



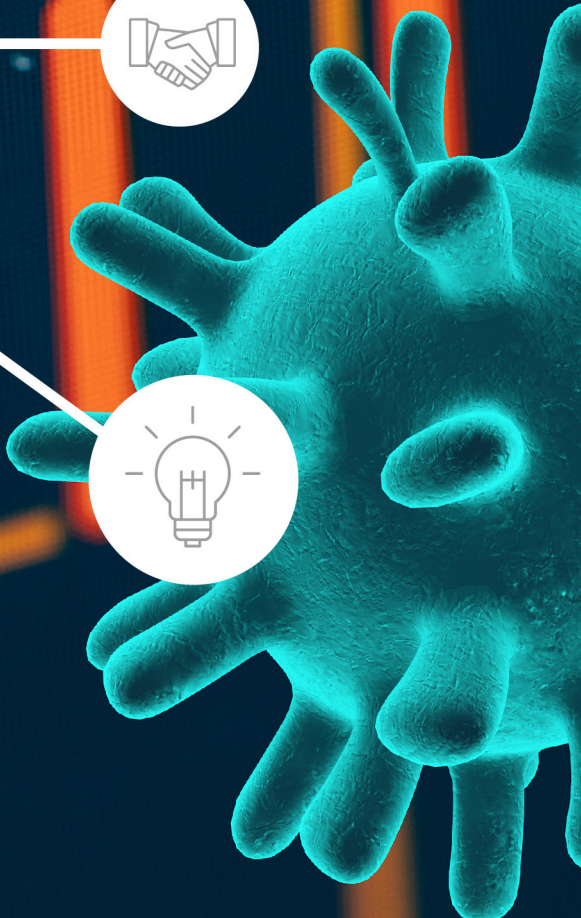
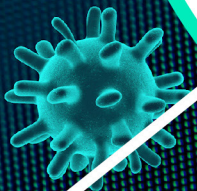
Digital  
Policy  
Toolkit



# Introduction



Resources  
for Patient  
Advocates in  
the context  
of Covid-19



# Introduction

Early in the Covid-19 pandemic, we held in-depth discussions with leaders of patient-based organizations throughout Latin America, as well as in South Africa and Lebanon. We wanted to see how they were managing with the pandemic in already very challenging environments. We asked them to describe changes they had made from a programmatic and operational perspective, and we asked for their views on the national response to the emergency in their countries. We asked if they had become involved in public policy discussions to address the new challenges, and how their pre-pandemic advocacy agenda with government and policymakers had changed due to the coronavirus.

It became quickly evident that patient leaders were already extremely active and had little extra time to consider a policy agenda much beyond what was happening day-to-day. However, most were also interested in ideas for the future. What might be public policy opportunities look like for patient groups once the pandemic begins to recede? We endeavored to help.



**What are public policy opportunities for patient groups once the pandemic begins to recede? We identified four relevant topics and developed policy resource toolkits for each intended as an evidence base to guide patient leaders in their advocacy.**

We begin with general observations that have since been reflected in other studies and survey findings related to Covid-19. First, in many countries, the stature of patient-based organizations has been enhanced by their activities during the peak of the Covid-19 emergency. Given difficult economic times ahead, capable patient organizations will continue to be important as demand for their services increases. Second, there is a broad trend of increased collaboration. Patient organizations are working with each other more often and increasingly more with other health stakeholder groups, as well. Third, the idea of “building back better” permeates the current environment and all health stakeholders, including patient organizations, are eager to see challenges in a new light and to participate in innovative programming. Fourth, patient organizations will benefit from specific new tools and resources that can help guide their advocacy efforts in “building back better.” It is one thing to know what organizations have been through; it is another to energize and motivate organizations to consider new opportunities into the near future.

We identified four health policy subject areas that we consider important opportunities for patient organizations. For each, we developed detailed policy resource toolkits that provide an evidence base and guides patient advocacy leaders with key messages and other suggested text adaptable to different modes of communication. The four policy subject areas are described briefly here:

## Space for Policy Dialogue

Outside of high-income countries, patient organizations are not yet regarded as important as other stakeholder sectors in health care policy. Physicians, academics, system payers, insurers, and the many industries that supply the health system generally enjoy much greater recognition. This allows for each of those sectors to speak and to act more or less as one voice with their governments in health care policy debates and discussions. The Covid-19 pandemic has changed this dynamic in many places, at least temporarily, because governments have needed to coordinate with all sectors to meet new and unprecedented challenges. In this way, **the pandemic has led to more consistent interaction between patient organizations and health authorities. Creating a formal space for regular policy dialogue between patient groups and government would help cement this working relationship at a time of continued uncertainty.** Of course, this opportunity is not equal everywhere. In countries where patient organizations continue to be shut out of policy discussions and where a regular space for dialogue seems impossible, the resources included in this toolkit can also be adapted by advocates to argue for change.



## Remote Health Access

Just about everywhere, some portion of the shift to remote access to health services (telehealth, home medicine infusions, etc.) is likely to continue even after the Covid-19 emergency subsidies. Of course, which portions will remain and how quickly these will expand depend on a variety of factors. **As patient organizations are expert in disease education and navigation of health systems--an expertise sharpened by the pandemic--many are positioned to play a larger role as intermediaries in how a health system delivers remote access services.** They should be recognized as such, with legal and regulatory frameworks where possible to allow for reimbursement as intermediaries. At the very least, patient advocates should be part of the policy discussions on how remote access services can help even more patients while also maintaining (or improving) standards of health care quality. The resources in this toolkit can help patient advocates make the policy case for continued access and expansion of these services, while also positioning patient organizations as effective implementing partners in this expansion.



## Combat Health Misinformation

The Covid-19 pandemic has demonstrated how bad information can be destabilizing and even deadly with its rapid spread among a citizenry eager to access information and products for protection. Much of this is unintentional, but bad actors also seed and/or exploit bad information for political or commercial gain. In some cases, governments have used the threat of bad information as an excuse to limit journalism and freedom of expression. As such, health misinformation and disinformation have now firmly entered the international public health lexicon. **They will likely remain there even as Covid-19 recedes. Meanwhile, providing accurate information has long been a driving mission for patient organizations.** As governments become more determined to regulate or legislate in this space--or to make potentially bad decisions based on inaccurate information--patient advocates can and should be important voices. There will also be future opportunities for patient organizations to become involved in “infodemiology” research related to the diseases they represent.



## Mainstream Patient Navigation

In rich countries, health navigation is a service of growing popularity being provided by local health systems to patients with cancer and/or targeting other specific at-risk populations. It is also used as a pioneering approach in many global health-related projects for low-income settings. The idea is to provide comprehensive assistance well beyond any immediate health need so that patients and their caregivers are better equipped to handle the sometimes devastating impact of a disease on every other facet of life. Being better equipped has been shown to improve the likelihood of treatment success in a number of disease areas. **The Covid-19 pandemic's impact on patients with chronic and disabling disease not related to the coronavirus has brought to light the importance of patient navigation provided by patient organizations.**

Some groups already did this prior to the pandemic, while others learned quickly that navigation was what was needed most and adapted their programs accordingly. In either case, there is now an opportunity moving forward for the patient advocacy community to harness this expertise and convince their governments to invest greater amounts for navigation as a priority in health service delivery.



# some final thoughts...

As we begin to disseminate these toolkits to patient advocacy leaders and their organizations, a few caveats are important.

First, the suggested text and messages in each of the toolkits are not intended for direct copy-and-paste activities. **We encourage patient organizations to adapt suggested text as necessary to the local context and to even expand on the suggested messaging in each of the different formats provided.** Copy and paste without adaptation to a particular context or for a particular audience will not be effective as an advocacy approach. Second, the four topics are only some of the possible policy topics moving forward. We are open to further suggestions from the patient advocacy community in terms of additional toolkits for a post-pandemic advocacy context. Please let us know. Third, we are well aware that the situation for patient groups in each country is as different as the countries themselves. One or more of these toolkit topics will make intuitive sense for some, but not for all patient organizations, and may or may not be entirely applicable for every country.

For these reasons, we chose four broad policy areas meant to encourage continued coalition-building and collaboration among patient-based organizations to address difficult and challenging topics. **In the end, in our view it is this coalition building that will allow for civil society organizations to continue to strengthen their capacity to influence health decision making for the patients they represent.**





More information at:  
[www.emoluva.com](http://www.emoluva.com)