Orphanet Report Series
Reports collection

2023

2023 User Satisfaction Survey of the Orphanet Website

www.orpha.net

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TABLE OF CONTENTS

METHODOLOGY

This year's satisfaction survey was conducted in one phase launched in February 2023 via a pop-up window appearing on the first page users landed on. The survey was translated into 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 9,852 users gave answers to the questions this year. This is slightly superior compared to last year (9,389 respondents).

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. 9,852 respondents replied to this question, i.e. all of the respondents.

A large majority of our users (71%) discovered Orphanet via a search engine like Google (Figure 1). Word of mouth was the second source of discovery of Orphanet (15,2%).
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.

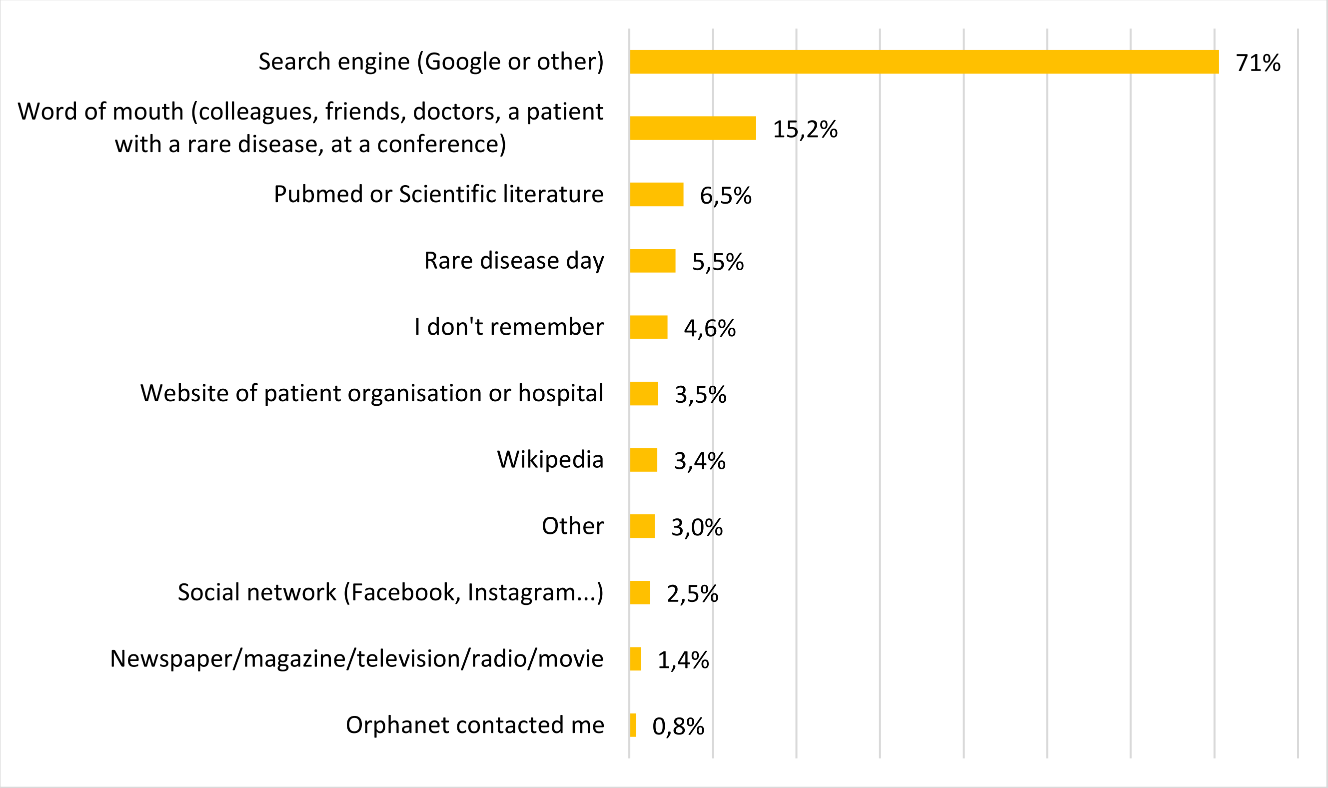


Figure 1: Mode of discovery of Orphanet by respondents (n=9852)

Compared to last year, these results are the same : access through a search engine like Google is still the preponderant way to discover Orphanet and the percentage of discovery by word of mouth is is still on the rise (15,2% vs. 14% last year and 13% 2 years ago).

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%) is accessing Orphanet by typing a keyword in a search engine.

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. 9,852 respondents, i.e. 100%, replied to this question.

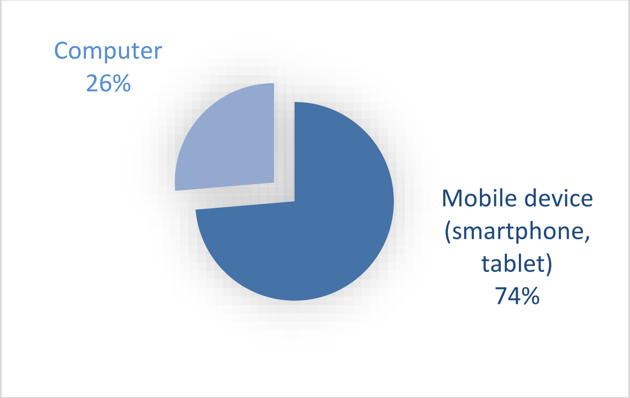


Figure 2: Mode of accessing Orphanet by respondents (n=9852)

74% of respondents accessed to Orphanet using a mobile device (smartphone or tablet) with an Internet connection (Figure 2). This result is the same as last year's survey and 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 making it easy to 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. 8,922 respondents replied to this question, i.e. 91% 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 47% 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 (41%).
This top three is the same than last year.

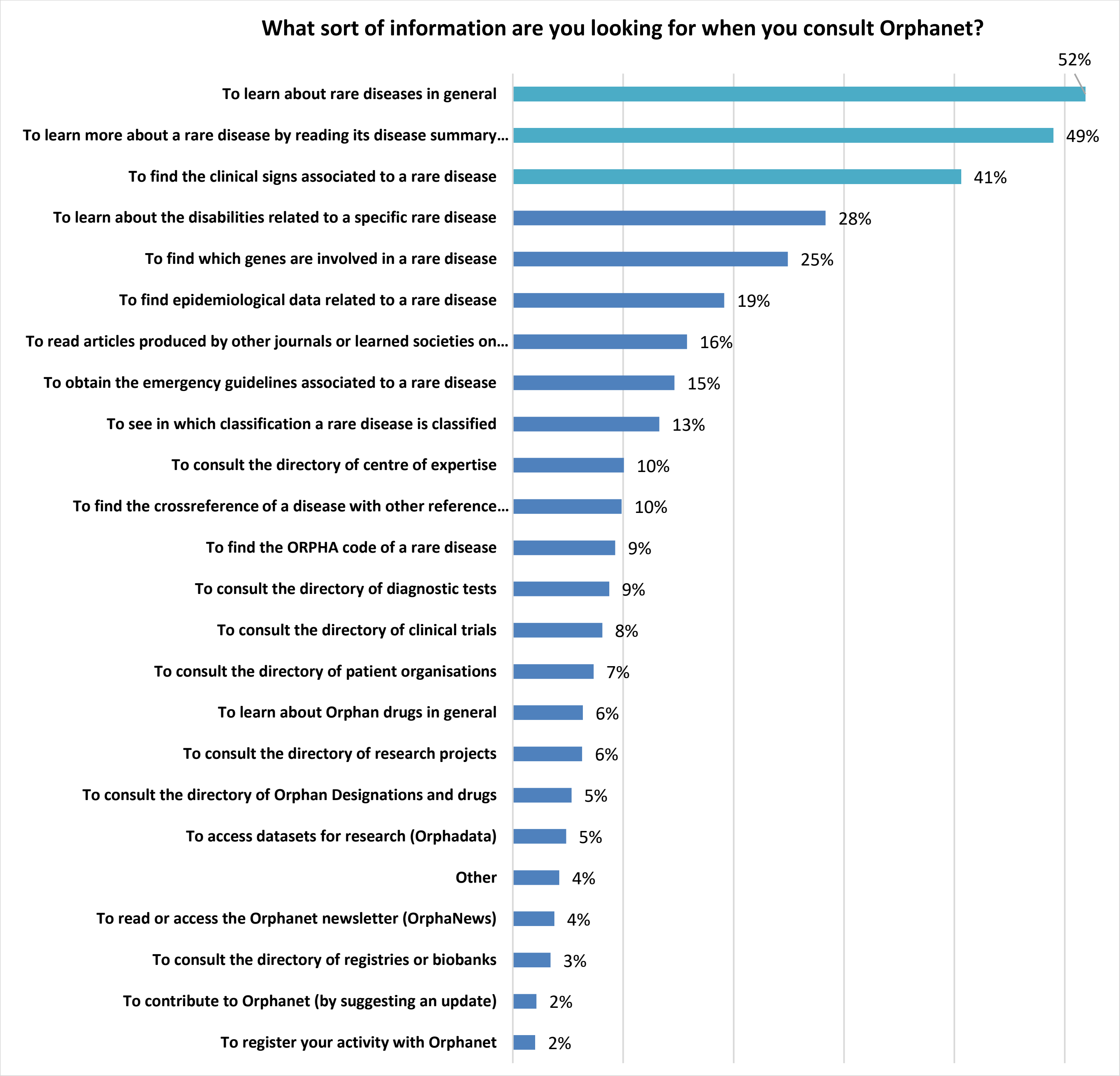


Figure 3 : Information sought by respondents during their connection to Orphanet (n=8922).

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 (25%), to find epidemiological data related to a rare disease (19%), to read articles produced by other journals or learned societies on a rare disease (16%) and to obtain the emergency guidelines associated with a rare disease (15%).
Regarding directories offered by Orphanet, the directory of centres of expertise is the most consulted usually (10%), then the directory of diagnostic tests (9%). This result is 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 curiosity.

Question 4: How often do you visit Orphanet?

Only one response was possible and an answer was not required. 8,771 respondents replied to this question, i.e. 89% of the respondents.

Around 47% were visiting Orphanet for the first time whereas 53% of those answering the survey can be considering as regular users (i.e. 4,661 respondents) (Figure 4).

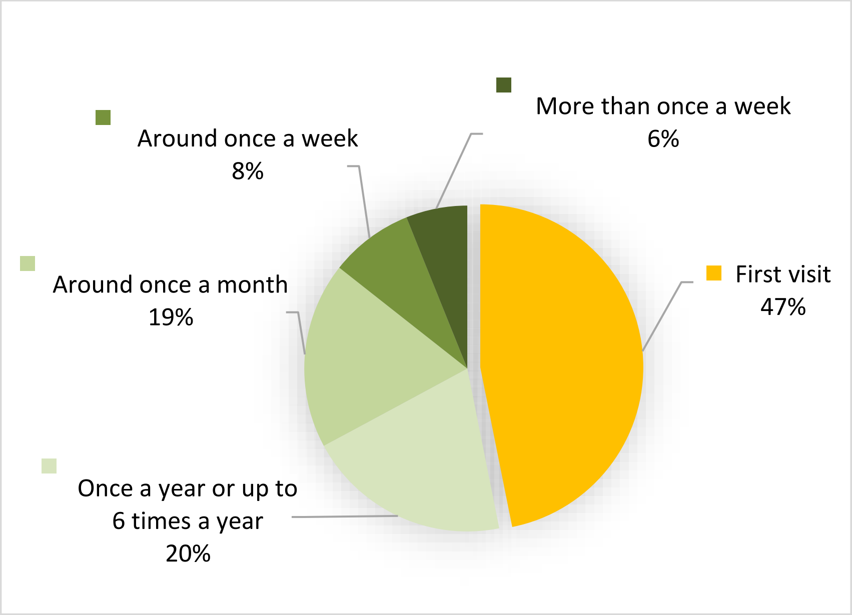


Figure 4 : Visiting frequency of respondents (n=8771)

There are slightly less first users this year compared to the last survey (47% compared to 49% last year). Moderately regular users (several times a year) have increased a little (39% compared to 37% last year) and there is the same percentage of frequent users (≥ once a week) than in the last survey.
We kept the same trend from last year: it seems that we have more and more regular users (53% this year compared to 51% last year and 43% 2 years ago) 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 was composed of 6 questions and 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 4,661 respondents.

Users who answered they were visiting our website for the first time in question 4 were directly taken to part 3 of the questionnaire because they would not have had time to form an opinion on Orphanet website.

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 an answer was not required. 4,555 respondents answered this question, i.e. almost all regular users (97,7%) representing 46% of the total respondents.

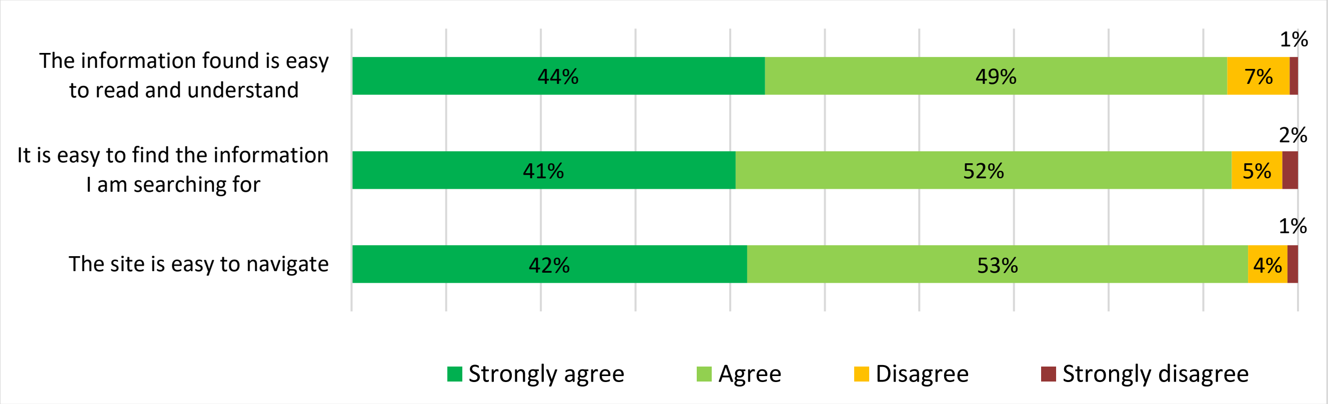


Figure 5: Segmentation of the response rate on the ease of use the Orphanet website and to understand the information found (n=4555)

These results show that most of the respondents (more than 90%) find that the Orphanet website is easy to navigate, 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 8%) disagree or strongly disagree with these statements.

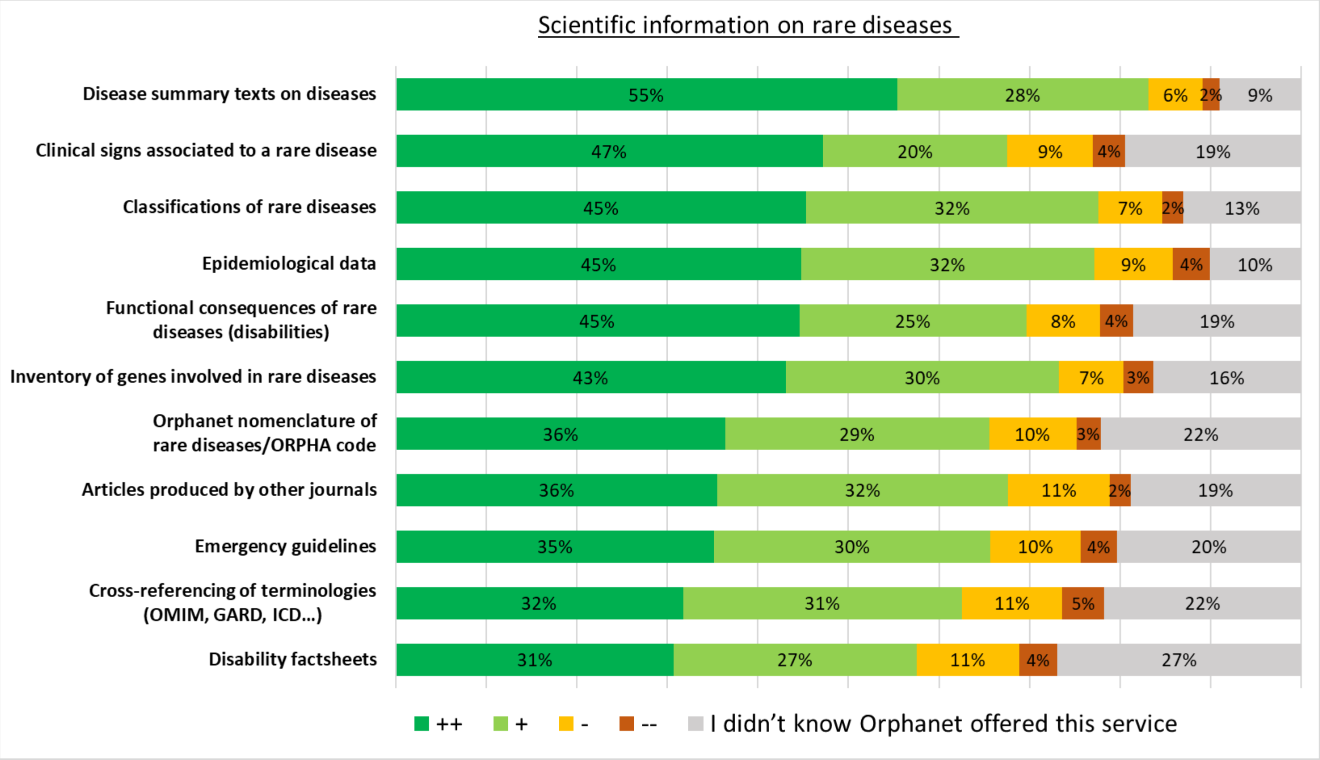
These results should, however, be considered in relation to questions 6, 8 and 10. In these questions, we asked how useful they found Orphanet services, how satisfied they are and why and what Orphanet could do to better serve its users. Answers to these questions showed that users do not know certain

Orphanet functions, resources 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/resource or to specify that they did not know this service/product.
An answer was not required for all services / products and 3,847 respondents replied to this question, i.e. most regular users (82,5%) representing 39% 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.



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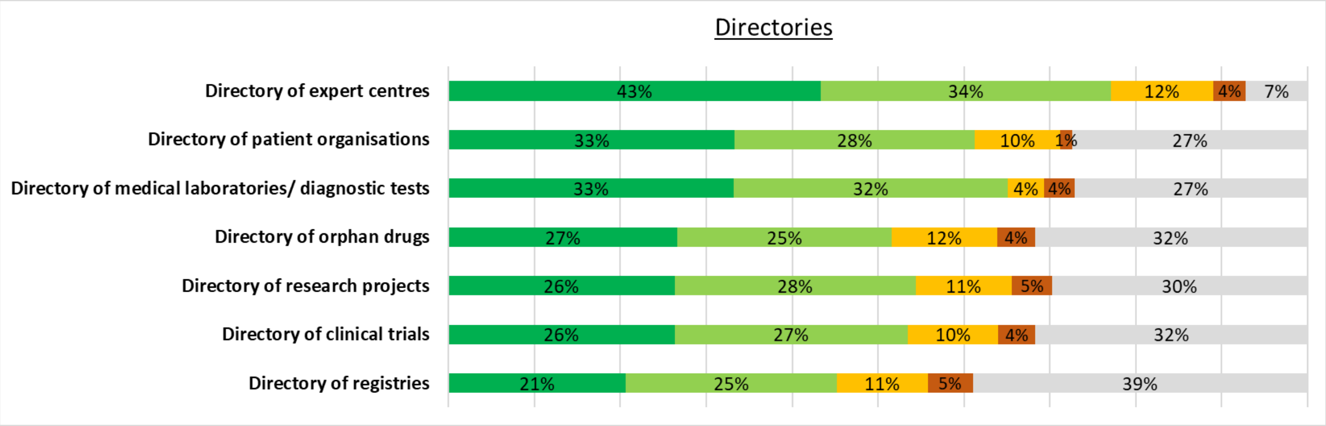

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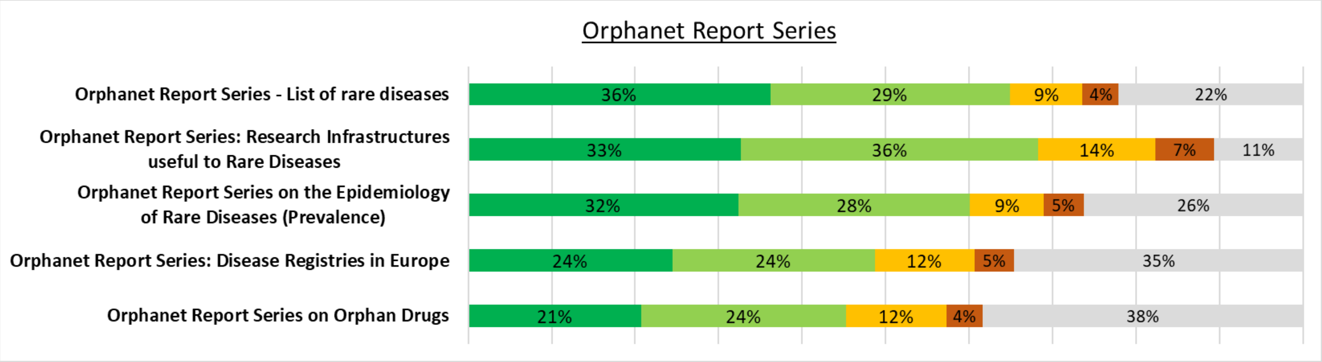

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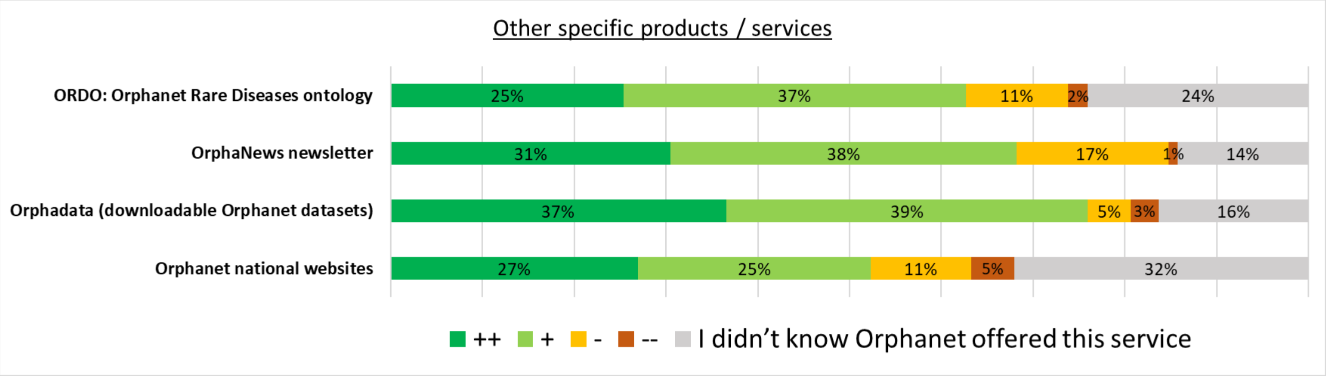

6d.

Figure 6: Segmentation of response rate on utility and knowledge of services/products offered by Orphanet (n=3847)

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).

Respondents judged that the most useful scientific information provided by Orphanet are the disease summary texts (83%), the classifications of rare diseases and epidemiological data (77% for both), followed by the inventory of genes involved in rare diseases (73%) and the functional consequences of rare diseases (70%) This trend is approximately the same as last year.

The clinical signs associated to a rare disease is also a useful service for the respondents as well as articles produced by other journals and published on the Orphanet website and Emergency guidelines (68% for the three) followed by the Orphanet nomenclature of rare diseases / ORPHAcodes (65%) and alignments with other terminologies (considered useful for 63% of the respondents), both unknown to 22% of respondents. Disability factsheets although less known to respondents (27% of Orphanet users didn't know about these services) are still useful to 58% of the respondents. These results make sense as these are services made for specific uses and our users who want to know more about rare diseases are not necessarily looking for this kind of specific information.

About the directories of expert resources proposed by Orphanet (Fig.6b), the best known and most useful one for our respondents is, as was the case last year and even so more this year, the directory of expert centres (77% this year compared to 70% last year).The other directories of expert resources are still unknown to 27% to 39% of the respondents. The directory on medical laboratories/ diagnostic tests and the directory concerning patient organisations are judged useful for about 65% of our respondents.

Services dedicated to research (registries, research projects and clinical trials) are the less well known, as well as the information on orphan drugs.

Orphanet also offers different "Report Series" (Fig.6c). The Orphanet Report Series presenting the list of Research Infrastructures is the best known and most useful for our users (almost 70%) followed by the Orphanet Report Series listing rare diseases (65%) and the one on the Epidemiology of Rare Diseases (60%). This result is different from that of last year. The Research Infrastructures report is better known and more useful for the users than last year(50% last year).

The Orphanet Report Series on Registries and the one on Orphan Drugs are not well known to our users (35 and 38%). Orphanet should therefore increase the visibility of these products. As of this year, the format of these reports has changed. Orphanet has opted for a different approach, moving away from a list-based presentation and instead focusing more on data analysis. This decision aims to generate increased interest in these products, given that the analysis results are valuable in the field of rare diseases.

Concerning the other specific products and services (Fig.6d) provided by Orphanet, they seem to be increasingly recognized and used by our users. Orphadata (which provides access to aggregated data from Orphanet) is much better known and useful for 76% of the respondents compared to 46% last year. The same applies to Orphanet Rare Disease Ontology (ORDO) now judged useful for 64% of the respondents compared to 45% last year. Although these services have their own website in addition of the one provided in Orphanet website, they are increasingly recognised and used.

Orphanet national websites remain little-known as they are not highlighted on the Orphanet site and have their own access.

Depending on the service/product considered, up to 20% 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 satisfie they are 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, the 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 certain 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 3,903 respondents replied to this question, i.e. most regular users (83%) representing 40% of the total respondents.

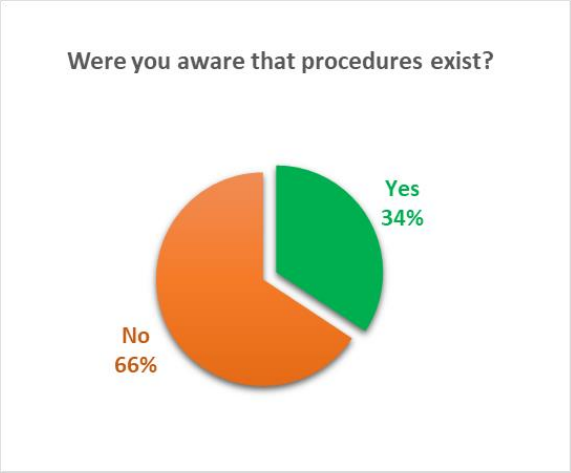

Figure 7 : Repartition of the respondents about knowledge of Orphanet procedures (n=3903)

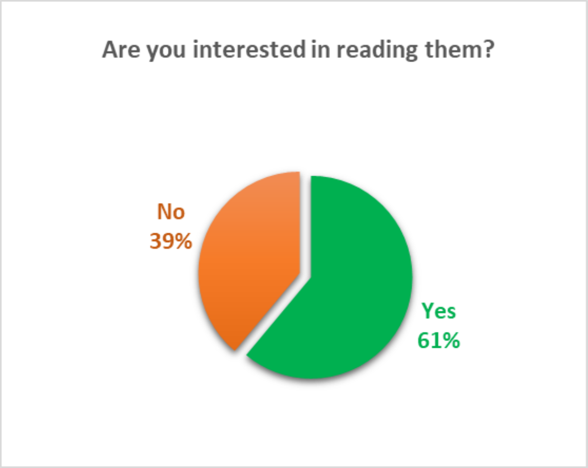

Figure 8: Repartition of the respondents interested in reading Orphanet procedures (n=3903)

As last year, the majority of respondents (66%) did not know of the existence of these procedures (Figure 7) but 61% 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 includes these procedures to each search page. However, the 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 3,676 respondents replied to this question, i.e. 79% of regular users representing 37% 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 473 individuals.

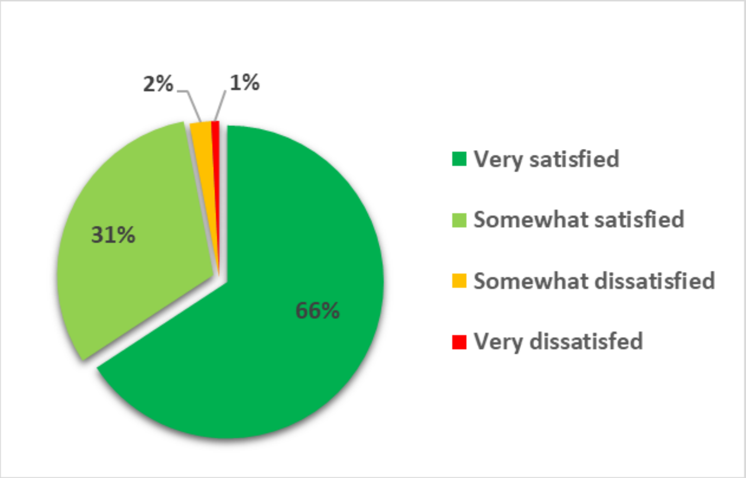

Figure 9: Global satisfaction of the Orphanet website users (n= 3676)

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

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

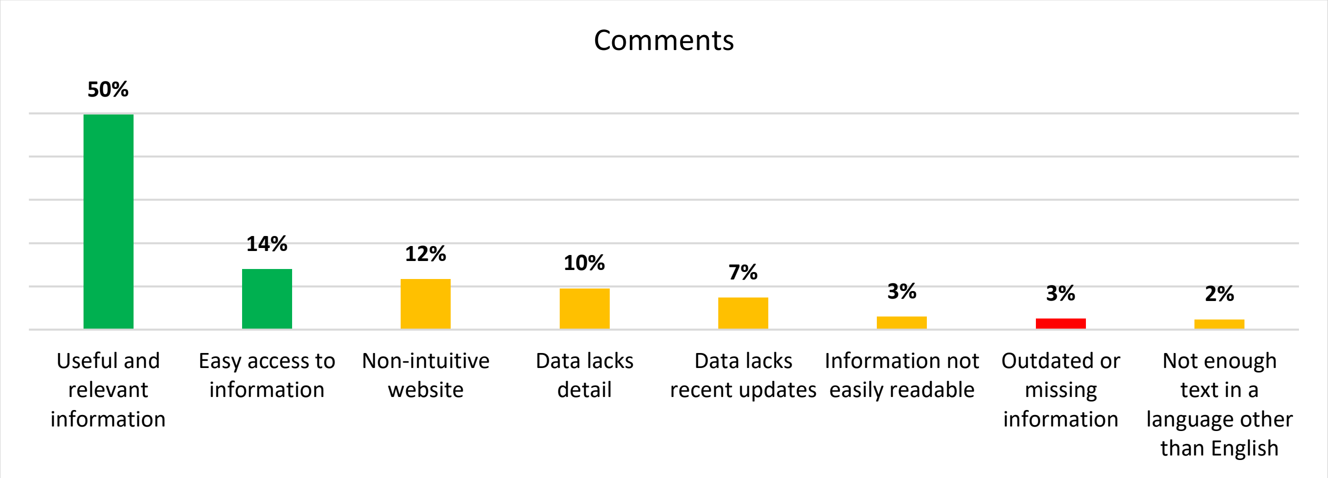

Figure 10: Free comments of the Orphanet website users (n= 459)

Among the 97% very satisfied or satisfied users, 50% considered that information provided by Orphanet is useful and relevant and 14% that information is easy to access (Figure 10), showing the same trend than last year.
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 updated frequently enough 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 of 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 3,695 respondents replied to this question, i.e. almost 80% of regular users representing 37% of the total respondents.

65% of those responding turned out to be promoters as they responded with a score of 9 or 10, 26% were passive (score of 7 or 8) and 9% were detractors (score of 0 to 6). This gives a NPS of 55,6 (Figure 11).

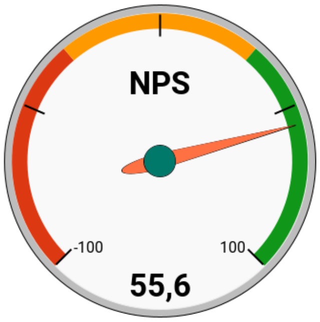

Figure 11: Orphanet Net Promoter Score (NPS) (n= 3695)

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 during 4 years : in 2019 survey, NPS was 47,8 (n=4,199); in 2021 it was 54,3 (n=5,299) and in 2022, NPS was 57,7 (n=3,303). This year, NPS has fallen slightly but remains at a quite satisfactory level.

Moreover, it is noteworthy that according to these results 65% of the respondents would recommend using Orphanet while only 9% 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 724 individuals, i.e. 16% of regular users questioned representing 7% of the total respondents.

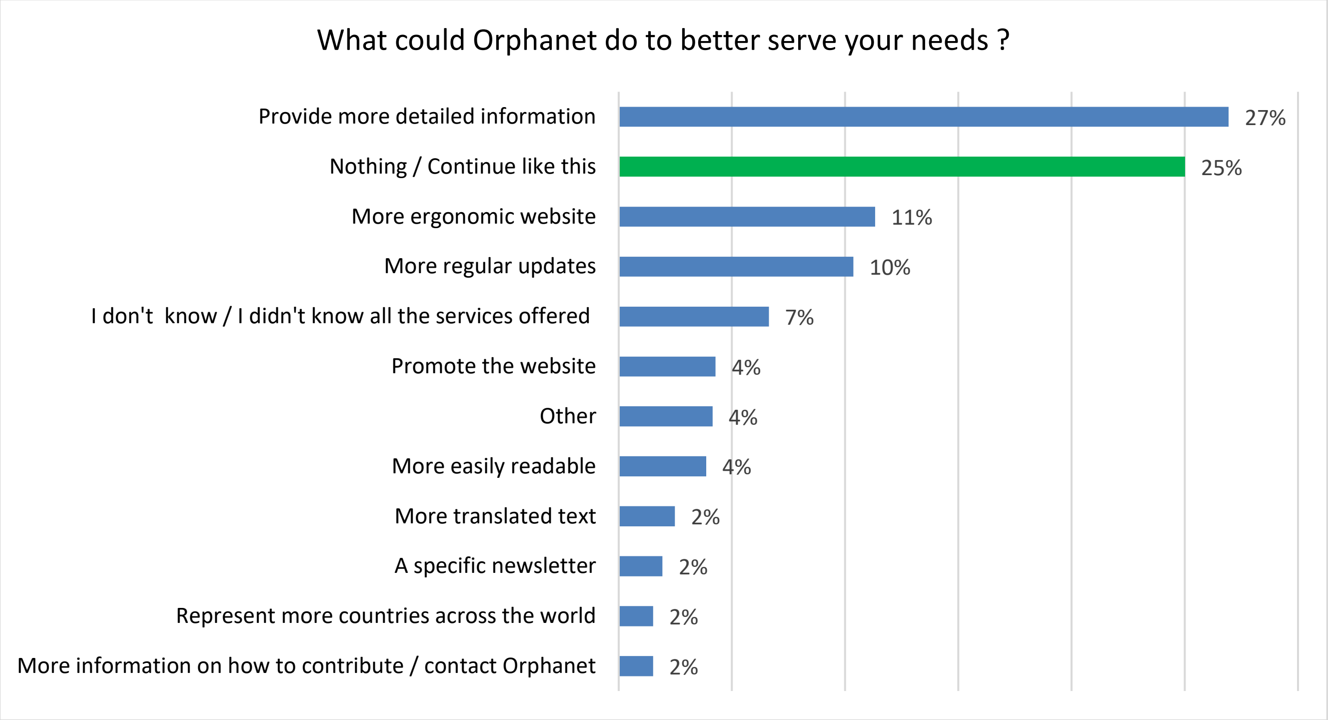

Figure 12: Free comments on what could Orphanet do to better serve your needs (n= 724)

The most frequent comments relate to the need for more detailed information (27%), a more ergonomic website (11%) 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.

It is interesting and encouraging to note that 25% of those who provided comments were satisfied by the service provided by Orphanet and left messages of encouragement and support for Orphanet's activities. Furthermore, this percentage has seen an increase compared to last year (21%).

Regarding the need for a more detailed information (Figure 13), Orphanet's users were mainly interested in more detailed information in clinical signs and symptoms (22%) suggesting that pictures, or medical imagery could be added, as well as a diagnostic aid. Although this suggestion is very interesting, Orphanet is only partially in capacity to respond to this need. Indeed, pictures are subjected to copyright and a fair selection process should be put in place with the expert community: 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. To mitigate this, Orphanet selects and disseminates high-quality articles on rare diseases that frequently present pictures or medical images.

Orphanet has recently implemented a search by clinical signs and symptoms that is not an assistance-to-diagnosis tool but that can help finding information on diseases with a combination of clinical signs (https://clinicalsigns.orphanet.app/).
In addition, we are delighted to announce the release of a tool aimed at helping front-line healthcare professionals orientate possible rare disease patients to appropriate expert care. This application is the fruit of a unique public-private partnership combining the expertise of Orphanet-Inserm and Tekkare's technology, among others. This application, called RDK (Rare Disease Knowledge), stands as the first web and mobile application specifically designed for healthcare professionals to combat diagnostic delays in patients with rare diseases, harnessing the power of the Orphanet disease-phenotype annotations and directory of centres of expertise. This medical device is for the moment only available in France but exists in a French and an English version.

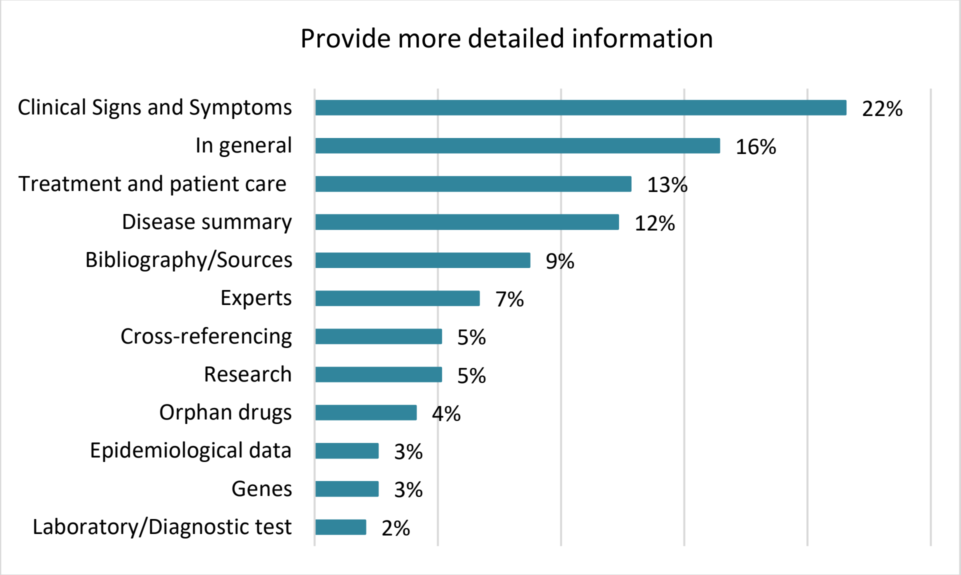

Figure 13: Free comments on what could Orphanet do about more detailed information (n= 222)

Orphanet's users are also interested in more details about treatment and patient care (13%,) suggesting improving the visibility of expert centres and emergency guidelines as well as providing information on alternative medicines, for example. 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.

Some comments also related to the need for more information in general (16%) and making the disease summary text more detailed (12%) 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 review articles providing more detailed information on specific rare diseases, when they exist.

Moreover, around 10% of Orphanet's users would like more information about sources and bibliography used to produce its data. The way disease summaries are produced is presented 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.

Regarding the need for a more ergonomic website (Figure 14), Orphanet's users comment mainly about the site's navigation (28%), the search function (20%) and the website layout (20%).

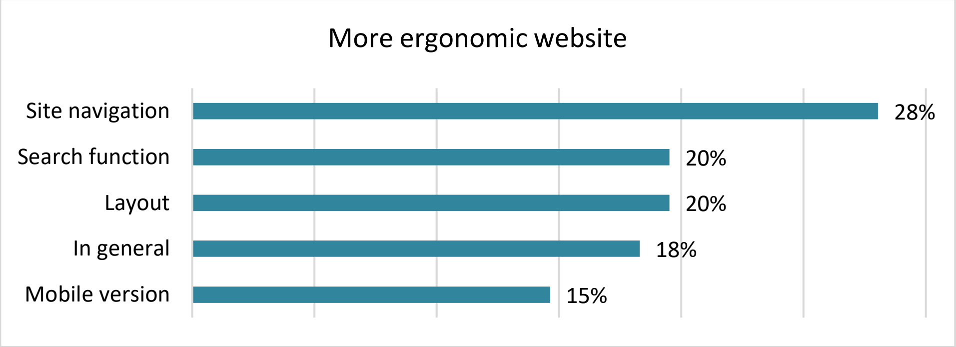

Figure 14: Free comments on what could Orphanet do about the website (n= 91)

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 a user knows that it exists. Users expressed the fact that the navigation on Orphanet is too complicated which could explain some percentage of unknown services/products in 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 15% commented on the mobile version and respondents expressed their wish to have a website more adapted for navigation via a mobile phone. The website is, nonetheless, responsive by design, but it's possible that the issue stems from the pop-up implemented for this survey.

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 or with 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 survey aimed at updating 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 largely dependent on the good will of the professionals as they are the only ones that can update their data, even if some data are collected from aggregated sources (i.e. clinical trials, research projects, orphan designations and orphan drugs, and expert centres in countries where an official designation policy exists). 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 by conctacting Orphanet national team at any time throughout the year via Orphanet'website contact page.

Orphanet must continue to improve and offer increasingly advanced services to meet the growing needs of our users. This entails ongoing attention to their feedback and constant adaptation to developments in the field of rare diseases, ensuring that we remain a reliable and relevant resource for the medical community and the affected patients. By pursuing this path of continuous improvement, Orphanet will continue to play a crucial role in promoting research and the management of rare diseases.

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 of everyone but an answer was not required and 7,361 respondents replied to this question, i.e. 75% of the total respondents.

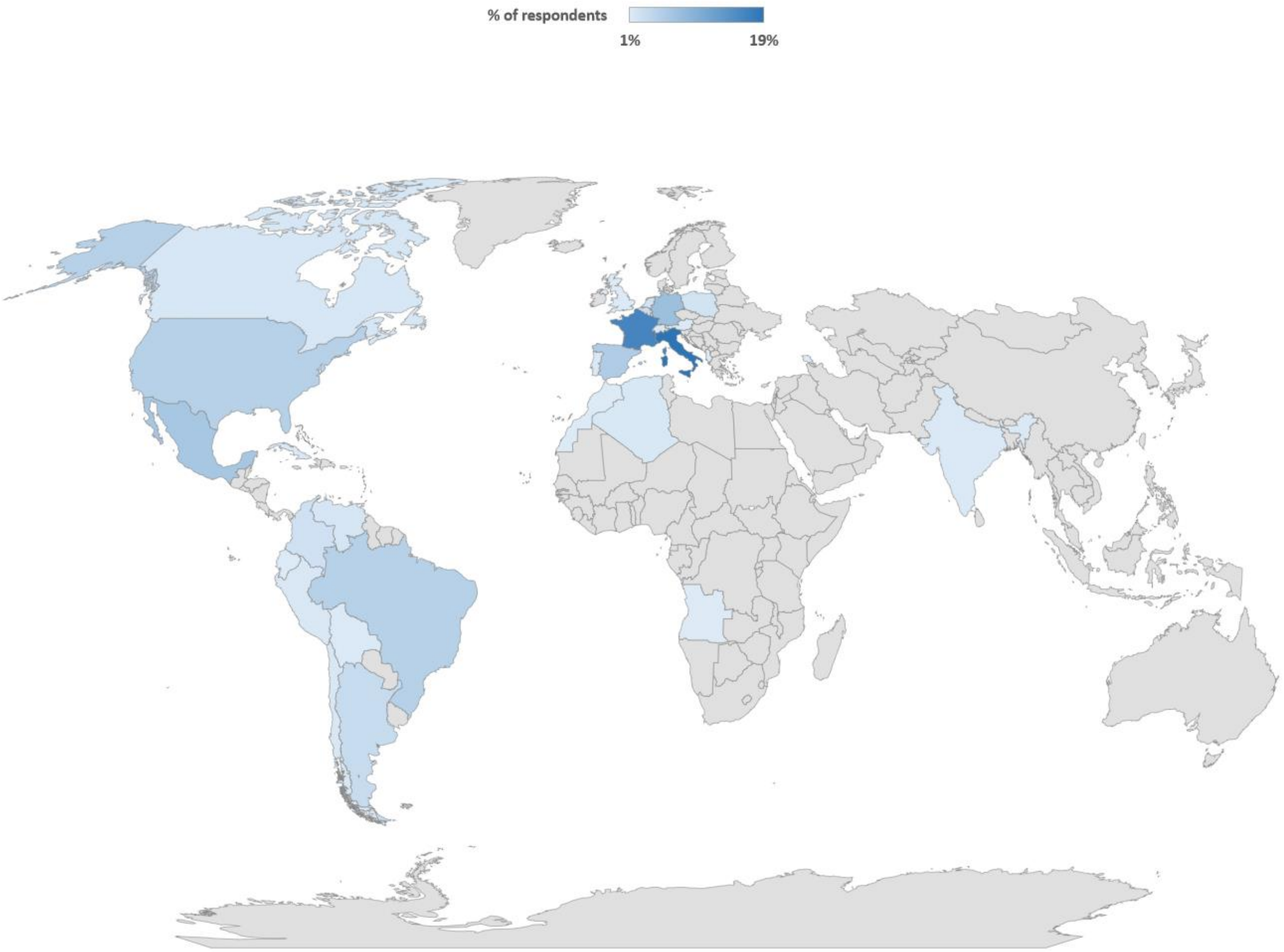

Figure 15: Countries of provenance of respondents to the satisfaction survey (n=7361)

The top ten countries replying to the survey were: Italy (n=1398, 19%), France (n=1211, 16%), Germany (n=536, 7%), Mexico (n=454, 6%), Spain (n=391, 5%), United States of America (n=343, 4,7%), Brazil (n=339, 4,6%), Argentina (n=206, 3%), Belgium (n=180, 2,5%), and Colombia (n=151, 2%).
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. 7,361 replies were registered for this question, i.e. 75% of the total respondents.

Figure 16 shows the distribution of respondents amongst these categories:

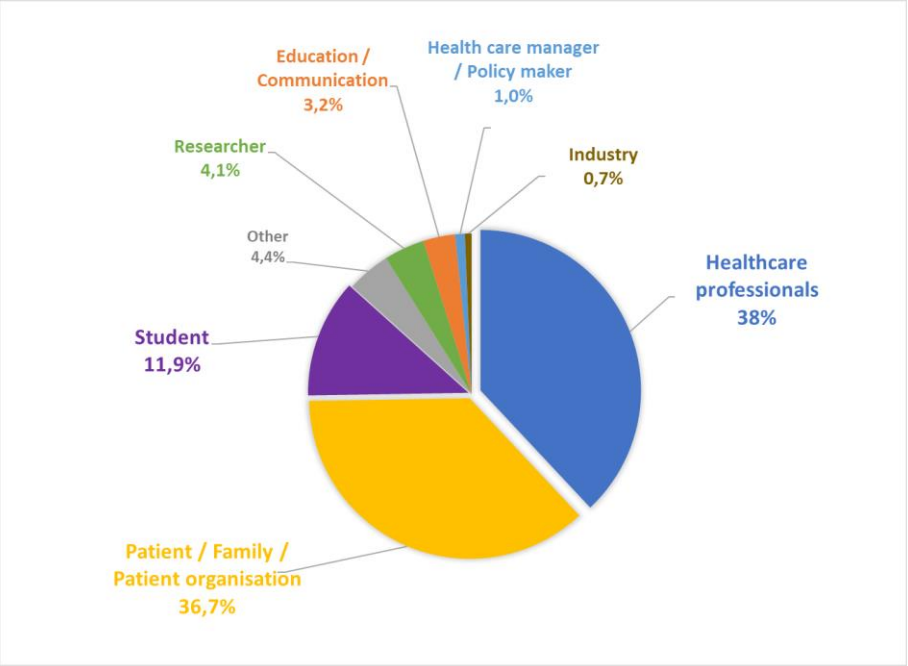

Figure 16: Types of Orphanet user (n =7361)

The largest categories of respondents are healthcare professionals (38%) and patients and their entourage including patient organisations (36,7%). These findings highlight the active involvement and participation of both healthcare professionals and patients in the field of rare diseases.

Students also replied the survey (11,9%), followed by researchers and users working in education / communication (respectively 4% and 3,2%).

The "Other" category (n=324) is mainly composed of those visiting the site for their general knowledge or curiosity, including those who were conducting 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 an increase in healthcare professionals (35% last year) who are our main users this year. Students remain the 3rd category of our users although they are less numerous than last year (14%).

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= 2,799):

Hospital specialists constitute the main category of respondents (40%) (Figure 17). Independent specialists and general practitioners each account for 14% of respondents. In total, 68% are medical doctors (compared to 72% in the last survey). There are a few more respondents identifying themselves as nurses or medical coders. Respondents from other healthcare professional categories (e.g., midwives, psychologists, physiotherapists, paramedical personnel, etc.) and other professional categories remain equally represented compared to the previous year.

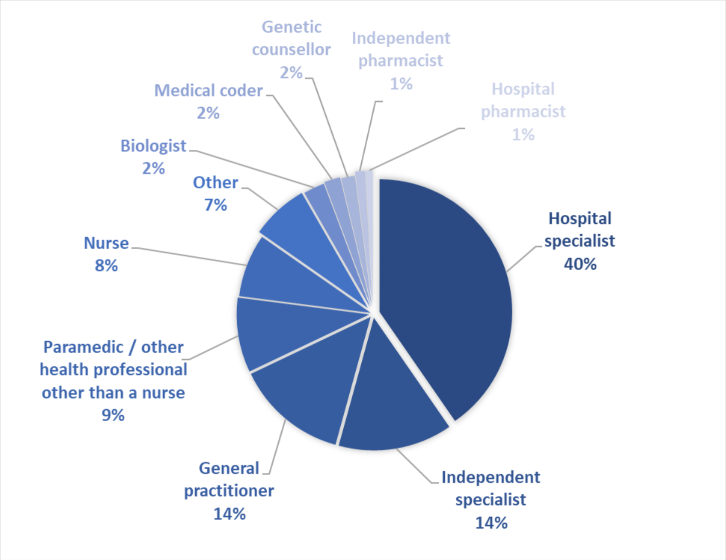

Figure 17: Types of respondents qualifying themselves as health professionals

Patient / Family / Patient organisation (n= 2,563):

Most of the people who selected this category are patients (45,5%) and family members of a patient with a rare disease (44,5%) (Figure 18). The results are globally similar to those of the previous survey.

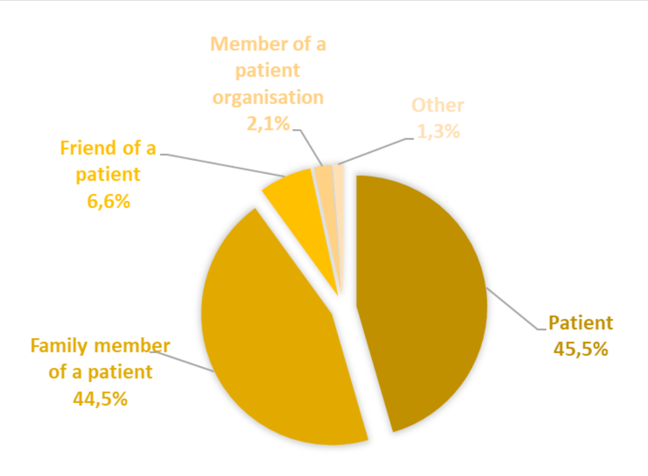

Figure 18: Types of respondents qualifying themselves as a patient, part of a patient's entourage or member of a patient organisation.

Students (n= 876):

Medical students represent 64% of this category (Figure 19). The other respondents were students in biology, physiotherapy, psychology, pharmacy, communication, information technology, etc. The results are almost similar to the last survey, medical students remain the largest category.

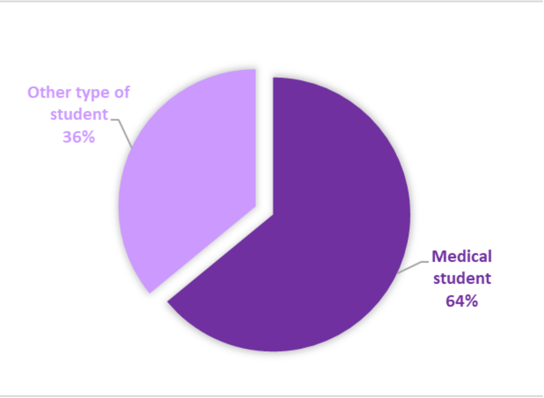

Figure 19: Types of respondents qualifying themselves as students

Researchers (n= 288):

Academic researchers represent the main sub-category of respondents working in the field of research (Figure 20) with 65%. Industry researchers and social sciences researchers represent 9% and 8%, respectively. Notably, all professional categories have maintained their representation at similar levels compared to the previous year's survey.

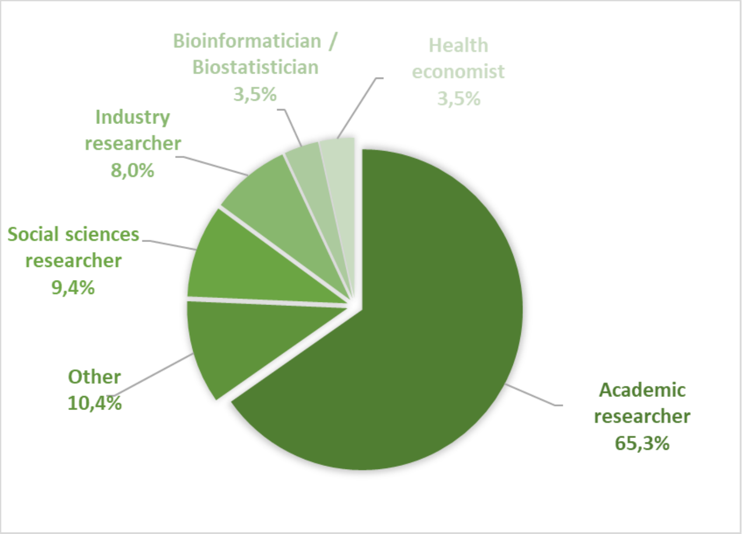

Figure 20: Types of respondents qualifying themselves as working in the field of research.

Education / Communication (n=229):

In this category, teachers are the majority, comprising 40.2% of the respondents (Figure 21), but this represents a significant decrease compared to the previous year's survey of 57%. Social workers form another important sub-category, representing 15.7% of the participants. The administrative education staff, as well as professionals in roles such as librarian, translator, and journalist, have remained consistent with their representation levels observed in the last survey.

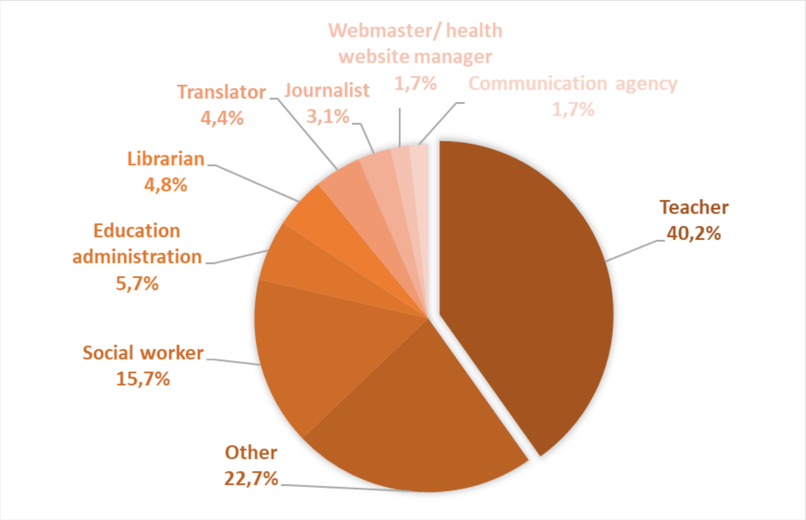

Figure21: Types of respondents qualifying themselves as working in education/communication.

Health care manager / policy maker (n= 70):

In this category, 31% work in health services administration or insurance (public, private or administration) and 24% in hospital administration (Figure 22). There is a decrease in respondents working in health services administration (45% of this category of users in the last survey).

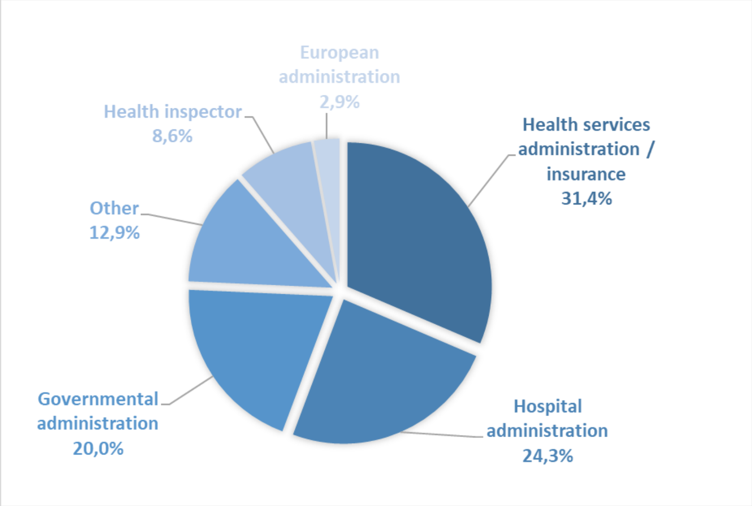

Figure22: Types of respondents qualifying themselves as working in the field of health care management/policy making.

Industry (n=48):

56% of the respondents work in the biotechnology or pharmaceutical industry, while 25% are consultants in this sector (Figure 23). It is worth noting that this distribution shows a consistent trend compared to the last survey, with these two categories remaining as the main sectors

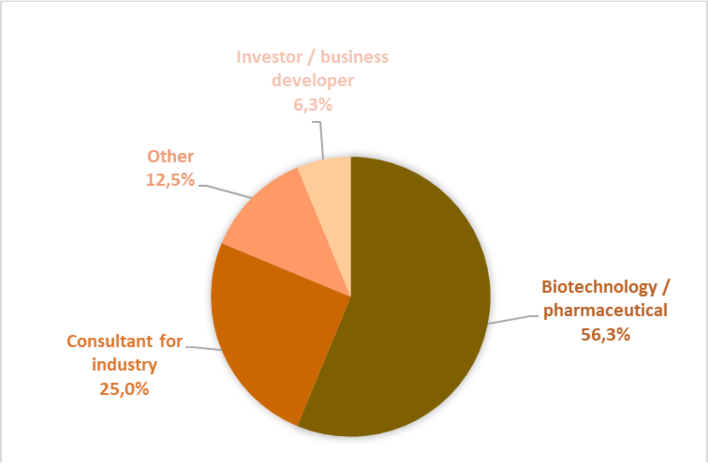

Figure 23: Types of respondents qualifying themselves as working in the biotechnology or pharmaceutical industry

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 7,257 respondents replied to this question, i.e. 74% of the total respondents.

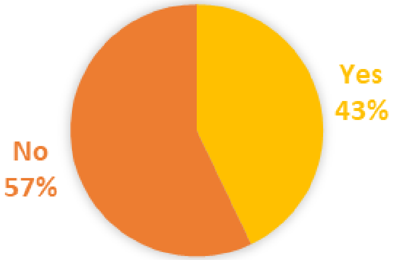

Figure: Repartition of respondents considering having a expertise in rare disease (n=7257)

43% of the respondents indicated that they had expertise in the field, with 48% belonging to the healthcare professional category and 33% from the Patient/Family/Patient organization category. These results are almost similar to those of last year.

On the other hand, the majority of our users (57%) responded 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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