Mediating between medicine and data science

“I’d like to help people better understand why sharing medical data is important” says Catherine Jutzeler, Tenure Track Assistant Professor of Biomedical Data Science. The professorship is funded by the Wilhelm Schulthess Foundation.

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The research conducted by ETH professor Catherine Jutzeler is paving the way for patients with bone marrow injuries to be given treatments tailored to their specific needs.

I’m meeting you in the Zurich Schulthess Klinik – why is your workplace here and not at ETH?

CATHERINE JUTZELER – I analyse data from patients with spinal cord injuries: data on their health, age, blood values, previous illnesses, medication treatment and so on. This involves working together with doctors, therapists and statisticians, and the clinic provides the perfect venue for this interdisciplinary research. Theoretical models often don’t work when you apply them to medical data, as this real-life data may be incomplete or contain biases, for example. To do my job well, I need to understand why the data looks as it does. The models can then be improved but, to be effective, proximity to the clinical world is essential. This is where you realise that it can make a difference to the data whether it’s been compiled by a junior doctor or a doctor higher up the hierarchy, for example. It could be that a doctor with more experience may take a patient’s temperature less often, making the data less complete than that of an inexperienced colleague. First and foremost, a doctor is there for the patients and not to generate ideal data sets for us researchers. Another factor is that my presence allows me to build trusting relationships. This creates acceptance for the fact that I’m using the clinical data to generate knowledge that can support clinical decision-making.

In concrete terms, how does your research improve the treatment of patients?

Let me give you an example: many people suffer from back pain often caused by increasing wear and tear of the intervertebral discs and joints of the spine. Infiltration is a non-surgical pain therapy used to treat the condition in which a mixture of pain- killers and anaesthetics is injected into the epidural space in the spine. A large number of patients respond, but some do not. But why do certain patients respond and others not? What is the difference between the two groups? This is what I’m hoping to find out in a project with Zina-Mary Manjaly, a neurology consultant at the Schulthess Klinik. The aim is to be able to better predict the effectiveness of this treatment in the future. To do this, I’m looking for patterns in the data that will help us distinguish between the groups. Much of my work consists of preparing data and getting it into a format that we can then use for our analyses. For the latter, we use statistical methods – and machine learning too.

Why do you think talking to the patients is so important?

We researchers sometimes find one particular goal – such as getting people to walk again – to be particularly worth pursuing. But if you speak with the patients, you realise that their priorities are different: being able to go to the toilet without difficulty, or being relieved of pain, is far more important to many.

I therefore ask them quite specifically: “What would help you most?” This is only fair, in fact, as the data I work with doesn’t belong to the clinic, nor to research, but to the patients themselves. During my postdoc in Vancouver, I came across a format that I’d like to set up here too: a café scientifique. This is a place where research results are shared with those who provided the underlying data. Overall, I’d like to help people not only better understand why sharing medical data is important but also all the things we do to protect this data.

Which is?

Firstly, we work on secure platforms that are specifically designed for highly sensitive data. My staff and I regularly undergo further training on legal requirements and ethical standards. In addition, my projects are assessed by the Cantonal Ethics Committee. Since there are comparatively few patients with spinal cord injuries in Switzerland, the committee also checks factors like whether people can be identified. If identification is possible, we’re not allowed to publish the information for data protection reasons. The privacy and protection of the patient or study participant is of the greatest priority.

Are there other research groups that operate similarly to yours?

Researchers acting at the interface of medicine and data science and taking on the function of a mediator is a recent phenomenon. With my unconventional career path, which led from studying pharmacy to a doctorate at Balgrist University Hospital to diving into machine learning with ETH professor Karsten Borgwardt in Basel, I understand enough about all the disciplines to be able to fulfil this function. The ETH research group led by Diego Paez Granados at the Swiss Paraplegic Centre in Nottwil works in a similar way.

What are the next steps on the journey towards a perfect form of personalised treatment?

Initially, treatments will become increasingly better adapted to certain subgroups: to women with a certain genetic basis, for example. In contrast to other research fields – such as cancer research – the journey for neurological diseases is still long. But we’re making progress every day.

Find out more about ETH's Rehab Initiative

Meetings made easy: Catherine Jutzeler works closely with Zina-Mary Manjaly, a neurology consultant at the Schulthess Klinik.

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