

Q & A with Greg Sebepos-Rogers

Questions	Answers
How would participants send in samples?	We would send pre-stamped envelopes and sample bottles for the stool and saliva samples, along with instructions.
I have an ileostomy - would that make it easier to sample small bowel fluids?	We haven't factored stomas into our project, but this is certainly something we should consider. In theory sampling would be easier but it would probably be best done via endoscopy (stomoscopy) rather than a sample from the bag, to ensure consistency with other samples.
Is the same info available from the testing if you are not having a flare up?	Thank you and very relevant question. The evidence about generated organoids suggests they are less likely to survive when the starting sample is inflamed rather than healthy bowel. As a result, our default strategy is to sample healthy looking bowel at endoscopy.
Will the subjects receive any feedback?	We do not plan to give any specific individual feedback about the organoids as they will not be identifiable/link to patients once they enter the lab. However, we aim to publish in papers and hopefully return to PPI Day next year to update.
What if my local hospital undergoes research works with the London hospitals, can we be involved?	Thank you very much for your interest. As we are limited by our current ethical approval, we can only recruit if your primary care where you have your endoscopies and bloods (for example) is at the two hospitals (University College London and Royal Free Hospital). If the research progresses well, we would of course like to reach out to other centres in the future but currently this is not within our ethics approval. Thanks.
I don't really trust cloud storage, so not convinced that it can't be 'hacked'.	Thank you for this. I am with you in always being sceptical about data safety. The 'Data Safe Haven' hosted by UCL is designed to be very safe with numerous checks and balances plus auditing of

	<p>access. In order to even log in, I have to go through 4 different steps. It's impossible to give guarantees but it seems secure and is the 'gold standard' for research data storage compared to PC hard drives and paper. Hopefully that's somewhat reassuring for you.</p>
<p>Is it likely the mini guts model could be used in the future for researching other IBD clinical research outside of this project?</p>	<p>Yes, we would like to ensure this mini-gut model can help academic research more widely. There will be strict checks and balances about this, but we would hope that the benefits of this research can be shared widely.</p>
<p>Would the organoids trial be able to inform dietary requirements e.g. I believe some gums used as fillers in processed foods can impact the epithelial cells lining the intestine?</p>	<p>There is a technique to test epithelial barrier resistance which can be considered but we are unaware of any techniques (as yet) to test dietary emulsifiers etc. Certainly something to consider in the future as the organoid technology matures.</p>