

To: [redacted] 5.1.2e [redacted] 5.1.2e @minvws.nl]
 From: [redacted] 5.1.2e
 Sent: Thur 1/19/2023 2:47:25 PM
 Subject: RE: tekstje
 Received: Thur 1/19/2023 2:47:25 PM

Van: [redacted] 5.1.2e
 Verzonden: donderdag 19 januari 2023 15:47
 Aan: [redacted] 5.1.2e <[redacted] 5.1.2e @minvws.nl>
 Onderwerp: tekstje

- Alle Lidstaten herkennen het probleem en steunen op dit terrein EU coördinatie of ondersteuning.
- In verschillende (middelgrote en grote landen vinden afzonderlijke onderzoeken plaats naast de onderzoeken gedaan in Horizon Europa ondersteunde consortia.
- Minister heeft op 9-12 gesproken met ITA, DUI, IER, BEL, DEN, POR; daar brede steun om gezamenlijk op te trekken om patienten met Post COVID perspectief te bieden en meer synergie te creëren op onderzoeksinspanningen

Voorbeelden Nationale onderzoekinzet en reacties op uitvraag Nederland voor dit initiatief

- **België**
 - KCE (Federal Knowledge Centre for Health Care – Federaal Kenniscentrum voor de Gezondheidszorg) has published a report on the pathophysiology-epidemiology and patient needs of long COVID in 202, and there are three ongoing pragmatic trials in this area as part of the KCE Trials Programme. Please find the links to the projects below:
 - KCE reports:
 - [Long COVID: Pathophysiology – epidemiology and patient needs | KCE \(fgov.be\)](#)
- **Zweden**
 - There are several ongoing research projects on post-COVID syndrome. The research shall contribute to developing knowledge within health and medical care, and improving diagnosis and therapy alternatives for patients with long-term symptoms following COVID-19. Examples of questions that the projects seek to answer are whether post-COVID syndrome is caused by an auto-immune reaction, or by residual virus. Are there any disruptions or genetic variations in the immune systems of those affected? And what, if any, are the long-term effects on the brain? What neurological symptoms can arise, and why are some patients affected by them?
 - Several projects have also been initiated on this issues. For instance *Priority setting of future research into long-term symptoms of Covid-19 infection (post-acute sequelae of Covid-19 or Long Covid)*
 - <https://www.sbu.se/324e>
- **Frankrijk**
 - 1. Does France support research on this subject: if so, which aspects more precisely, in order to be able to define the possible gaps in research and expertise that we need at European level?
 - The organisation of Covid-19 research in France :
 - The inter-ministerial research cell (CIR), a working group between the Ministry of Higher Education, Research and Innovation (MESRI) and the Ministry of Health and Prevention (MSP), ensured the organisation of crisis research from the start of the epidemic. It steered the ad-hoc national steering committee for therapeutic trials and other research on COVID-19 (CAPNET), created at the end of 2020 to prioritise studies relating to high-potential national research priorities in order to accelerate them. On the Long COVID theme, the coordination of research within the ANRS-Emerging Infectious Diseases (ANR-MIE) has been strengthened by the creation in January 2021 of a Coordinated Action "Long COVID" within it, intended to strengthen the structuring of research and awareness around this theme in order to facilitate the emergence of convincing projects.
 -
 - On 01/04/2022, the ANRS-MIE was commissioned by the government to take over the steering of CAPNET.
 - The priority research areas defined by the ANRS-MIE around the theme of covid long are :
 - 1) deepening epidemiological knowledge ;
 - 2) the medico-economic impact of the infection;
 - 3) the search for pathophysiological causes of persistent forms;
 - 4) the study of the social dimension and the epistemological changes linked to the emergence of a new health state;
 - 5) intervention research (evaluation of care, care pathways, etc.).

- 2. Is France in favour of more exchanges between EU experts in charge of Covid long issues?
- **The services of the ministry in France are in favour of better European coordination of research programmes on the long Covid. So yes, given the FDR axes, but which experts are targeted? research experts? what kind of exchanges? research partnerships?**
 - The High Council for Public Health (HCSP) also recommends *"the coordinated continuation of national prospective cohorts, possibly linked to European cohorts, that have systematically and prospectively included patients followed up after a Covid-19 and the collection and sharing of data by the ANRS - MIE in a centralised national database"*.
 - We also **support better coordination between MS in the development of our patient management recommendations** to best integrate post-COVID-19 services into existing health service structures, train health professionals (from primary care to long-term hospital care) and provide evidence-based information on post-COVID-19 conditions to the general public.
 - Finally, we are in favour of the MSP (especially AHP) reinforcing the EC's financial contribution to the research efforts undertaken by the MS through dedicated funds, notably through **the Horizon financial instrument**.
- **Duitsland**
 - In Germany, there are already different measures in place. E.g., it will be establishing a research programme that will create a dynamic opportunity for exchange in the form of a knowledge-generating networking of research and healthcare for long/post-COVID. Germany has already initiated several support programs with the aim of understanding the pathogenesis, improving the diagnosis and developing treatment concepts for the disease. Considering the projects with a main focus on long/post-COVID, the Federal Ministries for Health, for Research and for Labour and Social Affairs are funding research projects in a total amount of approximately 38 million euros. There are additional projects, which partly investigate long/post-COVID. Germany has created several cohorts that are meant, over time, to provide insights into the delayed sequelae of a COVID infection.
 - Germany support the proposal to have an exchange on expert level on long/post-COVID across member states. We are very interested in finding common definitions for long-COVID and post-COVID. We are also very interested to hear from your ideas and experience on how to deal with long/post-COVID, e.g. about your programmes on how to optimize health care for long/post-COVID patients.
 - Oostenrijk
 - 1. if your capital is supporting research on this topic and if so to what aspects of post-covid, so that we can define possible gaps in the research and expertise we need at European level.
 - The Austrian Ministry of Health has funded the establishment of a Long COVID point-of-care webtool, which aims to advise primary healthcare physicians on the latest scientific developments regarding diagnostics and treatment regarding Long COVID. The MoH is currently funding maintaining and updating of this webtool for the year 2023. Furthermore, two public health institutions (GÖG and AIHTA) have been assigned to collect and summarize research findings.
 - Since research generally lies in the responsibility of the Ministry of Science, the MoH is currently not involved in funding of clinical research for Long COVID.
 - 2. if there is interest in organizing more exchange between the experts in the EU dealing with Long Covid.

There is great interest in sharing data/study results/information regarding Long COVID within Europe. An EU-platform for Long COVID, as mentioned below, would be a great tool for exchange.