



2012

2012 user satisfaction survey of the Orphanet website in English

www.orpha.net



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Methodology

An on-line survey was designed in November 2012, using the online survey tool Survey Monkey (www.surveymonkey.com). In the first part of the survey, questions were based on previous Orphanet surveys carried out in 2011 and earlier, while the second part focused on the new design of the Orphanet homepage and the development of a mobile application. 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 2012: a pop-up window was added to the first page users landed on. The survey was translated into the 6 languages of the website presently available at the moment (i.e. English, French, Spanish, Italian, Portuguese or German) and was displayed respecting the language of consultation. The survey was closed when 1,000 answers were collected.

The English language results are presented in this document.

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

Results

QUESTION 1

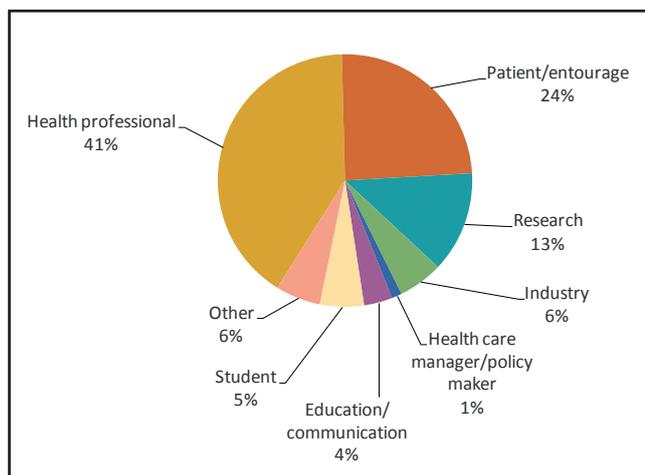
By what capacity are you consulting the Orphanet website TODAY?

This question aimed to determine the profile of Orphanet's users.

Seven categories were proposed (i.e. health professional, patients/entourage, researcher, industrial, health care manager/policy maker and, for the first time, students), and a free text field was included for other types of users to enter their profession. Only one response was possible.

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

ANSWER OPTIONS	RESPONSE PERCENT	RESPONSE COUNT
Health professional	40,7%	407
Patient/entourage	24,5%	245
Research	12,9%	129
Industry	5,7%	57
Health care manager/policy maker	1,3%	13
Education/communication	3,6%	36
Student	5,6%	56
Other	5,7%	57
<i>Total</i>	<i>100%</i>	<i>1000</i>



The largest category of respondents is the health professionals category (41%). The second largest category of respondents is patients and their entourage (including patient organisations, alliances and support groups) with 24% of responses. These results are consistent with 2011 figures for the Patient category, but the health professionals category has decreased by 10 points, most likely due to the creation of the Student category.

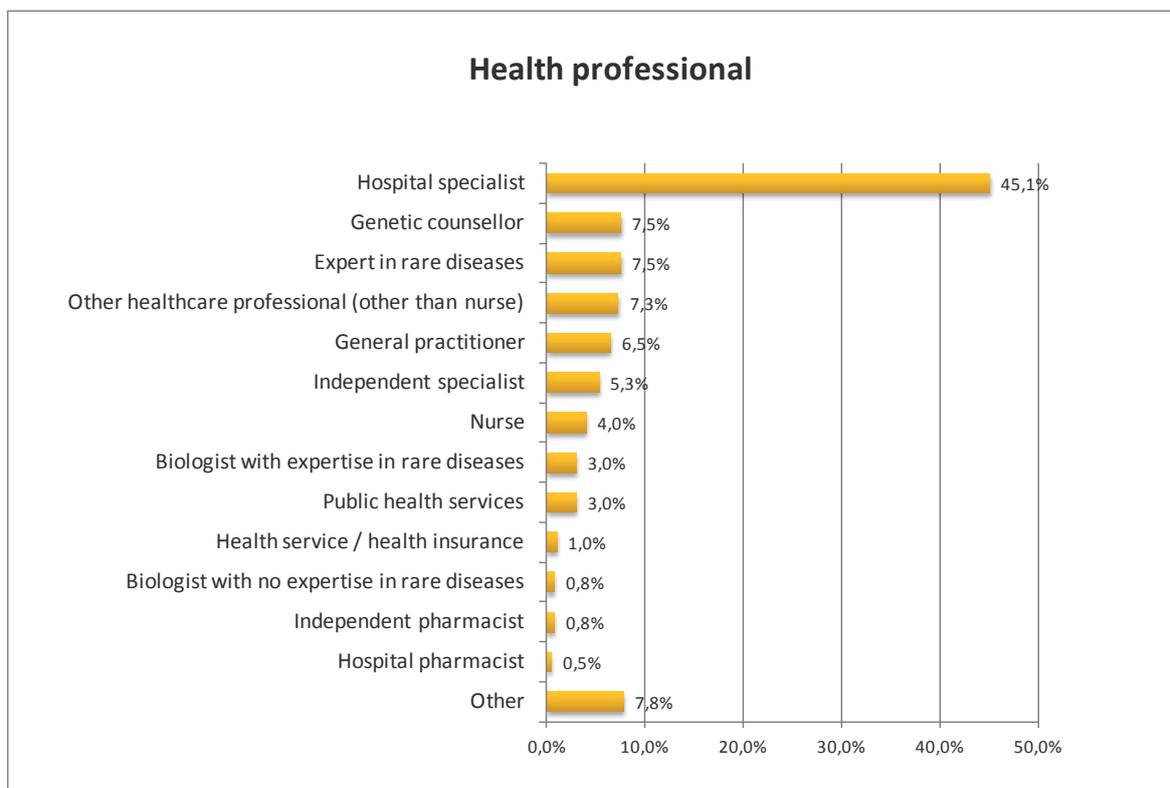
Amongst the "Other" types of users in the table above, were several health professionals, attorneys, medical translators and clinical coding technicians, but the large majority (28) were patients or patients' relatives. This might be linked to a misunderstanding of the term « entourage ».

Then, for each category, respondents were asked to choose the sub-category that would best describe them.

Health professionals (n=399):

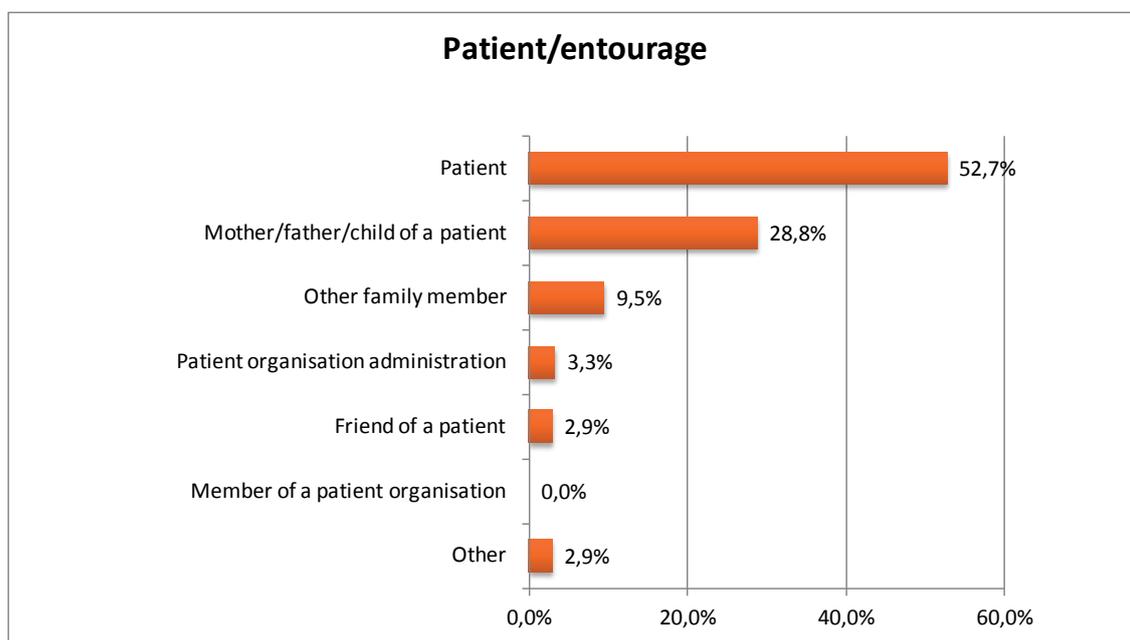
Hospital specialists represent by far the main category of respondents (45%). All together, 57% are specialists. Healthcare professional (nurses and others) represent more than 11% of the health professionals, genetic counsellors for 7.5%, general practitioners for 6.5%.

In the "Other" category, a third of the respondents are clinical or medical geneticists.



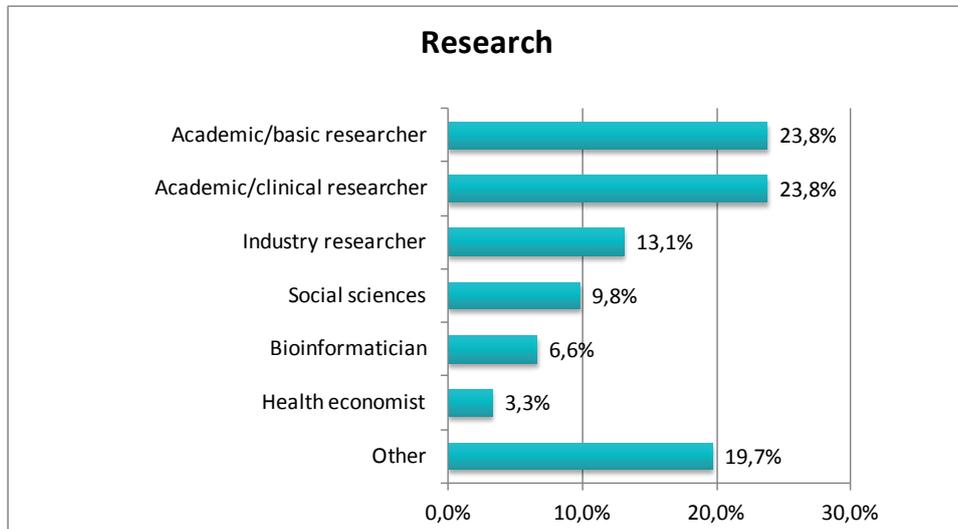
Patient/entourage (n= 243):

Most of the people who selected this category are patients (52%). More than 38% are family members of a patient with rare diseases.



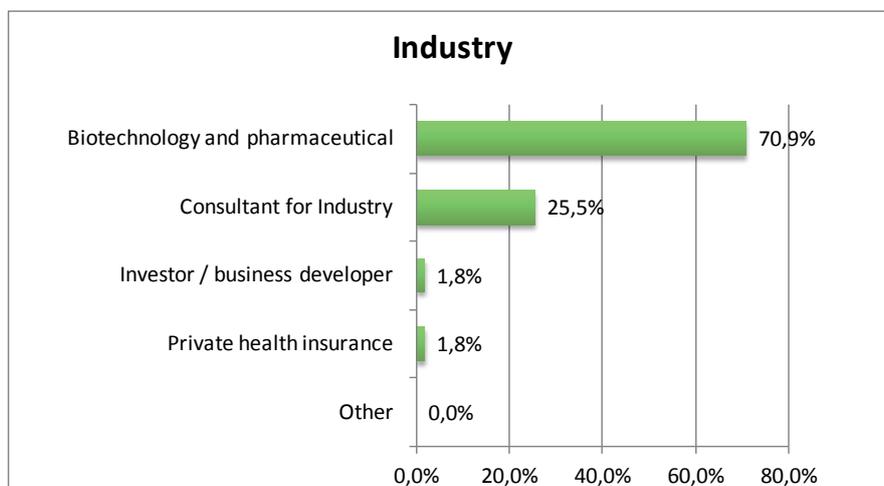
Research (n= 122):

Academic researchers represent 48% of respondents of the research category, and are equally divided between basic and clinical research. The newly created 'Social sciences' category gathers 10% of researchers, underlining the emergence of this domain in the rare diseases field.



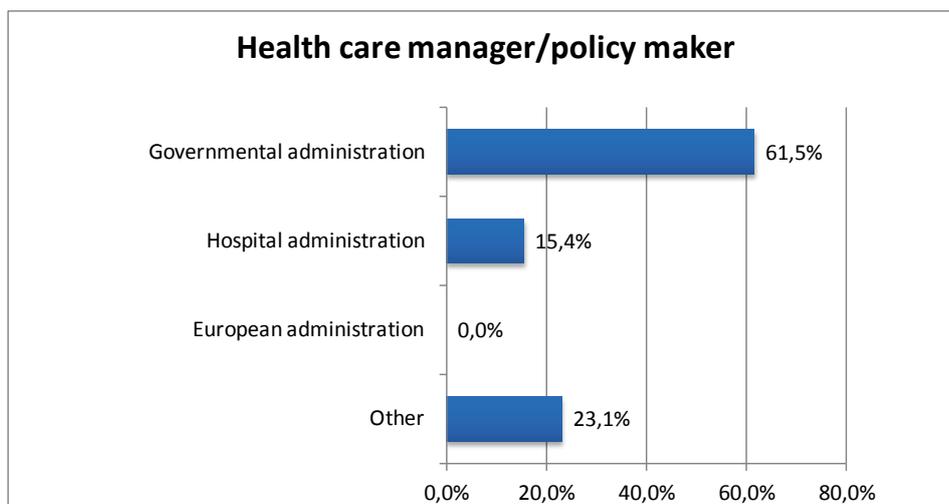
Industry (n=55):

More than 70% of respondents in this category work in biotechnology or pharmaceutical industry. Others are mainly consultants for industry (25.5%).



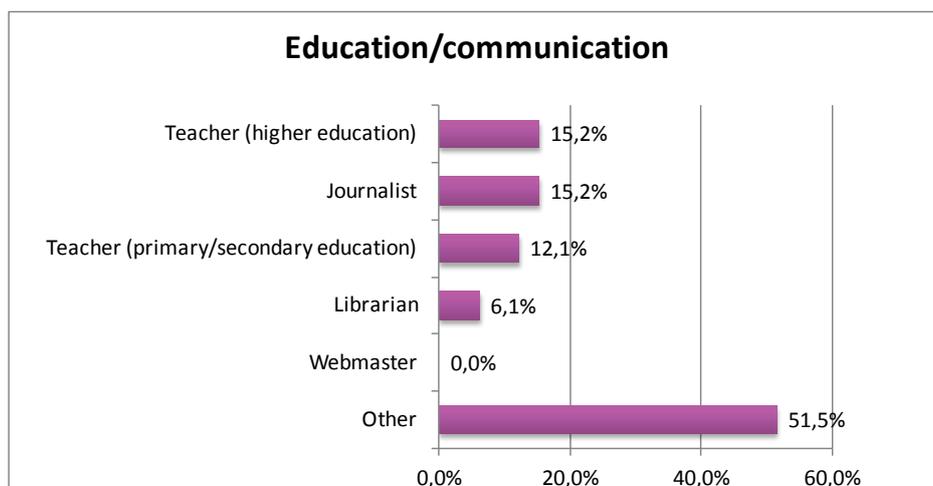
Health care manager/policy maker (n=13):

In this category, 8 individuals work for governmental administration (61%) and 2 work for a hospital administration (15%).



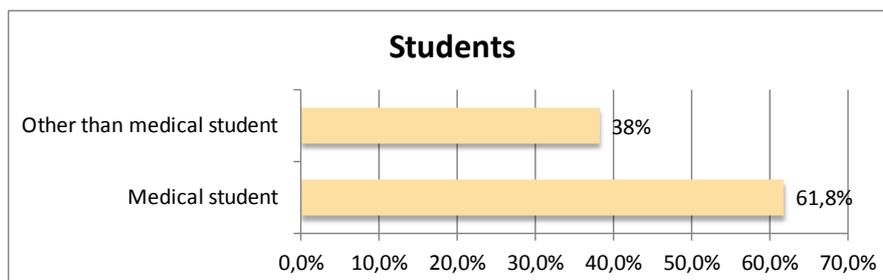
Education/communication (n=33):

Instructors represent 27% of this category and journalists 15%. In the Other category, there were several students, teachers and medical writers.



Students (n=55):

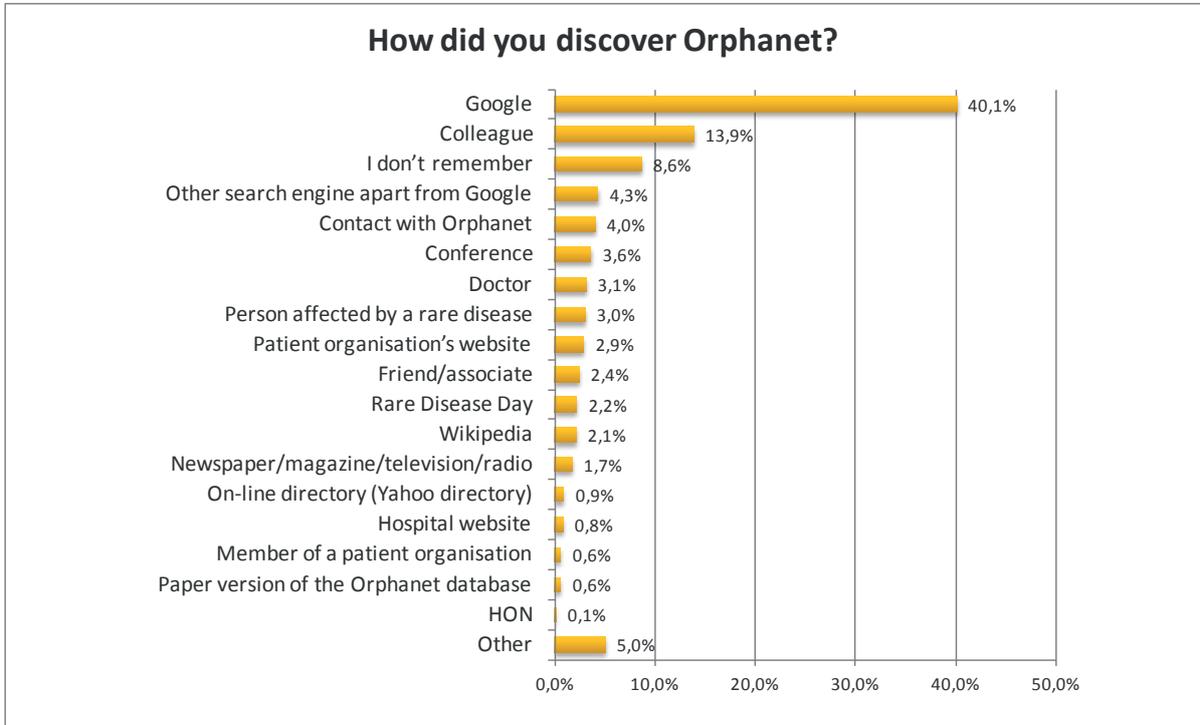
Medical students represent 62%. Other students are mainly biology students, but also biotechnology, bioinformatics, pharmacy or nursing students.



QUESTION 2

How did you discover Orphanet?

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



The majority of our users discovered Orphanet via internet, either by a query via a search engine (around 45%) or through a patient organisation website (3%) or a hospital website (0.8%). In addition, through the "Other" category, 16 individuals declared that they first discovered Orphanet through institutional websites such as the NIH (National Institutes of Health: Office of Rare Diseases Research, Pubmed, Genetics Home Reference...), or OMIM (Online Mendelian Inheritance in Man).

Word of mouth has worked well too (about 26%): many of our users first learn about Orphanet thanks to a colleague, a doctor, a friend or a patient recommendation. These results are similar to those of 2011.

QUESTION 3

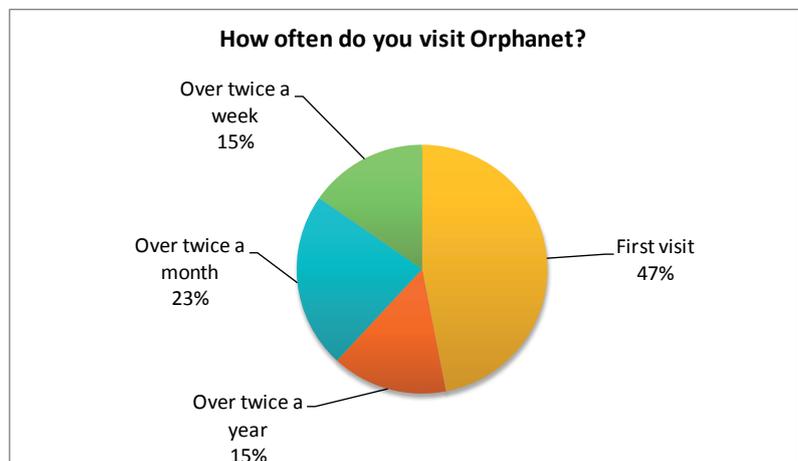
How often do you visit Orphanet?

Only one response was possible.

Around 38% of those who answered this survey are regular users whereas 47% were visiting Orphanet for the first time.

About half of first time visitors are patients and entourage.

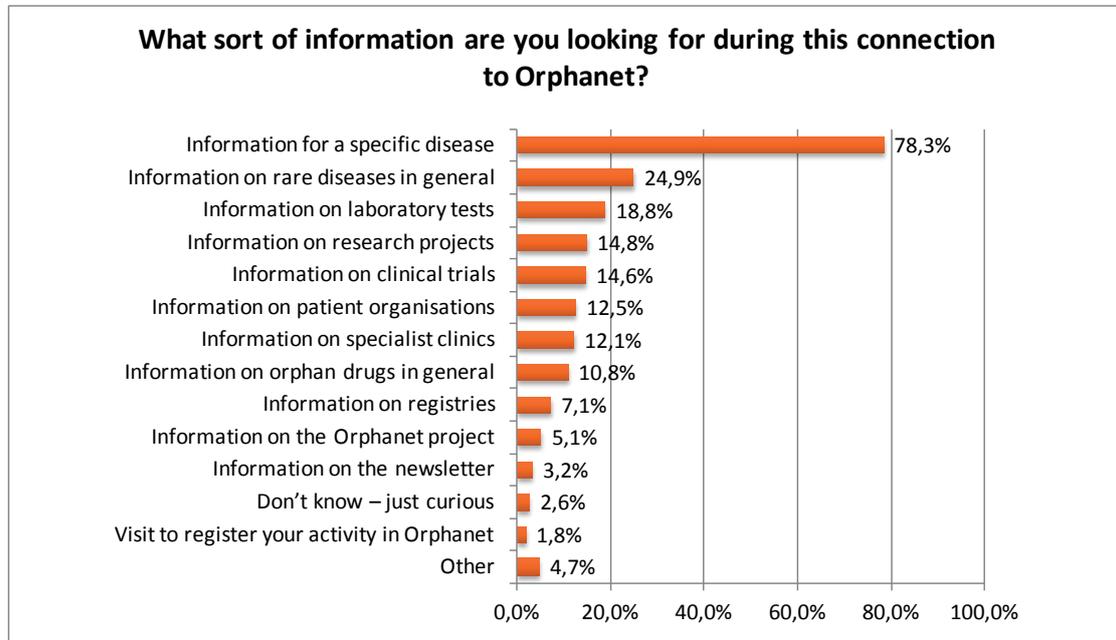
Health professionals are more than 58% to visit the Orphanet website more than twice a month, industrials are 49%, whereas patients are less than 11%.



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.



The results show a clear trend: most of the respondents were looking for information for a specific disease (78%). Our visitors also look for information on rare diseases in general (25%), on laboratory tests (19%), on research projects (15%) or on clinical trials (15%).

32% of health professionals are looking for information on a laboratory test; 40% of students are looking for information on rare diseases in general. As expected, those in industry are looking for information on orphan drugs (33%) and research data (research projects, clinical trials, registries), and also on patient organisations. Compared to 2011, our respondents seem to be looking more frequently for information on rare diseases in general.

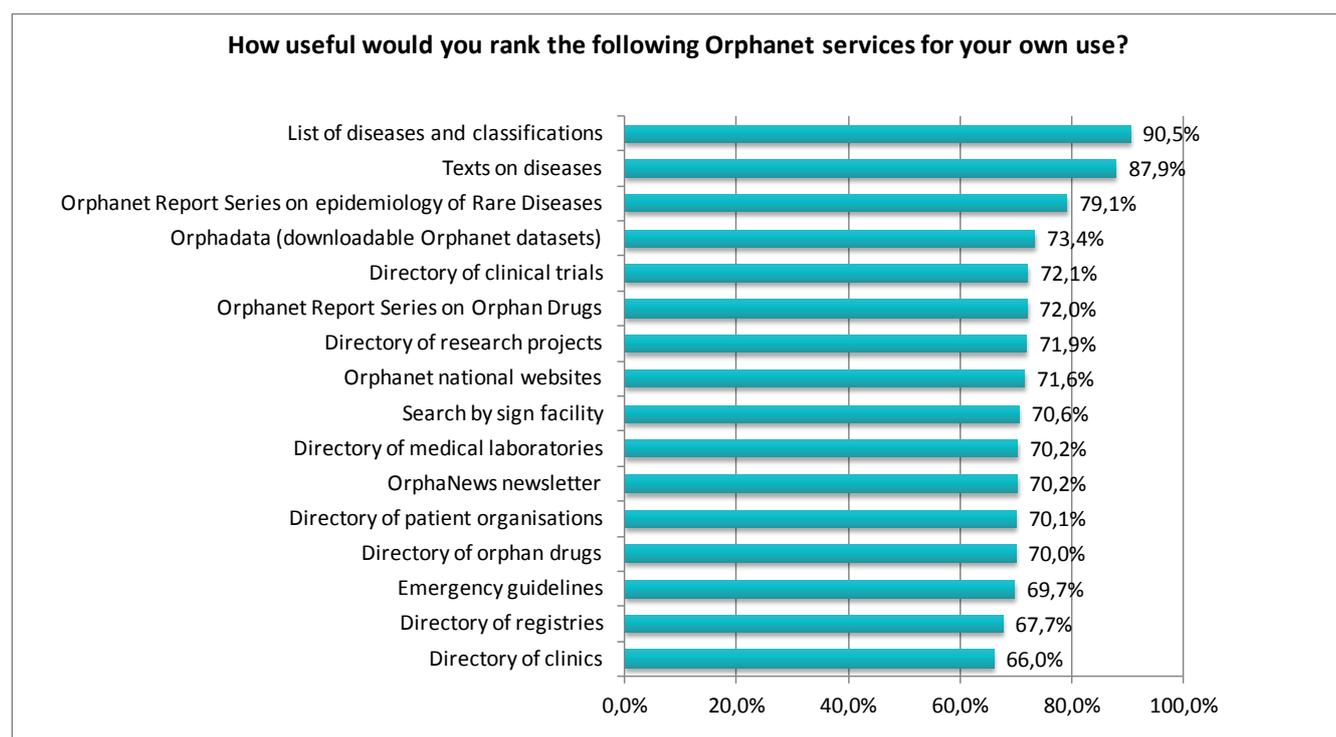
QUESTION 5

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 the 810 respondents. The results show that Orphanet products are highly appreciated but not sufficiently well known:

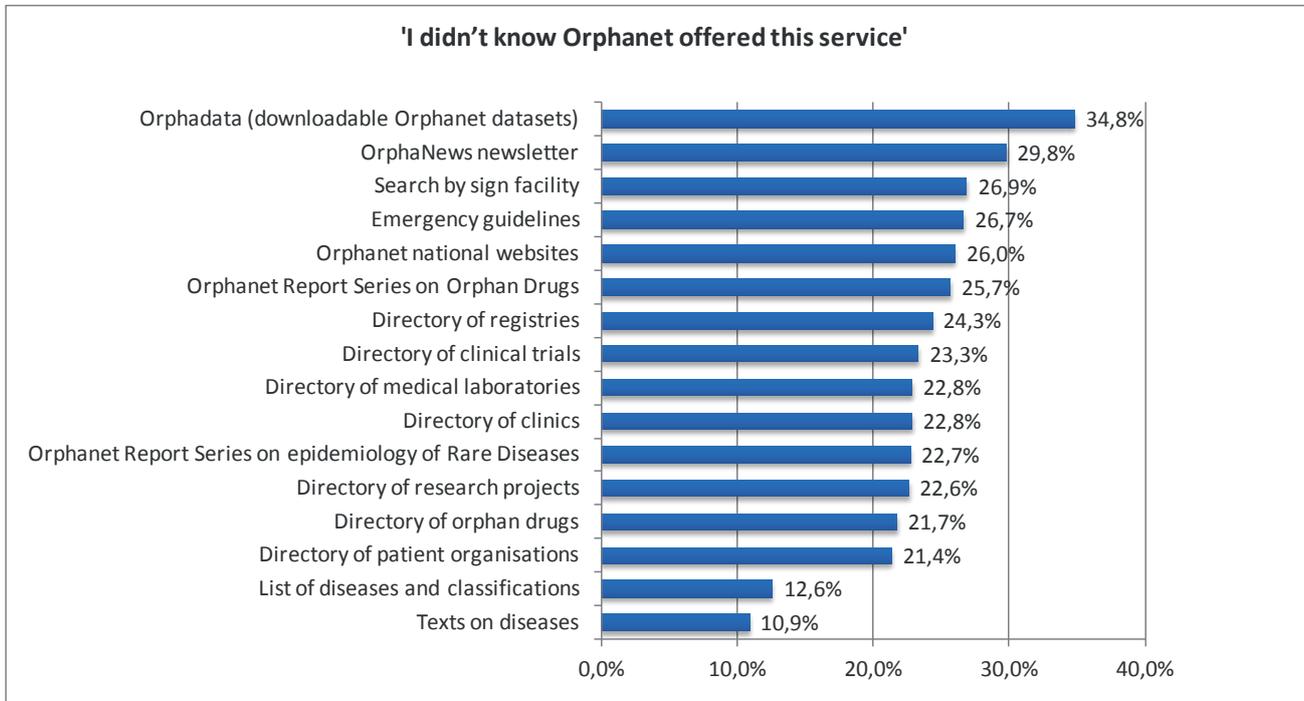
Orphanet product	Very useful	Useful	Fairly useful	Not useful	No opinion	I didn't know Orphanet offered this service
List of diseases and classifications	370	210	53	8	67	102
Texts on diseases	324	259	75	5	59	88
Emergency guidelines	126	169	95	33	171	216
Search by sign facility	111	184	86	37	174	218
Directory of clinics	116	179	105	47	178	185
Directory of medical laboratories	139	175	89	44	178	185
Directory of patient organisations	144	205	119	30	139	173
Directory of research projects	134	212	104	31	146	183
Directory of clinical trials	151	193	95	38	144	189
Directory of registries	114	181	106	35	177	197
Directory of orphan drugs	149	182	112	30	161	176
Orphanet Report Series on epidemiology of Rare Diseases	192	191	84	17	142	184
Orphanet Report Series on Orphan Drugs	132	171	92	26	181	208
OrphaNews newsletter	102	164	84	29	190	241
Orphanet national websites	139	163	87	33	177	211
Orphadata (downloadable Orphanet datasets)	118	138	68	25	179	282

The following graph presents the usefulness of Orphanet products ('very useful' and 'useful' answers). The 'no opinion' and 'I didn't know Orphanet offered this service' answers were subtracted from the results to more faithfully represent the utility of the products, according those aware of these Orphanet services.



The key Orphanet service remains the encyclopaedia: the texts on diseases (88%) and the inventory of diseases and the classifications (91%). The Orphanet Report Series collection is also highly appreciated.

An analysis of the newly introduced category 'I didn't know Orphanet offered this service' is presented in the following graph, highlighting the fact that our users are not sufficiently informed about our range of products.



Orphadata, the website that allows researchers to download Orphanet datasets, is well appreciated but also not very well known by our respondents. This is understandable as this service is recent (2011), research oriented and therefore not useful for the vast majority of users.

Patients and their entourage is the category that seems to know the least about Orphanet services: often more than 40% declare that they did not know about a service provided by Orphanet.

In particular, nearly a third of the respondents did not know about the OrphaNews newsletter even though health professionals, researchers and industrials seem to be more often aware of the existence of this product compared to patients.

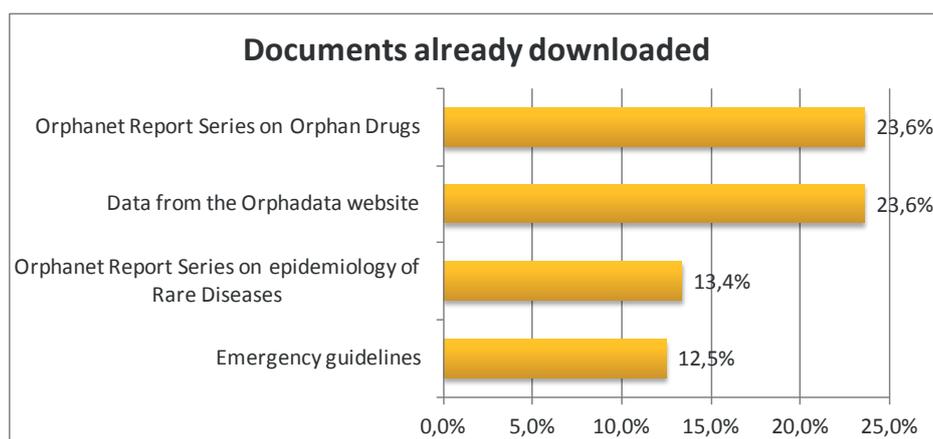
The search by sign facility suffers from a lack of exposure in our user community, as well as our collection of emergency guidelines (which is better known in the health professionals category than in all others). These products are mainly dedicated to clinicians, who are more aware of these products than the average.

QUESTION 6

Have you ever downloaded the following documents?

This question aims to determine whether our documents have already been downloaded by the website users. Only one response per row was possible.

Answer Options	Yes	No	Response Count
Orphanet Report Series on epidemiology of Rare Diseases	189	612	801
Orphanet Report Series on Orphan Drugs	100	701	801
Emergency guidelines	107	694	801
Data from the Orphadata website	189	612	801



A quarter of our users have downloaded the Orphanet Report Series on orphan drugs or a table from Orphadata.

More than 39% of industrial users have already downloaded the Orphanet Report Series on epidemiology of rare diseases (vs. 31% of health professionals) and 30% have downloaded the report on orphan drugs. Patients are the group that have downloaded Orphanet products the least.

QUESTION 7

What should Orphanet do to better serve your needs?

Comments were left by 364 individuals in response to this question. About a quarter of them are satisfied by the Orphanet website as of December 2012, or left messages of encouragement and support for the Orphanet action. Orphanet users mainly request that the diseases summaries be completed when they are not yet available, and that the update of disease summaries be more regular. A frequent update of the services database is also necessary, especially for laboratories.

Despite the new homepage design, the Orphanet website still needs to be more user-friendly with pages less cluttered to ease navigation.

Several people asked to receive personal notifications when the information on a disease or a drug is updated. Our users would like Orphanet to be present in more countries, especially in the USA, to become completely international. Furthermore, they would like to have all resources of the database available in all 6 languages and to have the website translated in even more languages.

For health professionals, the main improvement requested is greater ease of use for the search by sign tool, which is quite complex at the moment.

In addition, they would like to have access to more clinical guidelines and review articles as well as bibliographic references.

Health professionals have suggested that photos or medical imagery to illustrate dysmorphological diseases would help them in their diagnoses.

They also call for more details about the precise nature of tests offered by various laboratories.

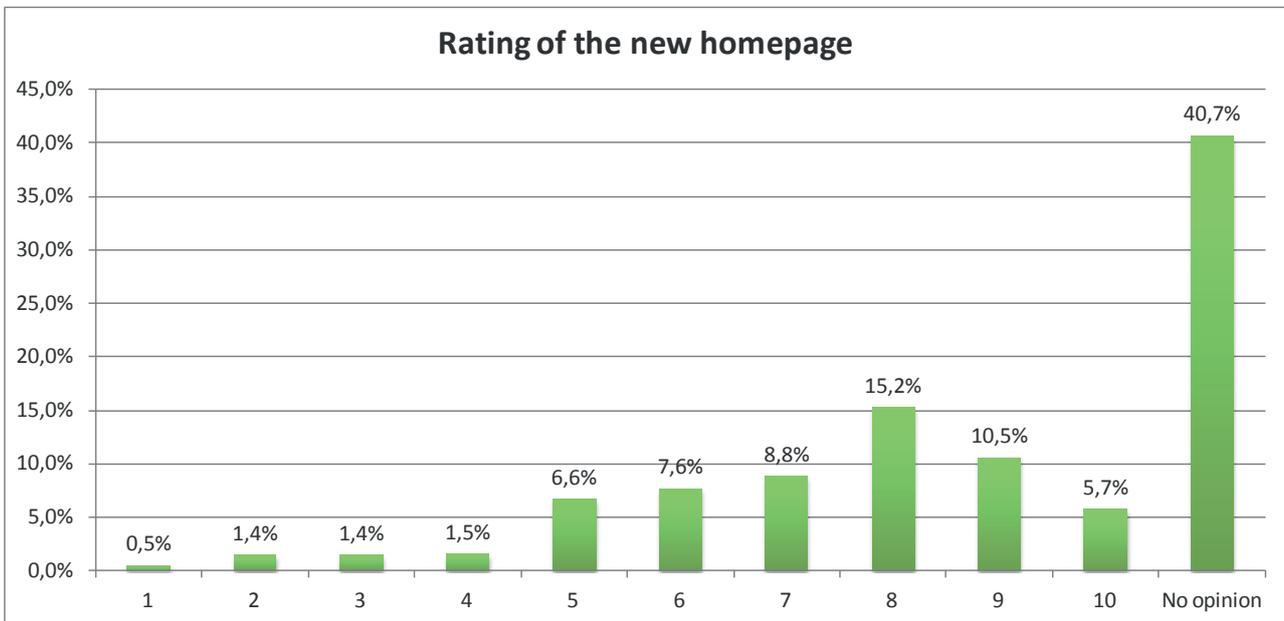
Our users would like us to better disseminate information regarding Orphanet and its services, many of which were unknown to them.

Finally, several respondents were unsatisfied by the way the pop up of the survey appeared repeatedly on the website and failed to find the "close" button to shut it down. Next year, we will modify this pop up in order to make it more user-friendly.

QUESTION 8

What do you think of the makeover of the Orphanet homepage?

This question aims to determine how our users rate the new homepage design from 1 [Bad, it is worse than before] to 10 [Very good, significant improvement].



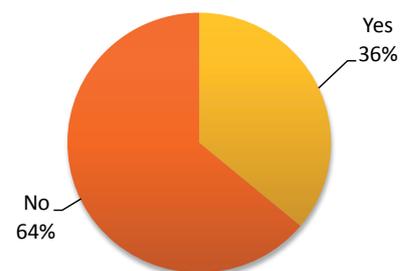
The average note to the new homepage is 7.21. More than 40% of the respondents have no opinion about the design, most of these respondents (65%) are first time visitors.

QUESTION 9

Since the makeover of the homepage, have you discovered services you did not know about?

Important changes were made to the Orphanet homepage, and this question aims to determine if this had an impact on its popularity/notoriety and to determine which services were discovered.

A third of our users discovered new services thanks to the makeover of the homepage. Yet, some services, better identified on the new homepage, are still insufficiently known.



The main services that were discovered since the new design of the Orphanet homepage are: the classifications and the inventory of rare diseases.

Furthermore, our regular users discovered the emergency guidelines and the Orphanet Report Series collection, which are both highlighted on the new homepage.

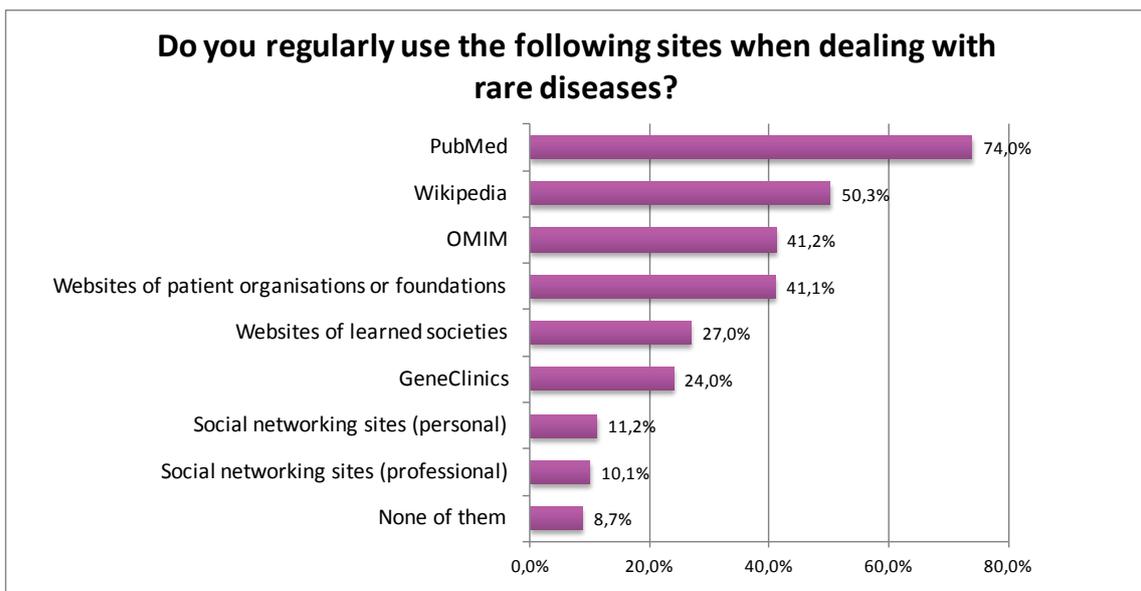
Services discovered since the makeover of the homepage



QUESTION 10

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.



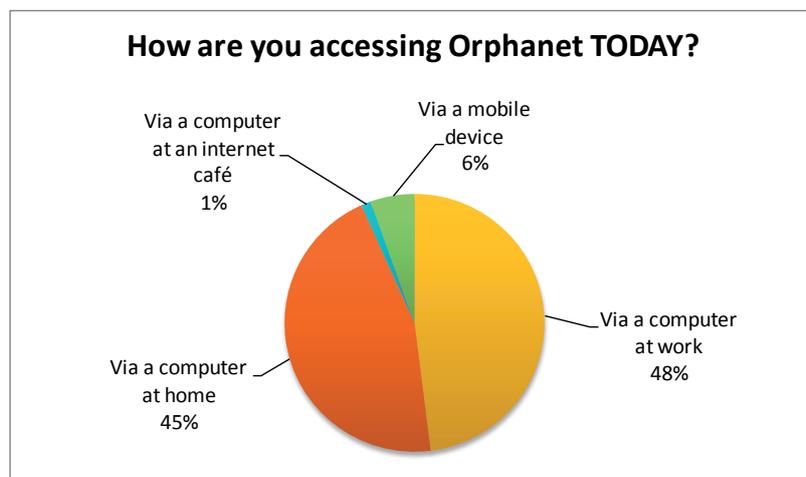
To obtain information on rare diseases, Pubmed is used by 74% of those who answered this question; 50% of them find information on Wikipedia; the OMIM website reaches the third position with 41%, as well as websites of patient organisations or foundations. Social networks represent less than 21% of the total.

Pubmed is massively consulted by healthcare professionals (88%), researchers (73%) and industry (85%) but patients also use this website as a source of information on rare diseases (46%). OMIM is mainly used by healthcare professionals (64%), researchers (39%) and not by patients (12%) or industrials (15%). Websites of patient organisations or foundations are more often consulted by industry (60%) or patients (54%). This analysis also underlines that Wikipedia remains a main source of information for all categories of respondents.

QUESTION 11

How are you accessing Orphanet TODAY?

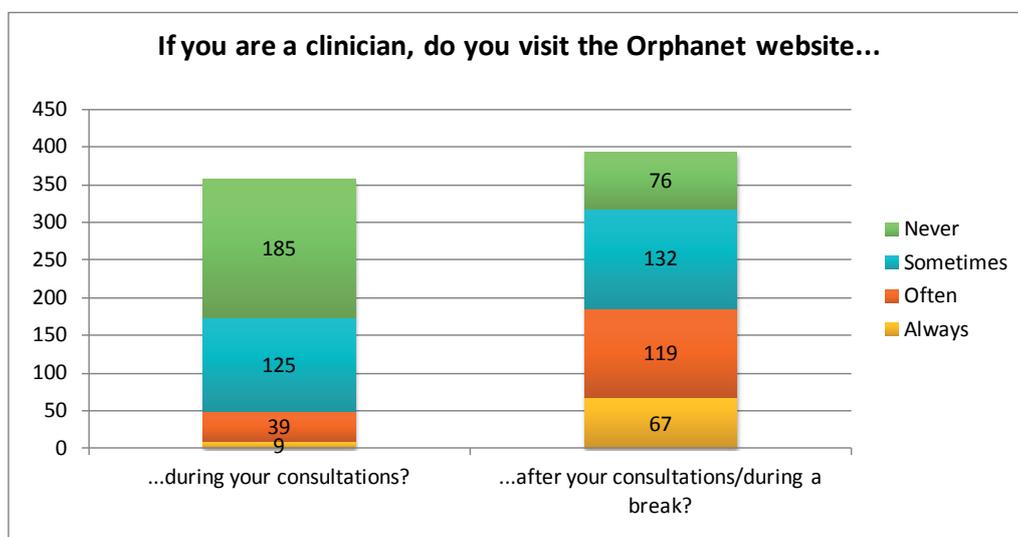
Only one response was possible for this question.



About 45% of those who participated in this survey did so from home, whilst 48% did it from their workplace. The use of a mobile device with an Internet connection is growing and now represents 6% of the respondents.

QUESTION 12

If you are a clinician, do you visit the Orphanet website...

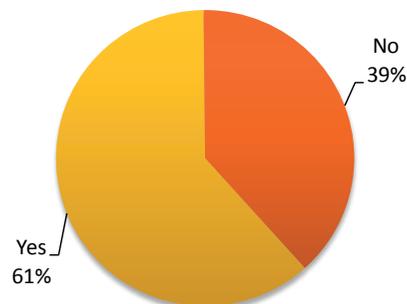


It appears that clinicians more often visit the Orphanet website after their consultations or during a break than during a consultation. Half of them never consult Orphanet during a consultation.

QUESTION 13

Do you possess a mobile device (Smartphone, tablet)?

ANSWER OPTIONS	RESPONSE PERCENT	RESPONSE COUNT
Yes	61,5%	466
No	38,5%	292
<i>Total</i>	<i>100%</i>	<i>758</i>

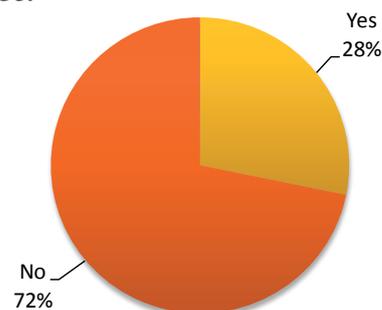


A majority of our users declare that they possess a mobile device (smartphone or tablet). Amongst whom, 47% are health professionals.

QUESTION 14

Do you use your mobile device to look for information on Orphanet?

ANSWER OPTIONS	RESPONSE PERCENT	RESPONSE COUNT
Yes	28,2%	131
No	71,8%	334
<i>Total</i>	<i>100%</i>	<i>465</i>

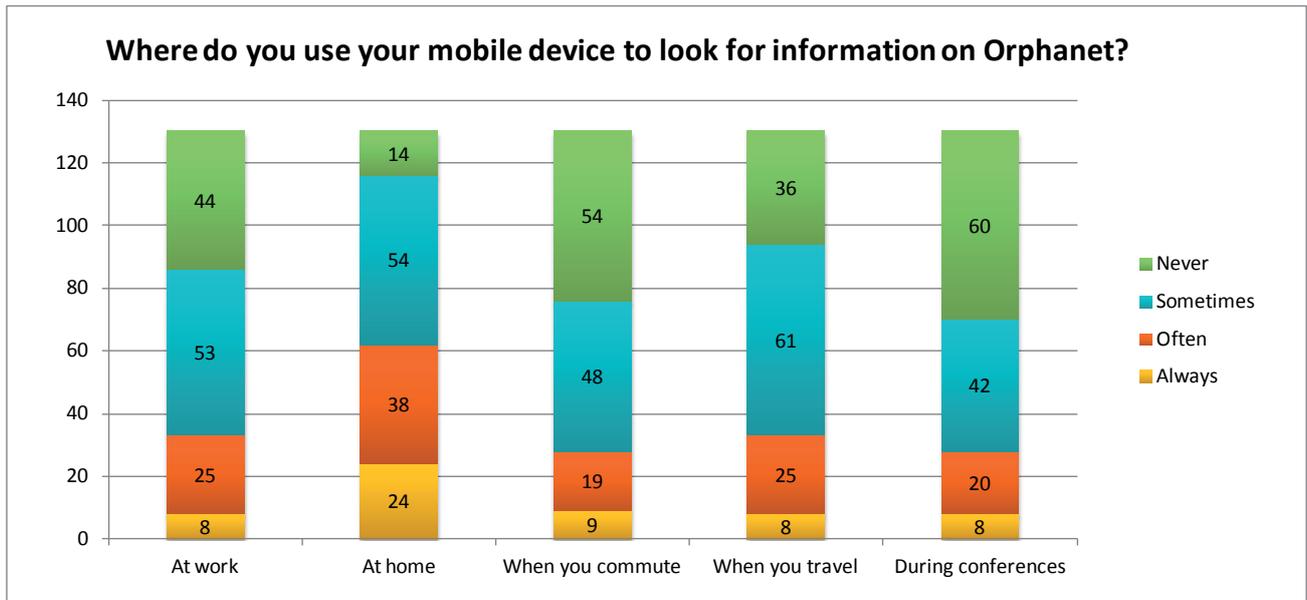


These results show that among the 61% of users that possess a mobile device (smartphone or tablet), more than a quarter (28%) of them use it to search for information on Orphanet. This already significant percentage is expected to increase with the introduction of the Orphanet mobile application for iOS (iPhone, iPad).

QUESTION 15

Where do you use your mobile device to look for information on Orphanet?

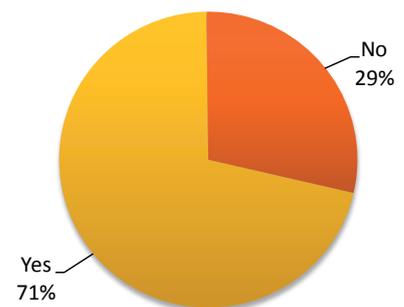
People mainly consult Orphanet on their mobile device from home. Researchers and health professionals are more likely to consult it when they travel and at work.



QUESTION 16

Orphanet is developing a mobile application. Would you be interested in using it?

ANSWER OPTIONS	RESPONSE PERCENT	RESPONSE COUNT
Yes	71,2%	329
No	28,8%	133
<i>Total</i>	<i>100%</i>	<i>462</i>



About the two thirds of our users would use the Orphanet mobile application.

QUESTION 17

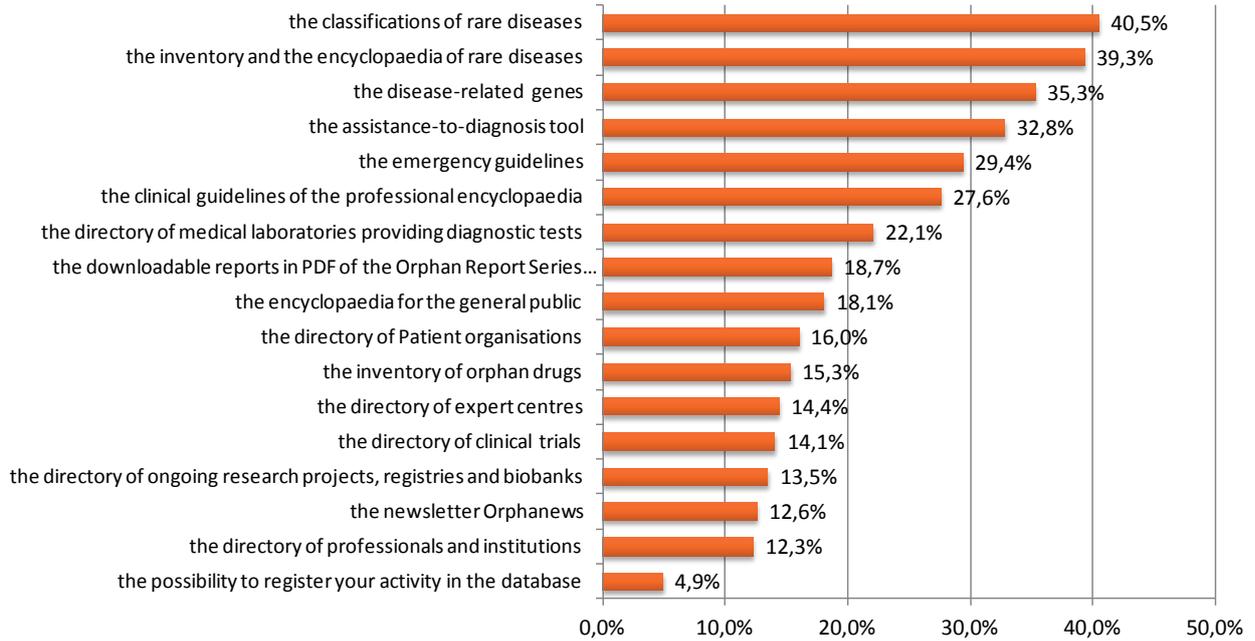
Which Orphanet service would you like to access using this application?

This question aims to determine the services that should be found in the Orphanet mobile application to best meet the needs of our users. They were asked to prioritise up to 4 services (between 1 to 4 choices possible).

The services users would like to find in the Orphanet mobile application are the classification, the inventory and the encyclopaedia of rare diseases, the disease-related genes, the assistance-to-diagnosis tool (search by sign facility) and the emergency guidelines.

The mobile application, which has been released at the end of February 2012, provides most of these services. The assistance-to-diagnosis tool will not be available as the tool must first be redesigned. It could be added in a later version of the application.

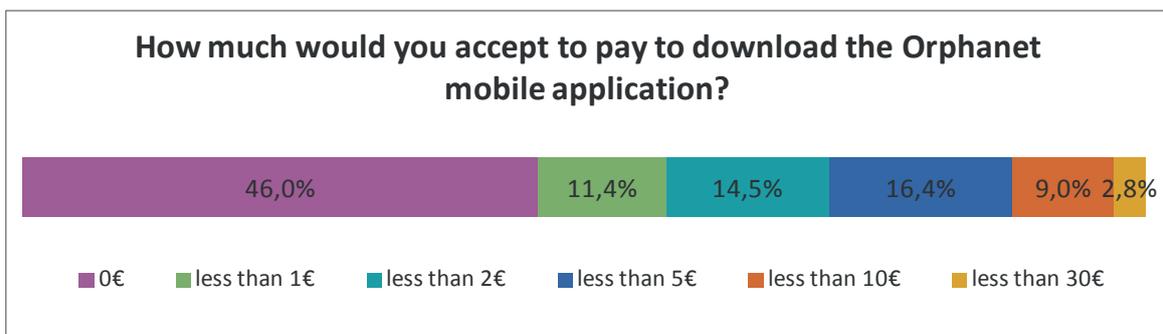
Which Orphanet service would you like to access using this application?



QUESTION 18

How much would you accept to pay to download the Orphanet mobile application?

This question aims to determine the value of the Orphanet mobile application, bearing in mind that the Orphanet application will be free to access.



Although the majority (46%) would prefer the application to be free, 28.2% of site users are willing to pay more than 2 euros to download the application Orphanet and 11.8% between 5 and 30 euros.

This reflects that users of Orphanet value its services and would be willing to remunerate for a broader access.



Conclusion

The results of the survey have helped the Orphanet team evaluate the expectations and needs of our users. Several improvements were planned in 2012 that have fulfilled some of the requests made by respondents in 2011: the first was to complete more disease summaries, and to at least give access to a definition for every condition; the next was to create a clearer and more user-friendly homepage that has been put on-line this summer; the third was to identify more clinical guidelines, whose numbers are growing. Finally, the Orphanet mobile application was launched in March 2013 and should help patients and professionals to maintain a direct link with information on rare diseases.

These developments aim to enable Orphanet to best fulfill its mission of providing quality information to the rare disease community.

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

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