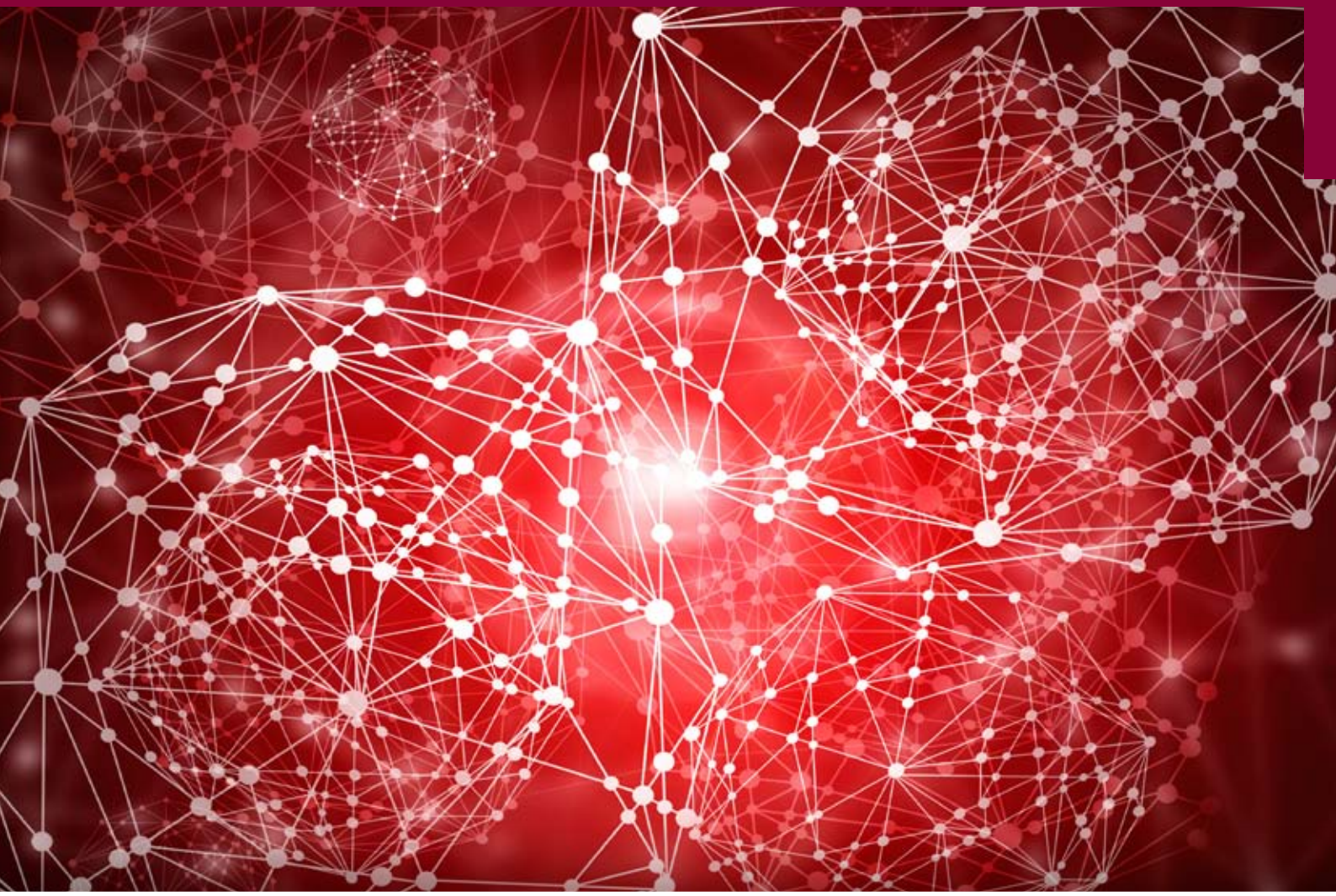
ATOMIUM
EUROPEAN INSTITUTE
FOR SCIENCE, MEDIA AND DEMOCRACY

REI Search
EMPOWERING KNOWLEDGE

# CITIZEN ENGAGEMENT AND MEDIA CAMPAIGN ON CHRONIC DISEASES

## Analysis and results of the launch of the beta version of REIsearch



DER STANDARD EL PAÍS Frankfurter Allgemeine ZEITUNG FÜR DEUTSCHLAND Il Sole 24 ORE THE IRISH TIMES

Cell La Libre.be Luxemburger Wort wyborcza.pl EuroScientist

**Atomium – European Institute for Science, Media and Democracy (EISMD)** – brings together some of the most authoritative universities, newspapers and businesses in Europe in the first intersectoral platform to promote knowledge sharing and "out of the box" thinking on issues regarding the development of a European knowledge society.

Atomium – EISMD was launched publicly by the former President of France Valéry Giscard d'Estaing and by Michelangelo Baracchi Bonvicini, currently Honorary President and President, and by the leaders of the institutions engaged during the first conference on the 27 November 2009 at the European Parliament in Brussels.

Atomium – EISMD seeks to balance the interests and needs of six different societal actors: researchers, universities, businesses, media, policy makers and, most importantly, citizens. The fastest way to solve a Rubik's Cube is to choose one face to start with, and it is our citizens that we choose as our primary focus.

EISMD, focussing on the role of science in the 21st century, seeks to align the five key areas:

1) Science-Based Policy Making
2) Science Communication
3) Education
4) Equality and Equal Access
5) Innovation through Collaboration

Aligning these categories with respect to each other will enable European citizens to successfully account for all the varied faces of society in an ultimately positive way.

Atomium – EISMD brings together 25 universities, over one hundred thousand researchers, over one million students, seventeen newspapers, around ten million European readers per day, and some of the most important businesses in Europe with a total turnover of 720 billion Euro.



Author: **Erika Widegren**,
***Chairman of the Advisory Board of REIsearch***

co-Author: **Fiorenza Lipparini,**
***Head of the Editorial Team of the Citizen Engagement and Media Campaign on Chronic Diseases***

*REIsearch is funded by the European Commission's Directorate-General for Communications Networks, Content and Technology. The views expressed do not necessarily reflect the views of the European Commission. (contract nr 30-CE-0682336/00-34).*

# INDEX


**Foreword** ..... 2
**Acknowledgements** ..... 5

**1. REIsearch** ..... 8
**Introduction** ..... 8
**What** ..... 9
**Tools** ..... 10
**Governance** ..... 12

**2. Citizen Engagement and Media Campaign on Chronic Diseases** ..... 14
**About** ..... 14
Aim
Topic
Format
**Background on the Challenges Posed by Chronic Diseases** ..... 16
**Media Partners** ..... 18
**Knowledge Partners** ..... 19
**Committees** ..... 27
Editorial Committee
Scientific Committee

**3. Outcomes** ..... 32
**WEEK 1- Prevention is the Better Cure** ..... 41
Overview
Background
Results
Recommendations
**WEEK 2- New Technologies and Innovation** ..... 55
Overview
Background
Results
Recommendations
**WEEK 3- Citizen's Rights and Responsibilities** ..... 69
Overview
Background
Results
Recommendations
**WEEK 4- Diabetes and Nutrition** ..... 85
Overview
Background
Results
Recommendations
**WEEK 5- More and Better Data** ..... 101
Overview
Background
Results
Recommendations
**4. Conclusions** ..... 116
**5. Evaluation of Methodology** ..... 121
**List of Graphs** ..... 125
**Annexes** ..... 129

# REISEARCH - A necessary bridge between citizens, researchers, and policy makers

*"Innovation and new scientific discoveries are improving people's lives and making our economy more competitive. Science should be open and freed from its traditional ivory tower; to be discussed, submitted to critique and fed with new perspectives. That's why I warmly welcome efforts such as the REIsearch initiative to get Europeans engaged in the debate about science and research and inspire fresh ideas about how to solve some of our society's most pressing problems."*

***Jean-Claude JUNCKER,***
***President of the European Commission***

*"REIsearch wants to successfully overcome the challenge of connecting the experience of EU citizens and the expertise of EU researchers to support policy makers in taking decisions that will affect society as a whole."*

***Valéry GISCARD D'ESTAING,***
***Honorary President of Atomium-EISMD,***
***former President of France***

***Michelangelo BARACCHI BONVICINI,***
***President of Atomium-EISMD***

*"Innovation is Europe's key to remaining the 'old continent' only in historical sense - and to succeeding as a young, dynamic continent in the sense of our ability to solve even the most complex problems. It is not only about economic competitiveness, new technologies, research, jobs, products or the integrated market. It is about building whole innovation ecosystems in which citizens, researchers and policymakers come together for open discussion. This is what makes programmes such as the REIsearch initiative so important: they create the necessary 'meeting points' for innovation."*

***Jerzy BUZEK,***
***MEP, former President of the European Parliament***

*"REIsearch will foster evidence-based policy making by putting science in the centre of an open, transparent and more citizen-centred culture of debate. It will help build trust of citizens in policy decisions, scientific evidence and their underlying assumptions. It will allow innovators to have immediate access to knowledge they might need. REIsearch being transparent, borderless and participatory, can be a practical implementation of the ambitions of open science."*

***Günther OETTINGER,***
***EU Commissioner Digital Economy and Society***

*"REIsearch will put science in the centre of an open, transparent and more citizen-centred debate. It aims to enable via an online collaborative platform an open, engaged, evidence-driven and transparent debate on pressing societal challenges. The REIsearch platform will facilitate and encourage a debate across a variety of actors - scientists gathering and analysing evidence on a given societal challenge, citizens providing and contemplating evidence and expressing preferences, journalists stimulating public debate and policy makers engaging in transparent and publicly accountable actions."*

***Roberto VIOLA,***
***Director-general for Communications Networks,***
***Content & Technology (DG CONNECT) of the European Commission***

*"Only with a renewed dialogue between researchers, citizens and policy-makers will Europe be able to meet its increasingly complex challenges. And cooperation across sectors and countries is indeed the best trigger for creative thinking, and the key incentive for innovative solutions to complex problems. REIsearch provides the right kind of genuine push towards stronger evidence-based policy making, more informed citizens, and better science - this is why I so eagerly look forward to the results of the first REIsearch initiative on Chronic Diseases."*

***Xavier PRATS-MONNE',***
***Director-general for Health and Food Security (DG SANTE) of the European Commission***

# ACKNOWLEDGEMENTS

This report and the Citizen Engagement and Media Campaign on Chronic Diseases could not have been carried out without the financial, intellectual and collegiate support of the participating organisations: the European Commission, the European Parliament, ALL European Academies, European Research Council, Karolinska Institutet, League of European Research Universities, London School of Economics, NESTA, Royal College of Surgeons in Ireland, Swedish Research Council, Universitá di Pisa, European Respiratory Society Advocacy Council, International Diabetes Federation Europe, The Standing Committee of European Doctors, FORTE, Bayer, Cefic, Elsevier, Mendeley, Merck, Nokia, Sanofi, European Association of Science Editors, European Journalism Centre, European Science Foundation, EuroScience, Financial Times, German Research Centre for Science & Innovation Communication; International Communication Association, OpenAIRE, Science Direct, The Lancet, The New Scientist, the Cell, Der Standard, El País, EuroScientist, Frankfurter Allgemeine Zeitung, Gazeta Wyborcza, La libre Belgique, Luxemburger Wort, Público, Sole24ore, and The Irish Times.

The active and enthusiastic participation in all stages of an unfolding process of Ron Mobed (Elsevier), Dr Vladimir Šucha (Joint Research Centre), Mr Nils Torvalds (MEP), Dr Hossein Moiin (Nokia) and Prof. Massimo Marchiori (EISMD) was of inestimable benefit to the EISMD team in helping define and shape the project initially and achieve the overarching, collective and individual organisational goals.

We would also like to thanks Ms Stella de Sabata, Dr Katrín Fjeldsted, Dr Bernard Maillet, Prof. Dr Gelu Onose and Prof. Dr Rutger Jan van der Gaag who greately contributed to prepare and validated the contents for the initiative.

We would like to extend a special thank you to Erika Widegren for her dedication to the success of REIsearch and this publication and to Dr Fiorenza Lipparini for her unwavering enthusiasm and hard work for the success of the Citizen Engagement and Media Campaign on Chronic Diseases.

The project team is also extremely grateful to all the scientists, policy makers, stakeholders and citizens who tested the platform and participated to the campaign.

**Valéry Giscard d'Estaing,**
*Honorary President of Atomium-EISMD,*
*former President of France*

**Michelangelo Baracchi Bonvicini,**
*President of Atomium-EISMD*

# EXECUTIVE SUMMARY

This report presents the first results of the *Citizen Engagement and Media Campaign on Chronic Diseases* that ran in February and March 2016 for the launch of REIsearch.

Coordinated by Atomium – European Institute for Science, Media and Democracy (EISMD) the *Citizen Engagement and Media Campaign on Chronic Diseases* was launched to create a responsible and informed multi-stakeholder debate on the issues involving thousands of European citizens, researchers, policymakers and stakeholders. It wanted to create and promote access to reliable information, increase inter-disciplinary and inter-sectoral debate and collect and analyse results to deliver to researchers and policymakers.

The campaign was developed by EISMD for the launch of REIsearch, an online tool proposed by the European Parliament and co-funded by the European Commission, created to be a bridge that connects citizens, researchers and policy makers on topics linked to the scientific research and to societal challenges that Europe will face in the years to come.

To demonstrate how the tool works and to launch the beta version of REIsearch, a campaign was run reaching out to a readership of over 8 million citizens (cumulative reach of all media partners engaged in the initiative), in ten European countries (Austria, Belgium, France, Germany, Ireland, Italy, Luxembourg, Poland, Portugal, Spain), and in seven languages (English, French, German, Italian, Polish, Portuguese and Spanish). The campaign saw the participation of nearly 60 000 Europeans and nearly 18 000 responses to the survey.

The aim of this report is twofold:

- On the one hand it wants to present **REIsearch** as a tool, analyse the successes and errors done during the first campaign and evaluate the methodology in order to come up with concrete solutions for future developments.
- On the other hand it wants to present the first **citizen engagement and media campaign on chronic diseases**, looking in detail at the issues at hand and analyzing the responses and perspectives given by the participants.

## REIsearch

The questions that the pilot project set out to answer were:

**a)** Is it possible to develop an online tool to create a direct dialogue between scientists, policy makers and the public with the support of the media?

**b)** Do people want to be more engaged in European debates?

**c)** Do people want to be more informed about what science has to contribute to discussions regarding societal challenges?

**d)** Can REIsearch support this direct dialogue?

**e)** Are policy makers willing to engage in a constructive debate with the public at large on these issues?

The pilot project proved that the answer to all the questions above is an overwhelming YES.

The public at large is not only interested in participating to European debates but asked directly for more interaction. They are curious to find out what the facts say about a specific issue whilst underlining the importance that experts better understand the "human" side of questions.

REIsearch managed to support this dialogue bringing together different communities around a common interest and spark inter-disciplinary and inter-sectoral debates.

The results underline the need for further efforts such as the ones promoted by the European Commission in engaging citizens more in policy debates. The clear position of the Commission in this regard and the aim to ensure that Horizon 2020 takes account of the opinions and concerns of citizens is a laudable way to lead by example.

## CITIZEN ENGAGEMENT AND MEDIA CAMPAIGN ON CHRONIC DISEASES

The questions that the campaign set out to answer were:

**a)** Is it possible to work together with policy makers, scientists and key stakeholders to develop a shared vision of what are the core questions that need to be resolved?

**b)** Do citizens feel that Europe needs more citizen engagement initiatives?

**c)** Can citizens add layers to the debate on chronic diseases that is useful to policymakers, scientists and other key stakeholders?

**d)** Do citizens feel that chronic diseases is a priority issue that needs the engagement of all actors of society in order to come up with innovative and creative solutions?

The campaign proved that the answer to all the questions above is an overwhelming YES.

44 organisations were engaged in the activities leading to the launch, as well as during the campaign. They included 9 research organisations, 4 civil society organisations, 7 large companies, 2 policy-making institutions and 22 media organisations.

The campaign was received very well by a majority of the participants and it is clear from the results of the survey that over 90% of participants agreed that health is a priority issue.

85% of participants further stressed that health and the prevention of chronic diseases cannot be considered in isolation and should be taken into consideration in all decisions about the future choices of a society. In fact, the results underlined the need to increase the multi-stakeholder approach to developing a coherent and realistic vision for combatting chronic diseases where education and the media have a key role to play.

REIsearch and the Citizen Engagement and Media Campaign on Chronic Diseases received a lot of positive feedback and has demonstrated that novel ways of cooperation between policy makers, media and researchers can create active debates and conversations with citizens on important questions relating to societal challenges in general and the challenge posed by chronic diseases in particular.

In this report you will find the results of the individual questionnaires and the concerns of the public at large in reference to the individual themes: *prevention, new technologies and innovation, citizen's rights and responsibilities, diabetes and nutrition and more and better data*.

# 1 - ABOUT REISEARCH

## INTRODUCTION

### *REISEARCH - A necessary bridge between citizens, researchers, and policy makers*

REIsearch was proposed by the European Parliament as a Pilot Project to be a bridge that connects citizens, researchers and policy makers on topics linked to the scientific research and to societal challenges that Europe will face in the years to come.

REIsearch is an innovative non-profit European initiative co-funded by the European Commission to demonstrate how a technological tool, coupled to a broad network of leading media, research institutions, researchers, civil society organisations, and citizens, can help policy makers to make better use of all knowledge and experience - wherever it may come from - to make better decisions, based on evidence and experience, for the benefit of society as a whole.

REIsearch is promoted by Atomium – European Institute for Science, Media and Democracy, launched seven years ago at the European Parliament by the former President of France Valéry Giscard d'Estaing and by Michelangelo Baracchi Bonvicini, today Honorary President and President of the Institute.

"Innovation and new scientific discoveries are improving people's lives and making our economy more competitive. Science should be open and freed from its traditional ivory tower; to be discussed, submitted to critique and fed with new perspectives. That's why I warmly welcome efforts such as the REIsearch initiative to get Europeans engaged in the debate about science and research and inspire fresh ideas about how to solve some of our society's most pressing problems" commented the President of the European Commission Jean-Claude Juncker.

REIsearch wants to successfully overcome the challenge of connecting the experience of EU citizens and the expertise of EU researchers to support policy makers in taking decisions that will affect society as a whole.

"To win such an ambitious challenge - declared Valéry Giscard d'Estaing and Michelangelo Baracchi Bonvicini - together with our partners we have opted for a gradual approach, aiming at developing initiatives linked to specific scientific topics starting with those of greatest impact, limiting the platform's functions to the essential.

In the coming years additional functionalities will be available, allowing citizens to directly interact with experienced researchers at both national and European level".

REIsearch is a non-profit project headed by EISMD. It aims to provide a secure and reliable platform that ensure the privacy of user data.

# WHAT

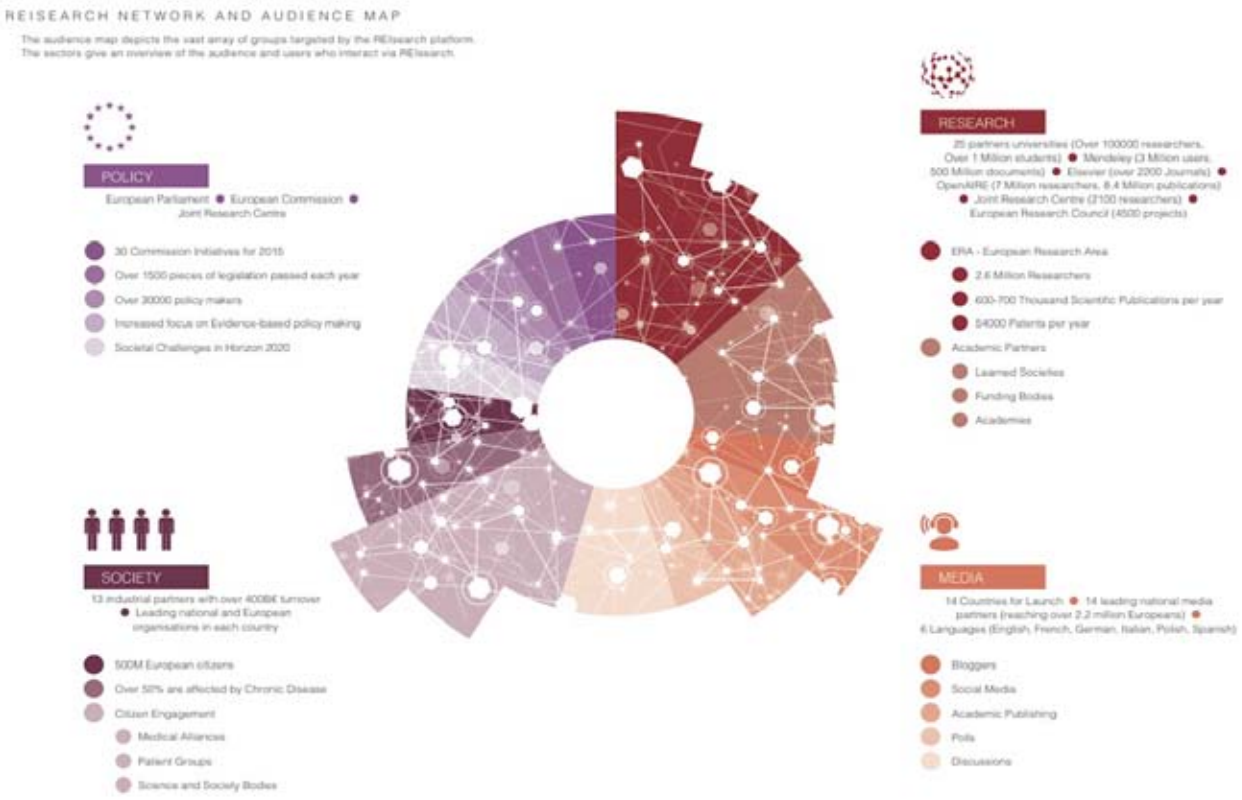
REIsearch is an online tool that brings together different and existing communities around specific challenges with the aim to bring together the experience and expertise to the benefit of society as a whole.

REIsearch communities will be built by bringing together individuals and organisations around specific challenges, starting from the societal challenges as outlined by Horizon 2020, the EU's Research and Innovation programme and reflect the policy priorities of the Europe 2020 strategy:

- Health, demographic change and wellbeing;
- Food security, sustainable agriculture and forestry, marine and maritime and inland water research, and the Bioeconomy;
- Secure, clean and efficient energy;
- Smart, green and integrated transport;
- Climate action, environment, resource efficiency and raw materials;
- Europe in a changing world - inclusive, innovative and reflective societies;
- Secure societies - protecting freedom and security of Europe and its citizens.

For the beta test of REIsearch, the platform will be opened on the challenge of **health**, **demographic change** and **wellbeing**.

In particular the fist *citizen engagement and media campaign* that will be run for the launch of the beta of the platform will focus on the challenge posed by **chronic diseases**.



# TOOLS

The Beta of REIsearch will have the following tools:

**1. Have your say!** Polling tool
REIsearch allows citizens and researchers to respond to questions that related to issues that are very timely from a policy perspective. Initially these questions will be developed in collaboration with the EU institutions, knowledge partners, Scientific Committee and Editorial Committee to
ensure their reliability, scientific validity and timeliness.

**2. Dig deeper** article search
REIsearch allows member to access and search for articles related to the field that are authoritative and reliable from a scientific perspective.
Articles are divided into three categories: research, policy and media.

*Research:* refer to peer-review research article

*Policy:* refer to policy papers and reports

*Media:* refer to all media and social media content

Through collaboration with knowledge partners REIsearh searches existing databases and makes the articles accessible through REIsearch. For research articles REIsearch is already collaborating with ScienceDirect, Mendeley and OpenAIRE. For policy articles, REIsearch is already collaboratiog with EU databases. For media articles REIsearch is collaborating with the media partners of the platform.
In time collaborations with expand as well as allowing individual users to suggest and make content available, provided that the content is reliable and authoritative.

**3. Find people** search
This tool makes it easier for users to find other users whom they would like to follow or connect with.

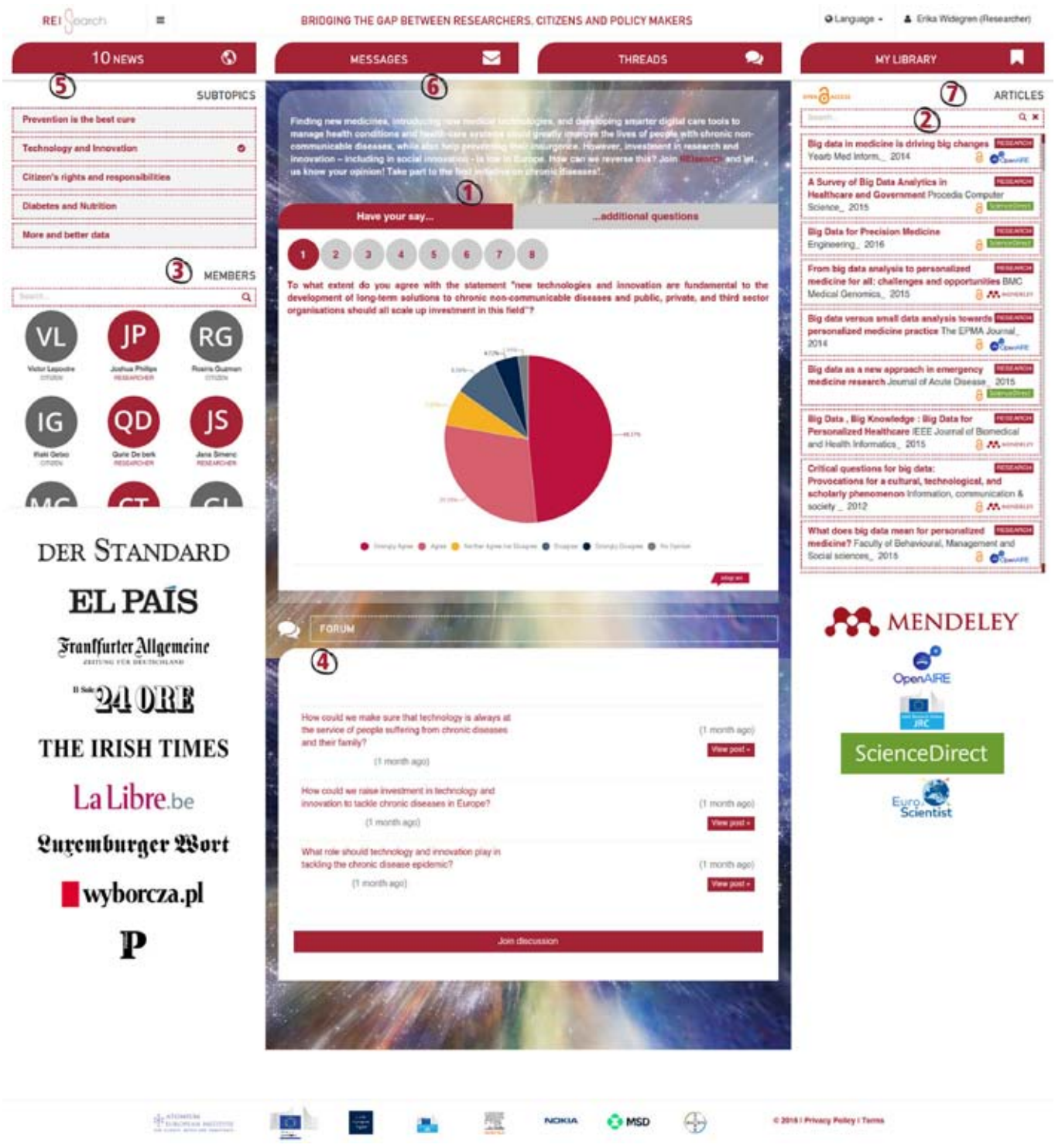
**4.** Forum
This tool allows user to create debates and continue the discussion allowing for all different stakeholders the share experiences and perspectives.

**5.** News
This tools notifies users when something is happening that could be useful for them to know.

**6.** Messaging
To have private conversations with other users.

**7.** Library

To bookmark and store articles of interest.


REI Search
BRIDGING THE GAP BETWEEN RESEARCHERS, CITIZENS AND POLICY MAKERS
Language
Erika Widegren (Researcher)
10 NEWS
MESSAGES
THREADS
MY LIBRARY
SUBTOPICS
Prevention is the best cure
Technology and Innovation
Citizen's rights and responsibilities
Diabetes and Nutrition
More and better data
MEMBERS
ARTICLES
Have your say...
...additional questions
To what extent do you agree with the statement "new technologies and innovation are fundamental to the development of long-term solutions to chronic non-communicable diseases and public, private, and third sector organisations should all scale up investment in this field"?
FORUM
How could we make sure that technology is always at the service of people suffering from chronic diseases and their family?
How could we raise investment in technology and innovation to tackle chronic diseases in Europe?
What role should technology and innovation play in tackling the chronic disease epidemic?
Join discussion
DER STANDARD
EL PAÍS
Frankfurter Allgemeine
24 ORE
THE IRISH TIMES
La Libre.be
Luxemburger Wort
wyborcza.pl
MENDELEY
OpenAIRE
ScienceDirect
EuroScientist
NOKIA
MSD

# GOVERNANCE

REIsearch brings together four different key stakeholder groups: science, policy, media and society. This set-up is reflected in the set-up of the Steering Committee and Advisory Board of REIsearch.

## STEERING COMMITTEE

The Steering Committee serves as the main decision making body for REIsearch and is co-chaired by the Honorary President and President of Atomium – European Institute for Science, Media and Democracy:
Valéry Giscard d'Estaing and Michelangelo Baracchi Bonvicini.

Members of the Steering Committee are:

- **Valéry Giscard d'Estaing**, ***Honorary President of Atomium – European Institute for Science, Media and Democracy, former President of France, former President of the European Convention***
- **Michelangelo Baracchi Bonvicini**, ***President of Atomium – European Institute for Science, Media and Democracy***
- **Ron Mobed**, ***Chief Executive Officer of Elsevier***
- **Dr Hossein Moiin**, ***Executive Vice President and Chief Technology Officer (CTO) of Nokia Networks***
- **Dr Vladimír Šucha**, ***Director General of the Joint Research Centre***
- **Nils Torvalds**, ***Member of the European Parliament, journalist and writer***

## ADVISORY BOARD

The Advisory Board serves as the main advisory group for the development of REIsearch.

Bringing together leading representatives of the key European institutions and organisations engaged in the dissemination of science and innovation results to society at large. The outcomes of the deliberations of the Advisory Board serve as a guide for the Steering Committee when making its decisions.

Members of the Advisory Board are:

- **Erika Widegren,** ***Chairman of the Advisory Board;***
- **Cissi Askwall,** ***Secretary General of Vetenskap och Allmanhet (Science and Society);***
- **Morten Busch,** ***Head of Science and Media learning Centre Experimentarium;***
- **Donatella Castelli,** ***Italian National Research Council and Technical Director of OpenAIRE;***
- **Anna Maria Fleetwood,** ***Head of External Relations of the Communication Department of the Swedish Research Council;***
- **Alexander Gerber,** ***Director of the German Research Centre for Science & Innovation Communication;***
- **François Heinderyckx,** ***President of the International Communication Association;***
- **Martin Hynes,** ***Chief Executive of the European Science Foundation;***
- **Natalia Manola,** ***OpenAIRE;***
- **Joan Marsch,** ***President of the European Association of Science Editors;***
- **Wilfried Ruetten,** ***Director of the European Journalism Centre;***
- **Dr Stephane Berghmans,** ***VP Academic & Research Relations EU, Elsevier;***
- **Markus Weisskopf,** ***Director of Wissenschaft im Dialog (Science in Dialogue).***


# 2 - CITIZEN ENGAGEMENT AND MEDIA CAMPAIGN

*"Only with a renewed dialogue between researchers, citizens and policy-makers will Europe be able to meet its increasingly complex challenges. And cooperation across sectors and countries is indeed the best trigger for creative thinking, and the key incentive for innovative solutions to complex problems. REIsearch provides the right kind of genuine push towards stronger evidence-based policy making, more informed citizens, and better science - this is why I so eagerly look forward to the results of the first REIsearch initiative on Chronic Diseases."*

*Mr Xavier Prats-Monné,*
*Director General of the Directorate General for Health and Food Safety of the European Commission*

## ABOUT

In February and March 2016, Atomium – European Institute for Science Media and Democracy (EISMD) launched a *citizen engagement and media campaign on chronic diseases* for the launch of the beta version of REIsearch. With the aim to create a public debate between policymakers, scientists and citizens to create a real public discourse on the topic and better understand the evidence, the constraints and the opinions of citizens across Europe, the campaign was developed together with the collaboration of the European institutions, leading research organisations, key stakeholders and some of the most authoritative newspapers in Europe.

REIsearch coordinated 12 European media organisations – including Der Standard, El País, EuroScientist, Frankfurter Allgemeine Zeitung, Gazeta Wyborcza, La libre Belgique, Luxemburger Wort, Público, Sole24ore, and The Irish Times– to run a citizen engagement campaign through their online editions as well as through REIsearch's IT platform. Elsevier, Mendeley, OpenAIRE, and the European Commission's Joint Research Centre facilitated the engagement of researchers. Some of the most important European organisations operating in the Chronic Disease sector (ALL European Academies, European Respiratory Society, EuroScience, International Diabetes Federation Europe, Karolinska Institutet, League of European Research Universities, Royal College of Surgeons in Ireland, Science and Technology Options Assessment Panel – European Parliament, The Standing Committee of European Doctors), together with relevant Directorates-General of the European Commission, cooperated to write questions that were addressed to both researchers and the public at large.

The results of this campaign were presented to the leading representatives of the European Parliament and European Commission. The outcomes presented in this report will allow policy makers across Europe to obtain useful and significant insight, expertise, and data on key issues in chronic disease management and prevention.

The campaign engaged over 60 000 users from over ten European countries with the publication of over 70 articles published in seven different languages.

## AIM

The aims of the campaign were to:

1) Create a responsible and informed multi-stakeholder debate on the issues involving thousands of European citizens, researchers, policymakers and stakeholders;

2) Create and promote access to reliable information on the issue;

3) Increase inter-disciplinary and inter-sectoral debate;

4) Collect and analyse results to deliver to researchers and policymakers;

5) Bridge the gap between science, society and policy;

6) Pilot an innovative way for increased dialogue and discussion between science, media, society and policy.

## TOPIC

The topic selected for the *citizen engagement and media campaign* of REIsearch was Chronic Diseases, a theme of the utmost importance in the European policy agenda given both its burden on Member States' public budgets and, most importantly, its impact on EU citizens' well being. Today chronic diseases in Europe are responsible for 86% of all deaths and affect over 80% of people over 65 taking up almost 80% of the health budgets of EU member states.

*More information is provided below.*

## FORMAT

The initiative ran for five weeks in February and March 2016.

Preparatory work was done with the knowledge partners of the initiative as well as representatives of the European Institutions to analyse and pinpoint the most pressing issues from a policy-timeliness perspective.

Evidence was the mapped and analysed on these issues to reflect what the most relevant research results said on these issues. This analysis was interdisciplinary in scope and included research from medicine, engineering, biology, chemistry, sociology, economics, philosophy and many more.

Each week of the campaign one key "question" relating to the issue was introduced by:

1) An editorial piece published by our media partners o n the topic;

2) A social media campaign to encourage communities already involved and interested in this debate to join the campaign.

Researchers, citizens and journalists where accessing REIsearch to respond to questions, participate to the debate and access additional information about the topic.

Participation provided both quantitative and qualitative data to be able to give to the policy makers.

Chapter 3 (Outcomes) and 4 (Conclusion) outlines the detailed results of this campaign and a thorough evaluation is provided in chapter 5 (Evaluation of Methodology).

# BACKGROUND ON THE CHALLENGE POSED BY CHRONIC DISEASES

*"Healthy citizens are the greatest asset any country can have"*

*Sir Winston Churchill*

One of the biggest challenges that Europe will have to face in the coming years is the strain that changing demographics, and lifestyle are putting on the healthcare sector.

Today chronic diseases cause 86% of deaths in the European Union. Chronic diseases, or Non-Communicable Diseases (NCD), are long-term health conditions, mostly non-communicable (i.e. non-infectious) that are predominantly not curable but require lifelong management. Chronic diseases in the European Union affect all member states.

In Europe chronic diseases affect more than 80% of people aged over 65 and they are responsible for nearly 80% of the health budgets. And the trends are showing that chronic diseases affect more and more young people.

The current situation has precipitated the need to redefine the European healthcare system to suit the needs and challenges of the 21st century.

In the light of the changes that will be necessary for the coming decades the debates need to shift the paradigm. As Dr. Margaret Chan, Director General of the World Health Organisation states, "All ministers are health ministers". In order to address behaviour modification across the value chain, different approaches and thinking are needed.

**CITIZENS AFFECTED IN EURASIA BY SELECT CHRONIC DISEASES**

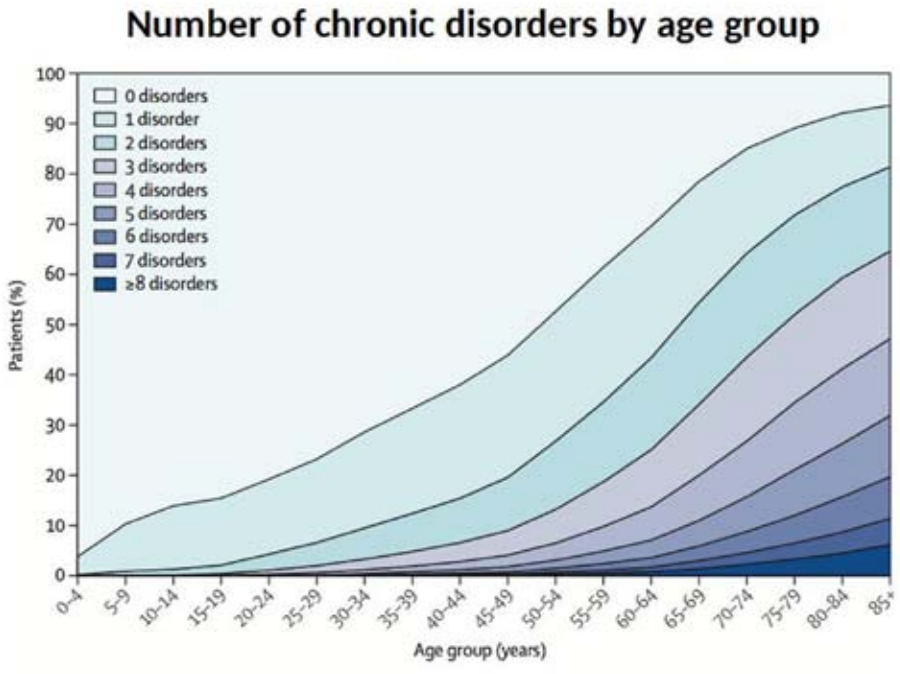
| | |
|---|---|
| Cancer | 36 M |
| Neurodegenerative Conditions | 9 M |
| Mental Illness | 125 M |
| Cardiovascular Conditions | 100 M |
| COPD and Respiratory Conditions | 55 M |
| Diabetes | 56 M |

Changing patterns of disease, socio-demographic transitions, emerging technologies, emerging models of care, changing expectations of consumers and changes in the political and economic environment (globalisation, economic constraints) are all challenges facing our healthcare and that require new thinking and approaches.

Take for instance prevention: according to the World Health Organisation, avoiding cigarettes, alcohol and junk food and making 30 minutes of physical exercise each day, could prevent up to the 80% of new heart disease, stroke, and type 2 diabetes cases. But how can we encourage healthy habits and prevent chronic diseases from arising?

It is often noticed that only around the 3% of EU public health budget is spent in prevention, and that citizens often lack the information necessary to take healthy choices. But is this a responsibility of the public sector or the individual citizen? Seeing that today 10% of patients – the so-called high-cost patients - account for 65% of spending on healthcare budgets should good behavior and habits be incentivized? What is the role of employers or schools?

These are the type of questions where it is still unclear what the right answer should be.

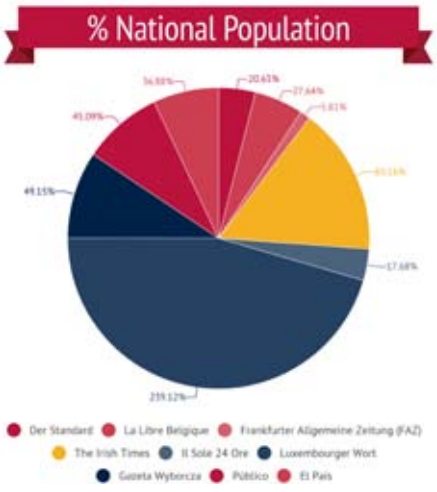


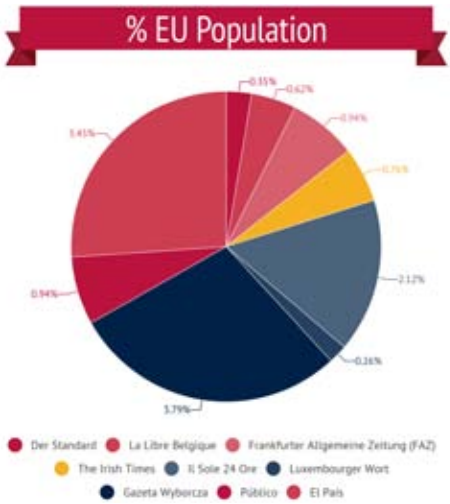

Source: Barnett et al. 2012. Lancet 370: 37-43.

# MEDIA PARTNERS

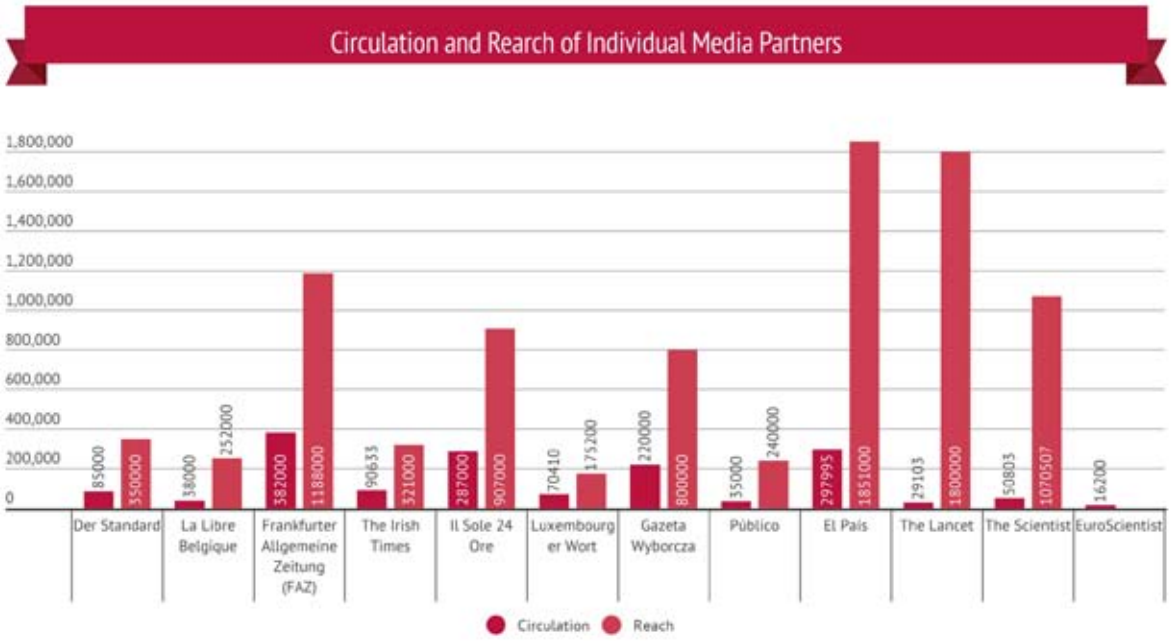
The Citizen Engagement and Media Campaign ran in seven different languages and with the support of twelve leading media partners including national newspapers as well as science magazines and journals.

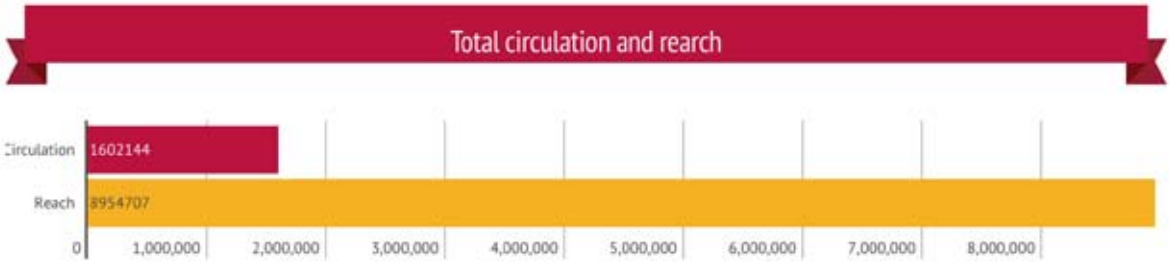

Below you can see the reach of the individual media partners in terms of percentage of national population and of the European population.



Together the media partners of the campaign have a circulation of over 1.6 million and reach over 8 million people. If one looks at the online statistics, the partners jointly have on average around 61 million unique users per month and over 800 million page visits allowing the campaign to reach a significant number of citizens.




Please find below a detailed list of the media partners:

## AUSTRIA – DER STANDARD

*Der Standard* is an Austrian national daily newspaper that is published in Vienna.

*Der Standard* is one of Austria's best-selling quality newspapers and is readily quoted by foreign media when an opinion from the Austrian press is required.

*Der Standard* is published in accordance with the honour code of the Austrian press (which sets rules on matters such as a transparent division between news and comment and the right to privacy). The paper's general editorial stance could be described as socially liberal and most of its regular columnists also tend to this position, although guest writers come from a wide variety of political positions.

## BELGIUM – LA LIBRE BELGIQUE

*La Libre Belgique* (literally, "The Free Belgium"), now sold under the name *La Libre*, is a Belgian newspaper in French. The paper was started as Le Patriot in 1884 and had a pro-Catholic stance. It was renamed *La Libre Belgique* and was published as part of the underground press in February 1915 during the occupation of Belgium by German Empire.

*La Libre* is published six times per week (from Monday to Saturday) by the IPM publishing group and has its headquarters in Brussels. The online edition of the paper was started in 2001. The paper has been published in tabloid format since 2002.

In Belgium, it is seen as roughly equivalent to the Flemish De Standaard. It is the only Francophone newspaper that is also distributed in Flanders. Along with another high circulation French-speaking newspaper it dominates the market in Wallonia and Brussels.

## GERMANY – FRANKFURTER ALLGEMEINE ZEITUNG

*Frankfurter Allgemeine Zeitung (FAZ)* is a German daily published in Frankfurt. Founded in 1949, this major conservative-liberal daily is a reference tool in business circles and among intellectuals, who appreciate its literary supplement, *Feuilleton*.

The *FAZ* is the German daily with the widest circulation abroad and one of the world's largest networks of correspondents, which makes it by and large independent from the press agencies.

The *FAZ* promotes an image of making its readers think. The truth is stated to be sacred to the *FAZ*, so care is taken to clearly label news reports and comments as such. Its political orientation is classical liberal with an occasional support for conservative views by providing a forum to commentators with different opinions. In particular, the *Feuilleton* and some sections of the Sunday edition cannot be said to be specifically conservative or liberal at all.

## IRELAND – THE IRISH TIMES

*The Irish Times* is an Irish daily published in Dublin. *The Irish Times* is considered to be Ireland's newspaper of record.

Though formed as a Protestant nationalist paper, within two decades and under new owners it had become the voice of Irish unionism. It is no longer considered a unionist paper; it is generally perceived as being politically liberal and progressive, as well as being centre-right on economic issues.

## ITALY – IL SOLE 24 ORE

*Il Sole 24 Ore* is an Italian daily published in Milan. Italy's reference business daily was founded in 1965 after the merging of *Il Sole* (founded in 1865) and *24 Ore* (1946).

It is the third national daily, with circulation boosted by an increase in publication of non-economy related articles. Its Sunday culture supplement *Domenica* pulls in an intellectual readership that normally shows little interest for economics.

*Il Sole 24 Ore*'s website is more like a portal: in addition to a selection of articles published in the print edition, it features a wide range of services related to the stock exchange and the economy, most of which are subscriber-only.

## POLAND – GAZETA WYBORCZA

*Gazeta Wyborcza* was one of the first independent newspapers, established in 1989, the year when communism collapsed. It was founded as the mouthpiece of the Polish freedom movement Solidarność.

Many of the people who subscribed to *Gazeta Wyborcza* in those times still subscribe to it today. Consequently it is Poland's leading quality newspaper in terms of circulation. It is published by Agora, one of the largest Polish media groups.

## LUXEMBOURG – LUXEMBURGER WORT

*Luxemburger Wort* was founded in 1848 by Bishop Johannes Theodor Laurent, the paper was originally owned by the Catholic church. The paper was founded just three days after press censorship was abolished.

*Luxemburger Wort* is the Grand Duchy's leading daily and is read by 40 percent of the population. The paper is published by Saint-Paul Luxembourg SA group which is majority owned by the archdiocese of Luxembourg. For 42 years the paper was shaped by its director and editor-in-chief Léon Zeches, who resigned in 2010. Articles are printed in German, French and Luxembourgish.

## PORTUGAL – PÚBLICO

*Público* was first published on 5 March 1990. Founded as a joint project by a group of journalists and the investor group Sonae, this liberal paper quickly became a newspaper of reference, particularly among the political class, entrepreneurs and intellectuals. *Público* is published in tabloid format and has its headquarters in Lisbon.

*Público* is one of the first Portuguese mainstream newspapers to have an online edition which was started in 1995. The online edition of Público was named as Europe's online-medium of the year in 2013. The paper was awarded the European Newspaper of the Year in the category of nationwide newspapers by European Newspapers Congress in 2014

## SPAIN – EL PAÍS

*El País* is the world's leading daily newspaper in Spanish and a byword for quality in the field of journalism in the Hispano-American world. It was first published on May 4, 1976, and its founders envisaged it as an independent quality, European-oriented newspaper, and an advocate of multiparty democracy.

Today, the newspaper remains true to its founding principles, while it continues to adapt to the changing times. *El País* can be read today in its print version, on the Internet, in any electronic format and through social networks.

## GLOBAL – THE LANCET

*The Lancet* has a prestigious heritage as one of the world's leading independent medical journals. It is renowned as a major contributor to health and medical research worldwide. When Thomas Wakley founded *The Lancet* in 1823, he announced "A lancet can be an arched window to let in the light or it can be a sharp surgical instrument to cut out the dross and I intend to use it in both senses". This philosophy remains at the heart of the The Lancet today.

## GLOBAL – THE CELL

Founded by Benjamin Lewin (author of Genes), *Cell* remains at the forefront of exciting developments in biology, continually redefining the important areas of science with cutting edge papers.

Published biweekly, *Cell* includes original research articles of exceptional significance in areas including molecular biology, biochemistry, cancer research, cell biology, developmental biology, genetics, immunology, microbiology, neurobiology, plant biology, structural biology and virology.

## EUROPEAN – EUROSCIENTIST

*EuroScientist* is the official publication of the EuroScience organisation and publishes articles, opinions, expert perspectives and curated content on a variety of topics and issues affecting scientists, particularly when it comes to issues arising at the interface with society in Europe, including science policy. The vision is to ensure that *EuroScientist* reflects the diversity of voices of scientists and those working in fields related to science and on matters related to European research. Its motto is: "European science conversations by the community, for the community."


# KNOWLEDGE PARTNERS

The Citizen Engagement and Media Campaign was made possible thanks to the close collaboration with leading organisations and stakeholders working on the issue of chronic diseases. The partners represented the different stakeholders in the debate in supported the editorial team in developing the content and ensuring that this was comprehensive and accurate.

Please find below a detailed list of the knowledge partners:

## ALL EUROPEAN ACADEMIES

*ALLEA,* the federation of All European Academies, was founded in 1994 and currently brings together 57 Academies in more than 40 countries from the Council of Europe region. Member Academies operate as learned societies, think tanks and research performing organisations. They are self- governing communities of leaders of scholarly enquiry across all fields of the natural sciences, the social sciences and the humanities. *ALLEA* therefore provides access to an unparalleled human resource of intellectual excellence, experience and expertise. *ALLEA* is independent from political, commercial and ideological interests.

## ELSEVIER

*Elsevier* is a world-leading provider of information solutions that enhance the performance of science, health, and technology professionals, empowering them to make better decisions, deliver better care, and sometimes make groundbreaking discoveries that advance the boundaries of knowledge and human progress. *Elsevier* provides web-based, digital solutions – among them ScienceDirect, Scopus, Elsevier Research Intelligence and ClinicalKey – and publishes over 2,000 journals, including The Lancet and Cell, and more than 33,000 book titles, including a number of iconic reference works. *Elsevier* is part of RELX Group, a world-leading provider of information and analytics for professional and business customers across industries.

## EUROPEAN ASSOCIATION OF SCIENCE EDITORS

The *European Association of Science Editors* is a non-profit membership organisation for people interested in science communication and editing. Founded in 1982, in France, *EASE* has about 400 members who live in more than 50 countries, not only in Europe but also in other parts of the world. Members work in many disciplines and trades. The association offers the opportunity to stay abreast of trends in the rapidly-changing environment of scientific publishing.

## EUROPEAN JOURNALISM CENTRE

The *European Journalism Centre (EJC)* is an independent, non-profit institute, based in Maastricht, Limburg, The Netherlands. Its aim is to give further training to mid-career journalists and media professionals and says it is dedicated to the highest standards in international as well as European journalism. The institute also acts a partner and organiser at the European level for media companies, professional organisations, journalism schools and government bodies seeking to establish activities and projects.

## EUROPEAN RESPIRATORY SOCIETY ADVOCACY COUNCIL

The *European Respiratory Society (ERS)* is an international organisation that brings together physicians, healthcare professionals, scientists and other experts working in respiratory medicine. It is one of the leading medical organisations in the respiratory field, with a growing membership representing over 140 countries worldwide.

*ERS*'s mission is to promote lung health in order to alleviate suffering from disease and drive standards for respiratory medicine globally. Science, education and advocacy are at the core of everything they do.

## EUROPEAN SCIENCE FOUNDATION

With 40 years' experience in all areas of research, the *European Science Foundation (ESF)* was originally set up to act as a coordinating body for Europe's main research funding and research performing organisations. But as the research landscape has evolved, so has *ESF*'s role in supporting scientific endeavours.

*ESF* is now a services-based organisation that continues to contribute to the European Research Area (ERA). It is building on core strengths developed in peer review, evaluation and project management services and continues to host five Expert Boards and Committees that provide in-depth and focused scientific expertise in selected disciplines.

## EUROSCIENCE

*EuroScience* is the non-profit grassroots association of researchers in Europe. Open to European researchers across disciplines and countries, *EuroScience* undertakes to advance science and innovation in Europe, thereby promoting the interests of its thousands of members. From its inception in 1997, *EuroScience* has been active in shaping policies for science, technology and innovation (STI), from the discussions leading to the European Charter and Code for Researchers, establishing the ERC, or the shaping of Horizon 2020 and its budget in the EU Financial Framework 2014-2020. *EuroScience* also plays a key role in RRI Tools, a major project on Responsible Research and Innovation.

## GERMAN RESEARCH CENTRE FOR SCIENCE & INNOVATION COMMUNICATION

The *German Research Centre for Science & Innovation Communication (INNOCOMM)* investigates and develops solutions for internal and external communication both in research and innovation processes of companies and academic institutions. We focus on teh diffusion of research results in markets and society.

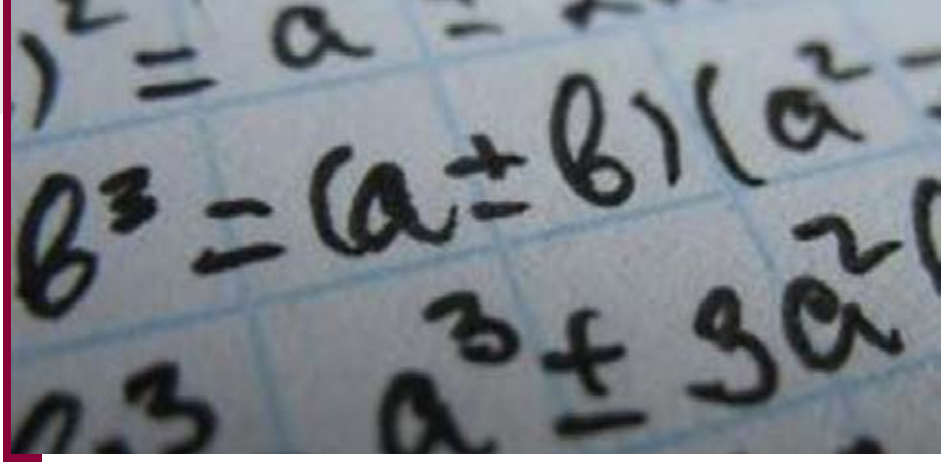
The Research Center profits from an inter- and transdisciplinary think-tank in the form of a scientific Board of Trustees, consisting of nine academic institutions so far. Innocomm is constructed as a network and mainly virtual enterprise in the so-called third sector (besides the for-profit and the non-profit sectors).

## INTERNATIONAL COMMUNICATION ASSOCIATION

The *International Communication Association (ICA)* is an academic association for scholars interested in the study, teaching, and application of all aspects of human and mediated communication. *ICA* began more than 50 years ago as a small association of U.S. researchers and is now a truly international association with more than 4,500 members in 80 countries. Since 2003, *ICA* has been officially associated with the United Nations as a non-governmental association (NGO).

## INTERNATIONAL DIABETES FEDERATION EUROPE

The *International Diabetes Federation (IDF)* is an umbrella organization of over 230 national diabetes associations in 170 countries and territories. It represents the interests of the growing number of people with diabetes and those at risk. The Federation has been leading the global diabetes community since 1950. The Federation's activities aim to influence policy, increase public awareness and encourage health improvement, promote the exchange of high-quality information about diabetes, and provide education for people with diabetes and their healthcare providers. *IDF* is associated with the Department of Public Information of the United Nations and is in official relations with the World Health Organization (WHO) and the Pan American Health Organization (PAHO).



## KAROLINSKA INSTITUTET

Founded in 1810, *Karolinska Institutet* is a medical university in Solna within the Stockholm urban area, Sweden, and one of the largest and most prestigious medical universities in the world. The vision of the university is to make a significant contribution to the improvement of human health; its mission is to conduct research and education and to interact with the community. Since 1901 the Nobel Assembly at *Karolinska Institutet* has selected the Nobel laureates in Physiology or Medicine.

## LEAGUE OF EUROPEAN RESEARCH UNIVERSITIES

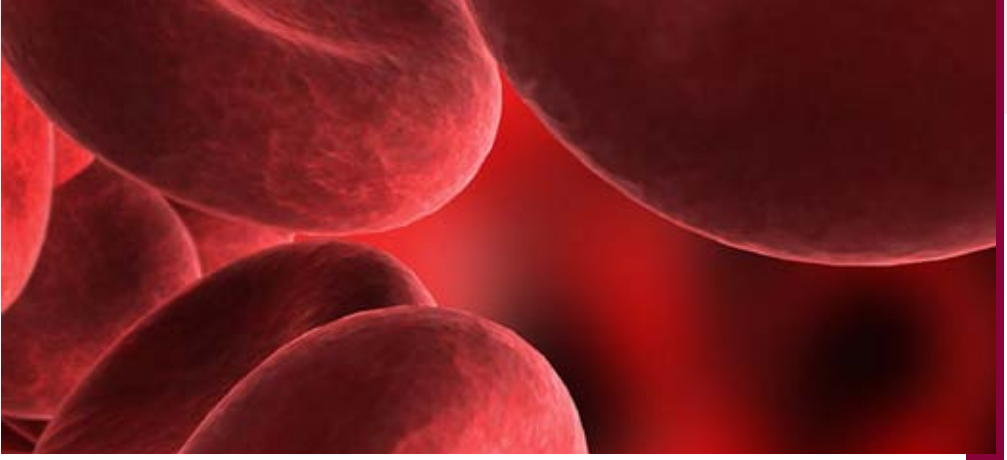
The *League of European Research Universities (LERU)* is a consortium of some of the most renowned research universities in Europe. Founded in 2002, as a partnership of 12 leading multi-faculty research universities, it expanded its membership to 21 universities in 2010. *LERU* has emerged as a prominent advocate for the promotion of basic research at European universities. *LERU* strongly believes that basic research plays an essential role in the innovation process and significantly contributes to the progress of society.

## LONDON SCHOOL OF ECONOMICS

The *London School of Economics and Political Science (LSE)* is one of the foremost social science universities in the world. *LSE* is a specialist university with an international intake and a global reach. Its research and teaching span the full breadth of the social sciences, from economics, politics and law to sociology, anthropology, accounting and finance. Founded in 1895, the School has an outstanding reputation for academic excellence. 16 Nobel prize winners have been *LSE* staff or alumni.

## MENDELEY

*Mendeley* is a desktop and web program for managing and sharing research papers, discovering research data and collaborating online. It was founded in November 2007 by three German PhD students and is based in London and has today over 3 million users. It combines Mendeley Desktop, a PDF and reference management application and Mendeley for Android and iOS, with Mendeley Web, an online social network for researchers. *Mendeley* was purchased by the Elsevier publishing company in 2013.



## OpenAIRE

*OpenAIRE* supports the implementation of Open Access in Europe. It provides the means to promote and realize the widespread adoption of the Open Access Policy, as set out by the ERC Scientific Council Guidelines for Open Access and the Open Access pilot launched by the European Commission.

Funded under FP7 *OpenAIRE* has built the *OpenAIRE* portal and e-Infrastructure for the repository networks and explores scientific data management services together with 5 disciplinary communities. It provides a repository facility for researchers who do not have access to an institutional or discipline-specific repository.

## SCIENCEDIRECT

*ScienceDirect* is a leading full-text scientific database offering journal articles and book chapters from over 3,500 journals and more than 34,000 books. It is operated by the Anglo-Dutch publisher Elsevier. It was launched in March 1997.

## SWEDISH RESEARCH COUNCIL

The *Swedish Research Council* is an authority within the Ministry of Education and Research. The *Swedish Research Council* has a leading role in developing Swedish research of the highest scientific quality, thereby contributing to the development of society.

Besides research funding, the agency advises the government on research-related issues and participates actively in the discussions to create understanding of the long-term benefits of research.

## THE STANDING COMMITTEE OF EUROPEAN DOCTORS

*The Standing Committee of European Doctors (CPME)* is a medical organization representing all medical doctors in the European Union. *CPME* aims to promote the highest standards of medical training and medical practice in order to achieve the highest quality of health care for all patients in Europe.

## THE SWEDISH RESEARCH COUNCIL FOR HEALTH, WORKING LIFE

*The Swedish Research Council for Health, Working Life (Forskningsrådet för arbetsliv, hälsa och välfärd, Forte)* supports and initiates basic and needs-based research within the fields of health, working life and welfare. Forte's operations build on our vision of a more equal, inclusive and sustainable society. To achieve this vision we work strategically at all levels. Here you can take part of *Forte*'s vision and strategies for 2015-2018.

## UK SCIENCE MEDIA CENTRE

The *Science Media Centre* has its roots in the influential House of Lords Science and Technology Select Committee third report on Science and Society, which wanted to renew public trust in science. Established in 2002, it was originally based in the Royal Institution of Great Britain, until becoming a separate charity in its own right in April 2011. The Centre is now housed in the Wellcome Collection, and believes that scientists can have a huge impact on the way the media cover scientific issues, by engaging more quickly and more effectively with the stories that are influencing public debate and attitudes to science.

The SMC's philosophy is: "The media will DO science better when scientists DO the media better."

## VETENSKAP I ALLMANHET

*Vetenskap & Allmänhet*, (Swedish: "Public & Science") (VA) is a Swedish non-profit membership organisation that works to promote dialogue and openness between researchers and the public. The organisation was founded in 2002 and is based in Stockholm, Sweden. *VA*'s members consist of some 80 organisations, authorities, universities, companies and associations. In addition, it has a number of individual members.

## WISSENSCHAFT IM DIALOG (SCIENCE IN DIALOGUE)

*Wissenschaft im Dialog (Science in Dialogue, WiD)* promotes discussion and exchange about research in Germany. *WiD* organises dialogue events, exhibitions and competitions, as well as developing new formats for science communication. Wissenschaft im Dialog was founded in 1999 on the initiative of the Stifterverband für die Deutsche Wissenschaft and has the backing of all major scientific organisations in Germany and partnerships with a number of philanthropic foundations. Many *WiD* projects receive support from the German Federal Ministry of Education and Research.

# COMMITTEES

The *Citizen Engagement and Media Campaign on Chronic Diseases* required two characteristics to be fulfilled in order to be seen as trustworthy and reliable and therefore a success:

- Firstly, the scientific validity of the information presented and the questions asked had to be ensured. The campaign had to present the most relevant information from an interdisciplinary and intersectoral perspective whilst ensuring that there was no bias built into the content.
- Secondly, the editorial content had to be independent, relevant and represent the interest of the citizens.

In order to ensure the two above conditions be met, two committees where set-up to support the editorial team when developing the content and drafting the questions: an Editorial Committee and a Scientific Committee.

The **Editorial Committee** aimed to support the editing team by highlighting the priority and key questions of interest to their diverse readership. They also ensured the independence and authoritativeness of the information presented and the questions developed for the campaign.

The members of the Editorial Committee represents the media partners of the initiative that come from different countries, backgrounds and political orientations.

The **Scientific Committee** represented the different areas of expertise of the scientific community around chronic diseases. It comprised experts across the selected discipline that served to guide and to provide insight to the development of the content and questions of the campaign.

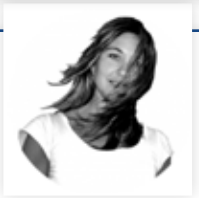
The members of the Scientific Committee were selected with the help and support of the knowledge partners of the campaign.

# THE EDITORIAL COMMITTEE

### *Dick Ahlstrom*

***Science Editor of* The Irish Times**

Dick Ahlstrom is science editor of The Irish Times, Ireland's leading daily newspaper. He provides news reportage for the newspaper and also edits the weekly Thursday science page, Life Science. He holds a BA degree from Temple University, Philadelphia and an MA in Anglo Irish Literature from University College Dublin.



### *Francesca Cerati*

***Science Editor of Sole24ore***

Francesca Cerati is Science Editor at Il Sole24Ore. She has a degree in pharmaceutical studies from the University of Milan and has worked as a science journalist and expert in scientific communication for nearly twenty years.

### *Patricia Fernandez de Lis*

***Editor in Chief of Science and Technology of El País***

Patricia Fernandez de Lis has been working for over 15 years as a journalist, covering the economy, science, and technology. She is the Editor in Chief of Science and Technology of El País and a Lecturer on the Master's degree in Communication of Science, Technology and the Environment at the University Carlos III Madrid.

### *Dorian de Meeûs*

***Science Editor of La Libre Belgique***

Dorian de Meeûs is the online Editor in Chief at Belgian daily newspaper La Libre Belgique (LaLibre.be). He is a visiting professor at IHECS and a graduated from the Université Libre de Bruxelles.

### *Teresa Firmino*

***Science Editor of Público***

Teresa Firmino is Science Editor in Chief at Portuguese daily newspaper Público. She holds a Degree in Social Communication from Lisbon New University and was a Knight Science Journalism fellow at Massachusetts Institute of Technology (MIT).

### Christophe Langenbrink

***Science Editor of Luxemburger Wort***

Christopher Lagenbrink is Editor in Chief of the Luxemburger Wort, with responsibility for the daily management of the newspaper, including coordinating its main themes and supplements. He has an MBA and a master in Political Science from Universität des Saarlandes.

### Sabine Louët

***Science Editor of EuroScientist***

Sabine Louët is a media entrepreneur and an experience science communicator, science journalist, editor and consultant based in Dublin, Ireland. She is the Editor of EuroScientist and was previously News Editor for the international peer-reviewed journal Nature Biotechnology. In 2014, she founded SciencePOD, an open access platform for science communication.

### Joachim Mueller Jung

***Science Editor of Frankfurter Allgemeine Zeitung***

Joachim Mueller-Jung is Chief Science Editor of Frankfurter Allgemeine Zeitung, a national German daily newspaper. He joined in 1995 and took responsibility for the science department "Natur und Wissenschaft" in 2003. His had a journalism training at the "Kölnische Rundschau" in Cologne after graduating in Biology in Heidelberg, Cologne.

### Iwona Pawluk

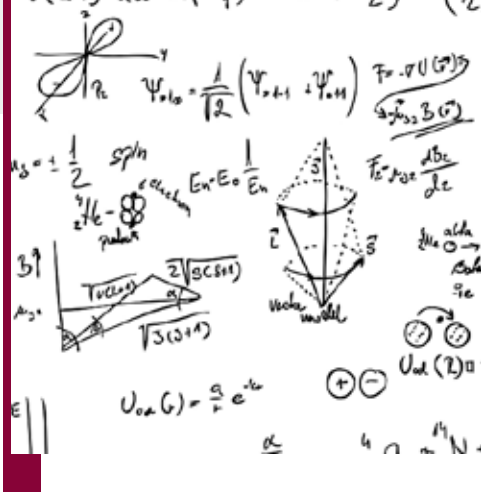
***Science Editor of Gazeta Wyborcza***

Iwona Pawluk is Editor and Coordinator of Social Campaigns at Gazeta Wyborcza, the biggest opinion-making daily newspaper in Poland. Graduated from Warsaw University, she holds a Master in Iberian Studies. She has been responsible for many campaigns, among them: Magic Roads, two Polish editions of Editors Lab Hackdays and City Labs.

### Klaus Taschwer

***Science Editor of Der Standard***

Klaus Taschwer is science editor of the Austrian daily newspaper Der Standard. He was trained in sociology, political science and social studies of science. Klaus co-founded a course-programme on communicating science and authored books on the history of Austrian science in the 20th century.



# THE SCIENTIFIC COMMITTEE

### *Prof. Elias Mossialos*

***Brian Abel-Smith Professor of Health Policy, London School of Economics and Political Science (LSE), and Director of LSE Health***

Elias Mossialos is Brian Abel-Smith Professor of Health Policy within the Department of Social Policy at the London School of Economics and Political Science (LSE), and Director of LSE Health. His research interests concentrate on health policy relating to health care systems, and he is the author of more than 200 articles.

### *Boris Azaïs*

***MSD, Director, Public Policy Europe Canada***

Boris Azaïs is currently Director, Public Policy Europe Canada for MSD (a subsidiary of Merck & Co., Inc.). In this capacity, Boris Azaïs interacts with policy makers to promote greater patient access to pharmaceutical innovation. He is a member of the Advisory Board of Pharmaceutical Executive and has participated in working groups of the World Economic Forum and of the Global Health Policy Summit.

### *Renata Briano*

***Member of the European Parliament, Member of the STOA Panel***

Renata Briano is a Member of the European Parliament since July 2014. She sits in the STOA panel and is Vice-Chair of the Fisheries Committee and of the "Biodiversity, hunting and countryside" intergroup. She is graduated in natural sciences and worked as Researcher at the Institute for Educational Technology CNR in Italy.

### *Prof. Jan Eggermont*

***Vice-dean of the Faculty of Medicine at the University of Leuven***

Jan Eggermont is vice-dean of the Faculty of Medicine at the University of Leuven. He is faculty member of the University of Leuven since 1992. His research interests revolve around cell physiology. He is a member of the League of European Research Universities.

### *Dr. Jacques de Haller*

***President of the Standing Committee of European Doctors/Comité Permanent des Médecins Européens***

Dr. Jacques de Haller is also CPME Rapporteur on Self-care, Integrated Care, Physicians' Health and Mental Health. He worked as a GP in Geneva for 21 years and served as President of the Swiss Association of General Practitioners and of the Swiss National Medical Association.

### *Prof. Christina Gratziou*

***Chair of the European Respiratory Society Advocacy Council***

Professor Christina Gratziou is Chair of Advocacy Council of ERS, Professor of Pulmonary Medicine, Medical School of Athens University and Head of University Respiratory Unit , Asthma and Allergy Center. She has lectured and taught extensively on lung diseases and is an expert on smoking prevention and smoking cessation.

### *Prof. Günter Stock*

***President of ALL European Academies***

Professor Günter Stock has been serving as ALLEA President since 2012. A physiologist by training, he has held many positions in the field of academia. He has been involved in the production of over 370 scientific and science-policy papers as well as in the creation of several patents in the medical field.

### *Prof. Massimo Massi Benedetti*

***President, Hub for International Health Research, Former President IDF Europe***

Massimo Massi-Benedetti, former Associate Professor of Endocrinology and Metabolic Diseases at the University of Perugia, is President and Scientific Director of the HUB for International health ReSearch-HIRS and Co-director of the WHO Collaborating Centre for Improvement of Diabetes Care. He is the author of approximately 350 publications.

### *Dr. David Smith*

***Royal College of Surgeons in Ireland***

David Smith is Associate Professor of Health Care Ethics in Royal College of Surgeons in Ireland and Director of the MSc in Health Care Ethics and Law. He lectures in a number of Irish Universities and is an Ethics Consultant to a number of Healthcare Systems and Professional Bodies in Ireland.

### *Prof. Carl Johan Sundberg*

***Karolinska Institutet***

Carl Johan Sundberg is a licensed physician and professor at Karolinska Institutet where his research is focused on human genetics, genomics and epigenetics in relation to physical activity. Carl Johan was for a decade the vice-president of Euroscience and the initiator of Euroscience Open Forum.

# 3 - OUTCOMES

*"Citizens have a right—and are expected—to be involved in the crucial decisions of what their futures will look like and how science and technology can contribute to its betterment."*

*The European Commission*

The challenges that changing demographics, individual behaviour, economic conditions and environment will put on Europe's already frail healthcare system is one of the big societal challenges facing European society in the decades to come.

Within this broader discussion the impact of chronic diseases, or, more exactly, non-communicable chronic diseases (NCDs), responsible for over 86% of death in Europe, affecting over 80% of people over 65 and responsible for nearly 80% of the health budget in the EU, cannot be underestimated.

Solutions to this challenge will require policy makers, scientists, practitioners, industry, civil society organization and citizens to work together to find innovative and creative solutions.

This topic was therefore chosen to be the focus of the first Citizen Engagement and Media Campaign to be launched by REIsearch. In February and March 2016 the European Institute for Science, Media & Democracy (EISMD) worked together with 12 media partners and 34 knowledge partners reaching together over two million researchers, thousands of practitioners and over 8 million citizens (over 60 million unique users if counting online platforms).

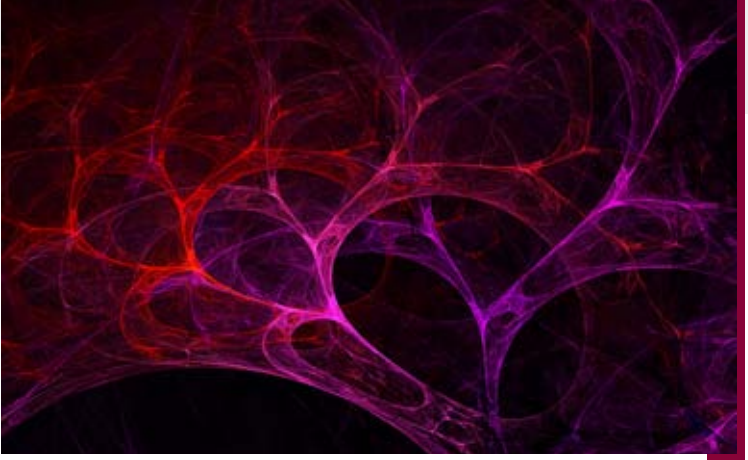
## AIM

The aim of the campaign was threefold:

1) To create awareness about the launch of REIsearch and the potential of this platform;

2) To start a public debate on the topic of chronic disease that brought together the interest and expertise of the different stakeholders;

3) Collect and analyse the opinions of the different actors to better understand the opinions and suggestions of the different stakeholders across Europe.



**From the Forum**

I take we know the measures against chronic diseases.Now **the challenge is to repeat the message often and regularly.** Would I listen to a fancy marketing campaign? No. Would I listen to a politician telling me what to do? No. I would probably listen to my peers (many ways on how to define those). **Hence the task for politicians in my mind would be to start some sort of public engagement.** Could be formal health clubs and the reward be something like recognition (but certainly not money).

## REACH

The campaign was run in 7 languages and saw the publication of over 70 articles on the paper and online versions of the media partners as well as thousands of tweets and social media entries.

The campaign was built on three types of media platforms: traditional media (through the collaboration of leading national newspapers), science media (through the collaboration of science publications and partners), social media (through the collaboration of all partners on twitter and facebook).

The campaign ran for 5 weeks with a different sub-topic debated each week. The subtopics where chosen based on three criteria (policy timeliness, scientific interest, public interest) and were selected after a careful analysis and collaboration with the knowledge partners. In order to get more data to assess the methodology of REIsearch 5 very different topics were chosen: one more general on the issue (Prevention), one related to technology (new technologies and innovation), one on a moral question (citizens rights and responsibilities), one on a specific disease (diabetes and nutrition) and lastly a more technical and very current debate (more and better data).

Each week the same protocol followed in order to be able to analyse how different actors responded to the different topics with the format described in chapter 2.

**From the Forum**

**Listen to the patients,** every step of the way. Get them involved on the various levels in your organisation, ad hoc or continuously.

Policy makers should get proper training on grades of **evidence (of scientific research)** and interpretation

## PARTICIPATION

In less then five weeks the campaign saw the access to the survey of nearly 60 000 users and the completion of the survey of nearly 18 000 European citizens with the highest participation coming form the German and Spanish-speaking countries (Graph 1.1).

It is interesting to view which topics where more popular among which language-groups (graph 1.2). Overall the campaign saw more than one third of the participants were Spanish-speaking (mostly from Spain) with nearly another one third being German-speaking (mostly from Austria, Germany and Luxembourg) and the other language groups making up the remaining 30% of participants. It is important to note that there was no traditional media partner in France and in the UK that clearly affected the participation of the English and French-speaking countries.

This is particularly true as when analysing the results it is clear that the majority of participants were connected to the initiative through the traditional media partners as opposed to the social media campaign.

The German-speaking participants dominated the debates on "Prevention", "New Technologies and Innovation", "Diabetes and Nutrition" and "More and Better Data". Whilst the week on "Citizen Rights and Responsibilities" saw a surge in Spanish-speaking participants with nearly fifteen thousand respondents only from Spain sparking over one thousand comments on the forums and social media platforms.

Seeing that the methodology was the same for each week this says a lot about the interests of different countries across Europe and that the sensibilities are very different.

Overall there was a higher participation of men than women during the campaign (graph 1.3), however this varied significantly from week to week and country to country with participation from Polish and Portuguese-speaking participants being mainly female. The biggest variation was seen during the week on "more and better data" where nearly 70% of participants were male.

The age distribution remained quite constant throughout the campaign with a majority of participants being between the ages of 36-65 (graph 1.4). This is not surprising seeing the readership of the media partners involved in the initiative.

Also the education level of participants remained high above the EU average with over 80% of participants having a tertiary degree or more compared to the 40% EU average (graph 1.5). This is also unsurprising if comparing to the readership of the media and knowledge partners of the initiative. In fact on average 12% of respondents were researchers ensuring a significant participation from researchers thanks to the support of the knowledge partners and the science-oriented media partners.

Detailed results are analysed in the coming chapters.

# RESULTS

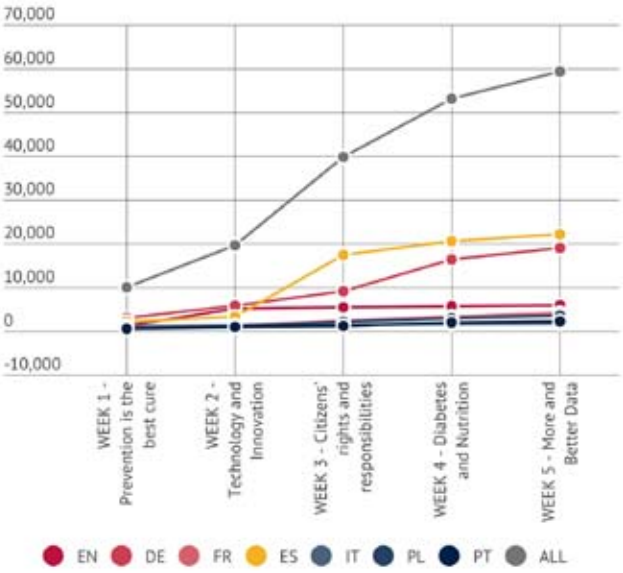
GRAPH 1.1

## Citizen Engagement and Media Campaign on Chronic Diseases

OVERALL PARTICIPATION

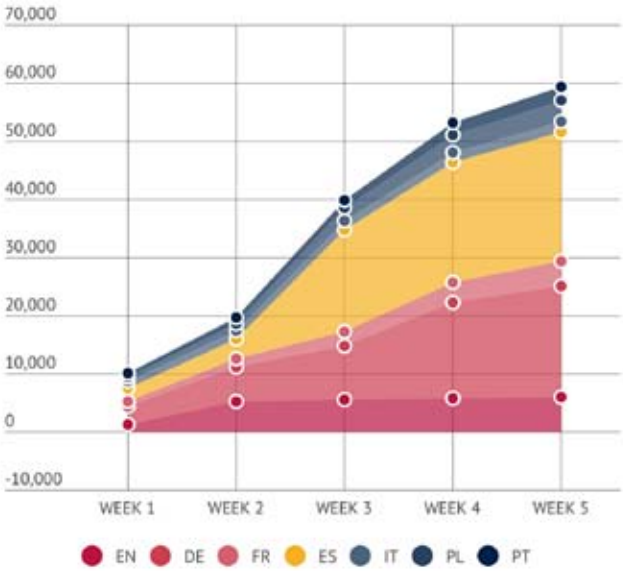
### 1.1.1 total access to campaign by language

(line graph)



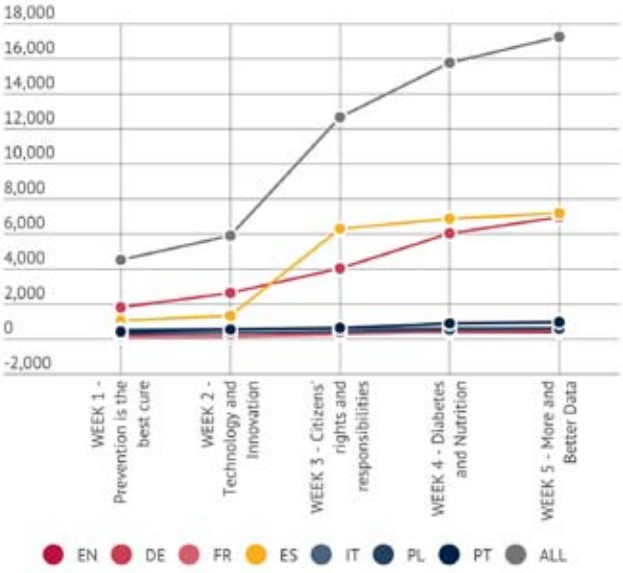

### 1.1.2 total access to campaign by language

(stacked area chart)




### 1.1.3 total responses to survey by language

(line graph)



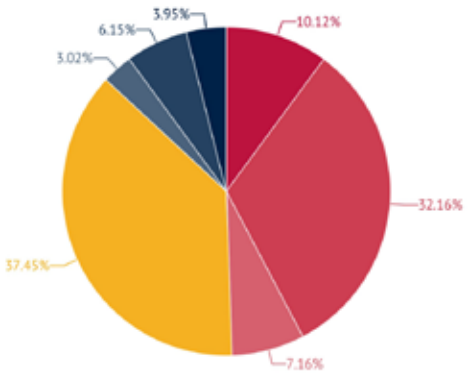

### 1.1.4 total responses to survey by language

(stacked area chart)

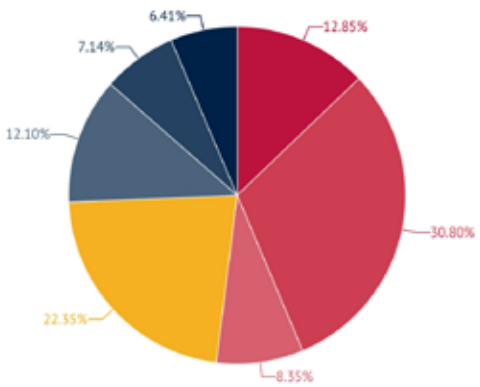
GRAPH 1.2

# Participation distribution by week and language

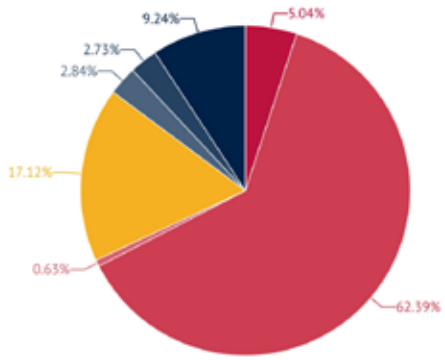
## 1.2.1 overall language distribution



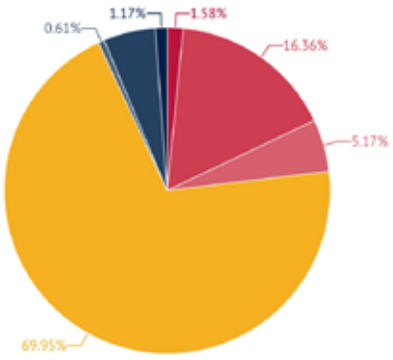

## 1.2.2 WEEK1 - Prevention



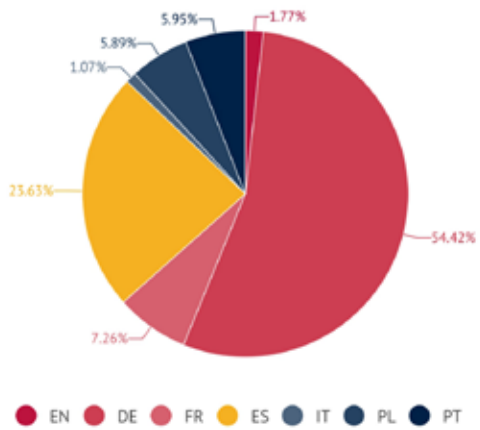

## 1.2.3 WEEK 2 - New Technologies and Innovation



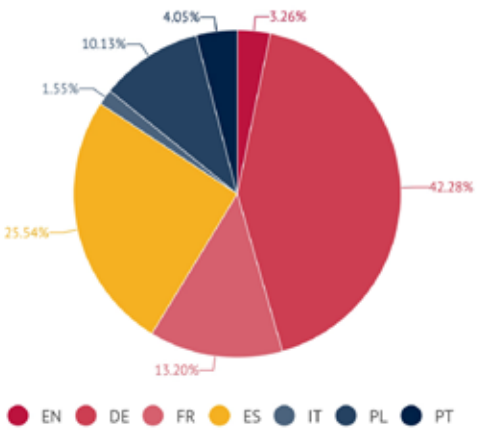

## 1.2.4 WEEK 3- Citizen's Rights and Responsibilities




## 1.2.5 WEEK 4 - Diabetes and Nutrition



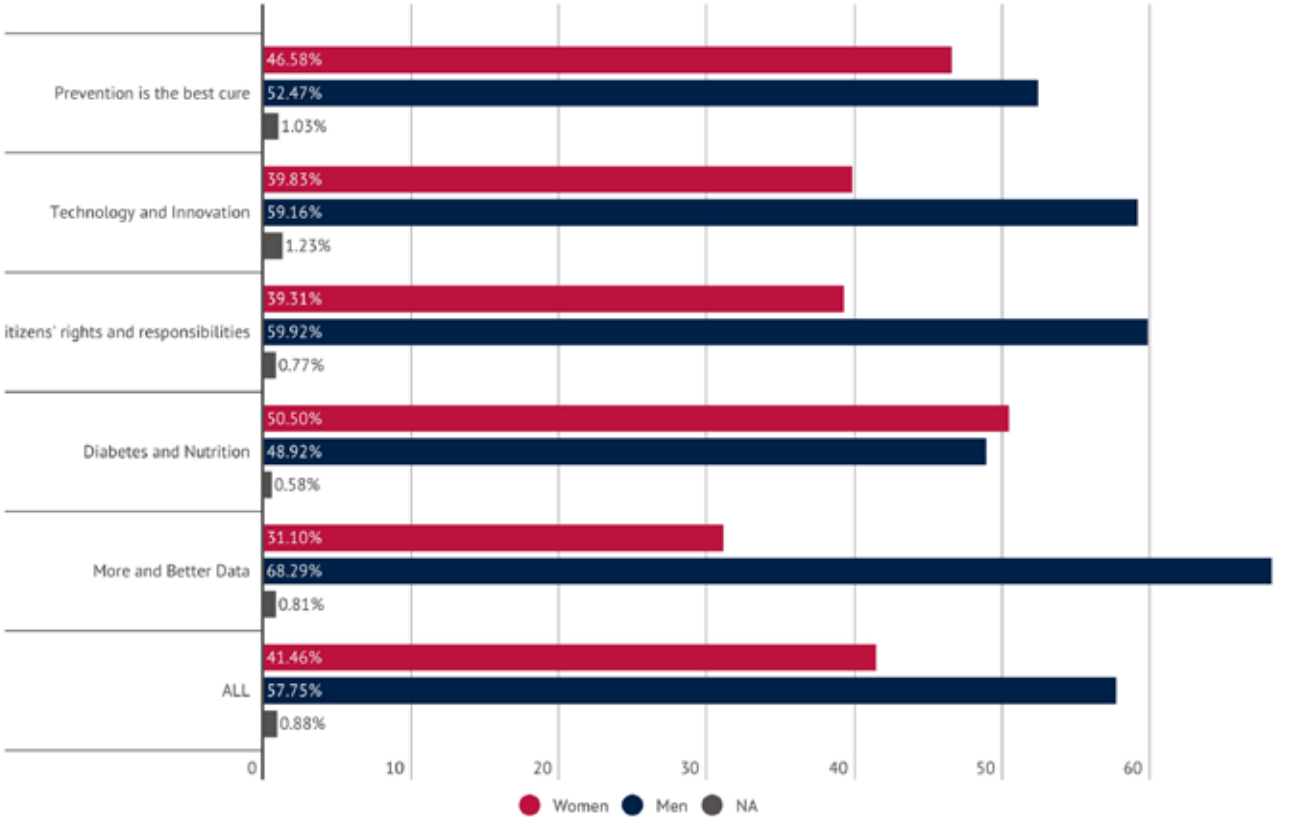

## 1.2.6 WEEK 5 - More and Better Data

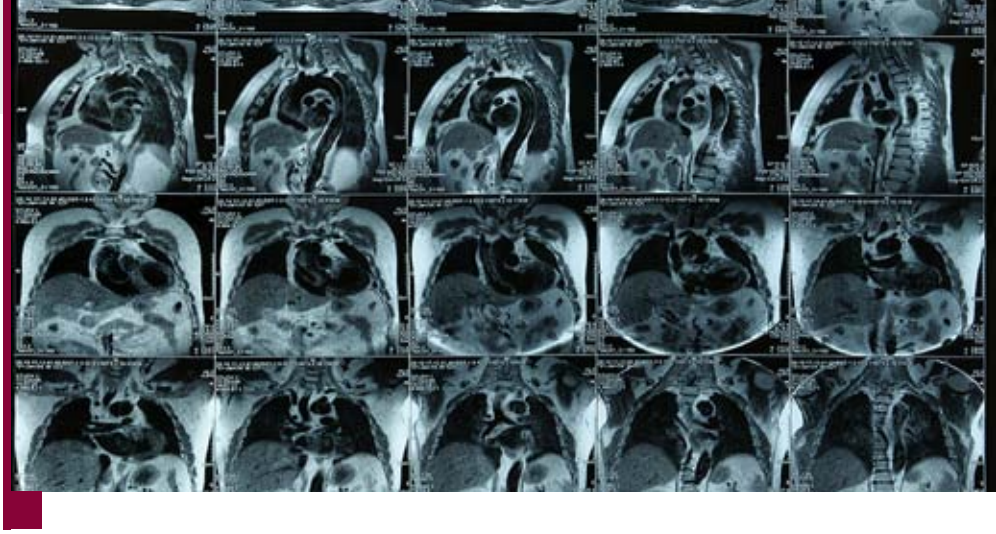


GRAPH 1.3

## Overall Participation by Gender

distribution by week

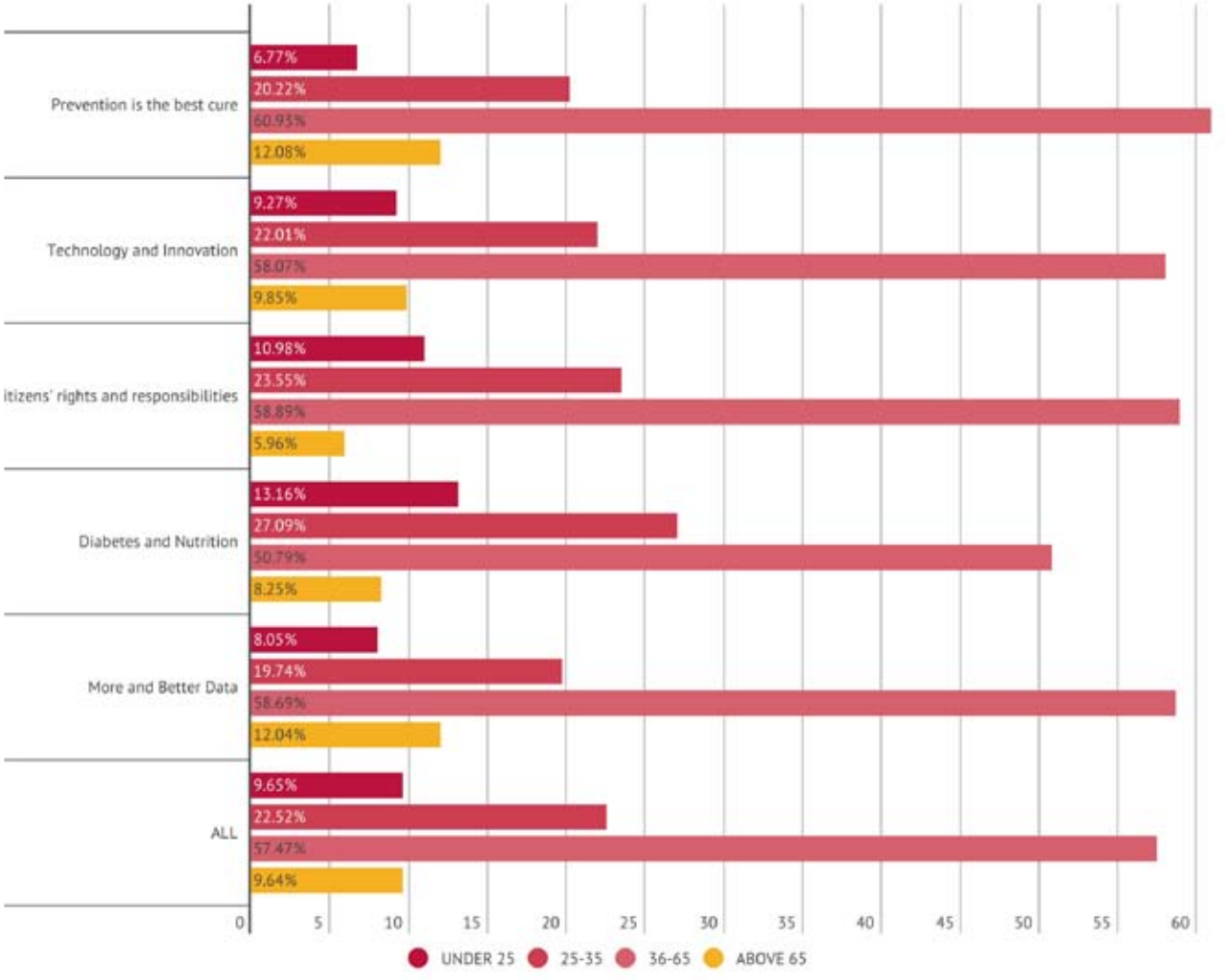




GRAPH 1.4

## Overall Participation by Age

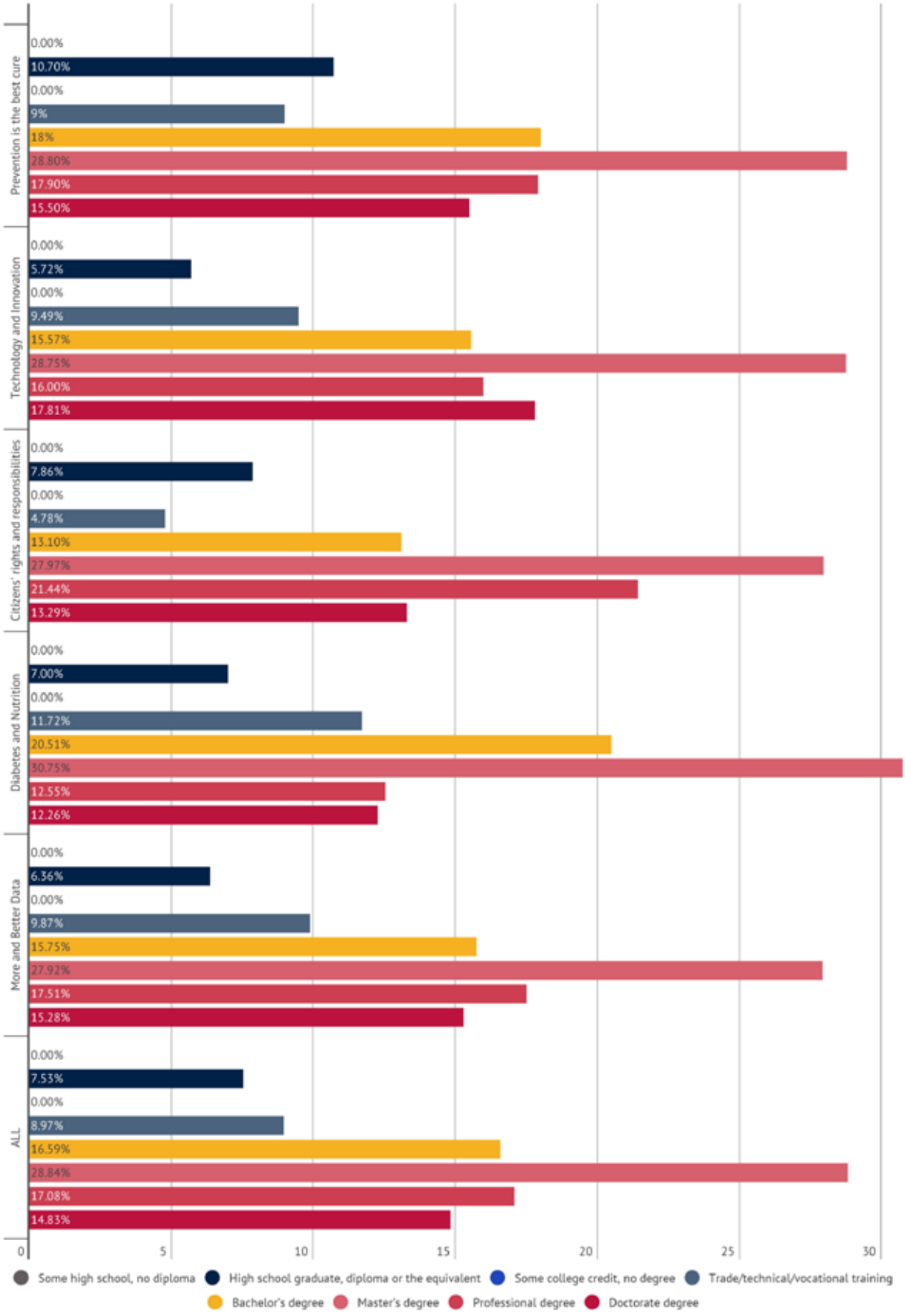
distribution by week

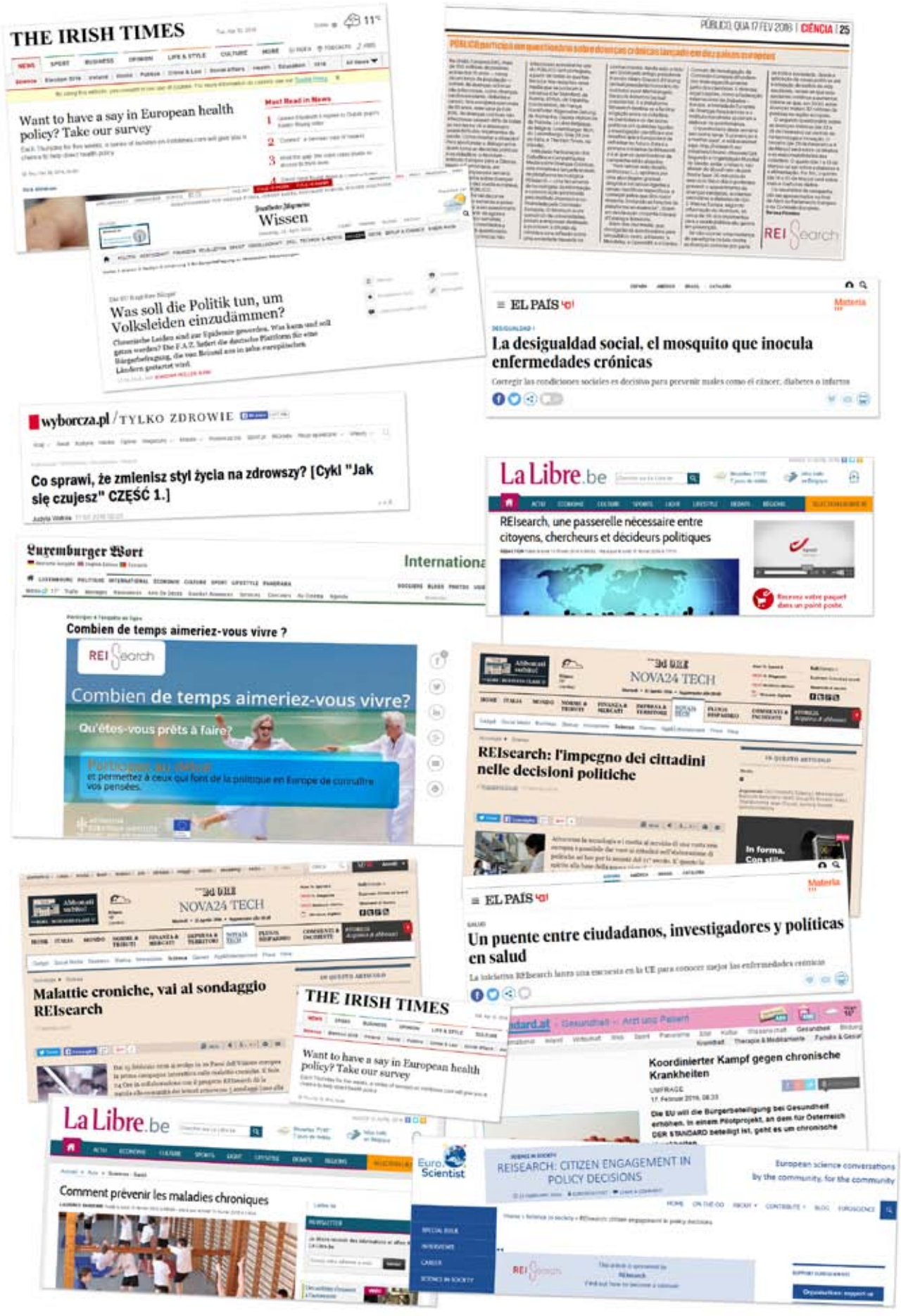


GRAPH 1.5

# Overall Participation by Education Level

distribution by week






These are the headlines of some of the articles published during the week on "Prevention is the Better Cure" of the Citizen Engagement and Media Campaign on Chronic Diseases.

# WEEK 1 – PREVENTION IS THE BETTER CURE

## OVERVIEW

In February 2016 *the Citizen Engagement and Media Campaign on Chronic Diseases* was launched by starting a discussion on "prevention". In Europe, NCDs affect today around one third of people above the age of 15 - over 100 million people - and 80% of people aged over 65 (WHO, 2010), and are responsible for nearly 80% of the health budgets. They are responsible for the 86% of all deaths in Europe and are the cause of long-term disability and loss of working years for many.

While the NCD epidemic continues to grow, health research has shown that many NCDs are in fact reversible or preventable. According to the World Health Organisation, avoiding cigarettes, alcohol abuse and junk food and making 30 minutes of physical exercise each day, could prevent up to the 80% of new heart disease, stroke, and type 2 diabetes cases. So why is this not being done? How can we encourage healthy habits and prevent NCDs from arising?

During the week of the 15th of February 2016 the media and knowledge partners of the campaign launched a debate on the importance of prevention to combat the increase of NCDs. The aim of the campaign was twofold: to increase awareness of the importance of preventive measures on the spread on NCDs, and; to start a public debate on this issues to understand the opinions and suggestions of a variety of different actors – including citizens – on this topic.

Participants from over ten countries joined the debate with 12 media partners publishing together 24 articles in seven different languages to raise awareness and invite people to join the debate. This was coupled with a social media campaign that engaged participants through twitter and facebook. All the articles are available in the annex to this report.

The campaign received a very warm welcome with several participants pointing out the need for increased dialogue between different actors and stakeholders in particular citizens still feel left out of the conversation.

**From the Forum**

First of all, as both a 'simple' citizen and a chronic pain patient, i'd like to be considered as a person with a functional mind, that is with my actual abilities to understand, learn and discuss with researchers, policy makers, and more generally medical professionals. There is still a gap there, as well as a lot of the old ill-founded attitude that patients are somehow unable to be part of a real exchange. The increasing ability of citizens and patients to access all kind of information is sometimes perceived as a threat, or quickly labelled as 'inadequate' or biased, to the point that even doctors may fall 'out of grace' when they become patients themselves.

Some current trendy concepts such as 'multidisciplinary approach' and 'patient as partner' are still far from being part of reality in many situations. I therefore invite researchers, policy makers and the medical professionals to walk their talk, so to speak...

During the first week of activity, the distribution of participants represented more or less the readership of the media partners engaged highlighting the important contribution of the traditional media in reaching out. Gender participation was quite balanced overall but with a slightly more men participating from the Italian and French speaking countries and where Polish and Portuguese participants where around 70% women (graph 2.1.2).

Nearly 60% of participants were between 36-65 years old. The "under 25" and the "over 65" were under represented. Compared to average levels of education among the European population the participants proved to be relatively more well educated that also reflects the statistics of the readership of the media partners involved. In fact over 80% had a tertiary degree or more compared to the 40% EU average.

It is interesting to note that the responses to the questions do not vary significantly if dissected by language, gender or education levels. 80% of participants strongly agreed or agreed with the statement that "healthy citizens are the greatest asset any country can have" with less than 4% disagreeing. This was marginally more so in by the French speaking participants but not significant enough (5%).

It is clear that across Europe there is also a similar understanding of the causes of chronic diseases *where smoking, lack of physical activity and eating junk food* where rated as main causes of non-communicable diseases with *air pollution* and *genetic pre-disposition* following and *drinking even small amounts of alcohol* was seen as the least significant (graph 2.3).

The awareness of the respondents of the negative impact of bad individual behaviour can be noticed across the whole campaign. In fact when asked to say which actor has the biggest role to play in promoting healthy behaviours *schools (81.7%)* where seen as the most important actors followed by *citizens (73.2%)*, *the Media (68.5%) and healthcare providers (57.5%)*. Less than one third of respondents felt that *businesses* has an important role to play with *civil society organisations (42.3%)* and *researchers (43.4%)* also seen as having a smaller role (graph 2.7).

**From the Forum**

Provide children with access to healthy food (school / kindergarten) & educate them about what is healthy to eat (e.g. prepare a meal together at school etc).

Further, when asked what they where most interested in finding out more about over half of the respondents selected *behavioural risk factors* and *citizen lifestyle behaviours* underlining the interest that people have in getting more information about the effects of their behaviour (graph 2.8); only 12.3% where interested in knowing about *value for money.*

In fact when asked what they thought were the most important measures for preventing chronic diseases over 20% selected *improve awareness*, followed by *increase investment in research* and *design cities and workplaces in a way that facilitates healthy lifestyles* (graph 2.5).

The importance of education, awareness and city design shows an understanding of the complexity of addressing the question of combatting chronic diseases. The participants clearly did not feel that this is something that is only of responsibility of the healthcare sector. In fact when asked if they agreed with Dr Margaret Chan's, Secretary General of the World Health Organisation, statement that "all ministers should be health ministers" over 85% of respondents agreed. Only the French-speaking respondents had over 30% disagreeing with the statement whilst the average was around 8%.

# BACKGROUND

*"Healthy citizens are the greatest asset any country can have"*

*Sir Winston Churchill*

Chronic non-communicable diseases (NCDs) represent a very complex challenge, which needs to be faced in a holistic way, taking an inter-sectoral approach and building on both the knowledge developed globally by researchers with different disciplinary backgrounds and on the experience and knowhow of businesses, civil society organisations, affected people and their families.

Changing patterns of diseases, socio-demographic transitions, emerging technologies, evolving models of care, changing expectations of citizens and changes in the political and economic environment (globalisation, economic constraints) are all challenges that require new thinking and approaches.

It is often noticed that only around the 3% of EU public health budget is spent in prevention, and that citizens often lack the information and the infrastructures necessary to take healthy choices. Improving health education over the life course is of course key to slowing or stopping the NCD epidemic. But is this a responsibility of the public sector or the individual citizen? Is the health sector the only sector concerned? What is the role of the private sector and civil society organisations?

The current situation has precipitated the need to redefine the European healthcare system to suit the needs and challenges of the 21st century. In the light of the changes that will be necessary for the coming decades the debates needs to shift the paradigm. In order to address behaviour modification across the value chain, different approaches and thinking are needed.

Firstly, it is necessary to break the silos between different departments and levels of government. As Dr. Margaret Chan, Director General of the World Health Organisation states "All ministers are health ministers".

Health policies need to become transversal to every policy, from industrial policy to agriculture, from research and education to employment: we won't tackle entrenched societal challenges such as NCDs unless we adopt a holistic approach.

Research also shows that education is fundamental. According to a study led by the Commission's Joint Research Centre (JRC), all the 28 EU Member States have policy guidelines for school food even though they still differ widely and we are still far for having a clear standard on healthy nutrition for children.

### ROLE OF CITIES IN ENCOURAGING HEALTHY LIFESTYLES

According to the United Nations, nearly all global population growth from 2016 to 2030 will be absorbed by cities, and particularly in developing countries, with about 1.1 billion new urbanites over the next 14 years.

Recent studies have shown that there is a correlation between NCDs and urbanisation, with city residents more likely to smoke and to show higher levels of blood pressure, and less likely to be involved in any physical activity. This correlation is particularly striking in the case of diabetes, to the extent that experts started to talk about a specific "urban diabetes challenge".

According to International Diabetes Federation (IDF), "today, nearly two thirds of the 382 million people with diabetes live in cities. If this trend continues, by 2035 as many as half a billion people will have diabetes" – nearly all of them in cities. Working in a synergic way to understand what are the cultural and social factors driving or preventing NCDs across different cities, and using this knowledge to design streets and buildings to encourage movement and healthy habits, is key to stop the NCDs diseases pandemics.

Another key aspect will be to better align public and private interests to achieve positive economic and social impact, as highlighted by an increasing number of scholars. From the "triple bottom line" put forward by John Elkington (1997) to Michael Porter's "shared value", it is becoming increasingly clear that economic profit is closely correlated to the achievement of positive social and environmental impact.

According to the International Social Security Association, for every euro invested in occupational safety and health there is a return of 2.2 euros. Companies are increasingly investing in the health of their workforce, and in increasingly sophisticated ways, which could be adopted by other public and private organisations.

As in many other cases, also for prevention the rule that "the media is the message" applies: the same word "diet" is associated in most EU countries with "starving" or eating flavourless food.

Clearly, we need a paradigm shift if we want to improve both EU citizens' health outcomes and make our public health systems economically sustainable. This paradigm shift requires deriving a larger budget for prevention from many other sectors and not just from the health care system. This would increase the budget for disease prevention, without the need for detrimental cuts to the budget for disease management, which remains vital for the short and long term treatment of NCDs.

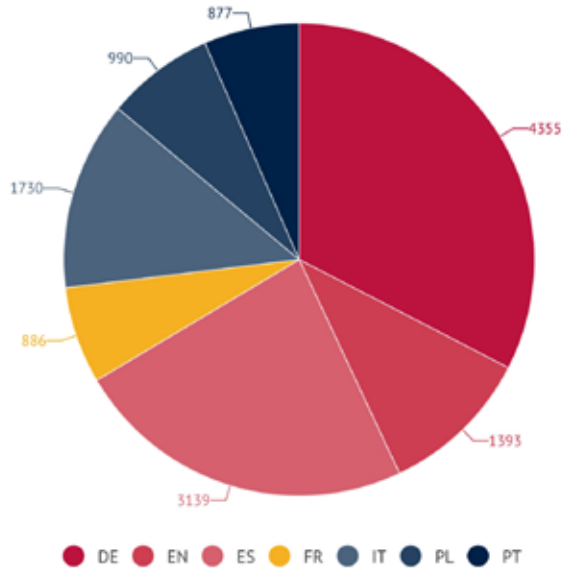
# RESULTS

GRAPH 2.1

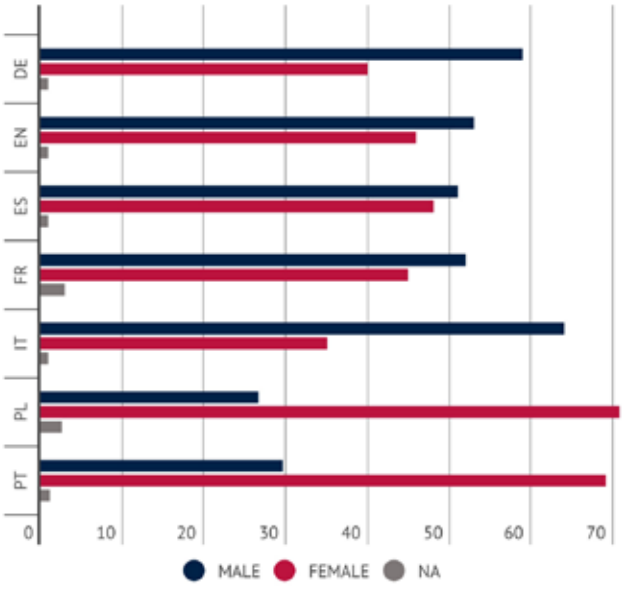
## HOW LONG WOULD YOU LIKE TO LIVE FOR?

What are you willing to do?

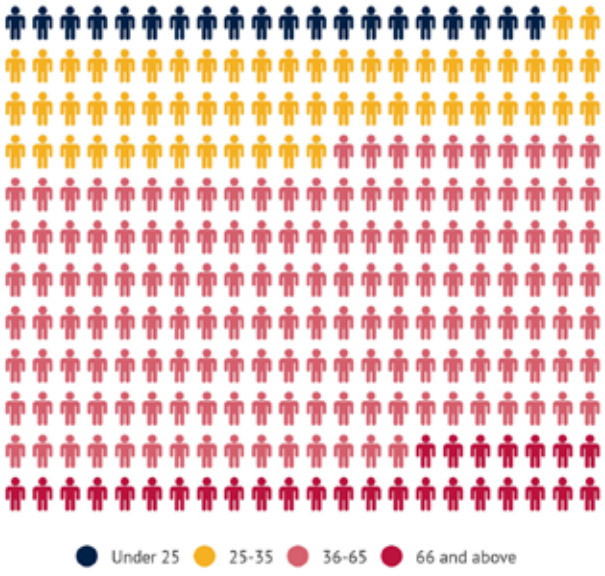
### 2.1.1 participation by language



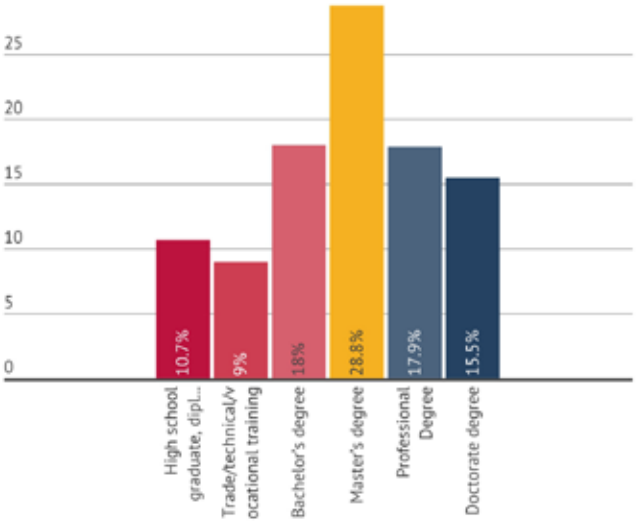

### 2.1.2 participation by gender




### 2.1.3 participation by age




### 2.1.4 participation by education

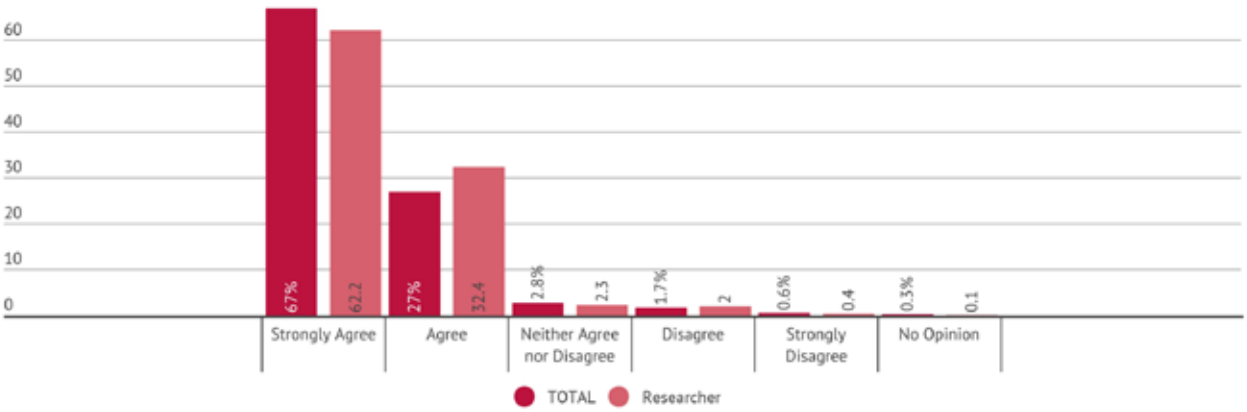


GRAPH 2.2

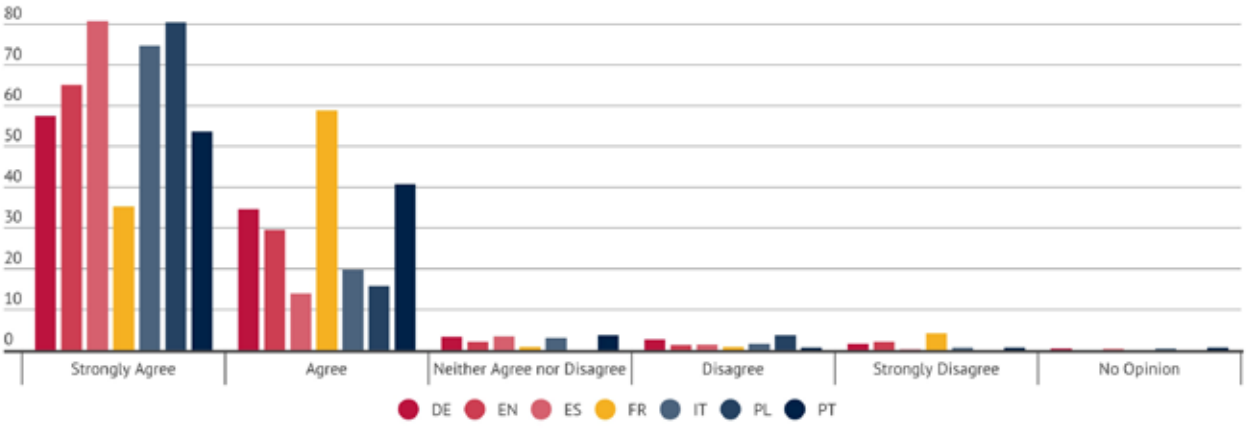
# "Healthy citizens are the greatest asset any country can have" Winston Churchill

Do you agree?

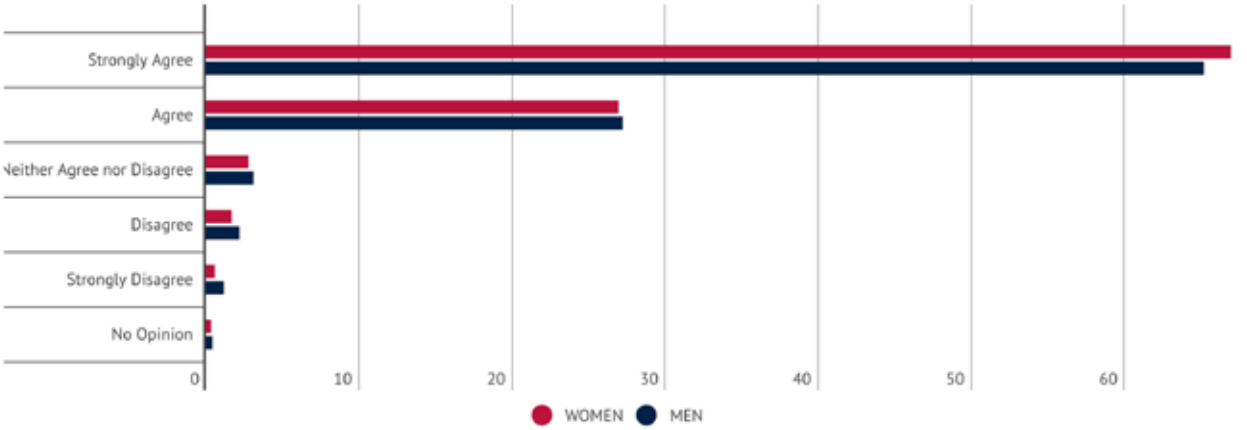
## 2.2.1 all & researcher responses (percentage of total)




## 2.2.2 by language




## 2.2.3 by gender

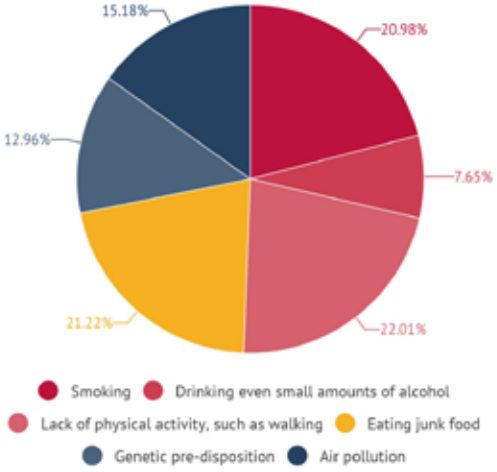


GRAPH 2.3

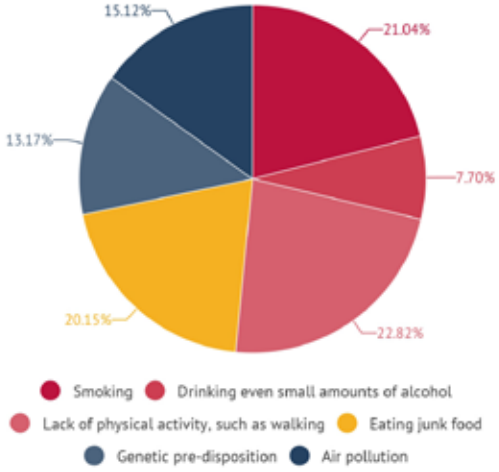
# What do you think are the main causes of non-communicable diseases?

Choose as many options as you feel appropriate

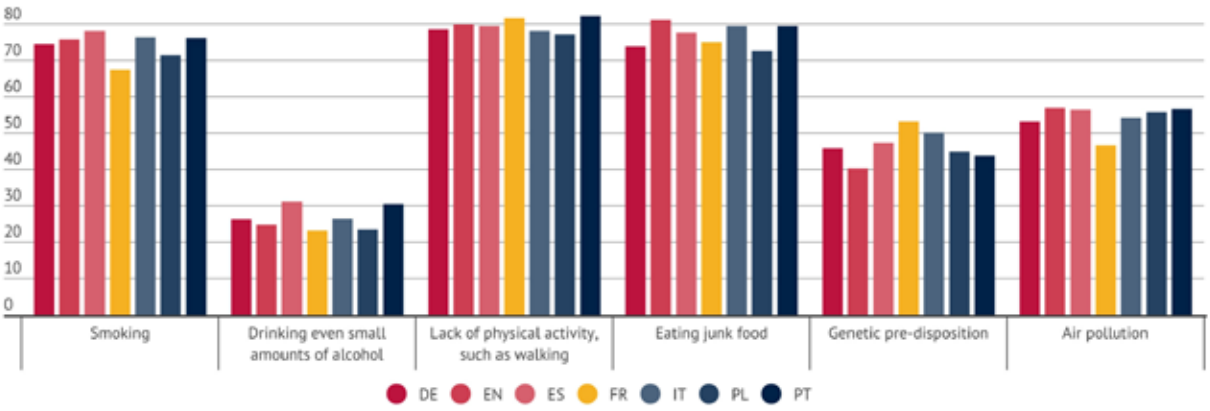
## 2.3.1 all responses



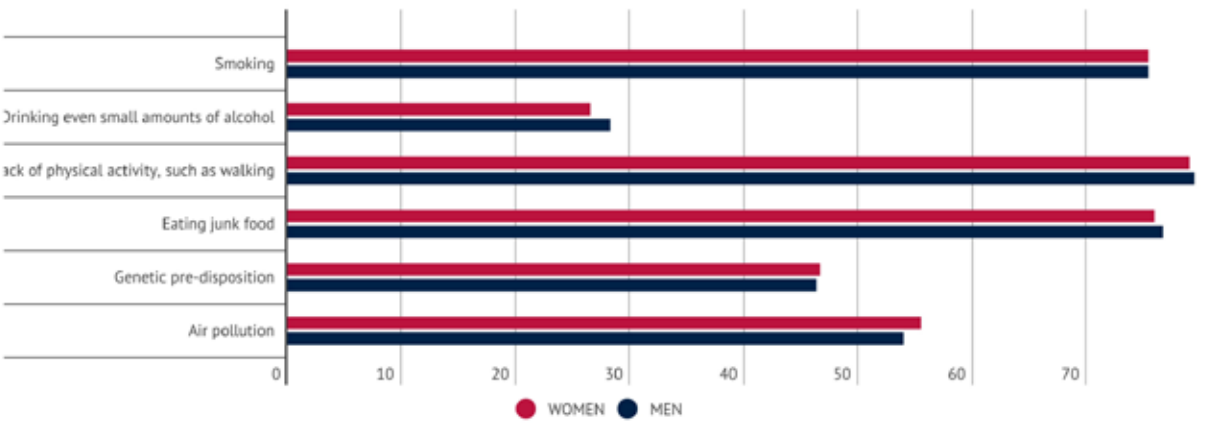

## 2.3.2 researcher responses




## 2.3.3 by language




## 2.3.4 by gender



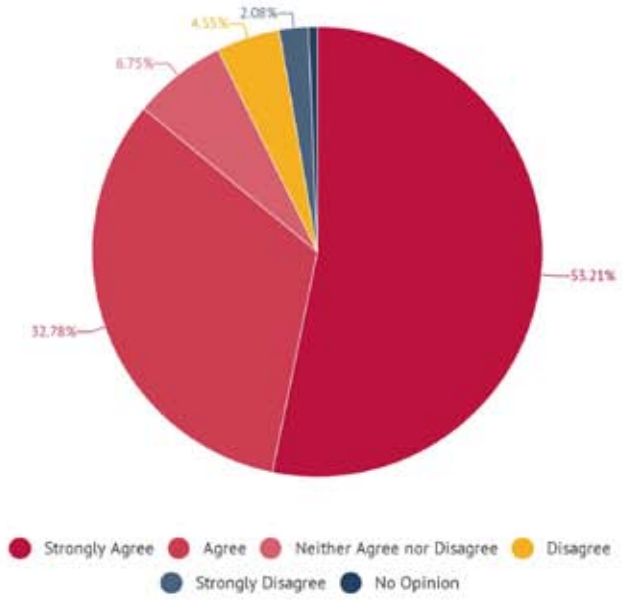
GRAPH 2.4

# "ALL MINISTERS ARE HEALTH MINISTERS"

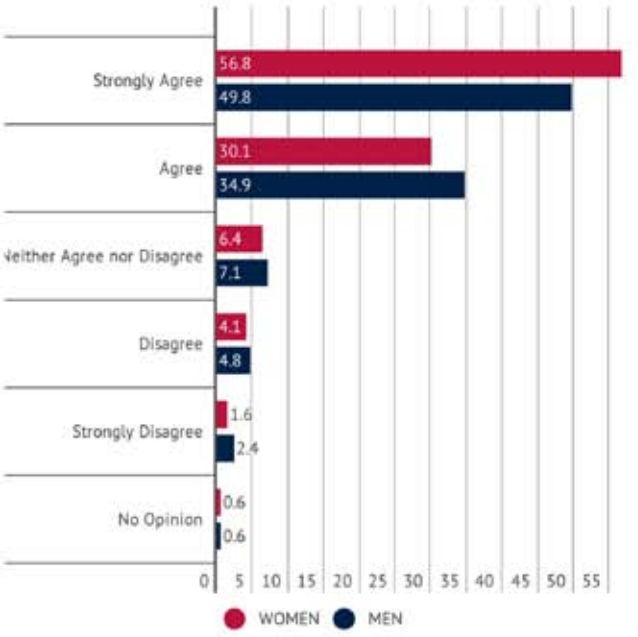
Dr. Margaret Chan, World Health Organisation

Do you agree?

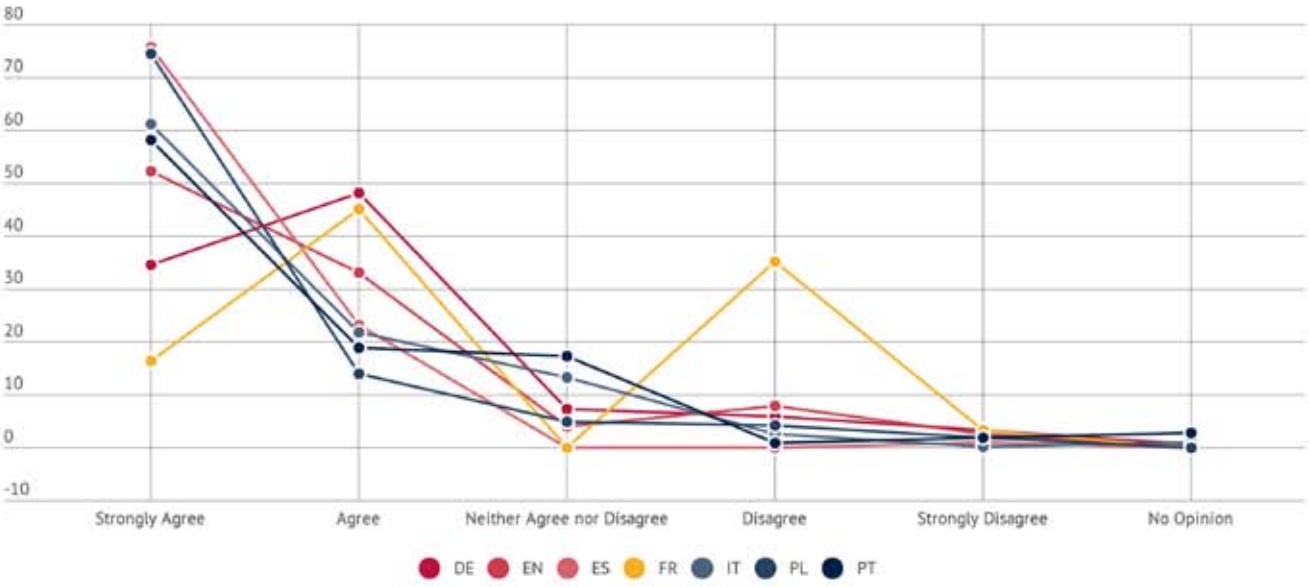
## 2.4.1 all responses




## 2.4.2 by gender




## 2.4.3 by language

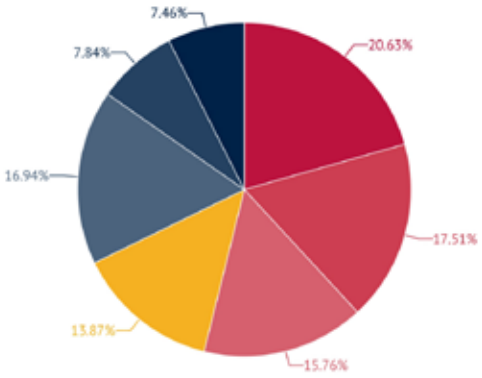


GRAPH 2.5

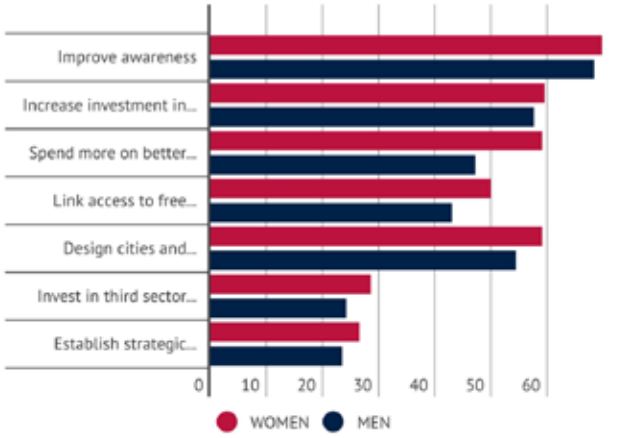
# What are the most important measures for preventing NCDs?

Select as many as you feel appropriate

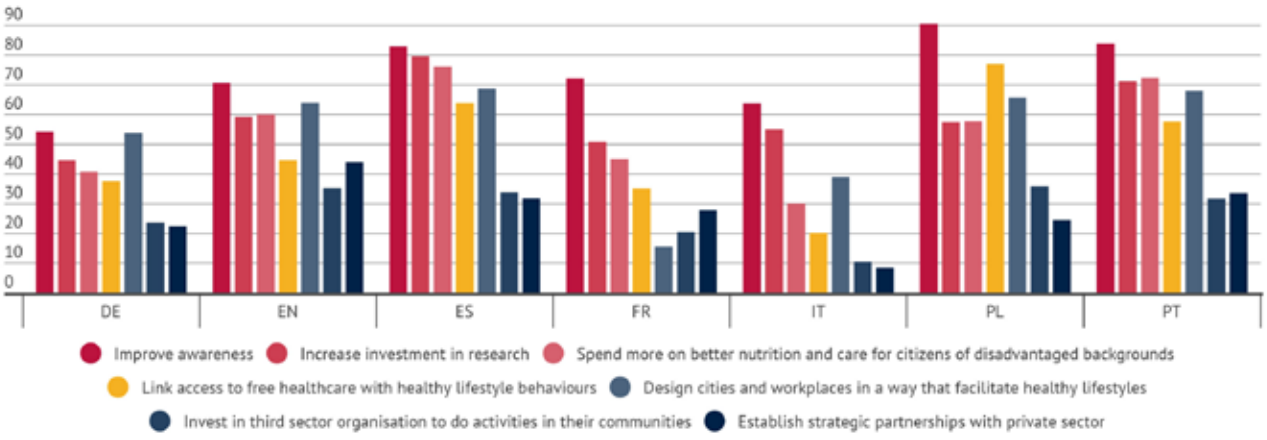
## 2.5.1 all responses



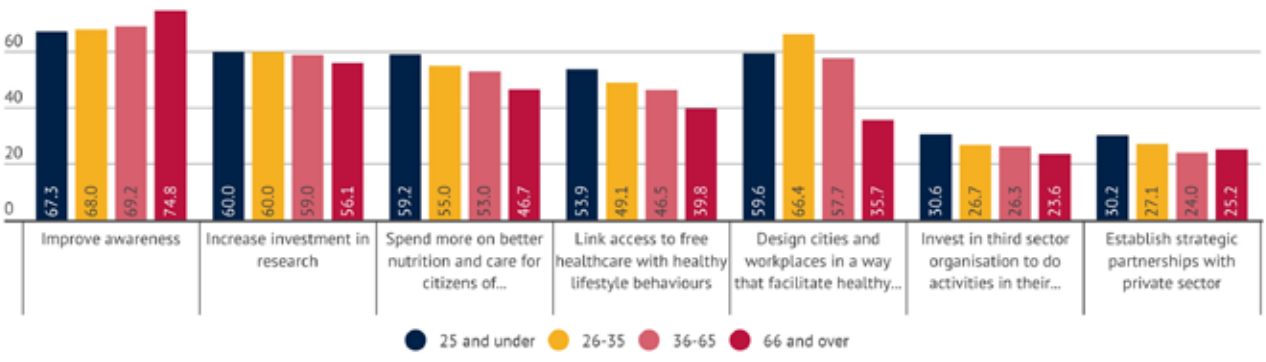

## 2.5.2 by gender




## 2.5.3 by language



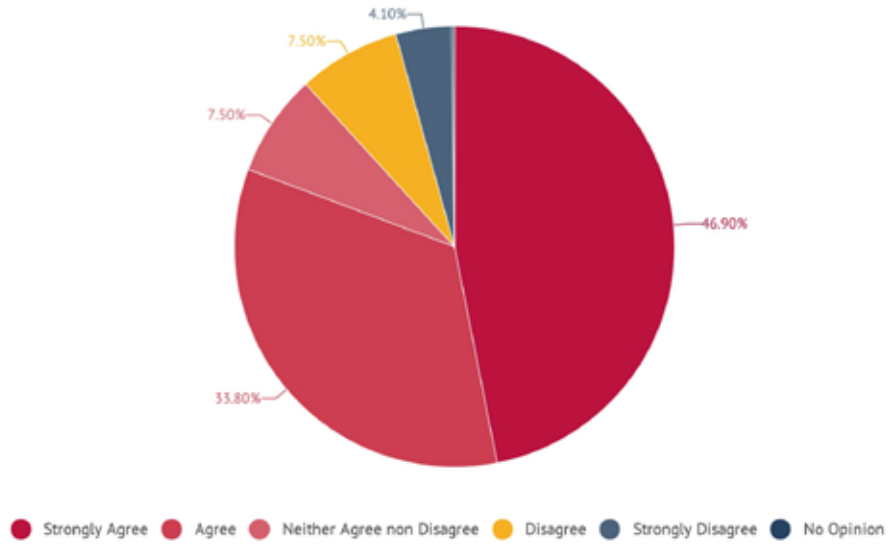

## 2.5.4 by age



GRAPH 2.6

## "Chronic non-communicable disease prevention should be an investment priority not only for government and public organisations, but equally for businesses (small and large companies active in any sector) and non-profit organisations"

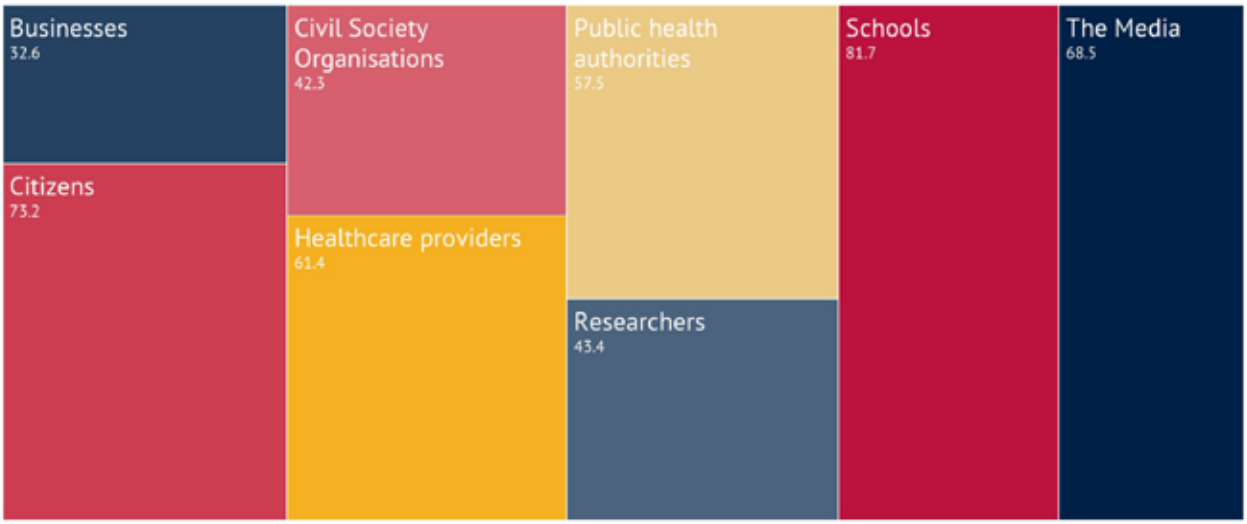
Do you agree?




GRAPH 2.7

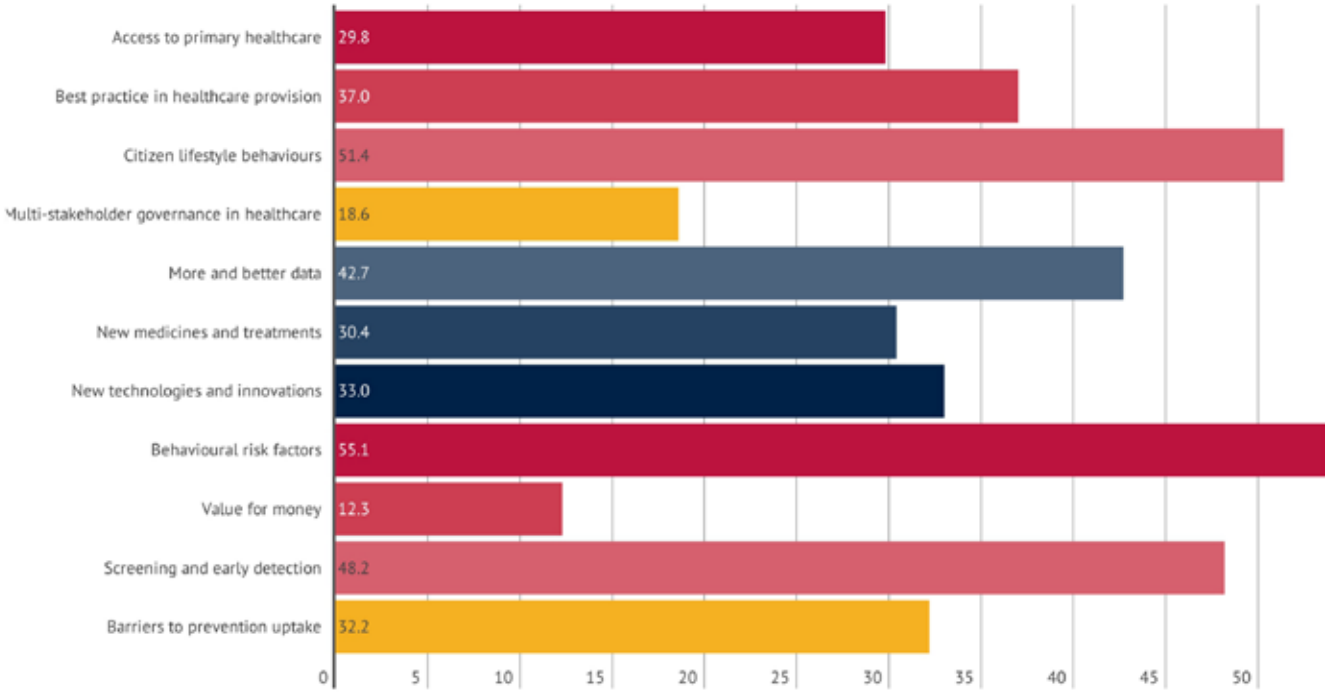
## Who has the most important role to play in promoting healthy behaviours to help prevent chronic non-communicable diseases?

Tick as many as you feel appropriate



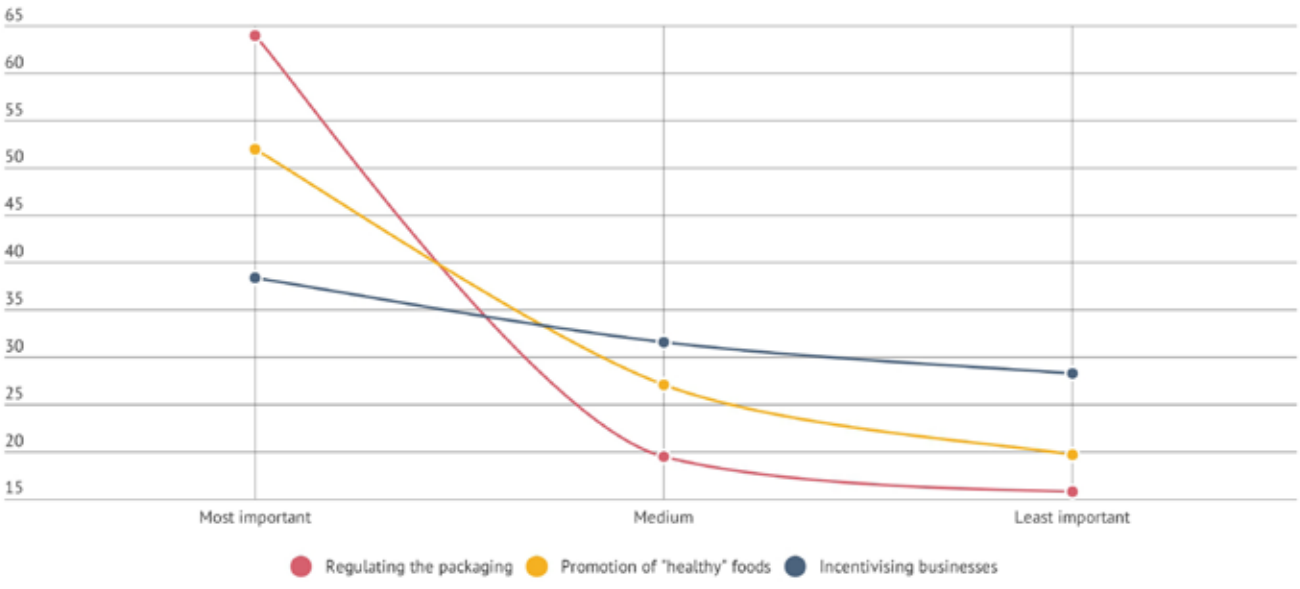
## GRAPH 2.8
## What are you most interested in finding out more about in relation to NCDs?

Tick as many as you feel appropriate




## GRAPH 2.9
## What should governments focus on in order to promote healthy nutrition?

Rank in terms of significance



# RECOMMENDATIONS

Based on the needs as highlighted by policymakers, the facts as put forward by researchers and the suggestions and opinions of citizens, the following policy recommendations are in line with the findings of the campaign.

## 1- Education and Awareness

It is clear that education and increasing health literacy is seen as a major tool to reduce health inequalities and to address social determinants of health in Europe. As also pointed out by the WHO, there is evidence that at present NCDs are particularly affecting the most deprived EU citizens and that the gap between rich and poor has been widening in most EU countries in the last decades, both in terms of onset of illnesses and in terms of access to appropriate care and mortality rates.

The key role played by media and professional communicators also cannot be underestimated, so for instance, six weeks after the debut of Morgan Spurlock's "Supersize Me" documentary on the effects of eating McDonald's food, McDonald's dropped its supersize portions.

## 2- Coordination across departments, sectors and disciplines

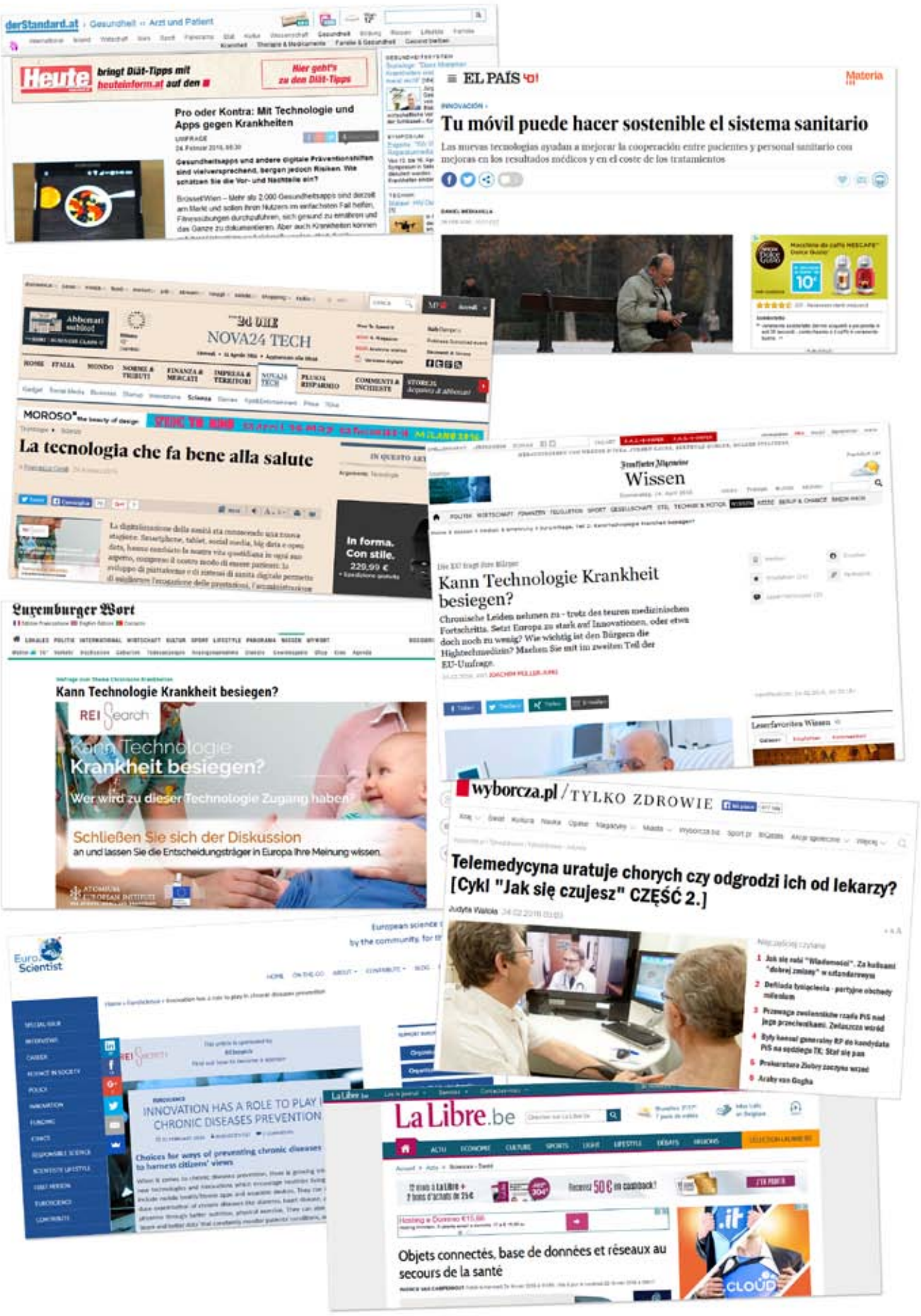
This challenge requires a holistic multi-sector and multi-stakeholder approach, to promote the core concepts of healthy lifestyles, shared value, and sustainable development, at the same time as satisfying the expectations, desires, and needs of different people in society. Methodologies and conditions such as 'nudging' from behavioural economics could be used for healthy lifestyle changes to be adopted nearly unconsciously by the population, reversing for example youth trends towards junk food and computer games on a global scale; and utilising new media and communication channels such as social media to engage society, beyond for example the ineffective 'food pyramid' campaigns of the past.

## 3- Consumer protection

The role of food corporations and regulators when it comes to protecting consumers and promote healthy nutrition has also been the object of a lively debate in the last decades: so for instance Austria, Hungary, Iceland, Norway and Switzerland followed the example of Denmark, which in 2003 was the first country in the world to nearly ban trans fats – one of the main causes of cardiovascular diseases - from the food market through regulation. The European Commission's Joint Research Centre (JRC) provided independent scientific input to and helped draft the "Report from the Commission to the European Parliament and the Council regarding the presence of, and appropriate means for reducing, trans fat in foods and in the overall diet of the Union population".

The EU Regulation No 1169/2011, which will apply from 13 December 2016, foresees stricter rules concerning nutrition information to be displayed for a majority of pre-packaged processed foods, and discussions on the opportunity to ban advertising of unhealthy food and to introduce more easily readable labels indicating amounts of sugars and fats are on-going.

The issues of "new technologies and innovation", citizen rights and responsibilities", "diabetes and nutrition" and "more and better data" will be dealt with specifically in the next chapters.




These are the headlines of some of the articles published during the week on "New Technologies and Innovation" of the Citizen Engagement and Media Campaign on Chronic Diseases.

# WEEK 2 – NEW TECHNOLOGIES AND INNOVATION

## OVERVIEW

The second week of the campaign tackled the question of "new technologies and innovation". New technologies and innovations in health are developing worldwide at a remarkable pace. Some of the most recent technologies and innovations are exploring: gene therapy to predict, treat, or prevent specific diseases; stem cell therapy; digestible sensors; wearable healthcare technologies; 3D printing of biological materials; microchips for modelling clinical trials without the need for human or animal testing; and cloud-based integrated data management systems.

For chronic diseases in particular, there is growing interest in new technologies and innovations that encourage healthier living – such as mobile health/fitness apps and wearable devices – to reduce exacerbation of chronic diseases like diabetes, heart disease, and emphysema through better nutrition, physical exercise, and 'more and better data' that constantly monitor patients' conditions, as well as supporting self-management and self-empowerment.

During the week of the 22nd of February 2016 the media and knowledge partners of the campaign launched a debate on the importance of new technologies and innovation as bringing new solutions to living with and tackling NCDs. The aim of the campaign was twofold: to increase awareness of the importance of new technologies and innovation, and; to start a public debate on this issues to understand the opinions and suggestions of a variety of different actors – including citizens – on this topic.

Below you can see the detailed outcomes of the campaign.

Compared to the first week there was a very high participation from the German-speaking countries this week with over 60% of participants from Germany, Austria and Luxembourg. This says something about the interest for this topic and it is important to keep in mind when looking at the overall results.

Also, whilst the first week opinions were very similar from country to country, across age groups, gender and education levels, this second week saw bigger differences. For instance it is clear that women are more willing to use new technologies, such as apps, DNA testing, or digestible sensors if these leads to improved health whilst only 50% of the male respondents were equally willing.

**From the Forum**

Technology can be very important in affecting human behaviour but it is imperative that we do not forget the human element.

The discussions shows that the majority of respondents felt that it was important to continue to invest in research and innovation and that this should be done by different actors although national governments and the European Union should play a key role.

It was however highlighted in the REIsearch Forum debates that people felt that often the question around technology was framed in the wrong way and could be more successful if the role of technology was framed within the broader societal question.

**From the Forum**

I sometimes feel this questions is wrongly framed. It should not be about how society accepts technology but **how technology is adapted to society**. Then this becomes an immensely interesting question!

# BACKGROUND

*"Science and technology revolutionize our lives, but memory, tradition and myth frame our response"*

*Arthur Schlesinger*

If we want to better understand, manage, and prevent chronic diseases, then new technologies and innovation are vital.

New technologies and innovations in health are developing worldwide at a remarkable pace. Some of the most recent technologies and innovations are exploring: gene therapy to predict, treat, or prevent specific diseases; stem cell therapy; digestible sensors; wearable healthcare technologies; 3D printing of biological materials; microchips for modelling clinical trials without the need for human or animal testing; and cloud-based integrated data management systems.

For chronic diseases in particular, there is growing interest in new technologies and innovations that encourage healthier living – such as mobile health/fitness apps and wearable devices – to reduce exacerbation of chronic diseases like diabetes, heart disease, and emphysema through better nutrition, physical exercise, and 'more and better data' that constantly monitor patients' conditions, as well as supporting self-management and self-empowerment.

There is also increasing interest in new technologies and innovations in the field of eHealth including telemedicine and mobile health (mHealth) to help provide more efficient and personalised services to patients. eHealth covers many aspects, ranging from engaging patients in self-managing their chronic health conditions, to improving access to diagnosis of rare and complex diseases, to improving health literacy. While eHealth cannot substitute conventional medicine entirely, it can be seen as a powerful tool to support more personalised and person-centred medicine. Here, Sweden's Esther Network provides one example of good practice. Following the experience of one elderly citizen (called Esther) who had to report her story to 36 different service providers before getting the care she needed, the Esther Network was set up in 1997 to significantly improve the care-giving referral system in Sweden by consolidating over 7,000 care institutions onto one single online network.

On the prevention side, a growing number of free apps, on-line courses, resources and communities exist to spread information, facilitate contacts, and offer peer-to-peer support and motivation. However, it is often difficult to choose between the many available options, and to understand if users' data is stored and used securely and respecting privacy. In this respect, the role played by health professionals and civil society organisations in testing, selecting and recommending the most useful apps is key.

High-tech social enterprises are also entering this market, developing products that make economic profit while also delivering health benefits to their users.
Despite their rapid advancement, new technologies and innovations still face a number of barriers within the European healthcare system.

First and foremost is a lack of trust and coordination between the players involved in research and innovation processes. On the one hand, the public sector invests heavily in 'risky' technology and innovation, only to be left out of the commercialisation processes that are dominated by for-profit private companies. On the other hand, public policy changes and regulatory structures can hamper private sector investment in research and innovation. This is in addition to the barriers of finance access; the lack of a unified European patent system; and a lack of technology transfer in Europe.

There is also concern for the role of citizens and users, who have the potential to be ignored, disregarded, manipulated, or 'used' in the tech innovation processes. The example of drugs withdrawn from the market due to previously alleged 'unrecognised' side effects is quite instructive here.

If we are to harness the potential of technology and innovation for better health outcomes, we do not only need technologic progress: social innovation is also very important, not only to involve and empower citizens and patients, but also to foster collaboration between different disciplines across multiple levels of government and to promote integrated approaches to health and social care, switching the focus from managing diseases to prevent them.

Finding new medicines, introducing new medical technologies, and developing smarter digital care tools to manage health conditions and health-care systems could greatly improve the lives of people with chronic non-communicable diseases, while also help preventing their insurgence. However, investment in research and innovation – including in social innovation - is low in Europe. How can we reverse this?

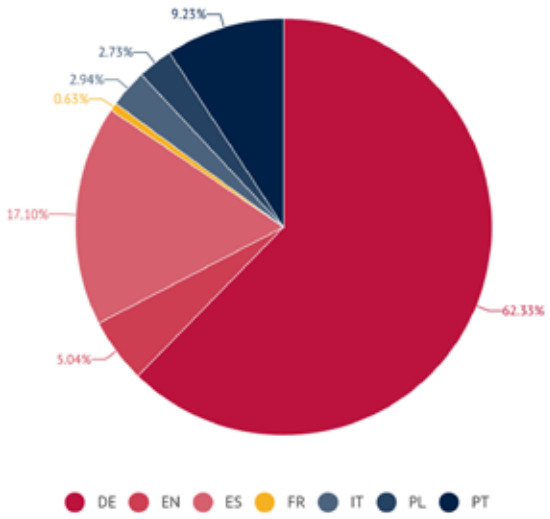
# RESULTS

GRAPH 3.1

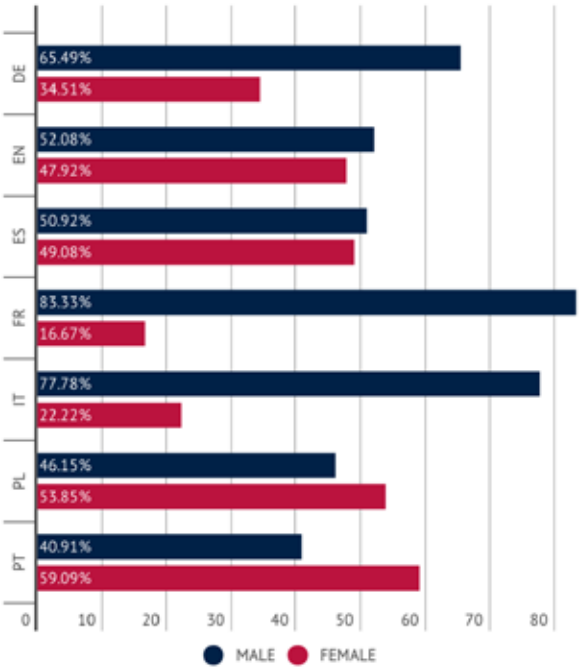
## WILL TECHNOLOGY DEFEAT SICKNESSES?
## And who will have access to this technology?

OVERALL PARTICIPATION

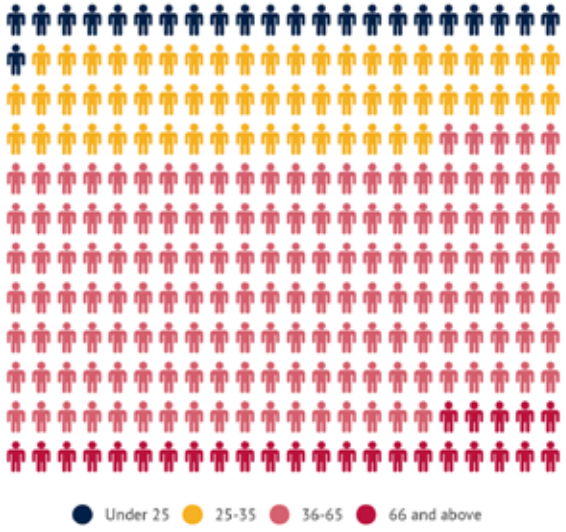
### 3.1.1 participation by language



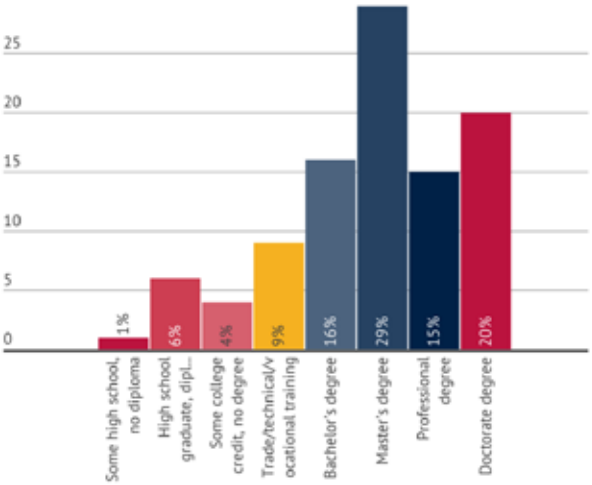

### 3.1.2 participation by gender




### 3.1.3 participation by age




### 3.1.4 participation by education

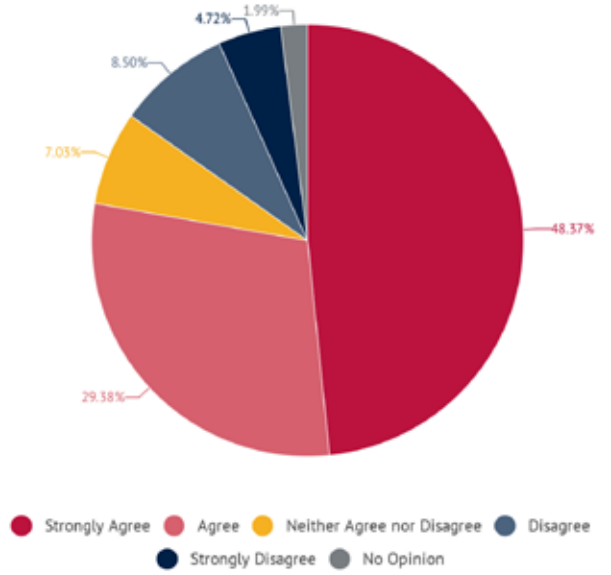


GRAPH 3.2

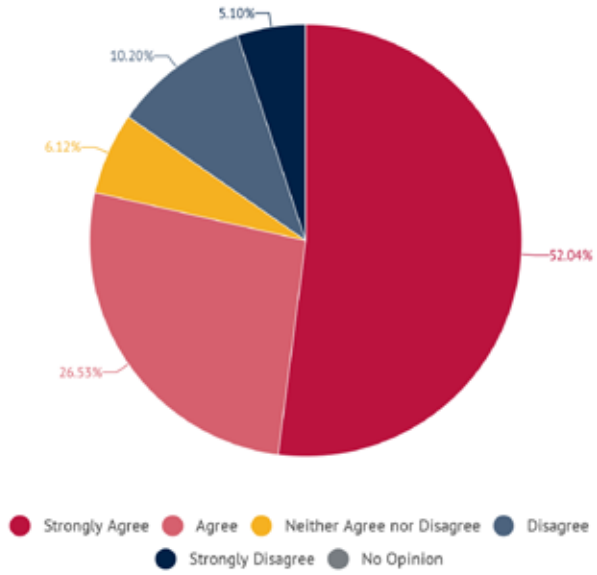
# "New technologies and innovation are fundamental to the development of long-term solutions to chronic non-communicable diseases and public, private, and third sector organisations should all scale up investment in this field"

DO YOU AGREE?

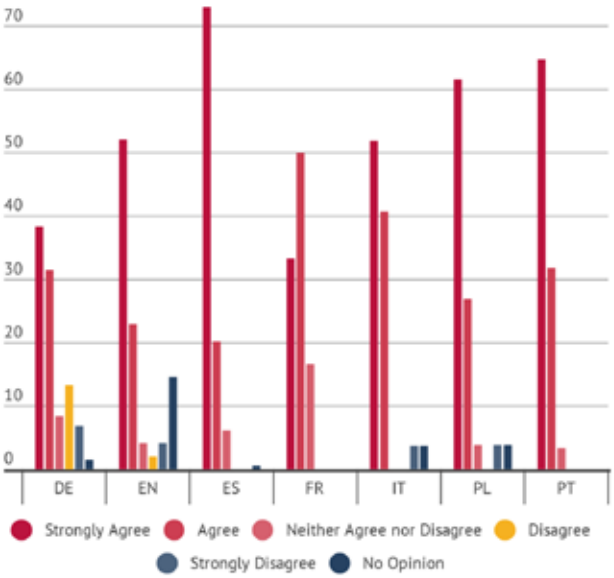
## 3.2.1 all responses



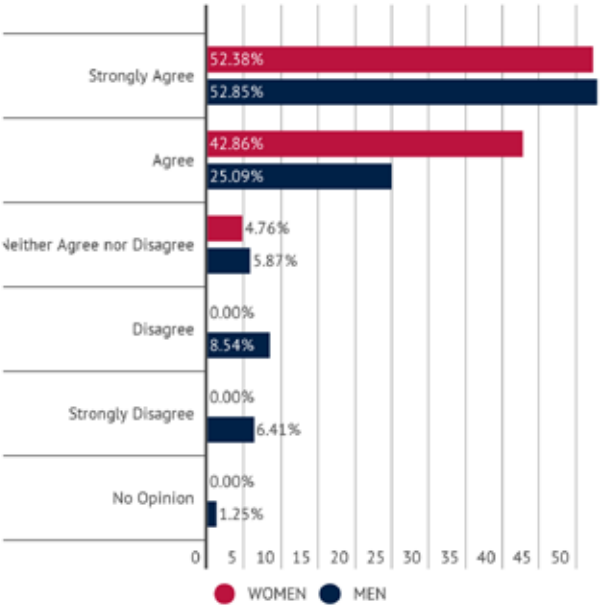

## 3.2.2 researcher responses




## 3.2.3 by language




## 3.2.4 by gender

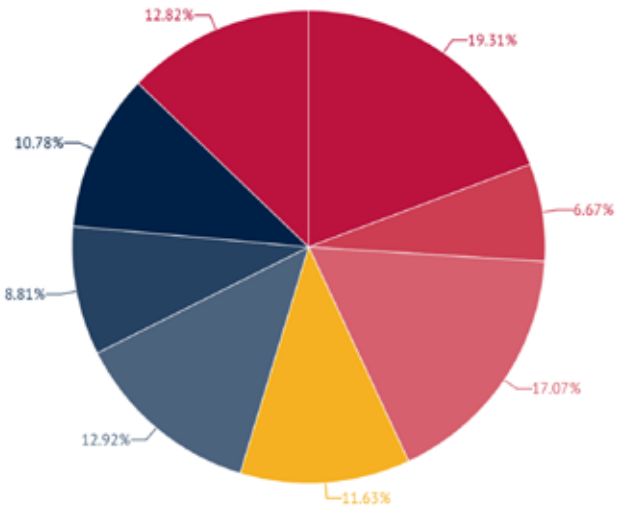


GRAPH 3.3

## Provided that they are appropriate and transparent, which of the following do you consider a possible source of funding for new technologies that help manage chronic non-communicable diseases?

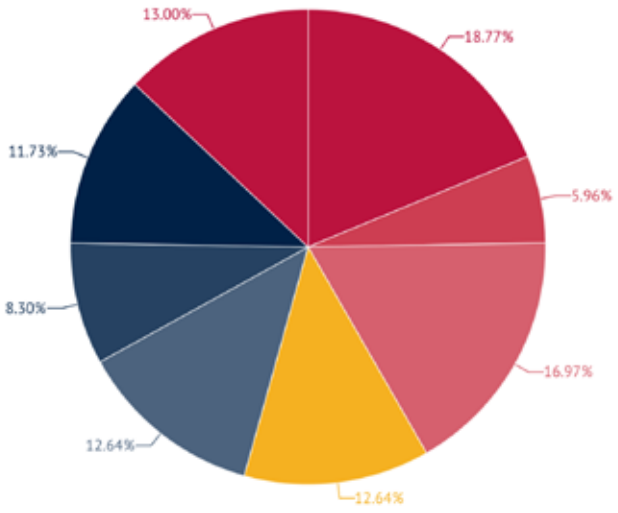
What do you think?

### 3.3.1 all responses



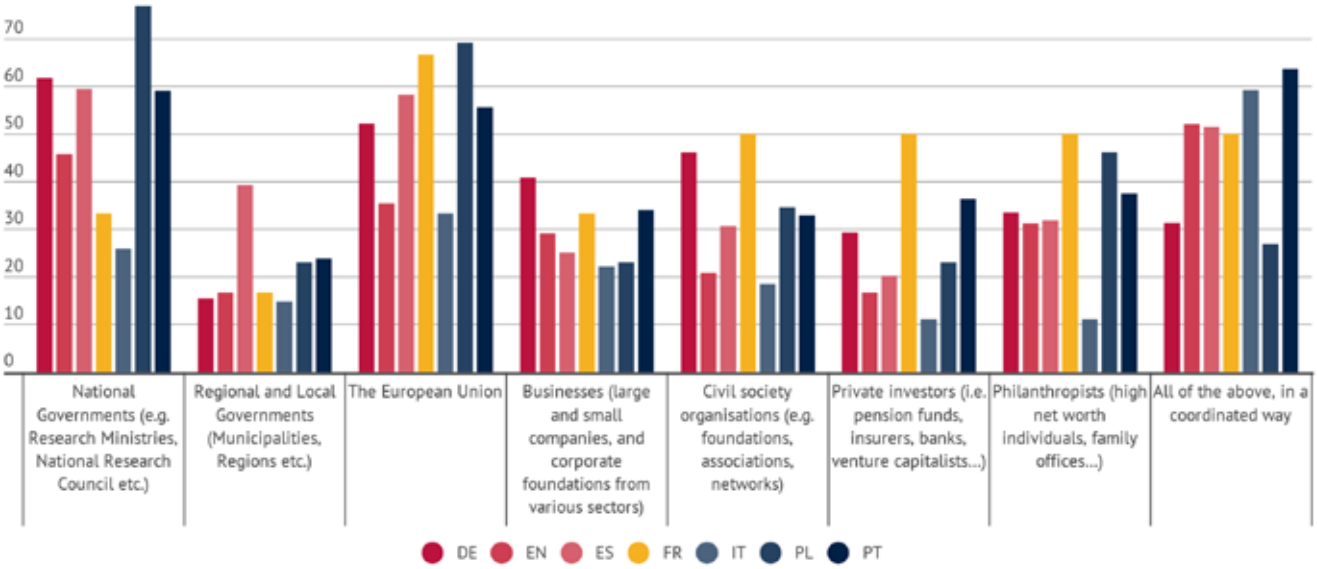

- National Governments (e.g. Research Ministries, National Research Council e...
- Regional and Local Governments (Municipalities, Regions etc.)
- The European Union
- Businesses (large and small companies, and corporate foundations from vari...
- Civil society organisations (e.g. foundations, associations, networks)
- Private investors (i.e. pension funds, insurers, banks, venture capitalists...)
- Philanthropists (high net worth individuals, family offices...)
- All of the above, in a coordinated way

### 3.3.2 researcher responses

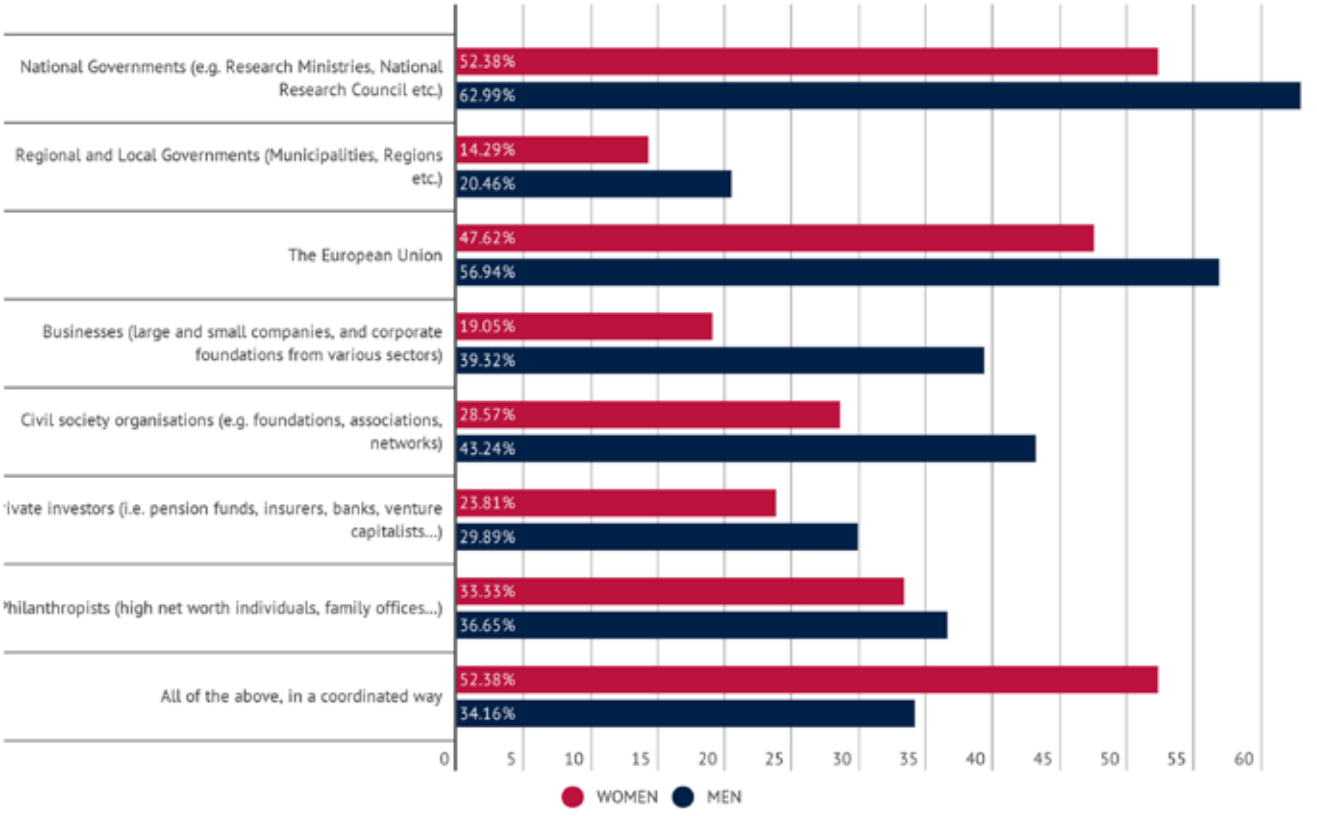



- National Governments (e.g. Research Ministries, National Research Council e...
- Regional and Local Governments (Municipalities, Regions etc.)
- The European Union
- Businesses (large and small companies, and corporate foundations from vari...
- Civil society organisations (e.g. foundations, associations, networks)
- Private investors (i.e. pension funds, insurers, banks, venture capitalists...)
- Philanthropists (high net worth individuals, family offices...)
- All of the above, in a coordinated way

## 3.3.3 by language




## 3.3.4 by gender

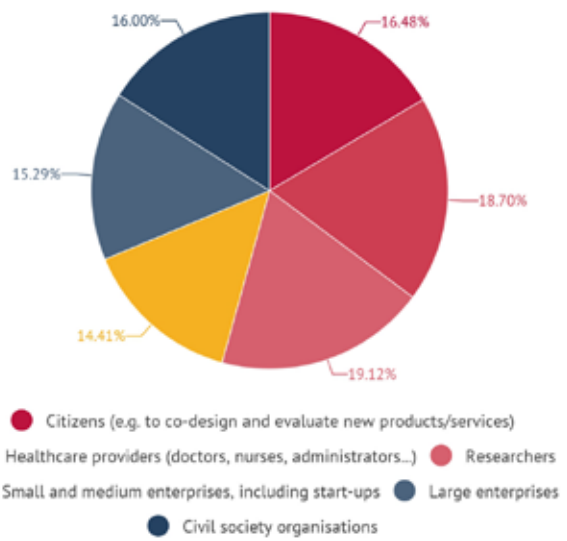


GRAPH 3.4

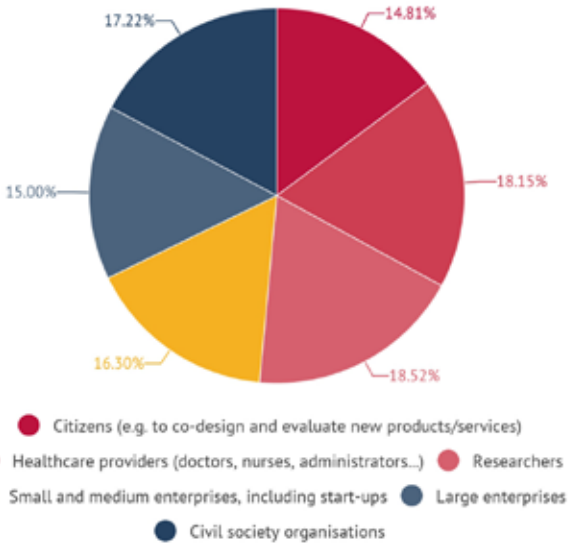
# The development of new technologies and innovation for chronic non-communicable disease prevention or management should include:

tick as many as you feel appropriate

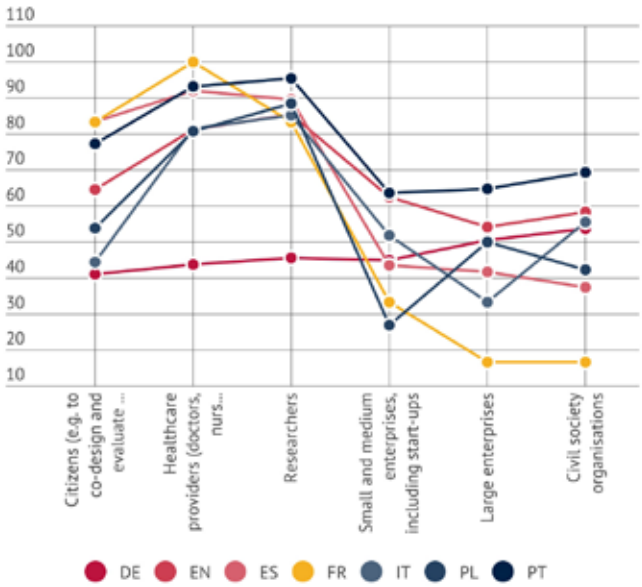
## 3.4.1 all responses



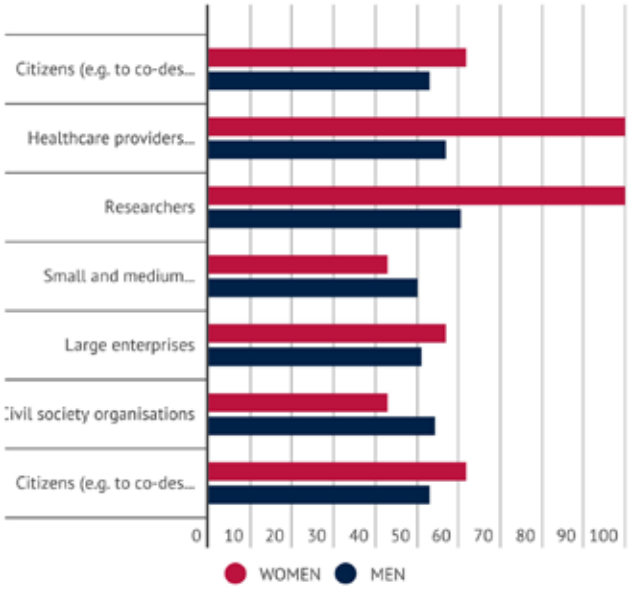

## 3.4.2 researcher responses




## 3.4.3 by language




## 3.4.4 by gender

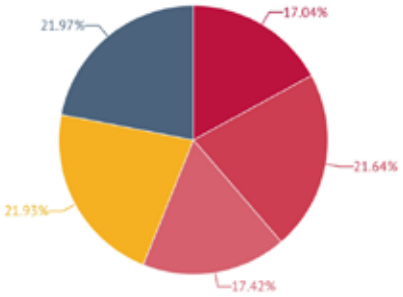


GRAPH 3.5

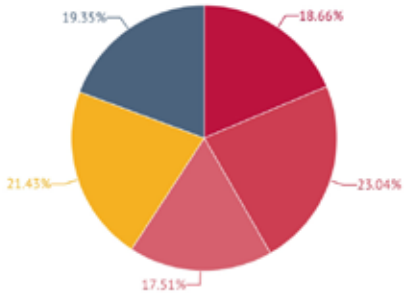
# ★ Technology, if applied to support the necessary lifestyle changes and policy interventions, can be a formidable ally to tackle chronic diseases. ★

**Which of the following technologies would you be willing to use to manage or prevent chronic diseases?**

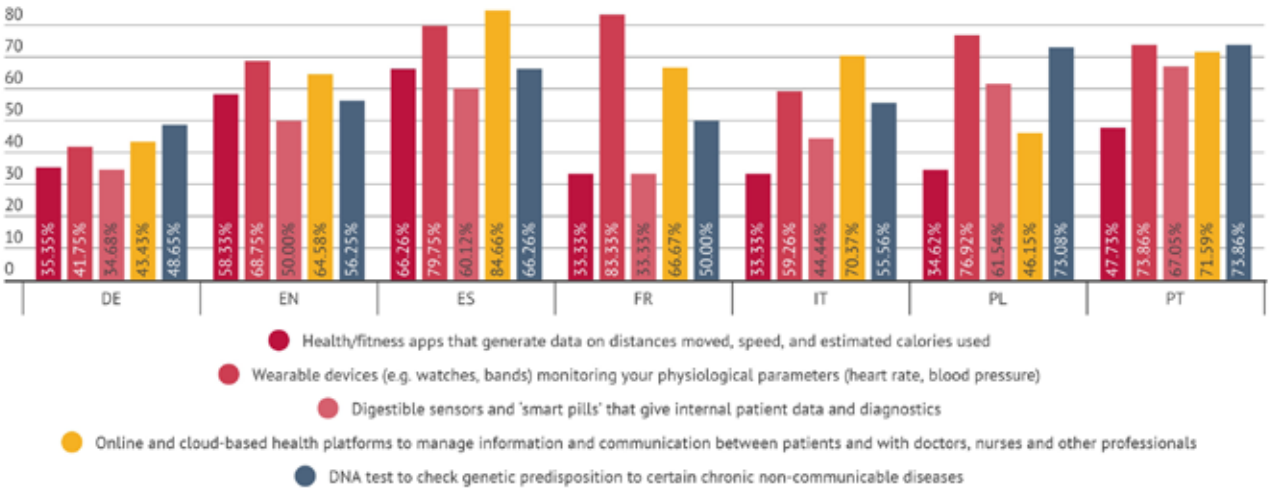
## 3.5.1 all responses



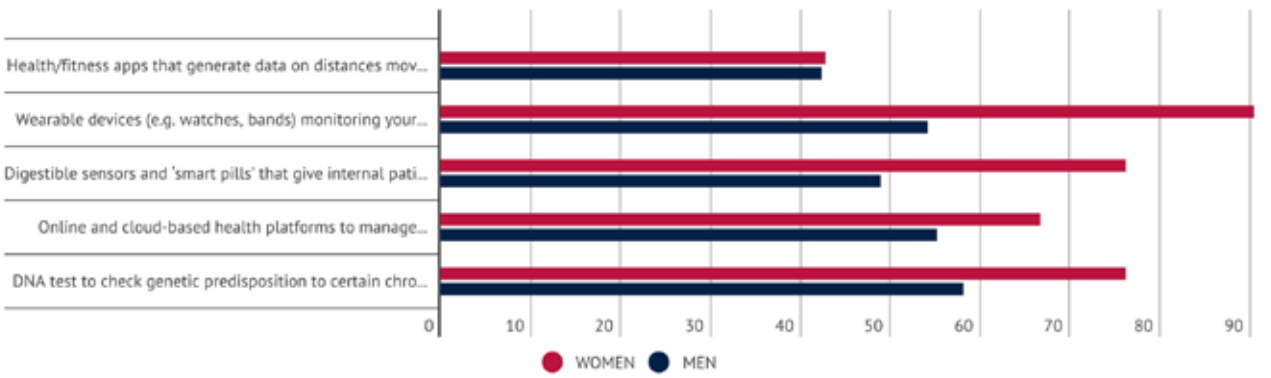

## 3.5.2 researcher responses




## 3.5.3 by language



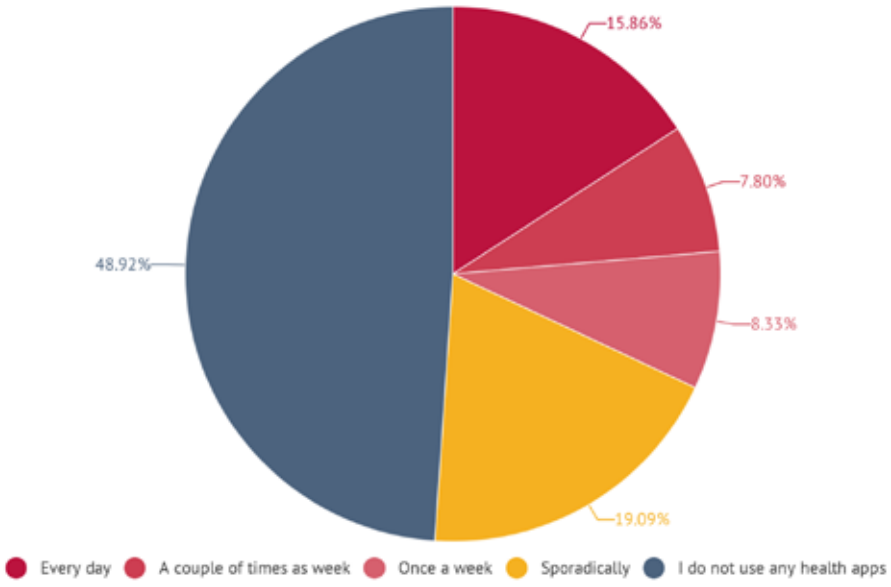

## 3.5.3 by gender



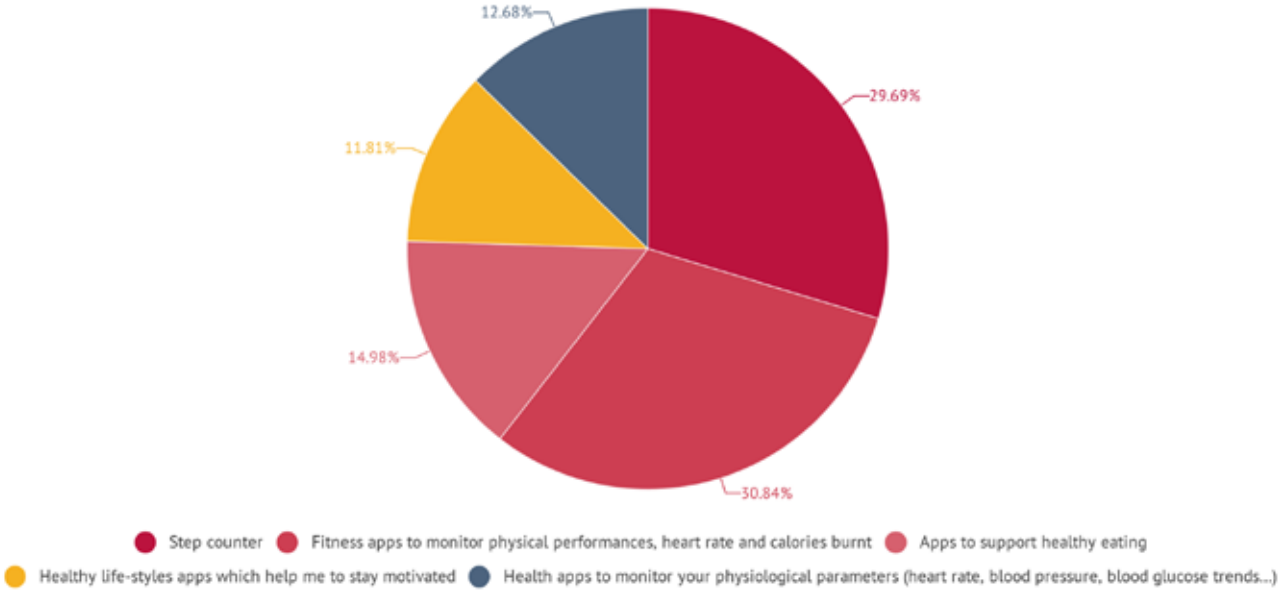
GRAPH 3.6

# Do you use any health apps?

## 3.6.1 How often do you update these apps with reliable information?




## 3.6.2 Which apps do you use?



## GRAPH 3.7

## Which of the following do you consider barriers to new technologies and innovation?

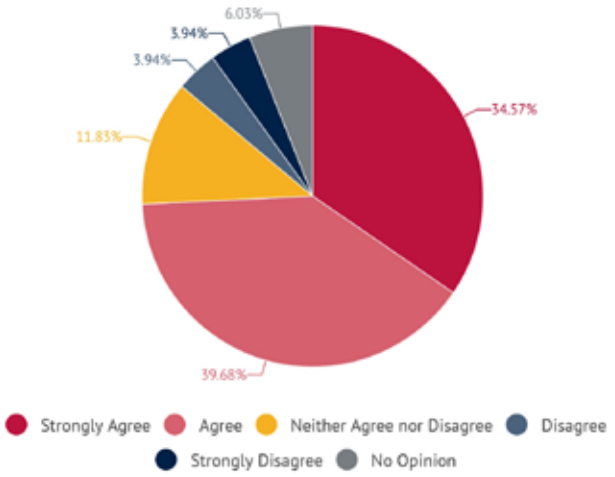
Tick as many as you feel appropriate


## GRAPH 3.8

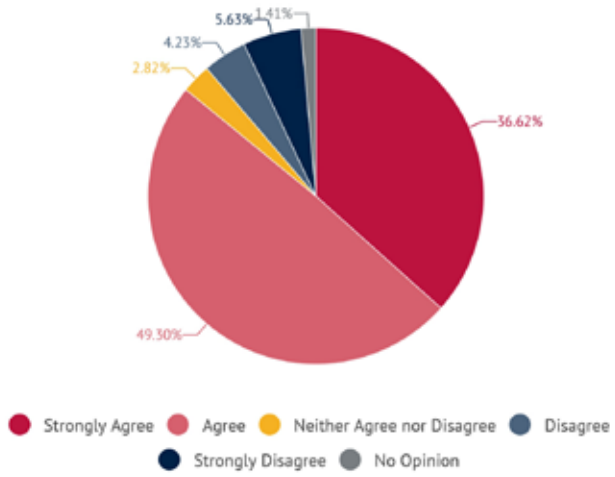
## "If we want technology and innovation to make a difference for citizens and patients, then we need more investment and collaboration to combine innovative and traditional approaches, putting users at the centre of the process"

To what extend do you agree with the above statement?

### 3.8.1 all responses




### 3.8.2 researcher responses




1 oo
2 abc
def 3
4 ghi
5 jkl
mno 6
7 pqrs
8 tuv
wxyz 9
0
#

# RECOMMENDATIONS

Based on the needs as highlighted by policymakers, the facts as put forward by researchers and the suggestions and opinions of citizens, the following policy recommendations are in line with the findings of the campaign.

## 1- Increase Investment

One of the biggest challenges for innovative researchers and companies in the healthcare sector is finding finance. Healthcare innovation is expensive yet investments are low - while the rewards can be great, the risks are similarly high, and a lack of venture capital funds investing in life sciences has left the 'big money' with more risk-averse institutional investors. The appearance of new players (e.g. funds specialised in buying very early stage research's results, preventing other players to take part to their commercialisation phase) and the fast-changing relationships between new and old players (with companies increasingly retreating from blue-sky research and shrinking public budgets) are further complicating the picture.

Whilst the campaign shows that there is a view that funding should come from a variety of actors, the participants still saw national governments and the European Union as the key actors in bridging this gap.

## 2- Increase coordination and trust between the various players

There is a lack of trust and coordination between the different stakeholders of the innovation chain in Europe. On one hand, costs associated with the riskier blue-sky research phase are nearly entirely covered by the public sector, which is then often excluded from the rewards stemming from the commercialisation of research results. On the other hand, policy and regulatory risks associated with the commercialisation of innovative products are seriously hampering the participation of the private sector into research and innovation.
Another key issue is the sometimes scarce involvement of prospective users and stakeholders in the development of new products, which often leads to very low innovation acceptance levels of the finalised products. Thus, further efforts are required to engage with the broadest possible spectrum of autonomous and informed stakeholders – starting from citizens and policy makers – into the whole research and innovation cycle if we want technological breakthroughs to positively affect our lives.

## 3- Decreasing bureaucracy

Demanding regulatory hurdles for SMEs, and expensive, complex, and fragmented systems for approving new products, which can take 10-20 years and cost more than € 1 billion to develop from research lab to sold product.

The issues of "more and better data" will be dealt with specifically in the next chapters.


These are the headlines of some of the articles published during the week on "Citizen's Rights and Responsibilities" of the Citizen Engagement and Media Campaign on Chronic Diseases.

# WEEK 3 – CITIZEN'S RIGHTS AND RESPONSIBILITIES

## OVERVIEW

The first weeks of the *Citizen Engagement and media Campaign on Chronic Diseases* paved the way for assessing more in detail the public view and opinion on the role of "citizen's rights and responsibilities". The fact that 80% of new cases of chronic diseases can be avoided through lifestyle changes like not smoking, not drinking, avoiding junk food and increasing physical activity has prompted the debate around rights versus responsibilities of citizens.

For policymakers and citizens, one central challenge is to find a balance between citizen's rights to public services on the one hand, and citizen's responsibilities to adopt responsible lifestyle behaviours on the other. According to the World Health Organisation, avoiding cigarettes, alcohol abuse and junk food and making 30 minutes of physical exercise each day, could prevent up to the 80% of new heart disease, stroke, and type 2 diabetes cases. But how can we encourage healthy habits and prevent chronic non-communicable diseases from arising?

Should citizens be nudged or forced into certain lifestyle changes to reduce chronic non-communicable diseases? Should access to free healthcare be linked to healthy lifestyles? Should citizens who abuse of alcohol, smoke, or eat foods with high sugar, salt, and trans fat have to pay more for healthcare? What would this mean for personal choice, privacy, monitoring, and proving your lifestyle was 'healthy'? Would such an intervention have a disproportionate burden on socio-economically disadvantaged citizens who are most at risk? Are governments and businesses doing enough to inform citizens about chronic non-communicable disease risk factors, or protect citizens from these risks?

These are some of the difficult questions that were launched during the week of the 29th of February 2016. The aim of the campaign was twofold: to increase awareness of the difficulties posed by these questions and to find out more about what citizens actually feel about some of these difficult moral questions.

Compared to the previous week there was a very high participation from the Spanish-speaking countries this week with over 70% of participants. This did not reflect a diminishing interest from the other countries but a surge in the interest of the Spanish-speaking participants who during this week contributed with over 1000 comments to the forums within El Pais and the REIsearch forums and over 17500 active users. This says something about the interest for this topic and it is important to keep in mind when looking at the overall results.

Around 60% of Spanish and German-speaking participants were male whiles over 60% of Polish and Portuguese-speaking participants were female. Over 60% were between the ages of 26-35 and, as always the vast majority had a degree (graph 4.1).

From the Forum

**We each of us a certain degree of responsibility, but has to take into account that society as a whole also has a degree of responsibility for our behavior.**

We can see how the professor who taught us in school, along with our parents, failed to inculcate healthy habits desirable. We can also set those governments who decided through their economic, social and educational policies as working class to form specialized to surrender ourselves more in companies and ignoring their responsibility to humans in itself: ultimately choosing to treat citizens as mere numbers and labor for companies using humans for the welfare of the economy and not vice versa which is what we should aspire and use the economy to welfare "all" citizens.

It has been found from many cases that **the best strategy is comprehensive information and education for everyone without condition to anyone.**

The opinions where very similar across languages and gender when asked who was responsible for ones health with most participants mentioning themselves as the most responsible, with healthcare providers, governments and pharmaceutical companies coming second. Graph 5.2 depicts in details the different views of the participants.

However, even though most participants felt the individual is responsible for his or her own health, around 60% or participants felt that access to free healthcare should be granted to everyone, irrespective of his or her personal lifestyle choices (Graph 5.5). There was no difference from a gender perspective whilst there were clear differences across countries with nearly 50% of Italian-speaking respondent neither agreeing nor disagreeing.

Similar difference of opinion could be seen when asked if employers should reward workers for participating in wellness programmes and meeting health benchmarks. Overall most participants agreed but the French-speaking participants where mostly against this proposal. Also, although most men and women supported the idea, men were more in strongly in favour of employers rewarding workers (Graph 5.6).

On the other hand there was nearly a unanimous view that governments, companies and third sector organizations should all use their knowledge of citizens' habits to induce healthy behaviours, while collaborating to create healthy environments and products (graph 5.7).

Again, as in the first week on the campaign, the participants underlined the importance that they feel education has in combatting chronic disease by selecting schools as playing the major role in promoting healthy lifestyle behaviours to help prevent or manage chronic diseases. This was followed by public health authorities, citizens themselves and the media. Slight variations could be detected across gender and language divisions but these were only marginal.

When asked whether they would be willing to give some of my free time to initiatives aimed at chronic disease management one could also detect differences depending on gender and language. Women were on average more willing to give time than men as were Italian, Polish and Portuguese-speaking participants (important to note that the majority of Polish and Portuguese-speaking participants were women).

This difference was less accentuated when asked if they would be willing to give some free time to citizen-led campaigns and initiatives (e.g. online forums, petitions, rallies, lobbying, action groups) aimed at chronic disease prevention.

Please see the detailed results below.

**From the Forum**

All citizens, at whatever level, are expected to cooperate actively, according to their means, to ensure the best own health and that of others. **Good health, as it depends on us, it is a social duty, a public good.** A choice (food or other) wrong is to be considered as guilty as a reckless or careless driving of a road vehicle. If I hurt even my health, knowingly and intentionally, I subtract resources to the society to which I belong: family, friends, company, town, country ...

# BACKGROUND

## Citizens' Rights and Responsibilities

*"Assuming that responsibility for health rests either with individuals or with society, it follows that society should also help to promote health and prevent disease."*

*Resnik, 2007*

How can we balance citizens' rights to healthcare on the one hand, with citizens' responsibilities to adopt healthy lifestyles on the other?

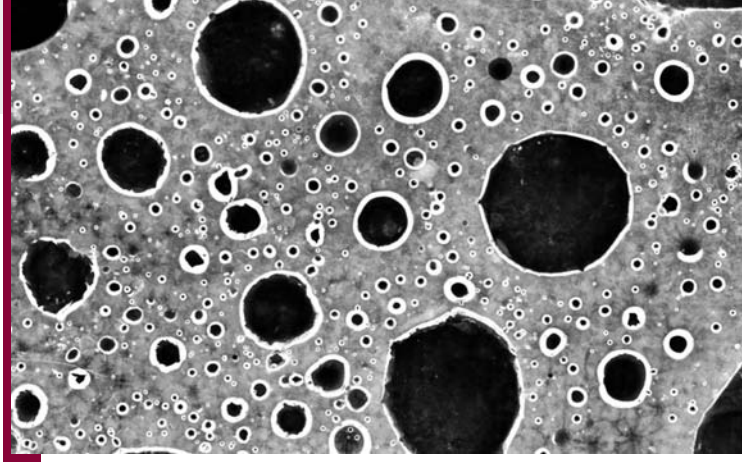
On a global scale, there is an imbalance. Despite advances in our understanding of management and prevention, chronic diseases are still on the rise. By 2030, 52 million more people will die from chronic diseases. Public healthcare systems are under strain, and their budgets are getting smaller. How can we reverse the chronic disease epidemic?

First and foremost, citizens can help themselves. According to the World Health Organisation (WHO), citizens can reduce new cases of heart disease, stroke, and type 2 diabetes by up to 80% if they avoid the risk factors of tobacco, alcohol, and junk food, while doing 30 minutes of exercise a day. But how can citizens be encouraged to make these healthier lifestyle choices?

The idea of linking healthcare benefits and services to 'healthy behaviours' has been fiercely debated, and dropped by policymakers in the past. Evaluating 'healthy behaviour' is far from straightforward. Even if we accept self-reporting, how can we differentiate between causes – are urban and social environments taken into account? Are individuals' socio-economic backgrounds taken into account? Is there a risk of stigmatising people who don't make the 'right' choices? And if we don't accept self-reporting, then how can peoples' lifestyle behaviours be monitored? Isn't this an invasion of privacy and personal freedoms? Or should people be more accountable for their lifestyle choices?

Some governments in Europe have already tried to encourage healthier lifestyle choices by introducing public smoking bans; heavy tax duties on tobacco and alcohol products; and nutritional information on processed food packaging. Austria, Hungary, Iceland, Norway and Switzerland followed the example of Denmark, which in 2003 was the first country in the world to nearly ban trans fats – one of the main causes of cardiovascular diseases - from the food market through regulation. Is promoting healthy lifestyles authoritarian? Or is a government that fails to do so guilty of neglect?

Governments and corporations alike are increasingly borrowing from behavioural economics to 'nudge' citizens into healthier lifestyle choices. For example, in Iceland a "LazyTown" television programme and mobile app was created in 1996, in which the healthy superhero "Sportacus" motivates children to eat healthy food and be more active, while parents reward these bahaviours with small prizes. The programme successfully reduced child obesity rates. In addition, 27-42% of pre-school children perceived LazyTown's branded health food to be tastier than identical non-branded alternatives. In the corporate sphere, Google re-designed its staff cafeterias to encourage healthy eating, with the number of Googlers eating fresh fruit and vegetables climbing by two-thirds. In China, work starts with half an hour of exercise. Nestlé adopted the same approach in his Swiss Headquarters.



As the spread of big data make citizens' and employees' behaviours and habits increasingly transparent for both the private and public sector, opportunities to influence their choices to increase their wellbeing are multiplying, however, moral implications with reference to privacy and freedom are far from being clear while the border between "nudging" and "manipulating" appears sometimes very thin.

Clearly, citizens can't do it alone. Multi-stakeholder partnerships between public, private, and third sector actors are needed to co-create healthier societies and tackle big societal issues including: environmental pollutants such as insecticides, pesticides, and fertilisers; artificial additives used in the food processing industry such as refined sugar and trans-unsaturated fatty acids; and air pollution, which is responsible for 400,000 premature deaths in Europe every year, and has become the world's top environmental cause of premature mortality ahead of dirty water and lack of sanitation. They are also tasked with developing and delivering healthcare products and services.

Further action is required by citizens, policymakers, healthcare providers, businesses, and other stakeholders in order to better manage and prevent chronic non-communicable diseases. However, key questions and points for debate remain about how these actions could or should affect citizen's rights and responsibilities.

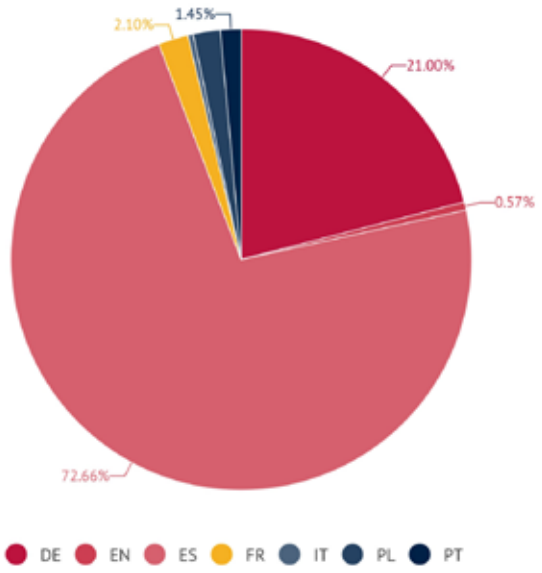
# RESULTS

GRAPH 4.1

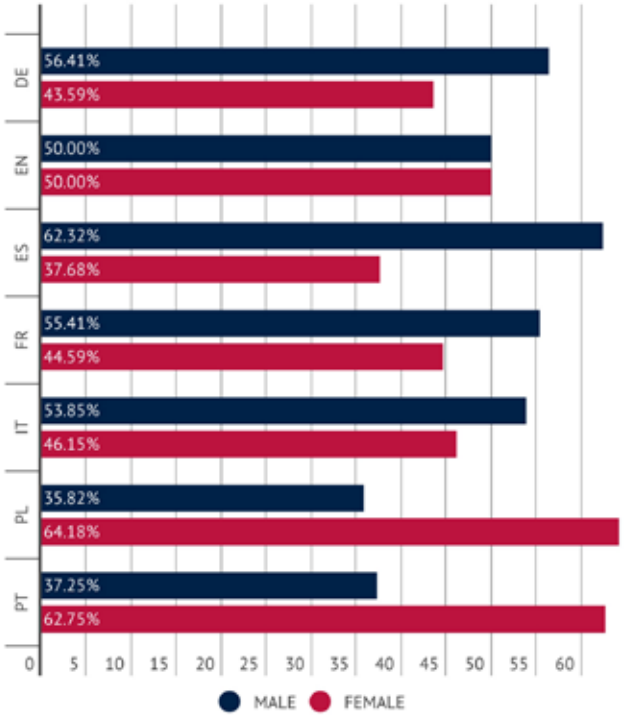
## HOW MUCH DO YOU VALUE YOUR HEALTH?

**And what value do others place on it?**

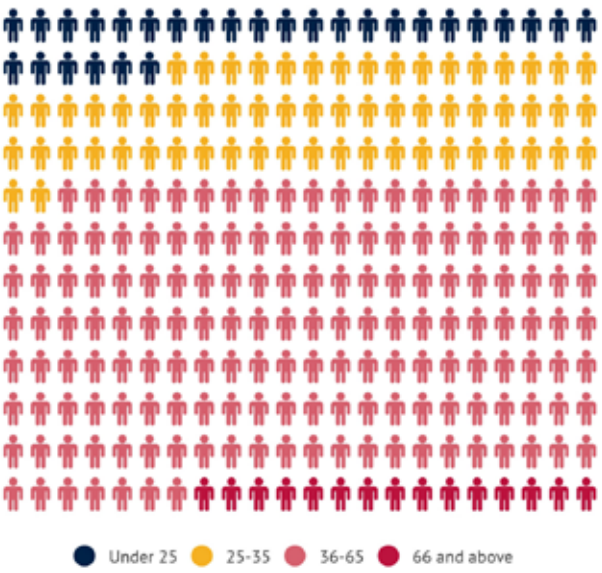
### 4.1.1 participation by language



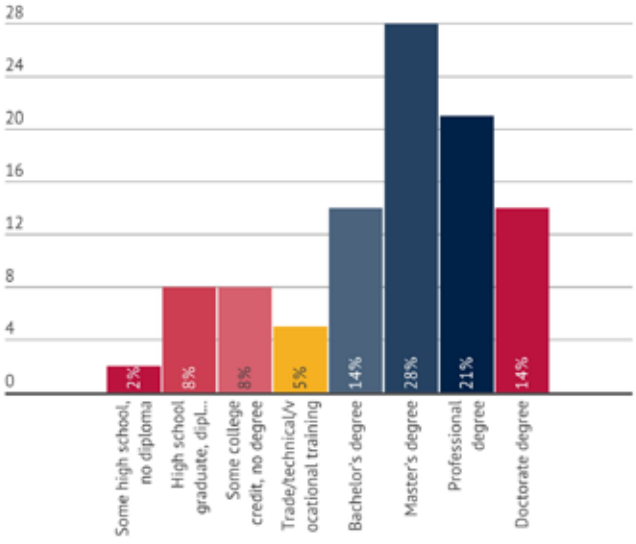

### 4.1.2 participation by gender




### 4.1.3 participation by age




### 4.1.4 participation by education

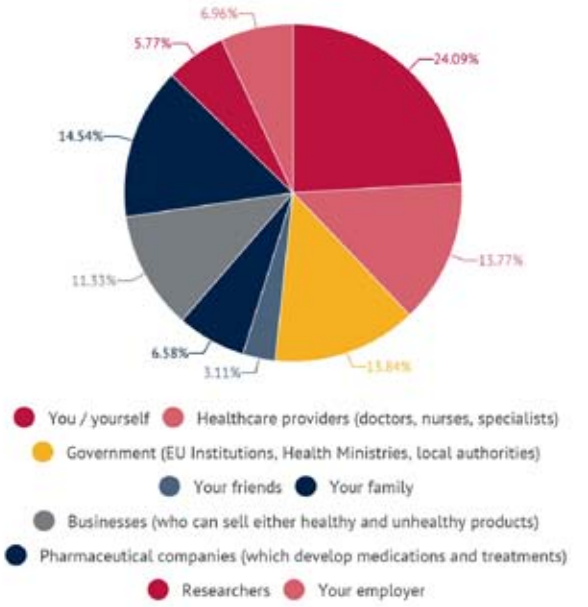


GRAPH 4.2

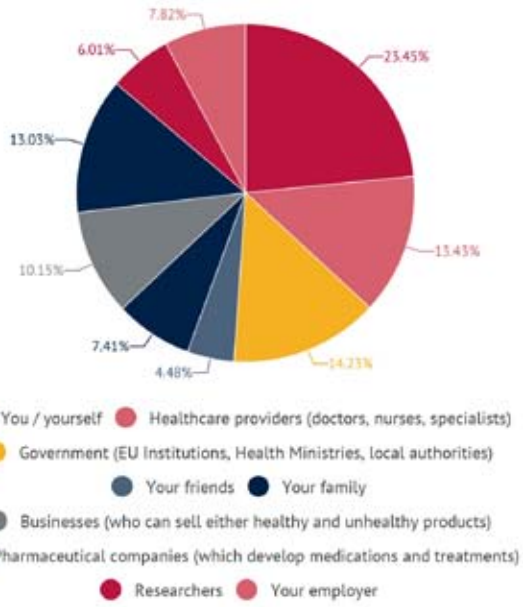
# Who is responsible for your personal health?

Tick as many as you feel appropriate

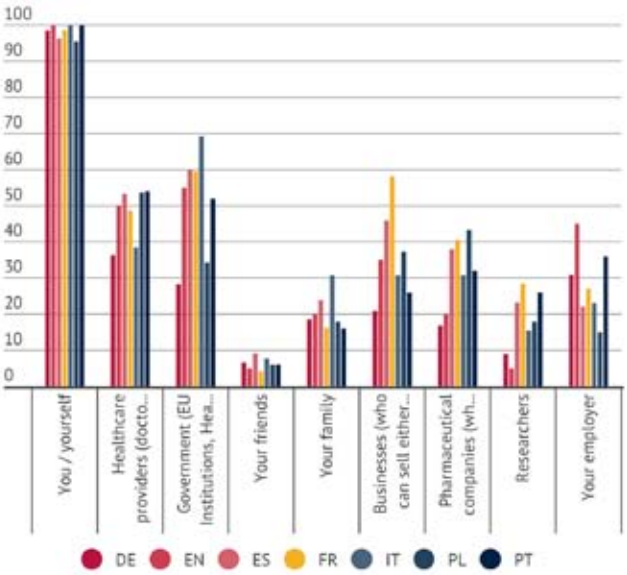
## 4.2.1 all responses



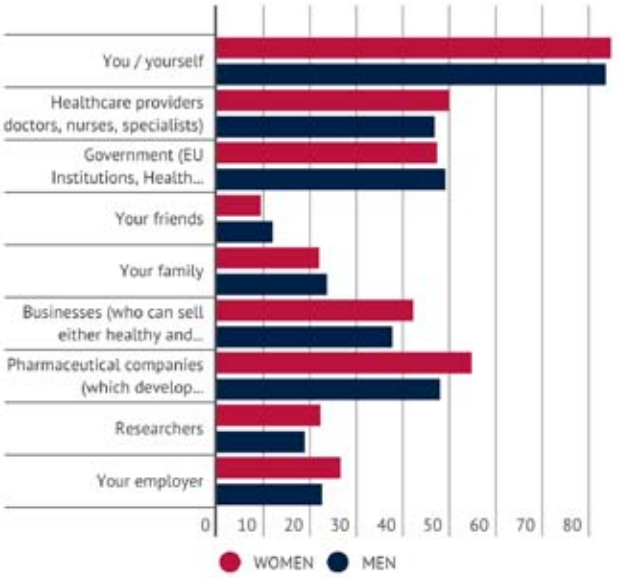

## 4.2.2 researcher responses




## 4.2.3 by language




## 4.2.4 by gender

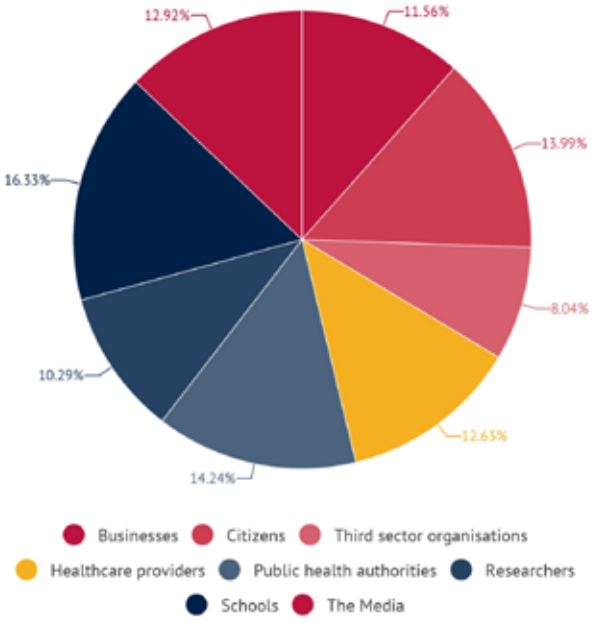


GRAPH 4.3

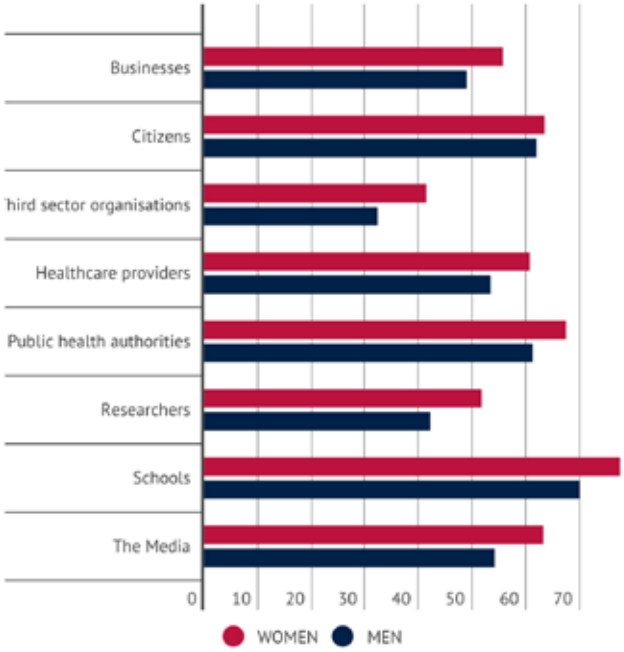
# ★ The following stakeholders should play a major role in promoting healthy lifestyle behaviours to help prevent or manage chronic diseases ★

Tick as many as you feel appropriate

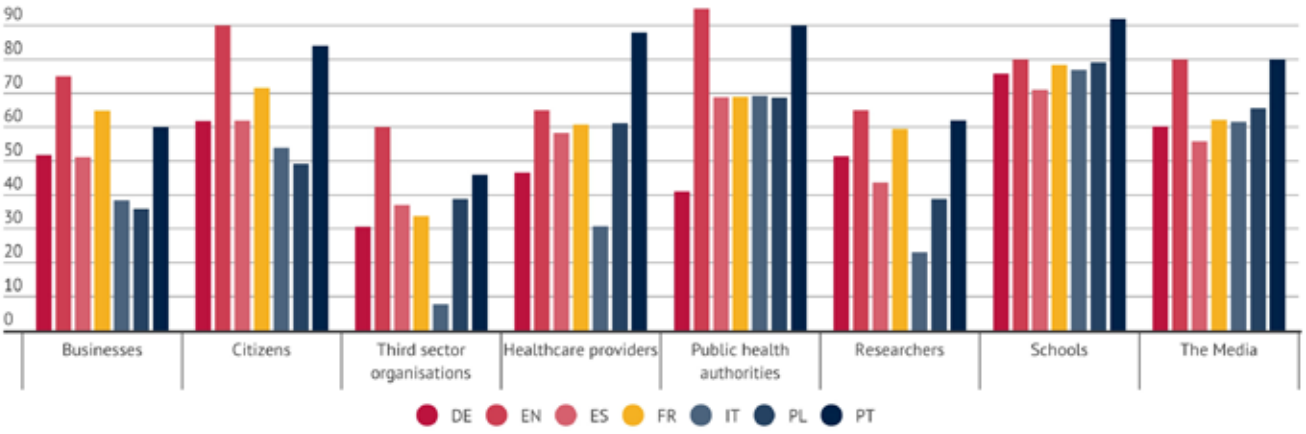
## 4.3.1 all responses




## 4.3.2 by gender

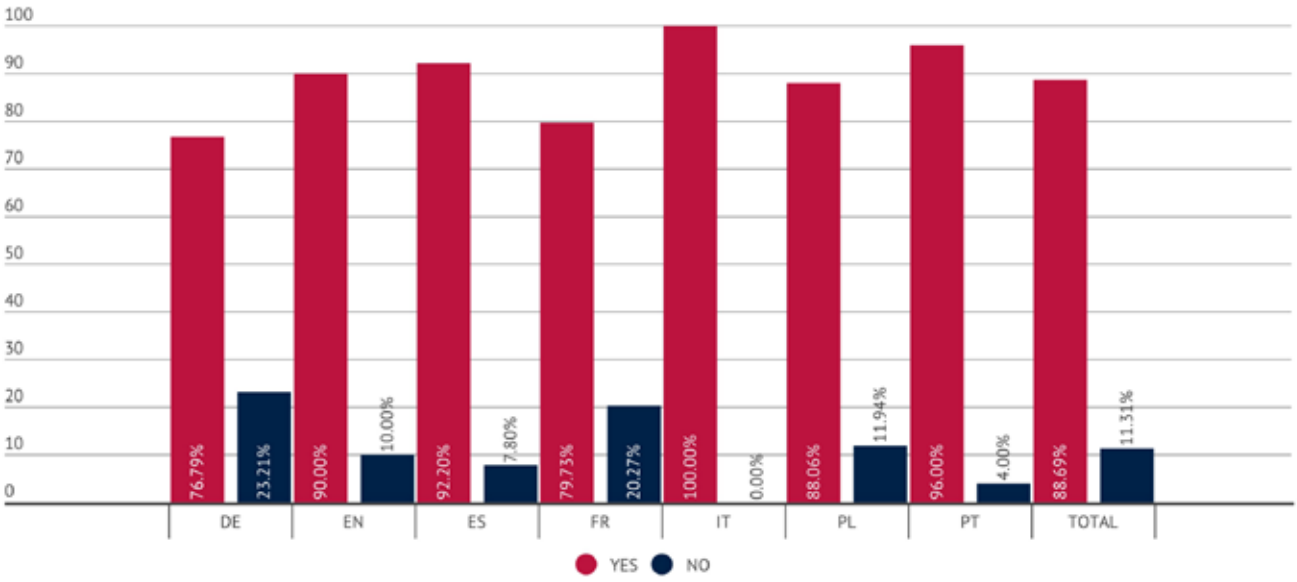



## 4.3.3 by language



GRAPH 4.4

## ★ As a citizen, I want to learn more about my rights and responsibilities in the field of chronic disease prevention ★

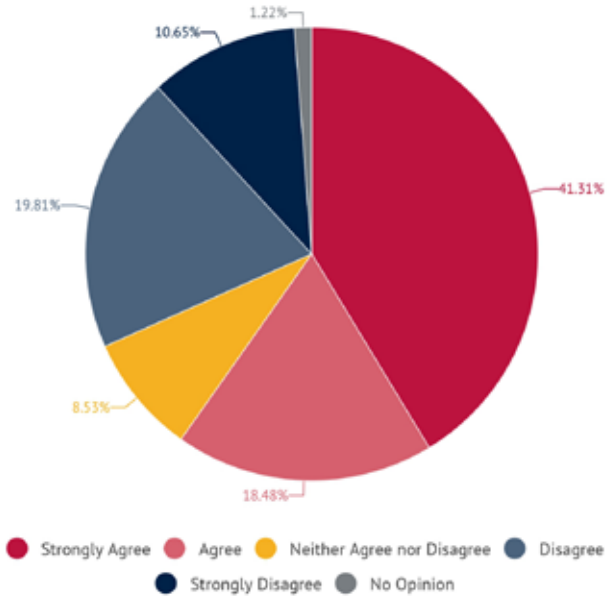


GRAPH 4.5

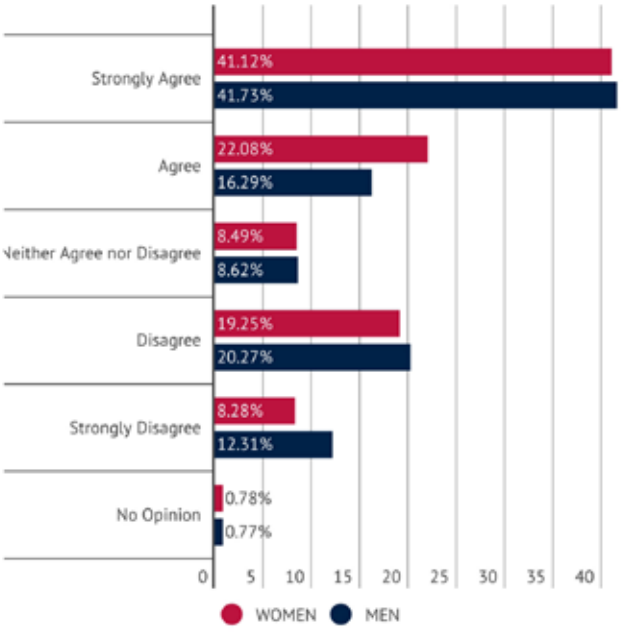
# ★ Access to free healthcare should be granted to everyone, irrespective of his or her personal lifestyle choices ★

DO YOU AGREE?

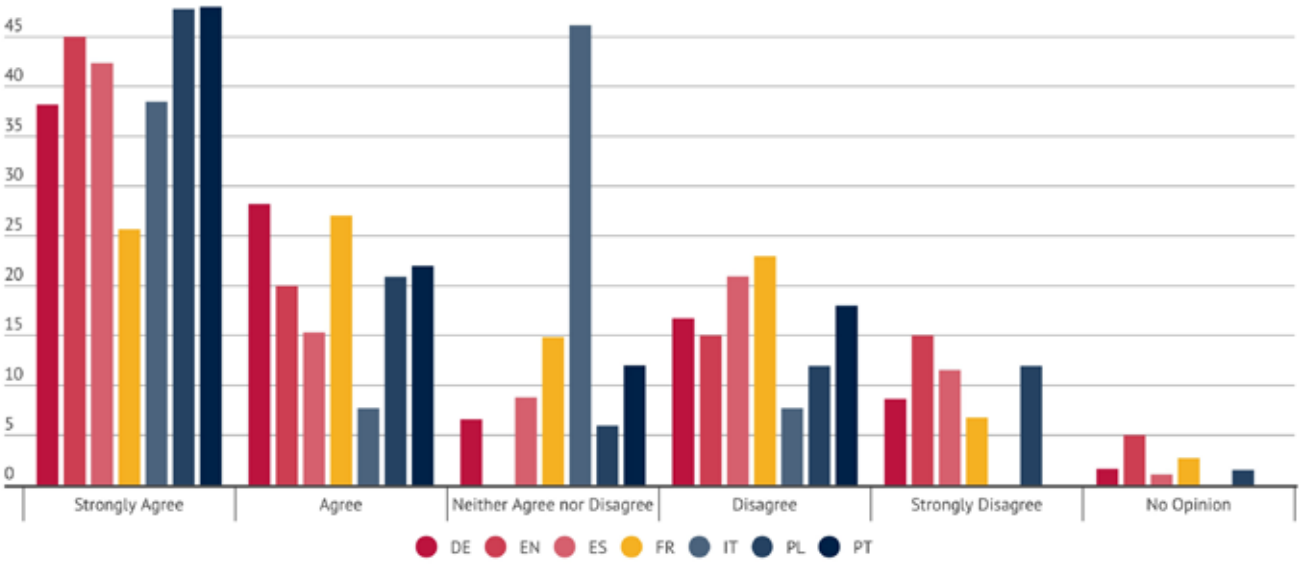
## 4.5.1 all responses




## 4.5.2 by gender




## 4.5.3 by language

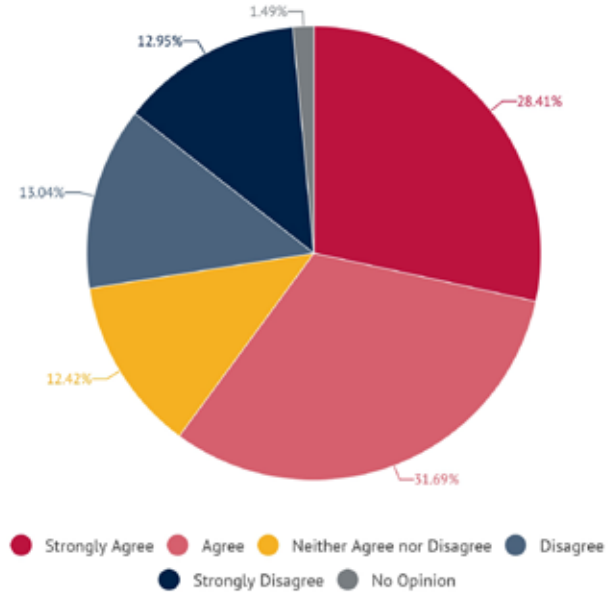


GRAPH 4.6

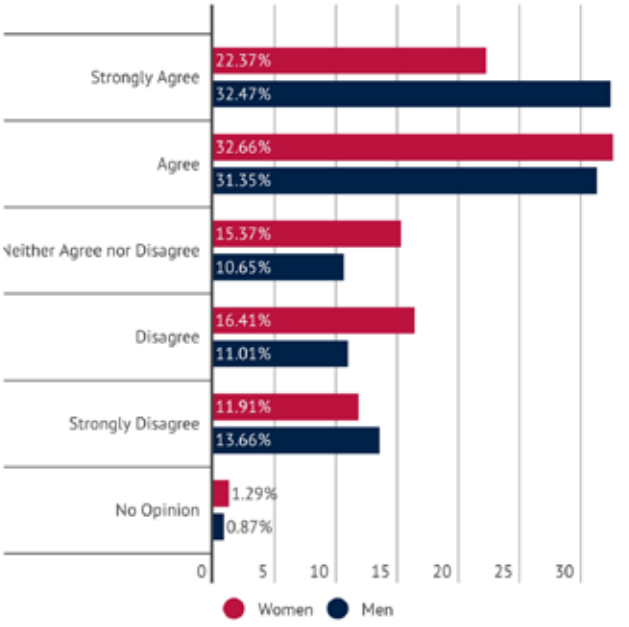
# ★ Employers should reward workers for participating in wellness programmes and meeting health benchmarks. ★

DO YOU AGRRE?

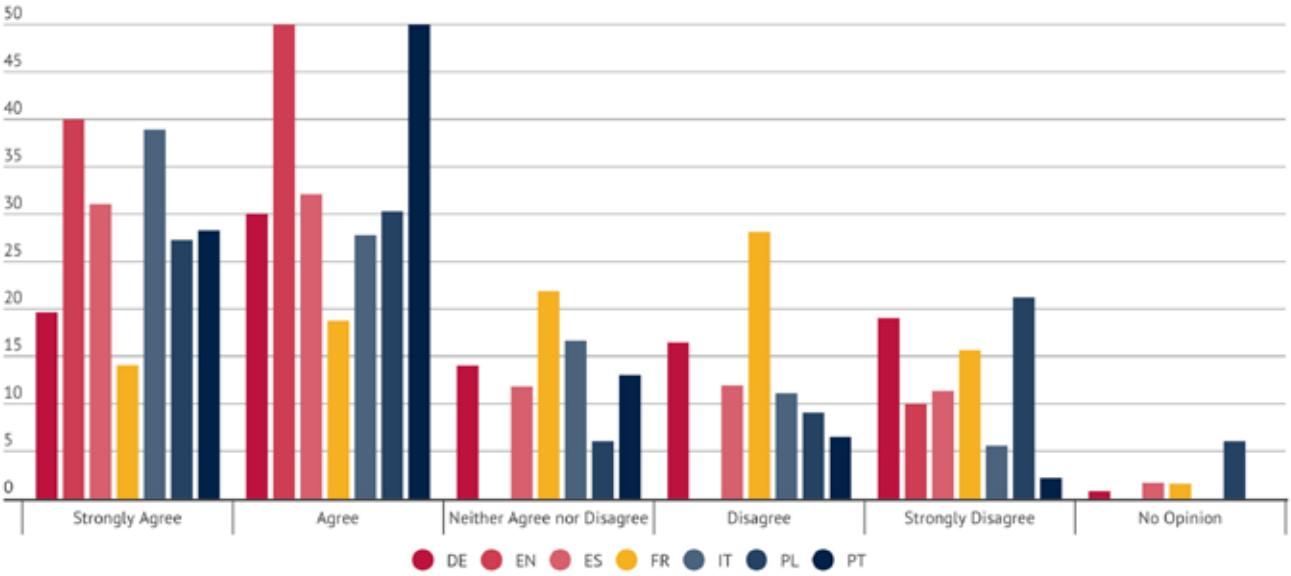
## 4.6.1 all responses




## 4.6.2 by gender



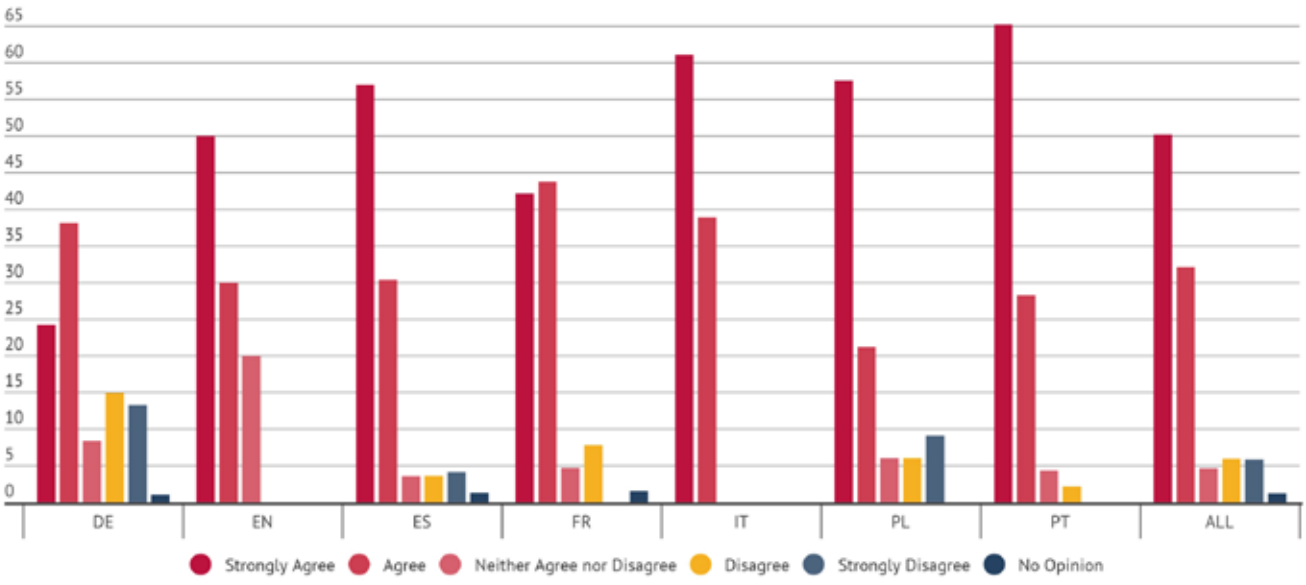

## 4.6.3 by language




GRAPH 4.7

## I believe that governments, companies and third sector organizations should all use their knowledge of citizens' habits to induce healthy behaviors, while collaborating to create healthy environments and products.

Do you agree?

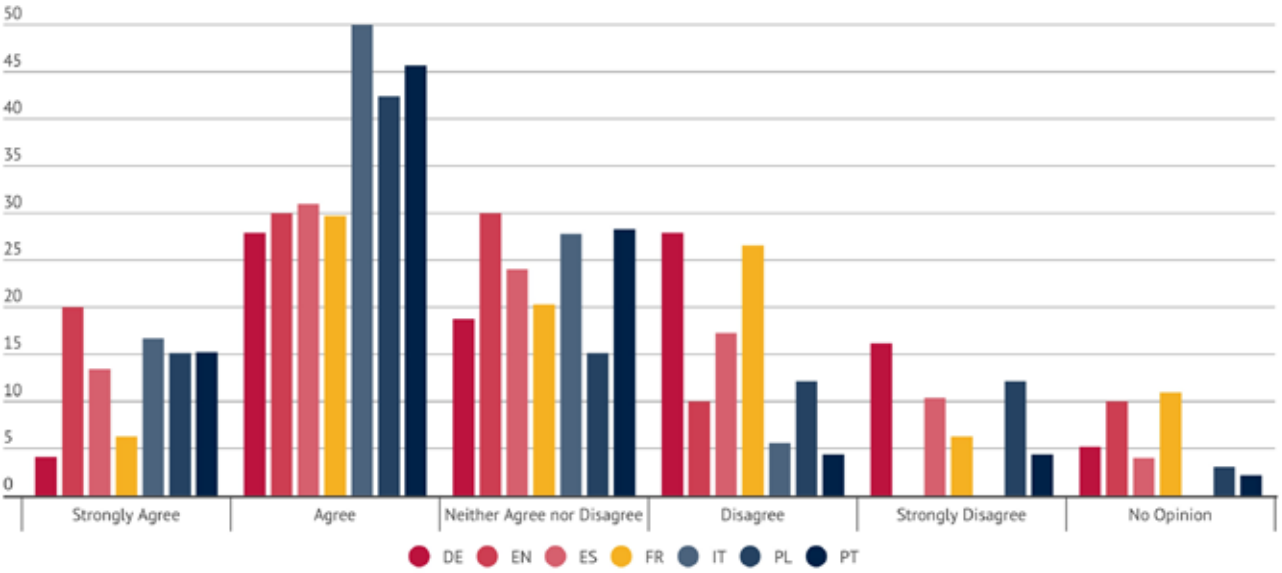


GRAPH 4.8

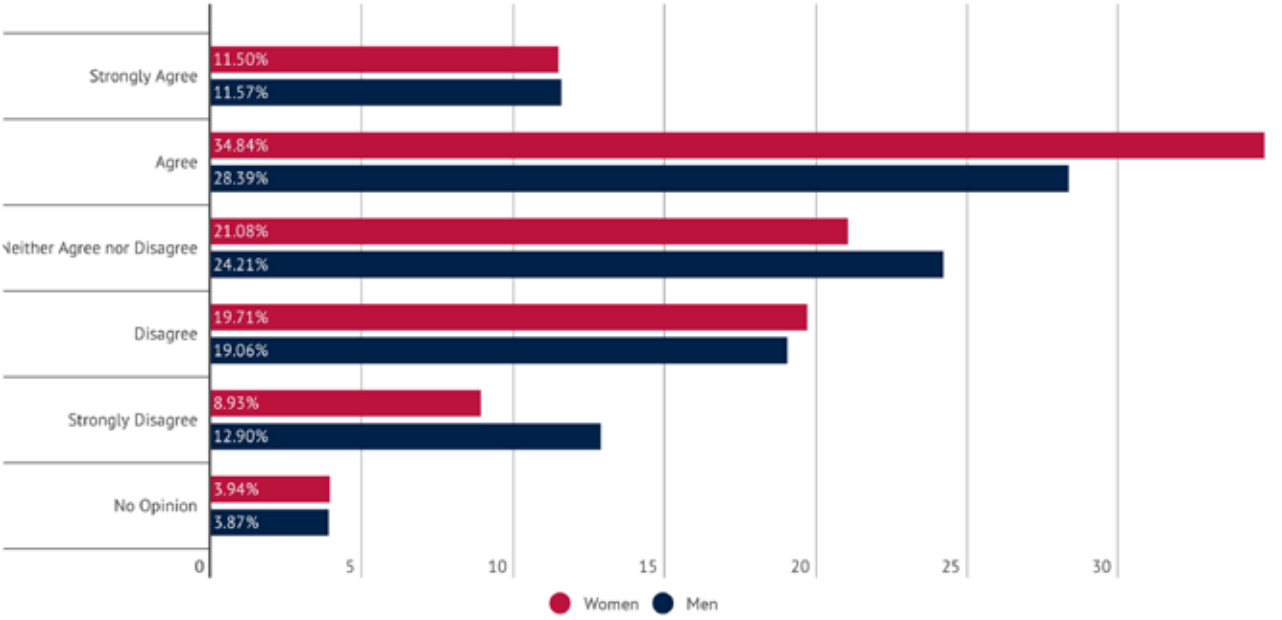
# ★ I would be willing to give some of my free time to initiatives aimed at chronic disease management. ★

**Do you agree?**

## 4.8.1 by language




## 4.8.2 by gender

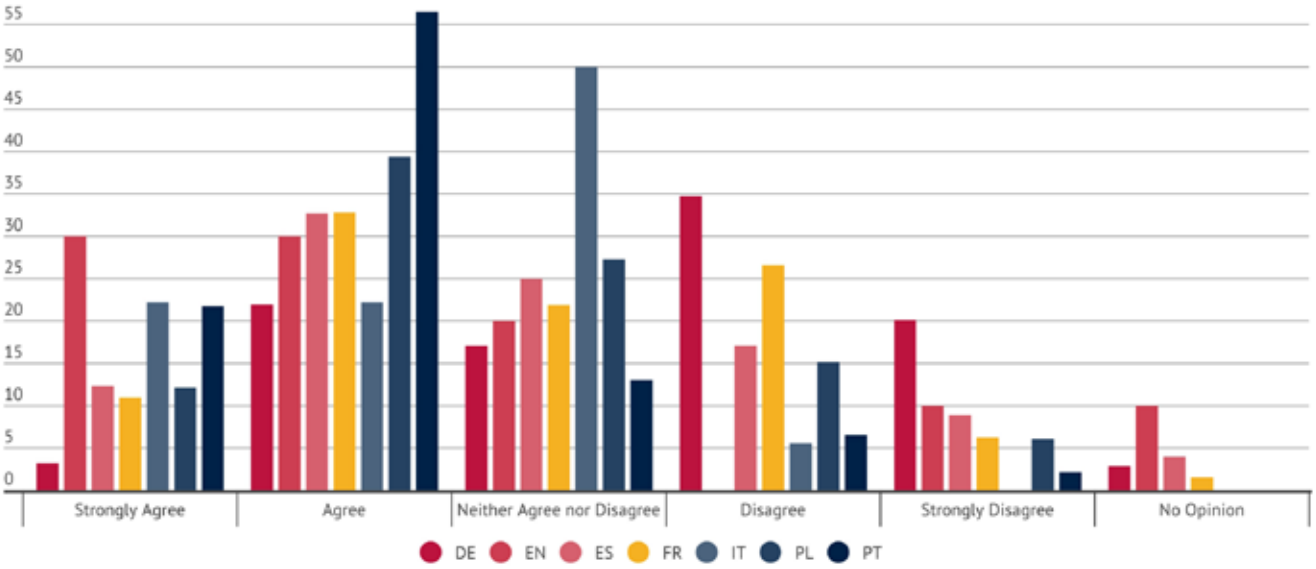


GRAPH 4.9

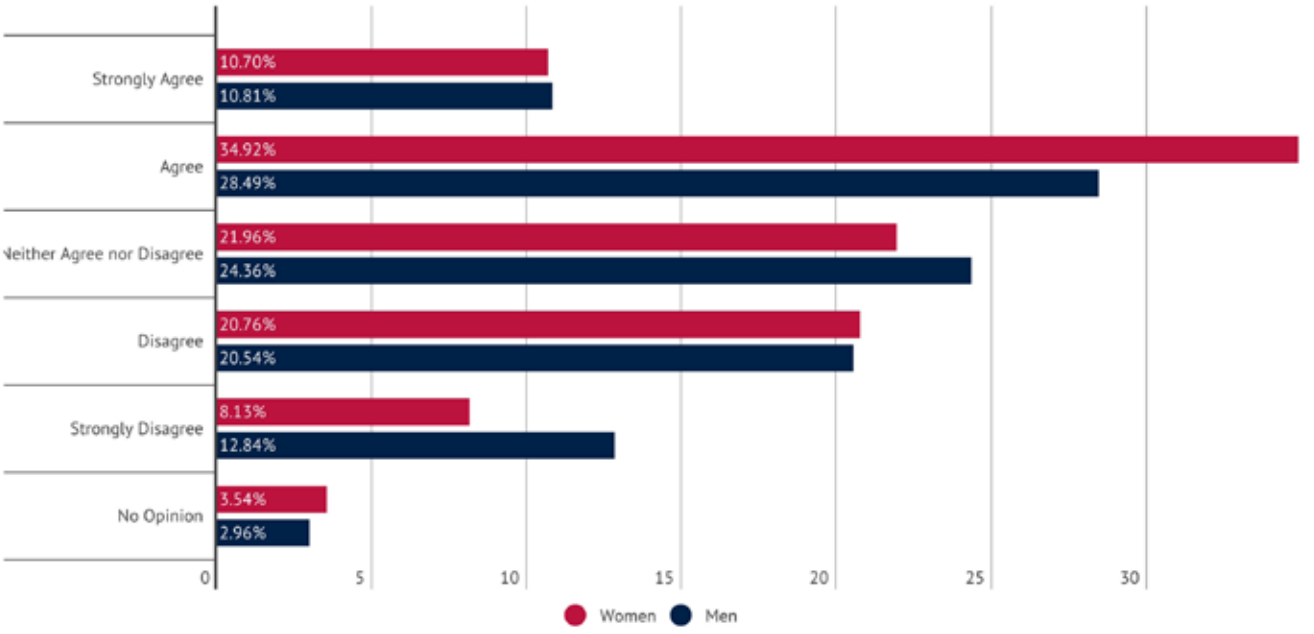
## "I would be willing to give some of my free time to citizen-led campaigns and initiatives (e.g. online forums, petitions, rallies, lobbying, action groups) aimed at chronic disease prevention"

**Do you agree?**

### 4.9.1 by language




### 4.9.2 by gender



# RECOMMENDATIONS

Based on the needs as highlighted by policymakers, the facts as put forward by researchers and the suggestions and opinions of citizens, the following policy recommendations are in line with the findings of the campaign.

## 1- Education

The results of the campaign clearly show how EU citizens see education as the most important tool to eradicate health inequality and to empower people to become responsible for their wellbeing. According to a recent study led by the Commission's Joint Research Centre, all the 28 EU Member States have guidelines for school food, aiming at providing children with balanced nutrition and healthy habits that will accompany them all along their lives. Seminars and courses aiming at preventing and reducing youth smoking and drinking are also becoming increasingly common. Both the public sector and the third sector have been working with targeted communities or citizens at large to promote healthy behaviours. These initiatives should receive further support by policy makers, and further research and knowledge transfer should be encouraged to better understand how to empower different groups of citizens to take the best decisions for their health and wellbeing.

## 2- Nudging - Role of the Media

'Nudging' is based on behavioural economic models and aims to get citizens to make healthier lifestyle choices nearly without realising it. In the UK, a Behavioural Insights Team was established in 2010 in the Cabinet Office to look at how citizens could be nudged in subtle ways to choose behaviours and activities positive to their health and wellbeing.
Success of media activities is this area is also demonstrated by the responsibility that the participants set on the media.
However, "positive" nudging is increasingly used by the private sector too.
Further research is needed to better understand how to adjust the most effective marketing techniques to the goal of promoting healthy life-styles.

## 3- Regulation

Regulations, such as branding and taxing tobacco are important tools in incentivising good behaviour. It seems however that a majority of the participants still felt that these regulations should be about incentives and raising awareness but still allow everyone to have access to free healthcare irrelevantly of their behaviour.

The issues of "more and better data" will be dealt with specifically in the next chapters.


These are the headlines of some of the articles published during the week on "Diabetes and Nutrition" of the Citizen Engagement and Media Campaign on Chronic Diseases.

# WEEK 4 – DIABETES AND NUTRITION

## OVERVIEW

Diabetes has been identified as a 'global health emergency' and 'global public health crisis' that urgently needs to be addressed. Despite better awareness and new developments in the management and/or prevention of diabetes, there has been an unrelenting increase in the number of people with diabetes over the last 50 years. At current rates, the number of people suffering from diabetes worldwide is estimated to increase from 415 million (1 in 11) adults in 2015, to 642 million (1 in 10) adults by 2040.

Prevalence of diabetes is increasing steadily among all ages, both among men and women, mainly due to increases in overweight and obesity, stemming from unhealthy diet and physical inactivity. What we can do to stop this epidemic?

These are some of the difficult questions that were launched during the week of the 7th of March 2016 that focussed the *Citizen Engagement and Media Campaign on Chronic Diseases* on the issue of "diabetes and nutrition". The aim of the campaign was twofold: to increase awareness of the difficulties posed by these questions and to find out more about what citizens actually feel about some of these difficult moral questions.

The campaign saw the highest participation from German-speaking participants and a men being over-represented with the German, French and Italian-speaking participants. Within the English, Spanish, Polish and Portuguese-speaking participants there was instead an over-representation of women with the latter three seeing over 70% of participants being female. As with the other weeks a majority of participants were between the ages of 26-35 and had a degree (graph 5.1).

A majority of participants were mostly interested in type 2 diabetes (graph 5.5) and that tackling this disease will require a coordinated effort of all the stakeholders including: businesses, citizens, Civil Society Organisations, healthcare providers, public health authorities, researchers, schools and the Media.

The awareness of the complexity of the issue at hand and that every actors has a role and a responsibility was further shown when nearly 90% of the participants agreed that diabetes prevention and management requires the coordinated intervention of the public, private and third sector, and the active involvement of patients and citizens (graph 5.3).

**From the Forum**

We went from a society where we did not know what was obesity that food were not processed nor refined and where physical activity was the order of the day to a society that barely moves and where processed foods are so easily available and addictive. It would be a pity if Europe with its culinary diversity and history cannot change its course.

When asked which initiatives could help prevent type 2 diabetes nearly 90% of participants included *nutrition education, healthy meals, and physical activity in schools* compared to 75.6% who choose *regulate the amount of sugar in industrial food products, 60.4% nutrition education, healthy meals and physical activity in the workplace* and 53.8% who suggested *urban re-development to encourage movement*. Banning of advertising (38.7%) was the least selected choice of action (graph 5.4).

**From the Forum**

I propose excursions for children and youth, as part of their education, to processed food factories where they can see and learn what all these snacks and drinks have inside. It is important that they understand that this is not good for them. **Education is not only the role of the family but also of society.**

However over 75% of participants want governments to regulate amount of sugar salt and trans fat present in industrial food products (graph 5.8) underlining the clear role of governments in protecting consumers. Similar numbers can be seen when looking at whether participants agreed that governments, companies and civil society organizations should use marketing and communication technologies to nudge citizens into eating healthy food and doing some physical activity to help prevent the rise of diabetes.

Looking also at the debates within the REIsearch forum and social media outlets, there seemed to be a concern about the issue and the willingness to change behavior provided that these were made easier by education and awareness, regulation (salts, sugars, trans fat), incentives and environment.

Participants seemed less enthusiastic about their willingness to use new technologies (e.g. watches, bands, sensors) to monitor their diabetes risk factors (e.g. nutrition, physical exercise) and then share this data for public health research and policy purposes. Only slightly more than half of the participants would be willing to do so. Interestingly, this number increases to 75% when asked if they would be willing to do so "if they were diabetic".

Please see the detailed results below.

**From the Forum**

Despite the enormous number of affected people, there is not enough interest in the investigation into diabetes. Medical and pharmaceutical industries continue with the same as always and earn billions. The hospitals flourish. There is no incentive to chnage the status quo.

That diabetes (at least type II) is curable, is disputed by doctors. However, there are numerous indications that a healthy lifestyle can certainly cause diabetes disappears. So lets do more and make more people aware!

# BACKGROUND

## Diabetes and Nutrition

*"Diabetes is one of the largest global health emergencies of the 21st century."*

*International Diabetes Federation, Diabetes Atlas 2015*

Diabetes is one of the largest global health emergencies of the 21st century. On a global scale, there are an estimated 415 million people aged 20-79 with diabetes, including 193 million who are undiagnosed, and a further 318 million adults with impaired glucose tolerance at high risk of developing the disease. In 2015 alone, diabetes and its related complications will have caused 5 million deaths, and cost $673-1197 billion in healthcare expenditure - 12% of the global healthcare spend. How can we slow, stop, or reverse the diabetes epidemic?

There are 3 main types of diabetes: type 1, type 2, and gestational diabetes. In developing and developed countries alike, the worrying increase in type 2 diabetes has been inherently linked to ageing populations, economic development, increasing urbanisation, less healthy nutrition, reduced physical activity, and a chronic rise in overweight and obese populations.

While some risk factor such as ageing are unavoidable, type 2 diabetes treatment, reversal, and prevention must focus on 'modifiable' risk factors, and particularly the adoption of healthy nutrition, increased physical activity, and maintenance of a normal body weight. These healthy lifestyle behaviours could reduce all new cases of type 2 diabetes by as much as 65-80% according to the World Health Organisation (2016). New healthcare technologies that monitor and promote physical exercise, such as health and fitness apps, wearable devices (e.g. watches, bands) for monitoring physiological data, and online cloud-based health management platforms are increasingly contributing to improve the quality of life of people affected by diabetes.

Of course, diabetes management and prevention cannot be left to patients alone. Much can be done by policy makers, businesses, and civil society to build physical and cultural environments conducive of healthy habits. Re-designing cities, public spaces and work spaces to encourage physical activities, for instance by ensuring that work-places, schools and shops are well-connected to residential areas through cycle lane and pedestrian walkways, that there are a sufficient number of green areas and pedestrian areas, that air-pollution is under control and that stairs are as easy to spot as elevators, could strongly contribute to contain the diabetes 2 epidemics. Are public and private institutions doing enough in this regard? How much should they invest? Can they afford not to? How do you measure the benefits?

Universalistic approaches to balanced nutrition have proved effective in some EU Countries, so for instance in Finland, where school children, students and employees all receive free or subsidised low-fat meals at school or in the workplace, socioeconomic inequalities in the use of butter and high-fat milk have remarkably declined. Tailored approaches, aiming at making healthy food more attractive to children for examples, have also proved successful.

Many questions remain: what is the best nutrition for preventing diabetes? What is the best way to inform and encourage 'health literacy' at school, work, and home? Should policymakers legislate against unhealthy food products and adverts at the national or EU institutional level? How can we include socio-economically disadvantaged groups - who are most at risk of diabetes – in management and prevention initiatives?

Greater knowledge of the societal constructs underpinning diabetes could certainly help design more effective interventions. For example, the "Cities Changing Diabetes" project brings together pharmaceutical companies, universities, third sector organisations, and policy makers from 11 cities around the world to address the rise of diabetes in urban centres by mapping its extent, understanding its social, economic and cultural drivers, and by sharing and implementing effective approaches to collectively overcome this challenge. They found that diabetes in Mexico city is associated with stress, and particularly long commutes, exploitation, social insecurity, and delinquency; while diabetes in Shanghai is strongly stigmatized and associated with weakness and old age.

An anthropologic approach is needed to understand how to better fight diabetes, and a holistic intervention, bringing together different actors and expertise, and building on shared value and sustainable development theory and practices, is needed to implement effective strategies.

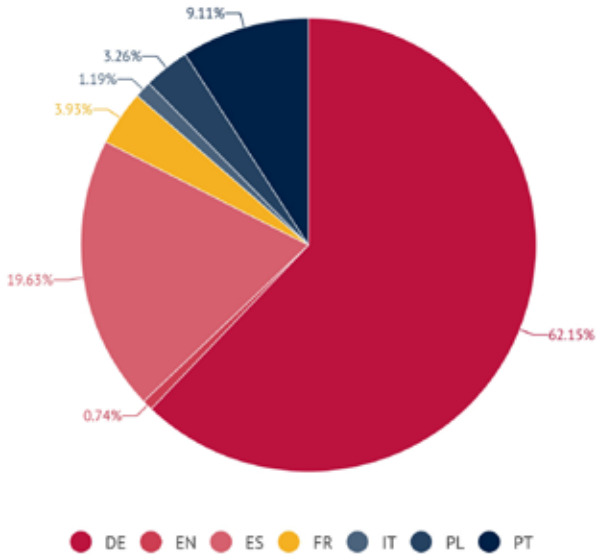
# RESULTS

GRAPH 5.1

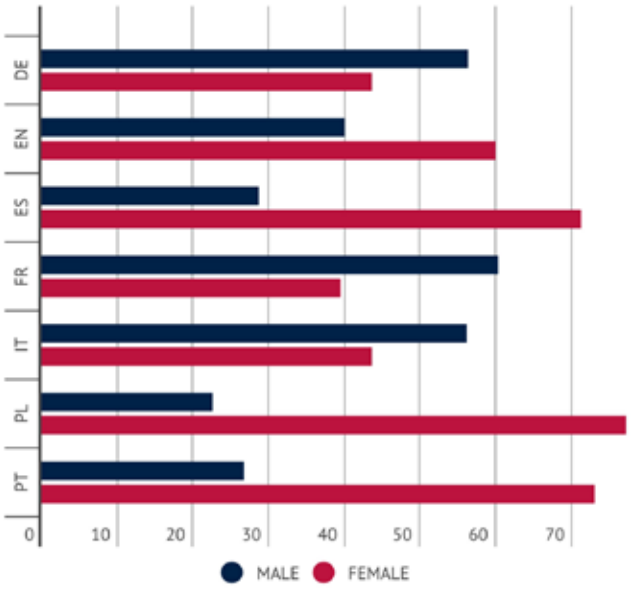
## DO YOU KNOW WHAT YOU ARE EATING?

**Do you control your diet or does your diet control you?**

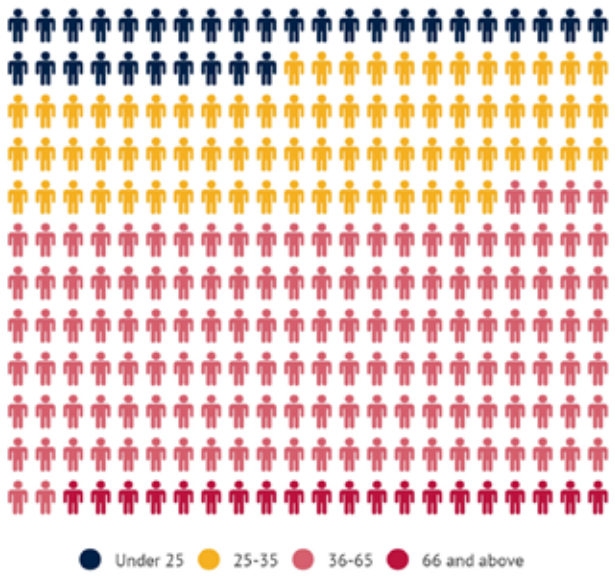
### 5.1.1 participation by language



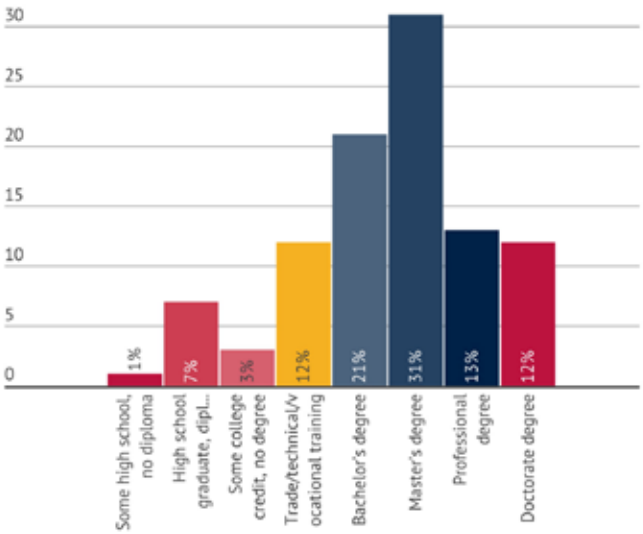

### 5.1.2 participation by gender




### 5.1.3 participation by age




### 5.1.4 participation by education

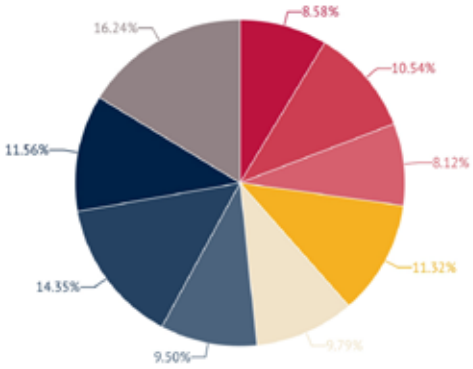


GRAPH 5.2

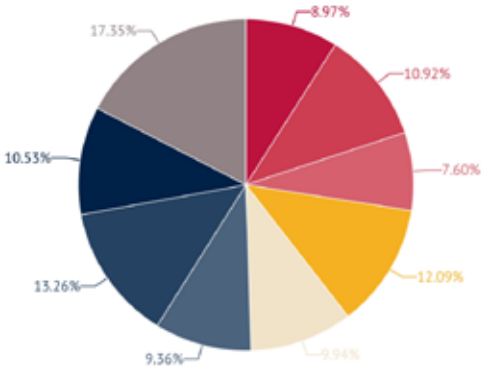
# ★ In your opinion, which of the following stakeholders has a role to play in type 2 diabetes prevention? ★

**Choose as many options as you feel appropriate**

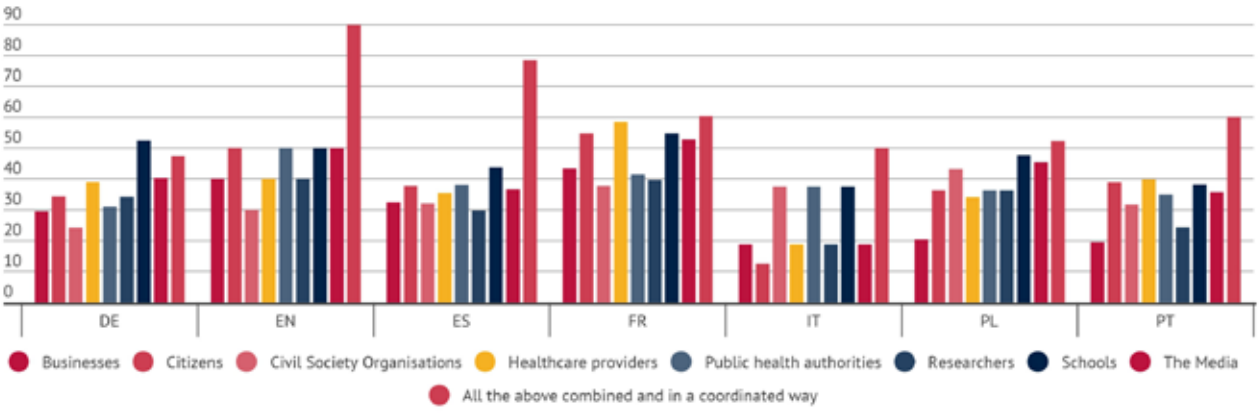
## 5.2.1 all responses




## 5.2.2 researcher responses




## 5.2.3 by language



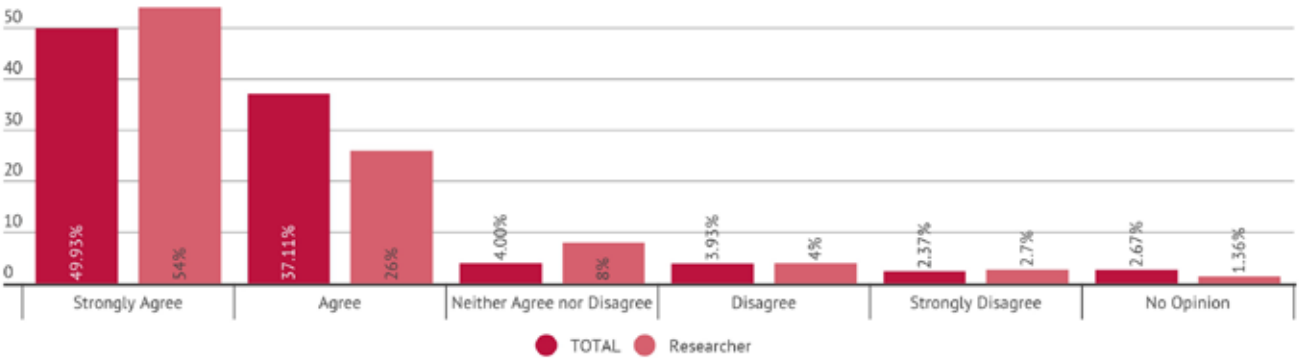

## 5.2.4 by gender

GRAPH 5.3

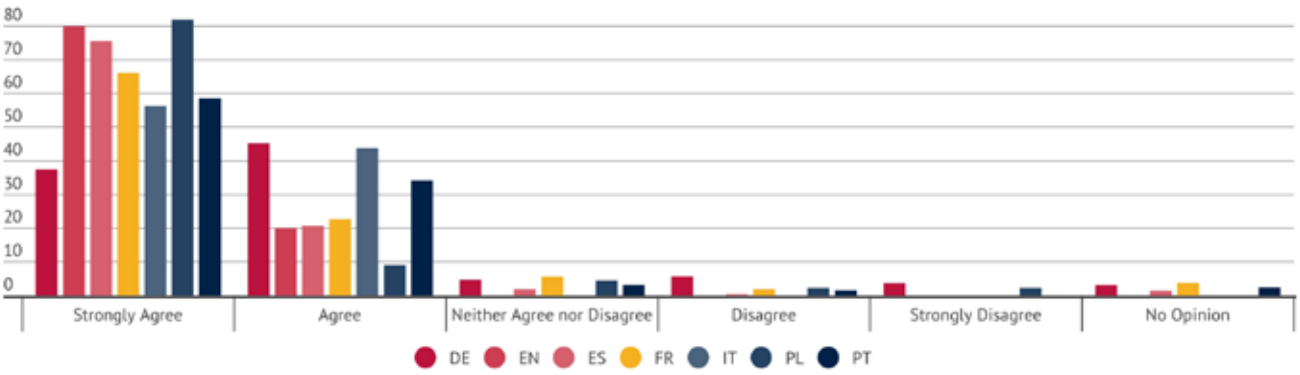
# Diabetes prevention and management requires the coordinated intervention of the public, private and third sector, and the active involvement of patients and citizens

Do you agree?

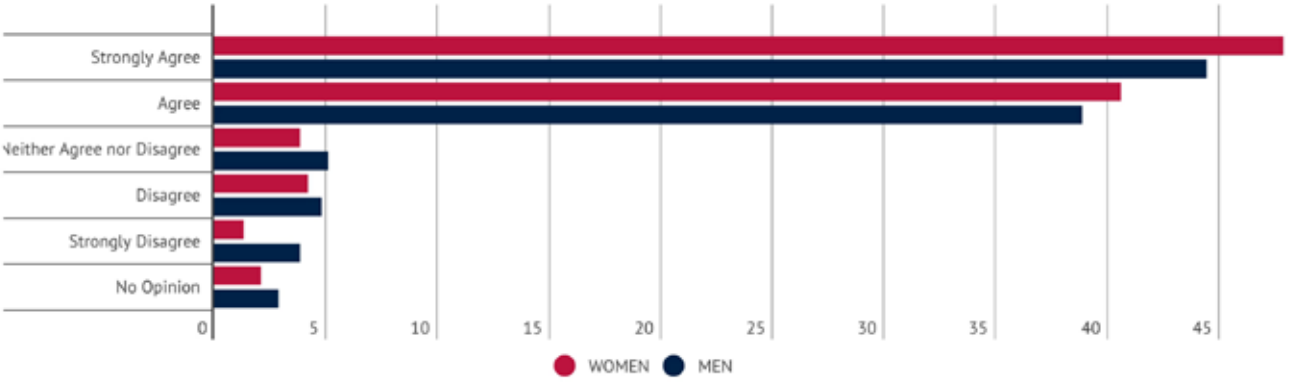
## 5.3.1 all & researcher responses (percentage of total)




## 5.3.2 by language




## 5.3.3 by gender

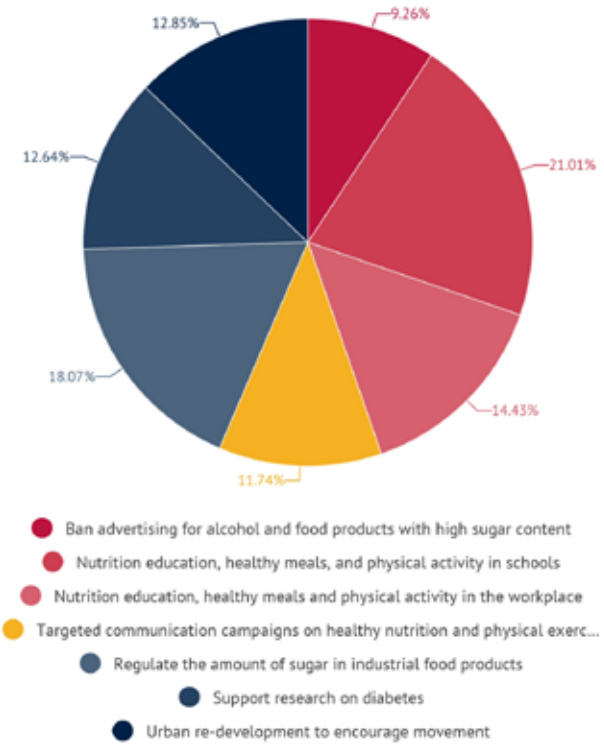


GRAPH 5.4

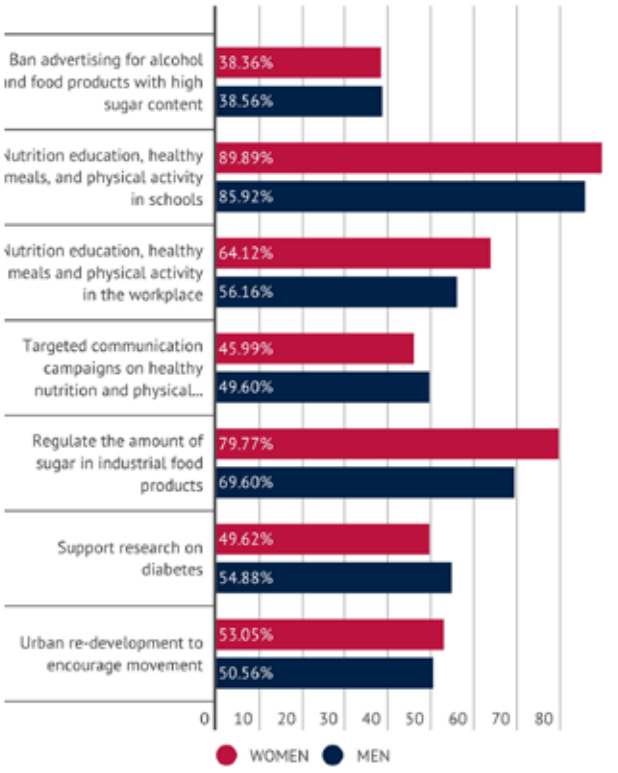
# In your opinion, which of the following initiatives can help prevent type 2 diabetes?

Select as many as you feel appropriate

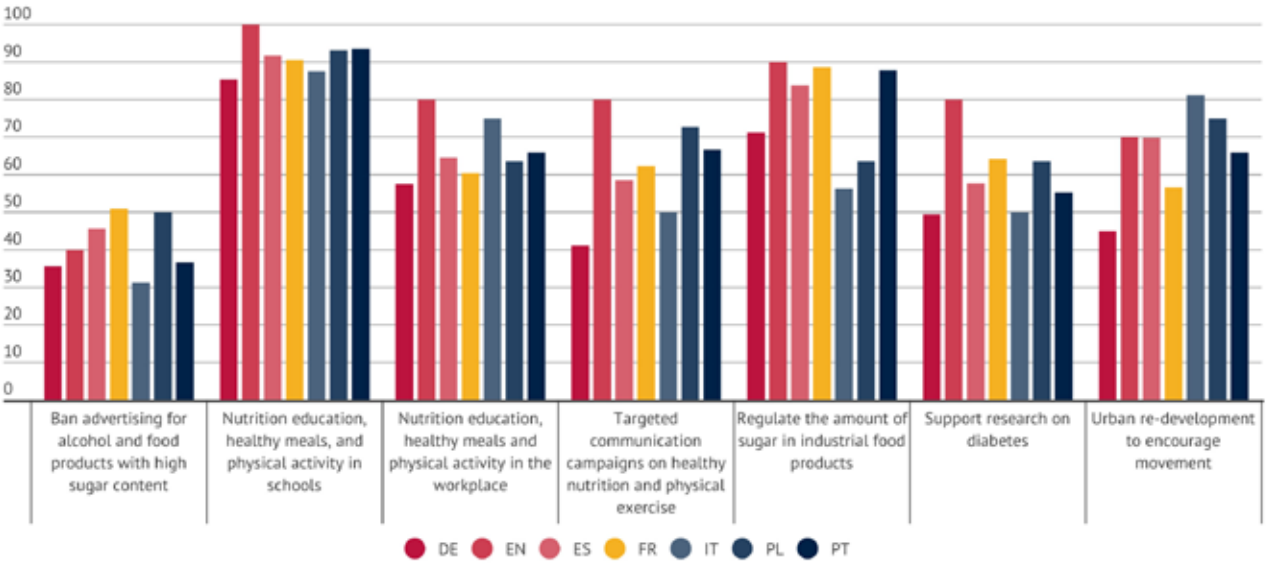
## 5.4.1 all responses




## 5.4.2 by gender




## 5.4.3 by language

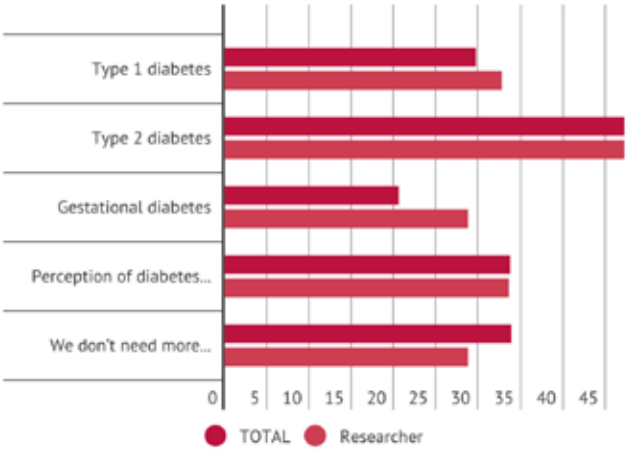


GRAPH 5.5

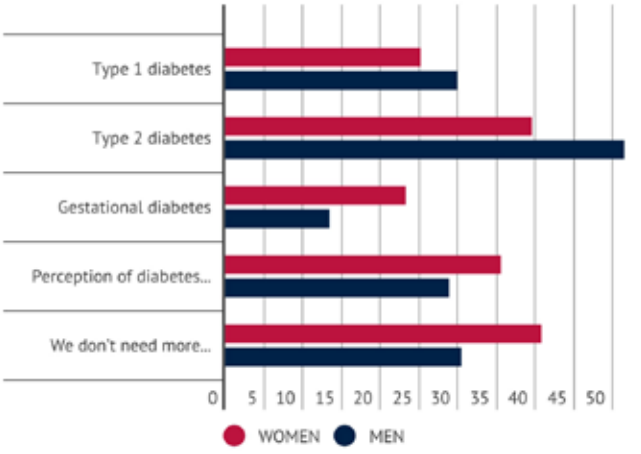
# What are you most interested in finding out more about ?

Tick as many as you feel appropriate

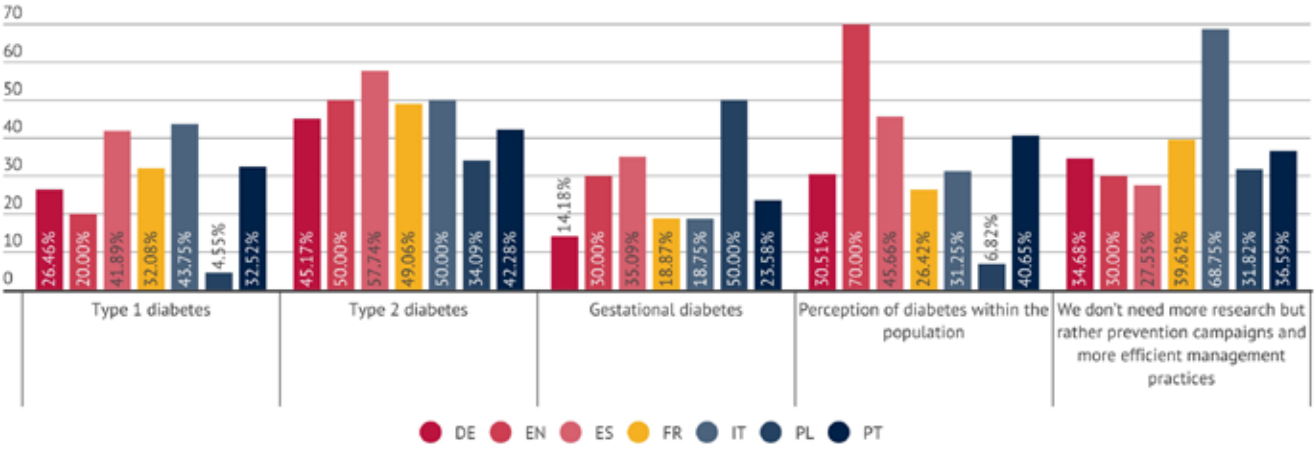
## 5.5.1 all & researcher responses




## 5.5.2 by gender




## 5.5.3 by language

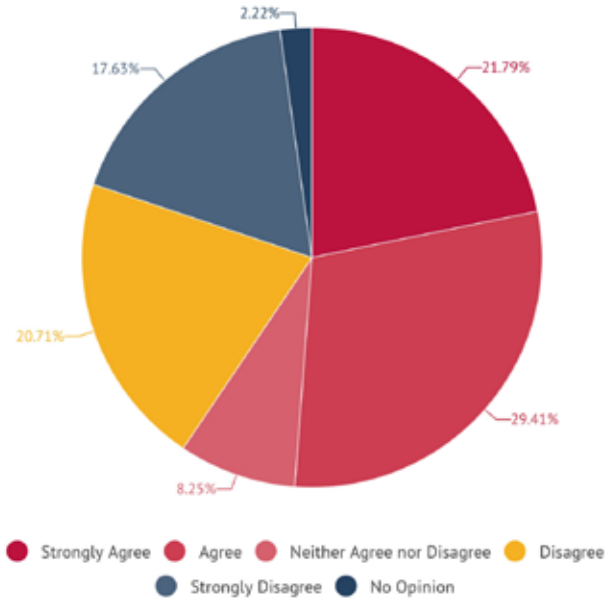


GRAPH 5.6

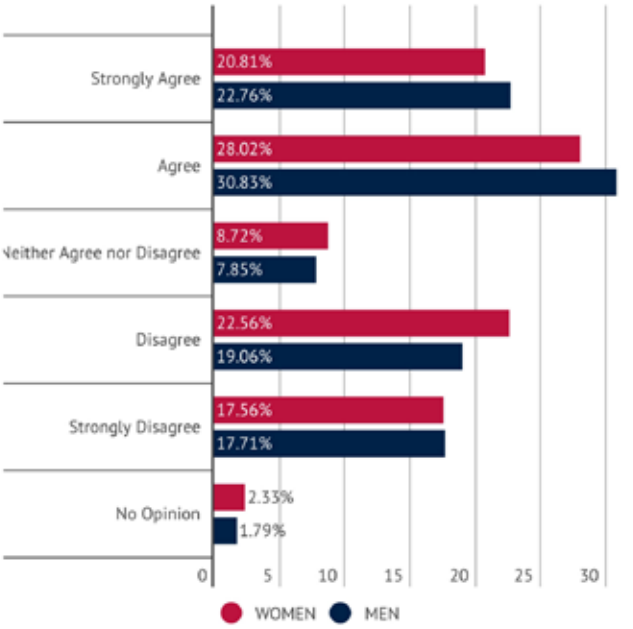
# "I would be willing to use new technologies (e.g. watches, bands, sensors) to monitor my diabetes risk factors (e.g. nutrition, physical exercise) and then share this data for public health research and policy purposes"

Do you agree?

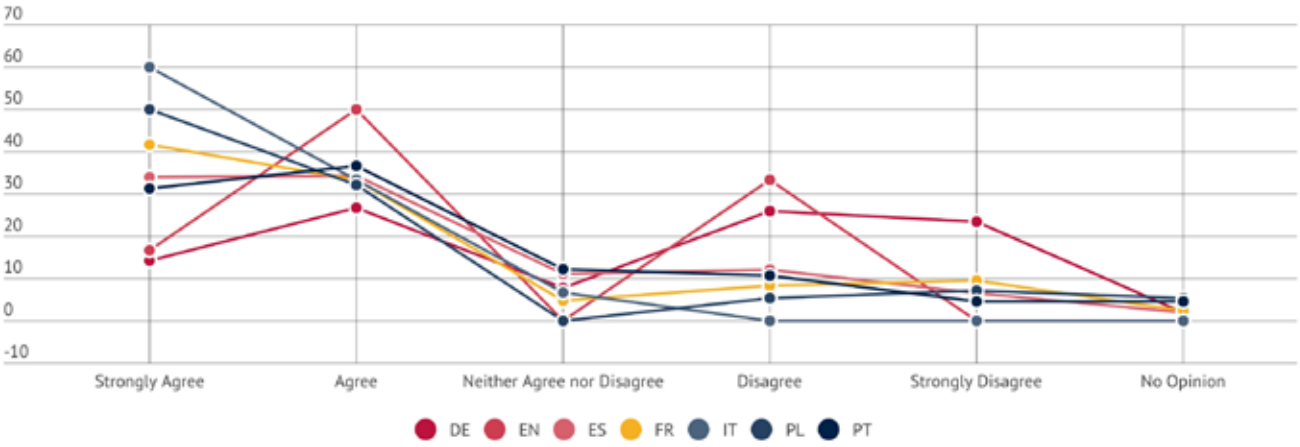
## 5.6.1 all responses




## 5.6.2 by gender




## 5.6.3 by language

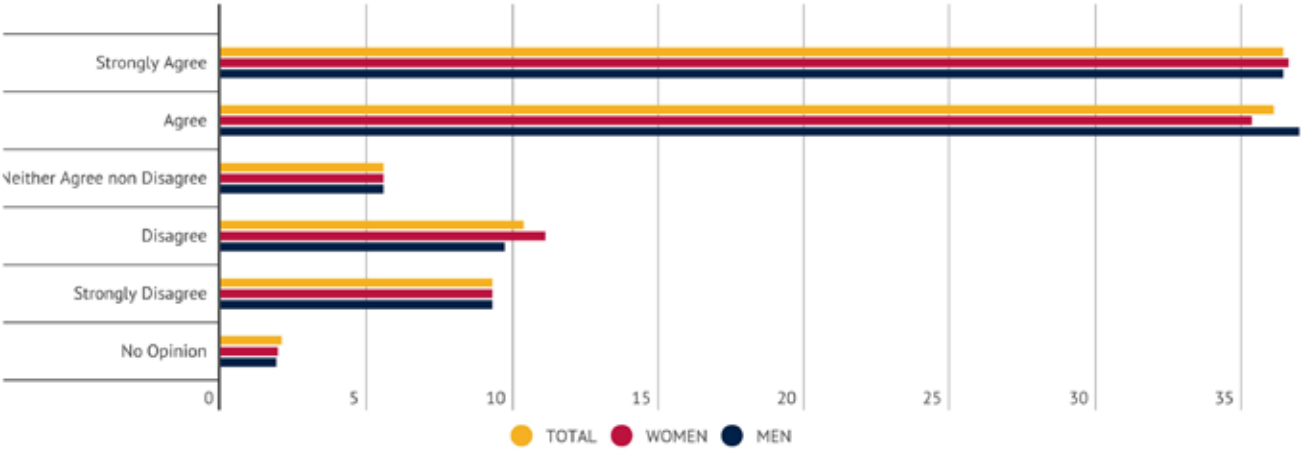


GRAPH 5.7

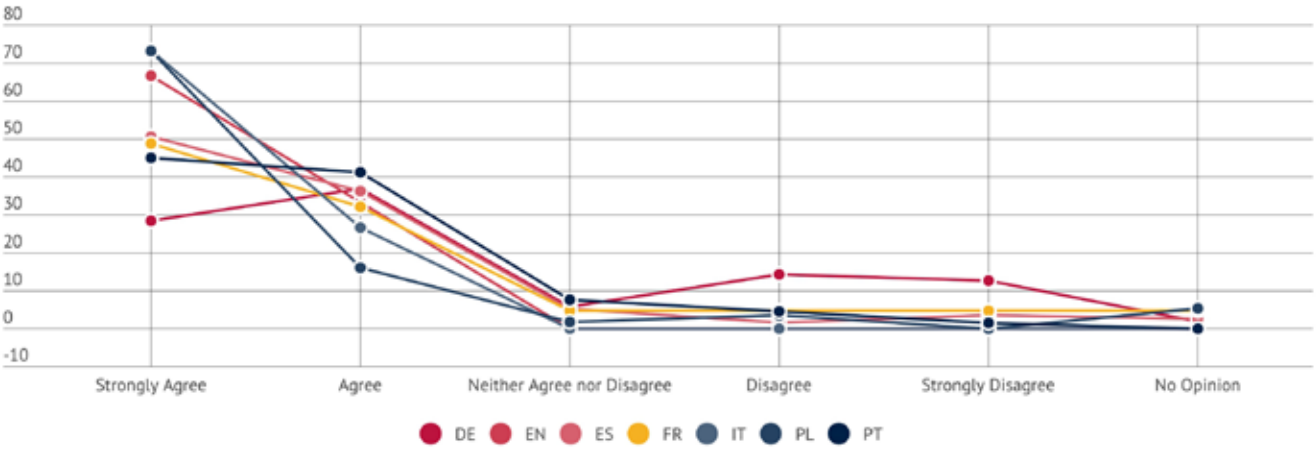
## "If I were diabetic, I would be willing to use new technologies to monitor and manage my condition (e.g. to be aware of the levels of sugar in my blood) and then share this data for public health research and policy purposes."

Do you agree?

### 5.7.1 all responses and by gender




### 5.7.2 by language

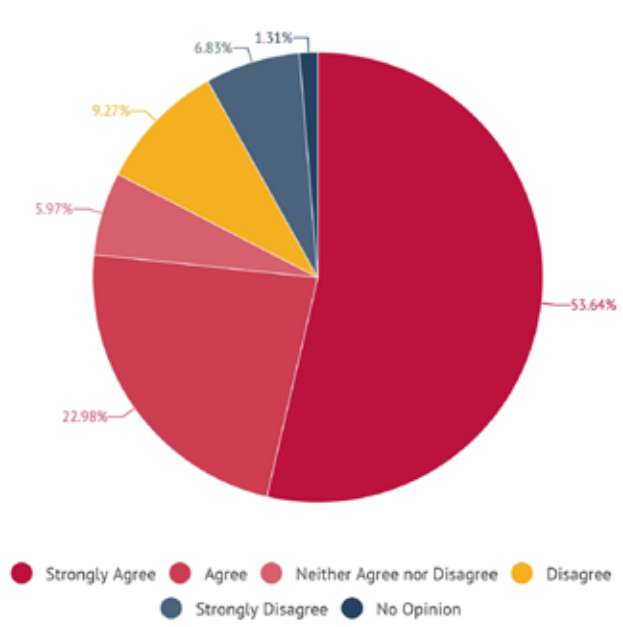


GRAPH 5.8

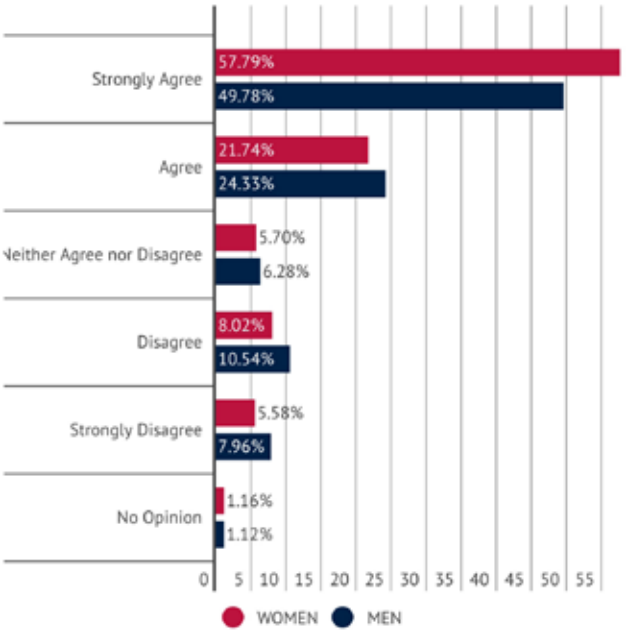
# ★ "I want governments and businesses to regulate the amount of sugar, salt, and trans fat in industrial food products" ★

Do you agree?

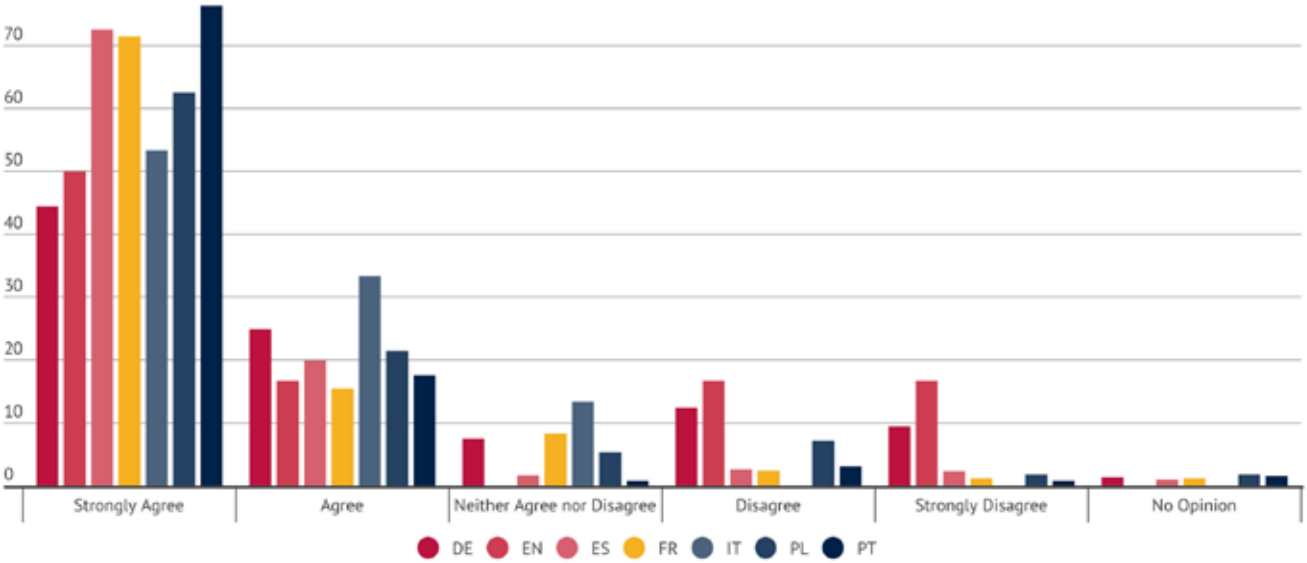
## 5.8.1 all responses




## 5.8.2 by gender




## 5.8.2 by language

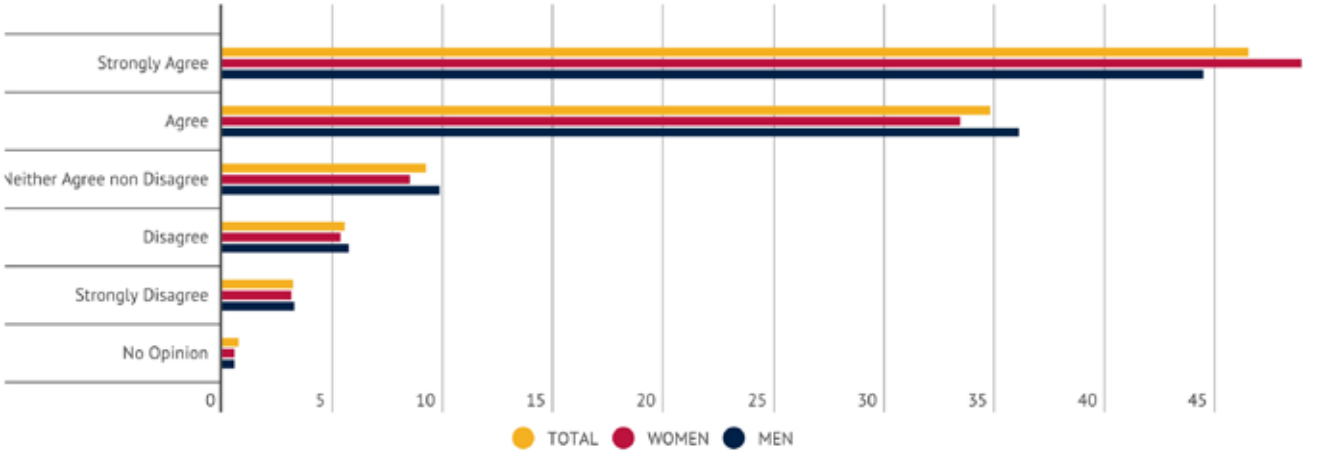


GRAPH 5.9

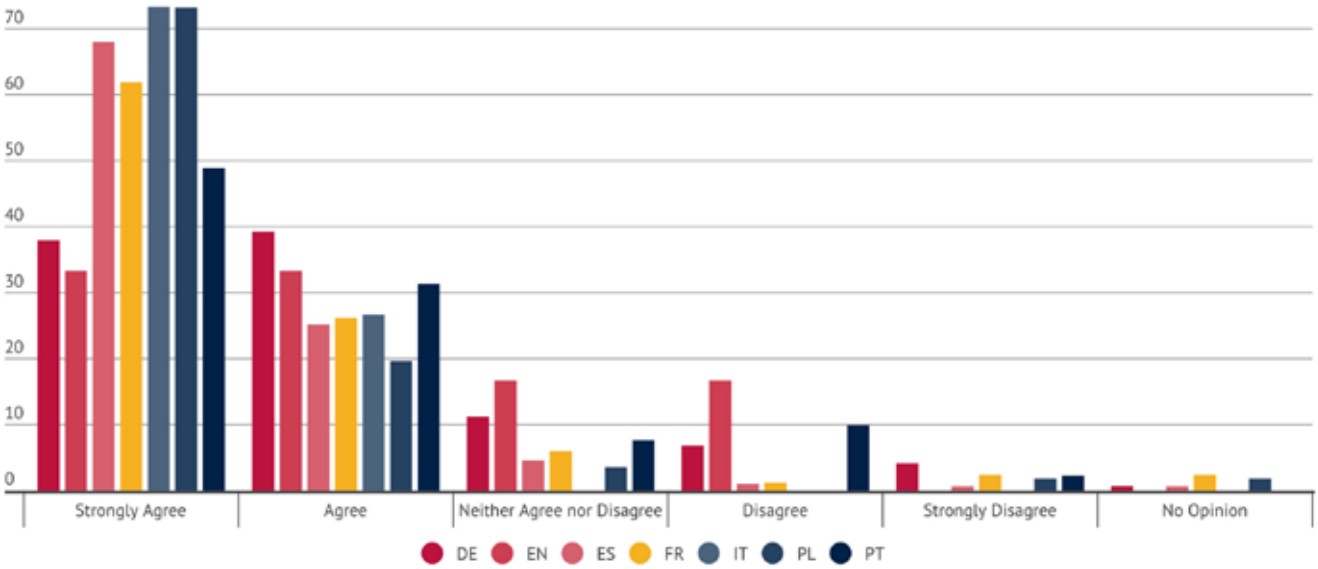
## "Governments, companies and civil society organizations should use marketing and communication technologies to nudge citizens into eating healthy food and doing some physical activity to help prevent the rise of diabetes.

Do you agree?

### 5.9.1 all responses and by gender




### 5.9.2 by language



# RECOMMENDATIONS

Based on the needs as highlighted by policymakers, the facts as put forward by researchers and the suggestions and opinions of citizens, the following policy recommendations are in line with the findings of the campaign.

## 1- Prevention

The most influential factors in the rise of diabetes are in fact 'modifiable' lifestyle behaviours commonly associated with urbanisation – physical activity, nutrition, and weight in particular. EU citizens and researchers strongly believe that tackling diabetes requires a coordinated effort of all the stakeholders - including: businesses, citizens, Civil Society Organisations, healthcare providers, public health authorities, researchers, schools and the Media – and the active involvement of patients and citizens. Capitalising on this belief by supporting cross-border, multi-stakeholder partnerships, patient centric approaches and citizen engagement, for instance through a dedicated EIP, should be considered.

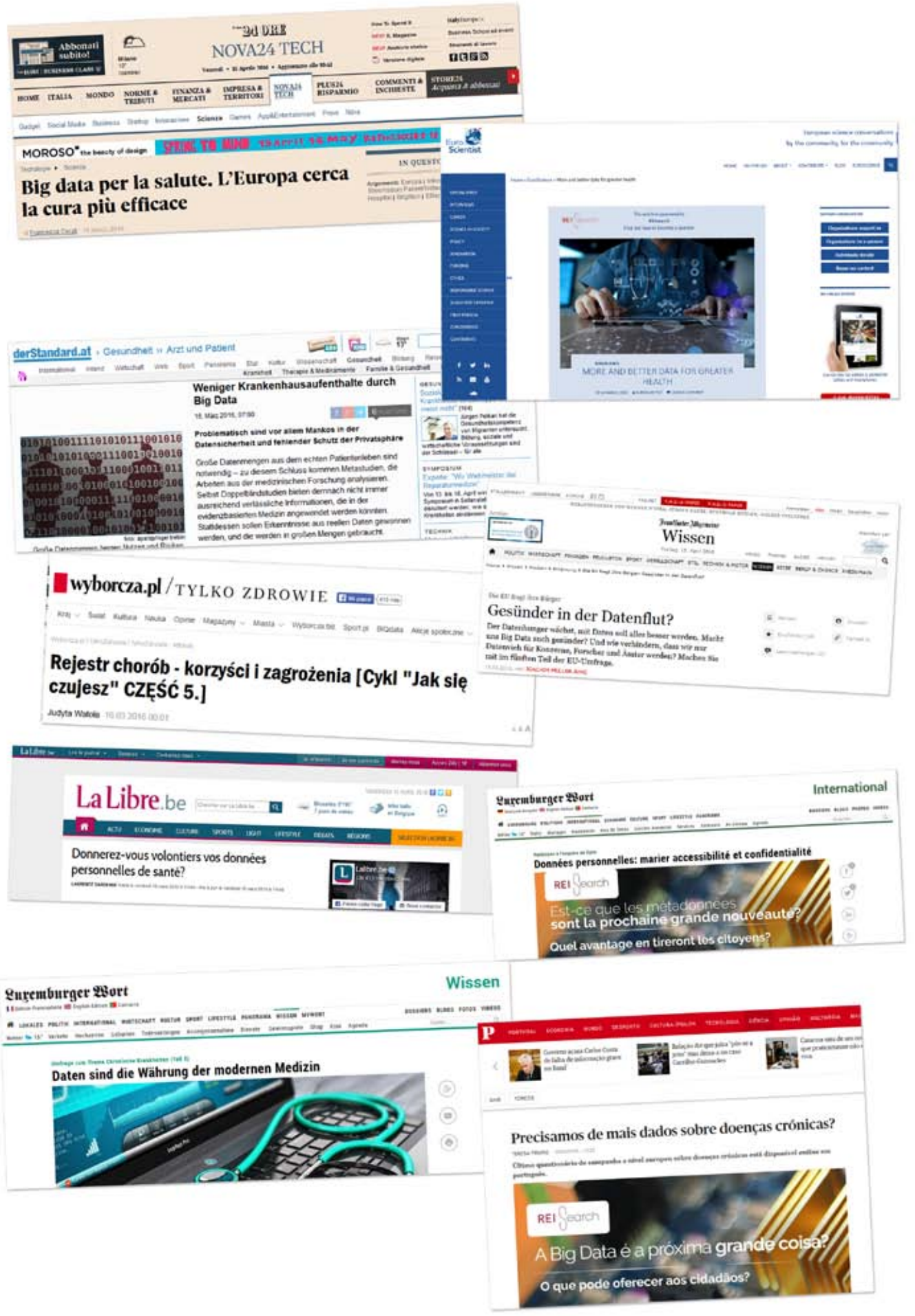
## 2- Education and Awareness

EU citizens grant great importance to the role played by schools in promoting healthy habits, and wouldn't mind being "nudged" towards healthy behavior by companies and civil society organisations: further investigation on the case for policy intervention in these field is encouraged.
Universalistic approaches to balanced nutrition have proved effective in some EU Countries, so for instance in Finland, where school children, students and employees all receive free or subsidised low-fat meals at school or in the workplace. Tailored approaches, aiming at making healthy food more attractive to children for examples, have also proved successful: the "LazyTown" TV programme and mobile application created in 1996 in Iceland to lower obesity rates in children and young people was very successful, and between 27% and 42% of pre-school children in a trial felt that LazyTown branded food tasted better than identical non-branded food.

## 3- Regulation and Consumer Protection

There are a number of different ways that governments and the European Union are and can incentivize healthy habits and disincentive bad habits. Taxes on tobacco and alcohol, banning of advertisement for tobacco products, regulating levels of salts, sugars and trans fat are some of them.
While citizens seem unimpressed by the efficacy of banning advertisement for unhealthy products, they do support regulation of amount of sugar salt and trans fat present in industrial food products, and positive advertisement of healthy habits/products: this should be kept in mind by both regulators and food producers, and could deserve further research.

The issues of "more and better data" will be dealt with specifically in the next chapters.




These are the headlines of some of the articles published during the week on "More and Better Data" of the Citizen Engagement and Media Campaign on Chronic Diseases.

# WEEK 5 – MORE AND BETTER DATA

## OVERVIEW

To conclude the *Citizen Engagement and Media Campaign on Chronic Diseases* the issue of "more and better data" was addressed. Recent advances in information technologies (IT) have created revolutionary opportunities to collect, manage, analyse, and share "more and better data" – understood as data that are increasingly reliable, usable, representative, comprehensive, ethical, available, equitable, efficient, and shareable, depending on the societal issues or aims that the data address.

Achieving a balance between protecting and enhancing public health and protecting privacy and personal data is still a very difficult mission. In the context of defining 'data concerning health', it is not simply the nature of the data but what the data is being used for that should be considered.

In the context of chronic non-communicable diseases, the need for more and better data is vital to all stakeholders in order to:

- Better understand the extent of chronic non-communicable disease risk behaviours, preventive care practices, and the epidemiology of chronic non-communicable diseases;
- Monitor the progress of prevention efforts; and
- Help health professionals, administrators and decision makers engaged in chronic non-communicable disease prevention/management to deliver more timely and effective decisions, programmes, and interventions.

However, within this rapidly developing and innovative field of public health, key questions and points of debate remain regarding what "more and better data" actually looks like in practice, and who has the rights and responsibilities to collect, manage, analyse, and share these data. Are citizens willing to share their private health data for research and policy purposes? Should citizens be given the choice to share their personal data, or should it be compulsory for the greater societal good? Who should manage citizens' personal health data – is it a job for public or private institutions? Who should invest in chronic non-communicable disease data technologies and innovations? Is the economic investment worth the scientific, medical, or societal benefits?

These are some of the difficult questions that were launched during the week of the 14th of March 2016. The aim of the campaign was twofold: to increase awareness of the difficulties posed by these questions and to find out more about what citizens actually feel about some of these difficult moral questions.

The campaign saw the highest participation from German-speaking participants[1] (63%) and men being over-represented (above 60%) in all languages with the exception of Polish and Portuguese-speaking participants that saw the opposite gender bias. As with the other weeks a majority of participants were between the ages of 36-65 and had a degree although the most represented group this week had reached a bachelor as opposed to the overall majority of participants holding a masters degree (graph 6.1).

The participants agreed that "more and better data" was an important issue in particular *to understand why and how chronic diseases are spreading (56.3%), to develop new or better therapies and drugs (55.5%) and to allow more targeted and personalised care (49.5%)*. All of the English-speaking participants also selected to *allow policy makers to take informed decisions* as a key reason. More detailed information about the preferences of different language-speaking groups or gender variations can be see in graph 6.5 below.

The campaign showed that participants agreed that healthcare providers (doctors, administrators) need more and better data to manage and prevent chronic non-communicable diseases with only the German-speaking participants being more cautious (graph 6.8).

There were significant difference in participants awareness of their rights concerning the protection and use of personal health data: only 45% of participants (51% of researchers) felt that they were aware of their rights with no variations depending on gender. However this was very different in different language groups with the English and Italian-speaking participants feeling very well aware of their rights compared to the German and Spanish-speaking participants who were more divided.

In the light of the new data protection reform package recently approved by the European Parliament and Council that should enter into force in all EU member states in 2018. Particpants where asked what they would be most interested to know to increase their awareness of their rights.

Overall participants confirmed their interest in receiving more information about the directive with the prioritz areas being: "my right to access my data anytime, to bring it with me wherever I move, and to have it rectified or deleted if I can prove there are no legitimate grounds for retaining it" (79.5%), "the fact that companies are obliged to notify me in case of serious data breaches" (60.3%) and "the fact that my data, provided that my privacy is guaranteed, can be shared for research purposes" (53.4%). These opinions were largely similar across languages and gender.

Overall participants agreed with the statement that "governments should invest public money from multiple sector budgets – not just healthcare – and pool resources from the private sector, to develop 'more and better data' for chronic disease management and prevention" with the German and French-speaking participants being more divided than the other language groups (graph 6.6).

The campaign also wanted to see how participants felt about sharing data and making it available to different actors to help prevent chronic diseases. It was clearly specified in each case that the data sharing was dependent on the fact that the data are anonymised and used safely, ethically and securely.

Over half of the participants agreed that all personal health data should be shared to help prevent and manage chronic diseases, without the need to ask individual citizens for their consent (graph 6.7). However this question saw very significant differences in the different language groups with German speaking participants being very cautious compared to the English and Spanish-speaking citizens who were nearly fully in favour.

**From the Forum - Germany**

**How can I as a participant ensure that my data is treated according to my expectations in any given context? And how can I control that when I want to do so and keep the power to stop problems from developing when I choose to do so?**

Interestingly the opinion did not change significantly when participants were asked if they would share their personal health data to help Pharmaceutical Companies to develop new and better drugs (graph 6.9). A majority would be willing to do so with the German-speaking participants disagreeing.

**From the Forum - Spain**

I trust public authorities, but not in private. In both cases there may be individuals who misuse the data available.

It can be done:

- Educate people to reject bad practices (education in long-term securities)
- Punishing individuals who misused their access to data,
- Big companies do the same (large fines, disqualification to operate even if they change their name, location, etc ...) sanction,
- Legislation at European level and if possible worldwide.

Participants showed an understanding of the risks of data sharing when asked more in detail in which cases they would be willing to share data. Only 19% (12% of researchers) would be willing to share data always and openly. This was much higher in the English-speaking participants. Nearly 18% would not be willing to share their personal health data (19.5 % amongst researchers). Most participants where willing if certain conditions were met: *if I was explicitly asked to consent to the use of my health data for a specific scope/project* (44.35%), *for research purposes only* (35.5%), *only with non-profit organisations* (19.8%) *or only if there was a proven benefit* (16.3%) (graph 6.4).

Here national differences played a significant role in the responses with the English and Italian speaking being more open and the German, French and Polish-speaking being more cautious.

These results show the importance and impact of the different historical and cultural backgrounds of the participants and how these affect opinions and feelings towards the moral questions surrounding the question of more and better data.

Please see the detailed results below.

**From the Forum - Germany**

I believe that evaluating centrally collected Europe-wide data and information is useful and profitable under ideal conditions.

The "ideal" conditions would be for me:

- An absolute anonymity for generations (with which IT technical and organizational solution ?!)
- A meaningful sole purpose relevant data selection must be ensured
- A neutral, objective, in-depth, specialized commercial and political interests free evaluation and exploitation of the data collected.

However, I do not believe that such conditions can be realized as things stand. Please provide us with a coherent and proven concept before selling our data!

[1] *It is important to point out the high levels of German-speaking participation in the light of their strong positions towards privacy. The history of privacy protection laws in Germany is the oldest in the world. The experience of Germany in the 30s and 40s have made Germans very sensitive or very careful about lists made by the federal state.*

## BACKGROUND

*"The recent availability of huge amounts of data, along with advanced tools of exploratory data analysis, data mining/machine learning and data visualization, offers a whole new way of understanding the world."*

*Thanos, Manegold, Kersten, 2012, European Research Consortium for Informatics*

If we want to better understand, manage, and prevent chronic diseases, then *more and better data* are vital.

Data is the currency of today's digital economy. Collected, analysed and moved across the globe, personal data has acquired enormous economic significance, with the value of European citizens' personal data on track to reach € 1 trillion per year by 2020. Everyone needs more and better data. Policymakers need data to inform their healthcare decisions and initiatives. Healthcare professionals need data to maintain and improve their service provisions. Researchers need data to develop new knowledge and create new solutions. And citizens need data to inform and empower their health choices and voices.

So what do more and better data initiatives and outcomes for healthcare actually look like in practice? Here are two cutting edge examples from the public sector in Europe:

1) Scottish Patients at Risk of Readmission and Admission (SPARRA)

SPARRA is a risk prediction tool developed by Scotland's Information Service Division, which predicts an individual's risk of being admitted to hospital as an emergency inpatient within the next year. SPARRA creates risk scores for 4.2 million Scottish citizens, which are passed on to relevant healthcare providers (e.g. doctors, nurses, social carers) who can put in place personalised and preventive care plans, rather that reacting to emergencies and giving treatment after the event. Overall, SPARRA has achieved great success, including 20% less emergency admissions, 10% shorter stays in hospital, and € 16 million in cost savings for the Scottish healthcare system (YECH, 2013).

2) Big Data for Better Outcomes (BD4BO)

The European Commission's Innovative Medicines Initiative is leading a Big Data for Better Outcomes (BD4BO) programme. BD4BO is exploiting the opportunities offered by big and deep data sources to develop more value based, outcome focused, and sustainable healthcare systems in Europe through: central repositories of information and knowledge; common ethical and personal data protection review and advice; common standards for collection, analysis, and management of personal data; and common/aggregated data models from multiple sources (including patient organisations, regulators, payers, providers, and other public stakeholders). The full impact and outcomes of this programme are eagerly awaited.

The potential advantages for public health providers, policymakers, and researchers appear clear – more and better data to understand the challenges and provide more efficient solutions to citizens. But are there some bits of personal data that you wouldn't want to share? Is your "loss of privacy" worth the trade off for the "greater societal good"? And do you trust your data are kept confidential and secure?

Some citizens are taking the fight to the big corporations, for example exercising the "Right to be Forgotten" that removes Google search results for certain names. Yet stories of large-scale data breaches, hacks, cyber attacks, and leaks have become increasingly common. In the health sector for instance, the Brighton and Sussex University Hospital was fined £325,000 after sensitive patient data of thousands of people was discovered on 232 hard drives sold on eBay; while the UK's Bloomsbury Patient Network was fined £250 after staff mistakenly shared by email the identities of 200 patients who are HIV-positive.

In December 2015, the data protection reform package, including the General Data Protection Regulation ("Regulation") and the Data Protection Directive for the police and criminal justice sector, was endorsed by both the EU Parliament and Council. The new framework aims at empowering citizens with respect to their personal data, making easier to access and transfer personal data, but also to have it deleted (right to be forgotten) if there are no legitimate grounds for retaining it. In addition, companies and organisations are obliged to notify the national supervisory authority of serious data breaches as soon as possible so that users can take appropriate measures. From the point of view of companies and organisations, the reform establishes one single set of rules which will apply all across the EU, including for companies based in third countries when they operate in Europe. A risk-based approach has been adopted to avoid a burdensome one-size-fits-all obligations, in addition, the regulation will guarantee that data protection safeguards are built into products and services from the earliest stage of development (Data protection by design).

In order to help manage and prevent chronic diseases, what stakeholders need is not just a larger quantity of data (*more*), but also a greater quality of data (*better*). This means data that are increasingly accessible, usable, inclusive, efficient, and shareable, but at the same time being private, trusted, secure, and ethical. Marrying data accessibility with privacy is no easy task, and requires ever-evolving information technologies, innovations, and infrastructure for collecting, storing, analysing, and sharing data. Furthermore, these data have to be used for initiatives that produce more and better *outcomes*, otherwise the data – and the resources used to create it – will be wasted.

The potential for more and better data in chronic disease management and prevention is enormous, but at each stage we must consider the 'costs' in terms of money, but also in terms of maintaining citizen's privacy and empowerment as much as possible.

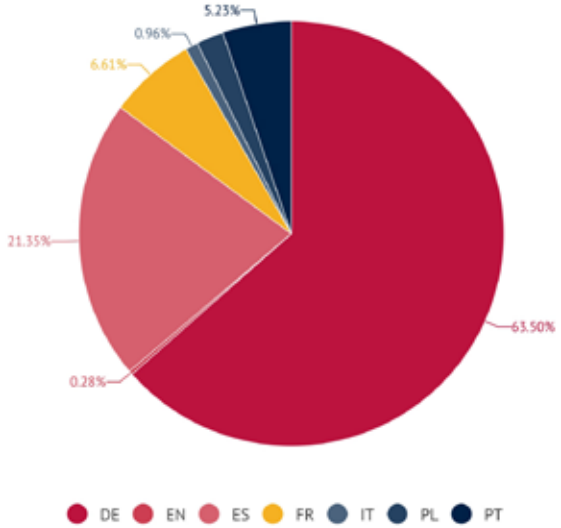
# RESULTS

GRAPH 6.1

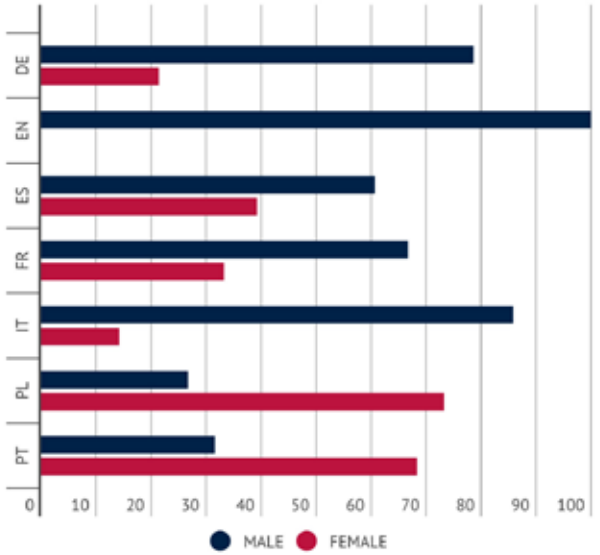
## IS BIG DATA THE NEXT BIG THING?

### What is in it for the Citizen?

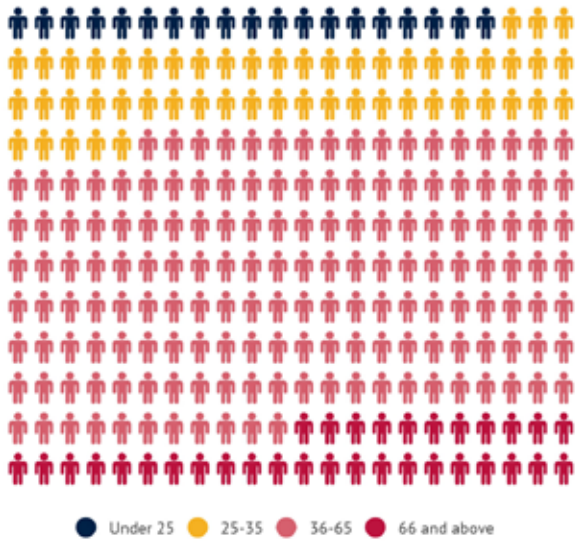
#### 6.1.1 participation by language



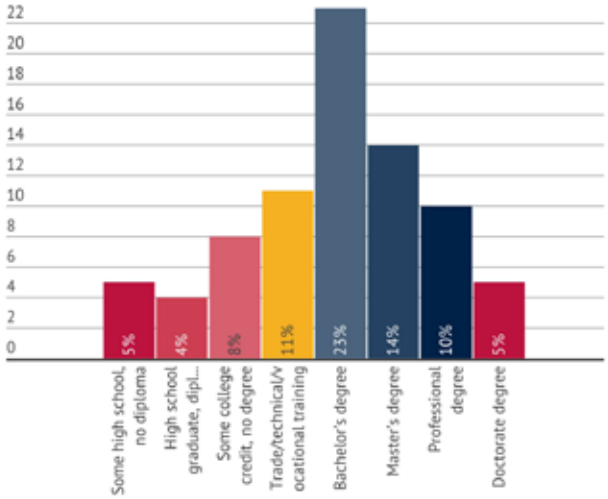

#### 6.1.2 participation by gender




#### 6.1.3 participation by age




#### 6.1.4 participation by education

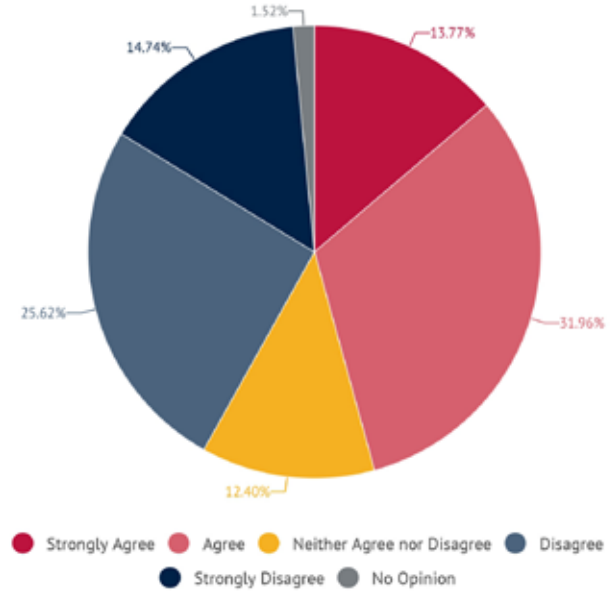


GRAPH 6.2

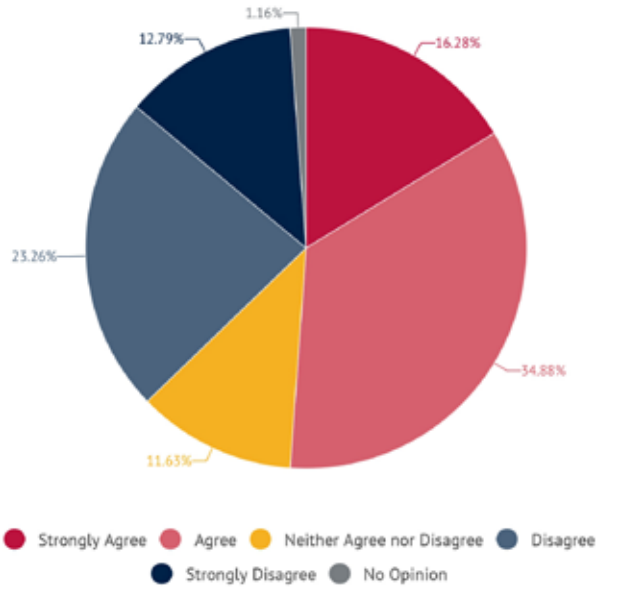
# ★ "I am fully aware of what my rights are concerning the protection and use of my personal health data" ★

DO YOU AGREE?

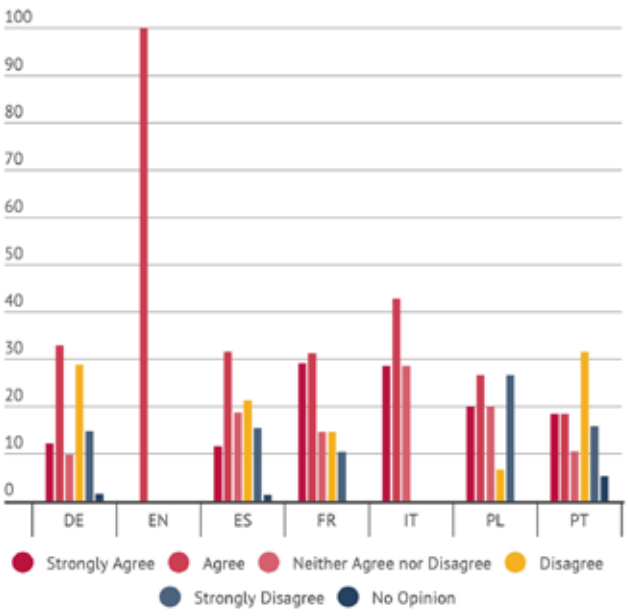
## 6.2.1 all responses



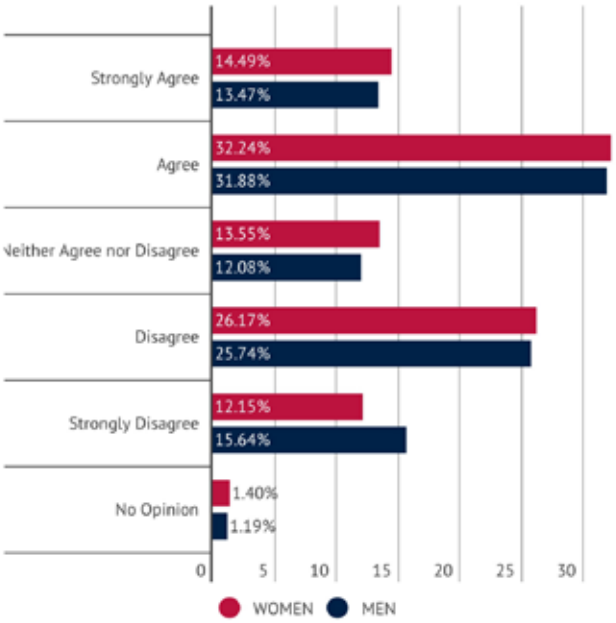

## 6.2.2 researcher responses




## 6.2.3 by language




## 6.2.4 by gender



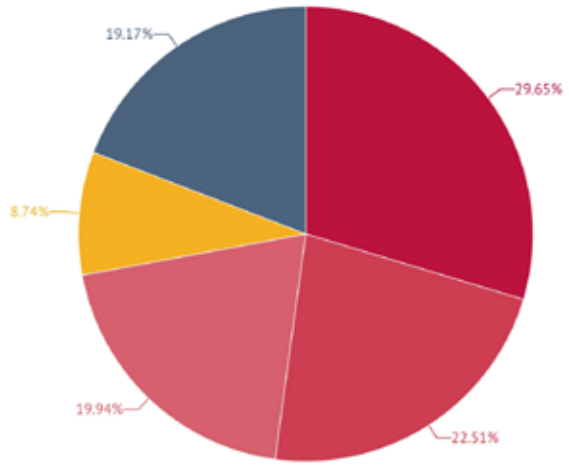
# Personal data protection is a fundamental right in Europe, guaranteed by the Treaty on the functioning of the European Union and by the Charter of Fundamental Rights.

GRAPH 6.3

## A new data protection reform package has recently been approved by the Parliament and Council of the EU, and should enter into force in all EU member states in 2018. On what aspects of the new legislation would you be interested in finding out more?

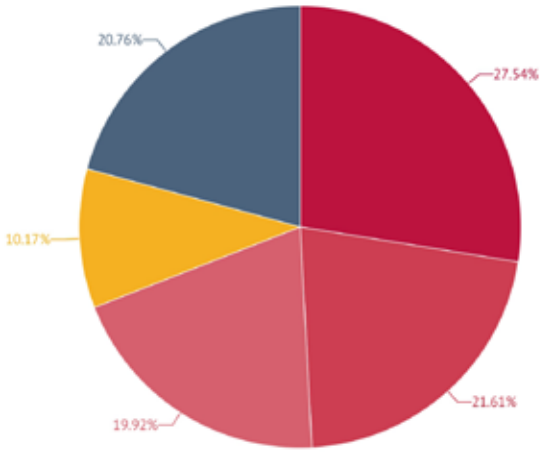
Tick as many as you feel appropriate

### 6.3.1 all responses



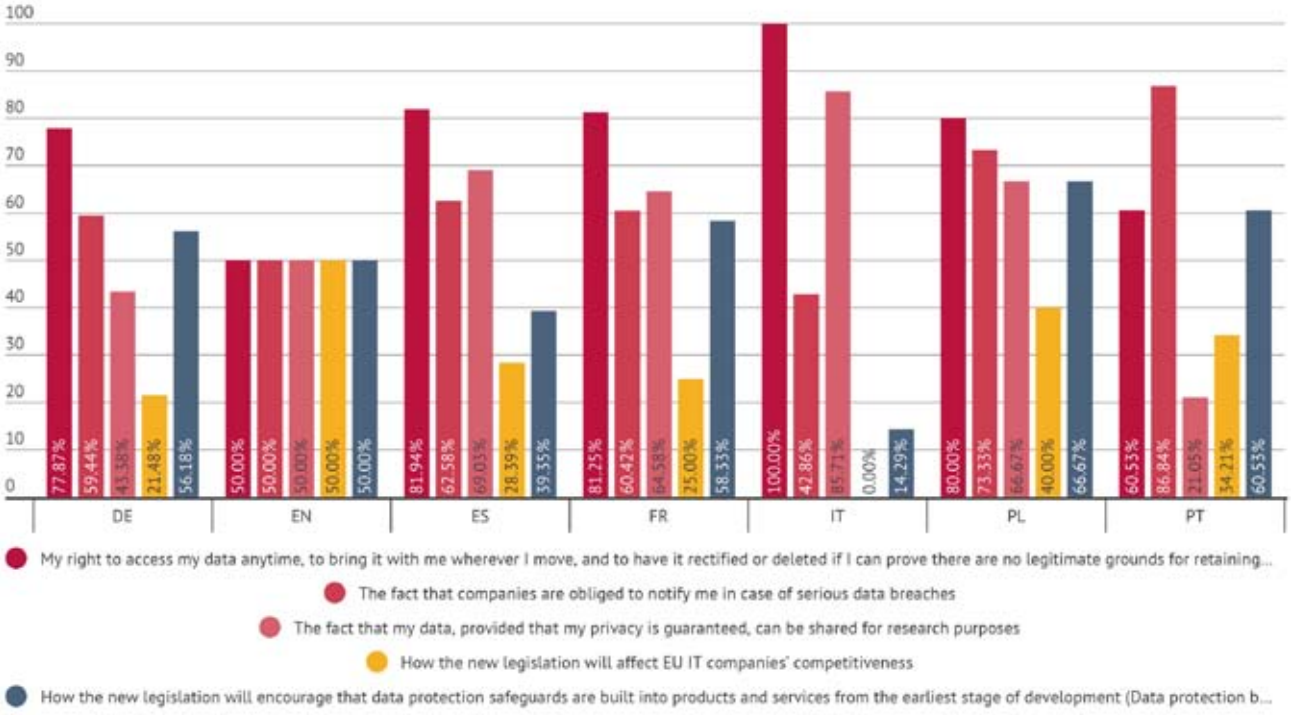

- My right to access my data anytime, to bring it with me wherever I move, an...
- The fact that companies are obliged to notify me in case of serious data bre...
- The fact that my data, provided that my privacy is guaranteed, can be share...
- How the new legislation will affect EU IT companies' competitiveness
- How the new legislation will encourage that data protection safeguards are ...

### 6.3.2 researcher responses

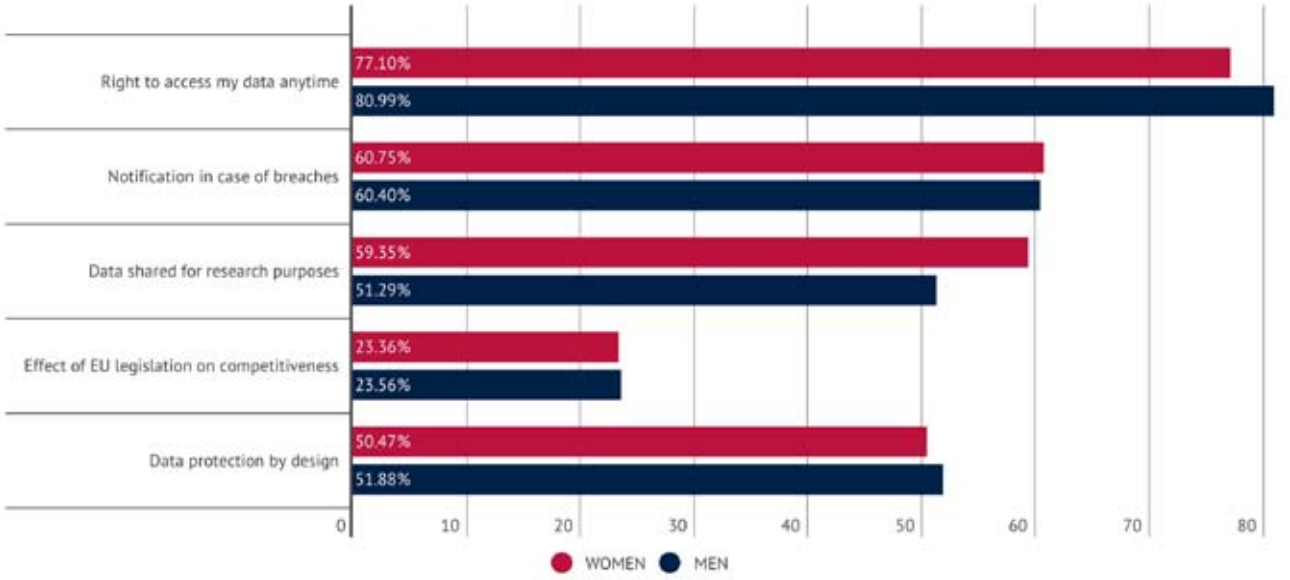



- My right to access my data anytime, to bring it with me wherever I move, an...
- The fact that companies are obliged to notify me in case of serious data bre...
- The fact that my data, provided that my privacy is guaranteed, can be share...
- How the new legislation will affect EU IT companies' competitiveness
- How the new legislation will encourage that data protection safeguards are ...

## 6.3.3 by language




## 6.3.4 by gender

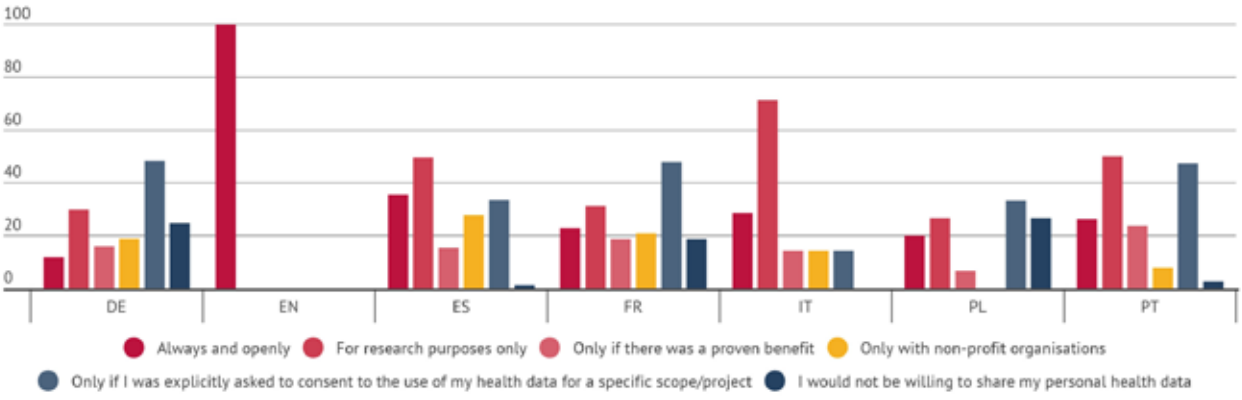


GRAPH 6.4

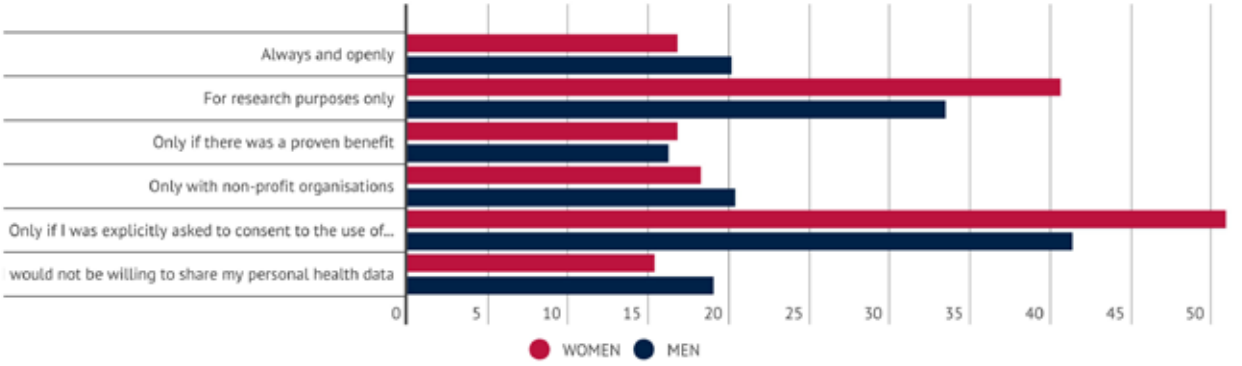
# Provided that data are anonymised and used safely, ethically and securely, I would share my personal health data to help prevent and/or cure chronic non-communicable diseases

## 6.4.1 all & researcher responses


## 6.4.2 by language




## 6.4.3 by gender

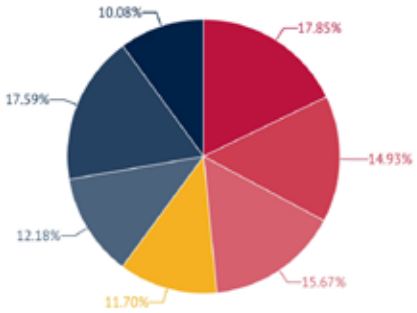


GRAPH 6.5

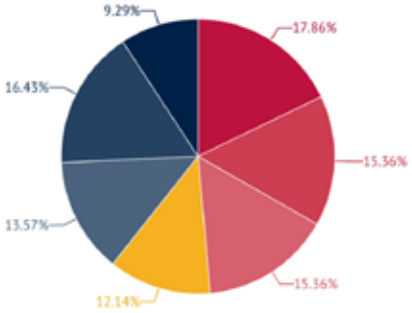
# Why do you think more and better data are important?

Tick as many as you feel appropriate

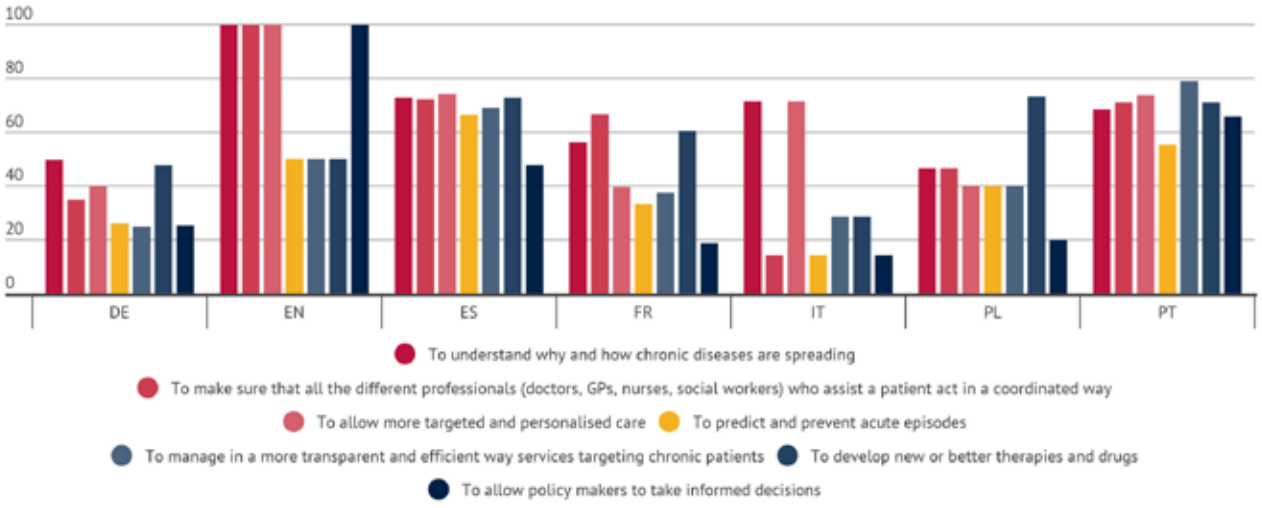
## 6.5.1 all responses



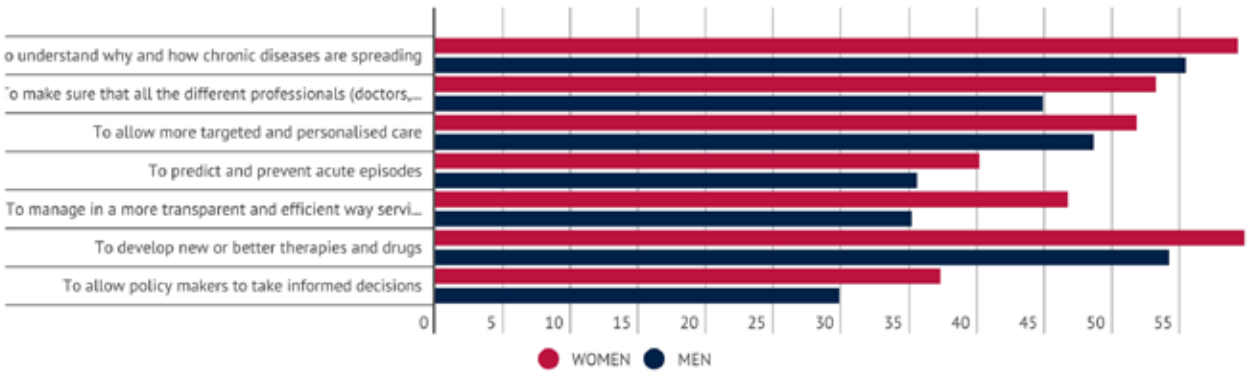

## 6.5.2 researcher responses




## 6.5.3 by language




## 6.5.4 by gender

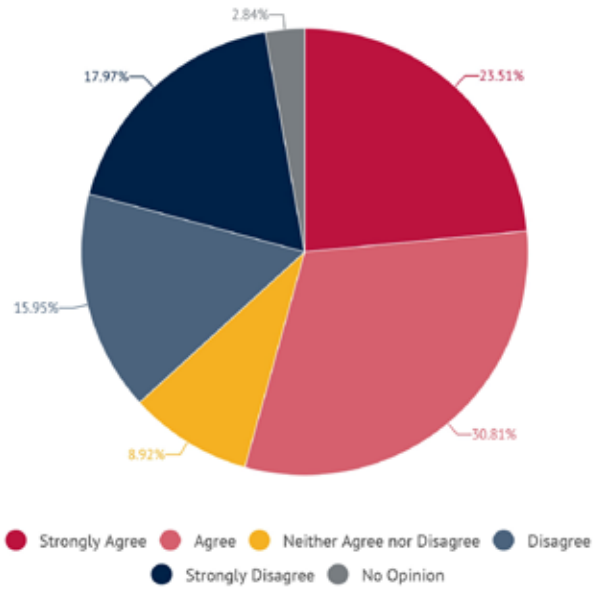


GRAPH 6.6

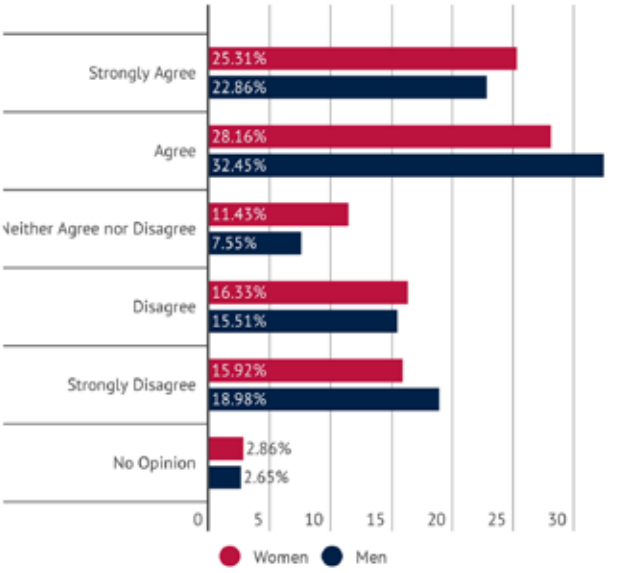
# "Governments should invest public money from multiple sector budgets – not just healthcare – and pool resources from the private sector, to develop 'more and better data' for chronic disease management and prevention"

To what extend do you agree with the above statement?

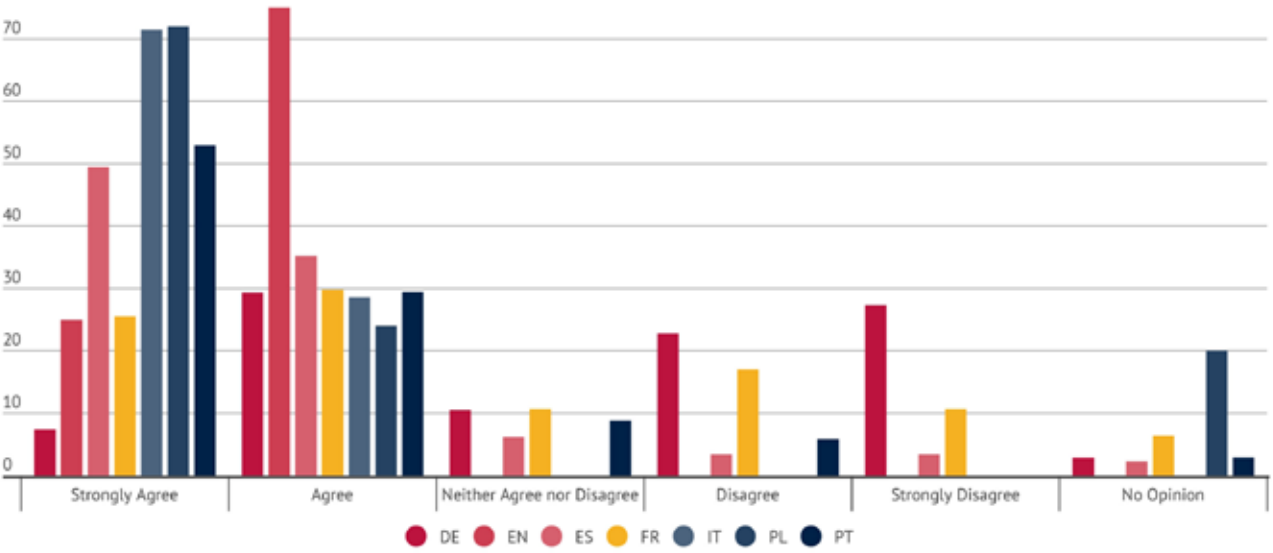
## 6.6.1 all responses




## 6.6.2 by gender




## 6.6.3 by language

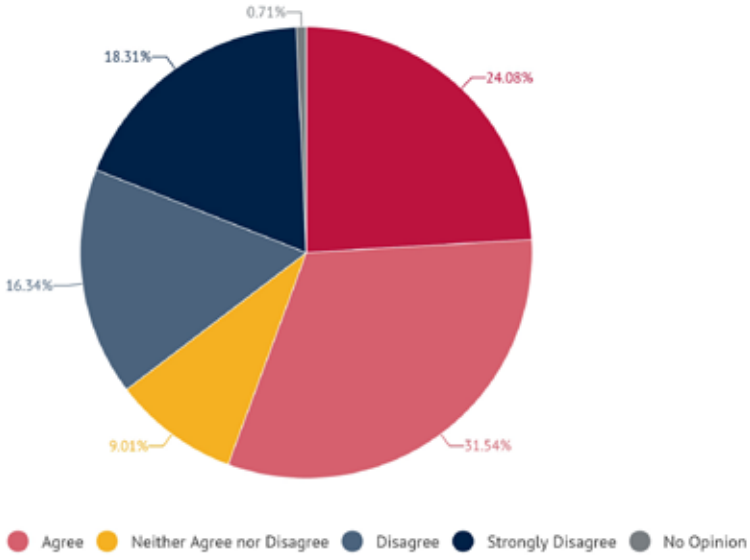


GRAPH 6.7

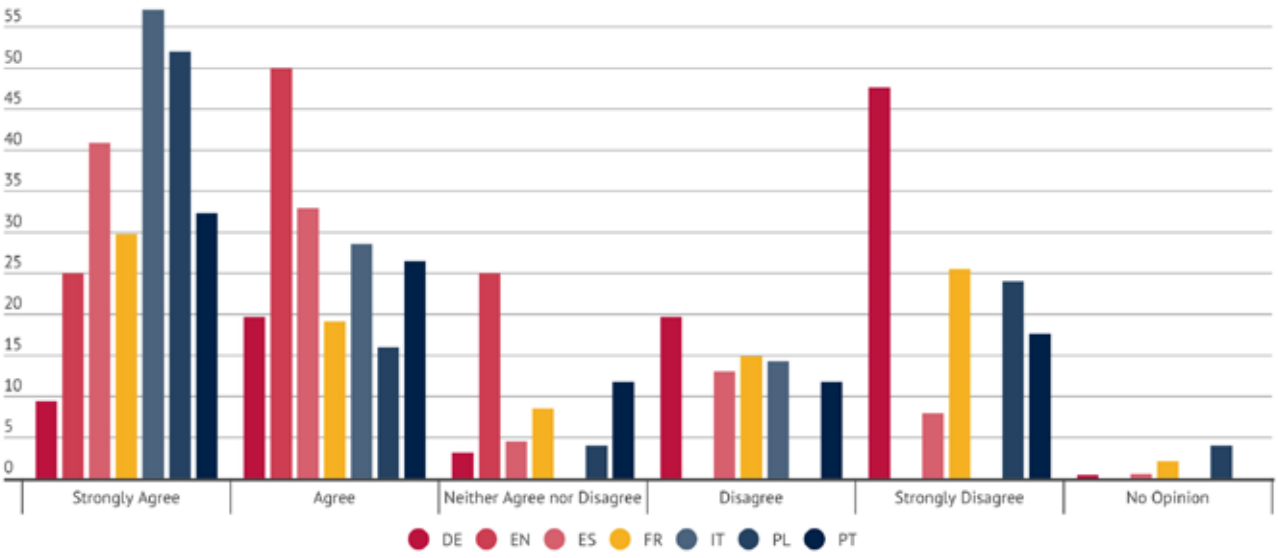
## "Provided that data are anonymised and used safely, ethically and securely, all personal health data should be shared to help prevent and manage chronic diseases, without the need to ask individual citizens for their consent"

Do you agree?

### 6.7.1 all responses



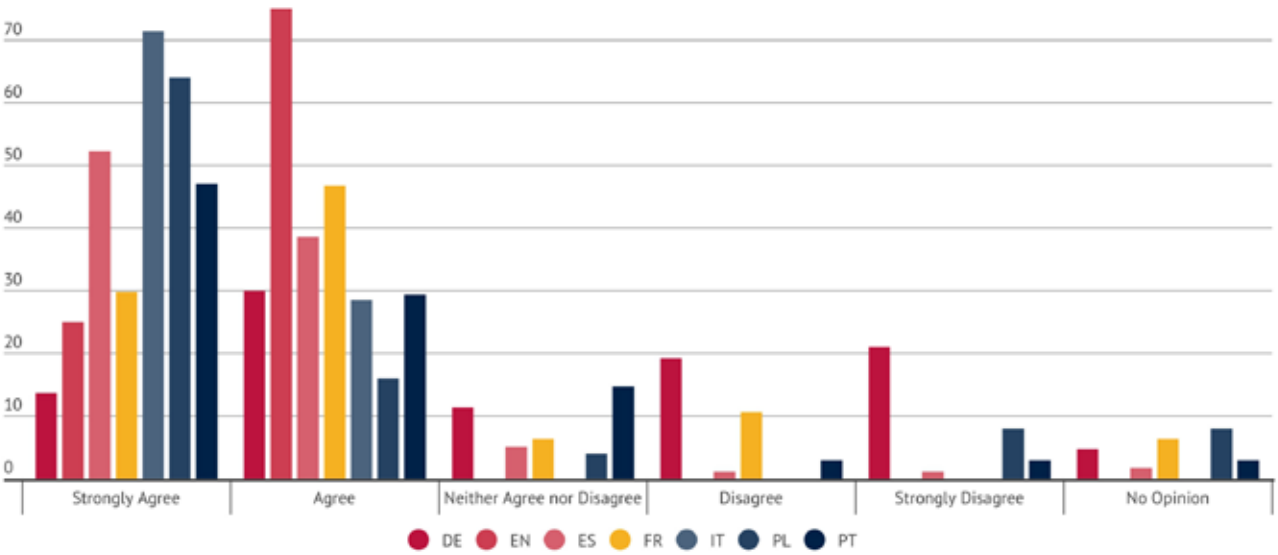

### 6.7.2 by language



GRAPH 6.8

## ★ "Healthcare providers (doctors, administrators) need more and better data to manage and prevent chronic non-communicable diseases"- ★

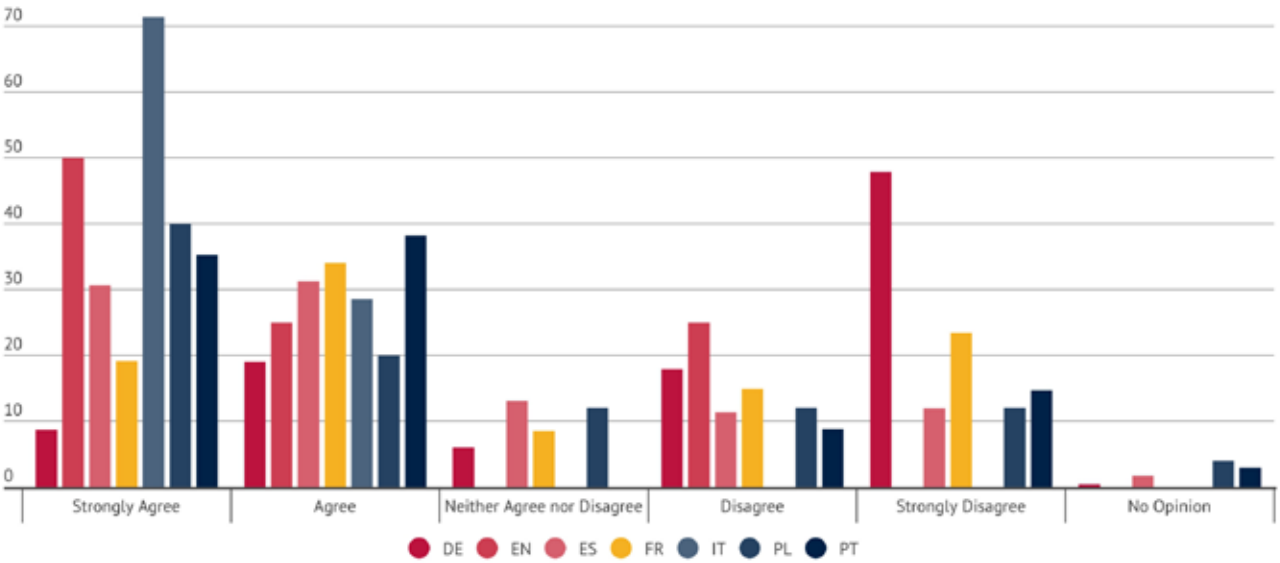
Do you agree?




GRAPH 6.9

## ★ "Provided that data are anonymised and used safely, ethically and securely, I would share my personal health data to help Pharmaceutical Companies to develop new and better drugs" ★

Do you agree?



# RECOMMENDATIONS

Based on the needs as highlighted by policymakers, the facts as put forward by researchers and the suggestions and opinions of citizens, the following policy recommendations are in line with the findings of the campaign.

## 1- Transparency and accountability

The campaign shows that participants are willing to share personal health data to help prevent and/or cure chronic non-communicable diseases provided this is done transparently and with accountability. However this willingness was more cautious than during previous weeks underlining the need to improve the dialogue and collaboration on these issues as well as increase awareness. Looking at the REIsearch forums and social media debates there is a clear concern over the actual capabilities of being able to guarantee security and accountability of data usage today and the feeling that this has to be a continuous process.
It is therefore essential not only to ensure that strong safeguards and governance structures are used by all organisations including research organisations to ensure that personal information is used safely, ethically and securely, but also to keep alive the debate around the issue, and to make sure citizens are part of it.

## 2- Research

Participants demonstrated a will to make their data available for research purposes in line with the exception that research has been given within the General Data Protection Regulation ("Regulation") and the Data Protection Directive.
In the context of defining 'data concerning health', it is not simply the nature of the data but what the data is being used for that should be considered. The Regulation should provide a proportionate legal framework to help medical research progress while protecting the rights and interests of the individuals.

## 3- A tailored approach to policy action

Based on the results of the survey, it is clear that national and gender bias is a strong determinant of citizens' positions towards data regulations and policies. More in particular it would seem necessary to put in place specific measures to raise women's' interest towards data and to further investigate the influence of national historical-cultural factors on citizens' opinion and behaviors when use of personal data is concerned.

# 4 - CONCLUSIONS

The need to reform Europe's healthcare systems is something that has been discussed for a long time. The current situation with changing demographics and cutting in public spending has precipitated the need to redefine the European healthcare system to suit the needs and challenges of the 21st century. New models, declarations and buzz words are continuously launched. Yet the discussion remains set within the existing systems and structures.

In the light of the changes that will be necessary for the coming decades the debates need to shift the paradigm: Reforming Europe's healthcare systems will change the rules of the game for all stakeholders in a multi-billion euro sector, averaging in Europe nearly 10% spending of GDP on health, and that affects every single European citizen.

This change will need to see researchers and experts, industry, civil society organisations, policy makers join forces and start an open dialogue with the public and media to push forward the necessary paradigm shift.

The *Citizen Engagement and Media Campaign on Chronic Diseases* was launched to create a responsible and informed multi-stakeholder debate on the issues involving thousands of European citizens, researchers, policymakers and stakeholders. It wanted to create and promote access to reliable information on the issue, increase inter-disciplinary and inter-sectoral debate and collect and analyse results to deliver to researchers and policymakers.

Reaching out to a readership of over 8 million citizens (cumulative reach of all media partners engaged in the initiative), in ten European countries (Austria, Belgium, France, Germany, Ireland, Italy, Luxembourg, Poland, Portugal, Spain), seven languages (English, French, German, Italian, Polish, Portuguese and Spanish) the campaign saw the participation of nearly 60 000 Europeans and nearly 18 000 responses to the survey.

**From the Forum**

I take we know the measures against chronic diseases.Now **the challenge is to repeat the message often and regularly.** Would I listen to a fancy marketing campaign? No. Would I listen to a politician telling me what to do? No. I would probably listen to my peers (many ways on how to define those). **Hence the task for politicians in my mind would be to start some sort of public engagement.**

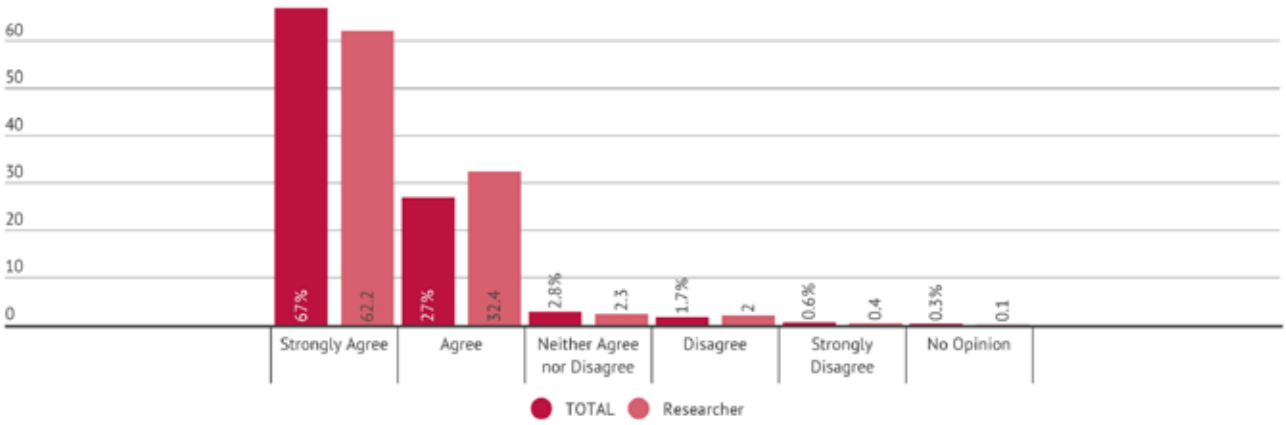
The campaign was received very well by a majority of the participants and it is clear from the results of the survey that over 90% of participants agreed that health is a priority issue.

GRAPH 2.2

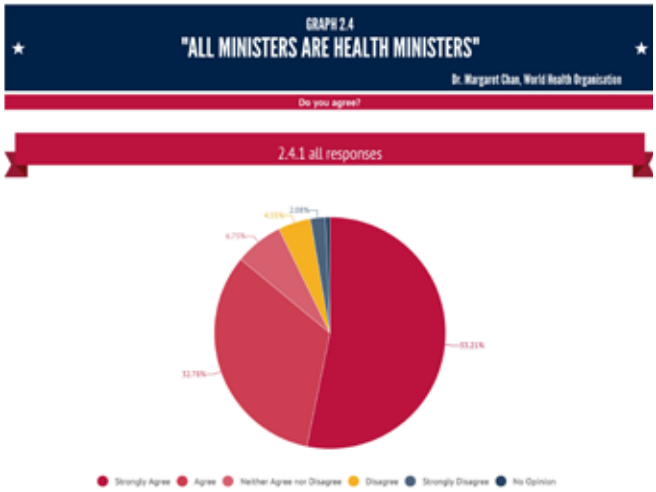
## "Healthy citizens are the greatest asset any country can have" Winston Churchill

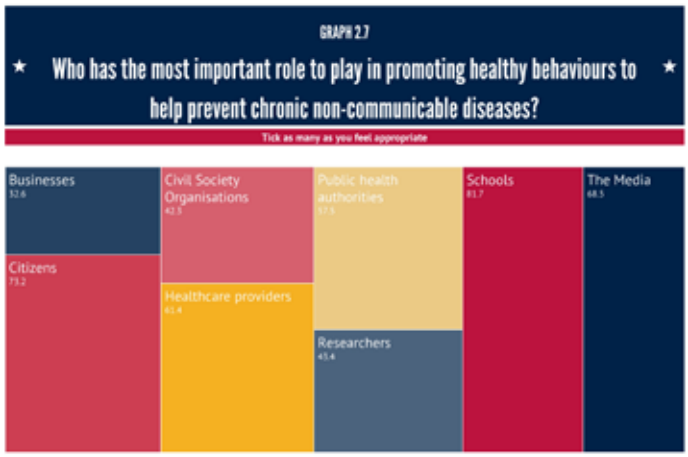
Do you agree?

2.2.1 all & researcher responses (percentage of total)



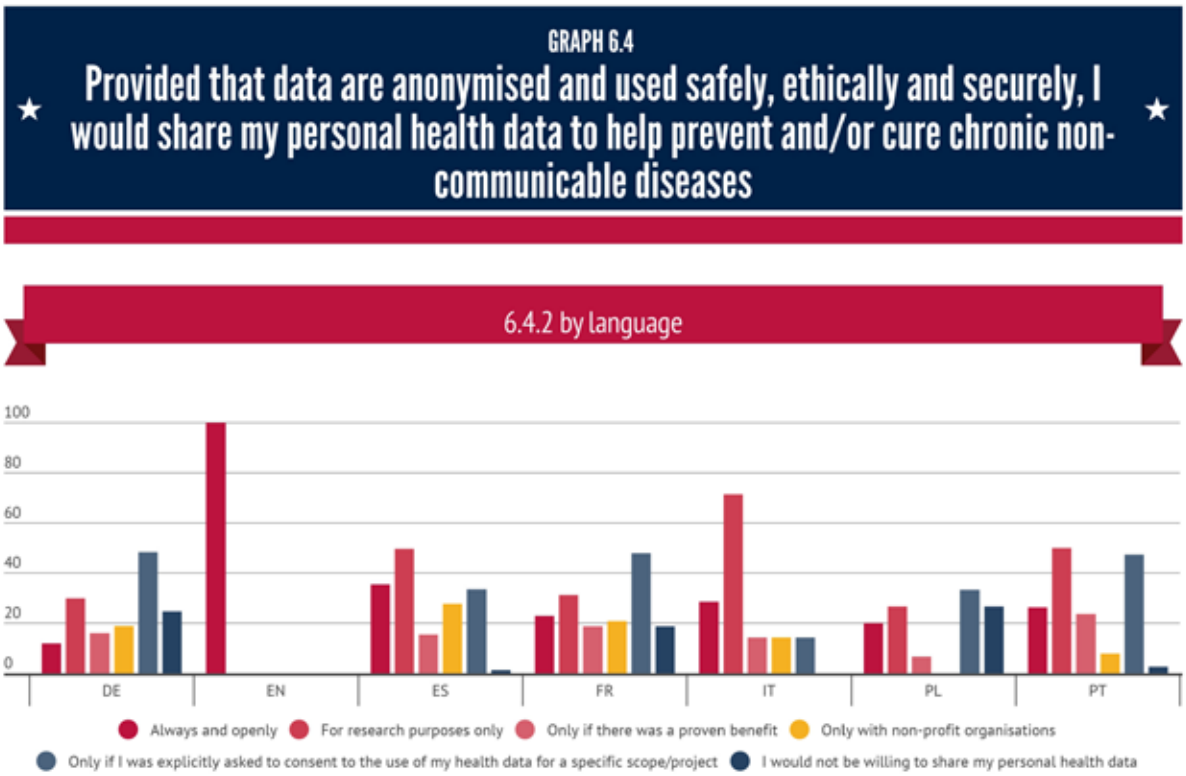

Health and the prevention of chronic diseases cannot be considered in isolation as it is relevant and should be taken into consideration in all decisions about the future choices of a society. In fact 85% of respondents thought health should be considered a priority by all government portfolios. Further, the results underlined the need to increase the multi-stakeholder approach to developing a coherent and realistic vision for combatting chronic diseases where education and the media have a key role.



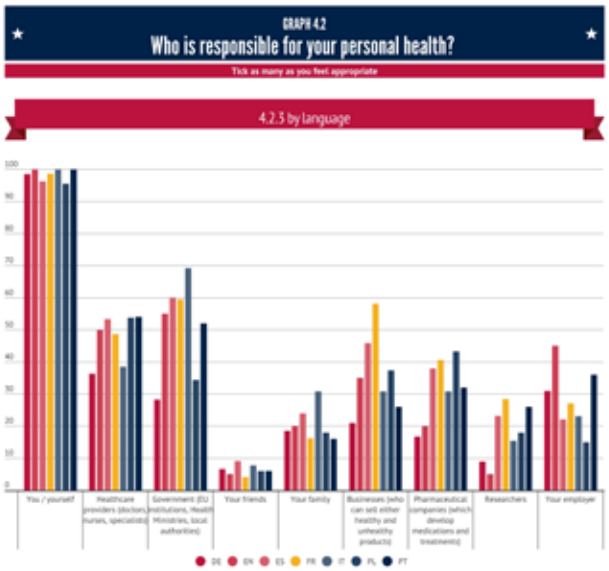

It is interesting to note that throughout the campaign there were no major differences of opinion between participants based on gender, education level or age. The only factor that did play a role was language. This underlines the importance of the cultural background on which the questions is posed, like the interest of Spanish citizens in the rights and responsibilities of citizens or the different perspective of the German speaking participants when looking at the issue of more and better data.

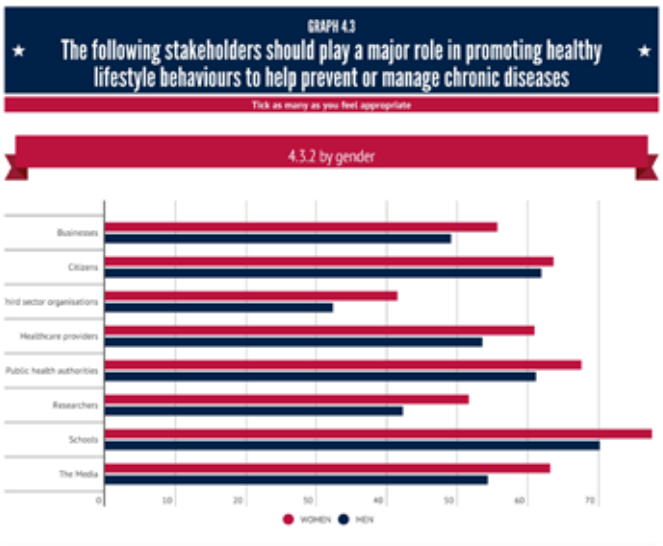
In fact this cultural bias is very clear when looking at the debates on the forum and social media outlets. This is particularly visible during the discussion on more and better data where we see the participants from the German-speaking countries being more cautious about giving access to their personal data.



This underlines the need for more education and awareness campaigns and programs to increase the understanding of different perspectives across Europe and how to move forward in a unified level. It also demonstrates the complexity in trying to develop a vision and action plan that works for all European citizens.

In fact, the importance of education and awareness is something that the participants of the campaign underline themselves. Across the different weeks education is always seen as a key to addressing the challenges of the spreading of NCDs in Europe. In particular when it comes to healthy lifestyle choices and behaviour we can clearly see that respondents feel that they as citizens have the biggest responsibility in this regard followed by government and healthcare providers.




Citizens ascribe significant responsibility also to government in particular in the important priority of funding research and innovation, creating awareness through education and campaigns, facilitating healthy behaviour through regulation, urban planning and other incentives and ensuring a balanced and inclusive debate on these issues that include all interested parties.

Detailed results outlining the opinions and concerns of citizens on the issue of prevention, new technologies and innovation, citizen's rights and responsibilities, diabetes and nutrition and more and better data can be found in the previous chapter.

Overall there is significant understanding of the challenge that the issue of chronic diseases poses on today's societies. Citizens are eager to engage in a more reliable and inclusive discourse and are interested in find out more about the issue and what they can do to better the situation.

**From the Forum**

Thank you for a good discussion and necessary platform!

Table 1: REIsearch's impact goals, outputs, impact indicators and targets, and outcomes.

**IMPACT GOAL 1: To create a virtual cluster on the topic of "chronic diseases" that brings together researchers, industry, media and policy makers to enhance collaborations on these key themes, starting from the existing European collaborations creating an easy and useful tool to facilitate dialogue and collaborations.**

| Outputs | Impact Indicators and targets | Outcomes |
|---|---|---|
| Direct engagement of relevant stakeholder organisations and people in the design, validation and dissemination of contents related to the first REIsearch's communication and media campaign on chronic disease. | - Number and diversity of organisations involved: at least 40 relevant organisations involved, representing all the targeted audiences (researchers, industry, media, policy makers).<br><br>- Proactivity of organisations involved: at least 2/3 of the organisations involved actively participate to the contents creation, validation or dissemination activities.<br><br>- Global reach of the organisations involved: at least 5MIL citizens and 1MIL researchers potentially exposed to the campaign.<br><br>- Number of policy-makers reached through the initiative (at least 30 high profile policy-makers informed of the initiative's outcomes, out of whom at least 15 committed to act upon it).<br><br>- Sustainability: stakeholders organisations are satisfied with the outcomes of the initiative and willing to further develop it over time. | - 44 organisations involved representing all the targeted audiences.<br><br>- 95% of the organisations involved took part to the foreseen activities.<br><br>- Media partners' reach alone is nearly 9MIL EU citizens, Knowledge and business partners reach above 2 million researchers.<br><br>- REIsearch presented to over 50 policy-makers 15 MEPS involved in the REIsearch Policy Group. Outcomes will be monitored over time.<br><br>- Nearly all the organisations involved confirmed their willingness to support the further development of the chronic disease cluster on REIsearch. |

**IMPACT GOAL 2: To create a direct dialogue between these virtual clusters and citizens through the participation of leading European media to the project.**

| Outputs | Impact Indicators and targets | Outcomes |
|---|---|---|
| Direct engagement of leading European Media to implement the first REIsearch's communication and media campaign on chronic diseases and to mobilize EU citizens and researchers on the REIsearch platform through a survey related to the contents presented during the campaign. Further citizens and organisations to be reached through social media. | - Number and reach of newspapers engaged (at least 10 newspapers with a total reach of at least 5MIL readers, in at least 6 EU languages).<br><br>- Number of citizens reached through the organisations involved: at least 30.000 citizens to visit the REIsearch platform.<br><br>- Proactivity of citizens and researchers reached by the campaign: at least 10.000 citizens, out of whom at least 10% are researchers, actively engaged on the platform by either answering the polls, writing on the forum or downloading available publications.<br><br>- Number and proactivity of citizens reached through social media channels: at least 10000 citizens exposed to the social media campaign, at least 500 followers/likes between twitter and facebook and at least 100 interactions. | - 9 newspapers and 1 scientific webzine engaged, with a total reach of nearly 9MIL readers, publishing 57 articles in 7 EU languages.<br><br>- Nearly 60.000 citizens visited the REIsearch platform.<br><br>- 17.261 citizens participated to the polls, 12% being researchers.<br><br>- About 1650 quests performed to download available materials.<br><br>- 46 posts on the forum and over 1388 comments on the media partners websites.<br><br>- 15000 people were reached by REIsearch's social media camapign, 474 liked the campaign facebook page and REIsearch tweets, followed by about 3000 followers, received a total of 90,700 impressions, with REISearch Twitter profile visited a total of 4,055 times. |

# 5 - EVALUATION OF METHODOLOGY

The launch strategy aimed at engaging four key stakeholder groups - research organisations, journalists, policy makers and the private/business community - in order to reach a broader 'public' of citizens, researchers and policy-makers through their proactive collaboration, and to engage them on the societal challenge of chronic diseases using the REIsearch platform as an online hub.

The initiative's impact goals, outputs, impact indicators and targets related to the launch activities were agreed prior to the launch of the REIsearch platform, together with the initiative's Steering Committee and Advisory Board, also building on the experience of the Special Initiative for Citizen Engagement in Science (www.eismd.eu/spices) that EISMD ran in 2013 to test the model of REIsearch.

Launch activities were designed to ensure that the REIsearch platform attracted from the very beginning a broad and active audience of citizens, researchers, policy-makers and their organisations, in order to achieve two of the main goals of the project:

- To create a virtual cluster on the topic of "chronic diseases" that brings together researchers, industry, media and policy makers to enhance collaborations on these key themes, starting from the existing European collaborations creating an easy and useful tool to facilitate dialogue and collaborations and
- To create a direct dialogue between these virtual cluster and citizens through the participation of leading European media to the project.

Direct engagement of relevant stakeholder organisations and people in the design, validation and dissemination of contents related to the first REIsearch's communication and media campaign on chronic diseases was key to reaching the first objective.

Concerning **the number and diversity of organisations involved**, 44 organisations were engaged in the activities leading to the launch, as well as during the campaign. They included 9 research organisations, 4 civil society organisations, 7 large companies, 2 policy-making institutions and 22 media organisations.

Concerning **the number and proactivity of citizens and researchers** targeted by the Campaign, nearly 60,000 citizens visited the REIsearch platform, and 17,205 participated in the polls (12% of them researchers), equal to over one third of users and in line with the very ambitious target set at the beginning of the campaign.

15,000 people were reached by REIsearch's social media campaign, 474 liked the campaign's Facebook page, and REIsearch tweets - followed by about 3000 followers - received a total of 90,700 impressions, with REISearch's Twitter profile visited a total of 4,055 times.

Concerning **the levels of satisfaction of the stakeholder organisations involved**, nearly all the partner organisations confirmed their willingness to support the further development of the chronic disease cluster on REIsearch and/or to take part in future initiatives focused on different topics.

The coordination of all the activities for the successful launch of REIsearch and the *Citizen Engagement and Media Campaign on Chronic Diseases* required a close collaboration and coordination of the three levels of governance (Executive, Management and Operative) and the two operative teams of REIsearch: the Technical Development Team and the Editorial Office coordinated by the Project Management Team.

At the Executive Level, the presence of a very proactive and authoritative Advisory Board and Steering Committee, in addition to Atomium EISMD's previously established network and the successful experience of SPICES, was key to connecting with all the stakeholders and ensure an overall coordination of activities. Further, the direct involvement of one of the Chairmen of the Steering Committee and the Advisory Board in the Executive Team ensured a close collaboration between the different levels of governance.

REIsearch also had the extreme benefit of being able to rely on the vision and experience of leading experts in their respective fields in setting up the editorial strategy and the technical development. The members of the Editorial Committee for the editorial strategy and Prof. Massimo Marchiori: a computer scientist who made major contributions to the development of the World Wide Web including creating HyperSearch, an engine that became the basis for future search algorithms such as PageRank, on which search engines such as Google are based. He is now dedicated to the development of third generation search engines that guide users in their research.

Clearly, whilst both citizens and researchers were keen to participate in the polls and share their opinion with EU policy makers, more effort will be required in the future to foster the use of the other tools available on the research platform.

Concerning citizens' and researchers' feedback on the published articles and polled questions, most comments on the newspapers websites and platform were positive, illustrating a willingness to share experiences and ideas and to learn more about the various topics.

The concept of REIsearch was praised by citizens, patients, researchers, journalists and policy makers. The editorial team got positive feedback as well as suggestions on how to further improve the platform from a variety of different actors; for instance, an expert from the Austrian ministry of health made contact with Der Standard, the initiative's Austrian media partner, showing great interest in the survey and requesting more information, especially on the outcomes.

## CONCLUSIONS

Overall, the REIsearch initiative's launch activities were successful, and all the targets set prior to the implementation of the REIsearch platform were met. REIsearch can now rely on a strong and committed community of experts and on the support of 44 organisations active in the field of chronic diseases, as well as in the scientific communication and media domain, including 9 research organisations, 4 civil society umbrella organisations, 7 large companies, 2 policy-making institutions and 22 media organisations.

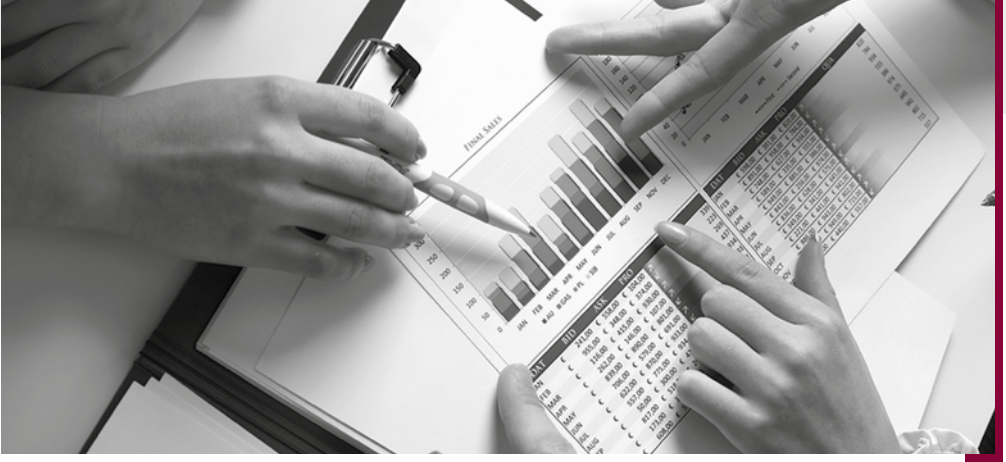
Partner organisations greatly contributed to the success of the first REIsearch's Citizen Engagement and Media Campaign on chronic diseases, both in the design and validation of contents, in the dissemination activities, and by ensuring access to over 100 million publications between peer-reviewed articles and non-academic documents and reports from the REIsearch platform. This in turn enabled the initiative to reach hundreds of thousands of citizens and researchers across Europe, and to actively engage nearly 20,000 EU citizens through the survey linked to the initiative, social media activities, and online discussions and other tools available on the REIsearch platform.

Based on feedback received by the partner organisations, three main areas of activities have been identified to ensure that the virtual cluster on chronic diseases will further develop, together with the REIsearch project, and that future campaigns will be even more successful:

1) **Growing the Chronic Diseases Virtual Cluster:** the virtual cluster brought together for the first campaign will need to be strengthen and continuous activities will need to be implemented to keep the cluster alive.

2) **Improving and developing the REIsearch platform:** the platform will be modified in order to better meet users' needs based on the feedback and experience of the first initiative.

3) **Outcomes based approach:** monitoring the project impact over time is fundamental to retain partner organisations and attract new stakeholders, as well as citizens and researchers. This is particularly evident when it comes to the goal of fostering evidence-based and inclusive policy making. For this reason, particular attention will be dedicated to monitor if and how the dissemination of the project's outcomes will affect policy-decisions in the coming months.





# LIST OF GRAPHS

**Graph 1.1: Citizen Engagement and Media Campaign on Chronic Diseases** ..... 35
**Overall participation**
- 1.1.1 total access to campaign by language (line graph)
- 1.1.2 total access to campaign by language (stacked area chart)
- 1.1.3 total responses to survey by language (line graph)
- 1.1.4 total responses to survey by language (stacked area chart)

**Graph 1.2: Participation distribution by week and language** ..... 36
- 1.2.1 overall language distribution
- 1.2.2 WEEK 1 – Prevention
- 1.2.3 WEEK 2 – New Technologies and Innovation
- 1.2.4 WEEK 3 – Citizen's Rights and Responsibilities
- 1.2.5 WEEK 4 – Diabetes and Nutrition
- 1.2.6 WEEK 5 – More and Better Data

**Graph 1.3: Overall Participation by Gender** ..... 37

**Graph 1.4: Overall Participation by Age** ..... 38

**Graph 1.5: Overall Participation by Education Level** ..... 39

**Graph 2.1: WEEK1 – PREVENTION** ..... 46
**HOW LONG WOULD YOU LIKE TO LIVE FOR? And what are you willing to do? Overall participation**
- 2.1.1 participation by language
- 2.1.2 participation by gender
- 2.1.3 participation by age
- 2.1.4 participation by education level

**Graph 2.2: "Healthy citizens are the greatest asset any country can have" (Sir Winston Churchill) Do you agree?** ..... 47
- 2.2.1 all & researcher responses
- 2.2.2 by language
- 2.2.3 by gender

**Graph 2.3: What do you think are the main causes of non-communicable diseases?** ..... 48
- 2.3.1 all responses
- 2.3.2 researcher responses
- 2.3.3 by language
- 2.3.4 by gender

**Graph 2.4: "All Ministers are Health Ministers" (Margaret Chan) - Do you agree?** ..... 49
- 2.4.1 all responses
- 2.4.2 by gender
- 2.4.3 by language

**Graph 2.5: What are the most important measures for preventing NCDs?** ..... 50
- 2.5.1 all responses
- 2.5.2 by gender
- 2.5.3 by language

**Graph 2.6: "Chronic non-communicable disease prevention should be an investment priority not only for government and public organisations, but equally for businesses (small and large companies active in any sector) and non-profit organisations" - Do you agree?** ..... 51

**Graph 2.7: Who has the most important role to play in promoting healthy behaviours to help prevent chronic non-communicable diseases?** 51
**Graph 2.8: What are you most interested in finding out more about in relation to NCDs?** 52

**Graph 2.9: What should governments focus on in order to promote healthy nutrition?** 52

**Graph 3.1: WEEK 2 – NEW TECHNOLOGIES AND INNOVATION**
**WILL TECHNOLOGY DEFEAT SICKNESSES? And who will have access to this technology? Overall participation** 58
- 3.1.1 participation by language
- 3.1.2 participation by gender
- 3.1.3 participation by age
- 3.1.4 participation by education level

**Graph 3.2: "New technologies and innovation are fundamental to the development of long-term solutions to chronic non-communicable diseases and public, private, and third sector organisations should all scale up investment in this field" - Do you agree?** 59
- 3.2.1 all responses
- 3.2.2 researcher responses
- 3.2.3 by language
- 3.2.4 by gender

**Graph 3.3: Provided that they are appropriate and transparent, which of the following do you consider a possible source of funding for new technologies that help manage chronic non-communicable diseases?** 60
- 3.3.1 all responses
- 3.3.2 researcher responses
- 3.3.3 by language
- 3.3.4 by gender

**Graph 3.4: The development of new technologies and innovation for chronic non-communicable disease prevention or management should include:** 62
- 3.4.1 all responses
- 3.4.2 researcher responses
- 3.4.3 by language
- 3.4.4 by gender

**Graph 3.5: Technology, if applied to support the necessary lifestyle changes and policy interventions, can be a formidable ally to tackle chronic diseases.**
**Which of the following technologies would you be willing to use to manage or prevent chronic diseases?** 63
- 3.5.1 all responses
- 3.5.2 researcher responses
- 3.5.3 by language
- 3.5.4 by gender

**Graph 3.6: Do you use any health apps?** 64
- 3.6.1 How often do you update these apps with reliable information?
- 3.6.2 Which apps do you use?

**Graph 3.7: Which of the following do you consider barriers to new technologies and innovation?** 65

**Graph 3.8: "If we want technology and innovation to make a difference for citizens and patients, then we need more investment and collaboration to combine innovative and traditional approaches, putting users at the centre of the process" - Do you agree?** 65
- 3.8.1 all responses
- 3.8.2 researcher responses

**Graph 4.1: WEEK 3 – CITIZEN'S RIGHTS AND RESPONSIBILITIES**
**HOW MUCH DO YOU VALUE YOUR HEALTH? And what value do others place on it? Overall participation** 73
- 4.1.1 participation by language
- 4.1.2 participation by gender
- 4.1.3 participation by age
- 4.1.4 participation by education level

**Graph 4.2: Who is responsible for your personal health?** 74
- 4.2.1 all responses
- 4.2.2 researcher responses
- 4.2.3 by language
- 4.2.4 by gender

**Graph 4.3: The following stakeholders should play a major role in promoting healthy lifestyle behaviours to help prevent or manage chronic diseases** 75
- 4.3.1 all responses
- 4.3.2 by language
- 4.3.3 by gender

**Graph 4.4: As a citizen, I want to learn more about my rights and responsibilities in the field of chronic disease prevention** ..... 76

**Graph 4.5: Access to free healthcare should be granted to everyone, irrespective of his or her personal lifestyle choices - Do you agree?** ..... 77

**Graph 4.6: Employers should reward workers for participating in wellness programmes and meeting health benchmarks - Do you agree?** ..... 78
- 4.6.1 all responses
- 4.6.2 by language
- 4.6.3 by gender

**Graph 4.7: I believe that governments, companies and third sector organizations should all use their knowledge of citizens' habits to induce healthy behaviors, while collaborating to create healthy environments and products Do you agree?** ..... 79

**Graph 4.8: I would be willing to give some of my free time to initiatives aimed at chronic disease management Do you agree?** ..... 80
- 4.8.1 by language
- 4.8.2 by gender

**Graph 4.9: "I would be willing to give some of my free time to citizen-led campaigns and initiatives (e.g. online forums, petitions, rallies, lobbying, action groups) aimed at chronic disease prevention" Do you agree?** ..... 81
- 4.9.1 by language
- 4.9.2 by gender

**Graph 5.1: WEEK 4 – DIABETES AND NUTRITION** ..... 89
**DO YOU KNOW WHAT YOU ARE EATING? Do you control your diet or does your diet control you? Overall participation**
- 5.1.1 participation by language
- 5.1.2 participation by gender
- 5.1.3 participation by age
- 5.1.4 participation by education level

**Graph 5.2: In your opinion, which of the following stakeholders has a role to play in type 2 diabetes prevention?** ..... 90
- 5.2.1 all responses
- 5.2.2 researcher responses
- 5.2.3 by language
- 5.2.4 by gender

**Graph 5.3: Diabetes prevention and management requires the coordinated intervention of the public, private and third sector, and the active involvement of patients and citizens - Do you agree?** ..... 91
- 5.3.1 all responses
- 5.3.2 by language
- 5.3.3 by gender

**Graph 5.4: In your opinion, which of the following initiatives can help prevent type 2 diabetes?** ..... 92
- 5.4.1 all responses
- 5.4.2 by gender
- 5.4.3 by language

**Graph 5.5: What are you most interested in finding out more about?** ..... 93
- 5.5.1 all responses
- 5.5.2 by gender
- 5.5.3 by language

**Graph 5.6: "I would be willing to use new technologies (e.g. watches, bands, sensors) to monitor my diabetes risk factors (e.g. nutrition, physical exercise) and then share this data for public health research and policy purposes" Do you agree?** ..... 94
- 5.6.1 all responses
- 5.6.2 by gender
- 5.6.3 by language

**Graph 5.7: "If I were diabetic, I would be willing to use new technologies to monitor and manage my condition (e.g. to be aware of the levels of sugar in my blood) and then share this data for public health research and policy purposes" - Do you agree?** ..... 95
- 5.7.1 all responses and by gender
- 5.7.2 by language

**Graph 5.8: "I want governments and businesses to regulate the amount of sugar, salt, and trans fat in industrial food products" - Do you agree?** 96
- 5.8.1 all responses
- 5.8.2 by gender
- 5.8.3 by language

**Graph 5.9: "Governments, companies and civil society organizations should use marketing and communication technologies to nudge citizens into eating healthy food and doing some physical activity to help prevent the rise of diabetes" - Do you agree?** 97
- 5.9.1 all responses and by gender
- 5.9.2 by language

**Graph 6.1: WEEK 5 – MORE AND BETTER DATA** 106
**IS BIG DATA THE NEXT BIG THING? What is in it for the citizen? Overall participation**
- 6.1.1 participation by language
- 6.1.2 participation by gender
- 6.1.3 participation by age
- 6.1.4 participation by education level

**Graph 6.2: "I am fully aware of what my rights are concerning the protection and use of my personal health data" - Do you agree?** 107
- 6.2.1 all responses
- 6.2.2 researcher responses
- 6.2.3 by language
- 6.2.4 by gender

**Graph 6.3: A new data protection reform package has recently been approved by the Parliament and Council of the EU, and should enter into force in all EU member states in 2018. On what aspects of the new legislation would you be interested in finding out more?** 108
- 6.3.1 all responses
- 6.3.2 researcher responses
- 6.3.3 by language
- 6.3.4 by gender

**Graph 6.4: Provided that data are anonymised and used safely, ethically and securely, I would share my personal health data to help prevent and/or cure chronic non-communicable diseases** 110
- 6.4.1 all & researcher responses
- 6.4.2 by language
- 6.4.3 by gender

**Graph 6.5: Why do you think more and better data are important?** 111
- 6.5.1 all responses
- 6.5.2 researcher responses
- 6.5.3 by language
- 6.5.4 by gender

**Graph 6.6: "Governments should invest public money from multiple sector budgets – not just healthcare – and pool resources from the private sector, to develop 'more and better data' for chronic disease management and prevention" - Do you agree?** 112
- 6.6.1 all responses
- 6.6.2 by gender
- 6.6.3 by language

**Graph 6.7: "Provided that data are anonymised and used safely, ethically and securely, all personal health data should be shared to help prevent and manage chronic diseases, without the need to ask individual citizens for their consent"** 113
- 6.7.1 all responses
- 6.7.2 by language

**Graph 6.8: "Healthcare providers (doctors, administrators) need more and better data to manage and prevent chronic non-communicable diseases"**
**Do you agree?** 114

**Graph 6.9: "Provided that data are anonymised and used safely, ethically and securely, I would share my personal health data to help Pharmaceutical Companies to develop new and better drugs"**
**Do you agree?** 114

# ANNEX 1

Access to all the editorials and questionnaires of the
*Citizen Engagement and Media Campaign on Chronic Diseases*
can be found on:

www.REIsearch.eu
www-eismd.eu/REIsearch


ATOMIUM
EUROPEAN INSTITUTE
FOR SCIENCE, MEDIA AND DEMOCRACY


European
Commission