



2024

CMSS & NHC Patient-Centered Partnerships Summit

Summary

Building Meaningful Collaboration to Advance Patient Care and Research



Organizers:

Council of Medical Specialty Societies (CMSS)
National Health Council (NHC)



Date and Time



October 8, 2024



8:30 AM - 4:30 PM



Washington, DC
and virtual

Summit's goal

To foster collaboration between patient organizations, physician societies, and thought leaders to discuss strategies and tools to increase meaningful patient engagement and collaboration in patient-centered and patient-led comparative effectiveness research.



Dana's story: Patients as problem-solvers

Dana, a person living with Type 1 diabetes, contacted the maker of her continuous glucose monitor to ask for a louder alarm. The company declined to help her as a patient. So, Dana connected online with an engineer with the same concerns, who shared his method for reverse engineering the device to meet her needs.

The lesson:

Patients know their bodies, want access to their data, and are a valuable source of improvement and innovation.



Venus' story: Patients as networkers

When Venus was diagnosed with breast cancer, she found that there was little data on Latina breast cancer patients. She became committed to helping her community learn more about breast cancer by making connections to help create accessible resources and other healthcare initiatives.

The lesson:

Patients want to connect with others to spread knowledge and increase access to resources.

Important insights

Patient-centered vs patient-led: Patient-centered prioritizes the needs of patients, while patient-led actively involves patients in decision-making. Patient-centered does not necessarily change existing foundations, while patient-led pushes for more structural changes.

Trust: Building trust and having a presence in diverse communities is necessary but takes resources and time. How do we keep this “rapport building” funded?

Collaboration: This involves engaging and creating with diverse patients every step of the way – such as while designing, conducting, and reporting clinical trials.

Equity and inclusion: This involves not just specific strategies, but building a ‘culture’ of inclusion that includes patients, which allows us to look at issues from a community’s perspective. It is important to find patients who are *not* engaged, and make sure that more diverse communities are also represented. This also includes empowering advocates and community navigators to effectively engage communities and increase access.

Innovations in patient-centered research

Patient-led scorecards: A new baseline for meaningful engagement

The Council of Medical Specialty Societies (CMSS) and the Patient-Led Research Collaborative (PLRC) developed patient-led research scorecards with the goal of moving from minimal patient engagement to full patient-led collaboration throughout the entire research process.

The scorecards are a way for patients, researchers, and funders to quantify their collaboration by measuring their efforts in 5 domains, including how involved patients are in each phase and how decision-making is shared. Measuring how involved patients are in the research process can ensure that research findings are relevant and applicable to diverse populations, addressing potential health disparities and promoting equitable access to care and outcomes for all patients.

Arming patients with clinical trial expertise

The National Breast Cancer Coalition (NBCC) is focused on teaching patients about clinical trials, allowing them to communicate and collaborate at the same level as cancer researchers.

Ways to create **with** patients, instead of **for** patients

To help people with sickle cell disease (SCD), The American Society of Hematology (ASH) created the ASH Research Collaborative (ASHRC), which:

- Held town halls to learn about patients' lived experiences to build ASHRC.
- Gave communities the opportunity to give feedback on a wearable device.
- Paired researchers with those living with SCD to gather knowledge about SCD pain.

Technology in patient engagement and research

EverythingALS is an organization that aims to drive engagement with patients, caregivers, advocates, and researchers to find a cure for ALS.

EverythingALS:

Allows patients to do their own research by submitting data through a participant app and portal.

Analyzes patients' speech recordings using AI tools to learn more about the decline in speech with ALS.

Views research from a "product rollout" perspective using the Agile method, a collaborative, iterative process that involves continuous feedback to complete a project.

Challenges in patient and clinical group collaboration



- Budgetary, logistical, and time **barriers** to including patients.
- **Communication** and outreach that does not promote equitable access to information:
 - Lack of culturally relevant and health literate education.
 - Information needs to come from a trusted messenger invested in the community.
- Patients lack **trust** in the health care system and organizations.
- Culture gaps between patients' lived experience and scientific experience, and differing views on what constitutes data and outcomes.
- **Institutional Review Board (IRB)** complications, such as requiring methods that may not be culturally appropriate, or not allowing compensation for participants, which is vital. IRBs are committees that review and monitor clinical trials to ensure the rights and welfare of the trial participants are protected.

Ideas to improve patient engagement



Improve health equity

- Build a **culture of inclusion**, not just strategies for inclusion.
 - For example, at Northwest Kidney Centers, patients are involved in research and data gathering.
- Empower **patient advocates** to take on leadership roles.
- Mentor and train clinical trial **community navigators**.



Build trust with communities

- Approach communities with **humility**. Listen to their concerns, answer questions. It takes time and persistence to foster trust.
- Focus on building **interpersonal relationships** first.
- **Communicate** with communities about research goals, successful collaborations, and research results.



Engage patients online

- **Engage with patients through social media and online communities**. People want health care information quickly and want a sense of community. This is also a place to counter misinformation and gather patient insights.



Educate health care workers

- **Educate primary care doctors** about becoming a clinical trial site to help make trials more accessible for patients.
- Train and retrain health care workers on how to **effectively communicate with patients**, build humility, and improve patient advocacy.



Connect patients with researchers and clinicians

- Create a space and time for **direct dialogue** between researchers, clinicians, and patients. This empowers patients to share their ideas and feedback so their voices are heard.

Next steps

CMSS and NHC are committed to continuing this conversation and creating partnerships.



Links to organizations and resources in this summary:

- Council of Medical Specialty Societies (CMSS)
- National Health Council (NHC)
- Patient-Led Research Collaborative (PLRC)
- Patient-led research scorecards developed by CMSS and PLRC
- National Breast Cancer Coalition (NBCC)
- ASH Research Collaborative (ASHRC)
- EverythingALS



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