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Koops van 't Jagt, Ruth

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General Discussion

‘Learning is a process where knowledge is presented to us, then shaped through understanding, discussion and reflection.’

Paulo Freire
Limited health literacy is associated with poorer comprehension of health documents (e.g. Bostock & Steptoe, 2012; Morrow et al., 2006; Wolf, Gazmarian, & Baker, 2005). In addition, people with limited health literacy experience more difficulties in healthcare interactions (e.g. Henselmans et al., 2015). It is therefore widely recognized that it is important to improve health communication to support people with limited health literacy. This thesis reports on our quest to achieve such improved health-related communication, integrating methods to support the comprehension of health information materials aimed at people with limited health literacy (‘health-related documents’) and methods to support their communication with healthcare professionals. Because of the relatively high prevalence of low health literacy in older adults and its serious consequences for them, three of our five studies focused on older adults.

The objectives of this thesis were (1) to explore effective features and formats of health-related documents, (2) to gain insight into important health literacy domains to be included in health-related documents which aim to support communication, and (3) to study the effectiveness of such an evidence-based intervention. Throughout this thesis, these objectives were linked to different steps in information processing: paying attention to the message (attention), being motivated to process the message (motivation), comprehension of the message (comprehension) and accepting the message, resulting in cognitive and behavioural change (action) (e.g. McGuire, 1972; McGuire, 1985; McGuire, 2001). In line with the findings in Chapter 2, we adopted a special focus on narratives and photo stories, as these formats have increasingly been associated with benefits in health communication (e.g. Hinyard & Kreuter, 2007; Shen, Sheer, & Li, 2015; De Graaf, Sanders, & Hoeken, 2016). This chapter first briefly outlines the main findings in response to each research question formulated in the Introduction. We then discuss our findings according to the four steps of information processing. Finally, we discuss the strengths and limitations of our mixed-methods approach and formulate implications for research and practice.

Main findings

This thesis explored several ways to improve health communication to support people with limited health literacy, with a special focus on older adults. The main findings for each research question formulated in the Introduction are summarized below.

**Research question 1 (Chapter 2): which formats and features of health-related documents contribute to enhanced comprehensibility for older adults with different health literacy levels?**
The findings of the 38 studies included in our systematic review of comprehensibility of health-related documents for older adults with different health literacy levels show that there was supporting evidence, though no more than weak to moderate, only for narratives and multiple-feature revisions (e.g. combining revisions in textual and visual characteristics). Regarding most types of interventions, such as adding pictures or simplifying language, we found either inconsistent or inconclusive evidence that these design features increase comprehensibility. Using multiple-feature revisions of health-related documents, especially in a narrative format, thus seems to be the most promising strategy for enhancing the comprehensibility of health-related documents for older adults.

The heterogeneity in terms of operationalization of most of the studies we found impairs the generalizability of our findings and the strength of the evidence. We therefore stressed the importance of (a) using standardized research methodologies (e.g., standardized and sensitive measures of comprehension) and (b) conducting replications in intervention studies on health-related documents.

**Research question 2 (Chapter 3): to what extent are photo stories an effective health communication intervention for people with different health literacy levels?**

We conducted a randomized controlled trial (RCT) comparing a Dutch translation of an existing American photo story about diabetes (‘Sweet Temptations’) with a traditional brochure and a control condition (no brochure) among Dutch adults with lower and higher literacy levels. The results of our RCT showed that the photo story intervention led to higher levels of diabetes knowledge than the traditional brochure and the control condition, regardless of literacy level. No differences in behavioural intentions were found between the readers of the photo story and readers of the traditional brochure and the control group. The photo story readers who reported higher transportation levels also reported significantly higher levels of intention to talk to a doctor or pharmacist. Overall, the participants’ remarks, and the frequency of requests to take the photo story home to show it to relatives, suggest that participants with low literacy had particularly positive opinions about the photo story.

**Research question 3 (Chapter 4): how can we develop an effective narrative health communication intervention to support or increase older adults’ communicative health literacy?**

We performed a multi-stage formative evaluation which included 1) a literature review and 2) stakeholder interviews on relevant health literacy issues, 3) multiple
qualitative studies with the older adult target group, 4) intervention planning, and 5) a small-scale qualitative pilot test. We found that doctor-patient communication is an important health literacy domain for older adults. After this, we conducted Focus Group Discussions and Role Play Exercises in Hungary and the Netherlands to identify older adults’ most important barriers, facilitators and successful solutions and strategies to achieve active participation. The results of the Focus Group Discussions and Role Play Exercises showed that older adults' barriers to communicative health literacy (e.g. communicative aspects of health literacy) include (a) contextual factors such as the doctor’s availability, (b) patient-related factors such as stress, emotions and insufficient self-efficacy, (c) doctor-related factors such as providing incomprehensible or overwhelming information, and (d) interactional factors such as absence of mutual trust and asymmetry in expertise and knowledge.

We then developed a booklet with seven short photo stories incorporating principles from narrative and social learning theory. We tried to cover communication barriers on the one hand and strategies to overcome these barriers on the other. We had identified these strategies during focus group discussions and role play exercises. The photo stories explicitly addressed negative thoughts regarding communicative ability which can obstruct individuals with lower health literacy in their interactions with health professionals, and showed how to handle these problems to improve older patients’ awareness, communicative self-efficacy, and intentions. In a small-scale qualitative pilot test older adults considered the co-created photo story intervention as appealing and comprehensible.

Research question 4 (Chapter 5): to what extent do photo stories and non-narrative health communication formats differ in effectiveness and appreciation for older adults?
We evaluated the effectiveness and appreciation of our photo story booklet in three studies. We compared the photo story booklet in each of these studies to a non-narrative booklet which we had also developed and which was based on the same content as the photo story booklet. We conducted two RCTs, one in Germany and one in the Netherlands. The primary outcomes for both RCTs included self-efficacy, behavioural intentions and appreciation. The third study was an interview study which explored preferences for one of the two booklets and assessed the reasons for these preferences among a subset of the Dutch RCT participants. No significant quantitative differences in effectiveness or appreciation between the photo story booklet and the non-narrative booklet were found in the RCTs. However, the majority of participants in the interview study reported that they preferred the photo
story booklet over the non-narrative booklet, and that they had perceived the photo stories as recognizable, relevant, entertaining and engaging.

**Research question 5 (Chapter 6): to what extent do photo stories and non-narrative health communication formats differ in patients' uptake and preference within a natural setting, e.g. primary care practice waiting rooms?**

We compared the appeal of a photo story intervention, a non-narrative booklet which we also developed based on the same content as the photo story intervention, and an existing brochure on the topic of doctor-patient communication through a field experiment. Copies of the photo story booklet and the two brochures were randomly distributed in the waiting rooms of three participating primary care practices in the Netherlands. No statistically significant differences were found for observed and reported reading and pick-up rates. However, patients reported having noticed the photo story booklet significantly more often than the two brochures. These outcomes suggest that an innovative health communication format such as a photo story booklet can increase the chances that the material is noticed, but that this does not automatically mean that people will also pick it up and read it or take it home.

**Discussion of main findings**

In this thesis we explored multiple ways to improve health-related documents to support health communication for people with limited health literacy. We started our search by identifying four different information processing steps (based on McGuire 1972; 1985; 2001) which should be taken into account when developing and evaluating health communication materials: attention, motivation, comprehension and action (see Figure 1). From these different information processing steps we deduced the prerequisites for effective health communication messages in the Introduction. To be effective, health communication should: 1) increase the likelihood that the intended target group notices the health communication message (attention), 2) motivate the target group to process the health communication message (motivation), 3) support the target group in comprehending the message (comprehension), and 4) cause cognitive and behavioural change, by having an impact on knowledge, attitude, norms and behaviour (action). Below, we integrate our main findings regarding these four prerequisites. Attention and motivation to process are of course separate phases, but in view of their conceptual relationship we discuss them together. In Chapter 6 we studied the extent to which three different types of health-related documents were noticed (attention) and picked up for browsing or taken home (motivation). In Chapter 5 we approached motivation by assessing preferences for one of two types of documents and by analysing explanations for such preferences.
In Chapter 2 we studied comprehension by focusing on the comprehensibility of health-related documents. Furthermore, we assumed that higher levels of diabetes knowledge in Chapter 3 would also be indicative that the health-related documents studied had a positive impact on comprehension. We also analysed participant responses in Chapters 5 and 6 for explanations related to comprehension. Finally, we included possible and perceived cognitive and behavioural changes (action) in all the Chapters, by assessing the impact of health-related documents on comprehension and knowledge (Chapters 2 and 3), intentions (Chapters 4 and 5), self-efficacy (Chapter 5) and by analysing participant responses according to this step (Chapters 5 and 6).

Most of the studies in this thesis focused on older adults with limited health literacy or on people with limited health literacy in general, and paid special attention to narratives and photo stories. However, we addressed the four prerequisites mentioned above within a broader context of health-related documents, in order to improve the value of our findings for health communication researchers and practitioners in general.

**FIGURE 1.** Consecutive steps of information processing that are the starting point of this thesis and the trajectory of developing and evaluating health communication interventions.
How can health-related documents increase the likelihood that people pay attention to them and are motivated to process the messages they include?

We measured ‘preference’ in the evaluation study (Chapter 5) and conducted a field experiment in primary care practice waiting rooms (Chapter 6), because we acknowledged that for health communication messages to be effective, paying attention is a necessary and first condition, followed by motivation (McGuire, 1972; McGuire, 1985; McGuire, 2001). Insight into factors which can increase attention and motivation helps in designing health communication documents which the target groups notice and find appealing enough to pick up and commit effort into processing.

We found that most ‘older-old’ participants (>76 years, see Chapter 5) preferred the photo stories and that people in waiting rooms noticed the photo story booklet more often than the non-narrative brochure we developed (the ‘non-narrative booklet’) and also more often than an existing non-narrative brochure (‘existing brochure’) (Chapter 6). This suggests that narrative health communication formats can have some advantages over non-narrative and more traditional health communication formats regarding attention and motivation, as previously reported in the literature (e.g. Hinyard & Kreuter, 2007). Several older-old participants (Chapter 5) supported their preference for the photo stories by reference to the recognizability of the stories, which could suggest that these made them feel more involved and thus increased their motivation to process the materials. However, materials being noticed more often does not automatically mean that people are also read them or take them home, as we did not find any differences in observed and reported pick-up and browsing rates between the photo story booklet, the non-narrative booklet and the existing brochure in the same study. However, the waiting room setting may also have imposed some specific constraints on the motivation to process the materials, as many participants were busy reportedly with other activities, such as looking at their smart phones, or did not want to take the trouble of taking away one of the brochures, because they found the waiting room too busy or had to get past other people.

Evidently, the strong preference for the photo story intervention expressed by the participants interviewed (in Chapter 5) does not correspond with actual behaviour in a natural setting (in Chapter 6). For one thing, this could be due to the fact that the study in Chapter 5 was conducted among older-old participants, who were the original target group for the intervention, while the study in Chapter 6 was conducted among participants with a wider age range. These different outcomes might also reflect the often-observed gap between self-reported preferences and behavioural...
intentions on the one hand, and actual behaviour on the other. This gap is confirmed in Sheeran’s review of intention-behaviour relationships (2002). How intentions translate into behaviour is made explicit in models such as Fishbein and Yzer’s Integrated Model of Behavioural Prediction (2003) and Schwarzer’s Health Action Process Approach (2008). Our findings underline the value of conducting health communication research in real-life settings, as this evidently adds to the ecological validity of the findings (Kreps, 2001): the extent to which research ‘reflects what people do in the contexts in which their behaviour normally occurs’ (Frey, Botan, & Kreps, 2000, p. 133).

The interviews we conducted in the field experiment (Chapter 6) suggest that health communication material can easily be overlooked or may not be ‘within reach’ and that, at least today in the Netherlands, many patients may be spending their waiting time doing other activities, such as looking at their smart phones. Waiting rooms may thus be considerably less promising an opportunity for health communication interventions than suggested by, for instance, Moerenhout et al., 2013; Cass, Ball, & Leveritt, 2016. Taken together, this thesis’s findings indicate some caution with respect to the overall appeal of such health communication materials within this specific natural setting.

**How can health-related documents support people in comprehending the messages contained in those health-related documents?**

In this thesis we explored how health-related documents can support people in comprehending a message. We conducted a systematic review of interventions which aim to improve the comprehensibility of health-related documents (Chapter 2). We assessed the comprehensibility of health-related documents by exploring the participants’ diabetes knowledge levels (Chapter 3). In addition, we analysed the participants’ opinions and explanations for preferences related to comprehension (Chapters 5 and 6). Taken together, our findings provide some support for the claim that narratives can improve the comprehensibility of health messages and thereby support people’s comprehension.

Our systematic review’s findings suggest that narrative health communication formats might improve comprehensibility (Chapter 2). In line with this support, we also found in one of our studies that participants who had read a photo story booklet (*Sweet Temptations*) showed higher levels of diabetes knowledge compared to participants who had read a more traditional brochure and to participants who had read nothing at all (Chapter 3). In addition, most participants in our studies showed preferences for and positive opinions about the photo story intervention, both in the
evaluation study on a photo story intervention about doctor-patient communication (Chapter 5), and in the field experiment on the same intervention (Chapter 6). These participants reported that they felt the photo story format was accessible and helped them comprehend the main messages.

The conclusion that narrative health communication formats can support people’s comprehension aligns with the processing advantages of narratives previously reported in the literature, both within and outside the health communication field (e.g. Hinyard & Kreuter, 2007; Green, 2006; Graesser & Otatti, 1996; Zabrucky & Moore, 1999). Stories are assumed to be essential for human knowledge, for meaning-making and for memorizing, and narrative cognition is often considered the ‘standard’ mode of human thinking (e.g., Boyd, 2009; Read & Miller, 1995; Schank & Abelson, 1995). Stories are interwoven with our daily lives and thus provide a familiar framework which is inherently causal and simulates possible realities, in which human actors move through social interactions towards certain goals (Oatley, 1999; Read & Miller, 1995). As such, narratives are likely to require less cognitive capacity for comprehension compared to expository, informative formats when used to explain, describe and inform.

The potential of visual narratives to support comprehension is confirmed in other studies into the effectiveness of photo stories (e.g. James et al., 2005; Unger, Molina, & Baron, 2009; Unger, Cabassa, Molina, Contreras, & Baron, 2013; Boyte, Pilisuk, Matiella, & Macario, 2014, Cabassa et al., 2015). That photo stories are able to support people’s comprehension can be explained by the fact that the story is already visualized (either in video or in photos), which might leave more cognitive capacity for processing and comprehending its content. This is in line with the principles of multimedia understanding. An example is the modality effect, which posits that the integrated presentation of textual and visual information can minimize cognitive load and thus support learning (part of cognitive load theory: Sweller, Ayres, Kalyuga, 2011; Mayer, 2005). The importance of an integrated presentation of text and visuals in health-related documents is underlined by studies such as one by Liu, Kemper, and McDowd (2009), which suggested on the basis of eye-tracking data that older adults in particular can have problems integrating health-related text and explanatory illustrations placed below the text.

The findings from our systematic review (Chapter 2) and from our interviews with participants (Chapters 5 and 6) also suggest that deriving elements from multiple-feature revisions of health-related documents, with attention to both verbal and visual features, can support comprehension. Designing or revising health messages
with attention to both verbal and visual design (e.g. simplifying language, using bullet points and including relevant pictures) is often recommended in the health-literacy and health-communication literature (e.g. Abraham & Kool, 2011; Grene, Cleary, & Marcus-Quinn, 2017). The studies included in our systematic review provided some evidence for the effectiveness of these multiple-feature revisions to improve comprehensibility. Interviews with older adults (Chapter 5) and with people in waiting rooms (Chapter 6) seem to confirm the positive impact of careful verbal and visual design, as both older adults and people in waiting rooms explicitly welcomed the short and simple wording combined with large pictures in the non-narrative booklet we designed as one of the control conditions. Although we did not find evidence for the effectiveness of only using simple wording or ‘plain language’ in our systematic review (Chapter 2), the use of plain language to improve comprehensibility and to promote health literacy is supported by a recent systematic review by Grene, Cleary, and Marcus-Quinn (2017). It must be noted, however, that these authors stress that ‘we cannot assume that plain language alone can solve all health-communication problems’ (p. 397). All in all, it seems worthwhile to apply multiple-feature revisions of health-related documents to improve their comprehensibility, although it remains difficult to indicate which features in which combinations are most likely to increase comprehensibility and thereby to support the processing of the content of health-related documents.

How can health-related documents have an impact on people’s attitudes, norms, beliefs and behaviour, and cause cognitive and behavioural change?

The results of this thesis also provide insight into how health-related documents can have an impact on peoples’ attitudes, norms, beliefs and behaviour, and cause cognitive and behavioural change. The following strategies stand out as effective: including topics related to communication with healthcare professionals, explicitly addressing actual and perceived patient barriers, aiming for increased self-efficacy levels, and supporting people with action and coping planning by providing them with strategies or scenarios to overcome barriers and to bridge the intention-behaviour gap. In addition, this thesis’s findings suggest that it is not always necessary to develop culturally tailored health-related documents in order to have an impact on cognition and behaviour (Chapter 3). The approach found to be effective in affecting cognitions and behaviour will be discussed in greater detail below.

First, we found that there is a need for simple interventions which include content related to communication with healthcare professionals and thereby support or improve people’s communicative and critical health literacy (Chapter 4). Critical health literacy refers to applying advanced personal, information and social skills,
including effective interaction between health professionals and users, to enable informed decision-making and empowerment (Sykes, Wills, Rowlands, & Popple, 2013). Taken together, the literature review and expert interviews conducted in the context of this thesis revealed that doctor-patient communication is an important overarching health-literacy domain for older adults. Health-related documents should therefore be developed with attention paid to communication with health professionals, regardless of the main topic of the materials or interventions. Including informational content on certain health topics could educate people and as such strengthen and improve their functional health literacy, enabling them to make informed choices. Explicitly addressing how to communicate effectively with health professionals in documents or interventions about various health topics could improve peoples’ communicative health literacy and critical health literacy levels (e.g. Williams, Davis, Parker, & Weiss, 2002; Nutbeam, 2000; Rubin, Parmer, Freimuth, Kaley, & Okundaye, 2011; De Wit et al., 2018; Sykes et al., 2013). Such an approach is in line with wider conceptualizations of health literacy and with the call for interventions which aim to inform and empower people (Schulz & Nakamoto, 2013; Dawkins-Moultin, McDonald, McKyer, 2016).

Second, we found that insufficient self-efficacy could be an important barrier to communicative health literacy (Chapter 4), which is in line with theoretical behaviour and health literacy models (e.g. Sorensen et al., 2012 for an overview). According to Social Cognitive Theory (Bandura 1971, 1977, 1986, 1997) and Reasoned Action Theory (Yzer, 2013), self-efficacy is one of the three major determinants of intentions, and via intention of behaviour. People must feel self-efficacious to perform certain behaviours: they must believe that they are able to perform a proposed behaviour, even when situational or personal barriers make it more difficult to do so. In two studies in this thesis, interviewees and focus group participants confirmed that in order for the interventions to have an impact on self-efficacy, such interventions must identify, acknowledge and explicitly address the older adults’ barriers to engaging in the recommended behaviours (Chapters 4 and 5).

Third, providing people with strategies to overcome situational or personal barriers could be an important route to enhancing their self-efficacy levels and thereby increasing the likelihood that they will succeed in performing the behaviours suggested for communicating with their doctor (see also Fransen, Smit, & Verlegh, 2015). Such an approach is in line with behavioural change theories, such as the Health Action Process Approach (Schwarzer, 2008) and the Integrated Model of Behavioural Prediction (Fishbein & Yzer, 2003). Providing people with strategies could not only strengthen behavioural intentions, but it will most likely also help
bridge the gap between intentions and behaviour which often arises when it comes to health behaviour (Sheeran, 2002). The studies in this thesis (Chapters 4 and 5) confirm that people are often motivated to communicate actively with health professionals, but that they may feel they lack appropriate strategies to do so. Narratives are often built around main characters who have to overcome certain obstacles to reach their goals (e.g. Ryan, 2007; Hinyard & Kreuter, 2007). As such, including narrative elements in health communication seems a promising way to present people with problem-solving strategies and scenarios (see also Boeijinga, Jolinga, Hoeken, & Sanders, 2013; Schwarzer, 2008).

If using stories in health communication is a promising strategy, about what and whom should the stories then be? The studies in this thesis were conducted among different target groups (Chapters 3, 4, 5 and 6) and showed that people generally value recognizable health communication stories about topics they find relevant to their own situation. This is in line with findings from other studies of narrative health communication which suggest that if people identify with the main characters, the impact of narratives can increase. If people perceive themselves to be similar to the main characters and identify with those protagonists, this can enhance people’s feelings of efficacy and thus have an impact on behavioural intentions, story-consistent attitudes and behaviours (e.g. Moyer-Gusé & Nabi, 2010; Moyer-Gusé, Chung, & Jain, 2011; Igartua, 2010; Igartua & Barrios, 2012; Cho, Shen, & Wilson, 2014; De Graaf, 2014; Hoeken, Kolthof, & Sanders, 2016).

Storytelling thus seems to provide a suitable framework for developing health messages which meet the recommendations described above. First, stories could provide an excellent learning opportunity because they offer readers or viewers the possibility to experience the possible consequences of behaviour without the costs of actually going through those consequences themselves. This advantage of stories seems to be recognized by our older-old participants, as they explained their preference for the photo stories by stating that the photo stories made them intend to use the visualized strategy the next time they visited their doctors (Chapter 5). In the words of Pinker (1997), people see what happens to the main characters in the stories and take mental notes about the strategies that these characters use to achieve their goals. In that sense, narratives can be regarded as an age-old form of virtual reality in which the protagonists provide the lenses through which audiences perceive their learning environment. As Gottschall describes it: ‘Just as flight simulators allow pilot to train safely, stories safely train us for the big challenges of the social world.’ (Gottschall, 2012: p. 58.; see Oatley, 2008; Kreuter et al., 2007; Slater, 2002; Mar & Oatley, 2008 for similar views). The potential of stories to model
the desired behaviour is confirmed in a review by De Graaf, Sanders, and Hoeken (2016) on the promising characteristics of narrative interventions. The authors conclude that narrating healthy behaviour can effectively influence intentions.

Our qualitative studies (Chapter 4) provided an important addition to the theoretically based premise (e.g. Bandura, 1977; Bandura, 1986; Bandura, 1997; Bandura 2002, Schank & Abelson, 1995, Mar & Oatley, 2008) that stories should be built around similar others who successfully demonstrate target behaviours. Focus group participants commented that narrative interventions should also explicitly portray the doubts and insecurity of the main characters to be recognizable and believable. This portrayal could help make readers or viewers aware of their own behavioural barriers and increase their confidence that they can overcome such barriers, even when feeling insecure.

The studies in this thesis (Chapters 2, 3 and 5) provided some support for the persuasive impact of narrative health communication on people’s awareness, knowledge, attitudes, norms, beliefs and behaviour. Resistance is a well-known reaction against persuasive health communication, especially if people feel unable to perform the suggested behaviours (Fransen, Smit, & Verlegh, 2015; Moyer-Gusé, 2008). Stories are assumed to reduce resistance to being persuaded by decreasing counterargument and reactance, by increasing people’s perceived vulnerability, and by having a positive influence on people’s feelings of self-efficacy, via narrative mechanisms such as transportation and identification (e.g. Shen, Sheer, & Li, 2015; Moyer-Gusé, 2008). Narrative structures stimulate the experience of being immersed in a story world (transportation) and becoming involved with the story’s main characters (identification and parasocial interaction) (e.g. Green & Brock, 2000; Slater & Rouner, 2002; Moyer-Gusé & Nabi, 2010). In addition, stories can prompt self-referencing (relating a message to the self (Burnkrant & Unnava, 1989; 1995), by producing memories of a person’s own experiences, which can in turn influence the persuasive impact of the story (De Graaf, 2014).

We were not able to confirm these possible persuasive advantages of the photo story intervention compared to its non-narrative counterparts (Chapters 3 and 5). The participants’ comments (Chapters 5 and 6), however, do suggest that they at least recognized the persuasive potential of narrative formats of health communication. In addition, readers of the photo story on diabetes who reported higher levels of transportation also reported a higher intention to talk to a doctor about diabetes than those reporting lower levels of transportation. Furthermore, in line with the concept of self-referencing, older readers of the photo story booklet on doctor-
patient communication were apparently encouraged to share their own experiences with research assistants after reading the booklet. Finally, informal observations during focus group discussions also showed that reading the booklet encouraged people to exchange their own stories about doctor-patient communication.

Finally, the positive effects on diabetes knowledge reported on in Chapter 3 suggest that it is not always necessary to tailor health-related documents to the target groups’ culture. The photo story *Sweet Temptations* was originally developed for a Spanish-speaking audience in the US, but we also found positive effects on knowledge in a Dutch sample. Likewise, a recent study showed that conditions in which Arabic participants received a culturally or linguistically tailored version did not yield stronger effects on behavioural intentions and attitudes than when these participants received the original Dutch version of the photo story (Garate Gamboa, 2016). A study on a culturally adapted narrative video about cervical cancer showed that viewing the narrative video had the largest impact on the intended cultural target group of Mexican American women but also had a positive impact on women from other ethnic groups. These findings seem to contrast with other, more theoretically oriented publications in which the cultural tailoring of health-related documents is strongly recommended (e.g. Larkey & Hecht, 2010). Perhaps the power of well-told stories to transport viewers or readers into the story world and make them identify with the main story’s main characters can convince readers regardless of cultural background. Furthermore, the findings from our study on the photo story about diabetes (Chapter 3) showed that a narrative intervention originally developed for a low-literate audience can also be effective in increasing knowledge in people with higher levels of literacy (see also Meppelink, Smit, Buurman, & Van Weert, 2015).

Taken together, this thesis’s findings complement what has been reported in the literature in the following ways:

1) we found that also a set of one-page photo stories developed to support doctor-patient communication can also increase the likelihood that people 1) notice these health-related documents, 2) are motivated to process the stories, 3) are able to comprehend and 4) intent to act on the main messages. Earlier studies reported positive effects of longer, multiple-page photo stories or fotonovelas with regard to attention, motivation, comprehension and action.

2) non-narrative health-related document formats, including elements derived from multiple-feature revisions, can increase people’s self-efficacy and behavioural intentions.
3) narrative health-related document formats may be more effective and appealing if they not only demonstrate another’s successful behaviour, but also explicitly portray the doubts and worries of the main characters in order to overcome perceived barriers and increase people’s self-efficacy.

4) visual narratives such as photo stories can have a positive impact in audiences other than the intended target group. It may not always be necessary to tailor narrative health-related documents to the target group’s cultural background or literacy level.

All in all, this thesis’s findings partly confirm the advantages of visual narratives and photo stories with regard to attention, motivation, comprehension and action. These advantages should be tested further in studies which take into account the methodological considerations described below. Future studies could explore under which conditions and in which forms visual narratives in general and photo stories in particular are most likely to support health communication for people with limited health literacy.

**Methodological considerations**

In this section we will explore the strengths and limitations of the mixed-methods approach used throughout this thesis. We will then discuss the methodological lessons learned.

**Strengths**

Qualitative methods are usually considered more suitable to explore phenomena, build theory and develop interventions, whereas quantitative measures are often considered indispensable for testing theoretical assumptions and for comparing the effectiveness of different interventions. Using combinations, i.e. mixed methods, can provide a more comprehensive account than relying on only one type of method, because the various approaches complement each other, setting off weaknesses and combining strengths (e.g. Sale, Lohfeld, & Brazil, 2002; Bryman, 2006; Curry, Nembhard, & Bradley, 2009; Meissner, Creswell, Klassen, Plano Clark, & Smith, 2011). Below we discuss the strengths of the different methods used in this thesis.

We first systematically reviewed and summarized existing evidence on interventions aiming to improve the comprehensibility of health-related documents for older adults. By conducting a thorough and critical synthesis of the available research evidence, we were able to come up with conclusions based on a method which is generally considered to be at the top of the hierarchy of evidence (e.g. Gopalakrishnan &
Ganeshkumar, 2013). This enabled us to choose an evidence-based communication format to explore and adapt the following studies further, namely narrative health communication. Furthermore, the heterogeneity of findings and the lack of strong and consistent evidence for most other types of interventions in this review showed that it is important to conduct more studies and to explore whether narrative formats and multiple-feature revisions would also be successful with other target groups and other target behaviours than those included in the reviewed studies.

Second, we used a combination of literature review and qualitative methods to study health literacy domains for older adults with limited health literacy, and to explore associated needs, barriers, facilitators and communication strategies. Combining the findings from our literature review, expert interviews and focus group discussions, we were able to build a solid case to support communicative health literacy and focus on the communication of older people with healthcare professionals. Using group discussions and role play exercises, we involved people from the target group from the start. This enabled us to establish the target group’s own barriers to successful doctor-patient communication and to find solutions and strategies which they would consider relevant and recognizable. If we had only based our intervention on the literature review or on expert interviews, it would have been much more difficult to identify communication strategies considered effective by the target group of older adults themselves. The use of co-creation and participatory research approaches with vulnerable target audiences is in line with Action Media research (e.g. Parker & Becker-Benton, 2016) and with the concept of critical health literacy, in which active participation, critical thinking and community involvement are also emphasized (e.g. Chinn, 2011, De Wit et al., 2016).

Third, we used a combination of quantitative and qualitative methods to study the effectiveness and appreciation of the photo story intervention about doctor-patient communication. By including two RCTs to quantitatively assess the effects of the intervention and by interviewing a subset of Dutch RCT participants about explanations for qualitative preference measures, we were able to provide a comprehensive understanding of the potential effects of the photo story intervention. The interview findings helped frame the findings of the RCTs regarding the lack of differences in effectiveness found between the photo story booklet and a non-narrative booklet we had also developed. On the one hand, interview participants were often explicitly positive about both brochures, in line with the lack of quantitative differences in effectiveness. On the other hand, the majority of interview participants preferred the photo story intervention over the non-narrative brochure, suggesting the former might be more motivating to read. Furthermore, the findings
of the qualitative interview study supported and expounded on the theory and evidence-based design of the photo story booklet, as participants explicitly seemed to welcome elements we derived from narrative and Social Cognitive theory, and the findings from our literature review and qualitative studies with the target group. If we had only relied on the outcomes of our RCTs, we might have underestimated the impact of the intervention. If we had only conducted the interview study, we might have overestimated the differences in effectiveness between the two booklets.

Fourth, integrating the findings of the interview study, we were able to develop an updated version of the photo story booklet in which we incorporated evidence on multiple-feature revisions and elements of the non-narrative brochure which were explicitly valued by the interview participants (updated brochure is available here: https://drive.google.com/open?id=166Dhe2QO54F1I37My-1W3uWT0NVjR7KA ).

Fifth, we not only integrated qualitative and quantitative methods, but also combined multiple quantitative methods such as self-reports and observations. We paid attention to external validity by not only conducting studies in a forced exposure experimental setting, but also in the natural setting of primary healthcare practice waiting rooms. Using observations and self-reports in three primary healthcare centres, this study is one of the first in which the uptake of a narrative health communication format is experimentally explored in a real-life setting. The findings of this study put into perspective the optimistic impression of the effectiveness of health-related documents in waiting rooms which might have arisen from previous research.

Apart from the specific strengths discussed above, several other methodological strengths of this thesis can be identified. We succeeded in finding ways to deal with the challenges of conducting research among vulnerable and hard-to-reach target groups such as people with lower literacy levels, older-old people in general and older-old people with limited health literacy in particular (Chapters 3 to 5, see also Liljas et al., 2017; Bonevski et al., 2014). A key factor for successful recruitment was to involve stakeholders to enable possible participants to understand the purpose and procedure of the study and subsequently to provide informed consent. We involved stakeholders to recruit a diverse population of adults with lower levels of literacy in our study on Sweet Temptations, older adults with limited health literacy in the intervention development study, and older-old adults with lower and higher levels of health literacy in the evaluation. For the Sweet Temptations study, we approached sheltered employment organizations and the organizers of language learning courses for adults. This recruitment approach resulted in a diverse sample
of adults with lower literacy levels. When developing the photo story intervention on doctor-patient communication, one of the experts interviewed (the local General Practitioner) helped us establish a good relationship with the local care home. This enabled us to conduct our Focus Group Discussions and Role Play Exercises among a group of older adults with low levels of health literacy. For our evaluation study in the Netherlands, we sought cooperation with the ‘Embrace’ programme, which provides care and support to older adults aged 75 and older in the province of Groningen (cf. Spoorenberg, Uittenbroek, Middel, Kremer, Reijneveld, & Wynia, 2013). Based on earlier data collection conducted for Embrace, we were able to recruit older-old adults with lower and higher levels of health literacy. In Germany we recruited participants from senior day care and rehabilitation centres, as well as sports clubs and at structured meetings with older people.

Another strength of this thesis is that we succeeded in finding suitable research methods for vulnerable target groups. To support participants with low levels of health literacy answer questions, we developed measurement instruments taking into account suggestions from Loyen (2012): our questionnaires included short and simple words and sentences, and icons (smileys, crosses and checkmarks) accompanying answer options. Participants were assisted in completing their questionnaires by research assistants explicitly trained not to show any preference and not to provide answers when participants hesitated, in both studies conducted in the Netherlands.

We were also able to use a relatively new method to elicit older adults’ personal strategies and solutions for their own actual and perceived barriers to successful doctor-patient communication. We chose to provide older participants with scenarios and invited them to play these out in Role Play Exercises with an amateur actor who was also a retired General Practitioner in the Netherlands (Chapter 4). We assumed that such an approach would support older adults’ abilities to think about and act on hypothetical scenarios beyond the here and now. Our participants were positive about this approach. In addition, the fact that several older adults reported difficulties with the hypothetical nature of the questionnaire items in the evaluation study (they found it difficult to imagine possible situations) confirms the value of role play exercises in assessing people’s beliefs about future scenarios.

To sum it up, one of the main strengths of this thesis is the stepwise development and evaluation of a health communication intervention using both theory and evidence. We followed this stepwise path (1) to establish the optimal formats for health-related documents to improve comprehensibility, (2) to determine older adults’ barriers
and facilitators for successful doctor-patient communication, and (3) to assess to what degree a photo story booklet is appealing to the target group and can have a positive impact on knowledge, self-efficacy, intentions and behaviour. We aimed to select the research methods most suitable for each separate step in intervention development and evaluation.

Limitations
As discussed above, mixed-methods research can contribute to an enhanced understanding of research problems because the different methods complement each other. A possible concern when applying such a multiplicity of methods in our studies, however, is that we perhaps did not put enough effort into the optimal application of each type of method. Below, we will discuss the limitations of how we applied the methods used, and explore their consequences on the quality of the information obtained, the quality of the samples, causality and confounding, and the generalizability of the findings.

Quality of the information obtained
Unfortunately, we were not able to study the impact of the photo story booklet on actual doctor-patient interactions. In the current study design, we only measured effects on behavioural intention immediately after exposure to the interventions (Chapters 3 and 5). This limitation should be taken into account in future studies.

One other limitation is that we were not able directly to assess the effects of photo stories on comprehension. In the ‘Sweet Temptations’ study (Chapter 3), we operationalized comprehension as ‘knowledge about diabetes’ (in number of questions answered correctly) after reading one of the brochures, while we explored the impact on comprehension of the photo story booklet on doctor-patient communication by eliciting the participants’ preferences and opinions (Chapters 5 and 6). Measuring comprehension more directly could have taken the form of eye tracking (e.g. Rayner, Chace, Ashby, & Slattery, 2006) or including self-reports of comprehensibility. Nevertheless, measuring comprehension is complicated by its multidimensional character (e.g. Fletcher, 2006). It would therefore appear worthwhile to include multiple measures of comprehension in future studies.

Finally, despite our efforts to choose and apply research methods appropriate for our target group, some limitations regarding the measurements used in the studies in this thesis may have had an impact on the quality of the information obtained. Most of the research methods in this thesis were based on self-reports. Self-reports not only require participants to be aware of their own situation, but
they also rely on people’s ability adequately to describe or recognise their mental representations. This might be especially challenging for older adults with limited health literacy, as was reflected in the difficulties some participants experienced in answering the questionnaires (Chapters 3 and 5). Furthermore, self-reports can be affected by people’s tendency to provide socially desirable answers, which may have led people to overstate their positive opinions of the interventions included in our studies. However, the research assistants in all the studies were trained to only assist participants by repeating or rephrasing the questions openly. Moreover, we tried to minimise the risk that people would prefer the photo story intervention only because they thought that this was the primary intervention and that it was socially desirable to choose it over the other, non-narrative booklet by making both booklets graphically very similar.

In evaluating our qualitative analyses, we used the four quality measures proposed by Shenton (2004): credibility, dependability, confirmability and transferability. Credibility is linked to internal validity and refers to the degree to which findings reflect reality. Dependability is best described as the reliability of results, or the repeatability of the study. Confirmability means that qualitative researchers should pay sufficient attention to objectivity in order to ensure that the findings truly reflect participants’ ideas and experiences, instead of the researchers’ own preferences. Transferability is connected to external validity and describes the degree to which findings can be transferred to other groups or situations (Shenton, 2004). We discuss each of these components below.

We aimed to enhance the credibility of our findings by developing research guides for all the qualitative methodologies based on the literature and by consulting with qualitative research experts. We conducted qualitative analyses using multiple researchers to the point of saturation, on outcomes connected to previous research and quantitative findings, and discussed these findings and illustrative quotes repeatedly within the research team. In addition, we continuously encouraged participants to express all their ideas, experiences and opinions, regardless of valence. Moreover, by combining findings from previous research and findings based on a diversity of qualitative methods, we were able to incorporate the benefits of these methods (e.g. literature review, expert interviews, focus group discussions, role play exercises) and provide a credible picture of older adults’ barriers, needs, facilitators and strategies with respect to doctor-patient communication.

In addition, we provided detailed descriptions of data collection and analysis procedures and explicitly linked the participants’ quotes to all the themes identified,
in order to increase the dependability of our findings and to enable future researchers to repeat our studies following our methodology as a prototypical framework. By having independent, trained research assistants conduct the interviews, we tried to reduce the researchers’ bias towards the intervention they developed. Transferability is discussed in greater detail in the following section on sample quality.

**Quality of the samples**

Older adults and people with limited health literacy are generally less likely to participate in studies, in addition to having more difficulties in answering questionnaire items (e.g. Liljas et al., 2017; Bonevski et al., 2014). This may have resulted in a selection bias in the populations studied in this thesis, as older adults with very low levels of health literacy are possibly underrepresented. However, overall we seem to have succeeded in including a sufficient number of people with low health literacy, as indicated for instance by their low scores on Chew’s Set of brief health literacy screening questions (SBSQ: Chew, Bradly, & Boyko, 2004).

Another limitation may be the relatively small number of participants, particularly in the RCTs in which we evaluated the photo story booklet on doctor-patient communication. This study was not sufficiently powerful to detect small to medium effect sizes, while it is known that effect sizes in communication studies are usually small or medium (Jansen, 2017; Braddock & Dillard, 2016; Wakefield, Loken, & Hornik, 2010). We may thus have missed some of the effects of these interventions.

**Causality and confounding**

The photo story intervention and non-narrative booklet in the evaluation and the waiting room studies may have been too similar to find any significant differences in effectiveness. However, we purposely developed the non-narrative brochure to closely resemble the photo story intervention (‘plausible rival’), integrating evidence-based content and design principles. This helped ensure that possible differences in effectiveness would be due to differences between the narrative and non-narrative formats, and not due to differences in general attractiveness, for example. Such an approach is in line with guidelines for pharmaceutical studies, in which it is strongly recommended to compare new medicine with their best available competitor or ‘care as usual’ instead of a placebo (e.g. National Healthcare Institute, 2016).

Finally, we did not include a pre-test/post-test design in any of our studies, which makes it difficult to show changes in knowledge, self-efficacy and behavioural intentions after reading one of the booklets and to obtain firm conclusions about the causality of exposure to the interventions and outcome measures. However, including a pre-test also has limitations, as questionnaire items in the pre-test can
also have an impact on respondents and thus on outcome measures in the post-test.

**Generalizability of findings**

Although we realize that this thesis's results might not be fully transferable to other groups, health-related documents, methods or experimental settings, we aimed to increase the transferability of our qualitative findings in the following ways. First, we conducted focus group discussions and role play exercises both in the Netherlands and in Hungary. In addition, we conducted RCTs on the effectiveness of the photo story booklet on doctor-patient communication in Germany and the Netherlands. We also included adults from different age groups and different health literacy levels in our evaluation studies. We therefore believe our results are relevant for most other Western European countries. Second, we integrated the results of the systematic review, the study on the photo story intervention about diabetes, and the studies on the photo story intervention about doctor-patient communication, to be able to provide recommendations for health-related documents in general. Third, we purposely conducted studies in different settings using different methods. In sum, by relating the integrated findings of our quantitative and qualitative studies to the four steps of information processing, and by linking our findings to previous empirical research and theories, we aim to offer insights relevant to developing, designing and researching health communication in a broader, European context.

To sum up, in line with Robson and McCartan (2016), we used several available research methods which could be effective for exploring how to improve health communication to support people with limited health literacy. The use of mixed methods comes with some limitations, and may lead to problems integrating the possibly disparate results. Nonetheless, we linked the findings of the various research methodologies where possible and aimed to integrate the outcomes of the different studies in this Discussion section in order to establish a richer understanding of improved health communication and to support people with limited health literacy. The main findings and the methodological strengths and limitations discussed above could help establish which path researchers and health communication professionals should follow if they aim solidly to develop, evaluate and improve health-related documents which support health communication, especially for older adults and people with limited health literacy. The topic of how to develop and research such health-related documents is explored in the next two sections on the implications for practice and research, and is based on insights acquired during the conduct of this study.
Implications for practice

Our findings show that there is no conclusive evidence on the effectiveness of interventions which aim to improve the comprehensibility of health-related documents for older adults, nor on the effectiveness of photo stories about health communication. Practitioners and designers of health-related documents for older adults or other vulnerable target groups should therefore be cautious about applying health communication interventions which have proven successful in general populations, because these will not necessarily be beneficial for the target groups in question. However, our findings also show that it is not always necessary to tailor health-related documents to other cultural target groups or to people with specific levels of health literacy. All in all, it seems well worthwhile for health communication designers to work in close collaboration with trained health communication researchers, and to involve representatives from the relevant target group in order to design health communication materials which are most likely to have an impact.

Our findings in the waiting room study further indicate that the settings in which health-related documents are presented to their audience can strongly influence the extent to which these documents will be noticed and processed. Health communication professionals should therefore take into account the characteristics and possible constraints of these settings when designing health-related documents. In addition, health communication professionals should explicitly explore which distribution routes are most effective in reaching their target group. A possible strategy is that healthcare professionals distribute health-related documents to those patients they consider most in need of the information.

This thesis’s findings suggest that in order to develop effective health communication interventions, designers should explicitly address the topic of communicating with healthcare professionals, and should support people in identifying barriers to effective communication, and in formulating and planning problem-solving strategies to overcome these anticipated barriers (see also Abraham & Kools, 2011). We recommend including content in which the success of similar others is highlighted, and in which the desired behaviour is modelled or demonstrated in a series of steps. This thesis demonstrates that in order to make readers aware of their own barriers and to be recognizable and effective, health communication intervention should also explicitly portray people’s worries and doubts.

Our findings show that visual narratives such as photo stories could provide a suitable framework for incorporating the recommendations described above and could offer
a valuable and effective format for health communication to improve health literacy. The outcomes of the studies in this thesis show the possible advantages of visual narratives and photo stories with regard to attention, motivation, comprehension and action. These possible advantages of photo stories, however, need to be explored further in new studies which take into account the methodological suggestions described above.

Informal observations during the small scale evaluation (Chapter 4) suggest that the photo story intervention could easily be implemented in broader interventions such as group education programmes for patients, and in training and education programmes for professionals. The commonly experienced barriers in doctor-patient communication included in the photo stories could be taken as a starting point for discussions of the participants’ own experiences and their own solutions to the scenarios presented in the photo stories. The underlying method of ‘modelling’ problem solving strategies in visualized stories could be translated into other applications. This could for instance be through guided role play exercises based on recognizable scenarios, with feedback from a facilitator and from other participants (see also Kok et al., 2016).

It might also be interesting to integrate narrative elements of health communication with promising elements of multiple-feature revisions, that is, to combine photo stories with more traditional health communication formats. One such integrated edition of our photo story booklet on doctor-patient communication has been recently developed and will soon be actively distributed to healthcare organizations in the Netherlands (updated brochure is available here: https://drive.google.com/open?id=166Dhe2Q054F1I37My-1W3uWT0NVjR7KA). In addition, interactive editions of our photo stories are presented on a Dutch adult learning website (www.oefenen.nl). Moreover, the photo stories could be translated into other languages; they have already been translated into Arabic and English and will be used on social media websites for people from Syria and Eritrea. Finally, the possibility of presenting the photo stories in digital format on information systems in waiting rooms is being explored.

Finally, health communication developers could use the information processing model presented in this thesis as a starting point to ensure that the health-related documents they develop maximize attention, motivation, comprehension and action.
Implications for research

From our findings it can be concluded that the advantages of narrative health communication reported in the literature are not necessarily in agreement with the effects on cognition and behaviour in natural settings. This highlights the importance of taking into account the fact that health-related documents can only have an effect if they are both noticed and inspected. Future research should preferably include natural real-life settings in order to put into perspective the outcomes of studies conducted under more artificial circumstances. Furthermore, we suggest that future studies should preferably be designed so that all the different steps of information processing are covered: attention, motivation, comprehension and action. The model presented in the Introduction and discussed earlier in this Discussion could serve as a guiding framework to ensure that all these different steps are taken into account.

We found that in order to support health literacy using health-related documents, it is important to take into account a manifold of factors: to include content about effective communication with health professionals, to address patient barriers to effective communication explicitly, to aim for increased levels of self-efficacy, to provide strategies or scenarios to overcome perceived barriers, and to bridge the intention-behaviour gap. Future research could test whether all of these components are indispensable for improving health communication, and could explore which interventions will provide the best format to combine these different components in the most effective way.

Combining a range of quantitative and qualitative research methods in developing and evaluating health communication interventions provides valuable, complementary perspectives on health literacy and health communication. Future studies on health literacy and health communication could use multiple research methods similarly. Health communication researchers should consider exploring and applying research methodologies such as role play exercises to meet the needs and capabilities of vulnerable and low-literacy target groups in developing health communication interventions. Furthermore, it is essential that research instruments are developed and used that are appropriate for participants with lower levels of health literacy. An exemplary strategy to maximize the usability of questionnaires for vulnerable target groups is to offer participants the option of viewing and answering questions on a digital application presented on a tablet. We aimed to develop and use such an application, which would include an actress reading out the questions and answer options (see Figure 2; Hossteenge, 2015).
FIGURE 2. Consecutive steps of information processing that are the starting point of this thesis and the trajectory of developing and evaluating health communication interventions.

In this thesis we assessed the direct and immediate impact of photo story booklets about health-communication topics on knowledge, self-efficacy and behavioural intentions. Future studies should also assess the impact of such interventions on actual behaviour. To explore the impact of reading the photo story intervention on people’s behaviour during conversations with their doctors, it may be worth including other research methods, such as conversational analysis (CA). This method can be used, for example, to study how patients who have or have not read a photo story, such as the one developed in this thesis, articulate their lack of understanding to a doctor (e.g. Maynard & Heritage, 2005). In addition, future studies should not only focus on outcomes, but also aim at exploring the underlying processes or mechanisms which help explain possible effects. For example, including research methods such as eye-tracking could help unravel why strategies such as including pictures, simplifying language and using narrative structures do not always increase comprehension. Furthermore, exploring narrative mechanisms such as transportation, identification and self-referencing may help better to understand when narrative health communication formats achieve their aims or fail to do so, and may help establish under which conditions and with which ingredients these narrative formats are most powerful.

Despite the efforts we put into recruitment procedures, it was still challenging to find enough participants. It is therefore very worthwhile investing sufficient time
and effort into participant recruitment, especially for hard-to-reach groups. To reach vulnerable target groups for research, we recommend building sustainable relationships with stakeholders, to visit community centres and to participate in community practices.

As the studies conducted in this thesis were for a large part based on data from older populations in the northern Netherlands, future studies should assess whether our findings are also valid for people of other ages, cultural backgrounds and healthcare systems. Nevertheless, the studies in this thesis which explored the effects of photo stories in other groups than the intended target group suggest that photo stories originally developed for one audience can also be effective for audiences from other backgrounds.

**Conclusion**

The studies in this thesis provide some support for using visual narrative formats and photo stories to improve health communication specifically aimed at people with limited health literacy. Narrative health communication formats appear to provide a suitable framework for incorporating elements which improve health communication to support people with limited health literacy. Developing and evaluating seven photo stories on doctor-patient communication in partnership with the target group, based on mixed methods research, has yielded a health communication intervention which was noticed, preferred and valued by the target group of older adults with limited health literacy. Future research should address the effectiveness of these interventions, including the best ways to assess them. To begin with, these studies should test the effects of photo stories about health communication on actual behaviour in natural situations. We suggest that health communication researchers and designers who work on health-related documents for older people with limited health literacy should always consider *attention, motivation, comprehension* and *action*, work closely with the target group, and conduct studies in real-life settings where possible.
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