**Web Forum #3 Discussion Questions**

***Moving Beyond Population Averages: Developing Principles for a
Personalized Medicine Research Agenda***

**Overview**

If you were not able to join us live, or would like to provide additional feedback following our third web forum, we invite you to answer the following questions posed during the discussion. You are welcome to answer all or part of the questions. A recording of the webinar and the slide presentations can be viewed [here](http://www.personalizedmedicinecoalition.org/Research/Moving_Beyond_Population_Averages_Patient_Principles_for_a_Personalized_Medicine_Research_Agenda), and relevant timestamps from the recording are linked below.

Your feedback will inform our fourth and final web forum slated for January 2020 where we will finalize these patient-centered principles for a research agenda in personalized medicine and receive suggestions for in-person meeting to develop the agenda. The target timeframe for the final web forum is January 2020. Between then and now, we will form the project’s advisory committee and begin planning the in-person meeting.

**Please email your responses and any questions to David Davenport, Project Manager and PMC Manager, Public Policy, at** **ddavenport@personalizedmedicinecoalition.org****.**

**Contact Information:**

Name (First, Last):response

Email Address:response

Which of the following best describes you?

* Patient
* Patient advocate
* Caregiver
* Health care professional/provider
* Academic researcher / outcomes researcher
* Other

How would you describe your understanding of personalized medicine?

* I have not heard of it before this webinar.
* I have heard of it, but do not understand what it is.
* I understand what personalized medicine is.
* I or someone I know has been treated with personalized medicine.
* I advocate for personalized medicine, or use it in my profession.

**Part I. Definitions** (see recording at [17:02](https://youtu.be/rlW4a31Xj9o?t=1023))

Draft definition: ***Patient/caregiver values*** *includes personal priorities, religious/spiritual values, societal and cultural values (including family involvement in care decisions), views around quality of life, and beliefs about health and personal responsibility.*

1. What other factors should be considered?

**Response:**

Draft definition: ***Patient/caregiver circumstances*** *include emotional state, socio-economic situation, race/ethnicity, language, ability to work, access to care, social support, cognitive abilities, attitude toward illness, personality, symptom burden, health-related quality of life, ability to consent and choose, relationship with the healthcare provider, the role of patient as a caretaker, and other expressed needs or barriers.*

1. What other factors should be considered?

**Response:**

**Part II. Scope and Content** (see recording at [21:33](https://youtu.be/rlW4a31Xj9o?t=1293))

Draft principle: *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.*

1. How can providers improve communication to help patients make decisions about their health and health care? Do you agree with the approach described above?

**Response:**

1. To what extent should this research agenda address education of patients directly? And how? (see recording at [25:26](https://youtu.be/rlW4a31Xj9o?t=1536))

**Response:**

1. Should access challenges beyond those created by a lack of communication and education be considered? What about timely access to novel therapies (i.e. affordability, insurance coverage, provider availability)? (see recording at [39:37](https://youtu.be/rlW4a31Xj9o?t=2377))

**Response:**

***Disease Areas*** (see recording at [42:38](https://youtu.be/rlW4a31Xj9o?t=2558))

1. Should the research agenda apply across disease areas?

**Response:**

1. Or should it identify research priorities for particular disease areas? If so, which disease areas?

**Response:**

1. How can the research agenda apply to additional disease areas as new personalized medicine treatments come to market?

**Response:**

***Additional Factors and Perspectives*** (see recording at [46:53](https://youtu.be/rlW4a31Xj9o?t=2813))

1. Are there any other factors that should be considered in the research agenda? Is there any particular expertise or a perspective that we should consider is represented on the project’s advisory committee?

**Response:**

**Part III. Impact** (see recording at [52:22](https://youtu.be/rlW4a31Xj9o?t=3142))

Draft principle: *The research agenda should be holistic by identifying research topics inclusive of diverse patient needs, disease, backgrounds, and experiences, including patients under-represented in medical research.*

1. What else would a successful patient-centered research agenda accomplish? What other parameters should we set to ensure its impact and success?

**Response:**

1. How can the agenda best provide novel ideas?

**Response:**

1. What should NOT be a focus on the agenda? (see recording at [1:01:07](https://youtu.be/rlW4a31Xj9o?t=3667))

**Response:**

1. Should the agenda identify research priorities that only PCORI can fund? Or should it identify priorities that other institutions and organizations may want to fund? (see recording at [56:09](https://youtu.be/rlW4a31Xj9o?t=3369))

**Response:**

**Any additional comments:**

**Response:**

*Thank you for taking the time to share your feedback. We appreciate your contributions to the project and will consider these ideas in our next discussion.*

***Please email your responses to David Davenport, PMC Manager of Public Policy and Project Manager, at******ddavenport@personalizedmedicinecoalition.org******. Please feel free to contact him with any questions as well.***