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Towards an Advanced Digital Infrastructure Within the Non-University Sector Demonstrated by the PICOS App

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Abstract. The non-university sector is a central facility for the medical care of patients in Germany. So far, information technology infrastructure in this local health care sector is not developed and the many generated patient data are not further used. In this project, an advanced integrative, digital infrastructure will be established within the regional health care provider. Furthermore, a clinical use case will demonstrate the functionality and added outcome value of cross-sectoral data with a newly developed app to support follow-up care of former intensive care unit patients. The app will give an overview of current health status and generate longitudinal data for use in further clinical research.

Keywords. ICU, PICS, app development, longitudinal data, interoperability

1. Introduction

Large amounts of medical data are generated in acute care facilities, but also in downstream structures like rehab centers, nursing care or medical practices. However, only little innovation exists interlinking these chains of patient care and thus generating one available, longitudinal set of patient data. Although first approaches might be applied in high care facilities like university hospitals, particularly non-university areas lack of such developments. Within the framework of the progress hub DISTANCE (Digital Smart Hub for Advanced Connected Care), the interoperable data exchange is extended to medical facilities of regional care. A clear benefit for patients, but also for medical professionals and science is demonstrated in a clinical use case designing a special, former ICU-patient oriented application. In comparison to other existing patient-oriented apps such as ThessHF [1] or Ada [2] the use case "Post Intensive Care Outcome Surveillance" (PICOS) is aimed at capturing cross-sector longitudinally patient data at different times after treatment on ICU. The data are collected from patients prone to suffer from psychological and physical complaints known as Post Intensive Care Syndrome (PICS) [3] after prolonged intensive care treatment. In the long term, resulting

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data collected via the app will be anonymized, merged and made available for secondary data analysis and research purposes.

2. Methods

The overall task of the progress hub is to incorporate the pioneering work of the German medical informatics initiative on digitalization in medicine from university hospitals into the non-university health care system. Within the use case PICOS, a patient-oriented app is developed. For the first time, it will be possible to collect a variety of vital parameters as longitudinal data from the patients' homes while documenting psychological and physical conditions of ICU outpatients, that are susceptible for the PICS. After a prolonged ICU stay, while still in the hospital, health care personnel will approach fitting patients and engage and teach them in usage of the app. For controlling and improving of their functional outcome, the PICOS app will collect information on the individual patient state of health, and it will also support medical self-care in daily life. Via this app, patients will have a constant overview over their health status through answering a daily or weekly questionnaire. This questionnaire includes among other things vital signs, sleep quality and pain assessment, all indicators of the PICS ^[3]. Moreover medication, medical appointments and documents can be saved in one place. As a further motivation, after periods 1, 3, 6 and 12 months, patients using the app will be invited to participate in free follow up examinations. For the first time, we present the PICOS app which bundles information on the mental and physical condition, while large amounts of data are generated with which the data situation on the long-term course of critical illnesses can be improved.

3. Discussion and Conclusion

The DISTANCE project will be using methods of data management and data modeling. Beside merging all incurring data of such a complex and prolonged treated patient group within different levels of care, previously unknown relationships and dependencies of various diseases might be identified. Clinicians, researchers, computer scientists and other health professionals can use the collected data to optimize clinical conditions and treatment processes for specific patient groups by providing and analyzing long-term observational data using artificial intelligence methods.

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