



DeepMind Health

**Co-designing a patient and public
involvement and engagement (PPIE)
strategy for DeepMind Health**

Mustafa Suleyman

Rosamund Snow

DeepMind is a British technology company that I founded with two of my friends in 2010. We set up the company to help build machine learning systems, and then use these technologies to help make the world a better place. We joined forces with Google in 2014 and as founders we remain committed to using the technologies we develop to tackle some of society's greatest challenges.

In February 2016, we launched DeepMind Health. Our team were confident that we could deliver improvements in patient care by drawing on our expertise in digital technologies and machine learning. By spending time in clinics and on hospital wards, we identified areas where there is potential to have real impact. Our first projects have centred on how we can identify acute kidney deterioration earlier and improve diagnosis of sight threatening diseases on retinal scans. These initial projects were brought to us by frontline clinicians who were frustrated by the inadequacy of the paper-based systems and outdated desktop digital tools they use today. Through our work we have also met patients like Michael Wise and Elaine Manna (speakers at our [September event](#)) who were passionate about making a difference to diseases that had personally affected them.

Going forward I am committed to involving patients and carers more meaningfully in the work we do. Having spent time with many patients and advocates over the last couple of years, I was struck by Rosamund Snow's perspectives on how research groups and organisations could work better with patients and other service users. Rosamund agreed to spend time with DeepMind Health to provide recommendations on how we put patients at the centre of the work we do.

Rosamund has made some fantastic initial suggestions and we now want to open up the discussion to the wider patient community. If you would like to contribute further then there are a number of ways of doing so.

- Initial feedback on Rosamund's recommendations can be made [here](#)
- If you would like to join one of the independently run consultation events discussing Rosamund's recommendations in more detail please register your interest [here](#)
- We'd also like to start to understand who might be willing to provide feedback on new projects. Please register your interest [here](#)

Thanks for the really helpful feedback so far and I look forward to working with many of you in 2017.

Best wishes,

Mustafa Suleyman
Co-Founder of DeepMind and Head of Applied AI

Recommendations on patient and public involvement and engagement (PPIE) at DeepMind Health

Rosamund Snow

Introduction

I have spent a good number of years being “the patient” in various patient involvement and co-design initiatives, and I’ve seen both poor and excellent practice. Whilst progress has been made in that, sometimes, patients now have a seat at the table, very often our contribution can still feel tokenistic and not respected as much as it should be. I know we have a lot more to contribute, if we are only asked to do so.

Although DeepMind is a relatively young organisation the technologies it works on have the potential to make a big difference to our lives. The launch of DeepMind Health and the subsequent projects that have been announced have been covered widely in the press and received a lot of scrutiny and comment.

I first met Mustafa about four months ago. He has a background in charities and advocacy groups and wanted to bring this experience into how DeepMind Health works with clinicians and patients. Whilst it was clear from our initial meetings that DeepMind Health has built very strong relationships with nurses and doctors there was a need for more meaningful input from patients and carers in projects going forward.

Mustafa set me the challenge of helping define what DeepMind’s PPIE strategy should look like. In doing so, I have drawn on my own experience of the many groups and events I have contributed to, the shared wisdom of other patients and carers I’ve worked with in the past, and the detailed valuable feedback that people sent in following the DeepMind PPIE event in September. I have also spent many hours observing and interviewing the different ‘specialities’ of people working at DeepMind Health in an attempt to understand how the patient’s voice might have most impact within the organisation.

However, although I hope I’ve made recommendations that other patients and carers will welcome and are true to the feedback received so far, I would like to check I’m on the right lines and see what others think. I have suggested that in early 2017 DeepMind run events, starting outside London, where people can discuss the detail of these suggestions. Of course, not

everyone will be able to attend these events, but I hope those who cannot attend will contribute through an online forum that the DeepMind Health team can set up.

In the following few pages I first set out my views on what good and bad PPIE looks like. I then detail some of my findings from spending time with the DeepMind Health team. Finally, I set out some recommendations for what an effective PPIE strategy could look like before suggesting next steps.

What good PPIE looks like

People who are living with a health condition or who have experienced a particular healthcare situation will have ideas, insight, and expertise that others do not have. They are also the ultimate users of healthcare systems, so they need to define what 'good' looks like from that user perspective. This is why involving service users in healthcare projects is important. For ease of reading, I will use the word 'patient' to mean the range of people described above, although some are carers and some would prefer just to be called human beings who sometimes interact with healthcare systems - this is a compromise I hope you will forgive. There is no ideal roadmap for patient involvement, but there are lessons we can learn from people who are trying to do this in research, education, service delivery and design. The basic principles are the same as for working with anyone: treat us with respect and value the ways our input adds to the team's expertise.

Effective involvement projects

- All contributors know what their roles and scope are
- The patients are asked to advise because of specific perspectives, experience, connections or expertise that is relevant to the project
- The patients' expertise informs the project from the earliest design stage
- The patients have the support they need to discuss ideas equally alongside other contributors
- The patients are valued equally alongside other contributors (including remuneration)
- All contributors have a chance to make informal or social connections with each other as well as formal ones

Less effective projects

- Nobody is sure what the patient's role is or what they are allowed to contribute
- Information only flows one way with little or no discussion or co-design
- Patients are treated very differently from other contributors for no good reason; for example:
 - Patients are asked to "represent" the patient voice, although clinician contributors are not asked if they are "representative" of all clinicians
 - The patients are the only people on the project who are unpaid, or who cannot equally join in because of timings, location, use of jargon, or disabilities

- The scope of the project is mostly or wholly decided before patients are involved
- A patient is relatively alone, with no chance to have ‘water cooler’ conversations or build up social networks with colleagues, and/or is the only patient involved

What have I learnt at DeepMind Health

After agreeing to work with Mustafa I visited the DeepMind Health team on numerous occasions to see how the team work together and how decisions are made. I was able to interview senior staff from the design, product, clinical, research and communications groups. I also had the opportunity to observe daily ‘design stand-ups’, product meetings and the clinical advisory group.

I got a good sense of the level of enthusiasm and ambition of the team to build products and services that can positively impact on patients and clinicians. I was able to learn about the co-design and user testing approach that DeepMind takes and the importance they place on ‘lived experience’. This is very encouraging and a sign of the team’s readiness to value patient expertise and collaborate rather than having a ‘them’ and ‘us’ mentality.

At the moment, for all of DeepMind’s projects, there is extensive clinical input and sign off from full time clinicians, part time clinical advisors and an external clinical advisory group. The DeepMind Health team have a clear focus on their clinician facing platforms (Streams) but they need to avoid doors being closed in terms of design, discussions on who can contribute to data collection and where pathways begin/end. This reflects prevailing relationships in most healthcare systems, where clinicians expect to decide what information to elicit from patients rather than patients or carers contributing to those conversations. I would argue that it is never too early to ask for patient input on things that will ultimately affect us.

Key suggestions (for further discussion at consultation events)

The overarching principle behind these suggestions is simply: at every level where clinicians have influence, ensure patients do too.

1. Appoint a Patient Lead with the same level of influence as the Clinical Lead

This role should aim to ensure at the top level that decisions take into account the patient perspective, and the potential for patient input.

2. Resource an entirely patient-led AI project

To date, DeepMind's machine learning research projects have been suggested and designed by clinicians. An entirely patient-led project would be a groundbreaking initiative that would really illustrate how serious the company is about innovative patient involvement.

3. Appoint Patient Advisors alongside the clinical advisory team for existing projects

Aside from from the Clinical Lead and other full time clinicians, there are clinicians with specialist expertise on the advisory team which influences all the DeepMind projects. Patients with relevant experience could offer advice on existing projects, ensuring the scope is not just defined by doctors and nurses.

4. Create a Patient Panel

DeepMind is currently advised by an Independent Review panel, a number of whom are clinicians. The role of a patient panel could be to hold DeepMind Health to account from the patient point of view, help with networking to patient groups and other connections across the country, and provide 'critical friend' perspectives. As one contributor to the autumn PPIE event put it, "you want to have conversations with the people who don't let you get off lightly". It could work in parallel with the Independent Review panel, or send representative(s) to it.

5. Develop patient testing groups equivalent to clinical testing groups

DeepMind Health has a team of around 50 clinicians who are willing to be called in to advise and test products in the early stages of development. Although the pool might need to be bigger than 50 (depending on range of conditions, levels of literacy and experiences DM wishes to tap), the principle could easily be replicated for patient groups as required.

6. User research and testing on the ground

DM already understand and do this later-stage testing well; this is simply a question of ensuring that the definition of 'user' is wider than just healthcare professionals.

7. Offer research opportunities and internships to patient researchers

DeepMind offers internships, mainly to clinicians. Patients ("service user researchers") will spot different things to study and could help embed patient involvement and the value of incorporating patient expertise into DeepMind.

8. And finally...think better about language used

Once most or all of these changes have been made, "clinician-led, patient-centred" sounds rather old-fashioned. Perhaps something more on the lines of "Co-designed by clinicians and patients".

Next steps

- 1. Contribute thoughts to recommendations through electronic form - now**
- 2. Set up independent consultations/focus groups - Feb 2017**
- 3. Confirm PPIE strategy and publish on DMH website - March 2017**
- 4. Publish accessible guideline on machine learning research to support a patient led project - March 2017**
- 5. Appoint patient advisors/lead - April 2017**