The extent and effects of patient involvement in pictogram design for written drug information: a short systematic review

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This short review provides insight into the extent and effectiveness of patient involvement in the design and evaluation of pictograms to support patient drug information. Pubmed, CINAHL, Cochrane Library, Embase, PsycINFO, Academic Search Premier and Web of Science were searched systematically; the 73 included articles were evaluated with the MMAT. We see that, usually, non-patient end-users are involved in the design of pharmaceutical pictograms – patients are more commonly involved in the final evaluation of pictogram success. Repeated involvement of (non-)patients aids the design of effective pharmaceutical pictograms, although there is limited evidence for such effects on patient perception of drug information or health behaviour.

Introduction

Patients often struggle to retain verbally communicated information [1,2]. However, when written information about medication is available for patients it is often not targeted to the needs of its audience [3]. The use of informative stylised figurative drawings (i.e., pictograms) [4] can help to improve the usability of drug leaflets by drawing patient attention to important topics [5,6] and by making information easier to understand and recall [4,7–9], which can even lead to improved health behaviour [10]. Although there are some common features for pictogram success, such as minimising the amount of distracting detail and using the images in combination with simple text [11], pictograms are not necessarily universally understood – understanding can vary in particular between different cultural groups and age groups [12–15]. Therefore, it has been recommended to involve the target group in the design and evaluation of pharmaceutical pictograms to gain insight into their characteristics and to better tailor pictogram interventions [16].

In the field of design, there has been increasing emphasis on involving lay participants in an active rather than a passive role in development processes and on inviting end users during the 'pre-design phase', to give them a voice in determining initial design strategies [17,18]. Ranging from less to more active input, three levels of user involvement can be distinguished [19–21]:

- An informative role ('design for'): involving end users as passive objects of observation for researchers.
- A consultative role ('design with'): inviting end users to comment on pre-defined pictogram designs.
- A participative role ('design by'): involving end users in a way that they can actively take part in the design and have decision power regarding the design solution.

Despite extensive reviews on the use of pictures and pictograms in health communication [11,22,23], little is known about user involvement and its effectiveness in the design and evaluation of pharmaceutical pictograms. However, it is has been suggested that studies often do not involve relevant end users in effect measurements of pictograms [24]. The aim of this review is therefore to investigate the extent of lay – and in particular patient – end-user involvement in the design and evaluation of pharmaceutical pictograms and to find evidence on whether involvement in the design process can increase the success of pictograms and pictogram-enhanced drug information, so that future efforts of

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user involvement in pictogram design and evaluation can be evidence-based.

Study characteristics

All 73 articles that were found in a systematic search of databases Pubmed, CINAHL, Cochrane Library, Embase, PsycINFO, Academic Search Premier and Web of Science (see supplementary material A online) were published between 1993 and 2018, with over half published since 2011. Most studies were conducted in the USA and South Africa (17 and 13 studies, respectively), followed by Canada and India (eight and five studies, respectively). Mixed-Methods Appraisal Tool (MMAT) scores ranged from 25% to 100%. Almost 40% of the available studies intended to use their pictograms for patients with low (health) literacy, a quarter of the studies aimed to target 'patients in general' and about one-in-ten articles developed pictograms for a specific age group.

Main pictogram series

The most frequently evaluated pharmaceutical pictograms are the US Pharmacopeia Convention (USP) pictograms, reportedly developed by USP staff and redesigned in an iterative process with non-native speakers of English, elderly and people with varying literacy levels [16,25]. With the help of local participants, USP pictograms were adapted for a South African audience, leading to the 'SA' pictogram series [24]. Dowse and colleagues also developed pictogram sets for HIV/AIDS medication with repeated and active involvement of local participants [25,26]. By contrast, the Glyph system, a project to create automated illustrations of patient instructions [8], uses end users more as test subjects. A pictogram series developed by the International Pharmaceutical Federation (FIP) was designed for humanitarian medical missions with the help of a variety of cultural communities [27]. A subarea of the pharmaceutical pictograms field can be identified that is concerned with images that communicate about effects of drugs relating to driving [28–31].

User involvement and pictogram success

An overview of the main finding per outcome with respect to whether or not an effect of end-user involvement on pictogram success could be detected is presented in Table 1.

Pictogram 'understandability'

Effects of user involvement in the design on pictogram 'understandability' (see Supplementary material Table B-1 online) can be seen in particular when looking at the few studies that evaluate more than one set of pictograms. A study that compared pictograms developed by experts only to pictograms designed with lay involvement found that the latter were understood better [28]. Other studies saw that the locally adapted SA pictograms scored higher on 'understandability' than the original USP pictograms [24,32]. A fourth study developed pictograms based on design rules extracted from analysing USP pictograms and found better scores for the existing USP pictograms than their new pictograms, which had not been designed with end users [33].

These comparative studies imply that end-user involvement can indeed have a positive impact on how well pictograms are understood. Moreover, all studies that describe an extensive design phase with several redesign iterations involving lay participants resulted in highly understood pictograms [34–36], suggesting that repeated involvement might be a particularly effective strategy to increase the 'understandability' of pictograms. At the same time, the frequently evaluated USP pictograms show great variation in 'understandability' scores between target groups that differ with respect to country, age or literacy levels (see supplementary material Table B-2 online). This is an indication that pictogram 'understandability' should always be understood in the context of the intended target group. It should be noted that the only study in which all pictograms were sufficiently understood at initial exposure did not involve lay end-users in the design at all. However, compared to other studies, this article provided little information on the development process and had a low MMAT score [37].

Opinion on pictograms

All studies that measured perceived usefulness of pictograms (see Supplementary material Table B-3 online) and described a development process involved non-patient end-users in the design and, regardless of the exact moment or type of involvement, found that the resulting pictograms scored well on perceived usefulness [10,32,36,38–40]. In particular, low-literate end-users considered pictograms to be useful [10,32,36,38]. Two studies that redesigned pictograms based on consultative and informative input from lay participants found that the pictogram translucency scores (i.e., the perceived extent to which the pictogram manages to capture the intended message) increased significantly for the redesigned pictograms [41,42].

Involvement of lay participants in the design process led to pictograms that were preferred by that specific target group but were not necessarily universally preferred to other pictograms. This became apparent from several studies that compared USP pictograms to SA pictograms (see Supplementary material Table B-3 online): when evaluated in South Africa, SA pictograms were consistently preferred to USP pictograms [24,32,38]. An Indian study, by contrast, found preference for USP over SA pictograms [43]. Preferences for pictograms did not just differ between different cultural groups but also varied between patients and medical staff [44] and participants with adequate and low literacy levels [45]. Two studies that involved non-patient end-users as early as in the pre-design phase found that their pictograms were uniformly valued within the target group [40,46].

Information understanding and recall

Active involvement of lay participants, often in a participatory role and with patient end-users, was consistently seen to lead to a positive effect of pictograms on participant understanding or

TABLE 1

Effects of end-user involvement in design and final evaluation for different outcomes

Outcome	Effect of end-user involvement in design?
Pictogram 'understandability'	Yes
Opinion on pictograms	Yes
Information understanding and recall	Yes
Attention to information	Unclear – possible
Opinion on label or leaflet	Unclear – possible
(Pre-)intenders of health behaviour	Unclear – likely
Health behaviour	Unclear – contradictory

recall of information when presented in a drug label or leaflet (see Supplementary material Table B-4 online). Regardless of whether participants were involved in an informative or consultative role, all of these studies [8–10,47–52] made use of pictograms that had been redesigned repeatedly with involvement of lay participants, suggesting the importance of an iterative design process to optimise pictograms for understanding or recall of information. By contrast, studies that did not find an effect on understanding or recall described no development process [53,54], used USP pictograms without adaptations [55] or described only one moment of redesign with end users [7]. One study with an iterative design process involving native and non-native speakers of a variety of ages that evaluated their pictograms on a sample of elderly non-native speakers found no effect on information understanding for this group, but did find a positive effect for young native and non-native speakers [51].

Attention to information

Studies that evaluated the effect of pictograms on the extent to which participants pay attention to or notice information [6,31,56,57] involved either potential (i.e., non-patient) or patient end-users in the design phase, in informative or consultative roles, and found that pictograms contributed positively to attention to warnings [6], as well as the leaflet noticeability and likelihood of reading [57]. Not enough data were available to compare effectiveness of lay involvement in the design process. However, it was seen that samples with different characteristics, such as different cultures [31] or personal interests in the drug information [56], varied in the impact they perceived the pictograms to have and in how much attention they paid to the pictograms.

Opinion on label or leaflet

A similar effect was observed for outcomes relating to the perceived effectiveness and user-friendliness of drug information, as well as to preferences for different information formats. This was illustrated by two studies that evaluated USP pictograms in the USA: one study found no difference in perceived effectiveness between leaflets with and without USP pictograms in a general group of patients [58]; another study found that young participants perceived pictogram-enhanced information as more-effective than text-only information, but did not see this effect back in the intended target group of elderly participants [57]. Also examining a subgroup within a sample of general patients provided more-specific insights on patient perception of a drug label or leaflets: a study found that a general group of patients preferred a font-enlarged label to a pictogram label, but that elderly participants within this sample and those with a higher number of morbidities preferred the pictogram label [49].

With respect to the effect of lay involvement in pictogram development on how patients value resulting pictogram leaflets or labels, it could be seen that, regardless of whether or not end users had been involved in the design process or in what role, pictogram information generally had a high acceptability with respect to lay-out, liking of pictograms and amount of information [39,59–64]. Studies that compared pictogram-enhanced information with verbal- or text-only information (see Supplementary material Appendix B, Table B-6 online) almost all involved lay participants in the pictogram design – only in the example described above did the overall group prefer the text-only option [49].

(Pre-)intenders of health behaviour

All studies that described lay involvement in the design process found positive effects for the pictograms on pre-intenders of health behaviour such as self-efficacy, risk perception and behaviour change intention (see Supplementary material Table B-7 online). A study in which a pictogram-leaflet successfully increased patient self-efficacy involved non-patient end-users repeatedly in an informative and consultative role in an iterative design process [48]. Another study that compared pictograms about driving with medication found that those developed in a project with patient representatives conveyed a broader range of risk severity levels and corresponded with a higher intention to change behaviour compared with pictograms developed with experts only [28]. Similar as for 'attention to information', it was seen that the same pictograms could have different effects on risk perception and intention to change health behaviour between groups with different interests in the information presented [30].

Health behaviour

There was mixed evidence for the effect of end-user involvement on health behaviour, including dosing errors and adherence (see Supplementary material Table B-8 online); two studies that made use of the SA pictograms found better adherence in the pictogram leaflet group compared with the text-only group or those without a leaflet [10,65]. At the same time, a study that involved local patients from the very start of the pictogram development found no difference in adherence between a pictogram, standard or font-enlarged label [49]. A common factor for pictogram success in terms of an effect on health behaviour appeared to be the involvement of low-literate end-users in the evaluation [10,53,65–69].

Patient involvement

Many studies that develop or evaluate pharmaceutical pictograms sample non-patient participants (Table 2). This has been described as a less 'challenging' strategy when other characteristics of the target group already considerably narrow the sampling pool, such as when targeting low-literate patients [7]. In addition, access to a bigger group of participants can improve the cost-effectiveness and representativeness of a sample [70]. In this review, no difference could be detected of involving either patients or non-patients in the design of pictograms. However, pictogram outcomes can be improved by involving participants in the design with the same main characteristics (e.g., cultural background and age range) as the intended target group [24,32,51].

Groups with different cultural backgrounds, age range or literacy levels were also seen to differ in how they understand or evaluate pictograms. In addition, it was seen that samples with different personal interests in drug information can differ in how they perceive and respond to pictograms [31,49,56–58]. Together, these findings suggest that, although involving non-patient end-users in the development of pictograms is likely to lead to successful pictograms also for patient end-users, it is advisable to perform at least the final evaluation of pictogram success with actual patients. This has also been addressed by several authors

TABLE 2

Overview of moments, types and roles of end-user involvement

User involvement	Studies that describe		
	a pre-design phase (*n* = 8), % (*n*)	**a design phase (*n* = 39), % (*n*)**	**an evaluation (*n* = 72), % (*n*)**
Patients	0.0 (0)	7.7 (3) [7,41,49]	22.2 (16) [9,29,41,48–50,53,59,63–65,68,80–83]
Lay, non-patients	62.5 (5) [5,8,46,51,71]	51.3 (20) [8,25,26,28,34–36,40,42,44,45,56,60,62–64,71,78,84,85]	73.6 (53) [6–8,10,12,14,15,24–26,28,30–34,36–40,42–47,51,52,54–58,60–62,66,67,69–71,77,78,84–91]
In informative role	12.5 (1) [51]	15.4 (6) [34–36,42,56,64]	84.7 (61) [6–10,12,14,24–26,28–34,36–39,41–43,47–56,58–71,77,78,80–84,86–90,92]
In consultative role	12.5 (1) [71]	38.5 (15) [8,25,35,36,41,42,44,45,49,60,62–64,78,84]	50.0 (36) [5,7,10,15,24–26,28,30,32,36–45,49–51,54,57–64,78,81,82,85,87,91]
In participative role	50.0 (4) [5,8,46,71]	10.3 (5) [8,49,64,85]	1.4 (1) [46]

[23,61,62] who expressed the concern that people who do not have to use a particular treatment might not have the same interest to, for example, recall pictogram-enhanced written drug information as patients would.

Type of involvement

Participants were most commonly involved in an informative and/or consultative role in the design and evaluation of pictograms (Table 2). Relatively few studies involve end users in a role with creative freedom and decision power: the participative role [17]. However, early involvement of the target group in the development of pictograms corresponds with a more active type of input: lay participants in the pre-design phase are often involved in a participatory manner, for example by sharing their information needs [71], identifying topics that require visualisation [8] and having decision power on the selection of pictograms [46].

When end users are involved in the 'fuzzy front end' of the design (i.e., before initial design strategies are determined) [17] designers have more opportunity to incorporate preferences of the target group in the design in a more profound way compared with when they can only make adaptations to pictograms at a later stage of the development based on end-user feedback. Inviting end users to participate in the pre-design phase can contribute to the development of pictograms that are uniformly valued by the target group [40,46]. Targeting end-user preference with respect to design is essential, because pictograms that are viewed as appealing can act as peripheral cues for patients to process and be persuaded by information on therapy with low elaboration (i.e., with low levels of active cognitive information processing) [72,73].

A successful strategy to optimise pictograms appears to be repeated involvement of the target group, in an iterative design-evaluation-redesign process. This strategy works well to develop pictograms that are easily understood and valued by the target group and possibly also helps to design pictograms that have a positive effect on patient perception and understanding of written drug information, as well as on their sense of self-efficacy. Every design step that involves end users is an opportunity to gain more insight into how pictograms can be improved to better match the target group's information needs and preferences. An iterative approach has been a widely adopted strategy also in other design-related fields, such as computer system design [74–76].

Incomplete descriptions and heterogeneity

A limitation of studies that describe the design or evaluation of pharmaceutical pictograms, and consequently of this review, is that many articles provide an incomplete description of samples, materials and outcomes of evaluations, especially for intermediate steps in the design process. For example, the size in which pictograms were presented to participants was described infrequently, whereas pictogram size can affect how well they are understood [77]. In addition, criteria to score participant interpretations of pictograms as correct or incorrect are rarely provided, although this could make a considerable difference in 'understandability' outcomes. In addition to the information gap that limits the understanding of the context in which findings should be considered, there is considerable heterogeneity between studies. Sample characteristics and evaluation methods vary and, although the topic was limited to written drug information, the different messages that pictograms depict can affect their 'understandability' depending on how familiar participants are with them [78]. These issues in comparability are of particular concern because very few articles in the review directly compare different forms of end-user involvement within one study, so that conclusions mainly relied on similarities and differences between studies.

Implications and future research

Based on the available evidence, designers of new pictograms are advised to clearly define the key characteristics of their intended target group, to involve (non-)patient participants with relevant characteristics early on and repeatedly in the design process and to involve relevant patients or medication users at least in the final evaluation of pictogram success. When existing pictograms are used, care should be taken to select pictograms that have been designed for and evaluated on a population with similar characteristics to the patient group, in particular with respect to age, literacy levels and cultural background. In addition to more-complete and -comparative studies, limitations in our understanding of end-user involvement in the context of pharmaceutical pictograms could be addressed by research in the following areas. Developing or identifying instruments that make it easier for end users to contribute in a participative role. One of the few studies that did attempt to involve end users in a participative role found that their participants had no suggestions [8]. This is understandable, because thinking about solutions for drug information or pictograms can be a little abstract or perhaps even intimidating without proper guidance. More-interactive and -engaging exercises should be explored in pictogram design to scaffold idea-generation and make it more tangible and stepwise for lay participants, such as 'comicboarding' – a method in which participants are encouraged to brainstorm about solutions by filling in empty panels of a comic strip that introduces the design problem [79].

In addition, although the focus of this review was to explore the role of end users in design, it is also worth examining the role of experts. Where lay participants are the experts of their own experience, the design of pharmaceutical pictograms also draws on expertise in design, pharmaceutical sciences and communication sciences. If a target group has specific visual needs, such as is the case for a low-literate audience [45], it might also be advisable to include an expert on the target group. In addition to exploring effects of expert involvement, it would be interesting to see a truly collaborative pictogram design process, in which these different experts sit around the table with lay participants and all players have equal decision power [17].

Concluding remarks

This review shows that non-patient participants are often involved in the development of pharmaceutical pictograms and provides evidence that involving lay end-users in the design process helps to increase the likelihood that resulting pictograms are well-understood, well-received and aid understanding and recall of drug information they support. There is currently limited evidence for an effect of user involvement on whether the developed pictograms help to improve patient perception of drug information or their health behaviour. It is essential to involve participants that meet the key criteria of the intended target group in the evaluation of pictograms and pictogram-enhanced information, because it was seen that different audiences can vary considerably in how they perceive and respond to pictograms.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at https://doi.org/10.1016/j.drudis.2018.05.013.

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