

Colleen Ewart - I was involved from the proposal development stage of this project by the lead, Professor Kapil Sayal. It's still easy to forget on a new project that you are there because of 'lived experience' when faced with a new group of academics/clinicians. The appointment of Dr Alex Lang, an experienced PPI co-applicant was 'key' in helping me to navigate the unfamiliar and enable me to flourish in my role.

My first task was to consult a group of young people about a STADIA logo!



This was a significant task creating a visual identity for a 4 year project. I had never done anything like this before. Using my community contacts I set up a workshop to rank the fourteen logo options. I had no budget for this activity so prepared in advance a personalised certificate, thanking them from STADIA for their valuable contribution. These were well received. The shortlisted two logos were voted upon by the Trial Management Group.

The next task quickly followed; convene a parent/carer consultation to feedback on six documents (questionnaires/information sheets).

I returned to the parent/carers of the young people I had consulted about the logo. I had taken the opportunity to deliver a presentation to them on the same day. This group provided insightful and clear feedback in readiness for our ethics submission. This early work enabled me to build trust and rapport with a group steeped in 'lived experience'. I have recruited our 'core' parent/carer advisory panel from this group.



The recruitment of the young person's advisory group has proved to be so much harder. This cohort is more fragile due to their ongoing health challenges. Recruitment has been spread across numerous contacts which has proved to be 'long winded' and not often successful. Time spent building rapport has been 'key' and I am so grateful for their trust, engagement and wisdom.

Working in partnership with Alex has led to a number of opportunities. An invitation for us to co-author a book chapter in a volume exploring contemporary issues in Ergonomics. It's been an amazing experience to translate my involvement and knowledge of PPI activities within STADIA for an international audience. In addition we have now been invited as joint co-investigators to contribute to an international panel session on PPI at the U.S Human Factors & Ergonomics Society Congress 2020.

Ellen Bradley - The STADIA team have been trialling a novel application of Patient and Public Involvement (PPI) in developing and taking part in researcher recruitment. During the process of being recruited onto the study as a Research Assistant, I went

through a PPI-led process, which consisted of a role-play scenario being presented at the interview stage. There were a number of scenarios developed for this purpose, and I was tasked with enacting a phone call with an overprotective parent who wanted to complete the questionnaire on the young person's behalf. The parent in this scenario was played by Colleen – I believe that it is vital to have someone who has lived experience to take on this sort of role, and her insights made the role-play much more realistic. From my perspective, this was a very useful activity not only for the recruitment panel, but it also gave me a much clearer sense of what the role would involve, and an opportunity to demonstrate skills that would normally not be assessed in a standard interview process.

These first 18 months of STADIA have seen real integration of PPI throughout multiple work streams of the trial. The coming months will see the PPI leads, research team and advisory panels focussing on a range of communication outputs and knowledge transfer activities.

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