

APPENDICES

Appendix A. Description of the Community Advisory Board

Date and Location of Community Advisory Board (CAB) Meeting	List of Attendees and CAB Roles	Discussion
Jul. 29, 2013 Seattle, Washington	<ul style="list-style-type: none"> • Amy H. (family member), <i>Chair</i> • Gail M. (patient and family member) • Jennifer G-H. (family member) • Judy Y. (patient and family member) • Suzanne G. (clinician) • Maddie A. (Cambia rep) • Randy Curtis (faculty, study PI) • Ruth Engelberg (faculty, study co-I) • Elizabeth Nielsen (study staff) • Jimmy Hoard (CAB admin) 	<p>ICSI study materials and procedures: patient baseline questionnaire; sample patient’s feedback form (Jumpstart-Tips tip sheets); and recruitment. Observations and suggestions encompassed wording, definitions of terms (“palliative care,” “end of life”), inclusion of family concerns, formatting, and information flow.</p>
Nov. 1, 2013 Seattle, Washington	<ul style="list-style-type: none"> • Amy H. (family member), <i>Chair</i> • Gail M. (patient and family member) • Judy Y. (patient and family member) • Melissa B. (family member) • Suzanne G. (retired clinician) • Maddie A. (Cambia rep) • Randy Curtis (faculty, study PI) • Ruth Engelberg (faculty, study co-I) • Patsy Treece (research nurse) • Elizabeth Nielsen (study staff) • Brooke Lifland (study staff) • Jimmy Hoard (CAB admin) 	<p>ICSI study materials and procedures: patient baseline questionnaire (religion/spirituality items); 2 versions of Jumpstart-Tips feedback form; study recruitment (potential burdens of study correspondence and survey contacts)</p>
Jan. 8, 2014 Seattle, Washington	<ul style="list-style-type: none"> • Amy H. (family member), <i>Chair</i> • Adam B. (family member) • Catherine C. (community member) • Diane A. (family member and clinician) • Judy Y. (patient and family member) • Melissa B. (family member) • Randy Curtis (faculty, study PI) • Ruth Engelberg (faculty, study co-I) • Patsy Treece (research nurse) • Elizabeth Nielsen (study staff) • Jimmy Hoard (CAB admin) 	<p>ICSI study materials and procedures: patient, family member, and clinician Jumpstart-Tips forms and videos (cognitive and emotional content); questionnaire items (follow-up on religion/spirituality changes); discussion of “serious illness” to ensure concept and language understandable to patients and families</p>

Apr. 25, 2014 Seattle, Washington	<ul style="list-style-type: none">• Amy H. (family member), <i>Chair</i>• Adam B. (family member)• Melissa B. (family member)• Molly G. (family member)• Nita S. (patient)• Ron P. (community member)• Stephanie M. (clinician)	ICSI study materials and procedures: patient and family recruitment scenarios; current version of Jumpstart-Tips forms (additional feedback components that could be added)
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	<ul style="list-style-type: none"> • Ruth Engelberg (faculty, study co-I) • Patsy Treece (research nurse) • Elizabeth Nielsen (study staff) • Jimmy Hoard (CAB admin) 	
Jul. 18, 2014 Seattle, Washington	<ul style="list-style-type: none"> • Amy H. (family member), <i>Chair</i> • Adam B. (family member) • Christine K. (guest) • Diane A. (family member and clinician) • Jennifer G-H. (family member) • Judy Y. (patient and family member) • Melissa B. (family member) • Nita S. (patient) • Ruth N. (guest) • Stephanie M. (clinician) • Randy Curtis (faculty, study PI) • Ruth Engelberg (faculty, study co-I) • Patsy Treece (research nurse) • Elizabeth Nielsen (study staff) • Jimmy Hoard (CAB admin) 	Patient engagement for advisory board and study (areas to reach out to community organizations and other hospitals); ICSI study overview and enrollment update; individual study patient engagement due to severity of illness; recruitment challenges for family members and team clinicians
Oct. 10, 2014 Seattle, Washington	<ul style="list-style-type: none"> • Amy H. (family member), <i>Chair</i> • Diane A. (family member and clinician) • Eleanor O. (patient and family member) • Jennifer G-H. (family member) • Judy Y. (patient and family member) • Karen F. (clinician) • Katie P. (UW administrator) • Randy Curtis (faculty, study PI) • Ruth Engelberg (faculty, study co-I) • Elizabeth Nielsen (study staff) • Jimmy Hoard (CAB admin) 	ICSI study overview and enrollment update; review of materials: Barriers and Facilitators instrument (data on frequencies; items endorsed). Observations and suggestions addressed challenge of cognitive exercise, ambiguity of instructions, possible future reduction in number of items based on performance/endorsements.
Jan. 16, 2015 Seattle, Washington	<ul style="list-style-type: none"> • Amy H. (family member), <i>Chair</i> • Diane A. (family member and clinician) • Eleanor O. (patient and family member) • Gail M. (patient and family member) • Judy Y. (patient and family member) • Margaret K. (family member and clinician) • Nita S. (patient) • Ron P. (community member) • Stephanie M. (clinician) • Randy Curtis (faculty, study PI) • Ruth Engelberg (faculty, study co-I) • Patsy Treece (research nurse) • Elizabeth Nielsen (study staff) • Sudiptho Paul (study staff) • Jimmy Hoard (CAB admin) 	ICSI study overview and enrollment update; review recruitment strategies and collect recommendations (eg, approaching subjects by phone, more personalization)
Apr. 24, 2015 Seattle, Washington	<ul style="list-style-type: none"> • Amy H. (family member), <i>Chair</i> • Adam B. (family member) • Denise K. (clinician) • Eleanor O. (patient and family member) • Judy Y. (patient and family member) 	ICSI study overview and enrollment update; review and feedback on revised Jumpstart-Tips videos

	<ul style="list-style-type: none"> • Margaret K. (family member and clinician) • Maureen H. (clinician) • Melissa B. (family member) • Nita S. (patient) • Priscilla A. (family member) • Ron P. (community member) • Stephanie M. (clinician) • Susan E. (guest) • Randy Curtis (faculty, study PI) • Ruth Engelberg (faculty, study co-I) • Patsy Treece (research nurse) • Jimmy Hoard (CAB admin) 	
Sep. 25, 2015 Seattle, Washington	<ul style="list-style-type: none"> • Amy H. (family member), <i>Chair</i> • Adam B. (family member) • Denise K. (clinician) • Diane A. (family member and clinician) • Eleanor O. (patient and family member) • Judy Y. (patient and family member) • Laura N. (clinician) • Margaret K. (family member and clinician) • Priscilla A. (family member) • Ron P. (community member) • Stephanie M. (clinician) • Tracy B. (community member) • Hollis R. (UW administrator) • Randy Curtis (faculty, study PI) • Ruth Engelberg (faculty, study co-I) • Elizabeth Nielsen (study staff) • Sudiptho P. (study staff) • Jimmy Hoard (CAB admin) 	Detailed ICSI study overview and enrollment updates; reviewed and took suggestions on recruitment strategies (attracting more family members into the study). Presentation and discussion of findings from some preliminary baseline data analyses: Patients with higher depression scores and those whose religious beliefs influenced medical care were more likely to have conversations; patients who felt they weren't sick enough were not likely to have had conversations.
Jan. 29, 2016 Seattle, Washington	<ul style="list-style-type: none"> • Ron P. (community member), <i>Cochair</i> • Priscilla A. (family member), <i>Cochair</i> • Judy Y. (patient and family member) • Mara H. (researcher) • Margaret K. (family member and clinician) • Tracy B. (community member) • Randy Curtis (faculty, study PI) • Ruth Engelberg (faculty, study co-I) • Elizabeth Nielsen (study staff) • Sudiptho P. (study staff) • Jimmy Hoard (CAB admin) 	ICSI study overview and enrollment updates; review of proposed qualitative interview questions for comments and feedback (focusing on patients); discussion of low participation by family members (possible causes and contributing factors)
Apr. 29, 2016	<ul style="list-style-type: none"> • Ron P. (community member), <i>Cochair</i> • Priscilla A. (family member), <i>Cochair</i> • Adam B. (family member) • Amy H. (family member) • Bruce G. (clinician) • Catherine K. (community member) • CJ R. (community member) • Denise K. (clinician) • Jennifer G-H. (family member) 	ICSI study overview and enrollment updates; incorporation of feedback about patient interview; reviewing procedures and interview questions for family members (focusing on questions for family members who did not have the opportunity to participate in the main study)

	<ul style="list-style-type: none"> • Judy Y. (patient and family member) • Mary Jane K. (community member) • Maureen H. (clinician) • Melissa B. (family member) • Stephanie M. (clinician) • Valerie T. (community member) • Elizabeth Nielsen (study staff) • Jimmy Hoard (CAB admin) 	
Sep. 16, 2016 Seattle, Washington	<ul style="list-style-type: none"> • Ron P. (community member), <i>Cochair</i> • Priscilla A. (family member), <i>Cochair</i> • Adam B. (family member) • Amy H. (family member) • Judy Y. (patient and family member) • Laura N. (clinician) • Randy Curtis (faculty, study PI) • Elizabeth Nielsen (study staff) • Jimmy Hoard (CAB admin) 	Summary of current ICSI study, including feedback on outcome measures; participation rates, including subject withdrawals; discussion of possible new proposal building on the current study
Jan.27, 2017 Seattle, Washington	<ul style="list-style-type: none"> • Priscilla A. (family member), <i>Cochair</i> • Adam B. (family member) • Amy H. (family member) • Catherine C. (community member) • CJ R. (community member) • Eleanor O. (patient and family member) • Judy Y. (patient and family member) • Katherine B. (clinician) • Laura M. (community member) • Lee B. (clinician) • Melissa B. (family member) • Stephanie M. (clinician) • Randy Curtis (faculty, study PI) • Ruth Engelberg (faculty, study co-I) • Elizabeth Nielsen (study staff) • Jimmy Hoard (CAB admin) 	ICSI study overview; presentation and discussion of findings from qualitative interviews (overall study participation); Jumpstart-Tips form specifics
May 12, 2017 Seattle, Washington	<ul style="list-style-type: none"> • Priscilla A. (family member), <i>Cochair</i> • Amy H. (family member) • Denise K. (clinician) • Judy Y. (patient and family member) • Julie K. (clinician) • Laura M. (community member) • Lee B. (clinician) • Phillip W. (family member and clinician) • Randy Curtis (faculty, study PI) • Ruth Engelberg (faculty, study co-I) • Tami Music (CAB coordinator) • Blair Mills (Cambia PCCE admin) 	Summary of ICSI study: presentation and discussion of sample characteristics and Aim 1's results, indicating an intervention effect