

A National Coordinated Response to COVID-19 in Wales

Supporting NHS partners through delivering
high-quality digital innovations to the people
that need it, when they need it

Version 1.0

A report reflecting the period between March 2020 to December 2021, which will
be updated when analysis for Wave 3 of the Audit is published

Preface

On March 10th 2020, as we received reports of Italian hospitals struggling to cope with surging COVID cases, we had a meeting in University Hospital Wales run by the Infectious Disease consultants. They updated us on what was known about COVID from the Wuhan data, who was most at risk and what infection control measures should be put in place. Everyone was nervous, expecting the worst.

Patients started arriving fast, with initial outbreaks in Aneurin Bevan Health Board. Later that week, I realised that COVID-19 had created an opportunity to do something different in terms of developing and disseminating guidelines on how to manage this new disease. This perspective had been gained by working in partnership with the Institute for Clinical Science and Technology (ICST) to implement national solutions across other areas of respiratory medicine in Wales in the preceding years. Therefore, on Friday March 13th, I had a meeting with Chris Davies of ICST to ask that he focused his organisation on building and implementing a COVID hospital guideline in Wales. I knew that the success of this guideline would be dependent on the speed of its delivery and on it being highly adaptable as new information on management arrived.

Chris Davies immediately committed to this task and together we drew up plans for how to achieve this. A fixed pathway was created outlining flow through the hospital system with QR codes linking to videos from experts in Wales about how to manage specific aspects of COVID. Within two weeks, hard copies of the pathways were disseminated across all hospitals in Wales, and coordinators identified to promote signup of all relevant health care professionals into the platform. Over the following weeks, large numbers of expert physicians offered their time after shifts working on COVID wards to deliver video updates on changes to COVID management. The team at ICST likewise worked tirelessly to film, edit and animate the videos over weekends to ensure there were no delays to their publication.



The data presented in this report speaks for itself. More than 50% of all consultants of any speciality in Wales, signed into the system and excellent feedback about its relevance and quality. I'm not aware that anyone has created a national guideline like this, anywhere else in the world, and certainly not at such speed and reach.

The Hospital Guidelines served as the template for other interventions for COVID. A primary care guideline, a COVID recovery framework and, importantly, a COVID recovery app. All of these interventions were delivered in partnership with ICST and implemented using the same principles. The COVID recovery app was delivered in consultation with the Long COVID Wales group who helped shape it, and it has been enormously successful with more than 10,000 downloads in Wales to date.

I'm enormously proud of what has been created here in Wales during COVID. It shows what can really be achieved when true innovation is embraced, and I'm equally incredibly thankful for all the hard-working healthcare professionals who gave up their precious time to help with these endeavours. I am very grateful to the Chief Medical Officer and his team for their support which has been integral to this success. Lastly, I cannot underestimate the dedication and commitment of the team at ICST and Professor Chris Davies, without whose expertise none of this would have been possible.

Diolch yn Fawr iawn



Simon Barry

Lead, National Respiratory Health Implementation Group Wales



Authors

Professor Chris Davies, Principal and CEO of ICST

Dr. Simon Barry, Respiratory Consultant and National Clinical Lead



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Introduction

This document presents the large-scale programmes implemented by ICST in partnership with NHS bodies for NHS Wales during the COVID-19 pandemic. This document details the programmes specifically relating to COVID-19.

The structure of this document reflects the expertise that ICST brings to the NHS.

- 1) Innovation design
- 2) Governance
- 3) Implementation
- 4) Impact

Several large-scale programmes have been formally implemented across NHS Wales. These are unique because they are a combination of distinct features that has not been achieved before on this scale. Innovations are bespoke digital applications targeted towards specific healthcare professionals or members of the public. They are high quality and produced quickly as the timing of release for the target population to experience it is essential. Furthermore, the programme includes innovation design that coincides with their implementation. This is underpinned by implementation science methodology.

A good outcome is to deliver high quality innovations to the target population quickly. This is considered by clinicians, patients and government stakeholders to be the most impactful attribute that ICST brings to the health service to make



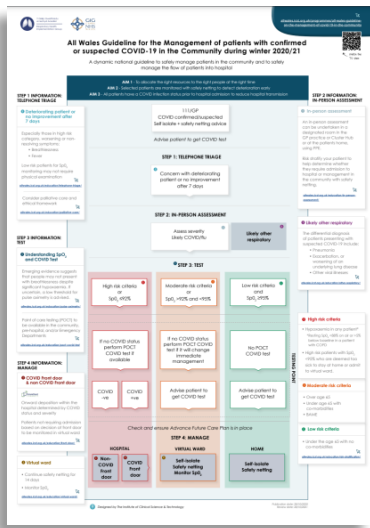
it function better. This document presents the impact of the following innovations:

- 1) Supporting hospital healthcare teams – *through implementing the dynamic **NHS Wales COVID-19 Hospital Guideline***
- 2) Supporting primary care – *through implementing the dynamic **NHS Wales COVID-19 primary care Guideline** and **NHS Wales Long COVID Guideline***
- 3) Supporting the public – *through implementing the **NHS Wales COVID Recovery App***
- 4) Supporting decision-makers – *through implementing the **NHS Wales COVID audit***



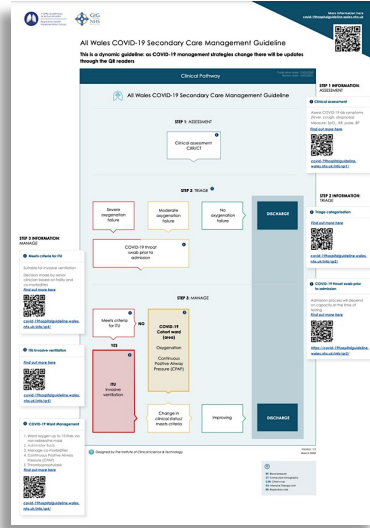
Acute COVID-19

Primary care



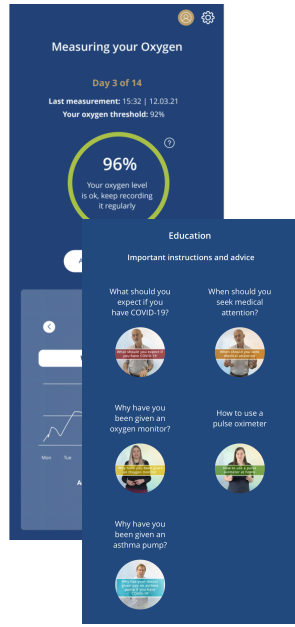
- ✓ Interactive All Wales Guideline, digital and printed copies
- ✓ Triage, assess, test and manage patients in the community
- ✓ When to admit to hospital
- ✓ When to manage in the community with safety netting advice
- ✓ TV show and 30+ tutorials featuring world-renowned experts
- ✓ Case based assessment and certificate

Secondary care



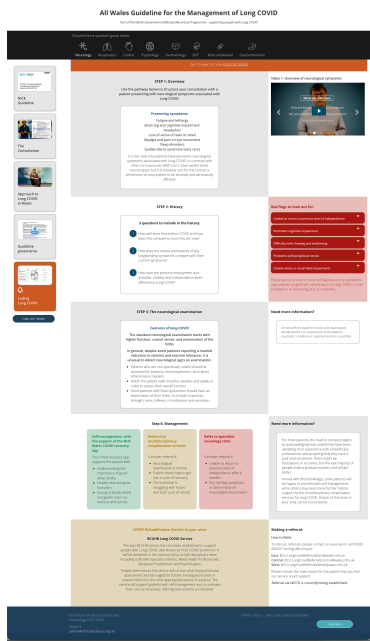
- ✓ Interactive All Wales Guideline, digital and printed copies
- ✓ Dynamic and responsive to emerging evidence
- ✓ From assessment, triage, admission to COVID ward or ITU, or discharge
- ✓ 6 core tutorials and 184 supplementary tutorials (and counting)
- ✓ 'COVID ready' assessment and certificate
- ✓ Featuring 56+ opinion leaders from a range of disciplines

Patients



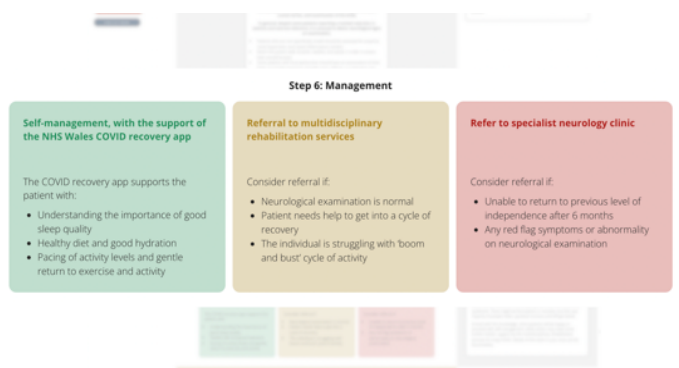
- ✓ The NHS Wales COVID-19 Recovery App for adults with acute COVID-19
- ✓ Support the patient on their journey of recovery from acute COVID-19
- ✓ Record your symptoms and oxygen saturations
- ✓ Understand when to seek help if your condition deteriorates
- ✓ Supplementary app videos

Long COVID

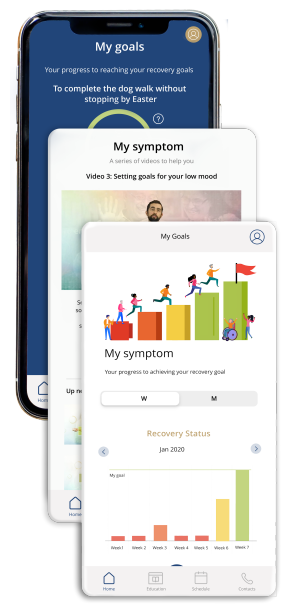


- ✓ Interactive All Wales Guideline
- ✓ Part of the Welsh Government Adferiad (Recovery) Programme
- ✓ A structured clinical assessment of a patients presenting with Long COVID

✗ No innovation for specialist rehabilitation teams



- ✓ However, the Long COVID guideline for primary care, outlines which patients should be referred to the multi-disciplinary rehabilitation services
- ✓ Ensuring the right patients are referred



- ✓ The NHS Wales COVID-19 Recovery App for adults recovering from COVID-19
- ✓ In collaboration with Long COVID Wales
- ✓ Promotes self-management; record your symptoms, set goals for your recovery, monitor your progress
- ✓ Hundreds of supplementary app videos
- ✓ Featuring 33 opinion leaders from a range of disciplines including rehabilitation

Figure 1: COVID management framework produced by RHIG and ICST to demonstrate the relationship between innovations

Whilst each of these products are linked, and interact with one another (Figure 1), for the purposes of the document they are described in the context of their primary target population. The programme for each of these innovations includes the scoping, design and development of the innovations, as well as the structured approach to implementation into the target organisations.

For each of the four components to this document above, further sub-components are included to focus on the core characteristics of each of the programmes evaluated.

- 1) Innovation design – including analysis of the quality, clinical representation and acceptability of the products produced
- 2) Governance – including the breadth of control through analysis of clinical, data, and policy assets
- 3) Implementation – demonstrating the process and framework applied to increase adoption across the target population
- 4) Impact – through the assessment of timeliness, acceptance, and adoption of innovations by the target population

This report uses innovation and implementation framework data and feedback from key stakeholders and members of the target populations, as well as relevant public facing reports and publications, where appropriate. It does not however, include service level or patient-level data.

For more information on the digital implementation system see [*A Proven Digital Implementation System from Policy to Patient*]. The formula is being applied in other areas of healthcare and will be reported in separate documents.



Context

The implementation strategy applied during COVID-19 has been developed over the preceding years in conjunction with the Respiratory Health Implementation Group (RHIG) and Liver Delivery Implementation Group (LDIG) to address several actions detailed in the Respiratory Health Delivery Plan (1) and the Liver Delivery Plan (2) published by Welsh Government in 2016.

Implementation science is the scientific study of methods to promote the systematic uptake and application of research findings and other evidence-based practices into routine practice to improve the quality and effectiveness of health services and care (3). At its core is the question: “How do we get what works to the people who need it, with greater speed, fidelity, efficiency, quality, and relevant coverage?” (4).

Whilst large scale programmes take time to achieve widespread adoption of the innovations (5), the COVID-19 pandemic brought a different contextual backdrop, uncertainty, and urgency, that has accelerated implementation success. This offers a unique window into the potential for implementing large-scale innovations using a particular methodology that has adapted over time. This methodology has been developed through a unique collaboration between ICST and NHS Wales leading to increases in efficiency, acceptance, and adoption.



All Wales Guideline for the Management of patients with confirmed or suspected COVID-19 in the Community during winter 2020/21

A dynamic national guideline to safely manage patients in the community and to safely manage the flow of patients into hospital



- AIM 1** To allocate the right resources to the right person at the right time
- AIM 2** Selected patients are managed with safety netting to prevent deterioration early
- AIM 3** All patients have a COVID infection control plan in hospital admission to reduce hospital transmission

STEP 1 INFORMATION TELEPHONE TRIAGE

- Deteriorating patient or no improvement after 7 days
- Especially those at high risk categories: worsening or new respiratory symptoms
 - + Dyspnoea
 - + Fever
- Low risk patients for SpO₂ monitoring may not require physical examination
- Consider palliative care and advance directives

STEP 2 INFORMATION TEST

- Understanding SpO₂ and COVID test
- Emerging evidence suggests that people may not present with lower oxygen saturation if circulation is low therefore be extra cautious if oxygen saturation is reduced
- Point of care testing (POCT) is not available in the community, see hospital or local Emergency Department

STEP 4 INFORMATION MANAGE

- COVID front door & non-COVID front door
- COVID decision within the hospital determined by COVID status and severity
- Patients not requiring admission based on decision of front door to be monitored in virtual ward
- Virtual ward
 - + Continue safety netting for 14 days
 - + Monitor SpO₂

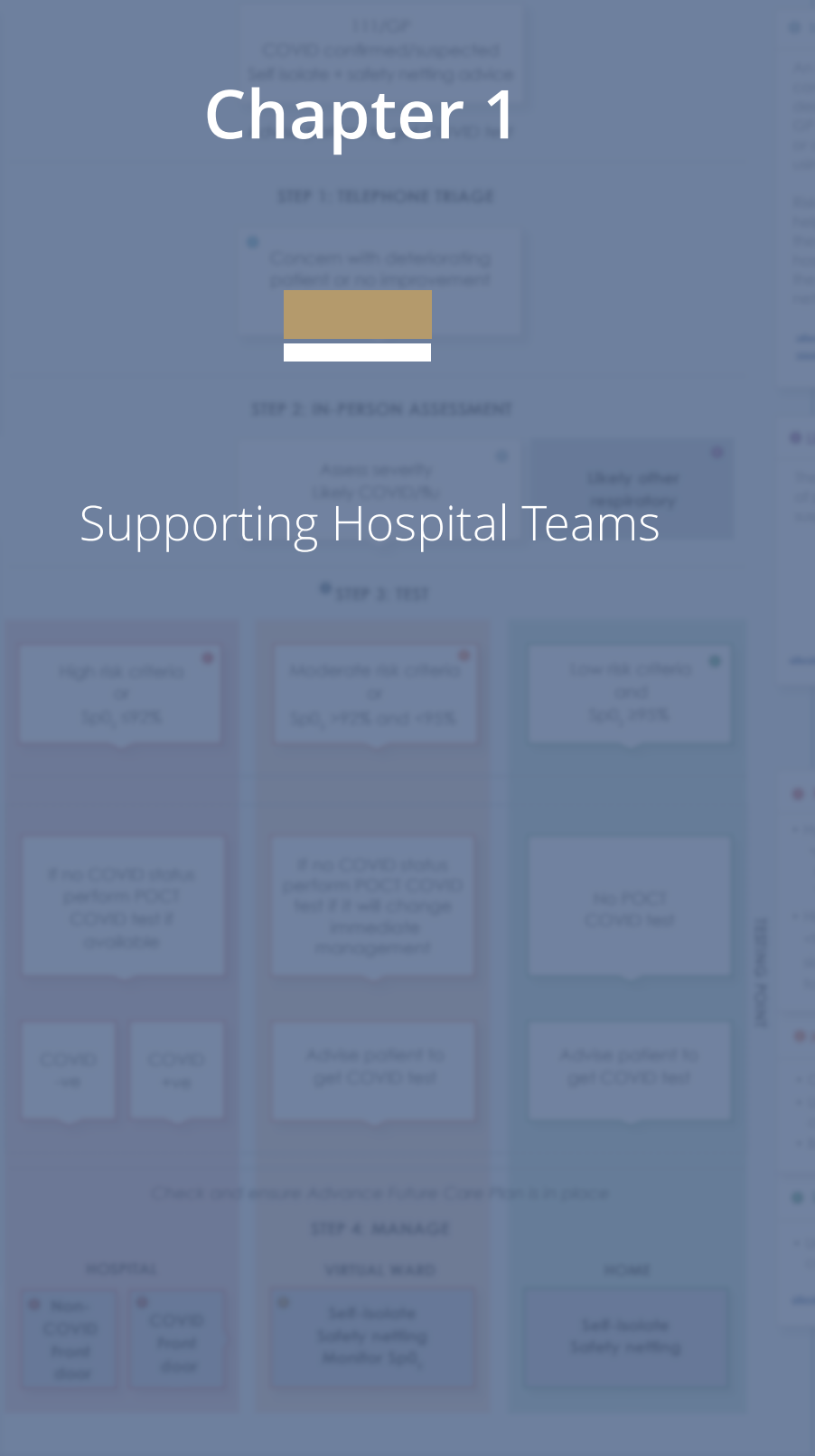
STEP 2 INFORMATION IN-PERSON ASSESSMENT

- In person assessment
- An in-person assessment can be undertaken in a designated room in the GP practice or Clinic hall or at the patient's home, using PPE
- We clarify your patient to help determine whether they require admission hospital or management in the community with safety netting
- Identify other respiratory
- The alternative diagnosis of patients presenting with suspected COVID-19 include
 - + Pneumonia
 - + Tuberculosis or worsening of an underlying lung disease
 - + Other viral/bacterial

- High risk criteria
 - + Represents in any patient "Warning SpO₂ <92% or <94% below baseline in a patient with COVID"
 - + High risk patients with SpO₂ <92% who are deemed to ask to stay at home or wish to virtual ward
- Moderate risk criteria
 - + Over age 65
 - + Under age 65 with co-morbidities
 - + Travel
- Low risk criteria
 - + Under the age of 65 with no co-morbidities

Chapter 1

Supporting Hospital Teams



Chapter 1: Supporting Hospital Teams

Including clinical, managerial and support staff that have a direct or indirect (a potential) role in managing or supporting patients admitted to hospital with COVID-19.

Hospital Guideline Highlights

High level excerpts from the implementation plan and implementation status.

Plan

- Innovation: ***The NHS Wales COVID Hospital Guideline***
- Innovation design/development (initiation (phase 1): March 14th, 2020 (Before first wave)
- Formal installation (phase 2): March 22nd, 2020 (During first wave)
- Target organisations: District General Hospitals within: Aneurin Bevan UHB, Betsi Cadwaladr UHB, Cardiff and Vale UHB, Cwm Taf Morgannwg UHB, Hywel Dda UHB, Swansea Bay UHB, (not Powys Teaching Health Board)
- Primary target population: Clinical decision makers – including respiratory consultants, emergency department consultants, intensive care consultants, palliative care consultants
- Secondary target population: Other hospital clinical staff including nurses and allied healthcare professionals



Current Status

- Current implementation phase: 4/4
- Adoption by target organisations: 100%
- Penetration of primary target populations: 100%



Background

It became evident in early March 2020 that clinical practice regarding aspects of managing COVID-19 varied markedly across the UK and even at local level. The evidence-base how to manage the pandemic was scant. It became clear that it was important to bring clinicians across Wales together to create a national approach to the management of COVID-19 that was adaptable and responsive, reflecting the likely changes in management as the pandemic unfolded and as new evidence emerged. This ranged from initial assessment at the doorstep, to management in ITU and acute palliative care approaches to minimise symptoms and distress.

This guideline needed to be focussed, built on core principles, accessible to all healthcare staff via smart phones, tablets or computers, and utilising clinical leads across the country to promote adoption, thus facilitating the implementation process.

The office of the Chief Medical Officer (CMO) in Welsh Government encouraged the use of the guideline in each health board in Wales by writing to all Health Board Chief Operating Officers in late March 2020.

Innovation Design

The guideline features a universal, evidence-based and regularly updated pathway for assessment, triage and management of patients presenting to hospital with COVID-19. This makes it applicable to any setting or service across Wales.



Whilst the guideline framework does not change, the clinical processes are dynamic, with updates delivered in a video format accessed through QR readers on colour-printed guideline posters and via email updates, as the disease burden and trajectory changes (Figure 2).

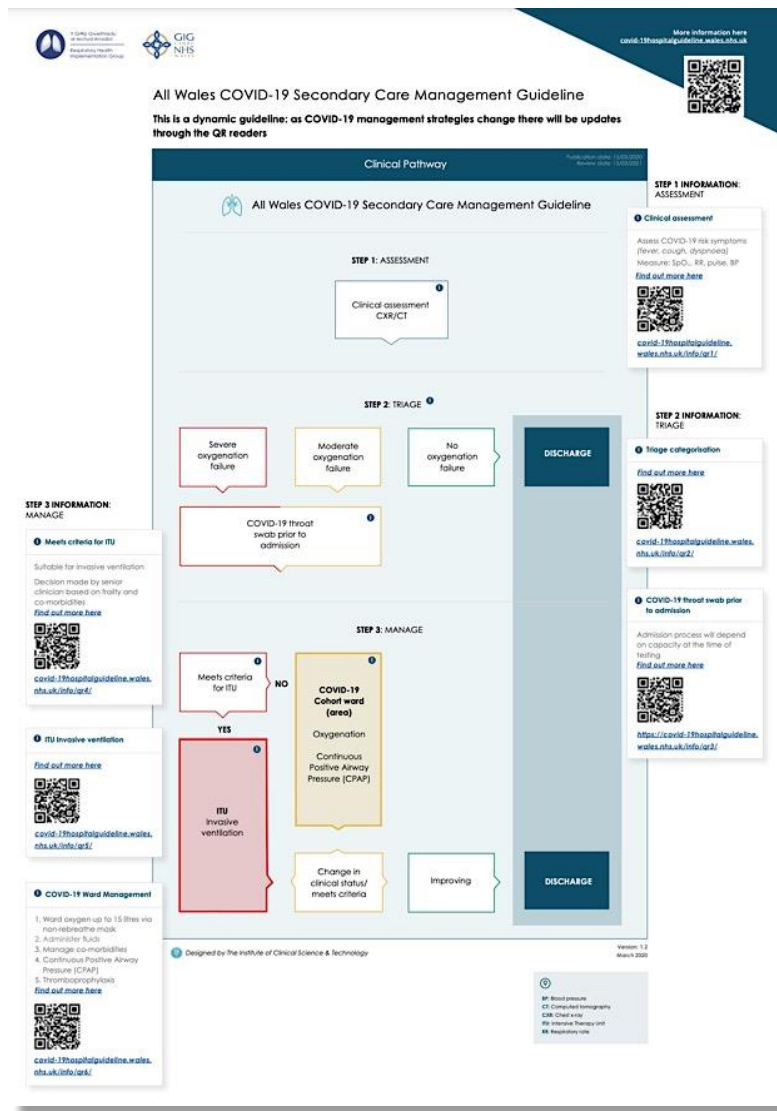


Figure 2: Illustration of the All Wales COVID-19 Secondary Care [Hospital] Management Guideline which demonstrates distinct steps representing the flow in the middle of the guideline with QR codes and links on the side to provide more information that is expected to change

The guideline is supported by a mobile-compatible digital platform hosting video-education delivered by experts across all parts of NHS Wales, ranging from intensive care to palliative care doctors.

Video topics (broad categories) include:


- What makes the virus novel?
- Mode of transmission of SARS-CoV-2
- PPE guidance for frontline teams
- Other tips for staying well at work and in the community
- On admission to hospital
- Diagnosis and investigations
- Treatment options for Acute COVID-19
- Managing a patient on a COVID-19 cohort ward
- CPAP and ventilator equipment
- Management of patients on ICU
- Rehabilitation and discharge
- All Wales Palliative Care Guidelines
- Symptomatic approach to Palliative care
- Communication during end-of-life care
- Registering a death



Chaplaincy and spiritual care during COVID-19

Chaplains are still operating in the hospital during the COVID-19 pandemic, working with healthcare teams to support patients on the ward including spiritual emotional distress and end-of-life situations. Another major role of the Chaplain, together with the wellbeing teams and the psychological support, is to support staff, of all faiths and none, during this difficult time.


The document attached below summarises the prayers and spiritual resources websites that are publicly available, and a list of the contact details of the lead Chaplains throughout Wales.



REVEREND CHRISTINE POWELL
CARDIFF AND VALE UNIVERSITY HEALTH BOARD CHAPLAINCY TEAM

0:13

Additional Resources

 **Chaplaincy links and contact details during COVID-19**

[DOWNLOAD](#)

Figure 3: An example of a video tutorial and text instruction hosted on the guideline platform. For all tutorial webpages relevant documents, reports, websites, links are added as additional resources. The subject matter specialists decide these. This tutorial is a member of the chaplain team explaining how chaplains can be contacted and support families during the pandemic, which illustrates the breadth of information delivered.



Breas VIVO 55 Ventilator: Setting up the patient circuit for non-invasive ventilation

This patient circuit is the equipment required to set up a patient with COVID-19 on a VIVO 55 non-invasive ventilator (or CPAP machine).

Patient interface

- The patient interface is a full-face non-vented mask which fits over the patient's nose and mouth and secured using straps
- Ensure the mask is not too loose or too tight
- The shape of the mask should be flat. This means that there is no exhalation valve which is important for infection control in COVID-19

Two antibacterial-viral filters

- The first filter sits immediately after the patient interface, and filters the air that the patient exhales
- The second filter, at the machine end of the circuit, filters the air that is delivered to the patient

Lock part (exhalation valve)

- The valve attaches to the antibacterial-viral filter and ensures the patient does not re-breathe their waste gases
- The exhalation valve **MUST** follow the antibacterial-viral filter in the circuit to prevent unnecessary penetration of the patient's exhaled breath

End-tidal CO₂ monitor

- The end-tidal CO₂ monitor monitors the carbon dioxide that the patient is exhaling
- It comes in two parts, the array adapter (longer patient use) and the sensor that connects to the ventilator

Standard 22mm circuit tubing

- The standard 22mm circuit tubing connects the end-tidal CO₂ monitor to the multilevel filter

FiO₂ sensor

- The FiO₂ sensor provides a measurement of the FiO₂ being delivered to the patient
- It connects to the patient or outlet on the right side of the ventilator, and the cable connects to the FiO₂ monitoring sensor input on the right side of the ventilator



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Figure 4: An example of a video tutorial and text instruction hosted on the guideline platform. For all tutorial webpages relevant documents, reports, websites, links are added as additional resources. The subject matter specialists decide these. This tutorial here is an instructional video about how to use a CPAP machine for managing COVID patients. This treatment strategy was decided very early and subsequently became normal first line treatment in hospitals across Wales. In this video the device specialist explains how to put a face mask on the patient. Other tutorials provide guidance around the CPAP machine and settings for example, another infection control and CPAP, for example.



Introducing Ronapreve for patients hospitalised with COVID-19

Tutorial presented by Dr Jonathan Underwood, Infectious Diseases and Acute Medicine Consultant, GCM&H.

In this tutorial you introduce Ronapreve, including the evidence behind this new treatment, eligibility criteria, and how this drug might be adopted locally.

Ronapreve is a combination of two antibodies to the spike protein of SARS-CoV-2 virus, casirivimab and imdevimab. These antibodies are active against all the current circulating variants of SARS-CoV-2 including delta.

The RECOVERY study, currently available as a pre-print (medRxiv), found that for all participants there was no difference in 28-day mortality for patients who received Ronapreve versus usual care. However, when stratified by anti-S antibody at baseline (seropositive at baseline or seronegative at baseline), there was a 6% absolute reduction in 28-day mortality in patients who were seronegative at baseline. This means that antibody testing at baseline is important for identifying patients who are going to benefit from Ronapreve.

The indications are outlined in the Updated Commissioning document from 6/11/2021 (also linked below) and include:

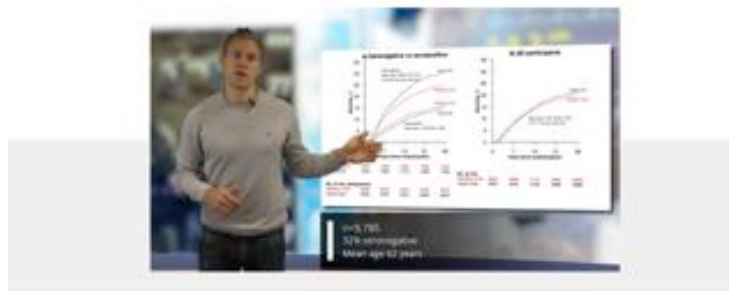
- Patients hospitalised specifically for the management of acute symptoms of COVID-19, and the infection is confirmed by PCR test
- AND Negative for baseline serum anti-spike (anti-S) antibodies against SARS-CoV-2

The commissioning document also outlines the use of Ronapreve in high risk patients who acquire COVID in hospital. This is not covered in the video as it wasn't an indication at the time of filming. Please see the commissioning documents for further details.

The following operational pathway outlines the broad principles for adopting this drug:

1. Has the patient been admitted specifically for acute COVID-19?
2. Is the patient eligible for Ronapreve?
3. Send antibody test to lab (but for antibody therapy on test request)
4. Antibody result likely the next working day
5. Is Ronapreve clinically indicated? Decision by treating consultant for seronegative patients only
6. Cases with pharmacy/sterile unit
7. Administer to patient

Last updated 11/11/2021



MARK AS UNDERSTOOD

Resources

Ronapreve Interim Clinical Commissioning Policy (updated document 6/11/2021)

Casirivimab and imdevimab for patients hospitalised due to COVID-19

VIEW PDF

Casirivimab and imdevimab in patients admitted to hospital with COVID-19 (RECOVERY)

A randomised, controlled, open-label, platform trial (pre-print)

VIEW PDF

Figure 5: This tutorial is an important notification about a new drug treatment and its efficacy when prescribed to patients with severe COVID. This tutorial is in fact the second in the series; the first providing an early overview of this study prior to publication, which has helped manage readiness.





Managing a patient with a Tracheostomy on a COVID-19 ward

Due to the current COVID-19 pandemic, the number of patients requiring intensive care rises, and therefore the frequency of tracheostomy operations is on the rise. These patients are likely to arrive on COVID-19 wards for weaning, and teams on the wards might not be familiar with caring for a patient with a tracheostomy.

The All-Wales TRACHES Checklist (linked below) provides a simple, step-by-step guide to safety care for a patient with a tracheostomy.

Tapes and dressings

- The tapes secure the tracheostomy in place and prevent it becoming dislodged.
- The dressing protects the skin around the tracheostomy and prevents it becoming irritated or macerated.
- The tapes and dressings should be changed once a day in hospital or as required (becomes soiled or discoloured).
- Ensure the tapes are not too loose or too tight; you should be able to pass two fingers between the tapes and the patient's neck.

Red flags

- Red flags are the often-observed warning signs that occur before an emergency.
- Common red flags include increased frequency to change inner tube, increased need to re-inflate the cuff, and ability to vocalise when the cuff is supposed to be inflated.
- Knowing what to look out for will allow early trouble shooting and stop minor problems escalating.

Suction

- Assess the need for suction at least 2 hourly. Suction should not be performed routinely, but only when the patient requires it.
- The frequency of suction varies widely between patients. Providing suction with an aseptic technique and the suction pressure (usually less than 200mmHg).
- Suction may need to be applied to two sites, the lumen of the tracheostomy tube where secretions may gather in the trachea, and above the cuff of a tracheostomy tube where secretions may build up from the upper airway.

Please note: the demonstrations of each step in the video below were filmed before the COVID-19 pandemic, and therefore the PPE worn by the healthcare team is not appropriate for the management of a patient on a COVID-19 ward with a tracheostomy. Please review up-to-date guidance on PPE in COVID-19.

For more information about managing a patient with a tracheostomy, as well as a whole series of videos on each of the seven steps, locate the **All-Wales TRACHES Checklist - Education package** below.

Get Wales TRACHES ready



Tracheostomies are conducted aseptically and full PPE should be worn in line with up-to-date guidance on PPE in COVID-19

MANA AG UNDERSTOOD

Resources



All-Wales TRACHES Checklist - Education package

This website was created to support teams to manage a patient with a tracheostomy, and contains a whole series of videos and resources on each step of the TRACHES acronym.

[View](#)



Emergency Tracheostomy Management Algorithm

The National Tracheostomy Safety Project developed emergency guidelines after researching what were the most common causes of tracheostomy problems.

[View](#)

Figure 6: In this tutorial, tracheostomy experts demonstrate a standardised approach to safe tracheostomy care according to the TRACHES mnemonic. 'T' in this case reflects 'Tapes and Dressings'

Timeliness of Production

The website and first-stage resources were developed in 5 days. Within this period nearly a thousand colour and laminated (for infection control purposes) guideline posters were distributed across clinical areas, staff rooms, and offices within 18 district general hospitals across Wales. This made it easy and convenient for healthcare professionals to access them. By the end of March 2020, the web-based platform was hosted on the Welsh Clinical Portal (WCP) to make it easier for clinicians to access information and educational videos whilst at work.

Content Production

For every video produced for this guideline it comprised of three distinct steps. Whilst several videos were produced simultaneously to maintain the flow of communication to the target population, the average timeframe for a single video to be published on the guideline platform was on average 5 days. In some cases, however, this was significantly quicker when the communication was expedited as high priority. For example, where emerging evidence for new treatments became apparent, in several tutorials the instruction was published within two days.



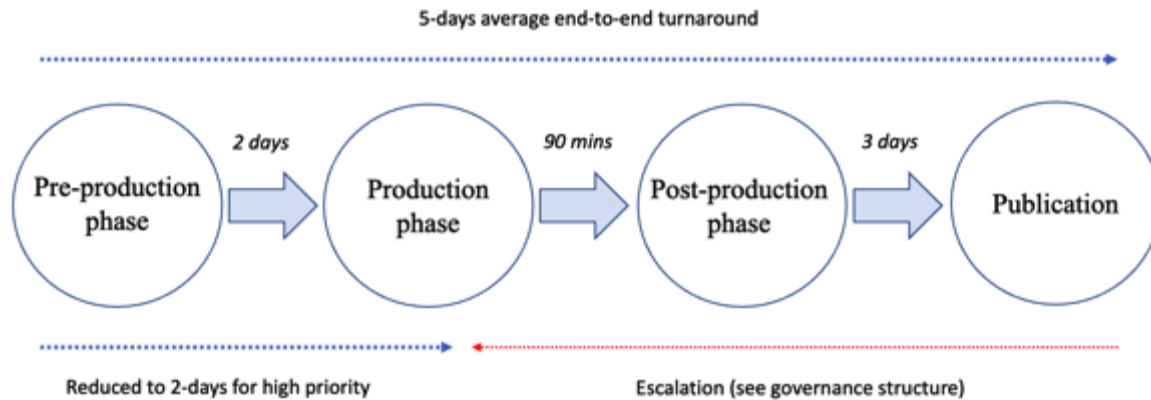


Figure 7: Video tutorial end-to-end production phase. Several messages were escalated due to the urgency of communication. Decision-making controlled by the implementation team via the governance process.

- Pre-production phase (2 days on average)
 - Video scoping, including identifying learning outcomes and preparing motion graphics
 - Governance team determines the most appropriate contributor(s)
 - Average 4 emails to align contributor and schedule filming date
- Production (90 minutes on average)
 - 30-minute pre-filming scoping session
 - 60-minute filming session
- Post-production (3 days on average)
 - 3-hour video edit
 - 1-hour motion graphics creation
 - 2 governance emails with contributor
 - 2 governance emails with clinical lead (where applicable)

- 1-hour to action changes to video/text following review
- 1-hour to build the page, embed the video, format the content, attach the resources/ guidelines, categorise on the platform and publish

In total the guideline has 184 instructional videos averaging approximately 5-7 minutes. There is over 1000 minutes (just under 17 hours) of video education available for healthcare professionals in the management of patients with acute COVID in hospital wards.

All video content is original and unique to NHS Wales. Experts almost exclusively deliver video content from NHS Wales. For every video there is accompanying text copy for people who prefer to read the instruction or cannot watch video content on a busy ward, for example.

From initial publication in March 2020, to December 2021, there were 184 content updates to the COVID hospital guideline platform, of which 151 tutorials (82%) were published within the first wave (March to end of June 2020) (Figure 8).



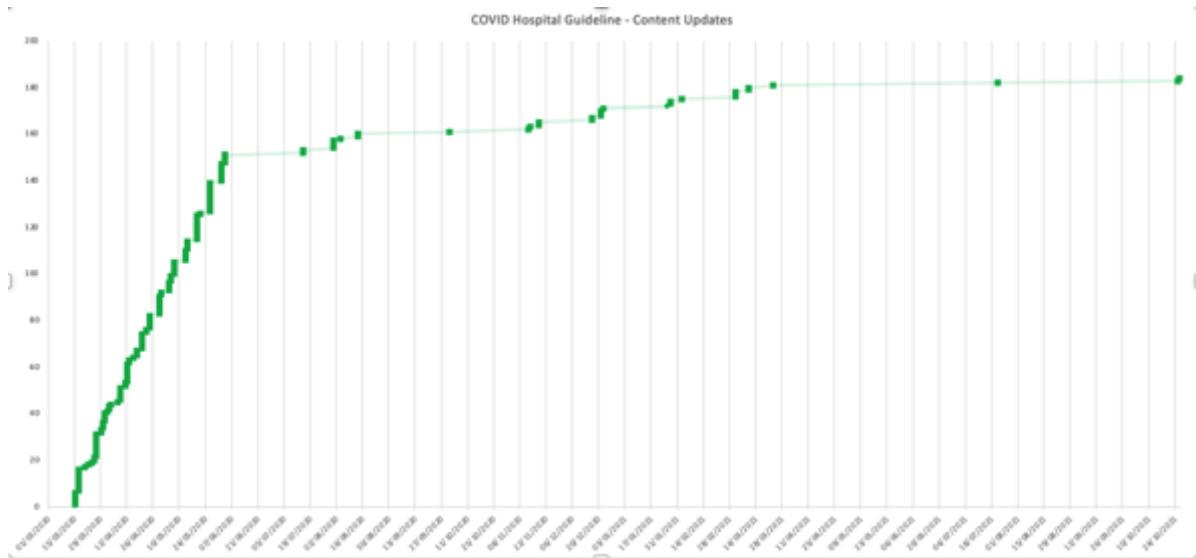


Figure 8: A cumulative graph, showing the number of content updates published to the All-Wales Hospital COVID Guideline. Note the progressive rise in knowledge transferred during the initial phase of the pandemic, reflecting new evidence and emerging recommendations to managing patients with COVID-19.

Opinion Leaders

The guideline features NHS Wales specific instruction from respected subject matter experts (opinion leaders). Opinion leaders improve the acceptability of an innovation by the target population (6). Opinions leaders feature in every video produced to supplement the guideline, which was a strategic decision to increase the probability of adoption of the guideline once it was launched.

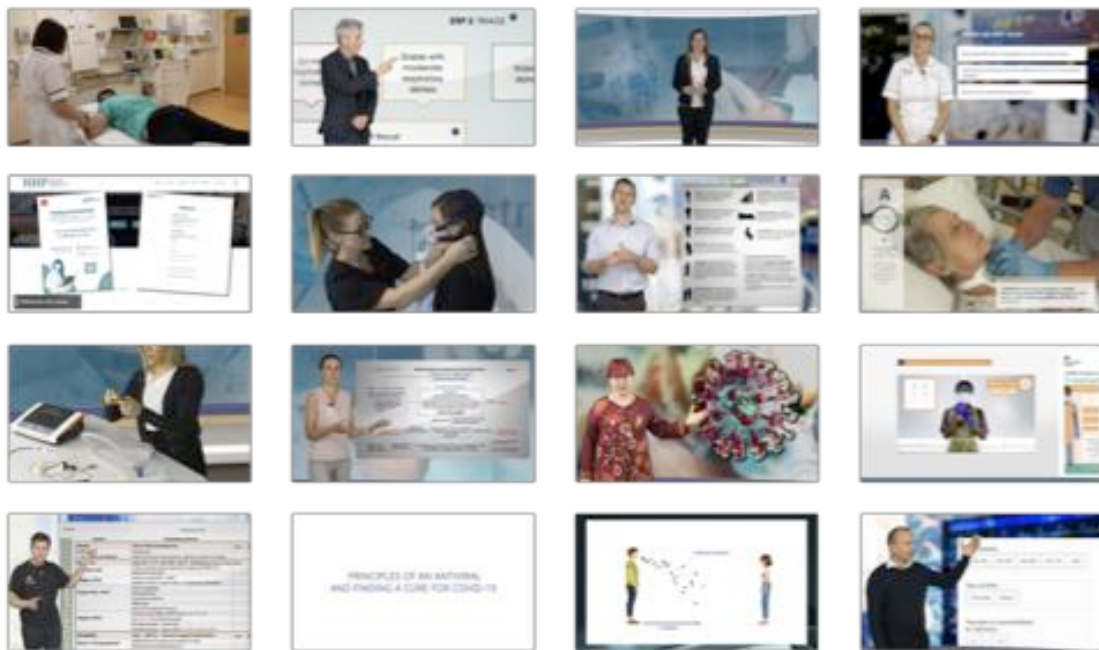


Figure 9: Opinion leaders who volunteered their time to film at the studio in Cardiff. These include respiratory physicians, intensive care doctors, virologists, ward nurses, and physiotherapists, to name a few.

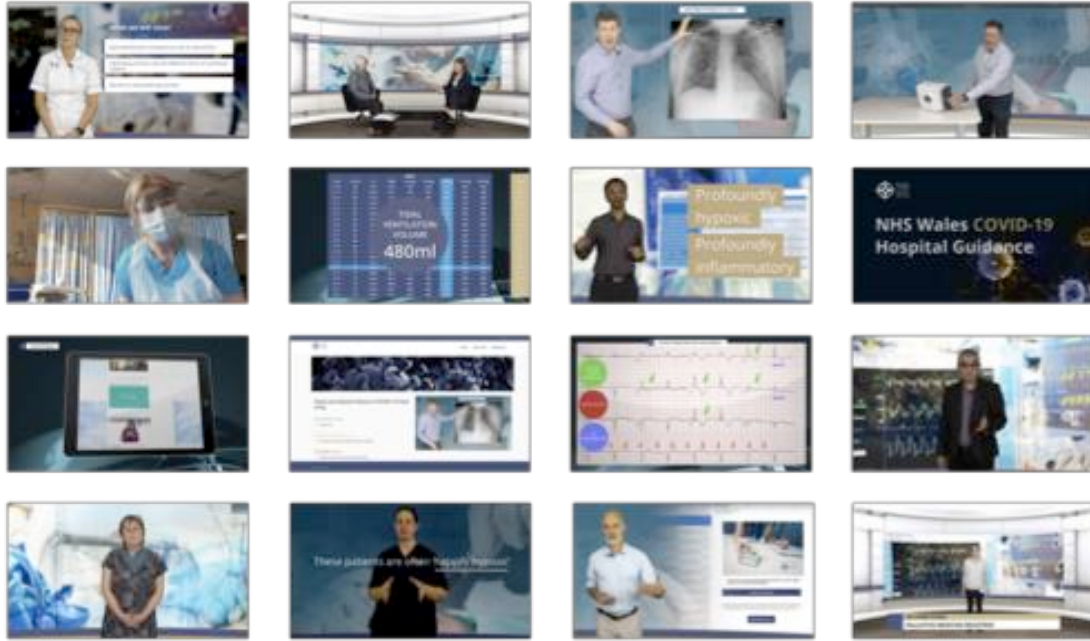


Figure 9 (cont.)

The target population for this guideline were senior decision makers. For the acute management of COVID in hospitals these are consultant-level doctors. Therefore, the predominant professional presenting in the tutorials were consultants (Figure 10) from a range of specialisms (Figure 11).

Profession	Number
Consultant	33
Registrar	5
Nurse	5
Physio	2
Scientist	1
Physiologist	1
Dietitian	1
Chaplain	1
Pharmacist	1
Junior Doctor	3
Medical rep	3

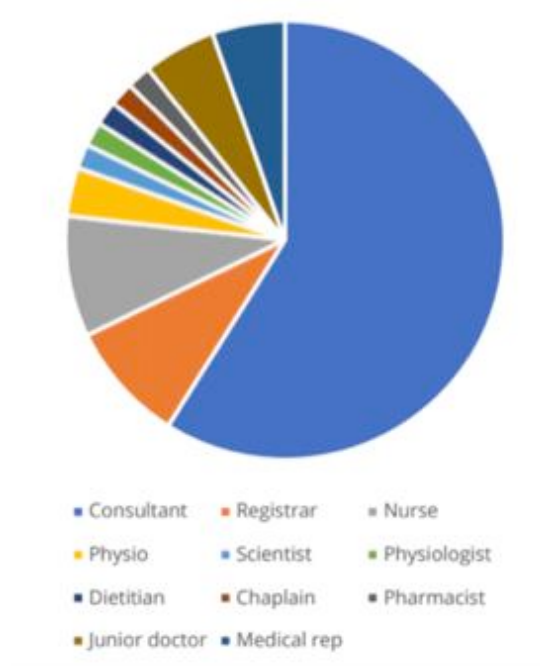


Figure 10: Proportion and number of video presenters representing a range of professionals in NHS Wales

As COVID was a novel disease much was unknown about the condition, particularly during the first wave of the pandemic. As new evidence emerged it was important this was relayed to the people who needed to apply the evidence into practice. Senior opinion leaders represented several different clinical disciplines that were directly or indirectly impacted by COVID (Figure 11).

Discipline	Number
Respiratory	23
Intensive care	8
Infectious diseases	4
Palliative care	4
Medical technology	3
Public health	2
Cardiology	1
Psychiatry	1
Virology	1
Dietetics	1
Dermatology	1
Geriatrics	1
Radiology	1
Immunology	1
Gastroenterology	1
Nephrology	1
Endocrinology	1
Chaplaincy	1

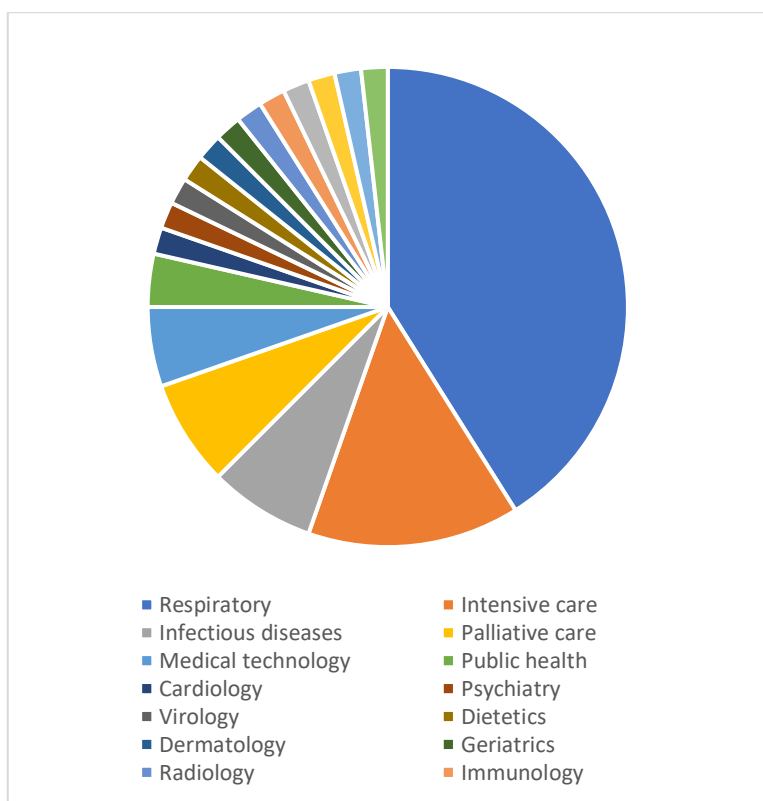


Figure 11: A breakdown of opinion leaders represented within the guideline by discipline

As the guideline was national and the remit was to generate adoption across all Health Boards, the strategy also required good representation from each of the Health Boards (Figure 12) to reduce the barriers to local (clinician-level) acceptance.

Region represented	Number
Cardiff and Vale UHB	35
Betsi Cadwaladr UHB	7
Aneurin Bevan UHB	3
Swansea Bay UHB	3
Hywel Dda UHB	2
Powys TH	N/A
Cwm Taf Morgannwg UHB	0
Public Health Wales	2
Other	3

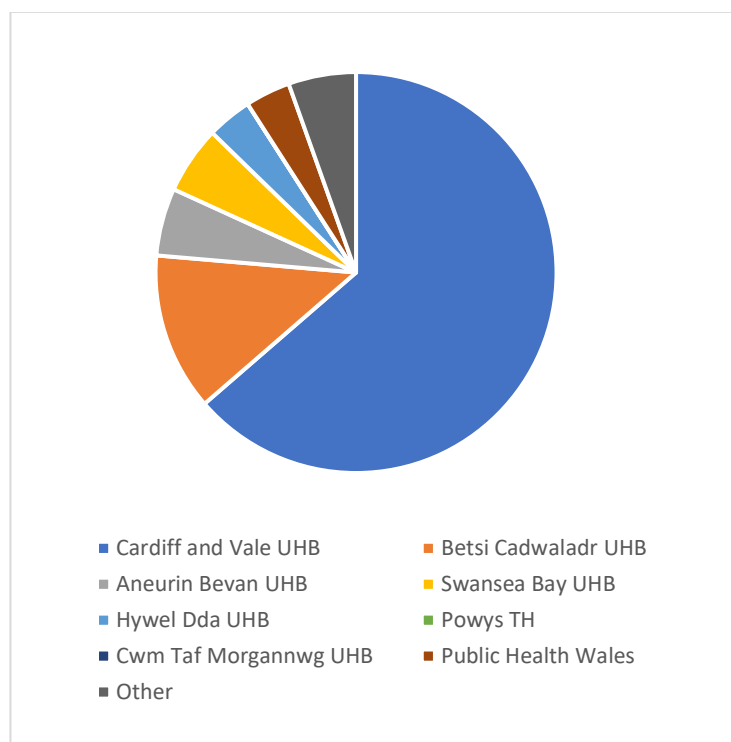


Figure 12: Proportion of opinion leaders presenting in video tutorials representing the different regions/organisations across NHS Wales

Powys teaching hospitals had no representative on the guideline as the region has no district general hospitals or acute specialists. Powys is therefore not representative of the target organization that would host the target population. Nor do they have opinion leaders/subject matter experts, respectively. Through capacity issues and unavailability for quick turnaround times, Cwm Taf Morgannwg UHB had no representation on the guideline.



Figure 13: The green-screen film studio in Cardiff. Here is National Clinical Lead for Palliative care presenting a tutorial on the symptomatic management of patients with COVID-19, towards the end of life. The green background allows the video team to put a virtual studio, animations and other imagery behind the presenter. Where presenters have a green outfit, for example paramedics, we must change it to a blue screen.

As the film studio is based in Cardiff and there were limitations around travel (to avoid further transmission of COVID), therefore most presenting on camera were from Cardiff and Vale UHB. Based on proximity this was feasible, which ensured that during lock down and as the pandemic peaked a rapid flow of video messages could be sustained to maintain knowledge transfer consistent with the emerging and quickly changing evidence base.

Governance

Leading experts in respiratory, intensive and palliative care developed the guideline content, with the national respiratory lead for Wales acting as the guideline coordinator. The national lead considered all decisions about what to include as updates for the guideline, then invited experts to deliver an update in a video format on specific topics. Many of these were practical in nature, for example, how to deliver Continuous Positive Airway Pressure (CPAP) therapy, how to prone patients, or how to provide palliative support, with others outlining emerging national evidence from clinical trials. Consultation amongst a network of clinical colleagues enabled consensus decisions around issues with a limited evidence base, such as the target oxygen saturation ranges, or decisions about thromboprophylaxis.

Governance Structure

The governance structure for the implementation of innovations is illustrated below. The governance map is specified and agreed during phase 1 of the implementation framework, by the Governance Team.





Figure 14: Example of a governance map, with areas, determined by the implementation team early in phase 1 of the implementation framework. This map identifies all the items (e.g. appropriate terminology to use and what to avoid, what content should be created, who are the contributors best suited to deliver the content) and assigns them a governance level determined by a risk assessment. For example, a video about the appropriate use of PPE, should be signed off by the contributor and the clinical lead, because this has large implications if it is wrong, so this would be Governance level 2 (see below).

The governance levels highlight a four tier sign off process determined by the implementation team during phase 1 (Figure 15).

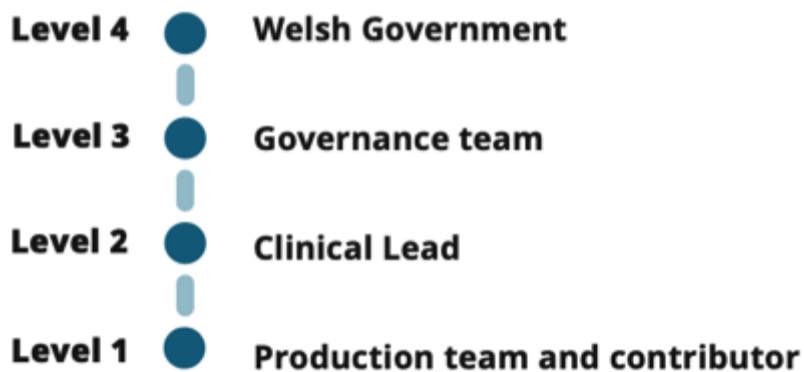


Figure 15: The governance levels for decisions relating to the innovation or implementation.

The clinical management team within ICST manages the risk register and works through the governance process for each area of the map (Figure 16).

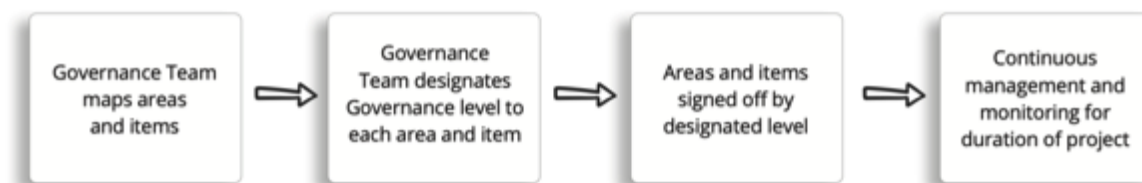


Figure 16: The governance process managed by the ICST governance team.

Wide Stakeholder Engagement

Consultation was sought throughout the pandemic with the British Lung Foundation and Asthma UK and their patient groups. Further national programs of work have continued during the pandemic, such as supporting high-risk respiratory patients with asthma and COPD through bilingual NHS Wales self-management apps, implemented using the same principles and methodology to the COVID hospital guideline. Palliative care guidelines have taken account of All-Wales bereavement surveys, and a large project is underway to examine the impact of COVID-19 related bereavement, which will impact some of the areas of our guideline that deal with death and dying, and the appropriate aftercare, for example.

Implementation

The All Wales Guideline for the Hospital Management of COVID-19 (the innovation) was developed by the Innovation Team, and implemented by the Implementation Team using a proven Implementation Science framework; SIMPSI. The SIMPSI framework, a bespoke framework developed by ICST, contextualises implementation science, starting with pre-implementation and setting up the programme, to launching the innovation into the system, and achieving nationwide adoption.

We believe that this is the first time that a national guideline has been created and embedded into target organisations following a structured implementation framework.

There are four phases of implementation:

Phase 1 – development/ exploration

The early phases are all about exploring and development of the programme, defining the aims and value propositions, identifying the implementation and governance teams, and scoping and developing the innovation.

Phase 2 – Installation

Often called a soft launch or pilot study, phase two is installing the innovation into the environment, and teasing out any issues that arise.



Phase 3 – Initial Implementation

Initial implementation is the phase where the innovation is formally introduced into the system and efforts are made to maximise the uptake by the target audience. The early phase of implementation to maximise the potential of implementation drivers.

Phase 4 – Sustainability

Sustainability is the phase where the innovation becomes part of the system, it is widely adopted and accepted, and it is contributing towards the desired outcomes for this programme. Active and coordinated implementation of the Guideline to convert the value proposition into value realisation



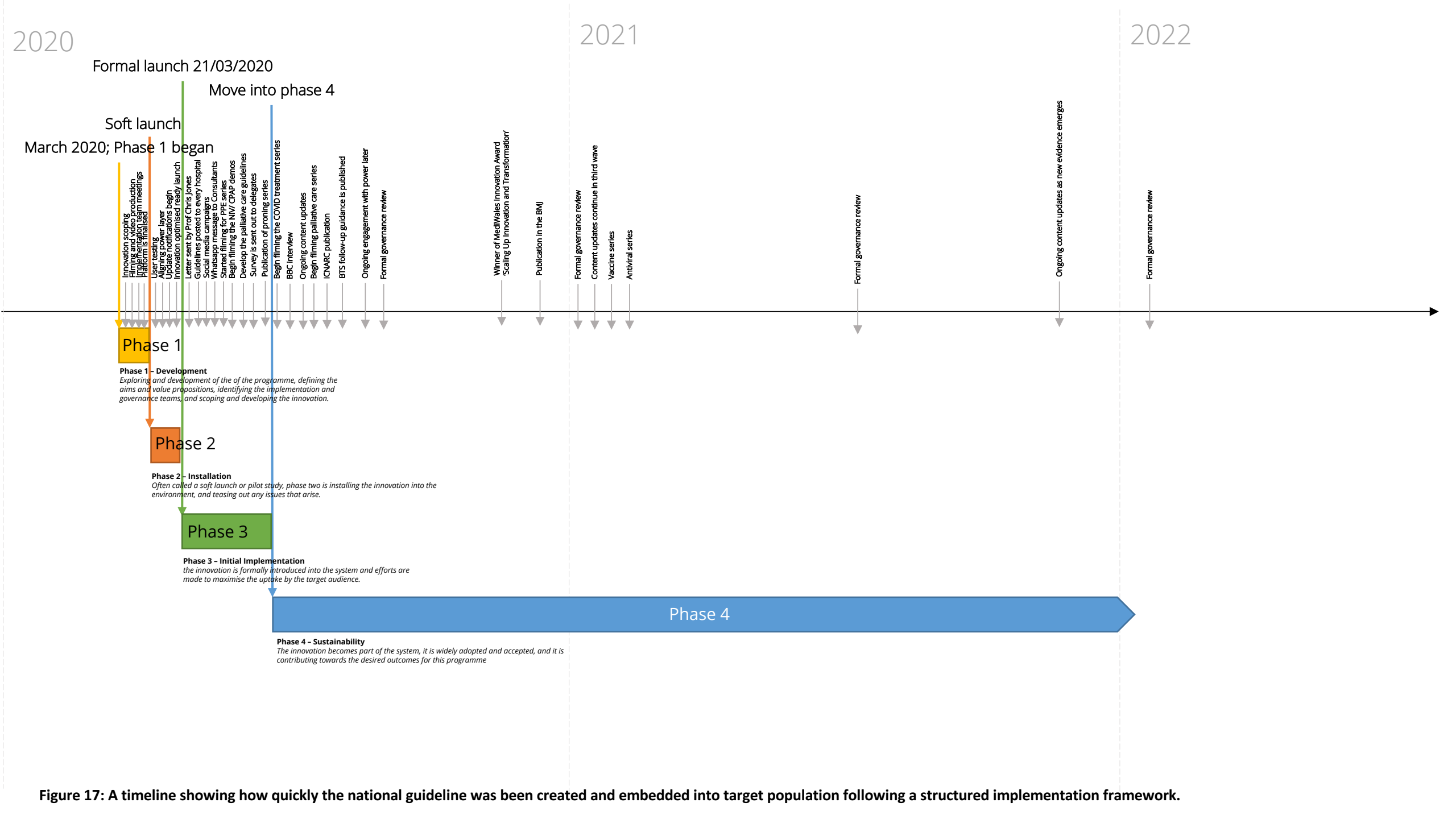


Figure 17: A timeline showing how quickly the national guideline was been created and embedded into target population following a structured implementation framework.

The Implementation Team

The implementation team, lead by Professor Chris Davies, meet regularly to progress through the four phases of the SIMPSI framework, addressing items such as:

- Readiness and capacity – understanding whether frontline teams are ready and have the capacity to make changes to their practices. In the context of acute COVID-19, the frontline teams were desperate for some guidance on how to manage patients with COVID-19.
- Alignment – are all the individual and group stakeholders, who have influence in the system, aligned and understand the value of this guideline? Are there any stakeholders or groups with barriers to alignment, and what are their reasons?
- Fidelity – clear and consistent messaging through multi-media channels to the target audience(s), ensuring there is fidelity in message
- Power layer – the power layer, sometimes called influencers or tutor/mentors, are the individuals who have a special interest in making change in this field, and are going to make the most impact on the uptake of this innovation.
- Governance - a key aspect of creating a successful innovation; it is the framework of authority that ensures that the innovation remains up-to-



date and relevant. If new research emerges or the environment changes, the governance process should identify it quickly and make changes.

Organisational Structure

The structure for implementation of the guideline involved a process of reverse engineering the connection between the senior decision makers within the hospital COVID-19 teams at the bottom of the pyramid with the executive team towards the top (Figure 18).

We used StatsWales to identify the primary target populations (7). For the guideline, these were consultants that would be expected to manage patients admitted with COVID-19. This estimate is calculated as the sum of all emergency departments, respiratory, intensive care, and palliative care consultants across Wales.

As part of the registration process to sign up to the guideline updates, registration included selecting your profession, specialism, region, and hospital.

Having direct engagement with a Health board executive means the implementation team only has six senior executives to engage with, which made decision-making, engagement, and communication more efficient. After establishing this connection, several hospital coordinators (facilitators) were selected by the Health Board executives.

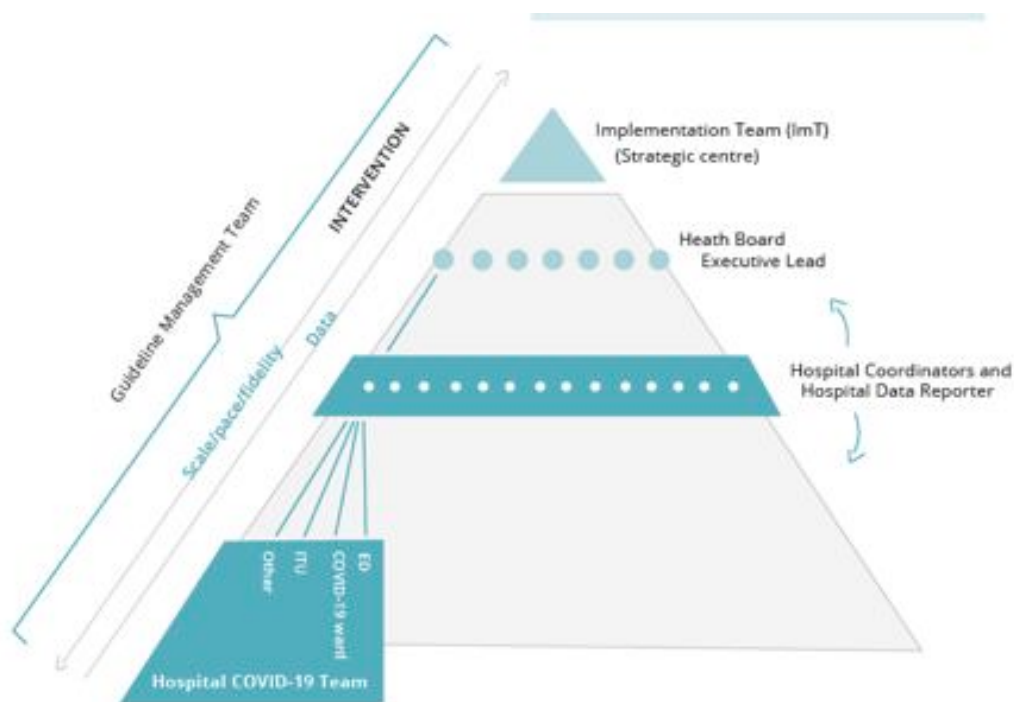


Figure 18: Relationship between the guideline implementation team, the target organisation and the target population, highlighting the bi-directional influence of the guideline hospital coordinator (facilitators).

Fundamentally, the local facilitators would be the active conduit between the executive, representing the target organisation, and the target population, that is front line clinicians.

Facilitation

Implementation software supports the implementation process, enabling locally selected facilitators to increase reach and regional acceptance. A facilitation dashboard provides engagement and activity tools with feedback. Implementation data is analysed, and reported in real-time by the implementation team, consisting of government, clinical and executive members of the wider stakeholder group with direct decision-making

responsibility. The Welsh Government received periodic implementation reports to support strategic decision-making.

The number of unique interactions (number of logged in page visits) with the facilitator dashboard were monitored and used to inform local teams. In total, during the first wave, there were 972 interactions with the facilitator dashboard (Figure 19).

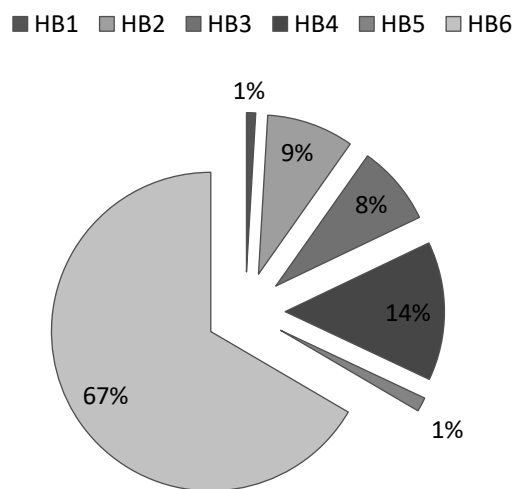


Figure 19: The relative proportion of all 972 interactions with the Guideline Facilitator Dashboard per Health Board. (HB6: Swansea Bay UHB, HB5: Hywel Dda UHB, HB4: Cwm Taf Morgannwg, HB3: Cardiff and Vale UHB, HB2: Betsi Cadwaladr UHB, HB1: Aneurin Bevan UHB).

Of these, Swansea Bay UHB had the most interactions (642, 67%). This coincided with the greatest number of consultant-level registrations (Figure 23). For context, the health board with least interactions was Aneurin Bevan UHB, with only nine interactions (0.9%), which also coincides with Aneurin Bevan UHB having the least number of consultant registrations (Figure 24). This statistic highlights the value of carefully selected and active facilitators to encourage local-level innovation adoption (8,9).

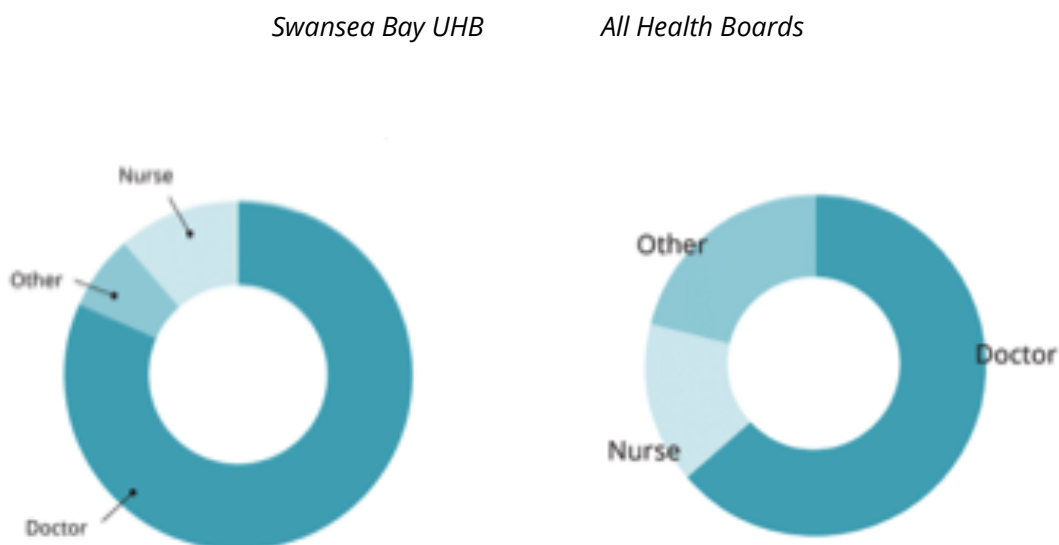


Figure 20: Number of doctors registered with the guideline for Swansea Bay UHB (left chart) is much greater in proportion to other Health Boards (right chart) on average. This is a result of effective facilitation reaching the target population.

Barriers

Barriers exist in the implementation of clinical guidelines (10). The two main barriers (Figure 21) to the adoption of this guideline were:

- 1) NHS Wales IT issues: the guideline website was initially flagged as a phishing site as a security measure against new websites with 'COVID-19' in the URL. This happened despite involvement of senior officials within NWIS who were made aware of the proposed URL, which demonstrates how easy problems can arise. Furthermore, the most common complaint from the target population was that the website did not always load on NHS computers, and for some, the videos would not play. This was a

common complaint for people using out of date versions of Internet explorer.

- 2) The weekend: even during a pandemic the weekend saw less activity, probably because there were less people in work. The guideline user survey highlights that most users accessed the guideline whilst at work.

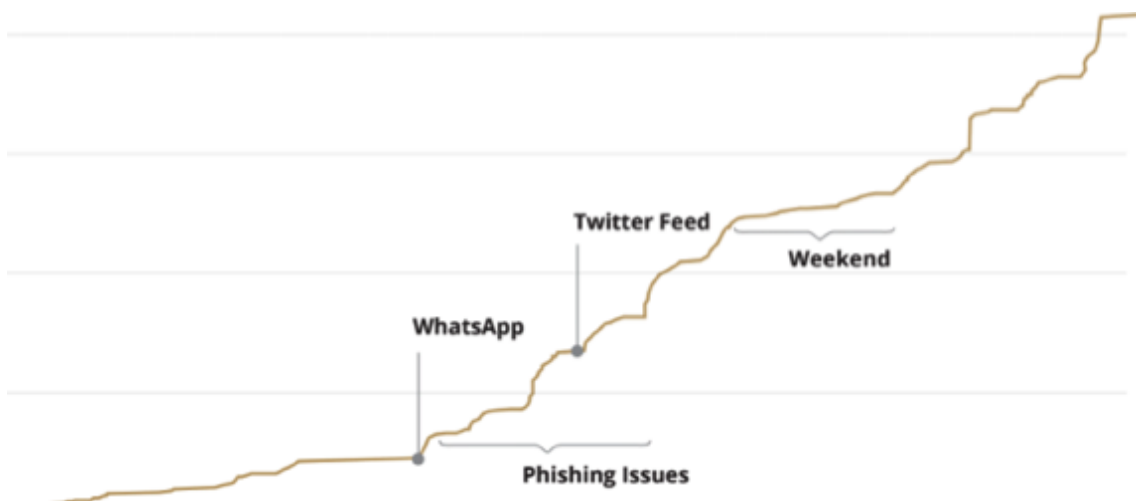


Figure 21: Whilst common communication methods such as using WhatsApp and Twitter facilitate dissemination, IT issues and not being in work (weekend) reduces activity.

Fulfilment

From March 21st, all 18 DGHs in Wales received several hundred hardcopy guideline posters, subsequently distributed in areas where relevant HCPs could easily access them, such as COVID-19 wards, medical assessment units and emergency departments. ICST managed the full fulfilment process.



Figure 22: The hospital guideline poster pack, printed and delivered to hospitals across Wales during the first wave. Within the pack, to accompany the hospital guideline, there were several supplemental pathways and posters, laminated for IPC purposes.

Through using a local printer in Cardiff, a stock of A3 colour posters of the guideline and other pathways, such as palliative care escalation, and posters, such as selecting the right oxygen device, were distributed to selected hospitals (Figure 22). Additional guidelines, pathways and posters were also printed and issued on request of managers and clinical staff across Wales. Notably, these

were posted (and in some cases hand delivered where necessary) within 24 hours of request.

Penetration

The publication of the guideline coincided when total confirmed COVID-19 inpatients and COVID-19 deaths were low. Registration rates increased substantially around 28th March in response to a range of alignment and facilitation activity, including email campaigns, formal guideline on boarding, and discussions promoting adoption with executive teams.

Total registrants reached 4521 during the first wave alone (Figure 23). New registration rate slowed commensurate with a reduction in the rate of patients admitted to hospital and dying from COVID-19.

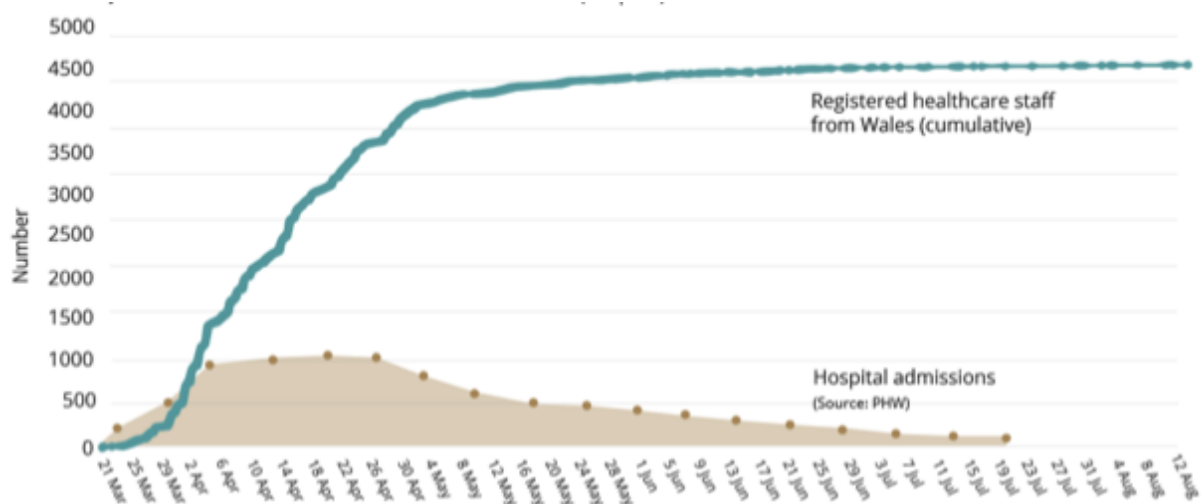


Figure 23: The rise in the number of registrants mirrored the number of COVID admissions and COVID deaths (not shown above) across Wales.

We have recently seen increased activity as the admissions gradually rise again.



Target Population

The target audience of consultant level doctors accounted for the greatest proportion of professionals registered with the guideline platform (23%). Uptake also included allied health professionals (including physiotherapists, pharmacists, dieticians and occupational therapists) that accounted for 21%, and nurses 21%.

From a possible 2505 consultants employed in Wales, 1131 (45%) registered with the guideline. As the total number employed within each health board was known, this was used to normalise uptake between health board and derive a penetration ratio.

Swansea Bay UHB showed the greatest penetration, with 74% (325 of a possible total 440) of all consultants registered, followed by 52% (111 of 214) within Hywel Dda UHB and 43% (238 of 551) in Cardiff and Vale UHB (Figure 24).

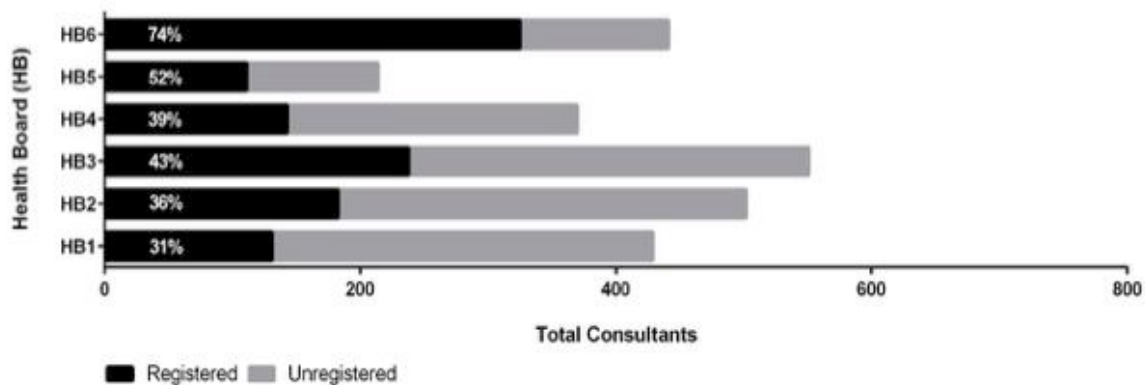


Figure 24: Consultant grade guideline registrants as a proportion of all consultant staff employed within each HB. (HB6: Swansea Bay UHB, HB5: Hywel Dda UHB, HB4: Cwm Taf Morgannwg, HB3: Cardiff and Vale UHB, HB2: Betsi Cadwaladr UHB, HB1: Aneurin Bevan UHB).

Uptake was lowest in Aneurin Bevan UHB at 31% (131 of 429 consultants) but still superseding the original target (x3.6-fold). This variation in consultant uptake between health boards was highly significant (Chi-squared testing, $p < 0.0001$).

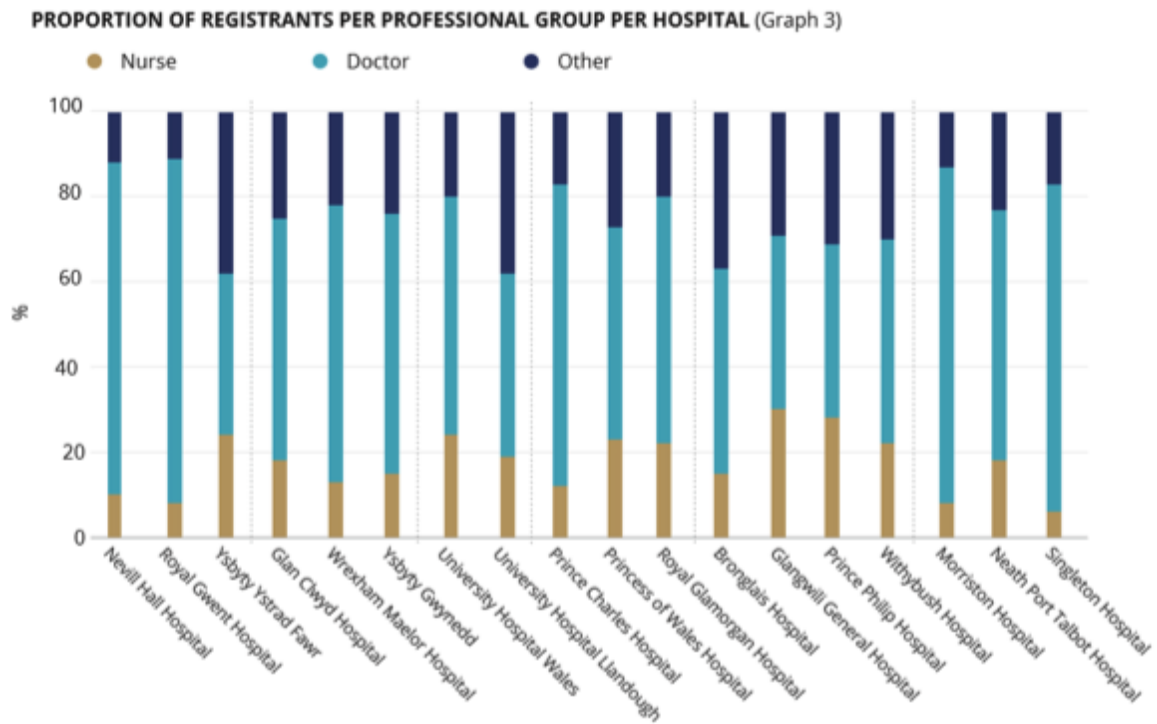


Figure 25: Proportion of registrants with the guideline per professional group against the 18 district general hospitals across Wales. Note Swansea Bay UHB (Morrison Hospital, Neath Port Talbot Hospital, Singleton Hospital) has a high relative proportion of doctors (consultants) registered. Whilst Aneurin Bevan (Nevill hall Hospital, Royal Gwent Hospital, Ysbyty Ystrad Fawr) also has a high relative proportion of doctors (consultants) registered; however, this accounted for a lower overall number of guideline registrants (Figure x).

Given the potential impact of sickness and staff transfers on this estimate of guideline uptake, additional sensitivity analysis was conducted to derive penetration ratios, using publicly available figures for total health board catchment population, total number of clinical staff, number of acute beds, and COVID-19 admissions (7). This confirmed the observed trend in guideline registration. Remarkably, a ratio of four HCPs registering within Swansea Bay UHB for every COVID-19 admission was observed. Within Aneurin Bevan UHB (which had the lowest penetration), this fell to approximately one HCP for every two COVID-19 admissions.

To explore further reasons for the low penetration in Aneurin Bevan UHB the burden of COVID-19 within each Health Board at the time of guideline publication was investigated. This estimated the degree of organisational readiness across each Health Board. At the time of guideline launch, Aneurin Bevan UHB had the greatest number of COVID-19 inpatients when compared to the other Health Boards. This equates to a greater percentage of the peak number of inpatients (37.4%) when compared to other health boards (4.9%, 10.4%, 6.3%, 5.7%, and 5.9%, respectively). This suggests Aneurin Bevan UHB had low organisational readiness at the time of guideline release resulting in lower uptake.

Guideline adherence continues to be analysed through implementation data and user surveys. A large multi-centre clinical audit is now underway, the findings of which will update the guideline and be communicated to all guideline registrants.



Knowledge Transfer

Knowledge transfer is an essential component of implementation (11). ICST delivers knowledge through guideline posters, web-based text instruction, and video-based education presented by opinion leaders. At the time of writing, 7 national pathways and approximately 260 information pages are freely available to HCPs online. Google analytics show nearly 50,000 sessions, consisting of an average 4.2 page views per session and average session duration of over 5 minutes. In total, from 32,200 unique video plays resulting in approximately close to 200,000 minutes of knowledge transfer.

Regarding the mechanisms of knowledge transfer, 22% of registrants accessed the platform daily, 23% 2-3 times a week, 25% weekly, and 17% when there was an update. Furthermore, 54% accessed the platform whilst being on duty and 19% accessed it in work whilst off duty. A further 27% accessed it from home. Consistent with this finding, 54% accessed the platform via the workplace computer, whilst the remaining 46% of survey respondents used personal devices (21% mobile phone, 20% computer, 5% tablet) (Figure 26).



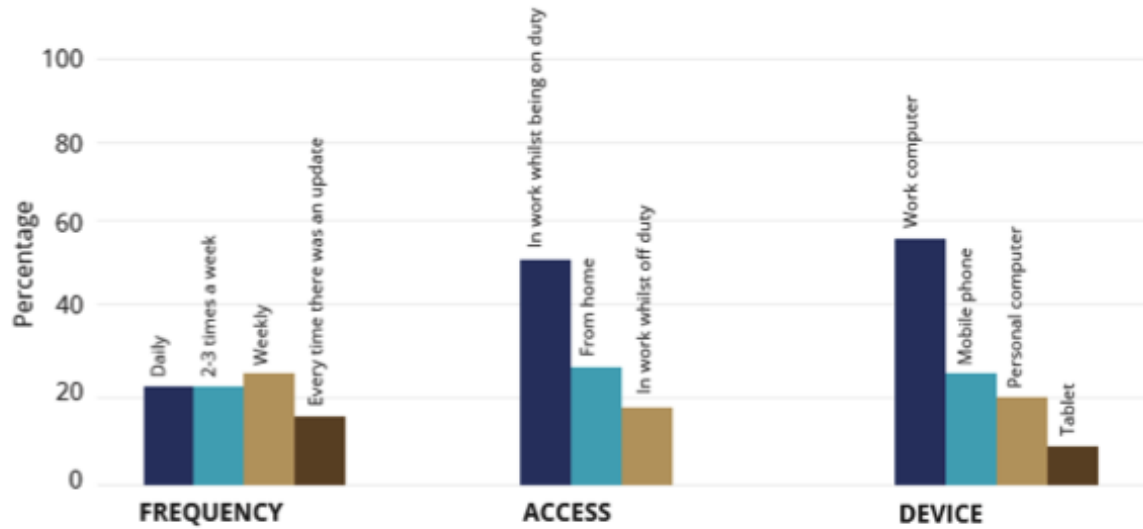


Figure 26: Accessibility behaviours of guideline platform users based on a survey response. Most clinicians access the guideline platform from work whilst on duty using a work computer either weekly, 2-3 times a week or daily.

These observations provide useful insights into the behaviours of a digital guideline platform. The frequency of access is mixed, but most accessed the information from work whilst on duty, using a work computer.

Communication

There were 101 email campaigns (mail-out clinical updates and video synopses, to registrants) during the first wave of the COVID pandemic. The communication campaign delivered approximately 3 updates on average per week. In busy weeks where changes and new evidence was emerging quickly the updates were distributed more frequently – on some days more than one update.

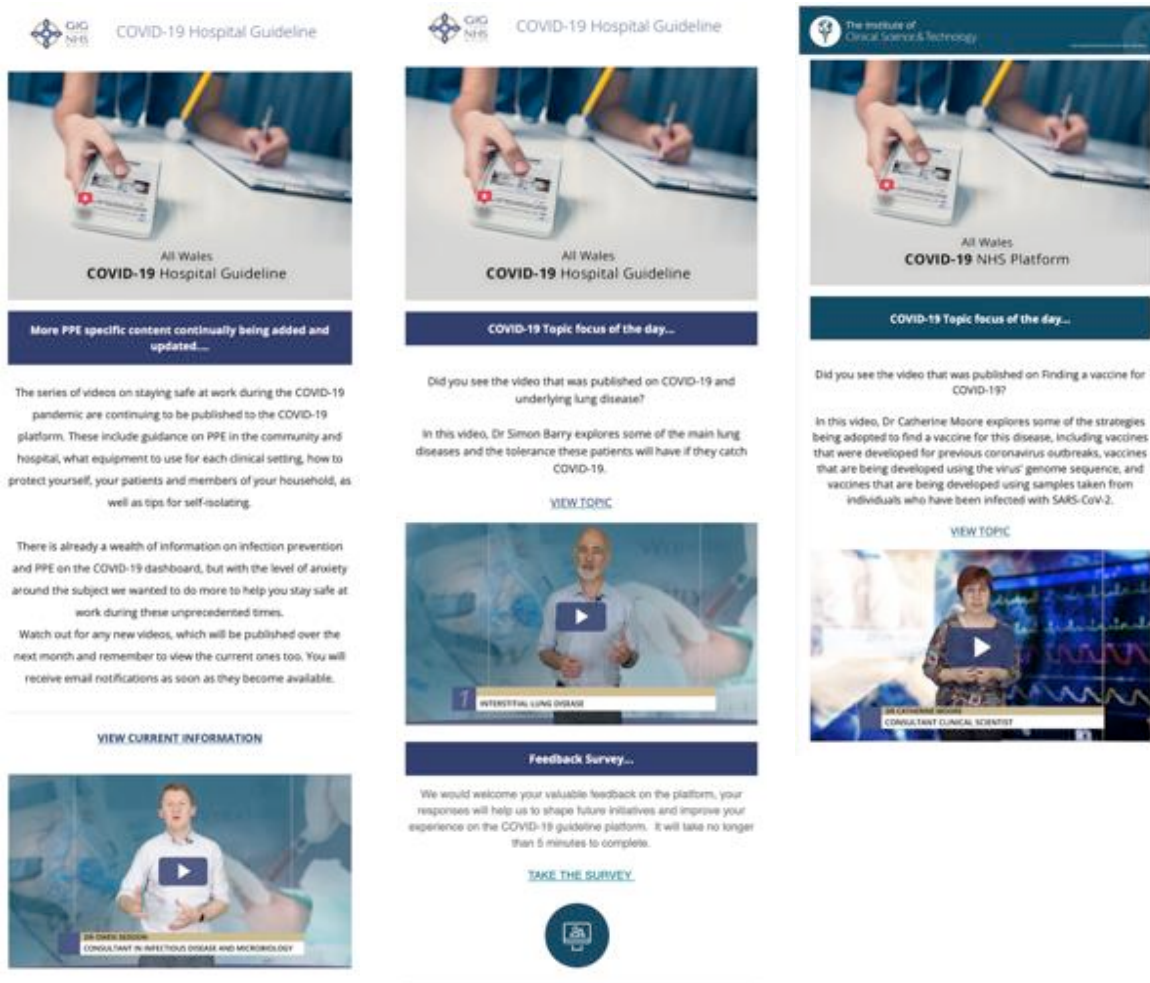


Figure 27: Example of email communications sent to users of the All-Wales Hospital Guideline Platform. The email includes a descriptor of the message and direct links to the platform to read more or watch the video illustrated within the email.

In total, 207 registrants unsubscribed to the emails (4.6% of total registrants). This equates to 2.5% unsubscribes per email campaign, or 0.04% of all users per email campaign. Of the un-subscribers who entered their job title (n=189, 91% of un-subscribers), the most unsubscribes came from Medical Students - 21% (n=40), followed by 'Other Healthcare Professional' - 17% (n=33) and Registrars - 16% (n=31). There are only 272 Medical Students, and 15% of these

have unsubscribed. There are 579 Registrars, 6% of these have unsubscribed. Compare this to consultants (representing the target population) that have an unsubscribe rate of just 0.4%. Of the un-subscribers who entered their service (n=188, 91% of all un-subscribers), the most unsubscribes came from UHW – 22% (n=41), followed by Morriston Hospital – 12% (n=22) and the Royal Gwent – 11% (n=21). Of the total number of registrants, this equates to 3.5% of UHW users have unsubscribed, 2.5% of Morriston Hospital, and 8.5% of the Royal Gwent. Of the un-subscribers who entered their department (n=73, 34% of all un-subscribers), the most came from Medical Assessment Units (16.4%, n=12), followed by A&E (15%, n=11) and COVID-19 Wards (12%, n=9). This equates to 5% of users who work on the medical assessment units have unsubscribed, 4% A&E, and 3% COVID wards.

The un-subscribe rate is remarkably low for a typical communication campaign probably because the context of COVID and little trusted evidence and instruction available at the time confirming the value proposition. The target population to whom the programme was pitched had the least unsubscribes, whilst staff with lower clinical autonomy, for example medical students, the most likely to unsubscribe. Furthermore, medical students were the most likely staff group to move on from clinical placements requiring direct care of COVID patients, therefore the information and updates would not be relevant to them.

Further communication channels included social media, Health Board communication channels, and mainstream news outlets.





Figure 28: Media teams from BBC and Channel 4 joined some of the opinion leaders in the Cardiff studio to showcase the work being done.

For example, in the National Clinical Lead presented this work to reassure the public that a coherent and co-ordinated approach was being taken to manage COVID across all hospitals in Wales (Figure 28).

Impact

This national guideline has influenced the clinical behaviour of healthcare professionals across all hospitals managing admissions of COVID-19 across Wales. User feedback has been excellent, with an overall rating of 4.1/5, with over 80% of respondents from across Wales wishing for email updates to continue (Figure 29).

Furthermore, around 70% of healthcare professionals have recommended the guideline to their colleagues, thus offering an effective mechanism to disseminate the guideline widely.

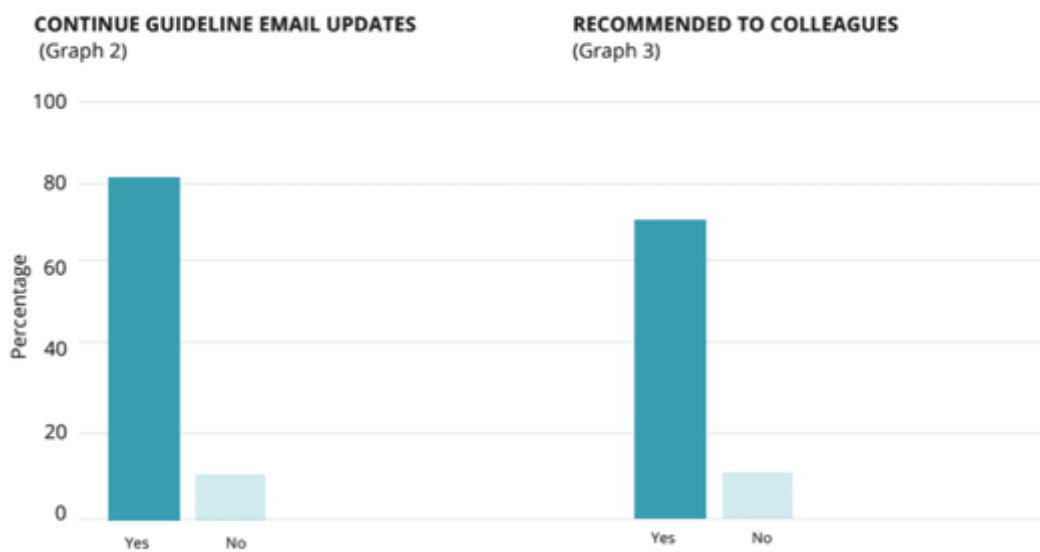


Figure 29: Proportion of guideline survey respondents that a) wish the guideline continues, b) have recommended the guideline to colleagues

There was no existing exemplar way of working in what has become a sustained, global pandemic. Much of this pioneering work was based on



evidence from previous viral outbreaks including SARS and MERS, but also management of acute respiratory distress syndrome. The dynamic elements of the guideline have had 18 updates as the core clinical information has changed and are evidence-based and consistent with UK guidance such as NICE.

The Intensive Care National Audit & Research Centre (ICNARC) report demonstrated that ICU mortality in Wales was lower than the UK average for the first wave (12). In addition, Wales had a statistically significantly lower mortality rate from COVID-19 than the rest of the UK for the first wave according to the Office for National Statistics (13). The potential we have in Wales to deliver in a rapid and collaborative manner has been used to full effect in this huge project.



Endorsements

The British Lung Foundation and Asthma UK, the British Thoracic Society, and multi-professional clinical groups have endorsed and promoted this guideline. It has received acknowledgment in published BMJ articles (14), with international praise from social media posts highlighting Wales leading the way in the coordinated management of COVID (Figure 30). It has also featured on the BBC Wales News as an innovative approach to COVID management (15) and our user-data shows that it is being accessed from not just the UK, but the rest of the world as well.

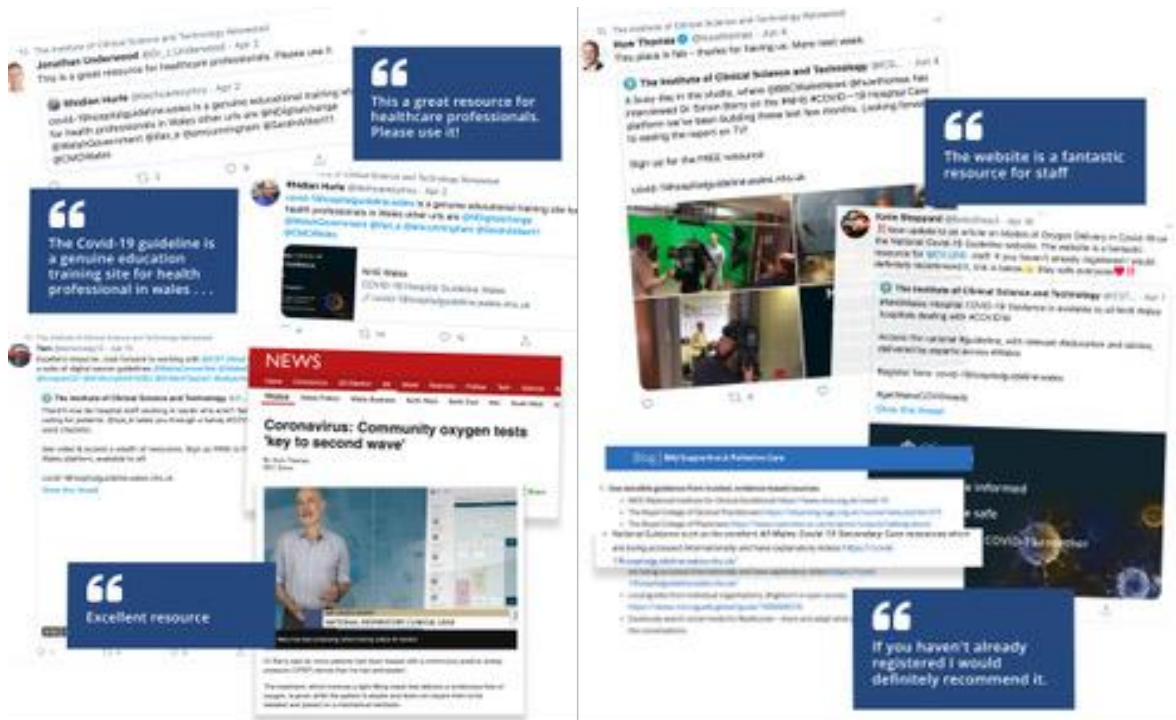


Figure 30: Example montage of comments, posts and news articles from guideline users, clinicians, managers, leaders and the public, from across the UK.

Reviews

ICST in conjunction with NHS Wales's bodies won the Scaling Up Innovation and Transformation Award for the guideline at the NHS Wales MediWales ceremony in 2020 (Figure 31).



Figure 31: MediWales Scaling up Innovation and Transformation winner awarded to NHS Wales Collaborative, the Respiratory Health Implementation Group and ICST for the design and implementation of the COVID hospital guideline.

"Excellent. This platform deserves every award it gets"



Dr. Mark Taubert, Palliative Care Consultant

“Certainly, in secondary care across Wales, it’s been recognised that the platform has been fantastic during the COVID pandemic, for us to have rapid updates on hospital care for an area which has been obviously very confusing, worrying and often with conflicting information. I think that when you have these pathways on this interactive setting, it can really help you tease out what you need to do.”



Dr. Tom Pembroke, Consultant Hepatologist

Summary

Guideline adherence continues to be analysed through implementation data and user surveys. A large multi-centre clinical audit is underway and into the third wave, the findings of which will update the guideline.

The guidelines, videos and website were set up in a matter of weeks and were delivered free of charge. Professionals from all walks of life came together to give their time, work on guidelines, review the literature and appear in videos. Crucially, this serves as a model to approach similar programmes of work for the future, such as a recently proposed community and primary care guideline for the management of COVID-19.



Choose from a symptom group below:

Neurology Respiratory Cardiac Paediatrics Dermatology GI Musculoskeletal Subspecialist

Next Page to look at: **Neurology**

STEP 1: Overview

Use the pathway below to structure your consultation with a patient presenting with neurological symptoms associated with Long COVID.

Presenting symptoms

- Tongue and swallowing
- Brain fog and cognitive impairment
- Headaches
- Loss of sense of taste or smell
- Shaking and pain on eye movement
- Seizure disorders
- Neurological features that may not fit the criteria of peripheral nervous system or be sensory and parietal in nature

STEP 2: History

1. How does the patient describe their symptoms?
2. How does the nature and severity of any longstanding symptoms compare with their current symptoms?
3. How have the patient's employment and activities, mobility and independence been affected by Long COVID?

STEP 3: The neurological examination

Features of long COVID

The standard neurological examination starts with higher function, cranial nerves, and examination of the limbs.

In general, despite some patients reporting a marked reduction in stamina and exercise tolerance, it is unusual to detect neurological signs on examination.

- Patients who are non-specifically unwell should be assessed for sensory, visual impairment, and cerebellar information markers.
- Ask of the patient with tremors, weakness and spasm in order to assess their overall function.
- Some patients with focal dysfunction should have an examination of their limbs to include inspection, strength, tone, reflexes, coordination and sensation.

STEP 4: Management

Self-management, with the support of the NHS Wales COVID recovery app

The COVID recovery app supports the patient with:

- Understanding the importance of good sleep quality
- Healthy diet and good hydration
- Pacing of activity levels and gentle return to exercise and activity

Referral to multidisciplinary rehabilitation services

Consider referral if:

- Neurological examination is normal
- Patient needs help to get into a cycle of recovery
- The individual is struggling with basic and best cycle of activity

Refer to specialist neurology clinic

Consider referral if:

- Unable to return to previous level of independence after 6 months
- Any red flag symptoms or abnormality on neurological examination

Need more information?

Discuss with the patient history and examination, discuss whether an examination of the cerebellum, sensory, motor or cognitive function is useful.

COVID Rehabilitation Service for your area

RCMB Long COVID Service

The pan-Wales service has now been established to support people with Long COVID, also known as Post COVID syndrome. It will be delivered in the community by a multi-disciplinary team including a GP with Specialist Interest, Allied Health Professionals, Advanced Practitioners and Psychologists.

People referred into the service will receive a full diagnostic assessment and be engaged for further investigations and to avoid referral to the most appropriate service if required. The service will support patients with self-management and to enhance their care as necessary, offering interventions as indicated.

Making a referral

How to refer

To discuss referrals, please contact us via email or call 0300 540007 during office hours.

East: WCUlong@wales.nhs.uk and [0300540007](tel:0300540007)
 Central: WCUlong@wales.nhs.uk and [0300540007](tel:0300540007)
 West: WCUlong@wales.nhs.uk and [0300540007](tel:0300540007)

Please include the main reason for the patient that you feel our service could support.

Referral via WCCG is currently being established.

Chapter 2

Supporting Primary Care Teams

Chapter 2: Supporting primary care

Including clinical, managerial and support staff that have a direct or indirect role in managing or supporting patients with acute COVID-19 or Long COVID presenting in the community.

Acute and Long COVID Guideline Highlights

High level excerpts from the implementation plan and implementation status.

Plan

Since NHS Wales had widespread adoption of the hospital guideline, there was standardisation of care in managing patients with COVID-19 across all hospitals in Wales. Using these principles, we developed two similar innovations to support primary care.

- Innovation 1: ***NHS Wales COVID-19 Guideline***
- Innovation design/development start date: November 2020 (After first wave)
- Formal implementations start date: December 2020 (During second Wave)
- Innovation 2: ***NHS Wales Long COVID Guideline***
- Innovation design/development start date: February 2021 (After second wave)
- Formal implementations start date: March 2021 (After second Wave)



- Target organisations: GP practices within: Aneurin Bevan UHB, Betsi Cadwaladr UHB, Cardiff and Vale UHB, Cwm Taf Morgannwg UHB, Hywel Dda UHB, Powys Teaching UHB, and Swansea Bay UHB.
- Primary target population: Clinical decision makers – GPs
- Secondary target population: Practice nurses and other relevant community-based and hospital healthcare professionals

Current Status

- Current implementation phase: 3/4
- Adoption by target organisations: 100%
- Penetration of primary target populations: 40%



Background Innovation 1:

NHS Wales Acute COVID in the Community

Guideline

The guideline is a simple guideline for all primary and community care clinical staff. This is to ensure there is a consistent approach to the management of suspected or confirmed COVID cases, so that the right patients, with a confirmed COVID status are taken to the right place in the hospital, and in the most efficient and safe way (Figure 32).

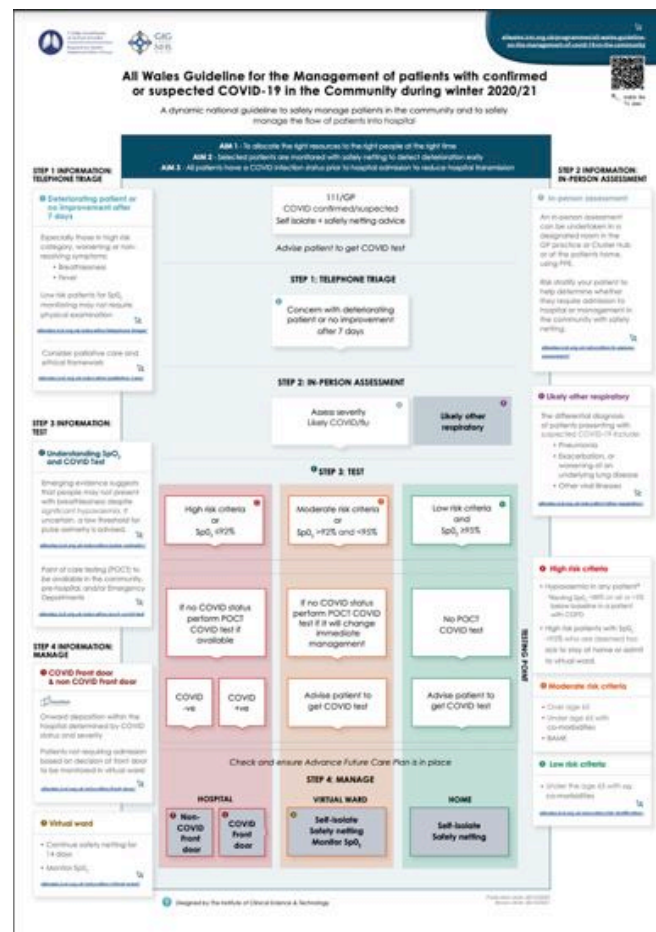


Figure 32: The All-Wales Guideline for the Management of patients with confirmed or suspected COVID-19 in the Community.

The guideline is flexible to accommodate a range of local level service models, such as that delivered by individual GP practices, GP Out of Hours, COVID hubs, WAST, and emergency departments, and to support the implementation of Point of Care Testing (PoCT) devices and oxygen saturation (SpO2) machines, implemented by other NHS representatives.

QR readers and links provide additional information and education about the aspects of each clinical decision point, so everyone knows what to do. This information aligns with the Primary and Community Care COVID-19 Framework for Wales to maintain consistency of instruction, and provides an accessible, simple and clear guideline for front-line clinical service providers.

Guideline Aims

The aim of the guideline is to implement a simple dynamic national guideline to manage the flow of COVID patients going into hospital, whilst supporting the safe management of other patients in the community. Implementation means everyone who needs to know about the guideline are actively informed about it, offered education about the clinical recommendations and processes within it, and they are notified about any clinical updates as the information changes, or as new evidence emerges. This means:

- There is clarity throughout Wales about what to do, at all stages throughout the pandemic
- An active process ensures the guideline is implemented successfully for the purpose it has been designed
- Implementation data supports central decision-making



A formal active process for guideline implementation is essential that the guideline delivers the following objectives:

- 1) All patients admitted through any route into hospital have a COVID infection status prior to their admission, thus reducing the potential for hospital transmission
- 2) Improved efficiency of patient flow through to the appropriate ward areas as the COVID status of the patient is known at the point of admission, not requiring delays to receive a subsequent in-hospital test
- 3) Continuous support, knowledge and updates for primary care, community services, the Welsh Ambulance Service (WAST), Emergency Departments (EDs), and hospital (COVID/non-COVID wards and ICU)
- 4) A joined up national approach to align relevant services so that everyone knows what to do, thus facilitating an effective service between primary and secondary care

This process helps to standardise care across Wales, using the best available evidence and to react quickly. Video updates from the clinical specialists in Wales update all registrants as new treatment and management strategies emerge, which provides advice, confidence and support for the decision-making process.

"It takes commitment from all involved in delivering these pathways, from the health board, the ambulance service and Welsh Government, to be committed to delivering something on a national scale that offers the patient the best possible outcome. It's going to reduce avoidable hospital admissions,



GP services are going to be supported because they are not out there by themselves, you've got community teams, ambulance services, primary care and secondary care all working together for the best outcomes of these patients."



Mike Jenkins, Consultant Paramedic

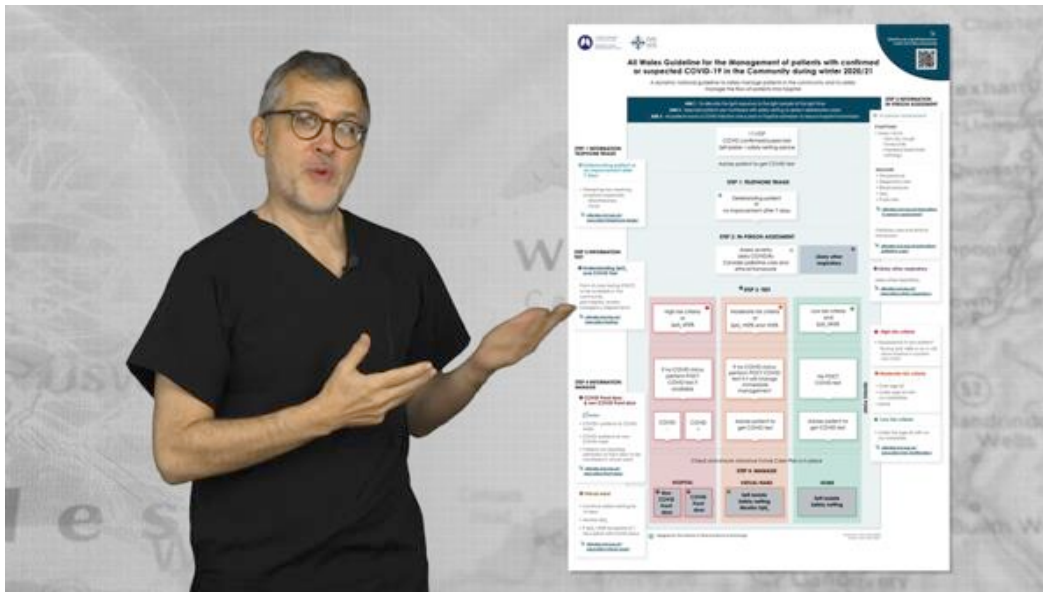


Figure 32: TV show about the acute COVID guideline for primary care presented by the Director of primary care to the target audience of GPs and practice nurses

“If we look back at the first version of the framework, a massive amount of work went into this, literature searches, and we produced a 26-page document which was really detailed. But not the sort of thing that your average clinician in the middle of a busy phone surgery or clinic, could access and maybe get the answer they needed to manage that patient in front of them. Hence, we have moved to this new platform, so that we’ve got the plan on a page, the pathway on a page, where all the information is accessible within two or three clicks.”



Dr Alastair Roeves, National Clinical Lead for Primary Care and Community Care in Wales

Background Innovation 2:

NHS Wales Long COVID Guideline

This is a dynamic national guideline, leveraging the impact and success of the All-Wales Hospital, and respiratory guidelines and the impact of the NHS Wales COVID Recovery App, which was launched a couple months prior. The guideline was developed to support primary and community teams in how to manage patients presenting with:

- Ongoing symptomatic COVID-19 – signs and symptoms of COVID-19 from 4 to 12 weeks
- Post-COVID-19 Syndrome – signs and symptoms that develop during or after an infection consistent with COVID-19, which continue for more than 12 weeks and are not explained by an alternative diagnosis.

“The main problem faced by many patients are lack empathy and understanding of long covid-19 symptoms by their own GPs, so there is real frustrations amongst patients. It's good that we have this guidance now and the hope is that all GPs, doctors and healthcare professionals update their knowledge and understanding of long covid-19 symptoms and management. And to show empathy when approached by patients struggling with these symptoms.”

Anonymous, attendee of the Long COVID launch event



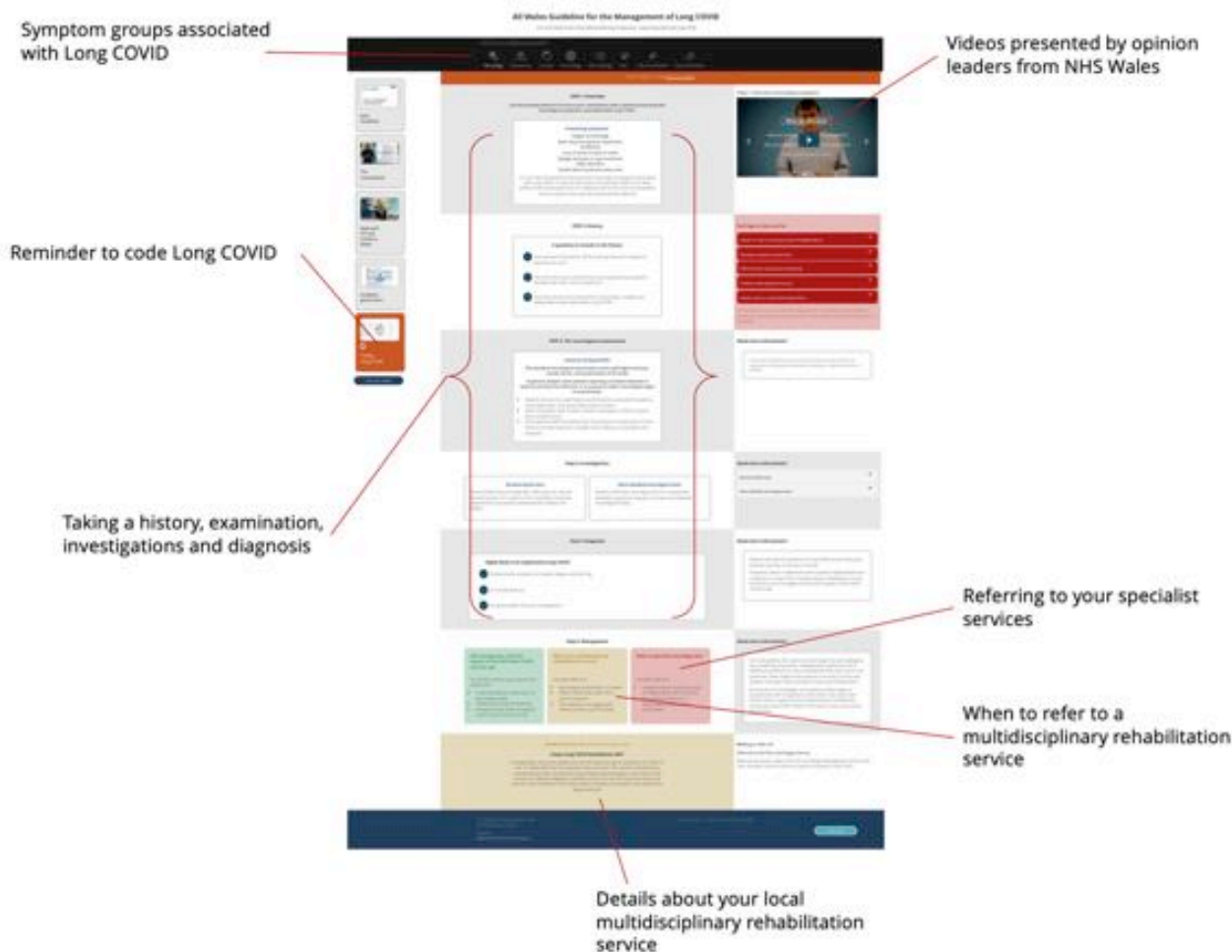


Figure 33: Interactive guideline on the management of Long COVID. A different strategy was applied to the formatting of the Long COVID Guideline, as there would be no requirement for paper poster versions. The recommendations and instruction must align closely with usual practice. The instruction would also be bespoke to each Health Board, particularly relating to the instruction and referral details for secondary care support.

This is a national approach to align relevant services so that everyone understands and knows what to do to manage these patients sensitively. Patients with Long COVID often present with a range of complex physical and psychological needs. This may require assessment and onward referral, whilst for others this may only require reassurance and self-management.

“I’ve been really excited to see how the pathway that we wrote has come to life in this far more dynamic tool that’s available; that’s updated, that’s current and available for practitioners, reducing ambiguity and ensuring consistency of management”



Dr Mark Walker, Senior Medical Officer, Co-author of the Long COVID Management Guideline

The guideline is an interactive web-based guideline for all primary and hospital staff-managing patients with symptoms consistent with Post-COVID Syndrome. The guideline is integral to the delivery of specialist rehabilitation, and advice provided in the COVID Recovery App. It also links with the acute COVID guidelines (See relationship below, Figure 33).

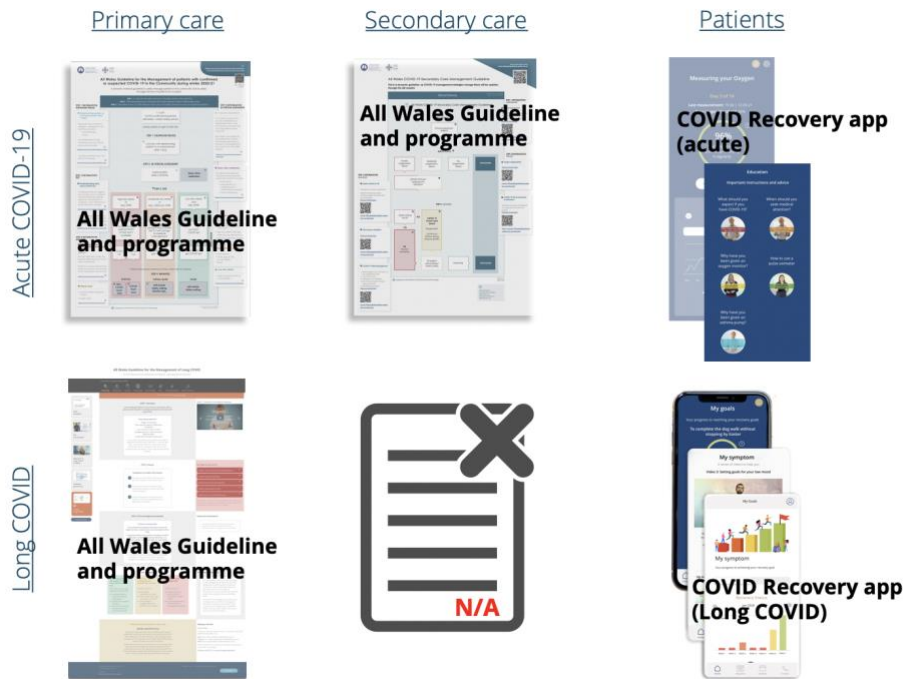


Figure 33: COVID management framework produced by RHIG and ICST to demonstrate the relationship between innovations

Patients are risk stratified and supported in the appropriate way in the community, where patients will receive the correct advice, investigations and onwards referral as necessary. The guideline is flexible to accommodate a range of local level referral criteria. The guideline will function as an interactive tool, where through scrolling or searching the system will present details and information about several symptoms or presentations mirroring that of the COVID Recovery App. For each symptom, a consistent and simple stepwise guide will support clinicians to ensure they make the appropriate action for the patient in front of them.

Guideline aims

- 1) All GPs, primary care nurses and hospital staff are up to date about the latest evidence and instruction for managing patients with a range of post-COVID symptoms.
- 2) The guideline is interactive and mirrors the symptoms reported by the thousands of patients using the COVID Recovery App.
- 3) In doing so, patients are actively involved in the guideline to ensure their needs are met (coproduction), where appropriate.
- 4) Patients will then receive relevant and consistent advice and support to manage their expectations irrespective the severity or number of symptoms, wherever they live in Wales.
- 5) The guideline aligns with each local Health Board processes and referral pathways.

In doing this we can say Wales has a joined-up system with National Guidance for healthcare practitioners to keep them informed and up to date so that all patients receive consistent advice and support, with appropriate referral or signposting. NHS Wales then has a coherent support infrastructure for patients presenting with acute and long-term symptoms of COVID-19.



Innovation Design

The Long COVID guideline differs slightly from the acute guidelines in that it is an interactive web-based guideline. It was decided not to create a guideline poster, nor to distribute hard copies for the Long COVID guideline. This enabled the design team to develop a more interactive and dynamic tool to support clinicians where patients were presenting with several symptoms, each with a varying potential for risk, management strategies, and necessity for onward referral.

Consistent with all other guidelines, however, the guideline platform includes supplemental education using video tutorials presented by the experts and clinicians from across NHS Wales. Further updates communicated through weekly newsletters highlighting new information and advice or changes to the evidence-base. This information will update the guideline information as necessary. A governance structure to authorise changes and updates functions according to the requirements of Welsh Government.

The estimate was approximately x5 3–6-minute videos for each symptom. It is expected there will be approximately 20 symptoms initially (~100 videos); however, this increased substantially as the Long COVID patient group highlighted reports where up to 200 symptoms were identified.

The dynamic elements of the guideline will change as new evidence emerges or the advice changes. Updates are delivered in a weekly newsletter, distinctly different to that for acute-COVID where communication was necessary more frequently. The newsletter featured up to three new updates or reminders.



The guideline is closely aligned with generalised advice and support offered in the COVID Recovery App. It also includes all Health Board referral processes – i.e., the information regarding whom, how and where to refer is bespoke to each Health Board as the service details differ.

“We wrote this guideline originally because we wanted to ensure that when patients presented, they were recognised as having the condition that they have, that they were supported in a proportionate and reasonable response, utilising the app where appropriate, having the additional support of the multidisciplinary team, but in those rare instances where there were concerns and red flags, that more urgent referral was undertaken.”



Dr Mark Walker, Senior Medical Officer, Co-author of the Long COVID Management Guideline

Opinion leaders

The target population for these guidelines are senior decision makers in primary care. For the acute management of COVID and the management of people with on-going symptoms of COVID (Long COVID) these are General Practitioners.

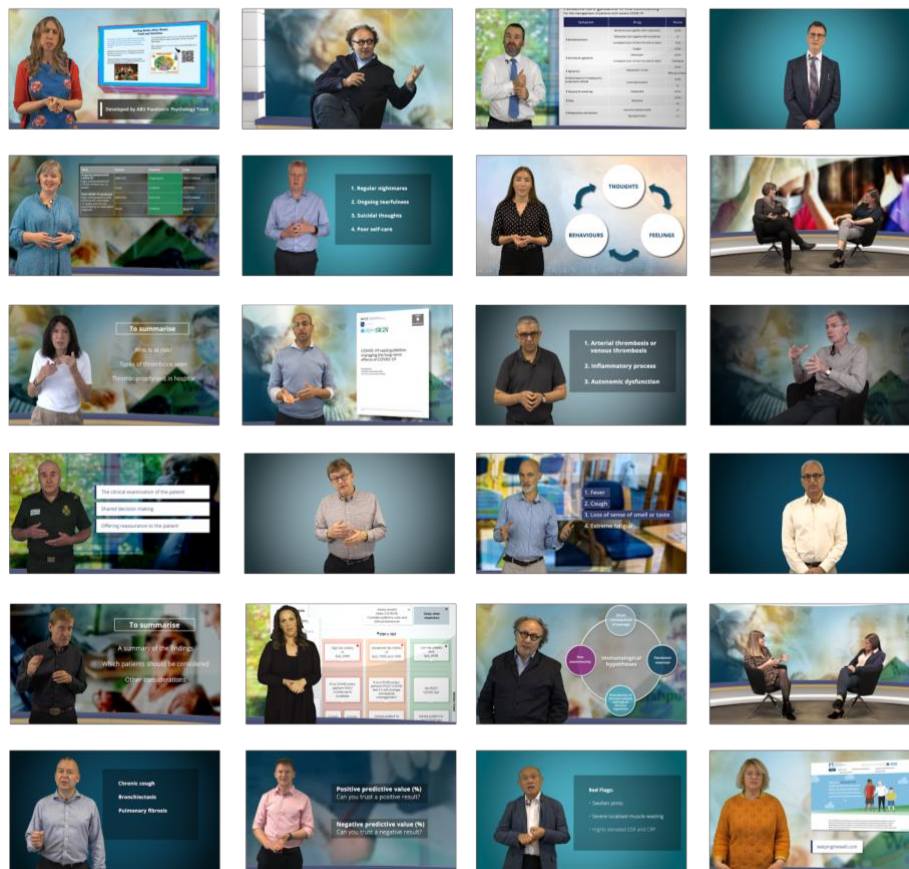


Figure x: Opinion leaders who contributed towards the guidelines. These included a world-renowned Immunologist and Haematologist, Respiratory, Cardiac, Neurology, Rheumatology, Gastroenterology Consultants, General Practitioners, Psychologists, Occupational Therapists and Paramedics, to name a few.



The predominant professional presenting in the tutorials are consultants for the specialist topics and General Practitioners for instruction relating to primary care practice from a range of specialisms (Figure 34).

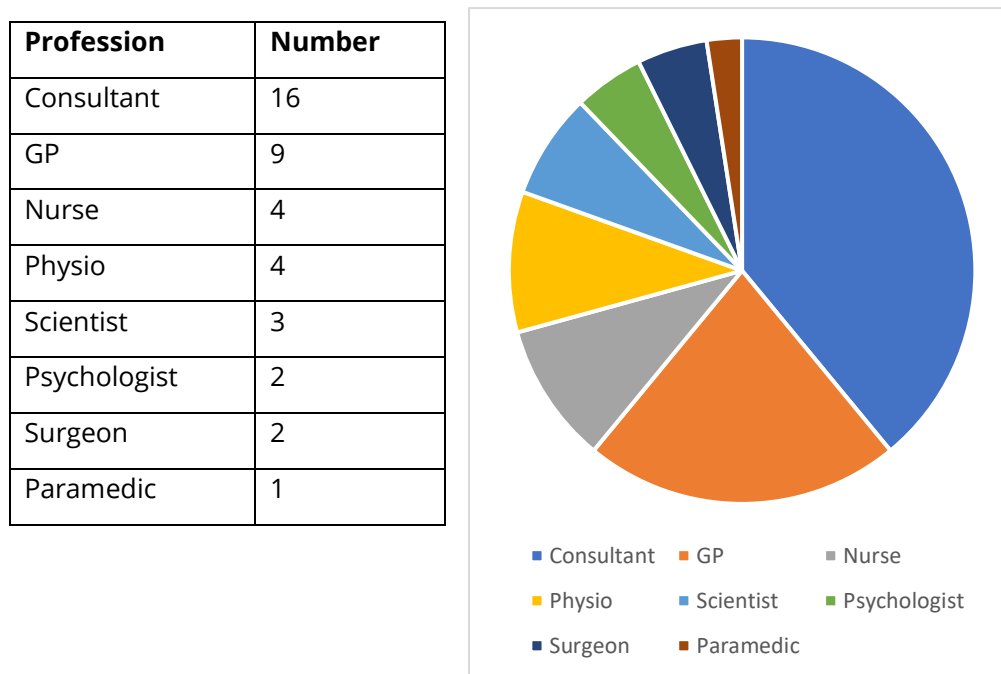


Figure 34: Proportion and number of video presenters representing a range of professionals in NHS Wales. GPs and consultant doctors presented 61% of instructional interviews. The primary target population is GPs

Discipline	Number
Respiratory	6
Emergency medicine	2
Infectious diseases	1
Palliative care	1
Medical technology	1
Public health	1
Cardiology	2
Psychology	5
Virology	1
Neurology	1
Dermatology	1
Rehabilitation	2
Rheumatology	1
Immunology	1
Haematology	1
Gastroenterology	1
ENT	1
General practice	10

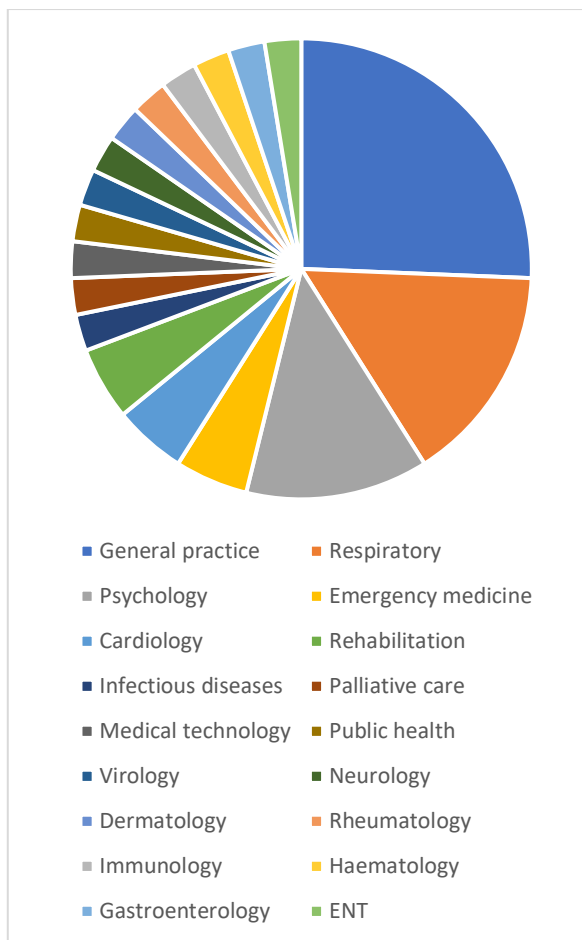


Figure 35: A breakdown of opinion leaders represented within the guideline by discipline. Instructional videos relating to general practice is the most common instructional video as the guideline serves the practice of GPs. Given the predominant symptoms are respiratory-related, this features next in order of volume of videos produced.

Region represented	Number
Aneurin Bevan UHB	3
Betsi Cadwaladr UHB	4
Cardiff and Vale UHB	19
Cwm Taf Morgannwg UHB	1
Hywel Dda UHB	2
Powys TH	2
Swansea Bay UHB	2
Other	8

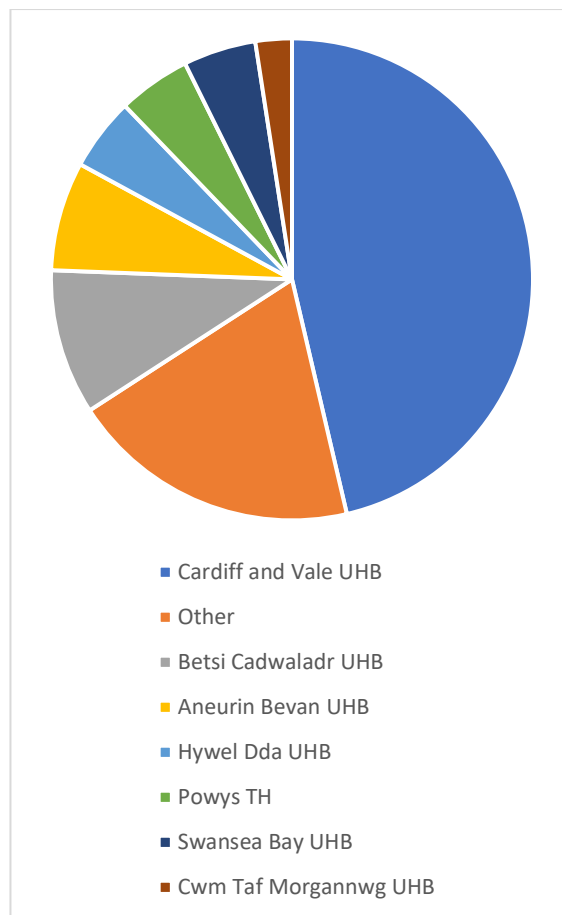


Figure 36: Proportion of opinion leaders presenting in video tutorials representing the different regions/organisations across NHS Wales. All Health boards have representation on the guideline. Again, Cardiff and Vale features most because of limitations for travel during the COVID pandemic

Video topics for the acute COVID guideline:

- How to assess a patient over the phone
- Pulse oximetry and Point-of-Care COVID Test
- The use of pulse oximeters as an advanced safety net for patients with COVID-19 in the community
- Palliative care and ethical framework
- Risk stratification; high, moderate and low risk
- Virtual ward
- Interpreting COVID-19 Test Results
- Findings from the PRINCIPLE Trial – Inhaled Budesonide
- Pharmacological symptom control measures for palliative care in the community
- Meeting the needs of people with learning disabilities during the COVID-19 pandemic
- COVID-19 Testing During Recovery
- The mental health impact of COVID-19 on NHS staff
- Addressing COVID-19 vaccine safety concerns
- Vaccines and blood clot

Video topics for the Long COVID guideline (broad categories) include:

- Overview of the typical symptoms
- What is the pathophysiology of these symptoms?
- Clinical assessment
- Management of patients presenting with these symptoms
- When to consider referral
- An immunological perspective of Long COVID
- The GP consultation



- Referral into Long COVID Rehabilitation Services in Wales
- The NHS Wales COVID Recovery App
- The Importance of Pacing
- Introducing SilverCloud Wales
- Heart rhythm issues in Long COVID
- When a child/ young person presents with possible Long COVID
- Coding Long COVID
- The risk of thrombosis in Long COVID

Timeliness of production

See Figure 6 for innovation development timeframes. However, there are two notable observations for innovation 1 and innovation 2, in terms of initiating the programme, i.e. the timeliness of their implementation.

Developing a national acute guideline for primary care was proposed by the national clinical lead for respiratory shortly after the launch of the hospital guideline. It was believed that a coherent system between primary and secondary care would reduce the burden on hospital admissions, pre-hospital care and GP services. Adoption of integrated pathways through an up-to-date and well-informed clinical workforce across primary and secondary care would clearly improve efficiencies between these services. However, it took several months to initiate this work, to the extent that it only started in September, after the first wave. This meant, by the time the innovation was produced and had completed governance process to sign off, the implementation was initiated into the second wave, just prior to Christmas. This was late, meaning practitioners in primary care sourced other mechanisms for their information



rather than that specific to NHS Wales. This has resulted in suboptimal engagement and a prolonged period and greater efforts to encourage widespread adoption.

Similarly, the long COVID guideline was launched in March 2021; where the optimal period for launch was several months earlier when the Long COVID framework was first announced by the health minister, Vaughan Gethin to the public (16). The guideline was also superseded by the launch of the COVID Recovery App, which was not ideal as this should have been part of a comprehensive package of support, not just a stand-alone intervention.



Launch event

For the Long COVID guideline (as with the COVID recovery app), we introduced a formal launch event to raise awareness of the innovation. The event was published on Microsoft Teams, which generated good awareness and increased uptake of the guideline. Subsequently, this strategy was introduced for all new innovations, or where innovations have been remarkably adapted, such as, for example, Version 2.0 of the COVID recovery app.



Figure 37: an example of the standardised slide deck and presentation of key opinion leaders during the event.

In this event, an interactive event provided exclusive access to the authors and key contributors to the development of the All-Wales Guideline for the Management of Long COVID. The event covered:

- Purpose of the guideline

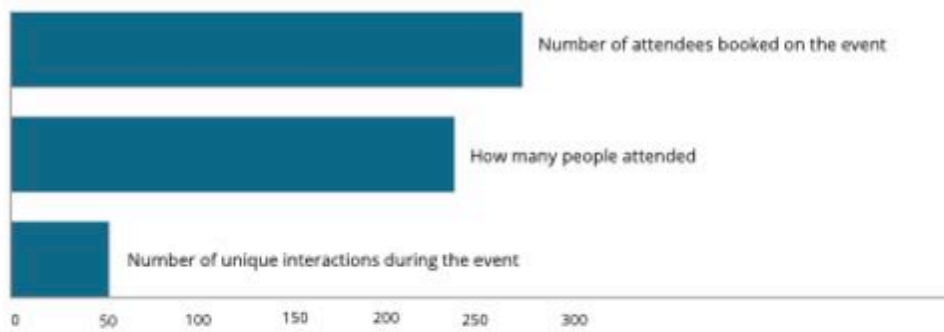


- Who is it aimed at and how it will help healthcare practitioners?
- Long COVID services in Wales
- What you can do to support patients with Long COVID

It was chaired by Dr Fiona Jenkins (MBE), Executive Director of Therapies and Health Science in Cardiff and Vale UHB and Cwm Taf Morgannwg UHB, which the expert panel (opinion leaders), included Claire Madsen, Executive Director of Therapies and Health Science PTHB, Dr Mark Walker, Senior Medical Officer, Welsh Government, Dr Avkash Jain, GP & Community Director PCIC CAV HB, Owen Hughes, Consultant Psychologist, Powys Teaching Health Board.



LAUNCH EVENT – ATTENDEES



LAUNCH EVENT – HEALTH BOARDS



LAUNCH EVENT – JOB ROLES



Figure 38: Event attendee demographics for the Long COVID guideline launch event. This demonstrates a good mix of healthcare professions and regions, consistent with the implementation strategy

For example, for this event, 62 questions were submitted before and during the live event, including questions about service provision, management of long COVID in children, how this model compares to other rehabilitation models,



and what support is offered to healthcare professionals who are living with Long COVID.

38 questions submitted during the live event were flagged as questions from sufferers of Long COVID, highlighting a lot of frustration with the services offered in Wales, delays to their referrals, and lack of medical-run clinics.

It was discovered that clinicians want an easily accessible event that doesn't take up too much of their time. Furthermore, clinicians selected a preference for events that were an hour-long, in the middle of the day (lunchtime), and preferably on a Thursday.



Governance

Innovation 1 (the acute guideline) was developed with the National Director for Primary care and the National Clinical Lead for Respiratory and coordinator of the hospital guideline and signed off by the Associate Medical Directors representing each of the seven Health Boards. Innovation 2 (the Long COVID guideline) was developed in conjunction with the senior medical advisor for Welsh Government, the lead Directors of Therapies for Long COVID and senior clinical leads. Welsh Government and the Directors of Therapies for the seven Health Boards signed off the guideline.

See figure 14, 15, 16 for governance structure and process applied to the guidelines.

To date, the dynamic elements of the acute guideline have received 6 updates as the clinical information has changed, or additional information added. The communication strategy has been sensitive to the fact we are now in the second wave, where the abundance of information can be overwhelming, and the workforce is better informed than the first. The weekly newsletter communicates the updates, rather than multiple weekly single video updates, as it was felt this reduced the burden and attention on busy practitioners, whom at the time were re-introducing usual services in addition to managing COVID.



Functions and roles

Formal implementation of the primary care guideline ensures there is quick and effective adoption of interventions into routine practice. There are five key functions for the implementation of the primary care guideline across Wales. Each function will require nominated individuals with key roles and responsibilities:

1. Implementation Team

- This will be a core team to provide leadership and direction in the implementation process. The Implementation Team will provide frequent reports and updates to Welsh Government and the Guideline Development Group. The implementation team host two separate meetings, each bi-weekly, with the Long COVID lead for Wales, and the policy leads for Long COVID from Welsh Government.

2. Health Board Executive Lead

- The exec lead will have direct line management and authority over local coordinators. The exec lead will receive and respond to local health board data updates.

3. Implementation facilitators

- This will be a designated people within the Health Board/Clusters to support and lead the local adoption of the guideline.

4. Clinical Teams



- These are the target audience for the guideline – the healthcare professionals delivering care to patients with suspected or confirmed COVID-19.

5. Implementation Management Team

- The Management Team will manage digital processes to empower coordinators to implement the Guideline and to support their local clinical teams. The Management Team will manage digital reporting processes, maintain alignment, system risk management, and maintain the function of the Guideline as necessary. Key to this function is supporting data flow from coordinator activity to the Exec lead and Implementation Team.

6. Guideline Development Group

- This group will provide governance and direction to the current and future content of the guideline and supplemental educational videos.



Implementation

Implementation means everyone who needs to know about the guideline are actively informed about it; they are offered education about the clinical recommendations and processes within it, they know what to do and when, and are notified about any relevant updates as the information changes, or as new evidence emerges. The key aims for the implementation process are:

- 1) All GPs and other relevant health care professionals across Wales, have access to the guideline and register to receive updates around new evidence or further developments.
- 2) All registrants receive weekly newsletter featuring video synopses about featured topics.
- 3) The guideline instruction integrates with the recommendations offered in the COVID Recovery App – this means the advice and support is consistent and clear for all.
- 4) That at least one person from every GP practice across Wales is registered and receiving updates about the guideline to inform local level practice.
- 5) Welsh Government receives periodic implementation reports to support central decision-making (example Appendix A).



This means there is clarity throughout the NHS workforce across Wales about what it is, and what they need to do and when, with updates about new or emerging evidence as things change. An active implementation process ensures the guideline is applied successfully for the purpose it has been designed.

Implementation Phases

Implementation of the Guideline will go through four phases.

1. Exploration phase, for example:
 - a. Assign Implementation Team and reporting processes
 - b. Identify local Health Board implementation coordinators
 - c. Establish alignment processes
 - d. Complete the Guideline design and infrastructure
 - e. Begin filming and production
 - f. Establish capacity and measures
2. Installation phase, for example:
 - a. Assign SOP's for the different implementation functions and roles
 - b. Train and on-board implementation coordinators
 - c. Establish and complete Management Team processes
 - d. Notify clinical teams via coordinators, national groups, Health Boards and through distribution of marketing materials
 - e. Establish a communication strategy
3. Implementation phase, for example:



- a. National start date of Guideline implementation
 - b. Manage clinical teams via coordinators
 - c. Begin reporting processes
 - d. Upload core skeleton of video education
 - e. Continue updating guideline throughout March
4. Data review, for example:
- a. Data analysis and support from the Implementation Team
 - b. Periodic reports and escalation to WG
 - c. Authorisation of updates and modifications

Engagement

The uptake trend increased during the last week before Christmas in response to the dissemination of a letter from Welsh Government recommending the use of the acute COVID guideline (Figure 39). However, as expected, the numbers of new registrants throughout the Christmas period and into the New Year has remained modestly consistent.



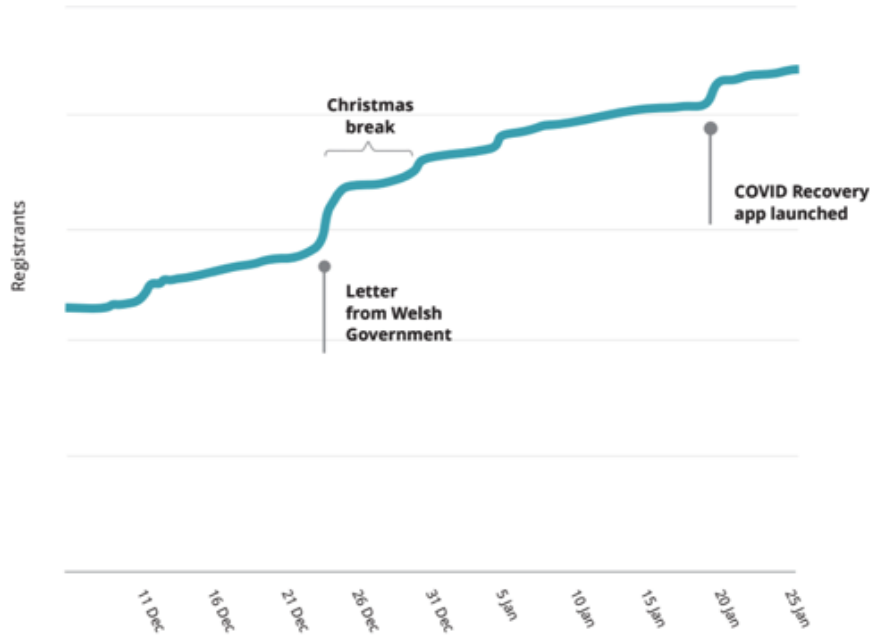


Figure 39: Key milestones and impact on guideline registrations in primary care

Impact

The impact of the guideline can be realised once it is accepted by the target organisation and adopted by the target population. All seven Health Boards have accepted both the acute and Long COVID guidelines across Wales via Associate Medical Directors (AMDs) and Directors of Therapies (DoTHs), respectively. The map below illustrates all GP surgeries. Where the practice has at least one member registered with the guidelines this is dark blue. Where there is no one registered with the guideline it is a light blue (Figure 40).



Figure 40: GP practices including branch surgeries across Wales. Those in dark blue dot represent practices with at least one member registered with the guideline. The light blue dot is a practice where no one is registered with the guideline.

Approximately 95% of all GP practices across Wales have at least one member registered with the platform.

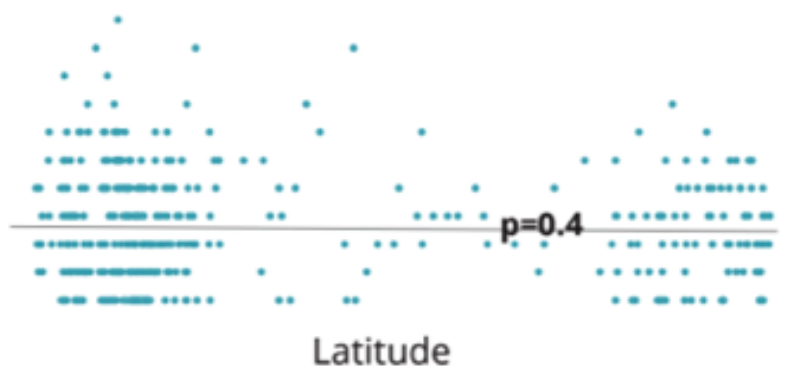


Figure 41: Registrants between north and south Wales by latitude demonstrate no significant difference in engagement (p=0.4).

There is no significant difference between the number of registrants per GP practice between North and South Wales ($p=0.4$) (Figure 41). The relative distribution of users between north and south Wales is similar. The percentage of practices with no users is 15.1% for south Wales, 18.8% for mid-Wales, and 16.6% for north Wales when dividing by latitude rather than Health Board (Latitude: South Wales -51, Mid-Wales - 52, North Wales - 53).

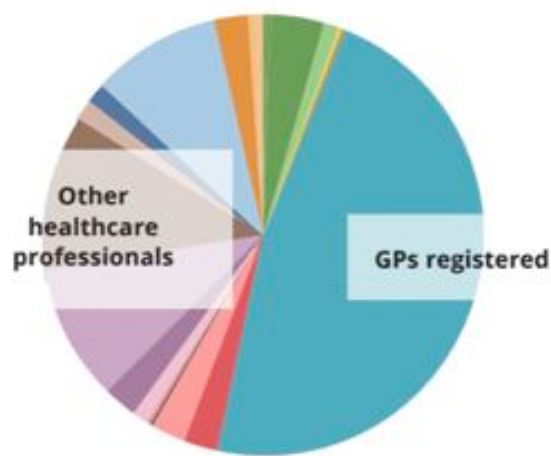


Figure 42: Distribution of GPs (target population) and 'other' healthcare professionals registered with the guideline

More GP's have registered with the guidelines than any other HCP. This is likely to be an underestimation to the absolute values, as several users have not set their title/profession.

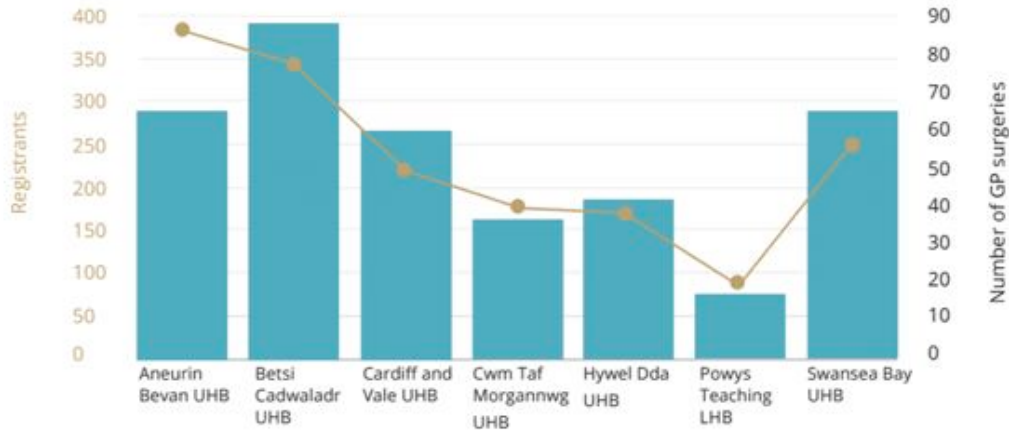


Figure 43: Number of registrants from primary care against the number of GP surgeries (data from January 2021).

The mean number of practitioners registered is 3 healthcare professionals per GP practice. At least 750 GPs are registered with the guideline. This represents nearly 50% of all GPs indicating the programme remains in implementation phase 3 and on-going implementation activities continue to raise the awareness of the guidelines.

There are two fundamental flaws to this guideline, which has impacted the rate of penetration across the target population (GPs):

- 1) **Timeliness:** this programme was commissioned late into the second wave. GP feedback has indicated the guideline would have offered most value during the first wave of the pandemic. The hospital guideline demonstrated that timely implementation is paramount to achieving high adoption rates.

2) Facilitation – effective facilitation through good selection of active local leaders and influencers is necessary for widespread adoption of innovations. This was evident in the actions of one facilitator in Swansea Bay who engaged a significantly higher population of consultants with the guideline than any other Health Board. Whilst cluster leads were identified for these guidelines, the team have failed to adequately identify and engage with them early in phase 3. Whilst facilitators are slowly emerging for respiratory and Liver disease, it takes time to engage this group in addition to their day-to-day role. Through wide discussions, personal capacity has been the major barrier to facilitator engagement in primary care.

“We are the consultant holistic practitioners, based in the community. We need to make sure everybody receives the support they need on their long COVID journey. We are constantly learning about COVID and how it evolves and develops. What this [guideline] does is gives us the additional knowledge and opportunity to support our patients to the best of our ability.”



Dr Mark Walker, Senior Medical Officer, Co-author of the
Long COVID Management Guideline

Summary

The long-term sequelae for some people following infection with COVID-19 is a complex presentation requiring several clinical interventions and support, ranging from general advice and discharge to clinical intervention, or referral to specialist rehabilitation support. Without a coherent national framework, joining up current national guidance, and reaching the health service providers that need to know about it – there will be variation and inconsistency in the management of people with Post-COVID Syndrome. This will undoubtedly cause significant impact to sufferers and will exacerbate a situation where currently these patient groups feel ignored.

Feedback from the Long COVID Group, for example highlights the lack of GP knowledge and acknowledgment about their condition, which is a significant factor affecting their recovery.

There is a clear opportunity for Wales to be leaders in standardising the acute and long-term management of patients affected by COVID-19. This is an opportunity to join policy to patient – where we can offer immediate support and advice through the COVID Recovery App, and a consistent and up to date messaging, managed by a well-informed workforce. Meeting the expectations of patients will ensure Wales remains at the forefront of patient care.

Clinical staff requires simple and coherent guidance that is relevant, informative to their needs, and of immediate value. Accompanied by contextual education and instruction delivered by the experts and leaders from NHS Wales will provide the clarity, consistency, and instruction to ensure they are empowered



to manage a range of complex Long COVID cases. A structured implementation process aligned with key stakeholders and decision-makers will ensure that the guideline actively reaches all relevant users to ensure the guideline delivers to the purpose it has been designed. We must therefore implement a dynamic national guideline to ensure all healthcare professionals managing patients with Post-COVID Syndrome across Wales remain at the forefront of the evidence-base. This will mean patients receive appropriate care and advice from informed service providers with confidence and sensitivity, thus meeting their expectations aligned with *A Healthier Wales*.

"I hope that this guideline raises the awareness of Long COVID, so that all HCPs can develop a wider understanding of Long COVID, acknowledging its existence and that it affects many different people in different ways. So, wherever you live in Wales, you should expect to see an HCP informed by the knowledge and tools and with access to the right services to manage long COVID sensitively, appropriately and timely"

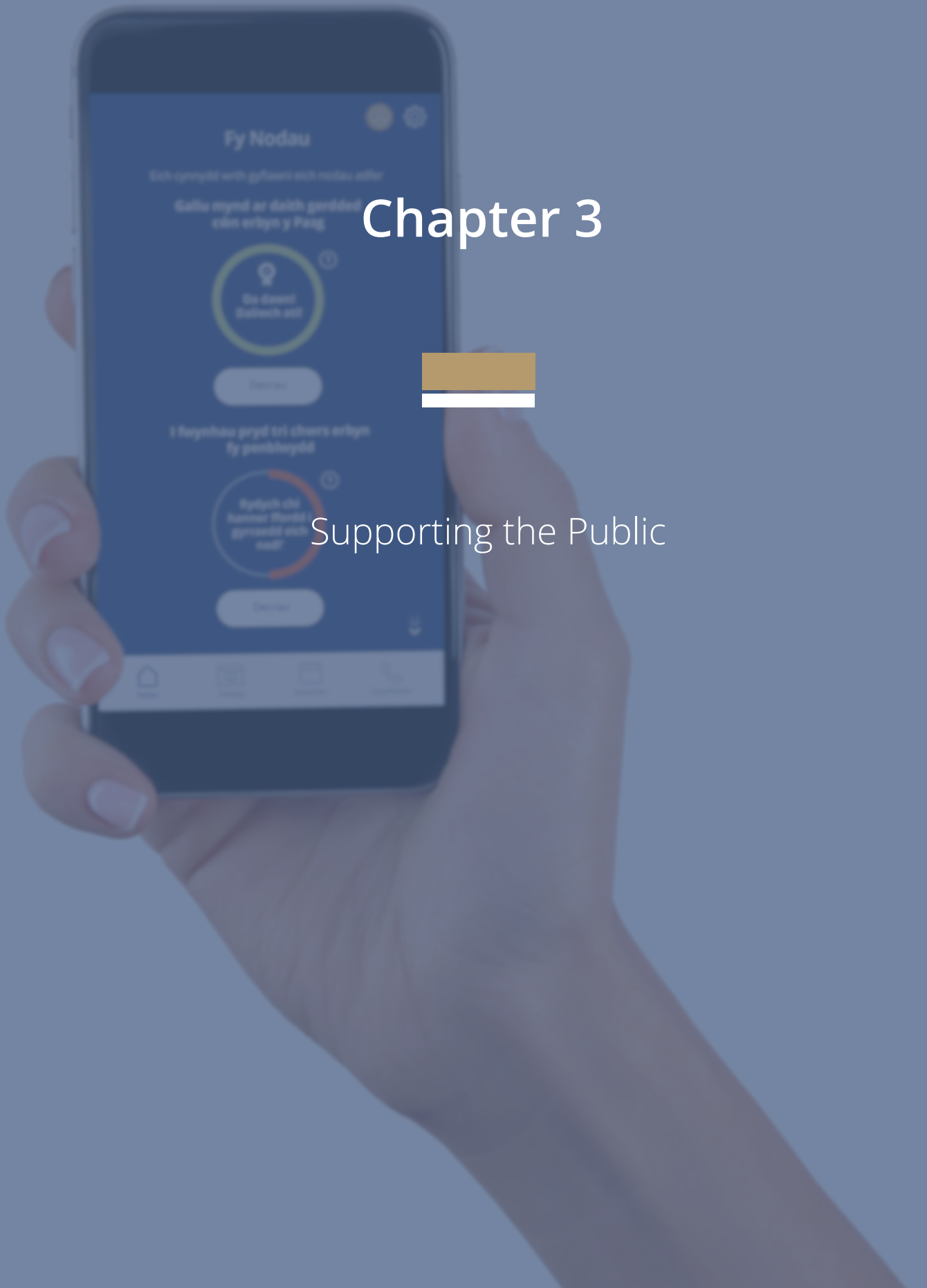


Dr Fiona Jenkins (MBE), Executive Director of
Therapies and Health Science in Cardiff and Vale
UHB and Cwm Taf Morgannwg UHB

Chapter 3



Supporting the Public



Chapter 3: Supporting the Public

Specifically, people and their families and carers who suffer with the acute and long-term effects of COVID-19 infection.

COVID Recovery App Highlights

High level excerpts from the implementation plan and implementation status.

Plan

- Innovation: The NHS Wales COVID Recovery App
- Innovation design/development start date: September 2020 (After first wave)
- Formal implementations start date: December 2020 (During second wave)
- Target organisations: People and patients within Aneurin Bevan UHB, Betsi Cadwaladr UHB, Cardiff and Vale UHB, Cwm Taf Morgannwg UHB, Hywel Dda UHB, Powys Teaching UHB, and Swansea Bay UHB.
- Primary target population: The public suffering from acute and long-term effects of COVID-19
- Secondary target population: Healthcare professionals that manage patients with acute and Long COVID to offer the app as part of self-management support



Current Status

- Current implementation phase: 4/4
- Adoption by target organisations: 100%
- Penetration of primary target populations: 100%

Background

The NHS Wales COVID Recovery App [App] is the first of its kind, developed here in Wales, for the Welsh public. The success of this App will put Wales as international leaders in the efforts to provide freely accessible support quickly to support the recovery process of patients suffering from the effects of COVID-19. This can be utilised whether the NHS is already managing these people, or for those people who remain at home self-isolating or suffering without the support of healthcare professionals.

This is a unique opportunity for NHS Wales to display a collaborative, dynamic and responsive action to the deleterious long-term effects of COVID-19, doing so quickly and on a national scale.

Utilising a structured implementation framework embeds the App into routine clinical practice. This is achieved with greater scale and pace than traditional approaches. The digital implementation framework supports and empowers stakeholders at all levels, including commissioner, Health Board executives and healthcare teams.



Programme Aims

1. To develop a bilingual NHS Wales branded COVID-19 Recovery App [App] for adults with or recovering from COVID-19
2. To implement the App as an integral component of the COVID-19 recovery programme (Welsh Government *Adferiad Programme* (17)), to offer support and a supplemental structured recovery programme for all patients across Wales – irrespective the level of disability from, the severity or number of COVID-19 symptoms.
3. The overarching message is to assist people in their recovery to becoming symptom-free from the effects of COVID-19. i.e. to help get them back to where you were pre-COVID-19 illness

Key Features

- Bilingual
- NHS Wales branded
- Free for patients
- Accessible on Apple and Android smart phones and tablets
- Supported by a comprehensive implementation framework
- Delivered as part of the Welsh Government *Adferiad Programme*

The App is freely available to any person with or recovering from COVID-19. This will be available on both the App Store and Google Play with Welsh/English selection. The app can be prescribed or signposted by HCPs or



downloaded directly by the patient without any interaction with a healthcare professional.

The App can support, motivate and encourage physical and/or psychological progress towards the complete recovery from the symptoms, and the impact of symptoms, from COVID-19. The App is dynamic, personalised, and appropriate for a wide spectrum of patients, such as for example, the recovering young fitness fanatic to the elderly and immobile.

Innovation Design

The app primarily features the users' goal(s) and their progress against them over time, a specific symptom-related education programme(s), with supplemental general education about other COVID-19 related topics, instruction, and advice, with recommendations about what to do to manage their condition, with a symptom checker to grade and monitor improvement.





Figure 44a: The COVID recovery app, developed to support, motivate and encourage physical and/or psychological progress towards recovery. Patients input their symptoms and set goals against each symptom, and then monitor their progress to recovery.

The relationship below illustrates the schematic logic for the App:

- Progress against goals based around their symptoms
- Personalised learning about their symptoms
- Rehab and measures pertaining to their symptoms
- Monitor symptoms over time, displayed by progress against goals

The Production Team in ICST developed each work package with the support of the Implementation Team. The programme features four main areas of work:



1. Developing assets (marketing and awareness campaign, dissemination materials)
2. Healthcare Professional Toolkit (standards, guidelines/protocols, education, user dashboard, tutor-mentor system, and referral materials)
3. App (App design, App Store / Google Play listing, Legal requirements, Website)
4. Implementation software and reporting
5. The on-going management includes user management (HCP and patient), on-going user testing and research, the maintenance and hosting of, and developing future iterations and improvements to the functionality of the App.

Functions and Roles

There are four key functions to the development process. Each function features separate groups of people with specific roles:

1. Implementation Team: the core team managing the design, functionality, content, quality assurance and reporting. This team shares roles between app development and programme implementation
2. Production Team: this includes the design, educational and technical teams responsible for developing all the digital aspects of the whole programme



3. Clinical Specialists: these are designated person(s) within each Health Board responsible for the design and presentation for video education, promotional, communication and dissemination materials. Clinical Specialists are selected by Health Board Executives (in this case the Director of Therapies (DOTHS))
4. User Testing: Nominated people including patients to test the quality and function of the App. This is an iterative process throughout the entire life cycle of the app

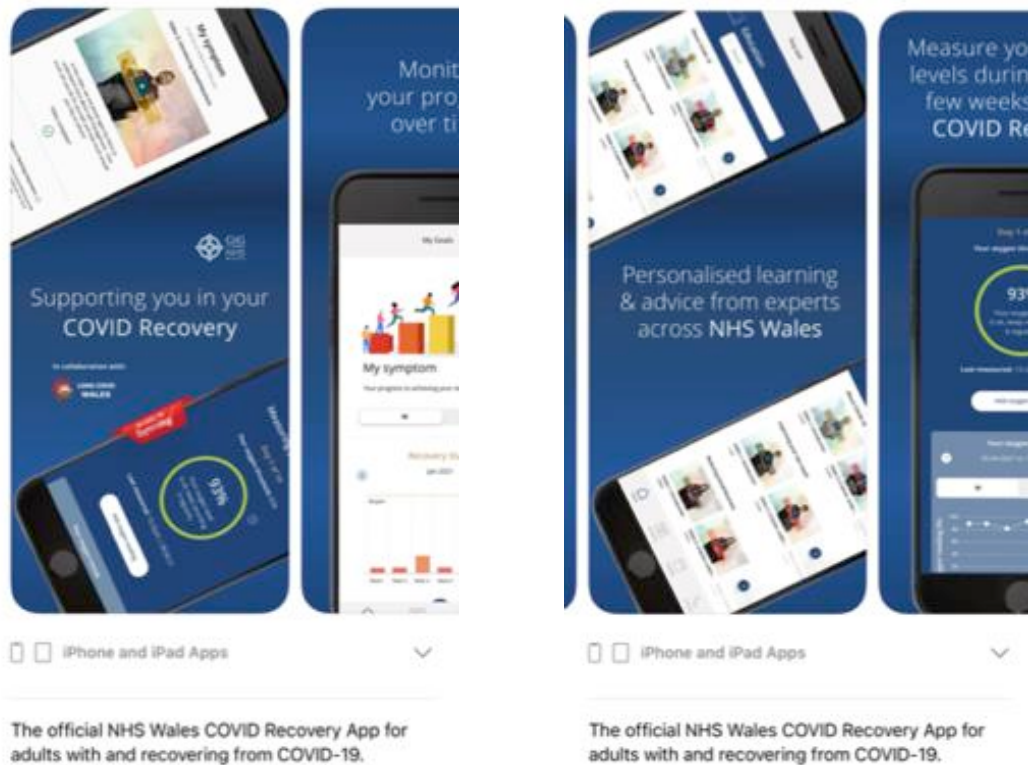


Figure 44b: Examples of the COVID images on the AppStore and Google play

Integration

The app supports the NHS Wales guideline for Long COVID by acting as a resource tool that can be offered to patients presenting with Long COVID symptoms. The GP or practice nurse offers this recommendation by following the instruction in the interactive guideline (Figure 45).

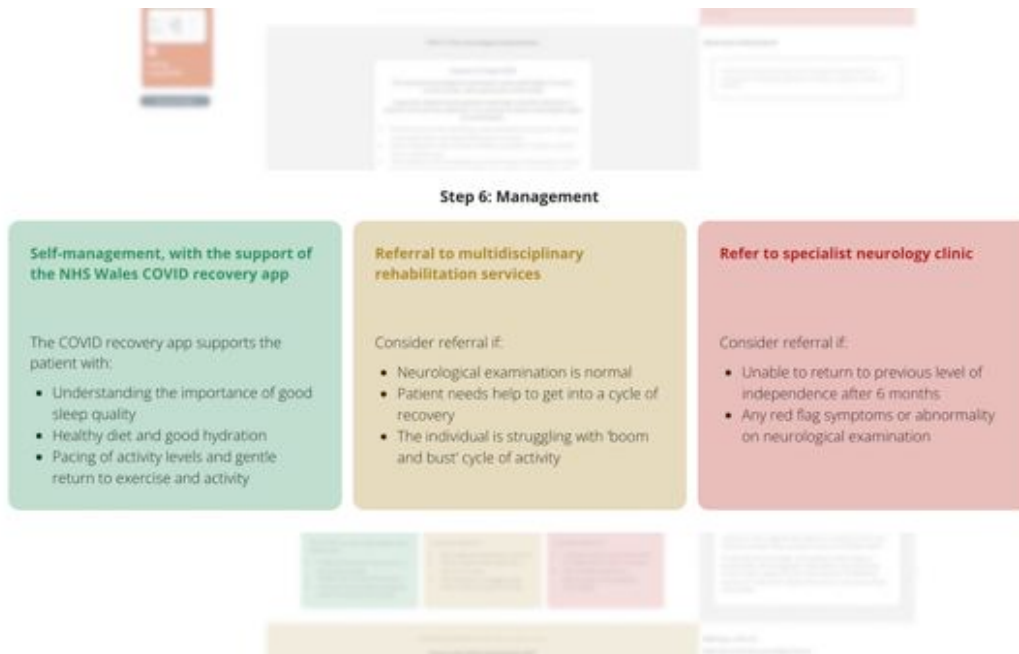


Figure 45: Instruction to healthcare professionals (GPs) within the NHS Wales Long COVID Guideline demonstrating an integrated approach to implementing evidence-based practices; when to consider referral to the specialist clinic (in this example a neurologist), when to consider referral to your local multidisciplinary rehabilitation service, and when to proceed with self-management with the support of the NHS Wales COVID Recovery app.

Examples of video topics hosted on the app:

- Why am I experiencing this symptom following infection with COVID-19?
- Setting self-management goals and monitoring improvement
- Making progress at home –what can I do to help myself?
- What if I don't notice any improvements? When to speak to your GP
- Keeping up the good work –making long term healthy lifestyle choices
- What to expect if you test positive for COVID
- When to seek medical attention with acute COVID
- Why has your GP given you a pulse ox?
- How to use a pulse ox
- Why has your GP given you an asthma inhaler (Budesonide) if you have COVID-19?
- Frequently asked questions
- Avoiding post-exertional malaise
- Why are you experiencing palpitations?
- How to safely increase your activity levels
- The importance of pacing
- What are breathing pattern disorders and how do I know if my BPD contributes to my symptoms?
- Why are you still getting gastro-intestinal symptoms?
- On-going loss of sense of smell or taste



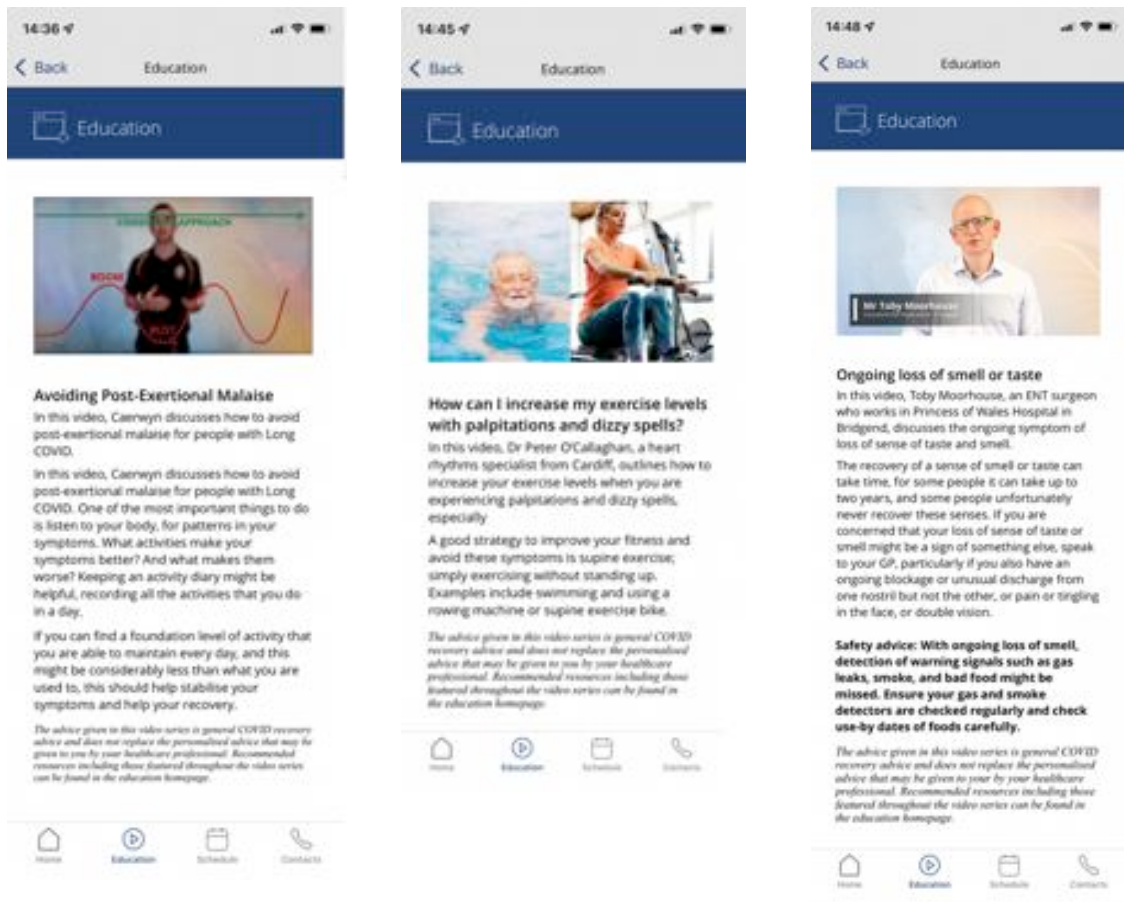


Figure 46: Examples of app tutorial and text instruction hosted on the COVID Recovery App.

Timeliness of production

It was imperative to assign the full list of topics to the clinical specialists and opinion leaders early in the production process. It takes time to secure their commitment and requires significant negotiation to advance filming dates within a short turn around. Note, that presenters are doing so outside of their job plans and offer their services voluntarily. This is therefore considered additional work, which emphasises the commitment and dedication to the project.



Content production is a notoriously slow process, posing a major risk for the timely completion of this programme. Content is also important contextualisation for the function of the App to enable early user testing.

For every video produced for the app it comprised of three distinct steps. Whilst several videos were produced simultaneously to ensure the videos were produced within the project plan.

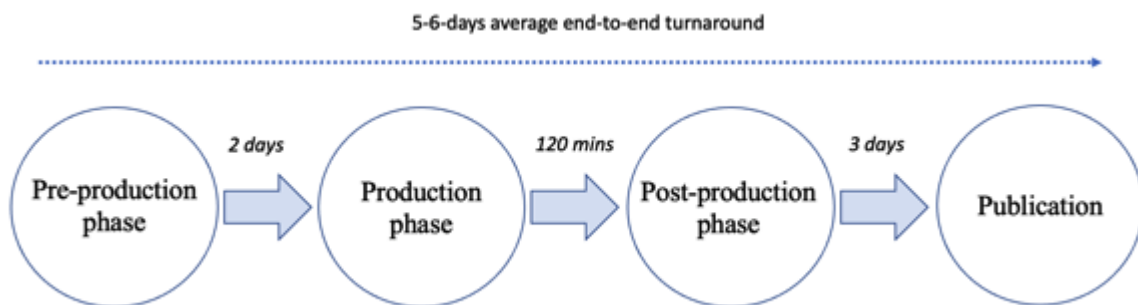


Figure 47: Video tutorial end-to-end production phase. Decision-making controlled by the implementation team via governance process.

The average timeframe for a single video to be published for the app was on average 6 days, however, to achieve this it was a testament to the flexibility of the production team to travel across Wales to film experts at their place of work. Had this not been the case, the average production time would have increased three- to four-fold longer in duration.

Furthermore, given the unique innovation of the app and the complex environment surrounding Long COVID at the time, in most cases additional

scoping and planning was required compared to usual production process to ensure the contributors were clear in their remit and the purpose of the app.

- Pre-production phase (2 days on average)
 - Video scoping, including identifying learning outcomes and preparing motion graphics
 - Governance team determines the most appropriate contributor(s)
 - Average 4 emails to align contributor and schedule filming date

- Production (120 minutes on average). However, this extends to 1-2 days where travel was required. There were several contributors outside of Cardiff and each of these were met in their own work environment. This included travel and set up of green screen studio in a locally arranged venue. Despite convenience for clinicians the video production time is significantly increased through this process. On the other hand, however, in some incidents visiting local filming has reduced the pre-production phase to ensure it is kept low so that the products are produced quickly.
 - 30-minute pre-filming scoping session
 - 90-minute filming session

- Post-production (3 days on average)
 - 3-hour video edit
 - 1-hour motion graphics creation
 - 2 governance emails with contributor
 - 2 governance emails with clinical lead (where applicable)
 - 1-hour to action changes to video/text following review



- 1-hour to build the page, embed the video, format the content, attach the resources/ guidelines, categorise on the platform and publish

Currently the app includes 161 videos averaging 4 minutes in length comprising of:

- An introductory/overview video
- 96 symptom videos
- 6 acute COVID videos
- 20 graded exercise videos (series)
- 32 FAQ videos
- 4 feature-length Long COVID patient stories

Currently there is approximately 644 minutes of video support and instruction available for the public directly relating to COVID recovery. All video content is relevant to people in Wales.





Figure 48: As well as educational videos, the app also hosts a series of Long COVID patient stories, featuring patients from across Wales who discuss their journey of recovery.

By the end of December marketing materials including promotional videos and flyers were available for all local Health Board to incorporate as part of their Long COVID services, local websites and as part of the advice offered to patients at a range of different touch points.

Opinion Leaders

The App features NHS Wales specific instruction from respected subject matter experts (opinion leaders). Opinion leaders improve the acceptability of an innovation by the target population (6). Opinions leaders feature in every video on the App, which was a strategic decision to increase the acceptability and trust in the advice given.



Figure 49: Opinion leaders from across Wales, giving up their time to film and contribute towards the NHS Wales COVID recovery app.

Opinion leaders/clinical specialists must meet the following criteria to ensure high quality videos are produced within deadline:

- Expert knowledge in the topic
- Excellent presentation skills
- The time and commitment to undertake filming quickly

The target population for the app are patients experiencing a wide range of symptoms. The Long COVID programme in Wales was therapist-led therefore the predominant professional present on the app was a therapist – including physiotherapists, occupational therapist, speech and language therapist and psychologist. Medical-related instruction is delivered by doctors (consultants) (Figure 50).

Profession	Number
Consultant	7
Psychologist	7
Occupational therapist	5
Physio	7
Surgeon	1
Scientist	1
Dietitian	3
GP	1
Speech & Language Therapist	3

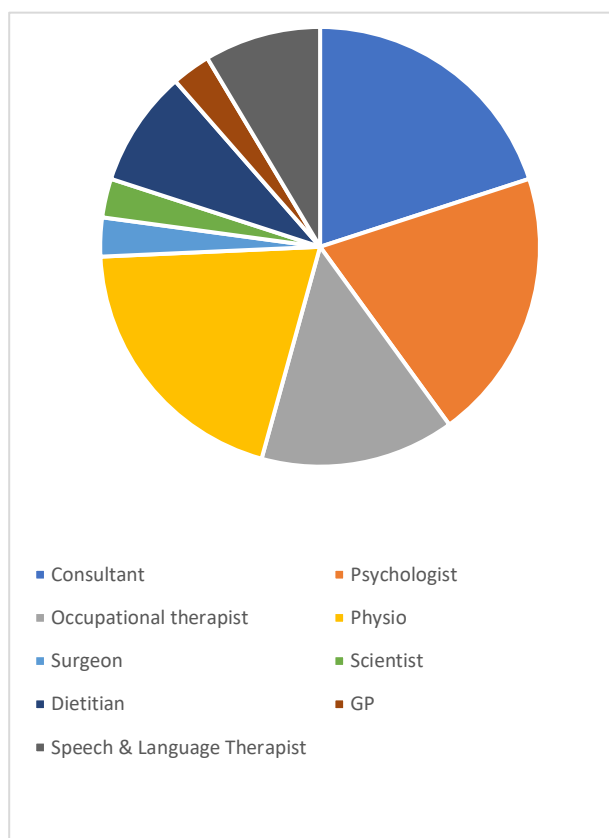


Figure 50: Proportion and number of video presenters representing a range of professionals across NHS Wales

App presenters represented specialisms from a range of disciplines (Figure 51). Most specialists had a respiratory background, followed by psychology and rehabilitation.

Discipline	Number
Respiratory	9
Psychology	6
Rehabilitation	6
Dietetics	3
General	2
Cardiology	2
ENT	1
Virology	1
Neurology	1
Gastroenterology	1
Other	1



Figure 51: A breakdown of opinion leaders represented within the guideline by discipline

As the strategy is to ensure there is widespread representation on the apps, presenters were accessed from across all but one Health Board. These were identified and filmed within a small window within the app development plan.

Region represented	Number
Aneurin Bevan UHB	1
Betsi Cadwaladr UHB	6
Cardiff and Vale UHB	14
Cwm Taf UHB	2
Hywel Dda UHB	0
Powys TH	3
Swansea Bay UHB	3
Other	4



Figure 52: Proportion of opinion leaders presenting in video instruction representing the different regions/organisations across NHS Wales

Most video presenters are from Cardiff and Vale UHB (42%), followed by Betsi Cadwaladr (18%). This is consistent with the patients on the apps; the highest proportion of users is in Cardiff and Vale UHB (23.9%) with Betsi Cadwaladr UHB second with 23.56% (Figure 52).

Acceptance of the App by App Store and Google Play

Registering a 'COVID' app with Apple and Google was a complex process, which took longer than first anticipated. To prevent misinformation around COVID, both app providers enacted a more strict acceptance policy to ensure the public across the world can access apps from a safe and trusted place. To fulfil this

expectation, the App Store and Google Play critically evaluate all COVID-related apps to ensure data sources are reputable. Notably, “that developers presenting these apps are from recognised entities such as government organisations, health-focused NGOs, companies deeply credentialed in health issues, and medical or educational institutions. Only developers from one of these recognised entities should submit an app related to COVID-19” (18).

Contacting both App Store and Google Play to discuss relevant documentations and evidence was also more difficult due to the different time zones of their customer services teams. Nevertheless, once the apps were accepted, all additional updates and new version release, whilst taking slightly longer than usual, was manageable within the deadlines.

The app is registered with MHRA as Class 1 self-care/reporting software. Ref no. 9213.

Governance

The Implementation Team manages and signs off all static content (content that is standardised within the programme architecture). Dynamic content, for the purposes of this document, includes video education, some text content, and some communications; the production team in conjunction with the Clinical Specialists manage this. The governance phases for content development are:

1. Define Themes, categories and topics pertaining to COVID-19 recovery
2. Select representatives from each of the Health Boards



3. Content production
4. Sign off
5. Embed and test

The content of the app aligns with the common Long COVID symptoms. Clinical Specialists identified by the DOTHs from each of the seven Health Boards determine what information is required against each topic. The DOTHs representing each Health Board put forward the nominees to present each topic. The Production Team manages this process.

The Implementation Team manages the day-to-day activities of the App developers. The DOTHs received a visual presentation with design and functionality updates on a periodic basis. Based on the feedback, the App underwent appropriate improvements where possible within the timeframe.

Overview of roles

1. Implementation Team: This team has a dual role, also including intervention management. Their role is to provide leadership and direction aligned with the process of programme implementation in a controlled way through established processes. The Implementation Team will provide frequent reports and updates to Welsh Government, the Respiratory Health Implementation Group, and the Directors of Therapies.
2. Health Board Executive Leads: Directors of Therapies or nominated deputies. The exec lead will have direct line management, support and



authority over Health Board coordinators. The exec lead will receive and responds to local health board data updates and respond to any local escalation issues.

3. Health Board coordinator(s) (facilitators): This will be a designated person(s) within each Health Board or Health Board region, with two deputies to support and lead the implementation of the App within local hospital/wards, community and primary care, and provide direct structured support to Healthcare Teams. Health Board coordinators will implement the programme through established implementation science techniques utilising specific software provided to them.
4. Healthcare teams: These are the clinical teams or clinical practitioners across the Health Board responsible for the promotion, uptake, and signposting their patients to the App. Health Board coordinators will provide the necessary support to the Healthcare teams.
5. Programme Management Team: The team manage digital processes to empower Health Board coordinators to implement the App and to support Healthcare Teams. The Programme Management Team in ICST manage:
 - a. Digital reporting processes to all levels of stakeholders pertaining to the activity and outcome of the implementation process
 - b. Acquiring and maintaining alignment with all relevant stakeholders, within and outside of the programme
 - c. System risk management by highlighting and escalating issue to the Implementation Team as they arise.



Implementation

This programme of work incorporates a dissemination and implementation programme consisting of a marketing and communication strategy, resources, an awareness campaign, and education for HCPs to provide contextualisation and understanding to increase the widespread utilisation and adoption of the App. Following scoping and planning phases, the development phase took around 10 weeks incorporating multi-level user testing by patients within and beyond the development period.

By following a structured implementation plan, clearly assigned roles and responsibilities and reporting mechanisms will embed the App at scale (nationally) into an establishment ready-to-adopt establishment, informed and adequately prepared to utilise it in practice. Using an implementation framework significantly increases the widespread use of the intervention more quickly. Critically, this system empowers provision at local level through Health Board coordinators (facilitators) – this is the ‘make it happen’ power layer – emphasis here on the significance and importance of their role locally. Health Board coordinators are supported by the central implementation team.

This innovation was developed in conjunction with NHS specialists, digital innovators, and the Long COVID Wales patient group who together provided in depth knowledge and breadth of understanding about the condition, implementation of digital innovations, and the target population, respectively. The implementation process will be on-going until the App becomes sustained routine clinical practice (a process of normalisation and institutionalisation).



"The app is easy to use, helps you track the intensity of activities and there are videos with extra information. Haven't found another app like this! Great you guys made this!"

Long COVID patient

Establishing the target population

Long COVID is a new and relatively unknown condition, with differing estimates on its prevalence. The most recent study from the ONS suggests that 1 in 40 (2.5%) of those diagnosed with COVID, both symptomatic & asymptomatic end up with COVID symptoms lasting longer than 12 weeks. However, it is estimated that this potentially drops to 1.5% of those diagnosed with COVID having COVID symptoms lasting more than 16 weeks (19), however more time is needed to validate this. Using these figures, we can approximate the Long COVID population in Wales based on official COVID infection case data (take away deaths), and how it changes over time. Using the official case data, in October 2021 approximately 6000 people in Wales have COVID symptoms lasting longer than 12 weeks, consistent with a diagnosis of Long COVID. As there was no official case data for the first wave however, it is likely that those with Long COVID from the first wave are not included in this estimate. As a result, we must rely on other sources to estimate the additional burden from the first wave. The Institute of Health Metrics and Evaluations estimated that in the UK between the start of the first wave and when mass testing began, there were 3.5 million COVID cases in the UK (20). Wales makes up 4.7% of the UK population; so extracting this suggests that Wales had around 167,320 COVID cases in the first wave (March-May). If 2.5% of these go onto develop Long COVID, this is an extra 4,183 people. If only 1.5% of these have Long COVID after 16 weeks, the



estimate is 2,509 people. Adding this to the 6000 from the official case data for the second wave suggests the number of Long COVID cases currently in Wales is around 8500 people.

App downloads (reach)

The total downloads for Wales reached 9454 by the end of November 2021 (Figure 52). The download rate has not changed remarkably since the launch of the app in January 2021.

However, there appears to be a small increase in the rate of downloads in November consistent in pattern with that observed in January and February. Furthermore, during the summer months (July, August, September) there appears to be a flattening of the trend line indicating less downloads over this period. This pattern may be reflective of the increased number of COVID cases during the winter periods thereby increasing the likelihood of more suffering with long COVID; the second and first wave observed in January and February, and third wave currently.



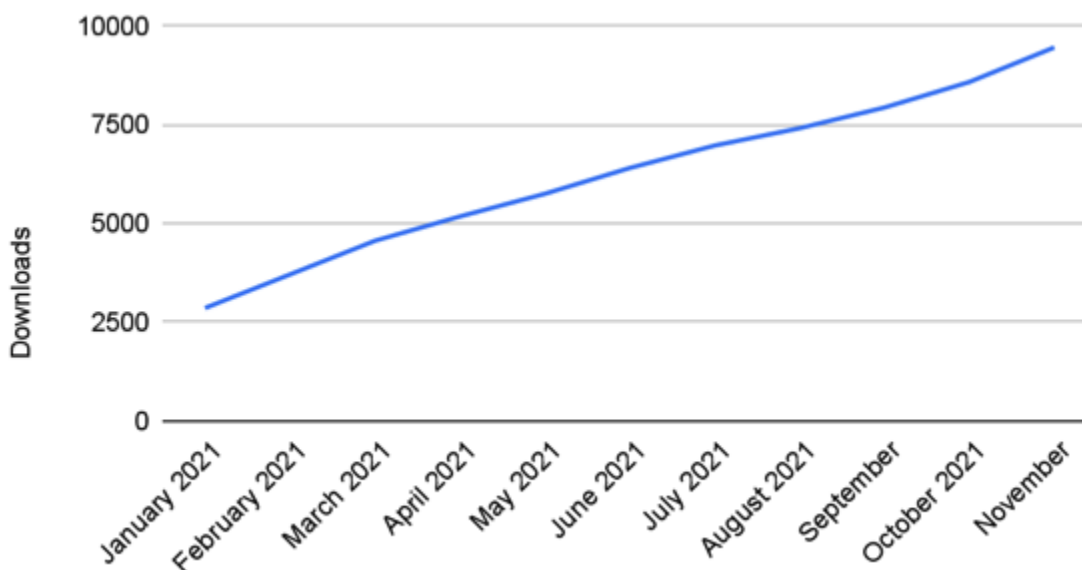


Figure 53: Running total of app downloads across Wales between January and November 2021. Note, a flatter rate of downloads over the summer period and an increase as we enter the winter period (Oct-Nov) similarly to Jan, Feb, March.

Nevertheless, the rate of downloads fluctuates around 30 downloads per day on average. It will be interesting to observe the pattern throughout the winter period where infection rates will likely be higher.

The conversion rate between downloads and formal registration with the app is 48%. This means around half of people who download the app go on to register and become active users of it. Typically, health apps observe a conversion rate of 42% (22). To date, 372 people have permanently deleted the app. This is considered a positive reflection of their recovery. Where this may not be the case the advice within the app is to contact the support team.

Launch Events

There were two launch events for the app. The first was an event to inform all relevant healthcare professionals about the app, the purpose and implementation plan to ensure widespread recommendation in primary and secondary care. This event was hosted on Teams in December 2020 and attracted a couple hundred healthcare professionals.

Following formal acceptance from the App Store and Google Play, Welsh Government were notified of a formal launch date of the app with a statement to the public via the BBC news by the then Health Minister, Vaughan Gethin in January 2021 (23).

Timeliness of implementation

Within less than 12-months, the specification, procurement, innovation development and national implementation has taken place. The urgency and dedication from all stakeholders has resulted in the widespread adoption of both guideline and app.

The past 9 months has involved development and updates as the evidence base changes, and formal implementation to ensure the innovation has reached and penetrated the target population (GPs and patients) on a national level.

This innovation has therefore succeeded in its endeavours to achieve scale across NHS Wales and has demonstrated impact through patient co-production, Health Board acceptance, clinical adoption and public utilization.



Co-production

This also set out a model for co-production, demonstrated by a rapid response of patient representatives through collaboration with the patient representation group, Long COVID Wales. This was important for two reasons: Firstly, to demonstrate patient co-production of innovations to support the public and secondly, as a strategy to drive the standards and expectations of patient care across Wales. This offers a framework of reference to increase the value of other large-scale public facing innovations.

In March 2021 following significant discontent from Long COVID sufferers through the Long COVID Wales patient lobbying group, the app was updated to consider the latest evidence presented by the group, and additional features and a list of nearly 50 links, documents and websites as a new resource feature within the app.



Figure 54: App Store listing demonstrating collaboration with the Long COVID Wales patient group

The technical adaptation involved considerable work, and this was undertaken over 6 weeks including 10 hours of Teams meetings with the Long COVID Wales group. In late March 2021 version 2.0 of the app was released published and marketed in collaboration with the Long COVID Wales patient group (App Store listing image in Figure 54 below).

Impact

The guideline platform has on average three healthcare professionals per GP practice from over 90% of GP practices registered with it and receive updates when new evidence or recommendations emerge. Early estimates based on self-reported symptoms suggested 1 in 10 patients had symptoms beyond 4 weeks (24) suggesting at one point up to 35,000 patients may have received care consistent with the guideline recommendations. However, the most recent study by the ONS exploring more prolonged symptoms of Long COVID in patients who had a positive diagnosis confirmed by PCR, suggest 1 in 40 people continue to have symptoms lasting beyond 12 weeks (21) – this suggests around 8500 patients across Wales currently have symptoms lasting beyond 12 weeks. The COVID Recovery App currently has around 10,000 downloads with equal spread between north and south Wales, i.e., Health Board reports demonstrate that around 90% of Health Board GP practices have at least one patient registered with the app.



Reviews from Healthcare Professionals and Contributors

"I felt it such a shame the app was not being recognised fully for its resources. I think the COVID app is fantastic"

Occupational Therapist

"Thank you so much for the video-it is brilliant. I am really impressed with how you have picked out key messages, I am actually feeling quite overwhelmed watching it."

Consultant in Sexual Health and HIV, Cardiff and Vale UHB
and Long COVID patient who filmed a patient case study
about the struggles of returning to work

"I have just watched the film and I am in tears. There is nothing I would ask you to modify, I think it is beautiful and captures the essence of my experience so well. I looked a mess, but it's interesting to see how well I am doing now compared to then. I don't even recognise myself from the film! Thankfully I am so much better than when I met you; I am walking regularly, have been hiking a number of times and even started jogging again. Still pacing carefully, but so much better. I am also looking to get back into work again, so hopefully I can get my life back soon. Thank you so much for treating my story with such sensitivity and skill"

Long COVID patient who filmed a patient case study about
their journey of recovery



Reviews from the Public

On the Apple Store & Google Play the app has an average rating of 3.5 stars. However, almost all the reviews are related to the release pre version 2.0 release, and most are from the day of release when users with a BT Email address were struggling to get verification emails, which was resolved shortly afterwards. The only reviews following the release of version 2.0 are due to the app being advertised for NHS Wales (bilingual with Welsh option) and not for those having English GP Surgeries listed.

"I have been using the app for over a week now and the content is helping me understand how long covid is impacting me and starting to help me"

Long COVID patient using the COVID Recovery app

"I like this app to keep track of my energy levels. I hope it will help me get fitter, I have been struggling with Long Covid for more than 6 months. I'm Dutch and it's actually strange that this app is only meant for people in Wales, while people everywhere could benefit. The app is easy to use, helps you track the intensity of activities and there are videos with extra information. Haven't found another app like this! Great you guys made this!"

Long COVID patient using the COVID Recovery app

"I struggled to create an account initially, but once I contacted the app people and they told me about the 'I do not belong to a surgery in Wales' option at the bottom of the list of surgeries, I've created my account and it has been great. Graphs and the like help me understand how I am doing and see progress-this is just what I needed. Thank you so much!"



Long COVID patient using the COVID Recovery app

"I think the App is an amazing idea as a long Covid sufferer myself"

Long COVID patient using the COVID Recovery app

"I eventually managed to download this and think it is a positive step towards managing recovery from Covid -solution focussed therapy. The app is good and sure it will be really useful. Thank you"

Long COVID patient using the COVID Recovery app

Independent Reviews

The COVID Recovery app has been recommended by ORCHA with a high rating score of 80%. Only 1 in 5 health apps are approved by ORCHA.

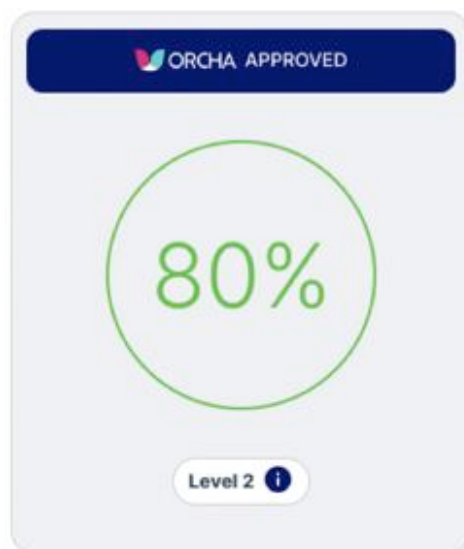


Figure 55: Independent ORCA rating for the COVID Recovery App, which puts the app in the top 20% of health apps based on data management, professional assurance, usability & accessibility

In early 2021, ORCHA rated the COVID Recovery app for both Apple and Android. ORCHA's mission is to increase the quality of mHealth apps, with 85% falling short of their quality threshold.

The COVID Recovery app was assessed as a Level 2 App. These apps are focused on general health. They may collect data and they may have several more advanced features. Where they collect data, we assess their data use policies and compliance with relevant standards. As they are health focused ORCHA also assess their compliance in the professional assurance as well as the usability and accessibility domains. ORCHA assesses the app based on what is publicly available. They do not do it in collaboration with app developers, so the review is entirely independent.

Domain	Apple rating	Android rating
Data management	80%	80%
Professional assurance	82%	82%
Usability & accessibility	73%	73%
Overall	80%	79%

Table 1: ORCHA scoring for each assessment domain

The overall ORCHA score is built up from the answers to each of the questions in the three review domains (table 1). Some questions earn positive points, and some earn negative points. The ORCHA Score aims to deliver a meritocratic evaluation with all Apps being treated equally and fairly, irrespective of their current popularity or the financial position of their developers.



Any score below 65% would indicate that an App has some issues that users should investigate further prior to using. Scores below 45% indicate that an App has considerable issues or challenges and in its current form is potentially unhelpful or unsafe.

How the app helps NHS Wales to understand Long COVID

Whilst the app has supported over 10,000 Long COVID sufferers across Wales, it has also served as a support tool for Health Boards and service providers. See Appendix B for examples of app executive reports issued to Health Boards across Wales.

The data used in the following section has been comprised from two sources:

- 1) The app database and implementation dashboard. This is actual data from all users of the app

- 2) An app survey: a 10 multiple-choice questions was sent via email to each group according to their self-reported recovery expectations. These were identified from the app database. The results were compiled and analysed according to each recovery expectancy group
 - a. 1-3 months
 - b. 3-6 months
 - c. 6-12 months
 - d. More than 12 months.



Two emails with a SurveyMonkey link were sent out to each of the four groups above in November, over a period of one week. There were approximately 5000 active users of the app at this time. The survey returned 488 responses, approximately 10% of active users of the app.

Care must be applied when interpreting the following data:

- Much of this information is derived from usage of the app, which is mostly self-reported by users
- Unless otherwise stated, the information is not generated from validated tools, where they may exist
- Aggregate data is generalised for the population
- There may be some bias in those that have responded to the survey when making broad statements. However, comparisons between Health Boards are probably more informative.

With these caveats in mind however, here is a list of 12 observations from users of the app.



OBSERVATION 1:

The population on the app is representative of Long COVID sufferers

The age distribution of the app users is consistent with other published reports, such as the ONS in October 2021 who identified that prevalence of self-reported Long COVID was greatest in people aged 35-69 years old (25). The pattern follows a typical Gaussian distribution peaking around the 45–54-year-old age group. Over half of all app users are between the ages of 35 and 55 years old (Figure 56).

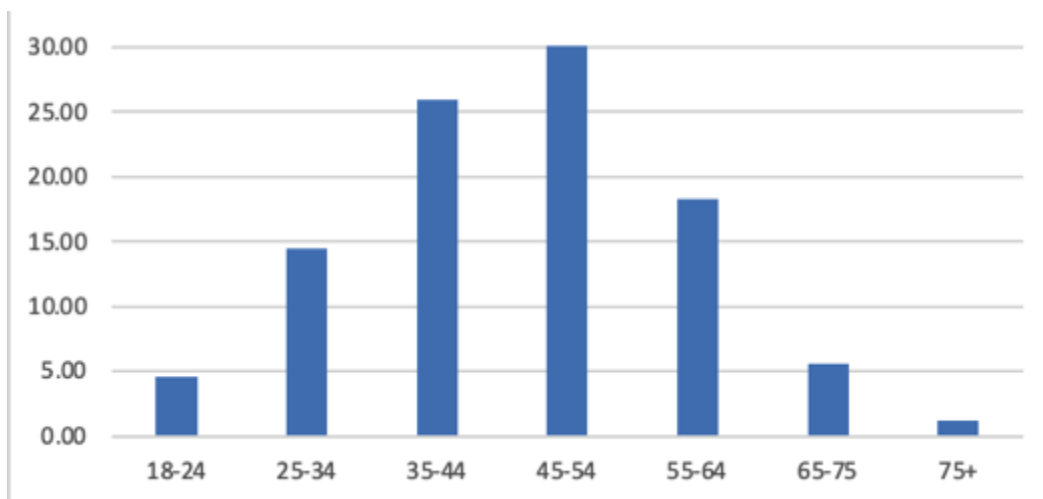


Figure 56: Age distribution, % of users in each age group selected during first registration

Less than 5% of app users are below 25 years old. Less than 2% of users are over the age of 75.

A survey sample of 488 app users generated further app information. Whilst the sex of the app user was not recorded during the registration process, the survey suggests that 71% are female & 29% are male (Figure 57).

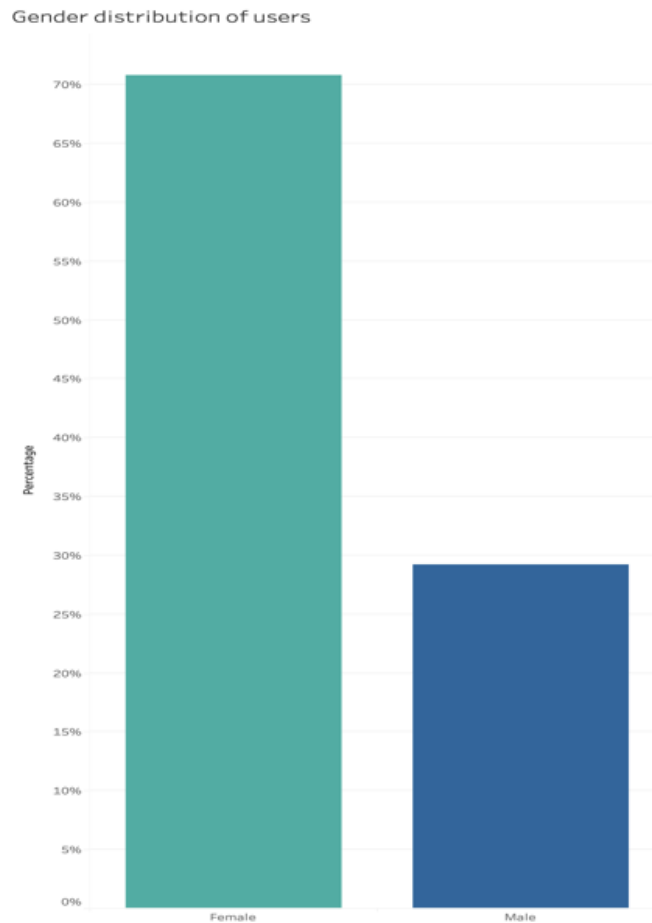


Figure 57: The gender and age distribution of long COVID patients, based off the survey responses of 500 users.

The ratio between male and females is similar across all groups based on recovery expectancy (1-3 months, 3-6 months, 6-12 months, more than 12 months). The distribution of age and sex presented by app users is consistent with published research (26).



Furthermore, the distribution of reported symptoms of all app registrants suggests fatigue, breathlessness and reduced fitness and muscle strength are the three most common symptoms. The full list of symptoms in frequency recorded in the app during registration is illustrated in Figure 58 below.

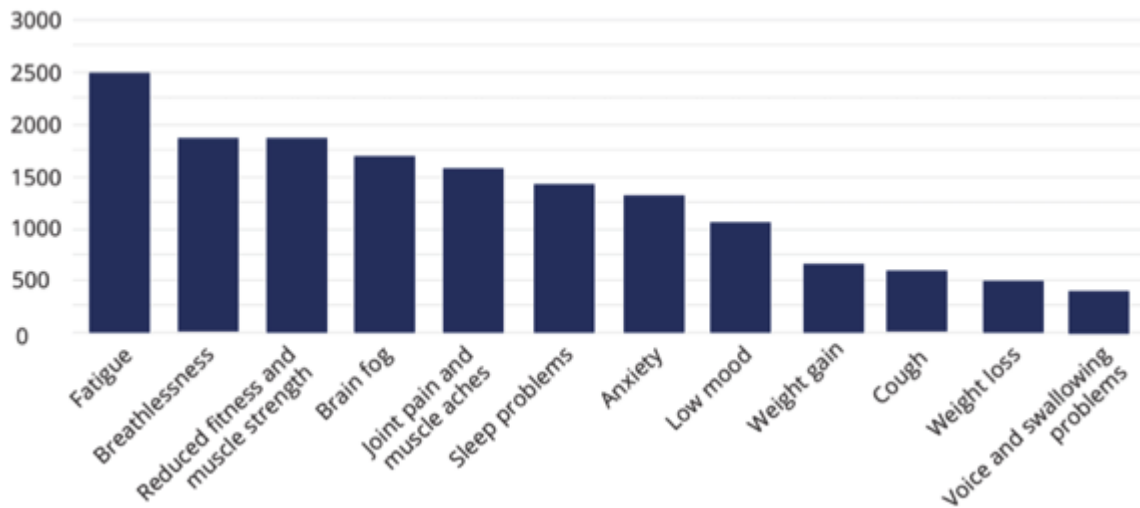


Figure 58: Frequency of symptoms based on those chosen from the common symptoms identified by experts across NHS Wales during the development phase of version 1.0 of the App.

However, a limitation to this observation is the inclusion of an ‘optional field’ following the release of version 2.0 of the App in April 2021 where users of the app could add other symptoms not listed.

Symptom	Number of users assigned
Fatigue	2902
Breathlessness	2192
Reduced fitness and muscle strength	2147
Brain fog	2020
Joint pain and muscle aches	1813
Sleep problems	1600
Anxiety	1527
Low mood	1370
Cough	937
Weight gain	886
Weight loss	537
Voice and swallowing problems	528

Table 2: Number of users assigned to each symptom listed (based on the functionality of version 1.0 of the app).

The additional symptom feature was added to version 2.0 of the app as new symptoms emerged and following multiple requests for this function.

Further reported symptoms are:

- Headaches
- Loss of smell/taste
- Dizziness
- Palpitations
- Tinnitus



The frequency of app symptoms from app users is consistent with published research (27,28). This suggests app users are representative of the general population of Long COVID sufferers across the UK.



OBSERVATION 2:

App users are represented proportionally across Wales

Relative to the population, north Wales has a similar proportion of patients assigned to the app compared to the south of Wales (Figure 59). This is the impact of a nationally coordinated implementation strategy.

Furthermore, Betsi Cadwaladr UHB was the first Health Board to request app data reports. See an example of an executive summary of the app data for Health Boards in the appendices. Further information that has been provided to Health Boards is the number of patients per GP. This has subsequently helped them identify areas where there is greatest need, and the magnitude of the demand.

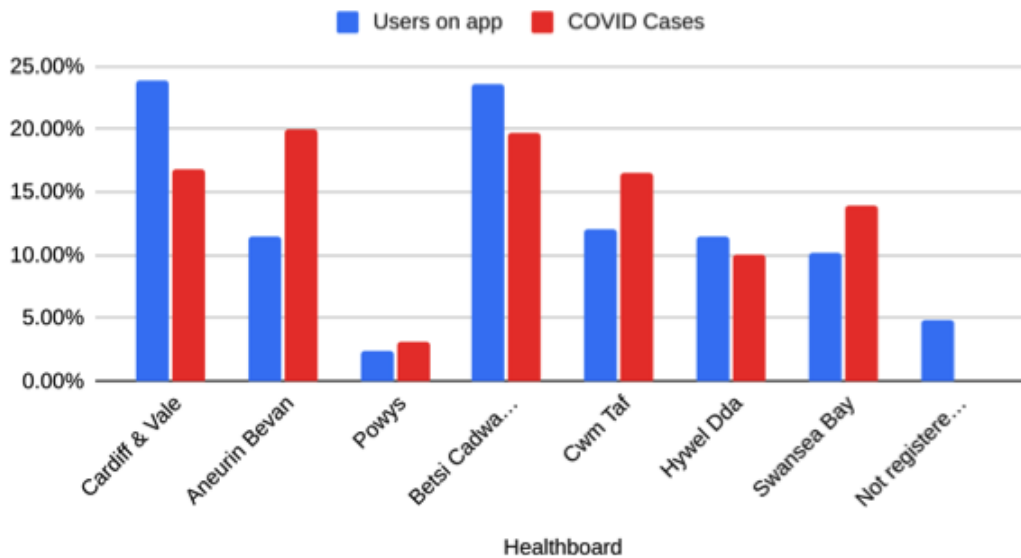


Figure 59: Proportion (%) of users on the app from each Health Board against the proportion of COVID cases in the region based off publicly available data.



The Health Boards with the greatest ratio of users to cases are Cardiff and Vale UHB, with 23.9% of app users and 16.78% of all COVID cases across Wales, Betsi Cadwaladr UHB (23.56% and 19.74%) and Hywel Dda UHB (11.56% and 9.98%).

The Health Board with least downloads relative to number of cases is Aneurin Bevan UHB (only 11.5% of all downloads despite 19.9% of cases).



OBSERVATION 3:

Nearly all GP practices in Wales have someone registered with the app

When registering with the app GP practice selection is a mandatory field. 92% of all GP practices in Wales, including branch surgeries, have at least one user registered with the app. The mean average based on downloads currently is 25 users on average per GP practice.

Knowing which GP practice the user is assigned to helps the implementation team identify areas where there is least reach or penetration. The executive lead and facilitators can be notified. Additional implementation activities, events, links to resources and education, as well as further distribution of flyers and posters have demonstrated good outcomes.



Figure 60: The darker and larger the dot representing a GP practice, the greater the number of people registered at that surgery that have downloaded the app

OBSERVATION 4:

Most support queries about the app are from people outside of Wales

Overall, there have been 410 support queries to the app support team. Nearly all issues relate to difficulties for people outside of Wales accessing the app. This is because the GP practice is not listed in the registration page for people outside of Wales. The average time to first reply to app queries is 2.5 hours. 71% of emails were resolved within one email.

Complaint	Resolution
BT emails not receiving verification link	We changed the email server & added a help button onto the sign-up page. This is now no longer an issue, and we individually contacted every person who was affected (71 users in total).
Date of birth selection confusion for android	Due to some Android phones default calendar, some users think they must scroll back through many months to find their date of birth. This is not the case, and we are able to provide them with instructions. The addition of a 'need help' button on the sign-up page allows users to get in touch for instructions.
Their symptom is not listed	The addition of a free text box for users to add their own symptoms. The involvement of the Long COVID support group increased the number of pre-populated symptoms added to the app. Additional supplemental video education was also added to each symptom.
English patients wanting	a GP surgery option for users not registered at a GP in

to use the app	Wales. Post release of version 2.0 this is the most common query.
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Table 3: Four of the most common complaints/issues and how the ICST support team resolved these

Whilst people outside of Wales cannot choose their GP practice, an 'I live outside of Wales' selection was added to broaden the use to other countries. For the purpose of this report, however, these users have been excluded from the analysis.

OBSERVATION 5:

Most app users have seen a healthcare professional about their condition

Most survey responders (65%) reported that they have visited their healthcare professional about their Long COVID symptoms. People in the eldest age group were least likely to have visited a healthcare professional for their long COVID symptoms (Figure 61).

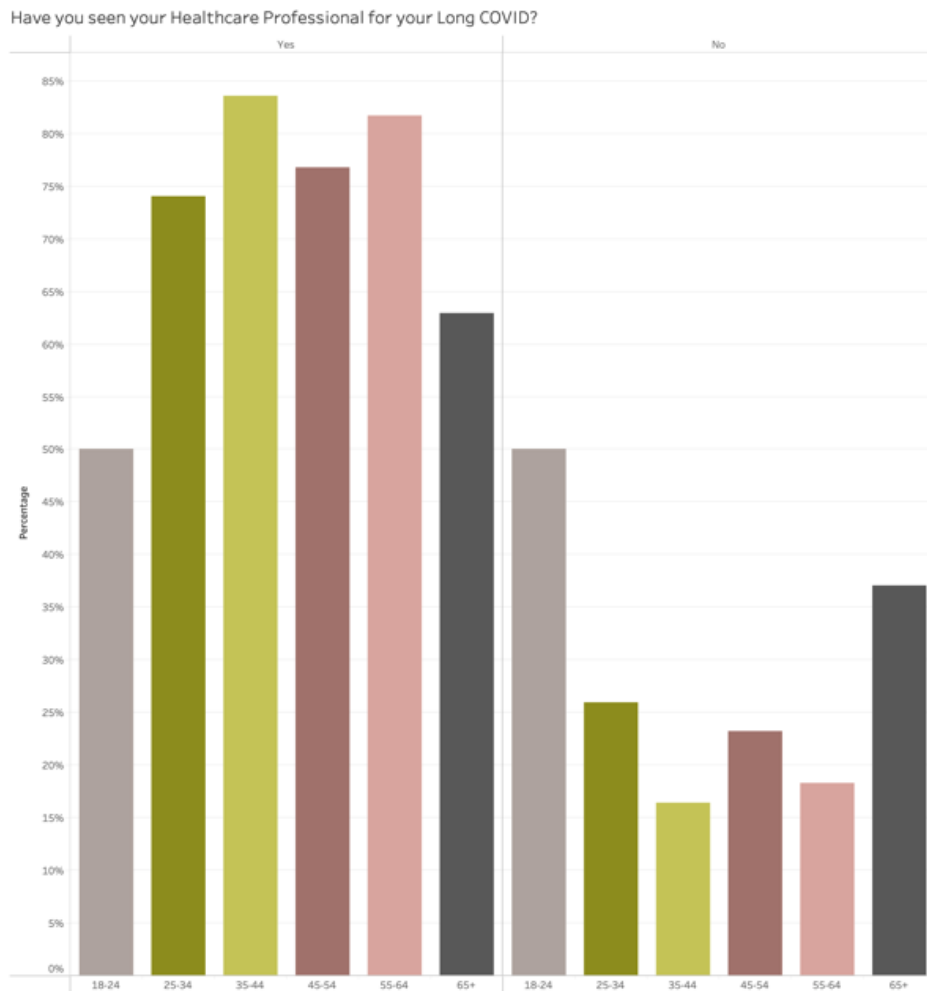


Figure 61: Survey responses whether they had visited their healthcare professional by age group.



Those with higher recovery expectancy were also more likely to say that they had seen their healthcare professional many times.

17% had seen a healthcare professional 20+ times.

42% had seen their healthcare professional more than 10 times.

People under the age of 34 reported positive benefits from the support offered by their healthcare professional.

People in the 35-44-age category found the support least beneficial (Figure 62).

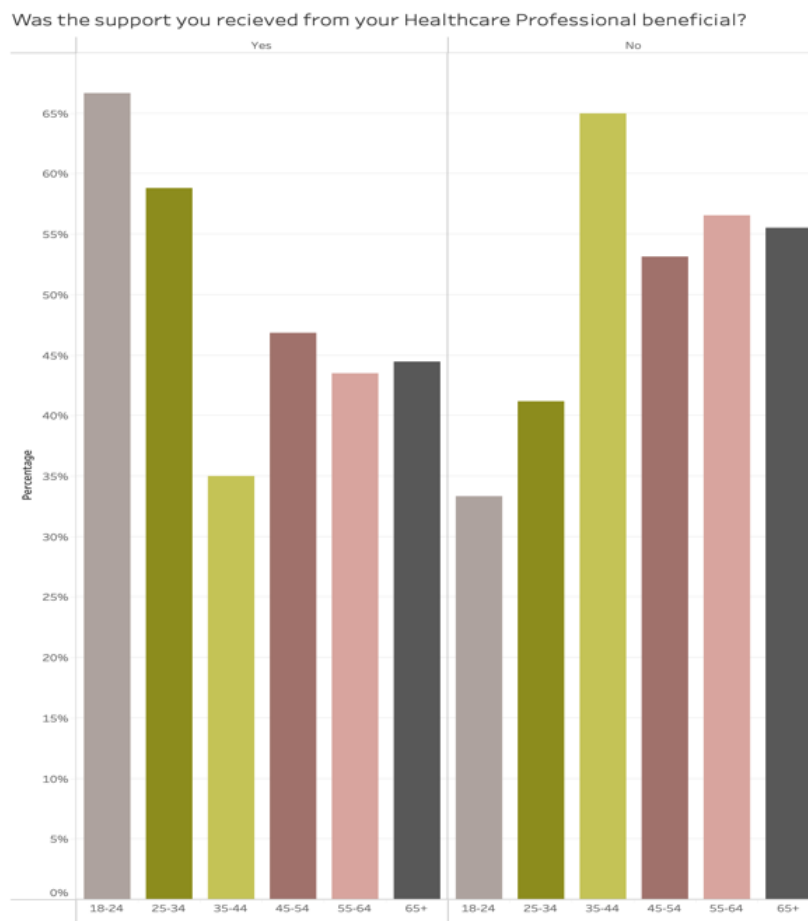


Figure 62: Survey responses whether they had benefited from visiting their healthcare professional by age group.



The more severe the symptoms, the more likely users are to have found seeing their healthcare professionals beneficial (Figure 63). Conversely, those with mild symptoms were least likely to have found seeing their healthcare professionals beneficial.

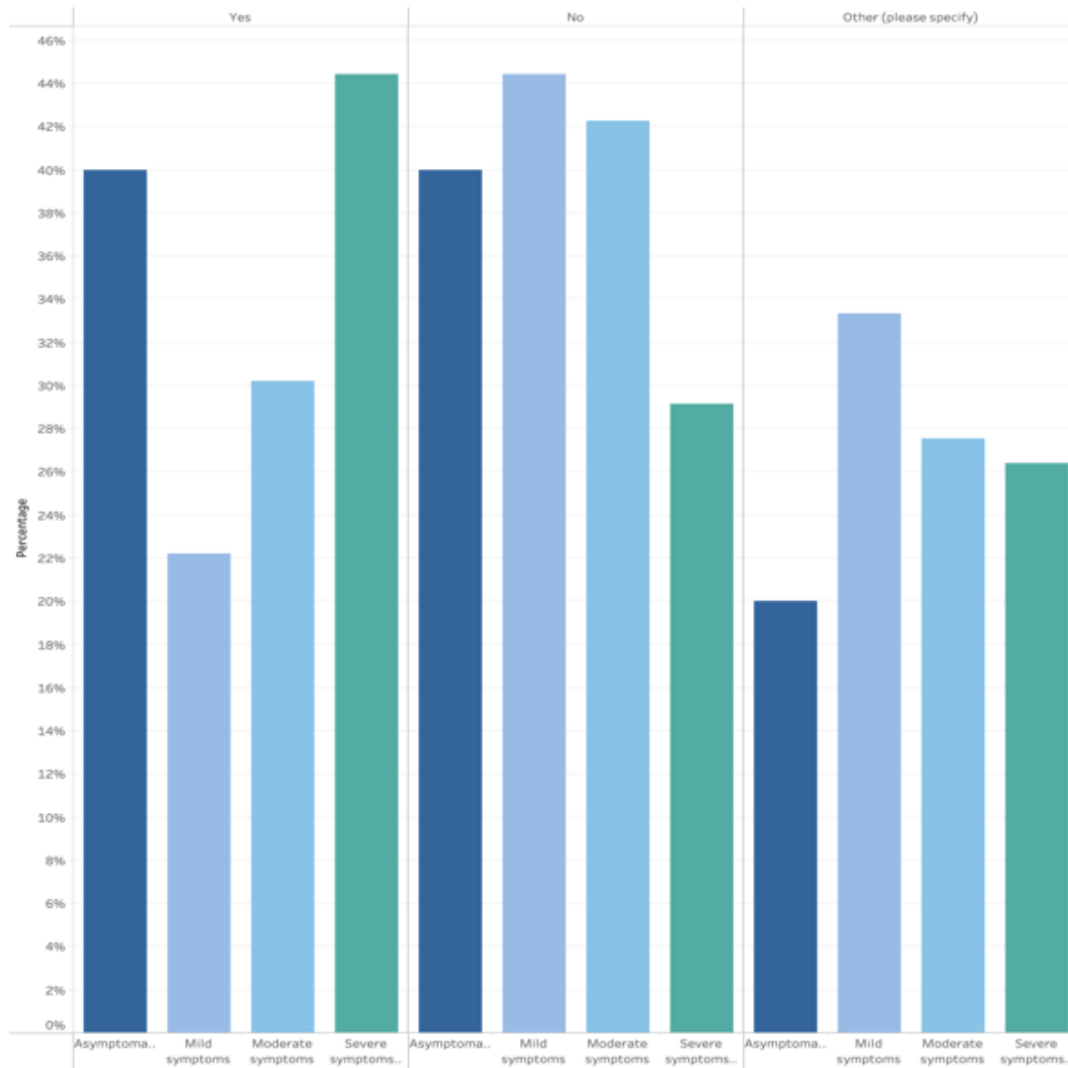


Figure 63: Survey responses whether they benefited from visiting their healthcare professional by symptom severity.

Of those who had seen their doctor, those in the 1-3- and 3-6-month category were more likely to say their support was beneficial. People in the other two



categories were more likely to say their support was not beneficial and gave lots of other answers such as *'was originally, but is no longer helpful'*, *'variable'* or *'somewhat helpful'*.

People in the 6–12-month category had the largest number of people who were dissatisfied with their care and had the greatest disparity between the *'yes beneficial'* and *'no not beneficial'* answers.



OBSERVATION 6:

Most users of the app expect to get better quickly

When signing up to the app, most users (48%) say they expect to recover from long COVID in 1-3 months. A further 26% expect to be better within 6 months (Figure 64).

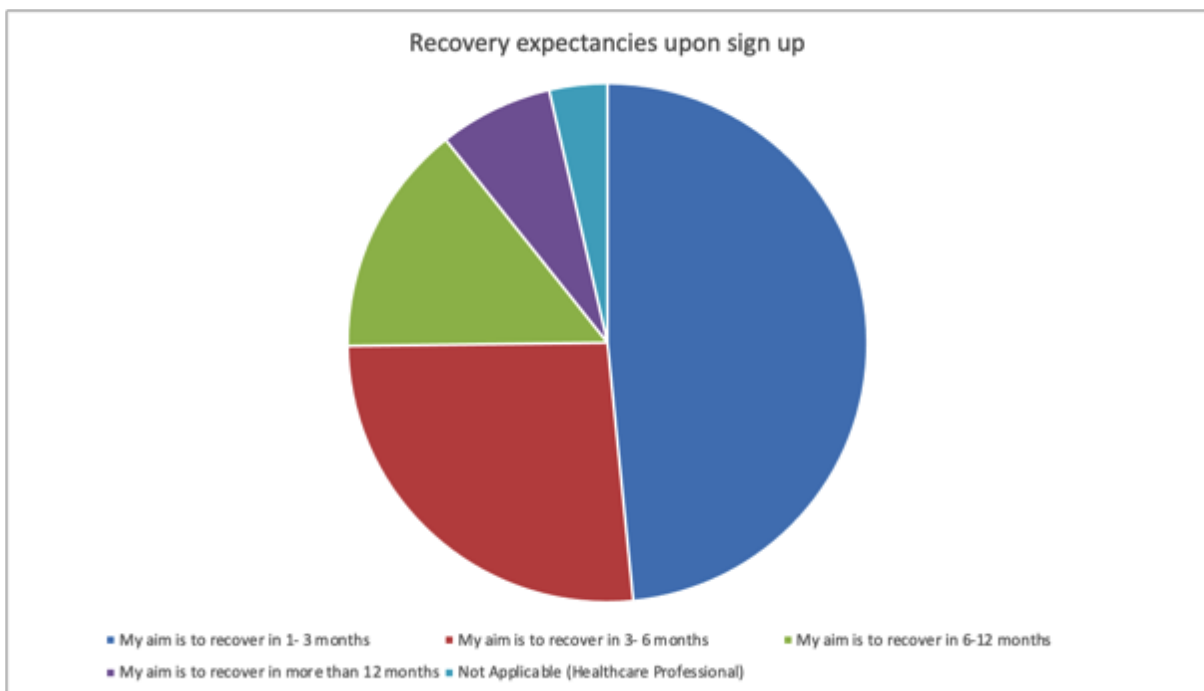


Figure 64: Recovery expectancy reported by users when first registering with the app (mandatory field).

Question: Based on the severity of your symptoms as they are now, when do you expect to recover from Long COVID?	Percentage of total users
My aim is to recover in 1- 3 months	48.41
My aim is to recover in 3- 6 months	26.38
My aim is to recover in 6-12 months	14.50
My aim is to recover in more than 12 months	7.09
Not Applicable (Healthcare Professional)	3.61

Table 4: Percentage of all app users and their recovery expectancy; a mandatory selection during registration

Whilst 14.5% expect to take up to 12-months, and 7% of app users expect to take longer than 12 months to recover.

Another way of interpreting this information is that three quarters of app users expect to recover within six months, and 90% within a year. However, just fewer than 10% of app users expect to take longer than a year to recover.

OBSERVATION 7:

People who expect to recover quickly are least likely to see a healthcare professional

In total, 65% of app survey respondents said they had visited a healthcare professional for their Long COVID. Those who expected to take 1-3 months to recover were least likely to have seen a healthcare professional (Figure 65).

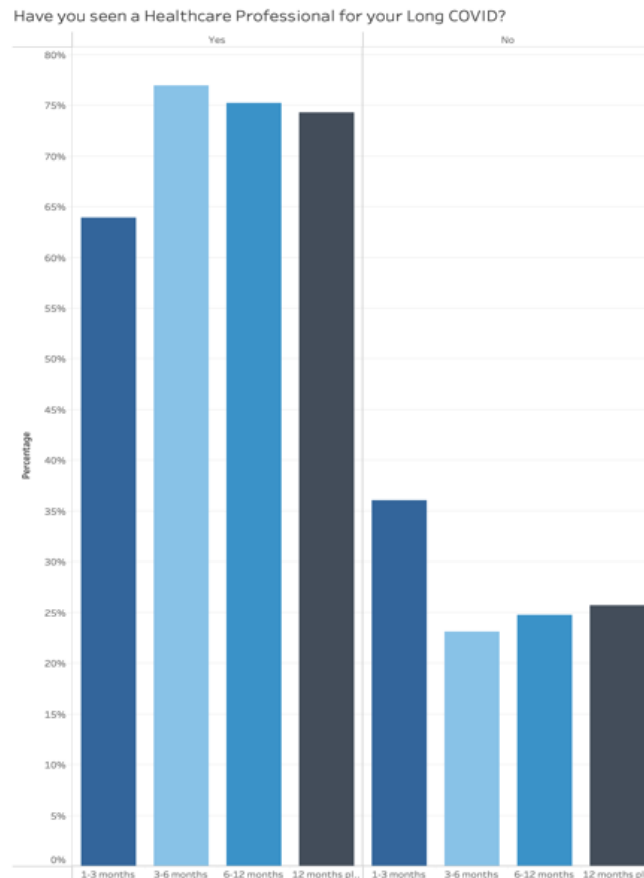


Figure 65: Likelihood patient seen a healthcare professional by self-reported recovery expectancy period



The likelihood patients have visited their healthcare professional about their long COVID symptoms is similar between those expecting to recover in 3-6 months, 6-12 months and over 12 months.

'Other' responses included people wanting to see a healthcare professional, but no appointments were available, or they were still waiting to have an appointment.



OBSERVATION 8:

The longer a user expects to recover, the more times they are likely to see their healthcare professional

Based on the survey response, people who expect to take longer than 12-months to recover were most likely to see their healthcare professional more than 10 and more than 20 times compared to all other groups (Figure 66).

Furthermore, people who expect to take longer than 12-months to recover were least likely to see their healthcare professional less than 10 times.



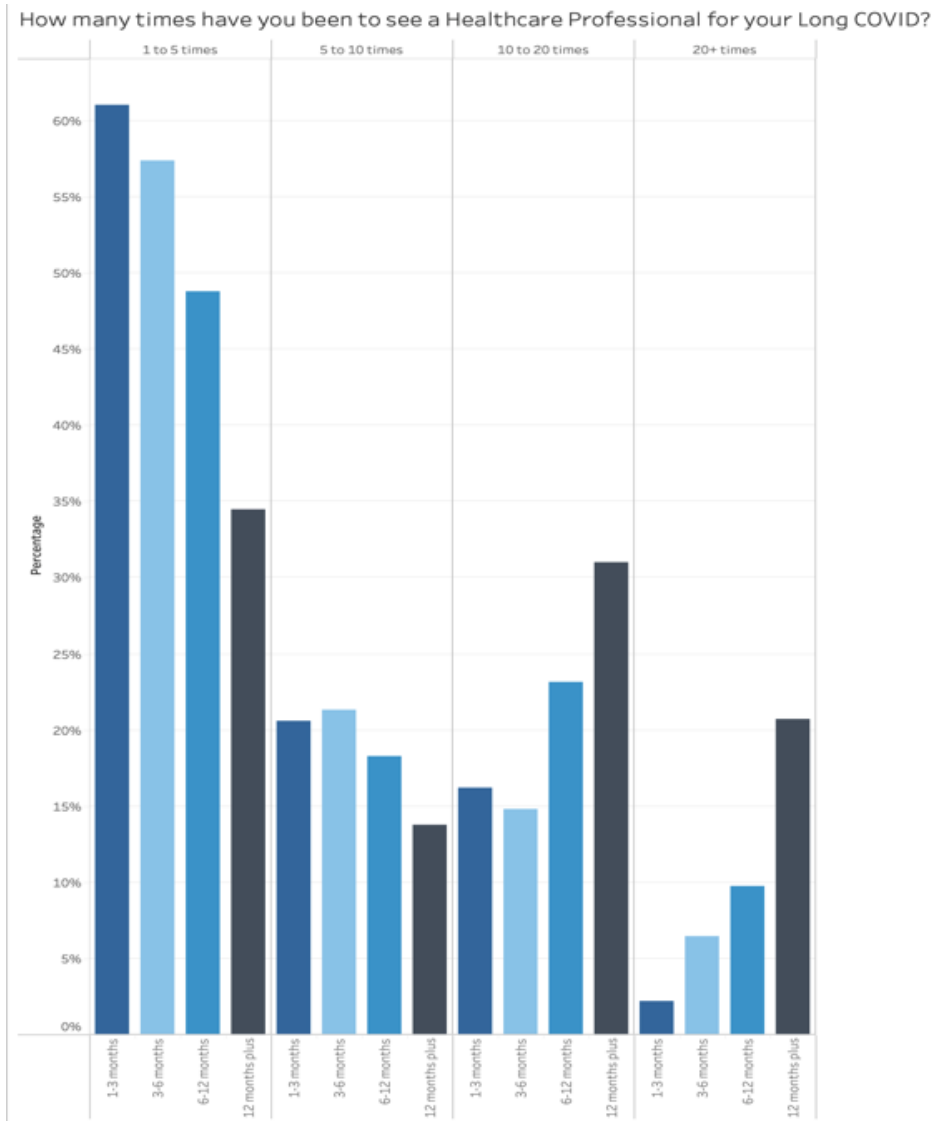


Figure 66: Number of times users of the app have seen a healthcare professional by self-reported recovery expectancy period

Not only are people who expect to recover within 1-3 months least likely to see their healthcare professional, when they do, they see them less frequently, compared to the other groups.



OBSERVATION 9:

People who expected to recover longer than 12 months have still not recovered

Based on the survey responses, 100% of people who originally said their recovery would take longer than 12 months have still not recovered (Figure 67).

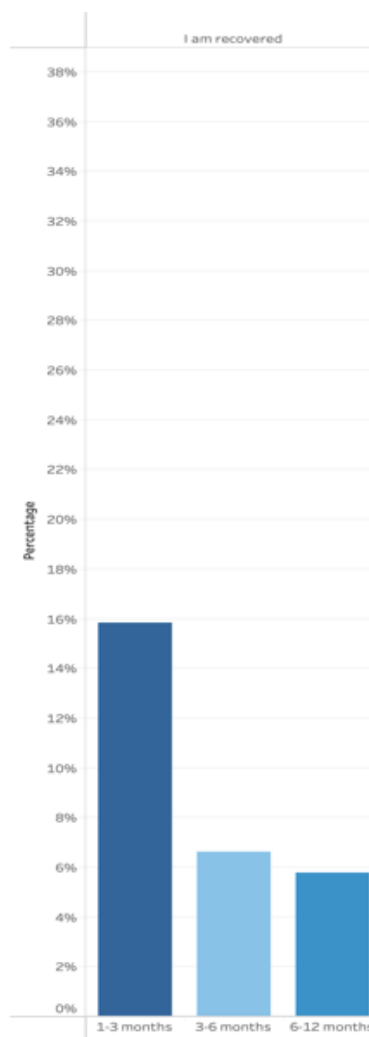


Figure 67: Based on the survey responses, the proportion of patients that have recovered from Long COVID.

Those who expected to recover quickly were more likely to still think this is the case when followed up in the user survey (Figure 68).

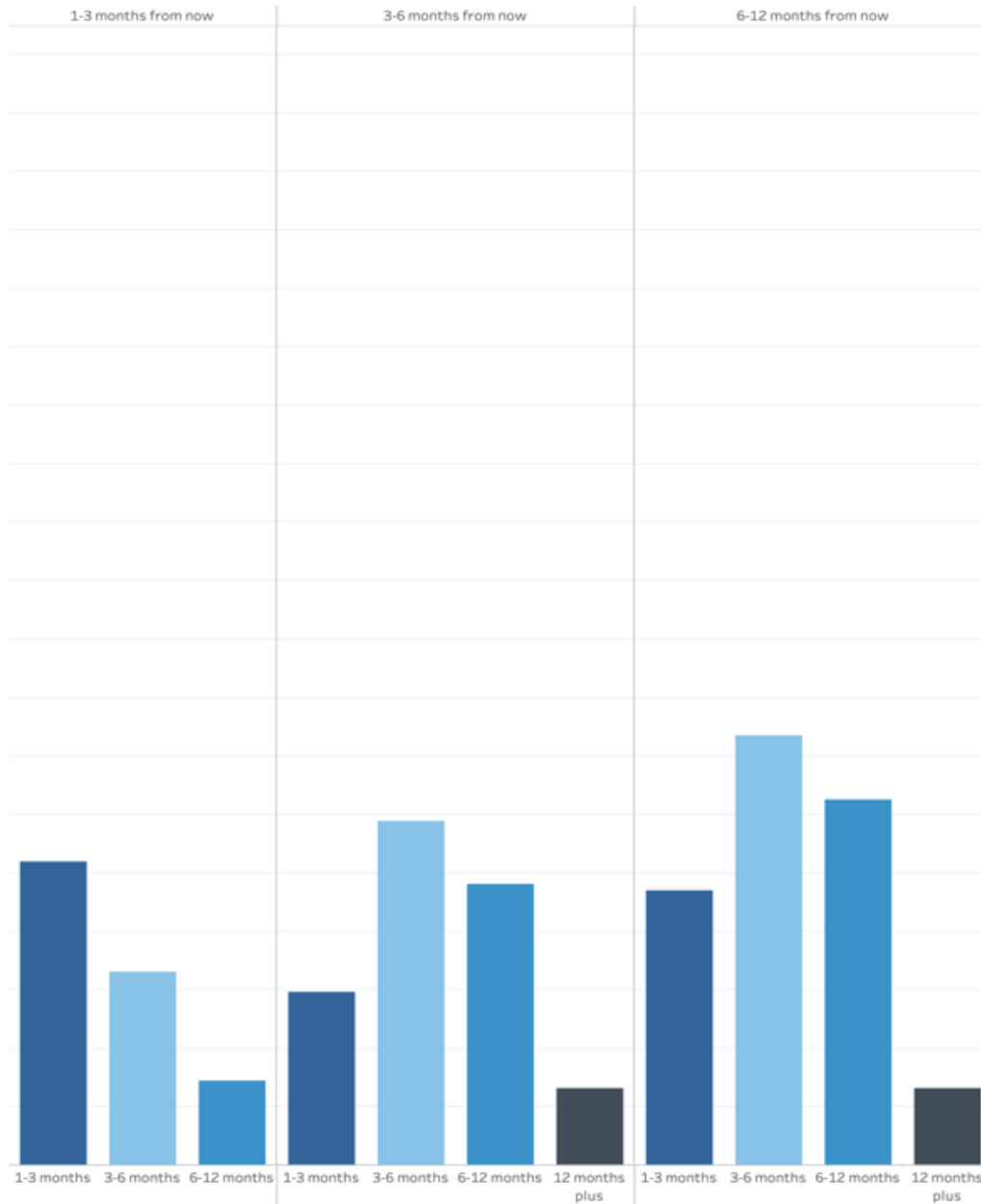


Figure 68: Recovery expectancy from now comparing the four groups from the original recovery expectancy when first registering with the app (1-3 months, 3-6 months, 6-12 months, over 12 months)



People in the 1–3-month category are much more likely to have already recovered from Long COVID (15%, compared to 0% for 12 months plus). Furthermore, people who expected to take longer than 12 months to recover are more likely than any other to say that they'll never recover from Long COVID (Figure 69 below).

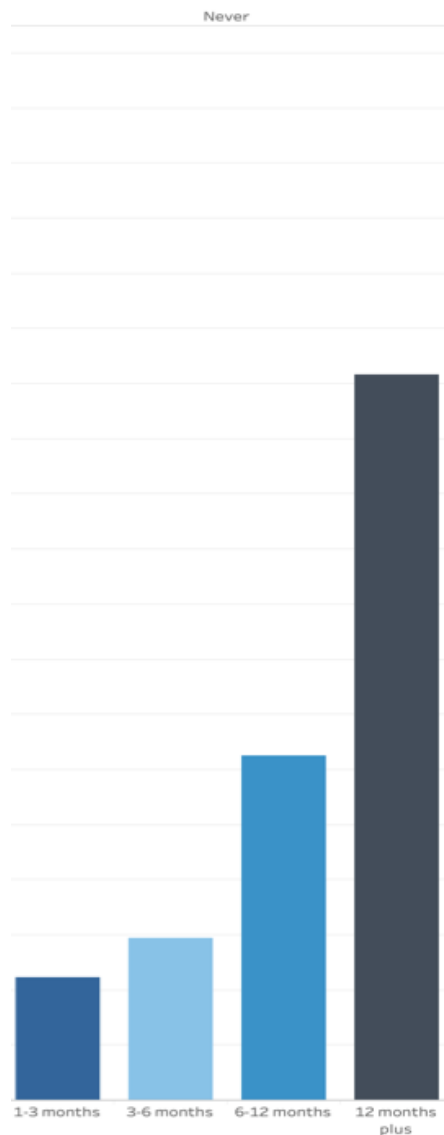


Figure 69: The proportion of patients from each group (that reported recovery expectancy 1-3 months, 3-6 months, 6-12 months, over 12 months) that now expect to never recover from long COVID

OBSERVATION 10:

App users record different activities to support their recovery

Users to the app have added over 1000 unique activities. It appears that users are adding activities regularly, some using it every day. The most common include walking, running, cycling, shopping, cooking and yoga.

When using MET categories to estimate the intensity of activities undertaken (29) the top 50 most reported activities account for the following:

Intensity group	MET units	Example	Number of times
Sedentary	1.0-1.5	Watching TV	7
Light intensity	1.5-3.0	Housework	28
Moderate intensity	3.0-6.0	Walking at pace	10
Vigorous	6.0+	Running	5

Table 5: Top 50 most reported activities according to intensity. Of the most common 50, over half of these logged in the app are light intensity.



OBSERVATION 11:

The age distribution of new app users is relatively consistent

Figure 69 shows some monthly fluctuations across age groups. Whilst the linear trend data is relatively steady across all age groups (Figure 70). The age group with most users is the 45-54-age category. However, between January 2021 and November 2021 there has been a slight decrease in the proportion of new users in this age category.

The 35-44-age group, however, shows a slight increase, and the 55-64-age category slightly downwards.

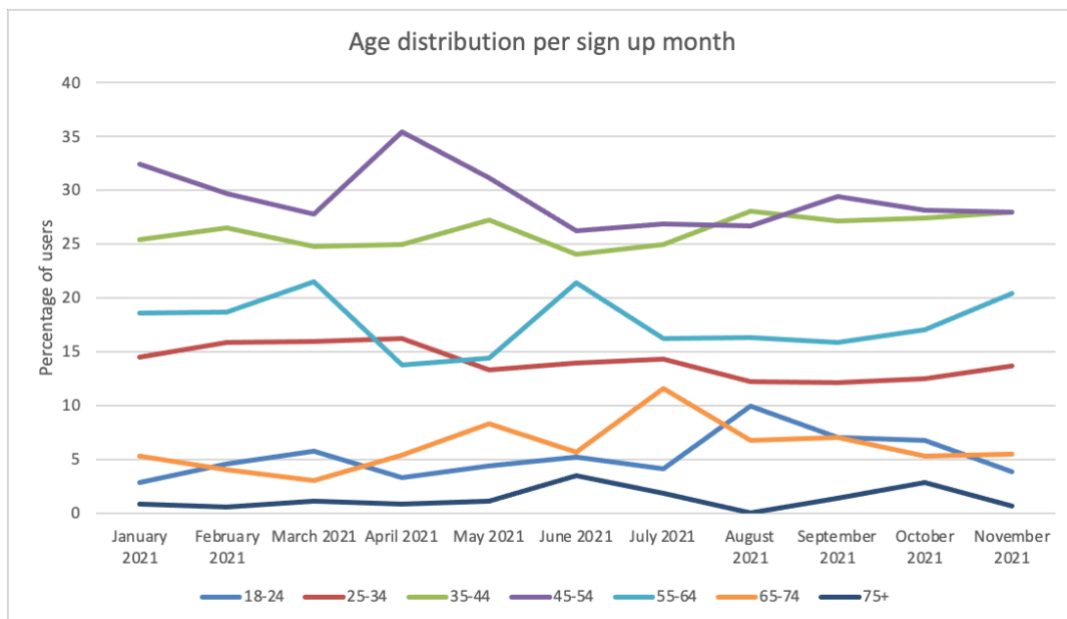


Figure 70: Age distribution of new registrants per age bracket per month; actual

The greatest upward trend is in the 65-74-age group (Figure 71), but the 75+ age category has remained stable.

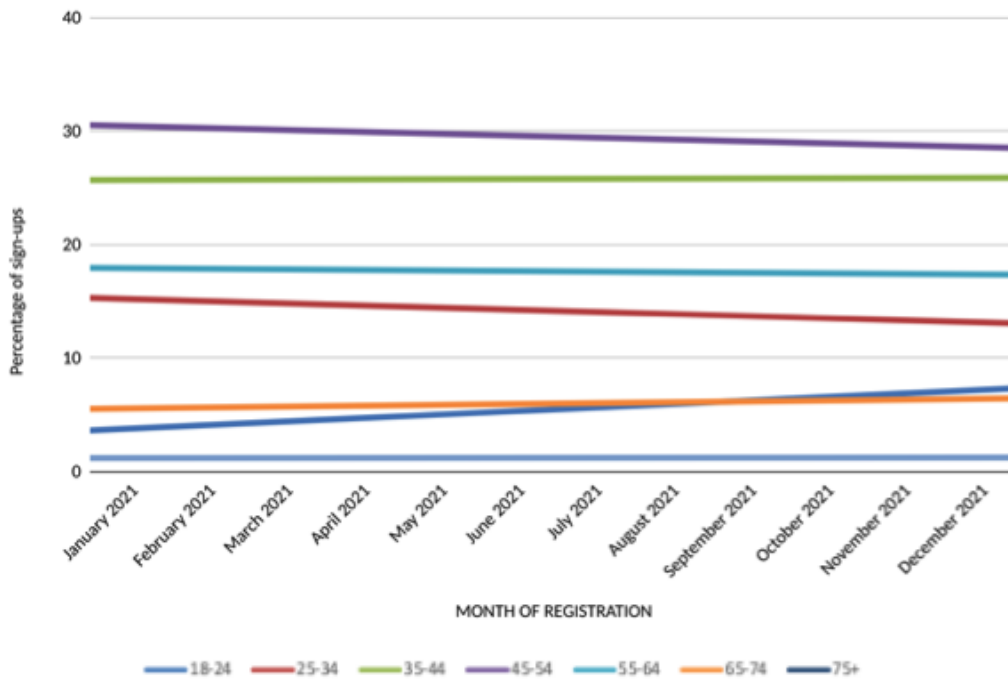


Figure 71: Age distributions of new registrants per age bracket per month; trend

For the younger age groups, the proportion of downloads for the 18-24-age group has increased the most over time, although, there has been a steady decline in registrants in the 25-34-age category.

OBSERVATION 12:

Breathlessness is the topic with the most videos watched

The top 10 most watched videos in the app and ticked as watched by the user within the app follow a similar pattern to the frequency of the most frequent symptoms (Table 6).

Order of frequency watched	Video title	Frequency of symptom recorded (see figure x)
1	Introducing fatigue	1
2	Introducing breathlessness	2
3	A better understanding of breathlessness	2
4	Introducing brain fog	4
5	A better understanding of fatigue	1
6	Introducing reduced fitness and muscle strength	3
7	Setting goals for your breathlessness	2
8	Setting goals for your fatigue	1
9	Introducing anxiety	5
10	A better understanding of reduced fitness and muscle strength	3

Table 6: Top ten most watched app videos when using the app.

Videos relating to breathlessness and fatigue account for 60% of the ten most frequently watched videos.



OBSERVATION 13:

Most app users had moderate-severe symptoms when they were acutely unwell with COVID

Based on the survey responses, most users of the app reported having moderate symptoms (64%) when they were initially infected by COVID-19. 17% of survey respondents were severely unwell when they had COVID (Table 7).

Scale used to score severity of original COVID symptoms when acutely unwell:

Severity of symptoms	Definition
Asymptomatic	No COVID symptoms
Mild	Similar to a cold, symptoms present higher up in the airways but no major breathlessness or fevers
Moderate	Symptoms present lower down the airways, with a more persistent cough and a fever
Severe	Hospitalisation

Table 7: Severity scoring within the app. Adapted from (30)

Initial COVID Symptom Severity of app users

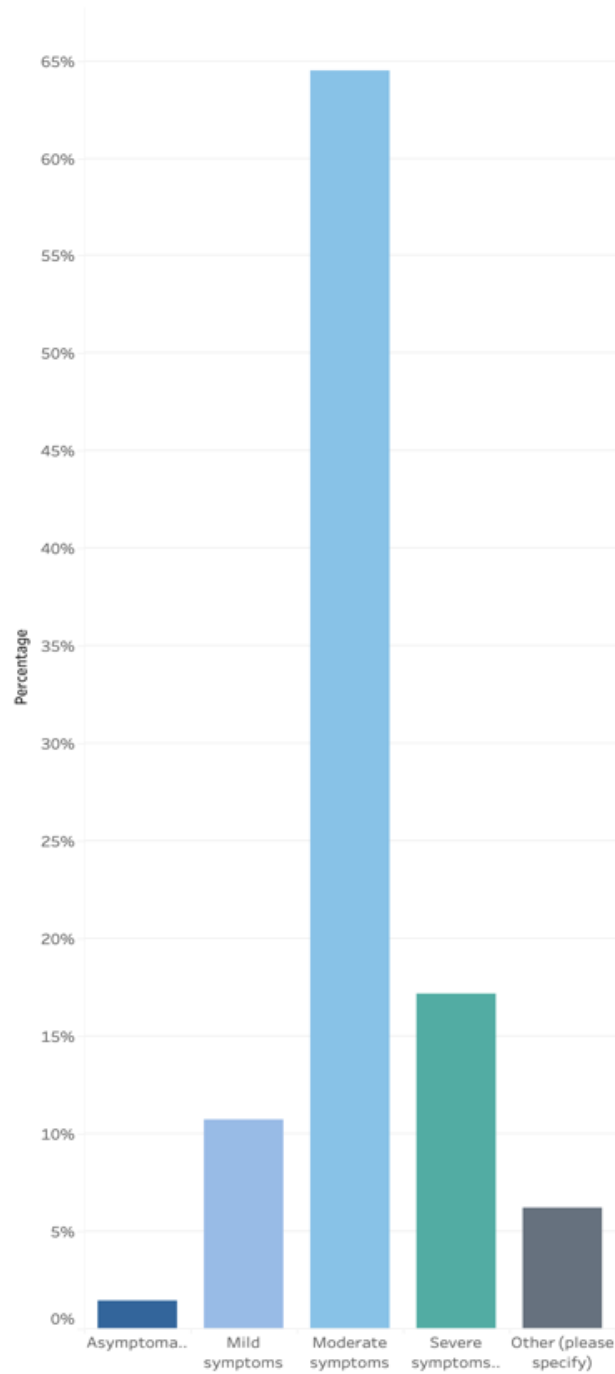


Figure 72: Reported severity of symptoms when first using the app

Whilst 11% had mild symptoms when acutely unwell, and a further 2% had no symptoms at all.



Severe symptoms during acute COVID infection were more common in people who expect to take over 12-months to recover (Figure 73).

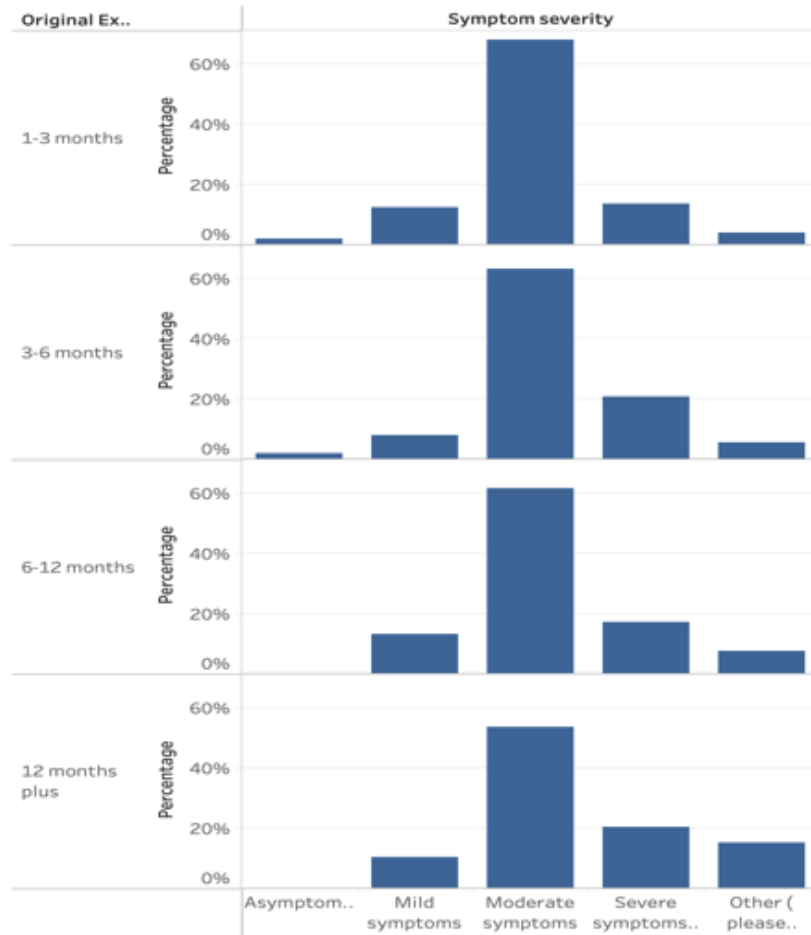


Figure 73: COVID symptom severity of patients for all recover-expectancy categories

‘Other’ responses included those who said they had severe COVID but were not admitted to hospital, or those who felt their symptoms could not be classified into any of these categories.

Whilst most people who answered the survey had COVID more than six months ago, a pattern is emerging that those who more recently developed COVID had a shorter recovery expectancy when they signed up to the app. 83% of those

who put an expectancy of more than 12 months when signing up to the app developed COVID more than 12 months ago, compared to just 35% of those with an expectancy of 1-3 months.

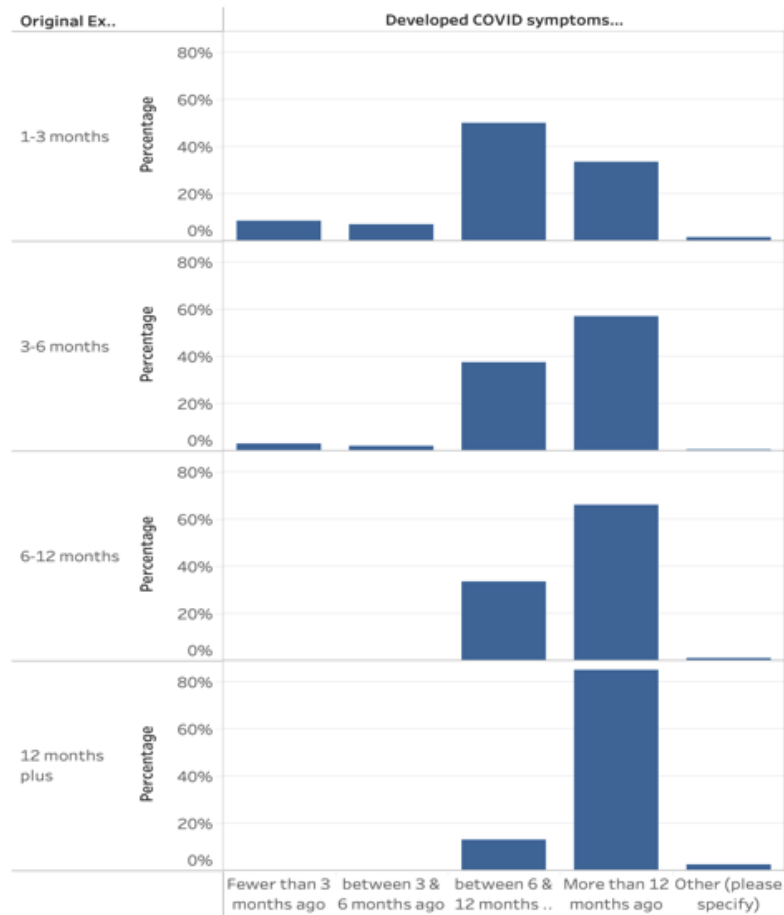


Figure 74: COVID symptom history of patients in all categories

Furthermore, those who developed COVID 6-12 months ago are much more likely to give a shorter recovery expectancy (50% in the 1–3-month category), compared to 10% for 12 months plus. Perhaps this is because those who developed COVID more than 12 months ago downloaded the app further into their recovery journey, as the app was not available until January 2021, and were therefore more likely to have a negative outlook regarding their recovery.

OBSERVATION 14:

Men had more severe acute symptoms, but are less likely to see their healthcare professional for Long COVID

Based on the survey responses, men are more likely to have had a more severe initial COVID infection. 28% of males report having severe symptoms, compared to 15% of females (Figure 75).

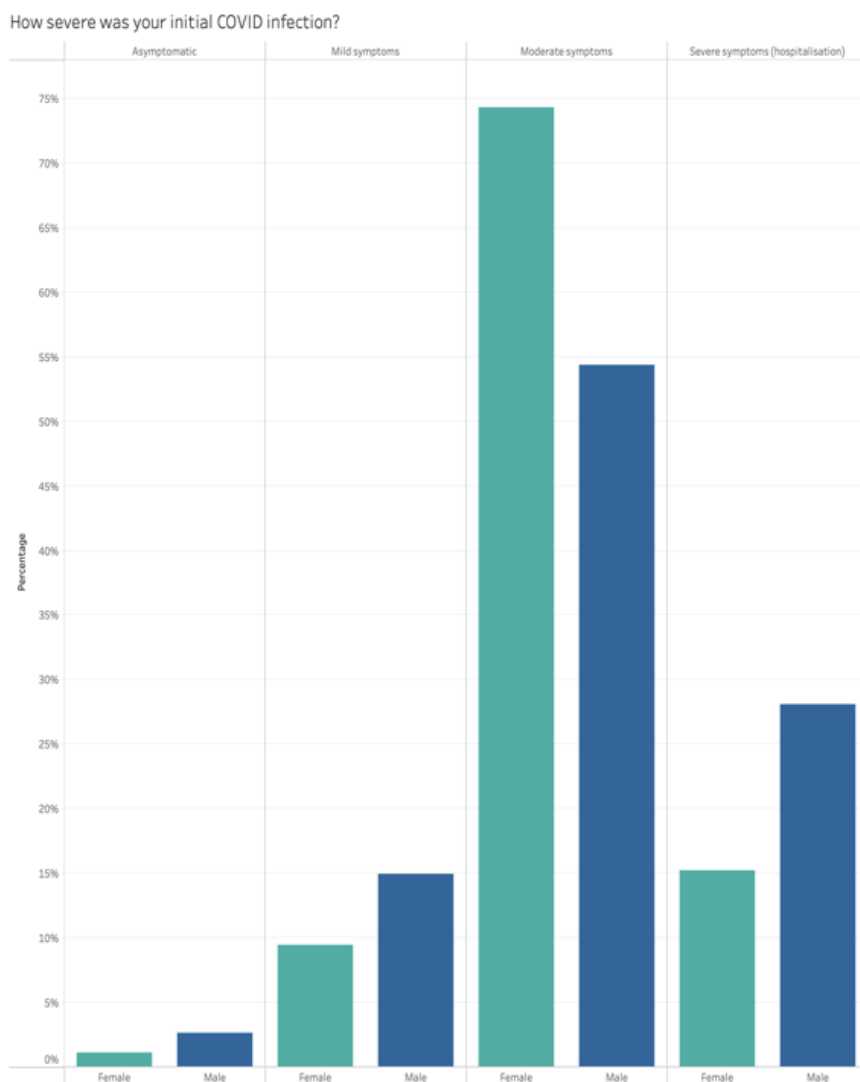


Figure 75: Severity of initial COVID symptoms – self reported survey response



Males are also slightly more likely to have mild symptoms. Females are most likely to describe their initial symptoms as 'moderate'.

However, according to the survey responses, females are 10% more likely to have seen their Healthcare Professional for their Long COVID symptoms (Figure 76)

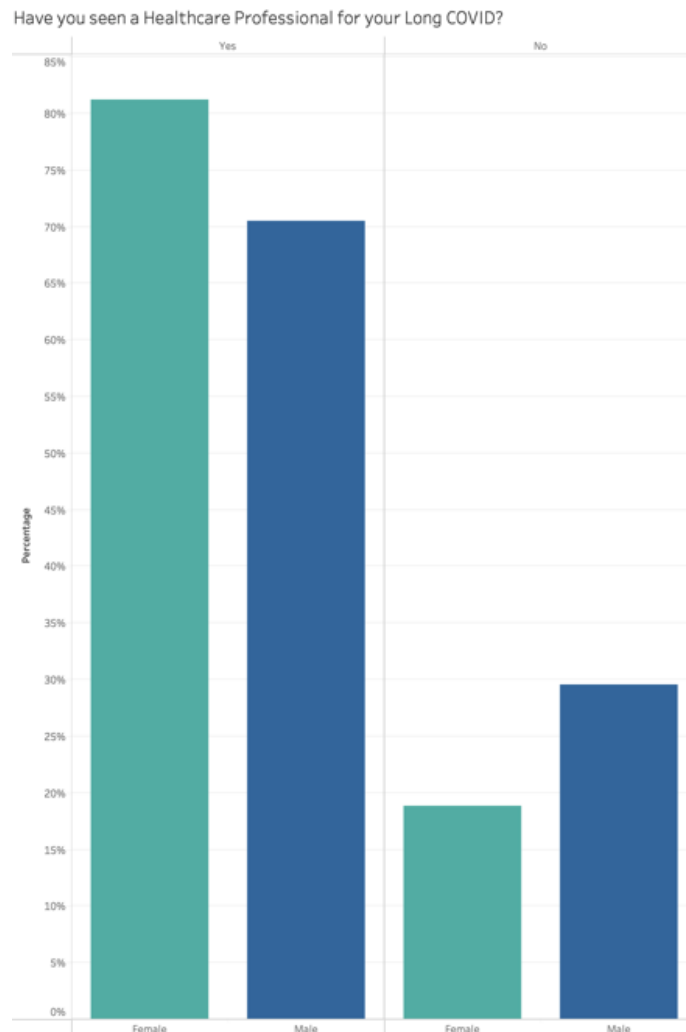


Figure 76: Proportion of males and females that have seen their healthcare professional about their long COVID symptoms. Note, the graph excludes the 'Other' response. These, for example were that they were awaiting an appointment to see their GP, or that they had a brief consultation, but they didn't feel like it counted.



Females are also slightly more likely to have found the support they did get beneficial (Figure 77).

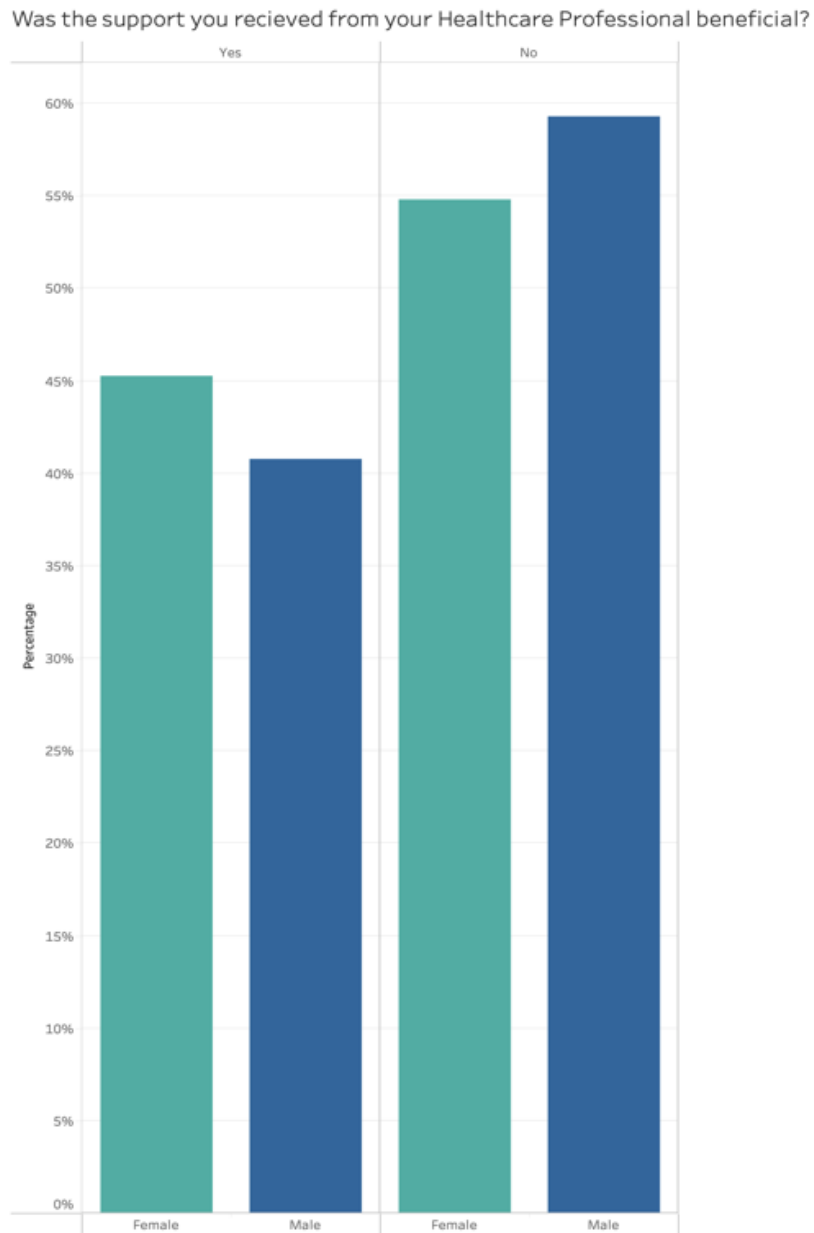


Figure 77: Was the support beneficial from consultation with healthcare professional by sex. 'Other' responses are excluded in the graph. These were where the support they received was variable in its benefit, some said they found one type of appointment but another not, for example.



Furthermore, men expect a longer time frame to recover (Figure 78).

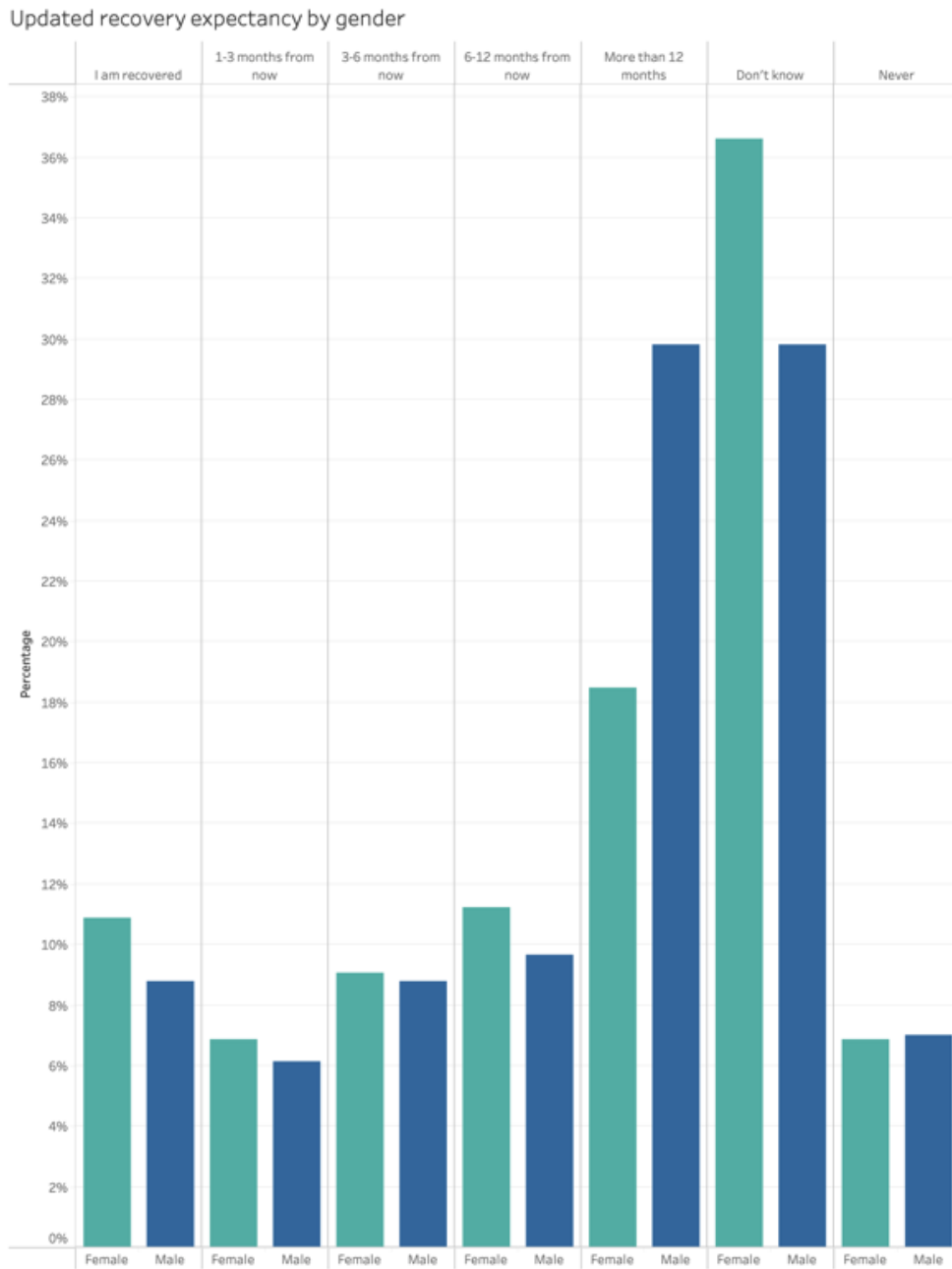


Figure 78: updated recovery status by gender – responses to the survey.

Females on the other hand were more likely to say they do not know when they are going to recover, and slightly more likely to say they should recover within 12-months.



OBSERVATION 15:

There are differences in recovery outlook between Health Boards

Based off the survey responses, people in Swansea Bay UHB were most likely to see a healthcare professional (76%), compared to other Health Boards on average (70%). Patients in Hywel Dda UHB were least likely to see a healthcare professional (66%) (Figure 79).

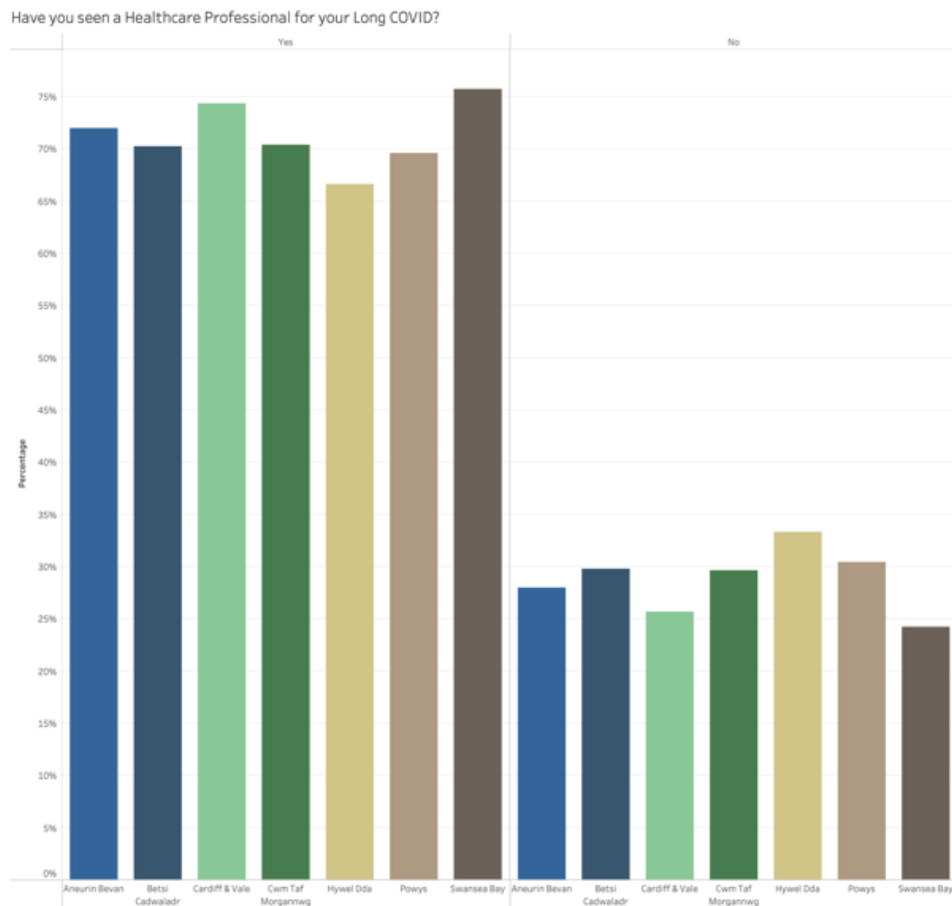


Figure 79: Survey response whether patients have seen a healthcare professional or not for each of the seven Health Boards



According to the survey responses, people in Powys THB were most likely to say they have visited their healthcare professional more than 20 times for their long COVID (Figure 80).

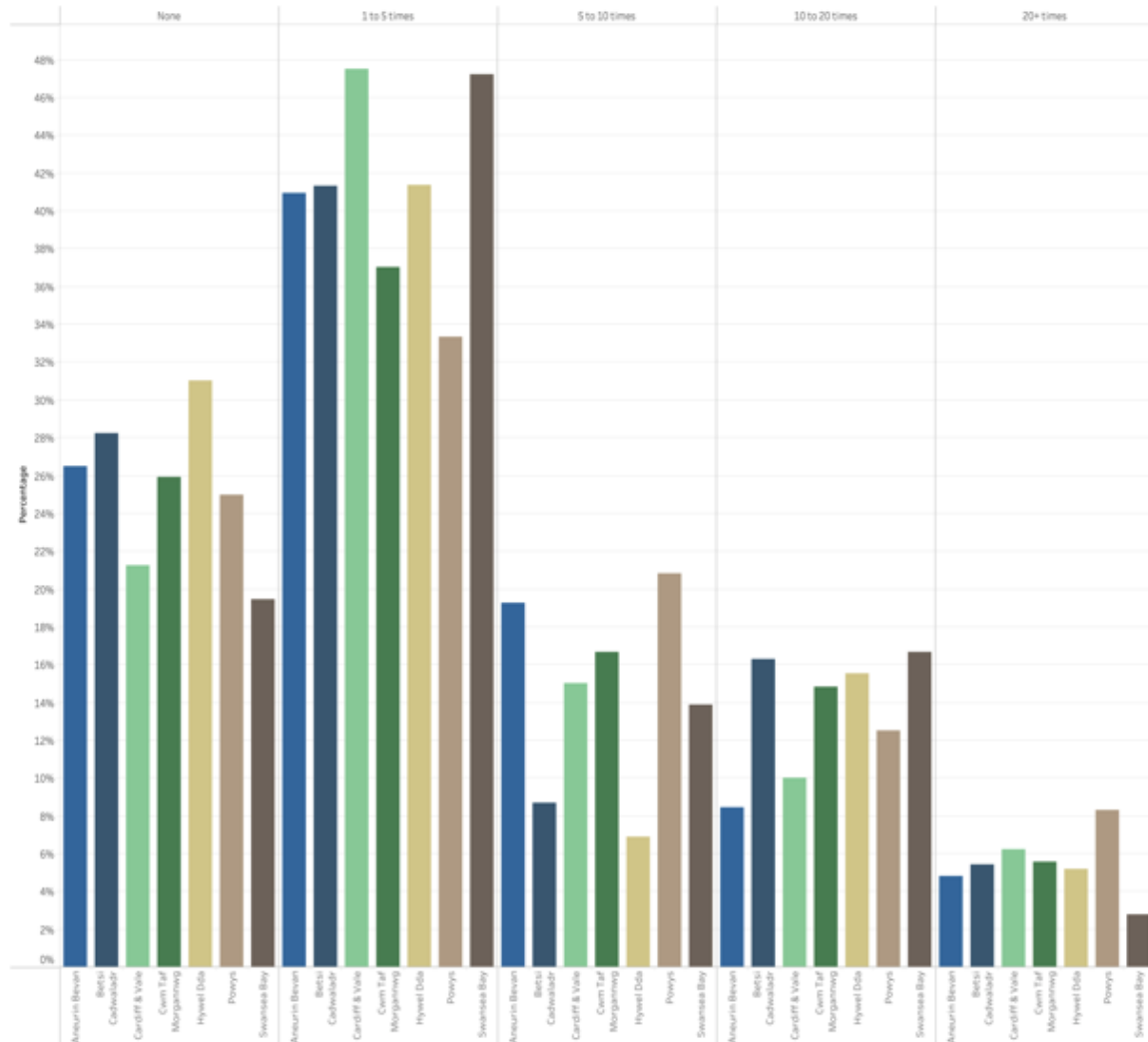


Figure 80: Based on survey answers, the number of visits to a healthcare professional for Long COVID per Health Board (categorised into, none, 1 to 5 times, 5 to 10 times, 10 to 20 times, more than 20 times).



Based off the survey responses, 68% of people in Betsi Cadwaladr UHB, followed by Aneurin Bevan UHB (59%) and Hywel Dda UHB (58%) were most likely to say they did not find the support they received beneficial (Figure 81).

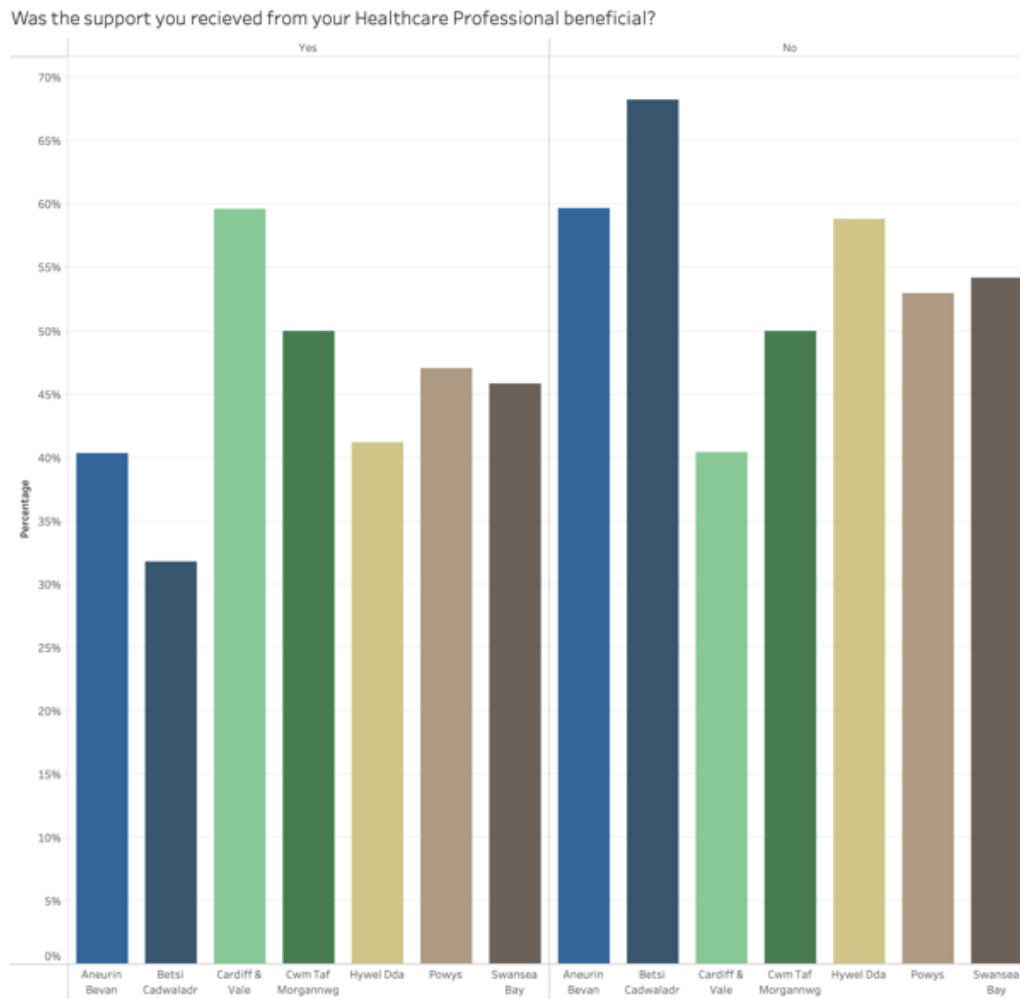


Figure 81: Survey responses per Health Board reporting whether the support they received from their healthcare professional was beneficial or not. This data excludes the 'other' category who mainly said that their support was variable or that they had not received any.

Cardiff & Vale are the only Health Board where people are more likely to say that their support was beneficial (60%) than not (40%) (Figure 81).



Betsi Cadwaladr UHB has a higher proportion of users in the 12 months plus category (35%) than any other Health Board. This is proportionally greater than the overall app representation for BCU (26%), and even larger than the 23% of survey respondents from BCU (Figure 82).

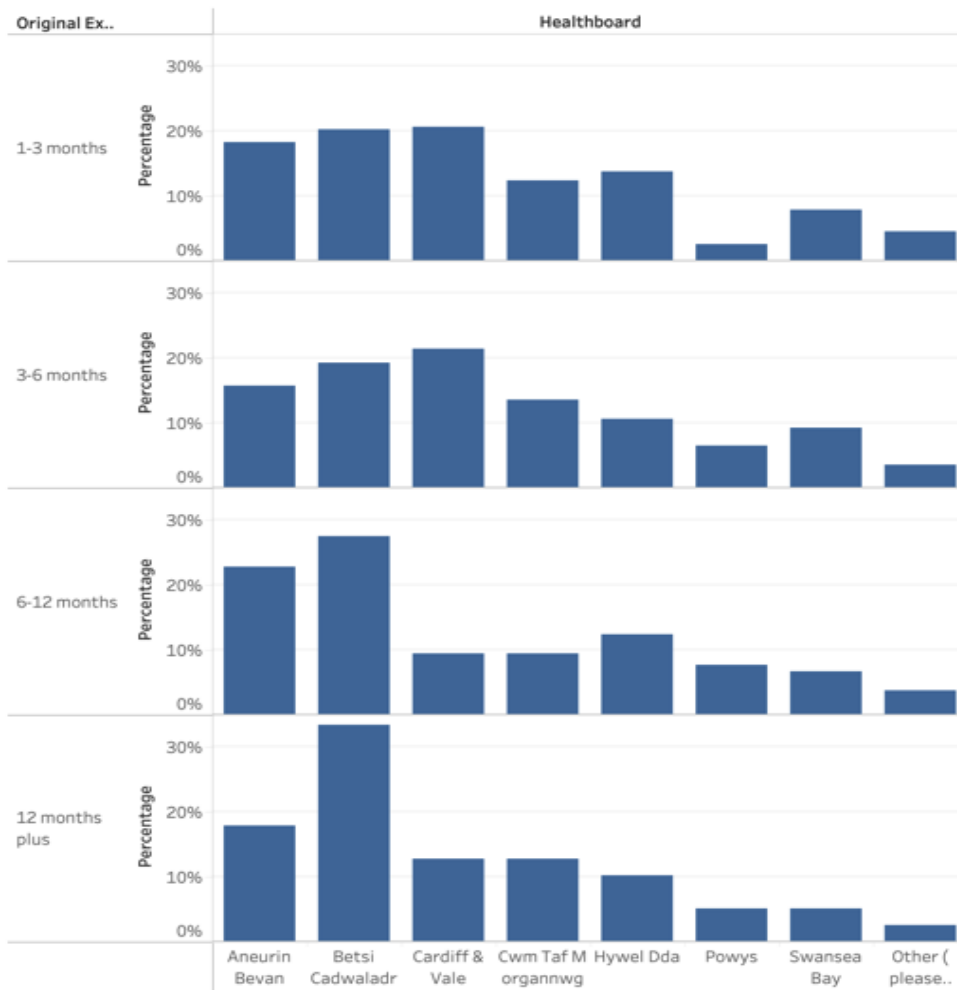


Figure 82: Health Board distribution according to recovery expectancy based off the survey responses

Conversely, based off the survey responses, Cardiff & Vale UHB has fewer people who expect to take over 12 months to recover, with only around 10% of people in this category.



Adaptation of the App

Not only has the app undergone significant infrastructure changes to update to version 2.0 to meet the requirements of the Long COVID Wales patient group, but an acute feature has also been introduced. This was in response to the requirements within the acute guideline for primary care, and requests from Welsh Government.

The added feature would provide the facility where higher risk patients could monitor their oxygen sats (SpO₂) and understand what to do should they drop (Figure 82). This is a core feature of the safety netting recommendations within the primary care guideline.

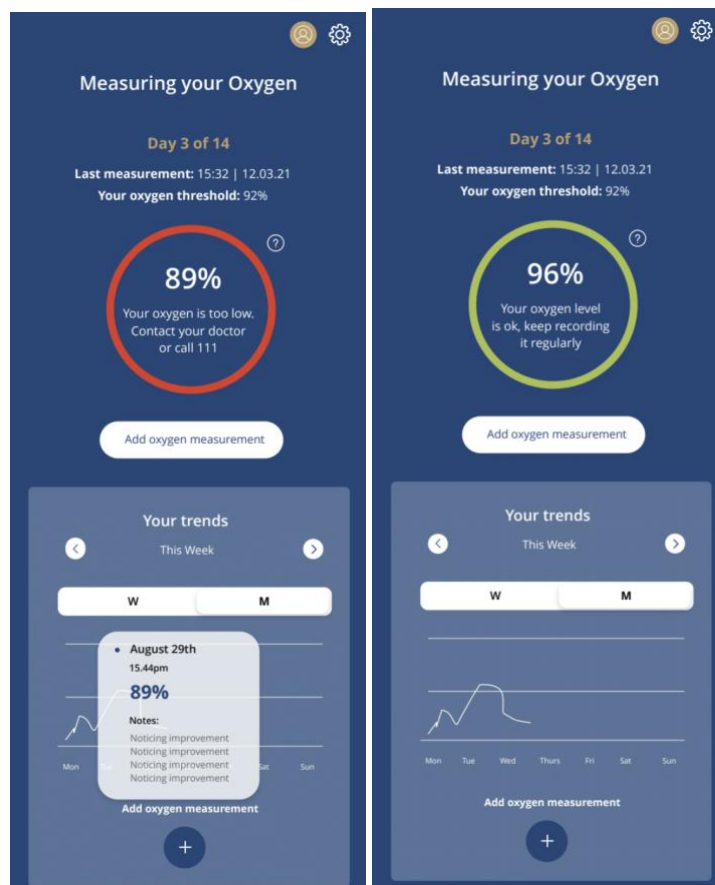


Figure 83: Instruction given to patients when their oxygen values are below the safe threshold determined by the national guidance for Wales



When the patient downloads the app, the self-reported date from which their symptoms first started sends them to the acute or long COVID home screens (Figure 84).

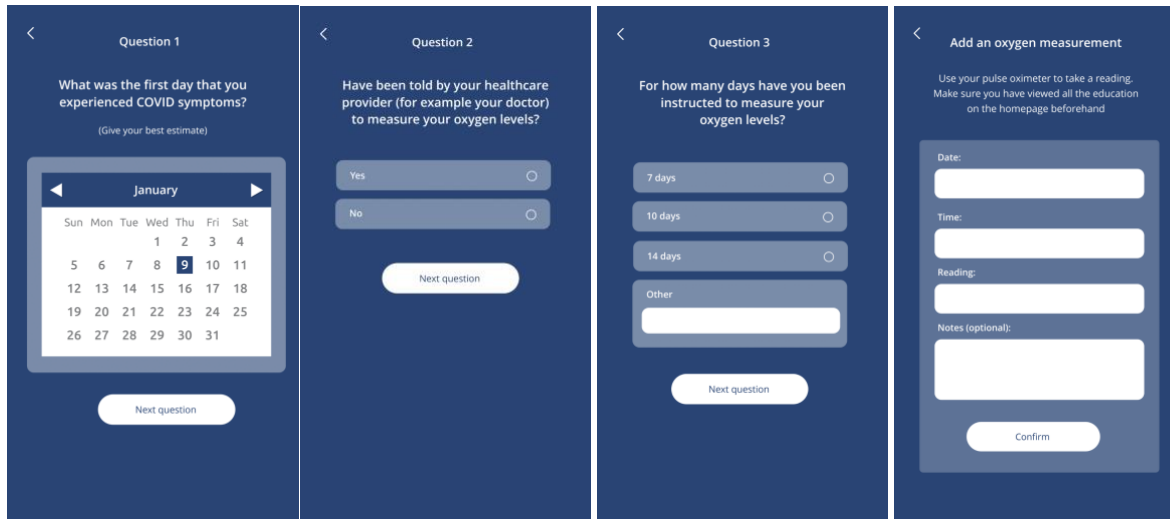


Figure 84: The series of questions to determine the date of infection and advice given by their healthcare professional to monitor their oxygen levels.

In the acute phase the patient can learn about their recovery expectations whilst acutely unwell, how to record their oxygen levels using a sats monitor issued to them, and what to do should the value drop (Figure 85).

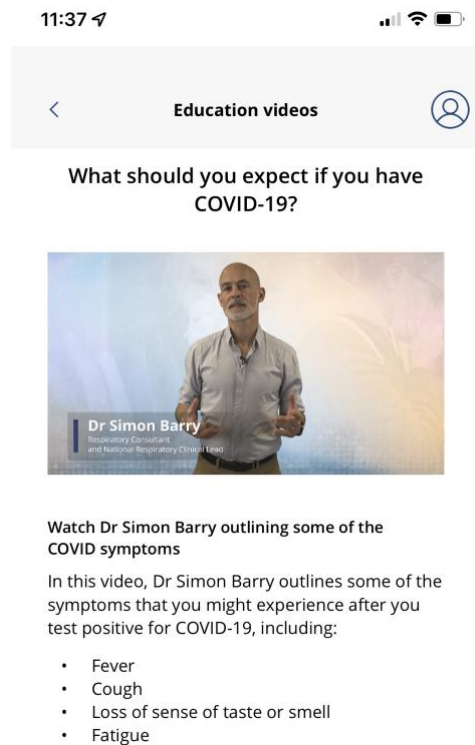


Figure 85: An example of a video hosted in the acute part of the COVID Recovery App. The video instruction is specific to the acute phase with a particular focus on managing expectations and offering clarity to patients and what to do should their oxygen values dip below the safe threshold.

Whilst this feature has only been used for a few hundred people, the feature reflects the guidance on safety netting of patients with borderline oxygen sats who turn up at the emergency department in hospitals.

The COVID audit (next chapter) identified that a large proportion of people were admitted with normal oxygen sats, where it is likely many of these could be monitored safely at home. This will free more beds in hospital and reduce the potential for nosocomial spread of COVID.

The strategy here is that people can be sent home with a sats monitor and advised to monitor their oxygen through following the instruction and educational videos on the COVID Recovery App. Patients can also add their oxygen reading into the app, which can be trended over the high-risk period of their acute infection. In circumstances where the value may drop below the safe threshold determined by the national guidance, they are advised accordingly.

This is feasible for three reasons:

- 1) The COVID Recovery App was implemented well and so it is widely available to the public
- 2) The app is integrated with national guidance and provenance of senior clinical decision makers
- 3) The app was called a COVID Recovery App; therefore, can feasibly encompass the entire recovery period (acute COVID and Long COVID)



Additional Innovation for the Public

In response to the growing public necessity for face coverings before PPE was readily available over the counter, ICST developed a programme on how to make a face covering at home, available in both English and Welsh. This was coordinated through Welsh Government and disseminated through their communication channels.



This was accompanied by a programme on PPE for healthcare professionals, disseminated through the COVID Hospital Guideline platform.



Summary

This innovation highlights a strategic, co-productive approach to utilizing digitalization to add value to an entire population rapidly. Through the design and application within a formal implementation framework, this has resulted in consistency in messaging, reduced variation, and collaboration between key stakeholders by pooling expertise and minimizing replication and waste.

The Long COVID group have been integral to the evolution of this programme through influencing new features within the app including important educational topics and relevant resources and links. They also identified people suffering with a range of complex symptoms and difficulties relating to Long COVID who have subsequently told their story on the app through short films reflecting their recovery difficulties, offering reassurance to others. The group have also identified key opinion leaders and experts in Long COVID from across the UK that has subsequently featured in both the app and the GP guideline.

In collaboration between the Long-COVID Wales patient group, NHS Wales, and ICST, an award application for COVID Recovery was submitted to MediWales in November 2021. Whilst this was not shortlisted on this occasion, it most importantly emphasises a collaborative relationship between patient representatives, the NHS and industry, respectively. Furthermore, the submission reflects a positive affirmation of support and endorsement from the patient group.

The aim of the app is to ensure that anyone suffering with the long-standing effects of COVID infection receive the right care and support from healthcare



professionals in primary care. Patients can also access self-management advice through downloading the app from the App Store or Google play. This means that wherever you live in Wales there is a consistency in care and adherence with evidence-based practices.

The Recovery app records and monitors a range of symptoms experienced by people with Long COVID. Data from the app has supported some Health Boards to assess the magnitude in demand to ensure additional support is offered where it is required. The next phase will use app data to identify people who are not recovering or may not have access to the services they expect, to offer further support and advice to guide their recovery.



COVID-19 Secondary Care Guideline Implementation Report

Health Board Executive Report

NUMBERS REGISTERED FOR HOSPITAL IN CARDIFF AND VALE UHB (cont 2)



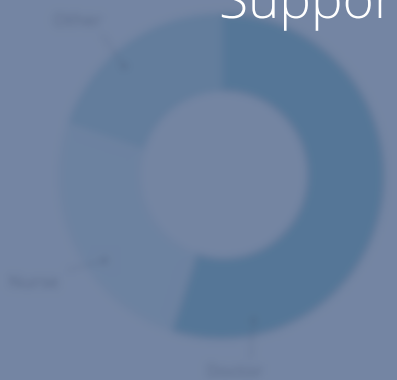
The number of healthcare professionals registered with the hospital guideline is greatest in the University Hospital Wales. The University Hospital Wales currently has the most registrations of any hospital across Wales.

REGISTRATION

Of healthcare professionals registered with the hospital guideline in University Hospital Wales:

Chapter 4

HEALTH CARE PROFESSIONALS BROKEN DOWN INTO PROFESSIONS ACROSS CARDIFF AND VALE UHB (cont 2)



The majority of healthcare professionals registered with the hospital guideline are doctors. This includes consultants, registrars, junior doctors and trainees.

Further information on the number of nurses and other healthcare professionals is given:

SUMMARY

The purpose of the guideline is that all healthcare professionals follow a consistent and coordinated approach to managing COVID-19 within hospital across Wales.

These include all healthcare professionals based on the recommendations above have access to these resources to support the management of COVID-19 across the hospitals within the UHB.

Access using the URL:

www.uhb.wales.nhs.uk/secondaryguideline/wales-uhb-uk

Supporting Decision Makers

NUMBER OF HEALTHCARE PROFESSIONALS REGISTERED WITH THE NATIONAL GUIDELINE IN CARDIFF AND VALE UHB COMPARED ALL OTHER HEALTH BOARDS (cont 1)



The number of healthcare professionals currently registered with the national COVID-19 secondary care guideline in the Cardiff and Vale UHB is above the average when compared to all Health Boards. Treys has been excluded from analysis as it does not have a district general hospital.

Chapter 4: Supporting Decision Makers

Policy makers, academics, clinical, and Health Board leads that will make informed decisions on the outcome data from the audit. This will help adapt service delivery, updates which are communicated through the national guideline platform.

COVID Audit Highlights

High level excerpts from the implementation plan and implementation status.

Plan

- Innovation: NHS Wales COVID Hospital Audit
- Innovation design/development start date: August 2020
- Formal implementations start date: October 2020
- Target organisations: Hospitals Aneurin Bevan UHB, Betsi Cadwaladr UHB, Cardiff and Vale UHB, Cwm Taf Morgannwg UHB, Hywel Dda UHB, and Swansea Bay UHB. Powys THB does not have district general hospitals therefore is excluded
- Primary target population: Data inputters based in each hospital
- Secondary target population: COVID ward/service clinical leads

Current Status

- Current implementation phase: 4/4
- Adoption by target organisations: 100%
- Penetration of primary target populations: 100%



Background

The national audit, commissioned by Welsh Government, provides a snapshot observation of the clinical factors that may influence mortality in patients admitted to hospital during the COVID-19 pandemic.

The audit is available in revised format to record datasets from patients admitted to all Welsh hospitals during:

- The first wave – data collected between 23rd July and 20th November 2020
- The second wave – data collected between 2nd June and 29th November 2021
- The third wave – data collected between 1st June 2021 and 15th December 2021

Aims of the audit

- 1) To inform local and national decision-making
- 2) To inform clinical recommendations delivered through national guidance
- 3) Academic publication



Governance

See governance structure and process in figures 13, 14, 15. Information governance (IG) leads for each Health Board have been signed off all board IG issues.

Data is collected according to agreed IG methodologies. Risk management and escalation to Welsh Government and the Health Board Executive Team through periodic implementation reports.

Implementation

Data inputters receive training and support throughout the data collection period. Data inputters have the necessary tools and allocated time to undertake the data collection processes.

Datasets are recorded for all patients included within the audit criteria as efficiently as possible and within the period of data collection. Local Health Boards are informed of local level data as soon as it is available in a digitally accessible and useful format. Welsh Government is provided with national data, updated at specified time points. Data reporters and teams receive certification towards CPD and revalidation.

This means:

- There is clarity across each of the Health Boards in Wales about what to do, how to do it, and in what time frame



- An active process ensures the audit is implemented successfully for the purpose it has been designed
- Implementation data supports audit data interpretation and central decision-making
- Wales offers a nation-wide dataset to contribute towards the evidence-base for managing COVID-19

Proposed Milestone Map for First Wave

- December 2020
 - First wave data analysed
- January 2021
 - Welsh Government letter to health boards supporting second wave data collection
 - Data template updated and communicated to clinical leads
- February 2021
 - Local data and outcomes for first wave provided to Health Board executives and lead clinicians
 - Executive support from each health board to deliver second phase of data collection
 - Audit teams allocated time during March 2021, training, devices, and support



- March 2021
 - Start of data collection period
- April 2021
 - Data feedback to Health Boards and Welsh Government

The structure for data collection included executive leads (Health Board Medical Directors) and clinical leads (respiratory consultants) overseeing data inputters (audit teams and junior doctors). Twenty iPads were purchased with audit management software installed to mitigate data risk. Data inputters also agreed safeguarding procedures. The iPads remain in each of the 18 district general hospitals and a convenient place to input the data, close to the patient records.

A secure web-based platform only accessible to data inputters is available to add data. This can be accessed through the iPads distributed to each hospital. The platform hosts a standardised template, agreed by the clinical teams and government to add the necessary datasets.



The screenshot shows a web-based data entry interface. At the top left is the GIG NHS Wales logo. The user is logged in as 'Rhys'. A 'DOWNLOAD AUDIT FORM' button is in the top right. The main content area is titled 'Data Entry' and contains several sections:

- Demographic Data:** Includes fields for Age (dropdown), Sex (at birth) with radio buttons for Male and Female, Ethnicity (dropdown), and Postcode (text input, containing 'CF111DH').
- Admission:** Includes Admission Date (text input), Select Admission Hospital (dropdown), and Admission Source (dropdown).
- Discharge or Death:** Includes Discharge Date / Date of Death (text input), Select Hospital of Discharge / Death (dropdown), and Discharge Destination (dropdown).
- Outcome:** Includes radio buttons for Discharge and Death.
- Clinical Data:** Includes a Comorbidities section with three columns: Cardio Vascular (IHD, CCF, HF), Respiratory (COPD, ILD, Asthma), and Other (CKD, Diabetes, Chronicity).

Figure 86: The standardised template for data collection embedded into a web-based platform, available to data inputters via secure code.

In total, nearly 200 data inputters have been managed through the process of data entry for each of the six Health Boards. The driver was to reach 30 data entries for each data inputter, which would reach the target denominator data. However, due to probably motivational and capacity reasons many data inputters added far less than this number (see wave implementation data from page 178).

Implementation functions and roles

Formal implementation of the audit ensures there is quick and effective adherence to the data collection processes. Without an active implementation framework, implementation takes much longer to complete with significantly less success. There are five key functions to implementation the audit across Wales. Each function will require nominated individuals with key roles and responsibilities:

1. Implementation Team

- This will be a core team to provide leadership and direction in the implementation process. The Implementation Team will provide frequent reports and updates to Welsh Government and Health Board executives and clinical leads

2. Health Board Executive Lead

- The exec lead will have direct line management and authority over clinical leads and data reporters. The exec lead will receive and respond to local health board data updates

3. Clinical Leads

- This will be a designated senior clinician within the Health Board/hospitals to support and lead the local data collection

4. Data Reporters

- People within the hospital, including clinicians and other healthcare practitioners, or audit teams, directly involved in the data collection, recording, and submission process



5. Implementation Management Team

- The Management Team manages the digital processes to support Data Reporters. The Management Team will manage digital reporting processes; maintain alignment and system risk management.

First wave

Data collection period was from 23rd July to 20th November. The organisational structure included Welsh Government deputy CMO, Health board Medical Directors, Clinical Leads (nominated respiratory consultants) and hospital data inputters. Data inputters ranged from junior doctors to audit teams.

To achieve 30 data entries, data inputters received a certificate of participation.

To lead local teams and encourage data input, nominated clinical leads have the opportunity to be co-authors of any journal articles that are published as an output of the data collection process.



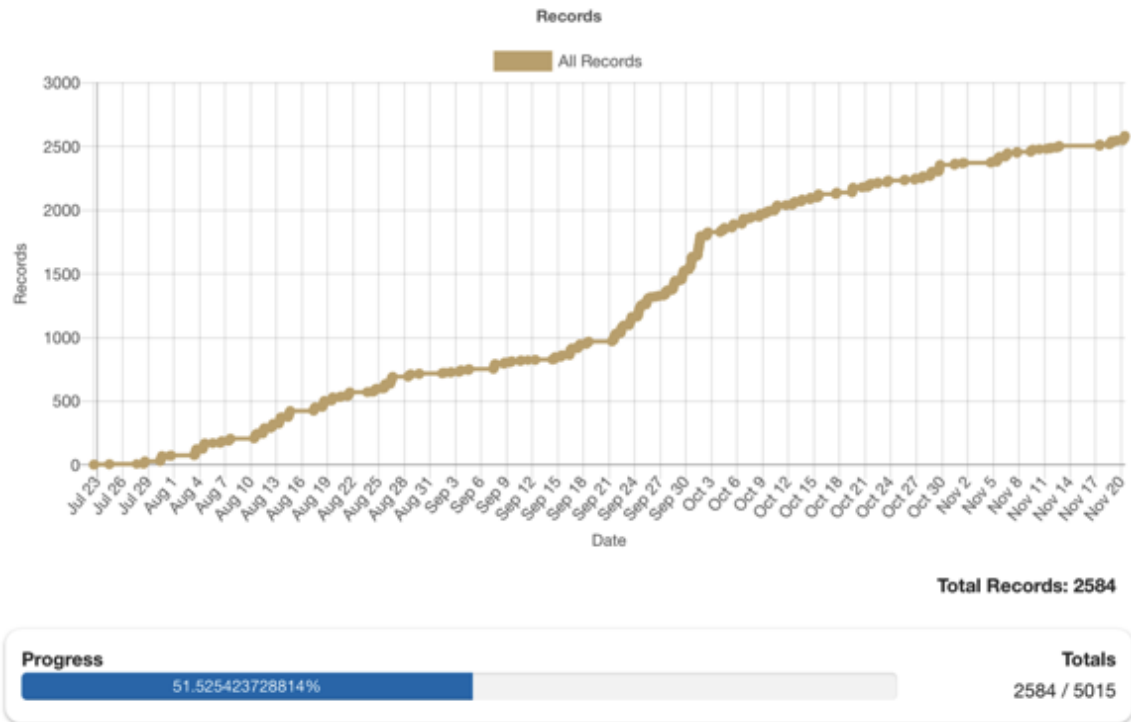


Figure 87: Number of records added into the audit dashboard over time (All Wales) for the first wave data input period. 2584 data sets were added out of a total of 5015 admissions during the first wave (52%).

Each Health Board’s activity could be monitored. This enabled the implementation team to offer additional support to the clinical lead or escalate potential risk of insufficient data collection through the governance process.

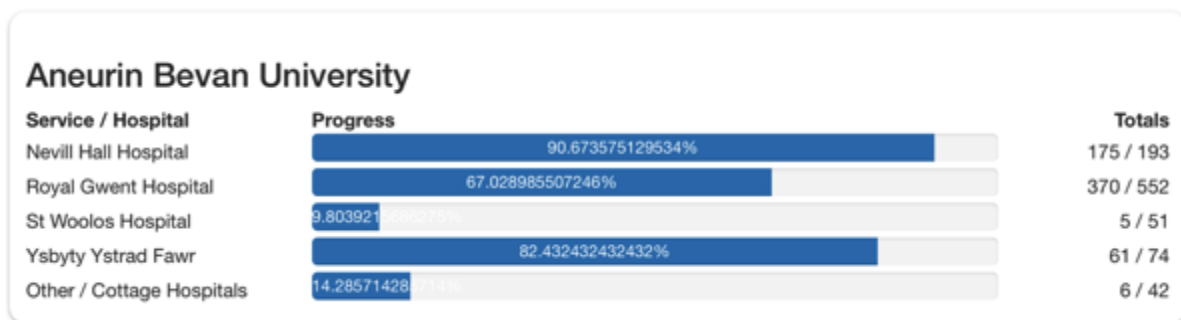


Figure 88: Completion rate for data input for Aneurin Bevan UHB demonstrating achievement (total inputs against the target) for each hospital



Aneurin Bevan UHB achieved an overall completion of 68%. Nevill Hall hospital achieved 91% of its target. Whilst the Royal Gwent achieved 67%, it recorded over double the number of patient records.

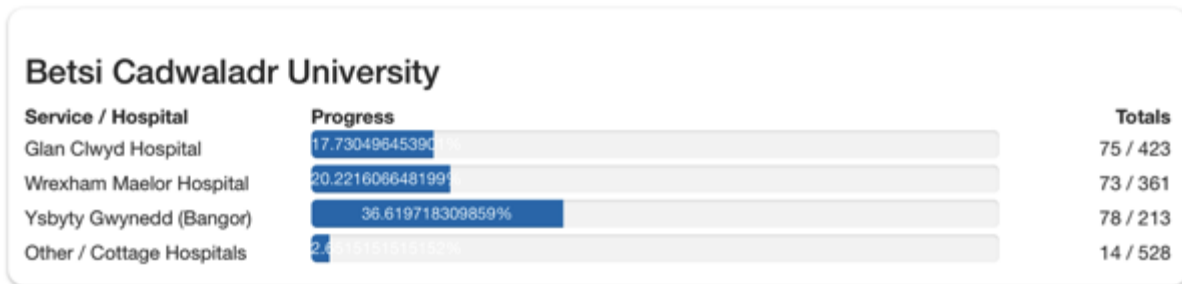


Figure 89: Completion rate for data input for Betsi Cadwaladr UHB demonstrating achievement (total inputs against the target) for each hospital

Betsi Cadwaladr UHB achieved an overall completion of 16%. Ysbyty Gwynedd (Bangor) achieved 37% of its target. Betsi Cadwaladr UHB identified capacity issues very early in the programme. Despite little efforts to resolve this, an arbitrary figure of 75 cases per district general hospital within the region was agreed.

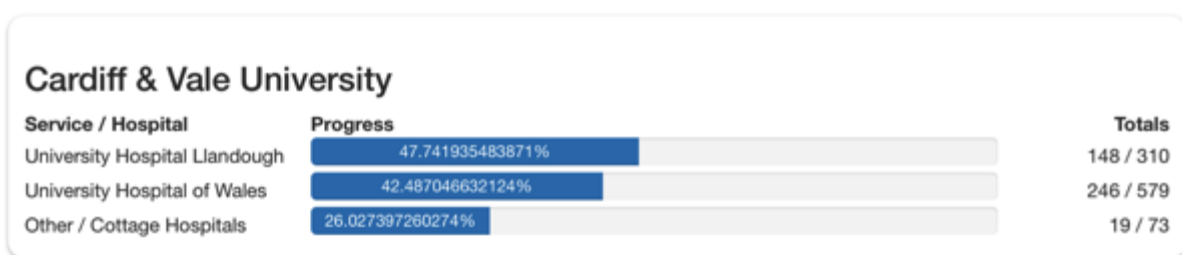


Figure 90: Completion rate for data input for Cardiff and Vale UHB demonstrating achievement (total inputs against the target) for each hospital

Cardiff and Vale UHB achieved an overall completion of 43%. Both University Hospital Wales (UHW) and University Hospital Llandough (UHL) failed to reach the 50% minimum target.

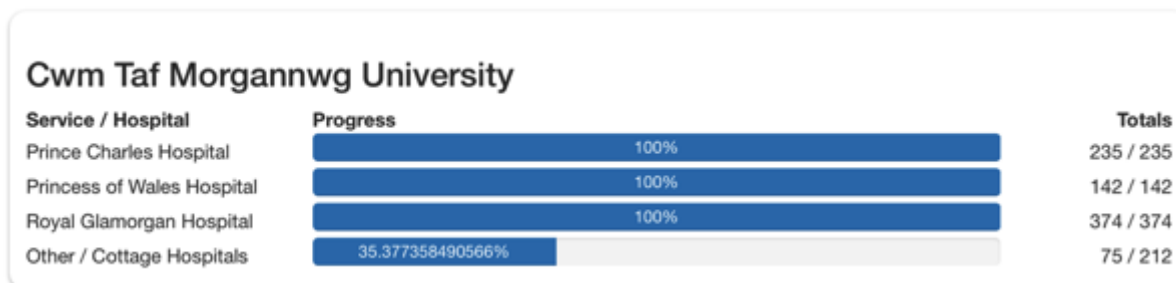


Figure 91: Completion rate for data input for Cwm Taf Morgannwg UHB demonstrating achievement (total inputs against the target) for each hospital

Cwm Taf Morgannwg UHB achieved an overall completion of 91%. Prince Charles Hospital, Princess of Wales Hospital, and the Royal Glamorgan Hospital each completed 100% of their records.

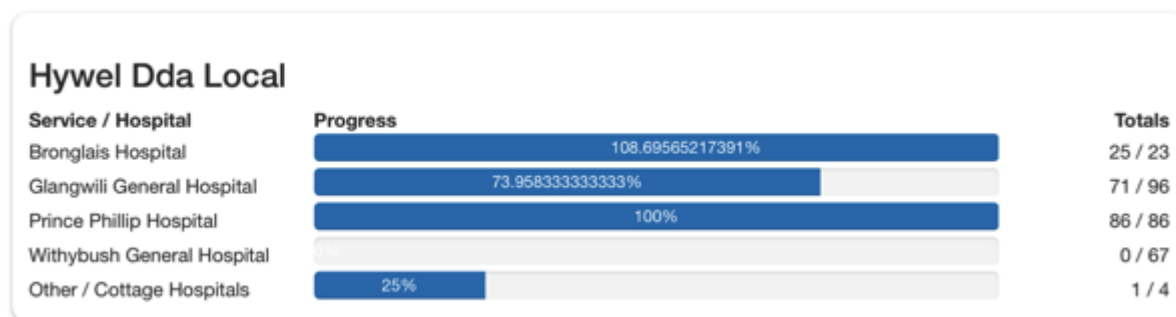


Figure 92: Completion rate for data input for Hywel Dda UHB demonstrating achievement (total inputs against the target) for each hospital

Hywel Dda UHB achieved an overall completion of 66%. Bronglais and Prince Philip Hospitals each completed 100% of their records. Withybush General hospital achieved 0% of their 67 patients admitted.

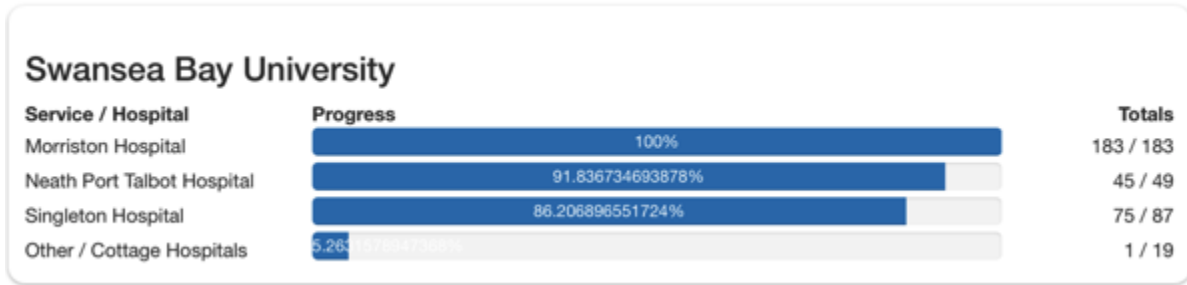


Figure 93: Completion rate for data input for Swansea Bay UHB demonstrating achievement (total inputs against the target) for each hospital

Swansea Bay UHB achieved an overall completion of 90%. Morriston Hospital completed 100% of their records, whilst Singleton and Neath Port Talbot Hospital reached 86% and 92%, respectively.

Hospital	No. data inputters	% of target	Target	Average entry per inputter
Prince Charles	2	100	235	117.5
Princess of Wales	4	100	142	35.5
Royal Glamorgan	2	100	374	187
Bronglais	3	100	23	7.6
Prince Philip	1	100	86	86
Morrison	7	100	183	26.1
Neath Port Talbot	8	92	49	5.6
Nevill Hall Hospital	8	91	193	21.9
Singleton	6	86	87	12.5
Mean average	4.5	97	152	56
Ysbyty Ystrad Fawr	13	82	74	4.7
Glangwilli	3	74	96	23.7
Royal Gwent	18	67	552	20.6
University Hospital Llandough	11	48	310	13.5
University Hospital Wales	16	42	579	15.4
Wrexham	7	37	361	10.4
Glan Clwyd	8	20	423	9.4
Bangor	7	18	213	9.8
Withybush	N/A	N/A	N/A	N/A
Mean average	10.4	48.5	326	13

Table 8: Number of data inputters, % of target patient data entries added and average entry per data inputted per hospital and averaged for the top 50% and bottom 50%. Withybush Hospital is excluded, as there was no activity and no data entries.

When analysing the patterns of data entry activity, several conclusions can be drawn. When listing the hospitals in order of completion rates and grouping

them into the top 50% and bottom 50% (Table 8) the following statements can be made:

1. The bottom 50% had on average over double more target data entries as the top 50%
2. The bottom 50% used on average over double the number of data inputters than the top 50%
3. The bottom 50% data inputters added on average just a quarter of those in the top 50%

When removing BCU from the analysis, the mean target % achieved is increased from 48.5% to 62.6%. Despite increasing the number of data inputters from 10 to 12, the average entry per inputter remains low, only marginally higher than the sum when BCU data is included (16 versus 13).



Second Wave

Data collection period was from 2nd June to 29th November 2021.

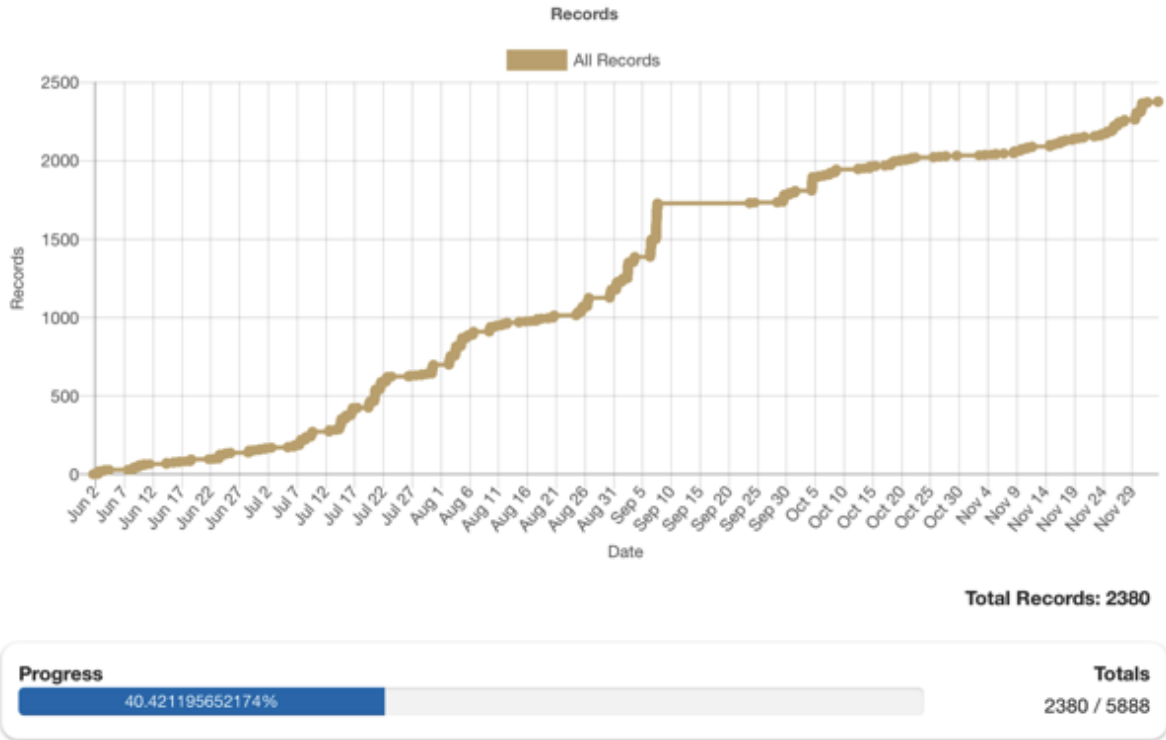


Figure 94: Number of records added into the audit dashboard over time (All Wales) for the first wave data input period. 2380 data sets were added out of a total of 5888 admissions during the first wave (40%).

The data collection achievement for the second wave is 40% across Wales. This is less than the first wave (52%).

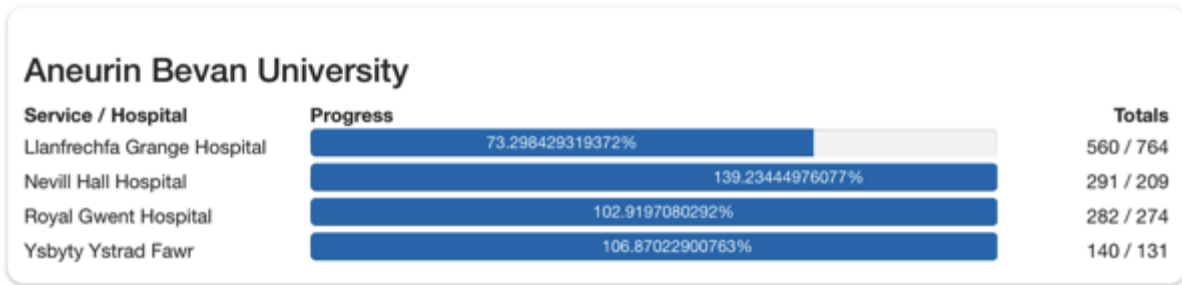


Figure 95: Completion rate for data input for Aneurin Bevan UHB demonstrating achievement (total inputs against the target) for each hospital

Aneurin Bevan UHB achieved an overall completion of 92%. Nevill Hall hospital, the Royal Gwent Hospital, and Ysbyty Ystrad Fawr superseded the projected target.

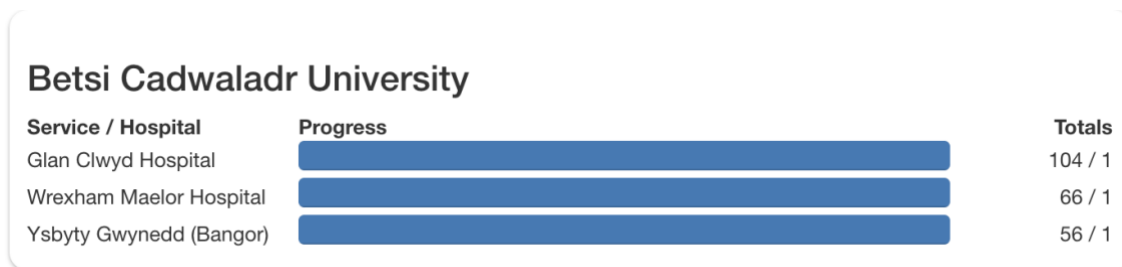


Figure 96: Completion rate for data input for Betsi Cadwaladr UHB demonstrating achievement for each hospital. Progress against data entry cannot be determined as denominator data was not provided (currently set at 1)

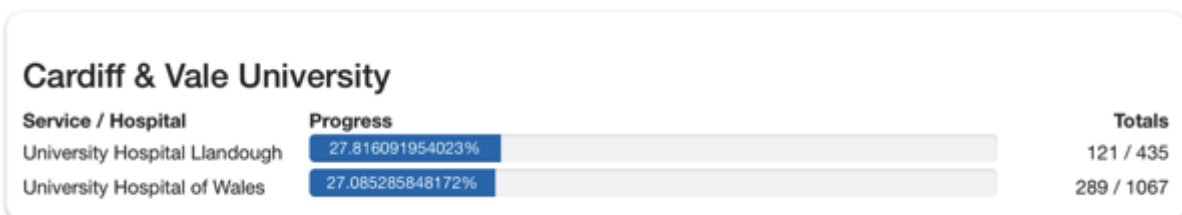


Figure 97: Completion rate for data input for Cardiff and Vale UHB demonstrating achievement (total inputs against the target) for each hospital

Cardiff and Vale UHB achieved an overall completion of 27%. Both University Hospital Wales (UHW) and University Hospital Llandough (UHL) failed to reach the 50% minimum target.

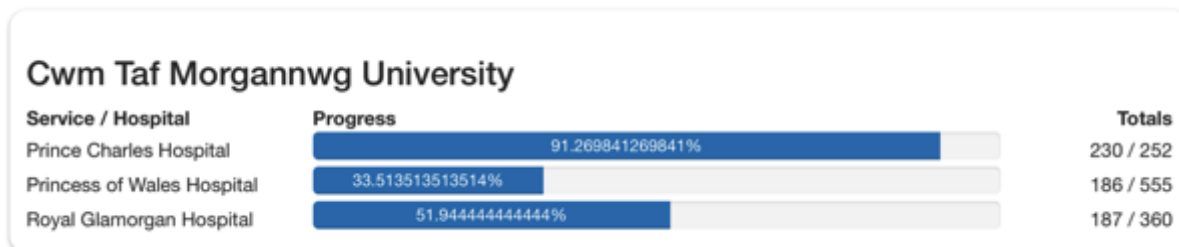


Figure 98: Completion rate for data input for Cwm Taf Morgannwg UHB demonstrating achievement (total inputs against the target) for each hospital

Cwm Taf Morgannwg UHB achieved an overall completion of 52%. However, Prince Charles Hospital, which had the highest target, completed 91% of the target.

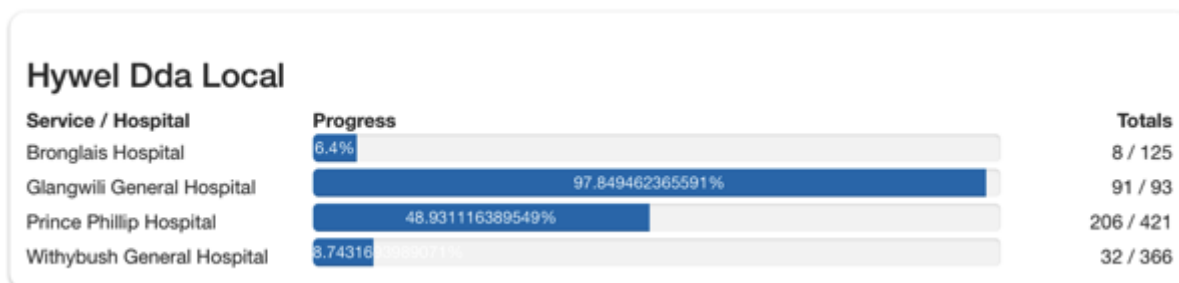


Figure 99: Completion rate for data input for Hywel Dda UHB demonstrating achievement (total inputs against the target) for each hospital

Hywel Dda UHB achieved an overall completion of 34%. Glangwili Hospital, however, completed 98% of their records. For the second wave Withybush participated in the audit achieving 9% of the target.

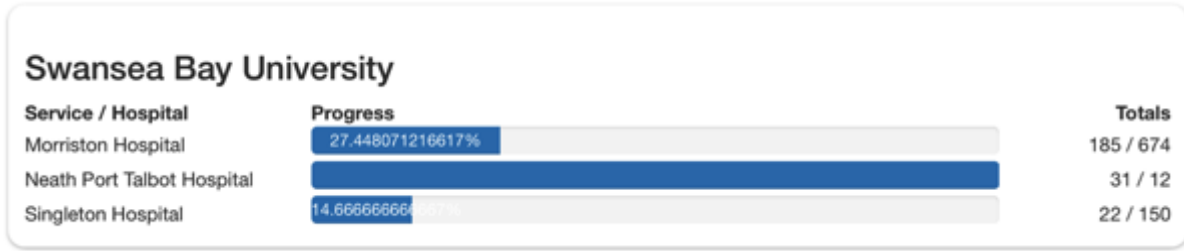


Figure 100: Completion rate for data input for Swansea Bay UHB demonstrating achievement (total inputs against the target) for each hospital

Swansea Bay UHB achieved an overall completion of 28%. However, Neath Port Talbot Hospital superseded the target, albeit very small numbers.

Third wave

Data collection period was from 19th June 2021 to current date. The number of data inputs is increasing significantly daily. The image below is a snapshot of the upload trend as of 14th December 2021.

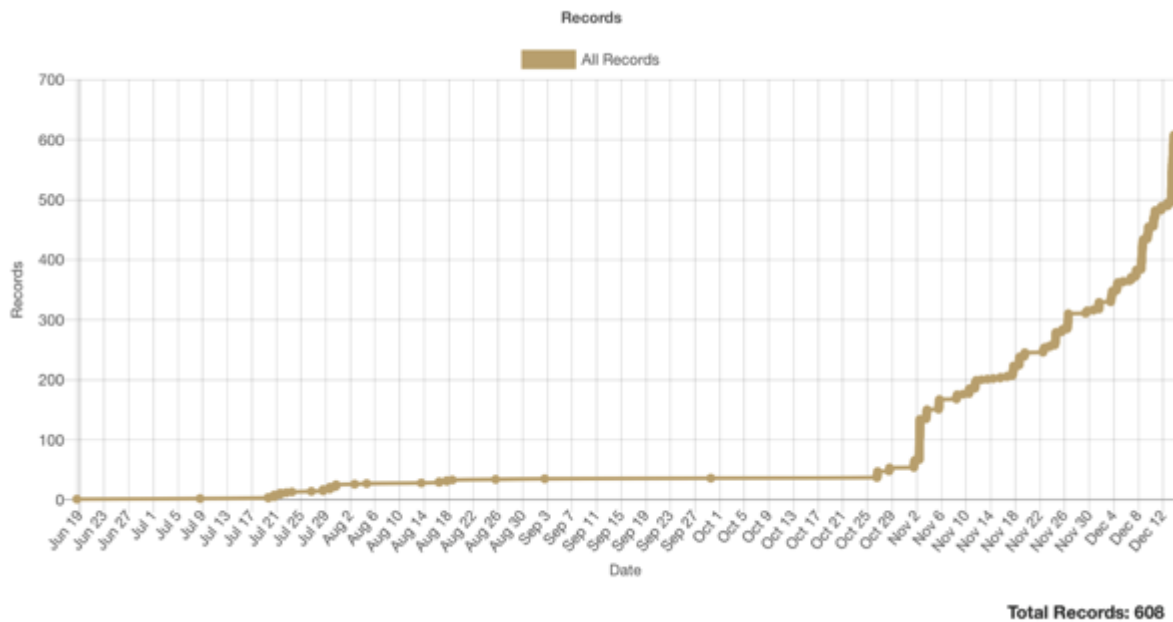


Figure 101: Number of records added into the audit dashboard over time (All Wales) for the third wave data input period. At the time of writing 608 records have been added, however this rate is increasing rapidly, therefore will be considerably greater at the time of reading.

Note, by the time the document is read the total number of patient record entries will have changed remarkably.

Data Presentation

The audit platform has several user levels that may access the dashboards for different reasons. The data inputters add information only, whereas the clinical and executive leads have access to all data for their Health Board or hospital. Health board data can be compared to all-wales data (Figure 102).

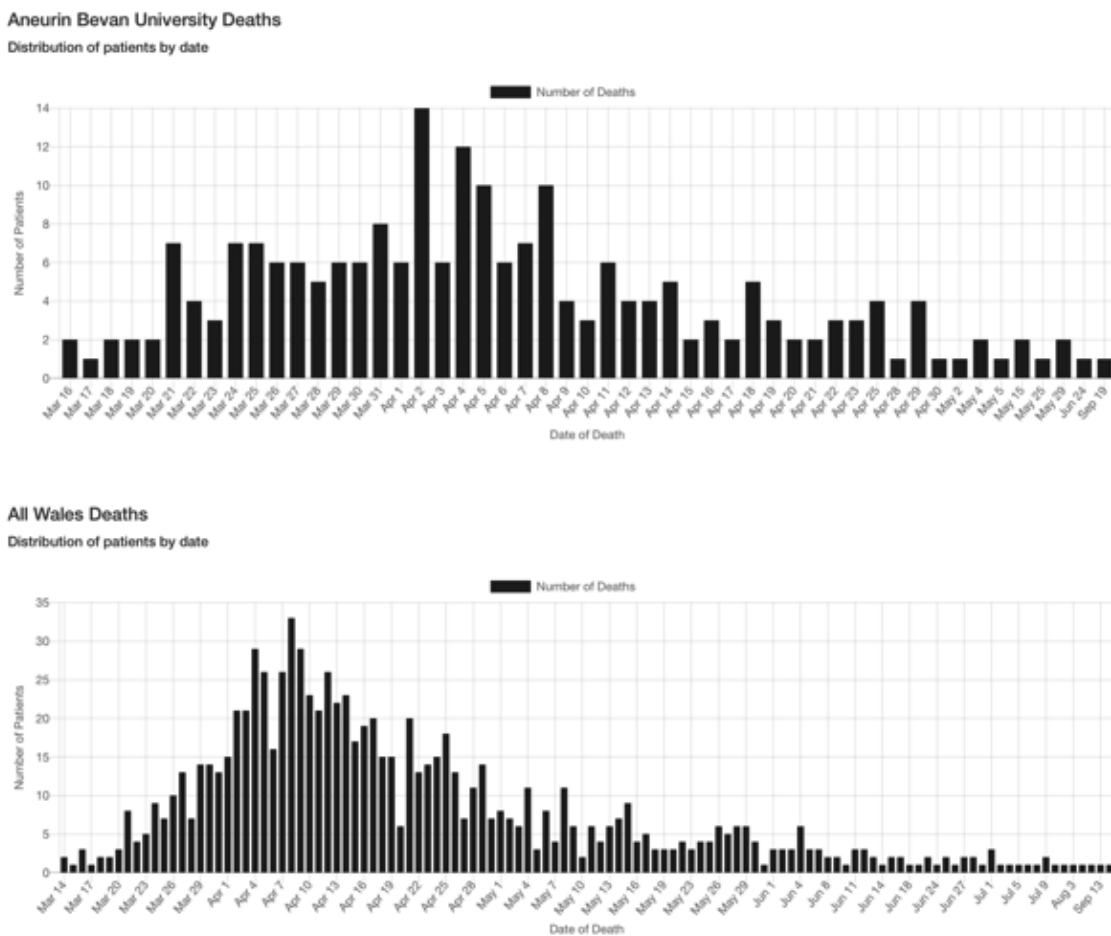


Figure 102: Example of the data dashboard for Aneurin Bevan UHB. Whilst data from the other Health Boards cannot be viewed, the information from Aneurin Bevan UHB can be compared to all-Wales data (aggregate data from all entries in all hospitals). Example here, first wave data.



The national lead and commissioners (government) can access several layers, including the Hospital, Health Board, Service implementation and All-Wales data.

Several filters and displays within the platform allow different views of the data (Figure 103).

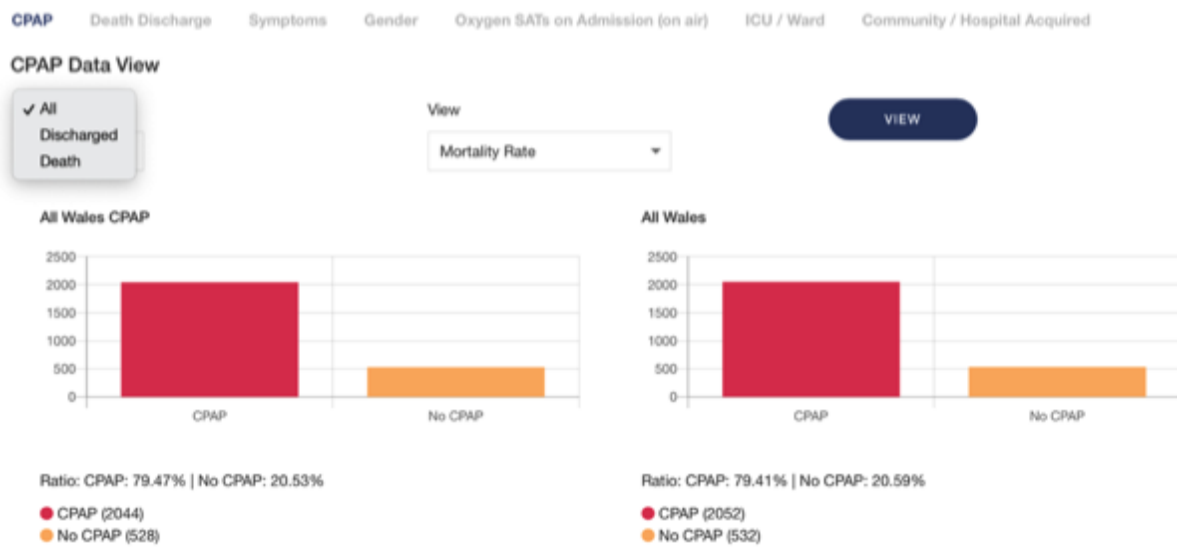


Figure 103: An example of the filter functions.

Furthermore, populations can be broken down according to their discharge destination, comorbidity, Rockwood Frailty Score, or socio-economic status (Figure 104).

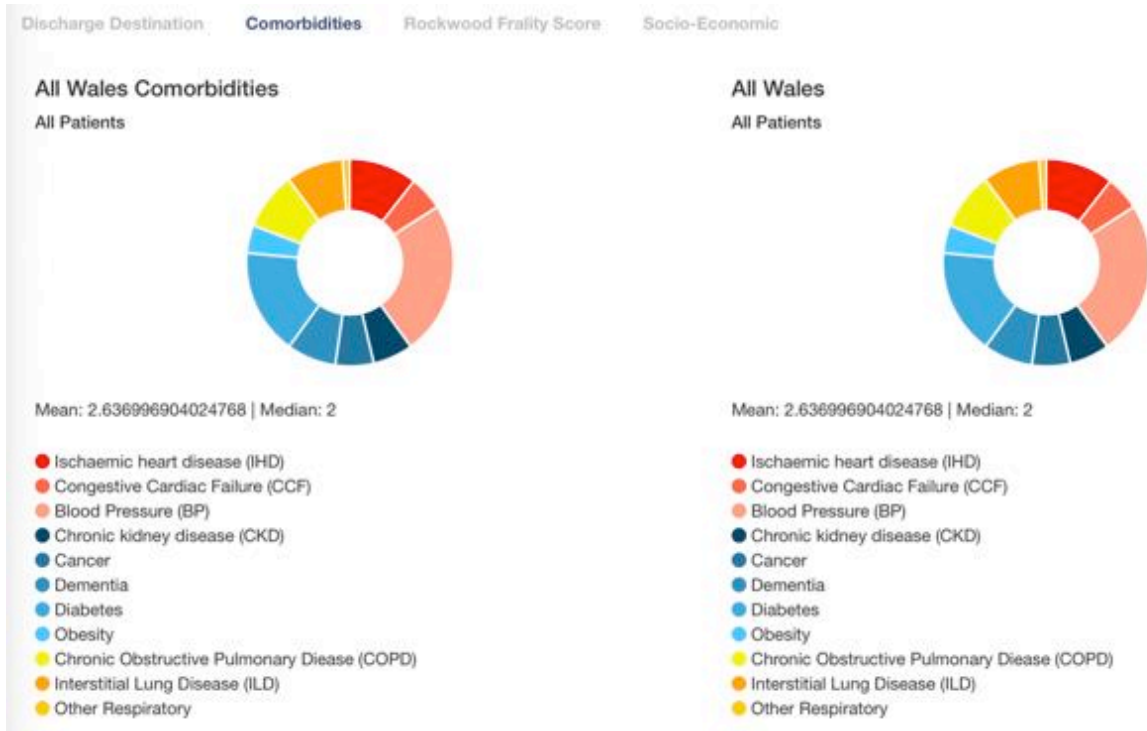


Figure 104: Population data broken down into discharge destination, comorbidity, frailty score and socio-economic status.

The data presentation exists for the data period for each of the three waves currently.

Impact

From implementation of the COVID audit data, 2,508 people, representing over 60% of the total adult population hospitalised with COVID-19 within Wales during the first wave (1 March to 1 July 2020) was analysed. Applying a standardised yet conservative definition for hospital-acquired COVID-19 (based upon the interval between admission and diagnostic testing exceeding 14 days), the team consisting of the national clinical lead, ICST representatives and academics from Cardiff and Swansea University identified 411 cases as “nosocomial” (16.4% of all COVID-19 admissions). Overall, 39% of patients with

nosocomial-infection died, compared to 32% with community-acquired infection. They found similar results over a range of case definitions. Individuals affected by nosocomial infection were typically older, frailer, and had more co-morbidities than those hospitalised with community-acquired COVID-19 (31). Early findings helped to change Welsh vaccination policy to prioritise vulnerable patients during second wave.

The study highlighted a “30-day window” for hospital inpatients to be vaccinated against COVID-19 to help reduce their risk of dying. The audit uncovered that the risk of dying from COVID-19 was far greater for patients who catch it while already in hospital than it is for those who get the virus in the community, reflecting the vulnerable nature of these individuals. The findings highlight a month-long window for vaccination between admission to hospital and SARS-CoV-2 infection.

The early findings were shared with the Welsh Government in January 2020 – and helped contribute to a change in vaccination policy in Wales to prioritise some of the most vulnerable patients during the second wave. Prior to this it was not policy to vaccinate COVID-19 negative inpatients.

“We also found that more than half of patients had been admitted for at least 30 days before they caught COVID-19, highlighting a window for vaccination or other infection control measures that we felt could help to reduce this risk.”

Dr. Mark Ponsford, co-author, Immunodeficiency
Centre for Wales



“Early research findings were presented to the Welsh Government in the Technical Advisory Group (TAG) and Vaccination Clinical Advisory and Prioritisation group (COVID-VCAP) in January and February 2021. This formed part of the evidence used in formulating government policy on enhanced vaccination of inpatients.

Study co-author Professor Stephen Jolles, a consultant immunologist and lead for the Immunodeficiency Centre for Wales

The analysis, carried out by specialists in respiratory medicine, immunology and public health from across Wales, also lays bare the high rate of mortality from hospital-acquired COVID-19. It suggests the risk of death in hospital-acquired COVID-19 is greater than previously suggested in the other published studies.

“It is increasingly clear that in-hospital transmission of COVID-19 can be an important contributor to adverse outcomes. It also highlights how important it is to understand how effective vaccination is within the more vulnerable patient groups. We are now addressing this question.”

Professor Ian Humphreys, who leads infection research at Cardiff University’s Systems Immunity University Research Institute



“We need to remember that those who are admitted to hospitals are at their most vulnerable and continue to look at ways to help reduce the risk of hospital-acquired infection in general.”

Senior author Dr Simon Barry, a consultant respiratory physician from Cardiff and Vale University Health Board

The researchers said further work was needed to explore if there were patient groups who might be particularly vulnerable to hospital-acquired COVID-19, and to understand how effective vaccination proves to be in breaking the link between infection and death in this hospital-acquired setting.



Summary

The audit has been conducted following implementation science principles, with a focus on easily accessible innovation (audit platform) and mechanism to record and display data in real time. The implementation process is managed through local leadership to ensure the target population of data inputters reach the expected denominator target number.

An outcome of acquiring a large data set is generating research that includes patients from across all Health boards admitted to Welsh hospitals. This is the first of its kind, as no other country is collecting national hospital admission data on this scale.

Analysis of the second wave data is underway in conjunction with Respiratory Innovation Wales (RIW).



Conclusions

This document provides insights into the impact of the work undertaken by ICST in collaboration with NHS bodies and Welsh Government, through true partnership with a shared vision and common goals. Adoption of innovations is complex; it requires alignment of a multitude of stakeholders, and key knowledge of the principles of implementation science to be successful. Failure to appreciate implementation, results in failure to deliver, lack of outcomes and low value.

Here we demonstrate the success achieved during the COVID pandemic in Wales by utilising the experience gained in the partnership between RHIG and ICST. We have created a hugely successful hospital guideline in a matter of weeks, which continues to deliver updates. This guideline is unique and is an exemplar of what true digital innovation and implementation can achieve. The primary care guideline was less successful, and it is important to understand why that was the case. This was delayed due to procurement issues and complexities of engagement with different stakeholders. Timeliness is undoubtedly one of the key factors in implementation success, and this one was frankly delivered too late.

The NHS Wales Long COVID Framework incorporating the COVID recovery app and Long COVID guideline to support therapies-led community-based care has been a great success. Understanding that Wales needed a strategic, coherent approach to managing the long-term sequelae of COVID, rather than offering secondary care long COVID clinics was felt by the key senior clinicians to be the most prudent approach. Again, there has been huge buy in from primary care



stakeholders, a group that is traditionally difficult to engage with at scale and pace. The COVID recovery app is a true example of co-production with members of the long COVID group involved in creating the current version of the app. Not only have very large numbers of patients downloaded it in Wales (and elsewhere), but it has also provided important insights into the expectations of the patients themselves in terms of their recovery.

No other country has created a single online data collection tool with widespread uptake to allow analysis of the outcomes from COVID across unfolding waves and understanding the impact of new treatments on mortality.

Using an implementation framework provides a structure, predictability, and transparency for getting innovations into the hands of motivated adopters. Only once the outcomes of implementation are achieved, such as acceptance, penetration, adoption, and adherence; can clinical outcomes be realised.

COVID has offered the contextual backdrop that has made things happen quicker. Whilst this speed cannot be feasibly expected in usual scenarios, such as that experienced in the chronic disease management of asthma or liver disease, for example, it does offer a window into what can genuinely be achieved on a large national scale with greater assurance for delivery than traditional methods.

Not everything has been captured within this document, but what has been included, is only possible where the people who have used them have experienced innovations. The magnitude of this experience is what defines the scale and impact of the implementation of high-quality innovations. What has



been achieved here has undoubtedly benefited society across Wales from healthcare professionals to the public and will continue to do so as we move into the next phase of the COVID pandemic. This is achieved through application of scientific methodology and a collaborative relationship between the public sector and a dynamic, committed, and innovative partner.



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Appendix A

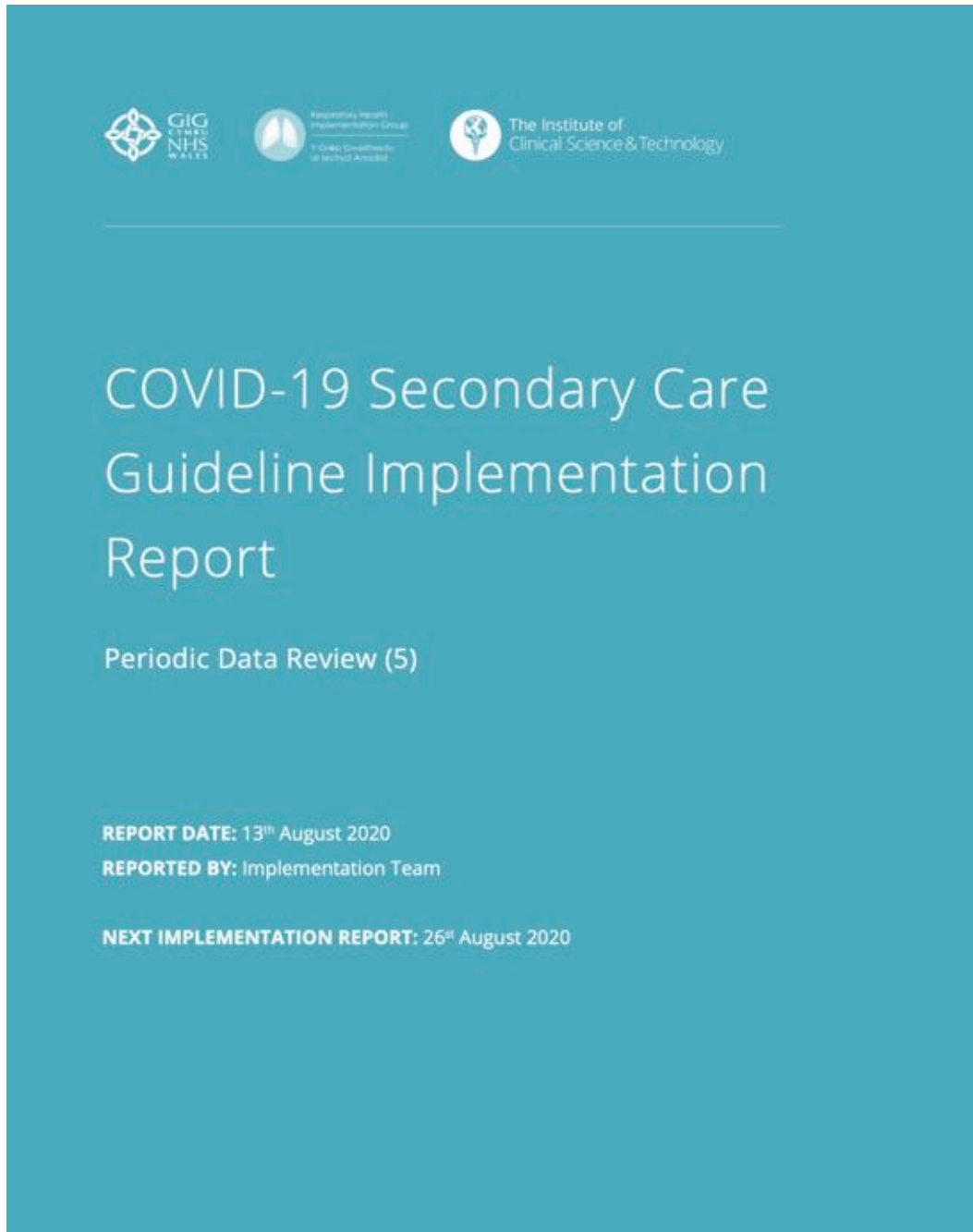


Figure 105: Example of Implementation Report to commissioners and decision-makers. This example is report number 5 for the hospital guideline



Appendix B

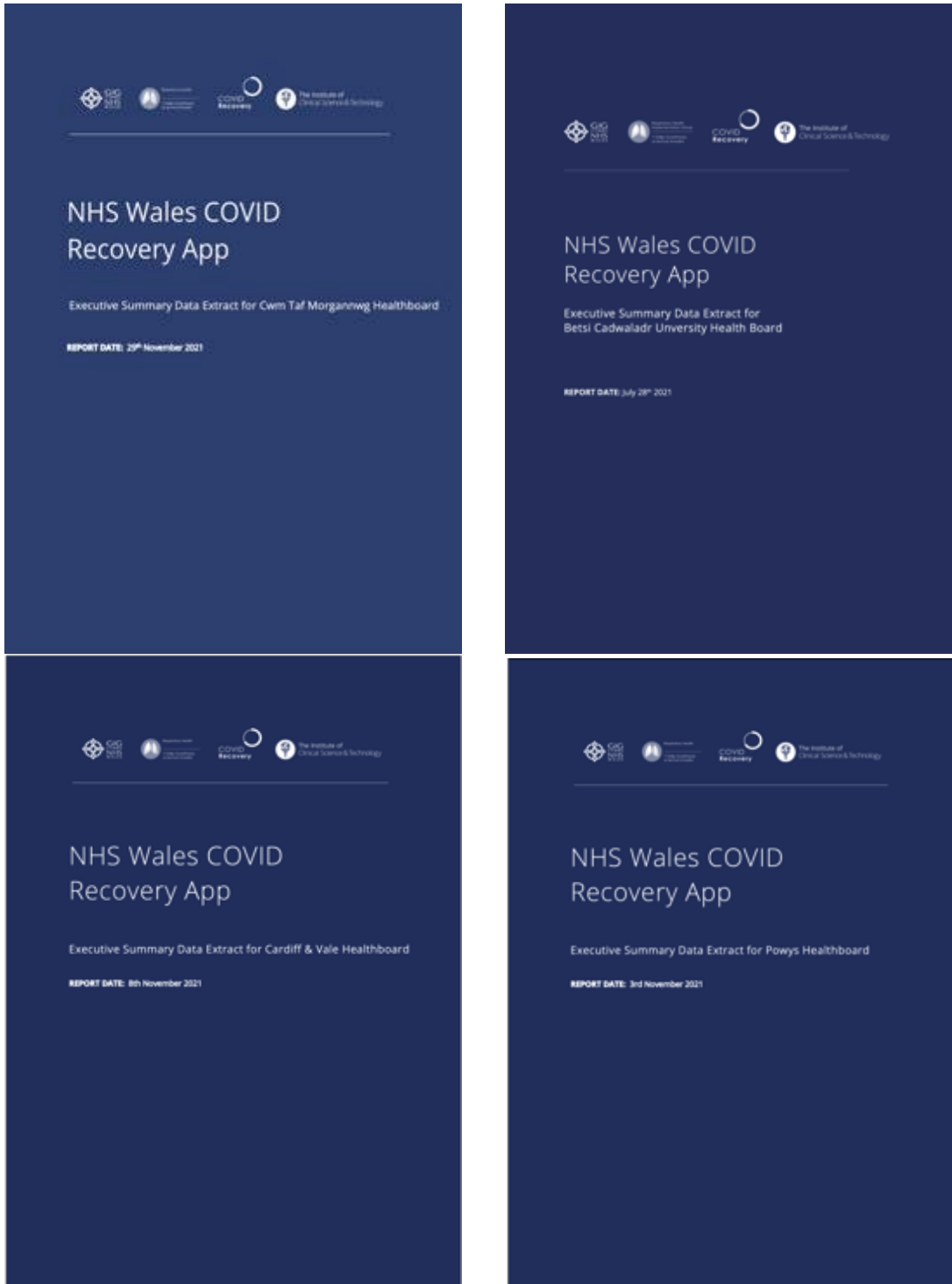


Figure 106: Examples of COVID Recovery App reports distributed to Health boards at their request



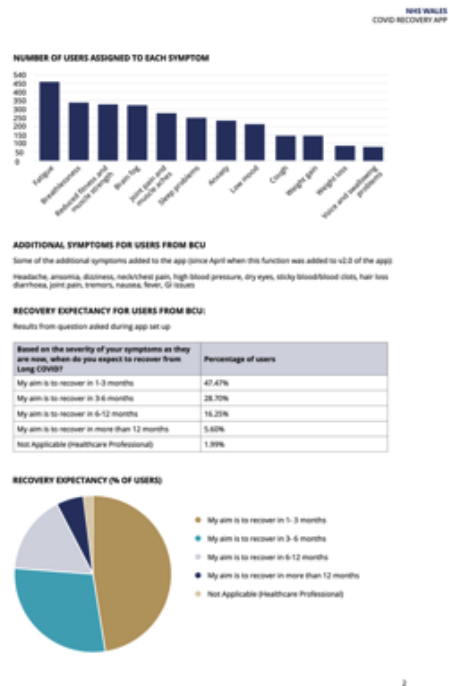


Figure 107: Example of COVID Recovery App Executive report

