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DESAM-ForNet Portal: A Novel Infrastructure to Integrate Distributed Information from Practice-Based Research Networks in the German Healthcare System

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Abstract. Currently the German healthcare system does not have a generic structure to answer research questions in primary care through clinical studies. The DESAM-ForNet initiative was founded as an association of German Practice-Based Research Networks (PBRN), to propose an appropriate and feasible solution. Aim is the integration of distributed, consensual information from practices into a single point of contact. To this end, a consensus-based concept for a digital infrastructure was developed in cooperation with all partners involved. Based on a joint requirements analysis the new concept integrates the federal structure of the German health system and the existing research structures.

Keywords. German healthcare system, clinical research, primary care

1. Introduction

Practice-Based Research Networks (PBRN) have been established as an integral part of the healthcare system in some countries [1]. To implement a PBRN concept in Germany, the peculiarities of the national healthcare system must be considered. There is little need for the structured exchange of information between General Practitioner Practices (GPPs), let alone the requisite networking. There is a lack of organizational and technical infrastructure to support this exchange. Healthcare services research is carried out in the institutes for general medicine, which are part of the medical faculties of the universities. Each institute cooperates with neighboring GPPs to form local networks. to develop a concept for such an infrastructure.

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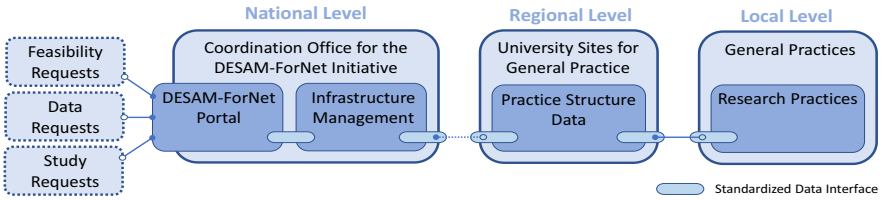

Figure 1. The general three-tier infrastructure.

2. Methods

A comprehensive requirements analysis was carried out that invited researchers from 29 institutes for general medicine, GPs and medical assistants in multi-disciplinary workshops. The objective was to develop specifications for all components required to facilitate centralized access to federally collected research data.

3. Results, Discussion and Conclusions

A three-level infrastructure concept was developed. It considers the requirements and specifics of the German healthcare system (Fig. 1). By enabling feasibility requests (e.g. structural data about GPPs), specific data requests and study requests to resolve research questions (e.g. the progress of a pandemic), it provides data exchange tools for research. At the *National level*, a web portal is hosted at the Coordination office for the DESAM-ForNet initiative. It provides a national single point of contact for interested parties. It enables requests to prepare and collaborate on clinical studies. No study and structural data are stored on this level. Requests will be forwarded to the university locations. An infrastructure management is provided to support the Federal Network Office.

Next, at the *regional / university level*, each participating institute manages its neighboring GPPs in a local PBRN. There, standardized structural data on GPPs is collected and maintained to enable comparative requests among all local PBRNs using a practice relationship management software (PRM). In addition to manage the local PBRN, the local network office acts as a study center, organizing and conducting clinical studies and processing requests from the portal.

Lastly, at the *local GPP level*, standardized data is collected supported by the local network office. GPP training and qualification is based on national standards to improve data processing quality and effectiveness.

Next, an interface to the portal infrastructure needs to be designed and developed that integrates existing solutions for research at the patient level in DESAM-ForNet. The proposed infrastructure and its interfaces have been approved by all members of the DESAM-ForNet initiative and enables nationwide clinical studies in the GPP setting.

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References

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