



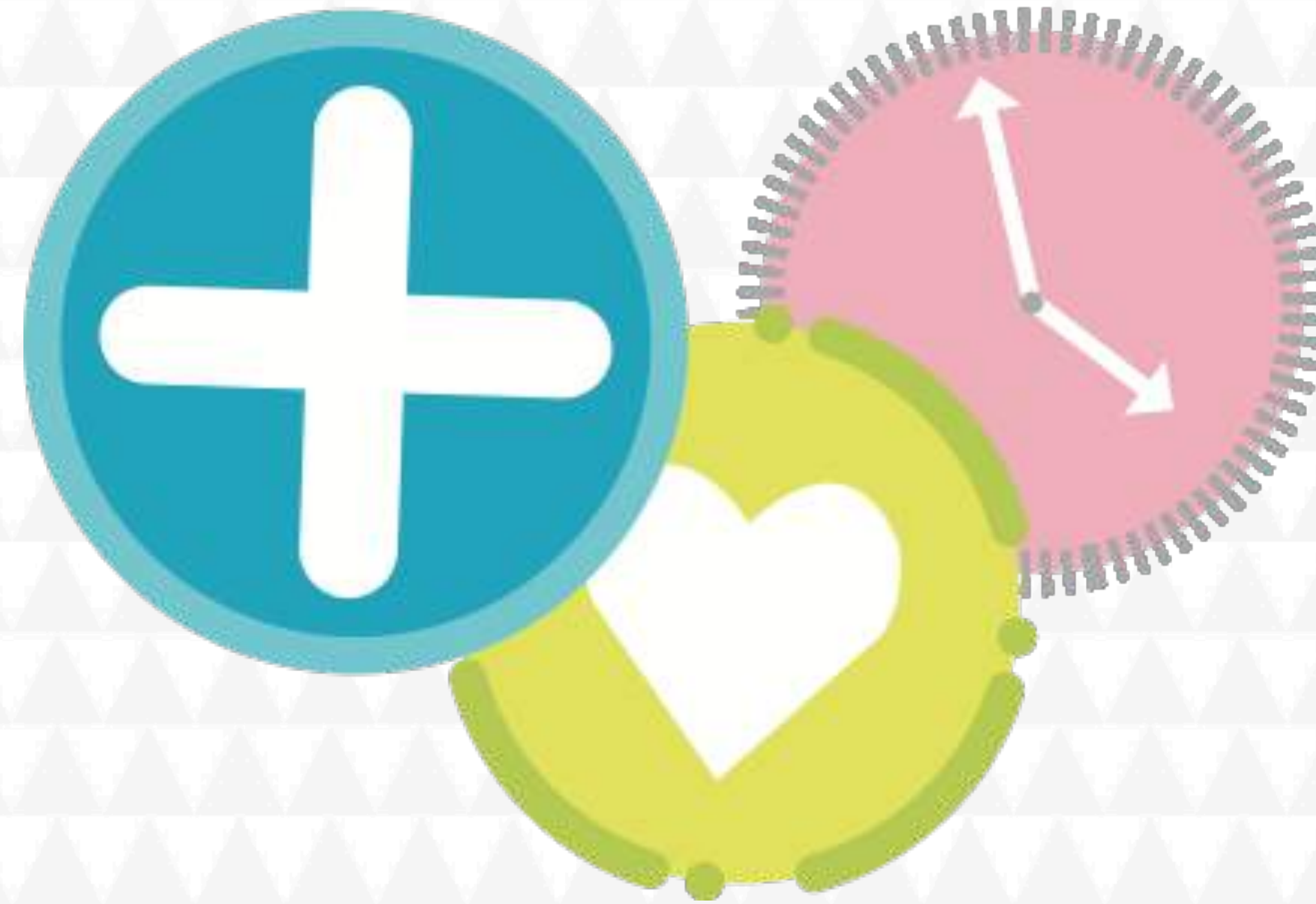
How is the Caregiver Doing?

Capturing Caregivers' Experiences with a Reflective Toolkit

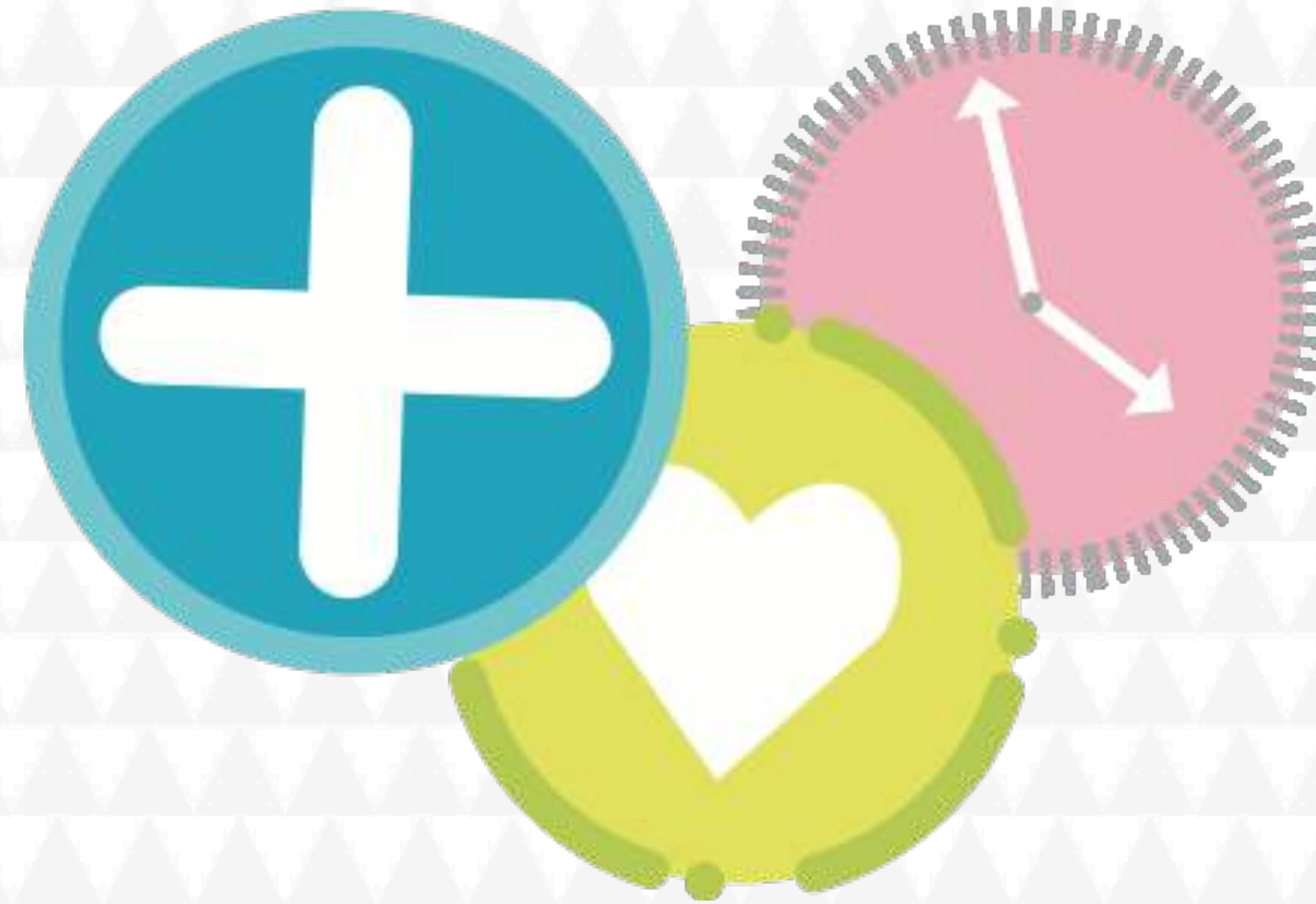
¹ Lilian Bosch, ¹ dr Marije Kanis, ^{1,2} Julia Dunn, ² dr Kearsley Stewart & ² dr Ben Kröse

The informal caregiver





**From managing care to
designing for well-being**



**From managing care to
designing for well-being**

How is the caregiver doing?

The National Alliance for Caregiving stated (2013)

*“There is an ongoing **need for research on family caregivers**, especially as technology dramatically impacts caregiving. More current, thorough and accurate data is needed about the diversity of caregiver roles and responsibilities, about **what caregiving involves day-to-day** and the nature of the burden it represents, and how much it impacts those around the caregiver.”*

Co-Care-KIT



**Reflective Toolkit for
informal caregivers**



What's in the box?

1. Custom designed Journal



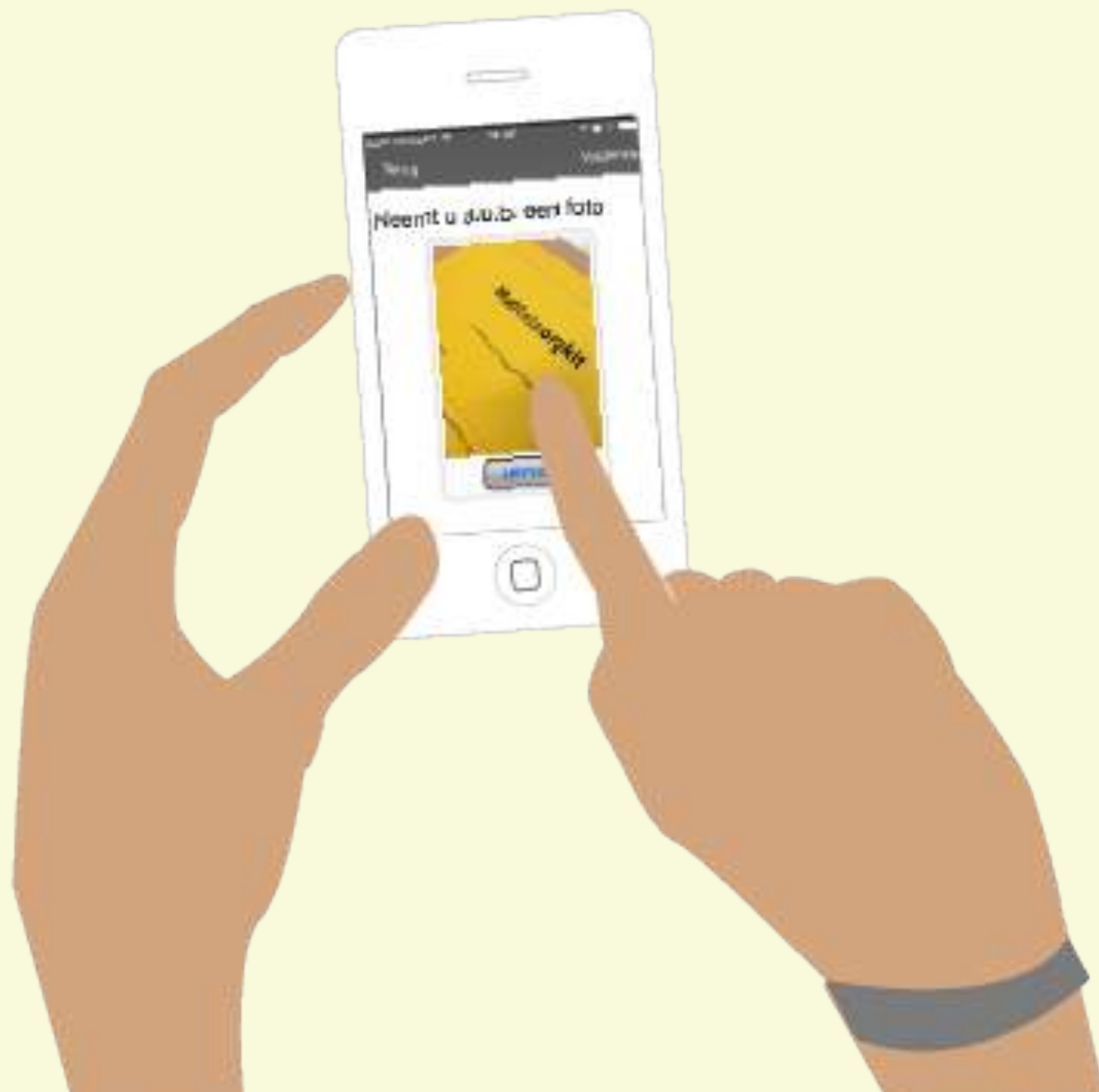
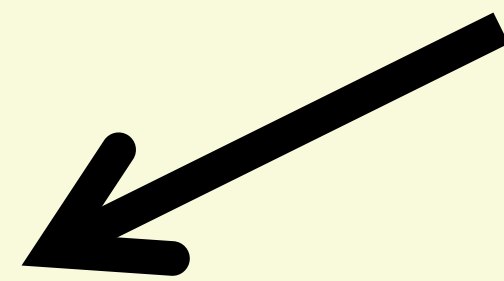
2. Photo based experience sampling app



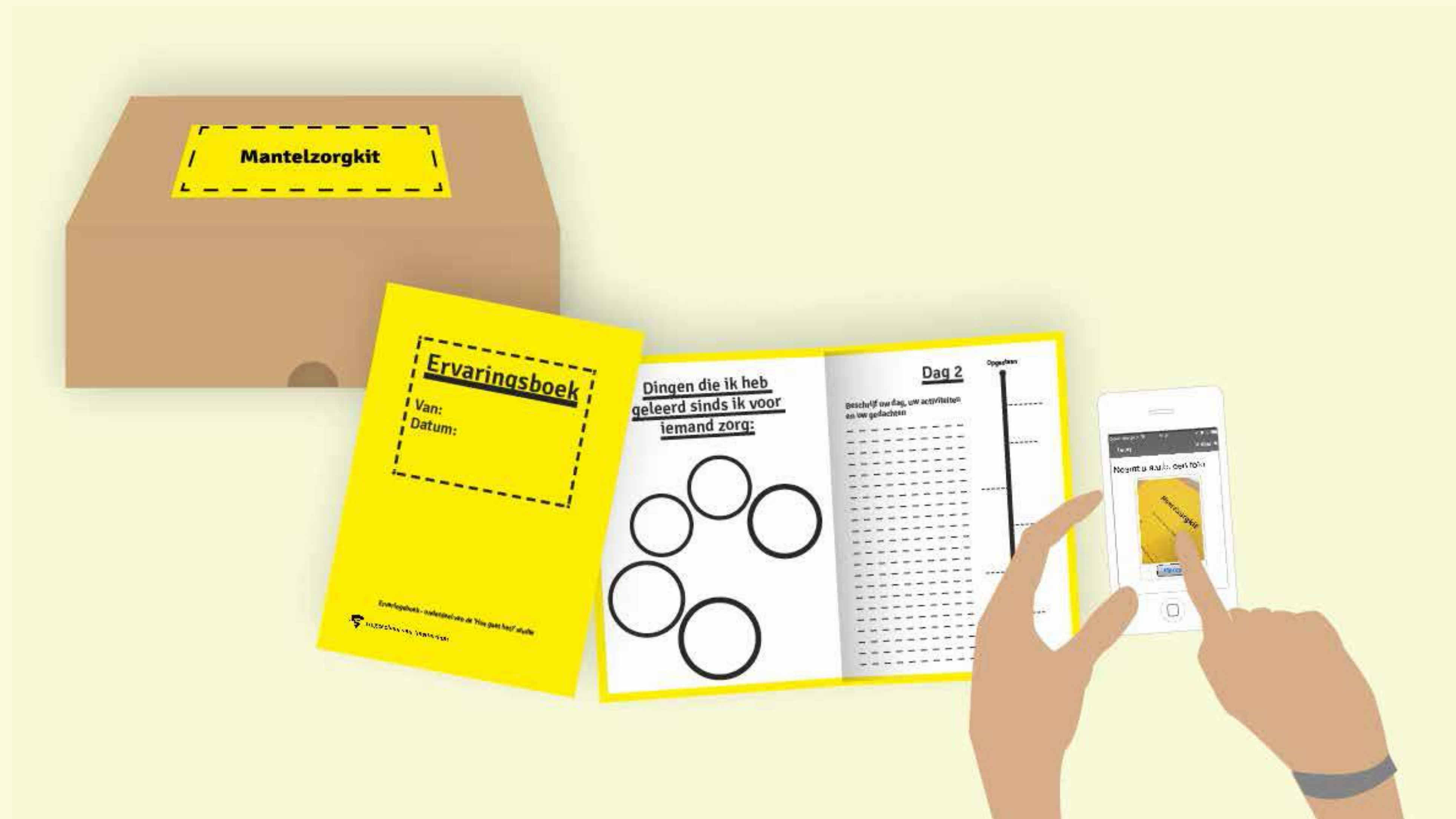
3. Heart Rate tracker



wearable on wrist



Field study with informal caregivers

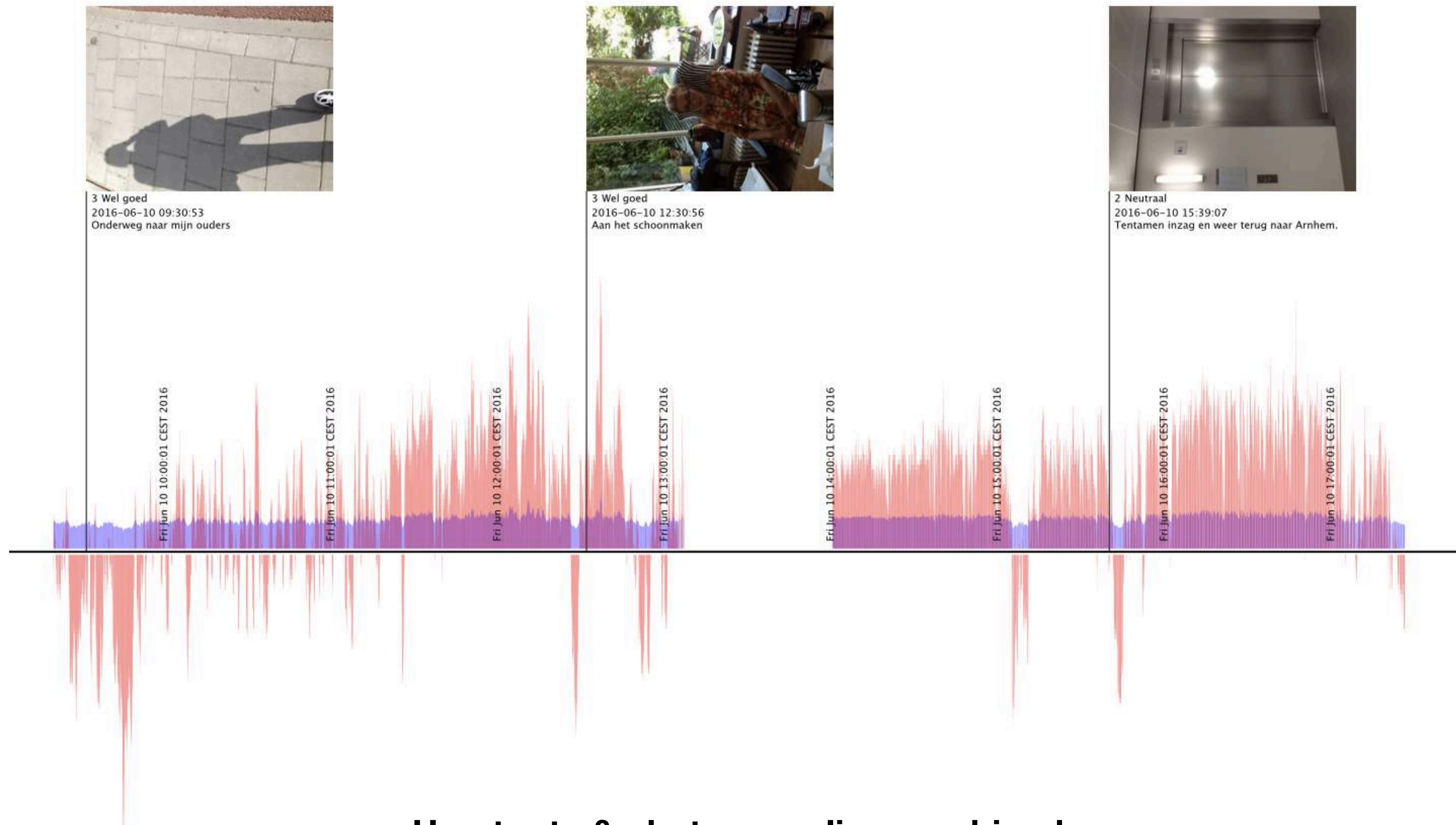


Study population and collected data

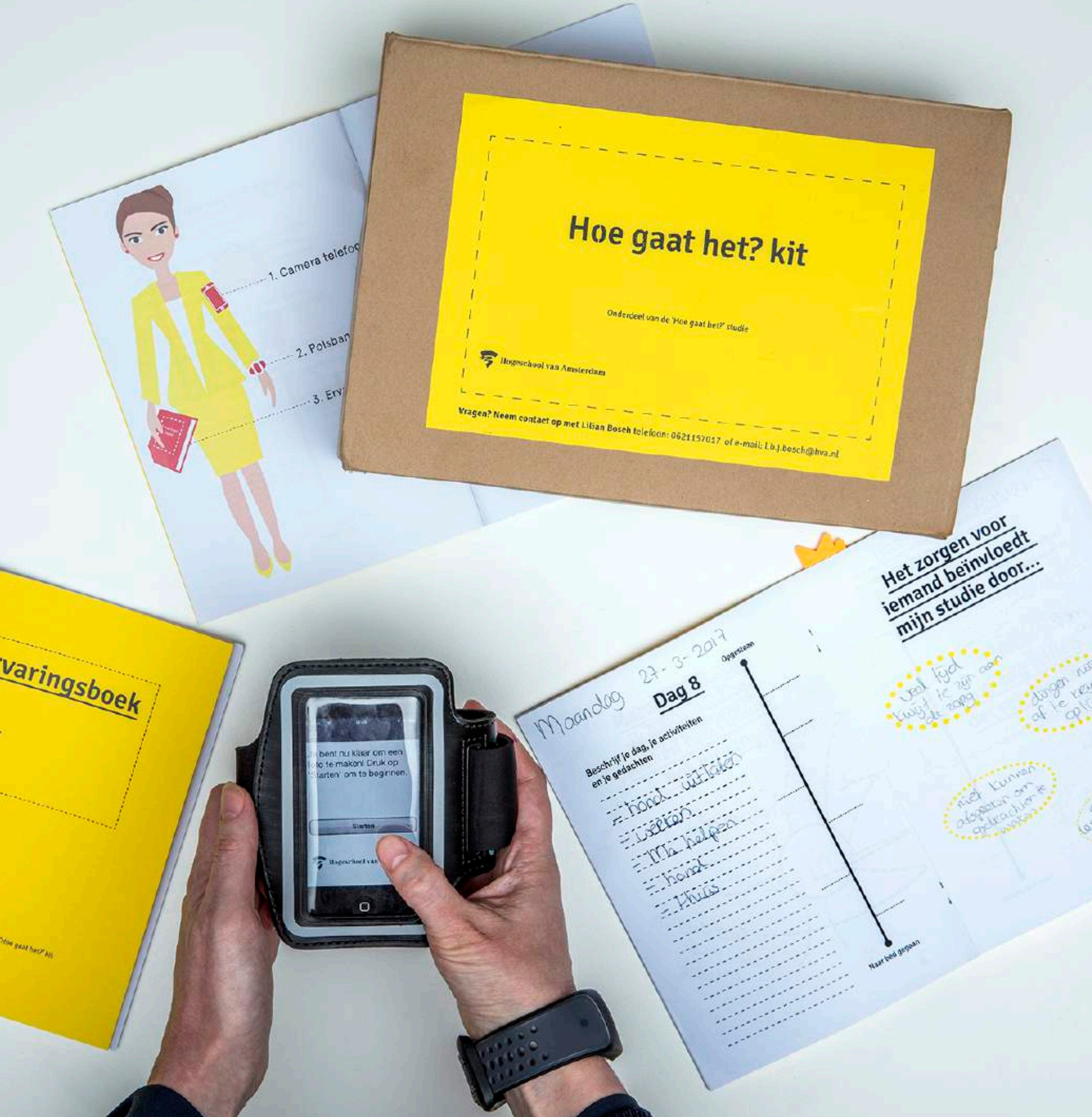


Participant	Gender	Age	Health concern(s) of care recipient	Relation to care recipient(s)	Hours spent caregiving per week	Duration of field study (days)	Photos collected	Heart rate tracking (days)	Journal kept
P1	M	63	Dementia, osteoporosis and visual impairment	Son/ son in law	3-8	8	30	7	Yes
P2	F	36	Stroke, stroke paralysis	Daughter	8-16	14	32	1	Yes
P3	F	35	Spinal cord injury	Neighbor	<3	14	30	11	Yes
P4	F	57	Dementia, osteoporosis	Daughter	8-16	11	42	3	Yes
P5	F	23	Amyotrophic Lateral Sclerosis (ALS)	Daughter	3-8	12	17	1	Yes
P6	F	22	Old Age, frailty	Grand- daughter	8-16	7	25	3	Yes
P7	F	26	Chronic pain	Daughter	8-16	14	23	5	Yes

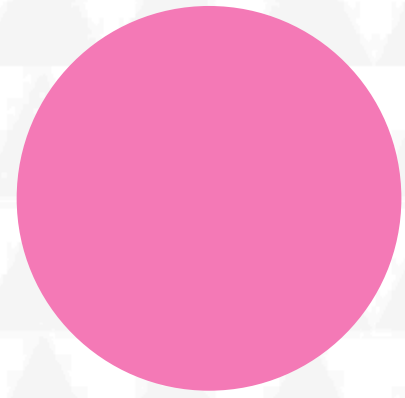
Collaborative reflection between researcher and caregiver



Heart rate & photo sampling combined

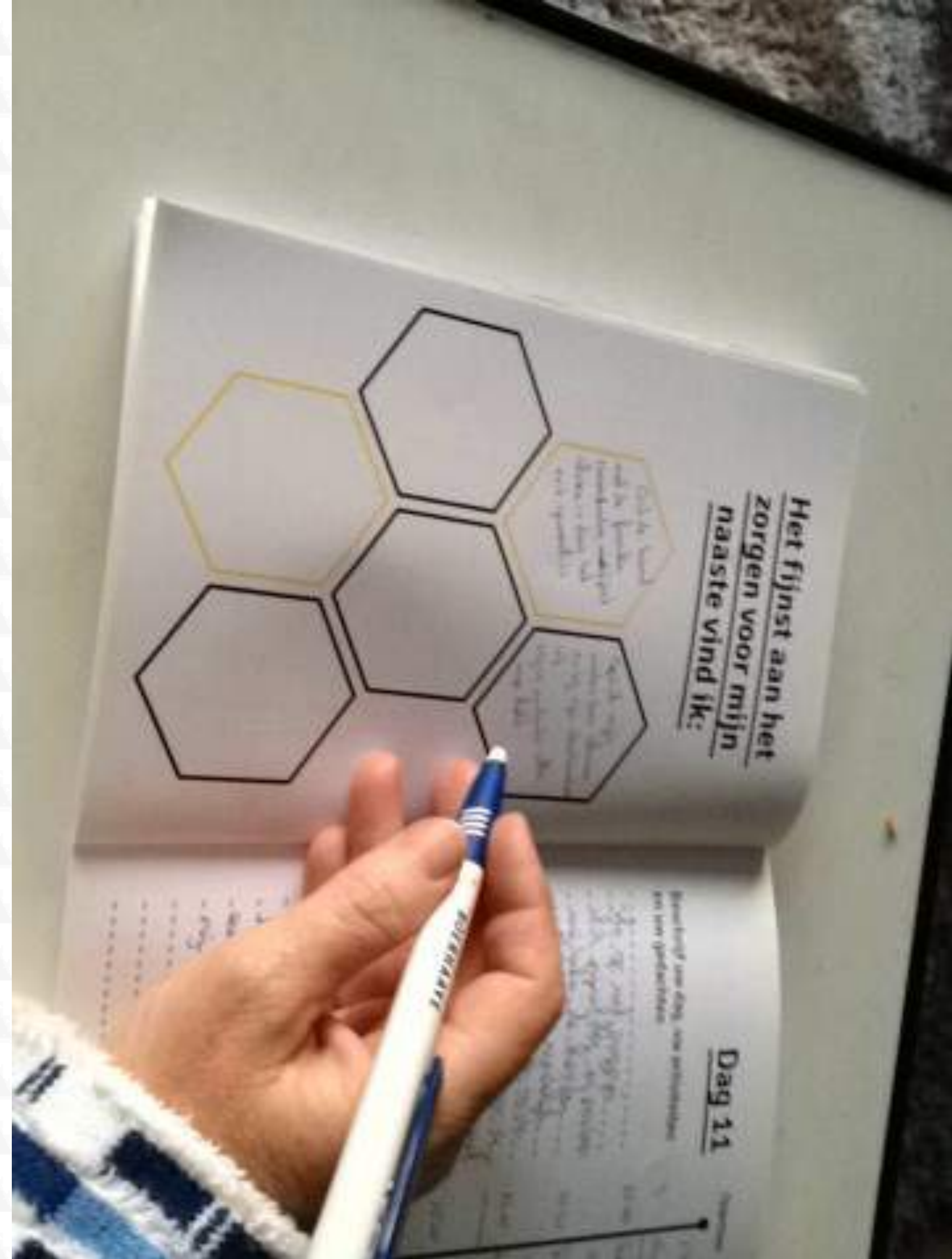


Outcomes?



People generally liked the kit

"I liked the journal a lot. It made me realize what happens and who are important to me. Writing down my days made me realize how much I accomplish in a day."





Enabled reflection on day-to-day needs and experiences



“She knows everyone, including me, has a lot on our plates, so when I take my time with her and don’t rush her through the store she is really appreciative and that makes me feel good about it.”



2

**Increased caregivers' awareness
of their own well-being**

*"From the kit I learned that
I spend WAY more time
caregiving than I thought".*

...

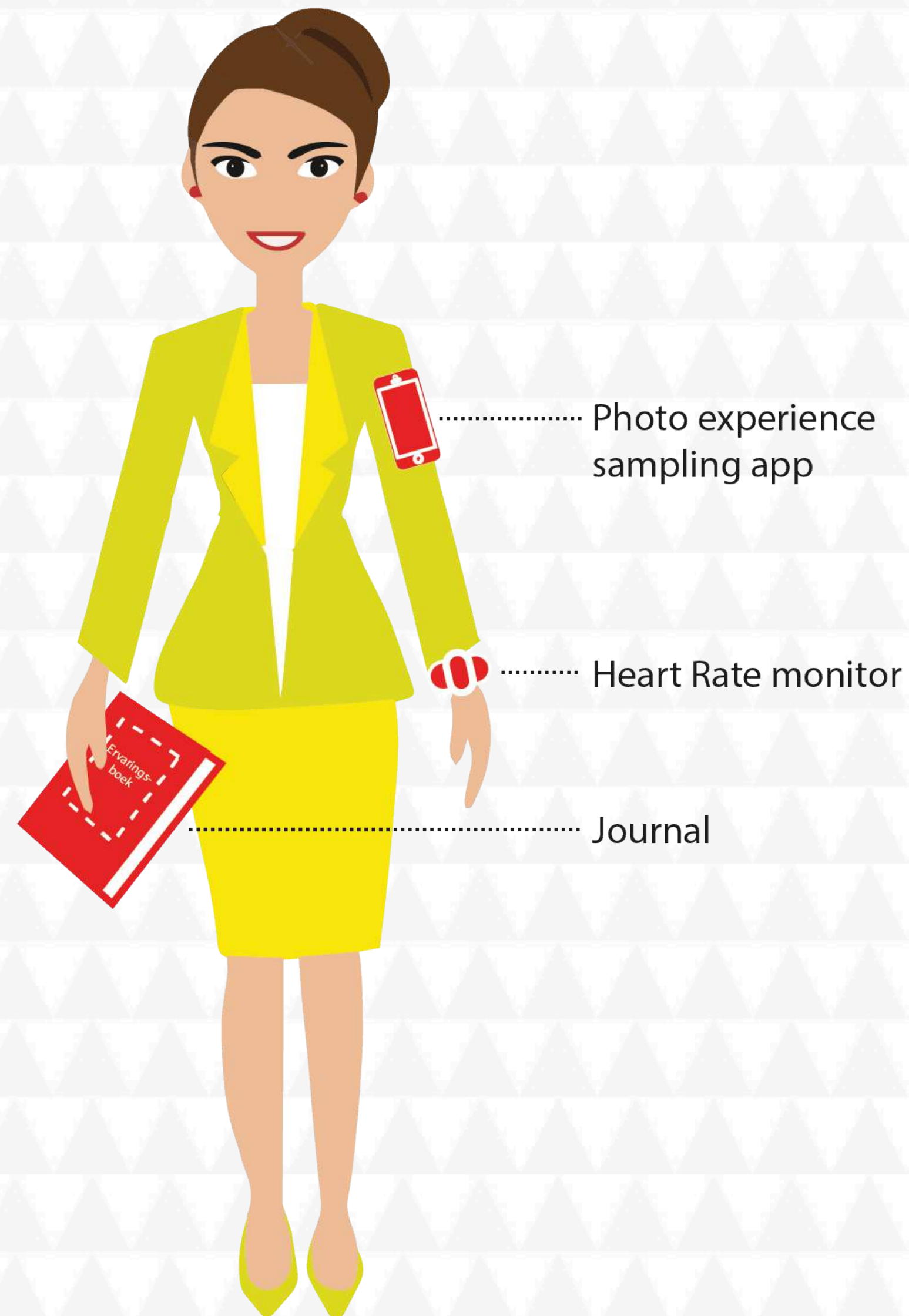
*"I am going to push harder
to get more formal help."*





3

**Empowered caregivers to share
their role and experiences within
their social networks**



“I’m never very explicit about being a caregiver, but I noticed that when I was doing this study, that people automatically asked me about it. Because I was taking photos and wearing the heart rate wristband.”

They said: “Oh, I didn’t even know that you were a caregiver”. It felt good to be able to tell them, to be honest.”



Enabled capturing positive experiences

"The kit helped to focus more on the positive, instead of thinking about the practical things you did that day (e.g. cleaning), you remember the feeling you had better."





5

**Provided reassurance about
their own mental health**



“From the photos I learned that I like where I am and I like what I do, during caregiving.”

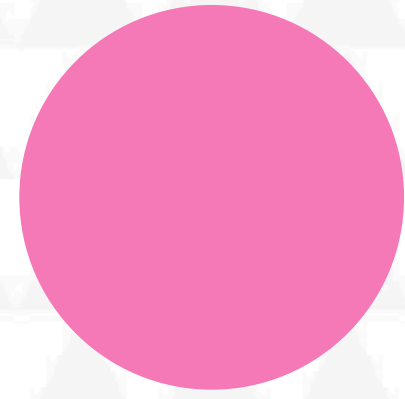
dr MARIJE KANIS

HCI for positive impact

Contact: m.kanis@hva.nl

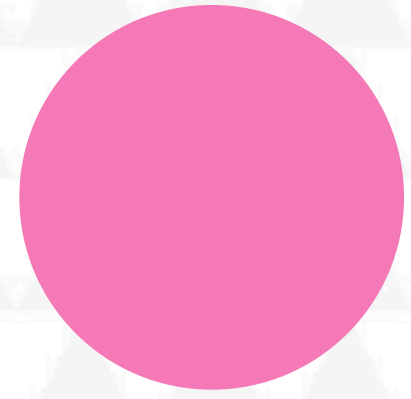
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Lilian Bosch, Marije Kanis, Julia Dunn, Kearsley Stewart & Ben Kröse
Amsterdam University of Applied Sciences | Duke University



The Co-Care-KIT...

- enabled reflection on day-to-day needs and experiences
- increased caregivers' awareness of their own well-being
- empowered caregivers to share their role and experiences within their social networks
- enabled capturing positive experiences
- provided reassurance about their own mental health



Dynamic conditions affecting caregivers' well-being

- How the care recipient is doing
- Uncertainties and unawareness
- Increased responsibility
- Talking about the care role and responsibilities to others