2022

2022 User Satisfaction Survey of the Orphanet Website

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RD ACTION
DATA AND POLICIES FOR RARE DISEASES

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METHODOLOGY

This year's satisfaction survey was conducted in one phase launched in January 2022 via a pop-up window appearing on the first page users landed on. The survey was translated in 8 out of 9 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 6 weeks of display on the website. This survey was composed of 13 questions split into 3 sections : Knowledge of and reasons for using the Orphanet website ; Your opinion on Orphanet's products / services and its website ; More information about you.

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 9,389 users gave answers to the questions this year. This is less than last year (12,436 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 respondents 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. 9,389 respondents replied to this question, i.e. all of the respondents.

A large majority of our users (71%) discovered Orphanet via Google (Figure 1), to which we can add the 4% of users who access Orphanet via another search engine, , i.e. 75% of users accessing Orphanet by typing a keyword in a search engine. Word of mouth was the second source of discovery of Orphanet (14%).
The other vectors cited by users include scientific literature, rare disease related events and websites of patient organisations or hospitals and Wikipedia. In the “Other” category, most (65%) said they had discovered Orphanet through their studies or work.

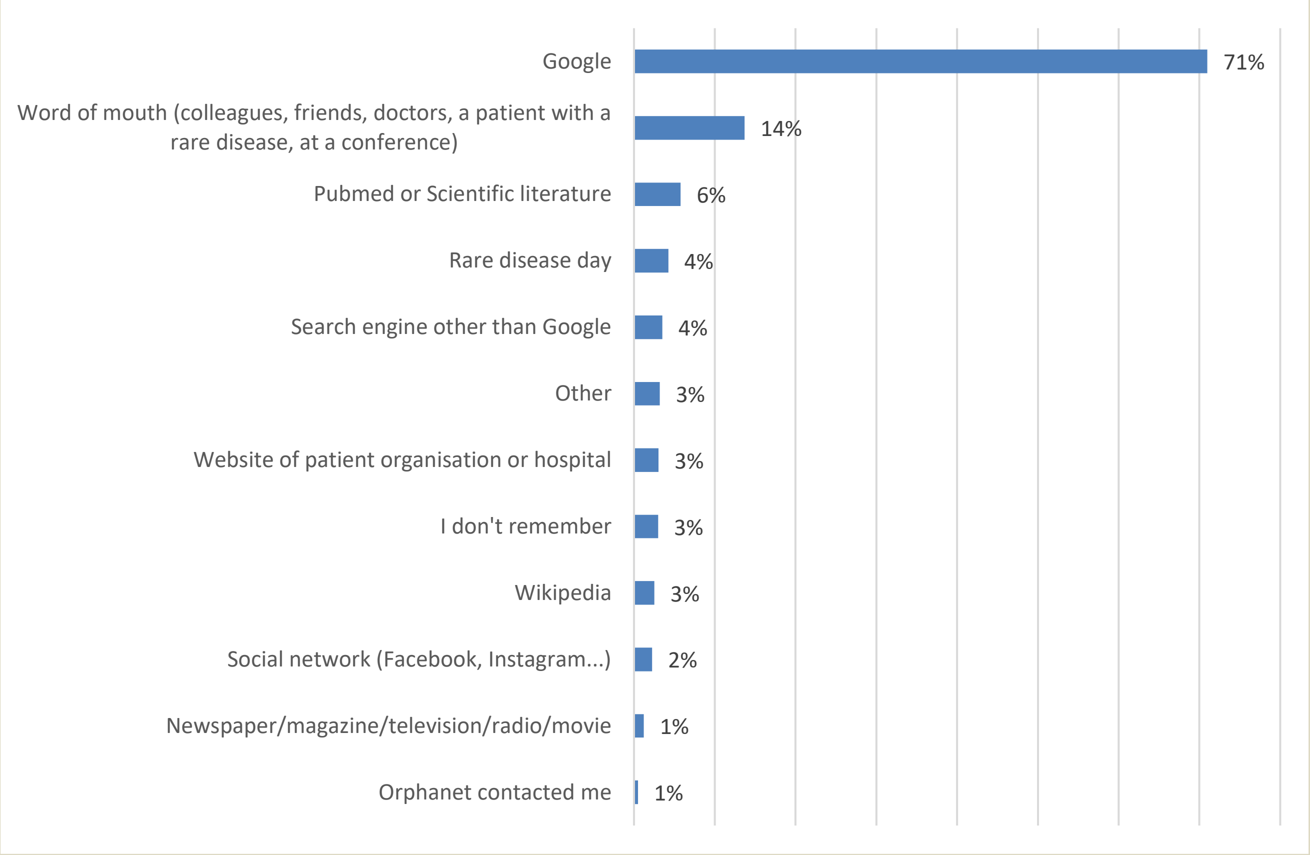

Figure 1: Mode of discovery of Orphanet by respondents (n=9389)

Compared to last year, these results are the same : access through Google or any search engine is still the preponderant way to discover Orphanet and the percentage of discovery by word of mouth is a little higher this year. The access via scientific literature 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 equivalent in all the languages of the survey.

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. 9,389 respondents, i.e. 100%, replied to this question.

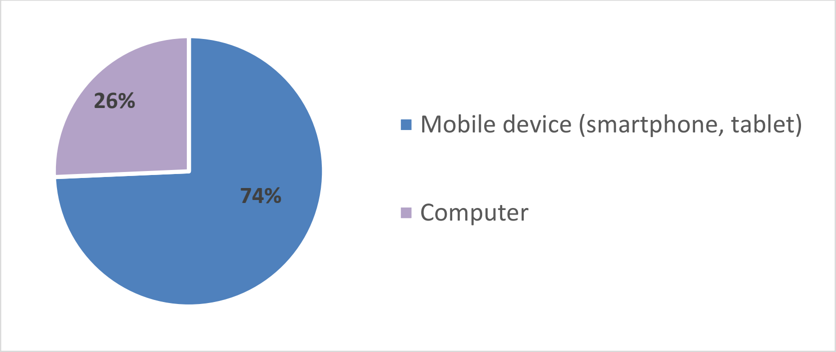

Figure 2: Mode of accessing Orphanet by respondents (n=9389)

74% of respondents accessed to Orphanet using a mobile device with an Internet connection (Figure 2). This result is lower than last year's survey (77%) but still confirms the trend that the majority of 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 easing its use on mobile devices.

Question 3: What sort of information are you looking for when you consult Orphanet?

This question aims to determine which kind of information visitors sought and usually look for on Orphanet. It was possible to select several categories (this explains why the total percentage of answers is greater than 100%) but an answer was not required. 8,465 respondents replied to this question, i.e. 90% of the total respondents.

The results show a majority of visitors consult Orphanet to learn about rare diseases in general (52%). This percentage can be correlated to question 4 which tells us that 49% of respondents are visiting the Orphanet website for the first time; it is probable that first time users are more likely to answer to a survey and mainly research general information compared to regular users.

The 2 main categories of information sought after are to learn more about a rare disease by reading its disease summary text (49%) and to find the clinical signs associated with a rare disease (40%).

This top three is the same than last year (although the question was asked slightly differently).

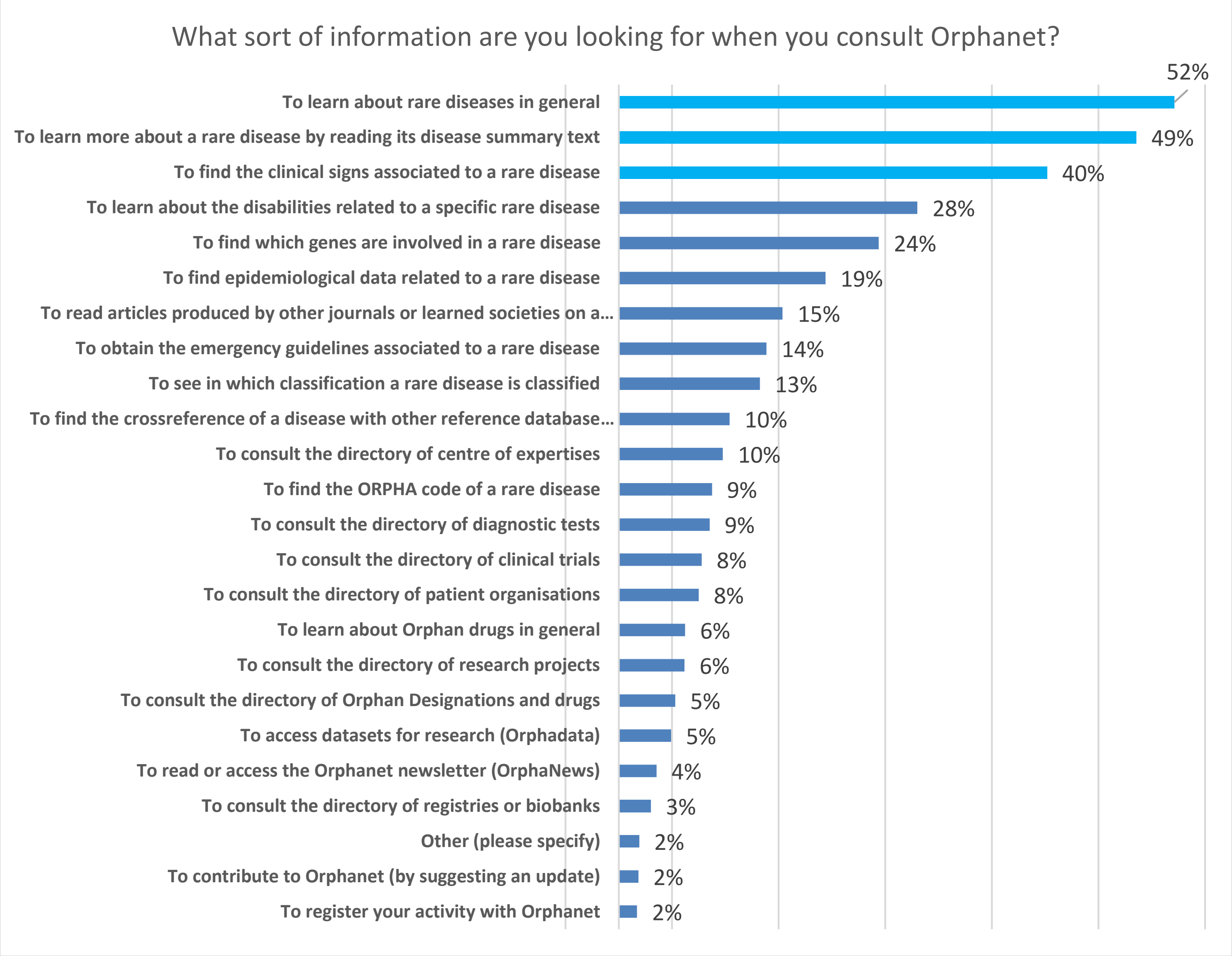

Figure 3 : Information sought by respondents during their connection to Orphanet (n=8465).

Our visitors also usually look for information about the disabilities related to a specific rare disease (28%), to find which genes are involved in a rare disease (24%), to find epidemiological data related to a rare disease (19%), to read articles produced by other journals or learned societies on a rare disease (15%) and to obtain the emergency guidelines associated with a rare disease (14%).

Regarding directories offered by Orphanet, the directory of centres of expertises is the most consulted usually (10%), then the directory of diagnostic tests (9%). They are exactly the same as in last year's survey

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.

Question 4: How often do you visit Orphanet?

Only one response was possible and answer was not required. 8,325 respondents replied to this question, i.e. 89% of the respondents.

Around 49% were visiting Orphanet for the first time whereas 51% of those answering the survey can be considering as regular users (i.e. 4,205 respondents) (Figure 4).

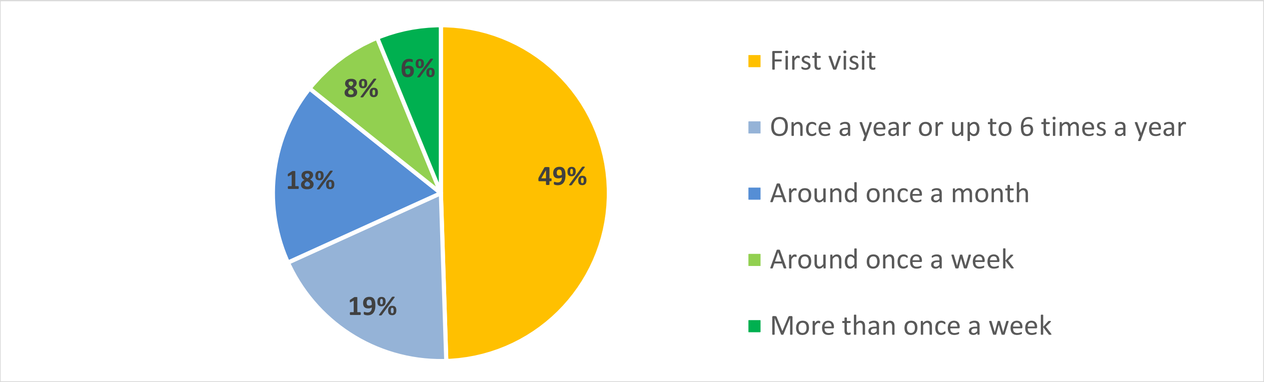

Figure 4 : Visiting frequency of respondents (n=8325)

There are far fewer first users this year compared to the last survey (49% compared to 57% last year).

On the other hand, moderately regular users (several times a year) have increased (37% compared to 31% last year) and there is also a little increase in frequent users (≥ once a week): around 14% this year compared to 12% in the last survey.

This trend is different from last year, it seems that we have more and more regular users (51% this year compared to 43% last year) or that these users are more interested giving their opinion about Orphanet.

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 part of the questionnaire composed of 6 questions was only proposed to those who answered that it was not their first visit to the Orphanet website in question 4, corresponding to what we called next "regular users", and representing 4,205 respondents.
Users who answered they were visiting our website for the first time in question 4 were directly brought to part 3 of the questionnaire because they wouldnot have had time to form an opinion on Orphanet website. Moreover, this takes into account the remarks that these types of users had made in the last survey. Indeed, this question was open to first visitors in the last survey, but respondents stated that they could not form an opinion yet so we decided not to present first visitors with this question again.

Question 5: 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 three statements but answer was not required. 4,097 respondents answered this question, i.e. almost all regular users (97%) representing 44% of the total respondents.

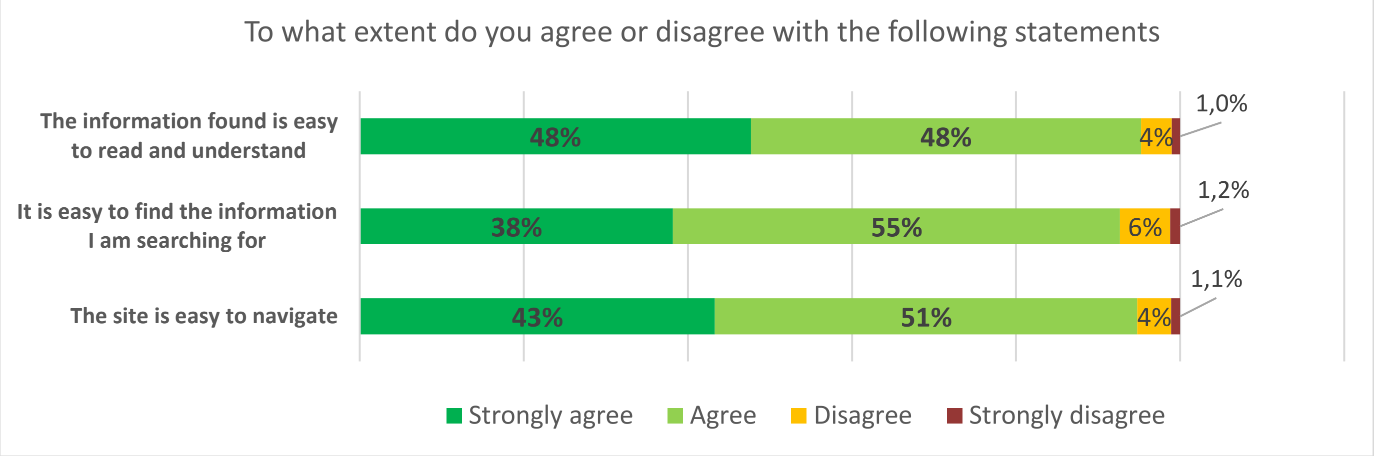

Figure 5: Repartition of the respondents rate on the ease to use the Orphanet website and to understand the information found (n=4097)

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 5). A minority of respondents (5 to 7%) disagree or strongly disagree with these statements.

These results should, however, be considered in relation to questions 6, 8 and 10. In these questions, we asked how useful they found Orphanet services, how satisfied are they and why and what Orphanet could do to better serve its users. Answers to these questions showed that users do not know certain Orphanet functions,ressources or services and that Orphanet must continue its efforts to continuously update the data and make its site even easier to use and clearer (e.g. more ergonomic website and more readable for non-health professionals).

Question 6: 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 service/ressource or to specify that they did not know this service/product.
Answer was not required for all services / products and 3,458 respondents replied to this question, i.e. most regular users (82%) representing 37% of the total respondents.

The results (Figure 6) are presented according to 4 categories of products / services offered by Orphanet: Scientific information on rare diseases ; Directories ; Orphanet Report Series ; Other specific products / services.

Fig.6a: Scientific informations on rare diseases

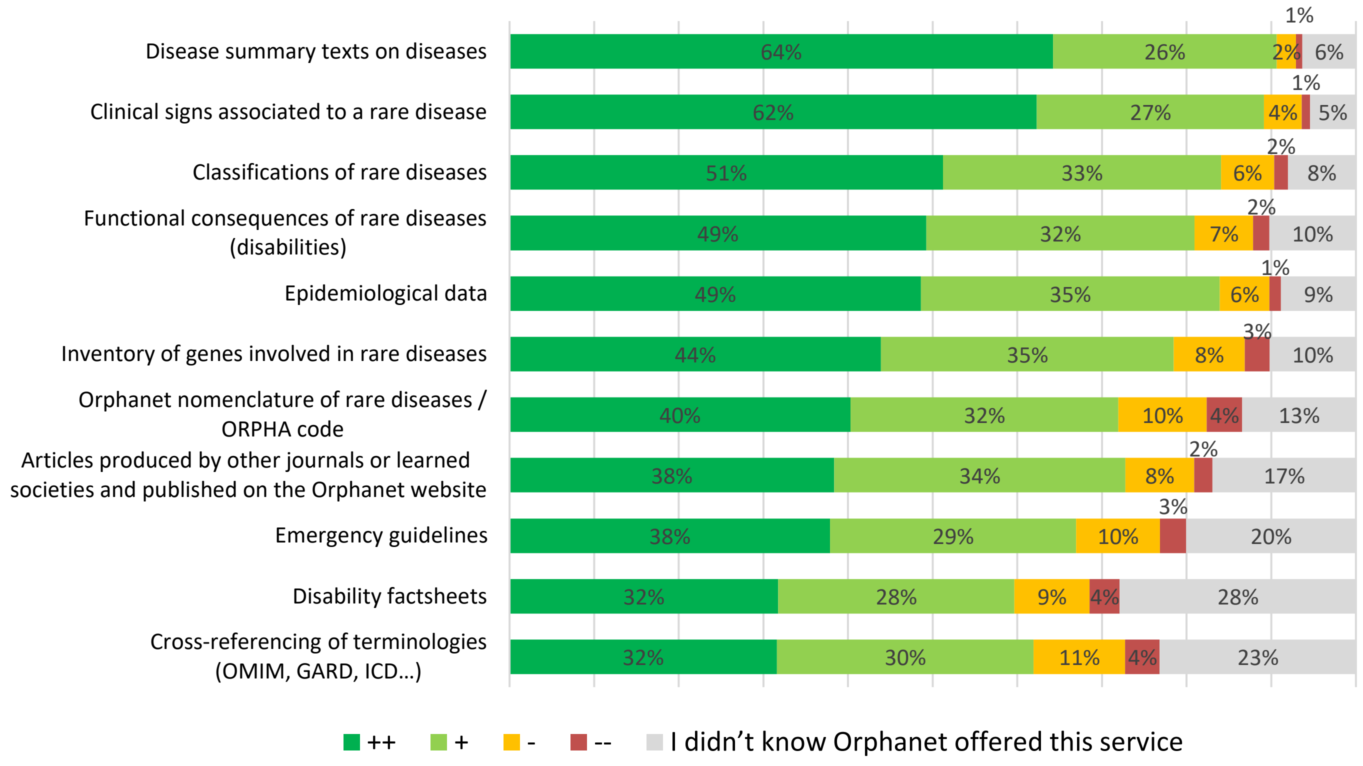

Fig.6b: Directories

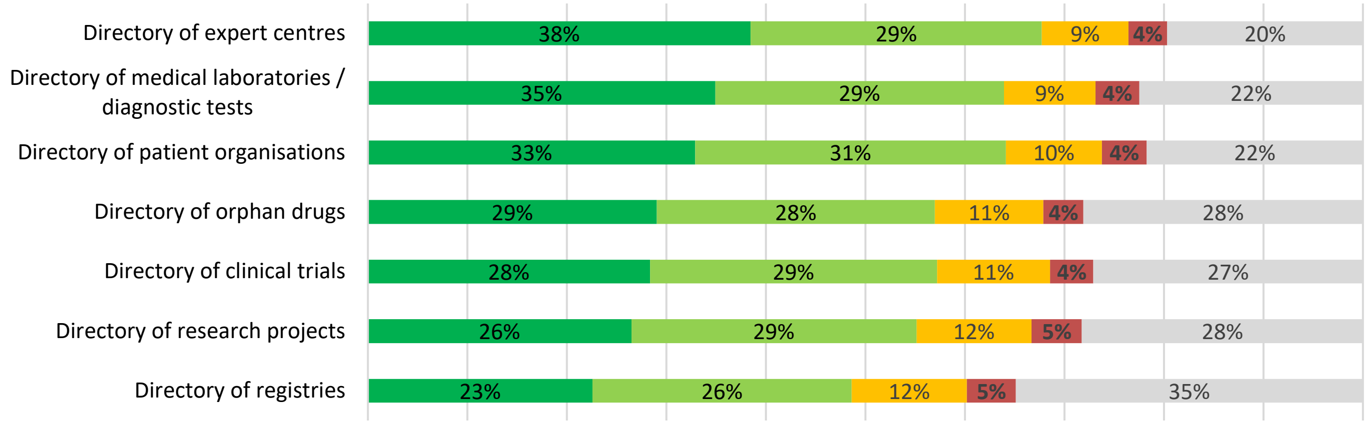

Fig.6c: Orphanet Report Series

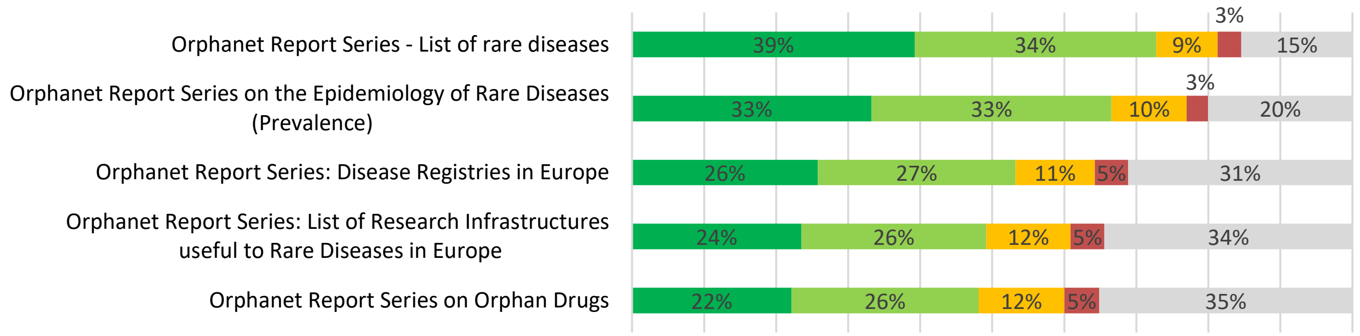

Fig.6d: Other specific products / services

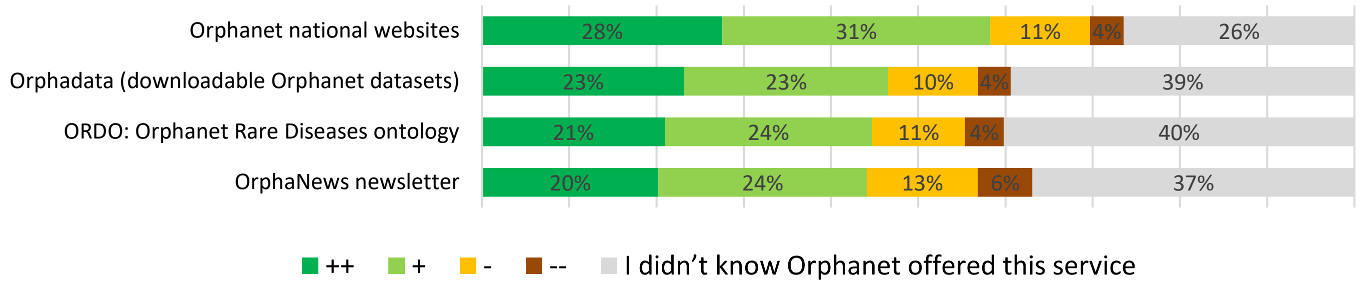

Figure 6: Repartition of the respondents' rate on utility and knowledge of services/products offered by Orphanet (n=3458)

Services and products giving scientific information on rare diseases (summary texts, clinical signs, epidemiological data, disabilities, etc.) are the best known to Orphanet users (Fig.6a). The most useful products for the respondents are the disease summary texts and the clinical signs associated to a rare disease (respectively 90% and 89%) followed by classifications of rare diseases and epidemiological data (84% for both), then functional consequences of rare diseases (81%). This trend is the same as last year with a slight increase in usefulness for disease summary texts (87% last year). The inventory of genes

involved in rare diseases is a very useful service for 79% of the respondents, followed by the Orphanet nomenclature of rare diseases / ORPHAcodes and articles produced by other journals and published on the Orphanet website (72% for both).
Emergency guidelines are useful for almost 70% of the respondents but unknown to 20% of respondents .Disability factsheets and cross-referencing of terminologies although less known to respondents (around 25% of Orphanet users didn't know about these services) are still very useful to 60% of 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 (Fig.6b) are still unknown of 20% to 35% of the respondents. Services dedicated to research (registries, research projects and clinical trials) are the less well known than the information on orphan drugs but are still useful to almost 60% of the respondents. Amongst the better-known services, the most useful one for our respondents is, as was the case last year, the directory of expert centres (almost 70%). The directory on medical laboratories/ diagnostic tests and that concerning patient organisations are judged useful for about 65% of our respondents.

Orphanet also offers different "Report Series" (Fig.6c). 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 (30 to 35%). Orphanet should therefore increase the visibility of these products.

Concerning the other specific products and services (Fig.6d) 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 (around 40%). 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. However, actions to improve the visibility of these services through the Orphanet website could be carried out.

Depending on the service/product considered, up to 19% of respondents do not find them useful for their needs. These results should, however, be considered in the light of the results of question 8 and 10, 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 less known services/products, results of questions 8 and 10 indicate that a more user-friendly site might lead to a better knowledge of the panel of products and services Orphanet offers.

Overall, these results show that services/products offered by Orphanet serve the needs of the majority of respondents. However, Orphanet should take action to make other products better known to Orphanet website users.

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 governed by Orphanet Standard Operating Procedures according to quality standards.
An answer was not required and 3,458 respondents replied to this question, i.e. most regular users (82%) representing 37% of the total respondents.

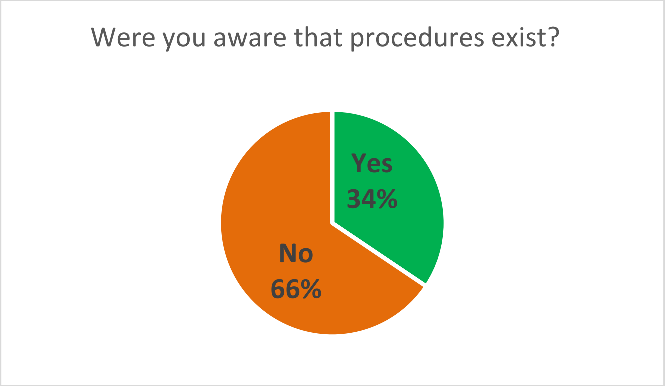

Figure 7 : Repartition of the respondents about knowledge of Orphanet procedures (n=3458)

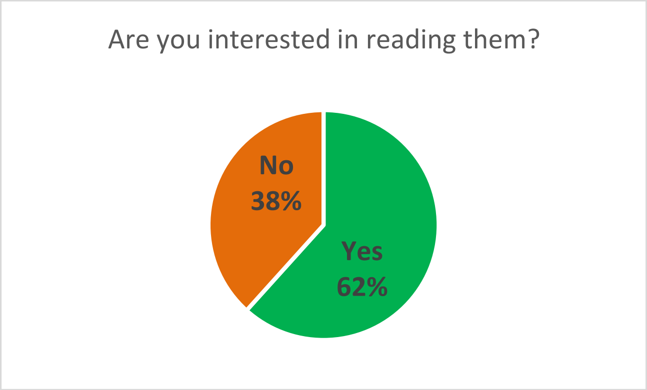

Figure 8: Repartition of the respondents interested in reading Orphanet procedures (n=3458)

As last year, the majority of respondents (66%) did not know of the existence of these procedures (Figure 7) but 62% are interested in reading them (Figure 8).
This indicates that we should increase the visibility of these procedures on the website. For several years, Orphanet has improved the visibility of its procedures by creating a dedicated page for them. 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 disseminate these documents more efficiently.

Question 8: 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 3,291 respondents replied to this question, i.e. 78% of regular users representing 35% 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 459 individuals.

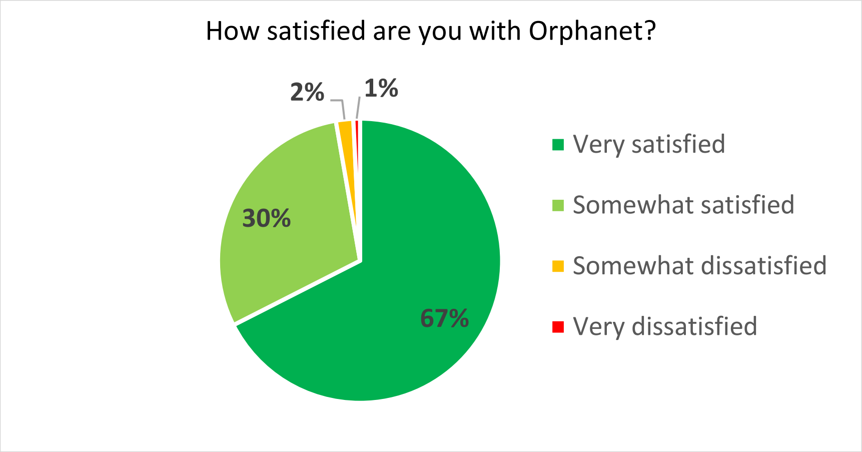

Figure 9: Global satisfaction of the Orphanet website users (n= 3291)

The vast majority of respondents were either very satisfied or satisfied with Orphanet with a total of 97% responding positively (Figure 9), almost the same result than in the last survey (98%, n=4,018).

The free comment field helped us to understand the reasons for satisfaction or dissatisfaction.

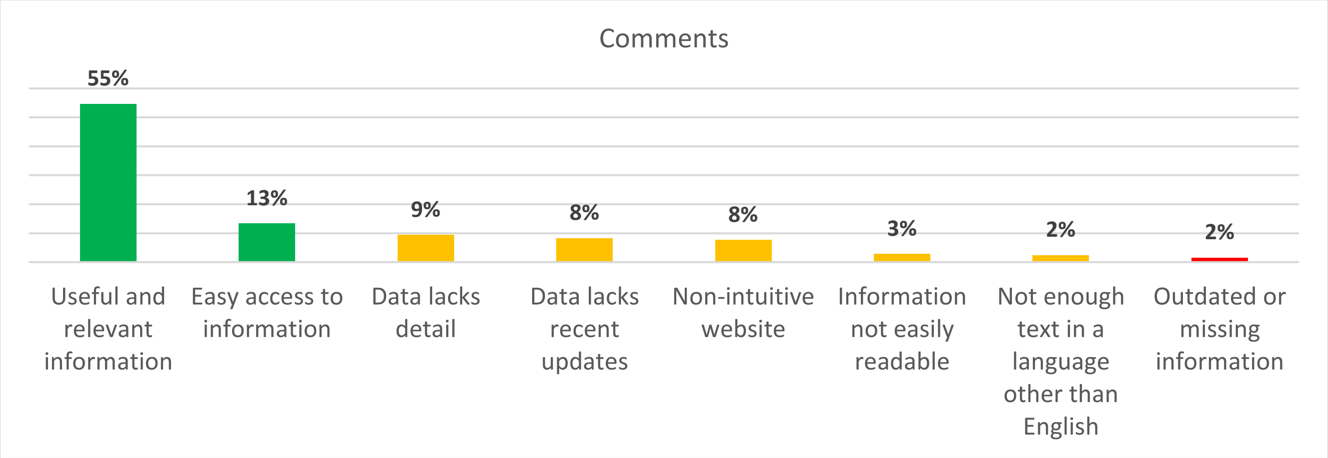

Figure 10: Free comments of the Orphanet website users (n= 459)

Among the 97% very satisfied or satisfied users, 55% considered that information provided by Orphanet is useful and relevant and 13% that information is easy to access (Figure 10), showing the same trend than last year with a slight increase of users considered the information useful and relevant.

2% of respondents were dissatisfied and 1% were very dissatisfied. The main free comments explained that the information is not detailed enough and not enough updated frequently but also that the website is not user-friendly. Another possible explanation was that some users would like the information to be more easily readable for non-health professionals.

These results are in adequation with the results obtained in question 5, where we questioned our users on the ease to use the Orphanet website and how easy it is to understand the information found in it.

Question 9: 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 3,303 respondents replied to this question, i.e. almost 80% of regular users representing 35% of the total respondents.

65% of those responding turned out to be promoters as they responded with a score of 9 or 10, 27% were passive (score of 7 or 8) and 7.5% were detractors (score of 0 to 6). This gives a NPS of 57,7 (Figure 11).

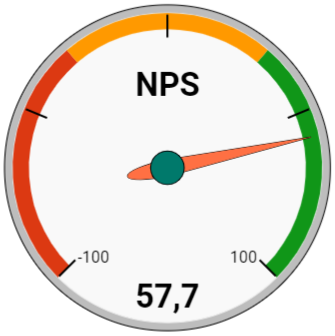

Figure 11: Orphanet Net Promoter Score (NPS) (n= 3303)

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 has greatly increased in the last 2 years : 2021 survey, NPS was 54,3 (n=5,299) and 2019 survey , NPS was 47,8 (n=4,199).

Moreover, it is noteworthy that according to these results 65% of the respondents would recommend using Orphanet while only 7.5% would not.

Question 10: What should Orphanet do to better serve your needs?

The question was not mandatory and was a free field to add any comment about what Orphanet can do to better serve needs of its users. Comments were provided by 694 individuals, i.e. 17% of regular users questioned representing 8% of the total respondents.

The most frequent comments relate to the need for more detailed information (32%), a more ergonomic website (13%) and more regular updates (10%) (Figure 12). These comments are in concordance with the answers obtained to question 8 concerning the free comment field of the overall satisfaction.
Also, it is interesting and encouraging to note that 21% of those who provided comments were satisfied by the service provided by Orphanet and left messages of encouragement and support for Orphanet's activities.

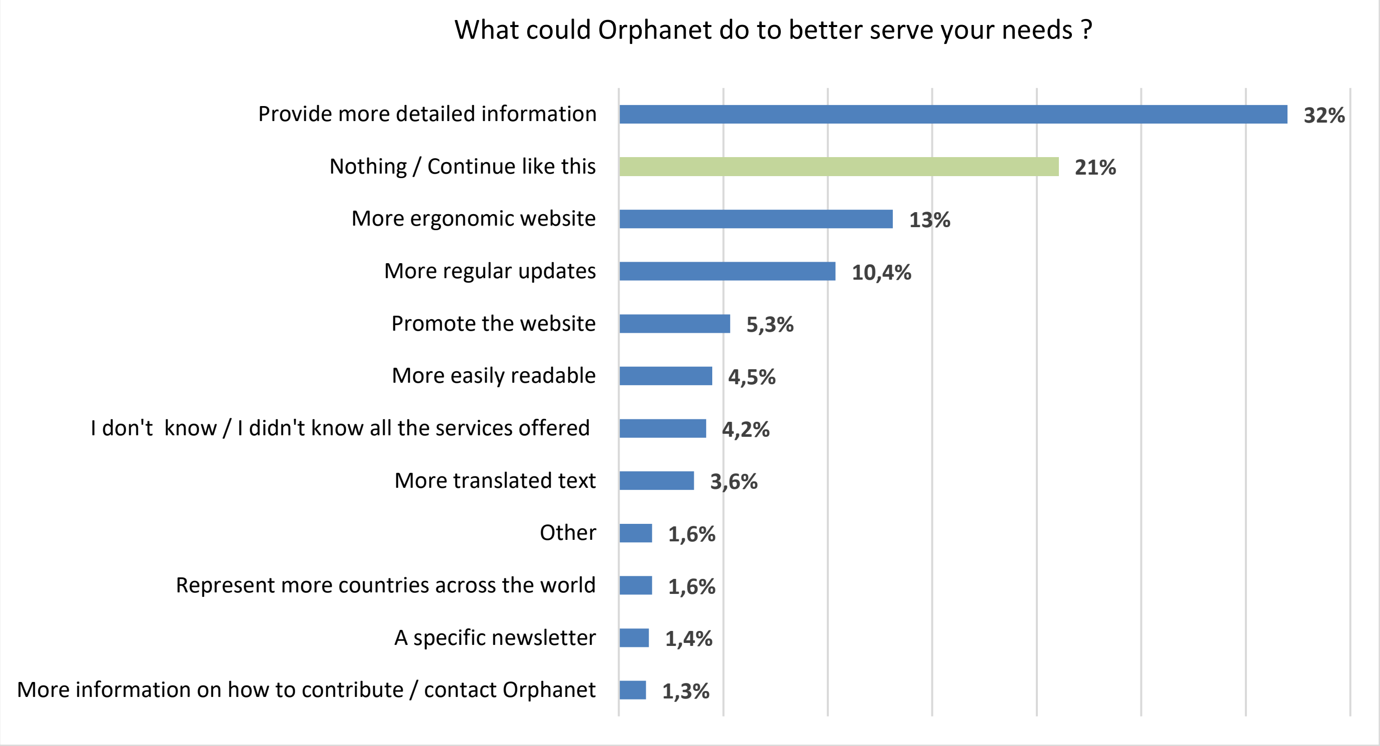

Figure 12: Free comments on what could Orphanet do to better serve your needs (n= 694)

Regarding the need for a more detailed information, Orphanet's users were mainly interested in more details about treatment and patient care (23%, Figure 13) suggesting improving the visibility of expert centres and emergency guidelines as well as providing information on alternative medicines for example. This percentage has increased compared to last year. Orphanet intends to take these remarks into account, in particular to improve the visibility of the expert centres. It should be also noted that Orphanet is continuously publishing best practice guidelines on recommended care when these guidelines exist.
Users are also mainly interested in more detail in clinical signs and symptoms (20%) 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 also related to making the disease summary text more detailed (16%) such as expanding the summary to involve the important points of features, investigation and treatment. In addition to in-house summary information, Orphanet provides links to reviews articles providing more detailed information on particular rare diseases, when they exist. Moreover, 8% 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 completed and validated by expert reviewers indicated at the bottom of each summary text.

Users are also interested about more general information about rare diseases (15%) 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.

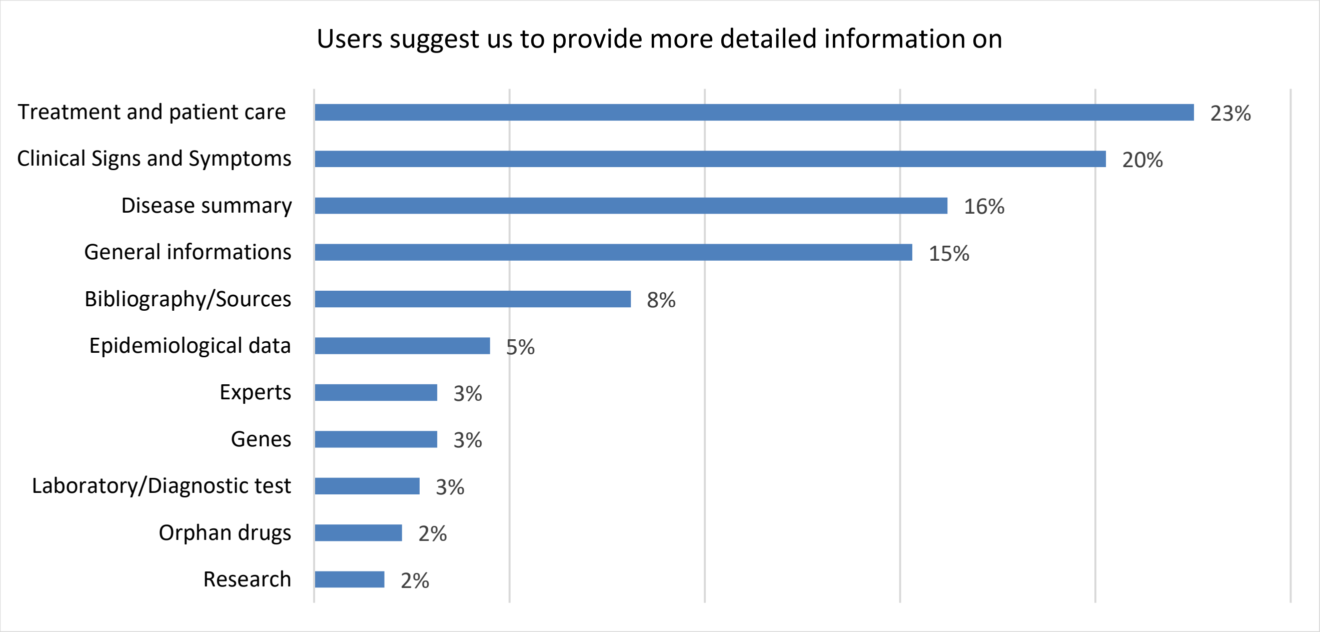

Figure 13: Free comments on what could Orphanet do about more detailed information (n= 222)

Regarding the need for a more ergonomic website (Figure 14), Orphanet's users comment mainly about the site navigation (31%), the website layout (24%) and the search function (23%).

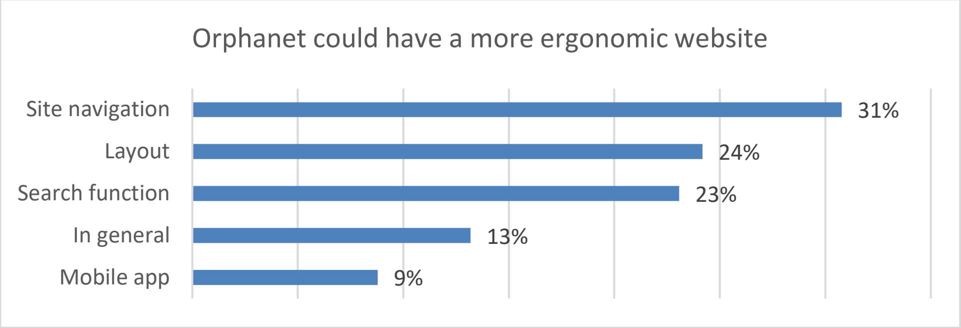

Figure 14: Free comments on what could Orphanet do about the website (n= 91)

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 5 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 is too complicated which could explain some percentage of unknown services/products to the question 6. They also expressed their wish to find 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 function that they consider too complex to use as well as the presentation of the data (layout) in this complex database.

Around 9% commented on the mobile app (much less than last year, 20%). Indeed, this no longer exists and respondents 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. However, specific apps could complement the Orphanet website : as an example, a new app was released in French, “Orphanet Guides”, containing 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 (10%, Figure 12). This comment has also been expressed in question 8.

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 improving 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 11: 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 7,080 respondents replied to this question, i.e. 75% of the total respondents.

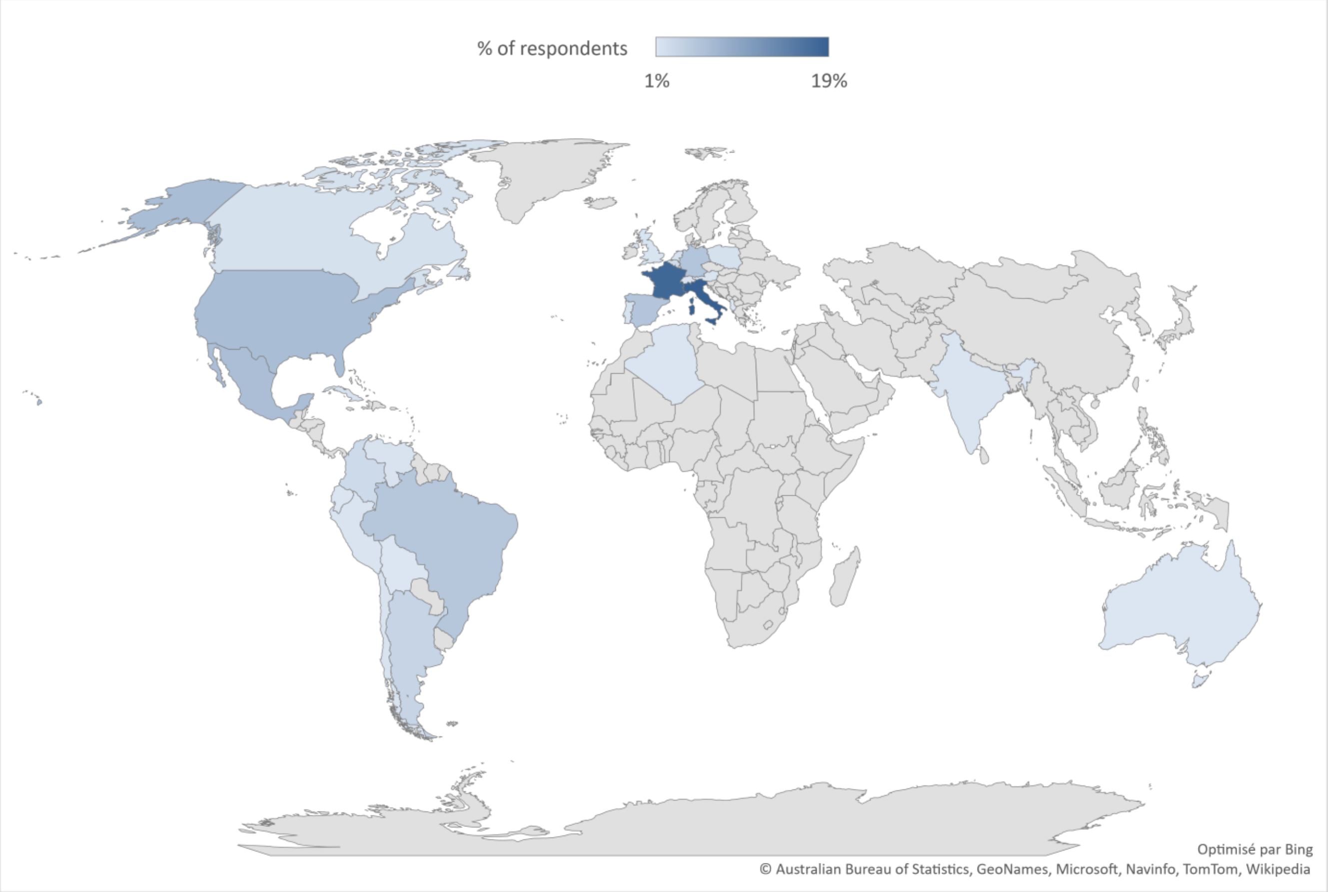

Figure 15: Countries of provenance of respondents to the satisfaction survey (n=7080)

The top ten countries replying to the survey were: Italy (n=1355), France (n=1280), United States of America (n=444), Mexico (n=434), Germany (n=366), Spain (n=360), Brazil (n=340), Argentina (n=216), Colombia (n=158), and Belgium (n=134).
This is the same top 10 countries as in the last survey with slightly different proportions.

Question 12: In what capacity are you usually consulting the Orphanet website ?

This question aimed to determine the profile of Orphanet users. Seven categories were proposed : 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 choose only one category and an answer was not required. 6,969 replies were registered for this question, i.e. 74% of the total respondents.

Figure 16 shows the distribution of respondents amongst these categories:

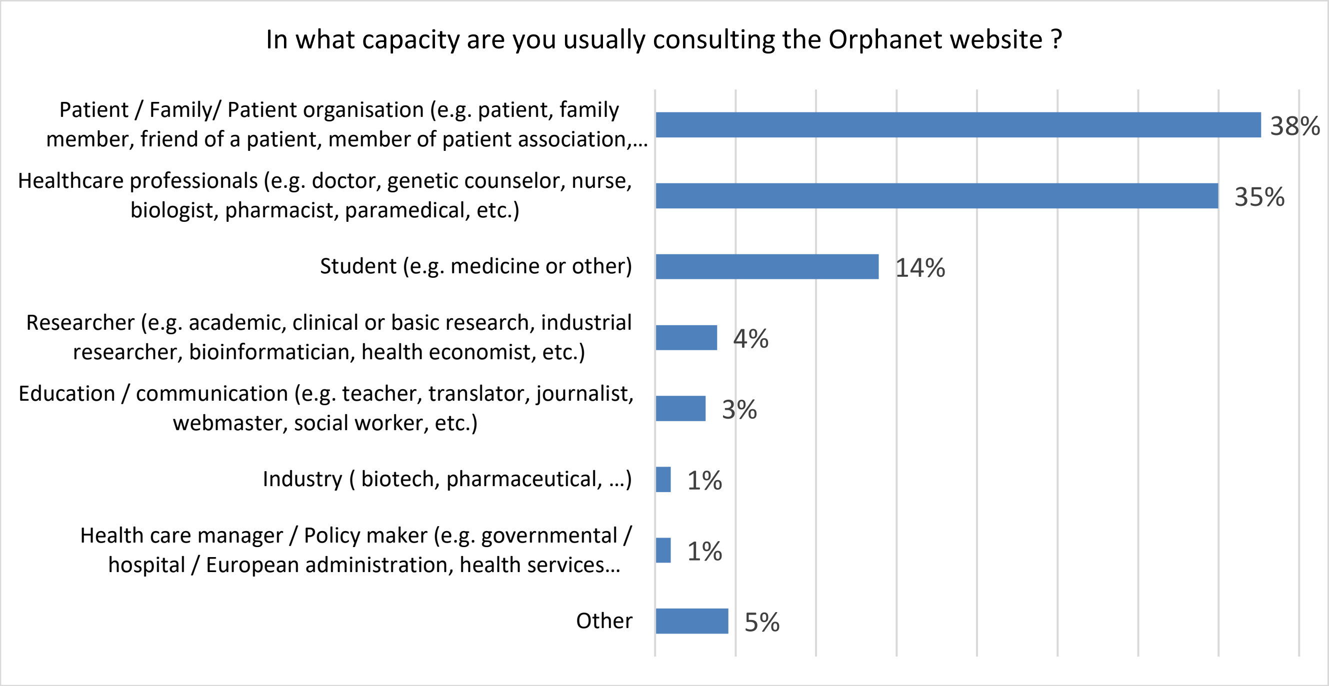

Figure 16: Types of Orphanet user (n =6969)

The largest categories of respondents are patients and their entourage including patient organisations (38%) and healthcare professionals (35%). Students also replied the survey (14%), followed by reseachers and users working in education / communication (respectively 4% and 3%).

The "Other" category (n=306) is mainly composed of persons visiting the site for their general knowledge or curiosity, 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 the 2 main categories of users but with a decrease of healthcare professionals (40% last year). Patients and their entourage, including patient organisations, are our main users this year. Students remain the 3rd category of our users although they are less numerous than last year (18.5%).

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.

Patient / Family / Patient organisation (n= 2,623):

Most of the people who selected this category are patients (48%) then family members of a patient with a rare disease (39%) (Figure 20). There is a slight increase of member of a patient organisation compared to the last year (3%) but the results are globally similar to those of the previous survey.

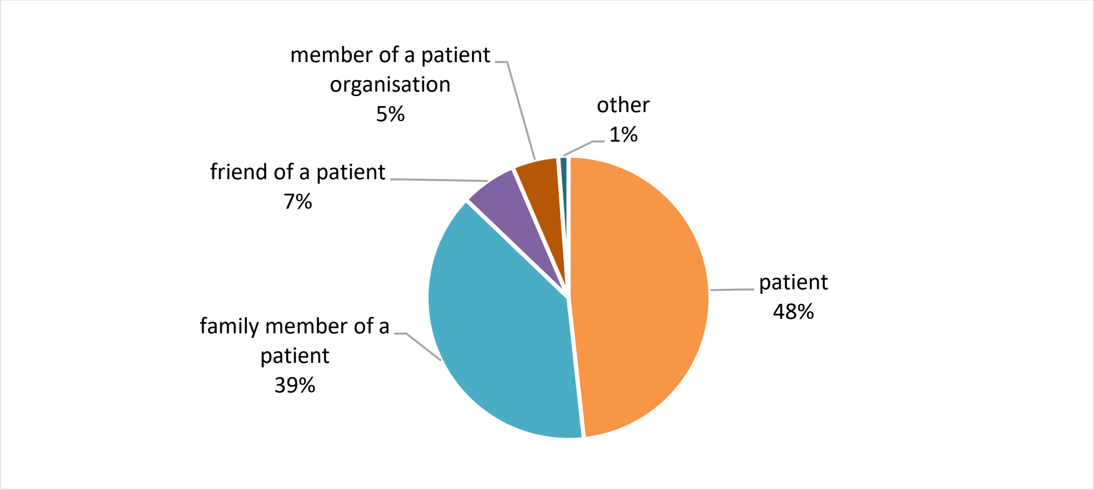

Figure 17: Types of respondents qualifying themselves as a patient, part of a patient’s entourage or member of a patient organisation.

Healthcare professionals (n= 2,437):

Hospital specialists represent the main category of respondents (42%) (Figure 18). Independent specialists represent 15% as well as general practitioners. Altogether, 72% are medical doctors (compared to 66% in the last survey).

On the other hand, there are fewer of respondents (10 % compared to 14% last year) belong to other healthcare professional categories (e.g. midwife, psychologists, physiotherapists, paramedical, etc...). Nurses represent 7% and like other professional categories, it remains equally represented compared to last year.

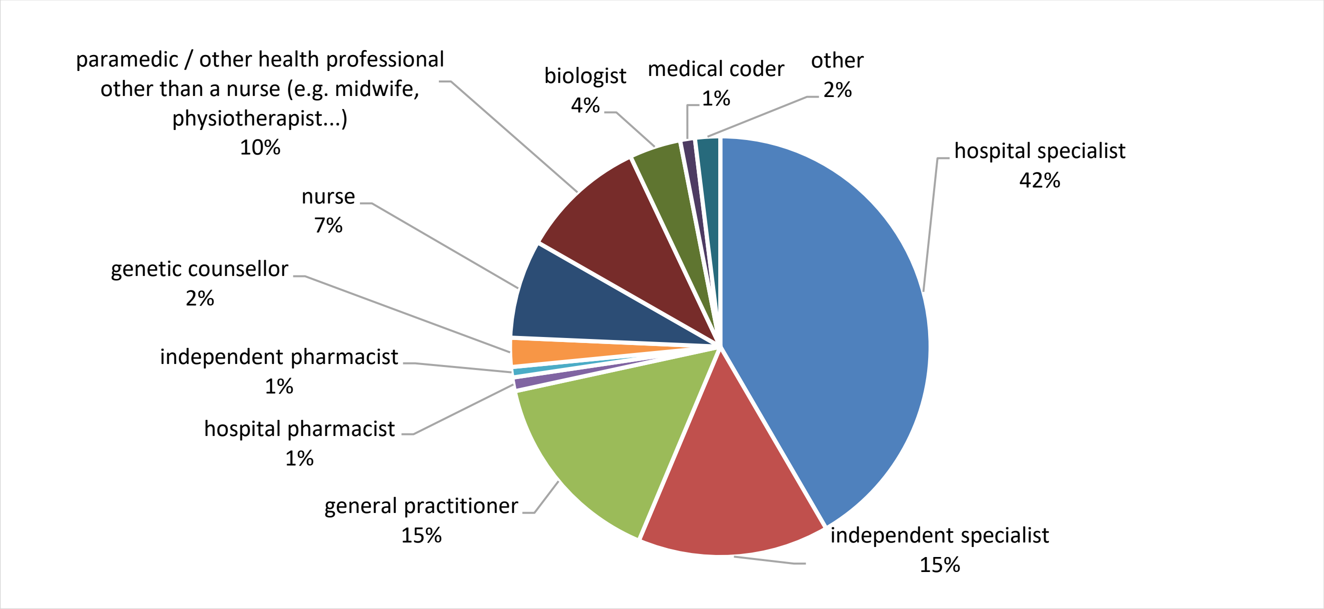

Figure 18: Types of respondents qualifying themselves as health professionals

<u>Students (n= 968):</u>

Medical students represent 68% of this category (Figure 19). The other respondents were students in biology, physiotherapy, psychology, pharmacy, communication, information technology, etc. The results are almost similar as last survey with an increase of medical students (62% last year).

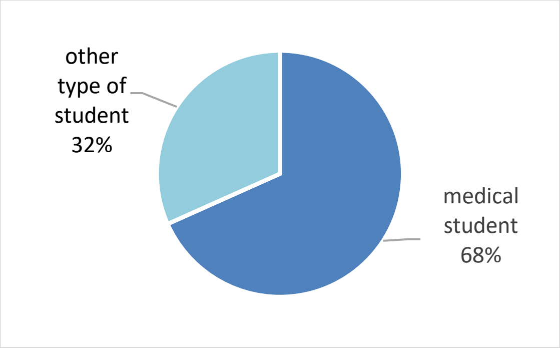

Figure 19: Types of respondents qualifying themselves as students

<u>Researchers (n= 269):</u>

Academic researchers represent 69% of respondents of the research category (Figure 20) which is almost the same percentage than last year. The percentage of industry researchers that responded to this survey increased a little compared to last year (8% this year, 7% in the last survey). The sub-category of Bioinformatician/biostatistician has doubled from 4 to 8%. Social sciences researchers represent 9% and like the other professional categories, it remains equally represented compared to last year.

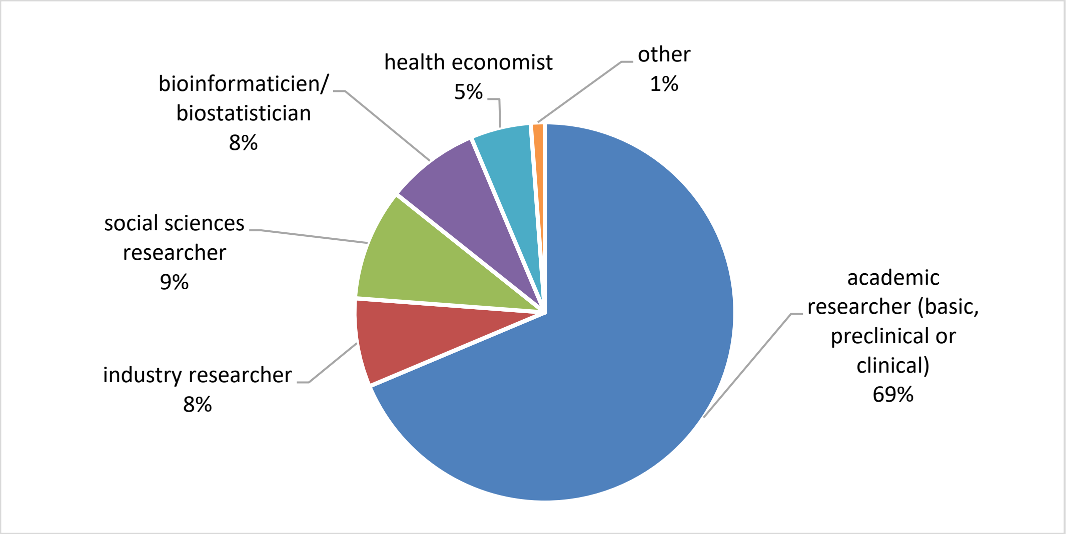

Figure 20: Types of respondents qualifying themselves as working in the field of research.

<u>Education / Communication (n=219):</u>

In this category, teachers represented 57% of respondents (Figure 21), which is an increase compared to last year (54%). Social workers are the second most represented sub-categories with 12% followed by administrative education staff with 9%, like in the last survey.

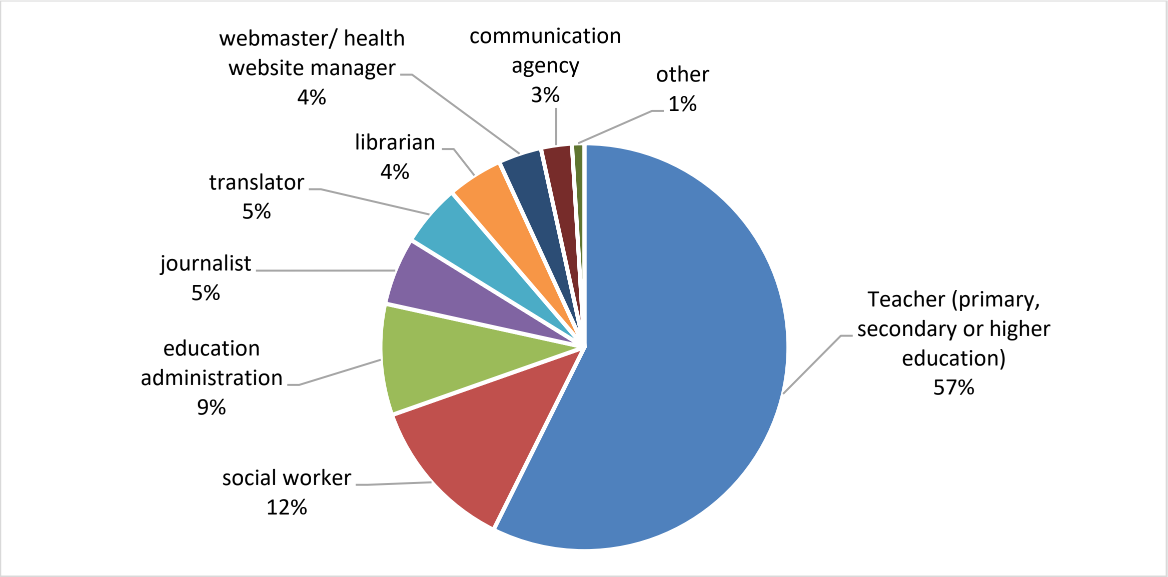

Figure21: Types of respondents qualifying themselves as working in education/communication.

Health care manager / policy maker (n= 68):

In this category, 45% work in health services administration or insurance (public, private or administration) and 33% in hospital administration (Figure 22). There is an increase of respondents working in hospital administration (25% of this category of users in the last survey). This year, health inspector represent 11% of this category, compared to 3% of last year, that's a big increase.

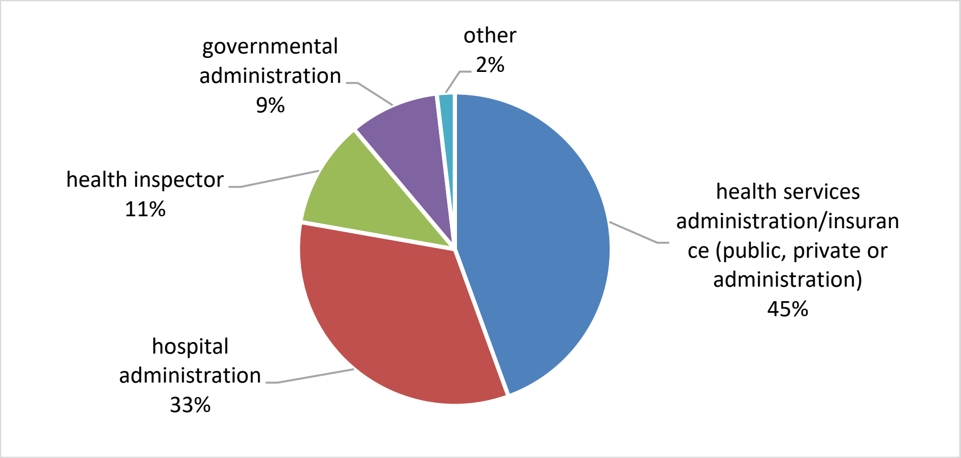

Figure22: Types of respondents qualifying themselves as working in the field of health care management/policy making.

Industry (n=68):

64% of respondents work in the biotechnology or pharmaceutical industry and 28% are consultants in the sector (Figure 23). Compared to the last survey, the percentage of respondents working in the biotechnology and pharmaceutical sectors have strongly increased (48% of respondents in this category last year) while the percentage of investor / business developer has decreased (14 to 5%). The percentage of consultants for industry is stable.

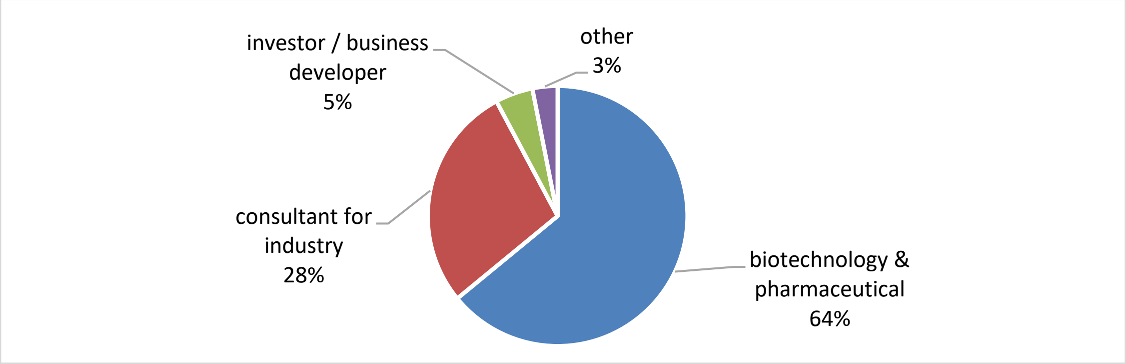

Figure 23: Types of respondents qualifying themselves as working in the biotechnology or pharmaceutical industry

Question 13: Do you have expertise in rare diseases ?

Respondents were also asked if they had, directly or indirectly, an expertise in the field of rare diseases. An answer was not required and 6,871 respondents replied to this question, i.e. 73% of the total respondents.

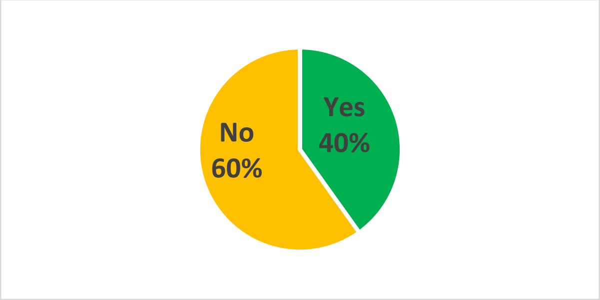

Figure: Repartition of respondents considering having a expertise in rare disease (n=6871)

40% responded that they had expertise in this field, of which 57% belong to the healthcare professional category and 42% of the Patient / Family / Patient organisation category. These results are almost similar to those of last year with an increase of users responding that they had expertise in rare diseases belonging to the healthcare professional category (52% last year) and the Patient / Family / Patient organisation category (37% last year).

Most of our users (60%) replied that they did not have expertise in rare diseases. This result is extremely interesting as one of the major Orphanet's missions is to increase the awareness and knowledge on rare diseases amongst non-expert audiences.

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

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