

## Digitalization of Patient Information Process from Hospital to Community (Home) Care Nurses: International Perspectives

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### Abstract

*For older people who transition from hospital to home, home care is an increasingly important and effective way of managing chronic illness with skilled nursing care in the home. Communication between clinicians across care settings is fundamental for continuity of care. Poor communication of patient information is acknowledged to be a root cause of sentinel events. In Scandinavia and the United States, researchers study the communication of patient information from hospital to home care. The health care systems of these two countries differ. Differences are reflected in the characteristics of patients transferred from hospital to home care, as well as the characteristics of health information systems (ICT). These differences help to elucidate key issues related to the transfer of patient information from hospital to home care.*

**Keywords:** Communication; Home Care Services; Continuity of Patient Care/standards; Nursing Informatics

### Introduction

For older people who transition from hospital to home, home care is an increasingly important and effective way of managing chronic illness with skilled nursing care in the home. Communication between clinicians across care settings is fundamental for continuity of care, as well as for patients' active participation in self-care activities at home. Poor communication of patient information is acknowledged to be a root cause of sentinel events and rehospitalization.

In Scandinavia and the United States, researchers study the communication of patient information from hospital to home care. The health care systems of these countries differ. Differences are reflected in the characteristics of patients transferred from hospital to home care, as well as the characteristics of health information systems (ICT). These differences help to elucidate key issues related to the transfer of patient information from hospital to home care.

The session will begin with a five-minute presentation by the moderator to describe the purpose and format of the panel, and to introduce the panelists. The international panel of three informaticians will draw on examples from their own research. A 18-minute presentation by each panelist will follow. Panelists will provide a context for their work with a brief description of their country's health care system and health information systems, as focused on the hospital to home care transition- in-

care. These descriptions will illustrate the current diversity in health information system needs and capabilities. The panelists will describe their studies and findings regarding the communication of patient information from hospital to home care. The findings will include a brief description of the health information system (ICT) challenges and opportunities. We will then open the floor to discussion among panelists and with the audience in the remaining 30 minutes. Audience discussion will focus on addressing health information system (ICT) challenges and opportunities identified by the panelists and those raised by audience members. The goal of this session is to open discussion and promote sharing around experiences of and questions related to interoperability between hospital and home care. We expect that the following topics will emerge from the presentations, promoting audience participation:

- Workflow challenges at the hospital and home care related to communication of patient information
- Differences in perspective related to what information should be communicated to home care and the impact on information availability and accessibility
- Interoperability hurdles between hospital EHRs and home care EHRs

### Panelist presentations

Paulina Sockolow will briefly describe the US health system characteristics in regards to patient with multiple chronic conditions, electronic health records at the hospital and at the home care agency that are not interoperable, and dependence on paper and telephone communication. In our US study, we asked home care nurses who admit patients what information they needed during an admission to make four important clinical decisions. We then observed nurses admit patients to home care, and recorded what information the nurses had available at the admission. To compare what information nurses said they needed to the information nurses had, we mapped both data sets to the Continuity of Care Document (CCD), which is an international specification for transitions in care information. We found that the referral documents generated by the hospital contained more of the information nurses said they needed as compared to the other available documents (intake form, discharge summary). However, the referral documents were not standardized in regards to the information contained and how it was organized. We observed nurses looking through many pages of referral documents looking for a single piece of information. Furthermore, no

document contained all the information that nurses said they needed, which caused nurses to look in multiple places to find information, which took nurse time, energy and cognitive effort away from patient care. Nurses searching among pages of documentation for information which may not be present introduces patient safety concerns of increased risk for errors.

**Ragnhild Hellesø:** The evolution of healthcare delivery, in terms of where service can take place, calls for new and deeper insights into how long-term care can best be provided. In Norway, it is stated that the municipalities should have the responsibility for long-term care. Ensuring access to accurate and in-time information when patients are transferred between healthcare settings, have shown to be difficult to achieve. Regardless of much effort to improve the information processes, several studies and reports emphasize that transitions put patients at risk due to insufficient and lack of information.

We conducted a descriptive study in 2017, in which we surveyed Norwegian nurses working in the municipality health care sector, i.e. nurses working in nursing homes or in patients home. We investigated their perceptions of their collaboration and information processes with the hospitals during their discharge planning. Building on previous studies, we developed and piloted a questionnaire addressing the nurses' collaboration and exchange of information when patients were transferred to municipal health care setting. We addressed issues about the information they received about the patients and the use of digitalization in this process. Findings from the nationwide study will be presented and in particular, the nurses' assessments of the accuracy and appropriateness of information they exchange as well as their modes of communication will be highlighted.

**Miriam Ekstedt:** Healthcare in Sweden is mainly publicly funded. All residents are insured by the state, with equal access to healthcare for the entire population. Out-of-pocket fees are low and regulated by law. The responsibility for healthcare services is divided on three levels: between the state, 21 county councils and 290 municipalities. The municipalities are in addition to social care, responsible for providing long-term inpatient health care and home healthcare for older people. Each county and municipality in Sweden has sovereignty as regards how to achieve collaboration between professionals and stakeholders at different levels of care, meaning that a wide variety of models for integrated care have emerged. In addition free choice of providers and the bolstering of private markets have, for example, in the Stockholm area resulted in that 26 municipalities and over 200 different homecare service companies struggle to coordinate homecare for the older people in need for care at home.

In previous research we have learned that patients with chronic or complex diseases often experience difficulties when transitioning from hospital care to self-care in their home. Many of the difficulties experienced can be attributed to the multiple caregivers involved in a single patient's care. Another factor may be the briefness of discharge meetings in hospital, which means that personnel do not have time to prepare patients for self-management, while patients might not know what to ask about. In our current studies following care trajectories in patients with chronic care conditions (i.e., COPD, heart failure, diabetes, cancer) we observed that the patients were excluded from the communication flow between different stakeholders in the care trajectory.

Drawing on our own and related research on care transitions and eHealth tools developed for more specific settings, we address these difficulties by developing an eHealth tool for patients – ePATH (electronic Patient Activation in Treatment

at Home) – intended to empower patients to navigate their care trajectory and perform their self-care activities at home. ePATH is a web-based and mobile application (mPATH) for smartphones linked to the web-application with a secure login for patients and care providers. The application contains access to tailored comprehensive information about diagnosis and treatment, a standardized care plan, list of medications and self-care support. ePATH supports functions enabling the patient to communicate with his health care contacts and report self-care activities (e.g., exercise based on the condition of the patient and in collaboration with a physiotherapist or dietary and food intake based on a dietitian's advice) as well as function to monitor and track their self-care activities, and symptoms of relevance for diagnosis and follow reported data over time. Notifications of exercises or medication can be activated to support and remind the patient.

The multidisciplinary research team has applied a user-centered design process (based on the ISO standard of "Human-centered design for interactive systems") that involved patients with multiple chronic conditions and healthcare personnel from different healthcare settings (e.g., specialist care primary care, home healthcare, social services and/or rehabilitation teams) in iterative design cycles. The design process resulted in a functional prototype that captures patient needs, but also emphasizes integration with the care processes of healthcare providers. Health professionals provide patients with individually tailored information about treatment goals and assessments to be aware of (e.g., blood pressure, HbA1c, weight) and self-care activities that can be performed at home. Tailoring and evaluation of self-care activities are done in collaboration with the patient during a care visit. Patients can bring the information to share with different care providers. The main lessons learned are that (1) it is necessary to develop the professionals' work processes and information paths, and (2) patients incorporate motivational components in the development of an eHealth tool to successfully overcome the gap between "knowing what to do" and what people really do (the "intention-behavior" gap) and form new and lasting self-management behavior. Guided by motivational theory (Self Determination theory) and gamification strategies, tailoring of self-care activities based on patients preferences and needs will increase user motivation, engagement and adherence to treatment.

We will present lessons learned during the development phase and present data from usability testing with patients with chronic conditions (i.e., diabetes, COPD, heart failure) and present preliminary results from the RCT in prostate cancer patients.

## Brief biographies of the panelists

Paulina Sockolow, Drexel University College of Nursing and Health Professions and College of Computing and Informatics, Philadelphia, PA, USA. Dr. Sockolow is an Associate Professor of Informatics. Her research focus is the development and implementation of health information technology (HIT) analysis and evaluation methods to discern the impact of HIT on work and clinical process. Specifically, she conducts research on development and implementation of HIT evaluation frameworks and instruments; and application of Mixed Methods approaches to HIT analysis and evaluation.

Ragnhild Hellesø, Institute of Health and Sciences at the University of Oslo, Norway; and Centre for Care Research, Gjøvik University College, Gjøvik, Norway. Dr. Hellesø is a Professor in Nursing Sciences. Over the last ten years, Dr.

Hellesø has investigated the experiences about facilitators and barriers from a broad spectrum of information processes both within and across healthcare settings and the clinicians' use of information systems. Her research has gained national and international recognition and she has been awarded for excellent research within the field.

Mirjam Ekstedt is a professor in nursing sciences and a research group leader at Linnaeus University, Kalmar/Växjö and Department of Learning, Informatics Management and Ethics, Karolinska Institutet, Stockholm, Sweden. She also holds a position as an affiliated professor at KTH, Royal Institute of Technology, Stockholm in system safety in healthcare organization. Her research on resilience engineering in complex adaptive systems is focused on developing, testing and implementation of methods and tools (i.e. eHealth-support based on gamification and motivational theories) to improve work processes and involve patients as active partners with specific focus on transitional care, cancer care, and home healthcare.

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