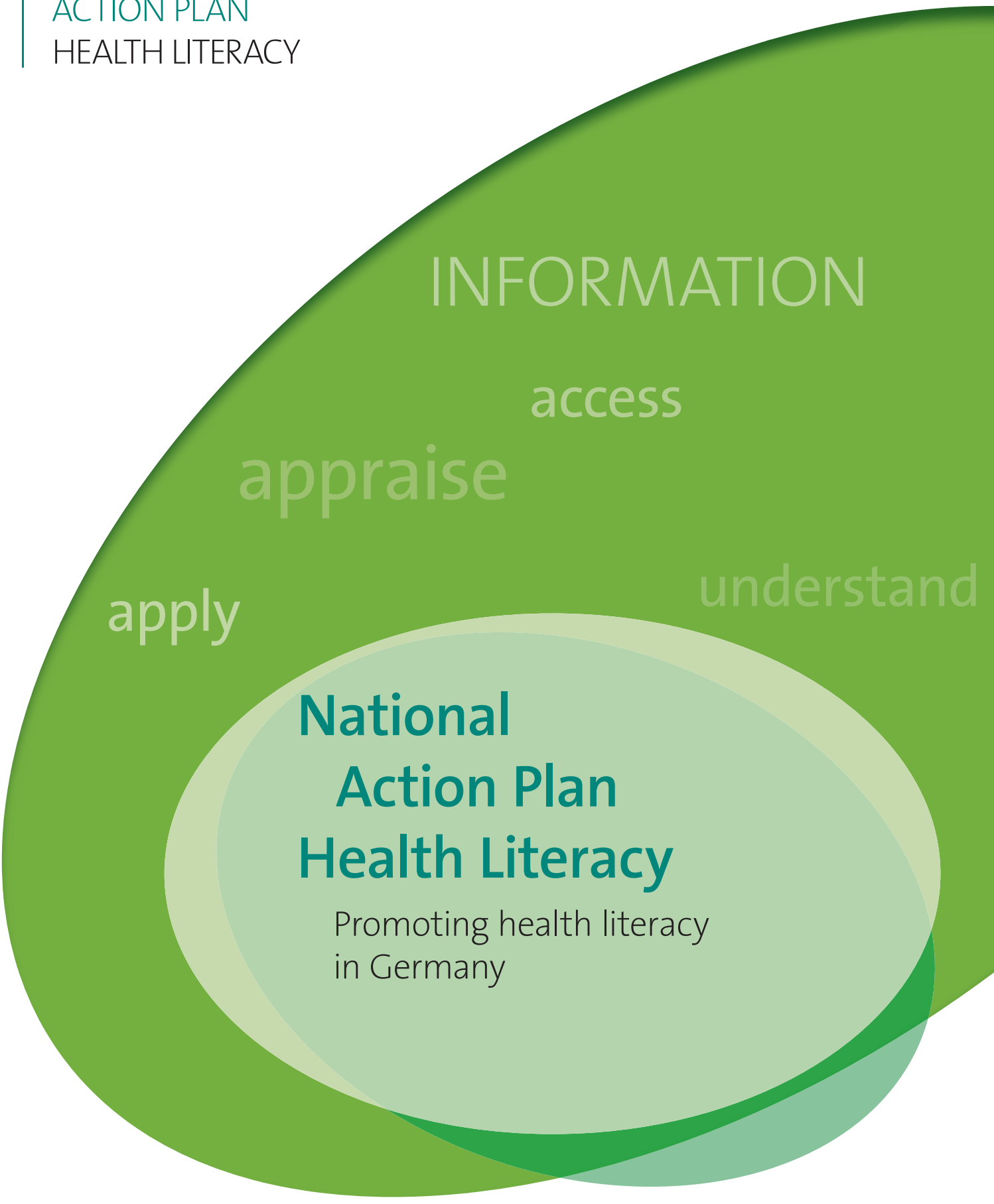
NATIONAL
ACTION PLAN
HEALTH LITERACY



National Action Plan Health Literacy

Promoting health literacy in Germany

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Preface

Dear reader,

Adequate health literacy enables human beings to live a healthy everyday life, maintain their health and find adequate help in case of illness. At the same time, it is the key to a high quality of life. The "National Action Plan Health Literacy for Germany" provides scientifically validated guidelines which show the responsible actors in politics, academia and practice how health literacy can be strengthened in our country. This involves education and training, consumer behaviour and diet, living and working, dealing with the media, but also more comprehensibility in the exchange between doctors and their patients.

I was very happy to assume patronage of the Action Plan because its concerns are also very important and personal for me. This is why I founded the "Alliance for Health Literacy" in June 2017 together with leading organisations in the healthcare sector. We need a joint effort of doctors, caregivers, hospitals, health insurance funds, pharmacies, self-help and consumer organisations, but also federal and state authorities to significantly strengthen health literacy in our country. To this end, the alliance partners have already launched a wide variety of new projects, and I hope that they will also take up the many good ideas of the Action Plan and advance them in the field.

If we all join efforts to implement the recommendations, we will be able to achieve much for the health literacy of the population!

Yours sincerely

Hermann Gröhe, MdB
Minister for Health

Editorial

The promotion of health literacy is an important task that touches upon all areas of public life and requires the commitment of many actors – in the healthcare sector, as well as in the areas of education, training, work, research, communication and consumption.

The present National Action Plan Health Literacy addresses this task. It looks at the action required in prevention and health promotion in everyday life contexts, in the healthcare system, in living with chronic disease, and in research. In 15 coordinated recommendations, it will be shown how health literacy in Germany can be promoted.

The National Action Plan Health Literacy was developed by a group of scientists and practitioners and thoroughly discussed with representatives (*) from politics, society, members of various healthcare professions, representatives of civil society organisations, as well as patients and citizens. The Federal Minister of Health, Hermann Gröhe, assumed patronage.

As the initiators and editors, we would like to thank the group of eleven experts involved and the many representatives from all sectors of society for their valuable input. We would like to express our special thanks to the Robert Bosch Foundation and the Federal Association of the AOK for the financial support they provided. After one and a half years of consultations, we are happy to present the National Action Plan Health Literacy to the public and begin with the implementation of its recommendations together with actors from all sectors.

Doris Schaeffer, Klaus Hurrelmann, Ullrich Bauer, Kai Kolpatzik
Berlin, February 2018

If only the masculine form is used in the following in order to improve readybility, this always stands for persons of both sexes.

In Brief

National Action Plan

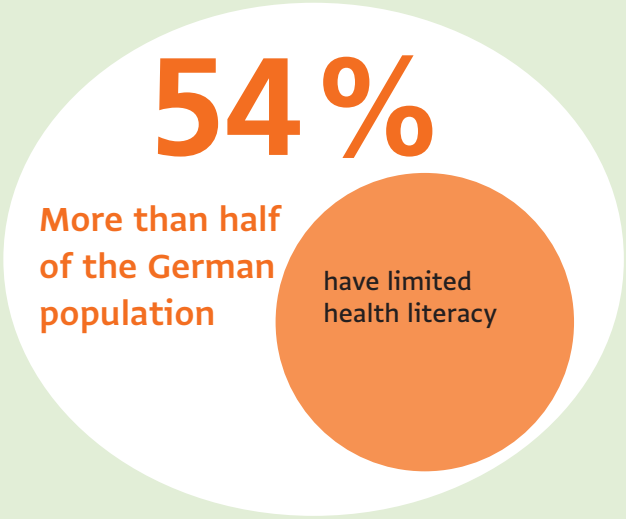
Promoting health literacy in Germany

In Germany, approximately every second individual has limited health literacy. People with limited health literacy find it difficult to find, understand, appraise and apply health-related information. Therefore, an expert committee has developed this national action plan to strengthen health literacy. The plan focuses on four areas of action and presents 15 specific recommendations to improve and strengthen health literacy in Germany.

RECOMM

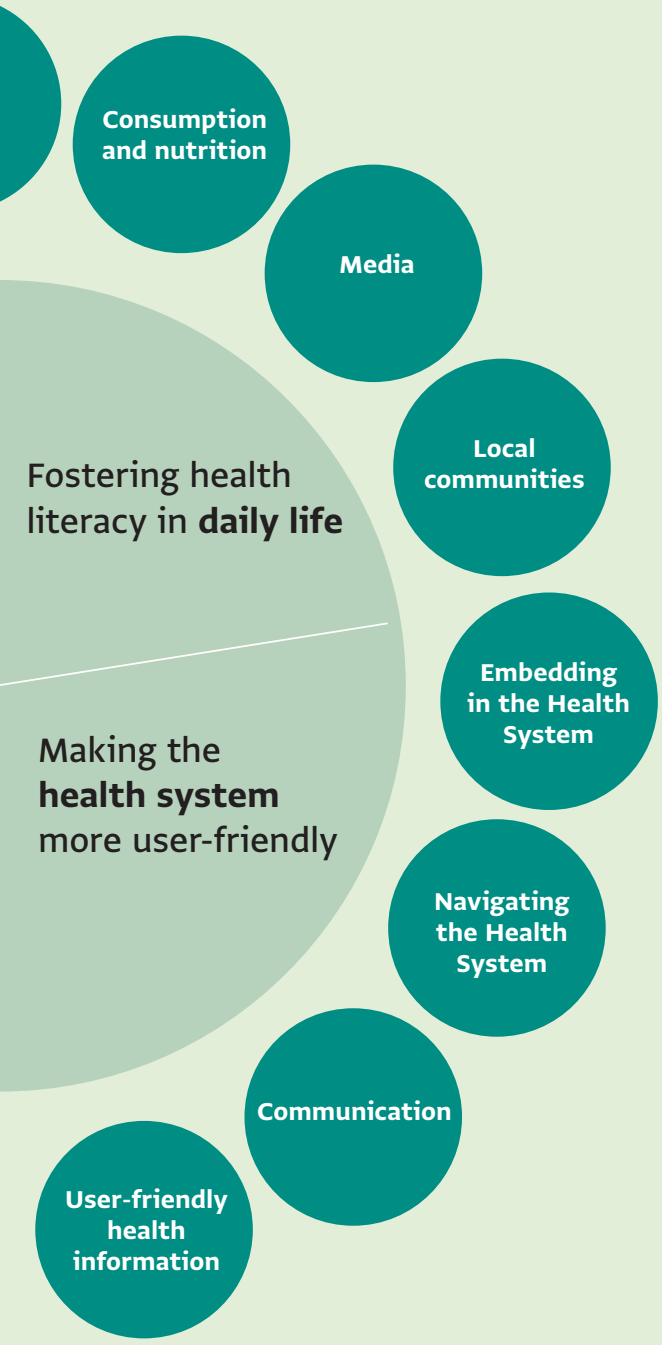
PROBLEM

What is the problem?



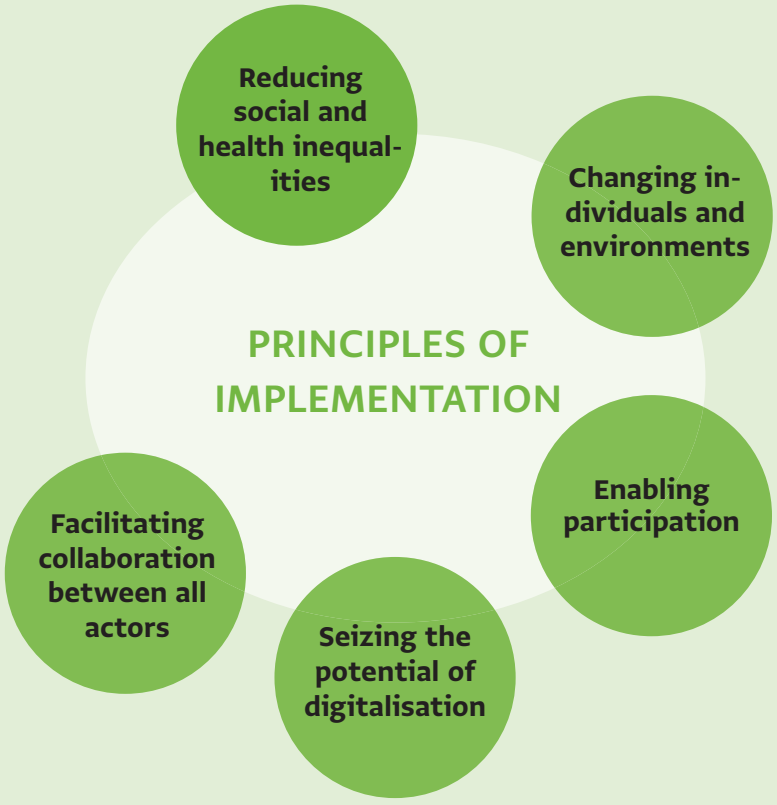
ENDATIONS

What has to be done?



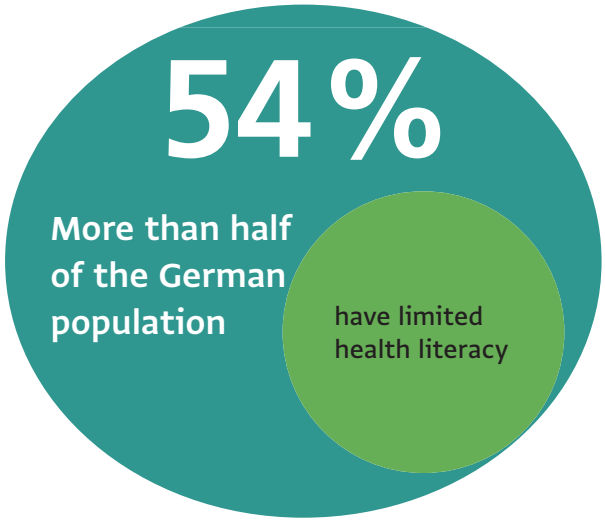
PRINCIPLES

What is important?



1

Why do we need a National Action Plan Health Literacy?



A recent representative survey has shown that more than half, actually more than 54 per cent, of respondents have limited health literacy. Only seven per cent have very good and 35 per cent sufficient health literacy (1).

Low health literacy makes it difficult to take health related decisions.

What is the challenge?

This means that the majority of the German population has problems to find, understand, assess, evaluate and use health-relevant information properly, for example in order to find the appropriate help for health impairments. This makes it difficult to make decisions in everyday life which are beneficial to their health. In short: They lack sufficient "health literacy" (2).

Insufficient health literacy is not only significant for individuals because they are unable to adequately care for their own health, but because low health literacy also constitutes a social challenge. The reasons for low health literacy levels are not exclusively attributable to a lack of knowledge or motivation, or the insufficient competences of individuals. Rather, health literacy is crucially dependent on the societal, lifeworld und social conditions in which people live and the challenges they face in their life situation and living environment (3). For example,

the way in which physicians or caregivers communicate with their patients can enormously impede or facilitate the way in which health information is assimilated and processed.

The situation is paradox: On the one hand, health literacy is gaining in significance in modern societies and constitutes an increasingly important but also more challenging task. At the same time, the acquisition of health literacy is connected with challenges for which many people are insufficiently equipped. It is true that more information than ever is now provided by the internet, but such information cannot always be easily found, and not all of it is reliable and of an assured quality. In addition, it is often influenced by economic interests. And not least, the vast amount of information is more often perceived as overwhelming than it is helpful.

Apparently, our education system does not sufficiently prepare people for these challenges. Also, the healthcare system apparently does not adequately fulfil the increasing need for information and support. The healthcare system is perceived by users as too complicated, and this is also true for the information required to use it. This can lead to overuse, underuse or misuse, which can not only cause unnecessary harm to those concerned but also create unnecessary costs for the healthcare system (4).

It is therefore time to strengthen the health literacy of every single citizen. At the same time, it is imperative to change the healthcare system, and to also include the lifeworld, education, work, consumption and media in the promotion of health literacy.

Costs of insufficient health literacy

According to estimates by the World Health Organisation WHO, three to five per cent of health expenses are caused by insufficient health literacy (4). This means between nine and 15 billion euros for the German healthcare system alone.

What must be done?

Improving health literacy is a task for all of society which requires a systematic approach and a comprehensive, nationwide programme. The National Action Plan Health Literacy presents an agenda for this task.

To improve health literacy, an overall societal, coordinated approach is necessary.

At the same time, the Action Plan underlines the great political importance of this problem. This is also emphasised by the initiatives undertaken by the World Health Organisation (WHO), for example the WHO fact sheet on health literacy (4) and the WHO's Shanghai declaration on promoting health published in 2016 in the

The WHO's Shanghai Declaration

The WHO's Shanghai Declaration was adopted within the framework of the World Health Assembly of the WHO. It postulates that health literacy facilitates and strengthens equal opportunities. With this declaration, the WHO member states commit themselves to develop and implement national and local strategies to improve health literacy (6).

Ottawa-Charter

With the Ottawa Charter for Health Promotion, which was adopted in 1986, the WHO called for active proceedings towards the goal of "Health for All". In this sense, health promotion aims for a higher degree of self-determination for all human beings with regard to their own health, and empowerment regarding the improvement of their health (5).

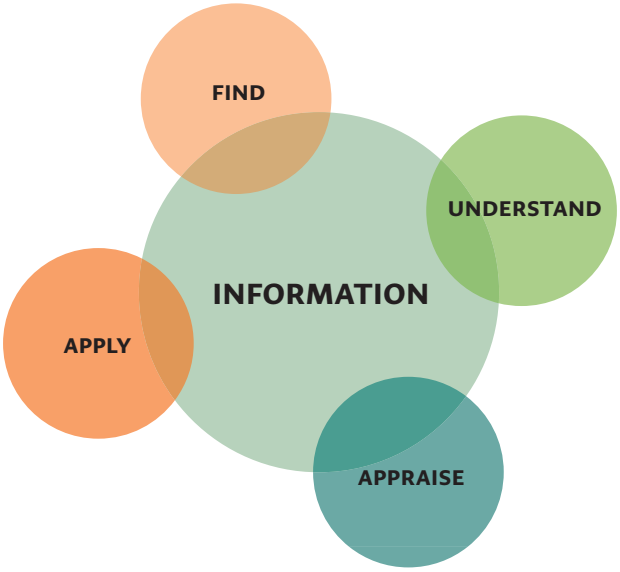
Agenda 2030 for sustainable development. In reference to the Ottawa Charter for Health Promotion (5), health literacy is named here as one of the priority action goals (6). Also, the present national action plans from other countries (7–13) demonstrate the great political significance of the topic.

The importance of health literacy is also increasingly recognised in Germany. Thus, the initiative Alliance for Health Literacy by the Federal Minister of Health, Hermann Gröhe, was launched in mid-2017 together with the leading German health organisations. In a joint declaration, the members committed themselves to the initiation of targeted projects for the improvement of health literacy within their spheres of influence, and to promote and coordinate activities in this area (14). The National Coordination Unit for Health Literacy at the Hertie School of Governance, which was also founded in 2017, pursues a similar objective. It aims to promote the implementation of the Plan and initiate other research projects.

In order to implement the goals of the National Action Plan in a sustainable manner, further actors from other social areas beyond the health sector must become involved, because it is only the commitment of all relevant actors from politics, science and practice that will make significant improvement of German health literacy possible within the next decade.

2

What is health literacy?



In the German-language discussion, the term "Gesundheitskompetenz" (health competence), which literally means "literacy with regard to health", has widely become the accepted translation of the English term "health literacy". This originally meant the basic capabilities of writing, reading and calculating required in order to read and understand written documents, such as information on treatment or medication directions (15, 16, 17).

This conceptual understanding, which was closely oriented to the challenges of medical treatment and the traditional concepts of the patient role, has widely expanded over time. Today, health literacy goes beyond the literal techniques described above and also includes the ability to find health-relevant information, to critically assess this information, relate it to the own life situation, and to use it to maintain and promote one's own health (18, 19).

According to this understanding, health literacy thus aims at the competent handling of health-relevant information – not only in order to fulfil the expectations placed on patients, but also to contribute to health maintenance and improvement.

Health literacy especially means that people are able to deal appropriate with health-relevant information.

2

This comprehensive understanding of health literacy is reflected in the definition developed by the European Health Literacy Consortium on the basis of a comprehensive analysis of literature:

> "Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course." (20).

According to this definition, health literacy is seen as the ability to deal with health-relevant information, particularly in the three areas of healthcare, disease prevention and health promotion. At times, the term health literacy also means the general ability to deal with health. However, expanding the term and at the same overloading it is not practical.

Why is health literacy necessary?

Health literacy is necessary in order to deal with the increase in options and meet the growing demands on individual responsibility in modern societies (21), because the responsibility to make individual decisions has clearly increased in all areas of everyday life and in all lifeworlds, be it in the area of health, at the workplace, in the areas of leisure and consumption, in the use of media or in the area of politics (22).

"Health literacy is determined by personal abilities and skills as well as demands and complexity of the environment.

Health literacy must always be understood as being relational, because

- it is based on the personal competences and abilities of every individual human being,
- but is also dependent upon the challenges and complexity of the systems, organisations and living environments in which these persons are situated and make decisions (23).

Figure 1: Interactive health literacy framework (4)

The present Action Plan assumes interaction of these two aspects – the personal and the systemic, or organisational, health literacy. This approach avoids stigmatising human beings with low health literacy, as their behaviour is also always determined by their living conditions.

This understanding of health literacy has consequences for the development of interventions and measures. Possible starting points of interventions for the promotion of health literacy are

- the development of adequate strategies and measures to improve personal health literacy, or
- the development of suitable systems and organisations, targeted further education and training for healthcare professions, and the improvement of the flow of information and communication in public health, as well as in other areas of society in order to

Both approaches to intervention are equally important and should ideally be combined (24).

Interventions can improve the individual as well as the organisational health literacy.

How is health literacy measured?

The personal health literacy of individuals and population groups, as well as the health literacy of organisations can be recorded and measured with scientific methods.

Health literacy is measurable.

Studies on personal health literacy record and quantify the ability to find, understand, appraise and apply health information. This makes it possible to collect data on how difficult or easy it is for the population or specific population groups to cope with the demands of handling specific health-relevant information.

Currently, various instruments are available for the collection of data on the personal health literacy of individuals. The best-tested and most-used measuring instrument for comprehensive health literacy is the questionnaire by the European Health Literacy Survey (HLS-EU-Q) (25), which is based on the definition of the European Health Literacy Consortium mentioned above. The HLS-EU-Q records the subjectively perceived difficulties in the management of health-relevant information, which also includes to what extent a system, an organisation, or a profession enables and facilitates, or makes it difficult, for users to find, understand, appraise, and apply health information.

The questionnaire was previously used in the following surveys in Germany:

- European Health Literacy Survey (HLS-EU) of 2011, assessing the health literacy of the population in Bulgaria, Germany (North Rhine-Westphalia), Greece, Ireland, the Netherlands, Austria, Poland, and Spain (25);
- Survey of insured persons by the Scientific Institute of the AOK (WIdO) of 2014 (26) (abridged version HLS-EU-Q16);
- Survey "Health literacy of vulnerable population groups (HLS-NRW)" conducted by the University of Bielefeld in 2014 (28);
- Survey "German Health Update (GEDA)" by the Robert Koch Institute (RKI) of 2015 (27) (abridged version HLS-EU-Q16), and
- Survey "Health literacy in Germany (HLS-GER)" conducted by the University of Bielefeld in 2016 (1).

Currently, instruments are being developed to assess organisational health literacy.

Appropriate methodological instruments for the assessment of systemic and organisational health literacy are currently being tested (29). These should record

- if the respective organisation (e.g. a hospital) includes the topic of health literacy in their strategic plans and trains their staff accordingly,
- if the professional staff answers to the needs of all (also vulnerable) patient groups,
- if effective communication strategies, including feedback, are used,
- if easy access to information and offers is ensured,
- if navigation of the organisation is easy,

3

How good is health literacy in Germany?

A number of very different social developments are making health literacy more important.

Increased life expectancy

Due to demographic change, the topic of health literacy has become increasingly significant to society. During the past century, life expectancy in Germany has increased by 30 years. According to forecasts, it will further increase by seven to eight years during the next 40 years (30, 31). The percentage of older people in the entire population has increased, as well, and will continue to increase in the future. The promotion of health literacy is of great importance to ensure that the increase in longevity we have gained is accompanied by a gain in health and quality of life for the majority of older people.

More and more people are living longer.

Increase in chronic diseases

More than 17 million people in Germany have an immigrant background (35), and this number will further increase. The cultural diversification of society has

More and more people have to live permanently with health impairments.

led to different languages, levels of education, lifestyles, values, health ideas and behaviours. This constitutes a tremendous challenge for the healthcare system. People with immigrant backgrounds often have more difficulty in finding the right access to the healthcare system. In addition, they are often used to other forms of communication and interaction with healthcare professionals, and often find it difficult to deal with health-relevant information.

The promotion of health literacy is vital in also enabling people with immigrant backgrounds to take good care of their health. Also, the health information offered should take cultural diversity into account. In addition, healthcare professionals should be aware of this diversity and develop strategies to better deal with various cultural identities and the challenges of limited health literacy.

Change in the patient role

Patients can and should have a greater say in decision making.

The role of patients has changed. Patients can no longer be considered as passive service recipients but as active subjects and cooperation partners with numerous options of involvement, choices and rights.

However, not all patients have the necessary ability and qualifications to really make use of these new options and apply them to their own everyday reality. This also underlines how important the improvement of health literacy is, and shows that the healthcare system is still not sufficiently prepared for this task.

Shared decision-making

Shared decision-making is a model of collaboration between patients and members of the healthcare professions which is characterised by a process of equal and shared decision-making. Scientific studies show that shared decision-making can lead to an increase of knowledge, active participation in the treatment process, and an improvement in the communication between physicians and patients (33).

Complexity of the health care system

At the same time, the healthcare system has greatly changed: The diagnostic and therapeutic options have multiplied within a relatively brief period of time. This has led to enormous growth of the healthcare system which, at the same time, has become increasingly differentiated and specialised. Thus, it has gained in efficiency but problems of varying fragmentation and complexity have increased. This development makes it more difficult for users to find access to the healthcare system and to find the right contact point, which can lead to overuse, misuse, and/or underuse. Especially people in difficult life situations and with low health literacy suffer from the system's lack of user-friendliness.
Research findings show that the following factors lead to better healthcare results:

- a user-friendly healthcare and welfare system,
- shared decision-making,
- involvement of users as co-producers and
- the strengthening of health literacy.

Thus, a user-friendly healthcare system which aims at the promotion of health literacy would not only provide advantages for the individual patients and their relatives, but could also contribute to the improvement of the safety, quality and cost efficiency of the healthcare system (34).

Increasing social inequality

As in most highly developed societies, economic and social inequality has also increased during the past three decades in Germany. This development also affects the health of the population; the life expectancy of the richest 20 per cent of the population is approximately 10 years higher than that of the poorest 20 per cent. People with a lower socio-economic status are affected much earlier and much more severely by diseases, and especially chronic diseases. Despite the comprehensive insurance offers in Germany, this inequality also affects healthcare in the case of illness. Healthcare is much more efficient for well-off population groups than for the poorer.

People with a lower socio-economic status are affected much earlier and much more severely by diseases.

Providing low threshold offers and free access to the healthcare system has lessened health inequality to a very limited extent to date. But not every possibility to influence health inequality by deliberately strengthening the health literacy of socially disadvantaged population groups has been exhausted. Therefore, the potentials of health literacy promotion should be used to provide equal healthcare opportunities for these groups.

Cultural diversification of society

More than 17 million people in Germany have an immigrant background (35), and this number will further increase. The cultural diversification of society has led to different languages, levels of education, lifestyles, values, health ideas and behaviours. This constitutes a tremendous challenge for the healthcare system. People with immigrant backgrounds often have more difficulty in finding the right access to the healthcare system. In addition, they are often used to other forms of communication and interaction with healthcare professionals, and often find it difficult to deal with health-relevant information.

The healthcare system is a great challenge for people with migration background.

The promotion of health literacy is vital in also enabling people with immigrant backgrounds to take good care of their health. Also, the health information offered should take cultural diversity into account. In addition, healthcare professionals should be aware of this diversity and develop strategies to better deal with various cultural identities and the challenges of limited health literacy.

3

> The more information available, the more difficult is it to find the necessary and reliable ones.

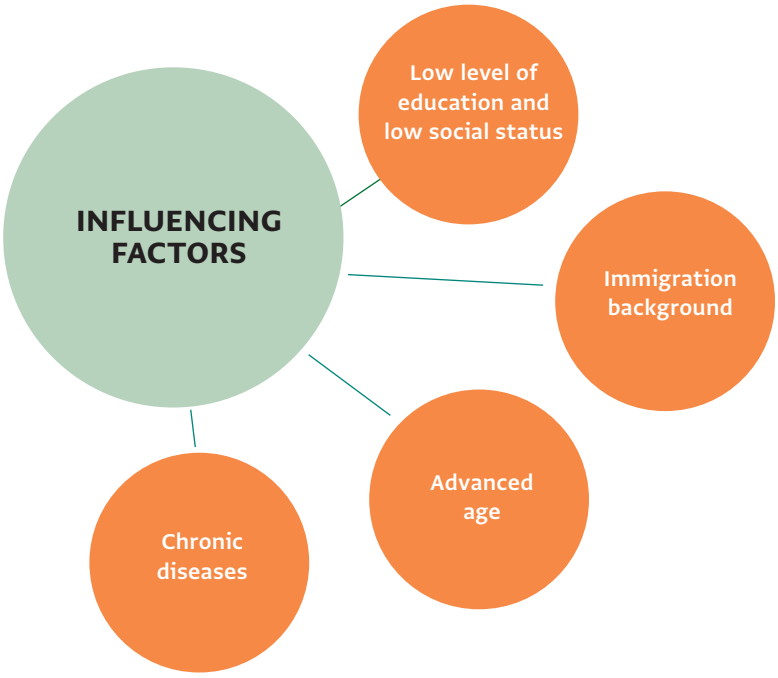
Flood of information in the digital knowledge and information society

Health literacy has gained in importance not least because of the rapid expansion of knowledge and available information. The range of available information has never been broader, and has been tremendously advanced by digitalisation. Information has become easily accessible, more channels, media, and sources are available, and the amount of information increases steadily. At the same time, digitalisation changes existing structures of treatment and interaction in the healthcare system. This development continues at a rapid pace and brings new chances but also new challenges.

An increased amount of information does not necessarily mean that the available information can also be used productively. Despite the rapid growth of health-related information and knowledge production, with more and more internet platforms, and more and more new apps, new knowledge does not necessarily land exactly where it is needed, because the variety of information also leads to confusion. In addition, much of the information is hard to understand, and in many cases is even qualitatively questionable or contradictory. The dissemination of false and wrong information has increased, as is shown, for example, by the campaigns of anti-vaccinationists or the propagation of non-evidence-based therapy options. This is reinforced by the fact that both health-promoting as well as health-damaging lifestyles are marketed in the media and in advertising. Such information is often difficult to assess without assistance and classification because today, each individual person is confronted with the task of filtering information, and judging and evaluating alternatives – and this requires a high degree of critical judgment. However, not everyone possesses this ability.

4

How good is health literacy in Germany?



Health literacy has been examined in various international and national studies during the past several years. The findings of the European Health Literacy Survey (HLS-EU) especially generated an intensive discussion about the topic of health literacy, which until then had received little attention in Germany. People in Bulgaria, Germany, Greece, Ireland, the Netherlands, Austria, Poland and Spain were interviewed in 2011 for this survey, and the result of this first European-wide study showed that more than 47 per cent of all respondents over the age of 15 possess only limited health literacy. They have substantial difficulty to adequately deal with health-relevant information (25). Germany, which was only represented in the European study by the federal state of North Rhine-Westphalia, ranked in the lower mid-range (25).

This result was confirmed in 2016 by a representative study on the health literacy of the population of all German federal states (HLS-GER). It was funded by the Federal Ministry of Justice and Consumer Protection (1). This survey ties in with the European study and is based on the same concept.

HLS-EU-Q

The HLS-EU-Q questionnaire (European Health Literacy Survey Questionnaire) was used in the European study on personal health literacy (25). It measures the self-assessment of difficulty in the management of health-relevant information. The health literacy of respondents is categorised as "excellent", "sufficient", "problematic", or "inadequate" in accordance with the frequency of questions answered with "easy" or "difficult".

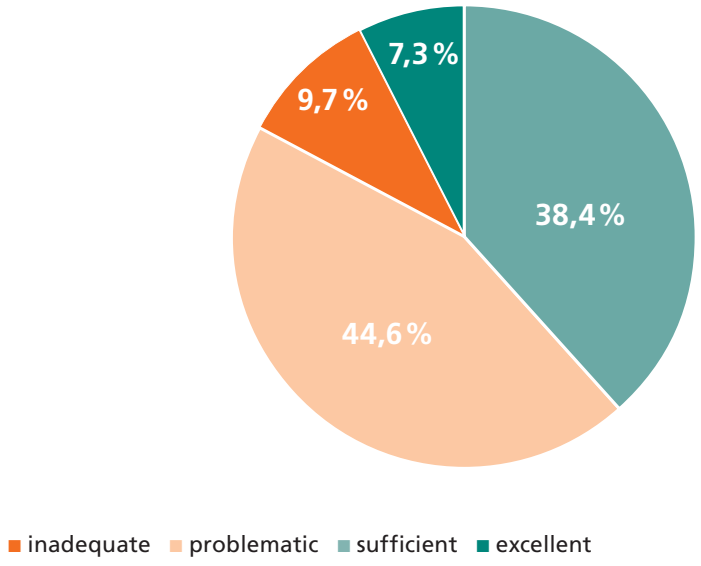
4

More than half of the German population has limited health literacy.

The results show that the percentage of the German population with limited health literacy is very high:

- More than half of the population in Germany – exactly 54.3 per cent – has enormous difficulty in handling health-relevant information.
- Less than every tenth person (7.3 per cent) does not see any problems in dealing with health-relevant information.

Figure 2: Health literacy of the German population (in percent) (1)



Where are the problems in dealing with health-relevant information?

The national study clearly indicates which topics are especially problematic for many people.

- The challenges outlined in health promotion are perceived as particularly difficult. More than 60 per cent of the respondents find it difficult to find, understand, appraise and apply health-relevant information.
- Nearly every second person (ca. 47 per cent) has trouble handling information on disease prevention, e.g. on changing dangerous health behaviour or the necessity of vaccinations.
- On the other hand, respondents find it somewhat easier to deal with information on disease management and healthcare. Only 41 per cent had problems in this area.

Information processing was examined in four steps: finding, understanding, assessing and applying. Of the four, especially the search for and assessment of information causes problems for the German population. More than 50 per cent find it difficult to find health-relevant information. The percentage is similarly high for the assessment of relevant information. More than 20 per cent of respondents find it very difficult to assess health-relevant information (1)).

Which factors influence health literacy?

Certain socio-demographic characteristics often go hand-in-hand with below-average health literacy (figure 3). This includes a low level of education, low social status, an immigrant background, a higher age, and chronic diseases.

Certain socio-demographic characteristics often go hand-in-hand with below-average health literacy.

Low social status

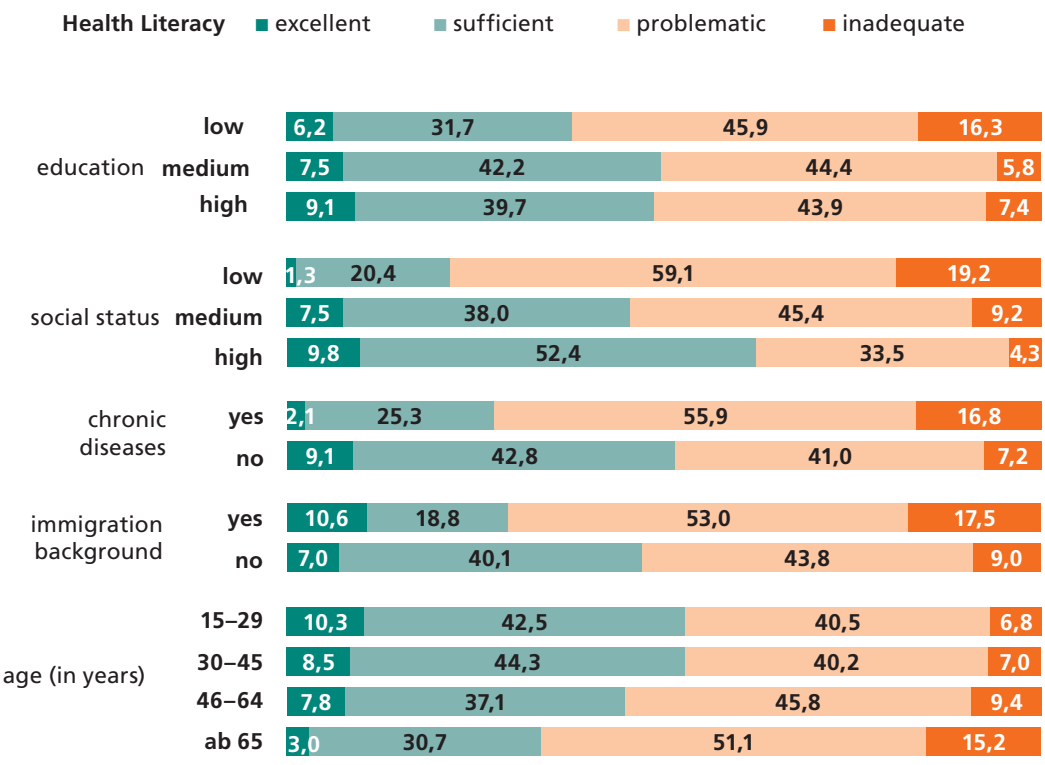
Health literacy is closely linked to social, economic, and health inequality. People who are disadvantaged due to a low level of education or limited access to financial and social resources have greater difficulty dealing with health-relevant information. Their health literacy is more limited, compared to people with a high social status and good resources.

- People with a low level of education find it difficult to deal with health-related information twice as often than those with a high education level.
- Health literacy is problematic or inadequate for 78 per cent of people with a low social status, but only for 38 per cent of those with a high social status.

There is a close relationship between social inequality and low health literacy.

The link between social inequality and health literacy constitutes a special challenge in times of increasing socio-demographic discrepancies. Limited health literacy and the lack of ability to deal with health-relevant information in an appropriate manner can lead to an increase in existing health inequalities.

Figure 3: Health literacy in the German population differentiated between education, social status, chronic diseases, immigration background and age (1)



People with migration background have considerable difficulties in dealing with health-related information.

Immigration background

People with an immigration background clearly perform worse than the average population:

- Almost 18 per cent of them have inadequate and 53 per cent problematic health literacy (1).
- The most difficult tasks to master are the challenges outlined in the area of health promotion: Almost 70 per cent have limited health literacy and substantial difficulty in assessing how their living environment affects their health and well-being, for example.

Because the percentage of people with diverse migrant backgrounds continues to increase in Germany, this population group will require more attention in the future – also with regard to the promotion of health literacy. The heterogeneity of this group, as well as its great cultural and linguistic diversity, must be considered.

Advanced age

Older people also belong to the groups which face special challenges in dealing with health information.

- Two thirds of the older population in Germany have limited health literacy.
- Only three out of 100 people over the age of 65 do not see any problems in finding, understanding, appraising and applying health-relevant information.
- For people older than 75, the percentage of people with limited health literacy is over 75 per cent (36).

The high percentage of older people with limited health literacy represents a challenge, particularly with regard to the continuing demographic change.

Older people have lower health literacy than the average population.

Chronic diseases

People with chronic diseases or disabilities encounter problems dealing with health-related information more often than the average population.

- Only a minority of respondents living with a chronic disease find it easy to deal with health-relevant information.
- Almost three quarters – approximately 73 per cent – perceive the accompanying challenges as difficult and have limited health literacy (1).

One of the causes is the greater challenges that people with chronic diseases face in coping with their disease and in navigating the healthcare system.

People with chronic diseases also often face challenges in dealing with health issues.

How does health literacy affect health status and health behaviour?

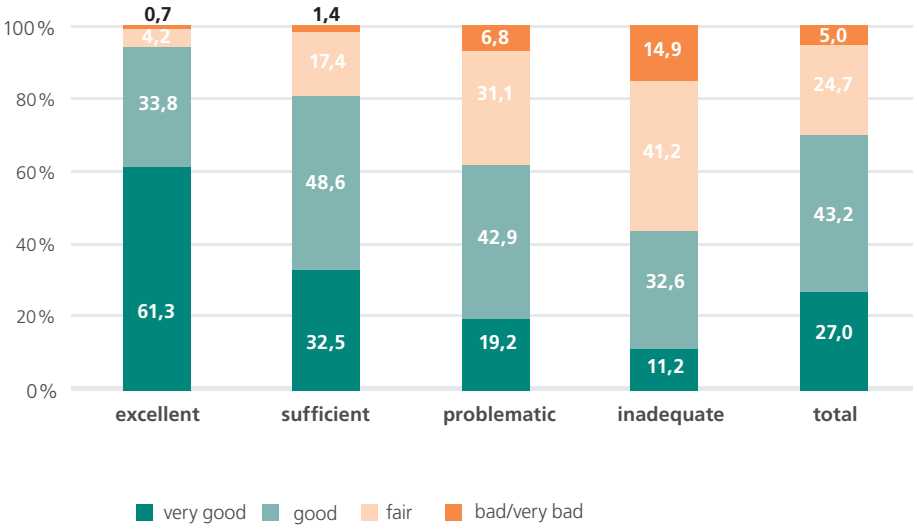
The degree of health literacy creates differences in the assessment of the own health status and health behaviour, in the use of the healthcare system, as well as in information behaviour.

Assessment of the own health status and health behaviour

Health literacy and health status are connected to one another. Previous research results point to a strong statistical correlation. People with higher health literacy normally assess their subjective health status as better and also tend to more health-promoting behaviour than people with limited health literacy.

People with higher health literacy assess their subjective health status as better.

Figure 4: Health literacy and subjective health (1)



Depending on the degree of health literacy, there are also clear differences with regard to health behaviour:

- Every sixth person with excellent health literacy is physically active almost every day. This is only true in 4 per cent of the cases of people with limited health literacy.
- People with high health literacy maintain a healthier diet: They eat more fruit and vegetables than others, for example, and refrain from consuming sugary beverages.

Analogous to the more unfavourable dietary and exercising habits, the percentage of overweight people among respondents with problematic or inadequate health literacy is higher than among those with sufficient or excellent health literacy (1).

The health literacy level is linked to the use of the healthcare system.

Type and extent of use of the healthcare system

There is also a link between the level of health literacy and the use of the health-care system. People with limited health literacy use the curative healthcare system more often, but use the prevention offers less often.

- Almost every third person with limited health literacy reports frequent visits to the doctor. This is only the case for 4 per cent of respondents with excellent

health literacy. Emergency medical services and the emergency room are also more frequently used by those with limited health literacy.
- Clear differences exist for hospital stays: While less than 10 per cent of respondents with very good health literacy were admitted to the hospital during the previous year, this applied to almost 40 per cent of respondents with inadequate health literacy.

These findings show that people who rely on the healthcare system more frequently also have more difficulty in dealing with information than those who use the healthcare system less frequently. One possible cause could be the complexity of the healthcare system, which represents a great challenge.

Information behaviour

When asked who the most important contact point is when searching for health-relevant information, the family physician is first, followed by the specialist. The internet ranks fourth. The social network and especially the family are also important sources of information for questions regarding health and illness (28, 37). Which source is used and in which intensity depends on the respective level of health literacy:

People with a higher health literacy level use the Internet more frequently.

- While almost every third person with sufficient health literacy claims to use the internet as a source of information, this is only the case for every fifth person with limited health literacy. These differences can be seen as an indication of a "digital gap".
- Some 30 per cent of respondents turn to their families when searching for information on health issues, physical problems and illnesses. For people with limited health literacy, the family as source of information is clearly ranked higher than the internet (1).

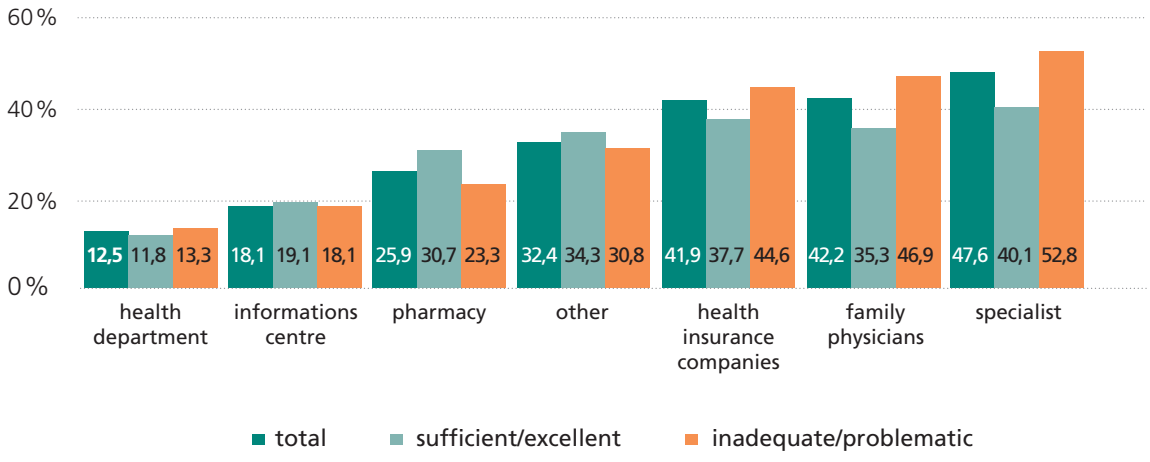
That family physicians and specialists are the most important source of information does not mean that they are always understood. Figure 5 shows that the percentage of people who at least once have not understood the explanations of their physician or specialist is alarmingly high.

Doctors are an important source of information, but their explanations are often not understood.

- More than 40 per cent of respondents have had difficulty at least once in following the explanations of their physician. Specialists are not correctly understood even more often. For respondents with limited health literacy, this percentage is even higher. 53 per cent did not understand their specialist and 47 per cent their family physician.
- Information provided by health insurance companies is often also poorly understood.

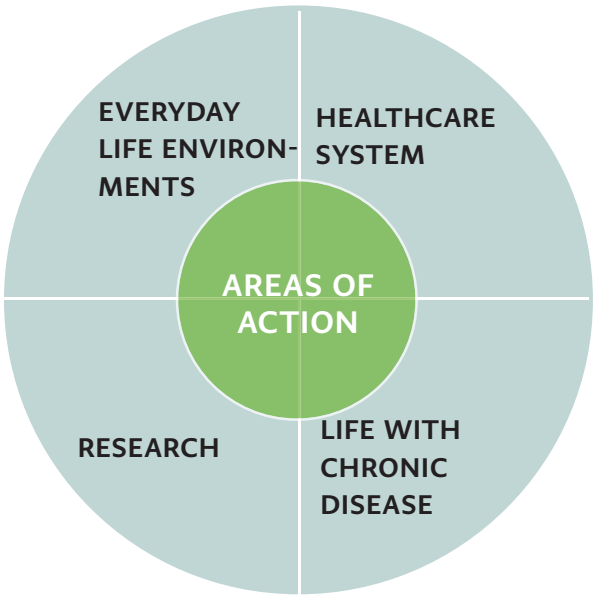
This shows that it is important to involve the healthcare system in the promotion of health literacy, and to strengthen the communication and information competences of the professionals working in that system.

Figure 5: Health literacy and source of information – percentage of people who at least once have not understood the explanations of the source



Overall, the results described above show that improvement of health literacy represents an important social task for the future, and also shows how broad the demand for action is.

How can health literacy be promoted?



In order to strengthen health literacy in a sustainable manner, a comprehensive, societal approach with an expansive programme is needed. The healthcare system and its various sections have a prominent role to play in this endeavour. But the education system and many other areas of social life are also affected and need to be sensitised for this task.

Health literacy should especially be promoted in the living environment and in daily life, because health literacy is shaped by everyday conditions. Therefore, the recommendations in part 5.1 focus on **everyday life environments,** and as such, on the challenges outside the healthcare system. In part 5.2, the focus lies on the challenges within the **healthcare system.** Here, a number of reforms have been initiated in recent years to improve information for system users. However, these efforts are not enough, and more efforts are necessary to make the healthcare system more health literate and user-friendly and reduce the challenges that users face. Part 5.3 focuses on **life with chronic disease.** Chronic diseases are given particular attention because they now constitute the majority

of illnesses and create considerable challenges with regard to health literacy and self-management. At the same time, chronic illnesses require particular skills in terms of dealing with health-relevant information, for example when navigating the healthcare system or making decisions about treatment and care options. The conclusion (part 5.4) deals with health literacy **research.** Such research is a prerequisite for developing effective interventions; however, there are currently major gaps with regard to health literacy research in Germany.

The recommendations are illustrated with national and international examples of best practice, which explore interesting approaches to strengthening health literacy.

5.1 Promote health literacy in all areas of everyday life

"Health literacy is of great importance in everyday life."

A representative survey investigating the health literacy of the German population shows that respondents have particular difficulty to find, understand, appraise and apply information on prevention and health promotion, as well as information that helps them lead healthy lives in their living environment (1). This applies to the neighbourhoods and communities in which people live, as well as to nurseries and schools, work, leisure time, consumption and the media. Given that the conditions within these environments influence the conscious and unconscious health-related decisions that people make daily, it is important to offer good on-site opportunities to access health information, and support and incentivise health-promoting decisions and behaviour.

RECOMMENDATION 1
Enable the education system to promote health literacy early in life

"The education system offers many opportunities to improve health literacy."

Why is this important?

Education institutions are of major importance for the promotion of health literacy. They accompany people throughout their entire lives, and are crucial in facilitating the development of cognitive, social and emotional knowledge, skills and abilities which in turn impact health literacy. Professionals working in nurseries, schools, extracurricular venues, universities, adult education centres, and other educational institutions can therefore significantly advance health literacy.
Up to now, however, no coordinated strategy exists on how health literacy can be promoted within the curricula and daily environments of education institutions.

What must be done?

- Incorporate health literacy into the curricula of nurseries, primary schools, secondary schools, universities, youth education and occupational training institutions as well as adult learning centres.
- Conduct project weeks on health literacy in nurseries, schools and other educational institutions and – if possible – establish health as a subject but at the least as a cross-sectional topic in schools.
- Incorporate first aid centres, which offer medical and psychological support and health care, in education institutions.
- Empower those who work in education institutions through further professional development to contribute to the promotion of health literacy.

Practice Example: ScienceKids

"ScienceKids: discovering health" is a programme that consequently builds on self-initiative and discovery. It is a basic, modular, health education teaching programme and targets students from the first to the tenth grades in all of Baden-Württemberg's schools. Students can find their own answers to questions on nutrition, physical activity and emotional well-being, and apply them to their lives, for example by preparing and enjoying food. The teaching material fits the formal school curriculum (in Baden-Württemberg) and can be incorporated into various subjects as part of the school routine or as part of school-based project days. The programme was developed by the Ministry of Youth, Culture and Sports and Baden-Württemberg's Institute for Physical Education, Arts and Music at School, academics, teachers, parents and students. It began in 2006 and is used in approximately 1,000 schools in Baden-Württemberg. Evaluations have shown an increase in knowledge among students with regard to diet, physical activity and health.

Further information: www.scienceKids.de

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RECOMMENDATION 2
Promote health literacy in professional life and at the workplace

"Strengthening health literacy should become part of operational health management programmes."

Why is this important?

More than half of Germany's population is employed. Since employees spend a large part of their lives at the workplace, it must be acknowledged that work demands and processes have a sustained effect on health. Accordingly, it is important that every opportunity is used to improve the health literacy of employees and empower them to recognise and represent their concerns directly at their workplace. The most appropriate way to do this is to communicate health-relevant information as part of existing workplace prevention and health promotion programmes.

What must be done?

- Strengthen the incorporation of health literacy into existing workplace health and safety programmes.
- Promote health literacy and active participation of all employees through organisational development and changes to social and temporal processes and procedures.
- Support management in taking responsibility for creating a health literate work environment and sensitising them to increased stress during the challeng-ing phases of starting a career, establishing a family, career changes, caring for relatives and transitioning into retirement.
- Establish internal and external health consultation free of charge, which allows employees to access independent information, advice and support in cases of stress, excessive demands and illness.

Practice Example: Health Literacy in the Market (GesiMa)
GesiMa is a toolbox with instruments and media to help managers strengthen their staff's health literacy. A guideline describes how health literacy can be developed and implemented at the workplace. The project aims to sensitise managers and HR personnel for the topic of health literacy, to motivate them to develop a leadership style which promotes health literacy, and to enable them to convey information and knowledge about health at the workplace. GesiMa was developed by a supermarket chain and the Institute for Health Prevention.
Further information: www.inqa.de

RECOMMENDATION 3

Strengthen health literacy in dealing with consumption and nutrition offers

Why is this important?

The leisure, consumption and food industries today offer such a wide range of products and services that it becomes increasingly difficult for consumers to evaluate their effects and make the right decisions regarding a healthy lifestyle. The competent dealing with food and luxury foods, as well as stimulating and relaxing recreational behaviour, necessitates reliable information. This information can often not be derived from the information provided by manufacturers because it contains advertising and other misleading information. Clear legal regulations are therefore necessary for transparent health information.

What must be done?

- Label consumption products, particularly food, luxury foods and dietary supplements, clearly and comprehensibly, for example by the use of a legally binding traffic light system.
- Facilitate healthy decisions by consumers through targeted incentives (nudging), such as price policies, transparent information and clear product labelling.
- Prohibit advertisements containing false information and the marketing of unhealthy food targeted at children on television, in the internet, in print media, on packaging, in stores and in public spaces.
- Expand legislation, regulation and taxation of unhealthy products, for example by mandatory measures to reduce salt, fat and sugar in convenience foods and a ban on false advertising.

Practice Example: Traffic Light System

The traffic light system constitutes an easily understandable labelling of nutritional values on food packaging. The traffic light colours red, yellow and green indicate the amount of different nutrients (fat, saturated fat, sugar and salt) to help consumers identify whether the product contributes to a balanced diet. The traffic light system is located on the front of the package. It has been used in the UK since 2006 and in France since 2016.

Further information: www.verbraucherzentrale.de

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"There is a need for legal regulations for transparent health information on consumption and nutrition.

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4

A large number of health information of different quality in the media makes it difficult to select relevant and reliable content.

RECOMMENDATION 4
Facilitate the handling of health information in the media

Why is this important?

Health information is disseminated more and more through mass media. Users are confronted with a great deal of information which is often contradictory and shaped by vested interests, and which is often difficult or impossible to evaluate. However, not only the evaluation of but also access to appropriate and comprehensible health information in the media causes problems for many people. This also applies to health-related and medical apps. Up to now, there are few opportunities to gain an overview of existing services or to evaluate their quality.

What must be done?

- Strengthen media competence and critical judgement among the population when dealing with digital health information, for example through systematic education campaigns on the use of social networks and health apps.
- Raise awareness among those responsible in mass media of the need to strengthen health literacy and the health implications of programmes, and ensure quality-based cooperation with healthcare system actors.
- Facilitate access to audiovisual health information and improve their availability, for example by removing existing obligations of the public broadcasting companies to delete health information and retain this information in the respective media archives.
- Create transparency of the services and quality of digital health apps, and empower healthcare professionals to recommend high quality analogous and digital health information.

5

Local communities have many possibilities to strengthen the health literacy of their citizens.

RECOMMENDATION 5
Empower communities to strengthen the health literacy of citizens in their living environment

Why is this important?

Local communities are the smallest administrative entities in Germany. They are the central places for social cohesion and a sense of belonging, and are the geographic centre of life for almost all citizens. They are mainly responsible for public services. Communities cross-sectorally coordinate economic, social and cultural services for all residents, ranging from education institutions to family-,

youth- and social work institutions to environment- and consumer care, leisure-, health- and senior citizen institutions, urban development and planning. Due to these wide-ranging tasks and opportunities, communities play a key role in strengthening health literacy and offering local, accessible services to improve health information.

What must be done?

- In cooperation with educational institutions, charities, sport clubs, gyms, citizen initiatives, and self-help groups, develop attractive events such as exhibitions, fairs, and action days in order to discuss health problems in the local community.
- Motivate restaurants, cafes, stores but also leisure facilities, sport clubs, counselling centres, and faith communities through public awards to organise activities to strengthen health literacy
- Integrate health literacy into projects by quarter management, into the programme "Social City", into community projects within the framework of prevention bills, and the network "Healthy Cities", and create contact points for health information ("health kiosk").
- Make resources available to the Public Health Service (ÖGD) in order to collect data on health and health literacy in the community and develop activities to promote health literacy together with citizens.

Practice Example: Optimising Health Literacy and Access to Health Information and Services (OPHELIA)

The project Ophelia is dedicated to improving health literacy in the community. Using a toolkit and a handbook, Ophelia provides a step-by-step guide to strengthen health literacy among those with chronic disease in the community. The concept is divided into three phases: First, identifying the health literacy strengths and limitations of the local community and important topical themes are identified. Based on questionnaires, interviews and focus groups, data on representatives from all sectors of the community are collected and discussed with local stakeholders in order to identify existing projects and develop ideas for improvement. Second, priorities are set and interventions developed which are then implemented and evaluated during the third phase of Ophelia. Ophelia has been tested in Victoria, Australia, and scientifically monitored.

Further information: www.ophelia.net.au

Stakeholder

A stakeholder is a person or group who is directly or indirectly affected by the course or the result of a project or who has any interest in the process or project. In German sometimes terms such as interested parties, affected parties or interest groups are used as synonyms for stakeholders (38).

5

Which actors are needed to implement these recommendations?

- State institutions and lawmakers
- Nurseries, schools, adult education institutions and other education institutions, as well as those professionals at these institutions
- Non-profit and commercial businesses and companies
- Welfare organisations
- Clubs
- Self-help groups
- Communities
- Media
- Journalists
- Federal Centre for Health Education

5.2 Creating a User-friendly and Health Literate Health System

"The health system is not user-friendly yet."

The healthcare system is crucial for the promotion of health literacy. At the same time, however, it presents great challenges to the users due to its complexity and lack of clarity. Therefore, it is important to involve the healthcare system, with its organisations and actors, in the improvement of health literacy and work towards the development of a system that is user-friendly and health literate at all levels. Its aim should be for all users to express their needs, make informed decisions and participate actively in treatment and care.

6

RECOMMENDATION 6
Integrate health literacy as standard at all levels of the healthcare system

"To enable health professionals to promote health literacy appropriate framework conditions are needed."

Why is this important?

In order to ensure a sustainable promotion of health literacy, it is important to incorporate this task structurally and programmatically into the healthcare system and its organisations. At the same time, it is also necessary to sensitise and ensure better qualification of healthcare professionals employed in the system, and to create framework conditions which enable them to recognise the importance of health literacy promotion.

What must be done?

- Structurally incorporate the promotion of health literacy into the healthcare system and minimise obstacles for its implementation by organisations and healthcare professions, e.g. by adequately developing the compensation system further.
- Develop and implement standards for health literate organisations in all sectors and areas of healthcare.
- Create framework conditions which serve the public interest in the healthcare system and which enable all healthcare professionals – medical as well as therapy professionals and caregivers – to actively promote the health literacy of their target groups by providing information, consultation, education and guidance.
- Develop and implement targeted strategies for the improvement of health literacy and user competence of various user groups in the healthcare system, and take special consideration of vulnerable groups such as people with low socio-cultural and economic resources, people with migration backgrounds, and people with chronic diseases or the elderly.

Practice Example: The Health Literate Social Insurance System

EA health literate social insurance system facilitates the process of finding, understanding, evaluating, and applying health information. The objective is to render the own products and services more comprehensible and usable, and to reduce the obstacles which impede orientation of the healthcare and social security system. To support this objective, the main association of the Austrian social insurance institutions issued a method box containing examples of good practice and suggestions for the design of information material, communication, staff training, access to guidance, and the inclusion of the target group. The method box "Health Literate Social Insurance" addresses various actors in the healthcare system.

Further information: www.hauptverband.at

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7

"The German healthcare system is so complex, that users need support in orientation.

RECOMMENDATION 7

Facilitate navigation within the healthcare system, increase transparency, and reduce administrative barriers

Why is this important?

The German healthcare system is one of the most efficient in the world but it is characterised by high fragmentation and sectoral segmentation, as well as a great number of institutions, responsibilities, regulations and processes. In addition, there are bureaucratic hurdles, complicated application procedures and processes, deadlines to be observed, and non-transparent administrative guidelines. It is difficult for many people – especially those with low health literacy – to meet the challenges resulting from these conditions. Therefore, it is important to shape administrative requirements, but also access to the system, in a way that keeps the entry threshold as low as possible, creates transparency, and at the same time offers support for all those who are unable to cope with these demands.

What must be done?

- Facilitate orientation and navigation in the healthcare system and care facilities, ensure low-threshold accessibility, simplify contact, and develop and implement easy-to-navigate guidance systems (signage).
- Create transparency with regard to the functioning and quality of care facilities, as well as with regard to the eligibility criteria of the various healthcare payers, and provide easily accessible and comprehensible information and consultation.
- Simplify procedures and administrative instruments such as notifications, forms and contracts pertaining to the funding organisations and service providers as much as possible and make them user-friendly.
- Expand cross-sectoral personnel support (e.g. case management and consulting services) and create healthcare pathways which guide people through the entire healthcare process, irrespective of the reason and location of the service, and facilitate navigation.

Practice Example: The Health Literacy Environment Activity Packet: First Impressions & Walking Interview

The activity packet "The Health Literacy Environment Activity Packet: First Impressions & Walking Interview" addresses the (executive) staff of healthcare facilities. Its objective is to gather feedback from users regarding the navigation and processes in healthcare institutions. The packet contains instruments to evaluate the user-friendliness of the respective facilities, as well as the written and oral communication. It should help introduce changes which facilitate navigation and increase transparency. The activity packet was developed by the Harvard T.H. Chan School of Public Health.

Further information: hsph.harvard.edu

RECOMMENDATION 8

Facilitate navigation within the healthcare system, increase transparency, and reduce administrative barriers

8

"Communication problems can have negative effects on the course of treatment.

Why is this important?

The German healthcare system is one of the most efficient in the world but it is characterised by high fragmentation and sectoral segmentation, as well as a great number of institutions, responsibilities, regulations and processes. In addition, there are bureaucratic hurdles, complicated application procedures and processes, deadlines to be observed, and non-transparent administrative guidelines. It is difficult for many people – especially those with low health literacy – to meet the challenges resulting from these conditions. Therefore, it is important to shape administrative requirements, but also access to the system, in a way that keeps the entry threshold as low as possible, creates transparency, and at the same time offers support for all those who are unable to cope with these demands.

What must be done?

- Firmly ensure patient-centred, accessible, culture- and gender sensitive communication by healthcare professions through the use of theoretically and methodically sound communication techniques and scientific standards.
- Develop and test scientifically sound standards for the qualification of all healthcare professionals in the area of communication expertise and competence, and firmly incorporate these into the curricula, syllabi, and education standards of universities and institutions of further- and advanced education and training in healthcare professions.

- Develop, test, and systematically implement pedagogical aids, media, and materials to support an effective and user-friendly communication.
- Establish interpreter and translation services, and firmly implement a plain language which is easy to understand and does not create barriers for migrants, immigrants, and refugees.

Practice Example: Feedback on Understanding Spoken Communication – "Teach-back"

Teach-back is a communication technique. It serves to ensure that patients have understood the specific information relayed to them and are able to remember it. In addition, it should assess the health professionals' ability to effectively communicate. The method can be conveyed by a simple, interactive learning module. The American Medical Association has a website available which contains information, interactive learning modules, videos, literature, and a checklist for self-evaluation. A description of the teach-back method can also be found in the German-language Collection of Material and Methods for Consumer- and Patient Consulting of Target Groups with Low Health Literacy (Material- und Methodensammlung zur Verbraucher- und Patientenberatung für Zielgruppen mit geringer Gesundheitskompetenz).
Further information: www.teachbacktraining.org

RECOMMENDATION 9
Create user-friendly health information

"In order to facilitate the understanding of health-relevant information, they have to be prepared more user-friendly."

Why is this important?

A majority of the German population has difficulty in understanding, assessing, and using health-relevant information, which creates new challenges and requirements in generating such information. This applies to information in the media as well as in package inserts, information sheets, or social care information, which are especially hard to understand for people with low health literacy. These include information edited for user-friendliness, as well as a language and text structures easily understood by non-experts. In addition, it is necessary to orient the creation of information on the reception habits, competence requirements, and preferences of the various user groups, and to also include users in the preparation process. It should also be noted that many people require support in finding and processing information, and that especially the assessment of this information can prove difficult.

What must be done?

- Further develop binding standards for generating scientifically sound, comprehensible, realistic, and lifeworld-oriented patient information and its usability at the national level and at the same time, take into consideration the information needs of various target groups, as well as cultural diversity.
- Simplify health-relevant information by writing it in plain language; in addition, multimedia formats should be introduced so that people with limited reading ability can also use the information.
- Provide targeted support for the procurement and processing of information through individual and flexible consulting services; likewise, guide users through a solution-finding consultation process and effectively support them on-site in personal conversations but also on the telephone, through video consultation or other media tools.
- Include potential users (and also self-help initiatives) right at the beginning when compiling and generating information, and in the process take advantage of the possibilities digitalisation offers.

Practice Example: Simplification of Forms and Other Written Material
Health-relevant information materials can be improved through the systematic inclusion of patients and users in the development and editing of forms and other written material. As a result, they can be aligned with individual needs and various target groups. Especially people with low health literacy are therefore provided support in dealing with health-related information.
Further information: www.healthliteracy.com

Plain Language

Plain language describes a markedly clear and distinct style of speech and writing. It avoids very long sentences, confusing sentence structures, foreign words and uncommon figurative ex-pressions (39). The words selected for the plain language are oriented on the spoken language. Thus, there is merely a reduction in linguistics and not in content. Plain language should adapt difficult texts to the reading abilities of large population groups.

RECOMMENDATION 10
Facilitate and strengthen patient participation

10

Why is this important?

Participation is extremely important for dealing autonomously with health problems and coping with illness. The quality of care can also be measured by the extent to which it gives users the opportunity for participation, which bolsters their health literacy. Attempts at inclusive participation should especially support and benefit people with low health literacy. Making them aware of patient rights and involving them in treatment and care is particularly challenging.

Health literacy is important to be able to decide autonomously how to deal with health issues.

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Participation

Participation means the individual or also collective sharing in decisions which are relevant for the own health, own lifestyle, and/or for the own social, economic and political situation – especially decisions about situations and areas of life in which health plays an explicit role (40).

What must be done?

- Develop standards in care facilities on how patients' votes can be recorded and taken into consideration during each phase of treatment and care ("no decision about me without me"), and at the same time increase support in recognising patients' rights with respect to service provision.
- To improve equal opportunity, devote special attention to the participation of socially disadvantaged groups and develop specific support measures which encourage and promote health literacy – especially for people with disabilities, with cognitive limitations, or with a native language other than German.
- Strengthen the communicative and critical health literacy of users and their social environment, as well as their ability to make informed decisions, and support this with comprehensible and well-edited pedagogical multimedia tools.
- Recognise the user as "owner" of the information collected about them and guarantee full access without obstacles to (electronic) patient medical records and comparable documents (such as care documentation).

Which actors are needed to implement these recommendations?

- Lawmakers and political representatives
- Professional associations, universities, federal states, institutions for occupational training and further education
- Health facility providers
- Health insurance companies
- Health facilities, for example hospitals, medical practices, physiotherapy and occupational therapy practices, speech therapy practices, care facilities
- Members of health professions
- Self-help groups and patient organisations
- Patients
- Peers, social environment, family, relatives

5.3 Living a Health Literate Life with Chronic Disease

Chronic diseases have gained in importance worldwide and affect almost a third of the German population. Chronic diseases have a great impact on lifestyle and life choices because of their diverse physical, psychological, and social consequences, and involve numerous challenges for those who are ill as well as for their social environment (relatives, friends, and acquaintances). Well-founded health literacy is necessary to cope with these illnesses. Thus, people with chronic diseases can benefit from the above-mentioned recommendations for promoting health literacy but require additional, targeted support measures which go beyond these recommendations.

Dealing with health-relevant information is particularly important for people with chronic diseases.

RECOMMENDATION 11
Integrate health literacy into caring for the chronically ill

11

People with chronic diseases need care, that is geared to their individual situation throughout their life course.

Why is this important?

Chronic diseases are very complex and long-term. They seldom follow the same progression but change over time, and involve varying degrees of symptoms and limitations which increase and become more concentrated in advanced stages. This varies from person to person, which is why people with chronic disease require care based on continuity, demand, and need, and which corresponds to the individual situation and aims to strengthen health literacy.

What must be done?

- Organise health care structures and processes in such a way that they make long-term, preventive care possible for people with chronic disease, ensure sufficient patient safety, and strengthen health literacy.
- Improve health literacy by shaping care in such a way that in addition to the physical challenges, it also aligns to the specific everyday life, psychological, social and economic challenges of living with chronic disease, and contributes to preserving autonomy despite limited health.
- Involve people with chronic disease and their relatives in the organisation of care, and empower and encourage them to deal competently, critically, and as partners with the health care system and its actors.

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- Improve communication and information in order to make informed decisions also in advanced stages of illness and at the end of life, to avoid or reduce treatment-related stress and unnecessary suffering, and to maintain a good quality of life.

RECOMMENDATION 12

Facilitate and support a health literate handling of disease progression and its consequences

People with chronic diseases need sufficient health literacy to deal with their disease in everyday life.

Why is this important?

In order to constructively deal with the progression of a disease and its consequences and to preserve the greatest stability possible, people with chronic disease and their relatives need a fundamental knowledge of the illness and health, and solid health literacy. The challenge for them is the ability to carefully observe the effects of the illness and the symptoms and to classify them properly, but also to swiftly recognise any downturns or crises and communicate the situation effectively and comprehensibly to the health professions.

What must be done?

- Provide flexible information- and learning opportunities – oriented on individual needs – which convey health knowledge, enable the use of this knowledge, and support people with chronic diseases in developing an understanding for the chronicity of their disease and the importance of health literacy.
- Establish more independent patient information centres which are easy to locate, always accessible and well-resourced with a diverse selection of user-friendly, edited media (such as brochures or films) for the targeted promotion of health literacy in the case of chronic disease, and which also convey pertinent skills, in addition to health-relevant knowledge.
- Create conditions for a prompt, appropriate risk communication which supports people with chronic disease and their relatives in monitoring their own safety when dealing with the illness and its effects, and to reflect critically.
- Support initiatives which make medication regimens (especially with multiple diseases) understandable and co-designable (for example through package inserts in a comprehensible and plain language), and which serve to promote health literacy among people with chronic disease in dealing with medication.

Medication regimen

A medication regimen refers to the directions or schedule for the daily intake of medication. For example, the medication regimen is comprised of the dosage, type and duration of the medication intake (41).

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13

RECOMMENDATION 13
Strengthen the self-management ability of people with chronic disease and their families

Why is this important?

People with chronic disease are confronted with the difficult task of shaping and organising a life over a long period of time that is full of health problems. Adjustment processes are repeatedly necessary to make decisions, compensate for health-related limitations, or to come to terms with a decreasing quality of life. Self-management is therefore an important and challenging task for those who suffer and requires a high level of health literacy. This similarly applies to the transformation of the patient role. Today, it includes very many active elements and demands great commitment on the part of those suffering from chronic disease to keep the illness under control or to actively participate in treatment and care.

What must be done?

- Develop a non-specific programme for people with chronic diseases to support and facilitate health- and self-management which does not focus on expert opinion but rather on the perspectives and problems of those who are ill and their relatives.
- Strengthen self-help structures, and train and employ peers/fellow patients, as well as full-time personnel in this area, in the methods of promoting and facilitating health literacy.
- Make easily-accessible, everyday help available for self-management (for example checklists, help with planning, help with decision-making, service boxes)
- Offer learning opportunities which empower people with chronic disease, as well as people with disabilities or care needs, to interact with health professions and healthcare system authorities.

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Health literacy facilitates self-management.

5

Practice Example: The "Chronic Disease Self-Management Program" (CDSMP) at Stanford University

The CDSMP at the Stanford Patient Education Center (USA) is a course programme for people with chronic disease which teaches self-management skills and tests them. The six-week courses take place directly in the community and teach problem-solving-, communication- and decision-making techniques, among other things. There are customised programmes for specific diseases (such as diabetes, chronic pain, cancer or HIV). The courses were continuously evaluated and further developed on the basis of controlled studies and have expanded internationally. The Initiative for Self-Management and Active Living (Initiative für Selbstmanagement und aktives Leben (INSEA)) has been working on the nationwide establishment of a self-management programme since 2014.
Further information: www.insea-aktiv.de

RECOMMENDATION 14

Promote health literacy for coping with everyday life and chronic disease

14

"People with chronic diseases face the challenge to integrate their disease into their everyday life.

Why is this important?

Chronic diseases impact and disrupt daily life. The effects can make themselves felt in the individual life environment, daily activities, in the family and the relationship, in the social and cultural life or also at work. The majority of these challenges must be met at home or everyday locations, places where the health professions have little insight. Thus, the information and knowledge they convey are seldom attuned to individual daily living conditions. The sick person is usually the one who must adapt this information to the individual life situation, which is not easy especially for people with chronic disease and low health literacy.

What must be done?

- Always consider the areas of everyday life of people with chronic disease – living space, shopping, work, leisure time – in the promotion of health literacy and systematically involve family members, friends, as well as neighbourhoods.
- Develop and distribute target group-specific media tools and materials for the promotion of health literacy which are geared to the diversity of people with chronic disease and their relatives, and which are available in accessible formats.

- Inform the public about the meaning and effects of chronic illness through mass media communication and in the process, render people with chronic diseases and their relatives visible, deliberately involve them, and thus sensitise the public for their issues.

Practice Example: Mental Health First Aid – Recommendation for a Health Literate Life with Chronic Disease

"Mental Health First Aid" is a first aid programme for people with mental health problems. The programme offers evidence-based courses which convey information and strategies for dealing with mental problems, and is intended to provide support in coping with the illness and utilising assistance. Course content includes the recognition of symptoms, treatment options, first aid, and support with mental problems, as well as dealing with crisis situations. A further objective is to train suitable professional groups to convey the course content in everyday life and at the workplace. "Mental Health First Aid" was developed in Australia in 2000. 22 countries have now adopted the approach.
Further information: www.mentalhealthfirstaid.org

Which actors are needed to implement these recommendations?

- Political representatives, such as health ministries, education and cultural affairs ministries, communities, federal states
- Autonomous actors
- Alliance for Health Literacy
- National Coordination Unit for Health Literacy
- Members of health professions
- Institutions for advanced and further education and training, adult education centres
- Providers of healthcare facilities and emergency care, long-term, and care facilities
- Self-help groups and patient organisations
- Patients
- Peers, social environment, family, relatives

5.4 Systematically research health literacy

In order to improve health literacy in Germany and implement the previously described recommendations, it is necessary to further develop and expand research. The rise, spread, and promotion of health literacy in Germany has, up to this point, been sporadic and not methodically researched – unlike in Anglo-American regions, for instance. Thus, a scientific basis is lacking in regard to many aspects of implementation. It is therefore vital to invest significantly more than is currently the case in basic research, needs assessment, intervention development, and evaluation research.

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RECOMMENDATION 15
Develop health literacy research

"Previously, health literacy research has been neglected."

Why is this important?

Basic research on health literacy is important for the creation of a suitable database to develop strategies for the promotion of health literacy, and to develop and plan evidence-based interventions. A regular survey of the population's health literacy is therefore a decisive component along the way to a health literate society. Current research shows that the acquisition and application of competences is closely linked to a person's personality, their biography, their individual and social opportunities, their life conditions, and their living environment. The examination of individual, organisational, and social factors of influence, which play a role in the development of health literacy, is therefore important in understanding the causes of inadequate health literacy and in facilitating the development of effective interventions.

"In order to be able to develop suitable interventions, research on health literacy should be expanded."

What must be done?

- Regularly evaluate data on health literacy in Germany according to population groups and regions in the form of monitoring.
- Further develop existing assessment tools and design new instruments to measure specific aspects of the health literacy of various population groups.
- Intensify research of influential factors on personal and organisational health literacy and the effect of health literacy on health behaviour, morbidity and mortality, as well as the quality of life.
- Establish health-related educational research in order to develop and influence learning conditions, learning requirements, and learning opportunities.
- Intensify research on strengthening the health literacy of vulnerable groups (for example people with chronic illnesses, people with migration backgrounds, people with a low level of education, elderly people, and children).

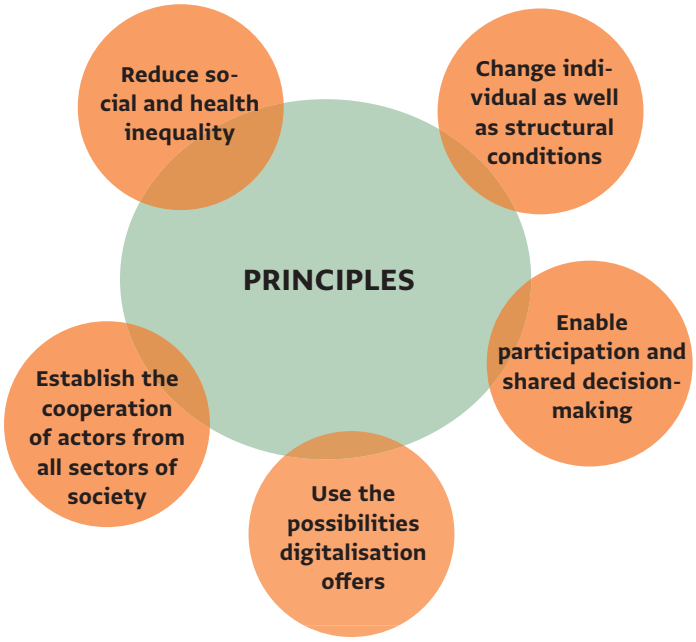
- Establish research on health literacy by organisations and professions in the health system.
- Develop and test performance models for interventions which take into consideration the personal as well as organisational health literacy.
- Promote participatory research in order that interventions align with the preferences and lifeworld conditions of the target group.
- Encourage and promote the development of implementation- and evaluation research, also for realisation of the National Action Plan.

Which actors are needed to implement these recommendations?

- Research sponsors and foundations
- Ministries of science
- Academic institutions
- Academics
- Practitioners and politicians

6

What should be considered in promoting health literacy?



There are five basic principles to consider in implementing the National Action Plan and generally in promoting health literacy which are required for successful good practice:

> Socially disadvantaged groups need special attention.

Principle 1: Reduce social and health inequality

The inferior socio-economic foundations of disadvantaged population groups are also usually reflected in limited health literacy. The reduction of health inequalities is therefore a core demand in the promotion of health literacy.

It is imperative for implementation that socially disadvantaged groups, who for the most part are also more difficult to reach, receive special consideration. This should proceed according to the principle of "proportionate universalism" (42): This means that efforts to strengthen health literacy should be geared towards the entire population but at the same time more strongly address those groups who are difficult to reach, and take into account their respective living environment in order to improve accessibility for these groups.

Principle 2: Change individual as well as structural conditions

Strategies to strengthen health literacy which exclusively aim at improving personal abilities achieve only limited effects. According to the relational understanding of health literacy, this is why structural conditions should always be included along with personal conditions.

The acquisition and application of health literacy depends on people's lifeworld and varies according to their socio-economic status. People who possess low self-esteem, a pessimistic view of the future, little self-efficacy and experience with helpful social networks have considerable more difficulty in finding, assessing and applying health information. An increase in these "basic resources" is necessary to acquire health literacy. This includes the development of opportunity structures for self- and group experience, the active, autonomous-oriented organisation of everyday life, and the creation of material and immaterial incentives from the social and physical environment.

These basic resources can be strengthened in many ways. One of these ways is a lifeworld-related project as foreseen by the amended Section 20 Primary Prevention and Health Promotion of 2015 (Paragraf 20 SGB V) (43). Approaches oriented to everyday life, such as in the areas of education, work, and leisure time, can improve conditions for the acquisition and application of personal health literacy.

"To what extent a person acquires and applies health literacy also depends on the living environment.

Principle 3: Enable participation and shared decision-making

Health literacy heavily depends on an individual's belief that it is possible to increase the quality of life through their own activities. This, in turn, presupposes the assumption that one's own behaviour can impact one's own health to a relevant degree (40).

Such a belief is primarily the result of positive experiences and daily practice. Since the World Health Organisation's (WHO) Ottawa Charter (5), health promotion has thus aimed particularly at facilitating experiences in self-determination. This is especially successful when it is possible to individually or collectively make decisions with effective and noticeable results, and which are significant for the own social, economic, and political situation, the own lifestyle and thus the own health (40).

"The experience of being able to impact one's own health and quality of life strengthens health literacy.

Participation is therefore a prerequisite for the success of initiatives which aim to strengthen health literacy within the area of medical care, as well as beyond it. A directly shared decision-making should apply to all phases and steps of the re-spective process – ranging from analysis of the situation and target-setting to drafting and implementing measures right up to the evaluation of the intervention's impact.

The rapid advancement of digitalisation offers great opportunities to improve health literacy.

Principle 4: Use the possibilities digitalisation offers

The rapid advancement of digitalisation should be used intensively for the promotion of health literacy. The use of audiovisual media (such as sound- and image recordings) can noticeably improve the reception and conveyance of health information. Digital applications can provide help in daily life and support patients' self-management. The ability to span greater distances also provides digital applications the chance to make the healthcare system and care services more accessible and to also decrease limited thresholds of use.

At the same time, digitalisation creates new challenges: It increases demands on the population for health literacy and also increases the risk of a digital gap based on divergent competences and the accessibility to media use. Both of these aspects must be especially considered in the promotion of health literacy

There are already various important initiatives in Germany. The challenge now is to join forces.

Principle 5: Establish the cooperation of actors from all sectors of society

A number of individual initiatives for the promotion of health literacy already exist in Germany. Many of them are innovative and successful. However, individual initiatives are not enough. In order to improve the population's health literacy in a sustainable manner, a comprehensive, cooperative approach is necessary which involves actors from all sectors of society.

The founding of the Alliance for Health Literacy and the National Coordination Unit for Health Literacy highlight important steps along the way to improving health literacy. Both can contribute to the implementation of the National Action Plan Health Literacy's objectives. The exploratory work by the initiative "gesundheitsziele.de" should also be drawn upon.

However, it is important to involve additional relevant actors from other sectors, such as education, work, and the areas of leisure, consumption and media.

The primary objective should be to motivate actors from all areas of society to join together in a cooperative approach for the implementation of the National Action Plan which extends beyond sectors and social regulations.

The National Action Plan

The recommendations – an overview

Recommendations 1–5

Promote health literacy in all areas of everyday life

1. Enable the education system to promote health literacy early in life
2. Promote health literacy in professional life and at the workplace
3. Strengthen health literacy in dealing with consumption and nutrition offers
4. Facilitate the handling of health information in the media
5. Empower communities to strengthen the health literacy of citizens in their living environment

Recommendations 6-10

Create a user-friendly and health literate healthcare system

6. Integrate health literacy as standard at all levels of the health-care system
7. Facilitate navigation within the healthcare system, increase transparency, and reduce administrative barriers
8. Create comprehensible, effective communication between health professions and users
9. Create user-friendly health information
10. Facilitate and strengthen patient participation

Recommendations 11-14

Living a health literate life with chronic disease

11. Integrate health literacy into caring for the chronically ill

12. Facilitate and support a health literate handling of disease progression and its consequences

13. Strengthen the self-management ability of people with chronic disease and their families

14. Promote health literacy for coping with everyday life and chronic disease

Recommendation 15

Systematically research health literacy

15. Develop health literacy research

Principles

There are five basic principles to consider in implementing the National Action Plan

1. Reduce social and health inequality

2. Change individual as well as structural conditions

3. Enable participation and shared decision-making

4. Use the possibilities digitalisation offers

5. Establish the cooperation of actors from all sectors of society

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