



Projects selected by the ANRS for Long Covid research

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ApresJ20 – Association Covid Long France

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Mr Director of ANRS,

We have been informed of the results of the first session of the "**Call for Long Covid Projects**" promoted by ANRS, within the framework of the coordinated action on Long Covid, in which our association participates.

<https://www.anrs.fr/fr/actualites/986/resultats-de-la-1re-session-appel-projets-covid-long>

Many researchers have conveyed their astonishment to us and some their dismay, upon discovering this list, which also raised questions for us.

For example, it was reported to us that several projects with **excellent reviewer scores** were not selected, and many were very surprised that the projects selected are **not more diverse** in terms of regional territory bases.

We were surprised that only one of the projects for which we had been asked **to include patient expertise** had been chosen even though they all met criteria for a robust methodology.

We cannot overstate our concern about the impact of such research in France on Long Covid patients.

Recently, the study by Matta, Lemogne and al in JAMA Internal Medicine stated that there was no association whatsoever between the most common prolonged symptoms recognised as Long Covid and actual infection with SARS-CoV-2.

Even though these conclusions have been **unanimously qualified as erroneous** by the international experts in cohort study methodology who have commented, we are particularly concerned that they strongly interfere with public health policy in France on Long Covid, with deleterious and prejudicial impacts on the proper care of patients.

We are surprised that this line of research is so prominently featured in two of the projects selected by ANRS on 21 January, for this same team. In contrast, several projects regarding research on the physiopathological causes of Long Covid were not selected.

In the end, it seems to us that a portion of the selected topics do not correspond, to the priority issues that appear in the international academic literature on the subject of post-acute sequelae of SARS-CoV-2 infections (notably - neurological, immune and vascular disorders), in both adult and pediatric populations.

To this end, we request, as a patient organization, **to be included in the selection committees** to fund studies on Long Covid and prolonged symptoms. This has already been done in several countries, such as in the UK within the British government agency NIHR, and this method of operation is bearing fruit, as it is perfectly in line with public health and democracy.

We would also like the involvement of **clinical physicians** who treat many Long Covid patients in these selection committees.

Finally, we believe that this selection committee should be independent. **The composition of the committee should be published**, as it is publicly funded.

Our commitment as an association is **to evidence-based research in medicine** (the "Evidence Based Medicine" requirement).

We believe it is essential that the scientific and medical community be presented **with solid evidence** that meets the scientific criteria for relevant and irreproachable research, for a health policy that is:

- **scientific**, based on evidence and not on weak interpretations,
- **inclusive**, placing the experience and expertise of patients in partnership with professionals at the heart of care,
- **ethical and fair**, mindful of rigor and equity, including in terms of communication.

Thank you for your consideration of our comments. We would like to discuss these issues with you at a future meeting.

Yours sincerely,

Pauline Oustric, pour l'association #AprèsJ20 Covid Long France

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Mail copied to Yazdan Yazdanpanah (Director ANRS|MIE) and Xavier Lescure (Advisor to French Minister of Health and Solidarity, in charge of Long Covid).