

Understanding Patient Data (UK): Dr Natalie Banner

Date of Discussion: Oct 4th, 2017

Location: IPPOSI AGM, Dublin Castle, Dublin 2

Natalie Banner is a Policy Adviser for [Understanding Patient Data](#), a UK-based organisation that aims to explain how and why data can be used for healthcare and health research. On October 4, 2017 she spoke to Derick Mitchell, CEO of IPPOSI, about what her team is doing, and what insights she has about patient data in the UK, and opening communication channels throughout the health field.

Natalie began by addressing the difficulty in finding a balance between patients and researchers when it comes to patient data; patients tend to be supportive of sharing their information if there is no commercial or third-party group(s) that will have access to their information. However, if researchers are to have robust access to patient data for research that can use material that has already been collected, sometimes third-parties get involved. So, the issue of private-versus-public information occurs.



How useful are patient stories to the work and mission of *Understanding Patient Data*, as it engages with government, industry and the media?

Natalie: Patient experience stories are very important to have but they are extremely difficult to find, specifically in the UK where there is not a lot of cohesion between groups to rally to find these patients to get these stories. Sometimes there can be a bit of recoil when you use a patient story because then someone may say “well it turned out so great for this person why do we even need the data for more research...” But, that is where the conversation can shift to say, “yes this went well but we can do so much more if we enable better access to more data.” We have begun to

work with the media; journalists are coming to us to ascertain if they have a story or not and are conscious about getting quotes from both sides.

How do we get patients to understand and support the sharing of patient data? Where does patient data go, and are there quality checks?

Natalie: It is very complex, and in a broad context it would be false to give assurances that data security is 100% guaranteed. We live in a world where hacking happens, and people are fallible: you can mitigate risks but you shouldn't pretend they don't exist. However, I think that we do not give patients enough credit – instead of presenting the idea how we always have, which is “we're using data for good research, just trust us”, we should begin to discuss data security governance and the trade-offs you might need to make to enable new discoveries. We should explain the potential risks and benefits, and we should be proactive about how to protect against information losses.

Should be an oversight group for all interested parties for patient data?

Natalie: No, because then the issue of “it's not my job, it is someone else's job” arises. There needs to be a more joined up approach, but delegating this thinking to a particular body would, I think, mean these issues are not embedded throughout research practice.

What if we put data back in the hands of patients, and they share their own data when asked. What do you think about this method?

Natalie: This can create some issues. If you want any analysis to be done you will get very small responses, and only certain demographics will truly respond to a request like that. Then there is an issue of identifying Personally Identifiable Information (PII) versus information that is not personal. Patients may want to release certain things versus other things when, in truth, they only have the right to control the release of certain PII.

I am aware of different models with levels of data release using patient's own release of the information and there seems to be some success from certain channels.

What communication channels do you use?

Natalie: We use the website, social media, we have committees that will reach out to patients and organisations, we host and attend events, and we do lots of talks – like this one. The website focuses on tools and resources for others to use to kickstart these conversations about patient data.

How does the [Science Media Centre](#) affect your role?

Natalie: We have worked with the Science Media Centre to producing briefings for journalists on issues relating to patient data, and it's been great to work with them to understand what journalists are looking for. Often the language of data is technical

and complex, and we've been very conscious of ensuring that the words we're using can be understood by people who are not technically trained in data science – the SMC have been a great sounding board as they're used to working to bring complex ideas and concepts to a broader lay audience through the media.

Is there any work that you are aware of with block chain?

Natalie: I am aware of Block Chain as a potential tool to ensure all data uses can be verified and audited, which could really improve transparency for patients. One of the key challenges here is how energy intensive blockchain systems are. It remains to be seen how wide or easily the technology can be applied as a way of providing transparency in data uses.

Where do you see the major weakness for the UK with regards to patient information and data sharing?

Natalie: A few years ago, no one was concerned but there were significant siloes of data, and data sitting unused. Now everyone has realised the potential of making better use of data and linking it, but this has understandably triggered concerns and there is a challenge of governance and trustworthiness. If you want to use the data there are hoops that you must jump through, and it's right that there are checks and balances in place. There is some progress but there really is no national conversation about patient information and data sharing, about the value it could bring to healthcare and research. I also think the scale of the UK is a challenge for creating good, carefully thought through data sharing initiatives, so it remains very challenging for researchers who are trying to access the information.