



### Key messages

- ▶ The majority of the population in Germany were satisfied or very satisfied with their most recent contact with the healthcare service.
- ▶ Women in particular gather information on health issues and before seeing a doctor or going into hospital.
- ▶ The internet is the third-most-common source of information on issues of quality transparency.
- ▶ Women and men feel ill-informed about where to complain if they suspect errors in treatment.
- ▶ Available possibilities for asserting patients' rights are regarded as not so good.
- ▶ A third of people say they had cause to complain about a contact with the healthcare system in the last two years; 13% of respondents actually did complain.

## Health literacy and self-confidence in the healthcare system – the user perspective

Against the background of reforms to the healthcare system, there have been significant developments towards a structure that supports a stronger citizen and patient orientation (user orientation) since 2000. For example, self-help and patient-advisory services have been promoted by statutory health insurance, a Federal Government Commissioner for Patients' Affairs has been appointed, patient representatives now have the right to participate in – and submit applications to – the Federal Joint Committee (Gemeinsamer Bundesausschuss), the Action Alliance on Patient Safety has been set up, and the subject has been made an integral part of the gesundheitsziele.de national health-targets process (Hölling, Brasseit 2003; RKI 2006, Horch et al 2009).

All these activities share two general health-related objectives: on the one hand greater efficiency and better quality in the healthcare system, and on the other improved prevention in the sense of empowerment through comprehensive health literacy. In this context, health literacy involves both a person's individual way of dealing with health and disease and their active participation in the treatment process. It also includes the person's willingness to participate in decision-making and in shaping the health system. In turn, participation based on literacy makes people more self-confident, enabling them to take more responsibility for their own health.

The development process from health literacy (empowerment) to self-confidence and participation is connected with the emergence of a new culture of communication in the healthcare system and is also taken into account in the analysis of individual health. Raising transparency is seen as an especially significant aspect in the complex processes of health-literacy development and raising people's self-confidence. This process also involves strengthening patients' rights and improving complaint-management systems.

An aspect that is directly linked – and closely interacts – with these developments is a new role of the user of the health service as both consumer and customer. Users are increasingly being accepted as important co-producers and as experts on their own health (Dierks, Schwartz 2003; Hölling, Brasseit 2003). The paradigm shift from a passive user of health services to a user who can (and does) exert a certain influence on those services is leading to a redefinition of relationships and modes of behaviour in the healthcare system – for example to changes in the doctor-patient relationship («shared decision-making»).

A topical contribution on these issues comes from a written survey entitled »Information Behaviour and Self-Determination of Citizens and Patients« conducted by the Robert Koch Institute in 2009 in the context of the »German Health Update« (GEDA) telephone health survey. The respondents were asked how

satisfied they were in their contacts with the healthcare system, how they obtained information on health-related issues, how much they knew about various health- and system-relevant subjects, what activities they engaged in, and what possible ways they saw of exerting an influence. The data were initially examined to determine whether parameters of health literacy, attitude, action and satisfaction differed according to socio-demographic and socio-economic criteria. The following selected results provide an initial descriptive overview.

### »Information Behaviour and Self-determination of Citizens and Patients«

#### Additional GEDA survey

|                       |   |
|-----------------------|---|
| <i>Data holder:</i>   | Robert Koch Institute   |
| <i>Objectives:</i>    | To provide up-to-date data on healthcare users' satisfaction level, information behaviour and possible ways to influence the system |
| <i>Survey method:</i> | Postal Survey   |
| <i>Population:</i>    | Residential population of Germany aged 18 and over  |
| <i>Sample:</i>        | 5,296 women and men: only participants in the GEDA 2009 survey who had agreed to take part in a further survey                      |
| <i>Response rate:</i> | 57.3%   |
| <i>Survey period:</i> | January to March 2009   |

### General satisfaction with the healthcare system contacts

Surveys on user satisfaction provide information on how the population perceive and assess the medical treatment provided by the healthcare system and on the extent to which they have confidence in it (e. g. Bestmann, Verheyen 2010; Koch et al 2010). The data from the additional survey show a very high level of satisfaction with people's most recent contact with the healthcare system, e. g. with their family doctor (Table 1). The majority of the respondents were »very satisfied« or »satisfied« (88 % altogether).

**Table 1**  
Satisfaction with most recent contact with the healthcare  
In percent

Data basis: Additional 2009 GEDA survey

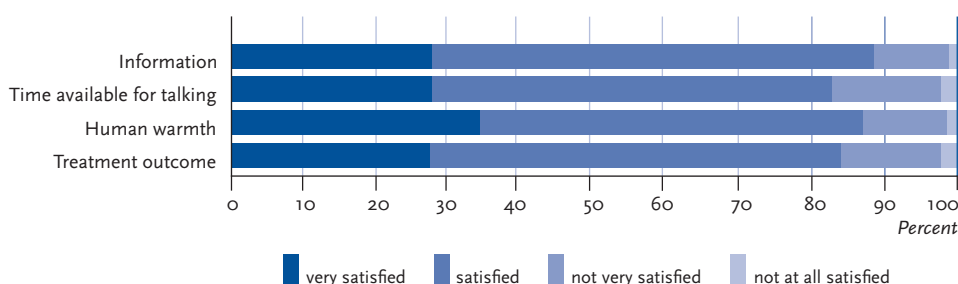
|                     | very satisfied | satisfied | not very satisfied | not at all satisfied |
|---------------------|----------------|-----------|--------------------|----------------------|
| Total               | 26.2           | 61.5      | 11.1               | 1.2                  |
| Sex**               |                |           |                    |                      |
| Women               | 26.7           | 59.9      | 11.4               | 2.0                  |
| Men                 | 25.9           | 63.0      | 10.7               | 0.4                  |
| Age groups***       |                |           |                    |                      |
| 18–39 years         | 26.9           | 57.7      | 14.1               | 1.3                  |
| 40–59 years         | 25.7           | 62.4      | 10.0               | 1.9                  |
| 60 years +          | 26.1           | 65.4      | 8.2                | 0.3                  |
| Social status***    |                |           |                    |                      |
| Low                 | 18.4           | 59.9      | 19.0               | 2.7                  |
| Middle              | 28.0           | 60.6      | 10.4               | 1.0                  |
| High                | 27.6           | 63.8      | 7.8                | 0.8                  |
| Health insurance*** |                |           |                    |                      |
| Statutory           | 24.3           | 62.2      | 12.2               | 1.3                  |
| Private             | 36.8           | 57.3      | 5.3                | 0.6                  |

\*p<0.05; \*\*p<0.01; \*\*\*p<0.001

The men were significantly more satisfied than the women; as regards the different age groups, older people were more satisfied. People with private health insurance reported higher satisfaction rates than those with statutory health insurance. The analysis according to social status – which took variables such as education, income and career status into account – showed that people with middle or high social status were more satisfied than people in the low social-status group.

Looking at satisfaction with most recent contact in a more differentiated fashion – from the perspectives of information received, time available for talking, human warmth and treatment outcome – some differences came to light despite a high overall level of satisfaction in this field. The main aspects classified as unsatisfactory were the amount of time available for talking, which was criticized by 17 % (19 % of women, 16 % of men), and the result of treatment by 16 % (15 % of women, 16 % of men) (see Figure 1).

**Figure 1**  
Satisfaction with the last contact with the healthcare system  
Data basis: Additional 2009 GEDA survey



## People want more information

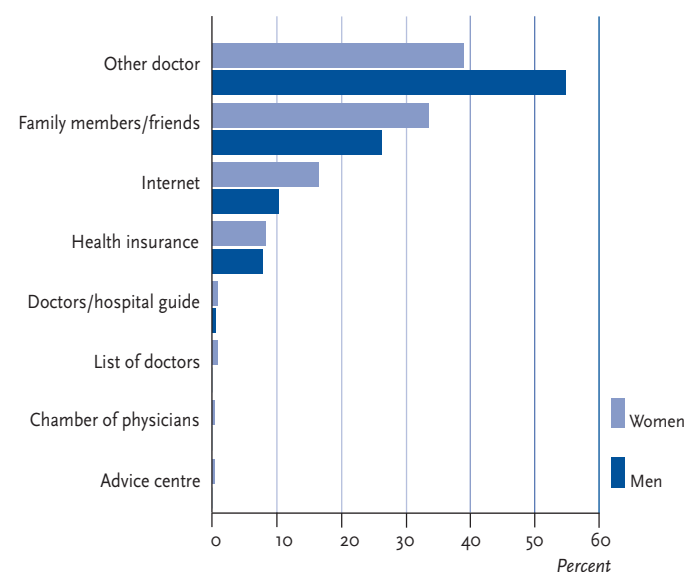
Transparency and being well-informed are regarded as crucial for strengthening the users' position as partners in the healthcare system, both in their choice of health services and in their taking a degree of responsibility for regaining and maintaining their own health (Horch, Wirz 2005). As previous studies have shown, the population are highly interested in health information in general. According to a study conducted by the Bertelsmann Foundation as part of the annual Health Monitor scheme, four out of five adults look for information about health and diseases out of their own interest (Bertelsmann Stiftung 2004). The data from RKI's 2003 Telephone Health Survey (GSTelo3) showed that the population were very interested in health-related topics: only 2 % of the respondents (2.5 % of the men, 1.5 % of the women) did not use any of the specified information sources (Horch, Wirz 2005).

According to data from the additional 2009 GEDA survey, 28 % of people specifically gathered information from an institution of their choice before seeing a doctor or going into hospital (Table 2). Women obtained information slightly more frequently than men in this context. More people in the older age groups tended to look for information in the run-up to a medical contact. Differences also appeared with rising social status: people with a higher social status were more likely to search for information than those with a low status.

People obtain information from different sources before seeing a doctor or going into hospital. Both women and men obtain information most frequently in their social environment, i.e. from family and friends or from other physicians (Figure 2). This has been confirmed by data from the Bertelsmann Foundation's Health Monitor

(Marstedt 2007; Bertelsmann Stiftung 2007). The data from the GEDA additional survey showed that the internet was the second most commonly used source of information, especially among people aged between 18 and 39. People with a high social status used the internet as a source of information much more often than people with a low and middle social status.

**Figure 2**  
Sources of information before seeing a doctor or going into hospital  
Data basis: Additional 2009 GEDA survey



People would often like to have more information about various areas of the healthcare system. Areas in which a majority of people felt ill-informed included where to report suspected errors in treatment (88 %), the quality of old people's and nursing homes (83 %), mobile nursing services (81 %), and cost aspects (78 %). There were no significant differences between the genders. A large group of people (73 %), including more younger than older people, also expressed a desire for more information on their rights as patients. In terms of social status, it became clear that people with a higher social status felt less well informed in some areas. This was especially evident in relation to the quality of care facilities (Table 3). Perhaps this result suggests that different social-status groups have different ideas on what to expect from healthcare facilities.

The results also showed that very few people knew which departments or offices in the healthcare system represented patients' interests. For example, only 14 % (12 % of women, 17 % of men) had heard of the Federal Government's Commissioner for Patients' Affairs ([www.patientenbeauftragter.de](http://www.patientenbeauftragter.de)), a post that was introduced with the Statutory Health-Insurance Modernization Act on 1 January 2004. This percentage rose with age and social status.

**Table 2**  
Search for information before seeing a doctor  
In percent  
Data basis: Additional 2009 GEDA survey

|                     | Previous information search |
|---------------------|-----------------------------|
| Total               | 28.2                        |
| Sex**               |                             |
| Women               | 30.5                        |
| Men                 | 25.7                        |
| Age groups***       |                             |
| 18–39 years         | 26.1                        |
| 40–59 years         | 29.9                        |
| 60 years +          | 28.2                        |
| Social status***    |                             |
| Low                 | 22.5                        |
| Middle              | 27.9                        |
| High                | 33.7                        |
| Health insurance*** |                             |
| Statutory           | 27.5                        |
| Private             | 31.3                        |

\*p<0,05; \*\*p<0,01; \*\*\*p<0,001

**Table 3**  
Areas of the healthcare system in which respondents feel ill-informed,  
by social status

In percent

Data basis: Additional 2009 GEDA survey

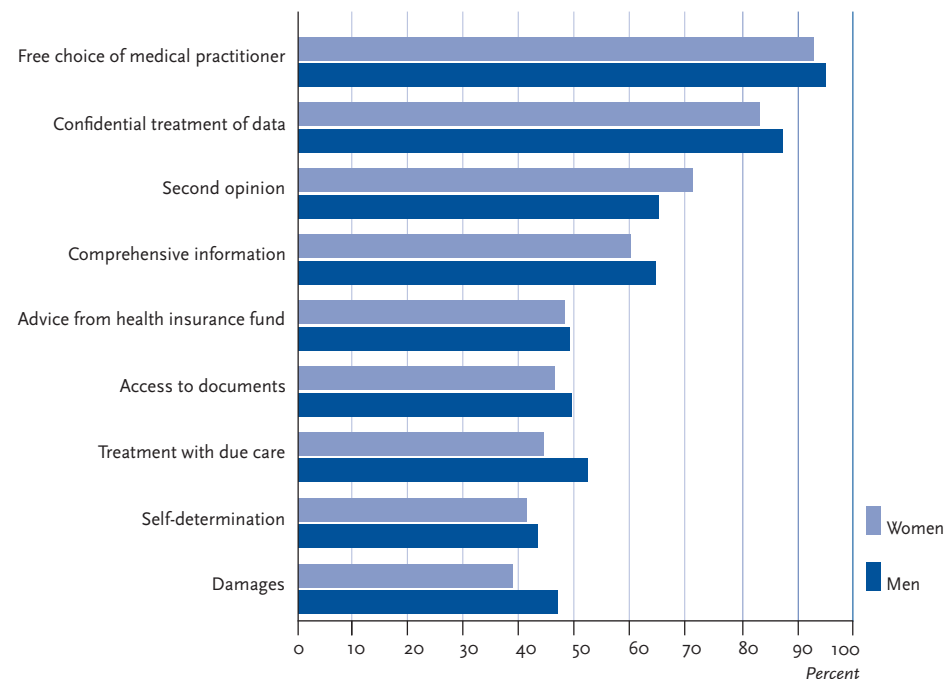
|  | Social status |        |      |
|--|---------------|--------|------|
|  | Low           | Middle | High |
| Rights as a patient**  | 67.0          | 74.9   | 70.9 |
| Ways of preventing diseases***   | 44.2          | 39.0   | 29.8 |
| Treatment alternatives*  | 62.5          | 67.4   | 61.2 |
| Where to report suspected errors in treatment***                         | 81.1          | 89.3   | 89.2 |
| Quality of doctors**   | 65.6          | 65.5   | 72.9 |
| Quality of hospitals*  | 60.9          | 65.7   | 69.6 |
| Quality of old peoples' and nursing homes***                             | 75.6          | 85.0   | 84.0 |
| Quality of mobile nursing services***                                    | 74.9          | 81.2   | 87.1 |
| Costs of medical treatment***  | 75.7          | 81.3   | 66.1 |
| Changes in the way health insurance companies pay for health services*** | 74.7          | 79.7   | 72.3 |
| Patients' contributions to the cost of drugs***                          | 65.4          | 71.0   | 60.3 |

\*p<0.05; \*\*p<0.01; \*\*\*p<0.001

Since 2004 patient representatives have been working in an advisory capacity in decision-making bodies of the German healthcare system. Here again, only a small proportion of the population knew about this function (6%); 7% of the women and 5% of the men were aware of this legal recourse. Only 4% of women and 2% of men (3% overall) knew the brochure 'Patients' Rights in Germany' ([www.bundesgesundheitsministerium.de](http://www.bundesgesundheitsministerium.de)). There were no significant differences here according to age or social status.

**Figure 3**  
Awareness of patients' rights

Data basis: Additional 2009 GEDA survey



### Possibilities for asserting patients' rights were rated »not so good«

Individual patients' rights were better known, however. Respondents were queried about nine specific rights; the best known of these were the free choice of medical practitioner and the right to confidential treatment of personal data (Figure 3). The least well known rights in the population were the right to self-determination, damages, access to documents, treatment with due care, and advice by the patient's health insurance fund. Fewer than 50% knew about these rights. In the 60+ age group only 34% knew about the right to damages; the 18- to 39-year-olds were the least familiar with the right to advice from their health-insurance provider (41%). All nine patients' rights were less well known among people with a low social status than among members of higher status groups.

The respondents were also asked to rate their opportunities to assert their rights as patients in Germany. About 36% considered these possibilities to be good or very good (Table 4). Nearly half judged their chances to be as »not so good«, and about 16% rated them as bad to very bad.

### People have cause to complain, but rarely do so

Being aware of what people complain about is regarded as a valuable resource. It helps to optimize processes, improve patient and user satisfaction, and identify risks.

In the survey, 37% of the women and 28% of the men said they would have liked to complain about a contact in the healthcare system over the past two years (Figure 4). This applies especially to people aged between 18 and 39.

There were no significant differences after stratification according to social status. Seen from the point of view of health-insurance status, privately insured people less frequently had cause to complain. Overall, 13% of the people actually did complain: 14% of the women and 12% of the men (Figure 4).

**Table 4**  
Assessment of possibilities for asserting patients' rights

In percent

Data basis: Additional 2009 GEDA survey

|                     | Assessment |      |              |      |          |
|---------------------|------------|------|--------------|------|----------|
|                     | Very good  | Good | weniger good | Bad  | Very bad |
| Total               | 2.2        | 33.9 | 48.2         | 12.6 | 3.1      |
| Sex                 |            |      |              |      |          |
| Women               | 2.2        | 33.6 | 49.7         | 12.0 | 2.5      |
| Men                 | 2.2        | 34.1 | 46.6         | 13.4 | 3.7      |
| Age groups***       |            |      |              |      |          |
| 18–39 years         | 1.5        | 36.9 | 46.6         | 12.3 | 2.5      |
| 40–59 years         | 1.9        | 28.0 | 52.9         | 13.2 | 4.0      |
| 60 years +          | 3.4        | 37.6 | 44.3         | 12.1 | 2.6      |
| Social status       |            |      |              |      |          |
| Low                 | 3.1        | 33.6 | 47.5         | 12.3 | 3.5      |
| Middle              | 2.2        | 32.2 | 49.8         | 12.8 | 3.0      |
| High                | 2.0        | 40.4 | 43.7         | 11.3 | 2.6      |
| Health insurance*** |            |      |              |      |          |
| Statutory           | 2.2        | 34.1 | 47.4         | 13.4 | 2.9      |
| Private             | 3.0        | 36.1 | 49.0         | 7.4  | 4.5      |

\*p<0.05; \*\*p<0.01; \*\*\*p<0.001

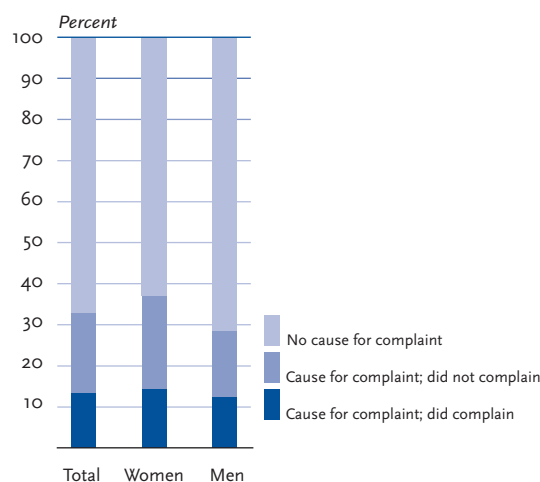
The respondents were also asked about the specific cause for complaint. Most frequently cited were general practitioners (44%) and hospitals (26%) (see Figure 5). Gender differences were especially evident in the case of complaints to hospitals (29% of women, 21% of men) and health insurance funds (18% of women, 25% of men).

## Conclusion

The analysis of the data from the additional 2009 GEDA survey on »Information Behaviour and Self-determination of Citizens and Patients« reveals that the population lacks knowledge not only on certain areas of the healthcare system, but also on patients' rights, how to assert these rights, and how to complain. It emerges that different population groups have different needs, and this information can be used to improve target-group orientation when it comes to knowledge transfer and developing health literacy. Gender, age and social status prove to be relevant impacting factors in this context, and a differentiated picture emerges for different sub-groups, indicating ways of improving how information and communication services are geared to the needs of different interest groups.

**Figure 4**  
Cause for complaint on contact with the healthcare system over the past two years

Data basis: Additional 2009 GEDA survey



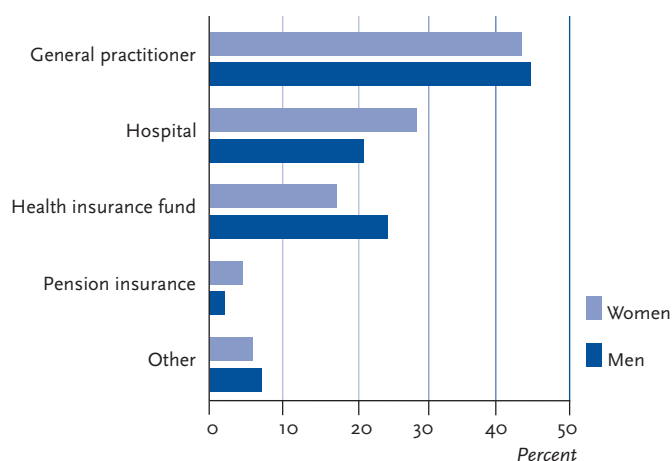
Overall, there are evidently considerable information gaps on issues relating to quality and cost transparency and on where to seek support when errors of treatment are suspected. Similarly, the majority feel they are poorly informed on their patients' rights and are not sure how best to assert them.

The results show that more differentiated and versatile support services are needed in order to offer healthcare users the kind of development opportunities that might enable them to become health-literate partners, empowering them to play a role not only as »payers« but also as »players« in the healthcare system. In particular, people in the low social-status group seem to require such forms of support. They look for information less frequently, are less aware of their rights, and are also the least satisfied.

Gender differences become particularly evident when it comes to searching for information. Women are more active than men in this context. On the other hand,

**Figure 5**  
Where there was cause for complaint

Data basis: Additional 2009 GEDA survey



they are less aware of their rights as patients. The above-mentioned overall conditions in the healthcare system and their further development represent an essential foundation on which health literacy can be strengthened among patients/users. At the same time, development conditions are relevant in social contexts, for example in the family, school and workplace. This also applies to areas outside the health sector, such as education and social services, which can provide knowledge that can raise literacy.

These results represent a contribution both to public-health science – particularly in terms of research into health literacy and prevention – and to health-services research, which aims at a more patient-focused orientation when it comes to improving the quality of healthcare.

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