Accelerate
Change Together
Heart Failure
Gap Review
Contents

Section 1. Foreword 01
Section 2. Executive Summary 02
Section 3. General awareness and understanding of heart failure 06
Section 4. The health system impact of heart failure 12
Section 5. Conclusion: Bridging the Gap between the burden of heart failure and public/policymaker concern 16
Section 6. Appendix: Methodology 20
Section 7. References 22

Funded by AstraZeneca.
Section 1

Foreword

Despite significant medical advances in the diagnosis and management of heart failure (HF), and the extensive body of knowledge available on the causes and precipitants of this clinical syndrome, HF remains a leading health care challenge in both high- and low-income countries. Regardless of socioeconomic status, ‘lack of awareness’ about HF has recurrently been identified as a major stumbling block for patients with HF and their families, communities at large, healthcare workers at all levels of care, and policymakers.

The World Heart Federation (WHF) and AstraZeneca have come together in recognition that the deficiency in HF awareness is a universal problem that requires multifaceted interventions. This collaboration aims to, not only identify the barriers as outlined in this report and the WHF Heart Failure Roadmap, but also develop a platform for action. This report highlights that there are significant gaps in the understanding of HF and the burden it places on health care systems and society.

Dr Sarah Kraus
World Heart Federation Emerging Leader
Section 2

Executive Summary

Heart failure (HF) affects approximately 64 million people worldwide\(^1\) and is a condition where a person’s heart cannot pump enough blood to their organs.\(^2\) While the prevalence of the condition increases with age and most patients are over 60 years old,\(^3\) HF can affect people of any age. People with HF experience significant impairment of their quality of life compared to the general population.\(^4-6\)

Despite significant advances in HF treatment and prevention, morbidity and mortality remain high.\(^7\) Overall, annual mortality rates range from 6.6% to 26.6%,\(^8-15\) and patients have a significantly reduced life expectancy compared to the general population as half of people diagnosed with HF die within five years of their diagnosis.\(^16\)

Cardiovascular and non-cardiovascular comorbidities increase the risk of developing HF and contribute to poorer clinical outcomes in patients with the condition.\(^2\) Among the most prevalent comorbidities are high blood pressure, diabetes and decreased renal function.\(^9,17,18\)

The condition is a leading cause of hospitalisations in the US and Europe, accounting for 1-2% of all admissions.\(^19\) It is also a leading cause of hospitalisations in Canada, with hospital visits due to HF going up every year for the past several years.\(^20\)

In 2016, patients with HF had more than twice as many hospital admissions compared to age and gender-matched control patients without HF.\(^21\) These patients also have a high re-admission rate,\(^22,23\) and hospitalised HF patients have a significantly higher post-discharge mortality.\(^24\)
Despite significant advances in HF treatment and prevention, half of people diagnosed with HF die within five years of their diagnosis.\(^\text{16}\)

In 2014, the mortality for patients who had been hospitalised for their HF was 6.4% in hospital, 11% after 1 month, 29% within a year and 40% after 2 years.\(^\text{24}\) Hospitalisations and inpatient care can account for up to 87% of spending associated with HF,\(^\text{25}\) thus the hospitalisation of HF patients and subsequent costs of inpatient care result in a significant healthcare burden. There is a need to reduce the worsening of HF that leads to patients being hospitalised.

Looking to address this issue, the World Heart Federation (WHF) produced a HF Roadmap, which identifies roadblocks and provides potential solutions for improving prevention, diagnosis, treatment and monitoring of HF with the overall objective of reducing the global burden.\(^\text{2}\) The Roadmap acknowledges the need for improved awareness and understanding of the condition.

To complement the WHF’s work, AstraZeneca commissioned research across four continents in nine countries (UK, Spain, Italy, Germany, Canada, US, Brazil, Japan and China) to better understand current levels of awareness and knowledge of HF and its impact on health systems.

The research was conducted by YouGov through online surveys. Approximately 2,000 members of the general public were surveyed in each of nine countries, and approximately 30 policymakers (i.e. politicians and their senior staff) were surveyed in each of six countries (UK, Spain, Italy, Germany, Canada, US).
The research found that, generally, the public and policymakers have heard of HF, however, their understanding of the disease, including the risks and symptoms generally associated with it, is limited. For example, when asked to identify the definition of HF from a list of definitions of multiple cardiovascular diseases, nearly half (48%) of the general public who claimed to know at least ‘a fair amount’ about the disease were not able to do so.

18,243 members of the general public across nine countries, and 190 policymakers across six countries, were surveyed.
There is also a lack of awareness of the close link between HF and other conditions, such as diabetes and high blood pressure, and despite it being the leading cause of hospitalisations for people over 65, only 32% of the general public recognise this to be the case.27

Results also showed that while policymakers recognised there is a need to reduce hospital admissions in their country, they did not understand the role of HF in driving these hospital admissions.26 For example, more policymakers believed the number one reason for avoidable hospital admissions in their country to be accidents than HF.26 Additionally, results showed that only 4% of policymakers recognised that up to 87% of government spend on HF is associated with hospitalisations.26

This research has indicated a need to ensure policymakers better understand the burden of HF so that improving the management of it and reducing the burden can be prioritised accordingly.
Section 3
General awareness and understanding of heart failure

Heart failure (HF) is a condition where the patient’s heart cannot pump enough blood to their organs\(^2^3\) and 1 in 5 people will develop this disease in their lifetime.\(^7\) While HF can affect people of any age, its prevalence increases with age and most patients are over 60 years old.\(^3\) HF can cause irreversible damage to the heart, if not treated adequately, but it cannot be cured.\(^1^7,2^8\)

The survey found that while a majority of people have heard of HF,\(^2^7\) they do not necessarily have an understanding of the condition and its symptoms.

When asked to identify the definition of HF from a list of definitions of multiple cardiovascular diseases, over half (55%) of the general public were not able to do so.\(^2^7\) Among those who claimed to know at least ‘a fair amount’ about HF, the result was similar – 48% of those respondents were unable to recognise the definition.\(^2^7\)

Among the general public there was awareness of some key disease characteristics. 50% of respondents recognised that irreversible damage can be done to the heart, and while HF is a condition that predominantly affects people aged over 65, 85% correctly recognised that it can affect people of all ages.\(^2^7\)

While the survey found that the general public were familiar with the term ‘heart failure’, the survey also found a tendency for people to either overestimate their knowledge of the condition or have misconceptions regarding what a HF diagnosis means, a person’s risk of developing the condition and its severity.\(^2^7\)

**Symptoms of HF**

People with HF can experience a range of symptoms. The main symptoms are shortness of breath when resting or being active; feeling unusually tired or weak; and swelling of the feet, ankles, legs, abdomen, or in the small of the back.\(^2^9\)

When presented with each of the three main symptoms, the general public did not tend to recognise these as symptoms of HF. While 40% of people recognised ‘feeling unusually tired or weak’ to be a symptom of HF, just 23% and 25% respectively associated ‘shortness of breath when you are resting or being active’ and ‘swelling of the feet, ankles, legs, abdomen, or in the small of your back’ to be symptoms of HF.\(^2^7^*\)

\(\ast\) Respondents were asked to select one disease for each symptom from a list of: heart failure, diabetes, heart attack, stroke, asthma.
Globally, 55% of people did not recognise a description of what HF is. Which of the following statements do you think best describes heart failure? Please select one answer.

- Heart failure is when your heart does not pump blood around your body as well as it should
- Heart failure is when your heart stops beating
- Heart failure is when the supply of blood to the heart is suddenly blocked, usually by a blood clot
- Heart failure is a serious life-threatening condition that happens when the blood supply to part of the brain is cut off
- Heart failure is a gradual and natural weakness of the heart as a person ages
- Don’t know

Total respondents:

<table>
<thead>
<tr>
<th>Country</th>
<th>UK</th>
<th>Italy</th>
<th>Germany</th>
<th>Spain</th>
<th>US</th>
<th>Canada</th>
<th>Brazil</th>
<th>Japan</th>
<th>China</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>18,243</td>
<td>2,047</td>
<td>2,012</td>
<td>2,057</td>
<td>2,018</td>
<td>2,041</td>
<td>2,013</td>
<td>2,018</td>
<td>2,012</td>
</tr>
</tbody>
</table>

Accelerate Change Together Heart Failure Gap Review
HF risk factors and mortality

Cardiovascular and non-cardiovascular comorbidities such as diabetes, high blood pressure and coronary heart disease increase the risk of developing HF and contribute to poorer clinical outcomes in patients with the condition.\(^2\) Among the most prevalent comorbidities are high blood pressure, diabetes and decreased renal function.\(^9,17,18\) People with HF also have a significantly reduced life expectancy compared to the general population, with half of patients dying within 5 years following their diagnosis.\(^3\)

The survey findings indicated low awareness of the connection between other conditions and HF. 67% of respondents underestimated conditions such as diabetes, high blood pressure and coronary heart disease as the leading risk factor for developing HF.\(^27\)

There was also an indication of low awareness of the impact of HF on mortality. Only 11% of people recognised that half of people diagnosed with HF die within five years of their diagnosis.\(^27\) Over a third of respondents thought most people do not die as a result of HF, but usually from old age or another condition.\(^27\)

While it is positive that most people have at least heard of HF,\(^27\) the survey findings show there is still some way to go to improve understanding of what the disease is and its impact. These findings show a gap exists between awareness of HF and understanding of the disease.
67% of people underestimated conditions such as diabetes, high blood pressure and coronary heart disease as being the leading risk factor for developing HF\textsuperscript{27}

**General Public.** Which of the following do you think has the most impact on a person’s risk of developing heart failure? Please select one answer.

- **Smoke:** 23%
- **Age:** 5%
- **Other conditions, such as diabetes, high blood pressure, coronary heart disease:** 33%
- **Family history of the illness:** 12%
- **Diet:** 11%
- **Don’t know:** 5%
- **Exercise:** 5%

**Total respondents:** 18,243
Only 11% of people recognised that half of people diagnosed with HF die within five years of their diagnosis.27

General Public. Which of the following statements about heart failure do you think is true? Please select one answer.
Section 4

The health system impact of heart failure

Heart failure (HF) is a leading cause of hospitalisations in the US and Europe, accounting for 1-2% of all admissions.\textsuperscript{19} HF patients have more than twice as many hospital admissions compared to age and gender-matched control people without HF and are also at higher risk of re-admission.\textsuperscript{21-23} Furthermore, hospitalisations and inpatient care can account for up to 87% of spending associated with HF.\textsuperscript{25,29} Thus, the hospitalisation of these patients and the subsequent costs of inpatient care result in a high healthcare burden.

When asked about the sustainability of their healthcare system, the majority of policymakers (74%) reported thinking their healthcare system is at least ‘somewhat sustainable’.\textsuperscript{26} While only 6\% of policymakers went so far as to say their country’s healthcare system is ‘extremely sustainable’, 6 in 10 policymakers nonetheless recognised a need to reduce hospital admissions.\textsuperscript{26}

However, while most policymakers agreed there is a need to reduce hospital admissions, there was some confusion on the drivers of hospital admissions. Only 4 in 10 policymakers knew HF was the leading reason people over 65 are admitted to hospital.\textsuperscript{26} Also, when asked about hospitalisations that are ‘avoidable’, only 12\% recognised HF as the leading cause.\textsuperscript{26} More policymakers (28\%) believed accidents to be the leading cause of avoidable hospitalisations.\textsuperscript{26}
60% of policymakers agreed there is a need to reduce hospital admissions in their country²⁶

Policymakers. To what extent do you agree or disagree that there is a need to reduce hospital admissions in your country? Please select one answer.

- Don't know
- Strongly disagree
- Slightly disagree
- Neutral
- Slightly agree
- Strongly agree

<table>
<thead>
<tr>
<th>Country</th>
<th>Total respondents</th>
<th>Strongly agree</th>
<th>Slightly agree</th>
<th>Neutral</th>
<th>Slightly disagree</th>
<th>Strongly disagree</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>190</td>
<td>28%</td>
<td>32%</td>
<td>7%</td>
<td>23%</td>
<td>7%</td>
<td>3%</td>
</tr>
<tr>
<td>UK</td>
<td>30</td>
<td>37%</td>
<td>19%</td>
<td>19%</td>
<td>9%</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Italy</td>
<td>32</td>
<td>20%</td>
<td>31%</td>
<td>30%</td>
<td>19%</td>
<td>9%</td>
<td>7%</td>
</tr>
<tr>
<td>Germany</td>
<td>30</td>
<td>7%</td>
<td>22%</td>
<td>7%</td>
<td>13%</td>
<td>7%</td>
<td>9%</td>
</tr>
<tr>
<td>Spain</td>
<td>33</td>
<td>15%</td>
<td>18%</td>
<td>36%</td>
<td>21%</td>
<td>17%</td>
<td>6%</td>
</tr>
<tr>
<td>US</td>
<td>35</td>
<td>26%</td>
<td>26%</td>
<td>53%</td>
<td>21%</td>
<td>17%</td>
<td>3%</td>
</tr>
<tr>
<td>Canada</td>
<td>30</td>
<td>20%</td>
<td>20%</td>
<td>37%</td>
<td>19%</td>
<td>19%</td>
<td>3%</td>
</tr>
</tbody>
</table>
Only 12% of policymakers recognised HF as the leading cause of avoidable hospitalisations\textsuperscript{26}

**Policymakers.** What do you think is the number one reason for avoidable hospitalisations in your country? Please select one answer.

<table>
<thead>
<tr>
<th>Reason</th>
<th>UK</th>
<th>Italy</th>
<th>Germany</th>
<th>Spain</th>
<th>US</th>
<th>Canada</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't know</td>
<td>13%</td>
<td>9%</td>
<td>6%</td>
<td>9%</td>
<td>17%</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>6%</td>
<td>13%</td>
<td>13%</td>
<td>12%</td>
<td>3%</td>
<td>23%</td>
</tr>
<tr>
<td>Heart failure</td>
<td>12%</td>
<td>3%</td>
<td>3%</td>
<td>3%</td>
<td>9%</td>
<td>3%</td>
</tr>
<tr>
<td>Chronic Kidney Disease</td>
<td>2%</td>
<td>27%</td>
<td>13%</td>
<td>27%</td>
<td>6%</td>
<td>37%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>23%</td>
<td>6%</td>
<td>33%</td>
<td>24%</td>
<td>9%</td>
<td>20%</td>
</tr>
<tr>
<td>Respiratory diseases (e.g. asthma, COPD)</td>
<td>28%</td>
<td>34%</td>
<td>7%</td>
<td>9%</td>
<td>27%</td>
<td>23%</td>
</tr>
<tr>
<td>Accidents</td>
<td>10%</td>
<td>7%</td>
<td>12%</td>
<td>9%</td>
<td>17%</td>
<td>9%</td>
</tr>
<tr>
<td>Cancer</td>
<td>3%</td>
<td>6%</td>
<td>12%</td>
<td>6%</td>
<td>3%</td>
<td>37%</td>
</tr>
</tbody>
</table>

Total respondents: 190 for UK, 30 for Italy, 32 for Germany, 30 for Spain, 33 for US, 35 for Canada, 30 in total.
Furthermore, the survey found that very few policymakers were aware of the cost of HF-related hospitalisations.

Finally, when asked about improvements that should be prioritised regarding the care of HF patients, 42% of policymakers selected ‘prevention’. This was more than those who selected ‘earlier detection, screening and diagnosis’ (29%), and only 14% selected ‘improving quality of care in hospital and after discharge’ as the priority area for improvement. Fewest (12%) saw ‘improving the lives of patients with HF’ as the priority.

**Only 4% of policymakers recognised that up to 87% of government spend on HF is associated with hospitalisations**

**Policymakers.** Governments spend 1-2% of their health system budget on heart failure. Globally, this amounts to around $108 billion spent annually on heart failure (2012 data). Approximately what proportion of this spend do you think is associated with hospital admissions? Please select one answer.

<table>
<thead>
<tr>
<th>Proportion of Spend</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–19%</td>
<td>6%</td>
</tr>
<tr>
<td>20–39%</td>
<td>18%</td>
</tr>
<tr>
<td>40–59%</td>
<td>34%</td>
</tr>
<tr>
<td>60–79%</td>
<td>27%</td>
</tr>
<tr>
<td>80–100%</td>
<td>4%</td>
</tr>
</tbody>
</table>

Don’t know: 11%

Total respondents: 190
Section 5

Conclusion: Bridging the Gap between the burden of heart failure and public/policymaker concern

Despite the high prevalence of the disease, in the last 10 years there has been limited change in the levels of understanding among both the general public and policymakers of what heart failure (HF) is and the risk and burden associated.²,3⁰ The findings of this survey indicate a gap exists in the general public’s and policymaker’s understanding of the reality of the disease.

This research shows a similar pattern to previous studies in this area. Research of the general public, conducted in Europe in 2005, showed that although 86% of respondents had heard of HF, only 3% could correctly identify the condition from a description of typical signs and symptoms.³⁰ 15 years later, this survey’s findings suggest while 99% of general public survey respondents globally had heard of the disease, not all are able to recognise the definition of HF or identify the symptoms.²⁷

In a previous survey conducted by the World Heart Federation (WHF), a “low level of understanding among patients with HF” was the highest ranked perceived roadblock in early diagnosis; almost 48% of survey respondents cited this as the highest, or second highest, priority area in the prevention of HF in the general population.²

The results of this study also suggest that people overestimate their knowledge of the disease and underestimate the risk and burden associated.²⁶,²⁷ It has also indicated that policymakers underestimate the costs associated with the disease and the numbers of hospitalisations it causes.²⁶
The lack of understanding of HF signs and symptoms may prevent people seeking medical attention promptly\(^\text{10}\) and large numbers of premature deaths occur through low awareness of the causes and symptoms of HF.\(^\text{17}\) To support awareness of the severity of the condition there is a pressing need for public awareness programmes that explain the signs and symptoms, and emphasise the need for urgent attention.\(^\text{17}\) Furthermore, given low awareness of the link between HF and other conditions such as diabetes and coronary heart disease, guidelines should be updated to encourage healthcare professionals to initiate discussions about comorbidities with their patients.

There is also evidence to suggest that policymakers’ understanding of the burden of HF on their health systems could be increased. This survey has highlighted that policymakers recognise the need to reduce hospitalisations and improve preventative and diagnostic measures to reduce the burden of this disease.\(^\text{26}\) Improving their knowledge of the burden associated with HF and the number of avoidable hospitalisations could see the condition prioritised in decision making.
Globally, 71% of policymakers believe that prevention and earlier detection of HF should be the priorities for improvement of the care in HF26

**Policymakers.** From what you know about heart failure and thinking about how patients are treated in the health system in your country, which areas should be prioritised for improvement? Please select one answer.
The WHF has set out an integrated approach to improving awareness of HF, with recommendations including better support for patient organisations to communicate with the general public about HF, as well as raising the profile of the condition on national agendas. The development of national strategies that can address the lack of understanding of HF and the burden associated with it could better focus attention on this disease and improve outcomes.

**Recommendation 1**
Implement public facing campaigns focused on disease awareness, the signs and symptoms of HF and the associated risks of comorbidities.

**Recommendation 2**
Issue a National Strategy on HF and its impact on patients, the health system and society, outlining steps for improving outcomes for patients living with the disease and reducing its burden.
To gain an understanding of the general public and policymakers’ awareness and perceptions of heart failure (HF), and other health conditions, market research was conducted through online surveys.

The market research (i.e. surveys) and data analysis was conducted by a syndicated market research company, YouGov, in compliance with the Market Research Society Professional Code of Conduct and data protection laws, including General Data Protection Regulation (GDPR). Data has been verified by YouGov and the results have been compiled and analysed to compare trends.

**General public polling**

A closed-question survey was developed specifically to understand the general public’s:

- Awareness and understanding of what HF is, in comparison to other common conditions
- Awareness and understanding of HF symptoms, risk factors and mortality
- Views around hospital admissions in their country

A total of 18,243 members of the general public across the following countries completed the survey in their local language:

- UK
- Spain
- Germany
- Italy
- US
- China
- Japan
- Brazil
- Canada
Policymaker polling

A closed-question survey was developed specifically to understand policymakers’:

- Awareness and understanding of what HF is, in comparison to other common conditions
- Awareness and understanding of the causes of hospital admissions in their country
- Views on the sustainability of the health system and health budget priorities

A total of 190 policymakers (i.e. politicians and their senior staff) across the following countries completed a survey designed to understand their awareness of what HF is, as well as its impact on their health system:

- UK
- Spain
- Germany
- Italy
- US
- Canada

Participants were informed of the online surveys via email. The general public survey was live for a two-week period in February 2020, and the policymaker survey was live for a five-week period in February-March 2020.
Section 7
References


