

# Public awareness of heart failure in Europe: first results from SHAPE

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## KEYWORDS

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**Aims** Appropriate heart failure (HF) care and adequate resourcing require recognition of its clinical, social, and economic importance by the general public besides healthcare authorities and providers. The extent of public awareness in Europe is not known.

**Methods and results** A total of 7958 subjects were randomly selected from nine European countries (minimum 100/group per country). Each completed a 32-question survey on HF covering recognition, impact on health, comparative prevalence and severity, treatment, and costs. Although 86% of respondents had heard of HF, only 3% could correctly identify HF from a description of typical symptoms and signs, 31% correctly identified angina, and 51% identified transient ischaemic attack/stroke. Only 29% thought that HF signs and symptoms indicate a 'severe' condition. Most thought that HF patients should reduce all physical activity and 34% believed HF a normal consequence of ageing. Sixty-seven per cent thought that HF patients live longer than cancer patients. Only 9% believed that HF leads to greater healthcare expenditure than cancer, HIV, or diabetes. Overall, responses were comparable between countries.

**Conclusion** In Europe, community awareness of HF is low. Therefore, the general public is unlikely to demand appropriate measures by healthcare authorities and providers. A better understanding of HF could improve its prevention and management. Strategies to educate the public about HF are needed.

## Introduction

Heart failure (HF) is a major public health problem. With a prevalence of ~2%, it affects an estimated 14 million Europeans.<sup>1,2</sup> The lifetime risk of developing HF is one in five.<sup>3</sup> Prevalence rises rapidly with age. As the age of the population increases, the number of individuals with HF also increases. Moreover, better treatment of myocardial infarction has resulted in more survivors with left ventricular dysfunction—the initial stage of HF.

HF has a poor prognosis. More than 40% of patients die within 1 year of their first hospitalization with HF as the primary diagnosis.<sup>4</sup> It also has a high morbidity, reflected in frequent hospital admissions.<sup>5</sup> Approximately 25% of all patients are re-admitted within 1 year of their first hospitalization.<sup>6</sup> As a consequence, HF leads to high healthcare

costs, consuming 2–2.5% of the total healthcare budget with 70% spent on hospital admissions.<sup>7</sup>

Appropriate HF care and adequate resourcing of care and research require recognition of its clinical, social, and economic importance not only by healthcare authorities and providers but also by the general public. Without recognition of symptoms and their seriousness, people with HF will not seek medical attention promptly—patients often present with a long history of dyspnoea.<sup>8</sup> Awareness of the causes of HF may help to make appropriate lifestyle changes to reduce risk. In addition, awareness of treatment benefits could aid compliance and prompt patients to seek appropriate care. However, there is a lack of information on public awareness of HF. Studies have shown relatively poor understanding and treatment of HF by general practitioners (GPs).<sup>9,10</sup> If doctors are unaware of the importance of HF, it is unlikely that the general public will have good understanding.

SHAPE (Study of Heart failure Awareness and Perception in Europe) aims to improve HF care by increasing awareness

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and perception of the disease in Europe. Awareness and perception of HF among the general public and healthcare providers (primary care physicians, cardiologists, internists, and geriatricians) were documented in nine European countries. The results will be used to design and implement suitable awareness and educational programmes in these groups, aimed at improving HF care. This article reports the results of the awareness survey among the general public in Europe.

## Methods

The study was carried out between April and July 2002 in France, Germany, Italy, the Netherlands, Poland, Romania, Spain, Sweden, and the UK. The design of the study has been previously published.<sup>11</sup> A total of 47 985 households were randomly selected to identify a sample of 800 persons per country of either sex, aged 25–45 or 65–85, and living either in a rural or urban area, to participate in the survey. Participation was voluntary, confidential, and anonymous.

## Questionnaire

A draft questionnaire was produced by the Steering Committee and fine-tuned by the organization selected to perform the survey.

Together with socio-demographic questions about sex, age, education, and place of residence, there were 32 questions about HF. The first three were open-ended and consisted of brief descriptions, each having of the clinical picture of a patient with coronary pain, a stroke or transient ischaemic attack (TIA), and HF. Respondents were asked unprompted to name each condition (and could give multiple answers). Next, respondents were asked whether they thought that the typical symptoms of HF were important and what they would do if they had these symptoms. Then, they were asked whether they had heard of HF, asked to select HF from a list of cardiac conditions, and whether any of their family had heart disease. Next, the definition of HF was given and further questions focused on comparative prevalence and severity (against cancer, HIV, and AIDS), quality of life (against diabetes, arthritis, and hypertension), and the potential effectiveness and costs of different forms of therapy. Other questions related to possible causes of HF, including ageing, lifestyle requirements, and perceived risks.

The initial English version of the questionnaire was translated into the language of each country by a professional agency and the medical terminology was checked by SHAPE study group members.

The questionnaire was tested in two pilot studies in four countries and modified with respect to duration and potential order bias, and some of the questions were rephrased for clarity. The final version was endorsed by the Steering Committee.

## Survey

The purpose of the study was to obtain a net response of at least 800 people in the right age groups per country and equally distributed as to sex and location (urban vs. rural). In this way, for each of eight combinations of sex, age, and location, a cell of 100 respondents could be generated. A formal sample size calculation is not straightforward for a study of this kind, but age, sex, and location specific samples of at least 100 per country were estimated to yield sufficient precision around the point estimates for the prevalences of the answer categories for the main questions. Therefore, a gross sample of 42 518 households was drawn for the telephone part of the survey and 5467 for the face-to-face part—together a gross sample of 47 985.

Interviews were conducted by an experienced interviewer in the mother tongue of the respondent. The survey was carried out by random digital dialling in all countries except Poland and

Romania. With this method, countries were divided into specific regions, existing postal codes sought, and then area codes attached to these. Only one number per postal code was imported in the system and then the last two digits changed continuously. In Poland and Romania, surveys were performed face-to-face using a random route method in which every 10th house was surveyed in housing areas or every third block was surveyed in apartment blocks, alternating between first and upper floors. Samples were drawn throughout the whole population, but only people with ages 25–45 and 65–85 were included. Addresses of families not including members in the required age ranges were withdrawn. Consequently, not every address could be used and many were left out because there was no person of the right age group. If several members did meet the age ranges at an address, the one with the nearest birthday was selected. The survey continued in each country until the required number of participants was included. In this article, we report the overall responses and country comparisons.

## Results

A total of 7958 completed questionnaires were available for analysis after 42 527 households were approached by telephone and another 5467 door-to-door in Poland and Romania. Excluding unavailability, refusals, and sickness as reasons for not participating, a net sample of 22 161 people resulted. Falling outside the age range was the major reason for a 'net' response rate of 38% (33% telephone and 57% face-to-face). In total, only 34 people refused to proceed during the interview. They are not included in the net sample size.

There were no significant differences concerning age and sex between rural and urban locations as a result of the pre-designed sampling strategy (*Table 1*). The highest completed level of education was equally distributed. In general, answers did not differ between countries, except when described.

**Table 1** Sample structure

	<i>n</i>	%
Gender		
Male	3832	48
Female	4126	52
Age		
25–45 (years)	4048	51
65–85 (years)	3910	49
Region		
Urban	4198	53
Rural	3760	47
Highest completed level of education		
Less than primary	844	11
Primary studies	1314	17
Traineeship/apprenticeship	1253	16
Secondary school O-level	1494	19
Secondary school A-level	1485	19
University	1435	18
Higher degree	75	1
Do not know/does not want to say	58	1
Presence of heart disease (respondent/family)	2343	31
Presence of HF (respondent/family)	469	6
Total participants	7958	

## Questions before the definition of HF was provided

When asked what condition was being described by 'a heavy feeling on the chest occurring during physical exertion and disappearing at rest', 28% identified this as angina, heart attack, or infarct (*Table 2*); 48% identified a stroke or stroke equivalent from the symptoms of 'a distorted face, double vision, or suddenly no use of an arm'.

In contrast, only 3% identified HF from the description of 'breathlessness, tiredness, or swollen ankles'. This was despite 6% of households reportedly having a person with HF. In contrast, when respondents were asked whether they had ever heard of HF, 86% had heard of (*Table 2*), ranging from 61% in the Netherlands to 94% in Italy. Even when provided with a set of possible answers to the question 'what do you think heart failure is?', only 52% choose the answer 'when the heart becomes less efficient at pumping the blood around the body'. Answers varied considerably between countries, with a correct answer given by 66% in Italy and only by 36% in Sweden (*Table 3*).

When respondents were asked about their perceptions of the severity of a disease characterized by breathlessness, tiredness, or swollen ankles, only 29% thought it 'a severe complaint' (*Figure 1*). On being asked what they would do if they had these symptoms, 86% said that they would 'go and see my general practitioner.'

At this point, respondents were queried about the presence and type of heart disease in their family and whether they wished to proceed. Subsequently, the definition of HF was provided.

## Questions after the definition of HF was provided

### Causes of HF

When given the statement 'HF is a normal consequence of getting older', 34% were agreed (*Figure 2*). When asked 'which of the following gives you a greater chance of getting HF' and given the option of high blood pressure or lung disease, 80% of the respondents choose high blood pressure.

### Perceptions of HF compared with other conditions

Of the respondents, 82% thought that HF was more common than AIDS, but 43% thought it more common than cancer. When asked about prognosis, 67% thought that HF patients lived longer than cancer patients (17% thought the opposite) and 66% than patients with HIV (only 21% believed HIV patients lived longer). On being asked to imagine a colleague, neighbour, or friend was being treated for HF, 58% agreed that they would worry that he/she might suddenly drop dead. Responses varied widely between countries (*Figure 3*).

When asked to choose which affects quality of life the most from among four conditions, 41% picked HF (ranging from 33% in Italy to 48% in the UK), 25% diabetes (ranging from 14% in Sweden to 36% in Italy), 18% arthritis (ranging from 10% in Romania to 29% in the UK), and 11% hypertension (ranging from 7% in the UK to 18% in Romania).

### Treatment of HF

When asked how HF can be treated, 35% did not think drugs were an option and 62 and 64% thought the same for pacemakers and heart surgery, respectively. However, only 1% thought that there is no treatment. When asked, 'Suppose

you were told you were suffering from HF, if you had to choose, which treatment would you prefer?', 67% of respondents choose treatment to improve quality of life, 26% choose treatment to live longer, and 8% could not decide between these options. However, respondents in Romania and Poland preferred long life (44 and 56%, respectively) when compared with Spain and Sweden (16 and 14%, respectively). Overall, 73% of respondents disagreed with the statement 'modern drugs cannot cut the number of deaths due to HF', though these figures were lower in Poland and Romania (63% in each), and 76% disagreed with the statement 'modern drugs cannot improve the physical and emotional well-being of HF patients' (66% in Poland and 69% in Romania). Overall, 31% thought that modern drugs cannot prevent the development of HF, though responses varied considerably between countries (*Figure 4*).

On being asked to imagine a colleague, neighbour, or friend was being treated for HF, 61% agreed that he/she should live quietly and reduce all physical exertion. Again, responses varied considerably between countries (*Figure 5*).

### Costs of HF

From a list of conditions, most respondents (40%) thought that cancer incurred the highest healthcare costs, followed by HIV (27%). HF was thought to be the most expensive by only 9% (*Figure 6*). When asked which HF treatment costs the most, most respondents selected surgery (36%), then hospital admission (26%), drugs (19%), and last pacemakers (13%), although this did vary between countries (*Table 4*).

### Sources of information about HF

If respondents needed information on HF, 49% would consult their GP and 35% a medical specialist. In Poland and Romania, more respondents would go to a medical specialist than to a GP (64 vs. 31% and 66 vs. 22%, respectively), whereas in the UK, Sweden, the Netherlands, France, and Germany, more respondents would go to their GP (75 vs. 3%, 57 vs. 18%, 56 vs. 13%, 59 vs. 31%, and 55 vs. 30%, respectively). Few respondents would search elsewhere, with the exception of 13% in the Netherlands who would search the Internet.

## Discussion

This is the first study to assess the awareness of HF among the general public in Europe. It unequivocally demonstrates that awareness and perception of all aspects of HF in the community are low compared with other cardiovascular conditions. This is perhaps unsurprising given that results of surveys among GPs show that their knowledge of HF is also sub-optimal.<sup>9,10</sup> Generally, although, the answers were comparable between countries, there were major differences in the response to some of the questions.

### Knowledge of HF

The presence of HF in a household member was reported by 6% of respondents and 86% had heard of HF, however, only 3% were able to identify HF from its clinical description. In contrast, respondents were significantly better at recognizing angina/MI and TIA/stroke. In addition, the percentage of interviewees who responded 'do not know' to the HF

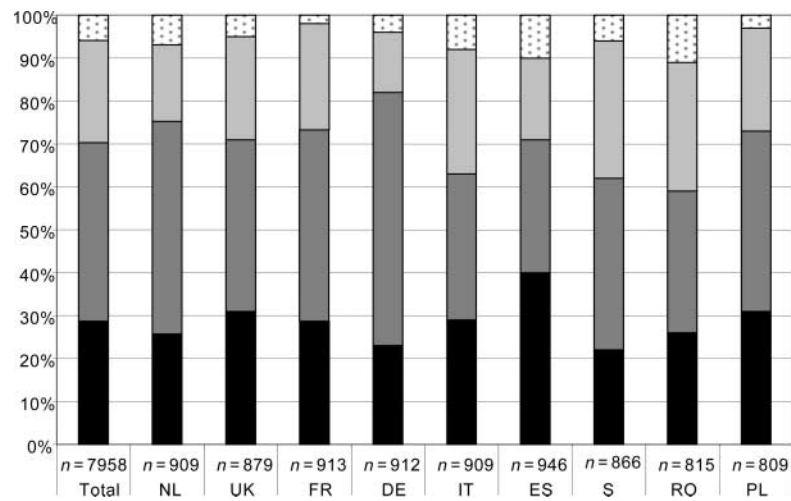
**Table 2** Responses to the description of three clinical syndromes (open questions) and acquaintance with the term HF (closed question)

Number respondents	Total (n = 7958)	NL (n = 909)	UK (n = 879)	FR (n = 913)	DE (n = 912)	IT (n = 909)	ES (n = 946)	S (n = 866)	RO (n = 815)	PL (n = 809)
<i>Of which condition would you think</i>										
If someone has symptoms such as a heavy feeling on the chest occurring during physical exertion and disappearing at rest?										
Angina pectoris, heart attack, or infarct (%)	28	16	36	44	33	24	27	20	15	35
Vascular disorders (%)	3	1	0	1	3	4	1	13	3	3
Heart unspecified (%)	44	69	44	38	45	35	38	36	53	40
Lung disorders (%)	11	6	13	9	11	8	12	5	25	16
Do not know (%)	10	4	8	10	9	17	16	15	8	7
If someone has symptoms such as a distorted face, double vision, or suddenly no use of one arm?										
Stroke or equivalent (%)	48	78	70	25	76	59	12	53	3	54
Brain unspecified, Parkinson, and epilepsy (%)	4	8	3	5	1	3	2	6	4	4
Heart unspecified (%)	8	6	6	9	2	5	13	6	17	6
Angina pectoris, heart attack, or infarct (%)	15	6	9	21	8	19	28	15	19	11
Do not know (%)	18	8	12	31	9	20	31	17	13	15
If someone has symptoms such as breathlessness, tiredness, or swollen ankles?										
HF (%)	3	2	2	2	3	2	1	4	9	5
Heart in general (%)	26	25	28	31	24	20	22	31	31	24
Heart attack, heart infarct, or angina (%)	19	6	12	24	16	39	18	9	20	28
Lung disorders (%)	15	22	10	8	15	12	20	6	29	11
Do not know (%)	24	24	24	29	29	22	30	32	11	15
Have you ever heard of heart failure?										
Yes (%)	86	61	93	88	76	94	91	91	87	90
No (%)	14	39	7	12	24	6	9	9	13	10

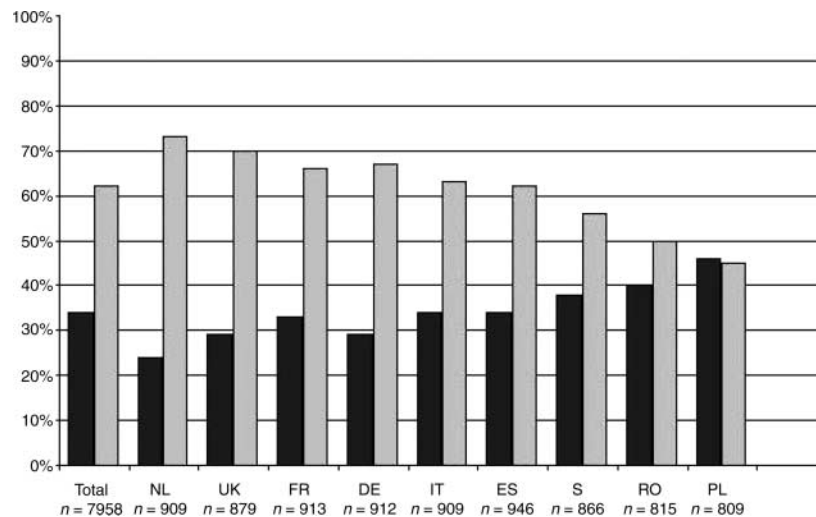
NL, Netherlands; UK, United Kingdom; FR, France; DE, Germany; IT, Italy; ES, Spain; S, Sweden; RO, Romania; PL, Poland.

**Table 3** Response to the question 'What do you think heart failure is?'

	Total (n = 6809)	NL (n = 559)	UK (n = 819)	FR (n = 805)	DE (n = 690)	IT (n = 853)	ES (n = 857)	S (n = 785)	RO (n = 710)	PL (n = 731)
Other word for heart attack (%)	8	6	29	6	4	3	5	4	5	9
Other word for heart rhythm disorder (%)	18	30	6	8	18	13	7	38	25	24
Weakness of the heart as a natural result of ageing (%)	13	11	11	18	17	10	10	12	15	10
When the heart becomes less efficient at pumping blood around the body (%)	52	45	42	62	52	66	60	36	53	49
Other (%)	3	3	8	0	2	2	6	2	0	2
Do not know (%)	6	5	4	6	7	5	12	8	3	6



**Figure 1** Response to the question, 'if you had these symptoms (breathlessness, tiredness, or swollen ankles) what would you think? Would you think you had ...'. Black bar represents severe complaint. Dark grey bar represents somewhat severe complaint. Light grey bar represents minor complaint. Spotted bar represents do not know. UK, United Kingdom; NL, the Netherlands; FR, France; DE, Germany; IT, Italy; ES, Spain; S, Sweden; RO, Romania; PL, Poland.



**Figure 2** Response to the statement 'heart failure is a normal consequence of getting older'. Black bar represents agree. Grey bar represents disagree.

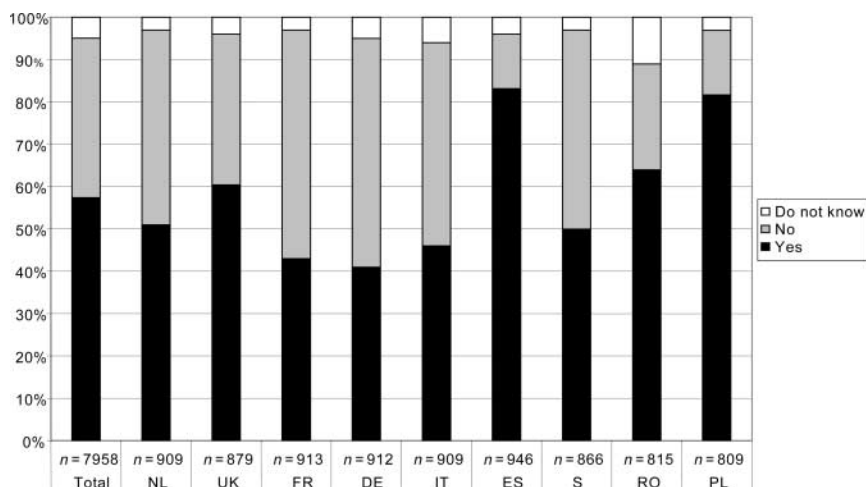


Figure 3 Variations between countries in answer to questions about whether a person suffering from HF might suddenly drop dead. Black bar represents yes. Grey bar represents no. Open bar represents do not know.

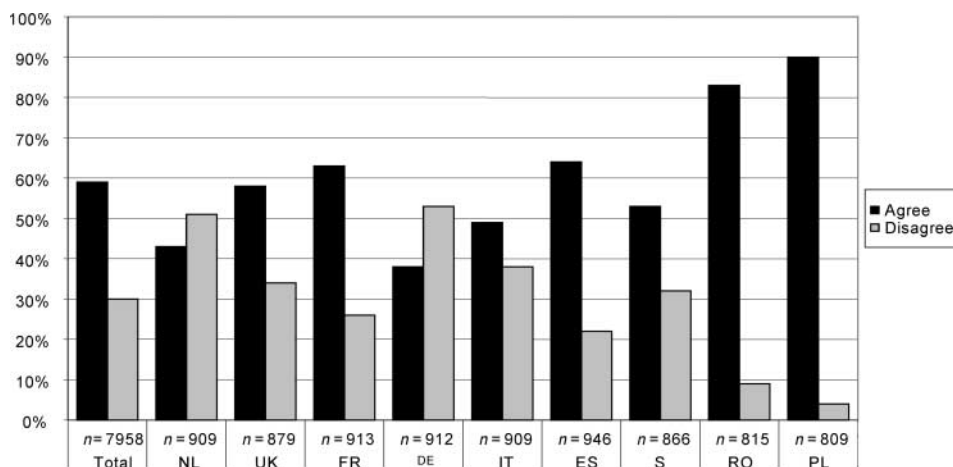


Figure 4 Variation between countries in response to the statement 'drugs can prevent the development of heart failure'. Black bar represents agree. Grey bar represents do not agree.

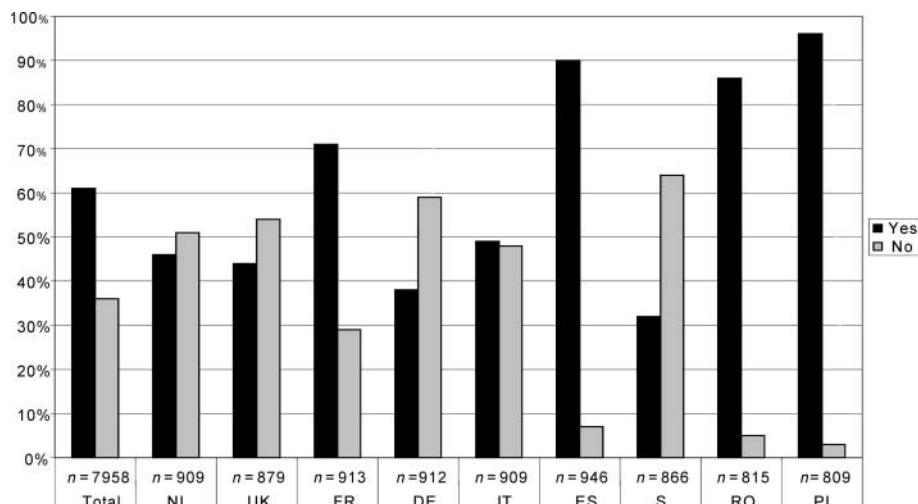


Figure 5 Variations between countries in answer to questions about whether a person suffering from HF should live quietly and avoid physical exertion. Black bar represents yes. Grey bar represents no.

description was higher than to that for angina/MI (24 vs. 10%, respectively). Even when provided with a list of definitions including one for HF, which could scarcely be mistaken, only about half of the respondents choose correctly. Clearly, although the general public claim to have heard of HF, they have little idea what it actually is and their knowledge of HF is considerably poorer than that of other cardiovascular conditions. This presumably results from a lack of information, although it may also be explained by the fact that HF symptoms are less specific than those of angina/stroke. The better knowledge of other conditions is borne out by other studies. Schneider *et al.*<sup>12</sup> found that 70% of 2173 respondents in a general public survey in the USA correctly listed at least one of the five established warning signs of stroke and 72% at least one of the established stroke risk factors.

Among our respondents, the symptoms of HF were not seriously considered. Only 29% considered them to be a severe complaint. This inability to recognize the symptoms of HF or their significance, along with the fact that many respondents thought that HF was a normal consequence of ageing, could result in delays in seeking medical attention.

Two-thirds of our respondents thought that HF patients live longer than patients with HIV or cancer, further demonstrating misunderstanding of the severity of HF among the general public. This is in contrast with reality. HF has a worse 5-year survival than bowel, prostate, or bladder cancer in men and than breast, bowel, or ovarian cancer in women.<sup>13</sup> Similarly, only 41% of respondents thought that quality of life was reduced more by HF than by

diabetes, arthritis, or high blood pressure, a well-documented fact.<sup>14,15</sup>

Respondents also underestimated the prevalence of HF. Although, the overall prevalence of AIDS was thought to be lower than HF, in Romania and Spain at least one in five interviewees thought that AIDS was more prevalent than HF, whereas it is much less so. More respondents thought that cancer was more prevalent than HF. Although this is true for all cancers combined, Stewart *et al.*<sup>13</sup> showed that more patients are admitted to hospital with HF than those with any of the most common cancers. In fact, the lifetime risk for breast cancer is one in eight when compared with one in five for HF.<sup>3</sup>

### Perceptions of treatment

Almost one-third of respondents wrongly thought that modern drugs cannot prevent the development of HF, whereas several drugs do so.<sup>16–18</sup> This low expectation may reflect the commonly held view of our respondents that HF is a natural consequence of ageing.

Misconceptions also existed regarding lifestyle. Most respondents wrongly believed that patients with HF should live quietly and reduce all physical exertions. This could have important implications, e.g. patients with HF might be wrongly discouraged from exercising by their caregivers.

Interestingly, there was a generally positive attitude towards drug treatment for HF. Most respondents thought that drugs can minimize the number of deaths and improve physical well-being. This contrasts with the well-documented under-treatment of HF—only 20–50% of HF is prescribed ACE-inhibitors by their GP and often at sub-optimal doses.<sup>9,10</sup> Knowledge of this shortfall could lead to a demand for better care of patients with HF.

### Healthcare costs

The general public is unaware of the cost aspects of HF. When asked which disease causes the greatest healthcare expenditure, most said cancer and HIV and only 9% said HF. HF consumes a greater percentage of healthcare costs than HIV or cancer,<sup>19,20</sup> ~2–2.5% of the total healthcare budget.<sup>7,21,22</sup>

Surgery was believed to be the most expensive form of HF treatment by our respondents. Fewer thought this of HF hospitalizations, drugs, or pacemaker treatment (in declining order). In fact, hospitalization is the most costly aspect of HF care, accounting for ~70% of the cost.<sup>7</sup> In contrast, less is spent on drugs than on hospitalizations, outpatient visits, diagnostic procedures, or laboratory analyses.<sup>23</sup>

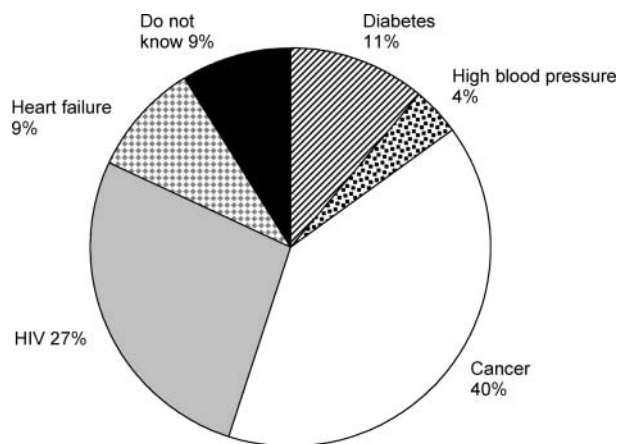


Figure 6 Response to the question, 'which condition leads to the highest healthcare costs?'

Table 4 Response to the question which treatment for HF would cost most

	Total (n = 7958)	NL (n = 909)	UK (n = 879)	FR (n = 913)	DE (n = 912)	IT (n = 909)	ES (n = 946)	S (n = 866)	RO (n = 815)	PL (n = 809)
Hospital admission (%)	26	31	18	34	19	29	33	34	20	13
Supply of drugs (%)	19	17	32	13	28	23	16	15	12	17
Surgery (%)	36	40	41	40	40	29	26	33	42	30
Pacemaker (%)	13	8	6	11	8	9	10	11	23	33
Do not know (%)	6	4	4	3	4	11	15	6	3	8

## Differences between countries

Although responses from the different countries tended to conform, major differences were apparent in several of the questions. Italy had the highest level of recognition of the term HF (94%), followed by the UK (93%). In contrast, in the Netherlands, only 61% of responders reported that they had heard of HF. This is of interest as an intensive campaign on HF was conducted by the Dutch Heart Foundation in the year preceding the SHAPE survey. All countries scored poorly at recognizing the signs and symptoms of HF, Romania being the best with 9% correct identification against overall 3%.

Although, overall, modern drugs were thought to reduce mortality and improve well-being, respondents from Germany and the Netherlands were least likely to believe that drugs could prevent HF (38 and 43%, respectively). In contrast, the Polish and Romanian respondents were very positive (90 and 83%, respectively, agreed to this statement).

The French (71%), Romanians (86%), Spanish (90%), and the Polish (96%) were convinced that people with HF should live quietly and avoid exercise, in contrast to the Germans (38%) and Swedish (32%), whereas the British (44%), Dutch (46%), and Italians (49%) were uncertain. This may be related to their perceptions of the risk of sudden death as the Spanish (84%) and Polish (81%), as well as the Romanians (64%), were more concerned that patients may drop dead than their Italian (46%), French (43%), or German (41%) counterparts.

There were also significant differences between countries in their preferred sources of information about HF, with Poland and Romania preferring to visit a medical specialist rather than their GP.

## Strengths and limitations

The study took place across Europe involving a substantial number of respondents who were balanced in terms of gender, age, and urban residence vs. rural residence. A breakdown of the sample structure also shows a balanced distribution in terms of highest completed level of education overall (pre-defined but not selection criteria). To capture both employed and unemployed respondents, the telephone surveys took place at different times of day. The analysis used for the presentation of the main results in this study was mainly descriptive. Detailed statistical analyses of pre-specified subgroups fall outside the scope of this study and will be reported separately.

Providing the definition of HF and the fact that the term HF appeared in most questions may have influenced the responses. Efforts were made to prevent this as much as possible by including questions in which HF was compared with other diseases. In addition, when respondents had to choose between different answers, they were always provided in a random order.

## Conclusion

This survey, as part of the SHAPE programme, indicates that the awareness of most aspects of HF in the general population in Europe is low. There are clear misconceptions for the nature, severity, treatment options, and costs. Under these conditions, the general public is unlikely to demand appropriate measures by healthcare authorities

and providers. Strategies to educate the general public about the importance of HF are needed. A better understanding of HF in the community could lead to better funding of HF healthcare and research, and generally should further improve the prevention and management of HF in Europe. The second phase of SHAPE will implement suitable awareness and educational programmes aimed at improving HF care, the results of which will then be assessed during a second survey, comparable to the parent study.

## Appendix

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**Conflict of interest:** We declare that we have no conflict of interest.

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