2019 OrphaNews Reader Satisfaction Survey

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Methodology

In the framework of the Orphanet's quality management system, Orphanet seeks the level of satisfaction of its users with the services provided. This is conducted through an annual satisfaction survey conducted in two stages (please consult the Orphanet Report presenting the results for more information on the methodology of the main survey).

In the context of this exercise, it was also decided to investigate the level of satisfaction of OrphaNews readers with the newsletters provided. The readers of OrphaNews were sollicited to reply

to a short questionnaire in the first semester of 2019. The survey was addressed to readers of the international and the French editions, through a publication in the newsletter, and via social medial channels. In total 89 users replied to the questions concerning the newsletter OrphaNews.

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

Results

Question 1: Who are you?

The respondents were asked in what capacity they were replying to the survey: 29% were health care professionals, 22% were patients or their families or patient organisation representatives, and 21% were researchers.
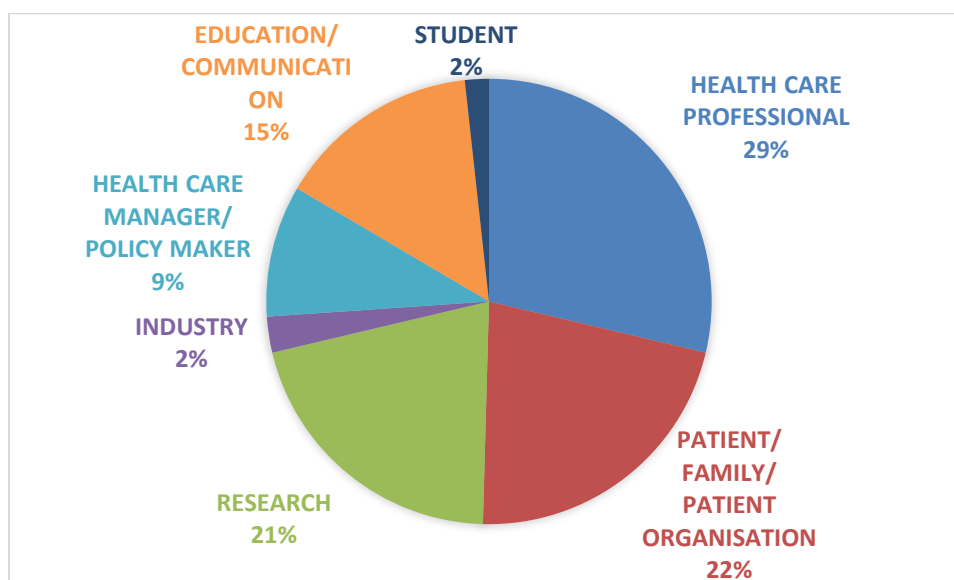

FIGURE 1 USERS REPLYING TO THIS SECTION OF THE SURVEY (N=89)

Question 2: How often do you open the OrphaNews newsletter?

This question was aimed at ascertaining the reading habits of subscribers to the newsletter. Only one response was possible. The results show that 83% of the 89 respondents open the newsletter at reception of every edition. The second most popular option, but with only 11% of responses was once a month.
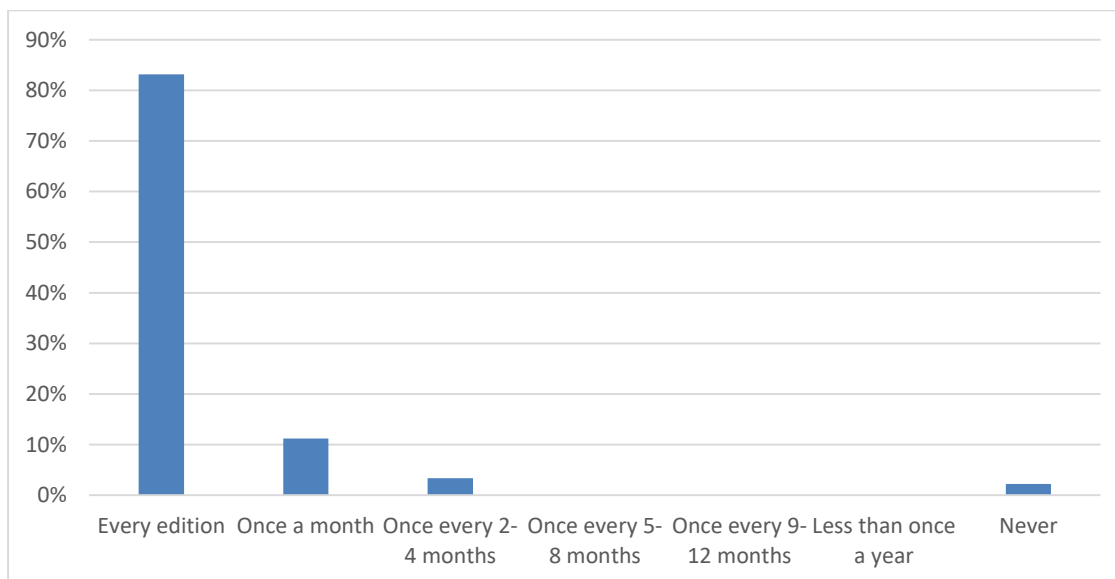
FIGURE 2 FREQUENCY AT WHICH RESPONDENTS OPEN THE NEWSLETTER (N=89)

Question 3: How interested are you in the following sections of the newsletter?

This question was aimed at investigating the level of interest of respondents for each of the main sections of the newsletter. The results show that 97% users are either highly interested or quite interested in the scientific news section, this percentage dips to 81% for the editorial and 76% for the political news, and descends to 49% for the jobs, grants and press section.
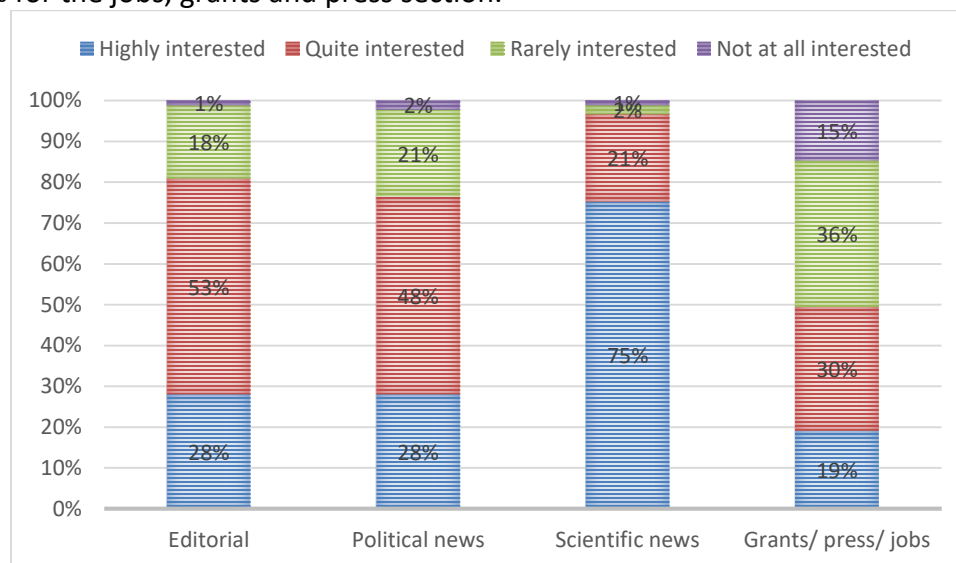

FIGURE 3 INTEREST FOR EACH OF THE MAIN SECTIONS OF THE NEWSLETTER (N=89)

Question 4: To what extent do you agree with these descriptions of OrphaNews?

This question was aimed at assessing respondents' views concerning a number of statements about the newsletter. They were able to choose one response for each statement from 'strongly agree', 'agree', 'disagree' and 'strongly disagree'. The responses showed a highly favourable view of the newsletter. 96% of respondents agreed that what they learn from OrphaNews is useful in the professional/personal capacity, and 98% thought that OrphaNews is well researched and written. In terms of the newsletter providing up-to-date information, 97% agreed that the scientific news was up-to-date (with 53% strongly agreeing), and 96% agreeing that the political news was up to date. In terms of the ease of consultation and readability of newsletter, 85% agreed that the format was easy to consult and read: this statement garnered more negative responses than the other statement (13% disagreed, and 1% strongly disagreed).
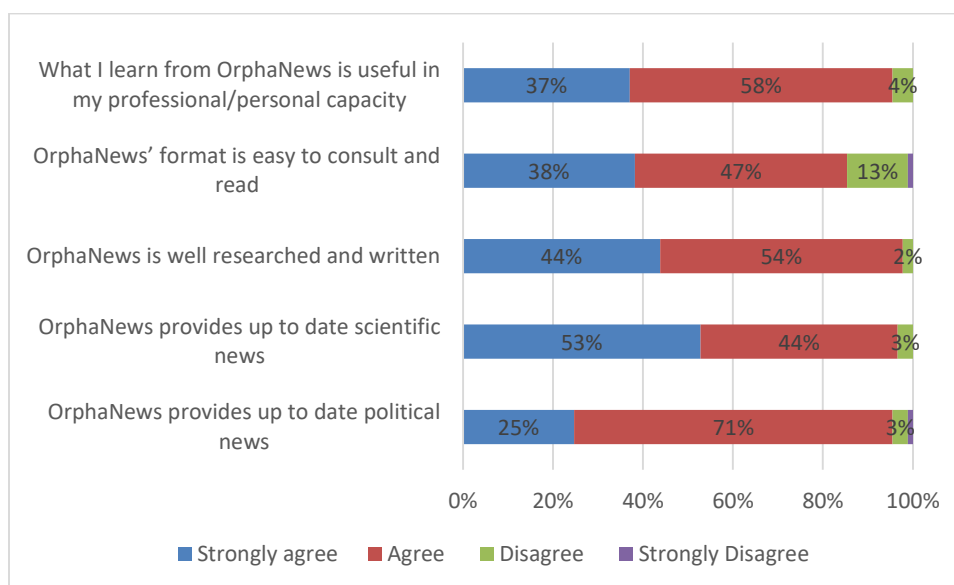
FIGURE 4 AGREEMENT OF RESPONDENTS TO STATEMENTS ABOUT THE NEWSLETTER (N=89)

Question 5: Do you use the search functions of the newsletter?

Respondents were asked if they used, or not, one of the search functions of the newsletter: archive search, simple search, advanced search or none of the above. A single choice was possible. The results show that just over half of respondents do not use the search options (52%). Of those that do, most use the simple search option (21%), followed by searching the archives with the index (19%), and only 8% of respondents use the advanced search/search by thesaurus. This feature was added when the newsletter was relaunched in a new format in 2017.
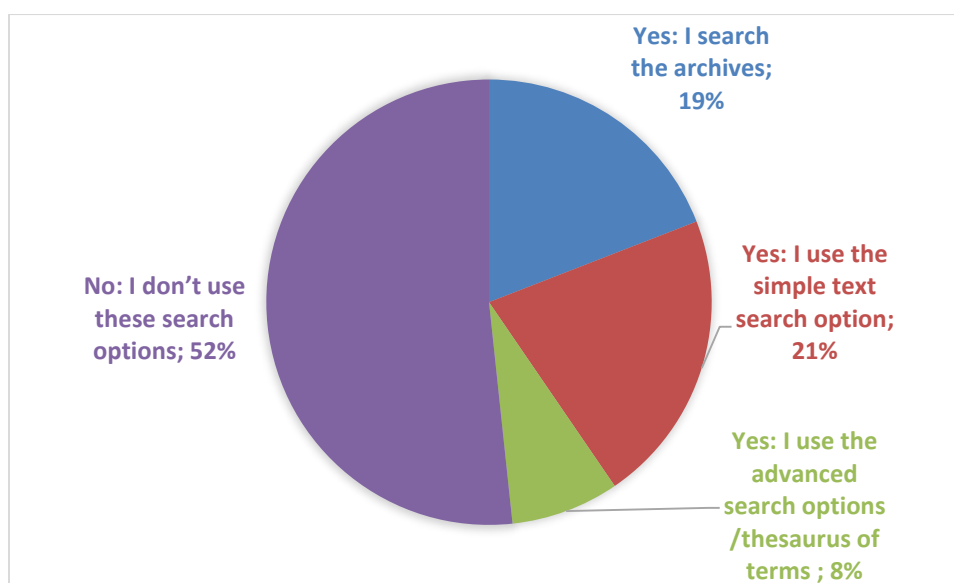
FIGURE 5 USE OF SEARCH FUNCTIONS (N=89)

Question 5: What do you think about the simple search/advanced search functions?

The respondents who answered that they used the simple or advanced search functions were asked to give their opinions on the ease of finding and using the search functions. They were able to choose one response for each statement from 'strongly agree', 'agree', 'disagree' and 'strongly disagree'. 18 respondents replied to the simple search question, and 7 to the advanced search question. The replies showed that the 94% respondents agreed that the simple search option was easy to find, and 86% agreed that the advanced search option was easy to find. In terms of ease of use, 89% found the simple search easy to use, and 100% found the advanced search easy to use. However, the small sample size for this question makes the data difficult to interpret, as we cannot eliminate the possibility that users may not use the search options (and thus have answered the previous question with a negative response) as they may be hard to locate and/or use.
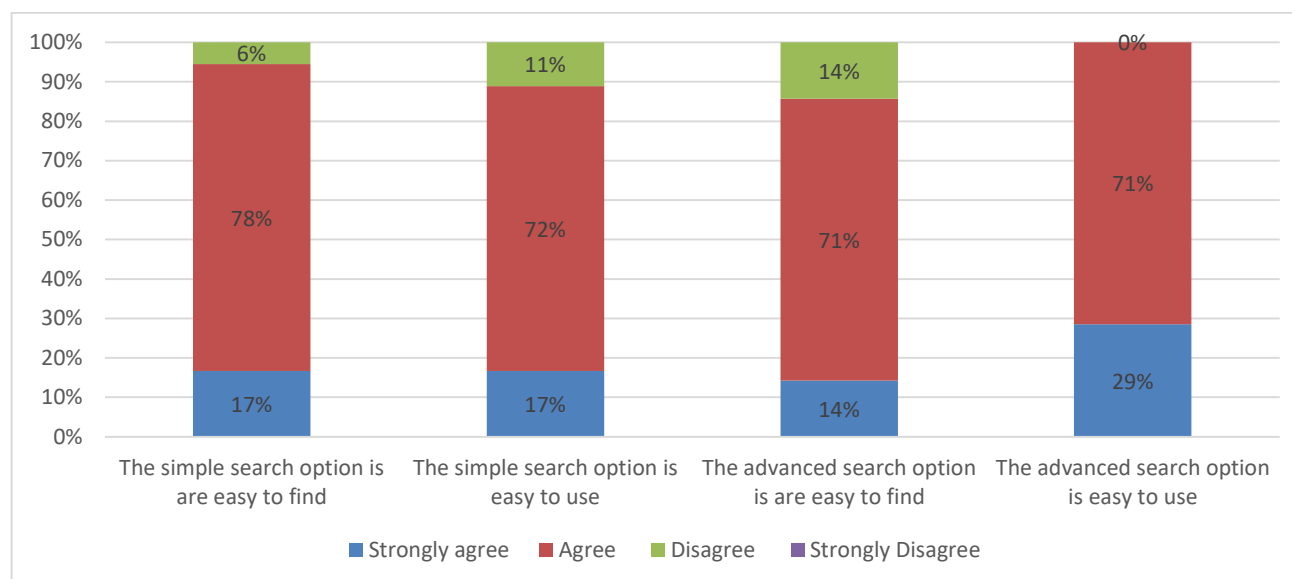
FIGURE 6 VIEWS ON THE EASE OF FINDING AND USING THE SIMPLE AND ADVANCED SEARCH FUNCTIONS (N= 18 FOR SIMPLE SEARCH, N=7 FOR ADVANCED SEARCH)

Question 5: How pertinent do you find the results to be?
The respondents who answered that they used the simple or advanced search functions were asked to give their opinions on the pertinence of the results obtained. Of the 18 respondents using the simple search function, 94% found the results obtained to be pertinent. Of the 18 respondents using the advanced search function, 100% found the results obtained to be pertinent. However, the small sample size means that we must apply the same caveat as for the responses to the previous question.

Question 6: How likely is it that you would recommend OrphaNews newsletter to a friend or colleague?
This question was asked in order to determine OrphaNews' Net Promotor Score (NPS), which measures the

likelihood, on a 1-10 scale, that someone will recommend a company to someone else. The Net Promoter Score was calculated by subtracting the percentage of customers having ranked this probability from 0 to 6 from the percentage of customers having ranked this probability from 9 to 10. Thus, results can vary from -100 to +100.

The average score was 7.6/10 in this exercise. The net promoter score was also calculated, giving a score of 14. Orphanet as a whole scored 47.8.

Question 7: How could OrphaNews better serve your needs (e.g. subjects reported on, technical evolutions)?

This open question was responded to by 31 respondents. Some respondents gave words of encouragement or congratulations, others said they needed no changes. Some asked for features that already exist (such as news on orphan drug approvals) perhaps meaning that they do not easily find this information, perhaps as the newsletter is quite long, or perhaps because columns are not named in the most appropriate manner: we will investigate this further when we repeat this exercise. Some comments were directed at Orphanet the database and not the newsletter. In addition, one comment asked for open access to cited articles; this unfortunately is beyond the remit of OrphaNews, but Orphanet does try to establish collaborations to provide access to quality open-access articles on rare diseases from its website.

There were requests for translations of the newsletter into different languages: the newsletter is translated by Orphanet country teams when a national budget is available. The tool is available if a country wishes to translate the newsletter. Some respondents remarked that the email received to access the newsletter could have more text so that the reader can better understand what parts concern them, and that they prefer the view on the website. One reader found the text on the site to be too small, with too much white space. One person wished to see more graphical elements, such as tables and videos.

A French respondent remarked that they would like to have all the scientific news translated into French: due to the sheer volume of publications, a choice has been made to only translate part of the scientific news into French, but we will evaluate if more resources become available. One person found that the scientific section was too technical for a lay person to understand, as this is not the primary audience of this section. There was a suggestion to relay news in a flash format when there is an important evolution in the field: this will be considered as it could be highly useful for the community.

All these suggestions will be considered to see what can be put into action to improve the newsletter.

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

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http://www.orpha.net/orphacom/cahiers/docs/GB/OrphaNews_survey2019.pdf