For the purposes of these questions, the term “patients” refers to patients, caregivers, and groups representing patients/caregivers (e.g. patient advocacy organizations, disease-specific interest groups, etc.).

### Survey Questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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<tbody>
<tr>
<td><strong>01</strong> How would you describe patient-centricity?</td>
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<tr>
<td><strong>02</strong> On a scale of 1 to 5, with 1 being “poor” and 5 being “excellent,” rate how well your organization has engaged patients as advisors (i.e., not as study participants/subjects) in the drug research and development process.</td>
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<tr>
<td><strong>03</strong> What barriers have you encountered or anticipate encountering when trying to engage with patients and caregivers as advisors in drug research and development?</td>
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<td><strong>04</strong> Do you invite patients to co-develop your Medical Affairs materials/projects/activities?</td>
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<tr>
<td><strong>05</strong> What barriers to patient-centricity have you encountered?</td>
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<tr>
<td><strong>06</strong> TRUE or FALSE: My organization has effective community outreach and sustainable engagement strategies and programs that are tailored to meet the needs of patients/caregivers.</td>
<td></td>
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<tr>
<td><strong>07</strong> TRUE or FALSE: My organization has strategies in place to try to demonstrate trustworthiness to the patient/caregiver community.</td>
<td></td>
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<tr>
<td><strong>08</strong> Does your organization currently involve patients in the following communication activities?</td>
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</tbody>
</table>
We collected responses from a total of 31 pharma/biotech and associated industry professionals, who described medical affairs, clinical trials, and commercialization as their main areas of focus. Responses were collected from January 4 to February 25, 2022.

### Survey Responses

**Best-Suited Description of Patient-Centricity**

*(Participants could choose up to 3 options)*

- 68% Placing the patient’s well-being at the core of all initiatives
- 48% A shift from disease-centered to a patient-centered strategy and from product-led to a patient-led development process
- 32% Adding patients in the scientific process, including patient-centered endpoints in study development
- 32% Ensuring health equity and inclusion, including access to drugs at all socio-economic levels
- 29% Key development and performance indicators, including remuneration structures, adapted to put patient-first initiatives as priority
- 23% Clear communication about drug development and the risks and benefits of medicines in patient-friendly language
- 19% Patient-preference information is included in the regulatory risk-benefit assessment
- 6% Including patient authors, peer-reviewers, guest editors, and contributors to journal articles for clinical trial publications

### Organization’s Engagement of Patients as Advisors in the Drug Research & Development Process

- 26% Don’t know/Not sure
- 13% Excellent
- 16% Very good
- 13% Good
- 23% Fair
- 10% Poor

\[n = 31\]
Survey Responses

Barriers to Engaging Patients & Caregivers as Advisors in Drug Research & Development
(Participants could select multiple options)

- 40% Determining which patients to engage with/representativeness
- 33% Concerns about regulations governing engagement with patients
- 30% Lack of trust from patients
- 27% Patients’ knowledge of the research process and science
- 27% Patients’ lack of objectivity, unrealistic expectations, and “wishful thinking”
- 23% Do not know/not sure of the barriers the organization has faced/may be facing
- 20% Lack of knowledge about how to engage patients
- 17% Lack of time
- 13% Lack of money
- 13% Lack of clarity on the value that patient engagement has for their organization
- 10% Lack of interest/prioritization from peers/leadership
- 7% None of the above
- 10% Other

n = 30

Organization Invites Patients to Co-develop Medical Affairs Materials/Projects/Activities

- 36% Never
- 18% Almost never
- 29% Sometimes
- 11% Often
- 7% Always

n = 28
**Survey Responses**

### Overall Barriers to Patient-Centricity
*Participants could select all options that applied*

- **57%** Historical precedent to only ask for clinicians’ input
- **47%** Lack of standard operating procedures related to involving patients/caregivers
- **27%** Lack of sufficient information-sharing across the industry
- **20%** Lack of understanding of or respect for qualitative research methods
- **20%** I’ve not encountered any barriers
- **13%** Direct engagement with patients/caregivers is inappropriate
- **3%** Other

*n = 30*

### Organization has Effective Community Outreach and Sustainable Engagement Strategies and Programs that are Tailored to Meet the Needs of Patients/Caregivers

- **84%** True
- **16%** False

*n = 31*

### Organization has Strategies in Place to Demonstrate Trustworthiness to the Patient/Caregiver Community

- **87%** True
- **13%** False

*n = 31*
Survey Responses

Organization Currently Involves Patients in the Following Communication Activities
(Participants could select all options that applied)

- 60% Disease-state education initiatives
- 52% Post-launch patient education
- 44% Patient plain language summaries
- 24% Patient publications
- 12% Patient-focused scientific platform
- 8% Clinical trial summary results

n = 25