www.orpha.net

2014 User Satisfaction Survey
of the Orphanet Website

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Methodology

An on-line survey was designed in November 2014, 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 December 2014: 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 5 weeks on the website.

The results from all of the languages of the survey, totaling 3224 responses, were analysed for this survey. Prior to this analysis, when appropriate, the respondents who were not able to class themselves in the provided categories and sub-categories of user (Question 1) were reattributed to the corresponding category/sub-category.

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	1501	46,6%
Patient/entourage/patient organisation	846	26,2%
Student	544	16,9%
Research	123	3,8%
Education/communication	62	1,9%
Health care manager/policy maker	44	1,4%
Industry	33	1,0%
Other	71	2,2%
Total	3224	

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

The largest category of respondents is the health professional category (47%). The second largest category of respondents is patients and their entourage (including patient organisations, alliances and support groups) with 26% of responses. The 'other' category included respondents working in non-related socio-professional categories, retirees and those generally interested in rare diseases but who did not state their professional category.
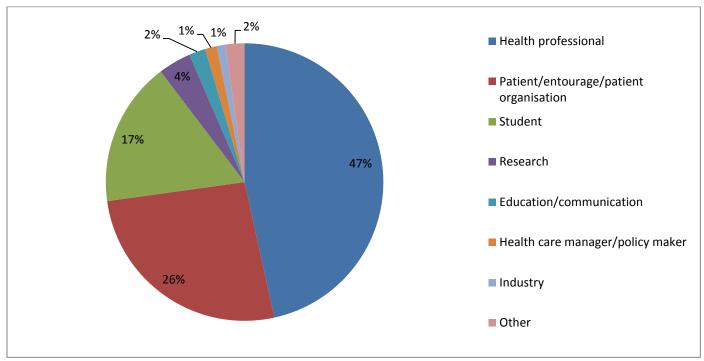
Figure 1b: Types of Orphanet user (percentage of total respondents) n = 3324

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=1496):
Hospital specialists represent by far the main category of respondents (41%). All together, 57% are specialists.
Genetic counsellors represent 4% within this category, general practitioners represent 13% of the healthcare professionals.
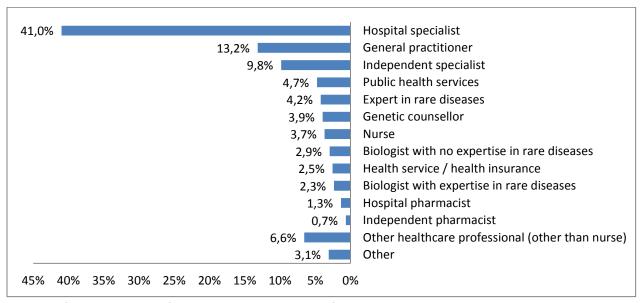

41,0%	Hospital specialist
13,2%	General practitioner
9,8%	Independent specialist
4,7%	Public health services
4,2%	Expert in rare diseases
3,9%	Genetic counsellor
3,7%	Nurse
2,9%	Biologist with no expertise in rare diseases
2,5%	Health service / health insurance
2,3%	Biologist with expertise in rare diseases
1,3%	Hospital pharmacist
0,7%	Independent pharmacist
6,6%	Other healthcare professional (other than nurse)
3,1%	Other

Figure 2: Types of respondents qualifying themselves as health professionals

Patient/entourage (n=838):

Most of the people who selected this category are patients (50%): 40% are family members of a patient with a rare disease.
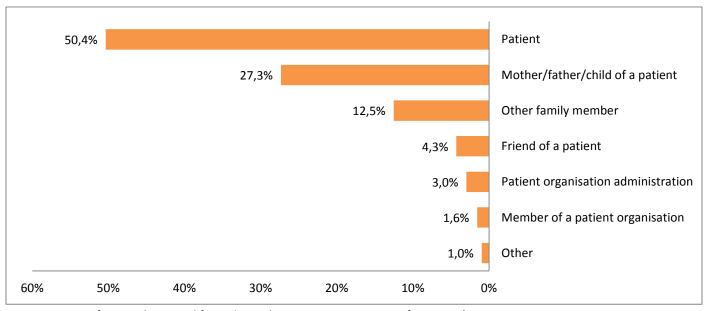

50,4%	Patient
27,3%	Mother/father/child of a patient
12,5%	Other family member
4,3%	Friend of a patient
3,0%	Patient organisation administration
1,6%	Member of a patient organisation
1,0%	Other

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

Research (n=114):

Academic researchers represent 69% of respondents of the research category, and are divided between basic (21%) and clinical research (48%). Industry researchers (10%) and bioinformaticians (8%) are also represented. The 'other' category included research business developers, pharmaceuticals analysts, and research funding organisations.
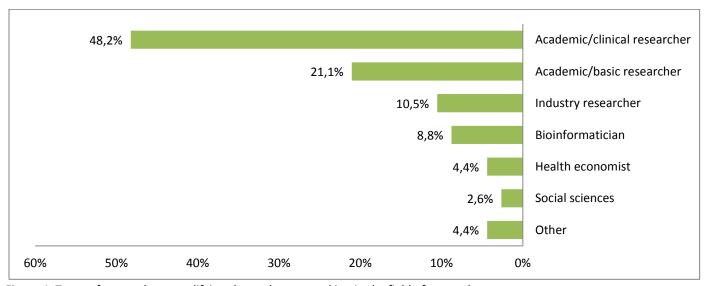

48,2%	Academic/clinical researcher
21,1%	Academic/basic researcher
10,5%	Industry researcher
8,8%	Bioinformatician
4,4%	Health economist
2,6%	Social sciences
4,4%	Other

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

Industry (n=33):

67% of respondents in this category work in the biotechnology or pharmaceutical industry. A small number were consultants for industry (15%), or investors/business developers (9%).
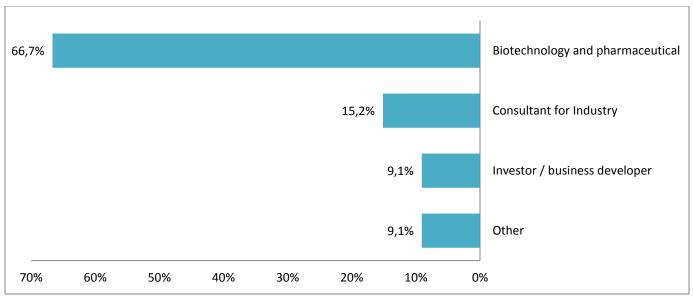

Figure 5: Types of respondents qualifying themselves as working in the biotechnology or pharmaceutical industry.

Health care manager/policy maker (n=44):

In this category, 41% work in governmental administration and the remainder mostly in hospital administration (32%). The others worked in health inspection, cross-border healthcare administration, and local administration.
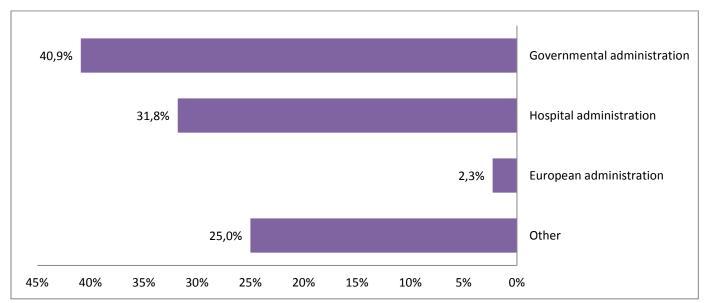

Figure 6: Types of respondents qualifying themselves as working in the field of health care management/policy making.

Education/communication (n=61):

In this category teachers represent 36% of responses. Journalists were the second most represented sub-category with 28% of respondents for this category. The other sub-category included several retirees, social workers, and health website managers.
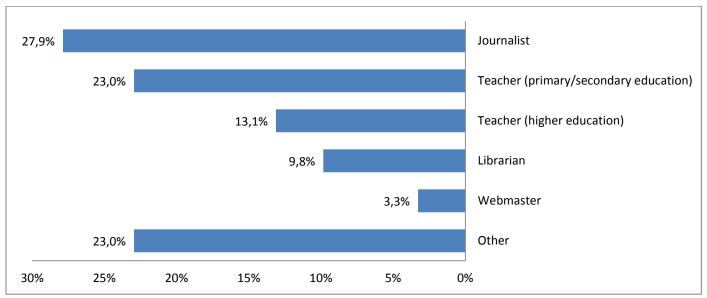

Figure 7: Types of respondents qualifying themselves as working in education/communication.

Students (n=541):

Medical students represent 84% of this category. The other respondents were studying biology, hospital administration, genetic counselling, or pharmacy.
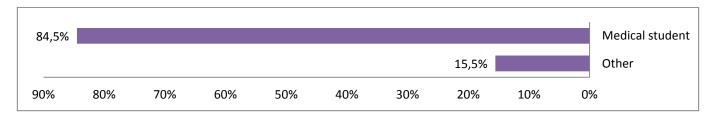

Figure 8: Types of respondents qualifying themselves as students.

Question 2 : How did you discover Orphanet?

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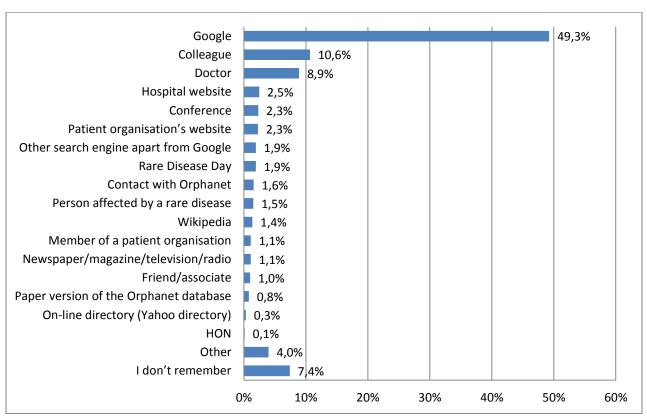

Figure 9: Mode of discovery of Orphanet by respondents

The majority of our users discovered Orphanet via internet, either by query via a search engine (around 50%). 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 answering in the 'other' category are institutional websites (National Institutes of Health, Center for Disease Control), company websites, or Facebook.

Question 3 : How often do you visit Orphanet?

Only one response was possible. Around 49 % of those answering the survey are regular users, whereas 25% were visiting Orphanet for the first time.

Around 50% of first time visitors were patients and their entourage. Of those respondents that visit the site over twice a month, than 55% were health professionals and 23% were students, compared to 12% of patients and their entourage. Of the respondents that visit the site over twice a week, 63% are medical professionals and 18% are students.
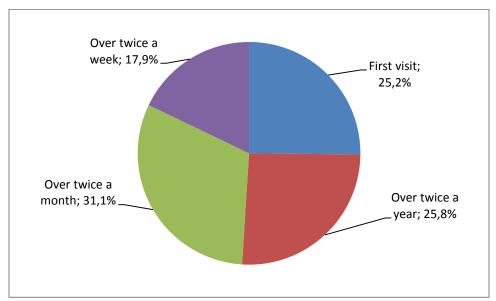

Figure 10: Visiting frequency of respondents

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.
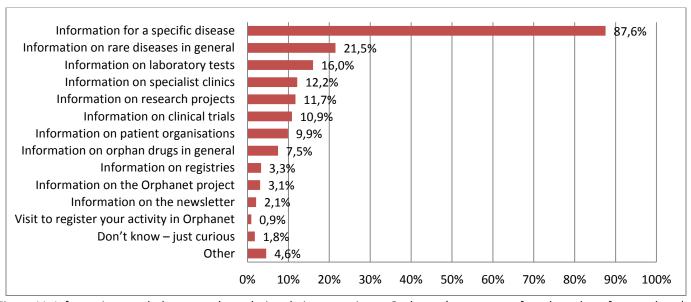

Figure 11: Information sought by respondents during their connection to Orphanet (percentage of total number of respondents)

The results show a clear trend: most of the respondents were looking for information for a specific disease (87%). Our visitors also look for information on rare diseases in general (22%). A smaller percentage of respondents were seeking information concerning an expert resource in particular: laboratory tests (16%), specialist clinics (12%), research projects (12%), on clinical trials (11%), patient organisations (10%).

The principle reason for visiting the site across all categories of users is information on a specific disease or rare diseases in general, after these two reasons, the main reason varied across categories of user.

22% of health professionals responded that they were looking for information on a laboratory test and 13% were looking for information on specialist clinics; 20% of researchers were looking for a research project; 20% of patients and their entourage were looking for information on a research project (interestingly this ranked higher than information on rare diseases in general, 18%). Those in industry were interested in information on orphan drugs (21% of respondents) and research data (clinical trials, registries, research projects, for a total of 39% of respondents) and on expert centres (18%). Students are looking for information on rare diseases in general (27%).

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.
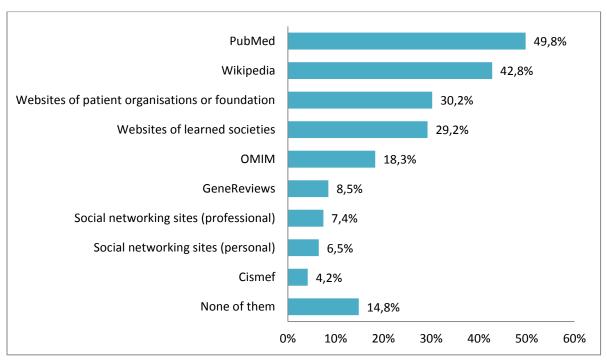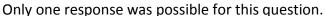

Figure 12: Other sources of information used by respondents to find information on rare diseases (percentage of total number of respondents)

To obtain information on rare diseases, 50% of respondents use PubMed, with Wikipedia in second place (43%), and the websites of patient organisations and learned societies sharing the third place at 30% and 29% respectively. OMIM was a less commonly used source of information (18%). Social networks are not a commonly used source of information, with around 7% of respondents citing professional social networking sites, and 7% citing personal networking sites.

Pubmed is significantly used by healthcare professionals (with 67% of healthcare professionals citing the resource), researchers (60%), students (52%) and industry (81%), but patients also use this site (13%) as a source of information on rare diseases. OMIM is mainly used by healthcare professionals (25%), researchers (36%), and Industry (45%) but less frequently by patients (4%). Websites of patient organisations or foundations are more often consulted by industry (51%) or patients (37%), with 25% of healthcare professionals citing this resource. The analysis also underlines that Wikipedia remains a main source of information for all categories of respondents.

Question 6: How are you accessing Orphanet today?

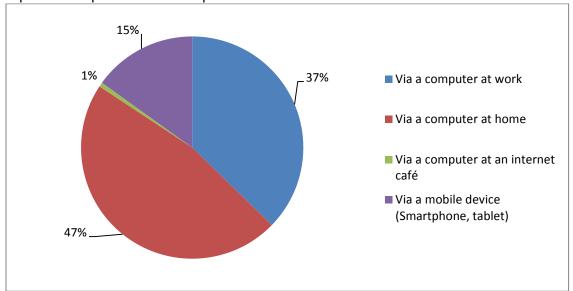Only one response was possible for this question.

Figure 13: Mode of accessing Orphanet by respondents

Of those who responded to the survey, 37% did so from home, whilst 47% did so from their workspace. The use of a mobile device with an Internet connection is growing and now represents 15% of the respondents (compared with 10% of respondents in 2013).

Question 7: Have you downloaded the Orphanet application?

Only one response was possible for this answer. Around 10% of respondents had downloaded the Orphanet mobile app.
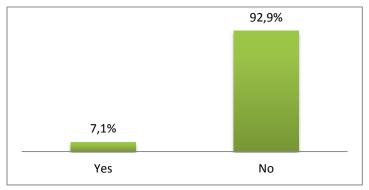

Figure 14: Respondants having downloaded the Orphanet mobile application.

Of the 222 respondents who stated that they have downloaded the Orphanet mobile application, 55% are health care professionals, 18% are patients and 15% are students. The analysis also shows that the application, which is primarily geared towards health professionals for an on-the-go use at work, has only been downloaded by 8% of the health professionals responding to this question in the survey. 94% of the respondents who were accessing Orphanet on a mobile device at the time of the survey had not downloaded the Orphanet mobile application.

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. Only one response was possible for each product for the 2852 respondents. This question was not asked in Dutch version of the survey. The results show that Orphanet products are highly appreciated but not sufficiently well known.

Orphanet Product	Very useful	Useful	Fairly useful	Not useful	No opinion	I didn't know Orphanet offered this service
Texts on diseases	60%	25%	7%	1%	2%	6%
List of diseases and classifications	55%	25%	6%	1%	3%	10%
Emergency guidelines	29%	22%	12%	4%	10%	24%
Search by sign facility	29%	23%	11%	4%	9%	25%
Orphanet Report Series on epidemiology of Rare Diseases	25%	23%	10%	3%	10%	29%
Directory of patient organisations	24%	24%	15%	4%	11%	21%
Directory of medical laboratories	23%	20%	14%	6%	12%	26%
Directory of clinics	21%	21%	15%	4%	12%	26%
Directory of orphan drugs	21%	22%	11%	5%	14%	27%
Directory of clinical trials	20%	23%	15%	4%	12%	25%
Directory of research projects	20%	23%	15%	4%	13%	25%
Orphanet Report Series on Orphan Drugs	18%	20%	11%	4%	14%	34%
Orphanet national websites	17%	19%	11%	3%	15%	34%
OrphaNews newsletter	14%	15%	11%	4%	16%	39%
Directory of registries	14%	21%	14%	5%	17%	30%
Orphadata (downloadable Orphanet datasets)	13%	13%	9%	3%	15%	47%
ORDO: Orphanet Rare Diseases ontology	11%	13%	9%	3%	17%	48%

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 'very useful' or 'useful' answers. The percentage of these replies was calculated from the total number of replies to this question for this product, with the 'no opinion' 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 (i.e. total replies = answers 'very useful', 'useful', 'fairly useful', 'not useful').
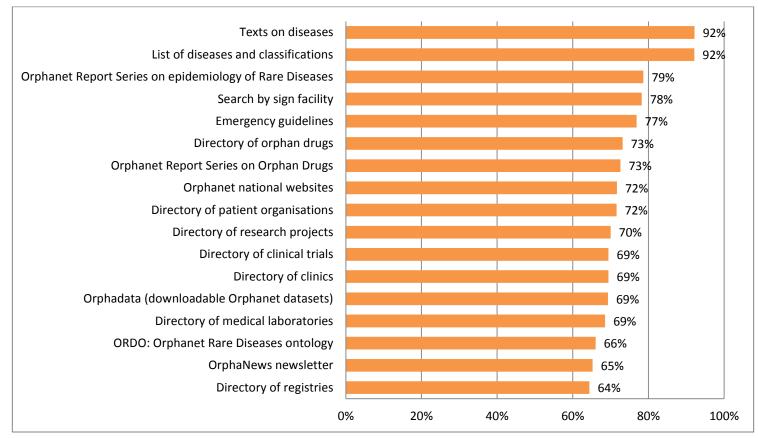
Figure 16: The most useful services offered by Orphanet according to respondents (answers 'very useful' or 'useful').

The most useful Orphanet services, according to our users, are the texts on diseases (92%) and the list of diseases and classifications (92%). The Orphanet Report Series on the epidemiology of rare diseases is also highly appreciated (79%) as is the Report on Orphan Drugs (73%). 78% of respondents highly appreciated the search by sign facility and 77% were satisfied with the emergency guidelines. The Orphanet Rare Diseases Ontology, a relatively new service launched in 2013, is appreciated by those who use it, with 66% rating it very useful or useful.

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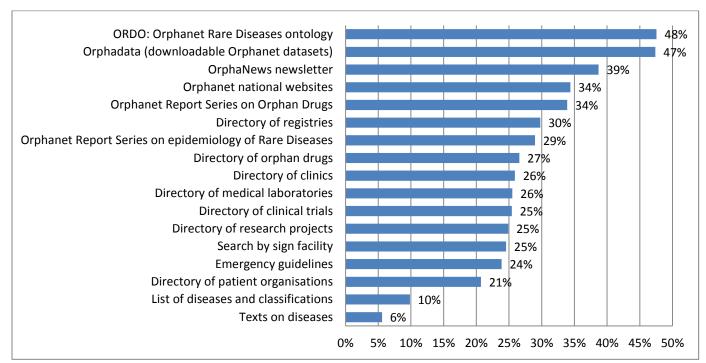
Figure 17: Least well-known Orphanet products (respondents answering 'I didn't know this service existed')

Orphadata, the website that allows users to download Orphanet datasets for research purposes, is well appreciated but not well known by those answering the survey (47%). 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 48% 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 relatively unknown to users with 39% of users citing it as unknown to them. 34% 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.

The most well known products remain the texts on diseases and the list of diseases and classifications with only 6% and 10% of users respectively not aware of their existence.

In addition, we examined the products least well-known by each category of user. ORDO and Orphadata were the least well-known products across all categories of user, but were comparatively better known by the researcher category (unknown to only 35% of researchers) than other categories (i.e. unknown to 58% of students, 48% of health professionals, and 47% of Industry), which can be expected as these are tools geared to research. OrphaNews, which boasts around 16 000 subscribers was not well known to the field of education/communication (40%) and students (52%), and also surprisingly to healthcare professionals (unknown to 38%), but better known to policymakers/healthcare managers (unknown to only 15%), researchers (unknown to only 24%), patients (unknown to only 33%).

This analysis showed that, surprisingly, around a quarter of researchers did not know about the directory of registries and the Orphanet Report Series on epidemiological data, and around 20% did not know about the data concerning clinical trials, research projects or the Orphanet Report Series on Orphan Drugs. A quarter of respondents from Industry did not know about the Orphanet Report Series on epidemiological data, and 30% did not know about the

Orphanet Report Series on Orphan Drugs. 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 1322 individuals in response to 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.

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.

Users were interested in expanded epidemiological data: this expectation will hopefully be met as new data on prevalence and incidence were added to Orphanet recently and are available for download on www.orphadata.org.

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 improve the number of translations available. Users also requested that data concerning expert resources in countries outside of the current consortium be included to make the database truly international.

A number of users were interested in having the ability to search for available research grants, and in networking to develop research partnerships.

A few users requested a helpdesk to answer queries, and one suggested a service to chat or network with others concerning a specific disease or topic. Although this is not Orphanet's vocation, the information provided concerning rare disease helplines, alliances of patient organisations and online patient communities could be presented differently to orientate users.

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. Users also highlight that Orphanet is a tool that could help all health care professionals and that could be better publicized to this public.

Users have a poor awareness of the availability of Orphanet's downloadable dataset, and require better guidance on how to use the files available via this platform. Users also were confused about the differences between Orphanet and Orphadata: this is a recurring issue to be addressed.

Finally, several respondents, in particular first time users, were unsatisfied by the way which the survey had popped-up when trying to access Orphanet as they were unable to find the 'close' button to shut the window. The current format of the pop-up will be reconsidered in future years to improve the users' experience.

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