

Meeting Agenda

Group: ISPOR Patient Representatives Roundtable (PRR) – North America		
Date: Monday, May 21, 2018	Time: 12:00 pm – 4:45 pm EDT	
Meeting Location: Baltimore Convention Center (Room 308 - Level 300), Baltimore, MD, USA		
Time	Topic	Presenter(s)
12:00 – 12:30	Lunch	All Participants
12:30	Call to Order	Nadia Naaman
12:30 – 12:45	Introduction of ISPOR PRR Participants	All Participants
12:45	ISPOR Antitrust Compliance Statement	Nadia Naaman
12:45 – 12:50	Welcome by ISPOR	Nadia Naaman
12:50 – 1:00	Review of Agenda and Reflections from the 2017 PRR <ul style="list-style-type: none"> Defining and Measuring Meaningful Patient Engagement: A Multistakeholder Perspective Article produced by PRR – North America and published in ISPOR <i>Value & Outcomes Spotlight</i> Tool or checklist to measure/validate patient engagement 	Suz Schrandt
1:00 – 1:15	Defining Patient Engagement in Research <ul style="list-style-type: none"> ISPOR Patient Centered Special Interest Group 	Rachel Harrington
1:15 – 2:15	Case Studies on Patient Engagement in Value Assessment <ul style="list-style-type: none"> Review of PRR preliminary survey results Arthritis Foundation ICER Review Patient member experience with HTA committees (Ontario, CA) <p>Open discussion: Other examples to share (+/-)</p> <ul style="list-style-type: none"> <i>Examples in your disease community (Why/why not?)</i> <i>What resources are needed to execute such efforts?</i> 	<u>Speakers:</u> - Suz Schrandt - Maureen Smith All Participants
2:15 – 2:30	Coffee Break	All Participants
2:30 – 3:30	Data Review in Regulatory Approval and Value Assessment <ul style="list-style-type: none"> Hearing from regulators and payers: <ul style="list-style-type: none"> <i>What types of patient-provided information¹ are/are not reviewed by assessors and decision makers?</i> <ul style="list-style-type: none"> <i>Use of patient preference data in regulatory decision-making</i> <p>Open discussion: <i>How can we move toward broader inclusion of patient-provided information in approvals and value assessments?</i></p>	<u>Speakers:</u> - John Watkins - Brian O'Rourke - Anindita Saha All Participants

3:30 – 4:30	<p>Patient Initiatives</p> <ul style="list-style-type: none"> • ISPOR partnership in IMI PARADIGM Project • Patient engagement in HTA for rare disease treatments • ISPOR/National Health Council Patient-Research Matchmaking Project • Other focus areas: <ul style="list-style-type: none"> ○ Potential webinar series – what topics are most valuable? <ul style="list-style-type: none"> ▪ Quality-Adjusted Life Years (QALYs) ▪ Patient-Reported Outcomes (PROs) 	<p><u>Speakers:</u></p> <ul style="list-style-type: none"> - Theresa Tesoro - Sandra Nestler-Parr - Richard Willke / Eleanor Perfetto - Suz Schrandt
4:30 – 4:45	<p>Summary and next steps</p> <ul style="list-style-type: none"> • Key points from the day • Decision points about deliverables, activities and next steps 	Suz Schrandt
4:45	Adjournment	All Participants

¹ <http://www.nationalhealthcouncil.org/sites/default/files/NHC-GA%20Feb2017.pdf>