



REDEFINING MEASUREMENT: EXPLORING COUPLE'S SOCIAL INTERACTION DATA FOR PSYCHOLOGICAL WELL-BEING ASSESSMENT

Investigating how to design a holistic and
collective remote patient monitoring approach:

A data-enabled design for uncovering design opportunities, needs, guidelines,
and pitfalls to support future design and research activities

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Investigating how to design a holistic and collective remote patient monitoring approach: A meta-strategy for uncovering design opportunities, guidelines, and pitfalls to support future efforts.

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Abstract

The increasing demand for hospital check-ups strains our national healthcare system. Over the next 10 years, diagnosis and survivorship rates of colorectal cancer are expected to rise due to better detection methods and treatment innovations. Therefore, Remote Patient Monitoring (RPM) is being explored as a telehealth solution, but it faces challenges in addressing the multifaceted and subjective nature of mental health. Current mental health assessments are often biased and limited by a Western, individualistic perspective. This creates an opportunity to design a more inclusive, collective RPM strategy that involves a patient's social environment, especially their spouse, as dyadic coping (shared stress regulation) is more effective than individual coping. Therefore, the objective of this thesis is to investigate 'how to design a strategy to remotely monitor and contextualize mental health by leveraging romantic couples' collective and contextual data'.

This thesis indicated that social interaction is essential in maintaining relationship satisfaction, crucial in enhancing effective dyadic coping. A data-enabled design approach was applied to design a custom remote research tool-kit for seamlessly and compliant data collection, and contextualizing social interaction through visualizing and co-analyzing the collected data. User research was conducted over a period of 7 days (where 2-3 days were dedicated to data collection) with three Dutch, romantic couples aged between 55 and 75 years old, living together. Thematic analysis resulted in design guidelines, along with identified strengths, limitations, and future research opportunities regarding social interaction interpretation and contextualization. This thesis contributes to the design and research community by offering insights into romantic couples' social interactions and providing guidelines for creating holistic, collective RPM strategies for telehealth innovations, beneficial for cancer survivorship follow-up care.

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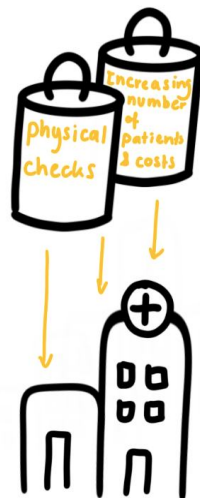


CHAPTER 1

INTRODUCTION TO THE PROJECT

In this chapter, I present the topic along with its key challenges, objectives, scope, and significance, supported by the main research questions. Additionally, I introduce the project's use case: colorectal cancer survivorship, which outlines the motivation behind selecting these objectives.

The increasing demand for physical check-ups in hospitals places a significant burden on our national healthcare system (Thomas, Banbury, Snoswell, Haydon, Rejas, Smith & Caffery, 2021). To address this challenge, healthcare innovation has increasingly focused on decentralizing care by bringing it into patients' homes. Remote patient monitoring (RPM) is a cutting-edge telehealth innovation that holds great promise in this regard. It enables timely medical interventions, improves health outcomes, and has the potential to reduce hospitalizations and associated healthcare costs.



1.1 Challenge

Remote patient monitoring (RPM) introduces unique challenges, particularly in understanding health as a complex interplay of biological, psychological, and social factors, rather than viewing it purely through a biological lens (Vizzotto, De Oliveira, Elkis, Cordeiro, & Buchain, 2013). While physiological monitoring is already prevalent in various healthcare settings, psychological monitoring is equally crucial but more challenging due to its multifaceted and context-dependent nature. Existing approaches, such as patient self-reports, often fall short by adopting a limited, Western individualistic perspective that overlooks the social dimensions of mental health and is prone to patient biases. Unfortunately, research on addressing these shortcomings remains sparse, highlighting a significant gap in the development of more holistic and effective RPM strategies.

1.2 Project Aim and Scope

To effectively address this challenge, a novel approach is needed that incorporates an holistic perspective on remote monitoring of mental health, taking an collective and context-aware approach. In this respect, the psychosocial environment, which refers to the influence of social factors on an individual's mind and behavior (Van Diest, S. L., Oudsten, Aaronson, Beaulen, Verboon, Aarnoudse & Van Lankveld, 2023), should be central.



Recent research highlights the potential for new methods of monitoring mental health, focusing on patients' romantic relationships as a primary social factor. Studies by Conradi et al. (2020) and Krocze et al. (2020) reveal the connection between spatial information and proximity-seeking behavior in couples, which is associated with attachment (Adamson, 2013) and dyadic coping (Bodenmann, Randall & Falconier, 2017). These dynamics are influenced by relationship satisfaction and the quality of interactions for the physical and emotional exchange of support (Ogolsky, Mejia, Chronopoulou, Dobson, Maniotes, Rice, Hu, Theisen & Leite (2021).

Relevance

After-treatment care plans often include psychosocial support, recognizing that physical, psychological, and emotional issues also, in turn, influence a patient's social behavior (Vizzotto et al, 2013). The impact of illness during recovery extends beyond the patient, affecting their social environment, particularly spouse (and family) caregivers (Rutherford et al, 2020). Spouses, especially, play a critical role in providing support and coping with stress to adjust a reality (Rutherford, Müller, King & White, 2020), and the satisfaction of this relationship is closely linked to the patient's mental well-being (Appleton, Goodlad, Irvine, Poole & Wall, 2013); Andreu, Martinez, Soto-Rubio, Fernández, Bosch & Cervantes, 2021). Assessing mental health from a holistic perspective, which includes the well-being of both the patient and their spouse, can inform more effective care plans and timely interventions tailored to their collective needs and context.

Aim

Therefore, my goal is to investigate how to design a strategy to remotely monitor and contextualize mental health by leveraging romantic couples' collective and contextual data. To be able to do this, I formulated three research questions:

- What is the psychosocial impact on couples in recovery after an illness and how does it affect mental health?
- How do couples navigate their emotional and physical space to (or not) maintain relationship satisfaction?
- How can (technology) design facilitate the interpretation of patient mental health data?



1.3 Use Case: Colorectal-Cancer Survivorship

To narrow the focus within this project, and being the main initiator to engage in this projects objective, I decided to use a *Use Case* as a lead for healthcare and illness-spectrum specific aspects regarding the design of a hollistic RPM strategy. Therefore, the use-case within this project is colorectal cancer survivorship.

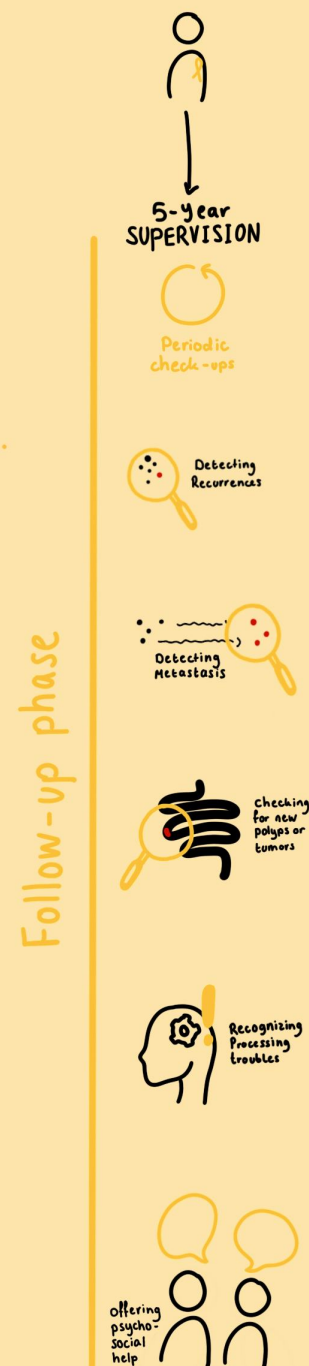
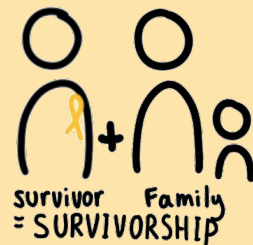
Colorectal Cancer Survivorship

Colorectal cancer is one of the most common forms of cancer in the Netherlands (Praagman, Slotman, Van Disseldorp & Lemmens, 2022). Anually, 128.000 number of people are diagnosed, and it is expected that this number will increase in the future (IKNL, 2024). Currently, 70% of colorectal cancer survivors live (IKNL, 2024).

The aforementioned trend and survival-rate does show the relevance for considering the after-cancer stage of living and healthcare, called cancer survivorship. Currently, cancer survivors are post-treatment under the supervision of their doctor(s) for 5 years; also called the follow-up phase (Maag Lever Darm Stichting, 2023). In this phase, cancer survivors have periodical check-ups on physical and mental health, most of the times within the hospital, and form a treatment plan together with their physician(s) accordingly.

Partner Involvement

As previously noted, the impact of cancer survivorship extends beyond the patient, affecting spouses and family caregivers as well. For this reason, the term "cancer survivorship" also encompasses these close caregivers (Rutherford et al, 2020).



However, in current therapeutic practices, the patient's partner is often only intermittently involved and is primarily viewed as a source of support in psychoeducational programs, rather than as an integral participant in the therapeutic process (Bodenmann, Randall & Falconier, 2017).

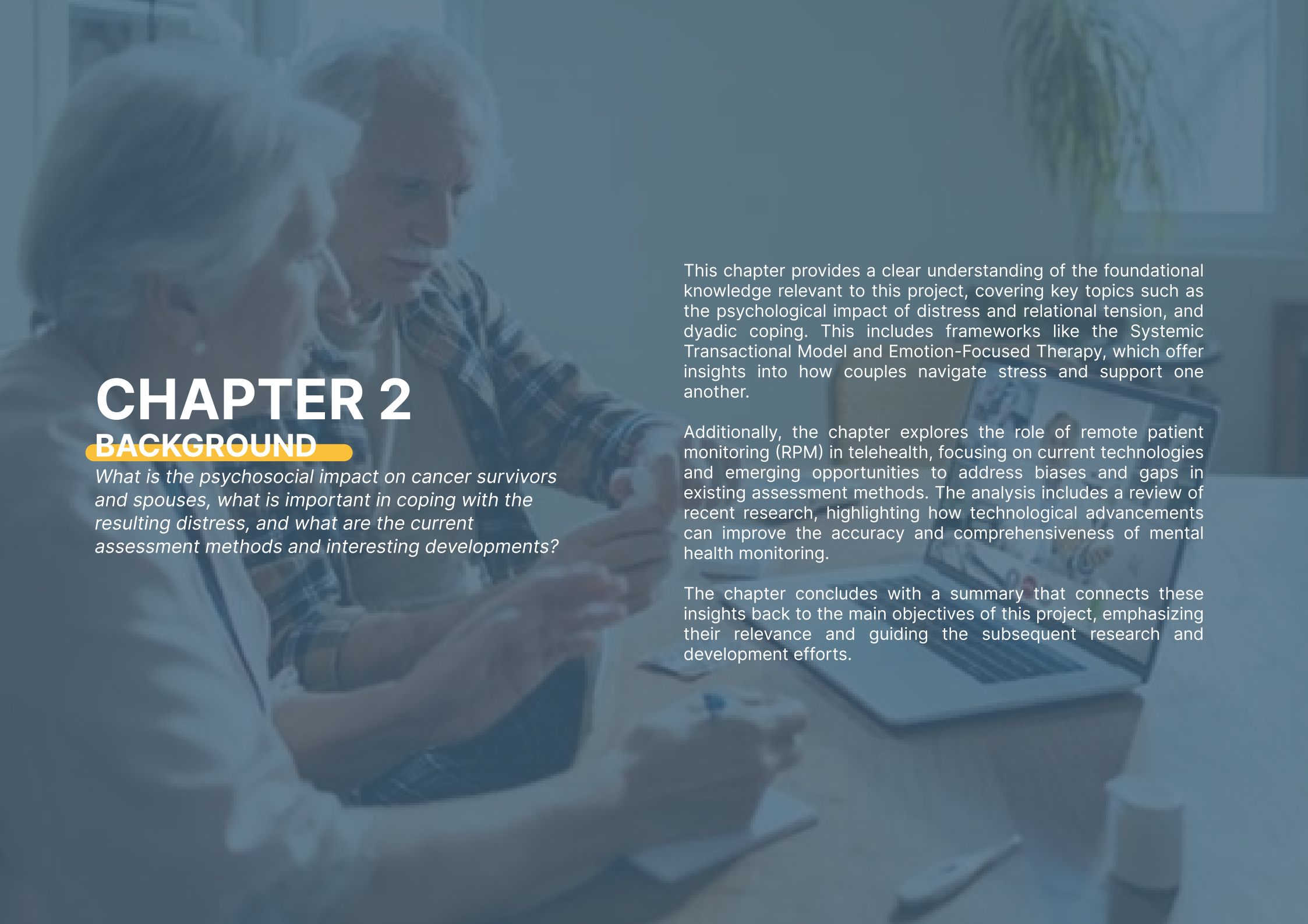
Target group

Colorectal cancer is most prevalent among individuals aged 55-75 years (IKNL, 2024), across various socio-demographic groups. However, to maintain focus and avoid unnecessary complexity in this project, I chose to concentrate specifically on patients and their spouses in general. Therefore, the target group for this use-case consists of cancer survivors aged 55-75 years, living in a romantic relationship, and within five years of their cancer survivorship.

Disclaimer

Given the sensitivity of this target group, engaging with them poses significant challenges and risks to their integrity. To mitigate potential difficulties and because relationship satisfaction, a key indicator of dyadic coping effectiveness related to mental health, is not necessarily illness-specific, the scope of the target group could be broadened. This would include romantic couples aged 55-75 years without direct experience or relation to cancer survivorship.

Fig. 1. Survivorship patient journey



CHAPTER 2

BACKGROUND

What is the psychosocial impact on cancer survivors and spouses, what is important in coping with the resulting distress, and what are the current assessment methods and interesting developments?

This chapter provides a clear understanding of the foundational knowledge relevant to this project, covering key topics such as the psychological impact of distress and relational tension, and dyadic coping. This includes frameworks like the Systemic Transactional Model and Emotion-Focused Therapy, which offer insights into how couples navigate stress and support one another.

Additionally, the chapter explores the role of remote patient monitoring (RPM) in telehealth, focusing on current technologies and emerging opportunities to address biases and gaps in existing assessment methods. The analysis includes a review of recent research, highlighting how technological advancements can improve the accuracy and comprehensiveness of mental health monitoring.

The chapter concludes with a summary that connects these insights back to the main objectives of this project, emphasizing their relevance and guiding the subsequent research and development efforts.

2.1 Psychosocial Impact in Cancer Survivorship

An illness, and the post-illness phase, does affect how patients and their family navigate their daily life depending on the diagnostic and curative intervention consequences (Van Diest et al, 2023). Therefore, I aimed to investigate aspects of daily life post-illness that lead to distress, negatively affecting mental health.

Method Used

To address the first main research question, *"What is the psychosocial impact on couples in recovery after an illness and how does it affect mental health?"*, I employed a systemic approach to identify individual and relational distress to understand the problem space, specifically within the use-case. This involved conducting desktop research and an exploratory investigation within an online community (Kanker.nl) to gather insights about the psychosocial impact. Below, I present the findings regarding physical-, psychological-, and social-related distress.

Demographic Characteristics

Patients immediately post-treatment are more likely to experience unmet psychological and social support needs (Andreu et al, 2021). Older patients, in particular, tend to underreport these unmet needs due to lower expectations of health services, a greater sense of stoicism, and the presence of taboos surrounding psychological or sexual issues.

Individual-Specific Distress

Cancer survivors often endure significant distress from psychosocial challenges, including sleep difficulties that contribute to fatigue, pain, bowel issues, changes in sexual functioning, fear of cancer recurrence, and financial strain (Averyt & Nishimoto, 2014). These challenges can lead to social impairments and negatively impact quality of life (QoL) (Appleton et al, 2013). Additionally, survivors frequently struggle with psychological consequences such as altered body image, low self-esteem, and survivor's guilt.

Spouses are also deeply affected by these psychosocial challenges, often taking on caregiver roles while managing additional household and financial responsibilities. The demands of caring for a partner's health-related needs can conflict with a spouse's autonomy and sense of personal significance, leading to emotional strain as their lives become increasingly oriented around their partner's well-being.

Relational Tension

Differences in survivorship experiences and a lack of emotional awareness can create misunderstandings and strain within a relationship. For example, while a spouse might see the survivorship phase as a new beginning and expect a return to normalcy, the cancer survivor may still struggle with feeling unwell or incapable of resuming their previous life, taking up pre-illness responsibilities within their household and in their romantic relationship. This disconnect can lead to added pressure and tension between partners. Psychological distress in couples is closely tied to the level of relational intimacy they share (Van Diest et al, 2023), making joint appraisals of distress crucial for preventing relational strain.

Intimacy

A secure and supportive partner relationship can help individuals cope with daily distress and adjust to physical challenges (Rutherford et al., 2020). However, the emotional regulation capacity of both partners is crucial (Appleton et al, 2013), and interpersonal stress regulation is often more effective than intrapersonal regulation (Van Diest et al, 2023). Therefore, problems and tensions in a relationship can undermine the ability to cope with physical and emotional challenges, as social support is commonly obtained through family, particularly one's partner (Taskforce Cancer Survivorship, 2020), and depends strongly on emotional intimacy, referring to how partners discuss their cancer-related concerns and the extent to which they avoid these discussions.



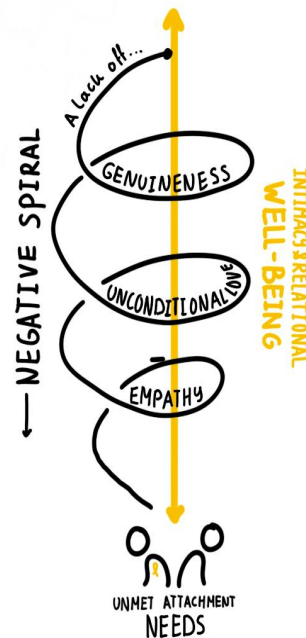
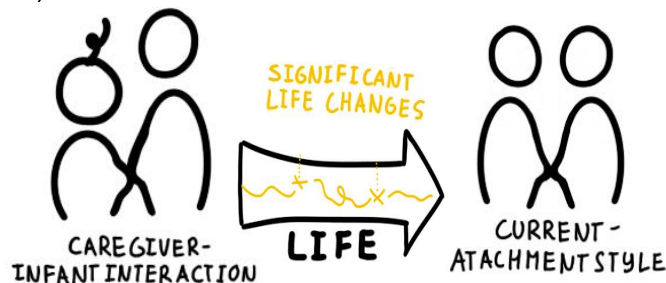
Fig. 2. Individual & shared distress experience resulting from the systemic approach

2.2 EFT-Framework

Emotionally Focused Therapy (EFT) focuses on understanding the patterns of interaction between partners, including how they make requests and fulfill each other's needs (Adamson, 2013). Distressed couples often find themselves trapped in a negative cycle where genuineness, empathy, and unconditional positive regard are lacking due to tension in their relationship, and attachment needs go unmet.

Attachment in Adult Relationships

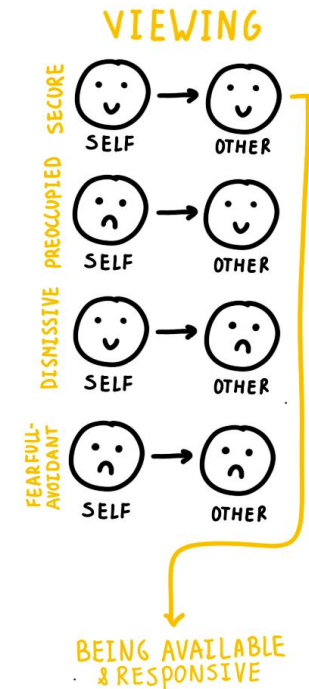
The attachment theory provides a foundational framework for understanding adult intimacy and love. It explores the emotional bonds and connections individuals form with others, particularly in close relationships (i.e., attachment). This theory focuses on the behavioral and emotional dynamics central to interactions, which can either support or undermine emotional well-being. Attachment styles, initially developed through early caregiver-infant interactions, can evolve in response to significant life events such as a cancer diagnosis, treatment, and survivorship. These life changes may prompt shifts in attachment needs and relationship dynamics, making it essential to explore and address these evolving needs to manage emotional changes effectively through heightened emotional awareness (Enestrom, Bar-Kalifa, Bar-Shachar & Lydon, 2022).



Modern Attachment Styles

The modern attachment theory identifies four basic attachment styles:

- Secure Attachment - Individuals with a secure attachment style have positive views of themselves and others.
- Preoccupied Attachment - Individuals with a positive view of others but a negative view of self may worry about others' reactions to them.
- Dismissive Attachment - Individuals with a negative view of others but a positive view of self show little interest in fostering interpersonal relationships.
- Fearful-Avoidant Attachment - Individuals with negative views of both themselves and others feel unworthy of or disinterested in close relationships.



A secure attachment develops when partners consistently reinforce mental and physical proximity by being available and responsive to each other's needs for validation and support (Conradi et al, 2013). However, this constant availability can be strained during the emotionally and physically demanding stages of cancer survivorship, affecting both partners' capacity for emotional regulation (Appleton et al, 2013).

The Spatial Domain

While emotional intimacy is a challenging concept to measure in research and healthcare, physical proximity is more tangible. Attachment manifests not only through emotional intimacy but also through physical interpersonal distance. Proximity seeking is a primary attachment strategy for organizing validation and support between romantic partners, involving both verbal and non-verbal behaviors to maintain a preferred level of closeness (Conradi et al, 2020). Thus, proximity may be related to the quality of couple's interaction where it allows for physical exchange of support (Ogolsky et al, 2021).

Extremes

Extreme closeness or distance can indicate attachment issues. Anxiously (pre-occupied) attached individuals may exhibit exaggerated proximity seeking, such as clinging behavior, or avoid closeness to protect themselves, leading to approach-avoidance conflicts driven by fear, frustration, resentment, or anger (Conradi et al, 2020). Conversely, avoidantly attached individuals typically maintain more distance as they do not expect partner's attention. The preferred levels of mental and physical proximity depend on individual experiences and responses to proximity-seeking behaviors (Greene, Derlega, & Mathews, 2006) as sociopsychological (i.e., culture) and environmental factors (i.e., temperature) (Sorokowska, Sorokowski, Hilpert, Cantarero & Gyesook Yoo, 2017).

Current research has yet to effectively measure interpersonal distance related to attachment in real-world settings, as most studies have been conducted in controlled environments using video, virtual agents, diary studies, or questionnaires (Krocze et al, 2020; Conradi et al, 2020; Sorokowska et al, 2017). One study measured interpersonal distance in relation to relationship quality, stress, and daily experiences (including biometric data like heart rate) in real-life settings, but it was limited to research performed only within the homes of community-residing couples (Ogolsky et al, 2021).



Fig. 3. Spatial proximity framework by Conradi et al (2020) and Sorokowska et al (2017).

2.3 Dyadic Coping

Dyadic coping is essential for effective stress regulation within relationships, as it involves how couples manage and address stress together. Bodenmann, Randall & Falconier's (2017) Systemic Transactional Model (STM) highlights the interconnected nature of individual and joint coping strategies, demonstrating that one partner's daily stress, stress-related behavior, and overall well-being significantly influences the other partner, even when the stressor directly affects only one of them. Given that both partners typically experience distress, the Systemic Transactional Model (STM) highlights the importance of actively engaging in shared dyadic coping strategies. When couples collaborate in managing stress, they are better equipped to navigate the challenges of survivorship. This collective approach not only enhances their ability to cope but also fosters individual psychological and physical health, boosts relationship satisfaction and life satisfaction, improves performance, and cultivates a sense of unity, mutual trust, intimacy, and connectedness.

Appraisal

In this model, distress appraisal involves a two-part process. The first part, primary appraisal, hinges on how significant the individual perceives the situation to be, their interpretation of their partner's appraisal, and the comparison of both evaluations.

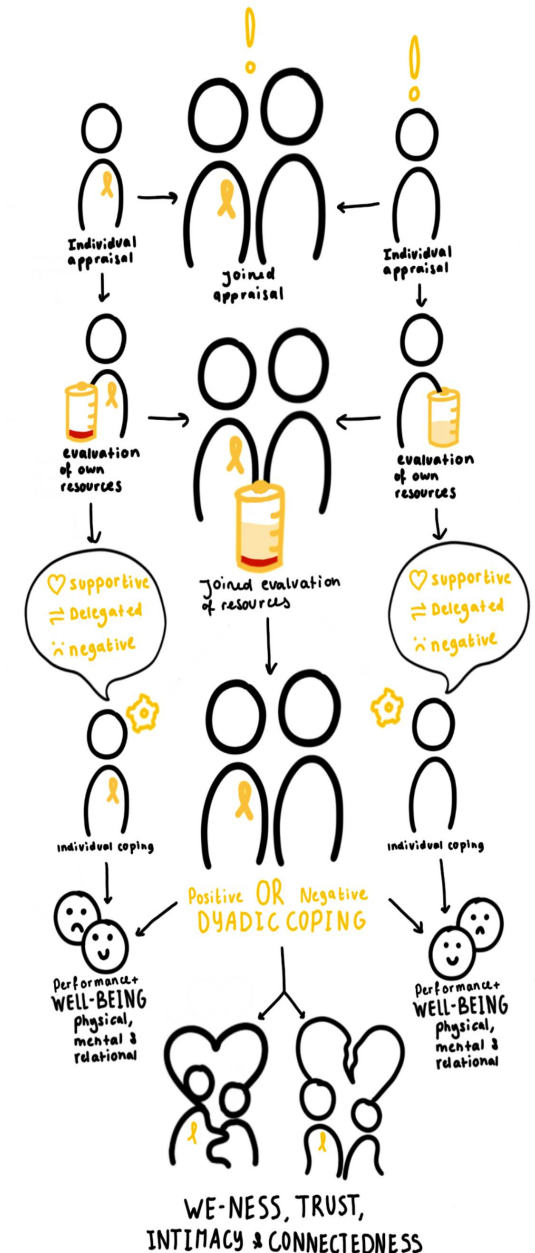


Fig. 4. STM model & coping strategies from Bodenmann, Randall & Falconier (2017)

This comparison can lead to either congruence or discrepancy, ultimately resulting in a joint appraisal. The second part, secondary appraisal, encompasses three key aspects: the individual's assessment of their resources to meet the demands of the situation, their partner's assessment of these resources, and again the joint evaluation of whether there is congruence or discrepancy in these appraisals.

Coping Styles

Dyadic coping encompasses both positive and negative coping styles (Figure 4) that are relevant for understanding how couples address stress.

Positive coping

Positive dyadic coping seeks to restore a sense of equilibrium for both individuals and the couple as a whole in the face of challenges. Bodenmann, Randall & Falconier's (2017) Stress and Coping Theory emphasizes the critical components of positive dyadic coping, particularly the importance of emotion-focused stress communication within adjustments of individual and couples mental health regarding illness affects (Adamson, 2013). This involves partners actively seeking each other's attention and support to manage issues and regulate emotions effectively (Coyne and Smith, 1991). Hence, positive dyadic coping encompasses both emotional support—such as offering empathy, understanding, and motivation—and practical support, like assisting with tasks to alleviate stress, including confronting or accepting challenges and fostering positive emotions (González-Herrera, Pujol-Ribera, Esteva, Ruiz-Marcos & March, 2023). Additionally, cancer survivors positively cope through humour, positive outlook on life, maintaining routine and normality (Appleton et al, 2013).

Negative Dyadic Coping

In contrast, negative dyadic coping attempts to regulate stress by expressing negativity. Negative dyadic coping is characterized by hostility, ambivalence, or superficiality, and arises when one partner is either unwilling or unable to provide adequate support. This imbalance can create skewed power dynamics, where one partner assumes greater responsibility or influence in the relationship. Consequently, negative coping strategies, such as protective buffering (i.e., lack of disclosure in fear of harming the other) or overprotectiveness, are linked to reduced well-being, intimacy, and relationship satisfaction (Hasson-Ohayon, Goldzweig, Braun & Hagedoorn, 2022). In the context of cancer survivorship, negative individual coping similarly involves distancing and negative emotions (González-Herrera et al. 2023).

Dyadic Coping & Conflict Resolution

However, the ways in which couples appraise and cope with distress vary widely due to personality, socio-economic, demographic, and treatment-related factors (Andreu et al, 2021). Therefore, there is no one way how couples cope with the above distress appraisals.

Moreover, appraisals of situations can differ based on perceived threat, loss, damage, or challenge, possibly resulting in a conflict. Therefore, conflict resolution is essential for maintaining equality and effective dyadic coping. Addressing these conflicts is crucial for fostering a supportive and balanced relationship, enabling both partners to navigate distress together effectively.

2.4 Mental Health Monitoring

Currently, mental health is mainly assessed in healthcare settings through behavioral observations, interviews, and patient self-reports (Celestine, 2024). For follow-up care in the Netherlands, insights from an interview with a PhD student and physician involved with PROMISE (Erasmus ROD, n.d.) reveal that patients receive periodic questionnaires, such as the CR29 (Stiggelbout et al, 2015) (Appendix L), from the polyclinic (E. van Driel & C. Offerman, personal communication, January 17, 2024).



EORTC OLO – CR29

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problem during the past week. Please answer by circling the number that best applies to you.

During the past week:

	Not at All	A Little	Quite a bit	Very Much
31. Did you urinate frequently during the day?	1	2	3	4
32. Did you urinate frequently during the night?	1	2	3	4
33. Have you had any unintentional release (leakage) of urine?	1	2	3	4
34. Did you have pain when you urinated?	1	2	3	4
35. Did you have abdominal pain?	1	2	3	4
36. Did you have pain in your buttocks/anal area/rectum?	1	2	3	4
37. Did you have a bloated feeling in your abdomen?	1	2	3	4
38. Have you had blood in your stools?	1	2	3	4
39. Have you had mucus in your stools?	1	2	3	4
40. Did you have a dry mouth?	1	2	3	4
41. Have you lost hair as a result of your treatment?	1	2	3	4
42. Have you had problems with your sense of taste?	1	2	3	4

During the past week:

	Not at All	A Little	Quite a bit	Very Much
43. Were you worried about your health in the future?	1	2	3	4
44. Were you worried about your weight?	1	2	3	4
45. Have you felt physically less attractive as a result of your disease or treatment?	1	2	3	4
46. Have you been feeling less feminine/masculine as a result of your disease or treatment?	1	2	3	4
47. Have you been dissatisfied with your body?	1	2	3	4
48. Do you have a stoma bag (colostomy/ileostomy)? (please circle the correct answer)	Yes	No		

During the past week:

	Not at All	A Little	Quite a bit	Very Much
49. Have you had unintentional release of gas/flatulence from your stoma bag?	1	2	3	4
50. Have you had leakage of stools from your stoma bag?	1	2	3	4
51. Have you had sore skin around your stoma?	1	2	3	4
52. Did frequent bag changes occur during the day?	1	2	3	4
53. Did frequent bag changes occur during the night?	1	2	3	4
54. Did you feel embarrassed because of your stoma?	1	2	3	4
55. Did you have problems caring for your stoma?	1	2	3	4

During the past 4 weeks:

	Not at All	A Little	Quite a bit	Very Much
49. Have you had unintentional release of gas/flatulence from your back passage?	1	2	3	4
50. Have you had leakage of stools from your back passage?	1	2	3	4
51. Have you had sore skin around your anal area?	1	2	3	4
52. Did frequent bowel movements occur during the day?	1	2	3	4
53. Did frequent bowel movements occur during the night?	1	2	3	4
54. Did you feel embarrassed because of your bowel movement?	1	2	3	4

During the past 4 weeks:

	Not at All	A Little	Quite a bit	Very Much
56. To what extent were you interested in sex?	1	2	3	4
57. Did you have difficulty getting or maintaining an erection?	1	2	3	4

For men only:

58. To what extent were you interested in sex?	1	2	3	4
59. Did you have pain or discomfort during intercourse?	1	2	3	4

For women only:

58. To what extent were you interested in sex?	1	2	3	4
59. Did you have pain or discomfort during intercourse?	1	2	3	4

Fig. 5. Example of the 2-page CR29-questionnaire, clearly illustrating an individualistic perspective in mental health monitoring, and overlooking or pay limited attention to other aspects related to mental health, such as social, economical and cultural factors (Cooke, Melchert & Connor, 2016) 12

Although these methods are commonly employed, research also highlights several alternative approaches for evaluating mental health.

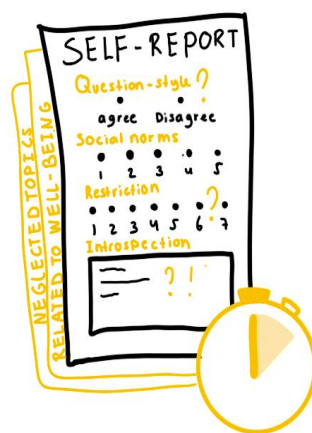
Alternative Methods in Literature

Cooke, Melchert & Connor (2016) categorized (commercial) mental health assessment tools into hedonic, eudaimonic, quality-of-life, and wellness instruments. These methods include psychological assessments, scales, and physiological measures like heart rate variability, cortisol levels, sleep, sociability, cognition, and movement related to stress, anxiety, or mood (De Angel, Lewis, White et al, 2022; Celestine, 2024).

However, Cooke et al (2016) show, through the categorizations, the significant disagreement on how to conceptualize and assess psychological health. Moreover, current tools often lack comprehensiveness and consistency, leading to interpretive variability.

Biases and Limitations

Methods currently used for assessing mental well-being, especially self-report methods, are susceptible to various biases, including social desirability, introspective limitations, restrictive rating scales, and response biases (Salters-Pedneault, 2023). Additionally, crucial aspects of well-being—such as financial security, family dynamics, sexual health, and sociocultural influences—are frequently overlooked (Cooke, Melchert & Connor (2016). These limitations often reflect a predominantly Western, individualistic perspective on health, highlighting the need for a more comprehensive and context-sensitive approach to evaluating psychological well-being.



2.5 Telehealth Innovation

With the growing need for comprehensive and consistent mental health assessments, digital tools for tracking mental health variables are advancing at the crossroads of computer science, engineering, and clinical science (De Angel et al, 2022), providing valuable opportunities.

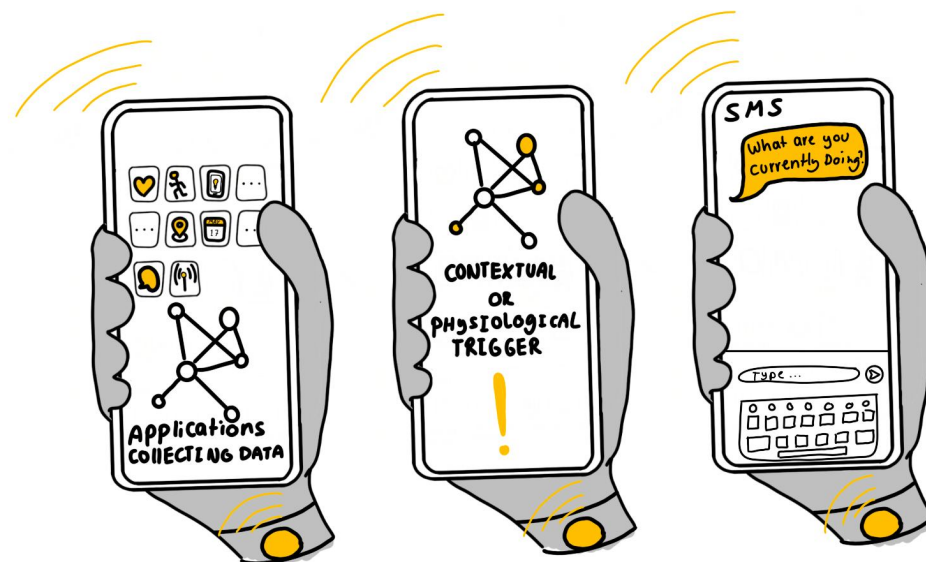


Fig. 6. Illustration of a (G)EMA methods

Geographically-Explicit EMA

Ecological Momentary Assessment (EMA) combines active methods, such as self-reports and event-triggered surveys delivered via text messages, phone calls, or app notifications, with passive, continuous data collection. This approach utilizes wearables, smartphone sensors, app usage data, and environmental monitors within participants' natural environments (Hilty, Armstrong, Luxton, Gentry, & Krupinski, 2021). A more advanced variation on EMA, geographically-explicit ecological momentary assessment (GEMA), incorporates geospatial data to better understand the interaction between behaviors, experiences, and environmental contexts. These methods are increasingly applied in research exploring mental health and behavior related to conditions such as depression, PTSD, and suicide prevention (Thomas et al, 2021; Stinson, Lui & Dallery, 2022; Gromatsky, Sullivan, Spears, Mitchell, Walsh, Kimbrel & Goodman, 2020). By aggregating low-level features, such as physiological indicators like heart rate, sleep/wake cycles, skin conductivity, movement, cognitive activity, and mobile activity, as well as GPS and proximity-based data, these tools can define high-level behavioral markers that provide meaningful insights regarding mental health.

Integrating Technology

Combining these assessment methods allows for a comprehensive understanding of patient experiences by identifying contextual triggers of certain behaviors or emotional states. Innovations such as AI, nanotechnology, and cloud computing facilitate the real-time collection, analysis, and modeling of patient-specific information, enabling timely interventions and tracking of health trajectories (Hilty et al, 2021).

However, the proliferation of technology, particularly smartphones, can disrupt interpersonal interactions—a phenomenon known as "phubbing" (McDaniel & Drouin, 2019). Phubbing, where phone use takes precedence over in-person engagement, can lead to feelings of exclusion and weaken emotional connections. According to Expectancy Violation Theory, such disruptions can violate social expectations, triggering negative emotional responses. Individuals with high attachment anxiety are particularly vulnerable to "technoference," where technology-related disruptions amplify feelings of neglect and dissatisfaction, negatively impacting relationship quality.

2.6 Discussion

Cancer survivorship impacts both patients and their spouse, affecting daily life, psychosocial well-being, and relationships. Effective dyadic coping—where both partners actively support each other through positive dyadic coping—is crucial for managing these stresses.

To design an effective remote patient monitoring strategy, it's essential to integrate data from patients, their partners and their context to display how couples navigate their challenges (i.e., attachment) and maintain relationship satisfaction to support dyadic coping. Leveraging a (G)EMA approach (Thomas et al, 2021) can provide a comprehensive understanding of dyadic coping as it involves a contextual perspective needed to make informed assessments on behavioral aspects fueled by individual appraisals, coping resources (Bodenmann, Randall & Falconier, 2017), and coherent evaluations based on emotional awareness. However, the GEMA approaches discussed in this chapter only provided insights regarding an individualistic perspective and still rely on a form of patient self-reporting, therefore again illustrating the gap in research regarding taking a holistic perspective in mental health that mitigates the active assessment efforts by patients to reduce bias and strain.

The research addressed in this chapter has indicated that to understand the dyadic coping effectiveness of a couple, communication, support, equality, and conflict resolution are essential. Therefore, these elements need to be further explored regarding the emotional and physical outlets of attachment, as it is for now unknown how couples navigate through life to maintain relationship satisfaction. How do couples make efforts to maintain secure attachment? How do they handle conflicts, and what are their effects? And what is important within communication related to emotional awareness? These questions are the drivers for the next phases of the project, further highlighted in chapter 4 - Understanding The System. The next chapter addresses the overall design approach and methods leading to the 'How' in designing a strategy to remotely monitor and contextualize mental health by leveraging romantic couples' collective and contextual data.

CHAPTER 3

PROJECT APPROACH

In this chapter, I discuss the design process and approach used in this project, focusing on the data-enabled design methodology and the double diamond framework. These approaches provide a structured pathway for developing a remote patient monitoring (RPM) strategy that leverages collective interaction data from couples to assess mental health.

I also provide a clear overview of how the project is structured, detailing the key questions and activities involved in each phase of the design process. This includes the exploration, ideation, prototyping, and testing stages that ultimately lead to the research toolkit for uncovering RPM strategy design guidelines, opportunities, and pitfalls.

Additionally, I cover the participant recruitment process, highlighting the ethical considerations that guided the study. This section outlines the procedures followed to ensure informed consent, privacy, and the well-being of participants throughout the research.

3.1 Design & Process Approach

Since this project aims to translate collective behavioral and contextual aspects into quantitative data for gaining mental health insights through a passive RPM strategy, I chose a design approach that utilizes quantitative data. This approach allowed me to explore both the behavioral dimensions and the design implications of integrating data into the RPM strategy.

Data-Enabled Design

The data-enabled design approach facilitates the integration of detailed contextual insights by embedding prototypes within the target group's real-life environment (Funk, Lovei, & Noortman, 2024). This approach enables me to gather crucial design insights by leveraging the collected data as a creative design material, ultimately guiding the development of an adaptive RPM strategy that is finely tuned to meet the specific needs and medical context of the target group.

Double Diamond Structure

To ensure a structured process, the project's methodology is organized according to a 'double diamond structure' (Design Council, n.d.), consisting of four phases: Discover, Define, Develop, and Deliver (Figure 7).

By following this structured approach, I aimed to engage in a well-informed design process to first discover and define the problem space, whereafter I engage in the data-enabled design approach to develop research probes and reflect how to design a strategy to remotely monitor and contextualize mental health by leveraging couple's collective data.

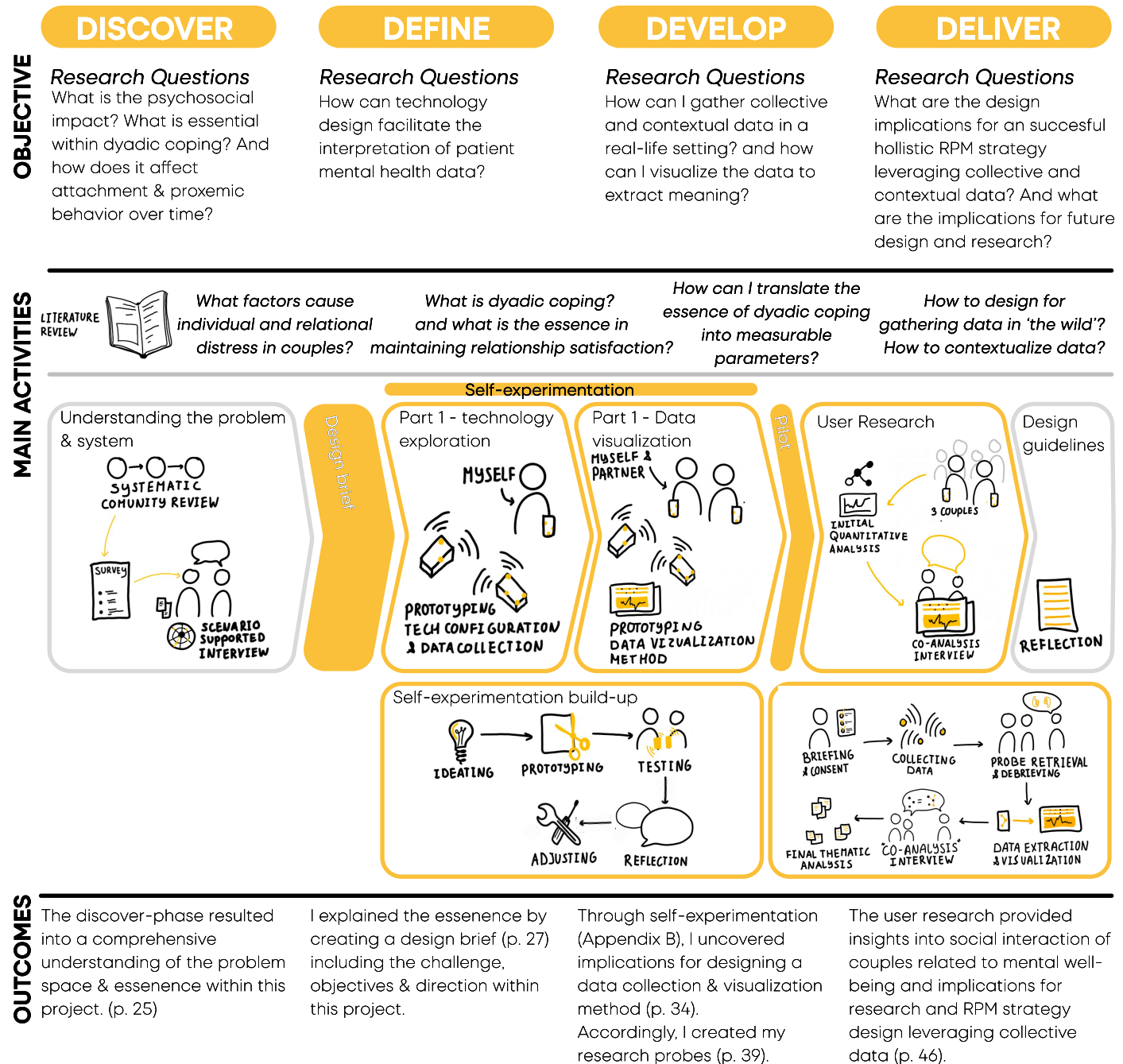


Fig. 7. Project approach broken-down into objectives, main activities, and outcomes

3.2 Discover

Within the discover-phase I gathered insights to understand the complexity of the problem space by exploring experiences, needs, and behavior, specific to the target group (within the use-case), regarding uncovering what is essential within joined coping mechanisms to maintain relationship satisfaction.

Systemic Thinking

A couple's system is inherently complex, dynamic, reciprocal, and multifaceted, involving simultaneous and interdependent interactions among various components. Additionally, it is open to external influences that drive transformation processes, either positive or negative.

Understanding Couples' Dynamics

These interactions within the system result in patterns. Patterns can be understood through the lens of the dynamical systems theory, where an attractor represents a systemic tendency for a relationship to become settled in specific interaction patterns over time. For this project, it is particularly relevant to recognize patterns that emerge sequentially and can be monitored or tracked.

To navigate this complexity, I employed a 'systemic thinking' approach (Stanton & Welsh, 2012) (Figure 8), that allowed me to examine dyadic coping from an individual, interpersonal, and macrosystemic point of view.

3.3 Define

Having uncovered the essence in maintaining relationship satisfaction, and therefore a key element in dyadic coping, I explain the core issues along with the guiding principles (i.e., design goals and interaction visions) and directions. I did this to set clear objectives for the creative process and final design through using the 5WH method (Van Boeijen, Daalhuizen & Zijlstra, 2020) (Appendix D). I communicated this in the form of a *design brief*.

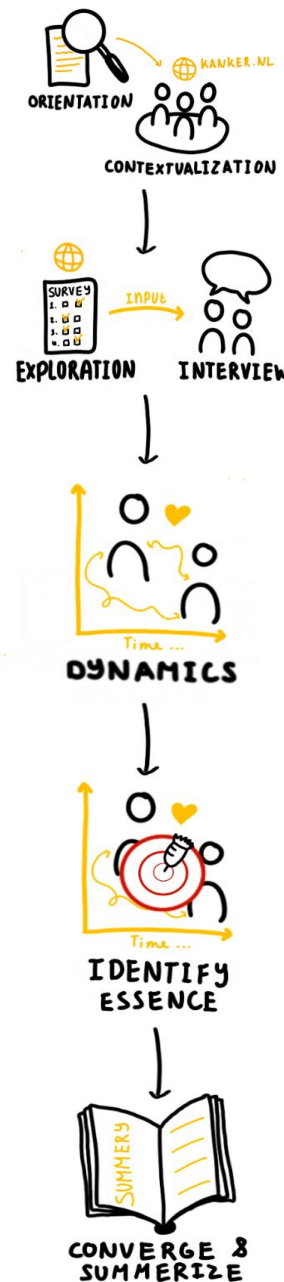


Fig. 8. The Systemic Thinking framework by Stanton & Welsh (2012)

1. Identifying Collective Variables

Collective variables were identified through a two step approach: desktop research and a community review (Appendix E). I categorized my observations into individual and mutual distress appraisal. Subsequently, these results were compared with the Systemic Transactional Model (STM) to identify which factors are crucial for understanding dyadic coping within a romantic relationship.

2. Characterizing Behavioral Attractor States

To characterize the behavioral attractor states within the couple's system, I conducted two key research activities: 1) Identify the primary factors influencing emotional and physical closeness in couples through an online survey and 2) examining how couples navigate emotional and physical intimacy through a scenario-supported interview (Appendix C).

3. Describing the Dynamic Trajectory of Collective Variables

In the analysis of the data, I reviewed the results on a trajectory level to develop a conceptual model, specifically a behavior-over-time diagram (Kim, n.d.). This model illustrates how the collective variables evolve and interact over time, providing a visual representation of their dynamic trajectories.

4. Identifying Points of Behavioral Change

Consequently, I identified what is necessary to maintain relationship well-being and effective dyadic coping by performing a 5WH (see Appendix D).

5. Summarizing Essential Indicators for Relational Well-Being

To gain deeper insights into the essential indicators of relational well-being, I conducted additional desktop research. This research aimed to enhance my understanding of the factors affecting relationship dynamics and address the design challenge outlined in the design brief (Define).

3.4 Develop

During the development phase, I focused on integrating previous insights and investigating technological solutions for remotely monitoring and visualizing collective data to explore design implications for an RPM strategy assessing mental health. By adhering to the six-step process outlined in the data-enabled design framework (Funk, Lovei & Noortman, 2024) (Figure 9), I systematically examined data collection and visualization, applying design insights derived from real-life contexts and interactions.

Situating Prototypes in Everyday Life

To understand the practical implications of the technology, I conducted self-experimentation within my own romantic relationship by situating the prototypes in our real-life context. This provided firsthand insights into the user experience and technological functionality regarding data collection capability.

Data as Exploration Material

The data collected during self-experimentation was initially analyzed using 'Orange,' a data analytics tool (appendix B). This analysis aimed to identify patterns and explore the effectiveness of data aggregation and visualization methods. The visualized data was then discussed either through self-assessment, cognitive walkthrough (Interaction Design Foundation, n.d.), or with my partner to evaluate the effectiveness of the data visualization method regarding data interpretation, gaining contextual meaning, and reflection.

Evaluating and transforming

The aforementioned iterative process resulted in systematic refinements and improvements based on real-time, event-based input and insights aligned with design objectives and priorities. This allowed me to perform rapid and informed prototyping and iterations.



Fig. 9. Data-enabled design steps (Funk, Lovei & Noortman, 2024)

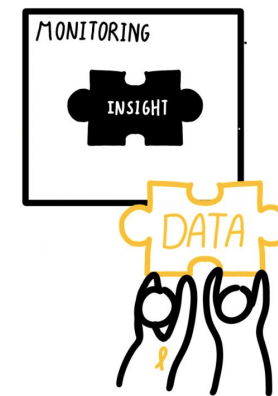
3.5 Deliver

The goal of this stage was to conduct user research to gain insight in the strategy's effectiveness, appropriateness, strengths, weaknesses, and potential directions for future research. Thus, *'what are the design implications for an succesful holistic RPM strategy leveraging collective data?'*

The insights retrieved from contextualizing social interaction data collection during the user research are detailed in this section of the report. In chapter 7 and Appendix I, I provide more detailes about the user research and analysis method.

Implications for RPM in Cancer Survivorship

The final insights are summarized and transformed into design guidelines. Additionally, a proposal for future research on RPM for mental health in cancer survivorship using a data-enabled strategy is provided. Finally, a personal reflection on my academic and personal experiences and development within this thesis concludes the section.



3.6 Participants Recruitment & Ethics

Recruitment

Convenience sampling was attempted, after recruitment efforts directed through organizations like the NFK (Dutch Federation of Cancer Patient Organizations) and Stichting Darmkanker (Dutch Colorectal Cancer Foundation) as these were ultimately unsuccessful. Consequently, and already mentioned within the disclaimer Chapter 1 - Introduction, the target group was expanded to include all couples aged 55-75 years living together in a romantic relationship, therefore gathering generalized insights regarding the subject.

Ethics

Ethical approval was sought and granted in two stages. Initially, I submitted the ethical considerations and safeguards for the pre-user research, which focused on exploring psychological impact and dyadic coping. Subsequently, I applied for an amendment that included additional considerations and measures to guide the user research phase. This phase aimed to uncover design implications for developing an RPM strategy that adopts a collective approach to mental health.



CHAPTER 4

UNDERSTANDING THE SYSTEM

How does dyadic coping in romantic couples relate to the attachment and proxemic behavior?

This chapter provides a clear understanding of how key elements of dyadic coping influence and relate to attachment and proxemic behavior in couples over time. The analysis is conducted through a two-stage method enabling a deep dive in how couples navigate communication, decision-making, conflicts, and support over time.

The findings offer valuable insights into the dynamics of relationship behaviors to derive the essence for maintaining relationship satisfaction.

The chapter concludes by synthesizing the key insights, linking them back to the primary objective by formulating new questions that bring me closer to reaching the objective.

To investigate how communication, support, equality, and conflict resolution key manifest in emotional and physical intimacy, I engaged in research activities involving the target group.

4.1 Method Used

I adopted a two-step research approach that strategically combined an online survey and scenario-supported interviews. Initially, the survey (n=16) served as an initial exploration. By gathering broad insights from the survey, I was able to identify focal points for the subsequent interviews. Next, the scenario-supported interviews (n = 3 couples) were designed to help couples reflect on their past experiences by relating them to provided scenarios. This approach encouraged participants to connect the scenarios with their own relationship dynamics, enabling richer recollection and discussion of relevant experiences. This method allowed for a deeper understanding of how couples navigate emotional and physical spaces over time and under varying circumstances (Figure 10).

By integrating findings from both the survey and interviews, alongside existing literature, I developed a conceptual "behavior over time" diagram (Figure 13). This diagram visually represents how these factors influence relationship dynamics and informs how they can be leveraged in designing technology to support relational well-being. Additional methodological details are available in Appendix C.

4.2 Communication

Through analysis, it is clear that dyadic coping relies on both verbal and non-verbal communication, making the presence or absence of communication pivotal for a relationship's dynamics.

Communication

Effective communication fosters emotional awareness, enabling couples to understand and support each other. It builds trust, comfort, and a sense of being cared for, understood, and validated by one's partner (Johnson et al, 2022). Johnson et al also explain that the quality of a couple's communication predicts relationship satisfaction over time. Experiencing less negative communication leads to higher relationship satisfaction, while avoiding communication creates emotional and physical distance, leading to frustration

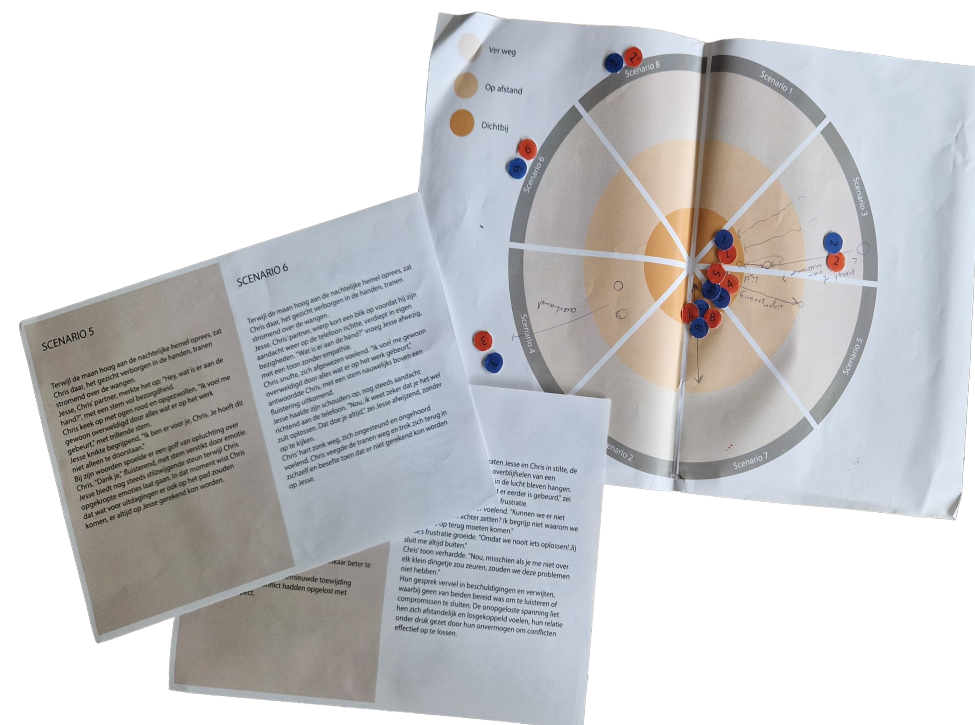


Fig. 10. Interview set-up including scenario's and a distance map to co-creatively map emotional and physical distance related to support, conflict and resolution, and equality (in decisionmaking)

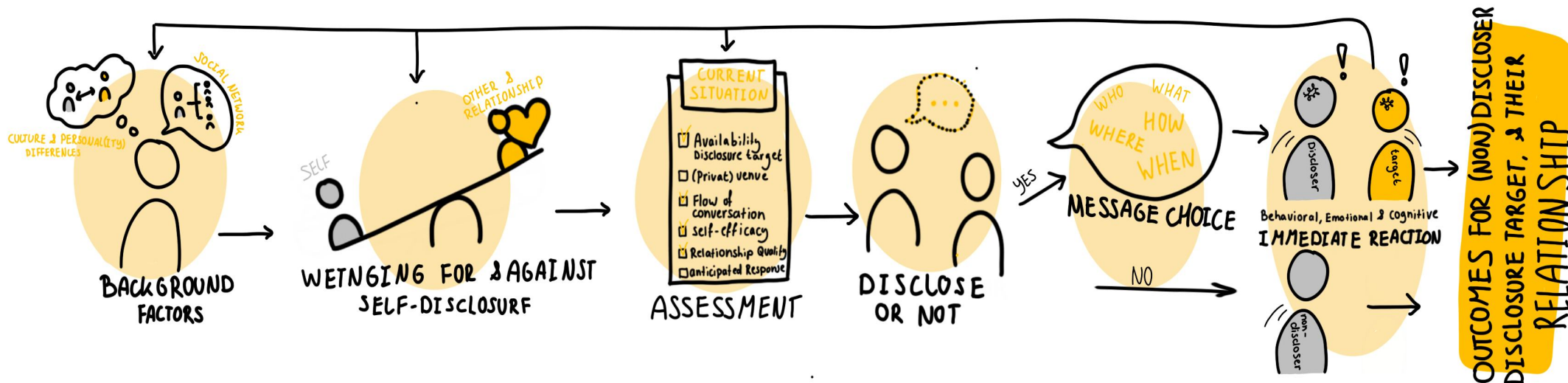


Fig. 11. Decision-making process for disclosing personal information (Green, Derlega & Mathews, 2006)

Positive communication involves demonstrating interest and clarifying one's position instead of being critical and withdrawing. External stress often prompts more frequent and extended conversations. In contrast to emotional intimacy, physical intimacy shows a negative correlation with the frequency and duration of disclosures, possibly due to the challenge of interpreting facial expressions and body language during intimate moments.

Decision Making in Communication

Determining when to communicate involves a complex decision-making process (Figure 11), as highlighted by Greene, Derlega, & Mathews (2006), who view disclosure as a deliberate choice made in specific situations. This process involves several key aspects:

Background Factors

The couples interviewed emphasized the significance of individuals' past experiences and personal characteristics in communication related to support, conflict resolution, and decision-making. A person's upbringing influences their behavior within relationships, consistent with attachment theory (Adamson, 2013), which states that attachment and intimacy behaviors are shaped in childhood. Intense life experiences can alter perspectives on stressful events,

either heightening sensitivity or desensitizing reactions. Character traits also play a crucial role in shaping communication styles, conflict resolution approaches, and comfort levels with emotional and physical intimacy. These factors determine whether an individual tends to confront (fight), withdraw (freeze), or avoid conflict (flight) in relationships, reflecting both intra- and interpersonal differences rooted in past experiences and personality traits.

Weighing Reasons For and Against Self-Disclosure

In this context, two critical aspects influence the ability to assess the reasons for disclosing or withholding information. Firstly, one's own emotional awareness significantly impacts their ability to perceive and understand their partner's emotions. Higher personal emotional intensity and stress levels can hinder receptiveness to their partner's emotions, potentially leading to increased conflicts or avoidance behaviors. Conversely, deeper familiarity with each other can serve as a buffer, fostering understanding and acceptance of a partner's emotional reactions or behaviors. This familiarity also aids in making joint decisions and compromises based on what holds significance for each partner and the situation.

Assessment of Current Situation

Another crucial aspect in the decision to disclose or not is assessing the current situation. A key element here involves evaluating your partner's emotional availability. Couples pointed out that interpreting facial expressions, body language, and intonation is essential within this assessment, which also implies the importance of physical presence and proximity (Conradi et al, 2020).

Resolving a Conflict

In conflict resolution, choosing the right moment to address an issue depends on emotional readiness (i.e., when emotions have settled), which may require time and space. Conflicts often bring feelings of anger and tension, necessitating not only calming down but also reflection and gaining perspective. Couples mentioned that readiness for resolution is often signaled spontaneously, such as through physical gestures and verbal cues or setting boundaries (e.g., "I want to resolve this before dinner"). Anticipating your partner's response helps avoid creating or escalating conflicts, an ability that improves with familiarity.

Assessing Relationship Quality

Additionally, assessing relationship quality involves mutual goals, interest in each other, and respect. A lack of motivation to nurture relationship well-being diminishes overall satisfaction and interest in the partner. Maintaining interest means understanding each other's priorities and actively engaging in the relationship, particularly in making compromises. While complete understanding of each other's situations may not always be possible, demonstrating effort in offering support remains crucial. Over time, a lack of interest, especially in emotional aspects, can erode relationship

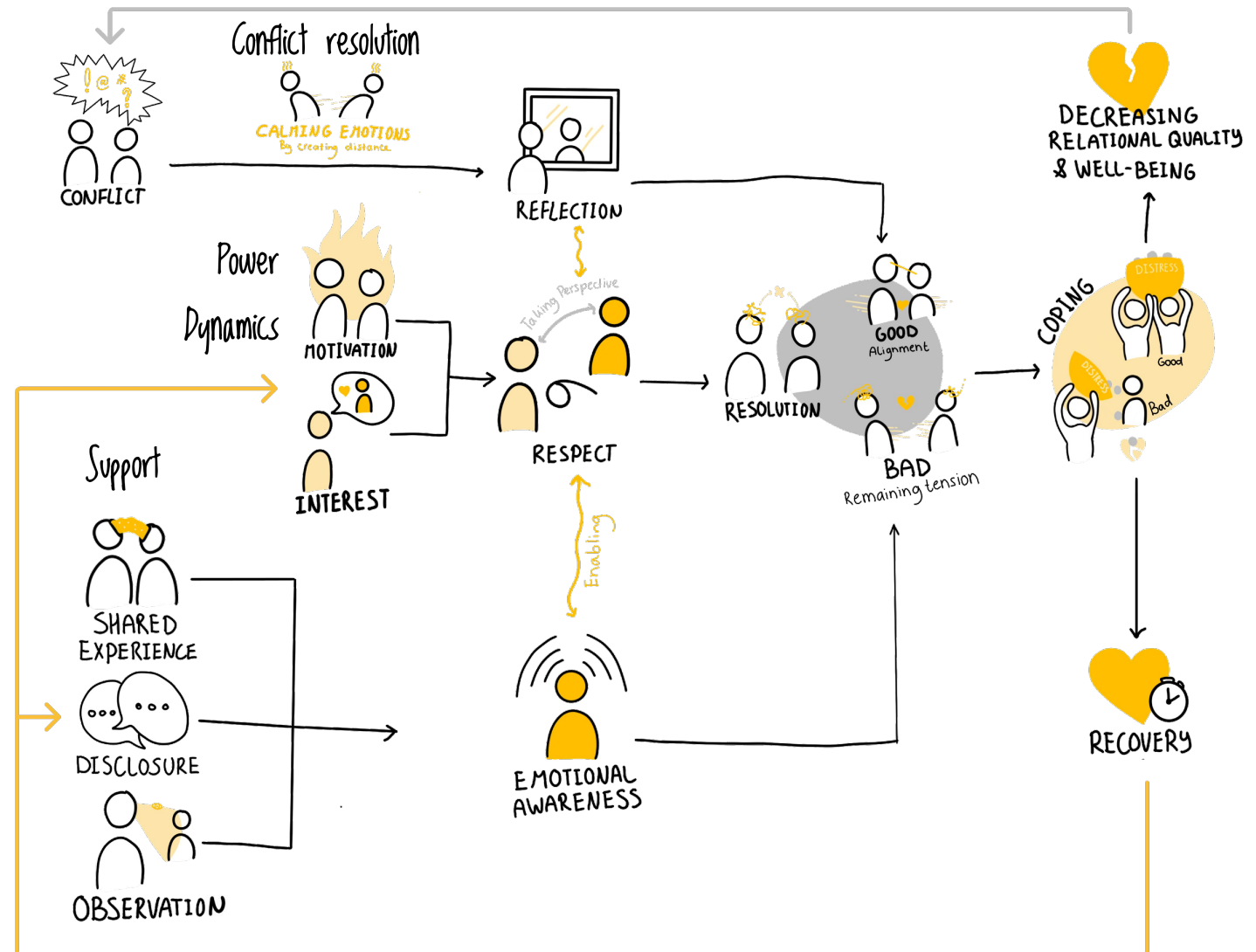


Fig. 12. Interrelation of relationship elements as discussed by couples

quality and mental well-being, leading partners to coexist rather than thrive together. Ultimately, maintaining respect through recognizing the impact of actions and showing empathy is essential for sustaining a meaningful relationship based on active listening, love, care, and encouragement. Conversely, a lack of respect stemming from disregard for these elements can jeopardize relationship viability.

4.3 Conflict Impact

The impact of conflicts hinges on the alignment of opinions and the importance of the topic to each partner, rather than the frequency of conflicts. The absence of support or equality can be perceived as a cause of conflict. Significant topics can affect individual and relationship well-being during conflicts. Resolving conflicts is crucial for creating and maintaining both relationship and individual well-being. Addressing conflicts promotes relationship growth and alleviates accumulated tension. However, depending on the topic's significance, the compromise made, or the conflict resolution style, it may take some time to recover from the conflict if possible.

4.4 Navigating Through Time and Space

The conversations with couples provided temporal and (emotional and physical) spatial implications within dyadic coping in terms of relationship quality.

Short-Term Impact

As aforementioned, the topic's significance and opinion alignment influence the short-term impact on individual and joint well-being. Consequently, a couple may take some physical space apart to calm their emotions and reflect on the situation. This implies that joint emotional and physical intimacy during a conflict and resolution may be less.

Long-Term Impact

Resolved conflicts might have a long-term impact where couples need to recover from the conflict to regain normal intimacy and comfort. Unresolved conflicts and ongoing tension can lead to frustration and create greater emotional distance between partners over time. Avoiding conflicts altogether

has a similar effect. Tension within a relationship leads to less communication and less motivation for receptiveness to the other's well-being, decreasing joint support capacity. An accumulation of negative exchanges in communication erodes couples' satisfaction. Therefore, an accumulation of negative communicative aspects can have a significant long-term impact on one's emotional state and relationship quality.

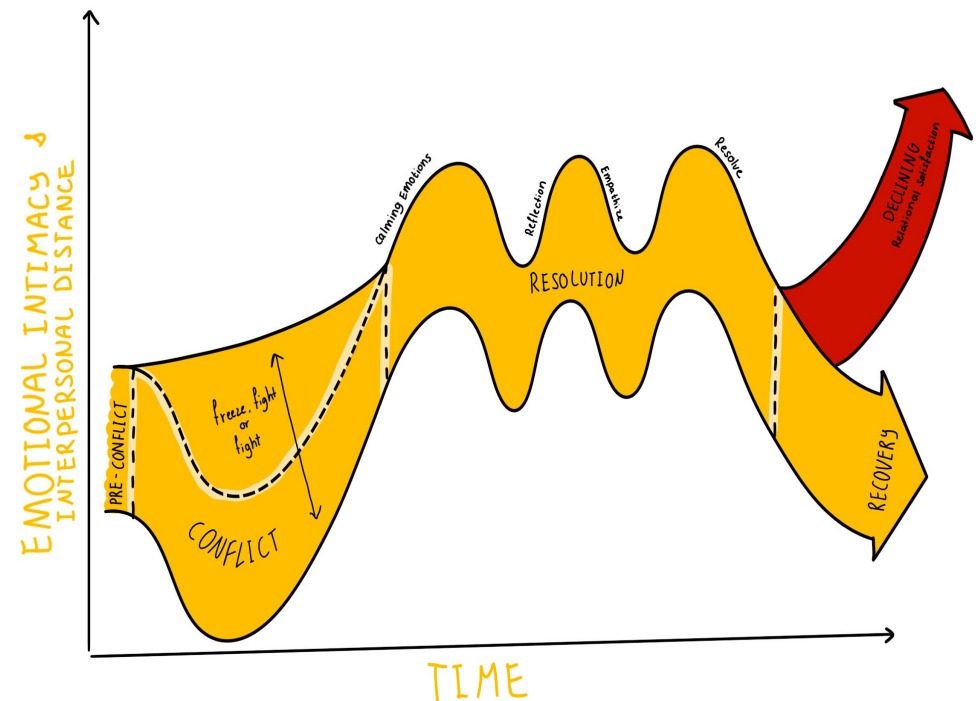


Fig. 13. A behavior-over-time diagram illustrating emotional and physical outlets regarding conflicts, resolution, and recovery, ending either in regaining emotional and physical intimacy, or declining relationship satisfaction.

Not Just About Concerns

A recurring theme in the conversations with couples was that individual and relational well-being isn't solely dependent on sharing worries and concerns. Engaging in mutual activities and sharing everyday experiences without specific significance also contributes significantly to mutual understanding and overall relationship satisfaction, enhancing dyadic coping.

4.5 Discussion

The research reveals that effective dyadic coping is strongly influenced by communication, conflict resolution, and mutual understanding. The two-step approach—combining online surveys and scenario-supported interviews—highlighted that both verbal and non-verbal communication are critical in shaping emotional awareness necessary for dyadic coping and effective support.

Key findings include the importance of timely and respectful communication in resolving conflicts, which is crucial for maintaining relationship satisfaction and individual well-being. Conflict resolution depends on factors such as emotional readiness and the significance of the issue, with unresolved conflicts leading to long-term emotional and physical distance. Moreover, the study emphasizes that relationship quality is not solely based on addressing concerns but also on engaging in everyday activities and shared experiences. Thus, dyadic coping should be understood as encompassing broader social interactions beyond mere communication, incorporating all aspects of mutual engagement and support.

The latter is particularly interesting as this creates a shift from focussing on elements within daily life focused on dealing with (survivorship-related) distress, to more generalized interactions that have a meaning towards relationship satisfaction which can be described as social interaction focused within the romantic relationship. So, what is social interaction? What are key elements of social interactions? What are my design objectives for leveraging social interaction to explore RPM strategy desing opportunities and guidelines? I adressed these questions in the next chapter, chapter 5 - The Design Brief

Define

Research qu...

5WH

CHAPTER 5

THE DESIGN BRIEF

How can technology design facilitate the interpretation of patient mental health data?

Design goal

Interaction vision...

Requirements

Design goal Prior...

Interaction vision...

Desi...
Inter...

Data...

Desi...
Pres...
Expe...

This chapter provides a clear understanding of the design challenge, outlining my objectives and the creative guidance that shaped this project, including interaction visions and the overall design direction. I also detail the prioritization process, specifying the requirements that guide design decisions.

The chapter concludes with a summary which leads to the formulation of new questions that guide the project's development phase.

5.1 Design Challenge

Given the importance of social interaction for relationship satisfaction, it requires further exploration in order to use this aspect in shining new light on RPM strategies.

Social interaction

Social interactions involve encounters between at least two people, where each individual pays attention to the other and adjusts their behavior accordingly (Hoppler, Segerer, Nikitin, 2022). During these interactions, individuals express relevant aspects of their experiences and what they find meaningful. Therefore, social interaction might be suitable in uncovering dyadic coping dynamics that we can use in RPM. However, there is currently no method that adequately captures social interaction in real-life settings, nor has explored how we can integrate social interaction of romantic couples into technology design for an RPM strategy concerning patient's mental health.

5.2 Objectives

To address the initial research question, "How can (technology) design facilitate the interpretation of patient mental health data?" I established two design goals with a corresponding interaction vision that will allow me to create a design to do so:

- Design a passive data collection method that discreetly and accurately captures the dynamics of couple-related social activities in real-world settings.
- Design a visualization method that enables couples to interpret, discuss, and contextualize sensor data related to their social activities.

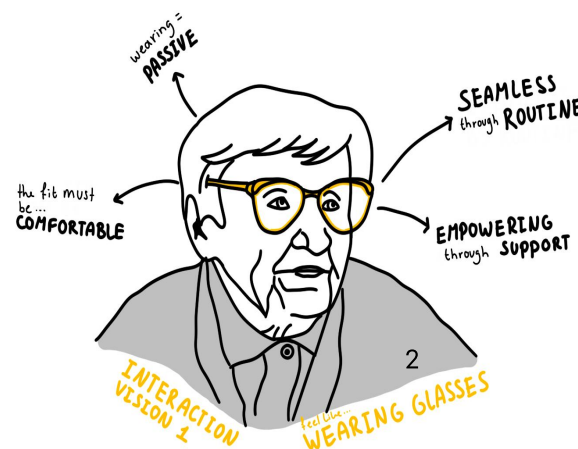


Fig. 14 . Interaction vision 1

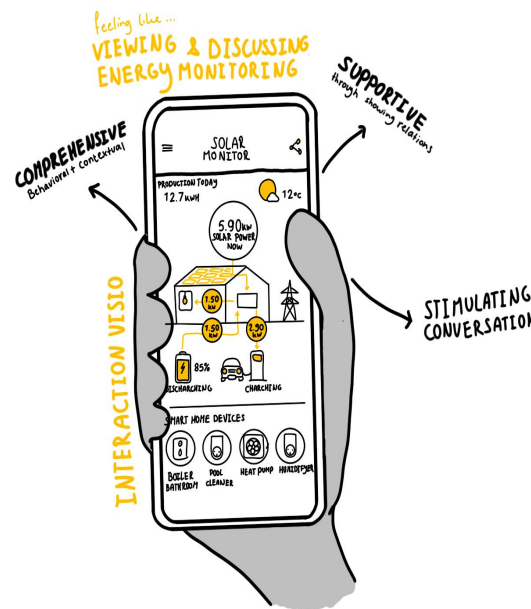


Fig. 15. Interaction vision 2 & core values

The methods should be suitable for remote research and capable of collecting and displaying rich and detailed data. The elements within the design goals are divided into design priorities to steer the designed solutions in the right direction.

Seamless Integration & User Empowerment

In this research, it is essential that the data collection process integrates seamlessly into participants' daily lives without causing disruption. Moreover, it is desired to be able to support the patient with the designed data collection probe to empower confidence and comfort (Figure 14).

Respectful & Engaging Data Visualization

The data visualization method requires a distinct interaction vision from the data collection process. This method should be evocative and interpretative, enhancing collaboration and supporting discussion while respecting each partner. Additionally, it should inform the couple in a meaningful way (Figure 15).

5.3 Design Direction

Relating to the design objectives, I formulated two design directions that were elaborated through the project.

A Wearable Sensor Kit

To capture data that reflects the dynamics between two individuals within a relationship system, the device needs to remain in close proximity to the users. As a result, I chose to focus on designing a wearable for this project.

A Collaborative Data Visualization Template

To represent the data in a way that captures social activity and facilitates reflection on its significance for dyadic coping, I focused on designing a data

visualization template that supports collaborative interpretation. This approach allows the participants (facilitated by the researcher) to "complete the picture" together by adding contextual details.

Design Priorities

The design objectives were broken down into specific design priorities, in order of importance, to guide the process and establish a clear focus for the project (Figure 16):

1. Seamless Integration & Compliance - Ensure the design adapts to and supports different couples and contexts, ensuring unobtrusive and comfortable design
2. Reliable Data Capture & Feasibility - Ensure sensors reliably record couple-related activities with low-cost technology and within the timeframe of this project implying less priority to accuracy as it does not inhibit discussion.
3. User-Friendly Visualization - Create an intuitive tool for easy collaborative data analysis considering data-literacy.
4. Integrity and Security - Implement strong measures to protect personal data and participant's integrity.

These design priorities served as the foundation for developing a solution that balances usability, data integrity, and ethical considerations, ultimately aligning ensuring practical application within this project's time-frame and resources.

Scenario's

To enhance the design of both the data collection and data visualization methods, I identified key interaction points that need to be addressed. For the wearable device, it is essential to integrate it into participants' daily routines, ideally ensuring it is worn as part of their morning routine when dressing. Additionally, the device should accommodate various aspects of daily life to ensure consistent use. The data visualization method, on the other hand, involves a single interaction point during an interview, which is intended to contextualize the collected data.

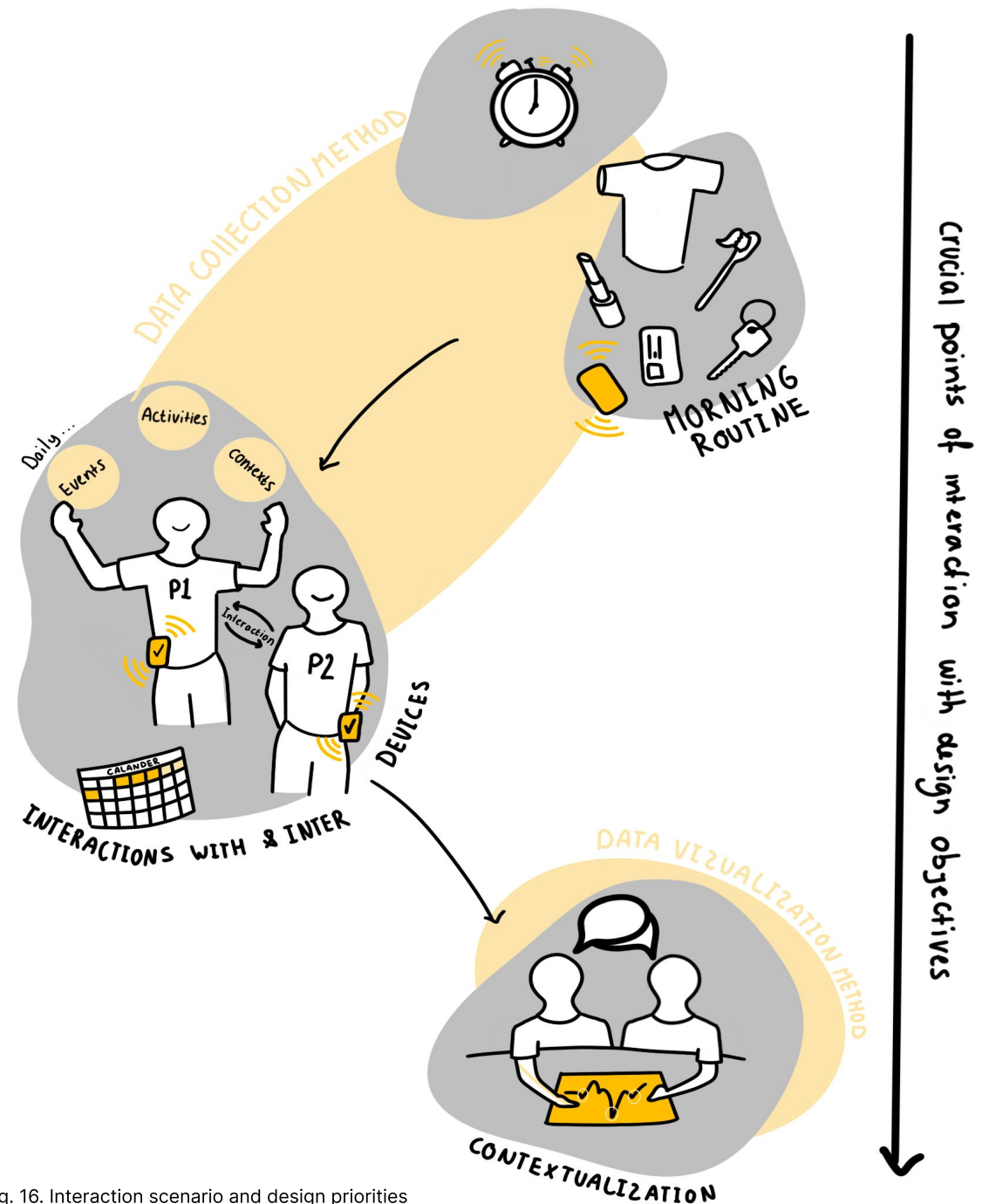


Fig. 16. Interaction scenario and design priorities

5.4 Discussion

The design challenge underscores the need for new methods to capture and interpret social interactions within dyadic coping frameworks. Recognizing the significance of social interactions in revealing the dynamics of couple relationships, the project addresses a gap in existing methodologies for integrating social interaction into technology for remote patient monitoring (RPM) strategies.

To tackle this, I set clear objectives: (1) creating a passive data collection method that unobtrusively captures couple-related social activities and (2) designing a visualization tool that supports collaborative interpretation of this data. The chosen design approach focuses on a seamless and empowering wearable sensor kit that ensures close proximity to users for accurate data capture and a collaborative visualization template that facilitates co-analysis by couples to contextualize the data facilitated by the researcher.

However, how do I transform these key elements of social interaction to quantitative measurable parameters? How do I analyse the data to use as creative design material? And, how do I gain contextual meaning about these parameters to help me understand RPM strategy design needs? I addressed this question in chapter 6 - Self-Experimentation.



CHAPTER 6

SELF-EXPERIMENTATION

How can I gather collective and contextual data in a real-life setting? and how can I visualize the data to extract meaning?

Chapter 6 aims to provide you a clear understanding on how social interaction was broken down into quantifiable parameters and then integrated within the design of the data collection and visualization method. Therefore, I also provide you with a general overview of the design process and methods, prototypes generated and used, and the design insights leading to the final design tool-kit that can be used for uncovering design opportunities and guidelines.

6.1 From Social Interaction to Data

To develop a passive and robust data collection method that discreetly and accurately captures the dynamics of couple's social activities in real-world settings, I first selected the APRACE framework (Hoppler, Segerer, Nikitin, 2022). This framework provides a detailed breakdown of the building blocks of social interaction and offers insights into the multiple layers I need to explore in my project.

Next, I implemented a structured three-step approach alongside the design of the data visualization method. This process ensured that the method integrates seamlessly into participants' lives while delivering meaningful insights.

APRACE - Framework

To design a RPM strategy that leverages social interaction to assess the quality of dyadic coping in patients and spouses, I selected the APRACE framework (Hoppler, Segerer, Nikitin, 2022) to guide my creative outcomes.

The APRACE framework offers a taxonomy that categorizes the components of social interaction and offers a common language, developed from everyday life experiences without theoretical constraints such as gender-based samples or specific age ranges. Therefore, this framework is well-suited for the exploratory nature of this project.. This hierarchical structure served as a valuable guideline for my research.

First Level: Data Type Identification & Sensor Matching

The first level allowed me to identify the types of data needed to capture the independent thematic areas of social interaction: Actor, Partner, Relationship, Activity, and Context.

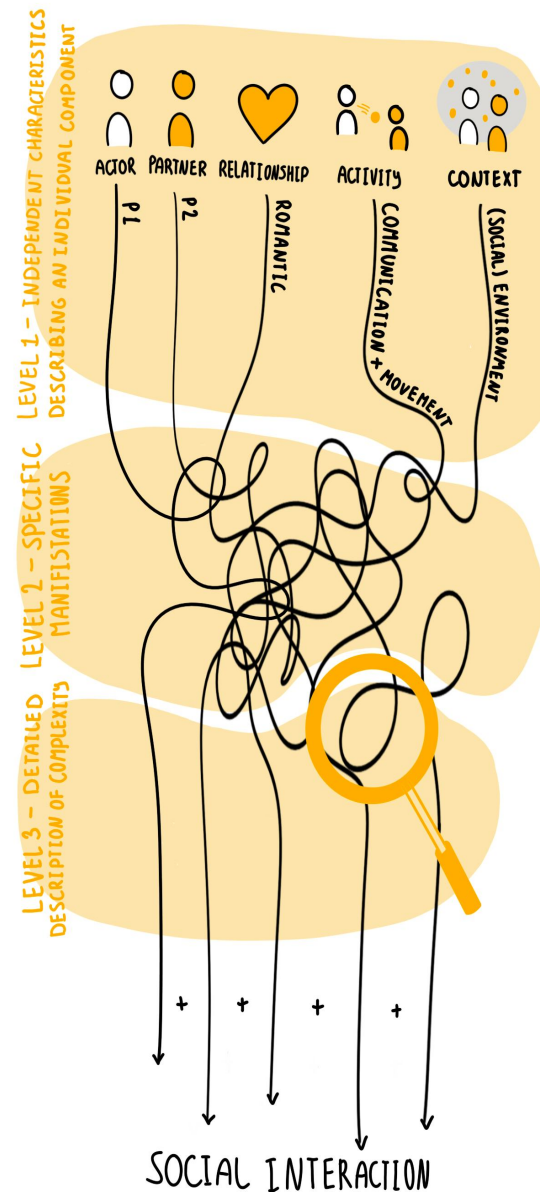


Fig. 17. APRACE-framework (Hoppler, Segerer, Nikitin, 2022)

Data Type Selection

I began by determining the specific types of data necessary for a comprehensive understanding of social interactions. This step involved a brainstorming session focused on the key elements of social interaction and the contextual information required to support experience recollection through data visualization (Figure 17) (see Appendix F). This resulted in selecting sound, movement, location, and interpersonal distance as data types.

Sensor Selection

Based on the identified data types, I matched each with appropriate sensors. This involved both individual and collaborative brainstorming, ensuring that the data collected accurately reflected the various aspects of couple-related social activities.

Second Level: Self-Experimentation

At the second level, I iteratively developed the research probes allowing me to collect and visualize data, enabling me to illustrate the specific manifestations of these thematic areas.

The process included self-experimentation and retrieving feedback to address issues related to user experience and interaction, software, hardware, and data aggregation and visualization, ensuring reliability and accurate interpretation. A comprehensive overview of the design process can be found in Appendix A and B.

Third Level: Contextualization

At the end of each self-experimentation field test (detailed in Chapter 6.2, Technology Exploration), contextualization, as part of the evaluation of the opportunity for leveraging couple's collective data for mental health assessment through remote patient monitoring, allowed me to further dissect these

manifestations to uncover the complexity and meaning of social interaction within romantic relationships and their connection to dyadic coping.

This process included brief interviews with my partner, using data visualization templates filled with data illustrating the manifestations of the thematic areas. Through this, I gained insights into both data visualization and aggregation regarding people's ability to interpret the data, to derive contextual meaning and understand the connection to dyadic coping.

Design Process & Prototypes

Along this process, different design methods were performed, and prototypes were explored to finally come towards the final tool-kit design for investigating design guidelines for developing a strategy to passively and remotely monitor and contextualize mental health by leveraging couple's collective data (Figure 18). The results of this process are further discussed in 6.2 Technology Exploration, 6.3 Data Collection, and 6.4 Visualizing Data. More detail on this process (and design insights) can be found in Appendix A en B.

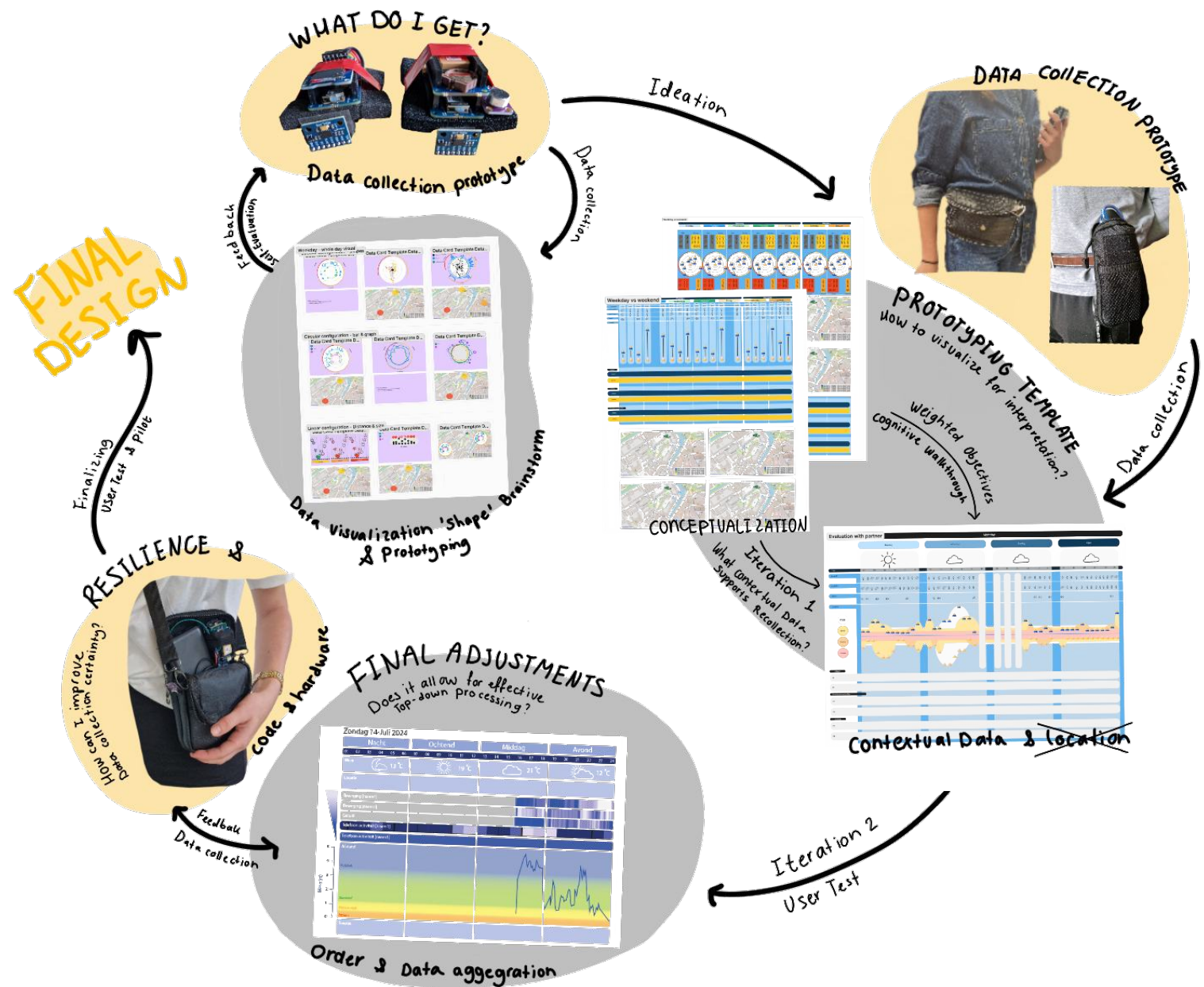


Fig. 18. General overview of design process & prototypes

6.2 Self-Experimentation Process

As aforementioned, I structured the self-experimentation process into three distinct field tests. This approach allowed me to prioritize different elements in each iteration and incorporate evaluation points to gather feedback on my methods and prototypes (Appendix B). The design process outlined in the previous chapter is interwoven throughout this process, highlighting the steps taken between each field test (Figure 19).

Fieldtest 1

The first fieldtest aimed to explore the functionality and capabilities from the sensors that I selected. Therefore, I expected to be able to understand what challenges there would be for the data collection method design.

Field test 2

Fieldtest 2 aimed to explore how much data is necessary to allow for a sufficient data analysis, and for the participants to reflect on their social interaction related to mental well-being. This included exploring data collection-rates, aggregation, and visualization.

Field test 3

Field test 3 aimed to improve the resilience of the data collection probe. As the insights show, several external influences caused the device to malfunction. Therefore, hardware & software solutions were explored to maintain data collection.

Final Design

Insights from all three field tests were incorporated into the final design, leading to adjustments in the sensor kit, reconfiguration of the technology, and refined user instructions for the contextualization phase. These developments are further highlighted in 6.2 Data Collection (p. 34) and 6.3 Visualizing Data (p. 36).

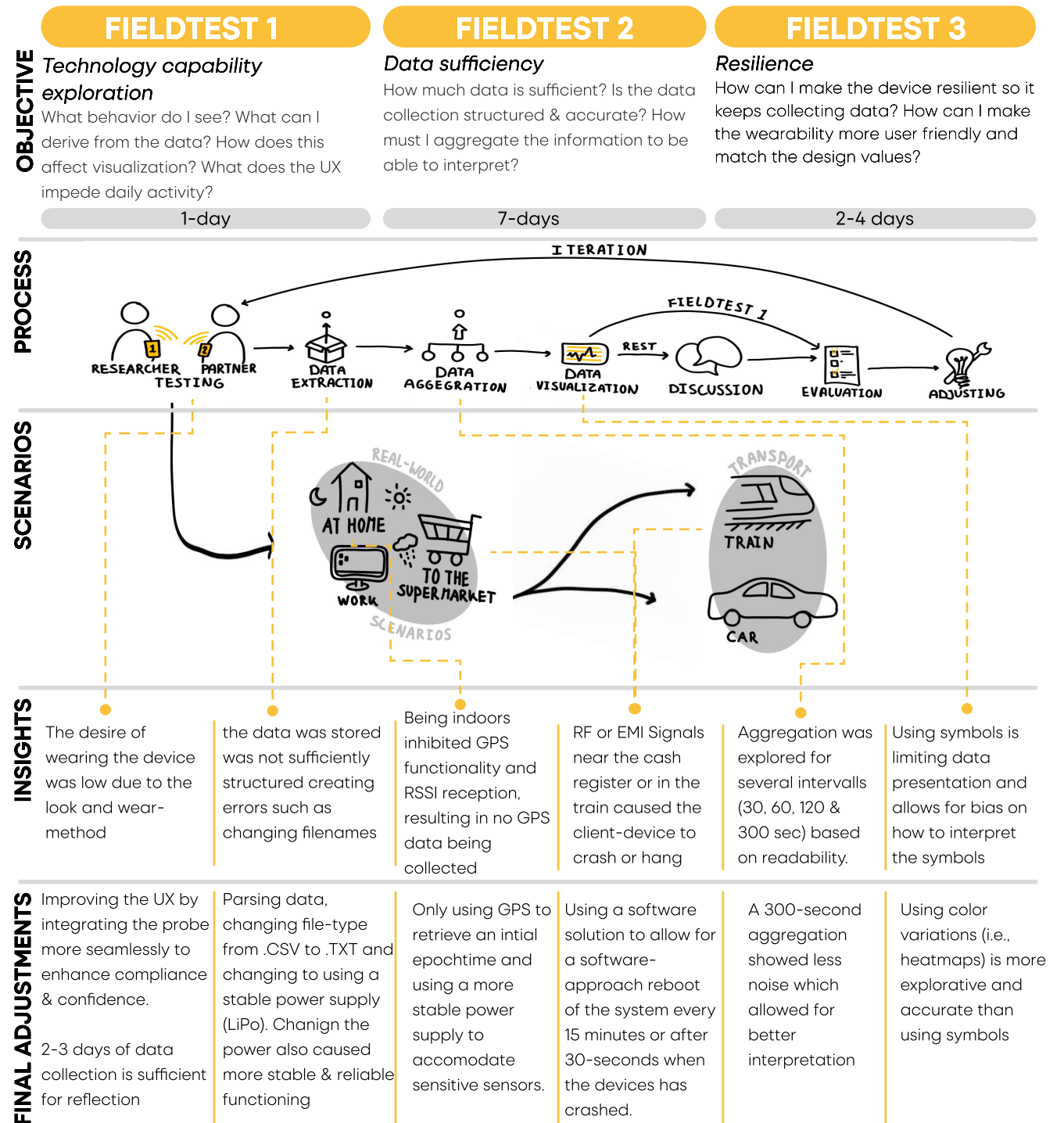


Fig. 19. Field tests self-experimentation process

6.3 Data Collection

The data collection method aimed to passively and remotely capture social interaction data from couples in real-life settings, utilizing a seamless and supportive design.

Design Insights

Throughout the process of designing the data collection method, the self-experimentation provided valuable insights regarding the usability and user experience of the prototypes. This resulted in several learnings, eventually leading to the design of the final data collection method (Figure 20). More on the design process can be found in Appendix B.

Seamless Integration and Empowerment

The design process pointed out that to ensure that a wearable integrates seamlessly into daily life, its design should prioritize appearance besides size. Therefore, I designed the sensor kit to resemble an everyday item: a neutral, adaptable bag. This makes it suitable for all users, regardless of gender or style preferences, allowing for comfortable and confident wear. In addition to data collection, the sensor kit offers practical value as a functional accessory, providing space for essentials like a phone, keys, and cards.

Limitation

Wearable devices risk being forgotten or unused during certain activities. To address this, the design provides clear instructions and practical solutions for easy removal and reattachment, ensuring flexibility and encouraging consistent use.



Fig. 20. Design process insights

Technology Configuration

To gather data on individual movement, interpersonal distance, and sound over time, I integrated four sensor types (Appendix F):

- Interpersonal Distance - WiFi was used not only for data transfer but also as the sensor for measuring distance. The received signal strength indicator (RSSI) from the server device was converted into an estimated distance between sensor kits using a logarithmic function.
- Movement - An accelerometer captured movement, with data from the x, y, and z axes combined into linear acceleration to simplify analysis by reduce data collection.
- Sound - A sound intensity sensor measured environmental decibel levels.
- Time Synchronization - A GPS sensor retrieved epoch time (UTC) for accurate timestamps, later adjusted to Dutch time (UTC+2).

Data was securely stored on a MicroSD card, ensuring privacy by avoiding complicated cloud or other solutions and protecting against potential data breaches.

Resilience

Several key improvements were made to address challenges. Real-time GPS tracking was removed due to its impracticality indoors, with location data now gathered only during the contextualization phase. GPS is used solely for initialization to retrieve the epoch time, reducing power consumption. LiPo batteries with built-in protections

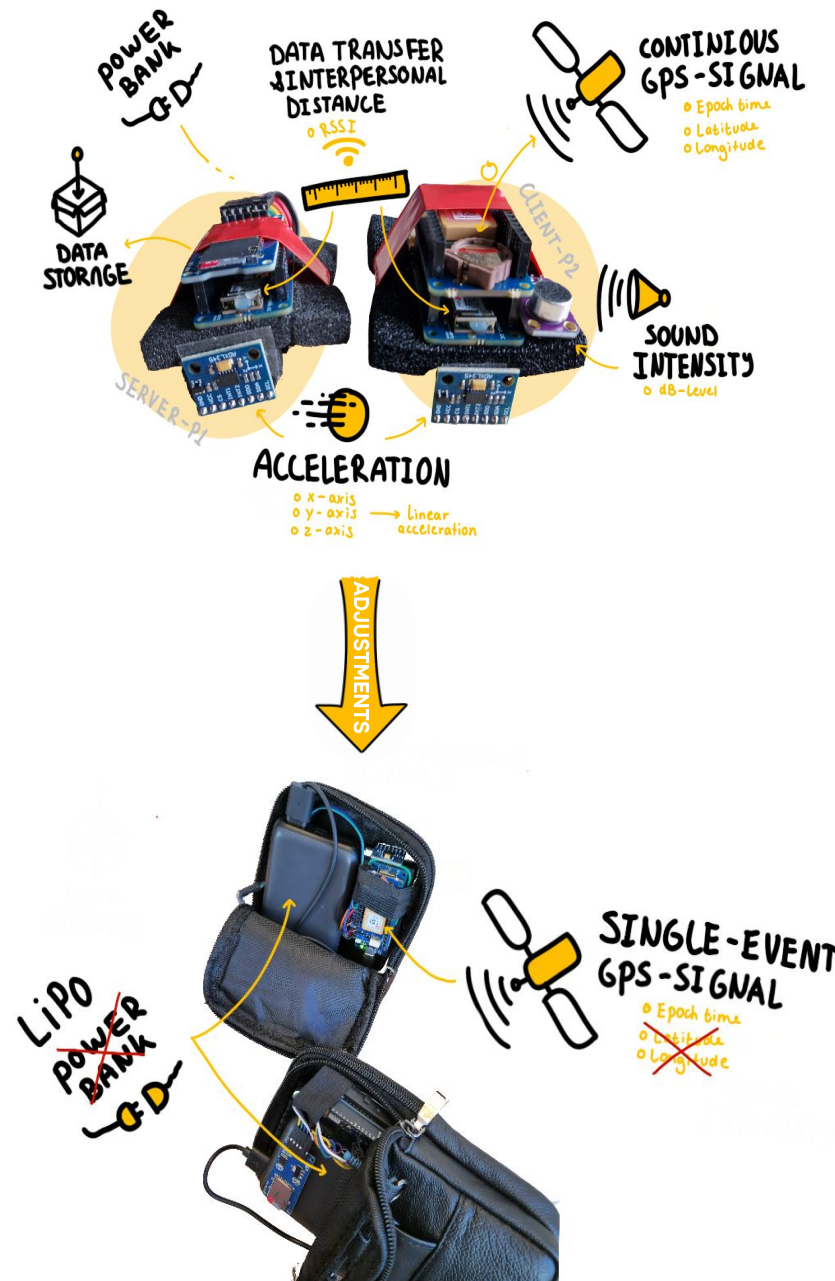


Fig. 21. Data collection probe wearability & sensor configuration

replaced the unreliable power banks, ensuring consistent performance. To mitigate issues with EMI, RF interference, and software crashes, participants received detailed instructions on device monitoring and troubleshooting.

Protecting Privacy

Another reason for excluding location data from subsequent research was to minimize the collection of personally identifiable information. The evaluation of the initial sensor kit revealed that location data could be gathered during the contextualization phase instead. This approach added an extra layer of privacy protection by allowing participants to share location details only when they felt comfortable during the co-analysis in the contextualization interview.

Limitation

Using remote storage in this project meant data couldn't be accessed until the sensor kits were physically retrieved from participants. This delay impacted the timeline for subsequent research activities, as additional time was needed to process and visualize the data before conducting the contextualization interviews.

6.4 Visualizing Data

The core objective of the data visualization method is to aid couples in recalling and reflecting on their shared experiences. Therefore, data visualization is a combination of data-informed perceptual stimuli that allows for tapping into the long-term memory (LTM) (Branaghan & Lafko, 2020).

Perception to Visualization Style

Branaghan and Lafko explain that perception involves sensing and recognizing stimuli through sight, sound, touch, and other environmental inputs. It relies on both bottom-up processes, which analyze the physical properties of stimuli, and top-down processes, which draw on prior knowledge and expectations from long-term memory (LTM). Since short-term memory (STM) typically lasts only 15 to 30 seconds (McLeod, 2023), this research focuses on how visual data presentation aids in recalling experiences from LTM (covering the past 2 to 3 days) and reflecting on them. Considering that STM can hold just 7 ± 2 items, this guideline influenced how data is presented to participants.

Design Insights

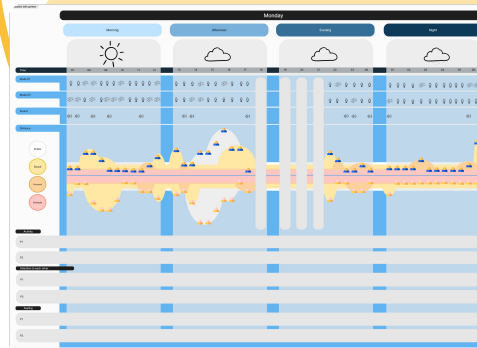
The data collected during the field test was used as creative design material to create data visualization prototypes (Figure 22). In-between evaluations provided insights regarding the extend of interpretation and collaboration the prototype provided, resulting in the final prototype. More details about the design process can be found in Appendix A.

Prototype 2

Day-overview

Insights

- As symbols are illustrative, they are prone to interpretation bias and limits the detail of data that can be shown
- The legend of space categories is unclear
- The space for mapping does limit data-presentation.
- Time intensive to make
- Does not allow mapping of geospatial information or mobile activity

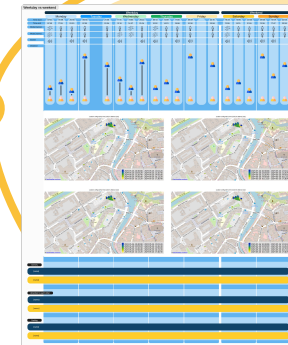


Prototype 1

Week-overview

Insights

- Week-overview and current layout limits the possibility to show sufficient amounts of data



Final Design

Graph-style visualization

Insights

- Allows for showing detailed information, with easy adaptable aggregation
- Clear legends by using colors
- Provides enough space for data presentation and mapping all-over the template
- Easy and fast to fill in
- Enhancing top-down processing by effective funnel-style visualization and information grouping.

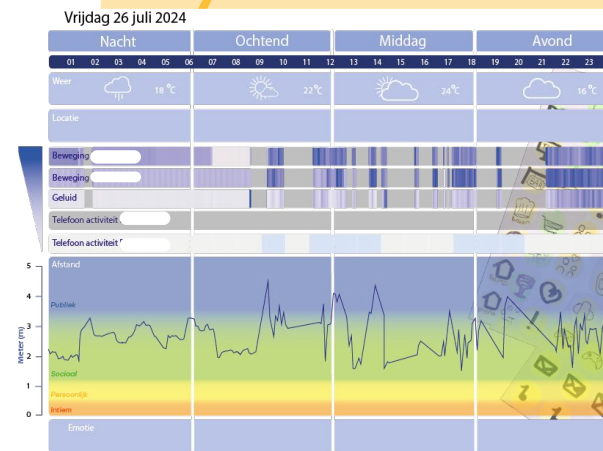


Fig. 22. Insights derived during the design process

Supporting Interpretation

The insights from the iterations after each field test resulted into an effective data visualization template that allowed for a layout that supports the contextualization process by directing participants' focus from general to specific information. Moreover, the field tests revealed that color intensities and graphs with clear legends were more effective for data interpretation than symbols in this context. As last, additional contextual information was added, as the space to indicate and show geospatial and mobile activity information.

Collaboration and Respect

The initial design allocated space for contextualization but was revised to offer more room for data display, enhancing collaborative efforts. Additionally, the updated template empowers participants in the co-analysis process by presenting data in a neutral format, allowing them to interpret and share insights according to their comfort level.

Limitation

The template visualizes aggregated data to simplify interpretation, as unaggregated data can be too complex and detailed. However, aggregating data within a physical template limits flexibility, as it does not allow for switching between different levels of aggregation. This decision significantly impacts the level of detail available for understanding the contextual meaning of social interaction data. Since this impact was initially unclear, it was further explored in the user research (see Chapter 7).

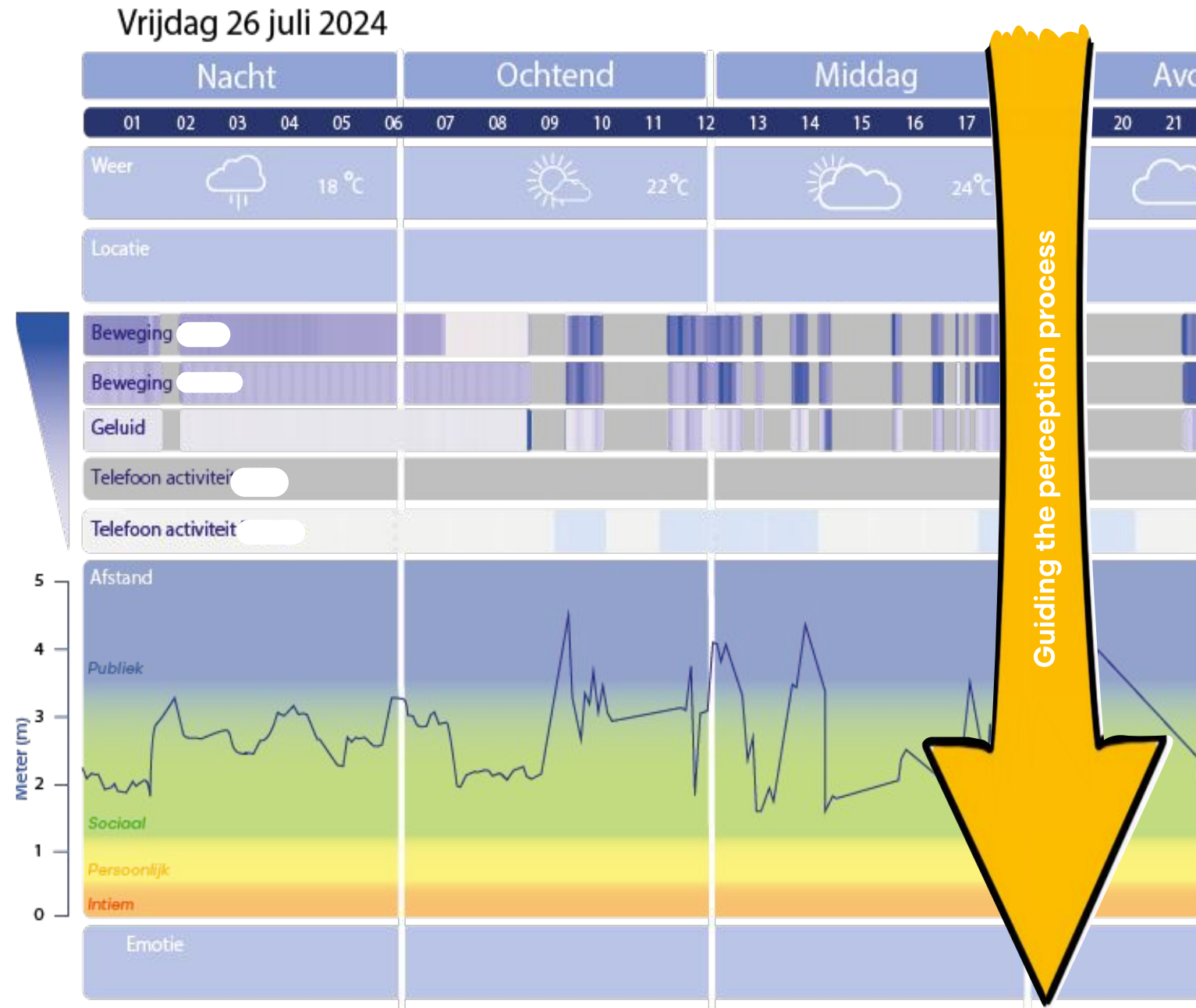


Fig. 23. Final template & stickers filled with data from participant 1 & 2 in the user research (chapter 8)

Data Integration

The aggregated sensor data was synchronized with contextual and temporal details, including time of day, day-part, and weather data from the Royal Dutch Meteorological Institute (KNMI) (Figure 24). This integration aimed to enhance participants' recollection by accounting for factors like temperature, which can affect social behaviors such as preferred proximity, thereby providing deeper insights into interactions (Sorokowska et al, 2017).

Sensor Data

Sensor readings were aggregated at five-minute intervals, averaging data for better analysis. Acceleration and sound data were converted into heatmaps, which were then segmented according to the measurement time and inserted into the templates. Interpersonal distance data was represented as a line chart, manually aligned with the time axis in the template for accurate integration.

Contextual Data

Weather data from KNMI was integrated by aligning it with the dates and locations of participants' activities, collected during sensor-kit retrieval and analyzed using Orange. Additionally, phone activity, including screen usage, was tracked as a heatmap using the 'Digital Health' app on Android or a similar tool on iOS.



Fig. 24. Illustration explaining where data is integrated within the data visualization template

6.5 The 'Final' Toolkit

The final toolkit exists of both the data collection- and visualization method and is designed to collect data regarding social interaction between romantic partners.

Data Collection Method

The data collection method exists of two stand-alone devices, which are connected to each other through WiFi, and provide reliable and safe data collection through unobtrusive and seamlessly integration into daily life while ensuring usability and participant compliance.

Safety & Adaptability

Data is stored locally ensuring secure storage by eliminating the risk of online data breaches. This offline approach also enables the device to function without other network connectivity, making it a resilient design suitable for a wide range of contexts.



Fig. 25. Showcase of the final data collection method

Compliance

To promote consistent use of the sensor kit, the bag design incorporates a functional advantage by serving as a convenient carrier for personal items. This dual-purpose approach eliminates the need for additional bags, fostering a more positive perception of the sensor kit while seamlessly integrating it into daily routines. Additionally, hooks on the back allow the user to secure the bag to their trousers, reducing movement during activities and further enhancing comfort and practicality.



Fig. 26. Dual-purpose data collection method allowing participants to carry every-day items



Fig. 27. Showing the flexibility of the design. Participants are able to hook the device to their clothing to accommodate active activities.

Seamlessness & Flexibility

the final design accommodates user preferences by seamlessly integrating with everyday clothing for improved comfort and wearability. This adaptability does not compromise measurement accuracy, as the device's position remains consistent, and sensors are recalibrated each time the device is activated.

Data Visualization Method

The data visualization template enables fast, efficient, and intuitive data integration, effectively capturing detailed social interaction data.

Collaborative Co-Analysis

The design of the data visualization method allows the researcher to collaboratively co-analyse the social interaction data by 'completing the picture' together. Participants can reflect top-down using their knowledge on routines to contextualize their data. Researchers can dive into more detail using the template as support during interviews, pointing at the data in specific moments to also support bottom-up (i.e., data-enabled) reflection.

The stickers offer an easy and interactive way to add contextual information to the template that supports subsequent analysis to gain rich contextuul insight regarding social interaction.

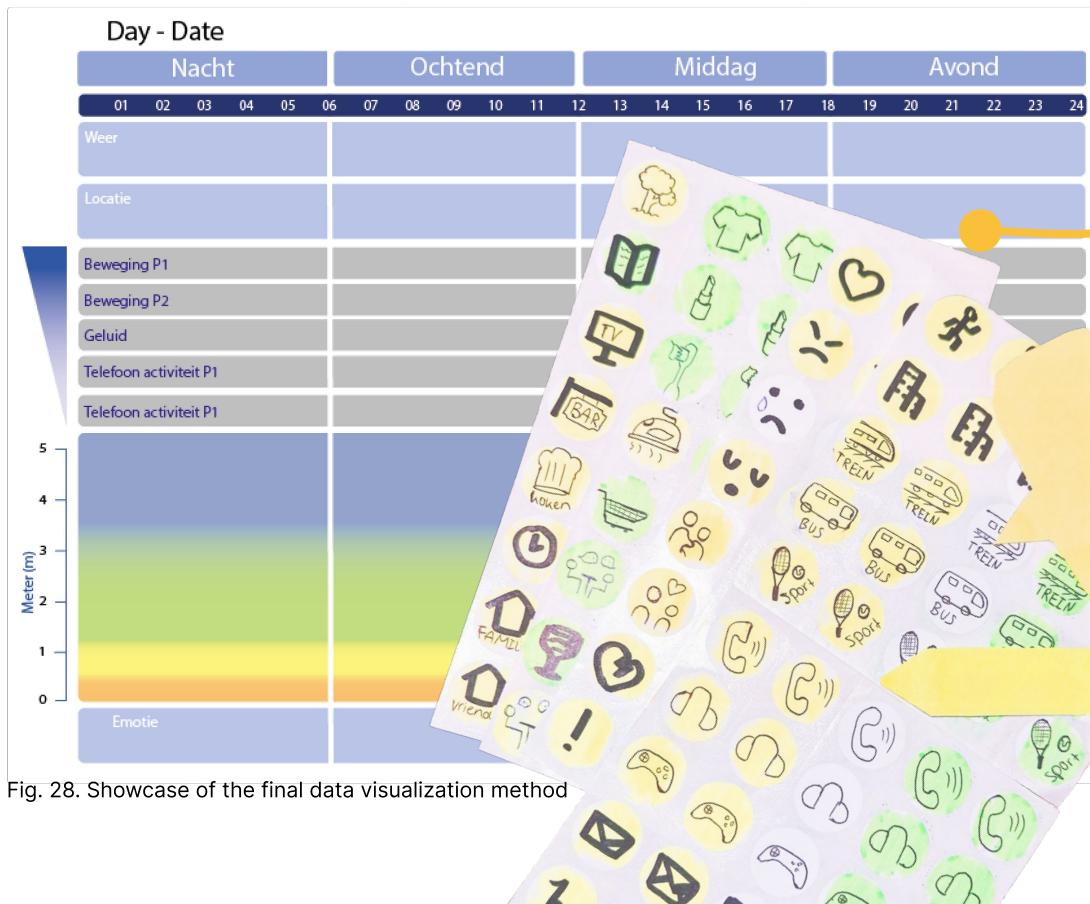
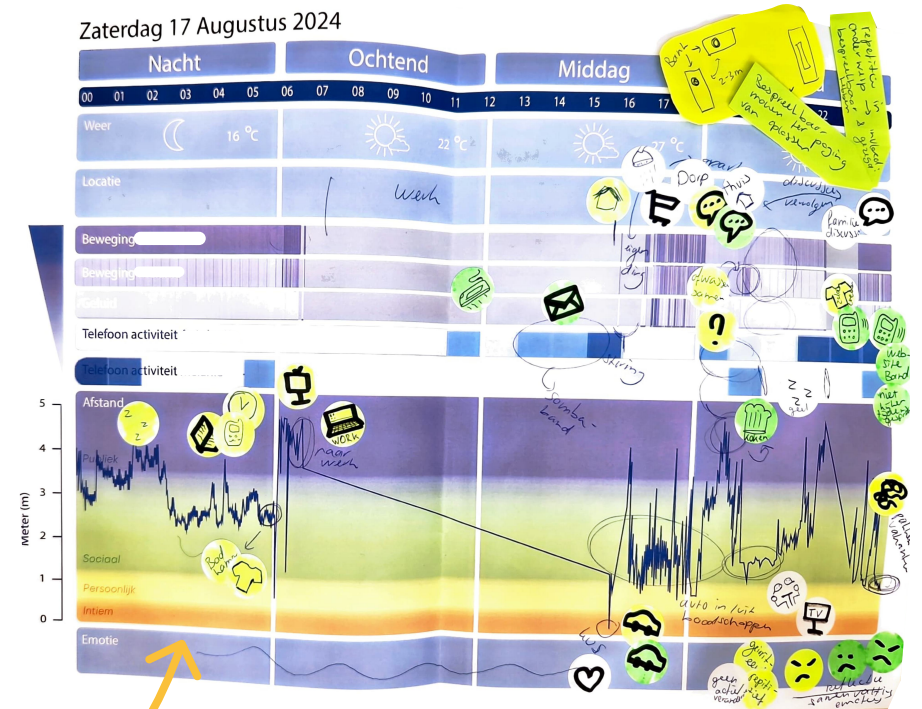


Fig. 28. Showcase of the final data visualization method



Funnel-Style Design

The template itself is designed to guide the contextualization process using a funnel-style layout, which can also be used to guide the interview discussion, starting with general information to prompt recollection, then progressively narrowing down to more detailed insights, revealing the data's contextual meaning.

6.6 Discussion

Within this chapter, I explained how I developed a passive data collection and visualization method designed to capture social interaction data from couples, offering significant potential for remote patient monitoring (RPM) in healthcare and research. The design process leveraged the APRACE framework to identify essential social interaction data and match it with appropriate sensors. Through iterative testing and self-experimentation, I refined the data collection method to ensure seamless integration into daily life, balancing technical reliability with user comfort.

The visualization approach was designed to support top-down cognitive processing, enabling participants to easily recall and reflect on shared experiences. This method offers valuable insights for healthcare and research by demonstrating how social dynamics can be systematically captured and analyzed to retrieve insight in dyadic coping. Moreover, the design process emphasizes the importance of user-centered, iterative development in creating RPM tools that harness social interaction data, opening new possibilities for personalized and context-aware healthcare solutions.

Nonetheless, the final design of the tool-kit as described in this chapter does show some limitations regarding timing and compliance were still a challenge to be addressed. So, how do I mitigate these challenges to still perform research with participants in their real-life context without having to interfere? I further addressed this challenge within the pilot (Appendix H), exploring instruction methods. Next, I performed a research activity to uncover design implications, pitfalls, and opportunities, addressed in chapter 7- Uncovering Design Opportunities and Guidelines.

CHAPTER 7

UNCOVERING DESIGN

OPPORTUNITIES AND GUIDELINES

What are the design implications for an succesful RPM strategy leveraging a collective perspective regarding patient mental well-being? How can we avoid strategy pitfalls? And what are the implications for future design?

This chapter provides an overview of the research approach used to contextualize social interaction data from participating couples, aiming to highlight the significance of social interaction in mental health assessment and the design implications for interpreting this data. It covers the process of contextualizing data with participants and its impact on RPM design. Insights gathered throughout the project are synthesized to formulate design guidelines for creating a holistic RPM strategy that leverages collective data from romantic couples. Additionally, the chapter identifies potential pitfalls and future opportunities for further exploration. The chapter concludes with a discussion, elaborating the contribution of the results to formulating the design guidelines and illustrating the importance of RPM design needs regarding the data-enabled design approach.

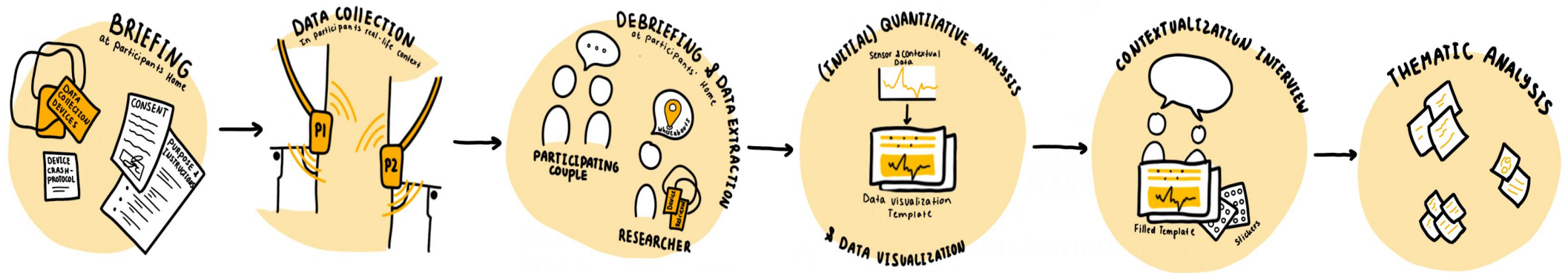


Fig. 29. User research process with participants

7.1 Aim

To investigate the implications of this strategy of leveraging social interaction data of couples (in cancer survivorship) to monitor mental well-being, I wanted to find answers the research question: *'What are the design implications for an succesful RPM-strategy leveraging collective data?'* I formulated the following sub-research questions to support me in the contextualizing interviews and analysis:

- What were the struggles and constrains when aiming to collect couple's geographical and ecological information?
- How well were the participating couples able to interpreted and reflect on their own data?
- How effective is this strategy in giving insight into mental health?
- What scope is there for further improvement or research?

Underneath these questions was also the aim to gain insights on the relationship between social interaction and patient's mental well-being, and uncover design insights and opportunities, and design guidelines for designing a RPM strategy leveraging couple's data.

Participants

For this study, I recruited three couples aged between 55 and 75 years, all in long-term romantic relationships and living together. Recruitment was conducted through personal networks, ensuring that participants had no prior connection to colorectal cancer (with the exception of one participant who had experience with cancer survivorship in a previous relationship). Nonetheless, this selection aligns with the study's focus on general relationship dynamics rather than cancer-specific experiences, both for ethical considerations and to maintain the viability of the research.

7.2 Method

Within the user research, I engaged in five steps involving (1) Preperation, (2) data collection within the real-life setting of the participants, (3) intital analysis and data visualization, (4) interview, and (5) thematic analysis, to retrieve the final results through data contextualization inspired by (Bourgeois,van der Linden, Kortuem, Price & Rimmer, 2014) (Figure 29).

Preperation

Each couple was briefed about the study's goal and protocol beforehand, and they provided informed consent through a consent form (see Appendix G). Activity days were scheduled based on the participants' availability and estimated time together to ensure sufficient data collection. After data collection, the participants were invited to a co-analysis interview not later than 3 days after data extraction.

Pilot

A pilot study conducted before the user research highlighted the need to ask participants about their visited locations to accurately align weather data with their experiences. It also emphasized instructing participants on hard resets for device crashes and retrieving screen activity on Android/iOS, which they managed well. The contextualization setup (Figure 30) effectively facilitated collaborative discussion, with the researcher using stickers to add contextual information, supporting thematic analysis. More details about the pilot can be found in Appendix H.

Data Collection

During the 2-3 activity days, the couples were asked to wear the designed data probe (Figure 31) at all times, except during sleep or sports. The data collection probe gathered data every 5 seconds, but only when the couple was within signal range of each other.

After the data collection period, I collected the devices and gathered information regarding user experience and travel (e.g., whether they were at home or other places, for weather context). I then extracted the data from the microSD cards.



Fig. 30. Couple engaging in co-analysis (interview) supported by the data visualization and self-created stickers

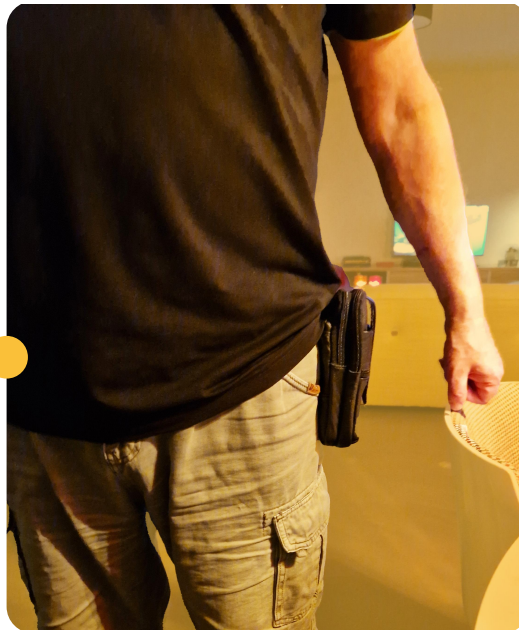


Fig. 31. Participant wearing device how they like to wear it

Initial Analysis & Data Visualization

The initial analysis focused on aggregating and visualizing the sensor data extracted from the data collection probes. Next, the contextual information was integrated with the sensor data within a personalized data visualization template, tailored to each participant's needs and data.

Interview

The 50-minute interview, conducted at the participants' home (Figure 30), was designed to gain insights into how effectively participants could interpret and reflect on their own data, guided by a completed data visualization template. Additionally, the interview aimed to contextualize the data by capturing ethnographic insights drawn from the couple's experiences. The setting also provided an opportunity to observe and understand the couple's personal environment. Sketches were made from the couple's environment when necessary to support the subsequent analysis.

Thematic Analysis

In order to analyze the interviews, I followed 6 phases of thematic analysis described by Braun & Clarke (2006). I transcribed and coded (elements of) the interviews and extracted the themes from the data (Appendix I).

Results

To answer the main research question, I divided the results in three scopes (1) Designing the approach, (2) Designing for Interpretation & Contextualization, and (3) Uncovered RPM Design Needs, leading as input (together with insights gained throughout the project) for formulating the design guidelines.

7.3 Uncovered Design Opportunities

In the process of designing the tool-kit, a variety of approaches and questions were uncovered that are useful for any future effort to design a RPM strategy (through self-experimentation). The opportunities were divided into 3 scopes, explained in the following chapters.

Scope 1:

Designing The Approach

The research detailed in this chapter demonstrates the effectiveness of the current tool-kit in capturing behavioral and contextual insights in real-life settings. Based on these findings, I developed a design framework to support and guide other designers with similar objectives.

Through my project's process, I identified five key stages that, when combined, provide a comprehensive understanding of the target group behavior, context, and the technological and contextualization implications, expanding upon the existing data-enabled design framework.

Define - What Do I Need?

Start by identifying the core essence of the behavior you want to focus on within user research by outlining your key objective(s) and investigate them accordingly.

Plan - How to Approach?

Break down the project's essence into quantifiable low-level features (Thomas et al, 2021) and select the appropriate sensors to capture these measurements. Therefore, this planning phase involves translating abstract goals into specific, actionable steps and choosing technology that aligns with these requirements.



Self-Experimentation - What to Mitigate?

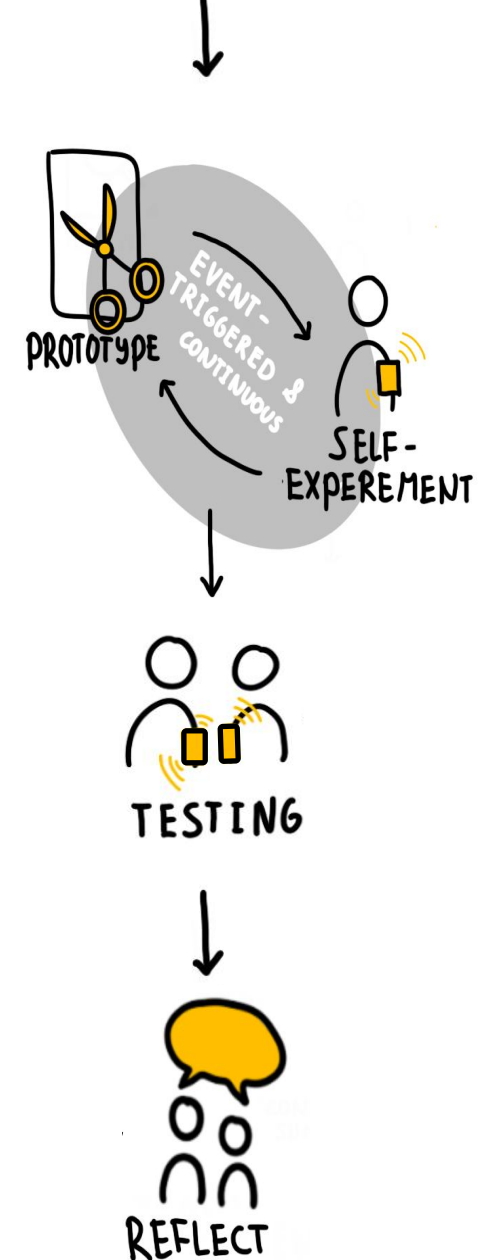
Engage in iterative prototyping through self-experimentation, situating prototypes within your real-life context as soon as possible. Focus on the prototype's usability and subsequent user experience, performance, and resilience within daily life, refining it based on issues encountered. Incorporating feedback from others (in your close environment) can further improve accuracy and relevance.

User Research - What Do I Want To Know?

The prototype developed through self-experimentation is now ready for user research within a specific target group and their real-life context. By leveraging the insights and solutions gained during self-experimentation, we can focus directly on gathering data that reveals user experience, performance, and design opportunities, without being sidetracked by previously encountered issues.

Reflect - What Did I Learn?

Assess the design's effectiveness and the adequacy of the data output. Reflect on whether the collected data aligns with the project's objectives and offers meaningful insights. Additionally, evaluate the feedback and insights gained from the target group and their contextual environment.



Scope 2:

Designing for Interpretation & Contextualization

The research presented in Chapter 7 offers critical insights into the social interactions of couples, underscoring the importance of considering factors such as diversity, location, social company, and mobile activity for accurately interpreting these interactions. The study also highlights the significance of participants' contextualization processes, the need for optimized data visualization, and the effective integration of multiple data sources. These findings have important implications for designing tools and methods to better interpret social interactions and contextualize the data derived from them, which are detailed in this section.

Interpreting Social Interaction

Interpreting data on the diversity within couples and their unique contexts, and distinguishing patterns to understand their social interactions, is a complex task.

Routine Behavior

Couples typically follow distinct patterns in their daily routines. Mornings often involve individual tasks, such as getting ready for the day, while evenings are more likely to feature shared activities like reflecting on the day's events or discussing feelings. These end-of-day conversations may be prompted by the increased availability of time after daily responsibilities or work, allowing couples to engage in more meaningful interactions.

"That is my day to do things on my own. And I like that as well. And P6 also has her own day to do things on her own. And she likes that too. [...]" Because then I can do things that P6 enjoys less, and vice versa."

- P5 Interview couple 3

"Yes, that was only about health. Just health. I did find that very frustrating."

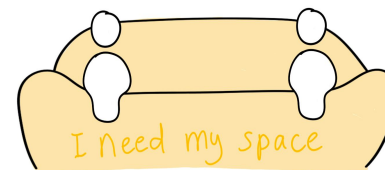
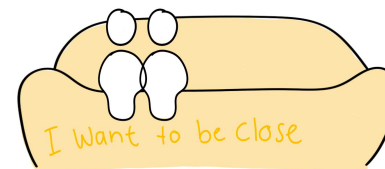
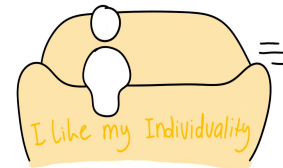
- P3 Interview couple 2

"Look, you have couples that still work, who are more away from each other."

- P3 Interview couple 2

"Exactly, we are at home, well, not the whole day together, but it is still different than with people that work"

- P4 Interview couple 2



"This is a typical Saturday evening"

- P6 Interview couple 3

"[...]We wake up around half past 9. And then I go, before the bar opens, get some groceries. Yes. [...] Most of the time around 10."

- P2 Interview couple 1

Respecting Individuality

In a relationship, both partners generally respect each other's need for personal interests and hobbies. Days spent apart offer valuable opportunities for pursuing individual interests, fulfilling external commitments, or addressing different needs and preferences at a given moment. These differing needs might stem from factors like non-matching interests or varying physical health/symptoms at that moment. Such "alone days" can be influenced by factors like differing work schedules, but are not necessarily dictated by them. Despite this, couples often strive to spend time together whenever possible. Therefore, time spent apart is not necessarily an indication of declining relationship satisfaction, however can be when couples spend increasingly time apart when being able to spend time together.

Recognizing Diversity

Couples vary significantly in their dynamics due to factors such as, personal situation regarding work-life, health, etc., personality regarding comfort with personal space and need for individuality, and living environment. For example, working couples may spend less time together compared to retired couples. However, spending less time together in this context does not necessarily indicate avoidance or lower relationship satisfaction. Additionally, in care-centered relationships, more frequent close moments may be observed in the data, but this does not automatically reflect relational or individual well-being, as it largely depends on the couple's individual and joint coping strategies. These nuances are crucial to consider when analyzing social interactions within relationships.

Geospatial information

Accurately interpreting couples' social interactions requires taking their location into account, as it helps identify patterns across different contexts and reveals how external influences shape their dynamics (Figure 32), overlooking location and spatial context can lead to misinterpretations regarding the meaning of the data to relationship satisfaction, emphasizing, the importance of incorporating geospatial data to accurately differentiate between meaningful interactions and how they are shaped by external factors, as noted by Green, Derlega, and Mathews (2006).

Social Company

The aforementioned insight also highlights the importance of considering the broader social context when studying partner interactions.

While couples often enjoy spending time with others, their attention during these periods is more focused

on the company than on each other (30). Couples frequently discuss life events or provide practical or informational support to their social circle, whether in work or private settings. Interestingly, the analysis revealed that patterns of couple-only activities can appear similar to those involving other social partners. This underscores the need to account for the influence of the wider social environment to make distinctions in data.

Additionally, the data suggests that couples tend to stay physically closer when in the company of others (e.g., visiting family or friends) compared to

"From here to here we were together. [...] Walking next to behind within the bar? Or that someone is in the kitchen and the other...yes, no."

- P2 Interview couple 1

"P6 has mostly done things, here in the garden."

- P5 Interview couple 3

"And you have mostly talked with your mother, I think then."

- P6 Interview couple 3

"Eh, I ordered things for my mother, online"

- P5 Interview couple 3

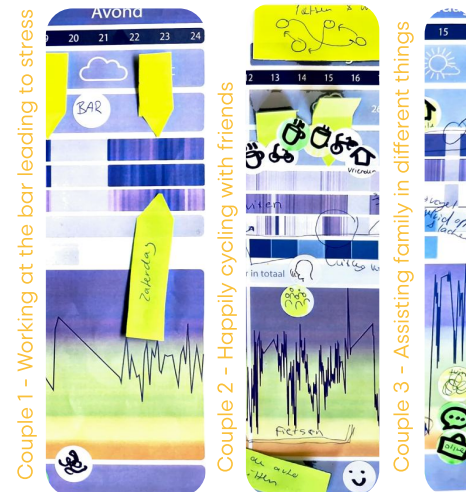
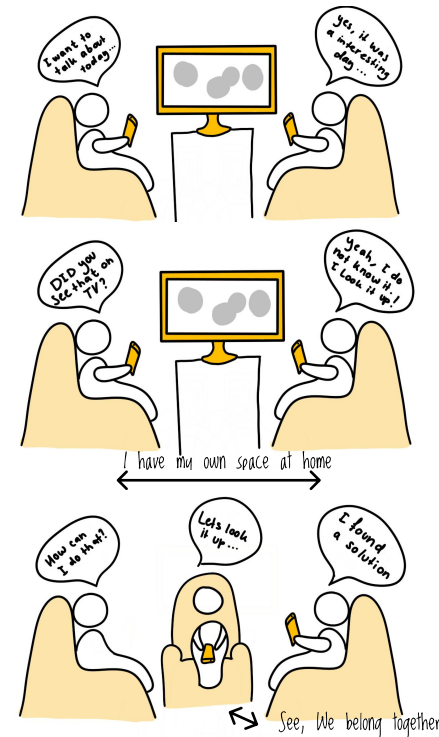


Fig. 32. Similar rapid fluctuations, however different emotional consequences

when they are at home during static moments. This could imply that at home, individuals gravitate toward their own preferred spaces, likely influenced by the layout of their living environment. In contrast, when socializing outside the home, couples may feel a social obligation to remain physically closer together.

Mobile Phone Activity

This study indicated that mobile phones play a role in social interactions (both intra-couple and in social company) as they were used as tools to support or initiate conversation. Therefore, mobile activity should not be a solely dependent for a meaningful interaction. However, this study indicated that increased mobile activity together with a decrease in communication over time might indicate declining relationship satisfaction



"When you do much on your phone, then you can be together. That is no bad sign, no"

- P6 Interview couple 3

"No, because everybody is enjoying its own hobby"

- P5 Interview couple 3

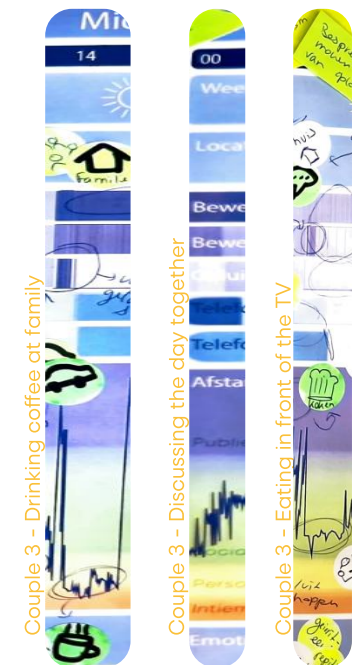


Fig. 33. Similar close patterns, but difference in meaningful interaction

Meaningful Interactions

Not all shared interactions foster a similar level of meaning towards (understanding) relationship satisfaction. For example, time spent in a car or doing household tasks together may have limited impact on understanding a couple's social dynamics, as these activities often don't encourage engagement and may lead to more individual-focused behaviors. Similarly, morning routines, while occurring in shared spaces, are typically carried out independently. While, On the other hand, evenings are particularly significant as couples often engage in reflective conversations or share daily experiences. This time is conducive to meaningful interactions due to fewer work-related distractions and a more reflective atmosphere. Therefore, certain moments in a couple's day are more significant for understanding their social interactions and the effectiveness of their relationship than others.

Design Opportunity 1: Co-Creating Interpretation

Design an tool-kit that allows participants to create their own 'base-line' relationship characteristics and behavior, by allowing them to map both individual and mutual routines through out the week and settings.

Design for Data Contextualization

Contextualizing data with couples revealed how they engage with data, the effectiveness of visualizations, the benefits of combining data sources, and potential design opportunities.

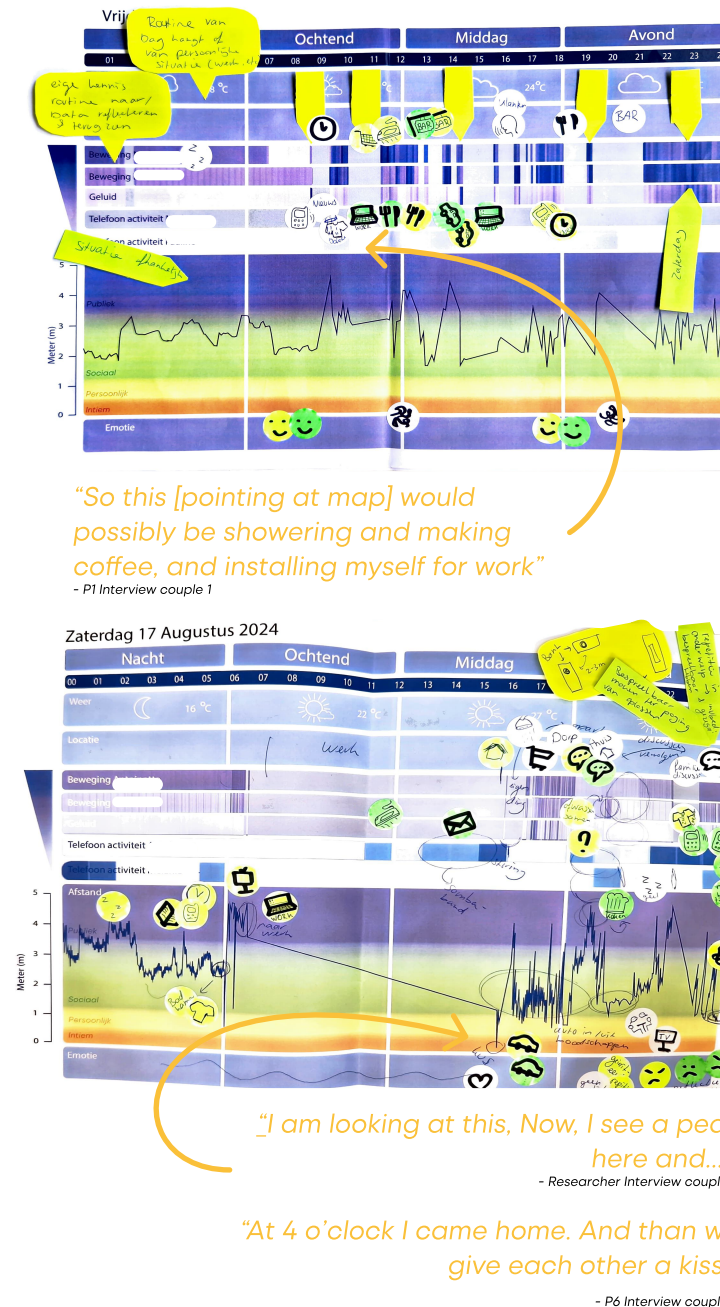


Fig. 34. Differences in data aggregation resulting in different visualization & more detailed and accurate contextualization

Recollection of Events and Experiences

The contextualization approach combined participants' routine knowledge (top-down) with data-driven insights (bottom-up). Participants first used their understanding of individual and mutual daily routines to interpret data and identify potential inaccuracies. Following this, they worked with the researcher to select specific moments from the data and reflected on corresponding behaviors and experiences, leading to a deeper understanding of detailed interactions.

Data Literacy & Visualization

Participant familiarity with technology affected their ability to interpret data, often necessitating researcher support, though this did not impact the quality of discussions. Data aggregation also influenced the detail of interactions revealed. Five-minute intervals proved insufficient for capturing close-proximity interactions, such as providing physical consolation or showing affection. Therefore, I switched to 45-second intervals, which offered clearer insights into short and close-proximity interactions. However, this occasionally obscured the interpretation of the data.

Combining Data Sources

Combining multiple data sources was key to accurately contextualizing behaviors and interactions. Cross-referencing sensor data provided deeper insights than individual sensor outputs related to participants' recollections. Participants also used tools like mobile health monitors, mobile schedules, and location-based applications, like Google

Maps and another study application related to mobility, to verify data and aid memory recall (Figure 35). This multi-layered approach offered a richer understanding of social interactions and implications for designing an RPM strategy leveraging social interaction data.

Design opportunity 2: Reflection, Scenario-Building, and Literacy Support

Design an interface that facilitates reflection by allowing scenario building and moment annotation. Include adaptive visualizations for zooming in on details or viewing broader patterns, and AI-driven summaries to ensure accessibility across different levels of tech and data literacy.



Fig. 35. P3 using an governmental mobility research application to support activity recollection

Scope 3:

Uncovered RPM Design Needs

The third scope outlines the needs important for designing an effective RPM strategy that leverages social interaction data. In this respect, 'needs' is defined as the essential requirements or conditions that must be met for an individual, group, or system to function effectively, achieving a desired outcome or fulfill a particular goal (System needs - standard business, n.d.). The project process, including the systemic thinking (Stanton & Welsh, 2012) and data-enabled design approach (Lovei, Funk & Noortman, 2024), prioritized relevant behavioral and contextual information to create a tool-kit tailored to the real-life varying dynamics of couples considering relationship satisfaction as driver of dyadic coping through monitoring and contextualizing social interaction to uncover meaningful insights regarding the design of an RPM strategy. These meaningful insights were synthesized into RPM design needs that address both the design process and RPM architecture.

By addressing these needs, designers can enhance the likelihood of creating a seamless and comprehensive solution for remotely monitoring patients' mental health. This process led to the identification of four core needs for RPM design in mental health: (1) Seamless & Resilient Design, (2) Meaningful Data Retrieval,

(3) Accurate Interpretation, and (4) Data Minimalization. These needs present four new design opportunities (fig. x), which will be explored in detail in the next chapter, along with a set of key elements to address them.



Fig. 36. Design opportunities related to the uncovered design needs

7.4 Design Guidelines

The insights gathered throughout the project have led to the development of design guidelines specifically tailored for the design process and system architecture of a holistic, collective, and passive RPM strategy that leverages social interaction data from couples to assess mental health. The proposed guidelines are: (1) Ensure Reliability, (2) Ensure Clarity, (3) Ensure Support, and (4) Ensure Efficiency & Safety. These guidelines apply to the overall design approach, system development, and data interpretation, serving as guiding principles for healthcare professionals. A detailed explanation of each guideline is provided in the following sections.



Need: Retrieving Meaning Provide Clarity

A reliable RPM strategy is essential for providing accurate information that supports mental health assessments through data interpretation. To achieve this, the system should be underpinned by precise representations of mental health, incorporating data from both couples' social

interactions and physiological metrics. It must effectively identify patterns within the data to detect potential improvements or declines in patient mental health. Therefore, the design of the RPM strategy should emphasize a research-driven approach that addresses the complexities of mental health, integrating all relevant data to ensure a holistic and comprehensive solution.

Combine Relevant Data

Taking a holistic approach within remote mental health monitoring should embrace the combination of couple's geospatial, sociability, social interaction, and physiological data retrieved from numerous sources to understand their patients mental well-being.

Connote Up-and-Down

Contextualizing the combination of data must account for top-down (routine knowledge) and bottom-up (data-enabled) reflection from participants to recollect meaningful insights regarding the meaning of data.

Derive Parameters

To provide clarity among essential patterns within data, the contextualization results should be formulated in essential parameters, relevant to address diversity, for recognizing mental well-being in the multifacet data.

Integrate Baseline Behavior

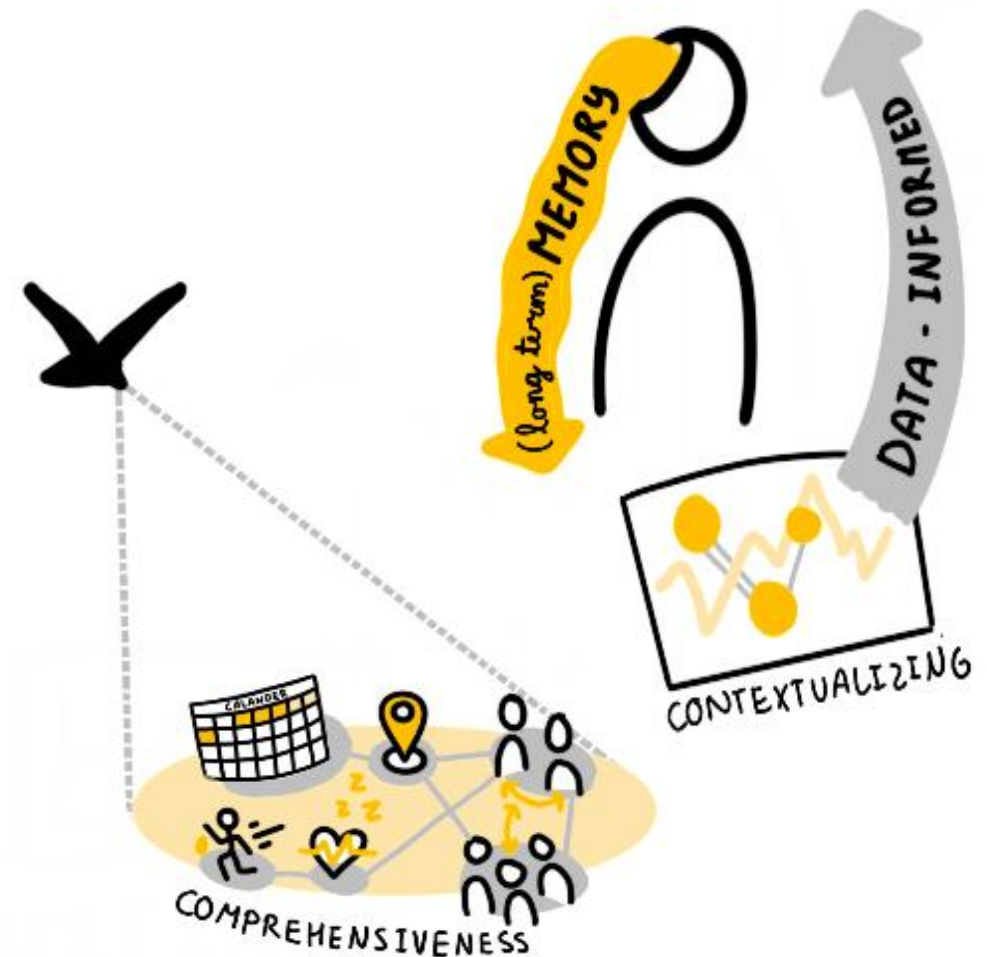
To deliver personalized insights that account for the diversity among couples and contexts, the RPM strategy should enable the co-creation of baseline behavior profiles in collaboration with physicians. The contextualized parameters derived from this process can then be used to tailor data interpretation, ensuring more accurate and meaningful insights.

Recognize Trends

Long-term changes in a couple's routines or activities can reveal important aspects of their relationship. Increased mutual or individual activity might indicate shifts such as stronger bonds, caregiver dynamics, growing independence, or avoidance. Regardless of whether these trends are positive or negative, they offer valuable signals for physicians to assess and evaluate well-being.

"It becomes more quiet in house ofcourse, I think, and you will be doing more your own thing. P4 will be going away more with her friends."

- P3 Interview couple 2





In developing an RPM system, it is essential to consider the diversity among couples and their unique contexts. The design must accommodate this variability and ensure that data collection is comprehensive and unobtrusive, covering all daily activities—from sleep to exercise. Additionally, the

Embrace diversity

"If you were to interview a normal couple, they work. They go out the door and come back around five or six o'clock."

- P2 Interview Couple 1

Go Into-the-Wild

"Yes, but that's not the case with us. We actually have many more interaction moments throughout the day than you would normally expect."

- P1 Interview Couple 1

Create Seamless Decentralized Design

*"Then we walked to the fair,
and it malfunctioned again."*

- P6 Interview Couple 3





Need: Appropriate Interpretation Provide Support

The insights in this project indicated that the (possible) multitude of data sources makes the distinction within and between data patterns uncomprehensible for the human's eye and interpretative capabilities. Therefore, technology should be integrated in order to support, within this project's

context, physicians to make informed and unbiased assessments regarding declining or decreasing mental health of their patients.

Train Models

Contextualization insights from a sufficiently large sample can be used to train models with technologies like machine learning, enabling precise data differentiation to allow physicians to interpretate the data.

Customize

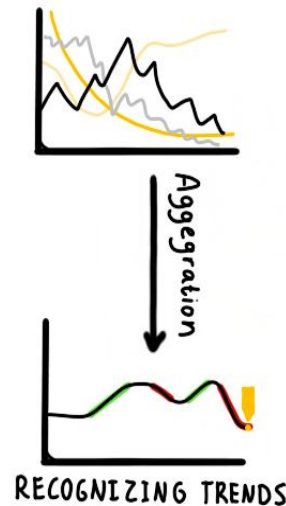
Key parameters that capture diversity among couples can be utilized to customize the system's models, enhancing their ability to recognize trends specific to each couple during the follow-up phase.

Simplify Interpretation

Interpreting mental well-being data should be streamlined through effective aggregation, providing a centralized overview of mental health rather than dispersing information across multiple separate data streams.

Avoid Interpretation Bias

To minimize interpretation bias regarding the interpretation of trends within data, the RPM physician user interface should effectively indicate and visualize a trends significance regarding mental health assessment.



"I find this somewhat complicated. What is the difference of here with that?"

- P4 Interview couple 2



Need: Data Minimalization Provide Efficiency & Safety

An effective way to minimize data storage is to collect only essential personal data (of users and their social environment) for the shortest time necessary (Forbes Technology Council, 2024; Dabah, 2024). In remote patient monitoring, focusing on purpose-

driven data collection improves analysis, supports ethical practices, lowers legal risks, and reduces healthcare costs.

Target Data Collection

To optimize remote patient monitoring (RPM), data collection should focus on periods that offer the most valuable insights into relational dynamics by targeting meaningful interactions regarding couple's social interaction.

Use Sensors Selectively

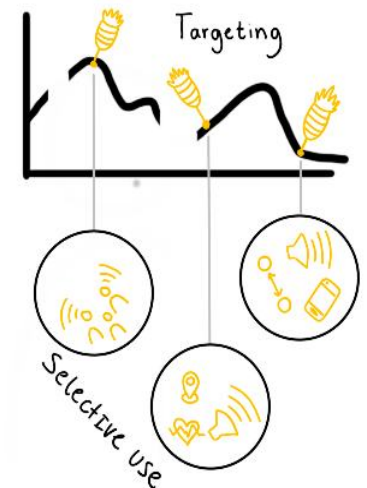
An RPM strategy should selectively and occasionally gather data from specific sensors to avoid redundant collection during periods of less meaningful or absent social interactions. For example, during sleep, the collection of social interaction data is irrelevant.

Design Integrity-Preserving Data Visualization

To design a comprehensive RPM strategy, the combination of data and can reveal sensitive and indirect personally identifiable information (PII) about the patient and their spouse. Therefore, technology must be used to safeguard their privacy and integrity by aggregating and visualizing data in a manner that avoids disclosing PII within the physicians UI, and only communicates the result from analysing the multitude of data. This ensures the protection of the couple's privacy.

"If you have a normal work situation and you work both all 5 days, then it is probably not necessary to measure all days [or moments]"

- P1 Interview couple 1



7.5 Guideline Pitfalls

Regarding the guidelines, I identified several aspects that are either underexplored in this project or require additional attention. To address these gaps, I offer design opportunities that help avoid potential pitfalls.

Lack of Meaningful Interaction Awareness

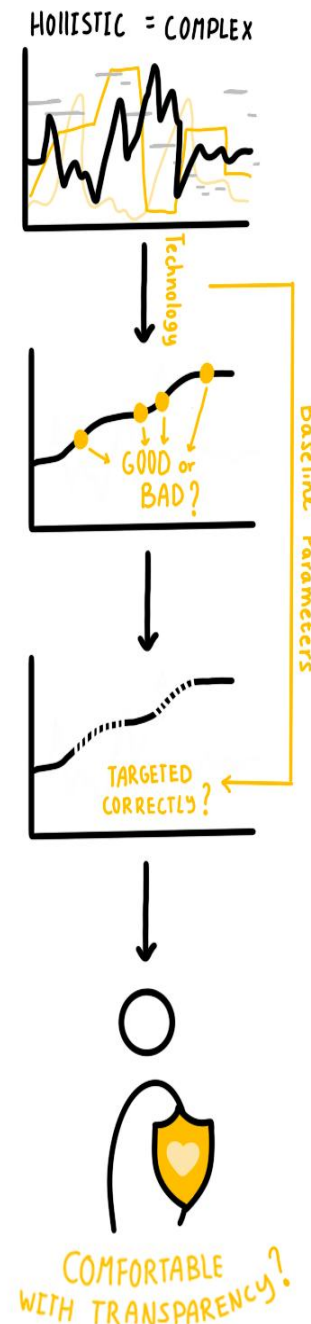
The design guidelines do not describe how to retrieve information about meaningful interactions. Earlier, I defined the design opportunity for co-creating a baseline behavior regarding how a couple typically goes through life. Participants, patients, and even physicians or researchers might be unaware about what interactions are meaningful to monitor.

Design Opportunity to Avoid Pitfall: Designers need to create a tool that does not only uncover obvious behavioral traits of couples, but also latent and implicit knowledge to uncover more rich insights being able to make more informed decisions on meaningful interactions informed decisions on meaningful interactions

Missing Important Data

When selectively collecting data based on situational factors, there is a risk that if the monitored data doesn't align with predefined parameters, significant information could be missed. This includes sudden changes or short-term trends that may have a substantial impact.

Design Opportunity to Avoid Pitfall: Designers should be mindful of the risks associated with data minimalization through targeted data collection. To address this, there is an opportunity to integrate a validation mechanism that prompts patients, participants, or spouses to contextualize any uncertainties, thereby enhancing the understanding and relevance of monitoring dyadic coping.



Transparency Comfort

As the RPM strategy strongly builds upon combining datasources from the patients context and behavior such, that may or may not provide indirect PII, the risks exists that this level of transparency is uncomfortable for patients and their social context involved.

Design Opportunity to Avoid Pitfall: During the design of the RPM strategy, designers must take into account privacy and comfort in sharing data. Therefore, they must explore this with the target audience as a research activity.

Physiological and Mental Well-being Interconnections

Adopting a holistic and comprehensive approach to monitoring mental health necessitates the integration of physiological measurements besides social interaction measurements. However, this project's scope did not extend to exploring the implications of combining these measurements. As a result, the extent to which physiological well-being influences mental well-being, and vice versa, remains unclear. This uncertainty complicates the development of an RPM strategy that effectively leverages both types of data, particularly when using statistical models to accurately distinguish changes in mental health.

Design Opportunity to Avoid Pitfall: Designers should prioritize physiological measurements during the contextualization phase to better understand the relationship between physiological well-being and mental health, as well as the potential reciprocal effects.

7.6 Discussion

The purpose of this chapter was to address the research question: “What are the design implications for a successful RPM strategy leveraging collective data?” To answer this, I focused on: (1) identifying challenges and constraints in data collection, (2) interpreting and reflecting on data, (3) assessing the effectiveness of mental health insights, and (4) exploring future design and research opportunities.

The findings were categorized into three areas: (1) Designing the Approach, (2) Uncovered Design Opportunities, and (3) RPM Design Needs. These areas led to the formulation of four design guidelines: ensuring reliability, clarity, support, and efficiency & safety in RPM design.

Uncovered Design Opportunity Scopes

Scope 1 and the design process guidelines were based on my experiences throughout the project and the application of a data-enabled approach. Consequently, these guidelines provide a preliminary framework rather than a complete set of universal requirements for designing an RPM strategy. This preliminary framework is particularly relevant in the process of designing the prototypes that can be situated into real-life contexts of the target group.

The design opportunities identified in Scope 2 are closely tied to the methods used for contextualizing couples' social interaction data. These opportunities represent an initial step and may lead to further discoveries as they are explored and developed.

Similarly, the RPM design needs in Scope 3 and the corresponding guidelines are linked to the aspects explored in this project. While they do not constitute a complete list of requirements, they offer valuable initial insights and highlight areas for further exploration in designing RPM strategies that leverage collective data.

Guidelines & Pitfalls

The presented design guidelines show a strong relationship with the uncovered design opportunities and RPM-design needs. Additionally, some insights were more present in certain stages of this design project than others. Figure 38 illustrates how the design guidelines can be mapped onto the project's phases. Knowing where the design guideline insights mostly manifest within a design

approach might support designers in creating prioritizations and design decisions in particular stages of their creative processes. Similarly, the guideline pitfalls might provide designers caution on what to focus on or to address in order to mitigate insufficiencies within RPM design.

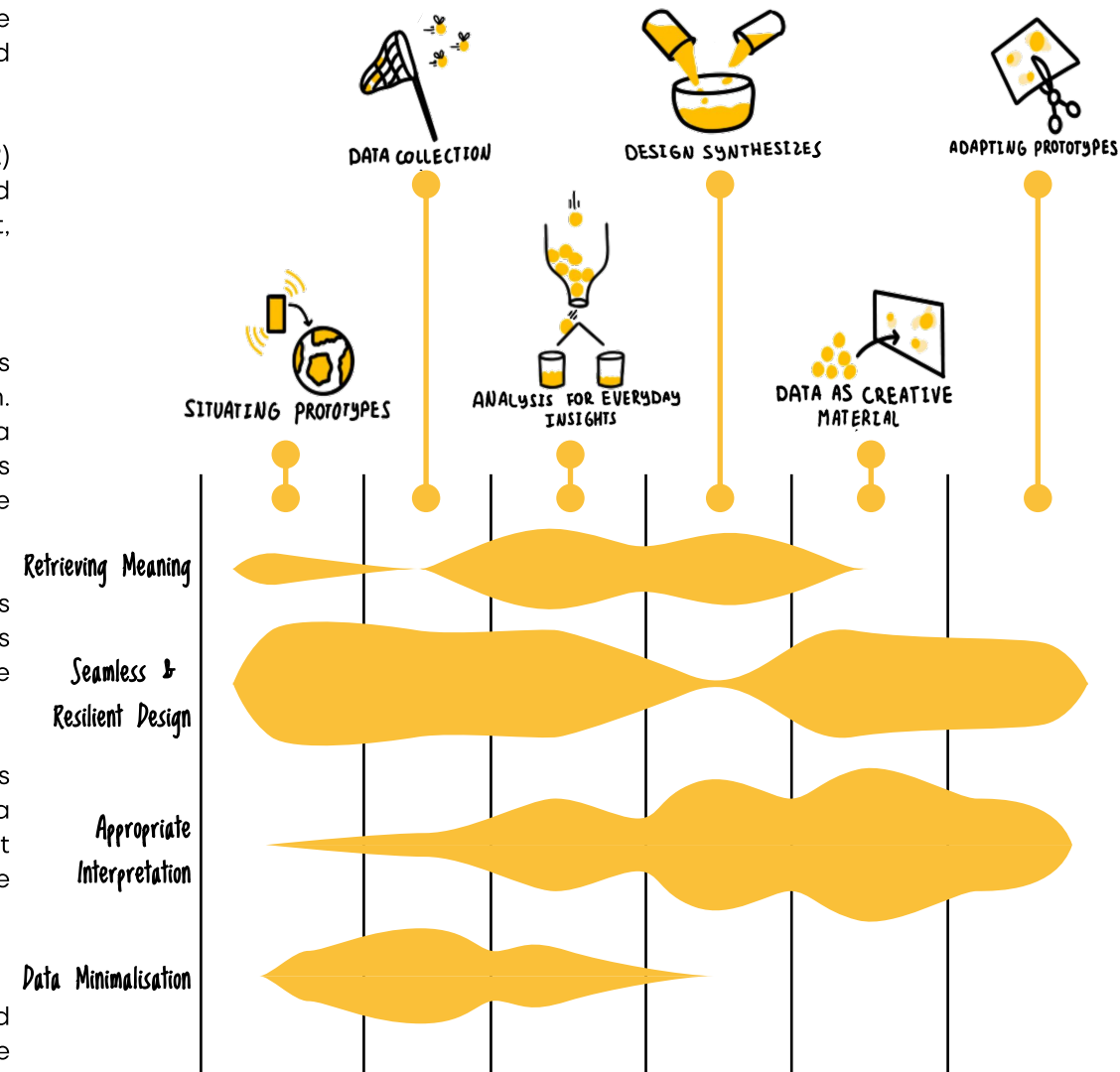


Fig. 38. Indication of uncovered RPM design needs centered within the data-enabled design approach



CHAPTER 8

DISCUSSION & CONCLUSION

what are the contributions, strengths, and limitations of this project results and process.

In this chapter, I summarize the study's findings and their implications for understanding dyadic coping, designing RPM systems for mental health, and addressing the needs of colorectal cancer survivors. I also compare the strengths and limitations of a collective RPM strategy with an individual-oriented approach for assessing mental well-being.

Additionally, I evaluate the project's methodologies, participant considerations, and technological constraints, highlighting both the strengths and limitations of our approach. Based on these insights, I provide recommendations for future design exploration and research.

The chapter concludes with a reflection on my academic journey and personal growth throughout the project.

8.1 Discussion

This thesis aimed to investigate how to design a holistic RPM strategy leveraging collective data of romantic couples. The resulting guidelines, design opportunities, and strategy pitfalls are further discussed here regarding contribution, strengths and limitations, and opportunity for future activities.

Results and Contributions

This research offers new insights into RPM strategies by adopting a systemic and data-enabled design approach for exploring the design implications regarding the design of a passive and holistic RPM strategy leveraging collective data from couples. Social interaction was identified as the main driver to maintain relationship satisfaction, essential for dyadic coping. However, this study highlighted again the interconnectedness of physiological, psychological, and social factors (Vizzotto et al, 2013). Therefore, understanding mental health of patients through remote monitoring still requires an effective combination of the three. Leveraging social interaction is a first step in psychological and social factors, where physiological input is still to be explored.

Moreover, the research activities performed have provided modest yet valuable insights into emotional and physical outlets within couples relationship dynamics regarding maintaining relationship satisfaction (or not). Likewise, contextualization of social interaction data slightly uncovered insights regarding social interaction in couples, which are especially interesting regarding designing a RPM strategy that effectively analysis a diverse set of data. Moreover, these insights can aid in future design of data minimalisation strategies, as targeting essential measurement periods and using sensors selectively can aid in reducing data collection and consequent usage of resources, as Forbes Technology Council (2024) explain that reducing the amount of (personal) data, leveraging high quality of data over quantity, and focussing on collecting data for specific, defined purposes are effective data minimalization strategies. This also accommodates the GDPR, as it improves adequate, relevant, and limited data collection necessary for the purpose which is processed for (Goldsteen et al, 2022). However, it should be noted that one major pitfall is the risk of missing data that does not match expected (baseline) behavior, therefore also affecting analysis and training of models

outcomes. Additionally, the process that I went through in this thesis offers a contribution to the data-enabled design community, as it guides designers create the prototypes that will be situated in real-life contexts

The results build on existing literature concerning dyadic coping in couples, especially during illness (Bodenmann, Randall & Falconier, 2017), as well as therapeutic settings leveraging frameworks like the EFT-framework (Adamson, 2013) and systematic thinking in psychology (Stanton & Welsh, 2012), and the APRACE-framework regarding social interaction. Moreover, Input from the target group was incorporated and cross-referenced with literature to ensure the findings align with established knowledge about dyadic coping as discussed within this thesis. Additionally, this thesis underscores the benefits, challenges, and design opportunities within the RPM design process and system development. The design opportunities identified in this thesis point to new avenues for future exploration in both design and research. Investigating these opportunities could further refine the design guidelines for collective and comprehensive passive RPM systems. This research also contributes to the broader field of data-enabled design community by sharing successes and challenges encountered when situating prototypes in real-world settings and contextualizing data with participant collaboration.

Strengths and Limitations of Collective RPM Design Guidelines

What distinguishes an individual-oriented RPM strategy from a collective RPM strategy is the recognition that well-being also depends on fostering effective relationships, as interpersonal stress regulation is more effective than intrapersonal stress regulation. Moreover, illness, or cancer survivorship specifically, affects not just the patient but also family members, friends, and caregivers, all of whom are included in the broader definition of survivorship (Rutherford et al, 2020). This collective approach offers a comprehensive assessment of patient well-being but also complicates data interpretation. The focus of this thesis was to focus on social interaction to create insight into relationship satisfaction to support dyadic coping, hence the results from the contextualization made implicit that physiological factors play a role in interpreting social interaction. Therefore, physiological data was included within the formulation of holistic RPM design guidelines regarding leveraging social interaction data to assess mental health, however is not explored within this project regarding the extend physiological factors play a role in social interaction.

A holistic approach that integrates diverse data sources covering various aspects of a couple's activities makes it challenging to reliably identify positive and negative indicators of mental well-being. Proper design is essential to manage this complexity, requiring the integration of data science elements, as telehealth innovation already suggests (De Angel, Lewis, White et al, 2022), such as training models, customizable parameters, and effective visualizations that minimize cognitive load, interpretation bias, and time constraints. The contextualized data retrieved from data-enabled design efforts, if successfully implemented, can serve as a baseline for machine learning algorithms to personalize key elements of couple interactions related to dyadic coping, ultimately providing a more accurate indication of the patient's mental well-being. However, the insights retrieved within this thesis are not yet sufficient to do so, but offer a starting point.

a holistic RPM design also raises privacy concerns, as it requires collecting significant amounts of (indirect) personally identifiable information from the patient, their spouse, and possibly others in their social context, referring to geospatial indicators as an example in this project (IBM, n.d.). Nonetheless, the actual design of an RPM strategy according to the guidelines discussed in this project might probably raise more PII-concerns that need to be addressed in the future. This needs to be addressed in future efforts.

One strength of the RPM approach in this project is its passive nature, which reduces compliance issues and user experience limitations associated with active methods like self-reporting. This passive method allows for monitoring within the patient's natural environment, reducing patient self-report bias (Salters-Pedneault, 2023) and stress associated with hospital visits (Maag Lever Darm Stichting, 2023), limiting the need for in-person check-ins to instances where trends indicate a need for further verification by healthcare professionals. However, it's important to note that some patients might find comfort in regular hospital visits, a factor not yet addressed by the current passive RPM design and guidelines. Moreover, seamless design through decentralization, leveraging the concept of blending in with everyday objects, is not further explored within this project regarding challenges for data synchronization, nor what other (meta) data is collected through this approach.

Strengths & Limitations of Project Approach and Process

In reflecting on my project approach and processes, I have identified several strengths and limitations that I will address in this section.

Design Process & Methods

Using a systemic approach to understand mental health from a collective perspective, considering the patient's direct social context (e.g., their spouse), allowed me to explore dyadic coping and its implications. This understanding informed the process of designing an RPM strategy, supported by knowledge from the literature. The data-enabled approach, where I tested prototypes within my own romantic relationship through self-experimentation, enabled an informed design process for a research toolkit that could explore the implications of a passive, collective RPM strategy. Self-experimentation saved time and effort by identifying and resolving hardware, software, and UI/UX design issues before engaging the target group. To avoid self-induced bias, I included my partner (with no experience with UX/UI design nor data analytics) within the evaluation of concepts. Moreover, a pilot was performed with the target group to make sure that the device, hence tested in my own romantic relationship, would also accommodate remote research with other couples varying in demographics, particularly age.

Additionally, the data analytics conducted in 'Orange' (Orange Data Mining, 2024) were focused solely on creating visualizations through data cleaning and aggregation. This project did not include statistical analysis due to the small sample size, which is not representative of the broader population. Instead, the emphasis was on conducting an initial exploration of the data. That is also why I did not include significant quantitative insights within the final analysis of the interview for contextualizing the participating couples social interaction data.

Participants

The participant pool in this project was limited. Sixteen individuals participated in the survey exploring dyadic coping related to communication, conflicts, equality, and support, of whom only two had a connection to cancer survivorship. Three couples (six individuals) with no cancer-survivorship experience participated in the systemic phase of the research. Three other couples participated in user research outlined in chapter 7, with only one participant having cancer-survivorship experience by coincidence. This limited participant diversity means that the knowledge generated cannot be considered universally applicable and requires further exploration for validation. Nevertheless, it provides a solid baseline for future studies.

Relation to the Use Case

The project was initially inspired by colorectal cancer survivorship, but due to challenges in recruiting participants within this field and the sensitivity of the topic, the research was conducted with participants who only matched the criteria for age, living situation, and relationship type. Nonetheless, couples within survivorship do express in literature (derived from the systemic approach as discussed in chapter 2 and Appendix E) similar value regarding effective communication, as one essential part in social interaction (i.e., disclosing information that is meaningful to one) (Hoppler, Segerer & Nikitin, 2022). Thus, the insights and guidelines developed in this theses are not specific to cancer survivorship or any illness-related context, however, it establishes a baseline applicable to various contexts involving couples' social interactions in RPM design, still beneficial for design for cancer-survivorship remote mental health assessment.

Sensitivity

To address the sensitivity of the topic, the research activities were designed to allow participants to control what they disclosed. During the scenario-supported interviews, participants reflected on general scenarios, choosing which experiences to share. In the contextualization phase, participants co-analyzed their data with me, allowing them to decide which behaviors to emphasize and explain. However, participant control also carries the risk that some data may remain non-contextualized.

Research Methods

To understand the design implications for a collective RPM strategy, research was conducted over seven days per participating couple, including 2-3 days of data collection followed by a contextualization interview within three days after. This timeframe provided sufficient data for contextualization and reflection but did not capture behavioral changes over time in the data, which could indicate shifts in mental health. Insights in this area were based on participants' reflections on long-term outcomes, suggesting a need for longitudinal studies to further explore these trends.

Technology Constraints

The data collection devices experienced intermittent crashes due to an unidentified issue that could not be resolved with the available resources. While this may have impacted data collection, participants were well-

prepared to recognize and address these crashes. Despite these challenges, the devices still gathered sufficient data over the 2-3 day period. The presence of faulty data, while problematic, added depth to the contextualization discussions. Additionally, the sensors used in this project were generally reliable for real-world application, though their accuracy varied. For example, measurements of interpersonal distance were influenced by environmental factors such as obstacles and nearby signal-emitting devices. This variability likely introduced a bias toward larger distances and may explain the limited detection of intimate space in the collected data. However, as noted earlier in the project, intimate space might not be the most critical factor in understanding dyadic coping. Effective communication and emotional awareness often require a larger interpersonal distance, which may hold more significance in this context.

8.2 Next Steps

Through this project, I uncovered numerous opportunities for further exploration. Here, I outline them as next steps.

Exploring the Uncovered Design Opportunities

This activities within this project have uncovered numerous design opportunities worth while to further explore (1) contextualization of data, and (2) design for an holistic & collective RPM strategy regarding the close social context of patients. A logical next step would be to dive deep into these design oportunities. My recommendation within this is to start with exploring the design opportunities regarding contextualization and social interaction design, as to use these insights within the design of an RPM strategy.

Refining a Toolkit for Social Interaction Research

The toolkit developed in this project has proven effective for researching social interactions within romantic couples. The next step could involve refining the toolkit to address the identified challenges, such as data collection and visualization issues, and applying it to social interaction research in other target groups. I recommend integrating location-based and additional proximity sensors to capture a broader range of relevant data for analyzing social interactions comprehensively, and support contextualization through simplifying recollection of experiences.

Taking a Closer Look Into Social Interaction for Indicating Behavior Change

As the amount of participants was limited within this research, a logical next

step is to further engage in exploring social interaction of romantic couples to indicate changes in dyadic coping. For this, I recommend to not only take a larger sample size, but also perform the research over a longer period of time. Nonetheless, the research should be performed in a research where changes within couples capacity of dyadic coping, through increasing or declining relationship satisfaction, is expected, such as cancer survivorship.

Dive Deeper Into RPM Design for Cancer Survivorship

That said, this project has indicated that monitoring social interaction can provide important insights regarding mental health of patients. However, to provide a full picture on patient well-being, the monitoring of both physiological and psychological measurements should be considered. Moreover, some cancer survivors might not have romantic partners, making it important that this aspect will also be explored in future design and research efforts. Therefore, a next step would be to take the learnings and design opportunities of this project as a base-line for further exploring the RPM design that leverages all aspects of health assessments within cancer-survivorship. This can be done in combination with other health care innovation initiatives, such as PROMISE, aimed to provide personalized follow-up in the home environments of patients, giving patients more control on their trajectory and insight and feedback on their QoL, overall health, and tumour markers (Erasmus RDO, 2023)

8.3 Conclusion

This project aimed to design a strategy for remotely monitoring and contextualizing mental health by leveraging couples' collective data. A systemic approach was used to identify the core of "collective data" in the context of dyadic coping—specifically: social interaction. This focus guided a data-enabled approach to uncover design opportunities, needs, and limitations. The research highlighted the shortcomings of current RPM approaches in healthcare, particularly during the follow-up phase of cancer survivorship, and led to the discovery of a new holistic and collective perspective for RPM strategy design. This passive approach differs significantly from existing active RPM strategies typically implemented in healthcare settings, addressing issues related to biases and incompleteness in mental health assessments.

The findings from this project suggest that an effective RPM strategy for mental health assessments must adopt a holistic and collective perspective, integrating multiple data sources related to patient and spouse interactions and patient physiological well-being, which are then contextualized to retrieve parameters for personalized design.

The research also identified opportunities to enhance the contextualization and visualization of such data by leveraging technologies like machine learning to support the recognition of patterns in mental health changes through models trained with contextualized data. To prevent this complexity from burdening physicians during patient assessments, it is essential to aggregate and simplify the data streams to reduce cognitive load and minimize interpretation biases. Caution must be taken regarding the collection, analysis, and possible (unintentional) disclosure of PII. This research offers concrete insights that support designers in creating contextualization methods and holistic RPM strategies, providing guidance through a design approach and identifying design opportunities as a starting point. There are still many aspects of contextualization, social interaction in dyadic coping (especially in cancer-survivorship), and RPM strategy design that warrant further exploration. I hope this project serves as a solid foundation for future research in these areas.

8.4 Reflecting on the Project

Within my Graduation project brief, I identified three learning ambitions that I liked to pursue within this graduation. Here, I reflect upon the achievements made regarding them.

Achieving Academic goals

Here, I detail my reflection upon whether I did or did not achieve my academic goals.

Data-enabled design

As part of my academic goals, I enjoyed exploring data-enabled design approaches to understand how data can enhance user and context investigation, ultimately supporting the design process. During this project, I successfully applied a data-driven approach, discovering the significant benefits of creating research probes that collect contextual data from

target groups. This approach allowed me to derive deeper insights compared to traditional methods like observation or interviews. The contextualization phase, supported by data, revealed implicit and latent knowledge that would have otherwise been missed. I also gained a deeper understanding of the importance of using high-quality, calibrated sensors and appropriate data aggregation techniques, ensuring that the level of detail aligns with the objectives of the research. These insights emphasized how crucial it is to handle data thoughtfully in both research and design. Going forward, I am confident that I will continue using data-enabled design approaches in future projects, particularly in user research and complex system design.

Project management & planning

In the past, I often struggled with formulating the right questions at the appropriate stages of the design process, making it difficult to find a clear direction. This challenge was partly due to not selecting a process framework to guide me. For this project, I made a conscious decision to adopt the Double Diamond framework, structuring my work into four phases: Discover, Define, Develop, and Deliver. This helped me focus on distinct aspects of the design process. With feedback from my supervisors, I was able to formulate key questions at each stage, which effectively guided me throughout. Additionally, I incorporated other frameworks from literature, such as systems thinking and the data-enabled design framework, to provide further guidance, particularly in the discovery phase.

Using a structured approach also improved my ability to plan. However, I realized that I tended to create overly detailed plans, leaving little room for flexibility or creative exploration. As a result, I plan to adopt a more general approach in future projects, focusing on the estimated time needed to answer key questions rather than planning specific activities that may not be predictable at the outset. This will allow for a more adaptable and creative design process.

Feedback from users

My final learning ambition was to better integrate user feedback into my design process to ensure that design choices aligned with the needs of the target group.

During this project, I quickly realized that involving users for tasks like testing remote data collection and contextualization would be time-

consuming and could slow down my progress due to the need for continuous participant recruitment. To address this, I adopted a self-experimentation approach, using my own romantic relationship as a testing context. This allowed me to gather meaningful insights from a real-world setting, while still incorporating external input, which helped me make more informed decisions regarding user experience. In future projects, when time or participant availability is limited, I will continue to use self-experimentation as part of my creative process. This approach enables me to explore and resolve UX/UI and contextual challenges while preserving valuable participant involvement for validation testing, ensuring the best use of time and resources.

Personal Learnings

Through my process, I also uncovered some personal learnings that I like to take into account for future design efforts.

Asking for help

As an independent worker, I often find it challenging to ask for support when needed. During this project, I reflected on this tendency and realized that I could have sought help earlier for some of the technological issues I encountered. While solving problems on my own does offer valuable learning opportunities (which I still value), it's important for me to recognize when a problem requires outside assistance. Although this didn't create significant setbacks in this project, reaching out sooner would have allowed me to manage my time more efficiently. Moving forward, I aim to improve in identifying when to seek support to optimize my workflow.

Using time more efficiently

In terms of time management, I also noticed that I tend to go down the rabbit hole when exploring a subject, which is partly due to my struggle with asking the right questions, as mentioned earlier. As a result, particularly during the formulation of the project brief and the early stages of my thesis, I spent too much time on desktop research. However, after receiving feedback from my coaches, I was able to redirect my focus and become more efficient in determining what was truly valuable to explore, selecting appropriate methods and setting clear time limits for each task.

Hopefully, my academic and personal learnings can help others in their design process when reading this thesis.

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APPENDICES

Appendix A - Design process - visualization method

Appendix B - Self-experimentation - data collection insights

Appendix C - Questionnaire & scenario-supported interview setup

Appendix D - 5WH

Appendix E - Systemic Approach Investigating Psychosocial Impact

Appendix F - Data type identification & sensor selection co-brainstorm

Appendix G - Informed Consent Documents

Appendix H - User Research Pilot insights

Appendix I - User Research Thematic Analysis Process

Appendix J - Graduation Project Brief

Appendix K - Ethical Applications Forms

A. Design process - visualization method

The design process for developing the visualization method involved three key stages: brainstorming, shape exploration, and prototyping. Between these stages, I conducted evaluations, either independently or with my partner, to ensure alignment with the design objectives and priorities.

Contextualization brainstorm

The APRACE framework was broken down into category-specific factors, as detailed by (Hoppler, Segerer & Nikitin, 2022) (see Figure 39). I identified which elements could be visualized using the data I planned to collect and which would require contextualization. Additionally, I recognized potential differences between couples that could influence the discussion, though these differences would not impact the design itself. Furthermore, (Sorokowska et al, 2017) highlighted the influence of weather on social interaction, prompting me to include weather data not only as a tool for aiding recollection but also as a data point of interest for studying social interaction dynamics.

Shape exploration

Within the shape exploration, I used sketching and some parts of data collected within the field-tests to explore visualization methods based regarding (1) Day vs Activity centered, (2) Day vs Day-parts (seperate visual), (3) Linear - circular configuration, and (4) symbol vs Graph style (see Figures 40)



Fig. 39. Contextualization brainstorm result

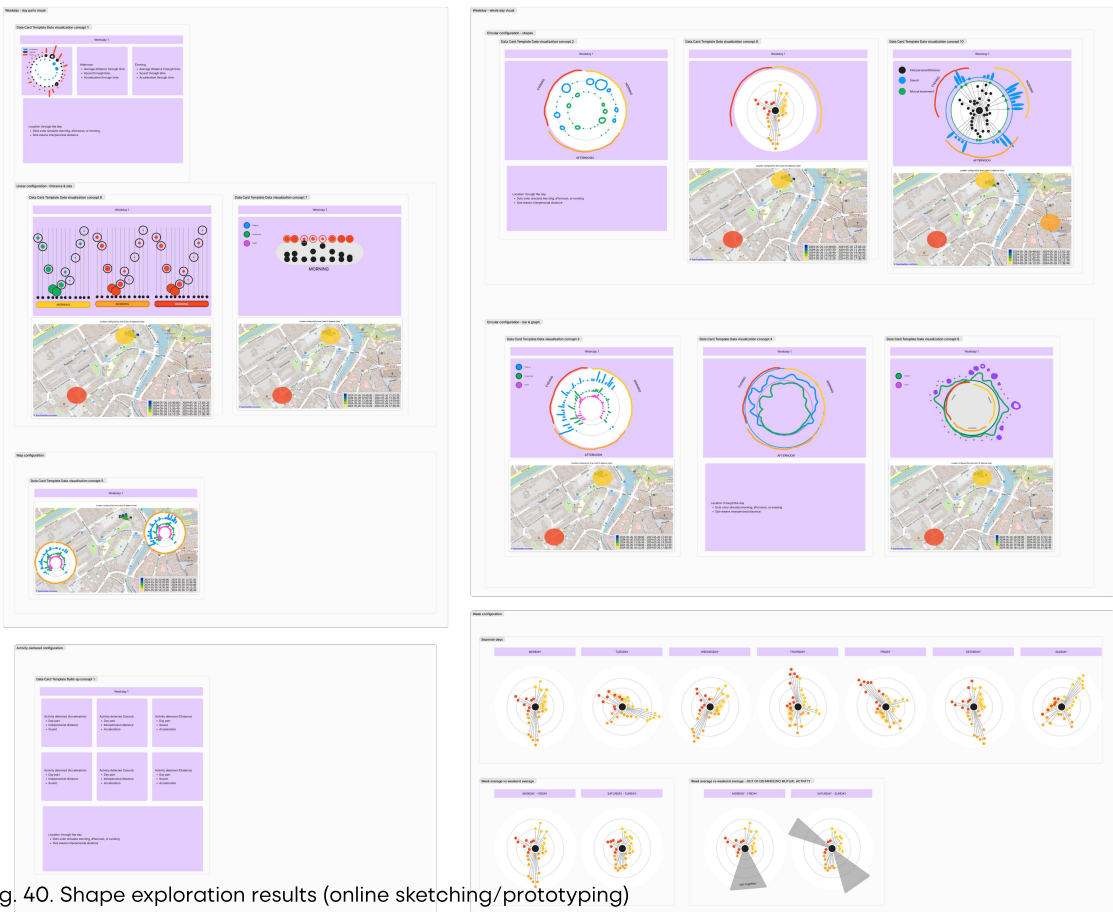


Fig. 40. Shape exploration results (online sketching/prototyping)

Consequently, I engaged in prototyping regarding integrating visualization for multiple days (as data collection would cover numerous days). The resulting concepts were evaluated through weighted objectives (Delft Design Guide, x) and taking both a research and participant perspective (through cognitive walkthrough (Interaction Design Foundation, n.d.). This

Data contextualization & appreciation	Evocative	Interpretative	Collaborative	Supportive	Integrity	Feasibility (regarding time)	Total
Weight	5	30	25	20	10	10	100
Evaluation concept 1 - circular	7	3	1	8	8	4	
	35	90	25	160	80	40	430

Fig. 41. Evaluation: Weighted objectives

Data contextualization & appreciation	Evocative	Interpretative	Collaborative	Supportive	Integrity	Feasibility (regarding time)	Total
Weight	5	30	25	20	10	10	100
Evaluation concept 2 - linear	7	4	7	9	8	7	
	35	120	175	180	80	70	660

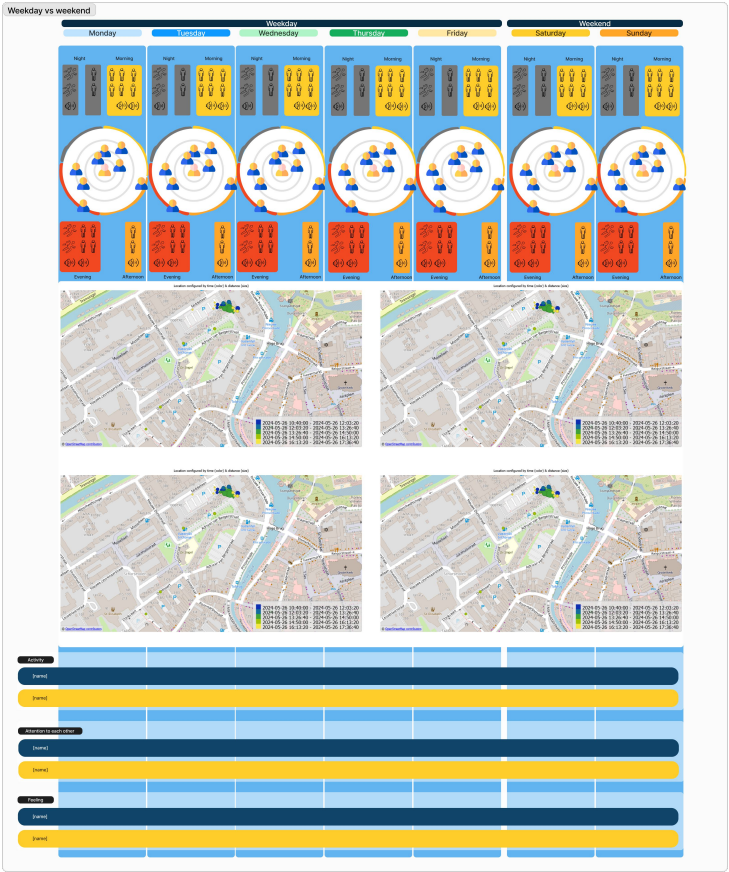


Fig. 42. Prototype 1a: Circular created from data collected in fieldtest 1

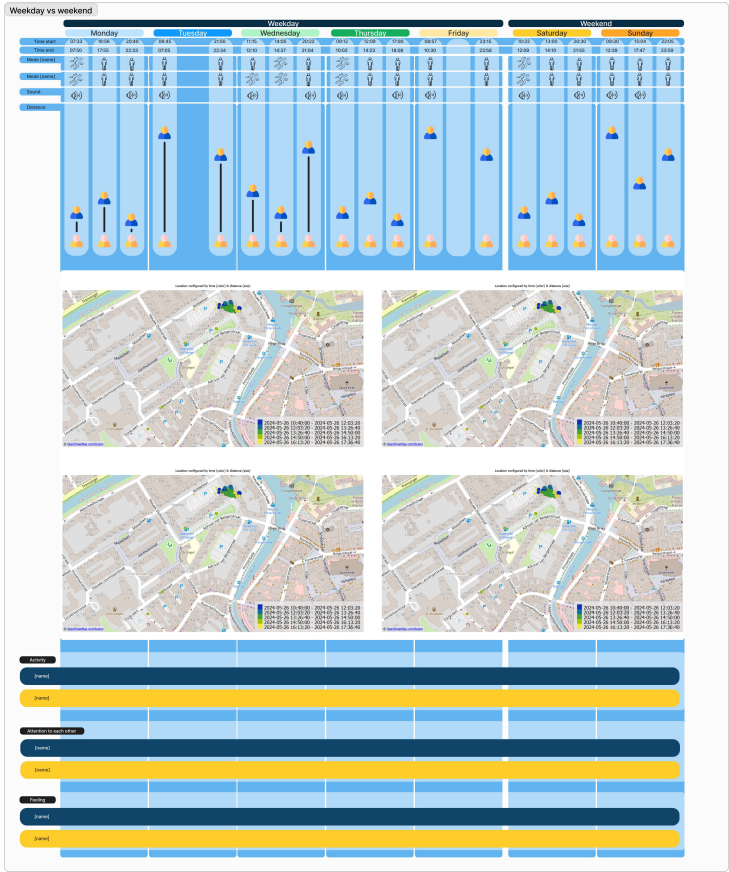


Fig. 43. Prototype 1b: Linear created from data collected in fieldtest 1

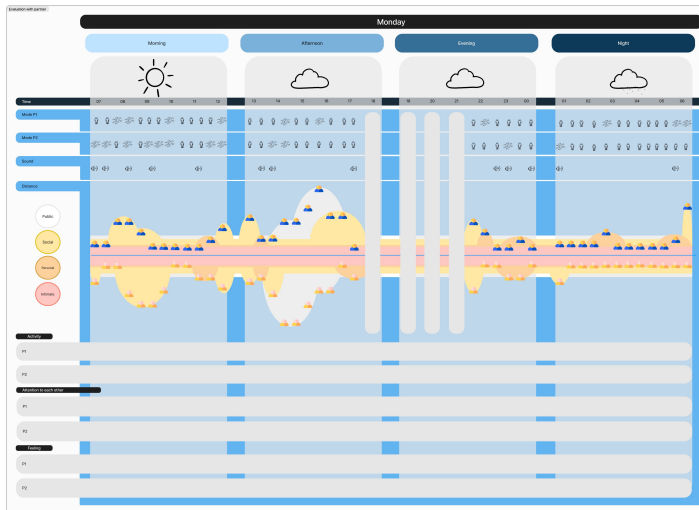


Fig. 44. Prototype 2 filled with data of fieldtest 2

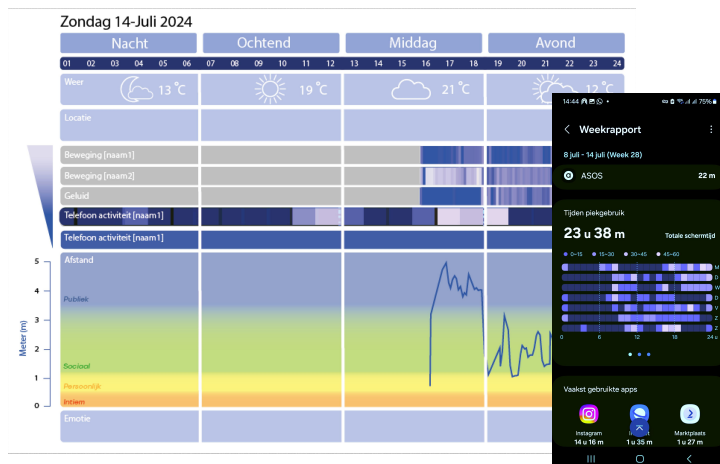


Fig. 45. Prototype 3 filled with data collected in fieldtest 3 and mobile screen activity data derived from a screenshot from the Digital Health application in Android

Prototyping

The concept was thereafter further explored through prototyping. Data collected from fieldtests served as prototyping material in order to explore the sufficiency of the template for contextualization.

Prototype 2

The first prototype included changes regarding location and space indication. Location was removed from the visualization template as location data was not longer possible to be collected due to technology constraints. Plus, removal of location data would reduce the risk for participants regarding data breaches.

Evaluation

The evaluation highlighted that the linear, top-down design is clear but needs flexibility to accommodate participants who interpret data based on their routine knowledge. While symbols were seen as informative, they introduced interpretation bias due to varying meanings and offered limited detail on social interactions, resulting in a more generalized reflection. In addition to weather data, which offered valuable context for shared activities, integrating other data, such as location and phone usage, could further support memory recall. However, the space dedicated to mapping activities, attention, and emotion felt unnecessary. Directly placing relevant information at the exact data points would be more efficient.

Prototype 3

Based on the evaluation, several adjustments were made to the second prototype. To gain deeper insights into social interactions, symbols were replaced with color intensities and a graph-based representation. To aid in the interpretation of these graphs and color intensities, clear legends were added. Additionally, phone activity data was incorporated by extracting information from digital health apps on Android and screen activity on iOS.

Evaluation

The evaluation of the second prototype confirmed that the overall design was effective in providing contextualization without requiring excessive time to create the template. The color intensities and groupings could be easily derived from data analysis in Orange using line charts and heatmaps. Minor adjustments were needed for the sound heatmap, as it required visualizing sound in reverse to align with the legend, however the prototype stayed the same in the final design. Additionally, to enhance user research, I developed stickers representing everyday activities and contexts. These stickers were used to annotate the map, as feedback from my partner showed that adding information directly to the map significantly supported contextualization.

Final Design

This resulted in the final design visualization template, further addressed in chapter 6 regarding data integration. Here, I present the empty template.

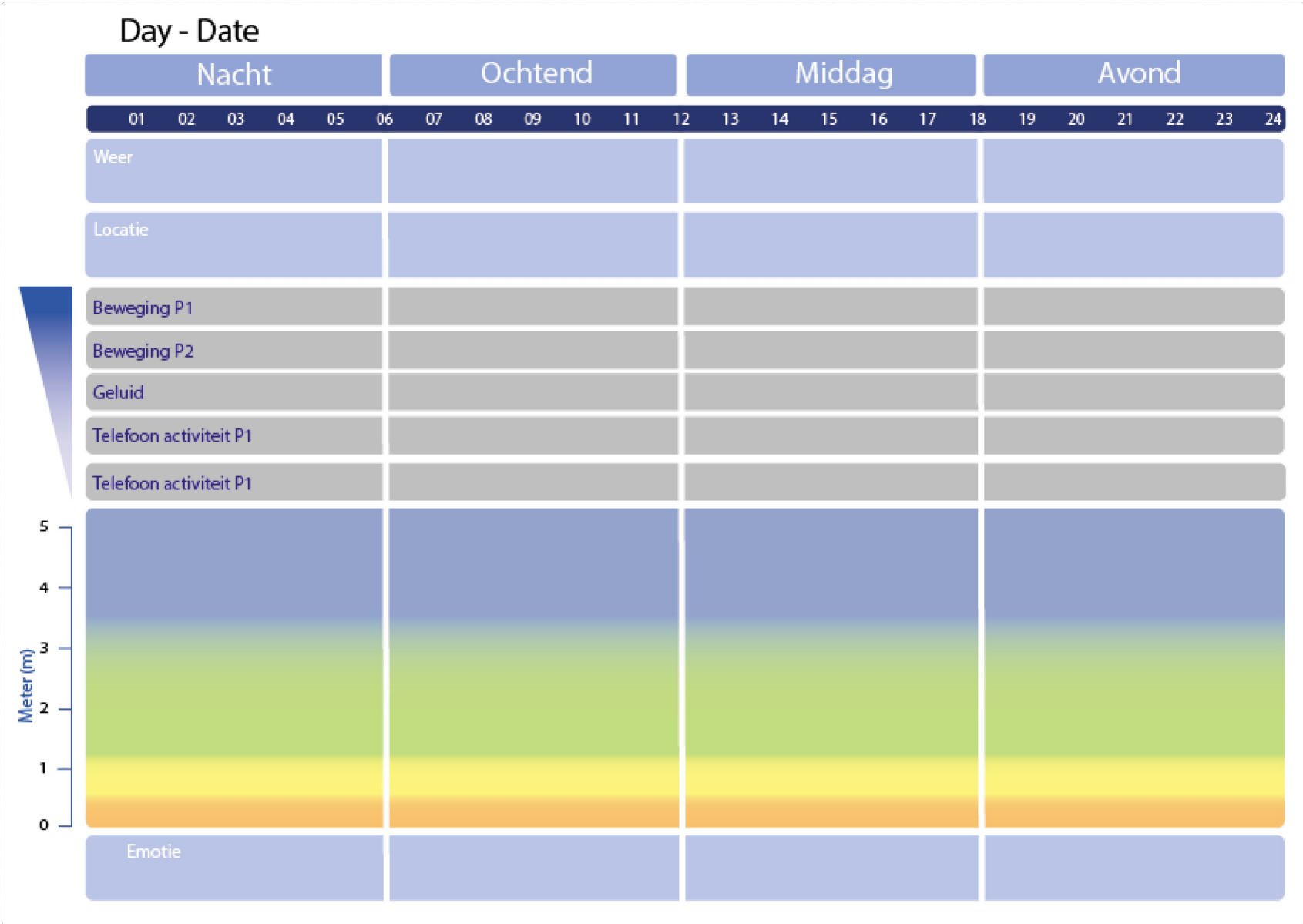


Fig. 46. Final Design Empty Template

B. Self-experimentation - data collection insights

Field Test 1: Testing the sensor kit in real-world conditions.

Protocol:

- Both my partner and I wear devices (I as the server, my partner as the client). The devices were put into pockets of our sweater.
- Data was retrieved from the SD card multiple times on the first day to monitor functionality and visualized using Orange Data Mining (Orange Data Mining, 2024).
- At the end of the day, we discussed the data to interpret results and derive meaning.
- I reflected on the outcomes to identify improvements, address limitations, and consider optimal measurement periods and frequency.

Design insights

Design insights were gathered through several trials within the field test period, due to technological malfunctioning and problem solving. Here, I describe the main observations.

Behavioral Insights

From the data, several key aspects of technological behavior and performance were identified. The server occasionally shuts down when connected to a power bank due to low power draw, causing the power bank to enter sleep mode when idle. Adding a resistor resolves this issue. A red light (CHRC) appears after about an hour but does not affect measurements. GPS functionality is reliable only outdoors, which may impact measurements and requires further investigation.

Additionally, reconnecting to Wi-Fi after a disconnection initially required a hard reboot. To address this, the Wi-Fi connection code (C/C++) in Arduino (Arduino, n.d.) was integrated into a loop, and preliminary testing showed improvement—reconnection occurred within minutes after being out of range for 10 minutes. Without reconnection, the server's battery lasted 5 days, while the client's battery lasted at least 7 days. Data is sent every second, with the server connecting only to receive data before disconnecting. Nonetheless, while measuring, the battery (server) did last significantly less time.

During evaluation of field-test 1 and derive design insights, I asked myself the following questions:

- What behavior do I see from the sensor kit show and what areas for improvement do I see or how can I mitigate limitations or deal with it?
- What can I derive from the data and what limitations or areas of improvement do I see?
- What is the implication of visualization-style from the data that I derive? and can I use it to design for data-discussion
- Is the complete sensor-kit easy to wear and does it not impede with the wearer's daily activities? (UX)

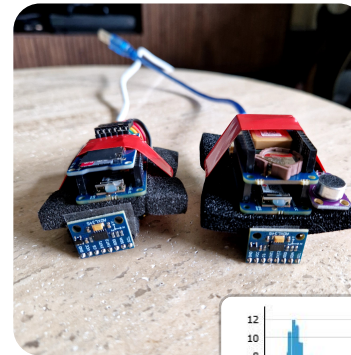


Fig. 47. Data-collection device prototype 1 carried within large clothing pockets, powered by a power-bank.

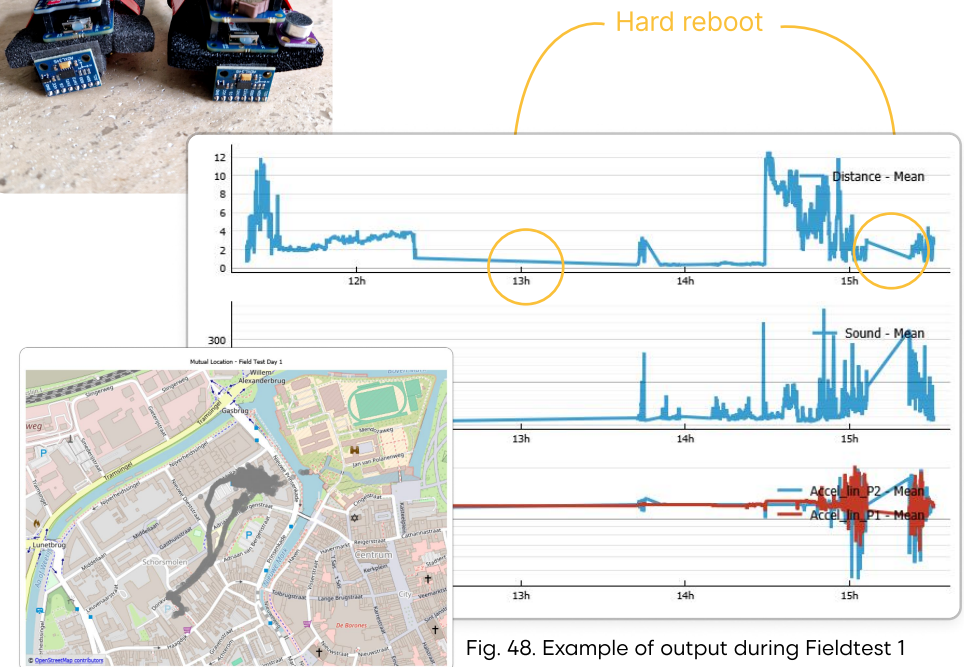


Fig. 48. Example of output during Fieldtest 1

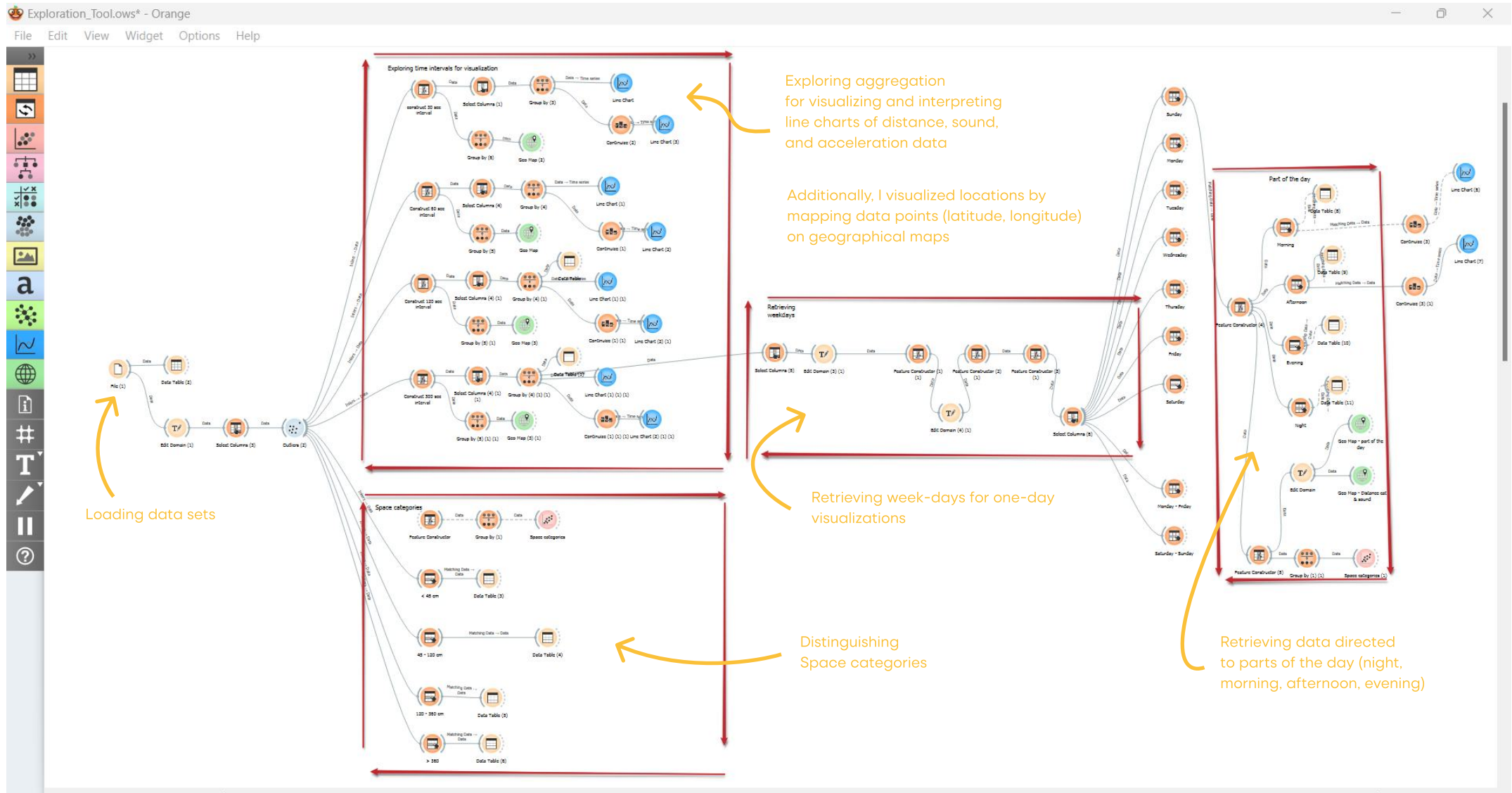


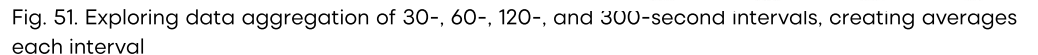
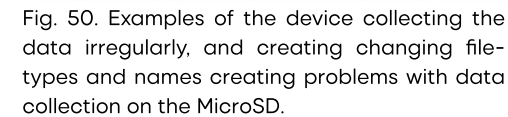
Fig. 49. Orange widget flow for analysing the results within self-experimentation. Orange Data Mining is an open-source machine-learning and data visualization tool especially convenient for designers through its widget-based user-interface. Within this overview, I organized the widgets to clean, aggregate and visualize data to extract insights.

Several data logging issues were encountered. The SD writer sometimes created multiple files or recorded data incorrectly, leading to measurement interruptions. While the .TXT format remained stable, an error in file naming prevented files from opening, halting measurement and data logging. To rectify this, the protocol was revised: ensure the SD card is formatted and wiped before use, load the Arduino sketch with the SD card removed, then insert the SD card without power, and reconnect the Arduino to the power source.

Data Insights

Visualization Insights

The current graphs are unclear and require additional data filtering for better visualization. Therefore, I explored several data aggregation methods (from 30 seconds to 5 minutes) in Orange Data Mining (Orange Data Mining, 2024). Moreover, patterns in sound, distance, and acceleration should be further explored for me to gain insights in what is interesting for discussing the data (i.e., contextualization) of shared activities.



Field Test 2 - Exploring data sufficiency for contextualization

Protocol:

- I wear the server board device for 7 days.
- At the end of the test, I visualize the data and discuss the insights with my partner, focusing on the effectiveness of the data visualization template.
- I review the results to identify areas for improvement and address any limitations, reflecting on the measurement period and frequency.

The evaluation was conducted online due to my partner's work absence, providing insights into remote contextualization.

Design insights

During the 7-day trial, the device's battery was insufficient for longer use, and a larger power supply would have disrupted user experience, limiting measurements to 2 days. Significant data gaps on the second day prompted an analysis of the first day's data. This evaluation, discussed with my partner, helped gauge data sufficiency and determine a manageable data collection period for future research.

User experience

The data collection device did not interfere with daily activities as it was worn close to the body, minimizing any perceived annoyance. However, attaching it to a belt was inconvenient, especially when layering clothing over it. A more flexible design would improve usability.

Additionally, the device did not provide extra benefits to the user, which could make wearing it feel uncomfortable or unusual. Therefore, the design should be more flexible and seamless to enhance user comfort.

Data sufficiency

Analyzing a single day's data revealed that people often reflect on their routines and deviations from them, which is crucial for deriving meaningful insights and long-term reflection. Therefore, gathering large amounts of data over many days is unnecessary and reduces privacy risks. To gain insights into routines and

Key Questions:

- Does the battery last for 7 days?
- How does being outside the connection range affect the device? Does measurement resume when back within range?
- Is the data collection reliable and accurate, or are there irregularities?
- User Experience: Does the device hinder daily activities? Did it cause discomfort or frustration?

various activities, the data collection period is now set to approximately 2-3 days, depending on battery life, rather than focusing on just one day.



Fig. 52. For fieldtest 2, I advanced the prototypes to initial wearables, allowing me to also research the user experience regarding designing a wearable research probe. The prototype was used in numerous contexts, as described in chapter 6.2 Technology Exploration.

Field Test 3 - Making a resilient and effective data collection and visualization method

Protocol:

- Me and my partner wore the data collection devices for 3 days (till the battery run out)
- After data collection, I took 2 days to visualize the data.
- Thereafter, me and my partner engaged in a contextualization session of maximum 50 minutes.
- After contextualization, I evaluated the outcomes to formulate refinements for the design of the data visualization template.

Key Questions:

- What additional steps need to be taken in order to safeguard data collection over a period of 2-3 days?
- How effective was the data visualization method in supporting contextualization?

Redesign

The redesign of the data visualization template proofed that leveraging less symbol, and using more intuitive methods to display variations through data such as color intensities and lines with effective color legends to create a reference towards space (i.e., distance classifications of (Conradi et al, 2020; Sorokowska et al, 2017). The template proofed to be effective to not only recall activities and experiences for contextualizing the data, even the moments of missing data could be contextualized.

Insufficiencies

The evaluation highlighted key issues, including an incorrect color legend for sound, which needed adjustment to match color intensity with movement. Additionally, relocating location from the bottom to the top of the interface improved the effectiveness of top-down information processing and contextual data grouping. These changes were incorporated into the final design, which is now ready to launch the research phase.

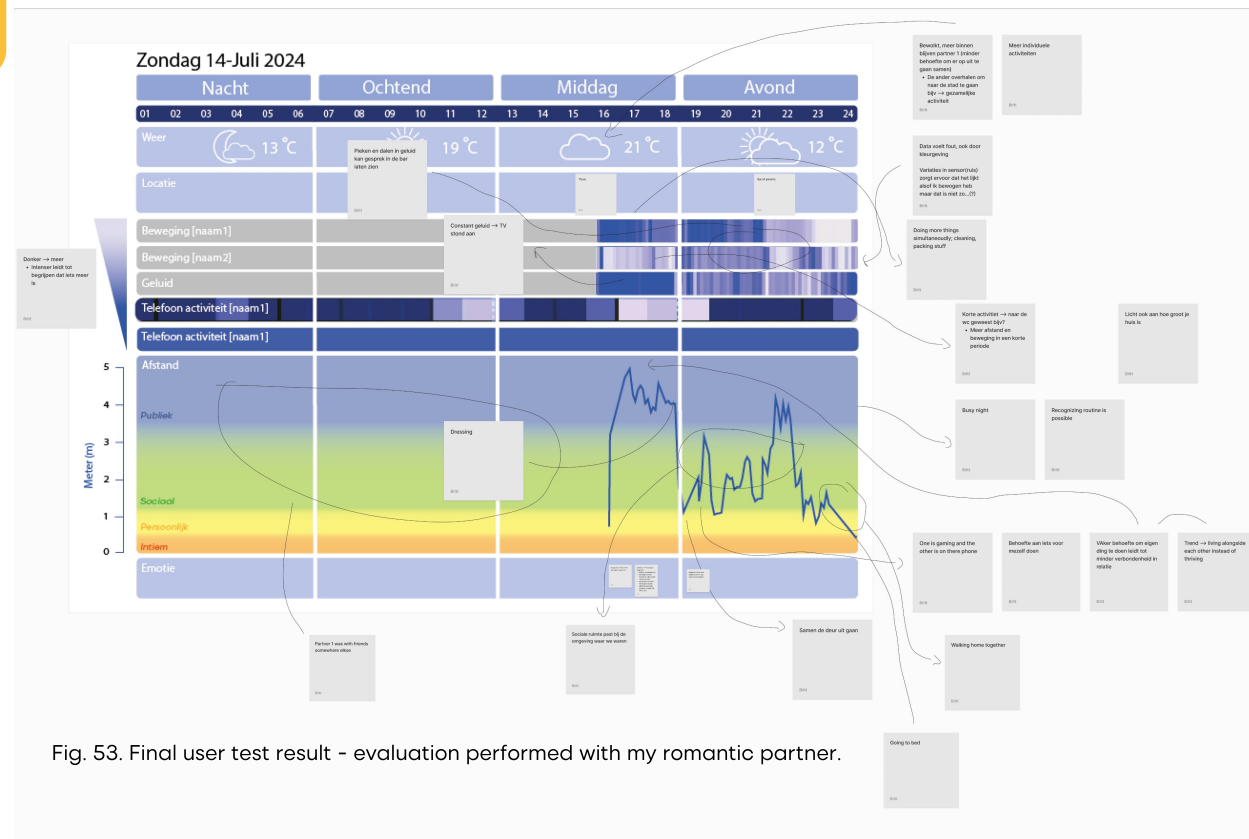
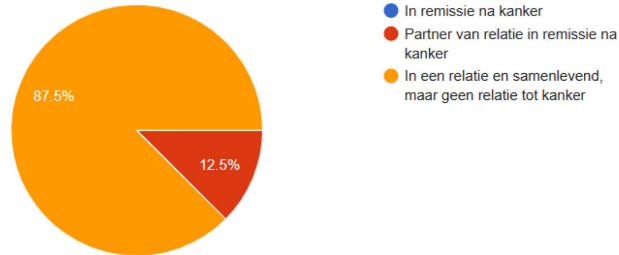


Fig. 53. Final user test result - evaluation performed with my romantic partner.

C. Questionnaire & scenario-supported interview setup

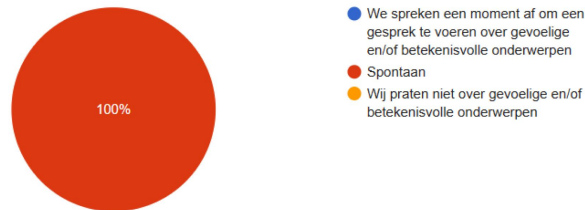
Kunt u kiezen wat op u van toepassing is?

8 responses



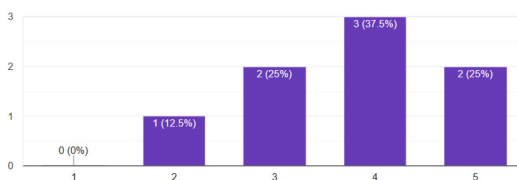
Hoe ontstaan deze gespreken?

8 responses



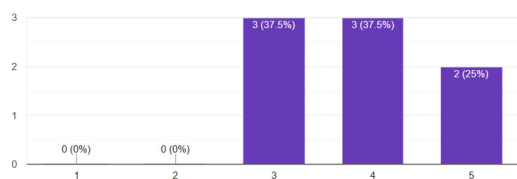
Hoe tevreden bent u met het niveau van communicatie in uw relatie?

8 responses



Hoe tevreden bent u met het niveau van emotionele ondersteuning in uw relatie?

8 responses



Purpose of the questionnaire

The purpose of the questionnaire was to explore communication, support, equality, and conflict resolution within romantic relationships, diving also deeper into self-efficacy related to individual resources subsequent to the aforementioned aspects. Therefore, the results allowed me to create the setup from the scenario-supported interviews, as allowing me to be more informed when engaging in discussions with couples. The online questionnaire can be derived from this link: <https://forms.gle/4Wt3hkaPzATagaws9>

Setup

The setup of the questionnaire was designed to fill in easily, providing multiple choice options, along with the option 'other' if the multiple-choice options did not match the participant's desired answer. Therefore, the results could be quantified in order to easily compare.

Questionnaire Participants

From the 16 participants, 2 participants stated to be in a relationship with a cancer survivor, where as the other 14 participants did not have a relation to cancer. Moreover, except from two participants, participants stated to be generally happy with the level of communication and emotional support in their relationship.

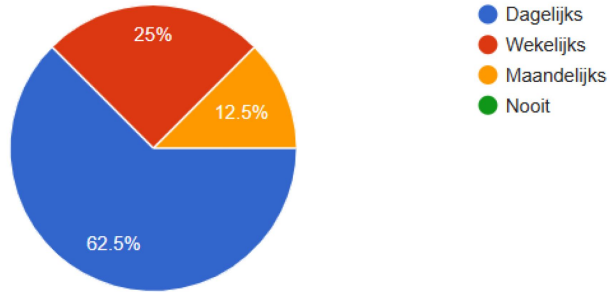
Results

In this Appendix, I detail the generalized findings from the questionnaire in form of post-its relating to the statistical overviews. The findings were further explored through desktop research that is again integrated within the main report.

Hoe vaak hebben u en uw partner gevoelige en/of betekenisvolle gesprekken?

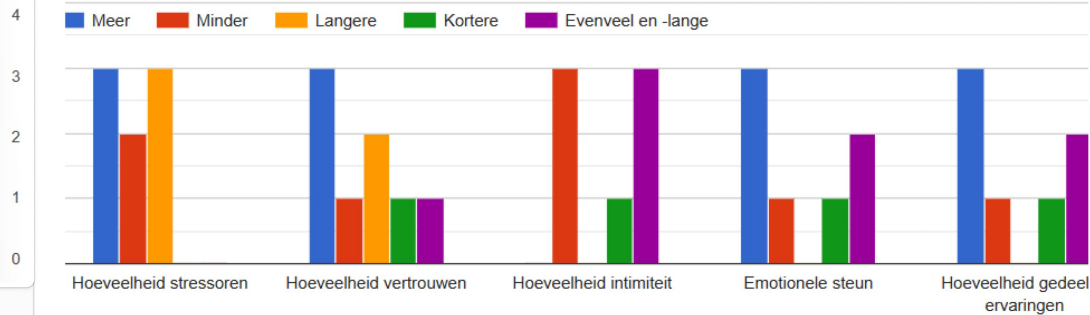
8 responses

Copy



Vul de stelling in aan de hand van de onderstaande factoren: *'Ik en mijn partner hebben ... gesprekken naar mate de ... die wij ervaren meer wordt.'*

Copy



More frequent conversations when more stressors, more trust, more emotional support, more shared experiences

Britt

Longer conversations when more stressors and more trust

Britt

Less or similar conversations when more intimacy

Britt

Character dependent

Britt

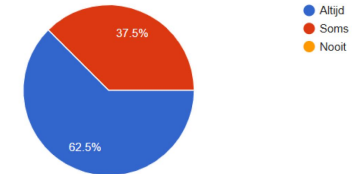
When stating less sometimes, does this mean that you feel supported, trusted, shared experiences, and therefore the need to talk is less?

Britt

Voelt u zich emotioneel ondersteund door uw partner?

8 responses

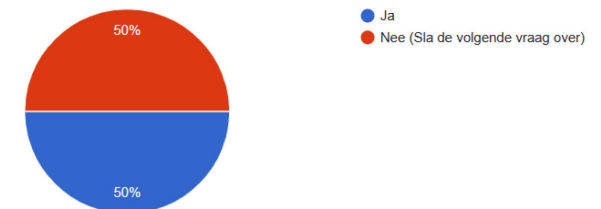
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Ervaart u soms gesprekken over kanker en/of persoonlijke zorgen met uw partner als niet ondersteunend, maar ook niet als een conflict?

Copy

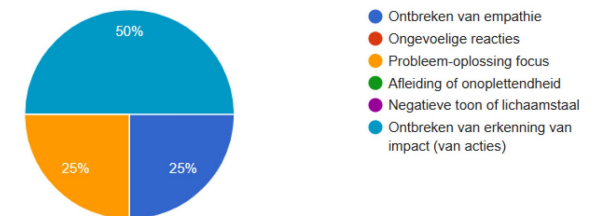
8 responses



Indien ja, waarom is dit?

4 responses

Copy



Lack of recognizing impact of actions

Britt

Lack of empathy

Britt

Problem solution focus

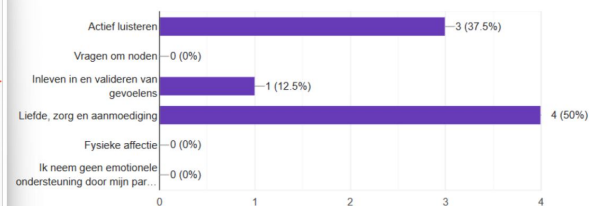
Britt

Perception vs comfort

Hoe neemt u waar dat uw partner u emotioneel steun geeft?

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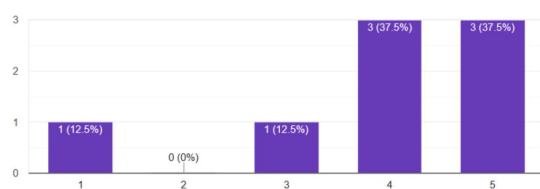
8 responses



Maakt dit u comfortabel in het uiten van uw gevoelens en zorgen?

Copy

8 responses



Active listening & love, care & encouragement are the most perceived elements in emotional support

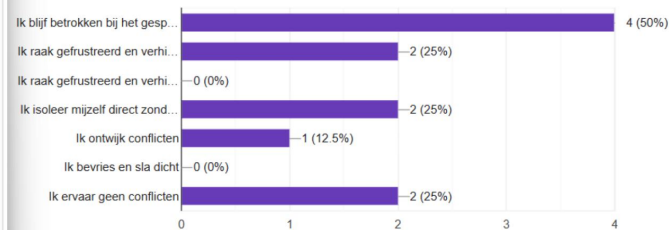
Karakter influences on comfort in discussing feelings?

Conflict & reaction

Wat doet u wanneer een conflict opkomt? (U kunt meerdere antwoorden tegelijk aankruisen)

Copy

8 responses



Waarom gebeuren deze conflicten tussen u en uw partner? (U kunt meerdere antwoorden tegelijk aankruisen)

Copy

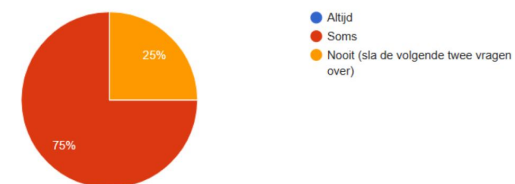
8 responses



Komt het voor dat u in conflict raakt met uw partner tijdens gevoelige en/of betekenisvolle gesprekken?

Copy

8 responses



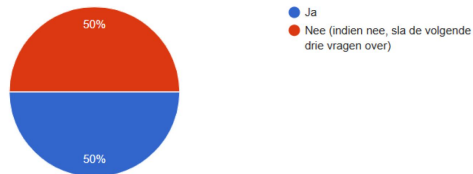
Lack of active listening

Behavior when conflict arises might be very dependent on karakter

Incapability giving support + reaction

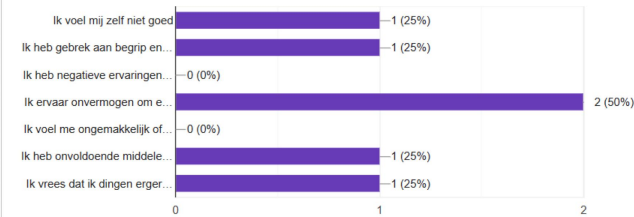
Voelt u zich (soms) niet in staat om uw partner emotionele steun te bieden?

8 responses



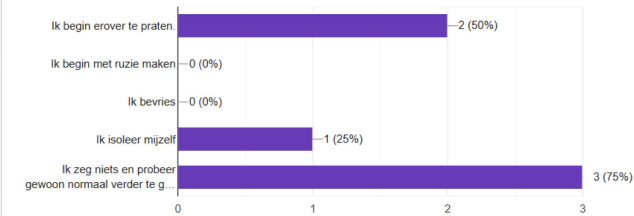
Indien ja, waarom voelt u zich zo? (U kunt meerdere antwoorden tegelijk aankruisen)

4 responses



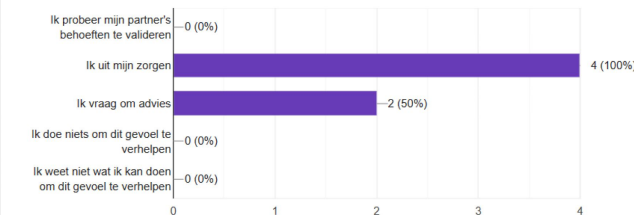
Indien ja, wat doet u wanneer u dit gevoel ervaart? (U kunt meerdere antwoorden tegelijk aankruisen)

4 responses



Indien ja, wat doet u om dit gevoel te verhelpen? (U kunt meerdere antwoorden tegelijk aankruisen)

4 responses



Reasons why you feel incapable of giving emotional support varies; mostly feeling incapable

Britt

Most do not tell → does this affect mental well-being and giving support even more?

Britt

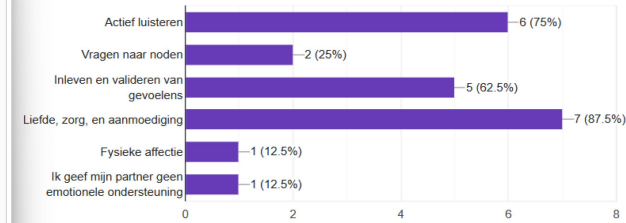
To overcome, they ask advice or talk about concerns → but how frequent and when if they first just want to go on?

Britt

Giving vs receiving

Hoe geeft u op dit moment emotionele steun aan uw partner? (U kunt meerdere antwoorden tegelijk aankruisen)

8 responses



Active listening

Britt

Having a feeling of giving too little physical affection → is there a need for more physical affection in general?

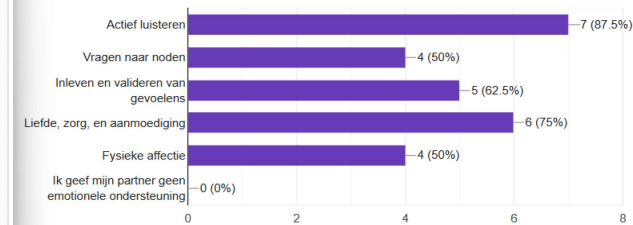
Britt

Having a feeling of asking too little about needs → is there a need for asking more for needs? why?

Britt

Hoe zou u graag emotionele steun willen geven aan uw partner? (U kunt meerdere antwoorden tegelijk aankruisen)

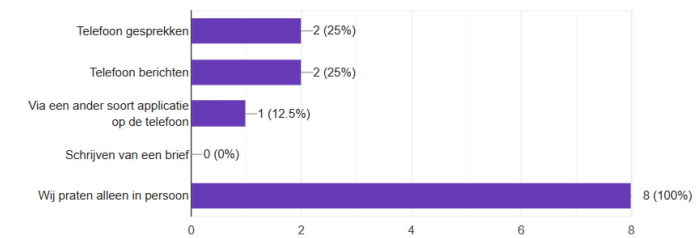
8 responses



Digital media usage

Welke media gebruiken u en uw partner om gevoelige en/of betekenisvolle gesprekken te voeren? (U kunt meerdere antwoorden tegelijk aankruisen)

8 responses

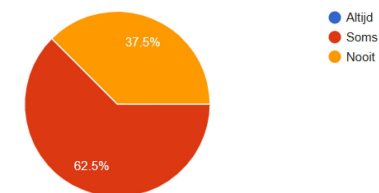


Phone either enabling or distracting - context specific

Britt

Bent u afgeleid door het gebruik van een telefoon (door u of uw partner) tijdens het voeren van gevoelige en/of betekenisvolle gesprekken?

8 responses



Phone is an accepted tool to communicate when it allows communication, but the phone is not accepted when it interferes with communication (conflict with intentions)

Britt

Questionnaire & scenario-supported interview setup

The online questionnaire can be derived from this link: <https://forms.gle/4Wt3hkaPzATagaws9>

Interview Setup

The interview used a scenario-supported approach featuring maps for emotional and physical distance (see Figure 54 - left). Participants were asked to map these aspects based on scenarios provided (Figure 54 - right), which illustrated both positive and negative aspects of communication, support, equality (through decision-making), and conflict resolution. These scenarios, created with ChatGPT's assistance, were designed with clear indicators of distance or gender roles by omitting geospatial details and using gender-neutral names.

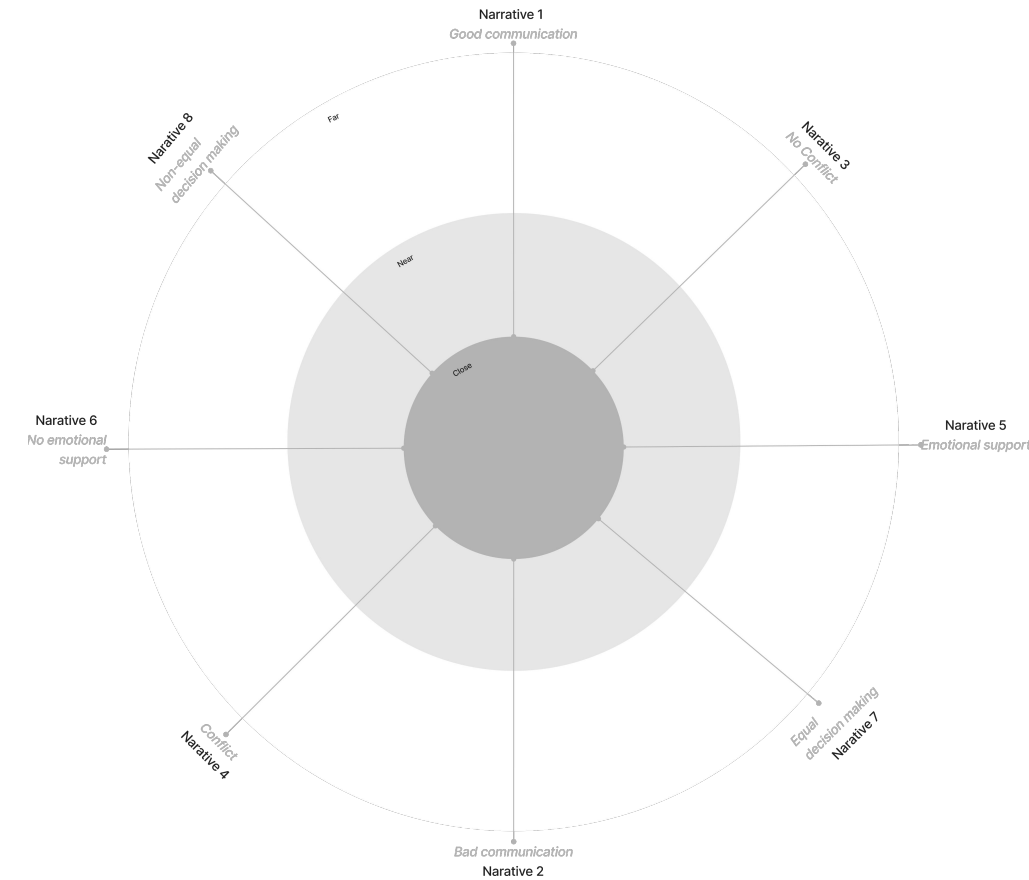


Fig. 54. Emotional and physical distance map for participants to map their estimated distance regarding the scenarios with the help of stickers.

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Narrative 1 - Good communication

As dusk settled, Robin and Sam sat together, the air thick with unspoken concerns. "Robin, you seem off. What's on your mind?" Sam asked, with a voice filled with concern. Robin hesitated, then confessed, "I've been feeling insecure about work lately." Sam reached for Robin's hand, offering comfort. "You're incredibly talented, Robin. I believe in you." Robin's shoulders relaxed while absorbing his words. "Thank you, Sam. I needed to hear that." In that moment, their bond grew stronger, fortified by honest communication and unwavering support.

Narrative - Bad communication

As the sun dipped below the horizon, Robin and Sam sat in strained silence, the tension palpable between them. "Robin, you seem distant. What's going on?" Sam asked, with a voice tinged with frustration. Robin shifted uncomfortably, unsure of how to express her concerns. "It's nothing," she muttered, avoiding his gaze. Sam sighed, feeling shut out. "You always say that. I wish you'd just talk to me." Robin bristled, feeling defensive. "I don't want to talk about it, okay? Just drop it." Their conversation stalled, leaving them both feeling disconnected and unheard as the evening wore on.

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Narrative 3 - Good conflict resolution

As the sun dipped below the horizon, Jesse and Chris feeling tensions lingering from an earlier disagreement. "Chris, I felt frustrated earlier," Jesse began, with a tone calm but honest. Chris nodded, acknowledging Jesse's feelings. "I'm sorry if I seemed dismissive. I should've listened better." They talked openly, each expressing their perspective and listening to the other without interruption. They identified the issue and agreed on ways to communicate better in the future. "I'm glad we talked," Jesse said, smiling. "Let's make an effort to understand each other more." With a shared understanding and renewed commitment, they knew they had resolved the conflict with mutual respect.

Narrative 4 - Bad conflict resolution

As the sun set, Jesse and Chris sat in silence, the tension thick between them, remnants of an unresolved disagreement lingering in the air. "Chris, I need to talk about what happened earlier," Jesse said, with a voice tinged with frustration. Chris sighed, already feeling defensive. "Can't we just drop it? I don't see why we have to keep going over this." Jesse's frustration grew. "Because we never resolve anything! You always shut me down." Chris's tone hardened. "Well, maybe if you didn't nag me about every little thing, we wouldn't have these problems." Their conversation devolved into accusations and blame, with neither willing to listen or compromise. The unresolved tension left them feeling distant and disconnected, their relationship strained by their inability to resolve conflicts effectively.

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Narrative 5 - Good support

As the moon rose high in the night sky, Jesse sat, face buried in the hands, tears streaming down the cheeks. Chris, Jesse's partner, noticed it. "Hey, what's wrong?" Chris asked softly with a voice filled with concern. Jesse looked up, eyes red and puffy. "I'm just feeling overwhelmed with everything going on at work," Jesse confessed, with a trembling voice. Chris nodded understandingly, "I'm here for you, Jesse. You don't have to go through this alone." Jesse feels a wave of relief wash over at Chris' words. "Thank you," whispering with a voice choked with emotion. Chris is still offering silent support as Jesse lets out pent-up emotions. In that moment, Jesse knew that no matter what challenges lay ahead, Jesse could always count on Chris to be there.

Narrative 6 - Bad support

As the moon rose high in the night sky, Jesse sat, face buried in the hands, tears streaming down the cheeks. Chris, Jesse's partner, glanced at Jesse briefly before returning attention to the phone, engrossed in Chris' own activities. "What's wrong?" Chris asked absently, with a tone lacking empathy. Jesse sniffled, feeling dismissed. "I'm just feeling overwhelmed with everything going on at work," Jesse replied, with a voice barely above a whisper. Chris shrugged, attention still on the phone. "Well, I'm sure you'll figure it out. You always do," Chris said dismissively, without looking up. Jesse's heart sank, feeling unsupported and unheard. Jesse wiped away the tears, retreating, as Jesse realized Jesse was alone in her struggles.

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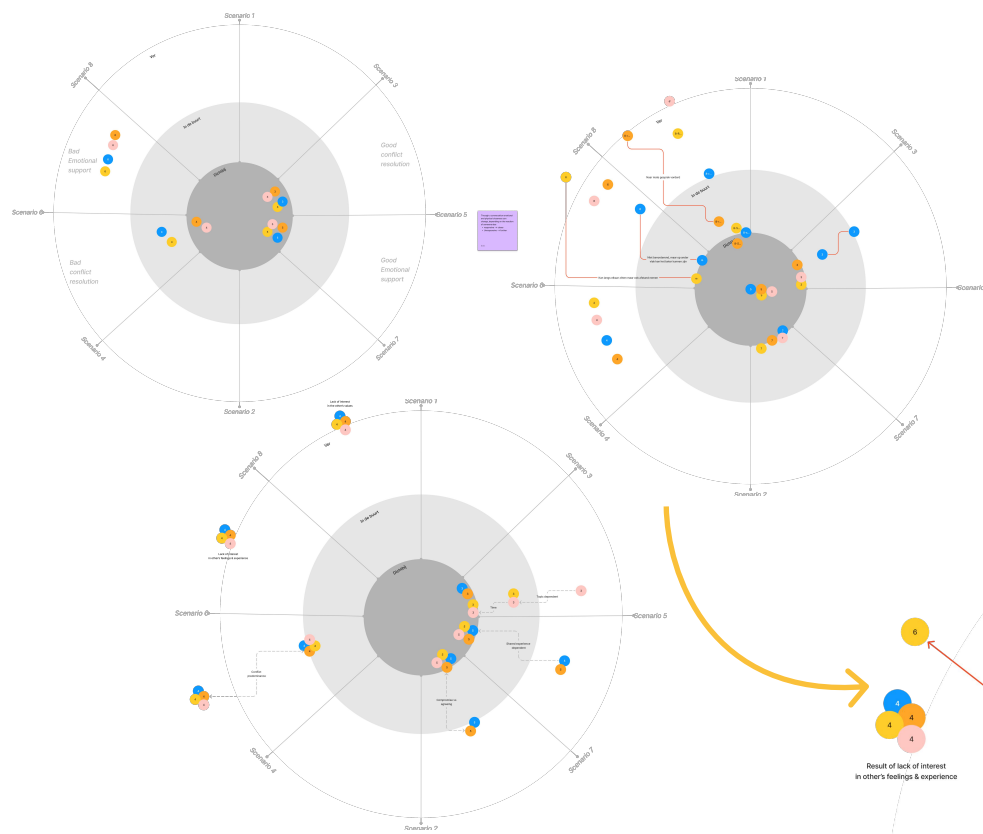
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Narrative 7

Robin and Sam sat, a stack of travel brochures spread out before them, each depicting enticing destinations for their upcoming vacation. "I've been looking forward to planning this trip," Robin remarked, flipping through the pages of a beach resort brochure. "I could really use some sun and relaxation." Sam nodded, glancing at the brochure, featuring picturesque mountain cabins. "I get that, but I've been craving some mountain air and outdoor adventures." Robin smiled, appreciating the perspective. "That sounds like fun too. Maybe we should consider both options and see which one appeals to us more." Sam agreed, and they began comparing the pros and cons of each destination, discussing factors like travel time, activities available, and budget constraints. After a thorough discussion, they reached a decision together, feeling excited about the prospect of their upcoming vacation and the memories they would create together. "I'm glad we could decide together," Sam said, reaching across the table to squeeze Robin's hand. Emma returned his smile, feeling grateful for their shared decision-making process. "Me too. I think this will be an amazing trip!"

Narrative 8

As they sat, Robin and Sam poured over brochures for their upcoming vacation. Robin's eyes lit up and pointed to a tropical beach resort, with evident excitement. "This looks amazing, Sam! I've always wanted to visit a beach like this," Robin exclaimed, enthusiasm bubbling over. Sam glanced at the brochure briefly before returning attention to the phone. "Eh, I'm not really feeling the beach. I'd prefer something more adventurous, like a mountain cabin," Sam replied nonchalantly. Robin's smile faltered, disappointment creeping in. "But we went to the mountains last time. Can't we try something different this year?" Sam shrugged, attention still on the phone. "I don't see why not. But the mountains are where I feel most relaxed and happy." Robin sighed, feeling frustrated. "Fine, we'll go to the mountains again. Whatever makes you happy," Robin said, resigning to his decision. As they continued to plan their vacation, Robin couldn't shake the feeling of disappointment, knowing that Robin's preferences had taken a backseat once again.



Protocol

Before the interview, participants gave full consent (see Appendix G). They read positive and negative scenarios, discussed their observations, and related them to their own experiences. Participants then individually mapped their physical and emotional distances in each scenario, noting their feelings of connection. We reviewed their maps in reflective discussions to explore emotional and physical intimacy, repeating this for each scenario.

Analysis

I thematically analyzed the insights from the mapping and reflective discussions to formulate the results.

The mapping results in couples were synthesized into one overview to find clear insights regarding emotional and physical distance in positive and negative communication, support, decision-making, and conflict resolution.

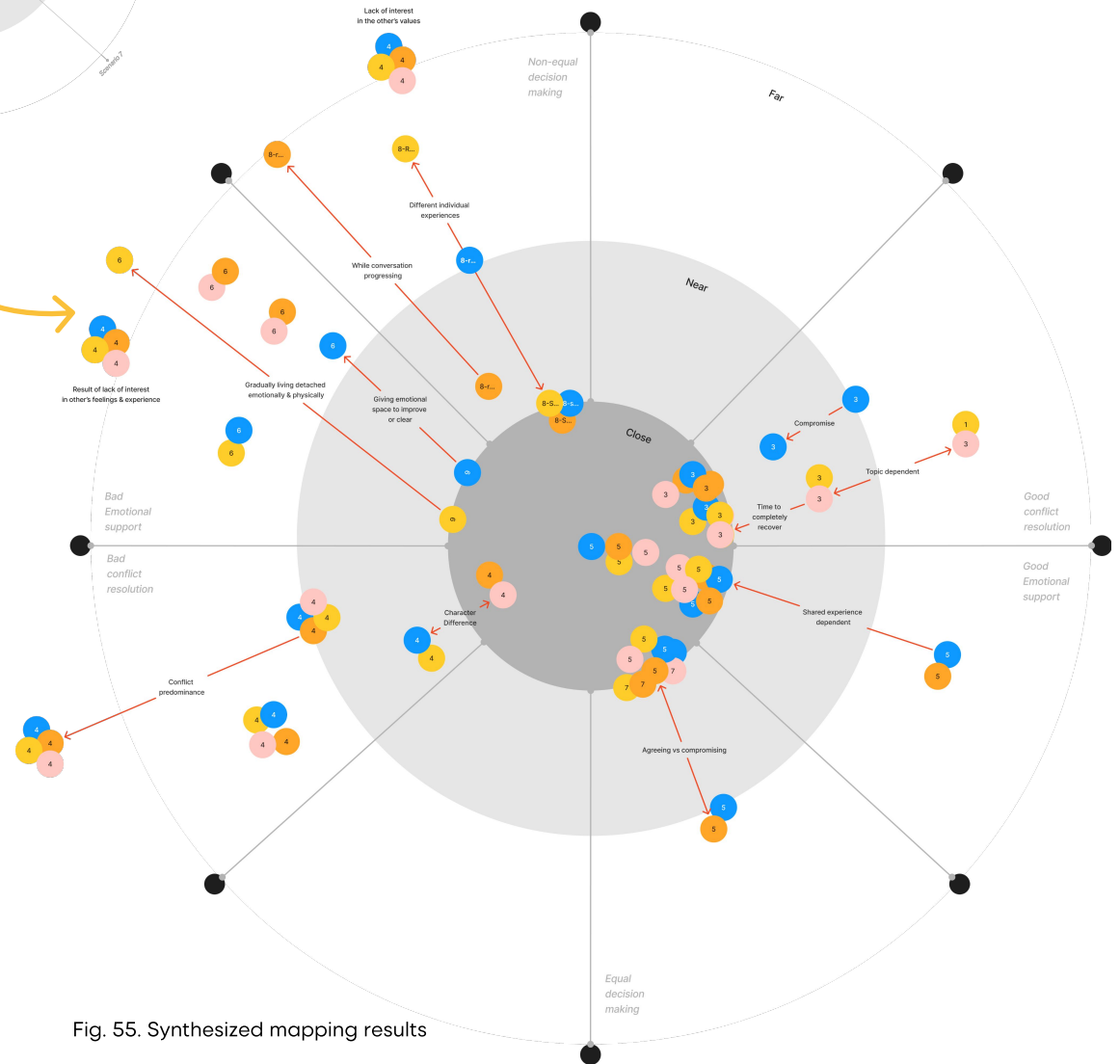


Fig. 55. Synthesized mapping results

D. 5WH

The 5WH (Van Boeijen, Daalhuizen & Zijlstra, 2020) was used to synthesize all the insights gathered within the discover phase to find the essence within dyadic coping in romantic couples: social interaction, and to formulate the design brief.

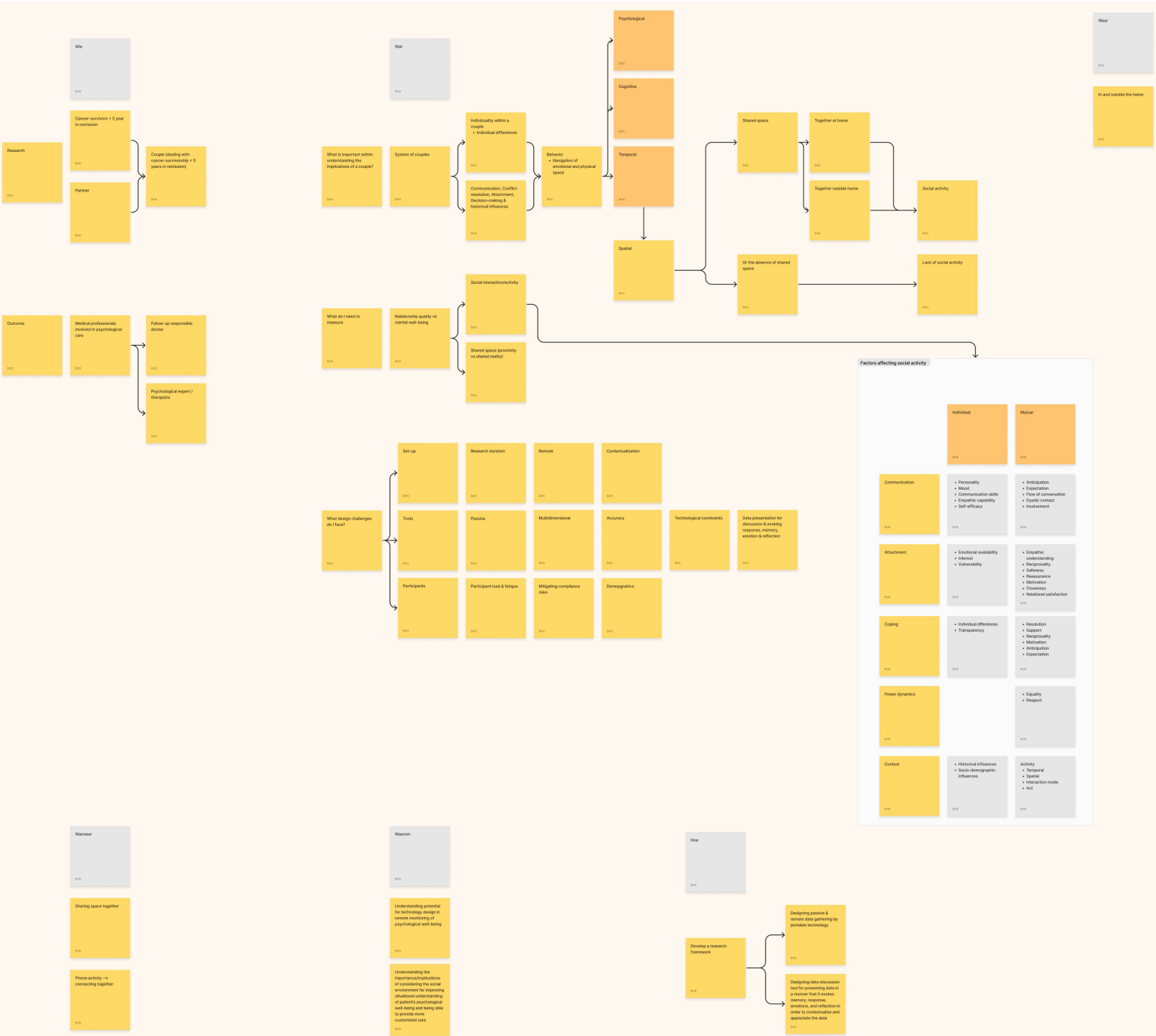


Fig. 56. 5WH result

Fig. 57. Overview of literature leveraged for the project brief formulation and within the systemic approach as described in this section.

I chose Kanker.nl as the primary platform for reviewing community discussions to explore dyadic coping and distress experiences among couples in cancer survivorship. This platform was selected due to its large and diverse member base.

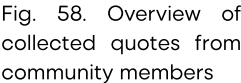
The goal was to gather insights into relationship dynamics from individuals affected by cancer survivorship. Expanding the target group to include a broader range of experiences helped ensure sufficient information on dyadic coping and distress.

I performed a systematic search within forum discussions using keywords such as "partner," "colorectal cancer," "partner experience," "survivorship," "influence on life," "influence on relationship," "support," "communication," and "life after treatment" (originally in Dutch).

I collected and categorized quotations from relevant discussions into key themes (see right). This process helped refine the focus and scope of the study, providing insights into individual, interpersonal, and external causes of distress in couples dealing with cancer survivorship.

The collected quotations were organized into thematic categories, which were then used to contextualize individual, relational, and external factors contributing to distress.

Kanker.nl is an open-access community. Given the exploratory nature of this review, I did not collect large volumes of data. To ensure privacy, I avoided recording names or usernames, only noting whether contributors were ex-patients, partners, family members, or others. In total, I gathered quotations from a diverse group of individuals (n=26).



Results

The results were then synthesized within an ecosystem map (Interaction Design Foundation, n.d.), focused on distress factors rather than systems and services within couple's environment, to gain an understanding of the interrelations of experienced distress. This supported me within Identifying Collective Variables, as described in section 3.2 - Discover.

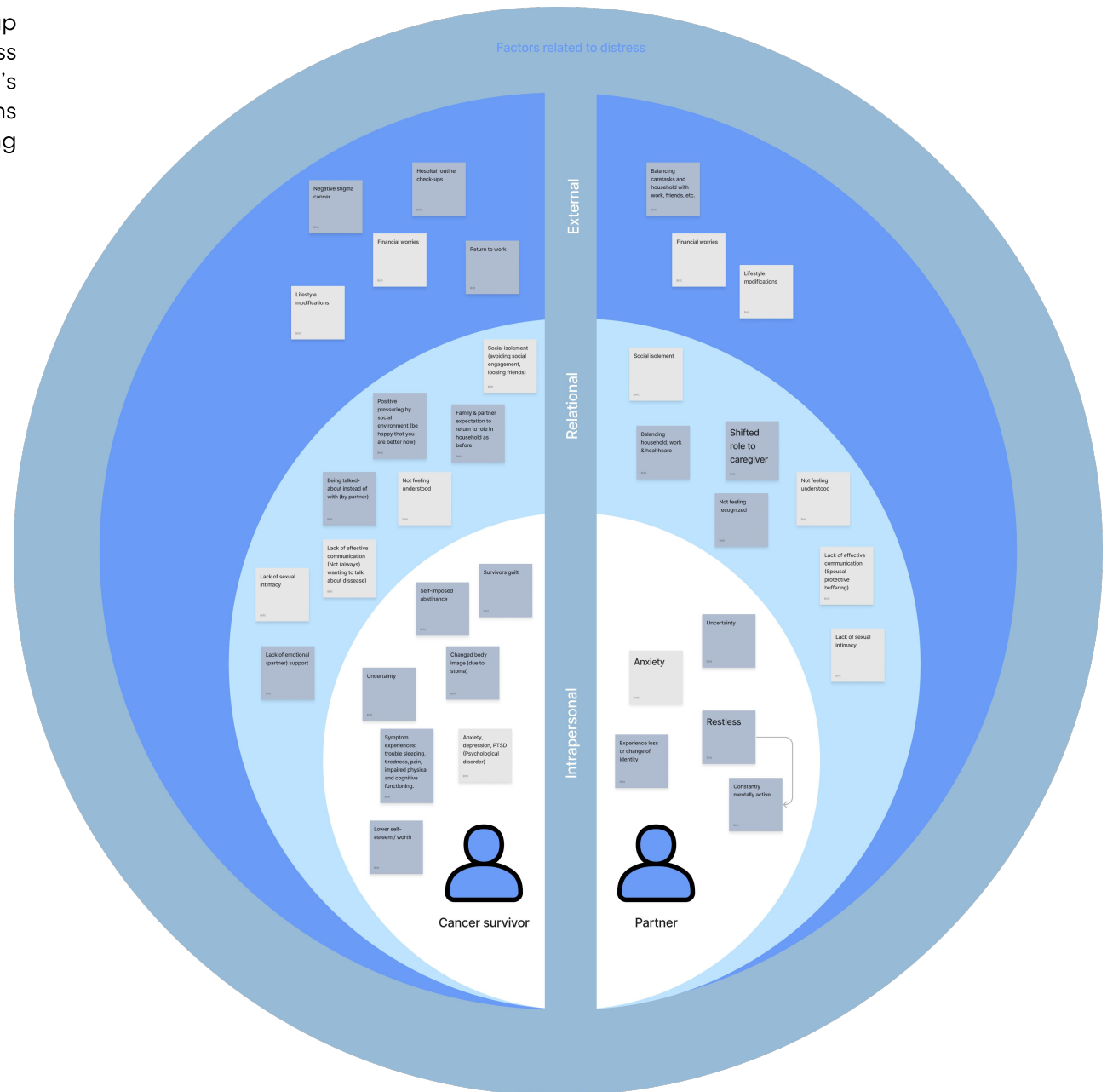


Fig. 59. Ecological map displaying distress factors on intrapersonal, interpersonal (relational), and external causes.

F. Data type identification & sensor selection co-brainstorm

To identify the types of data and appropriate sensors, I engaged in two brainstorming sessions.

Data Type Brainstorms

The first brainstorming session focused on translating social interaction into quantifiable parameters. I initially made an effort in synthesizing all factors affecting social interaction (Figure 61), uncovered from desktop research, the questionnaire, and scenario-supported interview (see chapter 2 and 4). Thereafter, I tried to regroup those insights regarding the APRACE-framework (i.e., actor, partner, activity, context, and evaluation), resulting in communication, approach behavior, tool usage, and activity engagement. As last, I brainstormed about transforming the aforementioned elements into quantifiable parameters.

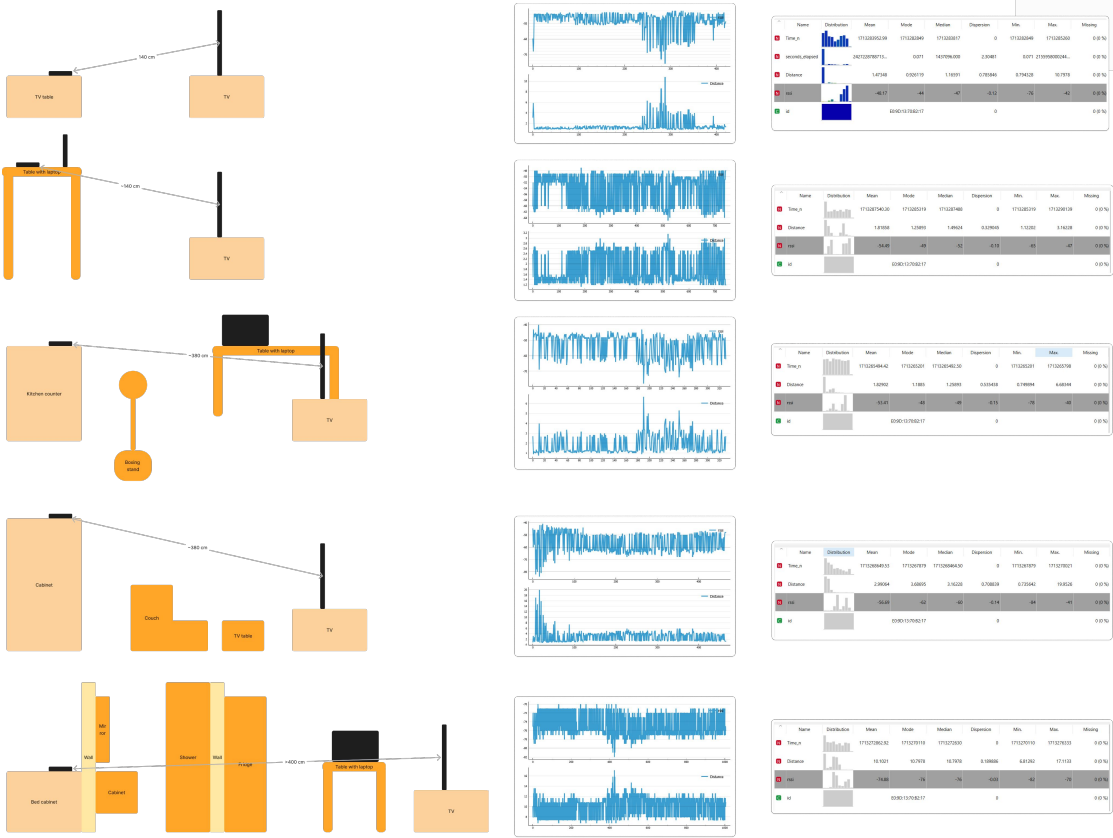


Fig. 60. RSSI exploration using bluetooth



Fig. 61. Data type brainstorm

One key element, particularly relevant within the context of attachment, was the approach-seeking behavior, highlighting the need to measure interpersonal distance. To explore this, I conducted desktop research, which revealed that technologies like WiFi and Bluetooth (with similar mechanisms) use signal strength (RSSI) to estimate distance through a logarithmic function (iotbymukund, 2016).

Interpersonal Distance Technology Experimentation

I then began exploring the feasibility of applying this concept in home environments, which are typically filled with numerous interfering obstacles such as digital devices and furniture. I leveraged the sensor logger application (Kelvin Tsz Hei Choi, 2024) to measure the distance between two devices within a short period of time (Figure 60). The data revealed to be very fluctuating, however the average distance proved to be quite reliable, making ap

$$d = 10^{\frac{txPower - rssi}{10 * FreeSpaceFactor}}$$

Fig. 62. Logarithmic formula used to estimate distance. d = distance, txPower = RSSI at 1 meter distance, RSSI = measured signal strength, FreeSpaceFactor = indicator between 1 and 4 about the crowdedness of a space. In this context, I used 4.

Co-Brainstorm

To deepen my understanding of using RSSI for measuring interpersonal distance, I (online) collaborated with a fellow Integrated Product Design graduate student from TU Delft who was researching a similar topic. This co-brainstorm provided valuable insights into the essential utilities of working with WiFi and Bluetooth sensors. The student also shared knowledge on remote, standalone measurement techniques, emphasizing the importance of GPS not only for collecting geospatial data but also for timestamping the data. Additionally, we discussed the power supply requirements, considering the estimated power consumption for the measurements.

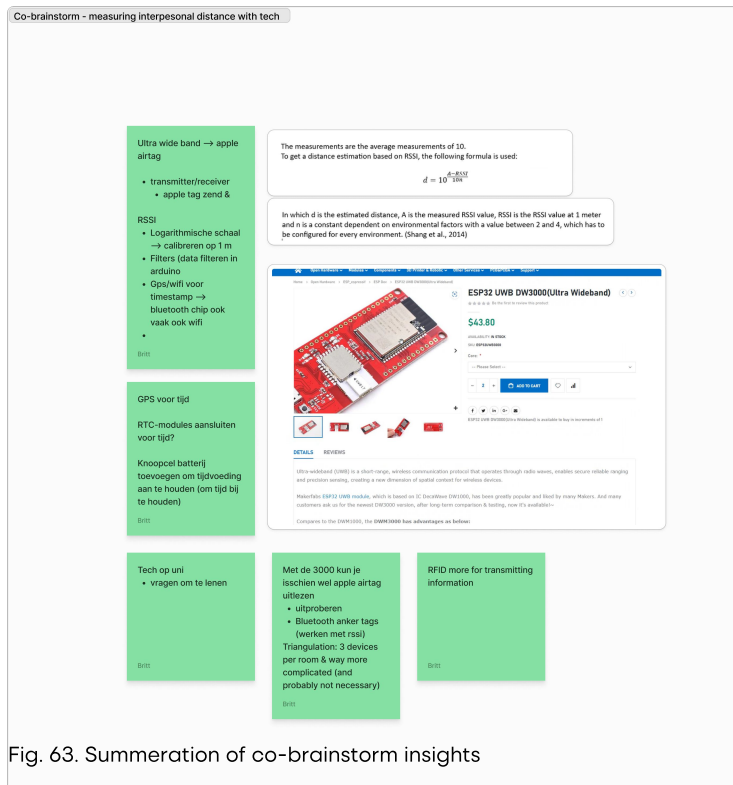


Fig. 63. Summation of co-brainstorm insights

Sensor Selection

Taking all the aforementioned insights into account, I engaged again in desktop research and selected the following sensors suitable for this project's objective. Below is a summary of the chosen sensors and their functionalities:

- **Arduino MKR WiFi Module**
 - Function - Measures RSSI (Received Signal Strength Indicator) between two devices.
 - Connectivity - Utilizes WiFi or BLE for data transfer between devices, allowing for centralized data storage. One device acts as a 'server,' while the other functions as a 'client,' connecting via the server's broadcasted IP.
- **MAX4466 Microphone Amplifier Module**
 - Function - Measures ambient sound levels and amplifies the audio signal.
 - Application - Detects even subtle sounds, useful for capturing acoustic activities.
- **DXL345 Digital 3-Axis Accelerometer Module**
 - Function - Measures acceleration along the x, y, and z axes.
 - Data Usage - Linear acceleration, a combination of all three axes, is used to indicate movement (see formula...).
- **Arduino MKR GPS Shield**
 - Function - Provides epoch time for accurate timestamps and retrieves latitude and longitude for location tracking.

For data storage, I opted to use a microSD card attached to the server board. This choice ensures a secure and straightforward method for storing personal data. The initial configuration of the two devices is illustrated in Figure 64.

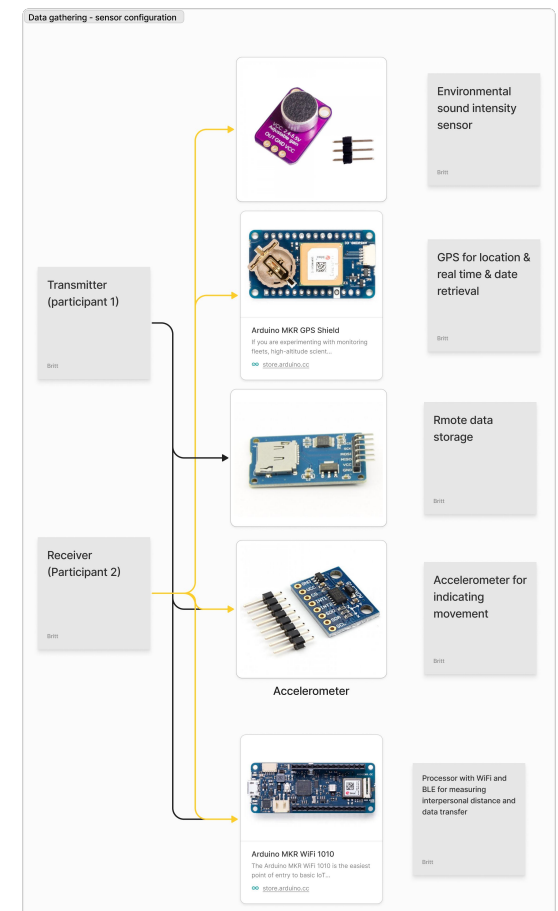


Fig. 64. Initial technology configuration

G. Informed Consent Documents

A. Scenario-Supported Interview

Informed Consent Form Interview

Participant information

You are being invited to participate in a research study titles *Redefining Measurement: Exploring Shared Reality and Spatial Data for Psychological Well-Being Assessment*. This study is being performed by B.G.A. (Britt) van der Rijt, from the TU Delft, as part of a Master's Thesis.

The purpose of this research study is to explore communication and support behavior in relation to communication-, conflict resolution, and support styles, and self-efficacy within couples. In this study, I will ask the participants (the couple) to provide their experiences and feelings within their relationship related to the aforementioned topics of approximately 30 minutes. The data will be used for the sake of this research and not shared beyond the supervisory team. All data and de-identified information will be stored in the safe and secure data environment (TU Delft project drive). The thesis will be published within the TU Delft graduation project repository, which is accessible by TU Delft staff and students. The pseudonymized and anonymized data not be stored publicly, and only be shared with a part of the supervisory team for future research purposes in accordance with the TU Delft Research Data Framework Policy.

As with any (online) activity the risk of a breach is always possible. To the best of our ability your answers in this study will remain confidential. We will minimize any risks by making the study anonymous. The data will be stored in a safe and secured environment (TU Delft project drive) and the data will be anonymized with identifiers, in which personal data will be stored separately from these identifiers.

Your participation in this study is entirely voluntary and you can withdraw at any time. You are free to omit any questions.

If you have any questions, you can contact B.G.A. (Britt) van der Rijt via

Agreements

PLEASE TICK THE APPROPRIATE BOXES	Yes	No
A: GENERAL AGREEMENT – RESEARCH GOALS, PARTICIPANT TASKS AND VOLUNTARY PARTICIPATION		
1. I have read and understood the study information dated [DD/MM/YYYY], or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction.	☐	☐
2. I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, without having to give a reason.	☐	☐

PLEASE TICK THE APPROPRIATE BOXES	Yes	No
3. I understand that taking part in the study involves:	☐	☐
Gathering information on how you communicate, cope, and provide support within your relationship with your partner.		
5. I understand that during the interview audio may be recorded and transcribed as text for the sake of this research, whereafter the recordings will be destroyed.	☐	☐
6. I understand that the study will end, if not consented to participate in further research, after the interview session.	☐	☐
B: POTENTIAL RISKS OF PARTICIPATING (INCLUDING DATA PROTECTION)		
7. I understand that taking part in the study involves the following risks and will be mitigated by [See Below] :	☐	☐
- A risk of personal information breach and that I will do all in our power to mitigate this risk by secured and anonymous storage in a safe data storage platform - That sensitive questions might arise during research involving relational well-being, which may lead to discomfort. To mitigate this risk, all questions are voluntary and can be dismissed at all times without any given reason.		
8. I understand that taking part in the study also involves collecting specific personally identifiable information (PII) (name) with the potential risk of a part of my identity being revealed because of online storage breach or mistakes in anonymizing the information.	☐	☐
9. I understand that steps will be taken to minimize the threat of a data breach, and protect my identity in the event of such a breach by storing information anonymously or (pseudo-) anonymized or aggregated, in a secured data storage.	☐	☐
10. I understand that personal information collected about me that can identify me (within this document), such as (i.e., name) will not be shared.	☐	☐
11. I understand that the (identifiable) personal data I provide will be destroyed a maximum of four weeks after the master's thesis.	☐	☐
C: RESEARCH PUBLICATION, DISSEMINATION AND APPLICATION		
12. I understand that after the research study the de-identified information I provide will be used for publication within the TU Delft graduation repository and that pseudonymized and anonymized data will only be shared with a part of the supervisory team for future research purposes.	☐	☐
13. I agree that my responses, views or other input can be quoted anonymously in research outputs	☐	☐
D: (LONGTERM) DATA STORAGE, ACCESS AND REUSE		

B. Contextualization User Research

PLEASE TICK THE APPROPRIATE BOXES	Yes	No
14. I give permission for the de-identified qualitative information that I provide to be archived in TU Delft Graduation Repository so it can be used for future research and learning.	☐	☐
15. I understand that access to this repository is open to staff and students of TU Delft	☐	☐

Informed Consent Statement (online) Survey

Participant information

You are being invited to participate in a research study titled 'Redefining Measurement: Exploring Shared Reality and Spatial Data for Psychological Well-Being Assessment' within the context of (colorectal) cancer survivorship. This study is being performed by B.G.A. (Britt) van der Rijt, from the TU Delft, as part of a Master's Thesis.

The purpose of this research study is to explore communication and support behavior in relation to styles, deconfliction, and self-efficacy within couples dealing with cancer survivorship (less than 5 years after treatment). In this study I will ask you to provide your experiences in an anonymous survey with a duration of approximately 10 minutes.

The data will be used for the sake of this research and eventually published in a master thesis. I believe there are no known risks associated with this research study; however, as with any online related activity the risk of a breach is always possible. To the best of our ability your answers in this study will remain confidential. We will minimize any risks by making this survey anonymous and all data will be stored on a secured drive.

If you have any questions, you can contact B.G.A. (Britt) van der Rijt via

Informed Consent – Research participation to investigate couple-related social interaction concerning individual well-being

You are being invited to participate in a research study titled 'Redefining Measurement: Exploring social interaction and spatial data of couples for psychological well-being assessment. This study is being done by B.G.A. (Britt) van der Rijt from the TU Delft

The purpose of this research study is to investigate the relationship between couple-related social activity and individual well-being, and will be performed over a period of 7 days, in which prior and after, you are asked to take part in an audio-recorded introduction session and final interview, both taking you approximately 1 hour to complete. The data about social activity will be used to support you and your partner, by analyzing it together with the researcher, in providing insight on your individual well-being. Therefore, I will be asking you to participate in both the introduction session and final interview, as to wear a sensor kit for a period of 7 days.

As with any research activity the risk of a breach is always possible. To the best of our ability your answers in this study will remain confidential. We will minimize any risks by gathering the data offline on a portable storage device. All personal data will be anonymised using identifiers and safely stored within a protected online environment.

Your participation in this study is entirely voluntary and you can withdraw at any time. You are free to omit any questions. If you wish to remove data, you can let the researcher know within 5 working days via

PLEASE TICK THE APPROPRIATE BOXES	Yes	No
A: GENERAL AGREEMENT – RESEARCH GOALS, PARTICIPANT TASKS AND VOLUNTARY PARTICIPATION		
1. I have read and understood the study information dated [DD/MM/YYYY], or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction.	☐	☐
2. I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, without having to give a reason.	☐	☐
3. I understand that taking part in the study involves participating in an introduction session, remote research activity, and final interview in which both sessions are recorded by audio and written notes. Moreover, I understand that I have to wear a sensor kit for 7 days. The recordings and notes will be destroyed not later than 7 days after the end of this graduation project. The session transcripts and sensor kit data will be kept and shared with the research team for further research purposes.	☐	☐
4. I understand that I will NOT be compensated for my participation.	☐	☐
5. I understand that the study will end after the final interview session that will take place not later than 3 days after the 7-day research period.		
B: POTENTIAL RISKS OF PARTICIPATING (INCLUDING DATA PROTECTION)		
6. I understand that taking part in the study involves the following risks: Addressing (relationship) information that potentially is experienced as uncomfortable to discuss with the researcher.	☐	☐

PLEASE TICK THE APPROPRIATE BOXES	Yes	No
As wearing of the sensor kit does not include potential safety and health risks, wearing a device can potentially cause physical discomfort. I understand that the first risk will be mitigated by analysing the data together with me and my partner, in which I can filter out any information I am not comfortable with discussing. Moreover, I understand that I can retract participation at any time. Moreover, to avoid physical discomfort I am allowed to remove the sensor kit when experiencing discomfort for a brief moment of time, and I am not asked to wear the device during sleep, physical exercise, and personal hygiene activities.		
7. I understand that taking part in the study also involves collecting specific personal information (PI) (sound, acceleration, interpersonal distance, and location) and associated personally identifiable research data (PIRD) (name, home address, and contact information such as phone number or e-mail address) with the potential risk of my identity being revealed through aggregating the information or a data breach.	☐	☐
8. I understand that the following steps will be taken to minimise the threat of a data breach, and protect my identity in the event of such a breach: - Anonymous data collection - Secure data storage & limited access - Anonymised audio transcription	☐	☐
10. I understand that personal information collected about me that can identify me, such as name, contact information, and where I live will not be shared.	☐	☐
11. I understand that the (identifiable) personal data I provide will be destroyed not later than 5 working days after the end of the graduation project (anticipated) in September 2024.	☐	☐
C: RESEARCH PUBLICATION, DISSEMINATION AND APPLICATION		
12. I understand that after the research study the de-identified information I provide will be used for reporting within the Master's graduation thesis.	☐	☐
13. I agree that my responses, views or other input can be quoted anonymously in research outputs	☐	☐
D: (LONGTERM) DATA STORAGE, ACCESS AND REUSE		
16. I give permission for the de-identified transcripts and sound, acceleration, location, and interpersonal distance data that I provide to be shared with the project's Chair Dr. Ir. J. Bourgeois so it can be used for future research.	☐	☐

Signatures		
_____ Name of participant [printed]	_____ Signature	_____ Date
I, as researcher, have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands to what they are freely consenting.		
_____ Researcher name [printed]	_____ Signature	_____ Date
Study contact details for further information: B.G.A. (Britt) van der Rijt;		

H. User Research Pilot insights

The pilot study, only performed for one day, was aimed to investigate whether the research method (see section 7.2 Method), along with the research probes (i.e., toolkit) were effective in data collection especially, as this was not sufficiently explored whether the data collection would work in other contexts than my own, as the data collection method earlier displayed some insufficiencies regarding reconnection.

Instructions

The participating couple within this pilot (n=1 couple) were instructed with a protocol besides the regular introduction to this research activity:

- Malfunctioning detection: The devices had each had one inbuild LED that provided feedback regarding data collection effectiveness. The participants were each briefed on how to detect whether their own device was still functioning or not.
- How to solve the malfunction: The participants were instructed to hard reboot the system when recognizing a malfunctioning device. Both devices needed to be rebooted around the same time, most effectively outside for GPS-signal reception. This did not have consequences for the collected data.
- Notify the researcher: when this occurred, the participants were instructed to notify me so I could contact them whether the instructions and execution of hard rebooting were effective.

At the end of the day, I would collect the data from the data collection devices to examine whether the device had correctly stored the data on the MicroSD

Conclusion

Device handling

Participants were well-able to perceive and perform hard reboots to correct the malfunctioning device. This was also necessary as the pilot pointed out that at some points the device still crashed, due to unknown reasons, leading to missing some data. However overall, the device seemed to effectively collect data, and discussing the data with the couples was not hindered due to missing data as participants were well capable to collect activities and experience during the contextualization interview within 3-days after data collection took place.

I took into account to mention to couples to not overly check the device, as it would bias the results, however occasionally check the functioning of their device when being in near proximity of each other, which would also less affect the results, and accompany a reboot that would happen together.

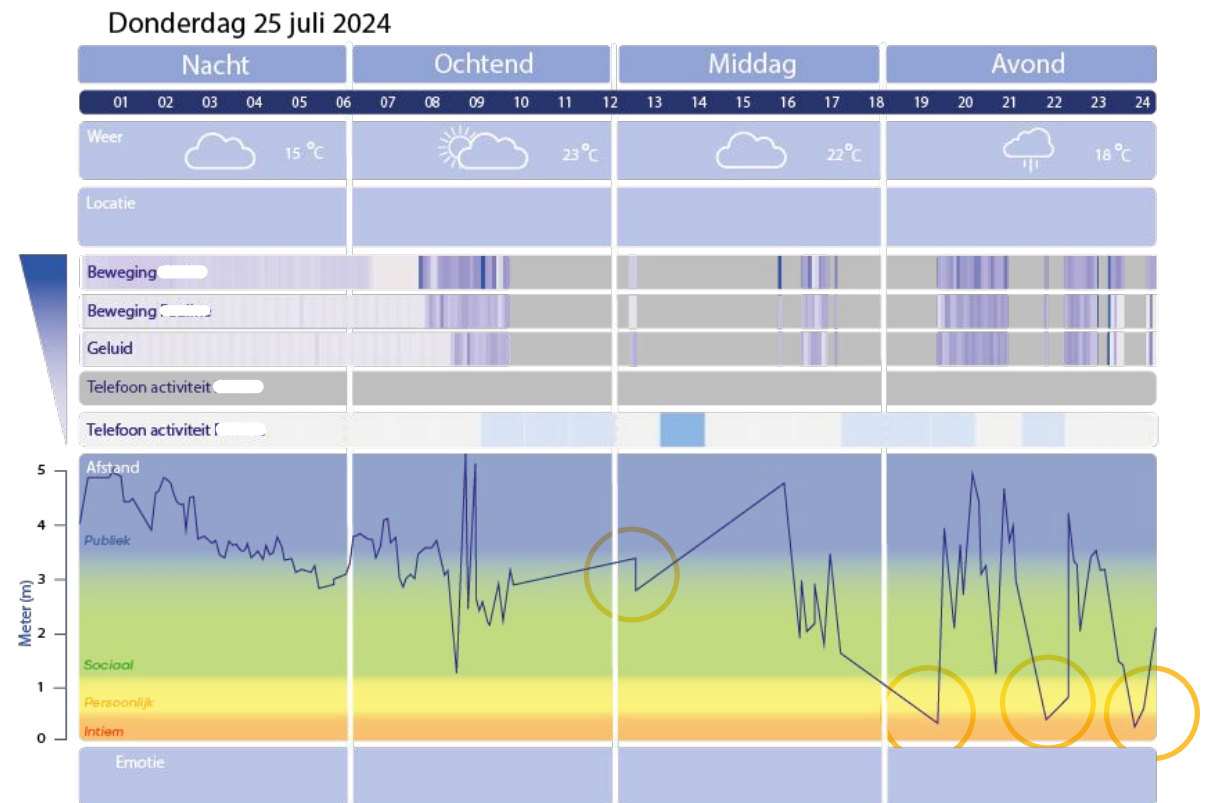


Fig. 65. Data derived from the participating couple in the pilot, indicating where reboots were necessary.

Contextualization process

In the pilot study, my goal was to assess whether the contextualization process was effectively designed for engaging with the target group, independent of the specific use case.

Set-Up

Participants were given a data visualization template pre-filled with their collected data, along with additional materials like stickers, post-its, and writing tools to help them physically add contextual meaning to the map.

Conclusion

The data visualization template effectively provided participants with a balance of support and flexibility. Participants were able to contextualize the data based on their own experiences, particularly daily routines, while also using the data to identify more detailed interactions.

Although the stickers were convenient, they required too much effort for participants to use collaboratively while simultaneously interacting with the template. However, this was not a drawback, as I, as the researcher, could assist in the contextualization process by placing the stickers for them. This demonstrated that the stickers and template served as valuable tools for the researcher, helping to complete the picture for analysis with the participants' input.

Additionally, participants expressed some discomfort with sharing photos of their homes. As a result, I chose to sketch the relevant layouts based on discussions with the participants.



Fig. 66. The contextualization set-up showing the data visualization template, stickers and post its.

I. User Research Thematic Analysis Process

The thematic analysis was performed according to the framework of Braun & Clarke (2006), and was as followed:

1. Familiarization: I went through all the data collected within the user research, including the re-listening the audio-files, re-reading the audio-transcripts, and adding quotes to the data-visualization templates (i.e., contextualizing the contextualized visualized data templates).
2. Creating Initial codes: I selected quotes from the audio-transcripts, and put them in a quote format where I could add an initial quote to it in Figma.
3. Generating themes: I clustered the coded data into themes, by identifying patterns and overarching themes.
4. Iteration: I reviewed the themes that I created after a few days to re-define themes if necessary for refinement.
5. Formulating results: The results from the thematic analysis are discussed within chapter 7.

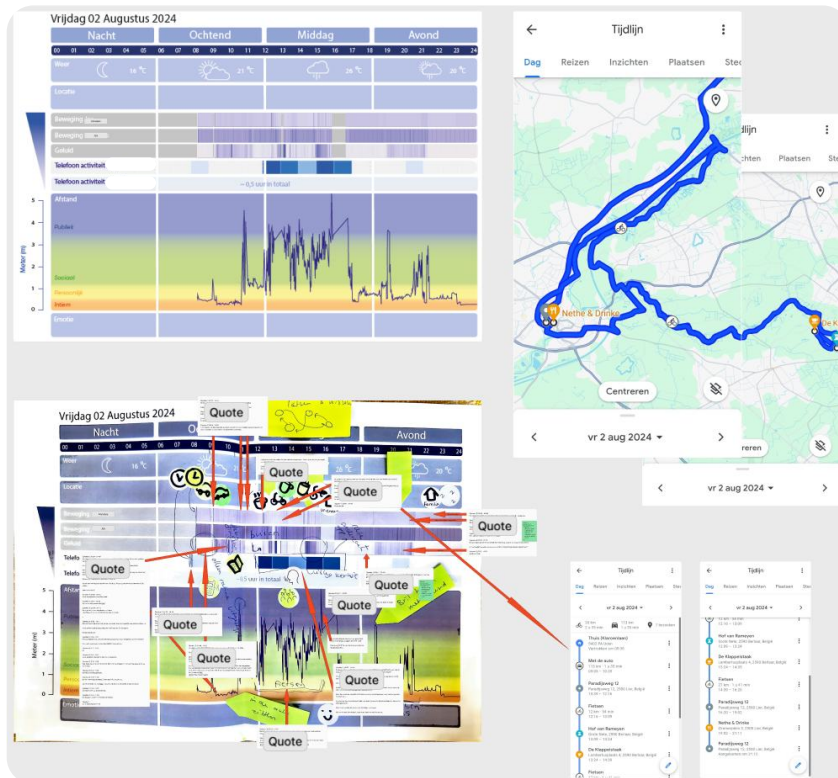


Fig. 67. Contextualizing the contextualized data visualization templates

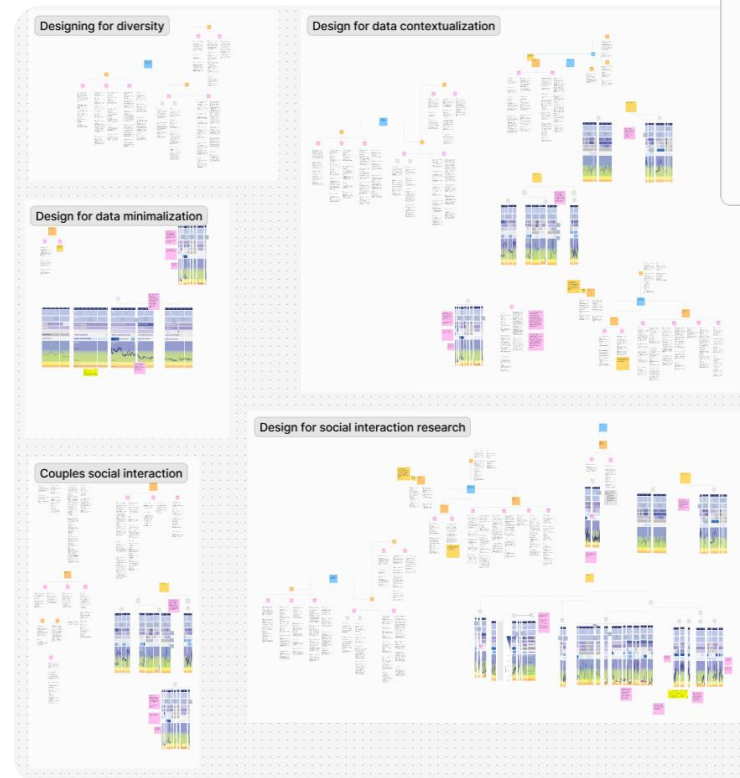


Fig. 68. Overview of themes

Couple 3

Code

Telefoon onderdeel van ochtendroutine

[Speaker 1] (24:58 - 25:22)

Dan gaat ze wakker aan. Ja. Maar ik ben 1050 uur wakker geworden en heb wel op de telefoon zitten kijken, ja.

Ja, precies. Dat niet zo vaak. Ik kijk altijd, als het wakker wordt, eerst op de telefoon.

Toen ik naar werk ga, heb ik eerst al het nieuwsje stilgenomen. Ik heb heel Google afgestruimd. Google als in, eh, weer, eh, marktplaatsende?

Nee, nee, nee. Of, hoe het werkt?

[Speaker 3] (25:22 - 25:24)

Nee, het zijn nieuwtjes. Nieuwsberichten.

[Speaker 1] (25:24 - 25:26)

O, nieuws. Ah, zo.

Fig. 64. Coding format in Figma

Familiarization

Here, you can find a close up of the familiarization with the data in the data visualization template, by added quotes to the contextualized data points (derived from the co-analysis with couples). Couple 2 (see Figure 69) also provided screenshots of their geospatial diary of the day (of measurement) which allowed me to better analyse the templates, and also supported recollection of activities and experiences during the interview.

On the templates, you can also find sketches of scenarios uncovered during the interview that seemed relevant to illustrate for analysis.

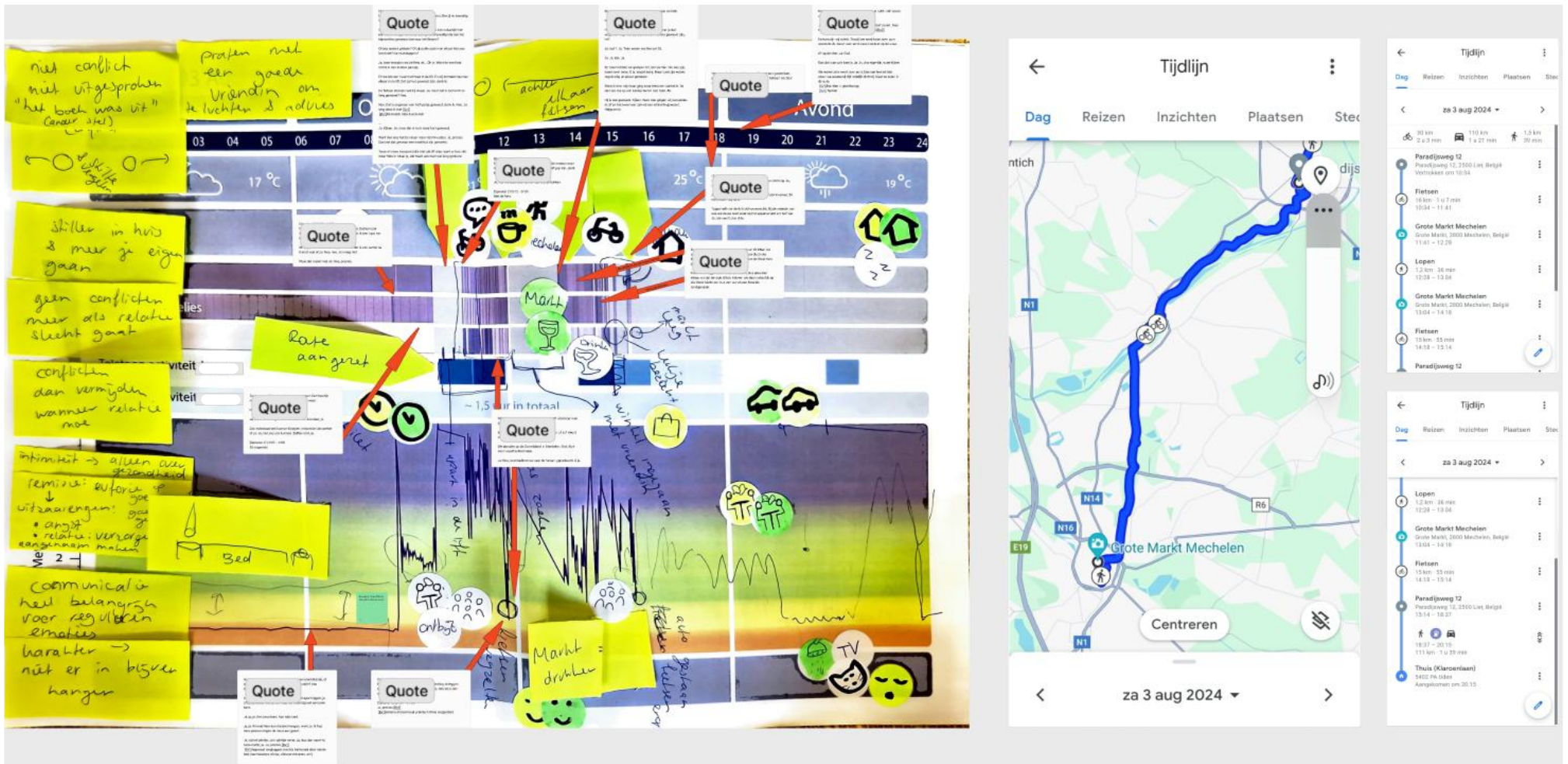


Fig. 69. Closer look at the contextualizing contextualized templates, where I also show what couple 2 shared regarding geospatial and activity data, and the sketches created during interesting scenario's to support analysis

Clustering

Here is an example of one of the themes, and sub-themes, I derived from the thematic analysis, showing clearly how I divided quotes and snippets of the data visualization templates. Regarding dividing the snippets, I divided them based on matchin scenario's relevant for, in this case, design for social interaction (research), to compare the patterns in between measurement day (of one couple) and couples.

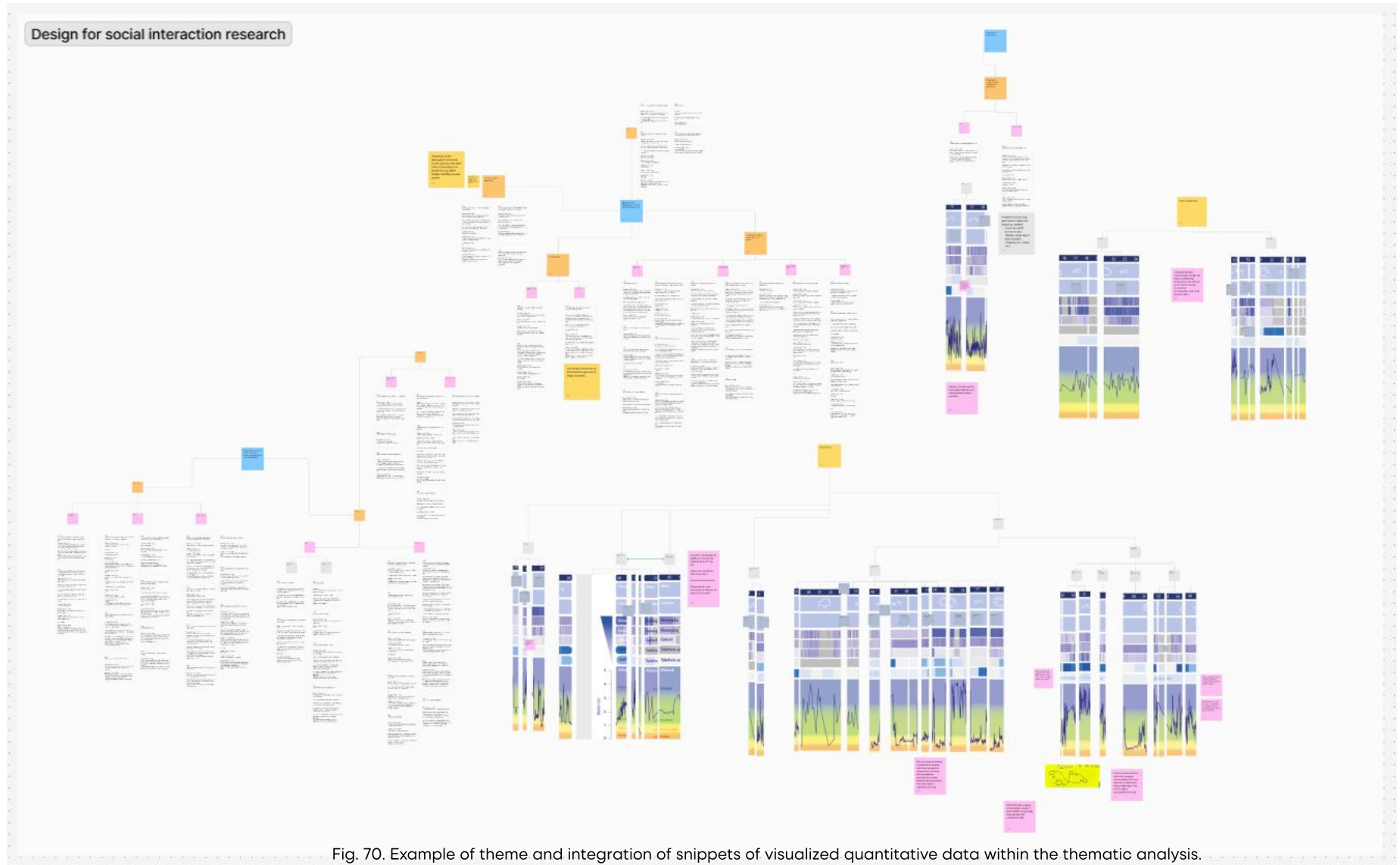


Fig. 70. Example of theme and integration of snippets of visualized quantitative data within the thematic analysis.

J. Graduation Project Brief





IDE Master Graduation Project

Project team, procedural checks and Personal Project Brief

In this document the agreements made between student and supervisory team about the student's IDE Master Graduation Project are set out. This document may also include involvement of an external client, however does not cover any legal matters student and client (might) agree upon. Next to that, this document facilitates the required procedural checks:

- Student defines the team, what the student is going to do/deliver and how that will come about
- Chair of the supervisory team signs, to formally approve the project's setup / Project brief
- SSC E&SA (Shared Service Centre, Education & Student Affairs) report on the student's registration and study progress
- IDE's Board of Examiners confirms the proposed supervisory team on their eligibility, and whether the student is allowed to start the Graduation Project

STUDENT DATA & MASTER PROGRAMME

Complete all fields and indicate which master(s) you are in

Family name		IDE master(s)	IPD ☐	Dfi ☒	SPD ☐
Initials		2 nd non-IDE master			
Given name		Individual programme (date of approval)			
Student number		Medisign	☒		
		HPM	☐		

SUPERVISORY TEAM

Fill in the required information of supervisory team members. If applicable, company mentor is added as 2nd mentor

Chair		dept./section	SDE	! Ensure a heterogeneous team. In case you wish to include team members from the same section, explain why. ! Chair should request the IDE Board of Examiners for approval when a non-IDE mentor is proposed. Include CV and motivation letter. ! 2nd mentor only applies when a client is involved.
mentor		dept./section	AED	
2 nd mentor				
client:				
city:		country:		
optional comments				

APPROVAL OF CHAIR on PROJECT PROPOSAL / PROJECT BRIEF -> to be filled in by the Chair of the supervisory team

Sign for approval (Chair)

Signature

Name

Date

Signature

CHECK ON STUDY PROGRESS

To be filled in by SSC E&SA (Shared Service Centre, Education & Student Affairs), after approval of the project brief by the chair.
The study progress will be checked for a 2nd time just before the green light meeting.

Master electives no. of EC accumulated in total EC

Of which, taking conditional requirements into account, can be part of the exam programme EC

☒	YES	all 1 st year master courses passed
☐	NO	missing 1 st year courses

Comments:

Sign for approval (SSC E&SA)

Name

Date

Signature

APPROVAL OF BOARD OF EXAMINERS IDE on SUPERVISORY TEAM -> to be checked and filled in by IDE's Board of Examiners

Does the composition of the Supervisory Team
comply with regulations?

YES	☐	Supervisory Team approved
NO	☐	Supervisory Team not approved

Comments:

Based on study progress, students is ...

☐	ALLOWED to start the graduation project
☐	NOT allowed to start the graduation project

Comments:

Sign for approval (BoEx)

Name

Date

Signature

Personal Project Brief – IDE Master Graduation Project

Name student

Student number

PROJECT TITLE, INTRODUCTION, PROBLEM DEFINITION and ASSIGNMENT

Complete all fields, keep information clear, specific and concise

Project title

Redefining Measurement: Exploring Shared Reality and Spatial Data for Psychological Well-Being Assessment

Please state the title of your graduation project (above). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

Introduction

Describe the context of your project here; What is the domain in which your project takes place? Who are the main stakeholders and what interests are at stake? Describe the opportunities (and limitations) in this domain to better serve the stakeholder interests. (max 250 words)

Having colorectal cancer has a major impact on a patient's quality of life (QoL). Physical and psychological health are negatively affected by the disease. Unfortunately, the affects do not stop when entering the survivorship phase. Colorectal cancer survivors are more likely to have an increased level of psychological morbidity caused by physical & cognitive functioning, altered body image, financial concerns, lack of social support, depression, anxiety, embarrassment, and concerns about cancer recurrence. The psychological distress, however, does limit itself to the patient, but also affects the QoL of their partner (Diest, den Oudsten, Aaronson, Beaulen, Verboon, Aarnoudse & van Lankveld, 2023). This is called psychosocial impact: the effect caused by environmental and/or biological factors on individual's social and/or psychological aspects (Martini de Oliveira et al, 2013). In this project, the focus will be on the relationships within the home environment.

Andreu, Martinez & Soto-Rubio (2021) indicated that emotional support and support by partner or family are two unmet care needs of cancer survivor's within the psychological domain that increase experienced psychological distress. The experienced lack of emotional and partner support comes with another few symptoms within the relationship, being incomprehension about both individuals situation (i.e., emotions, thoughts, challenges, etc.) and feeling misunderstood or being forgotten (Kanker.nl, n.d.). This creates frustration and pressure. However, fostering a secure and supportive partner relationship is beneficial for stress regulation, as interpersonal stress regulation is found to be superior to intrapersonal stress regulation (Diest et al, 2023). The experienced psychological distress depends significantly on the intensity of relational intimacy that partners experience. This intimacy is related to the way partners discuss their cancer related concerns, but also by the extent to which they avoid talking about these concerns.

Therefore, the opportunity exists to explore intimacy in relation to psychological well-being of (colorectal) cancer survivors in health care.

→ space available for images / figures on next page

introduction (continued): space for images

Table 2. Unmet supportive care needs: prevalence and association with distress (N_{total} = 200; N_{unmet needs} = 145; N_{met needs} = 55)

	Total group N (%)	Unmet needs N (%)	Met needs N (%)	p
Comprehensive care information	145 (72.5)	139 (74.1)	32 (58.2)	.001
1. Up-to-date information	45 (22.6)	39 (70.0)	16 (29.0)	.001
2. Information for others	45 (22.6)	32 (59.4)	13 (23.6)	.019
3. Understandable information	39 (58.1)	36 (62.2)	19 (33.9)	.001
4. Best medical care	60 (30.5)	49 (82.3)	20 (35.9)	.001
5. Local health care services	64 (32.0)	54 (90.9)	25 (45.5)	.001
6. Manage health with ease	118 (59.5)	81 (57.8)	37 (67.3)	.056
7. Doctor talks to each other	112 (56.0)	87 (55.4)	25 (45.5)	.002
8. Complaint addressed	134 (67.0)	107 (65.5)	27 (49.1)	.012
9. Comprehensive follow-up	71 (35.5)	53 (32.3)	18 (32.7)	.004
Physical effects	45 (22.6)	26 (36.0)	17 (30.9)	.001
11. Manage side effects	34 (17.0)	13 (16.7)	13 (23.6)	.001
12. Changes to quality of life	26 (13.0)	13 (16.0)	13 (23.6)	.001
13. Fatigue	8 (4.0)	4 (2.5)	4 (7.3)	.012
14. Changes to my body	20 (10.0)	7 (2.3)	13 (23.6)	.001
15. Emotional distress	69 (34.5)	41 (25.2)	28 (50.9)	.001
16. Reduce stress in my life	30 (15.0)	13 (16.0)	17 (30.9)	.001
17. Concerns about cancer coming back	39 (19.5)	22 (15.2)	17 (30.9)	.001
18. Emotional support for me	31 (15.5)	13 (8.3)	18 (32.7)	.001
19. Talk to others	29 (14.5)	19 (11.7)	10 (18.2)	.001
20. Move on with my life	16 (8.0)	3 (2.3)	13 (23.6)	.001
21. Changes to beliefs	21 (10.5)	8 (4.9)	13 (23.6)	.001
22. Acknowledging the impact	15 (7.5)	5 (2.3)	10 (18.2)	.001
23. Survival expectations	12 (6.0)	4 (2.3)	8 (14.5)	.001
24. Decisions about my life	20 (10.0)	8 (4.9)	12 (21.8)	.001
25. Spiritual beliefs	9 (4.5)	3 (2.3)	6 (10.9)	.001
26. Make my life count	16 (8.0)	4 (2.3)	12 (21.8)	.001
Practical issues	36 (18.0)	32 (51.6)	22 (39.7)	.001
31. Employment	15 (7.5)	6 (3.3)	9 (16.4)	.001
32. Financial support	45 (22.5)	25 (35.4)	19 (34.5)	.001
33. I do travel insurance	19 (9.5)	11 (6.9)	8 (14.5)	.001
34. Legal services	22 (11.0)	11 (6.9)	11 (20.0)	.001
35. Affordable hospital parking	22 (11.0)	15 (9.3)	7 (12.7)	.005
36. Choosing care manager	40 (20.0)	27 (16.6)	13 (23.6)	.004
37. Knowledge	47 (23.5)	29 (19.3)	18 (32.7)	.001
38. Support patient/family	37 (18.5)	16 (10.3)	21 (38.2)	.001
39. Impact on my relationship	19 (9.5)	6 (3.3)	13 (23.6)	.001
40. New friendships	12 (6.0)	2 (2.3)	10 (18.2)	.001
41. Handle awkward situations	18 (9.0)	11 (6.7)	7 (12.7)	.011
42. Problems with sex life	25 (12.5)	13 (7.6)	12 (21.8)	.001
Total	179 (89.5)	136 (75.4)	55 (100.0)	.001

* Chi-square obtained based on 2x2 or 2x3 at least in two subgroups using pooled scores for continuity sample.

image / figure 1 Unmet supportive care needs: prevalence and association with distress (Andreu et al, 2021)

Table 3. Sociodemographic and cancer-related predictors of unmet supportive care needs (N = 200)

	Comprehensive care information p N (%)	Physical effects p N (%)	Psychological effects p N (%)	Practical issues p N (%)	Relationships p N (%)
Age	.001	.001	.001	.001	.001
≤ 55	21 (37.5)	12 (50.0)	14 (58.3)	16 (66.7)	11 (45.8)
55-65	57 (79.2)	20 (27.8)	23 (31.8)	30 (41.7)	19 (26.4)
≥ 66	83 (81.4)	11 (10.8)	30 (29.4)	28 (27.3)	15 (14.7)
N (%)	495	523	666	631	791
Gender	.001	.001	.001	.001	.001
Male	108 (81.2)	27 (20.3)	39 (29.3)	48 (36.1)	30 (22.6)
Female	54 (81.0)	16 (24.2)	28 (42.4)	26 (39.4)	16 (24.2)
Living situation	.001	.001	.001	.001	.001
Married/lived with partner	116 (90.4)	51 (39.5)	61 (45.4)	68 (51.3)	54 (41.6)
Single/divorced/widowed	44 (65.0)	13 (24.2)	17 (25.7)	16 (24.2)	12 (22.6)
Education level (years)	.001	.001	.001	.001	.001
Without studies	26 (57.5)	3 (6.4)	12 (27.5)	11 (24.2)	8 (25.0)
Primary studies	51 (72.9)	18 (25.7)	22 (31.4)	23 (32.9)	17 (24.3)
Secondary studies	55 (85.4)	10 (24.4)	16 (31.6)	22 (32.7)	19 (24.4)
Bachelor's degree	58 (84.8)	11 (21.4)	14 (31.1)	15 (33.3)	9 (20.0)
Employment status	.001	.001	.001	.001	.001
Working outside home	26 (81.3)	6 (18.5)	10 (31.3)	11 (34.4)	6 (18.8)
Unemployed	6 (9.0)	8 (18.6)	8 (18.0)	8 (18.0)	6 (9.0)
Retired/own sick leave	111 (81.6)	31 (22.8)	41 (30.1)	48 (35.3)	30 (22.1)
Homemaker	11 (98.8)	2 (12.5)	8 (50.0)	6 (37.5)	3 (18.8)
Medical primary treatments	.001	.001	.001	.001	.001
Surgery (S)	57 (85.1)	7 (10.4)	19 (28.4)	21 (31.3)	14 (20.9)
Chemotherapy (CT)	65 (77.4)	19 (22.6)	30 (35.7)	34 (40.5)	16 (19.0)
S + CT + Radiotherapy (RT)	60 (78.9)	18 (24.4)	34 (45.3)	37 (49.3)	13 (17.3)
Other*	11 (100.0)	0 (0.0)	3 (27.3)	3 (27.3)	3 (27.3)
N (%)	132	120	130	125	121
≤ 12 months (RT subgroup)	25 (52.1)	10 (20.8)	11 (22.9)	12 (24.5)	7 (14.3)
> 12 months ≤ 2 years (S subgroup)	82 (76.6)	22 (20.6)	41 (38.3)	39 (36.4)	27 (25.2)
> 2 years (S subgroup)	26 (84.6)	12 (38.2)	16 (51.6)	24 (76.9)	12 (38.2)

* "Other" category groups together other primary treatment strategies that were not reported in this study: supportive care, radiotherapy, surgery plus radiotherapy and chemotherapy plus radiotherapy.

image / figure 2 Sociodemographic and cancer-related predictors of unmet supportive care needs (Andreu et al, 2021)

Personal Project Brief – IDE Master Graduation Project

Problem Definition

*What problem do you want to solve in the context described in the introduction, and within the available time frame of 100 working days? (= Master Graduation Project of 30 EC). What opportunities do you see to create added value for the described stakeholders? Substantiate your choice.
(max 200 words)*

QoL and psychological well-being is commonly measured through qualitative and quantitative patient self-reports and surveys in hospitals. However, this method is subject to mood changes and is perceived to be cognitively demanding and hard to integrate in daily life (Voukelatou, Gabrielli, Milliou et al, 2021). Additionally, measuring quantitatively through scales lacks contextualization. There is therefore need to measure psychological well-being differently.

When partners go beyond the limits of their own reality, they can create a shared reality where they perceive an overlap of thoughts, feelings, and concerns (Enestrom, Bar-Khalifa, Bar-Shachar & Lydon, 2023). Shared reality is in recent research associated with the measurement of spatial proximity, which can indicate relationship well-being and in turn a positive atmosphere for a supportive environment. Thus, by exploring shared reality through spatial data, we might be able to better grasp the psychological well-being of the patient and the correlation with the psychosocial environment.

Assignment

This is the most important part of the project brief because it will give a clear direction of what you are heading for. Formulate an assignment to yourself regarding what you expect to deliver as result at the end of your project. (1 sentence) As you graduate as an industrial design engineer, your assignment will start with a verb (Design/Investigate/Validate/Create), and you may use the green text format:

Develop a strategy for assessing the psychological well-being of cancer survivors by leveraging couples' spatial data to deliver and contextualize remote monitoring outcomes.

Then explain your project approach to carrying out your graduation project and what research and design methods you plan to use to generate your design solution (max 150 words)

I aim for a data-centric design approach and will use the double diamond model to structure my project's process. In the discover part I will research and explore numerous concepts (together with others, through literature, or a survey), technologies and research frameworks. In the define phase I will bring all results together and define my research method, design goal, and technology and research tools requirements. These requirements will be input for the evaluation of my concepts in the Develop stage. In the develop stage, I will do some co-creation (for inspirational input), brainstorming and interactive prototyping to explore solutions. At the end of this stage, I will perform an evaluation (as aforementioned) and iterate. As last, in the deliver phase I will focus on realize all the probes & tools I need for the research stage and perform user tests to make sure they are able to be used without significant problems. In the research stage, I will perform first a pilot, and second an evaluation (and if needed some tweaking) before continuing on the actual research period. Ethical approval and gathering participants will be realized as soon as possible. If I am not able to find cancer survivors as participants, I will focus on couples in general to safeguard my process.

Project planning and key moments

To make visible how you plan to spend your time, you must make a planning for the full project. You are advised to use a Gantt chart format to show the different phases of your project, deliverables you have in mind, meetings and in-between deadlines. Keep in mind that all activities should fit within the given run time of 100 working days. Your planning should include a **kick-off meeting, mid-term evaluation meeting, green light meeting and graduation ceremony**. Please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any (for instance because of holidays or parallel course activities).

Make sure to attach the full plan to this project brief.
The four key moment dates must be filled in below

Kick off meeting	1 mrt 2024
Mid-term evaluation	8 mei 2024
Green light meeting	17 juli 2024
Graduation ceremony	11 aug 2024

In exceptional cases (part of) the Graduation Project may need to be scheduled part-time. Indicate here if such applies to your project

Part of project scheduled part-time	✓
For how many project weeks	25
Number of project days per week	4,0

Comments:

I will work two days a week for the complete duration of my graduation

Motivation and personal ambitions

Explain why you wish to start this project, what competencies you want to prove or develop (e.g. competencies acquired in your MSc programme, electives, extra-curricular activities or other).

Optionally, describe whether you have some personal learning ambitions which you explicitly want to address in this project, on top of the learning objectives of the Graduation Project itself. You might think of e.g. acquiring in depth knowledge on a specific subject, broadening your competencies or experimenting with a specific tool or methodology. Personal learning ambitions are limited to a maximum number of five.

(200 words max)

Along my bachelor's and master's, I recognized my passion for (mental) healthcare. However, I always noticed that the design is in most cases focused solely on the patient's wellbeing, and the social environment is considered as context. I am therefore more curious about how we can empower patient-family relationship well-being as a process for improving mental wellbeing of the patient.

Learning ambitions. For this graduation project, I identified three learning ambitions that I feel are important for concluding my academic journey:

- Using a data-centric approach in design research to explore the opportunities of quantitative data and patient understanding of this data in future design
- Improve my competences in project management by time management & creating a specific focus & scope in my problem statement, and stay concise.
- Make more use of input of others during explorations (research & ideation) to increase creativity and validity

K. Ethical Applications Forms

A. HRX checklist

Delft University of Technology
HUMAN RESEARCH ETHICS
CHECKLIST FOR HUMAN RESEARCH
(Version January 2022)

IMPORTANT NOTES ON PREPARING THIS CHECKLIST

1. An HREC application should be submitted for every research study that involves human participants (as Research Subjects) carried out by TU Delft researchers
2. Your HREC application should be submitted and approved **before** potential participants are approached to take part in your study
3. All submissions from Master's Students for their research thesis need approval from the relevant Responsible Researcher
4. The Responsible Researcher must indicate their approval of the completeness and quality of the submission by signing and dating this form OR by providing approval to the corresponding researcher via email (included as a PDF with the full HREC submission)
5. There are various aspects of human research compliance which fall outside of the remit of the HREC, but which must be in place to obtain HREC approval. These often require input from internal or external experts such as [Faculty Data Stewards](#), [Faculty HSE advisors](#), the [TU Delft Privacy Team](#) or external [Medical research partners](#).
6. You can find detailed guidance on completing your HREC application [here](#)
7. Please note that incomplete submissions (whether in terms of documentation or the information provided therein) will be returned for completion **prior to any assessment**
8. If you have any feedback on any aspect of the HREC approval tools and/or process you can leave your comments [here](#)

I. Applicant Information

PROJECT TITLE:	
Research period: <i>Over what period of time will this specific part of the research take place</i>	100 days divided over 25 working-weeks – starting from 1 March 2024
Faculty:	Industrial Design Engineering
Department:	Sustainable Design Interaction
Type of the research project: <i>(Bachelor's, Master's, DreamTeam, PhD, PostDoc, Senior Researcher, Organisational etc.)</i>	Master's graduation project 'Design for Interaction (Dfi)'
Funder of research: <i>(EU, NWO, TUD, other – in which case please elaborate)</i>	-
Name of Corresponding Researcher: <i>(If different from the Responsible Researcher)</i>	B.G.A. (Britt) van der Rijt
E-mail Corresponding Researcher: <i>(If different from the Responsible Researcher)</i>	
Position of Corresponding Researcher: <i>(Masters, DreamTeam, PhD, PostDoc, Assistant/ Associate/ Full Professor)</i>	Masters
Name of Responsible Researcher: <i>Note: all student work must have a named Responsible Researcher to approve, sign and submit this application</i>	J. Bourgeois
E-mail of Responsible Researcher: <i>Please ensure that an institutional email address (no Gmail, Yahoo, etc.) is used for all project documentation/ communications including Informed Consent materials</i>	
Position of Responsible Researcher : <i>(PhD, PostDoc, Associate/ Assistant/ Full Professor)</i>	Assistant professor

II. Research Overview

NOTE: You can find more guidance on completing this checklist [here](#)

a) Please summarise your research very briefly (100-200 words)

What are you looking into, who is involved, how many participants there will be, how they will be recruited and what are they expected to do?

<i>Add your text here – (please avoid jargon and abbreviations)</i>
Assignment: develop a strategy for assessing the psychological well-being of cancer survivors by leveraging couples' spatial data to deliver and contextualize remote monitoring outcomes. QoL and psychological well-being are commonly measured through qualitative and quantitative patient self-reports and hospital surveys. However, this method is subject to mood changes and is perceived to be cognitively demanding and hard to integrate into daily life. Additionally, measuring quantitatively through scales lacks contextualization. There is, therefore, a need to measure psychological well-being differently, in this case, in the context of (colorectal) cancer survivors. In the exploration phase, I will perform research activities to understand more about communication-, conflict resolution-, and support patterns and styles, self-efficacy, and their (subjective) relationship with interpersonal distance. To be able to do this, I will ask participants, recruited through foundations or my network, to provide information related to their experiences and feelings. I will do this through an online anonymous survey (with a duration of c.a. 15 minutes) and interviews with couples (n = 8 (4 couples)) living together

(with a duration of c.a. 40 minutes) and a specialist (n = 1) in the area of psychiatry and/or relationship therapy (with a duration of c.a. 30 minutes).

- b) **If your application is an additional project** related to an existing approved HREC submission, please provide a brief explanation including the existing relevant HREC submission number/s.

Add your text here – (please avoid jargon and abbreviations)

- c) **If your application is a simple extension of, or amendment to,** an existing approved HREC submission, you can simply submit an [HREC Amendment Form](#) as a submission through LabServant.

III. Risk Assessment and Mitigation Plan

NOTE: You can find more guidance on completing this checklist [here](#)

Please complete the following table in full for all points to which your answer is “yes”. Bear in mind that the vast majority of projects involving human participants as Research Subjects also involve the collection of **Personally Identifiable Information (PII)** and/or **Personally Identifiable Research Data (PIRD)** which may pose potential risks to participants as detailed in Section G: Data Processing and Privacy below.

To ensure alignment between your risk assessment, data management and what you agree with your Research Subjects you can use the last two columns in the table below to refer to specific points in your Data Management Plan (DMP) and Informed Consent Form (ICF) – **but this is not compulsory**.

It’s worth noting that **you’re much more likely to need to resubmit your application if you neglect to identify potential risks**, than if you identify a potential risk and demonstrate how you will mitigate it. If necessary, the HREC will always work with you and colleagues in the Privacy Team and Data Management Services to see how, if at all possible, your research can be conducted.

			If YES please complete the Risk Assessment and Mitigation Plan columns below.		Please provide the relevant reference #	
ISSUE	Yes	No	RISK ASSESSMENT – what risks could arise? <i>Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!</i>	MITIGATION PLAN – what mitigating steps will you take? <i>Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.</i>	DMP	ICF
A: Partners and collaboration						
1. Will the research be carried out in collaboration with additional organisational partners such as: - One or more collaborating research and/or commercial organisations - Either a research, or a work experience internship provider¹ <i>¹ If yes, please include the graduation agreement in this application</i>		x				
2. Is this research dependent on a Data Transfer or Processing Agreement with a collaborating partner or third party supplier? <i>If yes please provide a copy of the signed DTA/DPA</i>		x				
3. Has this research been approved by another (external) research ethics committee (e.g.: HREC and/or MREC/METC)? <i>If yes, please provide a copy of the approval (if possible) and summarise any key points in your Risk Management section below</i>		x				
B: Location						

			if YES please complete the Risk Assessment and Mitigation Plan columns below.		Please provide the relevant reference #	
ISSUE	Yes	No	RISK ASSESSMENT – what risks could arise? <i>Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!</i>	MITIGATION PLAN – what mitigating steps will you take? <i>Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.</i>	DMP	ICF
4. Will the research take place in a country or countries, other than the Netherlands, within the EU?		x				
5. Will the research take place in a country or countries outside the EU?		x				
6. Will the research take place in a place/region or of higher risk – including known dangerous locations (in any country) or locations with non-democratic regimes?		x				
C: Participants						
7. Will the study involve participants who may be vulnerable and possibly (legally) unable to give informed consent? (e.g., children below the legal age for giving consent, people with learning difficulties, people living in care or nursing homes.).		x				
8. Will the study involve participants who may be vulnerable under specific circumstances and in specific contexts, such as victims and witnesses of violence, including domestic violence; sex workers; members of minority groups, refugees, irregular migrants or dissidents?		x				
9. Are the participants, outside the context of the research, in a dependent or subordinate position to the investigator (such as own children, own students or employees of either TU Delft and/or a collaborating partner organisation)? <i>It is essential that you safeguard against possible adverse consequences of this situation (such as allowing a student's failure to participate to your satisfaction to affect your evaluation of their coursework).</i>		x				
10. Is there a high possibility of re-identification for your participants? (e.g., do they have a very specialist job of which there are only a small number in a given country, are they members of a small community, or employees from a partner company collaborating in the research? Or are they one of only a handful of (expert) participants in the study?		x				
D: Recruiting Participants						
11. Will your participants be recruited through your own, professional, channels such as conference attendance lists, or through specific network/s such as self-help groups	x		There exists the risks that specific networks/communities (such as Kanker.nl) do not accept a researcher to gather participants themselves and potentially compromise the safety & privacy of the community users.	To mitigate violating the safe space of community users I will do thorough investigation of the network, understand their rules, and make it clear what my intentions are. Additionally, most communities have a specific points of contact (poc) for asking for participants, so I make sure to contact this poc.		
12. Will the participants be recruited or accessed in the longer term by a (legal or customary) gatekeeper? (e.g., an adult professional working with children; a		x				

			If YES please complete the Risk Assessment and Mitigation Plan columns below.		Please provide the relevant reference #	
ISSUE	Yes	No	RISK ASSESSMENT – what risks could arise? <i>Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!</i>	MITIGATION PLAN – what mitigating steps will you take? <i>Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.</i>	DMP	ICF
community leader or family member who has this customary role – within or outside the EU; the data producer of a long-term cohort study)						
13. Will you be recruiting your participants through a crowd-sourcing service and/or involve a third party data-gathering service, such as a survey platform?		x				
14. Will you be offering any financial, or other, remuneration to participants, and might this induce or bias participation?		x				
E: Subject Matter <i>Research related to medical questions/health may require special attention. See also the website of the CCMO before contacting the HREC.</i>						
15. Will your research involve any of the following: - Medical research and/or clinical trials - Invasive sampling and/or medical imaging - Medical and <i>In Vitro Diagnostic Medical Devices</i> Research		x				
16. Will drugs, placebos, or other substances (e.g., drinks, foods, food or drink constituents, dietary supplements) be administered to the study participants? <i>If yes see here to determine whether medical ethical approval is required</i>		x				
17. Will blood or tissue samples be obtained from participants? <i>If yes see here to determine whether medical ethical approval is required</i>		x				
18. Does the study risk causing psychological stress or anxiety beyond that normally encountered by the participants in their life outside research?		x				
19. Will the study involve discussion of personal sensitive data which could put participants at increased legal, financial, reputational, security or other risk? (e.g., financial data, location data, data relating to children or other vulnerable groups) <i>Definitions of sensitive personal data, and special cases are provided on the TUD Privacy Team website.</i>	x		If not properly designed my research can uncover, unintentionally, relational problems which are not the scope of this research. This is because I will refer to relational satisfaction, communication and deconfliction, and coping, which might cause conflict between partners and harm their relationship	I will make sure that my research design (i.e., questions and set-up) provides a secure environment where no relation or individual will be hurt. Besides, I will try to ask other professionals to validate my methods upon this topic.		
20. Will the study involve disclosing commercially or professionally sensitive, or confidential information? (e.g., relating to decision-making processes or business strategies which might, for example, be of interest to competitors)		x				
21. Has your study been identified by the TU Delft Privacy Team as requiring a Data Processing Impact Assessment (DPIA)? <i>If yes please attach the advice/approval from the Privacy Team to this application</i>		x				
22. Does your research investigate causes or areas of conflict?		x				

			If YES please complete the Risk Assessment and Mitigation Plan columns below.		Please provide the relevant reference #	
ISSUE	Yes	No	RISK ASSESSMENT – what risks could arise? <i>Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!</i>	MITIGATION PLAN – what mitigating steps will you take? <i>Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.</i>	DMP	ICF
<i>If yes please confirm that your fieldwork has been discussed with the appropriate safety/security advisors and approved by your Department/Faculty.</i>						
23. Does your research involve observing illegal activities or data processed or provided by authorities responsible for preventing, investigating, detecting or prosecuting criminal offences <i>If so please confirm that your work has been discussed with the appropriate legal advisors and approved by your Department/Faculty.</i>		x				
F: Research Methods						
24. Will it be necessary for participants to take part in the study without their knowledge and consent at the time? (e.g., covert observation of people in non-public places).		x				
25. Will the study involve actively deceiving the participants? (For example, will participants be deliberately falsely informed, will information be withheld from them or will they be misled in such a way that they are likely to object or show unease when debriefed about the study).		x				
26. Is pain or more than mild discomfort likely to result from the study? And/or could your research activity cause an accident involving (non-) participants?		x				
27. Will the experiment involve the use of devices that are not 'CE' certified? <i>Only, if 'yes': continue with the following questions:</i>		x				
• Was the device built in-house?						
• Was it inspected by a safety expert at TU Delft?						
<i>If yes, please provide a signed device report</i>						
• If it was not built in-house and not CE-certified, was it inspected by some other, qualified authority in safety and approved? <i>If yes, please provide records of the inspection</i>						
28. Will your research involve face-to-face encounters with your participants and if so how will you assess and address Covid considerations?	x		When performing physical research activities, such as interviews at the participants home, the chance exists that the Covid-guidelines will be violated (intentionally or not intentionally).	To mitigate the risk of violating the covid-guidelines, I make sure to be up-to-date on the covid-guidelines and will arrange the space in a way the chance can be mitigated, and I will inform the participants about the guidelines during the activity.		
29. Will your research involve either : a) "big data", combined datasets, new data-gathering or new data-merging techniques which might lead to re-identification of your participants and/or		x				

			If YES please complete the Risk Assessment and Mitigation Plan columns below.		Please provide the relevant reference #	
ISSUE	Yes	No	RISK ASSESSMENT – what risks could arise? <i>Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!</i>	MITIGATION PLAN – what mitigating steps will you take? <i>Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.</i>	DMP	ICF
b) artificial intelligence or algorithm training where, for example biased datasets could lead to biased outcomes?						
G: Data Processing and Privacy						
30. Will the research involve collecting, processing and/or storing any directly identifiable PII (Personally Identifiable Information) including name or email address that will be used for administrative purposes only? (eg: obtaining Informed Consent or disbursing remuneration)	x		The risk exists that this PII data will be unintentionally exposed during my research. This includes name, e-mail address, and profession of specialists, and name and e-mail address of participants (through a survey).	I will mitigate this risk by only collecting PII information necessary for my research, and I will anonymize all information immediately after collection. I will ask specialists for consent to use their name and profession within my Master Thesis.		
31. Will the research involve collecting, processing and/or storing any directly or indirectly identifiable PIRD (Personally Identifiable Research Data) including videos, pictures, IP address, gender, age etc and what other Personal Research Data (including personal or professional views) will you be collecting?	x		The risk exists that if not portrayed properly or with consent, I will share professional views of specialists that unintentionally leak or they do not want to be shared that might damage their reputation.	I will mitigate this risk by asking consent of professionals on the statements that I want to store and share within my Master Thesis.		
32. Will this research involve collecting data from the internet, social media and/or publicly available datasets which have been originally contributed by human participants	x		I will use data from public available online communities to (systemically) gather target group perspectives on discussions that are interesting for my project for exploratory purposes. The risk exist that, if not properly anonymized, I expose people's sensitive topics that point back to the person that has written them.	I will mitigate this risk by anonymizing all data that I collect from public available online communities To avoid mistakes in later stages of the project		
33. Will your research findings be published in one or more forms in the public domain, as e.g., Masters thesis, journal publication, conference presentation or wider public dissemination?	x		The Master's thesis will be published in the public domain. The risks exist that results / data described in my report may lead to exposing the participants PII.	I will mitigate this risk by anonymizing all data in my thesis.		
34. Will your research data be archived for re-use and/or teaching in an open, private or semi-open archive?		x				

H: More on Informed Consent and Data Management

NOTE: You can find guidance and templates for preparing your Informed Consent materials) [here](#)

Your research involves human participants as Research Subjects if you are recruiting them or actively involving or influencing, manipulating or directing them in any way in your research activities. This means you must seek informed consent and agree/ implement appropriate safeguards regardless of whether you are collecting any PIRD.

Where you are also collecting PIRD, and using Informed Consent as the legal basis for your research, you need to also make sure that your IC materials are clear on any related risks and the mitigating measures you will take – including through responsible data management.

Got a comment on this checklist or the HREC process? You can leave your comments [here](#)

IV. Signature/s

Please note that by signing this checklist list as the sole, or Responsible, researcher you are providing approval of the completeness and quality of the submission, as well as confirming alignment between GDPR, Data Management and Informed Consent requirements.

Name of Corresponding Researcher (if different from the Responsible Researcher) (print)

B.G.A. (Britt) van der Rijt

Signature of Corresponding Researcher:



Date: 27-03-2024

Name of Responsible Researcher (print)

Dr. Ir. J. Bourgeois

Signature (or upload consent by mail) Responsible Researcher:



Date: 27-03-2024

V. Completing your HREC application

Please use the following list to check that you have provided all relevant documentation

Required:

- **Always:** This completed HREC checklist
- **Always:** A data management plan (reviewed, where necessary, by a data-steward)

- **Usually:** A complete Informed Consent form (including Participant Information) and/or Opening Statement (for online consent)

Please also attach any of the following, if relevant to your research:

Document or approval	Contact/s
Full Research Ethics Application	After the assessment of your initial application HREC will let you know if and when you need to submit additional information
Signed, valid Device Report	Your Faculty HSE advisor
Ethics approval from an external Medical Committee	TU Delft Policy Advisor, Medical (Devices) Research
Ethics approval from an external Research Ethics Committee	Please append, if possible, with your submission
Approved Data Transfer or Data Processing Agreement	Your Faculty Data Steward and/or TU Delft Privacy Team
Approved Graduation Agreement	Your Master's thesis supervisor
Data Processing Impact Assessment (DPIA)	TU Delft Privacy Team
Other specific requirement	Please reference/explain in your checklist and append with your submission

Plan Overview

A Data Management Plan created using DMPonline

Title: Redefining Measurement: Exploring Shared Reality and Spatial Data for Psychological Well-Being Assessment - Exploration phase

Creator: Britt van der Rijt

Affiliation: Delft University of Technology

Template: TU Delft Data Management Plan template (2021)

Project abstract:

QoL and psychological well-being are commonly measured through qualitative and quantitative patient self-reports and hospital surveys. However, this method is subject to mood changes and is perceived to be cognitively demanding and hard to integrate into daily life. Additionally, measuring quantitatively through scales lacks contextualization. There is, therefore, a need to measure psychological well-being differently, in this case, in the context of (colorectal) cancer survivors.

In the exploration phase, I will perform research activities to understand more about communication-, conflict resolution-, and support patterns and styles, self-efficacy, and their (subjective) relationship with interpersonal distance. To be able to do this, I will ask participants, recruited through foundations or my network, to provide information related to their experiences and feelings. I will do this through an online anonymous survey (with a duration of c.a. 15 minutes) and interviews with couples ($n = 8$ (4 couples)) living together (with a duration of c.a. 40 minutes) and a specialist ($n = 1$) in the area of psychiatry and/or relationship therapy (with a duration of c.a. 30 minutes).

ID: 147993

Start date: 01-03-2024

End date: 30-09-2024

Last modified: 30-03-2024

Redefining Measurement: Exploring Shared Reality and Spatial Data for Psychological Well-Being Assessment - Exploration phase

0. Administrative questions

1. Name of data management support staff consulted during the preparation of this plan.

The data management plan is developed together with my graduation supervisors and is based on a plan that was earlier approved by my data steward Jeff Love

2. Date of consultation with support staff.

2024-03-28

1. Data description and collection or re-use of existing data

3. Provide a general description of the type of data you will be working with, including any re-used data:

Type of data	File format(s)	How will data be collected (for re-used data: source and terms of use)?	Purpose of processing	Storage location	Who will have access to the data
Qualitative interview data participants	.docx or .csv	Interview audio recording	Understanding couple communication and support in terms of cancer survivorship-related topics	TU Delft Project Drive Storage	Responsible researcher & supervisory team
Qualitative interview data specialists - professional view & experiences	.docx or .csv	Interview audio recording	Understanding professionals/specialists' views on couple communication and coping in terms of cancer survivorship-related topics and professional feedback/view on research methods	TU Delft Project Drive Storage	Responsible researcher & supervisory team
Anonymous Survey data participants - experiences	.csv	Survey	Understanding couple communication and support in terms of cancer survivorship-related topics	TU Delft Project Drive Storage & Google Drive	Responsible researcher & supervisory team
Online community data Kanker.nl	.csv	Internet	Systemically exploring cancer survivors and partner's perspectives and experiences	TU Delft Project Drive Storage	Responsible researcher & supervisory team
Name, e-mail address, profession - specialists	.csv	Survey or informed consent form	Contacting participants and specialists, and asking for informed consent	TU Delft Project Drive Storage	Responsible researcher
e-mail participants (optionally)	.csv	survey	Recruiting couples for participating in a follow-up interview / research. Participants can leave this information voluntarily	TU Delft Project Drive Storage	Responsible researcher
Name participants	.csv	Informed consent form	Asking for informed consent	TU Delft Project Drive Storage	Responsible researcher

B. DMP

4. How much data storage will you require during the project lifetime?

- < 250 GB

II. Documentation and data quality

5. What documentation will accompany data?

- Data dictionary explaining the variables used
- README file or other documentation explaining how data is organised
- Methodology of data collection

III. Storage and backup during research process

6. Where will the data (and code, if applicable) be stored and backed-up during the project lifetime?

- Another storage system - please explain below, including provided security measures
- OneDrive
- Project Storage at TU Delft

Google Drive - Survey data will be captured there initially. After enough input is gathered, all data is transferred to the project storage at TU Delft and removed from Google Drive.

IV. Legal and ethical requirements, codes of conduct

7. Does your research involve human subjects or 3rd party datasets collected from human participants?

- Yes

8A. Will you work with personal data? (information about an identified or identifiable natural person)

If you are not sure which option to select, first ask your [Faculty Data Steward](#) for advice. You can also check with the [privacy website](#). If you would like to contact the privacy team: privacy-tud@tudelft.nl, please bring your DMP.

- Yes

Name, profession, and e-mail address of specialists, e-mail address of participants (if they provide any) to recruit participants through an online survey

8B. Will you work with any other types of confidential or classified data or code as listed below? (tick all that apply)

If you are not sure which option to select, ask your [Faculty Data Steward](#) for advice.

- No, I will not work with any confidential or classified data/code

9. How will ownership of the data and intellectual property rights to the data be managed?

For projects involving commercially-sensitive research or research involving third parties, seek advice of your [Faculty Contract Manager](#) when answering this question. If this is not the case, you can use the example below.

The datasets underlying the published papers will be publicly released following the TU Delft Research Data Framework Policy. During the active phase of research, the project leader from TU Delft will oversee the access rights to data (and other outputs), as well as any requests for access from external parties. They will be released publicly no later than at the time of publication of corresponding research papers.

10. Which personal data will you process? Tick all that apply

- Other types of personal data - please explain below
- Email addresses and/or other addresses for digital communication
- Data collected in Informed Consent form (names and email addresses)
- Signed consent forms
- Name and profession of specialists

11. Please list the categories of data subjects

- Cancer-survivors (< 5 years in survivorship)
- partner's (living together with cancer-survivor) of cancer survivors
- Students
- Couples not cancer-related living together
- Specialists / doctors

12. Will you be sharing personal data with individuals/organisations outside of the EEA (European Economic Area)?

- No

15. What is the legal ground for personal data processing?

- Informed consent

16. Please describe the informed consent procedure you will follow:

All study participants will be asked for either written (interview) or digital (survey) consent for taking part in the study and for data processing before the start of any research activity.

17. Where will you store the signed consent forms?

- Same storage solutions as explained in question 6

18. Does the processing of the personal data result in a high risk to the data subjects?

If the processing of the personal data results in a high risk to the data subjects, it is required to perform [Data Protection Impact Assessment \(DPIA\)](#). In order to determine if there is a high risk for the data subjects, please check if any of the options below that are applicable to the processing of the personal data during your research (check all that apply).

If two or more of the options listed below apply, you will have to [complete the DPIA](#). Please get in touch with the privacy team: privacy-tud@tudelft.nl to receive support with DPIA.

If only one of the options listed below applies, your project might need a DPIA. Please get in touch with the privacy team: privacy-tud@tudelft.nl to get advice as to whether DPIA is necessary.

If you have any additional comments, please add them in the box below.

- Sensitive personal data
- Relational dynamics/well-being related to communication and support satisfaction and behavior
- Professional view of specialist related to communication and support in couples, and, research methodology

19. Did the privacy team advise you to perform a DPIA?

- No

I did not contact the DPIA

22. What will happen with personal research data after the end of the research project?

- Personal research data will be destroyed after the end of the research project
- Anonymised or aggregated data will be shared with others

23. How long will (pseudonymised) personal data be stored for?

- 10 years or more, in accordance with the TU Delft Research Data Framework Policy

24. What is the purpose of sharing personal data?

- For research purposes, which are in-line with the original research purpose for which data have been collected

25. Will your study participants be asked for their consent for data sharing?

- Yes, in consent form - please explain below what you will do with data from participants who did not consent to data sharing

If participants do not give consent to data sharing, the data will be removed from the data set and not explicitly mentioned within research outputs (i.e., thesis)

V. Data sharing and long-term preservation

27. Apart from personal data mentioned in question 22, will any other data be publicly shared?

- All other non-personal data (and code) underlying published articles / reports / theses
- All other non-personal data (and code) produced in the project

29. How will you share research data (and code), including the one mentioned in question 22?

- My data will be shared in a different way - please explain below

At the end of research, my data will be handed (not in a data repository) over to my supervisor, and co-owner, Dr. Ir. J. Bourgeois - assistant professor

30. How much of your data will be shared in a research data repository?

- < 100 GB

31. When will the data (or code) be shared?

- At the end of the research project

32. Under what licence will be the data/code released?

- CC BY

VI. Data management responsibilities and resources

33. Is TU Delft the lead institution for this project?

- Yes, the only institution involved

34. If you leave TU Delft (or are unavailable), who is going to be responsible for the data resulting from this project?

Dr. Ir. J. Bourgeois - Assistant Professor

35. What resources (for example financial and time) will be dedicated to data management and ensuring that data will be FAIR (Findable, Accessible, Interoperable, Re-usable)?

4TU.ResearchData can archive 1TB of data per researcher per year free of charge for all TU Delft researchers. We do not expect to exceed this and therefore there are no additional costs of long-term preservation.

f

Plan Overview

A Data Management Plan created using DMPonline

Title: Redefining Measurement: Exploring Shared Reality and Spatial Data for Psychological Well-Being Assessment - User Research Phase

Creator: Britt van der Rijt

Affiliation: Delft University of Technology

Template: TU Delft Data Management Plan template (2021)

Project abstract:

The second stage of my Master's graduation project includes performing remote research with a maximum of 10 romantic couples living together, with or without living in cancer survivorship.

- In this research activity, I will ask the participants to provide little information that characterizes their relationship and themselves, and how they deal with inside and outside stressors. This information will support me in analysis.
- In the second stage, I ask the participants to wear a sensor kit, that gathers quantitative data about social interaction and activity: sound, acceleration, location, and interpersonal distance using a sound and acceleration sensor, a GPS module, and RSSI.
- In the third stage, the data is initially analyzed and visualized. The data visualizations are then used to support an interview where I will discuss the data to gain contextual insight on the data and discuss couple-related social interactions concerning individual well-being.

ID: 153347

Start date: 01-03-2024

End date: 30-09-2024

Last modified: 05-06-2024

Redefining Measurement: Exploring Shared Reality and Spatial Data for Psychological Well-Being Assessment - User Research Phase

0. Administrative questions

1. Name of data management support staff consulted during the preparation of this plan.

The data management plan is developed together with my graduation supervisors and is based on a plan that was earlier approved by my data steward Jeff Love

2. Date of consultation with support staff.

2024-06-14

I. Data description and collection or re-use of existing data

3. Provide a general description of the type of data you will be working with, including any re-used data:

Type of data	File format(s)	How will data be collected (for re-used data: source and terms of use)?	Purpose of processing	Storage location	Who will have access to the data
Interview transcripts	.docx	Audio recorded interviews	Supporting analysis of user research & user research data contextualization	Project storage drive	Responsible researcher & supervisory team
Sound intensity, linear acceleration, RSSI, latitude & longitude	.csv	Wearable sensor kit	Understanding couple-related social activity & visualization for discussing the data within the final interview with the couple to contextualize the data	Project storage drive	Responsible researcher & supervisory team

4. How much data storage will you require during the project lifetime?

- < 250 GB

II. Documentation and data quality

5. What documentation will accompany data?

- Data dictionary explaining the variables used
- README file or other documentation explaining how data is organised
- Methodology of data collection

III. Storage and backup during research process

6. Where will the data (and code, if applicable) be stored and backed-up during the project lifetime?

- Project Storage at TU Delft
- OneDrive

IV. Legal and ethical requirements, codes of conduct

7. Does your research involve human subjects or 3rd party datasets collected from human participants?

- Yes
- Romantic couples living together with or without dealing with cancer survivorship

8A. Will you work with personal data? (information about an identified or identifiable natural person)

If you are not sure which option to select, first ask your [Faculty Data Steward](#) for advice. You can also check with the [privacy website](#). If you would like to contact the privacy team: privacy-tud@tudelft.nl, please bring your DMP.

- Yes
- Personal contact / recruitment: e-mail address, phone number & living location
- Informed consent: name
- Aggregation of sensor kit data: location (latitude & longitude)

8B. Will you work with any other types of confidential or classified data or code as listed below? (tick all that apply)

If you are not sure which option to select, ask your [Faculty Data Steward](#) for advice.

- No, I will not work with any confidential or classified data/code

9. How will ownership of the data and intellectual property rights to the data be managed?

For projects involving commercially-sensitive research or research involving third parties, seek advice of your [Faculty Contract Manager](#) when answering this question. If this is not the case, you can use the example below.

The datasets underlying the published papers will be publicly released following the TU Delft Research Data Framework Policy. During the active phase of research, the project leader from TU Delft will oversee the access rights to data (and other outputs), as well as any requests for access from external parties. They will be released publicly no later than at the time of publication of corresponding research papers.

10. Which personal data will you process? Tick all that apply

- Data collected in Informed Consent form (names and email addresses)
- Signed consent forms

- Email addresses and/or other addresses for digital communication
- Telephone numbers

11. Please list the categories of data subjects

- Romantic couples living together with or without dealing with cancer-survivorship less than 5 years after cancer treatment
 - Between 55 and 75 years old
- Myself and my partner as part of self-experimentation

12. Will you be sharing personal data with individuals/organisations outside of the EEA (European Economic Area)?

- No

15. What is the legal ground for personal data processing?

- Informed consent

16. Please describe the informed consent procedure you will follow:

All study participants will be asked for their written consent for taking part in the study and for data processing before the start of the interview.

17. Where will you store the signed consent forms?

- Same storage solutions as explained in question 6

18. Does the processing of the personal data result in a high risk to the data subjects?

If the processing of the personal data results in a high risk to the data subjects, it is required to perform [Data Protection Impact Assessment \(DPIA\)](#). In order to determine if there is a high risk for the data subjects, please check if any of the options below that are applicable to the processing of the personal data during your research (check all that apply).

If two or more of the options listed below apply, you will have to [complete the DPIA](#). Please get in touch with the privacy team: privacy-tud@tudelft.nl to receive support with DPIA.

If only one of the options listed below applies, your project might need a DPIA. Please get in touch with the privacy team: privacy-tud@tudelft.nl to get advice as to whether DPIA is necessary.

If you have any additional comments, please add them in the box below.

- Data concerning vulnerable data subjects

If the subjects do live within cancer survivorship, there is a chance that they experience mental and physical symptoms that might affect their vulnerability.

19. Did the privacy team advise you to perform a DPIA?

- No

22. What will happen with personal research data after the end of the research project?

- Personal research data will be destroyed after the end of the research project
- Anonymised or aggregated data will be shared with others

23. How long will (pseudonymised) personal data be stored for?

- 10 years or more, in accordance with the TU Delft Research Data Framework Policy

24. What is the purpose of sharing personal data?

- For research purposes, which are in-line with the original research purpose for which data have been collected

25. Will your study participants be asked for their consent for data sharing?

- Yes, in consent form - please explain below what you will do with data from participants who did not consent to data sharing

The data from participants who did not give consent for data sharing will be removed from the dataset before sharing.

V. Data sharing and long-term preservation

27. Apart from personal data mentioned in question 22, will any other data be publicly shared?

- All other non-personal data (and code) underlying published articles / reports / theses
- All other non-personal data (and code) produced in the project

29. How will you share research data (and code), including the one mentioned in question 22?

- My data will be shared in a different way - please explain below

At the end of research, my data will be handed (not in a data repository) over to my supervisor, and co-owner, Dr. Ir. J. Bourgeois - assistant professor

30. How much of your data will be shared in a research data repository?

- < 100 GB

31. When will the data (or code) be shared?

- At the end of the research project

32. Under what licence will be the data/code released?

- CC BY

VI. Data management responsibilities and resources

33. Is TU Delft the lead institution for this project?

- Yes, the only institution involved

34. If you leave TU Delft (or are unavailable), who is going to be responsible for the data resulting from this project?

Dr. Ir. J. Bourgeois - Assistant Professor

35. What resources (for example financial and time) will be dedicated to data management and ensuring that data will be FAIR (Findable, Accessible, Interoperable, Re-usable)?

None

8

L. CR29 Questionnaire

ENGLISH



EORTC QLQ – CR29

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
31. Did you urinate frequently during the day?	1	2	3	4
32. Did you urinate frequently during the night?	1	2	3	4
33. Have you had any unintentional release (leakage) of urine?	1	2	3	4
34. Did you have pain when you urinated?	1	2	3	4
35. Did you have abdominal pain?	1	2	3	4
36. Did you have pain in your buttocks/anal area/rectum?	1	2	3	4
37. Did you have a bloated feeling in your abdomen?	1	2	3	4
38. Have you had blood in your stools?	1	2	3	4
39. Have you had mucus in your stools?	1	2	3	4
40. Did you have a dry mouth?	1	2	3	4
41. Have you lost hair as a result of your treatment?	1	2	3	4
42. Have you had problems with your sense of taste?	1	2	3	4

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
43. Were you worried about your health in the future?	1	2	3	4
44. Have you worried about your weight?	1	2	3	4
45. Have you felt physically less attractive as a result of your disease or treatment?	1	2	3	4
46. Have you been feeling less feminine/masculine as a result of your disease or treatment?	1	2	3	4
47. Have you been dissatisfied with your body?	1	2	3	4
48. Do you have a stoma bag (colostomy/ileostomy)? (please circle the correct answer)	Yes		No	

Please go on to the next page

During the past week:

Not at All A Little Quite a Bit Very Much

Answer these questions ONLY IF YOU HAVE A STOMA BAG, if not please continue below:

49. Have you had unintentional release of gas/flatulence from your stoma bag?	1	2	3	4
50. Have you had leakage of stools from your stoma bag?	1	2	3	4
51. Have you had sore skin around your stoma?	1	2	3	4
52. Did frequent bag changes occur during the day?	1	2	3	4
53. Did frequent bag changes occur during the night?	1	2	3	4
54. Did you feel embarrassed because of your stoma?	1	2	3	4
55. Did you have problems caring for your stoma?	1	2	3	4

Answer these questions ONLY IF YOU DO NOT HAVE A STOMA BAG:

49. Have you had unintentional release of gas/flatulence from your back passage?	1	2	3	4
50. Have you had leakage of stools from your back passage?	1	2	3	4
51. Have you had sore skin around your anal area?	1	2	3	4
52. Did frequent bowel movements occur during the day?	1	2	3	4
53. Did frequent bowel movements occur during the night?	1	2	3	4
54. Did you feel embarrassed because of your bowel movement?	1	2	3	4

During the past 4 weeks:

Not at All A Little Quite a Bit Very Much

For men only:

56. To what extent were you interested in sex?	1	2	3	4
57. Did you have difficulty getting or maintaining an erection?	1	2	3	4

For women only:

58. To what extent were you interested in sex?	1	2	3	4
59. Did you have pain or discomfort during intercourse?	1	2	3	4