

Improving healthcare through support systems...

...for communication and information sharing between patients and care providers...

The Centre for Shared Decision Making is a research department at the Rikshospitalet Medical Centre, the largest medical research environment in Norway. The Centre has a dedicated research programme related to the development and testing of support systems for communication and information sharing between patients and care providers. Using participatory design and agile methods, we focus on mobile and device-independent solutions that are helpful and user-friendly for diverse user groups in different contexts of use and that apply strict security mechanisms. Our goal is to improve healthcare, patient outcomes and safety; empower patients through systems that allow them to stay connected with their care providers between clinical encounters; monitor and report their symptoms and health problems; help them better understand and manage their illness; become more engaged in their care; and have more control over their own health data.

Examples of current applications include:

- 'Choice' is an interactive tailored patient assessment tool. Prior to a clinical encounter, patients use a portable device to report their symptoms and health problems to their care provider, including the degree of bother and priority for care. Questions that are asked are tailored to each patient individually, based upon his or her initial response. In that manner, superfluous questions are eliminated and questions that remain are more relevant to the patient. When done, the system creates an assessment summary that is integrated into the patient's electronic health record and that displays patients' selected symptoms ranked by their priorities

for care. This information is used by patients and clinicians for subsequent shared care planning and assists clinicians to better tailor treatment and care individually to each patient. The 'Choice' application has consistently demonstrated to significantly improve patient-centred care in rehabilitation and cancer patients.

- 'WebChoice' is an internet support system to help patients to manage their symptoms and health problems from where and whenever they need it. Its 'Assessment Component' allows patients to report and monitor online their symptoms, distress, health problems over time and their priorities for support. In the 'Tailored Symptom Self-management Support' section patients' self-reported symptoms trigger the display of the appropriate subset of evidence-based self-management activities from which patients can choose. Each message contains an explanation of what the activity is, how to perform it, potential risks, side-effects, contraindications, when to contact a physician, level of evidence, references to the source of information from where the evidence was obtained, and links to other relevant, reliable websites that contain related information. In the 'Communication Component' patients can ask questions to a clinical nurse specialist who enters the communication area daily to answer patients' questions, provide information and emotional support. Patients have also access to an unrestricted peer support forum for group



discussion, where they can share their experiences with other patients.

- 'SiSom' is an interactive assessment and communication tool for children, with the purpose of giving them a voice in their own care. SiSom helps children with cancer report their symptoms/problems in a child-friendly, age-adjusted manner, and clinicians to improve patient-provider communication and patient-centred care. Healthy children and children with cancer participated actively in all stages of the design process. SiSom uses spoken text, sound, animations and intuitively meaningful metaphors and pictures to depict symptoms and problems that even younger children who cannot read can respond to.

The main navigation theme in 'SiSom' is a 'sailing from island-to-island' (see pictures) metaphor, where symptoms are placed on



An example of the 'SiSom' application



islands that children can visit with the help of a self-selected figure. Each symptom/problem is represented with a picture, for example: trouble sleeping.

When the child has visited all the islands, a child-friendly report that summarises the child's reported problems is displayed and can be printed. This report can be used by health professionals together with the child during consultations to tailor patient care to each child individually.

- A shared electronic health record (EHR) for patients and care providers provides a seamless environment where patients can share their data, communicate with their care providers, and obtain support from wherever and

whenever they need it, all within the same system.

Our tools have repeatedly shown in clinical trials to improve patient-centred care, patient-provider communication and patient outcomes. Patients become more knowledgeable, more accountable and more active participants in their own healthcare. The tools have broad applicability for many patient groups.

The strength of our department is that it combines informatics with clinical research. A particular focus in our informatics research is directed towards solutions that allow patient access to a shared EHR and other support systems through a mobile environment in a manner that ensures adaptation, readability, mobility and security while the user is moving seamlessly through heteroge-

neous networks from different locations. Key issues are safeguarding data security and confidentiality and verification of usability and readability that is needed on a mobile platform with limited display size and diverse user interfaces. The personal and omnipresent nature of mobile phones makes them well suited for day to day tracking of medical status and early detection and prevention of risk factors; and they provide personal and secure communication between the patient and care providers.

Other research areas include theoretical, methodological as well as cognitive and behavioural questions associated with decision-making, patient comprehension of health information, interoperability between professional and consumer-oriented systems and vocabularies, questions related to streamlining and adapting communication systems into standard clinical practice, user-centred design and usability, and effects on patient, provider, societal and economic outcomes.

The Centre has been very successful in obtaining external funding. Enjoying a strong international collaboration with researchers from the US, Europe and Norway, our interdisciplinary research group includes currently five professors, 10 PhD students from interdisciplinary backgrounds, system developers and designers, and a large number of externally funded research staff.

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