



Moving Beyond Population Averages

A Roundtable to Develop a Patient-Centered Research Agenda Advancing Personalized Medicine

Roundtable Discussion Materials

Dear Colleague,

Thank you for participating in the Personalized Medicine Coalition (PMC)'s virtual roundtable discussion series titled *Moving Beyond Population Averages: Developing a Patient-Centered Research Agenda Advancing Personalized Medicine*. This meeting is part of a two-year project led by PMC and funded by an Engagement Award from the Patient-Centered Outcomes Research Institute (PCORI) to develop an agenda identifying research questions ensuring personalized medicine treatment strategies better align with priority patient outcomes.

Patients, patient advocates, health care professionals, researchers, and other stakeholders from diverse backgrounds, disease areas, and with varying levels of experience with personalized medicine will convene for a series of roundtable discussions to help develop this research agenda.

To help you prepare for our discussion, we encourage you to review the following materials, including:

- A. Session Schedule.....page 2
- B. Project Background.....page 3
- C. Patient Principles for the Research Agenda.....page 6
- D. Proposed Research Questions (for Discussion).....page 8
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- H. Videoconferencing Best Practices.....page 18

We encourage you to join all three sessions, but we understand that you may not be able to. If needed, there will be opportunities to watch the session recordings and provide feedback offline. We look forward to speaking with you soon.

Sincerely,

Cynthia A. Bens
Senior Vice President, Public Policy
Personalized Medicine Coalition

A. SESSION SCHEDULE

Moving Beyond Population Averages: A Roundtable to Develop a Patient-Centered Research Agenda Advancing Personalized Medicine

Session 1: Patient-Centered Principles for a Personalized Medicine Research Agenda

Friday, June 19, 2020

1:00 – 3:00 p.m. ET

Session 2: Practical Considerations to Improve the Delivery of Personalized Medicine within the Current Health Care System

Monday, June 22, 2020

1:00 – 3:00 p.m. ET

Session 3: Disrupting the Health Care System for Personalized Medicine

Thursday, June 25, 2020

1:00 – 3:00 p.m. ET

Note: We will share dial-in details for each session via calendar invite.

Using the Video Conferencing Platform

These sessions will be held via videoconference. We encourage you to join from your computer with your video camera. Please plan to join the sessions 15 minutes early to connect your video and audio.

If you would like to check that your AV works and practice using the videoconferencing features in advance of the roundtable sessions, we will be holding two technology demos. These demos are optional, but we encourage you to join one of the following technology demos if you are new to videoconferencing or concerned about having technology issues.

Technology Demo (Option A)

Tuesday, June 16

1:00 – 1:30 p.m. ET

Technology Demo (Option B)

Thursday, June 18

1:00 – 1:30 p.m. ET

Note: We will share dial-in details for each demo via calendar invite.

B. PROJECT BACKGROUND

What is personalized medicine?

Personalized medicine, often referred to as precision medicine, is an evolving field in which physicians use molecular diagnostic tests to determine which medical treatments will work best for their patients. By combining the data from those tests with an individual's medical history, circumstances, and values, health care providers and patients can develop targeted treatment and prevention plans.

Personalized medicine can benefit patients in a number of ways, including by (1) shifting the emphasis in medicine from reaction to prevention, (2) reducing trial-and-error prescribing, (3) reducing adverse drug reactions, (4) revealing additional uses for medicines, (5) increasing patient adherence to treatment, (6) reducing high-risk invasive testing procedures, and (7) helping control the overall cost of health care.

Source: http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/The_PM_Report.pdf

What is patient-centered outcomes research?

Patient-centered outcomes research (PCOR) helps people and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options. This research answers patient-centered questions, such as:

1. "Given my personal characteristics, conditions, and preferences, what should I expect will happen to me?"
2. "What are my options, and what are the potential benefits and harms of those options?"
3. "What can I do to improve the outcomes that are most important to me?"
4. "How can clinicians and the care delivery systems they work in help me make the best decisions about my health and health care?"

To answer these questions, PCOR:

- Assesses the benefits and harms of preventive, diagnostic, therapeutic, palliative, or health delivery system interventions to inform decision-making, highlighting comparisons and outcomes that matter to people;
- Is inclusive of an individual's preferences, autonomy, and needs, focusing on outcomes that people notice and care about such as survival, function, symptoms, and health-related quality of life;
- Incorporates a wide variety of settings and diversity of participants to address individual differences and barriers to implementation and dissemination; and
- Investigates (or may investigate) optimizing outcomes while addressing burden to individuals, availability of services, technology and personnel, and other stakeholder perspectives.

Source: <https://www.pcori.org/research-results/about-our-research/patient-centered-outcomes-research>

Project Overview

Scientific advances have led to more targeted interventions that are informed by a patient's biology as well as environmental and behavioral factors. Technological innovation presents opportunities to understand how individual variability affects health, so that treatment may be guided to only those patients who will benefit. However, there are fundamental gaps in awareness and evidence that impact the speed at which personalized medicine products and services are integrated into health care.

Personalized medicine and patient-centered outcomes research (PCOR) share the same goal of shifting health care from a one-size-fits-all, trial-and-error approach toward a targeted approach that utilizes patients' characteristics and preferences to inform healthcare decisions. Despite this clear connection between personalized medicine and PCOR, all relevant stakeholders across the healthcare spectrum have not been engaged in setting a research agenda that is informed by early successes in personalized medicine adoption and builds on principles defined by patients.

Funded by a Eugene Washington Engagement Award from the Patient-Centered Outcomes Research Institute (PCORI), the Personalized Medicine Coalition (PMC), a nonprofit education and advocacy organization comprised of patients, researchers, innovators, providers, and payers, is convening stakeholders virtually to develop a patient-centered personalized medicine research agenda and establish connections between patients and other healthcare stakeholders that foster collaboration to fill evidence gaps and accelerate more widespread adoption of personalized medicine.

The capacity building project, titled "Moving Beyond Population Averages: Patient Principles for a Personalized Medicine Research Agenda," began with four web forums organized by PMC with its patient partners to convene primarily patients and patient advocates to develop principles for the research agenda. PMC then established an advisory committee of patients, researchers, health care providers, and a payer to guide the translation of these principles into research questions to improve the delivery of personalized medicine for patients. Through an online collaboration platform, web forum participants and the advisory committee suggested and ranked potential research questions based on these principles. The advisory committee has assisted PMC in organizing this virtual roundtable to help translate these principles into research questions and to further refine the proposed research questions. The patient-centered principles and proposed research questions are included in the following packet.

The outcome of this virtual roundtable series will be a patient-centered research agenda published as a white paper that includes a list of research questions that could be later funded by PCORI or other entities, such as public-private partnerships, to improve the delivery of personalized medicine in ways that matter most to patients. The long-term goal of this project is to help foster strategic relationships between patients and researchers that encourage patients to participate in future research advancing personalized medicine.

This project is supported by the GO₂ Foundation for Lung Cancer and the National Alliance against Disparities in Patient Health (NADPH). GO₂ is one of the largest patient-founded, patient-focused, and patient-driven philanthropies devoted exclusively to eradicating lung cancer through research, early detection, education, and treatment. NADPH is a research network focused on reducing health disparities through science-based community research, technology, education, and training in the health sciences.

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About Personalized Medicine Coalition (PMC)

The [Personalized Medicine Coalition](http://www.personalizedmedicinecoalition.org) is a coalition of over 230 organizations representing innovators, scientists, patients, providers and payers to promote the understanding and adoption of personalized medicine concepts, services, and products to benefit patients and the health system. For more information about PMC, please visit www.personalizedmedicinecoalition.org.

About Patient-Centered Outcomes Research Institute (PCORI)

PCORI is an independent, nonprofit organization authorized by Congress in 2010 to fund comparative effectiveness research that will provide patients, their caregivers, and clinicians with the evidence needed to make better-informed health and health care decisions. PCORI is committed to seeking input from a broad range of stakeholders to guide its work. For more information about PCORI, visit www.pcori.org.

C. PATIENT-CENTERED PRINCIPLES FOR A PERSONALIZED MEDICINE RESEARCH AGENDA

During the first phase of its project to develop a patient-centered research agenda in personalized medicine, the Personalized Medicine Coalition led a series of online web forums to engage primarily patients and patient advocates, as well as health care professionals and researchers, in developing a set of patient-centered principles to inform the research agenda. Over 120 participated, including more than 90 representatives from the patient, caregiver and patient advocacy communities. The participants had varying levels of familiarity with personalized medicine and patient-centered outcomes research, and they represented an array of disease areas and backgrounds.

1. Patient/caregiver values include 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, socioeconomic 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 underrepresented 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.

D. PROPOSED RESEARCH QUESTIONS (FOR DISCUSSION)

Earlier this year, the Personalized Medicine Coalition (PMC) invited patients and other members of the health care community who had been participating in PMC's web forum series to develop patient-centered principles for a research agenda in personalized medicine to brainstorm the following potential research questions. Through an online collaboration platform, participants were asked, "If you could choose one research question to improve the care or treatment of people through personalized medicine, what would that be?" There were 40 contributors, including 44 percent patients, 26 percent representatives of patient advocacy organizations, 28 percent healthcare professionals or researchers, and 3 percent other.

The following research questions will serve as a starting point for discussion during each of the roundtable sessions:

Session 1: Framing Research Questions in the Context of the Patient-Centered Principles to Improve Delivery of Personalized Medicine

1. How can education, communication and health care delivery strategies close the existing gap between a **patient/caregiver's expectations** about personalized medicine and the **reality** of how and when test results and treatment options are currently delivered?
2. What kinds of new and existing **educational tools and resources**, including those using digital platforms, would empower patients and providers, with varying levels of understanding about personalized medicine and its benefits, to discuss personalized medicine treatment options during visits?
3. How can patients and caregivers be encouraged to more **actively participate** in their personalized treatment when they prefer not to think about it, want to rely on their trusted medical team, or feel inadequate to participate?
4. How can conversations between a patient and health care professional about personalized medicine treatment options best address issues related to **access and affordability** of care?
5. How can healthcare professionals and patients navigate **language and cultural differences** when discussing personalized medicine treatment options or delivering/receiving care?
6. How do a patient's needs and access barriers, including those related to cost and affordability, change depending on the **purpose of a genetic test** (e.g., to identify risk of developing a disease vs. to identify an appropriate treatment)?
7. How can outcomes research in personalized medicine consider the impact of treatment on a **patient's financial health, psychosocial well-being, and experience receiving care**?

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Session 2: Identifying Practical Research Topics to Improve the Delivery of Personalized Medicine

8. How can the roles of **other health care professionals** beyond a patient's physician, such as nurses, nurse navigators, genetic counselors, and pharmacists, be maximized to improve the delivery of personalized medicine?
9. How can **barriers for physicians** and their medical teams in discussing and sharing with patients and caregivers information on personalized medicine, including testing, patients' results, treatment options, and enrollment in clinical trials, be addressed?
10. What strategies should be used to improve the knowledge and expertise of **primary care providers** in the integration of personalized medicine into clinical practice?
11. What kinds of **tools and technologies** (e.g., clinical decision support tools) could be made better available to providers in varying health settings, health disciplines, and health specialties to improve the delivery of personalized medicine?
12. How can conversations between a patient and health care professional about personalized medicine treatment options best account for **shared-decision making**?
13. How can shared decision-making tools and resources better facilitate conversations between patients and providers about how personalized medicine treatment options align/do not align with a **patient/caregivers' values and circumstances**?
14. How does a patient's and a health care provider's **understanding of genomics**, including the patient's understanding of his/her own genetic information, impact the integration of personalized medicine into clinical care?
15. What **mitigating strategies** are needed to address 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?

Session 3: Identifying Disruptive Research Topics That Will Change the Health Care System for Personalized Medicine

16. How does affordability and insurance coverage impact a patient's **timely access to novel and/or off-label therapies**?
17. How can longitudinal outcomes research track the value of personalized medicine in **preventing** the onset of a disease or condition?
18. How can insurance providers and other members of the health care community work together to develop **value-based contracts** for personalized treatments that have higher up-front costs?

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19. What factors contribute to **underutilization** of personalized therapies? How must the health care system change to address these factors?

20. How can the **informed consent** process for research participation be improved to account for evolutions in technology, such as artificial intelligence, and establish trust with patients over the use of their data in health research?

E. GROUND RULES FOR PARTICIPATING

Patients, patient advocates, patient advocacy organization representatives, health care professionals, researchers, and other stakeholders from diverse backgrounds, disease areas, and with varying levels of experience with personalized medicine will be participating in the roundtable discussions.

To facilitate an open discussion, we encourage you to practice the following ground rules:

1. Introduce yourself when you speak.
2. Be respectful.
3. Share the mic, but don't be afraid to speak up when you have something to say.
4. Ask for clarification if you are confused.
5. Speak from your own experience whenever possible.
6. Critique ideas, not people.
7. Build on one another's comments; work toward a shared understanding.
8. Recognize that each participant has a different perspective, experience, and area of expertise; be willing to learn from each other.
9. Consider and be willing to address the diversity of patient needs, diseases, backgrounds, and experiences.
10. Follow up with us afterward if you were not able to share a comment you think is important for us to consider.
11. Understand that even though we do not have the answer to a question, you should still ask it. The purpose of this discussion is to identify those unanswered questions and gray areas that need to be better understood.

F. SESSION AGENDAS

Friday, June 19, 2020

Session 1: Patient-Centered Principles for a Personalized Medicine Research Agenda

See calendar invite for videoconference access instructions. This meeting will be recorded and shared publicly.

12:45 p.m. ET Attendees start joining

1:00 p.m. ET Welcome and Introduction

Cynthia A. Bens

Senior Vice President, Public Policy, Personalized Medicine Coalition

1:15 p.m. ET Framing Panel Discussion: Patient-Centered Principles for a Personalized Medicine Research Agenda

See “Patient-Centered Principles” in discussion materials.

Moderator:

Susan McClure

Founder and CEO, Genome Creative

Laura Holmes Haddad

Writer

Gabriella Balasa

Patient and Advocate, Cystic Fibrosis

C. Grace Whiting, J.D.

President and CEO, National Alliance for Caregiving

Adolph P. Falcón, M.P.P.

Executive Vice President, National Alliance for Hispanic Health

2:00 p.m. ET Group Discussion: Framing Research Questions in the Context of the Patient-Centered Principles to Improve Delivery of Personalized Medicine

See “Proposed Research Questions” in discussion materials.

Moderator:

Susan McClure

Founder and CEO, Genome Creative

2:45 p.m. ET Wrap-Up and Next Steps

3:00 p.m. ET Conclusion and Evaluation Survey

*This project is supported by a Eugene Washington Engagement Award
from the Patient-Centered Outcomes Research Institute*

Monday, June 22, 2020

Session 2: Practical Considerations to Improve the Delivery of Personalized Medicine within the Current Health Care System

See calendar invite for videoconference access instructions. This meeting will be recorded and shared publicly.

12:45 p.m. ET Attendees start joining

1:00 p.m. ET Welcome and Introduction

Cynthia A. Bens

Senior Vice President, Public Policy, Personalized Medicine Coalition

1:10 p.m. ET Recap of Previous Session

Susan McClure

Founder and CEO, Genome Creative

1:30 p.m. ET Framing Panel Discussion: Practical Considerations to Improve the Delivery of Personalized Medicine within the Current Health Care System

Moderator:

Susan McClure

Founder and CEO, Genome Creative

Jennifer J. Bute, Ph.D.

Associate Professor, Communication Studies, Indiana University-Purdue University Indianapolis

Nadine Channaoui, M.S., L.C.G.C.

Licensed Genetic Counselor, Cardiovascular Genetics Program, Brigham and Women's Hospital

Lee S. Schwartzberg, M.D., F.A.C.P.

Medical Director, West Cancer Center; Chief Medical Officer, OneOncology

2:00 p.m. ET Group Discussion: Identifying Practical Research Topics to Improve the Delivery of Personalized Medicine

See "Proposed Research Questions" in discussion materials.

Moderator:

Susan McClure

Founder and CEO, Genome Creative

2:45 p.m. ET Wrap-Up and Next Steps

3:00 p.m. ET Conclusion and Evaluation Survey

This project is supported by a Eugene Washington Engagement Award from the Patient-Centered Outcomes Research Institute

Thursday, June 25, 2020

Session 3: Disrupting the Health Care System for Personalized Medicine

See calendar invite for videoconference access instructions. This meeting will be recorded and shared publicly.

12:45 p.m. ET Attendees start joining

1:00 p.m. ET Welcome and Introduction

Cynthia A. Bens

Senior Vice President, Public Policy, Personalized Medicine Coalition

1:10 p.m. ET Recap of Previous Sessions

Susan McClure

Founder and CEO, Genome Creative

1:30 p.m. ET Framing Panel Discussion: Disrupting the Health Care System for Personalized Medicine

Moderator:

Susan McClure

Founder and CEO, Genome Creative

Anne Quinn Young, M.P.H.

Chief Marketing & Development Officer, Multiple Myeloma Research Foundation

Jonathan Hare

Co-Founder, EP3 Foundation; CEO, WebShield

Tina Whitney, R.N., B.S.N., C.C.M.

Manager, Network Medical Management - Clinical Quality & Compliance, Harvard Pilgrim Health Care

2:00 p.m. ET Group Discussion: Identifying Disruptive Research Topics That Will Change the Health Care System for Personalized Medicine

See "Proposed Research Questions" in discussion materials.

Moderator:

Susan McClure

Founder and CEO, Genome Creative

2:45 p.m. ET Wrap-Up and Next Steps

3:00 p.m. ET Conclusion and Evaluation Survey

*This project is supported by a Eugene Washington Engagement Award
from the Patient-Centered Outcomes Research Institute*

G. PARTICIPANT LIST

Patient, Caregiver, Patient Advocate, and Patient Advocacy Organization Representatives

Jeff Allen, Ph.D.

President & CEO
Friends of Cancer Research

Gabriella (Ella) Balasa* *(speaker)*

Patient and Advocate, Cystic
Fibrosis

Alex Carlisle, Ph.D.*

Founder, Chair and CEO
National Alliance Against
Disparities in Patient Health

Andrew Ciupek, Ph.D.*

Manager, Clinical Research
GO₂ Foundation for Lung Cancer

Adolph P. Falcón, M.P.P.

(speaker)
Executive Vice President
National Alliance for Hispanic
Health

Andrea Ferris

President and CEO
LUNGeivity Foundation

Romina Foster-Bonds, M.S.*

Director, Programs
CureDuchenne

Caroline Gainer*

State Captain and Patient
Advocate
COPD Foundation

Marcela Gaitan, M.P.H.*

Senior Director, External Relations
National Alliance for Hispanic
Health

Kathy Giusti

Founder and Chief Mission Officer,
Multiple Myeloma Research
Foundation and Multiple Myeloma
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Michael Graglia

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Syngap Research Fund

Peter Halliburton

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Syngap Research Fund

Diane Heditsian*

CEO, Founder, deClarity;
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Athena Breast Health Network

Candace Henley

Chief Surviving Officer
The Blue Hat Foundation

Laura Holmes Haddad* *(speaker)*

Writer

Annie Kennedy

Chief of Policy and Advocacy
EveryLife Foundation for Rare
Diseases

Richard Knight

President
American Association of Kidney
Patients

Michael D. Miller, M.D.

Senior Policy Advisor
HealthyWomen

Carissa Miyano*

Research Advocate
FORCE: Facing Our Risk of
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Philip Posner, Ph.D.

Patient Advocate, Multiple
Sclerosis
PCORI Ambassador

Joan Powell*

Patient Advocate, Myelodysplastic
Syndrome

Bradford Power*

Founding Member
MyCancerDB

Anne Quinn Young, M.P.H.

(speaker)
Chief Marketing and Development
Officer
Multiple Myeloma Research
Foundation

Sandra Shaw*

Vice President, Strategic Alliance
and Patient Engagement Strategy
MJH Life Sciences

Margie Sherlock*

Global Health Principal
ConText

Eric Sokol

Vice President, Public Policy
Alzheimer's Foundation of America

Yasmeem Watson

Research Advocate
Fight Colorectal Cancer

C. Grace Whiting, J.D.* *(speaker)*

President and CEO
National Alliance for Caregiving

Ronit Yarden, Ph.D., M.H.S.A.*

Adjunct Associate Professor,
Georgetown University and Patient
Advocate

** these participants also serve on the project's Advisory Committee*

(continued)

Health Care Professional and Researcher Representatives

Jane Binger, Ed.D.

Co-Founder & Chief Learning Officer, DeepTok; Senior Advisor, Center of Excellence in Diversity in Medical Education, Stanford Medical School

Patricia Brennan, Ph.D., R.N., M.S., D.F.N.A.P.*

Clinical Research Nurse, PARADIGM Study, Department of Surgery, Division of Transplant University of California, San Francisco

Jennifer Bright, M.P.A.

Executive Director
Innovation and Value Initiative

Jennifer J. Bute, Ph.D. * (speaker)

Associate Professor,
Communication Studies
Indiana University-Purdue
University Indianapolis

Nadine Channaoui, M.S.,

L.C.G.C. * (speaker)
Licensed Genetic Counselor,
Cardiovascular Genetics Center
Brigham and Women's Hospital

Mary E. Cooley, Ph.D., R.N.,

F.A.A.N.*
Scholar-in-Residence
Oncology Nursing Society

Greg Feero, M.D., Ph.D.

Family Medicine Physician and Human Genetics Specialist, Four Seasons Family Practice; Professor of Community and Family Medicine, Maine Dartmouth Family Medicine Residency Program

Christine Formea, Pharm.D.,

BCPS, FCCP, FASHP*
Pharmacogenomics – Pharmacist Specialist
Intermountain Healthcare

Lori Frank, Ph.D.*

Senior Behavioral Scientist, RAND Corporation;
Board Member, Personalized Medicine Coalition

Lawrence Goldberg, M.D.*

Physician Surveyor, The Joint Commission;
Co-Chair, Advisory Committee for Comparative Effectiveness Research, PCORI

Peter J. Hulick, M.D., MMSc

Medical Director, Center for Personalized Medicine
NorthShore University HealthSystem

Deborah Hunt, Ph.D., R.N.*

Associate Dean of Nursing and Professor
Mercy College

Jen Laws

HIV and Trans Community Advocate/Policy Analyst
Policy Candy Strategies

Konstantinos Lazaridis, M.D.

Associate Director, Center for Individualized Medicine;
Consultant, Division of Gastroenterology and Hepatology, Department of Medicine; Professor of Medicine, Mayo Clinic College of Medicine
Mayo Clinic

Nita A. Limdi, Pharm.D., Ph.D.,

M.S.P.H., F.A.H.A.
Professor, Department of Neurology & Epidemiology;
Director, Program for Translational Pharmacogenomics; Associate Director, Hugh Kaul Precision Medicine Institute
University of Alabama at Birmingham

Sean C. McConnell, Ph.D.*

Senior Policy Analyst, Genomics and Precision Medicine
American Medical Association

Arnold I. Pallay, M.D., F.A.A.F.P.

Associate Medical Director, Jacobs Levy Genomic Medicine & Research Program
Atlantic Health System

Lee S. Schwartzberg, M.D.,

F.A.C.P. (speaker)
Medical Director, West Cancer Center;
Chief Medical Officer, OneOncology

Agnieszka Swiatecka-Urban, M.D., F.A.S.N.

Associate Professor of Pediatrics and Cell Biology, University of Pittsburgh School of Medicine
Children's Hospital of Pittsburgh of UPMC

Apostolia-Maria Tsimberidou, M.D., Ph.D.

Professor, Department of Investigational Cancer Therapeutics, MD Anderson Cancer Center, University of Texas;
Board Member, Personalized Medicine Coalition

** these participants also serve on the project's Advisory Committee*

(continued)

Other Representatives

Suzanne Belinson, Ph.D., M.P.H.
Vice President, Commercial
Markets
Tempus

Carla Easter, Ph.D.*
Branch Chief, Education and
Community Involvement
National Human Genome
Research Institute

Jonathan Hare (*speaker*)
Co-Founder, EP3 Foundation
(Empowering People with Privacy
and Personalization);
CEO, WebShield

**Jennifer Mills, Ph.D., M.S.W.,
M.P.H.***
Vice President, Patient and
Professional Partnerships
Foundation Medicine

**Tina Whitney, R.N., B.S.N.,
C.C.M.*** (*speaker*)
Manager, Network Medical
Management - Clinical Quality &
Compliance
Harvard Pilgrim Health Care

** these participants also serve on the project's Advisory Committee*

H. VIDEOCONFERENCING BEST PRACTICES

Log on Instructions

- Please ensure you are using Google Chrome as the designated browser
- Once the program link is clicked, the link will open and prompt you to “join” the meeting

Connectivity and Testing

- When possible, please situate yourself at a location close to your router
- Hardwire connection direct to the router is preferred over wi-fi due to reliability
 - All devices connected to your internet have a “reserve” on wi-fi bandwidth even if the device is not in use. If you have any iPads, TVs, phones, computers, security cameras, Ring doorbells, Nest thermostats, or Amazon Alexas connected to your network and it is possible to do so, please disconnect them from wi-fi or turn them on airplane mode before you connect to the stream site. This releases the reserve bandwidth and distributes it to other connected devices.
 - If possible, make sure no one is streaming a movie (Disney+, Netflix, etc.) during the program
- Ensure that your device’s power cord is plugged in
- Close out of all other browsers
- Make sure all computer speakers, cell phones, and any other devices are muted, turned off, or placed in airplane mode
- If possible, use wired earbuds or a gaming head counsel as opposed to the computer microphone as the sound quality is far better
- As a reminder, we ask that you be available and log on to the virtual meeting **15 minutes prior** to the program start time. This is in case of technical difficulties that require assistance.

Location, Location, Location!

- Choose a location that is out of direct sunlight, quiet, smaller to better avoid echoing, and has a door to shut out noise disturbances (e.g., dog barking, children playing, phone or doorbell ringing)
- Find a location without a disruptive background or environment that can be seen by the other program participants through your webcam (e.g., no mirrors behind you as everyone will see the back of your head, squeaky chair, or background clutter)
- Ensure that the location you have chosen is suitable for the duration of the meeting

Best Practices for Participating

- Have a beverage available, but try to avoid drinking on camera while speaking
- Place your device on a solid surface, such as a flat desk or table with the camera level with your face without having to tilt the monitor
- Have your browser window with the program on the same monitor as your camera so that as you participate you are still facing the other program participants
- Avoid distracting behavior such as swiveling or rocking back and forth in your chair
- Business casual attire is suggested. Solid, dark-colored shirts/jackets are preferred. Avoid busy prints, checks, plaids, and stripes. Subtle prints are best and try to avoid large or busy jewelry.

(continued)

- ❑ Lastly, **please mute your own microphone** during the presentation to limit noise distractions by simply clicking on the microphone icon at the top of the right-hand navigation pane. If you wish to ask a question, you can simply click on that same microphone icon to unmute your microphone.

Technical Instructions

- ❑ If you experience any technical difficulties, a good quick fix is pressing F5 on your keyboard for Windows, and for Mac, press Command-R (hold down the “Command” key and then, while still holding it, press the “R” key on your computer’s keyboard). This will simply refresh your browser.
- ❑ If you continue to experience technical difficulties, click on the moderator chat icon on the right-hand navigation pane to seek assistance. A member of our technical team will endeavor to assist you.
- ❑ During the session, we may ask some polling questions. Using the poll icon on the right-hand navigation pane, select your response and press the submit button when directed to do so by the moderator.
- ❑ To increase the size of the video or the slides for better viewing, there is a slider bar to change the size of the video vs. slide. Note: You will need to roll your mouse over the window for the video/slide sizer slider to appear at the bottom of your viewing platform.