

A NEW ANALYSES FROM PATIENTVIEW Supporting patients in Ukraine — 2022/2023

The views of six Ukrainian patient groups

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For over a decade, Ukrainian patient groups have played an increasingly active role in the country's healthcare—supporting, and advocating for, patients. Among their key campaigns have been a concerted fight against corruption, and calls for the introduction of a more-level playing field for the procurement of medicines. Ukraine's patient movement has become even more vital to the citizens of a country now gripped by war. Despite facing war-imposed hardships of their own, Ukraine's patient groups have responded to the conflict by stepping up their support to the soaring numbers of vulnerable Ukrainian patients.

By July 2022, the World Health Organization identified what it regarded as the **priority public health concerns** stemming from the now war-damaged nature of Ukraine's healthcare services: • *conflict-related trauma*; • *outbreaks of potential communicable disease*; • *nuclear and chemical hazards*; • *human trafficking*; • *sexual violence*

Plus particular worries about the following **five areas of Ukrainian health and healthcare**: • maternal, and newborn, healthcare; • chronic disease care, • mental healthcare; and • food security.

By the end of 2022, over a quarter of the country's population had been displaced. Nearly ten months of war had seen Ukraine suffering 707 violent attacks on the country's hospitals, medical infrastructure, and healthcare workers. An estimated one-in-three Ukrainian citizens found themselves devoid of access to medical services.²

Against such a backdrop, PatientView decided, in late 2022, to gain a more-detailed understanding of patient, and patient-group, experiences in Ukraine during the war, by undertaking and funding its own research on the subject. Six patient groups from Ukraine participated in the project, offering accounts of the ways in which they were coping with the horrors of war. In addition, seven pharmaceutical companies provided PatientView with information on how they are supporting patients during the war.

- https://reliefweb.int/report/ukraine/destruction-and-devastation-one-year-russias-assault-ukraines-health-caresystem#:~:text=While%20the%20full%20extent%20of,the%20International%20Organization%20for%20Migration
- 2. https://reliefweb.int/report/ukraine/destruction-and-devastation-one-year-russias-assault-ukraines-health-care-system#:~:text=While%20the%20full%20extent%20of,the%20International%20Organization%20for%20Migration

UKRAINIAN PATIENT GROUPS: INDEPENDENT PATIENTVIEW STUDY

In 2022 and early 2023, PatientView collected feedback from six Ukrainian patient groups about their wartime experiences, and crucially those of the patients they serve. The six patient groups specialised in coeliac disease, haemophilia (two patient groups), infectious disease, mental health, and stroke. These six groups estimated that, collectively, they provided wartime support and services to more than 22,000 Ukrainian patients.

➤ Wartime challenges

Remaining active under wartime conditions was the first problem that Ukrainian patient groups had to overcome when Russia invaded in February 2022. Areas of Ukraine became warzones overnight, and patient groups needed to find safe spaces to continue working, supporting patients, and raising funding.

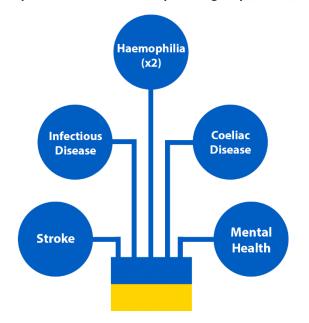
The reckless destruction of Ukraine's national infrastructure (including electricity, internet access, transport) made this extremely difficult, and led to patient groups losing touch with many of the patients they normally served. Government support was understandably limited, with political effort focused on defence.

➤ Finding solutions

Despite these issues, the six Ukrainian patient groups emphasised that they have continued to function—and, in some cases, very successfully. For example, one group reported being able to attract extra volunteers wanting to help. "The number of people we provide care to has now increased from 450 to 1,150 people."

Sophisticated online patient consultations, identification of active medical hubs providing treatment, and aid from international patient groups were all solutions used by patient groups in Ukraine to further support patients.

➤ Specialities of Ukrainian patient groups, 2022/23



"The main concern of the organisation's employees is to move to a safe place."

- National haemophilia patient group

"Maintaining the organisation is more difficult, due to a reduction in funding."

National mental-health/rehabilitation
 NGO

"The employees of the organization have been working to solve all of the problems that have arisen, including: a) providing psychological and moral support to patients; b) constantly maintaining contact with patients by telephone; and c) ensuring the timely supply of drugs to patients by different methods, when public or regional transport wasn't running."

Regional infectious-diseases patient group

SUPPORT FOR UKRAINE FROM PHARMACEUTICAL COMPANIES

Large pharmaceutical companies have had a significant footprint in Ukraine¹ for some years. PatientView asked six Ukrainian patient groups to comment on the wartime support they had seen pharmaceutical companies provide to Ukrainian healthcare services, and to Ukrainian patients and patient groups. There was little awareness from the groups of support from companies, except for some efforts to help Ukrainian patients get better access to medicines.

> Summary of pharma support for Ukrainian patients and patient groups during wartime

Respondent pharma companies include:

- AbbVie
- Bayer AG
- Boehringer Ingelheim
- Merck KGaA / EMD Serono
- Novartis
- Pfizer
- ViiV Healthcare



➤ Moving on

When the six Ukrainian patient groups were asked what single measure could be given to their patient group to provide the greatest benefit to Ukrainian patients, replies included:

"Humanitarian aid from European countries and communities, patients' organisations."

National coeliac patient group

"Cooperation with the Ministry of Health."

National haemophilia patient group

"Dissemination of information about the organisation among the general population."

International mental-health/rehabilitation NGO

"PatientView would like to thank the participating Ukrainian patient groups, and the participating pharmaceutical companies, for their contributions to the project. PatientView hopes that the project's results might be of interest to any of the public and professional bodies looking to support Ukrainian patients whose care is impacted by the war. May the Ukrainian healthcare institutions seeking to build back, and restore, the country's war-damaged healthcare services be successful in their task."

This report is provided free online, in two languages (Ukrainian and English).

For further information on how to obtain a copy of PatientView's 'Supporting patients in Ukraine – 2022/2023' report, please email: report@patient-view.com

Note on PatientView:

For the past two decades, UK-based PatientView has undertaken regular evidence-based research into the different perspectives of patient organisations around the world on a range of issues. PatientView's reach among these patient organisations is unique, with as many as 40,000 such groups in our informal network.

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