

Appendix 2. Challenges and potential solutions identified in interviews (Numbers correspond to instances of coding; I = investigator interviews; P&FC = patient and family caregiver interviews)

CHALLENGES	CODES PRESENT			POTENTIAL SOLUTIONS	CODES PRESENT		
	I	P&FC	Total		I	P&FC	Total
Justice and engaging diverse participants	32	25	57	Understand what voices you need	1	3	4
				Include more people	2	4	6
Facilitating participation of those with serious illness	29	12	41	Have meetings in the community and/or hosted by trusted community organization - at least initially.	1	2	3
				Use virtual methods to overcome certain challenges (such as travel)	2	10	12
Managing issues of death and illness, including progression	23	8	31	Engage patients before they are too sick	1	1	2
Avoiding paternalism or gatekeeping	12	5	17	Recruit sensitively and unobtrusively	5	9	14
Meeting virtually (i.e. not in person)	3	14	17	Have strong patient personalites	1	0	1
Minimizing burdens	5	10	15	Have support services available (e.g., parking)	2	2	4

Respecting privacy and confidentiality	5	9	14	Set expectations upfront	19	11	30
Managing Expectations	10	2	12	Set expectations upfront	19	11	30
Navigating decision capacity or its fluctuation	7	2	9	Have family caregivers involved to support cognitive limitations	3	1	4
Fairly compensating participants	7	2	9	More money	1	1	2
Knowledge	4	4	8	Vet the list of board members	2	3	5
Respecting participants' time	2	6	8	Give time on the agenda	1	1	2
Clinicians recruiting patients they care for	7	0	7	Recruit sensitively and unobtrusively	5	9	14
Dealing with different communication abilities (e. g., due to neurological illness)	3	4	7	Allow additional time for communication	1	0	1
				Have short or alternative means of feedback	7	11	18
				Have a peer partner to support the participant	3	1	4
Being authentic about engagement	2	4	6	Share feedback back to participants	5	3	8

Finding the right time to recruit partners, including caregivers	2	4	6	Recruit sensitively and unobtrusively	5	9	14
Time	1	3	4	Set expectations upfront	19	11	30
				Seek input in other ways	3	1	4
Providing opportunities for authorship/credit	3	0	3	Have a patient Co-I	1	0	1
				Set expectations upfront	19	11	30
Challenges managing participants' different perspectives	2	1	3	Have short or alternative means of feedback	7	11	18
				Have strong patient personalites	1	0	1
				Set expectations upfront	19	11	30
Cultural sensitivity	3	0	3	Have cultural sensitivity training	0	1	1
How to respond when the patient and caregiver voices are conflicting	3	0	3	Having a joint patient and caregiver together on the team is useful dialogue	2	1	3
Lack of familiarity with technology	2	1	3	Vet the list of board members	2	3	5

Money	1	1	2	More money	1	1	2
Defining ownership over data	1	0	1	Set expectations upfront	19	11	30
				Share feedback back to participants	5	3	8
Challenges engaging a diverse 'community'	1	0	1	Have multiple research sites	3	2	5
Research funding structures constrain engagement	0	1	1	More money	1	1	2
Totals	174	119	293	Totals	68	68	136