



# Design and Development of Digital Health Platforms

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submitted to the Department of Computer Science  
at Reykjavík University in partial fulfillment  
of the requirements for the degree of  
**Doctor of Philosophy**

August 2024

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ISBN Print version: 978-9935-539-36-6  
ISBN Electronic version: 978-9935-539-37-3  
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## Abstract

By providing equitable care, digital health platforms can lessen the pressure on global healthcare systems. Digital platforms are pieces of software that connect users, data, services, and systems. In industry, the use of digital platforms has brought advancements in optimizing and automating processes, which could likewise benefit healthcare. Digital health platforms have been utilized effectively in recent years to connect patients, healthcare experts, researchers, and study participants and provide general care, disease and symptom management, and palliative care. They further allow for the collection of data that enables the monitoring of patients and research participants. In care, sharing patient data between patients and healthcare experts facilitates more effective care, while in research, the data fosters the development of novel diagnostic and predictive algorithms and more effective treatments. For advancing care and research in these ways, a meaningful design of digital health platforms that engages users in the longitudinal collection of reliable data is vital.

Current literature has focused on identifying aspects of meaningful digital health platforms through literature reviews, patient outcome analysis, and surveys with health experts. However, the design of a digital health platform is created during its design and development process. Still, research rarely examines digital health platforms from the insider view of a designer or a developer, and as a result, there is a lack of interpretation of the design and development processes of digital health platforms.

This thesis addresses this gap and contributes to the information system literature by examining the design and development process of the Sleep Revolution digital health platform. The Sleep Revolution digital health platform was designed and developed with the goal of modernizing sleep healthcare and collecting data for the research and development of models and algorithms that have the potential to uncover patterns and provide novel insights. It connects researchers, sleep experts, and study participants to do so. A co-design process has been employed to design and develop the Sleep Revolution digital health platform. Co-design involves stakeholders such as end-users and health experts as active members in the design and development process. Research has highlighted promises and challenges of co-design and has criticized the failure to incorporate it beyond the initial ideation stage of the design of digital health platforms.

Drawing from the experience of designing and developing the Sleep Revolution digital health platform from early ideation stages to active usage in sleep studies in multiple European countries, this thesis documents the learnings and challenges of a four-year action design research project that employed co-design through the insights gained from five papers. The included papers look into the design and development of both a mobile and web application for study participants, which are part of the Sleep Rev-

olution digital health platform. Paper P1 follows the digitization process of an analog sleep diary involving expert and user feedback into a mobile application and derives design guidelines for similar mobile applications to record health-related data from the findings. Building on that research, paper P2 analyses user compliance with the digital sleep diary, and the results contribute to an understanding of improving the challenges associated with the analog version. This paper gives insights into the feasibility of collecting longitudinal sleep-related data with a mobile application and highlights compliance challenges. Paper P3 examines dignity affront responses that users experienced through digital nudging built into the mobile application. Through the formulation of design guidelines, this paper contributes a better understanding of digital nudging and the design of effective and dignity-preserving digital nudges. Concentrating on the technical side of the digital health platform, paper P4 investigates the modularization of its design through a design system, and it presents conclusions about achieving a clear structure of design systems. Paper P5 shifts the focus from the mobile application to the web application by addressing the digitalization of an in-laboratory tool for measuring cognitive functioning into an at-home web tool and frames the learnings from this research as design guidelines. While the five papers focus on different parts of the Sleep Revolution digital health platform, they all reflect various stages of its design and development process.

Based on the findings of these five papers, along with supplementary insights gleaned from the design and development process of the Sleep Revolution platform, the thesis (i) examines how the continuous co-design process of the digital health platform addresses emerging challenges and (ii) presents a framework that conceptualizes three socio-technical key factors for engaging design of digital health platforms for reliable data collection. The thesis also presents the different dimensions of those key factors and how they are interconnected to inform future digital health platforms' design and development. Together, the findings contribute to the discourse on digital health platforms in the information systems literature with the conceptualization of engaging design and the examination of a continuous co-design process.

**Keywords:** Digital Health, Digital Platforms, Digital Health Platforms, Co-Design, Meaningful Design, Information Systems

# Included Publications

**Paper 1.** Towards a Digital Sleep Diary Standard

Full reference: Schmitz, L., Sveinbjarnarson, B. F., Gunnarsson, G. N., Davíðsson, Ó. A., Davíðsson, . B., Arnardóttir, E. S., ... & Islind, A. S. (2022, August). Towards a Digital Sleep Diary Standard. In AMCIS.

**Paper 2.** Evaluating User Compliance in Mobile Health Apps: Insights from a 90-Day Study Using a Digital Sleep Diary

Full reference: Kristbergisdóttir, H.<sup>1</sup>, Schmitz, L.<sup>1</sup>, Arnardóttir, E. S., & Islind, A. S. (2023). Evaluating User Compliance in Mobile Health Apps: Insights from a 90-Day Study Using a Digital Sleep Diary. *Diagnostics*, 13(18), 2883.

**Paper 3.** Nudging with Dignity: A Critical Examination of When and How to Use Digital Nudging

Full reference: Schmitz, L., Richert, E., Larusdóttir, M., Arnardóttir, E. S., & Islind, A. S. (2024). Nudging with Dignity: A Critical Examination of When and How to Use Digital Nudging. In *15th Scandinavian Conference on Information Systems (SCIS 2024)*. Uddevalla.

**Paper 4.** The Cosmic Design System Development and Application of Design Principles for Clarity in Design Systems

Full reference: Schmitz, L., & Islind, A. S. (2024). The Cosmic Design System Development and Application of Design Principles for Clarity in Design Systems. Submitted to *Scandinavian Journal of Information Systems*. (Accepted with major revisions and resubmitted).

**Paper 5.** VALID Care Pathways: A Framework for Meaningful Digital Platform Design

Full reference: Schmitz, L., Richert, K., Jóhannsdóttir, K., M., Arnardóttir, E. S., & Islind, A. S. (2024). VALID Care Pathways: A Framework for Meaningful Digital Platform Design. Submitted to *Communication of the AIS*. (Accepted with major revisions and resubmitted).

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<sup>1</sup>These authors contributed equally.



# Other Selected Publications by the Author

Sveinbjarnarson, B. F., Schmitz, L., Arnardottir, E. S., & Islind, A. S. (2023). The sleep revolution platform: A dynamic data source pipeline and digital platform architecture for complex sleep data. *Current Sleep Medicine Reports*, 9(2), 91-100.

Sveinbjarnarson, B. F., Schmitz, L., Islind, A. S., & Arnardottir, E. S. (2022). Platform-based streamlining of research on diversified sleep data. *Sleep Medicine*, 100, S300.



# Acknowledgements

This is where the story of my Ph.D. studies begins. It tells how I designed and developed a digital health platform and what I learned from doing so. As with all stories, this story's author had to embark on an adventure to find it, and by adventure I mean the old-fashioned definition of the word that appears in the Zamonian Dictionary: "A daring enterprise undertaken in a spirit of curiosity or temerity, it is potentially life-threatening, harbours unforeseeable dangers and sometimes proves fatal."<sup>1</sup> Indeed, I can attest to the many perils an adventure holds, for mine was full of them. Dreaded deadlines, sudden side-quests, relentless reviews and pits of procrastination lurked behind each corner.

In light of such danger, the prudent adventurer does not embark on a voyage all by herself. Instead, she is wise enough not to scoff at the sagacious—if not slightly sentimental—saying, "Alone, it's just a journey. Now adventures, they must be shared,"<sup>2</sup> for who can be curious and temerarious alone? Thus, no story is complete without the cherished companions who transformed its mere journey into a true adventure, and I shall duly recognize those who traveled alongside me.

An unfortunate adventurer is the one deprived of guidance, and how fortunate I have been to have had the guidance of not one, but two adept mentors. My utmost thanks are directed to you, Anna Sigga and Marta, for diligently preparing me for the dangers ahead and presenting me with those very challenges when I was deemed ready.

Yet, even then, when I confronted those dangers, I was never truly alone. I was accompanied by grandiose allies who shared in my tribulations, and, most crucially, possessed the remarkable ability to transform even the direst of circumstances into moments of mirth. You know who you are, my intrepid friends, for you have been with me in situations of both profound stress and genuine happiness. You have aided me in the refinement of my manuscripts, trained alongside me in mastering aerial skills to ascend beyond the grasp of any peril and infused the desolate halls and corridors of the university during the summer with your humor and cheerful disposition. For all this and more, I extend my heartfelt gratitude to you.

And to my most steadfast ally, Hlynur, who has been my partner throughout this entire journey, I owe my deepest thanks. From your own adventure, I was privileged to learn first-hand the virtues of toughness and diligence. I am profoundly thankful for the support you have shown me and for reminding me that an adventure is not solely

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<sup>1</sup>Moers, W. (2007). *The City of Dreaming Books* (J. Brownjohn, Trans.). Vintage Books. (Original work published 2004). p. 9.

<sup>2</sup>Hutchison, G., Payne, J. D., & McKay, P. (Writers), & Yip, W. C. (Director). (2022). *Alloyed* (Season 1, Episode 8) [TV series episode]. In J. D. Payne, P. McKay, & J. Bayona (Executive Producers), *The Lord of the Rings: The Rings of Power*. Amazon Studios.

defined by the perils we overcome, but also by the joy and fulfillment to be discovered amidst the trials. One of those joys has undoubtedly been Lumos, the fluffiest, littlest guy, who joined my adventuring party recently and since then, has brightened every day. I am glad to have you both by my side.

Genauso wichtig wie diejenigen, die uns auf einem Abenteuer begleiten, sind diejenigen, die uns darauf vorbereiten. Es ist einfach, sich auf ein riskantes Abenteuer zu begeben, wenn man ein sicheres Zuhause hat, zu dem man jederzeit zurückkehren kann. Ich kann euch nicht genug danken, Mama und Papa, dafür, dass ihr mir geholfen habt, meinen Rucksack für mein Abenteuer zu packen und mich in die Welt habt ziehen lassen, auch wenn es sicherlich nicht immer leicht für euch war—besonders wenn mein Weg mich an weit entfernte Orte geführt hat.

Lastly, it must be acknowledged that any grand adventure is costly, and mine would not have been possible without the requisite funding. Thus, I hereby inform my esteemed readers that the research in my Ph.D. studies was carried out as a part of the Sleep Revolution project, which has received funding from the European Union's Horizon 2020 Research and Innovation Programme under Grant 965417.

Now, having properly expressed my appreciation to all those who accompanied me on my adventure, let me waste no more time and commence the story of my Ph.D. studies.

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# Chapter 1

## Introduction

”Invention in digital health may be fast, but diffusion of *innovation* is rather slow. The main reason for the slow uptake is that design rarely continues after implementation. Too little time and effort is spent on *configuring* the systems and *adapting* the clinical practices and the day-to-day activities of patients (not) using the new systems. In many projects, designing with users is something that happens before the new system is implemented — active user involvement in co-design workshops and prototyping sessions is considered good enough.” - Andersen, *Large-Scale and Long-Term Co-Design of Digital Health* [1], p.74

Global healthcare systems are under pressure. The aging population demands a level of care that existing healthcare systems are struggling to meet. Digital platforms have proven effective in optimizing and automating business processes in various industry sectors [2], and they hold similar promise for the healthcare industry [3]. Digital platforms can be understood as pieces of software that facilitate interactions among a diverse network of users, enabling them to exchange goods, services, or social values [2], [4], [5]. By connecting patients, researchers, and healthcare experts, these digital platforms can enhance research and standardize healthcare procedures, paving the way for preventative care. Aside from the traditional reactive healthcare approach, this opens up opportunities to introduce preventative care. However, when compared to the overall digitalization of society, the healthcare sector still lags significantly behind [6]. This technological gap in digitalizing healthcare can be attributed to the challenging nature of entering the highly regulated healthcare market, as well as the difficulties associated with developing software that aligns seamlessly with healthcare practices [7], [8]. As the healthcare sector is struggling with the present challenges that are likely to worsen in the future [9], it has become imperative to bridge this gap.

Patient-centered at-home digital health solutions are key to addressing this need [10], [11]. These solutions allow for a more cost-efficient [12], longitudinal data collection of higher completeness [13] and higher quality [14] compared to analog solutions. Larger data sets, in turn, make the application of advanced algorithms and models for pattern recognition feasible and create the potential for new diagnostic insights [10], [15]–[17]. However, in order to revolutionize healthcare with advanced algorithms and models, we need solid data that is gathered in a structured manner and to get there, we need digital health platforms.

Designing and developing a meaningful digital health platform comes with challenges. Numerous of them are illustrated through examples of failed integration of digital solutions in general and digital platforms, in particular, in the literature [7], [8], [18]. Among other causes, poor user experiences stemming from a lack of continuous involvement of users and stakeholders in the design process is a reason why the design of digital health platforms is not effective [19]. While the involvement of users in the early design of a digital health platform has become more common, their inclusion in design activities beyond the initial ideation stage is not a consistent part of the design process [1], [20]. Continuous user involvement has been shown to be important to a holistic design approach for digital health platforms that address users' needs adequately [10], [21]. This holistic design approach is embodied in 'co-design', which advocates for the involvement of end-users and stakeholders in the design activities during the development process [21]. Particularly for digital health platforms that are commonly used by user groups with different needs, such as patients, healthcare experts, or researchers, the co-design approach becomes a valuable strategy for their design and development [22]. Considering the benefits of utilizing this approach, exploring the importance and impact of continuous co-design in meaningful digital health platforms is a vital area for research. The documentation and conceptualization of the process and the key aspects of digital health platform design that a continuous co-design process reveals have the potential to foster a better understanding of the process. In turn, a better understanding of the process can aid the design and development of future digital health platforms.

In particular, sleep care stands to benefit significantly from digital platforms. Sleep affects a wide range of physiological functions [23]. From restorative processes and hormonal regulation to cognitive performance and immune system functioning, quality sleep plays a vital role in maintaining overall well-being [24]–[27]. Traditionally, the assessment and management of sleep-related issues have, in many cases, relied on subjective reporting or cumbersome in-laboratory sleep studies, limiting accessibility and scalability and without combining subjective and objective data [28]. The issue of the cumbersome collection of objective sleep data in laboratory settings has caused a lack of studies on long-term sleep deficiency and daily fluctuations in sleep [15], [16], [29] and further research is needed to investigate the effects of long-term sleep issues [15], [30], [31]. Digital platforms offer a convenient way to collect continuous longitudinal data to identify such long-term sleep issues remotely. Not only can they be used to track subjective sleep-related behavior, but they can also integrate objective data from wearable devices in the form of smartwatches and sleep-tracking sensors [28]. A collection of such data creates the opportunity to include algorithmic medicine to provide real-time data analysis. Through the results of the data analysis, patients and healthcare experts alike can gain insights into the patient's sleep and make informed decisions regarding lifestyle or medical interventions [28].

The Sleep Revolution project has made it its goal to create a digital health platform to collect longitudinal sleep-related data through a digital sleep diary, cognitive tests, and questionnaires in a mobile application and a web application (hereinafter also called 'mobile app' or 'web app', respectively) and connect researchers, patients and sleep experts [32]. The collected data is send to a back-end that stores the data in a database on a high-performance cluster. In turn, this data is used to develop learning algorithms and predictive models, specifically for the detection of obstructive sleep apnea. Thus, the European Union's Horizon funded project ultimately aims to make

sleep disorder diagnosis available to a broader audience through increased automation of sleep studies [32].

When I began my Ph.D. studies in November 2021, the Sleep Revolution digital health platform had already been in development for several months and was set to be tested in a pilot study with 45 participants in Iceland. Co-design workshops had previously been conducted to gather requirements and involve sleep experts and users in the design and development activities of the Sleep Revolution mobile and web app. Multiple prototypes had been designed, developed, and tested. By the time I joined the project, the mobile app featured a morning and evening sleep diary for daily recording of sleep-related data, such as bedtimes and caffeine intake, along with four cognitive tasks that participants could complete once a week, and was available for both Android and iOS devices. The web app had views for participants, researchers, and study coordinators that offered an overview of the diary data and additional data collected during the study period, such as data from a smartwatch.

At this stage, it appeared that the design and development process was complete, and the Sleep Revolution digital health platform was ready to be used in upcoming studies with no further modifications required. However, events turned out differently. As it was, I spent the majority of my time as a Ph.D. student designing, developing, maintaining, and researching the mobile and web app of the digital health platform, as well as guiding others in doing the same. Use data was analyzed, participants and study coordinators requested changes and new features, and work on the digital health platform continued. The continuation of co-design was crucial in adding necessary features, improving existing software, and ensuring maintainability to make the Sleep Revolution digital health platform what it is today.

Based on the learnings from the design and development process of the Sleep Revolution digital health platform, this thesis contributes to existing information systems (IS) literature that is interested in the formation of digital platforms [33], [34] and innovative health solutions [35]–[37]. The thesis examines how the Sleep Revolution digital health platform for collecting research data can achieve user engagement while respecting the user’s dignity, building on previous research [38]–[40]. Since the Sleep Revolution digital health platform has been developed in a co-design approach, the thesis is further investigates the process itself and how co-design challenges were addressed over an extended period of time, furthering previous research on challenges and structure of long-term co-design [21], [41], [42]. The research questions in this thesis are:

- RQ1: How does a continuous, long-term co-design process address emergent challenges in the design and development of a digital health platform?
- RQ2: What key socio-technical factors influence the meaningful design and development of digital health platforms for user engagement and reliable data collection?

Since the goal of the Sleep Revolution digital health platform is to integrate sleep-related data from multiple sources and exchange data with a mobile app and a web app, it constitutes a digital health research platform for data collection for the development of diagnostic and predictive algorithms and models. The main focus of this

thesis is thus on similar digital health platforms. Digital health platforms for other application areas such as sharing patient data between health experts may have different requirements and challenges. However, designing with users, no matter whether they are patients, study participants, researchers, or health experts, has been shown to be beneficial for a variety of digital health platforms [3], [43]–[45]. Therefore, the answers to the research questions in this thesis are likely relevant for other types of digital health platforms that aim to foster user engagement and collect reliable data.

This thesis includes five papers and both research questions are addressed by looking at all included studies cumulatively. The answers provide a comprehensive view of the continuous co-design process and its evolution over time on the example of the Sleep Revolution digital health platform. RQ1 addresses the challenges that were experienced in the co-design process during and in between the studies. This research question examines the project in a holistic view, viewing it as one continuous process. The second research question RQ2 draws different aspects from the five included papers. The papers do not focus equally on social and technical aspects. Moreover, the insights gained in controlled user evaluations and actual use in sleep studies differed. To answer RQ2, the learnings from each paper will be presented independently and only later synthesized in key aspects. This approach was chosen to demonstrate the development of the design over time, as well as the value of continuous co-design in different settings.

By addressing these two questions, this thesis aims to contribute to the development of sustainable and meaningful digital health platforms that can adapt to evolving user needs and technological advancements. Figure 1.1 gives an overview of the setting and the focus of the five papers.

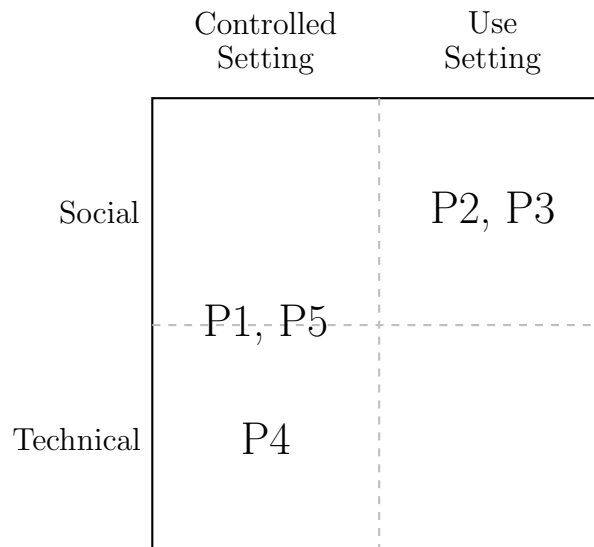


Figure 1.1: Overview of the setting and the focus of the five papers P1-P5. The papers that include evaluations that mainly draw from data gathered in user evaluations are considered to be carried out in a controlled setting, while the papers that use data from studies where the Sleep Revolution digital platform was used to gather data for sleep research are considered to be carried out in a use setting.

In the first paper P1 titled "Towards a digital sleep diary standard", published in the proceedings of Americas Conference on Information Systems (AMCIS) in 2022, a

digital version of a sleep diary was created in the Sleep Revolution mobile application. A sleep diary is an important tool for gathering subjective sleep data, which provides key information for the diagnosis of a variety of sleep disorders. The sleep diary was developed based on the Consensus Sleep Diary (CSD), a pen-and-paper sleep diary that was created by an expert panel in 2012. However, pen-and-paper has certain limitations; in particular, it is difficult to monitor participant compliance and memory bias. These limitations were improved upon with a digital design and the benefits and drawbacks of the pen-and-paper format compared to a digital sleep diary were identified in an empirical study based on an action design research project. The paper presents insights and lessons learned about usability and user experience from a two-year co-design process involved in designing and developing a mobile app. This process engaged a variety of stakeholders and end-users who tested and provided feedback on multiple prototypes. The final artifact of this process, along with design guidelines for similar symptom tracker apps, constitute the paper's contributions.

The second paper P2 titled "Evaluating User Compliance in Mobile Health Apps: Insights from a 90-Day Study Using a Digital Sleep Diary" and published in *Diagnostics* 2023, presents an analysis of user engagement with the digital sleep diary within the Sleep Revolution mobile app. This analysis is based on data collected over a three-month period from 45 participants who were instructed to record their sleep habits twice daily using the mobile app. The study reveals that overall compliance with the digital sleep diary was notably high during the first two months but showed a decline as the study progressed. It was observed that the correlation between morning and evening diary entries was strong, indicating consistent use. On average, participants were more likely to complete diary entries in the morning than in the evening, with an average of 4.1 more morning entries over the course of the study. These findings suggest that implementing a daily diary protocol in a longitudinal sleep study via a mobile application is not only feasible but likely to achieve high user compliance. The insights into user engagement were used to guide future additions to the mobile app's design, aiming to promote user engagement and compliance.

The third paper P3, titled "Nudging with Dignity: A Critical Examination of When and How to Use Digital Nudging," was published in the Proceedings of the Scandinavian Conference of Information Systems (SCIS) in 2024. It investigates the responses to digital nudges utilized to foster user compliance with a digital sleep diary in the Sleep Revolution mobile app. The study involved a qualitative analysis of 42 semi-structured interviews conducted after the three-month period of data collection outlined in the previous paper, during which participants were asked to fill out a digital diary in the Sleep Revolution mobile app twice daily. The analysis focused on the responses to dignity affronts resulting from daily digital nudging derived from the participants' accounts in their interviews. Dignity affronts refer to instances that offend one's dignity or self-respect. The analysis was based on the CARE (claims, affronts, responses, equilibrium) theory, which suggests that people tend to respond negatively to dignity affronts. The findings revealed various responses to digital nudges in the form of forfeit, flight, and fight responses. Importantly, the paper highlights that a digital nudge can have negative effects and thereby become a dark pattern under certain circumstances, even if it is responsibly designed. The paper provides an in-depth analysis, offering a contribution through the conceptualization of digital nudging, nuanced empirical insights into when digital nudging can be helpful versus harmful, and practical design guidelines to mitigate potential dignity affronts. These

insights shed light on potential harmful experiences that users encountered during the study in a real-world setting with the mobile app.

The fourth paper P4 titled "The Cosmic Design System Development and Application of Design Principles for Clarity in Design Systems" has been accepted with major revisions and resubmitted to *Scandinavian Journal of Information Systems (SJIS)* and takes a closer look at design systems. In particular, it examines the Atomic Design system used to organize the design and code for the Sleep Revolution digital health platform. Design systems have emerged as a solution to address the challenges of designing and maintaining consistent and cohesive UIs across digital platforms. However, design systems have outgrown their original purpose and are increasingly being used to organize the codebase of applications. Additionally, many existing design systems stem from industry and thus lack scientific evidence. This paper investigates the underlying principles that guide the creation of design system components to provide a theoretical foundation for developing design systems. The paper contributes three design principles for design systems components. Thus, the paper gives insights into the technical architecture and modularization of digital platform design and development components, thereby enhancing the understanding of the technical dimensions in digital platform design and development.

The fifth paper P5, called "VALID Care Pathways: A Framework for Meaningful Digital Platform Design", has been accepted with major revisions and resubmitted to *Communications of AIS (CAIS)*. Based on findings from a two-year action design research project, the paper explores dimensions of the design and development of a digital health platform to deliver at-home measuring of cognitive functioning. Cognitive functioning has been connected to sleep disorders but has, to date, not been researched to a large extent. Traditionally measured in a laboratory setting, there is a beneficial opportunity for digital at-home measurement. Therefore, measuring cognitive functioning was integrated into the Sleep Revolution digital health platform in a web app and was designed with the primary objective of achieving high usability while preserving the validity of relevant clinical measurements. The main contribution of this paper consists of conceptualizing and theorizing care pathways through digital platforms based on the findings from co-designing and evaluating a digital health platform with professionals and 55 participants, leading to the formulation of learnings regarding the design of the web app. These learnings reflect the social and technical dimensions of the design and development of digital health platforms.

Co-design research, specifically on large-scale, long-term digital health platforms, has been conducted but not described in detail [46], [47]. Combining the results of the introduced papers, this thesis addresses this gap and offers insights into the process, the key aspects of digital health platforms that were encountered in the process, as well as the challenges and dynamics of it.

# Chapter 2

## Theoretical Background and Related Work

”Although substantial progress has been made in research, commercial enterprises, and clinical care, health IT is in many ways still in its infancy. In particular, the human aspects of these systems leave open many challenges and opportunities. Whether we are talking about making and using abundant data; reimagining the role of the clinician, caregiver, and patient; or using technologies for the masses to create healthcare for large populations, considerations of the entire health system, including people and technologies, will be essential. Thus, the future of interactive systems for health lies in the deep connections and collaborations among computing, social-behavioral, and biomedical researchers and professionals.” - Hayes, *Interactive Systems for Health* [48], p.23

### 2.1 Digital Platforms

A digital platform is defined as an online infrastructure that acts as an intermediary, connecting resources and services among users [2], [4], [5]. Thus, it facilitates interactions, transactions, and value creation [49], [50]. Tiwana, Konsynski, and Bush (2010) characterize digital platforms as standardized foundations comprising a core architecture and extensible modules, facilitating rapid evolution and the continuous addition of new features. Digital platforms act as intermediaries that streamline interactions and transactions in diverse contexts, from social media (Facebook, Instagram) to on-demand services (Uber, Airbnb) and e-commerce (Amazon, Alibaba) [50], [52]. Digital platforms commonly target various devices and systems. Furthermore, corporations like Amazon often provide a multi-sided digital platform, offering various services to different target groups [5], [53], thus adding to modern digital platforms’ complexity.

Research into digital platforms broadly spans five key areas: social, technical, legal, economic, and ethical. Social research delves into the societal implications of digital platforms, examining privacy issues, user behavior, and the formation of online communities [54], [55]. Technical studies address challenges in digital platform architecture, modularity, and data management, emphasizing scalability and performance [56], [57]. Legal research focuses on the evolving regulatory landscape, particularly with data governance, intellectual property, and competition laws [53], [58]. Eco-

nomically, studies explore new business models, digital platform economies, and the disruption of traditional industries [59], [60]. Ethical research critically examines algorithmic biases, the digital divide, and digital platforms' accountability regarding user welfare and misinformation [40], [61].

Socio-technical research focuses on the interaction between the social and technical dimensions of digital platforms. Orlikowski and Iacono [62] emphasize the intricate relationship between technology and human agency and how digital platforms shape and are shaped by social practices. These elements illustrate how technology not only alters social dynamics but also affects individual cognition and behavior, which are central to understanding the full socio-technical scope. Recent research explores how digital platforms influence mental health and social behavior, such as through addictive tendencies and shifts in self-perception [63]. Other studies look into the effects of design and personalization on user engagement [38]. To achieve a design that is engaging but does not have an aversive effect on the user's well-being, it is important to follow a holistic design strategy that aims not only for a positive technological but also societal impact of the design. User involvement in the design process is a way to gain insights into users' needs and how technology needs to be designed to have a predominantly positive impact on the users without undermining their values.

## 2.2 Design

The emphasis on a holistic approach in socio-technical research resonated strongly in Scandinavia. During the 1970s, Scandinavian researchers integrated this approach into local organizational and research practices [64]. They adapted this approach into a design process that involved designers and stakeholders alike [65]. Designs were created together with stakeholders, including end-users, and iteratively tested and improved. This stood in contrast to less flexible methods that were mainly used up to that point [66]. This approach became known as participatory design.

Participatory design has since played an important role in the design and research of digital platforms. The emphasis on the collaboration between designers and users during the design phase helps to create meaningful digital platforms that meet the actual needs of their users and not simply the designer's vision [67], [68]. Thus, participatory design helps to create digital platforms with high user engagement [69]. When applied to the design process, participatory design for digital platforms involves workshops with domain experts and users, as well as user test sessions that help designers to understand user behaviors, needs and preferences.

Co-design is a form of participatory design that calls for collaboration between designers and stakeholders, in particular in the ideation phase of the creation of a digital product [70]. Today's digital platforms are often large-scale and high in complexity, involving multiple stakeholder groups. Co-design emphasizes the involvement of all stakeholders as equal parties in the design process [70]. However, conducting co-design in a complex setting might require a variety of design activities. When used with a smaller group of users and other stakeholders in the ideation stage of a design, participatory design activities often use workshops between the designer or developer and the stakeholders, or prototyping sessions with users. Organizing such design activities becomes more complex with a large number of involved stakeholders, multi-sided

platforms, and long-term development. Traditional methods, such as small workshops or one-on-one sessions with participants, are often not suited to these more complex environments and, therefore, must be adjusted. This change of methods further impacts the role of the designers and developers and their involvement in design activities with users and other stakeholders. Participatory design of minor features can happen directly between the designer or developer and the user [41]. In contrast, an iterative design or one that spans multiple sites is likely co-designed in a more removed manner [41].

Differing requirements from the individual stakeholder groups can pose challenges in the design process, which co-design tries to overcome with the inclusion of boundary resources that can help to bridge the gap between the groups [71]. Boundary resources work as a medium to communicate about a digital platform between different stakeholders. For example, they can constitute a shared language between designers and users to communicate design ideas [3] or act as a contract between the service provider and the service creator, detailing service regulations [72]. Boundary resources are reshaped during use through influence from involved stakeholders or outside forces [72]. In co-design, boundary resources are to tools that enable effective communication about the design between stakeholders [73]. As the co-design approach aligns stakeholder needs that inform the design, the resulting artifact often integrates smoothly with the work practices it was created to enhance [74].

## 2.3 Digital Health Platforms

Digital health platforms are digital solutions that enhance healthcare delivery, management, and provide support for both individuals and healthcare experts. When implemented effectively, digital health platforms can make healthcare more accessible to various societal groups. Through wider reach, digital health platforms also have the potential to transform healthcare from being a mainly reactive measure to one that also acts in a preventative manner. This transformation not only leads to a more effective and cost-efficient healthcare system but also enables longitudinal data collection. Such data is crucial for powering machine learning algorithms that can potentially discover new patterns for diagnosis and treatment [75].

Digital health platforms have been employed to ease the burden of healthcare systems and encourage self-care to varying degrees of success. In this context, digital platforms aim to enhance patient outcomes [76], [77], improve care coordination, and facilitate communication between stakeholders [21]. Previous research has focused on creating impact through these digital platforms [78], [79], enhancing user engagement [39], [80], and promoting user-centered design [81]. Studies have shown the importance of prioritizing patient needs and preferences in digital platform design, which can be effectively addressed through innovative approaches such as digital nudging [82] and gamification [80].

Additionally, the term 'digital health' refers to practices that have evolved by utilizing technological advances. These technologies are integral components of digital platforms and often overlap in definition and their temporal emergence. Marent and Henwood [83] categorize digital health into four main areas: (i) telemedicine, (ii) eHealth, (iii) mHealth, and (iv) algorithmic medicine. Each category represents a dis-

tinct aspect of digital health but collectively contributes to the ecosystem of a digital health platform.

Telemedicine refers to the practice of providing medical care remotely, using telecommunications technology to diagnose, treat, and manage patients who are not physically present with the healthcare provider [84]. Telemedicine has been utilized to extend healthcare services to remote or underserved areas where direct face-to-face patient-provider interactions are not always feasible [85]. As defined by the World Health Organization, telemedicine is the "delivery of health care services, where distance is a critical factor, by all healthcare professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment and prevention of disease and injuries, research and evaluation, and for the continuing education of health care providers, all in the interests of advancing the health of individuals and their communities" [86].

The evolution of telemedicine has been significantly influenced by advancements in technology, particularly the development and spread of the internet and mobile devices. Initially, telemedicine was conducted through telephone and radio [87]; however, the advent of the internet brought about a change in how healthcare services could be accessed [88]. Through it, digital platforms have become effective mediums to deliver telemedicine services [89].

The term 'eHealth' refers to technologies that provide information and enable communication for health, to deliver treatment, conduct research, provide education and monitor individual diseases as well as public health [90]. As this definition shows, it is a broad term that applies to any technology that enhances the provision of healthcare services. The goal of these technologies is to improve the quality of healthcare by increasing the efficiency of communication between healthcare experts and patients, increasing accessibility of healthcare [91], and aiding clinical decision-making. Patient information is thereby stored in the eHealth solutions, which allows healthcare experts to exchange data and continue healthcare delivery [35].

Mobile health, or mHealth, is defined as any health-related service that is provided by a mobile device, such as mobile phones, or other wireless technological devices [92]. It encompasses a variety of applications that leverage mobile technology to deliver health services and manage patient information. The primary categories of mHealth include (i) treatment compliance, (ii) provision of information and educational materials, (iii) data collection and monitoring, and (iv) diagnostic treatment support, including the burgeoning field of digital therapeutics [93], [94].

The integration of mHealth into digital platforms further enhances the accessibility of healthcare services [95], and they allow for the personalization of healthcare services [96]. Moreover, the pervasive nature of mobile technology allows for patient-centered healthcare approaches that are more engaging. As mobile devices have become persistent companions for many people, mHealth solutions can help to gather longitudinal data, which in turn contributes to more proactive healthcare [97]. They also facilitate the deployment of applications that assist in the monitoring of chronic diseases and preventative wellness programs, which are important for overall improved health outcomes [98].

Algorithmic health involves the use of advanced algorithms, including machine learning and artificial intelligence algorithms, to improve healthcare outcomes [99].

These technologies are utilized to understand large medical datasets such as Electronic Health Records, genetic information, and data collected through wearable devices. The insights gained from such analysis are used to predict patient outcomes, personalize treatments, and automate diagnostic processes [100].

Although algorithmic health represents a significant technological advancement with the potential to transform healthcare, it is not the primary focus of this thesis. Since this thesis emphasizes the key aspects of a continuous participatory design and development process, the algorithmic developments are not directly relevant to the main discussion points. This thesis prioritizes patient engagement and the iterative design and development of digital platforms that collect and display data rather than the processing of that data with advanced algorithms.

While telemedicine, eHealth, mHealth, and algorithmic medicine are digital health technologies, neither constitutes a digital health platform. However, they can be integrated parts of digital health platforms and are relevant related concepts. A digital health platform mainly distinguishes itself by its function as an intermediary that connects systems, data, and users.

Digital health platforms have been designed and developed for many different purposes involving various stakeholders, settings, and data types. They are often used to support and provide general care by delivering online consultation [101], diagnosis [102], or treatment [103]. Through online consultation [101], digital health platforms can connect care providers with patients. Patients from rural or remote areas are often less well-connected to healthcare services, and online delivery of care can thus help establish more equitable care [104]. In particular, in the area of mental illness, digital health platforms can provide treatment through online sessions and digital treatment modules [103]. Digital platforms have thereby successfully been employed, providing services with non-inferior treatment outcomes and a significantly reduced time involvement of health experts [103]. Aside from consultation and treatment, digital health platforms can offer diagnosis suggestions through advanced models and predictive algorithms [102]. The collection and combination of large data sets through digital health platforms can inform the development of such models and algorithms, which can then be integrated into platforms to provide this information to health experts and patients. These advanced algorithms and models also pave the way for personalized medicine by combining a variety of data and preparing an individual treatment plan.

Digital health platforms further provide services that support disease or rehabilitation management [3], [105], including various aspects of patient monitoring [3], and care coordination [106]. These services support care workers in providing management strategies to patients as well as support patients in self-managing their health [105]. This approach can lead to improved well-being in patients and a heightened sense of control over their health [107] and assists patients and care workers with tools to improve the patient's health outcomes [105].

Aside from health outcome improvements, digital health platforms may provide patients with care support and management to help them gain relief from symptoms of chronic illnesses as well as associated stress [108]. Real-time data collected through sensors or wearables, as well as self-recorded subjective health data, can deliver insights into the patient's illness and support the facilitation of timely treatment.

Digital health platforms connect not only patients with experts but also experts with each other [109]. Electronic health records (EHR) systems delivered through digital platforms are used to share health-related data between health experts such as physicians [110]. By sharing medical information such as testing result or medication usage, procedures can be more effective in terms of both outcome and time. This information can also be used to monitor prescription medication usage [111]. Recently, methods for data analytics have been integrated more prominently with electronic health records [112], [113] to predict complications [114], hospital re-admissions [115], or mortality rates of patients [116]. Researchers have recognized the value of EHR data and have used it, for example, in clinical cardiovascular research [117]

Data in general and health data in particular has become more valuable with the advent of the new golden age of machine learning. Advanced algorithms, models, and data analytics have been developed for diagnosis [112], prediction of adverse events [114], and the development of more cost-effective treatments [36]. There has been a need for longitudinal data collection for the development of more precise predictive models [118]. Digital platforms offer the infrastructure for data collection by connecting data from mHealth apps, wearables, web apps, and other sources. In another avenue, collecting data for research and care can help track the impact of interventions. In research settings, digital health platforms enable streamlined data collection that is then evaluated for its treatment outcomes and efficiency [119]. In a care setting, extensive data enables more personalized treatment that fits the individual [120].

While the collected data can be used for the development of more advanced algorithms, it can also be used to enable the monitoring of patients [121], treatment adherence [122], or symptoms [123]. Moreover, the collected data provides researchers with information about participant compliance. This can be valuable if the collection of timely and complete data is essential for effectively interpreting the data. In a care setting, monitoring data related to a patient and their symptoms can help improve the efficiency of care delivery while maintaining the care outcome [105].

Furthermore, digital health platforms may also be used to connect patients or participants with each other [124]. Health communities and health-focused social media [125] provide information about health and a space to share individual health experiences. This type of digital health platform influences the way people educate themselves about their health [126]. Not only can they support individuals in learning about their health, but they can also provide access to information that was less readily available in remote and rural areas previously [104].

To summarize, digital health platforms have been used to provide services that connect health experts with patients, providing general care, disease and symptom management, as well as palliative care. They also allow for the collection of data that enables the monitoring of patients and research participants. Through digital health platforms, different care and health experts can connect and share access to patient data for more effective care. Connected devices such as wearables, sensors, or mobile apps enable data collection from patients, participants, and health experts. This data can be used for research purposes and the development of novel diagnostic algorithms, tracking the effectiveness of treatment and monitoring patients and their symptoms. Online health communities hosted on digital platforms can complement official health services by providing information and exchanging experiences. Table 2.1 shows application areas of digital health platforms based on the presented literature

and the stakeholders that are likely to connect through the services. However, the overview presented in the table should not be understood as an exhaustive list of all possible application areas of digital health platforms; instead, it aims to illustrate the variety of application areas and stakeholders involved in digital health platforms.

Area	Experts	Patients	Participants	Researchers
Care Provision	✓	✓		
Disease Management	✓	✓		
Palliative Care	✓	✓		
Electronic Health Records	✓			✓
Data Collection	✓		✓	✓
Monitoring	✓	✓		
Information & Support		✓		

Table 2.1: Potential application areas and involved stakeholders in digital health platforms.

As there is a broad variety of digital health platforms, a design approach for different types of digital health platforms would likely look different. Depending on the involved users and their level of health expertise, digital health platform requirements vary. A digital health platform that has been designed and developed for sharing EHR between health experts does not require patient involvement in the design process, as they are not the intended users. Depending on their health domain, health experts' requirements are also likely to differ. Due to domain- and application-specific requirements, it is even more vital that all stakeholder groups that will become active users of the system are represented in the co-design procedure for the design and development of digital health platforms [127].

### 2.3.1 Challenges of Digital Health Platforms

Creating a digital health platform with a meaningful design that fully uses its potential is a difficult task. There are a few obstacles that stand in the way of achieving a meaningful digital platform design. One of those obstacles stems from the nature of the data that needs to be stored on digital health platforms. Patient health data is highly sensitive and requires high security and privacy standards to ensure that it can be safely stored and sent between parties [128]. With the handling of sensitive data also come complex legal regulations that need to be found out and followed [129]. Despite strict standards, digital health platforms used in various healthcare institutions are not necessarily built to be compatible [130], which makes integration of new software into existing systems challenging [130].

Even if all technical and legal requirements have been met, a lack of involvement of patients and healthcare experts can still hinder the adoption of digital health platforms. A result of the omission of involving users can be a system that is not fully aligned with the needs of its users, impacting its usability [131]. Unfortunately, initial attempts to involve stakeholders are also no guarantee for designing a meaningful digital health platform. Early abandonment of co-design after the ideation phase can lead to crucial oversights that hinder the adoption of the system due to its limited utility [132]. Not gathering input from healthcare experts throughout the development process can lead to misalignments between the functionalities of the digital health platform and the

real-world workflows [133]. Similarly, without continuous patient involvement, digital health platforms may not adequately address patient concerns or encourage sustained engagement [134]. Therefore, a co-design approach for designing and developing digital health platforms can be highly beneficial.

### 2.3.2 Co-Design in Digital Health Platforms

Co-design involves various stakeholders in the design process to ensure that a product is usable and technically sound. In a healthcare setting, these stakeholders can be end-users as well as healthcare, technical, or legal experts. Specifically the involvement of end-users is important to create a user-centered system, which fosters greater satisfaction among users. This is a critical factor for an engaging design that increases the chances of adoption and sufficient user compliance [135]. User involvement and the collection of consistent feedback can help to identify reasons for low engagement early on. Identifying these issues is the first step in improving the design and making it more user-friendly [136]. The system can then be enhanced with interactive and personalized design elements specifically built to combat the found issues and increase user motivation to interact with the system. Examples for these interactive elements are features like gamification and tailored feedback [135]. However, user involvement cannot only help to identify the lack of interactive elements in the systems, but also areas in which it is too complex. An easy-to-use system that does not unnecessarily overload the user can be beneficial for a quicker adoption [136]. Moreover, when involving end-users in the design process, the inclusion of users representative of a wide variety of age, tech literacy, and physical abilities can be beneficial for designing an inclusive system that is easy to use [44]. Equally vital as end-user involvement is the collaboration with healthcare experts. Designs need to be not only innovative and engaging but also fit into the established workflow and practices. Even more important, the designs need to adhere to healthcare standards in order to be not only user-friendly for both end-users and healthcare experts but also effective and reliable [137].

While co-design is a helpful approach to deal with the complexities involved in the design and development of digital health platforms, the process also has its own challenges. Reported difficulties range from lack of participation and collaboration, in particular over an extended period of time, [42], [46], lack of time and resources [42], as well as technical and scaling issues [1], [138].

## 2.4 Technical Aspects of Digital Health Platforms

The technical research on digital health platforms encompasses a wide array of subjects that range from software development to system infrastructure. Research in this area can include the development and evaluation of software applications, analysis of data management systems, and the optimization of supply chains for digital health platforms [139]. Shaw and Donia [139] categorize these technical components into distinct research areas, such as application software, material devices and their supply chains, interoperability between systems, data governance structures, and cybersecurity. Among these, application software and modularity stand out as particularly relevant to the co-design process of designing and developing digital health platforms. Application software should be designed and developed with the active involvement of end-users—including patients and healthcare professionals—to ensure that the soft-

ware meets real-world needs and enhances user experience. Modularity, on the other hand, refers to the design principle where a digital platform is divided into separate components that can be independently created and then integrated or interchanged. Modularity allows for flexibility in updating and improving specific parts of a system without needing to overhaul the entire digital platform. By engaging users in the design of these modular components, the digital platform becomes more adaptable and responsive to the evolving needs of its users.

### 2.4.1 Application Software

As a piece of software, insights into software design and architecture are relevant for digital platforms. Software architecture has been extensively discussed in the literature over the years, and a variety of definitions and concepts of the topic have emerged. According to the works of Perry and Wolf [140] and Shaw and Garlan [141], software architecture can be described as a way of defining elements that makeup software systems. Other research emphasizes the need to distinguish architectural design from other design activities [142], [143]. A definition of design activities is the modularization of systems into design elements, algorithms, and procedures. Architecture, on the other hand, focuses on the selection of architectural elements, their interactions, and the constraints on those elements [144].

However, the term *software architecture* is often confused with the term *software design* [144], which refers to the process of defining software solutions that meet functional and non-functional requirements. This is a critical step in the software development process as it affects the resulting software system's quality, maintainability, and performance. Eden and Kazman argue that software design usually focuses on the definition of implementation details of individual components, while architecture patterns aim for an abstraction of the overall structure of the software system.

### 2.4.2 Modularity

Modularization is part of the design activities involved in designing digital systems. It is a popular approach in structuring information and design, with the goal of increasing reprogrammability and maintainability of the system. Hürsch and Lopes [145] introduced the separation of concerns in 1995 as a design methodology that focuses on creating separate modules for every concern. This act of modularization provides a way to structure information systems in a more scalable and maintainable way. Thus, a system can become more manageable, which is particularly important due to the increasing complexity of information systems and, specifically, digital platforms [50]. Managing complex digital platforms requires a design approach that fosters consistency and maintainability. One such a approach has emerged in the form of design systems [146]. A design system is the collection of components, guidelines, and rules used to create a digital platform's user interface [147]. It includes elements that make up the visual design of the digital platform, such as components for input, forms, navigation, and other interactive elements. Design systems can improve design scalability and consistency and provide a mutual visual language for a team that reduces confusion and miscommunication [148]. The concept of design systems related to early work on design patterns [146]. Design patterns have been introduced in 1977 by Alexander, Alexander, Ishikawa, *et al.* [149] in the context of architectural design. Design pat-

terns are described in Alexander, Alexander, Ishikawa, *et al.*'s work as a collection of solutions to recurring problems. Accordingly, the idea of design systems is not new, and it stands on solid ground with roots in the pattern language [149]. Reusable components are the key to design systems, and they are guided by clear standards that can be assembled together to create a digital platform and to enhance collaboration and communication through documentation among various kinds of digital platform stakeholders [146].

However, design systems for visual interface designs have only recently become the subject of scientific studies [146]. Aside from academic literature, there is a body of practical fieldwork on the definition and development of design systems. According to Hacq [150], design systems should consist of a style guide and a pattern library of design components. Fanguy [151] also emphasizes a pattern library as the core of a design system and describes a process for constructing design systems. The process starts with a visual audit of current designs that leads to a formulation of a design language. Based on these steps, a UI pattern library can be created. Similarly, Fessenden [152] argues that a set of reusable components and patterns is essential for achieving a scalable design. In summary, the sentiment of the fieldwork is that design systems act as pattern libraries comprised of reusable components that hold great promise for promoting sustainable design, development, and documentation.

One example of a design system that has emerged as a way to structure the UI components of digital platforms is Atomic Design [153]. Atomic Design is a design system for designing and developing user interfaces by breaking them down into smaller, modular components. These components are categorized into different levels of complexity, including atoms, molecules, organisms, views, and templates. Atoms are the building blocks of any UI, such as buttons, inputs, and labels. These atoms can be combined into molecules, which are small groups of atoms that work together to perform a specific function, such as a search bar or a login form. Organisms, on the other hand, are larger groups of molecules and atoms that form a more complex UI component, such as a header or a sidebar. Views are complete pages or screens that are made up of multiple organisms and molecules. Templates are recurring view layouts that can be used across multiple views. By breaking down the UI into these smaller components, Atomic Design promotes code separation and reusability in an intuitive way. It provides an efficient and consistent way of developing UIs, making it easier to maintain and update them. However, it is worth noting that Atomic Design does not provide explicit guidelines for integrating application logic, as it focuses solely on the design aspect of UI development. However, Atomic Design has two important drawbacks. First, it is industry-driven; ergo, it has not been widely tested. Second, it shares the limitations of other design systems, as it lacks the cohesion and ties between design elements and code.

## 2.5 Social Aspects of Digital Health Platforms

The research on the social aspects of digital health platforms covers a broad spectrum of interactions and impacts that these technologies have within healthcare ecosystems. This research includes analyzing how digital health interventions affect individual behaviors, interpersonal relationships, and the broader socio-organizational environment [139]. Shaw and Donia [139] delineate these social dimensions into several categories,

such as individual health-related practices, interpersonal relationships between patients and providers, organizational policies, and the influences of broader governmental regulations and policies. These aspects examine how personal health management practices are transformed by digital platforms and how these digital platforms facilitate or hinder communication between healthcare providers and patients. Organizational policies explore how healthcare institutions adapt their frameworks to incorporate digital health tools, affecting everything from daily medical practices to patient privacy concerns. Governmental policies additionally play a significant role by setting the regulatory environment that shapes the development and usage of digital health technologies.

Among these social aspects, individual health-related practices stand out as particularly vital for a co-design approach. By directly involving patients in the design and development process, digital health platforms can better align with the unique needs, preferences, and daily health management routines of individuals, leading to more effective and personalized solutions.

### 2.5.1 Individual Health-Related Practices

Individual health-related practices within digital health platforms refer to the actions and behaviors that patients adopt to manage their health conditions, guided and supported by digital tools [139]. These practices encompass monitoring, medication adherence, symptom tracking, and health education. Digital health platforms offer the option of including features like nudging and gamification to motivate individuals to adhere to their health goals and treatment plans [154]. Nudging involves subtle prompts or reminders that encourage healthy behaviors [155], while gamification employs elements like rewards, challenges, and social connections to make health management more engaging [156].

Digital nudging encompasses subtle interventions or cues laid out within the environment with the aim of influencing peoples' decision-making process [157]. Essentially, it is the digital equivalent of nudging in the physical world. The concept of nudging was introduced in Thaler and Sunstein's (2009) and refers to the practice of subtly influencing an individual's decision-making process through deliberate alterations in their choice architecture [155], [158]. *Choice architecture* refers to the arrangement of available choices, which has been shown to significantly impact an individual's decision-making [155]. The choice architect, or nudger, can deliberately modify the choice arrangement to influence an individual's decisions by leveraging cognitive biases and heuristics [155], [159], [160].

Digital nudging is a concept that draws on traditional principles of nudging to influence behavior in the digital world [157]. By employing subtle interface design, interaction, and information, digital nudging aims to guide user behavior on digital platforms [157], [161], [162]. Thus, the digital environment becomes part of the choice architecture, opening novel avenues for nudging research within IS [163]. IS researchers have recognized that the digital environment has unique properties and that not all findings about nudging in the physical world can be seamlessly transferred to digital contexts [163]. This has resulted in a growing interest in studying digital nudging per se. Digital nudging allows for more personalized and on-demand nudges to influence behavior compared to nudges presented within the analog world [164]. While the integration of nudges in digital environments is relatively low-cost and offers a high

degree of freedom in designing them, there is a risk that nudge designers may overuse them [165]. As digital nudges have proven to be effective in promoting healthier habits and achieving other pro-social goals [162], responsible nudge design has become an important topic of discussion in IS research. Lembcke, Engelbrecht, Brendel, *et al.* (2019) linked ethical considerations from the nudging literature with knowledge about digital nudging, presenting a starting point and call for papers contributing to that type of discourse in IS research. Our paper contributes to that discourse.

Parallel to the discourse on digital nudging is the discourse on dark patterns. Dark patterns are harmful digital nudges that influence an individual's behavior in a manner that conflicts with their personal values and beliefs [166]–[168]. However, dark patterns do not have a singular definition [169]. In their review, Mathur, Kshirsagar, and Mayer [169] found that definitions of dark patterns include elements of misleading design elements [170], subversion of user expectations [171], exploitation of users and harm to users [172]. As dark patterns generally lead to aversive outcomes for the nudgee, they violate the principle of libertarian paternalism [155]. Libertarian paternalism amounts to employing nudges that are in the nudgee's own best interests as long as it preserves the choice selection in the environment [173]. However, the design of acceptable nudges following the principles of libertarian paternalism is not without controversy, as has been illustrated in the scientific community. More specifically, critics of libertarian paternalism argue that this design approach still restricts the nudgee's autonomy [164], [174], [175] and that it should, therefore, be reconsidered.

Researchers have recognized this issue and have explored ethical considerations from the nudgee's point of view, focusing on the nudged individual rather than the nudgee's intentions (e.g., [176]–[178]). For example, Sunstein [179] advocates for transparency of nudges. Nudges influence the responses to the choice environment by triggering one of two decision-making processes [159], [180]. The model separates human decision-making into intuitive system one responses and calculated system two responses. Nudges can belong to either system one or system two depending on their evoking response processes [181]. Sunstein recommends the usage of system two over system one nudges, as they target a deliberative decision-making process rather than an intuitive one to increase awareness of the nudgee being nudged. By raising the nudgee's awareness of the nudge, they increase the likelihood of rejecting nudges that go against their preferences. Clavier [182] took a different perspective and stated that a nudge should be acceptable as long as it seeks to attain a beneficial outcome consistent with the personal values of the nudgee. Combining those positions, the optimal nudge would consequently be designed so that the nudgee has no objections to being nudged, that the nudgee's autonomy is preserved, and that the nudge is sufficiently transparent [164]. Moreover, recent recommendations for empowering digital nudge design is to present information in an engaging way, for example, with feedback and data visualization [183]. If nudges violate any of these design recommendations, they can cause aversive emotions in the form of frustration [184], [185], which can lead to responses such as workarounds, avoidance or piggybacking [186]–[188].

While these design recommendations of transparency and autonomy preservation emphasize the importance of the nudgee's perception of the nudge, they still overlook the complexity of designing digital nudges that align with personal preferences. Previous research has shown that the response to a nudge depends on the individual [176]–[178]. It is, therefore, crucial to further examine the individual factors that con-

tribute to aversive responses to nudges. In particular, there is a gap in the research on digital nudges related to their potential harmfulness to vulnerable populations, such as those with limited digital literacy or cognitive impairments. Therefore, more research is needed to evaluate the impact of nudges on user dignity and inform the design of digital nudges that avoid harming user dignity.

## 2.6 Digital Health and Sleep

Sleep impacts a range of physiological functions, such as the hormonal system, cardiovascular system, immune system, and brain health [24]. Sleep disorders cause a major socioeconomic burden on healthcare systems worldwide. Using the current diagnostic criteria, almost 1 billion people between the ages of 30-69 years are affected by obstructive sleep apnea (OSA), the most common type of sleep-disordered breathing [25]. This manifests in billions of US dollars annually in lost productivity, cost of accidents, and other downstream health sequelae [189]. There is profound evidence that sleep disorders are associated with a range of physical health problems leading to a higher risk of mortality and morbidity rates, including diabetes, cardiovascular disease, obesity, and hypertension [25]–[27], [190]. Individuals with untreated sleep disorders are also at higher risk of deteriorating cognitive functioning that may impact occupational performance and social participation, thus compromising the quality of life and individuals' socioeconomic status [15], [191], [192]. Sleep disorders are strongly associated with cognitive decline, attention loss, and memory impairment and play a vital role in mood regulation and the pathogenesis of mood disorders [191], [193], [194]. Therefore, sleep disorders are one of the leading health challenges today and a serious threat to public health if left undiagnosed and untreated.

Our understanding of sleep disorders and possible underlying mechanisms is challenging. Sleep research faces several limitations, such as expensive and time-consuming diagnostic procedures, small and homogeneous sample sizes, lack of long-term studies on sleep disorders, and daily fluctuations in sleep [15], [16], [29]. Hence, while the impact of short-term and acute sleep deprivation has been well documented, our understanding of long-term sleep disorders with daily fluctuations in a naturalistic setting (i.e., home environment) needs to be clarified [15], [30], [31].

Although polysomnography (PSG) is considered the gold standard for sleep measurements, it is time-consuming, expensive and does not include any subjective information from the patient, e.g., for sleep hygiene and insomnia diagnosis. Additionally, PSGs require manual scoring, and the queues for studies tend to be lengthy and the overall resources are scarce. Continuous measurement for long-term studies of sleep in a naturalistic setting would be revolutionary and relying heavily on the combination of subjective and objective measurements would be beneficial as both provide their own unique sleep features [195], [196]. Therefore, sleep diaries and self-report measurements are more compatible with long-term and continuous measurements, where the long-term effect and compliance over time are studied [28]. Sleep diaries have been the primary focus of digitization efforts in sleep care [22], [197], [198]. These can be outlined as digitization efforts instead of digitalization efforts as most sleep diaries have primarily been moved from an analog survey format to a digital survey format, taking little or no advantage of dynamic structures and generativity that the design and development of novel digital solutions can bring. Taking advantage of the gener-

ative nature and integrating different users' needs have been outlined as key factors for moving from digitization to digitalization [199]. Digitization is thereby understood as efforts to translate an analog artifact into a digital artifact, while digitalization is seen as efforts to fully utilize the digital environment to enhance digital processes. However, some efforts have been more innovative, including new interactive features such as sliders and gamification elements that allow for enhanced interaction, which in turn leads to higher user experience [22]. Sleep diaries outline a promising way of collecting longitudinal subjective data that can aid the diagnosis of sleep disorders such as insomnia. However, the data from a sleep diary alone is, in most cases, not sufficient to identify sleep disorders with certainty [200]. While advances have been made in the development of equipment for at-home home sleep measurement devices, which can allow for sleep measurements at patients' homes [201], the equipment is still costly and cannot be easily distributed to a broader demographic. In addition to that, the gold standard for at-home sleep measurements is one to three nights, which simply does not allow for enough time for fluctuations in sleep patterns, for instance, for females, where the sleep patterns can differ extensively brought on by the menstrual cycle [202]. In sum, there have been some advances in terms of subjective data, others in terms of objective data but there is a gap in the literature concerning the integration of heterogeneous longitudinal data sources into reliable care pathways.

### 2.6.1 Sleep Diaries

The ready access to wearables on the customer market and take-home sleep equipment provides an opportunity to transform sleep research and healthcare [203]. In addition, digital applications can be easily distributed to a broad audience [204] and therefore present an opportunity to bring additional sleep measurement tools to consumers. When a person experiences sleep-related issues, a sleep diary is an important tool for gathering subjective sleep data, which provides key information for the diagnosis of many sleep disorders [205]. A sleep diary can be used for monitoring severe sleep disorders, and it can function as a valid assessment tool for insomnia with the potential of identifying candidates for cognitive behavioral therapy as a treatment trajectory [206]. A sleep diary is also a valuable research tool for sleep studies. Traditionally, sleep diaries are designed to be printed out and filled in on paper [207], [208]. However, the pen-and-paper format is rigid and neither scalable nor customizable. It provides limited possibilities to interact with the participants, personalize the diary, respond to questions or misunderstandings in time, or control the data during collection. To process and analyze the results, the pen-and-paper requires significant manual work [198], making it prone to errors. Moreover, an analysis of the data can only be provided after the data has been collected and transferred to the researchers [3]. In addition, sleep patterns can vary due to lifestyle changes, menstrual cycle, shift schedule, and daylight savings, and collecting subjective data over an extended period to capture these fluctuations would likely yield more reliable results [202]. A comprehensive data collection could allow insights into new factors influencing sleep quality over time.

In 2012, an expert panel created a standardized sleep diary in a pen-and-paper format called the Consensus Sleep Diary (CSD) [207]. However, one major drawback of the CSD is that it comes in three different versions: (i) a core, (ii) an extended core, and (iii) an evening version. The core version of the CSD was designed with the intention of creating a minimally viable set of questions for sleep diary research to

be asked in the morning. The extended core version additionally tracks daytime data (CSD-M). The evening version was developed specifically to be filled out both in the morning and in the evening (CSD-E) and contains the same questions as the CSD-M with additional instructions on which set of questions to fill out in the morning and which set in the evening [197], [207]. The pen-and-paper format of the CSD made it necessary to treat each of these three variants as different versions of the sleep diary. However, to advance standardization further, it would be preferable to arrive at one single sleep diary standard. A digital sleep diary version could, however, allow for time-controlled restrictions, and due to that, a digital sleep diary could thus combine the three CSD versions into one [203].

Monitoring participant compliance in a pen-and-paper design is complicated, and counteracting it even more so. Participant feedback has shown that there is a tendency to forget to fill out pen-and-paper symptom trackers and try to make up for it by filling it out at a later time, also referred to as the "parking lot syndrome" [209]. This is a significant drawback since symptom trackers and sleep diaries - when filled out in close temporal proximity to the occurrence of the event - can contribute reliable and stable data for identifying certain sleep disorders [203]. For diagnosing sleep disorders, timely data has significant value compared to retrospectively collected data. Also, the retroactively entered data cannot be accounted for or filtered out since it is difficult to detect it in a pen-and-paper format [197]. Entering data retroactively also introduces another problem; namely, it gives rise to the potential problem of memory bias. Memory bias refers to the tendency to intentionally or unintentionally rely on recalling certain events and autobiographical memories and favoring those memories over others [210]. This recall process often relates to significant events, including traumatic, unconventional events, or even to systematically selecting the most recent events in a series of events [211]. Memory bias and the tendency to rely on the most recent events are evident when dealing with a prolonged condition period [212]. Therefore, filling out the sleep diary based on recall can result in potentially biased and less reliable data. This is why finding alternative ways to increase compliance and counteract memory bias, thus improving the integrity and quality of the sleep diary data, should be a priority [213]. A digital solution can prevent these issues.

There have been attempts to develop a version of a digital sleep diary. For instance, Tonetti, Mingozi, and Natale created a digital sleep diary based on the CSD in 2016. It was a mobile application developed for iOS, specifically targeting iPads. They compared their digital sleep diary to the pen-and-paper diary and received promising results; the digital version performed similarly to the pen-and-paper version. Unfortunately, the study does not detail the design of the app, and since it was only developed to support iPads, this digital sleep diary version limits the potential uptake significantly. In 2019, another version of a digital sleep diary was developed by Văcărețu, Batalas, Erten-Uyumaz, *et al.* This version was not based on the CSD, but instead on another analog sleep diary, the Karolinska Sleep Diary [208]. This analog sleep diary has a different format compared to the CSD and does not encompass the same set of questions. The research project focused more on studying the usability and user experience of this digital sleep diary and less on the sleep diary per se [198]. In 2021, Vallo Hult, Islind, and Norström found that, when transformed appropriately, digital healthcare applications have a positive influence on professional practices as well as patient awareness and participation. Therefore, when turning an analog artifact into a digital one, it is important to take into account possible context changes like the ones

described by [214]. The general need for further standardization of a digital sleep diary is illustrated in an overview of the current state of sleep measurements by [203]. What can be derived from these studies is that there should be a three-folded focus in future research on digital sleep diaries: (i) to create a standard for digital sleep diaries, (ii) to take into account the context and multiple stakeholders, and (iii) to design such digital sleep diary to fit multiple mobile operating systems to increase potential uptake.

## 2.6.2 Cognitive Functioning

Research has shown a significant connection between sleep-related health issues, particularly obstructive sleep apnea (OSA), and neurodegenerative processes characterized by the loss of neuron structure and function [215]. These processes have been linked to declines in cognitive and motor functioning, highlighting the importance of early detection and intervention for OSA. Indicators of neurodegeneration in OSA patients include changes in cerebrospinal fluid [216] and alterations in brain anatomy and activity as observed through structural [217]–[219] and functional neuroimaging techniques [220], [221]. To assess the cognitive impairments associated with OSA, researchers have employed various neuropsychological tests. Despite some inconsistencies in findings due to methodological variations and the challenge of selecting tests with suitable difficulty levels to avoid floor and ceiling effects, certain cognitive functions, such as working memory, have been consistently found to be impaired in OSA patients [222]–[225]. The differentiation between short-term memory span, dual-task measures, and fast-paced working memory tasks has uncovered the diverse impacts of OSA on cognitive functions [223]. The assessment of these cognitive functions is crucial for tracking the progression and understanding the impact of neurodegenerative processes in patients with sleep disorders. Evaluating cognitive functions enables researchers and clinicians to determine the severity of neurodegeneration, facilitating the early diagnosis and customization of treatment strategies. Moreover, identifying specific cognitive impairments linked to OSA can direct interventions aimed at alleviating these effects, thereby enhancing the quality of life and reducing the risk of long-term neurological decline.

However, sleep research currently lacks a set of standardized cognitive tests [223]. Existing cognitive tests that are designed to measure sleep and cognitive functions often exhibit significant variability and rely on in-laboratory testing. Instead of merely making them available for at-home testing, there is a dire need to embrace the full extent of the novel digital means that are at the forefront [32]. Therefore, there is a pressing need for more efficient and modern approaches to collect and visualize cognitive data over an extended period of time in order to tailor digital care pathways and provide an in-depth understanding of the impact of sleep. This would provide a more accurate representation of individuals' cognitive abilities [226].

To address these challenges, Jóhannsdóttir, Ferretti, Árnadóttir, *et al.* [223] propose a set of tests suitable for assessing various cognitive functions within the realm of sleep care. They emphasize that it is crucial to consider cognitive factors at all levels in the selection of the tests to gain a comprehensive understanding. Adhering to this requirement, Jóhannsdóttir, Ferretti, Árnadóttir, *et al.* recommend, among others, the following tasks: (i) Simple Reaction Time, (ii) Word List Learning, (iii) Digit Symbol Coding, (iv) Line Orientation, and (v) Paced Auditory Serial Addition Test. Those tasks cover a range of different domains of cognitive functioning. Furthermore,

Ballesio, Aquino, Kyle, *et al.* [227] highlight the Tower of London as an interesting task for testing cognitive functioning in sleep research as individuals with insomnia tend to exhibit worse performance on this task compared to control groups.



# Chapter 3

## Research approach

”During [...] long-term engagements in a particular domain of practice, problems will evolve, shift, change, vanish, or emerge. The exploration of a domain of practice becomes a journey with multiple different starting points, milestones, and, certainly, endings. ”- Stevens, Rohde, Korn, *et al.*, *Grounded design* [228], p. 17

### 3.1 Action Design Research Methodology

The Sleep Revolution digital health platform was designed, developed, and evaluated using mixed methods in an action design research (ADR) approach [229]. ADR is an iterative methodology for finding practical and innovative solutions for complex problems [229]. ADR aims to solve a problem encountered in practical settings in an iterative manner that involves researchers and practitioners, while it also focuses on solving a practical problem through the creation of a digital artifact and contributing theoretical knowledge gained from finding a problem solution [229]. As ADR assesses digital artifacts within their usage contexts, it has become popular as a research method in information systems (IS) [230]. ADR facilitates the production of solutions that are not only theoretically sound but also practically applicable [231]. ADR is also a participatory approach, as it typically involves multiple stakeholders such as experts and end-users in the design and development process, fostering a design that aligns with the genuine needs of stakeholders rather than merely addressing those anticipated by the designers [229]. Moreover, action design researchers are actively involved in the design and development of the problem solution.

The Sleep Revolution digital health platform, specifically the mobile and web app for participants, is the center of the thesis. Its design and development is motivated to find a solution to the problems of mostly cumbersome conduction of sleep studies in research and care. The Sleep Revolution digital health platform constitutes a practical research outcome in the form of a digital artifact that had been developed iteratively and with stakeholder inclusion. During the process, the research in this thesis focused not only on understanding the artifact and improving it but also on contributing to broader discourse on digital health platforms by reflecting on the findings. The ADR project of the Sleep Revolution digital health platform aimed to uncover critical socio-technical aspects and dimensions involved in designing a digital health platform for efficient data collection for research purposes and to understand the dynamics

of addressing emergent challenges in a co-design process. This conceptualization can guide the design and development process by focusing on addressing each of the factors appropriately.

The five studies that resulted in five papers included in this thesis form a longitudinal ADR project, where each study marks one or more cycles of the ADR process. The stakeholders involved in these studies include health experts from different fields, designers and developers, as well as study participants. Figure 3.1 gives an overview of the entire project and to which stages of the project the five papers—labeled in the figure as P1-P5—in this thesis refer.

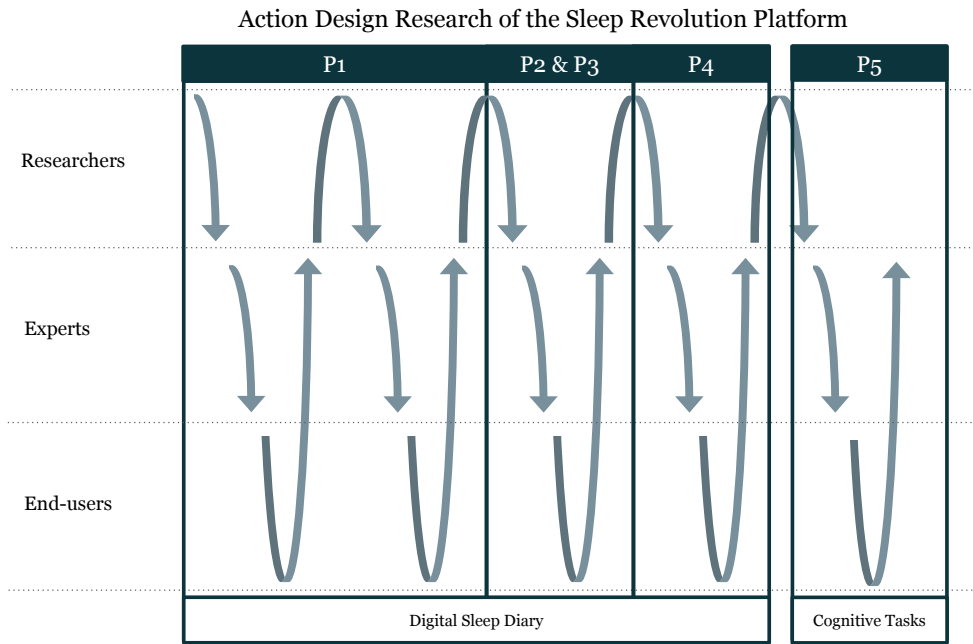


Figure 3.1: The Action Design Research phases of the Sleep Revolution digital health platform and the position of the papers P1-P5 within it.

Research regarding the mobile app looks at the digitization of a sleep diary (P1) and the analysis of user engagement and compliance (P2) with a focus on digital nudging (P3). Research on the software architecture design was motivated by the encounter with difficulties with the current system and led to an investigation of the applied design system in particular and desirable design system qualities in general (P4). Research on the web app focuses on the design of digital tests for the measuring of cognitive functioning (P5).

The participatory nature of ADR makes it well suited for research of digital platforms in a healthcare context. It allows researchers to gain a deeper understanding of the challenges within the healthcare setting from the views of different user groups. On the one hand, feedback from healthcare professionals can help uncover pain points in their daily work that could benefit from technological enhancements [43]. The iterative nature of ADR allows researchers to design and develop digital health platforms that integrate seamlessly into the existing workflow and match the capabilities of healthcare professionals. On the other hand, close cooperation with the end-user group of patients fosters user-centered design that leads to a design with higher user compliance and acceptance [43].

## 3.2 Empirical Context: The Sleep Revolution Digital Health Platform

The focal point of the research presented in this thesis is a digital health platform developed for the Sleep Revolution project. The Sleep Revolution is an EU-funded research project conducted for over four years. It involves 39 research institutions in 24 countries and aims to modernize sleep healthcare. The Sleep Revolution digital health platform combines data from smartwatches, sleep reports, questionnaires, a web app, and a mobile app through a back-end. As can be seen in the overview shown in Figure 3.2, the back-end of the digital health platform used in the Sleep Revolution project consists of a server that takes in data from smartwatches, sleep reports, and questionnaires and stores it in a database. The server also takes data from and provides data to the front-end of the digital health platform, consisting of a mobile app for participants, a web app for study participants and a web app for researchers. The focus of this thesis lies on research based on the design and development of the front-end components—a mobile app and a web app—for study participants. The mobile app includes a digital sleep diary, and the web app allows users to complete a series of tasks to measure cognitive functioning. The digital health platform content has been translated into 16 languages.

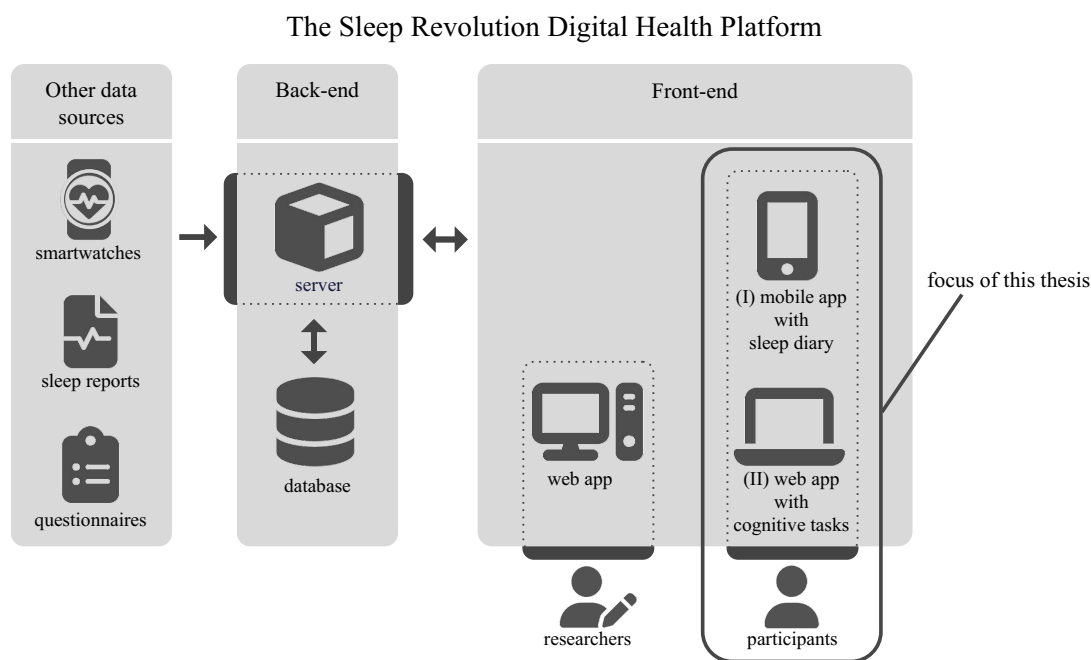


Figure 3.2: Overview of the components of the Sleep Revolution digital health platform. The five papers P1-P5 featured in this thesis focus on the design and development of either the (I) mobile app (P1-P4) or the (II) web app (P5) for study participants as end-users<sup>1</sup>.

The mobile app and the web app are both connected to the same back-end which stores the collected data in one database. The data collected from the mobile app and the web app is combined with other data sources, such as the one from smartwatches, and associated with the same participant. The data is made available via an application programming interface (API) to the mobile app and the web app. The mobile app

<sup>1</sup>Icons used in the figure by Font Awesome, licensed under CC BY 4.0.

collects data from onboarding settings, such as general sleep-related preferences and location-based information, sleep diary entries and results from four cognitive tasks. The web app includes cognitive tasks as well, but a larger variety of it, as not all selected for the Sleep Revolution project by experts are suited to be delivered on a mobile device. The web app also displays an overview of the data recorded via the mobile app and users can see how regularly they filled out various parts of the digital diary and how often they completed the cognitive tasks in the mobile app. The European Sleep Questionnaire, a novel questionnaire developed by Sleep Revolution members, is further included in the web app. The web app and the mobile app both offer a chat feature to users that are active study participants and allows them to contact study coordinators. The chat is synchronized between the web app and mobile app and has a shared chat history. Both the back-end including a server and a database, as well as the Sleep Revolution web app are hosted on a high-performance cluster at Reykjavik University which is maintained by employees of the Sleep Revolution and the university.

### 3.3 Data Collection and Analysis

During this process, multiple developers were involved in the creation of the Sleep Revolution digital health platform, and features were added and updated incrementally. The healthcare tools the digital platform provides have their origins in different fields and require input from neuropsychologists, sleep technologists, and sleep science experts. Research from this thesis focuses on the design and development of the web application and mobile app for sleep study participants. This includes various aspects such as the digitalization process for at-home data collection through a sleep diary and tests of cognitive functioning, structuring the design and code based on a novel design system and the improvement of user engagement through the inclusion of digital nudging.

A variety of methods was used to gather qualitative and quantitative data in the design and development process of the web app and mobile app of the Sleep Revolution digital health platform to gain insights into the needs of the involved stakeholder groups from various angles in controlled and use settings. The quantitative methods used involve application analytics, and standardized questionnaires. Qualitative data was collected through custom-developed surveys, and semi-structured and structured interviews. Prior to the interviews, participants were briefed on its purpose and asked to provide consent for its recording, and asked to sign an informed consent form. The data from the interviews was then analyzed using qualitative content analysis [232]. Qualitative content analysis, as described by Graneheim and Lundman [232], is a method used to analyze qualitative research data. This approach involves identifying, analyzing, and reporting themes within the data. The data collection of this large-scale project was extensive and involved several different qualitative and quantitative measures to fit each ADR cycle and research setting best. Figure 3.3 provides an overview of the used data gathering methods of each study as well as the type and number of participants.

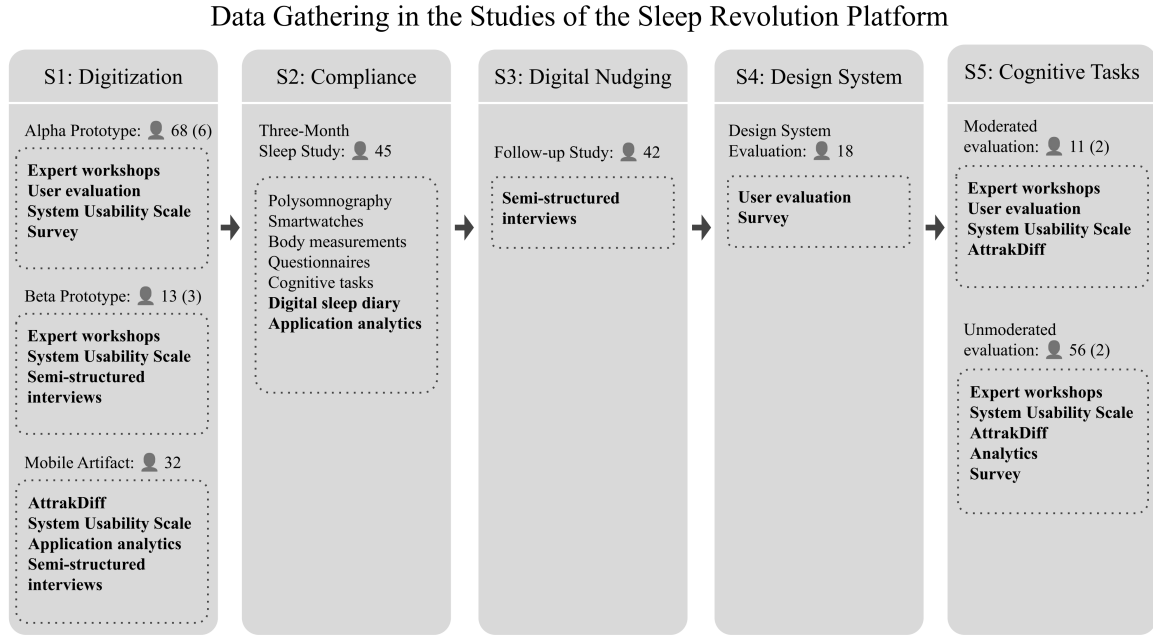


Figure 3.3: Data gathering methods in the included studies S1-S4 involving the Sleep Revolution mobile application and study S5 involving the Sleep Revolution web application. The gathered data used for the analysis included in this thesis is marked in bold. The amount of participants is noted for each study part. If a number appears in parentheses following the participant count, it signifies how many were experts; the remainder were end-users.

One aspect of ADR that sets it apart from other methodologies is the active role that the researcher takes [229]. Instead of researching an artifact from an outsider’s perspective, the action design researcher takes an active role and participates in the design and development of the artifact. During my Ph.D. studies, I assumed the role of designer, software developer, and architect, as well as a researcher of the Sleep Revolution digital health platform. At the beginning of my studies, it became clear that the software architecture in both the back-end and front-end needed updates to be maintainable and reusable. Therefore, I started the project restructuring and refactoring the back-end and front-end for both the mobile and web apps, together with my fellow Ph.D. student Bjarki Freyr Sveinbjarnarson. We focused on creating modular code components and a modular database structure that would allow for straightforward integration of additional sleep-related data in the future.

Outside of work on the studies included in this thesis, I was the lead designer and developer for the new features of a chat function between researchers and participants, myofunctional exercises for participants, and dynamic notifications. The chat features allowed researchers to use the web app to contact and answer participants actively enrolled in studies the researchers were responsible for. The participants can use the chat functionality in the mobile and web app to ask for support or clarification about their study participation. Moving away from static local notification, I developed a back-end controlled notification system that allowed setting custom notification texts for specific users on selected dates to prepare for researching different notification texts. I also took an active role in the creation of a goal-setting feature for the mobile app, gathering requirements and creating prototypes for various types of goals. I then

actively guided the design and development, including the setup and onboarding for the development of the Sleep Revolution digital health platform, planning sessions, as well as design and code reviews. When I started in the Sleep Revolution project, the web app had a different look than the mobile app and it was not immediately clear that they belonged to the same system. I therefore redesigned the look of the web app to resemble the mobile app and create a cohesive look across the platform.

For the design and development of a novel questionnaire developed by the Sleep Revolution, the digital European Sleep Questionnaire, in the web app I assumed setup the development environment for a hired developer, and I reviewed the design and code. I was also active in the guidance and writing of code for the addition of cognitive tasks in the web app. I reviewed and updated the code for the individual cognitive tasks and was solely responsible for developing a mode for testing a specific serial test setup. Researchers can set parameters for the cognitive tasks, such as a timeframe, and the cognitive tasks are presented accordingly to participants in the serial mode. Moreover, I worked intensively on the code regarding the database models and on the application programming interface (API) to provide the functionality needed to connect the web app and mobile app and enable data exchange.

The data from the studies S1-S5 has been collected over four years. From this data collection, this thesis illustrates results from multiple user evaluations involving a total of 243 participants. I was involved in the process and the conduction of studies to various degrees. By the time I started the project, the data collection, as well as the design and development regarding the digitization of the mobile app and the web app for study participants, had been completed in study S1. The results from this process had been partially analyzed, but a comprehensive, holistic interpretation of how the findings from different phases relate to each other was performed by me. The second study S2, which included the analysis of the data from the mobile app from participants from a three-month sleep study from the Sleep Revolution and its planning, had been a collaborative effort of many members of the Sleep Revolution team at Reykjavik University. I was involved in planning the participant orientation meetings, where they were provided with information about the study and equipment, testing the participant orientation meeting setup, cleaning and preparing the sleep study equipment, and delivering support and providing updates for the mobile and the web app with fixes and new features. The data preparation and analysis from this study was performed to equal parts by my co-author Hlín Kristbergisdóttir and myself. I was not involved in the data collection of the follow-up interview study S3, but I performed the qualitative analysis of the interview data. Regarding the fourth study S4, I planned the study, conducted the data gathering, and performed the data analysis. Finally, I was involved in the planning of the fifth study S5 together with other members of the Sleep Revolution. The data collection and an initial assessment was carried out by a group of students. However, in my paper about study S5 I delved deeper than the initial surface-level assessment and I derived a conceptual framework.

### **3.3.1 Study S1: Expert Workshops and User Tests for the Digitization of a Sleep Diary**

The digitization of a sleep diary marked the beginning of the ADR project. To gain insights into end-user needs, several types of data gathering methods were utilized in

the digitization process. Those included the SUS and the AttrakDiff, and application analytics to collect quantitative data and complement that with the qualitative data gained from a custom-developed survey and semi-structured interviews. The two questionnaires that were used for the evaluation were the System Usability Scale (SUS) to measure usability and the AttrakDiff to measure user experience. The SUS, developed by Brooke in 1996, is widely validated. The questionnaire measures usability and is comprised of ten rating scales ranging from 0 to 10, and the ratings are added up to an overall usability score that ranges from 0 to 100 [233]. The average SUS score, in general, is 68, and any result below this threshold indicates some underlying issues. If the score exceeds 80.3, the system is considered to be of high quality. The AttrakDiff measures experienced hedonic and pragmatic quality and user experience of interactive products [234]. It evaluates four aspects of the artifact, those being pragmatic qualities (PQ), hedonic qualities—identity (HQ-I), hedonic qualities—stimulation (HQ-S), and attractiveness (Att). PQ describes the usability and how well users are achieving their goals. HQ-I indicates how well the users identified with the product. HQ-S measures to what extent a product supports the need to develop and move forward. ATT describes the global value of the artifact based on the quality of perception.

The custom-developed survey was designed for the purpose of this project to evaluate the user experience of the alpha prototype. It contained twelve questions and was sent out to and answered by 59 participants. Additionally, 32 participants completed the AttrakDiff questionnaire for the digital artifact. All that data, coupled with the analytics from the application, gave insights into the use aspect. Furthermore, the semi-structured interviews were individual interviews, ranging from 15-40 minutes, with the aim of gaining in-depth insights. The design and development process went through multiple iterations utilizing mixed method data gathering activities [235], moving from an alpha prototype in the form of a web application to a beta prototype designed as an app, which was then turned into a digital artifact in the form of the Sleep Revolution mobile app.

### **3.3.2 Study S2: Analysis of Compliance with the Sleep Revolution App in a Three-Months Sleep Study**

Subsequently, the Sleep Revolution mobile app was used in a three-month pilot study. Fifty-nine participants were recruited by word of mouth and local advertisement at Reykjavik University. Inclusion criteria were that participants had to be of age 16 or older, own a smartphone and be willing to download the Sleep Revolution mobile app, and finally, not working shifts. Participants were asked to (i) complete an online questionnaire on background information and self-report sleep and lifestyle measures, (ii) complete a three-night self-applied polysomnography, and (iii) complete a sleep diary twice a day. I was involved in the organization and participant support of this three-month study, as well as the maintenance of the Sleep Revolution digital health platform. The data collection with the participants was performed by hired research assistants. A total of 45 participants (mean age = 50.3 years, range 23-74, 25 females, 20 Males) completed all three tasks and were included in the analysis. Those not included dropped out of the study at the beginning and did not complete the questionnaires or the three-night self-applied polysomnography.

Prior to participation in the main sleep study, participants completed questionnaires on demographics, lifestyle and self-reported sleep measures as well as screening lists. Participants were then subjected to a three-night self-applied polysomnography and asked to keep a daily sleep diary in the Sleep Revolution mobile app. The purpose of the morning diary was to assess the participants' sleep the night before, while the purpose of the evening diary was to log the well-being and habits during the day that could contribute to participants' sleep hygiene.

### **3.3.3 Study S3: Analysis of Interviews on Digital Nudging following the Three-Months Sleep Study**

At the end of the three-month study period of study S2, participants were invited to take part in an interview regarding their experience during study participation. A total of 42 one-on-one interviews performed by hired research assistants are the subject of a subsequent analysis. The interviews followed a semi-structured format, guided by an interview guide. The interview guide covered topics such as participants' experiences of the multifaceted data collection and living with technologies; using smartwatches, and inputting data into the mobile app. Moreover, a large part of the interview focused on the participant's experience of the digital nudges that were used within the mobile app. Flexibility was maintained during the interviews to allow for follow-up questions to probe a deeper exploration of specific topics of interest when needed. Still, in general, the interview guide was followed. The interview duration of the 42 interviews ranged from 20 to 96 minutes, with an average interview length of 33 minutes. All interviews were transcribed verbatim and translated from Icelandic to English prior to analysis.

### **3.3.4 Study S4: User Evaluation of a Design System**

A user evaluation was performed when issues with the design and code structure were encountered. The design system that was used for structuring the design and code of the Sleep Revolution digital health platform, the Atomic Design system, was analyzed with a group of 18 students (3 females) from the course "Interaction Design" from Reykjavik University as participants. This course is a mandatory part of the first-year curriculum in the Computer Science program. First-year students of the program take courses that provide them with a basic technical understanding of information systems but no extensive practical experience with system development. This selection was a strategic choice as the participants' previous experience with information systems would allow them to understand the problem statement while being able to approach it from a new angle free from bias due to their limited exposure to and experience with various design systems. The research methodology employs a mixed-methods approach, combining qualitative and quantitative data to gain a better understanding of the design system's efficacy. The participants were asked to organize components of two provided views using the Atomic Design system. After completing the tasks, participants answered open-ended questions in a structured written survey and provided feedback on their experience with the design system. The participants were given a week to answer the survey at home.

### 3.3.5 Study S5: Expert Workshops and User Evaluation of the Measuring of Cognitive Functioning

Lastly, the Sleep Revolution web app was to be enhanced with the functionality of measuring cognitive functioning. The design of this new functionality underwent testing in two phases to ensure its usability and user experience. The alpha phase involved a workshop with two experts in neuropsychology. The primary goal of this workshop was to gather essential requirements for developing a digital health platform that enables individuals to complete cognitive tests in their own homes and to decide on a minimal but sufficient set of cognitive tests to include on the digital health platform. The general user experience of the digital health platform was assessed in a user evaluation with nine participants. During the user testing, the participants were given the task of completing the cognitive tests individually on the digital health platform over a span of four days. Following the completion of the tasks, they were asked to provide feedback by filling out the AttrakDiff and SUS questionnaires. During the beta phase, the refinement of the digital health platform continued in an iterative manner based on the feedback received from the alpha phase. To ensure usability, the collected user preferences were discussed in another workshop with the same two experts in neuropsychology before changes were implemented. This workshop included a discussion of the results of the user evaluation conducted in the alpha phase and identified specific areas for improvement. To conduct another evaluation of the digital health platform's performance, more comprehensive data was gathered through an extensive experiment involving 54 participants. These participants were all students enrolled in the "Sleep" course at Reykjavik University. Course participants received a presentation of the project and an explanation of the cognitive tests they would be required to perform in the user test. Each participant completed a set of cognitive tasks four times as part of the experiment. The first administration of the tests took place during a classroom session in the sleep course, where participants were able to gain support and clarify any uncertainties about the digital health platform and the experiment setup. Subsequently, the participants completed the tests three more times at 1 pm self-moderated. The testing sessions were conducted under three different conditions: after a 4-hour sleep restriction, after a normal night of sleep, and after a night of sleep extension. Importantly, there was always a night of normal sleep between each testing condition to ensure sufficient recovery and eliminate potential carry-over effects. Following the completion of the tests, the participants were asked to provide feedback through the SUS and AttrakDiff questionnaires. Additionally, a structured written survey that included open-ended questions was sent to the participants which they could answer freely. The form covered various aspects of the digital health platform, including inquiries about the participants themselves and their experiences with the digital health platform. This feedback provided an opportunity for the participants to share their thoughts on the digital health platform's functionalities, ease of use, and overall satisfaction.

## 3.4 Thesis Background

This thesis analyzes five papers, four of which have been published or accepted with major revisions in IS conferences and journals and one of which has been published in a journal on medical diagnostics. The focus of the thesis contribution thus lies clearly

on IS, while the publication in medical diagnostics emphasizes the health application area.

In order to interpret the results of the five papers and create a more general stand-alone contribution, I followed an approach inspired by the strawberry analysis for a paper-based Ph.D. thesis [236]. This approach presents four steps for making sense of results from multiple papers, which entail (i) the creation of a summary of each paper, (ii) the identification of themes and trends, (iii) the abstraction and explanation of those themes and trends, and (iv) the synthesis and framing. For the synthesis of the papers in this thesis, I started by creating a summary of each paper, focusing on the design guidelines and learnings presented in each paper. This step paved the way for the identification of themes across the papers and abstracting them into dimensions. Finally, I synthesized these dimensions into key factors that highlight the interplay of the dimensions.

The analysis is based on the previous literature presented in the related work section and is grounded in the socio-technical system theory. This theory is based on the view that information systems are both technical and social systems, consisting of technologies and their users [237]. From a socio-technical perspective, these systems are interrelated and should not be separated when examining an information system [238].

When I started in the Sleep Revolution project, the question of how to design and develop the parts of a digital health platform for reliable data collection drove my research. My first paper looked into the digitization of a sleep diary, and it became clear that the most prominent issues associated with an analog sleep diary were user compliance and memory bias. Users had difficulties filling out the diary regularly and occasionally filling in answers at a later point in time despite no longer remembering the events accurately that the diary questions asked about. As one of the goals of the Sleep Revolution project is the data collection for the development of advanced diagnostic and predictive algorithms and models, the collection of reliable data was of the highest importance.

Over time, in my role as designer and developer, I recognized not only the social aspect of user engagement that played a role in the collection of reliable data but also the technical one. Thus, it became clear early on that I needed to view the digital health platform from a socio-technical perspective to understand the factors involved in user engagement and reliable data collection. The thesis followed recommendations from the digital platform literature on creating a modular, interoperable technical system. At the same time, literature on user engagement, in particular through digital nudging, drove the development of the social component of the digital health platform. Each paper focuses on a slightly different part of the digital health platform, addressing technical and social aspects to a different degree.

During the design and development process of the Sleep Revolution digital health platform, interviews, discussions, and other co-design activities were conducted. This data had been partially analysed for the five included papers already. Challenges associated with co-design arose during the design and development process, but it became apparent that a continuous co-design approach was able to overcome most of them with time. This motivated the research question on how long-term co-design addresses emergent challenges, and in addition to the data used in the papers, addi-

tional notes on discussions and co-design activities were thematically analyzed [239]. This analysis is the basis of the second contribution in this paper that goes beyond the analysis presented in the paper and takes into account additional data of the design and development process.



# Chapter 4

## Sleep Revolution Mobile App

”The growth of smartphones has far-reaching implications for healthcare. Simply put, smartphones and other mobile technologies might be the single most promising avenue we have to help individuals manage their health, and to do so at scale.” - Klasnja and Pratt, *Managing Health with Mobile Technology* [240], p.66

As part of the Sleep Revolution, a digital version of a sleep diary was to be developed. The digitization process began with the creation of a web prototype of a digital sleep diary and eventually led to the development of the Sleep Revolution mobile app. The process involved close collaboration with experts in workshops and the incorporation of feedback from user testing sessions. These design activities led to the development of an alpha for the web and then a beta prototype for mobile before the final artifact in the form of a mobile app was created. The digitization had been carried out before I started my Ph.D. studies, and I documented the results of this process in a formative study presented in paper P1.

To assess the effectiveness and user engagement of the digital sleep diary, a comprehensive three-month real-life study was conducted. I took part in the study organization and the support of the study participants. I was also responsible for designing and developing any necessary additions and improvements to the Sleep Revolution mobile app during the study period. Participants were encouraged to interact with the app twice daily, enabling the collection and analysis of data on usage patterns in paper P2, with a focus on understanding compliance—a well-known challenge with analog sleep diaries. Another goal was to enhance the understanding of the effectiveness of the prototype through semi-structured interviews, seeking qualitative feedback on app usage and user experience, particularly concentrating on the impact of digital nudging integrated through native notifications. These aspects were of particular interest to me and others in the project team, as we wanted to know how to design the app to achieve high compliance to gather quality data without negatively impacting mobile app users. This was explored in detail in paper P3. Both papers, P2 and P3, aim to gain a better understanding of the mobile app in particular and retaining compliance and the effects of digital nudging in general.

As I was deeply involved in the design and development process of the mobile app, my responsibilities extended beyond researching compliance and optimizing user experience. I actively engaged in the technicalities of mobile app creation, from crafting

design elements to coding. This led me to discover some issues with the design system that we had used to structure the design and code into components. A clear and easy-to-use design system can be an important asset to enhance the communication between designers and developers, as well as to simplify maintenance. Therefore, I further researched the used design system, Atomic Design, in a user study and gathered insights into requirements for a clear design system in paper P4. Insights from this study contribute to a better understanding of how to achieve a clearly structured design system that could then be used to inform the structure of the Sleep Revolution digital health platform design beyond the paper.

## 4.1 Paper P1: Digitization of a Sleep Diary

**Title:** Towards a Digital Sleep Diary Standard

**Status:** Published

**Outlet:** American Conference of Information Systems

**Type of outlet:** Conference proceedings

**Full reference:** Schmitz, L., Sveinbjarnarson, B. F., Gunnarsson, G. N., Davíðsson, Ó. A., Davíðsson, . B., Arnardóttir, E. S., ... & Islind, A. S. (2022, August). Towards a Digital Sleep Diary Standard. In AMCIS.

Monitoring participant compliance in a pen-and-paper design is difficult, and preventing it even more so. Participant feedback has shown that there is a tendency to forget to fill out pen-and-paper symptom trackers and try to make up for it by filling it out at a later time. This is a major drawback since symptom trackers and sleep diaries—when filled out in close temporal proximity to the occurrence of the event—can contribute reliable and stable data for identifying certain sleep disorders [203]. For diagnosing sleep disorders, timely data has significant value in comparison to retrospectively collected data. On top of that, the retroactively entered data cannot be accounted for or filtered out since it is difficult to detect it in a pen-and-paper format [197].

Entering data retroactively also introduces another problem, it gives rise to the potential problem of memory bias. Memory bias refers to the tendency to intentionally or unintentionally rely on recalling certain events and autobiographical memories and favoring those memories over others [210]. This recall process often relates to significant events, including traumatic, unconventional events, or even to systematically selecting the most recent events in a series of events [211]. Memory bias and the tendency to rely on the most recent events are especially visible when dealing with a prolonged condition period [212]. Therefore, filling out the sleep diary based on recall can result in potentially biased and less reliable data. This is why finding alternative ways to increase compliance and counteract memory bias, thus improving the integrity and quality of the sleep diary data, should be a priority [213]. Since a digital solution can prevent these issues, a formative study was performed in order to develop a digital version of the Consensus Sleep Diary (CSD).

### 4.1.1 Alpha Prototype

At the start of the development process, the needs of the three primary user groups were mapped out: (i) end-users, (ii) researchers, and (iii) healthcare experts. In total, nine participants took part in one-on-one semi-structured interviews, three from each user group. Next, a pen-and-paper format of the extended CSD (CSD-E) was handed out to 59 end-users to be filled out for one week. The diary data was collected and their experience filling out the CSD-E was evaluated. The goal was to identify the key needs to consider and incorporate into a digital sleep diary. After the end-users had completed that task, they were asked to fill out a survey regarding their experience and how they would have liked to have their data visualized.

Based on the results from this phase, the alpha prototype was developed as a web application. The initial designs were printed out on paper as low-fidelity wireframes and were tested with nine participants: three professionals and six end-users. They were asked to complete a list of tasks as part of a think-aloud test using the prototype in the presence of an observer who took notes. From the feedback, we created an overview of the issues and prioritized them according to severity. The prototype was then updated in order to improve these critical issues. Subsequently, another evaluation was conducted for the refined version with the same participants using a high-fidelity prototype. In addition to completing tasks with this prototype, the same nine participants were asked to answer questions using the SUS to measure its usability.

The results of a survey, which was conducted after the end-users had filled out the pen-and-paper CSD for a week, showed that 81.36% of the end-users preferred the sleep diary in the form of a website instead of on paper. Overall, the majority of the end-users had a positive attitude towards the sleep diaries. However, over half of the end-users reported trouble remembering to fill out the sleep diary in time. Therefore, over 80% of the end-users wanted to be able to receive reminders and over 70% said they would prefer to receive those in the form of a native app notification.

### 4.1.2 Beta Prototype

Next, a beta prototype for a digital sleep diary was developed in the form of a mobile app with optional reminders. The reminders in the form of native mobile notifications were a strongly requested feature by participants in the study phase with the alpha prototype and drove the decision to change from a web to a mobile design. In order to digitize the CSD and turn it into a mobile app, sleep experts, a clinical sleep specialist, sleep researchers, and an expert in patient-reported outcomes participated in a design workshop as part of the development process. The expert feedback drove the development of a low-fidelity prototype that was tested with five end-users. Those five end-users completed a list of tasks using the prototype. Afterwards, the participants were asked to fill out SUS questionnaire, followed by a semi-structured interview. Based on those results, another high-fidelity prototype was developed. The user tests were repeated in the same fashion as before with the same five end-users that tested the low-fidelity prototype, asking them to complete tasks, answer a SUS questionnaire, and take part in a semi-structured interview.

In a workshop with experts, requirements for the context change of the sleep diary from a pen-and-paper format to a mobile app were discussed and included in a new beta prototype. Native iOS and Android input elements were included in the design

to collect the sleep diary answers. Furthermore, instructions for answering the evening questions were included on a separate instruction view. This view is accessible through an information button positioned at the top right corner of the screen, as shown in 4.1. Participants were also allowed to fill out entries only for the current day and not for any of the previous or following days. In this phase, one focus point was the definition of the notification requirements. The participants had the option to receive notifications in the morning and in the evening at a chosen time. By default, the notification times were set to 9 AM and 9 PM. However, there was a need among the participants for this to be customizable (which was implemented in the following phase).

Some changes to the CSD-E questions were necessary in order to keep them understandable in the new context. All changes to the sleep diary questions are shown in Table 4.1. Follow-up questions like 12b and 13b are displayed isolated on the screen like all the other questions, which is why they needed clarifying updates. Conditional questions like 6d were simply omitted if the condition was not fulfilled. Question 14 expects two different answer inputs, which is why it was separated into two questions in order to keep the diary entry layout consistent. Questions 16-20 were added as a five-point visual analog scale for additional information on end-user daytime functioning. Additionally, end-users indicated in the onboarding process of the beta prototype if they drank alcohol or caffeine or took sleep medication. This was a need derived from the results of the end-user tests on the one hand and the workshops with experts on the other hand. The end-users could adjust the answers to these questions later on in the application settings if needed. If one of these setup questions was negated by the end-user, the corresponding diary questions were not displayed. This way the end-users did not need to answer questions that were irrelevant to them. Since the beta prototype was supposed to be used shortly before the end-users went to sleep, both light and dark themes were evaluated, revealing that the dark theme was preferred, with the argument of it being good to reduce light exposure through the app as much as possible before sleep. All of the aspects that worked well during user testing in this phase were fully implemented in the artifact phase that followed. The beta prototype went through two rounds of user tests. In the first round, the prototype achieved a mean SUS score of 91.0, with a minimum score of 85.0 and a maximum score of 100.0. After the incorporation of the user feedback from this round, the mean SUS score of the next iteration of the beta prototype improved to a mean score of 97.5, with a minimum score of 85.0 and a maximum of 100.0.

### 4.1.3 Artifact

Next was the development of the digital sleep diary as a functional mobile app for Android and iOS. The mobile app was made accessible to 32 end-users who were divided into two groups. The first group consisted of 17 Reykjavik University students, who all had previous experience with pen-and-paper sleep diaries, whereas the second group consisted of twelve external end-users of which only one person had prior experience with filling out sleep diaries. The first group received an on-site introduction to the mobile application, while the second group received instructions via mail. Before the end-users of both groups got to use the application, they were asked to fill out an AttrakDiff questionnaire. For the following week, the participants were asked to fill out the diary daily, both in the morning and evening. The end-users were able to give continuous feedback throughout this phase, which led to minor bug fixes regarding the

Question	CSD	Sleep Revolution mobile app
6d	If yes, how much earlier?	How much earlier?
12b	What time was your last drink?	What time was your last alcoholic drink?
13b	What time was your last drink?	What time was your last caffeinated drink?
14	Did you take any over-the-counter or prescription medication(s) to help you sleep? If so, list medication(s), dose, and time	a) Did you take any over-the-counter or prescription medication(s) to help you sleep? b) List medication(s), dose and time taken
15	-	Was today a workday? (If not, then it was a freeday)
16	-	How fatigued were you today?
17	-	How sleepy were you today?
18	-	How stressed were you today?
19	-	How was your mood today?
20	-	How much did you exercise?

Table 4.1: Changes that were made to the questions of the extended version of the Consensus Sleep Diary (CSD-E) in its digitization process.

text translation and notification cancellation. Additionally, end-user activity in the application was logged. After the end-users had completed the week of filling out the sleep diary, they were given the SUS questionnaire and an AttrakDiff questionnaire to answer. To conclude the study, semi-structured interviews were conducted with these end-users who had used the digital sleep diary.

The data collected from the user tests with the digital artifact showed that 81.4% of the end-users preferred to use an app rather than a pen-and-paper format. The participants gave reasons for this in the interview; they found the digital sleep diary more engaging, accessible, and easier to comply with than pen-and-paper. On average, the morning questions of the digital sleep diary were answered 6.66 out of 7 times and the evening part was filled out 6.47 out of 7 times. It took the average end-user 397 sec (SD = 2449) to fill out the morning sleep diary, with a median of 121 sec. The evening sleep diary was filled out in an average of 75.4 sec (SD = 57.2), with a median of 61 sec. Since there were occurrences of outliers, most likely caused by opening the diary in the evening and then keeping it open until the morning, the median time gives a more accurate estimate than the average. 22 out of the 32 end-users filled out the SUS questionnaire that was handed out during this phase, eleven participants from the first group and eleven end-users from the second group. Overall, the answers resulted in a mean SUS score of 88.9 (SD = 9.0). In the first group, the mean SUS score was 85.2 (SD = 9.6), while it reached a mean of 92.5 (SD = 8.4) in the second group. Furthermore, the AttrakDiff helped to determine the digital sleep diary's user experience compared to end-user expectations. The first AttrakDiff questionnaire was filled out by all 32 participants, whereas only 21 of the participants chose to answer the second one. The digital sleep diary received the lowest score for the hedonic quality for stimulation (HQ-S), meaning that the users did not find the app very stimulating, but other aspects were well received. In the interviews, the end-users commented

positively on the setup of the sleep diary, finding it easy to understand and learn. They also mentioned that it was quicker to fill out than the pen-and-paper version. The notifications were generally appreciated and praised frequently by the end-users. They found that it helped to remember to fill out the diary and even described them as "motivating". However, some difficulties came up when filling out the diaries. The end-users found it hard to estimate times and sometimes did not understand the questions. Unfortunately, they often overlooked the instruction button which could have helped to avoid this issue. Figure 4.1 shows selected screens of the digital sleep diary, including the onboarding, the diary, and the data visualization screens.

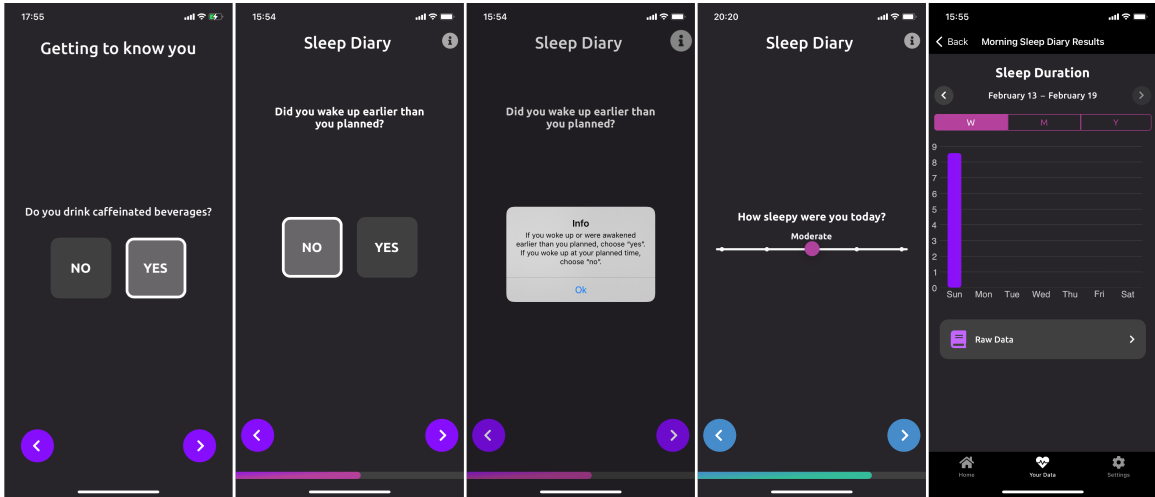


Figure 4.1: Selected views of the digital sleep diary in the Sleep Revolution mobile app.

#### 4.1.4 Usability and User Experience Evaluation

The initial step of the design and development process addressed two areas of interest. Firstly, the research focus was on the main benefits and drawbacks of the pen-and-paper format in comparison to the digital sleep diary. The findings from that part outline the app requirements. Secondly, those requirements informed the design and development of a digital sleep diary with the aim of increasing compliance and counteracting memory bias, which were the main issues found while using the pen-and-paper version. On a piece of paper, it cannot be controlled when and how participants enter information. Examples include various time formats that are used to enter data, wrongly entered data and unprompted comments [198]. These issues can be avoided with input control in a digital sleep diary. Choosing native inputs for time, numbers, booleans or text prevents the participant from entering incorrect data and ensures data homogeneity.

The interviews with the participants showed that they were interested in their data and liked to see it visualized. This finding suggests that insightful data visualizations combined with actionable feedback can further increase compliance and engagement. Instead of only collecting data with the sleep diary, a visualization of the sleep diary data can offer an analysis and feedback to the end-users. In this way, the sleep diary can be transformed from a pure data collection device to a corrective tool with the potential of continuously improving the sleep hygiene of the end-users.

A digital companion app also has the potential to gather additional data through, for example, cognitive tests and can potentially include data from wearables, such as fitness and tracking devices. This data can be used to complement data collected through the diary, automatically fill out sections of the sleep diary, and evaluate the accuracy of the sleep diary data [203]. Along those lines, the CSD paper by Carney, Buysse, Ancoli-Israel, *et al.* shows the value in comparing the collected data with data from a medically valid sleep assessment such as data from a PSG. Even though it cannot be expected that a sleep diary can lead to similar conclusions as a PSG assessment, it could still be insightful to compare subjective sleep quality with an objective sleep score.

The results of the user experience tests show that the vast majority of participants prefer a digital sleep diary over a pen-and-paper format. However, the participants were comparatively young, and some of them were even students of computer science. A certain bias towards digital artifacts is probably reflected in the results. Nevertheless, since the results were clearly in favor of the digital sleep diary, it can be concluded that the general tendency towards a preference for a digital sleep diary is still substantial. However, particularly among older participants, the sleep diary in analog format was sometimes preferred over a digital sleep diary. Moreover, it turned out to be a good decision to move from a web application to an app. Considering that the notifications were mentioned as well-liked by a notable number of participants during the evaluation of the digital sleep diary, it is worth highlighting them as one of the key features of any digital symptom tracker. By utilizing a notification system to remind participants to fill out the digital sleep diary, their compliance can be influenced far better than with a pen-and-paper version. Notifications can be set up at individual times for each participant, thereby tending to different daily routines and minimizing the participants' workload. Most importantly, though, a digital sleep diary provides options for restricting the times that the diary is filled out and makes it possible to log the exact date and time of a data entry, hence accounting for memory bias, which is clearly shown in our results.

The low score that the mobile application achieved in the HQ-S category of the AttrakDiff stands out as the most negative aspect of this version of a digital sleep diary. It agrees with the feedback from participants who filled out a pen-and-paper diary: more than 38% did not enjoy filling out the sleep diary (end-users who found filling out the diary "okay," "annoying," "pointless," or "boring"). Therefore, the digital sleep diary still has similar issues with user engagement as the pen-and-paper version. This can be explained by the fact that the sleep diaries, which the participants tested, functioned first and foremost as a clinical sleep assessment tool. The current design does not offer any additional value to the participants. However, the participants have shown interest in their data, and augmenting the data visualization with actionable feedback could be a valuable addition to the mobile application.

#### 4.1.5 Design Guidelines

The combined findings from this study can be summarized into the following five design guidelines for designing and developing digital symptom trackers in general and for designing and developing digital sleep diaries in particular:

- **Use the native environment:** It is important to use the advantages that come with a native app design. Native input control and notifications are clear advantages from the digital format. However, it is important to evaluate changes that are made to the original question setup to ensure that they do not affect the way a participant answers the questions.
- **Utilize established input methods:** It is important to use native control elements instead of coming up with new input ways. Users have shown to be most comfortable with familiar input methods.
- **Embed customization to minimize participant workload:** It is important to utilize customization and onboarding to omit questions that are not relevant to particular participants. Since feedback indicated that filling out the symptom tracker is not enjoyable enough for every participant, it is even more important to avoid any unnecessary questions.
- **Evaluate the application continuously using analytics:** It is important to embed analytics to enable continuous design and development. Moreover, this type of data can be collected easily and does not require work from the participants.
- **Integrate digital elements to increase compliance:** It is important to integrate gamification elements for the content and include more insightful data visualization, which would improve the entertainment value of the app since not all participants enjoyed filling out the diary. Some of them mentioned that notifications increased their motivation to fill out the symptom tracker.

## 4.2 Paper P2: User Compliance

**Title:** Evaluating User Compliance in Mobile Health Apps: Insights from a 90-Day Study Using a Digital Sleep Diary.

**Status:** Published

**Outlet:** Diagnostics

**Type of outlet:** Journal

**Full reference:** Full reference: Kristbergdottir, H.<sup>1</sup>, Schmitz, L.<sup>1</sup>, Arnardottir, E. S., & Islind, A. S. (2023). Evaluating User Compliance in Mobile Health Apps: Insights from a 90-Day Study Using a Digital Sleep Diary. *Diagnostics*, 13(18), 2883.

Overall compliance was high over the study period. Participants answered a total of 2,711 times out of the 4,049 possible morning diary entries (67%) and 2,525 times out of the 4,050 evening entries (62%). Simple linear regression revealed a significant linear trend of compliance tending to decrease over time for both mornings and evenings.

Compliance was high at the beginning of the study and stayed considerably stable through the first two months of the study. At the beginning of the study, compliance was 98% for the morning diary and 78% for the evening diary. In the first month, average compliance was high, 80% (morning) and 67% (evening), and then slightly

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<sup>1</sup>These authors contributed equally.

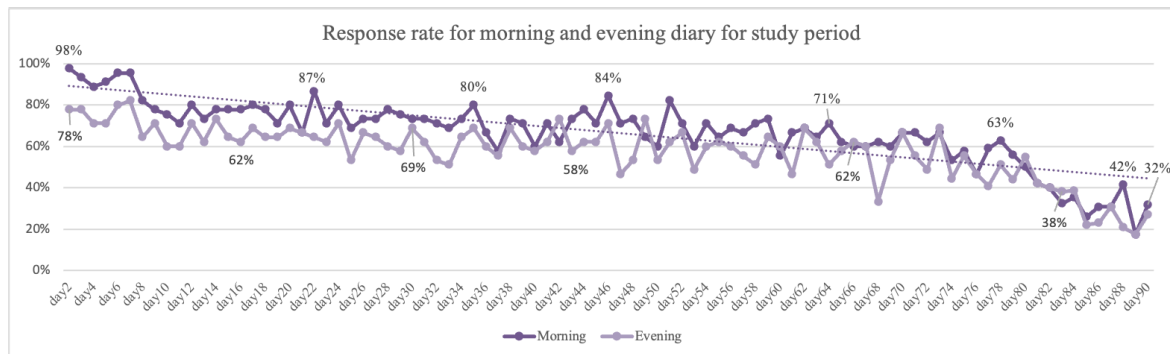


Figure 4.2: Daily compliance for morning and evening diaries for the study period.

dropped between the first and second months, 70% (morning) and 60% (evening). During the last month, compliance started to decline and dropped to 31% (morning) and 26% (evening) in the last days of the study (see Figure 4.2).

#### 4.2.1 Compliance by Individual Differences

Compliance for the morning and evening diaries was analyzed by individual differences with simple linear regression, i.e., demographic profile, sleep measures, and mental health. A significant difference by age was found for evening diary entries, where older individuals tended to be more compliant than younger. For other demographics, objective, and subjective sleep measures and symptoms of depression, anxiety, and stress, a significant mean difference in compliance was not found.

#### 4.2.2 Compliance Over Time

The findings showed high compliance rates (98-62%) throughout the study period and that the digital sleep diary was accessible to all, regardless of demographic profile, possible sleep problems, or symptoms of depression, anxiety, and stress. However, compliance did significantly decline over time, as expected. At the beginning of the study, approximately 98% of study participants completed their morning sleep diary entries, and 78% completed their evening diary entries. By the end of the study, 52-46% of participants remained compliant. For the last days of the study, compliance rates dropped to 26-31%, indicating participants experienced a higher respondent burden. The decrease in compliance could be attributed to participants' fatigue or a lack of motivation to continue reporting over an extended period. Another explanation could be that participants were asked to attend a final interview at the end of the study and were able to choose a date that fitted them well. Some participants chose a date before they had finished their 90 days and likely stopped using the app after the interview. This is a limitation to the study and the interpretation of compliance as only 50% of the total sample used the app for the 90-day study period as there was no special endpoint or treatment being monitored in the study, which could have affected compliance.

### 4.3 Paper P3: Digital Nudging with CARE

**Title:** Nudging with Dignity: A Critical Examination of When and How to Use Digital Nudging.

**Status:** Published

**Outlet:** Scandinavian Conference on Information Systems

**Type of outlet:** Conference proceedings

**Full reference:** Schmitz, L., Richert, E., Larusdottir, M., Arnardottir, E. S., & Islind, A. S. (2024). Nudging with Dignity: A Critical Examination of When and How to Use Digital Nudging. In *15th Scandinavian Conference on Information Systems (SCIS 2024)*. Uddevalla.

The mobile app included various types of digital nudges, but the reminder nudge in the form of native notifications was the most noticeable nudge in the mobile app. The notifications were an optional nudge that would remind participants to fill out the sleep diary in the mobile app in the morning and the evening at custom times, which the participants could adjust themselves. Upon registration in the app to partake in the research study, participants were asked to provide their notification preferences. They were given the option to choose the time they wanted to receive notifications in the morning and the evening and whether they wanted to receive them at all. Participants could choose to only receive notifications in the morning or evening, or they could turn them off completely. Participants could update these preferences at any time in the app settings. The qualitative analysis of the interviews taken after the three-month sleep study revealed different types of dignity affronts that the participants experienced through nudging from using the Sleep Revolution mobile app. An overview of the dignity affront responses per affront category is displayed in Figure 4.3. Affront responses were found in the form of micro-level affronts of forfeit, fight, and flight. No responses in the form of befriending, tending, mobilizing, complying, or regulating were found.

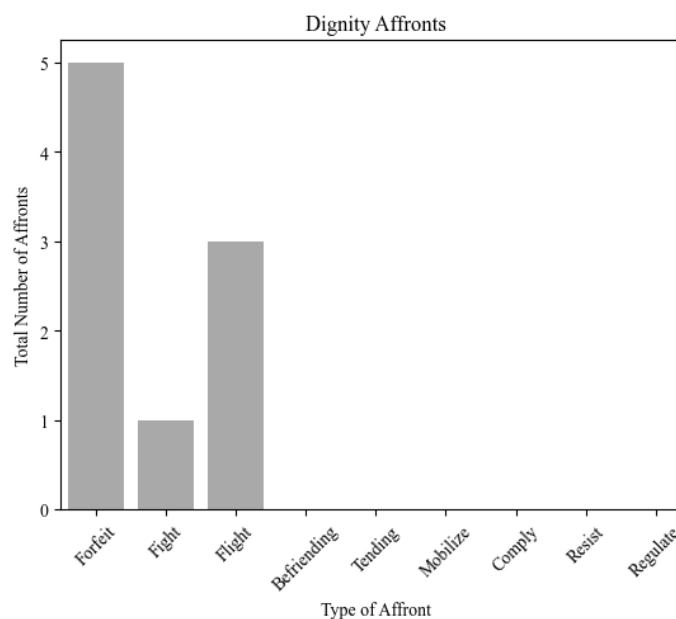


Figure 4.3: Number of summed affront responses per affront category to digital nudging in the Sleep Revolution mobile application in form of twice daily native notification reminders. The responses were found in eight out of 42 participants.

The majority of affront responses came in the form of a forfeit action, where participants chose not to engage with the notifications they received. For some participants who chose to receive notifications but mostly ignored them, the notifications served as a constant reminder of an unwanted task that they were asked to complete in the app and as such, the digital nudges reinforced their bad conscience. This bad conscience led to reported stress for some participants, even if they found them helpful at first. When the task of filling out the digital sleep diary became part of the daily routine, some participants said that they felt stressed by the notifications as they no longer looked forward to filling out the sleep diary in the app. As a fight response, actions were noted, such as modifying the notification settings, including adjusting the sound and vibrations, to better suit the participants' preferences. When participants showed actions with the goal of completely avoiding notifications, then their behavior was noted as a flight response.

### 4.3.1 Responses to Digital Nudging

The qualitative analysis of the interviews with the sleep study participants revealed only three out of the nine types of dignity affronts described by Leidner and Tona [40], and all three response types were micro affronts. The responses came mostly in the form of ignoring, modifying, or turning off the digital nudges in the form of notifications. While many participants made appreciative comments about the digital nudges, it highlighted the importance of allowing personalization and tuning of the notifications. Most of the participants who showed fight or flight responses to the digital nudging experienced a one-time affront that did not reoccur after the digital nudge was adjusted or removed according to their needs. However, a dignity affront in the form of digital nudge forfeiting led to the most reported stress related to nudges. This illustrates the notion that digital nudges can contribute to techno-stress, although this might not always be the case. Many of the participants did not experience any kind of stress set off by the digital nudges, which is in line with other researchers' findings [241]. Those participants who did experience stress were aware of the digital nudges occurring and accepted them the way they were but did not react to them even though they provoked reported feelings of stress and guilt. In this research, the digital nudges that did provoke stress were also ineffective, as these participants did not react to them.

### 4.3.2 The Many Shades of the Same Digital Nudge

No indications were found in the interviews that participants in the research study experienced frustration, unlike the findings of M. Bhoot, A. Shinde, and P. Mishra [184]. However, they found frustration responses to be a reaction to manipulative digital nudges [184]. This could be the reason why this study only found emotional responses to digital nudges in the form of guilt and stress, as the digital nudges in the Sleep Revolution mobile app were not manipulative in their nature. More specifically, the Sleep Revolution mobile app did not include any nudges that would intentionally go against the participants' will or make them do something that could be seen as harmful. The participants who decided to partake in the study did so with the intention of complying, adhering, and contributing to the research, which may partially explain why they experienced guilt when they did not end up doing what they set out to do. This suggests that the intention behind the nudging and the nudgee's support of the

intention can affect the form of emotional responses. It is important to note that even unintentionally harmful digital nudges can evoke negative emotional responses.

These findings raise the question of what constitutes a dark pattern. As discussed in the literature review by Mathur, Acar, Friedman, *et al.* [167], there is no clear definition of what is a dark pattern. Some definitions focus on the intention of the nudger and state that a dark pattern is an intentionally harmful nudge [242]. Other definitions state that any harmful nudge, regardless of intention, is a dark pattern [171], [172]. Looking at the findings of this research, the digital nudges in the Sleep Revolution mobile app were both helpful and harmful, depending on the participant. This illustrates that perhaps a digital nudge can become a dark pattern under certain circumstances, even if it is responsibly designed.

Participant comments, however, implied that feedback mechanisms, such as personal check-ins or digital feedback, could have a positive impact on the responses toward digital nudge. This, in turn, could help to improve the effectiveness of the nudge. A similar observation has been made by Mirsch, Lehrer, and Jung [163], who found that feedback can further improve the effectiveness of digital nudges. Although feedback is valuable, it does not always guarantee that digital nudges will be well-received. This is especially true for intrusive nudges like native mobile notifications. In such cases, it is wise to take advantage of the flexibility of the digital environment and modify or remove the nudge if it's being ignored for an extended period of time.

### 4.3.3 Design Guidelines for Digital Nudge Design

The emphasis on a critical, philosophical perspective on digital transformation [243] further illustrates the multi-dimensional nature of value positions in this field. The perspective advocates for a responsible, critical examination of digital nudging as a growing interest within information systems (IS) research to ensure that digital nudges contribute positively to society without undermining individual agency. Therefore, the dialogue around digital nudging and IS is deeply entwined with value positions. The challenge for researchers and practitioners lies in navigating these different perspectives and ensuring that digital environments are designed, developed, and used in ways that respect and uphold the complex web of values.

The cumulative findings of this study point towards the need to personalize and tune digital nudges, which is an important pathway for designers of digital nudges. To synthesize the findings, they are summarized in design guidelines for the conscientious nudge designer, conceptualized as *digital nudging with dignity*. Firstly, it is important to be aware of the potential stressful effect of digital nudges and allow for the automatic removal of stressful digital nudges by the user. In our research, the digital nudges that did provoke stress were also ineffective, further strengthening the notion of allowing for removing those. Secondly, the intention behind the nudging and the nudgee's support of the intention can affect the form of emotional responses. It is important to note that even unintentionally harmful digital nudges can evoke negative emotional responses. Hence, digital nudges should always be used with care, and personalizing them is imperative. Thirdly, while digital nudging can be effective and, in our research, truly effective in most cases, incorporating feedback mechanisms, such as personal check-ins or digital feedback, could have a positive impact on the participants' response toward the task they were nudged to do. This, in turn, could help to improve the effectiveness

of the nudge. Finally, it is vital to take advantage of the flexibility of the digital environment and modify or remove the nudge if it is being ignored for an extended period of time. Ergo, analyzing click-logs to illuminate which users act on digital nudges and removing the digital nudges after, for instance, ten days if not acted on, could contribute to a reduced feeling of stress for the users.

## 4.4 Paper P4: Clarity in Design Systems

**Title:** The Cosmic Design System Development and Application of Design Principles for Clarity in Design Systems

**Status:** Accepted with major revisions and resubmitted

**Outlet:** Scandinavian Journal of Information Systems

**Type of outlet:** Journal

**Full reference:** Schmitz, L., & Islind, A. S. (2024). The Cosmic Design System Development and Application of Design Principles for Clarity in Design Systems. Submitted to *Scandinavian Journal of Information Systems*.

System architecture outlines the foundation for designing, developing, and constructing complex software systems. It is one of the cornerstones of information systems (IS) research, which has, in recent years, expanded into a growing interest in the design and organization of software systems in general and digital platforms in particular [244]. This research has highlighted the importance of modularity and reusability in the development of information systems [245]. IS architectural approaches typically focus on the entire system by offering guidelines for high-level architecture [246]. However, translating high-level architecture into everyday code, particularly when incorporating consistent and functional UI elements, can be a considerable challenge when designing and developing complex digital platforms.

In order to address this challenge, design systems have been used to structure not only user interface (UI) components but also the codebase of digital platforms. A design system commonly consists of a set of components and guidelines that inform the design and implementation of a product. Thus, a design system allows for the decomposition of a complex system into smaller, more manageable parts. Design systems have become a popular method for interaction design and development in the industry and have been adopted by large corporations such as Google and Apple. Examples of such design systems that are currently in use across multiple products include Google's Material Design and Apple's Human-Interface Guidelines [247]. Despite their widespread use, there has been little research on design systems. The few studies that have been conducted mainly focused on the benefits and values of design systems [248], [249]. However, the investigation of challenges and strategies related to the creation and maintenance of design systems is underdeveloped.

Particularly in the context of IS research, there is a lack of literature on the topic of design systems. However, the topic fits well into IS research as design systems serve as communication tools between designers and developers regarding ways in which the development of information systems can be furthered. The investigation of design systems has the potential to generate novel design knowledge and provide a

medium-technical lens. This approach examines the communication between system designers and developers, contributing to a better understanding of interaction design and the development of information systems. Research in this area has the potential to enhance the understanding of the design and development of information systems. The use of design systems not only benefits traditional front-end systems but also provides benefits to no-code/low-code [250]. With the rapid increase in the popularity of no-code/low-code, the need for consistent, reusable UI components is more important than ever. Unlike traditional front-end development where the UI is built by developers, no-code/low-code systems allow non-technical users, also referred to as citizen developers, to create and customize the UI [251]. This makes it increasingly crucial to ensure that all the components are consistent and easy to use. The use of design systems to deal with this issue is likely motivated by a desire to fix the missing relationship between design and implementation components [252] and to attempt to connect high-level architecture and everyday code. However, design systems do not usually address how the design components relate to implementation components, and there is a gap in the literature in that regard. Moreover, design systems are typically not research-based; instead, they stem from industry, meaning that they currently lack scientific evidence [146]. Nevertheless, the essence of design systems, which is its component-based structure, is a compelling concept to explore in a systematic manner.

To structure the design and code of the Sleep Revolution web and mobile app, the Atomic Design system [153] was used. However, I and other colleagues who were actively involved in the design and development noticed some issues regarding the clarity of the design system's structure. Based on this experience during real-world work on the system, I decided to conduct a user study and a follow-up survey to get to the root cause of the issues we experienced and formulate them into actionable guidelines for creating a clear structure in a design system. Most participants reported issues with the two higher-level component classes, the Organisms and Molecules in the design system. Some participants stated that they found it unnecessary to have both categories and thought they could be represented as one component class. In contrast, participants showed a positive attitude towards the separation into base and higher-level component classes and found it helpful for structuring an application. As the basic building blocks of a system, base components such as Atoms seemed necessary and reasonable to the participants, and they had no issues identifying them. In summary, the participants expressed that (i) they found the classification of base components sensible and intuitive, (ii) it was unclear how to distinguish Molecules and Organisms, and (iii) that these two higher-level components could be summarized into one higher-level component.

The results of this study highlight the advantages of a component-based application structure and point out the drawbacks of the Atomic Design system. Participants had a positive experience with the base components of the Atomic Design system but were confused by the higher-level components. This suggests that the system may be effective for creating reusable, modular base components but that additional work is needed to ensure that the higher-level components are clear and easy to understand. Additionally, the results also suggest that focusing on fewer higher-level components could improve the user experience. The findings also imply that to improve the user experience, it may be beneficial to ensure that the higher-level components are clearly differentiated from one another and that they serve distinct and unique purposes. This

way, users will have a better understanding of how to use the system and will be able to navigate and find the components they need more easily.

The study results demonstrate the importance of designing clear and easy-to-understand component structures to improve the user experience. By using a component-based application structure, designers and developers can create reusable and modular base components while also ensuring that higher-level components are clearly differentiated and easy to understand.



# Chapter 5

## Sleep Revolution Web Application

”While personal use and self-reflection are central to these systems, involving healthcare professionals as part of the ecosystem can greatly increase the value of these apps. Involving healthcare professionals can also help boost their adoption and sustained use.” - Chen, *Health Information Technology: Opportunities Abound. Challenges Remain.* [253], p.83

The Sleep Revolution digital health platform includes various components for sleep research and at-home testing of cognitive functioning is one of them. Multiple stakeholders were included in the co-design process. More specifically, design workshops with neuropsychology experts were performed to ensure test validity while aiming for high usability and user experience alongside end-user involvement with a total of 55 participants. The user tests included extensive evaluation of the usability of the digital health platform through questionnaires and a written form where all participants completed the cognitive tests in the digital health platform prior to evaluation.

In the Sleep Revolution project, testing of cognitive functions had, up to that point, solemnly been conducted in a lab setting. However, this is cost-, and labor-intensive and does not allow for effective scaling between countries, which makes it unfit for broader distribution. To overcome these drawbacks, a decision was made to design and develop a custom module for at-home cognitive testing as part of the Sleep Revolution digital health platform, primarily to ensure it could integrate seamlessly with the existing database and other services. This approach allowed for the creation of specific functionalities that meet the unique research requirements of the Sleep Revolution project. Such capabilities were not readily available in established digital platforms. Having complete control over updates and maintenance meant that it was necessary to be able to make adjustments as needed, which was essential for maintaining stability and reliability that matched the specific workflow needs. Moreover, implementing the cognitive functioning software in-house was particularly advantageous for supporting at-home testing. The flexibility of the digital health platform has been indispensable, especially when several of the project partners were unable to host on-site testing. By designing the Sleep Revolution digital health platform to adapt to various home environments, it has been easier to manage experimental conditions and data collection, ensuring consistent quality and integrity of data across diverse settings. The digital health platform design followed the overall design approach of co-design alongside the graphical profile of the Sleep Revolution project while keeping a neutral and functional look to allow for high validity of the cognitive tests. The tests were implemented ac-

ording to the literature, but several elements on the broad spectrum of gamification were prioritized by the designers and were implemented to enhance the user experience.

The tests that were selected due to the results of previous studies and implemented as part of the digital health platform were: (i) Simple Reaction Time, (ii) Word List Learning, (iii) Digit Symbol Coding, (iv) Line Orientation, (v) Paced Auditory Serial Addition Test (PASAT) and (vi) Tower of London. For the Word List Learning test and the PASAT, written and verbal versions were provided. In the written version, text was displayed on the screen. In contrast, the verbal version involved the presentation of the text as audio, without any visible text. Counting those as alternative versions of different tests, the digital health platform included eight tests in total. The requirements gathered from the workshop were used to create the elements within the Sleep Revolution digital health platform that incorporated the recommended tests discussed in the related work section.

## 5.1 Paper P5: At-Home Measuring of Cognitive Functioning

**Title:** VALID Care Pathways: A Framework for Meaningful Digital Platform Design

**Status:** Accepted with major revisions and resubmitted

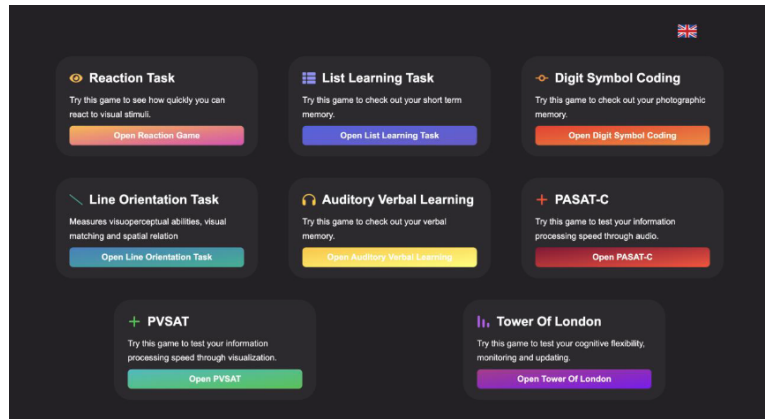
**Outlet:** Communication of the AIS

**Type of outlet:** Journal

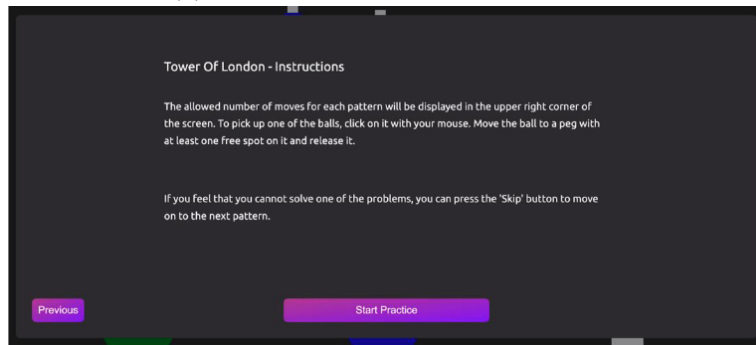
**Full reference:** Schmitz, L., Richert, K., Jóhannsdóttir, K., M., Arnardottir, E. S., & Islind, A. S. (2024). VALID Care Pathways: A Framework for Meaningful Digital Platform Design. Submitted to *Communication of the AIS*.

The Sleep Revolution web app for assessing cognitive functioning was designed and developed following the requirements gathered in the workshop with neuropsychologists. The web app was then tested in two phases in user evaluations. The first user evaluation was moderated while participants completed the tasks and they had a week time to fill out the SUS and AttrakDiff per mail. The second evaluation was self-moderated, and after the participants received instructions, they were left to complete the cognitive tasks and, right after, fill out the SUS and AttrakDiff on their own. The design of the web app was created prioritizing usability while maintaining the validity of the measuring tools. A set of cognitive measurement tools were selected carefully to offer a minimal set of tasks that cover a wide variety of cognitive domains. Progress bars were implemented for tasks where they did not affect measuring validity. An overview of all available tasks for participants was implemented in order for them to start the tasks themselves, as well as a view that would present a predefined set of tasks sequentially. The page with the overview of the tasks and selected other task views are shown in Figure 5.1.

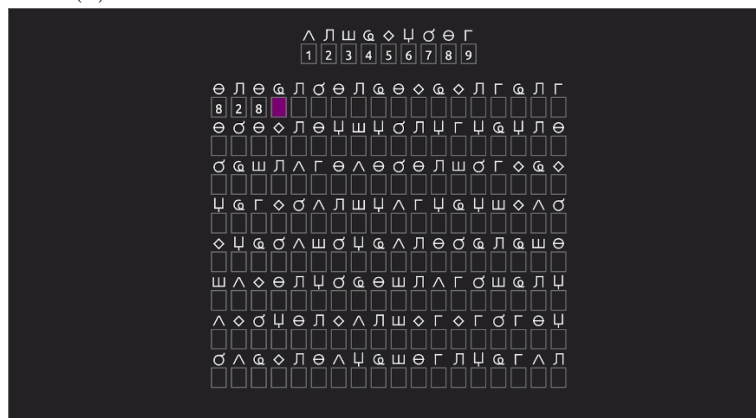
Each task started with a display of the task instructions and an optional practice round. The practice round included simple instructions and feedback. Users can solve the practice round without time constraints and can repeat the practice round until they solve it correctly. After the practice round, the users receive additional information that the round is about to start, and they can initiate the task with a



(a) View of the overview of the tests.



(b) View of instructions for the Tower of London test.



(c) View of the Digit Symbol Coding test.

Figure 5.1: Selected views of the digital health platform for testing cognitive functioning.

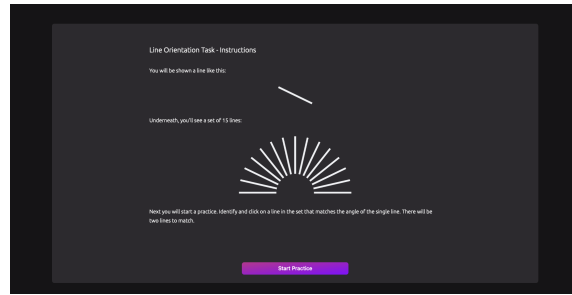
button click. Upon completing the task, the users receive an overview of their task performance and can finish and return to the overview or the next task. Figure 5.2 shows these steps in the example of the Line Orientation task.

The results of this study showed that the majority of the participants liked the overall look and feel of the Sleep Revolution web app and thought it was easy to use and understand. Moreover, they also reveal that the instructions for PASAT-C were not clear enough and it was hard for participants to understand what they were supposed to do even though they were offered a practice phase. The score from the participants in the moderated testing (88.89) was notably higher than the one from the self-moderated test (66.32). A reason for this difference in the average SUS score among participant groups could be attributed to the distinct setups for each group. In the moderated tests, the focus was on the look and usability of the web app, and the participants were able to take breaks between the tasks. They also received the questionnaires by mail and could thus fill them out at a time that was convenient for them. In contrast, participants in self-moderated tests had to take the set of cognitive tasks for the fourth time in a span of six days right before answering the questionnaires. In particular, the task they completed last, which was the PASAT, is designed to create and evaluate frustration in participants. This might have influenced the perceived attractiveness and usability of the web app negatively. Taking these circumstances into consideration, it can be concluded that the usability of the web app is good even though the SUS score from the self-moderated observation study test group was slightly below average. In addition, there was a difference in the AttrakDiff results between the two test groups. All four scores were lower in the self-moderated test group than in the moderated test group, displaying a similar trend as the SUS results. The biggest difference was in attractiveness, where the score from the self-moderated test group was 0.21, but the score from the moderated test group was 2.44. The reason for this could be that the sequential task setup is not as attractive as the individual task setup. In the individual task setup, participants started on a landing page where they could select the tasks and participant feedback from the moderated testing indicated that this was the most attractive view of the web app. In the sequential task setup, this view was missing. The attractiveness of the sequential task setup might be improved by making the results screens, which are not part of the tasks themselves, more attractive.

### 5.1.1 Design Guidelines

The workshops with experts revealed that aiming for high usability in a digital health platform for measuring cognitive functioning while maintaining the reliability of the measurements is a delicate balancing act. Designing a reliable but engaging tool is a complex but worthwhile endeavor and can best be achieved by involving members from both the user and expert groups in multiple stages of the design process. In this case, the workshops with experts and the usability and user experience tests with end-users resulted in several specific learnings that influenced our digital health platform design:

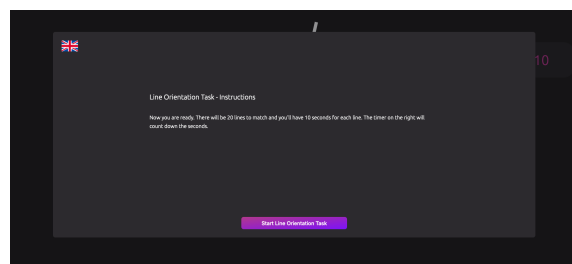
- **Use a web application to maximize accessibility.** For the tasks to work for participants regardless of the operating system they are using, a web application is a preferred format to deliver the tasks. Accessibility is an important factor for the success of digital health platforms, and it is, therefore, imperative



(a) Users receive instructions on the task they are about to perform.



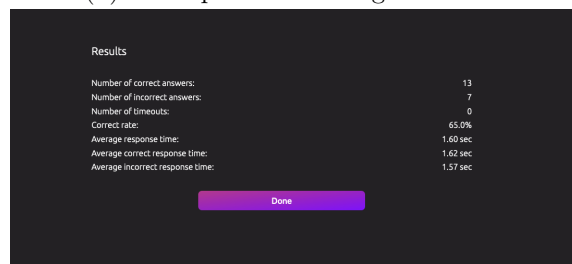
(b) Users start a practice round with short instructions and feedback and without time constraints to make sure they understand the task (users can also skip practice in case they are already familiar with the tasks).



(c) Users are informed that the practice is over and the task is about to start.



(d) Users perform the cognitive task



(e) Users receive a summary of their task performance and can return to the overview page.

Figure 5.2: The different views and steps involved in performing a cognitive task in the Sleep Revolution web app are shown in the example of the Line Orientation task. The steps to complete the task are in order.

to support as many devices as possible. In addition, digital platforms that run in the browser do not require an installation step, which contributes further to achieving a low technical complexity [254]. All participants in our user tests were able to run the cognitive tasks on their own personal computers. Aside from supporting multiple operating systems, browser compatibility should be prioritized in the development. Digital platform performances can vary by browser, and it is imperative to ensure a comparable performance.

- **Display progress between task rounds.** Progress bars are a vital element of user experience design. They grant the user a sense of control and help to keep them engaged [255]. The results showed that the attractiveness and usability suffered in a sequential task setup. If such a sequential task setup is required for proper measuring of cognitive functioning, a progress bar between tasks has the potential to uphold the users' engagement.
- **Avoid using a sequential task setup if possible.** The attractiveness of the system suffered from the delivery of the tasks in a continuous sequential format. While conventional cognitive measuring in a university or clinical location often involves a sequential task setup due to temporal and location constraints, participants can be given the flexibility to complete one task at a time in an at-home setting. It is important to leverage the advantages of the environment to improve the user experience design.
- **Design engaging interfaces around the task views.** Digital cognitive tasks have been carefully designed and even small deviations from validated designs can potentially render the measured data unreliable. Therefore, the task views have to be designed following official guidelines for the implementation and cannot be updated with engaging design elements without validation. The results of our user experiments showed that participants who were only exposed to the task views in a sequential setup rated the attractiveness of the Sleep Revolution digital health platform lower than the users who completed the tasks individually and were brought back to a more attractive overview screen of the tasks. It is, therefore, important to use engaging and attractive designs on views around the views of tasks, such as the landing page, instruction page, or result page, which is not subject to those restrictions. As our results showed, participant perception of the Sleep Revolution digital health platform was better when presented with the more attractive overview screen.
- **Minimize distractions in the digital environment.** Even in an in-laboratory setting, the involved experts in neuropsychology reported interruptions of the measuring through phone calls and notifications participants received. While this can also not be fully controlled in an at-home setting, since participants complete the tasks on their own devices, certain technical options are given to minimize those distractions. A full-screen mode was used to deliver the tasks, and further options can be explored in terms of notification oppression and warnings if the browser tab is not in focus.
- **Collect metadata for post-collection data validation.** While the prevention of unreliable data is a priority, it is equally important to enable post-validation methods [256]. Moreover, in-laboratory measuring of cognitive functioning is commonly done with special equipment, such as keyboards and mice,

that shows minimal delays. At home, participants might not have comparable equipment. It is, therefore, vital to collect metadata such as timestamps and device or browser information to include in the analysis. Metadata can also potentially be used to identify whether the participants were focused on outside distractions, thus enabling further validation and rating of the data reliability.

- **Incorporate guided practice rounds.** Participants showed difficulties understanding the tasks just through instructions. Considering the emphasis on usability, user experience and the importance of fulfilling participants' needs [39], [77], [80], [81], while designing and developing digital health platforms, navigating possible solutions for this issue is a priority. In light of that, the practice phase can, for instance, be improved through a mandatory trial round with insightful feedback. This is especially important in an unsupervised setting. A practice round can not only help users understand their tasks but also ensure that the technical equipment is fully working, e.g., the audio is audible for the user. Practice rounds should be as short as possible to avoid frustration before the task as well as learning effects. At the same time, they should be sufficiently long for users to understand the nature of the task. Insightful feedback on errors in the practice round can enhance the user experience additionally and is to be preferred over purely positive and negative feedback.

These learnings gave valuable insights for improvement and optimizations of the design of the web app for at-home measuring of cognitive functioning. The expert workshops that were held throughout the ideation and implementation phase ensured that while improving usability based on feedback from user evaluations, the validity of the measuring was not compromised.



# Chapter 6

## Synthesis

”[Plans] must be plans for learning rather than plans for implementation.”  
- Christensen, *The Innovator’s Dilemma* [257], p.126

The cumulative results drawn from the five appended papers, in combination with the cover text about the Sleep Revolution digital health platform, provide a holistic view of the design and development of digital health platforms and deliver insights into the various evolutionary stages of a digital health platform for the tracking of sleep-related data in a co-design process. The results presented in this thesis stem from research that has been deeply involved in digital health platform development, from early design and testing to various stages of actual use in research practice. My role in the Sleep Revolution project involved an active part in the design, technical development, research and maintenance of the digital health platform. Due to this comprehensive involvement, my research uniquely illustrates the design and development of a large-scale digital health platform from a technical insider’s perspective. Thus, my interpretations allow me to draw conclusions about the key aspects of digital health platforms that are anchored in practice, following the call for more practically relevant research of information systems. Moreover, the research in this thesis goes beyond the analysis of snapshots of the digital health platform at certain points in time but also captures the transitions in between and the motivations behind them.

Paper P1 follows the digitization process of an analog sleep diary involving expert and user feedback. Building on that research, paper P2 analyses user compliance and the results contribute to an understanding of the improvement of the challenges associated with the analog version. Paper P3 examines the dignity affront responses to digital nudging. It is vital for a large-scale system such as the Sleep Revolution digital health platform that is accessed by hundreds of users to be maintainable. In practice, bugs must be dealt with as soon as possible, updates need to be easily deployed, and adding new features needs to be simple. Thus, it was necessary to ensure the reusability and maintainability of the digital health platform through modularization in the design and development process, which was addressed in paper P4. The next phase in the design and development of the Sleep Revolution digital health platform entailed the digitalization of an in-laboratory tool for measuring cognitive functioning into an at-home tool in a web app and was documented in paper P5. While the papers focus on different parts of the Sleep Revolution digital health platform, they are all parts of its ecosystem and contribute to an overall meaningful design.

## 6.1 Learnings

Conducting co-design during the ideation phase of the Sleep Revolution mobile application was key in ensuring the validity of the sleep diary implementation, foundational for collecting high-quality data. The transition from an analog pen-and-paper sleep diary to a digital format called for significant modifications to the original design, as its validity and reliability needed to be preserved during the digitization step. Thus, the involvement of experts in the ideation phase was of great value. Expert workshops often led to the development of guidelines aimed at ensuring the accuracy and integrity of the collected data. In the ideation phase of the Sleep Revolution mobile app, special attention was given to the selection of input formats. The incorporation of suitable digital elements to let users input data needed to be easy-to-use but also maintain data validity. Discussions during expert workshops also involved additional features, such as the inclusion of explanatory help texts and onboarding processes. These elements were all aimed at enhancing user guidance and support in data collection.

Equally important were the user evaluations conducted in the early stages. These results highlighted the value of native mobile notifications as reminders for filling out a digital sleep diary. Had the evaluation with users been overlooked, the digital sleep diary might have been developed as a less effective web application, losing out on the broader and more immediate reach that native mobile notifications offer over reminders through email or SMS. The positive reception of these reminder notifications in promoting compliance over a three-month study validated this design choice. Participants frequently mentioned how the reminders helped them remember to complete their sleep diary entries regularly.

User feedback from the three-month study also pointed towards the potential for making the Sleep Revolution mobile app more engaging through enhanced visualization and the inclusion of intriguing sleep facts. Moreover, user evaluations in actual use settings in a sleep study resulted in the identification of both minor and significant design concerns, ranging from difficulties in locating the information button to the users' desire to logging activities like caffeine intake during the daytime instead of having to recount that data while filling out the evening diary. The need for personalized reminder times also became clear, countering the initial expert recommendation for fixed scheduling.

As the design and development phase progressed, challenges with the initially chosen design system were encountered during its active use. Feedback provided by developers that used the design system suggested, that the structure of the used design system was not clear enough and could be improved upon. This discovery led to a dedicated evaluation focused on these issues, providing clear insights into the design system's drawbacks and areas for refinement.

In the design of a cognitive measurement tool for the Sleep Revolution web app, gathering expert feedback was a useful starting point, given their extensive experience with similar digital health platforms and insights into features that were lacking. For instance, experts highlighted the need for participants to be able to test the audio functionality before the start of testing. They reported that they had experienced cases where headphones were not connected correctly, and this was only discovered when the tests had already started. Since some of the tasks rely on audio, the unavailable audio compromised the validity of data collected at the beginning of the measuring.

During the ideation stage of the web app for measuring cognitive functioning, the user evaluations made it apparent that task instructions followed by short practice rounds with simple positive and negative feedback were insufficient. The users required detailed feedback during practice rounds since it became clear that they did not understand how certain tasks were intended to be completed. Additionally, user feedback exposed compatibility issues with the tool's full-screen mode across different web browsers.

Another significant revelation was the importance of offering flexible scheduling options. Although it was ideal for participants to complete all tasks consecutively, this was not always feasible due to practical constraints. By allowing individuals the option to take breaks between tasks, varied schedules could be accommodated.

### 6.1.1 Dimensions of Digital Health Platforms

While the presented learnings from the design and development of the Sleep Revolution digital health platform are specific to the use case of a digital sleep research platform, the underlying motivations and challenges are arguably not. The learnings from this study provide valuable insights into the generally desirable dimensions of digital health platforms. Table 6.1 presents an overview of these dimensions with specific examples and interventions within the digital health platform.

Each dimension — Engaging, Viable, Accessible, Lean, Informed, and Doable — combines insights derived from our findings. For example, 'Engaging' digital health platforms are important to ensure that users comply and collect high-quality data. The 'Viable' dimension is based on the importance of following the expert requirements for the design in order to not compromise test validity by only embedding gamification elements such as progress bars when it did not affect the measurements. 'Accessible' was informed by user feedback, emphasizing the need for clear instructions and showing the benefits of practice rounds with detailed feedback. The 'Lean' dimension was drawn from feedback that emphasized the importance of a clear design with few but purposeful design elements. The 'Informed' dimension was derived from the need to collect metadata for validation that experts expressed in order to obtain reliable, high-quality data. Finally, the 'Doable' dimension came from user feedback and observations that showed the need for additions in the design that made it easier for them to comply, such as flexible timing for filling in data and completing tasks.

## 6.2 Challenges

A co-design process for the development of digital health platforms in controlled and use settings does not only provide valuable learnings but also comes with challenges [42]. If not addressed, these challenges can hinder the creation of meaningful digital health platform design. Documenting the challenges can, therefore, be helpful for other projects to prepare for these challenges and plan actions on how to deal with them before they arise. In the participatory design and development process of the Sleep Revolution digital health platform, challenges with stakeholder participation and expectations, resources, and technical setup and issues.

Table 6.1: Dimensions and Examples in the Digital Health Platform Design

<b>Dimension</b>	<b>Examples in the Digital Health Platform Design</b>
Engaging	<p>The digital health platform utilized native input elements, mobile reminders, progress bars and an appealing look to increase compliance and engagement.</p> <p>In the mobile app, it became important to ensure that the notification reminders, which were intended to be engaging, were not overwhelming instead. To make sure that the engaging elements do not have the opposite effect on the users, user testing is necessary to confirm that the design has the desired effect.</p>
Viable	<p>The cognitive tasks were designed following official guidelines and were evaluated by experts.</p> <p>The digitalization and the accompanying changes to the pen-and-paper sleep diary were carefully planned with experts.</p> <p>Digital elements, such as progress bars, native input elements and native notification reminders to improve user experience, such as progress bars, were only added when previous research or expert evaluation strongly suggested that they had no influence on measurement outcomes.</p> <p>A full-screen mode was used to deliver the cognitive tasks and make it less likely for users to exit the digital health platform during cognitive measuring and minimize distractions that could compromise measured results.</p>
Accessible	<p>The digital health platform was designed to be accessible through the most popular browsers on desktop computers.</p> <p>Instructions and practice rounds were offered to make it easy for all users to understand and complete the cognitive tasks in the digital health platform.</p> <p>Familiar native elements such as time input were used for the sleep diary where it was appropriate.</p>
Lean	<p>Selected gamification elements with a clear purpose, such as progress bars, were added to improve user engagement and minimize frustration while keeping the interface designs straightforward.</p> <p>A user-friendly overview page of the cognitive tasks was created in a simple yet friendly design to act as a clear and attractive landing page.</p> <p>Customization was used to omit design elements that were irrelevant to the users. In the sleep diary, questions that did not concern the user were not displayed.</p>
Informed	<p>Metadata was collected in the form of timestamps to be able to perform an informed analysis of the measurement validity in the future and to ensure the collection of reliable data in the sleep diary.</p>
Doable	<p>The cognitive tasks could be completed individually in addition to the traditional sequential task setup in laboratory settings to allow for more flexible time management.</p> <p>Not all users enjoyed filling out the sleep diary. Keeping a lean design where unnecessary steps were removed was done with the intention of turning the data collection in the sleep diary into a more manageable task for users.</p>

### 6.2.1 Challenges with Participation

Several challenges came up during the design and development process of the Sleep Revolution digital health platform. Particularly, managing stakeholder engagement across the process' extensive scope proved difficult. It is common in co-design projects that stakeholders have different expectations in terms of time and effort that should go into the co-design process [70]. Scheduling conflicts, also due to geographic distance and differences in time zones, can additionally hinder active participation and complicate the collaboration of stakeholders [67], [70].

The Sleep Revolution project involves a wide range of research institutions and collaborators from various disciplines, research institutions and countries. The stakeholders had many other responsibilities and involving all to an equal degree proved challenging. Some design activities, such as providing a translation that is contextually appropriate, were carried out with varying care. Additionally, opinions about the importance of certain features and design additions differed. Certain features, while beneficial for one smaller study, might not have been necessary for the ones that involved the majority of the project's participants. The interests and priorities of stakeholders were not always overlapping, and there was disagreement over the importance of features. Providing equal opportunities for stakeholders to participate in the co-design process [258] became a priority. Depending on the features that were the focus of the user tests, prototyping and workshop sessions with the stakeholders were scheduled to give them the opportunity to participate in design activities. These sessions were carried out in a way that design participation was accessible to stakeholders [259].

Not only stakeholders but also end-user participation in the co-design process was challenging. Some of the participants in the three-month sleep study lacked the technical knowledge to actively use the Sleep Revolution mobile app with the digital sleep diary. Since they did not use the app, no feedback could be incorporated from them regarding the current design and potential design additions. The lack of technical know-how has shown to be a common issue with co-design participation from end-users, specifically in use settings [42].

Unexpected difficulties with participation arose, particularly in the ideation phase of the sleep diary, when COVID restrictions only made it possible to include participants who were related and already in regular close proximity to the involved researchers and designers. These restrictions were made only after user evaluations had already started and the structure for the controlled tests had been established. As a result, the data from the related end-users had slightly more positive results in the AttrakDiff and SUS data. This event demonstrates how the formal structure of controlled user evaluations can pose a problem for end-user participation [260].

In summary, challenges regarding participation in co-design activities included differences of opinion on the importance of features and based on this, the willingness to participate in co-design sessions, lack of technical knowledge that prohibited participants from using parts of the digital health platform and outside forces outside of the project teams control that limited participation in the already planned and structured user evaluations.

## 6.2.2 Technical Challenges

Technical issues in co-design process are not unusual, especially in use settings outside of the laboratory. For example, difficulties with connectivity and setup are common challenges in a participatory design and development process [42]. Technical issues can disrupt the data collection from co-design activities if they arise during testing. Additionally, some issues, such as access to the Internet, can lie outside the power of the digital health platform designer and developer, and solutions in the form of workarounds have to be found.

One of the technical issues the Sleep Revolution project faced was related to the configuration and hosting of the back-end server and database. The grant agreement of the Sleep Revolution included the hosting of the back-end on a cluster owned by the Sleep Revolution itself. While some issues related to the hosting and subsequent technical setup were resolved in a fast manner, others, such as configuring the back-end for job scheduling, required extensive iterative testing to address. The scheduling issues, in particular, led to a failure to send notification reminders in a sleep study that has not been analyzed for any of the papers included in this thesis. This failure had a potential effect on user compliance in this study and, with it, on the quality and completeness of the collected data. On a larger scale, the data collection was affected by network failures at Reykjavik University. As the back-end is hosted there, an inaccessible back-end due to network failures hinders the synchronization of data with the mobile app and the web app. During this time, data collection through the mobile app and the web app was not possible. Moreover, a webpage with information regarding data deletion in the mobile app was not accessible during those times, as it was hosted by the university. This led to difficulties in the publishing process of the Sleep Revolution mobile app for Android devices and resulted in delayed updates.

In the three-month sleep study, another technical challenge regarding the notification reminders arose. At that time, the notification reminders were triggered locally by the mobile devices the Sleep Revolution mobile app was installed on and not by the server. However, due to changes in the Android operating system, the notification reminders stopped working. A similar issue occurred later in the project during another study, when the handling of notification permissions was changed in a newer version of the Android operating system. Participants reported these issues to the support and they were addressed as quickly as possible.

The initial database design of the Sleep Revolution digital health platform back-end proved to be inflexible and not modular enough to reflect the variety of data sources that were to be included in the Sleep Revolution data collection. Considering that the inclusion of other data sources such as the European Sleep Questionnaire—which was still in work at the time—was to be expected in the future, the database design needed an update. Following advice for a flexible and robust infrastructure for data storage and management [119], [261], a new modular design was developed.

In summary, during the design and development of the Sleep Revolution digital health platform, technical challenges through self-hosting of its back-end, changes in target operating systems and legacy code presented themselves.

### 6.2.3 Challenges with Resources

Several types of resources and their limited availability can affect and hinder the co-design process. A limited budget, limited time that stakeholders are available and ensuing differing opinions on how the limited resources should be located pose challenges during the c-design process [42], [260].

Operating within a limited funding budget, the Sleep Revolution project prioritized addressing urgent issues and incorporating essential functionalities during the design and development stages. Funding had been secured before projects started and acted as a limiting resource for how much time and human resources could be spent on co-design activities. The focus in Sleep Revolution project was to provide stable and reliable core functionalities, as well as a good user experience. Due to this, not every functionality requested by stakeholders could be designed and developed. For example, videos with myofunctional exercises were included in the Sleep Revolution mobile app for one study only. Similar to how researchers could monitor the compliance with the digital sleep diary on the Sleep Revolution web app, a new functionality was included to monitor the compliance with the performance of myofunctional exercises. However, additional nice-to-have features for the researchers in order to monitor and filter the participant data that would have only affected this particular study could not be incorporated due to limited budget for the design and development on the digital health platform.

Limited time to include all necessary functionalities also meant that not every feature could be tested in user evaluations or designed with input gathered in multiple expert workshops. On occasion, stakeholders realized that a necessary feature was missing and it needed to be added in a short period of time. Sometimes, these features were well-received by participants, but other times, their design proved to be not ideal. For example, after user feedback from the three-month study indicated an advantage of a pre-filled diary in the Sleep Revolution mobile app based on previous data, some stakeholders wanted this feature included. This was also motivated by the finding that certain data, such as bedtimes and get-out-of-bed times, were similar each day for many participants. However, feedback from a later study showed that some participants found the pre-filled input confusing. This feature would have benefited from end-user evaluation before it had been included in the design. However, the iterative and flexible design approach used for the Sleep Revolution digital health platform made it possible to gather design feedback on hastily added features in a later design cycle. Co-design activities in use settings have proven particularly useful in catching design flaws introduced that way in a timely manner so that they could be improved upon later on [262].

The interdisciplinary nature of the project required the integration of distinct perspectives from psychology, sports science, machine learning, computer science, and sleep research. Identifying which requirements to include in the digital health platform's design was complex, and the large number of stakeholders made it impractical to involve everyone in every phase of design and development, constrained by time and resources. Moreover, stakeholders did not always have a realistic grasp of the work and resources required to design and develop a feature, which further complicated decisions regarding which features to design and develop next. Managing competing demands

and limited availability from stakeholders is a known challenge, but managing them through continuous engagement is key for an effective co-design approach [67], [74].

To summarize, challenges regarding resource availability and management in the design and development in the Sleep Revolution platform included a limited budget, limited time to develop and co-design features, and stakeholders reaching a consensus on how to spend resources.

# Chapter 7

## Discussion

”Skeptics of co-design still cite the famous Henry Ford quote—if you asked users what they wanted, it would not have been a car but “a faster horse”—as evidence that participation in design should be limited to a narrow set of professionals. But more are now realizing that facilitating the participation of users and other stakeholders involves far more effort than merely asking them “what they want.” - Sanders and Stappers, *From Designing to Co-Designing to Collective Dreaming: Three Slices in Time* [263], p.29

At-home digital health assessment and improvement tools delivered through digital platforms are a promising solution to the struggles that the healthcare sector currently faces and will likely encounter in the future. Aside from relieving stress from healthcare systems, digital at-home health tools have the potential to transform healthcare as we currently know it [3], [10], [11]. Such tools open up opportunities for the collection of longitudinal health data, which in turn can be used to feed advanced algorithms and models that could detect patterns and aid participatory healthcare with personalized feedback [10], [15]–[17]. However, entering the highly regulated healthcare market with a digital health tool is a lengthy process, and once a product is registered as a clinical tool, making changes to the product becomes a laborious task. Therefore, it is even more important than in other sectors that the design and development process of digital healthcare tools is holistic and includes all involved stakeholder groups in a co-design approach [21]. Unfortunately, digital health platforms still suffer from ineffective design due to a lack of continuous co-design [1]. However, research into the design and development process of digital health platforms is lacking [33].

The literature on digital health platforms has focused on examining existing platforms, such as PatientsLikeMe, by analyzing how these systems are used [81], integrated [264], adopted [265], and perceived [266]. At the same time, information system research has been interested in a user-centered approach for collecting and integrating various data sources and developing frameworks for a better understanding and more precise prediction of patient engagement [36]. These are matters of exploring the design and development of digital health platforms rather than matters of analyzing existing ones.

Data on digital health platforms collected by researchers that have not been part of their design and development has formed the basis of previous analysis [33]. However, to truly understand the design and development, data provided by an actively involved

designer and developer is needed to complement previous research with learnings from an insider's view. Outsiders view the outcomes of the design and development while potentially lacking practical insight into and experience with the process that led to the outcomes. Therefore, research from the perspective of an active design and development member is vital to answer questions about the conceptualization of the design and development of digital health platforms.

Researching how digital health platforms grow in their design and development process provides a different perspective on digital health platforms from the one usually taken. Digital platforms do not just come to be. On the contrary, their design is complex [50], and requirements can change drastically over time. Simply looking at the final product of this process does not accurately reflect digital platforms in their entirety. Investigating how digital health platforms develop provides an opportunity to understand how they come to be in a participatory process. There has been interest in long-term and large-scale participatory processes [41], their challenges [42], and their benefits [267], and there is more to be learned.

In addition, focusing on how digital platforms are designed and developed allows researchers to understand the socio-technical factors at play. In the context of digital health platforms, it is important to recognize that they need to be designed and developed for their social context to fit into workflows and address the needs of their stakeholders [268]. Digital health platforms are technical solutions, and as such, they need to provide interoperability [269] by following the principles of modularity [244]. A digital health platform design needs to be sufficient on a social and technical level to be considered meaningful.

The continuous co-design approach taken in the design and development process of the Sleep Revolution digital health platform helped to align stakeholder and user needs, as well as gather a rich collection of data that provided insights into the effectiveness of the design. The case of the Sleep Revolution digital health platform thus serves as an exemplary case of the importance of continuing design with users and stakeholders throughout its use. Applying this approach also revealed a set of key aspects that make up a meaningful design of a digital health platform.

## **7.1 RQ1: The Importance of Continuous Co-Design of Digital Health Platforms**

Co-design is a valuable approach for designing and developing complex digital platforms [45]. Involving stakeholders and users in the design process fosters a design that is meaningful, referring to a design that fulfills the stakeholders' needs while simultaneously engaging its users [69]. While co-design is utilized more commonly in the ideation phase of a design [70], researchers have argued for the need for a continuous co-design process [42]. Conducting design activities not only in controlled settings early on but also later in more naturalistic settings is important for a comprehensive insight into the effects of the design [42]. Despite its benefits, co-design comes with difficulties, such as challenges with stakeholder and user participation, technical issues, and challenges managing resources [42], [270]. These challenges were also, to a certain extent, part of the co-design activities of the Sleep Revolution digital health platform. However, utilizing a continuous co-design approach helped to address and

overcome several challenges with time, as the design and the development of the digital health platform evolved with the co-design process. Thus, the co-design of the Sleep Revolution digital health platform not only helped in developing a more meaningful design but also using it continuously throughout the digital health platform's development and use helped to mitigate some of the challenges associated with co-design. In particular, co-design helped with the design and development process of the Sleep Revolution digital health platform in the following ways:

- **Iterative design activities:** A feature that lacked user and stakeholder involvement in the ideation phase could be included in design activities with users and stakeholders in a later development cycle. Necessary digital platform features are not always planned in advance or delivered in time, which can lead to the inclusion of features that are mainly designed by the designer in the ideation phase [271]. Continuous co-design offers the possibility of including these features in design activities in a later development cycle [272] and making adjustments as needed.

Moreover, difficulties in user participation are not as damaging to the design if design activities are being planned often and repeatedly at different stages in the project. If one user group turns out to be not as heterogeneous as desired, later design activities offer the opportunity to balance this in the following design activities [272].

- **Continuous engagement of diverse stakeholders:** Involving stakeholders helped to manage expectations and allocate resources. All relevant stakeholders should ideally be involved in equal parts in the co-design process [70]. Due to time and availability constraints, this is not always possible and can lead to mismatched expectations and requirements [67], [70], which, in turn, can create an unfavorable allocation of resources [74]. Prioritizing the involvement of all stakeholders can help prevent this issue.

When stakeholders participate in design activities instead of just providing requirements, they can become more engaged in contributing to the actual design [272]. Such engagement increases the awareness of the digital context of the design and reconsiders some of their initial requirements. In a continuous co-design process, stakeholders cannot only become more aware of their own design requirements through active engagement but also through greater awareness of user experience with the design [135]. This way, the design not only meets the stakeholders' expectations but also provides an engaging experience for users [65]. Participating in design activities can also make stakeholders more aware of what features are important for the end users. Additionally, design activities with developers help clarify the scope and resources needed to design and develop a new feature.

- **Holistic design evaluation:** A combination of qualitative and quantitative data from end-users and stakeholders in controlled and use settings at different times of the development gives a more comprehensive picture of the design experience. A mixed-method approach of co-design leads to insights that provide a holistic view of the design [273], which is important for understanding how the design affects all its users and stakeholders [272]. Analyzing both qualitative and

quantitative data from controlled and use settings helps to identify gaps in the design and support findings with multiple data sources.

By including developers in the the co-design activities, issues such as those associated with legacy code can be caught early and addressed before they affect the use of the digital health platform negatively. Furthermore, other stakeholders are able to better understand the consequences of design decisions and can thus make more informed design decisions.

While a holistic design process alone is unlikely to overcome larger issues regarding technical know-how, it can address smaller technical difficulties that users experience. Particularly in user evaluation in use settings, minor technical issues get exposed and can be addressed [270]. Thus, the design can become more accessible and robust.

The continuous co-design process used for the design and development of the Sleep Revolution digital health platform helped to address several of the challenges that emerged during the co-design process. Challenges related to participation, technical issues, and resource allocation and management that appeared in the co-design process are common and have been discussed in the co-design and participatory design literature [42], [270]. However, the continuous use of co-design activities and design discussions made it possible to overcome these challenges to a certain degree. Not every challenge could be resolved through a continuous co-design approach, as issues related to self-hosting and network issues or changes in target operating systems were challenges independent of the design but which affected co-design activities nonetheless. Several challenges that were related more inherently to the design and its stakeholders were alleviated in the continuous co-design process. Iterative design activities helped to overcome challenges with limited resources, as they could be addressed in later design activities. Issues with participation, also caused by a formal structure of user evaluations, had a lesser effect on the design activity outcomes, as sufficient participation in later design activities mitigated limited earlier participation. Stakeholder engagement further aided issues with resource allocation, as discussions and workshops between various stakeholders helped to communicate different viewpoints and realize design consequences. Stakeholders were exposed to other views of the design, including the ones of the end-users. Moreover, engaging developers in the design activities contributed to overcoming technical issues and addressing them before they posed a problem. Equally important to designing with several stakeholders were design activities in different use settings. In particular, technical issues regarding accessibility and minor technical issues were mostly discovered in design activities in use settings outside of the laboratory environment. Thus, the continuity of the co-design project in the design and development of the Sleep Revolution digital health platform addressed challenges that would not have been possible to overcome by using co-design only in the early ideation stages of the design.

These benefits would have been lost if co-design was only used for the ideation of digital platform features. By utilizing different co-design activities throughout the development, the Sleep Revolution digital health platform design has been developed comprehensively with a variety of end-users and stakeholders. The design has been adjusted several times throughout the Sleep Revolution project, starting at the first prototype of the sleep diary and then continuously between studies after new design

insights were gained or new features were requested. Not only does this approach effectively address users' and stakeholders' needs, but it also helps in overcoming challenges associated with co-design [42], [270].

Another advantage of the continuous development of the Sleep Revolution digital health platform was the diversity of design activities that were employed. The data gained from user evaluations, workshops with experts, questionnaires, surveys, and semi-structured interviews was rich in themes and provided insights into a variety of design aspects. Every co-design activity led to either new findings or strengthened the previous ones, underlining how different design activities can support and inform each other [273]. Feedback gathered in controlled or use settings often influenced the following ones, painting a thorough picture of the effectiveness of the design [272]. Insights from the controlled settings often led to design changes that made the existing design clearer and easier to use, such as refinement of input elements or placement of content. In contrast, insights from use settings often revealed the need for more drastic changes, such as changing the medium from a web application to a mobile application. These kinds of insights were more likely to be found after users or stakeholders used the Sleep Revolution digital health platform in its intended setting for an extended period of time. The more comparable the setting was to the actual use setting of a sleep study that would require data collection for several months, the more realistic were the insights into the effects of the design. This is in line with research emphasizing the need for different co-design activities in the actual use setting or a setting that mimics the use setting conditions [42].

Repeated co-design activities also meant more opportunities for feedback loops between users and stakeholders [272]. This enhanced collaboration on the design enabled it to be close to both users' and stakeholders' needs. The stakeholders were able to see the users' perspective and adjust their expectations and resource allocation accordingly [135]. The involvement of stakeholders in the design also helped to achieve a mutual understanding between them, which helped to align their requirements [65].

In summary, the continuous process was important to overcome challenges that come with co-design and helped to reap the benefits it promised. Design activities in controlled settings were important for initial feedback on design, while observing the design in use settings allowed us to understand the deeper impact it made. Overall, all of the design activities that were carried out in the four-year-long design and development process provided valuable insights that contributed significantly to the Sleep Revolution digital health platform design.

## **7.2 RQ2: Key Factors for Meaningful Digital Health Platform Design**

Addressing the challenges described in the co-design process of the Sleep Revolution digital health platform required an iterative and flexible process. The mixture of insights from design activities in controlled and use settings revealed several design improvements in each iteration. The insights gained in one setting often informed or motivated the other and together formed the current design of the Sleep Revolution digital platform. Combined, the insights from the five studies included in this thesis form a set of dimensions that are important for the meaningful design of a digital health

platform. These dimensions have been found important for digital health platforms independently of each other, but the importance of their composition is highlighted through the case of the Sleep Revolution digital health platform. Those dimensions are the following:

- **Engaging:** Digital health platforms that involve end-users need them engaged to comply with recording their data. Without the data, the digital health platform can usually not operate correctly and reliable long-term data is necessary to further inform ML algorithms to perform algorithmic health analytics. With an engaging design, it is not only easier to collect high-quality data, but user satisfaction is also higher, increasing changes in the adoption of the system [135]. However, engaging features such as nudging could unintentionally become manipulative [168] or evoke aversive responses [184], [185]. A considerate design takes this into account and ensures that engaging features do not become overwhelming.
- **Viable:** Digital health platforms need to be, above all, 'viable' in their implementation. This means that a system is in accordance with scientific findings and that it is able to generate intended value through health outcomes [137]. Scientific soundness needs to be shown through rigorous user testing and evaluations. A co-design process that includes experts at every stage of the development phase is vital to ensure that the system is not only accepted by the end-users but also that it generates value for them and is scientifically sound [1]. Therefore, the perspectives of healthcare professionals and researchers should be included in the design.
- **Accessible:** Digital health platforms must prioritize accessibility to reach a broader audience, both technologically and functionally [91]. The functional design of digital health platforms should be straightforward and user-friendly [44]. Cluttered interfaces and vague instructions can lead to user frustration and cause the user to feel a loss of control. Such negative experiences can significantly diminish the user experience and the system acceptance. From a technological standpoint, supporting a variety of devices is vital to ensure inclusivity. Thus, web applications are particularly suited as they can be delivered through different browsers on various devices. Furthermore, digital platforms that are accessible through a web application eliminate the need for installation, further reducing technical complexity [254]. Similarly, restricting the digital application to a specific laboratory setup significantly narrows down the potential audience. Only when users can engage with the application on their own devices, on their own schedule, and in the comfort of their homes can the full potential of accessible digital health platforms be created.
- **Lean:** A lean design of the digital platform is a key component of building an engaging, doable, and accessible system. A 'lean' design describes the use of straightforward, clean and efficient interfaces. Including elements such as nudging [164] or gamification [96] can help to make the digital platform more engaging, but at the same time, it is important to not overload the user with the interface. It is important that every design choice is carefully evaluated and, thus, deliberate. Unnecessary features that do not add value can add unwanted

complexity. Moreover, while it is important to make the interaction with the digital health platform engaging, the design must not compromise its validity and integrity. It is, therefore, vital to keep the digital health platform design 'lean' and focus on achieving a good user experience with few deliberate features rather than detracting from the core purpose of the system.

- **Informed:** To be able to draw valid, scientific conclusions from digital care pathways that aim to improve health behavior, the digital environment should be used to collect helpful metadata [119]. A complete image of a user's interaction is vital for an accurate outcome. Therefore, an 'informed' system collects relevant metadata and context, such as timestamps and device or browser specifics [135]. This information can greatly improve the chances of interpreting the collected data correctly and potentially finding new patterns with artificial intelligence or ML methods [75].
- **Doable.** Applications that serve as digital care pathways often require the user to perform tasks within the system. Those tasks must be realistic in terms of the time and frequency it takes the user to perform them [136]. Furthermore, they should be designed such that the majority of end-users is capable and able to understand and perform the tasks [44]. This is particularly important in the context of digital health platforms as the end-user group consists of people with diverse backgrounds, varying levels of technological abilities, and, potentially, disabilities. Moreover, as outlined earlier, low user engagement is a common cause of the failure of digital health platforms [134]. Therefore, it is important to design the system such that users do not abandon the system due to its high complexity. A 'doable' design contributes to improved user experience and helps to ensure the accessibility of the system.

Co-designing to achieve these dimensions can foster a meaningful design. In the Sleep Revolution digital health platform's design and development, they turned out to be the main areas that user and expert feedback called for changes in the design. The dimensions are related to each other, and the improvement of one can lead to the advancement of another. For example, gathering metadata creates an informed system, which in turn can result in producing better outcomes for the users and, thus, increase validity.

To enhance the understanding of these dimensions and their relations, I comprised them into three interrelated key aspects of digital health platforms, which are (i) robustness, (ii) integrity, and (iii) user experience.

### 7.2.1 Robustness

The robustness of a digital health platform refers to its technical accessibility, reusability and maintainability as well as validity. In other words, that a digital health platform should be robust means that it should be easy for users to access the digital health platform [91], that the digital health platform code and design should be modular and lean [5], [50], and that the data collected through the digital health platform is trustworthy [75].

In terms of accessibility, it is important to lower technical complexities as much as possible. This involves skipping or simplifying the installation process as well as

offering access to the digital health platform on a variety of frequently used devices. However, the nature of the treatment or data collection tool delivered through the digital health platforms highly influences the choice of a medium with suitable accessibility. Expert requirements and frequency of data collection are exemplary dimensions of a digital health platform that influence the accessibility choices in the design. Regarding the design and development of the Sleep Revolution digital health platform, accessibility has been ensured in the studies involving the design and development of both the web app and the mobile app. The web app runs in the browser and can thus be accessed by most personal computers regardless of the operating system. The mobile app has been developed for Android and iOS systems and runs on many different system versions and devices. This decision was specifically informed by results from the user evaluations. As the sleep diary is supposed to be filled out twice a day, a mobile app is the more appropriate target medium in terms of accessibility, as smartphones are used much more frequently than personal computers. This is one reason why mHealth has become a promising technology [95]. In the case of the Sleep Revolution digital health platform, by providing the digital sleep diary for a variety of mobile devices, this digital sleep diary [22] had a notably broader reach than the one developed by Tonetti, Mingozzi, and Natale [197] targeting only iPads. Unlike the sleep diary, the measuring of cognitive functioning is not something that should be done daily, and thus, a web app was a medium with suitable accessibility for this tool.

Maintainability and reusability of digital health platform components are not only important aspects of digital health platforms but also software systems, in general, [245]. Modular code, an extensive test suite, and coding conventions are just a few examples of good software development practices. The Sleep Revolution digital health platform follows recommended practices by using modular, maintainable code and design [151], [152]. A design system was used to structure the front-end and easily translate from design to code components. This ensures a lean design and codebase with small, reusable system components for both the web app and mobile app. It also fosters collaboration between designers and developers [146] and allows easy entry for those with varying levels of technical competency.

Both the Sleep Revolution mobile app and the web app are connected to a back-end that securely sends and stores the data in a database on a locally maintained high-performance cluster [32]. In addition to that, the collected data is only associated with users through an anonymized research ID and thus provides protection of personal data for participants while still granting access to the digital sleep research platform. Moreover, the trustworthiness of data is an important element of robustness and greatly influences the other two key factors, integrity and user experience. Without trustworthy data, no reliable insights, diagnoses or feedback can be given. In that case, the trust in the system could be lost and negatively affect user experience. Both the Sleep Revolution web app and mobile app also collect metadata and augment the collected data with timestamps [22], [119]. This has proven valuable in the case of the digital sleep diary already, as it was used to synchronize entry dates and times.

### 7.2.2 Integrity

The integrity of a digital health platform describes the scientific and clinical validity of the provided tool. Specifically, it refers to the extent that the collected data can be used to measure the true value of the relevant health condition. Only if the digital tool

is designed following scientific and clinical guidelines can the digital health platform provide true value for healthcare experts and users [75], [274].

The co-design approach that was taken throughout the Sleep Revolution project was an integral part of ensuring the integrity of the digital health platform. Results from the design and development of a digital sleep diary and cognitive tasks have shown the importance of keeping integrity in a digitization and digitalization process. It is vital to provide a digital health platform that enhances and does not hinder the work of healthcare experts and adheres to healthcare standards, which can be achieved by involving the experts in the design activities [133], [137].

Regarding digitization, embracing new opportunities while moving a tool from the physical into the digital realm is key to a successful transformation. However, this transformation also bears risks that need to be accounted for in order to maintain the scientific and clinical value of the tool [275]. The feedback that was gained from regular workshops with experts during the ADR process of the Sleep Revolution digital health platform greatly influenced its design. This finding emphasizes the importance of a co-design process that involves experts in the design of digital healthcare tools [1]. Similarly, when moving a digital health platform from a laboratory to an at-home setting, it is important to include experts in the process. Looking at the digital health platform through a developer's lens, integrating digital elements to improve engagement and user experience seems like a natural step in the digitalization process. However, this step should be taken only under expert guidance. In the design and development of the tool for measuring cognitive functioning, several design choices suggested by the developers would have been incompatible with keeping the validity of the tool. Specifically, one cognitive task was designed to measure stress endurance, and relieving that stress with more user feedback - while providing a better experience - would have potentially compromised measurement validity. However, other measurements through the tool were not influenced by such digitalization efforts and could thus be improved through elements that lessened user frustration and improved user experience, such as progress bars and mandatory practice rounds with feedback.

### 7.2.3 User Experience

The user experience of a digital health platform includes the ease of use of the digital health platform as well as the overall user experience. How easy it is to use a digital health platform stems partially from robustness dimensions such as accessibility and stability [276]. However, it also refers to the clarity of the tasks users have to perform in order to use the tool [277]. As previously mentioned, accessible design does not only have the goal of maximizing reach but also the aim of choosing the right medium for the specific tool. This focus is vital for easy entry into the digital health platform. Moreover, not only accessing but also using the digital health platform should be of low complexity. In the evaluation of the Sleep Revolution mobile app, one finding was that the lowest value in user experience was found in the hedonic quality of the application [22]. Arguably, this is an inherent issue of user experience in many health tools, as their primary goal is not entertainment. Therefore, this aspect should receive a particular focus in the design and development of digital health platforms.

Aside from accessing and understanding the tool, the experience of using it is another vital dimension of user experience. Engagement of users is key in gathering

longitudinal data, in particular, [278], which, in turn, creates opportunities for the application of ML and AI methods that have the potential to uncover new patterns [75]. The Sleep Revolution project aims to integrate ML methods and, therefore, puts a high level of importance on frequent, longitudinal data collection. This influenced the design and development process of multiple parts of the Sleep Revolution digital health platform. In the digitization process of the sleep diary, the focus in the design phase was not only on maintaining clinical and scientific validity but also on the integration of the digital environment and the added value it could provide. This manifested in the use of native notifications, as well as data visualizations. Later on in the digitalization of the sleep diary, novel gamification elements in the form of goal setting were included. The compliance analysis showed that the digital diary had, overall, satisfactory compliance rates with high compliance throughout the first two months of the evaluated three-month study and only declined in the last days of the study period. Furthermore, the analysis of the user experience and usability of the prototypes and the early version of the digital artifact showed good results in that regard. The design and development process of the measurement of cognitive functioning also involved active efforts to provide a good user experience. Improvements in task clarity, as well as feedback on the task completion progress, were the main contributions in that area.

### 7.3 Dimensions of the Key Factors

The three key factors are interconnected and can create a synergistic effect that enhances the overall utility and effectiveness of the digital health platform. They summarize and connect the dimensions that were found most important in the design activities with end-users and stakeholders of the Sleep Revolution digital health platform. They can, thus, be understood as the dimensions of the key factors. Figure 7.1 illustrates how they are interconnected.

Dimensions and Key Factors in the Design and Development of Digital Health Platforms

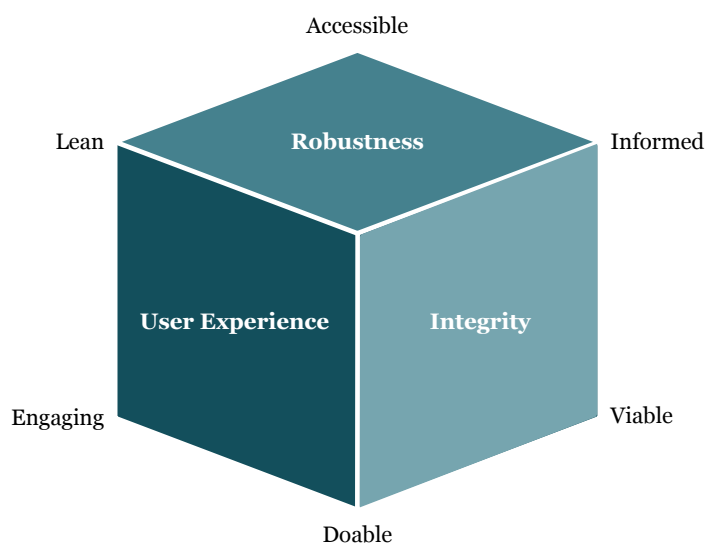


Figure 7.1: Dimensions in the design and development of digital health platforms and how they interconnect and contribute to the key factors.

As outlined previously, robustness refers to the accessibility and availability of the digital health platform. A system that is available easily and *accessible* to a wide variety of users will find greater adoption and can be distributed not only to selected users but to a broad, general audience, enabling greater data collection [91]. In addition, an *informed* system that collects metadata and uses extensive logging is more likely to reveal bugs or other inconsistencies in the tool that can be addressed early on. Thus, the data is more reliable, meaning that this dimension contributes equally to the integrity of the system. Reliable data enables effective data analysis [75]. However, not only the data itself but also the way it is collected needs to be scientifically sound [274]. Therefore, the *viable* design of the health tool is of great importance. Since longitudinal and frequent measures are vital to gathering a sufficient amount of data, the digital tool needs to be *doable* as well. Without enough data, no conclusions can be drawn from the collected data [75], [274], even if the tool used for the gathering is scientifically sound, making *doable* another dimension of the integrity of the digital health platform. This dimension also affects the user experience. As my studies showed, users can easily be overwhelmed by tools and to increase acceptance, a *doable* complexity and frequency of using the digital tool should be focused on [277]. In that regard, an *engaging* design can assist in minimizing the burden of using digital health platforms and boost user experience [278]. Novel features, such as the addition of game elements [96], can lead to a more enjoyable experience. However, it is important to use those features responsibly for them to be effective and not overwhelm the user with interactive elements. Therefore, striving for a *lean* design will ultimately be beneficial for the digital health platform's user experience. Additionally, a lean design with a minimal amount of design components is reflected in the design and codebase of the digital health platform software. This allows for quick changes, simplifying maintenance, and making it easier for new developers to work on the digital health platform [151], [152]. This is why this dimension not only supports user experience but also contributes to the digital health platform's robustness. With this analysis of the dimensions and the contribution to various key factors, these thesis contributes a synthesis of key factors in the design and development of a digital health platform. They are meant to foster a holistic understanding of a digital health platform and enable a focus on these core aspects in the design during continuous co-design activities.

## 7.4 Future Work & Limitations

The thesis follows the design and development of a digital health platform for research purposes. It looked into the digitization of tools presented on the digital health platform and touched on digitalization and digitization. However, the tools, at the point of the study, had the purpose of tracking symptoms and collecting data without offering a diagnosis. Therefore, key factors and benefits from a co-design process for other digital health platforms might differ. The Sleep Revolution project does look into pattern recognition for the data collected through the digital health platform and diagnosis or feedback based on the data might be offered in the future. Moreover, the Sleep Revolution project has been developed by researchers and is currently aimed to be used mainly in a research setting. Digital health platforms that are applied in a hospital setting or are open to a broader audience might require a different prioritization and a focus on different socio-technical aspects in the design and development process. Thus,

future work could focus on exploring a continuous co-design development process on digital health platforms in other settings.

# Chapter 8

## Conclusion

Digital health platforms can ease the pressure on global healthcare systems and provide equitable proactive and reactive care to society at large, including those that currently have only limited access available. They also offer great potential to gather large amounts of data for research using machine learning and AI algorithms. Existing research has mainly focused on identifying key factors for meaningful digital health platforms through literature reviews, patient outcome analysis, and surveys with health experts but rarely looks into the design and development of a digital health platform from the view of a designer and developer. Further documentation of similar design and development processes is lacking and can enrich the literature as practical examples.

This thesis addresses this gap and comprehensively traces the journey of a multi-faceted digital health platform for research from early ideation stages to active usage in studies in multiple European countries in a four-year ADR project. The studies included in this thesis look into various aspects of the Sleep Revolution digital health platform, that connects researchers, sleep experts and study participants as end-users. Moreover, the thesis draws on the experience of designing and developing the Sleep Revolution digital health platform and documents the learnings and challenges of the process beyond the findings presented in the included papers. The cumulative implications highlight the role of a continuous co-design after the initial ideation phase in creating a meaningful digital health platform design. The case of the Sleep Revolution digital health platform demonstrated that this approach helped to alleviate common challenges of co-design. In particular, challenges regarding stakeholder and end-user participation in co-design activities, technical issues and resource management and allocation could be mitigated through (i) iterative design activities, (ii) continuous engagement of diverse stakeholders, (iii) holistic design evaluation. This documentation of specific benefits of a continuous co-design process provides a practical contribution to the digital health platform literature. The contribution brings together previous findings regarding continuous co-design and derives insights and learnings from a real-world application. Moreover, illustrating how a continuous co-design process can help to overcome co-design challenges addresses the need for research that highlights for the importance of continuous co-design [1].

The co-design process enabled the discovery of three socio-technical key aspects in the design of a digital health platform design and development and how they interconnect. The aspects essential to meaningful design uncovered in this thesis are (i) robustness, (ii) integrity, and (iii) user experience. The thesis also presents the differ-

ent dimensions of those key factors and how they are interconnected in order to inform the design and development of future digital health platforms. This conceptualization of these aspects is a theoretical contribution to enhancing the current understanding of meaningful digital health platform design through a co-design process. The conceptualization of digital health platforms and expands existing information system (IS) literature [2], [50], [244], [279].

## 8.1 Theoretical & Practical Implications

The Sleep Revolution digital health platform has been developed by a comparatively small research team with the aim of modernizing sleep healthcare and collecting data that can inform the development of algorithms that automatically detect patterns in the gathered data. As part of the small research team and an active member in the design and development of the digital health platform, the implications of my studies reflect a unique perspective of the process that compliments the existing literature. While IS research often examines a certain aspect of a system at a specific point in time, my work reflects multiple aspects involved in the design and development of a digital health platform over a long period of time.

My work in this thesis combines insights from my perspective as an active designer and developer, and draws conclusions that enhance current literature on digital platforms as well as present contributions that are close to practice. The examination of a digital health platform during its design and development in this thesis enhances the general understanding of how digital platforms are created and grow [33], [34]. In particular, the thesis contributes to the IS literature on participatory design [21], [41], [45], [70] by documenting its challenges and usefulness in a continuous co-design process of a digital health platform. Moreover, the design with users combined with findings on dignified user engagement [38]–[40], in particular through digital nudging [157], [164], [165], [280], in the IS literature led to the conceptualization of socio-technical key factors for user engagement in a digital health platform. Thus, the thesis follows the recent interest in creating human-centered digital health platforms and enhances information system literature on new and innovative IS health solutions [35]–[37].

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# Appendix A

## Publications

### A.1 Paper 1

*Towards a Digital Sleep Diary Standard*

## **Towards a Digital Sleep Diary Standard**

*Completed Research*

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### **Abstract**

A sleep diary is an important tool to gather subjective sleep data, which provides key information for the diagnosis of a variety of sleep disorders. In 2012, an expert panel created a standardized sleep diary in pen-and-paper format. However, pen-and-paper has certain limitations, in particular, it is difficult to monitor participant compliance and memory bias. We improve upon these limitations with a digital design and identify benefits and drawbacks of the pen-and-paper format in comparison to a digital sleep diary in an empirical study based on an action design research project. The main contribution consists of five design guidelines: i) use the native environment, ii) utilize established input methods, iii) embed customization to minimize participant workload, iv) evaluate the application continuously using analytics, and v) integrate digital elements to increase compliance. Furthermore, we propose a mobile application design for a digital sleep diary that is in accordance with these guidelines.

### **Keywords**

Consensus Sleep Diary, Digital Sleep Diary, Sleep Assessment, Information Systems, mHealth

### **Introduction**

The digitization of sleep medicine is decades behind the digitization of society in general (Arnardottir et al. 2021). When a person experiences sleep-related issues, a sleep diary is an important tool to gather subjective sleep data, which provides key information for the diagnosis of many sleep disorders (Sateia 2014). A sleep diary can be used for monitoring severe sleep disorders and it can function as a valid assessment tool for insomnia with the potential of identifying candidates for cognitive behavioral therapy as a treatment trajectory (Buysse et al. 2006). A sleep diary is also a valuable research tool for sleep studies. Traditionally, sleep diaries are designed to be printed out and filled in on paper (Åkerstedt et al. 1994; Carney et al. 2012). However, the pen-and-paper format is rigid and neither scalable nor customizable. It provides limited possibilities to interact with the participants, personalize the diary, respond to questions or misunderstandings in time, or control the data during collection. To process and analyze the results, the pen-and-paper requires significant manual work (Văcărețu et al. 2019), making it prone to errors. Moreover, an analysis of the data can only be provided after the data has been collected and transferred to the researchers (Islind et al. 2019b). In addition to that, sleep patterns can vary due to lifestyle changes, menstrual cycle, shift schedule and day-

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light savings, and collecting subjective data over an extended period of time to capture these fluctuations would likely yield more reliable results (Óskarsdóttir et al. 2022). An extended data collection could allow for insight into new factors that influence sleep quality over time.

During the past years, there has been a rise in digital symptom trackers in general (Lavalée et al. 2020) but little progress in digital sleep diaries in particular although the potentials are seemingly high. With a digital sleep diary, data can be directly transferred to and looked at by professionals, creating a bridge between these user groups. Such a connection would enable researchers to react and initiate communication with participants, even during the period of the data collection if needed. Most importantly, digital symptom trackers, such as a digital sleep diary can easily be provided to a broad audience (Lu et al. 2021). There would be no need to restrict the usage and analysis to a defined study period and participants could track their sleep habits for as long as they wish. This way, professionals (researchers and sleep specialists) would be able to collect more data and participants would benefit from a regular sleep assessment and feedback on how to improve their sleep.

This paper presents an action design research project with the aim of digitizing subjective data collection within sleep medicine through a digital sleep diary. We focus on analyzing the ability of a digital sleep diary to address the pen-and-paper format limitations and derive design guidelines for our design and development process of the digital sleep diary. Thus, we arrived at two research questions: *i) What are the benefits and drawbacks of the pen-and-paper format in comparison to a digital sleep diary?* and *ii) How can a digital sleep diary be designed and developed to increase compliance and counteract memory bias?* The main contribution of this paper is a set of design guidelines which target these aspects specifically.

**Related work**

In 2012, an expert panel created a standardized sleep diary in pen-and-paper format, called the Consensus Sleep Diary (CSD) (Carney et al. 2012), an important work to facilitate comparison across research studies and for clinical work. However, one major drawback of the CSD is that it comes in three different versions: i) a core, ii) an extended core, and iii) an evening version. The core version of the CSD was designed with the intention of creating a minimal viable set of questions for sleep diary research to be asked in the morning. The extended core version additionally tracks daytime data (CSD-M). The evening version was developed specifically to be filled out both in the morning and in the evening (CSD-E) and contains the same questions as the CSD-M with additional instructions on which set of questions to fill out in the morning and which set in the evening (Carney et al. 2012; Tonetti et al. 2016). The pen-and-paper format of the CSD made it necessary to treat each of these three variants as different versions of the sleep diary. However, to advance standardization further, it would be preferable to arrive at one single sleep diary standard. A digital sleep diary version could however allow for time controlled restrictions and due to that, a digital sleep diary could thus combine the three CSD versions into one (Arnardóttir et al. 2021).

Monitoring participant compliance in a pen-and-paper design is difficult and counteracting it even more so. Participant feedback has shown that there is a tendency to forget to fill out pen-and-paper symptom trackers and try to make up for it by filling it out at a later time, also referred to as the "parking lot syndrome" (Cerna et al. 2020). This is a major drawback, since symptom trackers and sleep diaries - when filled out in a close temporal proximity to the occurrence of the event - can contribute reliable and stable data for identifying certain sleep disorders (Arnardóttir et al. 2021). For diagnosing sleep disorders, timely data has significant value in comparison to retrospectively collected data. Also, the retroactively entered data cannot be accounted for or filtered out, since it is difficult to detect it in a pen-and-paper format (Tonetti et al. 2016). Entering data retroactively also introduces another problem, namely, it gives rise to the potential problem of memory bias. Memory bias refers to the tendency to intentionally or unintentionally rely on recalling certain events and autobiographical memories and favoring those memories over others (Bianchi et al. 2020). This recall process often relates to significant events, including traumatic, unconventional events, or even to systematically selecting the most recent events in a series of events (Mogg et al. 1987). Memory bias and the tendency to rely on most recent events are especially visible when dealing with a prolonged condition period (Lindroth et al. 2018). Therefore, filling out the sleep diary based on recall can result in potentially biased and less reliable data. This is why finding alternative ways to increase compliance and counteract memory

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bias, thus improving the integrity and quality of the sleep diary data, should be a priority (Maich et al. 2018). A digital solution can prevent these issues.

There have been attempts to develop a version of a digital sleep diary. For instance, Tonetti et al. created a digital sleep diary based on the CSD in 2016. It was a mobile application (hereinafter app), developed for the iOS, specifically targeting iPads. They compared their digital sleep diary to the pen-and-paper diary, and received promising results; the digital version performed similarly to the pen-and-paper version. Unfortunately, the study does not detail the design of the app and since it was only developed to support iPads, this digital sleep diary version limits the potential uptake significantly. In 2019, another version of a digital sleep diary was developed by Văcărețu et al. This version was not based on the CSD, but instead on another analog sleep diary, the Karolinska Sleep Diary (Åkerstedt et al. 1994). This analog sleep diary has a different format compared to the CSD and does not encompass the same set of questions. The research project focused more on studying the usability and user experience of this digital sleep diary and less on the sleep diary per se (Văcărețu et al. 2019). In 2021, Vallo Hult et al. found that, when transformed appropriately, digital healthcare applications have a positive influence on professional practices as well as patient awareness and participation. Therefore, when turning an analog artifact into a digital one, it is important to take into account possible context changes like the ones described by Vallo Hult et al. (2021). The general need for further standardization of a digital sleep diary is illustrated in an overview of the current state of sleep measurements by Arnardottir et al. (2021). What can be derived from these papers, is that there should be a three-folded focus in future research on digital sleep diaries: i) to create a standard for digital sleep diaries, ii) to take into account the context and multiple stakeholders, and iii) to design such digital sleep diary to fit multiple mobile platforms to increase potential uptake.

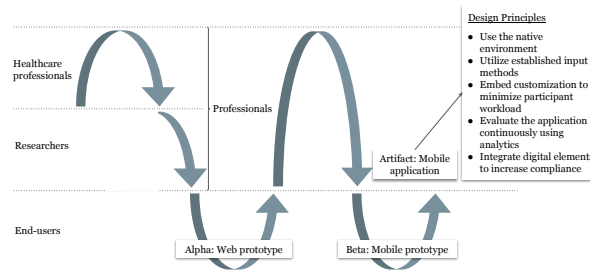
## Methods

This paper rests on an action design research project (Sein et al. 2011) with the aim of designing and developing a digital sleep diary as an app (see Figure 1). The app was co-designed, involving end-users (those that will be using the app), researchers and healthcare professionals in the design process. The motivation behind this was to ensure that the respective needs of the different user groups were met (Islind et al. 2019a). For our action design research project we utilized several types of data sources. We used two questionnaires, a survey and application analytics to collect quantitative data and complemented that with the qualitative data that we gained from the semi-structured interviews.

The first out of the two questionnaires is the System Usability Scale (SUS). SUS was used to evaluate the usability of the digital artifact. The questionnaire was developed by Brooke in 1996 and is widely validated. It contains ten rating scales with a score from 0 to 10 and the ratings are added up and compiled to an overall usability score that ranges from 0 to 100 (Brooke 1996). We collected data from 52 participants (alpha prototype: nine participants, beta prototype: ten participants, artifact: 32 participants) in four rounds (alpha prototype: one round, beta prototype: two rounds, artifact: one round) during the entire project. The second questionnaire is the AttrakDiff. AttrakDiff is a questionnaire that was developed to measure experienced hedonic and pragmatic quality and user experience of interactive products (Hassenzahl et al. 2003). It measures four aspects, pragmatic qualities (PQ), hedonic qualities—identity (HQ-I), hedonic qualities—stimulation (HQ-S), and attractiveness (Att). We employed this questionnaire to assess the user experience of the digital artifact. We asked 32 participants to complete the AttrakDiff questionnaire for the digital artifact in two rounds. Additionally, we designed a survey for the purpose of this project to evaluate the alpha prototype. It contained twelve questions and was sent out to and answered by 59 participants. All that data, coupled with the analytics from the application, gave us insights into the use aspect. Furthermore, the semi-structured interviews were individual interviews, ranging from 15-40 minutes with the aim of gaining in-depth insights. In total, we conducted five rounds of semi-structured interviews (alpha prototype: three rounds, beta prototype: one round, artifact: one round) with 55 participants (alpha prototype: 23 participants, beta prototype: ten participants, artifact: 32 participants).

We went through multiple iterations utilizing these mixed method data gathering activities (Byrne and Humble 2007), moving from an alpha prototype in form of a web application to a beta prototype designed as an app which was then turned into a digital artifact. Each user test round followed the setup of the Five-Act

Interview (Knapp et al. 2016), where the participants were asked to make use of the think-aloud technique (speaking freely about what came to mind during their user tests).



**Figure 1. Action Design Research approach.**

### **Alpha prototype**

We started the development process by mapping the needs of our three primary user groups: i) end-users, ii) researchers, and iii) healthcare professionals. In total, nine participants took part in a semi-structured interview, three from each user group. Following the results of this interview round, researchers and healthcare professionals were treated as one group (hereinafter professionals) in the subsequent phases of the research project, as their needs turned out to be almost identical. Next, we handed out a pen-and-paper format of the CSD-E to 59 end-users. We collected their pen-and-paper format sleep diaries and evaluated their experience after filling out the CSD-E for one week. Our goal was to identify the key needs to consider and incorporate into a digital sleep diary. After the end-users had completed that task, we asked them to fill out a survey regarding their experience and how they would like to have their data visualized.

Based on the results from this phase, we developed the alpha prototype as a web application. The initial designs were printed out on paper as low-fidelity wireframes and were tested with nine participants: three professionals and six end-users. They were asked to complete a list of tasks and do a think-aloud test using the prototype. From the feedback, we created an overview of the issues and prioritized according to their severity. The prototype was then updated in order to improve these critical issues. Subsequently, another evaluation was conducted for the refined version with the same participants using a high-fidelity prototype. In addition to completing tasks with the prototype, the same nine participants answered the SUS questionnaire to measure the usability of the alpha prototype.

### **Beta prototype**

We decided to develop the beta prototype for a digital sleep diary in the form of a mobile application with optional notifications, because reminders like those in a typical mobile application notification style were a strongly requested feature by participants in the study phase with the alpha prototype. In order to digitize the CSD and turn it into an app, we held a workshop with sleep professionals, a clinical sleep specialist, clinical sleep researcher and an expert in patient-reported outcome measures, in the development process. Based on the expert feedback, we developed a low-fidelity prototype and tested it with 5 end-users. We asked them to complete a list of tasks using the prototype. Afterwards, the participants filled out the SUS questionnaire followed by a semi-structured interview. Based on those results, we developed a high-fidelity prototype. We repeated the user tests in the same fashion as before with the same five end-users that tested the low-fidelity prototype, asking them to complete tasks, answer a SUS questionnaire and partake in semi-structured interviews.

### Artifact

Next, we developed the digital sleep diary as a functional mobile application for Android and iOS. This prototype was handed out to 32 end-users that were divided into two groups. The first group consisted of 17 Reykjavik University students, which all had previous experience with pen-and-paper sleep diaries, whereas the second group consisted of twelve external end-users of which only one person had prior experience with filling out sleep diaries. The first group received an on-site introduction to the mobile application, while the second group received instructions via email. Before the end-users of both groups got to use the application, they were asked to fill out the AttrakDiff questionnaire. For the following week, the participants were asked to fill out the diary daily, both in the morning and evening. The end-users were able to give continuous feedback throughout this phase, which led to minor bug fixes regarding the text translation and notification cancellation. Additionally, we logged the end-users' activity in the application. After the end-users had completed the week of filling out the sleep diary, they were given the SUS and AttrakDiff questionnaires to answer. To conclude the study, we conducted semi-structured interviews with these end-users who had used the digital sleep diary.

### Results

We will now present the findings from user tests with the alpha prototype, the beta prototype and the artifact.

#### Alpha prototype

The results of the final survey, which was conducted after the end-users had filled out the pen-and-paper CSD for a week, showed that 81.4% of the end-users preferred the sleep diary in form of a website instead of on paper. Overall, the majority of the end-users had a positive attitude towards the sleep diaries, almost 60% found it "entertaining" or "interesting", while more than 20% found it "okay". However, more than 17% had a negative experience while filling out the sleep diary as shown in Figure 2 and 4.6% of the end-users did not complete their pen-and-paper sleep diary.

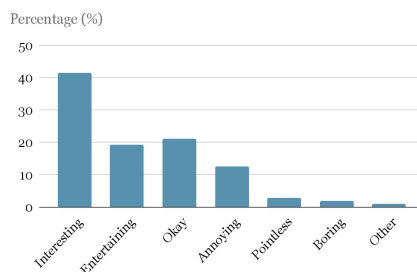


Figure 2. Survey answers to: "How did you find filling in the sleep diary?"

Over half of the end-users reported trouble remembering to fill out the sleep diary in time. As shown in Figure 3 (a), more than 40% filled in the sleep diary later on more than one occasion and almost 18% forgot to fill out the diary completely at least once. One important topic for over 80% of the end-users was that they wanted to be able to receive reminders and over 70% preferred to receive those in form of native app notifications (see Figure 3 (b)).

#### Beta prototype

In a workshop with professionals, we derived requirements for the context change of the sleep diary from pen-and-paper format to an app, these requirements were then included in a new beta prototype. We decided to use native iOS and Android input elements to collect the sleep diary answers. Furthermore, we

## Towards a Digital Sleep Diary Standard

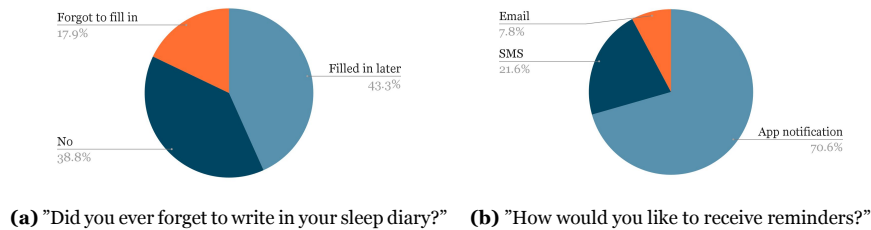


Figure 3. Survey answers.

agreed to include the instructions for answering the evening questions on a separate instruction view. This view is accessible through an information button positioned at the top right corner of the screen 5. We also allowed the participants to fill out entries only for the current day, and not for any of the previous or following days. In this phase we also worked on the requirement of notifications. The participants had the option to receive notifications in the morning and in the evening at a chosen time. By default, the notification times were set to 9 AM and 9 PM. However, we derived the need for this to be customizable (which was implemented in the following phase).

We had to make changes to some of the CSD-E questions in order to keep them understandable in the new context. All changes to the sleep diary questions are shown in Table 1. Follow-up questions like 12b and 13b are displayed isolated on the screen like all the other questions, which is why they needed clarifying updates. Conditional questions like 6d were simply omitted if the condition was not fulfilled. Question 14 expects two different answer inputs which is why we decided to separate it into two questions in order to keep the diary entry layout consistent. Questions 16-20 were added as a five point visual analog scale for additional information on end-user daytime functioning. Additionally, we asked the end-users in the onboarding of the beta prototype if they drink alcohol or caffeine, or take sleep medication. This was a need derived from our interaction with the end-users on the one hand and the professionals on the other hand. The end-users can adjust the answers to these questions later on in the application settings if needed. If one of these setup questions is negated by the end-user, the corresponding diary questions are not displayed. This way the end-users do not need to answer questions that are irrelevant to them. Since the beta prototype is supposed to be used shortly before the end-users go to sleep, we tested both light and dark theme and found out that the dark theme was preferred, with the argument of it being good to reduce the light exposure through the app as much as possible moments before sleep. All of the aspects that worked well during user testing in this phase, were fully implemented in the artifact phase that followed. The beta prototype went through two rounds of user tests. In the first round, the prototype achieved a mean SUS score of 91.0, with a minimum score of 85.0 and a maximum score of 100.0. After we incorporated the user feedback from this round, the mean SUS score of the next iteration of the beta prototype improved to a mean score of 97.5, with a minimum score of 85.0 and a maximum of 100.0. Based on those results, we moved on to the artifact phase.

### Artifact

The data collected from the user tests with the digital artifact shows that 81.4% of the end-users preferred to use an app rather than a pen-and-paper format. The participants gave reasons for this in the interview; they found the digital sleep diary more engaging, accessible, and easier to comply with than pen-and-paper. On average, the morning questions of the digital sleep diary were answered 6.66 out of 7 times and the evening part was filled out 6.47 out of 7 times. It took the average end-user 397 sec (SD = 2449) to fill out the morning sleep diary, with a median of 121 sec. The evening sleep diary was filled out in an average of 75.4 sec (SD = 57.2), with a median of 61 sec. Since there were occurrences of outliers, most likely caused by opening the diary in the evening and then keeping it open until the morning, the median time gives a more accurate estimate than the average. 22 out of the 32 end-users filled out the SUS questionnaire that was handed out during this phase, eleven participants of the first group and eleven end-users from the second group.

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Question	CSD	Our App
6d	If yes, how much earlier?	How much earlier?
12b	What time was your last drink?	What time was your last alcoholic drink?
13b	What time was your last drink?	What time was your last caffeinated drink?
14	Did you take any over-the-counter or prescription medication(s) to help you sleep? If so, list medication(s), dose, and time	a) Did you take any over-the-counter or prescription medication(s) to help you sleep? b) List medication(s), dose and time taken
15	-	Was today a workday? (If not, then it was a freeday)
16	-	How fatigued were you today?
17	-	How sleepy were you today?
18	-	How stressed were you today?
19	-	How was your mood today?
20	-	How much did you exercise?

Table 1. Changes to the CSD-E questions.

Overall, the answers resulted in a mean SUS score of 88.9 (SD = 9.0). In the first group the mean SUS score was 85.2 (SD = 9.6), while it reached a mean of 92.5 (SD = 8.4) in the second group. Furthermore, we used AttrakDiff to determine the digital sleep diary's user experience compared to end-users' expectations.

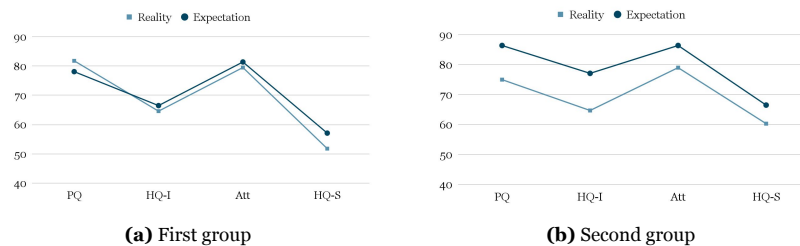


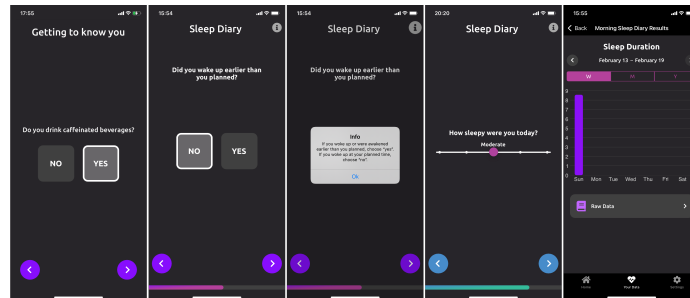
Figure 4. Results from the AttrakDiff questionnaires.

Figure 4 shows the calculated mean values for each AttrakDiff scale among the participants. The first AttrakDiff questionnaire was filled out by all 32 participants, whereas only 21 of the participants chose to answer the second one. The digital sleep diary received the lowest score for the hedonic quality for stimulation (HQ-S), meaning that the users did not find the app very stimulating but other aspects were well received. In the interviews, the end-users commented positively on the setup of the sleep diary, finding it easy to understand and learn. They also mentioned that it was quicker to fill out than the pen-and-paper version. The notifications were generally appreciated and praised frequently by the end-users. They found that it helped to remember to fill out the diary and even described them as "motivating". However, some difficulties came up when filling out the diaries. The end-users found it hard to estimate times and sometimes did not understand the questions. Unfortunately, they often overlooked the instruction button which could have helped to avoid this issue. Figure 5 shows selected screens of the digital sleep diary including the onboarding, the diary and the data visualization screens.

## Discussion

In this paper we address two areas of interests. Firstly, we focus on the main benefits and drawbacks of the pen-and-paper format in comparison to the digital sleep diary. The findings from that part outline our requirements. Secondly, we use those requirements to design and develop a digital sleep diary with the aim

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**Figure 5.** Selected views of the digital sleep diary in the developed mobile application.

of increasing compliance and counteracting memory bias, which were the main issues found while using the pen-and-paper version. We found that on a piece of paper, it cannot be controlled when and how participants enter information. Examples include various time formats that are used to enter data, wrongly entered data and unprompted comments (Văcărețu et al. 2019). We found that these issues can be avoided with input control in a digital sleep diary. Choosing native inputs for time, numbers, booleans (true/false) or text prevents the participant from entering incorrect data and ensures data homogeneity.

Our interviews with the participants showed that they were interested in their data and liked to see it visualized. Based on that, we theorize that insightful data visualizations combined with actionable feedback can further increase compliance and engagement. Instead of only collecting data with the sleep diary, a visualization of the sleep diary data can offer an analysis and feedback to the end-users. In this way, the sleep diary can be transformed from a pure data collection device to a corrective tool with the potential of continuously improving the sleep hygiene of the end-users. A digital companion app also has the potential to gather additional data through, for example, cognitive tests and can potentially include data from wearables, such as fitness and tracking devices. This data can be used to complement data collected through the diary, automatically fill out relevant sections of the sleep diary and evaluate the accuracy of the sleep diary data (Arnardottir et al. 2021). Along those lines, the CSD paper by Carney et al., shows the value in comparing the collected data with data from a medically valid sleep assessment such as polysomnography data. Even though it cannot be expected that a sleep diary can lead to similar conclusions as a polysomnography, it could still be insightful to compare subjective sleep quality with an objective sleep score. Therefore one of the next research steps is a clinical validation of the final version of the digital sleep diary in comparison to polysomnography data. This can also allow us to identify inconsequential or redundant questions and thus further narrow the core of the sleep diary questionnaire.

The results of the user experience tests show that the vast majority of participants prefer a digital sleep diary over a pen-and-paper format. However, the participants were comparatively young and some of them were even students of computer science. A certain bias towards digital artifacts is probably reflected in the results. Nevertheless, since the results were clearly in favour of the digital sleep diary, it can be concluded that the general tendency towards a preference of a digital sleep diary is still substantial. However, particularly among older participants, the sleep diary in analog format was sometimes preferred over a digital sleep diary. Moreover, it turned out to be a good decision to move from a web application to an app. Considering that the notifications were mentioned as well liked by a significant number of participants during the evaluation of the digital sleep diary, we want to highlight them as one of the key features of any digital symptom tracker. By utilizing a notification system to remind participants to fill out the digital sleep diary, we can influence them far better than with a pen-and-paper version. Notifications can be set up at individual times for each participant, thereby tending to different daily routines and minimizing the participants' workload. Most importantly though, a digital sleep diary provides options of restricting the times that the diary is filled out and makes it possible to log the exact date and time of a data entry, hence, accounting for memory bias,

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which is clearly shown in our results.

The low score that the mobile application achieved in the HQ-S category of the AttrakDiff (see Figure 4) stands out as the most negative aspect of this version of a digital sleep diary. It agrees with the feedback that we received from participants that filled out a pen-and-paper diary: more than 38% did not enjoy filling out the sleep diary (end-users who found filling out the diary "okay", "annoying", "pointless" or "boring"). Therefore, the digital sleep diary still has similar issues with user engagement as the pen-and-paper version. This can be explained with the fact that the sleep diaries, which the participants tested, functioned first and foremost as a clinical sleep assessment tool. The current design does not offer any additional value to the participants. However, the participants have shown interest in their data and augmenting the data visualization with actionable feedback could be a valuable addition to the mobile application. Based on our combined findings in this paper, we summarize our main contribution into five design guidelines for designing and developing a digital symptom trackers in general and for designing and developing digital sleep diaries in particular:

1. **Use the native environment:** It is important to use the advantages that come with a native app design. Native input control and notifications are clear advantages from the digital format. However, it is important to evaluate changes that are made to the original question setup to ensure that they do not affect the way a participant answers the questions.
2. **Utilize established input methods:** It is important to use native control elements instead of coming up with new input ways. Users have shown to be most comfortable with familiar input methods.
3. **Embed customization to minimize participant workload:** It is important to utilize customization and onboarding to omit questions that are not relevant to particular participants. Since feedback indicated that filling out the symptom tracker is not enjoyable enough for every participant, it is even more important to avoid any unnecessary questions.
4. **Evaluate the application continuously using analytics:** It is important to embed analytics to enable continuous design and development. Moreover, this type of data can be collected easily and does not require work from the participants.
5. **Integrate digital elements to increase compliance:** It is important to integrate gamification elements for the content and include more insightful data visualization, which would improve the entertainment value of the app since not all participants enjoyed filling out the diary. Some of them mentioned that notifications increased their motivation to fill out the symptom tracker.

## Conclusions

In this paper we show that the pen-and-paper version of the sleep diary has limitations and a digital sleep diary can enable closer monitoring of participant compliance and decrease memory bias. From our findings we derive five design guidelines for the design of digital symptom trackers in general and digital sleep diaries in particular. The five design guidelines are the following: i) use the native environment, ii) utilize established input methods, iii) embed customization to minimize participant workload, iv) evaluate the application continuously using analytics, and v) integrate digital elements to increase compliance. Moreover, we find that the key advantages of moving the sleep diary from a pen-and-paper format to a digital sleep diary stem from the ability to interact with the participants through notifications and custom application content. This is a valuable feature for increasing participant engagement which ultimately leads to more reliable data collection. We also show that the notifications have proven to be a useful and desirable element. Based on that, future work could include further examining and optimizing nudging and its effects on users. For example, testing different phrasing of notifications and how they effect user behaviour could be one way to improve compliance to a greater extent. Also, gamification elements could increase the attractiveness of tasks that are considered to be monotonous now. In addition to making the diary as accessible as possible, it is also important to make it fun for the end-users, to increase compliance.

## Acknowledgements

We thank Bergrós Pálmadóttir Morthens, and Birta Líf Baldursdóttir for their contributions. This research is a part of the Sleep Revolution project, with funding from the European Union's Horizon 2020 research and innovation program under grant agreement No. 965417. Senior author: Anna Sigridur Islind.

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## A.2 Paper 2



Article

## Evaluating User Compliance in Mobile Health Apps: Insights from a 90-Day Study Using a Digital Sleep Diary

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**Abstract:** Sleep diaries are the gold standard for subjective assessment of sleep variables in clinical practice. Digitization of sleep diaries is needed, as paper versions are prone to human error, memory bias, and difficulties monitoring compliance. **Methods:** 45 healthy eligible participants ( $M^{\text{age}} = 50.3$  years, range 23–74, 56% female) were asked to use a sleep diary mobile app for 90 consecutive days. Univariate and bivariate analysis was used for group comparison and linear regression for analyzing reporting trends and compliance over time. **Results:** Overall compliance was high in the first two study months but tended to decrease over time ( $p < 0.001$ ). Morning and evening diary entries were highly correlated ( $r = 0.932$ ,  $p < 0.001$ ) and participants significantly answered on average 4.1 days (95% CI [1.7, 6.6]) more often in the morning ( $M = 60.2$ ,  $sd = 22.1$ ) than evening ( $M = 56.1$ ,  $sd = 22.2$ ),  $p < 0.001$ . **Conclusion:** Using a daily diary assessment in a longitudinal sleep study with a sleep diary delivered through a mobile application was feasible, and compliance in this study was satisfactory.

**Keywords:** mobile sleep diary; digital health; sleep revolution; telemedicine; apnea–hypopnea index; compliance



**Citation:** Kristbergisdóttir, H.; Schmitz, L.; Arnardóttir, E.S.; Islind, A.S. Evaluating User Compliance in Mobile Health Apps: Insights from a 90-Day Study Using a Digital Sleep Diary. *Diagnostics* **2023**, *13*, 2883. <https://doi.org/10.3390/diagnostics13182883>

Academic Editor: Francesco Inchingolo

Received: 22 June 2023

Revised: 31 August 2023

Accepted: 6 September 2023

Published: 8 September 2023



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### 1. Introduction

Sleep is one of the fundamental pillars of good health. It impacts a range of physiological functions, such as the hormonal system, cardiovascular system, immune system and brain health [1]. Sleep disorders cause a major socioeconomic burden on healthcare systems worldwide, e.g., using the current diagnostic criteria, almost 1 billion people between the ages of 30 and 69 are affected by obstructive sleep apnea (OSA), the most common type of sleep-disordered breathing [2]. This manifests in billions of USD annually in lost productivity, cost of accidents, and other downstream health sequelae [3]. There is profound evidence that sleep disorders are associated with a range of physical health problems, such as diabetes, cardiovascular disease, obesity, and hypertension, that lead to increased mortality and morbidity rates [2,4–6]. Individuals with untreated sleep disorders are also at higher risk of deteriorating cognitive functioning that may impact occupational performance and social participation, thus compromising the quality of life and individuals' socioeconomic status [7–9]. Sleep disorders are strongly associated with cognitive decline, attention loss, memory impairment, issues with mood regulation, and mood disorders [8,10,11]. Therefore, sleep disorders are one of the leading health challenges today and a serious threat to public health if left undiagnosed and untreated.

Our understanding of sleep disorders and possible underlying mechanisms is challenging. We still face several limitations in sleep research, i.e., expensive and time-consuming diagnostic procedures, small and homogeneous sample sizes, lack of long-term studies on sleep disorders, and daily fluctuations in sleep [7,12,13]. Hence, while the impact of short-term and acute sleep deprivation has been well-documented, our understanding

of long-term sleep disorders with daily fluctuations in a naturalistic setting (i.e., home environment) needs to be clarified [7,14,15].

Although polysomnography (PSG) is considered the gold standard for sleep measurements, it is time-consuming and expensive. Moreover, it does not include subjective feedback from the patient, which can be pivotal for aspects like sleep hygiene and insomnia diagnosis. Additionally, PSGs require manual scoring, and the queues for studies tend to be lengthy and the overall resources are scarce. Continuous measurement for long-term studies of sleep in a naturalistic setting would be revolutionary [16]. Furthermore, a combination of subjective and objective measurements would be beneficial as both provide their own unique sleep features [17,18]. When it comes to subjective sleep measurements, sleep diaries and self-report measurements are more compatible with long-term and continuous measurements, where the long-term effect and compliance over time are studied [16]. Sleep questionnaires and sleep diaries outline the gold standard for subjective self-reported assessment of sleep variables in clinical practice. Sleep diaries are traditionally delivered on paper and have shown a high correlation with actigraphy measures on sleep onset and offset times, making them an essential support tool for diagnosing and treating sleep hygiene and insomnia [19,20]. However, although sleep diaries in pen-and-paper format are the conventional method for self-report sleep assessment, they are increasingly considered outdated and are prone to memory bias and difficulties in monitoring compliance [6,21–23]. Despite the rapid increase in digitization across different sectors, the consumer adoption of mobile apps and wearables, and their feasibility for delivering digital health solutions, there remain significant challenges in the design and development of digital health solutions for sleep, in particular in digital sleep diaries [16,24].

The adoption of digital health solutions and the rapid change towards more personalized and participatory healthcare is promising [25,26]. It enables more intensive and larger data collection than is possible with traditional data collection in sleep research. However, digitization of healthcare in general and for sleep, in particular, has been lagging significantly [7], although it is evident that digital health solutions outline an important factor for the future [26]. With the development of digital health solutions, there is great potential for longitudinal subjective assessment of sleep health, particularly the ability to monitor in real time and follow up continuously with subjects between more extensive examinations. Healthcare providers and researchers can be updated about key indicators of clinically significant changes such as the subjects' sleep and lifestyle habits, cognitive functioning, mood, and physical activity [25,27]. The benefits of digital health solutions include that they are cost-beneficial, improve accessibility, enable at-home monitoring for both clinical populations and the general population, and may provide new information in clinical evaluation and diagnostics that are currently not being captured [7,13,25,28]. For example, it is possible to measure symptoms more frequently and for longer periods by using digital health solutions for momentary assessments and, thus, to capture new domains of sleep that traditional in-laboratory assessments do not. A fundamental shift towards this new horizon of digital sleep health is imperative.

A mobile sleep diary has several benefits, including detailed real-time data on night-to-night variability in sleep and sleep habits [16,29]. A mobile sleep diary offers the possibility of reporting daily sleep measures close to the reported event, increasing data accuracy while minimizing the risk of recall bias [30]. Digital sleep diaries enable both patients and healthcare providers to evaluate their sleep measures and follow their progress in real time through informative data visualizations. However, the main concern and possible limitation of using sleep diaries (either on paper or digital), especially when used for a long consecutive period, is compliance [16,30]. Few studies have examined the usage of a digital sleep diary for prolonged periods (>7 nights) [13,31,32], and we found only one study, Thurman et al. [13], that investigated compliance specifically over a 16-week period. In that study, compliance decreased linearly over time.

The primary aim of this study was to examine the feasibility and provide a data-driven analysis of a longitudinal repeated mobile sleep diary assessment. Our mobile

app includes a sleep diary which was co-designed and developed as a part of the Sleep Revolution mobile application (app), based on the extended paper-and-pen Consensus Sleep Diary [21,24]. We examined the compliance in terms of reporting in the app for 90 consecutive days without any active intervention for a group of healthy sleepers and subjects with reported sleep problems. We hypothesized that compliance would decrease significantly over time according to a linear function. As a secondary exploratory aim, we examined individual differences in compliance across different types of sleep measures and demographic groups. We hypothesized that individuals with sleep apnea or insomnia were more likely to show higher levels of compliance and that compliance would not vary among different demographic groups. As a third exploratory aim, we examined if compliance would differ between weekdays and weekends, i.e., we hypothesized that individuals would be less compliant during weekends than on weekdays.

## 2. Materials and Methods

### 2.1. Study Participants

Fifty-nine participants were recruited by word of mouth and local advertisement in Iceland (within Reykjavik University, newspapers, radio, etc.) for this three-month pilot study. Inclusion criteria were that participants had to be of age 18 or older, own a smartphone and be willing to download the Sleep Revolution app, and not shift workers. Participants were asked to (i) complete an online questionnaire on background information and self-report sleep and lifestyle measures, (ii) complete a three-night self-applied polysomnography, and (iii) complete a sleep diary twice a day. A total of 45 participants (mean age = 50.3 years, range 23–74, 25 females, 20 Males) completed all three tasks and were included in the analysis. Those not included dropped out of the study at the beginning and did not complete the questionnaires or the three-night self-applied polysomnography. Participants were not paid or compensated in any form for their study participation.

### 2.2. Design and Procedure

Prior to participation in the main sleep study, participants completed questionnaires on demographics, lifestyle, and self-reported sleep measures as well as screening lists. Participants were then subjected to a three-night self-applied polysomnography and asked to keep a daily sleep diary in the Sleep Revolution app. Automated reminders were sent to participants to enhance compliance on a regular basis. Participants were only allowed to answer on the current day to ensure they reported their real-time experience. Participants signed an informed consent prior to their participation and the study was approved by the Icelandic National Bioethics Committee (ref. no. 21-070).

### 2.3. Measures

#### 2.3.1. Sleep Diary

The app was co-designed and developed through extensive user engagement within the Sleep Revolution project. The co-design approach outlines a novel way of approaching the design, as we have elicited the needs of the participants iteratively throughout the design process [33,34]. The design matured through multiple iterations and eventually, the app was ready for inclusion of participants. The results of this study outline the first cohort using the app in a longitudinal manner. In this study, the participants were instructed to complete the sleep diary twice a day for 90 consecutive days in an app developed by the Sleep Revolution [7,24]. The sleep diary in the mobile app is adapted from the Consensus Sleep Diary [21] and collects a subjective evaluation of sleep measures. In addition, the Sleep Revolution sleep diary also gathers information on lifestyle factors that might impact their sleep, i.e., mood and stress levels, number of naps, number of caffeine and alcohol units consumed, and duration of exercise conducted that day.

### 2.3.2. Three-Night Self-Applied Polysomnography

A self-applied polysomnography [35–37] was used at baseline over three consecutive nights and the apnea–hypopnea index (AHI) was derived. AHI was defined as the number of respiratory events (apneas or hypopneas) per hour of sleep. For adult subjects, AHI is traditionally classified as normal (AHI < 5/h), mild (AHI between 5 and 14.9 events per hour), moderate (AHI between 15 and 29.9/h), and severe (AHI  $\geq$  30/h). Due to this study's relatively small sample size, an AHI score of  $\geq$ 15 was considered the threshold criteria for having OSA for covariate analysis [14].

The recordings were annotated by expert sleep technologists in accordance with the AASM manual, version 2.6 [38]. To do this, the Noxturnal version 6.2.2 software (Nox Medical, Reykjavik, Iceland) was used. The N3 scoring rules were updated for the self-applied setup in accordance with Kainulainen et al. [36] and the recommended AASM rules for hypopnea scoring were used.

### 2.3.3. Insomnia Severity Index (ISI)

The ISI is a 7-item self-report instrument designed to assess the severity of both nighttime and daytime components of insomnia. The recall period typically consists of the most recent month. The tool evaluates the severity of sleep onset, sleep maintenance, and early morning awakening problems, sleep dissatisfaction, interference of sleep difficulties with daytime functioning, noticeability of sleep problems by others, and distress caused by the sleep difficulties. Each of these items is rated on a 5-point Likert scale (e.g., 0 = no problem; 4 = very severe problem), with a total score ranging from 0 to 28. The interpretation for the total score is as follows: absence of insomnia (0–7); sub-threshold insomnia (8–14); moderate insomnia (15–21); and severe insomnia (22–28). In this study, a cut-off of  $\geq$ 15 was used to indicate a significant risk of insomnia. The ISI is available in three versions—a version each for patients, clinicians, and significant others—but this paper focuses on the patient version only [39].

### 2.3.4. Epworth Sleepiness Scale (ESS)

The ESS is an 8-item self-report instrument that assesses the likelihood of dozing or falling asleep in common situations of daily living. A total score is calculated and ranges from 0 to 24, where higher scores indicate a higher likelihood of dozing or falling asleep and scores of >10 indicate a significant risk of excessive sleepiness [40].

### 2.3.5. Depression Anxiety and Stress Scale 21 (DASS-21)

The DASS-21 is a 21-item self-report instrument designed to measure the negative emotional states of depression, anxiety, and stress. Each subscale includes 14 items with the following cut-off scores as positive indicators for symptoms of depression ( $\geq$ 10), anxiety ( $\geq$ 8), and stress ( $\geq$ 15) [41].

### 2.3.6. Covariates

Based on previous research, the following covariates that may relate to sleep and compliance were included in the analysis: age (years), sex (female/male), education (high/low), employment status (working/not working), weekly exercise (count), marital status of married or cohabitating (yes/no).

## 2.4. Statistical Analytics

Statistics were calculated using IBM SPSS Statistics 28 and Python. Background data are presented descriptively, categorical data by frequencies (n) and proportions (%) and continuous data with means and standard deviations (S.D.s). The perceived total sleep time refers to the answer to the question “In total, how long did you sleep?”. Participants had the option to have this value automatically calculated from the answers to the questions “What time did you try to go to sleep?”, “How long did it take you to fall asleep?”, “In total, how long did these awakenings last?”, and “What time was your final awakening?”.

The result of the calculated value is referred to as the estimated total sleep time. To compare the mean count of morning and evening diary entries, a paired sample T-test was applied and multiple linear regression was used to examine individual differences in morning and evening diary entries by demographics, sleep measures, and relevant lifestyle factors. To account for multiple comparisons, the Bonferroni correction test was used and the significance level was adjusted ( $p$ -value of  $0.05/2 = 0.025$ ). Simple linear regression was used to explore linear trends in morning and evening diary entries over time. The resulting linear regression estimate ( $\beta$ ) can be interpreted as the average percentage point change in compliance per day.

### 3. Results

#### 3.1. Descriptive Statistics

Table 1 shows the descriptive sociodemographic profile of participants in the study.

**Table 1.** Measurements in morning and evening sleep diary app.

Variable	Total (N = 45) M $\pm$ SD <sup>1</sup> %
<b>Demographics and lifestyle</b>	
Age, M (SD)	50.3 $\pm$ 11.7
Sex, Female	55.6
Education, high	66.7
Work status, employed	66.7
Marital status, married/cohabitating	91.1
Weekly exercise, M (SD)	2.8 $\pm$ 2.00
<b>Sleep measures</b>	
AHI ( $\geq 15$ events per hour) <sup>2</sup>	26.2
ISI score ( $\geq 15$ ) <sup>3</sup>	31.1
ESS score ( $> 10$ ) <sup>4</sup>	42.2
<b>Mental health (DASS-21) <sup>5</sup></b>	
Depression score ( $\geq 10$ )	20.5
Anxiety score ( $\geq 8$ )	13.6
Stress score ( $\geq 15$ )	20.5

<sup>1</sup> Mean and standard deviation, <sup>2</sup> Apnea-hypopnea index, <sup>3</sup> Insomnia Severity Index, <sup>4</sup> Epworth Sleepiness Scale  
<sup>5</sup> The Depression, Anxiety and Stress Scale—21 Items.

#### 3.2. Overall Compliance

Overall compliance was high over the study period. Participants answered a total of 2711 times out of the 4049 possible morning diary entries (67%) and 2525 times out of the 4050 possible evening diary entries (62%). Simple linear regression revealed a significant linear trend of compliance tending to decrease over time for both mornings ( $b = -0.675$ ,  $t = -8.581$ ,  $p < 0.001$ ,  $R^2 = 0.456$ ) and evenings ( $b = -0.745$ ,  $t = -10.464$ ,  $p < 0.001$ ,  $R^2 = 0.554$ ).

Compliance was high at the beginning of the study and stayed considerably stable through the first two months of the study. At the beginning of the study, compliance was 98% for the morning diary and 78% for the evening diary. In the first month, average compliance was high, at 80% (morning) and 67% (evening), and then slightly dropped between the first and second months, to 70% (morning) and 60% (evening). During the last month, compliance started to decline and dropped to 31% (morning) and 26% (evening) in the last days of the study (see Figure 1). Figures 2 and 3 provide a visual presentation of compliance by each participant for the morning (see Figure 2) and evening (see Figure 3) sleep diaries.

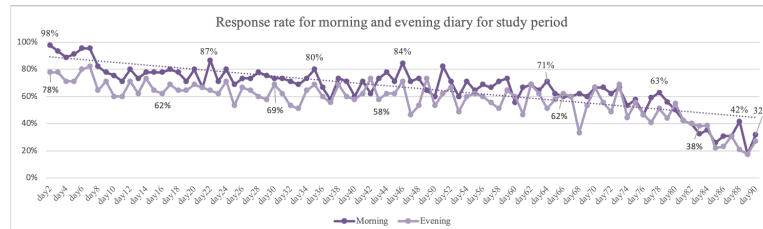


Figure 1. Daily compliance for morning and evening diaries for the study period.

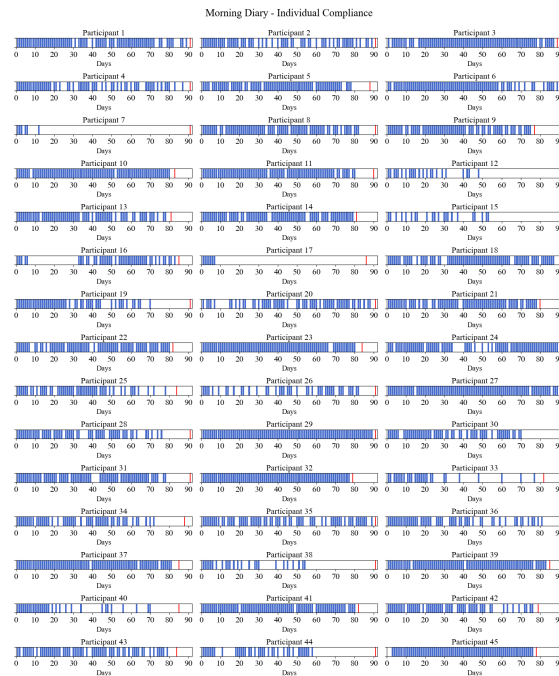
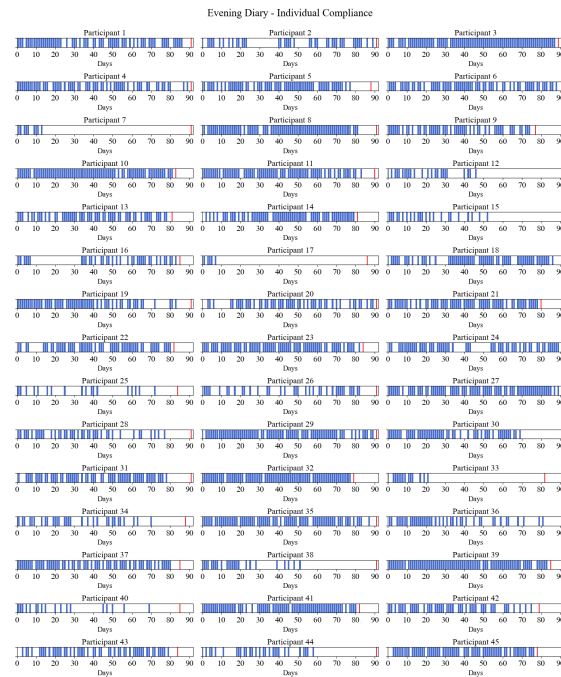


Figure 2. Visual presentation of individual compliance for the morning sleep diary. The blue bar marks the days the participants filled out the sleep diary. The red bar marks the end of the individual participant’s study period.

Morning and evening diary entries were highly correlated ( $r = 0.93, p < 0.001$ ), and results from paired sample t-test show a significant average difference ( $t = 3.38, df = 44, p < 0.002$ ). On average, participants answered 4.1 (95% CI [1.7, 6.6]) days more often in the morning ( $M = 60.2, sd = 22.1$ ) than in the evening ( $M = 56.1, sd = 22.2$ ).



**Figure 3.** Visual presentation of individual compliance for the evening sleep diary. The blue bar marks the days the participants filled out the sleep diary. The red bar marks the end of the individual participant's study period.

### 3.2.1. Compliance by Individual Differences

We examined compliance for the morning and evening diaries by individual differences with simple linear regression, i.e., demographic profile, sleep measures, and mental health. For demographics, objective and subjective sleep measures, and symptoms of depression, anxiety, and stress, a significant mean difference in compliance was not found (see Table 2).

Table 2. Simple linear regression results for morning and evening diary entries.

Variables	Morning Diary Entries					Evening Diary Entries						
	R <sup>2</sup>	Un-Standardized Coefficients		Standardized Coefficients	t	p	R <sup>2</sup>	Un-Standardized Coefficients		Standardized Coefficients	t	p
		B	SE	Beta ( $\beta$ )				B	SE	Beta ( $\beta$ )		
<b>Demographics</b>												
Age	0.087	0.594	0.298	0.294	1.995	0.053	0.097	0.630	0.297	0.311	2.118	0.040
Sex, female	0.016	5.570	6.645	0.127	0.838	0.497	0.041	8.930	6.594	0.202	1.354	0.183
Marital status, cohabitating	0.000	1.640	11.695	0.021	5.263	0.889	0.000	1.220	11.756	0.016	0.104	0.918
Education, higher	0.023	-7.033	6.980	-0.152	-1.008	0.319	0.020	-6.633	7.025	-0.143	-0.944	0.350
Working	0.007	-3.767	7.038	-0.081	-0.535	0.595	0.008	-4.067	7.071	-0.087	-0.575	0.568
Weekly exercises	0.008	4.499	7.851	0.090	0.573	0.570	0.016	-1.399	1.679	-0.126	-0.833	0.409
<b>Sleep Measures</b>												
AHI ( $\geq 15$ ) <sup>1</sup>	0.011	-1.175	1.675	-0.106	-0.702	0.487	0.003	2.924	7.953	0.058	0.368	0.715
ISI ( $\geq 15$ ) <sup>2</sup>	0.006	-3.776	7.167	-0.080	-0.527	0.601	0.024	-7.316	7.141	-0.154	-1.024	0.311
ESS ( $\geq 10$ ) <sup>3</sup>	0.009	4.223	6.709	0.096	0.629	0.532	0.002	2.176	6.766	0.49	0.322	0.749
<b>Mental Health (DASS-21<sup>4</sup>)</b>												
Depression ( $\geq 10$ )	0.031	-9.492	8.228	-0.175	-1.154	0.255	0.059	-13.175	8.132	-0.242	-1.620	0.113
Anxiety ( $\geq 8$ )	0.007	-5.333	9.789	-0.084	-0.545	0.589	0.022	-9.368	9.446	-0.147	-0.961	0.342
Stress ( $\geq 15$ )	0.006	4.337	8.331	0.080	0.521	0.605	0.000	0.095	8.382	0.002	0.011	0.991

<sup>1</sup> Apnea-hypopnea index, <sup>2</sup> Insomnia severity index, <sup>3</sup> Epworth sleepiness scale, <sup>4</sup> The Depression, Anxiety and Stress Scale—21 Items.

### 3.2.2. Compliance on Weekdays and Weekend Days

We compared the overall compliance for weekdays and weekend days for the morning and evening diaries. Table 3 shows the average compliance rate for all participants during the study period consisting of 2892 weekdays and 1158 weekend days. The compliance rates show no significant difference between weekdays and weekends for the morning and evening diaries.

**Table 3.** The average compliance rate for the morning and evening diaries on weekends and weekdays.

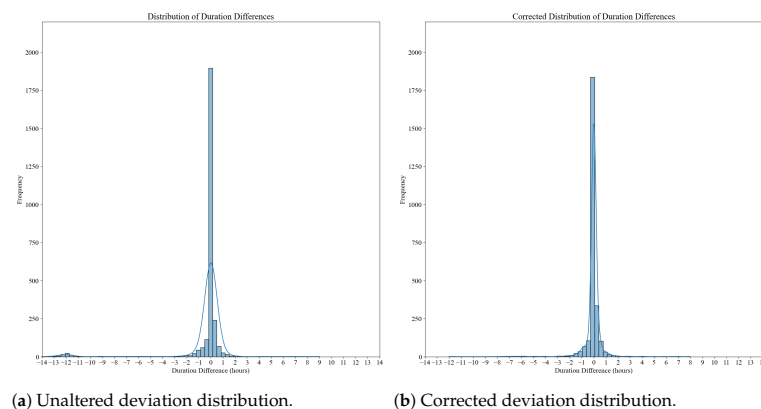
	Weekday Compliance (%) ( <i>n</i> = 2892)	Weekend Compliance (%) ( <i>n</i> = 1158)	<i>p</i> -Value
Morning diary	64.4	66.3	0.25
Evening diary	56.8	55.7	0.52

### 3.3. Total Sleep Time

The morning diary collects various data points regarding the participants' sleep the previous night. We evaluated the gathered data and found discrepancies regarding bedtimes and the corresponding total sleep time. The implementation of the application allowed participants to enter what time they went to sleep and when they woke up in an am/pm format. A button to estimate the total sleep time based on the previously entered data was provided to the participants in the app view for entering the total sleep time.

We examined the deviation of the participants' perceived total sleep time deviation from the estimated total sleep time. The data distribution is symmetrical around the mean, with most perceived total sleep time entries showing no deviation from the estimated total sleep time. However, a smaller second bell curve can be found around the  $-12$  h deviation mark. A possible explanation for this observation could be that incorrect time entries cause this deviation due to the am/pm format they were entered in.

Therefore, we also examined the distribution after correcting for the outliers. We corrected the data by adding 12 h to those deviation data points that show a negative correction greater than 8 h and subtracting 12 h from those that show a positive correction greater than 8 h. This eliminates the majority of outliers and results in a bell curve with fewer outliers, as can be seen in Figure 4.



**Figure 4.** Histograms of the unaltered and corrected deviation distributions of the perceived total sleep time from the estimated total sleep time.

The data (see Figure 4) show that over 90% of the total sleep time entries did not deviate more than an hour from the estimated duration.

#### 4. Discussion

The current study examined the feasibility of using a sleep diary in an app for 90 consecutive days and individual differences in sustaining compliance. To our knowledge, a study of this magnitude has not been performed previously, and our findings provide a novel addition to the existing literature on digital measures in sleep research.

Our main findings showed high compliance rates, especially for the first two months of the study (98–62%), and that the digital sleep diary was accessible to all, regardless of demographic profile, possible sleep problems, or symptoms of depression, anxiety, and stress. However, compliance did significantly decline over time, as expected. At the beginning of the study, approximately 98% of study participants completed their morning sleep diary entries, and 78% completed their evening diary entries. By the end of the study, 52–46% of participants remained compliant. For the last days of the study, compliance rates dropped to 26–31%, indicating participants experienced a higher respondent burden. The decrease in compliance could be attributed to participants' fatigue or a lack of motivation to continue reporting over an extended period. Another explanation could be that participants were asked to attend a final interview at the end of the study and were able to choose a date that fit them well. Some participants chose a date before they had finished their 90 days and likely stopped using the app after the interview. This is a limitation to the study and the interpretation of compliance, as only 50% of the total sample used the app for the 90-day study period. As there was no special endpoint or treatment being monitored in the study, this could have affected compliance. Nevertheless, we find the results interesting and novel despite this limitation as, to our knowledge, findings on compliance in a digital sleep diary for a three-month study period have not been reported.

Despite the immense knowledge of short-term and acute sleep problems and their effects on physical and mental health [2,42], previously, studies have not focused on daily fluctuations in sleep in a naturalistic setting for prolonged periods of time [13,15], e.g., in a recent systematic review of the relationship between daily sleep and mood, results show that the majority of studies lend support to a short-term dynamic association between sleep and daily mood, but studies of the long-term effects are few and still remain to be fully investigated [43].

Studies using a digital sleep diary have mostly reported findings on compliance for up to 14 days [30]. One study conducted by Thurman et al. [13] that examined compliance in using a digital sleep diary for 16 consecutive weeks showed compliance significantly decreased with time, consistent with our findings. While our sleep diary was designed with the goal of fostering engagement through notification reminders and data visualizations, additional measures should be taken to ensure high compliance for longer time periods. The app version that was used during the study period lacked actionable feedback, but another study in the Sleep Revolution is currently ongoing and investigates participant compliance and habit change through the use of goals as part of the gamification of the digital sleep diary. Studies have shown that the reliability of data collected by sleep diaries increases with the number of days used and is therefore important to support participants' motivation in answering the sleep diary for prolonged periods [31,32,44].

Our findings also revealed a high correlation of compliance between morning and evening diary entries, indicating consistency in participants' reporting. However, participants answered the morning diary more frequently than the evening diary, despite the presence of notification reminders in the app for both morning and evening diaries. This disparity may be attributed to the circumstance that the morning reminders were received at a more convenient time. It is conceivable that participants were more likely to be at home in the morning and, thus, had easier access to the diary, while in the evening, they might have been occupied by various activities. To our knowledge, such findings of a correlation

between compliance in the morning and evening entries of a digital sleep diary have not been reported elsewhere.

Interestingly our findings also revealed that compliance on weekdays and weekends showed no significant differences for either morning or evening diaries, suggesting that participants maintained consistent reporting habits regardless of the day of the week. The expectation was that compliance would decrease during the weekend, as people's schedules tend to be more irregular on those days than they are during weekdays. A possible explanation for the consistent compliance is the notification reminders that helped people to remember to fill in the diary during weekdays and weekends alike. Our findings suggest that a digital sleep diary supports data reliability. Previous studies have mainly focused on the accuracy of data collection between weekdays and weekends, suggesting a need for a minimum of 7–10 days of entries in order to obtain reliable data, especially on weekends [31,32]. However, findings on the difference in compliance during weekdays and weekends have not been reported elsewhere to our knowledge.

Lastly, our findings revealed discrepancies between participants' perceived total sleep time and the estimated total sleep time. The distribution of the deviation showed a symmetrical curve, indicating that most participants accurately estimated their total sleep time. However, a smaller portion of participants showed significant deviations, likely due to errors in entering sleep and wake times or confusion related to the am/pm format, which is generally not used in Iceland. Correcting for these outliers resulted in a more normalized distribution, suggesting that providing clearer instructions or formats for time entry could improve accuracy in estimating total sleep time.

#### *Strengths and Limitations*

The study has several strengths, including addressing gaps in the literature on digital solutions for sleep research. To our knowledge, this is the first study that investigates participant compliance with a sleep diary app in an intensive longitudinal setting. The results highlight the potential of digital health solutions in improving longitudinal sleep assessment and indicate that a digital sleep diary can foster compliance and, thus, overcome the limitations and drawbacks associated with the traditional pen-and-paper format [6,21–23]. The study emphasizes that the integration of longitudinal subjective measurements in digital health solutions opens up new possibilities for capturing comprehensive sleep information and contributing to meaningful changes in daily habits, mood, and overall well-being [8,10,11,16].

Furthermore, the study has addressed the lack of long-term studies in naturalistic settings [7,12,13,16] by evaluating digital solutions. By providing more accessible and cost-effective methods of sleep assessment, digital health solutions have the potential to mitigate the socioeconomic burden of sleep disorders on healthcare systems and improve overall public health outcomes [2–5].

Overall, the findings from this study provide valuable insights into compliance and sleep patterns among participants using a morning and evening sleep diary app. However, there are limitations to consider. First, the sample size in this study was relatively small, and our findings need to be interpreted with caution, as generalizability in such samples is limited. Future studies with larger and more diverse participant samples could provide a more comprehensive understanding of compliance and sleep duration patterns. Second, compliance in the study dramatically decreased in the last days of the study period, which could impact the reliability of the data. The fact that some participants attended a final interview before they had finished the study might explain the dramatic drop in compliance in the last 10 days of the study. In future studies within an intensive longitudinal setting, it might be beneficial to provide more frequent reminders and positive feedback to participants to promote their participation and promote the quality of data received. In addition, a final interview should occur only after participants have finished the study to ensure compliance throughout the study period. Lastly, the accuracy and quality of data collected in a sleep diary mobile application need further testing. In our study, a small

portion of participants showed significant deviations when entering sleep and wake times. This is likely due to the format being am/pm, but further testing on the reliability of the data being collected overall in a mobile application would be beneficial.

## 5. Conclusions

By providing more accessible and cost-effective methods of sleep assessment, digital health solutions have the potential to mitigate the socioeconomic burden of sleep disorders on healthcare systems and improve overall public health outcomes [2–5]. Thus, the findings from this study provide valuable insights into compliance and sleep duration patterns among participants using a morning and evening sleep diary app.

In conclusion, this study has demonstrated the potential of digital sleep diaries in revolutionizing sleep assessment and management. The integration of subjective measurements in an app holds promise for enhancing diagnostic procedures, designing targeted interventions, and ultimately improving the quality of life for individuals affected by sleep disorders. Ergo, using daily diary assessment in a longitudinal sleep study with a sleep diary delivered through an app is feasible, and compliance in this study showed to be satisfactory. Moreover, this paper contributes a compliance assessment of the novel sleep diary delivered through a mobile application. The results show that the app holds high potential both for the future of data collection in sleep medicine and clinical assessment.

**Author Contributions:** Conceptualization, A.S.I. and E.S.A.; methodology, A.S.I. and E.S.A.; software design, L.S. and A.S.I.; validation, H.K.; formal analysis, H.K. and L.S.; investigation, H.K. and L.S.; resources, H.K. and L.S.; data curation, H.K. and L.S.; writing—original draft preparation, H.K. and L.S.; writing—review and editing, A.S.I. and E.S.A.; visualization, H.K. and L.S.; supervision, A.S.I. and E.S.A.; project administration, A.S.I. and E.S.A.; funding acquisition, A.S.I. and E.S.A. All authors have read and agreed to the published version of the manuscript.

**Funding:** This study was funded by the European Union’s Horizon 2020 Research and Innovation Programme under Grant 965417.

**Institutional Review Board Statement:** This study was granted ethical approval by the National Bioethics Committee of Iceland (under the reference number VSN-21-070) and each participant of the study has signed an informed consent.

**Informed Consent Statement:** Informed consent was obtained from all subjects involved in the study. Written informed consent has been obtained from the patient(s) to publish this paper.

**Data Availability Statement:** The data analyzed for the purpose of this paper are not publicly available due to privacy and ethical restrictions.

**Acknowledgments:** This work is part of the Sleep Revolution project, supported by the European Union’s Horizon 2020 Research and Innovation Programme under Grant 965417. We would like to thank the participants in the study wholeheartedly for their invaluable contributions to science.

**Conflicts of Interest:** Erna S. Arnardottir discloses lecture fees from Nox Medical, Philips, ResMed, Vistor, Apnimed, Jazz Pharmaceuticals, Linde Healthcare, Alcoa Fjardaral, and Wink Sleep. Erna S. Arnardottir is also a member of the Philips Sleep Medicine and Innovation Medical Advisory Board.

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## A.3 Paper 3

## NUDGING WITH DIGNITY: A CRITICAL EXAMINATION OF WHEN AND HOW TO USE DIGITAL NUDGING

*Research paper*

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### **Abstract**

*Digital nudging has become an important research topic for information systems researchers to explore. In general, digital nudging is seen as a positive form of engagement while few study the impact of digital nudging in a critical manner. This paper examines people's responses to dignity affronts of digital nudging. Dignity affronts outline an offense to one's dignity or self-respect. In this paper, we rely on CARE theory, which posits that people tend to respond negatively to dignity affronts, to analyze 42 semi-structured interviews with participants in a three-month data collection that involved a mobile application with daily digital nudges. Our findings reveal various affront responses to digital nudges in the form of forfeit, flight, and fight responses. Importantly, our paper shows that a digital nudge can become a dark pattern under certain circumstances, even if it is responsibly designed. This paper provides an in-depth analysis and offers a three-fold contribution: i) a theoretical contribution through the conceptualization of digital nudging, ii) nuanced empirical insights into when digital nudging can be helpful versus harmful, and iii) practical implications through design guidelines to mitigate potential dignity affronts.*

*Keywords: Digital Nudging, CARE theory, User dignity, Design guidelines, Dignity affronts.*

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## 1 Introduction

As humans, we face choices every day. The choice architecture, ergo, the way each choice is presented, is neither neutral nor without a target (Weinmann, Schneider, and Brocke, 2016). Since the way choices are presented outlines a targeted pathway, the design of the choice architecture becomes a central element of the current discourse within the field of information systems (IS). Digital nudging encompasses subtle interventions or cues laid out within the choice architecture with the aim of influencing peoples' decision-making process (Weinmann, Schneider, and Brocke, 2016). Essentially, it is the digital equivalent of nudging in the physical world. The concept of nudging was introduced in Thaler and Sunstein's (2009) seminal work, which sparked a discourse on the acceptability of this practice. Initially, the focus of this discourse was on nudging in the analog world, but it has since been extended to digital nudging (Willermark and Isind, 2022). In particular, when it comes to digital nudging, it is important to consider the design and use of nudges carefully (Mirsch, Lehrer, and Jung, 2018). With most people being constantly connected to the digital environment through their smartphones (Stieglitz et al., 2023), escaping or avoiding nudges becomes more difficult in the digital realm than in physical environments.

The discussion around the acceptability of digital nudging has given rise to contrasting perspectives on how to minimize the adverse effects of the nudge on the person being nudged, also known as the nudgee. Nudging, in general, can be harmful if it exploits the nudgee's vulnerabilities and biases, forcing them to make decisions that are not in their best interest (Sunstein, 2015; Thaler and Sunstein, 2009). Some stipulate that the harm can be avoided if the nudge is designed with the well-being of the nudgee in mind (Thaler and Sunstein, 2009), while others argue that following this recommendation is necessary to preserve the nudgee's autonomy but not sufficient (e.g., Rebonato, 2014). In order to ensure that nudgee's autonomy is preserved, it has been suggested that the nudge's transparency needs to be ensured (Sunstein, 2016). Additionally, researchers have also advised that the nudgee should be in favor of the nudge's intention (Clavien, 2018; Hummel and Maedche, 2019). In short, the acceptability of a nudge varies across the literature but ties closely to the nudgee and their reception of the nudge for enhancing the nudgee's life, respecting the nudgee's desired way of life, or upholding the nudgee's autonomy (Costello, Yun, and K. C. Lee, 2022; Kollmer and Eckhardt, 2023). Across the literature, there is a common stance: the importance of value alignment between the nudge itself and the nudgee.

The inherent discourse on when it is acceptable to utilize digital nudges remains an unanswered question in the literature. Nevertheless, the literature indicates a nuanced and evolving discussion on the acceptability of nudging, highlighting the importance of understanding the impacts on individuals being nudged (e.g., Meske and Amojó, 2020; Renaud and V. Zimmermann, 2018; Veretilnykova and Dogruel, 2021). This focus suggests a commitment to respecting and enhancing individual agency in the context of digital nudging interventions. This is particularly important since there is a growing concern about the impact of digital environments on individuals (Demetis and A. S. Lee, 2018). As Leidner and Tona (2021, p. 4) aptly phrased it in their work, there is a risk of individuals "becoming artifacts of technology production," which poses a serious threat to personal agency. Digital nudges, as part of digital environments, contribute to this threat. Hence, it is essential to consider the role of digital nudge design in promoting human dignity. Human dignity can be defined in various ways, but it generally refers to the inherent value and worth that all individuals possess and that they should be treated with respect.

To address concerns around human dignity, Leidner and Tona proposed the CARE (claims, affronts, responses, equilibrium) theory. This theory emphasizes the importance of respecting individuals' autonomy and agency and provides a framework that can potentially guide the responsible design and use of digital nudging (ibid). In this paper, we apply the CARE theory to identify dignity affronts by digital nudges and unravel the potentials and pitfalls that digital nudges can infer. We do so to inform future research and potentially identify ways to design digital nudges that minimize the negative impact on nudgees. Thus, we can utilize the potential benefits of digital nudging in a responsible manner that aims to preserve the dignity of users, what we call *digital nudging with dignity*. To guide our research, we formulated the

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following questions:

- *RQ1: To what extent does digital nudging impact users dignity?*
- *RQ2: How can digital nudges be designed to consider the potential dignity affronts?*

Our paper is based on 42 semi-structured interviews conducted after our participants had been asked to use a mobile application (hereinafter also simply called app) where digital nudges were systematically used through the three-month period to foster user compliance and engagement. Our interviews were conducted after three months of use and focused on the experience of digital nudging and delved into the core of the user's responses to digital nudges incorporated in the app. Our analysis of the interviews led us to present a three-fold main contribution to the existing literature on the harm-avoiding design of digital nudges. Firstly, we provide theoretical contributions through the conceptualization of digital nudging with dignity through the lens of CARE theory. Secondly, we provide empirical insights into when digital nudging can be helpful as opposed to harmful. Thirdly, we provide practical implications through design guidelines that can be used by designers and developers of digital nudges to consider in order to mitigate potential dignity affronts.

## 2 Related Work

Nudging refers to the practice of subtly influencing an individual's decision-making process through deliberate alterations in their choice architecture (Thaler and Sunstein, 2009; Thaler, Sunstein, and Balz, 2013). *Choice architecture* refers to the arrangement of available choices, which has been shown to significantly impact an individual's decision-making (Thaler and Sunstein, 2009). The choice architect, or nudger, can deliberately modify the choice arrangement to influence an individual's decisions by leveraging cognitive biases and heuristics (Kahneman, 2011; Thaler and Sunstein, 2009; S. Zimmermann et al., 2021).

Digital nudging is a concept that draws on traditional principles of nudging to influence behavior in the digital world (Weinmann, Schneider, and Brocke, 2016). By employing subtle interface design, interaction, and information, digital nudging aims to guide user behavior on digital platforms (Caraban et al., 2019; Meske and Potthoff, 2017; Weinmann, Schneider, and Brocke, 2016). Thus, the digital environment becomes part of the choice architecture, opening novel avenues for nudging research within IS (Mirisch, Lehrer, and Jung, 2017). IS researchers have recognized that the digital environment has unique properties and that not all findings about nudging in the physical world can be seamlessly transferred to digital contexts (Mirisch, Lehrer, and Jung, 2017). This has resulted in a growing interest in studying digital nudging per se. Digital nudging allows for more personalized and on-demand nudges to influence behavior compared to nudges presented within the analog world (Lembcke et al., 2019). While the integration of nudges in digital environments is relatively low-cost and offers a high degree of freedom in designing them, there is a risk that nudge designers may overuse them (Schneider, Weinmann, and Vom Brocke, 2018). As digital nudges have proven to be effective in promoting healthier habits and achieving other pro-social goals (Caraban et al., 2019), responsible nudge design has become an important topic of discussion in IS research. Lembcke et al. (2019) linked ethical considerations from the nudging literature with knowledge about digital nudging, presenting a starting point and call for papers contributing to that type of discourse in IS research. Our paper contributes to that discourse.

Parallel to the discourse on digital nudging is the discourse on dark patterns. Dark patterns are harmful digital nudges that influence an individual's behavior in a manner that conflicts with their personal values and beliefs (Fansher, Chivukula, and Gray, 2018; Kollmer and Eckhardt, 2023; Mathur, Acar, et al., 2019). However, dark patterns do not have a singular definition (Mathur, Kshirsagar, and Mayer, 2021). In their review, Mathur, Kshirsagar, and Mayer found that definitions of dark patterns include elements of misleading design elements (e.g., Bösch et al., 2016), subversion of user expectations (e.g., Waldman, 2020), exploitation of users and harm to users (e.g., Zagal, Björk, and Lewis, 2013). As dark

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patterns generally lead to aversive outcomes for the nudgee, they violate the principle of libertarian paternalism (Thaler and Sunstein, 2009). Libertarian paternalism amounts to employing nudges that are in the nudgee's own best interests as long as it preserves the choice selection in the environment (Laugier, 2023). However, the design of acceptable nudges following the principles of libertarian paternalism is not without controversy, as has been illustrated in the scientific community. More specifically, critics of libertarian paternalism argue that this design approach still restricts the nudgee's autonomy (Lembcke et al., 2019; Rebonato, 2014; Whitman and Rizzo, 2015) and that it should, therefore, be reconsidered.

Researchers have recognized this issue and have explored ethical considerations from the nudgee's point of view, focusing on the nudged individual rather than the nudgee's intentions (e.g., (Gestel, 2021; Hagman et al., 2015; Al-Natour and Benbasat, 2009)). For example, Sunstein (2016) advocates for transparency of nudges. Nudges influence the responses to the choice environment by triggering one of two decision-making processes (Kahneman, 2011; Konstantinou, Panos, and Karapanos, 2024). The model separates human decision-making into intuitive system one responses and calculated system two responses. Nudges can belong to either system one or system two depending on their evoking response processes (Hansen and Jespersen, 2013). Sunstein recommends the usage of system two over system one nudges, as they target a deliberative decision-making process rather than an intuitive one to increase awareness of the nudgee being nudged. By raising the nudgee's awareness of the nudge, they increase the likelihood of rejecting nudges that go against their preferences. Clavien (2018) took a different perspective and stated that a nudge should be acceptable as long as it seeks to attain a beneficial outcome consistent with the personal values of the nudgee. Combining those positions, the optimal nudge would consequently be designed so that the nudgee has no objections to being nudged, that the nudgee's autonomy is preserved and that the nudge is sufficiently transparent (Lembcke et al., 2019). Moreover, recent recommendations for empowering digital nudge design is to present information in an engaging way, for example, with feedback and data visualization (Mettler and Stepanovic, 2023). If nudges violate any of these design recommendations, they can cause aversive emotions in the form of frustration (Costello, Yun, and K. C. Lee, 2022; M. Bhoot, A. Shinde, and P. Mishra, 2020), which can lead to responses such as workarounds, avoidance or piggybacking (Canhoto and Arp, 2017; Ferneley and Sobrepez, 2006; Mettler and Wulf, 2020).

While these design recommendations of transparency and autonomy preservation emphasize the importance of the nudgee's perception of the nudge, they still overlook the complexity of designing digital nudges that align with personal preferences. Previous research has shown that the response to a nudge depends on the individual (Gestel, 2021; Hagman et al., 2015; Al-Natour and Benbasat, 2009). It is, therefore, crucial to further examine the individual factors that contribute to aversive responses to nudges. In particular, there is a gap in the research on digital nudges related to their potential harmfulness to vulnerable populations, such as those with limited digital literacy or cognitive impairments. Therefore, more research is needed to evaluate the impact of nudges on user dignity and inform the design of digital nudges that avoid harming user dignity.

This brings us to the CARE theory that was presented in a paper by Leidner and Tona in 2021 and focuses on the role of human dignity in the digitalization of personal data. The authors discuss three distinct conceptualizations of dignity in their paper: inherent dignity, which is an innate quality of human beings; dignity as status, which centers on the societal treatment and respect for individuals; and dignity as character or bearing, which entails living a virtuous life and to behave well. Building upon these frameworks, our understanding of human dignity is based on one's capacity for reasoning and ability to make moral decisions autonomously while being respected as an individual with inherent self-worth. In line with this understanding, an affront to human dignity can be any act or condition that undermines an individual's inherent dignity, fails to recognize their worth within society, or impairs their ability to exercise rationality and moral autonomy. This could include actions that disrespect an individual's personal boundaries, fail to acknowledge their equal worth in society or treat them merely as a means to an end.

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In this regard, the authors break down the CARE theory into four components: Claims, Affronts, Response, and Equilibrium. Claims refer to the inherent value and rights of individuals, which must be respected in digital environments. To do so, human beings must be treated as equals, have a voice, and be autonomous. Affronts, on the other hand, highlight the potential for digital practices to undermine or violate human dignity. This can happen through humiliation, degrading treatment, or by restricting autonomy, manipulating, or coercing an individual. These ways of restricting individual freedom resemble issues with digital nudging and overlap with definitions of dark patterns. If such affronts occur, responses come in the form of forfeit, fight, flight, befriending, and tending on a micro level, and actions of mobilizing, complying, resisting, and regulating on a macro level.

Forfeiting by accepting certain dignity claims may be necessary to achieve other goals. Others may choose to fight back by taking legal action or manipulating their personal data. Those who opt for flight may choose to avoid technology altogether and seek alternative methods for achieving their goals. Befriending involves reaching out to others and joining online communities, while tending refers to actions such as providing support and empathy to those who have experienced a dignity affront. Mobilizing involves collective action and initiating class-action lawsuits, while complying may require modifying one's personal data policies or digitalization platform. Those who resist may force individuals to consent or signal transparency while regulating, which involves issuing laws and regulations to protect personal data and privacy. Lastly, the equilibrium component seeks to restore balance and ensure that digital environments respect and uphold the fundamental worth of every person. This theory provides a comprehensive framework for understanding the complex interplay between technology and human dignity. It seeks to guide academic and practical approaches to safeguarding dignity in the digital realm, emphasizing the need for a value-centric approach in IS. In this way, the CARE theory supports value positions in IS research that advocate for the consideration of moral and societal values in technology design and implementation. Prioritizing ethical data practices, privacy, and individual rights is crucial to upholding human values in the digital age (Leidner and Tona, 2021).

### 3 Research approach

This paper is based on a large-scale research study that focused on the sleep and well-being of individuals with a specific focus on sleep apnea. The study has been carried out as part of the Sleep Revolution project, which aims to modernize sleep research. For three months, the participants were asked to wear a smartwatch and use the Sleep Revolution app, a mobile app for iOS and Android devices that has been designed and developed by the authors of this paper (Schmitz et al., 2022). The app included digital nudges in the form of notifications and in order to delve into the experience of digital nudging, we performed a semi-structured interview at the end of the three-month period. All participants, regardless of whether they completed the entire study period of three months or not, were invited to participate in a semi-structured interview regarding their experiences generating personal data and living with technologies. A total of 42 interviews are included in this paper. Prior to the interviews, the participants were briefed on its purpose and asked to provide consent for its audio recording, and asked to sign an informed consent form. Additionally, they were informed of their right to withdraw from the study at any time without providing a reason. After that, the audio recording was started.

The interviews followed a semi-structured format, guided by an interview guide developed by the last author of this paper. The interview guide covered topics such as participants' experiences of the multifaceted data collection and living with technologies; using smartwatches, and inputting data into the app. Moreover, a large part of the interview focused on the participant's experience of the digital nudges that were used within the app. Flexibility was maintained during the interviews to allow for follow-up questions to probe a deeper exploration of specific topics of interest when needed. Still, in general, the interview guide was followed. The interview duration of the 42 interviews ranged from 20 to 96 minutes,

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with an average interview length of 33 minutes. All interviews were transcribed verbatim and translated from Icelandic to English prior to analysis.

### 3.1 Qualitative analysis

To gain a better understanding of individual reactions to digital nudging, we analyzed the interviews in a four-step content analysis (Graneheim and Lundman, 2004). Qualitative content analysis, as described by Graneheim and Lundman, is a method used to analyze qualitative research data. This approach involves identifying, analyzing, and reporting themes within the data. Using this approach, we analyzed the data to gain a more nuanced understanding of responses to digital nudging and inform the design of more responsible digital nudging strategies. The first step included classical content analysis, labeling participants' responses to any of the digital nudges incorporated in the app. The second step included a discussion within the research team, where the themes were discussed and further categorized by labeling affront responses towards any form of digital nudging from the app. The third step included labeling the participants' attitudes mentioned about the study or the nudges. In the fourth and final step, we applied the CARE theory as a deductive lens to analyze the users' responses to the digital nudges (Reichert, 2013). We labeled any affront responses to digital nudging from the app that a participant expressed in the interview. The excerpts that we marked were parts of answers to questions about how the participant experienced the use of the app, if they found the notifications useful or whether they found any aspects of using the Sleep Revolution app stressful. Following the identification of affront responses, we used the categories of forfeit, fight, flight, befriending, tending, mobilize, comply, resist and regulate as presented in Leidner and Tona's CARE theory work (2021) to classify the responses.

## 4 Results

Through the qualitative analysis of the interviews, we found different types of dignity affronts that the participants experienced through nudging from using our app during the three-month-long research study. An overview of the dignity affront responses per affront category is displayed in Figure 1. Affront responses were found in the form of micro-level affronts of forfeit, fight, and flight. We found five forfeit responses, two fight responses, and three flight responses in eight out of the 42 interviews we analyzed. No responses in the form of befriending, tending, mobilizing, complying, or regulating were found.

The app included various types of digital nudges, but most users only gave feedback on a reminder nudge in the form of native notifications. This digital nudge was also the most noticeable nudge in the app. The notifications were an optional nudge that would remind participants to fill out the sleep diary part of the app in the morning and the evening at custom times, which the participants could adjust themselves. The diary part of the app included a set of questions that were both on scales and open-ended. The purpose of the morning diary was to assess the participants' sleep the night before, while the purpose of the evening diary was to log the well-being and habits during the day that could contribute to participants' sleep hygiene. Moreover, the participants were asked to complete cognitive exercises in the form of small exercises (called brain games) in the app once per week. Upon registration in the app to partake in the research study, participants were asked to provide their notification preferences. They were given the option to choose the time they wanted to receive notifications in the morning and the evening and whether they wanted to receive them at all. Participants could choose to only receive notifications in the morning or evening, or they could turn them off completely. Participants could update these preferences at any time in the app settings.

### 4.1 Dignity affronts

Our findings revealed that the majority of affront responses came in the form of a forfeit action, where participants chose not to engage with the notifications they received. Participant P19 said: "There were

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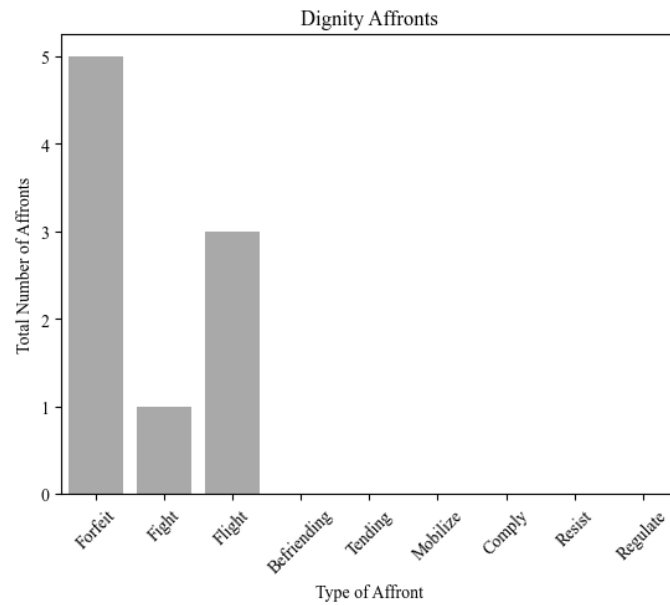


Figure 1. Number of summed affront responses per affront category. The responses were found in eight out of 42 participants.

many times I ignored the reminder for the weekly questions and cognitive tests." For some participants who chose to receive notifications but mostly ignored them, the notifications served as a constant reminder of an unwanted task that they were asked to complete in the app and as such, the digital nudges reinforced their bad conscience. Participant P11 felt stressed when they saw the reminders: "I always felt DING at 9 o'clock and if there was anything that caused me stress [in the study], it was the reminders." For participant P25, the notifications only became a cause of stress later on in the study: "I found [the notifications] helpful at first, but then it started to become a reminder for me to go to bed. ... I actually don't enjoy getting so much stimulation, I'd be happy to skip them. I found it tiring to be reminded to do something I did not bother to do." That participant reported that they did not fill out the sleep diary part of the app as regularly in the last one to two months of the study compared to their first month of the study participation. They found filling out the sleep diary "was a lot of fun at first, but then [the participant] got a little used to the app." This participant found the app and the task of filling out the diary pleasant, while it was still novel, and they perceived the notifications as helpful during that time, but as time passed, the novelty wore off and the notifications were no longer perceived as helpful. More specifically, when the task became part of the daily routine, the participant said they felt stressed by the notifications as they no longer looked forward to filling out the sleep diary in the app. Another participant, P16, did not report any affront response to the digital nudging but also expressed a similar loss of motivation later in the study: "At first, I really enjoyed it. I was very excited to answer the questions and made sure that everything was answered very well for me. As the research progressed, I felt my ambition begin to wane." P34 also felt a loss of motivation to comply and the adherence declined down over time: "I think I was very conscientious with the sleep diary, at least for the first nine weeks. I might have been a bit bored at the end." The lack of motivation prompted some participants to judge themselves negatively, like participant P34: "I really

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found it in the last two weeks that I was definitely a pretty poor participant."

As a fight response, we noted actions such as modifying the notification settings, including adjusting the sound and vibrations, to better suit the participants' preferences. Participant P20 preventatively changed the notification settings so they would not be bothered by them: "I did not notice the reminders. I often clear the reminders from my phone." This participant wanted to make sure that the notifications would not contribute to stress and acted accordingly. We also saw flight responses, where participants chose to turn off the digital nudges altogether or take similar actions to avoid being nudged completely. For participant P2, this was mostly due to missing flexibility of the reminder: "I never had the morning reminder on. I didn't want to turn it on when I started with this because I don't always wake up at the same time." Similarly, participant P23 said that they generally turn off notifications "because [they] can't get notifications. It stresses [their] life so much."

#### 4.2 Contrasting attitudes and emotional responses to digital nudging

Some participants showed affront responses without mentioning negative emotions. Participant P18 did not pay much attention to the notifications, saying: "I didn't pay much attention to [the notifications]. I set the app so that I would get a reminder at 09:00 in the morning, but then I often didn't start answering the questions until noon. I found the reminders unnecessary. Personally, reminders are not useful to me." This participant did not note any negative emotional responses to the nudging and seemed glad to have participated overall: "I've had a lot of fun [participating], and I'm very excited to get the results from it." Similarly, participant P19 found themselves ignoring a certain type of notification: "There were many times I ignored the reminder for the weekly questions." However, they did find the notifications helpful in general, saying: "They are useful to me. They helped me remember to answer the questions," and they would have even liked more notifications as "it would be helpful to have a reminder if [answering the weekly questions and brain games ] has not been completed."

Four participants out of the 42 reported a negative emotional response. Looking at these participants more closely, we see that they show different attitudes toward digital nudging and their overall participation in the research study. Participant P33 only showed a mild emotional response by finding the notification to be occasionally "annoying" and that they doubt that they would want to track any sleep-related data outside of the research study as: "I doubt I'd have the discipline to fill out [the digital sleep diaries] every day." Participant P11, who expressed a feeling of stress hearing the reminders' alarm tone, found that "they were helpful" regardless. Moreover, when asked if they would like to continue using the app after the research study was now over, participant P11 seemed overall in favor and not discouraged by their response to the digital nudges: "Yes, [continuing the participation] would be no problem. It's mostly just for me so I can keep track, and if I can get the data, something that's useful to me. But of course, it's good to be able to help in this kind of study."

Participant P20, who just cleared all notifications, seemed generally overwhelmed by the study participation: "I felt it was too much extra work to be in this study. There is so much I had to do." P23 also said that they did not want to receive notifications or any kind of digital nudges and, as a consequence, forgot to fill out the diaries regularly. They also expressed regret over not being able to comply with filling out the sleep diaries in the app as much as they would have liked. As a potential cause for their low compliance, they mentioned an event that impacted their life during the time of the research study and that it affected their health: "I had some kind of 'shit happens' in my life a quarter of a year after I started this. So I felt a little sad about my memory. I think my memory is not good enough when I'm under stress." When life presents its challenges, digital nudges, which are intended to be helpful, can end up amplifying stress levels. According to the report of this participant, it was the perceived obligation to adhere to these digital prompts that primarily fueled their stress. This feeling of needing to comply surfaced as a recurring theme during the analysis of the semi-structured interviews. Participant P34, who did not feel stressed by the digital nudges or showed any dignity affront, said: "I committed myself to this, and I'll finish it. Kind of

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dutifully." This kind of commitment to the study was also expressed by participant P39: "I had decided to participate and wanted to finish this."

Out of the eight participants who reported responses to digital nudging that could be categorized as a dignity affront, only four showed emotional responses to the digital nudges. That also means that, in general, most of the 42 participants were positive and thought that the digital nudges and the notifications, in particular, were truly helpful. As is often the case with qualitative data, there are nuances within each interview as well. For instance, one of those participants reported a negative emotional response toward the digital nudges in the form of notifications but showed general support for the research study and was positive towards using the app. This sentiment was in line with the attitude of many of the participants. Those who did not show any dignity affronts expressed excitement and support of the study unprompted. To showcase the diverse experiences of the participants with respect to the study participation and the digital nudges, we will present a selection of statements that illustrate positive remarks that were expressed by the majority of participants. For example, participant P10 said: "Just a great initiative, awesome in every way. Great that it should be done like this in Iceland as well. I think this is really important." Similarly, P13 showed support: "There was no stress, just fun [participating in the study]. [...] Just a great initiative, nice to participate."

Several participants explicitly stated that they enjoyed participating in the study. Participant P1 said: "I thought it was very nice and interesting to participate in this [study]," and also participant P27 said they "just enjoyed participating in it." Other participants expressed interest in the study, such as participant P1: "I thought [the study participation] went well, I was very interested in this study." Moreover, participant P25 showed excitement talking about the study: "I thought this was a fun study and I just enjoyed it, keep it up!" Participant P22 also enjoyed the participation as they thought that: "it's interesting to have done this," and they were interested in their own data: "I have found it very nice to be able to monitor my health and sleep." Participant P6 also expressed insights into their own sleep as a direct result of the participation and said that they enjoyed participating: "I'm just very happy to participate in this as well because it also gives me a lot of information personally, and it is just a win-win, I think." Participant P31 said simply that it: "was fun to watch how you sleep." Some participants even found that their sleep improved, such as participant P9: "I thought [the study participation] was really interesting. [...] I actually managed to maintain a better sleep routine." This attitude often carried over to the perception of the digital nudge in the form of notifications. Participant P35 spoke like this about the notification reminder: "It was just nice to get them because then you remembered to fill in the diary. So it was only positive and has benefited me." Several participants commented how the notifications were not only helpful but necessary. For example, participant P41 said, "The reminders to fill in the diary were great, absolutely necessary. I also got reminders for the [cognitive] tests, which was really nice and helpful."

## 5 Discussion

In the landscape of digital nudging and IS research, the ethical implications and value positions are central to the discourse, particularly regarding how digital environments impact individuals and societies (Conboy, 2019). Our findings around digital nudging reveal a complex array of value positions, underscoring the need for the well-intentioned nudger to ensure that their interventions do not inadvertently compromise or harm established ethical standards. Moreover, our data reveals that although there is value alignment and the nudgee is in favor of the digital nudges during a period in time, their willingness to be nudged can shift over time. Our qualitative analysis of the semi-structured interview data complements existing studies by providing detailed insights into individual experiences and perceptions, thus enriching the understanding of the value dimensions of digital nudging (Monteiro et al., 2022). This approach is crucial in a field where the impact of digital environments extends beyond mere functionality to touch on deeper ethical and societal concerns (Cecez-Kecmanovic, 2019; Conboy, 2019).

Through our analysis, we only found three out of the nine types of dignity affronts described by Leidner

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and Tona (2021), and all three response types were micro affronts. The responses we noted came mostly in the form of ignoring, modifying, or turning off the digital nudges in the form of notifications. While many participants made appreciative comments about the digital nudges, it highlighted the importance of allowing personalization and tuning of the notifications. Most of our participants who showed fight or flight responses to the digital nudging experienced a one-time affront that did not reoccur after the digital nudge was adjusted or removed according to their needs. However, we found that a dignity affront in the form of digital nudge forfeiting led to the most reported stress related to nudges. This illustrates the notion that digital nudges can contribute to techno-stress, although this might not always be the case. Many of our participants did not experience any kind of stress set off by the digital nudges, which is in line with other researchers' findings (Valta and Maier, 2022). Those participants who did experience stress were aware of the digital nudges occurring and accepted them the way they were but did not react to them even though they provoked reported feelings of stress and guilt. The conscientious nudge designer should be aware of this potential effect and do their best to remove stressful digital nudges automatically. In our research, the digital nudges that did provoke stress were also ineffective, as these participants did not react to them.

### 5.1 The many shades of the same digital nudge

We did not find that participants in the research study experienced frustration, unlike the findings of M. Bhoot, A. Shinde, and P. Mishra (2020). However, they found frustration responses to be a reaction to manipulative digital nudges (*ibid*). This could be the reason why our study only found emotional responses to digital nudges in the form of guilt and stress, as our digital nudges were not manipulative in their nature. More specifically, the app used in our study did not include any nudges that would intentionally go against the participants' will or make them do something that could be seen as harmful. The participants who decided to partake in the study did so with the intention of complying, adhering, and contributing to the research, which may partially explain why they experienced guilt when they did not end up doing what they set out to do. This suggests that the intention behind the nudging and the nudgee's support of the intention can affect the form of emotional responses. It is important to note that even unintentionally harmful digital nudges can evoke negative emotional responses.

These findings raise the question of what constitutes a dark pattern. As discussed in the literature review by Mathur, Acar, et al. (2019), there is no clear definition of what constitutes a dark pattern. Some definitions focus on the intention of the nudger and state that a dark pattern is an intentionally harmful nudge (Conti and Sobiesk, 2010). Other definitions state that any harmful nudge, regardless of intention, is a dark pattern (Waldman, 2020; Zagal, Björk, and Lewis, 2013). Looking at the findings of this research, the digital nudges in the app were both helpful and harmful, depending on the participant. This illustrates that perhaps a digital nudge can become a dark pattern under certain circumstances, even if it is responsibly designed.

As our results also showed, many participants who did not experience dignity affronts expressed strong support for the research study initiative and several enjoyed participating. Some said that they enjoyed their participation and that they would gladly continue. This starkly contrasts some of the participants' experiences that included negative emotional responses to the identified dignity affronts. P23, one of those participants, reported major impairment caused by a stressful life event that also seemed to affect the experienced stress by the study participation. Another participant, P20, reported that they experienced a high workload through participation and generally avoided any digital nudges. Participant P33 mentioned low compliance and forfeit response to the notifications due to a lack of discipline. Thus, it is possible that the levels of stress and workload experienced by participants are indicative of a wider experience of indignity in other areas of their lives. This implies that there is a more general pattern underlying the reactions of these participants, which is not limited to the context of the research study. All of these experiences point towards the need to personalize and tune digital nudges.

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## 5.2 Towards value alignment and theoretical development

Two participants reported that their motivation to record sleep-related data in the app decreased over time. One of those participants felt that the loss of motivation affected their response to reminders from the app. Initially, they found reminders to be helpful, but as their motivation decreased, the reminders became a source of stress. The participant who reported this change in their response to nudging also suggested a solution: "It would be good to have some meeting in the middle of the research to push the ambition." This statement implies that incorporating feedback mechanisms, such as personal check-ins or digital feedback, could have a positive impact on the participant's response toward the task they were nudged to do. This, in turn, could help to improve the effectiveness of the nudge. A similar observation has been made by Mirsch, Lehrer, and Jung (2017), who found that feedback can further improve the effectiveness of digital nudges. Although feedback is valuable, it does not always guarantee that digital nudges will be well-received. This is especially true for intrusive nudges like native mobile notifications. In such cases, it is wise to take advantage of the flexibility of the digital environment and modify or remove the nudge if it's being ignored for an extended period of time.

We used the dignity affront responses presented in the CARE theory Leidner and Tona, 2021 to categorize aversive responses to digital nudging discussed by the participants in our interviews. Our goal with this approach was to gain a deeper understanding of the effect of digital nudges through this categorization and to provide theoretical implications accordingly. As outlined earlier, we were only able to identify three out of the nine types of dignity affront responses in the form of forfeit, fight, and flight on a micro-level. We did not find any macro-level responses through our study. Based on those findings, the dignity affront responses that may be the most suitable tool to examine participants' responses to specific parts of an information system, such as digital nudging, may very well be the micro-level elements within the theory. As described earlier, one reason could be that the app purposefully did not include any type of dark patterns and instead utilized digital nudges with ethical design recommendations in mind through a thoughtful design process. However, the project's scale could be another explanation for this effect, as the CARE theory might be better applied to evaluate large-scale information systems. The micro-level elements of forfeit, fight, and flight were sufficient to categorize any aversive responses the participants outlined in the interviews. Thus, those three categories are useful for investigating IS on a smaller scale or specific parts of an information system, such as focusing on interaction design elements within the information systems. The CARE theory also enabled us to dig deeper into the attitudes and experiences with digital nudges in a structural way. It made organizing affronts into categories and looking specifically at those responses easier. Nevertheless, using the CARE theory, we could not differentiate between weaker and stronger emotional responses to being digitally nudged. For example, we found it useful to note when participants turned off the notifications and why. None of the participants who described that they disabled the notifications expressed high amounts of stress as their agency was preserved. This experience differs from the participants who did not react to the notifications but expressed stress whenever they saw them. Based on those findings, we extrapolate that such stronger emotional responses should be of greater interest to IS practitioners and designers who are eager to preserve their user's dignity and we hope that future designers do so. Therefore, we wanted to investigate participant attitudes alongside the affronts to paint a bigger picture based on our large interview corpus with our 42 participants. To further support this implication of our results, we call for more research that uses the CARE theory to interpret responses to dark patterns and identity dignity affronts.

## 5.3 Synthesis and design guidelines for the conscientious nudge designer

The emphasis on a critical, philosophical perspective on digital transformation (Rowe, 2018) further illustrates the multi-dimensional nature of value positions in this field. The perspective advocates for a responsible, critical examination of digital nudging as a growing interest within IS research to ensure that digital nudges contribute positively to society without undermining individual agency. Therefore,

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the dialogue around digital nudging and IS is deeply entwined with value positions. The challenge for researchers and practitioners lies in navigating these different perspectives and ensuring that digital environments are designed, developed, and used in ways that respect and uphold the complex web of values.

Our cumulative findings point towards the need to personalize and tune digital nudges, which is an important pathway for designers of digital nudges. To synthesize our findings, we summarize design guidelines for the conscientious nudge designer, what we herein also conceptualize as *digital nudging with dignity*. Firstly, it is important to be aware of the potential stressful effect of digital nudges and allow for the automatic removal of stressful digital nudges by the user. In our research, the digital nudges that did provoke stress were also ineffective, further strengthening the notion of allowing for removing those. Secondly, the intention behind the nudging and the nudgee's support of the intention can affect the form of emotional responses. It is important to note that even unintentionally harmful digital nudges can evoke negative emotional responses. Hence, digital nudges should always be used with care, and personalizing them is imperative. Thirdly, while digital nudging can be effective and, in our research, truly effective in most cases, incorporating feedback mechanisms, such as personal check-ins or digital feedback, could have a positive impact on the participants' response toward the task they were nudged to do. This, in turn, could help to improve the effectiveness of the nudge. Finally, it is vital to take advantage of the flexibility of the digital environment and modify or remove the nudge if it is being ignored for an extended period of time. Ergo, analyzing click-logs to illuminate which users act on digital nudges and removing the digital nudges after, for instance, ten days if not acted on, could contribute to a reduced feeling of stress for the users.

## 6 Conclusion

As digital nudges become more widespread, it is essential to consider their potentially harmful consequences. Our research, based on 42 semi-structured interviews, found that even with the consent of the nudged individual, nudging them in a digital environment can lead to feelings of stress or guilt. Through our findings, we developed an in-depth understanding of the impact of digital nudging on user dignity and provided guidelines for designers to consider the potential dignity affronts. The participants in a three-month research study reported responses to digital nudges that could be categorized as dignity affronts in the form of forfeit, flight, and fight actions. Identifying and analyzing these responses allowed for insights into the perception of the used digital nudges and we found the CARE theory is a helpful lens for identifying potential sources of harm through digital nudges. The theory can be used to inform future research about digital nudges, as well as to analyze and improve existing digital nudge designs. With these findings, we contribute to the ongoing discussion about the responsible design of digital nudges. Importantly, we note that a digital nudge can become a dark pattern under certain circumstances, even if it is responsibly designed, as illustrated through our findings. To sum up, our main contribution is three-fold. Firstly, we provide theoretical contributions through the conceptualization of digital nudging with dignity through the lens of CARE theory. Secondly, we provide empirical insights into when digital nudging can be helpful as opposed to harmful. Thirdly, we provide practical implications through design guidelines that designers and developers of digital nudges can use to consider in order to mitigate potential dignity affronts.

**Acknowledgements** This research was carried out as a part of the Sleep Revolution project, which has received funding from the European Union's Horizon 2020 Research and Innovation Programme under Grant 965417. The corresponding author is Lisa Schmitz and the senior author of this paper is Anna Sigridur Islind.

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## A.4 Paper 4

# The Cosmic Design System

## Development and Application of Design Principles for Clarity in Design Systems

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**Abstract.** When designing information systems in general and digital platforms in particular, the design of user interfaces (UI) plays a crucial role in determining the effectiveness and efficiency of the user experience. Design systems have emerged as a solution to address the challenges of designing and maintaining consistent and cohesive UIs across digital platforms. However, design systems have outgrown their original purpose and are increasingly being used to organise the codebases of applications. Additionally, many existing design systems stem from industry and thus lack scientific evidence. This paper investigates the underlying principles that guide the creation of design system components to provide a theoretical foundation for developing design systems. Using action research, we offer a two-fold contribution. On the one hand, we contribute three design principles for design systems components, and on the other hand, we present a design system called Cosmic Design, which was developed utilizing these principles.

*Key words:* system architecture, system design, robust design systems, information systems, digital platforms, action research.

## 1 Introduction

System architecture outlines the foundation for designing, developing, and constructing complex software systems. It is one of the cornerstones of information systems (IS) research, which has, in recent years, expanded into a growing interest in the design and organisation of software systems in general, and digital platforms in particular (Yoo et al., 2010). This research has highlighted the importance of modularity and reusability in the development of information systems (Nelson & Stolterman, 2014). IS architectural approaches typically focus on the entire system by offering guidelines for high-level architecture (Street & Gomaa, 2008). However, translating high-level architecture into everyday code, particularly when incorporating consistent and functional UI elements, can be a considerable challenge, especially when designing and developing complex digital platforms.

Digital platforms are pieces of software that also act as an intermediary, connecting needs with resources, users with service providers, or, more specifically, data consumers with data providers (Blaschke et al., 2019; Constantinides et al., 2018; Islind, 2018; Islind et al., 2019), fostering collaboration (Smith & McKeen, 2011; Tiwana et al., 2010). Famous examples of digital platforms (hereinafter also simply called 'platforms') are Google, Facebook, Amazon, and PatientsLikeMe (Gawer, 2014; Bonina et al., 2021). Platforms commonly target various devices and systems. Furthermore, corporations like Amazon often provide a multi-sided platform, offering various services to different target groups (Boudreau & Hagiu, 2009; Cusumano et al., 2019), thus adding to the complexity of modern platforms (Derave et al., 2024).

Libraries such as Flutter and React or React Native have emerged as one way to cope with the increasing complexity of platforms (Tăbușcă et al., 2022). These libraries allow software designers to develop applications that target various operating systems as well as the web simultaneously (Oliveira et al., 2023). In order to manage the variety of shared and system-specific modules in those libraries, design systems have been used to structure not only user interface (UI) components but also the codebase of platforms. A design system commonly consists of a set of components and guidelines that inform the design and implementation of a product. Thus, a design system allows for the decomposition of a complex system into smaller, more manageable parts.

Design systems have become a popular method for interaction design and development in the industry and have been adopted by large corporations such as Google and Apple. Examples of such design systems that are currently in use across multiple products include Google's Material Design and Apple's Human-Interface Guidelines (Handal et al., 2022). Despite their widespread use, there has been little research on design systems. The few studies that have been conducted mainly focused on the benefits and values of design systems (Yew et al., 2020; Vendramini et al., 2021). However, the investigation of challenges and strategies related to the creation and maintenance of design systems is underdeveloped.

Particularly in the context of IS research, there is a lack of literature on the topic of design systems. However, the topic fits well into IS research as design

systems serve as communication tools between designers and developers regarding ways in which the development of information systems can be furthered. The investigation of design systems has the potential to generate novel design knowledge that enhances the understanding of the design and development of information systems.

The use of design systems not only benefits traditional front-end systems but also provides benefits to no-code/low-code (Prinz et al., 2021). With the rapid increase in the popularity of no-code/low-code, the need for consistent, reusable UI components is more important than ever. Unlike traditional front-end development, where the UI is built by developers, no-code/low-code systems allow non-technical users, also referred to as citizen developers, to create and customize the UI (Yan, 2021). This makes it increasingly crucial to ensure that all the components are consistent and easy to use. The use of design systems to deal with this issue is likely motivated by a desire to fix the missing relationship between design and implementation components (Jacyntho et al., 2002) and to attempt to connect high-level architecture and everyday code. However, design systems do not usually address how the design components relate to implementation components, and there is a gap in the literature in that regard. Moreover, design systems are typically not research-based; instead, they stem from industry, meaning that they currently lack scientific evidence (Lamine & Cheng, 2022). Nevertheless, the essence of design systems, which is its component-based structure, is a compelling concept to explore in a systematic manner. Theoretical insights into the design of UI design systems are sparse, and there is a need for general design principles for building such a system. To formulate effective design principles, Gregor et al. (2020) suggest clarification of aim, context, mechanism, and rationale. Therefore, in this paper, we examine how design system structure can be incorporated into the system architecture of platforms and formulate design principles based on our findings.

In this paper, our main focus is on the design, development, and maintenance of information systems through the creation of a UI design system. Our study aims to address the lack of research in the area of design systems. We evaluated an existing design system, the Atomic Design system (Frost, 2016), to derive general design principles for organising design systems. We then apply those design principles and create a novel design system called *Cosmic Design*.

Atomic Design has been used to structure the design and code of the [name masked for blind review] platform, which includes longitudinal health data from participants across Europe. For an analysis of the design system, we asked 18 participants to complete multiple tasks applying the Atomic Design system to the mobile application design and collected data through a structured survey with open-ended questions to answer our two research questions:

1. Which design principles can be derived for crafting foundations for clear and usable design system components?
2. What are the key characteristics and components of a design system that effectively implements the derived design principles?

By answering these research questions, we provide a comprehensive understanding of the benefits and limitations of design systems in general and demonstrate their effectiveness in addressing the challenges of modern information systems. Moreover, we derive a novel design system based on those findings and conceptualize it herein. Thus, our main contribution is two-fold. Firstly, we outline three design principles for forming powerful design systems: (i) include a base component class, (ii) organise component classes in a flat hierarchy, and (iii) clearly differentiate higher-level component classes. Secondly, we provide a design system called Cosmic Design, which embodies the building blocks of the aforementioned design principles as a robust design system for designing and developing digital platforms of the future.

## 2 Theoretical background

System architecture has been extensively discussed in the literature over the years, and a variety of definitions and concepts of the topic have emerged. According to the works of Perry and Wolf (1992) and Shaw and Garlan (1996), software architecture can be described as a way of defining the set of elements that make up software systems. However, system architecture is often regarded as distinct from design activities (Monroe et al., 1997; Bass et al., 2003).

One of those design activities is breaking down systems into modular elements (Eden & Kazman, 2003). This activity, also referred to as modularization, provides a way to structure information systems in a more scalable and maintainable way. In this way, a system can become more manageable, which is particularly important due to the increasing complexity of information systems and, specifically, platforms (De Reuver et al., 2018). Considering this development, research has highlighted the importance of modular design and its benefits in preserving consistency among complex platforms that provide multiple services (Boudreau and Hagi, 2009). The benefits of modular design have not only been explored in the context of system architecture but also in organising system design (Nelson & Stolterman, 2014). A formal approach to this organisation has emerged in the form of design systems (Cheng & Lamine, 2022).

A design system is a collection of components, guidelines, and rules that are used to create a platform's user interface. It includes elements that make up the visual design of the platform, such as components for input, forms, navigation, and other interactive elements. A UI design system can provide consistency across the platform that promotes a clean look and good user experience (Kholmatova, 2017). The structure a design system provides also simplifies maintenance, as changes need to be made in one place and are then updated across the platform. Additionally, a design system can act as a communication medium. It provides designers and developers with a shared language to talk about and understand the platform.

Due to its benefits, modular design is not only used for structuring information systems but is also popular in UI design (Nelson & Stolterman, 2014). This approach to design, which emphasizes the separation of components to enhance reusability and scalability, aligns closely with the

principles of design systems, which organise UI components and design patterns into a cohesive and standardized framework. A UI design system is the collection of components, guidelines, and rules used to create a platform's user interface (Suarez et al., 2019). It includes elements that make up the visual design of the platform, such as components for input, forms, navigation, and other interactive elements. Design systems can provide a mutual visual language for a team that reduces confusion and miscommunication (Kholmatova, 2017). The concept of design systems related to early work on design patterns (Cheng & Lamine, 2022). Design patterns have been introduced in 1977 by Alexander in the context of architectural design. Design patterns are described in Alexander's work as a collection of solutions to recurring problems. Accordingly, the idea of design systems is not new and it stands on solid ground with roots in the pattern language. Reusable components are the key to design systems, and they are guided by clear standards that can be assembled together to create a platform and to enhance collaboration and communication through documentation among various kinds of platform stakeholders (Lamine & Cheng, 2022). Aside from academic literature, there is a body of practical fieldwork on the definition and development of design systems. According to Hacq (2018), design systems should consist of a style guide and a pattern library of design components. Fanguy (2019) also sees design systems as mainly pattern libraries and describes a process for constructing design systems. The process starts with a visual audit of current designs. The audit outcome should then be used to create a design language. Similarly, Fessenden (2021) argues that a design should be built from a set of reusable components.

One example of a system for structuring the design components of platforms is Atomic Design (Frost, 2016). Atomic Design is a design system for designing and developing user interfaces by breaking them down into smaller, modular components. These components are categorized into atoms, molecules, organisms, views, and templates. Atoms are the building blocks of a design, such as buttons, inputs, and labels. These atoms can be combined into molecules to perform a specific function, such as a search bar or a login form. Organisms are even more complex groups of molecules and atoms, such as a header or a sidebar. Any combination of these components can make up views, which are usually a screen or a webpage. Templates are layouts for views that might appear repeatedly throughout the design. Thus, Atomic Design provides a way of creating a collection of design components that can be used to form a platform design. However, Atomic Design does not provide explicit guidelines for integrating application logic, as it focuses solely on the design aspect of platform development. However, Atomic Design has two important drawbacks. First, it is industry-driven; ergo, it has not been widely tested. Second, it shares the limitations of other design systems, as it lacks the cohesion and ties between design elements and code.

These two particular drawbacks and gaps in the literature outline the foundational drivers behind this research endeavor, and in this paper, we bridge these gaps by providing design principles for design systems and then crafting and conceptualizing Cosmic Design based on those design principles.

### 3 Methods

Following an action research approach (Davison et al., 2004), we conducted an evaluation and user experiment with 18 participants using an existing digital healthcare platform. Action research (AR) is a process of problem-solving that involves direct intervention in a situation, with the aim of improving practices and contributing to academic knowledge. The AR process has four iterative phases: (i) diagnosis, which involves identifying a problem; (ii) action, which involves addressing the problem; (iii) analysis, which involves evaluating the actions taken to address the problem; and (iv) conclusion, which involves interpreting the findings from the previous phases (Davison et al., 2004).

As part of the [name masked for blind review] project, we designed and developed a digital health platform that enables researchers, healthcare professionals, and study participants to share data [reference masked for blind review] over a span of four years. To develop front-end for the mobile and web application of the the Sleep Revolution platform, React / React Native was used, which is compatible with iOS and Android devices as well as web browsers. The system architecture for the front-end software followed the principles of Atomic Design. However, during the design process, we identified a lack of clarity in the design system definition and limited guidance on how to integrate it into the application logic. The information is first transferred, stored, and processed in the database of the platform. The database runs on a high-performance cluster, and the data is made accessible via a web interface of the platform for healthcare professionals and researchers to examine. The data is utilized for various research purposes, such as implementing machine learning techniques to analyze the correlation between measured and experienced sleep quality. The platform's high level of automation enables the collection of large amounts of data in long-term studies. To date, it has been used to gather data from over one thousand participants so far across numerous studies that have lasted up to three months. Moreover, it is set to be utilized in a significant European study involving participants from 24 countries [further references masked for blind review].

We, the authors of this paper, played an active role in designing and developing the digital health platform that utilized an atomic design system in its front-end. However, we encountered a lack of clarity in the atomic design system during the design and development process, thus marking the 'diagnosis' phase of our action research. This phase also highlighted a gap in the literature on design systems, indicating a need for further investigation. Subsequently, we moved to the 'action' phase, where we conducted a comprehensive user study aimed at identifying the drawbacks of the atomic design system. Upon completion of the user study, we transitioned to the 'analysis' phase, wherein we examined the gathered data. Our analysis gave insights into the problems of the atomic design system and led us to formulate general design principles for design systems. These principles served as the foundation for the development of an enhanced design system, the cosmic design system. The development of this system signifies the 'conclusion' phase of the action research. This new system was formulated to address the limitations identified in the atomic design system, informed by the insights

derived from our analysis. It represents a methodological advancement in the structuring of design components, specifically tailored for platforms with a graphical user interface (GUI). The different phases of the action research that the project went through are shown in Figure 1.

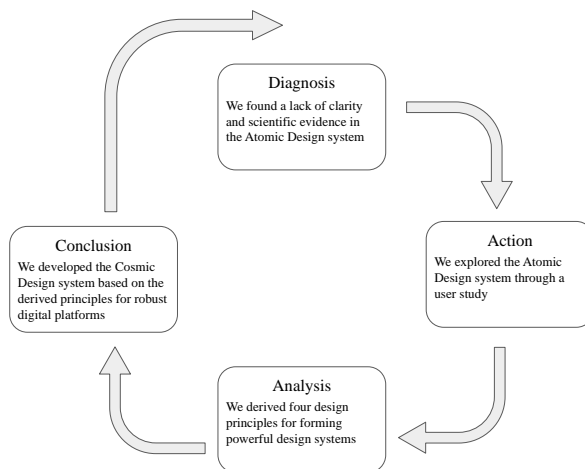


Figure 1. The phases of the action research cycle this project went through.

For the user study, we recruited a group of 18 students (3 females) from the course ‘Interaction Design’ as participants from [name masked for blind review] University, [country masked for blind reviews], in September 2022. This course is a mandatory part of the first-year curriculum in the software engineering program. First-year students of the program take courses that provide them with a basic technical understanding of information systems but no extensive practical experience with system development. This selection was a strategic choice as the participants’ previous experience with information systems would allow them to understand the problem statement while being able to approach it from a new angle free from bias due to their limited exposure to and experience with various design systems. Furthermore, as argued by Isild and Willermark (2022), it is important to include novice designers early on.

Our action research employs mixed-methods data gathering, combining qualitative and quantitative data to gain a better understanding of the design system’s efficacy. The participation was voluntary, and those that wanted to partake, were asked to sign an informed consent. After signing the informed consent, the participants were asked to complete a series of tasks using the Atomic Design system. After completing the tasks, participants participated in a follow-up questions evaluation where they were asked to provide feedback

on their experience with the Atomic Design system. The participants were given a week to complete the task and follow-up questions at home. The experiment was divided into two parts. In the first part, the participants received an explanation of the Atomic Design system and the purpose of the [name masked for blind review] app which is used to collect health data in sleep studies. They were then presented with the designs of the Home View (as shown in Figure 2) and Diary View (as shown in Figure 3), which were chosen from the aforementioned app. Both of the chosen views were strategically selected, as they had been designed, developed and used for the [name masked for blind review] app, which is actively used for research. During the implementation in which we were involved, the Atomic Design system was used to structure the design and application components. However, we encountered issues while using the system in practice. To determine if others also experienced similar or other issues, we presented participants with screenshots of the app in question as shown in Figures 2 and 3 and observed how they applied the Atomic Design system and their experience with it. We selected these views as they are both straightforward and have repeating design elements that can be identified as design components but vary in complexity. The Home View only has one state, which is why we presented only one view design, while the Diary View has more variation and we presented the participants with three different states of that view. We asked the participants to divide the design system into components and organise those components in a hierarchical order according to the Atomic Design system. This was done to understand the ease of use of the system and to identify any issues with the organisation of the design components.

In the second part of the experiment, the participants completed a structured survey with open-ended questions about their experience and difficulties using the Atomic Design system.

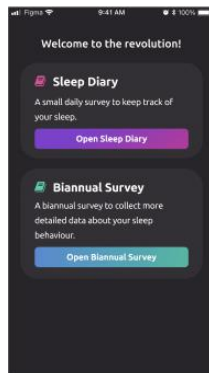


Figure 2. Home View of the [name masked for blind review] app.

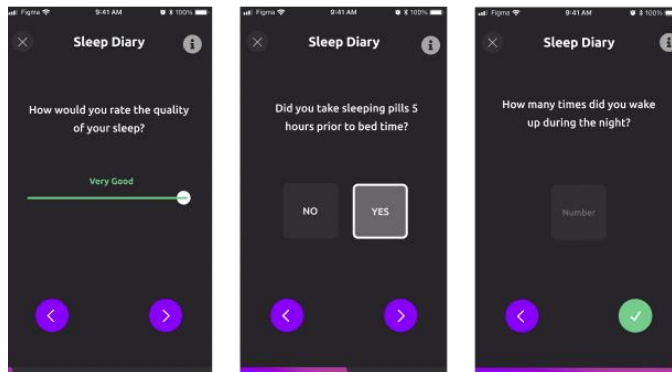


Figure 3. Diary View of the [name masked for blind review] app.

We evaluated the data from the first part of the experiment by sorting all the individual components that the participants had identified and which Atomic Design component class they had assigned them to. We did this by calculating the Gini impurity values of each component class. Gini impurity is a measure of how well an individual class is separated from the other classes. We calculated the Gini impurity for our dataset using the formula:  $Gini(D) = 1 - \sum_{i=1}^m (p_i^2)$ , where  $D$  represents the dataset,  $m$  is the number of classes, and  $p_i$  is the proportion of class  $i$  items in the dataset. We collected all the data points in an Excel file and computed the impurity values by applying this formula to all component classes separately for each of the two views.

The impurity values provide a measure of the homogeneity within each class. Lower values indicate a more homogeneous class and higher values indicate a more heterogeneous class. We only included components that were identified as such by at least five participants in our evaluation to guarantee we would only examine relevant design elements.

When evaluating the data from the structured surveys, we focused on problems that the participants found with the design system by relying on qualitative content analysis (Graneheim & Lundman, 2004). The underpinning of our approach is based on an abductive approach. The specific aim was to look for and distinguish various themes through the content analysis that outlines the benefits or drawbacks of design systems. Here, the abductive nature refers to the interplay between the empirical data, realized through real-world problems (inductively obtained) in combination with influences from theory (deductively inferred) by viewing “reality from the theoretical viewpoint or perspective” (Van de Ven, 2007, p. 104). The abductive nature thereby involved shifting between inductive and deductive reasoning to continuously revise, sharpen, and re-formulate the design system through engagement with the coding of the empirical data. We categorized the limitations mentioned by participants in the surveys into topic-based meaning units and subsequently analysed the frequency at which these units were raised

by the participants. The names of the participants in the following results chapter are pseudonyms, used for ease of reading.

## 4 Results

In this section, we will outline the results of the action research project and offer an analysis by calculating the impurity of the component classes of the Atomic Design system. The participants identified eight unique components for the Home View and 16 unique components for the Diary View. As mentioned before, we defined a unique component as a design element that was identified by at least five participants. We show the classification of the components by the participants in Table 1 for the Home View and in Table 2 for the Diary View.

<i>Component</i>	<i>Atom</i>	<i>Molecule</i>	<i>Organism</i>
Icon	5	0	0
Header 1	17	1	0
Header 2	17	1	0
Box	2	0	0
Body	14	0	0
Button	17	0	0
Box Content	0	9	0
Box Component	1	8	5
Box List	0	2	11

Table 1. The classification of the identified unique components by the participants for the Home View.

<i>Component</i>	<i>Atom</i>	<i>Molecule</i>	<i>Organism</i>
Header	17	0	0
Body	14	1	0
Label	11	0	0
Scale	15	0	0
Boolean Button	17	0	0
Arrow Button	18	0	0
Info Button	18	1	0
Cancel Button	17	1	0
Number Button	18	1	0
Boolean Group	0	7	0
Progress Bar	9	0	0
Scale with Label	2	8	0
View Header	0	7	2
Diary Entry	0	9	5
Diary View	0	4	11

Table 2. The classification of the identified unique components by the participants for the Diary View.

As can be seen in Table 1 and Table 2, on some rare occasions, participants put a component in multiple classes. In those cases, we counted the classification of those components for each class, thus sometimes receiving more classifications for a component than participants. Furthermore, since we left it to the participants to separate the view into design components, not each component was identified by each participant, thus resulting in far fewer classifications than participants. Examples of identified components can be seen in Figures 4, 5, and 6.



Figure 4. Examples of Atom components participants identified.

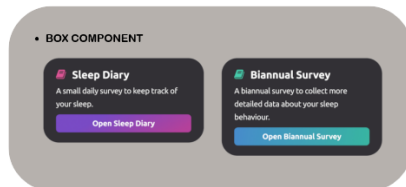


Figure 5. Examples of Molecule components participants identified.

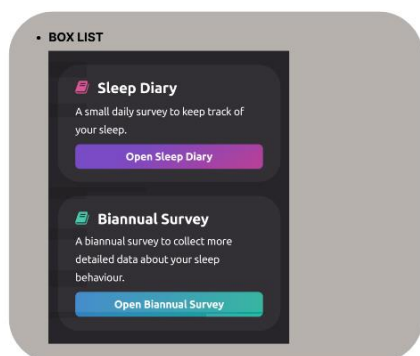


Figure 6. Examples of Organism components participants identified.

For each class, we calculated the impurity of its classification compared to the other classes. Table 3 gives an overview of the average classification impurity for each view. In both cases of the Home View and the Diary View, the class 'Atom' has the lowest impurity value of 0.03 for the Home View and 0.057 for the Diary View, which means that the samples in this class are the most similar to each other among the three classes. The class 'Molecule' has the highest impurity value of 0.107 for the Home View and 0.140 for the Diary View, indicating that the samples in this class are the most diverse among the three classes. The class 'Organism' has an impurity value of 0.09 for the Home View and 0.085 for the Diary View, which is lower than 'Molecule' but higher than 'Atom'. This means that in this study, a component classified as a molecule was about three times as likely to be put into a different component class by other participants than a component classified as an atom. The higher impurity values for molecules and organisms indicate that participants had the most difficulty putting a component in one of those two classes. The results show that the impurity values for the 'Molecule' and 'Organism' classes are notably higher than the one for the 'Atom' class. This indicates that these two classes are more heterogeneous than the 'Atom' class. Overall, the impurity values indicate a high degree of variation among the 'Molecule' and 'Organism' classifications, while the classification of 'Atoms' is more consistent.

	<i>Atom</i>	<i>Molecule</i>	<i>Organism</i>
Home View	0.030	0.107	0.090
Diary View	0.057	0.140	0.085

Table 3. The classification impurity of the identified unique components by the participants for the Home View.

This indication is further supported by the results from the follow-up surveys with the participants. When asked whether they encountered any issues with the design system, 50 % of the participants voiced difficulties related to the classification into Molecules and Organisms. One issue was that participants struggled with the distinction between them: "The only thing I didn't enjoy was the uncertainty if I was doing the right thing when organising into Molecules and Organisms" (Miria). Similarly, another participant voiced similar concerns: "It was a bit unclear to me what should be perceived as a Molecule and what an Organism" (John).

Some participants stated that they found it unnecessary to have both categories and thought they could be represented as one component class: "I struggled a little at filtering things into molecules as I did not quite see the difference between them and Organisms and am still pretty certain that Molecules are just budget Organisms" (Leon). On a similar note, another participant had difficulties with keeping those apart: "I do feel like the Molecules of the diary view could almost be exactly like the Organism" (Jack). Yet another participant pointed out that the difference was simply too insignificant to be able to distinguish between those easily: "The difference between Molecules and Organisms is so small that there's basically no point in making Organisms." (Helena)

In contrast, participants showed a positive attitude towards the separation into component classes and found it helpful for structuring an application. As the basic building blocks of a system, base components such as Atoms seemed necessary and reasonable to the participants, and they had no issues identifying them: "Pulling the views apart into their Atoms felt sensible" (Sebastian). Another participant saw it in terms of a building block: "I was thinking of it as blueprints for a bigger construct where the Atoms were the building blocks" (John).

In summary, the participants expressed that: (i) they found the classification of base components sensible and intuitive, (ii) it was unclear how to distinguish Molecules and Organisms, and (iii) that these two higher-level components could be summarized into one higher-level component.

The results of the study highlight the advantages of a component-based application structure and point out the drawbacks of the Atomic Design system. Participants had a positive experience with the base components of the Atomic Design system but were confused by the higher-level components.

During our investigation, we also compared the data obtained from male and female participants and we found no notable differences in the results between the genders.

## 5 Discussion

The discourse on design within IS research is vibrant and lively. The interest in design runs deep within our field and as Nelson and Stolterman in their seminal work stated: "Humans did not discover fire - they designed it" (Nelson & Stolterman 2012, p.11.) capitalizing the importance of us as a research field engaging with aspects of design. Within the Scandinavian school

of design, there has been an enduring focus on participation, inclusion and engagement in design (Bødker et al., 2000; Müller et al., 2023). In parallel, within the design science research community there has been a focus on creating and testing digital artefacts which serve as a basis for abstracting knowledge that serve specific classes of design problems (Simon, 1996; Walls et al, 1992; Pries-Heje & Baskerville, 2008; Tuunanen et al., 2024). Although there is a grounded interest in design within IS in general, and within the Scandinavian school of design and design science research in particular, there has been limited attention on crafting, curating and translating design knowledge between those involved in the design process in systematic ways that are appealing. Our paper rises from that particular need, the need for more research on design systems. Our paper shows that to thoughtfully engage others in design, design systems have the power to cultivate a thinking process that is useful, engaging and has translational power when curating a discussion with others around design.

More specifically, the classification of design components within the [name masked for blind review] platform's design revealed a significant variation in the classification of higher-level components, as shown in Tables 1 and 2. The average classification impurity for "Molecule" and "Organism" components (Table 3) shows the ambiguity of the class definitions in the Atomic Design system and the subsequent confusion participants experienced when tasked with distinguishing between these component classes. This supports the necessity for clearer, more intuitive classification of higher-level components if there are multiple. This is further supported by comments in follow-up surveys, where more than half of our participants voiced difficulties differentiating between molecules and organisms. These findings furthered the need for a novel design system with more clearly defined component classes. This feedback is in line with the concerns voiced by Nelson and Stolterman (2014) regarding too much complexity of modern design systems. On a more granular level our results suggest that (i) a modular, hierarchical structure is an intuitive way to organise design components, and (ii) the structure must be clearly defined to be effective.

As shown in previous IS research (Boudreau & Hagi, 2009; De Reuver et al., 2018) a modular structure comes with many benefits. It can be used to break down the complexity of modern information systems, which makes them more accessible and maintainable (Nelson & Stolterman, 2014). Our results showed that all participants were able to understand and apply the concept of modular structure and the majority found it a helpful tool for organising the presented design components. Therefore, modularity is not only important in the high-level architecture of IS (Street & Goma, 2008) but is also a key attribute of more detailed, technical architectures such as a design system.

This concept of a modular structure has been adopted in the Atomic Design system (Frost, 2016). However, as an industry approach, it has not, to the best of our knowledge, been scientifically evaluated. Knowledge about such a design system in terms of accessibility, advantages, and risks are therefore missing in the literature. Against that backdrop, our evaluation of the classification purity showed that the definition of higher-level components in

the Atomic Design systems lacked clarity. Moreover, the participants' responses indicated that they saw no purpose in having multiple higher-level components as they are defined in the Atomic Design system. By examining the clarity of the Atomic Design systems in structuring design, we derived a set of principles that will guide the creation of a clear design system that we propose other use when designing and developing complex digital platforms.

## Design Principles

Based on the results of your study, we derived three design principles and phrased them following the recommendations of Gregor et al. (2020). The three design principles are the following:

- **Include a base component class.** *Aim:* Provide a class of reusable components that form the basis of the system design. *Context:* Our results showed that the base components were appreciated for their intuitive definition and high reusability. *Mechanism:* Create a class for components that are essential to the system and will be used in many parts of it. *Rationale:* By creating a design system with a base component class, low-level design elements are clearly defined and can be reused in many different contexts.
- **Organise component classes in a flat hierarchy.** *Aim:* Improve the user experience of the design system by defining as few as possible higher-level component classes. *Context:* Our study results imply that design systems with a flat hierarchy are more convenient, as users find a system with fewer purposeful component classes less overwhelming. *Mechanism:* Determine the essential amount of component classes to accurately represent the different core functionalities of the system and only include those in the design system. *Rationale:* A design system with a flat hierarchy is easier to navigate as components can easily be assigned to and found in the correct component class. This makes the system more efficient to use.
- **Clearly differentiate higher-level component classes:** *Aim:* Avoid confusion by clearly defining and separating higher-level component classes from each other. *Context:* In our study, participants were confused by the definitions of the two higher-level component classes and had, thus, trouble defining those components and assigning them to a class. *Mechanism:* When defining higher-level component classes in a design system, each class should describe components with unique features and enable users to clearly distinguish between them. *Rationale:* By making it easy to identify and distinguish component classes from one another, users have an easier time understanding the system.

These design principles highlight the importance of a clear and easy-to-understand component structures which in turn will improve the user experience. By using a component-based application structure, designers and developers can create reusable and modular base components while also ensuring that higher-level components are clearly differentiated and easy to understand. From our design principles, we craft Cosmic Design, which outlines the main contribution of this paper.

### Cosmic Design

Based on these findings, we developed a UI design system that adheres to the principles of having clearly defined and distinct components. We call our system the Cosmic Design, and it is designed to be a universal system for both traditional front-end systems as well as no-code/low-code systems. The system is similar to Atomic Design but tries to fix its issue with an unclear definition of higher order components as well as a lack of contextualization of the components into an application structure. Our design system makes a distinction between application and design components and adds a pure application component to integrate application logic. The system is composed of the following:

- **Stars:** Stars are reusable modules. They contain basic building blocks of the system, such as a button, a section header, or an input field. These are components that contain no logic. A Star is a design and an application component.
- **Constellation:** Constellations are modules composed of Stars or other Constellations. Their purpose is to combine modules into a logical entity, such as a login form, without injecting data or application logic. There is no fixed amount of hierarchy levels, and Components can be nested multiple times if needed. A Constellation is a design and an application component.
- **Galaxy:** The Galaxy handles component changes and injects data into them. It communicates with the model to receive and send model data. Moreover, the Galaxy can contain system logic to handle the states of its components. A Galaxy is a pure application component.
- **View:** The View consists of at least one component. Its only purpose is to display compositions of components; it does not handle any state changes or logic itself. A View is a design and an application component.

Figure 7 illustrates the different component classes of the system and how they relate to each other.

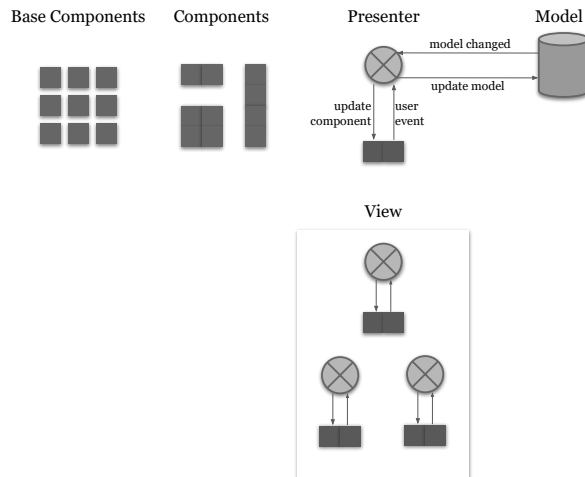


Figure 7. The component classes of Cosmic Design.

Cosmic Design, developed as a result of our findings and designed to address the inherent challenges identified within the Atomic Design system, is structured to promote clarity, intuitiveness, and modularity in digital platform development. To apply Cosmic Design in the design and development of a digital platform, we suggest first categorizing UI elements into components and then translating the design into code. The categorization of UI elements into 'Stars' (basic building blocks like buttons and inputs), 'Constellations' (combinations of Stars or other Constellations for logical entities, such as forms), and 'Galaxies' (components handling logic and data, ensuring state management and data integration) as a first step aims to promote a clear understanding of the role each component plays within the system architecture. In the second step, designers and developers should collaborate to translate the design into code and develop not only the design components (Stars and Constellations) but also application logic components (Galaxies). This way, the categorization can be used as a shared language between designers and developers to enhance efficiency and reduce misinterpretation during development phases.

While Cosmic Design consists of equally many components as the Atomic Design system, the structure and component definitions are different. When translating components from the Atomic Design system to the Cosmic Design, View components remain the same, and Stars replace Atoms, representing the most basic design elements. Molecules and Organisms, on the other hand,

would both be classified as Constellations, symbolizing interconnected elements.

With the Galaxy, however, a pure application component is added that has a place exclusively in the codebase rather than in the design. Adding this novel component with its exclusive function fosters several desirable system characteristics. The component organisation follows the separation of concerns (Hürsch & Lopes, 1995) by introducing the Galaxy, a pure application component, and elevates the system to a multi-purpose system that encourages a clean translation from UI components to software components. Moreover, the isolation of design and application logic promotes easier maintenance of the system. Changes in the handling of data can be integrated without affecting the design of the components, which reduces the time to undertake those changes. Additionally, by segregating application logic and data handling from the design, the system supports the reusability of design components. Design components can thus be easily reused across the system and even in different projects without the need to extricate application logic first. The separation of the different aspects of the system into specialized components also supports clear communication among practitioners. Different teams involved in the development process, such as designers and front-end developers, can collaborate more efficiently with fewer potential sources of conflict. Furthermore, a system with clearly separated application and design components paves the way for the inclusion of citizen developers. A citizen developer is someone who uses low-code/no-code platforms and technologies to develop digital components, even if they have limited or no formal training in development (Berardi, 2023). Citizen development empowers non-technical users to create, automate or optimize processes, applications, or systems that solve specific needs or challenges. It democratizes technology development by making it accessible to everyone, regardless of technical expertise. A design system with a clear separation of concerns allows practitioners with lower technical expertise to participate and contribute to the development of the system, leading to a more collaborative and innovative development environment (Iho et al., 2021).

Through the introduction of the Galaxy component, the Cosmic Design system transforms into a multi-purpose tool that not only fosters a clean and efficient transition from UI components to software components but also enhances the scalability and maintainability of the system. By creating a clear delineation between application logic and design components, the Galaxy component supports a more modular and adaptable structure, revolutionizing the process of integrating design changes and promoting a more sustainable and efficient development lifecycle. Moreover, while we analyzed design systems in the context of a digital health platform, the findings are not specific to this application area. Design systems are widely used across different fields to create a consistent brand identity, enhance collaboration, and simplify system maintenance through increased reusability. The issues and the derived design principles contribute to the general understanding of an ideal composition of design systems. Thus, our findings foster a transparent, inclusive, and engaging design process of IS.

The issues with the design system that our findings revealed show, that there is a need for further research in this area. Currently, design systems are

used in practice but lack a thorough scientific understanding. Our work takes a first step to bring together practice and research, by offering not only foundational design principles but also a distinct design system that can be applied by practitioners. By addressing the current challenges of IS practitioners and providing them with knowledge they can utilize, our research holds relevance in IS practice (Benbasat & Zmud, 1999). The [name masked for blind review] platform, central to our study, exemplifies the challenges and opportunities presented by modern digital health platforms. Its complexity in terms of data management, user interaction, and accessibility makes it an excellent environment to apply and evaluate design systems in practice. The Cosmic design system that we have developed presented a design solution to concerns regarding the increasing complexity of digital platforms (Blaschke et al., 2019).

Furthermore, our results also shed light on the theoretical understanding of the workings of design systems. Thus, we pave the way for a more informed development and use of such systems in practice, as well as provide a basis for further research on the topic. Our research, therefore, emphasizes practical engagement and addresses the need in IS to explore inclusive, engaging contemporary real-world problems in the spirit of the Scandinavian tradition of design, through theoretical engagement and development (Müller, 2023).

We see the need for further research to assess the effectiveness of the design system we have developed. This evaluation could involve examining the ease with which the design system can be implemented in the design process as well as its applicability in the application development phase. Specifically, the analysis could focus on the system's user-friendliness, adaptability, and compatibility with existing design and development practices. Furthermore, there is a need for empirical evidence to validate the effectiveness of proposed design principles in practical applications.

## 6 Conclusion

Our research focused on the benefits and drawbacks of modular design in the context of a UI Design system. We found that modular design can enhance the reprogrammability and maintainability of digital platforms and UI design systems, such as Atomic Design, can improve the efficiency and consistency of UI development. However, driven by the lack of clarity in the Atomic Design system's definition and limited guidance on how to integrate it into the application logic, we conducted an experiment using a mixed-method approach drawing on action research. The action research enabled the identification of the drawbacks of organising design components according to the Atomic Design principles, leading us to improve upon the component structure and contextualize the design components within the application logic. Based on the results of this experiment, we derived three design principles for UI design systems. To conceptualize those design principles and translate them into a meaningful design system, we crafted a novel design system called Cosmic Design, which specifically caters to the design and development of complex

platforms with a graphical user interface. The *Cosmic Design system*, outlines the main contribution of this paper. It follows the design principles we drew from the action research and enhanced the design components with an application component to aid with the translation of design into code. Overall, our research demonstrates the importance of modular design and the need for clear and effective design systems when designing and developing complex digital platforms.

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## A.5 Paper 5

## VALID Care Pathways: A Framework for Meaningful Digital Platform Design

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### Abstract:

Despite the advancement in design, development and use of digital platforms in general, data-driven platforms and novel use of emerging technologies in healthcare, in particular, have been lagging behind. Sleep is one of the fundamental pillars of health and the cognitive functioning connected to sleep deprivation has, to date, not been researched to a large extent. Moreover, cognitive functioning is usually measured in an in-laboratory setting, although digital measuring at-home would be beneficial. Thus, digitally measuring cognitive functioning over an extended period of time can provide valuable insights into sleep health. Based on findings from a two-year action design research project, dimensions of the design and development of a digital platform to deliver at-home measuring of cognitive functioning were explored. The digital platform was designed with the primary objective of achieving high usability while preserving the validity of relevant clinical measurements. The main contribution of this paper consists of conceptualizing and theorizing care pathways through digital platforms based on our novel findings from co-designing and evaluating the platform with professionals and 55 participants, leading to the formulation of VALID framework to inform the ongoing design and development process of digital platforms of the future.

**Keywords:** Action Design Research, Healthcare IS, Health Information Technology, Digital Care Pathways.

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## 1 Introduction

Emerging technologies have driven recent advances in the digitalization of healthcare systems worldwide. However, when compared to the overall digitalization of society, the healthcare sector still lags significantly behind (Hochwarter et al., 2022; Ellingsen & Monteiro 2012; Monteiro et al. 2013; Fitzgerald and Russo 2005; Fitzpatrick & Ellingsen, 2013). This technological gap in digitalizing healthcare, including sleep care, can be attributed to the challenging nature of entering the highly regulated healthcare market, as well as the difficulties associated with developing software that aligns seamlessly with healthcare practices (Fitzgerald & Russo, 2005; Ellingsen et al., 2013). This situation is disconcerting, considering that digital platforms hold great promise in addressing the increasing demands posed by factors like an aging population (Bonina et al., 2021; Isind, 2018; De Reuver et al., 2018). As the healthcare sector is struggling with the current demand and lack of resource, which will likely worsen in the future, it has become imperative to bridge this gap.

Digital health platforms that can be used at the by patient in their own home are key to addressing this need (Cancela et al., 2021; Golinelli et al., 2020). These digital platforms for at-home use can enable a more longitudinal data collection. Larger data sets, in turn, make the application of artificial intelligence and machine learning for pattern recognition feasible and create the potential for new diagnostic insights (Arnardottir et al., 2022a; Thurman et al., 2018; Cancela et al., 2021; Germine et al., 2019). Such longitudinal health-related data can consist of wide range of data points such as lifestyle, physical activity, physiological measurements and measuring of cognitive functioning. Due to the heterogeneity of the data collection that most multi-disciplinary research projects call for, there is a dire need for data-driven digital platforms to cope with such diverse data.

Within the healthcare sector, sleep care, in particular, holds immense potential for transformation through the power of digitization (Schmitz et al., 2022; Sveinbjarnarson et al., 2023). As one of the fundamental pillars of health, sleep affects a wide range of physiological functions. From restorative processes and hormonal regulation to cognitive performance and immune system functioning, quality sleep plays a vital role in maintaining overall well-being (Walker 2021; Benjafield et al. 2019; Filip et al. 2017; Hillman and Lack, 2013, Karlgren, Brown, & McMillan, 2022). However, the assessment and management of sleep-related issues have traditionally relied on subjective reporting or cumbersome objective in-laboratory sleep studies, limiting accessibility, scalability and reach (Arnardottir et al., 2021, Biedebach et al., 2023). These issues have caused a lack of longitudinal studies of sleep and cognitive function (Arnardottir et al., 2022a; Tai et al., 2022; Thurman et al., 2018) and further research is needed to investigate long-term effects and fluctuations in general and sleep deficiency in particular (Arnardottir et al., 2022a; Irwin et al., 2016; Deering et al., 2020).

The advent of digital platforms presents an impactful way forward to tackle this issue by revolutionizing sleep care through remote, continuous monitoring and feedback delivery to both individuals and healthcare providers (Benfeldt et al., 2020; van der Aalst et al., 2019; Pauli et al., 2021; Schrieck et al. 2023a,b). Wearable devices, such as sleep-tracking sensors, can collect objective sleep data in a non-intrusive manner (Pires et al., 2023). Similarly, mobile applications can enable the longitudinal collection of subjective data. Subjective data can be understood as lived experiences, whereas objective data typically refers to sensor data. Moreover, the integration of a mix of objective and subjective data into digital platforms has can help individuals can gain novel insights into their sleep quality and allow researchers to identify patterns. Thus, patients are enabled to make data-driven decisions regarding lifestyle modifications or seeking medical advice (Arnardottir et al., 2021). Simultaneously, healthcare professionals can remotely monitor their patients' sleep profiles, offer personalized recommendations, and intervene proactively (Arnardottir et al., 2021; Isind et al., 2019).

Moreover, the focus of sleep care has, up until this point, been on measuring sleep with several sensors for one night or by answering surveys at a certain point in time. Due to the known variations in sleep, understanding sleep in a more holistic way is therefore needed (Biedebach et al., 2023). Ergo, tackling and grasping the longitudinal elements of fluctuating sleep patterns and cognitive function for understanding the underlying elements of sleep and tailoring personalized digital care pathways outlines the focus of this paper.

Regarding the history of sleep measurements, sleep diaries have been the primary focus of digitization efforts in sleep care (Tonetti et al., 2016; Vacaretu et al., 2019; Schmitz et al., 2022). We outline these as digitization efforts instead of digitalization efforts, as most sleep diaries have primarily been moved from an

analog survey format to a digital survey format, taking little or no advantage of dynamic structures and generativity that the design and development of novel digital solutions can bring. Taking advantage of the generative nature and integrating different users' needs have been outlined as critical factors for moving from digitization to digitalization (Kempton, 2022). Digitization is thereby understood as efforts of translating an analog artifact into a digital artifact, while digitalization is seen as efforts of fully utilizing the digital environment to enhance the practices surrounding the digital processes in a cohesive socio-technical manner.

Some efforts have been more innovative, including new interactive features such as sliders and gamification elements that allow for enhanced interaction, leading to a better user experience (Schmitz et al., 2022). Sleep diaries outline a promising way of collecting longitudinal subjective data that can aid the diagnosis of sleep disorders such as insomnia (Kristbergssdottir et al., 2023). However, the data from a sleep diary alone is, in most cases, not sufficient to identify sleep disorders with certainty (Palagini et al., 2022). While advances have been made in the development of equipment for at-home home sleep measurement devices, which can allow for sleep measurements at patients' homes (Kainulainen et al., 2021), the equipment is still costly and cannot be easily distributed to a broader demographic. In addition to that, the gold standard for at-home sleep measurements is one to three nights, which simply does not allow for enough time for fluctuations in sleep patterns, for instance, for females, where the sleep patterns can differ extensively brought on by the menstrual cycle (Óskarsdóttir et al., 2022). In sum, there have been some advances in terms of subjective data and others in terms of objective data. Still, there is a gap in the literature concerning the integration of heterogeneous longitudinal data sources into reliable care pathways, and especially when it comes to cognitive functioning. Digitalizing it for at-home measuring has the potential to allow researchers to gain novel insights through the analysis of novel longitudinal data. Furthermore, due to the impact of sleep disorders on cognitive performance (Jóhannsdóttir et al., 2021; Arnardóttir et al., 2022a; Guo et al., 2017; Leng et al., 2017), a digital assessment of cognitive functioning could be pivotal for collecting objective data for improved detection of untreated sleep disorders. Measuring cognition can help monitor the cognitive capacities in a person and detect symptoms of a decline, such as attention loss, the downturn of executive functions, memory impairment, or effects on mood regulation (Jóhannsdóttir et al., 2021; Guo et al., 2017; Caporale et al., 2021; Palagini et al., 2019).

Therefore, the design and development of novel digital platforms that integrate heterogeneous objective and subjective data into cohesive care pathways that enable interoperability and congruence is vital for the future of sleep care. Nevertheless, inherent challenges are involved in designing and developing such a digital platform. It is crucial to establish user engagement as a priority while simultaneously ensuring the validity of measuring cognitive functioning and other similar impactful measures. This paper presents a two-year-long action design research project aimed at designing and developing a dynamic digital platform. The unit of analysis in this paper is on the elements of the digital platform, meant for digitally measuring the cognitive functioning of our participants. Our primary focus lies in evaluating the digital platform's usability to reimagine care pathways for sleep care, specifically focusing on measuring cognitive functioning. We pose the following research question:

**RQ1:** What are the characteristics of the design and development of a digital platform that allow for the creation of meaningful care pathways?

Our main contribution is theorizing care pathways through digital platforms based on our novel findings from digitalizing the measurement of cognitive functioning. We provide VALID care pathways as a framework to inform the ongoing design and development process of digital platforms for reimagining care pathway delivery of the future. The framework is a conceptual tool that delineates the essential characteristics of successful and effective digital care pathways: being *viable*, *accessible*, *lean*, *informed*, and *doable* (VALID).

## 2 Background

The healthcare sector is experiencing a digital transformation in the form of digital platforms that change care delivery. A digital platform can be understood as a piece of software that connects users with resources, services, and other users online (Constantinides et al., 2018; Blaschke et al., 2019; Boudreau & Hagiú, 2009; Gawer, 2022). Thus, digital platforms provide an infrastructure to facilitate interactions, transactions, and collaboration (Smith & McKeen, 2011; Hagiú & Wright, 2015). In the healthcare context, digital platforms are specifically used to provide care for patients (Islind et al., 2019) and, thus, generate value for patients (Porter & Teisberg, 2006; Teisberg et al., 2020). Previous research on digital health platforms has focused on health outcomes (Faik et al., 2020; Gleiss et al., 2021), user engagement (Barrett et al., 2016; Schmidt-

Kraepelin et al., 2020), user-centered design (Tempini, 2015) and on improving accessibility (Nicholson et al., 2021). This research has emphasized the importance of the user experience of digital platforms, which can be fostered through novel approaches such as digital nudging (Lehrer et al., 2021) or gamification elements (Schmidt-Kraepelin et al., 2020). Moreover, keeping the technical complexity of digital platforms low has been shown to improve the user experience of digital platforms (Jiang & Klein, 1999).

However, what characteristics foster a meaningful design is not entirely understood, as illustrated by the many examples of failed integration of digital health platforms in the literature (Ellingsen et al., 2013; Fitzgerald & Russo, 2005; Bygstad & Øvrelid, 2020). These studies describe designs that failed due to not meeting the needs of their users, which shows the importance of a holistic co-design approach for digital health platforms (Cancela et al., 2021; Islind et al., 2019). A careful digital platform design process involving relevant stakeholders is an important step for achieving meaningful design (Islind, 2018).

### 2.1 Measuring Cognitive Functioning

Research has shown a connection between sleep-related health issues and neurodegenerative processes (Przedborski et al., 2003). Neurodegenerative processes refer to the loss of neuron structure and function. Indicators of neurodegeneration have been found in patients with obstructive sleep apnea, which, in layman's terms, is a sleep disorder where the patients' breathing is interrupted during sleep. These show changes in cerebrospinal fluid (Cui et al., 2022) and alterations in brain anatomy and activity as observed through structural (Chen et al., 2015; Lee et al., 2022; Koo et al., 2023) and functional neuroimaging techniques (Canessa et al., 2018; Fortin et al., 2020).

To assess the cognitive impairments associated with sleep-related health issues in general and obstructive sleep apnea in particular, researchers have employed various neuropsychological tests in the lab, which poses a drawback as patients are in pressed environments, and the tests can merely be administered once and not continuously (Arnardottir et al., 2020). Despite some inconsistencies in findings due to methodological variations and the challenge of selecting tests with suitable difficulty level, certain cognitive functions, such as working memory, have been consistently found to be impaired in sleep-related health issues in general and for patients with obstructive sleep apnea in particular (Bucks et al., 2017; Jóhannsdóttir et al., 2021; Saunamäki & Jehkonen, 2007; Gagnon et al., 2014). The continuous measurement of cognitive functioning is important for tracking its progression and, thus, understanding the impact of sleep on neurodegenerative processes in patients with sleep disorders. Moreover, identifying specific cognitive impairments linked to sleep-related health issues in general and obstructive sleep apnea, in particular, can direct interventions aimed at alleviating these effects, thereby enhancing the quality of life and reducing the risk of long-term neurological decline.

Until now, cognitive functioning assessments have predominantly taken place within controlled laboratory environments. However, the concept of continuously monitoring cognitive functioning over time presents a groundbreaking opportunity to deepen our understanding of how cognitive performance correlates with sleep patterns. Traditional in-lab testing can be burdensome and exhausting for participants, as it usually involves a succession of tests with little respite. Previous research has largely concentrated on the creation and adaptation of singular cognitive tests for specific devices by digitizing them, moving them from analog to digital without altering any conditions around them. Instead of merely making them available for at-home measuring, there is a dire need to embrace the full extent of the novel digital means that are at the forefront (Arnardottir et al., 2022b). Therefore, it is vital to research efficient and modern approaches to collect and visualize cognitive data over an extended period of time in order to tailor digital care pathways and provide an in-depth understanding of the impact of sleep. This would provide a more accurate representation of individuals' cognitive abilities (Jaeger, 2018). Against that backdrop, our study proposes the digitalization of multiple cognitive tasks, integrating them into a single digital platform. This approach not only facilitates a more streamlined and efficient monitoring process but also offers a comprehensive overview of cognitive function trends over time.

To address these challenges, Jóhannsdóttir et al. propose a set of cognitive tasks suitable for assessing various cognitive functions specifically in the context of sleep health. To cover different domains of cognitive functioning, Jóhannsdóttir et al. recommend, among others, the following measures: (i) Simple reaction time, (ii) word list learning, (iii) digit symbol coding, (iv) line orientation and (v) paced auditory serial addition test. Furthermore, Ballezio et al. highlight (vi) the Tower of London as a suitable task for measuring cognitive functioning in sleep research, as individuals with insomnia tend to exhibit worse performance on this task compared to individuals without insomnia (Ballezio et al., 2019).

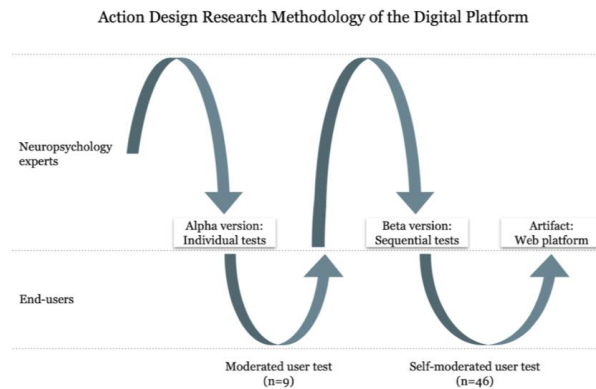
Firstly, the simple reaction time task measures motor skills by timing an individual's reaction time to a stimulus (Deary et al., 2011). Participants are asked to react to a visual stimulus by pressing the screen or a key on a keyboard. Secondly, the word list learning task measures the immediate and delayed recall of 10-15 words (Lezak et al., 2004). Participants are presented with a series of semantically unrelated words in either written or audio form and are then asked to recall as many as possible (de Sousa Magalhães et al., 2012). Thirdly, the digit symbol coding task is designed to evaluate attention and processing speed of information (Wechsler, 1955). Participants are presented with a table that maps the numbers 1-9 with specific symbols. Participants are then presented with a series of symbols and need to enter the number corresponding to each symbol as quickly as possible in a given time period (Jaeger, 2018). Fourth, the line orientation task measures visuoperceptual abilities, visual matching, and spatial relations (Lezak et al., 2004). Participants are shown a single line at a specific angle, followed by a set of 15 lines with different angles. Their task is to match the single line with the line in the set that has the same angle in a specified time interval (Strauss et al., 2006). Fifth, the paced auditory serial addition test (PASAT) assesses working memory, divided attention, information processing speed, and sustained attention (Lezak et al., 2004). Participants are either read or shown a random series of numbers from 1-9 and are required to add each pair of numbers. In the digital version, a circle of numbers from 1-18 is displayed on the screen. Participants are tasked with listening to or reading the first two numbers, calculating their sum, and clicking on the corresponding answer on the number circle as quickly as possible. The process continues for each subsequent number. This measure is frequently used for studying sleep disorders (Fulda & Schulz, 2001). The sixth test, recommended by Ballesio et al. (2019), is the Tower of London task. The Tower of London task evaluates executive functions such as cognitive flexibility and updating (Baker et al., 1996). Participants are shown three posts of different lengths and three colored balls. By rearranging the balls one at a time, participants need to transform the starting pattern of the balls on the posts into the given goal pattern.

### 3 Methodology

In a two-year spanning research project, we designed and developed a large-scaled digital platform. The platform includes various components for sleep research and at-home measuring of cognitive functioning, which is the focus of this paper. Figure 1 illustrates the design and development process following an Action Design Research (ADR) approach to measuring cognitive functioning. ADR is a methodology that combines action research and design science to address complex issues by iteratively designing and testing artifacts in real-world environments (Sein et al., 2011). This approach emphasizes joint development by researchers, experts, and users. ADR does not only help to develop effective practical solutions but also to uncover knowledge through the learnings from designing the solution (Mullarkey & Hevner, 2019).

In a co-design approach, we involved multiple stakeholders in the design process (Islind, 2022). More specifically, we have utilized co-design workshops with neuropsychologists to ensure measurement validity while aiming for high usability and user experience alongside end-user involvement with a total of 55 participants. The user tests employed a comprehensive approach to evaluate the usability of the digital platform. In the alpha phase, moderated user tests were performed individually under supervision with a focus on user experience. In contrast, the participants of the self-moderated user tests in the beta phase only received initial instructions and an opportunity for follow-up questions once and completed the tasks otherwise without supervision. Firstly, participants were asked to complete various cognitive tasks on the platform, which allowed us to gather real-time observational data on their interactions and behaviors during supervised sessions. Following the completion of these tasks, participants were asked to complete questionnaires to further assess their experiences and provide additional feedback.

The questionnaires that we used to evaluate were the System Usability Scale (SUS) and the AttrakDiff. The SUS, developed by Brooke in 1996, is widely validated. The questionnaire measures usability and is comprised of ten rating scales ranging from 0 to 10, and the ratings are added up to an overall usability score that ranges from 0 to 100 (Brooke 1996). The average SUS score, generally, is 68, and any result below this threshold indicates some underlying issues. If the score exceeds 80.3, the system is considered to be of high quality.



**Figure 1. Our design and development process following the action design research methodology.**

The second questionnaire we used was the AttrakDiff. The AttrakDiff measures experienced hedonic and pragmatic quality and user experience of interactive products (Hassenzahl et al., 2003). It evaluates four aspects of the artifact, those being pragmatic qualities (PQ), hedonic qualities—identity (HQ-I), hedonic qualities—stimulation (HQ-S), and attractiveness (Att). PQ describes the usability of the platform and how well users are achieving their goals. HQ-I indicates how well the users identified with the product. HQ-S measures to what extent a product supports the need to develop and move forward. ATT describes the global value of the artifact based on the quality of perception.

In order to measure cognitive functioning such as the aforementioned ones, researchers predominantly utilize software tools for measurement in experimental settings. These software tools are specifically designed to create and execute psychology and neuroscience experiments within an in-laboratory setting. The features of these software tools include different capabilities of stimulus presentation, response recording, and data analysis. However, they are not commonly optimized for extensive customization, wide browser and device support, or the data integration necessary for suitable testing of cognitive functioning at home.

We designed and developed the digital platform as part of the Sleep Revolution. The digital platform design followed the overall design approach of co-design alongside the graphical profile of the Sleep Revolution project while keeping a neutral and functional look to allow for high validity of the cognitive measuring. The measures were implemented according to the literature, but several elements on the broad spectrum of gamification were prioritized by our users and were implemented to enhance the user experience. After careful consideration, we chose not to use any of these available software tools on the market and instead designed and developed a custom digital platform for our pan-European project as we needed a cohesive approach to cognitive testing. Furthermore, we wanted the data to be readily available for everyone involved in the project, ergo 39 hospitals, universities and clinical practices in multiple countries with over a thousand participants using the digital platform for clinical studies across Europe. An additional element that further strengthened the decision was that we needed the digital platform and its cognitive tasks to be available in 17 languages, which none of the existing software tools supported.

These are further elaborated on in the results section. In the project, measuring cognitive functions has been conducted in a laboratory setting. However, this is cost- and labor-intensive and does not allow for effective scaling between countries, which makes it unfit for broader distribution. To overcome these drawbacks, we chose to design and develop a custom module for at-home cognitive testing as part of our digital platform, primarily to ensure it could integrate seamlessly with our existing database and other

services. This approach has allowed us to create specific functionalities that meet our unique research requirements. We found that such capabilities were not readily available in established platforms for cognitive testing. Additionally, having complete control over updates and maintenance meant that we could make adjustments as needed, which was essential for maintaining stability and reliability that match our specific workflow needs. Moreover, implementing the cognitive functioning software ourselves was particularly advantageous for supporting at-home testing. The flexibility of our digital platform has been indispensable, especially as one of the goals of the Sleep Revolution is to move all measurements from the hospital and the laboratory setting, to the patient's home. By designing and developing our own digital platform to adapt to various home environments, we have been better able to manage experimental conditions and data collection, ensuring consistent quality and integrity of data across diverse settings and in addition to that, it has impact on the data governance, as well-structured data governance is one of the pillars of the project.

The digital platform underwent testing in two phases to ensure its usability and user experience. In the alpha phase, we organized a workshop involving two experts in neuropsychology. The primary goal of this workshop was to gather essential requirements for developing a platform that enables individuals to complete cognitive tasks in their own homes and to decide on a minimal but sufficient set of cognitive tasks to include on the platform. The tasks that were selected due to the results of previous studies and implemented as part of the platform were: i) Simple reaction time, ii) word list learning, iii) digit symbol coding, iv) line orientation, v) paced auditory serial addition test (PASAT) and vi) Tower of London. For the word list learning task and the PASAT, written and verbal versions were provided. In the written version, text was displayed on the screen. In contrast, the verbal version involved the presentation of the text as audio, without any visible text. Counting those as alternative versions of different measures, the platform included eight measures in total. We used the requirements gathered from the workshop to create the elements within our digital platform that incorporated the recommended measures discussed in the related work section.

### 3.1 Data Collection and Data Analysis

In the alpha phase, we conducted co-design workshops with two neuropsychology experts to design and develop the digital platform. The first version of the functionality of measuring cognitive functioning in the digital platform was then assessed by conducting a moderated experiment involving nine participants with a focus on user experience. The participants were asked to complete the cognitive tasks and to express their opinions on the digital platform while they performed the tasks. After the completion of the tasks, the participants were asked structured questions about their thoughts on the digital platform and their understanding of the cognitive task instructions. Finally, the participants were instructed to fill out the AttrakDiff and SUS questionnaires. Each participant took part in this experiment individually and was closely observed by an experimenter for the entire duration, who also noted any difficulties the participant experienced in using the digital platform. Since the completion of the task was supervised by an experimenter, we refer to this experiment as 'moderated'.

During the beta phase, we continued to refine the digital platform in an iterative manner based on the feedback received from the alpha phase. To ensure the usability changes were aligned with user preferences and needs, we conducted more workshops with the same two experts in neuropsychology. During these workshops, we discussed the results of the user tests conducted in the alpha phase and identified specific areas for improvement. To further evaluate the digital platform's performance and gather more comprehensive data, we conducted a comprehensive experiment with 46 participants. We presented the project to the participants and provided an explanation of the cognitive tasks they would be required to perform in the user test. Each participant completed the set of cognitive tasks four times as part of our experiment. The first administration of the tasks took place during a classroom session in the sleep course, where participants were able to gain support and clarify any uncertainties about the digital platform and the experiment setup. Subsequently, the participants completed the tasks three more times at 1 p.m. self-moderated without supervision. The testing sessions were conducted under three different conditions: after a 4-hour sleep restriction, after a normal night of sleep, and after a night of sleep extension. Importantly, there was always a night of normal sleep between each testing condition to ensure sufficient recovery and eliminate potential carry-over effects.

Table 1 provides an overview of the number of participants involved in each round of the cognitive measuring, as well as the number of participants who successfully completed each of the five cognitive tasks in each round on the digital platform.

**Table 1. Number of participants who completed the cognitive tasks in the two testing phases.**

Cognitive Task	Alpha Phase	Beta Phase			
		Baseline	Restricted Sleep	Normal Sleep	Extended Sleep
Auditory verbal learning	9	46	43	41	31
Digit symbol coding	9	45	43	41	30
Line orientation	9	45	43	41	31
PASAT-C	9	42	40	41	30
Tower of London	9	45	43	41	30

Following the completion of the tasks, we asked the participants to provide feedback through the SUS and AttrakDiff questionnaires. Additionally, a structured written form that included open-ended questions was sent to the participants, which they could answer freely. The form covered various aspects of the digital platform, including inquiries about the participants themselves and their experiences with the digital platform. This feedback provided an opportunity for the participants to share their thoughts on the digital platform's functionalities, ease of use, and overall satisfaction. We then performed a qualitative analysis of the feedback, labeling any negative and positive aspects of the digital platform that the participants reported, and subsequently grouped them by themes.

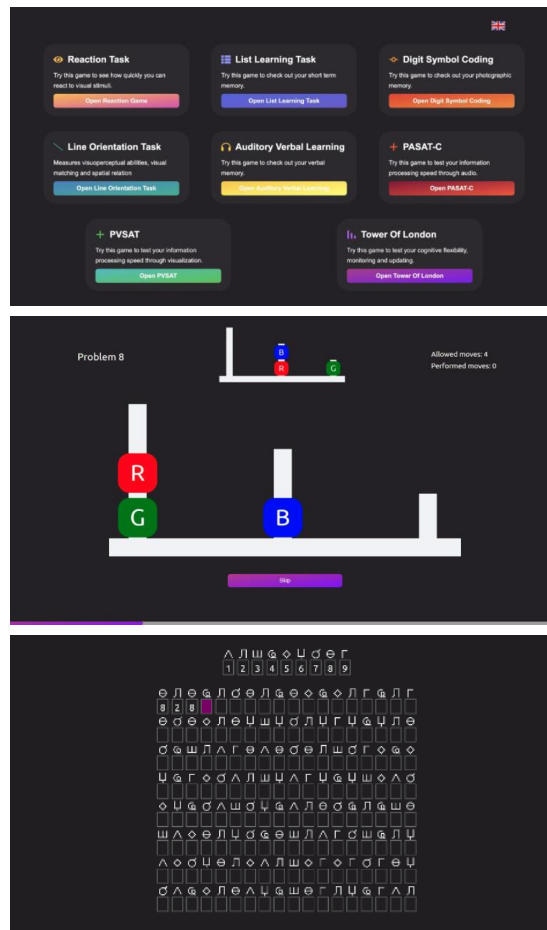
## 4 Results

As stated earlier in this paper, the digital platform as a whole is large-scale, but the particular part analyzed for the purpose of this paper is the measuring of cognitive functioning. The digital platform takes in and integrates objective and subjective data from a mobile application that includes a sleep diary while also taking in data from wearable devices, such as a smartwatch. Specifically, sleep studies that have been conducted in the context of the Sleep Revolution project and have used the digital platform have been collecting data from various sources. These studies have gathered sleep-related data from the Sleep Revolution mobile app, Withings scanwatch, at-home self-applied polysomnography, and additional measurements like body weight and height. All data sources, including the results from cognitive tasks, are sent to and stored in a secure database that is part of the Sleep Revolution platform. Researchers gain access to these results and perform data analysis and machine learning to uncover patterns and gain new insights into sleep health.

The overall goal of the digital platform, as such, is to enhance and modernize sleep care. The cognitive tasks had, up until this point, been delivered in a laboratory setting. However, the challenge of delivering them through a digital platform into the participants' homes in order to effectively monitor fluctuations in cognitive function alongside a decline in connection with sleep or lack of sleep is an important step both in terms of reimagining care pathways and moving diagnostics and treatment from the hospital to the home. The alpha phase of our research essentially outlined the development of the cognitive tasks in the digital platform, whereas the beta phase included digitalization, where we embraced the full extent of the digital technology by adding gamification elements such as a progress bar. During the beta phase, we gathered usability data through SUS and user experience data through AttrakDiff alongside qualitative results from the written form as well as the result data from the cognitive tasks on the digital platform.

### 4.1 Digital Platform Design

The digital platform was designed and developed following the requirements gathered in the workshop with neuropsychologists. The design of the digital platform was created prioritizing usability while maintaining validity of the measuring tools. A set of cognitive measurement tools were selected carefully to offer a minimal set of tasks that cover a wide variety of cognitive domains. Progress bars were implemented for tasks where they did not affect measuring validity. We implemented an overview of all available tasks for participants to start the tasks themselves, as well as a view that would present a predefined set of tasks sequentially. The page with the overview of the tasks and selected other task views are shown in Figure 2.




**Figure 2. Overview of the available cognitive tasks in the digital platform. Users can select a specific tasks from that view to perform. Selected views of the Tower of London and Symbol Digit Coding task.**


Each task started with a display of the task instructions and an optional practice round. The practice round included simple instructions and feedback. Users can solve the practice round without time constraints and can repeat the practice round until they solve it correctly. After the practice round, the users receive additional information that the round is about to start, and they can initiate the task with a button click. Upon completing the task, the users receive an overview of their task performance and can finish and return to the overview or the next task. Figure 3 shows these steps on the example of the Line Orientation task.

Line Orientation Task - Instructions

You will be shown a line like this:





Underneath, you'll see a set of 15 lines:



Next, you will start a practice. Identify and click on a line in the set that matches the angle of the single line. There will be two lines to match.

[Start Practice](#)




Click on the line in the set of lines matching the angle of the line on top.

[Skip Practice](#)



Incorrect, please try again!

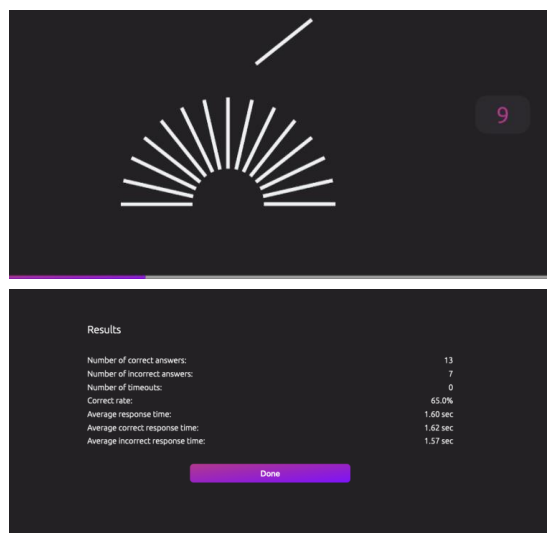
[Skip Practice](#)

 10

Line Orientation Task - Instructions

Now you are ready. There will be 20 lines to match and you'll have 15 seconds for each line. The timer on the right will count down the seconds.

[Start Line Orientation Task](#)



**Figure 3.** The different views and steps involved in performing a cognitive task in the digital platform, shown on the example of the Line Orientation task. The steps completing the task are in order: (i) users receive instructions of the task they are about to perform, (ii) the users start a practice round with short instructions and feedback and without time constraints to make sure they understood the task (users can also skip practice in case they are already familiar with the tasks), (iii) the users perform the cognitive task, and (iv) the users receive a summary of their task performance and can return to the overview page.

#### 4.2 Usability of the Digital Platform

The digital platform's final SUS score from the moderated user testing was 88.89, which indicates that participants considered the usability of the digital platform very good.

The digital platform's final SUS score from the self-moderated observation study was 66.32, indicating that participants considered the usability of the digital platform to have some underlying issues. The results from the form questions indicate that those issues were related to confusion regarding the task instructions. While optional practice rounds and detailed instructions were provided for all tasks, participants did not fully understand all tasks, which led to frustration.

#### 4.3 User Experience of the Digital Platform

Figures 3, 4 and 5 depict the AttrakDiff results from the moderated user testing. The portfolio presentation in Figures 3 averages values of the dimensions PQ and HQ. The horizontal axis shows the PQ and the vertical axis shows the HQ.

As shown in Figure 3, the confidence is slightly higher on the HQ scale, which means that participants were more conflicted on HQ than on the PQ. According to these results, the participant's experience of the digital platform was as desired, and they felt like they were completing tasks and moving toward a goal.

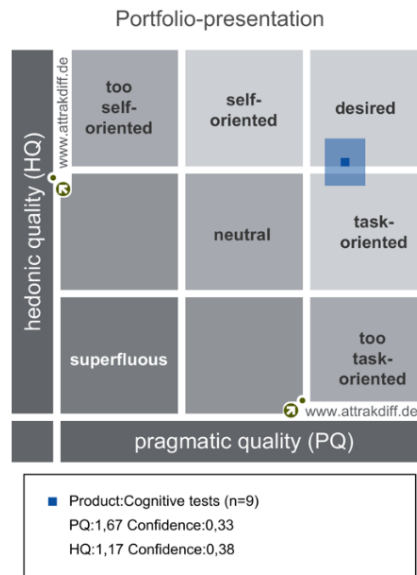


Figure 4. Moderated User Testing - AttrakDiff Portfolio Presentation

The diagram of average values in Figure 4 shows the score of the four categories in AttrakDiff and the overall attractiveness rating. PQ received a high score of 1.67 indicating that the users were successful in solving the task. HQ-I received a high score of 1.48, meaning the users can identify well with the digital platform. HQ-S received a score of 0.86. This is the lowest score, meaning the users felt the least support in the need for personal development. ATT received a high score of 2.44, indicating the users found the digital platform attractive.

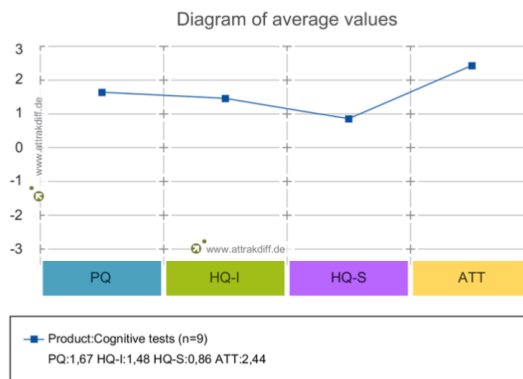


Figure 5. Moderated User Testing - AttrakDiff Diagram of Average Values

The description of the word pairs in Figure 5 shows the mean values of word pairs. It is noticeable that the attractiveness scores were high. Only one word pair (conventional) went below the neutral threshold while two other pairs (cautious and ordinary) were close to the threshold.

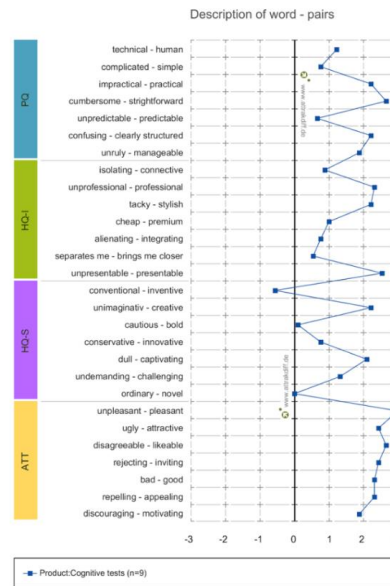


Figure 6. Moderated User Testing - AttrakDiff Description of Word Pairs

Figures 6, 7 and 8 depict the AttrakDiff results from the self-moderated observation study from the 36 out of 46 participants that answered the questionnaire.

The portfolio presentation in Figure 6 shows that the confidence is higher on the PQ scale, which means that participants were more conflicted on the PQ answers compared to the HQ answers. According to these results, the participant's experience of the digital platform was neutral.

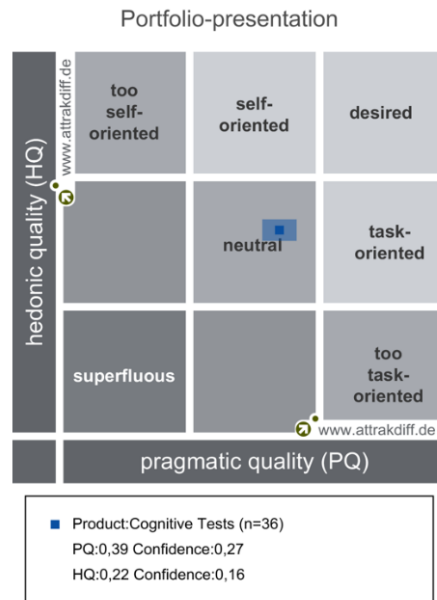


Figure 7. Self-Moderated Observation Study - AttrakDiff Portfolio Presentation

Figure 7 shows the diagram of average values received from the AttrakDiff questionnaire. PQ received a score of 0.39, HQ-I received a score of 0.17, HQ-S received a score of 0.26, and ATT received a score of 0.21.

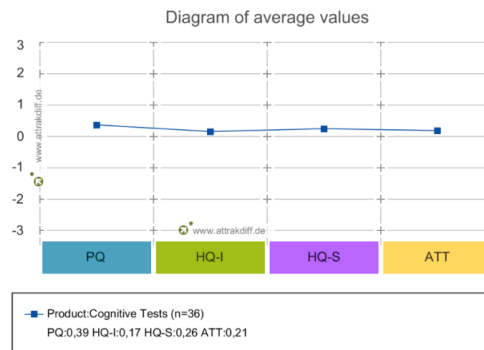
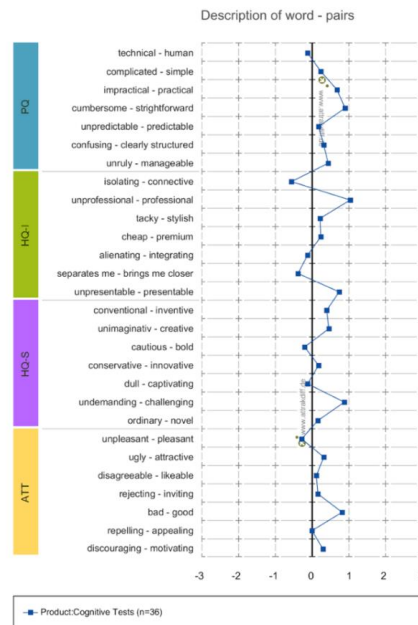


Figure 8. Self-Moderated Observation Study - AttrakDiff Diagram of Average Values

The description of word pairs in Figure 8 shows that most values are around the neutral threshold. It is noticeable that users found the digital platform professional and challenging, but also that it was isolating. In the context of an AttrakDiff evaluation, isolation refers to how separated or detached the user feels when interacting with a digital product.



**Figure 9. Self-Moderated Observation Study - AttrakDiff Description of Word Pairs**

The results of the study show that the majority of the participants liked the overall look and feel of the digital platform and thought it was easy to use and understand. Moreover, they also reveal that the instructions for PASAT-C were not clear enough and it was hard for participants to understand what they were supposed to do even though they were offered a practice phase.

The SUS scores showed a notable difference between the two test phases. The score from the participants in the moderated testing was 88.89, while the score from the 36 participants from the self-moderated test was 66.32. A reason for this difference in the average SUS score among participant groups could be attributed to the distinct setups for each group. In the moderated tests, the focus was on the look and usability of the digital platform and the participants were able to take breaks between the tasks. They also received the questionnaires by mail and could thus fill them out at a time that was convenient for them. In contrast, participants in self-moderated tests had to take the set of cognitive tasks for the fourth time in a span of six days right before answering the questionnaires. In particular, the task they completed last, which was the PASAT, is designed to create and evaluate frustration in participants. This might have influenced the perceived attractiveness and usability of the digital platform negatively. Taking these circumstances into consideration, it can be concluded that the usability of the digital platform is good even though the SUS score from the self-moderated observation study test group was slightly below average.

In addition, we found a difference in the AttrakDiff results between the two test groups. All four scores were lower in the self-moderated test group than in the moderated test group, displaying a similar trend as the SUS results. The biggest difference was in attractiveness where the score from the self-moderated test group was 0.21 but the score from the moderated test group was 2.44. The reason for this could be that the sequential task setup is not as attractive as the individual task setup. In the individual task setup, participants started on a landing page where they could select the tasks and participant feedback from the moderated testing indicated that this was the most attractive view of the digital platform. In the sequential task setup, this view was missing. The attractiveness of the sequential task setup might be improved by making the results screens, which are not part of the tasks themselves, more attractive.

## 5 Discussion

Despite the high potential for impactful care pathways through digital health platforms, there are still open questions in terms of what digital care pathways could look like (Connell et al., 2019) and which pitfalls to avoid (Ellingsen et al., 2013; Fitzgerald & Russo 2005; Bygstad & Øvreid, 2020). Patient-centered design that provide a good user experience have been shown to be important for the meaningful design of a digital health platform. A good user experience is fostered through a platform that is readily accessible, easy to understand and of low technical complexity (Jiang & Klein, 1999).

The insights we gathered throughout the action design research process further shed light on the unique challenges in the design of digital care pathways. Our workshops with experts revealed that aiming for high usability in a digital platform for measuring cognitive functioning while maintaining reliability of the measurements is a delicate balancing act. This finding is in line with the common reason for failed health application: low usability (Ellingsen et al., 2013; Fitzgerald & Russo, 2005; Bygstad & Øvreid, 2020). When the digitization of healthcare tools focuses the main attention on achieving validity, usability and user experience can unintentionally be neglected. However, the most reliable and effective tool is arguably of little use when it achieves only low rates of user engagement and compliance. We can, therefore, attribute the lag of digital health platforms (Ellingsen & Monteiro, 2012; Monteiro et al., 2013; Fitzgerald & Russo, 2005; Fitzpatrick & Ellingsen, 2013) to two main factors. Firstly, user experience and usability have proven low, which in turn leads to low acceptance of digital health applications. Secondly, the provider perspective has been valued higher in comparison to user perspectives, which in turn leads to a mismatch between technology and needs (Teisberg et al., 2020).

It is therefore of the utmost importance to employ a co-design approach for digital care pathways (Islind, 2022; Cancela et al., 2021; Islind et al., 2019). Finding the delicate balance of designing a reliable but engaging tool is a complex but worthwhile endeavor and can best be achieved by involving members from both the user and expert group in multiple stages of the design process. In our case, the workshops with experts and the usability and user experience tests with end-users resulted in several specific learnings that influenced our digital platform design:

**Use a web platform to maximize accessibility.** For the tasks to work for participants regardless of the operating system they are using, a web platform is a preferred format to deliver the tasks. Accessibility is an important factor for the success of digital health platforms, and it is therefore imperative to support as many devices as possible. In addition, digital platforms that run in the browser do not require an installation step, which contributes further to achieving a low technical complexity (Jiang & Klein, 1999). All participants in our user tests were able to run the cognitive tasks on their own personal computers. Aside from supporting multiple operating systems, browser compatibility should be prioritized in the development. Digital platform performances can vary by browser, and it is imperative to ensure a comparable performance.

**Display progress between task rounds.** Progress bars are a vital element of UX design. They grant the user a sense of control and help to keep them engaged (Harrison et al., 2010). Our results showed that the attractiveness and usability suffered in a sequential task setup. If such a sequential task setup is required for proper measuring of cognitive functioning, a progress bar between tasks has the potential to uphold the users' engagement.

**Avoid using a sequential task setup if possible.** The attractiveness of the system suffered from the delivery of the tasks in a continuous sequential format. While conventional cognitive measuring in a university or clinical location often involves a sequential task setup due to temporal and location constraints, participants can be given the flexibility to complete one task at a time in an at-home setting. It is important to leverage the advantages of the environment to improve the UX design.

**Design engaging interfaces around the task views.** Digital cognitive tasks have been carefully designed and even small deviations from validated designs can potentially render the measured data unreliable. Therefore, the task views have to be designed following official guidelines for the implementation and cannot be updated with engaging design elements without validation. The results of our user experiments showed that participants who were only exposed to the task views in a sequential setup rated the attractiveness of the digital platform lower than the users who completed the tasks individually and were brought back to a more attractive overview screen of the tasks. It is therefore important to use engaging and attractive designs on views around the tasks views, such as the landing page, instruction page or result page is not subject to those restrictions. As our results showed, participant perception of the digital platform was better when presented with the more attractive overview screen.

**Minimize distractions in the digital environment.** Even in an in-laboratory setting, the involved experts in neuropsychology reported interruptions of the measuring through phone calls and notifications participants received. While this can also not be fully controlled in an at-home setting, since participants complete the tasks on their own devices, certain technical options are given to minimize those distractions. We used a full-screen mode to deliver the tasks, and further options can be explored in terms of notification oppression and warnings if the browser tab is not in focus.

**Collect metadata for post-collection data validation.** While the prevention of unreliable data is a priority, it is equally important to enable post-validation methods (Ercole et al., 2020). Moreover, in-laboratory measuring of cognitive functioning is commonly done with special equipment, such as keyboards and mice, that shows minimal delays. At home, participants might not have comparable equipment. It is, therefore, vital to collect metadata such as timestamps and device or browser information to include in the analysis. Metadata can also potentially be used to identify whether the participants were focused on outside distractions, thus enabling further validation and rating of the data reliability.

**Incorporate guided practice rounds.** Participants showed difficulties understanding the tasks just through instructions. Considering the emphasis on usability, user experience and the importance of fulfilling participants' needs (Teisberg et al. 2020; Barrett et al. 2016; Schmidt-Kraepelin et al. 2020; Tempini 2015) while designing and developing digital health platforms, navigating possible solutions for this issue is a priority. In light of that, the practice phase can, for instance, be improved through a mandatory trial round with insightful feedback. This is especially important in an unsupervised setting. A practice round can not only help users understand their tasks but also ensure that the technical equipment is fully working, e.g., the audio is audible for the user. Practice rounds should be as short as possible to avoid frustration before the task as well as learning effects. At the same time, they should be sufficiently long for users to understand the nature of the task. Insightful feedback on errors in the practice round can enhance the user experience additionally and is to be preferred over purely positive and negative feedback.

### 5.1 VALID framework: Characteristics of Digital Care Pathways

While the presented learnings from this study are specific to our case for at-home cognitive measuring in a digital platform, we argue that the underlying motivations, challenges and contributions are not. We find that our learnings provide valuable insights into generally desirable characteristics of digital care pathways. These elements were conceptualized and synthesized into the VALID framework, which we propose as a contribution to the field of digital health platforms. The framework encapsulates a set of empirically derived design guidelines that inform the creation of effective digital health platforms. This conceptual framework extends beyond our immediate study, offering valuable insights into the general design and development practices of digital health solutions. In Table 2, we show which characteristics we derived from our results and learnings from the action design research to inform the creation of the VALID framework.

**Table 2. Elements of VALID Framework in our Digital Platform for At-Home Measuring of Cognitive Functioning.**

Characteristic	Examples in the digital platform design
Viable	<p>The cognitive tasks were designed following official guidelines and were evaluated by experts.</p> <p>Gamification elements to improve user experience, such as progress bars, were only added when previous research showed that they had no influence on measurement outcomes.</p> <p>A full-screen mode was used to deliver the task and make it less likely for users to exit the digital platform during cognitive measuring and minimize distractions that could compromise measured results.</p>
Accessible	<p>The digital platform was designed to be accessible through the most popular browsers on desktop computers.</p> <p>Instructions and practice rounds were offered to make it easy for all users to understand and complete the tasks in the digital platform.</p>
Lean	<p>Selected gamification elements with a clear purpose, such as progress bars, were added to improve user engagement and minimize frustration while keeping the interface designs straightforward.</p>

	A user-friendly overview page of the cognitive tasks was created in a simple yet friendly design to act as a clear and attractive landing page.
Informed	Metadata was collected in the form of timestamps to be able to perform an informed analysis of the measurement validity in the future.
Doable	An option was offered to complete each task individually to allow for more flexible time management instead of following the traditional sequential task setup in laboratory settings.

To develop the VALID framework, we began with a systematic analysis of the learnings we drew from our co-design, user evaluations and usability tests conducted to evaluate the usefulness, suitability, and proficiency of our digital platform for at-home measuring of cognitive functioning. Initially, the learnings were categorized into themes reflecting recurrent challenges and successful interventions. These themes informed the identification of key characteristics that should be taken into consideration in the design and development of a digital health platform in general. These characteristics were then mapped to specific examples and interventions within our digital platform, forming the basis of the VALID framework as presented in Table 2.

Each characteristic of the framework — Viable, Accessible, Lean, Informed, and Doable — combines insights derived from our findings. For example, the 'Viable' characteristic is based on the importance of following the expert requirements for the design in order to not compromise test validity by only embedding gamification elements such as progress bars when it did not affect the measurements. 'Accessible' was informed by user feedback, emphasizing the need for clear instructions and showing the benefits of practice rounds with detailed feedback. The 'Lean' characteristic was drawn from feedback that emphasized the importance of a clear design with few but purposeful design elements. The 'Informed' characteristic was derived from the need to collect metadata for validation that experts expressed in order to obtain reliable, high-quality data. Finally, the 'Doable' characteristic came from the feedback and observations that the sequential presentation of tasks typically done in laboratory settings was difficult for participants to complete.

We encapsulate the characteristics into the VALID framework for meaningful digital care pathways that foster a design that is:

- **Viable:** Digital health interventions need to be, above all, 'viable' in their implementation. This means that a system is in accordance with scientific findings and that it is able to generate intended value through health outcomes. Scientific soundness needs to be shown through rigorous user testing and evaluations. A co-design process that includes experts at every stage of the development phase is vital to ensure that the system is not only accepted by the end-users but also that it generates value for them and is scientifically sound. Therefore, perspectives of patients, healthcare professionals and researchers should be included in the design.
- **Accessible:** Digital care pathways must prioritize accessibility to reach a broader audience, both technologically and functionally. The functional design of digital care pathways should be straightforward and user-centered. Cluttered interfaces and vague instructions can lead to user frustration and cause the user to feel a loss of control. Such negative experiences can significantly diminish the user experience and the system acceptance. From a technological standpoint, supporting a variety of devices is vital to ensure inclusivity. Thus, web applications are particularly suited as they can be delivered through different browsers on various devices. Furthermore, web platforms eliminate the need for installation, further reducing technical complexity (Jiang & Klein, 1999). Similarly, restricting the digital application to a specific laboratory setup significantly narrows down the potential audience. Only when users can engage with the application on their own devices, on their own schedule, and in the comfort of their homes can we reach the full potential of accessible care pathways.
- **Lean:** A lean design of the digital platform that hosts the care pathway is a key component of building an engaging, doable, and accessible system. A 'lean' design describes the use of straightforward, clean and efficient interfaces. Including elements such as nudging or gamification can help to make the digital platform more engaging but at the same time, it is important to not overload the user with the interface. It is important that every design choice is carefully evaluated and, thus, deliberate. Unnecessary features that do not add value can add unnecessary complexity. Moreover, while it is important to make the interaction with the care pathway engaging, the design must not compromise its validity and integrity. It is, therefore, vital to keep the care pathway 'lean' and focus on achieving good usability with few deliberate features rather than detracting from the core purpose of the system.

- **Informed:** To be able to draw valid, scientific conclusions from digital care pathways that aim to improve health behavior, the digital environment should be used to collect helpful metadata. A complete image of a user's interaction is vital for an accurate outcome. Therefore, an 'informed' system collects relevant metadata and context, such as timestamps and device or browser specifics. This information can greatly improve the chances of interpreting the collected data correctly and potentially finding new patterns with artificial intelligence or machine learning methods.
- **Doable.** Applications that serve as digital care pathways often require the user to perform tasks within the system. Those tasks must be realistic in terms of the time and frequency it takes the user to perform them. Furthermore, they should be designed such that the majority of end-users is capable and able to understand and perform the tasks. This is particularly important in the context of digital care pathways as the end-user group consists of people with diverse backgrounds, varying levels of technological abilities, and, potentially, with disabilities. Moreover, as outlined earlier, low user engagement is a common cause of the failure of digital health platforms. Therefore, it is important to design the system such that users do not abandon the system due to its high complexity. A 'doable' design contributes to improved usability and helps to ensure the accessibility of the system.

By following these characteristics, distinct challenges in the design and development of digital care pathways can be overcome. The characteristics are related to each other, and the improvement of one can lead to the advancement of another. For example, gathering metadata creates an *informed* system which in turn can result in producing better outcomes for the users and, thus, increase *validity*.

The VALID framework outlines key elements necessary for the design and development of digital platforms, specifically in the context of digital care pathways. Unlike studies that examine the relationship between various risk factors and aspects of system success, such as the one by Jiang and Klein (1999), the VALID framework does not aim to identify success factors per se. Instead, it functions as a guide to fundamental design aspects that ensure the functionality and user engagement of digital platforms in general and digital health platforms in particular. While Jiang and Klein's work (1999) is centered on the impact of different risks on IS success dimensions, the VALID framework prioritizes collaborative, proactive design and development strategies. This approach shifts from a reactive risk management perspective to a proactive design perspective, emphasizing the creation of digital platforms that are accessible, engaging, and reliable. This focus on incorporating design principles from the outset enables the creation of digital platforms that inherently minimize risks rather than merely managing risks after they arise.

To sum up, the main contribution consists of theorizing care pathways through digital platforms based on our novel findings from co-designing and evaluating the digital platform with professionals and 55 participants, leading to the formulation of the VALID framework to inform the ongoing design and development process of digital platforms of the future. We contribute to the IS literature by theorizing design characteristics of digital care pathways and, thus, further the IS research on digital care pathways design (Ellingsen & Monteiro, 2012; Monteiro et al., 2013; Fitzgerald & Russo, 2005; Fitzpatrick & Ellingsen, 2013). Moreover, through our action design research, we designed and developed a digital platform that serves as a practical contribution and an example of the application of our provided conceptual framework of characteristics of digital care pathways.

## 6 Conclusion

We co-designed and developed a digital platform for measuring cognitive functioning and presented several learnings from our study that led to the formulation of general characteristics of digital care pathways in the VALID framework. The framework guidelines promote the design of digital health platforms that are scientifically sound (*viable*). They also emphasize *accessible* design that has a wide reach and is available to many people on a variety of devices. In addition, the guidelines include suggestions for a straightforward design that incorporates deliberate design elements to foster engagement without distracting from the core functionality (*lean*). Furthermore, utilizing digital platforms to collect context-relevant data that enables informed interpretations (*informed*) is highlighted. Lastly, the design needs to be *doable* for the users. They need to be able to easily integrate the care pathways into their lives or compliance will suffer. By following this framework, future digital health platforms can strive for improved usability, user satisfaction and compliance, as well as reliable data collection.

### **Acknowledgments**

We thank Eva Sól Pétursdóttir, Andrea Einarsdóttir and Hilmar Örn Jónsson for their contributions. This research was carried out as a part of the Sleep Revolution project, which has received funding from the European Union's Horizon 2020 Research and Innovation Programme under Grant 965417.

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