

Towards a New Model for Chronic Disease Consultations

Pietro Randine^{1,2}, John Graham Cooper³, Gunnar Hartvigsen^{1,4}, Eirik Årsand^{1,2}

¹UiT The Arctic University of Norway, Department of Computer Science, Tromsø, Norway pietro.randine@uit.no

²Norwegian Centre for E-health Research, University Hospital of North Norway, Tromsø, Norway

³Norwegian Quality Improvement of Laboratory Examinations, Haraldsplass Deaconess Hospital, Bergen, Norway

⁴University of Agder, Department of Health and Nursing Science, Grimstad, Norway

Abstract

Medical consultations for chronic diseases form an arena to provide information from health personnel to patients. This information is necessary for patients to understand how to deal with the possible lifelong symptoms and needed self-management activities. The amount of patient-generated health data is increasing. Today's patients gather an increasing amount of personalised health-related information. Meanwhile, the health personnel get more patients to care for and fewer resources. This paper summarises information and communication technologies possibilities for improved diabetes consultations. It aims to inform how the medical consultation for chronic diseases needs to change drastically to meet today and future's challenges.

Keywords

Health information system, Patient-generated health data, Chronic disease, Diabetes, Consultation

1 INTRODUCTION

Compared with the general population, those with chronic diseases (e.g., diabetes, cardiovascular diseases, and pulmonary diseases) require more frequent medical attention and symptom management [1]. Individuals from any age group, region and country can be affected by chronic diseases. Chronic diseases impose a significant economic burden on the global healthcare system [2], with predictions becoming more severe regarding the number of people affected and the costs to society.

Once an individual is diagnosed with a chronic disease, this often represents a life-long change in their life. First, the patient needs to understand their new condition and possibly define a health care plan together with the health personnel. This plan may include medication, exercise, therapy, and diet [3]. Then it should be explained and discussed during the medical consultations. After the first consultation, the following consultations often become periodic and are typically performed one to four times a year [4]. This scenario may be more complicated if the patient belongs to a vulnerable group such as children or the elderly. In this case, the medical consultation often involves others, such as parents, next of kin, and informal caregivers [5, 6], introducing additional challenges to the medical consultation.

1.1 Patient-generated health data

Especially in the last 5-10 years, patients have gained more access to health-related devices and information. It is now much easier to track, register and view physical activities, symptoms or treatments via smartphone applications

(apps), commercial wearable devices [7], and Internet of Things (IoT) solutions.

This new information can be used in the decision-making process during consultations and help to define an individual health care plan for the patient. The information flow also expands outside healthcare settings via patient groups on social media [8] and the possibility of sharing patient-gathered health data through apps and cloud-based solutions. Nowadays, social media groups are also used as an alternative resource to prepare before a consultation about symptoms, treatment options, related illnesses, self-management devices, and other health-related issues [9]. Social media groups may complement the consultation with information support without bypassing the health personnel [10]. However, patients seeking missing information on social media can be exposed to misinformation [11] due to difficulty ensuring information quality and accuracy [12, 13].

2 OBJECTIVE

This paper discusses a new model of medical consultation for chronic diseases. As our example, we will focus on a specific chronic condition, type 1 diabetes. First, we describe the current practice for medical consultation. Then we present the proposed model and discuss its implications.

The 18th Scandinavian Conference on Health informatics, Tromsø, Norway, August 22-24, 2022. Organized by UiT The Arctic University of Norway. Conference Proceedings published by Linköping University Electronic Press at <https://doi.org/10.3384/ecp187>. © The Author(s). This work is licensed under the Creative Commons Attribution-NonCommercial 4.0 International License. To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc/4.0/>

3 WHAT DO WE KNOW ABOUT MEDICAL CONSULTATIONS TODAY?

Medical consultations for chronic diseases are physical or remote meetings between patients and health personnel. A medical consultation represents an opportunity to clarify the patient's understanding of their condition [14] and can provide procedures, tools and advice for managing their disease(s) and challenges. Studies have shown that if the patient is an active part of the consultation and the decision-making process, they become better informed about their treatment options [15] and self-management alternatives [16].

The success of a consultation is often determined by how well the patients and the health personnel communicate [17]. A systematic review, including studies from 67 countries, discovered that consultations usually last only a few minutes despite the importance of the health issue. Short consultations may adversely affect patients' disease management and health personnel's workload [18] and increase the risk of medical errors [19].

3.1 A Use case: type 1 diabetes consultations

Patients with type 1 diabetes may use devices from diverse vendors, such as continuous glucose monitors (CGMs), insulin pump systems, blood glucose meters or insulin pens, based on their needs and availability. These devices allow the patient to record and monitor glucose levels, medication (insulin) use, and daily food intake. The devices are connected to the vendors' technological solution, typically a smartphone app for the patient, a web interface for the health personnel, and a cloud-based infrastructure that synchronises the collected information and possibly shares it with others such as relatives, family members, and health personnel.

The goals of diabetes treatment are to prevent or delay short- and long-term complications and optimise quality of life. Treatment goals and management plans should be created together with patients based on their individual preferences, health status, and goals. People with diabetes should have at least one annual consultation. This consultation should be a comprehensive medical evaluation that includes an assessment for diabetes complications and potential comorbid conditions together with a review of previous treatment and risk factor control. Together with the patient, the health personnel should then assess the need to adjust the individual treatment targets. There may also be a need to address diabetes-related psychosocial problems. In clinical practice, the health care provider will often have to prioritise the components of the medical

assessment due to limitations in available resources and time.

Modern diabetes devices can improve diabetes care and the patients' quality of life. A downside may be that data analysis from these devices can be very time-consuming and lead to "information overload" for both health personnel and the patient.

Additionally, the health personnel need to register summary statistics about these patient-gathered data inside the electronic health record (EHR) system, often manually using vendor-specific systems in addition to the EHR system. Although other relevant information such as physical activities, sleep duration, and stress may be discussed during the consultation, this information is usually neither registered nor followed up in the next patient consultation [20].

3.2 Community-based type 1 diabetes consultations

Some type 1 diabetes patients may participate in technical advanced Do It Yourself (DIY) projects. They are often well-educated patients, or engaged relatives, who have formulated, developed, and distributed solutions that answer specific problems to their needs in managing their disease [21].

The diabetes community's effort has also been reflected in patient-started companies like Tidepool, where their technological solution can be used instead of vendor-specific solutions [22]. Their system integrates a subset of CGM devices from different vendors inside the same platform and makes the information available to the patients and health personnel.

4 PROPOSED MODEL

We argue for a new way of defining the consultation, where we propose the inclusion of three different phases: before, during and after the consultation. The motivation behind including also "before" and "after" consultations is the increased possibilities of information and communication technology (ICT) for chronic disease management. Furthermore, the consultation should be conceptualised as a continuous process over time, with a preparation (before), a physical or remote meeting (during) and a follow-up phase (after) [23]. Consequently, the proposed model aims to use various ICTs, some diseases-specific (e.g., CGMs, insulin pumps), some commercial devices (e.g., physical activity trackers, IoT devices), and introduce new practices both for patients and health personnel, supporting the increased information gathering and exchange (see Figure 1).

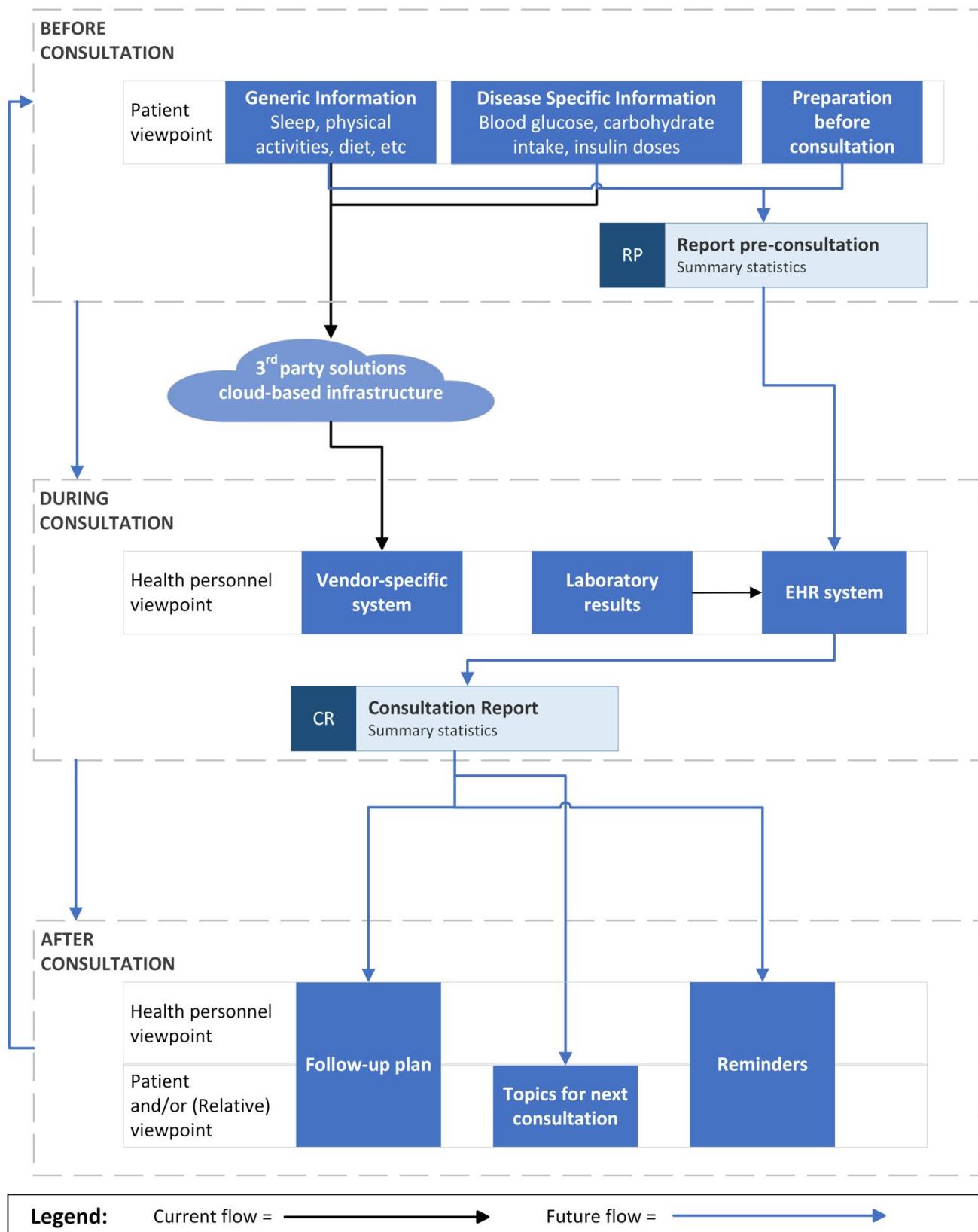


Figure 1 Proposed model, with current and future flow of information for type 1 diabetes consultation.

Before the consultation: patients could prepare themselves by looking at their self-gathered health data. Furthermore, make these available for the health personnel, e.g., physical activities, diet, and sleep, including disease-

specific data, such as blood glucose values, insulin doses, carbohydrate intake, and comprehensive summary statistics.

During the consultation: The data collected before the consultation should be reviewed and registered, preferably automatically, into the EHR system during the consultation. Meanwhile, the necessary adjustments to treatment goals and management plans could also be discussed based on this data during the medical consultation.

After the consultation: What was discussed during the consultation should be made available after the consultation. This can include understandable summaries and follow-up plans for the patients and/or their relatives. Meanwhile, the health personnel could follow up with the patients via reminders before the upcoming visits and encourage them to follow their care plans discussed in the previous consultation. Additionally, the patients can make notes about the side effects of the treatment and note down topics to discuss during their next consultation.

Overall, the presented model includes various elements of remote monitoring and envisioning the medical consultation to be extended beyond than the physical meeting between health personnel and the patient. Therefore, it could provide both parties with more information and better support in difficult situations, e.g., when the patients are not reaching their medical aims or have difficulties in their everyday life caused by their disease.

5 DISCUSSION

The adoption of commercial and medical devices in this model demands the use of third-party companies' devices and software, often located outside the European Union and European Economic Area (EEA). Due to existing regulations, such as the General Data Protection Regulation (GDPR), and their compliance, such a model may raise different critical points and challenges [23], especially from a European perspective.

5.1 Medical devices

The GDPR is not the only regulation that may impact the successful adoption of all the technologies mentioned previously. The recent European Medical Device Regulation (MDR), established in May 2021, updated and extended the definition of medical devices.

The new MDR regulation now also covers health-related smartphone apps. Partially motivated by the fact that thousands of commercial apps are publicly available, and patients with chronic diseases are one of the most prominent target groups [24]. Digital health apps are used in both developed and developing countries [25], and if the intended function of the apps is compromised, it could harm the users (aka patients) [26].

The proposed model would require trust from patients, health personnel and authorities in commercial and medical devices to be considered as a source of information for the medical consultation. In a previous study [27], health personnel ranked the main criteria for recommending medical devices such as digital health apps to patients based on information quality and usability, which employ the openness of health personnel to use these medical devices as part of the medical consultation.

An open question still remains to be answered: Will this European regulation facilitate the integration of what today

is not considered a medical device into the medical consultation? Or, on the other hand, will it slow down the integration?

5.2 Interoperability

Accepting the information gathered from commercial devices inside the medical consultation would require the information collected by the patients to be registered inside the EHR systems. Nowadays, there are technical and legal barriers to registering data generated from medical devices such as CGMs directly into EHRs.

Overall, one of the main challenges is to ensure interoperability and the possibility of data exchange using standards (e.g., FHIR, OpenEHR). Regarding the profiling of health sensor data, standardisation today is limited as well as the adoption of such standards for medical consultation for chronic diseases [23]

5.3 European health data space

The GDPR established in May 2018 has emphasised the potential value and challenges of managing e-health data, especially in terms of security and privacy issues.

Respecting patients' privacy and confidentiality are increasingly becoming more critical, and they represent two of the core values in health care [28]. A key to adopting such technologies is the security and privacy of data, considering the highly sensitive nature of medical data (confidentiality, availability, integrity).

The proposed model in Figure 1 describes an extensive data transmission with many security and privacy challenges. Using these ICTs give access to a vast amount of personally identifiable information and possible target of cyber-attacks. For the following reason, the proposed model will be further worked on in collaboration with the EU-funded HEIR project – a secured Healthcare Environment for Informatics Resilience (grant agreement No 883275).

In the coming years, new legislation, such as the Data Governance Act in 2023, may potentially impact access to more data within the EEA and open the possibility of a Health Data Space. The model presented in Figure 1 could align with such regulations and facilitate data exchange across EEA countries.

5.4 Strengths and limitations

The model presented reflects the findings from previous studies [23, 27, 29], where ICTs were used in intervention for chronic diseases [23] or specifically for diabetes self-management [29]. Many health-related ICTs of today have significant relevance for daily clinical practice, and this model empathises how ICT and interoperability standards may impact future clinical practice.

Therefore, caution should be exercised in evaluating the feasibility of such a model. The medical devices used daily by patients with diabetes are, in practice, the intellectual property of third-parties companies. Consequently, health-related information is often accessible only via proprietary systems, limiting the execution of such a model.

5.5 Future research

Since this study represents an early stage of a new model for medical consultations, future research is now required to interpret this model as a proof of concept to demonstrate

its feasibility. In addition, resource implications and limitations regarding medical device accessibility should be considered.

6 CONCLUSION

Chronic disease consultations are complex. Multiple and diverse stakeholders are often involved, such as health personnel, policymakers, vendors, relatives, and patients. Unclear definitions of the involved technologies [30] and the absence of a shared language in describing them make it harder to integrate apps and new services with health sector stakeholders [31].

This latest introduction of a vast number of medical devices, and commercial wearable devices that enable patients to collect health-related data themselves, calls for new routines and a revision of today's consultation model. Technological innovations are, to an increasing degree, being used by people with chronic conditions. However, consultations are still considered physical or remote meetings only and do not utilise all the potential that self-reported/gathered data can provide.

Regardless of the enthusiasm about these emerging technologies, we must address the adverse effects and risks these technologies can have on data security and privacy issues. Furthermore, we must facilitate the process and assume that patients will wear and adopt consumer technologies in everyday life and that health personnel will use them as part of the medical consultation.

In conclusion, such a model is technologically feasible, and its implementation in clinical practice will be dependent on the policymaking decision in the coming years.

7 SUMMARY

This paper has discussed a new model that views medical consultation as a continuous process in terms of preparation (before), a meeting (during), and a follow-up phase (after). We are in a phase where patients have more access to health-related information such as physical activities, symptoms or treatments via diverse technologies or social media communities. This new information can be used in the decision-making process during consultations and be used in refining the individual health care plan for the patient.

Designing a system that can possibly be integrated with the clinical EHR systems used for patient treatment and follow-up is conceptually possible. Although, mainly security, privacy and interoperability issues slow down the integration of such innovation in the medical consultation and the healthcare systems.

8 REFERENCES

- [1] Bernell, S. and S.W. Howard, *Use your words carefully: what is a chronic disease?* Frontiers in public health, 2016. 4: p. 159.
- [2] Roglic, G., *WHO Global report on diabetes: A summary*. International Journal of Noncommunicable Diseases, 2016. 1(1): p. 3.
- [3] Warburton, D.E., C.W. Nicol, and S.S. Bredin, *Health benefits of physical activity: the evidence*. Cmaj, 2006. 174(6): p. 801-809.
- [4] Gask, L., *Role of specialists in common chronic diseases*. Bmj, 2005. 330(7492): p. 651-653.
- [5] Martin, C.M., *Chronic disease and illness care: adding principles of family medicine to address ongoing health system redesign*. Canadian Family Physician, 2007. 53(12): p. 2086-2091.
- [6] Von Korff, M., et al., *Collaborative management of chronic illness*. 1997, American College of Physicians.
- [7] Brooke, S.M., et al., *Concurrent validity of wearable activity trackers under free-living conditions*. Journal of strength and conditioning research, 2017. 31(4): p. 1097-1106.
- [8] Kinnersley, P., et al., *Interventions before consultations to help patients address their information needs by encouraging question asking: systematic review*. Bmj, 2008. 337.
- [9] Bartlett, Y.K. and N.S. Coulson, *An investigation into the empowerment effects of using online support groups and how this affects health professional/patient communication*. Patient education and counseling, 2011. 83(1): p. 113-119.
- [10] Smailhodzic, E., et al., *Social media use in healthcare: A systematic review of effects on patients and on their relationship with healthcare professionals*. BMC health services research, 2016. 16(1): p. 1-14.
- [11] Waszak, P.M., W. Kasprzycka-Waszak, and A. Kubanek, *The spread of medical fake news in social media—the pilot quantitative study*. Health Policy and Technology, 2018. 7(2): p. 115-118.
- [12] De Martino, I., et al., *Social media for patients: benefits and drawbacks*. Current reviews in musculoskeletal medicine, 2017. 10(1): p. 141-145.
- [13] Gautschi, O.P., et al., *Web-based audiovisual patient information system—a study of preoperative patient information in a neurosurgical department*. Acta neurochirurgica, 2010. 152(8): p. 1337-1341.
- [14] Organization, W.H., *General principles of good chronic care: integrated management of adolescent and adult illness*. 2003: World Health Organization.
- [15] Stacey, D., et al., *Decision aids for people facing health treatment or screening decisions*. Cochrane database of systematic reviews, 2017(4).
- [16] Mosen, D.M., et al., *Is patient activation associated with outcomes of care for adults with chronic conditions?* The Journal of ambulatory care management, 2007. 30(1): p. 21-29.
- [17] Gask, L. and T. Usherwood, *The consultation*. Bmj, 2002. 324(7353): p. 1567-1569.
- [18] Irving, G., et al., *International variations in primary care physician consultation time: a systematic review of 67 countries*. BMJ open, 2017. 7(10): p. e017902.
- [19] Ancker, J.S., et al., *The invisible work of personal health information management among people with multiple chronic conditions: qualitative interview study among patients and providers*. Journal of medical Internet research, 2015. 17(6): p. e137.

- [20] Larbi, D., et al., *Do diabetes mHealth and online interventions evaluate what is important for users?* 2019.
- [21] Omer, T., *Empowered citizen 'health hackers' who are not waiting*. BMC Med, 2016. 14(1): p. 118.
- [22] Neinstein, A., et al., *A case study in open source innovation: developing the Tidepool Platform for interoperability in type 1 diabetes management*. Journal of the American Medical Informatics Association, 2016. 23(2): p. 324-332.
- [23] Randine, P., et al., *Information and Communication Technology-based Interventions for Chronic Diseases Consultation: Scoping Review*. International Journal of Medical Informatics, 2022: p. 104784.
- [24] Research2guidance. *mHealth App Economics 2017: Current Status and Future Trends in Mobile Health*. 2017; Available from: <https://research2guidance.com/product/mhealth-economics-2017-current-status-and-future-trends-in-mobile-health/>.
- [25] Agarwal, S., et al., *Guidelines for reporting of health interventions using mobile phones: mobile health (mHealth) evidence reporting and assessment (mERA) checklist*. bmj, 2016. 352: p. i1174.
- [26] Lewis, T.L. and J.C. Wyatt, *mHealth and mobile medical apps: a framework to assess risk and promote safer use*. Journal of medical Internet research, 2014. 16(9): p. e210.
- [27] Larbi, D., et al., *Criteria for Assessing and Recommending Digital Diabetes Tools: A Delphi Study*. Studies in health technology and informatics, 2021. 281: p. 850-854.
- [28] Williams, J.R., *The Declaration of Helsinki and public health*. Bulletin of the World Health Organization, 2008. 86: p. 650-652.
- [29] Larbi, D., et al., *Methods and Evaluation Criteria for Apps and Digital Interventions for Diabetes Self-Management: Systematic Review*. Journal of Medical Internet Research, 2020. 22(7): p. e18480.
- [30] Hou, C., et al., *Do mobile phone applications improve glycemic control ($HbA1c$) in the self-management of diabetes? A systematic review, meta-analysis, and GRADE of 14 randomized trials*. Diabetes Care, 2016. 39(11): p. 2089-2095.
- [31] Labrique, A.B., et al., *mHealth innovations as health system strengthening tools: 12 common applications and a visual framework*. Global health: science and practice, 2013. 1(2): p. 160-171.

9 ACKNOWLEDGEMENT

We would like to thank Celia Nilssen for her assistance and role as an “internal reviewer”. Furthermore, we thank Bruna Martins Catarino for her feedback on the figure and the EU-project “HEIR – a secured Healthcare Environment for Informatics Resilience (grant agreement No 883275). This work is part of the first author’s PhD project, funded by UiT The Arctic University of Norway.