

Altea Long COVID Network

EXECUTIVE SUMMARY

Background

With the global COVID-19 pandemic a new challenge has emerged: Long COVID. This term is used in general to describe the long-term consequences of a COVID-19 infection that cannot be explained by alternative diagnoses and that last for an unusually long time. According to the [NICE guidelines](#) (to which also the [Swiss medical network mediX](#) refers), Long COVID is the umbrella term for a prolonged COVID-19 infection and for a syndrome triggered by this infection. More specifically:

- acute infection: up to 4 weeks
- prolonged infection: 4-12 weeks
- Post-COVID syndrome: more than 12 weeks
- Long COVID: everything from 4 weeks

Given its novelty, science and medicine are not yet ready to offer clear diagnoses and therapies to affected people, who thus feel left alone. In this situation, it is crucial for those affected to be taken seriously, to receive reliable information and to find the right specialists. To fulfill this need, the Altea Long COVID Network (www.altea-network.com) was launched.

Why is Long COVID an important social issue?

Long COVID can lead to major limitations in everyday life and it can also limit the ability to work. There are still no reliable figures on the incidence of Long COVID, however, given the [estimated total](#) of more than two million COVID-19-infected people, tens of thousands of people could be affected by Long COVID in Switzerland. This will soon represent a long-term burden on the healthcare system and on the economy, in addition to the massive implications on the personal and family levels ([FOPH literature report](#)). Therefore, it is important to proactively address these challenges now and to mitigate them in the best possible way. This opinion is also shared by the [Federal Council and Parliament](#).

Who is behind Altea?

LUNGE ZÜRICH, a cantonal section of the Swiss Lung League, recognized the issue and initiated the project at the end of 2020, as Long COVID is often associated with respiratory difficulties. APS AG was on board from the very beginning as project partner. APS AG brings a lot of experience and a large network in the field of public health with the project management

of the research program [Corona Immunitas](#). Due to the great urgency to address Long COVID, a rolling project development was chosen. The platform has already been developed and implemented, while talks are being held in parallel for an institutionally broad-based, independent non-profit sponsorship. Partners, who will participate in the international scaling in the coming years, are being sought for this sponsorship.

What does Altea do?

Altea takes those affected seriously and offers them and their relatives a place where they can find evidence-based information and concrete help about Long COVID. Altea also provides a place for researchers and health professionals to share their findings and expertise regarding Long COVID. The platform follows a co-creation approach. This means that affected people, relatives, doctors, therapists, researchers, and other stakeholders jointly contribute to the development, functioning and success of the platform and help determine the most relevant content, that is thus tailored to the real needs of the different stakeholders. The knowledge about Long COVID is constantly developing. Altea is closely following these developments and regularly updates the published information to reflect the current state of knowledge.

Why does Altea need a grant?

Long COVID is an international challenge. As a virtual platform, Altea has the opportunity to reach a worldwide public, and to provide help to people affected by Long COVID internationally. Indeed, so far, there is no comparable offer, although the corresponding demand exists. Having started in Switzerland, Altea is already nationally oriented, for example with regard to the directory of contact points. However, weekly inquiries and urgent requests are received from abroad for version of Altea in other languages, and that include contact points and information of activities happening in different countries.

Support from large companies, organizations and associations has therefore the following high impact effects on Altea: First, their commitment provides Altea with the financial support needed to further develop the contents so to provide information and support to all those affected, regardless of their country of living. Second, a commitment to Altea sends an important signal to other potential partners who could provide further support. Increasing the Altea partner network is also an important call to action for high level health organizations, policy makers and governments. Partners' contribution helps thus to ensure the sustainability of Altea as long as there is a need for such a platform.

How can my company benefit from Altea?

Through its Community, Altea provides you with the opportunity to have a direct and worldwide contact with people affected by Long COVID, as well as with different stakeholders in the health

area. In this sense, it also provides you with the opportunity to stay up to date with the latest information about Long COVID, the relevant needs and wants of the affected people, as well as of those who work to find an effective and efficient solution/therapy. Altea gives you the possibility to be seen in a positive way, and to be visible worldwide, since Long COVID is not a country-specific syndrome.

Altea is implementing a multi- and interdisciplinary and co-created self-management health platform focusing on Long COVID. This model could potentially also be implemented with other health issues. The topic of Long COVID offers the (unfortunate) advantage that much is still unclear and media attention is becoming higher and higher. This opportunity must be used to gain as much experience as possible with the interdisciplinary multi-stakeholder Altea platform. The future of the healthcare industry lies in the collaboration of all players supported by digital tools.

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1. Project description

1.1. What does Altea offer?

At the moment no clear suitable diagnoses and therapies to treat Long COVID exist, and Long COVID sufferers and their relatives often feel left alone with their pain, fears, and questions. What sufferers particularly miss is adequate information on consultations, diagnoses and treatments, as a survey of hundreds of affected people has shown. Altea's goal is to close this gap.

Altea takes those affected seriously and offers them and their relatives a place where they can find serious, scientifically evidence-based information. Altea also provides a place for researchers and health professionals to share their findings and expertise regarding Long COVID. The platform follows a co-creation approach. This means that affected people, relatives, doctors, therapists, and researchers jointly contribute to the development, functioning and success of the platform and help determine the most relevant content, that is thus tailored to the real needs. The most important elements of Altea are:

- A [Vademecum](#) offering evidence-based tips for managing various symptoms.
- A [Directory](#) that bundles consultation hours and therapy services for Long COVID, searchable by place, symptom, and keyword.
- An [Agenda](#) listing events, webinars, seminars, and activities related to Long COVID.
- [Blogs](#) and [Stories](#) summarizing current developments in science, medicine, law, and policy, as well as presenting case studies told by those affected by and those who work with Long COVID.
- A Community, with a [Forum](#) in a protected member area of the platform, to enable patients, relatives, researchers, and medical professionals to exchange information among themselves and with each other.
- Altea has already served as a link between those affected and the scientific and medical community on several occasions (for example, with the [Long COVID Citizen Science Board](#) and the [study on the psychosocial consequences of Long COVID](#)). Altea would like to continue this function and become a center of excellence for Long COVID in the medium term.

Altea is currently offered in German. However, versions in Italian, French, and English are planned and are to be launched as soon as possible. Translations in further languages (Spanish and Portuguese among others) are considered. Indeed, the need to provide information on Long COVID across linguistic borders is strong, and documented in various patient-based online groups, as well as by the multitude of direct correspondence and requests that Altea regularly receives from people abroad. Translations in multiple languages will thus

allow to reach a worldwide public, across different groups: patients, health professionals, researchers, policy makers and others.

1.2. What is the aim of Altea?

ALTEA aims to improve the quality of life of Long COVID affected people and their families and to find suitable therapies by promoting the exchange of experiences as well as scientific findings on Long COVID between sufferers, therapists, and physicians as well as the scientific community. Altea does this by:

1. Taking those affected seriously, listening to their concerns and suggestions.
2. Collecting and sharing evidence-based advice on therapies, and doing so in a language that is professional, but also understandable by non-professional Altea users. The goals are: 1) to help those affected to better cope with the long-term effects of COVID-19, and 2) to help those who take care of Long COVID patients.
3. Giving the opportunity to those affected to be part of the solution (co-creation and empowerment approaches).
4. Giving the opportunity to those who work on Long COVID from different areas of expertise to share their knowledge and to learn from others.
5. Reducing "Doctor hopping" (going from one doctor to the next until a suitable consultation is finally found) through specific information (self-management and referral to contact points in the directory).
6. Providing therapists and physicians with direct feedback from patients on the effectiveness of therapies, including new suggestions on therapies that worked for them.
7. Functioning as link between people affected by Long COVID and researchers conducting studies on Long COVID and facilitating recruitment processes.

1.3. How does co-creation work on Altea?

Altea's offering is based on a preliminary survey that collected information on the current situation, on the needs, thoughts, perceptions and the wants of the different stakeholders (people affected by Long COVID, researchers and health professionals). The content on Altea is constantly being updated and evolving, and the needs and wants of the target audiences heard. An evaluation on whether the platform still covers the key needs is regularly conducted.

Apart from being in direct contact with Long COVID sufferers, Altea has appointed to an accompanying board various independent (not directly involved in the creation of Altea) medical and scientific experts coming from different expertise areas. The expert board has the task to provide input on new findings about Long COVID and thus input on new possible content, and to review the content developed by Altea, as to ensure quality and

interdisciplinarity. Interdisciplinarity and multidisciplinarity is also reached through the contact and exchange with various professional societies and organizations such as the Swiss Society of Pneumology, the Swiss association of Ergotherapy or World Physiotherapy, which is the global body for 125 physiotherapy member organizations.

Finally, input is constantly received from different stakeholders via direct contact with Altea. This approach enables an open and transparent exchange in every phase of this dynamic situation.

2. Milestones 2021

	Milestone	Deliverables	Delivery Date	Status
1	Altea One pager online	<ul style="list-style-type: none"> • Vision, Mission and Motivation defined • Project name defined • Logo developed • URL reserved • Content published 	End January 2021	Published 28.01.2021
2	Altea Network online	<ul style="list-style-type: none"> • Website is online with Vademecum, Blog, Stories, Directory, and Agenda. 	Mid April 2021	Published 16.04.2021
3	Altea Community online	<ul style="list-style-type: none"> • Community platform is online and the forum is opened 	Mid July 2021	In progress
4	Altea translated in FR, IT, ENG	<ul style="list-style-type: none"> • Version FR online • Version IT online • Version ENG online 	September 2021	In progress
5	Funding for the Altea association secured for 2021	<ul style="list-style-type: none"> • The financing of the year 2021 is secured. 	September 2021	In progress
6	Successful roll-out in Switzerland, Germany and Austria	<ul style="list-style-type: none"> • The Altea Network Website is visited by users from these regions • The Altea Community records high registration rates from these regions • Partners from these regions join Altea 	October 2021	In progress
7	First talks with governmental organizations in Austria and Germany	<ul style="list-style-type: none"> • At least 1 conversation with German and/or Austrian authorities 	November 2021	In progress
8	Successful roll-out in France and Italy	<ul style="list-style-type: none"> • The Altea Network Website is visited by users from these regions • The Altea Community records high registration rates from these regions • Partners from these regions join Altea 	December 2021	In progress
9	Further development for 2022 and 2023 defined	<ul style="list-style-type: none"> • The further development for the year 2022 and 2023 has been defined and approved by the association. • Developments include translations in further languages 	December 2021	In progress

3. Altea Association

Altea is currently being transferred from LUNGE ZÜRICH to an association, constituted as an association under private law with headquarters in Zurich. The Altea Association is politically and denominationally neutral. The purpose of the Altea Association is the implementation and guarantee of the Altea Long COVID Network project. The financing of the Altea Association is based on membership fees as well as support from members, partners, and sponsors. The Altea Association should also be able to accept donations in the foreseeable future.

In addition to the statutory bodies, the Altea Association also has an advisory board composed of affected people, health experts and researchers. This advisory board critically accompanies the activities of the Altea Association and the Altea Long COVID Network exchange platform and ensures the interdisciplinary exchange.

The Altea Association Board (elected by the members) determines the further development of Altea and sets the strategic guidelines. Currently, APS Advanced Productions and Support AG is mandated for the implementation, moderation, editing and development of the Altea Long COVID Network exchange platform.

4. Financing plan

Altea was initiated by LUNGE ZÜRICH, a private association, with start-up funding. In order for Altea to keep providing high quality information free of charge and in the long term, and for Altea to be available in multiple language regions, new funding must be secured.

The Altea project is to be rolled out nationally in the course of 2021. This requires funding of CHF 813,000 in 2021. Financial means in the amount of CHF 300'000.00 have already been provided by LUNGE ZÜRICH. Altea is currently seeking sponsors to cover the lacking funds, to be able to reach the defined milestones.

Based on the epidemiological situation, the assumption is that Long COVID will represent an important issue for at least that long. Below is the forecast for Altea budget until 2024. By the end of 2024, around CHF 4.3 million will be required.

Altea Long-COVID-Network
Budget / Finanzplan

Version: 23.06.2021

	2021	2022	2023	2024	Kumuliert 2021-2023
	Gründung des ALTEA-Vereins, Startkapital durch LUNGE ZÜRICH, intensives Fundraising und Partnersuche	Intensives Fundraising und Partnersuche	Intensives Fundraising und Partnersuche	Intensives Fundraising und Partnersuche	
	Aufbau Altea-Netzwerk als Community-Plattform, Übersetzung der Inhalte in ENG, FR, IT, SP	Entwicklung und Pflege der Altea-Community über Web, Intensivierung der Social Media Kanäle, Phase 1 der Internationalisierung	Entwicklung und Pflege der Altea-Community international, Phase 2 der Internationalisierung	Entwicklung und Pflege der Altea-Community international, Phase 3 der Internationalisierung	
TOTAL Mittel	825'000	1'020'000	1'150'000	1'330'000	4'325'000
Total GESCHÄFTSSTELLE	40'000	94'000	99'000	99'000	
Total REDAKTION	520'000	660'000	785'000	835'000	
Total KOOPERATIONEN	10'000	30'000	70'000	140'000	
Total PROGRAMMIERUNG / DESIGN	195'000	150'000	155'000	175'000	
Total VEREIN	35'000	50'000	40'000	40'000	
Total ÜBRIGE AUFWÄNDE	13'000	23'000	33'000	43'000	
TOTAL AUSGABEN	813'000	1'007'000	1'182'000	1'332'000	4'334'000
NETTO MITTELZUFUSS/ABFLUSS	12'000	13'000	-32'000	-2'000	

Figure 1: Budget Altea 2021 - 2024

Support from large companies, organizations, and associations therefore the following high impact effects on Altea: First, your commitment will provide Altea with the needed financial support to further develop the contents so to provide information and support to all those affected, regardless of their country of living. Second, a commitment by your company to Altea will send an important signal to other potential partners who could provide further support. Increasing the Altea partner network is also an important call to action for high level health organizations, policy makers and governments. Your contribution will thus help to ensure the sustainability of Altea as long as there is a need for it.

By choosing to support Altea, you have the opportunity to establish a direct and worldwide contact with people affected by Long COVID, as well as with the different stakeholders in the health area. In this sense, it also provides you with the opportunity to stay up to date with the latest information about Long COVID, the relevant needs and wants of the affected people, as well as of those who work to find an effective and efficient solution/therapy.



Altea gives you the possibility to be seen in a positive way, and to be visible worldwide, since Long COVID is not a country-specific syndrome.

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