

The perspectives of 1,720 patient groups during the Covid-19 pandemic



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- Survey conducted July to August 2020.
- Survey questionnaire in 20 languages.
- 1,720 respondent patient groups.
- Analysis of results for 27 countries [list is at end of press release].
- Analysis for 27 therapy areas [list is at end of press release].

The aim of the research

Many surveys have been undertaken during 2020 to learn about the Covid-related experiences of patients. By contrast, few surveys have focused on patient organisations' experiences during Covid—the subject of this PatientView 2020 survey.

The main topics covered by the questionnaire

Patient-group perceptions of how the Covid pandemic has affected:

- Patients.
- Pharmaceutical-company activities.
- Patient organisations themselves.

In addition, the survey asked the 1,720 respondent patient groups to assess the **effectiveness of their country's government** in tackling the Covid-19 outbreak.

WHY SURVEY PATIENT GROUPS?

Patient groups are perhaps the only healthcare stakeholder to interact across every aspect of the healthcare system: from regulators, physicians, healthcare providers, and healthcare payers, to patients. As experts in the field of patient needs, patient groups are uniquely positioned to have a 360-degree perspective on patients' lives, on patient care, and, in particular, on the care supplied to patients by the local healthcare system. So, when respondent patient groups offer the survey their perspectives, these opinions are drawn from a patient, not from a public, perspective.

THE IMPACT OF COVID ON PATIENTS

The survey aggregates what patient organisations have learned about how various communities of patients are coping during the pandemic—patients with different medical conditions, in different countries. Judging by the feedback and commentaries from respondent patient groups, fear is a dominant theme among patients.

The survey results show that patients living in the community are being sidelined—even abandoned—by their healthcare systems during the Covid pandemic. Patients feel both vulnerable and confused, uncertain about whether they will continue receiving care during the pandemic—not only of medical treatment, but of all the other services required for continued health. These isolated patients worry about:

Personal safety. % of respondent patient groups saying that personal safety is a major concern for patients during Covid:

- 79% of the 1,720 respondent patient groups.
- 95% of the respondent multiple-sclerosis patient groups.
- 90% of patient groups from Ireland. And ...
- 90% of patient groups from Germany.

Access to continued treatment and care. % of respondent patient groups saying that being able to access treatment and care is a major concern for patients during Covid:

- 70% of the 1,720 respondent patient groups.
- 93% of multiple-sclerosis patient groups.
- 90% of lupus patient groups.
- 62% of patient groups from Hong Kong. And ...
- 48% of patient groups from Greece.

An Australia-based patient-advocacy group that supports people with chronic illnesses sums up the situation for patients living in the time of Covid: “These are very anxious times. Myself and others within my communities online are very concerned about their conditions and treatments—if they will have to miss out on treatments for their current conditions, and whether others take the Covid pandemic seriously enough. I have been extremely anxious to even leave home, because I don’t believe it is being taken seriously enough.”

A Germany-based HIV/hepatitis patient group describes a number of Covid-related major worries for the patients known to the group: “Bezug von lebenswichtigen Medikamenten durch Lockdown, Reisebeschränkungen, geschlossene Grenzen und fehlende Krankenversicherung.” [“Obtaining essential medicines throughout lockdown; travel restrictions; borders closed; and absence of health insurance.”]

From Greece, a carers’ organisation notes: “Οι γενικοί προβληματισμοί για την επιδημία που είχαμε όλοι και ιδιαίτερα οι ασθενείς μέλη μας με κατεσταλμένο ανοσοποιητικό τους σύστημα. Ανασφάλεια αν θα συνεχίσουν την θεραπεία τους.” [“The general concerns about the epidemic that we all had—and, especially, our patient members with a suppressed immune system. Insecurity about whether they will continue their treatment.”]

GOVERNMENT EFFECTIVENESS AT TACKLING THE PANDEMIC

Patient groups responding to this PatientView survey vary considerably in their views on their home government's ability to manage the pandemic.

Japan: Patient groups in Japan, like their peers in many other countries, believe the needs of the long-term ill to have been mostly overlooked by governments battling Covid. A Japanese disability organisation asks the country's government: “慢性期の在宅患者に対する医療体制を、感染症対策とは別に確立すること”[“Establish a medical-care system for home-based chronic-phase patients that is in addition to, and separate from, the infectious-disease-control measures.”]

UK: A similar call is made by a UK-based rare-disease patient group: “More support for those at high risk, and vulnerable. Thought for the vulnerable, who are being told that they can go out—when, in fact, it is more dangerous.”

USA: Patient groups in several countries, including the USA, say that the geographically-fragmented nature of healthcare delivery has hampered a more unified response to Covid. A US-based breast-cancer patient group writes: “Some state governments are doing much better than the USA federal government—which has needed better risk communication, prioritization of PPE and testing for healthcare providers, etc.”

% of respondent patient groups from 27 countries stating that their government is doing a “Very effective” or “Effective” job at tackling the pandemic

Austria	100%
China	100%
Denmark	100%
Greece	100%
Ireland	94%
Australia	93%
Canada	93%
Finland	92%
Germany	92%
Norway	91%
Switzerland	89%
Portugal	87%
Argentina	86%
Italy	84%
Netherlands	81%
Hong Kong	77%
Sweden	76%
France	66%
Spain	55%
Belgium	53%
Poland	48%
Russia	41%
UK	39%
Brazil	29%
Mexico	26%
Japan	23%
USA	21%

THE PHARMACEUTICAL INDUSTRY AND PATIENTS DURING COVID

Patient groups responding to the PatientView survey note that the pharmaceutical industry has acted with speed to develop diagnostics, treatments, and vaccines for Covid. But they also report that pharmaceutical companies have paused many of their normal patient-related activities (whether relationships with patient groups, or support to patients outside of treatment). Examples include ...

Helping patients gain access to medicines: 46% of the 1,720 respondent patient groups state that the pharma industry has had “No impact”, or even a “Negative impact”, in helping patients gain access to medicines during the pandemic (only 16% rate pharma’s impact in this subject area as “Positive” under Covid). ■ In fact, as many as 80% of respondent patient groups specialising in pain-associated medical conditions, and 71% of epilepsy patient groups, assess pharma to be having “No impact”, or a “Negative impact”, on helping patients gain access to medicines during the pandemic.

Providing ‘beyond-the-pill’ support and services to patients: 39% of the 1,720 respondent patient groups state that the pharma industry has had “No impact”, or even a “Negative impact”, during the pandemic in providing patients with services beyond the manufacture of prescription medicines (23% rate pharma’s impact here as “Positive”). ■ Patient groups in the following therapy areas are the most negative about pharma as having “No impact”, or a “Negative impact”, at providing services ‘beyond the pill’ during the pandemic: 64% of patient groups specialising in pain-associated medical conditions; 57% of epilepsy patient groups, 56% of kidney-conditions patient groups; and 56% of multiple-sclerosis patient groups.

One respondent, a member of a US-based multiple-sclerosis patient group, writing in a personal capacity, interprets the pharma industry’s thinking on patient relations during the pandemic: *“I believe that the pharmaceutical companies are also trying to figure their next steps, as this pandemic is lasting much longer than anybody could have*

anticipated. First, only planning on a few months, and now learning that it can be many months before their educational patterns for the MS community can return to what things were pre-Covid-19.”

PATIENT GROUPS' RESPONSE TO THE PANDEMIC

Patient groups have become a major lifeline for chronically-ill patients living in the community. Deprived of customary forms of care and support from their healthcare systems during the pandemic, patients are turning to patient groups for help. Over half (52%) of the survey's 1,720 respondent patient groups report having more contact with patients since the onset of the pandemic.

The survey also finds that the vast majority of patient groups have embraced new responsibilities as they work to protect and maintain services for patient communities in the year of Covid. So, during the pandemic ...

- 77% of the survey's 1,720 respondent patient groups have taken steps to define the needs of patients known to them.
- 67% are hosting telephone helplines.
- 57% are bringing patients/carers together online for peer-to-peer support.
- 49% are offering medical advice.
- 26% are supplying personal protective equipment (PPE). And ...
- 23% are delivering treatment and care.

The scale and complexity of these endeavours varies from country to country, and therapy area to therapy area—depending on whether services are (or are not) available to patients through the normal healthcare systems.

Patient groups are finding ways of delivering patient-related services in safe, digital, virtual forms. Like many other types of organisations adapting to the pandemic, patient groups are relying more on e-communication tools, less on customary face-to-face interaction. For instance, 41% of the survey's 1,720 respondent patient groups have either increased their

organisation's levels of activity on direct messaging platforms due to the pandemic, or newly introduced them. In the case of patients who have little or no access to the Internet, or who find e-communication technology daunting (such as older people, or those with dementia), alternative methods of communication—such as the post, or telephone—have been deployed by patient groups during the pandemic.

A US-based patient group specialising in hypertension during pregnancy states: “We mobilized the distribution of BP [blood-pressure] monitors to the highest-risk women who are receiving telehealth, and, thus, are not physically with their healthcare providers.”

A Germany-based rare-disease patient group states that it has begun to supply medicines to at-home patients who have alpha-1 antitrypsin disease.

A Cyprus-based neuromuscular-conditions patient group states: “Ο Συνδεσμος μας κατά το lock down εργάστηκε όσο ποτέ άλλοτε να βοηθήσει τα μέλη του, αλλά η βοήθεια ήταν και για άτομα που δεν ήταν μέλη μας, αλλά είχαν διαγνωστεί με την πάθηση. Η στήριξη όλων, ήταν το μέλημα μας. Η επικοινωνία μαζί των, ήταν επι 24ώρου βάσεως. Ο Συνδεσμος μας έχει βοηθήσει ακόμη και ασθενείς που κατα την πανδημία εγλωβίστηκαν στην Κύπρου και ξέμειναν από φάρμακα, τα οποία δεν μπορούσαν να προημευτούν από ιδιωτικά φαρμακεία. Ασθενείς μελη μας, μετά από έκκληση του Συνδέσμου μας, προμήθευσαν τα άτομα αυτά, από τα δικά τους φάρμακα.” [“During lockdown, our association worked like never before to help its members. The association also helped people who weren't our members, and who had been diagnosed with the disease. The support of everyone, that was our concern. Communication with them was on a 24-hour basis. Our association also helped patients who were stuck in Cyprus during the pandemic, and who ran out of drugs, which couldn't be obtained from private pharmacies. Following our association's appeal, our patient members supplied these people with them from their own drugs.”]

THE CHALLENGES FOR PATIENT GROUPS DURING COVID

Patient groups face new financial hardships

Patient organisations are counting the financial cost of Covid. 67% of the survey's 1,720 respondent patient groups report a decrease in their revenue during 2020. As many as 30% call the decrease substantial. Only a few patient groups say that they have managed to obtain Covid-related extra

funding from government or pharmaceutical companies. Remote working during the pandemic has helped lower expenses for 54% of the respondent patient groups. But the savings appear marginal, due to a need to spend on new infrastructure and services as a result of Covid.

To meet the financial challenges posed by Covid, patient groups are having to reinvent themselves. Despite their economic hardship and added workloads during the pandemic, patient groups are reaching out to their fellow peer organisations. A US-based bleeding-disorders patient group reflects: “We are all working together more because of Covid. Competition seems to be a thing of the past. Barriers are down. Sharing is the way of 2020.”

The extraordinary demands and pressures placed on patient groups during 2020 have also compelled many to approach healthcare professionals for assistance. 41% of the survey’s 1,720 respondent patient groups are introducing, or scaling up, contact with doctors, nurses, and related health professionals because of the pandemic. These healthcare professionals have been able to supply medical expertise to patients who are relying on patient organisations for support.

Patient groups believe their efforts during the pandemic have positively affected their reputation

Among: ■ patients (61% of the survey’s 1,720 respondent patient groups say that the pandemic has had a “Positive” impact on their reputation among patients); ■ healthcare professionals (47%); ■ other health campaigners (36%); and, to a lesser extent, ■ the healthcare media/general media (34%).

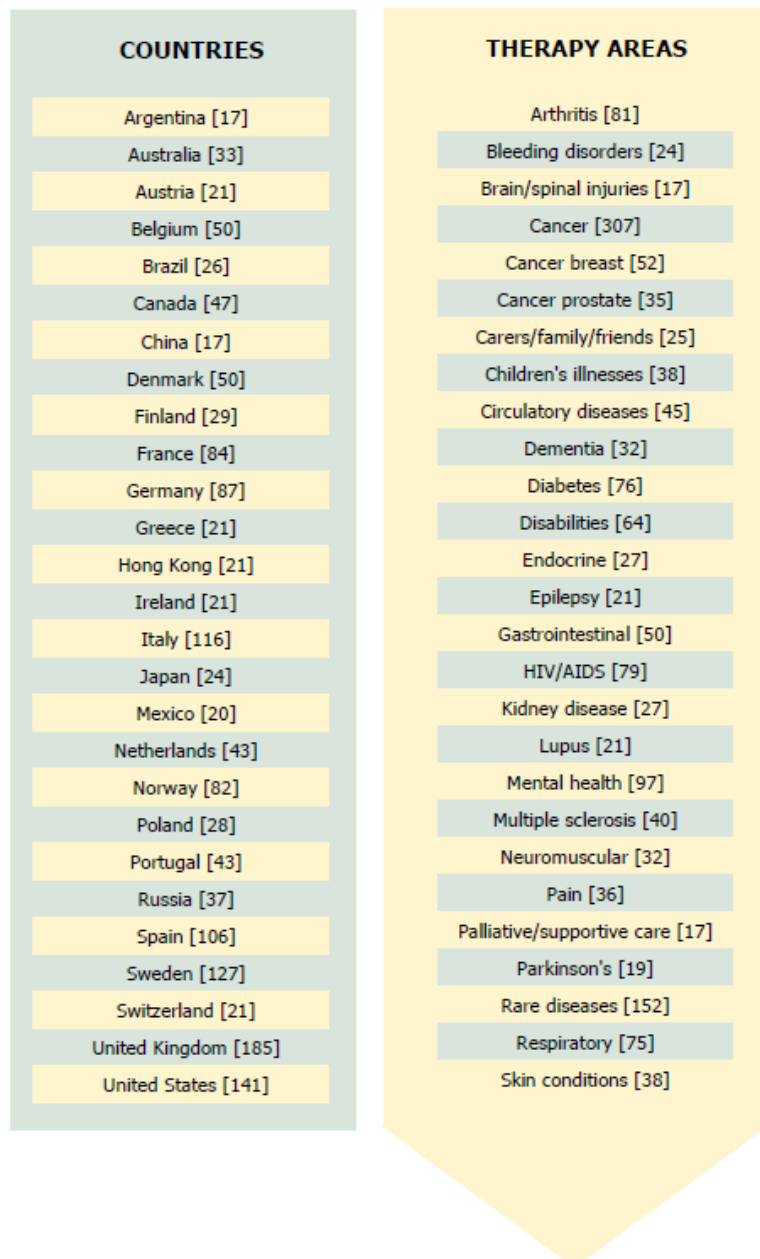
A comment from an Australia-based consumer-health organisation typifies the views of many respondent patient groups: “We have re-established connection with the health system—which, I hope, has been viewed positively.”

THE IMPLICATIONS FOR THE FUTURE

Patient groups (rather than healthcare systems) have become the first port of call during the pandemic for many chronically-ill patients—a trend

which is reinforcing the reputation of patient groups among the public. In addition, the new networking connections being created among patient groups during the Covid period have the potential to strengthen these groups' future position, potency, and leverage within their countries' healthcare systems. And patients groups can, today, say with certainty that they have pivotal role in healthcare.

PROFILES OF RESPONDENT PATIENT GROUPS [numbers in brackets are the number of respondent patient groups]



SPECIALTIES INCLUDED WITHIN EACH THERAPEUTIC CLASS ARE AS FOLLOWS:

- **Arthritis:**
ankylosing spondylitis; osteoarthritis; psoriatic arthritis; and rheumatoid arthritis.
- **Bleeding disorders:**
haemophilia.
- **Cancer:**
cancer in general; plus cancers of the bladder, blood, brain, breast, children's/young people's cancers, digestive, head and neck, kidney, lung, ovarian, pancreatic, prostate, rare, skin, testicular, thyroid, and men's and women's cancers.
- **Children's illnesses:**
children in hospital; children's mental-health conditions; and paediatric cancers.
- **Circulatory diseases:**
familial hypercholesterolemia; heart conditions; hypertension; and pulmonary hypertension.
- **Disabilities:**
hearing loss; loss of mobility; and visual impairment.
- **Endocrine conditions:**
adrenal, pituitary, and thyroid conditions.
- **Gastrointestinal conditions:**
Crohn's and colitis; coeliac conditions; and ostomy.
- **Mental health:**
ADD/ADHD; addiction; anxiety; bipolar disorder; depression; eating disorders; and schizophrenia.
- **Pain:**
fibromyalgia; headache; and migraine.
- **Rare diseases:**
alpha-1 antitrypsin deficiency; Behcet's; Fabry; Gaucher's; Huntington's; Klinefelter; Marfan; Niemann-Picks; Prader-Willi; rare cancers; tuberous sclerosis; Williams syndrome; Wilson's disease; and additional inherited and metabolic conditions.
- **Respiratory conditions:**
asthma; COPD; cystic fibrosis; pulmonary fibrosis; and sleep disorders.
- **Skin conditions:**
psoriasis; and scleroderma.



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