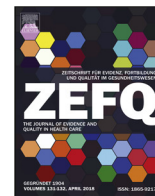




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Beteiligung von Patientinnen und Patienten / Patient Participation

## Health information for hard-to-reach target groups: A qualitative needs assessment



### Gesundheitsinformationen für schwer erreichbare Zielgruppen: Eine qualitative Bedarfsanalyse

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#### ABSTRACT

**Introduction:** Reaching socially disadvantaged families and older people with health information can be challenging. A needs assessment was conducted to learn more about their health-related needs and preferences and derive recommendations for health information.

**Methods:** Focus groups were conducted with socially disadvantaged families, older people and suitable disseminators, like counsellors from various types of counselling centres or welfare facilities (81 participants), and analysed using content analysis.

**Results:** Socially disadvantaged and hard-to-reach people want to understand health problems, become active in dealing with them themselves, and be involved in medical decision-making. Health information should consider the challenging everyday lives, the limited time available and the short attention span of socially disadvantaged families. There is a preference for short texts and videos. Older people may favour more comprehensive print products for complex topics. Matching photos and illustrations are vital to attract attention.

Health information is preferably received via personal contact. Furthermore, online services and social media channels are popular.

**Discussion:** Some recommendations can be helpful for all target groups of health information, like more illustrations. Others are more specific to the groups investigated and require conceptual groundwork and greater resources, for example, a specific service for disseminators.

**Conclusion:** Hard-to-reach target groups want to understand their health issues, and be proactive and involved in decision-making. Personal contact is of utmost importance. Disseminators play a crucial role and need information they can customize for their clients.

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##### Schlüsselwörter:

Evidenzbasierte Gesundheitsinformationen  
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 Zielgruppenorientierung  
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#### ZUSAMMENFASSUNG

**Hintergrund:** Für sozial benachteiligte Familien und Alleinerziehende sowie ältere Menschen ist der Zugang zu qualitativ hochwertigen Gesundheitsinformationen oft erschwert. Es wurde eine Bedarfsanalyse durchgeführt, um mehr über die gesundheitsbezogenen Bedürfnisse und die gewünschten Formate dieser Gruppen sowie geeignete Vermittlungskanäle zu erfahren. Daraus wurden Empfehlungen für die Erstellung und Verbreitung von Gesundheitsinformationen abgeleitet, um diese Gruppen besser zu unterstützen.

**Methoden:** Es wurden Fokusgruppen mit sozial benachteiligten Familien und Alleinerziehenden, älteren Menschen und deren Vermittlern, beispielsweise aus verschiedenen Beratungsstellen oder sozialen Einrichtungen, (n = 81) durchgeführt und inhaltsanalytisch ausgewertet.

**Ergebnisse:** Sozial benachteiligte und schwer erreichbare Menschen möchten Gesundheitsprobleme verstehen, im Umgang damit selbst aktiv werden und in die medizinische Entscheidungsfindung

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eingebunden werden. Gesundheitsinformationen sollen den herausfordernden Alltag, die begrenzte verfügbare Zeit und die kurze Aufmerksamkeitsspanne von sozial benachteiligten Familien und Alleinerziehenden berücksichtigen. Kurze Texte und Videos werden präferiert. Ältere Menschen nutzen bei komplexen gesundheitlichen Themen auch umfangreichere Printformate. Passende Fotos und Illustrationen sind ein wichtiges Element, um die Gruppen anzusprechen und die Bereitschaft zu steigern, sich mit den Informationen auseinanderzusetzen.

Der Zugang zu Gesundheitsinformationen erfolgt hauptsächlich über persönliche Kontakte. Darüber hinaus werden ausgewählte Online-Angebote und soziale Medien genutzt, um Informationen zu gesundheitlichen Fragen einzuholen.

**Diskussion:** Sozial benachteiligte und schwer erreichbare Menschen haben im Prinzip dieselben Ansprüche an Gesundheitsinformationen wie andere Gruppen. Persönliche Kontakte zu Vermittlerinnen und Vermittlern sind bei Gesundheitsfragen allerdings von herausragender Bedeutung, auch für den Zugang zu schriftlichen Informationen.

**Schlussfolgerung:** Um den Bedarf dieser Gruppen zu decken, ist es nötig, darauf zugeschnittene Gesundheitsinformationen zu erstellen, die Vermittlerinnen und Vermittler in ihrer Arbeit unterstützend einsetzen können.

## Introduction

In many countries, publicly funded sources provide evidence-based and up-to-date health information for patients and consumers to support decision-making on health issues. In Germany, one of these providers is the Institute for Quality and Efficiency in Health Care (IQWiG). For this purpose, the institute primarily uses a German- and English-language website [www.gesundheitsinformation.de](http://www.gesundheitsinformation.de) / [www.informedhealth.org](http://www.informedhealth.org) [1]

Health literacy is defined as the ability to find, understand and assess health-related information, and to use it to improve and maintain one's state of health [2]. As health literacy is a relational concept, it is not only determined by the individual competences of a person but also by the complexity of an organisation or a system he or she encounters. Evidence-based health information uses plain language, is patient-centred and reliable. It is meant to facilitate access to knowledge, especially for people with a low health literacy, and thus foster the motivation to gain further insights into health-related topics. [3] Old age, male gender, chronic diseases, a low educational level and social status, as well as a migration background, are among others associated with low health literacy [2,4,5]. These groups presumably require other access routes, formats and a different communication style [6,7] – otherwise there is a risk that the digitization of health information will widen the knowledge gap between well and poorly informed people (“knowledge gap hypothesis”) [8].

These so-called hard-to-reach groups need more than internet access to bridge this gap: the information provided needs to be both understandable and useful [9]. And only those who know how to search for health information online, and can assess the reliability of the sources, can benefit [10].

One of the main goals of evidence-based health information is to strengthen health literacy. This means not only providing reliable and understandable information, but also strengthening the ability to use this knowledge in everyday life and improving access to the healthcare system. Low health literacy makes it more difficult to make health-related decisions in accordance with one's own preferences [11]. Although this problem has been known for years, the needs and preferences of hard-to-reach groups with regard to health information content, detailedness, processing, formats, and access routes have hardly been investigated in German-speaking countries, and no evaluated concept exists on how to specifically address these groups [11].

Depending on their life circumstances, hard-to-reach groups presumably have different access routes and different needs with regard to health information. IQWiG therefore performed a qualitative needs assessment based on an explorative design and selected two hard-to-reach groups to start with: socially disadvantaged

families (including both two- and single-parent families, maximum middle school level, low income) and older people (65 years and older, maximum middle or secondary school level, low income). These two groups were chosen because both are likely to have a special interest in health issues: families as they feel responsible for the welfare of their children and older people as their health is often affected by (chronic) health problems. Furthermore, it is known that disseminators play a major role as confidants and multipliers for hard-to-reach groups [11,12]. Disseminators are understood to be professionals with direct contact to the above-mentioned target groups, such as employees of early help centers (“frühe Hilfen”), family centers, seniors services, senior centers, social welfare centers, or church institutions. They were also included in the qualitative needs assessment as the third target group.

The research questions of this project are:

- Is a health information website alone insufficient to reach socially disadvantaged target groups?
- Are other formats, channels, and forms of address required to meet the needs of these target groups?
- Do socially disadvantaged groups prefer information with a particularly high level of comprehensibility and practical relevance?

The aims of this project were

- to identify the health information needs of two hard-to-reach target groups, namely socially disadvantaged families and older people, as well as disseminators of the information (Part 1)
- to derive recommendations for health information (Part 2), and
- to examine the implementation of these recommendations in IQWiG's health information (Part 3).

The three parts of the project are described below.

### Part 1: Needs assessment

Using focus groups, we conducted a needs assessment with the three target groups mentioned above to determine their main health information needs and preferences, desired content, presentation formats, and communication channels. To ensure that data collection and analysis were not influenced by our position as publishers of health information, we commissioned external experts from the field of market research to recruit participants and perform these tasks. But we were involved in the design of the needs assessment, the development of the interview guidelines, the definition of the recruitment criteria, and the interpretation of the results.

## Methods

### Recruitment

In previous projects, recruiting hard-to-reach groups for studies (e.g. user testing of health information) was sometimes challenging. We therefore applied various strategies to recruit as many participants as possible corresponding to the criteria. The participants of the focus groups were recruited by market research studios in three different locations in Germany (Berlin, Erfurt, St. Ingbert). We chose these locations to be able to interview participants from both urban and rural as well East German and West German living contexts (each 50/50).

The participants were recruited from the region of the locations of the respective market research studios via databases containing potential study participants, key persons, and regional calls for participation using a purposive sampling strategy. We tried to achieve samples as homogeneous as possible in the individual target groups with people with the same or very similar demographic characteristics, such as income situation and educational status or age. In this way, we tried to create a pleasant, open group situation with people in similar life situations in order to promote a discussion as open as possible and to identify certain common issues and experiences. We used following selection criteria:

- Socially disadvantaged families: two- or single-parent families, maximum middle school level (secondary school level), low income (use of state support), min. 1 child under 10 years living in the household, fluent German speaking. It was planned to recruit 20 females and 10 males as well as 20 two-parent families and 10 single-parent families.
- Older people: people 65 years and older, fluent German speaking, 50% of the sample: socially disadvantaged (maximum secondary general school level, state support or income below the poverty line), the other 50%: maximum middle school level (secondary school level), average income or below, no state support. It was planned to recruit 15 females and 15 males.
- Disseminators: disseminators with direct contact with the groups mentioned above (like counsellors from various types of counselling centers, welfare centers, seniors services or child welfare facilities). It was planned to recruit 15 females and 15 males.

Exclusion criteria were homelessness, activity in a self-help organisation, professional training or professional activity in the health care sector and for the disseminators a status of a manager without direct contact with the target group and activity in self-help organisations as well.

### Data collection

Since we followed an exploratory design, it was not our goal to achieve data saturation and describe all aspects of a phenomenon. Rather, we would like to gain new insights or challenge our previous understanding of the phenomenon [13]. Therefore we decided to pre-determine the focus group number and size. We assume that about 4 to 8 groups with a homogeneous study sample are needed for reaching dense results [14–16].

We planned to conduct in total 18 semi-structured focus groups in two field phases with 90 participants. 5 participants per focus group and 6 focus groups for each of the 3 target groups were planned. Thus, 6 focus groups with socially disadvantaged families, 6 focus groups with older people and 6 focus groups with disseminators (30 participants for each target group) were planned.

We assumed that recruitment could be particularly difficult in the target group of families and single parents and over-recruited 1 person for each focus group. A lot of talks and preliminary contacts were necessary for the entire recruitment process.

Together with the external experts, we developed semi-structured interview guidelines (one for the target groups of socially disadvantaged families and older people / one for the target group of disseminators). After the first field phase, the guidelines were slightly adapted. The interview guidelines include semi-structured questions, for example on the following topics: Meaning of health and illness, information search and channels used as well as wishes regarding preparation, formats and distribution. The guidelines are available from the authors on request.

The focus groups, each lasting about 2 hours, took place between July and November 2020 and were conducted in market research studios at 3 different locations in Germany (Berlin, Erfurt, St. Ingbert).

Due to the Corona pandemic, in the second field phase some focus groups were not conducted face-to-face, but rather online. Some groups met on-site and facilitators were digitally connected. The target group of elders was invited to the studios and participated with prepared technology in separate rooms. The target group of families and facilitators were conducted entirely digitally. It was difficult to recruit highly aged elderly people. In the other groups, there were no recruitment problems beyond the known difficulties.

Two experienced facilitators (one female / one male, both psychologists) conducted the focus group sessions. The facilitators had no relationship to the participants before the focus groups were conducted.

### Data analysis

Each focus group session was recorded (video and audio) and transcribed verbatim. Additionally, notes were taken during each session. The transcripts were analysed based on qualitative content analysis according to Mayring [17]. After each focus group the impressions from the session were gathered and discussed with the whole team (two facilitators, two coders and the project manager) and condensed into first hypothesis. The next step comprised the analysis of the transcripts according to a codebook derived from the interview guidelines as well as the first hypothesis from the discussion right after each session using MAXQDA analysis software (version 2020 Analytics Pro). Additional themes discussed in focus group sessions besides the interview guidelines were included as well. Inductive development and deductive application of categories were worked out using an iterative analysis process. Results were condensed according similarities and differences between the target groups.

Certain themes have been repeated in the individual groups. However, new themes were always identified as well and the codebook was expanded continuously. We therefore assume that we were not able to achieve data saturation. However, the results of this study provide valuable information for health information providers and should be the basis for further studies. The coding tree is available from the authors on request.

The results of individual focus groups were interpreted and discussed with the entire project team. The analysis was conducted by two coders under supervision of the project manager and the interpretation of the results was conducted by the whole project team.

In order to avoid bias with regard to the analysis of results, none of the persons involved was an editor or publisher of health information. As client, IQWiG was not involved.

## Results

### Sample

The overall study population (socially disadvantaged families, older people and disseminators) included 81 of the 90 participants originally planned, and 18 focus groups were formed (Table 1). After the end of the first field phase after 9 group sessions, no

**Table 1**  
Characteristics of the study participants.

	Socially disadvantaged families and single parents	Older people	Disseminators	TOTAL
Female	19	16	23	58
Male	6	13	4	23
20 to 35 years	10	-	4	17
36 to 50 years	13	-	7	21
51 to 65 years	2	9	8	23
> 65 years	-	20	12	20
<b>TOTAL</b>	<b>25</b>	<b>29</b>	<b>27</b>	<b>81</b>

changes were made to the sampling strategy. All participants provided written informed consent and received an incentive. The amount varied from 50 to 100 € depending on the target group and region.

A total of 58 women and 23 men between the ages of 26 and 74 participated. The two hard-to-reach target groups included 54 participants (35 women and 19 men) with the following school leaving qualifications: none (n=1), foreign qualification (n=1, level unclear), primary school level (n=6), middle or secondary school level (n=44), and university entrance level (n=2). 35 participants were receiving state support, 18 were receiving pensions (old age: n=16, disability: n=2), and one had a low income. Between 1 and 5 children were living in the socially disadvantaged families. 30 participants reported having a chronic illness.

The 27 disseminators worked for organisations such as child welfare facilities and various other types of counselling centres (e.g. for senior citizens or socially disadvantaged citizens) and charities. The 23 women and 4 men were between 26 and 68 years of age.

51 participants lived or worked (in the case of the disseminators) in urban areas and 30 in rural areas.<sup>1</sup>

#### Target group 1: Socially disadvantaged families

Socially disadvantaged families described a challenging everyday life characterized by problems in personal relationships, schooling and financial worries. They also reported several health problems, such as allergies, obesity, attention deficit hyperactivity disorder, depression, self-harm, and addiction.

Parents often showed a high level of uncertainty and anxiety about their children's health, but paid less attention to their own. They noted that distinguishing between "harmless" symptoms and signs of serious health problems was often difficult and stressful. They were also worried about overlooking warning signs that could lead to serious illness, especially in young children. Discussions among family and friends about controversial topics, such as vaccinations or the role of vitamin D, tended to further increase uncertainty and anxiety.

Some participants reported unsolicited recommendations for action from daycare centres and schools or from the youth welfare office. Health issues were particularly challenging when people feared losing control of the situation (for example, regarding uncertainty about what to expect or what to do) – especially with regard to their children. The need for information varied, depending on whether a health problem was acute or chronic.

#### Reactions to acute and chronic health problems

With regard to minor symptoms in adults or children, participants often asked family or friends for advice, tried not to dramatize the situation, and strove to be proactive. With regard to more serious symptoms, especially in children, participants often visited a doctor or an accident and emergency unit. Explanations by doctors were mostly reported to be too short and not fully comprehensible, resulting in a further need for information.

Participants with chronic diseases described that they often felt a constant need for information and felt under pressure to obtain more detailed information, for example, on the benefits and risks of treatments.

The following channels were generally preferred by socially disadvantaged families to obtain health information:

- Personal contacts:
  - Doctors
  - "Everyday life influencers" (offline and online), e.g. other parents or neighbours
- Online services: websites / mobile access
- YouTube
- Instagram
- Facebook

#### Target group 2: Older people

The everyday life of this target group tended to be quiet and they often had a lot of free time. They frequently reported that illnesses were increasingly affecting their lives and were a major, time-consuming issue. They were often affected by both chronic progressive diseases and acute problems such as falls. The prevention of (further) illnesses was a major issue for many.

The participants reported that the increase in free time allowed them to care for themselves and others. Their state of health was often a dominant topic in their everyday conversations and there was a great need for communication. The people in this target group also tried to maintain control over their own health. They were especially interested in the following issues:

- Which new treatments or remedies are available?
- What can I do to prevent the condition from getting worse and to avoid late complications (e.g. in diabetes)?
- What do others do about it? How do they cope with the disease? Can I learn something from them?
- Before surgery: What do I have to expect?

After consulting a doctor, participants reported that they often had to conduct their own research to understand and "translate" the information they received, indicating that their need for information is often not satisfied by doctors. Second and third opinions were often sought from other doctors, but also from family, friends and other people affected with similar health problems.

The following channels were preferred by older people:

- Personal contacts:
  - Doctors
  - Family, friends and neighbours
  - Senior Centers
  - Other "everyday life influencers", like other patients, volunteers and persons of the same age

- Pharmacies, medical supply stores
- Websites
- Print products (of medium length)

The main wishes for health information were similar in both socially disadvantaged families and older people, and are summarised in [Figure 1](#).

#### Target group 3: Disseminators of information for both target groups

Disseminators reported that they were often involved in the health management of their clients for a longer period of time, liaised with their families, and had close insight into their clients' lives. They also often acted as mediators between clients and authorities.

The disseminators usually worked in professional structures in an institution or network, with a clear division of roles and access to experts on health issues. They distinguished between common, often socially problematical health issues they were heavily involved in (e.g. providing extensive support in the event of an unwanted pregnancy, behavioural problems, sexually transmitted diseases) and specific health issues they were only marginally involved in (e.g. accompanying clients to a doctor).

They used both print and online products. Sometimes they felt overwhelmed, and complained about “information graveyards” – that is large amounts of information they did not use as they had lost track of it.

## Part 2: Recommendations for health information derived from the results

About 30 target group-specific recommendations for the production and further dissemination of health information were derived from the results. These recommendations are summarised below.

#### Recommendations for the target group “socially disadvantaged families”

Health information formats should be adapted for this target group to take into account their challenging everyday lives, the

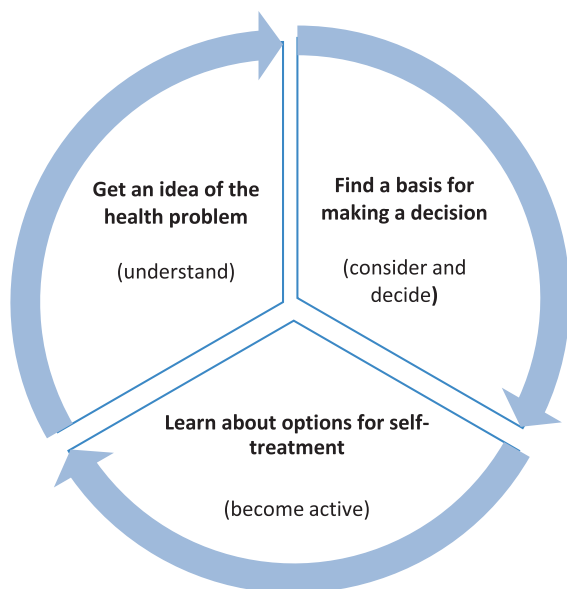


Figure 1. Wishes for health information.

limited time available and their short attention span, requiring the use of short texts, short videos, and tools containing playful elements.

The topics should start with specific content relevant to problems of everyday life, such as the condition's symptoms, treatment and effects of the condition. Information on seeing a doctor and using the healthcare system should also be placed more prominently. More abstract topics such as prevalence of the condition and risk factors should be mentioned later on.

In addition, treatment options should be presented by degree of invasiveness. This means first describing what patients and their families can do themselves, followed by non-invasive treatment options, and invasive ones. This does not apply to treatment options in emergencies.

When using photos, videos and other visuals, it is important to be considerate and select appropriate images. Real-life stories offer opportunities for identification and can thus also facilitate access to information. The target group-specific recommendations are summarised in [Figure 2](#).

In the case of online health information, plain and straightforward information that is free of cost and advertising is required. In addition, easy registration, the option of personalisation, and information on how data protection is ensured should be provided.

#### Recommendations for the target group “older people”

Older people prefer short formats, but they may prefer more extensive print products such as brochures for complex topics. Older people often have more time to consume information and when they are personally affected, some are more interested in learning about certain health topics. This is reflected in their preferences for health information formats.

For older people, information related to visits to the doctor and the healthcare system, as well as real-life stories, are of particular interest. Older people also want to have a list of treatment options ranked by degree of invasiveness. When using photos, videos and other visuals, the formats should be chosen carefully to ensure that the images are appropriate (see above).

The wishes expressed by older people for formats conveying health information are summarised in [Figure 3](#).

#### The following recommendations apply for both hard-to-reach groups

A plain introduction, for example a brief summary to start with, is important to encourage further use. In addition, it is essential to highlight the independence of the authors and provide details of the publisher.

For both hard-to-reach target groups, it became clear that the social environment and daily influencers play an important role in the communication of health information. Written information is often only noted and is then used when it is personally recommended. Patients and their families are active in this network, both as recipients of shared information and as mediators.

It is therefore important that health information can be shared in a straightforward way (e.g. by forwarding, ordering), both online and offline. Give-aways with a reminder effect can also be useful for publishers of information. In addition to this, we derived the following recommendations on editorial design:

- The content should be made as relevant to everyday life as possible, e.g., focussing on everyday problems related to a disease (e.g. dealing with loss of appetite).

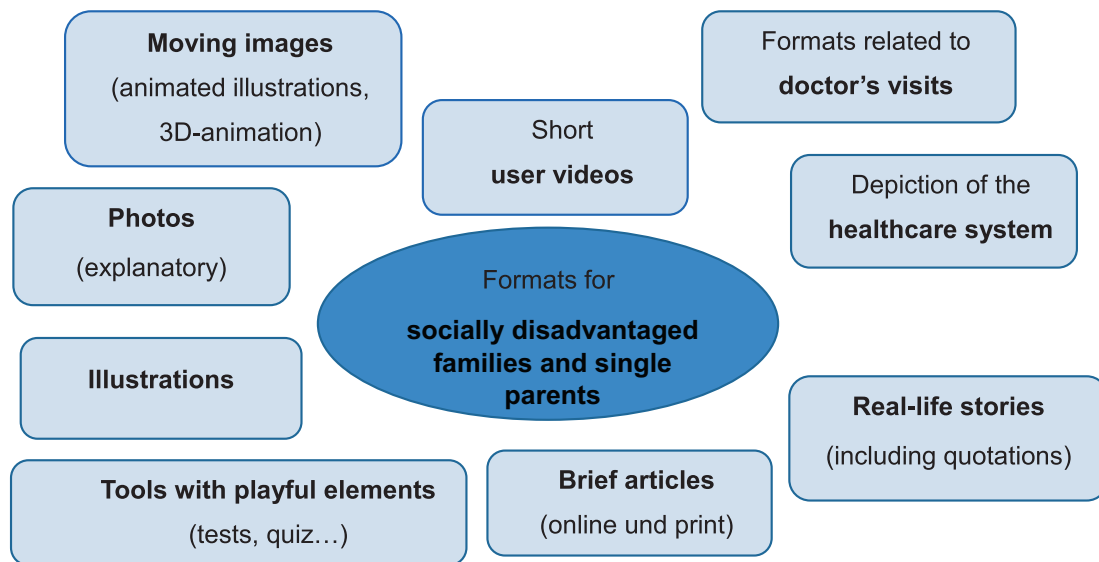


Figure 2. Formats for socially disadvantaged families and single parents.

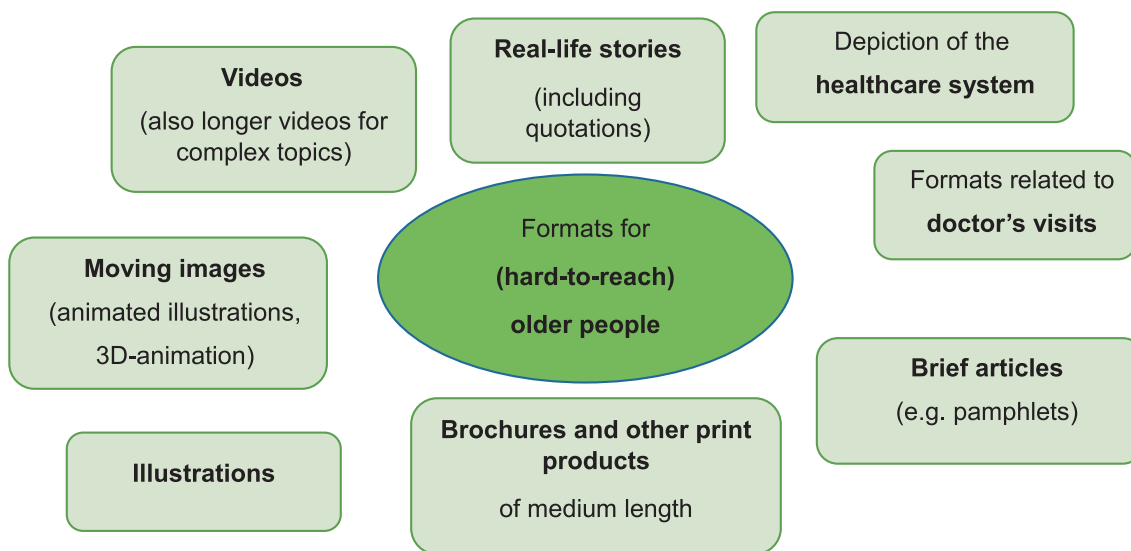


Figure 3. Formats for (hard-to-reach) older people.

- Practical, easy-to-use formats should be developed (e.g. printed graphs for people with diabetes to pin on the bathroom wall which show how to check their feet).
- The language used should be as plain as possible (e.g. when describing the potential benefits and harms of treatment options, the causes and course of disease, and the healthcare system.)
- Users should be addressed directly as often as possible.

There should also be a low-threshold referral to support services to increase the general appeal of health information.

*Recommendations for the target group “disseminators”*

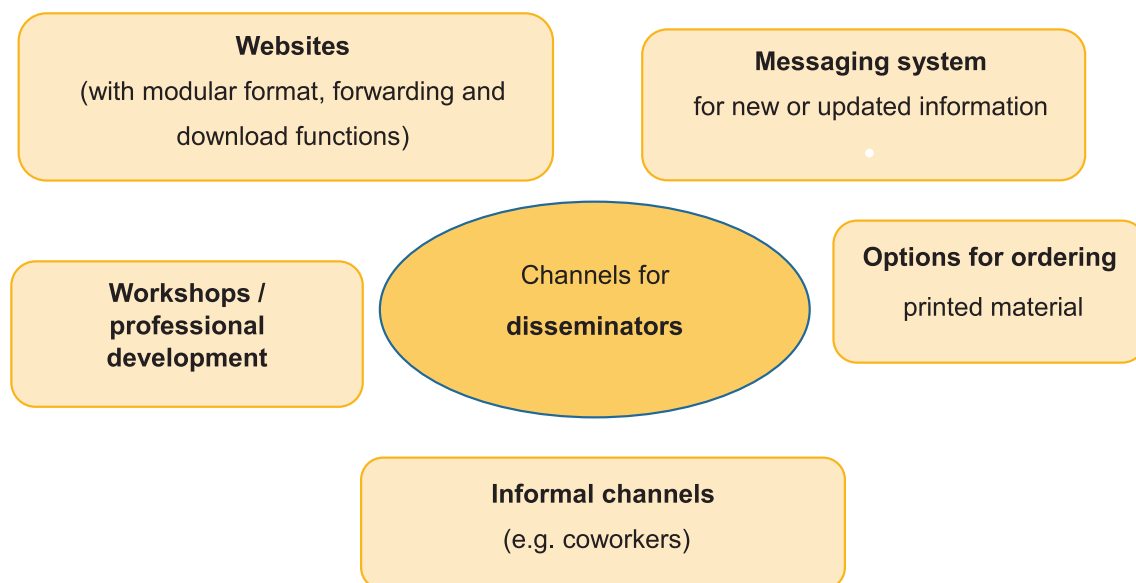
Disseminators use health information in two main areas:

- dissemination to clients and
- their continuing education.

Disseminators appreciate the access channels for information shown in Figure 4. Their preferred option is an online service in modular format. This means that disseminators can put together, forward, order or download various formats for different topics themselves, for example on a website. They prefer a service that is as personalised as possible, for example, a subscription only for the topics that interests them most.

**Part 3: Classification and implementation of the recommendations for IQWiG’s health information**

First, the recommendations for action from the needs assessment were aligned with the recommendations for health information that had already been implemented or were about to be implemented for [www.gesundheitsinformation.de](http://www.gesundheitsinformation.de) / [www.informedhealth.org](http://www.informedhealth.org). In the next step, we compared



**Figure 4.** Channels for disseminators.

- which recommendations could apply to all target groups and be implemented with manageable effort in short or medium term
- which recommendations could apply specifically to the target groups investigated and what effort (methodological, financial, personnel, time) would be involved.

*Recommendations for all gesundheitsinformation.de / informedhealth.org target groups*

We assume that some recommendations will be helpful for all users of our website. Many can probably be implemented with limited effort. These include:

- Facilitating technical transfer of the information
- Providing a desktop link
- Making the independence of the authors and publisher clearer
- Providing a brief summary for all electronic devices, e.g. tablets and smartphones (“At a glance”)
- Further developing graphics / including more graphics
- Making editorial adjustments, for example, directly addressing users, including subheadings in question form, establishing everyday relevance
- Listing treatment options by degree of invasiveness
- Describing the system of care (disease-specific)

*Specific recommendations for hard-to-reach target groups*

Other recommendations are more specific to the target groups investigated. The implementation of these recommendations requires conceptual preparation and piloting.

These recommendations include:

- Creation of a specific service for disseminators
- Involvement of everyday influencers as disseminators (for example, people who are trusted by the target groups, such as social media influencers, neighbors who work in the health care system, hairdressers)
- Further development of appropriate images (including access to appropriate photo databases, photos with explanatory value)
- Formats for the preparation and follow-up of medical consultations

- Personalised notifications for publications or updates (including dealing with data protection)
- Expansion of the range of videos (including target group-specific application and explanatory videos)
- Social media campaigns

## Discussion

The aim of the project was to identify the health information needs of socially disadvantaged families and older people and their disseminators (Part 1), to derive recommendations for health information (Part 2) and to examine the feasibility of implementing these recommendations for gesundheitsinformation.de / informedhealth.org (Part 3).

Our evaluation of the recommendations showed that some of the measures appear to be helpful for all target groups and can probably be implemented with an acceptable amount of resources. As expected, additional services are needed to reach the two hard-to-reach groups we investigated, requiring methodological discussions and resources.

*Main channel for the dissemination of information: personal contact*

The main research question of the project, namely, if a health information website alone is insufficient to reach socially disadvantaged target groups, was generally answered in the affirmative. When it comes to health issues, personal contact is of outstanding importance for socially disadvantaged families and older people. Our findings confirmed that not only doctors and other professionals take on the role of advisors, but also family members, friends and others with a (perceived) information advantage. There is a great need for communication regarding health information that is not, and perhaps cannot be satisfied by doctors alone.

In addition to direct face-to-face communication, exchanges via social media are important, but secondary to in-person exchanges. This is also reflected in a study on the health literacy of the population in Germany: people with a low educational level and social status use digital information channels significantly less often than those with a higher educational level and social status [2]. If the use of these channels (e.g. family groups on messenger services

or social media sites of influencers) is meant to become more attractive, the available information must be easy to share.

According to the study above, about three quarters of the population in Germany have difficulties assessing the quality of health information – especially in terms of trustworthiness and neutrality [11]. This finding also supports a result of our needs assessment: recommendations by disseminators, such as doctors, caregivers, and everyday influencers, seem to play a major role in trusting the information conveyed. Besides promoting the information via disseminators, one further recommendation is to place information about the publisher and its independence prominently in the offline or online health information.

#### *Practical information that tackles everyday concerns*

The users questioned in our assessment stated that they preferred concise texts with references to everyday issues and also wished to be addressed directly. The texts should deal with the challenges, questions and problems that patients with a specific illness encounter in everyday life and, where appropriate, be practical in terms of the text design and format chosen (e.g., a short text or a postcard that also addresses requirements arising from caring for a sick child). This is important as many people in Germany find it difficult to find specific health information to help cope with a health issue in everyday life [11].

A further research question in our assessment, namely if other formats, channels, and forms of address are needed, as well as a particularly high level of comprehensibility and practical utility of the information, was also largely answered in the affirmative. According to the study above [11], people with a low level of education, low social status, older people, and also younger people have problems finding their way around the healthcare system in Germany and are greatly interested in tailored information on the healthcare system. This is also reflected in our needs assessment.

#### *Scope of information*

In our needs assessment, how much text in a health information product was considered appropriate also depended on the importance of the topic and the degree of personal concern. Whereas a flyer was considered sufficient for the topic of head lice, for example, many older people found that a flyer on chronic obstructive pulmonary disease provided insufficient content. In addition, the willingness to deal with (longer) texts increased significantly with personal strain.

Print products generally seemed rather unattractive to socially disadvantaged families; only short flyers were considered helpful as a source of information. In contrast, older people were more willing to read a longer brochure on complex topics. These clear differences may not only be due to different life circumstances of the respective groups but also to a different media usage.

#### *Photos, illustrations and videos are crucial*

Photos and other illustrations are essential tools to increase the appeal of information and as an alternative to text-based presentations [18]. They facilitate understanding and are a prerequisite for being open to the information provided in the first place, whereby all types of formats (e.g. instructions for exercise or anatomical images) are considered helpful [18].

Whether users immediately feel addressed by information is of key importance for its acceptance. In the needs assessment, this was the case when users felt that the information reflected their situation. Photos had a great effect here, but might also be

counterproductive, for example, if the people depicted appeared to be too young and active for a particular illness.

Despite the abundance of photo databases, the recommendation that appropriate photos should be used for the respective target group is difficult to follow, as few databases provide photos depicting hard-to-reach target groups neutrally. Alternative options, such as separate photo shoots, should be examined here.

In our needs assessments, socially disadvantaged families reported that they preferred videos on health issues to written information; if low-threshold access to health information is required, these videos are an important means of communication because many people have difficulties reading and understanding written information (see, for example, a study on literacy in Germany [19]). However, if publishers of health information develop their own target-specific videos, besides clarifying methodological issues (e.g. risk communication), the financial and human resources required for their production need to be considered.

#### *Information channels*

In addition to communicating health information via personal contacts and (personalised) online services, social media channels such as Instagram and Facebook should also be used in line with the recommendations from the needs assessment.

#### *Facilitating orientation in the health care system*

A further German study on reading and writing abilities showed that more than half of the population in Germany find it difficult to understand the terms used by doctors and to ask the doctors to provide explanations [2]. This supports our recommendation that information for the preparation and follow-up of medical consultations should be provided, such as question lists for patients or formats explaining what information the doctor will need from the patient. This requires further research e.g. which specific content should be included and which format comes handy at which time.

#### *Shared-decision-making is the favoured approach*

Another remarkable result was shown for the publishers of evidence-based health information: the main preferences for health information were similar in both hard-to-reach target groups investigated, and are probably similar to those of other target groups. Both socially disadvantaged families and older people want to understand health issues, be proactive, and be involved in decision-making. Direct recommendations for certain treatment options were rejected by most participants.

Proactive involvement in decision-making would be supported e.g. by listing treatment options according to invasiveness, from “What can I do myself?” to surgical interventions.

#### *Need for further research*

It should be noted that further research is required regarding the limitations of this project (see below). Our results are not representative of the respective target groups. Both further qualitative research on the operationalisation of individual recommendations (e.g. “appropriate images” or “establishing references to everyday life”) as well as quantitative studies to verify the validity of the results would be useful. Other hard-to-reach target groups, such as people with experience of migration and a limited knowledge of the German language or people who are long-term unemployed, should also be investigated in order to determine their needs. Furthermore, evaluation strategies should be developed to examine whether the implementation of the recommendations described



in this article can help the target groups to cope with the respective disease and thus strengthen health literacy.

## Conclusion

The research questions of this project were largely answered in the affirmative: A website with health information alone is presumably insufficient to reach the target groups examined. Other formats, channels and forms of contact are needed, as well as a high degree of comprehensibility and practical utility of the information.

Among socially disadvantaged families and older people, there is a great need for communication about health and illness that is not and perhaps cannot be satisfied by doctors alone. These target groups also want to understand health information and be actively involved in decision-making on health issues. Some recommendations from the needs assessment could be helpful for all target groups of health information and can often be implemented without major effort. Other recommendations specific to the two target groups investigated require conceptual groundwork and greater financial and human resources.

## Implications for practice

As a result of this needs assessment:

- Both socially disadvantaged families and older people want to understand health issues, be proactive, and be involved in decision-making. Direct recommendations were mostly rejected.
- When it comes to health issues, personal contact is of outstanding importance for socially disadvantaged families and older people.
- Some recommendations seem to be useful for all target groups of health information and can be implemented with a manageable effort.
- Other recommendations are more specific measures for the two hard-to-reach target groups investigated and require the development of a concept as a basis for further action. These measures require greater methodological input as well as greater financial and human resources.
- Needs assessments for further hard-to-reach target groups of health information would be an asset.

## Limitations

It is often difficult to recruit participants from socially disadvantaged target groups for projects of this kind [20]. To what extent the individuals who agreed to participate in a focus group represent their target group is unclear. As described in the literature, we also had difficulties recruiting participants from these target groups. It was particularly difficult with the younger target group, for example due to a stressful everyday life, feelings of shame about one's own life situation, technical requirements such as fast internet access, and in some cases the incentive paid must be declared to the authorities.

Since only people up to the age of 74 were included, the results cannot be transferred to older people.

Although IQWiG was not involved in data collection and analysis, it was involved in the design of the needs assessment, the development of the interview guidelines, the definition of the recruitment criteria, and the interpretation of results. This may have resulted in an unconscious influence on the implementation

of the project as a publisher of health information and a commissioner of this project.

Due to the special challenges of the corona pandemic, data collection had to be adapted and in part shifted to online collection. This had an impact on recruitment and data collection, for example, the very elderly were no longer recruited and, possibly, the technical challenges and a virtual interview format made it difficult to participate despite several hygienic adaptation in the recording studios.

However, there were fewer cancellations than expected and 81 of planned 90 participants finally took part.

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## Conflict of interest

IQWiG produces and publishes evidence-based and freely accessible health information for the general population. In its role as producer and publisher, there is a risk of influence on project implementation, especially recruitment, data collection and analysis. In order to prevent this influence, an external expert group was commissioned to conduct the project.

## CRediT author statement

Beate Zschorlich: Conceptualization, Methodology, Resources, Validation, Visualization, Writing - Original Draft, Project administration.

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