**Contract PPI Information**

Table: Details of SSAG meetings

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| --- | --- | --- |
| **Date** | **Topic covered/activity planned** | **Output/learning** |
| 9 July 2016 | * Explanation of the project * *Explain why we want children, young people and parents to feed in to this project* * *Explain previous work around this project, and international trial* * Slight explanation of PPI * Specific questions to inform project * Show examples of recruitment videos already developed * Participant information sheets * Models and methods for working together * Training needs * Plans for future PPI work * *Explain that we want to get the group together in late August next and plan to have more people. Would they be willing to come together again to do this?* | * Lots of time spent developing rapport and establishing relationships * Learning about research method, appendicitis, appendicectomy and related info (SSAG members) * Attitudes to similar example recruitment videos, and suggestions for what to include in bespoke recruitment video for CONTRACT * Strong suggestion: Offer potential participants can watch video on tablet * Change age groupings of information sheets, language in both CYP- and parent information sheets * Plan for working together in subsequent meetings – all organized through PPI co-investigator, blend of locations. People happy to work in a group. |
| 23 August 2016 | * Quick re-cap of the project * *Explain the project again, as a reminder to those who were there last time, and an introduction to those who were new.* * Participant information sheets * General brainstorm around the room * Explain the use and necessity for the PIS. | * Lots of questions about the nature of appendicitis, and clinical decision-making around referral to surgery or antibiotics, and nature of participation in the study * Happy with the idea of information sheets along with a video to support decision to participate in trial * 12 – 15 year old version of the most liked, has the best level of information. Offer potential participants the option to look at all information sheets * Lots of ambitious ideas for a recruitment video, but many would be too costly, or take too long to produce, or simply not feasible * Group works well with some CYP who have had appendicitis, and some who have not * Study team to work on recruitment video script, and share with group electronically |
| 1 October 2016 | * Quick re-cap of last meeting * Randomisation study: Participant information sheets and video to feedback * *Distribute printouts of information sheets as an FYI, ask if there are any major concerns or omissions, otherwise will plan to submit these versions to ethics* * *Show video* * Qualitative research * Short introduction * *Short verbal background to the qualitative component of the study, why we’re doing it, what it aims to find out* * Topic guide for discussions * *In a whole group, go through topics included in the topic guide so far, specific questions to ask?* * *How can we make the interviews as young-person friendly as possible?* * *Can you suggest any techniques for making the interview more of a conversation as opposed to a formal interview?* * *Feedback questions: Are they comfortable with these questions? Is there something missing?* * Information sheets * *In separate groups (parents vs young people), read and go through information sheets. How is the language? What would they add or take out? Thoughts on young person booklet? Are they happy with the assent procedure we have planned?* | Suggestions for recruitment video:   * About 2-2.5 minutes is right length. * Should start with PI doing a video introduction that should get across the following points:   + Reassurance that being in the study is safe, not putting their child at risk   + Acknowledgement of the situation families are in   + Study is happening elsewhere too   + Treatment with antibiotics has been successful elsewhere   Then animated section that should:   * primarily explain what being involved in the study would involve * if describing the risks and benefits then this may be better as a conversation rather than animated, but not completely necessary to have that part in video as will be discussed and is on info sheet.   Compared to the animated video that was shown we should try to   * Have less ‘action’ as it detracts from the message * Use colour better * Voice-over should be adult not child although older sounding child could be used * Voice-over should be female * Should explain recovery in both arms better   Recommend final video section   * What happens next – have discussion ask questions, get info sheet * Mention whether involved or not it won’t affect treatment * Lots of time also spent on the information sheets. Advised to not use the word, ‘interview’ anywhere in qualitative study information sheets. Do not like coin tossing analogy to explain randomization. Do not like confidentiality statement, can be much shorter. Same with compensation statement, which should be moved further up the sheet. Suggested a simpler flow-chart than clinical flow-chart that was in the sheet. Add contact details. |
| 19 April 2017 | * Update on the project * *Showed the final approved recruitment video* * *Handed out the final approved study materials (the information sheets for 8-11 year olds, 12-15 year olds, and parent versions that we’d worked on last year together as a group)* * *Updated on the recruitment to the study so far, which at the time was 11 children* * Core outcome set * *Project will next include a lot of work around developing what’s called a ‘core outcome set’. There is good information about this on the COMET website:* [*http://www.comet-initiative.org*](http://www.comet-initiative.org)*. A core outcome set is an agreed group of outcomes that should be assessed in a given condition, in every study about that condition, especially when looking at a treatment or intervention for that condition. There is excellent information here about what a core outcome set is, and how research can go about developing a core outcome set, like what we want to do next in the project:* [*http://www.comet-initiative.org/ppi/patientsandpublic*](http://www.comet-initiative.org/ppi/patientsandpublic)     Materials from COMET website   * *Invitation letter to participants for COS online questionnaire* * *Wording about outcomes* * *Student project on what people understand about appendicitis* * *Plans for future PPI work* | * Lots of time was spent on explaining core outcome set development. It was a difficult concept to convey, and although at first we thought it had been grasped, once we started working on the wording of outcomes, and definitions, it became apparent that young people did not actually understand. We spent more time on this than we had anticipated, as we had a long list of outcomes to consider, and the meeting went very quickly. * Review of the information for the COS Delphi process went well, with helpful changes suggested by CYP and parents both. |
| 9 September 2017 | * Update on the project   + *Update on recruitment numbers for main study*   + *Update on qualitative study*   + *Publication in BMJ Open (Erin to hand out copies)* * Re-cap from last meeting * Core outcome set development   + *Continuation from last time, look at outcomes that are going to be scored*   + *Presentation of the COS sub-study draft video*   + *Draft website materials – registration page, instructions, directions* * Plans for future PPI work | * Since the last meeting, the team published an article in BMJ Paediatrics Open, about the protocol for the Core Outcome Set development (doi:10.1136/ bmjpo-2017-000151). All SSAG members were given a copy. This was a good training opportunity for the group, to learn about dissemination and how the peer review process works. * Group was informed that recruitment to main trial is at 25 participants, and feedback about the participant information sheets has been positive. * Qualitative study is going well, and now halfway finished. * Lots of time was spent going over the animated video that will be used to recruit surgeons, parents and CYP to the Delphi process for the COS sub-study. The group suggested more changes than the study team had expected but provided constructive criticism that was then used to improve the video. The study team embraced these critiques as it hopefully showed the CYP felt empowered to offer their true opinions. The final video is here: <http://tinyurl.com/contracthta> The COS registration website was shared with the group, which had been built based on work at the previous SSAG meeting. The group was happy with the content and tone of the website. |
| 9 December 2017 | * Re-cap from last meeting * Update on the project   + *Update on recruitment numbers for main study*   + *Update on qualitative communication study*   + *Update on COS work* * Dissemination plans (Nigel and Erin)   + *How do young people want to disseminate this? Video? Writing?* * ‘Guess who?’ game | * This meeting was largely to update the group on the various elements of the study, to start discussing the dissemination plans, and have a fun end-of-year social and as such was hosted in London. * The group was happy with any plans for dissemination. As the study wouldn’t be finishing for 11 months, it was difficult to speak in concrete terms, but the group agreed they would be happy to contribute to writing outputs, podcasts, and/or a video. * The meeting ended with a game which helped reinforce morale, and group spirit. |
| 24 July 2018 | * Re-cap from last meeting (Erin) * Update on the project, and COS questions (Nigel)   + *Update on quantitative and qualitative studies*   + *Questions about COS work – troubleshooting problems with engaging stakeholders* * Dissemination plans (Nigel and Erin)   + *How do young people want to disseminate this? Video? Writing? Where should we disseminate?*   + *Reflective writing task – List and write a bit about what you’ve liked, what you haven’t liked, and what you’ve learned so far, doing this PPI work* | * As it had been nearly 8 months since we had met in person, this meeting focused on group morale and updating people on study developments, for each part of the study. * At this point the COS sub-study was experiencing difficulties with retaining CYP in the Delphi process. The group were asked their opinions on offering financial remuneration as an incentive to complete the final Delphi round, and they unanimously agreed it would be an appropriate and likely helpful approach. The PI subsequently applied for an ethics amendment to the COS sub-study, and this was permitted. * We discussed again dissemination plans, and started to manage expectations that the study would soon be ending, although made it clear we would want to work with the SSAG after the study was officially closed, on dissemination products. |

Future activities

As mentioned in the main report, we are planning two further face-to-face meetings with the SSAG, to co-produce dissemination materials. We will defer to the opinions and preferences of the group members, but anticipated dissemination products will be another animated video, a conference attendance with one or two members of the SSAG and at least one manuscript co-authored by a member, or members, of the SSAG. One young woman who is now at university has expressed a keen interest in co-authoring a manuscript for publication, which she recognises would be advantageous for her curriculum vitae.