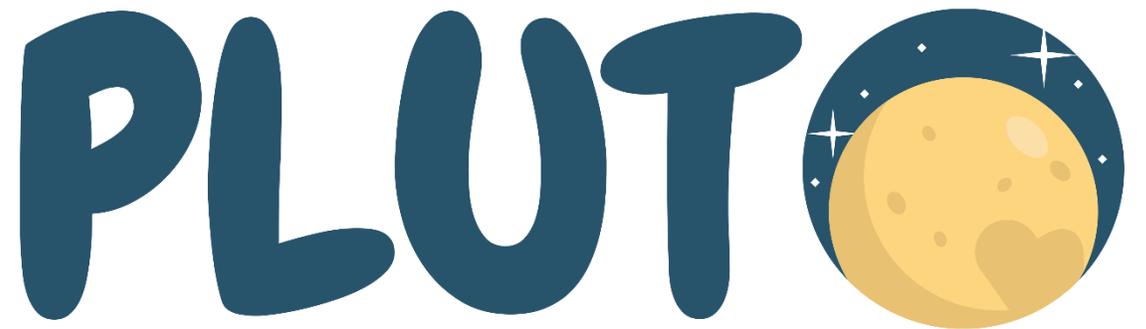
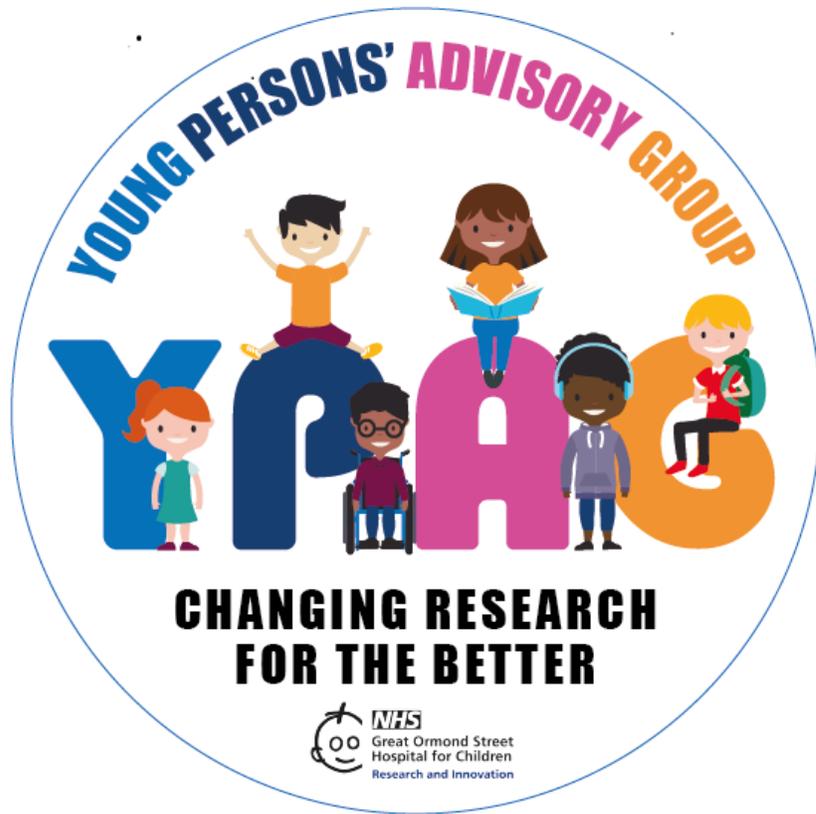


How involving a YPAG can IMPACT on a Clinical Trial



Plasma-Lyte Usage and assessment of
kidney Transplant Outcomes in children

How the PLUTO team reached out to YPAG

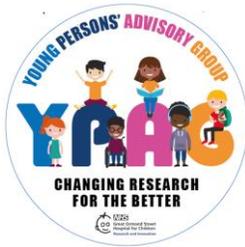


*“We are working on a trial looking into which fluid to use during a kidney transplant operation. The trial is called **PLUTO** which stands for ‘**P**lasma-**L**yte **U**sage and kidney **T**ransplant **O**utcomes in children’.*

We received funding for this trial from the NIHR and are now working on the protocol and information sheets. We’d really like to come to one of the London YPAG meetings and discuss the trial, the information sheets and other things with the group. Would this be possible and if so, when are the next available meetings? We’re hoping to submit to the ethics committee later this year and start recruitment in early 2020”

Top Tips v

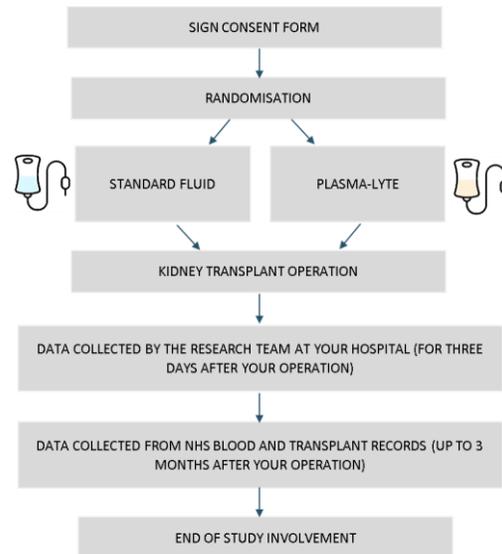
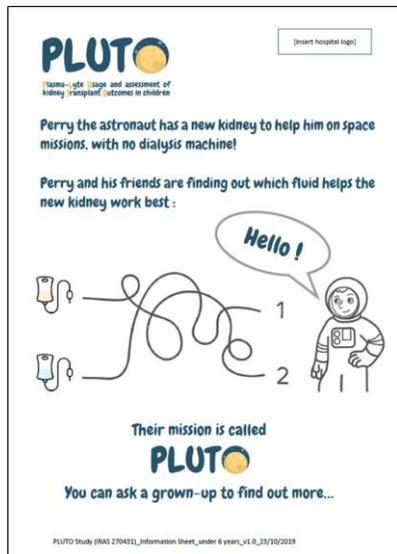
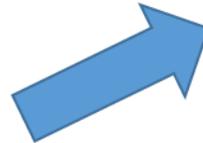
- Give a Plain English summary of your research trial or project
- Contact YPAG’s early – before you finalise your Patient Information Sheets!
- Think about what you want from the YPAG and how you want to work with them: the PLUTO trial team used both online and face to face to get feedback and input
- Tell us about your timescales and keep us updated – we like to know how you are progressing
- When you come to a YPAG meeting make sure you fully inform the group about the project – explain terms and be prepared to answer questions!
- Only by understanding your project properly can YPAG’s make an impact on it’s design and delivery



Where did the YPAG impact on the Trial?

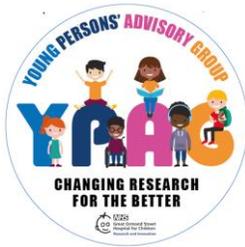
1. Patient Information Sheets

"The YPAG were consulted (via email) on the design and content of the participant information sheets (PIS) and had made some really helpful suggestions"



1. Suggestions for the Patient Information Sheets:

- Change some of the words to make them more understandable
bloodstream → blood
- Explain what we mean by ‘anonymised’ data
- Explain whether children who take part will know which group they are randomised into
- Make the under 6 PIS a fun one!
- Add a flowchart diagram

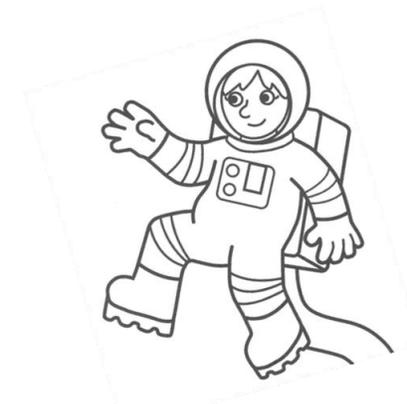


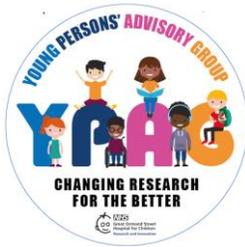
Where did the YPAG impact on the Trial?

2. Giving ideas and suggestions for a storyboard for a short video to help children better understand the PLUTO trial

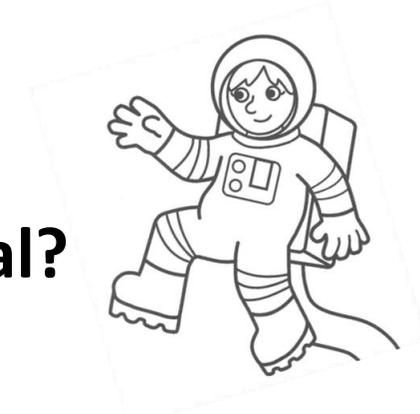
*“The PIS were subsequently submitted to the Research Ethics Committee (REC) who were extremely complementary, and commented that **they were the best examples of young person’s information sheets they had reviewed.** We are enormously grateful to the YPAG for their help in developing the PIS.*

During this face to face session, we will present the PLUTO study, followed by a brain storming session to discuss ideas for a short video that we could use for children to better understand the PLUTO trial. We will ask the group to think of a story board, and discuss some questions.



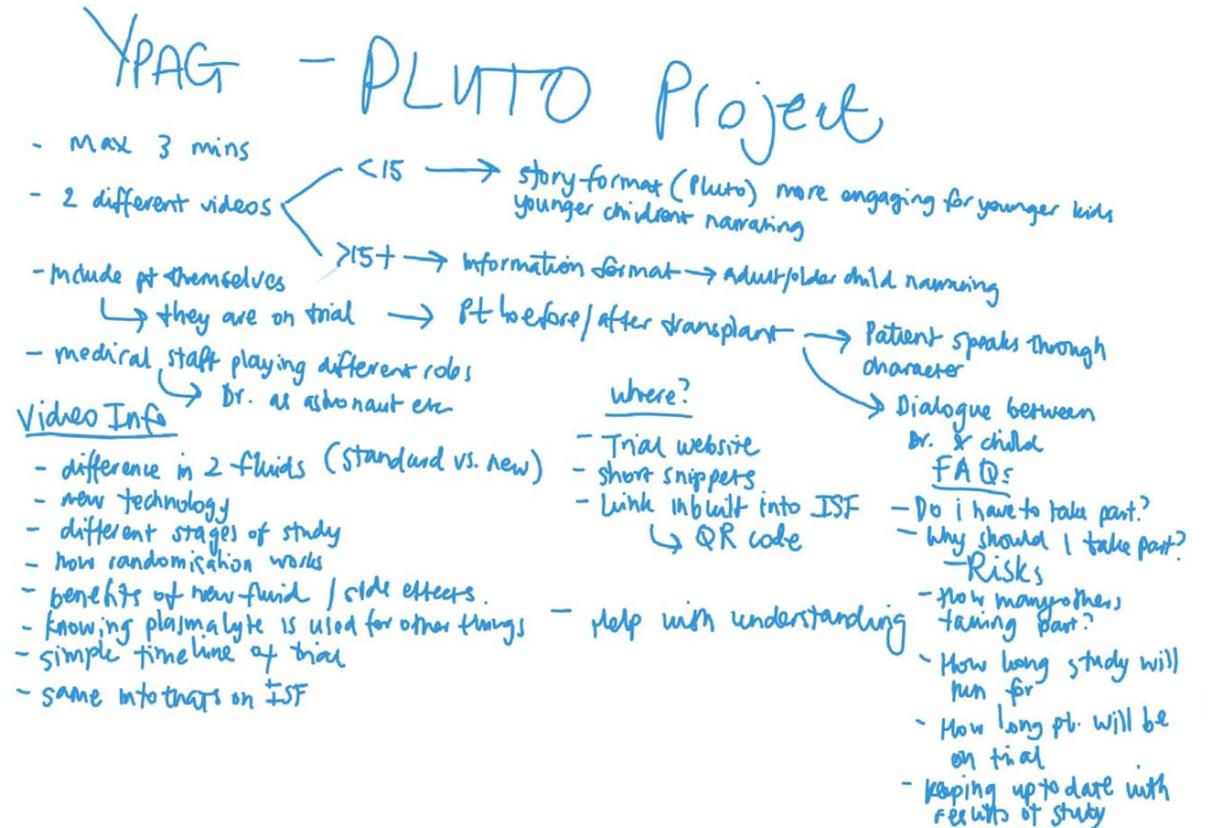


Where did the YPAG impact on the Trial?



2. Giving ideas and suggestions for a storyboard for a short video to help children better understand the PLUTO trial

- How can we best describe the study?
- Should it have a theme e.g. Pluto/planets etc
- What people/characters should we include?
E.g. doctors, nurses, child and their family
- Who should talk/narrate the video?
- What information should we include?
- Are there any important images we should include?
E.g. kidney, fluid bag etc.
- How long should the video be?
- Any other good tips for a video?
- Where should the video be found?
- Do you think children/young people will watch it?"



Next Steps & closing the loop on YPAG Impact

*“The support from the YPAG and their suggestions for both the design/content of the PLUTO information sheets and ideas for a PLUTO video has been fantastic and very useful. We have been tremendously impressed with how engaged, thoughtful and considered the feedback has been. Suggestions from the YPAG have already been included in the final REC approved information sheets. Our aim is to incorporate the design ideas for the video into a test version which **we would like to seek the YPAG’s feedback on in due course.**”*

“We’re very grateful to the YPAG for their help designing PLUTO study information resources. The study is now up and running with good feedback from families so far”

*“We are in the process of drafting a manuscript to publish the trial protocol, and **want to acknowledge YPAG input** and we will send it to the YPAG once published:*

Our thanks to the NIHR Great Ormond Street Hospital Young Persons’ Advisory Group for research (YPAG) who co-designed patient information resources.



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