Summary

The National Health Council Multi-Stakeholder Dialogue on Achieving Patient-Centered Core Impact Sets (PC-CIS)

Date and time:
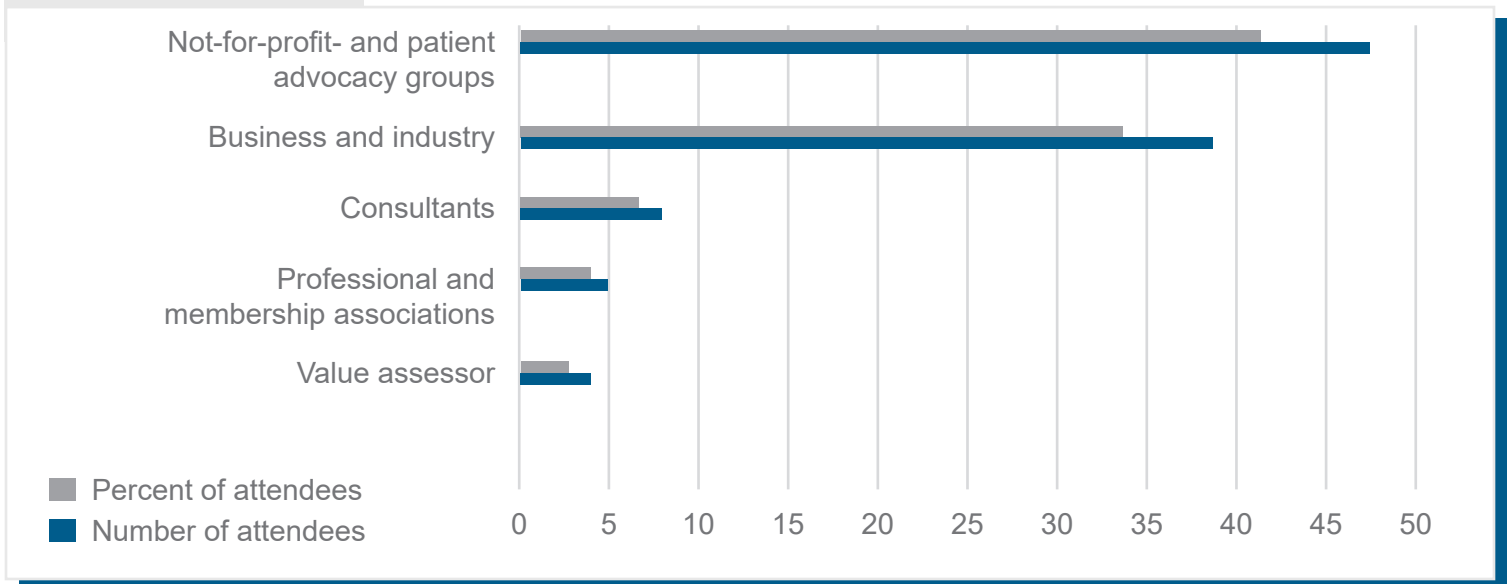August 17, 2022 from
10:00 a.m. - 3:00 p.m. ET

The National Health Council (NHC) held its Multi-Stakeholder Dialogue on Achieving Patient-Centered Core Impact Sets (PC-CIS) to receive comments on its PC-CIS Blueprint. The Blueprint is a path for developing patient-centered core impact sets, which are a patient-derived and -prioritized list of impacts a disease and/or its treatments have on a patient's life as well as their family and caregivers.

Objectives:
1. Support socializing the PC-CIS concept
2. Share the PC-CIS Blueprint
3. Capture the PC-CIS Blueprint strengths and challenges for operationalization and future PC-CIS development and use

Dialogue attendance

Pre-Dialogue sessions

From July 19-22, 2022, the National Health Council (NHC) held 3 pre-Dialogue sessions to prepare its membership and others for the opportunity to discuss the Blueprint.

Overall feedback was positive:
- Participants valued having this information **centralized**
- PC-CIS are a way to integrate **social determinants of health** into research methodologies

Challenges and solutions were noted:

Lack of resources in patient groups, including data infrastructure and management, and funding

How to make the tool **widely-usable** due to geographic and other differences

Suggested solutions:
- Keep blueprint region-, disease-, and group-specific, but learn from international efforts
- Have 1 core list of impacts, with others that vary by place or use

How to address **methodological concerns,** such as:
- Clarifying where the PC-CIS work stops, and the **outcome measure** development begins
- Guidance on the **data collection process** to ensure success at the end of the process
- Ensuring robust enough data for **FDA** use
- How to frame this as complimentary work, not displacing past or current efforts

How to ensure the process of using the blueprint is centered on **equity and diversity**

Blueprint usability could be a challenge due to its length and complexity

Suggested solutions:
- Improve the Blueprint process:
  - Make various uses more concrete, such as through examples and more use cases
  - Add more resources for thinking about collaborators and engaging the right partners

Dialogue

Panels

4 panels discussed the perspectives of patients, patient groups, researchers, industry representatives, and other stakeholders.

Overall feedback was positive:

"PC-CIS can be the starting point for **partnerships** between different stakeholders."

"There is a shifting culture…to **elevate the patient and family voice** that puts the patient perspective in the driver seat of scientific studies."

Panel members shared many benefits:

👍 PC-CIS could allow someone to **quickly and easily understand what is important to patients**, which informs and speeds downstream work

👍 PC-CIS can provide **structure around patient preferences**, such as the impact on relationships and ability to work. Panelists appreciated that a PC-CIS begins with patients, as data previously came through the lens of clinicians or researchers.

👍 PC-CIS impacts lead us to the right **outcomes** to measure, and help us find and develop the right measures

👍 PCI-CIS provides a **unique opportunity for certain sectors**, such as for managed care decision makers across different decision points, for employers wanting to understand employee decisions, and for medical product manufacturers who want to collect data reflective of their patient populations

Panel members shared challenges:

🚩 There is a need for **infrastructure and sustainability** to support data collection and convert it to usable forms

🚩 There are **value assessment considerations,** such as linking what patients have said is important (an impact) and the effect of a treatment on that impact

🚩 It will take time to address **organizational culture** and the changing power dynamic, as the Blueprint flips the typical dynamic of researchers as experts

🚩 How to address **outcome measurement**, for example the link between "impact" to "outcome" and "outcome measure"

🚩 How to address **organizational capacity**

🚩 People will need guidance on creating a **value proposition** to funders and explaining why investing early and often will de-risk downstream work

Panel members shared suggestions:

💡 Add guidance on creating a **value proposition** to funders and explaining why investing early and often will de-risk downstream work

💡 Pulling **social determinants of health (SDoH)** into the Blueprint is incredibly important in allowing researchers to consider these drivers at the very beginning. SDoH can affect barriers to care, access, diagnosis, and more.

💡 The Blueprint could include **more use cases and examples** of how patient groups and others can use the information in a PC-CIS

Polls
Attendees responded to questions via interactive polls.

Poll results

There is enthusiasm for developing and using the Blueprint and PC-CIS:
- 11% are already using the Blueprint
- 4% plan to start in the next year
- 4% want to be a pilot
- 7% intend to use a PC-CIS when available
- 26% are thinking about developing or partnering to create a PC-CIS

Next steps:

The National Health Council appreciates these comments that give us the opportunity to review and update the Blueprint. We will consider these issues as we revise and re-release the Blueprint and review organizational plans for 2023.

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