Building bridges for meaningful ehealth: aligning people, technology and practice through collaboration and knowledge sharing

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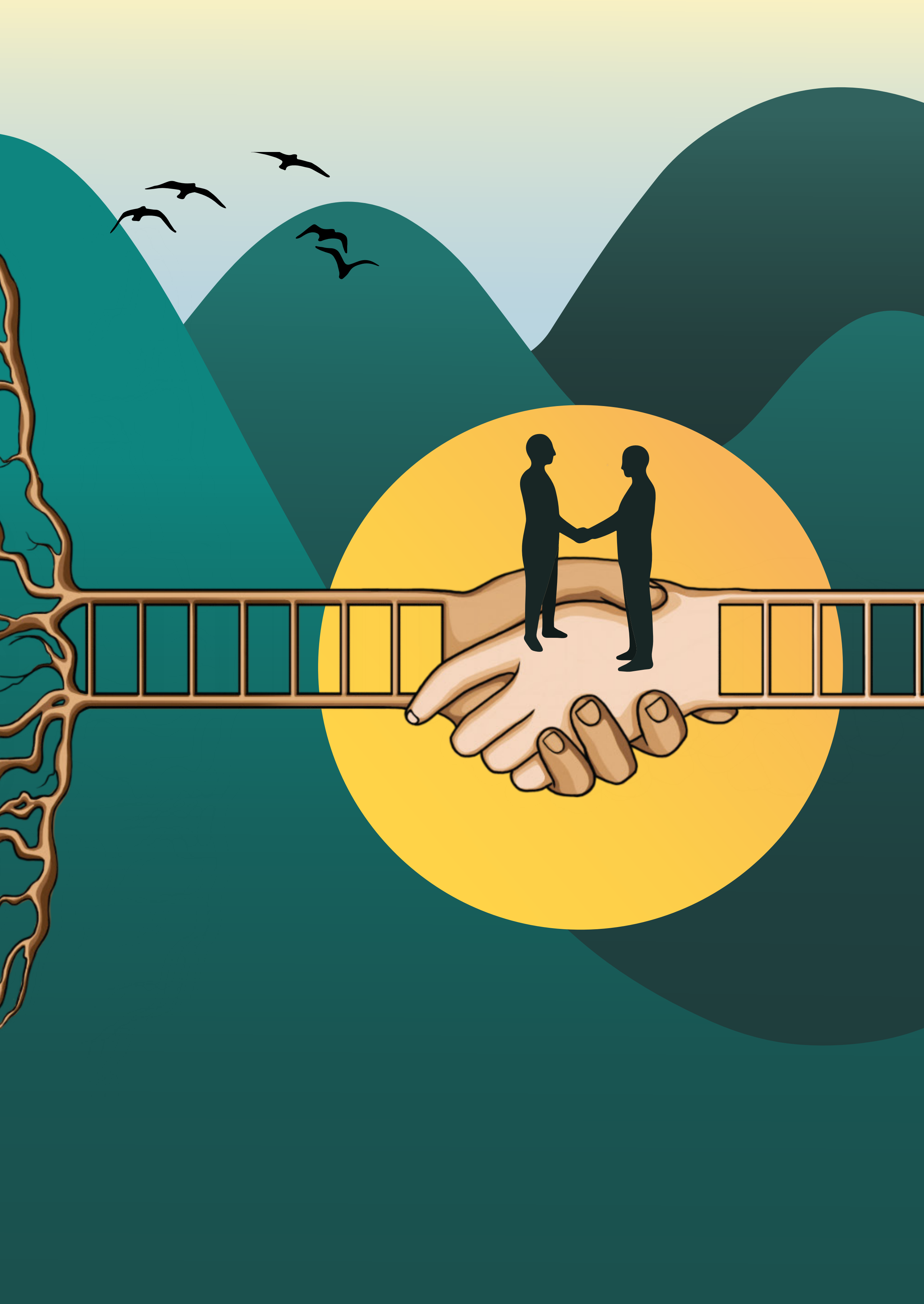
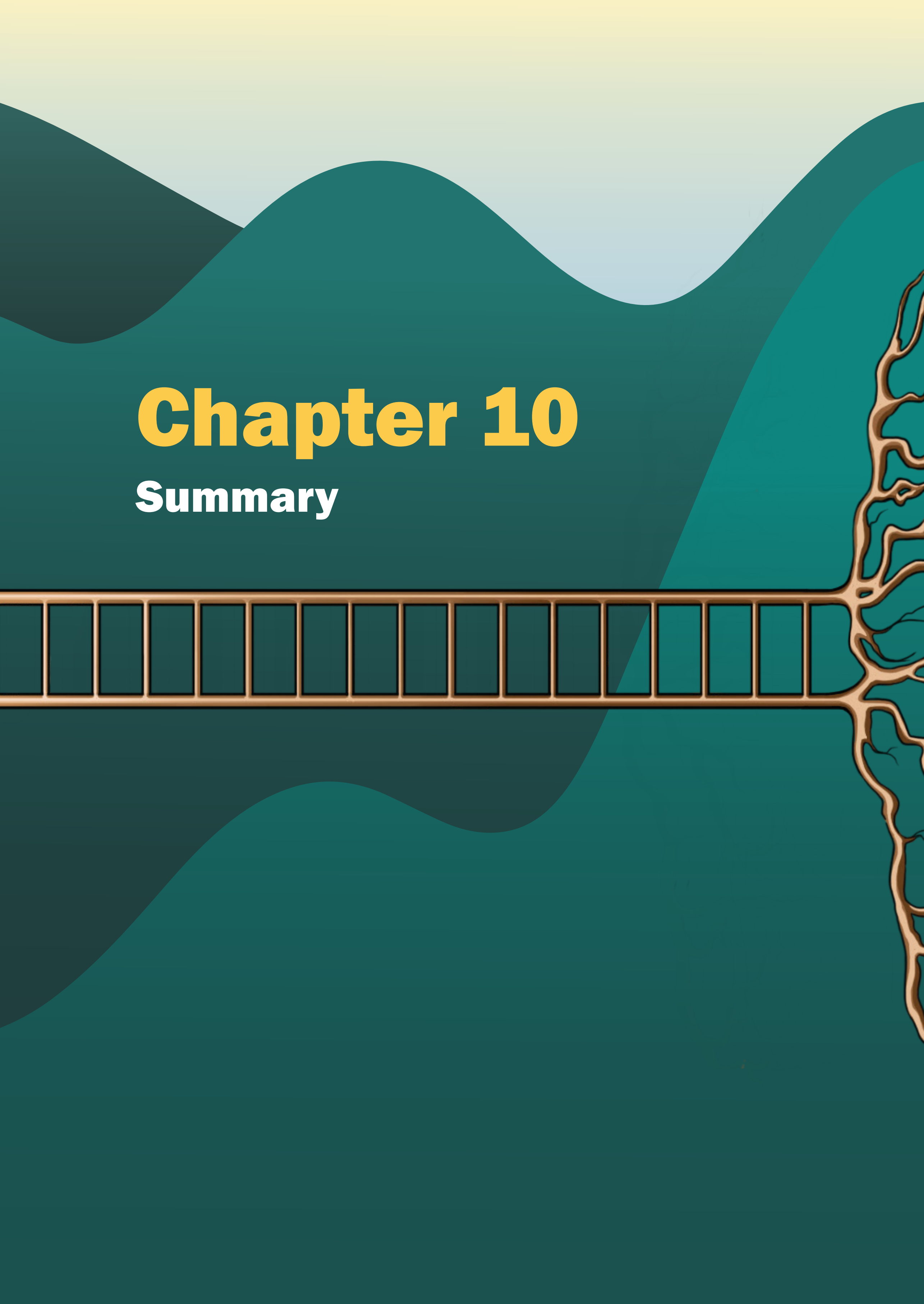


Chapter 10

Summary



Summary

The Dutch healthcare system is facing multiple challenges which have put a strain on the healthcare system in terms of finances and workforce shortages. eHealth offers innovative and promising ways of providing healthcare, including remote and digital care. However, despite the potential of eHealth to transform healthcare and improve patient outcomes, its wide-spread adoption and implementation have been limited.

In the general introduction of this dissertation, five challenges in the development, implementation and evaluation of eHealth were identified:

1. Misalignment with end-user needs due to the lack of active involvement of end-users in the design process.
2. Non-adherence caused by a lack of user engagement to the eHealth solution.
3. Missing those who benefit most in the development and evaluation of eHealth, risking a widening of the digital divide.
4. Limited real-world evidence on the effectiveness of eHealth and the need for alternative study designs.
5. Disconnection between evidence and its application, and the need for a practical guide to translate knowledge into practice.

Targeting and overcoming the above-mentioned challenges is essential to work toward meaningful eHealth that benefits patient, healthcare professionals and the healthcare system as whole. By addressing these challenges, eHealth has the potential to revolutionize healthcare and improve health outcomes for individuals and populations.

This dissertation addressed the above-mentioned challenges by presenting and discussing real-world case studies on the development and evaluation of various eHealth technologies using participatory design tools and generating real-world evidence, respectively. It also presented a study on the translation and validity assessment of the Dutch version of the eHealth Literacy questionnaire, and a step-by-step approach to guide the translation of research to inform evidence to inform decision-making.

Part 1 – Participatory design

In the first part of this dissertation, we demonstrated how participatory design can be used to actively involve end-users and other stakeholders in early stages of eHealth development). **Chapter 2** described the design of the persuasive game design 'Ademgenoot' to motivate people with asthma to be medication adherent. Through early involvement of end-users and use of participatory design tools we were able to identify several reasons for non-adherence and needs which led to the design of 'Ademgenoot'. User testing showed that Ademgenoot was engaging and has the potential to influence inhaler use behaviour by fostering motivation and combining personal goal setting and continuous direct visual feedback on medication use with game elements such as narrative and rewards.

In **chapter 3** we focused our participatory design efforts on people with limited health literacy and delved deeper into the application and tailoring of participatory design methods for people with limited health literacy. Through a study aimed at enhancing medication adherence, we presented strategies to overcome challenges specific to working with individuals with limited health literacy and asthma. We demonstrated how participatory design tools can be carefully selected, tailored, and applied to actively involve people with limited health literacy in eHealth design, identify their needs and foster mutual understanding during the design process.

In **chapter 4** we presented a multiple study report in which we described the development and pilot study of the 'Hospital Hero' app, an app aimed to reduce pre-procedural stress and create a more positive hospital experience for children. In the first study we employed participatory design, taking the experience of the user (child) as starting point to develop an application that supports children in their entire hospital journey, by providing preparation and distraction. A first version of the Hospital Hero app was subsequently evaluated in practice. Using a mixed-method approach, we evaluated the Hospital Hero app on use, usability, and user-experience. As such, we were able to demonstrate how children, as end-users, can be actively involved in the development of eHealth and emphasized the importance of evaluating eHealth solutions in practice to assess their value for children, parents, and healthcare providers.

Part 2 – Effectiveness assessment

Chapter 5 continued on the significance of evaluating eHealth interventions in real-world settings. It presented a protocol for a cluster RCT to evaluate a smart inhaler asthma self-management programme. The study aimed to provide real-world evidence on clinical outcomes, acceptance, and usability, while also considering patient characteristics such as beliefs about medication and eHealth literacy. The chapter also highlighted how patients can be involved in the design and execution of clinical trials, and ways to overcome limitations of traditional RCTs in studying effectiveness of eHealth.

The equivalent of the RCT as golden-standard study design for the evaluation of effectiveness, is the meta-analysis for the overall the effectiveness of multiple studies. **Chapter 6** presented a meta-analysis and systematic review on the effectiveness of integrated disease management programmes (IDM) for people with chronic obstructive pulmonary disease (COPD). The review pooled fifty-two studies on IDM interventions, performed across 19 different countries, and compared these with usual care on a number of health-related and clinical outcomes. The findings indicated that IDM programs probably improve disease-specific quality of life, exercise capacity, respiratory-related hospital admissions, and hospital days per person. No significant differences were found for mortality, courses of antibiotics/ prednisolone, dyspnoea, and depression and anxiety scores.

Integrated disease management programmes (IDM) are complex interventions, consisting of multiple components. Since eHealth interventions are also often also multi- component these can be considered complex health interventions as well. Consequently, challenges in meta-analysis of IDM programs can provide important insights and considerations in the evaluation of eHealth.

Part 3 – Tools and instruments

The third part of this dissertation presented two different tools. The first tool is a Dutch version of the eHealth Literacy Questionnaire (eHLQ) (**Chapter 7**). The tool can be used by researchers, eHealth developers and policy makers to identify eHealth literacy needs and inform the development of eHealth interventions to ensure that people with limited digital access and skills are not overlooked. **Chapter 7** described the translation, cultural adaptation, and validity assessment of the Dutch eHLQ using a validity-driven and multi-study approach. Validity was assessed on test content, response process and internal structure performing cognitive interviewing, confirmatory factor analysis, invariance testing and multi-group comparison. The Dutch version of the eHLQ showed strong properties for assessing eHealth literacy in the Dutch context. However, ongoing collection of validity evidence was recommended as validity should not be considered a characteristic of the instrument but depends on the context and purpose of use.

The second tool, a tool to facilitate effective knowledge creation towards decision-makers in healthcare to help bridge the knowledge-to-action gap, was presented in **Chapter 8.** By integrating principles of science communication, data visualisation and user-centred design, a step-by-step process was outlined for translating scientific research into actionable messages, focusing on 'how something is said' and 'how it is communicated.'

General discussion

In the closing chapter we reflected on the separate studies, placing them in a wider perspective on the development, evaluation and implementation of eHealth and sharing our lessons learned. We discussed the importance of empowering patients to participate in their healthcare choices but emphasized that differences in patients' eHealth literacy needs should be taken into account (**Theme 1**). Moreover, we discussed conditions that should be met when involving socio-economically disadvantaged groups in the development and evaluation of eHealth (**Theme 2**). We tapped into the importance of early stakeholder involvement, as stakeholders are important actors within the development and sustained use and implementation of eHealth technologies (**Theme 3**) and presented ways to identify stakeholders, their needs and how to create value, including taking a more business viewpoint on value. We furthermore discussed why evaluation of eHealth should be considered a continuous process, including formative (i.e., to gain understanding for improvements) and summative (i.e., to measure performance or specific endpoints) evaluation moments (**Theme 4**). By doing so we touched upon the need to create a more favourable research environment for eHealth research, in terms of medical ethical procedures, governance and academic reward structures (**Theme 5**).

This dissertation advocated for the early involvement of end-users and other stakeholders in the development and evaluation of eHealth. It underscored the importance of facilitating the expression of people's needs and inclusion of voices from socio-economically disadvantaged individuals who, when eHealth solution fit their needs, can benefit the most from eHealth. Moreover, it called for a critical examination of existing research paradigms that are to effectively guide the development and evaluation of eHealth solutions to create.