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PATIENT EXPERIENCE

INTERNATIONAL COLLOQUIUM

The patient experience, a global response to a society in search of high touch

SPX 2020 | KEY MESSAGES WEBINAR II

# HOW TO DEVELOP THE PATIENT EXPERIENCE IN A CONTEXT OF ISOLATION - COVID EXPERIENCES?

## PRESENTATION

The 2020 edition of the international conference organised by Shared Patient Experience (SPX) "The patient experience, a global response to a society in search of high touch" addressed the main components to promote the patient experience and guide institutions and professionals towards cultural change.

This document presents the key messages and the opinions of the experts who participated in the webinar.

Shared Patient Experience (SPX) is a non-profit organisation that works on the patient experience in order to improve it and share it with professionals. SPX wants to promote any initiative that aims to improve the Patient eXperience.

The second webinar addressed "How to develop the patient experience in a context of isolation - Covid experiences?". It was sponsored by Hospital Clínic in Barcelona, Spain.

The speakers for this session are presented in the next page. Dr. Joan Escarrabill, Director of the Chronic Care Program of the Hospital Clínic moderated this session.



DR. ANTONI CASTELLS

Doctor in Medicine and Surgery, he is currently Medical Director of the Hospital Clínic de Barcelona, coordinator of the Program for Early Detection of Colorectal Cancer in Barcelona, and professor of Gastroenterology at the Faculty of Medicine of the University of Barcelona. He develops his research lines in Genetics and screening strategies for colorectal cancer (CRC). He is an expert in the fields of CRC genetics and in the field of CRC screening.



MRS. JESSICA DENNING

Communications and Education Coordinator at the European Lung Foundation. Jessica has a background in clinical research. She has worked closely with public involvement groups to improve the quality of trials from a patient perspective. At ELF, Jessica's role includes provide easy to understand information for patients, members of the public and policymakers.



DR. ANTONI PLASÈNCIA

Director General of the Barcelona Institute for Global Health (ISGlobal). He is also Medical Consultant in International Health at the Hospital Clínic and Associate Professor at the University of Barcelona. His professional activity has been dedicated to epidemiology and public health, for more than 30 years, in various leading positions, combining research, teaching, practice and management activities.



DR. JOAN ESCARRABILL

Doctor of Medicine (UB), Bachelor of Medicine and Surgery (UAB) and Master in Management of Health Institutions (UAB), Dr. Joan Escarrabill has been director of the Evaluation area of the Agency for Quality and Health Assessment of Catalonia (AQuAS). He is currently the director of the Chronic Care Program of the Hospital Clínic and director of the Master Plan for diseases of the respiratory system of the Health Department of the Generalitat de Catalunya.

## 1. Introduction

The COVID19 pandemic has disrupted health systems inducing rapid change in processes, structures and behaviours for professionals and patients alike. Non-emergency consultations have been cancelled; patients lost their regular access to care. Moreover, certain hospitalized patients in severe conditions found themselves isolated from their loved ones when visits became prohibited. Within the hospital, professionals had to limit their contact with patients and use means of protection which anonymized them. In this context, where multiple forms of isolation have appeared, how can we advance the patient experience?

### 1.1. How is COVID19 different from other pandemics?

Social isolation has become an extended public health policy at a global scale, in an effort to stop the spread of the virus. Isolation has been practiced within homes and between family members, at different rates of intensity. Then, isolation has been implemented within health institutions. For critical patients at the end of life, isolation has been a tragedy affecting patients, close ones and professionals alike.

## 2. A local perspective: Hospital Clinic's response to COVID19 response

The first wave of COVID19 greatly stressed Hospital Clinic in its ability to provide care and services for all. The crisis was an unprecedented for its magnitude, the rates of admissions and the uncertainty that hampered the prevention, management and treatment of patients.

During the first wave of COVID19, the patient experience department at Hospital Clinic conducted surveys to both patients and health workers to reflect on their experiences. The results showed the main concern of professionals was how to take care of patients in context of isolation. Patients considered in general they had received good treatment, even when experiencing isolation.

### 2.1. Managing isolation: the shortening distances program

The Health Psychology section at Hospital Clinic devised a program to **address the needs of patients that were isolated**, in different ways:

- Providing devices to facilitate communication with close ones.
- Establishing or conducting phone calls when patients were unable to do by themselves.
- Offering psychological support

for patients, close relatives and professionals.

Patients were satisfied by this initiative. However, there were some patients that did not want to communicate with family members and some considered engaging in this type of communication could have negative effects on their recovery. Therefore, although the shortening distance program was founded on a needs-assessment analysis, one size did not fit all.

## 2.2. Managing clinical conditions other than COVID19-related during peak months

Hospital Clínic made great efforts to continue treating non-COVID19 patients during the peak-months of the pandemic. It was considered **a measure of equity to attend these patients from becoming invisible**, since they were not part of the strategies and programs focusing on responding to the crisis. In order to better cater to their needs, the hospital responded with:

- **Evaluations for patients and professionals via videoconference** of their care journeys and care provided.
- **Focus-groups** were created specific to certain diseases such as chronic headache, kidney transplant patient, dialysis patients and patients with obesity.

These evaluations addressed the quantity and quality of information patients received. Some patients complained there was too much information and felt overwhelmed; patients tended to ask for more practical tailored information regarding their condition in relation to COVID19.

## 3. The patients' perspective: COVID19 and non-COVID patients

The European Lung Foundation (ELF) and has been working for 20 years to bring together patients with respiratory professionally, to positively impact lung health. ELF has been working in two spectrums: directly involving patients in research and providing accessible information to the public. During COVID19, ELF has worked to present information to the public in a way that is useful and accessible. It began with a Q&A sent out to patients, more than 1000 questions were answered by professionals and translated in 11 different languages for an audience of more than 200,000.

Patients tended to be concerned about:

- **Cancellation of routine appointments.**
- **Lack of access to healthcare.**
- **Lack of information regarding routine appointments.**
- **Feeling insecure about visiting the**

hospital.

- Impact of not accessing medical appointments for an extended period of time.
- Isolation and self-isolation and its impact on mental health.
- How to addressing the technological divide and digital literacy.

### 3.1. Strategies to curve the impact of isolation on patients

Patients signalled solutions to some of the problems mentioned above:

- **Receiving calls** from their general practitioner.
- **Continuous updates** on how processes have changed and how patients can access care.
- **More clarity and tailored communication** about isolation, measures, length and impacts.
- Structured, specialized and accessible access to **mental health**.

**Patient organisation groups have been key in order to reduce the impact of isolation of patients throughout the pandemic.** For instance, certain patient organisation groups in Britain have increased their contact with patients – i.e. weekly meeting – and have begun teaching courses on digital literacy to access healthcare from their homes.

All over Europe, **patient organisations have mobilized to strengthen their network and build support groups** amongst patients with similar conditions to better manage isolation.

## 4. A global health perspective on information during the COVID19 pandemic

International health organisations – namely WHO, the European Commission and the European Centre for Disease Control – have an important role in global health governance through their interaction with governments. Beyond differences across countries and services, international health organisations were amongst **the most trusted sources of information during the first months of the COVID19 pandemic**, both individually and collectively. The overall appraisal is that **communicating on global health issues has to do with risk management communication**, and it is more challenging in a context of complexity and uncertainty.

In a context characterized by social isolation, international health organisations are making substantial differential efforts to fight rumours and misinformation that circulate through social networks and news platforms. These are suggestions to improve their communication of information relating to the pandemic:

- **Need to strengthen and deeper their communication strategies, actions and**

**resources** in this context of misinformation, complexity, insecurity and especially social isolation.

- Need to **consider and address low health literacy** of a large part of the population and devise strategies to provide information in contexts of social isolation.
- Need to **tailor communication** for different target groups: urban citizens, young adults, older populations, etc.
- Need to **involve digital health tools**, particularly with **social media platforms and innovative networks**, can be very effective in ways to get closer to people's expectations and attitudes during social isolation.

A global problem dealt at local levels leads to **a diversity of responses and lack of coordination and often puzzles the public and local authorities**. Such phenomena raise different challenges:

- **Knowledge management**  
Local authorities and individuals are sensitive to information, scientific knowledge and guidelines provided by international health organisations. However, the amount of information and scientific production was unparalleled during the first months of the pandemic further **complicating the synthetisation and communication of information**.

- **Independent advisory roles**

Advisory bodies have been debated at different levels and policy scales, which is a phenomenon that hadn't been seen before, further complicating the demise of rumours and misinformation.

- **Increasing trust**

Finding ways to increase the legitimacy of international public health institutions, and teaching the public how to critically evaluate information on the internet.

## 5. Conclusion

- COVID19 pandemic is an unparalleled global challenge for health institutions and **requires innovation, flexibility and dissemination of information**, which can be achieved more effectively by taking into account the patient needs and experience.
- **Evaluation of patients and professionals experience of isolation** can bring solutions to decrease the negative impacts of isolation and design programs and measures that work more effectively.
- Scientific knowledge is a collective learning process constantly evolving, thus international health institutions need to **address their governance role from a network perspective to effectively disseminate adequate and useful information** using non-conventional actors and nodes.
- **Involving patients in research** allows for patients and the public to gain knowledge of research processes. Their involvement also precludes its communication and dissemination in a way that reaches and is understandable by the public.
- **Patient organisation groups have been key in order to reduce the impact of isolation of patients throughout the pandemic.**

The institutional members part of the Shared Patient Experience Club are :

- AZ Jessa, Hasselt, Belgium
- AZ Maria Middelaes, Gand - Belgium
- AZ Nikolaas, Saint-Nicolas, Belgium
- CHC Liège, Liège, Belgium
- Clinique Saint Jean, Bruxelles, Belgium
- Ensemble Hospitalier de la Côte, Morges, Switzerland
- Hospital Clínic, Barcelona, Spain
- Hôpital Riviera-Chablais, Rennaz, Switzerland
- Hopitaux Robert Schumann, Luxembourg, Luxembourg
- Hospital Plató, Barcelona, Spain
- Institut de Pathologie et de Génétique (IPG) Charleroi, Belgium
- Unicancer, Paris, France
- UZ Brussel, Jette, Belgium



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