



HEART EU THE EUROPEAN CHOLESTEROL PATIENT FOUNDATION

THE PREVENTION AND RISK MANAGEMENT
OF HEART DISEASE AND STROKE
—*THE NEEDS OF PATIENTS*

MAIN REPORT

*A GLOBAL SURVEY OF HEALTH CAMPAIGNERS
SURVEY AND ANALYSES CONDUCTED BY PATIENTVIEW*

THE ADMINISTRATIVE COSTS OF THIS SURVEY WERE FUNDED BY
AN EDUCATIONAL GRANT FROM ASTRAZENECA

DECEMBER 2006

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***THE PREVENTION AND RISK MANAGEMENT
OF HEART DISEASE AND STROKE
— THE NEEDS OF PATIENTS***
A SURVEY OF PATIENT REPRESENTATIVES

A PROJECT INITIATED BY
HEART EU

Main Report

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Executive summary

The World Health Organization (WHO) advises that most heart attacks and strokes are preventable. Yet some 32 million people worldwide already suffer from cardiovascular disease (CVD), and a high number of these people may experience needlessly premature deaths. Not surprisingly, many patient organisations are now becoming involved in issues of prevention, early intervention, and the risk management of disease. One such group is HEART EU, a pan-European organisation that aims to support people with a serious increased risk for premature cardiovascular death because of (inherited) high cholesterol. A large proportion of these premature deaths is avoidable when (inherited) high cholesterol—a silent condition—is diagnosed and treated early. The problem for groups such as HEART EU, however, is that little information exists about the true needs of patients and the public in the area of prevention and risk management for heart disease and stroke. This survey has contributed to the identification of those needs, and will assist HEART EU and other like-minded organisations raise the issue's profile in the public domain, and offer high-quality information and help to all who might benefit from expert knowledge.

ABOUT THE SURVEY

Between March and May 2006, PatientView conducted a global survey of health campaigning groups on behalf of HEART EU. The survey aimed to determine the needs of patients in the area of prevention and risk management of heart disease and stroke. The administrative costs of the March-May 2006 survey were funded by an educational grant from AstraZeneca.

Executives and staff from 200 different groups in 47 countries responded to the survey. Almost half of the respondent organisations specialise in chronic disease conditions linked to heart disease and stroke. The remainder focus on one of the following subjects: alcohol and other addictions; diabetes; general public-health issues (including prevention); mental health; smoking; tissue transplantation; weight and obesity; or women's health. [For a profile of respondents, a list of respondent groups that wished to be named, and a complete set of figures for the survey's 15 questions, see Appendix, pages 42-61.]

Executive summary

“EXTRAORDINARY GAPS IN PUBLIC INFORMATION ...”

Almost two thirds of survey respondents regard prevention as a very important campaigning issue [questions 12 and 13]. Nearly two thirds also believe in the need to emphasise the importance of prevention and changing lifestyles to counter the onset of cardiovascular disease (CVD) [question 14].

ALARMING FINDINGS

Health campaigners are alarmed by the extraordinary gaps in public information on issues to do with the prevention of heart disease and stroke. Responses suggest that an ill-informed public has difficulty adopting preventive action [question 2]. According to

respondents, high-risk patients—even after diagnosis—take inadequate precautions to avoid the onset of disease [question 7].

Almost 90% of respondents state that the public are unaware of the symptoms which indicate the onset of cardiovascular disease (CVD). Nor do respondents think that people know about the links between diabetes, irregular heartbeat, and CVD [question 3]. Just as worrying is the fact that few high-risk patients understand the importance of genetic screening for familial hypercholesterolemia (FH) [questions 8 and 9]. Respondents emphasise that only some families with inherited blood cholesterol are aware of the meaning and personal health implications of their genetic trait [question 4].

Hardly surprisingly, respondents indicate that many of the public are complacent about prevention [question 1] and that a significant proportion of high-risk patients do not adhere to

their high-blood-pressure or cholesterol medication [question 10].

Respondents also report that the majority of patients do not exercise, or change to a healthy diet.

Although some patients may be fearful, in denial, or insufficiently motivated [question 1], respondents advise that poor-quality information is to blame for people’s reticence to take preventive action [question 5]. The public do, however, place significant trust in doctors as a source of information on prevention [question 11]. Some respondents insist that prevention messages can be contradictory, and are often only aimed at sections of the population (such as well-off, middle-aged men).

“... MEAN THAT FEW PEOPLE ADEQUATELY PRACTISE PREVENTION”

Executive summary

NOTES

1. Definition of a health campaigner: "A better phrase to describe the members of the present-day user-driven healthcare revolution than 'patient group' is 'health campaigner'. A health campaigning organisation is any group that claims to represent the interests of patients or the public in matters of health or healthcare. Such groups are led by the users of healthcare systems—not by health professionals or by staff from other categories of stakeholders. The definition should be seen as incorporating those statutory bodies that have been appointed by government or healthcare providers to speak up for and defend the interests of people using healthcare systems." A. Wyke, 'Leaders of the revolution: consumer-driven healthcare has arrived', *Scrip Magazine*, April 2006, pages 25-29.

2. Fourteen of the responses were received from executives attached to international health campaigning groups. Respondents from these organisations, however, answered the questionnaire from the viewpoint of the country in which they were based. The results obtained from these international groups were therefore counted as national responses, and allocated to the appropriate regional category for analyses.

3. Results in the survey were also analysed for respondents that came from predominately heart / stroke groups, including those specialising in angioma, arrhythmia, asphasia, chronic disease, heart disease, hypertension and stroke.

4. Some respondents suggested topics that they thought might also have been included in the questionnaire, or pointed out possible incoherencies. For instance:

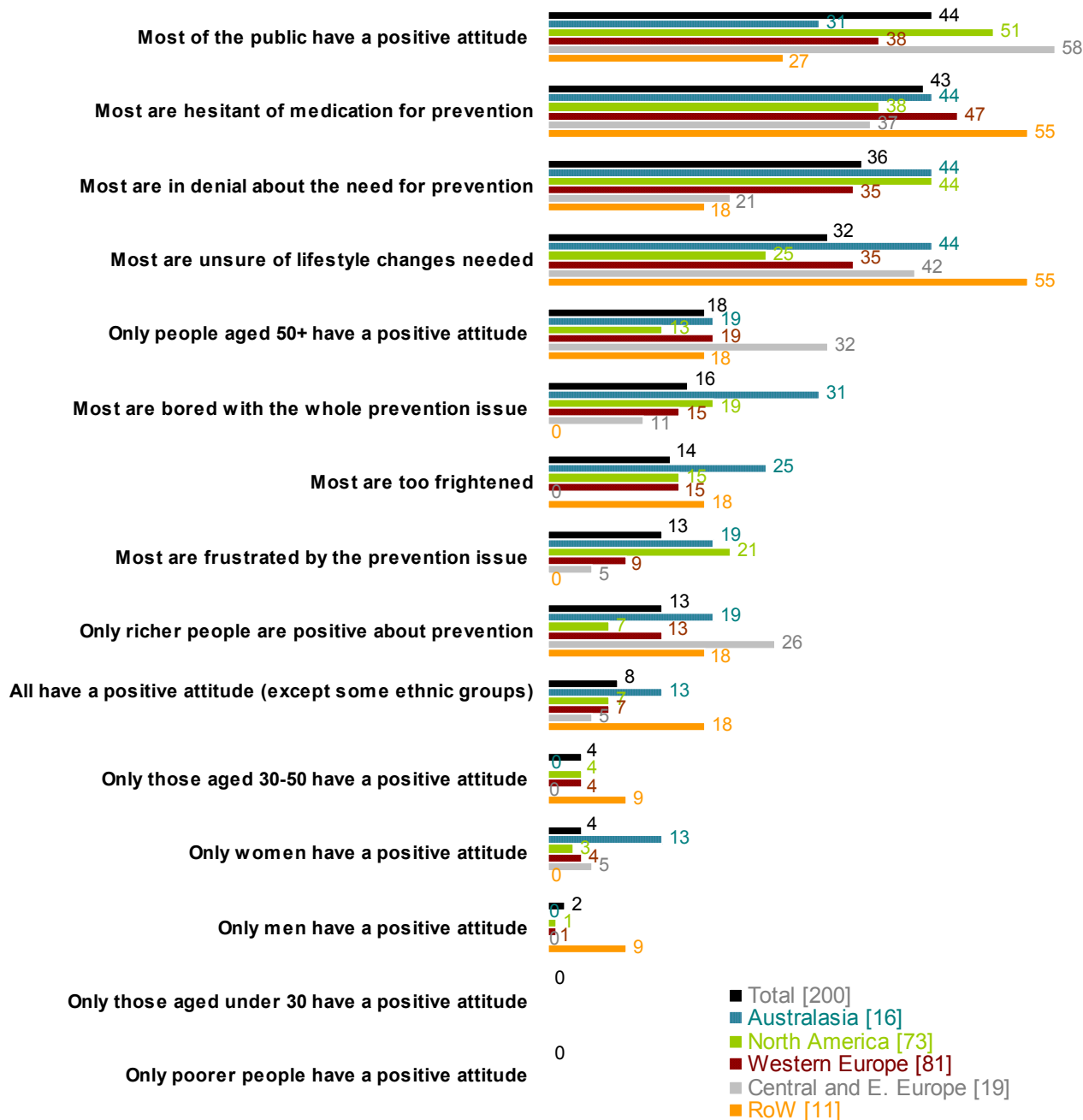
- "I think that the phrase 'positive attitude toward prevention' is misleading. I'm not sure what it means. Does it mean most people think that there is hope in the area of prevention? Or does it mean people think that there should be prevention? Or that people are more willing to act on their beliefs about prevention? Or does it mean awareness?"—president of US-based Florida on the Move.
- "Questions linking heart and stroke are confusing, as the answer may be positive for heart, and negative for stroke—for example, public knowledge re risk factors etc, are more familiar to the public for heart diseases than stroke. You have presented double-edged questions, which are not valid in questionnaires"—Israel-based Neeman Association for Stroke Survivors.
- "Your survey—like every other on heart disease—does not address high triglycerides and their role in atherosclerosis. Only a third of heart patients have high cholesterol. You are missing a lot of information by focusing on cholesterol, and not on lowering LDL [low-density lipoprotein] and triglycerides, and raising HDL [high-density lipoprotein]"—US group involved in cancer control and prevention.
- "You left out a vital issue—the question of the importance of drinking alcohol (or recognising the taking of one or more drinks a day) in relation to heart or stroke disease"—president of a Canadian group specialising in size discrimination.

The fifteen questions

Question 1

Do the majority of the public in your home country have a positive attitude towards the prevention of heart attack and stroke?

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]



Source: HEART EU, December 2006

Q1: Public attitudes toward prevention

HEALTH CAMPAIGNERS BELIEVE THAT THE POPULATION OF THEIR OWN COUNTRIES IS COMPLACENT ABOUT PREVENTION. PEOPLE—SAY SURVEY RESPONDENTS—ARE FEARFUL, OR IN DENIAL, OR MAY NOT KNOW HOW TO MODIFY THEIR LIFESTYLES TO BRING ABOUT HEALTHY CHANGE

As few as 44% of the survey’s participant health campaigners believe that the public has a positive attitude towards the prevention of heart disease and stroke. Campaigners based in Australasia or the ‘Rest of the World’ [Africa, Asia, and Latin America] are even more pessimistic about public attitudes towards prevention. Only 31% and 27% of the participants respectively indicate that the public in their region of the world maintain a positive attitude to the topic. The Australian Sudden Arrhythmia Death Syndromes (SADS) Foundation explains: “We

find that many [Australians] understand about heart disease and stroke, but still ignore the advice given anyway”.

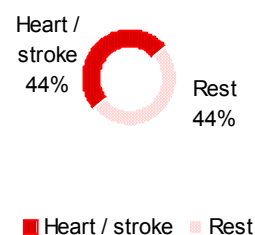
Most positive are people in Central and Eastern Europe—presumably because the incidence of cardiovascular disease (CVD) is higher there than in most other regions of the world. Nearly 60% of survey participants from that part of Europe see the public in their country as positive about prevention. But, in spite of the high figure, a respondent from Bosnia and Herzegovina expressed concern that the public might not necessarily translate their positive attitude into action.

Between 32% and 43% of survey respondents agree that the reasons for public ambivalence towards prevention include the following: hesitancy in relation to the subject; people in denial; people too frightened to see the need for prevention; and people unsure of the lifestyle changes needed.

WHAT CAMPAIGNERS SAY

A general hospital nurse attached to a US patient organisation warns: “I believe that most people think they are healthy—regardless—and that nothing is going to happen to them. When an illness strikes, they are shocked, and not really sure if they want to make lifestyle changes. This could be considered a form of denial”.

Heart/stroke groups who say that "people have a positive attitude towards prevention", versus the rest



Number of heart/stroke respondents = 88
 Number of non-heart/stroke respondents = 112

Source: HEART EU, December 2006

.....continued on next page

Q1: Public attitudes toward prevention

WHAT CAMPAIGNERS SAY

CENTRAL AND EASTERN EUROPE

"People often receive too much conflicting advice, including premature results of scientific research"—Secretary General, group involved in lifestyle issues, Lithuania.

"Health is the more important question. But less people focus on this because, they think, they haven't enough money to use the medical services. So I can't improve my health"—National Consumer Rights Protection Association, Latvia.

NORTH AMERICA

"The Ontario government is sending people to the US to have obesity surgery if they are accepted (and if they can afford the trip to the US, the hotel stay, etc). Once again, the rich win out. People on welfare cannot afford airfare, or two weeks in a motel where Canadian patients have to stay, pre- and post-op. Its a double standard all the way round"—activist, Canada.

"The government does not pay for preventive services—only acute—so people's attitudes don't matter. The healthcare system needs to be changed. All the education in the world won't help if people can't afford to take steps toward prevention"
—Miriam Berg, President, US Council on Size and Weight Discrimination.

"I think that the US is extraordinarily backward when it comes to stroke prevention. But, then, there probably isn't enough money in research and public relations. After all, it doesn't give us more oil. No, I think too little information is available, or cared about"
—respondent, National Aphasia Association, USA.

"It's not that the public as a whole are unaware or unconcerned—its whether there is information or help in aiding people to integrate healthy lifestyles with the realities of daily living"
—Sandy Schaffer, National Association to Advance Fat Acceptance (NAAFA), USA.

"I think that most people know what to do, but just don't think it could happen to them, until they (or someone close to them) develop symptoms—especially when it comes to smoking and obesity"—teacher and health advocate, USA.

WESTERN EUROPE

"People may know and feel positive about prevention of heart disease and stroke, but dislike the discomfort that comes from having to live a healthy lifestyle. A natural distrust of pharmaceutical companies also prevents people from taking medication to obviate chronic disease"
—respondent, organisation representing people with a rare heart condition, Germany.

"There is a need for more health-promotion and disease-prevention measures. People—at least the more educated and better-off financially—are becoming more aware about lifestyle issues in prevention. In general, the resources have been allocated to secondary treatment, rather than to disease prevention and health promotion"—Policy Outreach Officer, women's group, Ireland.

"The incessant publicity given to nutrition and exercise have provoked a certain frustration or boredom among the general public"—Project Manager, group specialising in 'secondary prevention' of diabetes, Switzerland.

"The young feel that they have no need to prevent anything at their age"—Chair, local voluntary group, UK.

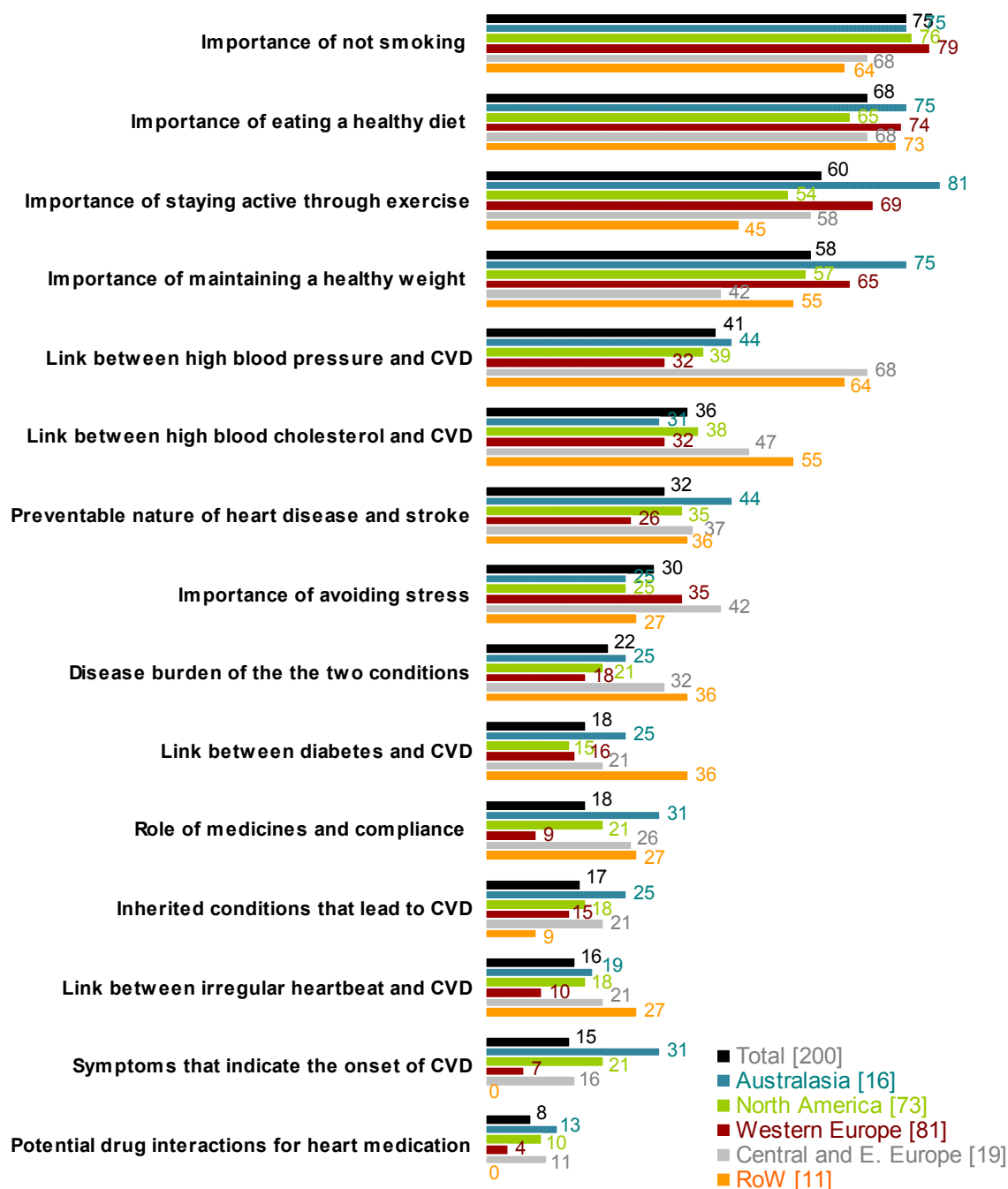
REST OF WORLD

"As people become educated, they take more responsibility about lots of issues, including AIDS"—Director, heart organisation, South Africa.

Question 2

Do you think that the public in your country are sufficiently informed to take appropriate action on issues related to heart attack and stroke?

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]



Source: HEART EU, December 2006

CVD = cardiovascular disease

Q2: An informed public?

THE PUBLIC POSSESSES A BASIC KNOWLEDGE ABOUT THE EFFECTS UPON HEALTH OF A BALANCED DIET, INCREASED PHYSICAL ACTIVITY, AND SMOKING CESSATION, BUT ARE ILL-INFORMED ABOUT MOST OTHER FACTORS WHICH MIGHT PROVOKE HEART DISEASE OR STROKE—AND ARE THUS UNABLE TO TAKE APPROPRIATE PREVENTIVE ACTION

While the majority of respondents are sure that the public is well-informed on lifestyle issues (such as staying physically active, maintaining a healthy weight and a healthy diet, and not smoking), they also specify that the public is ill-informed on other matters relating to the prevention of heart disease and stroke. For instance:

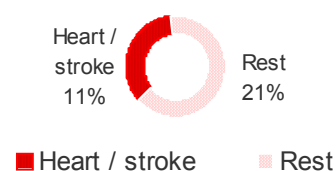
- Only 15% of the survey participants estimate the public to be aware of the symptoms that indicate the onset of CVD.
- Less than a quarter of participants think that the public knows about links between diabetes/arrhythmia and CVD.

- Less than half of the respondents [32% of those in Western Europe] consider that the people in their country know about the link between high blood pressure/high blood cholesterol and CVD.
- On questions of medication, only 18% of participants [9% of those in Western Europe] believe that the public knows about the role of drugs in prevention, and the need for compliance to drug regimens. Less than 10% describe the public as being aware of the dangers associated with potential drug interactions with heart medications.
- Only 17% of all participants [and just 11% of groups associated with heart/stroke] say that the public in their country are cognizant of the inherited conditions that lead to CVD.
- Respondents state that the least-known lifestyle factor appears to be stress, and stress avoidance.

WHAT CAMPAIGNERS SAY

A Policy Outreach Officer from a women’s organisation in Ireland points out the limitations of ad-hoc media reporting of CVD issues: “Overall, I think that the lack of coherent, sustained health promotion and disease prevention is reflected in the variety of people’s knowledge—and lack of knowledge!”

Heart/stroke groups who say people are informed about inherited conditions that lead to CVD, versus the rest



Number of heart/stroke respondents = 88
 Number of non-heart/stroke respondents = 112
 CVD = cardiovascular disease
 Source: HEART EU, December 2006

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Q2: An informed public?

WHATCAMPAIGNERS SAY

AUSTRALASIA

"I don't think that people really understand specifics. They know that healthy eating and physical activity can prevent myocardial infarction or stroke, but are not sure why"—Manager of Health Programmes, diabetes organisation, Australia.

"The Green Prescription Programme gives the public free exercise prescription and phone support for three months. Many doctors use this programme to educate their patients on what to do for a healthy lifestyle"

—Cardiac Rehabilitation Association of New Zealand.

CENTRAL AND EASTERN EUROPE

"Being informed does not mean that people act that way. Diabetes is still not connected to CV disease in Croatia, and Bosnia and Herzegovina. Drug interactions are almost unknown, even among some health professionals"

—University Hospital Mostar [Bosnia and Herzegovina], and Croatian Society of Hypertension.

NORTH AMERICA

"I do not think that inundating people with more information will help them to take appropriate action. I think that all the above information is readily available to anyone who wishes to read on the topic. Those who do not wish to read on the topic are simply likely to ignore anything they DO read or hear about the topic. **I think the issue is a core understanding that each**

person is ultimately responsible for their own health and well being. I am an American, and I think that the US public, in general, does not feel that they are ultimately responsible for their own health and well being. I think they turn that responsibility over to their doctor (or spouse, or parent, or child), and turn a deaf ear to any information that they do not want to pay attention to. Therefore, what I think is needed is a paradigm shift, and I'm not sure what would bring that about"—social therapist attached to obesity group, USA.

"I am not sure that MDs or healthcare providers take into consideration whether a person can afford the medicines prescribed, or the person's understanding or reading level. So little time is allotted to the MD before they have to go on to the next person. Healthcare is suffering, and, as a result, so is our population"—nurse and stroke center co-ordinator, general hospital, USA.

"Stroke is very little understood by doctors, much less by laymen"—National Aphasia Association, USA.

"The people we know in our age group are well informed (we are over 60)"—President, mental health rehabilitation group, USA.

"Many of our most recent consumer studies concentrate on knowledge about prevention and disease. Is it sufficient? More people still need to know. But among those who know, taking action is the challenge"—heart disease and stroke organisation, USA.

WESTERN EUROPE

"The importance of children's health promotion is not understood"—heart organisation, Finland.

"There can never be sufficient information about these important topics"—respondent, stroke organisation, Germany.

"On the subject of medicines, there is no general information—rather, only advertisements in pharmacies, newspapers, etc"—respondent, organisation representing the interests of people with a rare heart condition, Germany.

"I think that people's knowledge varies hugely. Knowledge about diet, exercise, smoking and weight is increasing, although more amongst the better off and well educated. There are many areas—such as the link between diabetes, the burden of disease, etc—of which I think the general population is unaware or confused. Overall, I think that the lack of coherent, sustained health promotion and disease prevention is reflected in the variety of people's knowledge—and lack of knowledge!"—Policy Outreach Officer, women's organisation, Ireland.

"People just don't believe that it is going to happen to them"—congenital heart group, UK.

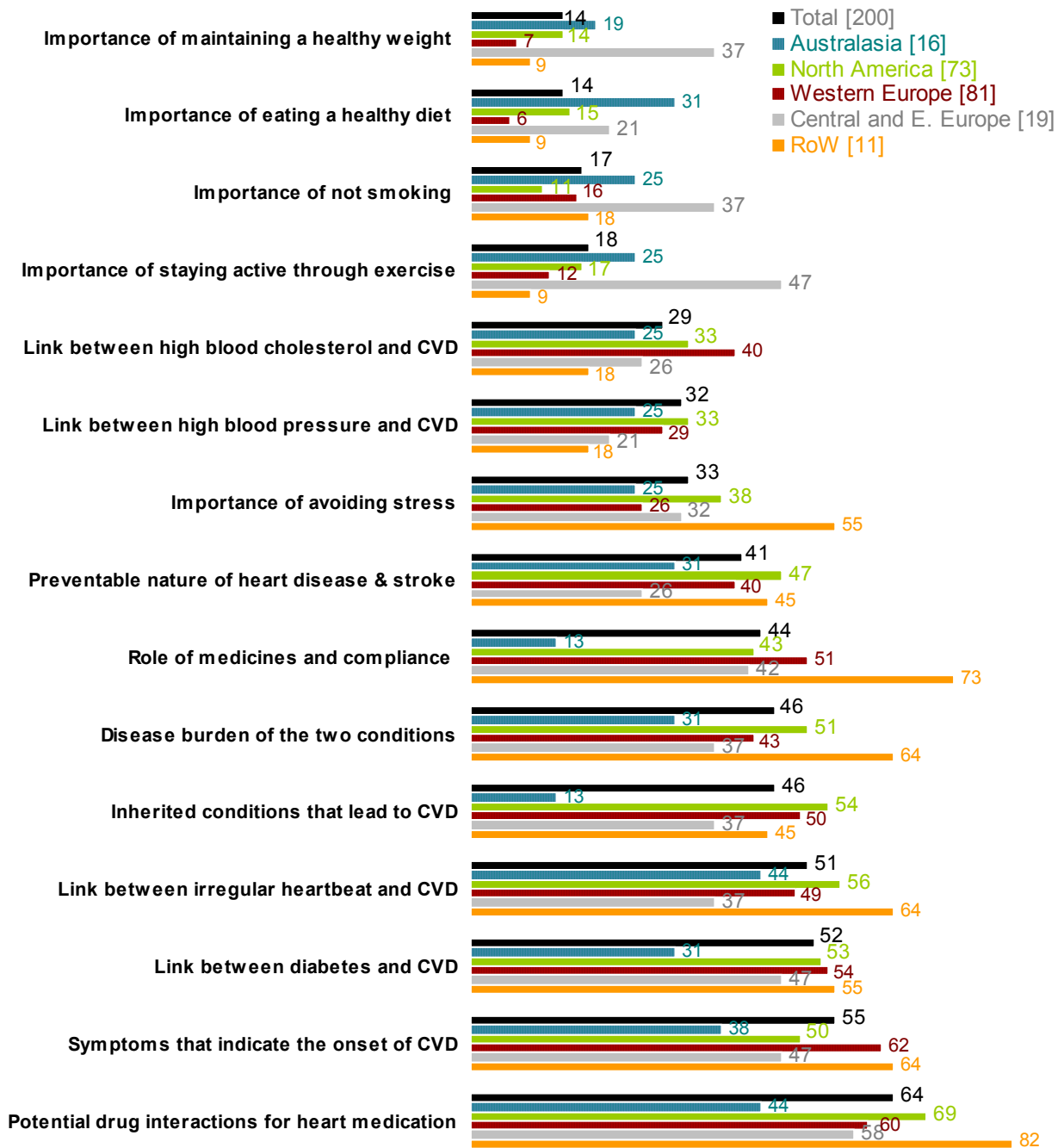
REST OF WORLD

"The majority do not have sufficient information"—Director, heart organisation, South Africa.

Question 3

Do you think that the public in your country have little or no information on any of the following issues in relation to heart attack and stroke?

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]



Source: HEART EU, December 2006

CVD = Cardiovascular disease

Q3: Availability of information for the public

MORE THAN HALF OF RESPONDENTS BELIEVE THAT PEOPLE DO NOT POSSESS ENOUGH INFORMATION ABOUT THE SYMPTOMS THAT PRESAGE THE ONSET OF HEART DISEASE AND STROKE. NOR, ADVISE CAMPAIGNERS, IS SUFFICIENT INFORMATION AVAILABLE ABOUT THE LINKS BETWEEN, ARRHYTHMIA, DIABETES, AND CVD

Although survey participants judge that ample public-domain information exists on lifestyle factors, they declare a deficiency in information on most other areas of prevention. Over half of respondents [or 66% of heart/stroke groups] note the absence of sufficient information about symptoms that indicate the onset of CVD. Around half of the participants from North America point to insufficient information about the preventable nature of heart disease and stroke. Not enough is known about the disease burden of the two conditions, they assert.

Other informational gaps highlighted by participants include the links between irregular heart beat/ diabetes and CVD; and (in Western Europe, particularly) the importance of medication. The Wellness Institute of Greater Buffalo and Western New York sums up: "There is a great deal of educational material. What is not understood are the roles of the environment, social capital, and how to build community capacity for creating a culture that supports healthy lifestyle."

WHAT CAMPAIGNERS SAY

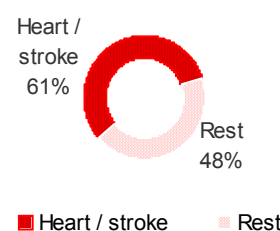
• **Symptoms of the onset of CVD.** "I think that people are not sure which symptoms are serious enough to warrant a visit by, or a call to, the doctor"
—President, Florida on the Move, USA.

• **Links between diabetes and CVD.** "Type-2 diabetes is the leading cause of heart disease and stroke. Little is known about this [by the public]"
—General Manager, diabetes group, New Zealand.

• **Links between high blood pressure and CVD.** "The goals of hypertension treatment are reached in 9% to 15% of cases"
—Executive Director, Slovenian Heart Foundation.

• **Inherited conditions.** "Many people still think that there is nothing you can do to avoid a heart attack produced by inherited cholesterol"
—Fundación Hipercolesterolemia Familiar, Spain.

Heart/stroke groups who say that "people have insufficient information about symptoms of CVD", versus the rest



Number of heart/stroke respondents = 88
Number of non-heart/stroke respondents = 112

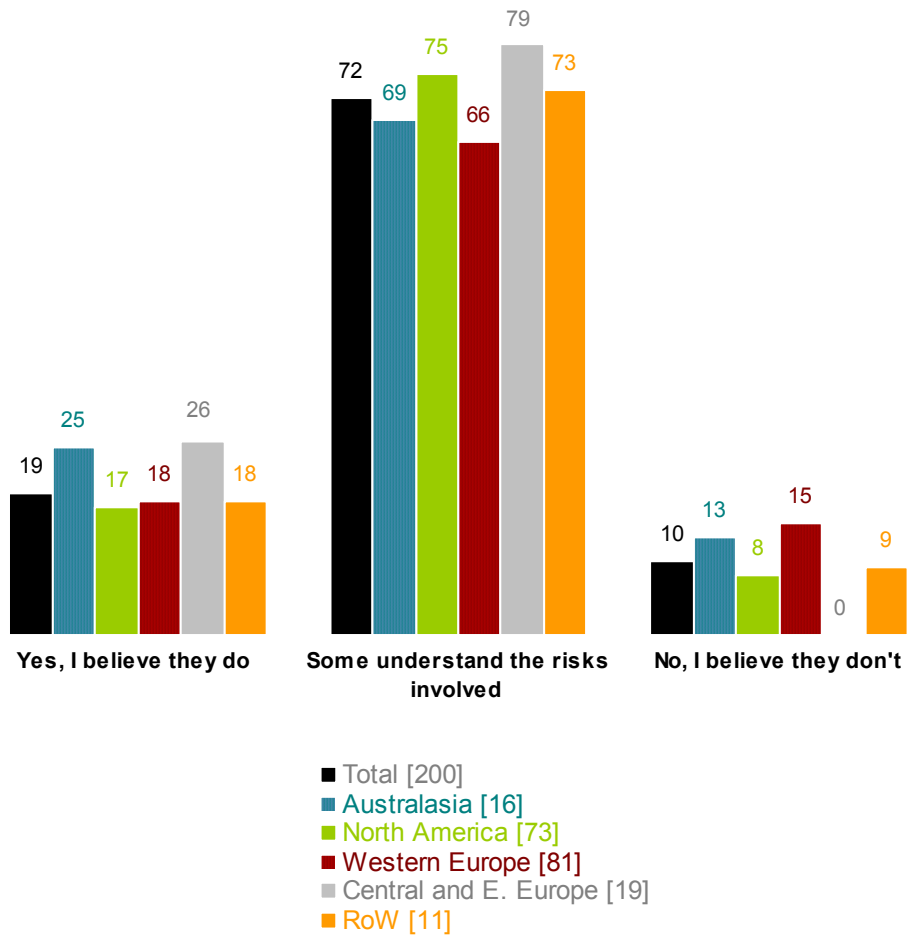
CVD = cardiovascular disease

Source: HEART EU, December 2006

Question 4

Do you think that people in your country with a family history of high cholesterol understand both the meaning and the personal health implications of hereditary cholesterol risk?

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]



Source: HEART EU, December 2006

Q4: Families with high blood cholesterol

CAMPAIGNERS IN MOST COUNTRIES FEEL THAT ONLY SOME FAMILIES WITH INHERITED HIGH BLOOD CHOLESTEROL APPEAR WELL AWARE OF THE RISKS INVOLVED WITH THEIR CONDITION

What happens when families have relatives with inherited high blood cholesterol? Do these people understand both the meaning and the personal health implications of hereditary cholesterol risk?

Most survey participants reckon that only some of the appropriate families understand the risks involved. One in ten

respondents submit that such families do not comprehend the risks involved. A similar pattern of responses was obtained from all geographic regions.

WHAT CAMPAIGNERS SAY

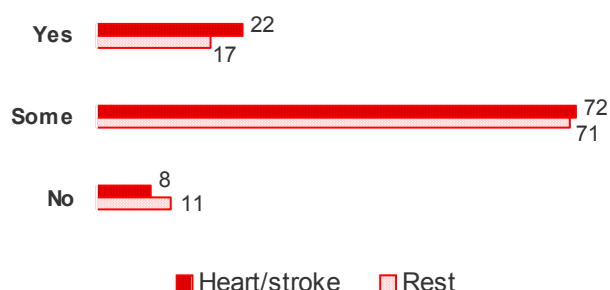
A project worker from the Australia-based Chronic Illness Alliance offers reasons for the apparent lack of discernment among many families: “People understand that, if their parent died at an early age, the same could happen to them. But they don’t understand the mechanics of it, or how it could be avoided. And, if the parent hasn’t died, it is meaningless to them”.

A US school social worker specialising in obesity issues identifies poverty as a major barrier to risk awareness: “I think that people in the lower income levels are most at risk. They see doctors less often, and generally see them only to address immediate and urgent concerns”.

A respondent from a US transplant organisation calls for action: **“I think we need to get the message out that if your father or other close relative died of heart disease at an early age, you need to see a physician about hereditary links and prevention”**.

Levels of understanding and the implicit risks involved among families who have inheritable high blood cholesterol

% heart/stroke groups, versus the rest



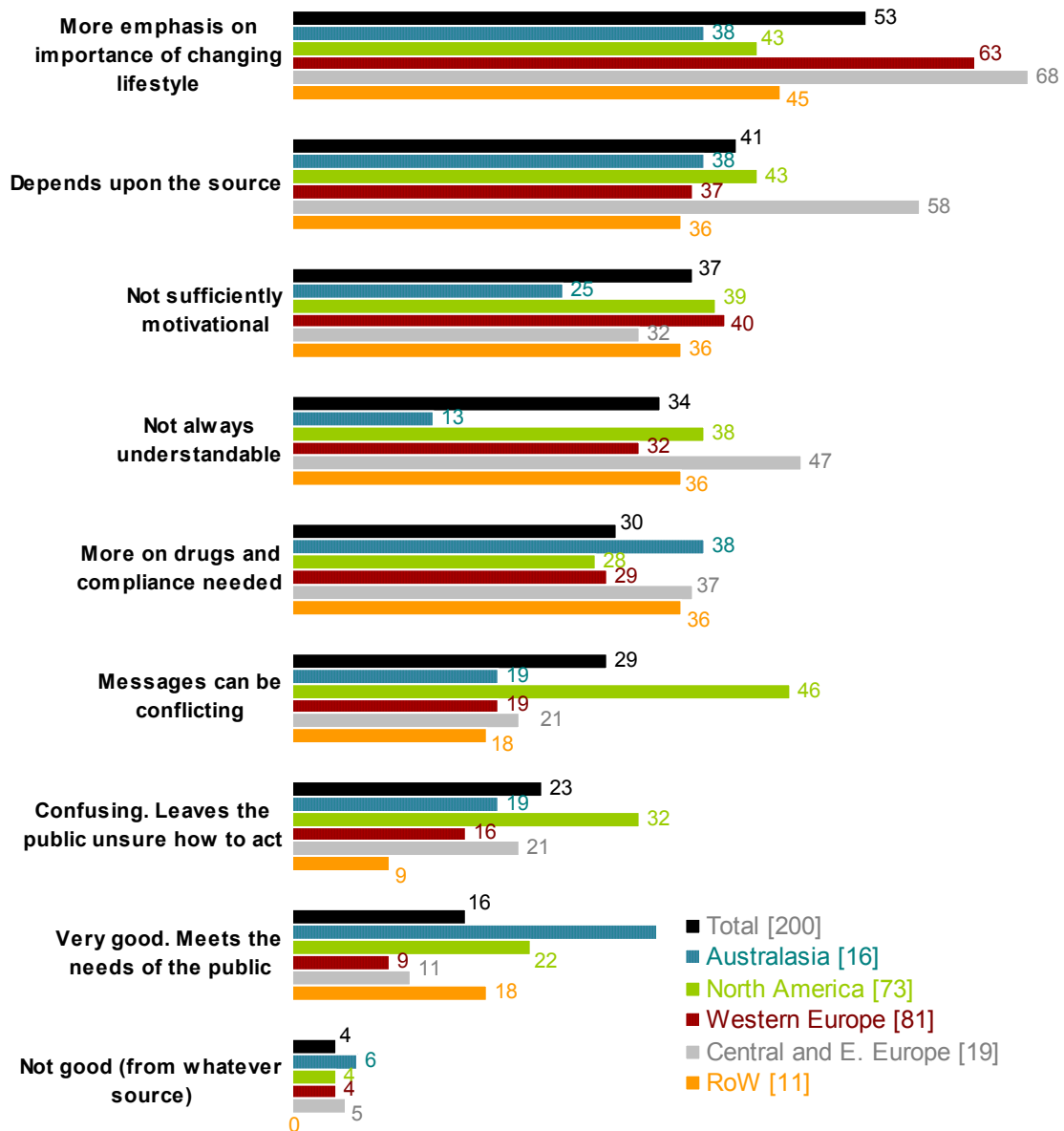
Number of heart/stroke respondents = 88
 Number of non-heart/stroke respondents = 112

Source: HEART EU, December 2006

Question 5

How do you rate the current quality of public-domain information on prevention of heart attack and stroke in your country?

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]



Source: HEART EU, December 2006

Q5: Quality of publicly-available information

THE VAST MAJORITY OF HEALTH CAMPAIGNERS THINK THAT INFORMATION ON THE PREVENTION OF HEART ATTACK AND STROKE IS LACKING IN QUALITY

A mere 16% of the participants [or 18% of heart/stroke groups] assess the quality of information on the prevention of heart disease/stroke as very good. Respondents supply the following explanations for the low rate of endorsement.

WHAT CAMPAIGNERS SAY

- **Not enough on lifestyle factors.** More than half of the respondents blame the lack of prominence that information gives to the need to change lifestyle.
- **Messages are directed only at white, middle-class, middle-aged men.** One US organisation specialising in equitable healthcare for women points out: “The messages are often aimed at heart disease in men (particularly Caucasian men). This results in confusion, a lack of

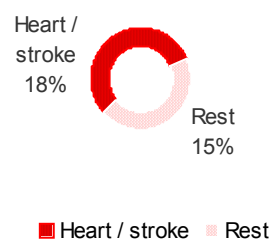
understanding, and a conflict of ideas as to what should be done in any particular case.”

- **A question of delivery—at the best time, and to the correct audience.** “Information does not reach the right people at the right time”, observes a pan-European heart group. “Good, but it is not always possible to reach the public (especially ethnic minorities)”, cautions the UK Stroke Association.
- **Contradictory information.** “So many studies have been conducted. One week we hear that a particular drug or intervention is good for prevention. Another week, the drug will be linked to something serious and fatal”, comments an advocate from a US group specialising in public health issues.
- **Information lacking in motivational impact.** “Plenty of good information is out there (even on TV), but not the motivational piece”, argues a nurse attached to a US group that provides telephone

support to people who want to change their behaviour to prevent CVD.

- **Media failings.** “The ability of journalists to relay information on prevention is poor. Their work is badly documented”, reflects a senior executive from the France-based Association de Sclérose en Plaques.

Heart/stroke groups that believe the quality of public-domain information on prevention is very good, versus the rest



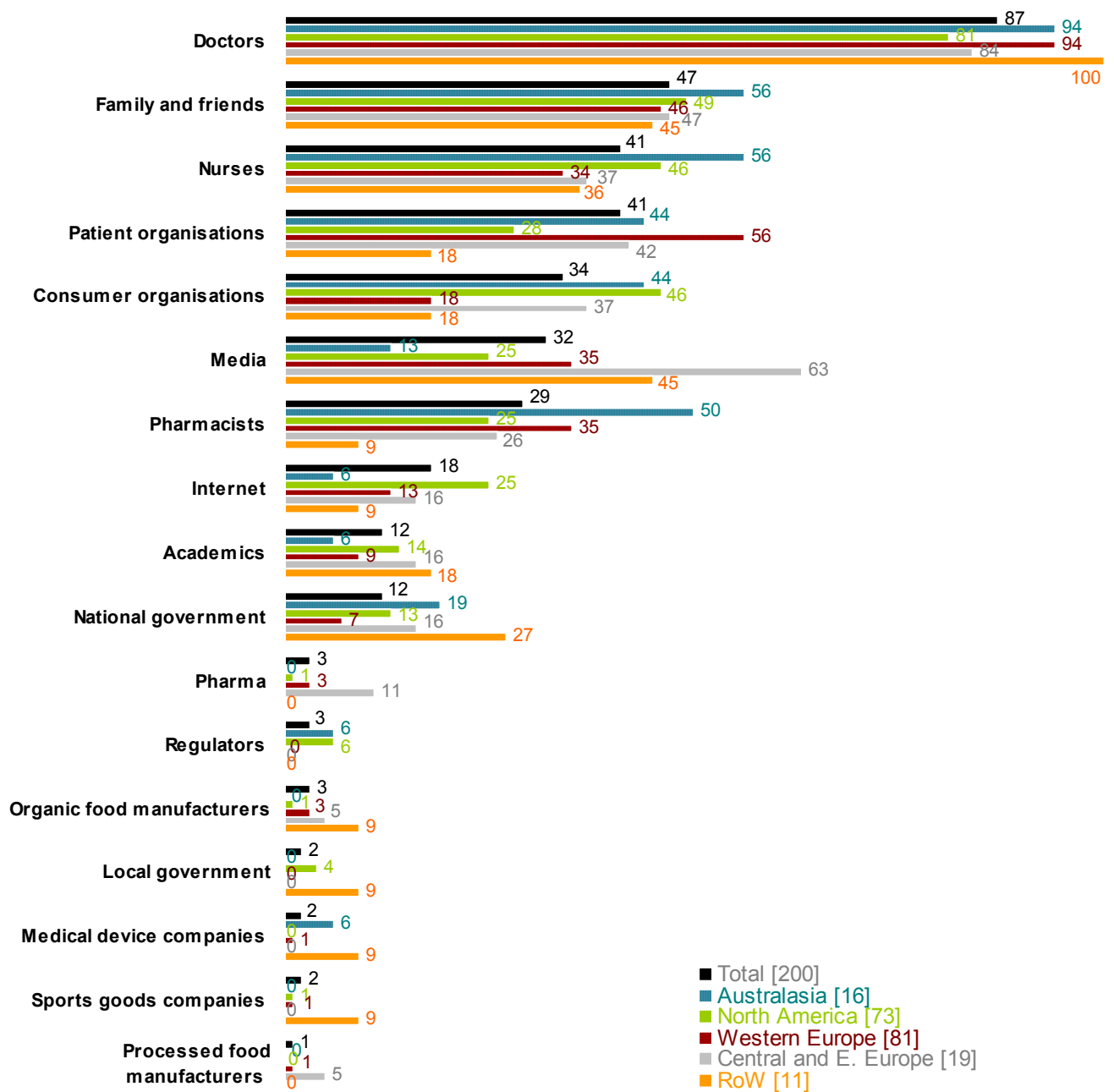
Number of heart/stroke respondents = 88
Number of non-heart/stroke respondents = 112

Source: HEART EU, December 2006

Question 6

In your personal opinion, who do the public in your country trust most in discussions about preventive medicine?

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]



Source: HEART EU, December 2006

Q6: Public trust

CAMPAIGNERS INDICATE THAT THE PUBLIC TRUSTS DOCTORS. LITTLE PUBLIC CONFIDENCE IS MAINTAINED IN OTHER ELEMENTS OF THE HEALTHCARE COMMUNITY (NOT EVEN REGULATORS)

Survey participants assert that the public trusts doctors above all other healthcare stakeholders as a source of information or support on prevention issues. The result is surprising given that few primary-care doctors are known to routinely offer advice or support on the prevention of heart disease or stroke (beyond recommending that patients lose weight, or cease smoking). Several US respondents

emphasise that the emergence of profit-driven managed healthcare in their country has side-lined the practice of prevention, damaging the trust of American citizens in prevention information. The general sentiment of survey participants (particularly those from the US) is that profit and prevention do not mix—probably the reason why respondents score industry (including pharma) so poorly.

WHAT CAMPAIGNERS SAY

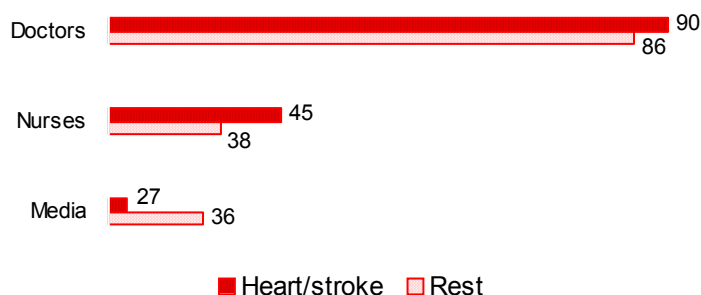
Campaigners also note regional differences:

- People from Australasia and North America are noticeably trusting of nurses. “People listen to nurses or others who don’t seem to get anything [financial] out of it”

—a respondent from a US kidney patient group who answered in a personal capacity.

- Patient organisations in Western Europe generally enjoy the public’s trust—particularly if they can prove their independence from industry.
- In Central and Eastern Europe—but not elsewhere—the public trusts the media. An executive at the Association de Sclérose en Plaques insists that the French public views its media in an unflattering light. The group’s efforts to raise awareness of the impact of CVD upon professional and family life have not been taken up by the media, says the respondent.

Where the public place their trust
% heart/stroke groups, versus the rest



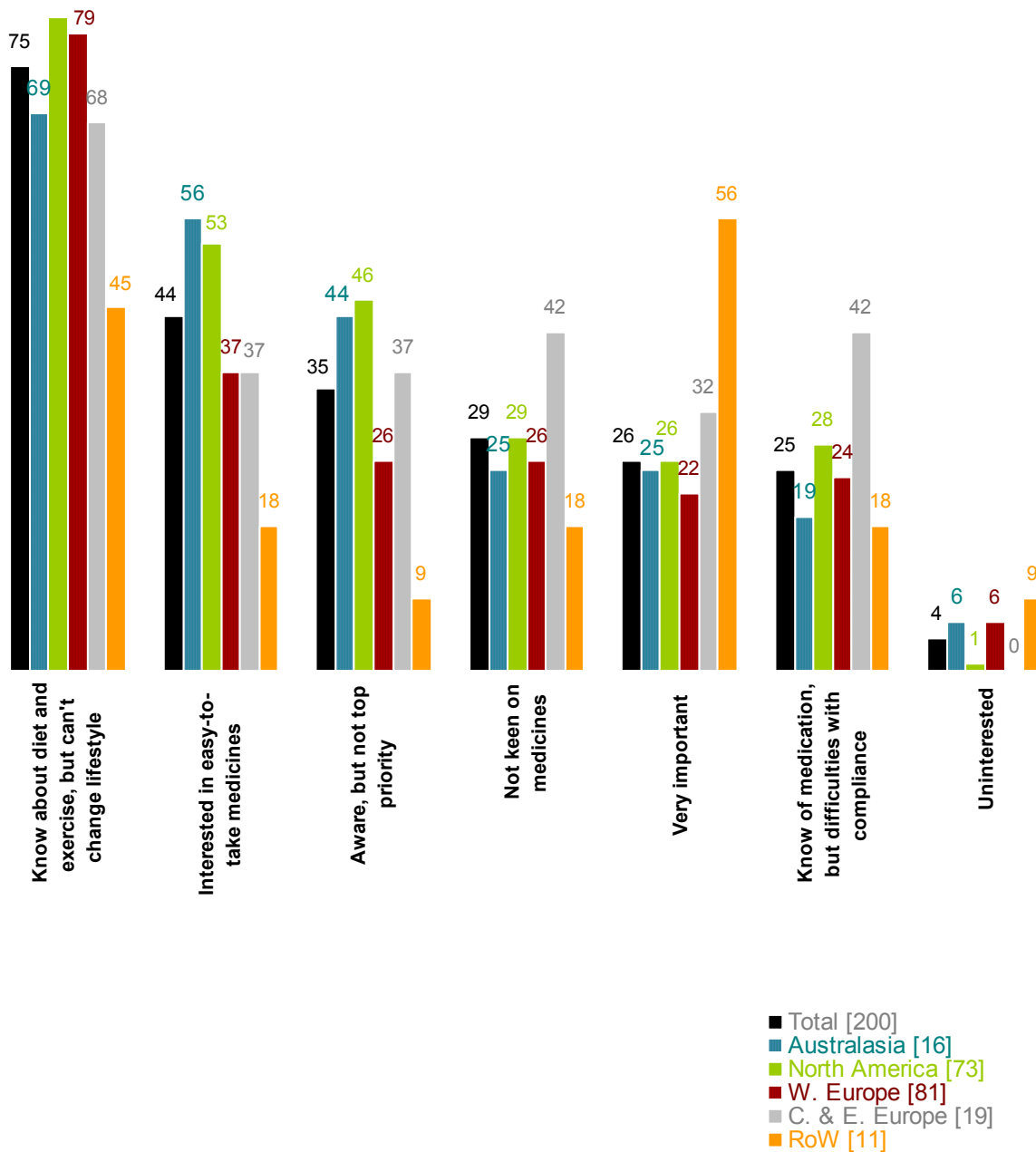
Number of heart respondents = 88
Number of non-heart respondents = 112

Source: HEART EU, December 2006

Question 7

In your personal opinion, what importance do patients in your country who are diagnosed as being at high risk of heart disease and stroke attach to risk management?

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]



Source: HEART EU, December 2006

Q7 : Risk management and its importance to patients

DIAGNOSED PATIENTS—WHILE BEING AWARE OF RISK—FIND PREVENTIVE ACTION OR MEDICATION DIFFICULT TO TAKE UNLESS IT FITS IN WITH THEIR LIFESTYLE

One of the more unexpected survey findings is that even people diagnosed as being at high risk of heart disease and stroke do not always attach significance to managing those risks (and thereby delaying the development of CVD). Only 25% of all participants assess that

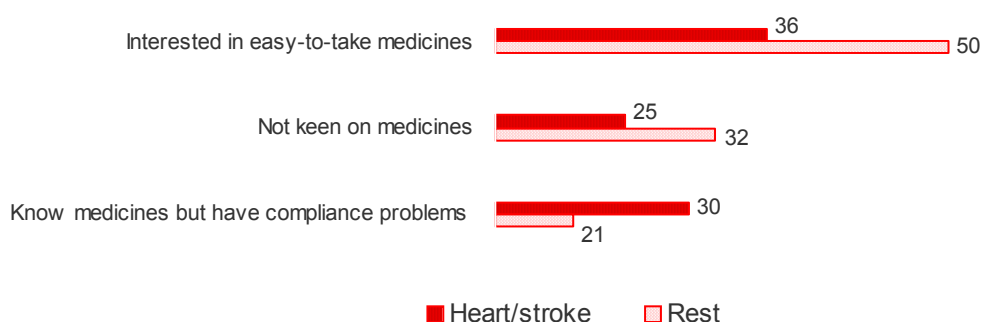
such people see risk management as very important. Three quarters of all respondents [and as many as 81% of North American respondents] believe that the public “know about diet and exercise, but can’t change their lifestyles”. 44% believe that patients would prefer medicines which fit in easily with their lifestyles.

WHAT CAMPAIGNERS SAY

Two noteworthy explanations are offered for the failure of high-risk patients to practice risk management:

- “I think it depends on the level of information received from health care staff when diagnosed”—policy outreach officer from an Irish women’s health group.
- “Many people discontinue the drugs prescribed because they cannot afford to pay for them. In some cases, the treatment is a big economic burden for patients”—Spanish heart group.

Patient risk management and medication
% heart/stroke groups, versus rest



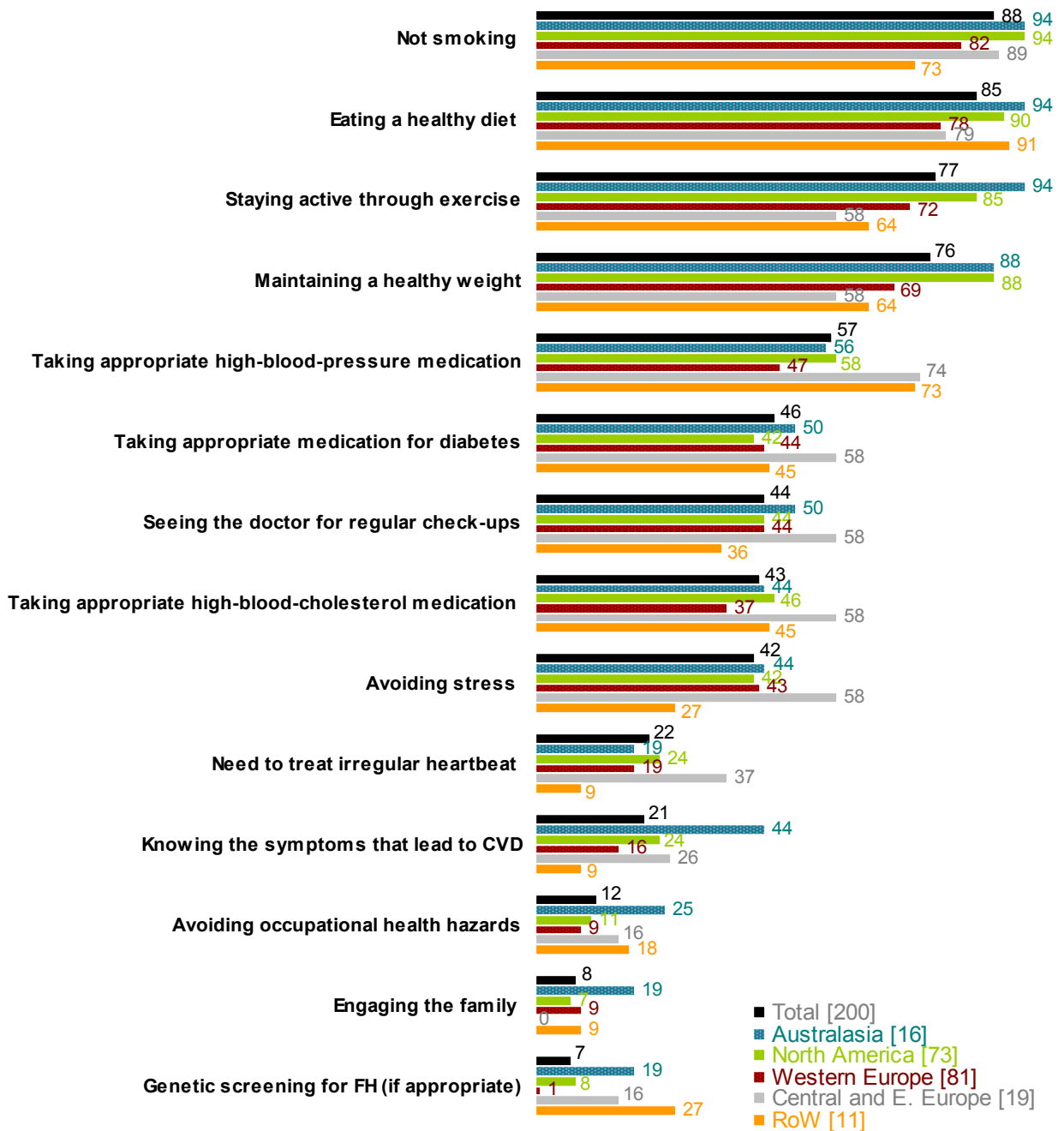
Number of heart/ stroke respondents = 88
Number of non-heart/stroke respondents = 112

Source: HEART EU, December 2006

Question 8

In your personal opinion, are patients in your country who are diagnosed as being at high risk of heart disease and stroke informed on key issues?

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]



Source: HEART EU, December 2006

CVD = cardiovascular disease
FH = familial hypercholesterolemia

Q8: How informed are patients at high risk?

CAMPAIGNERS SAY THAT EVEN PATIENTS WHO ARE DIAGNOSED AS BEING AT HIGH RISK OF HEART ATTACK AND STROKE ARE UNIFORMED ABOUT MANY KEY ISSUES RELEVANT TO THEM, INCLUDING THE PRE-ONSET SYMPTOMS OF CVD

The vast majority [70%-plus] of respondents consider that patients diagnosed at high risk of heart disease and stroke are well informed about many of the lifestyle changes required to prevent CVD. Yet the majority of participants (with the exception of those based in Central and Eastern Europe) believe that high-risk patients are unaware of other key issues: avoiding stress; seeing the doctor for regular check-ups; and the need to take (and continue to take)

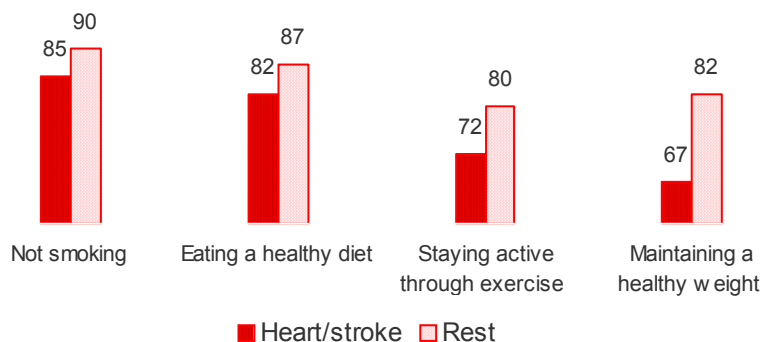
appropriate medication for diabetes, high blood cholesterol, and (in Western Europe) high blood pressure. Almost all participants think that high-risk patients are ill-informed of the need to treat irregular heart beat. And, just as staggering, 60%-plus of participants suspect that high-risk patients are ill-informed about the symptoms which lead to the onset of the medical condition. 80%-plus judge high-risk patients to be unaware of the need for genetic screening of familial hypercholesterolemia (FH).

WHAT CAMPAIGNERS SAY

Campaigners volunteer several explanations for patients' lack of awareness. An American woman with heart problems believes that the issues "have been relegated [by government]

to the backburner". The Slovenian Heart Foundation insists: "The problem is that the patients do not really understand what they are informed of". The US Council on Size and Weight Discrimination says: "Patients hear from their doctors, 'Just lose weight!' But it is the hardest thing to do. If doctors could just start treating them with proper diet, and other lifestyle changes, and not emphasise weight loss, patients could be more compliant, and would be healthier". And the UK-based Stroke Association states: "Doctors' practices are not always very good in ensuring that high-risk patients get regular health checks. The practices even question whether the patients need, for example, blood pressure checks".

How well-informed on lifestyle issues are high-risk patients?
% heart/stroke groups, versus the rest



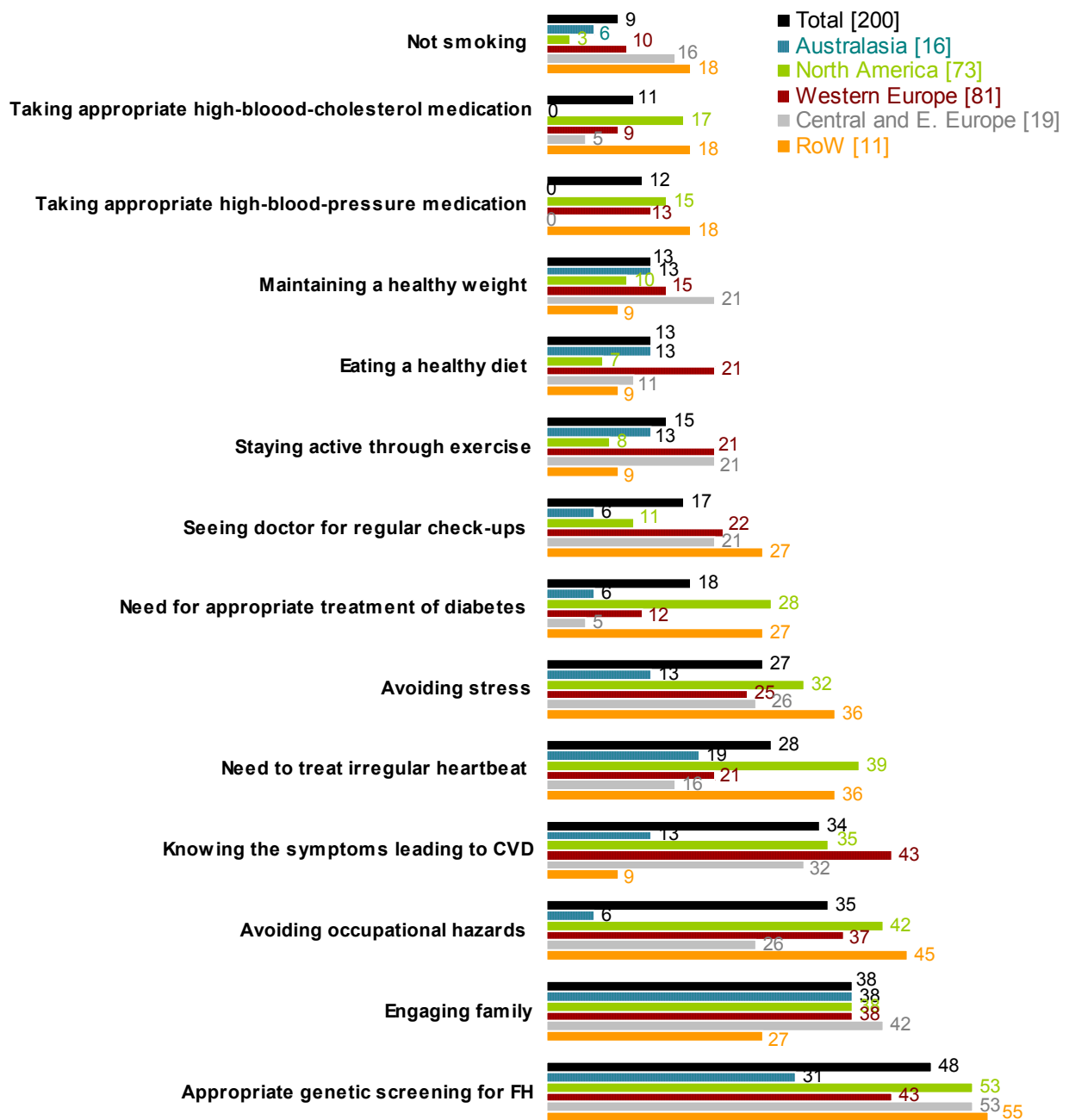
Number of heart/stroke respondents = 88 Number of non-heart/stroke respondents = 112

Source: HEART EU, December 2006

Question 9

Do you think that patients in your country diagnosed as being at high risk of heart disease and stroke have insufficient or no information on relevant issues?

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]



Source: HEART EU, December 2006

CVD = cardiovascular disease
FH = familial hypercholesterolemia

Q9: Levels of information for patients at high risk

HALF OF THE SURVEY PARTICIPANTS AGREE THAT PATIENTS AT HIGH RISK OF GETTING HEART DISEASE OR STROKE HAVE INSUFFICIENT INFORMATION ABOUT THE IMPORTANCE OF SCREENING FOR FAMILIAL HYPERCHOLESTEROLEMIA

One clear finding emerges from the question: half of all survey participants stress the inadequacy of the available information on the need for genetic screening for familial hypercholesterolemia (FH). 40% of the respondents specialising in heart diseases are concerned by the lack of information on the subject matter.

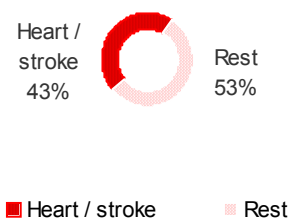
WHAT CAMPAIGNERS SAY

The Fundación Hipercolesterolemia Familiar of Spain (a member of HEART EU), emphasises: “People must know about the risk of inherited high cholesterol”.

A number of respondents talk about problems of accessing information—particularly if patients live alone. Other respondents mention the fact that information can be given, but not understood. Still more respondents declare that even well-informed patients frequently fail to take the necessary steps required to prevent the onset of CVD.

StrokeFamily.org of the USA suggest: “Information could be put into TV medical dramas, instead of the sensational shows we now have. Cable TV could run specials with the information, if they could put it in an appealing and non-academic, interesting format”.

Heart/stroke groups who think information on genetic screening for FH is insufficient for high-risk patients, versus the rest



Number of heart/stroke respondents = 88
 Number of non-heart/stroke respondents = 112

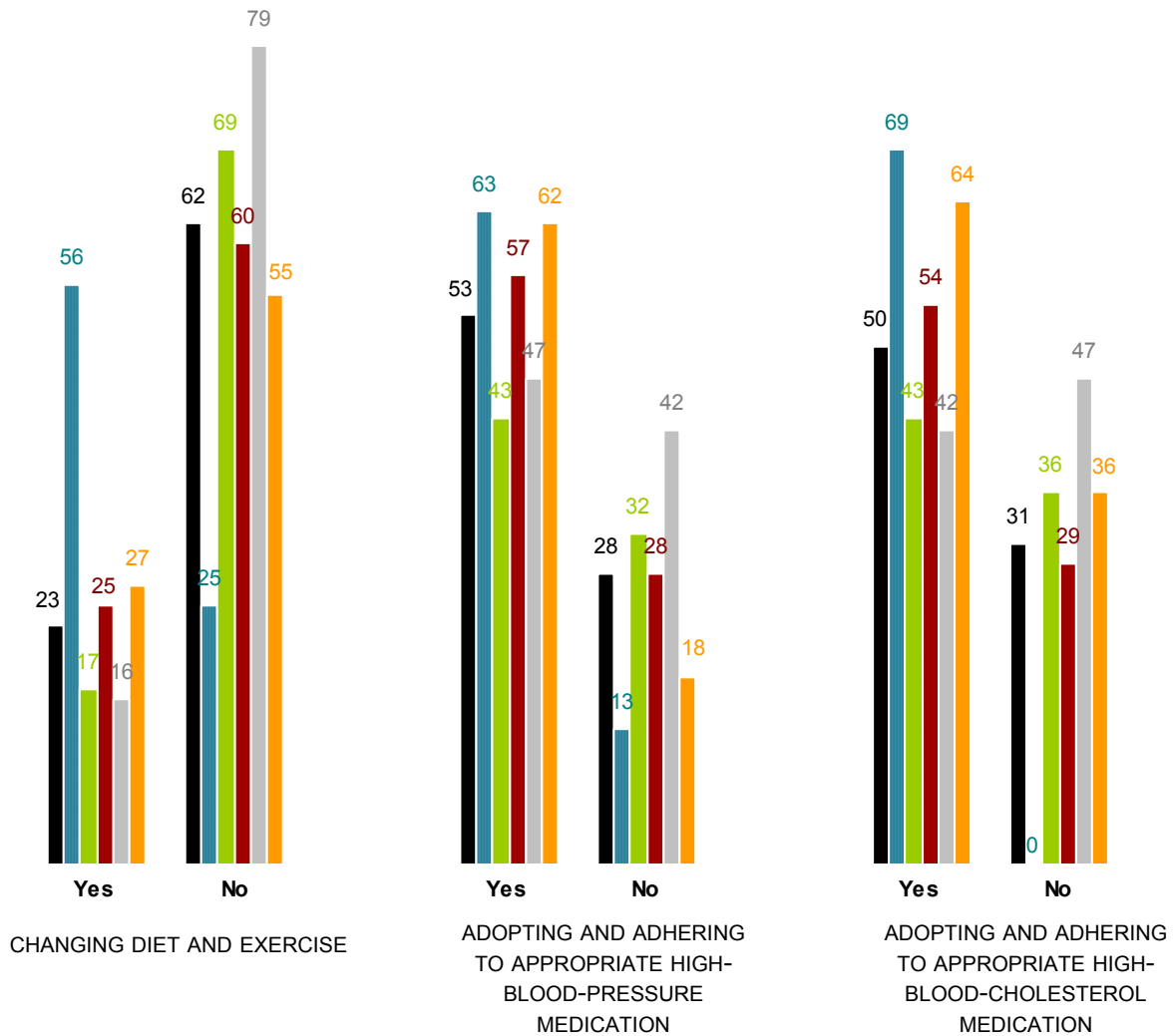
FH = familial hypercholesterolemia

Source: HEART EU, December 2006

Question 10

In your personal opinion, do patients actively and sufficiently practice prevention and management?

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]



- Total [200]
- Australasia [16]
- North America [73]
- Western Europe [81]
- Central and E. Europe [19]
- RoW [11]

Footnote: Remaining percentage of respondents stated "Don't know"

Source: HEART EU, December 2006

Q10: Patients practicing prevention and risk management

MOST PATIENTS AT HIGH RISK OF HEART DISEASE AND STROKE DO NOT ADEQUATELY EXERCISE, OR CHANGE THEIR DIET. ALMOST ONE THIRD OF THE SURVEY'S RESPONDENTS STATE THAT PATIENTS IN THEIR COUNTRY DO NOT TAKE APPROPRIATE MEDICATION

According to 62% of respondents, high-risk patients do not take adequate precautions (such as exercising and changing diet) to delay the onset of disease. And as many as 28% of survey participants indicate that people at high risk of CVD do not adhere to appropriate medication for high blood pressure. 31% feel that patients do not take adequate medication for high blood cholesterol. In Central and Eastern Europe, the respective figures were 42% and 47%.

WHAT CAMPAIGNERS SAY

Respondents highlight a number of reasons why so many high-risk patients fail to take adequate precautions:

- **Lack of support** in prevention and risk management.
- **Conflicting advice.** “Much is written about taking medication to lower cholesterol, but the differing opinions lead to confusion, and the over-the-counter availability of statins does not produce evidence-based value in terms of compliance or benefit to the general population”—Chairman of a UK-based diabetes group.
- **Adverse effects of medicines.** A number of respondents also perceive that the side-effects of drugs which treat high blood pressure or high blood

cholesterol affect people’s adherence to medication in cases when the drugs are taken for reasons of prevention.

- **Out-of-pocket expenses for medications.** “Medicines have become so expensive that many who do know about the diseases can’t afford the medicines”—US National Aphasia Association.

Do high-risk patients change their diet and exercise as recommended?

% heart/stroke groups, versus the rest



Number of heart/stroke respondents = 88
 Number of non-heart/stroke respondents = 112

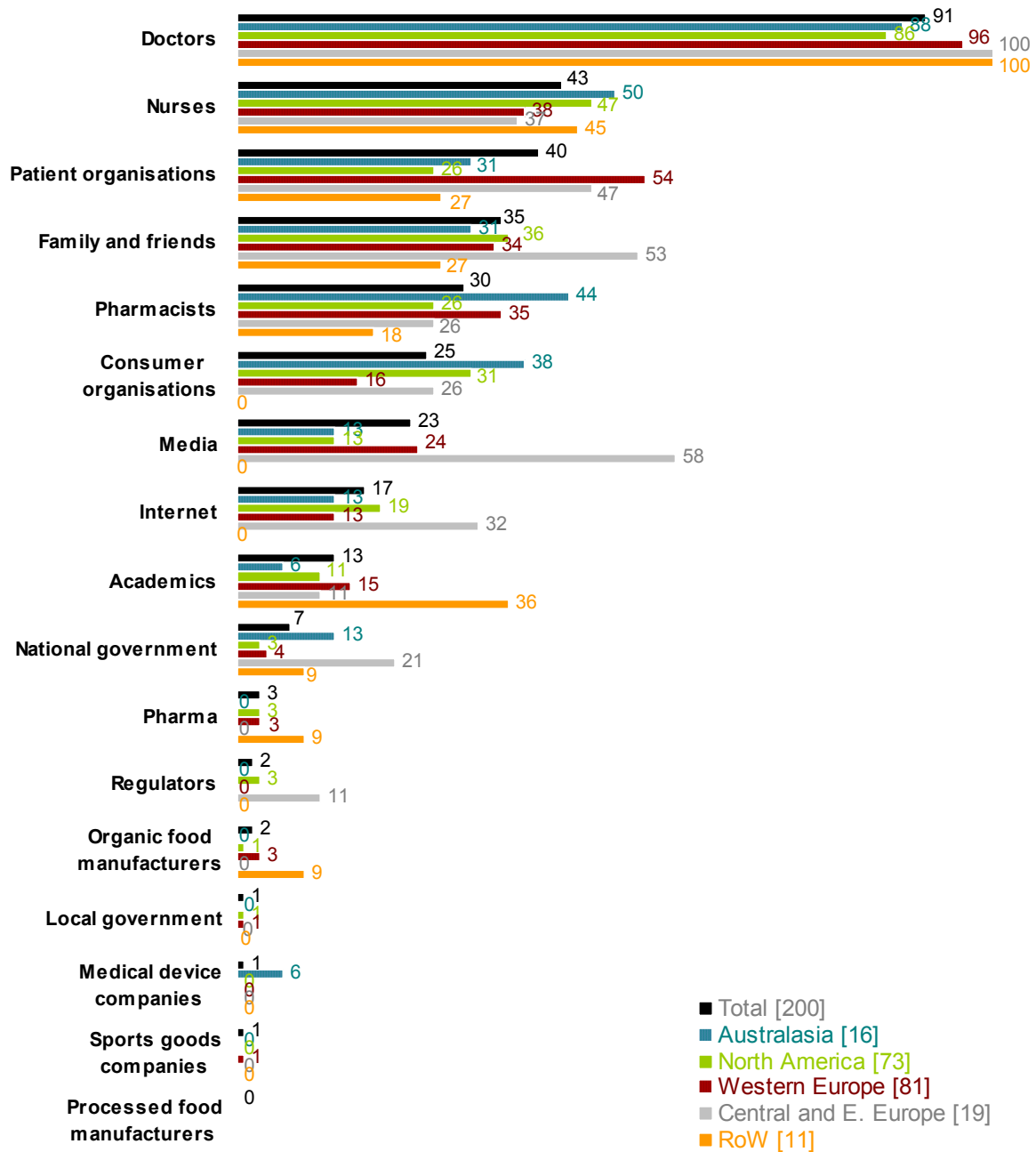
CVD = cardiovascular disease

Source: HEART EU, December 2006

Question 11

In your personal opinion, who do patients in your country diagnosed as being at high risk of heart disease and stroke trust the most in discussions about risk management?

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]



Source: HEART EU, December 2006

Q11: Trust in sources of information and patient support

RESPONDENTS SAY THAT MOST PATIENTS AT HIGH RISK OF HEART DISEASE AND STROKE—LIKE THE REST OF THE PUBLIC—PLACE THE MAJORITY OF THEIR TRUST IN DOCTORS, AS OPPOSED TO OTHER SOURCES OF INFORMATION

Doctors score highly among survey respondents as a trusted source of information for prevention and risk management—despite the fact that, in other parts of the survey, they are cajoled for being bad communicators. New Zealand doctors seem most active. They practise the ‘Green Prescription Programme’ [<http://www.sparc.org.nz/getting-active/green-prescription/overview>]. Only Australasian nurses receive similar levels of approbation—though the France-based Association de Sclérose en Plaques mentions “kinésithérapeutes” as a valued resource [kinesitherapists use movement and body balance to deal with medical conditions].

Western European respondents vouchsafe patient organisations as a trusted source of information. Over half of respondents from Central and Eastern Europe regard family and friends as a highly-trusted informational resource. Nearly 60% of the respondents from the same part of the world say that patients also put great faith in the media.

The lowest ratings on trustworthiness—10% or less—are reserved for industry (whether food, medical devices, or pharma), government (national or local), and regulators.

WHAT CAMPAIGNERS SAY

One US health campaigner involved with obesity, and who is also a social worker, observes that, irrespective of who patients trust: “I don’t think they generally act on the information they receive”.

% of heart/stroke groups that named patient organisations as a trusted source of information, versus the rest



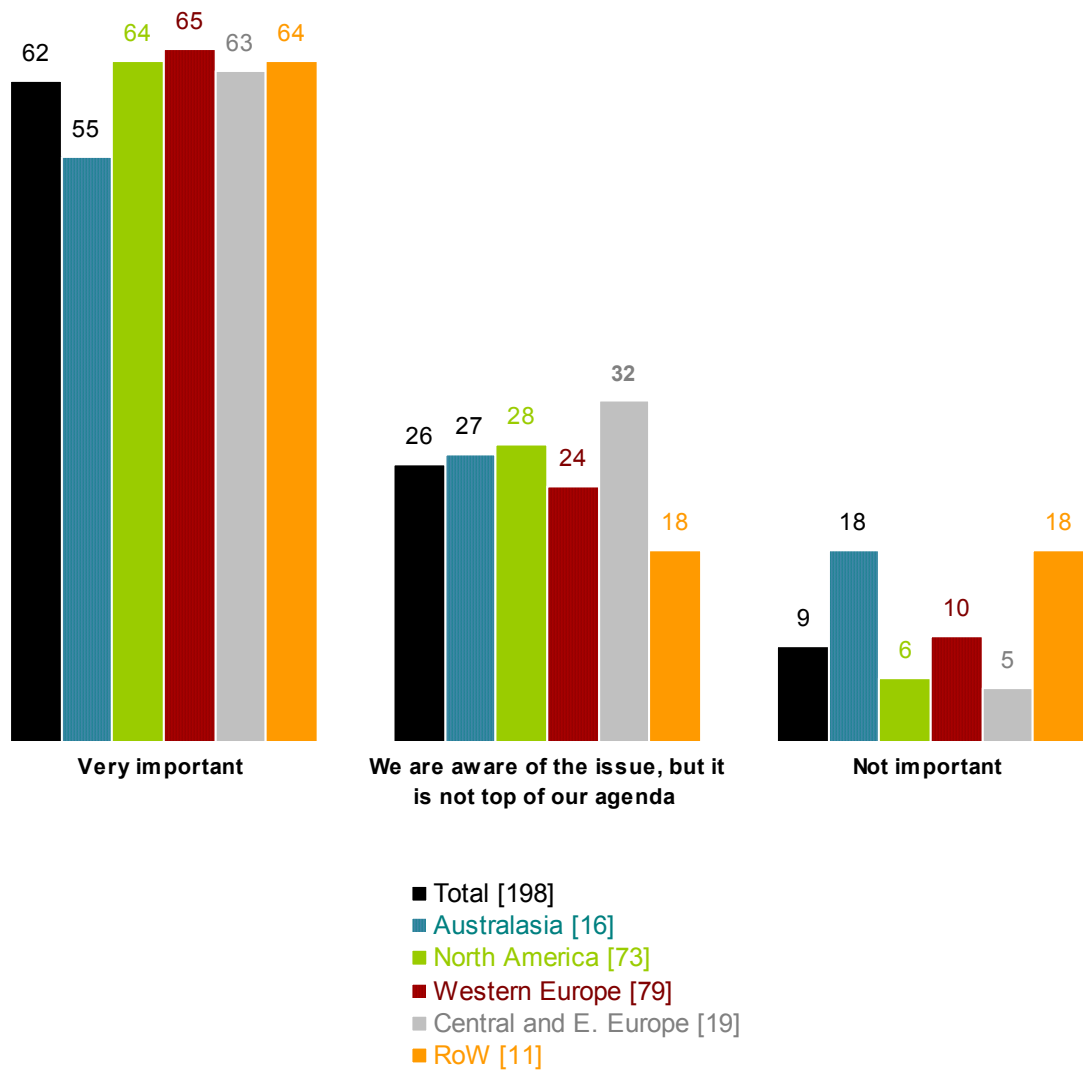
Number of heart/stroke respondents = 88
 Number of non-heart/stroke respondents = 112

Source: HEART EU, December 2006

Question 12

How important a campaign issue is prevention of heart attack and stroke within your organisation?

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]



Footnote: Remaining percentage of respondents stated "Don't know"

Source: HEART EU, December 2006

Q12: Importance of prevention as a campaign issue

ALMOST TWO THIRDS OF RESPONDENTS REGARD PREVENTION AS A VERY IMPORTANT CAMPAIGNING ISSUE

Two thirds of all respondents (and almost 80% of groups representing the needs of patients with heart disease or stroke) claim that prevention is an important campaign issue.

WHAT CAMPAIGNERS SAY

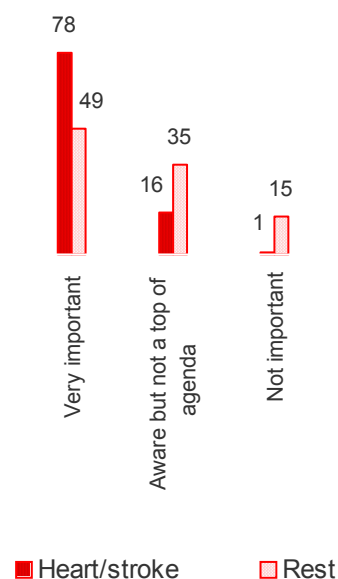
A number of participants reflect that, but for a lack of resources, they would do a lot more on prevention. "We don't find any possibilities to manage such projects. We need financial support. We are ready to make the programmes, and participate in education seminars, and—more important—to have possibilities to later share information and to get sustainability in this work", explains the Latvian National Consumer Rights Protection Association.

Examples of groups' campaigns include:

- The work of the Wellness Institute of Greater Buffalo and Western New York [<http://www.beActiveNys.org>] on improving the quality of life in communities is guided by the Healthy Communities model and the Ottawa Charter of Health Promotion Action Principles[‡].
- The Association de Sclérose en Plaques advises that sclerosis of the arteries produces additional pathological complications for patients.
- A German group focusing on a rare heart condition says that it provides social support and information to the families of children whose malformations of the heart have to be corrected surgically.
- A Swiss group specialising in secondary prevention in the field of diabetes states that it has just finished a big campaign on diabetes and

cholesterol, and how to prevent complications.

Importance of CVD prevention as a campaign issue % respondents from heart/stroke groups, versus the rest



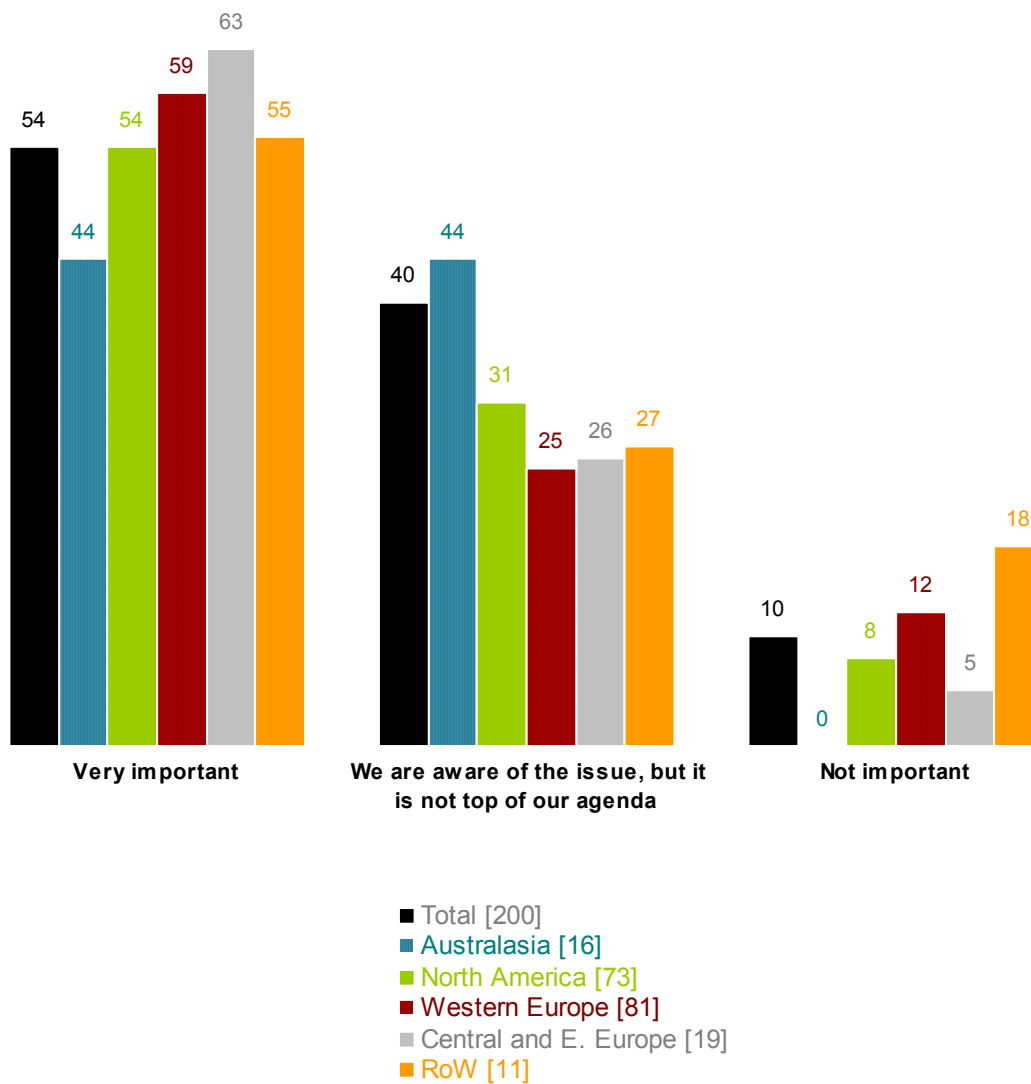
Number of heart/stroke respondents = 88
 Number of non-heart/stroke respondents = 112
 CVD = cardiovascular disease
 Source: HEART EU, December 2006

[‡] The Healthy Cities (commonly referred to as the Healthy Communities) movement, was conceived concurrently by the World Health Organization's (WHO) European office in 1986, and in North America by Hancock and Duhl. [See T. Hancock and L. Duhl, *Healthy Cities: Promoting Health in the Urban Context*, Healthy Cities Paper 1, WHO Europe, Copenhagen, Denmark, 1986.]; The Ottawa Charter of Health Promotion is to be found on http://www.euro.who.int/AboutWHO/Policy/20010827_2

Question 13

How important a campaign issue within your organisation is risk management for patients diagnosed as being at high risk of heart attacks and stroke?

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]



Footnote: Remaining percentage of respondents stated "Don't know"

Source: HEART EU, December 2006

Q13: Importance of risk management as a campaign issue

OVER HALF OF THE RESPONDENTS PUT RISK MANAGEMENT AS A VERY IMPORTANT CAMPAIGNING ISSUE. A FURTHER 40% RATE THE SUBJECT AS IMPORTANT, ALTHOUGH NOT TOP OF THEIR AGENDA

Between 44% (respondents from Australasia) to 63% (Central and Eastern Europe) of respondents view risk management of heart disease and stroke as a very important campaigning issue for their respective groups. Again, the figure is higher—at 74%—among participants from heart/stroke groups. But over one third of non-heart groups (nearly half) also regard their campaigns on the risk management of CVD as very important. Only 10% of all 200 respondents do not see the risk management of CVD as being important to their group’s campaigning agenda.

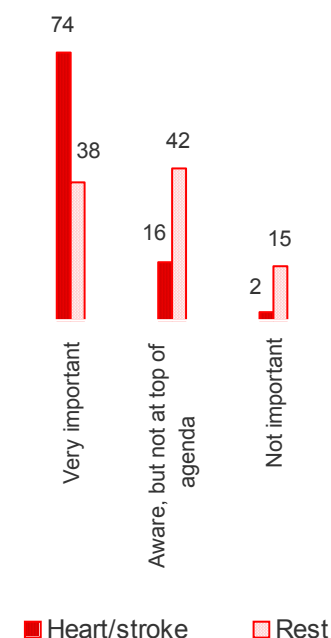
WHAT CAMPAIGNERS SAY

- “Right now, we are trying to engage the administration to undertake early diagnosis for family

members of patients with inherited cholesterol”—Fundación Hipercolesterolemia Familiar, Spain.

- “A priority for us would be to ensure that people at high risk of heart disease or stroke are made aware of the importance of stopping smoking. However, we are not a patient-focused organisation, and, therefore, this is not an overt part of our activity”—Research Manager, tobacco control group, UK.
- Some of our campaigns (which focus on diabetes) are related to heart disease, but not all”—Regional Manager, local diabetes group, UK.

Importance of risk management of CVD as a campaign issue
% respondents from heart/stroke groups, versus the rest

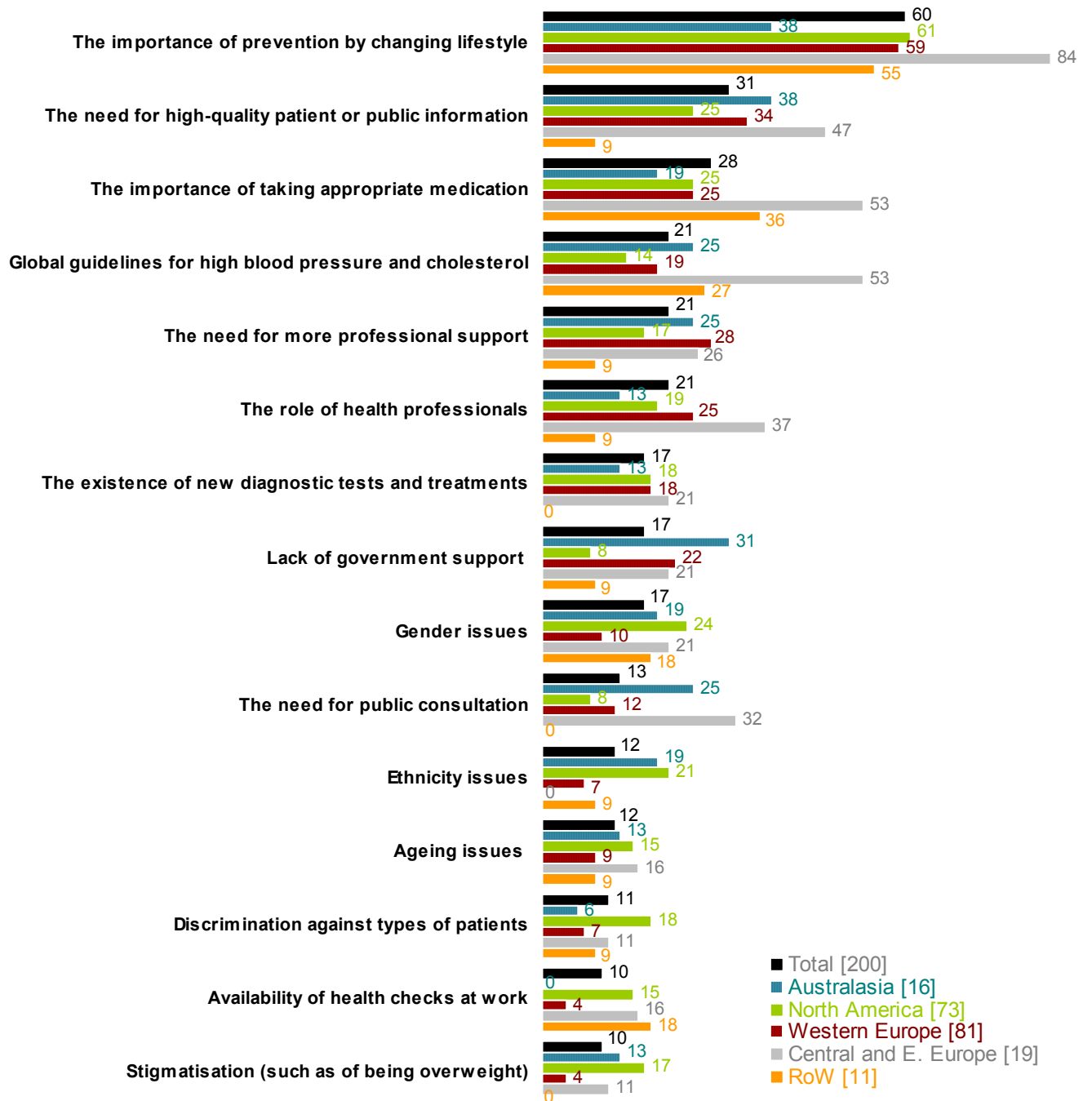


Number of heart/stroke respondents = 88
 Number of non-heart/stroke respondents = 112
 CVD = cardiovascular disease
 Source: HEART EU, 2006

Question 14

Is your organisation running a campaign—or planning to run a campaign—on any of the following subjects (the context being preventing or managing the risks for heart disease/stroke)?

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]



Source: HEART EU, December 2006

Q14: Campaigns running, or to be run

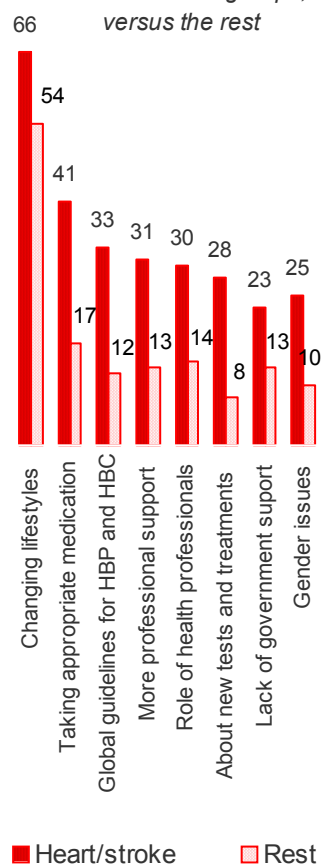
60% OF SURVEY PARTICIPANTS CONFIRM THAT THEIR GROUPS ARE RUNNING PREVENTION CAMPAIGNS

Some 60% of participants (though only 38% of those from Australasia) indicate that their groups are running, or planning to run, campaigns on the importance of prevention and the changing of lifestyles. The equivalent figure for groups specialising in heart/stroke conditions is 66%, and 84% for groups based in Central and Eastern Europe. Over half of the respondents from the latter region declare that they are also campaigning on the importance of taking

appropriate medication, and on raising the profile of international guidelines for high-blood-pressure medication and cholesterol medication.

In the case of heart/stroke groups, 41% are running, or planning to run, campaigns on the importance of taking appropriate heart disease/stroke medication. Only 17% of the non-heart/stroke groups specify that they are doing, or planning to do, the same [see chart, right].

Campaigns running (or to be run) on prevention
% heart/stroke groups, versus the rest



■ Heart/stroke □ Rest

Number of heart/stroke respondents = 88
 Number of non-heart/stroke respondents = 112
 HBP = high blood pressure
 HBC = high blood cholesterol
 Source: HEART EU, 2006

... continued on next page

Q14: Campaigns running, or to be run

WHAT CAMPAIGNERS SAY

AUSTRALASIA

“Our campaign is specific to diabetes, but would cover some of the same prevention messages as CVD and stroke”—diabetes organisation, Australia.

NORTH AMERICA

“People with aphasia are routinely denied rehabilitation services, are not invited to participate in research, are left out of community discussions, are often misdiagnosed as having ‘dementia’, and are locked away in facilities”—BC Aphasia Centre, Canada.

“Not running any campaign. I am in a school district. Little is done about prevention, but they do more than they did when I started, 16 years ago”—social worker attached to schools and to an obesity patient organisation, USA.

“We are involved with many of these issues at local, state, and national level”—Wellness Institute of Greater Buffalo and Western New York, USA.

“Not specific campaigning, but ongoing attention—because those are the main issues for us”—international organisation specialising in inheritable cardiovascular disease.

WESTERN EUROPE

“Our first focus is diabetes, together with obesity”—member of the board, International Diabetes Federation - Europe.

“Our organisation arranges medical conferences on prevention, stress, and diabetes, undertakes medical research, and supports patients undergoing cardiovascular surgery”—Serge Ligiardi, Association Francaise des Malades et Opérés Cardio-Vasculaires [French Association of Patients and Cardiovascular Operations].

“The Netherlands Heart Foundation runs public campaigns. We (a patient organisation) do not, but we are involved in the Heart Foundation’s campaigns”—consultant, stroke organisation, the Netherlands.

“We are always running campaigns about the importance of prevention by changing lifestyle, and taking the medical treatment whenever necessary”—Fundación Hipercolesterolemia Familiar, Spain.

“It is not within our remit to focus on particular at-risk groups, but our overall campaign objectives to reduce the incidence of smoking in society will result in a reduction in heart attacks and strokes”—Chairman, endometriosis group, Sweden.

“Only in combination with our campaigns on diabetes. But we are currently discussing a future campaign on the effects of smoking. This campaign would be a joint effort with the heart foundation and the diabetes association, as the cardiovascular risk is predominant”—organisation focusing on secondary prevention in the field of diabetes, and information/education of people diagnosed with diabetes, Switzerland.

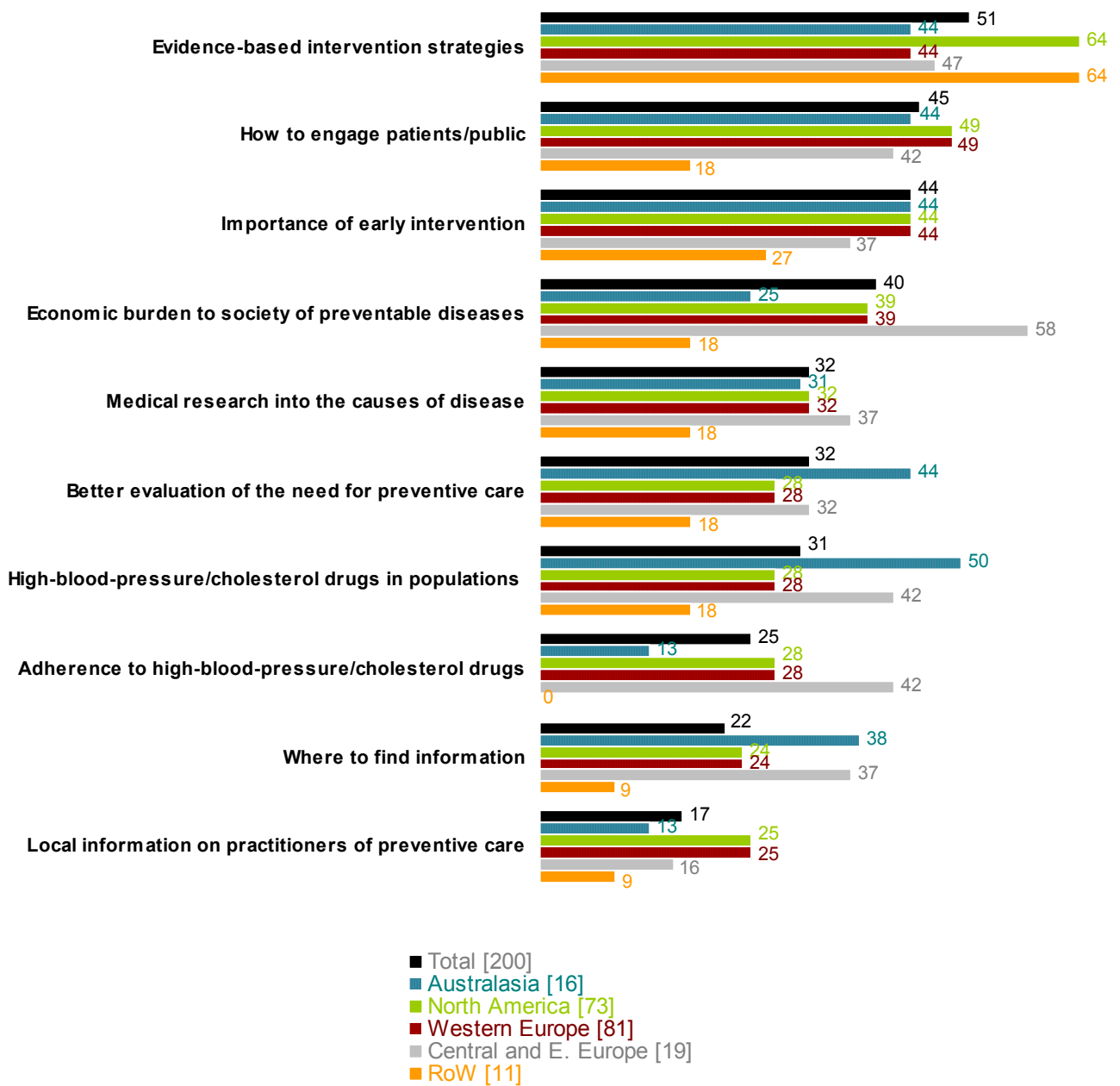
“I work for a project that focuses on changing the lifestyles of people with diabetes and/or congestive heart failure”—researcher, anti-smoking group, UK.

“Our campaigns focus on diabetes, and how this relates to heart disease, and not heart disease per se. Not all diabetes-related campaigns will touch on heart disease, as it is not the only complication”—Regional Manager, diabetes patient organisation, UK.

Question 15

Is further research needed to help support patients and the public practise prevention or risk management?

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]



Source: HEART EU, December 2006

Q15: Required research

ALMOST TWO THIRDS OF PARTICIPANTS ARGUE FOR FURTHER RESEARCH INTO EVIDENCE-BASED INTERVENTION STRATEGIES

Survey participants indicate four topics worthy of further research:

- **Evidence-based intervention strategies.** Almost two thirds of respondents from North America, Africa, Asia, and Latin America (and around half of all respondents) feel that more research is needed in this area.
- **The economic burden to society of preventable disease.** Nearly 60% of groups from Central and Eastern Europe (and 43% of groups with an interest in heart/stroke conditions) stipulate the need for research into the financial implications of heart disease and stroke, and other preventable diseases.
- **Early intervention.** Over half of groups with an interest in heart/stroke conditions point to this area of research

as being of importance. Only 38% of the survey's non-heart/stroke groups argue the same.

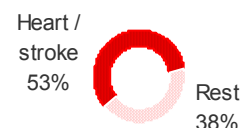
- **The effects of high-blood-pressure/cholesterol drugs on populations.** Half of all groups from Australasia believe that this subject requires research.

WHAT CAMPAIGNERS SAY

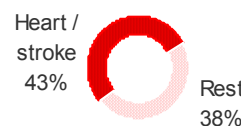
But, as the Neeman Association for Stroke Survivors, Israel, observes, the problem is that little current research is being translated into healthcare practice:

“There are a great deal of research findings out there which are not being applied in practice. We recommend less research, and more practice—with evaluation tools built in”. The interpretation is echoed by a Lithuania-based non-smokers’ rights group with an international remit, which writes: “It is now time to apply the results of the abundant research already carried out”.

Heart/stroke groups that want more research on the importance of early intervention, versus the rest



Heart/stroke groups that want more research on the economic burden of preventable disease, versus the rest



■ Heart / stroke ■ Rest

Number of heart/stroke respondents = 88
 Number of non-heart/stroke respondents = 112

Source: HEART EU, 2006

Appendix

1. Respondents that wished to be named
2. Profile of survey respondents
3. Tables for questions 1-15

RESPONDENT GROUPS THAT WISHED TO BE NAMED

Some respondents from the groups listed below answered in a personal, rather than an organisational, capacity

АСОЦИАЦИЯ ЖЕНИ БЕЗ ОСТЕОПОРОЗА [Association 'Women Without Osteoporosis'] [Bulgaria]
 Aivohalvaus-ja dysfasialitto ry [Finnish Stroke and Dysphasia Association]
 Alkoholpolitik [Alcohol Politics] [Switzerland]
 Angioma Alliance UK
 Afasiförbundet i Sverige [Aphasia Association in Sweden]
 Association de sclérose en plaques [Multiple Sclerosis Association] [France]
 Association des Diabétiques de la Métropole Nord à Lille [Diabetes Association, North of Lille] [France]
 Association Francaise des malades et opérés cardio-vasculaires [French Association of Patients and Heart Operations]
 Association Francaise des Malades et Opérés Cardio-Vasculaires (AFDOC Aquitaine) [French Association of Patients and Heart Operations, Aquitaine]
 Australian Sudden Arrhythmia Death Syndromes (SADS) Foundation
 BC Aphasia Centre [Canada]
 Chronic Illness Alliance Inc [Australia]
 Council on Size and Weight Discrimination [USA]
 Cardiac Rehabilitation Association of New Zealand (CRANZ)
 Croatian Society for Hypertension
 Defi-Gruppe Trier [Self-Help Group for Patients on Heart Defibrillators] [Germany]
 Deutscher Diabetiker-Bund Brandenburg e.V. [German Diabetes Federation, regional organisation, Brandenburg]
 Deutscher Diabetiker Bund, Landesverband Nordrhein-Westfalen e.V. [German Diabetes Federation, regional organisation North Rhine-Westphalia]
 Deutscher Diabetiker Bund, Landesverband Thüringen e.V. [German Diabetes Federation, regional organisation Thüringen]
 Diabetes Föreningen [Diabetes Association] [Sweden]
 Florida on the Move [USA]
 Fundacion Hipercolesterolemia Familiar [Foundation for Hypercholestermia] [Spain]
 Fundación Menudos Corazones [Foundation of Little Hearts] [Spain]
 Heart Children New Zealand
 Hjärt- och Lungsjukas Förening [Heart and Lung Association] [Sweden]
 Hungarian Heart Foundation
 International Diabetes Federation - Europe (IDF-E)
 Italian Stroke Forum (ISF)
 Israeli Forum for the Prevention of CVD
 Lipid and Atherosclerosis Society of Southern Africa (LASSA)
 National Association to Advance Fat Acceptance (NAAFA) [USA]
 National Aphasia Association [USA]
 Neeman Association for Stroke Survivors [Israel]
 Patērētāju Interesu Aizstāvības Asociācijas (PIAA) [National Consumer Rights Protection Association] [Latvia]
 Republican Scientific Center 'Cardiology' [International / Belarus]

Stroke Alliance For Europe (SAFE) [International]
Schlaganfallselbsthilfe [Self-Help Group for Stroke] [Austria]
Slovak League Heart to Heart
Slovenian Diabetes Association
Slovenian Heart Foundation
Sociedade Portuguesa de Menopausa [Portuguese Menopause Society]
Stroke Association [UK]
Stroke-Föreningen [Stroke Association] [Sweden]
StrokeFamily.org [International / USA]
Sunderland Cardiac Support [UK]

University Hospital Mostar [Bosnia and Herzegovina]

Vrhovac University Clinic [Croatia]

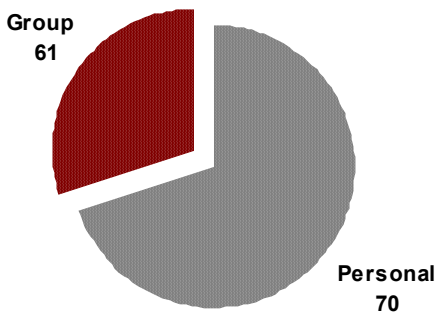
Wellness Institute of Greater Buffalo and Western New York [USA]
Womens Room [Croatia]

Zdruzenie Slovenskych Spotrebiteľov (ZSS) [Association of Slovak Consumers]

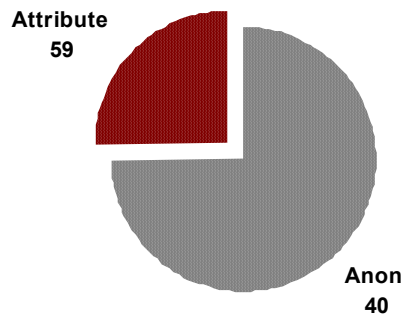
PROFILE OF RESPONDENTS

% OF RESPONDENTS [TOTAL = 198]

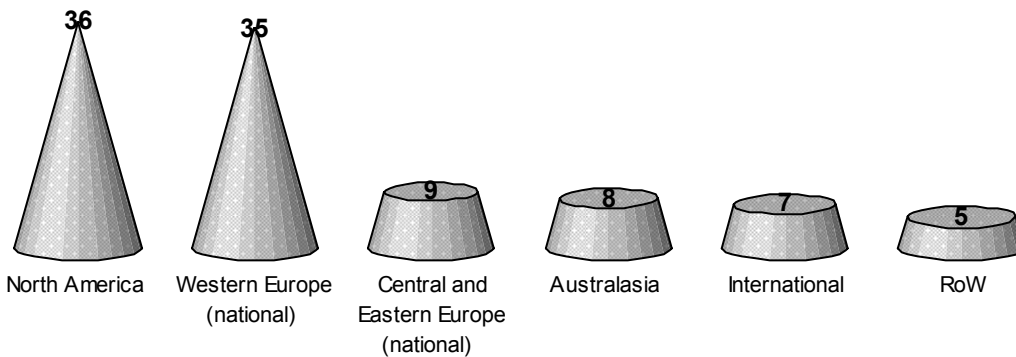
PERCENTAGE OF RESPONDENTS WHO REPLIED ON BEHALF OF THEIR ORGANISATION / PERSONALLY



PERCENTAGE OF RESPONDENT GROUPS THAT WISHED TO BE ATTRIBUTED / ANONYMOUS



GEOGRAPHIC BASE OF GROUPS (%)

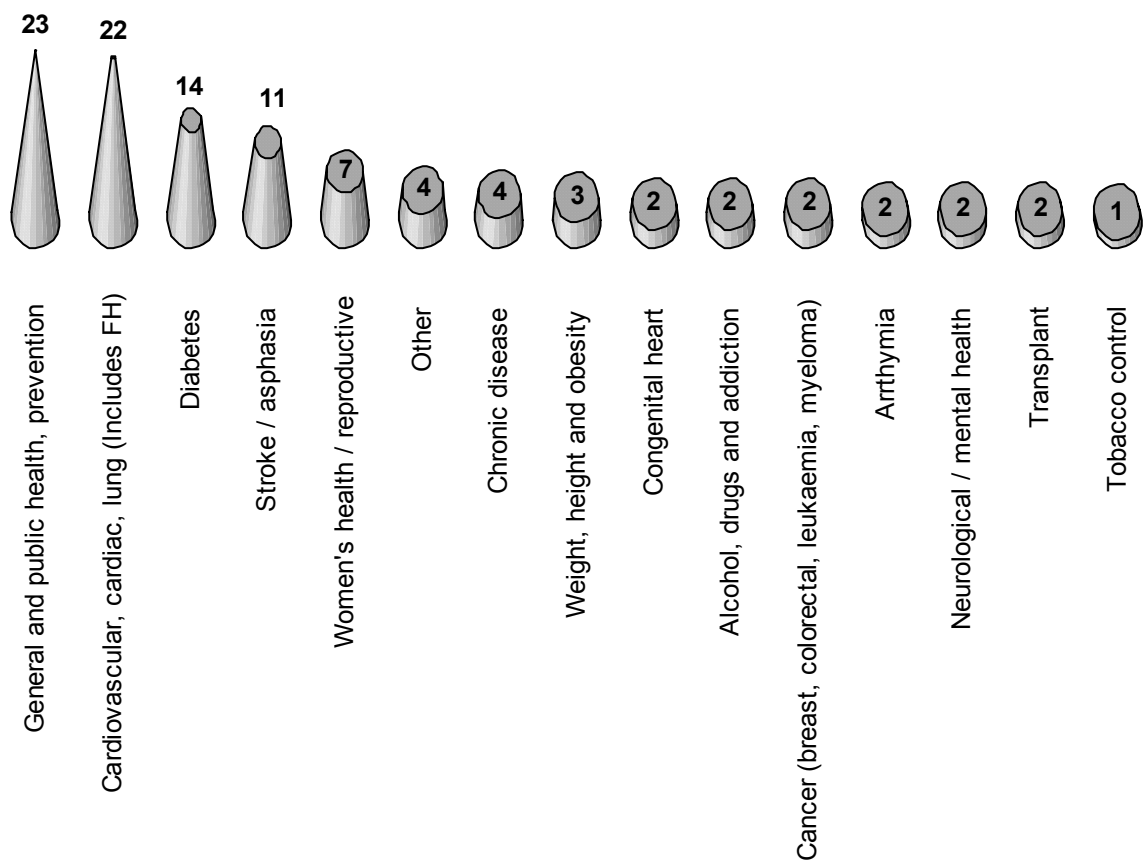


Source: HEART EU, December 2006

PROFILE OF RESPONDENTS BY SPECIALITY

% OF RESPONDENTS [TOTAL = 198]

[PERCENTAGES DO NOT TOTAL 100% DUE TO ROUNDING]



Source: HEART EU, December 2006

QUESTION 1: PUBLIC ATTITUDES TO THE PREVENTION OF HEART DISEASE AND STROKE (2006)*% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]*

Only poorer people have a positive attitude	0	0	0	0	0	0
Only people aged under 30 have a positive attitude	0	0	0	0	0	0
Only men have a positive attitude	2	0	1	1	0	9
Only women have a positive attitude	4	13	3	4	5	0
Only people aged 30-50 have a positive attitude	4	0	4	4	0	9
All are positive attitude (except some ethnic groups)	8	13	7	7	5	18
Only richer people are positive	13	19	7	13	26	18
Most are frustrated by the prevention issue	13	19	21	9	5	0
Most are too frightened	14	25	15	15	0	18
Most are bored with the whole prevention issue	16	31	19	15	11	0
Only people aged 50-plus have a positive attitude	18	19	13	19	32	18
Most are unsure of lifestyle changes needed	32	44	25	35	42	55
Most are in denial about prevention	36	44	44	35	21	18
Most are hesitant of medication for prevention	43	44	38	47	37	55
Most of the public have a positive attitude	44	31	51	38	58	27
<i>Source: HEART EU, December 2006</i>	Total [200]	Australasia [16]	North America [73]	Western Europe [81]	C. and E. Europe [19]	RoW [11]

QUESTION 2: ARE THE PUBLIC SUFFICIENTLY INFORMED TO TAKE ACTION TO AVOID FACTORS THAT CAN PROVOKE HEART DISEASE AND STROKE? (2006)

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]

Potential drug interactions for heart medication	8	13	10	4	11	0
Symptoms that indicate the onset of CVD	15	31	21	7	16	0
Link between irregular heartbeat and CVD	16	19	18	10	21	27
Inherited conditions that lead to CVD	17	25	18	15	21	9
Role of medicines and compliance	18	31	21	9	26	27
Link between diabetes and CVD	18	25	15	16	21	36
Disease burden of the two conditions	22	25	21	18	32	36
Importance of avoiding stress	30	25	25	35	42	27
Preventable nature of heart disease and stroke	32	44	35	26	37	36
Link between high blood cholesterol CVD	36	31	38	32	47	55
Link between high blood pressure and CVD	41	44	39	32	68	64
Importance of maintaining a health weight	58	75	57	65	42	55
Importance of staying active through exercise	60	81	54	69	58	45
Importance of eating a healthy diet	68	75	65	74	68	73
Importance of not smoking	75	75	76	79	68	64
<i>Source: HEART EU, December 2006</i>	Total [200]	Australasia [16]	North America [73]	Western Europe [81]	C. and E. Europe [19]	RoW [11]

QUESTION 3: WHERE PUBLICLY-AVAILABLE INFORMATION ON FACTORS THAT PROVOKE HEART DISEASE AND STROKE IS INSUFFICIENT (2006)

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]

Potential drug interactions for heart medication	64	44	69	60	58	82
Symptoms that indicate the onset of CVD	55	38	50	62	47	64
Link between diabetes and CVD	52	31	53	54	47	55
Link between irregular heartbeat and CVD	51	44	56	49	37	64
Inherited conditions that lead to CVD	46	13	54	50	37	45
Disease burden of the two conditions	46	31	51	43	37	64
Role of medicines and compliance	44	13	43	51	42	73
Preventable nature of heart disease and stroke	41	31	47	40	26	45
Importance of avoiding stress	33	25	38	26	32	55
Link between high blood pressure and CVD	32	25	33	29	21	18
Link between high blood cholesterol and CVD	29	25	33	40	26	18
Importance of staying active through exercise	18	25	17	12	47	9
Importance of not smoking	17	25	11	16	37	18
Importance of eating a healthy diet	14	31	15	6	21	9
Importance of maintaining a healthy weight	14	19	14	7	37	9
<i>Source: HEART EU, December 2006</i>	Total [200]	Australasia [16]	North America [73]	Western Europe [81]	C. and E. Europe [19]	RoW [11]

**QUESTION 4: LEVELS OF UNDERSTANDING OF THE IMPLICIT RISKS INVOLVED
AMONG FAMILIES WHO HAVE INHERITABLE HIGH BLOOD CHOLESTEROL (2006)**

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTES NUMBER OF RESPONSES RECEIVED]

	Yes, I believe that most of those with a family history of high cholesterol in my country do understand the health risks involved	Some understand the risks involved	No, they do not understand the risks involved
Total [200]	19	72	10
Australasia [16]	25	69	13
North America [73]	17	75	8
Western Europe [81]	18	66	15
C. and E. Europe [19]	26	79	0
RoW [11]	18	73	9

Source: HEART EU, December 2006

**QUESTION 5: QUALITY OF PUBLIC-DOMAIN INFORMATION ON
PREVENTION OF HEART DISEASE AND STROKE (2006)**

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTE NUMBER OF RESPONSES RECEIVED]

Not good (from whatever source)	4	6	4	4	5	0
Very good. Meets the needs of the public	16	38	22	9	11	18
Confusing. Leaves the public unsure how to act	23	19	32	16	21	9
Messages can be conflicting	29	19	46	19	21	18
More on drugs and compliance needed	30	38	28	29	37	36
Not always understandable	34	13	38	32	47	36
Not sufficiently motivational	37	25	39	40	32	36
Depends upon the source	41	38	43	37	58	36
More emphasis on importance of changing lifestyle	53	38	43	63	68	45
<i>Source: HEART EU, December 2006</i>	Total [200]	Australasia [16]	North America [73]	Western Europe [81]	C. and E. Europe [19]	RoW [11]

QUESTION 6: PUBLIC TRUST IN VARIOUS SOURCES OF SUPPORT AND INFORMATION (2006)*% OF RESPONDENTS [FIGURES IN BRACKETS DENOTES NUMBER OF RESPONSES RECEIVED]*

Medical device companies	2	6	0	1	0	9
Local government	2	0	4	0	0	9
Organic food manufacturers	3	0	1	3	5	9
Regulators	3	6	6	0	0	0
Pharma	3	0	1	3	11	0
National government	12	19	13	7	16	27
Academics	12	6	14	9	16	18
Internet	18	6	25	13	16	9
Pharmacists	29	50	25	35	26	9
Media	32	13	25	35	63	45
Consumer organisations	34	44	46	18	37	18
Patient organisations	41	44	28	56	42	18
Nurses	41	56	46	34	37	36
Family and friends	47	56	49	46	47	45
Doctors	87	94	81	94	84	100
<i>Source: HEART EU, December 2006</i>	Total [200]	Australasia [16]	North America [73]	Western Europe [81]	C. and E. Europe [19]	RoW [11]

**QUESTION 7: IMPORTANCE OF RISK MANAGEMENT AS PERCEIVED BY PATIENTS
DIAGNOSED AT HIGH RISK OF HEART DISEASE AND STROKE (2006)**

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTES NUMBER OF RESPONSES RECEIVED]

Uninterested	4	6	1	6	0	9
Know of medication, but difficulties with compliance	25	19	28	24	42	18
Very important	26	25	26	22	32	56
Not keen on medicines	29	25	29	26	42	18
Aware, but not top priority	35	44	46	26	37	9
Interested in easy-to-take medicines	44	56	53	37	37	18
Know about diet and exercise, but can't change lifestyle	75	69	81	79	68	45
<i>Source: HEART EU, December 2006</i>	Total [200]	Australasia [16]	North America [73]	Western Europe [81]	C. and E. Europe [19]	RoW [11]

QUESTION 8: KEY ISSUES ON WHICH PATIENTS DIAGNOSED AT HIGH RISK OF HEART ATTACK AND STROKE ARE INFORMED (2006)?

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTES NUMBER OF RESPONSES RECEIVED]

Genetic screening for FH (if appropriate)	7	19	8	1	16	27
Engaging the family	8	19	7	9	0	9
Avoiding occupational health hazards	12	25	11	9	16	18
Knowing the symptoms that lead to CV	21	44	24	16	26	9
Need to treat irregular heartbeat	22	19	24	19	37	9
Avoiding stress	42	44	42	43	58	27
Taking appropriate high-blood-cholesterol medication	43	44	46	37	58	45
Seeing the doctor for regular check-ups	44	50	44	44	58	36
Taking appropriate medication for diabetes	46	50	42	44	58	45
Taking appropriate high-blood-pressure medication	57	56	58	47	74	73
Maintaining a healthy weight	76	88	88	69	58	64
Staying active through exercise	77	94	85	72	58	64
Eating a healthy diet	85	94	90	78	79	91
Not smoking	88	94	94	82	89	73
<i>Source: HEART EU, December 2006</i>	Total [200]	Australasia [16]	North America [73]	Western Europe [81]	C. and E. Europe [19]	RoW [11]

QUESTION 9: WHERE INFORMATION IS INSUFFICIENT FOR PATIENTS DIAGNOSED AT HIGH RISK OF HEART DISEASE AND STROKE (2006)

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTES NUMBER OF RESPONSES RECEIVED]

Appropriate genetic screening for FH	48	31	53	43	53	55
Engaging family	38	38	38	38	42	27
Avoiding occupational hazards	35	6	42	37	26	45
Knowing the symptoms leading to CV	34	13	35	43	32	9
Need to treat irregular heartbeat	28	19	39	21	16	36
Avoiding stress	27	13	32	25	26	36
Need for appropriate treatment of diabetes	18	6	28	12	5	27
Seeing doctor for regular check-ups	17	6	11	22	21	27
Staying active through exercise	15	13	8	21	21	9
Eating a healthy diet	13	13	7	21	11	9
Maintaining a healthy weight	13	13	10	15	21	9
Taking appropriate high-blood-pressure medication	12	0	15	13	0	18
Taking appropriate high-blood-cholesterol medication	11	0	17	9	5	18
Not smoking	9	6	3	10	16	18
<i>Source: HEART EU, December 2006</i>	Total [200]	Australasia [16]	North America [73]	Western Europe [81]	C. and E. Europe [19]	RoW [11]

QUESTION 10: PREVENTION AND RISK MANAGEMENT, AS PRACTISED BY PATIENTS (2006)*% OF RESPONDENTS [FIGURES IN BRACKETS DENOTES NUMBER OF RESPONSES RECEIVED]*

CHANGING DIET AND EXERCISE		
	Yes	No
Total [200]	23	62
Australasia [16]	56	25
North America [73]	17	69
Western Europe	25	60
C. and E. Europe	16	79
RoW [11]	27	55

ADOPTING AND ADHERING TO APPROPRIATE HIGH-BLOOD-PRESSURE MEDICATION		
	Yes	No
Total [200]	53	28
Australasia [16]	63	13
North America [73]	43	32
Western Europe	57	28
C. and E. Europe	47	42
RoW [11]	62	18

ADOPTING AND ADHERING TO APPROPRIATE HIGH-BLOOD-CHOLESTEROL MEDICATION		
	Yes	No
Total [200]	50	31
Australasia [16]	69	0
North America [73]	43	36
Western Europe	54	29
C. and E. Europe	42	47
RoW [11]	64	36

Source: HEART EU, December 2006

QUESTION 11: PATIENT TRUST IN VARIOUS SOURCES OF SUPPORT AND INFORMATION (2006)*% OF RESPONDENTS [FIGURES IN BRACKETS DENOTES NUMBER OF RESPONSES RECEIVED]*

Processed food manufacturers	0	0	0	0	0	0
Sports goods companies	1	0	0	1	0	0
Medical device companies	1	6	0	0	0	0
Local government	1	0	1	1	0	0
Organic food manufacturers	2	0	1	3	0	9
Regulators	2	0	3	0	11	0
Pharma	3	0	3	3	0	9
National government	7	13	3	4	21	9
Academics	13	6	11	15	11	36
Internet	17	13	19	13	32	0
Media	23	13	13	24	58	0
Consumer organisations	25	38	31	16	26	0
Pharmacists	30	44	26	35	26	18
Family and friends	35	31	36	34	53	27
Patient organisations	40	31	26	54	47	27
Nurses	43	50	47	38	37	45
Doctors	91	88	86	96	100	100
<i>Source: HEART EU, December 2006</i>	Total [200]	Australasia [16]	North America [73]	Western Europe [81]	C. and E. Europe [19]	RoW [11]

QUESTION 12: IMPORTANCE OF PREVENTION AS A CAMPAIGN ISSUE FOR RESPONDENTS (2006)*% OF RESPONDENTS [FIGURES IN BRACKETS DENOTES NUMBER OF RESPONSES RECEIVED]*

	Very important	We are aware of the issue, but it is not top of our agenda	Not important
Total [200]	62	26	9
Australasia [16]	55	27	18
North America [73]	64	28	6
Western Europe [81]	65	24	10
C. and E. Europe [19]	63	32	5
RoW [11]	64	18	18

Source: HEART EU, December 2006

QUESTION 13: IMPORTANCE OF RISK MANAGEMENT AS A CAMPAIGN ISSUE FOR RESPONDENTS (2006)*% OF RESPONDENTS [FIGURES IN BRACKETS DENOTES NUMBER OF RESPONSES RECEIVED]*

	Very important	We are aware of the issue, but it is not top of our agenda	Not important
Total [200]	54	40	10
Australasia [16]	44	44	0
North America [73]	54	31	8
Western Europe [81]	59	25	12
C. and E. Europe [19]	63	26	5
RoW [11]	55	27	18

Source: HEART EU, December 2006

QUESTION 14: CAMPAIGNS RUNNING, OR TO BE RUN, BY RESPONDENTS (2006)*% OF RESPONDENTS [FIGURES IN BRACKETS DENOTES NUMBER OF RESPONSES RECEIVED]*

Stigmatisation (such as of being overweight)	10	13	17	4	11	0
Availability of health checks at work	10	0	15	4	16	18
Discrimination against types of patients	11	6	18	7	11	9
Ageing issues	12	13	15	9	16	9
Ethnicity issues	12	19	21	7	0	9
The need for public consultation	13	25	8	12	32	0
Gender issues	17	19	24	10	21	18
Lack of government support	17	31	8	22	21	9
The existence of new diagnostic tests and treatments	17	13	18	18	21	0
The role of health professionals	21	13	19	25	37	9
The need for more professional support	21	25	17	28	26	9
Global guidelines for high blood pressure and cholesterol	21	25	14	19	53	27
The importance of taking appropriate medication	28	19	25	25	53	36
The need for high-quality patient (or public) information	31	38	25	34	47	9
The importance of prevention by changing lifestyle	60	38	61	59	84	55
<i>Source: HEART EU, December 2006</i>	Total [200]	Australasia [16]	North America [73]	Western Europe [81]	C. and E. Europe [19]	RoW [11]

**QUESTION 15: REQUIRED RESEARCH IN THE FIELD OF PREVENTION AND RISK MANAGEMENT
OF HEART DISEASE AND STROKE (2006)**

% OF RESPONDENTS [FIGURES IN BRACKETS DENOTES NUMBER OF RESPONSES RECEIVED]

Local information on practitioners of preventive care	17	13	25	25	16	9
Where to find information	22	38	24	24	37	9
Adherence to high-blood-pressure/cholesterol drugs	25	13	28	28	42	0
High-blood-pressure/cholesterol drugs in populations	31	50	28	28	42	18
Better evaluation of the need for preventive care	32	44	28	28	32	18
Medical research into the causes of disease	32	31	32	32	37	18
Economic burden to society of preventable diseases	40	25	39	39	58	18
Importance of early intervention	44	44	44	44	37	27
How to engage patients/public	45	44	49	49	42	18
Evidence-based intervention strategies	51	44	64	44	47	64
	Total [200]	Australasia [16]	North America [73]	Western Europe [81]	C. and E. Europe [19]	RoW [11]
<i>Source: HEART EU, December 2006</i>						

HEART EU

HEART EU IS AN INTERNATIONAL ORGANISATION THAT AIMS TO SUPPORT PEOPLE WHO ARE CONCERNED ABOUT HIGH CHOLESTEROL AND THE PREVENTION OF CARDIOVASCULAR DISEASE.

HEART EU HAS A PARTICULAR INTEREST IN FAMILIAL HYPERCHOLESTEROLEMIA (FH), THE MOST FREQUENTLY-OCCURRING MONOGENETIC DISORDER WHICH IS, ON AVERAGE, PASSED ON TO HALF OF ALL OFFSPRING.

HEART EU PROMOTES THE HEALTH GAINS THAT CAN BE ACHIEVED FROM HEALTHY LIFESTYLES, EARLY DIAGNOSIS, AND (IF NECESSARY) EARLY EFFECTIVE PREVENTIVE TREATMENT.

HEART EU HAS FOUR MEMBER GROUPS (EACH IS A NATIONAL UMBRELLA ORGANISATION IN ITS OWN RIGHT):

- ▶ BLOEDLINK FOUNDATION IN THE NETHERLANDS,
- ▶ FH-NORWAY,
- ▶ FUNDACIÓN HIPERCOLESTEROLEMIA FAMILIAR IN SPAIN, AND
- ▶ H·E·A·R·T UK.

FURTHER INFORMATION ABOUT THESE GROUPS CAN BE FOUND AT
[HTTP://WWW.HEARTEUROPE.ORG](http://www.hearteurope.org)

BLOEDLINK'S ANNUAL REPORT 2004 IS ALSO AVAILABLE IN ENGLISH AT
[HTTP://WWW.BLOEDLINK.NL/FILES/DYNAMIC/97120.DYN?DOWNLOAD=1](http://www.bloedlink.nl/files/dynamic/97120.dyn?download=1)

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December 2006