Orphanet Report Series
Reports collection

2024

2024 User Satisfaction Survey of the Orphanet Website

www.orpha.net

Co-funded by
the Health Programme
of the European Union

TABLE OF CONTENTS

METHODOLOGY

This year's satisfaction survey was conducted in one phase launched in June 2024 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.

The on-line survey was designed using the online Survey Monkey tool. It 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 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 4,976 users responded to the survey this year. There are nearly half as many respondents as last year (9,852 respondents), but it is still sufficient for a meaningful analysis.

The results from responses in all languages were consolidated and then analysed. The results of this analysis are presented in this report with elements of comparison as regards to 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 responses as they wanted. At least one response to this question was required. 4,976 respondents replied to this question, i.e. all of the respondents.

A large majority of our users (63,2%) discovered Orphanet via a search engine like Google (Figure 1). Word of mouth was the second source of discovery of Orphanet (20,7%).
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 (70%) said they had discovered Orphanet through their studies or work.

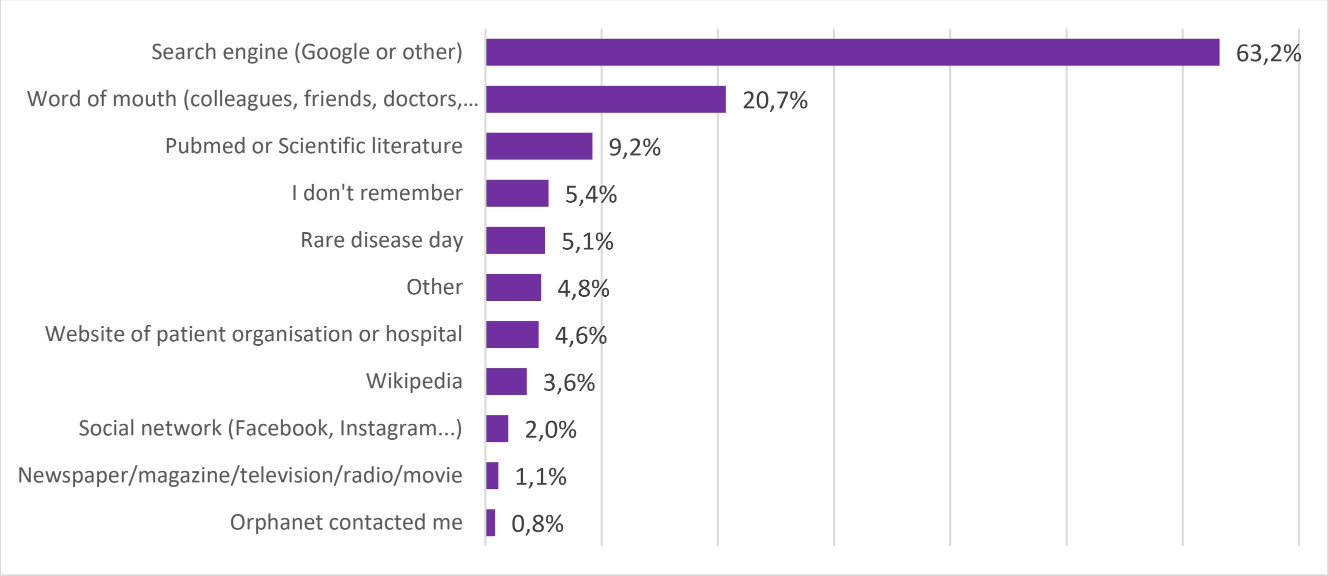


Figure 1: Mode of discovery of Orphanet by respondents (n=4976)

These results are comparable to last year's results: 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 still on the rise (20,7% vs 15,2% last year and 14% 2 years ago).
The access via scientific literature has also increased (9,2% vs 6,5% last year). The remaining vectors are marginal, as in the last survey, compared to the first two. These results are equivalent in all the languages of the survey.

In conclusion, these results show that web search engines remain, by far, the main way of discovering 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. 4,976 respondents (100%,) replied to this question.

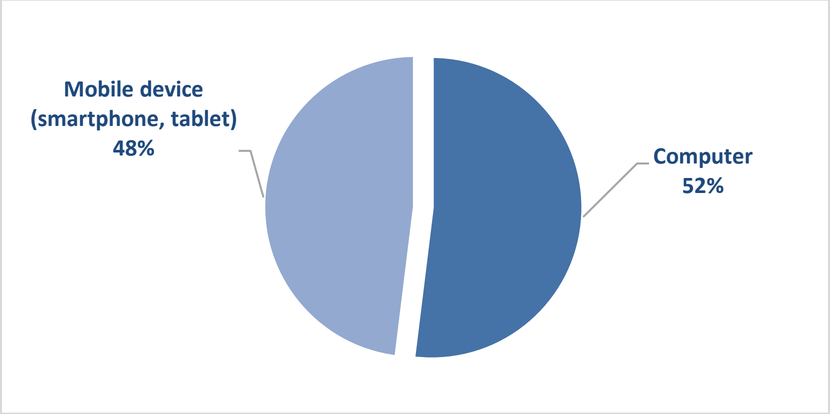


Figure 2: Mode of accessing Orphanet by respondents (n=4976)

52% of respondents accessed Orphanet via a computer, while 48% used a mobile device (smartphone or tablet) with an Internet connection (Figure 2). This result contrasts significantly with last year, when 74% of respondents reported accessing Orphanet via a mobile device.

The shift in how respondents accessed Orphanet, from predominantly mobile devices last year (74%) to a more balanced split this year (52% via computer and 48% via mobile devices) could be due to the professional profile of the respondents. The large increase in the number of healthcare professionals (see question 12), particularly hospital specialists, who took part in the survey this year, and who may be more accustomed to using computers for work, could explain the increased use of computers. In addition, Orphanet has improved several pages on its site, and some users who previously preferred mobile access may now prefer to use a computer for a better user experience.

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. 4,547 respondents replied to this question, i.e. 91% of the total respondents.

The results show that the majority of visitors consult Orphanet to learn more about a rare disease by reading its disease summary text (60%). The two main types of information sought are identifying the clinical signs associated with a rare disease (53%) and learning about rare diseases in general (46%). This top three is consistent with last year, but the order has changed: learning about a rare disease through its summary text and finding clinical signs have moved ahead. This shift may suggest that users are now seeking more detailed and specific information.

This percentage can be correlated with question 4, which tells us that 36% of respondents were visiting the Orphanet website for the first time, less than last year. More regular users responded to the survey this year (64%), which may explain their need for more detailed information. Indeed, new users are more inclined to look for general information than regular users.

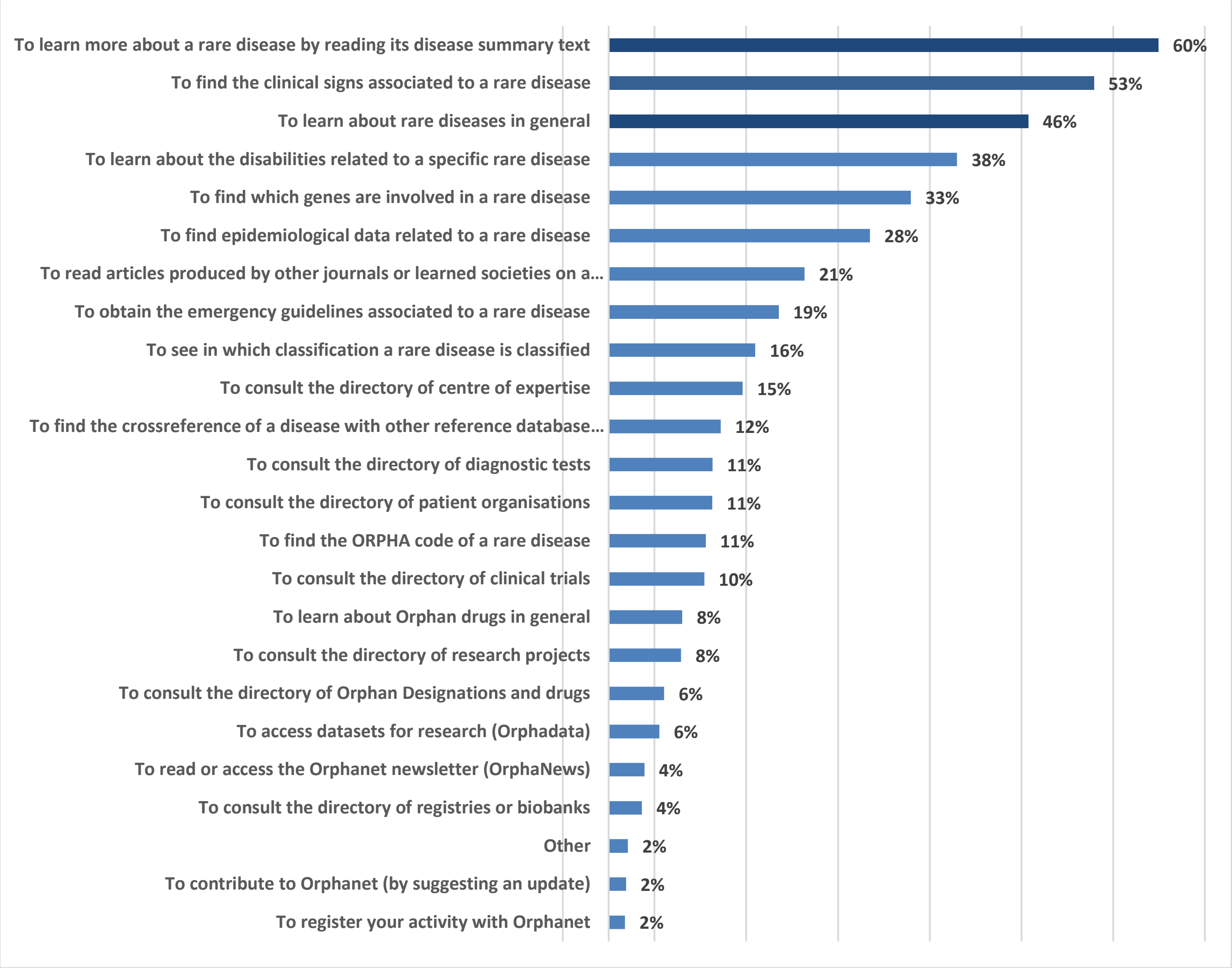


Figure 3 : Information sought by respondents during their connection to Orphanet (n=4547).

Our visitors also usually look for information about the disabilities related to a specific rare disease (38% vs 28% last year), to find which genes are involved in a rare disease (33% vs 25%), to find epidemiological data related to a rare disease (28% vs 19%), to read articles produced by other journals or learned societies on a rare disease (21% vs 16%) and to obtain the emergency guidelines associated with a rare disease (19 vs 15%). Regarding directories offered by Orphanet, the directory of centres of expertise is the most usually consulted (15% vs 10%), then the directory of diagnostic tests (11% vs 9%). These results are the same as in last year's survey but in a larger proportion.

Visitors who answered “Other” specified consulting Orphanet to search professional experts and contact details or 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. 4,505 respondents (90%) replied to this question.

Around 36% of respondents were visiting Orphanet for the first time whereas 64% are regular users (i.e. 2,889 respondents) (Figure 4).

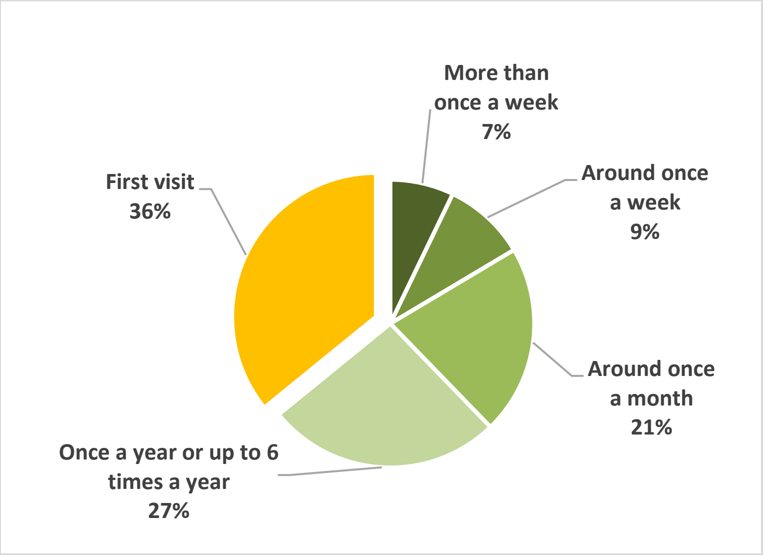


Figure 4 : Visiting frequency of respondents (n=8771)

There are less first-time visitors this year compared to the last survey (36% compared to 47% last year). Moderately regular users (several times a year) have increased (48% compared to 39% last year) and there are slightly more frequent users (≥ once a week) than in the last survey (16% vs 14%).

The same trend as last year is observed: it seems that we have more and more regular users (64% this year compared to 53% last year and 51% 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 to respondents to tell us what we should 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 "regular users", and representing 2,889 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 regard Orphanet's 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 statement,s but an answer was not required. 2,835 respondents answered this question, i.e. almost all regular users (98%) representing 57% of the total respondents.

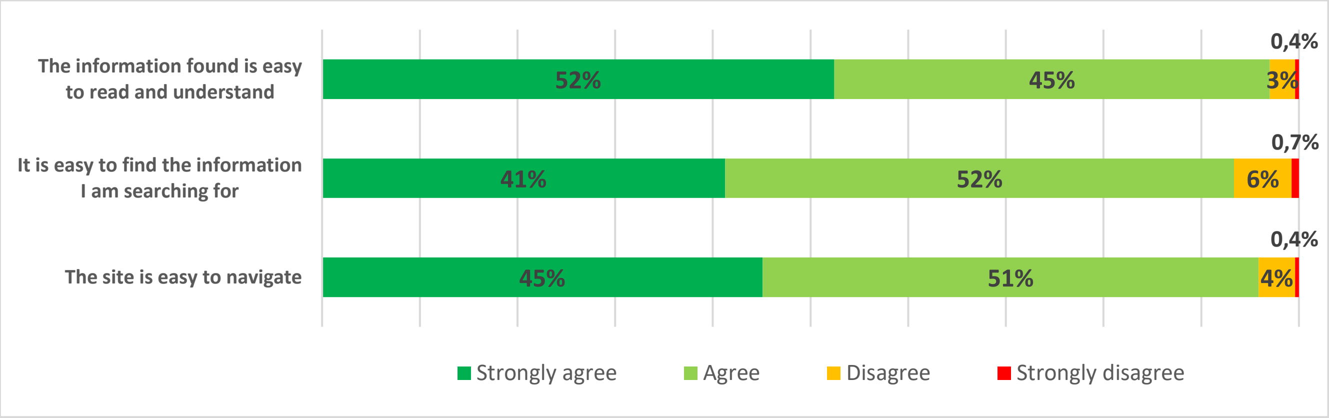


Figure 5: Segmentation of the response rate on the ease of use the Orphanet website and to understand the information found (n=2835)

These results show that most of the respondents (around 95%) 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 (3 to 7%) disagree or strongly disagree with these statements and what seems most problematic for users is finding the information they're looking for.

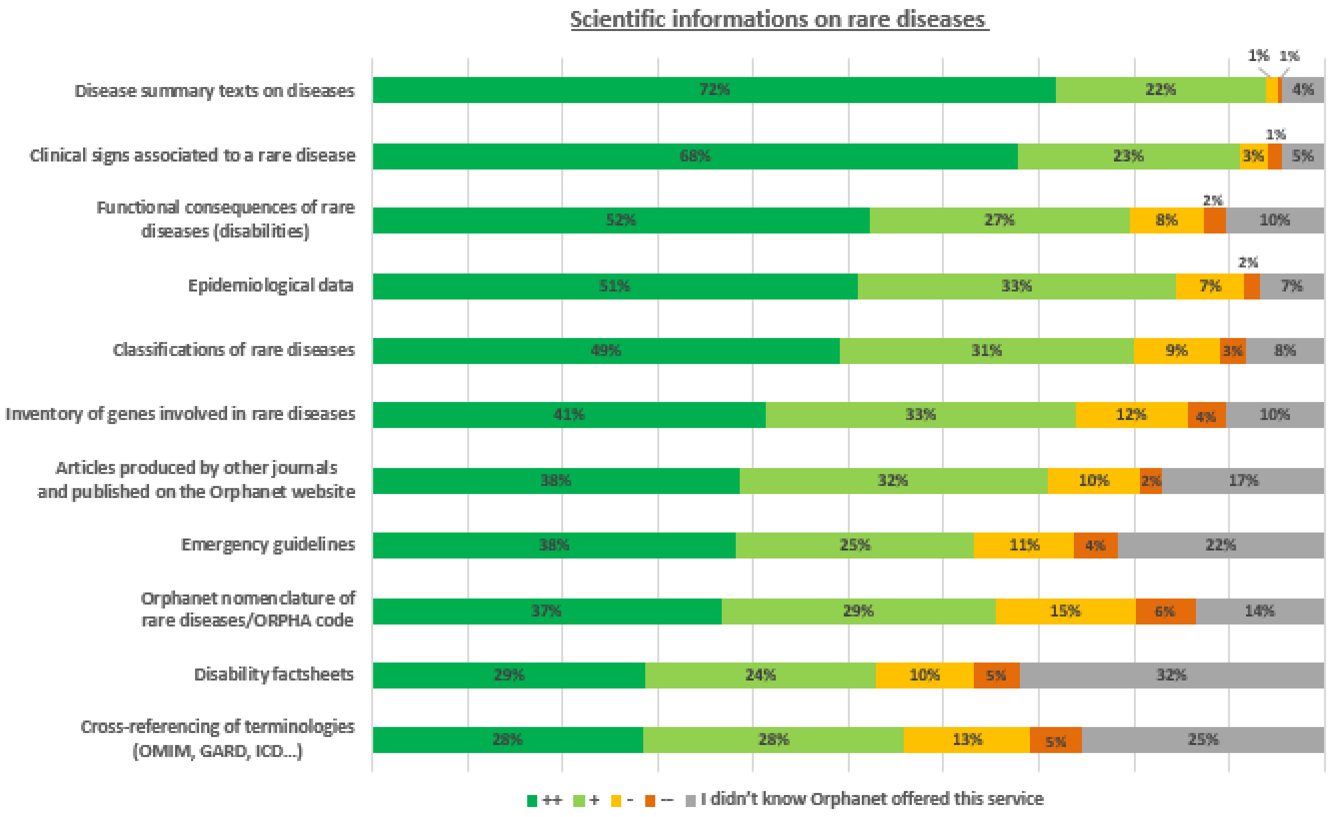
Compared to last year's survey, users agree even more with these 3 statements but these results should, however, be considered in relation to questions 6, 8 and 10. In these questions, we asked how useful they found Orphanet services, how satisfied they are and why and what Orphanet could do to better serve its users. Answers to these questions showed that users do not know certain Orphanet functionalities, resources or services and that Orphanet must continue its efforts to continuously update the data and make its website 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?

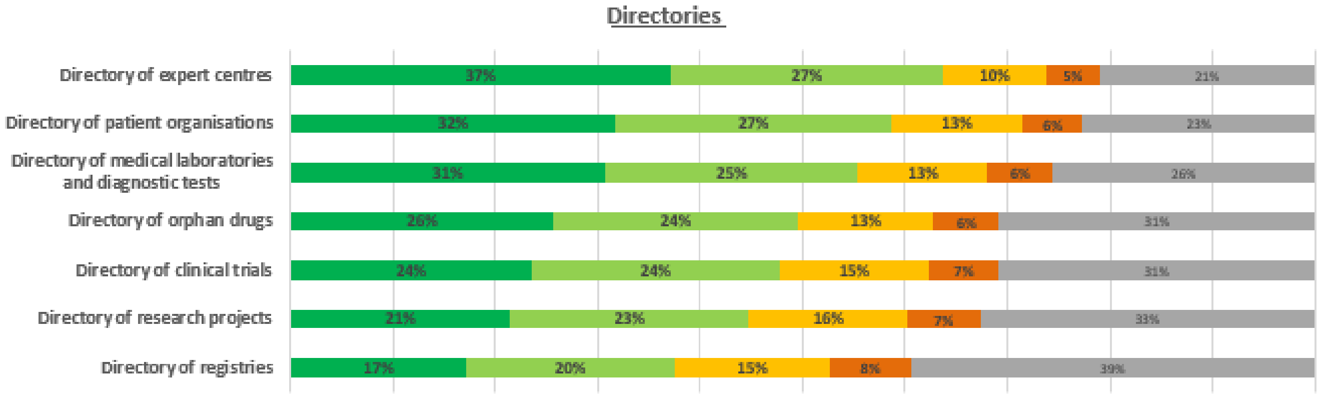
This question aims to determine the utility and users' knowledge of the various services/products offered by Orphanet. Respondents were asked to rate (++, +, -, --) each service/resource or to specify that they did not know this service/product.

An answer was not required for all services / products and 2,372 respondents replied to this question, i.e. most regular users (82,%) representing 47% of the total respondents.

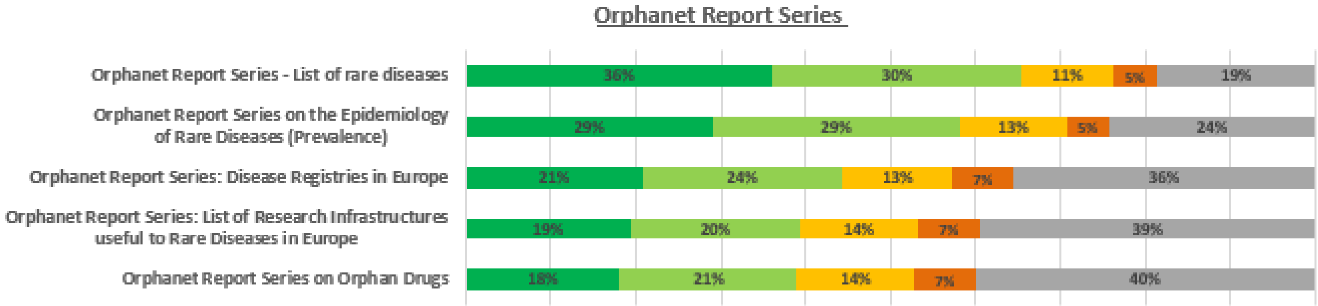
The results (Figure 6) are presented according to 4 categories of products/services offered by Orphanet: Scientific information on rare diseases ; Directories ; Orphanet Report Series ; Other specific products/ services.



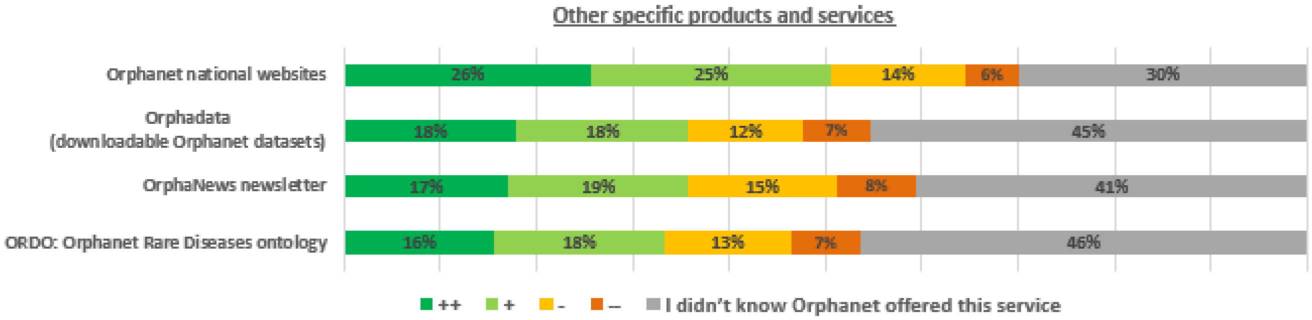
6.a



6b.



6c.



6d.

Figure 6: Segmentation of response rate on utility and knowledge of services/products offered by Orphanet (n=2372)

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 (94%), the clinical signs associated to a rare disease (91%), followed by epidemiological data (84%), classifications of rare diseases (80%) and functional consequences of rare diseases (79%). This trend is not exactly the same as last year: although the disease summary texts remain the best known and most useful scientific information provided by Orphanet, the clinical signs associated to a rare disease have increased in visibility (5% didn't know this service vs 19% last year) and usefulness (67% last year). The inventory of genes involved in rare diseases is also considered as a useful service for the respondents (74%) as well as articles produced by other journals and published on the Orphanet website (70%), followed by the Orphanet nomenclature of rare diseases / ORPHAcodes (66%) and Emergency Guidelines (63%), less well known than other services. Alignments with other terminologies and disability factsheets, although less known to respondents (respectively 25% and 32% of Orphanet users didn't know about these services), are still useful for around 55% 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.

Regarding the directories of expert resources offered by Orphanet (Fig. 6b), the most recognised and useful for our respondents remains, as in the previous year, the directory of expert centres (64%). Following in second position is the directory of patient organizations and the directory of medical laboratories/diagnostic tests, considered useful by 59% and 56% of respondents, respectively. The other directories, which focus on research-related services (registries, research projects, and clinical trials), along with information on orphan drugs, are less familiar to the respondents. Indeed, 31% to 39% of Orphanet users were unaware of these services. The research-related directories may be perceived as more complex or less accessible for the general public, making them less known or utilised, compared to patient-related directories that are more immediately relevant to patients, families, and clinicians. Orphanet might need to invest even more effort in promoting its expert centres and patient organisation directories, as these are crucial for many users seeking immediate support. Additional outreach or simplification might be needed to raise awareness of the research-related resources.

Orphanet also offers different "Report Series" (Fig.6c). The Orphanet Report Series listing rare diseases is the best known and most useful for our responding users (66%) followed by the Orphanet Report Series on the Epidemiology of Rare Diseases (58%). The Orphanet Report on Registries and the report presenting the list of Research Infrastructures are not well known to our users (respectively 36 and 39% didn't know about these services). Similarly, 40% of users were unfamiliar with the report on Orphan Drugs.
Since last year, the format of several 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. It is important to note that nevertheless these reports are perceived as more useful than not by Orphanet users.

Concerning the other specific products and services (Fig.6d) provided by Orphanet, they are not well known to respondents, which contrasts with last year's survey that showed a rise in use, particularly for Orphadata and ORDO. This year, around 45% of respondents are unaware of these services. This can be explained by the fact that Orphadata and ORDO are becoming increasingly known amongst researchers and industry professionals, who are less represented in this survey. Indeed, these users are accessing the dedicated platforms (Orphadata or ORDO) directly, rather than going through the main Orphanet site, which reduces their visibility in the survey results. This may also indicate that professionals such as researchers prefer using specialised platforms that are better suited to their needs, while the general public or clinicians, the majority of respondents to this survey, continue to rely on Orphanet website for other services. Concerning the OrphaNews newsletter, it remains unknown to 45% of respondents, but efforts are underway such as the promotion through social media. Orphanet national websites remain also little-known probably because they are not highlighted on the Orphanet site and have their own access, but still useful for 51% of respondents.

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 satisfied they are and what Orphanet could do to better serve its users : it emerges from these questions that 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 rang eof products and services Orphanet offers. Orphanet should take action to improve Orphanet website users experience enhancing the visibility of lesser-known resources through improved website navigation within the navigation structure that can make the information easier to find.

Overall, these results show that services/products offered by Orphanet serve the needs of the majority of respondents.

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 2,466 respondents replied to this question, i.e. most regular users (85%) representing 50% of the total respondents.

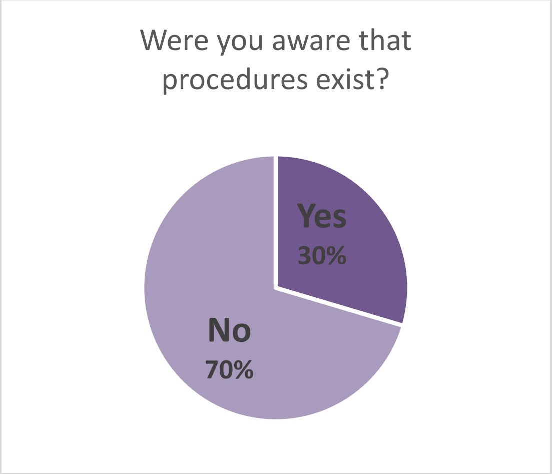


Figure 7 : Repartition of the respondents about knowledge of Orphanet procedures (n=2466)

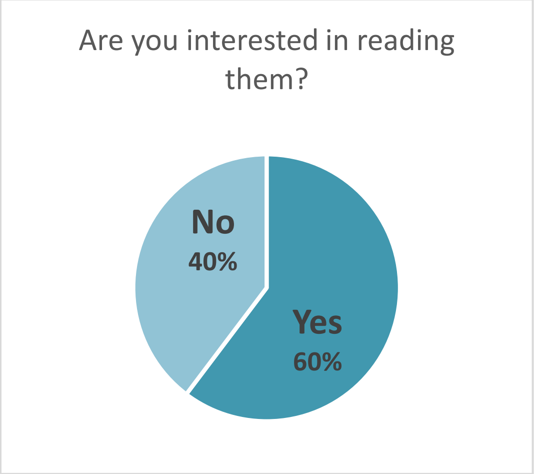


Figure 8: Repartition of the respondents interested in reading Orphanet procedures (n=2466)

As last year, the majority of respondents (70%) did not know of the existence of these procedures (Figure 7) but 60% 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 and also in the documentation displayed with associated Orphadata datasets. 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 2,387 respondents replied, i.e. 83% of regular users representing 48% of the total respondents.

Only one answer was possible plus a non-mandatory free field to add any comment that could explain the answer.

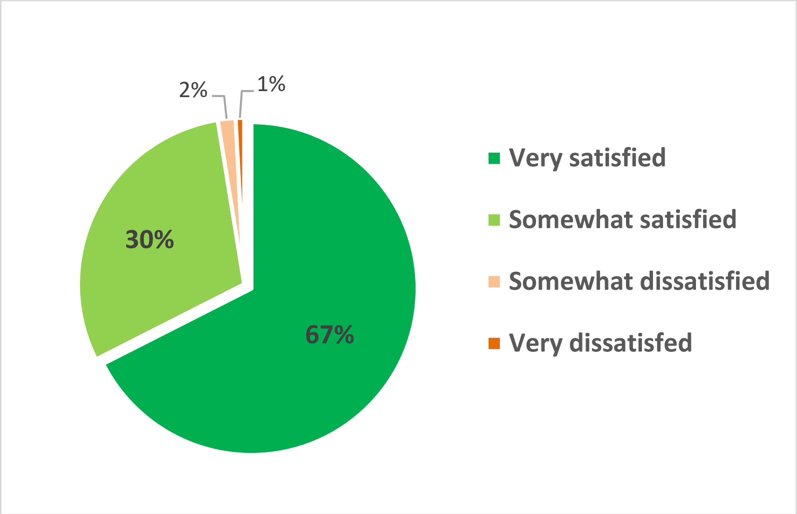


Figure 9: Global satisfaction of the Orphanet website users (n= 2387)

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. Comments were aimed at ascertaining in more detail what our users think of Orphanet and were provided by 489 individuals.

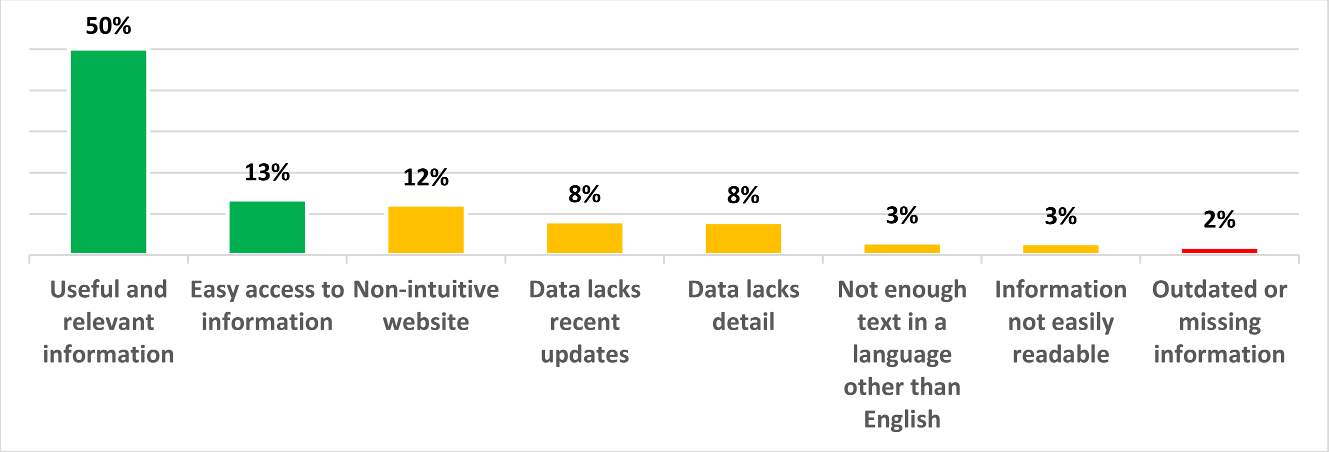


Figure 10: Free comments of the Orphanet website users (n= 489)

Among satisfied users who provided additional comments to explain their answers, 50% highlighted that the information provided by Orphanet is useful and relevant, while 13% noted that the information is easy to access (Figure 10), reflecting the same trend as last year.

On the other hand, 2% of respondents were dissatisfied, and 1% were very dissatisfied. The main comments from dissatisfied users indicated that the site is not sufficiently user-friendly. Additionally, they mentioned that the information is not updated frequently enough and lacks sufficient detail. Another reason for dissatisfaction is that some users would prefer the information to be more easily understandable for non-health professionals and translated into their native languages.

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 2,389 respondents replied to this question, i.e. almost 83% of regular users representing 48% of the total respondents.

70% of those responding turned out to be promoters as they responded with a score of 9 or 10, 23% were passive (score of 7 or 8) and 7% were detractors (score of 0 to 6). According to these results 70% of the respondents would recommend using Orphanet while only 9% would not. This gives a NPS of 63,5 (Figure 11).

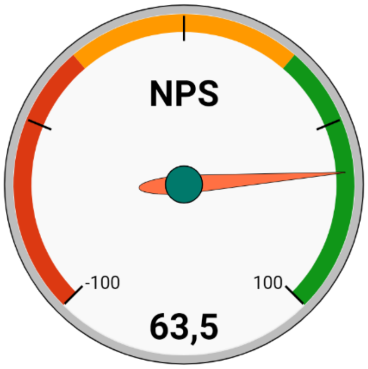


Figure 11: Orphanet Net Promoter Score (NPS) (n= 2389)

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 significantly increased over the past five years (Figure 12). In the 2020 survey, the Net Promoter Score (NPS) was 47.8 (n=4,199); in 2021, it rose to 54.3 (n=5,299). By 2022, the NPS reached 57.7 (n=3,303), and although it fell slightly in 2023, it remained at a satisfactory level of 55.6 (n=3,695). This year, the NPS has increased further, reaching an impressive 63.5 (n=2,389).

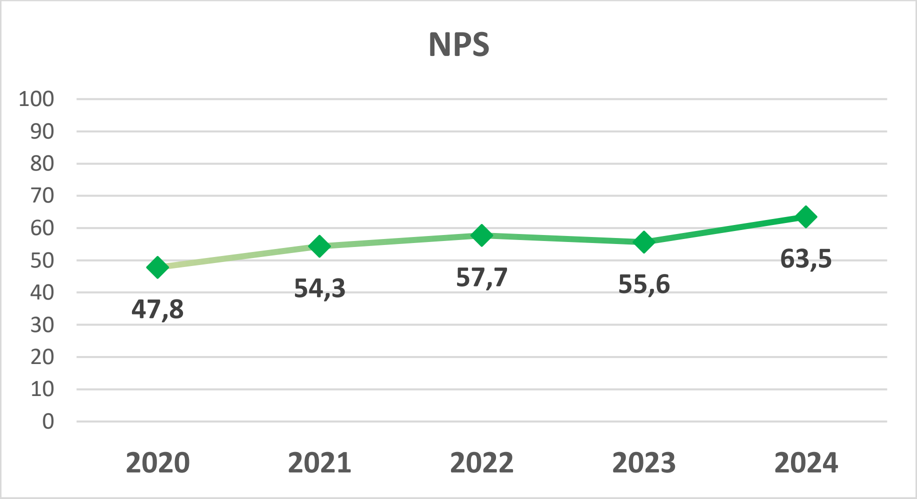


Figure 12: Orphanet Net Promoter Score (NPS) evolution over the year

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 578 individuals, i.e. 20% of regular users questioned representing 12% of the total respondents.

The most frequent comments relate to the need for more detailed information (29%), a more ergonomic website (14%) and more regular updates (8%) (Figure 13). 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.

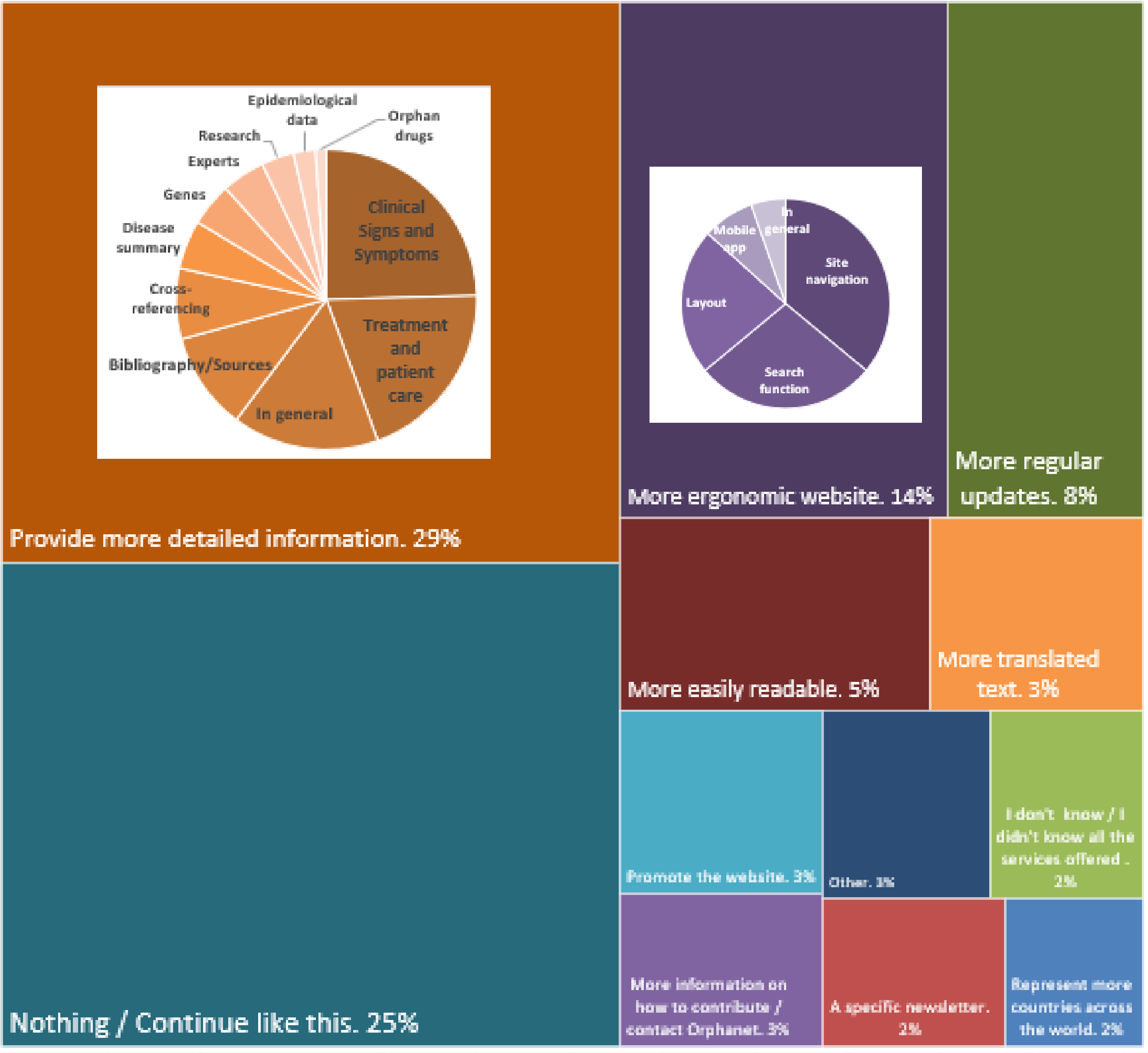


Figure 13: Free comments on what could Orphanet do to better serve your needs (n= 578)

Regarding the need for a more detailed information, Orphanet's users were mainly interested in more detailed information in clinical signs and symptoms (25%), 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's main objective, 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 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/). However, this facility is not longer available on the Orphanet website since we co-developed RDK. RDK is a tool (co-developed by Orphanet) 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^{TM} (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, and is aslo available as a web application.

Orphanet's users are also interested in more details about treatment and patient care (20%,) that is to say more details on care, medical treatments, impact on personal and professional life and suggest to improve 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, especially as concerns 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%) such as expanding the summary to include 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 11% 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. In addition, we are now dislaying the principal sources supporting the creation of a rare disease in our database.

Regarding the need for a more ergonomic website, Orphanet's users comment mainly about the site's navigation (36%), the search function (28%) and the website layout (23%).

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 for 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. It is worth noting that Orphanet's website technology has been recently overhauled, but it is too early to see the impact of these developments on users' satisfaction. We have plans to improve even more the website ergonomy in the future.

The third most frequent request is that Orphanet updates its data more frequently (8%, Figure 13). 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: 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 contacting 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.

All respondants were asked this question but an answer was not required and 3,857 respondents replied to this question, i.e. 77% of the total respondents.

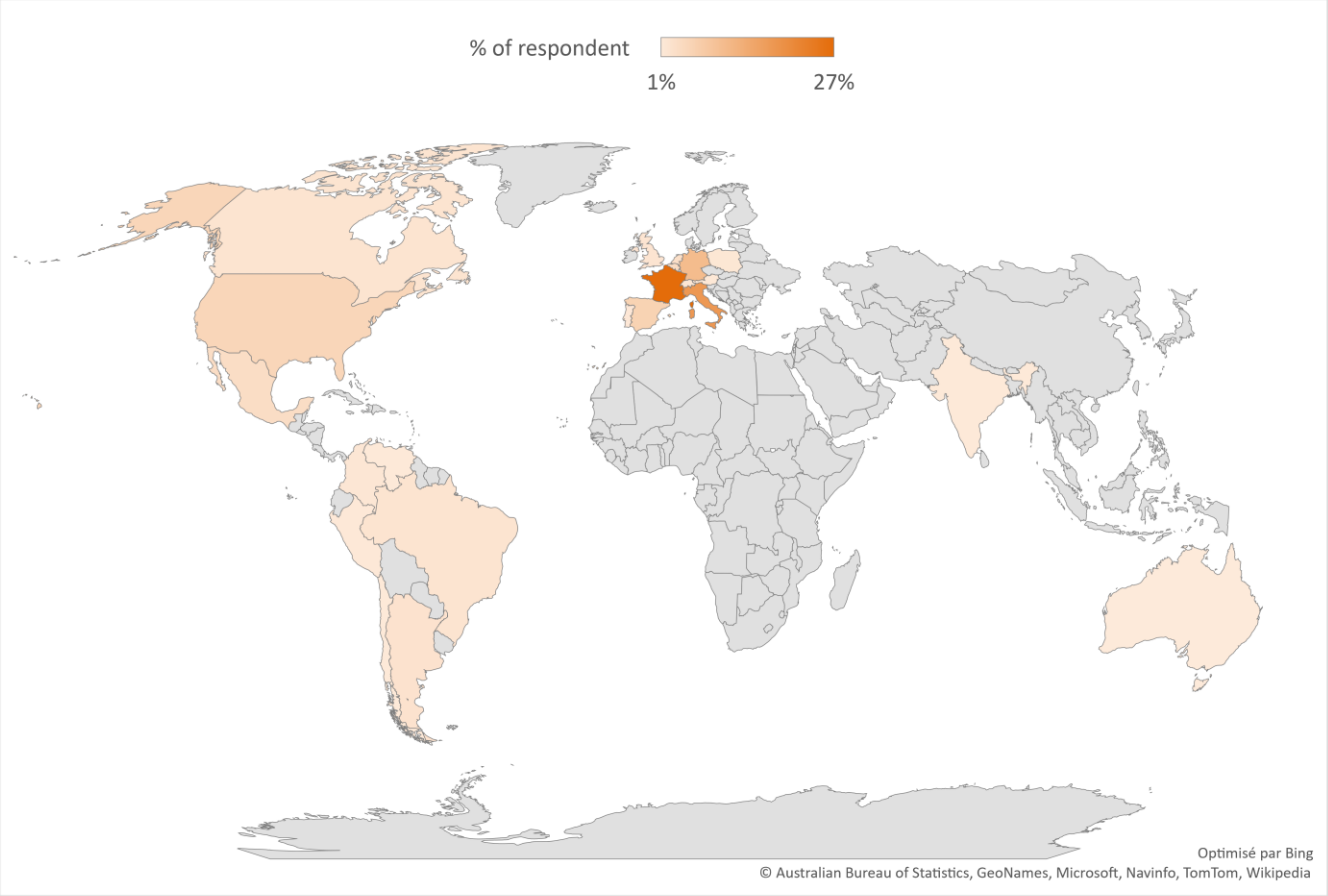


Figure 14: Countries of provenance of respondents to the satisfaction survey (n=3857)

The top ten countries replying to the survey were: France (27%), Italy (17%), Germany (10%), Spain (5%), United States of America (4%), Belgium (3%), Mexico (3%), Netherlands (3%), Argentina (2%), Brazil (2%).

This is almost the same top 10 countries as in the last survey with slightly different proportions and the entrance of the Netherlands. The consistency in the top 10 countries suggests a stable base of respondents from certain regions. The overall distribution of responses highlights strong engagement from European countries.

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. 3,857 replies were registered for this question, i.e. 77% of the total respondents.

Figure 15 shows the distribution of respondents amongst these categories:

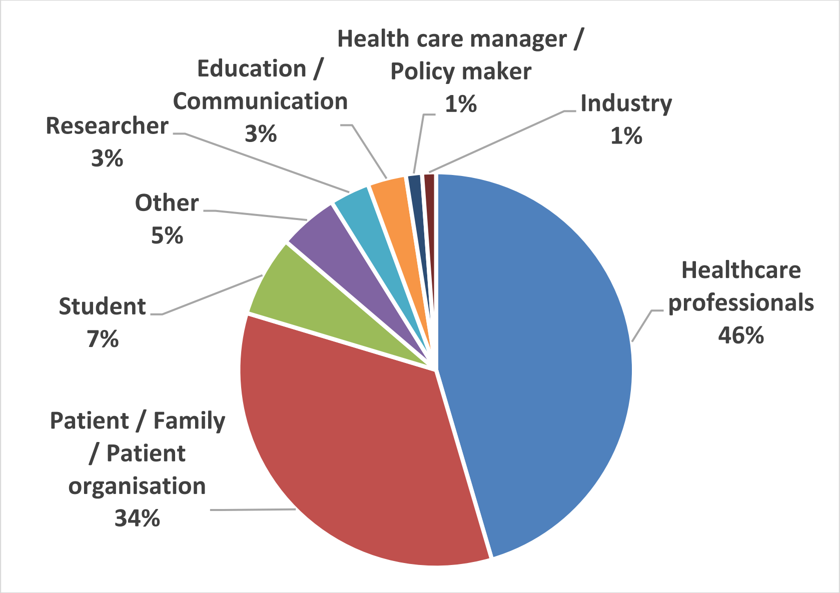


Figure 15: Types of Orphanet user (n =3857)

The largest categories of respondents are healthcare professionals (46%) and patients and their entourage including patient organisations (34%). 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 (7%), together with researchers and users working in education / communication (3% for both).The "Other" category (n=188, 5%) 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. Health care manager, Policy maker and users working in Industry are a minority (1%).

Compared to last year, we obtained the same result for the 2 main categories of users but with a large increase in healthcare professionals (38% last year) who are our main users. Patients and their networks continue to be highly represented, consistent with last year. This reinforces the importance of the patient voice and lived experience in shaping discourse around rare diseases. Students remain the 3rd category of our users although they are less numerous than last year (12%).

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=1753):

Hospital specialists constitute the main category of respondents (37%) (Figure 16). Independent specialists and general practitioners each account for 15% of respondents. In total, 67% are medical doctors, same results as in the last survey. There are a few more respondents identifying themselves as nurses or other healthcare professional categories (e.g., midwives, psychologists, physiotherapists, paramedical personnel, etc.). Biologists and medical coders are slightly more numerous this year. Genetic counsellors and pharmacists remain a minority.

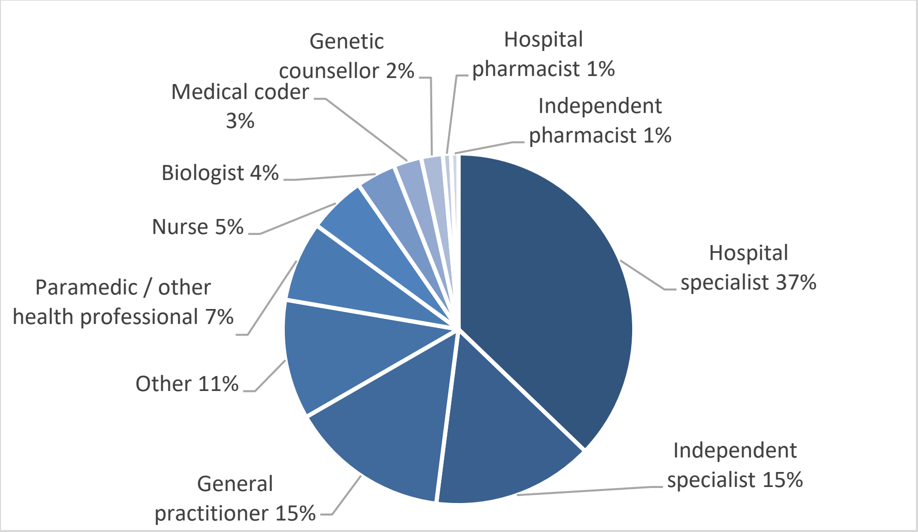


Figure 16: Types of respondents qualifying themselves as health professionals

Patient / Family / Patient organisation (n=1319):

Most of the people who selected this category are patients (55%) and family members of a patient with a rare disease (34%) (Figure 17). The results are globally similar to those of the previous survey with an increase of the number of patients (45% last year). This large proportion of patients suggests considerable interest or need and may reflect patients' desire to be more involved in health research, policy and practice. Family members of patients also continue to represent a significant proportion of respondents, highlighting the critical role they play in supporting and advocating for patients with rare diseases.

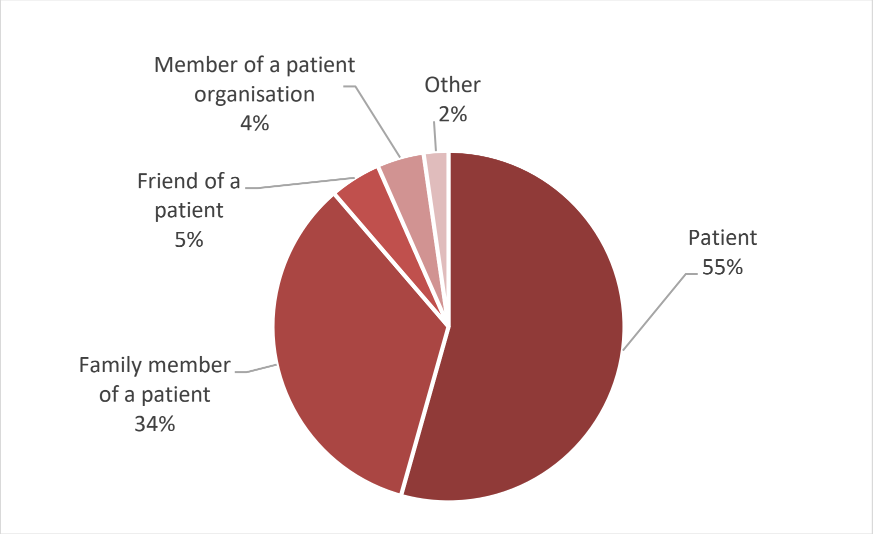


Figure 17: Types of respondents qualifying themselves as a patient, part of a patient's entourage or member of a patient organisation.

<u>Students (n= 255):</u>

Medical students represent 72% of this category (Figure 18). The other respondents were students in biology, physiotherapy, psychology, pharmacy, communication, information technology, etc. Medical students remain the largest category, with a larger proportion this year (64% last year). Overall, the result reflects the growing engagement of medical students.

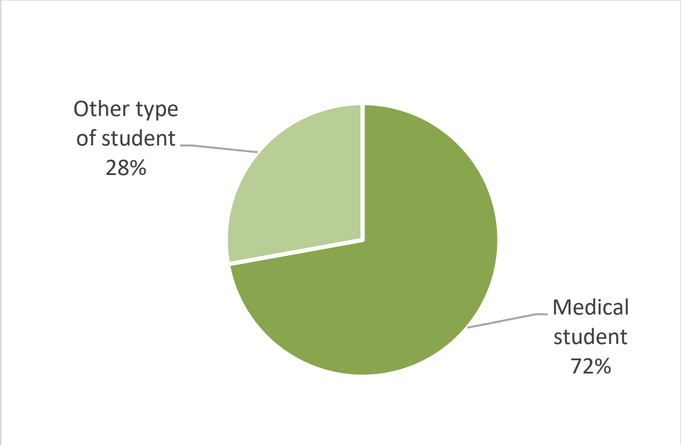


Figure 18: Types of respondents qualifying themselves as students

Researchers (n= 126):

Academic researchers represent the main sub-category of respondents working in the field of research (Figure 19) with 66%, reflecting the continued focus on rare diseases within universities and research institutions. Industry researchers and Bioinformatician / Biostatistician represent both 9%. Social sciences researchers represent 5%. Notably, all professional categories have maintained their representation at similar levels compared to the previous year's survey.

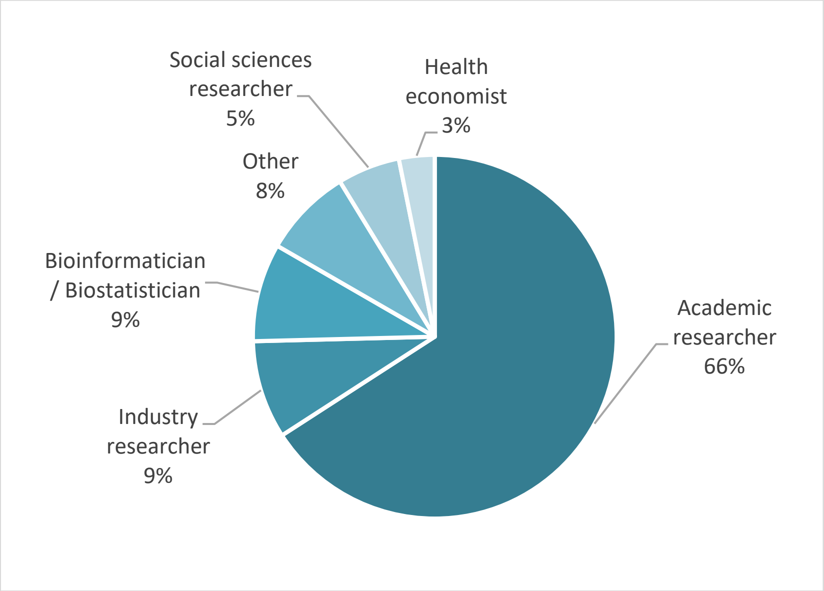


Figure 19: Types of respondents qualifying themselves as working in the field of research.

Education / Communication (n=121):

In this category, teachers are the majority, comprising 47% of the respondents (Figure 20). Social workers form another important sub-category, representing 17% of the participants. This provides insight into the involvement of educational and social service professionals in the rare disease community. 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.

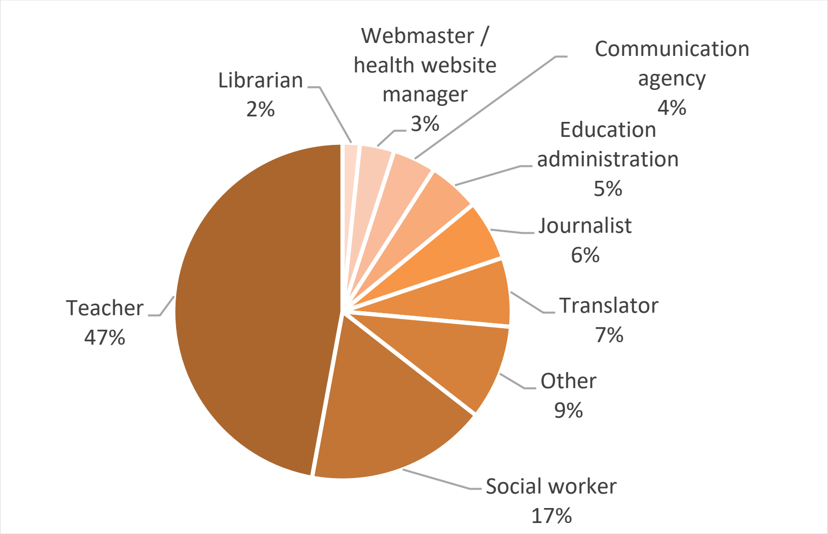


Figure20: Types of respondents qualifying themselves as working in education/communication.

Health care manager / policy maker (n= 51):

In this Health care manager category, 39% work in in hospital administration and 25% in health services administration or insurance (public, private or administration) (Figure 21). There is a decrease in respondents working in health services administration (32% of this category of users in the last survey) but a large increase of workers in hospital administration, which may suggest a growing need for hospital-level management of rare disease treatments, coordination of patient care and specialized services.

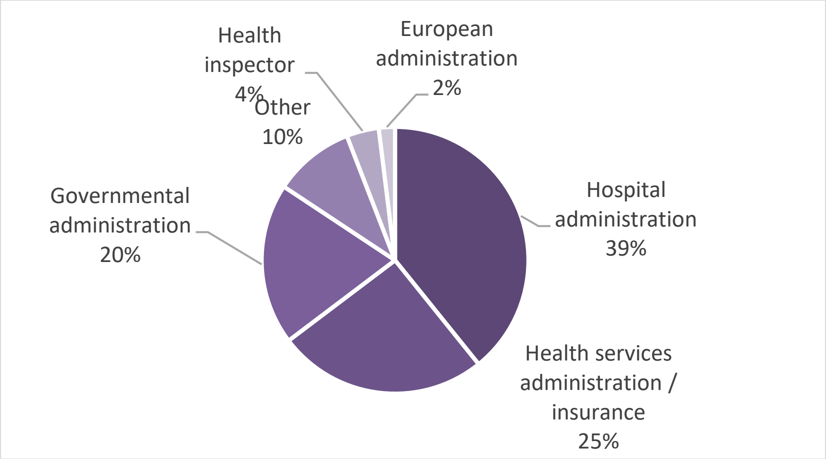


Figure21: Types of respondents qualifying themselves as working in the field of health care management/policy making.

Industry (n=44):

59% of the respondents work in the biotechnology or pharmaceutical industry, while 25% are consultants in this sector (Figure 22). 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.

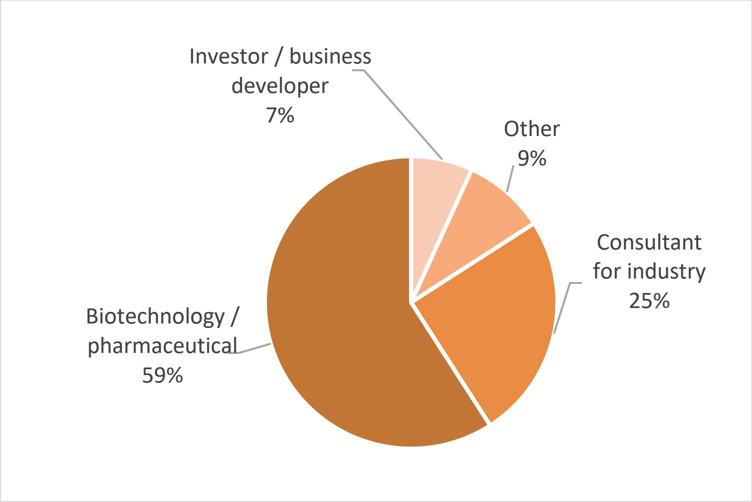


Figure 22: Types of respondents qualifying themselves as working in the biotechnology or pharmaceutical industry

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 3,454 respondents replied to this question, i.e. almost 70% of the total respondents.

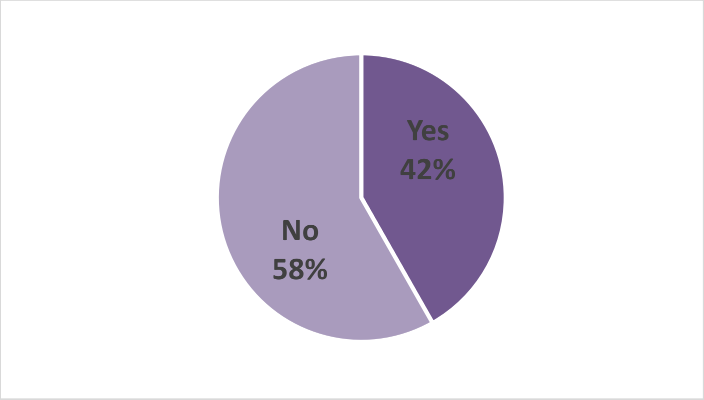


Figure 23: Repartition of respondents considering having a expertise in rare disease (n=7257)

42% of the respondents indicated that they had expertise in the field of rare diseases (Figure 23), with 56% belonging to the healthcare professional category and 26% from the Patient/Family/Patient organization category.

Compared to last year, healthcare professionals that have an expertise in the field of rare diseases are more numerous. These findings emphasize the critical role of both medical professionals and the patient community in shaping the conversation around rare diseases, driving research, and enhancing patient care. The increase in healthcare professionals with expertise is particularly encouraging, indicating a growing commitment to addressing the needs of rare disease patients.

On the other hand, the majority of our users (58%) 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

Editor-in-chief : Ana Rath – Editor of the report : Florence Sauvage
Technical support : Valérie Lanneau
The correct form when quoting this document is :
«2024 User Satisfaction Survey of the Orphanet Website», Orphanet Report Series, Reports Collection, 2024
http://www.orpha.net/orphacom/cahiers/docs/GB/Orphanet_survey2024.pdf