

How did you identify use / need for app?

I have been inspired for a long time by the prospect of citizen research - when I was interviewed for the job I mentioned that the RSPB manage to get people into their gardens to spot birds once a year and that this is now forming some interesting data. Surely there should be something similar for public health?

Concurrently we have seen an explosion in the 'measured self'; people collecting all sorts of data about their behaviours performance and laterly their health.



Being a cyclist my cycle computer not only tells me how fast I'm going but also has a wealth of data to review afterwards. Of course in this connected world I can share that data too. Now all sorts of medical devices connect to us to record, collate and interpret data. However in the research world we are poorly placed to do anything with this data, and in the medical world we are reluctant to connect this data with medical records. Here there was general reluctance to engage with anything mobile - in fact a positive warning away from this area. This was based on a lack of appreciation of how technology and data had changed to be more personalised, of how these things are no longer in the domain of 'experts' and are now in the palm of every citizens hand or strapped to their wrist.

I knew that we had to make progress in this area or we would be doing a disservice to the public in not allowing them to contribute to research in this way. A key sticking point was the issue of consent. We had been approached by pharma companies who were mulling over this particular issue. Our CEO mentioned this in passing that he had discussed the issue of eConsent. I had also been doing some preliminary work with Apple's then newly released '[Research Kit](#)' which included a tailorable eConsent process and suggested that I show this to CEO. He was enthused by the process. I suggested that we develop an app to test this process and he suggested capturing something non contentious like capturing 'step' data.

Who did you speak to get started?

No one. Due to the sensitivities around this work I downloaded the Apple Research Kit frameworks and worked my way through their processes. I investigated and modelled the process involved and found out what parameters we could call from an iPhone and how the data should flow. Its important to note that Apple's Research Kit is 'Open Source' and freely available. There are also versions for Android. I designed and developed the process through using the Research Kit frameworks - effectively 'storyboarding' the app. We then opened a

discussion with the Leeds Institute for Data Analytics (LIDA), part of the University of Leeds about hosting a secure database and developing the link between the app and the underlying databases - this is known as the Application Programmer Interface or API

How did you find a designer / developer to create the app?

We cast out to several app developers with our design. We realised that an app developer would be able to deliver the expertise we would require focused around our design. We made very little variation into the area of 'custom' design. This kept the process short, focused, and cost effective. Its important to recognise that sometimes we have the design skills in house and do not rely on 'consultants' or external design teams. We made our choice of developer based on track record and their approach to project management.

Did you have any regulatory or technology issues that were unexpected?

Data security and information governance is key. There is a lot of (understandable) nervousness about such technology capturing data. We've had it confirmed that the consent process we follow is robust and puts the user in control of their data. It is the security and handling the data that creates the concern. As the approach is novel it is seen as completely new - which it is not. For a long time we have captured data on paper forms then hand transcribed the data into data bases. We need to appreciate the difference of sending data directly from a device and the added ability to put the participant in control of their participation.