BEING PATIENT CENTRIC
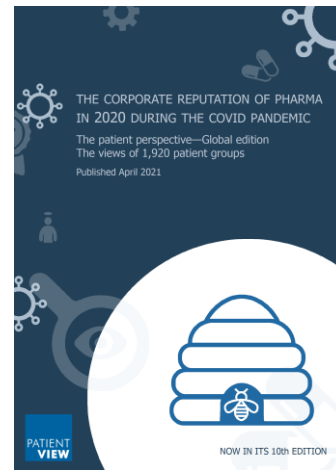
IN A POST-COVID WORLD

AN EVIDENCE-BASED UPDATE TO PATIENTVIEW'S MODEL OF 2017

PatientView...

The three main pieces of analyses to help understand the patient world post-Covid and their expectations of pharma

- ... is a UK-based research body, formed in 2000 in response to the emerging powerful new global patient movement.

- ...aims to help industry better understand the needs of patients, by giving patient groups a global platform.

- ...expresses the belief that the views of patients should be considered in all important healthcare decisions.
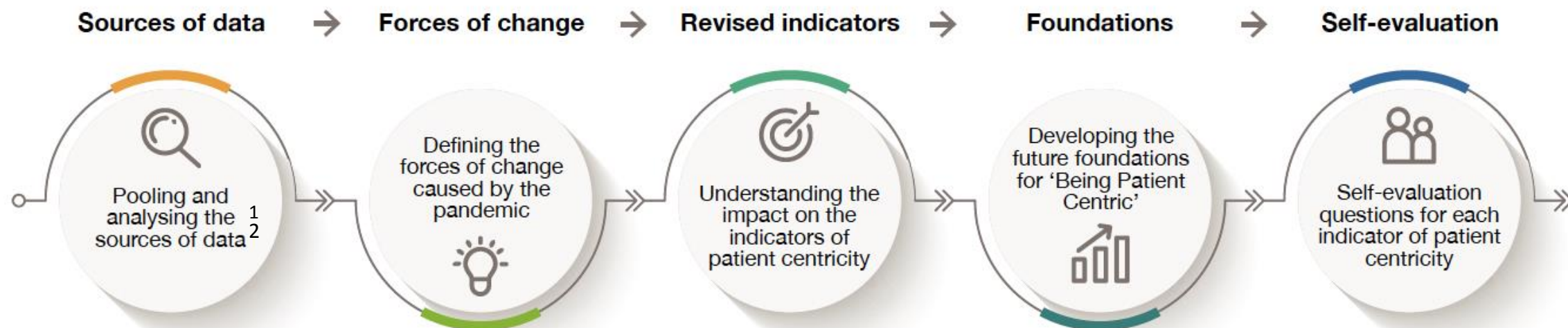
How we operate...

- PatientView relies on patient groups to willingly participate in the research that goes into the creation of PatientView products and services—as such, the data PatientView collects is evidence-based.

- PatientView has access to 40,000 patient groups worldwide.

- PatientView has built a trusted relationship with these patient groups, allowing us to approach senior managers in each patient association.

- Research is both quantitative and qualitative.

- PatientView provides consistent data sets, so that historic perspectives are possible.

METHODOLOGY

PatientView methodology for analysing Covid-19 evidence-based data

Sources of data → Forces of change → Revised indicators → Foundations → Self-evaluation

Pooling and analysing the sources of data [1] [2]

Defining the forces of change caused by the pandemic

Understanding the impact on the indicators of patient centricity

Developing the future foundations for 'Being Patient Centric'

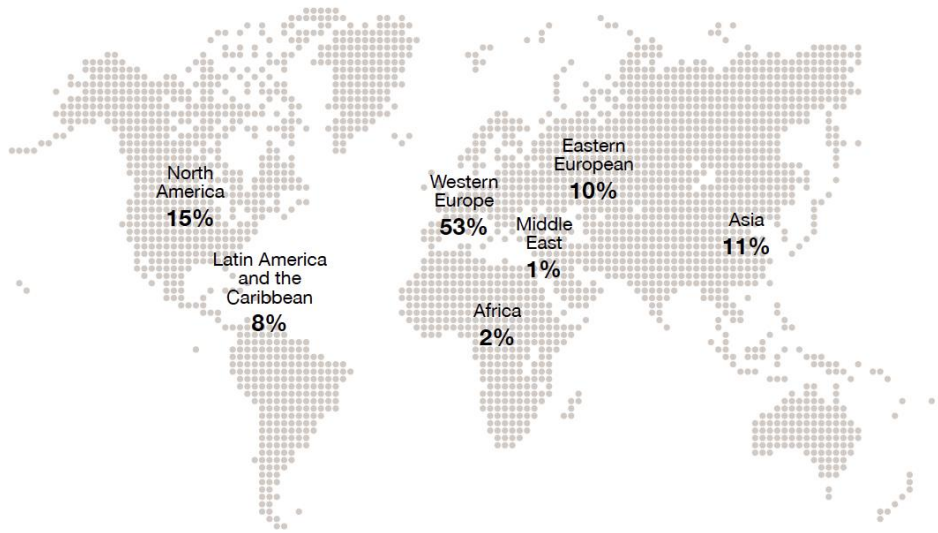Self-evaluation questions for each indicator of patient centricity

While this methodology emphasises the new, emerging trends driven by the Covid-19 pandemic, it does not ignore the fundamental patient needs that existed prior to the pandemic—which remain as important as before to all patients and patient groups.

1. *'Patient-Group Experiences during the Covid-19 Pandemic',* published September 2020

2. *'The Corporate Reputation of Pharma in 2020—from the Perspective of Patients',* published April 2021.

Evidence base and the key indicators

The geographic spread of respondent patient groups included in the 'Being Patient Centric' analyses, 2021

North America **15%**

Latin America and the Caribbean **8%**

Western Europe **53%**

Eastern European **10%**

Middle East **1%**

Africa **2%**

Asia **11%**

The key therapy areas of respondent patient groups included in the 'Being Patient Centric' analyses, 2021

Autoimmune conditions	13.3%	Immune disorders	0.6%
Blood disorders	0.7%	Kidney diseases	2.2%
Bone conditions	0.9%	Liver conditions	1.1%
Cancer	20.7%	Mental health	4.1%
Children's conditions	0.5%	Neurological conditions	11.8%
Circulatory conditions	2.8%	Rare diseases	10.6%
Disabilities	2.9%	Respiratory diseases	5.9%
Endocrine conditions	4.4%	Sexual health	1.2%
Gastrointestinal conditions	0.8%	Skin conditions (other)	0.5%
Heart conditions	0.7%	Women's health	0.2%
HIV/AIDS	8.6%	Other	5.7%

The nine indicators for Being-Patient Centric in the aftermath of a pandemic

PATIENT INFORMATION
Personal, accessible, timely and useable

PATIENT SAFETY
Reliable supply, and comprehensive patient safeguarding

PATIENT-CENTRED PRODUCTS
Products that deliver real value to patients

TRANSPARENCY
Being open and honest

INTEGRITY
Guaranteeing that all actions have a positive impact on healthcare

PATIENT-GROUP RELATIONS
The quality of a company's interactions with patient groups

SUPPORT AND SERVICES
'Beyond-the-pill' programmes valued by patients

ACCESS TO MEDICINES
Equity in healthcare

ENGAGEMENT OF PATIENTS IN R&D
Engagement of diverse patient populations throughout R&D

KEY THEMES EMERGING

How the Covid-19 Pandemic is Redefining Patient Centricity for Pharma
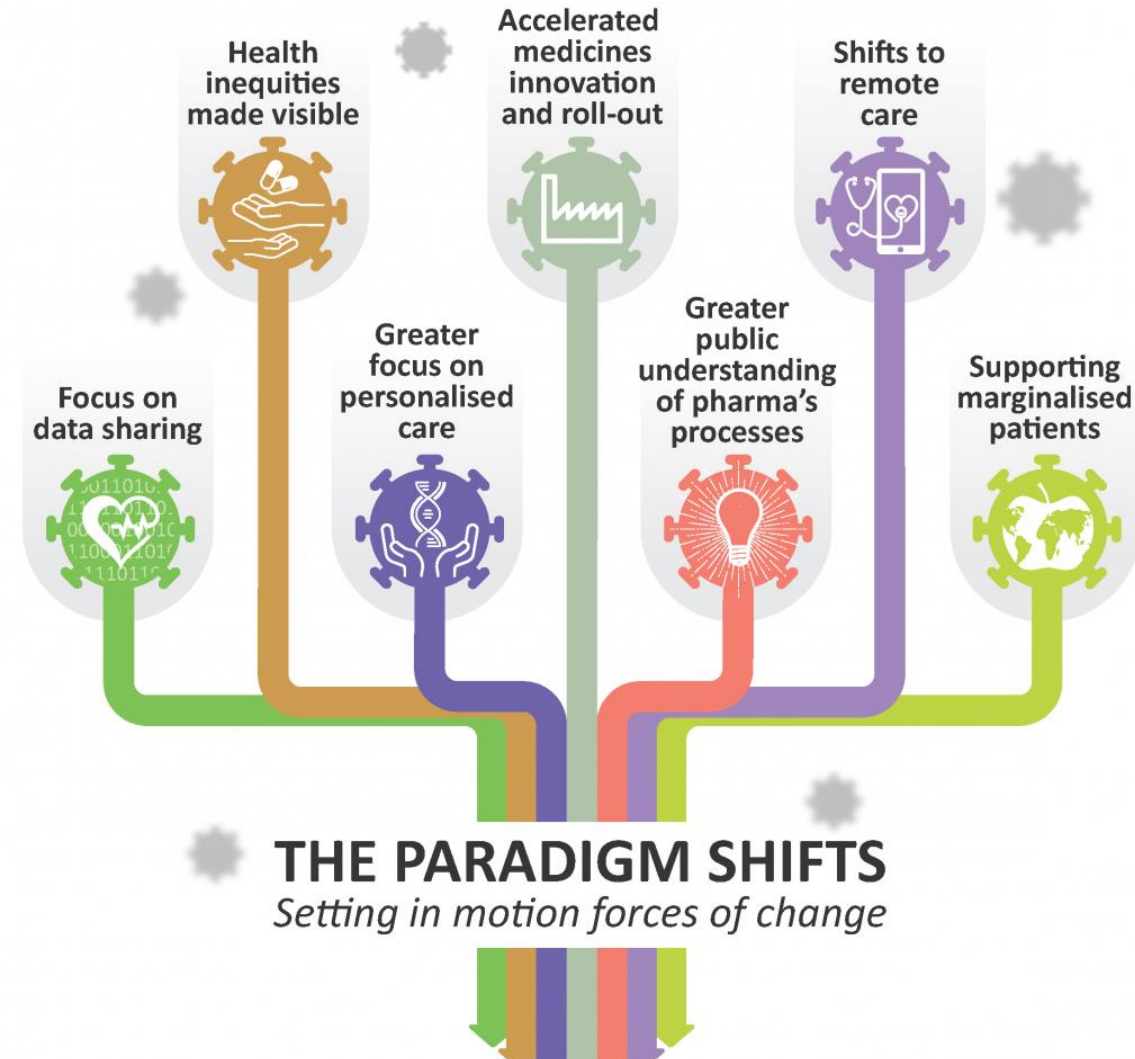
PRE-COVID (BPC 2017)

- Access was focused mainly on geography

- Trials were focused on regulatory 'approvable' cohorts

- Personal health was considered before public health

- Clinical trials confined to homogenous populations

- Patients unaware of possibilities of faster R&D processes

- Online interactions with healthcare professionals evolving slowly

- Patient Groups influence seen as charitable work

- Globalisation of supply chains accepted

Accelerated medicines innovation and roll-out
- transferring the learnings and activities from vaccine development to other disease areas

Health inequities *made visible*
- has been irreversibly and publicly exposed

Greater focus on personalised care
- to support all patient subgroups in convenient ways and settings

Shifts to remote care
- harnessing technology to improve access/ improve efficiencies and free resources

Focus on data sharing
- utilising new analytical technology to improve health interventions and outcomes

Greater public understanding of pharma's processes
- raising calls for transparency and better access to medicine

Supporting marginalised patients
- continuation of the the new roles for patient organisations providing services to patients during lockdown

POST-COVID (BPC 2021+)

- Focus more on the patient's complete lifestyle

- Improvements to access to medicines (including tackling drug shortages)
  - Greater emphasis on diversity of patients in clinical trials
  - Local production hubs valued highly
  - Speedier roll-out of new drugs worldwide
  - Real World Evidence to be used in real time

- Getting input from patients in the complete drug R&D lifecycle

- Pharma transparency under even greater scrutiny

- E-healthcare becoming a norm

- Patient groups included as vital partners in healthcare

How the Covid-19 Pandemic is Redefining Patient Centricity for Pharma
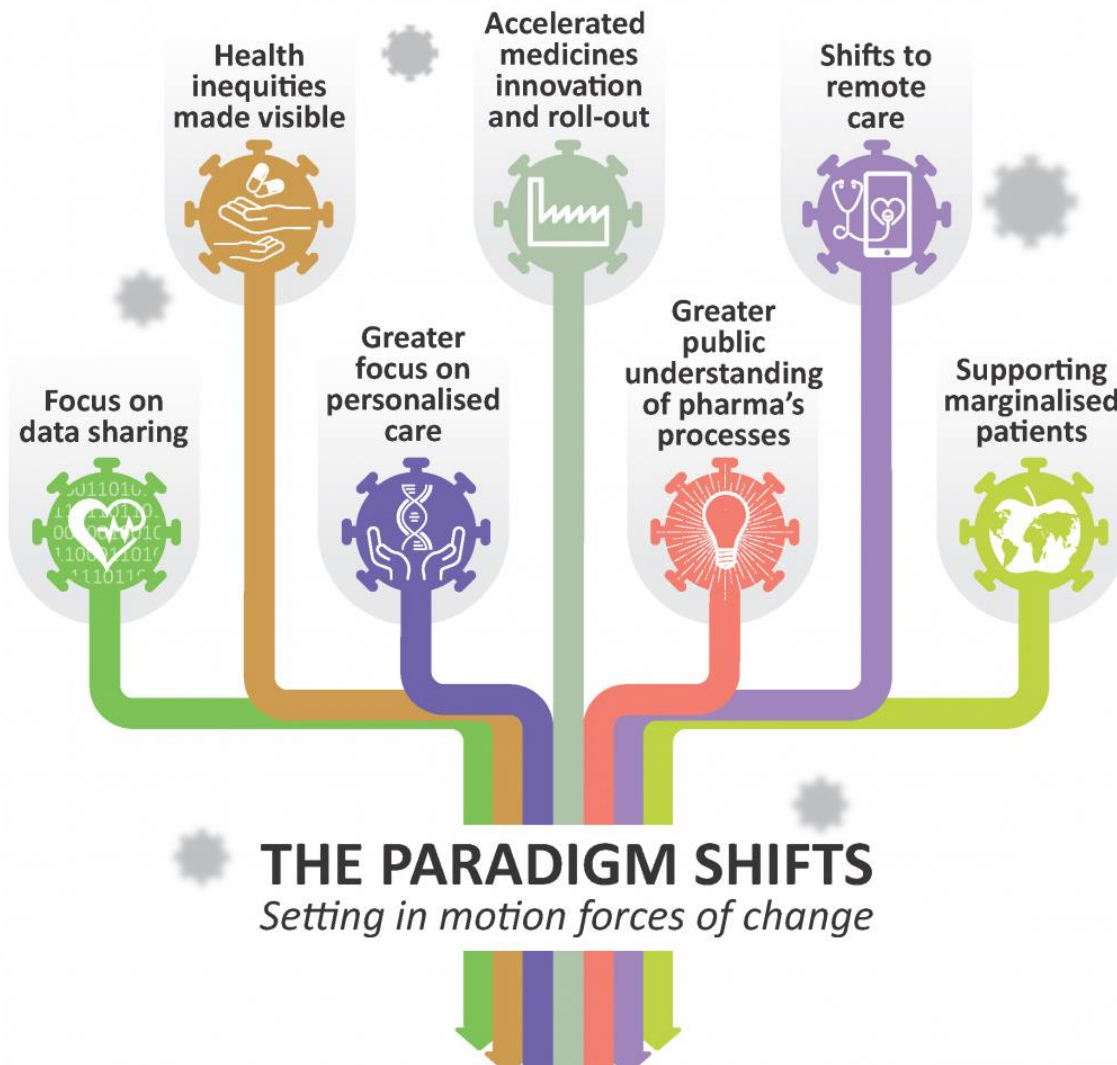
PatientView examines the nine core indicators of patient centricity—and, for each, provides the following:

- The *new forces of change* in patient centricity brought on by the Covid-19 pandemic.

- The *future foundations* required to realign companies' activities on patient centricity, post Covid-19.

- The *evidence base* for the conclusions that PatientView has drawn.

- And a *bank of questions*, to help companies put into action (and future proof) their 'Being Patient Centric' model for 2021 onwards—based on the priorities expressed by patient groups.

FOCUS ON: PATIENT GROUP RELATIONS

Patient-Group Relations

The quality of a company's interactions with patient groups

For details refer to the report.

❑ Patient groups have redefined their roles as a result of Covid-19.

❑ As patients sought more tailored information under Covid-19, they looked to patient groups as a source.

❑ Covid-19, almost overnight, forced patient groups to embrace digital media, and carry out more of their work virtually.

❑ Patient groups have struggled to convince governments of the challenges faced during the pandemic by the patients known to them

❑ Patient groups worldwide faced financial crisis during Covid-19, and have sought flexibility in their relationships with pharma.

Patient-Group Relations

The quality of a company's interactions with patient groups

Future foundations for 'Being Patient Centric' for patient relations

These five forces will redefine the nature of pharma's patient relations, as patient groups consolidate their positions within the healthcare system.

Pharmaceutical companies need to ...

→ **Show understanding**: being fully aware of the work done by each patient group—their roles within healthcare systems; their ambitions and goals; and their capabilities.

→ **Be flexible**: showing willingness to adapt administrative procedures, to work better with charity organisations, and to change priorities, by recognising the new challenges imposed on patient groups. Streamline the approval procedures for funding, grants, equipment donations, and the sharing of know-how.

→ **Communicate regularly, across multiple channels**: reacting to patient-group needs for tailored, up-to-date information; being aware of the new methods by which patient groups communicate with the patients known to them (not just membership)—and supporting them in that process.

...AND MORE

Patient-Group Relations

The quality of a company's interactions with patient groups

Samples from the evidence base for good patient relations

Landscape/understand the ecosystem of patient groups, and their roles

"Support organisations of all size, not just the multi-million dollar ones."
National mental-health patient group, USA

"Deberían interesarse por las asociaciones de pacientes no tanto nacionales como autonómicas, que son las que tratan directamente con los pacientes."
("They should take an interest in autonomous patient groups, not just national ones, who are the ones who deal with patients directly.")
Liga Reumatolóxica Galega a regional arthritis patient group, Spain

Understand patient-group strategies and priorities

"Reach out to patient groups and patients; communicate; determine issues; and work collaboratively to solve these, and to provide support. Tackle political and funding barriers."
National breast-cancer patient group, New Zealand

"Onderling afstemmen (farmaceutisch bedrijf met ons als vertegenwoordigers van de aangesloten leden) welke behoeftes er zijn."
("Mutually coordinate the pharmaceutical company with us representatives of our affiliated members—[being aware of] what needs there are.")
Antroposana a national general-health patient group, Netherlands

"Provide financial and other support to patient-advocacy organisations, so that we can support the patients. Listen to the needs of patient-advocacy groups. We know what the patients' needs are."
National ovarian-cancer patient group, Australia

Support patient-group advocacy goals

"Incoraggiare e supportare progetti di advocacy per ottenere dai regulators provvedimenti a tutela delle pazienti, fornire informazioni aggiornate e affidabili sui trend e sui risultati della ricerca, offrire un support svincolato dagli interessi di mercato."
("Encourage and support advocacy projects to obtain patient-protection measures from regulators; provide up-to-date and reliable information on trends and research results; offer support independent of market interests.")
National breast-cancer patient group, Italy

"Les pharmas se doivent non seulement nous appuyer financièrement mais aussi nous apporter leurs soutiens et savoir puisqu'ils ont plus de leviers que nous."
("Pharma companies have a duty, not only to help us financially, but also to provide their support and knowledge, since they have more leverage than us.")
Association Pulmonaire du Québec a regional respiratory-conditions patient group, Canada

Being Patient Centric post-pandemic:

Self-evaluation questions

Patient-Group Relations

The quality of a company's interactions with patient groups

Show understanding: being fully aware of the work done by each patient group—their roles within healthcare systems; their ambitions and goals; and their capabilities.

Regularly identify and map patient groups

Does my company:	✓
Plan well ahead to identify which specific patient organisations we may want to work with, and why (taking account of progress in our development pipeline or shifts in portfolio priorities)?	
Have an effective process for focusing investment in (patient group support) where it will make the biggest difference for patients?	
Have a proven process for identifying the most relevant, resilient and representative patient groups to work with?	

Identify what each group does and how it supports its communities

Does my company:	✓
Have an effective process for identifying the role of each relevant patient group, and the services it provides to support patients at local, national, or international levels?	
Have an effective process for defining why we want to work with each target patient group, and how this fits with our global, regional or national patient advocacy strategy, or Public and Patient Involvement and Engagement plans?	
Regularly evaluate how effectively each patient group supports its patient communities?	

Support patient group advocacy goals

Does my company:	✓
Have an effective way to explore with each patient group their challenges, strategy, goals and priorities in advocacy?	
Have an effective way to support patient groups' advocacy strategies to improve services for their communities?	
Have an effective way, within local compliance, to build patient group capability to advocate for its communities?	

…AND MORE

FOR FURTHER INFORMATION, PLEASE CONTACT:
alexwyke @ patient-view.com

OR

mat.patientview @ protonmail.com