Long-haul COVID project

Concept note - September 2021

The project at a glance

Co-design a free patient e-platform on long-haul COVID to better inform patients and care teams, and develop public knowledge on patient's profiles and cases, to feed medical and strategic purposes. The long haul COVID project is an international partnership between *Assistance Publique Hôpitaux de Paris* in France (AP-HP), ULB Public Health School in Belgium (ULB/PHS), and Howami, a startup specialized in patient experience platforms, with a strong focus on design approaches and teams spread over Belgium and Sweden.

Long-haul COVID challenges

An estimated 10% of the population affected by COVID-19 suffers from long-term complications more than 3 months after the initial infection (persistent fatigue, chronic pain, breathing difficulties, mental confusion & attention deficit, memory loss, others).

Despite a growing literature on the subject, little is known about the causes of these symptoms. Only a few hospitals are exploring since late 2020 - early 2021 treatment and support protocols for severe cases. General practitioners (GPs) are not yet relieved from impacts of the COVID-19 crisis, and often do not have the time and necessary guidance to properly diagnose and orientate their long-haul COVID patients. It results in erratic patient journeys, aggravated by the absence of social protection mechanisms. Impacts on the capacities of long-haul COVID patients can be dramatic, and seriously impact their health, social and economic status. It makes a number of researchers and analysts state that "*long-haul Covid (...) is our next public health disaster in the making*"[1].

Purpose of the long-haul COVID project

The purpose of the project is: (1) to strengthen capacities of a maximum number of patients suffering from long-haul COVID, and give them visibility; (2) to develop a public knowledge repository on patient experience (PX) with long-haul COVID incl. their feelings, preferences, behaviours and health journeys, in order to nurture patient-centric health initiatives.

The game-changing dimension of the platform resides in this generation of routine PX data by the patient. At an individual level, it allows characterizing the patient's profile and evolution for better care management and health journey. Once aggregated, those data constitute a unique and constantly updated information source on the disease and user experiences, useful for the development and transformation of health & social service delivery models, research activities, as well as strategic, political and financing decisions.

Considering the lack of response on long-haul COVID at present stage and the urge to provide actionable solutions to patients and health care professionals (HCPs), we intend to move fast and reach our Minimal Viable Product[2] (MVP) by December 2021. We are targeting France and Belgium as first markets prior to extension in other countries.

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[1] Phillips S & Williams MA, June 2021, "*Confronting Our Next National Health Disaster — Long-Haul Covid*". The New England Journal of Medicine. https://www.nejm.org/doi/full/10.1056/NEJMp2109285

[2] A « Minimum Viable Product » is a minimal version of the app aimed at testing and validating essential hypotheses in real-life conditions, based on feedbacks from the first users.

Key functions and development principles

The project consists in the co-design and deployment of a free patient app prefiguring a multi-user e-platform, that allows to keep patients and care teams informed about the state of knowledge regarding long-haul COVID, and to document evolution of the symptoms and feelings of the patient through three core functions:

- Allow the patient and / or his GP to assess suspicion of long-haul COVID based on the patient's symptoms, through a limited set of medically-validated questions.
- Provide patients, caretakers and HCPs with quality-proof knowledge resources in a popularized easy-to-read language to keep them updated on what they need to know about long-haul COVID, possible treatment options and additional services.
- Request patients to regularly feed voluntary PX feedback on their symptoms and life experiences, summarized in historical dashboards. It helps the patient prepare for discussions with HCPs, and provides the latter with structured information.

The feedback requested integrate the evolution of symptoms as perceived by the patient, and subjective PX data on his life with the disease (level of understanding, emotions and stress, impacts on private and professional life). It adopts a simple, visual and non-intrusive format to optimize the patient's response rate, as illustrated in these screens.

From initial onboarding through all stages of utilization, the platform must be highly attractive for patients and HCPs, and minimize all possible hassles. To do so, we adopt an interactive co-design approach from the start, and constantly collect feedback on what users do and do not like, use and need, to adapt the platform and extra services accordingly.

In addition to long-haul COVID patients and HCPs, the project requires and already gathers a vast range of expertises including:

- Long-haul COVID experts for medical guidance and the production of newsfeed.
- Public health experts for proper integration into existing systems and care pathways.
- Communication experts to rapidly reach a maximum number of patients and HCPs.
- Designers, to adapt the platform to user needs, optimize adoption and retention on the platform, and ensure PX data reflect patients' realities and raise HCPs' interest.
- Research institutions to ensure data produced match with the future research agenda (Design Research, Health Service Organization, Public Health, Change Management).
- IT development expertise for building and constantly improving the platform through successive iterations, together with recommendations from designers.