



December 2023

## 2023 User Satisfaction Survey of OrphaNews

[www.orpha.net](http://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 at the end of 2023. The survey was addressed to readers of the international newsletter through a publication in the newsletter, and via social medial channels.

In total 53 users replied to the questions concerning the newsletter OrphaNews.

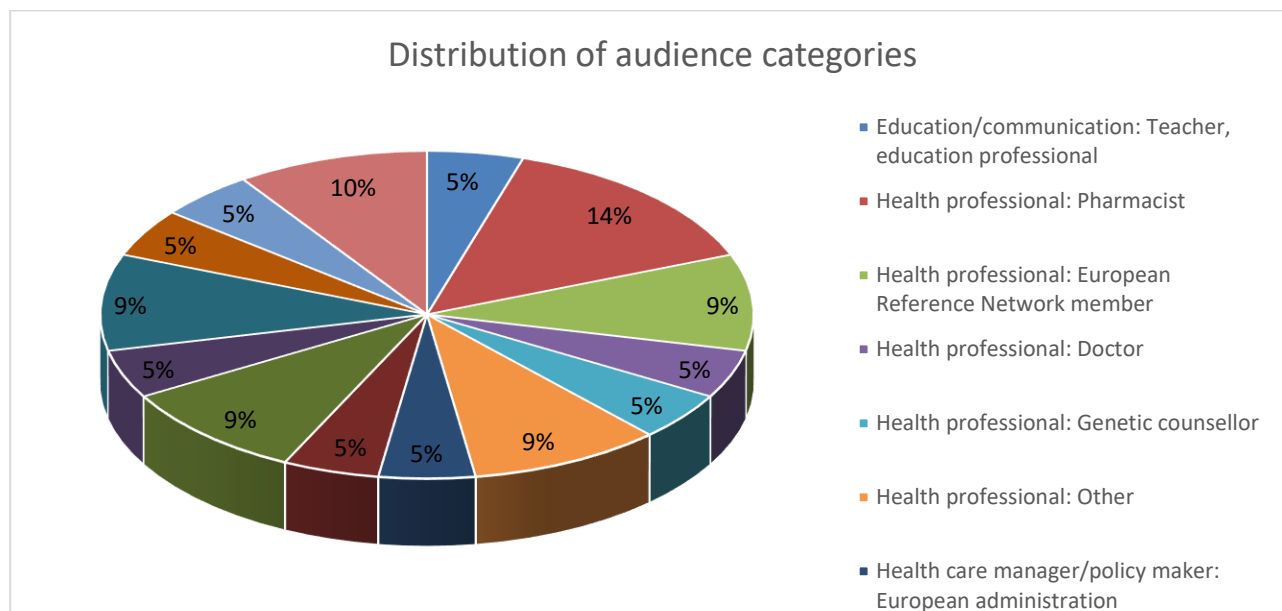
For any questions or comments, please contact us: [media.orphanet@inserm.fr](mailto:media.orphanet@inserm.fr)

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## Results

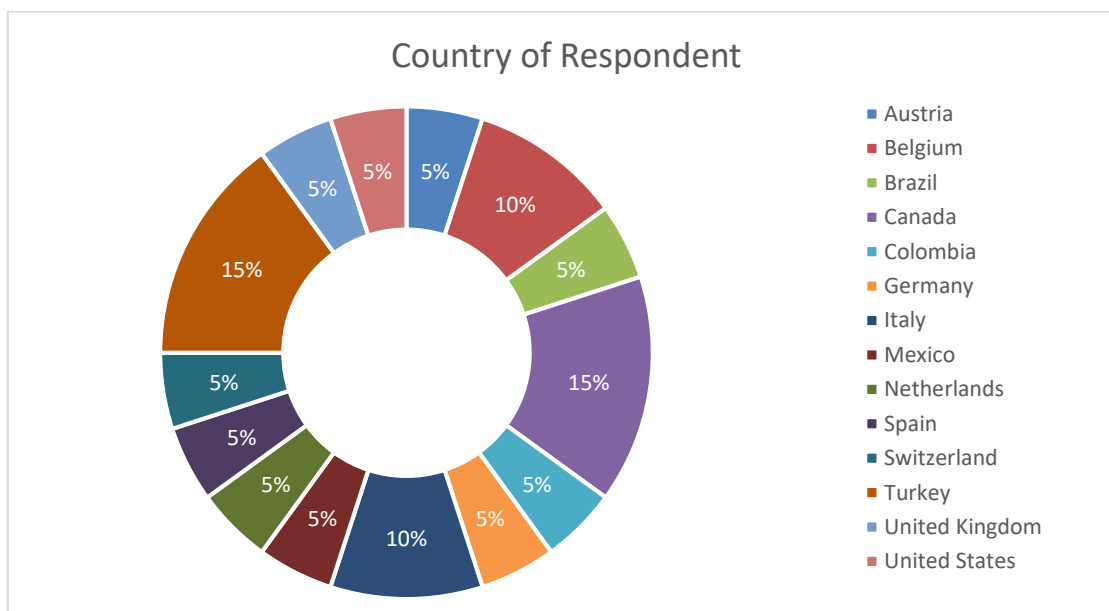
### Question 1: Who are you?

The respondents were asked in what capacity they were replying to the survey: 42.9% were healthcare professionals, 19.1% were patients or their families or patient organisation representatives, and students and others each made up 9.5% of responses.



**FIGURE 1 RESPONDENTS CATEGORIES (N=21)**

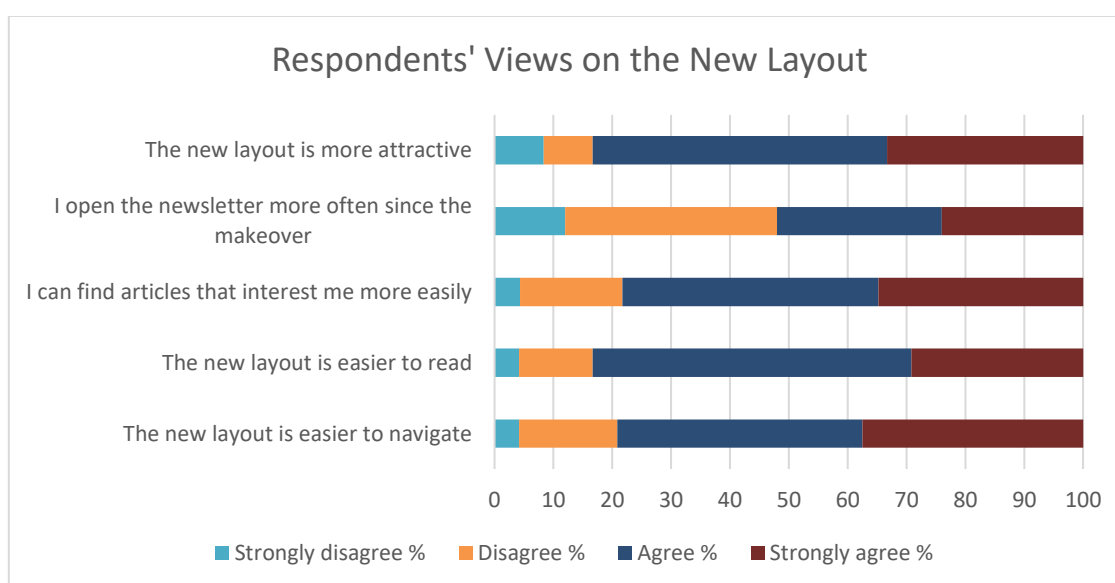
The respondents were asked in which country they were when replying to the survey. The range of countries represented is very broad, with 15% from both Canada and Turkey, and 10% from both Belgium and Italy.



**FIGURE 2 COUNTRIES OF RESPONDENTS (N=20)**

## Question 2: To what extent do you agree with these descriptions of the new layout?

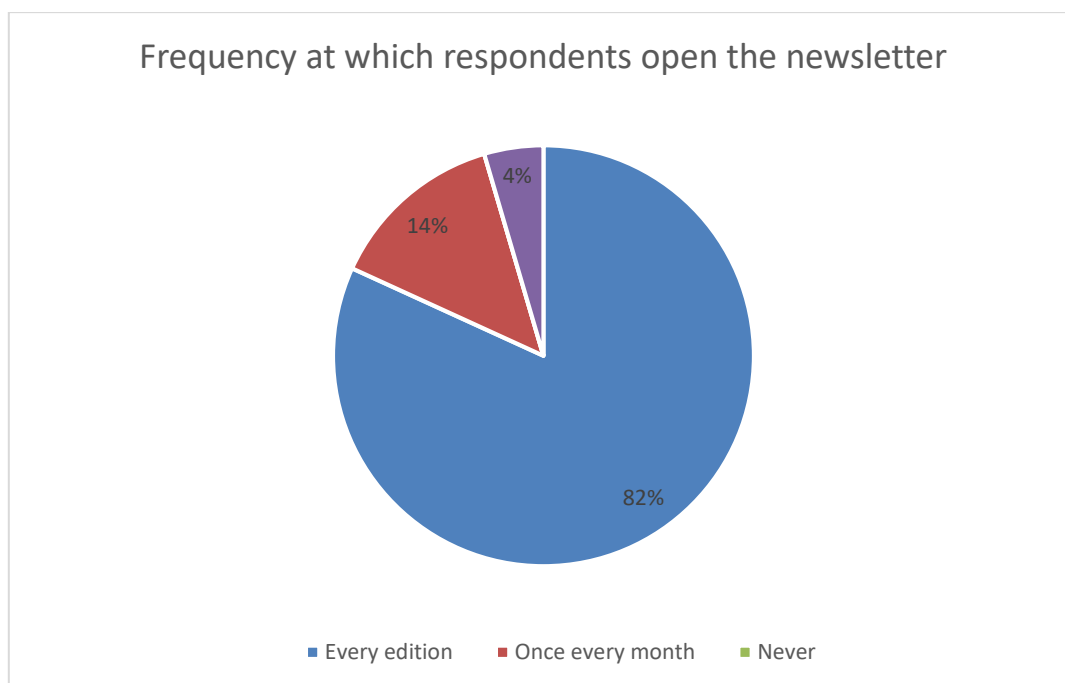
In August 2023, OrphaNews introduced an updated layout based on the results from the 2022 Reader Survey, where respondents highlighted that the old format was difficult to navigate. This question was aimed at assessing respondents' views concerning a number of statements about the new layout. They were able to choose one response for each statement from 'strongly agree,' 'agree,' 'disagree' and 'strongly disagree.' The responses were largely favourable, with 83% agreeing that the format was both more attractive and easier to read. 79% agreed that it was easier to navigate, and 78% said that they could find articles that interested them more easily. However, only 52% of respondents reported opening the newsletter more often since the update.



**FIGURE 3 AGREEMENT OF RESPONDENTS ON STATEMENTS ABOUT THE NEW LAYOUT (N=22)**

### Question 3: How often do you open the OrphaNews newsletter?

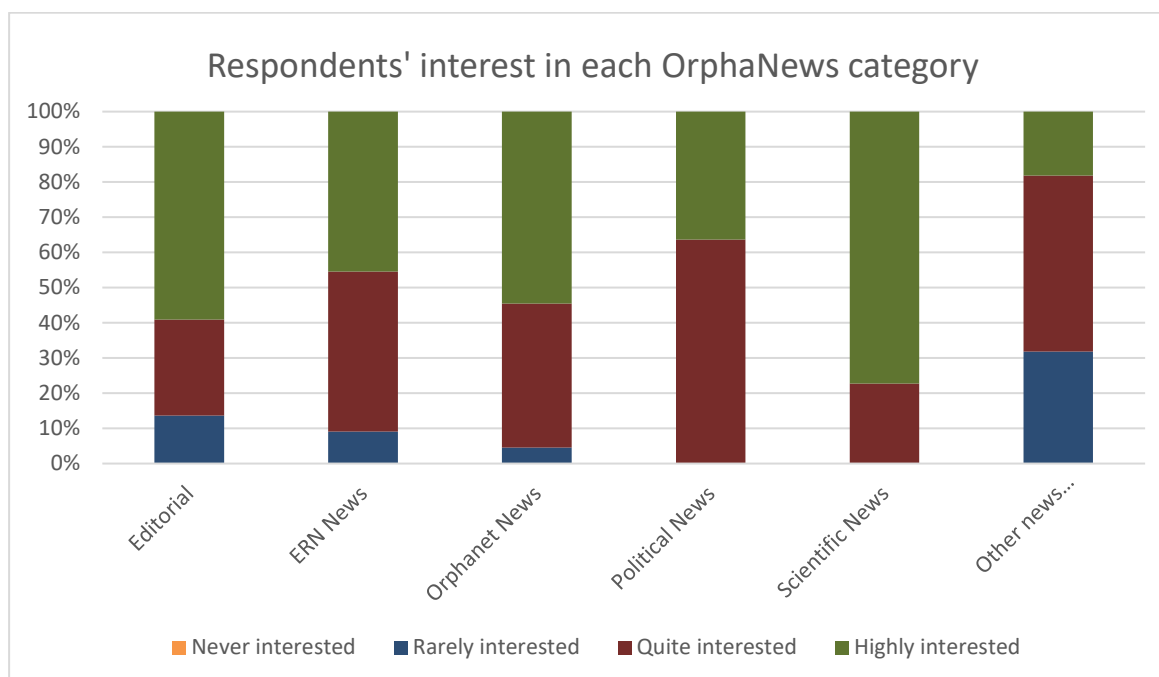
This question was aimed at ascertaining the reading habits of subscribers to the newsletter. The results show that 81.8% of the 22 respondents open the newsletter at reception of every edition. The second most popular option, but with only 13.6% of responses was once a month.



**FIGURE 4 FREQUENCY AT WHICH RESPONDENTS OPEN THE NEWSLETTER (N=22)**

#### Question 4: How interested are you in the following sections of the newsletter?

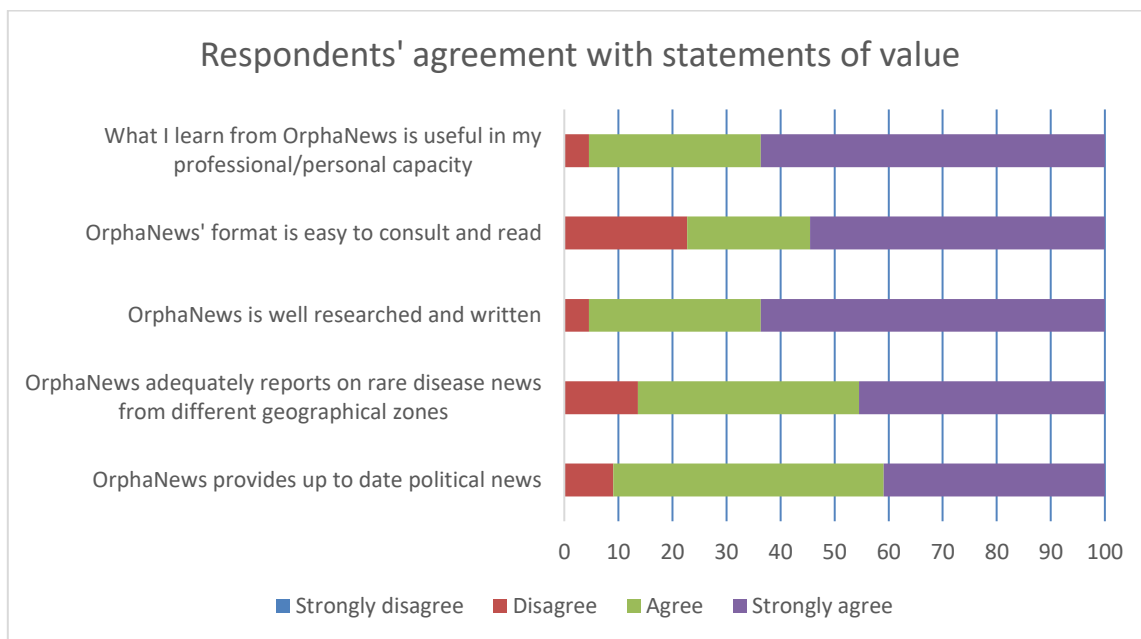
This question was aimed at investigating the level of interest of respondents for each of the main sections of the newsletter. The results show that all respondents are either highly interested or quite interested in both the scientific and political news sections; this percentage dips to 95% for the Orphanet News and 91% for the European Reference Network news, and finally 86% for the Editorial.



**FIGURE 5** INTEREST FOR EACH OF THE MAIN SECTIONS OF THE NEWSLETTER (N=22)

#### Question 5: To what extent do you agree with these descriptions of OrphaNews?

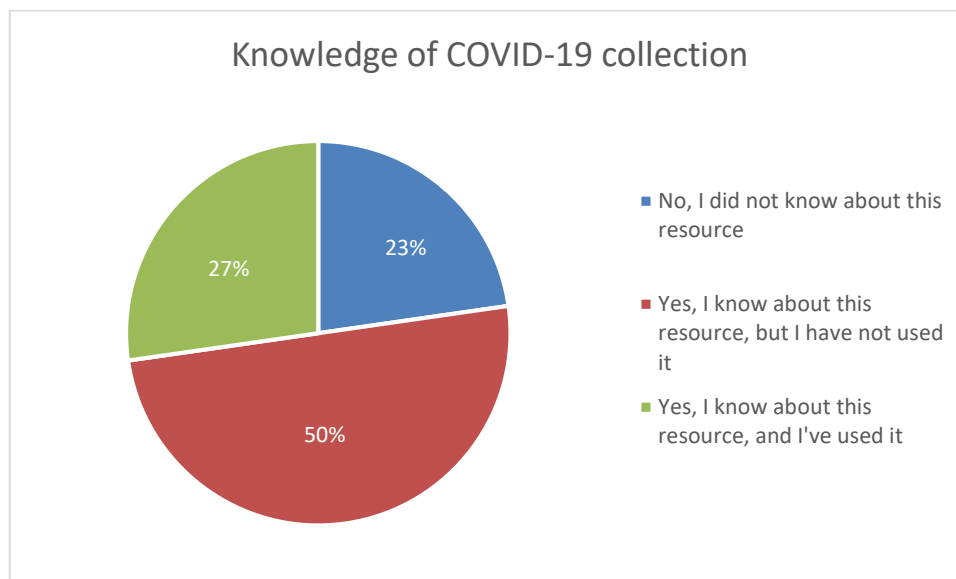
This question was aimed at assessing respondents' views concerning a number of statements about the newsletter. They were able to choose one response for each statement from 'strongly agree', 'agree', 'disagree' and 'strongly disagree'. The responses showed a highly favourable view of the newsletter. 90.9% of respondents agreed that what they learn from OrphaNews is useful in the professional/personal capacity, and 95.5% thought that OrphaNews is well researched and written. In terms of the newsletter providing up-to-date information, 90.9% agreed that the political news was up to date. In terms of the ease of consultation and readability of newsletter, 77.3% agreed that the format was easy to consult and read: this statement garnered more negative responses than the other statements, with 22.7% of respondents disagreeing. Regarding the adequate provision of reports on rare disease news from different geographical zones of the newsletter, 86.4% agreed.



**FIGURE 6 AGREEMENT OF RESPONDENTS TO STATEMENTS ABOUT THE NEWSLETTER (N=22)**

#### Question 6: Do you know about the COVID-19 collection?

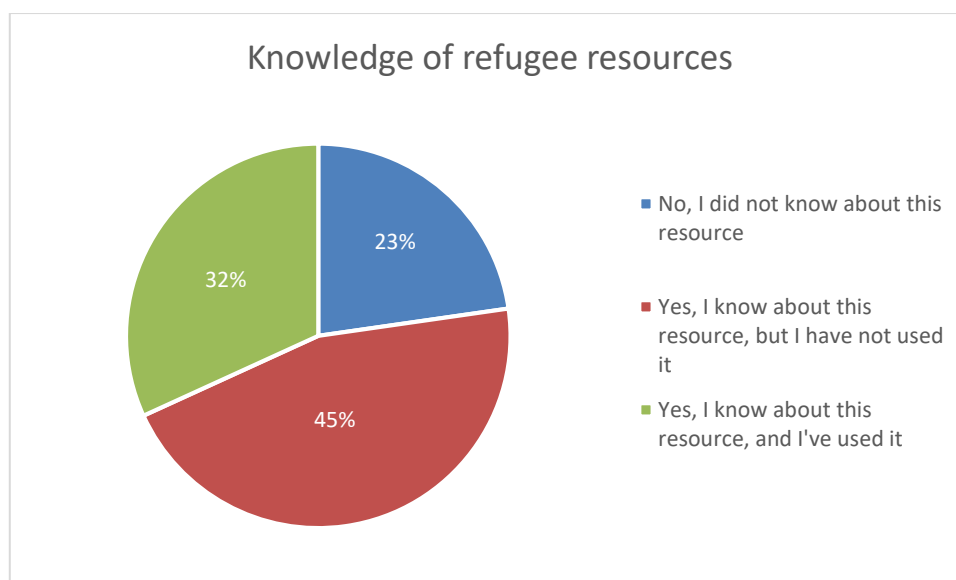
Overall, 77% of respondents know of the collection of resources provided by OrphaNews concerning [rare diseases and COVID-19](#), however, only 27% have used it in the past.



**FIGURE 7 KNOWLEDGE OF THE COVID-19 COLLECTION (N=22)**

## Question 7: Do you know about our refugee resources?

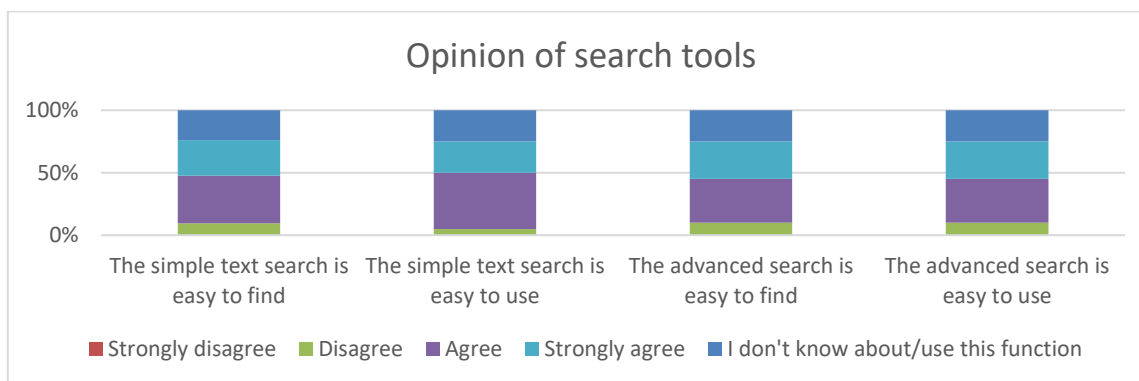
In total, 77% of respondents were aware of the collection of rare disease resources provided by OrphaNews for [refugees and displaced persons](#). However, only 23% have used the collection.



**FIGURE 8** KNOWLEDGE OF THE REFUGEE AND DISPLACED PERSONS COLLECTION (N=22)

## Question 8: 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: 21 respondents replied to the easiness of finding the option, while 20 answered the ease-of-use question. For the advanced search/thesaurus of terms ease of finding the option and ease of use, 20 respondents replied to each question. The replies showed that 66.7% respondents agreed that the simple search option was easy to find, and 65% agreed that the advanced search option was easy to find. In terms of ease of use, 70% found the simple search easy to use, and 65% found the advanced search easy to use. It is important to note that 23.8%-25% of participants did not know about or use these functionalities.



**FIGURE 9** VIEWS ON THE EASE OF FINDING AND USING THE SIMPLE AND ADVANCED SEARCH FUNCTIONS (SIMPLE SEARCH: N=20-21; ADVANCED SEARCH: N=20)



### Question 9: 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 61.9% found the results obtained to be pertinent. For the advanced search function, 57% found the results obtained to be pertinent. However, 33.3% of respondents have not used these functionalities.

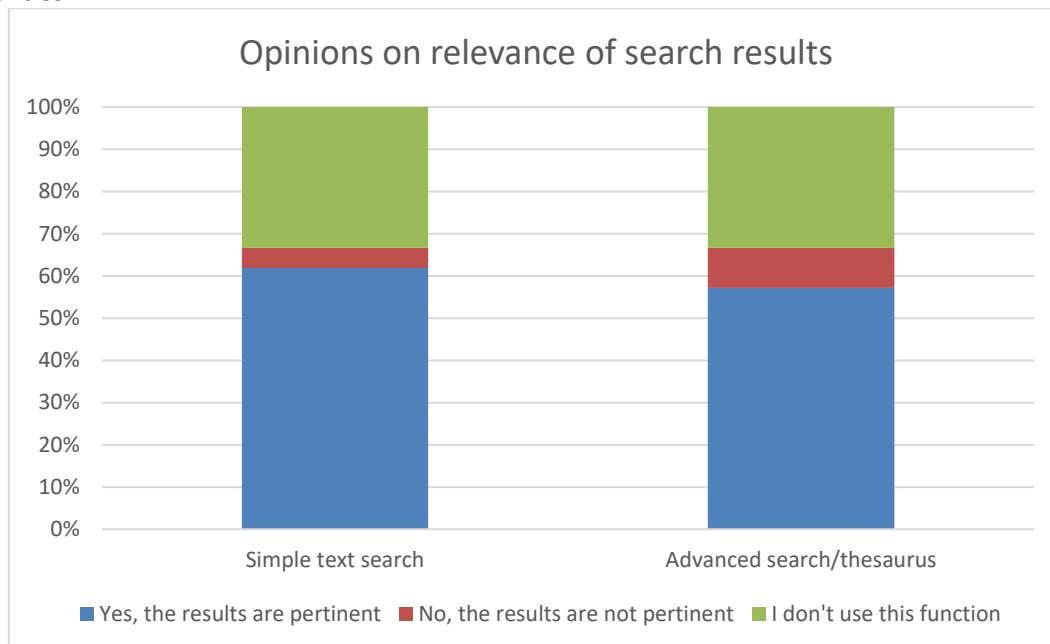


FIGURE 10 VIEWS ON THE PERTINENCE OF THE ADVANCED AND SIMPLE SEARCH RESULTS (N=21-22)

### Question 10: 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 8.9/10, an increase of nearly half a point from our previous survey in 2022. The net promoter score was also calculated, giving a score of 61.9.

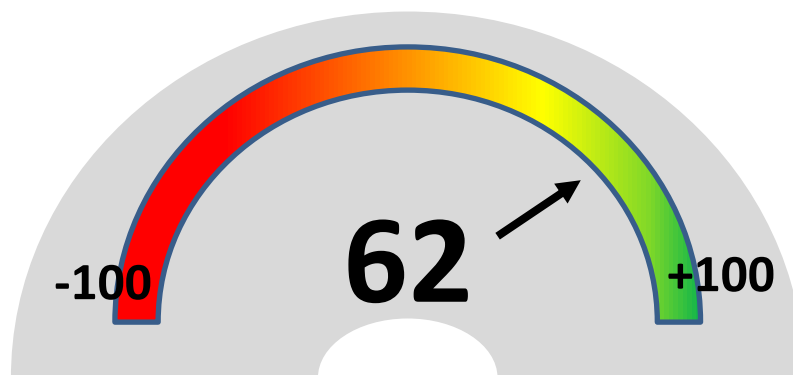


FIGURE 11 NET PROMOTOR SCORE GAUGE (N=21)

## Question 11: How could OrphaNews better serve your needs (e.g. subjects reported on, technical evolutions)?

This open question was responded to by 6 respondents.

Some asked for features that already exist on the [Orphanet](#) website, such as disease-specific information including expert centres and patient associations. This may suggest a lack of clarity in the distinction between the Orphanet database and OrphaNews. However, implementing an easier way to be alerted when articles regarding a specific condition are published could also be beneficial to readers.

In addition, one comment asked for more information on the interaction between different rare diseases in the same patient. While this is outside of OrphaNews' scope, information on disease aetiology and clinical presentation can be found on the Orphanet site.

A suggestion was to include a country-specific news section where local contributors can submit up-to-date information on developments in their country or region. It should be noted that we report on national news from outside of Europe in the International News section, with Orphanet Country Coordinators acting as contact points to supply us with national news. We also welcome submissions from readers who wish to bring specific items to our attention. Additionally, one respondent asked for more information on orphan medical devices in addition to orphan drugs.

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 (53 in total) are only a small sample of nearly 12 000 subscribers to OrphaNews International and the representativeness 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 (81.82%) is far superior to the approximately 19-32% 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](mailto:contact.orphanet@inserm.fr)

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