



Access Campaign: Patient survey Focus on access to medicines and medical devices

Rob Camp

On behalf of the DITA task force

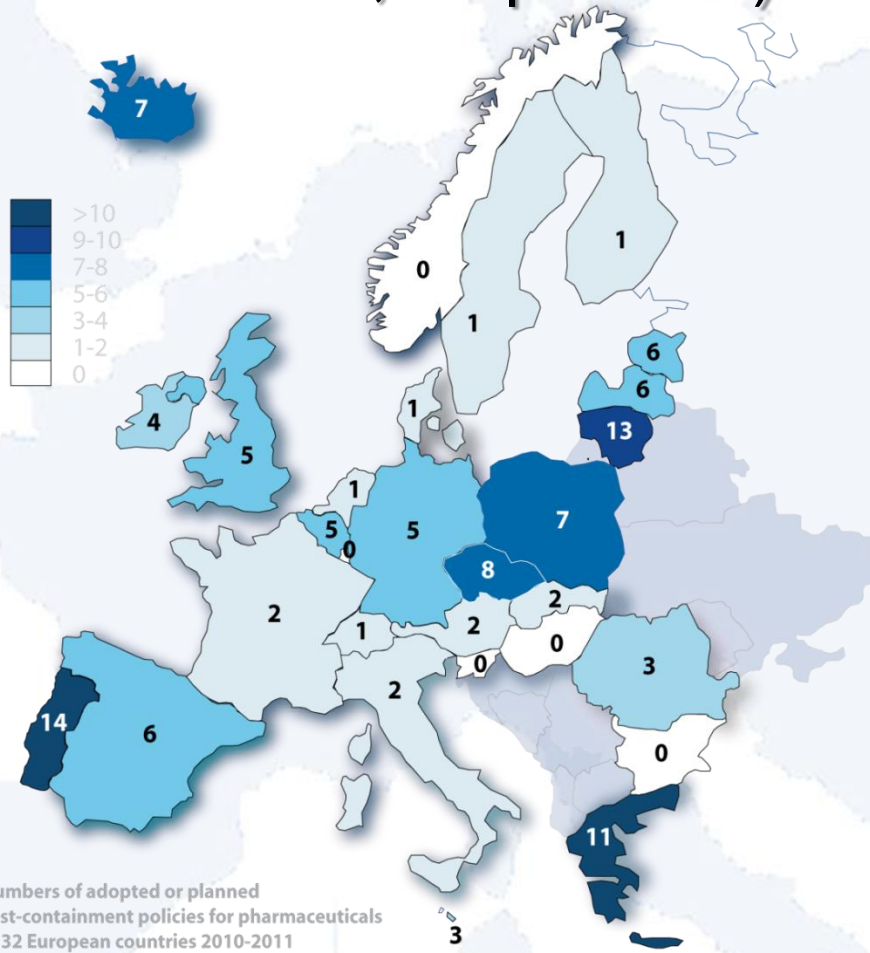
EMM 2015, Madrid (30 May, Workshop 2 -11:00-13:00. Room Cibeles)

CAMPAIGN FOR
ACCESS
To
MEDICINES FOR
PEOPLE WITH
RARE DISEASES



**IN THE CONTEXT OF THE
FINANCIAL/ECONOMIC CRISIS AND HEALTH
BUDGET CUTS, WHAT ACCESS (TO CARE)
DIFFICULTIES ARE WE FACING?**

116 reforms on pharmaceuticals to contain pharmaceutical expenditures (89 adopted 2010-2011, 27 planned)



Numbers of adopted or planned cost-containment policies for pharmaceuticals in 32 European countries 2010-2011 (from Vogler et al. 2011)

Adapted from Vogler S, Zimmermann N, Leopold C, Joncheere KD. Pharmaceutical policies in European countries in response to the global financial crisis. Southern Med Review (2011) 4;2:69-79



<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3471176/>



Most common cost-containment measures

Types of measures

- Price reductions of pharmaceuticals
- Changes in co-payment
- Reimbursement lists and procedures
- Reference pricing systems* and/or pricing of generics
- INN prescribing mandatory

Where

- 15 price reductions in 11 countries
- 13 measures in 9 countries
- 8 countries
- 10 countries
- Most frequent “other measures”

Each pricing measure has a short effect: typically 2 years

* Exaggerated depending on first price received

Questions

- **Considering that**
 - Most measures adopted with no due consideration of unexpected negative effects on public health
 - Access issues pre-existed previous to the current crisis
- **Can we learn from patients & their difficulties in this context?**
 - What are the exact problems they report, and can we provide recommendations regarding cost containment measures?
 - Is the situation stable?
 - How can we measure the impact of this on the health of patients with rare diseases?

April 2014: direct survey to patients

- Target: patients, members of an organisation or not
- Questions
 1. Name of product or type of care
 2. Disease, condition or indication
 3. Country
 4. Reasons why treatment/care is not reimbursed, if known
 5. Optional: ID
- Online survey
- 19 languages
- Dissemination:
 - Student from University South Brittany (L. Tessier)
 - Eurordis members database
 - Rare Diseases Facebook page
 - Online communities, e-news, ECRD 2014...

Invita altri membri della tua associazione a comunicare le difficoltà ad accedere alle cure



Campagna per l'Accesso !

<https://www.surveymonkey.com/s/P2BBPFV>



Hai difficoltà ad accedere al tuo trattamento? Sei pregato di segnalarcelo

Ti saremmo grati se vorrai dedicare qualche minuto del tuo tempo per completare questo questionario rigorosamente anonimo. Ti preghiamo di fornire risposte concise, brevi e precise. I dati raccolti saranno trattati da personale qualificato al fine di evidenziare (attraverso dei rapporti che saranno disponibili) i problemi esistenti da sottoporre alle autorità sanitarie nazionali impegnandosi ad avviare un dialogo tra le parti. Non abbiamo le risorse per rispondere ai singoli casi. I risultati di questa indagine non ti saranno comunicati direttamente, ma potrai consultarli sul sito di EURORDIS (verrà creata una pagina specifica "Campagna per l'Accesso"). Grazie per averci dedicato un po' del tuo tempo.



EURORDIS

L'Organizzazione Europea per le Malattie Rare (EURORDIS) è un'alleanza non governativa di associazioni di malati e individui attivi nel settore delle malattie rare in Europa, fondata nel 1997 e guidata dai pazienti. EURORDIS rappresenta oltre 600 associazioni di persone affette da malattie rare in circa 50 Paesi, che coprono più di 4000 malattie rare (per maggiori informazioni: www.eurordis.org)



Fare clic

<https://www.surveymonkey.com/s/P2BBPFV>



Поканете членове на Вашата организация да съобщат за трудности при достъпа до лечение и грижи



<https://www.surveymonkey.com/s/XYTK58W>

Working paper on the impact of the economic crisis for people living with a rare disease 2013

EURORDIS Working paper

The impact of the economic crisis and cost-containment measures on European citizens' health

- The survey questionnaire
- Survey content
- An introduction: the start of the crisis in 2008 and how European citizens were hit, how this related to their daily living in order to describe their situation.
 - How the impact of the crisis and of the measures to control the public deficit in the general population: on access to health services, communication channels.
 - A general focus on the situation of patients in Europe and beyond.
 - An analysis of some medicines with storage/availability options for some special populations, as an illustration of the methods and conclusions that may have been applied in other, with comparison on the access to treatment.
 - Patients' needs with:
 - Information on health expenditure, characteristics of some patients to control pharmaceutical costs (general population, young, technology innovation, health spending, genetic, diagnosis...)
 - High financial burden to control their costs
 - Questions to national Authorities in document on the impact of the crisis and of the economic measures from the patients' perspective.
 - All types of information contained in the working document.
 - A picture of the survey used in the document.

Изпитвате ли трудности при достъпа до лечение? Моля, съобщете ни за тях

Ще ви бъдем благодарни, ако отделите няколко минути, за да попълните тази анонимна анкета. Молим Ви за кратки, точни и ясни отговори. Събраните данни ще бъдат обработени от обучен екип с цел да се представят пред националните здравни власти съществуващите проблеми (чрез доклади, които ще бъдат на разположение) и да се инициира диалог по тях. Ние не разполагаме с необходимите ресурси, за да отговорим на индивидуални случаи. Няма да Ви информираме директно за резултатите от тази кампания, но вие ще можете да се запознаете с тях при публикуването им на сайта на EURORDIS (ще бъде създадена отделна страница "Access Campaign"). Благодарим Ви за отделеното време.



EURORDIS

Основана през 1997 г., Европейската организация за редки болести (EURORDIS) е неправителствен, управляван от пациенти алианс на организации и лица, които работят в областта на редките болести в Европа. EURORDIS представлява повече от 600 организации на пациенти с редки болести от над 50 страни, които обхващат повече от 4000 редки заболявания (за повече информация: www.eurordis.org)

Клик

<https://www.surveymonkey.com/s/XYTK58W>

Translations: 19 languages

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**EURORDIS' website professional translators
(French, German, Spanish, Russian, Portuguese, Italian)**

DITA Task force :

- Juan Fuertes, Isabel Fernandez & Rob Camp (Spanish)
- Ellen van Veldhuizen (Dutch)
- Sigurður Jóhannesson (Icelandic)
- Vesna Stojmirova (Macedonian and Croatian)
- Danijela Szili (Serbian and Hungarian)
- Tatiana Foltanova (Slovak and Czech)
- Rob Camp & Richard West

Volunteers :

- Anna Kole and her family (Polish)

Patient representatives :

- Dorica Dan (Romanian)
- Birthe Holm & Lene Jensen (Danish)
- George Iskrov (Bulgarian)
- Dimitrios Synodinos (Greek)



The Access Campaign Survey 2014

- **Outbound**

- 26 May → 30 September
 - 127 days, over summer break
- Thank you to all organisations that disseminated the survey to their members

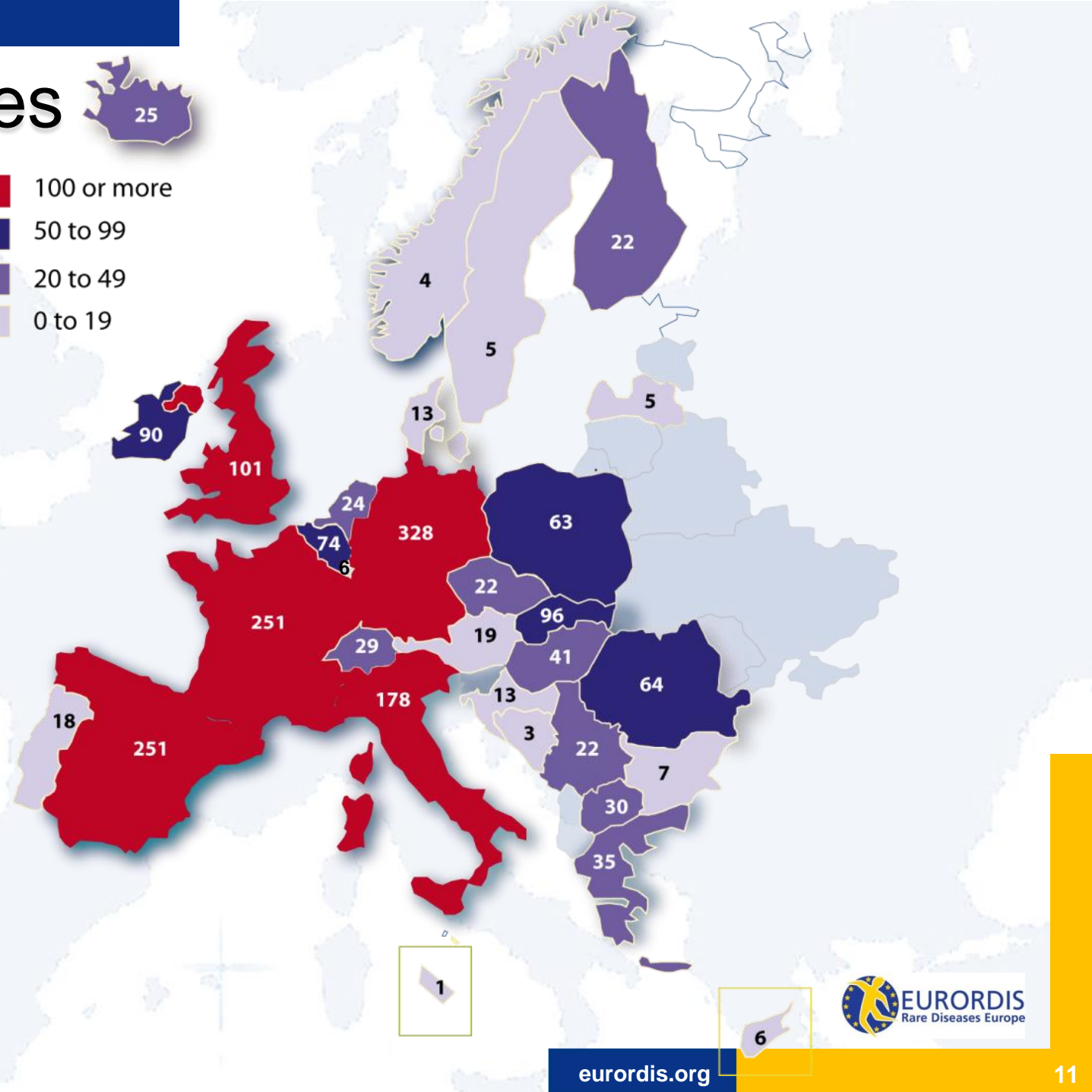
- **Inbound**

- 2021 received, from 62 countries, 31 Europe
 - Duplicates removed
 - Commercial spams removed
 - 1961 valid

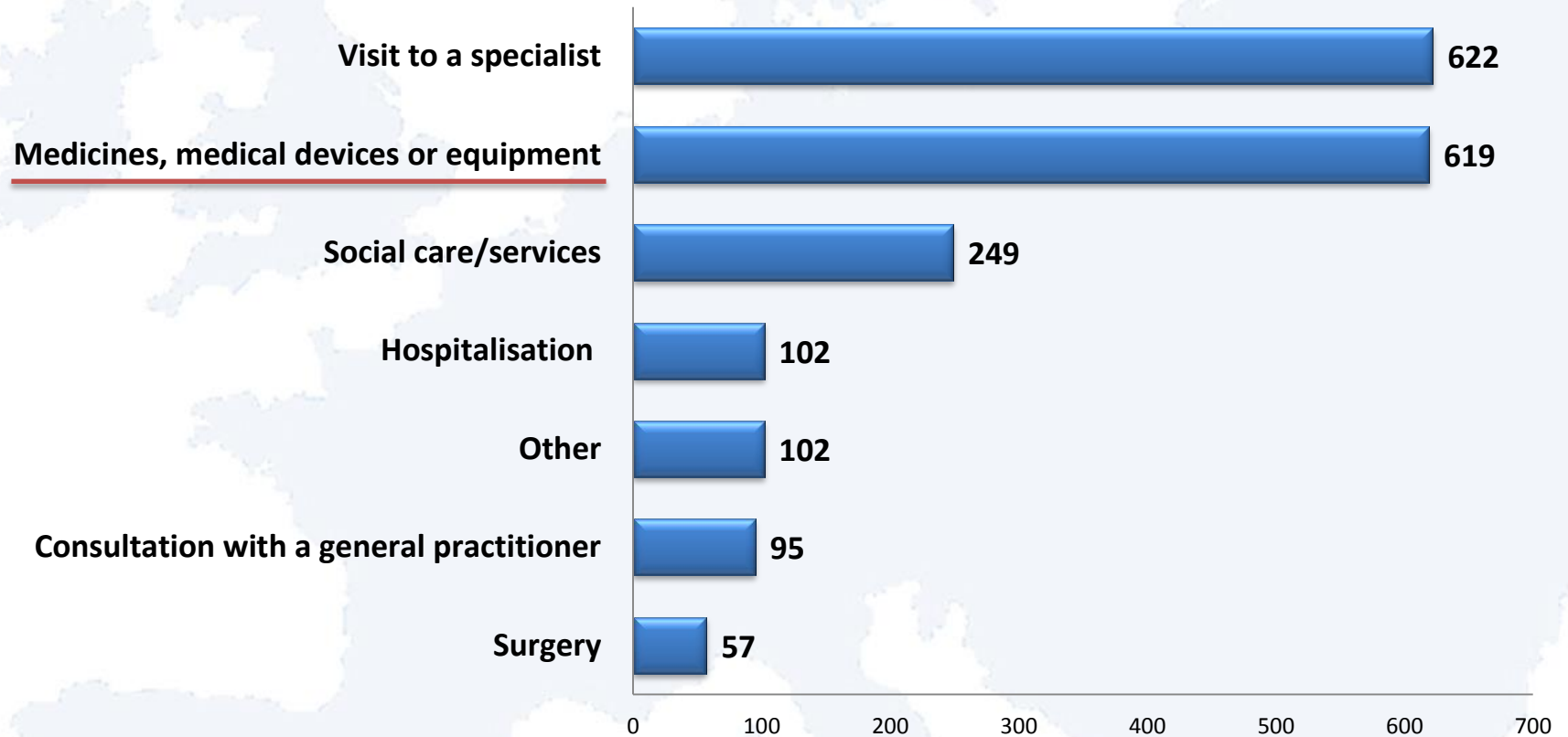
Responses by world region

N countries		N responses	%
62	Total	1961	100.0
31	Europe	1846	94.1
4	EurAsia	15	0.8
10	South America	43	2.2
7	Africa	11	0.6
4	Asia & India	6	0.3
2	Oceania	3	0.2
2	Northern America	35	1.8
2	Middle East	2	0.1

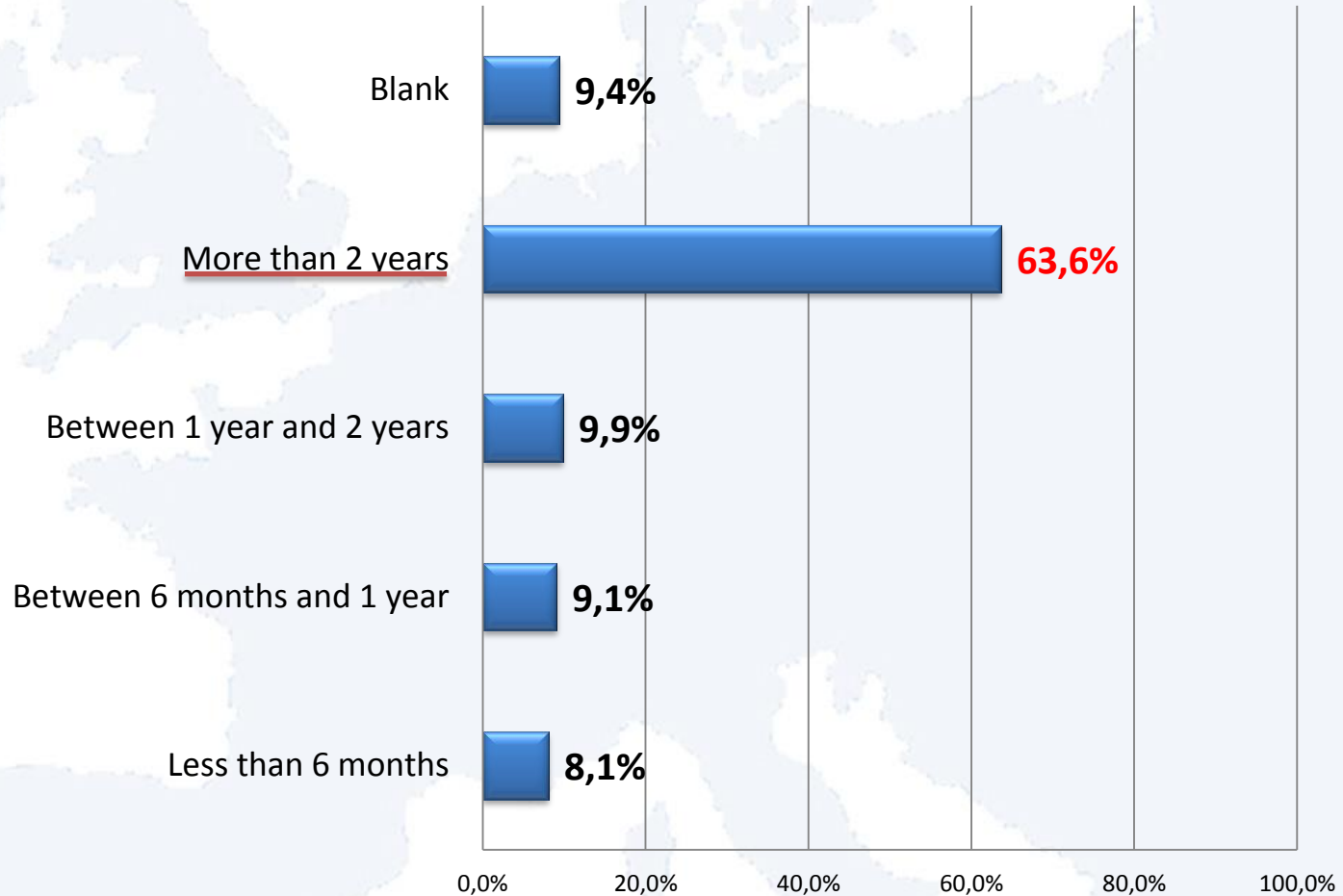
Responses



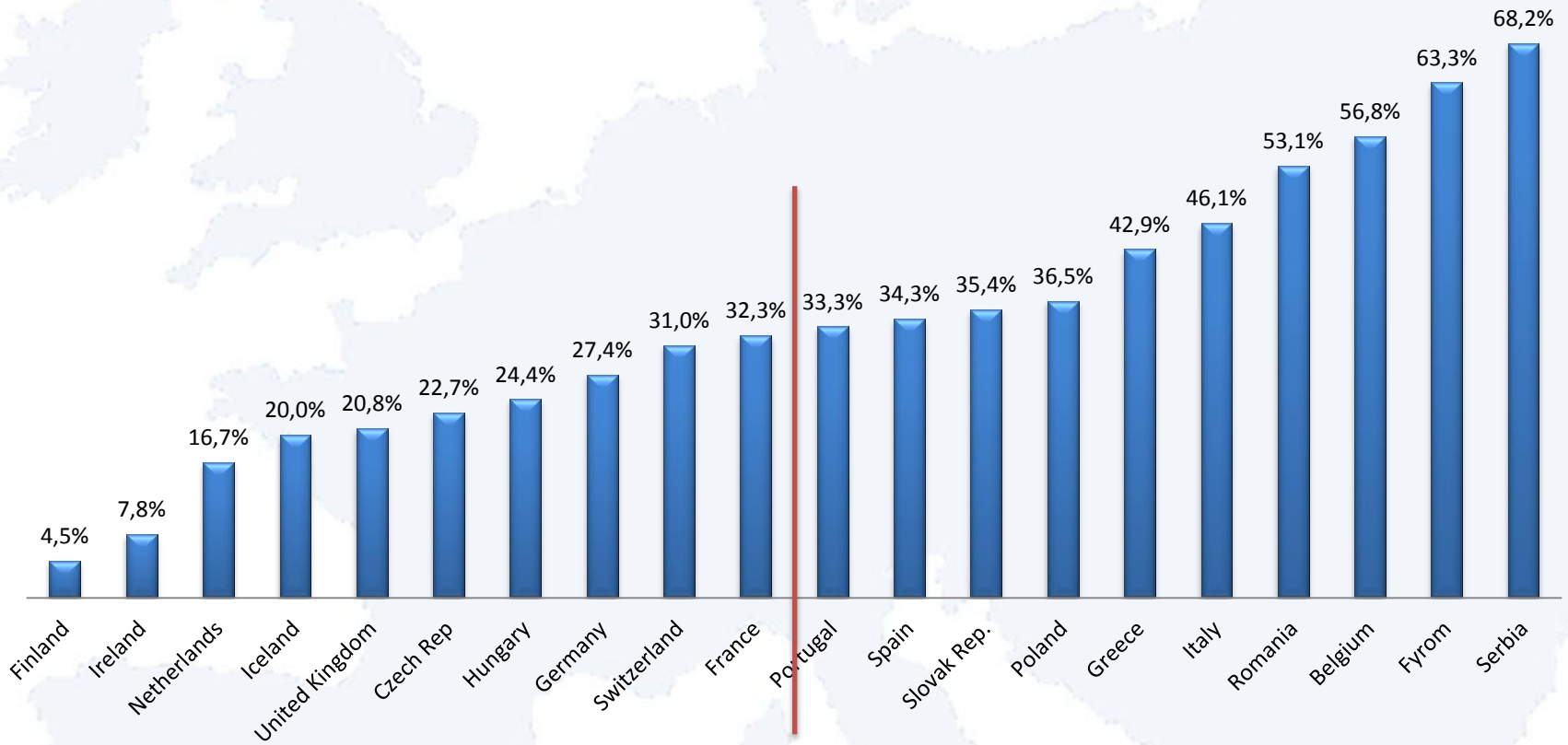
Question 1 : Please indicate for which type of care you wish to report difficulties about ? (Europe)



Question 7 : How long have you been on this type of care? Medicines and medical devices (618 responses)



Difficulties with medicines, medical devices or equipment (% who reported such difficulty, by country)



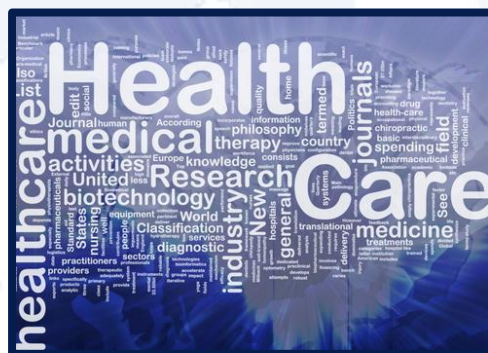
08/06/2015

Narrative: Gastrointestinal stromal tumor (GIST), incidence 1.5/100,000 - prevalence 1.3/10,000 ITALY

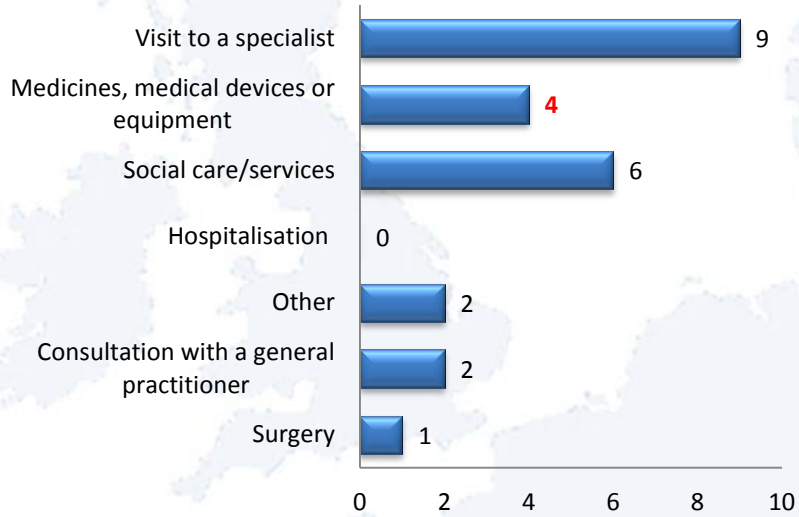


- 1: Sorafenib, 2: Dasatinib, 3: Nilotinib, 4: Regorafenib
 - All are OFF LABEL, cost not covered by the *Servizio Sanitario Nazionale*. Cost paid by hospital or patient.
 - Off Label use is banned by AIFA, while it is allowed and reimbursed by some regions resulting in inequalities
 - Drugs 1, 2, 3 are recommended to treat GIST (NCCN National Comprehensive Cancer Network guidelines)
 - Drug 4 approved by FDA for GIST, EMA has yet to authorise (authorised by EMA for metastatic colorectal carcinoma)*

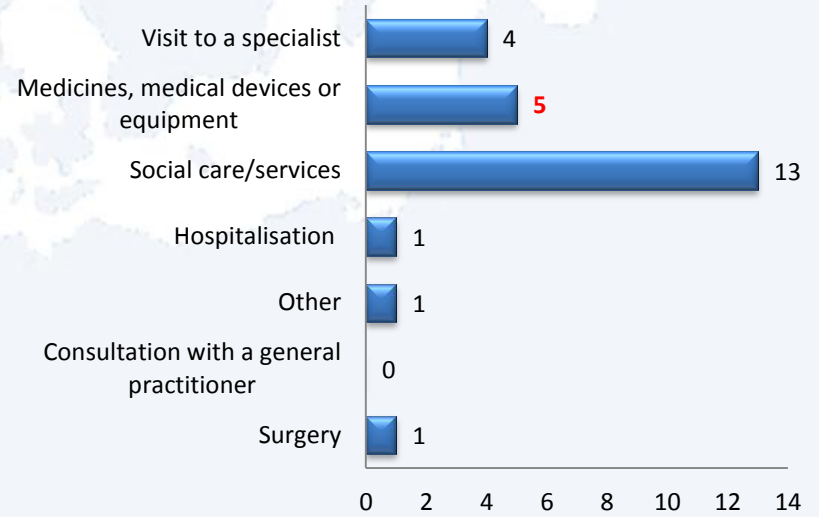
* EMA extended the indication to GIST: 09/2014



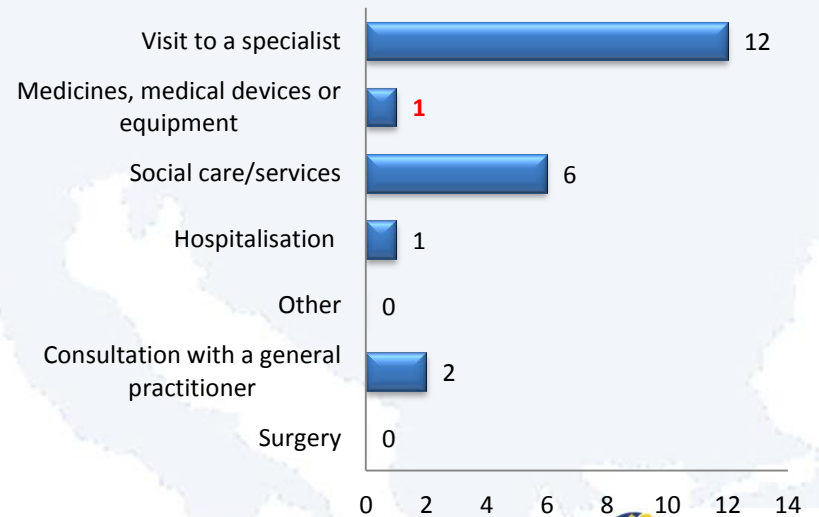
Netherlands



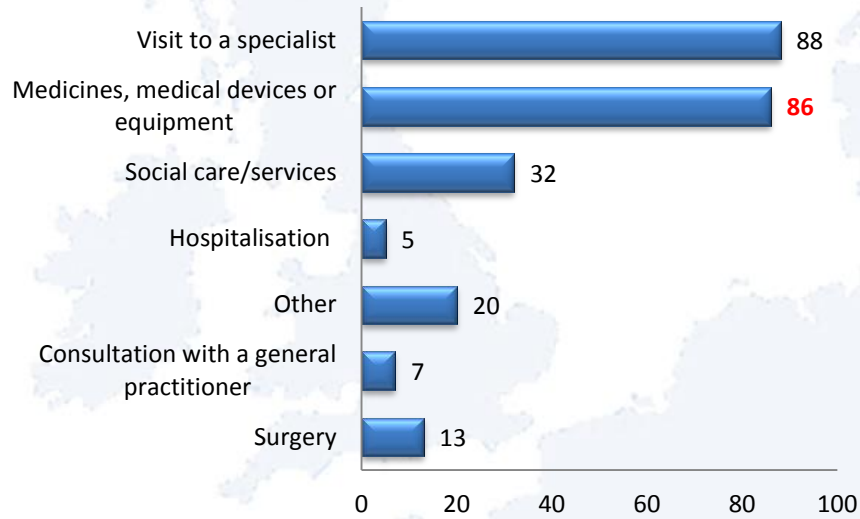
Iceland



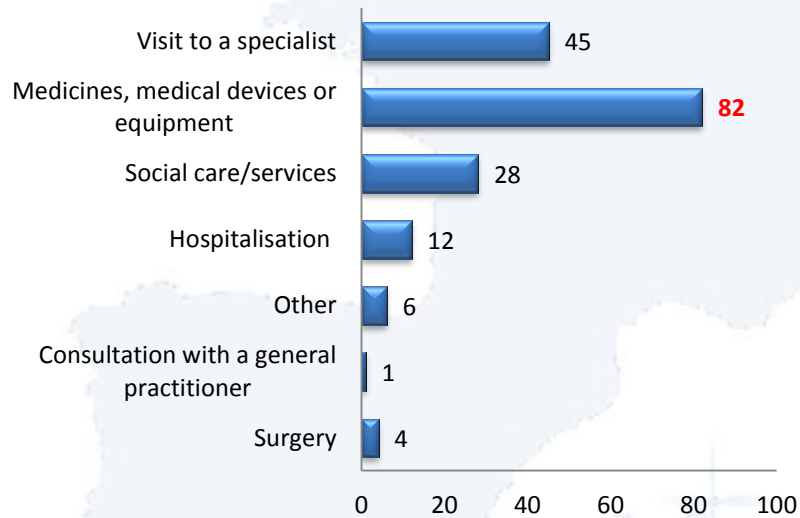
Finland



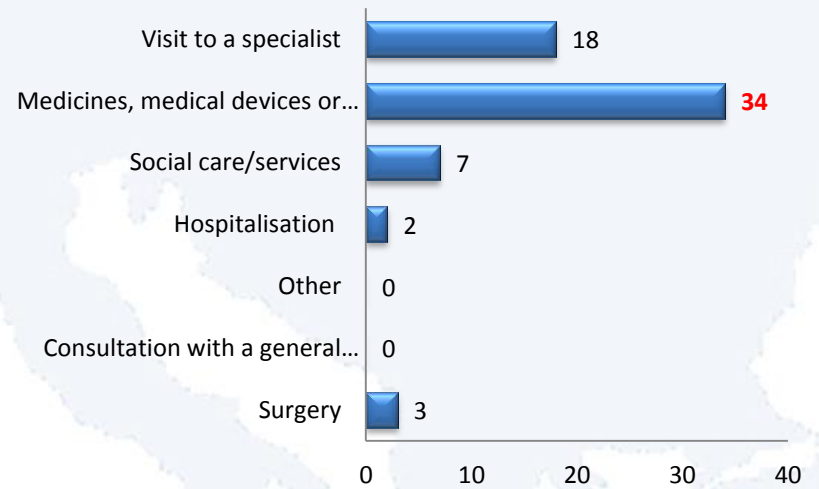
Spain



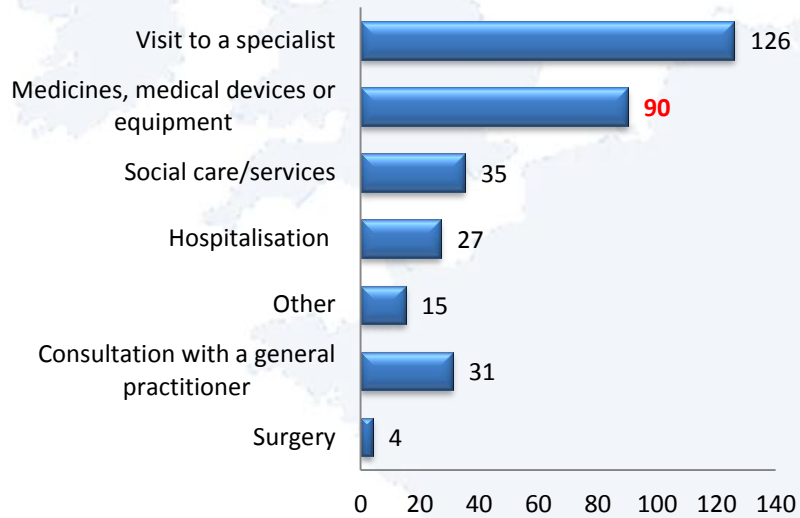
Italy



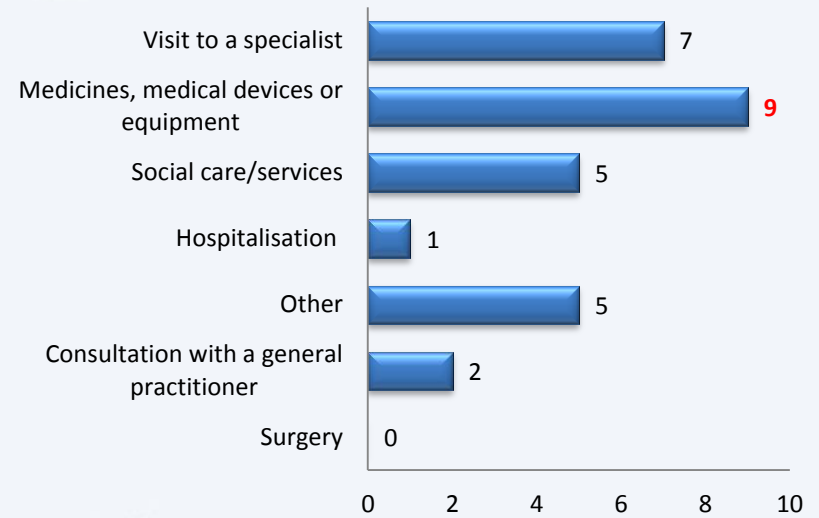
Romania



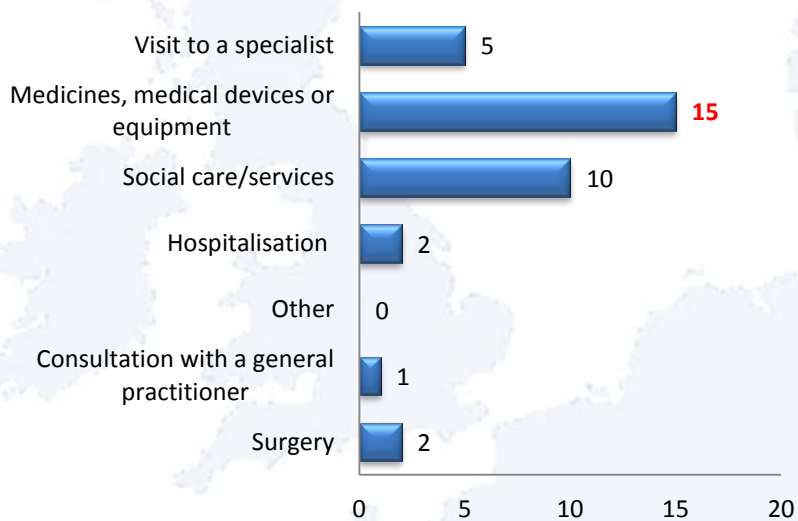
Germany



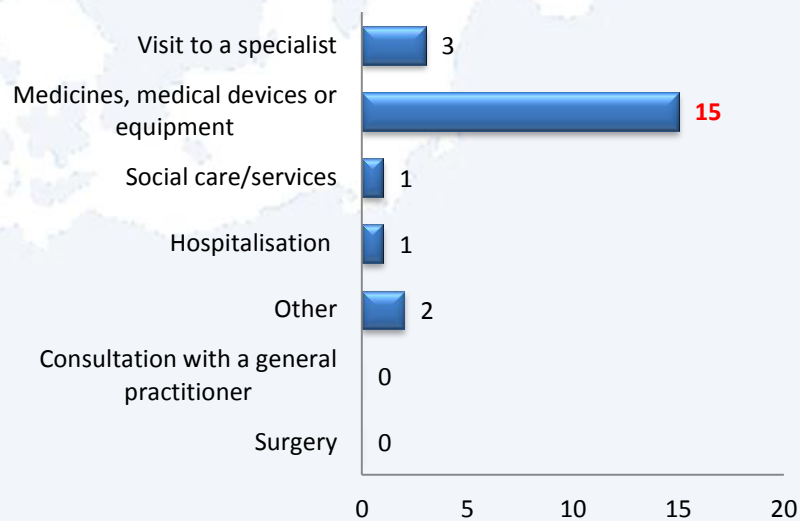
Switzerland



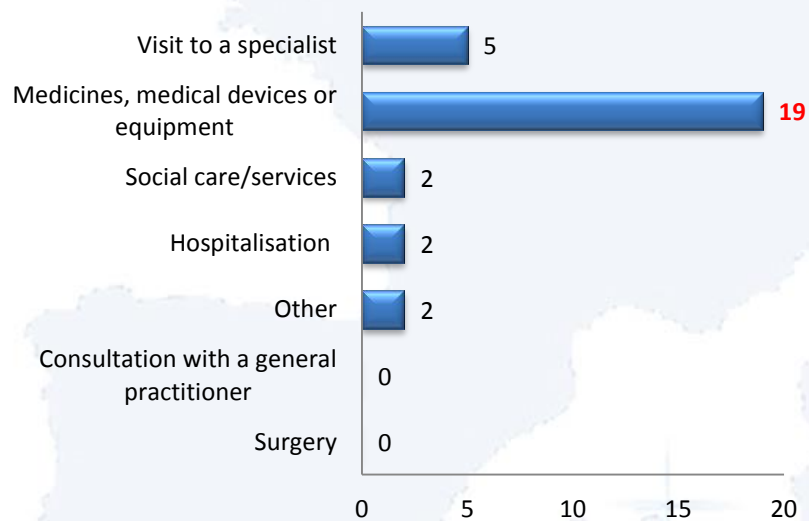
Greece



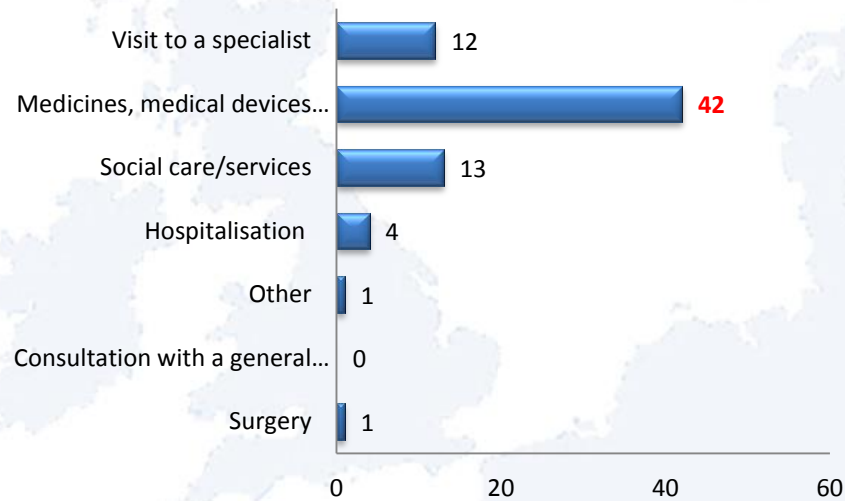
Serbia



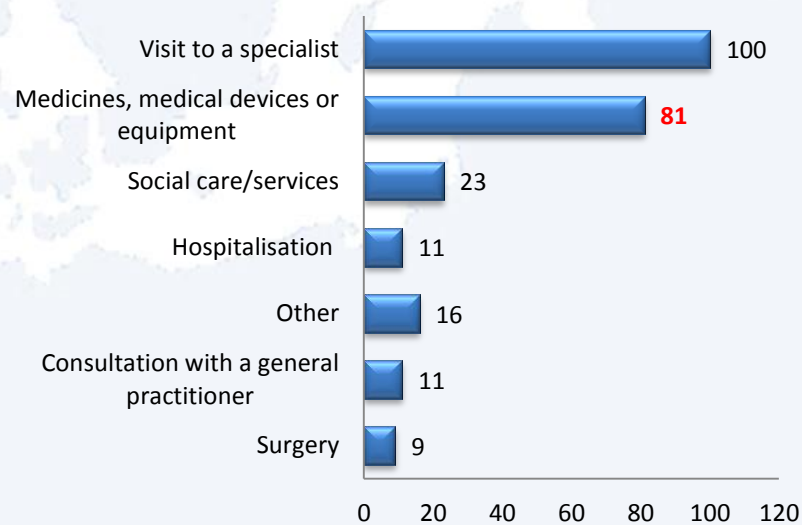
FYROM



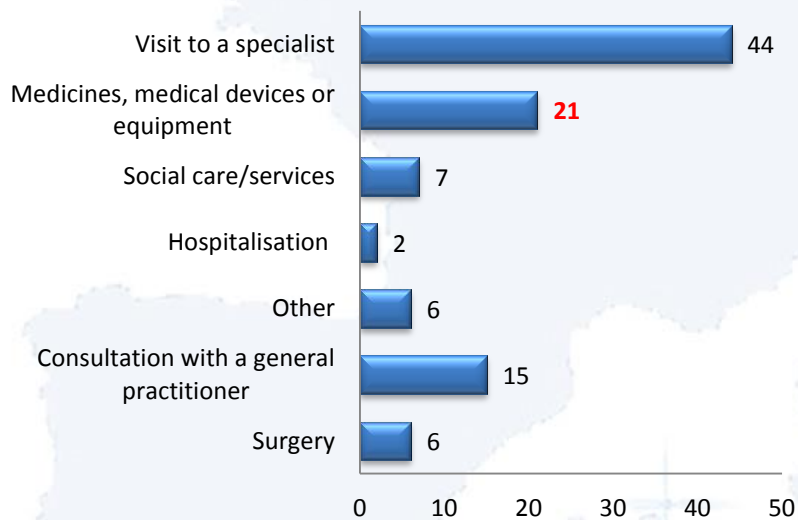
Belgium



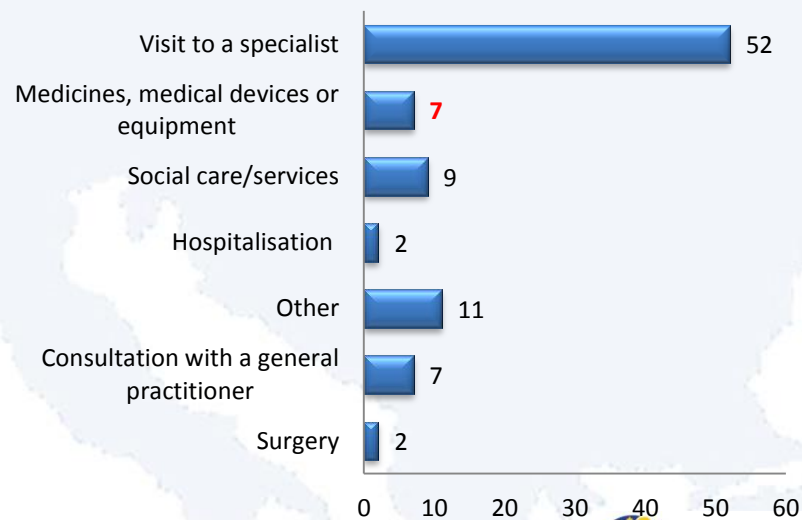
France



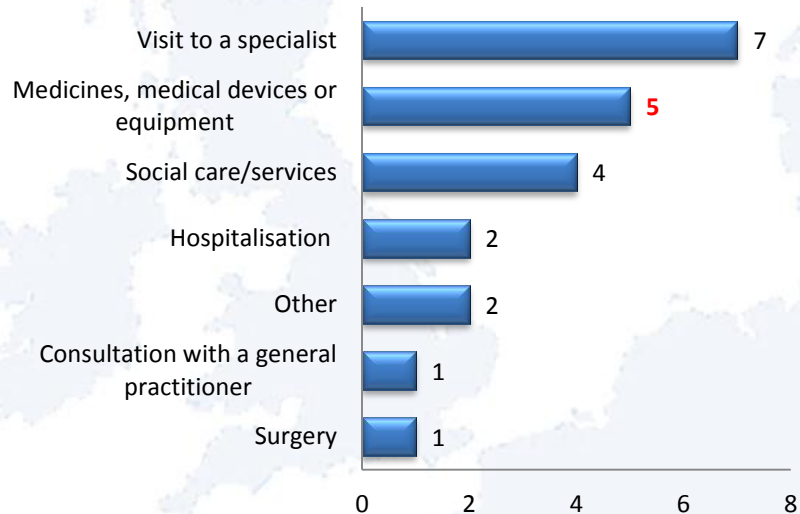
United Kingdom



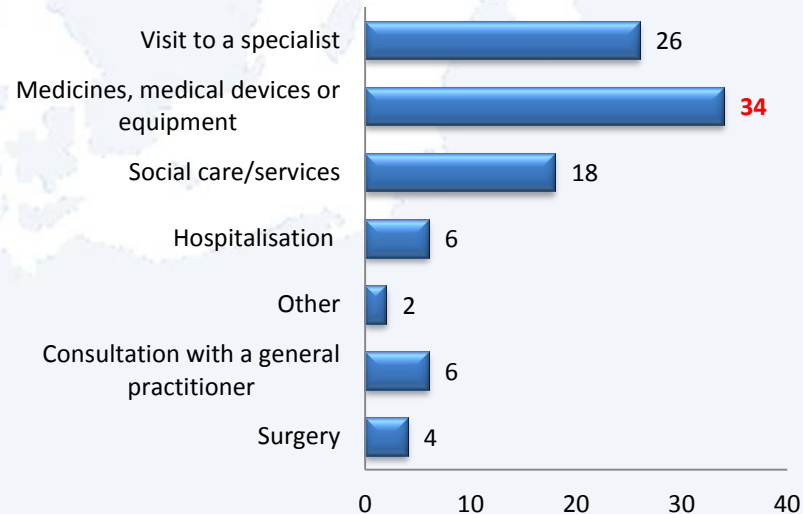
Ireland



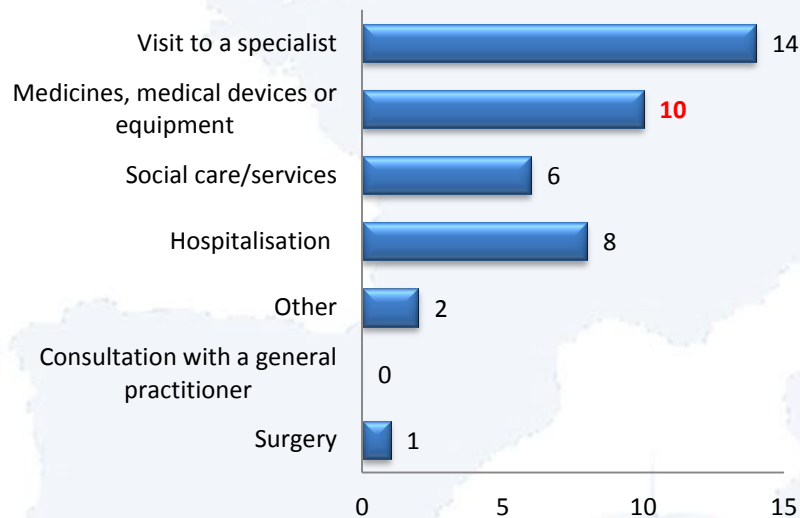
Czech Republic



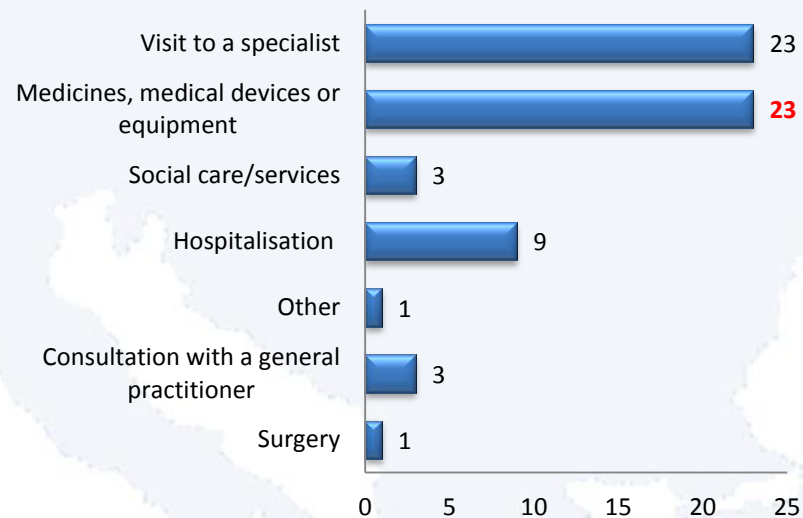
Slovak Republic



Hungary



Poland





Narrative: Systemic sclerosis with oesophageal and digestive manifestations ORPHA90291. Prevalence 1-5/10,000. SPAIN

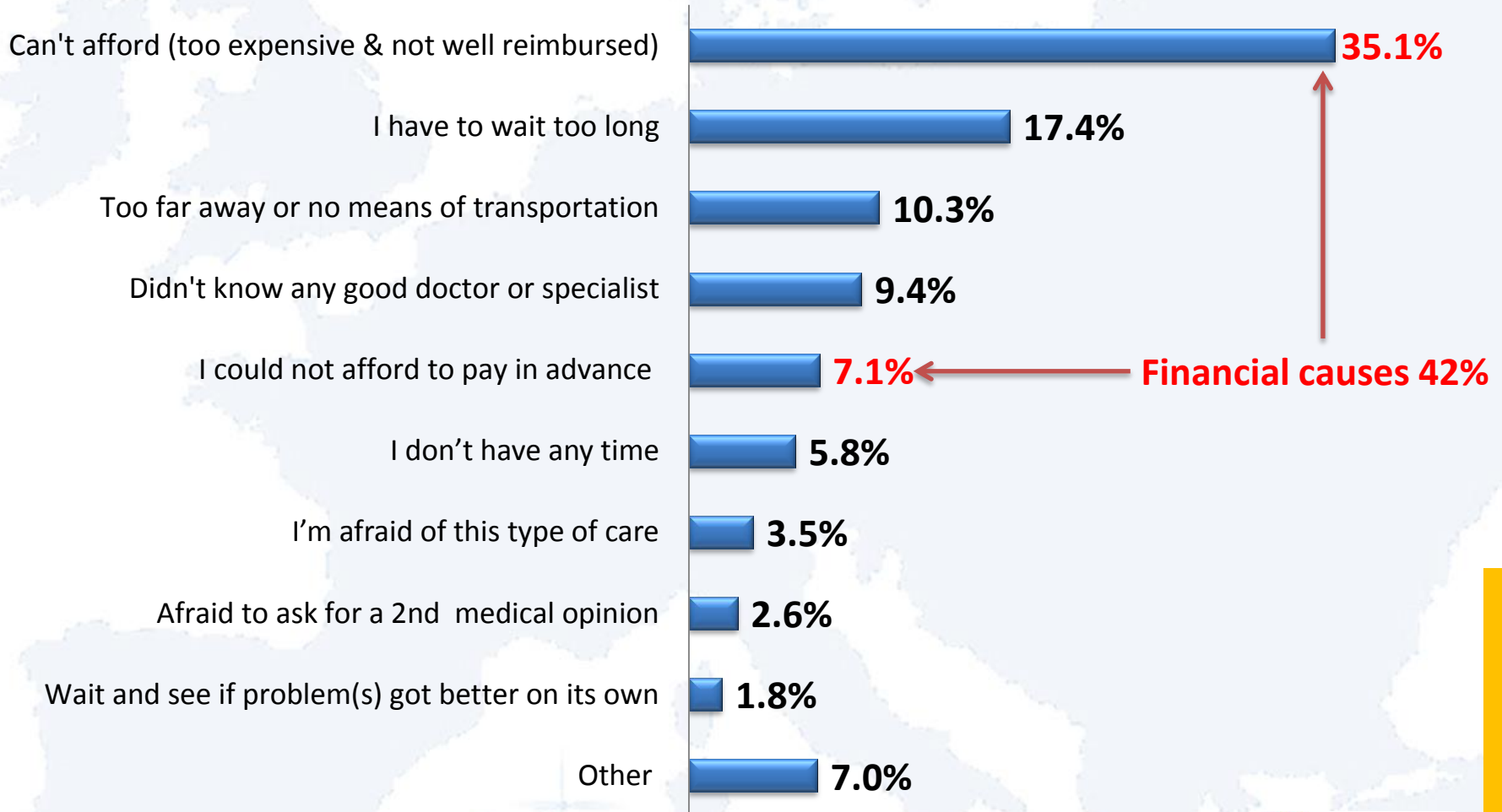
- **Axiago 40 and Pariet 20**

- I was prescribed the generic by my primary care physician for economic reasons, while my specialist prescribed the originator drugs with instructions not to substitute
- Same efficacy, but much more discomfort



Q5: What type of issues are causing you difficulties accessing medicines or medical devices?

(619 patients quoting 829 responses, several responses possible)



Narrative: Multiple Myeloma ORPHA 29073

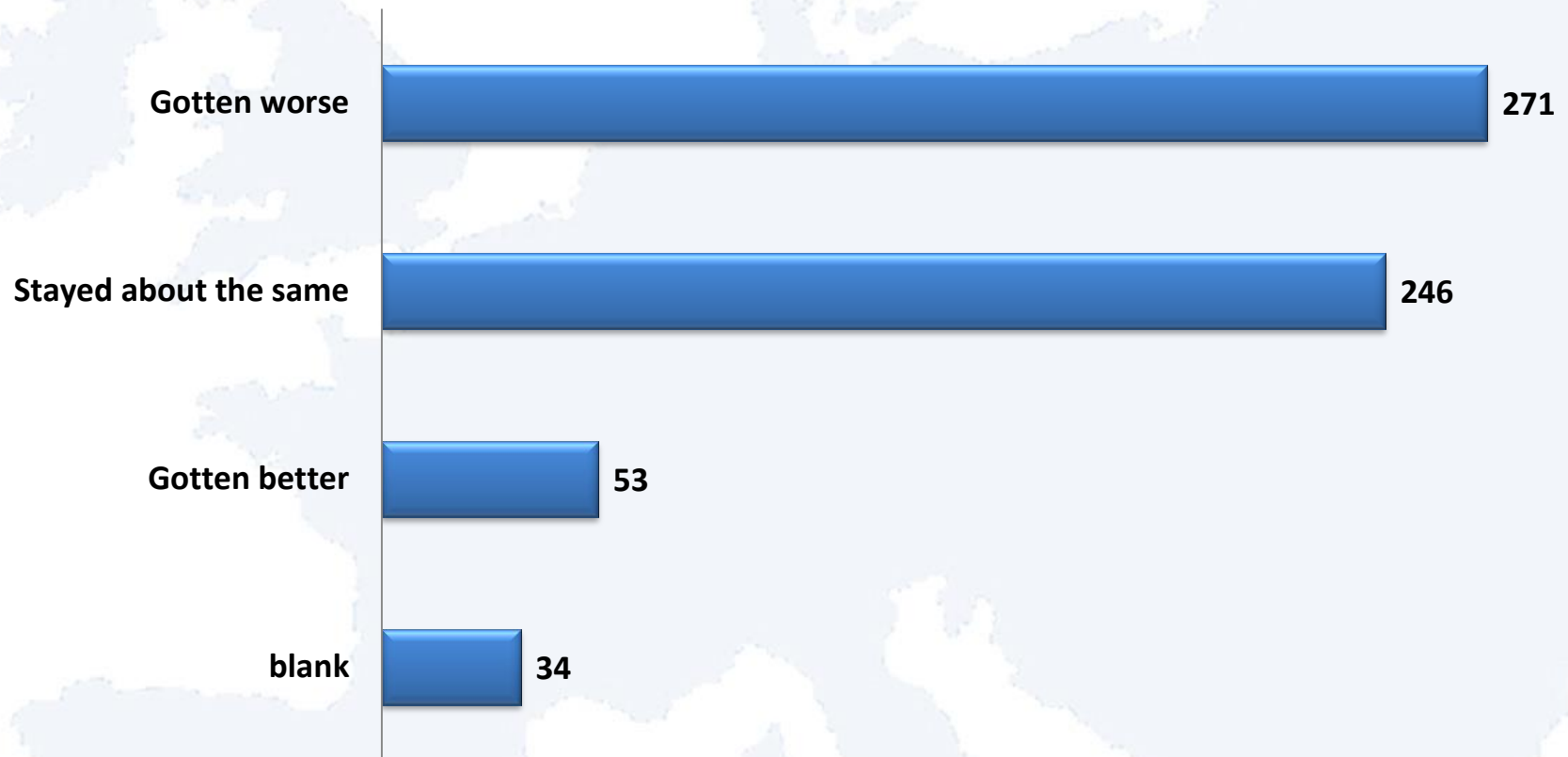
Prevalence 1-5/10 000. SLOVAK REPUBLIC



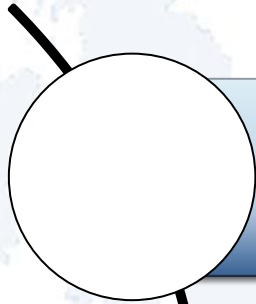
- Availability of a newly authorised medicine
 - According to doctors, I have exhausted all available treatments
 - He wants to use a new drug authorised in the EU
 - Insurance does not want to pay him back



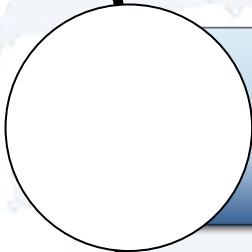
Question 8: In your personal experience, in the last 2-3 years, has the level of difficulty in obtaining **a medicines, medical device or equipment...**



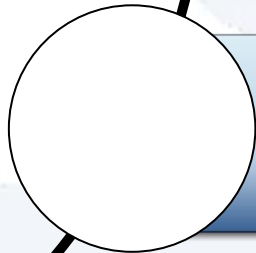
Conclusions and next steps



Conclusion 1



Conclusion 2



Conclusion 3