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2022 User Satisfaction Survey of OrphaNews

www.orpha.net

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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. 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 International were solicited to respond to a short questionnaire in the first semester of 2022. The survey was addressed to readers of the international newsletter through a publication in the newsletter, and via social medial channels.

In total 69 users replied to the questions concerning the newsletter OrphaNews.

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

OrphaNews is realised with the support of Fondation IPSEN, under the aegis of Fondation de France, as was this study.

Results

Question 1: Who are you?

The respondents were asked in what capacity they were replying to the survey: 38.81% were healthcare professionals, 17.91% were patients or their families or patient organisation representatives, and 28.36% were researchers.

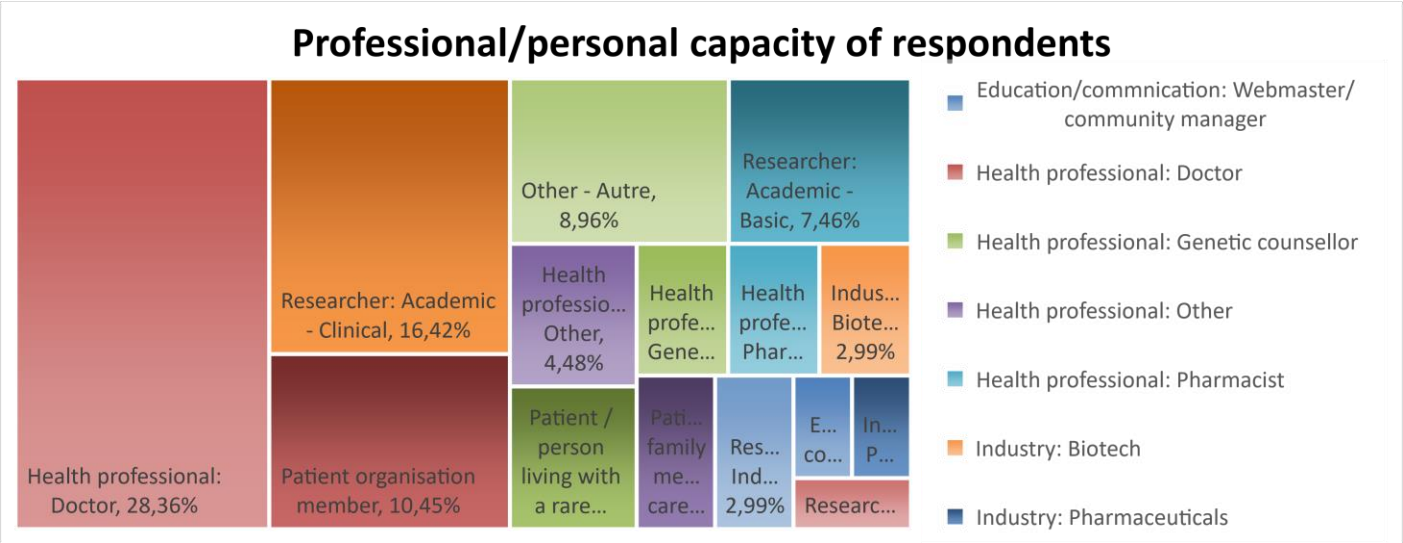


FIGURE 1 RESPONDENTS' CAPACITY (N=67)

The respondents were asked in which country they were when replying to the survey. The range of countries represented is very broad, with 23.88% from Italy, 13.43% from Spain, and 11.94% were from France.

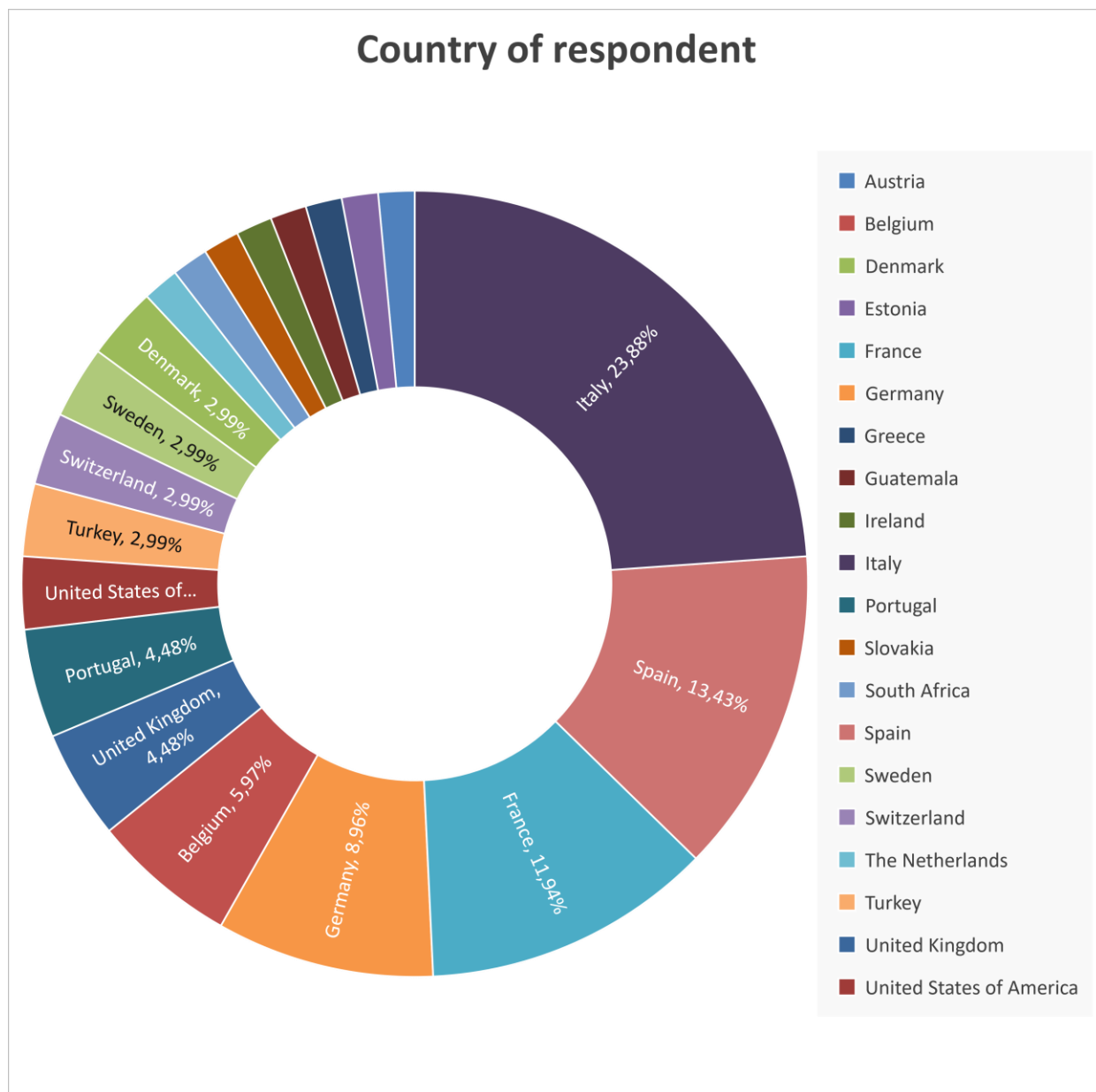


FIGURE 2 COUNTRY OF RESPONDENT (N=67)

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

This question was aimed at ascertaining the reading habits of subscribers to the newsletter. The results show that 85.51% of the 69 respondents open the newsletter at reception of every edition. The second most popular option, but with only 8.70% of responses was once a month.

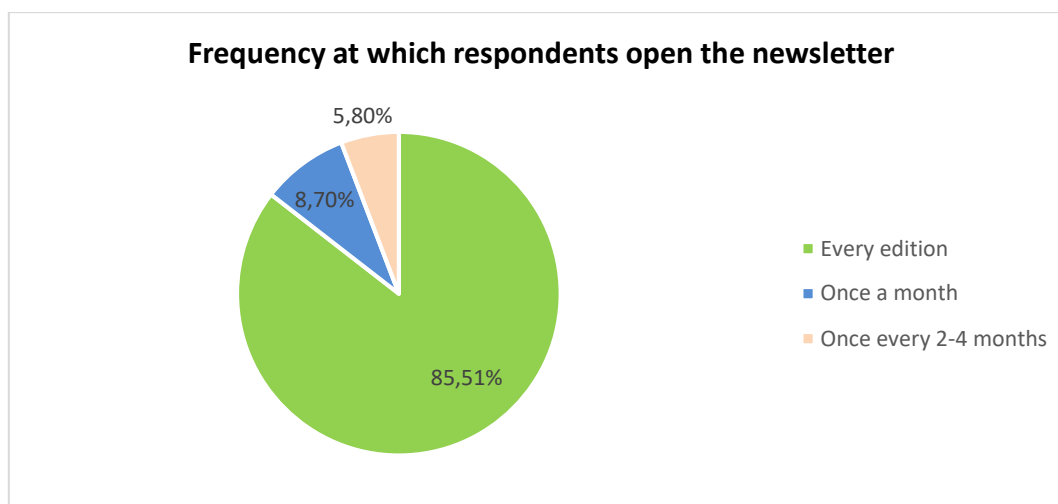


FIGURE 3 FREQUENCY AT WHICH RESPONDENTS OPEN THE NEWSLETTER (N=69)

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 98.55% respondents are either highly interested or quite interested in the scientific news section, this percentage dips to 84.06% for the Orphanet News and 76.81% for the European Reference Network news, and descends to 73.91% for the Editorial, and finally 71.01% for the Political

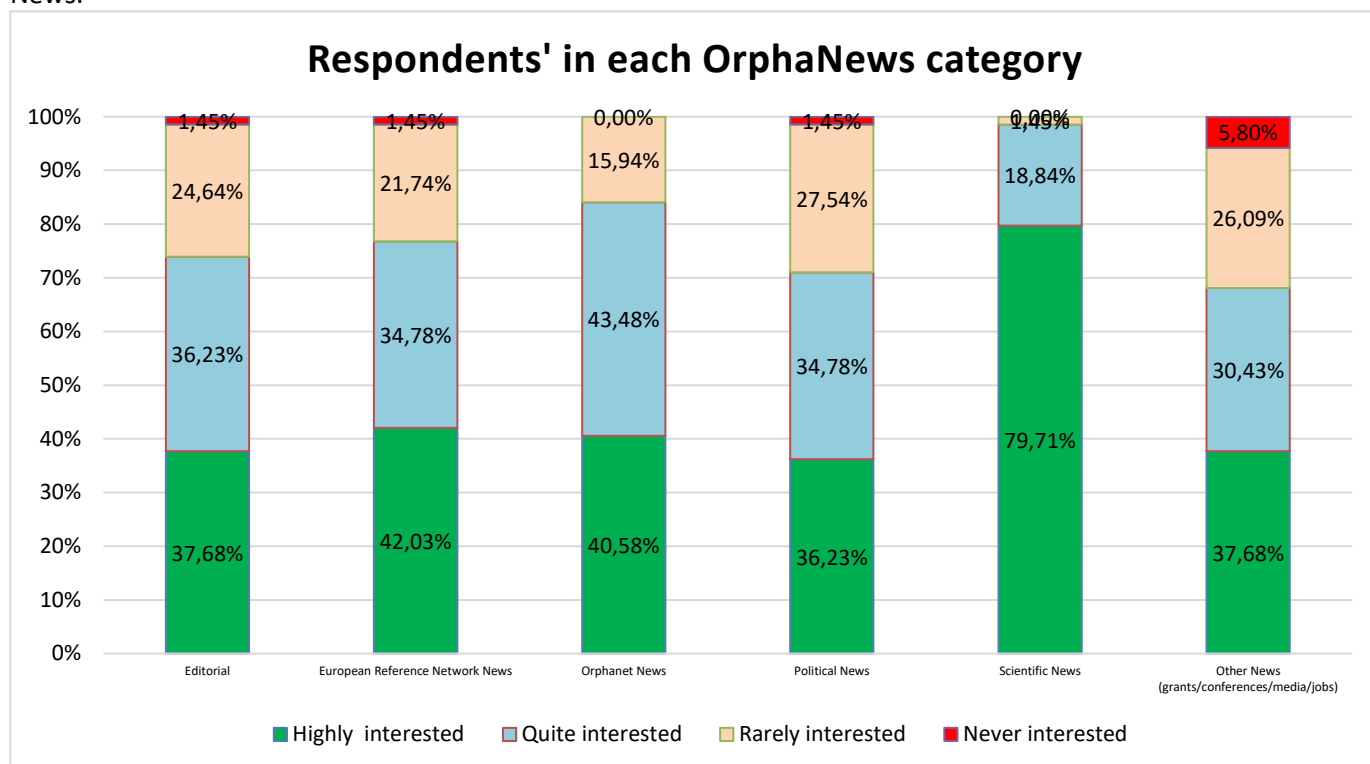


FIGURE 4 INTEREST FOR EACH OF THE MAIN SECTIONS OF THE NEWSLETTER (N=69)

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. 95.65% of respondents agreed that what they learn from OrphaNews is useful in the professional/personal capacity, and 97.1% thought that OrphaNews is well researched and written. In terms of the newsletter providing up-to-date information, 91.3% agreed that the political news was up to date. In terms of the ease of consultation and readability of newsletter, 86.96% agreed that the format was easy to consult and read: this statement garnered more negative responses than the other statement (5.8% disagreed, and 7.29% strongly disagreed). Regarding the adequate provision of reports on rare disease news from different geographical zones of the newsletter, 92.75% agreed.

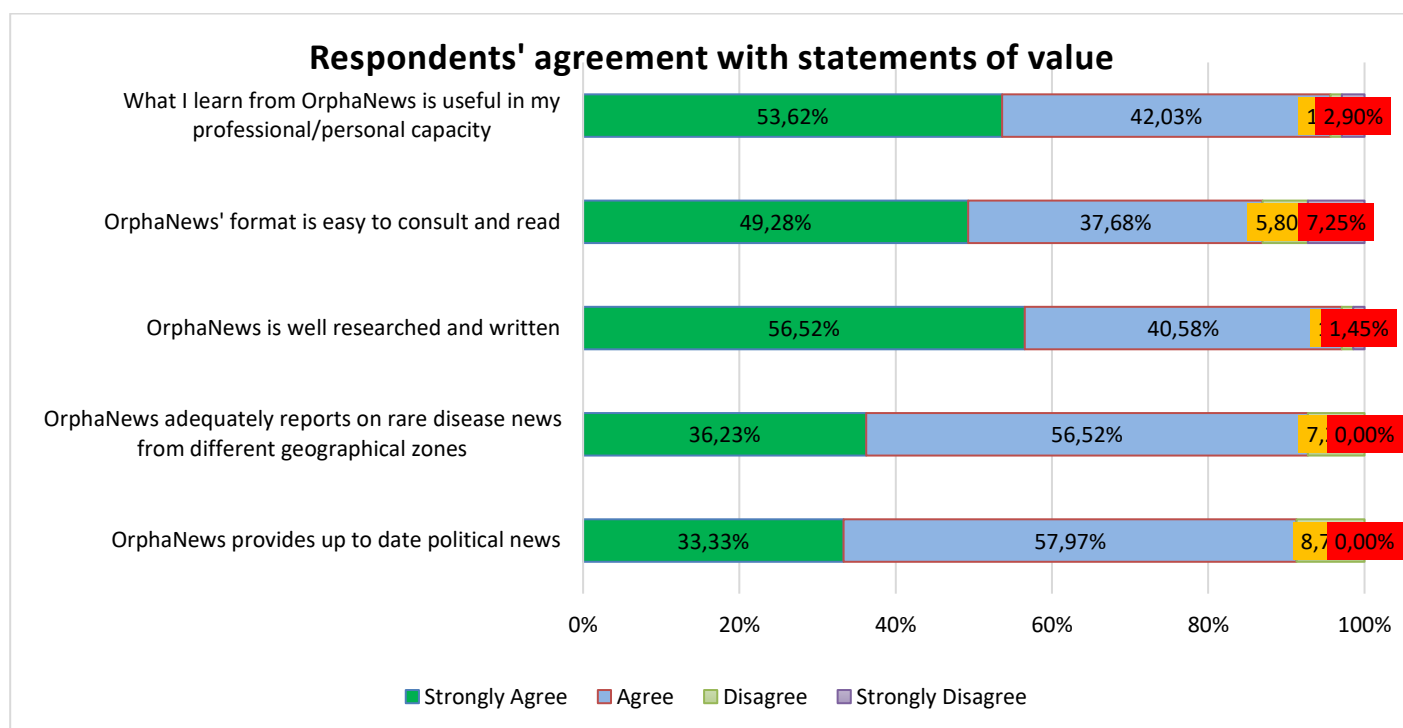


FIGURE 5 AGREEMENT OF RESPONDENTS TO STATEMENTS ABOUT THE NEWSLETTER (N=69)

Question 5: Do you know about the COVID-19 collection?

Overall, 68.12% of respondents know of the collection of resources provided by OrphaNews concerning [rare diseases and COVID-19](#), however, only 23.19% have used it in the past.

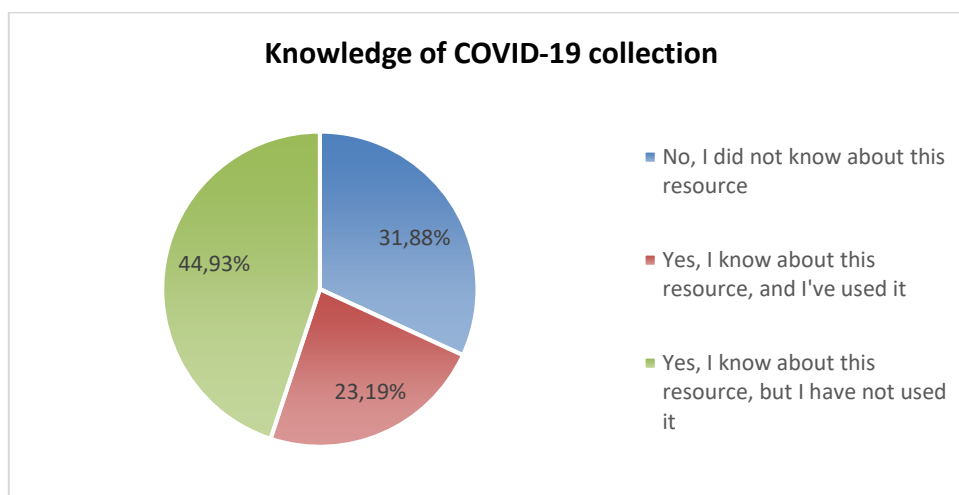


FIGURE 6 KNOWLEDGE OF THE COVID-19 COLLECTION (N=69)

Question 6: 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'. For the simple text search option: 63 respondents replied to the easiness of finding the option, while 55 answered to the ease-of-use question. For the advanced search/thesaurus of terms ease of finding the option and ease of use, 56 and 53 respondents replied respectively. The replies showed that the 55.56% respondents agreed that the simple search option was easy to find, and 53.57% agreed that the advanced search option was easy to find. In terms of ease of use, 56.37% found the simple search easy to use, and 54.71% found the advanced search easy to use. It is important to note that 32.73%-35.71% of participants did not know about or use these functionalities.

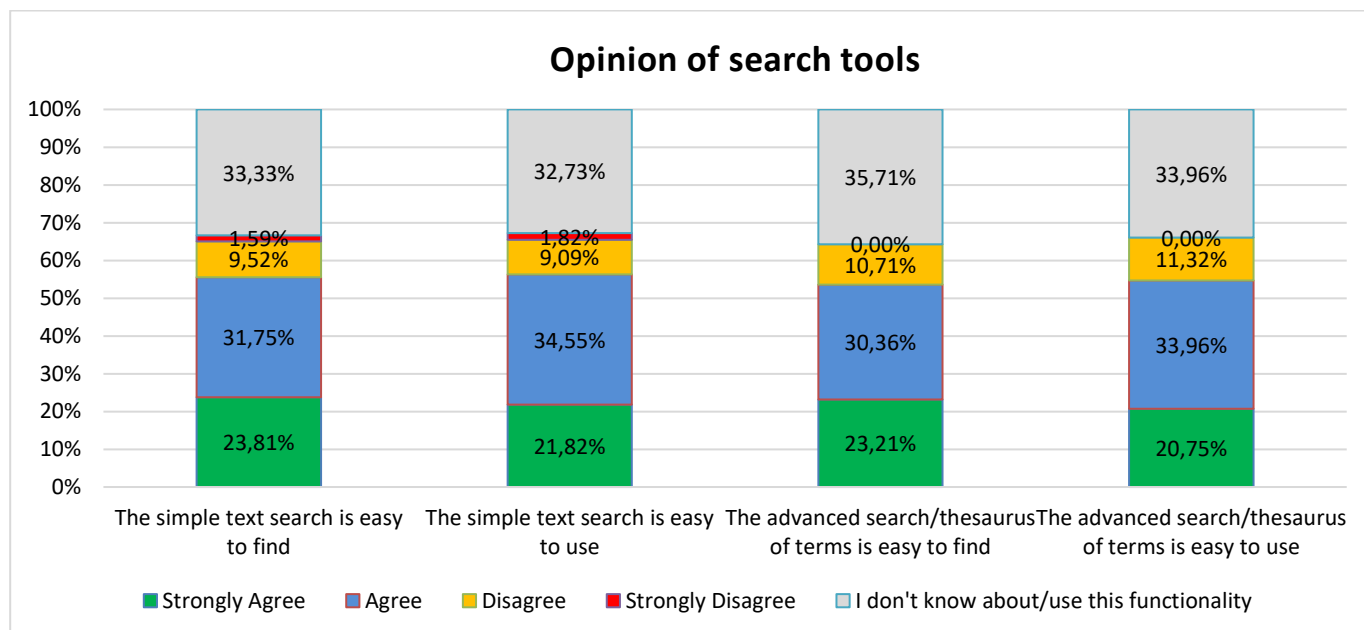


FIGURE 7 VIEWS ON THE EASE OF FINDING AND USING THE SIMPLE AND ADVANCED SEARCH FUNCTIONS (SIMPLE SEARCH: N=55 – 63; ADVANCED SEARCH: N=53 – 56)

Question 7: How pertinent do you find the results to be?

Respondents were then asked about the pertinence of the results provided by a simple or advanced search. For the simple search 42.65% found the results obtained to be pertinent. For the advanced search function, 36.76% found the results obtained to be pertinent. However, 51.47% to 55.88% of respondents have not used these functionalities.

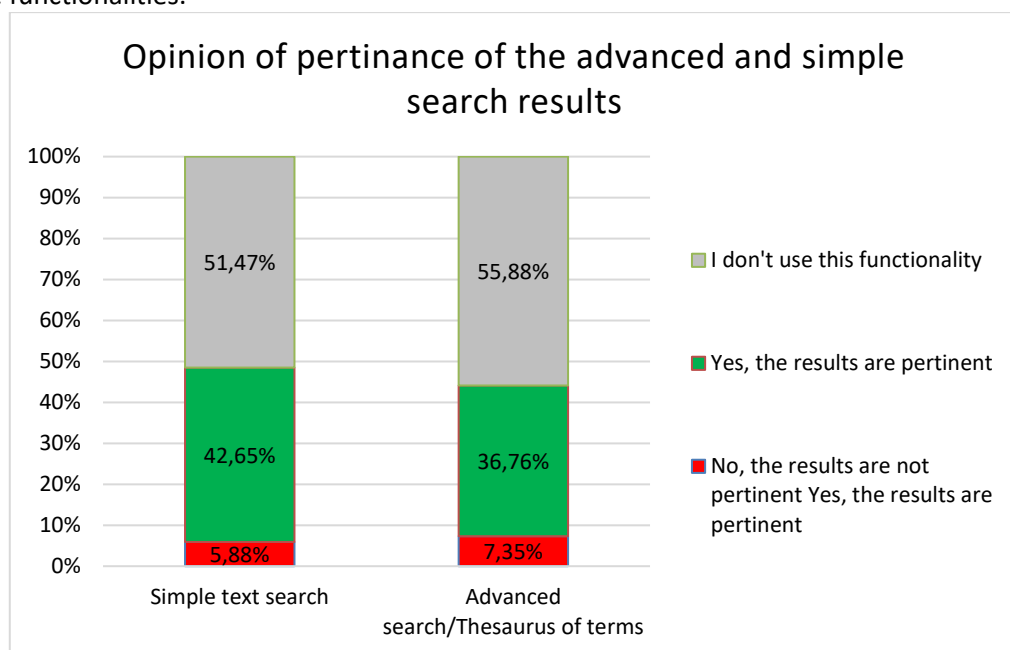


FIGURE 8 VIEWS ON THE PERTINENCE OF THE ADVANCED AND SIMPLE SEARCH RESULTS (N=68)

Question 8: How likely is it that you would recommend OrphaNews newsletter to a friend or colleague?

Respondents were asked to assess using a scale of 0-10, the likelihood that they would recommend the OrphaNews newsletter to a friend or colleague. The average score was 8.47/10, nearly one point higher than our previous survey in 2019. The net promoter score was also calculated, giving a score of 46.3.

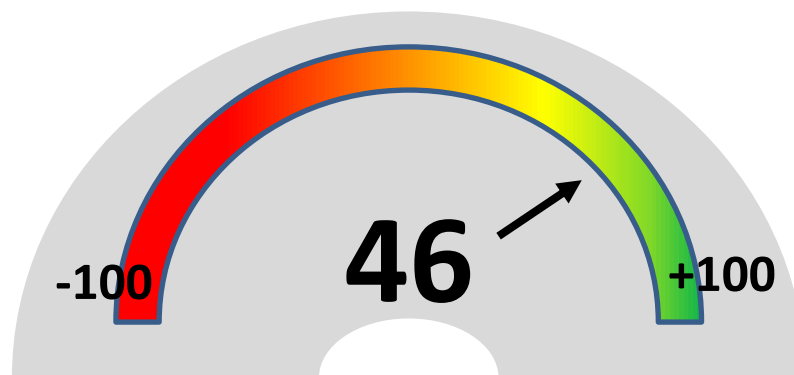


FIGURE 9 NET PROMOTOR SCORE GAUGE

Question 9: How could OrphaNews better serve your needs (e.g. subjects reported on, technical evolutions)?

This open question was responded to by 27 respondents.

Some asked for features that already exist perhaps meaning that they do not easily find this information, perhaps as the newsletter is quite long, or perhaps because articles could be better categorised within the newsletter. One addition to the website that was asked for was the inclusion of a library to revisit previous articles. However, it was unclear if this comment referred to a library of OrphaNews articles (an archive already exists as does a search function) or if it referred to a library of the publications cited in OrphaNews.

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, and a PubMed query by disease is linked from each disease page in Orphanet.

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, as well as including a summary of each article in the body of the email. We will consider this within our general reflection around the improvement of the format of the newsletter, but we also have to maintain brevity in the email as there are a large number of articles in each edition.

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.

Several comments about the user-friendliness of the newsletter were made, stating it was confusing, and that implementing a smarter reading format along with categorising better the articles would make for a

better user experience. Specifically, it was deemed difficult access the article links and return to the main menu.

A suggestion was to include a section to better understand the interaction between the political, pharmaceutical and scientific matters, which could be included in the Editorial. Another responder requested for a “Best Practice” section which does not have to be related to the ERN, which can focus more on the point-of-view and interview of the stakeholder regarding future perspectives: best practices, whether clinical or other, are currently included in different sections of the newsletter. Finally, it was advised to highlight technical developments and progress in rare diseases in the Newsletter: we aim to cover news on rare diseases across various domains, from policy, to science, to informatics but we will endeavour to widen the scope of publications reviewed for the newsletter as new domains emerge.

There were two criticisms regarding the exhaustiveness of the newsletter, one regarding the inclusion of all the ERN as opposed to a couple of them, while the other focused on the amount of articles centred on Europe and the United States compared to the quantity of articles on the rest of the world. OrphaNews carries out a bi-monthly scanning of ERN communication channels across all ERNs and is open to direct submissions from ERNs. As ERN activity develops and increases we hope to have more news to report on. We will also endeavour to capture rare disease news outside of Europe and the USA; our literature review already includes the websites and social media accounts of patient alliances across the world and our review of peer-reviewed publications is not limited by geographic region, but there is room for improvement.

One person looked for news on a specific rare disease but could not find them; thus implementing an easier way to be alerted when articles regarding a specific condition are published could be beneficial to readers. It could be that there were no updates in that period in the scientific literature for that specific disease.

Suggestions regarding the scientific section of the newsletter included suggestions that were perhaps more directed for the Orphanet database, and will be forwarded to the appropriate team members.

Finally, some remarks included the creation of a LinkedIn account to increase the number of readers, the increase in timeliness in pointing out research grant opportunities, and finally the increase in the number of papers analysed (on new genes and new disorders).

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

Conclusions

Though the feedback gathered during this survey is majoritarily positive, the respondents (69 in total) are only a small sample of nearly 12 000 subscribers to OrphaNews International and the representativity of OrphaNews’ readership cannot be guaranteed. For example, the number of respondents who open the newsletter every time they receive it reported in the results of the survey (85%) is far superior to the around 20% of letters opened at each dispatch of the newsletter. The points of view expressed in this survey, the very constructive feedback received, unfortunately may not reflect the opinion of all of our readers, as the most motivated readers are presumably those who have taken the time to reply.

Nonetheless the comments and input received will be duly considered in future decisions concerning the newsletter.

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

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