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Digital Patient Communication: Improving the Hospital-Patient Relationship

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> Abstract. Digitally engaging patients in their care processes was for many years limited to sharing care related documents (e.g. laboratory or radiology findings, discharge letters) with them through personal electronic health records. Newer concepts have led to the establishment of patient portals as patient frontends to a hospital's electronic health record. Rarely however have complete patient pathways with pre-hospitalization, inpatient stay and post-hospitalization been evaluated to identify chains of communication processes involving clinical care scenarios, as well as subsequent home monitoring scenarios. Neither have such approaches been integrated with digital communication processes related to a patient's engagement in medical research projects. In order to enhance hospitalpatient relationships in a holistic manner, we hypothesize that an integrated environment (e.g. patient portal) supporting shared decision making and communication in a patient's care situation and in the same time providing communication processes for patient research engagement will optimize the patient-hospital relationship and be supportive in binding a patient to this care providing institution.

Keywords. Electronic patient portal, digital patient communication

1. Introduction

"Citizens in Switzerland are digitally literate and use the possibilities of new technologies in an optimal way in order to care for their health. Health institutions and health care professionals participate in a digital network, exchange information along the care process digitally and can reuse once documented data for multiple purposes" This is the vision in the eHealth strategy Suisse 2.0 for the years 2018 to 2022 [1]. One of the five goals in this eHealth strategy claims that "if patients can self-determined decide about the access to their health data and can themselves access their data whenever they want to, they can be more actively involved in the decision making process in terms of their health behaviour their health problems and their medical treatment. They thus strengthen their own health competency". One of the major tools for this digitalization process with strong patient involvement is the electronic patient dossier (EPD) [2, 3]. In Austria a similar personal electronic health records for patients and their doctors, as well as other health records for patients and their doctors, as well as other health records for patients and their doctors.

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care professionals at hospitals, care facilities and pharmacies" [4]. Both system's architecture is based on a distributed network of data repositories and registries according to the IHE XDS integration profile. In Germany the eHealth law has been published in December 2015 and defined an electronic patient record which should be useable by every patient with statutory health insurance latest in January 2021. In December 2018 a first specification of the respective applications has been released [5]. All such approaches however have their major focus on a *"Health Information Exchange (HIE), which allows health care professionals and patients to appropriately access and securely share a patient's medical information electronically"* [6].

The wording in the above definitions always depicts the sharing of health (care) related documents and a shared access to such patient information. Technically many of those personal electronic health records are based on IHE profiles such as IHE Cross Enterprise Document Sharing (XDS) and IHE Cross-Community Access (XCA). Rarely do the specifications of such personal electronic health records directly relate the technical process of "document sharing" to real world clinical processes, especially to care process related communication processes between health care institutions and patients.

On the other side has the field of mHealth applications in recent years gained an enormous attention and data generation, e.g. based on miniature sensor technologies, directly by patients are meanwhile state of the art. The promotion of innovative mHealth applications (e.g. smart phone apps) will, in the context of the Swiss EPD play an important role for the increased patient involvement [1]. Last but not least, it has been mentioned in many scientific publications, especially coming from U.S. researchers, that the widespread electronic health record adoption has also led to an increasing interest to leverage patient portals to improve care [7].

Based on those current developments we will in the following propose digital patient communication processes, which aim at improving the hospital-patient relationship based on patient portals as entry points into a hospital's electronic health record systems. The focus of such patient portals will however not only be on document sharing, but rather on efficient support for dedicated patient care and translational research processes with efficient integration of various types of mHealth applications.

2. Digital patient communication processes in patient care pathways

The typical non-emergency patient pathway of a patient for a planned inpatient stay starts with providing the patient with general information about the hospital itself, how to locate to the hospital (e.g. parking lot), especially to the patient admission area and with information how to find the clinic/ward. The patient may be additionally informed about particular preparations she would need to take care of before coming to the hospital. Traditionally such information is still send to a patient by postal mail.

In a modern innovative hospital with an electronic patient portal however, the first step involved in a first contact with the patient might be to ask her, if she would prefer to communicate electronically via the hospital's patient portal, or if traditional surface mail or phone contacts would be her preferred communication channel. In the years to come we predict that a steadily increasing number of patients will prefer online communicate with their healthcare provider. According to the German internet usage statistics in 2018 the age group of over 70 was the one with the highest rate of increased internet use at all, whereby close to 70% of the group 70 and older and 82% in the group 60-69 are internet users already in 2018 [8]. According to "We are social" more than two-thirds of the world's population now has a mobile smartphone. They describe, that it's increasingly easy for people to enjoy a rich internet experience wherever they are [9]. Thus, in less than five years we can expect that more than 90% of the patients will prefer a mobile online communication with their hospital.

Therefore hospitals in Europe should follow the example of many U.S. hospitals which have already implemented patient portals and are now in the phase of evaluating their patient portals' effectiveness [10]. Others are investigating the usage of patient portals for communication scenarios with patients with chronic diseases (e.g. diabetes patients [11] or lung cancer patients [12]). Especially such chronic patients with many hospital inpatient and outpatient contacts will preferably stay in contact with their care provider based on digital communication through a patient portal. Thus, we imagine, that in a typical pre patient admission communication in future a patient portal may not only provide the patient with information about his upcoming stay, but may also directly gather some patient history information in order to make the later history taking process in the hospital more efficient.

Following a patient's pathway through the hospital we do already see investigations to also support hospitalized patients during their stay with inpatient portal functions directly at the bedside (e.g. [13,14]). After a patient's discharge, monitoring the patient's status electronically or supporting her in her control and self management (e.g. for diabetes patients) is already supported by numerous types of mobile smart phone applications [15]. Finally, many developments have already focused on continuous home based glucose monitoring [16], smart home-based health platform for behavioral monitoring and alteration of diabetes patients [17] or even sensor-based monitoring approaches with contact-lenses [18].

However, all such innovative new developments currently are singular standalone applications which are investigated in pilot implementations or early clinical trials. In a hospital the chance is currently high that different such mobile monitoring and patient communication technologies, applying sensor technologies and mobile applications, are investigated by different specialties for different disease scenarios. This illustrates the urgent need for a coherent platform approach, were a hospital defines a strategy on how to integrate the numerous pre-post- and hospitalization scenarios for monitoring a patient's status at home, but also continuously staying in touch with her and providing efficient, digital means for communication, into an EHR integrated patient portal. It further illustrates that improving the hospital-patient relationship can not just be solved by more or less static document exchange or sharing (e.g. via personal electronic patient health records), but requires a comprehensive understanding of complete patient processes in their pathway from a planned admission, through the inpatient phase and after the patient's discharge. Especially for patients with chronic diseases such pathways typically repeat themselves continuously and dedicated communication processes through such a chain of hospital contacts should by established and digitally supported.

3. Digital patient communication processes for patient research engagement

Digital patient communication however shall not only be related to the patient care process. In recent years there is also a growing interest in engaging patients in

healthcare research [19, 20]. As illustrated by Hearld et al however, although it is promising that people are interested in being engaged in research, the results suggest that there is work to be done to raise awareness of these engagement opportunities [21]. While raising awareness to opportunities for patient research engagement is one challenge, obtaining a patient's informed consent for the reuse of data, which are for example collected during their hospital care, for patient centered outcomes research and other types of real world data analysis is a further challenge. Large international data sharing and data reuse projects such as e.g. PCORNET [21,22] or OHDSI [24] are currently being followed by similar European initiatives, such as the German medical informatics initiative [24], the German biobank alliance [25] or the Swiss Personalized Health Network (SPHN) [26]. All such initiatives are currently working on creating (hopefully nationwide standardized) patient information folders to describe potential future use of data for research and healthcare in very general terms (modular broad consent) [27] and apply this for obtaining a patient's informed consent.

In a best practice approach engaging patients in such types of research partnerships, obtaining their informed consent, but also providing them easy ways to also withdraw their consent again, shall also be accompanied by personalized information about the use of their data in respective research studies. Spencer and colleagues for example have explored patient perspectives on the use of anonymized health care data for research purposes and evaluated patient perceptions about an electronic system to enable and implement ongoing communication and collaboration between patients and researchers [28]. In their case, patients can digitally tailor preferences about whom they share their data with and can change their preferences reliably at any time. Furthermore they propose electronic systems which provide opportunities for informing patients about data recipients and the results of research to which their data have contributed. Rare disease researchers have, in the RUDY (Rare UK Diseases of bone, joints and blood vessels) study successfully pioneered an approach which applies a custom-developed electronic platform for such research oriented patient communication and where patients can additionally contribute information over time about their disease experience, lifestyle and clinical history [29].

In a comprehensive research infrastructure, such as the data integration centers, which shall be established as integrated parts of a hospital's information system infrastructure in the German medical informatics initiative [24] many components need to be integrated for an efficient and data protected flow of data from the clinical environment to the respective research data repositories. In the MIRACUM consortium we build those data integration centers on the MIRACOLIX ecosystem, which amongst others comprises components for data pseudonymisation (ID-management), consent management and project proposal management [30]. The latter shall be applied for entering data usage requests for new research studies, support the internal review process of such a data request for obtaining the vote of the data access and usage committee, publishing data usage projects which have been initiated based on data from a respective MIRACUM site and finally tracking such projects for their research results.

In order to motivate the future engagement of patients in the medical informatics initiative research projects we propose to establish a patient portal in a respective university hospital as an entrance port towards the hospital's EHR, but also to the integrated environment of the project proposal management and the consent management components of a data integration center. As a major component for the support of research oriented patient communication processes the portal should provide means for accessing a multimedia (e.g. animated video) electronic patient information, a digital consent/withdrawal frontend, and, similarly to the RUDY portal, enable ongoing communication, information about data usage and collaboration between patients and researchers [29]. Additionally, the patient portal should contribute to patients providing information over time about their disease experience, lifestyle and clinical history.

4. Conclusion

In a society with more than 90 percent of people accessing the internet via their smartphone, where digitally booking one's train-/flight ticket, making hotel reservations, ordering foot and participating in social media communities are common activities of daily living for almost everybody, hospitals can not ignore that traditional paper and postal mail communication will be outdated soon. Even though today still parts of the older patient generation may not be online yet, this can't be taken as an excuse for not planning ahead and at least visioning future hospital-patient communication scenarios, where the relationship between a patient and "her" hospital will strongly depend on the efficiency and ease of use for digitally communicating with their doctors and with the hospital administration. Communication however is always embedded in more complex scenarios and treatment pathways and is much more, than just exchanging documents. We are therefore convinced that innovative hospitals planning ahead for the future, will analyze and model their communication scenarios, especially related to patients with chronic diseases, will in parallel also design relevant research related communication scenarios and thus create a set of requirements for their future EHR integrated patient portal. In the years to come we need to see many more such pilot implementations. However, we also need to realize that hospital-patient communications are still a very new area and that not just the technology but rather the socio-technological changes associated with such new communication channels will be the most important challenges to master. Thus, evaluation research on the acceptance of such portals and the features which will really be accepted and used by patients will be important for their successful stepwise introduction.

5. Conflict of Interest

The authors declare that there is no conflict of interest.

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