

**NOVEMBER 2019**

**BEING PATIENT CENTRIC**  
**What do I need to do in my country**  
**to be more patient-centric?**

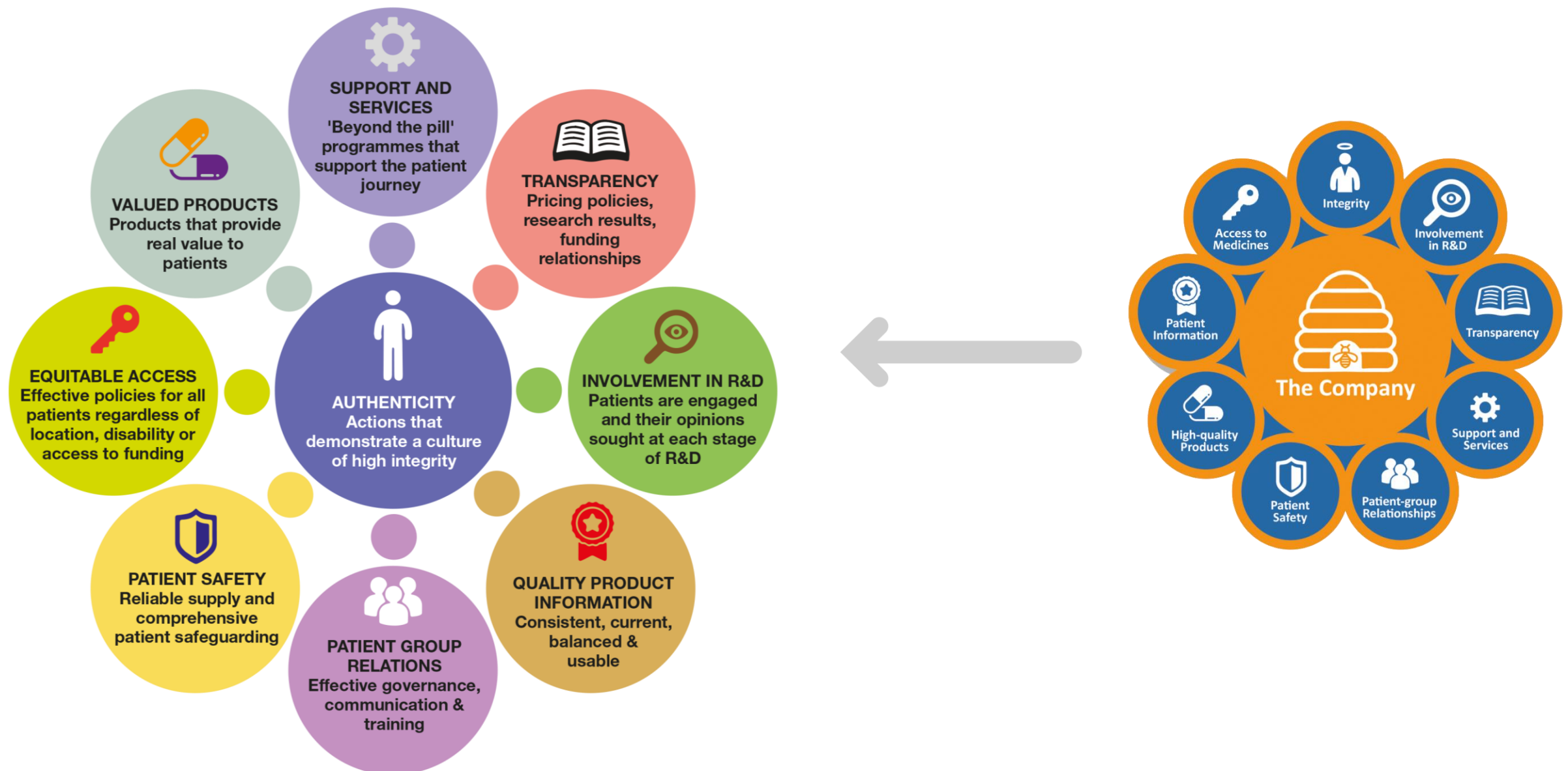
**A focus on drug treatment information**

# About Patient-View's Being patient-centric toolkits

# BEING PATIENT CENTRIC



The 'Being-Patient Centric' series of toolkits (currently four) evolved from **requests** to explore the subject of patient centricity in more depth



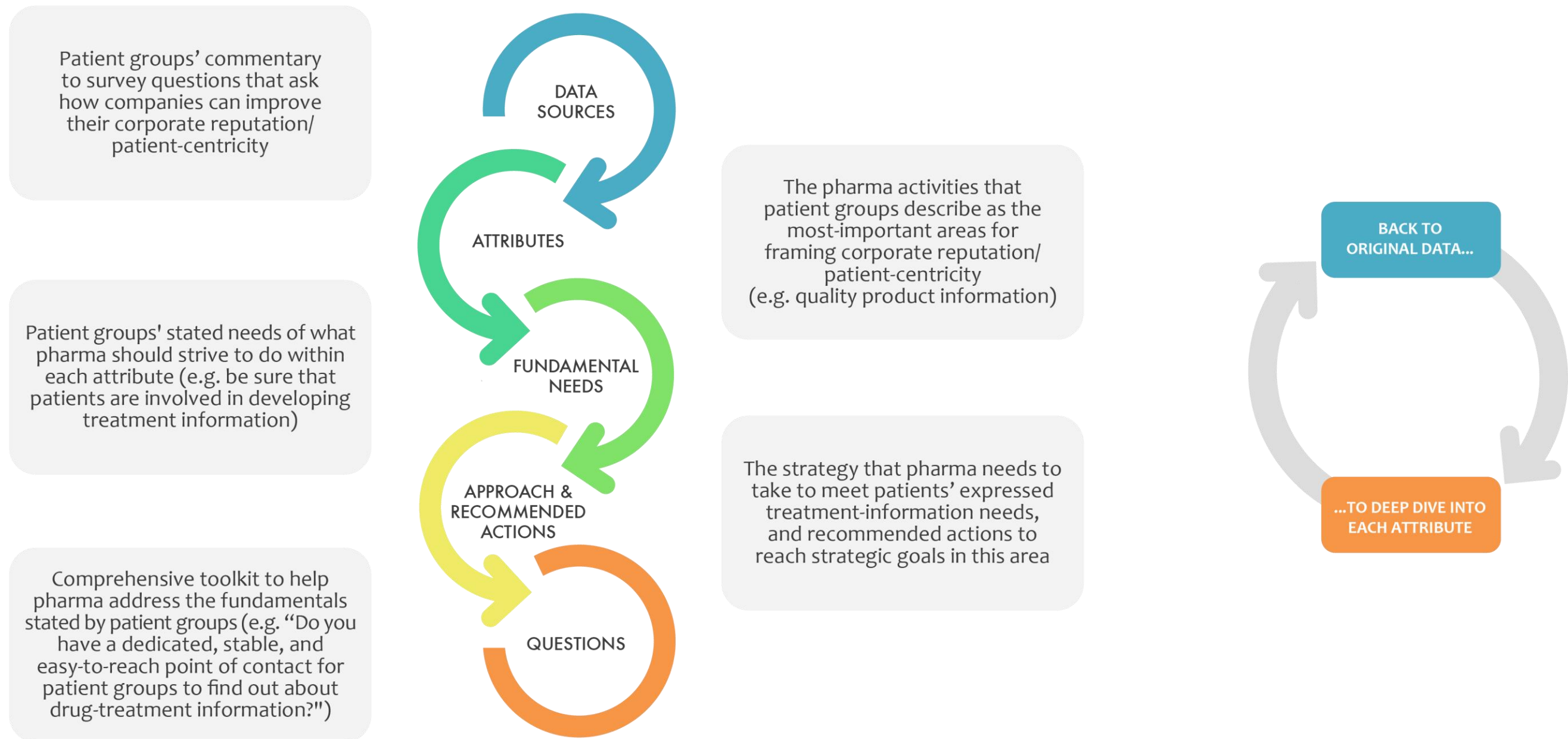
# BEING PATIENT CENTRIC: *THE FIRST OF THE TOOLKITS AND GUIDES*



- The first ‘Being Patient Centric’ toolkit provides a detailed framework for action planning.
- Nine core ‘attributes’ were generated from patient-group insights—which identified 53 **fundamental patient needs** – or what patients expect from pharma.
- Across these ‘fundamental needs’ 139 targeted questions were generated for internal discussion and self-evaluation .
- This allows actionable data to be built enabling companies to challenge their own strategies, and form suggestions for better corporate engagement.
- Each core attribute of patient centricity is continually being researched by PatientView in depth.
- The second and third publications in the series so far: ● ‘Patient Engagement in R&D’ (both in the US, and globally); and ● ‘Quality Product Information (Drug-Treatment Information)’.



# Constructing the BPC toolkits





# Peer-review validation



Gene Therapy  
<https://doi.org/10.1038/s41434-019-0110-7>

## REVIEW ARTICLE



## A rare disease patient/caregiver perspective on fair pricing and access to gene-based therapies

Wendy White<sup>1</sup>

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Fig. 1 Authenticity contributes to the perception of pricing for patients. Reproduced with permission from PatientView, [www.patient-view.com](http://www.patient-view.com), 2017–2018, in patient engagement in R&D: Still a Challenge? Being Patient-Centric Toolkit: The Opinions of Patient Groups Worldwide (PatientView, London, December 2018), p 10

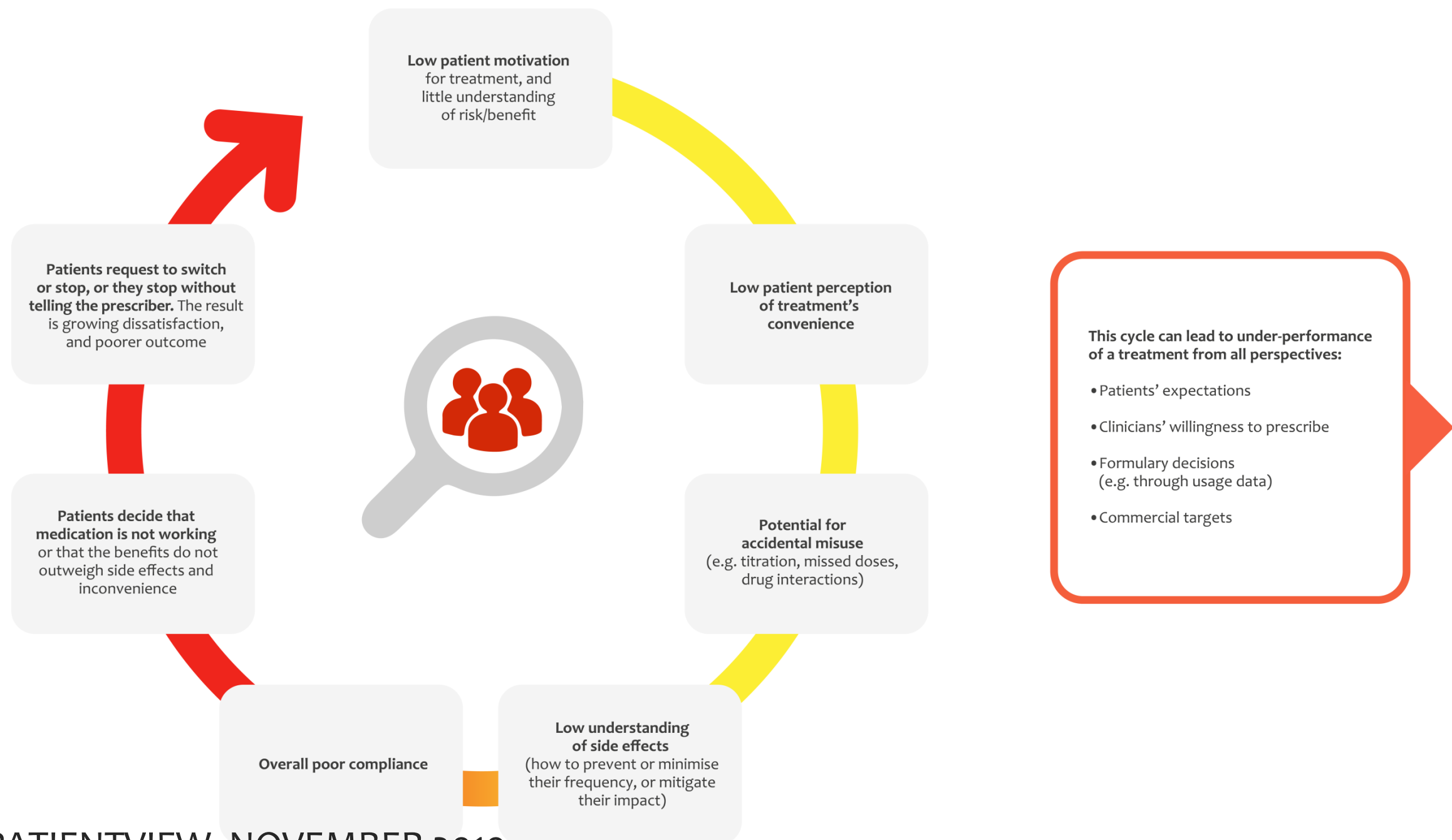


SPRINGER NATURE

# Drug-treatment information

## Being patient-centric

# Why is it important to be patient-centric in the creation and provision of drug-treatment information? ... when things go wrong





# Drug-treatment information – methodology & content

## Evidence-based PatientView guide on how to improve drug-treatment information—*what patients expect from pharma*

- 1) An online survey of 280 patient groups worldwide to enable the mapping of the drug-treatment-informational needs of patients (across different therapy areas, and different countries/regions of the world).
- 2) A list of patients' fundamental unmet needs in the area of drug-treatment information.  
And ...
- 3) A series of 116 questions designed to enable companies to self-evaluate the patient centricity of their product-information strategies, and to inform their planning of future drug-treatment-information support for patients.

# Are patients happy with their drug-treatment information?

e.g. in Germany [31 German patient groups, survey conducted July-August 2019]

In general, is the drug treatment information if the drug-treatment information provided by pharmaceutical companies **OF USE** to patients in your therapy are/specialties?

Germany	65%
Canada	64%
East Europe	61%
United Kingdom	61%
Asia	57%
France	57%
United States	55%
All countries	54%
C. & S. America	53%
Nordic	33%

... **BUT**

# Taking action: for instance, drug-treatment information

**... e.g. German patient groups still have many unmet drug-treatment information needs**

**What drug-treatment information do you believe patients in your therapy area/specialty would LIKE TO RECEIVE from pharma companies, BUT ARE NOT GETTING?**

The most-recent changes to the treatment's Indications	84%
Making informed choices, so that patients can compare treatments.	81%
Possible treatment interactions with other treatments (and, if so, the consequences for the patient).	80%
What to do if the treatment appears to be ineffective or slow to work.	80%
Forthcoming problems of supply (for instance, dates when shortages of the treatment are expected).	77%
The importance of taking the treatment—a clear statement.	73%
Adverse events/side effects—a clear statement.	71%
The most-recent changes to the treatment's safety information.	68%
How to use the treatment.	61%

## Taken together patients/patient groups have nine unmet drug-treatment information needs... *and provide detailed of expectations for each*

1: To receive useful and relevant information that helps all patients to know how to get the most from each treatment.

2: To be sure that patients have been involved in developing treatment information.

3: To support patients through channels that they prefer (including discussions with healthcare professionals).

4: To receive trusted, balanced, and clear information, capable of allowing the patients to compare treatments.

5: To be supported in shared decision-making with healthcare professionals.

6: To receive effective information to inform each key decision—from starting treatment, through to dosing adjustments, to switching, or stopping treatment.

7: To know where to find updates to treatment information.

8: To know that treatment information is continuously reviewed and improved.

9: To receive information on products, regardless of the relative importance to the company's commercial priorities.

## DRUG FUNDAMENTAL NEED # 1

*To receive useful and relevant information that helps all patients to know how to get the most from each treatment*

### ► **APPROACH: IMPROVE PROCESSES FOR CONTINGENCIES AND UPDATES**

This fundamental need includes your company effectively identifying patient satisfaction with your company's current drug-treatment information and key unmet needs. It involves mapping inequalities that may exist between different types of patients in how they access, understand and use the treatment information you provide. Internal analysis of the full repertoire of the mechanisms by which such information is delivered, within the limits of the law, is included as part of this review. Finally, companies, say patient groups, should identify personnel accountable for improving the effectiveness of treatment information.

#### • **POSSIBLE RECOMMENDED ACTIONS ARE:**

- Map the unmet needs of all types of patients that take your treatment
- Identify information inequality or exclusion
- Gain cross-functional support for patient-centric materials
- Put in place metrics for developing patient-centric treatment information, e.g. portfolio dashboards

## DRUG FUNDAMENTAL NEED # 1

*To receive useful and relevant information that helps all patients to know how to get the most from each treatment*

— Map the unmet needs of all types of patients that take your treatment

### SELF-EVALUATION QUESTIONS

- Do you have processes in place to determine the informational needs of smaller patient populations that fall within the drug licence (e.g. ethnic minorities, children, older people)?
- Have you mapped the whole range of specific types of patients prescribed your company's drug treatments?
- Have you mapped how well the informational needs of all patients taking your medications are being met within local regulatory frameworks?



## DRUG FUNDAMENTAL NEED # 1

*To receive useful and relevant information that helps all patients to know how to get the most from each treatment*

— Identify information inequality or exclusion

### SELF-EVALUATION QUESTIONS

- Do you have policies to ensure equal access to treatment information for all patients using your treatments?
- Do you ensure equal access to treatment information, regardless of whether or not a patient has joined a branded or unbranded support programme?
- Do you identify any critical barriers to accessing relevant treatment information for specific groups?
- Do you have an effective strategy in place to address gaps, unmet needs, and inequality of access for treatment information?

## DRUG FUNDAMENTAL NEED # 1

*To receive useful and relevant information that helps all patients to know how to get the most from each treatment*

— Gain cross-functional support for patient-centric materials

### SELF-EVALUATION QUESTIONS

- Is there clear, senior leadership commitment and accountability to improve treatment information?
- Is there cross-functional clarity on barriers, objectives, actions, and measures to improve treatment information?
- Is there dedicated budget to improve treatment information and patient compliance with treatment?
- Do your medical/legal/regulatory teams have an effective approach to enable patient-centric treatment information, while managing risk within current local regulation?
- Do you effectively review local pharma activity to identify any innovations in sharing treatment information that are allowed within local regulatory practice?
- Does your organisation lead the industry in innovating and challenging its processes for patient-centric treatment information?
- Do you systematically monitor recommendations on practical steps to improve patient information from regional, international, and local regulators (e.g. use of Key Information boxes, links for further information?)

## DRUG FUNDAMENTAL NEED # 1

*To receive useful and relevant information that helps all patients to know how to get the most from each treatment*

— Put in place metrics for developing patient-centric treatment information

### SELF-EVALUATION QUESTIONS

- Do you convey to patients the limitations placed on pharma in disseminating drug treatment information?
- Do you have consistent and effective processes in place to evaluate current patient satisfaction and dissatisfaction with current treatment information?
- Do you use all opportunities in information design, pacing and structuring of content, and level of detail required to make your PIL easier to navigate?
- Do you have an effective methodology and strategy to identify and address gaps and unmet treatment information needs?
- Do you have effective policies, process and metrics to improve how you involve patient groups and patients in developing and enhancing treatment information?
- Do you continuously use a mix of channels to gain the views of both patient groups and individual patients, for example through regular contact with patient groups and through monitoring social media?

## DRUG FUNDAMENTAL NEED # 2

*To be sure that patients have been involved in developing treatment information.*

### ► **APPROACH: INVOLVE PATIENTS IN CREATING ALL TREATMENT INFORMATION BEYOND THE MINIMUM REQUIRED BY REGULATION**

Patient groups are looking for more effective and sustained commitment for companies to involve patients more closely in the development, testing and communication of treatment information. Many patient groups currently play an active role in the supply of various aspects of drug-treatment information, and are often popular, trusted channels to share this with their communities. Patient groups recommend many ways in which patient group engagement can be improved.

- **POSSIBLE RECOMMENDED ACTIONS ARE:**

- Strengthen relationships with patient groups around the topic of treatment information
- Involve patients in preparing and testing information for new and existing treatments



## FOR MORE INFORMATION

EMAIL: [alexwyke@patient-view.com](mailto:alexwyke@patient-view.com)

PHONE: [011 from the US]-44-7960-855-0

