



Active & healthy EU citizens

- survey report



INTERNATIONAL
FEDERATION
for
SPINA BIFIDA
and
HYDROCEPHALUS

Introduction

Health is a fundamental human right indispensable for the exercise of other human rights. The highest attainable standard of health is conducive to living an active life in dignity.^{1,2}

It has been well-established that there are many social determinants of health, such as general socioeconomic, cultural and environmental conditions, living and working conditions, social and community influences, individual lifestyle factors, and age, gender and hereditary factors.^{3,4,5}

The realization of the right to health therefore requires a multidisciplinary approach, from childhood into adulthood, and access to affordable, adequate, and appropriate services is imperative.

Health is a national responsibility and health systems vary greatly within the European Union and worldwide. Medical care, medical devices and medical supplies available to citizens in one EU Member State, or region within a EU Member State, may be inaccessible to others.

These health inequalities create great obstacles to living an active life and to giving a meaningful contribution to society. This is especially true for people with disabilities with complex needs, such as people with Spina Bifida and Hydrocephalus, who still face exclusion from the healthcare system or who have difficulties finding access to the appropriate treatment and care.

For people with Spina Bifida and Hydrocephalus limited or inadequate access to healthcare can increase their marginalization in society and their risk of developing life threatening complications. Even though more people with Spina Bifida and Hydrocephalus reach adulthood, mortality levels remain high.⁶

The International Federation for Spina Bifida and Hydrocephalus (IF) conducted a survey among its European members to find out if people are aware of their rights as EU citizens and which barriers they possibly face in becoming or being an active citizen.

1. The Right to Health, WHO/OHCHR Fact sheet No. 31

<http://www.ohchr.org/Documents/Publications/Factsheet31.pdf>

2. CESCR General Comment No. 14: The right to the Highest Attainable Standard of Health (Art. 12)

<http://www.unhcr.org/refworld/pdfid/4538838d0.pdf>

3. Interim second report on social determinants of health and the health divide in the WHO European Region

<http://www.who.int/sdhconference/background/news/europeanreviewofsocialdeterminantsofhealth/en/index.html>

4. Fair Society, Healthy Lives (The Marmot Review)

<http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review>

5. The story of DETERMINE - Mobilising Action for Health Equity in the EU.

<http://eurohealthnet.eu/content/final-report-determine-consortium-story-determine-mobilising-action-health-equity-eu>

6. Why Do Adults with Spina Bifida and Hydrocephalus Die? A Clinic-Based Study (2000); G. V. McDonnell, J. P. McCann

<https://www.thieme-connect.com/ejournals/abstract/10.1055/s-2008-1072411>

The survey

The questionnaire was aimed at persons with Spina Bifida and parents of children with Spina Bifida. **IF received responses from 102 parents and 107 persons with Spina Bifida (209 people in total).** The sample can be considered very balanced to describe the situation of people with Spina Bifida and Hydrocephalus since parents of children with these disabilities play a fundamental role in assistance and support from birth to adulthood, in some cases for their entire life.

Chart #1 Respondents divided by typology

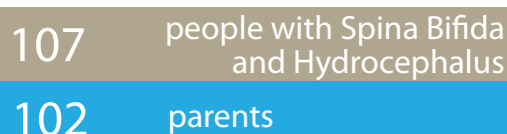


Chart #2 Respondents divided by gender

under 16 years old

male 59

female 42

above 16 years old

male 45

female 6

Chart 2 shows the balance between female and male children and (young) adults with Spina Bifida and/or Hydrocephalus. Parents provided the information for children below 16 years of age.

Chart #3 Respondents divided by age

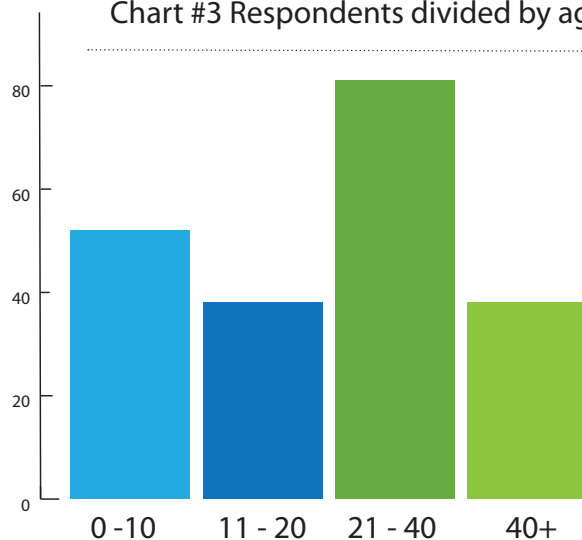
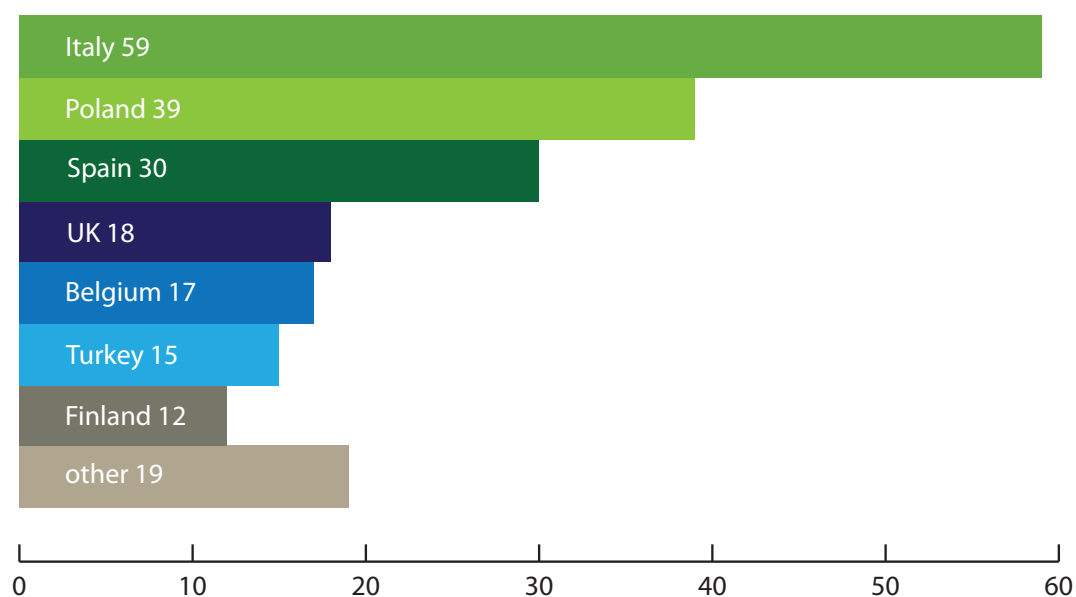


Chart #4 Respondents divided by country



Other country includes: Bulgaria, Estonia, France, Hungary, Ireland, the Netherlands, Norway, Portugal, Romania, Spain, and Sweden.

The survey has been made available in 7 different languages, English, French, Italian, Polish, Spanish, Turkish, and Dutch. The translation of the questionnaire helped in collecting information from parts of the European population still facing language barriers. The questionnaire was distributed in May and June 2013 through email, IF's social media and monthly newsletters, during IF's main events, and could be accessed on IF's website.

Social media played a very valuable role in the dissemination of the questionnaire. The survey distribution methods also shows the importance of the accessibility of website and social media since they easily reach people with mobility impairments who have less opportunities or willingness to take part in social activities or joint associations.

Access to affordable, adequate, and appropriate healthcare

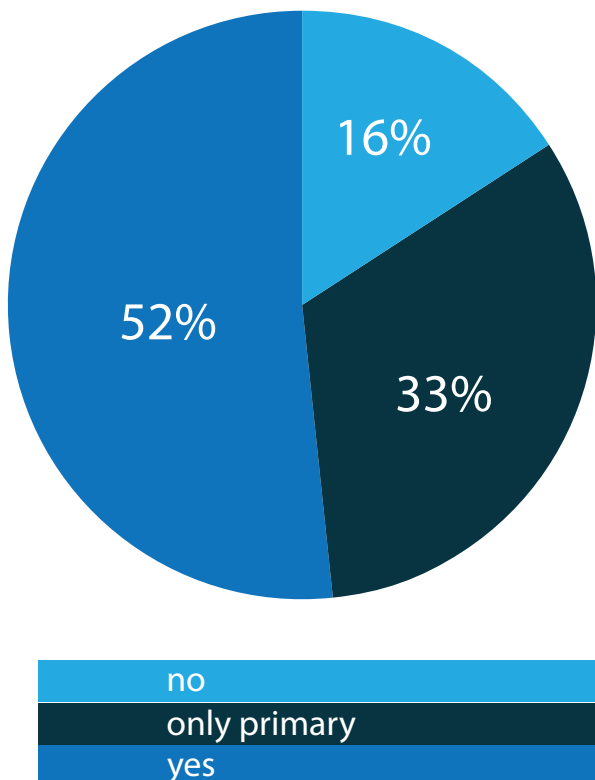
IF asked participants to share their experiences with primary and secondary healthcare. Primary healthcare was defined as the cost of basic treatments by a family doctor, for instance in case of a flu. Secondary healthcare included all costs related to specialists and hospital visits and in particular the costs connected to the specificity of Spina Bifida and Hydrocephalus.

For people with these conditions specialist care is essential. Even without any incidental problems or urgency, annual neurological, urological and orthopaedic check-ups are a necessity to prevent additional health issues.

Of all 209 respondents, **only half (52%) can afford all healthcare costs, meaning both basic and specialist care. A third of the respondents (33%) cannot afford the costs of specialist care. Chart 5 shows that there is still a part of the population, 16% of the sample in this survey, that is unable to afford either basic or specialist healthcare.**

Problems arise from differences between the healthcare that is needed and the care that is covered by the state or by healthcare insurance.

Chart #5 Are the costs of healthcare affordable?



"I had to ask for a loan to be operated a few years ago". Italy

"Yes, except physiotherapy services, which have to be paid at an exceptionally high cost". Spain

"My son was refused the permission of the hospitalisation insurance for bladder and back operations". Belgium

"At the moment, yes, because I'm still working as a parent of 66 years of age! To provide my child with the best possible care". Belgium

"The costs of transport and accommodation costs are borne by all of my family". Italy

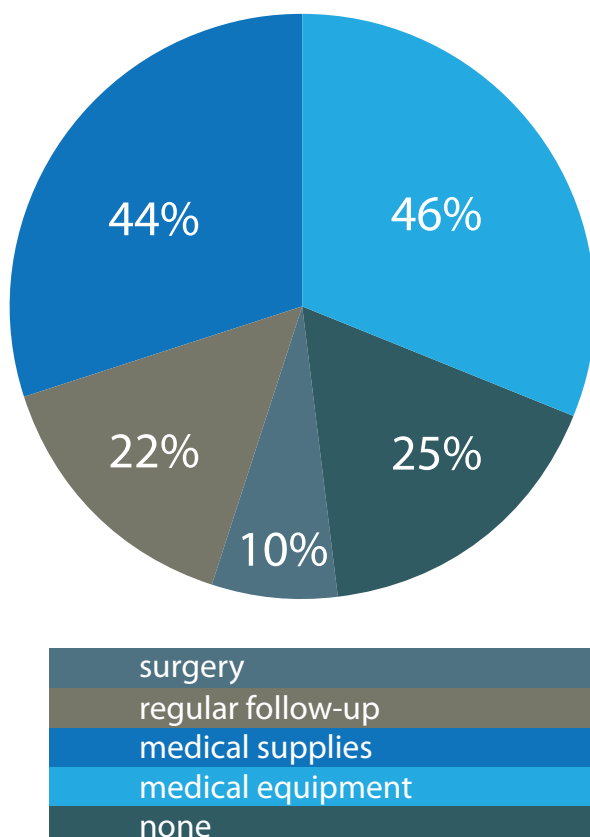
The biggest financial issues for persons with Spina Bifida and Hydrocephalus and/or their families are caused by the costs of medical equipment (46% of the respondents) and medical supplies (44% of the respondents).

The majority of persons with Spina Bifida have lifelong continence issues and often develop urinary tract infections. Medical supplies such as catheters and, if needed, medications are of great importance for good health and survival. Diapers and special bed sheets can be equally important for health, self-esteem and self-confidence.

If medical supplies are not adequately covered by health insurance, people with Spina Bifida and Hydrocephalus can be burdened with recurring additional costs throughout their lifetime. When medical supplies are covered by health insurance but unavailable in a country, this can lead to the necessity to find them abroad, which adds shipping costs.

Both situations create health inequalities between those who have the financial means to seek and pay for their medical supplies, if necessary across borders, and those who do not.

Chart #6 Which healthcare costs are creating the greatest financial difficulties?



"I was told that the antibiotic needed isn't covered by our insurance, so I had to buy it myself for a very long time". Romania

"For certain medical supplies, like diapers, they only issue a limited number of prescriptions without looking at the real need for changing diapers". Spain

"Necessary drugs are not available in Romania. I buy them in Austria and we do not have enough money for it, especially when you add the postage costs". Romania

"The following costs are not covered by the Bulgarian health insurance system and the parents have to pay by themselves: equipment – splints, walkers, wheel chairs, special bikes; medical equipment - shunts and other surgical implants such as osteosynthesis; catheters and other products for personal care". Bulgaria

"Personal payments for the purchase of a good lightweight wheelchair is very high". Belgium

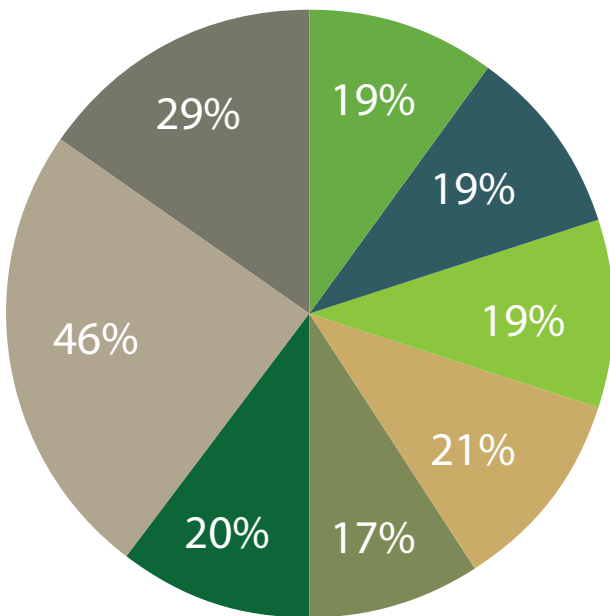
"In Turkey, currently they are not producing appropriate wheelchairs (durable, right size). We're getting them abroad – gets expensive". Turkey

Due to varying degrees of paralysis, many people with Spina Bifida also have mobility issues and need assistive devices, such as crutches and wheelchairs, to improve their ability to participate in society and to obtain independence. Many respondents commented upon the high cost of personal payments, the lack of equipment, standard equipment not fulfilling people’s needs and, just like medical supplies, certain equipment not being covered through the healthcare system at all. As a result of this situation, health inequalities can occur due to the need for and inaccessibility of both medical supplies and medical devices.

The majority of respondents (46%) commented upon the amount of time they had to wait before being able to see healthcare provider or to receive treatment. In order to avoid waiting lists, those who can financially afford to do so, may seek healthcare in private clinics.

For people with Spina Bifida and Hydrocephalus, who can encounter serious infections and/or shunt problems, immediate access to healthcare services can mean the difference between life or death.

Chart #7 Which are the most common obstacles in accessing medical care services?



- lack of transport
- lack of assistance
- financial problem
- inaccessible location
- opening hours
- time off from work
- long waiting list
- no problems

“You have to wait for a very long time, what in the case of rapidly progressive infections can be very dangerous”. Poland

“There are only a few centres in Italy for SB-H for children, and we always have to travel a lot. Making an appointment is a problem, you have to wait too many days”. Italy

“If we are in need of an operation or special screening we go to a hospital, but we have to wait a lot in the hospital and it is very tiring”. Turkey

There are a number of specialists which are difficult to reach, because their waiting list is long”. Spain

People with Spina Bifida and Hydrocephalus have very specific and often multiple healthcare needs. Chart 8 shows who provides their specialised healthcare and if people are satisfied with the care they are receiving.

The majority of people with access to multidisciplinary care rated this care as excellent or good. The respondents that did not rate multidisciplinary care (36%) pointed out that this type of healthcare was not available in their country or that the multidisciplinary clinic was too far away, and travel costs would add to their financial problems.

Another issue often mentioned was lack of knowledge about Spina Bifida and Hydrocephalus among non-specialised healthcare providers.

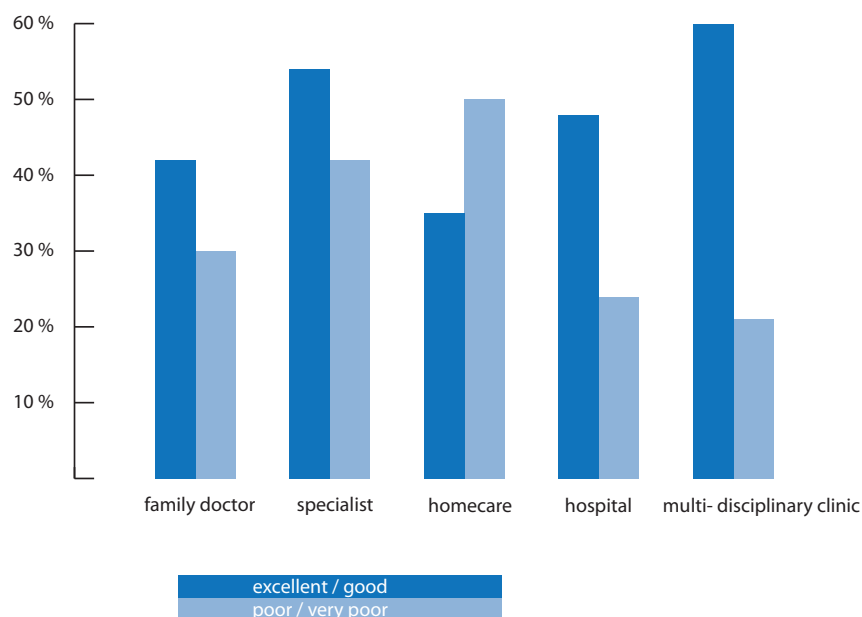
"I had to visit each specific specialist separately, a neurologist, a orthopaedist, a urologist,, bowel specialist. As a consequence, each specialist only treated his own branch, without considering the whole body and influences on me. They did not communicate". Belgium

"We still don't have any type of multidisciplinary care for people/children with SB/H. Each problem is treated separately by a single medical specialist, without consulting specialists of other fields. Most of the good specialists are located in the capital. Even these doctors do not have much experience in Spina Bifida". Bulgaria

"In Sardinia we don't have any multidisciplinary clinic. We have to travel to the north of Italy or Rome. In a regular hospital it is very difficult to be cured, because they have just general knowledge of SB/H". Italy

"The hospital specialists give the necessary treatments but there is no special Spina Bifida unit. We as parents often act as coordinators for the specialists. There is no contact between them, up till now, to follow up on my son". Spain

Chart #8 How do you rate the experience of your medical care providers?



Conclusions

1. Parents play a fundamental role in the lives of children born with Spina Bifida and/or Hydrocephalus. They coordinate care, they are responsible for healthcare insurance, appointments, transportation, co-payments, obtaining medical supplies and devices. Yet once their children reach adulthood, they need the security that care and support are in place for their children to live healthy, independent and active lives.
2. 48% of the respondents lack the financial means to cover the costs of specialist healthcare that is essential for a person with Spina Bifida and/or Hydrocephalus to maintain good health, prevent secondary health conditions and avoid premature death.
3. 44% and 46% of the respondents respectively lack the financial means to cover the costs of medical supplies (such as medication, catheters, diapers and special bed sheets) and medical equipment (including assistive devices, such as walkers, splints, crutches and wheelchairs).⁷
4. 46% of the respondents indicate that long waiting lists are the most common obstacle in accessing medical services.
5. Persons with Spina Bifida and/or Hydrocephalus and their parents need healthcare and social services to coordinate and cooperate with each other, in order to deliver appropriate, timely, adequate and efficient treatment and support. Services provided at an affordable and accessible multidisciplinary clinic are the best way to treat, support, and follow up a person with Spina Bifida and/or Hydrocephalus.

7. According to the 2013 WHO draft Action Plan "Better health for people with disabilities" half of persons with with disabilities cannot afford needed healthcare and they are 50% more likely than persons without disabilities to suffer catastrophic health expenditure, which pushes them into poverty" <http://www.who.int/disabilities/actionplan/en/index.html>

EU citizenship and barriers to being an active citizen

While 63% of the respondents travel to other EU countries, **21% state that they encounter accessibility issues. Having a disability prevents another 17% of respondents from travelling** to other countries altogether.

About 60% of the respondents answered that they have no time or are not interested to be involved in politics or to live in another EU country. **Disability issues are preventing another 17% of the respondents to be involved in politics, and 24% would not consider living in another EU country due to their disability.**

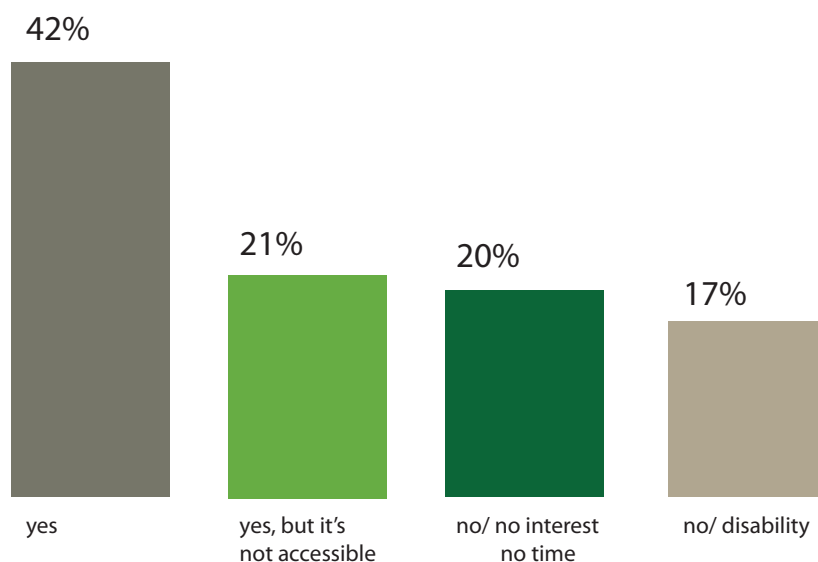
"I avoid travelling to another country because I don't know if I have access to medical supplies there (medicine, catheters)". Belgium

"The thought that something might happen gives me a lot of stress. That would increase with the fact of being abroad with language difficulties and not knowing whether there are adequate facilities". Italy

"I would love to live elsewhere but I'd be worried about good healthcare provision". UK

"I do not know how to deal with the difficulties that my condition and lack of knowledge of the host country might pose to me". Italy

Chart #9 Do you travel to other EU countries for your work, holiday or study?

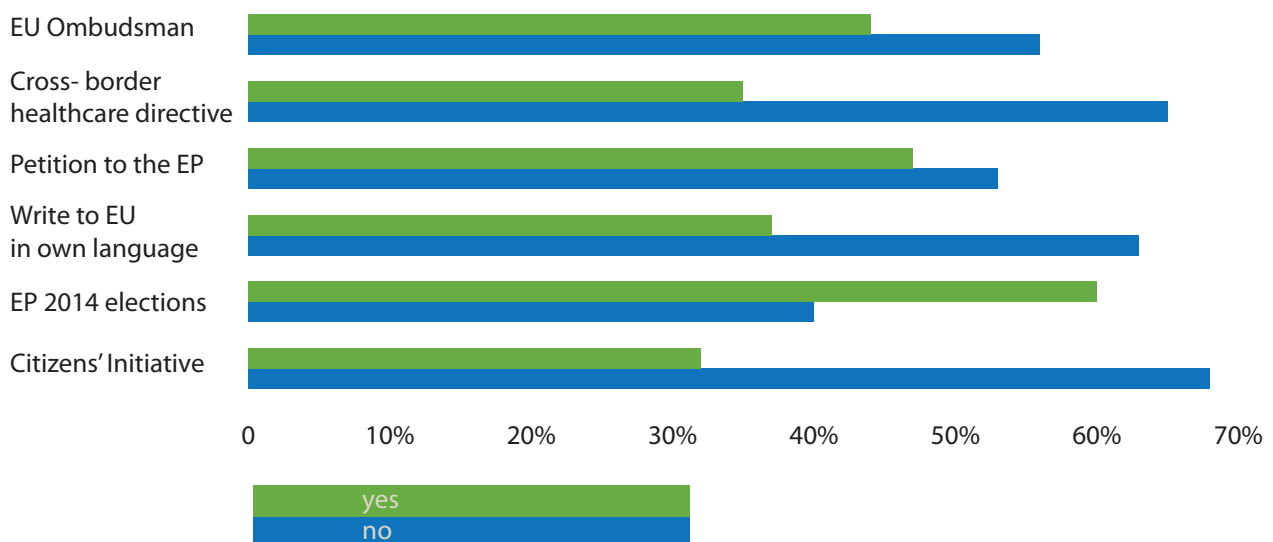


A majority of respondents is not aware of the existing European initiatives and instruments to change current legislation as a citizen, with the exception of the 2014 European Elections.

- **68% of the respondents does not know about their right to participate or start an EU Citizens' Initiative;**
- **65% of the respondents has no knowledge of the Cross-border healthcare directive;**
- **63% of the respondents does not know that they have the right to write to EU institutions in their own language.**

While people with Spina Bifida and/or Hydrocephalus are in need of legislation and protocols that will ensure their right to the highest attainable level of health, they often lack the time, knowledge and means to fight for their rights.

Chart #10 Are you aware of the existence of the following European initiatives and instruments?



Recommendations

IF urgently calls on governments to undertake immediate, effective and appropriate measures to ensure that persons with Spina Bifida and Hydrocephalus, including newborns, children and adults, achieve the highest attainable standard of health, so that they can be active citizens, achieve their full human rights and participate in society on an equal basis with others.

To this end, IF recommends that governments invest in healthcare and social services to:

1. **Ensure timely and affordable access to appropriate, coordinated medical treatment and follow up care across the lifespan in specialised multidisciplinary clinics;**
2. **Provide financial support for transport and accommodation costs when essential healthcare services are not available in the city or area of residence;**
3. **Guarantee timely and affordable access to all the necessary medical supplies and equipment that can eliminate indignities arising from continence issues, reduce threats to life and health, and optimise the well-being, independence and activity of people with Spina Bifida and Hydrocephalus;**
4. **Encourage, enable and direct service providers, including medical professionals to receive education and training which will combat discrimination and raise awareness of the significant needs of people with Spina Bifida and Hydrocephalus;**
5. **Actively enable people with Spina Bifida and Hydrocephalus to be fully involved in and contribute to all measures and decision-making processes that may affect their health and well-being.**





European Commission
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Integration of People with Disabilities - Unit G3

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The information contained in this publication does not necessarily reflect the position or opinion of the European Commission.



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