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OrphaNews Europe Reader Satisfaction Survey

www.orpha.net



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Association Française contre les Myopathies

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



Introduction

OrphaNews Europe is the electronic newsletter of the European Union Committee of Experts on Rare Diseases (formerly the European Commission's Rare Diseases Task Force), which is published on-line, and sent to over 12,000 subscribed readers, twice a month. OrphaNews Europe was launched on the 15th June 2005 and over 80 issues of the newsletter have since been published.

Every issue of the newsletter presents news and views on rare diseases and orphan drugs in Europe and contains the following sections: Editorial; EU Committee of Experts on Rare Diseases news; EC policy news; other International news; Spotlight on an EU-funded project; New Rare Diseases; New Genes; New Basic Discoveries; New Clinical Research Outcomes; New Public Health Research Outcomes; New Orphan Drugs; Job and Funding Opportunities; News from Patient Organisations; New Publications; Calendar of Events.

The newsletter, produced in English, aims to reach all sectors of the rare disease and orphan drugs community across Europe, ensuring that all those concerned are informed of important developments and new initiatives in the field.

The publication of OrphaNews Europe is supported by the AFM (Association Française contre les Myopathies) and a Joint Action (Joint Action N° 2008 22 91) to support the scientific secretariat of the European Union Committee of Experts on Rare Diseases (which replaces the Rare Diseases Task Force following Commission Decision of 30 November 2009 2009/872/EC), running from the 1st of January 2009 to the 31st December 2011.

The joint action foresees the publication of 60 newsletters during the contract, as well as the implementation of modifications which will allow readers to subscribe to specific sections of the newsletter, and by medical field. The contract also stipulates that a survey of OrphaNews readers should be carried out in June 2010, mid-way through the contract, in order to assess their satisfaction with the newsletter and to gather feedback concerning the newsletter in general and proposed modifications.

The survey was launched at the end of May 2010 and the results of this survey are presented in this report.



Methodology

An on-line survey was designed by the editor and editor-in-chief of OrphaNews Europe in May 2010 using the online survey tool Survey Monkey (www.surveymonkey.com): questions were based on a previous survey of OrphaNews Europe carried out in 2006. This survey was designed to be brief in order to encourage readers to respond. Questions focused on the professional activity of the reader, their location, their opinion of the content and form of the newsletter, their opinion of proposed modifications to the newsletter (i.e. RSS feed, joint USA-Europe edition), as well as their overall satisfaction and their suggestions for improvement.

The survey was launched at the end of May 2010: an email explaining the survey with a link to the online survey was sent to all subscribed readers on 28th May 2010. A reminder was also published in the OrphaNews Europe newsletter on the 2nd June 2010. Over two months, 1082 readers accessed the link, and 1077 readers completed the survey.

The results of this survey were then analysed, and the findings are presented in this document.

Results

QUESTION 1

Please indicate your professional and/or personal interest in OrphaNews Europe.

This question aimed to determine the professional and/or personal interest in OrphaNews Europe of respondents. Fifteen main categories were proposed (i.e. medical professional, researcher, industrial, government representative and patient/family of patient) and an open field was included for other types of reader to enter their profession/interest. Some of the replies in this open field corresponded with the existing proposed categories and they were thus reassigned. After this reassignment 30 replies were classed in the category "Other".

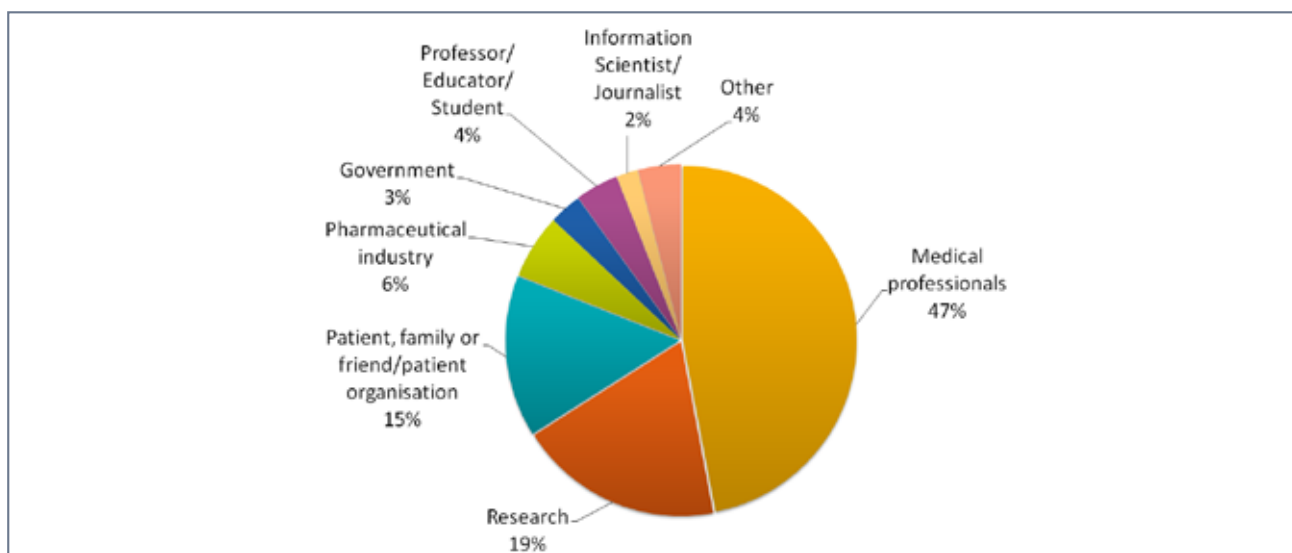
The table below shows the distribution of respondents amongst these proposed categories:

ANSWER OPTIONS	RESPONSE PERCENT	RESPONSE COUNT
Medicine: Academia/hospital	41.5%	447
Medicine: Private practice	2.9%	31
Medicine: Nurse, counsellor or other non-MD medical staff	2.4%	26
Medical services: Other	0.7%	8
Research: basic research	9.1%	98
Research: clinical research	8.7%	94
Research: Other	1.1%	12
Government: regional level	0.7%	8
Government: national level	2.0%	22
Government: European level	0.6%	7
Pharmaceutical industry: research	2.2%	24
Pharmaceutical industry: regulatory	0.9%	10
Pharmaceutical industry: sales and marketing	1.7%	18
Pharmaceutical industry: Other	0.8%	9
Patient or family member/friend of patient	11.2%	121
Patient organisation/support group	3.5%	38
Information Scientist/Journalist	2.3%	25
Professor/Educator	3.4%	37
Student	0.6%	6
Lobbying/Advocacy	0.4%	4
Non-profit organisations	0.2%	2
Other	2.8%	30
<i>answered question</i>	<i>100%</i>	<i>1077</i>

Other types of research cited included epidemiological research, public health research, legislative research, and social sciences research. Other types of 'medical' services included professionals in the fields of neonatal screening, genetics screening and gene therapy. Other professionals in the pharmaceutical industry work in the fields of pharmacovigilance, investment in pharmaceuticals, governmental affairs and public affairs. Amongst

the “others” in the table above were a public health project leader, a member of an RD-related ethics committee, different types of consultant outside of the pharmaceutical industry and a specialist in nomenclature.

After this analysis, and having regrouped the replies recorded in the “Other” section with the categories defined in the survey, we can see that the largest category of respondents is the medical and paramedical profession. The second largest category of respondents is research and the third largest category of respondents are patients and their entourage (including patient organisations, alliances and support groups). This graphic summarises these findings:



QUESTION 2

What is your country of residence?

The results were sorted by number of replies in each country:

COUNTRY	PERCENTAGE OF TOTAL REPLIES	NUMBER OF REPLIES
France	16.9%	182
Italy	15.2%	164
Germany	12.0%	129
Spain	10.8%	116
United Kingdom	8.3%	89
Switzerland	4.6%	50
Netherlands	3.9%	42
Belgium	3.4%	37
Portugal	3.2%	35
United States of America	2.9%	31
Finland	1.5%	16
Sweden	1.4%	15
Romania	1.2%	13
Denmark	1.1%	12

COUNTRY	PERCENTAGE OF TOTAL REPLIES	NUMBER OF REPLIES
Greece	1.0%	11
Argentina	0.9%	10
Austria	0.8%	9
Canada	0.8%	9
Hungary	0.7%	8
Poland	0.7%	8
Turkey	0.7%	8
Brazil	0.6%	6
Ireland	0.6%	6
Norway	0.6%	6
<i>Other</i>	0.5%	5
Australia	0.4%	4
Cyprus	0.4%	4
Czech Republic	0.4%	4
Slovakia	0.4%	4
Bulgaria	0.3%	3
Latvia	0.3%	3
New Zealand	0.3%	3
Algeria	0.2%	2
Croatia	0.2%	2
Egypt	0.2%	2
Georgia	0.2%	2
Iceland	0.2%	2
Israel	0.2%	2
Jordan	0.2%	2
Lithuania	0.2%	2
Luxembourg	0.2%	2
Russia	0.2%	2
Serbia	0.2%	2
Tunisia	0.2%	2
Columbia	0.1%	1
Estonia	0.1%	1
Iran	0.1%	1
Korea	0.1%	1
Lebanon	0.1%	1
Malta	0.1%	1
Mexico	0.1%	1
Morocco	0.1%	1
Peru	0.1%	1
Ukraine	0.1%	1
Uruguay	0.1%	1

The majority of respondents (84%) reside in countries within the EU27 with a further 6% of respondents residing in EU candidate countries and other European countries. 13% of respondents come from Anglophone countries (UK, USA, New Zealand, Canada and Australia), with 3% of the overall number of respondents residing in the USA. South American countries represent around 2% of respondents and the Middle Eastern and North Africa 1% in total.

The European readership of the newsletter is predominant, and the top 5 countries in terms of respondents are those whose language is represented by Orphanet, via which nearly 44% of readers questioned (see Question 4) learnt about OrphaNews Europe. The results also show that there is a strong Anglophone readership (13% of readers questioned): 33% of Anglophone respondents reside outside of the Eurozone.

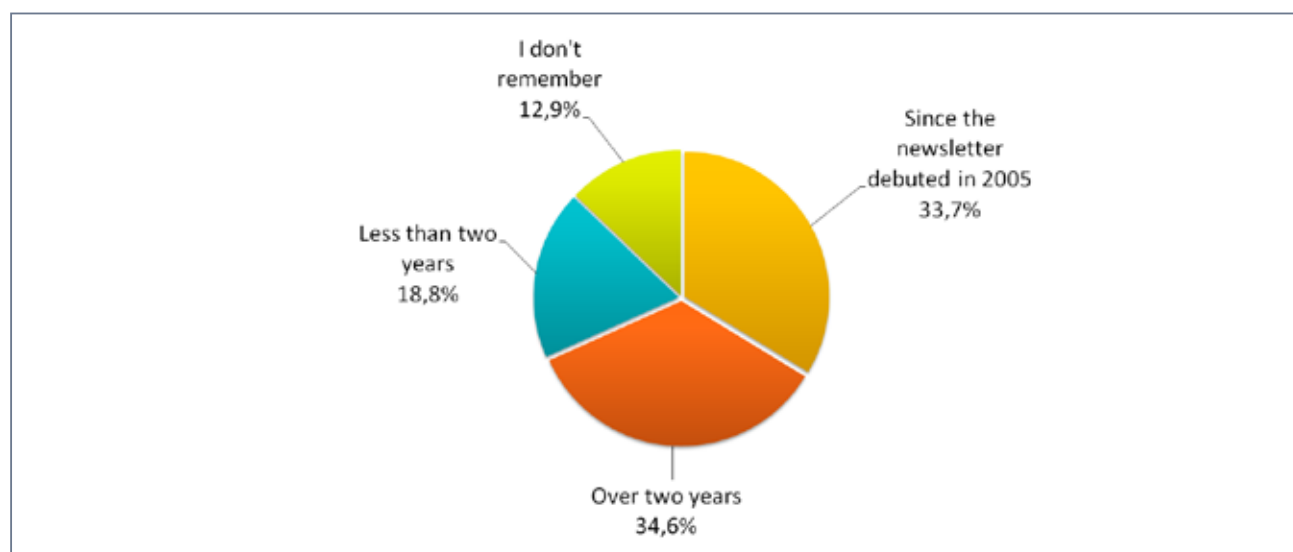
CATEGORY	PERCENTAGE OF TOTAL REPLIES	NUMBER OF REPLIES
EU27	84 %	905
Other European countries (EU candidate, EEC etc)	7 %	75
Anglophone countries	13 %	143
Anglophone countries (except UK and Ireland)	4.4%	47
USA	3 %	31
South America	2 %	20
Middle East and North Africa	1 %	13

QUESTION 3

How long have you subscribed to OrphaNews Europe?

The majority of respondents have subscribed to the newsletter for over 2 years (68.3%), with 33.7% of the respondents replying that they have subscribed to the newsletter since its debut in 2005.

These figures show that OrphaNews Europe readers continue to read the newsletter long after they subscribe for the first time.



QUESTION 4

How did you first learn of OrphaNews Europe?

This question aimed to determine how respondents first learnt of OrphaNews Europe: via the Internet, via Orphanet, via Cordis, via another association/institution, via word of mouth, or if the reader was a subscriber at the newsletter's debut. A space was included in order for respondents to give details of the association/institution through which they learnt of the newsletter, or to mention another way in which they heard of OrphaNews Europe. It was possible for many of these open-ended replies to be reassigned to an existing category and the following results show that the most common way respondents heard about OrphaNews was via Orphanet (43.8%); another (23.9%) heard about the newsletter via the internet:

ANSWER OPTIONS	PERCENTAGE OF TOTAL REPLIES	TOTAL NUMBER OF REPLIES
Via Orphanet	43.8%	470
Via the Internet	23.9%	257
Do not remember	11.3%	121
Word of mouth	10.1%	109
Via another association or institution (please specify)	4.8%	52
Subscription to OrphaNews Europe at the time of the debut of the newsletter	3.7%	40
Other	1.3%	14
Via Cordis (Community Research & Development Information Service)	1.0%	11
	100.0%	1074

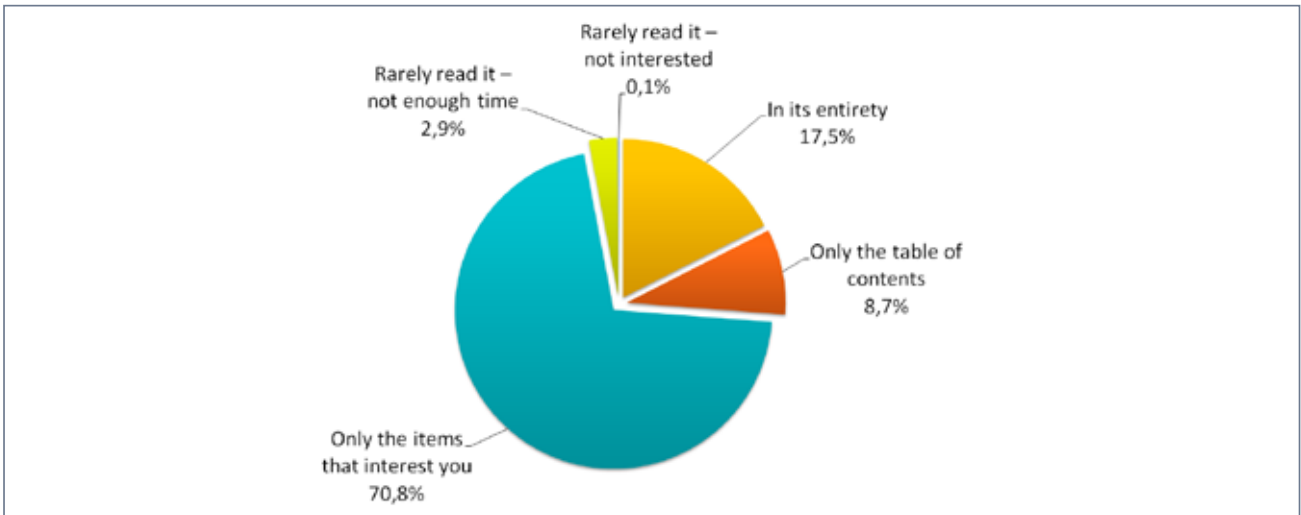
Amongst the associations/institutions cited were various professional medical and genetic societies, European networks, public health and research institutions, as well as European, international and national patient organisations: i.e. the European Society of Human Genetics, the National Institutes of Health Rare Disease Office (USA), CIBERER (Spain), ISS (Italy), Eurordis, etc.

A number of people who heard about OrphaNews Europe from an "Other" source identified press articles, the RDTF (Rare Disease Task Force) and the Telethon.

QUESTION 5

How much of OrphaNews do you usually read?

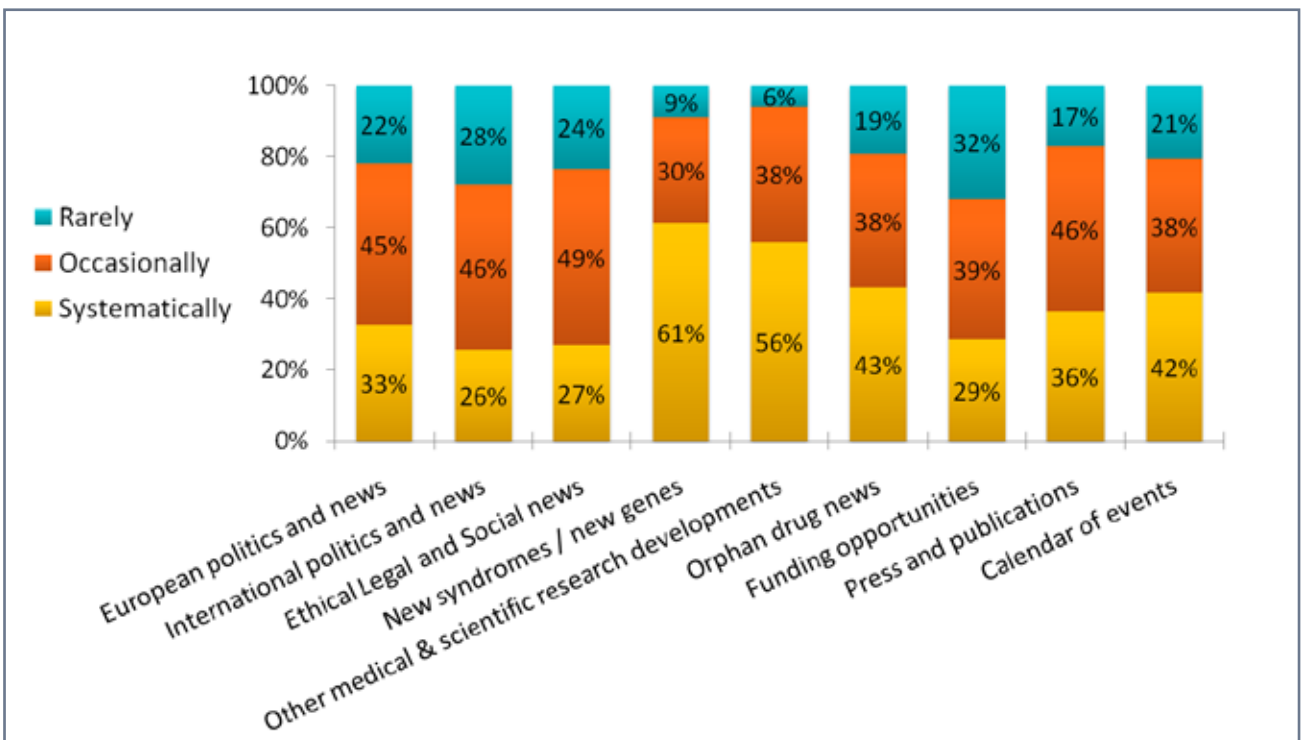
This question, along with Question 6 ("Which sections of OrphaNews Europe do you consult?"), aimed to find out more about the reading habits of subscribers. The results showed that the majority of respondents (70.8%) only read the items of interest to them in the newsletter. A further 8.7% of respondents usually only consult the table of contents in order to identify articles of specific interest to them. A significant number of respondents (17.5%) replied that they read OrphaNews Europe in its entirety.



QUESTION 6

Which sections of OrphaNews Europe do you consult?

This question focused on the reading habits of subscribers to the newsletter, asking them to state whether, for the sections of the newsletter they consult, they read these sections “systematically”, “occasionally” or “rarely”. These results were analysed and the percentage of replies for each section were calculated for the three proposed frequencies of consultation in order to evaluate reading trends.



ANSWER OPTIONS	SYSTEMATICALLY	OCCASIONALLY	RARELY	RESPONSE COUNT
European politics and news	32.7%	45.5%	21.8%	902
International politics and news	25.6%	46.3%	28.1%	883
Ethical Legal and Social news	27.0%	49.5%	23.5%	855
New syndromes / new genes	61.3%	29.6%	9.1%	1012
Other medical and scientific research developments	56.0%	37.9%	6.1%	989
Orphan drug news	43.3%	37.5%	19.2%	943
Funding opportunities	28.6%	39.4%	32.0%	875
Press and publications	36.4%	46.5%	17.1%	912
Calendar of events	41.6%	37.7%	20.7%	942

The results show a clear trend: “scientific information” (new syndromes/new genes, other medical and scientific research developments, orphan drug news) is read systematically by respondents, while “political” and “social” information (European politics and news/international politics and news, and ethical, legal and social news) as well as the calendar of events, information on press and publications, and information on funding opportunities are consulted occasionally.

The sections can be ranked in the following order by the percentage of respondents who read the section systematically:

ANSWER OPTIONS	SYSTEMATICALLY
New syndromes / new genes	61.3%
Other medical and scientific research developments	56.0%
Orphan drug news	43.3%
Calendar of events	41.6%
Press and publications	36.4%
European politics and news	32.7%
Funding opportunities	28.6%
Ethical Legal and Social news	27.0%
International politics and news	25.6%

This ranking shows that the section ‘new syndromes/new genes’ is the section the most widely read systematically by respondents, followed by news on other medical and scientific research and orphan drug news. This correlates with the results of Question 1, which show that the majority of respondents are in the medical/paramedical profession, or work in the field of research, and thus “scientific” information is of most relevance to them and is therefore read systematically.

The scores for systematic and occasional reading for each of the sections were ranked in the following table:

ANSWER OPTIONS	SYSTEMATICALLY/ OCCASIONALLY	RARELY
Other medical and scientific research developments	93.9%	6.1%
New syndromes / new genes	90.9%	9.1%
Press and publications	82.9%	17.1%
Orphan drug news	80.8%	19.2%
Calendar of events	79.3%	20.7%
European politics and news	78.2%	21.8%
Ethical Legal and Social news	76.5%	23.5%
International politics and news	71.9%	28.1%
Funding opportunities	68.0%	32.0%

These results were further analysed by category of reader (medical professionals/researchers/government/industry/patients) in order to see how reading trends differ across these categories.

MEDICAL PROFESSIONALS:

The results show that medical/paramedical professionals systematically read the new syndromes/genes and other medical/scientific research developments sections, and occasionally read the other sections.

ANSWER OPTIONS	SYSTEMATICALLY	OCCASIONALLY	RARELY	RESPONSE COUNT
European politics and news	25.8%	49.4%	24.8%	415
International politics and news	17.6%	51.0%	31.4%	408
Ethical Legal and Social news	23.7%	52.5%	23.7%	396
New syndromes / new genes	67.2%	27.6%	5.2%	482
Other medical and scientific research developments	57.5%	36.9%	5.6%	463
Orphan drug news	37.9%	40.6%	21.5%	438
Funding opportunities	23.3%	42.7%	34.0%	403
Press and publications	37.4%	43.9%	18.8%	431
Calendar of events	37.0%	38.4%	24.7%	438
<i>answered question</i>				499

RESEARCHERS:

Researchers systematically read the sections on new syndromes/genes, other medical/scientific research developments, and funding opportunities as well as the calendar of events; they occasionally read the other sections.

ANSWER OPTIONS	SYSTEMATICALLY	OCCASIONALLY	RARELY	RESPONSE COUNT
European politics and news	22.0%	52.0%	26.0%	150
International politics and news	17.0%	50.3%	32.7%	147
Ethical Legal and Social news	22.1%	45.0%	32.9%	140
New syndromes / new genes	69.1%	26.0%	5.0%	181
Other medical and scientific research developments	61.4%	36.4%	2.3%	176
Orphan drug news	30.4%	46.2%	23.4%	158
Funding opportunities	41.2%	38.8%	20.0%	165
Press and publications	35.0%	48.8%	16.3%	160
Calendar of events	43.3%	37.2%	19.5%	164
<i>answered question</i>				192

GOVERNMENT:

Respondents in government systematically read the European politics and news and international politics and news sections, whilst other sections are read occasionally (Ethical, Legal and Social News, and New syndromes/genes receive the same number of responses for the option “systematically” and “occasionally”).

ANSWER OPTIONS	SYSTEMATICALLY	OCCASIONALLY	RARELY	RESPONSE COUNT
European politics and news	50.0%	38.2%	11.8%	34
International politics and news	43.8%	34.4%	21.9%	32
Ethical Legal and Social news	40.6%	40.6%	18.8%	32
New syndromes / new genes	40.5%	40.5%	18.9%	37
Other medical and scientific research developments	33.3%	51.5%	15.2%	33
Orphan drug news	37.1%	42.9%	20.0%	35
Funding opportunities	28.1%	34.4%	37.5%	32
Press and publications	38.2%	41.2%	20.6%	34
Calendar of events	40.0%	51.4%	8.6%	35
<i>answered question</i>				37

PHARMACEUTICAL INDUSTRY:

Respondents from the pharmaceutical industry are most interested in the European and International politics and news sections, orphan drug news and calendar of events (read systematically).

ANSWER OPTIONS	SYSTEMATICALLY	OCCASIONALLY	RARELY	RESPONSE COUNT
European politics and news	56.0%	34.0%	10.0%	50
International politics and news	44.9%	44.9%	10.2%	49
Ethical Legal and Social news	24.5%	59.2%	16.3%	49
New syndromes / new genes	33.3%	37.5%	29.2%	48
Other medical and scientific research developments	45.1%	49.0%	5.9%	51
Orphan drug news	80.8%	17.3%	1.9%	52
Funding opportunities	15.2%	45.7%	39.1%	46
Press and publications	27.9%	53.5%	18.6%	43
Calendar of events	42.6%	31.9%	25.5%	47
<i>answered question</i>				52

PATIENTS:

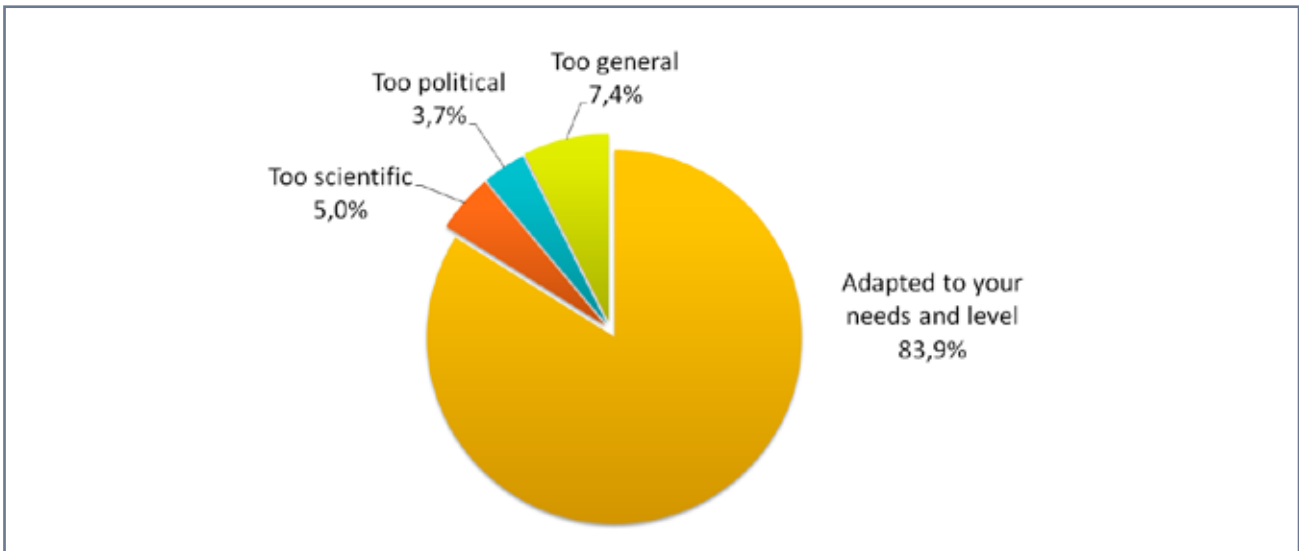
Patients systematically read the sections on European politics and news, as well as the sections on new syndromes/genes, other medical and scientific research developments and orphan drugs news.

ANSWER OPTIONS	SYSTEMATICALLY	OCCASIONALLY	RARELY	RESPONSE COUNT
European politics and news	41.4%	39.4%	19.2%	99
International politics and news	32.6%	37.9%	29.5%	95
Ethical Legal and Social news	36.8%	40.0%	23.2%	95
New syndromes / new genes	52.0%	35.0%	13.0%	100
Other medical and scientific research developments	56.7%	37.5%	5.8%	104
Orphan drug news	55.2%	30.5%	14.3%	105
Funding opportunities	29.9%	34.5%	35.6%	87
Press and publications	34.0%	53.2%	12.8%	94
Calendar of events	41.4%	42.4%	16.2%	99
<i>answered question</i>				115

QUESTION 7

What do you think of the contents of OrphaNews Europe?

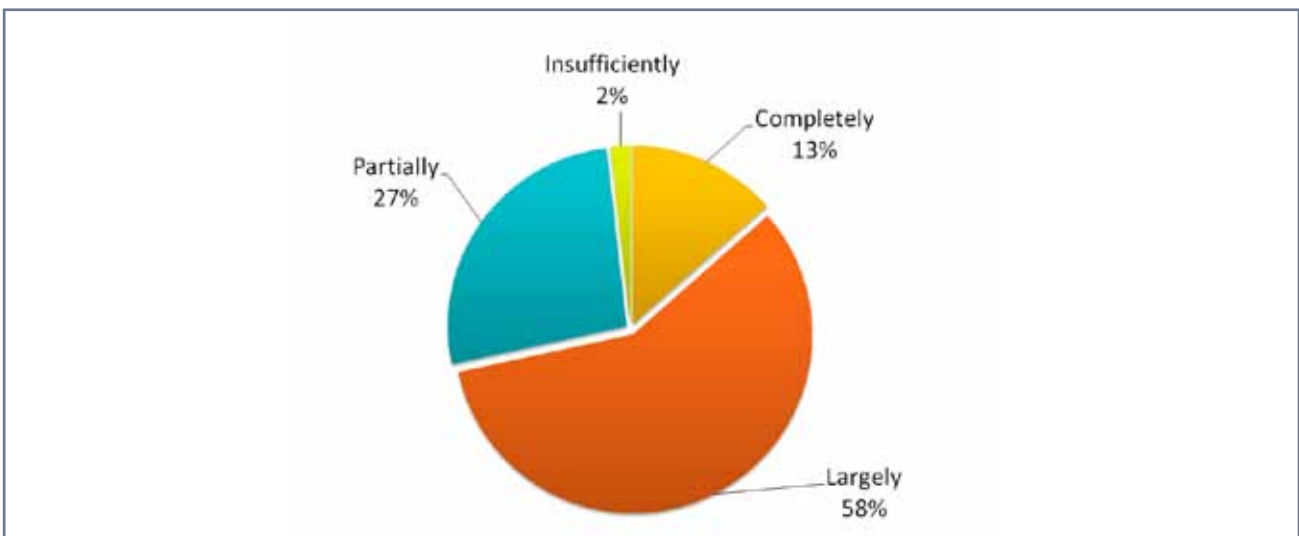
The results of this question show that the majority of respondents (84%) judge the contents of the newsletter to be adapted to their needs and their level of interest, with only small numbers of respondents replying that the contents are too scientific (5%), too political (3.7%) or too general (7.4%).



QUESTION 8

Do the contents of OrphaNews Europe meet your needs for rare disease information?

The majority of respondents (58.1%) judge that the contents of the newsletter largely meet their needs for rare diseases information, and another 13.5% of respondents replied that the contents meet their needs completely. The needs of 26.6% of respondents are partially met.



61 comments were left by respondents to this question: 12 were congratulatory remarks or words of thanks whilst the other comments suggested ways in which the contents of the newsletter could be improved to better meet their needs for rare disease information. These suggestions were analysed and the following themes of demand were identified:

- More information on the disease the reader is interested in (these are very personalised needs).
- More information on specific diseases and specific medical fields
- More information on rare forms of common diseases
- More information on expert networks
- More case studies
- Links to full text articles
- More information on the ICD revision process
- More information on availability of orphan drugs in individual MS and other non-EU countries
- More information on the evolution of the Orphanet database
- More information on grant proposals
- More information on the EU public health agenda
- More visibility for patient organisations
- More information on courses and meetings
- A new structure of information by organ system
- A way of adapting the newsletter to different audiences
- An easier to read format
- Editions of the newsletter in different languages
- A joint USA-Europe edition

Many respondents acknowledged that it is impossible to cover all elements of such a vast field in one newsletter. Respondents often commented that they subscribe to the newsletter in order to receive information about a specific disease/group of disease, but this disease-specific news is not necessarily available on a regular basis, so this means that the content does not always suit their needs.

The results were analysed by category of respondent in the table below:

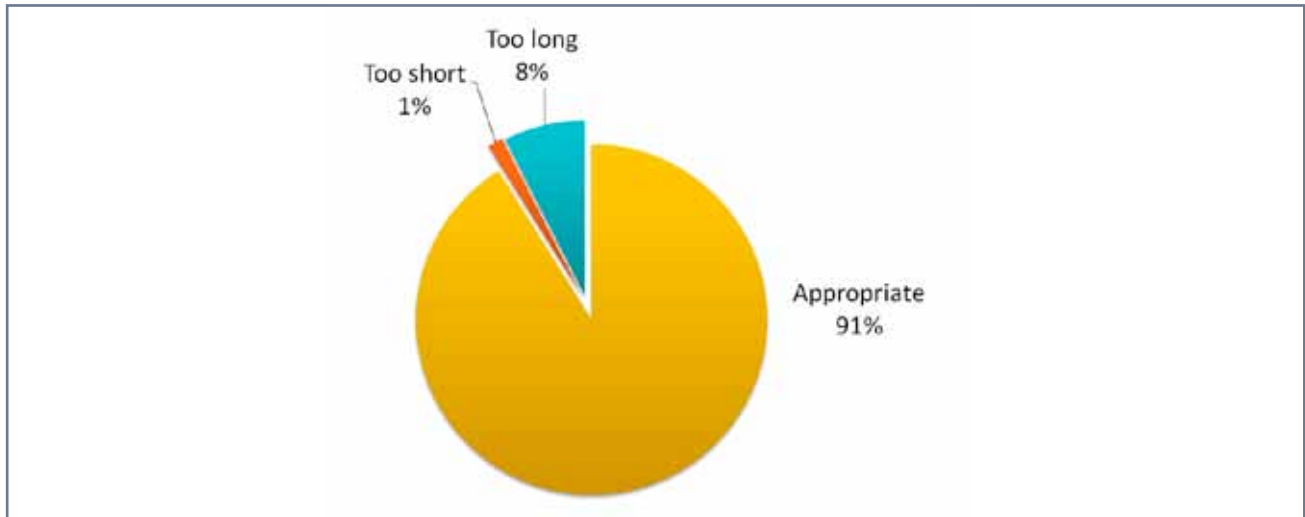
CATEGORY OF RESPONDENT	COMPLETELY	LARGELY	PARTIALLY	INSUFFICIENTLY
Medical professional	13.6%	59.1%	25.5%	1.8%
Research	9.9%	65.1%	25.0%	0.0%
Government	16.2%	73.0%	10.8%	0.0%
Industry	17.3%	61.5%	21.2%	0.0%
Patient	13.9%	41.7%	38.3%	6.1%

These results show that the newsletter largely meets the needs of each category of respondent: however a significant number of patients feel that the newsletter partially (38.3% of respondents in the patient category) or insufficiently (6.1%) meets their needs. Patients have a special interest in information concerning their disease, as previously highlighted in the paragraph above, and as their disease may not be represented in each newsletter they are more likely to find the newsletter only partially or insufficiently fulfilling their needs.

QUESTION 9

What do you think of the length of OrphaNews Europe?

The majority of respondents (91.1%) judge the length of the newsletter as appropriate, with 7,5% judging it to be too long.



Comments left by 15 respondents reflected that, although the newsletter is long, the table of contents helps respondents navigate through the newsletter to find the information relevant to them. Respondents leaving comments would like a customised subscription to the sections of interest to them. One reader complimented the OrphaNews Europe team on producing a newsletter which was just the right length: “[OrphaNews Europe] skirt[s] Scylla and Charybdis nicely”¹.

QUESTION 10

Are there other topics that you would like to see featured in OrphaNews Europe?

131 comments were received for this question suggesting topics that respondents would like to see featured in the newsletter. Analysis of these replies identified the following themes:

- Policy information
 - More international (non-EU news)
 - Historical perspective : focus on one element of policy through time
 - Highlight inequalities in healthcare across EU
 - Spotlight on deficient areas of policy
- New syndromes/new genes
 - Editorial comments in addition to article summaries
 - A section on rare forms of common diseases

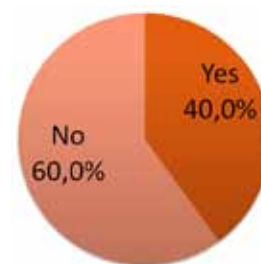
¹ Scylla and Charybdis were two sea monsters of Greek mythology noted by Homer; later Greek tradition sited them on opposite sides of the Strait of Messina between Sicily and mainland Magna Graecia (southern Italy). They were said to be located close enough to each other that they posed an inescapable threat to passing sailors; avoiding Charybdis meant passing too closely to Scylla and vice versa.

- Other medical/scientific research developments
 - Research on model organisms
 - Calls for scientific collaborations
 - More information on coding and nomenclature
 - More information on disease databases and genetics databases
 - More information on prenatal diagnosis
 - More information on epidemiology
 - More information on disease prevention
 - Articles on availability of genetic tests
 - Articles on pathophysiology
- Treatment and care
 - More information on best practice guidelines
 - Reference networks
 - Alternative treatments (non-medicinal)
- Orphan drugs information
 - Spotlight on OD policy and market authorisation procedures in different countries
 - What's going on in countries without OD regulations
 - More information on ongoing clinical trials
 - Spotlight on drugs in development for RD
- Ethical, legal, social issues
 - More spotlights on patient organisations
 - Information on handicaps
 - Stories of patients living with RD
 - Articles to help with capacity building for patient organisations
 - Recommendations to help RD patients in daily life
 - Information on lobbying groups
- Funding opportunities
 - More information on applying for funding
- Information on available jobs in the field

QUESTION 11

Do you forward OrphaNews Europe to others?

40% of respondents who replied to the questionnaire forward the newsletter to others: from the results, it can be inferred that the readership of the newsletter is significantly larger than the number of subscribed readers.



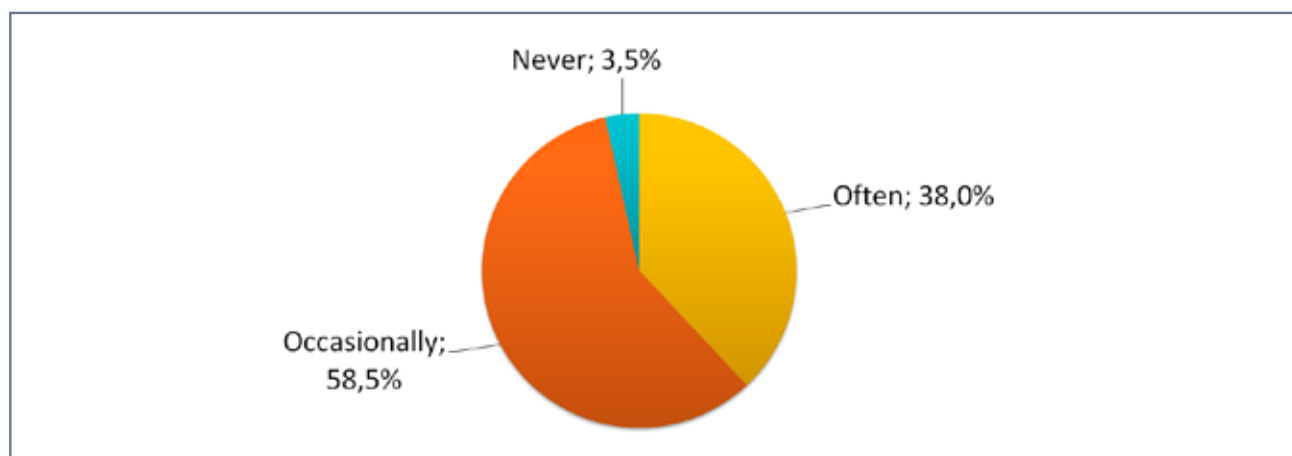
When these results were analysed by category of respondent, it could be seen that the majority of respondents in the patient category answered that they forward the newsletter to others, which implies that the newsletter is an important source of information for patients and their entourage.

CATEGORY OF RESPONDENT	YES	NO
Patient	56.5%	43.5%
Medical professional	37.9%	62.1%
Industry	36.5%	63.5%
Government	35.1%	64.9%
Research	29.7%	70.3%

QUESTION 12

Do you use the links provided?

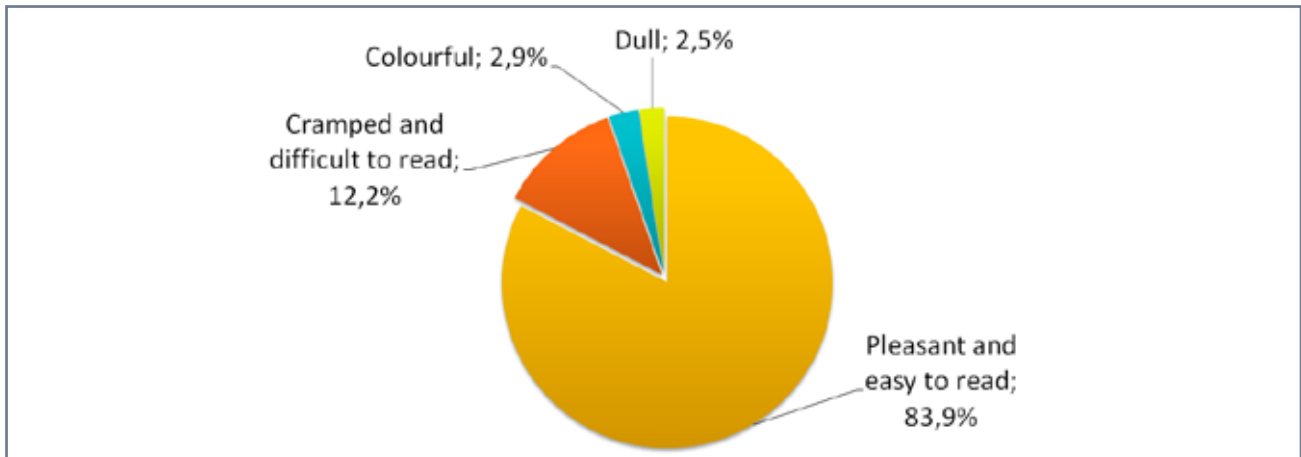
The majority of respondents use the links provided occasionally (58,5%), with a further 38% using these links often. Only 3,5% of respondents replied that they never use the links provided in the newsletter. This shows that respondents actively read the newsletter and find the information provided of interest and pertinence.



QUESTION 13

What do you think of the layout of OrphaNews Europe?

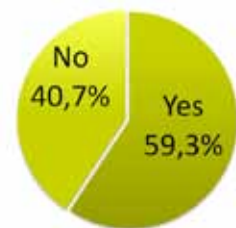
The replies to this question were mainly positive with nearly 84% of respondents judging the newsletter "easy and pleasant to read". Around 12% of respondents remarked that they found the newsletter was cramped or difficult to read. A few respondents remarked that the text of the newsletter is too small, and that the newsletter could benefit from having more photos.



QUESTION 14

Would you be interested in a customised newsletter that targets the topics of most interest to you?

The majority of respondents (nearly 60%) were in favour of a customised newsletter which would target their topics of interest. This is one of the modifications to the newsletter foreseen in the Joint Action contract which supports the publication of the newsletter.



When answers were filtered by type of users, a variation could be seen in the replies given by each category.

CATEGORY OF RESPONDENT	YES	NO
Medical professional	60.1%	39.9%
Research	55.7%	44.3%
Government	43.2%	56.8%
Industry	40.4%	59.6%
Patient	75.7%	24.3%

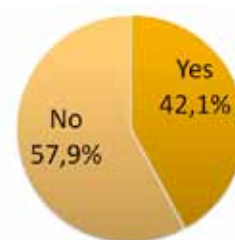
Patients were most in favour of this proposition (75.7%), followed by medical professionals (60.1%), and researchers (55.7%). This is a trend which shows, as do the replies to the open-ended questions, that patients and certain medical professionals/researchers are principally interested in news concerning the disease/diseases relevant to them.

However, the majority of respondents working in the pharmaceutical industry replied “no” (59.6%), as did 56.8% of respondents in the sector of government. This could reflect a preference amongst these groups for receiving the newsletter as a whole in order to monitor both political and scientific aspects of rare diseases and orphan drugs, both of which are relevant to their work.

QUESTION 15

Would you be interested in an RSS feed for OrphaNews Europe?

Around 42% of respondents were interested in an RSS feed for OrphaNews Europe. However, comments from the open-ended question at the end of the survey highlighted that some respondents are not aware of what an RSS feed is.



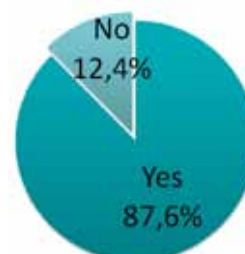
When the replies are filtered by category of user, it can be seen that the category of respondents most in favour of this evolution were patients (48.7% replying "Yes"), and respondents in the industry were least in favour (71.2% replying "No"). Patients' positive response to this proposal could be explained by their interest in being alerted to information concerning their disease as rapidly as possible, whereas readers in Industry perhaps prefer receiving this information in the context of the newsletter.

CATEGORY OF RESPONDENT	YES	NO
Medical professional	41.5%	58.5%
Research	42.7%	57.3%
Government	35.1%	64.9%
Industry	28.8%	71.2%
Patient	48.7%	51.3%

QUESTION 16

Would you be interested in a feature that allows you to search the archives of OrphaNews Europe?

Over 87% of replies were in favour of an archive search facility, one of the developments in store for the newsletter. This will enable readers of the newsletter to find articles of interest to them with greater ease.



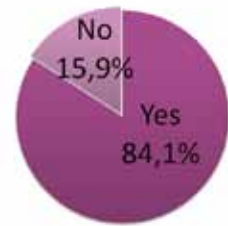
When the results are analysed by category of respondent, it can be seen that patients are most in favour of this measure (92.2%), followed closely by respondents from government (91.9%).

CATEGORY OF RESPONDENT	YES	NO
Medical professional	85.6%	14.4%
Research	88.5%	11.5%
Government	91.9%	8.1%
Industry	84.6%	15.4%
Patient	92.2%	7.8%

QUESTION 17

Would you be interested in a joint European-USA edition of OrphaNews?

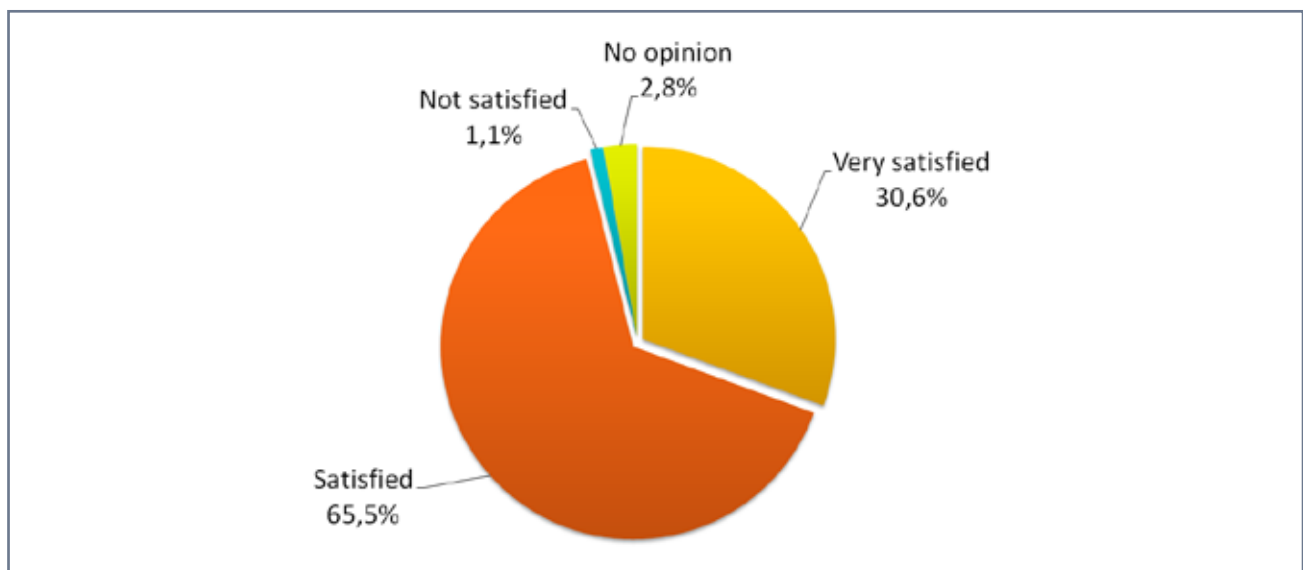
84% of replies were in favour of a joint European-USA edition of OrphaNews, which echoes comments made in the survey to open-ended questions calling for more news from the USA. Some respondents, in the comments section at the end of the questionnaire, would like a European-Northern American edition of the newsletter (i.e. USA and Canada), and others are keen to see OrphaNews Europe available in their own language (Italian and Spanish were the two languages cited).



QUESTION 18 & 19

Overall, what is your level of satisfaction with the quality of OrphaNews Europe? Do you have any other comments?

After having removed the number of respondents who answered “no opinion” (30 respondents) to Question 18, 98% of respondents were either very satisfied (31.5% once “no opinion” had been removed) or satisfied (67.3% once “no opinion” had been removed) with the quality of the newsletter. Only 12 respondents (1.1% once “no opinion” had been removed) said they were not satisfied.



33 respondents added comments and thanks in the “comments” section of Question 18: these comments emphasised that respondents wish for OrphaNews Europe to develop the “international” dimension of the newsletter, and to explore the possibility of publishing the newsletter in other languages. Other comments highlighted the usefulness of multiple RSS feeds and archive search facilities.

Respondents were given the opportunity to submit any other comments or suggestion at the end of the survey: in addition to the aforementioned comments received from Question 18, over 30 users left words of thanks, whilst others made suggestions concerning the format and the content of the newsletter. Amongst the comments left in this last section were: a suggestion for regular analytical articles comparing the USA and Europe; more analysis of rare disease projects and their impact; a suggestion to combine forces with the newsletter CanGeneTest; requests for a newsletter covering all of North America; requests for more prominence to be given to patient organisations and patient testimonies; and requests for as much information as possible in the newsletter even if this increases the length of the newsletter.

Respondents are on the whole satisfied with the quality and content of OrphaNews Europe: although the field of rare diseases and orphan drugs is vast, many acknowledged that OrphaNews Europe does an excellent job in selecting and publishing news on scientific and political developments in the field of rare diseases in order to inform all stakeholders of the state of the art in the field. One comment from a reader in North Africa echoed the spirit of many respondents who left comments: "Long life to OrphaNews and its staff!"



Conclusion

The results of the survey have helped the OrphaNews team to evaluate the expectations and needs of readers. Many improvements are planned in 2011 that will fulfill some of the requests made by respondents: the first is an archive search function, which will make it easier to find OrphaNews articles relevant to a certain disease, organ system or political topic; the next is the possibility for readers to customise their subscription by choosing which sections of the newsletter they wish to receive; the third development is the possibility to subscribe to an RSS web feed that will enable readers to be alerted of the publication of the latest articles of interest to them. The possibility of creating a Europe-USA version of the newsletter is also being explored. These developments aim to enable OrphaNews Europe to best fulfill its mission of providing quality information to the rare disease community on scientific, political, social, ethical and legal developments in this vast field.

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

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