

# 5.

## RARE DISEASES: INFORMATION HIERARCHY AND THE READER'S PARTICIPATION IN GENERAL AND SPECIALISED MEDIA

Àngels Álvarez y María Teresa Mercado  
(Grupo GIDYC. Universidad CEU-Cardenal Herrera)

Do news items about low-prevalence diseases usually appear on covers? How often do they do so? Is there any paper in which any inclination to presents news on RD on the front page can be seen? Can this conduct be extended to any kind of media? The conclusion is that it cannot, as was already pointed out at another part of the study. Low-prevalence diseases seldom manage to get onto the front page of the media, so the newspapers analysed do not reveal any special sensitivity or predisposition to locate information on RD on the cover. There are no preference criteria in the publications leading to the selection of these news items in designing covers or front pages, as is confirmed by the statistical formula:  $\chi^2(38, N=2443)=432.192, P<, 0002]$  in the analysis of the relation existing between both variables.

The front page is seen as a fundamental item in newspapers: the appearance on the front page or not and the order of the news items constitute a double criterion forming a symbolical language for the reader. The front page of a newspaper represents the culmination of the efforts that the newspaper makes to call the reader's attention, but this also involves an editorial decision at the same time, because the contents are valued and some are preferentially displayed above others. This is thus an advertising lure but also one that forms the identity of the paper. It can therefore be concluded, since failure to include information about these pathologies on the front page is widespread in all the newspapers, that the publications analysed are expressing a stance as regards the subject of seldom-found diseases. There was not much information on RD on either the summary front pages analysed or on the appeal covers, where the reader's attention is sought from a single news item. Quite the opposite in fact: in the general press on paper the values range from the frequency of 40 obtained for the daily *El País* and 6 for *Público*. The same thing occurs with the specialised press, with the general magazines, with the digital dailies or with the regional general press. In the latter there is a predominance of failure to appear on the front page, with a value of 482 as compared with the figure for cover location, which is 13. The same conclusion can be drawn as regards the specialised medical press: RD slip into the different news items on the front page in 22 publications.

## 1. RELATION BETWEEN THE POSITION ON THE PAGE AND THE TYPE OF MEDIUM

As already occurred with including RD on the covers or not, the location given to the news items on the page of the newspaper indicates a valuation or hierarchy-positioning exercise<sup>29</sup>. The value of the information is related to the dimension of the news item, that is, the space assigned and the position on the page, whether this is on the top half or the bottom half. This aspect bears relation to the reader's visual travel:

The process of reading the front page is held to be circular, starting in the upper left-hand corner and moving clockwise [...]. For this reason, the main piece of news is placed in the upper left-hand corner (...). A second theory divides the page into two horizontal halves and two vertical halves. It considers that the upper part is of greater value [...] and the left-hand side more than the right [...]. According to this theory [...] the eye starts in the upper left-hand corner, goes on moving horizontally to the right, drops to the lower left-hand side and concludes at the bottom right-hand side. In both theories the upper left-hand side [...] is the place where the most important news item in the paper must be placed (González and Bernabeu, 2008:28).

The most important news is located on the upper half of the page and the least important or even the fillers are placed at the bottom or on one side of the main item. That is why the upper left-hand corner is the most sought-after position. This is followed by the right and then the bottom half. Location on an odd or even page is however, also a factor of influence in this valuation exercise. From this point it was considered useful to go on to observe the relationship between the "position on the page" variable and "type of medium", after checking that there is a significant association:  $\chi^2(38, N= 2443)= 440.291, P<, 0006$ ].

In the nationwide general press on paper there is a prevalence of the layout of information on seldom-found diseases on the top half of the page. In the study carried out the values talk of 33 hits on the upper half as compared with 6 on the bottom half for El País, or of 20 on the top half of the page and 4 at the bottom in Abc. In the regional general daily papers there is also greater location at the top than at the bottom, with a value of 324 as opposed to 165. A similar pattern can be observed in the general magazines, in the digital general daily press, in the economic papers and the free or medical press. The only exception is found in the sports press and agencies, in spite of the figures not being very striking: 7 hits in the lower half as for 5 at the top in the sports press and one value in the bottom half for the agencies. Hence, although it has already been seen that the news

<sup>29</sup> The digital version of the newspapers does not allow us to discuss positions on pages due to the idiosyncrasy and layout of these media. The hierarchy becomes more vague and one can only observe the totals referring to hits on the Internet

items on RD do not as a general rule obtain headlines on the covers or front pages of the media, there is indeed a clear trend to locate these same items in the top corner of the inside pages, a corner with the greatest visual impact.

We will now look at the relationship between the type of medium and the location on an odd or even page. The formula  $\chi^2(38, N= 2443)= 420.150, P<, 0006$ ] reveals a clear association in the relationship between both variables. In spite of it being estimated that the odd pages are the ones read most, the prevalence of odd pages over even ones or vice-versa does not prove significant in the general daily papers on paper analysed, where the sums are similar: In El País, 21 hits on even pages as compared with 19 on odd; 12 on even and 13 on odd in the Abc; 6 on even in El Mundo and 9 on odd; 3 on even and 4 on odd in Público, etc. In La Vanguardia both totals are similar and only in La Razón does the location on even pages easily exceed the odd ones. with a value of 15 as compared with 6.

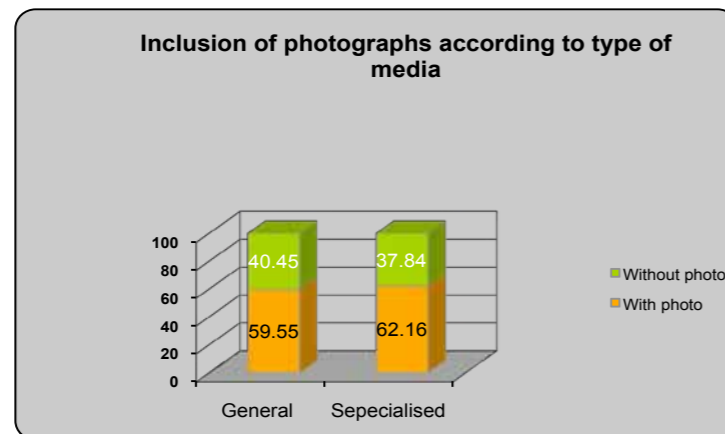
If we now stop to look at the regional general press, the numbers also reveal similar values on even and odd pages: 250 hits on odd pages and 247 on even ones. Something similar occurs with the specialised medical papers (145 on odd and 153 on even), also in the free press (11 and 9) and in the general magazines (16 and 11). The figures nevertheless show ties in the specialised economic press (9 for each of them) and in the sports press (6 for each of the locations).

## 2. PHOTOGRAPHY IN INFORMATION ON RD

Through the sheer fact of being on the pages of a newspaper, the photograph is a preferential focus of attention, acting as a magnet for the eyes, pulling them towards it. From this first contact, the receiver will be more easily 'hooked' by the reference information. It acts at the same time as a major factor in establishing hierarchies, as an illustration juxtaposed to the printed text, clearly distinguishable from this, and insofar as it occupies a part of the page. This means that it has an influence on the apparent importance of the news item as a factor of its "valorisation" (the emitter providing information value for the receiver) (Alonso, 1995:9). Photographs, (and also graphs) are items of great importance in the visual architecture of the pages, which is why their use forms part of the strategy of catching the reader's interest (Manfredi, 2000:115).

Some of the questions coming up as regards photography and information on RD are therefore whether their greater or lesser use is connected with the type of medium or with the thematic frame in which the piece is structured. In both cases, the reply is affirmative: there is great statistical association between the inclusion of photographs and the type of medium - $\chi^2(38, N=2443)=420.716, p<0.0004$ -, on one hand, and also in respect of the frame - $\chi^2(16, N=2445)=83.017, P<0.0005$ -.

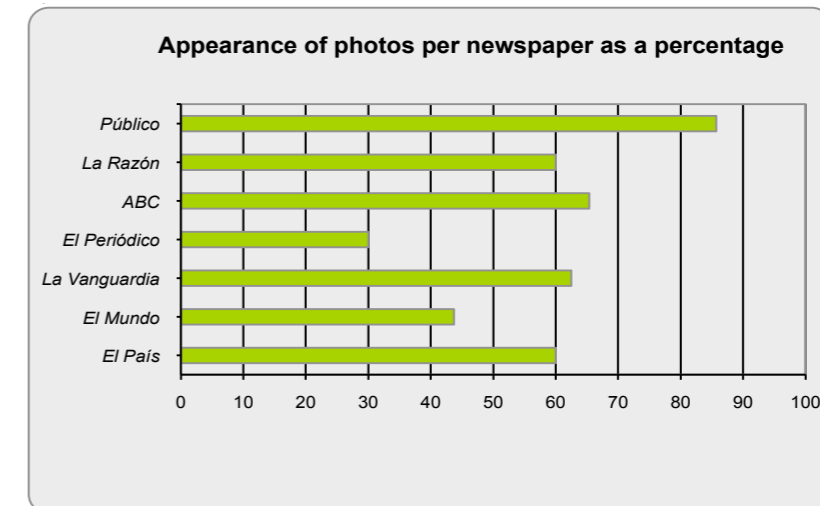
As for the type of media, in publications of a general nature the results range from the 58.5 per cent of the insertions recorded with a photograph in the printed editions of paid-for national daily papers, 59.8 in the case of regional ones and 60 per cent in the case of the free press. If all the entries in printed and digital printed media are taken into account, the percentage is of 59.55%. The proportion of items in which the information goes along with a photograph in the case of the specialised media is higher, with 62.16% in the publications specialising in medicine.



Graph 18

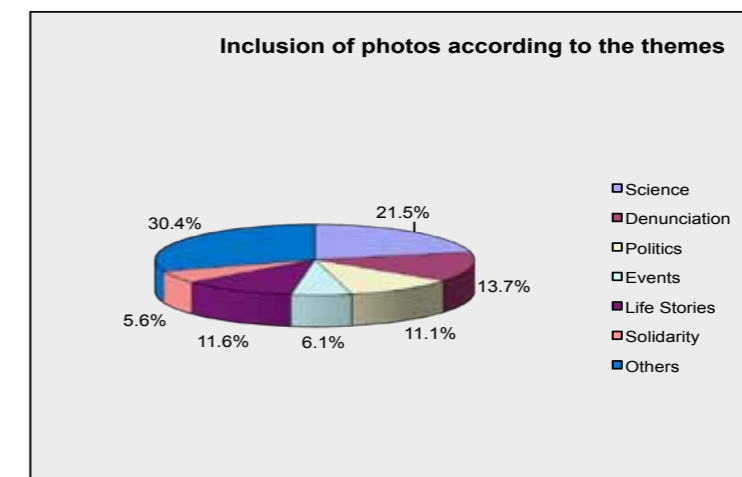
Paid-for national papers reveal disparate patterns as regards the use of photography in pieces on RD. From the highest percentage of *Público* (85.7% of the insertions) to that of *El Periódico* (30%), the other daily papers move from 60 per cent of the information items with a photograph (*El País* in 60% of these, *La Vanguardia* in 62.5 and *Abc* in 65.4). *El Mundo* would be the paper publishing fewest photographs on the issue of RD (43.75%). Including photographs depends, amongst other factors, on the model of newspaper and the general design of the medium, and the choice of journalistic genre. Hence, *El Periódico*, a publication with a large number of photographs, is the one that contributes least as regards the matter of RD, because no report or interview appears between the insertions analysed, as

can be confirmed in the section on Newspaper Genres. On the other hand, a prominent proportion of these interpretative genres is chosen in *Público*, *El País*, *La Vanguardia* and *Abc*.



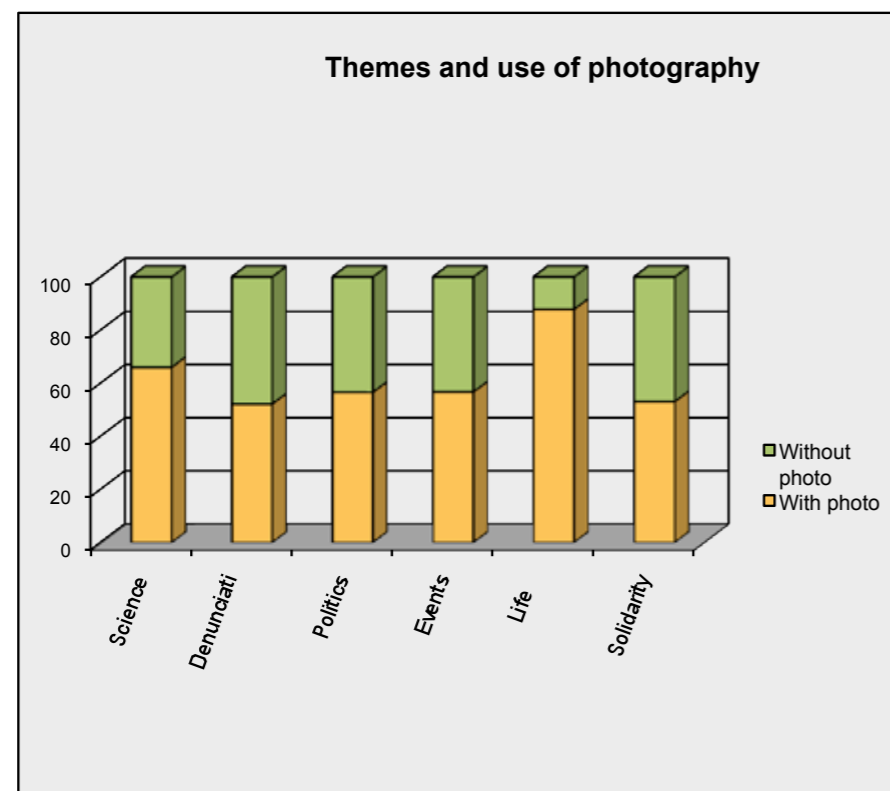
Graph 19

In respect of the total number of news items in which it is known whether photographs are used or not, those dealing with scientific discoveries are the ones showing greatest journalistic value as regards the use of photography. 21.5% of the total number of news items on RD with photographs refer to this issue. The other frame which obtains photographic accompaniment to the greatest extent is that of denunciations or claims (13.7%) followed on one hand by the one focussing on personal testimonies or life stories (11.5%), and on the other by the frame concerning institutional policy (11.1%), in which the pictures of public representatives are of central importance.



Graph 20

The analysis of the use of photography in relation with each of the frames recorded shows that more importance is given in some cases than in others. The case of life stories is prominent, since 88% of the news items on this subject have a photo. The second most highly-valued frame in this respect is that of scientific discoveries, with 66% including a photo. The rest give similar results with percentages indicating that on half of the occasions there is indeed a photo, and in the other half there is not, meaning that other production routines seem to come into play apart from the subject in question in the information. Hence, Denunciation has 52.1% with a photo and 47.9 without one; Institutional policy 56.5 with, 43.5 without, an almost identical proportion to that of Events and Commemorations (56.7 with, as opposed to 43.3% without). Lastly, in the case of information about Solidarity, in 53% of the cases these go with a photograph and in 47 without.



Graph 21

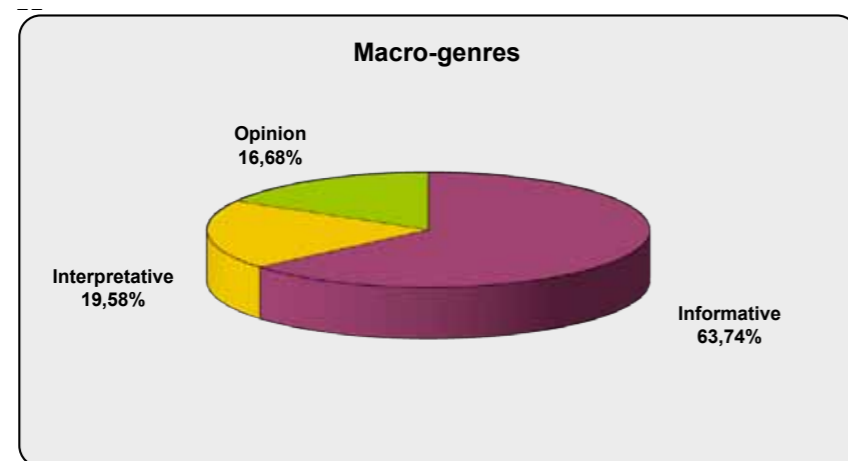
### 3. JOURNALISTIC GENRES. THE VALUE OF UNIFORMITY IN THE THREE MACRO-GENRES

There are considerable differences between communication theorists in classifying the different forms of writing a journalistic text, but many of them coincide in indicating the journalist's presence in the text as being the main differentiation criterion. Hence, the greater or lesser degree of subjectivity found in the text defines three major groups: information genres, genres for interpretation, and opinion. This piece of research has taken into account news items and news in brief in the information macro-genre; reports and interviews in the interpretative genre; and articles, criticism/reviews, columns and editorials in that of opinion. According to Alex Grijelmo (2003:27-30), a reader accustomed to a newspaper knows how to identify the greater or lesser information presentation being given to a subject, knowing the differences between a front page with a five-column header and an opening on two columns, and is aware of the way opinion articles are typographically laid out.

The existence of genres forms part of that non-verbal language surrounding words and conveying relevant data to readers about the approach to the text that they are reading. The importance of genres, beyond their use and function in editorial offices and journalism faculties, therefore resides in the fact that they may also be useful for the reader. The mindset with which the reader heads into a news item changes a lot from the approach to a report or an opinion article. Readers are on guard when tackling an opinion article: they know that what is being given there are value judgments in line with the specific idiosyncrasy of the person drafting the text. On the other hand the news item constitutes the essence of facts, reproducing data and declarations. The other genres lie somewhere between both of these, all with a different degree of author-involvement.

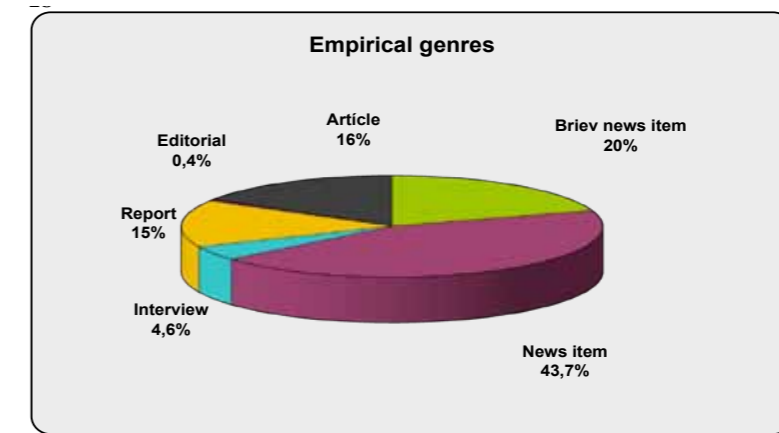
Interpretative genres entail greater preparation by the journalist, get greater space in the newspaper, greater coverage as opposed to succinct information. As a general rule interpretative journalism tends to be considered a form of going more deeply into the information, with precedents and analyses which provide a background situation or attempt to explain situations of current interest, not only to inform about these. Interpretative genres therefore entail greater preparation, dedication and knowledge of the subject being dealt with. Their use underlines the interest that the medium may have for a particular information topic.

Opinion genres, on the other hand, are a rhetorical discursive construction whose main aim is to persuade. As part of these, the editorial takes on particular importance as a text that reveals the ideological approach through valuing and judging a news item considered of particular importance for the medium. The choice of the journalistic genre represents a further item in journalistic valuation and the establishment of the thematic agenda of the medium. That is why the purpose of finding out what journalistic genres are most widely used by reporters writing about RD is to assess the degree of involvement in the preparation of the items and the hierarchy ranking given to the subject by the type of medium in question. The information macro-genre is the one appearing with greatest frequency in the total number of insertions recorded. With 63.8%, this triples interpretation, with 19.6. The difference in respect of the opinion macro-genre is still greater, with 16.68% of the total number of texts analysed.



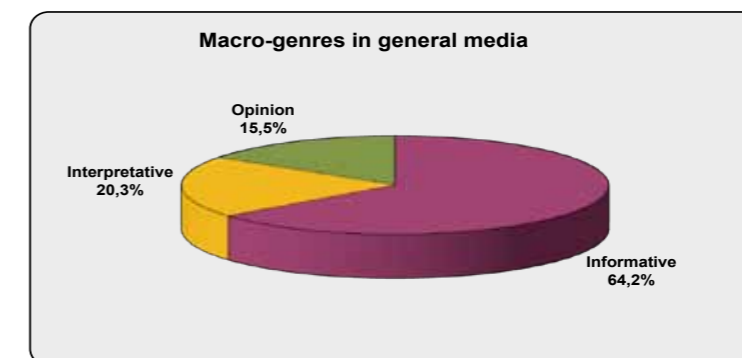
Graph 22

As for the empirical genres, the news item is the genre most widely used by all the media, on 43.8% of the occasions on which they inform about RD. The brief item is the other genre most commonly selected (20%). The amount of reports reaches 15%, while the interview is below five (4.6). Opinion articles signed by contributors represent 16.2. Editorials make up 0.5%. There are in short a lot of brief items, a few reports, extremely few editorials (none in the national dailies with greatest circulation) which shows that the media do not give the information on RD any prominent coverage as regards the choice of journalistic genres. As was stated above, they do not succeed in attaining the media's consideration as an item of priority interest on their agenda.

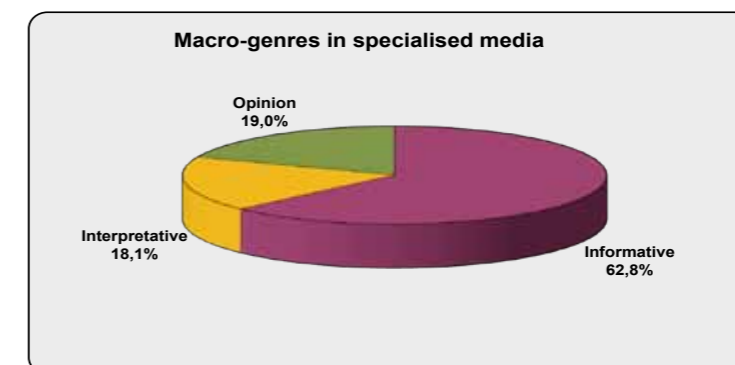


Graph 23

The  $X^2$  test shows that there is a significant association between the type of medium and the journalistic genre: [ $X^2(133, N=2443) = 678.343, p<0.0005$ ]. In the general media, the information and interpretative genres represent 64.2 and 20.3% respectively. Opinion is just 15.5. In the specialised press one can appreciate a greater number of opinion articles by experts, which make up 19% of the total, while the figures for informative (62.8) and interpretative texts (18.1) drop.



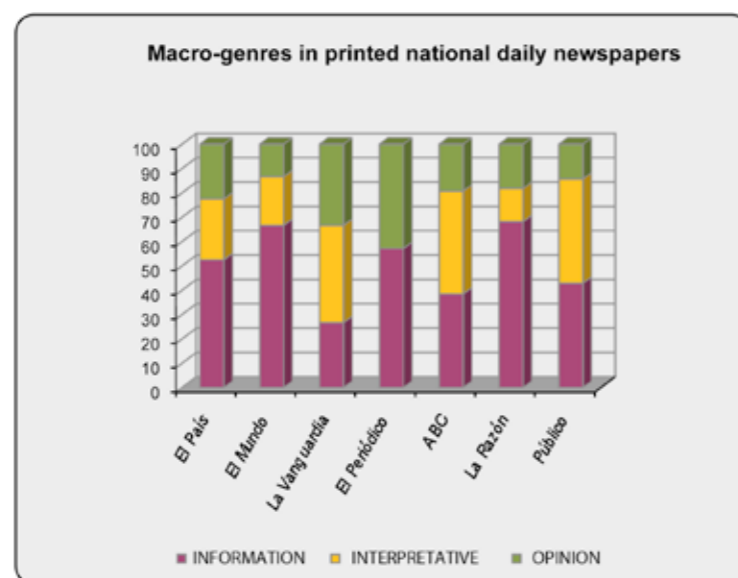
Graph 24



Graph 25

In printed editions of paid-for media the texts are informative in 64.6% of the insertions. La Razón is the daily national paid-for paper with greatest percentage of informative texts (68.2), followed by El Mundo (66.7) and El Periódico (57.1), the one giving most opinion on RD and the only one to publish an editorial on the issue. El País has over 50% of its texts in the informative genre (52.5). On the other hand La Vanguardia is the one with fewest informative genres, with 26.7% while interpretation reaches 40%. Abc and Público are the daily papers with greatest proportion of interpretation on their pages (42.3 and 42.8 respectively).

The data on the free papers (ADN, Qué and 20 Minutos) reveals a greater preference for informative genres, with 79% of their texts in this category, while interpretation and opinion come to 11% each.



Graph 26

After associating the type of medium informing about RD and the genre of journalism used to do this, we will now look more deeply at the intersection between the genre of informative pieces analysed and the frame. To answer the question of whether journalistic genres, understood as forms of encoding information, preferentially use certain informative frames over others in the treatment of RD, the statistical formula describes a significant relationship between both variables:  $\chi^2(56, N= 2445)= 361.188, P<, 0003]$ . Hence, if we are talking about informative macro-genres, one can see that the brief item gets a higher frequency in the use of the research frame, which is why these short informative items

first of all report news on discoveries, with a score of 33. The second approach used is that of formal events, with a frequency value of 30. The third and fourth places are taken by frames focussing on denunciation stories and solidarity campaigns, with 26 and 24 for frequency respectively. News items also give priority to the discoveries approach, with a frequency value of 108, followed by institutional policy and denunciation, with a score of 68 and 67. The same patterns already described for purely informative discourse are reproduced.

In the opinion macro-genre the highest frequency scores go to research and denunciation (with the same value of 35). Institutional policy and testimonies lag behind with scores of 13 and 20 respectively.

The editorial genre, acting as an institutional judgment and expressed in accordance with the medium's editorial line, gets the greatest frequencies in the denunciation frame. In the letters to the editor, the expositions in the denunciation frame are similarly plentiful, through including forcefully assertive arguments. The frequency value is 12, as compared with a value of 3 in the thematic topic of solidarity or of 1 in institutional policy.

As regards interpretative genres, in the interview type preference is given to demand for recognition, with a frequency value of 11. The people affected demand normalised healthcare and the right to a better quality of life. This is closely followed by the frame of discovery and policy, with a score of 8 for each of the themes.

The report, somewhere between information and interpretation, focuses its interest on the frame of life stories, since the format is seen to be suitable for going more deeply into personal accounts. As reports of human interest, relevance is given to the testimonies of people affected and their relatives. This manages to get a value of 47, as compared with the score of 19 for research or 12 for institutional policy.

After going through the topics and genres it was corroborated that of all the existing topics it is the Dependency Law which fails to obtain significant scores in any of the genres studied. For this reason no relationship is established by the media between this frame and that of low frequency diseases. The prevalence of news items analysed alludes to a portrayal of RD in an eminently informative pattern, as has already been stated, and confirmed by the frequency value of 654 obtained through a count of the figures for the news and brief items. The treatment proper to interpretative journalism reaches values similar

to that of opinion. If the figures obtained in the interview and the report genres are added, a value of 200 is recorded, only a little over the amount of 170 obtained by adding up the articles of opinion, criticism, columns and editorials.

The way news items on RD are narrated and the preferential frame in which these are structured helps to create a particular perception of the theme. Hence, by framing reality on RD in an informative context, this is removed from emotions, from interpretations and opinion discourse. The research and denunciation frame is structured in all the macro-genres on a discourse concentrating almost exclusively on stories talking of discoveries and demands or claims.

### 3.1. GENRE OF THE ITEM AND MOST FREQUENT TOPICS: AGAIN SOLIDARITY, RESEARCH AND INSTITUTIONAL POLICIES

After the analysis of the link that can be found between press frames and genres, an in-depth look will be taken at topical frames and macro-genres, a nexus in which there is again a clear association between both variables, as shown by the formula:  $\chi^2(98, N=2445)=189.170, P<.0009$ .

Out of all the most commonly repeated topical frames, the prominent approaches in the informative genre of the brief news item are solidarity, research and institutional policies, obtaining similar values, with 39, 36 and 33 respectively.

The same view is repeated in the news item: the frequency values most widely reproduced are those of the disease itself, with explanations of its diagnosis and traits, research, institutional policies and solidarity. Aspects connected with the economy, integration or isolation, installations, Dependency Law and disability reach only very low figures. The topic of employment is non-existent.

Along with the information macro-genre and the supremacy of this angle, similar treatment is to be found in interpretative discourse. The prevalent frame in both items with a report format and the interview genre is the one in which the disease and its characteristics are associated with institutional policy and research. Furthermore, in reports the information frame of solidarity and economic arguments is seen to reach a high frequency value. We

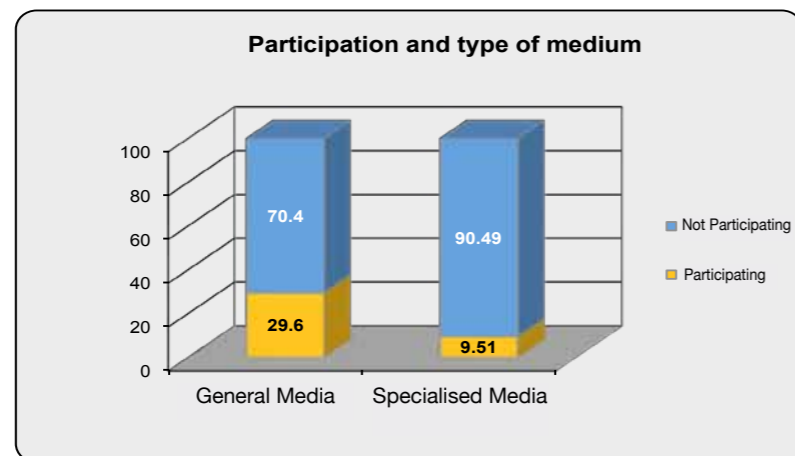
find very scant references to disability, integration, employment, the Dependency Law or alienation, in spite of being journalistic items which lend themselves to going deeper into the causes, effects and details surrounding uncommonly found diseases.

Articles, criticism and columns framed in opinion genres also connect the disease with research and institutional policy frames, as already happened with the other journalistic genres, and also, though to a lesser extent, with the topic of solidarity and the economy. As regards the figures obtained in the other opinion genres (editorials and letters to the editor), there are some differences in spite of involving low values. Solidarity and institutional policy get a higher frequency in letters to the editor, followed by the economic argument, while the most commonly repeated specific frames in the editorial format are research and the economic issue. Again there are few references to frames such as disability, transport, employment, integration, insulation or the Dependency Law, meaning that the same information patterns found in general frames are reproduced in the topics or specific frames.

### 4. READERS' PARTICIPATION IN ONLINE MEDIA

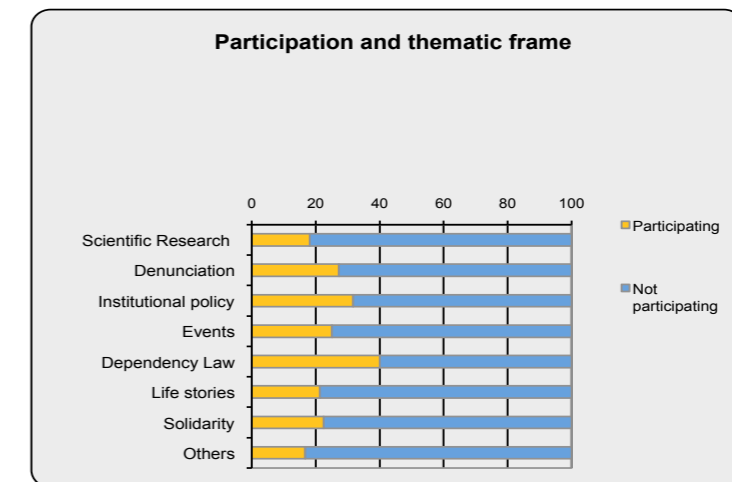
Participation is one of the salient features in the interactive communication of the so-called new media. It brings about a change in the reader's status, as the latter becomes an active user involved in the production of contents. The active role played is sustained by the capacities for communication with the people responsible for the content and with other users. The reader can get involved and have an influence on what is being disseminated, as never before. So far, nonetheless, the reality of the web does not tally with some of the Utopian principles of participation. Although the number of users connecting in better conditions is growing and the uses made of the web have diversified, only a low percentage of Internet users make use of the opportunities to participate and share resources, opinions and contents. In most online communities 90% of the users just have a look without getting involved, 9% contribute something and only 1 per cent really participate (Igarza, 2008:207). In all the insertions on RD recorded in online media, 21.8% make some comment. Considering that the users' participation may depend on the type of medium being consumed, depending on their interest in or knowledge of the matter in question, in this case RD, the statistical test gives a positive result, that is, a high association between participation and the type of medium can indeed be established:  $\chi^2(38, N=2445)=610.826, P<0.0002$ .

The readers of information on RD in the online versions of all the general media analysed (daily papers and magazines, national and regional, paid for and free) participate on 29.6% of the occasions in which they are given an opportunity to do so. If the digital editions of printed national media are taken separately, nevertheless, the percentage of participation reaches 31.57% in the case of paid for media and 48.2% for the free ones. The level of participation is seen to be directly associated with the audience rates. Hence the percentage of readers making comments in the specialised media drops sharply to 9.51%. Taking into account only the media specialising in medicine, disability or science, the figure drops further, to 8.59% of the readers of these media. The greater the specialisation, the lower the diffusion and the lower the participation.



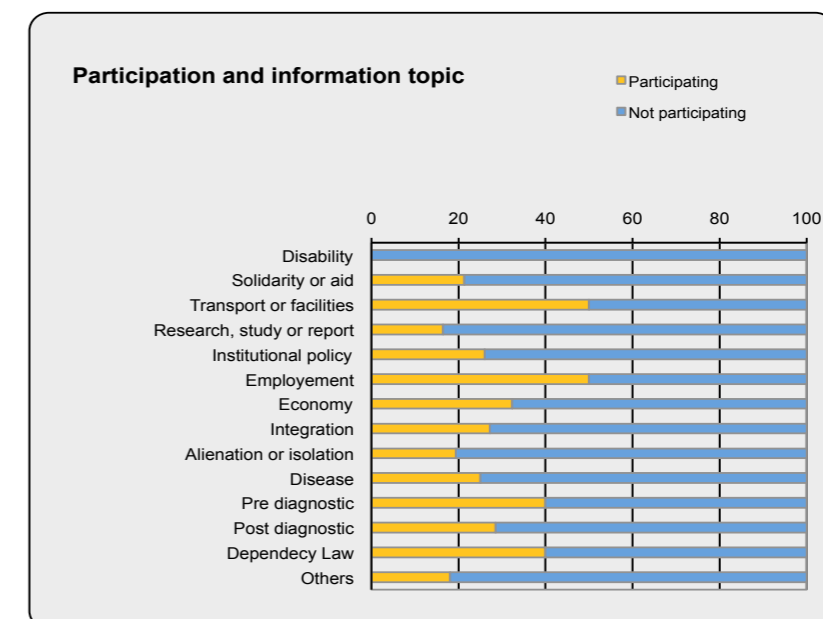
Graph 27

A minor relationship may be established between the participation and the topic of the text in view of the statistic [ $\chi^2$  (28, N= 2445) = 53.628,  $P < 0.002$ ], while the dependence between participation and the thematic frame is fairly significant: [ $\chi^2$  (16, N= 2445) = 61.913,  $P < 0.0002$ ]. The greatest participation takes place in themes alluding to the Dependency Law and Institutional Policy. In these information items the users comment on the insertions recorded in respectively 40 and 31.8% of the cases. This is followed by Denunciation or Demands for recognition with 27.2% of the information items in which there is participation. The frame which triggers off readers' comments least is that of Scientific Research and discoveries, with 18,2.



Graph 28

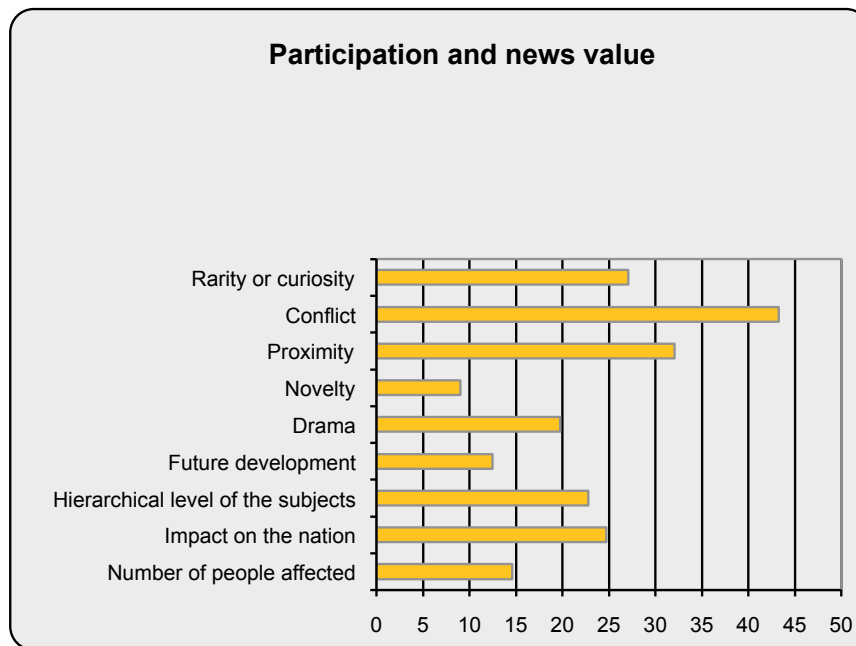
The information topics in which greatest participation is observed are Transport or adapted facilities and Employment. In both cases the user participates in 50% of the items. On the other hand, no-one makes remarks when the item deals with Disability. Over 25% of the participation is for the topics of Integration, Economy, Institutional Policy and the ones referring to Disease and Post-diagnosis. In the thematic field the readers' participation stands out in items dealing with Pre-Diagnosis, reaching 40, the same participation percentage in the items on the Dependency Law.



Graph 29



The significant relationship between readers' participation and news value is very prominent:  $\chi^2(18, N=2445) = 113.439, P < 0,0007$ . The news value which very particularly arouses readers' participation is conflict: in 43.3% of the items the user comments on the information. This is followed by proximity (32%). Novelty is the news value generating fewest comments from readers (9%).



Graph 30