Orphanet Report Series
Reports collection

2016

2016 User Satisfaction Survey of the Orphanet Website

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RD ACTION
DATA AND POLICIES FOR RARE DISEASES

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Methodology

An on-line survey was designed in Noevmber 2016, using the online survey tool Survey Monkey (www.surveymonkey.com). 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.

The survey was launched in January 2017: 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, with a total of 4071 respondants, 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.

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

Results

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. 4071 replies were registered for this question.
The top ten countries replying to the survey were: France, Italy, Spain, Germany, United States of America, Mexico, Belgium, Brazil, Algeria, and Canada / Switzerland (ex aequo).

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.

The table below shows the distribution of respondents amongst these categories:

Answer Options	Response count	Percentage
Health Professional	1908	47,6%
Patient/Family/PatientOrganisation	866	21,6%
Research	133	3,3%
Industry	62	1,5%
Health Care Manager/ Policy Maker	49	1,2%
Education/Communication	97	2,4%
Student	721	18,0%
Other	174	4,3%
Total	4010	

Figure 1a: Types of Orphanet user (number of responses and percentage of total responses) n =4010

The largest category of respondents is the health professional category (48%). The second largest category of respondents is patients and their entourage (including patient organisations, alliances and support groups) with 22% of responses. Many students (18%) also use Orphanet. 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 rise in the percentage of health professionals responding to the survey (48% this year, 45% last year), and a slight decrease in the percentage of professionals responding to the survey (22% this year, 26% last year).

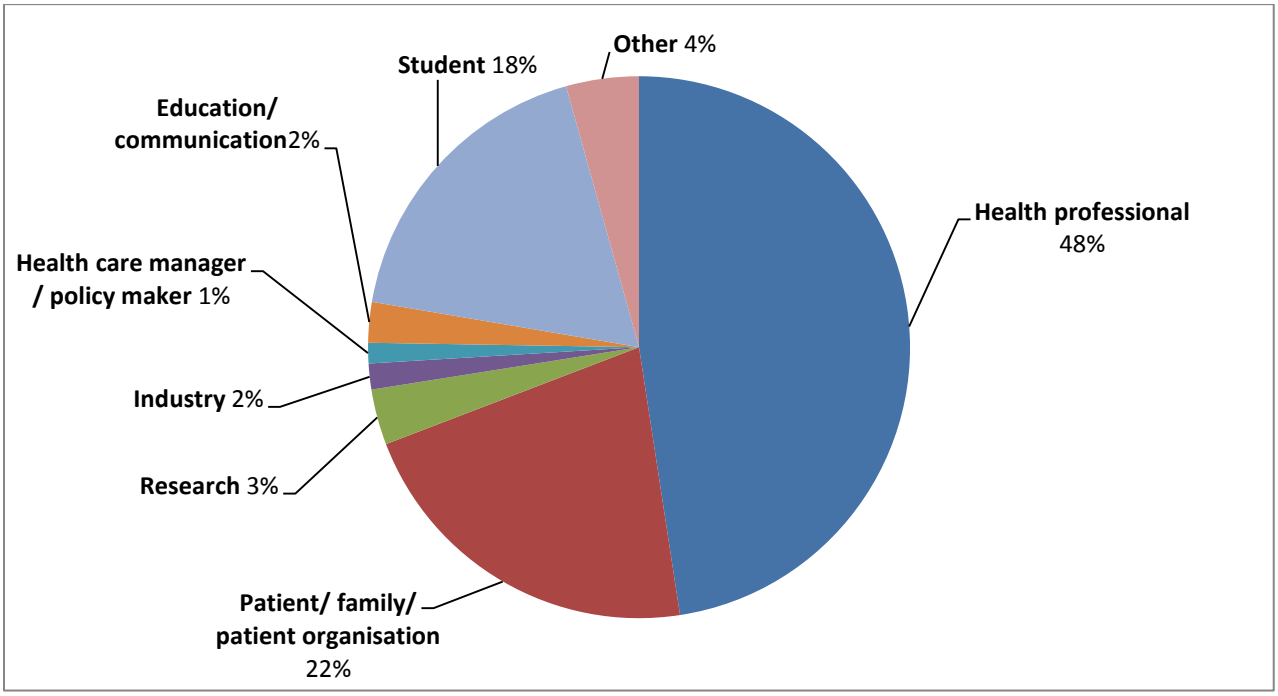

Figure 1b: Types of Orphanet user (percentage of total respondents) n = 4010

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: this answer was reassigned to a provided sub-category when appropriate.

Health professionals (n=1889):

Hospital specialists represent by far the main category of respondents (40%). All together, 49% are specialists. Genetic counsellors represent nearly 3% within this category, general practitioners represent 13% of the healthcare professionals. This category of user was also asked if they have expertise within in the field of rare diseases: 40% responded that they had expertise in the field. The results are globally similar to those of the previous year.

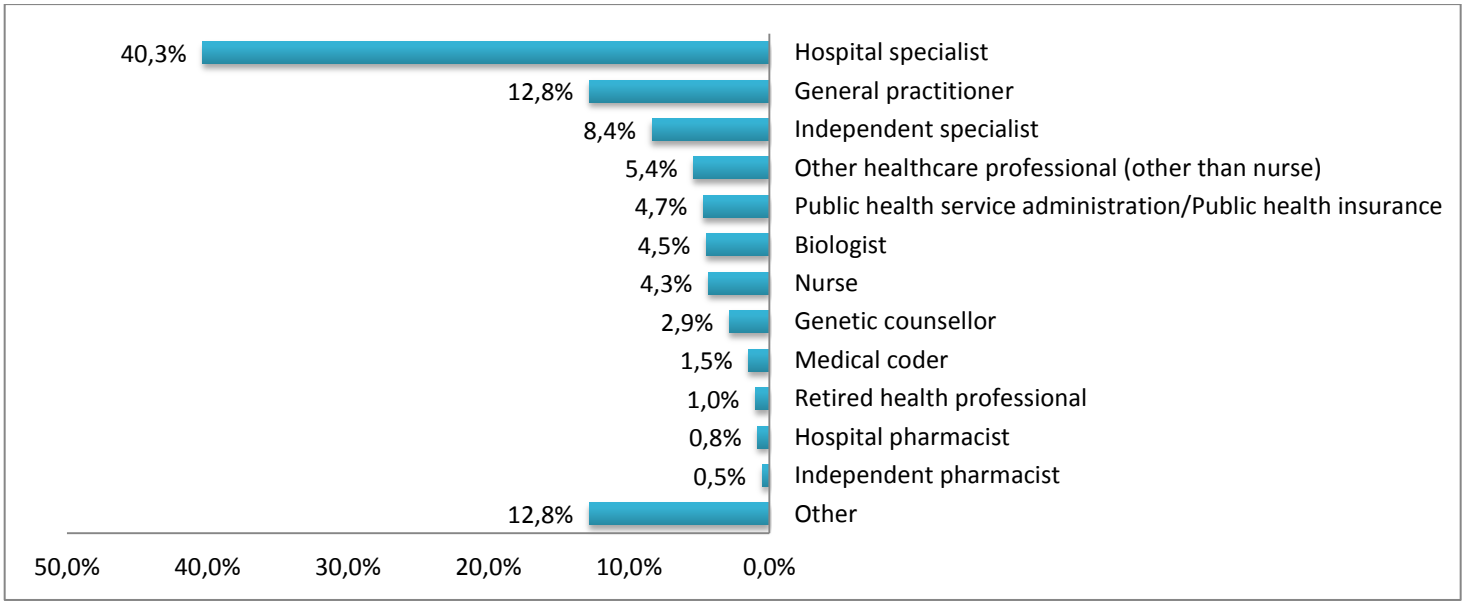

Figure 2: Types of respondents qualifying themselves as health professionals

Patient/entourage (n=857):

Most of the people who selected this category are patients (51%); 37% are family members of a patient with a rare disease. The results are globally similar to those of the previous year.

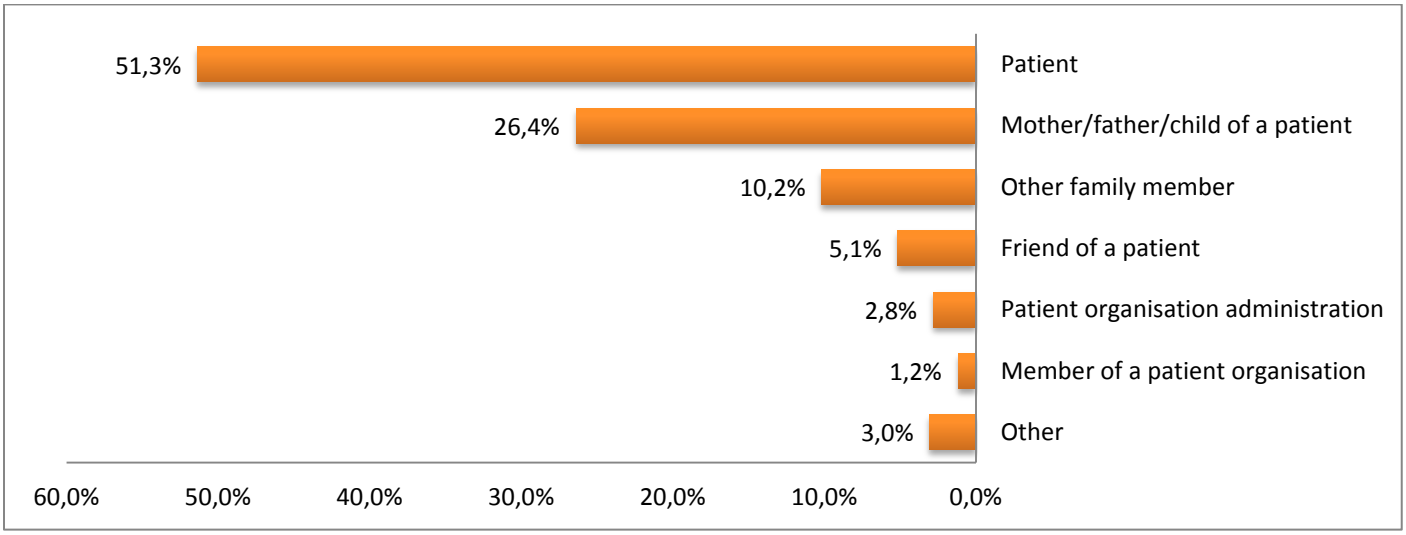

Figure 3: Types of respondents qualifying themselves as a patient or part of a patient's entourage.

Research (n=132):

Academic researchers represent 60% of respondents of the research category, and are divided between basic (24%) and clinical research (36%). Industry researchers (16%) and bioinformaticians (5%) are also represented. The 'other' category included research administrators and biostatictians. The results are globally similar to those of the previous year.

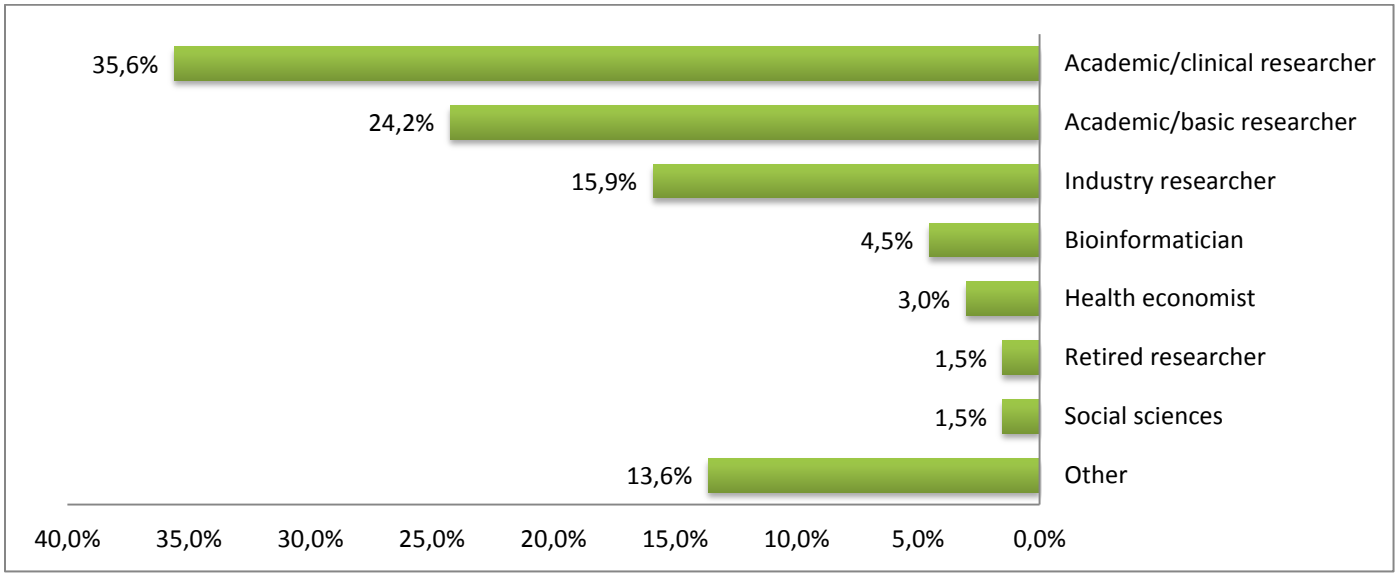

Figure 4: Types of respondents qualifying themselves as working in the field of research.

Industry (n=43):

41% of respondents in this category this year work in the biotechnology or pharmaceutical industry and 44% are consultants in the sector. A small number were private health insurance providers (7%). There is a higher percentage of responses this year from the biotech sector (65% compared to 42% last year), but a lower percentage of consultants (24% this year compared to 44% last year).

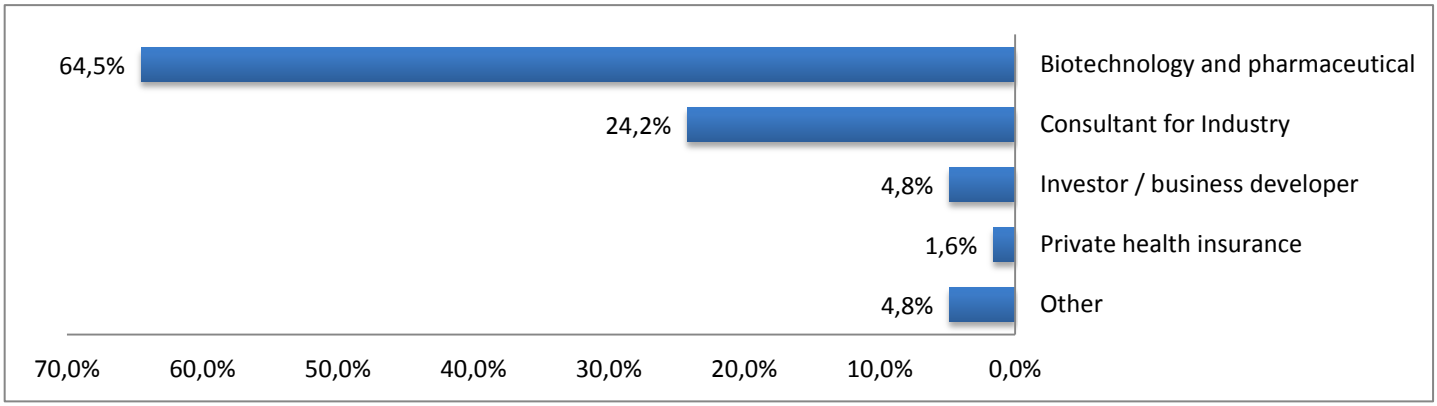

Figure 5: Types of respondents qualifying themselves as working in the biotechnology or pharmaceutical industry.

Health care manager/policy maker (n=49):

In this category, 33% work in governmental administration and 27% in hospital administration, with 27% working in public health insurance administration. There is a higher percentage of respondants from governmental administration this year (33% this year compared to 29% last year) but a lower percentage of hospital administrators (29% this year compared to 48% last year).

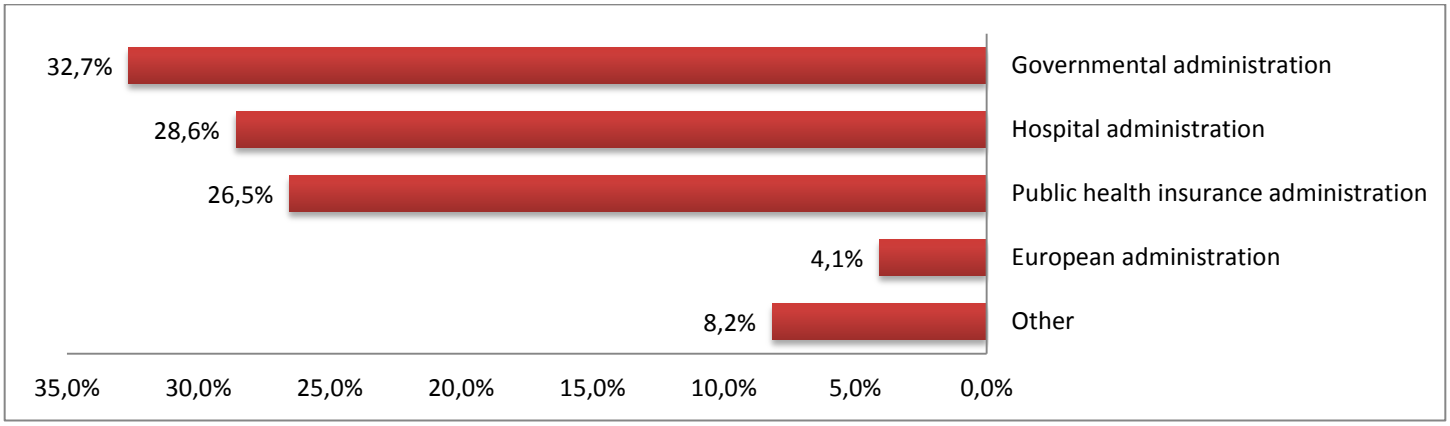

Figure 6: Types of respondents qualifying themselves as working in the field of health care management/policy making.

Education/communication (n=95):

In this category teachers represent 44% of respondants. Translators were the second most represented sub-category with 11% of respondents for this category. The results are globally similar to last year, although there is a progression in the percentage of translators (up to 10% from 4% last year) and primary/secondary educators (up to 21% from 12% last year.

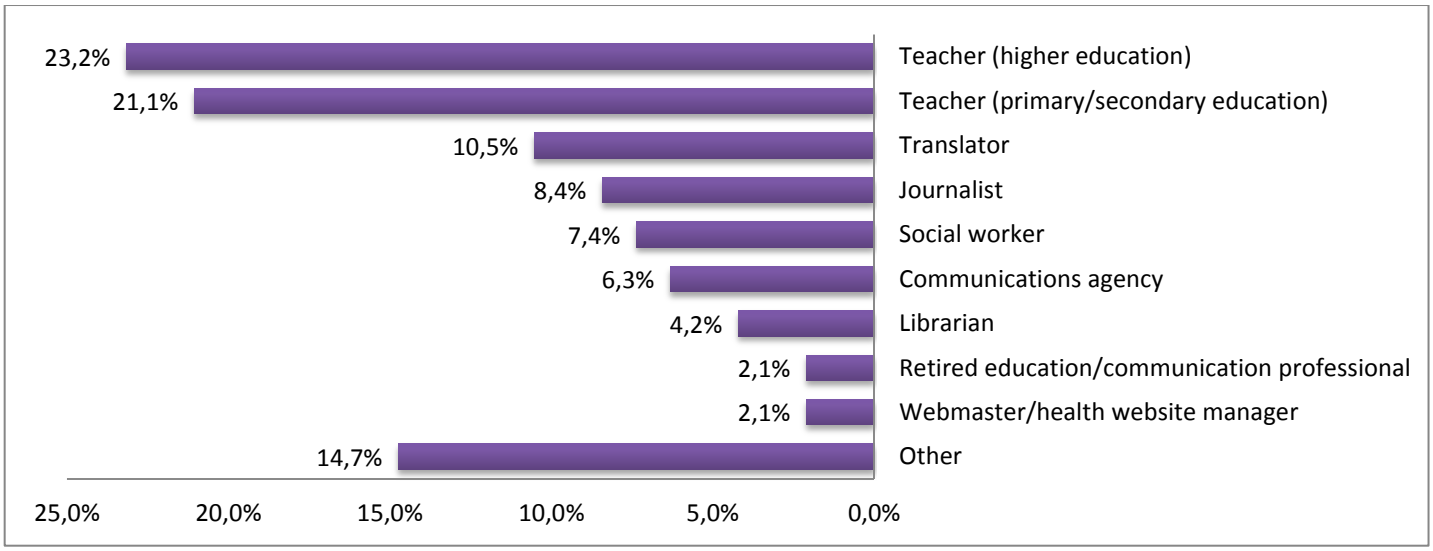

Figure 7: Types of respondents qualifying themselves as working in education/communication.

Students (n=718):
Medical students represent 87% of this category. The other respondents were studying biology, dentistry, genetic counselling, pharmacy, etc. The results are the same as last year.

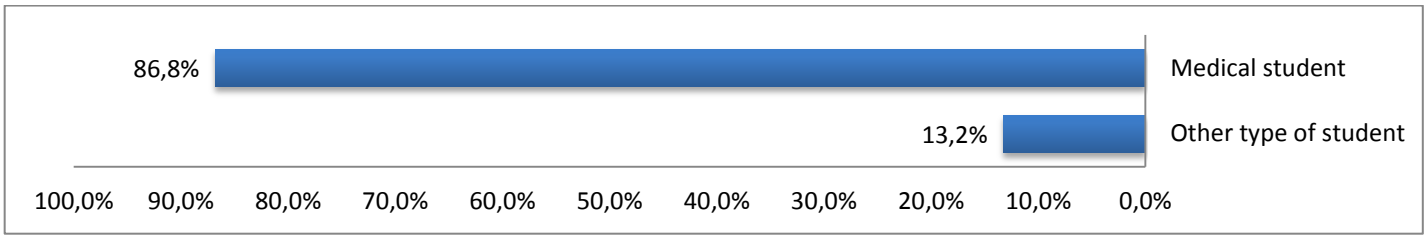

Figure 8: Types of respondents qualifying themselves as students.

Question 3 : How did you discover Orphanet?

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

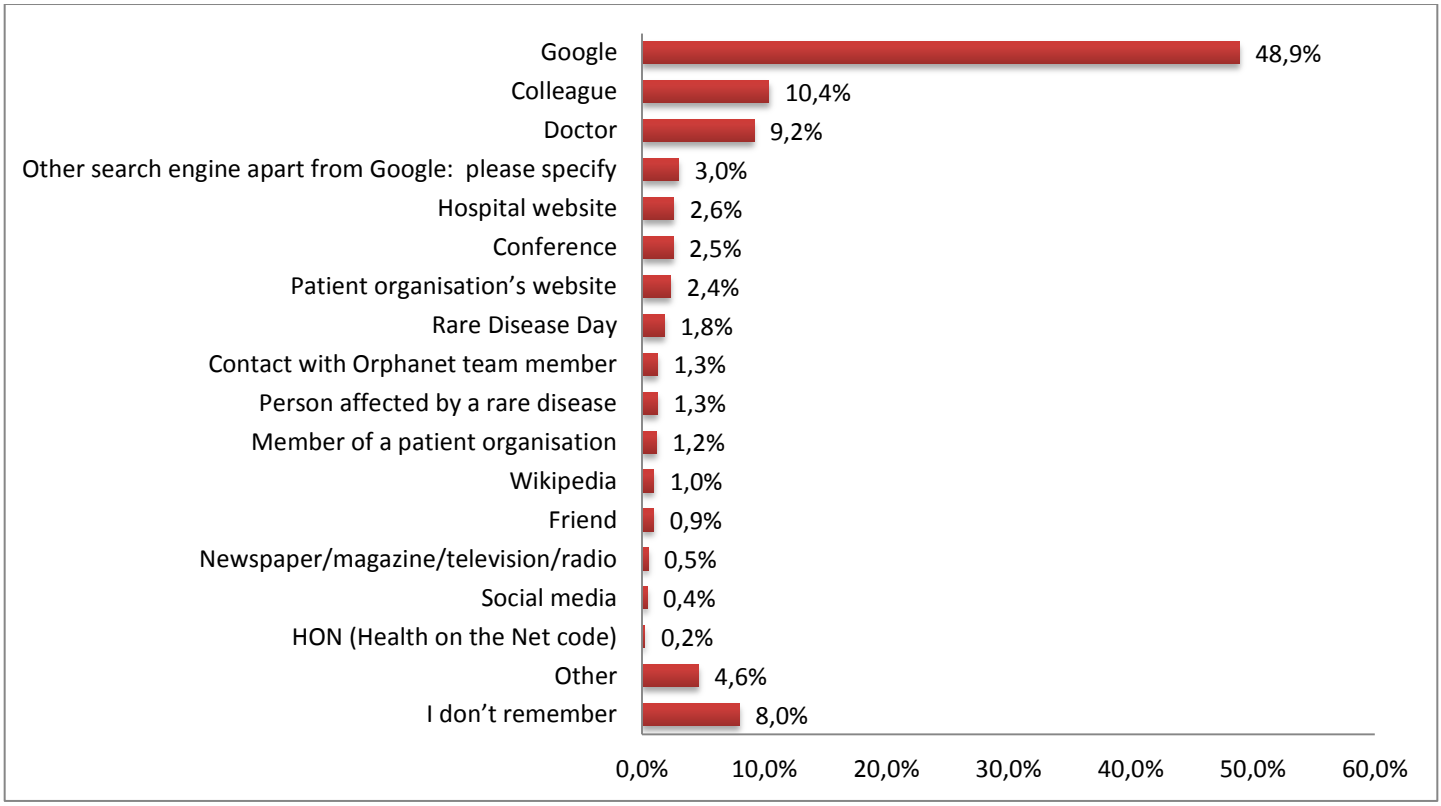

Figure 9: Mode of discovery of Orphanet by respondents (n=3949)

The majority of our users discovered Orphanet via Google (49%). Word of mouth has also brought a significant percentage of respondents to Orphanet (around 26%), 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.

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.

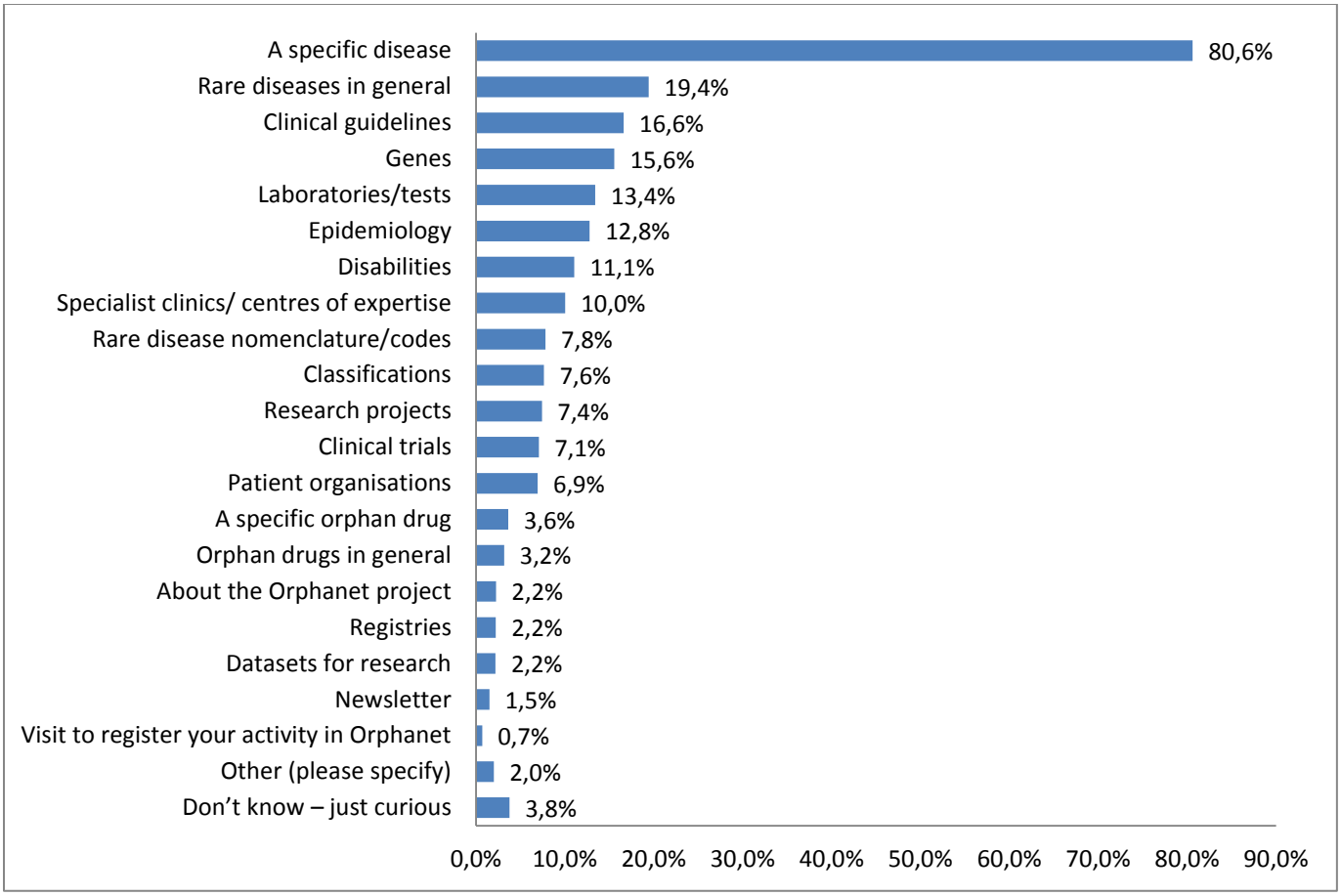

Figure 11: Information sought by respondents during their connection to Orphanet (percentage of total number of respondents n=3927)

The results show a clear trend: most of the respondents were looking for information for a specific disease (81%). Our visitors also look for information on rare diseases in general (20%) clinical guidelines (17%), genes (16%), laboratories/tests (13%) and epidemiology (13%). A smaller percentage of respondents were seeking information concerning other expert resources: specialist clinics (10%), research projects (7%), on clinical trials (7%), patient organisations (7%). 8% 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. Compared to last year's survey, general information on rare diseases had a 6 point progression.

The principle reason for visiting the site across all categories of users is information on a specific disease.

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

This question aimed to determine which other websites are visited by people looking for information on rare diseases at at which frequency. This year a new question was added: for each site, respondents were asked if they used the site daily, weekly, from time to time, or never.

Site	Daily	Weekly	From time to time	Never
Wikipedia	12%	20%	48%	21%
Websites of learned societies	6%	21%	44%	28%
Websites of patient organisations or foundations	4%	12%	56%	29%
PubMed	12%	20%	37%	31%
Social networking sites (professional)	5%	8%	24%	62%
Social networking sites (personal)	10%	6%	18%	66%
OMIM	5%	7%	21%	66%
GeneTests	2%	4%	17%	77%

Figure 12: Other frequency of use of other sources of information as stated by responden (n=3695)

To obtain information on rare diseases, 32% of respondents use PubMed or Wikipedia either daily or weekly. 79% of respondants use Wikipedia to obtain information on rare diseases, either daily, weekly, or time to time, compared to 72% for websites of learned societies, 71% for websites of patient organisations/foundations, and 69% for PubMed. OMIM and Genetests are less used by the respondants, with 34% and 23% of respondants stating they use these sites respectively.

Question 6: How are you accessing Orphanet today?

Only one response was possible for this question.

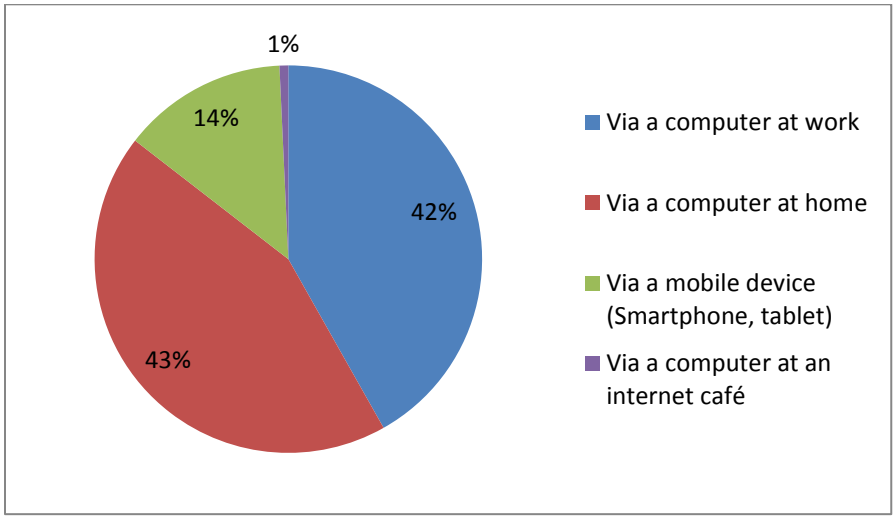

Figure 13: Mode of accessing Orphanet by respondents (n=3685)

Of those who responded to the survey, 43% did so from home, whilst 42% did so from their workplace. Last year 37% stated that they acced Orphanet from their workplace, marking a progression of 5% this year, to the detriment of consultation via a computer at home. The use of a mobile device with an Internet connection represents, as the previous two years, 14% of the respondents.

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

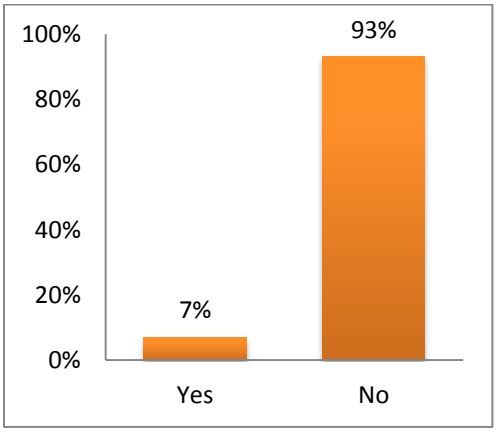

Figure 14a: Respondants having downloaded the Orphanet mobile application (n=3665).

Those that have not downloaded the app (93% of respondants) were asked the reason why they have not downloaded it.

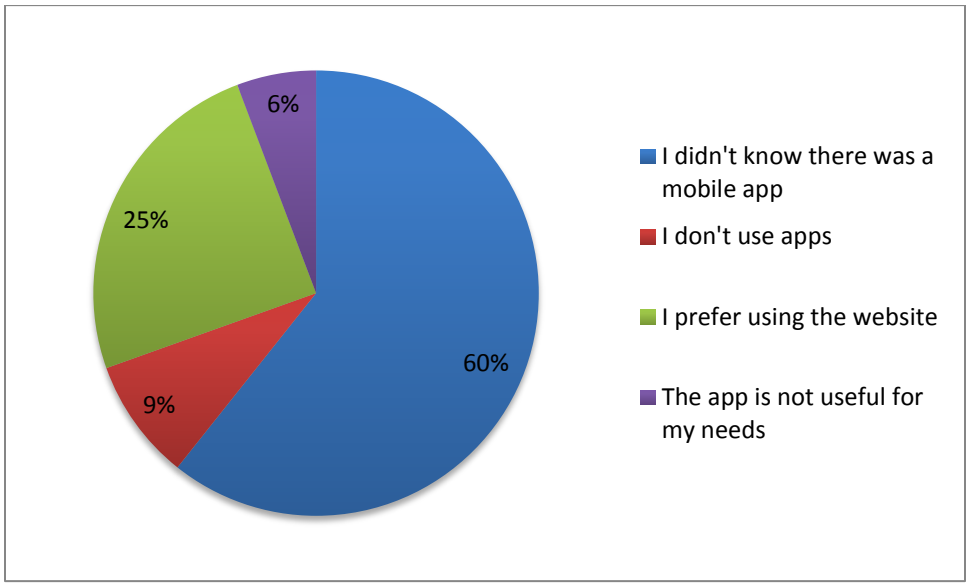

Figure 14a: Reasons for not downloading the Orphanet app, according to 3404 respondants.

The principal reason (60%) 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 9% 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.

Question 8 : How often do you visit Orphanet?

Only one response was possible. Around 56 % of those answering the survey are regular users, whereas 20% were visiting Orphanet for the first time.

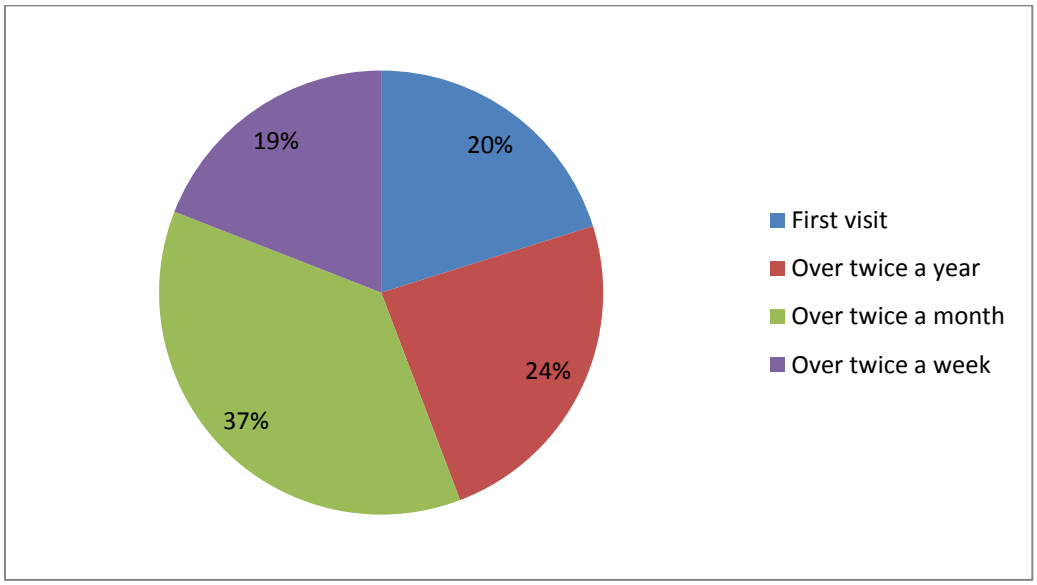

Figure 10: Visiting frequency of respondents (n=3646)

There were 6% less first time users this year compared to last year (26%), and 5% more users who use Orphanet twice a month.

Question 8: How useful would you rank the following Orphanet services for your own use?

The usefulness of Orphanet products was evaluated through this question. This question was asked to all respondants, except those consulting Orphanet for the first time 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 2600 respondents. For the first time a new scale was used for respondants 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 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 respondants**
Texts on diseases	65%	24%	3%	1%	4%	3%	2566
List of diseases and classifications	51%	27%	3%	1%	12%	6%	2569
Epidemiological data	42%	32%	7%	2%	11%	5%	2523
Clinical guidelines	41%	25%	6%	2%	15%	10%	2536
Genes	35%	29%	8%	2%	18%	7%	2519
Directory of expert centres	30%	22%	5%	2%	27%	14%	2494
Emergency guidelines	29%	22%	8%	2%	24%	14%	2520
Directory of medical laboratories/ diagnostic tests	28%	21%	6%	2%	29%	15%	2483
Indexation of diseases with functional consequences	26%	25%	7%	3%	22%	17%	2519
Orphanet Report Series - List of rare diseases	26%	23%	7%	3%	22%	18%	2522
Search by sign facility	23%	19%	8%	3%	24%	22%	2514
Directory of patient organisations	22%	26%	9%	2%	27%	14%	2479
Cross-referencing of terminologies	21%	26%	8%	2%	30%	14%	2499
Orphacode nomenclature	19%	19%	9%	2%	37%	14%	2522
Orphanet Report Series on epidemiology of Rare Diseases	19%	21%	8%	4%	27%	21%	2516
Directory of clinical trials	18%	22%	9%	3%	32%	16%	2466
Orphanet national websites	18%	20%	7%	2%	32%	20%	2452
Directory of research projects	18%	23%	9%	3%	32%	16%	2476
Disability factsheets	17%	20%	9%	3%	29%	22%	2503
Directory of orphan drugs	15%	17%	9%	4%	33%	21%	2500
Directory of registries	13%	18%	10%	3%	37%	19%	2456
OrphaNews newsletter	13%	16%	8%	3%	38%	23%	2448
Orphanet Report Series on Orphan Drugs	13%	15%	8%	4%	35%	25%	2508
Orphadata (downloadable Orphanet datasets)	9%	10%	6%	3%	35%	36%	2508
ORDO: Orphanet Rare Diseases ontology	8%	9%	6%	3%	36%	38%	2506
Orphanet mobile app	7%	7%	6%	2%	41%	36%	2462

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

In order to assess the usefulness of Orphanet products for the needs for each respondant, an analysis of the results for this question was carried out. A product was deemed to be of use for a user if they answer if they answered '++' or '+' in the scale proposed to assess the usefulness of Orphanet's services. The percentage of these replies was calculated from the total number of replies to this question for this product, with the 'I don't use this service' and 'I didn't know Orphanet offered this service' answers subtracted from the total results beforehand so as to more faithfully represent the utility of the products, according to those aware of these services and using them (i.e. total replies = answers concerning the scale of utility '++', '+', '-', '- -').

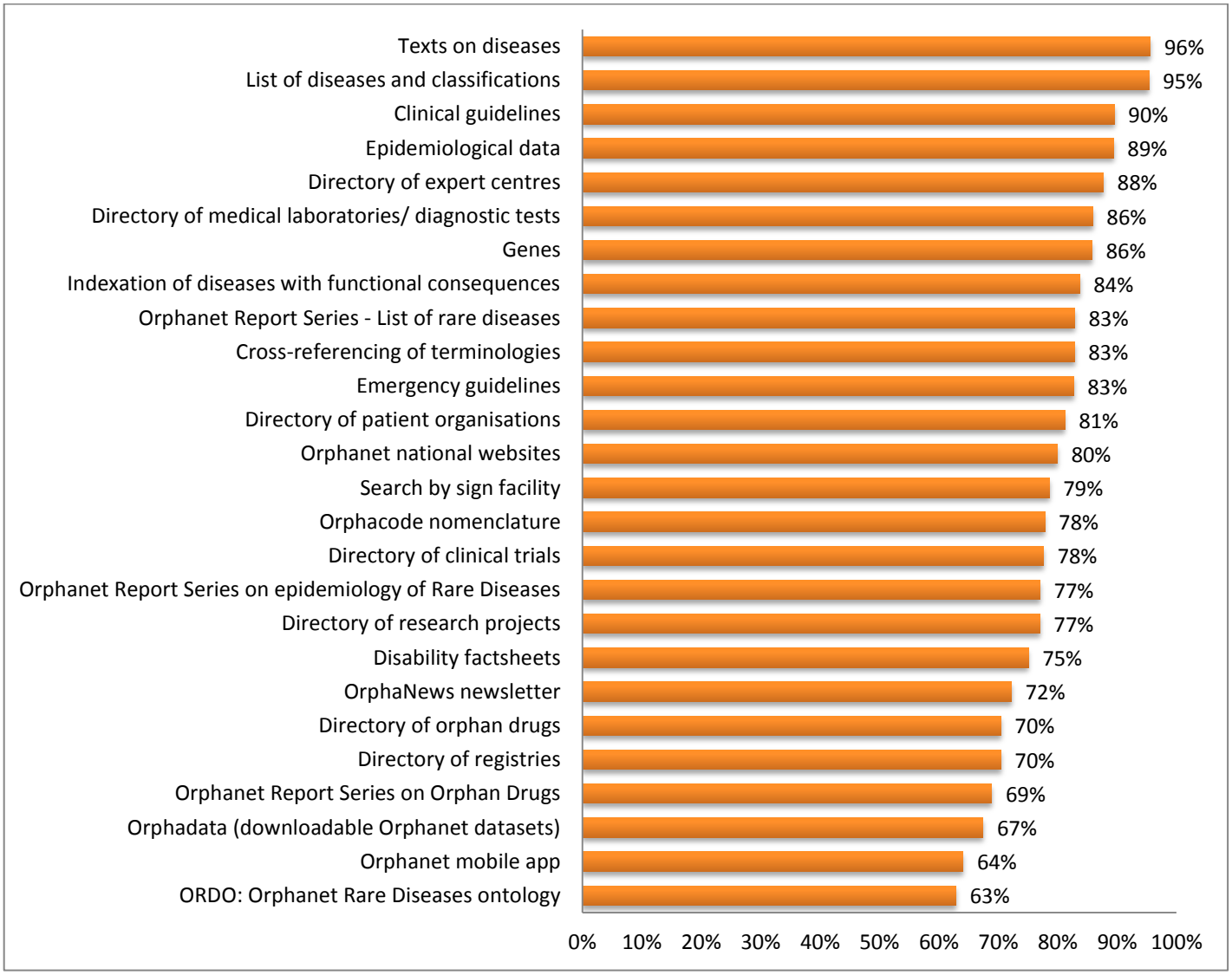

Figure 16: The most useful services offered by Orphanet according to respondents (answers '++' or '+' on the scale of usefulness).

The results show similar trends to previous years' surveys. The most useful Orphanet services, according to our users, are the texts on diseases (96%) and the list of diseases and classifications (95%). The data concerning the epidemiology of rare diseases is also highly appreciated (89%), as are the clinical guidelines made available via Orphanet (90%). The directory of expert centres were highly appreciated (88% of respondants who knew of, and used this service), as was the directory of medical laboratories (86%), and information on genes (86%). The

indexation of diseases with the functional consequences of the disease is highly appreciated by 84% of respondants who knew of and used this service, which was launched online in June 2016.

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.

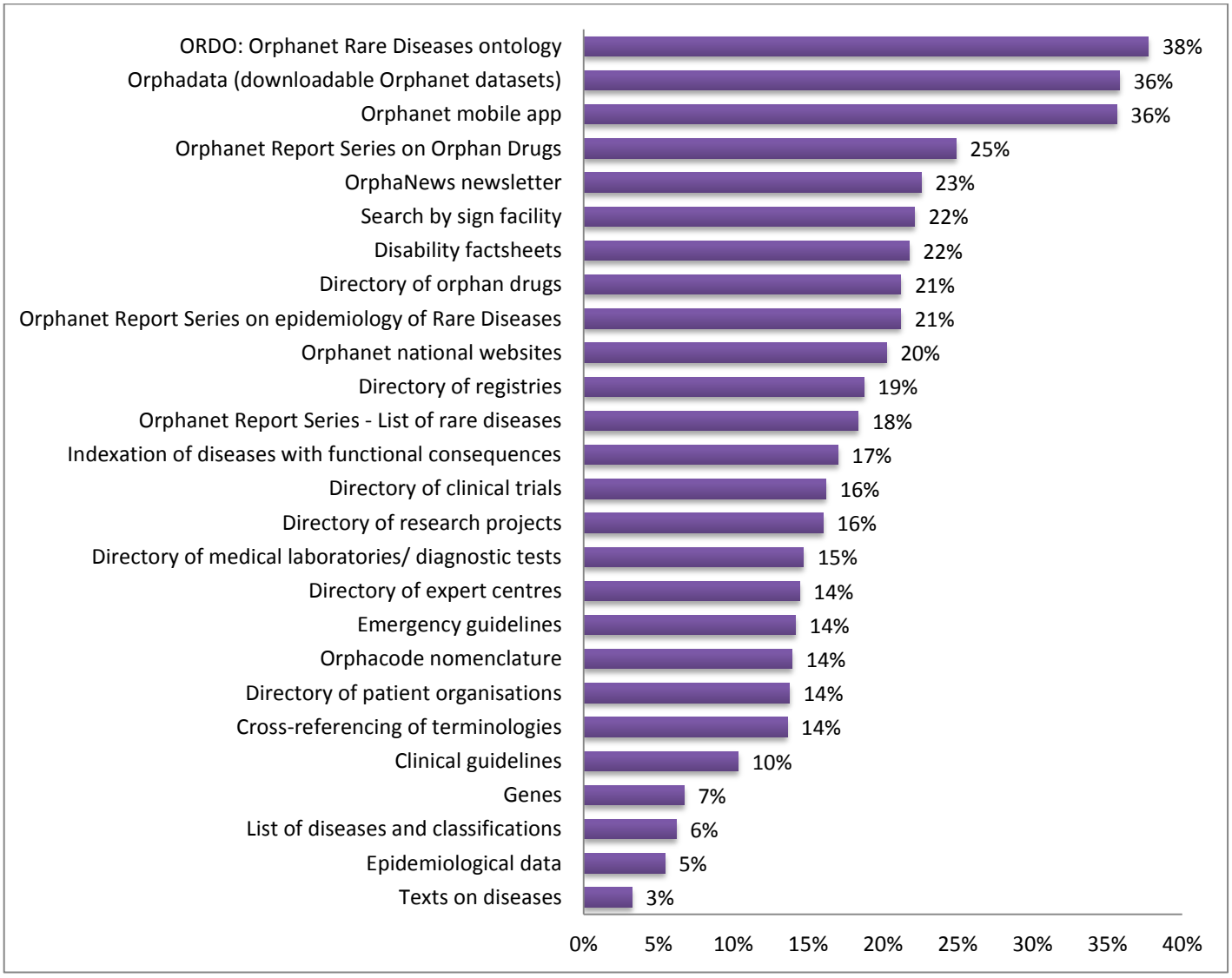

Figure 17: Least well-known Orphanet products (respondents answering 'I didn't know this service existed')

ORDO, the Orphanet Rare Disease Ontology, launched in 2013, is not known to 38% of our users, although amongst its users, it is well appreciated (63% 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. 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 (36% 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. As previously seen, the Orphanet mobile app is not well known (36% of users answering this question did not know it existed, compared to 41% of respondants in last year's survey)/

The most well known products remain the texts on diseases with only 3% not aware of their existence; only 5% of respondants did not know about the epidemiological data made available by Orphanet, and only 6% of respondants 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 9: 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 8. 1751 respondants provided an answer to this question. This question was asked for the first time this year; the results will serve as a benchmark against which to assess the improvement of the Orphanet website following the introduction of the new version of the site in March 2017. The results were analysed taking into account the respondants replying 'yes' or 'no', removing 'no opinion'.

Orphanet product	Easy to find ?	
	Yes	*No*
Texts on diseases	98%	2%
List of diseases and classifications	96%	4%
Genes	94%	6%
Epidemiological data	93%	7%
Orphacode nomenclature	88%	12%
Directory of expert centres	88%	12%
Cross-referencing of terminologies	87%	13%
Clinical guidelines	87%	13%
Orphanet Report Series - List of rare diseases	87%	13%
Directory of patient organisations	86%	14%
Directory of medical laboratories/diagnostic tests	85%	15%
Orphanet national websites	85%	15%
Indexation of diseases with functional consequences	84%	16%
Orphanet Report Series on epidemiology of Rare Diseases	82%	18%
OrphaNews newsletter	80%	20%
Directory of orphan drugs	80%	20%
Emergency guidelines	79%	21%
Directory of research projects	79%	21%
Directory of clinical trials	79%	21%
Search by sign facility	79%	21%
Directory of registries	75%	25%
Disability factsheets	75%	25%
Orphanet Report Series on Orphan Drugs	71%	29%
Orphadata (downloadable Orphanet datasets)	62%	38%
ORDO: Orphanet Rare Diseases Ontology	56%	44%
Orphanet mobile app	56%	44%

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

Orphanet product	Easy to use ?	
	Yes	*No*
Texts on diseases	96%	4%
List of diseases and classifications	95%	5%
Genes	94%	6%
Clinical guidelines	92%	8%
Epidemiological data	92%	8%
Orphanet Report Series - List of rare diseases	91%	9%
OrphaNews newsletter	90%	10%
Orphanet Report Series on epidemiology of Rare Diseases	90%	10%
Directory of patient organisations	90%	10%
Orphanet national websites	89%	11%
Indexation of diseases with functional consequences	89%	11%
Directory of expert centres	89%	11%
Emergency guidelines	88%	12%
Orphacode nomenclature	85%	15%
Cross-referencing of terminologies	85%	15%
Directory of medical laboratories/diagnostic tests	85%	15%
Disability factsheets	84%	16%
Directory of orphan drugs	83%	17%
Directory of clinical trials	83%	17%
Directory of research projects	81%	19%
Orphanet Report Series on Orphan Drugs	80%	20%
Directory of registries	79%	21%
Search by sign facility	75%	25%
Orphadata (downloadable Orphanet datasets)	69%	31%
ORDO: Orphanet Rare Diseases Ontology	67%	33%
Orphanet mobile app	63%	37%

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 Orphadata the second and third most difficult products to find and use. These latter two products are understandably harder to use due to them being geared to a research audience. 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.

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

Comments were provided by 873 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. 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. A frequent update of the services database was also requested. Users were also interested in subscribing to updates concerning specific diseases. Users also requested access to more 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.

A main concern is improving services to aid the diagnosis of patients with rare diseases. Some respondants have suggested that photos, or medical imagery, could be added to aid diagnosis. They also requested indexation of all rare diseases with HPO terms. They would also like an improved 'search by sign' tool and guidance on how to use this tool. This work to annotate rare diseases with HPO and to improve the 'search by sign' tool is already underway in the context of the eRare-3 project HIPBI-RD. In the context of this project, the aid to diagnosis tool will be improved: for the moment, on the new Orphanet website, the old 'search by sign' tool using the Orphanet thesaurus of clinical signs and symptoms has been replaced by Orphanet-Phenomizer.

Despite the overhaul of the Orphanet homepage in 2012, users request a more user-friendly, modern and clearer website with improved navigation, so as to make it easier to access all the information on the website. The new Orphanet website, launched in March 2017 should reply to this need. Next year's survey will seek users' feedback on the changed look and feel of the website. More evolutions, in line with the current transformation of the Orphanet database from a relational database to a knowledge base, are foreseen around the end of 2017. Users also requested an updated format for the OrphaNews newsletter: this was put into place at the end of January 2017. An update of the mobile app in order to render it more functional was also requested and will be considered.

Users expressed the need for a different lay out of texts on diseases, with clearer division of information into subtitled paragraphes and larger text to facilitate reading: this improvement is being rolled out progressively.

Many users highlighted that they are unaware of many of the services offered by Orphanet, and would like to have help (in the form of tutorials, for example) in how to best use the wealth of data provided: these tutorials will be put into place in 2017. They also highlighted that this resource could be better known by general practictioners in particular, and suggested that training in the use of Orphanet could be proposed to healthcare professionals: this measure should be considered by each Orphanet national teams in their presence at national conferences. In 2017 a communication strategy will be rolled out, taking into account all of these considerations.

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

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