-to-day basis without referring to it as Long Covid. Respondents’ definitions were anchored in their experiences. For some of them, the discovery of the term happened later in their journey.

> “I had not heard about that term Long Covid - I had not heard about this.”
> - Patient, Male, 35-44, Rural, Kenya
Patient Journeys

Given the lack of a widely used definition or diagnosis for Long Covid, participants’ understanding of Long Covid was grounded in their own experiences.

No two people’s Long Covid journeys are exactly the same, although we found similar stages across all journeys. The following journey maps show the main stages of the Patient journey: contracting Covid, experiencing persistent symptoms (including after a negative test), seeking advice and explanations for what is happening and finally, managing their symptoms and the symptoms’ evolution.

A young, active and healthy business woman from Kenya with no pre-existing conditions. She lives in an urban area with access to public hospitals and private clinics.

Themes:
• Period of remission following the acute phase of Covid-19
• Repeat prescription of antibiotics
• Significant testing without diagnosis
• Dismissal of concerns by healthcare professionals
• Experiences of poor mental health
• Self-exploration of treatment alternatives
• Use of support groups

A middle-aged fisherman from Malawi with no pre-existing conditions. He loves to walk, jog and has a small-scale farm. Emmanuel lives in a rural area with one public hospital nearby.

Themes:
• Initial self-diagnosis and treatment for Malaria before Covid-19 diagnosis
• Lingering symptoms following the Covid-19 acute phase
• Concerns normalised by healthcare professionals
• Repeated use of over-the-counter medication
• Stigma and isolation from community members
• Symptoms continue to impact life and work

These journey maps highlight the non-linear path to recovery as well as the actions participants are taking to cope with and manage their condition. The 2 Patient journeys presented also capture some of the key themes experienced by multiple patients.
**Wairimu’s Long Covid Journey**

**EXPERIENCE**

"*After getting [Covid], it took me a month of quarantine before being tested negative... After three weeks, I started to feel better and it lasted for 5 or 6 weeks. I went back to work.*"

"The fatigue and migraine were lingering. Starting 4pm, I wouldn’t be able to function anymore... It was chest pain, just like someone stabbing you in the chest and difficulty inhaling. I also had a feeling that I had an elephant sitting on my chest. Also, moving around was quite painful... It was everything I felt at the initial phase of COVID but worse.*"

"I thought I would just call my doctor and see what he says... He didn’t know what to do anymore... When I sent him the list of symptoms I was experiencing, he told me "clearly, this is not happening. You have to go see a therapist. How is your level of anxiety?" That experience with my doctor was really traumatic. And that feeling of complete dismissal was very difficult and isolating.*"

"I just didn’t know what was happening in my body... I wanted to figure it out because I realised I couldn’t stay like this. This is where the support groups came in... Hearing about them [people in the support groups], what they have tried, what their doctor has said, it feels less intimidating.*"

"The support groups have saved a lot of people. "[I learned that] the more you fight [the symptoms], the more they come back. You have to accept it and not spend more energy fighting it as the body doesn’t have much energy. So my days are very different. I just take it day by day." [6 months later, Wairimu continues to recover] "When you’ve been sick for a while and nobody gets it, it’s very hard. There is the trauma of the illness and the trauma it activates within your body... The loneliness and fear can really put you down.*"

**ACTIONS**

- Isolated at home after being in contact with someone who had Covid and started to develop symptoms.
- Was “diagnosed” with Covid by family doctor without a test, and prescribed antibiotics and vitamins (i.e., Zinc, vitamin D and C) to take at home.
- Tested negative after the quarantine period.
- Went back to work.
- Spoke to her doctor on the phone who recommended that she take another course of broad spectrum antibiotics in addition to a cough syrup for the chest pain.
- Tried traditional remedies including drinking a mixture of lemon, ginger and honey, gargling daily with salt water, and steaming with eucalyptus oil but it was painful for her chest so she stopped.
- Increased her daily water intake.
- Spoke to her doctor who tested for infections and underlying causes. When all results came back negative, the doctor communicated his skepticism. He implied it was all in her head and recommended that she seek psychological help in addition to taking the antibiotics and pain killers already prescribed.
- Stopped the antibiotics and began to research alternatives.
- Tapped into a network of support (i.e., Online support groups for Long Covid patients, friends, Church, etc.)
- Began pursuing treatment alternatives based on her own research including increasing her use of traditional remedies and making lifestyle changes.
- Continued to engage with online Long Covid support community.
- Started to see a therapist to help her process trauma.
- Changed her diet by cutting junk foods, eating lots of greens and continuing to drinking lemon, ginger and honey.
- Took supplements: vitamin D, C, Zinc, etc.
- Introduced gentle movement during the day to stretch.
- Took breaks at work when feeling tired.
- Continues to seek therapy to manage mental health.
Emmanuel's Long Covid Journey

COVID - ACUTE PHASE
PERSISTENT SYMPTOMS
UNDIAGNOSED LONG COVID
SYMPTOMS MANAGEMENT
SYMPTOMS EVOLUTION
ON THE PATH TO RECOVERY

EXPERIENCE

"When I started feeling those body pains, I went to buy antimalarial drugs. I took them, I noticed that they were not having any effect... I went to get tested and was found positive. It took a long time for the symptoms to go... Even after I tested negative for corona and started to feel better, the symptoms had not come to an end."

"I would find myself tired. I would walk a short distance and feel shortness of breath, and fatigue. I was coughing but it wasn't as persistent as before, and the headache was there but not as bad as before."

"I asked my friends who had also experienced corona and they had not experienced the same thing... I had been told that the corona was cleared but then I was experiencing these other problems; shortness of breath and other things... When I explained to the doctor, he said: don't worry, you will be fine. It takes some time but it is good that the corona is cleared and you will be better in time."

"I still feel some pain inside my chest... Every time the doctors ask me how I am feeling, I just tell them how I am feeling. They just give me medication and tell me go. They don't ask a lot of questions."

My transition from being ill to going back to work in the market was very difficult. People still thought I was sick, they didn't want to be around me, they didn't want to come close to me, it took about a month and a half before people would accept me.

"Now, I am better and I thank God for that... However, things have changed quite a lot. Initially, I would jog long distances and now I cannot. My business has also been affected. Initially, I could work for long days, waking up at 5am but now I can't do this because I get body pains and it affects me."

ACTIONS

- Took malaria medicine that was bought without prescription at the pharmacy - they were no symptom improvement after using antimalarials.
- Was encouraged to go a covid facility by a friend to be tested, and tested positive.
- Was prescribed panadol and antibiotics (amoxicillin) at the testing center and sent home to isolate.
- Used traditional remedies including blue gum (eucalyptus) for steaming and warm water with ginger.
- Went back again to the hospital to get retested, and tested negative.
- Continued to complain of symptoms and received panadol from the health facility.
- Talked to other friends who also got Covid to learn about their experience and see if they were feeling the same as him.
- Visited the hospital again and received extra panadol.
- Stopped taking the natural remedies and was just taking the painkillers given at the hospital.
- Continued to be cared for by family members and friends, who also began to support him financially.
- Went back to work where he experienced stigma and isolation due to the fact that he had previously had covid.
- Visited the hospital 2 more times, each time receiving extra panadol.
- Continued to go to the hospital for panadol. However, less frequently as the symptoms reduced.
- Continued to be cared for by family members and friends, now requiring more financial support to meet daily needs.
- Continued to go to work where the stigma reduced after a month and half and social interactions eventually normalised.
- Engaged in less physical activity (i.e., walking, gardening, jogging) and worked fewer hours due to his lingering symptoms.
- Experienced a decrease in his livelihood.
Findings 2:
Research Agenda
Research Prioritisation

The prioritization exercise identified 8 symptoms and 2 socioeconomic barriers (marked by this symbol: *) as high priority for research. These include 4 physical and 4 psychological symptoms (number in parentheses represents the overall rank where 1 is high and 8 is low):

- Chest pain (2)
- Headache (4)
- Fatigue (5)
- Shortness of breath (8)
- Fear (1)
- Stress (3)
- Depression (6)
- Anxiety (7)

All of the symptoms were weighted equally across each variable. As a result, while some symptoms may rank high on one variable (for example, prevalence) they may rank comparatively low ranking across other variables (persistence, difficulty to manage and impact on life) resulting in its exclusion from the prioritised symptoms list.

Each of the priorities will be explored in detail through the analysis on pages (20-39).

In addition to symptoms and socioeconomic barriers, this study also explored whether participants felt vaccination had an impact on their Long Covid symptoms. Vaccination was not prioritised for inclusion in the learning agenda as the data did not identify a significant link between vaccination and changes to Long Covid symptoms. However, data on vaccination rates, perceived impact of vaccination, and vaccine acceptance amongst the 1600+ Long Covid patients can be found in the publicly available data set.

Table 4: Ranking of the prioritised symptoms across the prioritisation criteria

<table>
<thead>
<tr>
<th>Variables</th>
<th>Prevalence</th>
<th>Persistence</th>
<th>Impact on life</th>
<th>Difficulty to manage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chest Pain</td>
<td>#6 (24%)</td>
<td>#2 (17%)</td>
<td>#6 (194)</td>
<td>#3 (9.5%)</td>
</tr>
<tr>
<td>Headache</td>
<td>#1 (53%)</td>
<td>#1 (32%)</td>
<td>#26 (75)</td>
<td>#2 (13%)</td>
</tr>
<tr>
<td>Fatigue</td>
<td>#4 (31%)</td>
<td>#4 (15%)</td>
<td>#18 (132)</td>
<td>#6 (8.1%)</td>
</tr>
<tr>
<td>Shortness of Breath</td>
<td>#11 (17%)</td>
<td>#9 (9%)</td>
<td>#16 (146)</td>
<td>#10 (4.9%)</td>
</tr>
<tr>
<td>Fear</td>
<td>#3 (35%)</td>
<td>#3 (16%)</td>
<td>#2 (203)</td>
<td>#4 (9.2%)</td>
</tr>
<tr>
<td>Stress</td>
<td>#2 (36%)</td>
<td>#5 (15%)</td>
<td>#11 (165)</td>
<td>#5 (8.1%)</td>
</tr>
<tr>
<td>Depression</td>
<td>#14 (13%)</td>
<td>#11 (8%)</td>
<td>#4 (196)</td>
<td>#7 (6.9%)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>#9 (17%)</td>
<td>#6 (12%)</td>
<td>#3 (200)</td>
<td>#8 (5.6%)</td>
</tr>
</tbody>
</table>

The above graphic showcases the ranking (#) of the prioritised symptoms across all 4 variables (prevalence, persistence, impact of life and difficulty to manage). An explanation of the output for each variable can be found below:

- For prevalence: % of the population reporting the symptom as most prevalent.
- For persistence: % of the population reporting the symptom amongst the top 3 most persistent symptoms.
- For difficulty to manage: % of the population reporting the symptom as the most difficult symptom to manage or find relief from.
- For impact of life: the weighted output of the Likert score analysis across i) impact on social life, ii) impact on income generating activities, and iii) impact on domestic duties.

Charts for all symptoms across the 4 variables can be found in the appendices (pages 49-50).

Cost of care and stigma are not represented in this ranking as they are socioeconomic barriers that were not weighted across these 4 variables. The analysis of cost of care and stigma’s impact on patients with the prioritised symptoms can be found in the appendices (pages 51).
Chest Pain

Symptom definition
Chest pain was described as the feeling of pain, pressure or discomfort across patients' chests.

“It was chest pain, just like someone stabbing you in the chest and difficulty inhaling. I also had a feeling that I had an elephant sitting on my chest.”
- Female, 25-34, Urban, Kenya

Experience
Chest pain is the second most persistent symptom, with an average symptom duration of 3.1 months. For many patients the chest pain would evolve from being non-specific and more constant earlier in the patient journey, to being more situational, for example, triggered by exertion and cold temperature later in the journey. Further research is required to understand more about how and why chest pain evolves over time across the Long Covid journey.

“Even now [more than 6 months later] I can't walk for a long distance - if I do, I experience chest pains.”
- Female, 25-42, Urban, Kenya

Chest pain had a very large impact on patient's daily lives with 77% reporting it impacted their income-generating activities sometimes, often or always. The qualitative research seemed to indicate that this impact on life was more prevalent in rural areas and amongst those with employment that required physical activity, however, that relationship was not echoed in the qualitative data where chest pain was evenly distributed across all employment categories.

“I still feel pain inside my chest. I used to be able to go out and tend to my plants, cultivating them but now I cannot. I do not work for long periods anymore.”
- Female, 35-44, Urban, Kenya

Chest pain is strongly significantly associated with shortness of breath, with 27% of all those with chest pain also suffering from shortness of breath. This was echoed in the qualitative research where many felt that damage to their lungs during the acute phase of Covid, had resulted in their chest pain. This may indicate that chest pain associated with Long Covid is pleuritic chest pain, particularly as qualitative participants reported experiencing more pain while lying down or trying to sleep.

“I really had difficulties in breathing and pain when I slept facing up - so I had to sleep facing sideways.”
- Female, 35-44, Urban, Kenya

Prevalence

<table>
<thead>
<tr>
<th>Rank</th>
<th>#6</th>
<th>24%</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of the population</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Country variation: Chest pain was more prevalent in Kenya than Malawi.

Pre-existing condition variation: Chest pain was more prevalent amongst those with pre-existing conditions.

Persistence

<table>
<thead>
<tr>
<th>Rank</th>
<th>#2</th>
<th>3.1</th>
<th>17%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Months average duration</td>
<td>% of population reporting chest pain amongst top 3 most persistent symptoms</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Country variation: Chest pain was more frequently reported as one of the most persistent symptoms by those in Kenya compared to Malawi.

Pre-existing condition variation: Chest pain was more persistent amongst those with pre-existing conditions.

Impact on daily life

<table>
<thead>
<tr>
<th>Rank</th>
<th>#6</th>
<th>77%</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of population reporting chest pain impacts their income-generating activities sometimes, often or always</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Country variation: Chest pain had a more frequent impact on life amongst Malawians than Kenyans.

Difficulty to manage

<table>
<thead>
<tr>
<th>Rank</th>
<th>#3</th>
<th>9.5%</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of population reporting chest pain as the most difficult symptom to manage or find relief from</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

17% % of population that did not experience relief from chest pain using their management strategies.

Note: Demographic data is only reported where there is a significant difference from the mean (95% confidence interval). Country, gender, age, location (rural/urban), education, household size, and pre-existing conditions were all tested.
Chest Pain

condition in particular. Further research would be required to determine which pre-existing conditions are risk factors for chest pain associated with Long Covid.

Chest pain was very difficult to manage with patients exploring pharmaceutical therapeutics, supplements, and traditional remedies to overcome their chest pain. In Malawi, steroids (hydrocortisone) were more commonly prescribed to patients than in Kenya with 14% of those experiencing chest pain having used hydrocortisone compared to 3% in Kenya. Hydrocortisone was associated with relief from chest pain, however this was typically prescribed during the acute phase of Covid-19 and further research would be required to support its effectiveness for prolonged chest pain.

Decongestants and painkillers were also associated with relief from chest pain and were commonly used by those experiencing chest pain, with 16% using decongestants and 63% using painkillers. Antibiotics were also commonly prescribed amongst those experiencing chest pain (37% of patients prescribed antibiotics) and are also positively associated with some relief from chest pain.

Many participants took supplements, particularly Vitamin C, Vitamin D, and Zinc, (26%) often prescribed by healthcare professionals and these supplements were associated with some relief from chest pain.

Steaming using either Vicks Vaporub, or eucalyptus (locally known as blue gum) mixed with water was a commonly used traditional strategy (16% of all respondents) and was particularly popular in Malawi. In the qualitative research, many participants felt that steaming allowed them to sleep more comfortably at night.

“Also, we would do the steaming, where we were using blue gum. After the steaming, she would say I am feeling much better in my chest.”

- Carer, 33-44, Peri-urban, Malawi

2. Why is chest pain associated with Long Covid so persistent?
3. Are decongestants effective against chest pain associated with Long Covid?
4. Is hydrocortisone effective against prolonged chest pain associated with Long Covid?
5. Are supplements including Vitamin C, D and Zinc effective against chest pain associated with Long Covid?
6. Is steaming effective against chest pain associated with Long Covid?
Symptom definition

The term headache was used to describe all types of headaches including migraines. Participants used headache and migraine interchangeably while describing their symptoms. Further exploration would be required to identify the specific type of headache most commonly associated with Long Covid.

Experience

Headache was the most prevalent, most persistent and the second most difficult to manage symptom reported by participants in both Kenya and Malawi. In the qualitative interviews participants described either severe headaches or persistent headaches as difficult to find relief from for multiple days.

Headache was also frequently linked to fatigue in the qualitative research, and this positive and significant association between headache and fatigue can also be found in the quantitative data, with 33% of those who suffer from headaches also suffering from fatigue. In terms of psychological symptoms, headache was also positively correlated with stress, fear and anxiety.

“What I noticed was the fatigue and migraine were lingering. Starting 4pm, I wouldn’t be able to function anymore.”
- Female, 25-33, Urban, Kenya

Some headaches associated with Long Covid seem to be resistant to common painkillers. Painkillers were the most frequently used management strategy with 65% of patients in both Kenya and Malawi who experienced headache using painkillers. The qualitative data suggests that most patients were prescribed or recommended paracetamol, available over the counter. Of those who used painkillers, 20% did not find relief from headache from painkillers and continued to experience headaches.

“When I went to get retested [and tested negative], that is when I was given extra Panadol as the symptoms were still there and then I even went back another time, I went 3 times for Panadol.”
- Male, 45-60, Rural, Malawi

Relief from headache was also positively associated with anti-malarial drugs. 10% of those who experienced headache used antimalarial drugs (of those 62% (n=59) had a positive Covid test).

Of the non-pharmaceutical management strategies, herbal supplements were commonly used in Malawi and were positively associated with headache relief. Herbal supplements were often bought from suppliers or given to patients by friends and family members and contained a blend of unknown ingredients. Steaming was also positively associated with headache relief, with the majority of respondents using either Vicks Vaporub, or eucalyptus (locally known as blue gum) mixed with water for steaming.

Prevalence

<table>
<thead>
<tr>
<th>Rank</th>
<th>% of the population</th>
<th>#1</th>
<th>53%</th>
</tr>
</thead>
</table>

Persistence

<table>
<thead>
<tr>
<th>Rank</th>
<th>Months average duration</th>
<th>#1</th>
<th>32%</th>
</tr>
</thead>
</table>

Country variation: Headache was more frequently reported as a most persistent symptoms in Kenya compared to Malawi

Impact on daily life

<table>
<thead>
<tr>
<th>Rank</th>
<th>% of population reporting headache impacts their income generating activities</th>
<th>#26</th>
<th>81%</th>
</tr>
</thead>
</table>

Age variation: Headache had a more frequent impact on life amongst those over 50 year olds

Pre-existing condition variation: Headache had a more frequent impact on life amongst those with pre-existing conditions

Difficulty to manage

<table>
<thead>
<tr>
<th>Rank</th>
<th>% of population reporting headache as the most difficult symptom to manage or find relief from.</th>
<th>#2</th>
<th>13%</th>
</tr>
</thead>
</table>

16% % of population that did not experience relief from headache using their management strategies.

Education variation: Headache was more difficult to find relief from amongst those with no formal education

Note: Demographic data is only reported where there is a significant difference from the mean (95% confidence interval). Country, gender, age, location (rural/urban), education, household size, and pre-existing conditions were all tested.
1. What **types of headache** are associated with Long Covid?

2. Why are the headaches associated with Long Covid so **persistent**?

3. What is the relationship between **headache and fatigue** for Long Covid?

4. Why are headaches associated with Long Covid **resistant to common painkillers**? What types of painkillers can effectively address or prevent persistent headache associated with Long Covid?

5. Are **anti-malarial drugs** effective at against headache associated with Long Covid?

6. What ingredients within **herbal supplements** are particularly effective against headache associated with Long Covid?

7. Is **steaming** effective against headache associated with Long Covid?

8. Why are people who have **pre-existing conditions** more impacted by headaches associated with Long Covid than those who don’t?
Symptom definition
Fatigue was described as a feeling of extreme tiredness, typically as a result of physical or mental exertion.

Experience
Fatigue is one of the most prevalent and persistent symptoms, with participants reporting that fatigue symptoms last on average 2.8 months. Fatigue has a greater impact on those located in rural areas and those with less than tertiary education, which may be linked to these populations being involved in more physically demanding daily activities. In rural areas, this is likely due to high levels of employment in agriculture, construction, manufacturing and trading and repair. Similarly those with less than university education are disproportionately represented in construction, manufacturing, household service, trading and repair, which likely involved higher levels of physical activity.

"Pulling full days at work was very difficult at that time. I was very tired. I normally got to work at 7:30. By 10 I was always so very tired."
- Male, 25-34, Urban, Kenya

Fatigue is ranked as the 6th most difficult symptom to manage and the 3rd most difficult physical symptom to manage with 56% of the population reporting no finding relief from fatigue from the various management strategies they tried. This may be due to the nature of the management strategies currently used, which typically comprise of lifestyle changes, vitamins and supplements and do not include pharmaceutical therapies. The strategy for combating fatigue is geared towards improving general health and wellbeing.

"I was taking Vitamin C, I was told that would boost my energy. I was told that the fatigue would last a while and clear on its own as I recover."
- Female, 25-34, Peri-urban, Kenya

Vitamin C is among the most commonly used management strategies against fatigue (29% of participants with fatigue used Vitamin C, n=147) and is positively and significantly associated with finding relief from fatigue associated with Long Covid. Herbal supplements were also used by 8% of respondents and positively associated with relief from fatigue. As mentioned, herbal supplements were often bought from suppliers or marketplaces or gifted by friends and family members and contained a blend of unknown ingredients. Further research would be required to determine the specific ingredients within herbal supplements that support relief from fatigue.

Prevalence
<table>
<thead>
<tr>
<th>Rank</th>
<th>Prevalence</th>
<th>% of the population</th>
</tr>
</thead>
<tbody>
<tr>
<td>#4</td>
<td>31%</td>
<td>Country variation: Fatigue was more prevalent in Kenya than Malawi</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pre-existing condition variation: Fatigue was more prevalent amongst those with pre-existing conditions.</td>
</tr>
</tbody>
</table>

Persistence
<table>
<thead>
<tr>
<th>Rank</th>
<th>Persistence</th>
<th>% of population reporting fatigue amongst top 3 most persistent symptoms.</th>
</tr>
</thead>
<tbody>
<tr>
<td>#4</td>
<td>2.8</td>
<td>Country variation: Fatigue was more frequently reported as one of the most persistent symptoms by those in Kenya than Malawi.</td>
</tr>
</tbody>
</table>

Impact on daily life
<table>
<thead>
<tr>
<th>Rank</th>
<th>Impact</th>
<th>% of population reporting fatigue impacts their income-generating activities sometimes, often or always.</th>
</tr>
</thead>
<tbody>
<tr>
<td>#18</td>
<td>68%</td>
<td>Location variation: Fatigue had a more frequent impact on life amongst rural inhabitants.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Education variation: Fatigue had a more frequent impact on life amongst those with less than tertiary education.</td>
</tr>
</tbody>
</table>

Difficulty to manage
<table>
<thead>
<tr>
<th>Rank</th>
<th>Difficulty</th>
<th>% of population reporting fatigue as the most difficult symptom to manage or find relief from.</th>
</tr>
</thead>
<tbody>
<tr>
<td>#6</td>
<td>8.1%</td>
<td>Age variation: Fatigue was more difficult to find relief from amongst those between 26 and 42.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pre-existing condition variation: Fatigue was more difficult to find relief from amongst those with pre-existing conditions.</td>
</tr>
</tbody>
</table>

Note: Demographic data is only reported where there is a significant difference from the mean (95% confidence interval). Country, gender, age, location (rural/urban), education, household size, and pre-existing conditions were all tested.
Fatigue

For Long Covid treatment, some patients started doing some sort of physical activity and they seemed to recover better than those who stayed at home without activity.”
- Healthcare Professional, 25-34, Urban, Kenya

Healthcare professionals seemed to associate changes in lifestyle with improvement in Long Covid symptoms - particularly fatigue. Dietary changes, physical activity and sleep were only adopted by a small number of participants (each less than 5%), however were positively associated with relief from fatigue. Existing research cautions against the use of unsupervised graded exercise therapy (21) (a type of physical activity protocol) to manage chronic fatigue. Additional research on the effectiveness of these lifestyle changes would be required to determine whether they are effective and appropriate management strategies for fatigue associated with Long Covid.

1. What are the characteristics or determinants that increase a patient’s risk of developing fatigue associated with Long Covid?

2. What is the relationship between fatigue and mental health for Long Covid?

3. Are oral Vitamin C supplements effective against fatigue associated with Long Covid?

4. What ingredients within herbal supplements are particularly effective against fatigue associated with Long Covid?

5. Are dietary changes, physical activity and sleep effective at against fatigue associated with Long Covid?
Shortness of Breath

Symptom definition

Participants used the term shortness of breath to describe the experience of feeling out of breath or feeling unable to breathe normally.

Experience

While not the most prevalent or persistent symptom, shortness of breath had a large impact on participants lives and particularly their ability to work. This impact on daily life was particularly severe in Malawi where 90% of participants reported shortness of breath impacts their income-generating activities sometimes, often or always (compared to 68% in Kenya).

“I started experiencing shortness of breath. I couldn’t do things. The problem was when I got back to work, I just had serious challenges walking up and down the stairs, climbing the crane.”
- Male, 25-34, Urban, Kenya

As is to be expected, shortness of breath was more prevalent amongst those with asthma (30% of those with asthma experienced shortness of breath, compared with 15% of those who did not have asthma). Shortness of breath was also more persistent and more difficult to manage amongst those with asthma and other pre-existing conditions.

From the qualitative interviews, a pattern emerged: while some patients experienced non-specific shortness of breath during the acute phase of Covid-19, particularly those with very severe Covid-19, shortness of breath associated with Long Covid typically presented after physical activity (i.e., walking, lifting objects, taking a bath, etc.). Further research is required to understand more about the different presentations of shortness of breath and where in the Long Covid journey the symptom emerges.

“Some may complain of dyspnea, where they are okay at rest but if they do any small amount of work and they are immediately out of breath.”
- Healthcare Professional, 35-44, Rural, Malawi

While decongestants were used by small number of patients (11%), the most commonly used management strategy was traditional remedies (39%). Herbal mixtures (concoctions) were found to be positively and significantly associated with relief from shortness of breath. These were often homemade with the most commonly reported ingredients being ginger, lemon, garlic and honey. Onions were also said to enable better breathing and were used by 16% of those with shortness of breath.

“We would also put onions on her chest and under her feet. The onions, they say when someone is having flu, it helps them breathe better.”
- Carer, 35-44, Peri-urban, Malawi

Prevalence

#11 17%
Rank % of the population

Age variation: Shortness of breath was more prevalent amongst those over 50 years old.

Pre-existing condition variation: Shortness of breath was more prevalent amongst those with pre-existing conditions, particularly those with asthma.

Persistence

#9 2.7
Rank Months average duration
9%
% of population reporting shortness of breath amongst top 3 most persistent symptoms.

Pre-existing condition variation: Shortness of breath was more frequently reported as one of the most persistent symptoms by those with pre-existing conditions.

Impact on daily life

#16 82%
Rank % of population reporting shortness of breath impacts their income-generating activities sometimes, often or always.

Country variation: Shortness of breath had a more frequent impact on life amongst Malawians.

Difficulty to manage

#10 4.9%
Rank % of population reporting shortness of breath as the most difficult symptom to manage or find relief from.
57%
% of population that did not experience relief from shortness of breath using their management strategies.

Pre-existing condition variation: Shortness of breath was more difficult to find relief from amongst those with pre-existing conditions.

Education variation: Shortness of breath was more difficult to find relief from amongst those who did not have a university degree.

Note: Demographic data is only reported where there is a significant difference from the mean (95% confidence interval). Country, gender, age, location (rural/urban), education, household size, and pre-existing conditions were all tested.
Shortness of Breath

**Increased physical activity** was used by a small number of respondents with shortness of breath, however, it was positively and significantly associated with relief. During the qualitative research, some participants felt that slowly increasing their daily activities had a positive impact on their shortness of breath symptoms.

“On the 31st of July, I had tested negative, but I still feel that shortness of breath. When I start to feel that, I do breathing exercises, and I slowly increase my level of activity. I focus on breathing in and breathing out.”
- Female, 25-34, Peri-urban, Malawi

However, given that shortness of breath is significantly correlated with fatigue (39% of those with shortness of breath also experience fatigue), additional research would be required to determine the appropriateness of any physical activity protocols in managing shortness of breath associated with Long Covid.

**Steaming** was also frequently used and correlated with relief from shortness of breath. 28% of all patients with shortness of breath used steaming (n=83), and the majority of respondents used hot water mixed with either Vicks Vaporub, or eucalyptus (locally known as blue gum).

1. What is the relationship between shortness of breath associated with Long Covid and respiratory pre-existing conditions?
2. Are onions and other traditional remedies effective in easing shortness of breath associated with Long Covid?
3. Can gradually increasing physical activity improve shortness of breath associated with Long Covid?
4. Is steaming effective against shortness of breath associated with Long Covid?
Fear

Symptom definition

Fear was a feeling of concern or discomfort tied to a specific source (for example the fear of going to hospital with Covid-19 or the fear of dying from Covid-19). Fear and anxiety are significantly correlated. Of those with fear, 26% reported anxiety as a symptom.

Experience

Fear was the second most prevalent psychological symptom in both Kenya and Malawi (and 3rd overall). The qualitative research identified that fear was more commonly found amongst those who had experienced high Covid-19 incidence and death within their communities and therefore feared their own mortality. Given the sampling strategy used in the quantitative research (identifying Covid-19 hotspots as primary sampling units), the study may oversample those who experience fear. More research would be required to identify the prevalence of fear in the general population.

I was very, very afraid. The time I was tested positive was the time most people who had tested were dying, not surviving, and so I was very scared.”
- Male, 45-60, Rural, Malawi

Fear was both more prevalent and more persistent amongst those with larger household sizes (4 or more inhabitants). This quantitative finding was echoed in the qualitative research where participants in larger household feared passing Covid-19 to other family members.

We are a family of two children, and there was no way we could have put our parents at risk. So as a family, we decided that I [her sister] was the best person to care for her. I was so afraid but the love I had for her was more than being afraid of contracting Covid.”
- Carer, 25-34, Urban, Kenya

As perhaps is to be expected, fear was also significantly more prevalent and more difficult to manage amongst those with pre-existing conditions. This is likely due to the higher morbidity from Covid-19 amongst those with pre-existing conditions.

Fear was one of the most difficult to manage symptoms and the most difficult to manage psychological symptom. As mentioned, this is likely because participants were fearful of very real and present danger that they were seeing in their environments (loss of life, infecting loved ones, hospitalisation etc.), and as such, finding relief from this fear would be challenging. However, fear is also significantly associated with stigma and myths or rumours. Of those who experienced fear, 52% felt stigma in communities impacted their lives sometimes, often or always, and 65% felt myths and rumours impacted their lives sometimes, often or always (compared to 36% and 57% of those who did not

<table>
<thead>
<tr>
<th>Prevalence</th>
<th>#3</th>
<th>35%</th>
<th>Rank</th>
<th>% of the population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-existing condition variation: Fear was more prevalent amongst those with pre-existing conditions.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Household-size variation: Fear was more prevalent amongst those with larger households (4 or more inhabitants).</td>
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</table>

<table>
<thead>
<tr>
<th>Persistence</th>
<th>#3</th>
<th>2.9</th>
<th>Rank</th>
<th>Months average duration</th>
<th>16%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household-size variation: Fear was more frequently reported as one of the most persistent symptoms by those with larger households (4 or more inhabitants).</td>
<td></td>
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</tbody>
</table>

| Impact on daily life | #2 | 60% | Rank | % of population reporting fear impacts their income-generating activities sometimes, often or always. |

<table>
<thead>
<tr>
<th>Difficulty to manage</th>
<th>#4</th>
<th>9.2%</th>
<th>Rank</th>
<th>% of population reporting fear as the most difficult symptom to manage or find relief from.</th>
<th>95%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location variation: Fear was more difficult to find relief from amongst those who lived in rural areas.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-existing condition variation: Fear was more difficult to find relief from amongst those with pre-existing conditions.</td>
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<td></td>
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</tbody>
</table>

Note: Demographic data is only reported where there is a significant difference from the mean (95% confidence interval). Country, gender, age, location (rural/urban), education, household size, and pre-existing conditions were all tested.
Fear

experience fear. More research into how stigma and misinformation increase fear would be required to understand how improved information dissemination might support Long Covid patients experiencing fear.

“\nWhat has really affected people is the fear. What the government can do is higher sensitisation… I would want people to know is that it is curable, it is not a death sentence and people can recover from it.”
- Carer, 25-34, Urban, Kenya

Of all the management strategies used, sleep and physical activity were the only ones positively and significantly associated with relief from fear in both countries. In Malawi, herbal mixtures, particularly lemon, ginger and honey were also associated with relief from fear.

1. What is the prevalence of fear in the general population of those experiencing Long Covid (when not focussed on Covid hotspots)?

2. How might country governments and other stakeholders reduce stigma of Covid within the community?

3. How might country governments and other stakeholders address fear by reducing misinformation about the risk of death amongst Long Covid patients?

4. Is physical exercise effective in alleviating anxiety and fear associated with Long Covid?
Stress

Symptom definition
Stress was defined as a feeling of strain or tension brought about by a challenging circumstance within the broader Long Covid Patient experience.

Experience
Stress was the most prevalent psychological symptom experienced in both Kenya and Malawi. In the qualitative research, stress was most commonly linked to the financial impact of Long Covid on patients and their carers. This financial impact was typically both as a result of the cost of care (highlighted on page 36), but also the loss of income patients experienced while unwell.

"The thing that made me panic the most was the issue of funds. When you go to a private hospital, the expenses are crazy and so I was also worried about how I would cover the bills"
- Male, 25-34, Urban, Kenya

This link to financial hardship may explain the increasing prevalence of stress with age and with greater household size, which may demonstrate a link between stress amongst the working population and those with dependants. Stress is also more prevalent amongst those with lower levels of education and has a greater impact on daily life amongst those with vocational qualifications. This may be due to less secure income flows among these groups. Those with lower levels of education are more likely to be either unemployed, casually employed, or self employed (92% of those with no formal education, and 58% of those vocationally trained).

"I had a lot of stress about my job. If I had another source of income I could have had less stress during that time. I was more worried about the expense than my wellbeing"
- Male, 25-34, Peri-urban, Kenya

In the qualitative research, stress was very commonly reported at the initial diagnosis of Covid-19 (during the acute phase) but was also common later in the Patient journey as respondents found their symptoms persisting and were forced to seek further testing and treatment.

"I was stressed to get tested positive. I was about a level 8 stress on a scale of 1-10. The stress was worse when I went back to be retested."
- Male, 25-34, Urban, Malawi

As with many psychological symptoms, there were few effective management strategies deployed, and therefore stress was one of the most difficult to manage symptoms. Sleep and physical exercise were positively and significantly associated stress relief. In Kenya, recreational drug use (typically marijuana, alcohol, and miraa/khat) were also positively and significantly associated with relief from stress

Prevalence

<table>
<thead>
<tr>
<th>Rank</th>
<th>#11</th>
<th>36%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rank</td>
<td>% of the population</td>
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</table>

Age variation: Stress was more prevalent amongst those over 25, and increases with age.

Education variation: Stress was more prevalent amongst those with no formal education.

Persistence

<table>
<thead>
<tr>
<th>Rank</th>
<th>#5</th>
<th>3.1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rank</td>
<td>Months average duration</td>
<td></td>
</tr>
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</table>

15% of population reporting stress amongst top 3 most persistent symptoms

Impact on daily life

<table>
<thead>
<tr>
<th>Rank</th>
<th>#11</th>
<th>61%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rank</td>
<td>% of population reporting stress impacts their income-generating activities sometimes, often or always</td>
<td></td>
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</table>

Education variation: Stress had a more frequent impact on life amongst those with vocational training.

Difficulty to manage

<table>
<thead>
<tr>
<th>Rank</th>
<th>#5</th>
<th>8.1%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rank</td>
<td>% of population reporting stress as the most difficult symptom to manage or find relief from</td>
<td></td>
</tr>
</tbody>
</table>

95% % of population that did not experience relief from stress using their management strategies

Household-size variation: Stress was more difficult to find relief from amongst those with larger households (4 or more inhabitants).

As with many psychological symptoms, there were few effective management strategies deployed, and therefore stress was one of the most difficult to manage symptoms. Sleep and physical exercise were positively and significantly associated stress relief. In Kenya, recreational drug use (typically marijuana, alcohol, and miraa/khat) were also positively and significantly associated with relief from stress

but were used by only 2% of those suffering from stress. 36% of those experiencing stress did speak to someone as a management strategy, however, the majority spoke to either friends or family members, with less than 1% speaking to a trained counsellor, and less than 1% were part of support groups.
Stress

1. How might country governments and other stakeholders reduce financial stress through protections against loss of income associated with Long Covid?

2. What is the relationship between Long Covid and recreational drug use?
### Depression

#### Symptom definition
Depression describes a low mood that persisted over a prolonged period of time, feelings of helplessness, and challenges finding pleasure in things participants normally enjoyed. Respondents rarely used the term depression spontaneously but were able to associate their experiences with the description of depression.

> Her kids would go talk to her, and she would not talk at all. She would just say what is this life for. If I can’t interact with my kids, why am I still living.”
- Carer, 25-34, Rural, Kenya

#### Experience
The uncertainty around whether depression experienced as part of Long Covid is biological or psychological in origin was highlighted by the healthcare professionals in the qualitative research. They observed the profound psychological impacts of Long Covid but questioned the cause or risk factors.

> It may cause some neurochemical imbalance that affects the mental status of some people, but it definitely has psychological effects. It could be as a result from the Covid-19 or from being admitted.”
- Healthcare Professional, 25-34, Urban, Kenya

Depression was positively and significantly associated with respondents facing both stigma and isolation. Depression was also ranked amongst the most difficult to manage symptoms and was particularly difficult to manage for those who lived alone. Stigma and isolation may therefore be either risk factors for depression or may further complicate depression amongst those with Long Covid.

> I have noticed that some are still unable to recover their relationships and interactions based on the stigma caused by Covid-19.”
- Healthcare Professional, 35-44, Rural, Malawi

Few effective management strategies were employed to manage depression. Prayer was one of the most commonly used management strategies amongst those experiencing depression, with 52% of all respondents using prayer. While prayer was not associated with relief from depression, research on the role of religious institutions in supporting Long Covid patients with depression may create additional support pathways given limited mental health resources within the Kenyan and Malawian health systems.

Physical activity was the only management strategy reported that was associated with finding relief from depression associated with Long Covid.

Unlike in the management of anxiety, where 11% of respondents used medication to manage their psychological symptoms, less than 1% of those with depression used medication.

<table>
<thead>
<tr>
<th>Prevalence</th>
<th>Rank</th>
<th>% of the population</th>
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</thead>
<tbody>
<tr>
<td>#14</td>
<td>13%</td>
<td></td>
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</table>

Country variation: Depression was more prevalent in Malawi than in Kenya

Age variation: Depression was more prevalent amongst those between 34-42

Pre-existing condition variation: Depression was more prevalent amongst those with pre-existing conditions.

<table>
<thead>
<tr>
<th>Persistence</th>
<th>Rank</th>
<th>Months average duration</th>
<th>% of population reporting depression amongst top 3 most persistent symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>#11</td>
<td>2.6</td>
<td></td>
<td></td>
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</table>

Country variation: Depression was more frequently reported as one of the most persistent symptoms by those in Malawi compared to Kenya.

Age variation: Depression was more persistent amongst those between 34-42.

<table>
<thead>
<tr>
<th>Impact on daily life</th>
<th>Rank</th>
<th>% of population reporting depression impacts their income-generating activities sometimes, often or always</th>
</tr>
</thead>
<tbody>
<tr>
<td>#4</td>
<td>87%</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Difficulty to manage</th>
<th>Rank</th>
<th>% of population reporting depression as the most difficult symptom to manage or find relief from</th>
<th>% of population that did not experience relief from their management strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>#7</td>
<td>6.9%</td>
<td>Households size variation: Depression was more difficult to find relief from amongst those who lived alone.</td>
<td></td>
</tr>
</tbody>
</table>

Note: Demographic data is only reported where there is a significant difference from the mean (95% confidence interval). Country, gender, age, location (rural/urban), education, household size, and pre-existing conditions were all tested.
Depression

While there was evidence in the qualitative research that counselling and support groups could be valuable in managing depression, neither of these strategies were associated with relief from depression in the quantitative data. However, of those with depression 52% spoke to someone, typically friends and family (less than 1% to a trained counsellor), and 7% were part of support groups. Additional research is therefore required on the benefits of trained counsellors and support groups for those with depression.

1. How might an understanding of the biological relationship between depression and Long Covid support the development of therapeutics for depression?
2. How might country governments and other stakeholders reduce stigma of Covid within the community?
3. Which pharmaceutical therapeutics are effective at managing depression associated with Long Covid?
4. How might religious organisations be engaged as part of the management of depression associated with Long Covid?
5. How might trained counsellors and support groups be engaged as part of the management of anxiety associated with Long Covid?
6. Which management strategies would be most effective depression associated with Long Covid amongst those who live alone?
Anxiety

Symptom definition
Anxiety was used to describe feelings of agitation, nervousness or unease felt by participants that could not be tied to a specific source or expected outcome. Anxiety and fear are significantly correlated. Of those with anxiety 44% also reported fear as a symptom.

Experience
While, this work cannot tell whether there is a biological link between Long Covid and anxiety, the qualitative research suggests that some anxiety is linked to the patient’s circumstances. Respondents in the qualitative research expressed anxiety from not having a diagnosis or a concrete treatment plan, and not understanding the reason symptoms continued to persist long after the acute phase. Participants encouraged further exploration to clarify what Long Covid is and how to effectively diagnose it amongst those who experiencing it.

"At diagnosis [for Covid-19], I was ready to take on whatever symptoms came, but when they evolved differently, it was scary. It should be researched as to why the symptoms continue even when you have tested negative."
- Female, 25-34, Peri-urban, Kenya

Anxiety may also have been heightened by the inconsistent messaging and advice being offered by healthcare professionals. Healthcare professionals, particularly in the early stages of the pandemic, reportedly dismissed concerns, and there continue to be no treatment protocols for Long Covid which further contributes to inconsistent messaging.

"Most of my colleagues talk about the problematic management of these clients as they persistently came back. Initially they said that the patients are hypervigilant or had anxiety issues before we understood that they were suffering from Long Covid symptoms."
- Healthcare Professional, 25-34, Urban, Kenya

Anxiety was also more prevalent in Kenya as compared to Malawi. In the qualitative interviews, we found that in Malawi, prolonged symptoms following Covid-19 infection were somewhat normalised by healthcare professionals. However, in Kenya, patients underwent significant testing and either were dismissed or received unsatisfactory explanations, which may have increased anxiety.

Similar to fear, anxiety was significantly more prevalent amongst those with pre-existing conditions (particularly hypertension, asthma and HIV) and among the elderly. This may be as a result of their greater perceived risk of morbidity from Covid-19 or increased levels of anxiety within these populations to start with.

Prevalence

<table>
<thead>
<tr>
<th>Rank</th>
<th>% of the population</th>
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</thead>
<tbody>
<tr>
<td>#9</td>
<td>21%</td>
</tr>
</tbody>
</table>

Country variation: Anxiety was more prevalent in Kenya than Malawi.

Age variation: Anxiety was more prevalent amongst those over 50 years olds.

Pre-existing condition variation: Anxiety was more frequently reported as one of the most persistent symptoms by those in Kenya than Malawi.

Persistence

<table>
<thead>
<tr>
<th>Rank</th>
<th>Months average duration</th>
<th>% of population reporting anxiety amongst top 3 most persistent symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>#6</td>
<td>2.8</td>
<td>12%</td>
</tr>
</tbody>
</table>

Country variation: Anxiety was more frequently reported as one of the most persistent symptoms by those in Kenya than Malawi.

Impact on daily life

<table>
<thead>
<tr>
<th>Rank</th>
<th>% of population reporting anxiety impacts their income-generating activities sometimes, often or always</th>
</tr>
</thead>
<tbody>
<tr>
<td>#3</td>
<td>59%</td>
</tr>
</tbody>
</table>

Difficulty to manage

<table>
<thead>
<tr>
<th>Rank</th>
<th>% of population reporting anxiety as the most difficult symptom to manage or find relief from</th>
<th>% of population that did not experience relief from anxiety using their management strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>#8</td>
<td>5.6%</td>
<td>95%</td>
</tr>
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</table>

Note: Demographic data is only reported where there is a significant difference from the mean (95% confidence interval). Country, gender, age, location (rural/urban), education, household size, and pre-existing conditions were all tested.

Anxiety was very difficult to manage with only 5% of respondents claimed they found relief from anxiety. While there was evidence in the qualitative research that counselling and support groups could be valuable in treating anxiety, of
Anxiety

those with anxiety, only 31% spoke to someone, typically friends or family. Less than 1% spoke to a trained counsellor, and less than 1% were part of support groups. None of these strategies were significantly associated with perceived relief from anxiety.

"The support groups have saved a lot of people. There is something about knowing that you are not the only one going through something."
- Female, 25-34, Urban, Kenya

Furthermore, 11% of those with anxiety reported “taking medication” to manage their psychological symptoms, however, taking medication was not associated with relief from anxiety, which suggests that effective medications either are not reaching those in need or still need to be developed. Of lifestyle changes, physical exercise and sleep were positively significantly associated with relief from anxiety, particularly in Kenya.

1. Is there a biological link between anxiety and Long Covid?
2. What are the clinical presentations of Long Covid, and are there characteristics or determinants that increase a patient’s risk of developing Long Covid?
3. How might healthcare professionals diagnose Long Covid?
4. How might existing precedents in supportive diagnosis communication be leveraged to reduce anxiety amongst Long Covid patients?
5. Is sleep effective in alleviating anxiety associated with Long Covid?
6. How might trained counsellors and support groups be engaged as part of the management of anxiety associated with Long Covid?
7. What is the relationship between pre-existing conditions and anxiety associated with Long Covid?
8. Is physical exercise effective in alleviating anxiety associated with Long Covid?
9. Which pharmaceutical therapeutics are effective at managing anxiety associated with Long Covid?
Experience
Cost of care was repeatedly surfaced in the qualitative research as one of the most significant challenges patients and their carers faced while navigating Long Covid. Addressing the challenges associated with cost of care will be crucial to enable equitable access and use of therapeutics and effective management strategies in Kenya and Malawi.

While the quantitative research did not record the actual costs associated with Long Covid in either country, participants in Kenya raised cost of care as having a greater impact on their life as compared to those in Malawi. In Malawi, the majority of participants sought treatment from public facilities (70%) with a further 17% in private facilities, whereas in Kenya participants’ sought care from public (40%) and private (37%) facilities as well as pharmacies and chemists (29%). This more diversified health-seeking behaviour may be in part due to an additional fee charged to all those seeking treatment in public facilities (12) in Kenya, resulting in across the board higher out-of-pocket costs in Kenya.

Most insurance companies do not cover Covid-19 so people have to pay in cash and accumulate a huge bill which causes major stress as people go broke or bankrupt. Most people, including family members, have to dip into their pocket.”

- Female, 25-34, Rural, Kenya

Regardless of the facility being used, patients must still cover the cost of medication, other management strategies, and transportation if referred to other facilities for testing and treatment, which was raised in qualitative research as a significant barrier.

“Caring for and managing Covid-19 patients is expensive. Getting drugs, I would get some free from the hospital but going around and seeing the prices of drugs…for a typical Malawian, it would be very expensive.”

- Carer, 25-34, Rural, Malawi

Cost of care is closely related to loss of income. 56% of those who said that cost of care had a very high effect on them also said that loss of income had a very high effect. Loss of income had the greatest impact on those with lower levels of education. Of those with no formal education, 79% reported that loss of income had average, high or very high effect on them. Loss of income also varied by age and impacted those of working age and the elderly most significantly. Participants in the qualitative research advocated for government support and protections for those with Long Covid.

“What are the laws for illnesses like this? What’s available to people with Long Covid when it comes to protecting their livelihoods? Most people are fired, under-performing, or going to work, which is reinforcing their illness.”

- Female, 35-44, Urban, Kenya

Cost of care
64% % of population reporting cost of care had an average, high or very high effect on them.

Country variation: Cost of care had a greater impact in Kenya compared to Malawi (69% vs 59% reporting average, high or very high effect on them)

Pre-existing condition variation: Cost of care had a greater impact on those with pre-existing conditions (73% vs 60% reporting average, high or very high effect on them)

Loss of income
73% % of population reporting loss of income had an average, high or very high effect on them.

Pre-existing condition variation: Loss of income had a greater impact on those with pre-existing conditions (77% vs 71% reporting average, high or very high effect on them).

Age variation: Loss of income had a greater impact on those over 34 (greatest impact amongst those 34-42 with 79% reporting an average, high or very high effect on them).

Education variation: Loss of income had a greater impact on those without university education (greatest impact amongst those with no formal education with 79% reporting an average, high or very high effect on them).

Note: Demographic data is only reported where there is a significant difference from the mean (95% confidence interval). Country, gender, age, location (rural/urban), education, household size, and pre-existing conditions were all tested.

Both cost of care and loss of income have a greater impact on those with pre-existing conditions. Those with pre-existing conditions seem to experience a longer duration of symptoms - 31% of those with pre-existing conditions had symptoms lasting more than 12 weeks compared to 18% of those without which may result in greater loss of income. Across the 8 highest priority symptoms, those with pre-existing conditions also typically have a more difficulty managing symptoms which may result in higher cost of care.

“It is people that have had other chronic illnesses are those that have had problems with covid-19 recovery and trouble recovering from their symptoms”

- Health Care Worker, 35-44, Urban, Kenya
Cost of Care

1. How might country governments and other stakeholders reduce out-of-pocket costs associated with Long Covid?

2. What is driving demographic differences in management strategy access and use?

3. How might country governments and other stakeholders create protections against loss of income associated with Long Covid?

4. Is Long Covid impacting those with pre-existing conditions more severely? How might country governments and other stakeholders better support those with pre-existing conditions?
Stigma

Definition
Stigma was be described as the negative and often unfounded views of society or a community about Covid and Long Covid patients.

Experience
Many respondents experienced stigma from community members, which was often related to fear that Long Covid patients were still contagious after the initial infection and able to transmit the virus. Respondents in the qualitative research reported that stigma made it challenging to resume their daily life while they were recovering.

“
My transition from being ill to going back to work was very difficult. From the time I was going back to work in the market, people still thought I was sick. They didn’t want to be around me, they didn’t want to come close to me. It took about a month and a half before people would accept me.”
- Male, 45-60, Rural, Malawi

Stigma from family members was also common and was reported by both patients and caregivers in the qualitative research. Even after testing negative, family members did not know how to interact with and manage the risk associated with caring for their loved ones. This fear of interaction within the household often left patients feeling isolated, a finding which is echoed in the quantitative research: 43% of those who reported experiencing isolation also reported that stigma from family had an average, high or very high effect on them, compared to 25% of those who did not experience isolation. In addition to isolation, stigma from family members was also positively and significantly correlated with depression, anxiety and suicidal ideation.

“
Whenever I wanted to take her some food, I was anxious. Coming close to her I felt like I would contract it. I even blamed myself for some of her suicidal thoughts because I was showing her I was anxious.”
- Female, 25-34, Rural, Kenya

From the qualitative research it emerged that some participants had internalised stigma. This was either a real or imagined fear that they would be unwanted or unwelcome among members of their community. For some this resulted in them avoiding social situations. For others it led to them not disclosing their illness outside of very close friends and family. Both of these actions had a negative impact on patients as they either become isolated or were unable to get the support or workplace considerations they needed.

“
You feel in yourself that people are not comfortable. You feel like you shouldn’t be there and should stay away.”
- Male, 35-44, Rural, Kenya

Country variation:
Stigma from the community had a significantly greater impact in Kenya compared to Malawi (47% vs 37% reporting average, high or very high effect on them).

Pre-existing condition variation:
Stigma from the community had a significantly greater impact on those with pre-existing conditions (45% vs 41% reporting average, high or very high effect on them).

Stigma from family members
28%
% of population reporting stigma from family had an average, high or very high effect on them.

Country variation:
Stigma from family had a significantly greater impact in Kenya compared to Malawi (69% vs 59% reporting average, high or very high effect on them).

Pre-existing condition variation:
Stigma from family had a significantly greater impact on those with pre-existing conditions (30% vs 26% reporting average, high or very high effect on them).

Note: Demographic data is only reported where there is a significant difference from the mean (95% confidence interval). Country, gender, age, location (rural/urban), education, household size, and pre-existing conditions were all tested.

“
People are not talking about it and that is a problem because if we don’t talk about it, people won’t get the support they need.”
- Female, 35-44, Peri-urban, Malawi

Higher level of stigma in Kenya compared to Malawi, may be related to messaging around Long Covid in the two countries. In Kenya, many patients were either dismissed or received unsatisfactory explanations about prolonged symptoms of Covid-19, which could lead to greater feelings of risk. Whereas in Malawi, professionals normalised Long Covid and emphasized that patients could experience after-effects of Covid-19 but were no longer contagious, which may result in lower levels of internalised or family stigma.

“
We try to reassure them. I normally say, if you have ever been injured after the wound has healed, it may develop into a keloid and that could start itching and that itching is because of the wound that happened before. This is how we try to explain it. As complications coming after the initial illness.”
- Healthcare Professional, 35-44, Rural, Malawi
Stigma

1. How might country governments and other stakeholders address stigma by reducing misinformation about the risk of transmission by Long Covid patients to the community?

2. How might health care professionals equip carers with accurate information on the risk of transmission by Long Covid patients and home based care guidance to reduce in-home stigma?

3. What strategies could support patients to feel more confident in their recovery and sense of wellbeing as they transition back to their daily life?
Discussion
Contextualising the Study

Elevating publicly-led research questions across global Long Covid priorities

Existing Covid research agendas and Long Covid research agendas include: WHO coordinated global research road map (13), the Long Covid research agenda developed at the ISARIC & GLoPID-R Long Covid forum (03), the child-specific Long Covid research gaps identified by Munbilt, Sigfrid and Warner (14). These present a comprehensive array of research priorities across pathogenesis, epidemiology, clinical characterisation and management, candidate therapeutics and vaccines, and social sciences responses among others. However, while these agendas are informed by the public’s perspective, they take an expert-guided approach. This work adds to these research priorities by identifying specific, publicly-led research questions that cut across the thematic priorities identified in other agendas. Figure 25 in the appendices (page 52) maps the publicly-led research questions to the priority themes identified in both the WHO research road map and the ISARIC & GLoPID-R Long Covid forum. This work poses 52 specific research questions that can be grouped into the following themes:

- Clinical presentations, definition and diagnosis of Long Covid
- Underlying mechanisms of Long Covid symptom development to identify potential therapeutic targets
- Impact of chronic and acute co-infections and co-morbidities
- Therapeutics needed to treat Long Covid symptoms, including non-pharmaceutical interventions
- Health systems role in identifying and supporting Long Covid cases (through holistic care)

A review of research projects identified through the Living Mapping Review of COVID-19 funded research projects (15), demonstrates that some of the priorities posed in this study are aligned with published and ongoing research. Work has already begun to understand biomarkers and develop diagnostic criteria, identify the the determinants and mechanisms for several of the prolonged symptoms explored in this study, and explore the impact of Long Covid on the human brain (see endnote below).

This study distinguishes itself in the level of detail and specificity of the Long Covid research questions. Through the mixed methods approach, we were able to identify existing management strategies, including pharmaceutical therapeutics, supplements, traditional remedies, lifestyles changes, psychological support and socioeconomic strategies that are currently used by the public. This broad and comprehensive overview of management strategies offers new opportunities for targeted Long Covid therapeutic and rehabilitation research by elevating strategies patients perceive as being effective and available today.

Furthermore, the majority of published and funded Long Covid research projects are undertaken in upper and upper-middle income countries in Europe and the North America. This research broadens the geographic scope of Long Covid research, not just to lower and lower-middle income countries (LMICs) but to the African continent, specifically Kenya and Malawi (see Figure 04 below):

- Of the 121 Long Covid research projects currently underway, only 3 are on the African continent, and none are in Kenya and Malawi.

Note: The review of existing funded research is based entirely on projects identified from the Living Mapping Review of COVID-19 funded research projects, updated on 29 October 2021.

Figure 4: Locations of Long Covid research projects
The geographic scope of the work has enabled us to identify diverging and shared impacts of Long Covid across Kenya and Malawi and begin to explain some of the divergence, including differences in how Covid-19 is treated in the acute phase, how Long Covid is understood and communicated, how symptoms are managed, and the socio-economic contexts that impact patients’ experiences.

The addition of research questions grounded in the socioeconomic barriers that are impacting patients in Kenya and Malawi is also a distinguishing feature of this study. Of the completed and ongoing research, 1 research project has a specific focus on socioeconomic barriers, with an additional 4 exploring socioeconomic barriers as part of a broader study, and none of this work is being undertaken in LMICs.

Introducing new data and insights from Kenya and Malawi

Existing Long Covid research including Ortona and Malorni 2021 (16) and Sudre et al 2020-preprint (17) have identified a higher prevalence of Long Covid amongst women. While this study does not explore the prevalence of Long Covid in the broader population, statistical analysis was used to explore the association of key demographics including gender across the 4 variables of interest (prevalence of symptoms, persistence of symptoms, impact on life of symptoms, and difficulty to manage symptoms). Gender was not significantly associated with variation across any of the 4 variables for the 8 prioritised symptoms. Furthermore, gender was not significantly associated with variation with regards to the impact of cost of care or stigma.

Similarly to the findings of other research including Daugherty et al, 2021(18), pre-existing conditions are significantly associated with greater prevalence of many symptoms, but also greater difficulty to manage symptoms. Those with pre-existing conditions also experienced more significant socioeconomic challenges including cost of care and stigma in our study.

In addition to new data on how symptoms are experienced by patients, this study also provides new data on the use of traditional and complementary therapies in the management of Long Covid. WHO Global Report on Traditional and Complementary Medicine 2019 (05) highlights the opportunities for traditional and complementary medicine to manage chronic conditions, and particularly the cost-effective nature of some of these management strategies. The use of traditional and complementary medicine is normalised and an inherent part the culture of care in both Kenya and Malawi, as identified in the qualitative and quantitative research. Naturopathy and herbal medicine were the most common traditional and complementary therapies used by the participants in the study. While common ingredients such as ginger, lemon, garlic and onions were used broadly in home made herbal mixtures, participants used commercial herbal supplements and additional research would be required to determine the active ingredients used in these supplements. Building on these findings to identify effective traditional and complementary therapies could create new, cost-effective management and rehabilitation pathways for Long Covid patients.

Health-seeking behaviour has changed globally in response to the Covid-19 pandemic Public Perceptions of Health and Social Care, UK (19) and Xiao, Dai et al. 2021 (20) with a decline in patients seeking care from formal health facilities. While this study did not explore changes in health-seeking behaviour directly, qualitative insights surfaced participants reticence to use formal health facilities. This avoidance was tied to cost of care but also perceived risk associated with Covid-19 transmission from healthcare facilities. There was also stigma surrounding patients who were treated in-patient at facilities who were perceived as being more severely unwell. As treatment and rehabilitation protocols are developed for Long Covid, health-seeking behaviours should be taken into account to ensure equitable access to knowledge and care.

Limitations of the study

As with all retrospective studies, the possibility of recall bias could impact the reliability of patient reported data. Furthermore, given that the experience of Long Covid is impacted by socioeconomic barriers and country contexts, we suggest that the findings be considered only in the context of this study; extrapolation of the results to all patients with Long COVID requires caution.
References


10. “Logistic Regression.” NCSS Statistical Software Methodology Class. NCSS, LLC. All Rights Reserved.


Sample Demographics

Figure 5: Gender Kenya
% of the sample in Kenya (n=806)
Note: No other genders were reported

Figure 6: Gender Malawi
% of the sample in Malawi (n=885)
Note: No other genders were reported

Figure 7: Age Kenya
% of the sample in Kenya (n=806)

Figure 8: Age Malawi
% of the sample in Malawi (n=885)
Sample Demographics

**Figure 9: Education Kenya**
% of the sample in Kenya (n=806)

- Secondary complete: 27%
- Tertiary/college complete: 20%
- Primary complete: 13%
- Secondary incomplete: 9%
- University degree: 8%
- No formal education: 4%
- Tertiary/college incomplete: 4%
- Trade/Vocational qualifications: 4%

**Figure 10: Education Malawi**
% of the sample in Malawi (n=885)

- Primary incomplete: 24%
- Secondary incomplete: 22%
- Secondary complete: 22%
- Primary complete: 13%
- Secondary incomplete: 10%
- Tertiary/college complete: 8%
- Tertiary/college incomplete: 8%
- No formal education: 2%
- Trade/Vocational qualifications: 2%
- University degree: 1%

**Figure 11: Relationship status Kenya**
% of the sample in Kenya (n=806)

- Married (monogamous): 55%
- Single: 23%
- Married (polygamous): 7%
- Widowed: 6%
- Co-habiting: 4%
- Separated: 3%
- Divorced: 2%
- Prefer not to say: 0%

**Figure 12: Relationship status Malawi**
% of the sample in Malawi (n=885)

- Married (monogamous): 63%
- Single: 17%
- Widowed: 6%
- Married (polygamous): 5%
- Separated: 4%
- Divorced: 2%
- Co-habiting: 1%
- Prefer not to say: 1%
Sample Demographics

Figure 13: Number of other members of household Kenya
% of the sample in Kenya (n=806)

Figure 14: Number of other members of household Malawi
% of the sample in Malawi (n=885)

Figure 15: Occupation Kenya
% of the sample in Kenya (n=806)

Figure 16: Occupation Malawi
% of the sample in Malawi (n=885)
Figure 17: Economic sectors Kenya
% of the sample in Kenya (n=806)

- Agriculture, hunting, forestry and fishing: 18%
- Wholesale and retail trade, repair: 11%
- Hotels and restaurants: 11%
- Electricity, gas and water supply: 8%
- Education: 7%
- Manufacturing: 6%
- Other community, social and personal services: 5%
- Transport, storage and communications: 4%
- Real estate, renting and business activities: 2%
- Finance: 2%
- Mining: 2%
- Public administration and defense: 2%
- Fashion and beauty: 1%

Figure 18: Economic sectors Malawi
% of the sample in Malawi (n=885)

- Agriculture, hunting, forestry and fishing: 22%
- Wholesale and retail trade, repair: 20%
- Construction: 11%
- Other community, social and personal services: 7%
- Real estate, renting and business activities: 7%
- Transport, storage and communications: 6%
- Private household service: 5%
- Education: 5%
- Health and social work: 4%
- Manufacturing: 3%
- Finance: 3%
- Electricity, gas and water supply: 3%
- Hotels and restaurants: 3%
- Public administration and defense: 1%
Research prioritisation

Symptom prevalence
Symptom prevalence captures all the symptoms a patient has experienced, including those experienced during the acute phase of Covid. As such, cough and loss of taste and smell rank high on the list of symptoms with regards to prevalence but were not prioritised due to lower persistence, impact on life and difficulty to manage.

Symptom persistence
The addition, this variable aims to ensure that the symptoms prioritised are those associated with Long Covid, as opposed to symptoms associated with the acute phase of Covid-19. The variable is a measure of patients’ perceptions of which 3 symptoms were the most persistent. We found this comparative variable a more reliable measure of patient perceived persistence compared to symptom durations as patients may struggle to accurately self-report the exact duration across the multiple symptoms they experienced.

Figure 20: Prevalence
% of the population reporting symptom

<table>
<thead>
<tr>
<th>Symptom</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headache</td>
<td>52.9%</td>
</tr>
<tr>
<td>Stress</td>
<td>36.4%</td>
</tr>
<tr>
<td>Fear</td>
<td>25.4%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>13.6%</td>
</tr>
<tr>
<td>Cough</td>
<td>28.3%</td>
</tr>
<tr>
<td>Chest pain</td>
<td>24.4%</td>
</tr>
<tr>
<td>Loss of smell</td>
<td>23.7%</td>
</tr>
<tr>
<td>Loss of taste</td>
<td>22.6%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>21.0%</td>
</tr>
<tr>
<td>Joint pain</td>
<td>18.4%</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>17.3%</td>
</tr>
<tr>
<td>Recurrent fever</td>
<td>16.7%</td>
</tr>
<tr>
<td>Isolation</td>
<td>14.4%</td>
</tr>
<tr>
<td>Depression</td>
<td>12.5%</td>
</tr>
<tr>
<td>Body weakness</td>
<td>8.4%</td>
</tr>
</tbody>
</table>

Figure 21: Persistence
% of the population reporting symptom amongst top 3 most persistent symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Headache</td>
<td>31.5%</td>
</tr>
<tr>
<td>Chest pain</td>
<td>17.0%</td>
</tr>
<tr>
<td>Fear</td>
<td>15.9%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>15.1%</td>
</tr>
<tr>
<td>Stress</td>
<td>14.8%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>11.8%</td>
</tr>
<tr>
<td>Joint pain</td>
<td>10.8%</td>
</tr>
<tr>
<td>Recurrent fever</td>
<td>9.1%</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>8.9%</td>
</tr>
<tr>
<td>Loss of smell</td>
<td>8.8%</td>
</tr>
<tr>
<td>Depression</td>
<td>8.4%</td>
</tr>
<tr>
<td>Loss of taste</td>
<td>7.9%</td>
</tr>
<tr>
<td>Flu</td>
<td>5.1%</td>
</tr>
<tr>
<td>Isolation</td>
<td>5.0%</td>
</tr>
<tr>
<td>Body weakness</td>
<td>4.7%</td>
</tr>
</tbody>
</table>
Research prioritisation

Symptom difficulty to manage

This variable is a measure of patients’ perceived challenges finding relief from each symptom. Once again, we use a comparative variable to identify the symptom patients found the most challenging to find relief from. This measure therefore indicates where existing therapeutics and other management strategies are not effective, but may also represent challenges in access (for example, supply or cost barriers).

Cough is highlighted as the most difficult symptom to find relief from but was not prioritised overall given its limited persistence and impact on life.

Figure 22: Difficulty to manage

% of the population reporting symptom as the most difficult symptom to manage or find relief from

<table>
<thead>
<tr>
<th>Symptom</th>
<th>% of Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cough</td>
<td>26.2%</td>
</tr>
<tr>
<td>Headache</td>
<td>13.0%</td>
</tr>
<tr>
<td>Chest pain</td>
<td>9.5%</td>
</tr>
<tr>
<td>Fear</td>
<td>9.2%</td>
</tr>
<tr>
<td>Stress</td>
<td>8.1%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>8.1%</td>
</tr>
<tr>
<td>Depression</td>
<td>6.9%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>5.6%</td>
</tr>
<tr>
<td>Joint pain</td>
<td>5.2%</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>4.9%</td>
</tr>
<tr>
<td>Recurrent fever</td>
<td>3.9%</td>
</tr>
<tr>
<td>Loss of taste</td>
<td>3.8%</td>
</tr>
<tr>
<td>Loss of smell</td>
<td>3.8%</td>
</tr>
<tr>
<td>Isolation</td>
<td>3.4%</td>
</tr>
<tr>
<td>Memory loss</td>
<td>3.0%</td>
</tr>
</tbody>
</table>

Symptom impact on life

The qualitative research identified 3 dimensions: Impact on social life, impact on income-generating activities and impact on domestic duties as the most important to participants, and as such, were tested in the quantitative survey. The data shows that the 3 dimensions are positively and significantly correlated (99% confidence) across each symptom, meaning those who report high impact on social life also report high impact on income-generating activities. Using machine learning to analyse the Likert scores resulted in a weighted output that takes into account respondents perception of the impact of each symptom across each dimension.

Figure 23: Impact on Life

Weighted output of the likert score analysis across i) impact on social life, ii) impact on income generating activities, and iii) impact on domestic duties

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Weighted Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Isolation</td>
<td>219.0</td>
</tr>
<tr>
<td>Fear</td>
<td>203.1</td>
</tr>
<tr>
<td>Anxiety</td>
<td>200.0</td>
</tr>
<tr>
<td>Depression</td>
<td>196.1</td>
</tr>
<tr>
<td>Loss of taste</td>
<td>195.7</td>
</tr>
<tr>
<td>Chest pain</td>
<td>194.3</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>184.1</td>
</tr>
<tr>
<td>Backache</td>
<td>183.5</td>
</tr>
<tr>
<td>Muscle pain</td>
<td>168.1</td>
</tr>
<tr>
<td>Vomiting</td>
<td>167.7</td>
</tr>
<tr>
<td>Stress</td>
<td>164.9</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>164.1</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>146.3</td>
</tr>
<tr>
<td>Fatigue</td>
<td>132.2</td>
</tr>
<tr>
<td>Headache</td>
<td>74.9</td>
</tr>
</tbody>
</table>

Prioritised symptom | Not a prioritised symptom
Research prioritisation

Cost of care
In the qualitative research, cost of care was highlighted as one of the most pressing challenges that respondents faced while navigating Long Covid. Apart from headache and stress, cost of care had a positive and significantly greater impact on those respondents that experienced the symptoms compared to those who didn’t.

Figure 24: Cost of care
% of population reporting that cost of care impacts them either highly or highest

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Those reporting symptom</th>
<th>Those not reporting symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chest pain</td>
<td>30.0%</td>
<td>21.0%</td>
</tr>
<tr>
<td>Headache</td>
<td>22.3%</td>
<td>23.9%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>35.8%</td>
<td></td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>28.7%</td>
<td>28.3%</td>
</tr>
<tr>
<td>Fear</td>
<td>22.0%</td>
<td>30.1%</td>
</tr>
<tr>
<td>Stress</td>
<td>19.2%</td>
<td>25.5%</td>
</tr>
<tr>
<td>Depression</td>
<td>21.8%</td>
<td>32.1%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>21.6%</td>
<td>28.9%</td>
</tr>
</tbody>
</table>

Stigma
The qualitative research also identified stigma (both within the community and within families) as one of the most pressing challenges respondents faced while navigating their illness. Apart from stress, stigma had a positive and significantly greater impact on those respondents that experienced the symptoms compared to those who didn’t.

Figure 25: Stigma
% of population reporting that stigma in the community impacts them either highly or highest

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Those reporting symptom</th>
<th>Those not reporting symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chest pain</td>
<td>44.7%</td>
<td>34.6%</td>
</tr>
<tr>
<td>Headache</td>
<td>40.7%</td>
<td>32.8%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>44.0%</td>
<td>34.0%</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>48.5%</td>
<td>34.6%</td>
</tr>
<tr>
<td>Fear</td>
<td>48.2%</td>
<td>30.9%</td>
</tr>
<tr>
<td>Stress</td>
<td>37.0%</td>
<td>37.0%</td>
</tr>
<tr>
<td>Depression</td>
<td>43.7%</td>
<td>36.0%</td>
</tr>
<tr>
<td>Anxiety</td>
<td>41.4%</td>
<td>35.9%</td>
</tr>
</tbody>
</table>
### Research Agenda Mapping

**Figure 25:** Mapping of Wellcome publicly-led Long Covid research questions to research priorities identified by WHO and in the GloPID-R/ISARIC Long Covid forum (2020)

<table>
<thead>
<tr>
<th>Research priorities identified at the Long Covid Forum</th>
<th>Number of projects currently underway</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Virus: natural history, transmission and diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Identify pathogenesis</td>
<td>28</td>
</tr>
<tr>
<td>Investigate the impact of chronic and acute co-infections</td>
<td>7</td>
</tr>
<tr>
<td><strong>Epidemiological studies</strong></td>
<td></td>
</tr>
<tr>
<td>Define the clinical presentations of Long Covid and characterise the burden and spectrum of Long Covid across populations according to clear case definition</td>
<td>11</td>
</tr>
<tr>
<td><strong>Clinical characterisation and management</strong></td>
<td></td>
</tr>
<tr>
<td>Agree case definition and diagnosis</td>
<td>3</td>
</tr>
<tr>
<td>Relationship between acute disease and Long Covid development</td>
<td>1</td>
</tr>
<tr>
<td>Describe underlying mechanisms to identify potential therapeutic targets</td>
<td>4</td>
</tr>
<tr>
<td>Investigate pathogenesis to explain, e.g. thrombotic tendencies, organ impairment</td>
<td>30</td>
</tr>
<tr>
<td>Investigate the impact of chronic and acute co-infections and comorbidities</td>
<td>6</td>
</tr>
<tr>
<td>Characterise mental health and neurological impacts</td>
<td>23</td>
</tr>
<tr>
<td><strong>Candidate therapeutics R&amp;D</strong></td>
<td></td>
</tr>
<tr>
<td>Investigate antiviral and anti-inflammatory therapeutics and therapeutic timings to prevent Long Covid</td>
<td>1</td>
</tr>
<tr>
<td>Investigate therapeutics to treat Long Covid symptoms and non-pharmaceutical interventions</td>
<td>14</td>
</tr>
<tr>
<td><strong>Candidate vaccines R&amp;D</strong></td>
<td></td>
</tr>
<tr>
<td>Investigate the impact of COVID-19 vaccination on people with Long Covid</td>
<td>0</td>
</tr>
<tr>
<td>Investigate whether vaccination prevents Long Covid</td>
<td>0</td>
</tr>
<tr>
<td>Investigate re-infection in people with Long Covid and impact on vaccine priority list</td>
<td>0</td>
</tr>
<tr>
<td><strong>Social sciences in the outbreak response</strong></td>
<td></td>
</tr>
<tr>
<td>Health systems research on identifying and supporting Long Covid cases (through holistic care)</td>
<td>1</td>
</tr>
</tbody>
</table>

- **Bold text:** WHO mid-term and long-term research priorities: 2019 novel coronavirus
- **Not Bold:** Research priorities identified at the Long Covid Forum.
- **Wellcome Publicly-led Long Covid research questions mapped to Long Covid Forum research priorities**
Wellcome supports science to solve the urgent health challenges facing everyone. We support discovery research into life, health and wellbeing, and we’re taking on three worldwide health challenges: mental health, global heating and infectious diseases.