

Background

- **Person-First Language and Person-Centered Care:**
 - **Person-first language** emphasizes a person's autonomy and humanity by avoiding blaming or stigmatizing words, phrases, and names.¹
 - **Person-centered care** can increase trust and engagement in care for individuals with mental health disorders who frequently experience discrimination.^{2,3} This approach has the potential to improve cancer outcomes for marginalized populations.⁴
- The **Engage Initiative**⁵ is a coalition of diverse stakeholder dedicated to ensuring that mental illness is never a barrier to cancer care.


Specific Aims

- **Develop joint recommendations** for person-first language and care for adults with mental illness from marginalized populations, to promote engagement in care and research during the Covid-19 pandemic using community-based participatory research
- **Refine recommendations** by incorporating diverse perspectives.
- **Disseminate best practices** for person-first language and care using targeted approaches

Methods

- To **gather recommendations** for **person-first language** and **person-centered care**, researchers:
 - Developed a **Community of Practice (CoP)**,⁶ a group of people who share a common purpose and gain skills by learning together.
 - Conducted 10 virtual CoP sessions that utilized **co-learning** to address barriers to engagement in care and **co-designed recommendations** for person-first language and person-centered care.
- To **refine recommendations**, researchers:
 - **Discussed recommendations** and **incorporated feedback** from a working summit and town hall which included representation from patients, caregivers, clinicians, researchers, and administrators.
- To **disseminate best practices**, researchers:
 - Constructed **digital equity toolkit**⁷
 - Created an **ID badge card** with key principles for person-centered care.

Results




Gathering Recommendations through CoP Sessions

The Community of Practice was comprised of 18 stakeholders including:

- Older adults
- Latinos/as
- Individuals with lived experience (sometimes called service users, experts by experience, peer specialists, and patients)
- Caregivers
- Clinicians
- Patient Navigators
- Community Health Workers
- Researchers
- Advocates



The Virtual Working Summit reached 75 attendees



The Town Hall reached 100 attendees

Figure 1: Recommendations for Person-First Language





-  Ask what a person/community prefers being called
-  Begin with names
-  Offer options
-  Use "person with" language (e.g., "person with schizophrenia" instead of "schizophrenic")

Figure 2: Recommendations for Person-Centered Care

-  Ask patients what matters to them
-  Focus on strengths
-  Be curious
-  Acknowledge complexities in culture/identity (practice of cultural humility – guided by patient)
-  Acknowledge mistakes and openness to change

Conclusions

- **Community-Based Participatory Research methods** are effective in generating recommendations for person-first language and person-centered care.
- Further research is needed to **assess the impact of person-centered care on health outcomes** for marginalized populations.

Citations

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 3. Irwin K, Park E, Shin J, Fields L, Jacobs J, Greer J, Taylor J, Taghian A, Freudenreich O, Ryan D and others. Predictors of disruptions in breast cancer care for individuals with schizophrenia. *The Oncologist* 2017;2016-0489.
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