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Using administrative and claims data in the GNC-study - how to overcome legal restrictions

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Objectives

The German GNC-Health Study (GNC) will have duration of at least ten years and will compile medical examinations, bio-materials and computer assisted interviews of intended 200.000 participants (funding code: 01ER1301A). For the first time, this data collection will be supplemented with a multitude of administrative and claims data such as data of statutory health insurance funds, statutory pension funds as well as the Federal Employment Agency. The GNC extends this field of research to private health insurance funds, epidemiologic and clinical cancer and mortality registers. This supplementary use of claims data is strictly regulated by legal requirements. The challenges and solutions for scientific use of such data in Germany will be described.

Approach

The Social Security Code and data protection rules govern the scientific use of administrative data. These rules include requirements for the wording of important documents such as informed consent, release from confidentiality, participants' information, data protection concept etc. and often an authorization process by the supervisory authority of the data owner. These complex tasks, which are time consuming costly and labour intensive, are tied into the GNC-Competence Network for secondary and registry data (CNSRD).

Results

The GNC-CNSRD has helped to formulate legal informed consent for each data source, which describes the use of the information provided by the participants, as well as the period and limitation of its retro- and prospective use. Furthermore, only the GNC-trust agency is allowed to save the social security number but not the local study center. The modular consent process

and the IT - and data protection concept of the GNC is a prototype to enable the large scale use of administrative and claims data of future epidemiologic studies in Germany.

Conclusion

Unfortunately, one of the biggest obstacles for the scientific use of administrative and claims data still remains unsolved. The application for data use at the local supervisory authority of the data owner requires the description and limitation of the research question and the period of use of this data. This is in conflict with the modern longitudinal design of GNC because it wants to establish a research structure and data base in order to answer a variety of future and unspecified research questions. Hence, current legal requirements in Germany prevent the full utilization of the potential of administrative and claims data. Therefore, the German Federal Commissioner for Data Protection and Freedom of Information recommended an amendment to the social law.

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