



Patients in Action

understanding and supporting
the roles played by patient
groups in healthcare



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*PatientView is today launching a new report, '**Patients in Action**', which maps the patient movement (worldwide, and across therapy areas), looking at the roles that patient groups play in healthcare systems today, and the support these organisations need from other healthcare stakeholders to achieve their goals.*

SUMMARY

- When measured by some 60 variables, the majority of patient groups believe that they form an important part of their country's healthcare system (though the perspectives of patient groups do differ across countries and therapy areas).
- Patient groups interact with their own country's healthcare system at every level—from policymaking at national level, through to healthcare delivery at local level.
- Patient groups may supply practical support for patients when cash-strapped national healthcare systems are unable to do so—filling a vacuum. For example, almost one third of patient groups provide treatment and care unavailable in healthcare systems.
- Many patient groups wish to be engaged with healthcare systems on a more formal basis.



Having an influence

60% of the patient groups responding to the 2024 'Patients in Action' study see themselves as significant contributors to their country's healthcare system. The financial hardships affecting national healthcare systems have motivated patient groups to provide patient help and support not covered by healthcare systems. Recognition of the importance of patient groups by healthcare systems, together with the introduction of legislation promoting patient involvement in healthcare decision-making, have enabled patient groups to increase their impact on healthcare systems.

72% of patient groups worldwide responding to the 2024 'Patients in Action' study believe that they have an influence on the provision of healthcare services in their country, and 65% believe that they have an influence on patients' access to care in their country.

67% of patient groups say that they represent patients' interests to their country's drug-regulatory authorities. In Canada, the figure is 89%.

ABOUT THIS STUDY

The 'Patients in Action' report is based on the results of a PatientView survey, conducted June to August 2024. **1,144 patient groups responded, from 83 countries, and 65 therapy areas.**

The study **focuses on 19 countries and 20 therapy areas** [for list, see Appendix below].

This comparative data provides **an in-depth appreciation of patient groups' assets, activities, and current relations with other healthcare stakeholders.** Patient groups also describe the support they need to fulfil their goals.

The scale and variation of 'Patients in Action' data generates a comparative spectrum that adds a validity and reliability to the study's methodology and results.

The study’s 1,144 respondent patient groups supplied 1,085 comments highlighting why patient groups regard themselves as essential to their country’s healthcare system [see chart below].

Over 75% of patient groups in Australia, Norway, and Portugal believe themselves essential to their country’s healthcare system.

- Respondent Australian patient groups say that they contribute to Australia’s healthcare system by:
 - designing patient pathways for the healthcare system;
 - identifying treatment gaps (with government funding); and
 - providing funds for hospital equipment.
- Norwegian patient groups say that they contribute to Norway’s healthcare system by:
 - acting as active representatives on government drug-regulatory committees;
 - organising meetings between hospital staff and patients, to help each better understand the other; and
 - offering support to patients living with debilitating medical conditions (including support, too, to the families of these patients).
- In Portugal, patient groups
 - deliver medication;
 - provide informative materials to doctors; and
 - support patients through clinical trials.

Reasons why patient groups think themselves essential to their healthcare system

Theme	# of comments	% of comments
Improving care pathways, guidelines, and services	178	16.4%
Guiding policy development, advocacy activities	161	14.8%
Improving self-care and health literacy	122	11.2%
Raising awareness of disease and its impact	103	9.5%
Participating in regulatory, HTA, and insurer decisions	87	8.0%
Supporting individual patients and carers	85	7.8%
HCP education and engagement	78	7.2%
Involvement in research	76	7.0%
Providing healthcare	65	6.0%
Researching new treatments and disease insights	55	5.1%
Improving access to care and treatments	44	4.1%
Advocating for equitable access for treatments	28	2.6%
Other	3	0.3%
TOTAL	1,085	

“ Is your organisation an essential stakeholder in healthcare systems?”

Healthcare professionals such as specialists, pharmacists and researchers see us as a relevant organization. We work closely with the peak medical body [in Australia] and have collaborated with them to improve patient care over many years. Our voice [patient support organization] is different to the voice of the peak medical bodies, even though we share the common goal of improving patient care. Our roles in the health care system are different.

We offer free patient support to help patients manage everyday life with allergic disease, which compliments their clinical care. We play an important role in raising health literacy and engagement with their health care team. We make submissions in the health technology assessment process to share patient experience and to ensure the patient voice is heard during the assessment process. We are essential in the disease space and should be included as a significant stakeholder in all aspects of the way the health care system manages the disease space in Australia. The patient experience of the health system – helps inform improvements.



Being respected, and listened to

'Patients in Action' data show that patient groups do feel respected, and listened to, by most other healthcare stakeholders.

Percentages of the 1,144 respondent patient groups saying that the following healthcare stakeholders believe them to be essential to healthcare systems (at least some of the time)



KEY FINDINGS

Patient groups in Brazil, Canada, and Greece feel the most valued by the healthcare stakeholders in their country.

80% of the study's respondent patient groups state that the media view them with respect and listen to their opinions. In 2018, (when PatientView conducted a similar survey) the equivalent figure was just 32%.

The services patient groups provide

'Patients in Action' data show that patient groups provide a **wide range of services** to patients. These **services increasingly involve direct interaction with healthcare systems, and with pharmaceutical R&D activities.**



69%
host telephone
helplines



78%
arrange peer-to-
peer support groups



37%
support patients in
economic hardship



78%
offer healthcare
advice



32%
deliver treatment
and care



42%
support drug-
treatment clinical
trials



33%
undertake
healthcare research

A key motivation of many of the patient groups replying to the 'Patients in Action' study is to **provide aspects of patient care or support not offered by their country's healthcare system.**

100% of patient groups in **Finland** supply peer-to-peer support.

74% of patient groups in the **USA** are involved in drug-treatment clinical trials.

72% of patient groups in **Brazil** support patients in economic hardship.

70% of patient groups in **Spain** provide treatment and care to patients.

The support that patient groups need

The 1,144 patient groups responding to the 'Patients in Action' study were asked to identify three key interventions that would provide them with the support they need to achieve their goals. Some 2,631 comments were received on the subject. Top items on the list: • a call to improve patient access to care, through better patient pathways; plus • facilitating patient groups' ability to network with other healthcare stakeholders (including governments). Interestingly, patient groups placed improved

financing of themselves only 3rd on the list (even though many patient groups are often short of funds).

The support that patient groups say they need

Theme	# of comments	% of comments
Improve access to care, pathways and quality	468	20.2%
Enable networking and engagement with stakeholders	360	15.5%
Finance and resourcing	315	13.6%
Capacity building, expertise and training	255	11.0%
Enable patient engagement in research	196	8.5%
Raise patient group profile and reputation	193	8.3%
Improve patient and caregiver experience	182	7.9%
Raise disease awareness, prevalence and burden	173	7.5%
Improve integration of patient group into health systems	110	4.7%
Support patient-group goals and co-working	97	4.2%
Improve HCP education	93	4.0%
Support patient group advocacy	86	3.7%
Address inequity	45	1.9%
Enable and improve patient-group delivery of services	32	1.4%
Address stigma	12	0.5%
Other	14	0.6%
TOTAL	2,631	



Full recognition as elected patient representatives in all areas.
National liver-disease patient group, Austria

We need better involvement in decision-making processes, both EU-wide and regionally.
International cancer patient group, Belgium

Give adequate weight to patient-provided evidence.
National respiratory patient group, Canada

At the national health level, decisions that affect us, should not be taken without us, in the relevant decision-making centres that we participate in.
National respiratory patient group, Greece

Finally, PatientView would like to thank the 1,144 patient groups that gave up their time to respond to the 2024 'Patients in Action' survey.

For further information on this report, please use contact details below.

END OF PRESS RELEASE

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Appendix

The 19 countries, and 20 therapy areas, examined in detail. Number of patient groups

