Catalogue of measures for implementing the scenario

Third Workshop

The results of the online survey revealed several issues that could be an obstacle to the implementation of the scenario. The aim of the workshop was to develop measures for the individual thematic fields. To this end, solution strategies were developed step-by-step with experts from the first two workshops. Initially, individual work was carried out for each of the problem areas, followed by group work. In the group work, the participants selected the top 3 measures from the respective areas that were most important to them. Finally, the participants evaluated the solution strategies with regard to their priority and the expected effort for implementation.

Development of the catalogue of measures

The results of the third workshop were collected, processed and written down. When formulating the measures, care was taken to ensure that the objective of the measure, the path of implementation and the responsible institutions were named. A total of 15 measures emerged from seven thematic areas.

Thematic fields of the calalogue of measures:

- **Financing and investment**
- **Data protection and data security**
- **Technology acceptance**
- **Integration into the daily work routine**
- **Knowledge about availability**
- **Habit and preferences / Physician role**

About the project

Project team:

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Project homepage

https://tu-dresden.de/med/mf/imb/forschung/forschungsprojekte/bida-se

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DIE DRESDNER.

Implementation possibilities and clinical benefit of Big Data applications in the context of rare diseases

BIDA-SE

Current care situation of people with rare diseases

Aim of the project

The aim of the project is to develop a practical scenario and to make recommendations on the extent to which and under which organizational and technical conditions Big Data applications can be used in the future in the context of rare diseases. .

Development of an initial process model of the current care situation

In order to reflect the current care situation of people with rare diseases, a first draft of a care process model was developed based on a comprehensive literature search. The model includes primary care, outpatient specialist care, inpatient care, and care by a specialist outpatient clinic and a center for rare diseases.

First expert workshop

The process model was revised in the course of an expert workshop and agreed upon by the participants. The composition of the participants covered all of the previously mentioned medical areas. Since there is no uniform procedure for care in Germany, the idealized care process model refers to the environment of the University Hospital Dresden and the Centre for Rare Diseases located there. A transfer to other centers is nevertheless possible due to the claim to general validity in the development of the model.

Identification of potential Big Data applications in the context of rare diseases

Literature research

Relevant applications of Big Data for health care should be identified through a systematic literature search in subject-specific databases. In order to identify as many applications as possible, further selective research work was carried out and contributions from the first workshop were taken into account. For a better overview the applications were divided into groups according to their areas of application. The strengths and weaknesses, opportunities and risks of each group were identified by a SWOT analysis.

Sample functions of a Big Data application for diagnostic support:

- Decision support system that supports physicians in the process of diagnosing rare diseases
- Presents further information about the disease or contacts to specialists, and patient-relevant data
- Data is entered manually in the form of symptoms or automatically transferred from the patient's file and used to generate guideline-compliant recommendations
- Web application enables interdisciplinary, location-independent collaboration

Video about the application scenario

Development and evaluation of the application scenario

Second expert workshop

The goal of the second expert workshop was to create a realistic and medium-term feasible application scenario of one or more Big Data applications in the context of the care of people with rare diseases. The workshop was attended by experts from the fields of medicine, patient representatives, healthcare research, information technology and security, and data protection. At the beginning of the workshop, the experts were introduced to the previously identified technologies in order to get an impression of the possible applications of Big Data and IT.
In the group work phase, the care process model agreed upon in the first workshop was discussed, in which step of the care pathway the quality of care can be improved by which Big Data applications. The experts had the task of selecting possible Big Data applications for the individual process steps in order to optimize the patient care if possible.

Online survey

The scenario was evaluated in terms of the expected benefits, limits and barriers by means of an online survey. For this purpose, 113 representatives from the fields of medicine, patient representation, IT and health care research were shown a video at the beginning of the survey, which compares the health care process model from the first workshop and the optimized model from the second workshop. The participants were then asked questions to evaluate the application scenario, which served as a basis for the third workshop and the economic analysis.