

COVID-19 follow-up programmes across Europe: an ERS END-COVID CRC survey

To the Editor:

Copyright ©The authors 2022.

This version is distributed under the terms of the Creative Commons Attribution Non-Commercial Licence 4.0. For commercial reproduction rights and permissions contact permissions@ersnet.org

Received: 4 May 2022 Accepted: 11 July 2022 SARS-CoV-2 is responsible for a multi-organ syndrome that can last over 12 months after the initial infection, which includes pulmonary and systemic consequences with residual radiological or functional alterations [1–3]. According to international guidelines, post-COVID-19 syndrome or condition is defined by a variety of signs and symptoms occurring during or after an infection consistent with COVID-19, lasting for more than 8–12 weeks and not explained by an alternative diagnosis [4, 5]. Main symptoms are fatigue, dyspnoea, arthralgia, chest pain, cough and neurocognitive impairment [6]. Approximately one-third of patients reported an impaired quality of life 3 months after a COVID-19 diagnosis [7]. Given the wide range of symptoms and severity reported, no set of investigations and tests seems to be suitable for everyone and the optimal follow-up after severe COVID-19 infection is still unclear, with scarce data published on this topic [4, 8, 9]. Furthermore, criteria for patients' inclusion in COVID-19 follow-up programmes and standard operating procedures (SOPs), including for imaging and functional assessment, telemedicine availability and characterisation of the involved multidisciplinary teams across Europe, are unknown. Based on published reports it can be expected that approaches to follow-up will be heterogenous among European countries [10].

In order to address this topic, a survey about COVID-19 follow-up programmes was conducted by the European respiratory Network for Data sharing on COVID-19 (END-COVID) Clinical Research Collaboration (CRC). The survey was designed to explore the heterogeneity of COVID-19 follow-up programmes across Europe and included 31 questions about the general organisation of programmes, patients' inclusion criteria, telemedicine availability and characteristics of follow-up visits (https://ers.app. box.com/s/rkwf44vfcrp7s10992ve0043llukg135). The survey was sent *via* email to the END-COVID academic stakeholders (including representatives named in every the European Respiratory Society (ERS) assembly and representatives of national or local COVID registries), to the ERS assembly on interstitial lung disease (ILD) and to every ERS member having highlighted an interest in participating in data collection. Only one reply from each centre was allowed.

Responses until September 2021 were collected from 130 centres across 26 European countries. The majority of the respondents were pulmonologists (90.8%), either general respiratory physicians (57.7%) or ILD specialists (33.1%). Other respondents were radiologists, nurses, internists, infectious diseases specialists, thoracic surgeons, clinical researchers and intensivists. 79.2% of centres were university hospitals, 13.8% regional hospitals, 6.2% private clinics and 0.8% outpatient clinics. COVID-19 follow-up programmes were managed by a dedicated clinical unit in 66.9% of the cases and the majority of those belonged to the pulmonary department. Follow-up programmes incorporated a multidisciplinary team in 81.6% of the centres, with the most frequently involved healthcare professionals being physiotherapists (84.6%), nurses (63.1%), psychologists/psychiatrists (46.2%), dieticians (27.7%), infectious disease specialists (15.4%), cardiologists (15.4%) and neurologists (10.8%). Only in one centre a general practitioner (GP) was incorporated. 43.4% of centres included only patients after hospitalisation and 56.6% included both previously hospitalised patients and ambulatory patients with persistent symptoms. The most commonly used criteria to include patients in the follow-up programmes were the need for oxygen therapy at hospital discharge (88.5%), the need for mechanical ventilation during hospitalisation (87.2%), intensive care unit admission (85.9%) and severe, persistent post-COVID-19 symptoms (64.1%). Telemedicine was available in 30.3% of the centres, consisting of symptom assessment, review of tests requested at discharge





Shareable abstract (@ERSpublications)

A large heterogeneity in the management of post-COVID-19 syndrome and in standard operating procedures for COVID-19 follow-up programmes across Europe exists https://bit.ly/30dPxgF

Cite this article as: Valenzuela C, Nigro M, Chalmers JD, *et al*. COVID-19 follow-up programmes across Europe: an ERS END-COVID CRC survey. *Eur Respir J* 2022; 60: 2200923 [DOI: 10.1183/13993003.00923-2022].

and request of further control tests according to symptomatic evaluation. The most used tools evaluated during telemonitoring were pulmonary function tests (PFTs), including spirometry and diffusing capacity of the lung for carbon monoxide (D_{LCO}), chest high-resolution computed tomography (HRCT) scan, chest radiography (CXR), blood tests and quality of life questionnaires. Timing for follow-up visits through



FIGURE 1 Prevalence across different European countries of four different aspects characterising post-COVID-19 syndrome programmes, including a) multidisciplinary approach, b) telemedicine availability, c) rehabilitation availability and d) first follow-up visit timing. Responses until September 2021 were collected from 130 centres across 26 countries (25 from Italy, 13 each from Greece and Spain, 10 from UK, nine from France, seven from the Netherlands, five each from Belgium, Poland and Turkey, four each from Germany, Croatia, Romania and Switzerland, three from Portugal, two each from Austria, Bulgaria, Hungary, Lithuania, Russian Federation, Serbia and Ukraine, and one each from Denmark, Ireland, Israel, Republic of Moldova and Sweden). telemedicine across different centres ranged between 2 weeks and 3 months after hospital discharge. Timing for face-to-face follow-up visits ranged between 1 month and 6 months after hospital discharge: 40.3% at 1 month, 13.9% at 2 months and 37.5% at 3 months. During the first face-to-face visit the presence of dyspnoea was investigated in 94.4% of the programmes (mainly using the Medical Research Council scale), while cough was evaluated in 50.7% (mainly through the Leicester cough questionnaire). Both imaging and functional assessment were part of the workup, as they were performed regularly in most centres (95.5% and 79.1%, respectively). In terms of imaging evaluation, 37.5% of centres stated to use CXR alone, 39.1% HRCT alone and 18.8% both CXR and HRCT, while 3.1% were using low-dose CT scan. In terms of functional evaluation, 90.6% of centres reported they used both spirometry and D_{LCO} , and 9.4% used spirometry alone, while 6 min walking test was routinely performed in 71.7% of the centres. An integrated rehabilitation programme was available in 68.7% of the centres, either on-site or domiciliary. Psychological support was routinely offered in 63.3% of centres, mainly referring to psychologists/psychiatrics or physiotherapists. Follow-up visits were part of the SOPs for 98.3% of centres. with a different timing, ranging from 1 to 12 months after the initial evaluation (more commonly after 3 months). Both assessment of dyspnoea and imaging evaluation, including CT scan, were part of follow-up programmes in 93.1% and 86.2% of centres, respectively. A specific ILD consultation in case of persistent CT scan alterations was organised in 84.0% of the centres, while additional PFTs during follow-up were organised in 94.8% of the centres, either at every evaluation or every 3–6 months, according to patients' characteristics. Large differences in the management of post-COVID-19 syndrome have been detected among European countries, especially in terms of the presence of multidisciplinary teams (from 0 to 100%), telemedicine availability (from 0 to 43%), rehabilitation availability (from 0 to 100%) and first follow-up visit timing (from 1 to 6 months) (figure 1). Moreover, a wide heterogeneity was detected across Europe in terms of criteria for patients' inclusion in follow-up programmes as well as for imaging and functional evaluations.

According to our findings, a higher number of HRCT and PFTs are routinely performed in European countries than what is suggested by international guidelines [4]. Although a multidisciplinary team was part of most of the COVID-19 follow-up programmes, only one centre had a GP included in the team, hinting at a possible lack of integration between hospital and community management of patients. Psychological support is offered, when needed, in almost two-thirds of centres, as depression and anxiety are very common even 6 months after the acute infection [11]. Although important changes in telemedicine availability appeared during COVID-19 pandemic, our data showed that telemedicine is part of COVID-19 follow-up programmes in less than one-third of centres [12]. The heterogeneity in SOPs across different countries we found in our experience should be interpreted as a reasonable response to post-COVID-19 syndrome in view of the dissimilar temporal incidence of COVID-19 outbreaks, various epidemiology of SARS-CoV-2 variants, population characteristics and healthcare system structures. This is the first European survey on COVID-19 follow-up programmes with data from 130 centres across 26 countries, exploring several aspects of disease management. However, the majority of the respondents were pulmonologists, and a limitation of our study includes a lack of information about COVID-19 follow-up programmes managed by other healthcare professionals, such as internal medicine or infectious disease specialists. Furthermore, most of the responses were from university hospitals and more than 50% of centres were based in Italy, Greece, Spain, UK and France. Moreover, almost one-third of centres had a special focus on ILD, which might have led to an overestimation in our survey of the use of radiology, and particularly HRCT. Finally, another limitation is that our study ended in September 2021 and we can speculate that new follow-up programmes have emerged in different countries since then. We were not able to detect these changes and a follow-up of this study is planned in the upcoming years.

In conclusion, post-COVID-19 syndrome and lung sequelae represent a relevant burden on European healthcare systems. In order to include different health systems in the implementation of European interventional trials and to facilitate research on post-COVID-19 syndrome, a homogeneous approach to SOPs could be considered.

Claudia Valenzuela¹, Mattia Nigro ⁶, James D. Chalmers³, Scott Wagers⁴, Avinash Aujayeb ⁶, Merel E. Hellemons ⁶, Judith Löffler-Ragg⁷, Christopher E. Brightling⁸ and Stefano Aliberti ^{2,9}

¹Pulmonology Department, Hospital Universitario de La Princesa, Universidad Autonoma de Madrid, Madrid, Spain. ²Department of Biomedical Sciences, Humanitas University, Milan, Italy. ³Scottish Centre for Respiratory Research, University of Dundee, Dundee, UK. ⁴BioSci Consulting, Maasmechelen, Belgium. ⁵Respiratory Medicine Department, Northumbria Healthcare NHS Trust, Cramlington, UK. ⁶Department of Respiratory Medicine, Erasmus University Medical Center, Rotterdam, The Netherlands. ⁷Department of Internal Medicine II, Medical University of Innsbruck, Innsbruck, Austria. ⁸Institute for Lung Health, NIHR Biomedical Research Centre, University of Leicester, Leicester, UK. ⁹IRCCS Humanitas Research Hospital, Respiratory Unit, Milan, Italy.

Corresponding author: Stefano Aliberti (stefano.aliberti@hunimed.eu)

Conflict of interest: S. Aliberti reports grants from INSMED Incorporated, Chiesi and Fisher & Paykel; royalties from McGraw Hill; consulting fees from INSMED Incorporated, INSMED Italy, INSMED Ireland Ltd, Zambon, AstraZeneca UK Limited, CSL Behring GmbH, Grifols, Fondazione Charta, Boehringer Ingelheim, Chiesi, ZCUBE Srl, Menarini and MSD Italia S.r.l.; lecture honoraria from GlaxoSmithKline Spa; participation on advisory boards for INSMED Incorporated, INSMED Italy, AstraZeneca UK Limited and MSD Italia S.r.l; outside the submitted work. C. Valenzuela reports consulting fees and lecture honoraria from Boehringer Ingelheim, Hoffmann-La Roche, Ltd and BMS; travel support from Boehringer Ingelheim and Hoffmann-La Roche, Ltd; participation on advisory boards for Boehringer Ingelheim; outside the submitted work. J.D. Chalmers reports grants from AstraZeneca, Novartis, Boehringer Ingelheim, Insmed, GlaxoSmithKline and Gilead Sciences; consulting fees from AstraZeneca, Insmed, Boehringer Ingelheim, Janssen, Chiesi, Novartis, GlaxoSmithKline, Pfizer and Zambon; outside the submitted work. S. Wagers reports consulting fees from Kings College Hospital NHS Foundation Trust, Academic Medical Research, AMC Medical Research BV. Asthma UK. Athens Medical School. Boehringer Ingelheim International GmbH. CHU de Toulouse, CIRO, DS Biologicals Ltd, École Polytechnique Fédérale De Lausanne, European Respiratory Society, FISEVI, Fluidic Analytics Ltd, Fraunhofer IGB, Fraunhofer ITEM, GlaxoSmithKline Research & Dev Ltd, Holland & Knight, Karolinska Institutet Fakturor, KU Leuven, Longfonds, National Heart and Lung Institute, Novartis Pharma AG, Owlstone Medical Limited, PExA AB, UCB Biopharma S.P.R.L., Umeå University, University Hospital Southampton NHS Foundation Trust, Università Campus Bio-Medico di Roma, Universita Cattolica Del Sacro Cuore, Universität Ulm, University of Bern, University of Edinburgh, University of Hull, University of Leicester, University of Loughborough, University of Luxembourg, University of Manchester, University of Notthingham, Vlaams Brabant, Dienst Europa, Imperial College London, Boehringer Ingelheim, Breathomix, Gossamer Bio, AstraZeneca, CIBER, OncoRadiomics, University of Leiden, University of Wurzburg, Chiesi Pharmaceutical, University of Liege, Teva Pharmacauticals, Sanofi, Pulmonary Fibrosis Foundation and Three Lakes Foundation; outside the submitted work. M.E. Hellemons is an associate editor of ERJ Open Research. C.E. Brightling reports grants and consulting fees from GSK, AZ, Sanofi, Regeneron, Roche, Genentech, Chiesi, Novartis, BI, Mologic and 4DPharma; outside the submitted work. All other authors have nothing to disclose.

Support statement: The END-COVID CRC has been supported by financial contributions from the following partners: European Respiratory Society, AstraZeneca, Boehringer Ingelheim, Novartis and Roche. Funding information for this article has been deposited with the Crossref Funder Registry.

References

- 1 Huang L, Yao Q, Gu X, *et al.* 1-year outcomes in hospital survivors with COVID-19: a longitudinal cohort study. *Lancet* 2021; 398: 747–758.
- 2 Wu X, Liu X, Zhou Y, *et al.* 3-month, 6-month, 9-month, and 12-month respiratory outcomes in patients following COVID-19-related hospitalisation: a prospective study. *Lancet Respir Med* 2021; 9: 747–754.
- 3 Evans RA, McAuley H, Harrison EM, *et al.* Physical, cognitive, and mental health impacts of COVID-19 after hospitalisation (PHOSP-COVID): a UK multicentre, prospective cohort study. *Lancet Respir Med* 2021; 9: 1275–1287.
- 4 Shah W, Hillman T, Playford ED, *et al.* Managing the long term effects of Covid-19: summary of NICE, SIGN, and RCGP rapid guideline. *BMJ* 2021; 372: n136.
- 5 Soriano JB, Murthy S, Marshall JC, *et al.* A clinical case definition of post-COVID-19 condition by a Delphi consensus. *Lancet Infect Dis* 2022; 22: e102–e107.
- 6 Carfi A, Bernabei R, Landi F, et al. Persistent symptoms in patients after acute COVID-19. JAMA 2020; 324: 603–605.
- 7 Wong AW, Shah AS, Johnston JC, *et al.* Patient-reported outcome measures after COVID-19: a prospective cohort study. *Eur Respir J* 2020; 56: 2003276.
- 8 Raghu G, Wilson KC. COVID-19 interstitial pneumonia: monitoring the clinical course in survivors. *Lancet Respir Med* 2020; 8: 839–842.
- 9 Nurek M, Rayner C, Freyer A, *et al.* Recommendations for the recognition, diagnosis, and management of long COVID: a Delphi study. *Br J Gen Pract* 2021; 71: e815–e825.
- **10** Baraniuk C. Covid-19: how Europe is approaching long Covid. *BMJ* 2022; 376: 0158.
- 11 Huang C, Huang L, Wang Y, *et al.* 6-month consequences of COVID-19 in patients discharged from hospital: a cohort study. *Lancet* 2021; 397: 220–232.
- 12 Mann DM, Chen J, Chunara R, *et al.* COVID-19 transforms health care through telemedicine: evidence from the field. *J Am Med Inform Assoc* 2020; 27: 1132–1135.