

**Moving Beyond Population Averages:
Patient-Centered Principles for a Personalized Medicine Research Agenda**

1. Patient/caregiver values includes personal priorities, religious/spiritual values, societal and cultural values (including family involvement in care decisions), views around quality of life, privacy concerns, desired level of access to and understanding of personal genetic information, beliefs about health and personal responsibility, and attitudes and preferences toward end of life.
2. Patient/caregiver circumstances include emotional state, socio-economic situation, race/ethnicity, sex/gender, language, health literacy, ability to work, access to care, access or lack thereof to a caregiver, social support, cognitive abilities, attitude toward illness (e.g. acceptance of diagnosis, willingness to accept help), personality, symptom burden, health-related quality of life, ability to consent and choose, relationship with the health care provider, the role of patient as a caretaker, preferences of family members, treatment setting (e.g. community, academic, other), familiarity with personalized medicine and its benefits, other social determinants of health, and other expressed needs or barriers.
3. The research agenda would be most helpful if it focused on priorities that help providers in (a) identifying and communicating treatment options based on biological differences in the context of patient/caregiver values and (b) understanding patient/caregiver circumstances and presenting treatment options in ways that highlight how a treatment aligns/does not align with those circumstances.
 - The potential for shared decision-making tools and resources to facilitate these conversations should be explored.
4. The research agenda should address the education of patients directly by considering (a) the education of patients/caregivers as a continuing process over time and not just at diagnosis, including basic education defining personalized medicine and its benefits, (b) how both patients/caregivers and their providers can improve communication with each other, and (c) how to close the gap between patient/caregiver expectations and the reality of how/when test results and treatment options are delivered.
 - Educational tools and resources, including those available online, should address different learning styles and levels of health literacy.
5. Opportunities to educate providers in genomics should be considered, along with providers' varying levels of understanding of genomics and varying levels of access to new and existing resources, such as translational tools, depending on their health setting (e.g. community, academic, other), health specialization, and health discipline (e.g. pharmacists, physician assistant, genetic counselors, nurse).
 - This includes opportunities to educate providers and other health care professionals in training.

6. The agenda should consider how to use oncology as a prototype for patient and provider education in disease areas beyond oncology.
7. Access challenges beyond those created by a lack of communication and education should also be considered.
 - This includes timely access to novel and/or off-label therapies as a result of affordability, insurance coverage and provider availability.
 - This includes strategies for mitigating inequity in the proportion of variants of uncertain significance reported out for individuals of non-Western European ancestry/ethnicity compared with those of Western European ancestry/ethnicity.
8. The research agenda should be representative of diverse patient needs, diseases, backgrounds, and experiences (e.g. stage of life, disease trajectory, socioeconomic status and health literacy level), including patients under-represented in medical research.
 - Specifically, the research agenda should apply across disease areas.
 - This includes considering how the research agenda can apply to additional disease areas as new personalized medicine treatments come to market.
 - This includes potential research topics related to the management of comorbidities.
9. The advisory committee should consider areas the agenda must include and exclude to have the greatest impact, including the feasibility of proposed research topics.
 - This includes potential research topics related to artificial intelligence, data collection, data integration and interoperability, informed consent, and patient concerns related to data privacy and access.

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