

## Austrian patient registries require further development

**The Austrian Institute for Health Technology Assessment (AIHTA) has analysed the Austrian registry landscape to provide a first overview of in the existing Austrian registries and the health data collected in each case. Based on the results, the researchers developed a guideline with important aspects for planning and operating medical registries to utilise the collected data's potential to improve the healthcare system.**

Vienna, 23 January 2024 – The planned healthcare reform this year has brought the issue of the use of healthcare data back into focus. So-called patient registries record, for example, diagnoses, treatment steps and disease progression or document the effects of medication. For some disease groups, indications or interventions, data collection is required by law. These data collections are used to improve the quality of healthcare, support patient safety and general healthcare system planning. In addition, registry data could serve scientists as a valuable source for research projects if patient rights and data are adequately protected.

Until now, the number and type of existing medical registries in Austria has been unknown, as there is currently no comprehensive overview of health science or healthcare-relevant registries in the sense of a 'registry of registries'. The Austrian Institute for Health Technology Assessment (AIHTA) has now surveyed the registries with Austrian participation and is taking a first step towards an all-Austrian registry strategy with the research results.

### **Status quo of Austrian registries**

The AIHTA has identified 74 Austrian registries and 83 international or European registries with Austrian participation. General characteristics were collected for the 74 potentially health care-relevant registries - mostly disease-specific, epidemiological and quality registries. However, organisational aspects and data management, including data protection and quality assurance, were also examined. The identification of existing registries was not always easy, as study leader Christoph Strohmaier admits: "Our fundamental problem is that transparency is sometimes simply not there: Somewhere you find some information that there is a registry, but it's not clear what data is collected and where it can be found." The basic information was also very heterogeneous and not always up to date. As long as there is no Austrian or EU-wide central centre for health registries, the researcher recommends that registry operators sign up to one of the existing platforms to improve transparency. "However, the goal should be a 'registry of registries' for Austria. And this centralised registry must also consider merging with an EU-wide database at a later date," Strohmaier points out.

Christoph Strohmaier and his colleague Julia Kern examined twelve of the Austrian registries, primarily those with a legal basis, in more detail using a set of criteria: The evaluated quality criteria were generally fulfilled, a need for further development was identified for definitions of terms and interoperability, i.e. the ability of different systems to interact.

## Basics for planning, design and operation of patient registries

"When implementing a registry or a registry strategy, several things are relevant, and they all need to be considered, not only during planning and design but also during ongoing registry operation," explains the study author, emphasising that the guidelines developed by the AIHTA are not only aimed at registry operators. Rather, this 'best practice framework' also provides the basis for the further development of the medical registry landscape for health planners, decision-makers and health policy-makers in order to utilise the potential of Austrian registry data.

The AIHTA report identifies three important aspects with regard to the sustainable use of health science registries to improve care:

According to Strohmaier, sufficient - public - **funding** for the entire duration of the registry is often underestimated. However, high-quality data can only be produced if sufficient resources are also available for ongoing registry operations. The aforementioned lack of transparency in some registries could also be due to a lack of budget because "only with secure funding is it possible to professionalise the operation of a registry and, for example, set up websites where the latest information can be found."

The possibility of data access - under certain conditions - by the (scientific) public and health planning institutions is not only seen as a key point by AIHTA researchers. The Ministry of Health's eHealth strategy also calls for the secondary use of health data in research and science. However, access to registry data is often denied due to data protection and data security concerns. Strohmaier refers here to the Scandinavian countries, where data access "works well, and it is perhaps more acceptable to collect data due to the long history of quality registries".

In some circumstances, the demand for public access to data conflicts with the third aspect, protecting **patients' rights and data protection**. However, access to data to improve care or for scientific purposes can also be in line with individual patient rights: These include not only the right to autonomy, self-determination and informed consent but also the right to know the comparative evidence of different treatment options. In order to keep basic data protection considerations in mind, the AIHTA researchers recommend a plan that regulates data retention, data access rights and clear roles concerning data processing.

In conclusion, the authors of the study state that "a nationwide registry strategy or an Austria-wide registry model can only work if all eligible registries have a minimum level of quality. The collection of reliable data forms the basis for improving care in the respective healthcare areas."

### Further information:

– All 157 identified patient registries with Austrian participation were summarised in an Excel list and the results can be freely downloaded from the AIHTA website:

**Link to the Excel list:** <https://aihta.at/uploads/tableTool/UIICmsPage/gallery/register-uebersicht.xlsx>

**Link to the project report** <https://eprints.aihta.at/1489/>

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