



2010

## 2010 Orphanet English users satisfaction survey

[www.orpha.net](http://www.orpha.net)



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## Methodology

An on-line survey was designed in September 2010, using the online survey tool Survey Monkey ([www.surveymonkey.com](http://www.surveymonkey.com)). Questions were based on previous Orphanet surveys carried out in 2009 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 October 2010: a pop-up window was added to the first page users landed on. The survey was translated in the 5 languages of the website available at the moment (i.e. English, French,

Spanish, Italian or German) and was displayed in respect of the consultation language. The survey was closed when 1000 answers were collected for each language.

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

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# 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, industrial, and health care manager/policy maker), gathering forty eight sub-categories, and a freetext field was included for other types of users to enter their profession. Only one response was possible.

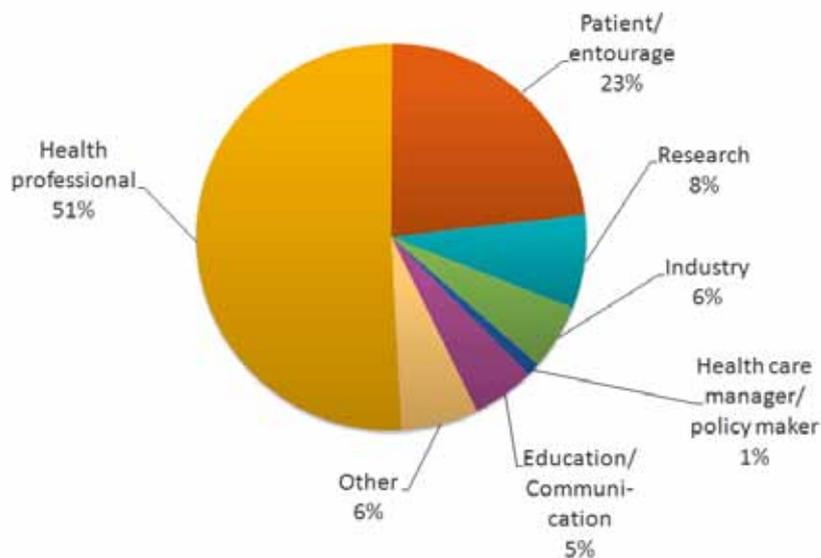
The table below shows the distribution of respondents amongst these categories proposed to respondents:

ANSWER OPTIONS	RESPONSE PERCENT	RESPONSE COUNT
Health professional: Hospital specialist	19.7%	197
Health professional: General practitioner	3.7%	37
Health professional: Independent specialist	2.4%	24
Health professional: Expert in rare diseases	5.1%	51
Health professional: Health service / health insurance	1.2%	12
Health professional: Hospital pharmacist	0.9%	9
Health professional: Independent pharmacist	0.6%	6
Health professional: Biologist with expertise in rare diseases	3.2%	32
Health professional: Biologist with no expertise in rare diseases	1.6%	16
Health professional: Physiotherapist	0.7%	7
Health professional: Psychologist	0.4%	4
Health professional: Nurse	2.9%	29
Health professional: Speech therapist	0.2%	2
Health professional: Social worker	0.4%	4
Health professional: Genetic counsellor	2.7%	27
Health professional: Medical student	2.6%	26
Health professional: Other	2.6%	26
Patient/entourage: Patient	10.3%	103
Patient/entourage: Mother/father/child of a patient	6.4%	64
Patient/entourage: Other family member	3.5%	35
Patient/entourage: Friend of a patient	0.9%	9
Patient/entourage: Member of a patient organisation	0.7%	7
Patient/entourage: Patient organisation administration	1.1%	11
Patient/entourage: Other	0.2%	2
Research: Academic/clinical researcher	2.4%	24
Research: Academic/basic researcher	2.1%	21
Research: Industry researcher	0.8%	8

ANSWER OPTIONS	RESPONSE PERCENT	RESPONSE COUNT
Research: Bioinformatician	0.5%	5
Research: Health economist	0.2%	2
Research: Other	1.8%	18
Industry: Biotechnology and pharmaceutical	2.8%	28
Industry: Information technology	0.0%	0
Industry: Private health insurance	0.0%	0
Industry: Consultant for Industry	2.1%	21
Industry: Investor / business developer	0.5%	5
Industry: Other	0.1%	1
Health care manager/policy maker: Governmental administration	0.7%	7
Health care manager/policy maker: Hospital administration	0.0%	0
Health care manager/policy maker: European administration	0.1%	1
Health care manager/policy maker: Other	0.3%	3
Education/communication: Journalist	0.7%	7
Education/communication: Librarian	0.6%	6
Education/communication: Webmaster	0.1%	1
Education/communication: Teacher (primary/secondary education)	0.5%	5
Education/communication: Teacher (higher education)	0.4%	4
Education/communication: Student (other than medical)	1.6%	16
Education/communication: Other	1.3%	13
If you don't belong to one of the categories above, who are you?	6.4%	64
<i>Total</i>	<i>100%</i>	<i>1,000</i>

Amongst the other types of users in the table above, were several health professionals and geneticists, paramedics, medical students, different types of consultants, patients and members of support groups.

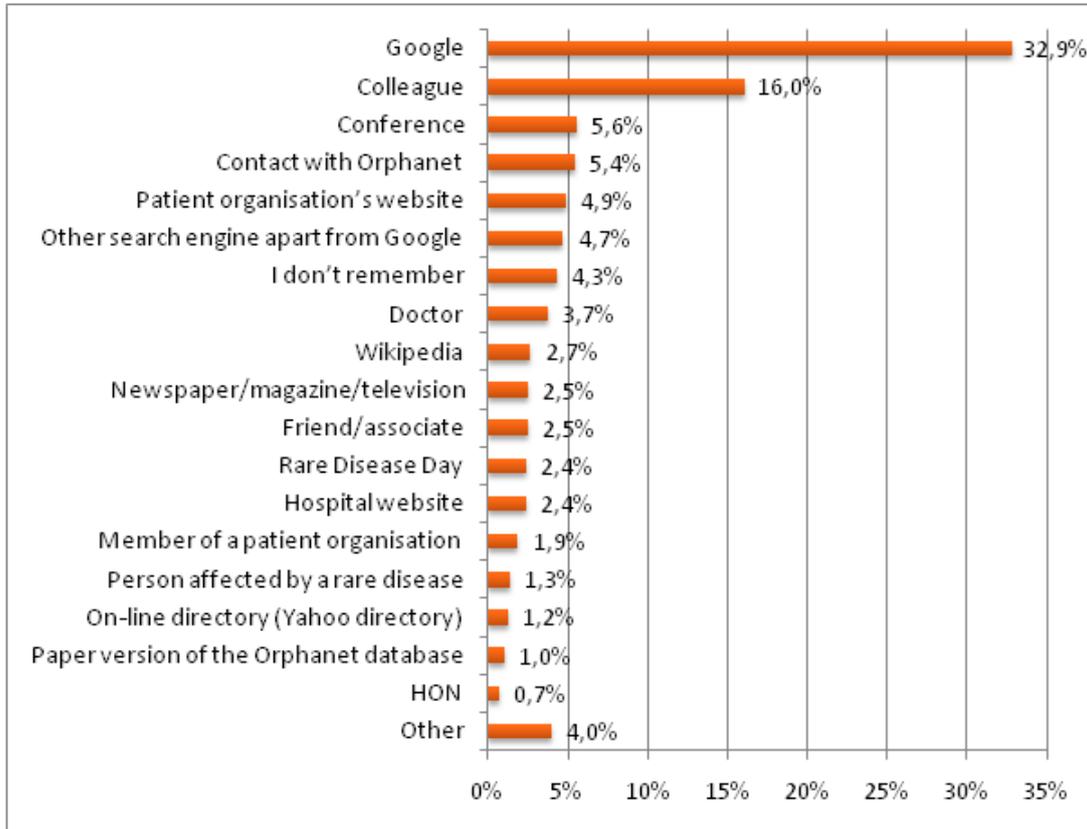
Having regrouped the replies by categories, we can see that the largest category of respondents is the health professionals category (51%), and especially hospital specialists who represent around 25% of all responses. The second largest category of respondents is patients and their entourage (including patient organisations, alliances and support groups) with 23% of responses. This figure summarises these findings:



## QUESTION 2

### How did you discover Orphanet?

This question aimed to determine how respondents first learnt of Orphanet. More than 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 38%) or through a patient organisation website (5%) or a hospital website (2.5%). In addition, through the "Other" category, several persons declared that they first discovered Orphanet through institutions websites like the NIH, the WHO, the GARD...

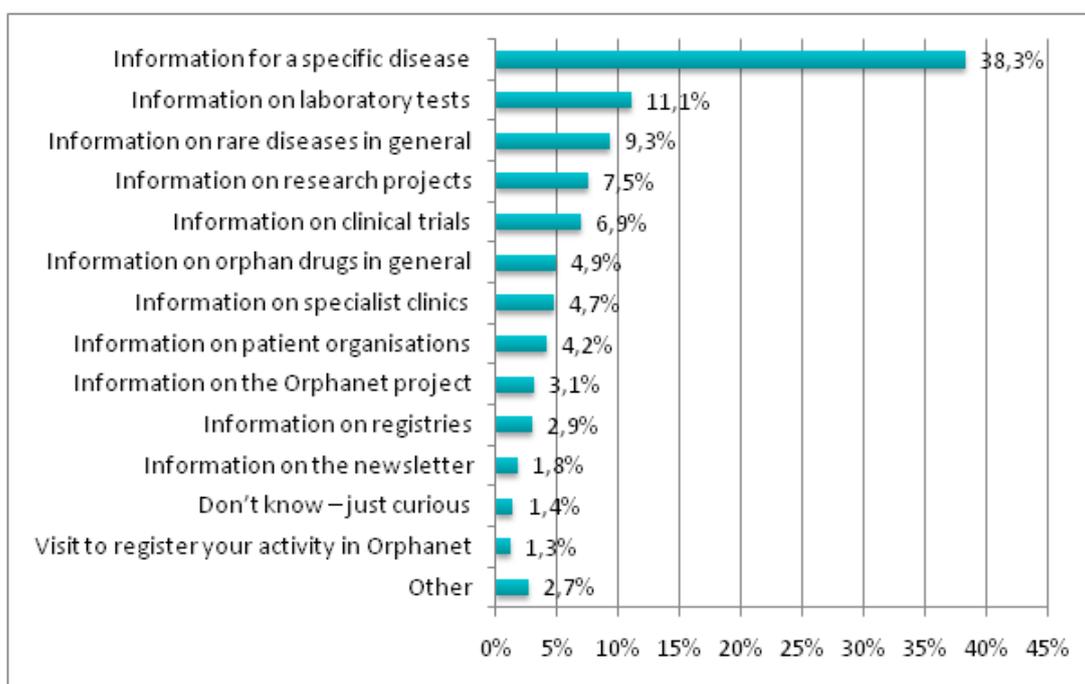
Word of mouth works well too (about 25%): many of our users first learn about Orphanet thanks to a colleague, a doctor, a friend or a patient recommendation.

## 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.

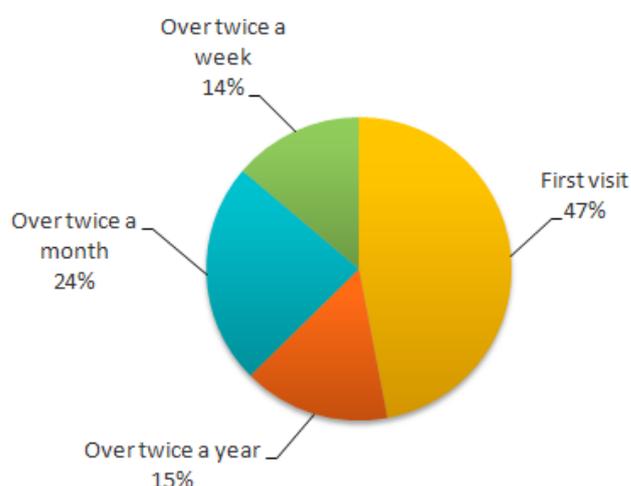
The results show a clear trend: most of the respondents were looking for information for a specific disease (38%). Our visitors also look for information on laboratory tests (11%), on rare diseases in general (9%), on research projects (7.5%) or on clinical trials (7%).



#### QUESTION 4

#### How often do you visit Orphanet?

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



#### QUESTION 5

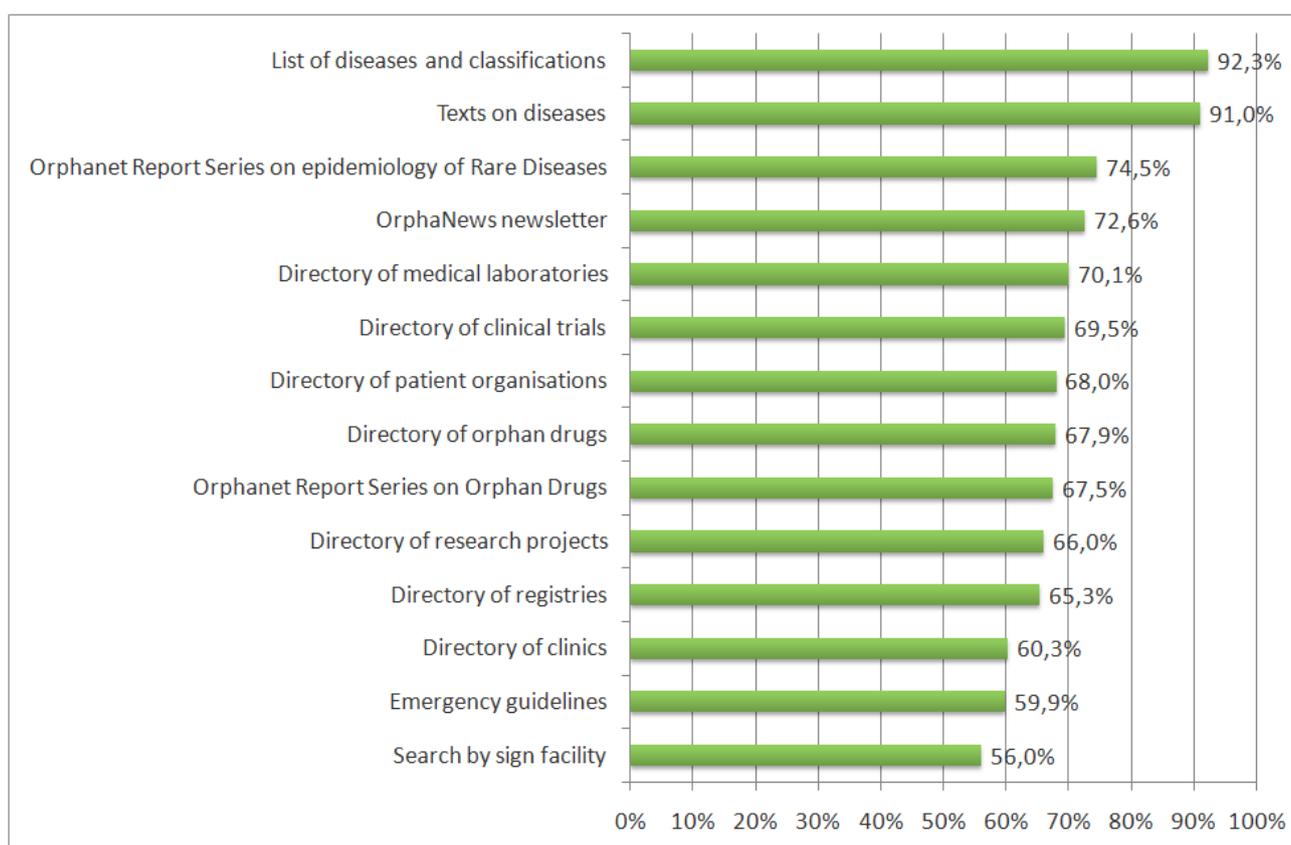
#### How useful would you rank the following Orphanet services for YOUR OWN use?

The usefulness of Orphanet products was evaluated through this question. Only one response was possible.

The results show that Orphanet products are highly appreciated:

	Very useful	Useful	Fairly useful	Not useful	No opinion
List of diseases and classifications	54,2%	35,0%	5,6%	1,9%	3,5%
Texts on diseases	53,7%	35,4%	6,9%	1,9%	2,1%
Directory of medical laboratories	28,0%	26,2%	16,0%	7,2%	22,7%
Orphanet Report Series on epidemiology of Rare Diseases	27,1%	28,5%	14,4%	4,6%	25,5%
Directory of orphan drugs	22,7%	25,2%	16,0%	6,7%	29,4%
OrphaNews newsletter	21,1%	26,9%	12,0%	6,0%	34,0%
Directory of patient organisations	20,8%	30,3%	16,7%	7,4%	24,8%
Directory of clinical trials	20,6%	31,0%	17,4%	5,3%	25,7%
Directory of research projects	19,7%	30,6%	19,4%	6,5%	23,8%
Orphanet Report Series on Orphan Drugs	18,3%	25,5%	14,4%	6,7%	35,2%
Search by sign facility	15,0%	21,8%	20,8%	8,1%	34,3%
Directory of clinics	15,0%	28,5%	18,8%	10,0%	27,8%
Directory of registries	14,4%	30,6%	17,1%	6,7%	31,3%
Emergency guidelines	13,2%	23,8%	16,4%	8,3%	38,2%

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 of the Orphanet website.



The key Orphanet service remains the encyclopaedia: the texts on diseases (91%) and the list of diseases and the classifications (92%).

The Orphanet Report Series collection is also highly appreciated.

## QUESTION 6

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### **What should Orphanet do to better serve your needs?**

432 persons left a comment in response to this question. About a third of them are satisfied by the Orphanet website as of December 2010, 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.

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.

The search engine could also be improved by allowing a multi-keywords search.

Some needs are related to stakeholders' activity:

First of all, patients and people without a medical training would like to have access to information in a less complicated language.

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 suggest including more alternative names, synonyms or abbreviations of disease names to help when interrogating the database. More clinical guidelines and review articles would be highly appreciated.

A disease description by organ or by system, and more information regarding anaesthesia was asked for by several professionals, as well as photos or medical imagery to illustrate dysmorphic diseases in particular.

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

## QUESTION 7

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### **Would you be prepared to participate in a translation project on a volunteer basis for Orphanet?**

122 persons would be willing to participate in the translation of a part of the Orphanet website on a volunteer basis. We warmly thank them. Those volunteers speak: Arabic, Armenian, Catalan, Chinese, Czech, Dutch (and Afrikaans), English, French, German, Greek, Hungarian, Indian (Malayalam, Urdu and Marathi), Italian, Polish, Portuguese, Romanian, Russian, Serbian, Slovenian, Spanish, Swedish, and Turkish.

## QUESTION 8

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### **Have you experienced any bugs when using Orphanet?**

Only 21 persons declared they already experienced a bug amongst the 427 who answered this question.

## QUESTION 9

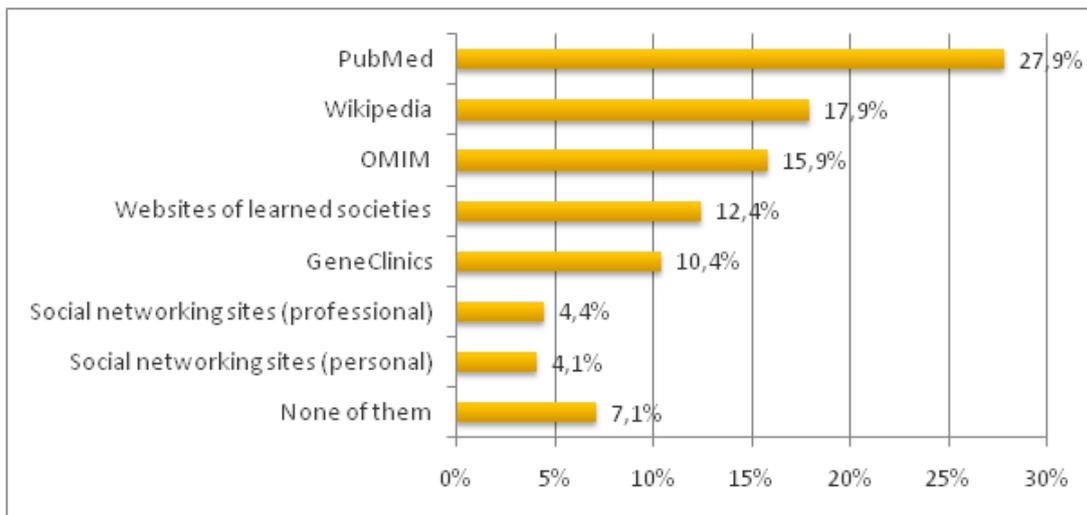
### Have you ever experienced unusual slowness when using Orphanet?

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

## 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 an information on rare diseases. More than one choice was possible.

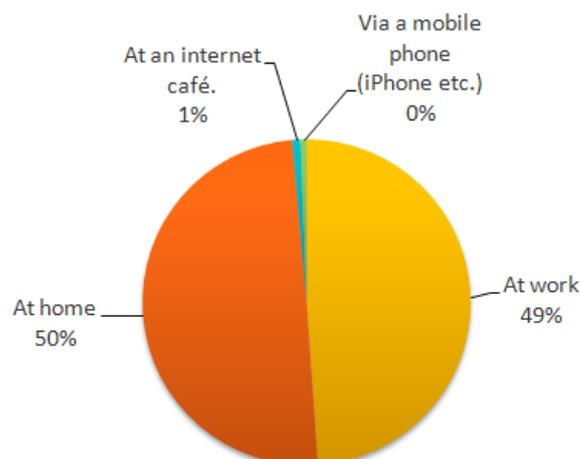


28% of those who answered the satisfaction survey also use Pubmed to obtain information on a rare disease; 18% find information on Wikipedia; the OMIM website reaches the third position with 16%. Social networks represent less than 9% of the total.

## QUESTION 11

### How are you accessing Orphanet TODAY?

Only one response was possible for this question.



About 50% 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 not yet significant with less than one 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 2010 and 2011 that will fulfill 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 ; 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](mailto:contact.orphanet@inserm.fr)**

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