

Supplementary table 1: Text and classifications by trial

Application	Text from outline application	PPI included in stage?			Level of involvement			Notes I=PPI provided by an individual M=PPI provided by multiple people
		OL	F	T	OL	F	T	
14	A trial steering committee will be set up to oversee the trial. [...]The panel will also include a Lay person who will act as the patient's advocate.	NS	NS	Y	-	-	TSC	I
15	A patient representative will be recruited via the [...] patient liaison scheme	NS	U	U	-	U	U	I
18	Team expertise: [...] [name] is a lay service user representative.	Y	Y	Y	M	M	M	I
21	The team includes [name], a consumer representative who is chair of the [.....] Research Group.	Y	Y	Y	M	M	M	I
22	Investigators have, and will continue to, collaborate with service users.	Y	Y	Y	U	U	U	M
24	Co-applicant	Y	Y	Y	M	M	M	I
26	Service users have been consulted on this proposal, via the [named research network], and service users will be involved at all stages of the proposal's development and implementation.	Y	Y	Y	R	U	U	M
60	Representation from the [named charity] is currently being negotiated for a patient representative on this multidisciplinary research team.	NS	Y	Y	-	M	M	I
61	Parents whose children have experienced [condition] are represented on the trial steering committee.	NS	NS	Y	-	-	TSC	M
64	<p>We have selected two primary outcomes based upon literature review and consultation with our consumer representative, to reflect health service and patient perspectives respectively.</p> <p>We have identified someone with [condition] who has agreed to be a consumer representative and are currently working with [named charity] to develop an advisory group of people with [condition].</p>	Y	Y	Y	R	R	R	I in OL M after
68	A [condition] user group, led by [name], a health service user representative, is providing patient involvement in the development of the proposal.	Y	Y	NS	R	R	-	M
73	Finally we intend to include people with [condition] & carers in the management of the proposed trial through [named	NS	NS	Y	-	-	M	M

Application	Text from outline application	PPI included in stage?			Level of involvement			Notes I=PPI provided by an individual M=PPI provided by multiple people
		OL	F	T	OL	F	T	
	research network].							
74	[...] a service user who can provide a user perspective	Y	Y	Y	M	M	M	I
75	A patient representative will be part of our team to help us regarding recruiting patients and assessing their attitudes to this novel approach to reducing the [condition].	NS	NS	Y	-	-	M	I
77	Other areas of expertise will be invited on to the full steering group, including [...] a consumer panel. A panel of service users will be asked to help with the design of the study and the patient information sheets.	NS	Y	Y	-	R	TSC R	M
81	The [named] Society has expressed interest in this proposal, and will be involved as a co-applicant. Their continuing input will be sought during further protocol development, study meetings and representation on the trial steering committee. They would also be involved in organising community workshops and dissemination of information related to the study.	NS	Y	Y	-	M	M TSC R	M
83	The TSG will incorporate lay representation	NS	NS	Y	-	-	TSC	I
3	We will recruit users of the services onto the Steering Group. Thus, we will ensure that the interests of all parties and the views of the public are fully represented in the conduct of the study.	NS	NS	Y	-	-	TSC	M
4	The research advisors (consumers) from [named] Research Partnership will provide advice on: participant recruitment, design of information leaflets, invitation letters, design and administration of outcome assessment tools and dissemination of results.	NS	NS	Y	-	-	R	M
5	We have identified consumer representation from participants in our previous [condition] studies, and one, who will be a grant applicant, has commented on the application, trial design and study documentation. We have identified consumer representatives to ensure that patients' views are incorporated into the design from the start.	Y	Y	Y	R	M	M	M

Application	Text from outline application	PPI included in stage?			Level of involvement			Notes I=PPI provided by an individual M=PPI provided by multiple people
		OL	F	T	OL	F	T	
29	Service user input will be organised through the [named] Service User Group [named lead]. Initial discussion with service users has contributed to the study design and summary in plain English, and for the study they would develop a brief, self-rated scale for participants regarding attitudes to the [intervention].	Y	NS	Y	R	-	O	O=scale development M
31	In preparation of the full submission a patient representative will collaborate on the design (e.g. in helping to clarify the value of a qualitative component) and ongoing management of the trial. [Name] has good links with INVOLVE and a range of patient interest groups and we greatly value the positive contribution this makes in improving our research.	NS	Y	Y	-	R	M	I
32	We will include people with [condition] and carers in the management of the trial through [named charity] and [named] Services Development Centres.	NS	NS	Y	-	-	M	M
34	[Name] is a lay service user representative.	Y	Y	Y	M	M	M	I
88	The project will be overseen by a steering committee (including a user representative)	NS	NS	Y	-	-	TSC	I
93	We will include users and carers in all aspects of the study with the help of [name] from the [named] Society and [named academic with PPI role]. Patient involvement has already been established and will be fully integrated in to each stage of the project and facilitated and supported by [named individual from Society] and [named academic with PPI interests]. Other formal collaboration with patient/carer groups (e.g. [named society, named charity]) will be established to seek further involvement and to ensure that the project is underpinned by the patient and carer voice.	NS	Y	Y	-	U	U	M
94	[Patients with condition] have been consulted as expert patients throughout the pilot study and [patients] involved in the pilot would be invited on to the steering committee of the proposed trial.	Y	NS	Y	R	-	TSC	M
96	Ethical & other issues will be fully discussed with patient representatives & their input will be incorporated into the	NS	Y	NS	-	R	-	M

Application	Text from outline application	PPI included in stage?			Level of involvement			Notes I=PPI provided by an individual M=PPI provided by multiple people
		OL	F	T	OL	F	T	
	final trial design.							
36	Our trial team includes patient representative and Dr [name]. The protocol, and in particular the patient information materials, have been designed with feedback from our patient and carer group.	Y	Y	Y	M	M	M	M
37	Our team is enriched by carer involvement [initials] who [experienced intervention]	Y	Y	Y	M	M	M	I
39	The other members are: [name1] (Carer, named local research network), [name2] ([condition] survivor, named local research network). [name3] and [name4] are the leads for service user involvement within the [named local research network] and [name2] (condition survivor) is a member. The National [name] Research and Development Forum will contribute.	Y	Y	Y	M	M	M	I
41	We will utilise public involvement in the design of the study, ethical evaluation, and in the development of the interventions.	NS	Y	Y	-	U	U	U
43	Service user rep from [named organisation]	Y	Y	Y	M	M	M	I
45	The trial will involve users from the outset, a user representative is a co-applicant on the grant and has inputted into the design of the study making it more appropriate and relevant to the needs of participants and will meet on a regular basis with the other co-investigators to manage the study. There is also a user representative on the Trial Steering Committee.	Y	Y	Y	M	M	M TSC	M
46	The chair (yet to be appointed) of the newly formed national [condition] consumer group, will also be invited as a consumer expert on to the team.	NS	Y	Y	-	M	M	I
50	We have had informal contacts with service users, carers and voluntary sector organisations in putting together this outline. If we were to be shortlisted we would work closely with local and national user and carer groups to ensure that the protocol reflects the needs and views of consumers.	Y	Y	NS	O	R	-	M

Application	Text from outline application	PPI included in stage?			Level of involvement			Notes I=PPI provided by an individual M=PPI provided by multiple people
		OL	F	T	OL	F	T	
52	Service users have been involved in the preparation of this proposal and would play an active contribution to each of the remaining stages of the project through participation in a project advisory group.	Y	Y	Y	U	R	R	M
54	A postal survey of potential participants, about the proposed trial, is underway. A public involvement advisory group will be constituted and consulted if a full proposal is requested. Further meetings of this advisory group will be arranged 6-monthly.	NS	Y	Y	-	R	R	M
55	The research team includes [...] and people who suffer from [condition]. Patient representatives have been very much involved in the preparation of this bid since its inception. [Name] is a [condition] sufferer who has helped on our Steering Committee for the trial and is a co-applicant. The National [condition] Society has been very supportive of this project and has identified a panel of 6 of their members who will provide independent advice on key discussions, such as who should be included and the most appropriate outcomes to be used.	Y	Y	Y	M	M	M/ TSC R	M
56	[Name] has an academic interest in patient/carer representation, and is the current chairman of [name], a charitable organisation advocating consumer issues in [condition].	Y	Y	Y	M	M	M	Co-applicant I
97	In addition the trial has been developed in discussion with the [named] Clinical Studies Group.	Y	NS	NS	O- CSG	-	-	U
98	We have already appointed an independent trial steering committee ([...] and lay representative, [name], [healthcare professional] and [experience of condition].	NS	NS	Y	-	-	TSC	I
101	The study will be piloted and refined with users	NS	NS	Y	-	-	O	-refined with users M
104	A former patient will represent the patients' views on the study team.	NS	U	U	-	M	M	I

Application	Text from outline application	PPI included in stage?			Level of involvement			Notes I=PPI provided by an individual M=PPI provided by multiple people
		OL	F	T	OL	F	T	
110	This outline has been reviewed by a non-medical lay service user [name]..... We will establish a lay user review group who will have active input to the developing proposal during the exploratory phase. Costs of convening that group along with appropriate honoraria will be met from the project budget. The group will have opportunity to comment on the proposal, suggesting amendments and modification in the light of their lived experience of access to [named services].	Y	Y	Y	R	R	R	M
111	A survey of potential participants to gauge interest in [intervention] and willingness to enter the trial	Y	NS	NS	O	-	-	M
112	The Project Steering Committee will include [...], and links are in place with self-advocacy organizations ([3 organisations listed]).	NS	NS	Y	-	-	TSC	U
115	[Name] of the local Service User Research Forum has contributed to the proposal.	Y	NS	NS	O	-	-	I
116	The involvement of service users in this research is key and [name] with the [named Trust], the largest voluntary organisation working with parents in the UK, is a member of the co-applicant group. Other service users will be invited to be members of the steering group for the study. We will use the INVOLVE good practice guidelines regarding user involvement in the design; oversight and dissemination of the research (see http://www.invo.org.uk/).	Y	Y	Y	M	M	M	M