Orphanet Report Series
Reports collection

2015

2015 User Satisfaction Survey of the Orphanet Website

www.orpha.net

Instituts thématiques
Inserm
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Liberté • Égalité • Fraternité
RÉPUBLIQUE FRANÇAISE
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RD ACTION
DATA AND POLICIES FOR RARE DISEASES

Co-funded by
the Health Programme
of the European Union

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Methodology

An on-line survey was designed in December 2015, 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 2016: 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. The survey was closed after 3 weeks on the website.

The results from all of the languages of the survey, totaling 3795 responses, were analysed for this survey.

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

Results

Question 1: 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	1713	**45,1%**
Patient/Family/PatientOrganisation	985	**26,0%**
Research	133	**3,5%**
Industry	44	**1,2%**
Health Care Manager/ Policy Maker	35	**0,9%**
Education/Communication	76	**2,0%**
Student	632	**16,7%**
Other	177	**4,7%**
Total	**3795**	

Figure 1a: Types of Orphanet user (number of responses and percentage of total responses) n =3795

The largest category of respondents is the health professional category (45%). The second largest category of respondents is patients and their entourage (including patient organisations, alliances and support groups) with 26% of responses. Many students (17%) also use Orphanet. The 'other' category included respondents working in non-related socio-professional categories and those generally interested in rare diseases but who did not state their professional category.

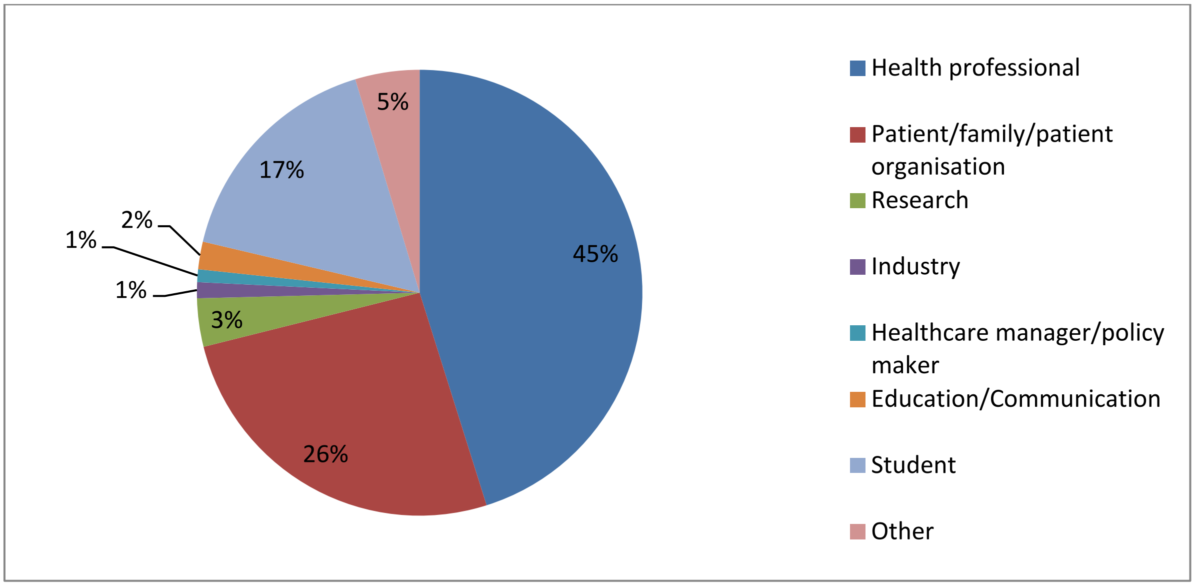


Figure 1b: Types of Orphanet user (percentage of total respondents) n = 3795

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=1687):
Hospital specialists represent by far the main category of respondents (40%). All together, 54% are specialists. Genetic counsellors represent nearly 5% 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: 39% responded that they had expertise in the field.

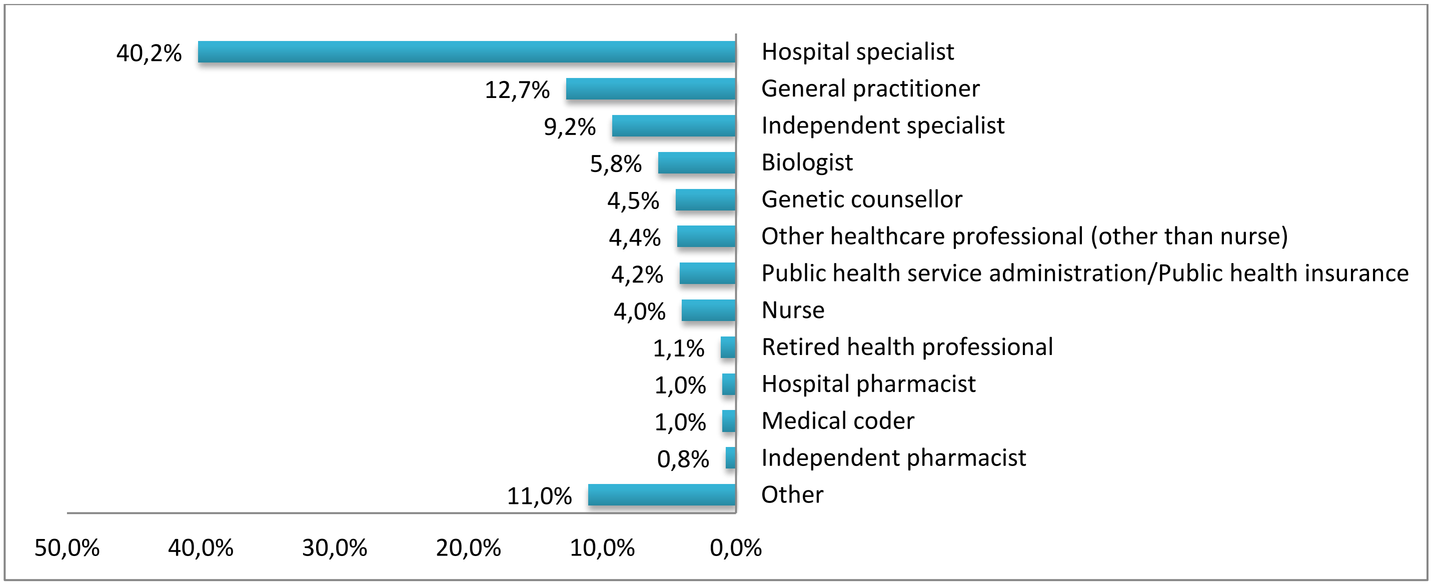


Figure 2: Types of respondents qualifying themselves as health professionals

Patient/entourage (n=979):

Most of the people who selected this category are patients (50%): 37% are family members of a patient with a rare disease.

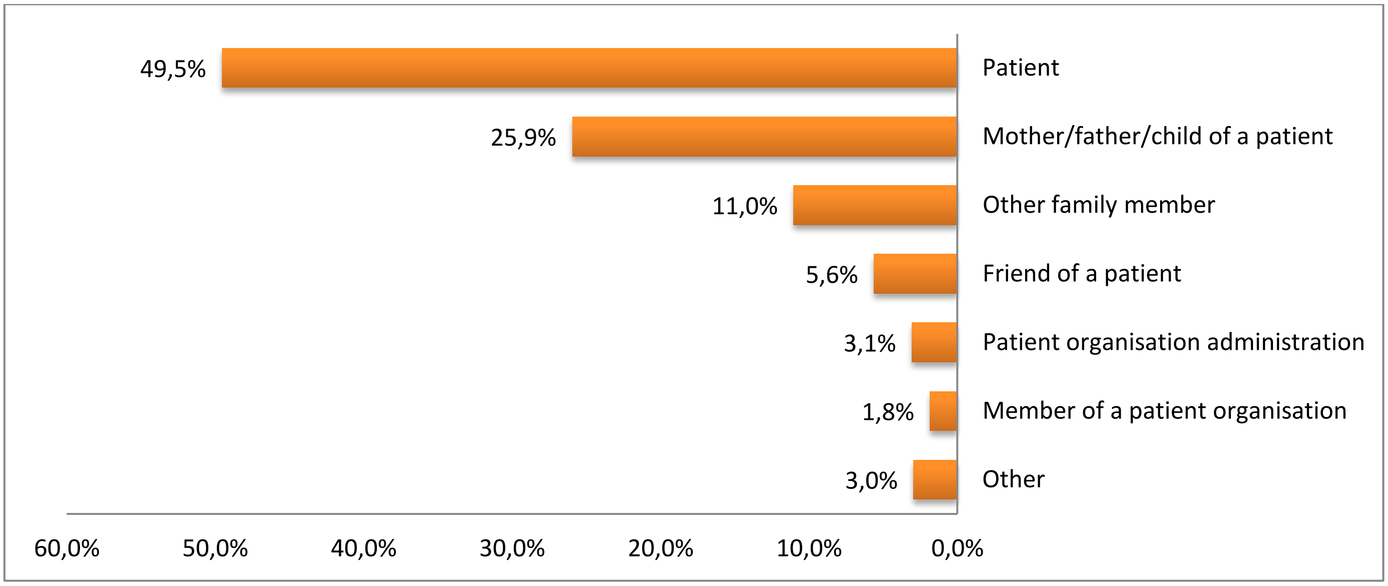


Figure 3: Types of respondents qualifying themselves as a patient or part of a patient's entourage.

Research (n=131):

Academic researchers represent 60% of respondents of the research category, and are divided between basic (23%) and clinical research (37%). Industry researchers (14%) and bioinformaticians (5%) are also represented. The 'other' category included research administrators and research funding organisations/charities.

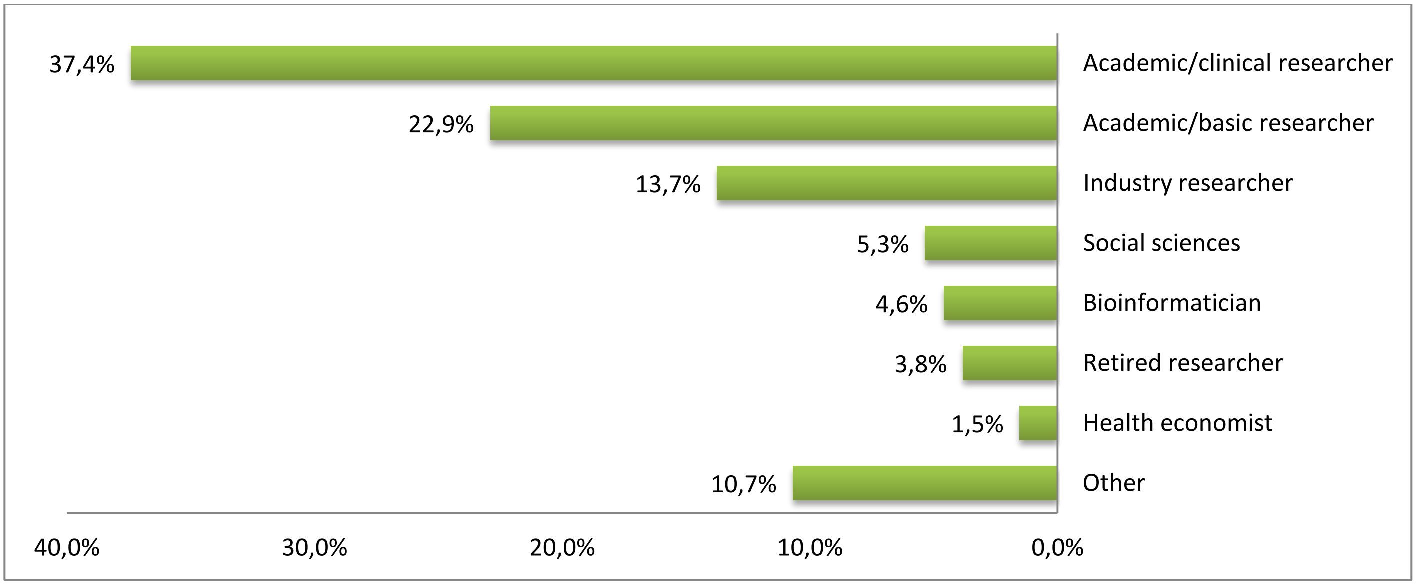


Figure 4: Types of respondents qualifying themselves as working in the field of research.

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%).

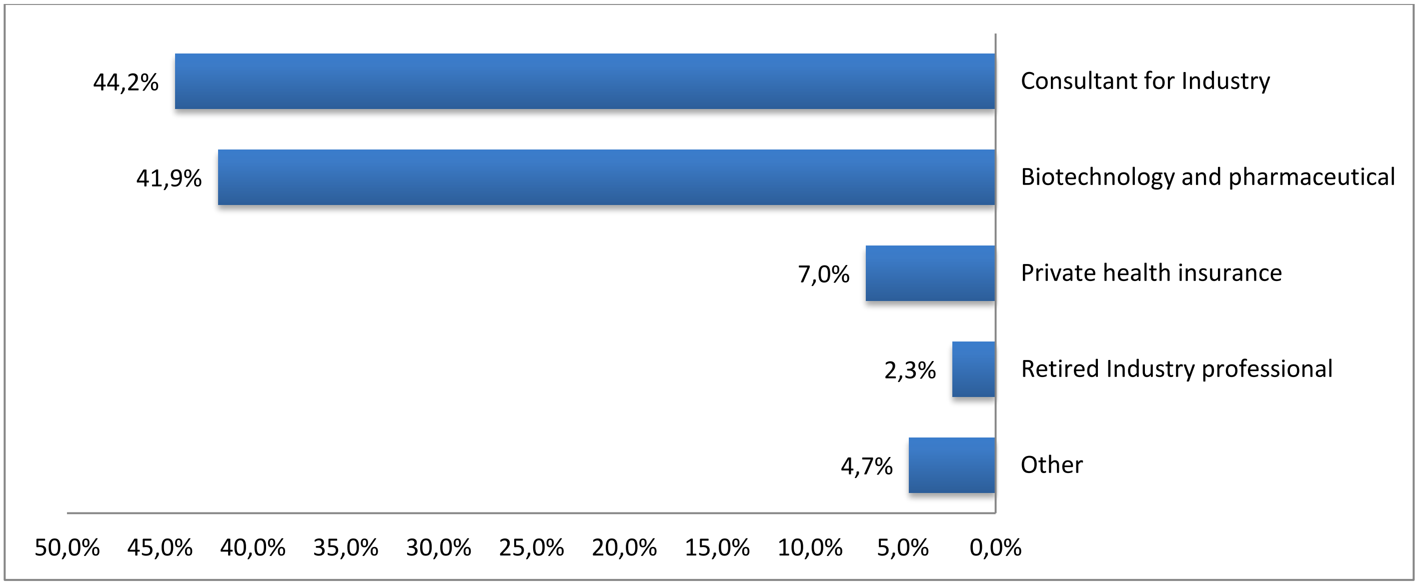


Figure 5: Types of respondents qualifying themselves as working in the biotechnology or pharmaceutical industry.

Health care manager/policy maker (n=35):

In this category, 46% work in hospital administration and the remainder mostly in governmental administration (29%).

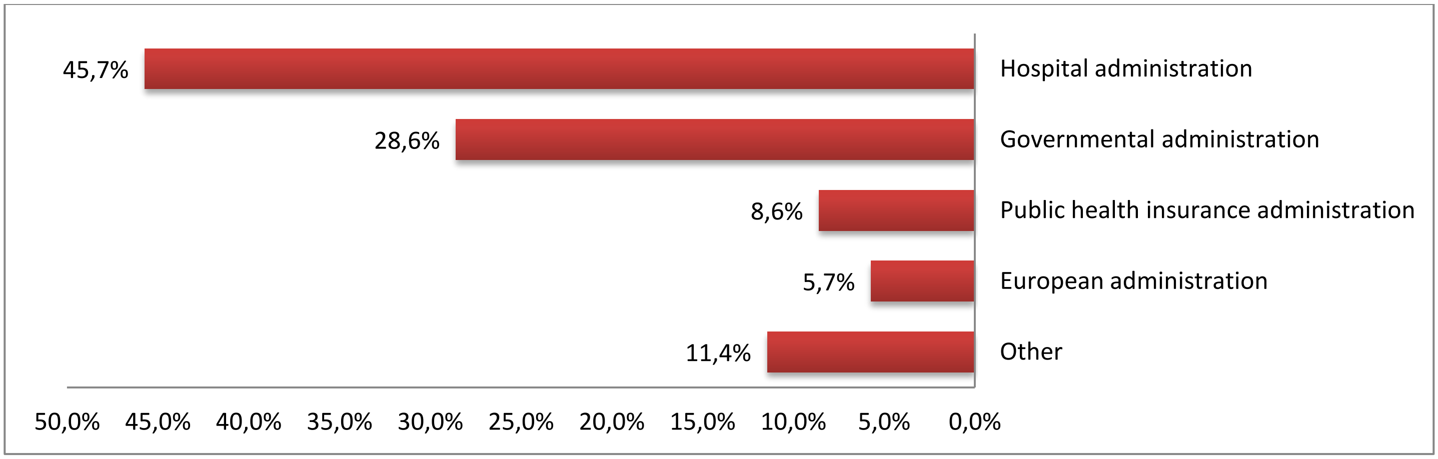


Figure 6: Types of respondents qualifying themselves as working in the field of health care management/policy making.

Education/communication (n=75):
In this category teachers represent 40% of respondants. Social workers were the second most represented sub-category with 9% of respondents for this category.

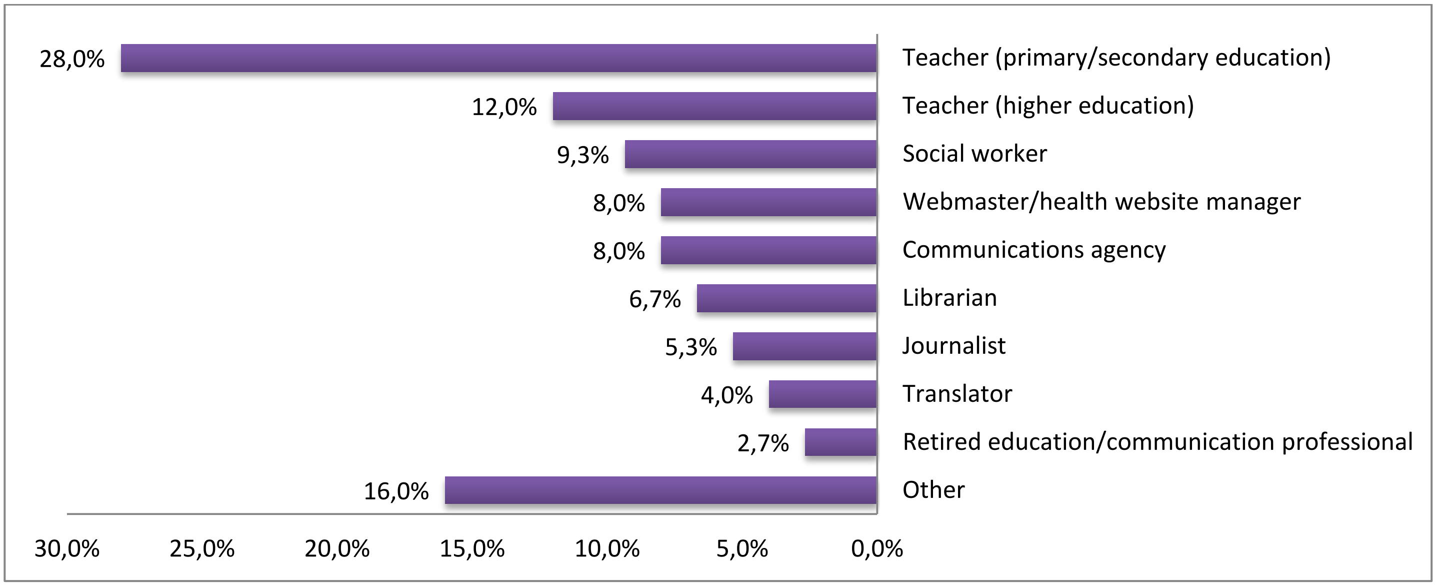


Figure 7: Types of respondents qualifying themselves as working in education/communication.

Students (n=630):
Medical students represent 86% of this category. The other respondents were studying biology, hospital administration, genetic counselling, pharmacy, etc

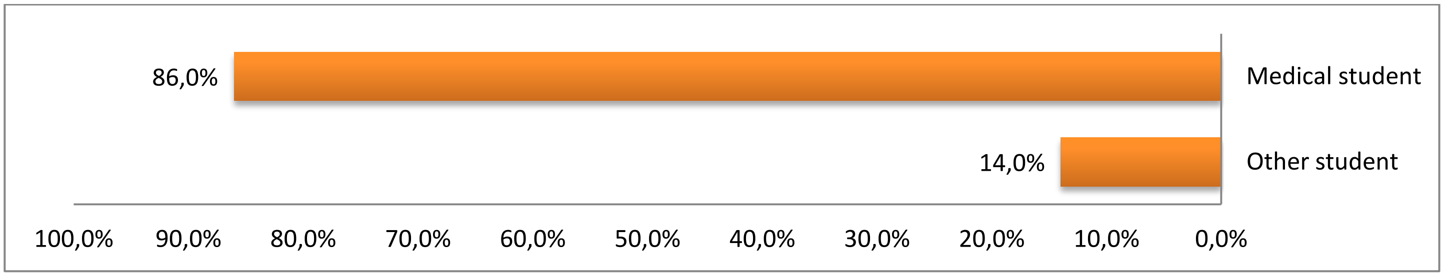


Figure 8: Types of respondents qualifying themselves as students.

Question 2 : How did you discover Orphanet?

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

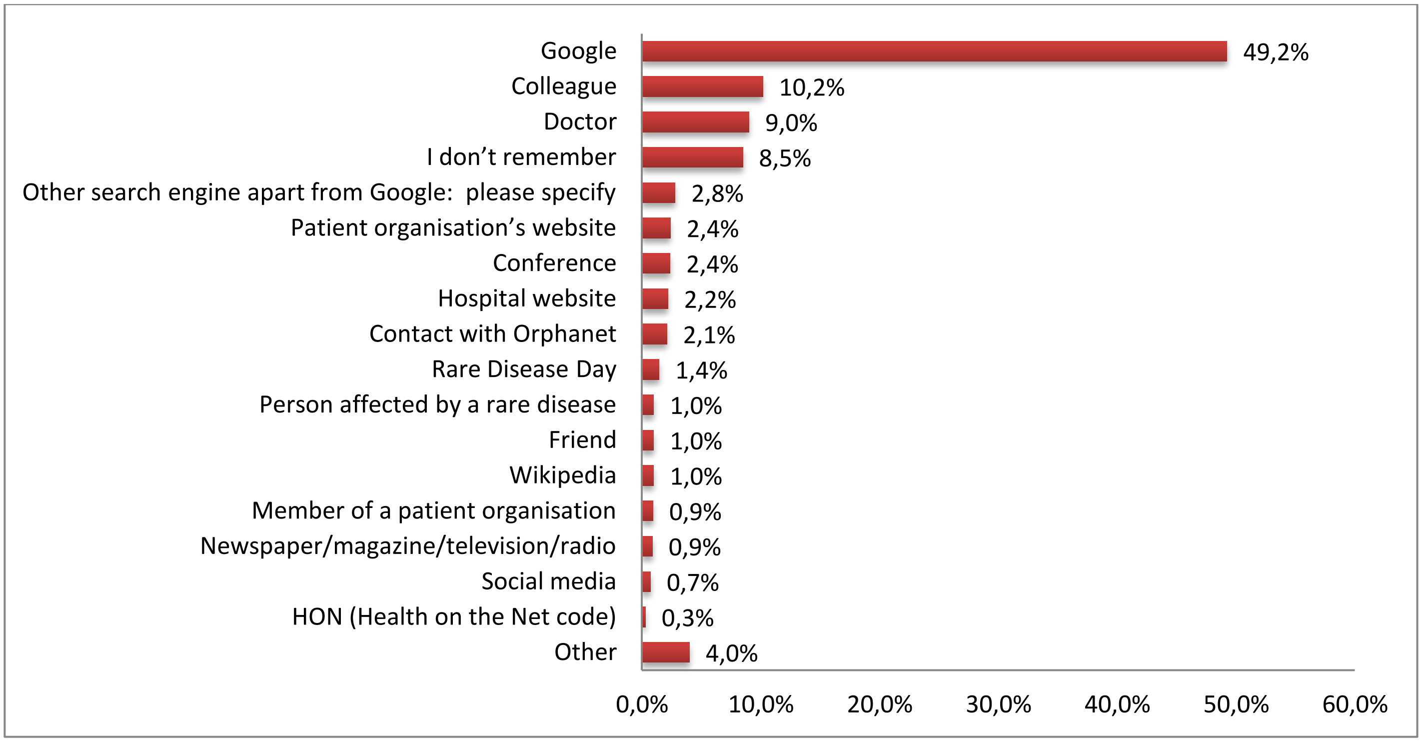


Figure 9: Mode of discovery of Orphanet by respondents (n=3725)

The majority of our users discovered Orphanet via a search engine (around 52%). 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, or at a conference. The other vectors cited by users include institutional websites, during a training session/lesson, and other databases.

Question 3 : How often do you visit Orphanet?

Only one response was possible. Around 50 % of those answering the survey are regular users, whereas 26% were visiting Orphanet for the first time.

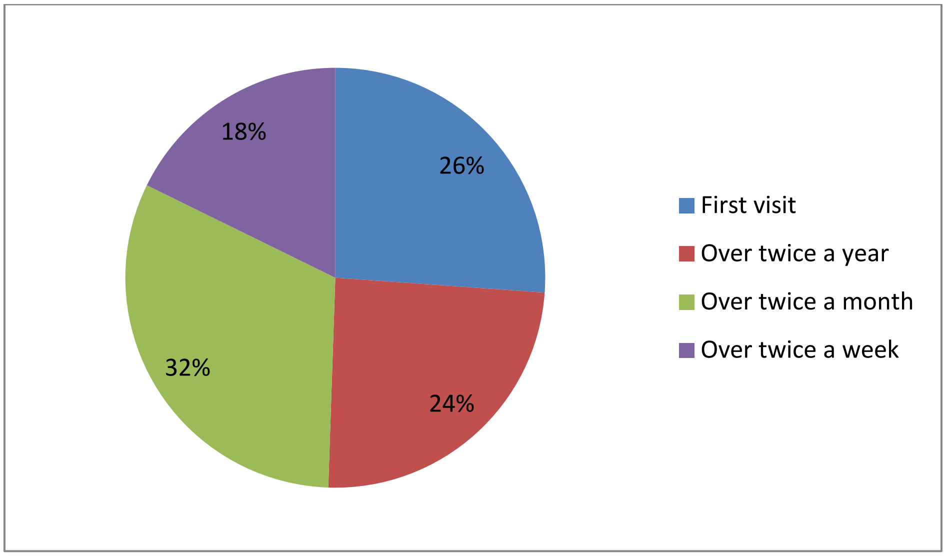


Figure 10: Visiting frequency of respondents (n=3647)

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.

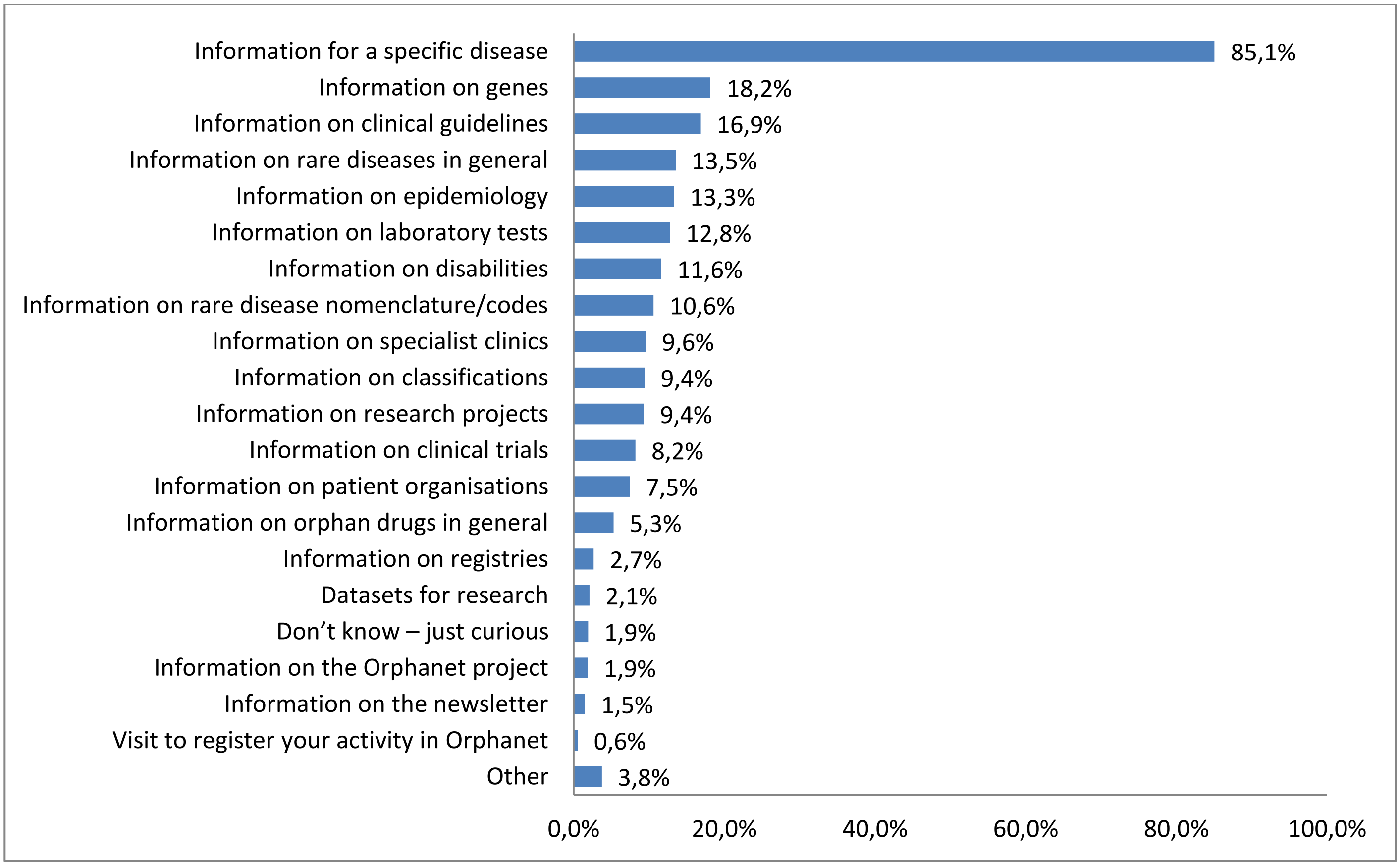


Figure 11: Information sought by respondents during their connection to Orphanet (percentage of total number of respondents n=3699)

The results show a clear trend: most of the respondents were looking for information for a specific disease (85%). Our visitors also look for information on genes (18%), clinical guidelines (17%), rare diseases in general (14%), and epidemiology (13%). A smaller percentage of respondents were seeking information concerning an expert resource in particular: laboratory tests (13%), specialist clinics (10%), research projects (9%), on clinical trials (8%), patient organisations (8%). 11% of users were looking for information related to the nomenclature and coding of rare diseases.

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

Question 5: Do you regularly 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. More than one choice was possible.

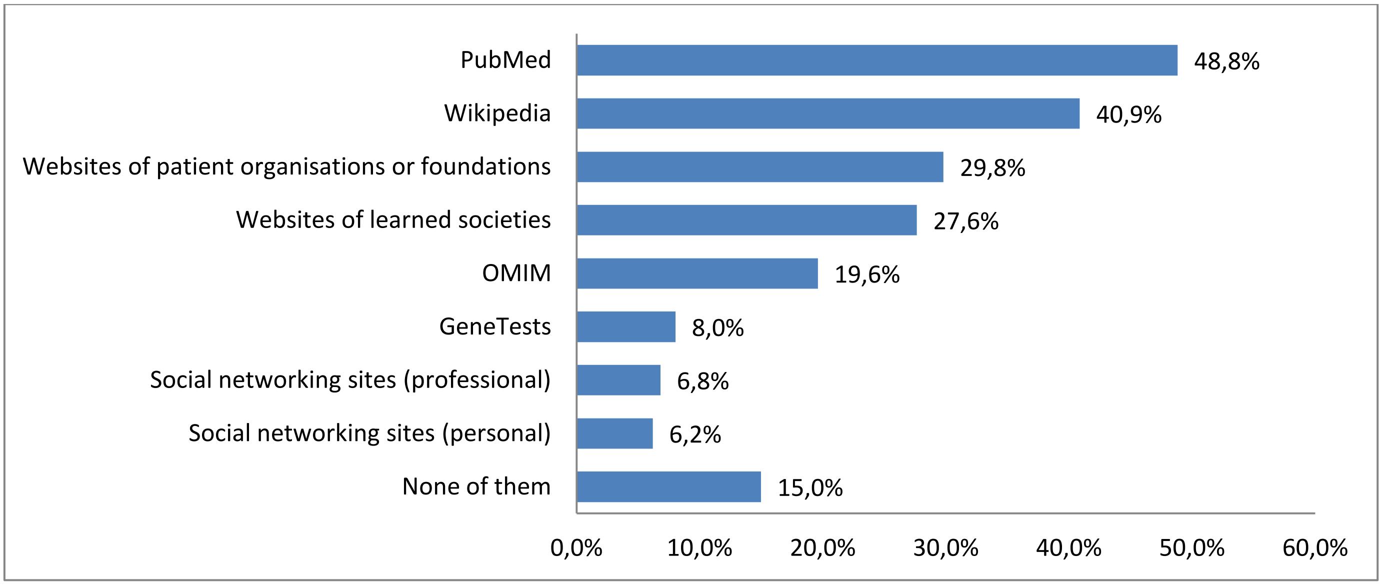


Figure 12: Other sources of information used by respondents to find information on rare diseases (percentage of total number of respondents, n=3684)

To obtain information on rare diseases, 49% of respondents use PubMed, with Wikipedia in second place (41%), and the websites of patient organisations and learned societies sharing the third place at 30% and 28% respectively. OMIM was a less commonly used source of information (20%). Social networks are a less not a commonly used source of information, with around 7% of respondents citing professional social networking sites, and 6% citing personal networking sites: this figure has not evolved since last year. The analysis underlines that Wikipedia remains from year to year a main source of information for all categories of respondents.

Question 6: How are you accessing Orphanet today?

Only one response was possible for this question.

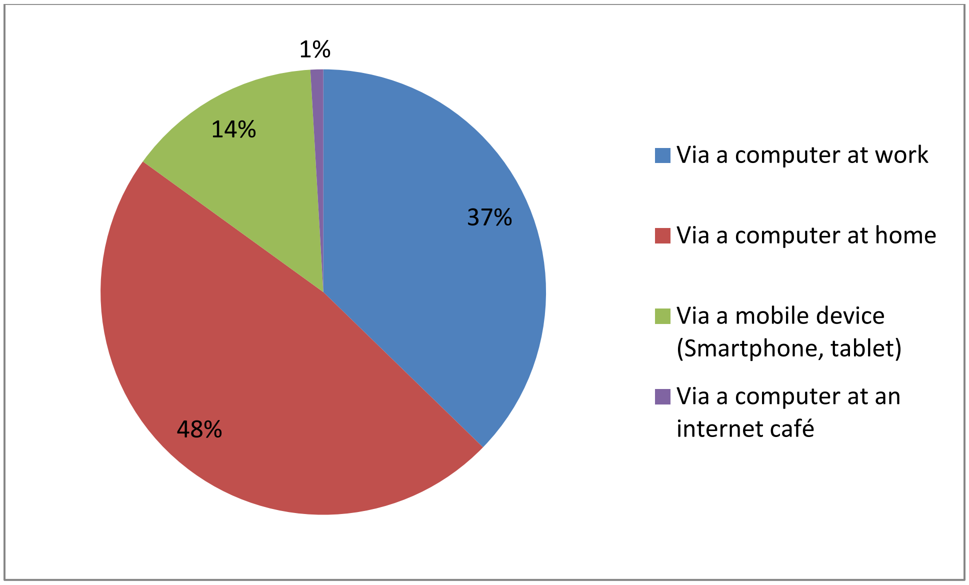


Figure 13: Mode of accessing Orphanet by respondents (n=3673)

Of those who responded to the survey, 48% did so from home, whilst 37% did so from their workplace. The use of a mobile device with an Internet connection is represents, as last year, 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.

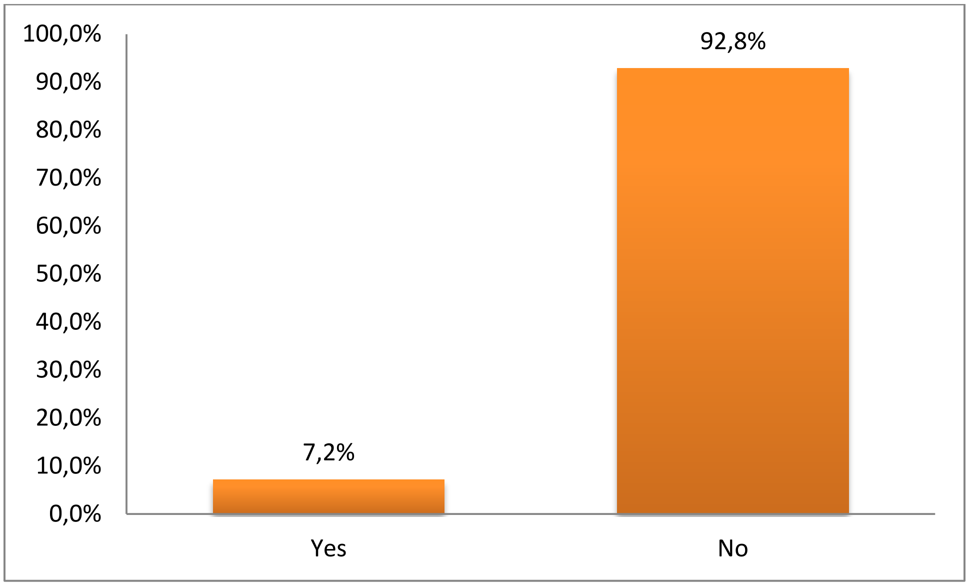


Figure 14a: Respondants having downloaded the Orphanet mobile application (n=3667).

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

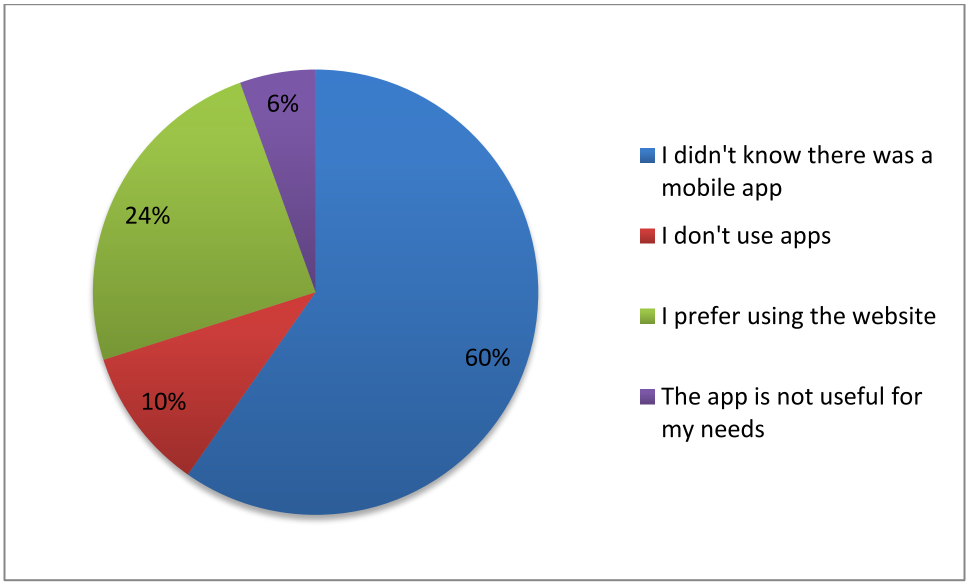


Figure 14a: Reasons for not downloading the Orphanet app, according to 3379 respondants.

The principal reason (60%) for not downloading the app was because users did not know it existed. More efforts to promote this tool will be made in the future. Around a quarter stated that they prefer using a website to an app, and 10% stated they do not use apps in general with 6% stating that the app was not suited to their needs.

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 2528 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	66%	24%	4%	1%	3%	2%	2422
List of diseases and classifications	53%	25%	3%	0%	14%	5%	2422
Epidemiological data	47%	33%	6%	1%	10%	3%	2314
Clinical guidelines	42%	25%	7%	2%	16%	8%	2361
Orphanet Report Series - List of rare diseases	29%	24%	6%	2%	23%	15%	2285
Emergency guidelines	27%	21%	10%	2%	27%	12%	2292
Search by sign facility	27%	18%	9%	3%	25%	18%	2293
Orphanet Report Series on epidemiology of Rare Diseases	22%	21%	7%	3%	29%	18%	2264
Cross-referencing of terminologies	22%	26%	7%	1%	31%	12%	2269
Orphacode nomenclature	20%	20%	8%	2%	40%	11%	2301
Directory of patient organisations	20%	22%	9%	3%	31%	14%	2276
Directory of medical laboratories	19%	19%	8%	3%	34%	17%	2287
Directory of clinics	17%	19%	9%	3%	35%	17%	2267
Directory of orphan drugs	16%	17%	9%	3%	38%	17%	2250
Directory of research projects	16%	19%	10%	4%	34%	17%	2277
Directory of clinical trials	16%	19%	10%	4%	34%	18%	2278
Disability factsheets	15%	18%	8%	3%	34%	21%	2261
Orphanet national websites	14%	15%	8%	4%	37%	22%	2208
Orphanet Report Series on Orphan Drugs	14%	16%	8%	3%	37%	22%	2233
Directory of registries	10%	14%	10%	4%	42%	19%	2213
OrphaNews newsletter	10%	11%	8%	4%	41%	26%	2203
Orphadata (downloadable Orphanet datasets)	7%	8%	6%	3%	40%	36%	2200
ORDO: Orphanet Rare Diseases ontology	6%	8%	7%	3%	43%	34%	2206
Orphanet mobile app	5%	6%	5%	3%	41%	41%	2218

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 '++', '+', '-', '- -').

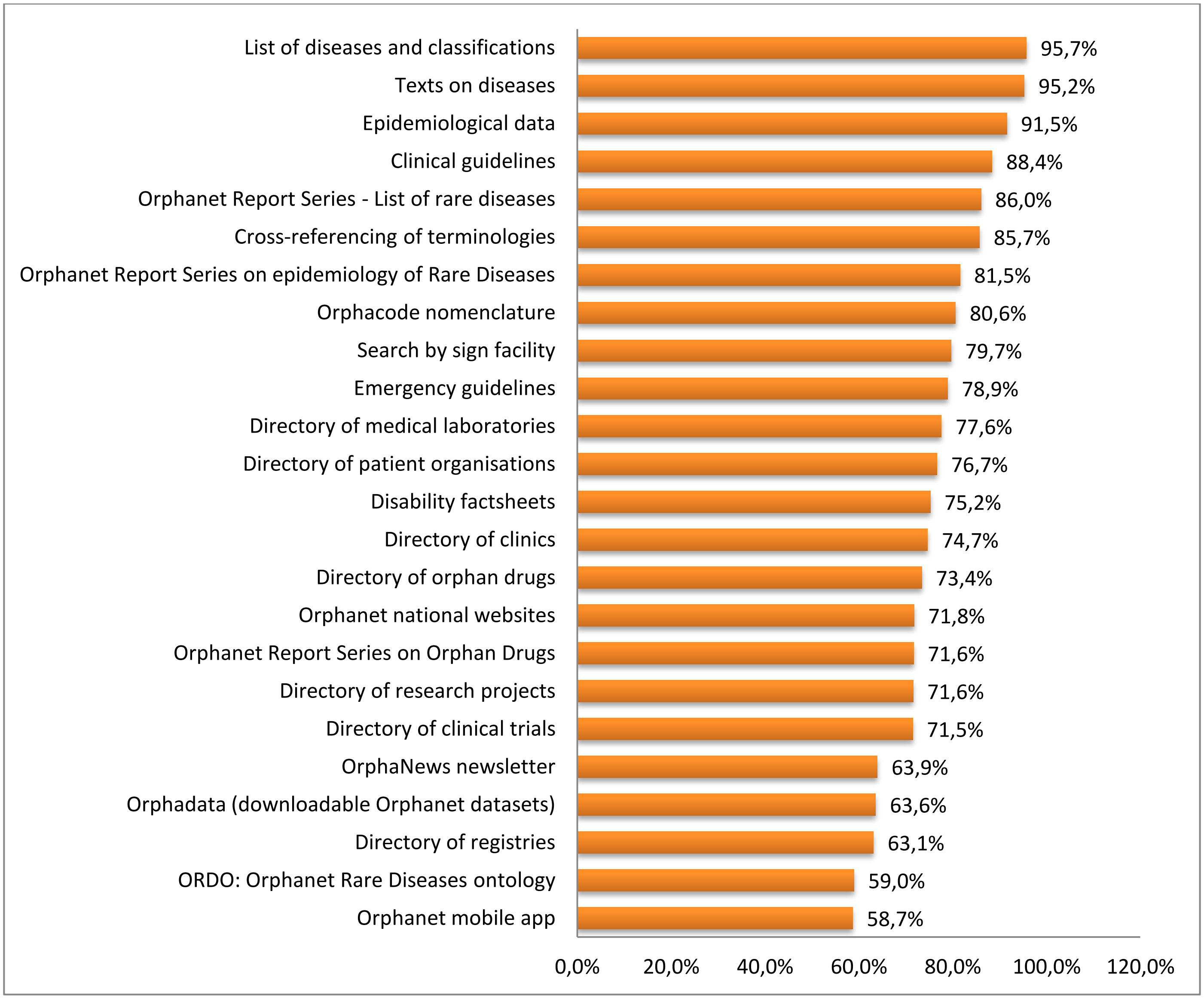


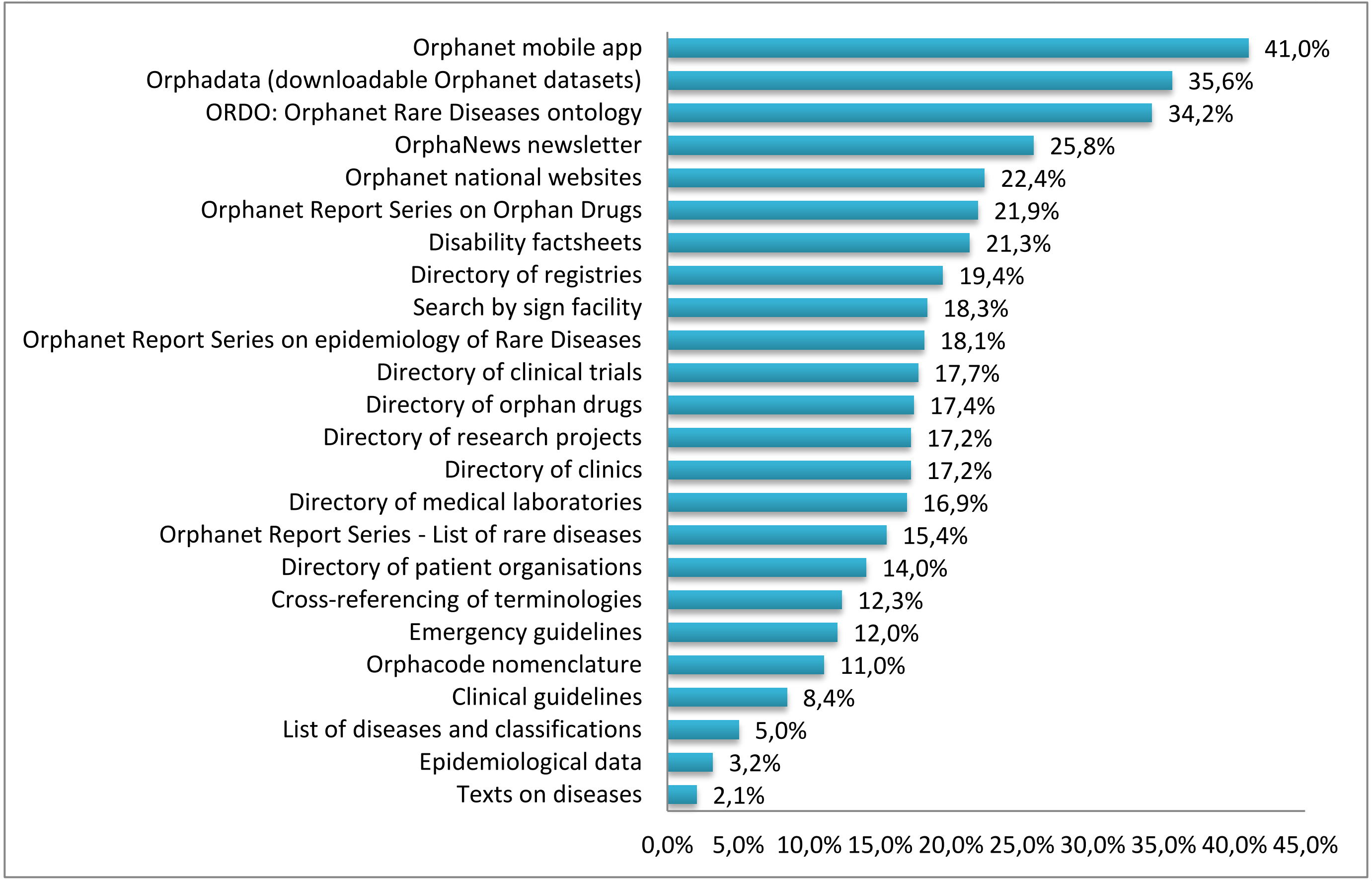
Figure 16: The most useful services offered by Orphanet according to respondents (answers '++' or '+' on the scale of usefulness).

The most useful Orphanet services, according to our users, are the texts on diseases (95%) and the list of diseases and classifications (96%). The data concerning the epidemiology of rare diseases is also highly appreciated (92%), as are the clinical guidelines made available via Orphanet (88%), the Orphanet Report Series - List of Rare Diseases

(86%), and cross-referencing of terminologies (86%). 80% of respondents highly appreciated the search by sign facility and 79% were satisfied with the utility of the emergency guidelines.

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’)



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. Similarly, ORDO, the Orphanet Rare Disease Ontology, launched in 2013, is not known to 34% of our users: as for Orphadata, 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.

The OrphaNews newsletter is also a service which is less well known to users with 26% of users citing it as unknown to them. 22% of users are also not aware of the existence of Orphanet’s national websites, introduced from 2011 onwards, and the Orphanet Report Series on Orphan Drugs (22%).

The most well known products remain the texts on diseases with only 2% not aware of their existence; only 3% of respondants did not know about the epidemiological data made available by Orphanet, and only 5% 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: What should Orphanet do to better serve your needs?

Comments were provided by 1079 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, in particular concerning laboratories. Requests for more frequent updates concerning drugs and clinical trials were also received. Users were also interested in subscribing to updates concerning specific diseases.

Users expressed a need for improved epidemiological data: improved data on prevalence and incidence were added in 2014 to Orphanet's database and are available for download on www.orphadata.org, but this is not accessible via the site thus explaining the enduring presence of these comments as this service is better known to researchers. This echos the fact that users have a poor awareness of the availability of Orphanet's downloadable datasets, and require better guidance on how to use the files available via this platform: this will be taken into account in our communication strategy.

Respondents are interested in accessing even more clinical guidelines and review articles. They are also interested in accessing these resources in their own languages, and to increase the number of translations available. A part time position is dedicated to adding this external content at Orphanet and in 2015 over extra 100 texts were included. Users also requested that data concerning expert resources in countries outside of the current consortium be included to make the database truly international: in 2015 the Orphanet Consortium has grown, and in addition it is possible for patient organisations and patient registries and biobanks outside of the Consortium to be added to the database.

Health professionals have suggested that photos, or medical imagery, could be added to aid diagnosis. They would also like an improved 'search by sign' tool and guidance on how to use this tool: this tool will be improved in the future through the annotation of diseases in Orphanet using Human Phenotype Ontology terms which will be supported by a new project in 2016.

Despite the overhaul of the Orphanet homepage in 2012, users request a more user-friendly, modern and clearer website with improved navigation. Users also highlighted that improvements could be made to how data is searched and the presentation of results, citing difficulties with accessing the range of information available. A way of saving search results in a PDF format was also highlighted as a need. Others suggested providing an interface by type of user to better orientate users. Some requested a more dynamic navigation of the classifications. 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. These suggestions will be studied during an upcoming revision of the look and feel of the Orphanet site and the current transformation of the database from a relational database to a knowledge base.

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. 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. In 2016 a communication strategy will be formulated by Orphanet, taking into account all of these considerations.

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

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The correct form when quoting this document is :
«2015User Satisfaction Survey of the Orphanet Website», Orphanet Report Series, Reports Collection, 2015,

http://www.orpha.net/orphacom/cahiers/docs/GB/Orphanet_survey2015.pdf

This Orphanet Report Series is part of the joint action RD-ACTION which has received funding from the European Union’s Health Programme (2014-2020).

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