Sydney Data Stories – Imagine 1

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[Beginning of material]

The greatest reward I have in my work is to see people improve over time and to see young people with very severe disorders who are out of school, who are really struggling to get out of their bedrooms, actually go back to school, go to university, get jobs, be in relationships and really prosper.

Adolescent brain development is a time of great change and a window of neuroplasticity that opens at this age, which means there are great opportunities to think about wellbeing and resilience in the community. But it's also the time when the major mental health disorders emerge. So disorders like complex mood disorders, bipolar disorder, schizophrenia. So if you're really going to be able to look at prevention, early intervention, we need to develop service systems and have our research that is geared towards this age group.

If you ask people what's important to them: going to school, being with friends, their body image and the way they see themselves is extremely important. So actually working with young people to help prevent some of the consequences of the mental health problems they have, particularly diabetes, obesity, changes in eating regulation are extremely important to the young people that we treat. The collection of data in our field has been really hampered by small sample sizes and very select groups, so what we've really concentrated on is collecting large data sets from cohorts of patients. That means you've got to set up the clinical service platforms to be actually engage young people into working collaboratively to provide that data.

Obviously, in teenage mental health, there are many confounders that confuse the results, and that means you do need to have large sample sizes. You need to think about what the biases are in your data. So not only do we think have to think about age, gender, ethnicity, socio economic status, we have to think about the different settings that people are in, the different regions that they live in, but also the different settings that treatment is provided. So what happens in primary care compared to secondary and tertiary care? So what we try and do with our data is sample across all of those sites, across many different places within Australia, if we can, around the world, so that we have a large pool of data which we can then use as comparative data.

In the work that we do with teenagers, issues of privacy, confidentiality have been a major issue, particularly for ethics committees. Surprisingly, young people are actually very happy to share their data as long as they understand what the purpose of it is and what the benefit is to potentially other young people within the community. So in the work that we've done, we've been overwhelmed by the participation rates of young peoples through our Headspace sites, through the work that we do in other settings. If the work is explained, if it is designed in collaboration with young people or young people are engaged in the process and engaged in the implementation and the communication, we have found overwhelmingly large high participation rates in the research that we do, for which I must say I'm extremely grateful.

It is possible to do randomised control trials in with young people in teenage mental health, but it's extremely difficult. So people do it, people with more courage than myself. But it takes a lot of energy. It takes a lot of resources. They're very expensive. They're very time consuming. We work a lot with digital technologies. And in the digital world, things change so rapidly that RCTs are not a very good way of determining the effectiveness of treatment interventions. By the time your data is released, usually the technology has moved on.

I wish I'd known that I could have had more courage to follow my curiosity and not be discouraged by others. Being able to see patterns is one of the skills in medicine and science. And if you see patterns, follow them. Don't be put off. My other advice would be if you're going to follow your curiosity, do it with others, work together, work collaboratively and work with the community of people whose lives you want to improve.

[End of recorded material]