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AREA OF EXPERTISE: Design of Information Systems

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DATE OF DISPUTATION: 3rd of November 2017

DISSERTATION TITLE: "In Illness and in Health"

A critical inquiry of the potential of digital health technology for supporting youth in health care

transitions

For young patients with chronic health challenges, turning 18 entails not only becoming a legal adult, but also an adult in health care. Young patients need to transfer from pediatrics to adult health services; services that represent two very different approaches to care and require different knowledge and skills from patients. Because of the many challenges and possible negative outcomes related to this transfer, transition has been suggested by the medical community as a concept to organize transfer of young patients as a planned process to ease patients into their new role and responsibilities. Norwegian hospitals and the ministry of health are developing new standards, guidelines, and tools for better transition care for young patients. Digital health technology is presented as holding a significant potential for supporting transition and empowering patients.

This thesis reports from a study of the transition care needs of young patients with Inflammatory Bowel Disease in order to map the possibilities for how technology can support the process of transition. The interviews with young patients were combined with document studies to provide a larger picture of the potential of digital health technologies for supporting young patients in health-seeking. The document study identified a substantial lack of critical discussion of digital health technology in the Norwegian media and public discourse and, paired with the results of the interviews, indicated that young patients' needs deviate from the potential of technology presented in the public discourse. Furthermore, this thesis proposes fluidity, a concept drawn from the field of Science and Technology Studies, as a helpful concept for understanding transition and transition care needs of young patients. This insight changes the design space for technologies for transition, where design should shift from process-oriented to passage-oriented. Lastly, the thesis questions the equation of patient empowerment with the use of digital health technology and argues for the need to include young patients in design of digital health technologies in order to represent their interests and the way in which they view their body.