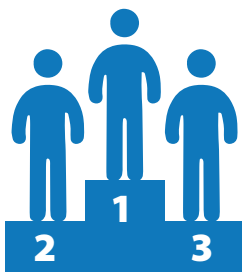
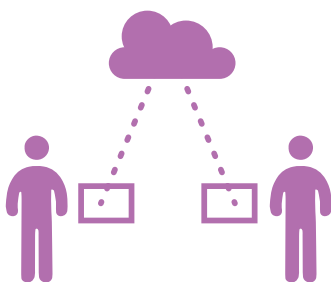


BENCHMARKING THE PATIENT MOVEMENT 2018

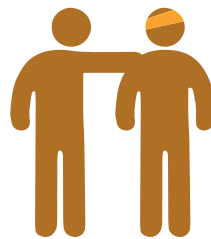
METHODOLOGY AND APPENDICES



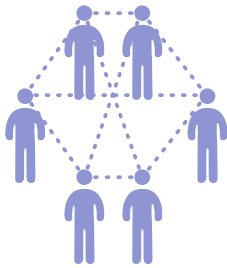
Business stability



e-communication

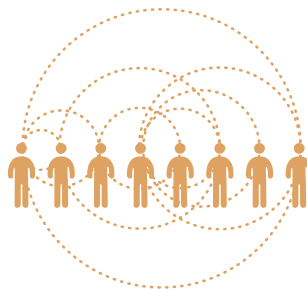


Services to patients



Networking with other healthcare stakeholders

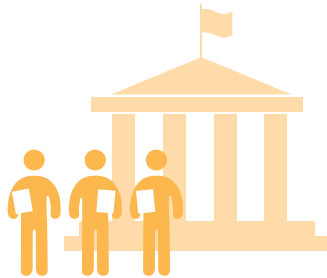
PATIENT
VIEW



Networking with peers



Reputation with other stakeholders



Impact on health policy



Resilience

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2018 results on the capabilities of the global patient movement compared with 2014 and 2012

INTRODUCTION

Introduction

Pinpointing a moment when the patient movement became a discernible, functional entity—capable of exerting change on healthcare systems—is a difficult task. One potential date might be 1987, when AIDS activists took to the streets in Washington DC, raising the issue of patients' rights to front-page news for the first time. Since then, all manner of patient groups and health NGOs have formed worldwide, their numbers expanding in response to the rationing of national healthcare systems.

The growing patient movement was empowered by the availability of new information technologies, particularly, the explosion of the Internet commencing in the early-to-mid 1990s, and then the subsequent rise of social-media tools: Facebook in 2004, Twitter in 2006, Instagram in 2010, and SnapChat in 2011. These e-communication outlets potentially enabled health NGOs to communicate with the people they represent, and those in their field of view. E-communication helped overcome the problems with language differences and physical distance.

The next breakthrough came with the challenging acceptance by health professionals and regulators of the patient movement that (1) health NGOs possess a unique and invaluable insight into healthcare systems; and (2) that patients, and people with a disability, have an inherent right of expression about their own treatment and care, without fear of repercussions.

Patients (and their group representatives) are experts on every aspect of treatment and care, and how that impacts their quality of life—from pre-diagnosis, through to withdrawal from treatment, as well as coping on a day-to-day basis. Healthcare professionals, on the other hand, are responsible for the medical choices made on behalf of their individual patients from a solely medical viewpoint. They therefore cannot be aware of the overall impact

of the medical condition, as well as treatment, on patients. The patients, and carers who contribute to patient groups, provide a perspective into what life is really like for patients—they identify unfulfilled needs, and highlight gaps in treatment and support.

Healthcare in general is increasingly challenged by the strain imposed by population growth, increased life expectancy, and the growing burden of chronic disease. The costs of medical technology and the greater specialisation of healthcare professionals, have led to cuts and rationing on transnational levels of much needed healthcare services. Many patient groups have stepped in to attempt to fill the gaps in healthcare services, providing treatment, care, nurses, psychotherapy, even hospitals and hospices.

Drawing on the data from our 2018 Benchmarking report, Tables 1 & 2 show that the provision of patient group-funded healthcare services is influenced by both geographic and therapeutic considerations. In the case of Spain; as many as 44% of patient groups provide healthcare services to patients. Compare the Spanish situation to that of the Netherlands, where patient groups do not appear to need to provide healthcare services at all. In the context of therapy areas, the patient groups focused on neurological conditions provide the most services to patients; and groups specialising in endocrine conditions provide the least—perhaps reflecting the different complexities and demands of the respective conditions.

Thus, the relationship between patient groups and healthcare provision, is changing radically. Where before there was a sharp divide between patients and care, nowadays, the two are more closely intertwined. Furthermore, the ever evolving nature of patient group relationships with healthcare systems is contributing to the heightened discussion of the importance of the patient movement in general.

Table 1: Patient groups' provision of healthcare services as determined by geographical need

Percentage of patient groups providing healthcare services

Spain	44%
Portugal	40%
Africa	39%
Eastern Europe	38%
Cyprus and Greece	38%
Central and South America	36%
Russia	31%
Italy	31%
Ireland	29%
Switzerland	28%
Nordic	28%
Asia	26%
Australasia	19%
German-speaking	18%
UK	18%
Germany	17%
Belgium	15%
Canada	10%
USA	10%
France	9%
Netherlands	0%

Source: *Benchmarking the Patient Movement, PatientView, 2018*

Table 2: Patient groups' provision of healthcare services, as determined by therapeutic need

Percentage of patient groups providing healthcare services

Neurological	32%
Blood disorders	30%
HIV/AIDS	30%
Mental health	30%
Rheumatological	29%
Cancer	28%
Liver/hepatitis	28%
Diabetes	22%
Circulatory and heart	22%
Respiratory	21%
Disability	19%
Rare diseases	18%
Carers/family/friends	16%
Gastrointestinal	15%
Renal	12%
Skin	9%
Endocrine	8%

Source: *Benchmarking the Patient Movement, PatientView, 2018*

Yet despite their obvious importance, no real mechanism exists to measure the patient movement's impact upon healthcare—besides the rather arbitrary measure of the numbers of patient groups, or patient groups' own accounts of their successes. In 2012, PatientView set about filling such a void in measurement, by developing a benchmarking tool to assess the impact of patient groups in their fields of activity, in an attempt to assess their significance in healthcare systems. This analysis in 2018, represents the 3rd time the benchmarking study has been undertaken. The previous study was completed in 2014.

METHODOLOGY

Methodology – the eight indicators for benchmarking the patient movement

When PatientView's tool for benchmarking the patient movement was first developed in 2012, its reliability was checked by healthcare professionals and industry representatives, to verify the validity of the indicators employed by the tool. The 2012 benchmarking exercise consisted of three surveys: 1,000 patient organisations worldwide; 20 healthcare professionals; and 30 health-industry executives [see page 6].

The tool defined eight indicators for measuring patient-group capabilities. Each of the eight indicators has a set of sub-categories. To simplify the process, virtually all questions are binary ('yes' or 'no').

CHANGES IN 2018

In 2018 a number of new sub-categories were added, to reflect the fact that patients, and patient groups, are increasingly involved in all aspects of healthcare, including research, development and even regulation.

In addition, six new therapeutic categories have been added, including disability groups. Such organisations understand the limitations of the healthcare service, which are often overlooked and can block the progress of treatment and care. Carer/family/friends' organisations are also featured in the 2018 analysis, since these latter stakeholders can form the cornerstone of long-term management of care.

In 2018, a total of 1,016 patient groups responded to the benchmarking survey, from 84 countries. However, the numbers of respondent patient groups for each therapy area vary significantly (from just 17 renal patient groups to 206 cancer patient groups). However, because the statistics are derived from a binary methodology, data are robust and valid—although results can only ever be viewpoints of the surveyed patient groups in that therapy area.

THE EIGHT INDICATORS OF PATIENT-GROUP CAPABILITY

Indicator 1: Business stability

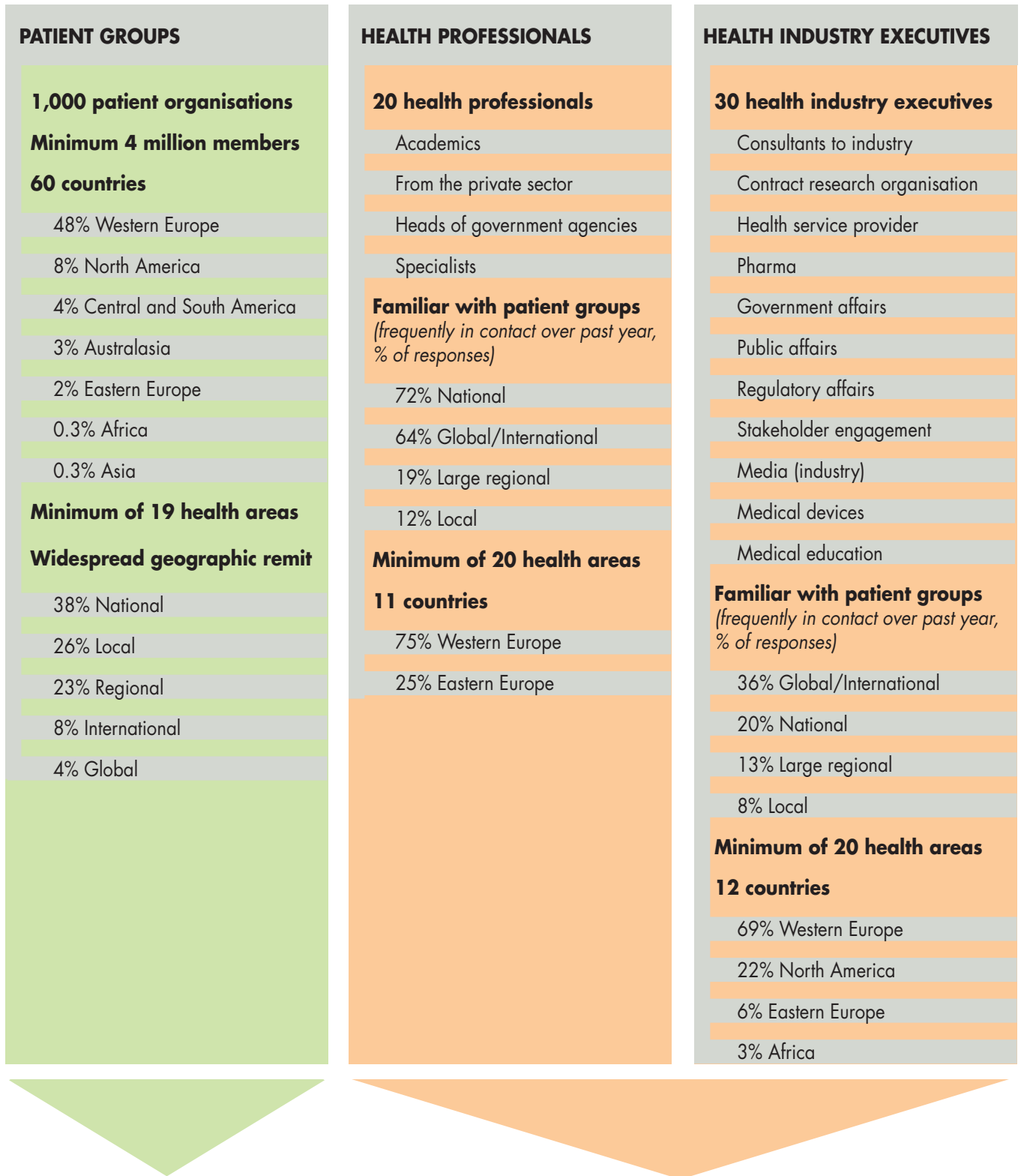
An indication of maturity among patient organisations and other health NGOs is their increasing sense of stability from a business-oriented perspective. Elements of a more businesslike approach include the following sub-categories:

- **A mission statement**, or some clear pronouncement of organisational purpose.
- **An operating or business plan**.
- **A formal structure of governance** (a non-executive board, or the production of accountant-audited annual reports).
- **A reliable (or, better still, guaranteed) income for a certain length of time**. Small-to-medium business enterprises are often assessed by their 'cash burn' (the rate at which they use up their cash resources or capital before producing a positive cash flow). In the case of charities, the key requirement here is having enough money to ensure a cash flow sustainable for at least a single year. (This variable makes no judgement on the source of the organisation's cash flow—government, public donations, industry grants, membership fees, etc.)
- **Independence from funding sources**. Health NGOs should be able to determine the direction of their activities without feeling compelled to seek the endorsement or approval of the suppliers of their funding.
- **Regular consultation with the constituency**—necessary if the group claims to be representative of the people for whom it campaigns and works. (From the results obtained, even in 2012, the vast majority of health NGOs do consult with members, other patients, or the public.)
- **A fundraising strategy**—this new sub-category was added for the 2018 survey, reflecting

Continued on page 7

Methodology: three online surveys

end April to mid-June 2012



PATIENT GROUP SURVEY
Helped create the tool for benchmarking patient groups

SURVEYS OF HEALTHCARE INDUSTRY EXECUTIVES AND HEALTH PROFESSIONALS
Verified the benchmarking tool

increasingly sophisticated levels of fundraising among patient groups (including campaigning for funds, the sale of products, and the canvassing of funds from industry and government).

Indicator 2: e-communication

The growth of the patient movement has been helped, in no small measure, by the presence of social media. The low financial costs and overheads involved in managing a website, or in running a Facebook or Twitter account, coupled with widespread public willingness to embrace social media, mean that health NGOs can readily exploit these electronic communicational tools to reach out to the people they seek to represent. Indeed, virtual healthcare communities have—sometimes, and, to some extent— replaced the more traditional membership arrangements that used to characterise charities. But, just how good are patient groups at harnessing the agents of social media? The benchmarking tool explores patient groups' engagement with:

- **The Internet (in general, in the form of a website).**
- **Facebook.**
- **Twitter.**
- **Other social media.**

Indicator 3: Services to patients

Patient groups perform a wide variety of activities. Nearly all of the 2018 respondent patient groups, for instance, supply information to patients and the public, and offer peer-to-peer support. Many of them campaign to government or healthcare providers on behalf of the people they represent. A few raise funds for medical research. Patient groups are also stepping in to fill service gaps within their country's national healthcare systems [as discussed previously, see tables 1 and 2]. Indicator 3 measures the whole repertoire of nine patient-group activities listed below. Any individual patient group is unlikely to engage in all of them, but the benchmarking study assumes that the more diverse a patient group's

range of activities, the greater their impact on society, and the more they are capable of achieving within their remit:

- **Supplying information to patients and the public.**
- **Offering peer-to-peer** support (such as seminars, meetings, etc).
- **Advocacy (representation) on behalf of patients to government.**
- **Advocacy (representation) on behalf of patients to healthcare providers.**
- **Supplying patients with healthcare services:** treatment; care; our own nurses; psychotherapy; own hospitals; own hospices.
- **Fundraising for medical research.**
- **Undertaking medical research.**
- **Representing patients in the development of drugs.** A new sub-category for 2018, introduced following the latest moves by both pharmaceutical companies and drug regulators to seek ways of getting patient input into R&D.
- **Representing patients in regulatory bodies—such as the US Food and Drug Administration (FDA), or the European Medicines Agency (EMA).** Another new sub-category for 2018, brought in to reflect recent 'patient-focused' initiatives— particularly the FDA's Patient-Focused Drug Development programme that emerged from the 21st Century Cures Act (passed into law in the USA in December 2016).

Indicator 4: Networking with stakeholders

Patient groups need to reach out to other healthcare stakeholders if they are to understand (and even to have a chance of changing for the better) the healthcare systems in which they function. Whatever a patient group's particular working remit, therefore, the scale of its networking with other healthcare stakeholders provides evidence of the capability and influence of the group. The healthcare stakeholders with which patient groups network include:

- **Academic/scientific bodies.**
- **Consultants/specialists.**

- General media.
- General physicians (GPs).
- Healthcare media.
- Health committees appointed by national government.
- Local government health committees.
- Medical-device companies [new for 2018].
- Medical-device trades bodies.
- Medical-professional societies.
- Nurses.
- Patients [new for 2018].
- Pharmaceutical companies [new for 2018].
- Pharmaceutical trades bodies.
- Pharmacists.
- Regulatory bodies (eg, the FDA) [new for 2018].

Indicator 5:**Networking with peer patient groups**

The patient-group movement is highly fragmented. As well as being numerous, patient groups can sometimes act in competition with each other, or duplicate their activities. When groups operate in a coherent manner, however—networking, liaising, combining efforts—they inevitably gain strength through association. Indicator 5 considers the extent that patient groups reach out to one another. Peer-to-peer networking includes:

- Other similar patient groups in your specialty/ies.
- Umbrella patient groups for your specialty/ties.
- Patient groups in other specialties.
- General umbrella patient groups in other specialties.

Indicator 6:**Reputation**

The patient groups in this survey are asked how other stakeholders perceive them in terms of their capability of fulfilling the needs of the people they represent. These stakeholders (all with an interest in healthcare) are:

- Academic/scientific bodies.
- General media.
- Government administrators.
- Government policymakers.
- Regulatory bodies (eg, the FDA) [new for 2018].
- Healthcare media.
- Healthcare professionals.
- Medical-device companies.
- Pharmaceutical companies.
- Pharmacists.
- Local politicians.
- Other health campaigners.

Indicator 7:**Impact on health policy**

The patient groups participating in the benchmarking study are asked whether their country's current government considers their organisation's therapy area (or areas) a healthcare priority. The question is indirectly probing into the capability of patient groups to influence government health policy. There could be a logical discrepancy with this question, as governments should tend to favour organisations that deal with most common disease areas, achieving the most healthcare improvements with the least amount of resources. The group representing the largest catchment would hold the larger voting population.

However, findings suggest government, instead, is swayed by the most vocal and impressive patient groups, irrespective of their therapy area. Blood-disorder, hepatitis, and HIV/AIDS patient groups are medical conditions that are relatively uncommon, but have been unusually effective at getting their therapy area onto the political agenda. So for this reason it is important to measure a patient group's capability (albeit from their own perspective) of influencing the government, as it is a factor over which patient groups have a degree of control.

Indicator 8:

Resilience

The patient organisations participating in the benchmarking study are asked to identify what they perceive to be the biggest hurdles that stand in the way of fulfilling their mission (choosing from up to eight challenges commonly faced by patient organisations). In principle, the more capable and skilled patient groups should have the least concerns over any of the following challenges:

- A lack of funding of your own organisation.
- Trying to secure patient access to effective, top-quality medications and other treatments (influencing HTA processes).
- Public apathy, or an unbelieving public.
- Difficulty of getting your organisation's message across in the media.
- Opposition (or lack of cooperation) from medical professionals.
- Opposition (or lack of cooperation) from government.
- Opposition (or lack of cooperation) from pharmaceutical companies.
- Lack of research investment in your therapeutic area.

Methodology: how the assessment and analyses are made (plus an important caveat)

PERSPECTIVES NOT FACT

The benchmarking process relies on a system of self-assessment. The findings should, therefore, be taken as a reflection of the views of participating patient groups, rather than as fact. Nonetheless, the percentages and rankings do measure how patient groups perceive themselves against one another.

PatientView employs several baselines against which the results from the 'benchmarking' tool can be compared. These baselines are:

- A global (therapy-wide) average for each of the eight indicators of patient-group capability.
- Country/region averages for each indicator.
- Average for therapy areas for each indicator.
- And ...
- Historic averages for both countries/regions and therapy areas.

The results of the 2018 benchmarking exercise highlight the latest strengths and weaknesses of the patient groups that comprise each therapy and geographic area—as well as the trends currently affecting the patient movement as whole.

THE 2018 BENCHMARKING SURVEY AND ANALYSES

The 'Benchmarking the Patient Movement' tool is now in its 3rd iteration (having been first carried out in 2012, then in 2014).

The 2018 benchmarking survey was conducted between April-July 2018. The survey received responses from 1,016 patient organisations of varying specialties, and from 84 countries. The results of the 2018 benchmarking survey are also compared with the equivalent results from the two previous benchmarking studies (2014 and 2012), to illustrate some historic trends.

2018's results have been broken into 17 therapeutic areas, and into 21 countries/regions—set out in two separate PowerPoint decks.

THE CAPABILITIES OF THE GLOBAL PATIENT MOVEMENT —2018'S RESULTS

(COMPARED WITH THE RESULTS FROM THE 2014 AND 2012 EXERCISES)

Changing trends, 2012-2018

Below are summaries for the overall trends in the patient movement worldwide, across all therapy areas, 2012-2018 [data accompanying these summaries can be found on page 13 onwards].

■ Business stability

The 2018 results indicate that **the patient movement as a whole has increased both its stability, and its forms of financing**. The biggest changes in business stability, 2012-2018, are positive, and can be seen in the increased adoption of mission statements, and a trend towards better governance. More patient groups are, for instance, appointing boards, and publishing annual reports, which is an indication that they have the resources for a corporate structure. A negative business trend, however, is that only 46% of patient groups state that they have a fundraising strategy (a new question introduced for the 2018 benchmarking survey)—one area in which many patient groups can improve.

■ Communication (via social media)

Social media have today become perhaps one of the most important mechanisms by which patient groups can reach out to, and understand the needs of, the people they represent—especially the younger elements of the patient movement. Although the percentage of patient groups which maintain websites has slightly declined (probably due to the associated maintenance costs) since the first benchmarking survey of 2012, **patient groups have ramped up their activities on Facebook, Twitter, and other social-media avenues**. Most significantly, in 2018, 77% of the 1,016 patient group respondents state that they have a Facebook account—compared with 60% in 2014, and 50% in 2012.

■ Services to patients

Patient groups provide a wide range of services to their patient constituencies (some patient groups more so than others). The vast majority of patient organisations provide two core services in the form of information and peer-to-peer support (and have done so since 2012, and even long before). However, **patient advocacy (that is, representation on behalf of patients)— whether to government, or to healthcare providers, or both—has markedly increased since 2012**. In 2018, as many as 68% and 63% of patient groups state that they undertake advocacy to these two vitally-important healthcare stakeholders, respectively—compared with 52% and 49% in 2012, respectively.

■ Networking with other healthcare stakeholders

If patient groups wish to be part of the healthcare environment, and to ensure that their perspective is included, they need to network with other healthcare stakeholders. **Since 2012 and 2014, the degree of networking between patient groups and healthcare professionals (academics; scientific bodies; consultants; and general physicians) has grown sharply**. Most notably, 65% of the 2018 survey's 1,016 respondent patient groups state that they network with academics/scientific bodies (in 2012 and 2014, the respective figures were 56% and 54%). In 2018, for the first time, the benchmarking survey asked patient groups about their levels of engagement with regulatory bodies—such as the US Food and Drug Administration (FDA), or the European Medicines Agency (EMA). 22% of 2018's respondent patient groups say that they have such a relationship. Although the figure is low, that is still most likely a marked improvement from previous years. 52% of 2018's patient groups network with pharma companies, and 30% with

medical-device companies. By contrast, patient-group interaction with the two industries' trades bodies has declined sharply since 2012.

■ **Networking with peer patient groups**

When patient groups speak collectively, they have greater impact on society than as an individual organisation. This networking question measures the willingness of the members of the patient movement to work together. However, the data show that **levels of networking with peer patient organisations has not changed markedly between 2012 to 2018. Fragmentation and competition continue to pervade the patient movement within their own speciality areas—a factor which dilutes its overall influence in healthcare systems, and also indicates that the movement has further to mature.**

■ **Reputation**

By their own account, **patient groups believe their overall reputation to remain largely unchanged for six years—and sits at a relatively low point. Interestingly, this finding comes despite an increase in patient-group reach among patients, and increased engagement with other healthcare stakeholders (notably regulators).** Indeed, on the subject of reputation with regulators, of the 22% of patient groups that have a relationship with regulators, only 40% believe regulators consider them "Very good" at fulfilling the needs of the patients and people they represent.

■ **Impact on health policy**

62% of 2018's respondent patient groups feel confident that the government considers their therapy area/s a healthcare priority (at least, sometimes, or depending on the situation). 30% of

patient groups are categorical that the government does not consider their therapeutic subject area a healthcare priority (the remainder "Do not know").

The 2018 results cannot be compared directly with those from the 2012 and 2014 surveys, as the question was phrased differently in the two previous years. However, what is noticeable is that the percentages of answers stating "No: the government does not consider our organisation's therapy area a policy priority" have declined sharply—from 42% in 2012, and 44% in 2014, to the 30% in 2018. Therefore, it is possible to conclude that **a sizeable number of patient groups in 2018 believe themselves capable of influencing government healthcare policy (at least some of the time).**

■ **Resilience**

This indicator measures how well patient groups cope with challenges that are common within their areas of activity. Responses received suggest that **patient groups still experience difficulty in 2018 in coping with a whole series of challenges, including but not limited to: lack of funding; inadequate patient access to needed medicines; public apathy in their message; inability to get their message across in the general media; and a lack of research investment (the latter, whether in their particular country, or in their therapy area).** On a positive note, patient groups' levels of cooperation with both medical professionals have marginally improved in 2018 (though only for a minority of patient groups). In 2018, only 23% of the 1,016 patient groups say that medical professionals are uncooperative, compared with 26% in both 2014 and 2012.

Changing trends, 2012-2018

Indicator 1: Business acumen

CAPABILITIES	2018	2014	2012	2018 v. 2014
Mission statement	82%	74%	75%	+8%
Operating or business plan	52%	48%	45%	+4%
Governance	80%	73%	73%	+7%
Fundraising strategy [new for 2018]	46%	-	-	-
Guaranteed cash flow	60%	57%	58%	+3%
Independence from funders	39%	34%	33%	+5%
Consulting with patients	69%	63%	59%	+6%
AVERAGE	61%	58%	57%	+3%

Indicator 2: e-communication

CAPABILITIES	2018	2014	2012	2018 v. 2014
Website	92%	90%	96%	+2%
Blog	20%	16%	16%	+4%
Twitter	45%	30%	23%	+15%
Facebook	77%	60%	50%	+17%
Other social media	33%	20%	13%	+13%
AVERAGE	53%	43%	40%	+10%

Indicator 3: Services to patients

CAPABILITIES	2018	2014	2012	2018 v. 2014
Supplying information	97%	93%	94%	+4%
Peer-to-peer support	86%	85%	85%	+1%
Provision of healthcare services	25%	24%	29%	+1%
Advocacy: government	68%	58%	52%	+10%
Advocacy: healthcare providers	63%	53%	49%	+10%
Fundraising for medical research	27%	29%	26%	-2%
Undertaking medical research	16%	15%	13%	+1%
Representation: drug development [new for 2018]	27%	-	-	-
Representation: regulatory bodies [new for 2018]	21%	-	-	-
AVERAGE	48%	51%	50%	-3%

Indicator 4: Networking with other healthcare stakeholders

CAPABILITIES	2018	2014	2012	2018 v. 2014
Academic/scientific bodies	65%	54%	56%	+11%
Consultants/specialists	74%	68%	74%	+6%
The general media	54%	45%	46%	+9%
General physicians	48%	42%	44%	+6%
Healthcare media	46%	39%	37%	+7%
National-government health committees	42%	40%	39%	+2%
Local-government health committees	40%	39%	39%	+1%
Medical-device companies [new for 2018]	30%	-	-	-
Medical-device company trade bodies	10%	12%	12%	-2%
Medical societies	50%	40%	37%	+10%
Nurses	51%	39%	41%	+12%
Patients [new for 2018]	86%	-	-	-
Pharma companies [new for 2018]	52%	-	-	-
Pharmaceutical-company trades bodies	13%	27%	22%	-14%
Pharmacists	25%	23%	24%	+2%
Regulatory bodies (eg, FDA, EMA) [new for 2018]	22%	-	-	-
AVERAGE	44%	39%	39%	+5%

Indicator 5: Networking with peer patient groups

CAPABILITIES	2018	2014	2012	2018 v. 2014
Other similar patient groups in your specialty/ies	51%	47%	48%	+4%
Umbrella patient groups for your specialty/ies	43%	41%	43%	+2%
Patient groups in other specialties	26%	20%	18%	+6%
General umbrella patient groups	28%	24%	22%	+4%
AVERAGE	37%	33%	33%	+4%

Indicator 6: Reputation with other healthcare stakeholders

CAPABILITIES	2018	2014	2012	2018 v. 2014
Academic/scientific bodies	46%	44%	43%	+2%
The general media	32%	32%	34%	0%
Government healthcare administrators	32%	31%	32%	+1%
Government policymakers	25%	24%	27%	+1%
Regulatory bodies (eg, FDA, EMA) [new for 2018]	13%	-	-	-
Healthcare media	29%	28%	32%	+1%
Healthcare professionals	54%	52%	54%	+2%
Medical-device companies	19%	16%	27%	+3%
Pharmaceutical companies	36%	32%	29%	+4%
Pharmacists	18%	17%	19%	+1%
Local politicians	29%	27%	34%	+2%
Other health campaigners	47%	41%	45%	+6%
AVERAGE	32%	33%	33%	-1%

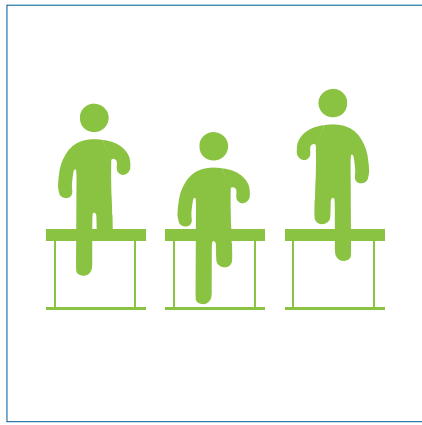
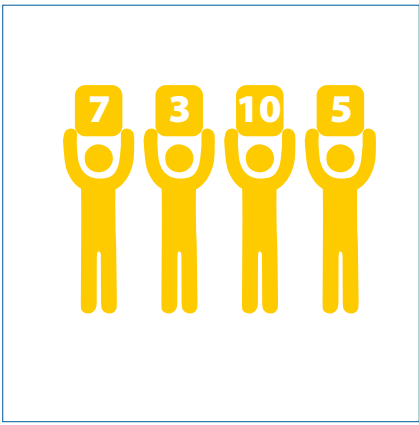
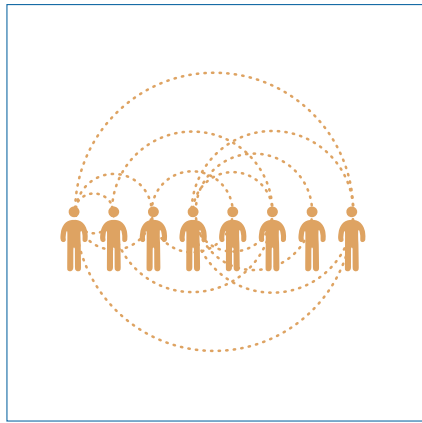
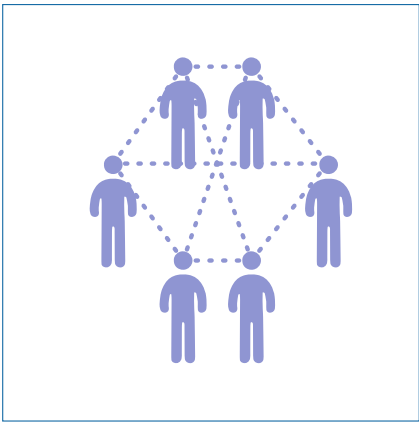
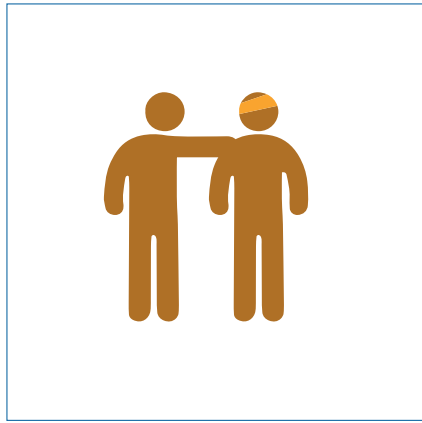
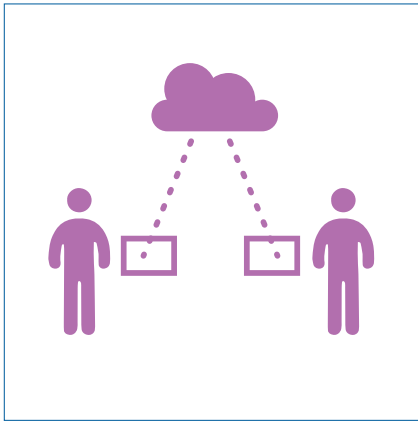
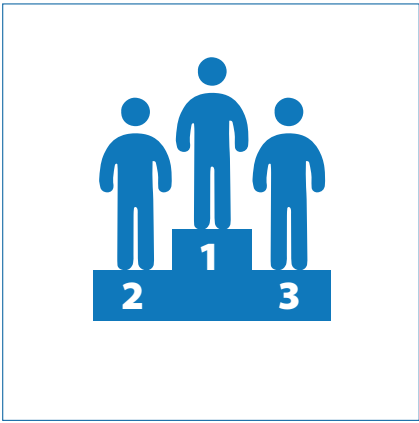
Indicator 7: Impact on health policy

CAPABILITIES	2018	2014	2012	2018 v. 2014
Yes	25%	34%	32%	-
Possibly/sometimes [new for 2018]	37%	-	-	-
No	30%	44%	42%	+14%
I do not know	9%	22%	25%	+13%

Only one subcategory, therefore no average

Indicator 8: Resilience

CAPABILITIES	2018	2014	2012	2018 v. 2014
Lack of funding	70%	67%	71%	-3%
Inadequate access to medicines	36%	33%	30%	-3%
Public apathy	40%	40%	41%	0%
Media disinterest	46%	43%	41%	-3%
Lack of cooperation from medical professionals	23%	26%	26%	+3%
Lack of cooperation from government	36%	37%	36%	+1%
Lack of cooperation from pharma companies [new for 2018]	13%	-	-	-
Lack of research investment in the therapy area	43%	42%	36%	-1%
AVERAGE	38%	41%	40%	+3%



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