

## Case study

### Innovative concepts to communicate science

DURING COVID-19

**Contributor**

Altea Long COVID Network Association

**Country of implementation**

Switzerland

**Start date of the initiative**

January 2021

**Track**

From science to action

**Target audience**

Prospective vaccine receivers

**Website**

<https://www.altea-network.com/en>



# Altea: A network for sharing evidence-based information on the long-term effects of COVID-19

## Summary of the initiative

Altea is a platform that connects people who are keen to understand the long-term consequences of contracting coronavirus disease (COVID-19), also known as long COVID or post COVID-19 condition, and to exchange expertise and experience. Around a quarter of people who have had COVID-19 continue to experience symptoms for at least a month, and one in 10 are still unwell after 12 weeks. Symptoms are still being studied but appear to include generalized chest and muscle pain, fatigue, shortness of breath and cognitive dysfunction; the mechanisms involved affect multiple systems and include persistent inflammation, thrombosis, and reduced autoimmunity. Altea has categorized some of the symptoms into groups along with some practical advice for relief.<sup>1</sup>

The target audience for this platform includes:

- people who are experiencing symptoms of post COVID-19 condition;
- people who have overcome post COVID-19 condition;
- people who got infected with COVID-19;
- health care professionals; and
- researchers and scientists working on therapies and treatments of post COVID-19 condition.

The platform has six main components:

- a **vademecum** that provides evidence-based information and helpful tips to cope with and/or overcome symptoms;
- a **directory** that helps find health professionals specialized in post COVID-19 condition by location or by symptom;
- a **blog** where the latest news and updates about post COVID-19 condition are published;
- a compilation of personal **stories** from people who have experienced post COVID-19 condition either in their private or professional life;
- an interactive online **forum (the Altea Community)** where users can ask questions and receive responses from other platform users, who include people living with post COVID-19 condition as well as professionals; and
- a **newsletter** for subscribers with the latest news on post COVID-19 condition and on Altea.

The team monitors the evolving scientific evidence on post COVID-19 condition and regularly collects feedback on the usability of the platform and on the needs of the target audiences. The findings are used to keep the platform up-to-date and user-friendly.

Photo above: A user browsing the Altea webpage, Switzerland, 2021. Copyright: Altea. Credit: Mirco Dalla Lana

## Context and relevance of the project

The nonprofit Altea Long COVID Network Association, based in Zurich, was launched by LUNGE ZÜRICH and APS Advanced Productions and Support AG. LUNGE ZÜRICH, also a nonprofit organization, specializes in respiratory health and recognizes the need to address post COVID-19 condition in an evidence-based and accessible way. However, while reports of long-term symptoms are increasing among stakeholders and the public, very little is yet known on post COVID-19 condition, and patients and their relatives report feeling alone with their questions and concerns. To address this information and support void, the team developed a platform to provide these patients with up-to-date, evidence-based information and offer a venue for exchange and mutual support.

APS Advanced Productions and Support AG, a consultancy firm with an interdisciplinary team of experts in public health and communication, provides operational support to the project.

## Summary of the analysis



### Innovation factors

This initiative aims to improve the quality of life of people impacted by post COVID-19 condition. The platform allows free exchange of experiences and offers practical advice. The innovative add-on of the platform is that it creates a one-stop shop taking a 360-degree perspective by involving all relevant stakeholders:

- patients with post COVID-19 condition requiring peer support, expert advice and scientific guidance;
- experts such as health care workers and researchers who learn patients' perspectives through direct communication, and share their expertise and new findings on post COVID-19 condition.

The team has applied a participatory approach during the development process. Members analysed the needs and preferences of the target audience through three online surveys: one for people affected by post COVID-19 condition; one for health professionals; and one for researchers working on long COVID. Continuous feedback is collected from emails, phone calls, and surveys developed to keep Altea up-to-date with findings and needs, as well as to improve the user interface.

The project establishes trust in science and evidence-based practice by facilitating direct interactions between the public and academic and health care experts. This reduces the chance of misconceptions and misinformation. The content covers all aspects of post COVID-19 condition, including health, social and economic consequences.

The online forum is a valuable feature of the platform. It enables two-way communication among patients with post COVID-19 condition, their relatives and health care and research professionals. The forum provides a safe space to discuss concerns and receive professional and peer support. The Altea team monitors the forum, has access to user subscriptions for transparency, and intervenes if any suspicious activity is detected.

### Accuracy of scientific information

Information shared on the platform is derived from reliable sources such as: scientific studies and guidelines published by national and international health authorities and organizations on post COVID-19 condition; and websites of specialist organizations on related topics such as chronic pain, and chronic fatigue syndrome.

Quality of content is further ensured as members of the founding team include public health professionals and/or respiratory disease experts.







Altea handbook user exercising based on tips to overcome symptoms of post COVID-19 condition, Switzerland, 2021. Copyright: Altea. Credit: Mirco Dalla Lana



## Impact on knowledge, attitudes and behaviour of the target audience

A qualitative impact survey is planned for March 2022.

The team has received messages of appreciation from platform users including patients with post COVID-19 condition and health care professionals managing patients with the condition.

Platform analytics as of February 2022 show:

- 1 496 subscribers to the newsletter
- 53 652 unique visitors on the website
- 226 686 webpage views
- 178 070 user engagements
- 11 313 downloads of the content
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- top 10 countries that visit the website: Switzerland, Germany, Italy, the United States of America, Austria, France, the Netherlands, the United Kingdom, Spain and China.

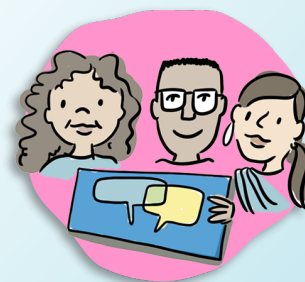
## Gender equality, equity and human rights considerations

The Altea team is moderately gender balanced with five men and eight women in the operational unit, and eight women and ten men in the scientific expert board.

Health professionals are included in the directory of post COVID-19 condition care providers, regardless of their sociodemographic background.

The content is written in lay language to make it accessible to audiences with varying literacy levels. Acknowledging the multilingual context of Switzerland and its high migration rate, the website is available in English, German, French and Italian.

The team promotes equitable access to health care. This is established by responding to all queries irrespective of the enquirer's background and providing all resources free of cost.



## Limitations

Scientific evidence and regulations or health insurance coverage for new or non-traditional therapies for post COVID-19 condition are still emerging. Therefore, many questions posed in the forum cannot currently be answered.



## Looking forward

The team will continue its existing work and make relevant updates to the platform, based on the findings of the impact survey. An expansion to include offline services and consultations is being planned, depending on needs and funding.

The model of Altea could be used for future health emergencies for two main reasons:

- it enables the timely dissemination of scientific information; and
- it provides a platform to build trusted relationships and exchanges between different stakeholder groups, which helps to track current knowledge and concerns and respond to them promptly.

## References

- i. Altea. Symptoms overview (<https://www.altea-network.com/en/long-covid/symptoms-overview/>).

Illustrations by Sam Bradd

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