Linked Care - Information Transfer in Mobile Care and Support

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***ABSTRACT*—Mobile care professionals are facing immense workload, less time, and little recognition. They often have to finish their documentation work in leisure time and do not get enough information from the other health professionals. Information and Communication Technology (ICT) support can bring significant improvements for home care and the involved care giving parties. To increase its potential and operating range, the project, named Linked Care (LICA, consisting of the first to letters of both words), develops IT systems that address and support practice-oriented challenges, increase digital data availability and reduce the work-related burdens of health care professionals as well as clients/patients and their involved support system. Experiences with existing IT systems plus the current existing Austrian Electronic Health Record System (ELGA, an acronym of Elektronische Gesundheitsakte) serve as a starting point to enable a continuous information supply in mobile care and support within the project. The solution will provide interdisciplinary support and the connection of relevant participants in the care process, offering a new type of responsive user interface. The LICA-project investigates the end-users' needs and specifies the processes in workshops with local representatives and regional political and administrative stakeholders. In this way, the LICA-solution allows for the exchange and evaluation of care data via standardized interfaces throughout Austria, in consideration of the socio-economic regional and national environments. The project will create an ELGA-compatible software portal that can be linked to existing systems. Large-scale tests will be carried out in different federal states with at least 60 clients/patients (persons who are in the need of homecare) while implementing/using different survey methods to collect data. The consortium parties will ensure the development of the solution as a business model. Requested findings include feedback on software usability, application and affordability for the care giving and care receiving target group. The generated Care Summary creates new possibilities for data exchange within the health care sector.**

Keywords-IT documentation systems; communication systems; health care and nursing; interdisciplinary research

I. INTRODUCTION

Nurses experience many burdens and challenges in their daily work. Documentation is often described as particularly stressful [3]. According to estimates, about 30% of working hours are used for documentation. This time cannot be spent with clients/patients, which in turn can lead to nurses finishing documentation work in their free time to have more available hours for direct client-based care [5]. The increasing number of people in need of care leads to an increase not only in the objectively measurable but also in the subjectively experienced care effort. As the complexity within the formal and informal care support network is increasing, the need for adequate client-related coordination between the involved parties is also growing. A continuous and detailed client documentation is the starting point of client related coordination and communication. However, the organization of client documentation in the care system is not only challenging in terms of effort, it also shows deficiencies and complications regarding the information flow and exchange between the different formal and informal care giving/providing parties. Adequate documentation is indispensable for high-quality nursing and medical care, as well as interdisciplinary cooperation. Due to the dual financing system of medical care, nursing care and homecare, the resulting responsibilities may be different in nature and "not necessarily conducive to the efficiency of the systems" [2]. Furthermore, the lack of interdisciplinary exchange is closely related to financial and time constraints: only 60% of all mobile care service providers cooperate with professional groups outside their own services [2]. On the one hand, the heterogeneity of the documentation and communication systems offered by different providers complicates the communication connection/link within the different mobile services/software solutions. On the other hand, the non-existence of an obligatory uniform solution forms a massive barrier to continuous information transfer. Sophisticated services, which are needed to support recent technological innovations, have not been provided while creating data gaps in all areas of social welfare and health care. This causes discontinuance and translation problems within software solutions.

So far, the record validity was and still is questionable due to existing language barriers between the carer’s first language and the available application languages. Comprehensive documentation is particularly important. As an example, specific groups were identified, that are not familiar with professional care within their households (e.g., people with migration background, people with mental illnesses, etc.). The lack of affordability in the presence of social disadvantage or the lack of information of particularly vulnerable groups, for whom care is mainly provided informally or within the family. The situation described above points out the need for comprehensive documentation and communication that combines several information clusters. Therefore, it contributes to a subjectively facilitated situation and to an objectively increased efficiency [2]. It also advocates the improvement of communication and interface management based on detailed surveys.

The aim of this project is to enable a technology-based cooperation between clients/patients as well as their support system and professional caregivers, nursing professionals, doctors, therapists, and pharmacies while using an efficient, secure and low-threshold digital tool, offering optimal IT support.

This paper will give an insight into the LICA-project; starting with the ‘State of the Art’ in Section 2, followed by Section 3, ‘Method’, and finally describing the ‘Results’ as well as the ‘Conclusion and Further Works’ in Section 4 and 5.

II. STATE OF THE ART

Care network services exist all over the world. However, they neither include all necessary participants (medical care providers, pharmacies, care organizations, etc.) nor do they function on a digital level. Once integrated into one organization other services needed such as visiting services, home services and nursing care have to be organized by the employees [7].

In the EU and the USA there have been some digital developments in this field. Siemens eHealth Solutions [10] has created an electronic health network that brings together clients/patients, care teams and medical doctors to exchange relevant data. This system was designed for the clinical setting and not for the homecare sector. Furthermore, it does not include clients involved relatives or therapists. In the USA, the My HealtheVet portal [9] is available for Veterans by Veterans Health Administration (VHA) to renew prescriptions, organize doctor's appointments, contact health care teams, and retrieve information.

Online Care is an US-platform for clients/patients and healthcare providers that is oriented towards GPS (or postcode) entries and enables corresponding connections. In Europe, cross-border healthcare data flow is already established, especially in the "eHealth Digital Service Infrastructure" [8]. Patient Summaries, ePrescriptions and eDispensation, are currently being rolled out. In Austria, the electronic health record system ELGA uses the same IT and technology standards, to create a feasible connection. In addition to numerous other initiatives, the EU is also striving for an "EU Health Data Space" to make available data more accessible for practical use within the healthcare system.

III. METHOD

The research project started in April 2021 und will last until 2025. Five end-user partners, five technology partners and three scientific/research partners are included, whereby one partner is accountable for the information privacy protection mechanisms.

All required technical functionalities of the product will be identified and described by the team of developers and the potential end-user, while implementing the user-centered design approach [4], which is already currently running. Moreover, a mixed method approach, supported by a profound literature research, is used to identify, and approach the target groups in question as well as implement the appropriate methods for the various target groups and settings. By now, methods like focus group interviews, one-on-one interviews as well as research diaries are applied. The use of a participatory approach [6] enables the involvement of people and groups that are difficult to reach (e.g., 24-hour care but also very vulnerable people). All research methods are applied low threshold and in a culturally sensitive manner.

Additional stakeholders from the regional and national environment are involved to find solutions for specific issues. Over the duration of the project, goal-oriented, cross-disciplinary, and cross-role networks of individuals and organizations will be created. Sustaining and continuing these networks after the end of the project, represents one of the long-term goals. Acceptance factors are defined by the experts for all development steps, validated several times during the project in an iterative manner and therefore, influence the development process directly.

IV. RESULTS

The results of the project LICA contribute to the expansion and further development of innovative methods in data collection and participatory product development. New knowledge tools are going to be developed, which will be available for further research issues in the field of care and support after the end of the project. Now, during the project, data gaps and new (data) information regarding the various stakeholders in the care sector are identified and collected. On the one hand, this data refers to the situation and needs of people in care as well as professional caregivers in the informal or formal sector. On the other hand, this data refers to the communicative interaction between the care and the medical sector. Thus, it provides a valuable basis for the development of new projects in both, the nursing, and the care sector. Furthermore, the newly developed data sets (indicators) will enable previously unused possibilities for data exchange in the care sector and for the first time allow for a standardized data exchange between general medicine practices and pharmacies as well as therapists and other stakeholders without digital data discontinuity. The comprehensive involvement of different service providers in the development of the product offers a solid foundation for the adoption of the product and ensures a high-quality exchange of relevant information. The job satisfaction of those working in the health sector may increases due to reduced documentation effort, duplications, and losses of information – leaving more time for the care of the clients/patients themselves.

The inclusion of affected clients/patients and their relatives in the (ongoing) product development process, ensures the consideration of their needs and requirements. This increases the quality of care considerably in two regards: Firstly, the improvement of care and nursing on a somatic level is addressed and secondly the consistent participation of clients/patients and their social environment also increases the quality of care according to the WHO comprehensive concept of health:

Since physical as well as mental and social factors are equally included in the documentation process and clients/patients themselves can play a decisive role during the process, they experience themselves as individuals with the power to act, who can influence their environment and living conditions. Having the power to act represents a central resource for subjective well-being according to the salutogenic approach [1].

The interoperability between the project solution and other software systems, such as ELGA, general practitioners' software, pharmacies, mobile services, etc. is a novelty. The elaboration and application of indicators in the form of a care summary is an essential part of the content-related work and is only possible in a meaningful way by bringing different areas closer together. The increase in knowledge is possible due to the cooperation of mobile services, economy, scientific partners, and those affected.

V. CONCLUSION AND FUTURE WORKS

The LICA-project is innovative – for the first time the broad use of ICT and the strong networking of different organizations and people involved, will make it possible to assess, which practical benefits each of the intended functionalities will create for the mobile care services, caring relatives and how the user interfaces need to be designed to fit their needs. The user-centered design approach, which is applied in the whole research process enables this plan.

The profound literature research as well as the currently conducted focus group interviews show first significant results. These results provide a solid basis for the imminent research methods, which will take place in the upcoming four years.

ACKNOWLEDGMENT

This research is sponsored by the Austrian research promotion agency (FFG) under grant number 884194. Project partners are: Akademie für Altersforschung am Haus der Barmherzigkeit, Johanniter Österreich Ausbildung und Forschung gem. GmbH, Wiener Rotes Kreuz- Rettungs-, Krankentransport-, Pflege- und Betreuungsgesellschaft m.b.H., Volkshilfe Gesundheits- und Soziale Dienste GmbH (GSD GmbH), Volkshilfe Wien gemeinnützige Betriebs-GmbH, CareCenter Software GmbH, Loidl-Consulting & IT Services GmbH, Compugroup Medical CGM, Österreichische Apotheker-Verlagsgesellschaft m.b.H, Steszgal Informationstechnologie GmbH, Fachhochschule Technikum Wien, Universität Wien.

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