

AGENDA		
7:30 - 8:00	Registration and light breakfast, coffee and tea – time to get settled in for an exciting day!	4016 Varnes, SON
8:00-8:20	Welcome and Introduction – Russ Waitman <ul style="list-style-type: none"> • What is the GPC? (for those not present on Sunday) • Brief Site and Cohort introductions • How we will work and what are the products by the end of the day: • Cohorts: clarity on cohort characterization and survey activities 	4016 Varnes, SON
8:20 – 8:30	Sharing from Sunday’s Patient Experience discussion – Patient Leaders <ul style="list-style-type: none"> • How do you want to learn about trials/research and be contacted? Recruitment • How do you want to decide to join the trial? Consent • How do you want to receive the trial? Intervention • How do you want to report how you’re doing? Patient Reported Outcomes • How do you want to learn how the trials going? Monitoring and feedback 	4016 Varnes, SON
8:30-8:45	Other Important Work Ahead – Russ Waitman <ul style="list-style-type: none"> • Data Sharing: model for patients in data governance at our sites and the GPC; plan/governance for obtaining/linking additional data • Phase 2 planning, next trials/cohorts, and sustainability 	4016 Varnes, SON
8:45 – 9:00	BREAK	
We will break into five different smaller groups that will alternate between group discussion and coming back together to share:		
9:00 – 11:00	These 3 breakout groups are designed to discuss the each of the focus areas for the GPC. (Note each group has a different room assignment) (A) Cohorts (focus: initial characterization results and data pulls; interactive review) <ul style="list-style-type: none"> • (A1) Cohort Characterization: Breast Cancer (Betsy Chrischilles and Lindsay Cowell) • (A2) Cohort Characterization: ALS (Rick Barohn and Prakash Nadkarni) • (A3) Cohort Characterization: Obesity (Dan Hale and Alfredo Tirado-Ramos) 	(A1): 4030 Robinson (A2): 4019 Varnes, SON (A3): 1049 SON

9:00 – 11:00	<p>This group will focus on the discussion of how comparative effectiveness research during the course of a patient’s care and experience. How can we accomplish collecting the data we need for research while respecting the patient/family/caregiver and provider’s priorities?</p> <p>(B) Comparative Effectiveness Research and the Patient Experience (Jim McClay and Laura Fitzmaurice)</p>	(B): 4016 Varnes, SON
9:00-11:00	<p>(C) Data Sharing Agreements and Data Governance (focus: socialize DSA; patient needs) (Brad Taylor and Russ Waitman)</p>	(C): 2050 SON
11:00 - 11:15	BREAK	
11:15 - 11:40 11:40 – 12:15	<p>Discussion and sharing</p> <p>Combined (A) Cohorts: Group characterization</p> <p>Combined (A) Cohorts: Surveys</p>	4019 Varnes, SON
11:15 – 12:15	<p>(B) Comparative Effectiveness Research and Patient Experience (continued)</p> <p>(C) DSA (focus: socialize DSA; patient needs) break-out (continued)</p>	(B): 4016 Varnes, SON (C): 2050 SON
12:15 - 12:30	BREAK	
12:30 - 1:30	Working Lunch: All groups will report back on the morning sessions	4016 Varnes, SON Box Lunch Provided
1:30 - 1:45	BREAK	
1:45 - 2:45	<p>All Cohorts Discussion</p> <p>(Discussion focus: survey deployment - how do we meet the needs of each of the will do for all three cohorts)</p>	(A): 4019 Varnes, SON

<p>1:45 - 2:45</p> <p>1:45 – 2:45</p>	<p>(B) Comparative Effectiveness Research in the Patient Experience: Nuts and Bolts reality check with Laura Fitzmaurice and Jim McClay</p> <p>(C) Data Sharing Agreement action plan draft; focus on data sharing to support trials</p>	<p>(B): 4016 Varnes, SON</p> <p>(C): 2050 SON</p>
<p>2:45 - 3:00</p>	<p>BREAK</p>	
<p>3:00 - 4:00</p>	<p>What have we learned today? A synthesis and review – Russ Waitman and all</p>	<p>4016 Varnes, SON</p>
<p>4:00 - 5:00</p>	<p>Final discussion, next steps, wrap-up</p>	<p>4016 Varnes, SON</p>