Orphanet Report Series
Reports collection

2017

2017 User Satisfaction Survey of the Orphanet Website

www.orpha.net

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RÉPUBLIQUE FRANÇAISE
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RD ACTION
DATA AND POLICIES FOR RARE DISEASES

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Methodology

An on-line survey was designed in November 2017, using the online survey tool Survey Monkey. 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. Replies were mandatory to all questions, apart from questions 9 to 12 which are designed to allow respondents to give detailed feedback if they wish to. These questions were also not asked of first time users.

The survey was launched in January 2018: a popup window was added to the first page users landed on. The survey was translated into the 7 languages of the website available at the moment (i.e. English, French, Spanish, Italian, Portuguese, Dutch or German) and was displayed respecting the language of consultation via a pop-up. The survey was closed after 4 weeks on the website.

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 year's results. The number of total respondents for each question in particular are given.

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

Results

A total of 5263 users gave answers to the questions this year.

Question 1: What country do you live in/work in?

This question was aimed at ascertaining the geographical situation of the users replying to the survey. A free text field provided for their answers. 5263 replies were registered for this question.
The top ten countries replying to the survey were: France, Italy, Spain, Germany, Mexico, United States of America, Brazil, Switerland, Belgium, and Canada.

Question 2: In what capacity are you consulting the Orphanet website TODAY?

This question aimed to determine the profile of Orphanet's users. Seven categories were proposed (i.e. health professional, patients/entourage, researcher, industry, health care manager/policy maker and students), and a free text field was included for other types of users to enter their profession. Only one response was possible. Respondents from the 'other' category were reassigned to one of the seven proposed categories when appropriate. 5131 replies were registered for this question.

Figure 1a shows the distribution of respondents amongst these categories:

Answer Options	Response count	Percentage
Health Professional	2366	46,1%
Patient/Family/PatientOrganisation	1295	25,2%
Student	909	17,7%
Researcher	163	3,2%
Education/Communication	81	1,6%
Health Care Manager/ Policy Maker	47	0,9%
Industry	44	0,9%
Other	226	4,4%
Total	5131	

Figure 1a: Types of Orphanet user (number of responses and percentage of total responses) n =5131

The largest category of respondents is the health professional category (46%). The second largest category of respondents is patients and their entourage (including patient organisations, alliances and support groups) with 25% of responses. Many students (18%) also replied to the survey. The 'other' category included respondents working in terminology standards, biocuration, as well as non-related socio-professional categories and those generally interested in rare diseases but who did not state their professional category.

This year there was a slight decrease in the percentage of health professionals responding to the survey (46% this year, 48% last year), and a slight increase in the percentage of patients and their entourage responding to the survey (25% this year, 22% last year). The percentage of students remained stable.

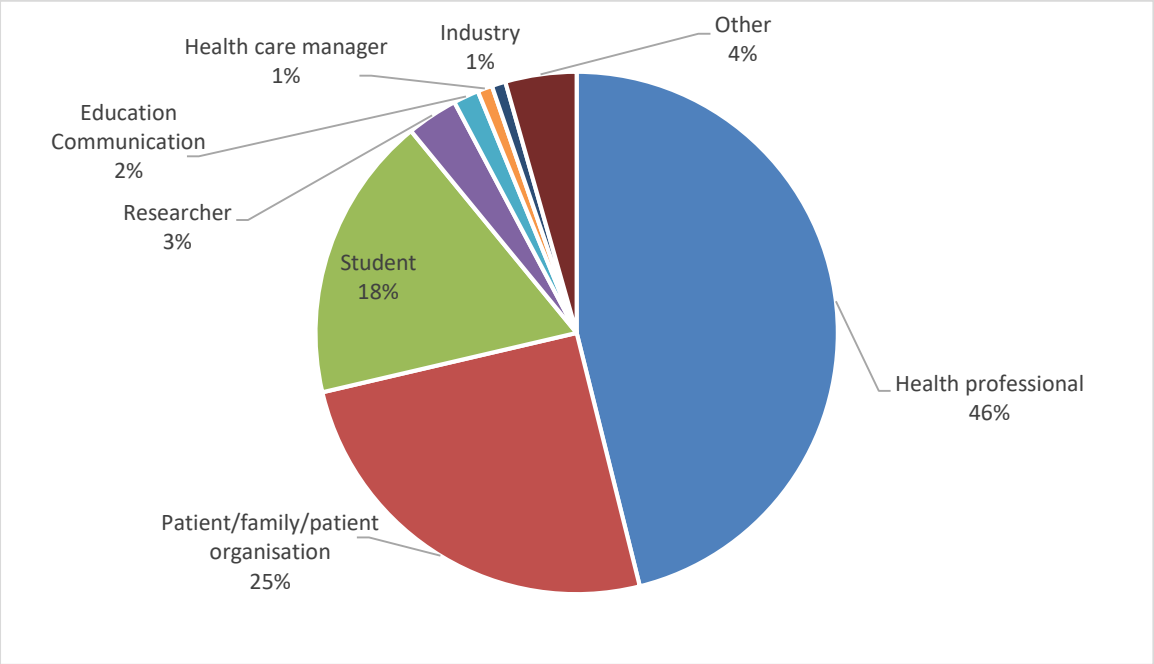

Figure 1b: Types of Orphanet user (percentage of total respondents) n = 5131

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.

Health professionals (n=2338):

Hospital specialists represent by far the main category of respondents (42%). All together, 52% are specialists. Genetic counsellors represent nearly 3% within this category, general practitioners represent 13% of the healthcare professionals (stable in comparison with last year). This category of user was also asked if they have expertise within in the field of rare diseases: 38% responded that they had expertise in the field. The results are globally similar to those of the previous year.

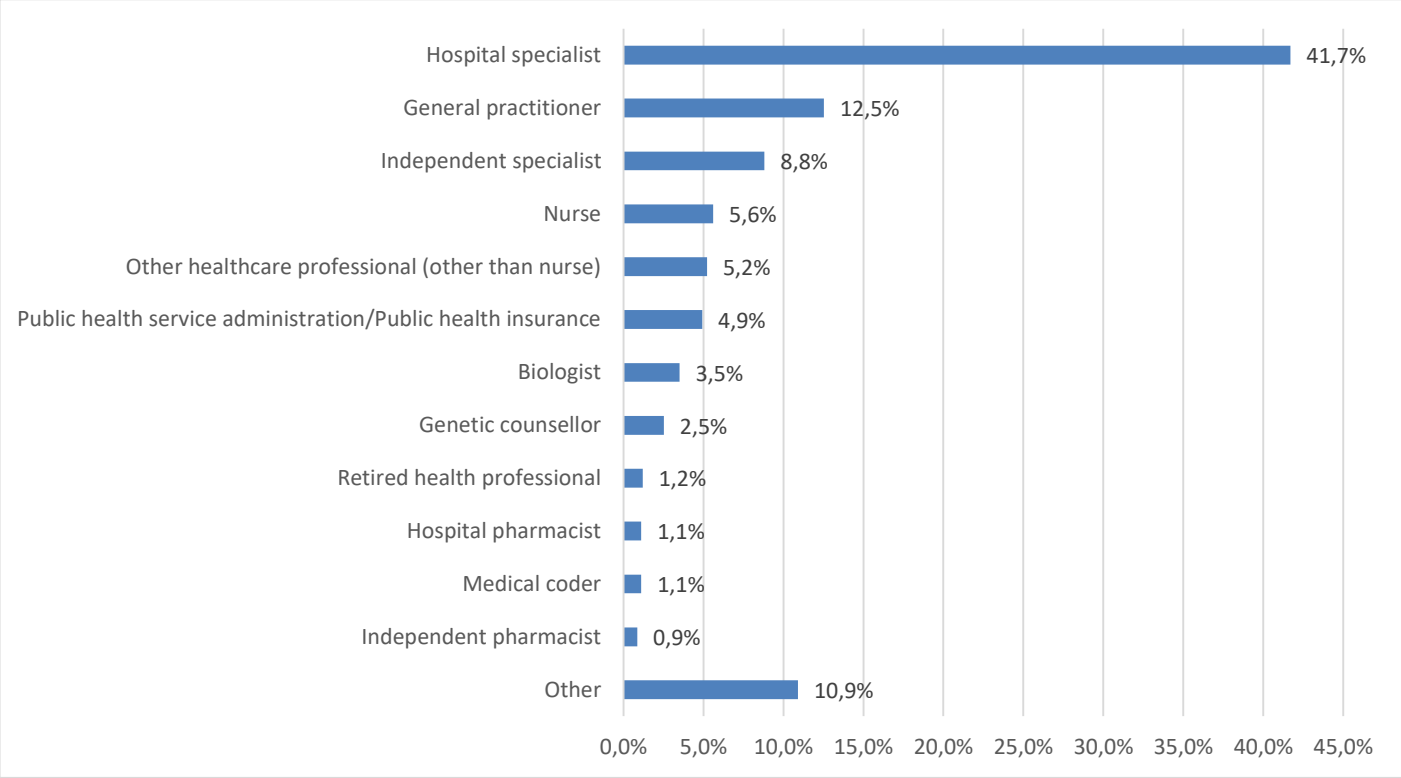

Figure 2: Types of respondents qualifying themselves as health professionals

Patient/entourage (n=1286):

Most of the people who selected this category are patients (46%); 40% are family members of a patient with a rare disease. The results are globally similar to those of the previous year.

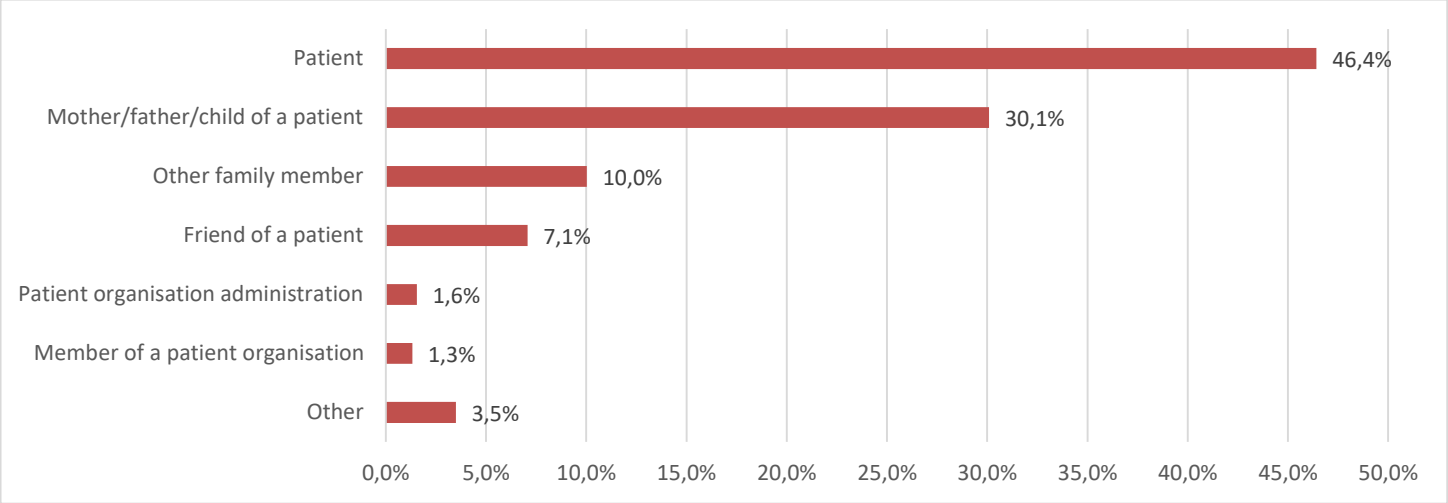

Figure 3: Types of respondents qualifying themselves as a patient or part of a patient's entourage.

Research (n=157):

Academic researchers represent 55% of respondents of the research category, and are divided between basic (24%) and clinical research (30%). Industry researchers (10%) and bioinformaticians (5%) are also represented. The 'other' category included research administrators and biostatisticians. The results are globally similar to those of the previous year.

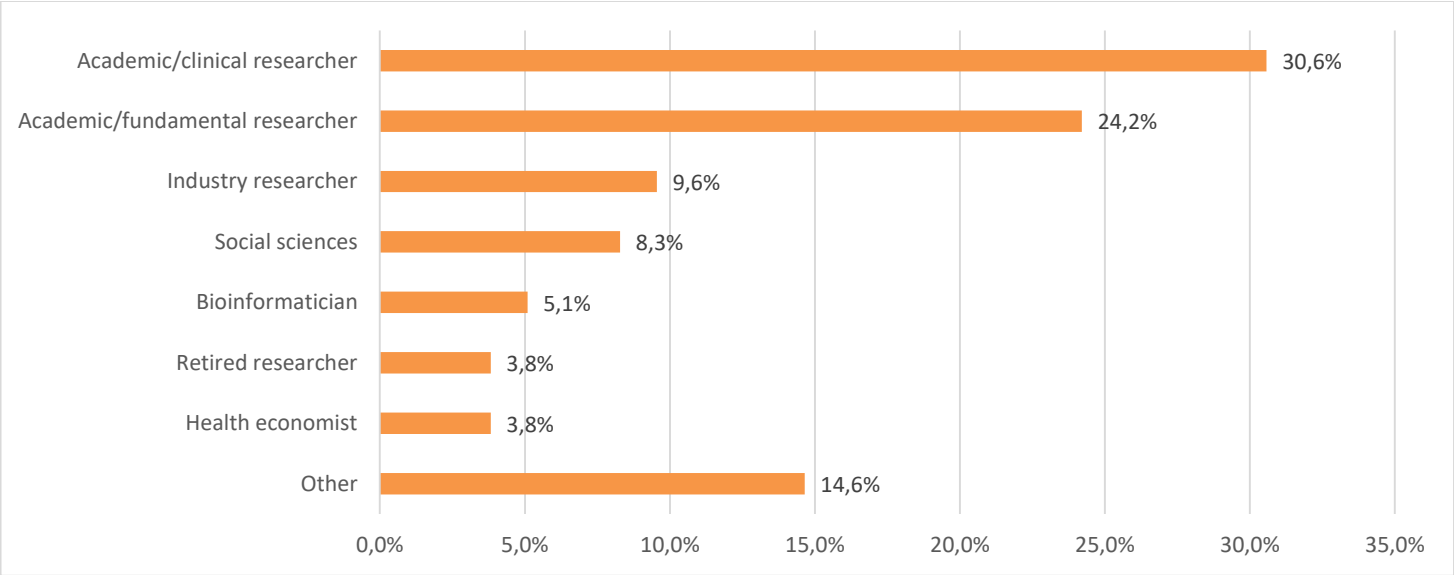

Figure 4: Types of respondents qualifying themselves as working in the field of research.

Industry (n=43):

60% of respondents in this category this year work in the biotechnology or pharmaceutical industry and 19% are consultants in the sector. A small number were private health insurance providers (9%). There is a higher percentage of responses this year from the private health insurance sector (9% this year compared to 2% last year), although the small sample size (43 this year compared to 62 people last year) should be noted when assessing this evolution.

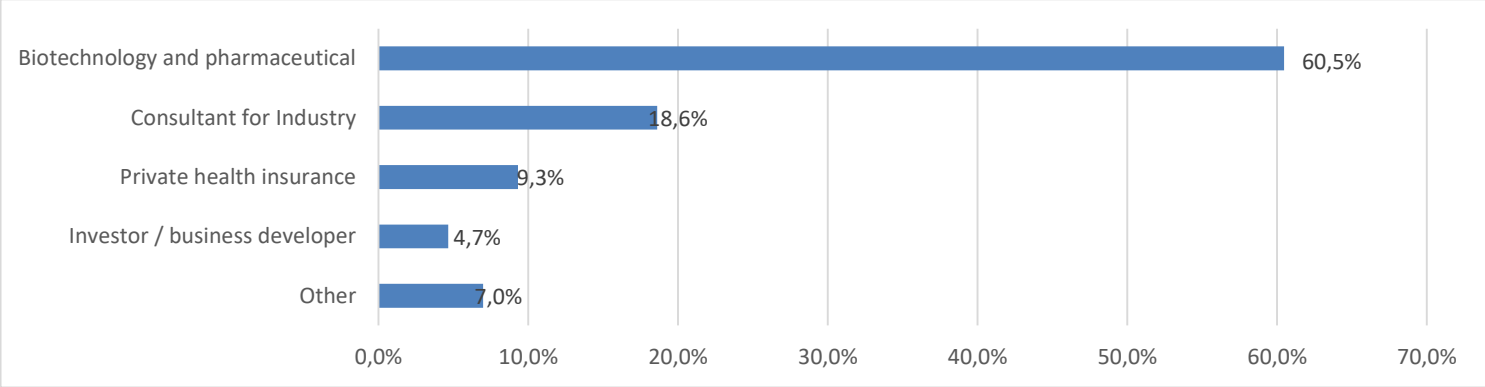

Figure 5: Types of respondents qualifying themselves as working in the biotechnology or pharmaceutical industry.

Health care manager/policy maker (n=46):

In this category, 35% work in governmental administration and 37% in hospital administration, with 20% working in public health insurance administration. There were no responses from the European administration sector this year, but a higher percentage of hospital administrators (37% this year compared to 29% last year).

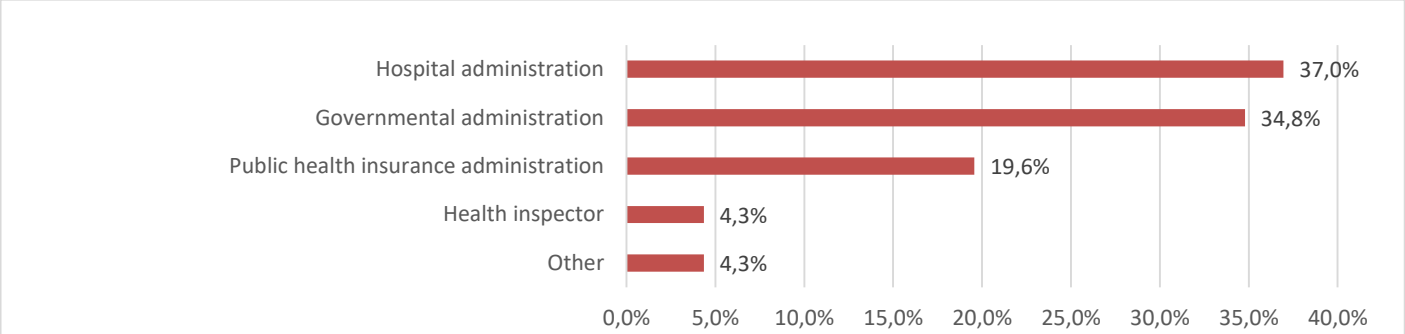

Figure 6: Types of respondents qualifying themselves as working in the field of health care management/policy making.

Education/communication (n=82):

In this category teachers represent 38% of respondents. Social workers were the second most represented sub-category with 11% of respondents for this category. The "other" category included other professionals from the education sector, or professions linked to communications (writer, publisher, information scientist). The results are globally similar to last year.

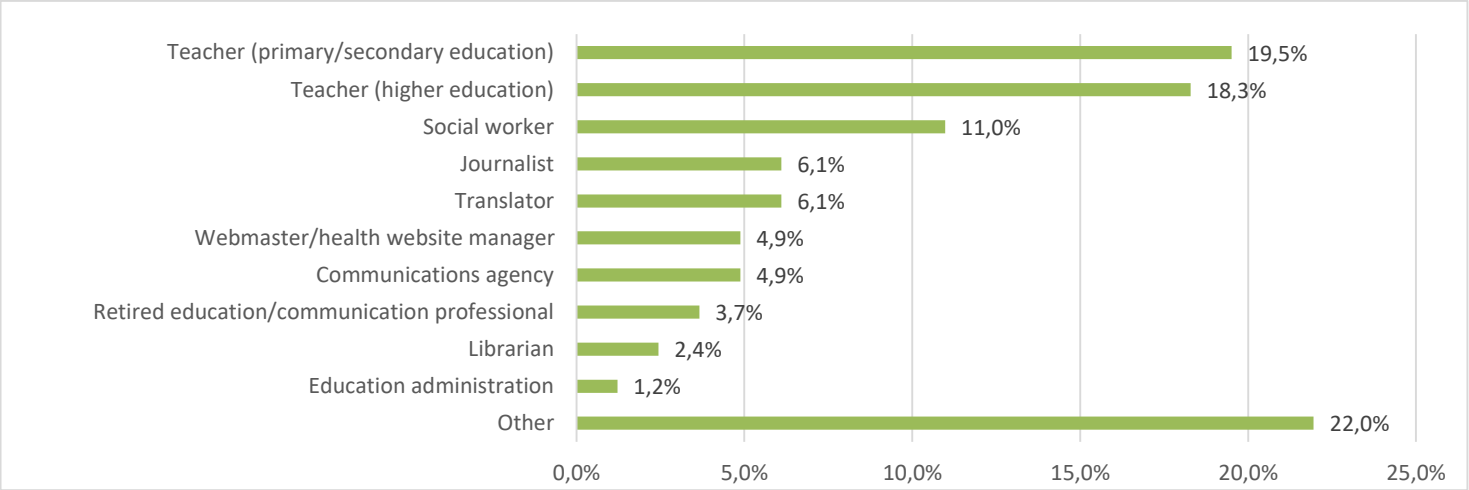

Figure 7: Types of respondents qualifying themselves as working in education/communication.

Students (n=908):

Medical students represent 85% of this category. The other respondents were studying biology, dentistry, genetic counselling, pharmacy, etc. The results are the same as last year.

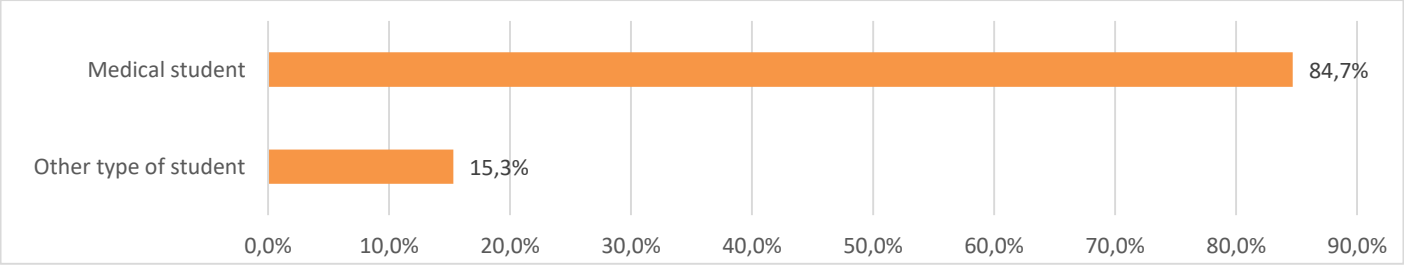

Figure 8: Types of respondents qualifying themselves as students.

Question 3: How did you discover Orphanet?

This question aimed to determine how respondents first learnt about Orphanet. Only one choice was possible. 5036 respondents replied to this question.

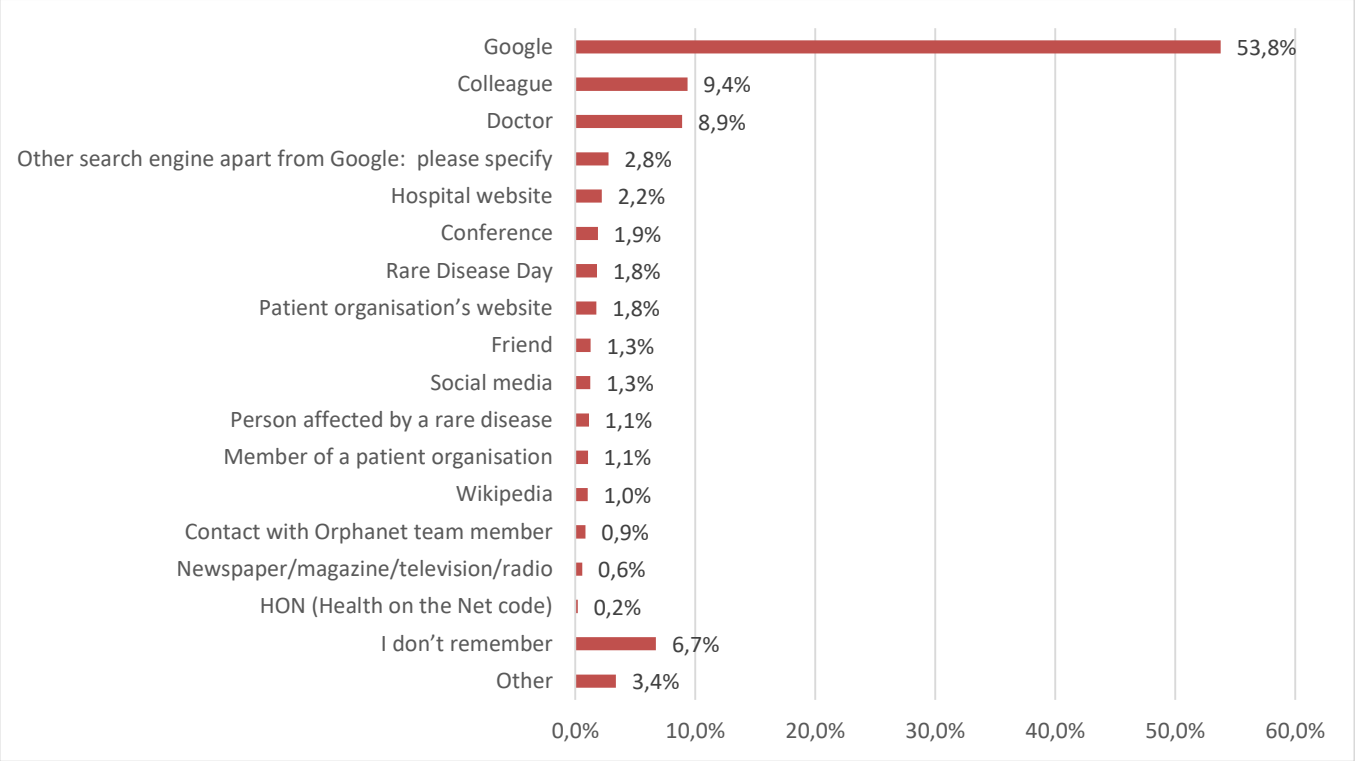

Figure 9: Mode of discovery of Orphanet by respondents (n=5036)

The majority of our users discovered Orphanet via Google (54%). Word of mouth has also brought a significant percentage of respondents to Orphanet (around 25%), via recommendations from colleagues, friends, doctors, a patient with a rare disease, at a conference, or through meeting a member of the Orphanet consortium. The other vectors cited by users include institutional websites, training session/lessons, or rare disease related events. The results are nearly identical to last year, with a slight progression of nearly 4 points for Google.

Question 4: What sort of information are you looking for during THIS CONNECTION to Orphanet?

This question aims to determine which kind of information visitors sought on Orphanet. More than one choice was possible. 4972 respondents replied to this question.

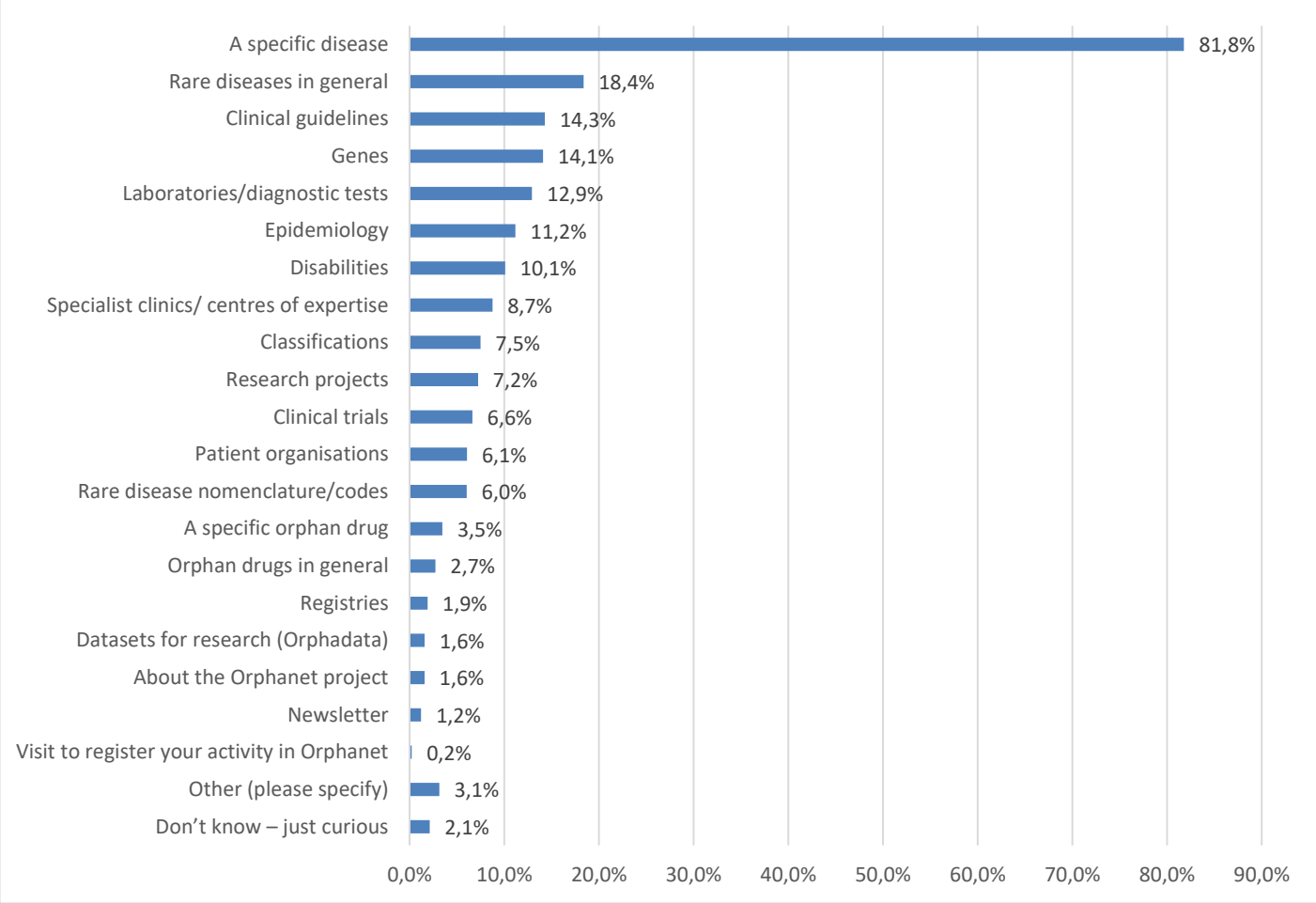

Figure 11: Information sought by respondents during their connection to Orphanet (percentage of total number of respondents n=4972)

The results show a clear trend: most of the respondents were looking for information for a specific disease (82%). Our visitors also look for information on rare diseases in general (18%) clinical guidelines (14%), genes (14%), laboratories/tests (13%) and epidemiology (11%). A smaller percentage of respondents were seeking information concerning other expert resources: specialist clinics (9%), research projects (7%), clinical trials (7%), patient organisations (6%). 6% of users were looking for information related to the nomenclature and coding of rare diseases and 8% were looking for information pertaining to the classification of rare diseases. The trends are stable compared to the previous year.

Question 5: Do you use the following sites when dealing with rare diseases?

This question aimed to determine the frequency of use of other websites for information on rare diseases. 4709 respondents replied to this question.

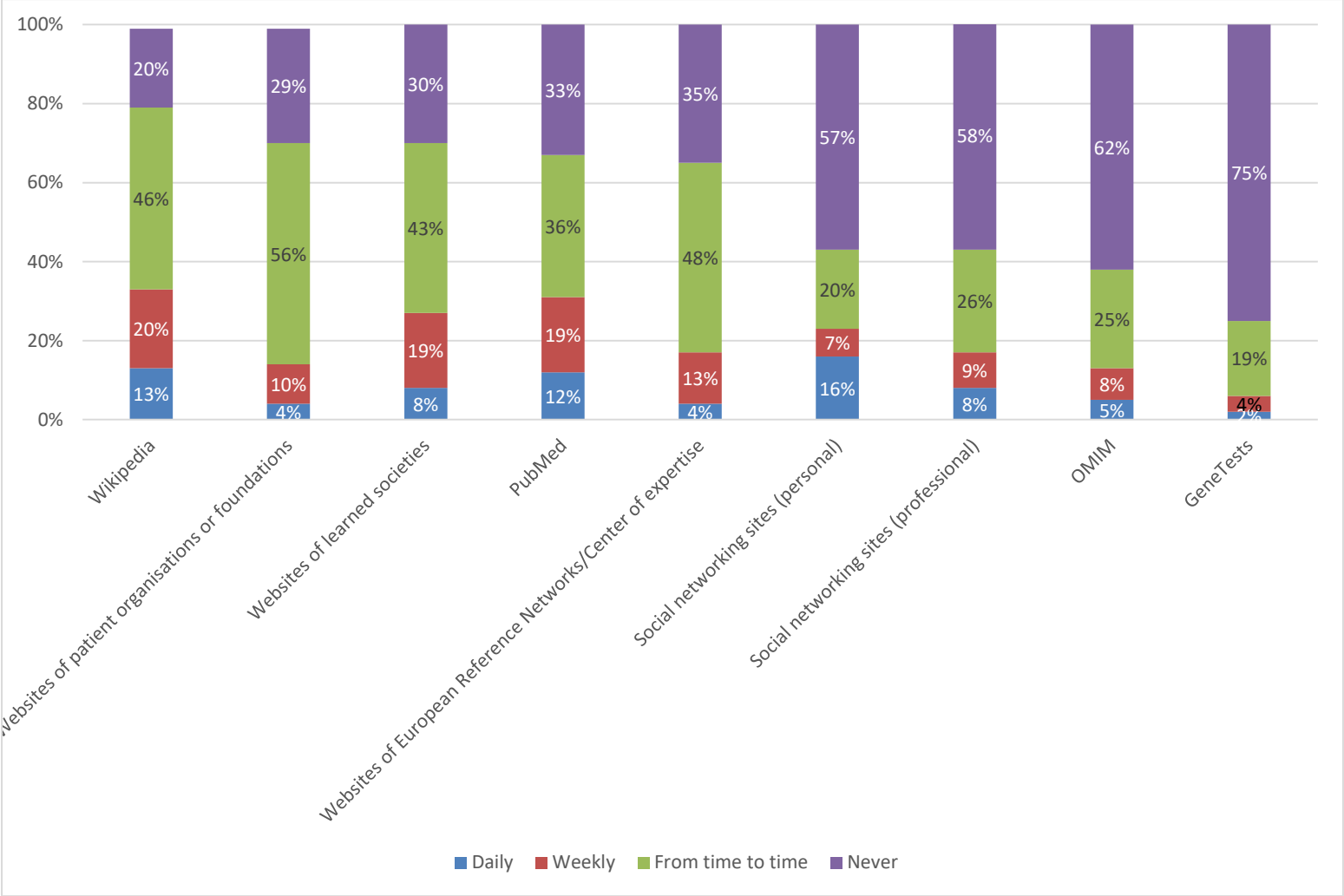

Figure 12: Other frequency of use of other sources of information as stated by respondents (n=4709)

To obtain information on rare diseases, 33% of respondents use Wikipedia or Pubmed either daily or weekly. 80% of respondents use Wikipedia to obtain information on rare diseases, either daily, weekly, or time to time, compared to 71% for websites of patient organisations/foundations, 70% for websites of learned societies, 67% for PubMed, and 65% for ERN/centres of expertise websites. OMIM and Genetests are less used by the respondents, with 38% and 25% of respondents, respectively, stating they use these sites.

Question 6: How are you accessing 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 for this question. 4682 respondents replied to this question.

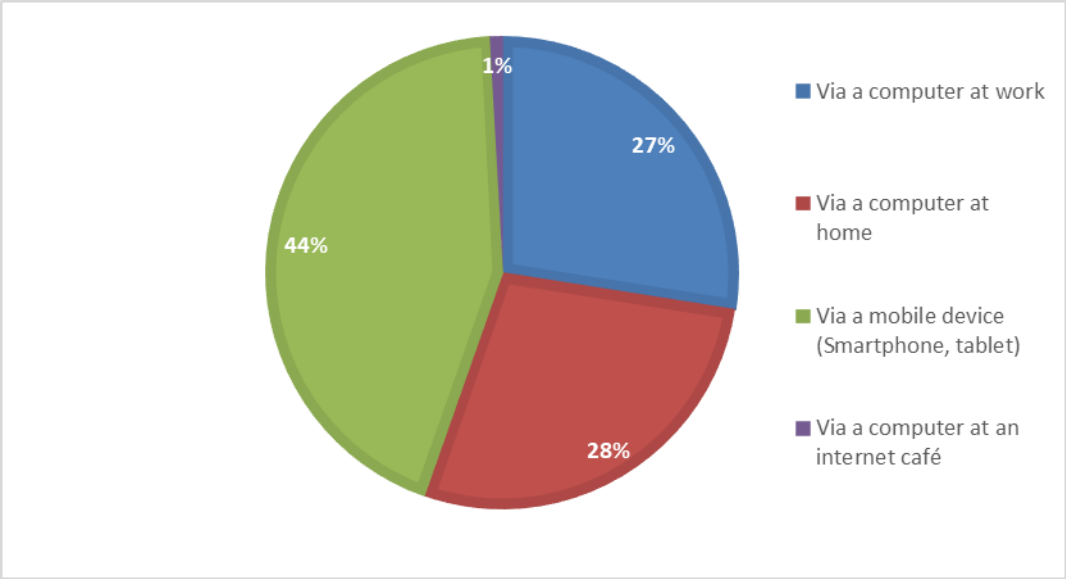

Figure 13: Mode of accessing Orphanet by respondents (n=4682)

Of those who responded to the survey, 28% did so from home, whilst 27% did so from their workplace. The use of a mobile device with an Internet connection represents 44%, a progression of 30% compared to the previous year's survey.

Question 7: Have you downloaded the Orphanet application? If not, why have you not downloaded the app?

Only one response was possible for this answer. Around 7% of respondents had downloaded the Orphanet mobile app. This figure is the same as last year.

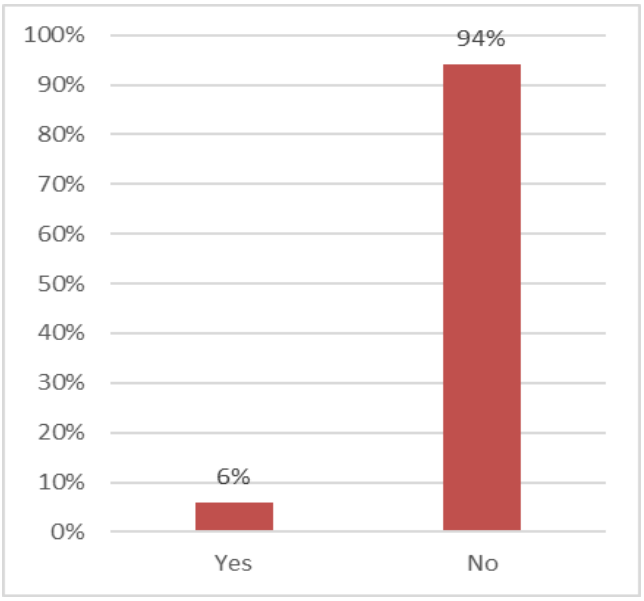

Figure 14a: Respondents having downloaded the Orphanet mobile application (n=4654).

Those that have not downloaded the app (94% of respondents) were asked the reason why they have not downloaded it.

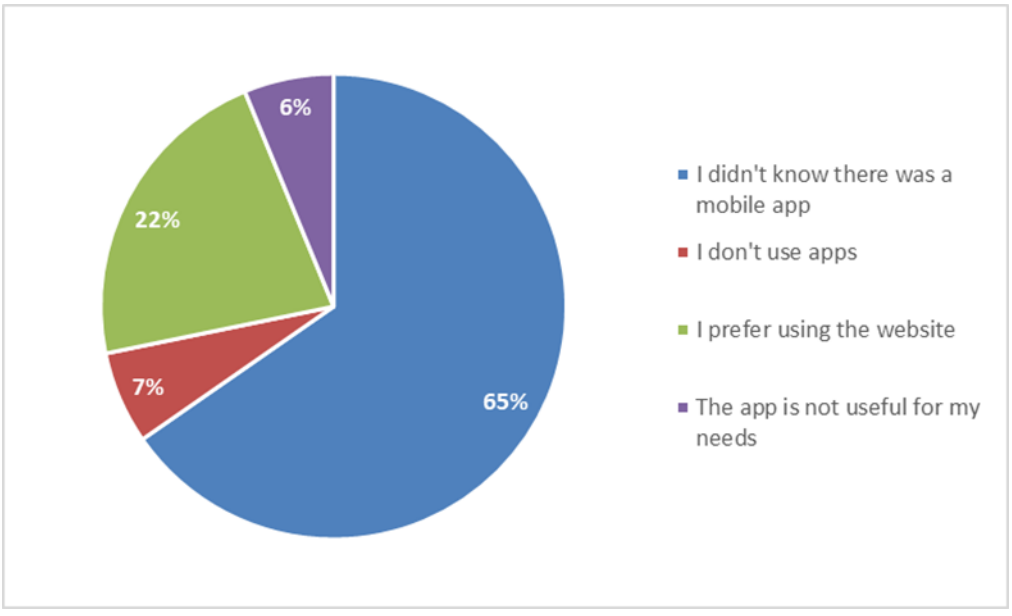

Figure 14a: Reasons for not downloading the Orphanet app, according to 4367 respondents.

The principal reason (65%) for not downloading the app was because users did not know it existed. More efforts are being made to promote this tool: for instance, information about the app and a link to download it appeared next to this question in the survey. Around a quarter stated that they prefer using a website to an app, and 7% stated they do not use apps in general with 6% stating that the app was not suited to their needs. This repartition is the same as last year, showing that communications efforts to make the app more well known are not yet making headway: they should be adapted to the users' profiles.

Question 8: How often do you visit Orphanet?

Only one response was possible. 4608 respondents replied to this question. Around 50% of those answering the survey are regular users, whereas 27% were visiting Orphanet for the first time, the remaining 50% visited either over twice a month, or over twice a year.

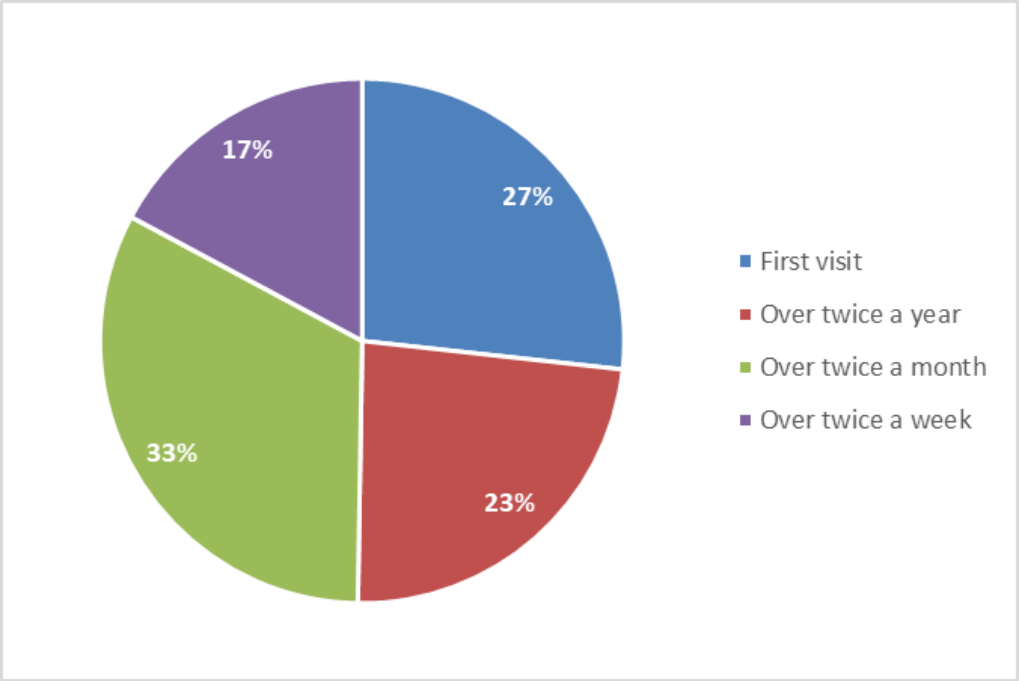

Figure 10: Visiting frequency of respondents (n=4608)

There were 7% more first time users this year compared to last year (20%). There was a slight decrease in users consulting the site more than twice a month (33% compared to 37%, and a slight decrease in the number of respondents stating they use the site over twice a week (17% compared to 19%).

Question 9: How useful would you rank the following Orphanet services for your own use?

The usefulness of Orphanet products was evaluated through this question. All respondents, except those consulting Orphanet for the first time, were asked this questions as the aim was to assess the usefulness of available tools and services for users' needs, based on their experience, and to also assess their knowledge of the existence of range of

available services. Only one response was possible for each product for the 2777 respondents. Respondents are not obliged to give an answer for every product, but can if they wish. Respondents were asked to rate the services according to their utility for their own use: ++, +, -, - -. Two other options were given: 'I do not use this service', and 'I did not know Orphanet offered this service'. The results show that Orphanet products are highly appreciated but some services are not sufficiently well known.

	Assessment of utility for users' own use						
Orphanet Product	**++**	**+**	**-**	**- -**	**I do not use this service**	**I didn't know Orphanet offered this service**	**Number of respondents**
Texts on diseases	61%	25%	3%	1%	5%	5%	2746
List of diseases and classifications	50%	28%	2%	0%	13%	7%	2761
Epidemiological data	44%	31%	4%	1%	13%	6%	2722
Clinical guidelines	44%	27%	4%	1%	14%	9%	2738
Genes	37%	31%	6%	2%	17%	6%	2717
Orphanet nomenclature of rare diseases/Orphacode	34%	26%	5%	1%	26%	8%	2747
Indexation of diseases with functional consequences	32%	26%	5%	2%	21%	14%	2719
Emergency guidelines	33%	23%	7%	2%	22%	13%	2720
Orphanet Report Series: List of rare diseases	30%	25%	5%	2%	24%	14%	2715
Cross-referencing of terminologies	27%	28%	6%	1%	27%	11%	2718
Directory of expert centres	30%	24%	5%	1%	28%	12%	2672
Directory of patient organisations	25%	26%	6%	2%	28%	12%	2664
Directory of medical laboratories/ diagnostic tests	28%	22%	5%	2%	31%	13%	2662
Orphanet Report Series: Epidemiology of Rare Diseases	24%	24%	6%	2%	28%	17%	2721
Search by sign facility	28%	19%	7%	2%	25%	19%	2715
Disability factsheets	22%	23%	7%	2%	29%	17%	2713
Directory of research projects	20%	24%	7%	1%	33%	14%	2660
Directory of clinical trials	20%	23%	7%	2%	33%	15%	2656
Orphanet national websites	20%	23%	6%	2%	34%	16%	2644
Directory of orphan drugs	21%	20%	7%	3%	34%	17%	2717
Orphanet Report Series: Disease Registries in Europe	18%	19%	7%	2%	33%	21%	2701
Directory of registries	15%	21%	7%	2%	39%	16%	2648
Orphanet Report Series: Orphan Drugs	17%	19%	6%	2%	35%	21%	2705
Orphanet Report Series: List of Research Infrastructures useful to Rare Diseases in Europe	17%	17%	6%	2%	35%	22%	2698
OrphaNews newsletter	16%	18%	7%	1%	40%	18%	2635
Orphadata	15%	14%	6%	2%	35%	29%	2690
ORDO: Orphanet Rare Diseases ontology	12%	13%	6%	2%	38%	29%	2684
Orphanet mobile app	10%	10%	4%	2%	41%	32%	2649

Figure 15: Utility of services according to 2777 respondents (number of responses) sorted by utility

In order to assess the real utility of our services for the respondents using them, an analysis of the results for this question was carried using the total of answers concerning the scale of utility '++', '+', '-', '- -'. The 'I don't use this service' and 'I didn't know Orphanet offered this service' answers were not considered. A user was deemed to be satisfied with the a product for their personal use if they answer if they answered '++' or '+' in the scale proposed to assess the usefulness of Orphanet's services.

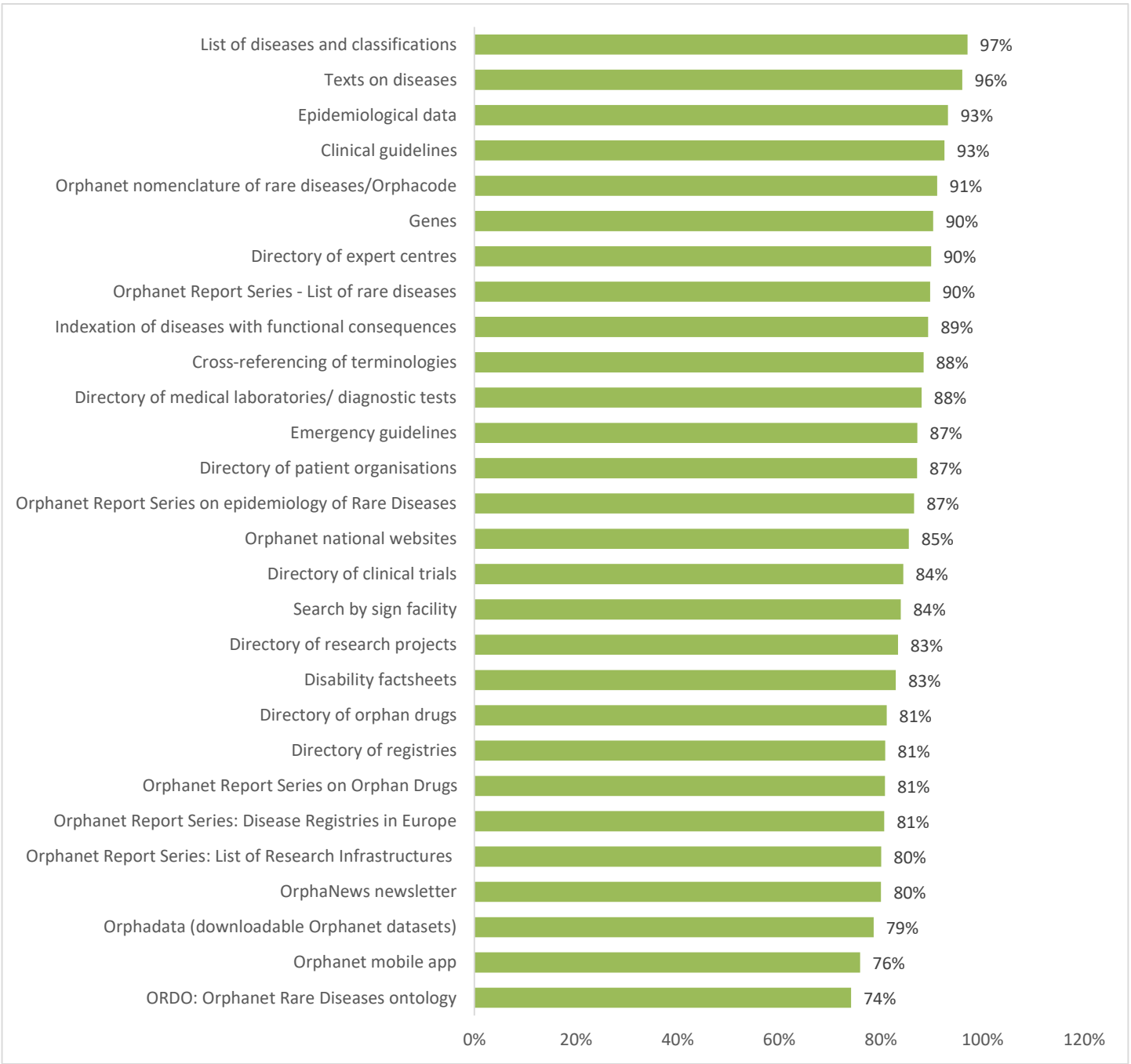

Figure 16: Satisfaction of users with the Orphanet services they use according to respondents (answers '++' or '+' on the scale of usefulness).

The results show similar trends to previous years' surveys. The most useful Orphanet services, according to the users that used them and knew of them, are the the list of diseases and classifications (97%) and texts on diseases (96%). The data concerning the epidemiology of rare diseases is also highly appreciated (93%), as are the clinical guidelines made available via Orphanet (93%). The Orphanet nomenclature of rare diseases and codes are also highly appreciated (91%.0) as are the directory of expert centres (90%), and information on genes (90%). The annotation of diseases with the functional consequences of the disease is highly appreciated by 89% of respondents. The trends are similar to last year, and show that Orphanet users are generally very satisfied with the products they use and know about.

An analysis of the answer 'I didn't know that Orphanet offered this service' highlights that our users are not sufficiently informed about our range of products and services.

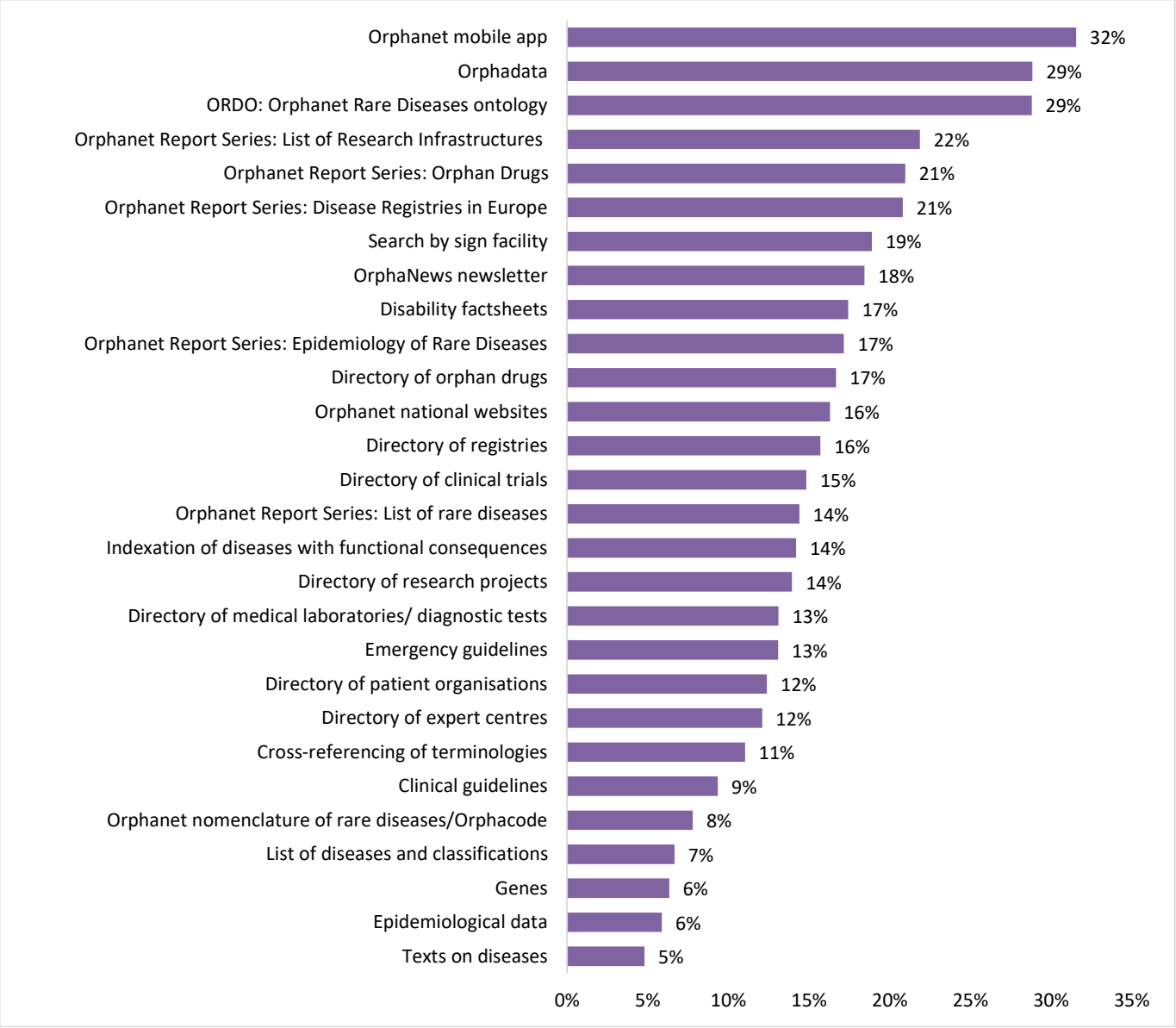

Figure 17: Least well-known Orphanet products (respondents answering 'I didn't know this service existed')

ORDO, the Orphanet Rare Disease Ontology, launched in 2013, is not known to 29% of our users, although amongst its users, it is well appreciated (74% highly appreciate this service). The targeted audience for this service is researchers, and in particular those in the bioinformatics sphere, which may explain why it is relatively unknown to those responding to the survey who are users of the www.orpha.net website. It should be noted that ORDO is better known this year (29% compared to 38%).

Similarly, Orphadata, the website that allows users to download Orphanet datasets for research purposes, is fairly well appreciated but is one of the least well known services to users of the website (29% of respondents). This service was launched in 2011, and is research orientated which may explain why it is not known or used by most or Orphanet's users; it should be noted that last year 36% of users did not know of Orphadata, compared to 29% this year.

As previously seen, the Orphanet mobile app is not well known (32% of users answering this question did not know it existed, compared to 36% of respondents in last year's survey).

The most well known products remain the texts on diseases with only 5% not aware of their existence; only 6% of respondents did not know about the epidemiological data made available by Orphanet or information on genes, and only 7% of respondents did not know about the existence of the list of diseases and classification.

This analysis will help the Orphanet team structure outreach activities in the future, especially for newer services such as the Ontology and Orphadata.

Question 10: Are Orphanet services easy to find/use?

This question aimed to find out whether users found Orphanet services easy to find or use. First time users, as they have no established experience of the site, were not asked this question. A 'yes', 'no', or 'no opinion' answer was possible for each of the services cited in question 9. 1480 respondents provided an answer to this question: respondents were not obliged to give their opinion on all the services. The results were analysed taking into account the respondents replying 'yes' or 'no', removing 'no opinion'.

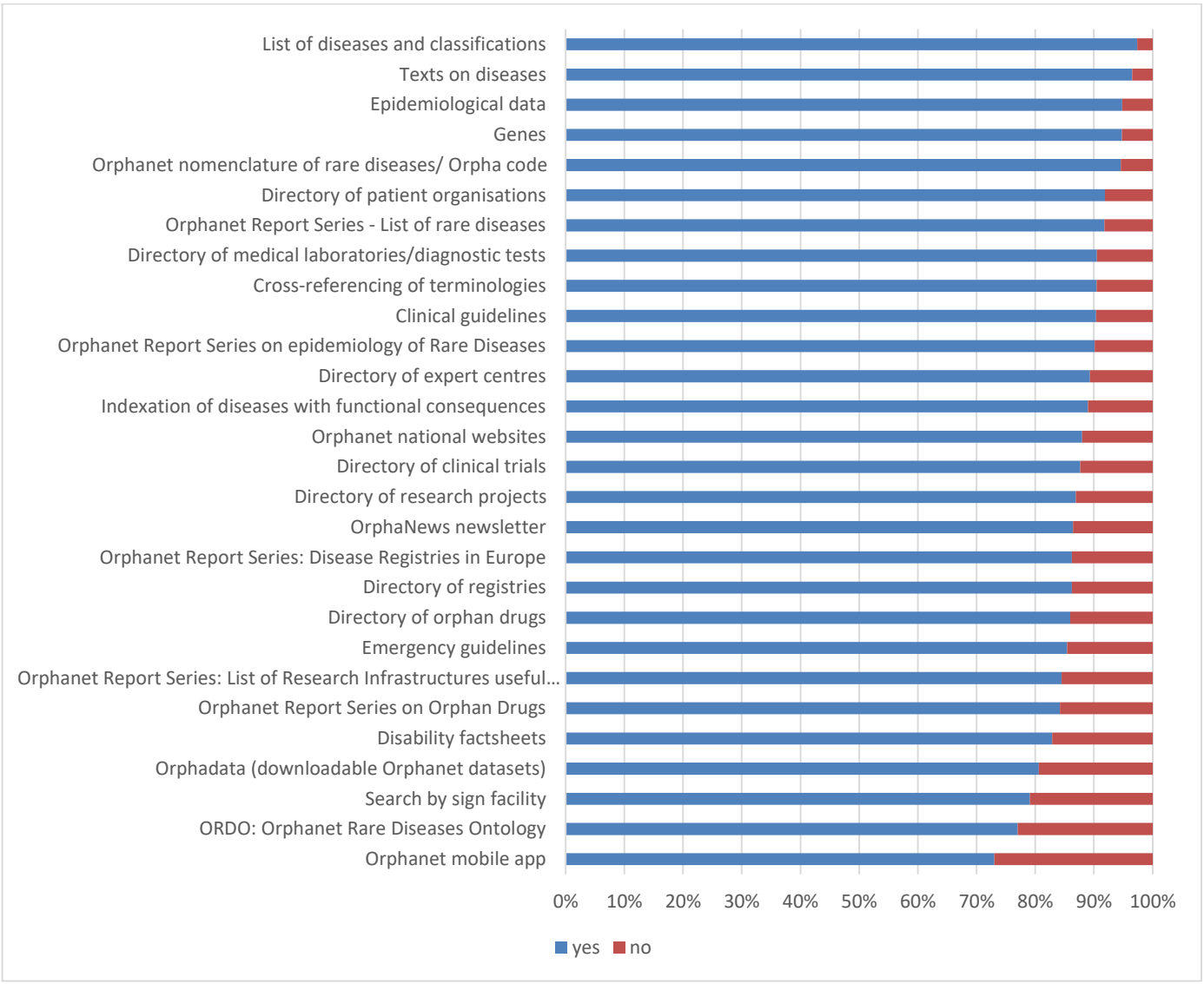

Figure 18a: Easiest to find Orphanet services, according to those expressing an opinion

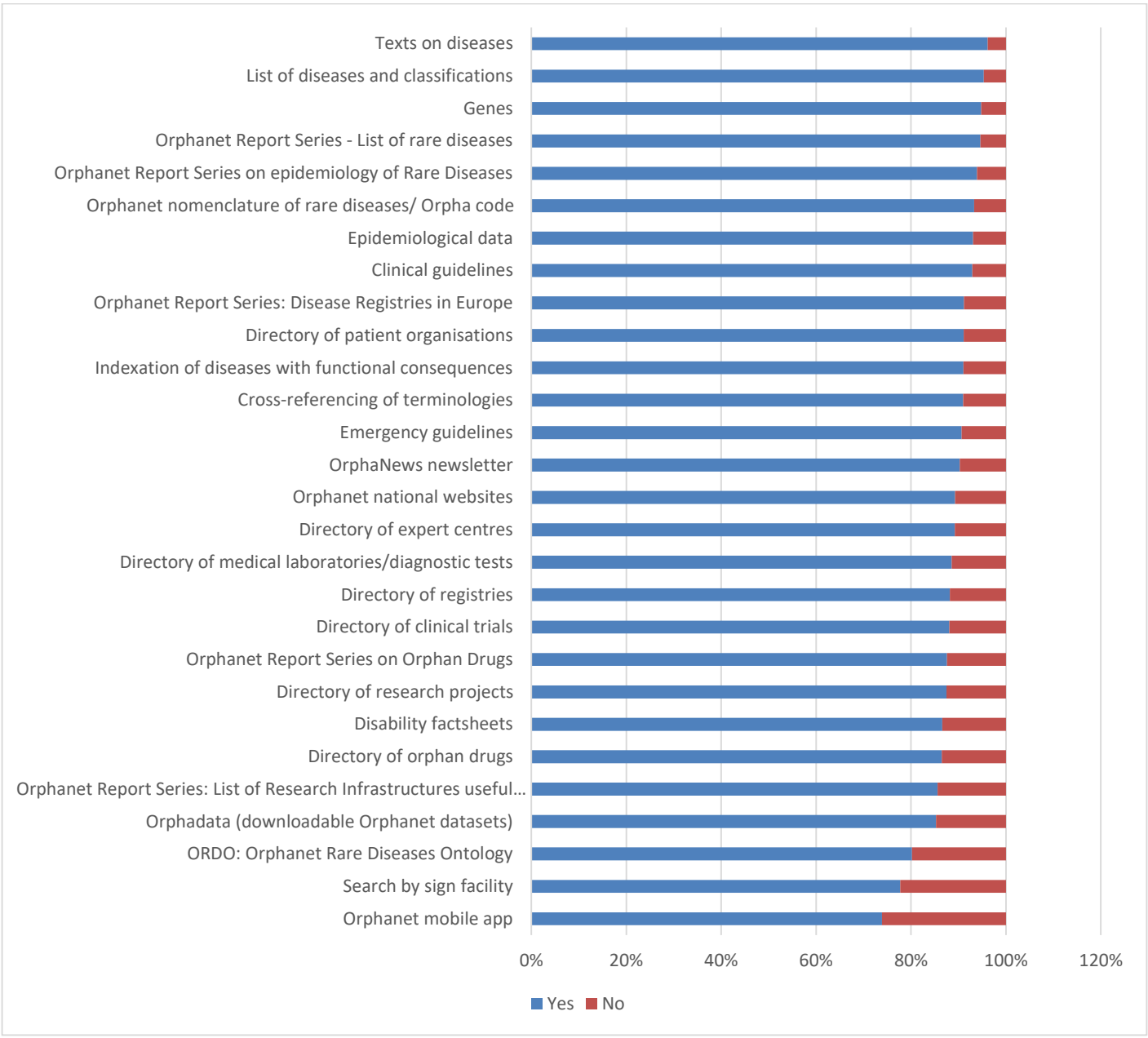

Figure 18b: Easiest to use Orphanet services, according to those expressing an opinion

The texts on diseases and list of diseases, as well as information on genes were the easiest services to find and to use according to those who expressed their opinion. The Orphanet mobile app was the product the least easy to find and use, with ORDO and the search-by-sign facility the second and third most difficult products to find and use (in echo with the response to the previous question which showed that the app was the least well known product).

ORDO is geared to a bioinformatics/research audience, available on Orphadata, so it is understandable that it is not easy to use, or find for users that do not need this service. However, there is has been a 21% increase in ease of finding this service this year compared to last, perhaps due to a better visibility on the Orphanet home page. This is also reflected via the 18% increase in the findability of the Orphadata website this year compared to last.

The search-by-sign facility is currently being completely overhauled in the context of the eRare3 project HIPBI. The tool was tested in a beta version in 2017. The search-by-sign tool overhaul involves the complete reindexation of the Orphanet nomenclature of rare diseases with Human Phenotype Ontology terms and the development of new algorithms to provide a more effective aid-to-diagnosis tool. In 2017, with the new look Orphanet website, a beta tool was launched, and following feedback from users it was decided to take the beta tool offline ahead of launching a finalised, and more user-friendly tool, hopefully around the end of 2018.

Question 11: How has your experience of using the website changed with the new look website?

This question was added this year to best assess how users have perceived the overhaul of the look and feel of the Orphanet website, launched in March 2017 to mark the 20th anniversary of the resource. We hope that the new organisation and look of the Orphanet website will improve the users' navigation of the site, make it easier to find all the information available via Orphanet, and also improve the ease of use of the services, no matter their intended audience. 3322 respondents answered this question.

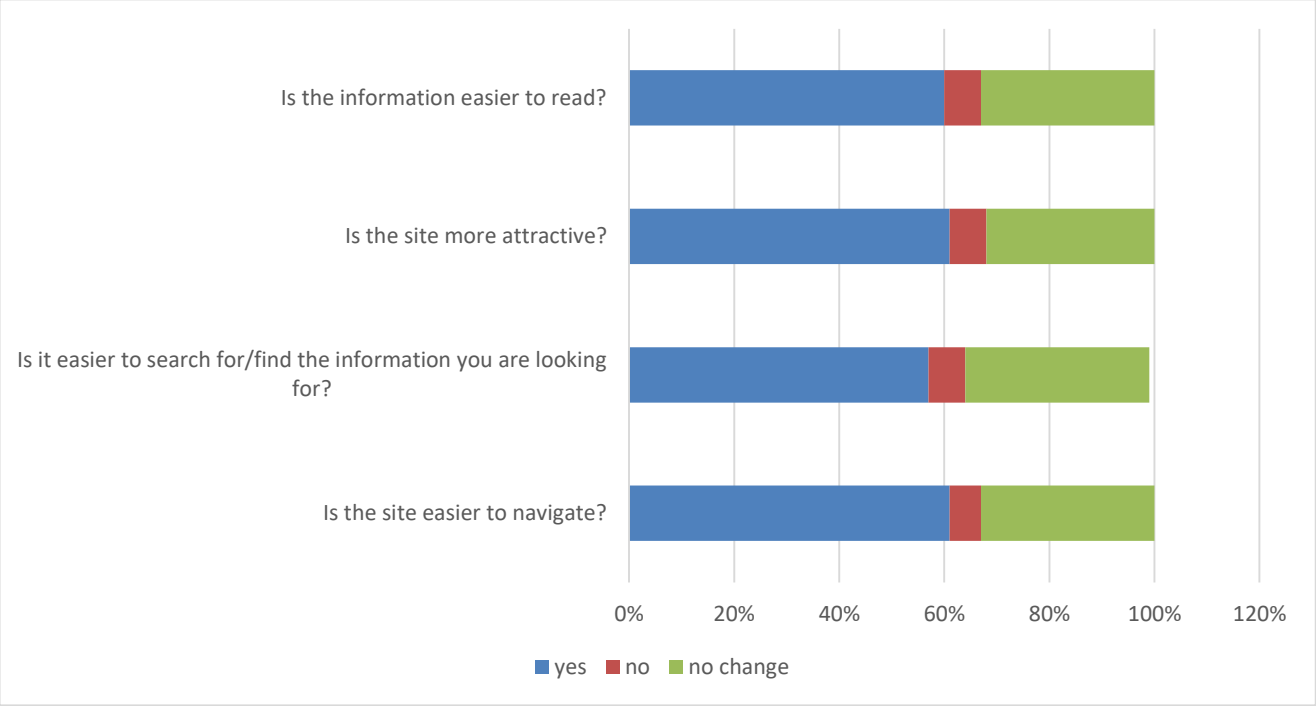

Figure 19: Evaluation by respondents of the change to their experience following the launch of the new look Orphanet website (n=3322)

The majority of respondents find the new site easier to navigate, easier to use to find the information they are looking for, more attractive, and that the information contained in Orphanet is easier to read. Around a third of users found that there was no change to their experience, and very few (no more than 7%) found that their experience of using the site had been negatively affected by the change to the new site.

Question 12: What should Orphanet do to better serve your needs?

Comments were provided by 669 individuals in response to this question. First time users, as they have no established experience of the site, were not asked this question.

Around a quarter of those who provided comments were satisfied by the service provided by Orphanet, or left messages of encouragement and support for Orphanet's activities. Although many users expressed their approval of the new Orphanet website, launched in March 2017, some users highlighted the need to improve the search functionalities: the IT infrastructure is currently being overhauled and hopefully this will improve in the near future. Comments also gave a number of suggestions of how to improve the presentation of the data in this complex database, notably in a cartographical way.

Many comments suggesting improvements necessary to services provided mirrored those of previous years. Orphanet's users mainly request that the disease summaries be completed when not available, and that the update of disease summaries be carried out more regularly. It is hoped that the new Orphanet curation platform, launched in 2017, and the harnessing of the expertise of European Reference Networks for Rare Diseases, will help address these issues by providing the tools to best catalyse this expertise to improve information on rare disease. A frequent update of the services database was also requested; an annual update of this part of the database is carried out once a year through an email campaign to professionals, and we depend on their reactivity to keep this data up to date. Professionals are able to update their data via the Orphanet professionals' registration tool at any time throughout the year.

Users were also interested in receiving notification of updates to certain types of data, or concerning specific diseases. Some respondents requested access to more precise epidemiological data concerning rare diseases: this data is currently available for research purposes via signature of a data transfer agreement, or annual licence, via www.orphadata.org. Users also requested that information be made available in even more languages, so that patients and healthcare professionals can access this information in their own language. This is dependant on the availability of national funding for the translation; in 2018 the site will be made available in Polish.

A main need expressed by users is access services to aid the diagnosis of patients with rare diseases. Some respondents have suggested that photos, or medical imagery, could be added to aid diagnosis. Many comments concerned the Orphanet aid to diagnosis tool: since 2016 work is underway to annotate rare diseases with Human Phenotype Ontology terms and to develop efficient algorithms to remplace the previous in-house 'search by sign' tool in the context of the eRare-3 project HIPBI-RD. In March 2017, on the new Orphanet website, the old 'search by sign' tool using the Orphanet thesaurus of clinical signs and symptoms was replaced by the beta version of the Orphanet-Phenomizer tool. Following feedback from users, we decided to take this tool off-line until the algorithm and user interface is improved. The additional comments provided by survey respondents will help the team in their efforts to provide a satisfactory and efficient replacement tool.

Users also suggested improvements such as the introduction of a dynamic glossary to explain medical terms for non-professional users, providing links to ongoing resarch papers when an Orphanet text is not available (this is already provided by the links to PubMed searches on disease pages, but is perhaps not well known to users), or developping information on best practices concerning the use of orphan drugs. Orphanet provides access to existing best practice guidelines in several languages, developed by groups of experts.

A number of comments highlighted the need to update the Orphanet mobile app: work has started to improve and update this app and it is hoped that it will be launched this year.

Some comments highlighted that resources could be better known by the general public and health professionals, in particular general practictioners. It was also suggested that students could be better informed concerning this resource, in particular in the scope of their training. Ways to improve outreach will be explored by the Orphanet strategic committee.

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

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