

A Collection of Essays on “Patient Centricity” in Intervention Development

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Objectives

- The biopharmaceutical industry has focused on improving health and well-being in recent years and has gradually moved, over the past two decades, from an innovation-centered model of intervention development to a patient-centered model of intervention development.
 - Company mission statements now include terms like *“focusing on accelerating the delivery of life-changing medicines that create enduring value for patients and society”* (AstraZeneca) and *“chase[ing] the miracles of science to improve people’s lives”* (Sanofi).¹
- Patient-centricity (PC) in intervention development has been defined as *“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”*.²
- However, the general public generally do not believe that patients are at the heart of intervention development.^{3,4}
- This research aimed to gather perspectives on patient-centric intervention development from diverse stakeholders — where we are today (2024-2025) and what improvements are still to be made.

Methods

- People who work in and around the biopharmaceutical industry were invited to answer 5 questions on patient-centric intervention development (see Box 1).
 - They were invited to answer the questions in a way that made sense to them — through a personal narrative, a review of research, a poem, or a series of drawings. Whatever they wanted.
- Various pharmaceutical company executives, small biotechnology manufacturers, patient representatives/patient advocacy organizations with lived experiences, patient experience data (PED) researchers, regulatory representatives and payer and health technology agency (HTA) advisors agreed to participate (see Box 2).
- Each contribution was presented as an essay, and the essays were collated into a book.
- Key themes from the essays were identified and discussed.

Results

- Thirty-one authors contributed twenty-four essays. Six themes were identified (see Figure 1):
 - PC has evolved significantly in the past decade, driven by regulatory bodies, patients and advocacy groups. Patient-centered intervention development and clinical care is now encouraged.
 - All definitions of PC offered by authors put the focus on the patient at the centre of intervention development, but the nature of intervention development inherently poses challenges to achieving this. Applications of PC are thus inconsistent, sporadic and non-systematic.
 - The primary mechanism by which PC intervention development has taken hold is through the generation of patient-experience data (PED) in clinical trials, and in particular through the use of patient-reported outcome (PRO) instruments. Other PC initiatives (e.g., patient-focused trial design, plain language summaries of trial data, in-trial interviews) should be encouraged.
 - Patients want to be considered as equitable partners in the co-development of interventions. This requires a standardized framework for systematic, ethical and transparent patient engagement across all stages of intervention development.
 - Patients have heterogeneous experiences which need to be explored and understood. Patient advocacy groups, patient organizations and charities can broaden the demographic reach of community research & bridge the gap between individual patients and the broader healthcare system.
 - There is as yet no clear and compelling reason for the industry to engage patients as partners in a standardized and systematic way, particularly as the process of truly involving patients as equal partners in intervention development is complex and time-consuming. It is thus important for them to focus on what is likely to offer a return on investment (ROI).

Conclusion

Patient partnerships (involving heterogeneous patients longitudinally throughout intervention development) offer an alternative paradigm to PC and should be encouraged.

Work is needed to facilitate patient partnerships, including the generation of partnership frameworks and empirical demonstration of ROI.

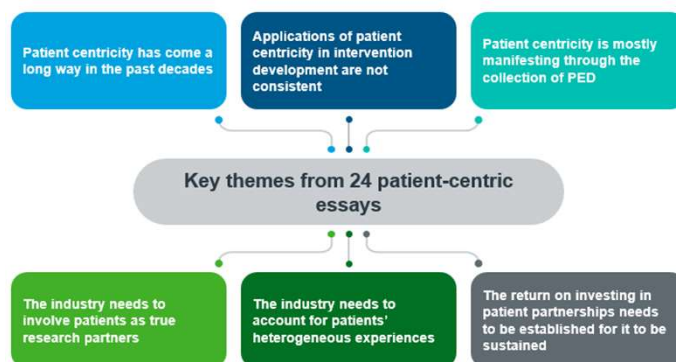
Box 1: Questions asked to the essay authors

- How important do you believe the patient perspective is in pharmaceutical drug development and decision-making in 2024; and how has your perspective on this changed over time?
- How has the pharmaceutical industry involved patients during drug development, how has this changed in your career, and how should it change in future drug development?
- What opportunities have there been, and are there now, for patients to share their stories to inform pharmaceutical drug development and decision-making?
- What have been, and are, the challenges to “patient-centricity” in the pharmaceutical drug development and decision-making around drug development?
- What do you think should (or must) happen in the future to ensure that new drugs are developed in line with patient priorities, preferences and needs?

Box 2: Essay author organizations

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| • US Food & Drug Administration (FDA) | • Tufts Center for the Study of Drug Development (CSDD) |
| • Heartbeat | • Novartis |
| • University of Tasmania Menzies Institute for Medical Research | • LUNGEVITY |
| • Ferring Pharmaceuticals | • Sanofi |
| • Accelerated Cure Project for Multiple Sclerosis (MS) | • AbbVie |
| • Astellas | • CSL Behring |
| • Prostate Cancer Research | • MediPaCe |
| • Boehringer Ingelheim | • University of Birmingham Centre for Patient Reported Outcomes Research (PCOR) |
| • Paladin Consortium | • Association of the British Pharmaceutical Industry (ABPI) |
| • Imbria Pharmaceuticals | • Aspen Consulting |
| • Gibson Research Ltd. | • Parkinson’s Europe |
| • Angela Radcliffe | • Miller Economics Ltd |
| • IQVIA Patient Centered Solutions (PCS) | |

Figure 1: Key themes across the collection of essays



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Download a free copy of the essay collection here:
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