

EOSC Support Office Austria: Visionen, Bedürfnisse und Anforderungen an Forschungsdaten und -praktiken

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In 2015 the vision of a federated system of infrastructures supporting research by providing an open multi-disciplinary environment to publish, find and re-use data, tools and services led to the launch of the [European Open Science Cloud](#) (EOSC). Against this background, bodies such as the [EOSC Association](#) on the European level and the [EOSC Support Office Austria](#) on the national one have been established.

Within this framework and since research has always been at the heart of EOSC, we are eliciting visions, needs and requirements for research data and practices from researchers who are located at public universities in Austria. Let's see what neurologist, intensive care physician and tropical medicine specialist Erich Schmutzhard has to say!

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KF: In which fields do you do research?

ES: I am a neurologist, intensive care specialist and a tropical medicine specialist. These are also my three main clinical and basic research areas. In an international sense, and because I was professor of neurological intensive care medicine at the Medical University of Innsbruck from 1999 until my retirement, my most important area is neurological intensive care medicine.

KF: Could you please give me examples of research in your discipline?

ES: Of course. Since I was initially a tropical medicine physician, I first integrated this expertise into tropical neurology and tropical neurological intensive care medicine and have therefore done many projects in tropical countries. Likewise, I was and/or am active in basic research, prognosis research and drug research and have participated in so-called *door-*

to-door surveys and worked on case series. Currently, members of my team are also involved in the [CENTER-TBI](#) project.

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As far as basic research is concerned, we have conducted research in the mouse model on craniocerebral trauma and cerebral malaria, for example. In the clinical field, prognostic research is essential, especially for life-threatening diseases, as it enables better assessment of disease progression and appropriate measures to be taken.

Pharmaceutical companies commission drug trials to test medicines. Such studies can also be stopped. For example, if the drug group comes out equally well as the group receiving the placebo, or if the side effects suddenly increase. In this case, the study is negative and – this is an extremely important point for me, which is why I would like to mention it here – negative studies should also be published, which works relatively well in Europe.

KF: Why should negative studies be published?

“Depending on the type of study, patient data is anonymized or pseudonymized.”

ES: On the one hand, publishing negative results contributes to trust because it reflects honesty. In my opinion, trust in this context is only possible if I can assume that my colleagues have the same medical ethics or scientific ethics.

On the other hand, it is simply important to know when something has not worked or may even have been harmful. Moreover, even in a negative study, some results may be positive. These could be researched in more detail in a further study.

KF: You also mentioned *door-to-door surveys*, case series and the CENTER-TBI.

ES: Exactly. In *door-to-door surveys*, team members go from house to house to inquire into certain issues, such as the frequency of certain diseases. In Africa, for example, we surveyed the frequency of people with migraine.

Case series are often the basis for further studies. For example, we studied the Wapogoros – an African ethnic group that still lives very isolated – in connection with epilepsy. We came

across an unknown form of epilepsy: the *nodding syndrome*.

CENTER-TBI is part of a global initiative with projects in Europe, the USA and Canada. CENTER-TBI aims to improve the care of patients with traumatic brain injuries. For example, we collect and share data from people with brain injuries. Over the last seven years, we have collected data from well over 10,000 patients with severe traumatic brain injury - all aspects from management to epidemiology to prognosis. About once a month, there are video conferences. Data is then updated and we discuss what is already ready for publication.

KF: So data is shared here. Is that the norm in medical research?

ES: We share our data in other research as well: Case series can take an incredible long time. For example, the study I mentioned before started about 17 years ago. You almost have to think of colleagues and pass on your knowledge completely – otherwise they would have to start all over again. Thus, we have shared our data completely and not only what was published in the publication. We also published the data from the *door-to-door survey* in full. As far as basic research is concerned, it is also enormously important to share all data. Publications in renowned journals are often no more than five A4 pages long. There therefore is a supplement to these publications in order to make details of the research publicly accessible and usable.

KF: What kind of data do you actually collect as part of your research?

ES: Among other things, we collect the number of patients, their age and gender, and their professional and social position. We also document the imaging and clinical courses and the management and all information relevant to the clinical picture. Depending on the type of

study, patient data is anonymized or pseudonymised.

“I would like to emphasize that patients' data must not be passed on or published without their knowledge and consent.”

KF: What would this mean against the background that the EOSC is supposed to serve the exchange and reuse of data, among other things?

ES: I don't think that initiatives like the EOSC would be needed or accepted in the context of certain research that is based on international cooperation and the exchange of data anyway. This applies to drug research, for example. In addition, the economic interests of pharmaceutical companies play an important role here. They would presumably only disclose certain information if there were corresponding benefits. In other research areas, however, such an initiative could make sense.

KF: Are there any other points that are particularly important to you and that you would like to address?

ES: Yes. I would like to emphasize that patients' data must not be passed on or published without their knowledge and consent. If we were to do that, it would be a serious data breach. The data belong to the patients.

KF: Thank you!



Erich Schmutzhard graduated from Medical School, Innsbruck, in 1974; he is a trained neurologist and intensivist with special interest in intensive care neurology, neuro infectious diseases and tropical neurology. He was trained in Lienz and Innsbruck, Austria, Liverpool, UK and Bangkok, Thailand. Beside neuro-infectious diseases and intensive care neurology he concentrated – based upon his international trainings and his 4 years working experience in Southern Tanzania, East Africa– on tropical diseases of the nervous system and migration neurology.

In the year 2000, he was appointed Professor of Intensive Care Neurology at the Medical University Innsbruck, Austria, a position which he held until his retirement in September 2017. Since 1994, he is Senior Lecturer in Tropical Neurology at the Bernhard-Nocht-Institute for Tropical Medicine, University Hospital Hamburg-

Eppendorf, Hamburg, Germany and since 2020/2021 lecturer in Tropical Neurology in Munich and Jena, Germany, respectively.

His major clinical research focuses on neuro-critical care and infectious diseases of the CNS, invasive neuro-monitoring in severely brain-injured patients, early prognostication and the contributory role of NICU-complications to morbidity and mortality. He has published >370 peer reviewed papers and textbooks both as editor, author and/or contributor with specific chapters. He and his team contributed to and participated in a wide range of multi-center studies addressing severe TBI, SAH, meningitis, temperature management in NICU, bacterial meningitis, cerebral malaria etc.