

Creating a health-related registry means investing in the future!



A register requires that a permanent record be established, that the cases be followed up and that basic statistical tabulations be prepared both on frequency and survival.¹



The usefulness of a register increases the longer it has been in existence. It may therefore be necessary to continue careful documentation and quality-control procedures for many years before a register becomes fully productive.¹



Patients provide their personal clinical data to a registry and they are also the main beneficiaries of the knowledge obtained thanks to the registry. This makes them the most important interest group.

HEALTH-RELATED REGISTRIES

Investing in the future!

The importance of registries for research and for improving public health has long been known. A celebrated example is the successful battle against leprosy in Northern Europe.

Around 1850, the growing prevalence of leprosy in Norway was a major problem. The cause of the disease was unknown and there was no cure. Against this background, the Norwegian Leprosy Registry was established in 1856 - the world's first national patient registry. This helped to improve knowledge of the incidence, characteristics and spread of the disease. In 1873, the Norwegian physician G.H. Armauer Hansen discovered the leprosy bacillus and showed that the disease was infectious. Patients were therefore isolated, and the effectiveness of this approach was confirmed by the registry.

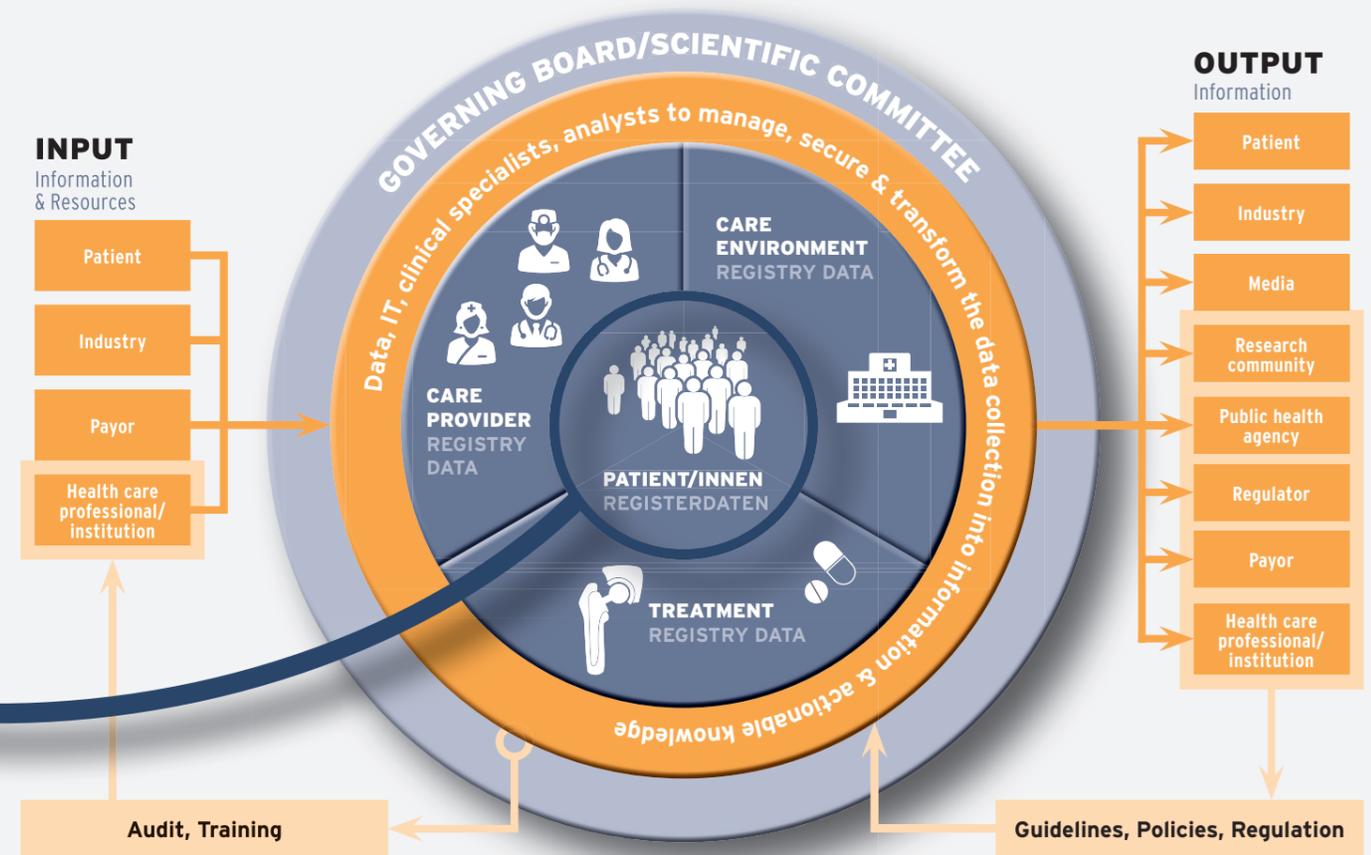
Since then, numerous registries have been created to gain a better understanding of emerging public health problems and to provide a basis for the development of new treatments or health policy measures. An example from recent decades is the prevention and control of HIV/AIDS, in which registries have played an important role.

Quality criteria for a registry

- 1 Registry design
- 2 Expertise required for registry management
- 3 Data protection and data ownership
- 4 Data collection
- 5 Quality assurance
- 6 Data use
- 7 Change of purpose and dissolution

How does a registry operate and who are the stakeholders?²

Relevant and interested parties and their relationships with the registry



Health-related registries in Switzerland³

The number of registries in Switzerland is steadily rising. Effective registries promote national collaboration and harmonisation. A number of Swiss registries are attached to international registry networks.

Examples of active registries

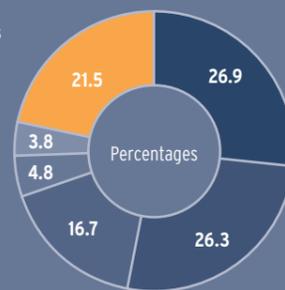
- 2020 Swiss National Cancer Registry
- 2012 Swiss National Joint Registry, Hip and Knee
- 2007 Swiss Transplant Cohort Study
- 2000 Swiss Hepatitis C Cohort Study
- Swiss Neonatal Network & Follow-up Group
- 1997 Swiss Clinical Quality Management in Rheumatic Diseases
- Acute Myocardial Infarction in Switzerland
- 1991 Study on Air Pollution And Lung Disease In Adults
- 1988 Swiss HIV Cohort Study
- 1977 Swiss Cochlear Implant Registry
- 1976 Swiss Childhood Cancer Registry
- 1969 Basel Cancer Registry

Development of active registries



Registry supporting organisations

- Medical societies
- Hospitals
- Universities
- Healthcare associations
- Industry
- Other



The top 8 medical disciplines

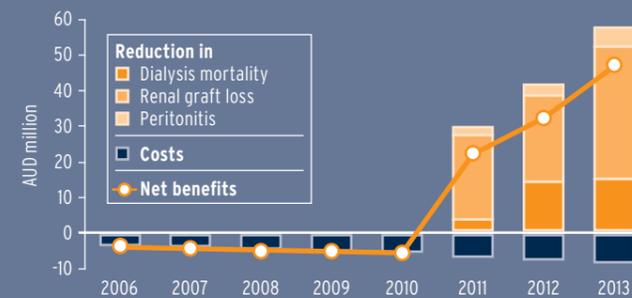
Question: "For which disciplines is the registry relevant?" (45 specialties) Multiple responses were possible.



Cost-effectiveness of registries⁴

Australia has long used public funding to support the establishment and operation of registries. In 2016, the costs of selected registries were evaluated, together with their impact on patients' quality of life, complication rates, and avoided treatment costs (i.e. benefits).

The Australia and New Zealand Dialysis and Transplantation Registry showed total benefits of AUD 58 million



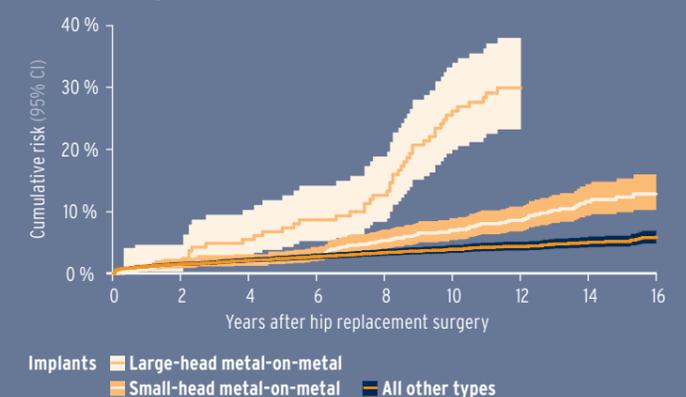
Economic evaluation of Australian registries

	Period (years)	Benefits	Costs
Trauma (VSTR)	8	●●●●●●●●	●
Intensive care (ANZICS APD)	12	●●●●●●●●●●	●
Transplantation (ANZDATA)	9	●●●●●●●●●	●
Prostheses (AOANJRR)	12	●●●●●●●●	●

The benefits of registries

Clinical registries play a crucial role, for example, in long-term, real-world surveillance of implants and pharmaceuticals. Analyses of the Australian and UK joint replacement registries revealed sharp increases in revision rates for metal-on-metal hip implants compared to established implants. As a result, in the new EU Medical Devices Regulation, regular clinical monitoring of implants is required, e.g. using registry data. In this context, Germany has decided to establish a national implant registry.

Risk of early revision after hip replacement⁵



HEALTH-RELATED REGISTRIES

Ensuring the benefits and sustainability of registries

To provide the widest possible benefits, a registry should focus on the following key goals:

QUALITY: The registry is part of the quality assurance system and helps to evaluate treatments, thus providing evidence of their effectiveness.

BENEFICIAL CHANGE: The registry has mechanisms whereby knowledge obtained from data analysis is used to drive beneficial changes in healthcare. For this purpose, the registry collects actionable data and makes relevant information available to decision makers in a timely manner.

EFFICIENCY: The registry is embedded in the healthcare system in such a way that data collection is integrated into service providers' operations and use is made of data already otherwise available.

TRANSPARENCY: The management structure, data access and analytical processes are transparent, and key stakeholders are involved in important steps in the development of the registry.

OPENNESS TO RESEARCH: Registry data is made available for qualified research projects, and a structured procedure is available for this purpose.

LINKAGE: Information in the registry can be linked to other data resources.

The recommendations for registries are designed to support these goals. They cover the key quality criteria for the development and operation of registries:

<https://www.anq.ch/en/publications/register-recommendations/>



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ANQ www.anq.ch

The National Association for Quality Development in Hospitals and Clinics coordinates and implements quality reviews. Its members include the Swiss Hospital Association H+, santésuisse, curafutura, the federal social insurance organisations, the cantons and the Conference of Cantonal Ministers of Public Health (GDK).



FMH www.fmh.ch

The Swiss Medical Association represents over 40,000 members and, as an umbrella association, around 90 medical organisations. It seeks to ensure that all patients can access high-quality, affordable healthcare.



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H+ www.hplus.ch

The Swiss Hospital Association H+ is the national association of public and private hospitals, clinics and nursing institutions. H+ has 220 hospitals, clinics and nursing institutions at 370 sites as active members, as well as around 160 associations, authorities, institutions, companies and individuals as partners.



SAMS www.sams.ch

Founded in 1943 as a research funding institution, the Swiss Academy of Medical Sciences now serves as a bridge builder between science and society. It sees itself as a think tank, supporting positive developments in medicine and healthcare.



unimedsuisse www.unimedsuisse.ch

The Swiss University Medicine Association brings together the University Hospitals of Basel, Bern, Geneva, Lausanne and Zurich, and Switzerland's five medical faculties. It is responsible for questions relating to university medicine at the national level.

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- 2 Lübbecke A, Carr AJ, Hoffmeyer P. Registry stakeholders. EFORT Open Reviews 2019
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- 4 Australian Commission on Safety and Quality in Health Care. Economic evaluation of clinical quality registries. Sydney 2016
- 5 Adapted from Geneva Arthroplasty Registry Annual Report 1996-2018