World Health Organization
European Region

Service delivery models for people with post COVID-19 conditions in selected European countries: **summary report**

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ABSTRACT

Coronavirus disease (COVID-19) has affected millions of people across the WHO European Region. While the acute phase of the pandemic has passed, it is estimated that 10–20% of those infected with SARS-CoV-2 continue to have symptoms long after their initial illness. Using a tool devised by WHO for collecting data on the management of the post COVID-19 condition (PCC), also known as long COVID, three countries – Israel, Italy and the United Kingdom of Great Britain and Northern Ireland – and two autonomous regions of Spain – Aragon and Catalonia – collated detailed descriptions of service delivery models that support patients with PCC. This report synthesizes findings from those countries and regions, showing differences and similarities, and concludes with suggestions as to how other health systems can adjust their services to better meet the needs of patients with this debilitating condition.

Keywords

COVID-19; LONG COVID, PREVALENCE, WORLD HEALTH ORGANIZATION

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Contents

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This summary report is based on deep-dive reports from Israel, Italy, Spain and its regions of Aragon and Catalonia, and the United Kingdom of Great Britain and Northern Ireland (or England only, in some specified instances) that describe, in detail, elements of the respective countries' and regions' approaches to identifying, diagnosing and managing patients with post COVID-19 condition.

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Abbreviations

COVID-19	coronavirus disease
DGAS	*Dirección General de Asistencia Sanitaria* [General Directorate of Health Care] Aragon, Spain
GP	general practitioner
HMO	health maintenance organizations
ICD-10	International Classification of Diseases, Tenth Revision
ISS	*Istituto Superiore di Sanità* [National Institute of Health] Italy
MoH	Ministry of Health
NHS	National Health Service, United Kingdom
PCC	post COVID-19 condition
PCR	polymerase chain reaction
SALUD	*Servicio Aragonés de Salud* [Health Service, Aragon] Spain
SARS-CoV-2	severe acute respiratory syndrome coronavirus 2

1. Background

Coronavirus disease (COVID-19) has had a major economic, health and social impact across all countries of the WHO European Region, affecting hundreds of millions of people. While the acute phase of the pandemic has passed, COVID-19 has left its legacy on health systems; with high rates of burnout and COVID-19-related illnesses among health workers causing professionals to exit the workforce, exacerbating labour shortages, extending wait times for patients to access services, and significant demand on health services to treat those experiencing lingering symptoms following an acute infection.

These medium- and long-term disabling symptoms are collectively known as post COVID-19 condition (PCC) or, commonly, long COVID. WHO defines this condition as the continuation or development of new symptoms three months after the initial severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection, with the symptoms lasting for at least two months with no other explanation *(1)*. PCC can present with an array of symptoms and more than 200 have been reported in the literature so far, with common ones being breathlessness, fatigue, pain, psychological effects and cognitive dysfunction including brain fog. Children can also experience PCC *(2)*.

While the exact number of people affected is not clear, published evidence indicates that approximately 10–20% of individuals continue having symptoms for weeks, months and years following acute SARS-CoV-2 infection *(1)*. The Institute for Health Metrics and Evaluation estimated that, by the end of 2021, more than 17 million people across the Region may have experienced the condition during the first two years of the pandemic (2020–21) *(2)*.

PCC is a new and disabling condition about which we still have much to learn and for which, yet, we have no specific diagnostic tests and treatments. In conjunction with the high prevalence of the condition among populations, this is exerting significant pressure on already stretched health systems across Europe, particularly on health and psychosocial support, and the associated costs to optimally manage care. The complex nature of the condition requires a long-term, multidisciplinary approach. However, many countries in the Region still have limited or no service delivery structures for patients with PCC *(3,4)*.

With a tool devised by WHO for collecting country information on their management of patients with PCC, the WHO Regional Office for Europe has collated detailed descriptions of existing service delivery models that support patients with PCC across countries. Three countries (Israel, Italy, United Kingdom) and two autonomous regions of Spain (Aragon, Catalonia) were identified as models where services for patients with PCC had been established and where relevant information on their design was accessible and could be retrieved. Based on the tool, and through consultation with health system stakeholders, national key health system informants gathered relevant information and described, through the country deep dives, the changes introduced in their respective health systems to adapt existing services to the needs of patients with PCC. These deep-dive reports cover in detail the elements of the health system that have been modified to accommodate service needs, including identifying, diagnosing and managing patients with PCC, as well as challenges and limitations to the respective service delivery models.

This overview report synthesizes these individual country and regional reports and provides a summary of their key findings, highlighting similarities as well as major differences between countries. It concludes with central lessons on how the closely studied countries and regions are managing care for patients with PCC and provides suggestions for other countries in the Region on how to adjust their existing models of care to meet the needs of people living with this new and debilitating condition.

2. The health systems in observed settings

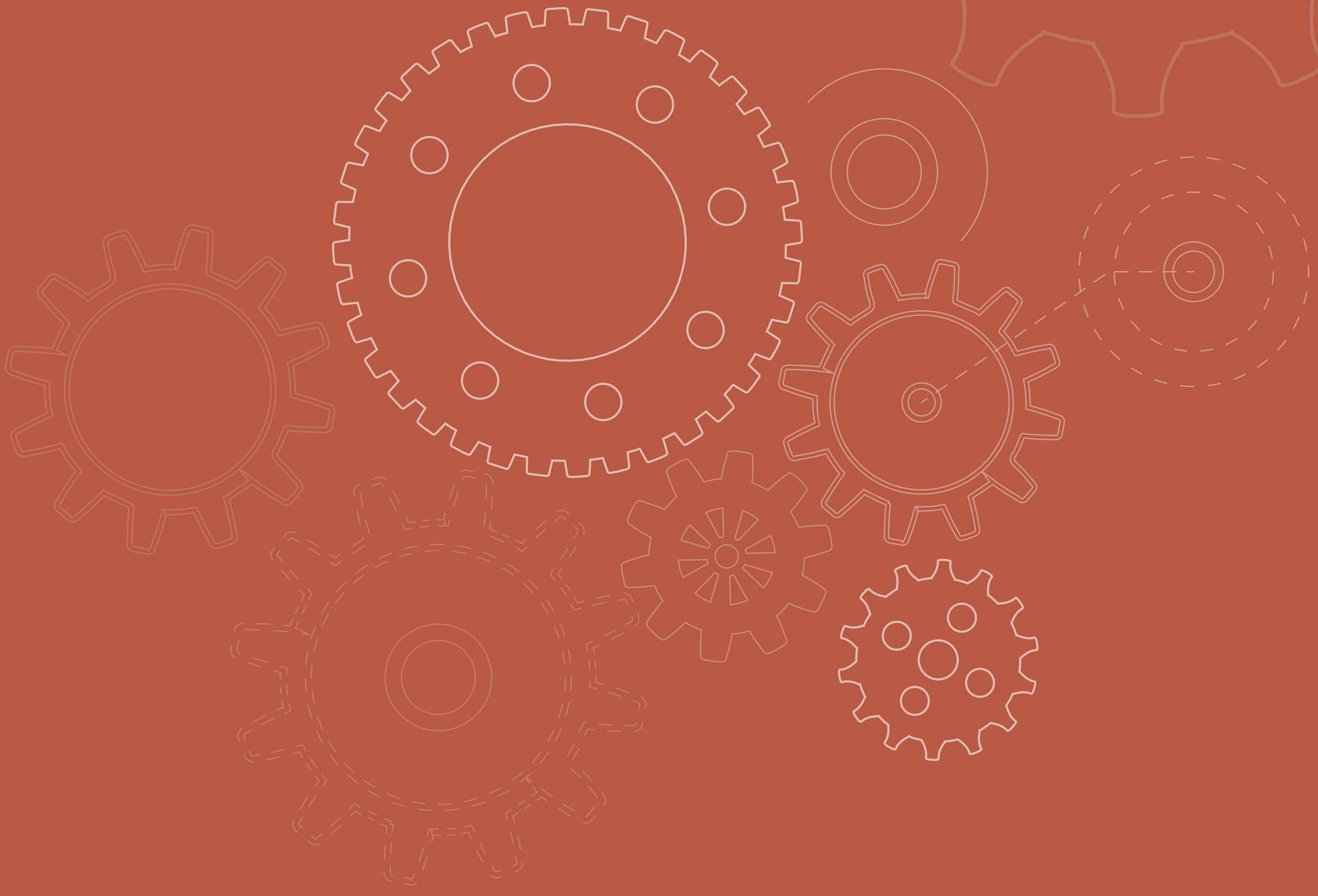
Each of the countries and regions provides free health care funded through taxation. COVID-19 and PCC are managed mainly in primary care, with severe cases referred to specialist services and emergencies treated in hospitals.

In Italy and Spain, the overall structure and management of the health service is overseen centrally, with each country's regions and autonomous provinces responsible for coordinating local health agencies.

Catalonia, for example, is divided into seven health regions, each of which provides the primary and specialized care resources required to serve its population's needs. CatSalut (*Servei Català de la Salut*) [Catalan Health Service] manages COVID-19 and PCC cases at all levels of health care. In Aragon, the *Servicio Aragonés de Salud* (SALUD) [Aragonese Health Service] manages and administers public health-care services. Responsibility for the management of PCC cases lies with the *Dirección General de Asistencia Sanitaria* (DGAS) [General Directorate of Health Care].

In Israel, community health-care services are mainly covered by four Health Maintenance Organizations (HMOs), including Clalit, Maccabi, Meuhedet and Leumit, which have their own clinics throughout the country where COVID-19 and post COVID-19 cases are treated primarily.

In the United Kingdom, the predominant health-care system is the National Health Service (NHS), which is free at the point of contact for all those with a right to reside in the country. Visitors to the country can access some limited services, such as emergency services, for free but must pay for non-essential care (which includes care for PCC). Some limited private care providers, such as Nuffield, Spire and Bupa, provide either NHS-commissioned services for free or as a paid service to individuals paying on their own or via insurance coverage. Any service in the country, whether public or private, follows guidelines and policies set centrally by the NHS and the National Institute for Health and Clinical Excellence.



3. Post COVID-19 condition: case definition and diagnostic criteria

Case definition

Various terminology has emerged to describe PCC, including “long COVID” and “long-haul COVID”. The absence of a single terminology and clinical case definition was seen as a drawback to research and management of patients with PCC *(5)*. Therefore, WHO employed a Delphi methodology to determine a standardized clinical case definition for PCC.

“Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others which generally have an impact on everyday functioning. Symptoms may be new onset, following initial recovery from an acute COVID-19 episode, or persist from the initial illness. Symptoms may also fluctuate or relapse over time. A separate definition may be applicable for children” *(5)*.

The most widely employed case definition of PCC in Spain is an abbreviation of the above used by WHO in a PCC factsheet: “The continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation” *(1)*. In Catalonia, *COVID persistente* (long COVID) is the term commonly used to denote PCC. A case is defined as: “Any person with a clinical diagnosis of COVID-19, with or without a virologic diagnosis, that, after the acute phase of the disease (after the third week) continues presenting any symptom related to the infection, whether persistent or fluctuant.” The term adopted by SALUD in Aragon is “post COVID-19 condition”, along with *COVID persistente*. These terms are used interchangeably. WHO’s clinical definition of PCC is the one most widely used.

“Long COVID” is commonly used in the United Kingdom to describe signs and symptoms that continue or develop after acute COVID-19 illness *(6)*. The term covers both ongoing symptomatic COVID-19 (from four to 12 weeks) and post COVID-19 syndrome (12 weeks or more).

In Israel, PCC is defined as occurring in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually three months from onset, with symptoms that last for at least two months, and which cannot be explained by an alternative diagnosis (according to the WHO definition).

PCC in Italy is defined as a syndrome characterized by signs and symptoms that persist or develop more than four weeks after an acute SARS-CoV-2 infection *(7)*. Although other definitions of PCC, including that of WHO, are used by some organizations, the four-week threshold was chosen because it allows for rapid identification and treatment of the consequences of the SARS-CoV-2 infection.

Diagnostic criteria

In Spain, a confirmed microbiological diagnosis is not required as a diagnostic criterion, as there was a period during the first wave when no tests were available. This stance is recommended by WHO so as not to exclude those without access to testing. The CIBEREPOSTCOVID Project *(8)*, led by *Instituto de Salud Carlos III* [Carlos III Health Institute] and commissioned by the Ministry of Health (MoH) to investigate PCC, says that, to diagnose the condition, “a previous diagnosis of an acute COVID-19 infection registered in the clinical records and/or clinical laboratory tests (a confirmation by polymerase chain reaction (PCR) or antigenic test techniques)” is required. In Catalonia, diagnostic criteria are based on a person’s reported symptoms and the epidemiological plausibility of previous COVID-19 infection *(9)*. A positive diagnostic test for COVID-19 is not necessary for a diagnosis of PCC. Diagnostic criteria in Aragon are confirmed SARS-CoV-2 infection (there is no reference to the kind of test used) and, exceptionally, a clinical diagnosis of SARS-CoV-2 between February and April 2020, when no test was available; and symptoms that continue after 12 weeks or which appear after an acute SARS-CoV-2 infection and cannot be explained by an alternative diagnosis.

In the United Kingdom, a confirmed PCR test is not a requirement for diagnosis of PCC *(6, 10)*. There are no confirmatory laboratory tests for the condition. If one or more symptoms are consistent with PCC and have either started after the patient has been unwell with acute infection or have worsened after the infection, a diagnosis of PCC is considered. PCC usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. PCC may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.

Diagnostic criteria in Israel were established in accordance with the case definition (above), determined through laboratory tests and imaging, which can rule out other illnesses.

In Italy, diagnostic criteria based on symptom occurrence were not defined for PCC *(7)*. However, good practice recommendations underline the need to perform a multidimensional evaluation in patients screened for or with suspected PCC. The decision to prescribe laboratory tests and radiological and functional examinations is left to the physician in charge of the patient based on the patient's signs and symptoms.

Who decided the criteria?

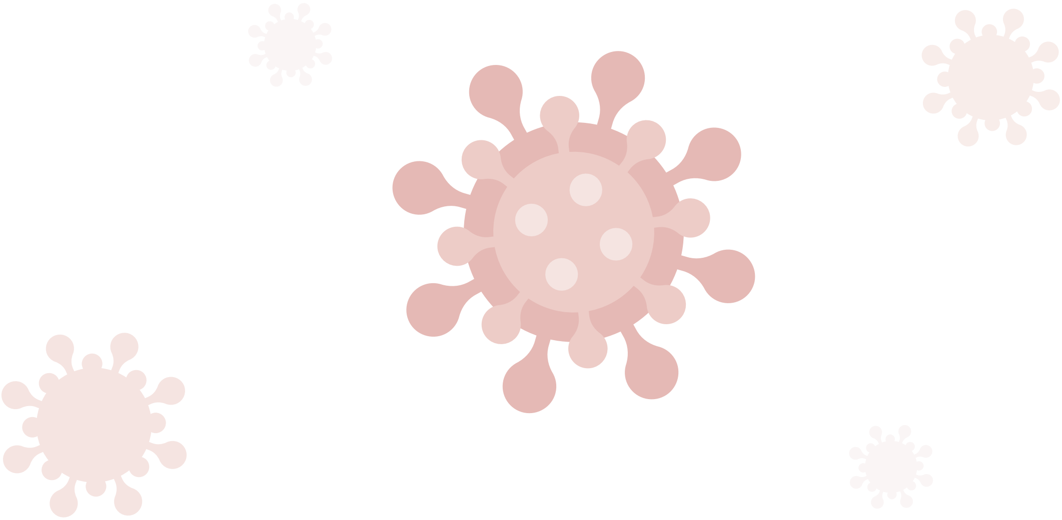
As part of Spain's CIBERPOSTCOVID Project *(8)*, case definition and case criteria have been defined through a Delphi consensus with the participation of patient representatives, clinical professionals, teaching and research professionals, managers and planners.

The clinical guideline for the management of people with persistent symptoms of COVID-19 in Catalonia was published in March 2021 *(11)*. The guideline was initiated by the Health Department, and patient representatives and professional specialities participated in its production. The guideline is not compulsory but acts as a recommendation tool for day-to-day practice. Diagnostic criteria in Aragon were decided by those in charge of formulating health-care procedures concerning PCC and led by the DGAS. There is only one version of this document from November 2021 *(12)*.

In the United Kingdom, the National Institute for Health and Care Excellence and NHS England provided the above definitions and diagnostic criteria *(6)*.

A committee of professional associations appointed by the MoH in Israel in September 2021 decided diagnostic criteria and they have not changed since the committee's establishment.

The diagnostic criteria in Italy were established by the National Institute of Health (*Istituto Superiore di Sanità* (ISS) in collaboration with the MoH, and with representatives of regional offices and national experts. The ISS is the institution responsible for the development and approval of guidelines for clinical practice.



4. Estimated prevalence and the impact of PCC on health services

Estimation of occurrence of symptoms potentially related to PCC in primary care

There is known to be a high prevalence of PCC in many countries yet there is insufficient clear and continuous surveillance/monitoring to provide detailed and reliable national data in many countries in the Region. Challenges with establishing prevalence include the wide range of symptoms associated with PCC, which may lead clinicians to alternative diagnoses; associated dismissive stigma associated with the condition; and the lack of a single diagnostic test.

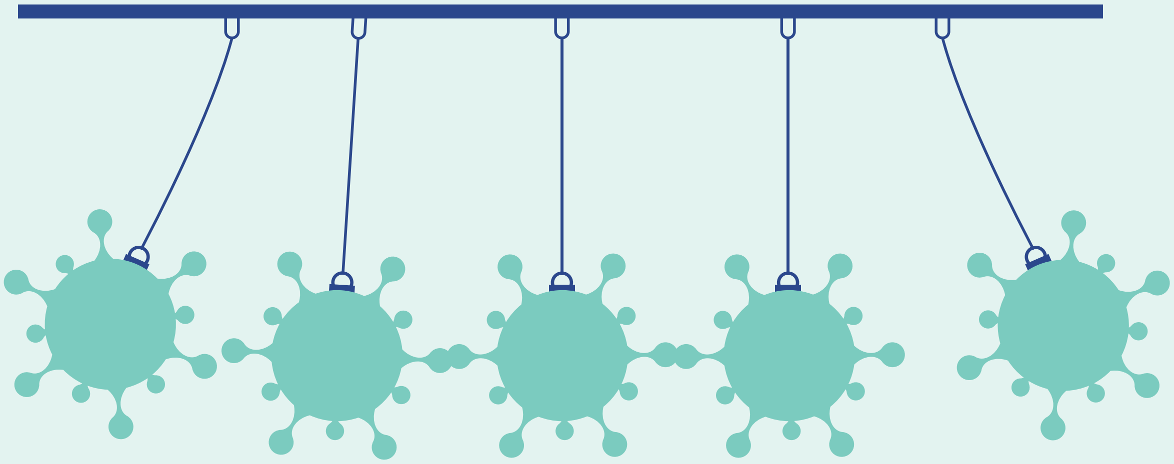
That said, in Italy, a primary care data source was used to select and follow up 78 539 patients aged 18 years or older experiencing COVID-19 in the period 1 January 2020–30 June 2021. In the follow-up period of 28 days, 13 733 patients (17.5%) experienced at least one symptom potentially associated with PCC. This is in line with estimates quoted in the background section of this report suggesting that approximately 10–20% of individuals who have had acute SARS-CoV-2 infection will continue to have symptoms for weeks, months and years afterwards.

A nationally representative sample of the Israeli population online survey, conducted from November to December 2021, found that, on average, 46.7% of respondents reported one or more PCCs *(13)*. In the low-income cohorts, a statistically significant higher rate of long-term fatigue was observed.

There are no official data available on the prevalence of PCC in Spain. A second phase of the CIBEREPOSTCOVID Project was to have been a prevalence study in various cohorts but it is unlikely that this will be carried out because of a lack of funding.

The data available in Aragon and Catalonia are related to the number of PCC diagnoses codified in computerized medical records at the primary care level. In Aragon, this corresponds to an estimated prevalence of 0.38% (1780 PCC diagnoses codified in 464 717 people with a confirmed SARS-CoV-2 infection) and 0.5% in Catalonia (there were 13 437 people with a PCC codification out of 2 681 683 COVID-19 cases up to 31 March 2023 *(14)*).

The Office for National Statistics in the United Kingdom analyses data from the Coronavirus (COVID-19) Infection Survey, a large national study in which participants could answer questions relating to PCC regardless of whether they had previously tested positive for COVID-19. As of March 2023, an estimated 1.9 million people living in private households in the United Kingdom (3% of the population) self-reported PCC symptoms (symptoms continuing for more than four weeks after the first confirmed or suspected COVID-19 infection) *(10)*.



Estimation of the impact of PCC on service use

Results of analysis in Italy show that, as expected, in almost all specific SARS-CoV-2 phases, individuals who recovered from a previous acute SARS-CoV-2 infection after hospital admission for non-intensive and intensive care units reported significantly higher rates of utilization of health-care services in the six months after infection (including hospital admission, specialist visits and instrumental diagnostic tests), and therefore higher expenditure, than those who never became infected.

In Israel the analysis is ongoing, and in Spain there is no overall data available. The information provided by the DGAS in Aragon shows that, in 2022, 263 people diagnosed with PCC were referred from primary care to secondary care for consultation. Most referrals were seen either in internal medicine (64 patients) or pneumology (63 patients). In Catalonia, according to the region's Scientific Advisory Committee for COVID-19, 3.3% of patients with PCC have visited an emergency room and 13% have attended outpatient consultations in hospitals, with most being seen in departments for infectious diseases, internal medicine, physical medicine and rehabilitation, neurology, rheumatology, cardiology, and otorhinolaryngology.

Primary care services in England are becoming increasingly skilled in managing PCC and can provide initial advice and formulate a management plan. Specialist PCC clinics have staff from a variety of disciplines including cardiology, respiratory medicine, rehabilitation medicine, psychology, physiotherapy, occupational therapy, speech and language therapy and dietetics.

PCC surveillance system

There is no ongoing national PCC surveillance system based on the use of administrative data in Italy and Israel. However, in January 2023, the ISS in Italy started a national surveillance on PCC using a shortened version of the post COVID-19 case report form from the WHO Global Clinical Platform for COVID-19 *(15)*.

Each autonomous community in Spain is responsible for public health surveillance within its territory, and the collected data must be reported to the Public Health Department of the MoH. From March 2022, weekly reporting of COVID-19 has been limited to patients over 60 years old, the number of hospital and intensive care admissions, and deaths from COVID-19 infection in each autonomous community.

The United Kingdom Health Security Agency undertakes COVID-19 surveillance in England. It reports monthly on case detection, hospitalization, and death rates per region.

5. Patient management

The diversity of health providers in Spain makes it difficult to map patients' care in each facility or territory and to implement a unique patient management protocol. Thus, in Catalonia, the management varies according to each individual facility. Access to services for patients with PCC is via primary care and, as with other conditions, referral to secondary care or rehabilitation is dependent on main symptoms. Some primary care centres have created services for PCC, such as mutual support groups or emotional well-being workshops *(11)*. The patient can be referred to the primary care centre's social worker if social needs are detected. Secondary care is accessed via referral from primary care, emergency care or intrahospital consultation. Several hospitals have created specific multidisciplinary units. Patients with PCC who have fatigue as a main symptom, and which is of more than six months' duration, can be referred to a specialized chronic fatigue syndrome unit. In some hospitals, PCC management is integrated into outpatient departments. Primary care professionals can also refer patients to rehabilitation services but in some areas the waiting time can be more than four months.

Aragon has opted for a patient management model led by primary care and integrated into pre-existing services *(12)*. This approach guarantees continuous and accessible management, complemented by secondary care in cases of high complexity. A health-care procedure for PCC was developed with the participation of various disciplines. This is not compulsory but works as a recommendation tool for those in primary and secondary care. Primary care doctors are responsible for initial assessment. Those classified as having a low risk of developing PCC will be followed by their primary care team. For those at moderate risk, the family doctor will request a virtual consultation for the patient with internal medicine or pneumology, or with the rehabilitation service. Severe risk refers to patients who were hospitalized in the acute phase of COVID-19. After discharge, primary and secondary care teams will coordinate follow-up. Referral to secondary care depends on the patient's main symptom. Referral aims to diagnose reversible damage and provide treatment if required. Generally, secondary care services include the management of PCCs in their regular activities. Some have created specific services but there are no disaggregated data available yet.

There are 90 specialist PCC services funded by the NHS in England, which have so far treated more than 40 000 patients *(16)*. Most specialist clinics have a multidisciplinary team of professionals led by a doctor, nurse, or rehabilitation professional, such as a physiotherapist or occupational therapist with expertise in PCC management. These clinics are mostly in primary care, with some in secondary care. Guidance from NHS England and the National Institute for Health and Care Excellence provides management protocols *(6,18)*. Usually, patients with acute COVID-19 infection are advised on their recovery and how to seek support regarding new, ongoing, or worsening symptoms. Patients with symptoms extending beyond four weeks should be offered an initial assessment that includes a comprehensive clinical history and assessment of cognitive, psychological, and psychiatric symptoms, as well as physical symptoms. Investigations should be tailored to the patient's symptoms. Patients should be managed in integrated, multidisciplinary rehabilitation services provided by a core team of practitioners in occupational therapy, physiotherapy, psychology and psychiatry, and rehabilitation medicine. Because PCC symptoms are so wide-ranging, other areas of expertise that could be useful include neurology, cardiology, paediatrics, dietetics, speech and language therapy, nursing, pharmacy and social care, and patients are supported to return to education or work.

National good practice recommendations for patients with PCC in Italy *(7)* provide key principles for service organization and patient management. The recommendations stress that a specific PCC evaluation should be undertaken:

- in all patients hospitalized for COVID-19 four to six weeks after discharge; and
- in patients who were not hospitalized but who present with new or persistent signs or symptoms not explained by an alternative diagnosis for more than four weeks after acute infection. Special attention should be paid to patients with frailty or clinical complexity who are at higher risk of developing typical or atypical complications of PCC.

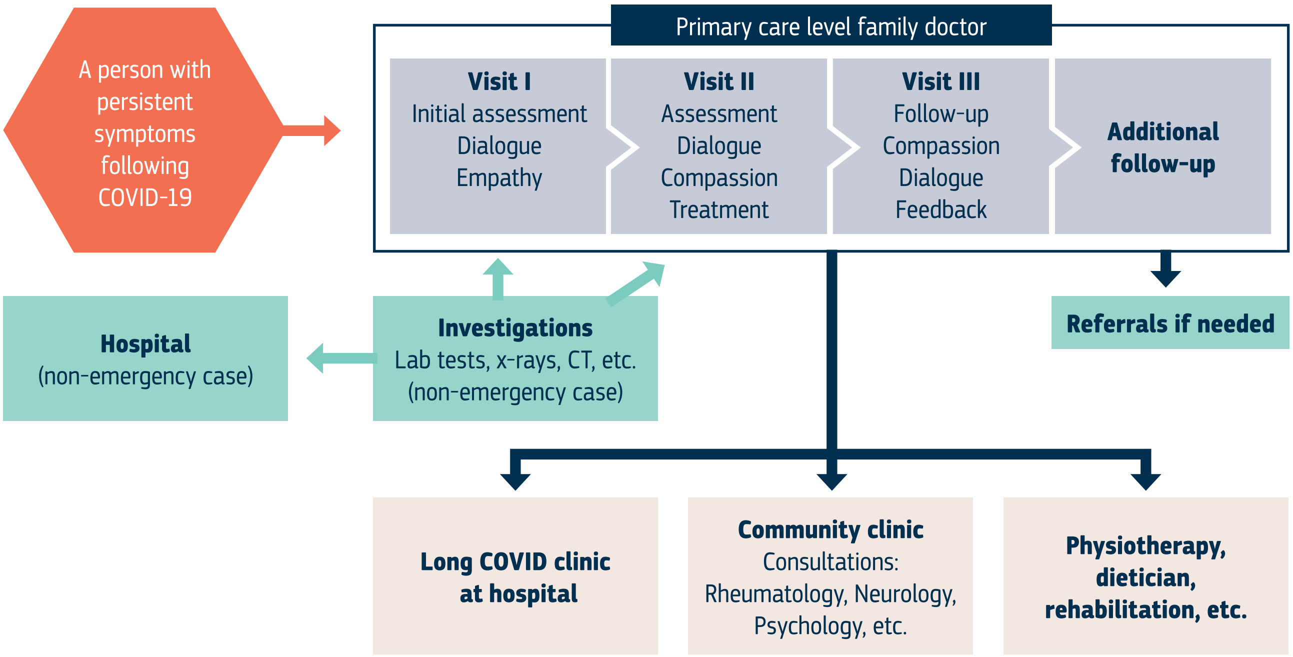
Primary care providers (general practitioners (GPs) and paediatricians) should be the first health professionals to evaluate patients with suspected PCC. Care of those with a low level of clinical complexity can be coordinated and managed by primary care providers. Patients with a high level of clinical complexity can be managed in a different context (for example, hospitals) but direct contact with the primary care provider should be maintained. In patients who have been hospitalized for COVID-19, an evaluation for symptoms of PCC can be performed either by the primary care provider or in multidisciplinary services. Follow-up visits and diagnostic tests should be scheduled in a personalized and tailored manner, according to the clinical needs of the patients.

The composition of PCC teams in Israel varies depending on whether they are health providers in hospitals or HMOs. In hospitals, treatment providers tend to be pulmonologists, neurologists, or virologists, generally without additional staff members. There are a few hospital clinics that deploy rehabilitation doctors and multidisciplinary staff. Among HMOs in the community, most clinics are managed by family doctors, either without additional staff or alongside health professionals, such as physiotherapists, speech therapists and occupational therapists. The family doctor is the first point of access as PCC consists of many complications pertaining both to physical and mental health. In most cases, the family doctor issues treatment recommendations and, depending on the patient's medical situation, might refer him or her to a consultant, such as a neurologist or pulmonologist. Management protocols are, for the most part, determined by the judgement of the medical professionals directly involved in treatment.

6. Service organization and patient pathways

Primary health care is the point of access for most PCC patients in Israel and, if necessary, the doctor can either arrange to see the patient again for more detailed assessment or refer the patient to other hospital- or community-based health service providers (Fig. 1). A small minority of patients go to providers of alternative medicine, such as acupuncture or natural health centres. Patients who are hospitalized are treated in regular wards according to their medical needs and not in wards dedicated to PCC. There are no specific guidelines, as the course of action is determined by the condition of the patient and whether he or she requires treatment provided only in the hospital or whether treatment can be provided in the community. Family doctors can refer patients for most of the required laboratory tests and screenings, with a few exceptions, such as magnetic resonance imaging. If the request does not include the appropriate level of detail, there may be a need to obtain a referral from a consultant.

Fig. 1. Patient pathways for PCC in the Israeli health system



Note: CT: computer tomography

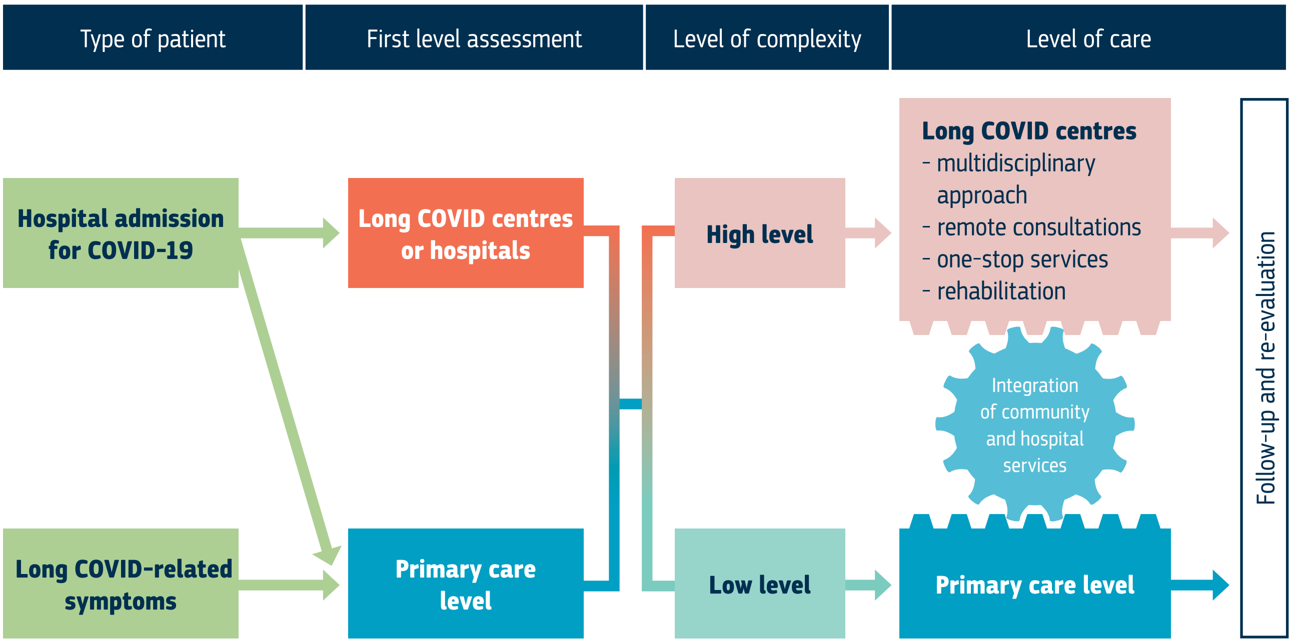
Source: from Professor Bishara Bisharat, Israeli MoH, unpublished data

The MoH in Italy did not issue mandatory directives on the organization of care for patients with PCC. Regions and autonomous provinces defined their own directives for pathways and for service organization of PCC care centres. To monitor service organization, in May 2022 a national survey was undertaken to assess the organizational response of health services to PCC and to define the characteristics of PCC care centres *(15)*. Overall, 124 care centres were identified and survey results showed a high heterogeneity in service organization. More specifically:

- access to centres followed multiple pathways that included scheduled visits for previously hospitalized patients (67.7%), referral from primary care (62.1%) or other specialists (46.8%), and, less commonly, access from other territorial services;
- almost all the centres (93.5%) had communication pathways with primary care physicians;
- only 6% of centres offered rehabilitation services;
- most of the centres were hospital-based and only 4% provided home care; and
- tests and evaluations performed in centres were highly variable. Only half of the centres provided multidimensional assessment (54.8%) or psychological evaluation (46.8%). Less than half provided an assessment of cognition (37.9%) or nutritional status (30.6%).

Given the high heterogeneity in the organization of services and centres, the ISS produced and released national good practice recommendations for the management of people with PCC in December 2022. Fig. 2 shows the proposed pathway for patients with long COVID. As described above, entry points in the care pathway can vary. Generally, patients who have not been hospitalized have a first appointment with their GP (or paediatrician for children), while hospitalized patients have their first follow-up visit at the hospital where they were admitted for COVID-19. From these two first points of entry, patients can be referred to specialized clinical centres for PCC, according to their level of clinical complexity.

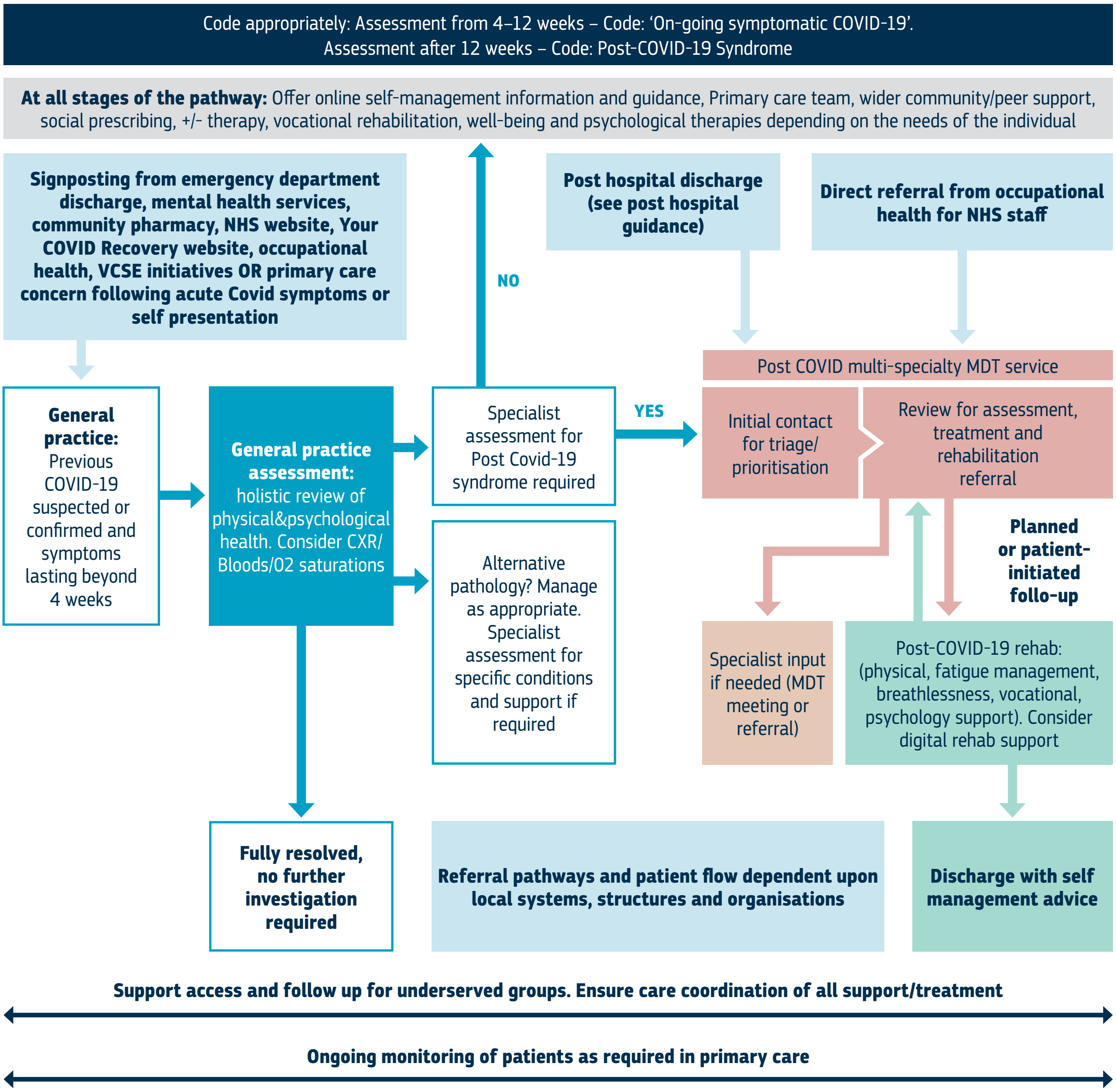
Fig. 2. Proposed patient pathway for patients with PCC in Italy



Source: from Professor Graziano Onder, Italian National Institute of Health, unpublished data

The PCC primary care/community pathway for adults in the United Kingdom is shown in Fig. 3, while Fig. 4 shows the post-hospital discharge pathway *(16)*. Initial GP assessment following suspected or confirmed COVID-19 infection and symptoms lasting beyond four weeks includes a holistic review of both physical and psychological health. Alternative pathologies will be managed appropriately, but if further assessment for PCC is required, the patient may be referred to a specialist multidisciplinary team. Options thereafter include multifaceted rehabilitation and digital support via a dedicated application and eventual discharge with self-management advice.

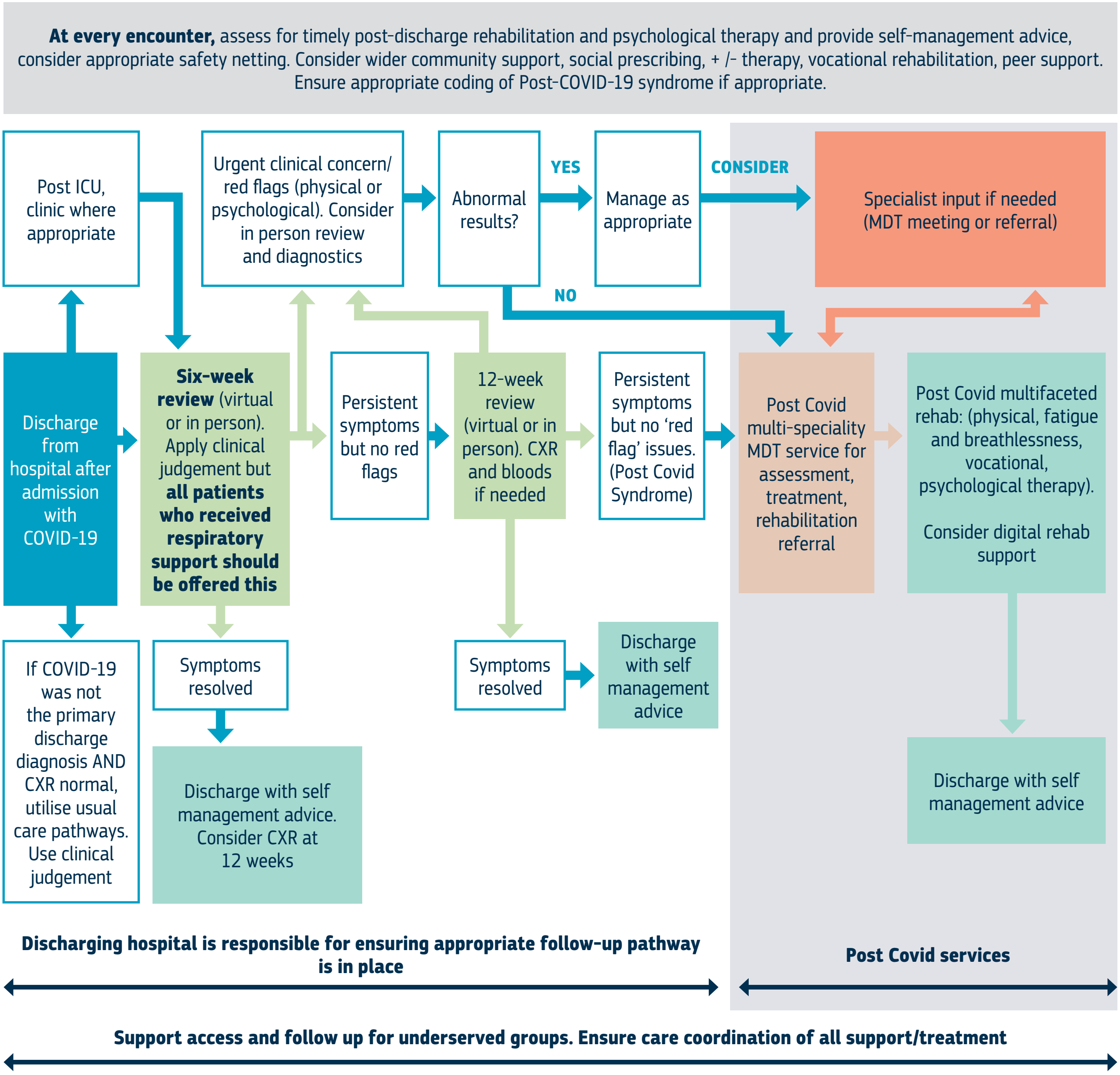
Fig. 3. Primary care/community long COVID pathway for adults in the United Kingdom



Notes: CXR: chest X-ray; MDT: multi-disciplinary teams; VCSE: voluntary, community and social enterprise sector

Source: reproduced by permission of the publisher from NHS England *(18)*

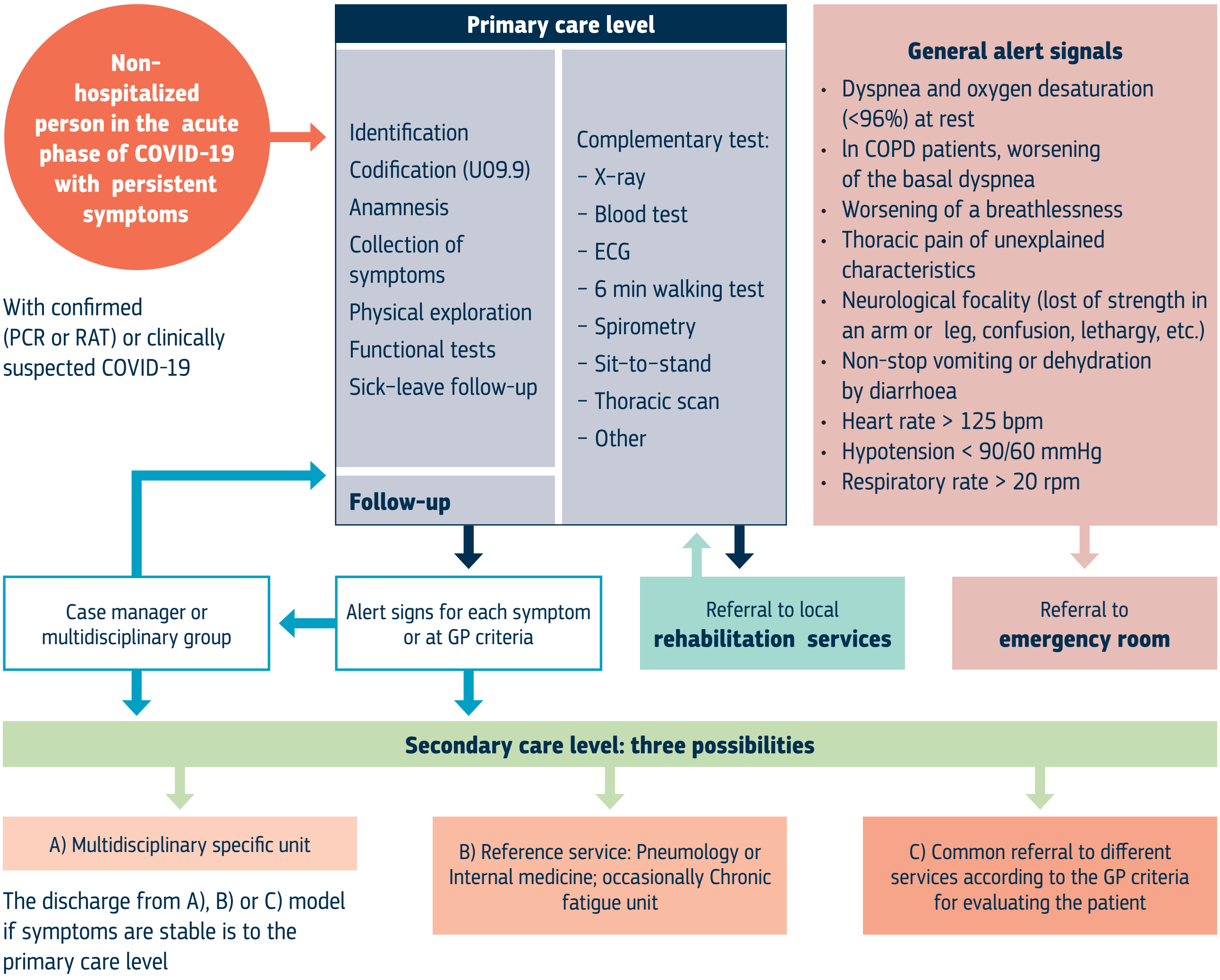
Fig. 4. Post-hospital discharge pathway for adults with long COVID in the United Kingdom



Notes: CXR: chest X-ray; ICU: intensive care unit; MDT: multi-disciplinary teams
Source: reproduced by permission of the publisher from NHS England *(18)*

Fig. 5 shows the pathway of non-hospitalized patients with PCC through the health system in Catalonia, following the clinical model recommended by Catalonia's clinical guideline on PCC *(11)*. As with other diseases, assessment and clinical tests in primary care may lead to secondary care referral. However, depending on the hospital's management of PCC, the patient can then be referred specifically to a specialist PCC team, to other departments, such as internal medicine or pneumology, which works as a reference service for the disease, or, if fatigue is the main symptom, to the chronic fatigue unit. Fig. 6 shows the pathway for patients hospitalized during the acute phase of COVID-19 infection but who develop persistent symptoms. They are likely to be referred after discharge to specialist respiratory services and, after evaluation, returned to primary care for follow-up and rehabilitation. Primary and secondary care coordination depends in each territory on the model of care used for the management of PCC. Some regions have organized patient pathways through the available services and institutions; others have not yet done so. As coordination has been the exception, most primary care centres have not been informed about which organizational model has been implemented at their reference hospital to care for patients with PCC. This means that, although the management model lies theoretically with primary care, the way PCC is managed depends mostly on how the reference hospital has organized its PCC services.

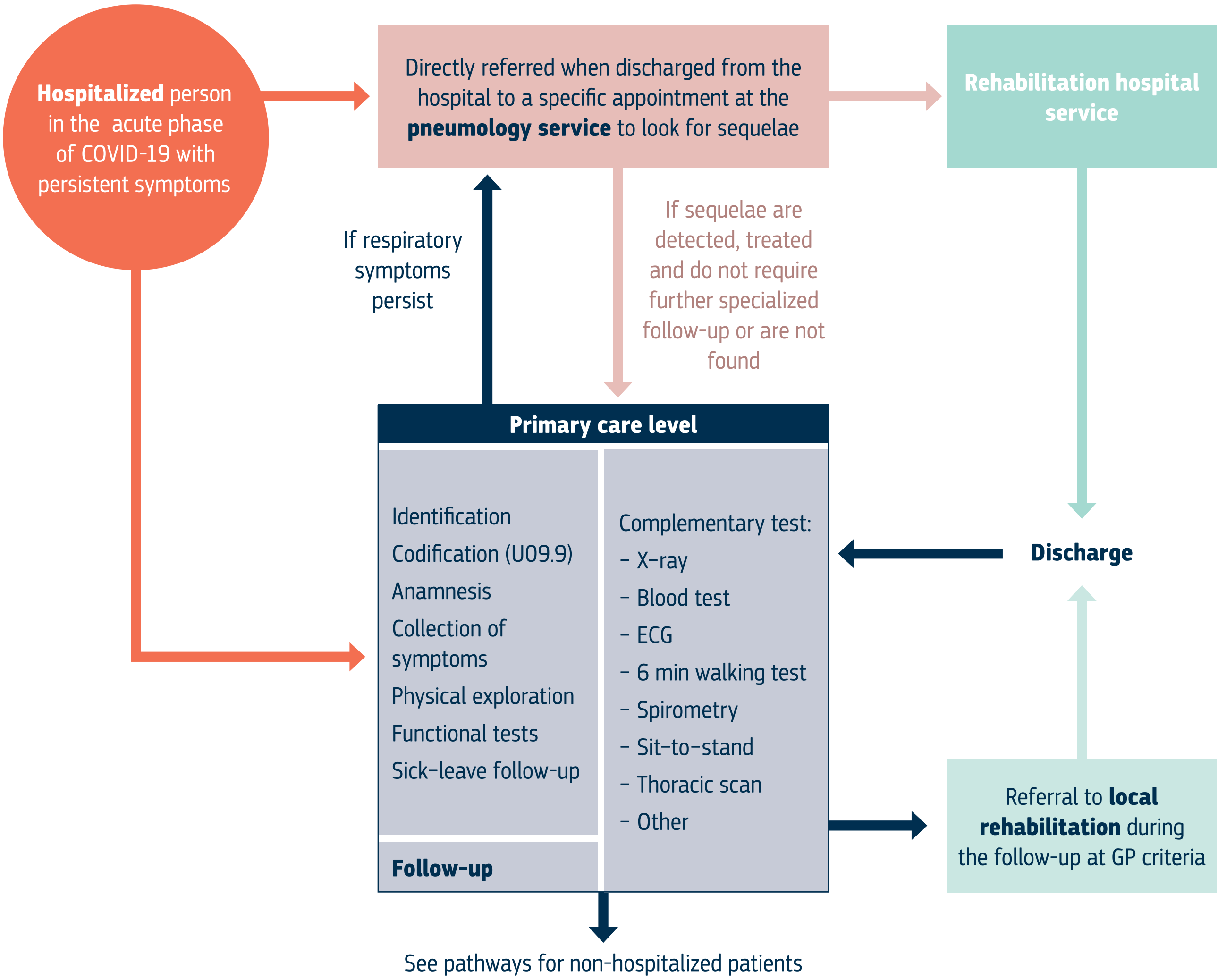
Fig. 5. Generic pathway for non-hospitalized patients during the acute phase of COVID-19 with persistent symptoms in Catalonia



Notes: COPD: chronic obstructive pulmonary disease; ECG: electrocardiogram; PCR: polymerase chain reaction; RAT: rapid antigen test

Source: from Gemma Torrell Vallespín, Catalan Health Institute, unpublished data

Fig. 6. Generic pathway for hospitalized patients during the acute phase of COVID-19 with persistent symptoms in Catalonia

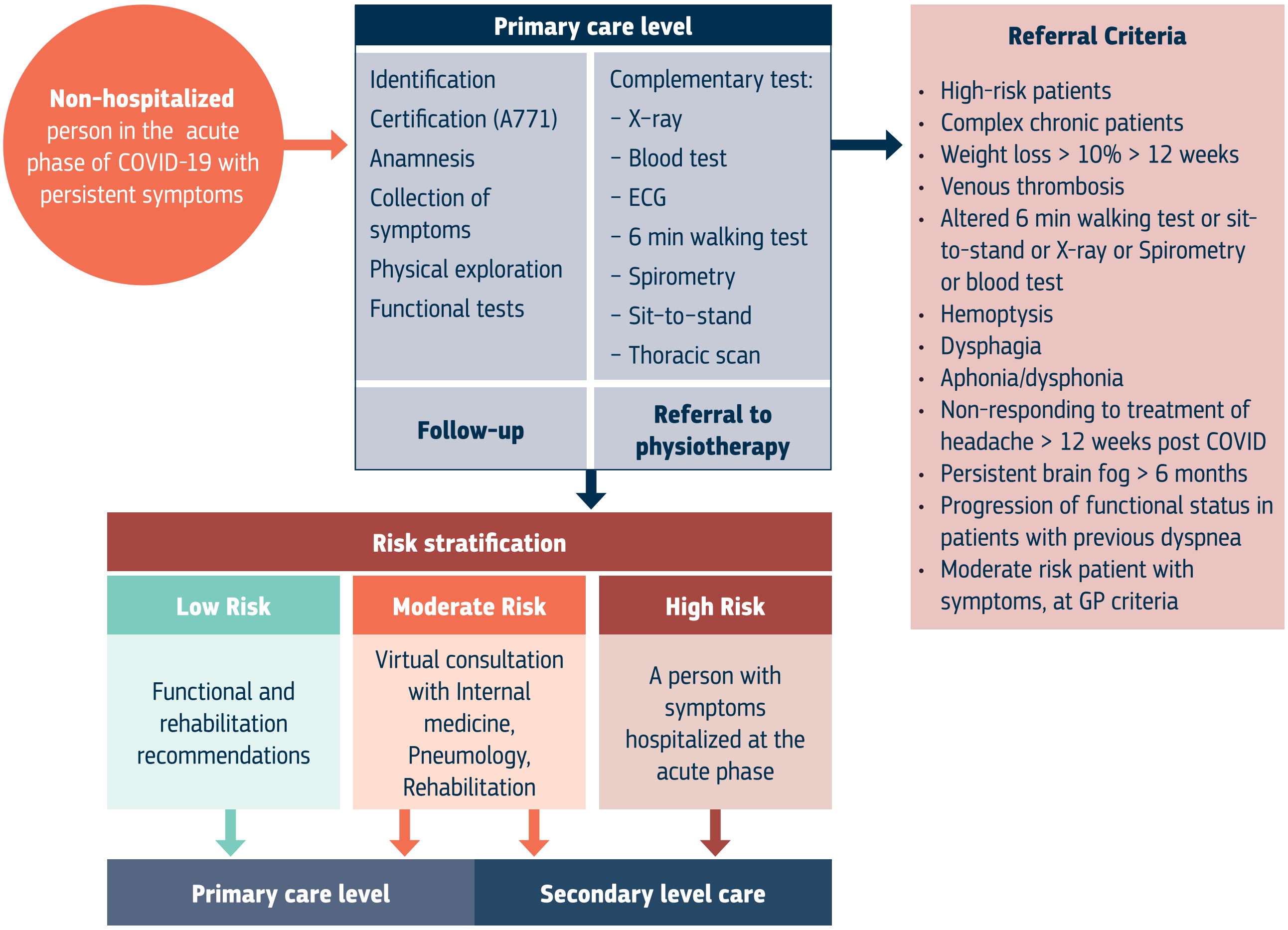


Notes: ECG: electrocardiogram

Source: from Gemma Torrell Vallespín Catalan Health Institute, unpublished data

Fig. 7 shows a similar pathway for a patient with long COVID through health-care services in Aragon, where onward referral decisions are based on risk assessment undertaken at the primary care level and integrated into pre-existing referral pathways and hospital services.

Fig. 7. Pathway for a patient with PCC through the health-care system in Aragon



Notes: ECG: electrocardiogram

Source: from Gemma Torrell Vallespín, family doctor, Catalan Health Institute, unpublished data

7. How is PCC integrated into health information systems?

The 90 specialist PCC clinics in England, United Kingdom (England) provide basic statistics on admission, discharge and caseload to NHS England. Patient-identifiable information is not provided due to information governance and data protection rules. Funding for services depends on the scale of the region and population served. The individual PCC clinic will generate its detailed service evaluation for audit and clinical governance. NHS England is trying to evaluate outcomes in these 90 specialist clinics using the ELAROS digital platform and Living With digital application systems. Even though the number of patients managed in these services is known, the outcomes are not entirely clear and will be better understood when the service evaluation findings are published later in 2023.

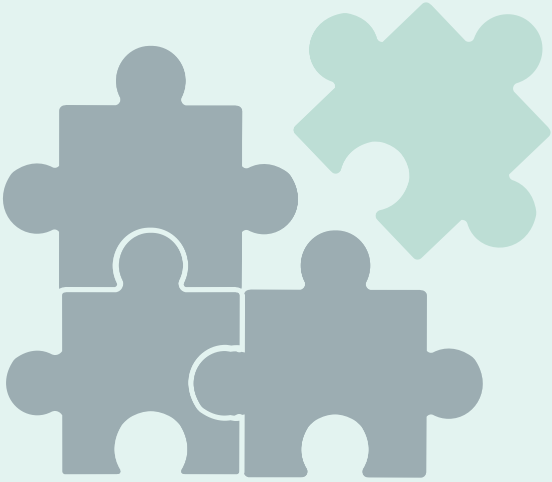
The information system of the National Health System (*Sistema de Información del Sistema Nacional de Salud*) in Spain was set up in 2003 and is managed by the MoH. For COVID-19, the epidemiological surveillance system of each of the 17 autonomous communities is responsible for reporting all cases recorded in primary and secondary care, both public and private, by preventive services and all diagnostic laboratories. Data from nursing homes on COVID-19 infection was reported weekly until January 2023 by each autonomous community to the Ministry of Social Rights. The *Secretaría General de Salud Digital, Información e Innovación*, and the *Subdirección General de Información Sanitaria*, part of the MoH, gathers data from the 17 autonomous communities through the primary care clinical database *(Base de datos clínicos de atención primaria*).

In Catalonia, the computerized medical record platform in primary care uses the WHO International Classification of Diseases, Tenth Revision (ICD-10) register. Since 1 January 2022, the code used for a diagnosis of PCC is U09.9, together with the code of the main persistent symptoms reported. In 2020 and 2021, the code used was B94.8 (other infectious diseases sequelae), again with the code for the main persistent symptoms also reported. This codification is also used in referrals from primary care to other services. The data are automatically collected through primary care services information system (*Sistema d'informació dels serveis d'atenció primària)*, a tool used to provide information on clinical management to health professionals and managers.

PCC in Aragon is reported in primary care through codification in computerized medical records. At the secondary care level, the codification system used is ICD-10, with data collected at discharge. In outpatient departments, activity generated by PCC is reported as part of general activity.

ICD-10 codes are used in Italy mainly for coding causes of death. Based on this classification system, codes U09.9 (post COVID-19 condition), U08.9 (personal COVID-19 medical history) and U10.9 (multisystem inflammatory syndrome associated with COVID-19) are adopted on death certificates to identify the long-term consequences of SARS-CoV-2 infection. The International Classification of Diseases, Ninth Revision, Clinical Modification is used for the coding of clinical information contained in hospital discharge forms and for the remuneration of hospital services. A decree by the MoH in October 2020 integrated this information with a specific code to identify people with potential risk of disease concerning their family and personal medical history of SARS-CoV-2 infection.

Acute COVID-19 cases in Israel have, in general, been integrated into the surveillance system. The approach may be different for PCC cases because PCC may not be considered a separate disease but a sequel or prolongation of the acute infection or a syndrome without specific symptoms. The elements that are being reported differ. Some health systems may record only the activity (for example, outpatient consultation, rehabilitation session, etc) and not the diagnosis, while others may record the main symptom(s). The way these patients and the activity they generate are recorded may also depend on the characteristics of the health information system and may range from aggregated reports of activity to individual clinical records from which diagnostics and activity are automatically reported. Hospitals report according to post COVID-19 diagnoses as well as symptoms, while among HMOs in the community, reporting is conducted primarily according to symptoms. Activity generated by post COVID-19 patients is reported in hospital databases, but it is not yet sufficiently precise or reliable.



8. Implementing the service delivery model: challenges and limitations

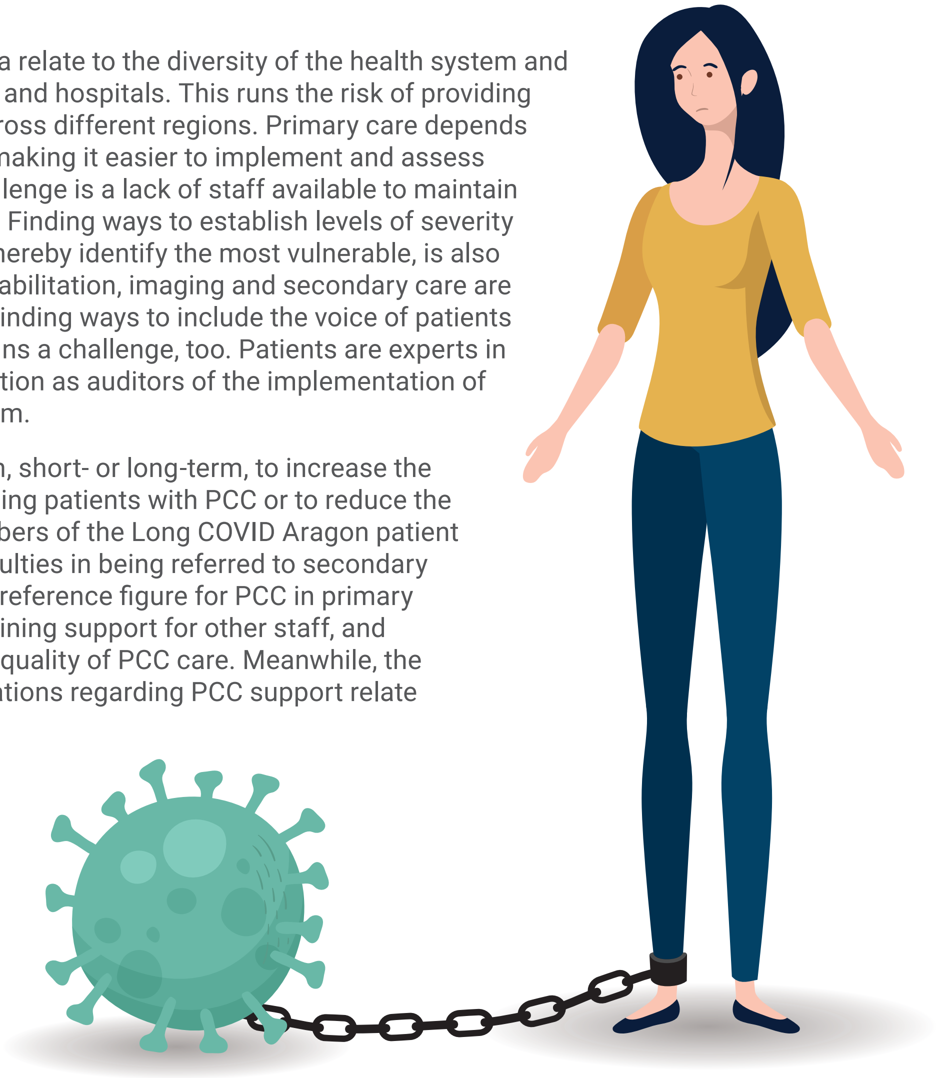
In Israel, results of laboratory tests and scans are understood increasingly as a means of ruling out other illnesses before PCC is considered. There is also work ongoing in raising awareness among health system managers to recognize the importance of training family doctors in PCC diagnosis, support and treatment. There is still no specific funding for PCC services and there are no plans at present to increase staff availability in such services. The goal is that post COVID treatment becomes an integral part of medical follow-up, in line with other illnesses and complications in the community health system.

The United Kingdom is experiencing a shortage of staff across all specialties including PCC services. Every specialist providing PCC service is predominantly staffed by nurses, physiotherapists, occupational therapists and counsellors, with a visiting medical doctor present for a few sessions a week. NHS England has strongly recommended that PCC services be led by doctors with experience and skills in PCC medicine and who have links with all relevant specialists. NHS England spends £124 million on running the 90 specialist PCC clinics and funding has been extended until March 2024. The biggest challenge remains the lack of proven treatments for PCC. There is still no clear biomarker for the condition or a pharmacological agent that can reverse symptoms. Therefore, specialist PCC services are unable to offer any treatment that is experimental and currently being tested in some countries, such as hyperbaric oxygen, anticoagulants, plasmapheresis, or immune-modulating agents.

The main challenges and limitations to service delivery in Italy are resources and the regional organization of the health service. A national decree issued in August 2021 guaranteed funding for the care of people with PCC until 2023. With health care decentralized, responsibility for services and service delivery lies with the country's 19 regions and two autonomous provinces but the MoH is responsible for monitoring whether essential levels of care are being provided to people with PCC in each region and province.

The main challenges in Catalonia relate to the diversity of the health system and streamlining between territories and hospitals. This runs the risk of providing different services to patients across different regions. Primary care depends mostly on one unique provider, making it easier to implement and assess a single model, but here the challenge is a lack of staff available to maintain continuity of care and follow-up. Finding ways to establish levels of severity among patients with PCC, and thereby identify the most vulnerable, is also a challenge. Waiting lists for rehabilitation, imaging and secondary care are a further barrier to better care. Finding ways to include the voice of patients in the organization of care remains a challenge, too. Patients are experts in their disease, and they also function as auditors of the implementation of any care model that involves them.

Aragon has no specific provision, short- or long-term, to increase the number of qualified staff managing patients with PCC or to reduce the impact of staff shortages. Members of the Long COVID Aragon patient group have reported some difficulties in being referred to secondary care. The group has called for a reference figure for PCC in primary care who acts as clinical and training support for other staff, and for specific units to improve the quality of PCC care. Meanwhile, the DGAS states that the main limitations regarding PCC support relate to the dissemination of the PCC procedure to staff and the need for training that reaches many health workers. Challenges also include finding more ways to engage patients in the organization of health-care services.



9. Communication and patient/community participation

While the DGAS has not planned any communication strategy to disseminate information about PCC to the population of Aragon, nor about the model of management or the organization of services, there was a press conference to announce the launch of the health-care procedure for the management of PCC. DGAS spokespeople have also been interviewed in the media. The Long Covid Aragon patient group, created in January 2021, now has 600 members and has met with the DGAS three times since. Group members were invited to review a draft of the health-care procedure before it was published. Long COVID Aragon also asked the Aragon parliament to create specific multidisciplinary units to manage PCC. This request was subsequently approved.

The health care and participation secretary of the Health Department in Catalonia and the Long COVID Catalan patient group (*Col·lectiu*) began a collaborative project in June 2020, creating infographics and a video to inform the public about the persistence of symptoms after COVID-19 infection. Information for primary health professionals about the main symptoms was also shared through social media. The *Col·lectiu* was created in May 2020 when a person affected by PCC asked, via Twitter, if anyone else was experiencing symptoms. The group currently has about 1500 members. Through contacts in the media, the *Col·lectiu* has been an active advocate for strengthening the public health-care system and primary care.

In Israel, PCC symptoms and treatment are referred to in published literature within the health system, including certain hospital and community clinic websites, as well as through family medicine practitioners. The public at large is freely able to make inquiries about PCC to doctors and nurses in the community clinics that are widely accessible throughout the country.

Communication with patients and other United Kingdom health services about specialist PCC teams was made in time and using good existing channels within the NHS. Patients with PCC have been very vocal and have driven change in services, research and national priorities related to this novel condition. The term “long COVID” was coined by patients in the United Kingdom and is now well-recognized worldwide. Patients are represented on the NHS England, which decides on the funding structure for PCC services. There was strong patient involvement in the National Institute for Health and Care Research’s investment of £50 million in PCC research, and all successful projects have a strong component of patient and public involvement.

The ISS in Italy has worked to increase awareness and knowledge of PCC among citizens and health professionals and to improve the access of patients to available services. This was mainly realized through the ISS website, which represents a reliable and accessible channel for reaching the public, to disseminate updated information and distribute documents. The website contains a section dedicated to PCC; and web content, in Italian and English, is regularly updated and is available for download on smartphones. A list of PCC care centres and how to access them is also published on the website. The ISS manages the main social media channels through a specific press office, offering regular updates on health topics. Relevant publications on PCC have been promoted through these social platforms.

10. Performance of PCC services and future plans

A performance assessment is yet to be carried out on PCC services in the United Kingdom, but NHS England has suggested an extensive list of performance indicators. This includes, among other suggestions, that referral to the service should be offered to all affected patients from four weeks after the start of acute COVID-19 illness, regardless of whether they were hospitalized. Also, triage should be offered if the waiting time for the first assessment is longer than six weeks and should be undertaken by a registered health-care professional with experience in PCC. Further, a single point of access to the pathway should be considered to enable consistent approaches. PCC services report to NHS England on caseload and outcomes regularly and their funding has been agreed until March 2024.

In Italy, a performance assessment of PCC services is not routinely performed. As stated above, in May 2022 a national survey aimed at assessing the organizational response of health services to PCC and defining the characteristics of PCC care centres was performed by ISS jointly with the MoH. The results of the survey, based on a specifically designed questionnaire, showed a high heterogeneity in service organizations. Several indicators were assessed, including access pathways, availability of telemedicine tools and rehabilitation services, and implementation of multidimensional assessment or psychological evaluation. However, this evaluation was not meant to be used for routine assessment of the performance of PCC services.

According to the DGAS in Aragon, there are no results available yet on the performance of post COVID-19 services and there are no plans to modify the model of health-care organization for long COVID. However, the registration of standardized symptoms of PCC indicators are incorporated in computerized medical records in primary care. The indicators are included in the contract between the DGAS and each decentralized area of management of primary care, called *sector sanitario,* regarding performance in primary care.

There are no indicators defined to assess the overall performance of PCC services in Catalonia because there is no shared and homogeneous model followed. In areas where a programme to coordinate management has been designed, some indicators to evaluate the programme have been included. The Catalan health minister has prioritized a PCC situation document as a first step in establishing a model of care for patients, which is likely to be communicated in the next few months.

Israel has yet to design performance indicators for PCC services or conduct any performance assessment. However, great importance is attached to considering and planning for the near future following global research on PCC and its treatment. As such, clinical guidelines will be updated appropriately in due course and metrics established to measure treatment quality.

11. Summary and conclusions

It may be premature to draw firm conclusions from the data presented in the reports that are synthesized here. Countries around the world are, to varying degrees, still adapting their health services to meet the needs of patients with PCC, and surveillance systems are not yet sufficiently robust to offer a wholly accurate portrayal of the prevalence of PCC and whether services are meeting patients' needs. That said, some common themes have emerged from the country/region reports.

When defining PCC, most of the countries studied seem to refer to and work with the WHO definition of PCC, particularly regarding the duration of symptoms pre-diagnosis – 12 weeks or more.

There remain no confirmatory laboratory tests for PCC or agents that can reverse symptoms but good practice recommendations in most countries highlight the need to perform a multidimensional assessment of patients being screened for or with suspected PCC. Further training for clinicians in recognizing PCC and considering it as a diagnosis will benefit patients.

Prevalence is known to be high in many countries, but detailed data are currently lacking. A further challenge to establishing robust prevalence data arises from the array of symptoms, which may be present in patients with PCC. This diversity can result in patients receiving alternative diagnoses. In the countries covered by this report, prevalence ranged from about 5% in Israel to more than 17% in Italy. Accurate prevalence data will support the case for better services.

Concerning patient management and service delivery, there were commonalities among the countries studied. Primary care is the first point of contact for patients with PCC; coordination and management of cases are undertaken by GPs/family doctors; and referral to hospitals, dedicated PCC departments and clinics, and/or specialities, such as pulmonologists and neurologists, is the usual next step in more complex cases. Multidisciplinary teams play a vital part in the treatment of PCC and virtual consultation is common in some countries. It is widely acknowledged that collaboration between hospital and community services, including rehabilitation, is critical in the PCC pathway.

Beyond service delivery, PCC services are commonly challenged by funding and resourcing issues. Other reported challenges included workforce shortages, waiting times for rehabilitation and other services, identifying the most vulnerable patients, weak service organizations, integrating PCC services into community health systems and a lack of proven treatments. As with better prevalence data, measuring the performance of PCC services should ultimately contribute to improved care.

Patients have an important role to play in the way PCC services are delivered and evaluated, and there were examples of strong patient inclusion in the development of services in the countries studied. Raising public awareness of PCC and its symptoms was recognized as an important function of governments and health services, and a variety of channels were used to good effect.

Given that PCC emerged relatively recently as a widespread health concern, structures for systematic surveillance are still evolving and will contribute to a better understanding of the condition. Similarly, performance indicators for PCC services, still being developed and refined, will build the foundation for countries undertaking a comprehensive performance assessment of their delivery structures.

Call for actions

The findings of this report reflect the key outcomes from a side event *(17)* on health systems' response to PCC, in September 2022 during the WHO Regional Committee for Europe, that called for actions in Member States. These actions should prioritize establishing service delivery structures to provide patient-centred, integrated care pathways that are based in primary health care and that are the point of referral for more severe cases. Such structures should aim to model an individualized multidisciplinary care pathway in which patients' multi-system symptoms and rehabilitation needs are assessed and managed, informed by real-world outcome data and patient experience. Improving monitoring, surveillance and data management of the condition are foundational to these services.

Promoting recognition of the condition is also a priority and can help combat the associated stigma that some people with PCC experience.

Also, options for diagnosis and treatment for the condition, as well as training and support in managing PCC for health-care professionals, should be improved universally, with health systems adequately resourced for all these tasks.

Patients need to be at the core of strategies and services dedicated to the condition, and experiences, lessons and evidence need to be shared between and within countries.

The WHO Regional Office for Europe continues to raise awareness of the issue and advocate for adequate and long-term funding for diagnosis, treatment, and research on PCC.

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The WHO Regional Office for Europe

The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

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