

Being Patient-Centric

An evidence-based self-evaluation toolkit for pharma
...as recommended by patient groups



November 2017 • 1st edition

“The way to become different from the rest is to work beyond the business, to get patients to feel that pharmaceutical companies—in addition to creating drugs and being companies—have the patient as the centre of all their business. When they think this, it should motivate them to improve. I think we are on the right track, and something is changing... let’s continue this way.”

Coordinadora Española de Asociaciones de Espondilitis (CEADE), Spain, 2016

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BEING PATIENT-CENTRIC

Foreword

Since first signs of patient advocacy in the 1950s and its subsequent development and acceleration to 2017, patient groups have emerged as key players within most healthcare systems. It is no surprise therefore that the term ‘patient-centric’ is now firmly established within the lexicon of the pharmaceutical industry and that patients and their representative groups are considered as important customers alongside healthcare professionals, payers and policy-makers. As companies commit more time, resource and energy into being more patient-focused, many have attempted to define what it means to be ‘patient-centric’.

For well over a decade, PatientView has undertaken research into the opinions of patient groups on a wide variety of topics, and most recently on what it is to be patient-centric in a corporate sense. The launch in 2011, of our annual *Corporate Reputation of the Pharmaceutical Industry* survey, at a time when the subject of corporate patient-centricity began to gain traction, has allowed us to collect written feedback from literally thousands of patient groups worldwide on this important topic. Most recently, the translation of the survey into multiple languages (18 in 2017), has permitted the capture of views of patient groups from Asia-Pacific to Eastern Europe.

In November 2013, PatientView launched its curation site www.myhealthapps.net and later in 2017 its related blog www.myhealthappsblog.com, which in turn led

to further accompanying research into the mHealth arena. These undertakings have enabled PatientView to collect information from patient groups on their digital needs, and what the support they might expect and want from industry in this regard.

To provide an answer to pharma’s question—‘How do we become more patient-centric?’—PatientView has analysed its register of patient group feedback, developed insights and produced a structured toolkit that enables companies to both evaluate their own performance for patient-centricity and make future plans based on evidence (as provided by patient groups), not instinct.

This first roll-out of the toolkit, *Being Patient-Centric*, is intended for use across healthcare industry organisations to begin to help them embed and develop dynamic strategies, placing patients at the heart of their business.

Being Patient-Centric questions will be included within future surveys carried out by PatientView to ensure that it is always relevant, representing the latest thinking of patient groups as well as best practice examples from industry. We hope that companies will adopt this toolkit, challenge their own thinking and make being patient-centric something tangible and real to the industry.

Alexandra Wyke

CEO

PatientView

November 2017



INTRODUCTION

INTRODUCTION

What is the ‘Being Patient-Centric’ toolkit about?

Over the past decade, patient-centricity has been increasingly talked about and become an aspiration of healthcare systems and industry. Yet the constant challenge remains: turning ambitions into effective actions. Corporate actions that are intended to be patient-centric need to be chosen, measured and assessed for their impact on health systems (and the companies themselves), from a patient perspective.

Patients, as the core stakeholder, are best placed to determine both what matters to them (the right metrics) and whether industry is meeting their needs. Since 2011, PatientView has been building a substantial register of feedback from patient organisations, as well as from industry and to some extent health professionals.

This report brings together this data, to provide:

- 1) An overall template for patient-centricity (the attributes for patient-centricity)
- 2) A roadmap to effective patient-centricity from a patient perspective (the fundamental factors that define those attributes)
- 3) A self-assessment questionnaire for internal use to gauge the patient-centricity of a company from the patient perspective (for each of the fundamental factors and attributes).

THE STARTING POINT

It is important to recognise that much good practice in the field of patient-centricity exists today. Of particular importance in defining patient-centricity is the work of the International Alliance of Patient Organizations (IAPO), the Picker Institute and AstraZeneca.

IAPO’s declaration on patient-centred healthcare

Whilst industry considers patient-centricity from its own perspective, ‘what it means to us’, patient-centricity is also central to the planning and delivery of care in many health systems, to some degree at least. IAPO is an alliance representing the voice of patient groups worldwide. In 2016 they published their latest update consensus declaration on patient-centricity for healthcare systems. The declaration emphasised the need to accommodate the patient view in every aspect of the delivery of healthcare. The declaration was backed up by its 2012 global study of 42 healthcare stakeholders, including academics, healthcare industry representatives, healthcare professionals, and patient organisations.

“Healthcare must be designed and delivered to meet the needs and preferences of patients... Greater patient responsibility and usage will lead to improved quality of life, a more cost-effective system and, ultimately, better healthcare for everyone.”

IAPO Declaration rev. 2016
<https://www.iapo.org.uk/patient-centred-healthcare>

Picker’s 8 principles of patient-centred care

The respected Picker Institute, a leading think-tank, together with Harvard Medical School, acting in response to a perceived crisis in the US healthcare system, published in 2001 eight principles about what patients need and expect from healthcare, in the form of a hierarchy of needs.

“Healthcare today harms too frequently and routinely fails to deliver its potential benefits.”

Editors: Institute of Medicine (US) Committee on Quality of Health Care in America, *Crossing the Quality Chasm: A New Health System for the 21st Century*. (Washington DC, National Academies Press, 2001; and <http://www.picker.org/about-us/principles-of-patient-centred-care/>)

These eight principles, which have since been refined and updated, are:

- Fast access to reliable healthcare advice
- Effective treatment delivered by trusted professionals
- Continuity of care and smooth transitions
- Involvement of, and support for, family and carers
- Clear, comprehensible information and support for self-care
- Involvement in decisions and respect for patient’s preferences
- Emotional support, empathy and respect
- Attention to physical and environmental needs.

AstraZeneca’s definition of patient-centricity for pharma

One of the most important contributions looking at pharma’s role at being patient-centric, was the cross-stakeholder paper, published in the *British Medical Journal*, identifying a number of principles of importance to patients. The article drew on workshops conducted with patient/carers, and patient forums with 470 US-based patients and 703 patients based in Europe across diverse therapy areas.

“Putting the patient first in an open and sustained engagement of the patient to respectfully and compassionately achieve the best experience and outcome for that person and their family.”

Defining patient centricity with patients for patients and care-givers: a collaborative endeavour. Yeoman G et al. *BMJ Innov.* 2017;0:1–8 <http://innovations.bmj.com/content/3/2/76>

Five key issues/values were identified as being important:

1. Inclusiveness
2. Sharing goals that are patient and family-centred
3. Empowering patients to take control of their own health
4. Working in a way that shows respect, compassion and openness
5. Working in partnership.

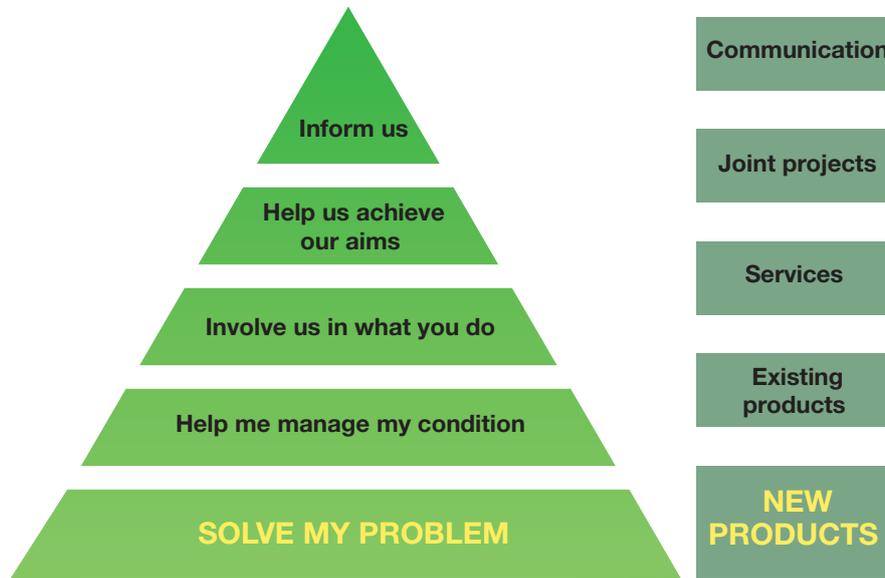
The implications for companies, such as those in the pharmaceutical industry were as follows:

- Make sure that the people who need medicines have access to them
- Communicate *transparent/unbiased* information with care and compassion
- Provide easy-to-understand *and convenient information*.
- Help patients gain *affordable access* to their medications
- Equip patients to make *informed choices*
- Listen and respond to patient/carer *feedback* with respect and humility
- *Partner* with patients/carers to innovate and measure impact and health outcomes
- Provide access to support programmes and resources to help *improve quality of life*
- *Understand* patient/carer needs and experiences
- *Empower patients to help others* in their position and their families.

CONSIDERING THE COMPLEXITIES OF CORPORATE PATIENT-CENTRICITY

The work by IAPO, the Picker Institute and AstraZeneca has helped to set some of the founding principles for patient-centricity. PatientView’s research clearly indicates that for patients the primary goal of pharma can be simply expressed in a single objective: that companies should provide new products that cure and/or help patients manage conditions. Improvements to existing products, new services, joint working and good communication are built on this foundation.

A hierarchy of needs



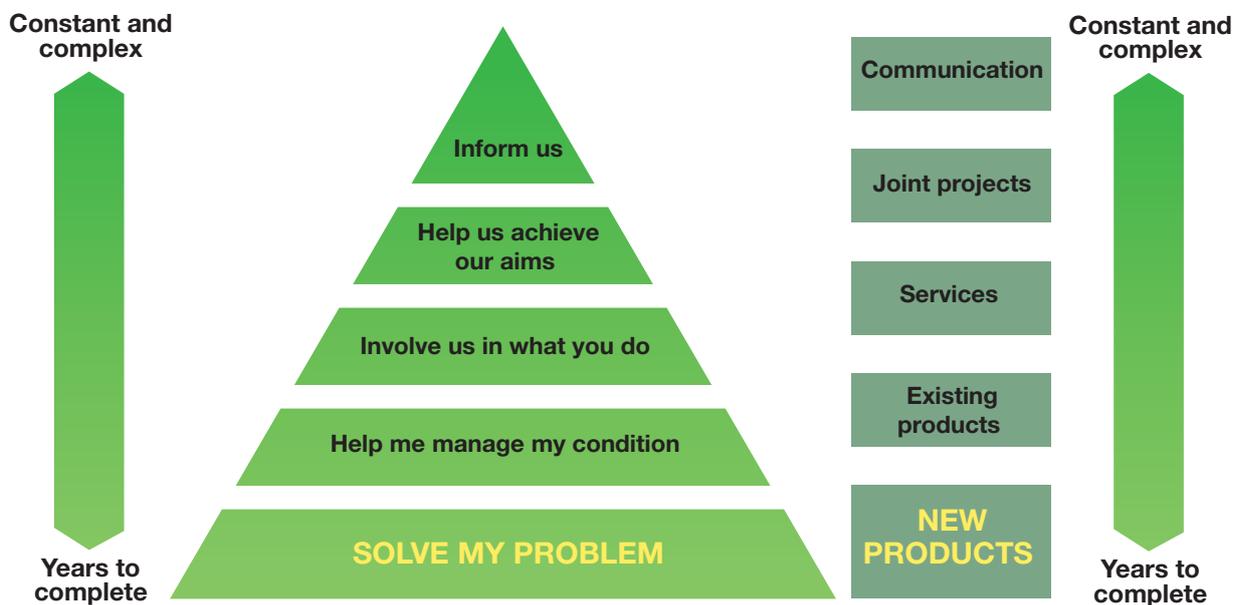
The idea can be visualised as a hierarchy of patient needs as in the diagram above:

- The development of new products helps patients solve their medical problems
- Existing products support patient management of their condition
- The involvement of patients with pharma can be partly addressed by ‘beyond the pill’ services the company provides

- Patients’ goals are also met through their working with pharma in joint projects
- All of the above needs must to be communicated to patients, so patients feel informed.

However, despite the seeming clarity of patients’ objectives, the reality is far more complex. Behind the scenes pharma’s

A hierarchy of needs





METHODOLOGY

METHODOLOGY

An evidence-based approach to develop a corporate self-evaluation toolkit for patient-centricity

PatientView has been researching the views and needs of patient groups for the last 14 years. Today, we have the capacity to reach out to some 40,000 patient groups worldwide.

During this time, we have built up a substantial register of patient group opinions and feedback on a wide variety of topics of importance to patients. The launch in 2011, of our annual *Corporate Reputation of the Pharmaceutical Industry* survey, at a time when the subject of corporate patient-centricity began to gain traction, has allowed us to collect written feedback from literally thousands of patient groups worldwide on this important topic. Most recently, the translation of the survey into multiple languages (18 in 2017), has permitted the capture of views of patient groups from Asia-Pacific to Eastern Europe.

In November 2013, PatientView launched its curation site www.myhealthapps.net and later in 2017 its related blog myhealthappsblog.com, which in turn led to further accompanying research into the mHealth arena. These undertakings have enabled PatientView to collect information from patient groups on their digital needs, and what support they might expect and want from industry in this regard.

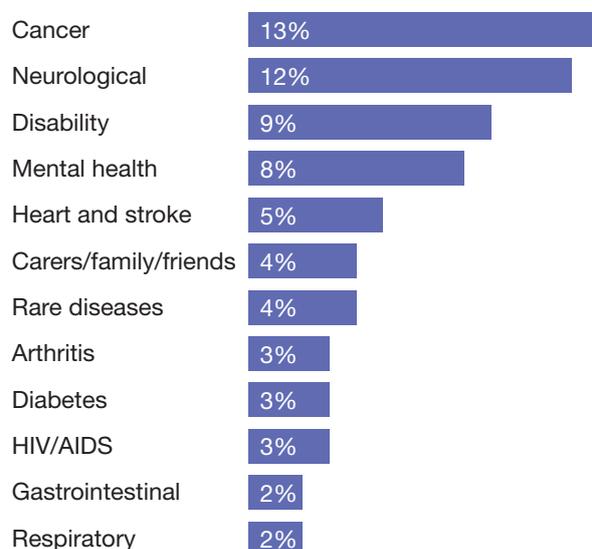
Through this accumulation of data, PatientView has therefore collected ample evidence from patient groups on their disparate views of what makes companies patient-centric. The corporate self-evaluation toolkit is derived from this latter evidence. Examples of the types of patient group feedback received are to be found in Appendix I, pages 33-60.

How does PatientView define a patient group?

For the purposes of this toolkit a patient group is defined as any legal organisation that seeks to represent the interest of patients, their carers/family/friends. The organisations are only able to achieve this aim through constant contact with the people they represent (through social media or as members of the patient organisation).

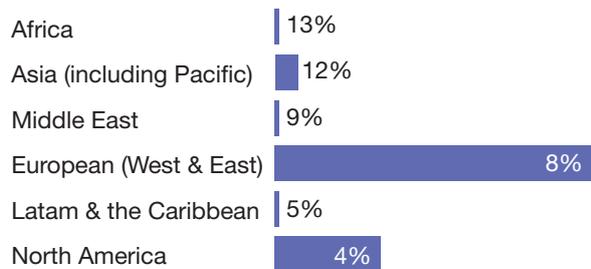
Patient groups are wide-ranging in nature and will include: age-related organisations, carers' groups, disability groups, family/friends' organisations, gender-based organisations, as well as the many charities that specialise in different medical conditions. PatientView can count in its database almost 1,000 different types of patient organisations in terms of their medical specialities or interests. In areas like cancer there exist at least 50 different types of cancer patient group—all in different specialities.

Top specialisms for patient groups



Patient organisations and patient advocacy have spread like wildfire across the world, though some countries are more advanced than others, due to differences in • demographics • government healthcare expenditures • levels of national health inequities • the local healthcare culture (doctor-patient relationships) • the levels of political support for patient advocacy organisations • the degree to which patients feel empowered • the scale of government involvement with patient organisations • the strength of the local healthcare infrastructure • and national levels of usage of the Internet and social media by patients.

Geographic spread of patient groups



PATIENTVIEW METHODOLOGY

Four stages were involved in the building of the PatientView *Being Patient-Centric* toolkit or self-evaluation questionnaire.

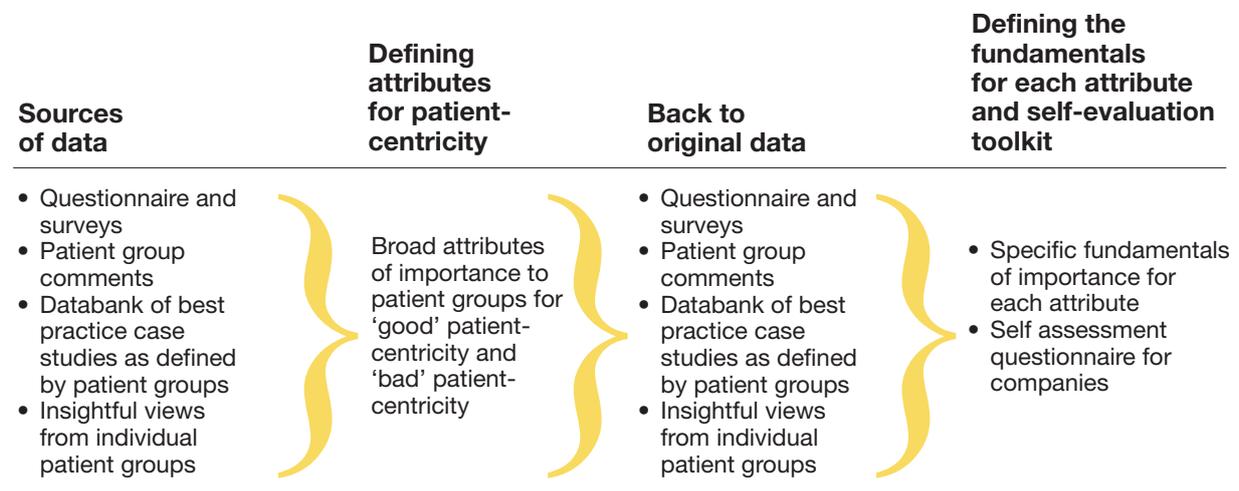
The many patient groups, and the patient movement that they form, have become one of the biggest disruptive influences in healthcare systems in years. These groups are well entrenched within these healthcare systems, and also have an extensive understanding of the corporate world of healthcare, particularly pharmaceutical companies – unlike patients, who typically identify only with the treatments that pharmaceutical companies produce. Therefore, patient groups are well placed to comment on what they believe contributes to corporate patient-centricity.

STAGE 1

In the first stage, multiple sources of data were drawn from surveys and other forms of patient group input to build a register of patient group written feedback. A specific focus was made on the years 2016 and 2017. Included were:

- 1. PatientView Corporate Reputation of the Medical Device Industry** *global* survey conducted among patient groups. The year included was 2017 (513 patient group responses from a wide range of specialities)

PatientView methodology



2. **PatientView Corporate Reputation of Pharmaceutical Companies** *global* survey conducted among patient groups worldwide. The year included was 2016 (1,473 patient group responses from a wide range of specialities)

3. **Pharma and the Connected Patient** – results of a *global* survey by PatientView (funded by Deloitte UK Centre for Health Solutions), 2017 (190 patient group responses from a wide range of specialities)

4. **Understanding of Scientific Information About Cancer Among Carers, Patients and the Public**, results of a survey by PatientView (funded by AstraZeneca), 2017 (124 cancer patient group respondents)

5. Selections of reviews and blogs on PatientView’s **www.myhealthapps.net** and **www.myhealthappsblog.com**.

Taken together these surveys accounted for contributions from an estimated 2,000 unique responses from patient groups worldwide. Each provided multiple comments.

STAGE 2

The register of patient group comments was broadly categorised into attributes which described ‘good’ and ‘bad’ patient-centricity, thereby creating a general template. The 9 attributes are seen in the table below:

The 9 attributes that patient groups say qualify corporate patient-centricity

STAGE 3

The patient group feedback was then broadly organised into the 9 attributes, for further categorisation.

STAGE 4

Thus organised, patient group comments were further analysed to identify fundamental factors (now called fundamentals) that helped define each attribute. Therefore, stage 4 allowed for the description of a roadmap towards effective patient-centricity from a patient perspective. For example, for the attribute Authenticity, one fundamental named by patient groups was the importance of having a corporate leadership and culture that endorsed the concepts of patient-centricity.

The latter step then led to the final element of the project. Patient group comments were examined and reframed as questions patient groups might put to companies. The

The 9 attributes that patient groups say qualify corporate patient-centricity	
AUTHENTICITY	Actions that demonstrate a culture of high integrity
SUPPORT AND SERVICES	‘Beyond the pill’ programmes that support the patient journey
TRANSPARENCY	Pricing policies, clinical research results, financial relationships
EQUITABLE ACCESS	Effective policies for all patients regardless of location, disability or access to funding
VALUED PRODUCTS	Products that provide real value to patients
PATIENT SAFETY	Reliable supply and comprehensive patient safeguarding
QUALITY PRODUCT INFORMATION	Consistent, current, balanced, usable
PATIENT GROUP RELATIONS	Effective governance, communication, training, respect
INVOLVEMENT IN R&D	Patients are engaged and their opinions sought at each stage of R&D

Maximum scores possible in the corporate self-evaluation toolkit How do you score?

AUTHENTICITY	24
SUPPORT AND SERVICES	18
TRANSPARENCY	11
EQUITABLE ACCESS	11
VALUED PRODUCTS	8
PATIENT SAFETY	9
QUALITY PRODUCT INFORMATION	17
PATIENT GROUP RELATIONS	19
INVOLVEMENT IN R&D	22
TOTAL	139

questions thus act as a self-assessment questionnaire intended for internal company use to gauge its patient-centricity (now called the self-evaluation toolkit)

HOW TO USE THE TOOLKIT

At present the corporate self-evaluation toolkit has been designed from a global perspective,

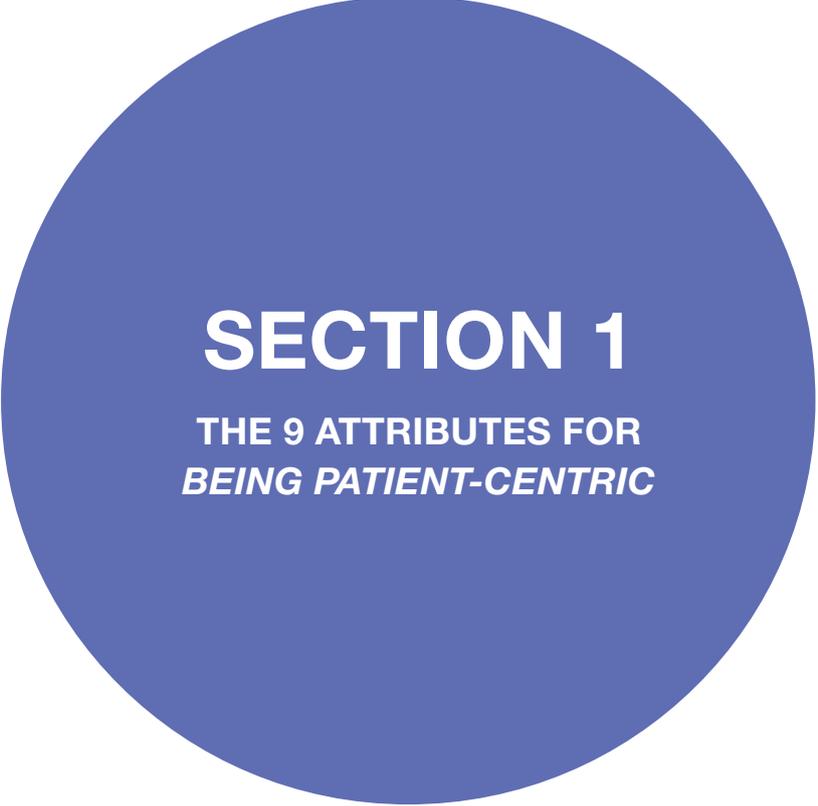
with all fundamentals and self-evaluation questions considered of equal importance.

You can use the current 2017 toolkit to help evaluate your company's current performance in areas identified by patient groups as important. Answers to all questions should be "yes".

The process of self-evaluation enables you to:

- Identify attributes where you feel your company already performs strongly, and validate this with evidence
- Identify attributes where you feel your company performs less strongly, and agree priorities for improvement
- Gather and compare views on current patient-centricity from different stakeholders in the company and track your performance over time
- Compare performance in different countries and regions.

Note that the attributes, fundamentals, and questions are currently at a pilot stage, and are being further validated by testing with patient groups in 2018, when the 2nd edition of *Being Patient-Centric* will be released.



SECTION 1

**THE 9 ATTRIBUTES FOR
*BEING PATIENT-CENTRIC***

1. AUTHENTICITY

Actions that demonstrate a culture of high integrity



Patient groups judge companies by their actions, and how they live up to their promises. Most companies will now claim to be patient-centric. However, there are still real differences in how

they are perceived by patient groups, and in how well patient-centricity is embedded, lived and demonstrated in the organisation. Patient-centricity is key to each company's reputation with patient groups, and means that a company needs to demonstrate integrity and authenticity through all its actions.

FUNDAMENTALS CONTRIBUTING TO A CULTURE OF HIGH INTEGRITY

- CEO and leadership
- Investment structure (budgets and people)
- Training of company employees
- Performance management
- Corporate communications
- How the company comes across in the media
- Compassion, humanity and philanthropy
- Easy to work with
- Embedded across functions
- Company strategy reflects patient-centricity

2. SUPPORT AND SERVICES

'Beyond the pill' programmes that support the patient journey



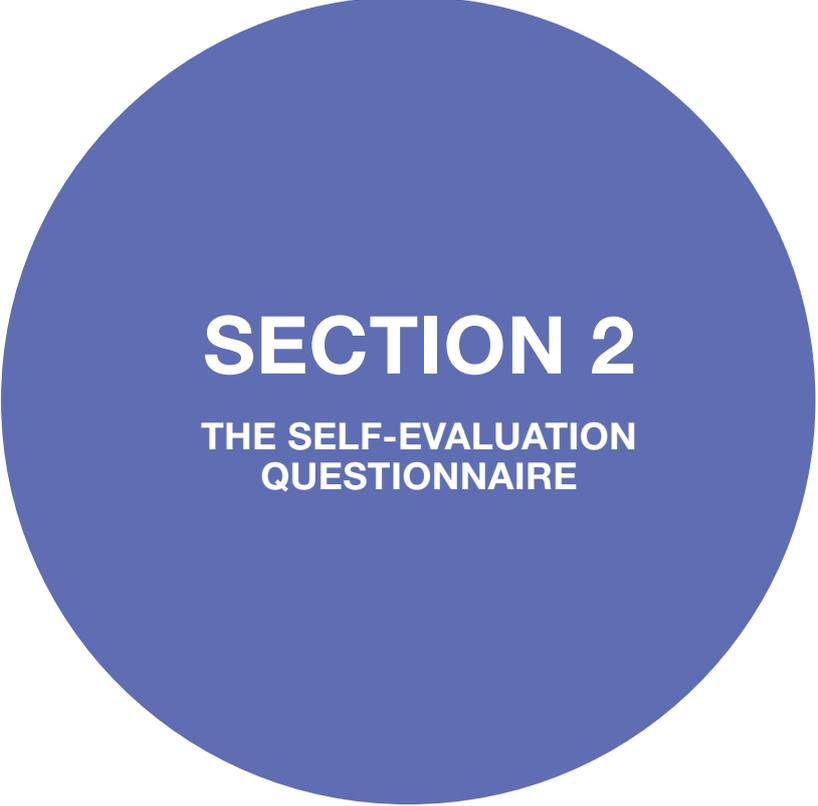
From the patient perspective getting medical treatment is just one part of their overall journey. Patients can face numerous challenges on receipt of a diagnosis. They may have problems telling friends and

family about their diagnosis. They may then struggle to understand the nature of their medical treatment and the risks and benefits of all the treatments on offer, or in following complex treatment regimes. They may worry about symptoms recurring and need to make decisions when they should go to their doctor. Patients may also typically have more than one medical condition, and may not find it easy to juggle all the treatment demands made on them. Some patients will seek help from carers, family and friends to help them through these difficulties. So, from the patient

perspective it is important that healthcare companies, including pharma, not only understand all the issues that patients face 'beyond the pill' but also provide assistance in dealing with them.

FUNDAMENTALS CONTRIBUTING TO A 'BEYOND-THE-PILL' PROGRAMME

- Care pathways
- Enabling informed choices
- Compliance, adherence and concordance
- Personalised and individualised medicine
- Health literacy
- Psychosocial support
- Digital tools: Web, eHealth and mHealth
- Targeted intervention along the patient journey
- Supporting lifestyle changes
- Education for healthcare professionals and other stakeholders supporting the patient



SECTION 2

THE SELF-EVALUATION QUESTIONNAIRE

SECTION 2

The self-evaluation questionnaire

For the 9 attributes of ‘Being Patient-Centric’

For nearly a decade, patient groups have consistently identified, in PatientView surveys, 9 attributes as being the most important to address their needs and expectations of the pharmaceutical industry. The priority given to each attribute varies from group to group,

depending on geography, therapy and the size and objectives of each group. However, there is a clear, unified and sustained view across most patient groups that performance in each of these 9 attributes is looked for, expected, and demanded

The following tables list the 9 attributes, the fundamentals that define them, and their corresponding self-evaluation questionnaires.

ATTRIBUTE:

- One of the 9 aspects identified by patient groups as being important for corporate patient-centricity.

FUNDAMENTAL:

- A patient group issue to evaluate your company’s current performance against.

SELF-EVALUATION QUESTIONS: To help:

- Evaluate your company’s current performance in areas identified by patient groups as important
- Identify attributes where you feel your

company already performs strongly, and validate this with evidence

- Identify attributes where you feel your company performs less strongly, and agree priorities for improvement
- Gather and compare views on current patient-centricity from different stakeholders in the company to track your performance over time
- Compare performance in different countries and regions.

Answers to all questions should be “yes”.

Note:

The attributes, fundamentals, and questions are currently at pilot stage, and are being further validated by testing with patient groups in 2018, when the 2nd edition of *Being Patient-Centric* will be released

Maximum scores possible in the corporate self-evaluation toolkit

How do you score?

	Maximum score	Your score
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• INVOLVEMENT IN R&D	22	
TOTAL	139	

1. AUTHENTICITY



Fundamental

CEO AND LEADERSHIP

- > Do you have a publicly-available policy statement to demonstrate your commitment to patient-centricity, against which company practice is monitored effectively and routinely?
- > Is your patient engagement run at a company-wide level rather than being devolved to local affiliates and/or regional partners to define?
- > Is there specific responsibility for patient-centricity at board level?
- > Does the board define patient-centricity as a key activity that is also communicated to shareholders?
- > Do you have specific employees whose job is dedicated to managing relationships with patient groups?

INVESTMENT STRUCTURE (BUDGETS AND PEOPLE)

- > Is there a dedicated and connected management structure, that strategically co-ordinates long-term activity to provide optimum support and guide effective working with patient groups?

TRAINING OF COMPANY EMPLOYEES

- > Is training for patient-centricity provided, beyond required compliance modules?
- > Are all employees trained in patient-centricity?
- > Is employee performance in addressing the patient agenda evaluated?

PERFORMANCE MANAGEMENT

- > Does the company have a way of measuring company performance on patient-centricity?
- > Are company employees recognised for how they deliver patient-centricity?
- > Does your company create regular opportunities for employees to meet patients and understand their world?

CORPORATE COMMUNICATIONS

- > Are steps taken to ensure that financial and corporate communications do not undermine patient confidence?
- > Are patients and patient groups regarded as a key audience for corporate communications, with channels identified to reach them?

HOW THE COMPANY COMES ACROSS IN THE MEDIA

- > Are patient views considered in corporate and financial communications?
- > Is your communication with investors, health professionals and patients fully aligned?

COMPASSION, HUMANITY AND PHILANTHROPY

- > Does your company consider the needs of clinical trial participants when trials close, for example by providing continuity of treatment with the drug in clinical trial, if a patient wishes?
- > Does your company consider the needs of patients gaining access to unapproved medicines?
- > Do your human resources (HR) policies support employees at times in their lives when they are patients or carers, for example offering flexibility in taking time off for sickness or care leave, or providing support when they return to work?
- > Do your internal HR policies for sickness and equality go beyond legal requirements to reflect your organisation as a company that cares about your employees' needs as patients?

EASY TO WORK WITH

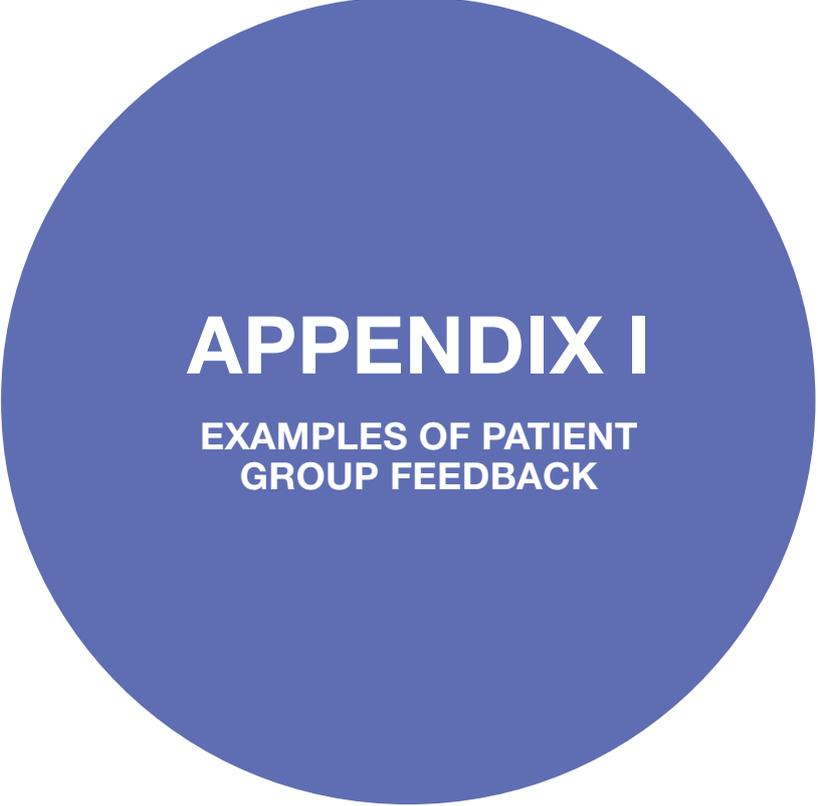
- > Within the restrictions of local regulations, can patients/patient groups find the right contact (person) in your company—whatever the issue/their enquiry?
- > Are the limited human and financial resources of patient groups considered when your legal or compliance departments are involved, for example, when dealing with the complexity of completing contracts?

EMBEDDED ACROSS FUNCTIONS

- > Do you consider patient satisfaction when measuring products' success, beyond adverse drug reporting, patient uptake and market share?

COMPANY STRATEGY REFLECTS PATIENT-CENTRICITY

- > Are cross-company collaborations actively sought out?



APPENDIX I

EXAMPLES OF PATIENT GROUP FEEDBACK

APPENDIX I

Patient group feedback

EXAMPLES OF PATIENT GROUP FEEDBACK ON PATIENT-CENTRICITY

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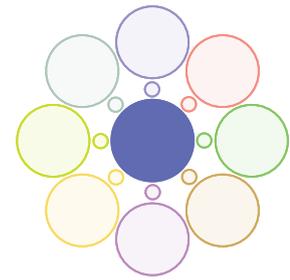
enabled PatientView to collect information from patient groups on their digital needs, and what support they might expect and want from industry in this regard.

In this Appendix is an extensive listing of examples of the feedback we have received from patients groups, mostly from our Corporate Reputation Surveys and myhealthapps endeavours of 2016 and 2017. It is primarily this feedback which has helped PatientView draft its first iteration of the corporate self-evaluation toolkit, *Being Patient-Centric*. A reading of the feedback should help explain how and why we have established 9 corporate attributes for being patient-centric, the fundamental factors that contribute to these attributes, and the self-evaluation questions that derive from the latter.

The 2017 **Corporate Reputation of the Pharmaceutical Industry** survey, which was launched in November 2017, is also intended to provide further information and subsequent refinements to this new toolkit. In addition, PatientView seeks to test its toolkit out through direct discussions with patient groups.

1. AUTHENTICITY

Actions that demonstrate a culture of high integrity



CEO AND LEADERSHIP

Associação Brasileira do Déficit de Atenção (ABDA), Brazil

“Create a strong internal mission to relate to patients.”

National colorectal cancer patient group, France

“Integrate into its boards an association of patients representing the associations.”

Borderline Dialog Kassel e.V., Germany

“Integrity means being genuine, with everything that goes with it. The greatest possible openness in information, both positive and negative.”

National patient groups specialising in support services for patients, Italy

“Put a patient on the board. Not as an observer, but with decision-making capacity.”

Coordinadora Española de Asociaciones de Espondilitis (CEADE), Spain

“But the way to become different from the rest is to work beyond the business, to get patients to feel that pharmaceutical companies—in addition to creating drugs and being companies—have the patient as the centre of all their business. When they think this, it should motivate them to improve. I think we are on the right track, and something is changing ... let’s continue this way.”

Riksförbundet för SuicidPrevention och Efterlevandes Stöd, Sweden

“Be honest. Integrity can be achieved with more openness [‘dragging the curtain aside’].”

National patient group specialising in a neurological condition, UK

“Actually show us they are patient-centred, and be clear and open about how they are doing this. Just saying they are patient-centred in a mission statement is meaningless.”

Regional hearing-loss patient group, USA

“I think inviting consumers (why do we call them patients??) to be involved at every level—from marketing to research, to feedback and social media—would be an effective way to create consumer-centered strategies.”

INVESTMENT STRUCTURE (BUDGETS AND PEOPLE)

Iraqi Hemophilia Society, Iraq

“Corporate reputation decreases when these companies do not gain the national tender for the supply of anti-hemophilic factors. Yet the corporate reputation should still be high, even if the drug company does not win the national tender of supply.”

National lymphoedema and breast cancer patient group, Japan

“It seems that it is not a patient-centred medical treatment, but a doctor-centred medical treatment. I would like you to arrange a system to listen to the patient’s voice in some form, convince society in general (including medical professionals), and change from the current system to patient-centred medical care.”



AUTHENTICITY



EQUITABLE
ACCESS



INVOLVEMENT
IN R&D



PATIENT GROUP
RELATIONS



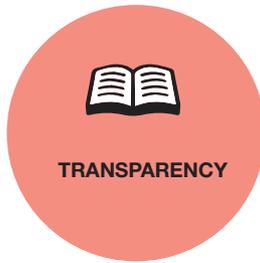
PATIENT SAFETY



QUALITY PRODUCT
INFORMATION



SUPPORT AND
SERVICES



TRANSPARENCY



VALUED
PRODUCTS

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