

# “Excellence Entails Exertion [1,2]”

Reflections about the position and compass of medial quality assessment of medical services – in particular in the field of oto-rhino-laryngology



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## ABSTRACT

In case of acute symptoms, medical issues or physician search, more and more patients tend to retrieve information on the internet. That pre-information and the German law regarding patient rights led to a considerably altered relationship between patients and health professionals. With the increasing quantity of information, the question about its quality and validation comes to mind. There is already neutral and assured information of independent providers existing but their awareness level – even though among health professionals – is low; in addition, depth and width of it are missing. Nevertheless, the classification of information and the communication between health professionals and patients continue to be essential.

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Why do I as journalist write a contribution for this booklet? Well, quality assessment of information is the daily bread of journalists. This is especially true when new topics arise and long-term expertise is missing. So I performed a research which information sources exist for non-medicals, how much healthcare professional know about them, and which quality rating of medical service is possible in this way.

## 1. An international football match and a snoring child – I research on the internet

“Our child is snoring”, I told my husband who watched an international football match on TV and stared spellbound on the screen. “He resembles me”, he laughs. But I am worried. What may be the reason? Has our child caught a cold or is it something more serious? I do not want to wait for the doctors’ offices to open on Monday. I want to know it now. “Goal”, shouts my husband. What shall I do? Call my mother? Search on the internet? Look up the manual

of pediatric diseases or – as in former times – hope, pray, and lay on healing hands?

I decide for internet research for symptoms, treatment options, and physicians that I want to contact on Monday.

And this is the way many other people go as well. According to a study from 2003 [3], acute complaints were the primary motivation for the search of health-related information. So patients were no longer passively undergoing the physicians' suggestions but looked actively for information about diagnoses and therapies. Twelve years later, in comparison to the former results, a study [4] found out that about 89 % of the population search actively for information about health-related topics.

## 2. How did German legislation react on researching patients?

With the law of patients' rights [5] from 2013, the physicians' obligation to inform their patients and the interaction of physicians and patients regarding treatment was clearly defined. According to that, the relationship between physician and patient changed from a paternalistic to a participative system. Based on the German Civil Code, the physician has to inform the patient about the diagnosis and (alternative) therapy options and the patient has to agree. Thus the joint decision is a patients' right and according to a survey [6] it is favored by 80 % of the people. Hereby, 92 % stated that they know that the patient information is legally defined, however, 77 % [7] think that the physician has to provide the information material.

The wording of the law [8] only indicates that documents may also complete the information that the patients receives. So if they are available, there is the possibility that the patients inform themselves. However, this information does not make patients to be medical experts. Several questions always seem to remain open. Beyond the information given by the physicians, patients for example retrieve information via the cancer information services (Krebsinformationsdienst, KID) of the German Center of Cancer Research (Deutsches Krebsforschungszentrum, DKFZ) that answered between 28 000 and 35 000 individual enquiries by phone or e-mail from 2013 to 2018 [9]; most of them focusing on topics like diagnoses and first treatment.

The self-responsibility desired by legislation with regard to the own health leads to the situation that people acquire abilities and skills in the context of health-related questions and develop a certain understanding of evidence-based medicine [10], which is called health literacy. This literacy encompasses the collection and evaluation of information by the patients as well as the implementation of the information that is considered being beneficial. In view of information acquisition on the internet, the term of "digital health literacy" is applied that includes the competent use of digital media.

The major significance of this term is the correlation between health literacy and mortality. According to a trial [11], people with a lower health literacy seem to show a 1.5–3 times increased risk for an unfavorable course of their diseases as well as the rare participation in vaccination and prevention programs such as mammography

screening. Digital health literacy seems to be relevant for the course and the prognosis of diseases, as stated by the authors [12].

## 3. How do physicians meet pre-informed patients who have to be informed according to legal acts?

According to a trial from 2016 [13], 98 % of physicians working outpatiently reported from the previous 5 years that their patients are more frequently informed about medical or disease-related questions than in former times. During a normal working day, about one of four practitioners (24 %) discuss with more than 30 % of their patients about information that the patients had retrieved elsewhere.

Based on a study [14], the Germans use more than 3 different sources on the average to get information about health-related topics.

In 81 % of the cases, they look up therapies, followed by disease-related symptoms (72 %), and general diseases as well as options offered by health insurances (both 66 %).

According to a study [15], about 28 million Germans as of 16 years – and thus 60 % of all internet users and 38 % of the population – researched on the internet in 2011 about diseases, injuries, and nutrition, while 78 % of the people in the USA who had internet access in 2012 (70 % of the population) stated that the internet was the primary source of information regarding health-related questions.

However, patients who are pre-informed by the internet or personal discussions prior to visiting a doctor do not only encounter enthusiasm of the physicians who in the past had the monopoly of health-related information. As shown in a study [16], more than half (54 %) of the physicians reported that this information had sometimes positive and sometimes negative impact for the physician-patient relationship.

This aspect even deteriorated over the time. In 2003, nearly one third (31 %) of the physicians stated that pre-informed patients needed less explanation and had better understanding (47 %). These values reduced to the half in 2015. Only 15 % perceived that pre-informed patients needed less explanation and only 24 % of the physicians thought that understanding was facilitated. Especially physicians who treat a high number of patients with a lower level of education rate self-retrieved information three times as negative compared to those who have higher-educated people among their patients.

Nonetheless, more than one third of the physicians (37 %) agreed that it is easier for patients to participate in decisions regarding their health based on collected information, although only 16 % of the physicians believe that this information contributes to more security for the patients.

In view of the impact of well-informed patients, the physicians' opinions are not really changed. Nearly one third stated in 2003 (32 %) as well as in 2015 (30 %) that the information retrieved by the patients themselves mostly confuses them and impairs their confidence.

A large US-American trial from 2003 [17] showed that physicians often had the feeling that pre-informed patients would question their authority.

#### 4. Quality of information about disease- and health-related topics, in dependence of information sources

And what about the quality of information? As it is well-known, not all retrieved information is worth the paper on which it is written. Already defining the term of quality has an own “qualitas”, because it is not easy for every patient to determine the level of conformity [18] with the requirements towards information. It is rather easy to answer the question if information is understandable, but to judge if this information is correct, relevant, complete, consistent, up-to-date, and transparent – with regard to the author’s intention – expects too much of laypeople. Finally, the evaluation of the quality of information is associated with expertise.

In the world of media, this responsibility is taken by the editorial staff, the publisher, the editor, proofreader, or librarian. They professionally check, select, and compile the information. Patients who have not accomplished medical studies have to align the retrieved health information (actual) with the requirements (target) to the quality of information with common sense and experience. But already the requirements to the “target” may be very different. There are people who are happy when they can follow the explanations linguistically even if they do not fully understand the content. “Sounds good”, is then the answer.

In this way, the actual-target alignment may lead to different results. In addition, the current world of information is much more complex and confusing compared to the time two decades ago. The number of media products and the accompanying competition for the attention of possible recipients massively increased. The consequences resulting from the elimination mechanisms of competitors are not always clear for the observer. So the quantity of available information is constantly increasing but not necessarily the quality. Often readers feel sufficiently informed when they read journals that are available for free and take online contributions shared in social media at face value.

Researchers from the USA [19] found out that at the occasion of the Zika virus spread misleading videos were more frequently distributed via Facebook than correct information of public health institutions such as the World Health Organization (WHO). In an article [20] published by the medical historian Robert Jütte of the Institute for History of Medicine of the Robert Bosch Foundation stated that people have always been particularly susceptible for fake news in the context of health topics. Possible dangers for life cause fears. This fact, according to the psychologist Claus-Christian Carbon of the University of Bamberg in the same contribution [21], makes it difficult for people to categorize risks and dangers with the necessary rationality.

The speed and the simultaneity, with which information from all over the world and the direct neighborhood reach people, have an important impact on their reception behavior. Who, facing this enormous amount and power, stops and questions the source?

Who takes the time and tries to figure out who is the author of the information when it is not visible at first or second view?

Editorial staff is reduced due to economic reasons which also leads to the fact that the verification of information has to be performed in an even more efficient way. In contrast, companies increase the number of employees in the field of public relations and search for strong communicators in order to elaborate the information related to the company in a reader-friendly style and to distribute it – possibly unfiltered. At the same time, journal editors who are permanently fed with those messages from the PR departments have to sort out what can be published.

Press officers of large companies are indispensable staff members – in particular in times of crises. Thus, the idealism of eloquent people is put to a grave test if they receive 1.20 Euro per line or 22.50 Euro per hour [22] working for a high-quality journal instead of earning five times as much when they write a lively contribution for a colorful glossy magazine of a company. The readers who are used to linguistically condensed, emotionalized, and personalized texts (e.g. “We are the Pope” [23]) and who are subtly influenced by “framing” (suggestion by everyday semantics, e.g. taxes versus tax burden) has more and more difficulties to get an objective view. Information are not automatically true by publication. The sentence which is heard very often “But it was written in the newspaper” is no quality criterion per se. If the requirement of quality to the information is high, the search for it may lead to qualm.

When compiling information, editors differentiate which distribution channel is planned besides focusing on the quality. Sometimes it is said that in the digital era the Hamlet question is asked again: “online or offline” because the styles to address the target groups are very different. Writing an online text, attention must be paid to use certain key words in order to be found by search engines. Furthermore, online distribution provides other possibilities to optically design the information. While offline publications document and focus on selling figures, online media have other ways to investigate the user behavior of the readers (number of clicks that need not being published by the providers), the duration, or from which website the reader was linked to the article.

The trial from 2015 shows [24] that more than half of the people asked (56 %) were informed via direct contact with the physicians and 55 % by free flyers as well as hospital or pharmacy leaflets [25]. Talks with people from the personal surroundings (43 %) and print media, radio, or TV (40 %) ranked before internet research (38 %), followed by conversations with pharmacists (20 %), consultation of books (18 %), discussions with other patients (8 %), phone calls with health insurances or patient associations (5 %) as well as consultation of information centers (3 %). Nearly one third of 1 728 enquired people (29 %) stated that they did not use the internet for health-related questions. They had a mean age of 55 years, had a lower socio-economic status and a nearly equal gender ratio (47 % males, 53 % females).

#### 5. The internet as medical information medium for advice-seeking people

In contrast, “onliners” frequently use the internet and consult it also for health-related questions. Already in 2004, US researchers

[26] considered the internet as the largest library for medical topics worldwide and assumed already at that time that it would play a crucial role for the future communication in the context of health-related issues.

The study [27] also showed that women and people with a higher internet affinity were more likely to look up health information on the internet, the average age of health-online searchers amounts to about 45 years. Especially younger target groups seem to use the internet and social media to retrieve information about health and fitness and to seek advice for sensitive topics such as mental diseases, drugs, or sexual health – topics that are harder to address in a personal conversation.

The more dissatisfied people are with their family practitioner, the higher is the chance that they search answers for their health-related questions on the internet.

As stated in the study [28], for health-oriented people and those who suffer from chronic diseases, the internet is a particularly important source of information and is rated predominantly as positive in its benefit for the individual health, the information status, and healthcare [29].

With regard to internet research for otolaryngology topics, the authors of a trial evaluated six international studies [30] and found out that the internet was a subordinate and less relevant source of information for the users. Conversations with physicians or friends, information flyers (such as patient information [31] of the Association of Otorhinolaryngologists entitled “Praxis der Sinne”) and books were the mostly used sources. The authors postulate that possibly traditional information sources come into the focus when the individual health is explicitly affected. However, and US American trial from 2018 [32] revealed that more than one third of ENT patients retrieve information on the internet about their health status prior to visiting a doctor.

The authors of the trial [33] refer to two investigations from 2002 and 2004, which show that the internet search strategies of laypeople for health-related topics are often suboptimal because they usually only poorly use the numerous possibilities of search engines to refine or limit their search queries.

Another trial [34] revealed that more than half of the users start their research by means of search engines, frequent users also start with alternatives (42 %).

Furthermore, the study [35] showed that laypeople mostly use only general search engines such as google and nearly never medical portals. Furthermore, the investigation [36] revealed that only few hits of the search results are pursued and in less than 3 % of the cases the hits ranking 10<sup>th</sup> and further are clicked.

In 2016, about 2 trillion [37] of search queries were performed on the internet worldwide, the percentage for the market leading search engine, Google, amounts to about 92 % [38]. In Germany, Google is asked in 9 of 10 cases [39]. In this context, the users are already content with the first page [40].

The order of the results that are achieved with the search engine of Google follows more than 200 factors, which as well as their weighting are not published by Google [41].

So the contents appearing on the first ten hits of Google queries are those of which the websites have been optimized for search engines, but they are not automatically of highest quality. On the first ranks, mostly paid hits are found that are marked as advertise-

ments. As the trial [42] showed, ten widely distributed ENT-related diseases were entered and the first 10 hits were investigated respectively so that a total of 100 websites were visited. Nearly one fifth (19 %) of them consisted mainly of advertisements, furthermore, chronic diseases led to significantly more partly advertisement-focused results compared to the query of acute diseases.

The low-threshold the access to publications on the internet is, the high is the risk that users find disinformation and – as shown in the study [43] about the false reports about the Zika virus – frequently distribute it.

Since users do not receive a “package insert” together with their internet access – for example “instructions for internet use” – it is even more important that neutral institutions warn innocent users regarding the risks and give hints on how to find information quality and verify sources.

The trial [44] differentiates between users who use the internet frequently or rarely. Those who have less experience with internet use, might be less habituated to problem solving strategies of the internet, be less trained in finding orientation, and maybe they lack of the necessary critical distance regarding the offers. This is especially important in the context of source verification because reliable information makes transparent which interests are pursued.

Not every user knows that the responsible has to be mentioned in the imprint of a website in terms of the Telemedia Act, as described in the summary [45]. For lack of knowledge, they do not care about the actuality of information, do not categorize the topic of the contribution in view of the authors’ intention, and do not pursue how the website is cross-linked in the internet.

This check-up is even less sound in the context of contributions from social networks. These dialogue media that bypass classic media and directly publish their message, often distribute anecdote-like information without scientific verification and in the worst case – as mentioned as one of the conclusions of the already cited trial [46] about the Zika virus – even false reports that lead to wrong herd behavior in cases of pandemic.

In addition, there are relevant objections regarding data protection. The authors [47] write that in the context of health-related experiences that cannot be attributed to own experiences, patients are possibly primarily interested in examples of experiences and decisions of other people.

Journalism lives from the fact that people love stories about people. Similarly, these self-presentations about health and diseases in social media provide a certain attraction (for readers) and they will keep a key role in the digital healthcare system (e-health), which was revealed in the study [48].

According to the trial [49] citing a social media analysis, 49 % of the users who write own contributions on websites, blogs, or communities also discuss diagnoses and treatments of diseases. Social media entries where affected people or interested healthcare laypeople exchange thoughts and where the advice of healthcare professionals is less important meanwhile seem to be established as information source for health-related questions. This exchange may be interpreted as strategy of empowerment and informational support. Furthermore, the study [50] confirms that the creation of own health information by means of blogging or creating contributions in social media also influences the patients’ experience and has an

impact on their role understanding with regard to the maintenance of the own health.

The authors [51] refer to studies that consider the efficient and targeted possibility of social media channels for communication between physician and patient as an advantage of social media because sharing contributions fosters the speed of information transfer.

On the other hand, this form of information reception and delivery bears risks because the quality of the information on the internet cannot be guaranteed. The authors [52] state that an algorithm was investigated for the discipline of otorhinolaryngology that was made available on an internet site for diagnostic procedures. While the correct diagnosis was found in 70.5 % of the persons from the patient group, it was only one of an average of 13 differential diagnoses and only in 16.4 % the first one was the correct one.

Besides, the portals of self-help groups appear very positive that are well organized with regard to their disease and/or medical care. In the context of otorhinolaryngology, the Association of Patients after Laryngeal Surgery [53] (Verband der Kehlkopferoperierten), the German Cochlea Implant Society [54] (Deutsche Cochlea Implant Gesellschaft e.V.), and the German Cancer Aid [55] (Deutsche Krebshilfe) must be mentioned. They provide high-quality information of physicians and patients, referring to the respective disease.

In contrast to that, the portals of healthcare providers that do not only offer indicated services and request additional payment from the patients that health insurances do not pay – for good reasons. By means of enthusiastic – however fake – patients, potential clients are expected to think that they have found the best hospital of the world. Models wearing satin clothes with bleached teeth smile into the camera and seem to be still impressed and inspired by the “intervention” that has never happened. Furthermore, apparently self-created certificates are intended to transport the impression of credibility and trustworthiness that cannot be met and that do not withstand thorough research.

## 6. Searching for a physician – rating portals

Since the range of information regarding health-related and medical issues on the internet is as large as never, rating portals should provide neutral orientation for non-transparent and confusing aspects in medicine that otherwise would cause confusion when looking for a physician on the internet.

In 2007, the physician rating portal named “Jameda” was founded that belongs to Burda Digital GmbH as 100 % subsidiary since 2016. It calls itself – in a semantically incorrect way – the most important recommendation for doctors. After entering the discipline and the place, a selection out of 275 000 physicians is displayed, however, the result is not transparent because it does not become clear how the rating was performed.

In an investigation [56] with about 6 500 doctors from 2018, Jameda states that ratings of doctors contribute relevantly to more transparency because the medical quality would otherwise be kind of a black box for patients.

Not every user necessarily knows that the business model of the provider is based on payment of physicians. The investigation shows that these physicians are represented over average in the list and show an uneven distribution of the single ratings that result in the overall score of the physician. Furthermore, this portal lost the revision process of the Federal Court (Bundesgerichtshof, BGH) in 2018 when a complaining dermatologist requested the deletion of her individual person-related data. The BGH confirmed that the neutrality of the information is not assured when paying customers are preferred.

In an article [57] published by a physician, the possibility was mentioned to publish the results of own patient surveys, that have to be assessed in the context of office-internal quality management, on the webpage and by means of this larger sample to provide a more objective impression of the office than rating portals.

Regarding the enormous quantity of information about health topics that is found on the internet, the question must be asked if the internet fosters or reduces the informational imbalance.

In 2007, a trial [58] revealed that about half of 1 500 individuals looked for a new physician. The range of information provided at that time was perceived as insufficient and recommendations were regularly taken from the individual environment. In this context, information deficits regarding structural quality (education, experience, waiting times) and process quality (enough time for the patient) were reported. The people involved in the survey wanted to retrieve mainly information about the focus and the specialization of the physicians.

With regard to the search for a physician, a study [59] could confirm differentiated ways of assessment depending on the education of the internet users as most important parameter. Before choosing new doctors, relatively uneducated patients rarely inform themselves about them, they look more rarely for other general practitioners or specialists, rarely use the different options in medical care, and thus fail to benefit from the chance to have an individually better quality of healthcare service. A traditional, authority-obedient attitude towards physicians as well as the delegation of therapy decisions to “experts” is more frequently found in people who are rather unaccustomed to education.

In order to shed light on the dark and to support patients with their search for a doctor by means of understandable criteria that help objectifying quality differences, the German Agency for Quality Assurance in Medicine (Ärztliches Zentrum für Qualität in der Medizin, ÄZQ) – a joint institution of the German Medical Association (Bundesärztekammer) and National Association of Statutory Health Insurance Physicians (Kassenärztliche Bundesvereinigung) – elaborated the booklet [60] entitled “How to identify a good doctor’s office” (“Woran erkennt man eine gute Arztpraxis?”) in 2015. This checklist for patients lists practical (e.g. local accessibility and availability by phone) as well as personality- and data protection-related aspects, for example if the provided information can be easily understood, if second opinions are accepted, or if qualification measures are performed in the office.

Furthermore, the ÄZQ published a catalogue [61] of quality requirements for rating portals of physicians in 2011. It contains questions that the patients should ask when using these portals, for example if the criteria are clear that lead to the depiction of the



results, if physicians are informed about being listed in the portal, or if advertisement and information are clearly distinguished.

Those who include these hints in their check of the results will more rapidly identify black sheep among healthcare providers. Breakthrough in medicine is generally preceded by many years of basic research and clinical trials that are discussed in quality media. It is quite another matter with a service provider in otolaryngology who presents a “brand-new invention” that is currently controversially discussed. The internet page [62] entitled “the hearing loss” calls itself a German healthcare portal that provides only proven and reliable information. The stumbling block is an alleged medication for people suffering from hearing loss that is advertised on this page. The providers promise that the use of the eardrops would make wearing hearing aids obsolete. The Federal Association of Hearing Aid Industry (Bundesverband der Hörgeräteindustrie) warns on its internet page against this advertisement and the National Guild for Hearing Aid Audiologists (Bundesinnung der Hörgeräteakustiker, BIHA) considers the option of taking legal action in terms of the Act on the Advertising of Medical Products (Heilmittelwerbegesetz, HWG).

Furthermore it is problematic that even a written warning would not reach the authors because an imprint is not found on the page – which is a breach of the Telemedia Act (Telemediengesetz). So it is not possible to find out who is responsible for the internet presentation because even the mentioned phone number does not reach anybody.

## 7. Information portals on health topics

This example shows once again how manifold the range of “information” providers is on the internet or who presents products, and how important it is that users check thoroughly the quality requirements in the context of online businesses that are common practice in analogue purchases.

The authors [63] write that beside the quality requirement to correspond to the language level of the target group, the contributions have to inform about the authors, financing, disclosure of sources and references as well as the time of creation and revision.

With regard to the quality (of information) the initially mentioned comparison of the requirement (set point) with the actual situation is recalled. Before the correctness of information can even be verified by laypeople, the reader must be in a position to actually understand the text. The chosen language level is often such an obstacle that the verification in terms of completeness, consistency, relevance, transparency, and especially correctness seems to be impossible; most likely the check of the up-to-dateness is possible. The authors [64] refer to trials, mostly from English-speaking countries that show that health-related information is nearly always difficult to understand by laypeople. The US American Ministry of Health recommends to adapt the language of the contributions to the level of the 7<sup>th</sup> grade of the education system of the USA, which would significantly reduce the length of the sentences and the number of syllables per word. Also the difficulty of a text in German language can be defined by means of the readability index [65], however, this does not give any hint to the complexity of the contents.

A trial [66] from England investigated the quality – with regard to legibility and correctness – of ENT-specific diseases on the internet. According to the results, 70 % of the English patients retrieved online information about medical and health-related topics. Beside the two sources (patient.co.uk and cancerresearchuk.org) that are fed by healthcare professionals, also the online encyclopedia of Wikipedia plays a major role. Despite the risk that everybody may become a Wikipedia author and possible conflicts of interest do not need to be mentioned, the authors of the trial could state that healthcare contributions on Wikipedia.org were clicked about 4.8 billion times only in 2013. The researchers attributed to the investigated Wikipedia articles that, in comparison to both other sources, the information was correct but incomplete and understandable for university students. In contrast, the institutional source (cancerresearchuk.org) could be understood even by 13-14-year-old people.

Further guidance for patients is provided with the instrument called DISCERN [67] that has been developed in England and is also available in German. It evaluates the quality of patient information that describes treatment alternatives. Each of the 15 items corresponds to a quality criterion (e.g. up-to-dateness, transparency, completeness, reference to sources) and concern the reliability and the benefit of the contribution.

The Swiss foundation named Health On the Net [68] (HON) is committed to deliver reliable information sources in the field of healthcare in cyberspace for laypeople as well as medical professionals. However, the 20 000 websites that have been certified based on a criteria catalogue of HON only deal with a part of the health-related information available on the internet.

The trial [69] mentions the information service of the United States National Library of Medicine that describes a catalogue of 1,000 diseases and provides guidance with specific dictionaries, links, definitions, and addresses in the US-American healthcare system.

With regard to the information quality of ENT-specific topics, the trial [70] mentions numerous – also international – investigations and states that not only ENT-related but all information of US-American medical societies available on the internet are difficult to read. Hits concerning ENT-specific diseases and procedures that have been examined by means of the above-mentioned tools such as readability indexes, DISCERN, or HON revealed that the information goes beyond the literacy of many users.

A central internet portal in German that provides users with high-quality information is currently not available.

Therefore the physicians now have a changed role because the multitude of information on the internet influences the relationship between physicians and patients. As mentioned above, not all physicians welcome the information the patients acquired in the described ways. Nonetheless, the cooperative relationship where decisions are made together is a relief for the physicians. The consultation may take longer time when patients have misunderstood information from the internet, developed unrealistic expectations, or trusted in a dubious source. It takes time that is not reimbursed, requires the physicians' patience, and may even convey the impression that the “informed” but ignorant patient believes to know better. Finally, according to the study [71], the internet is the first innovation in the healthcare system that is not fully controlled by physicians but at least to the same extent by patients.

In order to reach patients in their research effort where they try to find information and orientation, physicians might take on the role of guides. This means that physicians have to become familiar with the range of information on the internet and lead their patients through this information jungle because physicians as experts are able to verify and rate the information. In this way, physicians do not become less important for patients but the function of the physicians is shifted in the current knowledge-based society. Pre-informed patients are a benefit for physicians with regard to their readiness to actively deal with a topic and to show that they are open and intend contributing in the recovery process. The trial [72] gives hints to publications that emphasize the high importance of the personal relationship between physicians and patients despite the continuously developing digitization. The results [73] show that 30 % of the physicians encourage their patients to retrieve information after the consultation. Furthermore, 42 % of the physicians are happy about their patients' interest even if 25 % think that it takes too much time; 10 % are annoyed about the information behavior of their patients, and only 7 % feel that the confidence is jeopardized.

## 8. Many physicians do not know the information sources of their patients or have no opinion regarding the quality

The study [74] also shows that 70 % of the physicians question the origin of the information and about half of the physicians verify the information by means of own research. Only 18 % do not take the time to deal with the information found by their patients. In addition, 22 % of the physicians discourage their patients from taking own initiative to retrieve information, while 30 % strongly recommend it. More than half of the physicians (56 %) provide reliable information material or hints (49 %) to good information sources. 47 % of the physicians look themselves for appropriate patient information.

This heterogeneous impression of the physicians also arises due to the fact that the awareness level of high-quality information sources is rather low. The physicians who were asked for the trial [75] report that 96 % know about Wikipedia but only 56 % consider this source as being reliable; the website of "jameda.de" is known to 87 % but only 13 % think that it is serious, followed by the internet pages of "apotheeken-rundschau.de" that is known to 84 % but only 33 % estimate the information as sound. These results of the survey are astonishing also because the high-quality information sources are available but their reputation ranks near the end of the list. So among the 804 resident doctors who participated in the online survey [76] only 23 % know about the website called "krebsinformationen-dienst.de" of the DKFZ (Deutsches Krebsforschungszentrum; German Center for Cancer Research); at least 70 % of them consider this source as reliable, followed by the healthcare portals of "patienten-information.de" (a service of the ÄZQ), "patientenberatung.de" (Unabhängige Patientenberatung Deutschland; independent patient consultation in Germany), "gesundheitsinformation.de" (IQWiG), and the guideline of "Sich informieren und entscheiden" (IQWiG). These independent portals claim to provide information of evidence-based medi-

cine [77] in a format that is understood by laypeople. They are known to only about one fifth of the physicians and merely 6 % consider them as trustworthy.

Based on this low awareness level of the physicians, the question of the origin of the information presented by the patients appears in quite a different light. The study [78] recommends that not only laypeople but in particular physicians – as multipliers – should get familiar with the information range.

## 9. National health portal in Germany as possible solution?

In the current Government's coalition agreement between CDU and SPD from 2017, the parties agreed on implementing a national health portal. The Federal Health Ministry (Bundesministerium für Gesundheit, BMG) entitled the IQWiG with the creation of an extensive concept [79] for a national health portal. This concept [80] is available since August 2018, but up to now no decision has been made and thus the implementation of this concept has not yet started.

This concept includes international ideas for example from documents of English speaking countries (UK, USA, Australia) as well as previous projects from Germany such as the topic-related portals of the Bundeszentrale für gesundheitliche Aufklärung (Central of health-related information) that are already available for drug abuse and sexuality. The portal is supposed to meet the following requirements: central internet access in German about quality-assured, advertisement-free, and non-commercial information about health-related questions so that it may be used for discussions and decisions made together with physicians and is formulated in that way that it is appropriate for people with different requirements regarding exhaustiveness and depth of the contents.

Even if this national health portal is really implemented in the near future, the access will be reserved to only few people. A survey [81] performed among insured people of the KBV from 2018 revealed that half of German adults are interested in the national health portal planned by the Federal Government. According to that, 50 % of all insured people or 59 % of all those who use the internet would use such a portal with reliable information on medical issues. A total of 31 % would not do so, 16 % of all people between 18 and 79 years do not use the internet. Especially in the federal states of Thuringia and Mecklenburg-Vorpommern, the coverage of this central health portal would be limited because the people do not dispose of internet access (26 % in Thuringia, 29 % in Mecklenburg-Vorpommern).

Despite the partly limited use or availability of (high-speed) internet in Germany, at the long term there is no getting around the internet as information source with the described difficulties. The users have to be sensitized – sooner better than later – with regard to dubious providers, sources, and certificates as well as be aware of serious information found in the imprint and the references. Caution is and remains the mother of wisdom, whether it is the case of traveling miracle healers with ointment pots and herb bundles on medieval market places or websites of healthcare providers displaying enthusiastic and jubilant patients and presumptuous self-congratulations.

So there is still a lot to do in order to make considerably known already existing, high-quality information in medicine and to make it available for interested users in an easily identifiable way.

## 10. Advice for “the snoring child”?

With regard to the initially mentioned case of the snoring child, the mother might find information on the following pages: On the website [82] of the German Society of Oto-Rhino-Laryngology, Head & Neck Surgery (Deutsche Gesellschaft für Hals-Nasen-Ohren-Heilkunde, Kopf- und Hals-Chirurgie), after entering the term of “snoring” (Schnarchen) in the search field, an excerpt of the annual meeting of 2010 appears; for users who also understand English, the link (found in the field of “Publikationen”) to “PubMed” (Medline) provides the possibility to find information within 1,781 scientific articles on “snoring children”.

If the mother, however, decides for the webpage [83] of “hno-aerzte-im-netz.de” and search for “snoring” (Schnarchen), especially in children, in the search field of diseases, the information found might lead her to continue her research or set an abrupt end to the football evening of the father.

## Conflict of Interest

The author is a member of the professional association of free journalists freischreiber e.V. I quote this according to the guidelines for References under bibliography no. 22. It arises for me no economic or personal benefits.

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