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Can Patient Contributed Data (PCD) Leverage Connected Health Technology for Cardiac Rehabilitation in Austria?

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Abstract. New technologies such as devices, apps, smartphones, and sensors not only enable people to self-monitor their health but also share their health data with healthcare professionals. Data collection and dissemination occur across a wide variety of environments and settings, tracking everything from biometric data to mood and behavior, which has been termed Patient Contributed Data (PCD). In this work, we created a patient journey, enabled by PCD, to shape a connected health model for Cardiac Rehabilitation (CR) in Austria. Consequently, we highlighted the potential PCD benefit, which is a postulated increasing uptake of CR and improved patient outcomes through apps in a home-based setting. Finally, we addressed the related challenges and policy barriers that hinder the implementation of CR-connected health in Austria and identified actions to be taken.

Keywords. Cardiac rehabilitation, connected health, interoperability, patient-contributed data, patient journey

1. Introduction

Patient Contributed Data (PCD) is defined as "*Any data, information, or insights created, collected by, or originating from a person regarding his or her health and care. It is particularly relevant when shared with one or more clinical care team members for the purpose of collaboration around the person's health*" [1]. PCD can play an essential role in linking connected health technologies, such as: digital health, eHealth, mHealth, telehealth, telemedicine, telecare, remote care, and assisted living. Connected health is understood as "*a socio-technical model for healthcare management and delivery by using technology to provide healthcare services remotely*" [2]. Thus, it includes all of

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the systems, processes, personnel and technology used to meet a specific patient care goal. Recent studies highlight the benefits of connected health for cardiovascular disease prevention and management [3], via providing activity tracking, blood pressure monitoring, dietary interventions, smoking cessation, lipid management, and risk assessment. Consequently, connected health expands Cardiac Rehabilitation (CR) services by supporting home-based programs as an effective adjacent or alternate approach to center-based CR programs [4,5]. Notably, there are many barriers that hinder a wider uptake of CR [6], including lack of referral, digital literacy, and reimbursement, as well as lack of a legal framework for integration into the Austrian Electronic Health Record (ELGA), and further concerns with data protection.

2. Methods

To explore potential PCD benefits in providing connected health for CR in Austria [7], we used a patient journey method [8,9] to highlight the role of PCD in addressing and overcoming the current CR challenges.

2.1. Markus' Journey: Out-patient and home-based CR with rich data capture

During this patient journey (see Figure 1), Markus aims to better control his cardiovascular risk factors, i.e., mainly high blood pressure, cholesterol, and physical inactivity to reduce the risk of disease progression and future cardiovascular events. As a result, he is motivated to pursue further healthy behavior changes.

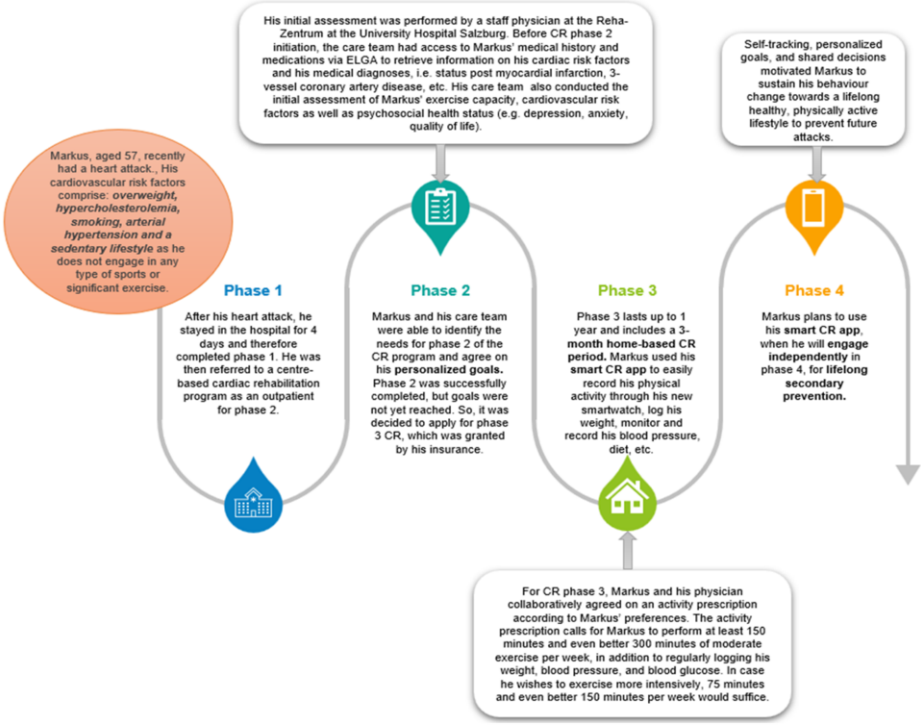

Figure 1. Markus' Journey during the four phases of cardiac rehabilitation.

Although Markus is not very engaged with technology, he finds a sense of satisfaction in using the smart CR app, recommended by his rehabilitation team, to track his progress and communicate with his care team during the four phases of CR in Austria [7].

2.2. Data Journey and used apps

The smart CR app enabled Markus to easily record his physical activity through his new smartwatch, log his weight, monitor and record his blood pressure (with the ability to link to a Bluetooth connected device and streamline blood pressure readings straight into the app). He also logged his daily caloric intake and dietary content of fat, saturated fat, sodium, and other nutrients in addition to eating habits. Tracking his diet was the hardest for Markus and he was pretty sporadic about doing so. His wife and daughter helped him in tracking these activities, entering the measurements when he complained about the burdensome tracking. Also, Markus worked on improving his skills in using the CR app, other health apps and his smartwatch.

On a weekly basis, all recorded data from Markus' smartwatch and smart CR app were transferred to his physician via passive data sharing. His weight from the app connected to his digital scale was automatically transferred (passive sharing). Markus had to select his mood indicator and enter other related symptoms via the smart CR app (active sharing). The physician requested all these data to assess Markus' risk factors during CR phase 2 (solicited) after working together to make a plan for tracking. Because of this collaboration, his clinician was able to assess Markus's risk factors weekly and make relevant shared-decisions on the required intervention plan and/or education. For example, when Markus did not achieve the physical activity goals one week, his rehab team was able to customize the activity plan for the following week to help him fulfill the World Health Organization (WHO) activity requirement, i.e., perform at least 150-300 min a week of moderate-intensity or 75-150 min a week of vigorous-intensity aerobic physical activity or an equivalent combination thereof. In addition, the multidisciplinary rehab team was able to share educational material on sustaining healthy lifestyles with Markus when he ran into barriers trying to lose weight during the three weeks. Markus also received educational material that helped him with smoking cessation. Figure 2 summarizes the used apps and aligned data journey. An extended discussion on PCD use in cardiac rehabilitation can be found in [1].

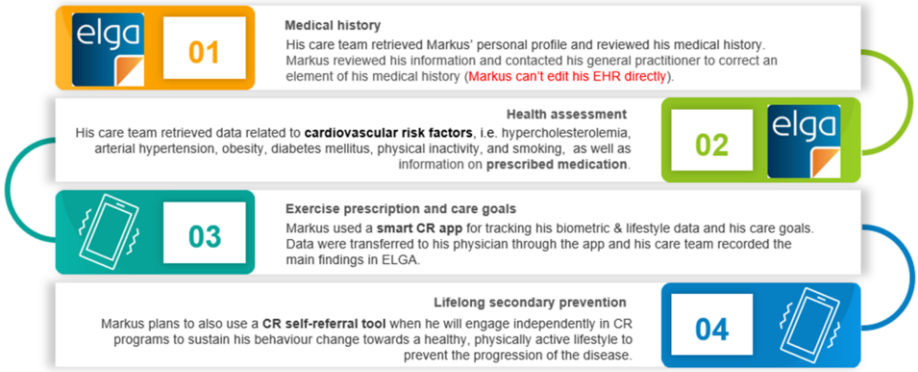

Figure 2. Markus' data journey and used apps.

3. Results and Discussions

The patient journey revealed the importance of PCD as a cornerstone in realizing a CR connected health model. Moreover, it identified current gaps, challenges in existing systems and relevant workflows, and the need for CR apps, as follows:

- The existing law of ELGA does not give the right to patients to write PCD into their records. Patients need to approach their care team who should be able to grant permission to upload the PCD on patients' behalf.
- Smart CR apps with proper educational material based on established behavioral change techniques are required to empower and engage patients, especially those with limited digital skills.
- Self-Referral apps can be introduced to overcome the challenge of the low referral and uptake rate of CR programs.

Subsequently, we addressed these challenges and recommended actions to be taken for realizing the CR connected health model in Austria as listed in Table.1.

Table 1. Challenges facing CR connected health model [6] and recommended actions to be taken

Policy Barriers	Ethical Concerns	Societal Factors	Technical Challenges
- Align the current national policies with the European Health Data Space (EHDS) regulations [10].	- Tackle the issues that hinder the uptake of digital health, e.g., data ownership, protection, sharing, and control. That's where the EHDS comes into play.	- Expand the existing programs of digital health literacy.	- Extend the infrastructure and interoperability layer for integrating (or linking) PCD with ELGA [11].
- Develop and finance a transparent certification process for CR apps.	- Support transparent, understandable, explainable, and fair use of Artificial Intelligence (AI).	- Provide easy access to digital platforms, e.g., single ID.	- Enable dynamic informed consent mechanisms.
- Harmonize the financing and cost for reimbursement policies.	- Provide equitable access to data within the connected health model.	- Promote knowledge about efficacy of home-based CR solutions.	- Develop AI automation tools and CR smart apps [12].

4. Conclusions

The described patient-centered connected healthcare model for CR integrates electronic health record, digital health technologies and cardiac telerehabilitation through PCD. This enables CR patients to stay in their home environment and capture rich data that supports them in reaching their health goals and has the potential to support their long-term priorities. These data are shared with the care team to monitor patients' cardiovascular risk factors and understand how patients are progressing. This also has a direct benefit to CR patients through improving the quality and outcomes of their care plan, which can be expected to translate into reduced morbidity and mortality. Indeed, it has been previously shown, that heart attack survivors who completed CR were 40% less likely to experience another heart attack [13]. In order to increase the number of patients who enroll in CR as well as to improve and individualize the quality of CR programs,

we need to overcome addressed challenges and policy barriers, which currently hinder the alignment with EHDS requirements [10].

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