



2020

2020 User Satisfaction Survey of the Orphanet Website

www.orpha.net

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METHODOLOGY

This year's satisfaction survey has been conducted in one phase launched in February 2020 via a popup window added to the first page users landed on. The survey was translated into the 8 languages of the website (i.e. English, French, Spanish, Italian, Portuguese, Dutch, German and Polish) and was displayed in the language of consultation via the pop-up. The survey was closed after 5 weeks of display on the website. This survey was made of 14 questions split into 3 sections.

The on-line survey was designed using the online survey tool [Survey Monkey](#), the questions focused on the professional activity of the users, their habits when they visit the Orphanet website, their opinion of the content as well as their overall satisfaction and their suggestions for improvement. A total of 14463 users gave answers to the questions this year.

The results from all of the languages of the survey were consolidated and then analysed. The results of this analysis are presented in this report with elements of comparison as regards last survey's results. The number of total respondents for each question in particular is given.

For any questions or comments, please contact us: contact.orphanet@inserm.fr

RESULTS

Part 1: Knowledge of and reasons for using the website

Question 1: How did you discover Orphanet?

This question aimed to determine how respondents first learnt about Orphanet. Respondents could choose as many choices they wanted. At least one response to this question was required. 14463 respondents replied to this question, i.e. all of the respondents.

A large majority of our users (74%) discovered Orphanet via Google (Figure 1). Word of mouth has also brought a significant percentage of respondents to Orphanet (14%).

The other vectors cited by users include scientific literature, rare disease related events, Wikipedia and websites of patient organisations or hospitals.

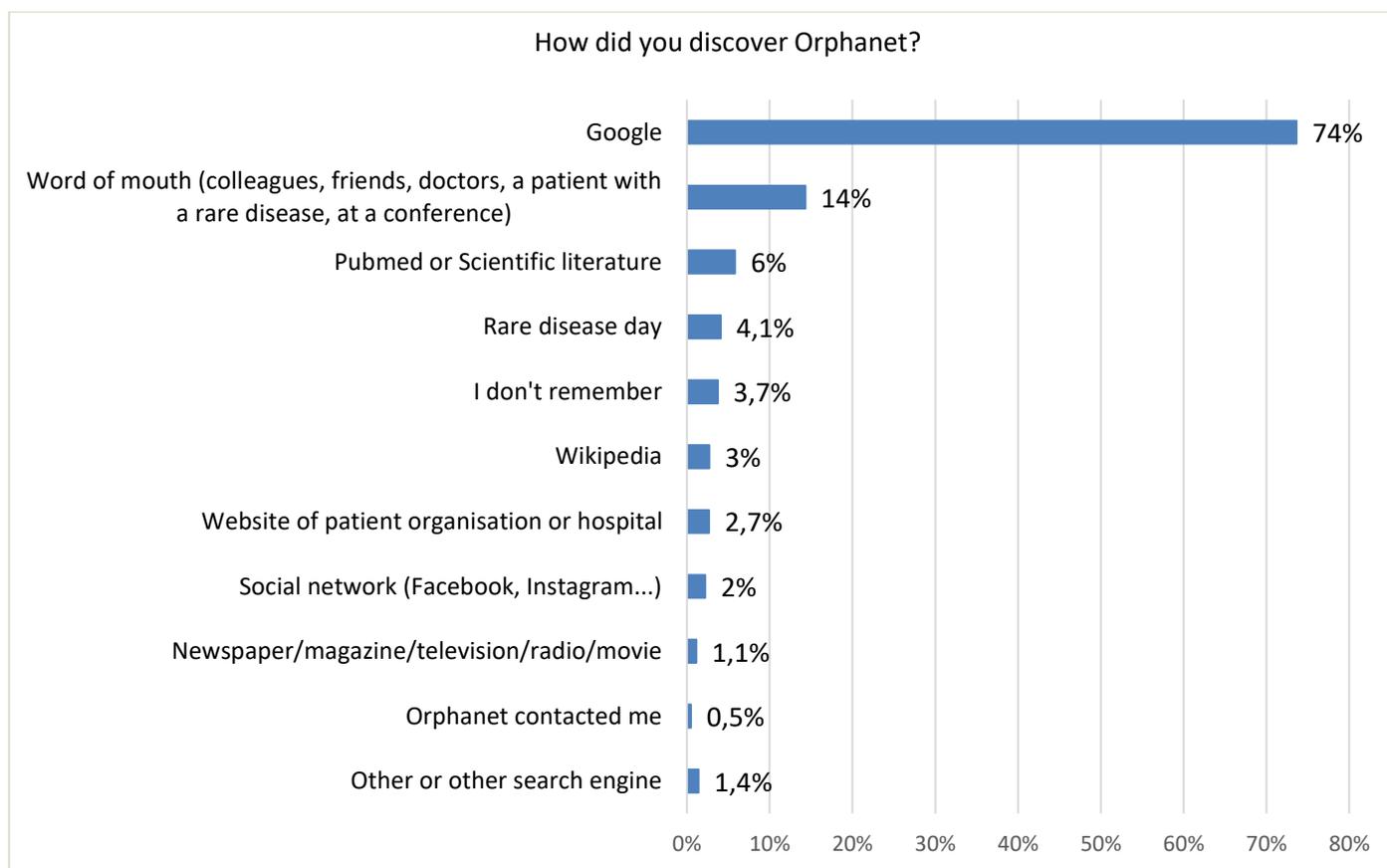


Figure 1: Mode of discovery of Orphanet by respondents (n=14463)

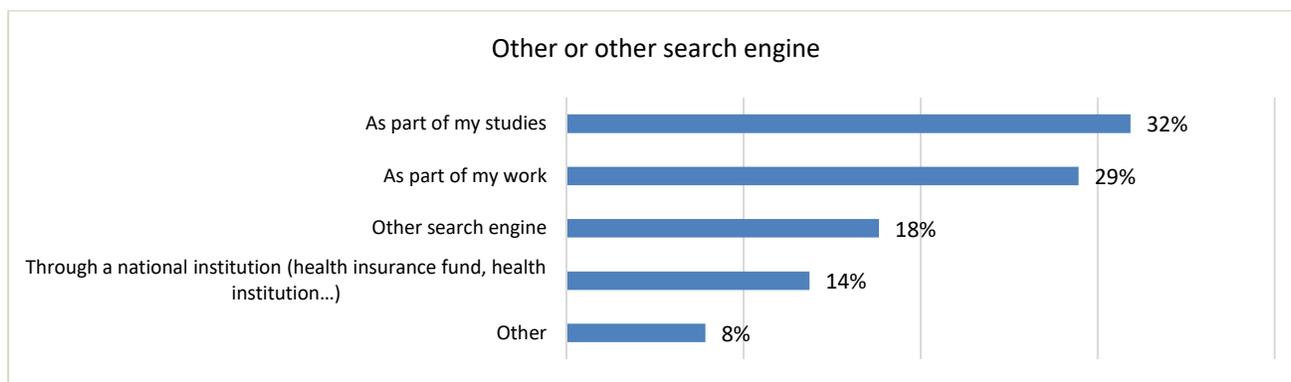


Figure 2: Mode of discovery of Orphanet by respondents who chose “Other” (n=205)

Compared to last year, these results show a new and interesting access through scientific literature (6%) and a continuing increase of access through Google (4 points more) while word of mouth is identical. The remaining vectors are marginal as in the last survey compared to the first two vectors. These results are the same in all the languages of the survey.

Question 2: What kind of device are you using to access Orphanet today?

This question was aimed at finding out more about the type of hardware used to access the site. Only one response was possible and an answer was required. 14463 respondents replied to this question, i.e. all of the respondents.

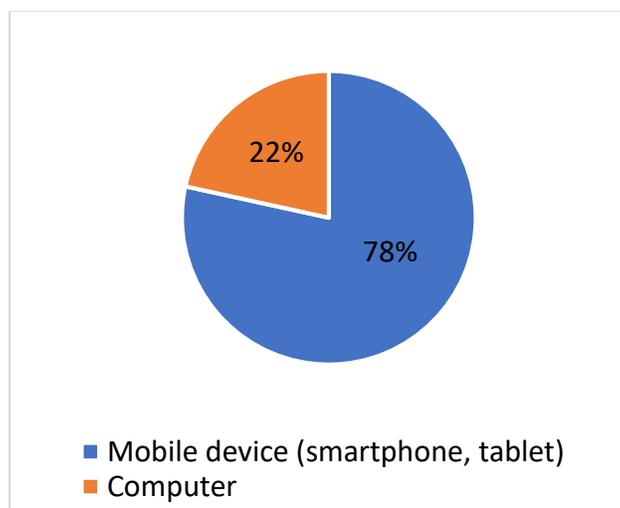


Figure 3: Mode of accessing Orphanet by respondents (n=14463)

78% of respondents accessed to Orphanet using a mobile device with an Internet connection (Figure 3). This represents a progression of 8% compared to the previous survey and confirms the trend that more and more people use a mobile device to connect to the Orphanet website, which follows the current trend in the use of mobile devices. It should be noted that the Orphanet website is responsive by design.

Question 3: How often do you visit Orphanet?

Only one response was possible and answer was required. 14463 respondents replied to this question, i.e. all of the respondents.

Around 48% of those answering the survey are regular users, whereas 53% were visiting Orphanet for the first time (Figure 4).

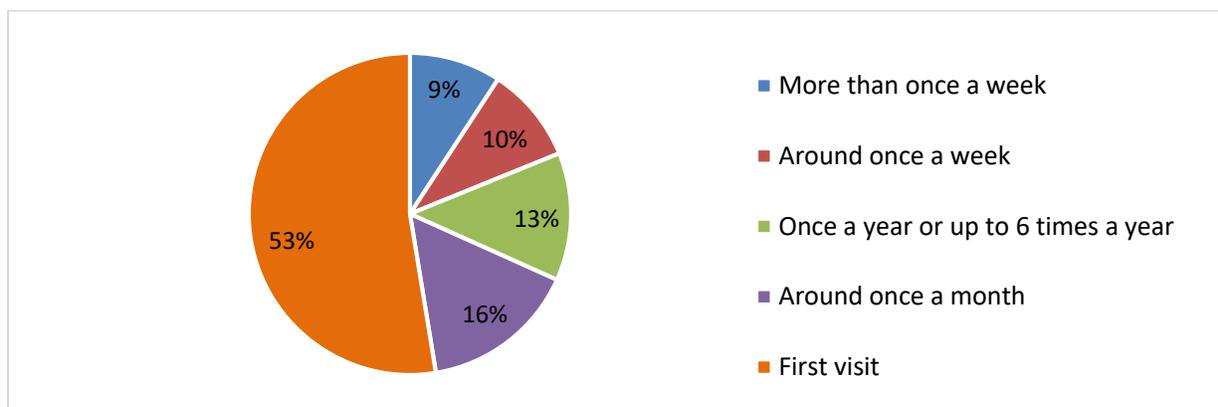


Figure 4 : Visiting frequency of respondents (n=14463)

There were still more first time users this year compared to last survey (53% compared to 44%) but also more respondents than the last survey (14463 compared to 8097).

On the other hand, there is an increase in very regular users (\geq once a week): around 20% this year compared to 12% in the last survey.

This trend is similar to that of last survey showing that people tend not to come back to Orphanet once they find the information they want or that first time users are more likely to answer to this survey as regular users already did last year or before.

But Orphanet seems to be becoming a tool used more and more regularly.

Question 4: Why do you usually consult Orphanet?

This question aims to determine what type of information visitors usually look for on Orphanet. It had not been asked in the last surveys. It was possible to select several categories but the answer was not required. 6498 respondents replied to this question, i.e. 45% of the total respondents.

The top three usually consulted information categories are(Figure 5):

- learn more about a rare disease by reading its disease summary text (58%);
- find the clinical signs associated with a rare disease (53%);
- learn about rare diseases in general (52%).

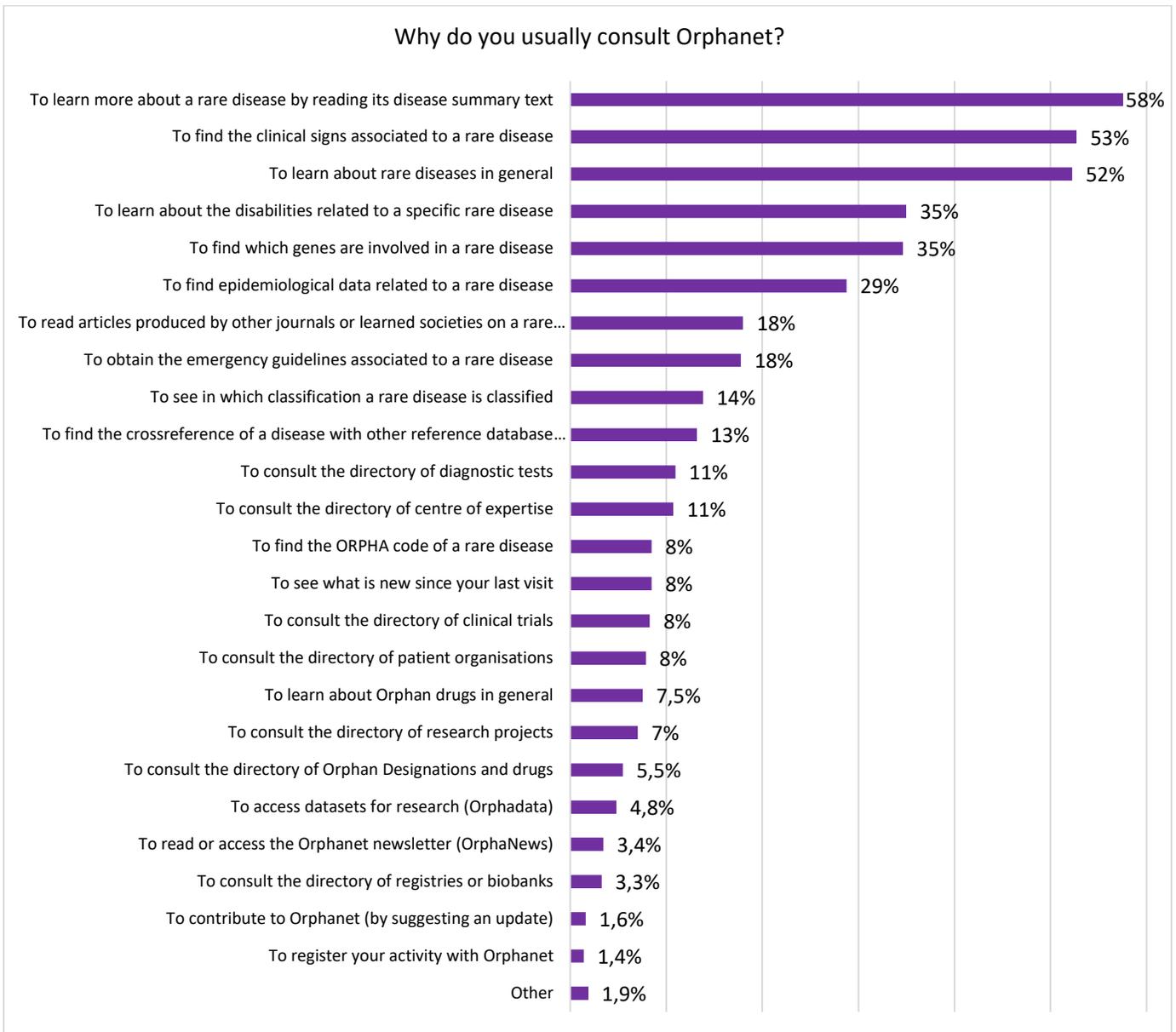


Figure 5 : Information sought usually by respondents during their connection to Orphanet (n=6498)

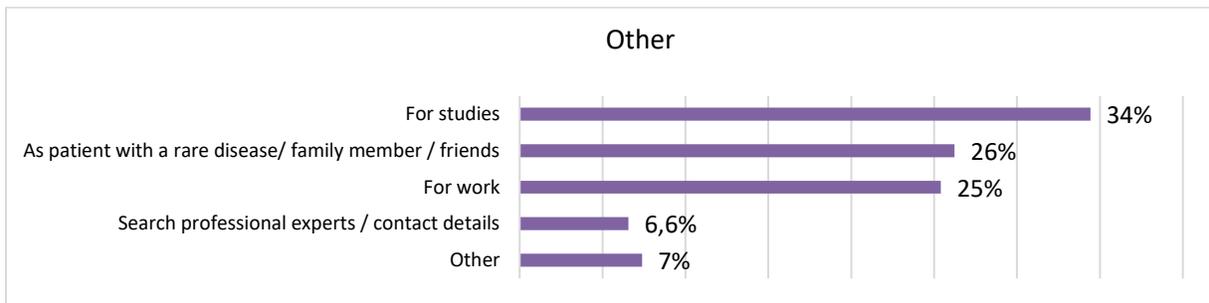


Figure 6: Information sought usually by respondents who chose "Other" (n=122)

Our visitors also usually look for information about the disabilities related to a specific rare disease (35%), to find which genes are involved in a rare disease (35%), to find epidemiological data related to a rare disease (29%), to read articles produced by other journals or learned societies on a rare disease (18%) and to obtain the emergency guidelines associated with a rare disease (18%).

Regarding directories offered by Orphanet, the directory of diagnostic tests and of centres of expertise are the most consulted usually (11%). 8% of respondents consult Orphanet to find the ORPHA code of a rare disease.

Question 5: What sort of information are you looking for during this connection to Orphanet?

This question aims to determine which kind of information visitors sought on Orphanet. Unlike the last survey, it was possible to select several categories but an answer was not required. 6941 respondents replied to this question, i.e. 48% of the total respondents.

This year, results show an increase in visitors consulting Orphanet to learn about rare diseases in general (54% compared to 23%). This can be explained by the fact we allowed respondents to choose multiple categories or because first time users are more likely to answer to this survey and mainly research general information compared to regular users.

But we can see the same top three consulted products during this connection are as in the last survey: information on rare diseases in general (54%), information on a specific disease (35%), and information about clinical signs associated to a rare disease (18%) (Figure 7).

Our visitors also look for information on disabilities related to a specific rare disease (13%) and on genes involved in a rare disease (10%), more so than in the last survey (1% for each category). This can be explained by the fact we allowed respondents to choose multiple categories but also show a trend that people are more and more interested in detailed information about a specific disease.

Articles produced by other journals or learned societies on a rare disease (8%), information about classifications and epidemiological data related to a rare disease (7%) and the emergency guidelines associated with a rare disease (6%) are also products for which people usually look.

What sort of information are you looking for during this connection to Orphanet?

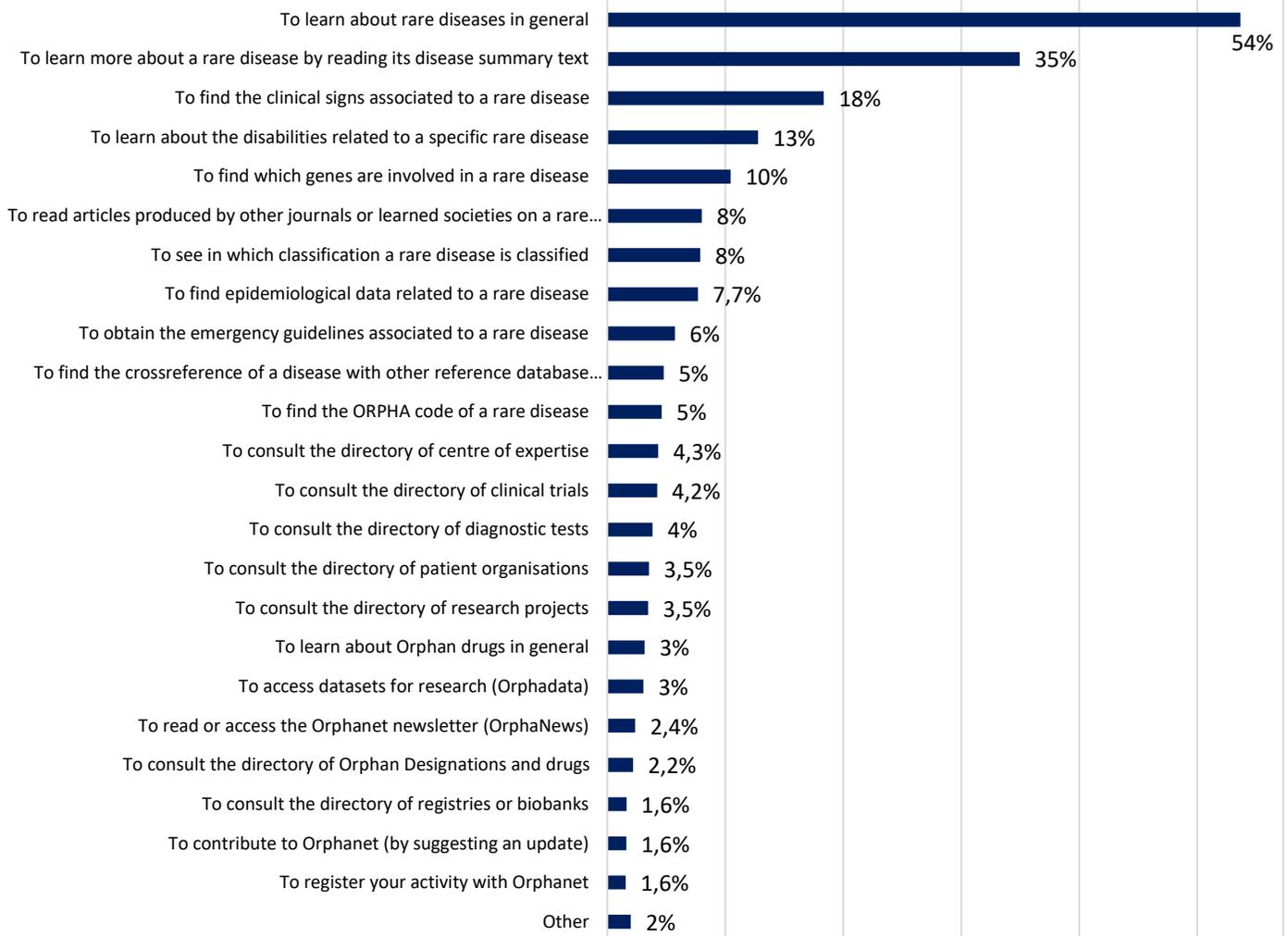


Figure 7 : Information sought by respondents during their connection to Orphanet (n=6941)

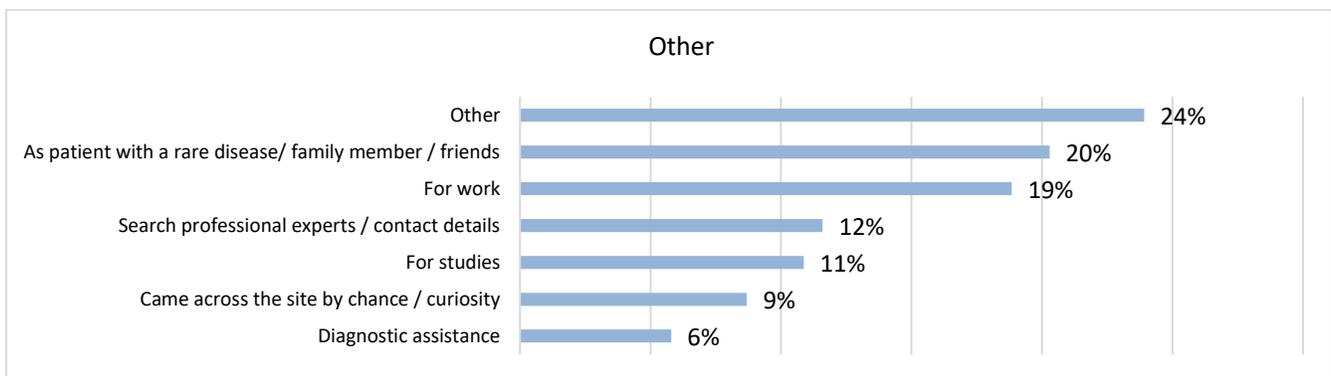


Figure 8: Information sought by respondents who chose "Other" (n=138)

Part 2: Your opinion on Orphanet's products / services and its website

This part of the questionnaire was aimed at deciphering our users' global satisfaction about our website and our products/services. This part also provided the opportunity for respondents to tell us what we should improve or develop to better serve their needs. This question was only directed to those who answered that it was not their first visit to the Orphanet site.

Question 6: To what extent do you agree or disagree with the following statement?

This question aimed to find out whether users found Orphanet website user friendly, easy to use and if the information found was easily understandable. Respondents were asked to rate (++ , + , - , --), to what degree:

- the site is easy to navigate,
- the information was easy to find,
- the information found was easy to read and understand.

Respondents were asked to provide answers concerning the three statements but an answer was not required. 6330 respondents replied to this question, i.e. 44% of the total respondents and almost the total of regular users (48%; question 3).

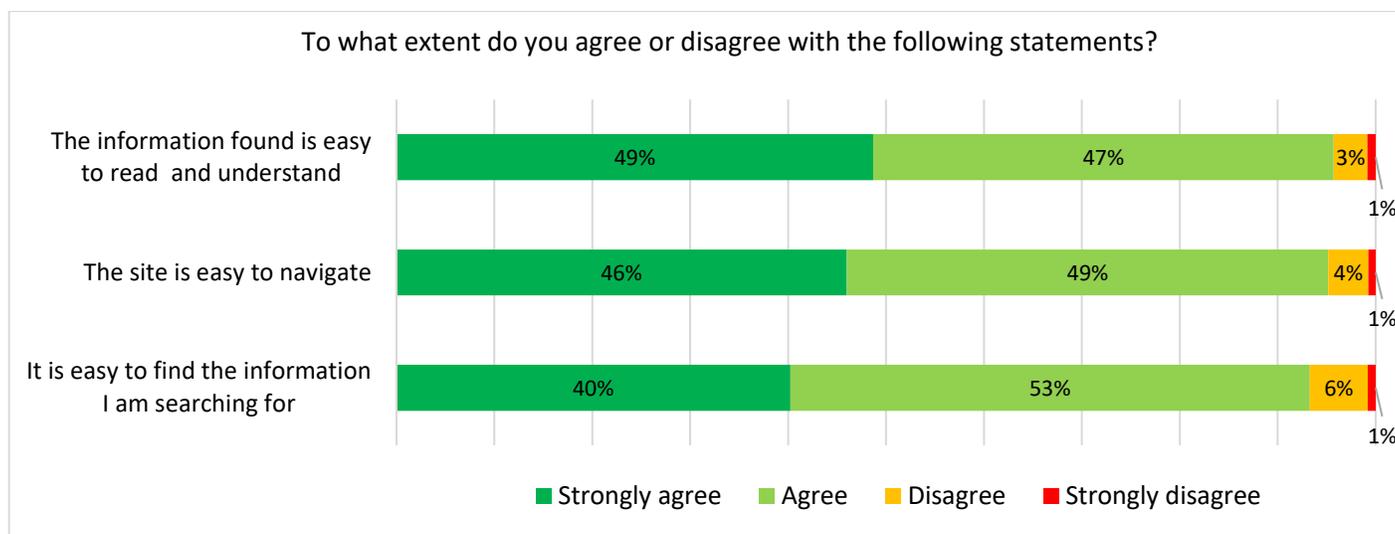


Figure 9: Repartition of the respondents rate on the ease to use the Orphanet website and to understand the information found (n=6330)

These results show that most of the respondents (more than 90%) find that the Orphanet website is user-friendly, that the information is easy to find and that once it is found the information is easy to read and understand (Figure 9). A minority of respondents (4 to 7%) disagree or strongly disagree with these statements. This is more than in the last survey (around 2%) but this can be explained by the fact that in the last survey we proposed an intermediate category showing that 13 to 19% of respondents are ambivalent.

These results should, however, be related to question 8 and 11. In these questions, we asked how useful they found Orphanet services and what Orphanet could do to better serve its users. Answers to these questions

showed that users do not know certain Orphanet functionalities or services and that Orphanet must make further efforts to make its site even easier to use and clearer (e.g. more ergonomic).

Question 7: Orphanet provides data on rare diseases according to quality standards. These procedures are available on the Orphanet website

This question aims to determine if Orphanet users were aware that procedures exist and if they were interested in reading them. Indeed, Orphanet produces its data according to published procedures : data collection, validation and publication is ruled by Orphanet Standard Operating Procedures according to quality standards.

Answer was not required and 6188 respondents replied to this question, i.e. 43% of the total respondents and almost the total of regular users respondents (48%; question 3).

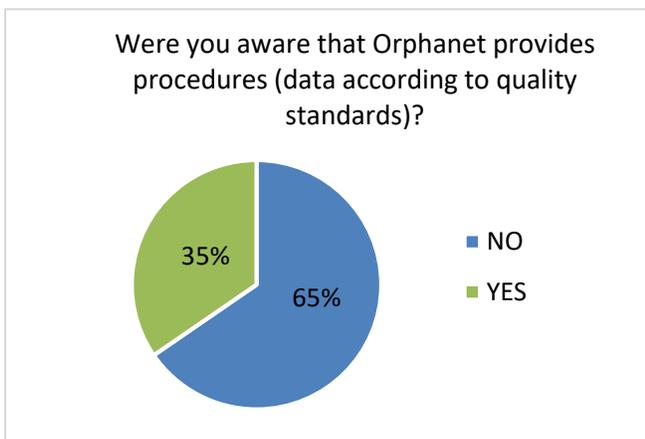


Figure 10 : Repartition of the respondents about knowledge of Orphanet procedures (n=6188)

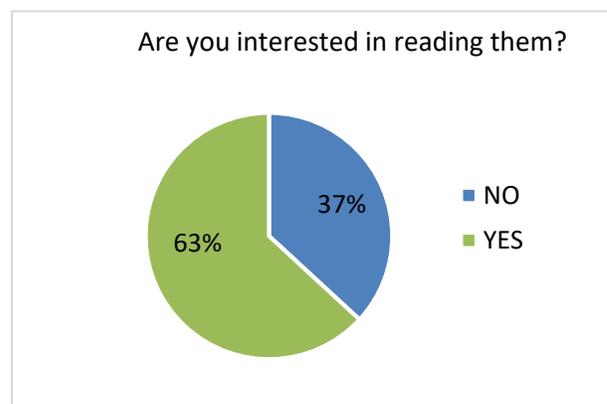


Figure 11: Repartition of the respondents interested in reading Orphanet procedures (n=6188)

The majority of respondents (65%) did not know of the existence of these procedures (Figure 10) but 63% are interested in reading them (Figure 11).

This indicates that we should increase the visibility of these procedures on the website.

Question 8: How useful would you rank the following Orphanet services for your own use?

This question aims to determine the utility and users' knowledge of the various services/products offered by Orphanet. Respondents were asked to rate (++, +, -, --) each services/products or to specify that they did not know this service/product.

Answer was not required and 5413 respondents replied to this question, i.e. 37% of the total respondents (the total of regular users respondents being 48%).

How useful would you rank the following Orphanet services for your own use

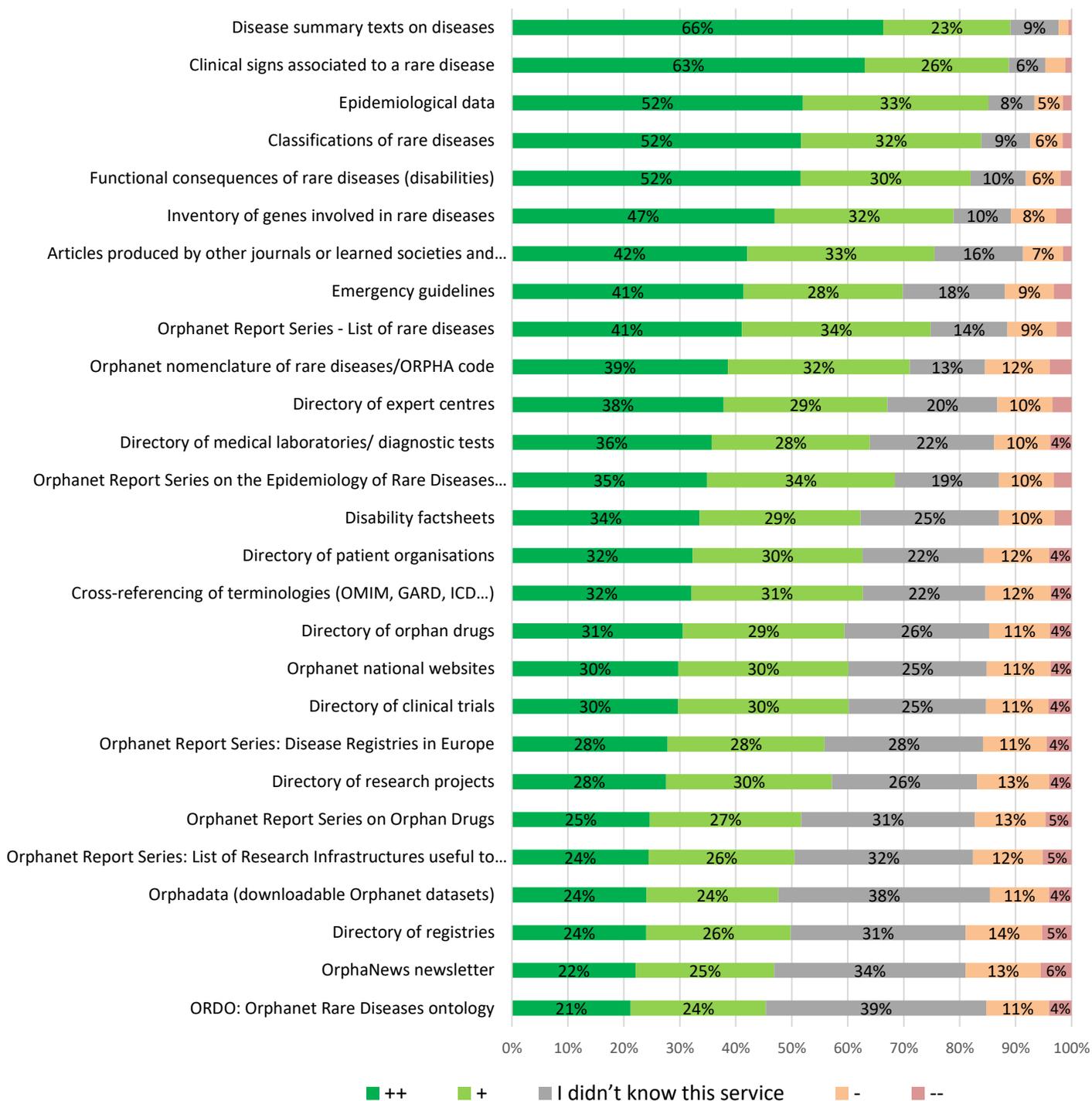


Figure 12 : Repartition of the respondents rate on utility and or knowledge of services/products offered by Orphanet (n=5413)

The most useful services for respondents (almost 90%) are disease summary texts and clinical signs associated to a rare disease (Figure 12) followed by epidemiological data, classifications of rare diseases, functional consequences of rare diseases (disabilities) and the inventory of genes involved in rare diseases

(around 80%).

Articles produced by other journals and published on the Orphanet website, Orphanet nomenclature of rare diseases / ORPHAcodes and emergency guidelines are also very useful services for Orphanet users (at around 70%).

4 to 15% of respondents do not find certain products/services useful for their needs. These results should, however, be considered in the light of the results of question 11, where we asked what Orphanet could do to better serve its users : it emerges from this question that detailed information would be more useful for some users.

Overall, the services/products offered by Orphanet are more useful than not for respondents.

The Orphanet Report Series on Registries, Orphan Drugs and Research Infrastructures and also the OrphaNews newsletter are not well known to our users (around 30%). Orphanet should therefore increase the visibility of these products and services.

Orphadata (downloadable Orphanet datasets) and Orphanet Rare Disease Ontology (ORDO) are the least known products (almost 40%) maybe due to the fact that these services have their own access in addition to the Orphanet website and that people who need these services do not come to the Orphanet website to find them.

Question 9: Overall, how satisfied are you with Orphanet?

The global satisfaction of Orphanet website users was evaluated through this question. An answer was not required and 5262 respondents replied to this question, i.e. 36% of the total respondents, the total of regular user respondents being 48%.

Only one answer was possible plus a non-mandatory free field to add any comment that could explain the answer. Comments were aimed at ascertaining in more detail what people think of Orphanet and were provided by 598 individuals.

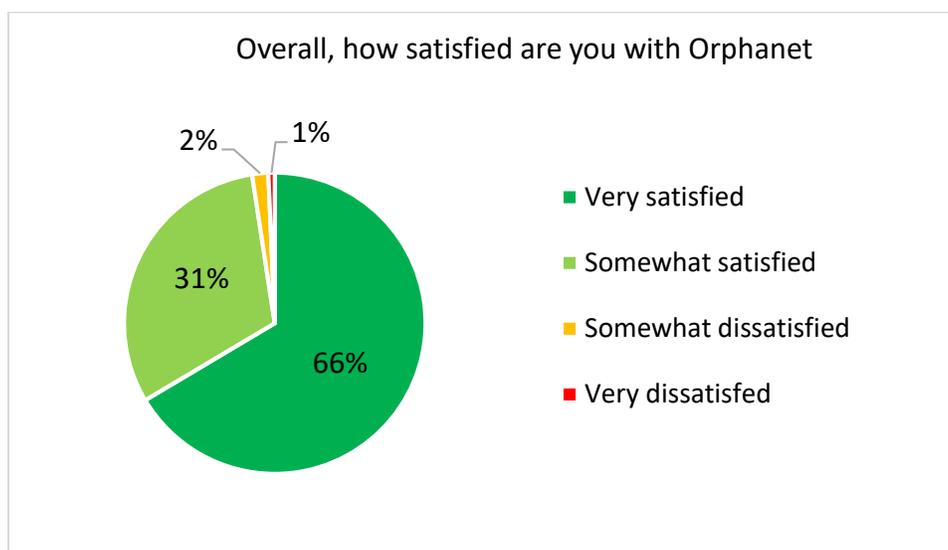


Figure 13: Global satisfaction of the Orphanet website users (n= 5262)

The vast majority of respondents were either very satisfied or satisfied with Orphanet with a total of 97% responding positively (Figure 13), increasing by 4 points compared to the last survey (93%, n=4369).

The free comment field helped us to understand the reasons for satisfaction or dissatisfaction (Figure 14):

- 57% considered that information provided by Orphanet is useful and accurate, showing the same trend as in the last survey.
- 2% of respondents were dissatisfied and 1% were very dissatisfied. The main free comments explained that the information is not detailed enough and not updated enough, and the website is not user-friendly enough.

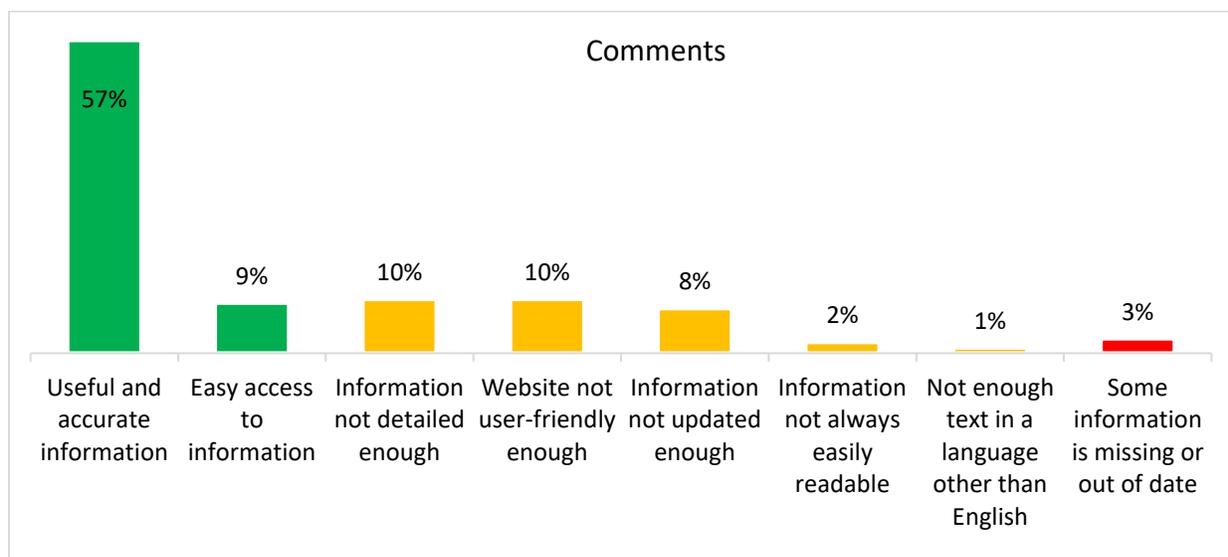


Figure 14: Free comments of the Orphanet website users (n= 598)

Question 10: How likely is it that you would recommend Orphanet to a friend or a colleague?

This question was asked in order to determine Orphanet’s Net Promoter Score (NPS), which measures the likelihood, on a 1-10 scale, that someone will recommend a company to someone else. The Net Promoter Score was calculated by subtracting the percentage of customers having ranked this probability from 0 to 6 from the percentage of customers having ranked this probability from 9 to 10. Thus, results can go from -100 to +100.

Answer was not required and 5299 respondents replied to this question, i.e. 37% of the total respondents, the total of regular users respondents being 48%.

Almost 63% of those responding turned out to be promoters as they responded with a score of 9 or 10, 29% were passive (score of 7 or 8) and 8% were detractors (score of 0 to 6). This gives a NPS of 54.3 (Figure 15).

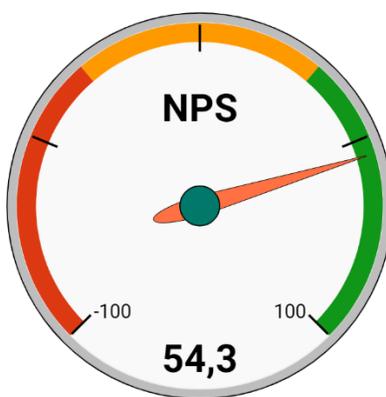


Figure 15: Orphanet Net Promoter Score (NPS) (n= 5299)

To our knowledge, Orphanet is the only service dedicated to providing free information on rare diseases and orphan drugs, that publishes its NPS. Thus, we cannot compare this score to other similar services but is useful in measuring our customer satisfaction when tracked. This score increased by 6.5 points compared to the last survey in 2018 (47.8, n=4199).

It is noteworthy that according to these results 63% of the respondents would recommend using Orphanet while only 8% would not.

Question 11: What should Orphanet do to better serve your needs?

Comments were provided by 1047 individuals in response to this question, i.e. 7% of the total respondents.

Around 34% of those who provided comments were satisfied by the service provided by Orphanet and left messages of encouragement and support for Orphanet's activities (Figure 16).

The most frequent comments relate to the need for more detailed information (23%), a more ergonomic website (14%) and more frequent updates (11%).

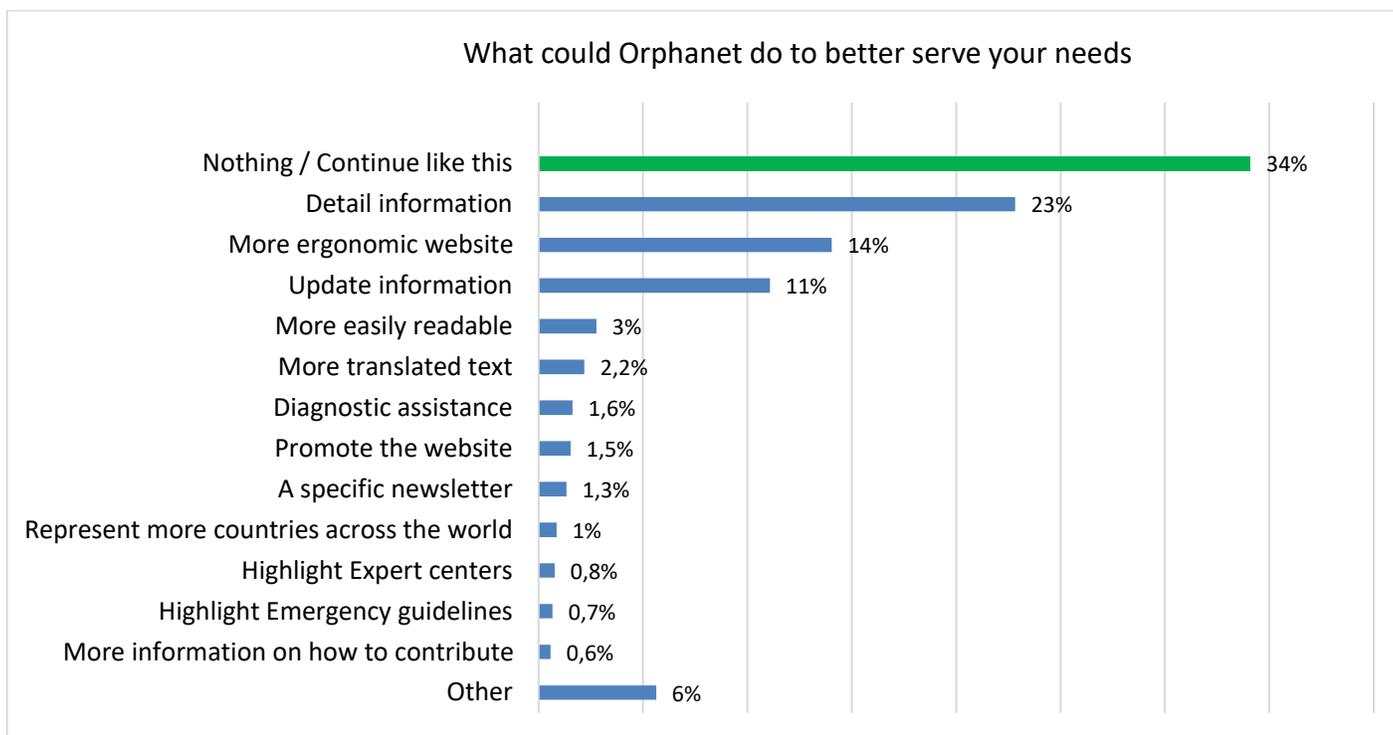


Figure 16: Free comments on what could Orphanet do to better serve your needs (n= 1047)

1) Regarding the need for a more detailed information, Orphanet’s users were mainly interested in more detail in disease summaries (36%, Figure 17).

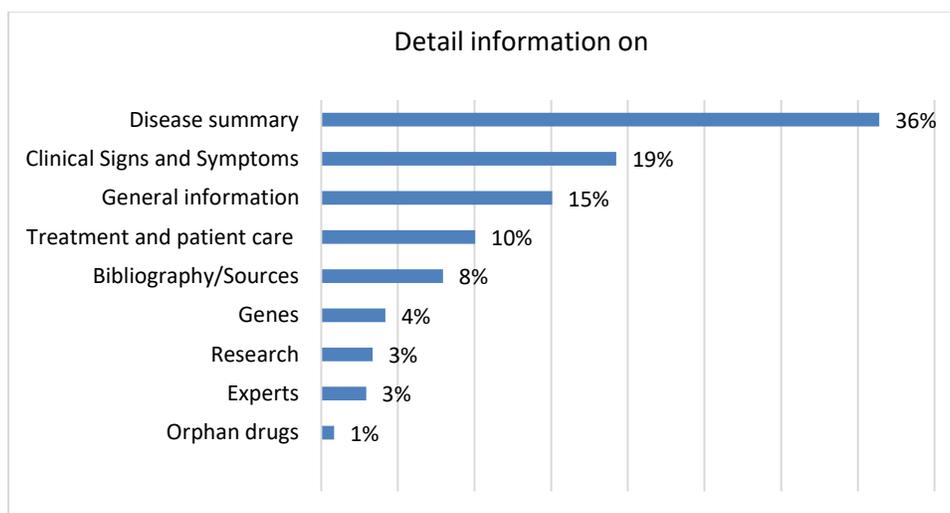


Figure 17: Free comments on what could Orphanet do about expanded information (n= 239)

Many respondents also wanted the clinical signs and symptoms be more detailed (19%) and suggested that pictures, or medical imagery, could be added to aid diagnosis, as well as the publication of clinical cases.

Some comments concerned the reintroduction of the aid to diagnosis tool (Orphanet-Phenomizer tool) that Orphanet took off-line following feedback from users as this tool was not sufficiently efficient. Orphanet is testing a new aid to diagnosis tool in order to include it in Orphanet.

More general information about rare diseases interested Orphanet's users (15%) as did health policy and health insurance. Orphanet provides information about rare diseases policies ([link](#)) but maybe it is not visible enough on our website or not detailed enough.

Around 10% of Orphanet's users would like more informations about treatments and patient care.

2) Regarding the need for a more ergonomic website (Figure 18), Orphanet's users comment mainly about the website layout (32%) and the site navigation (31%). The responses collected showed that some users consider the website as not user friendly enough, which could explain the few negative answers to the question 6 that some users find that the information is not always easy to find.

Respondents suggest to improve the presentation of the data in this complex database, and to highlight all the resources linked to each disease. Users were also interested in having more information on how to navigate.

It is worth to note that Orphanet offers some video tutorials to help understand the database and show how to use the Orphanet website ([Orphanet Tutorials](#)) but maybe these tutorials are not visible enough on our website.

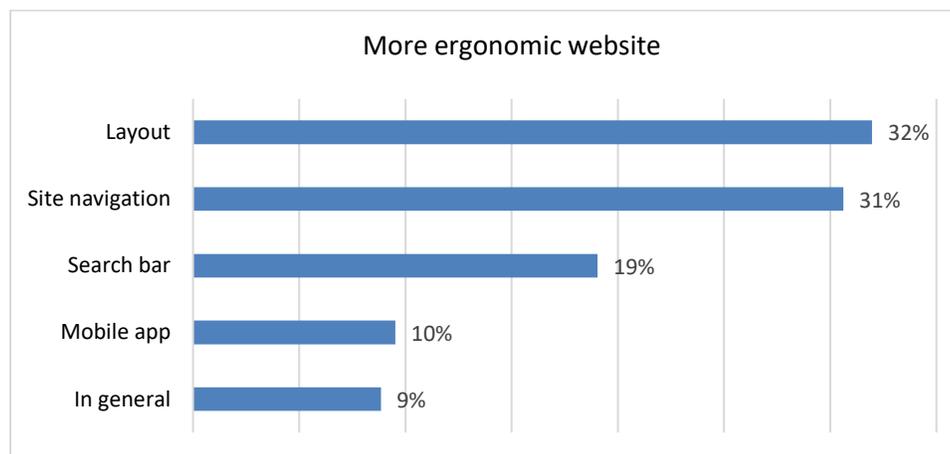


Figure 18: Free comments on what could Orphanet do about the website (n= 147)

Many comments were also on the search engine (19%) that is not performant enough and/or too complex to use. Many users also highlighted the need to improve the search functionalities and the search engine: the IT infrastructure is still being overhauled and hopefully this will improve in the near future.

3) The third most frequent Orphanet user request is that Orphanet update more frequently its data. Concerning the update of disease summaries, some of them are now directly produced by European Reference Networks (ERNs) who agreed to work with Orphanet and this new strategy has recently resulted in a much larger number of summaries being updated and enabled us to continue to improve the update frequency of the abstracts.

Concerning the updates of the expert resources (expert centres, patient organisation, medical laboratories and their associated diagnostics test, research projects, clinical trials and registries), Orphanet is always dependent on the good will of the professionals as they are the only ones that can update this data. This is why Orphanet carries out an annual email campaign to professionals and ask them to update their data. In parallel, professionals are able to update their data via the [Orphanet professionals' registration tool](#) at any time throughout the year.

Part 3: More information about you

Question 12: What country do you live in/work in?

This question was aimed at ascertaining the location of the users replying to the survey. Only one response in a drop down menu was possible for this question. This menu contained the 250 countries of the ISO norm 3166-1 alpha-2.

This question was asked to everyone but an answer was not required and 11326 respondents replied to this question, i.e. 78% of the total respondents.

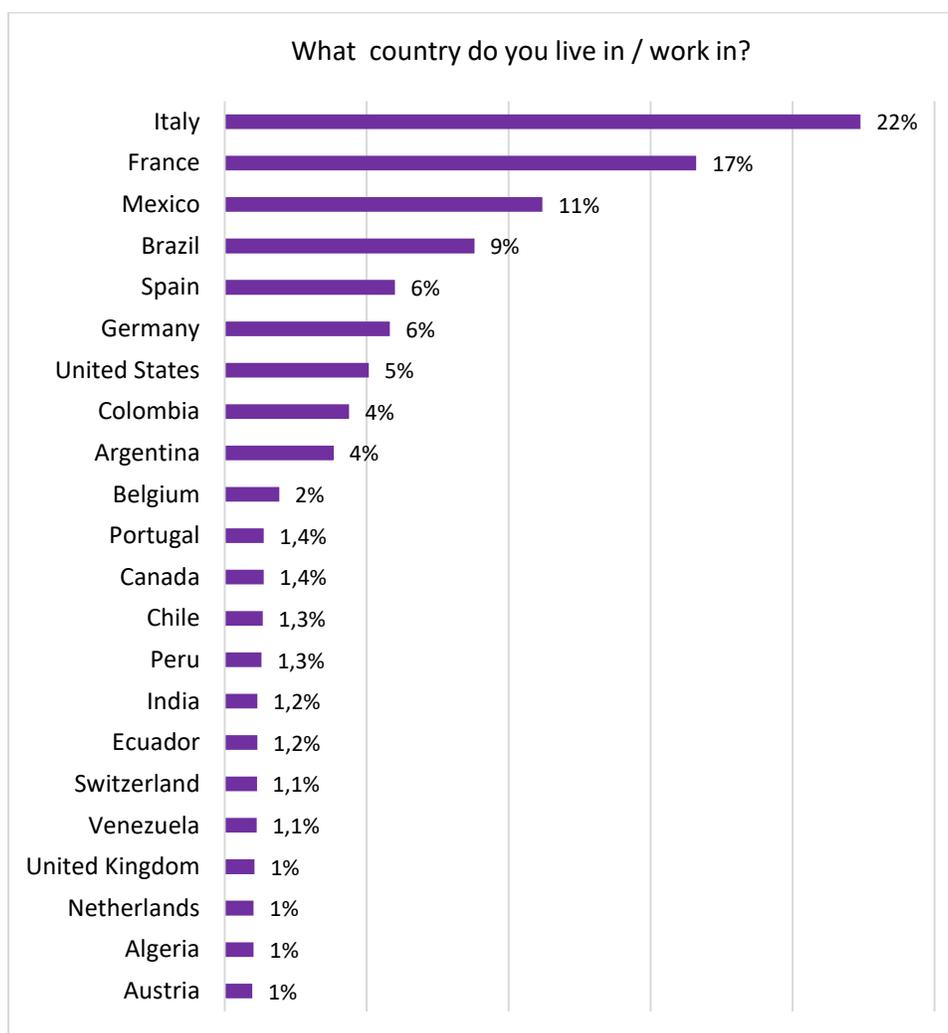


Figure 19: Top 20 countries replying to the satisfaction survey (n=11326)

The top ten countries replying to the survey were: Italy (n=2136), France (n=1584), Mexico (n=1067), Brazil (n=839), Spain (n=572), Germany (n=555), United States of America (n=484), Colombia (n=418), Argentina (n=366), and Belgium (n=183).

This is exactly the same top 10 countries as in the last survey.

Question 13: In what capacity are you consulting the Orphanet website?

This question aimed to determine the profile of Orphanet users. Seven categories were proposed (i.e. healthcare professional, patient / family / patient organisation, researcher, industry, health care manager / policy maker, education / communication and student), and a free text field was included for other types of users. Respondents from the 'other' category were reassigned to one of the seven proposed categories when appropriate.

Unlike last survey, it was possible to select several categories but an answer was not required. 11331 replies were registered for this question, i.e. 78% of the total respondents.

Figure 20 shows the distribution of respondents amongst these categories:

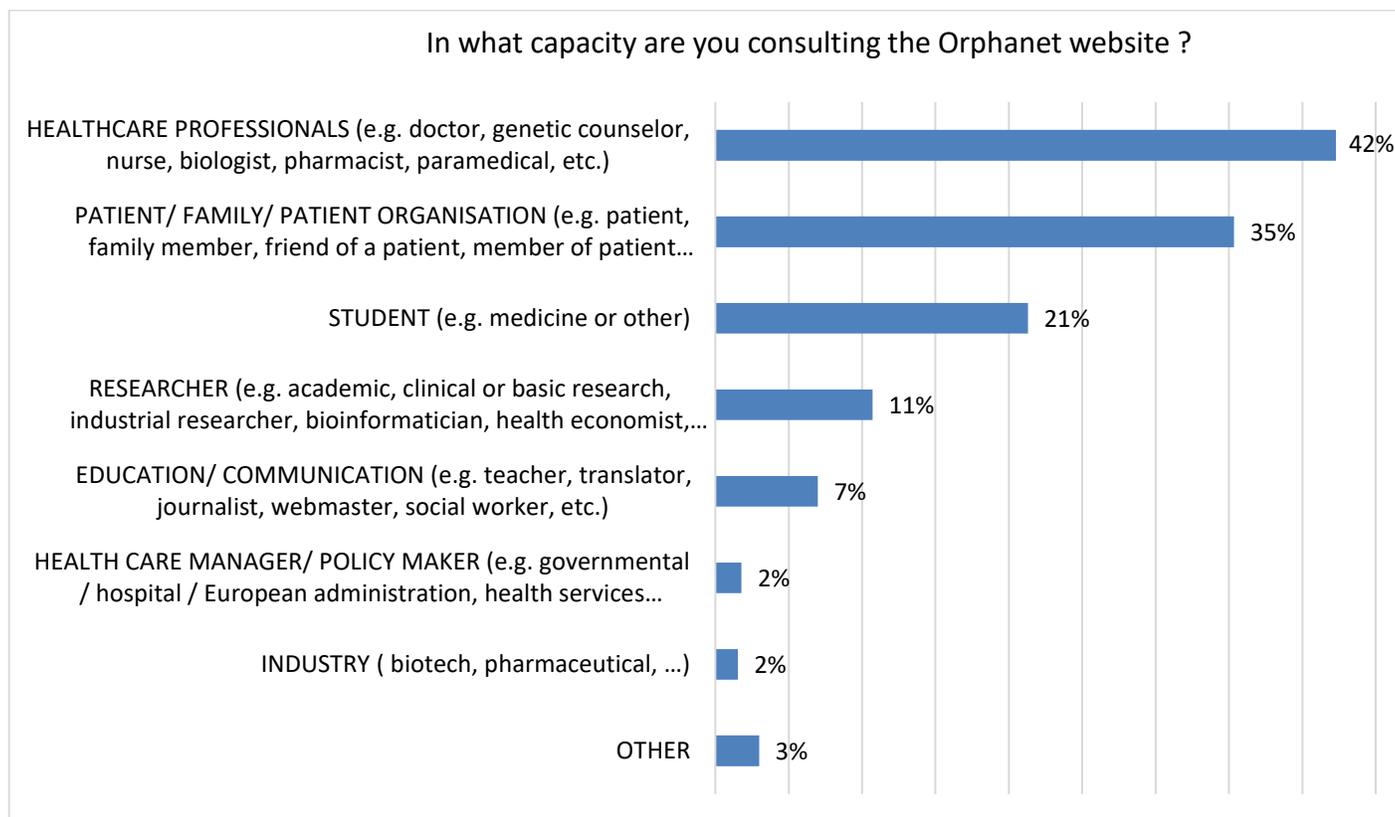


Figure 20: Types of Orphanet user (n =11331)

The largest category of respondents is the healthcare professional category (43%). The second largest category of respondents is patients and their entourage, including patient organisations with 35% of responses. Many students (21%) also replied the survey.

Around 60% of the 'other' category was composed of those visiting the site for their general knowledge or curiosity (n=203). The rest of this category included majoritarily those who did not state their professional category (n= 137).

There is an increase in the percentage of patients and their entourage, including patient organisations responding to the survey (35% this year, 26% last survey) and a slight increase in the percentage of healthcare professionals (43% this year, 39% last survey). The percentage of students responding to the survey remained stable.

Then, for each category, respondents were asked to choose the sub-category that would best describe them. If they answered 'other' they were invited to state in which capacity they were answering. Only one response was possible. Respondents from the 'other' category were reassigned when appropriate.

Healthcare professionals (n= 4612):

Hospital or independent specialists represent by far the main category of respondents (45%) (Figure 21). All together, 61% are medical doctors (compared to 71% in the last survey).

17% of the respondents belong to other healthcare professional categories (e.g. psychologists, physiotherapists, dentists, paramedical, etc...), which represents a fairly large increase compared to last survey (11%).

Other professional categories remain equally represented compared to last year.

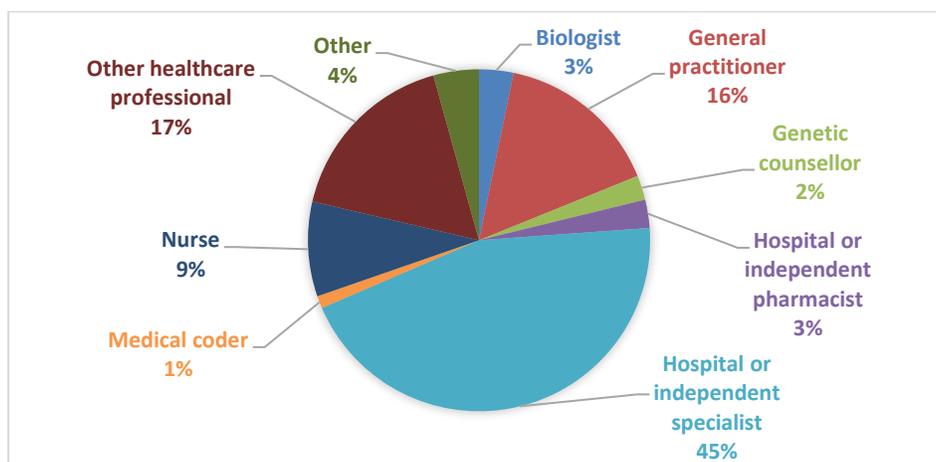


Figure 21: Types of respondents qualifying themselves as health professionals

Patient / Family / Patient organisation (n= 3755):

Most of the people who selected this category are patients (42%) or family members of a patient with a rare disease (41%) (Figure 22). The results are globally similar to those of the previous survey.

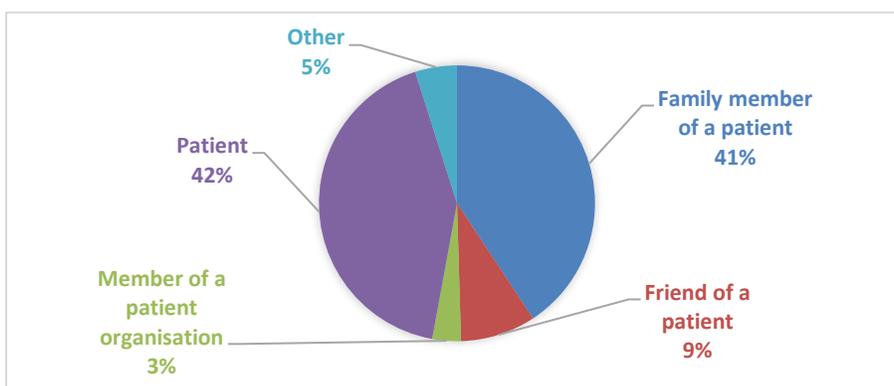


Figure 222 : Types of respondents qualifying themselves as a patient, part of a patient's entourage or member of a patient organisation.

Students (n= 2306):

Medical students represent 68% of this category (Figure 23). The other respondents were students in biology, dentistry, physiotherapy, genetics, etc. The results are almost similar as last survey with an increase of other types of students (32% this year compared to 24% last one).

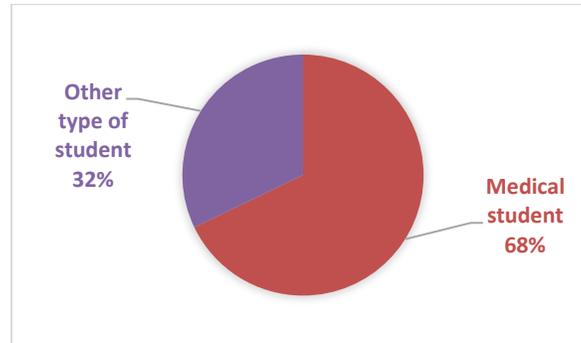


Figure23: Types of respondents qualifying themselves as students

Researchers (n= 1130):

Academic researchers represent 71% of respondents of the research category (an increase in comparison to 56% in the last survey) (Figure 24). The percentage of social science researchers that responded to this survey decreased compared to last year (7% compared to 12% in the last survey) as did the percentage of bioinformaticians / biostatisticians (3% this year, 9% in the last survey).

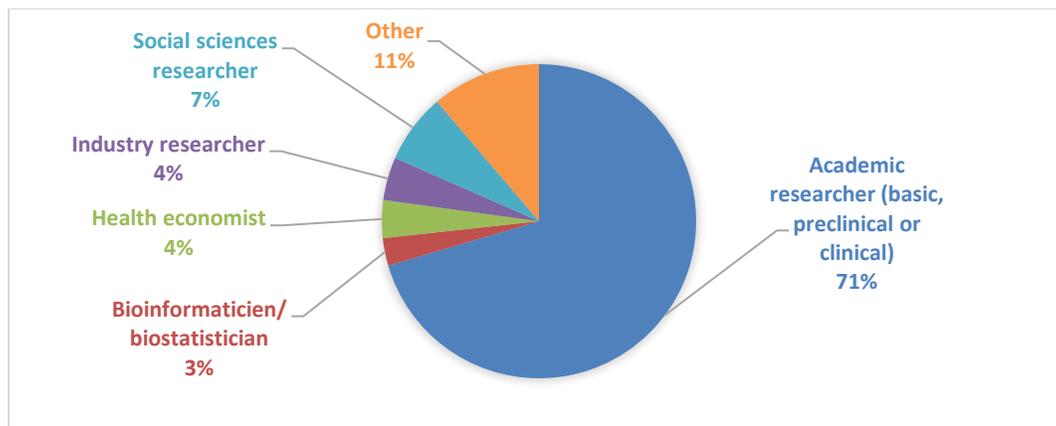


Figure 24: Types of respondents qualifying themselves as working in the field of research.

Education / Communication (n=613):

In this category, teachers represented 53% of respondents (Figure 25). Social workers and administrative education staff were the second most represented sub-categories with each 11% of respondents. The “other” category included other professionals from the education sector, or professions linked to research and communication (publisher, information scientist). The results are globally similar to last survey with an increase in the number of teachers (almost 10 points more this year).

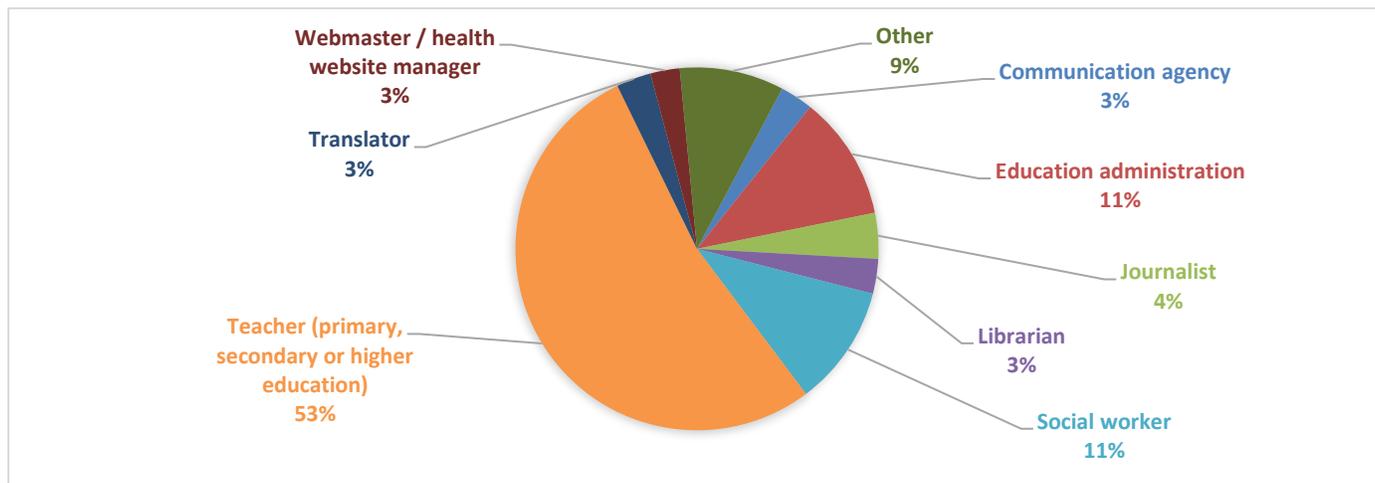


Figure25: Types of respondents qualifying themselves as working in education/communication.

Health care manager / policy maker (n= 167):

In this category, 35% work in health services administration or insurance (public, private or administration) and 32% in hospital administration (Figure 26). The results are globally similar to the last survey with an increase of respondents working in hospital administration (20% in the last survey).

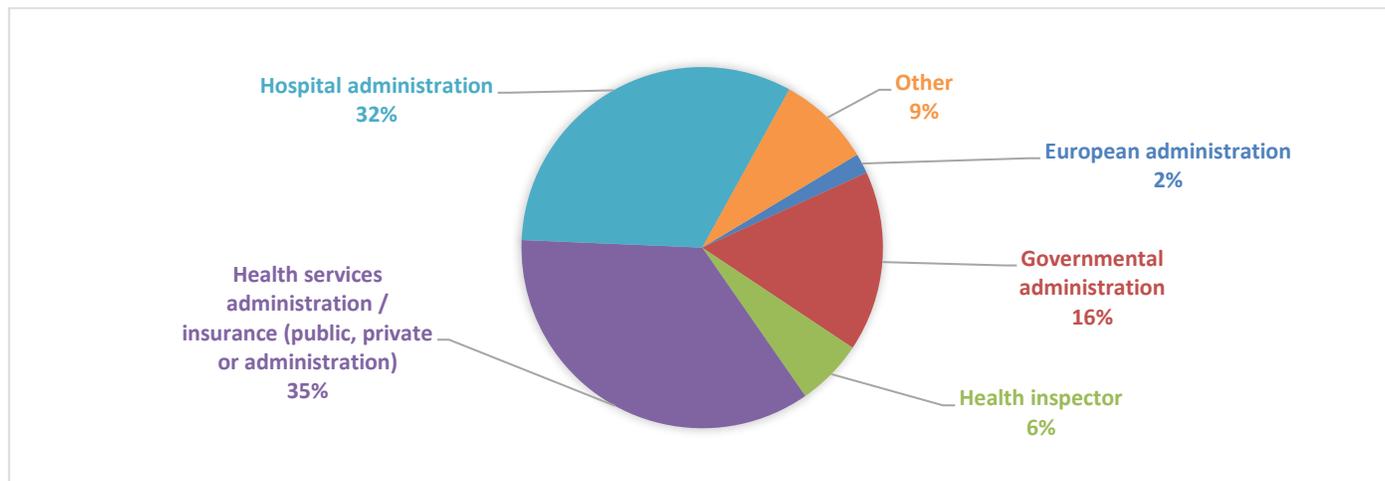


Figure26: Types of respondents qualifying themselves as working in the field of health care management/policy making.

Industry (n=153):

52% of respondents work in the biotechnology or pharmaceutical industry and 26% are consultants in the sector (Figure 27). Compared to the last survey, the percentage of respondents working in the biotechnology and pharmaceutical sectors increased by 15 % while the percentage of consultants in industry decreased by 19 %.

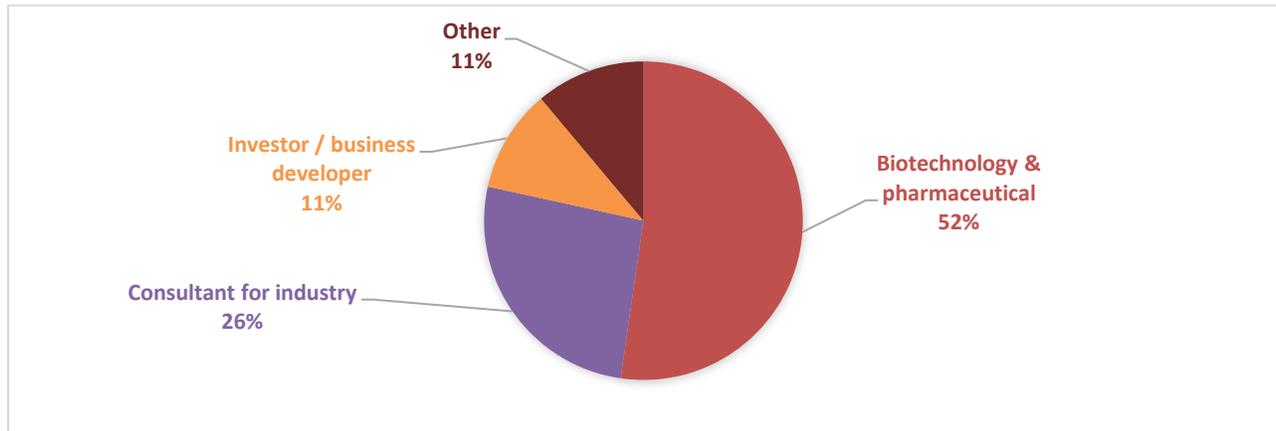


Figure 27: Types of respondents qualifying themselves as working in the biotechnology or pharmaceutical industry

Question 14: Do you have expertise in rare diseases ?

Respondents were also asked if they had an expertise in the field of rare diseases. An answer was not required and 11103 respondents replied to this question, i.e. 77% of the total respondents.



Figure28 : Repartition of respondents considering having an expertise in rare disease.

41% responded that they had expertise in this field, of which 55% belong to the Healthcare professionals category and 27% of the Patient / Family / Patient organisation category. These results are similar to those of last year.

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