



2011

2011 Orphanet English users satisfaction survey

www.orpha.net



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Methodology

An on-line survey was designed in November 2011, using the online survey tool Survey Monkey (www.surveymonkey.com). Questions were based on previous Orphanet surveys carried out in 2010 and before. This survey was designed to be brief in order to encourage users to respond. 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 2011: a pop-up window was added to the first page users landed on. The survey was translated in the 6 languages of the website available at the moment (i.e. English, French,

Spanish, Italian, Portuguese or German) and was displayed in respect of the consultation language. The survey was closed when 700 answers were collected for each language.

The answers were consistent from a language to another. The English results are presented in this document.

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

Results

QUESTION 1

Please select the category/sub-category which best describes you.

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

Six categories were proposed (i.e. health professional, patients/entourage, researcher, industry, and health care manager/policy maker), gathering forty five sub-categories, and a freetext field was included for other types of users to enter their profession. Only one response was possible.

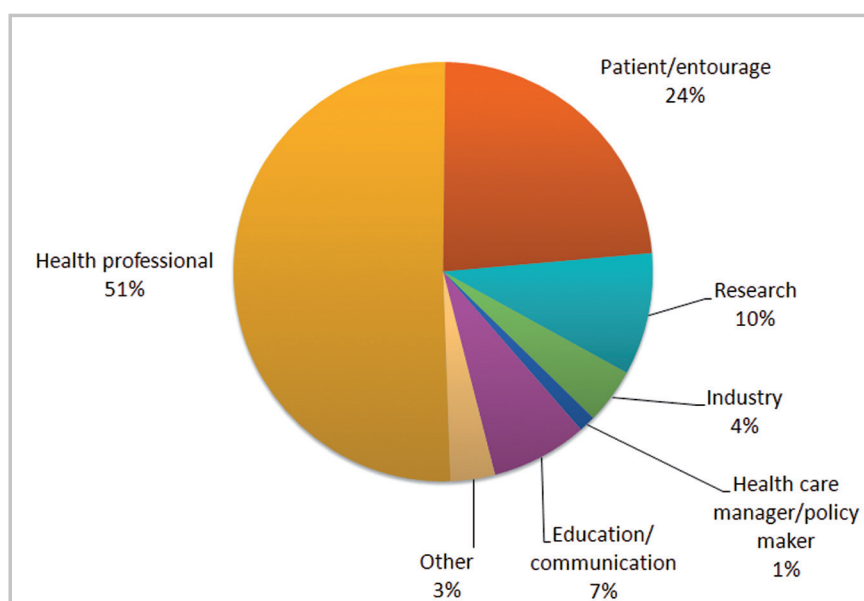
The table below shows the distribution of respondents amongst these categories proposed to respondents:

ANSWER OPTIONS	RESPONSE PERCENT	RESPONSE COUNT
Health professional: Hospital specialist	23,6%	165
Health professional: General practitioner	2,4%	17
Health professional: Independent specialist	2,7%	19
Health professional: Expert in rare diseases	5,7%	40
Health professional: Public health services	1,9%	13
Health professional: Health service / health insurance	0,7%	5
Health professional: Hospital pharmacist	0,6%	4
Health professional: Independent pharmacist	0,9%	6
Health professional: Biologist with expertise in rare diseases	2,7%	19
Health professional: Biologist with no expertise in rare diseases	0,1%	1
Health professional: Nurse	2,4%	17
Health professional: Other healthcare professional (other than nurse)	1,7%	12
Health professional: Genetic counsellor	3,7%	26
Health professional: Other	1,6%	11
Patient/entourage: Patient	10,9%	76
Patient/entourage: Mother/father/child of a patient	6,7%	47
Patient/entourage: Other family member	1,1%	8
Patient/entourage: Friend of a patient	1,0%	7
Patient/entourage: Member of a patient organisation	0,9%	6
Patient/entourage: Patient organisation administration	2,0%	14
Patient/entourage: Other	0,9%	6
Research: Academic/clinical researcher	3,7%	26
Research: Academic/basic researcher	2,6%	18
Research: Industry researcher	1,3%	9
Research: Bioinformatician	0,4%	3
Research: Health economist	0,3%	2
Research: Other	1,1%	8

ANSWER OPTIONS	RESPONSE PERCENT	RESPONSE COUNT
Industry: Biotechnology and pharmaceutical	2,0%	14
Industry: Private health insurance	0,0%	0
Industry: Consultant for Industry	1,3%	9
Industry: Investor / business developer	0,3%	2
Industry: Other	0,7%	5
Health care manager/policy maker: Governmental administration	0,4%	3
Health care manager/policy maker: Hospital administration	0,4%	3
Health care manager/policy maker: European administration	0,0%	0
Health care manager/policy maker: Other	0,4%	3
Education/communication: Journalist	0,3%	2
Education/communication: Librarian	0,3%	2
Education/communication: Webmaster	0,1%	1
Education/communication: Teacher (primary/secondary education)	0,6%	4
Education/communication: Teacher (higher education)	0,7%	5
Education/communication: Medical student	2,9%	20
Education/communication: Student (other than medical)	1,3%	9
Education/communication: Other	1,3%	9
If you don't belong to one of the categories above, who are you?	3,4%	24
<i>Total</i>	<i>100%</i>	<i>700</i>

Amongst the other types of users in the table above, were several health professionals, paramedics (midwife, psychologist) medical students, patients and members of their family or friends.

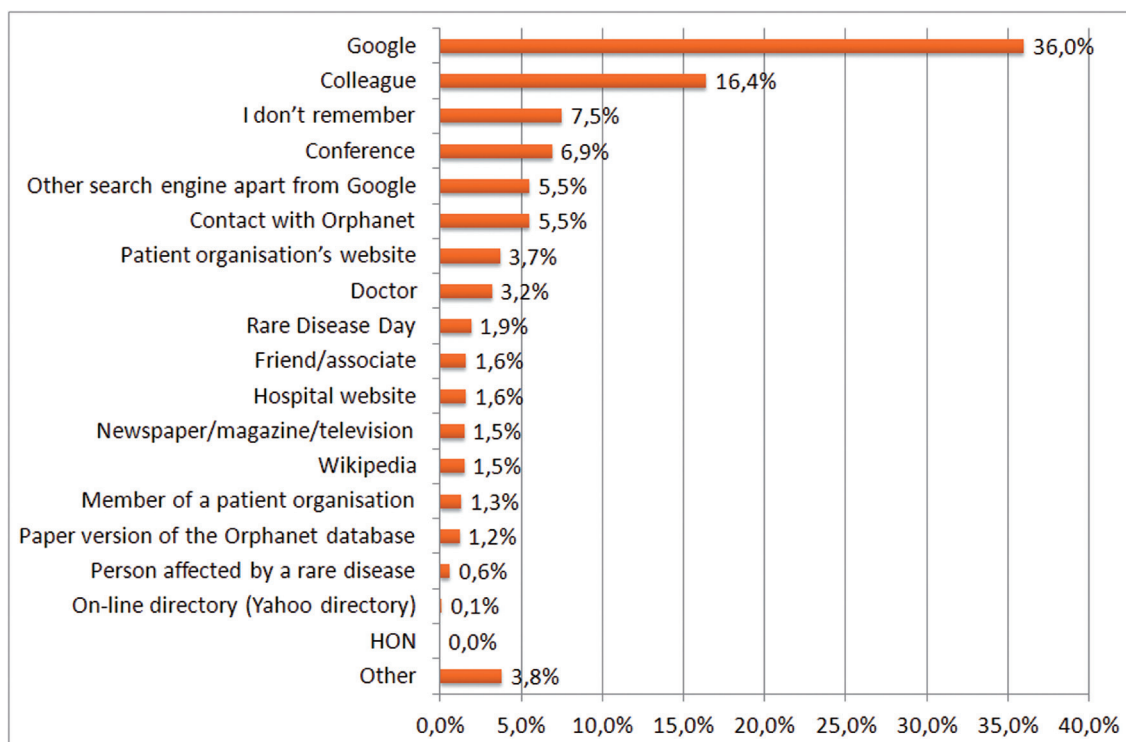
Having regrouped the replies by categories, we can see that the largest category of respondents is the health professionals category (51%), and especially hospital specialists who represent around 24% of all responses. The second largest category of respondents is patients and their entourage (including patient organisations, alliances and support groups) with 24% of responses. These results are consistent with 2010 figures.



QUESTION 2

How did you discover Orphanet?

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



We can see that the major part of our users discovered Orphanet via internet, either by a query via a search engine (around 42%) or through a patient organisation website (4%) or a hospital website (1.6%). In addition, through the "Other" category, 15 persons declared that they first discovered Orphanet through institutions websites like the NIH (National Institutes of Health: Pubmed, Genetics Home Reference,...), the EMA (European Medicines Agency) or OMIM (Online Mendelian Inheritance in Man).

Word of mouth works well too (about 23%): many of our users first learnt about Orphanet thanks to a colleague, a doctor, a friend or a patient recommendation. Those results are very similar to the 2010 ones.

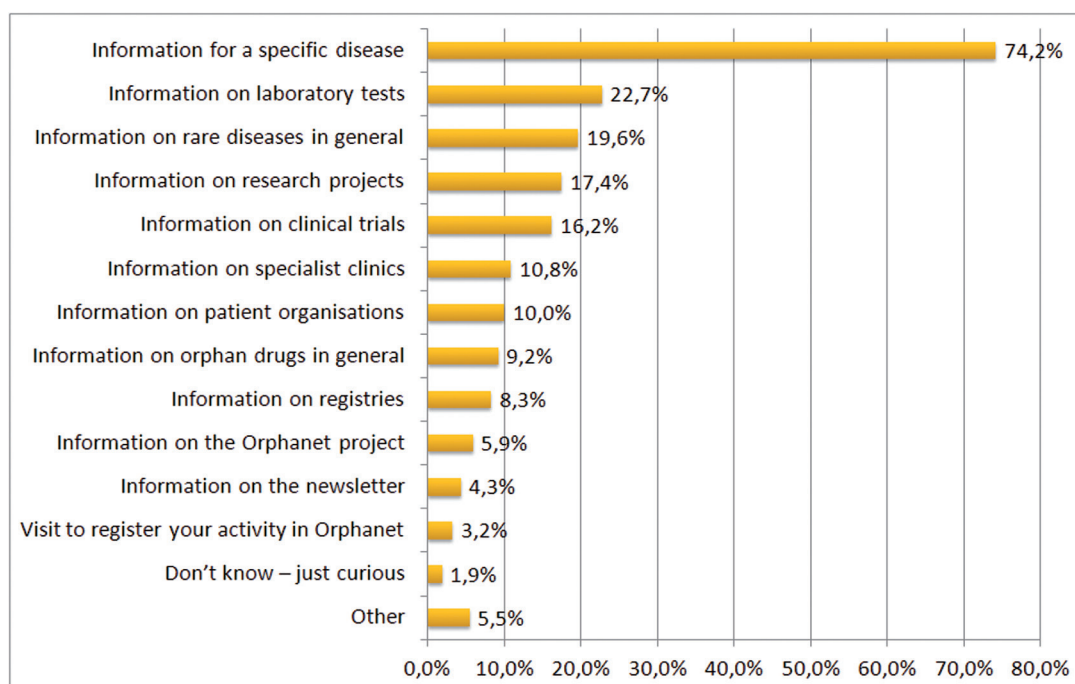
QUESTION 3

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

This question aims to determine which kind of information visitors look for 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 (74%). Our visitors also look for information on laboratory tests (23%), on rare diseases in general (20%), on research projects (17%) or on clinical trials (16%).

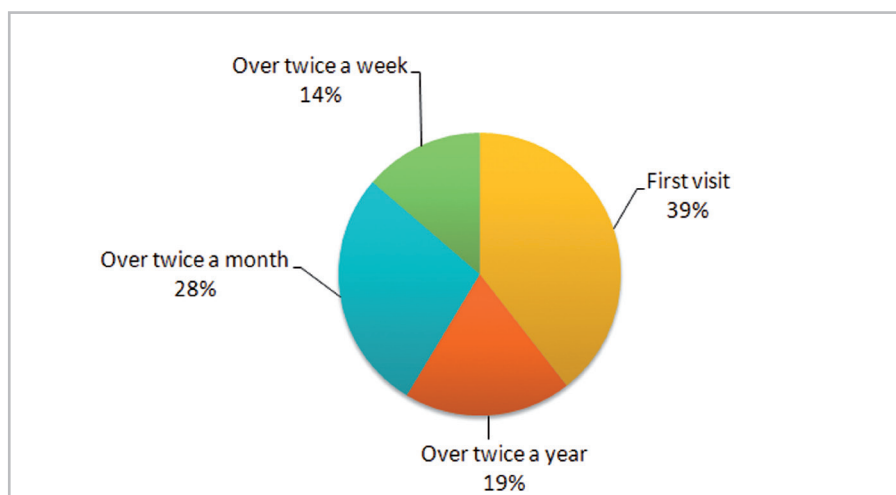
Compared to 2010, our respondents seem to be looking more frequently for information on research projects and clinical trials.



QUESTION 4

How often do you visit Orphanet?

Around 42% of the persons who answered this survey are regular users whereas 39% were visiting Orphanet for the first time.



Our visitors seem to be more regular. Among the respondents, less than 40% were visiting the Orphanet website for the first time, which represents a 7% decrease compared to 2010. Those 7% were equally split between the 'Over twice a year' and 'Over twice a month' categories, that thus increased in 2011, while the number of our very frequent users remained the same (around 14%).

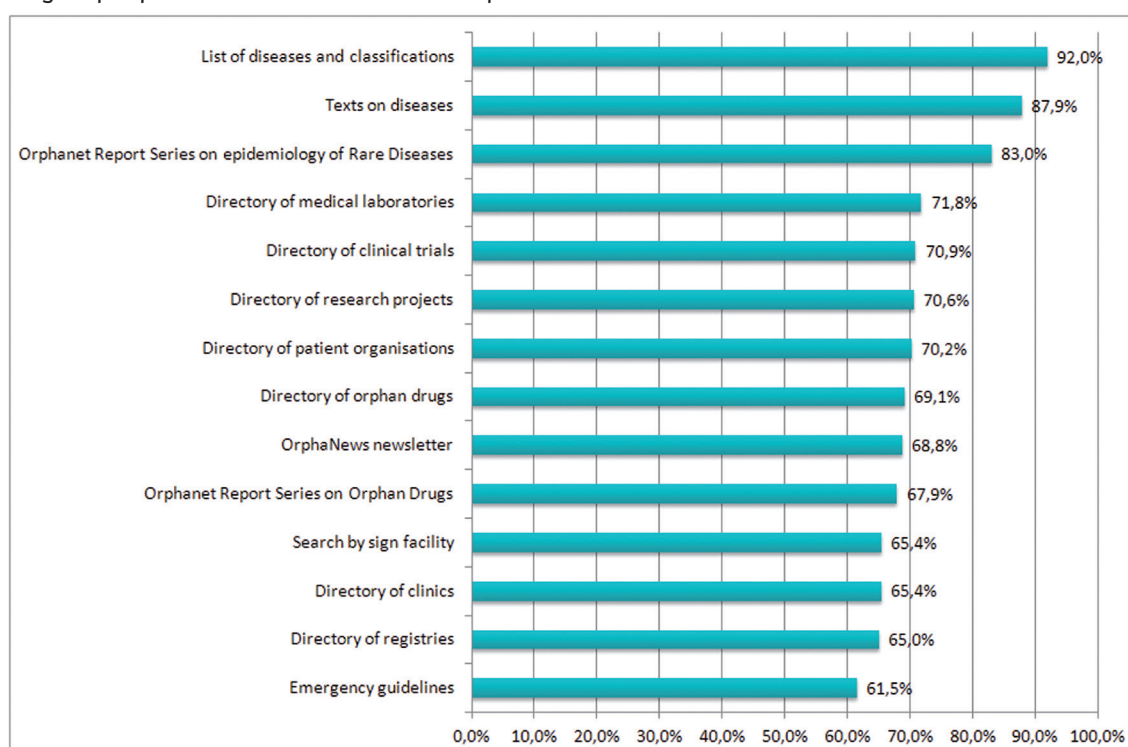
QUESTION 5

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. 363 persons answered this question, representing half of the total participants. Results show that Orphanet products are highly appreciated:

Orphanet product	Very useful	Useful	Fairly useful	Not useful	No opinion
List of diseases and classifications	184	137	24	4	14
Texts on diseases	161	143	39	3	17
Orphanet Report Series on epidemiology of Rare Diseases	100	140	41	8	74
Directory of medical laboratories	85	111	49	28	90
OrphaNews newsletter	73	92	55	20	123
Directory of patient organisations	70	121	63	18	91
Directory of research projects	68	129	68	14	84
Directory of clinical trials	64	116	59	15	109
Directory of orphan drugs	62	115	58	21	107
Search by sign facility	61	98	60	24	120
Directory of clinics	58	110	61	28	106
Directory of registries	56	104	71	15	117
Orphanet Report Series on Orphan Drugs	56	107	55	22	123
Emergency guidelines	55	92	65	27	124

The following graph presents the usefulness of Orphanet products ('very useful' and 'useful' answers). The 'no opinion' answers were subtracted from the results to show more faithfully the usefulness of the products according to people who know about the Orphanet website.



The key Orphanet service remains the encyclopaedia: the texts on diseases (88%) and the list of diseases and the classifications (92%).

The Orphanet Report Series collection is also highly appreciated.

Those answers show that our users insufficiently know about some of our products. A third of them did not have an opinion about the OrphaNews newsletter, but researchers seem to be more often aware of the existence of this product compared to industrials, healthcare managers or education/communication professionals, while patients and health professionals knowledge about the newsletter is in the average.

A majority of the persons who answered this question also had no opinion about the search by sign facility. This product is mainly dedicated to clinicians, who are more aware than the average of this product, but patient fairly know about it too.

The directory of registries, the information on Orphan Drugs (Orphanet Report Series and inventory), or the emergency guidelines suffer a lack of knowledge in our users community.

QUESTION 6

What should Orphanet do to better serve your needs?

363 persons left a comment in response to this question. About a quarter of them are satisfied by the Orphanet website as of December 2011, or left messages of encouragement and support to the Orphanet action.

Orphanet users mainly request that the diseases summaries be completed when they are not yet available, and that the update of diseases summaries be more regular. A frequent update of the services database is also necessary, especially for the laboratories.

A special effort has to be accorded to the website presentation to make it more user-friendly. A clearer design would help to improve the access to information, especially on the homepage.

Several persons ask to receive an email when the information on a disease or a drug is updated.

A mobile application has also been requested.

Our users would like Orphanet to be present in more countries and become completely international.

For health professionals, the main improvement to be brought to the Orphanet website would be to make smoother 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. Epidemiological data are asked to be country specific.

Health professionals would also like to have photos or medical imagery to illustrate dysmorphic diseases as it would help them in their diagnostic.

Finally, health professionals call for more details about the precise nature for tests offered by the various laboratories.

QUESTION 7

Have you experienced any bugs when using Orphanet?

Only 15 persons declared they already experienced a bug amongst the 361 who answered this question.

QUESTION 8

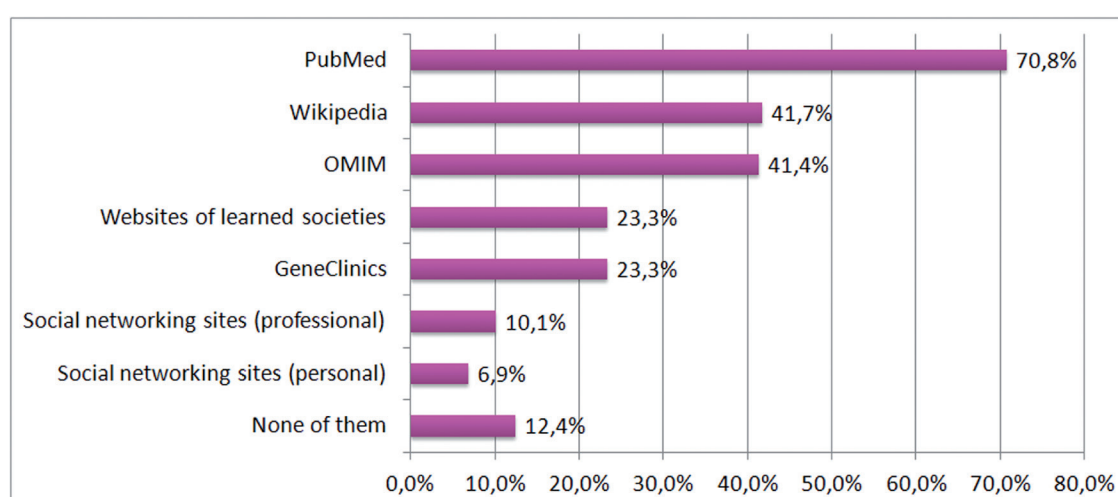
Have you ever experienced unusual slowness when using Orphanet?

36 persons declared they already experienced slowness when using the Orphanet website.

QUESTION 9

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.



71% of those who answered the satisfaction survey also use Pubmed to obtain information on a rare disease; 42% find information on Wikipedia; the OMIM website reaches the third position with 41%. Social networks represent less than 17% of the total.

Compared to 2010, the use of professional source of information like Pubmed or OMIM has increased by 7.5% and 6.5% respectively.

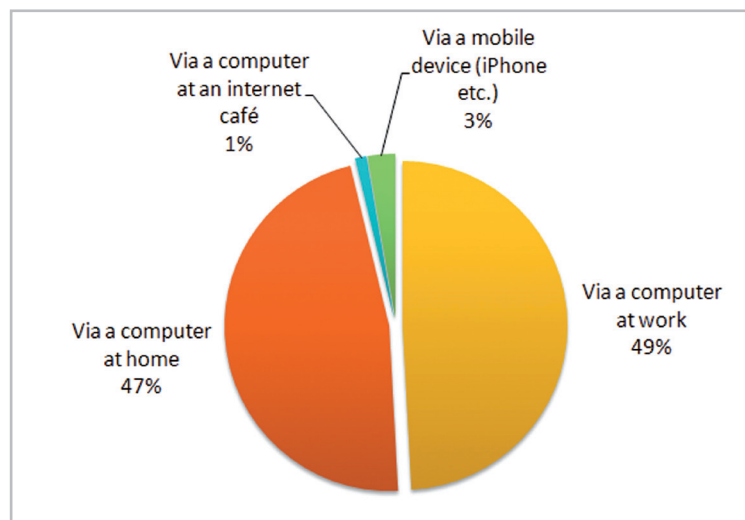
Pubmed is massively consulted by healthcare professionals (90%), but patients also use this website as a source of information about rare diseases (35%).

This analyse also underline that Wikipedia remains a main source of information both for patients (44%) and health professionals (40%).

QUESTION 10

How are you accessing Orphanet TODAY?

Only one response was possible for this question.



About 47% of the persons who participated to this survey did so from home, whilst 49% did it from their workplace.

The use of a mobile phone with an Internet connection is in progress but not yet significant with less than three percent of the respondents answering via a mobile device.

Conclusion

The results of the survey have helped the Orphanet team evaluate the expectations and needs of our users. Several improvements were planned in 2011 and 2012 that will fulfil some of the requests made by respondents: the first is to complete more disease summaries, and to at least give access to a definition for every condition; the next is to create a clearer and more user-friendly new homepage that should be on-line this summer; third is to identify more clinical guidelines.

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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