CROHN'S & COLITIS UK

Q & A with Iman Khwaja

Questions	Answers
What about diet - pain reaction?	There are a few questions in the surveys which touch on dietary aspects, however this area can become very in-depth and unfortunately is currently beyond the scope of this study.
I've never experienced pain with my UC (over 40 years) and subsequently from a stoma - embarrassment (sometimes acute), frustration and all sorts of other psychological effects. Will you make a study of those with my type of involvement?	There are many questions in the surveys about psychological aspects, but we are mainly looking at how this might affect pain for the time being. Just to clarify - you don't need to experience pain to be in the study! Some people will go on to develop chronic abdominal pain and others won't, so it's useful for us to have data from both groups, to be able to make comparisons.
Re newly diagnosed, are you selecting only recently being acute - it does not mean the IBD only just started - what about those who have had symptoms for several years and told IBS, then diagnosed and found to have existing strictures etc so long-term undiagnosed disease? Their pain etc will be usual for them - so this will not be the same as those diagnosed early in the progression of the disease.	This is a great point and needs to be considered when interpreting results. However, due to the fact that we overlap and collaborate with the IBD BioResource Inception study to collect biological samples, we must adopt their same inclusion/exclusion criteria. The Inception study only recruits newly diagnosed IBD patients.
Our 16 year old son has Crohn's, diagnosed aged 11. We think he may also have ADD. I wonder whether undiagnosed ADD/ADHD would influence pain/stress/anxiety of Crohns and also results, which would not give a clear outcome for research.	This is a great point. We do ask about any known comorbidities to try to get an idea about what else might be having an effect. However, undiagnosed/unknown comorbidities will be difficult to assess.
Re the phone sampling, you are excluding participants who can't have their phones on them when at work etc.	While there are 10 random timepoints, realistically we understand that not everyone will be able to make every single one. We do discuss with patients before enrolment about this app and answer any questions they may have, so we would expect something like this to come up in that conversation. Then we would be able to

	decide on a case-by-case basis if the study is really feasible for the participant in question.
Has the research programme considered the issue of random times being problematic due to availability of phone signal? If out of signal will the random time 'stack' and wait for a signal?	While there are 10 random timepoints, realistically we understand that not everyone will be able to make every single one. So if a participant's phone doesn't have signal for a certain amount of time (for example, while on the tube, etc), they would just skip any timepoint which came during this period and wait for the next one.
How long do you have to respond to each 10 random times? e.g. as a teacher I would have to wait until break or lunchtime / hometime.	There questionnaires will remain open for about 15 minutes. If this window is missed, then the questionnaires will lock and the participant will have to wait until the next timepoint. Realistically we understand that not everyone will be able to make every single timepoint, so if something like this happens from time to time, it is okay.
Smartphone use might limit sample group to younger people happy to use this method. Online might work for more people.	Yes, this is a natural limitation of a study which employs digital methods of data collection - even online data collection would limit sample group. This will have to be kept in mind when interpreting results.
Perhaps an email reminder for the questionnaires won't be enough to prompt participants to complete them. Will you do other reminders too? It would be a shame if you won't have all the data you need in the end.	Before the participants take part in the study, we have a video call with them to explain the procedures etc. This also serves the purpose of establishing a relationship with the participants. We also have regular contact with them throughout study periods. We would hope that due to these factors, participants would be responsive to e-mail reminders from us, however it is always a possibility that some participants may be lost to follow-up.