

2.2.8 Health information formats

Introduction

Currently, health information is available in various formats and through all kinds of media: printed matter such as brochures or flyers, audiovisual formats such as videos, CDs, DVDs, and also CD-ROMs or websites via the Internet.

In most cases, the products and services also differ in their length (scope), which should be based on what information is relevant for decisions and therefore has to be communicated. When selecting the format, orientation towards the objective of the health information and towards its target group plays an important role.

The heterogeneous target groups have different needs. To take these into consideration, special – interactive – information formats were developed. These formats offer personalized or individualized information, where the preferences of the user can be embedded using interactive elements. What the interactive formats have in common is that they all aim to convey the content in a demand-oriented manner using various media and forms of communication. The users are able to control the amount of information and can select the contents they require. Interactive formats have the potential to support inclusion and learning in an active way because the presentation/communication of the contents takes the respective preferences and needs of each individual user into consideration (1).

Examples of interactive elements:

- Games (e.g. in the case of cancer therapy for adolescents: destroy cells that have mutated in different levels and collect shields offering protection from the frequent side effects of chemotherapy (2, 3)
- Questions of knowledge and understanding the theme (with/without feedback; perhaps with the tip to re-read the paragraph) (4, 5)
- Input boxes for e.g. age, gender, risk factors etc. for generating personalized health information (6)

These interactive elements can be used singly or in combination for health information. They are integrated particularly in computer- and Internet-based offers but can also be found in printed material.

Film sequences, texts read aloud, dynamic graphics and real-time contacts (chats with experts, affected people) that are embedded in information offers do not count to the interactive elements here.

Apart from interactive elements, so-called drug facts boxes are being used increasingly for health information.

A drug facts box is a one-page, compact, tabular presentation of the benefits and harm of a therapy. The numerical or percentage of frequencies of the main aspects of benefits and side effects for patients undergoing an appropriate therapy are presented along with a corresponding comparison group of patients who either received no therapy or a different one. In addition, the drug facts box can be supplemented with further details, e.g. information about medication, or warnings (cf. Figure 2).

The drug facts box was developed in order to present the benefits and side effects of medication understandably and without distortion (7, 8). The information on the comparison group shows how the disease might progress if untreated or by using another therapy. The principle of the facts box can also be applied to non-drug measures.

Facts boxes can also be used in the process of shared decision-making by physicians and patients. They help the physician to communicate the benefits and harm of a therapy appropriately and to find out the patient's preferences (9).

Drug Facts: TAMOXIFEN (No Ivdex)

What is this drug for? To reduce the chance of getting breast cancer

Who might consider taking it? Women at high risk of getting breast cancer (1.7% or higher risk over 5 years). You can calculate your breast cancer risk at <http://bcr.nci.nih.gov/btc>.

Who should not take it? Women who are pregnant or breastfeeding

Recommended testing Have a yearly checkup that includes a gynecological examination and blood tests

Other things to consider doing No other medicines are approved to reduce breast cancer risk for women who have not had breast cancer

TAMOXIFEN STUDY FINDINGS TABLE

13,000 women at high risk of getting breast cancer were given TAMOXIFEN or a sugar pill for 6 years. Here's what happened:

What difference did TAMOXIFEN make?	Women given a sugar pill	Women given TAMOXIFEN (20 mg a day)
Did TAMOXIFEN help?		
Fewer women got invasive breast cancer	2.7%	1.4%
Fewer women died of from breast cancer	0.09%	0.05%
Did TAMOXIFEN have side effects?		
<i>Life-threatening side effects</i>		
More women had a blood clot in their leg or lungs	0.4%	0.8%
More women had a stroke	0.4%	0.6%
More women got invasive uterine cancer	0.2%	0.5%
<i>Symptom side effects</i>		
More women had hot flashes	69%	81%
More women had vaginal discharge	35%	55%
More women had cataracts needing surgery	1.1%	1.7%
Other things to know		
Dying for any reason	1.1%	0.9%

How long has the drug been in use?
Tamoxifen was first approved by the FDA in 1982 - Studies show that most serious side effects or recalls of new drugs happen during their first 5 years of approval.


Figure 2: Example of a facts box (7)

Questions

1. What effects does information with interactive elements have when compared with information without interactive elements?
2. What effects do facts boxes have when compared with other formats?

Recommendations

1. Interactive elements in health information

	<p>Recommendation</p> <p>“Interactive elements may be used in health information.”</p> <p>Agreed: 9, Disagreed: 0, Abstentions: 1</p> <p>Quality of the evidence: moderate quality</p>
<p>Comment on the recommendation:</p> <p>The recommendation refers to the comparison of health information without and with additional interactive elements.</p> <p>This comparison showed a positive effect for health information with interactive elements in one study on the cognitive outcome <i>risk perception</i> and in two of six studies on the outcome <i>knowledge</i>.</p> <p>Positive effects for the use of interactive elements could be shown in two of three studies on the affective outcomes <i>acceptance / attractiveness</i>. The third study points to an effect in favor of interactive elements.</p>	

Summary of the findings

Characteristics of the included studies


For this comparison six studies with a total of 1,555 participants were included (3-6, 10, 11). In the studies computer-supported health information with interactive elements was tested against videos (4), printed matter (3, 6, 10) and computer-supported information without interactive elements (5, 11). The interactive elements consisted of integrated knowledge issues (4, 6), games and sound/video sequences (3), personalized risk presentations (and value clarification tools) (11), and dynamic avatars (5). Content information was provided on the consequences of alcohol misuse (4), anticoagulant therapy for atrial fibrillation (10), cancer respectively cancer screening (3, 6), prenatal tests (11) and Type 2 diabetes (5).

All of the studies were carried out in the USA and included different age groups (3-6, 10, 11). Included in one study each were adolescents aged between 12-18 years (3), pregnant women (11) and African-Americans of both sexes (6).

Results on the relevant outcomes

No clear effects could be seen for the cognitive outcomes (11) (3-5, 10). For the outcome *acceptance / attractiveness* positive effects or tendencies were shown for interactive elements.

2. Facts boxes

	<p>Recommendation</p> <p>“Health information may be presented as facts boxes.”</p> <p>Agreed: 9, Disagreed: 0, Abstentions: 0</p> <p>Quality of the evidence: high quality</p>
<p>Comment on the recommendation:</p> <p>The recommendation refers to the comparison of facts boxes and short summaries for medications (American advertisements).</p> <p>For this comparison a positive effect on the cognitive outcomes <i>risk perception / knowledge</i> was shown in one study in favor of facts boxes. This effect was also found for <i>comprehensibility / readability</i>.</p>	

Summary of the findings

Characteristics of the included studies

For this comparison two randomized-controlled studies (*symptom & prevention trial*, two studies in a journal (12)) were included with a total of 518 participants. These studies were conducted in the USA and were supplemented by a survey (7, 12). The intervention was a compact presentation (facts box) on therapeutic-medicinal measures (H2 blockers or proton pump inhibitors for acid indigestion) or preventive-medicinal measures (statins or Clopidogrel for secondary prevention of cardiovascular events) (12). The facts box supplied basic information about the medication and presented in a table the likelihood of a benefit or harm occurring through the drug, using numerical formats which laypersons can understand. The control intervention consisted of the short summaries of medications that the *American Food and Drug Administration* require as mandatory for advertisements addressed directly to patients and which do not stipulate any standardized information about benefits and harm.

Results for the relevant outcomes

Positive effects in favor of the facts box were shown for the outcomes *risk perception / knowledge and comprehensibility / readability* (7, 12).

Evidenztabels

Table 24: Evidence table „Information with interactive elements versus information only“

Certainty assessment						Summary of findings				
						No. of participants per group		Effect estimates		
Outcomes [No. of studies]	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Intervention	Control	Effects	Quality of evidence	Importance
Information with interactive elements versus information only										
Understanding / risk perception [n=1] Kuppermann (11)	RCT	serious (-1)	not serious	not serious	not serious	N= 244	N=252	In one study effect for interactive elements (11).	moderate	critical
Knowledge [n=6] Jones (3) Alterman (4) Ruiz (5) Rawl (6) Holbrook (10) Kuppermann (11)	RCT	serious (-1)	not serious	not serious	not serious	N= 802	N= 753	In two studies effects for interactive elements (6, 11). In four studies no differences between groups (3-5, 10).	moderate	critical
Acceptance / attractiveness [n=3] Jones (3) Ruiz (5) Kuppermann (11)	RCT	serious (-1)	not serious	not serious	not serious	N= 410	N= 317	In two studies effects for interactive information (5, 11). In one study a tendency for interactive information (no test on statistical significance) (3).	moderate	limited importance

Table 25: Evidence table „Information in facts boxes versus description of drugs (advertisements)“

Certainty assessment						Summary of findings				
						No. of participants per group		Effect estimates		
Outcomes [No. of studies]	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Intervention	Control	Effects	Quality of evidence	Importance
Information in facts boxes versus description of drugs (advertisements)										
Risik perception / Knowledge [n=2] Schwartz (symptom & prevention trial, two RCT in one publication) (12)	RCT	not serious	not serious	not serious	not serious	N= 233	N= 217	In two studies effects for facts boxes (12).	high	critical
Comprehensibility / readability [n= 2] Schwartz (7) Schwartz (symptom & prevention trial) (12)	RCT, Survey	serious (-1)	not serious	not serious	not serious	RCT: N=233 Survey: N= 274	RCT: N= 217 Survey: -	Three studies showed that information could be found, comprehended and used (7, 12).	moderate	important but not critical

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