

What do European citizens think about tackling chronic diseases? And what are EU policy-makers doing to meet their needs?

Insights from REIssearch's media and communication campaign on chronic diseases

In February and March 2016, a citizen engagement and media campaign on chronic diseases was launched under EU funded project REIssearch, with the objective of promoting a responsible and multi-stakeholder debate on the issues involving thousands of European citizens, researchers, policymakers and stakeholders. Indeed, chronic non-communicable diseases cause today 86% of deaths in the European Union, affecting more than 80% of people aged over 65, and they are responsible for nearly 80% of the health budgets. 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.

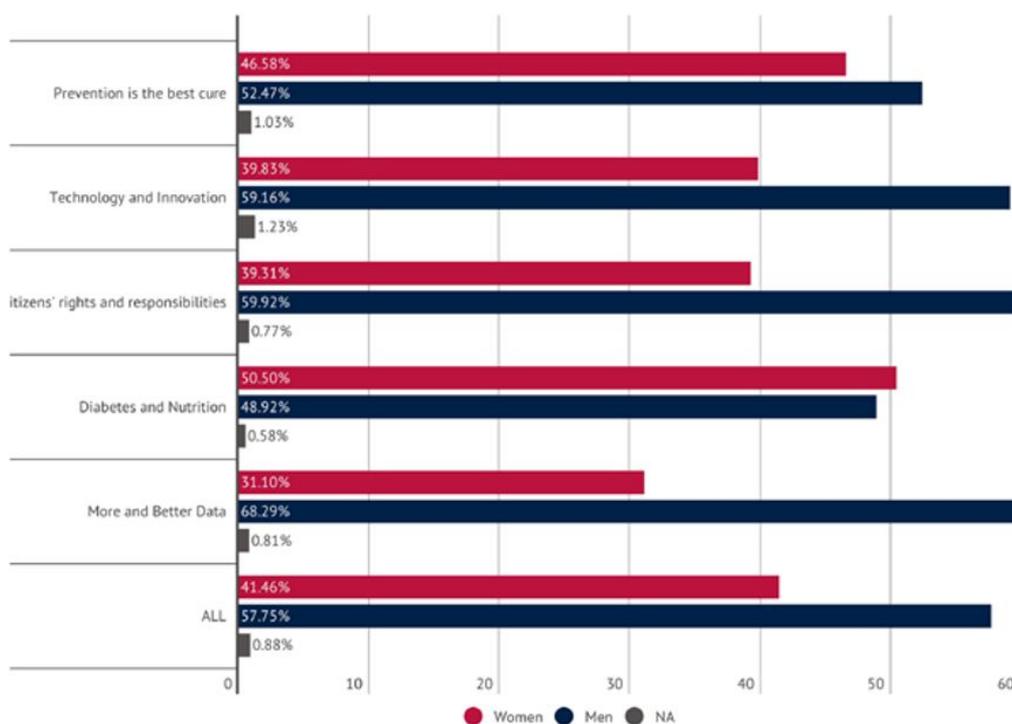
Coordinated by Atomium – European Institute for Science, Media and Democracy (EISMD), in collaboration with 44 stakeholder organisations, the campaign was run in 7 languages and saw the publication of over 70 articles by our media partners, including Der Standard, El País, EuroScientist, Frankfurter Allgemeine Zeitung, Gazeta Wyborcza, La libre Belgique, Luxemburger Wort, Público, Sole24ore, The Irish Times, Elsevier Direct, Cell and The Lancet. For 5 weeks, citizens and researchers were asked to comment on the articles by answering a short questionnaire on 5 topics related to chronic diseases: 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 lastly a more technical and very current debate (more and better data). Over 17.000 responses were collected, providing very interesting insights on citizens' and researchers' views for the benefit of EU decision-makers.

Overall, EU citizens agree on the fact that health is a priority issue, which should be considered by all government portfolios and taking a multi-stakeholder approach, with schools and the media being perceived as key players in tackling chronic diseases by raising awareness on risk factors and healthy behaviours.

In terms of participation, more than one third of the respondents 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 (English, French, Italian, Polish and Portuguese) making up the remaining 30% of participants.

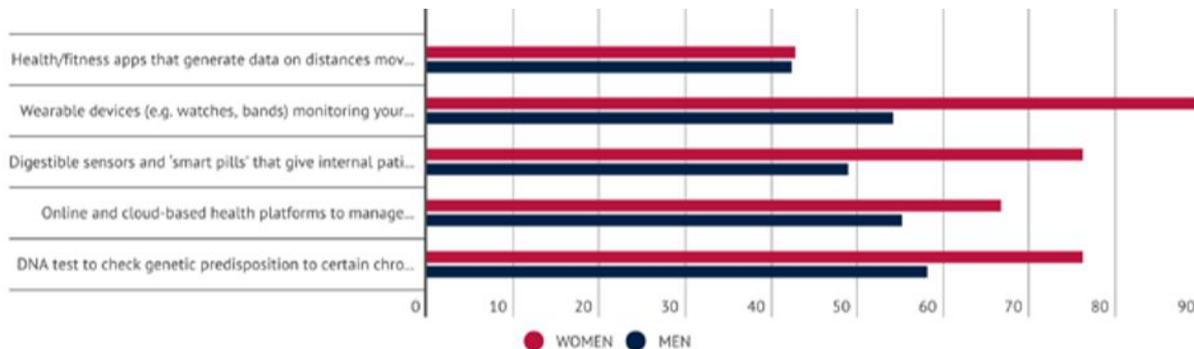
There was a higher participation of men than women during the campaign, however this varied significantly from week to week and country to country with participation from Polish and Portuguese-speaking participants being mainly female. The biggest variation was seen during the week on "more and better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

★ **GRAPH 1.3** ★
Overall Participation by Gender
 distribution by week

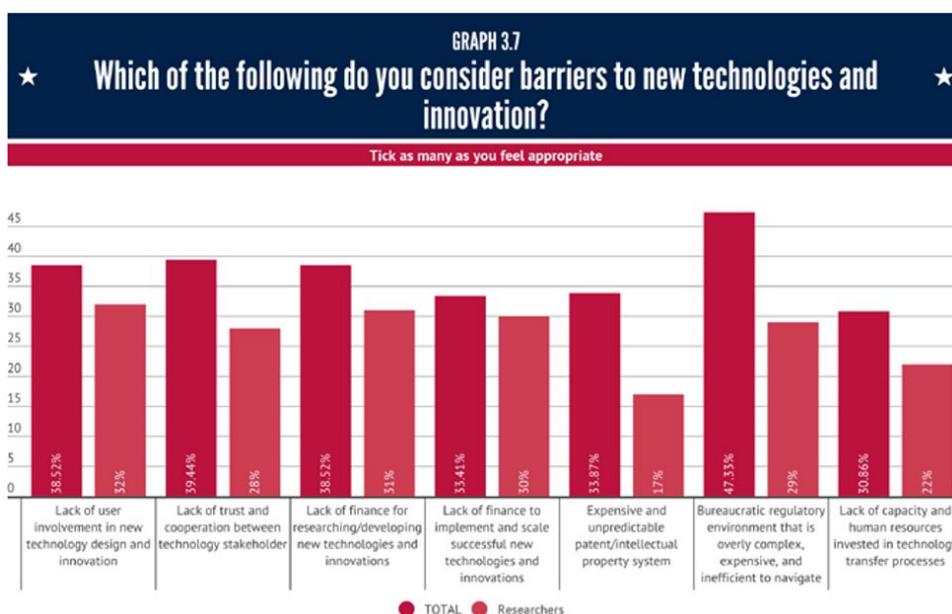


This suggests a “gender gap” when it comes to technical issues which might need to be addressed with specific measures. Indeed, and beyond participation rates, throughout the campaign there were no major differences of opinion between participants based on gender but in the technology and innovation domain: 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 seem to be equally willing:

★ **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?



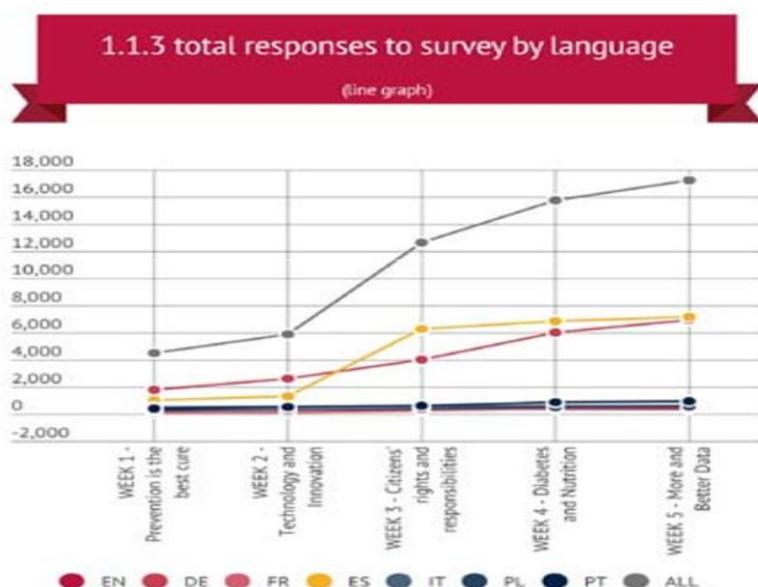
Over 12% of respondents were researchers; however, differences among the responses provided by researchers compared to the rest of the public weren't particularly significant, with a few exceptions, again in the research & innovation and in the data domains. For instance, in terms of barriers to the uptake of new technologies and innovation, "Bureaucratic regulatory environment" was the main barrier according to citizens, but not for researchers, and similarly for the patent system. However, both researchers and the general public agree on the fact that user involvement is key if we want technology and innovation to flourish:



All in all, throughout the campaign there were no major differences of opinion between participants based on gender, education level or age: the only factor that clearly played a role was language. This underlines the importance of the cultural background on which the question 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 ensuring data privacy and security.

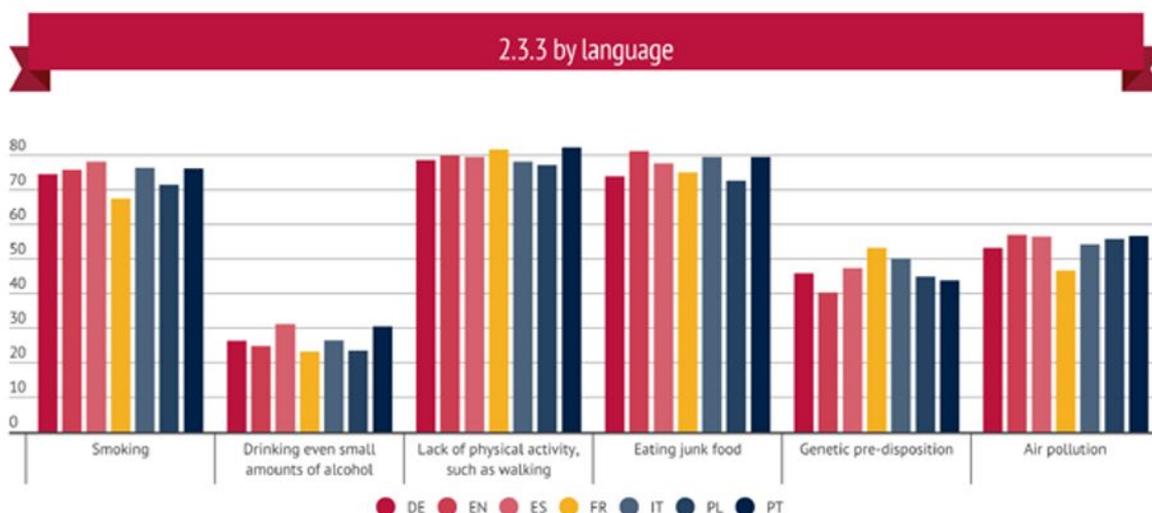
Indeed, it is interesting to view which topics were more popular among which language-groups. The German-speaking participants dominated the debates on "Prevention" and even more on "New Technologies and Innovation", whilst the week on "Citizen Rights and Responsibilities" saw a surge in Spanish-speaking participants with nearly over six thousand respondents (and 16.000

accesses) from Spain sparking over one thousand comments on the forums and social media platforms. The other topics saw similar rates of participation:

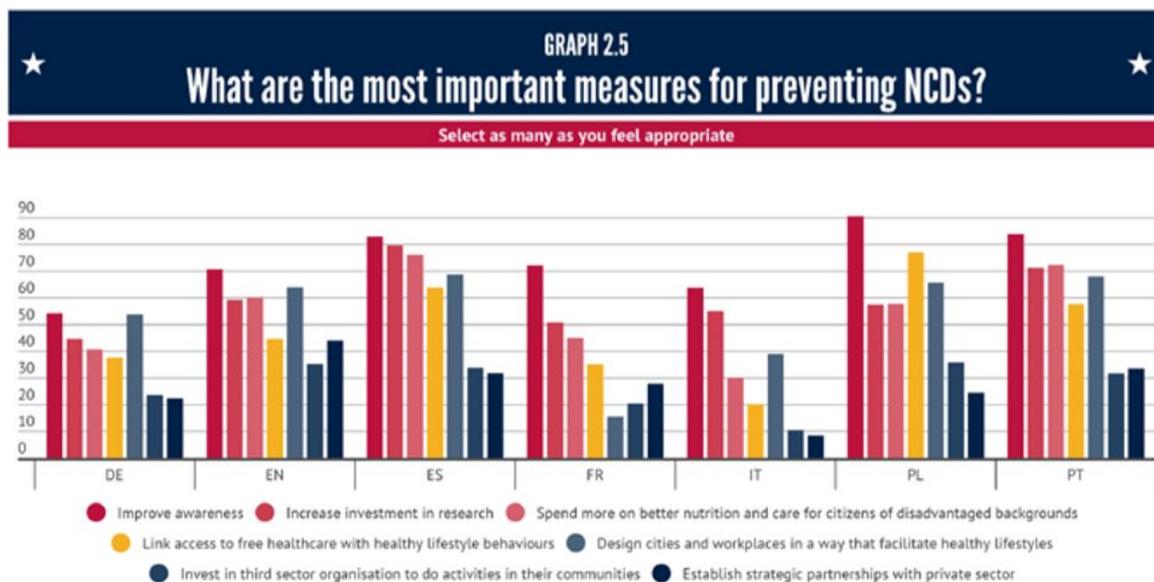


On the topic of Prevention, it is clear that across Europe there is a similar understanding of the causes of chronic diseases, where lack of physical activity, eating junk food and smoking were rated as main causes of chronic non-communicable diseases with air pollution and genetic predisposition following and “drinking even small amounts of alcohol” being seen as the least significant. However, a few variations occur, so for instance, French speaking respondents (mainly from Belgium) tend to grant less importance to smoking as a risk-factor, and more importance to genetic predisposition, compared to all other countries:

What do you think are the main causes of non-communicable diseases?
Choose as many options as you feel appropriate

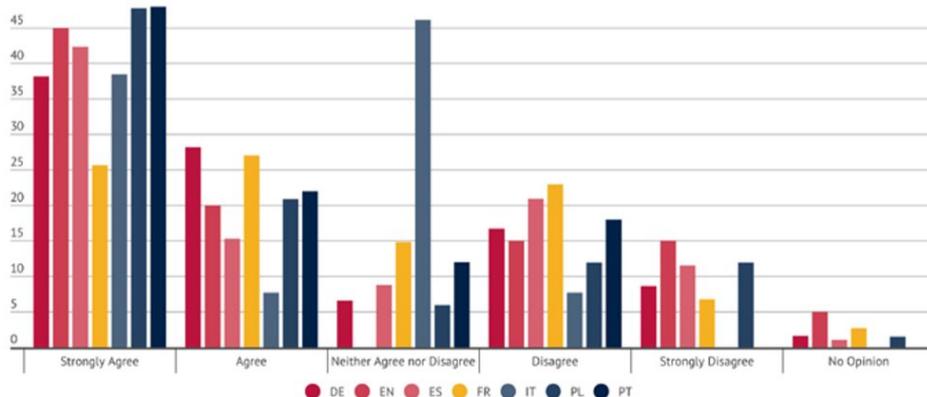


Despite these high levels of awareness, when asked what they were most interested in finding out more about, over half of the respondents selected behavioural risk factors and citizen lifestyle behaviours, underlining the interest that people have in getting more information about the effects of their behaviour, whilst, for instance, only 12.3% were interested in knowing about value for money. Similarly, 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. While promoting awareness was the most important measure for all linguistic groups, national differences could be spotted in respect of the other measures. For instance, in Poland linking access to free healthcare with healthy lifestyle behaviour was the second most voted priority, followed by city and workplaces design and spending more on better nutrition and care for citizens of disadvantaged backgrounds. This latest priority was the second most voted one in Portugal, scoring very high also in Spanish speaking, English speaking and French speaking countries:



Also under the “Citizen rights and responsibilities” topic, respondents made it very clear that they considered themselves responsible for their health. However, most participants (around 60%) also felt that in spite of this, access to free healthcare should be granted to everyone, irrespective of his or her personal lifestyle choices. 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:

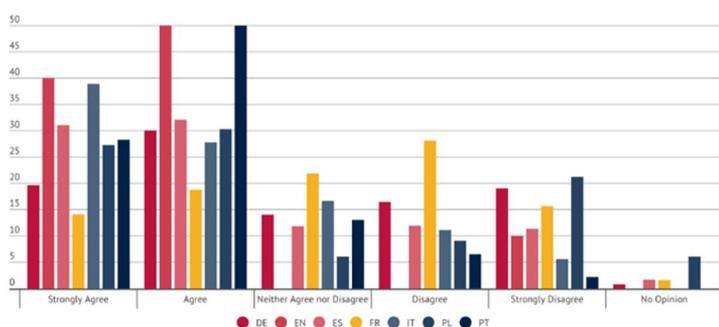
★ **Access to free healthcare should be granted to everyone, irrespective of his or her personal lifestyle choices** ★
 DO YOU AGREE?



Broad differences of opinion could be seen also 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 were mostly against this proposal:

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

DO YOU AGREE?



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. This consideration is further reinforced by answers provided under the Diabetes topic, where, quite counter-intuitively, over 75% of respondents 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”.

When asked to say which actor has the biggest role to play in promoting healthy behaviours schools (81.7%) were seen as the most important actors by large, 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:

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

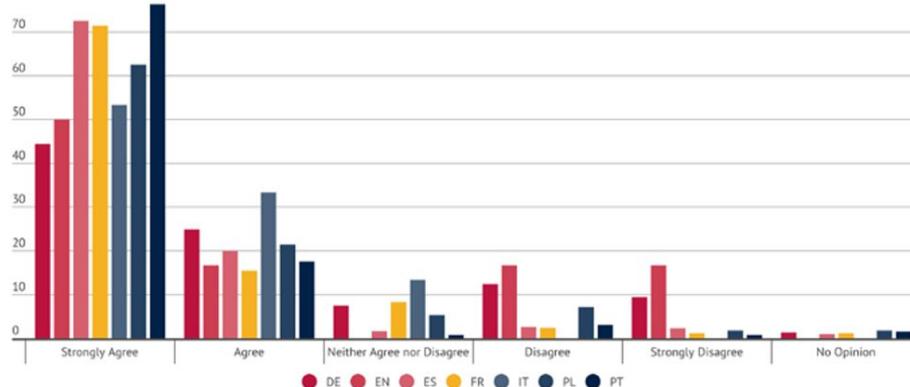
Tick as many as you feel appropriate



However, regulating food packaging was seen by most stakeholders as the main way for governments to promote better nutrition, ahead of both promotion campaigns and business incentives. The importance granted by citizens to regulation also emerges under the Diabetes topic, with over 75% of respondents asking governments to regulate amount of sugar salt and trans fat present in industrial food products. Interestingly, German and English speaking respondents are the only groups where disagreement towards regulating is above 10%:

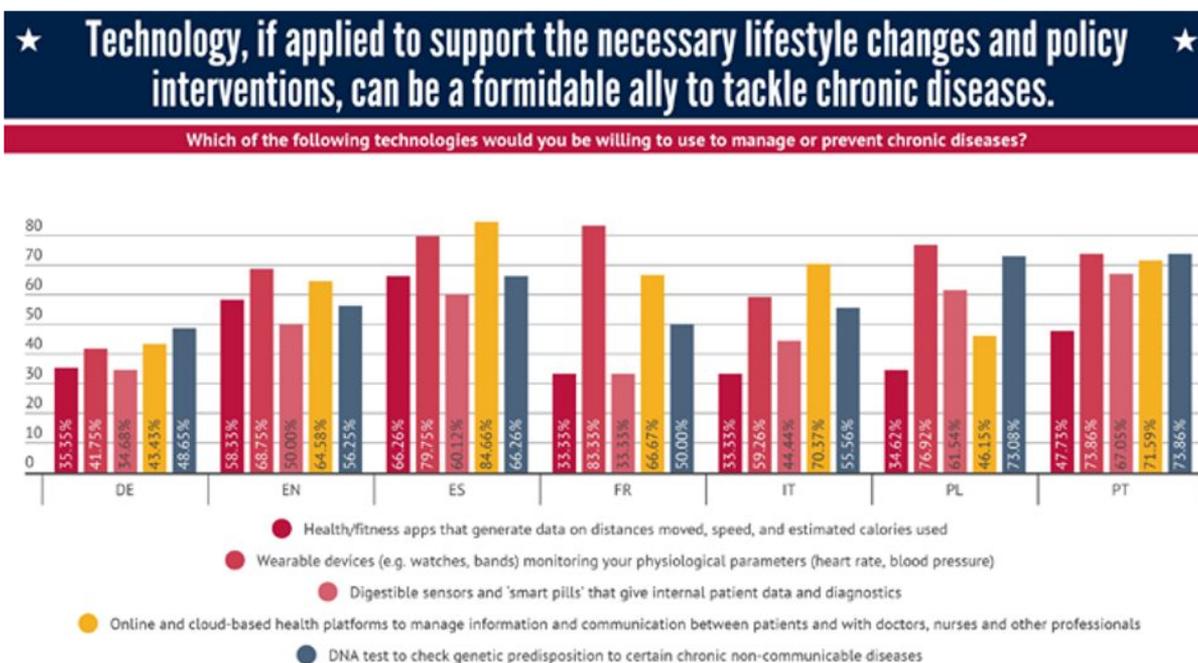
★ **“I want governments and businesses to regulate the amount of sugar, salt, and trans fat in industrial food products”** ★

Do you agree?



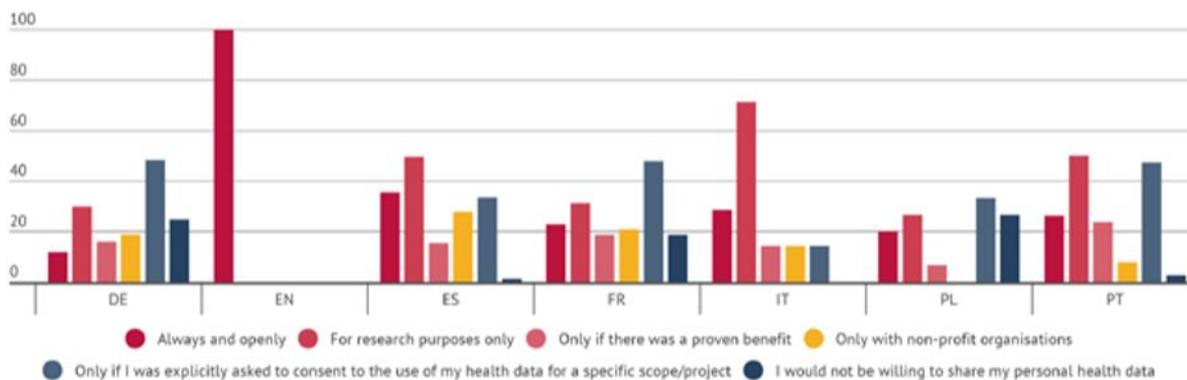
Concerning the importance of research and innovation, whilst in Spanish, French and Portuguese countries the totality of participants agreed that “new technologies and innovation are fundamental to the development of long-term solutions to chronic non-communicable diseases and public, private and third sector organisations should all scale-up investment in this field”, in German, English, Italian and Polish speaking countries over 15% of respondents, all male, disagreed or strongly disagreed with the statement. Concerning availability to use current or future technologies, German speaking countries seem to be way less open compared to all the other groups, with less than half the respondents likely to use any of the listed technological

solutions.



Interestingly, although over 50% of respondents use health apps, only 17% of respondents would use apps to manage or prevent chronic diseases. Citizens' relative lack of trust into technologies – including in terms of privacy – also emerged in the Diabetes and Data topics. Only slightly more than half of the participants would be willing 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. Interestingly, this number increases to 75% when asked if they would be willing to do so “if they were diabetic”. Concerns about data privacy and security emerged clearly under the “More and better data” topic, for which differences between countries and between researchers and the general public were more accentuated than for any other topic. Indeed, even though “anonymised and used safely, ethically and securely”, only 19% (12% of researchers) would be willing to share their health data always and openly. However, the 100% of English speaking respondents would. Nearly 18% would not be willing to share their personal health data (19.5 % amongst researchers and nearly 30% of German and Polish speakers) in any case. Most participants were 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:

★ **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** ★



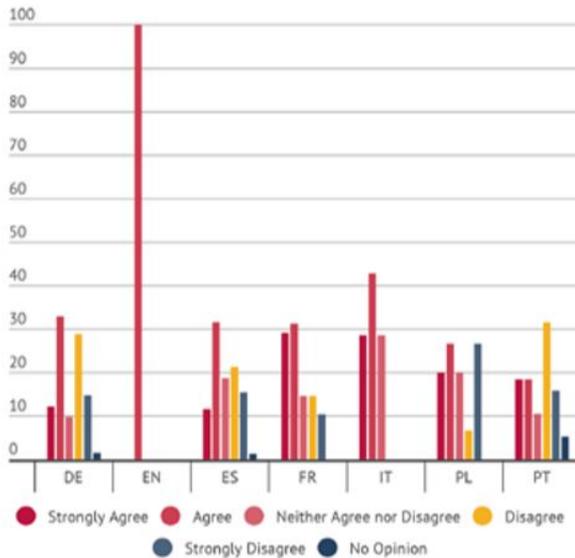
Interestingly, the opinion did not change significantly when participants were asked if they would share their personal health data to help Pharmaceutical Companies to develop new and better drugs. A majority – and the total of Italian respondents - would be willing to do so with the German-speaking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

Indeed, 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. Most respondents agreed that healthcare providers (doctors, administrators) need more and better data to manage and prevent chronic non-communicable diseases with only the German, French and Polish speaking participants being more cautious.

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, participants were 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 priority 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. On the other hand, 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:

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

DO YOU AGREE?



Are citizens' priorities aligned with EU policies and funding programmes?

The EU promotes and fund research and awareness raising on healthy behaviours across the EU, both via policy action and by direct and structural funds. "The aim is to tackle the key underlying causes of ill-health related to personal lifestyles and to economic and environmental factors (pollution from pesticides, heavy metals, endocrine disruptors). This entails, in particular, close coordination with other EU policy areas such as the environment, transport, agriculture and economic development."

'Air pollution remains the number one environmental cause of death in the EU, still leading to about 400.000 premature deaths each year in the EU due to elevated levels of fine particles and ozone. The Commission put forward an Air Quality Policy Package in 2013, including legislative proposals that are presently being considered by the European Parliament and Council. The main elements of this air quality policy package, i.e. the air pollutants it focusses on, their respective sources and origins, the scope for taking action and the benefits this would render for health, economy and environment are summarised in the Cleaner air for all infographic.' Also, to fight air pollution and improve citizens' quality of life, the EU funds several programmes and projects and studies to promote sustainable urban mobility and increased use of clean and energy efficient vehicles.

In all countries the level of disease and age that people die are strongly influenced by factors such as employment, income, length of education and ethnicity. The Commission's plans to address health inequalities are set out in the Commission Communication - Solidarity in Health: Reducing Health Inequalities in the EU, published on October 2009. In the area of employment, health and safety at work the Commission cooperates with the European Agency for Health and Safety at Work and the European Foundation for the Improvement of Living and Working Conditions to disseminate information, offer guidance and promote healthy working environments – particularly in small businesses. The European Commission also receives additional funding from the European

Parliament for pilot projects to improve future policy action in the area of health inequalities.

In relation to free healthcare, the Parliament is currently working on an own initiative report on 'EU options for improving access to medicines', which relates to the fundamental rights of citizens to medical treatment, the escalating prices of medicines and barriers to patients in accessing some products owing to shortages of essential medicines and other distortions in the pharmaceuticals market.

The 21 April 2016 during the meeting 'Towards better prevention and management of chronic diseases' the Commission presented and discussed its ideas with representatives of Member States, international organisations and stakeholders, and invited them to work jointly on the implementation of activities with a potential to reduce the burden of chronic diseases, improving health outcomes and reinforce the stability of health systems. The purpose of the meeting was to set out an approach towards better prevention and management of chronic diseases at EU level, complementary to that agreed to at the international level. The 29 November 2016 the EU Member States and the European Commission held the first meeting of the Steering Group on Promotion and Prevention. The Group's objective is to provide the Commission with advice on investments and priorities for annual work plans under the Health Programme to improve cross-sectoral cooperation and to create an environment for a positive change in public health systems in the EU in order to tackle chronic diseases and their determinants. The next meeting of the Steering Group is planned for March 2017.

In terms of awareness raising, the EU promotes initiatives to address major risk factors, such as smoking and alcohol consumption. To address smoking, the European Union and its Member States have taken various tobacco control measures in the form of legislation, recommendations and information campaigns. These policy measures include: the regulation of [tobacco products](#) on the EU market (e.g. packaging, labelling, and ingredients), [advertising restrictions](#) for tobacco products, the creation of [smoke-free environments](#), [tax measures and activities against illicit trade](#), [anti-smoking campaigns](#). Particular attention is given to youth smoking, as tobacco is an addictive product and 94% of smokers start smoking before they turn 25. Taking into account the significant cross border trade of tobacco products and diverging national legislation, EU-wide rules are necessary for these products. The rules ensure that all consumers are equally protected across the EU. On April 2014 entered into force the [Tobacco Products Directive](#) governing the manufacture, presentation and sale of tobacco and related products. To address alcohol consumption, the EU promotes coordination at EU level. The Commission's Public Health Programme funds [projects](#) and other initiatives addressing alcohol related harm. The [Joint Action on Reducing Alcohol Related Harm \(JA-RARHA\)](#), is a 3-year action (2014-2016) aiming at supporting EU Member States to address and reduce the harm associated with alcohol. The [Committee on National Alcohol Policy and Action \(CNAPA\)](#) – with representatives from the national governments – shares information, knowledge and good practice on reducing harmful alcohol consumption. The [Committee on data collection, indicators and definitions](#) develops key indicators for monitoring overall performance of the strategy. The [European Alcohol and Health Forum \(EAHF\)](#) is a platform where bodies active at European level can debate, compare approaches and act to tackle harmful levels of alcohol consumption.

Given the strict correlation between health and food safety, in order to improve nutrition and

prevent overweight and obesity, the Commission brought forward the [Regulation \(EU\) No 1169/2011](#) on the provision of food information to consumers (which entered into application on December 2014) and on the obligation to provide nutrition information (which applies from December 2016). The most significant changes introduced by the regulation are: improved legibility of information (minimum font size for mandatory information), requirement of certain nutrition information for majority of prepacked processed foods, list of engineered nanomaterials in the ingredients, specific information on the vegetable origin of refined oils and fats, strengthened rules to prevent misleading practices. On December 2015, the Commission adopted [a report to the European Parliament and the Council](#) regarding trans fats (also called fatty acids) in foods and in the overall diet of the Union population, based on a series of studies on the presence of trans fats in the foods and diets of the EU population, as well as on the possible impacts of different policy options aiming to reduce the trans fats intake in the EU. The report [Trans fatty acids in Europe: where do we stand?](#) identifies and summarises the available data on the content of trans fats in foods and on dietary intake of trans fats intake in Europe.¹

Regarding labelling of food, since April 2015 is applicable the [Commission Regulation \(EU\) No 1337/2013](#) setting out the modalities requiring the indication of the place of rearing and the place of slaughter for prepacked fresh, chilled and frozen meat of swine, sheep, goats and poultry is applicable. Similarly on May 2015 the Commission adopted two reports for the European Parliament and the Council: the first one regarding the mandatory indication of the country of origin or place of provenance for milk, milk used as an ingredient in dairy products and types of meat other than beef, swine, sheep, goat and poultry meat [COM\(2015\) 205 final](#). The second one regarding unprocessed foods, single ingredient products and ingredients that constitute over 50% of a food [COM\(2015\) 204 final](#).

Schools are considered a protected environment where children should learn healthy diet and lifestyle habits early on. Member States have developed policies to guide school food provision among other important aspects. In 2014, at a Joint Research Centre workshop entitled [School Food and Nutrition in Europe: policies, interventions and their impact](#), participants from national ministries, academia, and non-governmental organisations reviewed and discussed the current state of European school food policy, assessed knowledge gaps and suggested promising ways forward. The DG Agriculture and Rural Development runs two schemes tailored to schools to encourage good eating habits in young people: the [European School Milk Scheme](#) and the [School Fruit and Vegetables Scheme](#). The European School Milk Scheme is intended to encourage consumption among children of healthy dairy products containing important vitamins and minerals. The School Fruit and Vegetables Scheme besides providing fruit and vegetables, requires participating Member States to set up strategies including educational and awareness-raising initiatives to fight against obesity among children. From August 2017, the two current separate school schemes will be brought under a single legal framework. The new rules aim at greater efficiency, more focused support and an enhanced educational dimension.²

The EU Health Strategy ‘Together for Health’ supports the overall Europe 2020 strategy, which aims to turn the EU into a smart, sustainable and inclusive economy promoting growth for all – one prerequisite of which is a population in good health. In 2014 the third health programme

¹ http://ec.europa.eu/food/safety/labelling_nutrition/labelling_legislation_en

² https://ec.europa.eu/agriculture/school-scheme_en

called Health for Growth started, aimed at fostering health in Europe by encouraging cooperation between EU countries in order to improve the health policies that benefit their citizens. Its time frame is 2014-2020 and the overall budget is almost EUR 450 million, which represents an increase of EUR 128.5 million (+ 40%) compared to the budget of EUR 321.5 million that was allocated for the previous programme for 2007-2013.

In 2014 the European Commission launched the European [Joint Action on Chronic Diseases and Promoting Healthy Ageing across the Life Cycle \(JA-CHRODIS\)](#) to join forces towards prevention and care of major chronic diseases (including diabetes). The EU provides health investments under the [European Structural and Investment Fund \(ESIF\) 2014-2020](#) to support Member States in strengthening research, technological development and innovation and enhancing access to use, quality of information and communication technologies. An important principle of ESIF 2014-2020 is integrated funding and programming. In the health sector, integrated funding can help ensure the more effective interlinking of actions to address problems. For example, activities comprising equipment purchase, disease prevention programmes, screening examinations, training for medical staff, etc. could be combined. Indeed, it is unlikely that systemic change and improvement in the way services are delivered can be achieved within the confines of a single fund. Many health projects are funded through the EU's [7th Research Framework Programme \(FP7\)](#).

Every day within the EU, businesses, public authorities and individuals transfer vast amounts of personal data across borders. Conflicting data protection rules in different countries would disrupt international exchanges. Individuals might also be unwilling to transfer personal data abroad if they were uncertain about the level of protection in other countries.

In 2012, the European Commission proposed a comprehensive [reform of data protection rules in the EU](#). In December 2015, the European Parliament, the Council and the Commission reached agreement on the new data protection rules, establishing a modern and harmonised data protection framework across the EU. In April 2016 the Council and then the Parliament adopted the [Regulation \(EU\) 2016/679](#), on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and the [Directive \(EU\) 2016/680](#) on the protection of natural persons with regard to the processing of personal data by competent authorities for the purposes of the prevention, investigation, detection or prosecution of criminal offences or the execution of criminal penalties, and on the free movement of such data. The Regulation shall apply from May 2018 and the Directive has to be transposed by EU Member States into their national law by May 2018.³ The data protection regulation's aim is to give citizens back control of their personal data as well as simplifying the regulatory environment. Businesses will be required to show how they are complying with the legislation and they could incur in huge fines if they breach the law. It also makes it mandatory for large companies to employ a data protection officer. Citizens have the right to complain and obtain redress if your data is misused anywhere within the EU. The legislation will apply to any company that handles EU citizens' data, even if that company is not based in Europe.⁴

³ http://ec.europa.eu/justice/data-protection/reform/index_en.htm

⁴ <http://www.bbc.co.uk/news/technology-36037324>



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