As has already been explained, news values (meaning the importance criteria involved in selecting a fact) are used by journalists to choose the information texts or news that they are going to publish and thus to define which kind of events are sufficiently interesting and significant to become news and which are not. This selection and control process, which entails a form of processing reality, marks public agendas, social imaginaries, the public opinion, symbols and traditions, ultimately the way we see the world (Martini, 2000).

The news values considered in this piece of research are the ones defined by Carl Warren when he detailed the characteristics that an event has to involve in order to become news (Warren, 1975): novelty, proximity, relevance (hierarchical level), oddity, conflict, suspense, emotion or human interest (drama), consequences or significance. For the purposes of the research the suspense criterion was ruled out and the last of the ones considered by this North American is extended. Significance can therefore stem from the number of people involved, the impact on the country or the future development, based on the revision of news values made by Mauro Wolf (1991: 212-214).

In this chapter the values obtained in different items will be listed, the aim being to obtain more in-depth conclusions about the way the press studied has represented uncommon diseases by crossing different variables. As was already explained, the study of news value in the sphere of RD provides a list of values in which the easily outstanding ones are those of novelty and proximity, with frequency values of 458 and 441 respectively. The first of these is intrinsically connected with the “news” concept, understood as a recent circumstance which is not known, and the second associated with proximity as a value of vital importance insofar as it expresses a preference for a piece of information originating...
locally, in the most immediate surroundings. The local sphere has an effect on building the identity, the subject feels involved and in this respect it proves of great interest for the public. The significant role played by the regional press in covering orphan diseases was furthermore already pointed out.

The third of the news values is curiosity, with a frequency value of 316. The unusual or unexpected as a criterion for newsworthiness, as a component of the information frame, is a vital aspect when talking about what are known as rare diseases through having a prevalence under the standard rate, in short, through being minority matters or, amounting to the same thing, unknown.

The drama factor, stemming from narrated life stories, lies half-way down the list, above the hierarchical status of the subjects involved, the number of persons affected, and the impact on the country, in spite of the institutional representatives being the undisputed favourites of the media. The notion of conflict, of vicissitudes or tragedy, is also here, with a frequency score of 193, coming forward as a marked dimension in the information stories analysed given that this predominates over a less emotional approach.

The relationship between the type of medium and the news values presented in the information on RD is proven through the statistical formula \[ x^2(171, \ N=2443)=673.537, \ p<0.0008 \] and from the values obtained.

The news values most appreciated in the general national daily papers (El País, El Mundo, ABC, La Vanguardia, El Periódico and Público) are, as already stated, novelty, with 16.8 per cent of the total number of insertions recorded. In second place, there is human interest or drama, in 13.1 per cent of the information items selected by these papers, followed by the hierarchical status of the subjects involved (12.3 per cent). In the regional press, two of these values are not found among the three most prominent ones, being replaced by rarity/oddity or curiosity (9.8 per cent) and above all, by proximity, in 55.4 per cent of the news items, and shifting novelty to second place (13.3 per cent of the records).

In general information magazines less dependent on current affairs through coming out weekly, the news values of rarity/oddity or curiosity are prominent, with 26.8 % of the total number of insertions recorded, and drama, with 17.1 % of their news items. The third of the prominent values is the hierarchical rank of the persons involved (14.6 %).
One of the important criteria involved in defining the news item is its protagonist’s relevance, an argument which has been associated with the variable “proper names/representatives of institutions”, as has already been mentioned. When the subjects linked with some institution, concerned in the information on RD, and appearing with most frequency are associated, six names stand out above the rest: Trinidad Jiménez, Francesc Palau, Cristina Garmendia, Elena Salgado, Andrés Iniesta and Rosa Sánchez de Vega. The names of two institutions are also included: CIBERER and FEDER. The statistical test gives positive results and enables a high degree of association between the institutional representative value and news values to be established: \[x^2 (45, N= 2445)= 299.699, P< 0.0002\].

From the intersection between the news value variable and that of the institutional representative the major role of the Minister of Health stands out during the period studied, as has already been described. In the case of Trinidad Jiménez there is a prevalence of the criterion associated with the effect of the information on the population, the number of persons affected and the interest generated by the hierarchical position held by her. The novelty and future development of the information are also involved, though to a lesser extent.

Second place in this count is taken by the name of Francesc Palau, the scientific director of the Centre for Biomedical Network Research on Rare Diseases. The principle of novelty, of the impact on the country and the future development come forward as the predominant news values.

The Minister of Science and Innovation, Cristina Garmendia, appears in third position in this inventory. Along with the hierarchical importance of the post and the impact on the country the value of conflict emerges, based on the budget reduction undergone by the ministry which she is responsible for, and the effects that this cutback generates on research work.

The other three proper names seen on the list provide much lower figures and no particular news value stands out over another in the conversion of the information into news. The institutional representatives are Elena Salgado, Minister of Public Administrations in...
the period studied and later on of Economy and the Treasury, Andrés Iniesta, a Spanish footballer from Spain’s first division Barcelona F.C. and a member of the Spanish team, and Rosa Sánchez de Vega, president of the Federación Española de Enfermedades Raras. In Andrés Iniesta’s case the outstanding factor is his relevant position as a footballer, the proximity, future development and drama, since he is associated with an act in support of the D’Genes association in the struggle against RD. The relation between Rosa Sánchez de Vega and the criteria of number of persons affected and impact proves relevant, as these premises are connected with the current scope of FEDER, which is made up of roughly two hundred associations of people affected by different uncommon diseases.

When the two institutions included in the study, CIBERER and FEDER, appear in the media without being linked to their representatives, FEDER gets rather more presence in the media studied, though these are low frequency values. All the same, this repercussion ought to be conditional in both cases on the appearance of the proper name of the representatives of each concern, thus amplifying their echoes in the titles analysed.

The following graphs represent the news values stemming from the three most relevant names through the frequency of appearance.

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**News values of Trinidad Jiménez**

Graph 6

**News values of Francesc Palau**

Graph 7

**News values of Cristina Garmendia**

Graph 8
4. News values, frames and Rare Diseases

As was already stated in the previous chapter, the first of the frames used in studying RD in the texts analysed which should be mentioned, through the frequency of its appearance, is that of discovery or scientific research, with a frequency value of 507, this being the news frame with greatest impact. The triad of Rare Diseases, sick people and research displays the most customary media approach and insists on the necessary research to take prevention action and find diagnoses and therapies for those affected. As a result, the second and third most repeated frame is that of denunciation or demand for recognition, with a value of 414, and that of institutional policy, with 296. Both of these are connected with the development of orphan drugs and specific healthcare policies for uncommon diseases. They are followed by the celebration of formal events with 167, as a formula for awareness-raising and diffusion of illnesses, solidarity, with 139, testimonies or personal stories, with a frequency value of 129 and lastly the Dependency Law, with only 5 hits.

The media steer the reader’s attention towards research and demand for recognition as has already been concluded, expressing the two most significant facets of Rare Diseases.

2. PREFERENTIAL INFORMATION FRAMES: RESEARCH AND DENUNCIATION, A POWERFUL PARTNERSHIP

In this work the application of the Frame Theory allows us to describe the media treatment which the subject of RD has been given during the period analysed, specifically the news frames which have been prevalent in its media coverage. The frames, central ideas organising the information context, are patterns of thought which guide the interpretation process. Hence, this analysis will concentrate on the generic frames (or subjects) and on the specific frames (or topics).

The way news items on RD are narrated and the fact of providing these with a frame helps to accentuate or mitigate certain values in this treatment, which has an effect on the creation of a social framework (Sádaba, 2001). The framework created becomes a general tone which has organisational and social but above all psychological implications. The journalist tells us what is happening and brings his or her own viewpoint into this, as something inherent and necessary in the journalistic product (1996). The reader will therefore observe reality through one frame or another as a result of the journalist’s intermediation.
2.1. News frames on the Theme and those Affected by RD

This section lists those affected as regards the way they are identified in information texts, with the news frame that has been given to the theme. Hence there is a significant relationship between “what they are” for the journalist, what is being talked about in the medium and how the information is framed, as shown by formula: \[x^2 (80, N= 2445)= 517.050, P< 0.0003\].

The most frequently used terms used to refer to the subjects of the news item are “the sick” and “patients”, followed by the word “children” and to a lesser extent “those affected” or “dependents”, as was stated above. The terms “worker”, “disabled person” or “student” do not reach any significant frequency, which confirms that the sick subject is not talked about in their role as an active person, but neither are they linked to disability. The analysis of the texts thus reveals a general form of referring to the “who” of the news items by the extended use of the sick person-patient twin term, while the frequency of appearance of the child category stresses the link found between uncommon diseases, mostly genetic, and the impact on the child population.

If one stops to look more closely at the analysis by categories of those affected differences are again found. In the designation of “sick persons” the most reiterated news items associates these with medical discoveries, with a value of 112. This figure very closely associates this concept and thus RD with research, but it similarly relates them with denunciation, since a value of 81 is recorded. From the sick person’s position the clamour about the need for research and for institutional policy to be changed is prevalent over any other approach. It is also at the same time concluded that the need to become visible leads the sick to appear in a high number of life stories (17), of calls for solidarity (15) and formal events (14), as shown by the figures.

The most frequent thematic field in the “patients” group is Scientific Research, with a value of 89, as occurred with the term of the “sick”. This is very closely followed by Denunciation or Demand for Recognition with a value of 52. There are finally the frames connected with Institutional Policy, with 18; Celebration, about a day for a disease being established, or Testimony, with 8 each. Again, there is no mention at all of the Dependency Law.
2.2. Information Perspectives and Nature of the Medium

A closer look at the general press will be taken now, to see whether there is a prevalence of any particular frame in the treatment of RD, whether there is a significant relationship between the news frame used for the information and the typology of the medium, and the statistical formula shows that there is: \( \chi^2 (152, N= 2445)= 401.614, P<, 0002 \).

The figures lead to the conclusion that there is a dominance of two frames in the treatment of RD, that of research (which gets a value of 59) and that of demand for recognition (with 58); the desperate situation in which those affected are found is denounced, as well as talking about research. One aspect of this is the demand for the urgently needed excellence research, helping to take preventive measures and provide appropriate treatments; the other is newspaper reporting on the progress made in the sphere of biomedicine. El País, El Mundo and Público thus give priority to the research approach, and La Vanguardia, El Periódico and Abc to denunciation. El País is the newspaper which uses the research frame most and Abc that of denunciation.

We should also stress that of all the general newspapers on paper examined, the ones with the greatest percentage of information on RD are the daily El País with 2.9% and Abc with 2.5%. The rest obtain rather lower figures: El Mundo and La Razón get 1.6%, La Vanguardia 1.1%, El Periódico 0.9% and Público 0.5%.

The frame observed in third position is that of Testimonies, with a frequency value of 28, followed by that of Institutional Policy, with 26. In the case of Life Stories, combined with an attitude of denunciation, Abc obtains the highest figures (9), while El País is the medium with the greatest focus on institutional policy. Behind all these news frames comes the one for Celebration or Formal event with 21, and Solidarity with 19, in which the most prominent paper is El Periódico, obtaining a value of 6. The frame of the Dependency Law – LdD - proves non-existent, and is not covered in any of the general daily papers analysed.

Let us go on to look at what occurs with the regional general newspapers on paper support that we examined. Again, the conclusions referring to the national papers are extrapolated to the regional press and so the frames involving research and de-
nunciation exceed the rest, registering a value of 340, followed in third position by institutional policy with 115. The other approaches attain lower amounts: personal testimonies (65), solidarity (61) and celebration or commemoration (59). Right at the back of the scores is the Dependency Law, with only 3 mentions, in spite of the regional press being the only papers to present the LdD as an information approach. The media thus express their standpoint, an angle which gives priority to some values and puts others behind.

The sample of specialised press on paper was made up of 31 publications27, and the analysis concentrated on the specialised medical journals. The frames of discovery or research again stood out among these in first position with 131 hits, which is understandable, given the nature of the media, as well as the one for institutional policy and claims for recognition, with 75 and 70 entries respectively. At a considerable distance there are the news frames of the formal event (30), of solidarity (16), of testimonies (12) and the Dependency Law (0).

The economic press also uses the research frame in pride of place, though connected with monetary matters. In the sports press, however, the main information treatment is not that of research but solidarity, a value embodied mainly in the figure of Andrés Iniesta. The newspapers specialising in disability have formal events, commemorations and celebrations based on the international day for a disease as their pre-eminent frame. There is also a mention of the Dependency Law, which was something new. In the scientific press, the dominant news frames are demand for recognition, along with institutional policy and research.

As for general magazines, the information frame most often repeated is that of discovery, followed by life stories. In the sphere of the general digital press, made up of a group of 144 media, the prominent frames are research, denunciation and institutional policy. An identical approach to journalism is seen in the specialised digital press, consisting of 56 publications. Here the demand for recognition, research and institutional policy gain the highest percentages. Finally, in the free newspapers section, the angle of discovery, denunciation and institutional policy is the prevalent approach.

In view of the results displayed the conclusion to be drawn shows the existence of a persistent image, an information frame which is constantly repeated: this is research, a scientific angle prevailing over all the others.

### 2.3. Specific Topics or Frames and Type of Medium

After examining the general information structures, the study will now determine how far certain specific topics or frames have been used by the media in their coverage of uncommon diseases. These specific structures form part of the predominant frames in the treatment of RD in the press. Which has been given most emphasis? What perspective does this frame suggest? Which do not fit as topics? Is there any relationship between the type of medium and these information frames? These are some of the questions that we shall attempt to answer.

The statistical association stemming from “specific topics or frames” and “media” variables is positive, as shown by the following formula: \( \chi^2 (1266, N= 2443)= 557.053, P<, 0.0009 \), which confirms the existence of significant aspects in the inter-relation between both variables.

In the field of general newspapers with nationwide circulation the same conclusions as the ones stemming from the analysis of general frames were drawn. Qualitatively, this small group of newspapers is the one giving greatest coverage of RD issues. In these papers the most relevant topics were framed in terms of research and institutional policy. This is what is found in El País, El Mundo, Abc, La Razón and Público. On the other hand, the most often repeated topic is solidarity for La Vanguardia and El Periódico, though closely followed by research and by institutional policy. Again, it is the newspaper El País which gets the highest figures in the predominant specific frames.

Some topics can also be seen to have no place as specific frames in the treatment of RD. The little presence, if any, of the topics of disability, transports, adapted facilities, as well as employment, the economy, integration, alienation, or the Dependency Law confirm this. Journalists are once more expressing a stance which forms a hierarchy, a correlation between uncommon disease and specific information frames, with the research frame coming out strongest.

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27 Medical, economic press, gossip papers, sports, disability, scientific publications and those specialising in communication.
the Dependency Law, economic aspects or disability are brought into the news, as ingredients which normally come along with life stories published. These frames form a more complex approach through combining aspects and arguments not found in the national press. The local sphere as a synonym of closeness expresses less simplistic standpoints, with a polyhedral approach to rare diseases linked to the support created for those affected (Álvarez and Ramírez, 2010). This happens in the same way for the free press as it did in the national publications, with the highest frequency values being found in the topics affecting research and politics. What is more, as also occurred in the national press, the free papers exploit the concept of solidarity or help, with a frequency value of 16 as compared with the 35 for research. Likewise, the same journalistic patterns of action can be found in the specialised press. In the scientific newspapers the specific frame focuses on politics. In medical papers the information covers the topics given for the general press, characteristics of rare diseases, policies, and above all references to medical research that is being carried out. In the economic press research is also the most repeated frame, but now giving priority to aspects connected with the economic facet for the first time. For the press specialising in disability attention is split between institutional policy, research and solidarity or aid. In contrast to all of these, the sports press gives priority to the solidarity frame, which means providing the press treatment of RD with an essentially emotional quality, a facet connected with the emotive discourse proper to this type of media.

The analysis of value frequency also gives similar data in the case of information from agencies. The highest values lie in the topics of disease, politics and research, followed by solidarity. Similar conclusions are attained for general magazines: disease, politics, research and solidarity, as the most commonly repeated values. The same thing happens in the study of digital papers, in both the general and specialised ones, where the most relevant topics have been framed in terms of research, institutional policy and solidarity.

The analysis thus reveals the enormous power that the media give to the research approach, which appears to be a rising value in most of these.
3. RDS VERSUS ONE RD IN THE THEMATIC AGENDA

The media come forward as necessary instruments to end the social invisibility of RD, taking into account that the way the information is structured has an effect on how this reality and those affected are thought of, as explained in the methodological chapter. In this respect, it is of interest to find out whether the media have an influence on the aim of either considering RD as a whole, needing common policies, or whether they report on one of the thousands of individual RD, stressing singularity as regards the type of medium, the frame or the information topic. This slant stems from the European Commission’s assertion that “rare diseases call for a global approach based on special and combined efforts to prevent significant morbidity or avoidable early mortality, and to improve the quality of life or socio-economic potential of affected persons”.

The statistical association stemming from the variables ‘RD are talked about in general or not’ and the type of medium is very high: \( \chi^2 (38, N= 2445)= 76.194, P< .0001 \). In 60.7 per cent of the insertions recorded the general media refer to ‘RDs’ as opposed to the 32.7 per cent of the occasions when a specific RD is dealt with. In the specialised media the proportion of items in which information is given about aspects connected with an RD in particular increases, with a percentage close to 40 per cent (39.3).

![Graph 14: RD vs. one RD](image)

Test \( \chi^2 \) also shows the relationship with the thematic frame of the piece: \( \chi^2 (16, N= 2445) = 188.636, P< 0.0001 \). Hence, in over 80% of the pieces on Solidarity they refer to RD in general. There are also references with high percentages - over seventy per cent - to RD in general and to the Life Stories frame, specific cases which are structured in the general problem of RD (79.5%); in Events (72.6%) and in Denunciation (72.6%). The Scientific Research (48.4%) and Dependency Law (40%) frames are seen to get under fifty per cent, that is, referring to a greater extent to a specific RD.

A similar statistical result is produced by crossing with information topics \( \chi^2 (28, N= 2445)= 264.437, P< 0.0002 \). The topics in which the appearance of RD is highlighted as a global term are again Solidarity (in 81.7% of the pieces), followed by the Dependency Law (75%), Disability (73.3%) and Disease (73%). On the other hand, they allude to one specific RD to a greater extent when information is given about problems referring to the Economy (69%), to Transport or Adapted Facilities (60 per cent of the occasions), and Post-diagnosis in 58.6% of the pieces registered. In this respect, differences could be pointed out as compared with the Pre-Diagnosis topic, in which there are more commonly references to RD in general (68% of the information).

4. DIFFERENT ROLES FOR EACH INSTITUTIONAL REPRESENTATIVE

The relationship established between the “institutional representative” and “frame” categories proves highly significant: \( \chi^2 (72, N= 2445)= 323.278, P< 0.0001 \). This means that the spokesperson of an institution is seen preferentially associated with a particular number of information frames, revealing the viewpoint of whoever drew up the information and consequently with a clear influence on the reader. Hence, the name of former Health Minister Sanidad Trinidad Jiménez is found predominantly connected with the institutional policy frame, with a frequency value of 26, and also, though to a lesser extent, with that of formal events, with a score of 8. On far fewer occasions it is linked with research, denunciation or LdD frames, with only 4, 3 and 2 hits respectively.

The CIBERER representative is usually found in the frame of demand for recognition, through claiming greater visibility for RD in society, and in that of research (with a frequency of 12 and 7 respectively). In this respect, for doctor Francesc Palau his profile as a
researcher is prevalent, due to being identified with the policy of the institution to which he belongs. He is nevertheless also associated with other information frames, though of lower weight: formal event, testimonies, Dependency Law and that of solidarity. The figures obtained by the institution which he represents alone are not very significant. Additionally, the names of ministers Cristina Garmendia and Elena Salgado are associated with the frame of institutional policy, with 17 and 3 frequency values respectively. Footballer Andrés Iniesta is related only with the solidarity frame, where he gets 3 entries. The representative of FEDER, Rosa Sánchez de Vega, has hits in the information structure of denunciation through lobbying for an action plan for RD: a clear association can also be found between the proper names of the institutional representatives and the topical frames in the analysis on the treatment of these diseases in the media. Crossing both variables shows a clear relationship, as shown by the formula: \[x^2 (126, N= 2445)= 365.495, P<, 0003]\.

Journalists preferentially get the material for their information from institutional sources, which is why the frame of institutional policy is prevalent, as has already been pointed out. The results of the research therefore turn out to match those found in the general frames. The name of Trinidad Jiménez gets high figures in the institutional policy frame, with a value of 30, in the research frame with 9 and in that of the economy with 5, all of these being aspects inherent to the post that she holds. In the texts in which Minister Cristina Garmendia appears there is a prevalence of the institutional and economy frames, connected with budget cutbacks, and research, as confirmed by the numbers of 13, 9 and 6 obtained. The same frames are used in news on Minister Elena Salgado, although the numbers are much lower. The specific frames of research and institutional policy are used as a priority in the news items in which Francesc Palau appears, with values of 11 and 16 respectively.

In the news items in which the name of sportsman Andrés Iniesta appears the value of solidarity is used as their specific topic; in information covering the representative of FEDER the topics used are the frames of institutional policy, solidarity and alienation, with values of 4, 2 and 2. Again, when talking about CIBERER or FEDER the numbers recorded are rather low. The discourse on the former has as priorities the frame of institutional policy, with a value of one in each of these, while in the case of FEDER institutional policy is the main approach, with a value of 4, and research and solidarity, with a frequency value of 1 for each of these, as arguments clearly associated with the objectives pursued by each body.

### 5. RARE DISEASES: INFORMATION HIERARCHY AND THE READER’S PARTICIPATION IN GENERAL AND SPECIALISED MEDIA

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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: \[x^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 symbolic 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.