

# Registries – What for?

Evidence from registries in cardiovascular, spine related and neurological fields

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## Background

An important complementary approach to experimental studies is using registries. They can give a more population based view to a health problem and allow certain analyses that cannot be addressed in clinical studies, such as the identification of rare side-effects. Here we present the first step of a project that aims to evaluate the benefit of registries for health decisions. In this first step an exhaustive number of active registries in three clinical fields are identified to gain an overview of the types of questions and results that are addressed by registries.

## Method

A systematic search was developed and performed in Medline to identify publications that present results from registry projects. In the next step a web search for the identified registries (Table 1) and a collection of basic data from the registries was carried out. Additionally an email-request was sent to experts to help identify registries.

### Cardiovascular registries identification

"registries"[MeSH] AND "Cardiovascular Diseases"[MeSH] AND (swiss[AD] OR switzerland[ad] OR ".ch"[ad] OR sweden[AD] OR ".se"[AD]) OR germany[AD] OR ".de"[AD] OR austria[ad] OR ".at"[All Fields]) AND ("2003/01/01"[PDAT] : "2007/08/25"[PDAT])

### Neurological registries identification

("nervous system"[MeSH] OR "peripheral nerves"[MeSH Terms] OR "brain"[MeSH Terms] OR "spinal cord"[MeSH Terms] OR "nervous system"[MeSH Terms] OR "cerebral aqueduct"[MeSH Terms] OR "cerebral cortex"[MeSH Terms] OR "cerebrospinal fluid shunts"[MeSH Terms] OR "cerebral palsy"[MeSH Terms] OR "magnetic resonance imaging"[MeSH Terms] OR "nerve block"[MeSH Terms] OR "brain ischemia"[MeSH Terms] OR "cerebral hemorrhage"[MeSH Terms] OR "motor neurons"[MeSH Terms] OR "neurodegenerative diseases"[MeSH Terms]) AND "registries"[MeSH] AND ("2003/01/01"[PDAT] : "2007/11/25"[PDAT])

### Neurological registries identification

"Sciatica"[Mesh] OR "Back Injuries"[Mesh] OR "low back pain"[Mesh] OR "spine"[Mesh] OR "Back Pain"[Mesh] OR "spinal diseases"[Mesh] AND "registries"[MeSH] AND ("2003/01/01"[PDAT] : "2007/10/25"[PDAT])

Table 1: Search strategy

| German cardiovascular registries                              | Cited in [PMID] <sup>*</sup>   |
|---|--|
| AB1 Zentralregister   | 16896574   |
| www.kompetenznetz-vorhofflimmern.de                           |  |
| BHIR  | 16741630, 16255079,  |
| www.herzinfarktregister.de                                    |  |
| Deutsches Cypher Register                                     | 15747041, 17161068, 15085373   |
| www.herzinfarktforschung.de/Projekte/RegisterN/Cypher.html    |  |
| f13-database  | 17549292   |
| www.f13-database.de   |  |
| HealthTwist   | 17254407   |
| www.healthtwist.de  |  |
| HeLuMa  | 16183697   |
| www.herzinfarktforschung.de/Projekte/RegisterN/HeLuMa.html    |  |
| KORA-gen  | 16032514   |
| epi.gsf.de/kora-gen/  |  |
| Marburger Register  | Kardiomyopathie 16904777   |
| No website identified   |  |
| MITRA PLUS  | 14579045, 1 7478143, 6331364   |
| www.herzinfarktforschung.de/Projekte/RegisterN/MitraPlus.html |  |
| MONICA/KORA-Herzinfarkt (HI)-Register Augsburg                | 16032513, 16032515, 16032526, 16032532, 16032525, 15551512, 17153517 |
| www.helmholtz-muenchen.de/herzschlag-info/content5.htm        |  |
| PreSCD  | 17541867   |
| www.dgk.org/ikkf/details.aspx?id=9                            |  |
| QuIK  | 17323039   |
| No website identified   |  |
| Ross-Register   | 16159856   |
| No website identified   |  |
| SAMI Register   | 17628839   |
| No website identified   |  |

Table 2: Results from Germany: cardiovascular registries

## Result

365 cardiovascular, 366 neurological and 64 spine specific articles were identified in the search. 159 of the cardiovascular, 108 of the neurological and 46 of the spine specific articles mention registries. Additionally, 8 links to registries were brought in by experts. These hints were examined by a search in the WWW and the reference and basic metadata was saved into a database. Overall, about 86 cardiovascular, 38 neurological and 22 spine registries were identified (Figure 1). The relevant ones were then selected according to the inclusion criteria (only registries that have been active during the past 3 years with periodic reports, certain countries). 42 of them remained finally. The result of German cardiovascular registries is shown in Table 3. Additional results can be found on the project homepage: <http://eprints.hta.lbg.ac.at/784/>

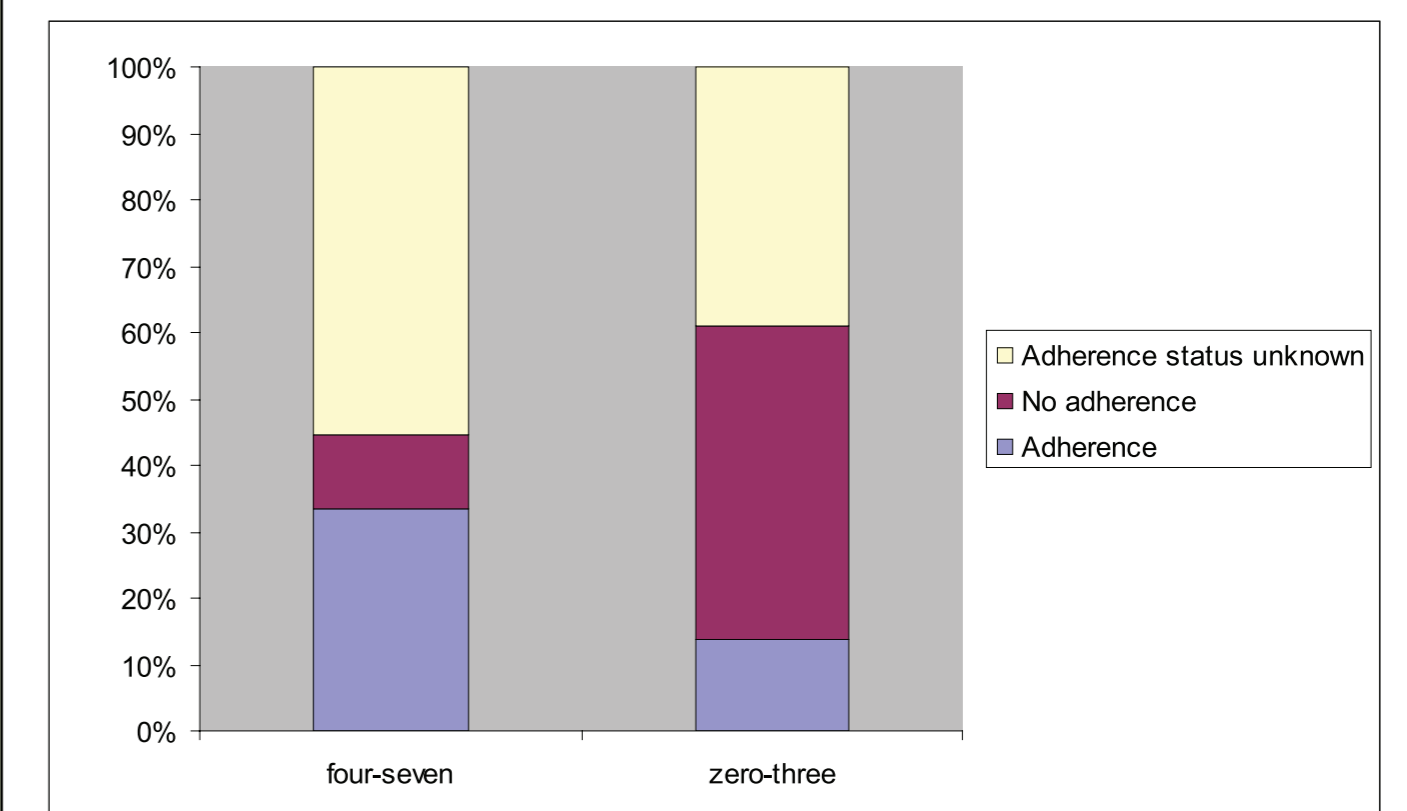


Figure 2, Association of adherence and number of citations

One of the primary items for getting an overview on the quality of evidence in the identified registries was the presence or absence of adherence of the register objectives to official guidelines or recommendations. Figure 2 demonstrates the association of adherence and number of publications. The figure indicates, that registers that adhere to guidelines or other regulations seem to be more efficient in producing published reports.

## Discussion/Conclusion

The here developed method to identify active registries by citations is successful for getting a decent sample. The sensitivity of the method is probably limited, especially in those registries, that do not published in scientific journals. Also the specificity may be limited in the cases, where initiatives that fulfil all criteria for registries are not denominated as registers. A big number of false positive articles can be ascribed to the equivocation of the term 'registry' but these could be easily separated out. One way to evaluate the potential of registries to offer evidence for HTA is the extent to which they are cited in publications. Registries developed according to national guidelines or regulations appear to be more effective, by means of more citations. Most of the registries with publications have homepages with general information that can also be used for a primary assessment of the quality of the evidence of registry results. The systematic coverage of registries could be a valuable step to coordinate national and transnational register activities to attain more efficiency and effectiveness of observational research.

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\* Use PMID to access the article in PubMed: <http://www.ncbi.nlm.nih.gov/pubmed/PMID>

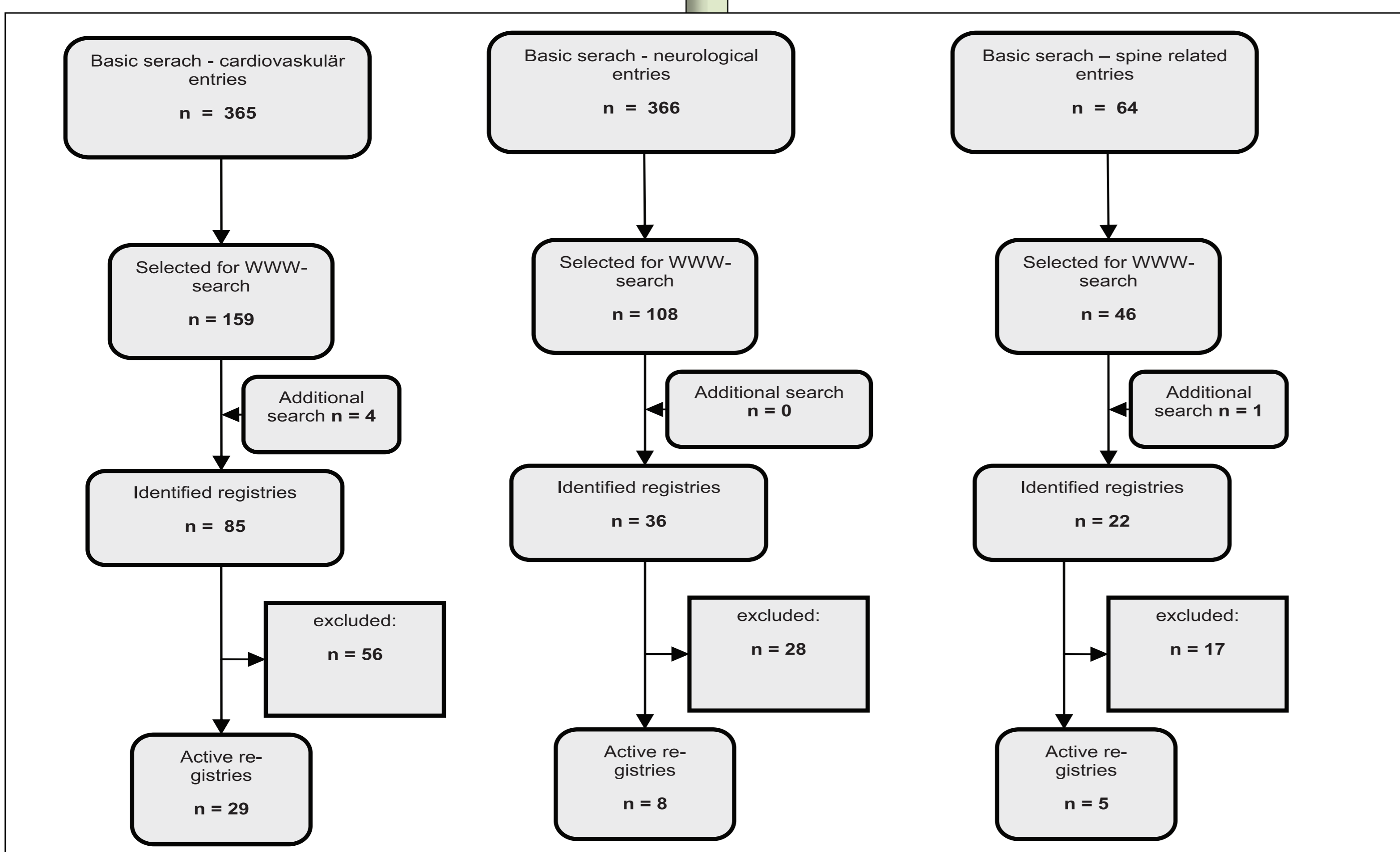


Figure 1: Search results

