Orphanet Report Series

Reports collection

2021

2021 User Satisfaction Survey of the Orphanet Website

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RD ACTION
DATA AND POLICIES FOR RARE DISEASES

Co-funded by
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METHODOLOGY

This year's satisfaction survey was conducted in one phase launched in January 2021 via a popup window appearing on 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 composed 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 12,436 users gave answers to the questions this year. This is a little less than last year (14,463 respondents) but still allows us to detect trends.

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 respondants for each question 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. 12,436 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 was the second source of discovery of Orphanet (13%).
The other vectors cited by users include scientific literature, rare disease related events and websites of patient organisations or hospitals and Wikipedia.

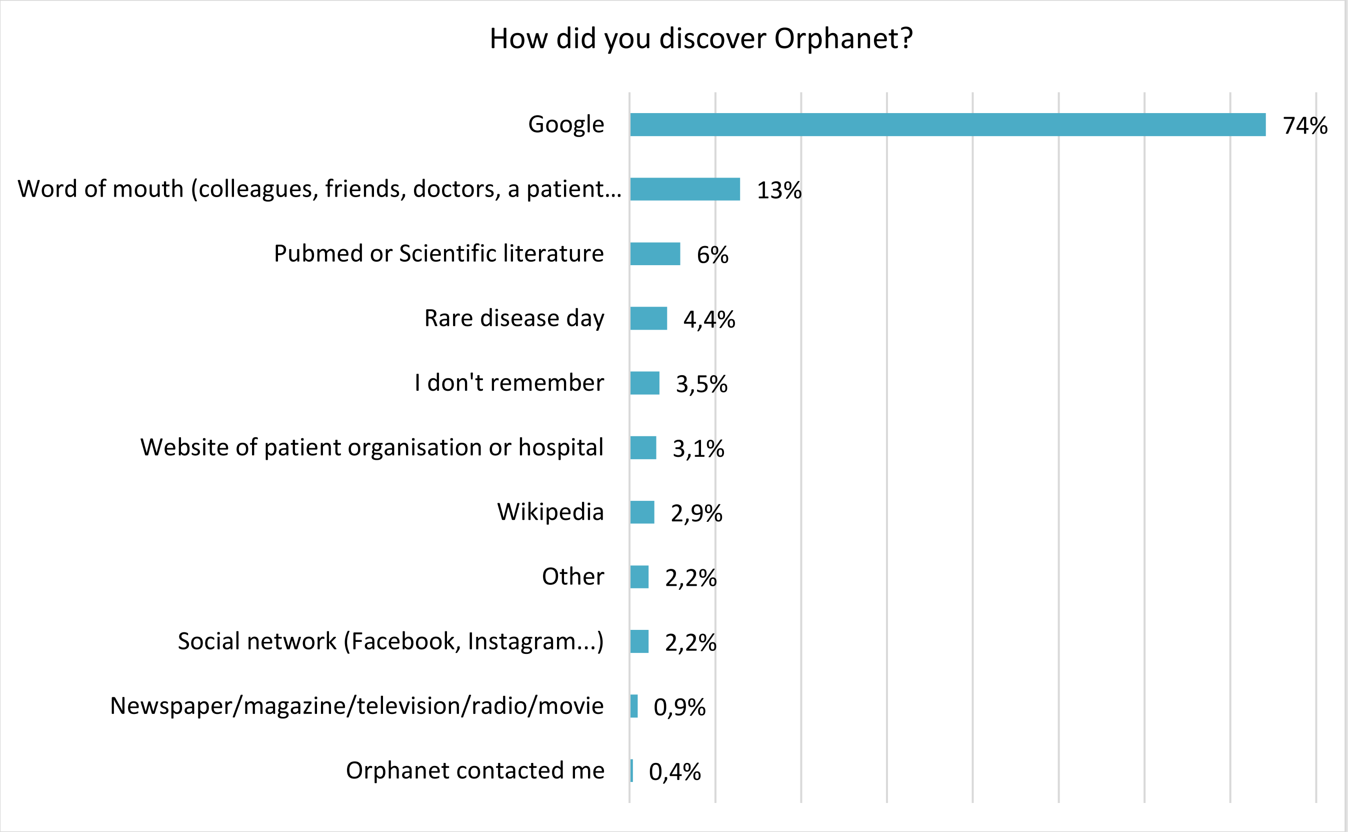

Figure 1: Mode of discovery of Orphanet by respondents (n=12436)

Compared to last year, these results are the same : access through Google is still the major way to discover Orphanet and the percentage of discovery by word of mouth is identical. The access via scientific literature, which had increased significantly last year, has remained at the same level. 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.

For those who choose “Other”, the majority of users have discovered Orphanet during their studies or work. The second method of discovery is through a search engine other than Google. This vector has increased compared to last year (27% vs 18%).

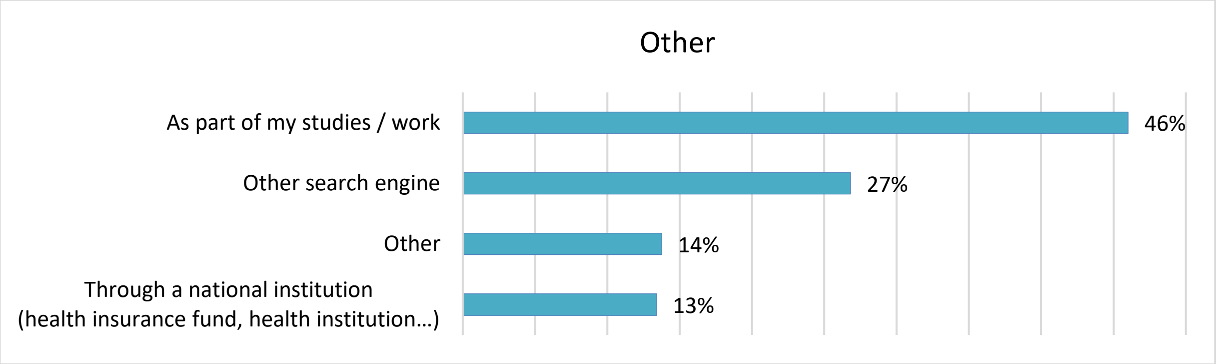

Figure 2: Mode of discovery of Orphanet by respondents who chose “Other” (n=276)

In conclusion, these results show that web search engines are, by far, the main way of discovering Orphanet (75%).

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. 12,436 respondents replied to this question, i.e. all of the respondents.

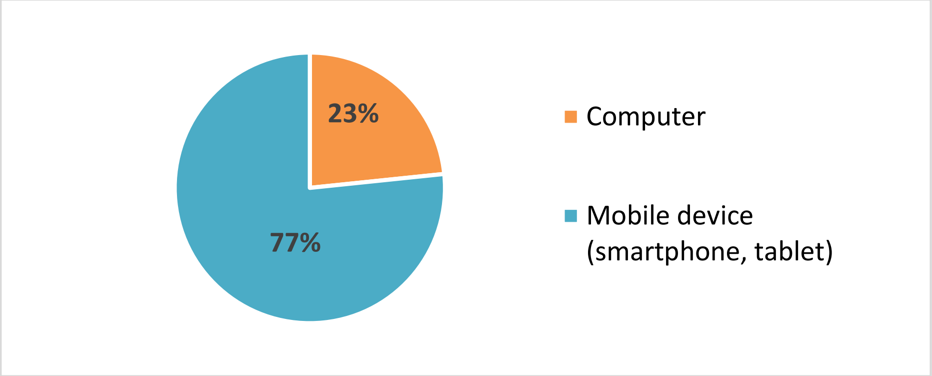

Figure 3: Mode of accessing Orphanet by respondents (n=12436)

77% of respondents accessed to Orphanet using a mobile device with an Internet connection (Figure 3). This result is the same as last year’s survey and continues to confirm 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. 12,436 respondents replied to this question, i.e. all of the respondents.

Around 57% were visiting Orphanet for the first time whereas 43% of those answering the survey are regular users (Figure 4).

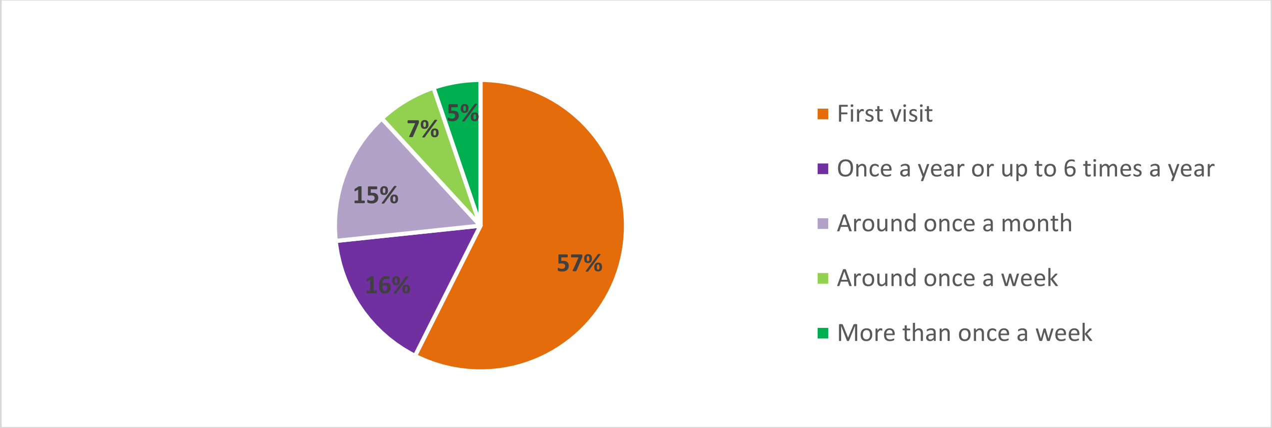

Figure 4 : Visiting frequency of respondents (n=12436)

There were still more first time users this year compared to the last survey (57% compared to 53%). On the other hand, there is a decrease in very regular users (≥ once a week): around 12% this year compared to 20% in the last survey. Moderately regular users (several times a year) have slightly increased (31% compared to 29% last year).
This trend is slightly different from last year but keeps showing us 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 and in the years before.

Question 4: Why do you usually consult Orphanet?

This question aims to determine what type of information visitors usually look for on Orphanet. It was possible to select several categories (this explain why the total percentage of answers is greater than 100%) but the answer was not required. 5,039 respondents replied to this question, i.e. 40.5% of the total respondents.

The top three categories of reasons are (Figure 5):

- learn more about a rare disease by reading its disease summary text (60% of the respondents);
- find the clinical signs associated with a rare disease (54%);
- learn about rare diseases in general (53%).

This top three is the same than last year.

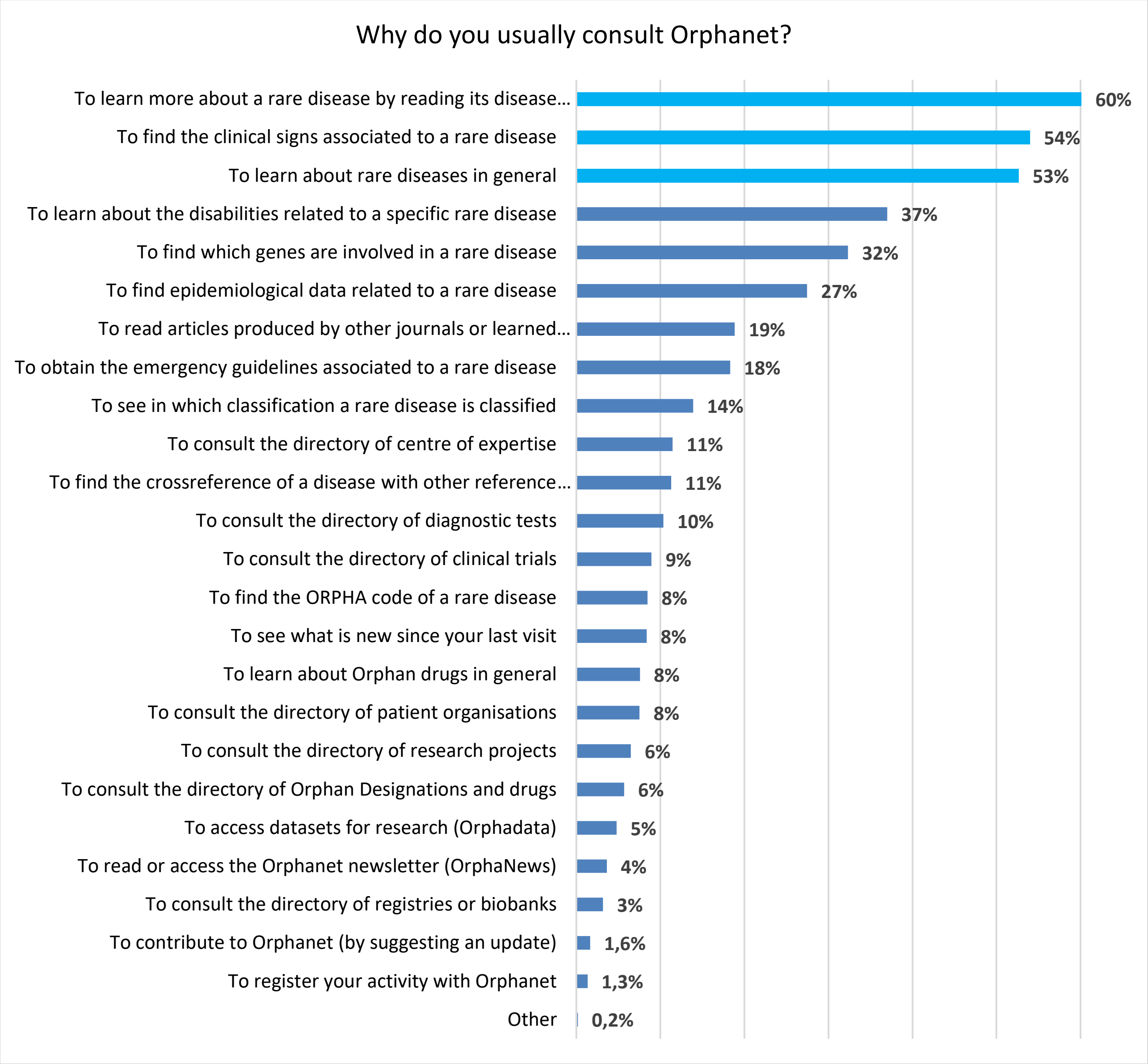

Figure 5: Information sought usually by respondents during their connection to Orphanet (n=5039). Visitors who answered "Other" and specified they had consulted Orphanet as a patient with a rare disease / member of the family / friend (n= 31) were reassigned to the category "To learn more about a rare disease", those who specified having consulted Orphanet for studies or for work (n= 49) were reassigned in the category "To learn about rare disease in general".

Our visitors also usually look for information about the disabilities related to a specific rare disease (37%), to find which genes are involved in a rare disease (32%), to find epidemiological data related to a rare disease (27%), to read articles produced by other journals or learned societies on a rare disease (19%) and to obtain the emergency guidelines associated with a rare disease (18%).

Regarding directories offered by Orphanet, the directory of centres of expertise is the most consulted usually (11%), then the directory of diagnostic tests (10%).

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. It was possible to select several categories (which is why the total is greater than 100%) but an answer was not required. 6434 respondents replied to this question, i.e. 52% of the total respondents.

The results show a majority of visitors consult Orphanet to learn about rare diseases in general (46%). This can be explained by the fact that 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 the same as in the last survey: information on rare diseases in general (46%), information on a specific disease (35%), and information about clinical signs associated to a rare disease (19%) (Figure 6).

Our visitors also look for information on disabilities related to a specific rare disease (14%) and for genes involved in a rare disease (10%). These are the same results as the last survey and show 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 usually consulted.

Visitors who answered “Other” specified consulting Orphanet to search professional experts and contact details or a diagnostic assistance, and some specify they came across the site by chance / curiosity.

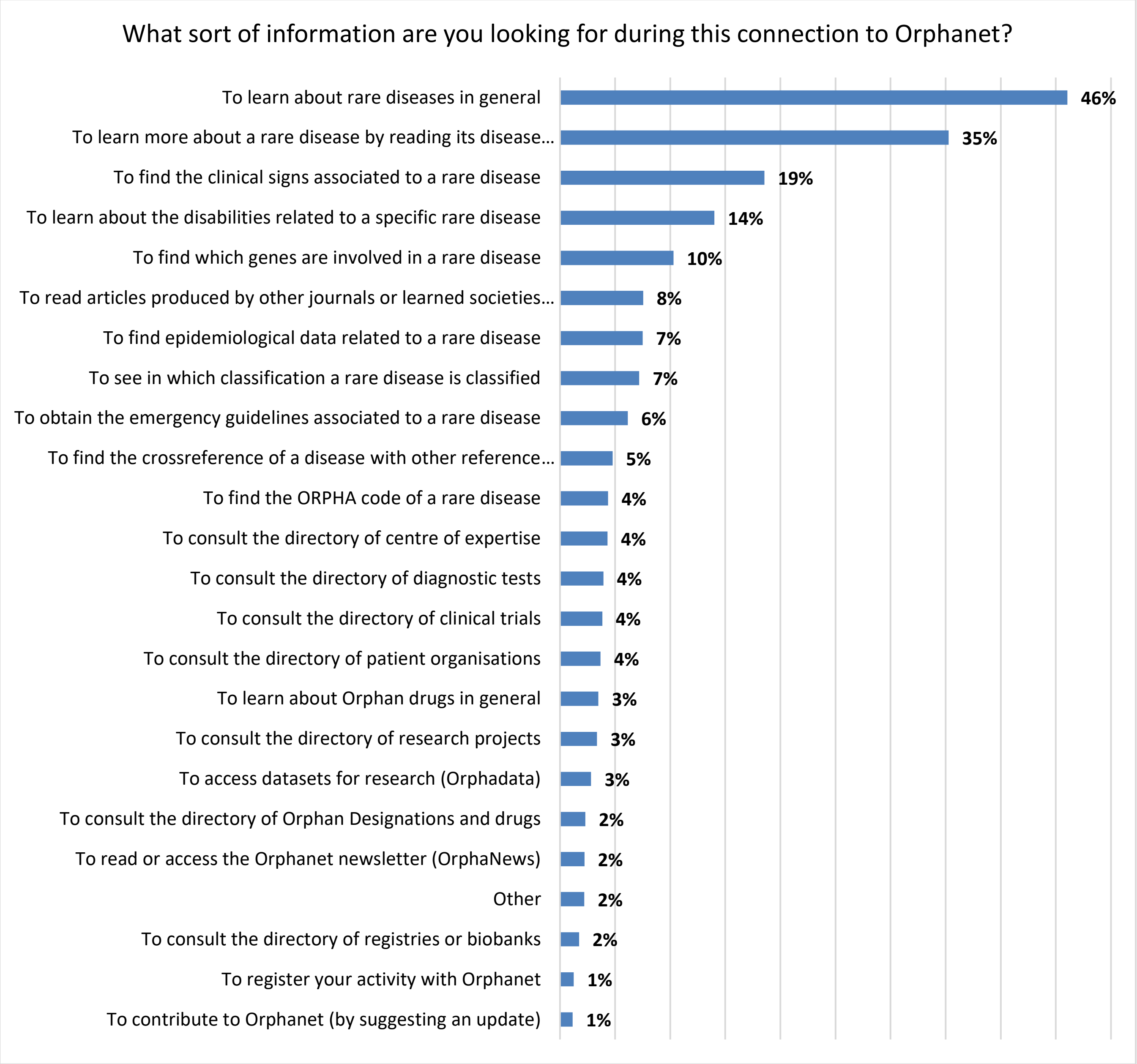

Figure 6 : Information sought by respondents during their connection to Orphanet (n=6434).
Visitors who answered "Other" and specified they had consulted Orphanet as a patient with a rare disease / member of the family / friend (n=47) were reassigned to the category "To learn more about a rare disease", those who specified having consulted Orphanet for studies or for work (n=35) were reassigned in the category "To learn about rare disease in general".

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 be 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 how users consider Orphanet website. Respondents were asked to rate (++, +, -, --), to what degree the website is user friendly, easy to use and if the information found was easily understandable.

Respondents were asked to provide answers concerning the three statements but an answer was not required for all statements. 4,891 respondents replied to this question, i.e. 39.5% of the total respondents and almost the total of regular users (43%; question 3).

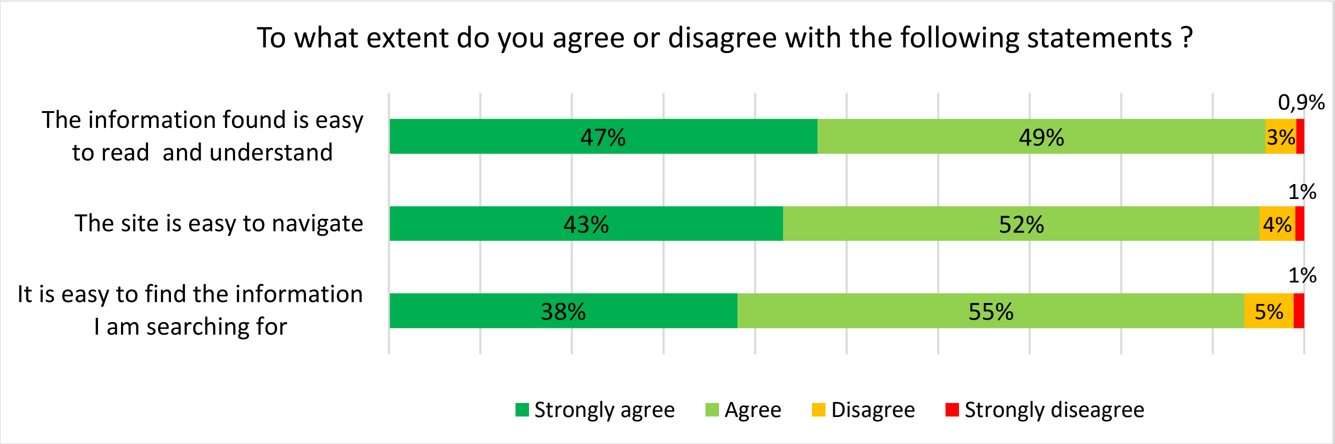

Figure 7: Repartition of the respondents rate on the ease to use the Orphanet website and to understand the information found (n=4891)

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 7). A minority of respondents (4 to 6%) disagree or strongly disagree with these statements.

These results should, however, be considered in relation to questions 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 continue its 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.
An answer was not required and 4,769 respondents replied to this question, i.e. 38.5% of the total respondents and almost the total of respondents in the regular users category (43%; question 3).

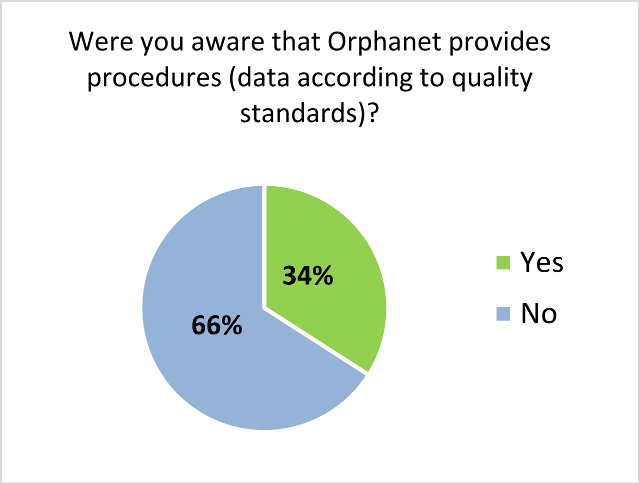

Figure 8 : Repartition of the respondents about knowledge of Orphanet procedures (n=4769)

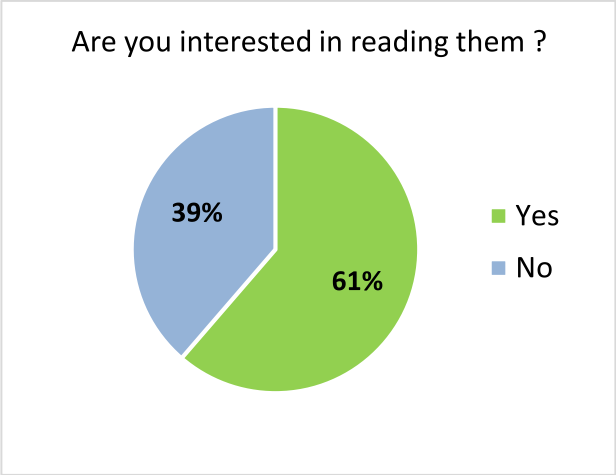

Figure 9: Repartition of the respondents interested in reading Orphanet procedures (n=4769)

As last year, the majority of respondents (66%) did not know of the existence of these procedures (Figure 8) but 61% are interested in reading them (Figure 9).
This indicates that we should increase the visibility of these procedures on the website. Since last year, Orphanet improved the visibility of its procedures by creating a dedicated page for these procedures. This page is visible in the main menu (https://www.orpha.net/consor/cgi-bin/Education_Procedure.php?lng=EN). Moreoever, Orphanet implemented these procedures to each search page. However, results of this survey indicates that Orphanet should keep trying to improve the visibility of these documents

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 for all services / products and 4,093 respondents replied to this question, i.e. 33% of the total respondents (the total of regular users being 43%).

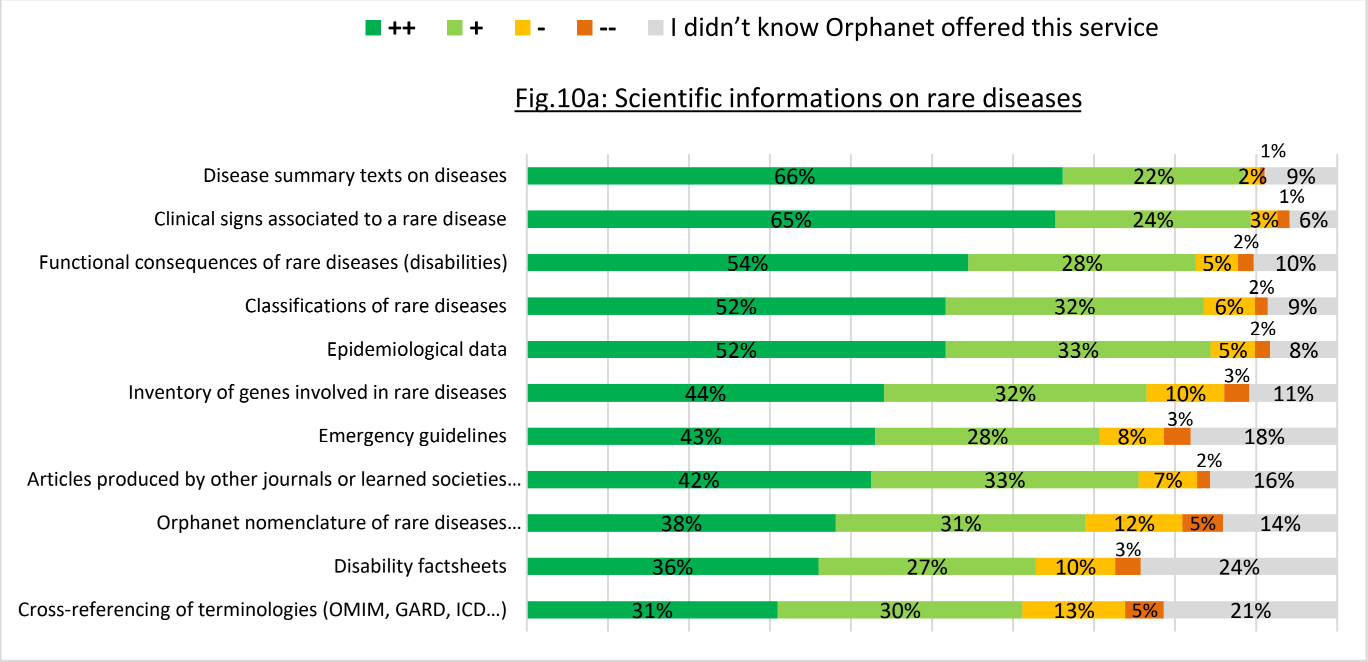
Fig.10a: Scientific informations on rare diseases

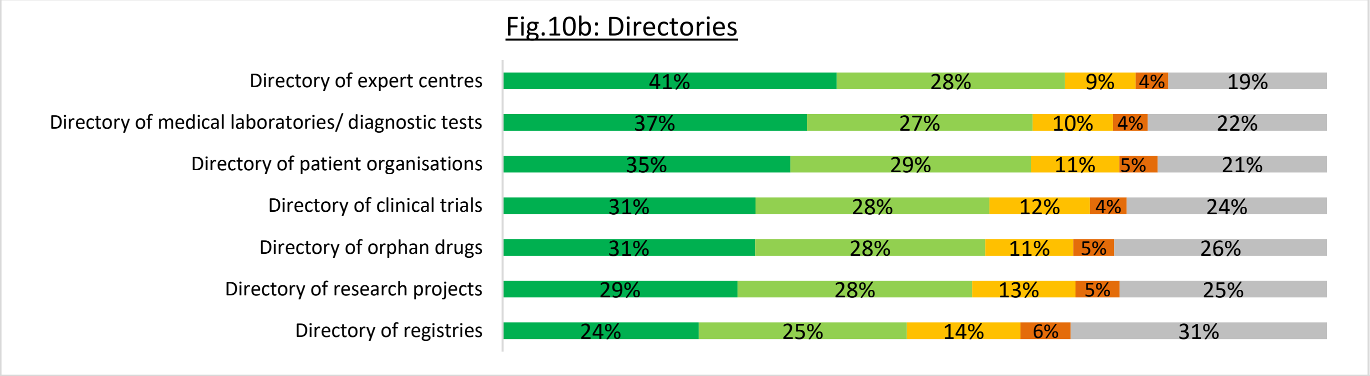
Fig.10b: Directories

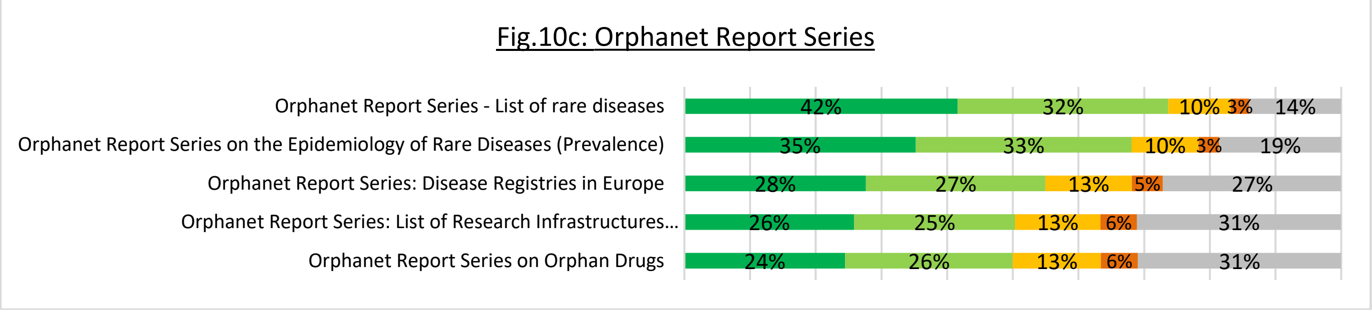
Fig.10c: Orphanet Report Series

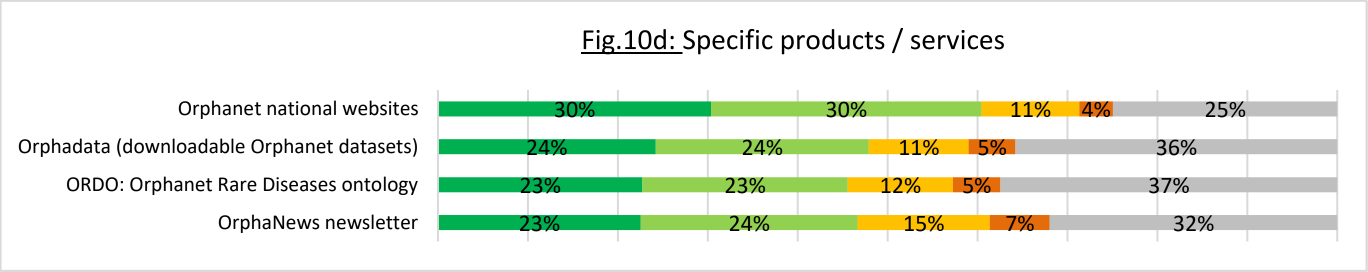
Fig.10d: Specific products / services

Figure 10: Repartition of the respondents rate on utility and or knowledge of services/products offered by Orphanet (n=4093)

Services and products giving scientific information on rare diseases (summary texts, clinical signs, epidemiological data, disabilities,…) are the best known to Orphanet users (Figure 10a).The most useful products for the respondents are the disease summary texts and clinical signs associated with a rare disease (respectively 87% and 89%) followed by functional consequences of rare diseases (disabilities, 72%), classifications of rare diseases and epidemiological data (respectively 84% and 85%). This trend is the same as last year. The inventory of genes involved in rare diseases, emergency guidelines and articles produced by other journals and published on the Orphanet website are also very useful services for about 75% of the respondents followed by the Orphanet nomenclature of rare diseases / ORPHAcodes (at around 70%). Disability factsheets and cross-referencing of terminologies although less known to respondents (around 20% of Orphanet users didn't know about these services) are still very useful to more than half the respondents. These results make sense as these are services made for particular uses and our users who want to know more about rare diseases are not necessarily looking for this kind of specific information.

The directories of expert resources proposed by Orphanet (Figure 10b) are still unknown of 20% to 30% of the respondents. Services dedicated to research (clinical trials, research projects etc.) are the less known. For known services, the most useful one for our respondents is, as last year, the directory of expert centres (almost 70%). The directory on medical laboratories/ diagnostic tests and the one on patient organisations are judged useful for about 65% of our respondents.

Orphanet also offers different "Report Series" (Figure 10c). The Orphanet Report Series presenting the list of rare diseases is the best known and most useful for our users (almost 75%) followed by the Orphanet Report Series on the Epidemiology of Rare Diseases, same as last year. The Orphanet Report Series on Registries, Orphan Drugs and Research Infrastructures are not well known to our users (around 30%). Orphanet should therefore increase the visibility of these products.

Concerning the specific products and services (Figure 10d) provided by Orphanet, the vast majority of respondents do not know or do not use them. Orphadata (which provides access to aggregated data from Orphanet) and Orphanet Rare Disease Ontology (ORDO) are the least known products for Orphanet website visitors (~35%) . This might be explained by the fact that these services have their own website in addition of the one provided in Orphanet website. Thus people using these services do not come to the Orphanet website to find them but might go directly to the dedicated website. Moreover, people visiting the Orphanet website are looking for information on a disease in particular or on rare diseases in general, and their primary interest is not finding aggregated data. The same applies to Orphanet national websites as they are not highlighted on the Orphanet site and have their own access.

Depending on the service/product considered, up to 15% of respondents do not find them useful for their needs. These results should, however, be considered in the light of the results of question 9 and 11, where we asked how satisfied are they and what Orphanet could do to better serve its users : it emerges from these questions that a more up-to-date and detailed information would be more useful for some users. Concerning the unknown services/products, results of questions 9 and 11 indicate that a more user-friendly site might lead to a better knowledge of the panels of products and services Orphanet offers.

Overall, these results show that services/products offered by Orphanet are more useful than not for the respondents. However, Orphanet should take action to make other products better known to Orphanet website users.

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

The global satisfaction of Orphanet website users was evaluated through this question. The question was not mandatory and 4,018 respondents replied to this question, i.e. 32% of the total respondents. 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 our users think of Orphanet and were provided by 471 individuals.

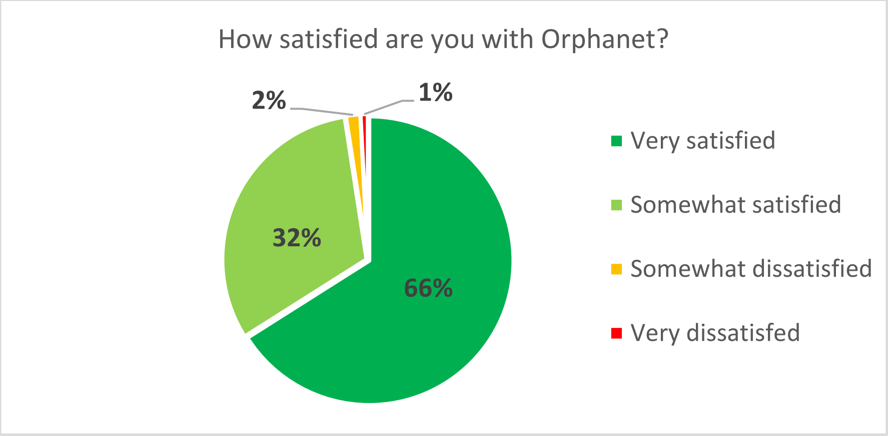

Figure 11: Global satisfaction of the Orphanet website users (n= 4018)

The vast majority of respondents were either very satisfied or satisfied with Orphanet with a total of 98% responding positively (Figure 11), almost the same result than in the last survey (97%, n=5,262).

The free comment field helped us to understand the reasons for satisfaction or dissatisfaction (Figure 12):

- Among the 98% very satisfied or satisfied users, 52% considered that information provided by Orphanet is useful and accurate and 16% that information is easy to access, showing the same trend than last year.
- 2% of respondents were dissatisfied and 1% were very dissatisfied. The main free comments explained that the website is not user-friendly and that the information is not detailed enough and not updated frequently enough.

These results are in adequation with the results obtained in question 6, where we interrogated our users on the ease to use the Orphanet website and how easy it is to understand the information found in it.

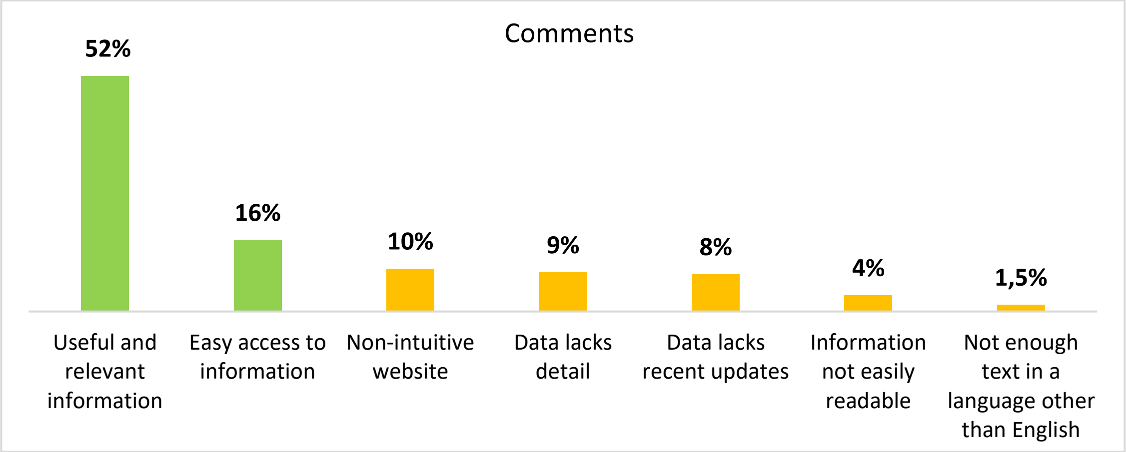

Figure 12: Free comments of the Orphanet website users (n= 471)

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.

An answer was not required and 4,039 respondents replied to this question, i.e. 32.5% of the total respondents.

Almost 63% of those responding turned out to be promoters as they responded with a score of 9 or 10, 28% were passive (score of 7 or 8) and 9% were detractors (score of 0 to 6). This gives a NPS of 53,2 (Figure 13).

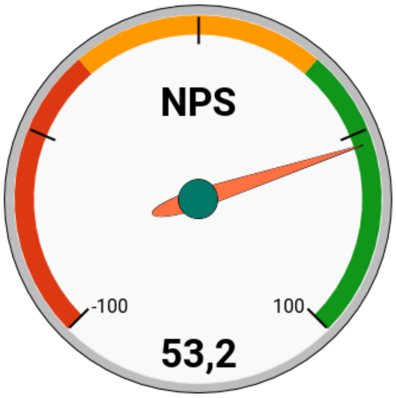

Figure 13: Orphanet Net Promoter Score (NPS) (n= 4039)

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 is not very different than last year (54,3, n=5,299) but had greatly increased compared to 2019 (47,8, n=4,199).

It is noteworthy that according to these results 62.5% of the respondents would recommend using Orphanet while only 9% would not.

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

Comments were provided by 764 individuals in response to this question, i.e. 6% of the total respondents.

Around 27% 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 14).

The most frequent comments relate to the need for more detailed information (25%), a more ergonomic website (14%) and more regular updates (8%). These comments are in concordance with the answers obtained to question 9 concerning overall satisfaction.

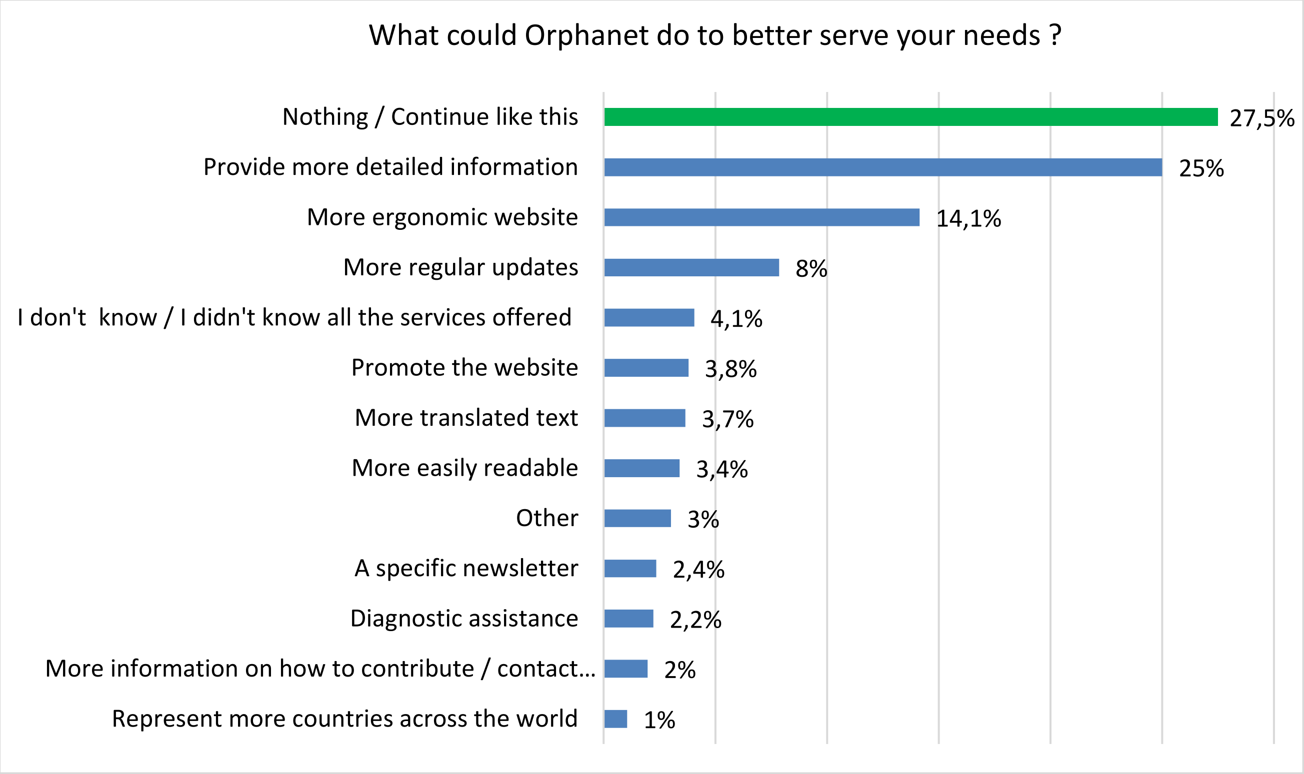

Figure 14: Free comments on what could Orphanet do to better serve your needs (n= 764)

Regarding the need for a more detailed information, Orphanet's users were mainly interested in more detail in clinical signs and symptoms (23%, Figure 15) suggesting that pictures, or medical imagery, could be added to aid diagnosis. Although this suggestion is very interesting, Orphanet is not currently in capacity to respond to this need. Indeed, pictures are subjected to copyright, implementing this suggestion would need a tremendous quantity of work and updating that would have to be carried out to the detriment to Orphanet objectives, that is to produce high quality and validated information on rare diseases.

Another comment was a request to publish clinical cases but Orphanet cannot publish clinical cases as it is not our mission to replace regular peer-reviewed journals which publish case reports.

Some comments concerned the reintroduction of the aid to diagnosis tool (Orphanet-Phenomizer tool) that Orphanet took off-line following feedback from users has this tool was not performant enough. Orphanet is open to collaboration with assistance-to-diagnosis developers in order to give access to available tools.

Users are also mainly interested in more detail about treatment and patient care (20%) suggesting improving the visibility of expert centres and emergency guidelines as well as providing information on alternative medicine for example. This percentage has doubled compared to last year maybe because there is an increase by 5% in the percentage of patients and their entourage, including patient organisations responding to the survey (question 13). It should be noted that Orphanet is continuously publishing best practice guidelines on recommended care when these guidelines exist.

Around 14% of respondents are also interested in more detail in disease summaries and around 12% of Orphanet's users would like more information about sources and bibliography used to produce its data. The way disease summaries are produced are exposed in the procedure "Creation and Update of Disease Summary Texts in English for the Orphanet Encyclopaedia for Professionals" : several articles are used to elaborate a text that is further copmpleted and validated by expert reviewers indicated at the bottom of each summary text.

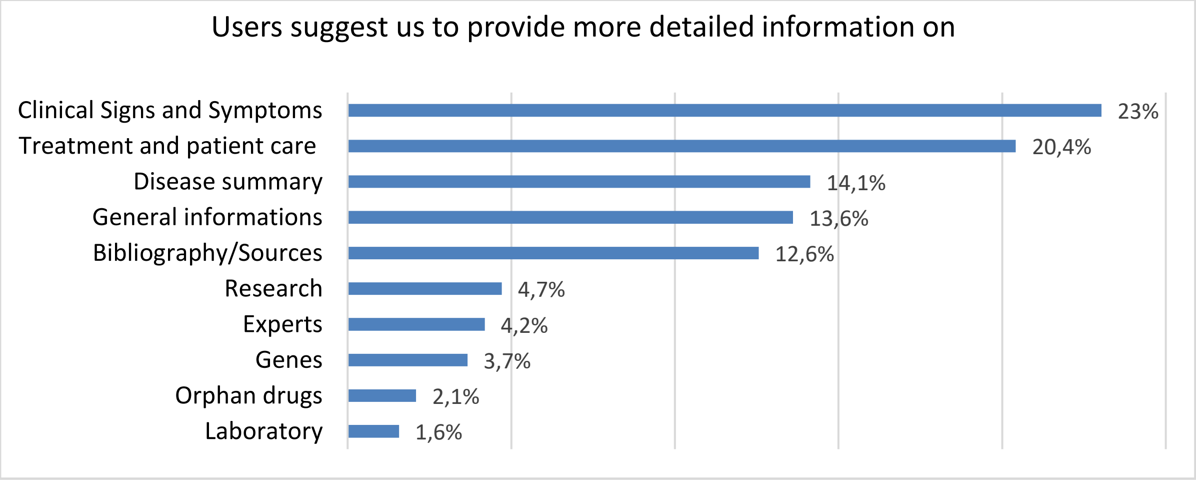

Figure 15: Free comments on what could Orphanet do about more detailed information (n= 191)

Users are also interested about more general information about rare diseases (13%) as health policy and health insurance. Orphanet provides information about rare diseases policies but maybe it is not visible enough on our website or not detailed enough. For example, the Orphanet newsletter, Orphanews, regularly publishes the new policy developments in the Rare Diseases field around the world.

Regarding the need for a more ergonomic website (Figure 16), Orphanet's users comment mainly about the site navigation (29%) the search bar (23%) and the website layout (21%).

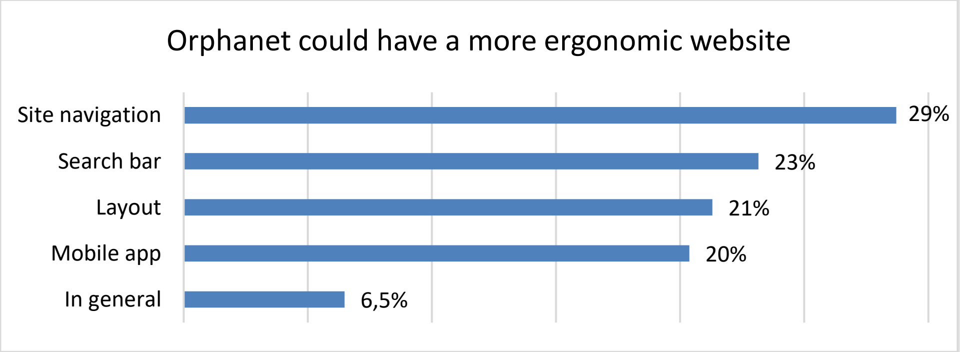

Figure 16: Free comments on what could Orphanet do about the website (n= 108)

As for comments on site navigation, the responses collected showed that some users consider the website is not user-friendly enough, which could explain the few negative answers to the question 6 and that some users find that information is not always easy to find even when you know that it exists. Users expressed the fact that the navigation on Orphanet was too complicated and expressed their wish to have more information on how to navigate and search diseases. It is worth noticing 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 still not visible enough on our website.

Many respondents suggest to improve the search bar that they consider too complex to use as well as the presentation of the data (layout) in this complex database.

Around 20% commented on the mobile app. This no longer exists and respondants expressed their wish to have access to this app again or to have a website more adapted for navigation via a mobile phone. The Orphanet website is responsive by design, we thus think that it is not necessary to duplicate by a mobile app the functionalities of the site for the users browsing on smartphones. On the other hand, we have made the choice to create a new application which is about to be released. It will be called “Orphanet Guides” and will contain the “guidebooks” that need to be consulted offline (the emergency guidelines, the disability factsheets and the guide “Vivre avec une maladie rare en France”).

The third most frequent request is that Orphanet update more frequently its data. This comment has also been expressed in question 9.

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. Moreover, Orphanet conducts an ongoing literature review and is best placed to update other data (scientific nomenclature and annotations) continuously as scientific knowledge evolves.

Concerning the updates of the expert resources (expert centres, patient organisations, medical laboratories and their associated diagnostics test, research projects, clinical trials and registries), Orphanet continues to be dependent on the good will of the professionals as they are the only ones that can update their 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 9,695 respondents replied to this question, i.e. 78% of the total respondents.

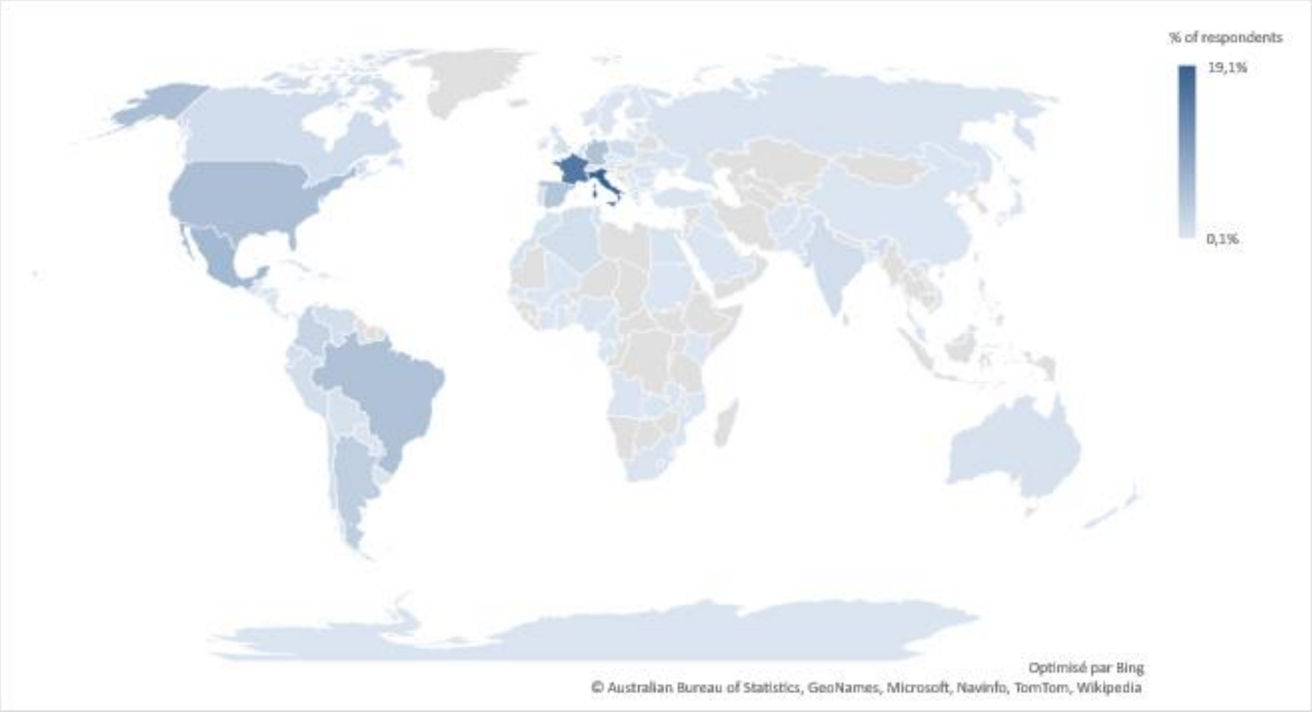

Figure 17: respondents countries replying to the satisfaction survey (n=9695)

The top ten countries replying to the survey were: Italy (n=1856), France (n=1515), Mexico (n=631), United States of America (n=548), Brazil (n=508), Germany (n=502), Spain (n=439), Argentina (n=323), Colombia (n=250), and Belgium (n=191).
This is the same top 10 countries as in the last survey with slightly different proportions.

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.
It was possible to select several categories but an answer was not required. 9,695 replies were registered for this question, i.e. 78% of the total respondents.
Figure 18 shows the distribution of respondents amongst these categories:

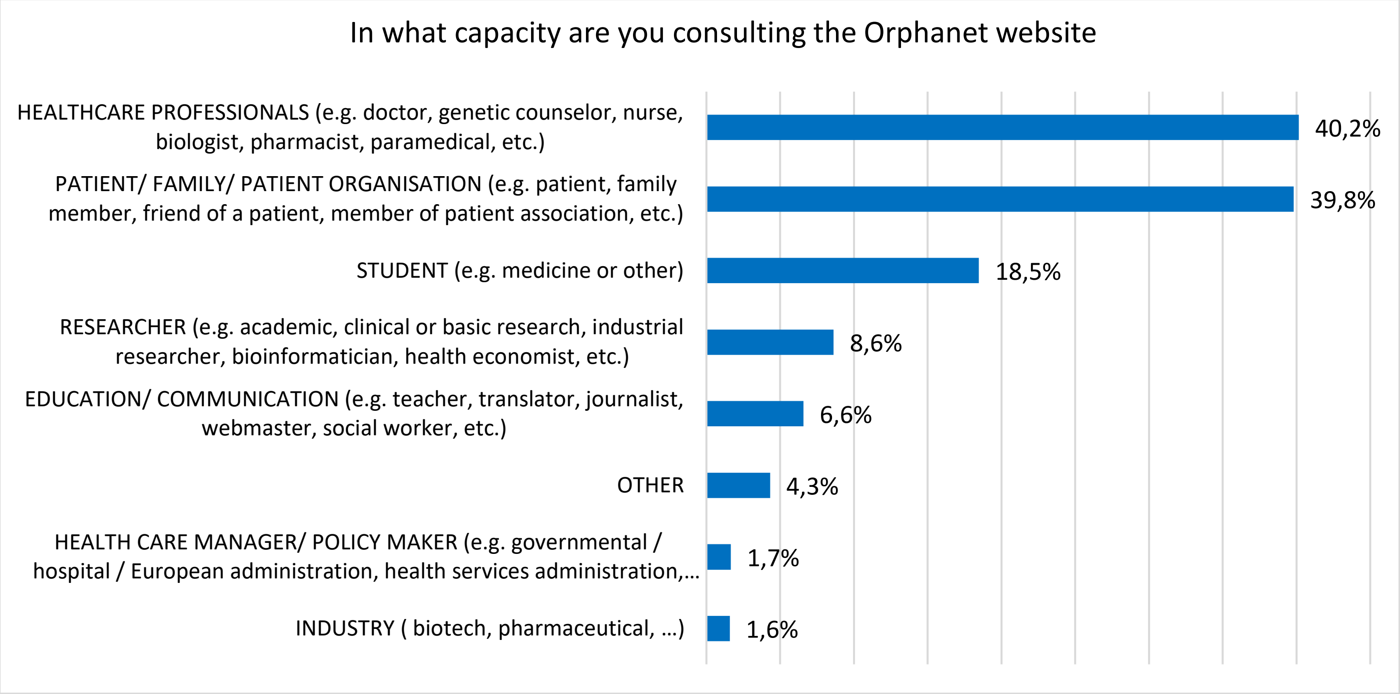

Figure 18: Types of Orphanet user (n =9695)

The largest categories of respondents are healthcare professionals and patients and their entourage, including patient organisations (around 40% for the 2 categories). Many students also replied the survey (18.5%), followed by reseachers and users working in education / communication.

Around 60% of the "other" category was composed of those visiting the site for their general knowledge or curiosity (n=244). The rest of this category included those who did a personal research and who did not state their professional category.

Compared to last year, we obtained the same result for healthcare professionals. But there is an increase by 5% in the percentage of patients and their entourage, including patient organisations responding to the survey (35% last survey). The percentage of students responding to the survey has a little less decreased than last year (21%).

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= 3;886):

Hospital or independent specialists represent by far the main category of respondents (49%) (Figure 19). All together with general practitiners, 66% are medical doctors (compared to 61% in the last survey).
14% of the respondents belong to other healthcare professional categories (e.g. midwife, psychologists, physiotherapists, dentists, paramedical, etc...), which represents a slight decline compared to last survey (17%).
Other professional categories remain equally represented compared to last year.

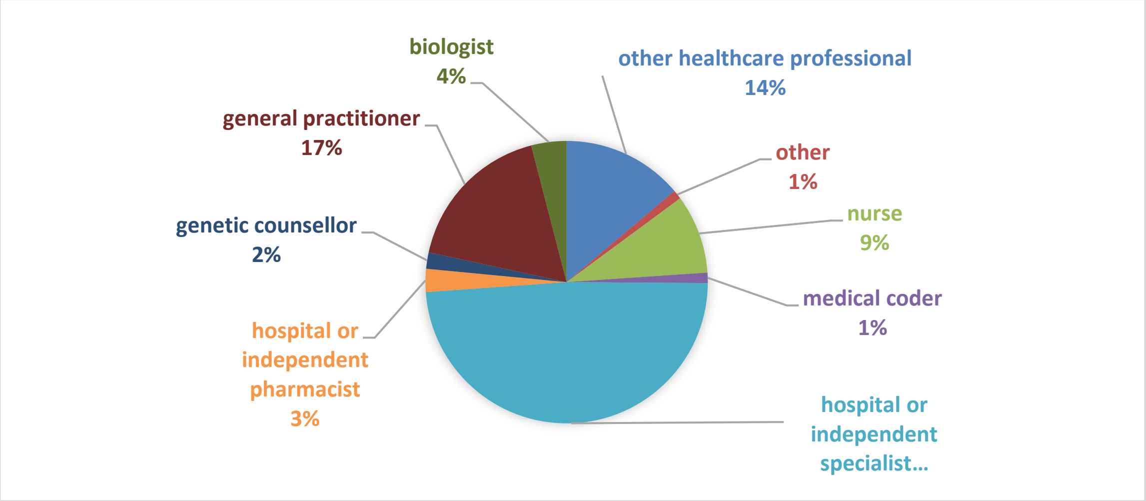

Figure 19: Types of respondents qualifying themselves as health professionals

Patient / Family / Patient organisation (n= 3,854):

Most of the people who selected this category are patients (47%) or family members of a patient with a rare disease (41%) (Figure 20). There is an increase of patients compared to the last year (42%) but the other results are globally similar to those of the previous survey.

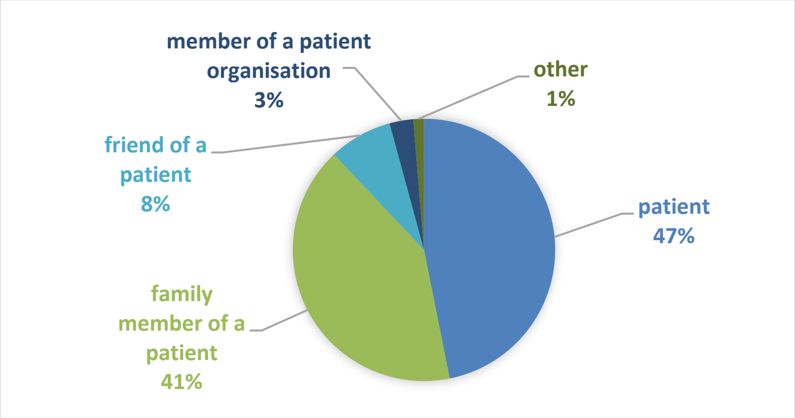

Figure 20: Types of respondents qualifying themselves as a patient, part of a patient's entourage or member of a patient organisation.

Students (n= 1,798):

Medical students represent 62% of this category (Figure 21). 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 (38% this year compared to 32% last one).

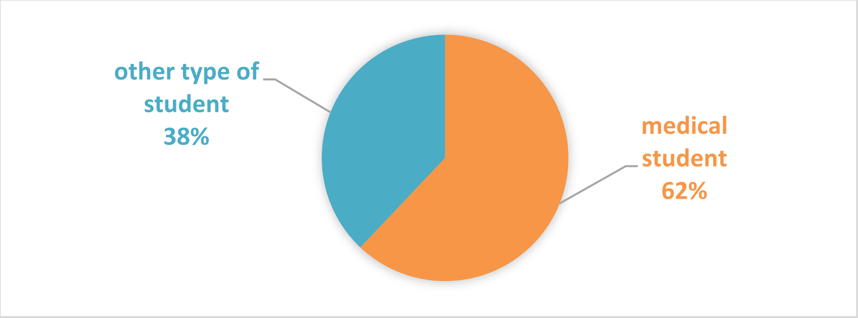

Figure21: Types of respondents qualifying themselves as students

Researchers (n= 828):

Academic researchers represent 72% of respondents of the research category (Figure 22) which is the same percentage than last year. The percentage of social science researchers that responded to this survey increased a little compared to last year (9% compared to 7% in the last survey) as did the percentage of industry researchers (7% this year, 4% in the last survey).

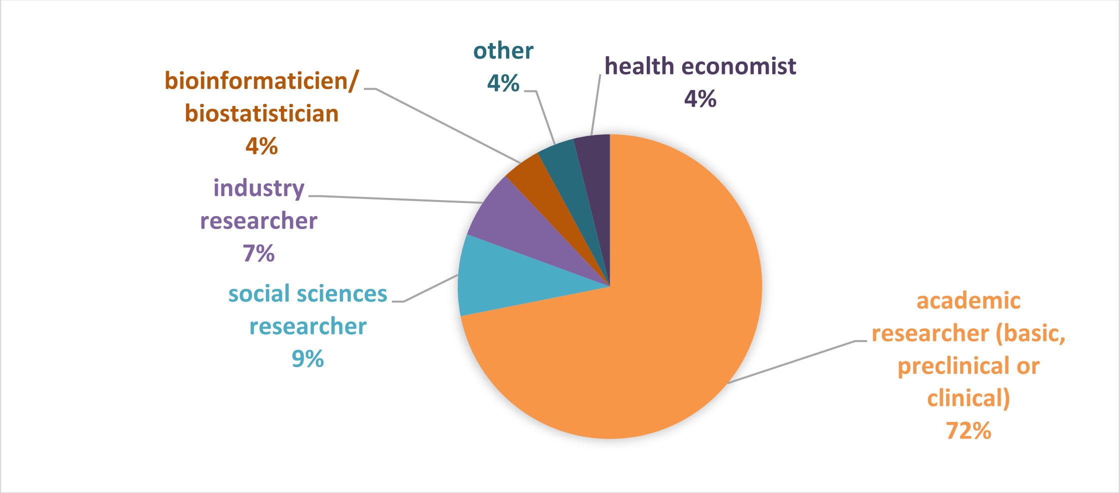

Figure 22: Types of respondents qualifying themselves as working in the field of research.

Education / Communication (n=637):

In this category, teachers represented 54% of respondents (Figure 23). Social workers and administrative education staff were the second most represented sub-categories with each 11%. 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.

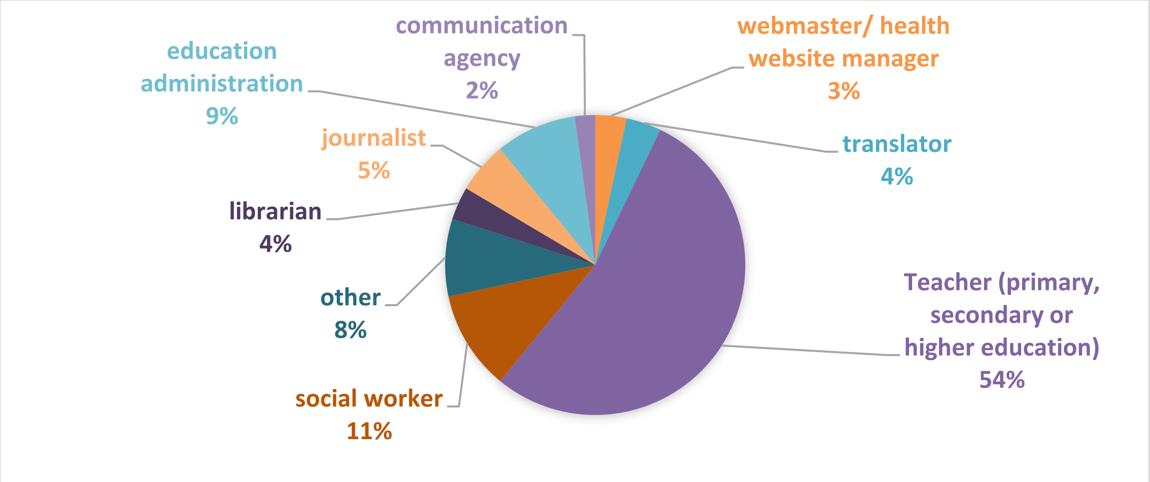

Figure23: Types of respondents qualifying themselves as working in education/communication.

Health care manager / policy maker (n= 159):

In this category, 38% work in health services administration or insurance (public, private or administration) and 25% in hospital administration (Figure 24). There is a decrease of respondents working in hospital administration (32% in the last survey) and an increase of respondents working in European administration (2% last year).

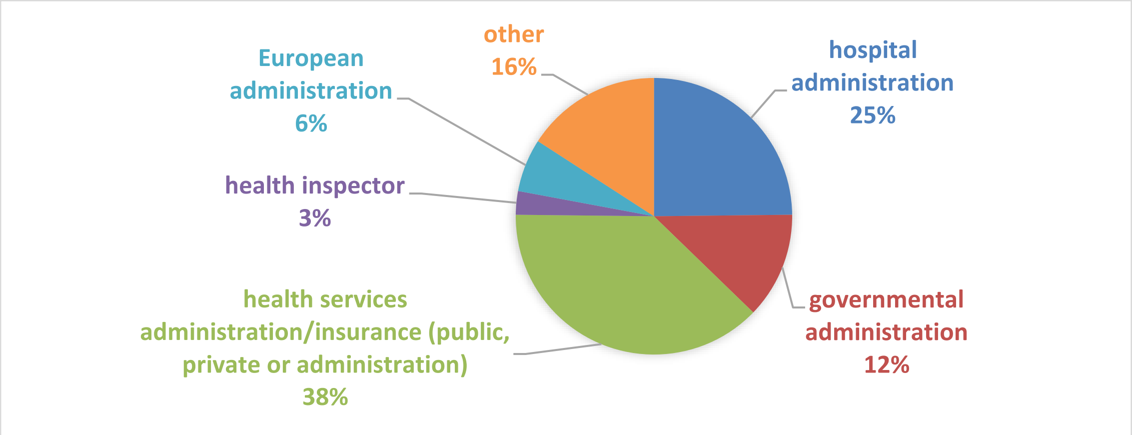

Figure24: Types of respondents qualifying themselves as working in the field of health care management/policy making.

Industry (n=152):

48% of respondents work in the biotechnology or pharmaceutical industry and 26% are consultants in the sector (Figure 25). Compared to the last survey, the percentage of respondents working in the biotechnology and pharmaceutical sectors decreased by 4 % while the percentage of investor / business developer increased by 3 %.

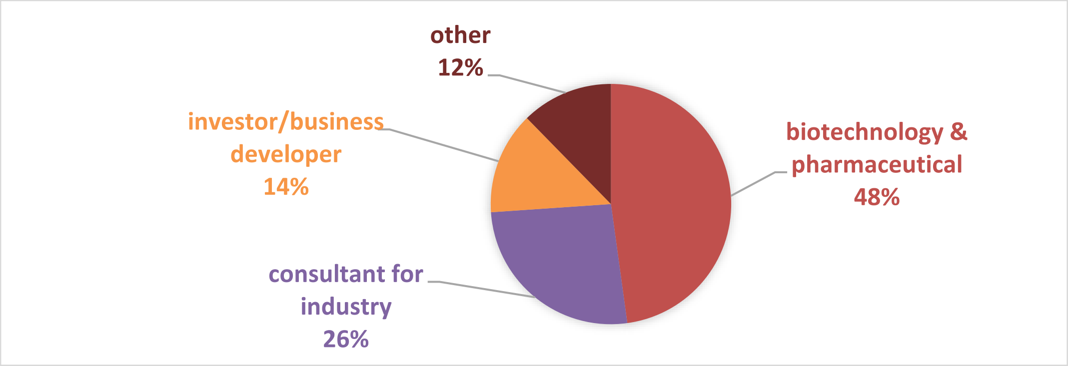

Figure 25: Types of respondents qualifying themselves as working in the biotechnology or pharmaceutical industry

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 9,507 respondents replied to this question, i.e. 76% of the total respondents.

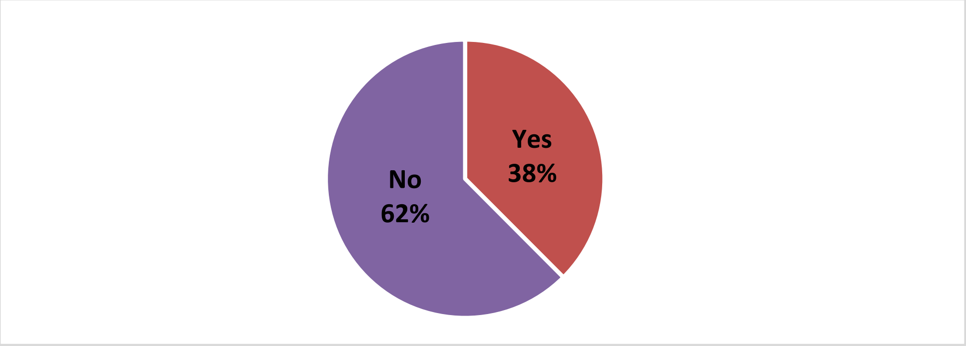

Figure26 : Repartition of respondents considering having a expertise in rare disease (n=9507)

38% responded that they had expertise in this field, of which 52% belong to the healthcare professional category and 37% of the Patient / Family / Patient organisation category.

These results are similar to those of last year apart from the percentage of users responding that they had expertise in rare diseases and belonging to the Patient / Family / Patient organisation category which has significantly increased (27 % last year).

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

Editor-in-chief : Ana Rath– Editors of the report: Florence Sauvage & Charlotte Gueydan
Technical support : Valérie Lanneau
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