# Pharmaceutical pictograms for low-literate medication users

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# Summary
# Samenvatting

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Approximately 12% of the Dutch population struggles to use textual information encountered in daily life [1]. When these people become patients, they are more likely to experience negative health outcomes compared to those with higher literacy levels [2]. Also written drug information can be difficult to use for this group [3, 4]. However, when designed to meet the information needs and preferences of the target group, drug leaflets can play an important role to empower patients and target medication adherence [5]. With the aim to develop information that is targeted to medication users with low literacy levels, this thesis describes the design of pictograms to support written drug information, developed together with the low-literate target group.

## Part I – Pictogram Pre-Design

**Chapter 1** describes the first step in the pre-design phase, in which people with low literacy were asked to share their experiences with using patient information leaflets, to express what they value in written drug information, and what roles images could play in this context. Focus group discussions and individual interviews were held with 45 low-literate participants. The study showed that people with low literacy find written drug information discouraging to use. They express that it is both difficult to find and understand relevant information. The target group values leaflets that are short, clearly structured, and easily legible and readable. Using visual aids can reduce the motivational barrier to read the leaflet and help low-literate medication users to find relevant information, understand it, or to ask other people for support to explain topics they are interested in. In these ways, low-literate people feel that visual aids can help to empower them.

In **chapter 2**, the results of these interviews and focus group discussions relating to preferences of the target group for the design style and content of visual aids in written drug information are discussed. The outcomes show that low-literate people value the use of informative, realistic, pictographic images. They recommend to use clearly legible lines and colour for emphasis, and to show prohibitory messages together with an image that shows what the recommended course of action is. With respect to the targeted content for these pictograms, low-literate people are especially interested in visuals that explain how the medicine should be used, what it is for, and how to store it.

At the same time, it became apparent that many people prefer to see only information that is relevant to their situation, i.e., they prefer tailored content to targeted content.

**Chapter 3** reinforces the importance of continuing to involve people with low literacy during the design process of the pictograms, by showing that people with different literacy levels can differ in their preference for how much contextual information they would like to see in an image. This finding resulted from interviews with 191 pharmacy visitors, who were shown icons of organs with systematic variations in the level of detail, background, and context. It was seen that low-literate people prefer to see less context in their images compared to those with adequate literacy levels.

## Part II – Pictogram Design and Evaluation

The pre-design phase ends with **chapter 4**, which describes the evaluation of the first ten pictograms that followed from the pre-design phase. In a group of 197 pharmacy visitors, five pictograms reached sufficient understanding (≥ 67%); looking at the subgroup of low-literate participants, two pictograms did. For most pictograms, people appear to have a good sense of whether or not they have understood the message, so that the risk of false-confidence in understanding is low. Qualitative evaluations with 25 low-literate and 30 adequately literate people further show that to improve the design of the pictograms, the design should be simple, clearly show the intake and effect of medicine, and use images and messages that are likely to be familiar to the reader. It is suggested in this chapter that this beneficial effect of familiarity can be taken advantage of by health professionals by going over the meaning of pictograms when educating new medication users.

**Chapter 5** continues the design process with the evaluation of five pictograms that were developed based on the findings of the previous study. Qualitative discussions with 16 low-literate participants showed that they value the use of simple text and multiple frames within pictograms. Quantitative evaluations with 150 participants at first exposure and 97 participants of this original group at follow-up, also demonstrated that with repeated exposure to the pictograms, participants' understanding of them increases with a medium to large effect size: initial understanding ranges between 29.3% and 94%; understanding at second exposure between 61.9% and 100%. This confirms the idea that healthcare providers should make use of pictograms when they educate medication users to optimise the effectiveness of the images. In addition, it is

suggested that to increase the population's exposure to the pictograms, the pictograms can be used for public education on medication safety.

The resulting pictograms were added to drug leaflets with good readability levels, intended for new users of antihypertensive medication. A cluster randomised study was set up to evaluate the effects of the pictograms on communication with and health behaviour of patients by comparing text-only leaflets to the same leaflets with pictograms added. **Chapter 6** describes an internal pilot study of the first seven months of this study and presents preliminary data. This assessment shows that the inclusion process needs to be optimised to increase the recruitment rate of participants at the pharmacy. The preliminary results suggest that patients appreciate the addition of the pictograms and that they may help to perceive topics in the leaflet more positively.

## Part III – Development Strategies

As a result of questions that arose during the design process on effective strategies to involve end-users, a systematic literature study was carried out as described in **chapter 7**. The review considered roles for end-users, moments of involvement, as well as types of end-users, and effects of these strategies on the success of pictograms and pictogram-enhanced written drug information. The sixty articles that were found indicate that in current literature, end-users are infrequently involved during pre-design or in a fully participative role. The review indicates that early and repeated involvement of (non-)patients helps to develop pictograms that are understood well and valued, and improve understanding and recall of textual information. However, there is limited evidence for effects of lay involvement in the design of pictograms on their effectiveness to improve patients' perceptions of drug information or health behaviour.

**Chapter 8** reflects on the development of the pictograms and visual grammar in this thesis. The resulting grammar is able to indicate (un)specific passing of time, moments in time, action-consequence, direction of effects, and provide context to the main message, as well as contrast negative and positive situations. The grammar can be applied to new information to expand the pictogram library. It is suggested that for long-term collaborations between researchers and designers, having an evidence-based design track as well as a purely creative design track helps to restrict neither scientific detail nor creativity. In addition, it is proposed that in some cases, a

consultative role may suit participants better than a 'design by [end-users]' approach, but that more decision-power could be given to these end-users.

## Discussion and Conclusion

The **general discussion** discusses the findings of the thesis. It is concluded that it is essential to supply low-literate medication users with printed and better suitable drug leaflets. In this context, pictograms can play an important role to empower the target group. Healthcare providers who want to use or design pictograms should opt for informative, realistic, simple images that show familiar messages and visual elements and present a complete message. Using such images in a short, well-structured, readable and legible leaflet can help to make written drug information more appealing and easier to read, understand and recall. In the development of pictograms, it is useful to involve end-users in the design so that they are likely to value and understand the images. To select pictograms for use, a hard understandability cut-off should not be guiding. For optimal effectiveness, pictograms should be used with text and be presented to patients repeatedly. For this reason, we recommend that pharmacists make use of pictograms in pictogram-enhanced leaflets to educate medication users about their therapy.