Information on rare diseases in Europe: a survey of organisations, their needs, sources, tools, services and expectations.

Final report prepared by Eurordis. Part 2

Data processing and analysis: Research International

March 2004
Summary

- Survey description
  - Context
  - Objectives
  - Methodology and sample description

- Results
  - 1. Description of the organisations
  - 2. Information
    - 2.1 Sources
    - 2.2 Tools
    - 2.3 Access to information
  - 3. Information Needs

- Conclusions
2 Information

2.2 Tools
### Means used to deliver information

**Q16 MEANS USED TO DELIVER YOUR INFORMATION**  * limited data

<table>
<thead>
<tr>
<th>Base</th>
<th>%Total</th>
<th>Central / Eastern Europe</th>
<th>Northern Europe</th>
<th>Western Europe</th>
<th>Southern Europe</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Z</td>
<td>A</td>
<td>B</td>
<td>C</td>
<td>D</td>
</tr>
<tr>
<td>At least one mention</td>
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<td>100</td>
<td>99</td>
<td>100</td>
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<tr>
<td>Specifically written leaflets</td>
<td>84 &gt;B</td>
<td>95 &gt;ZBC</td>
<td>73</td>
<td>85 &gt;B</td>
<td>86 &gt;B</td>
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<tr>
<td>Relevant medical texts</td>
<td>43</td>
<td>61 &gt;ZBCD</td>
<td>36</td>
<td>44</td>
<td>36</td>
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<tr>
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<td>98 &gt;ZBCD</td>
<td>64</td>
<td><strong>88 &gt;BD</strong></td>
<td>76</td>
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<tr>
<td>Referring enquirer to an expert</td>
<td>69</td>
<td>88 &gt;ZBCD</td>
<td>58</td>
<td>67</td>
<td>70</td>
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<tr>
<td>Face to face meetings, one to one discussions</td>
<td>55</td>
<td>68 &gt;CD</td>
<td>57</td>
<td>52</td>
<td>50</td>
</tr>
<tr>
<td>Emailed advice</td>
<td>67</td>
<td>76 &gt;B</td>
<td>57</td>
<td>69</td>
<td>66</td>
</tr>
<tr>
<td>Website</td>
<td>71</td>
<td>81 &gt;D</td>
<td>77</td>
<td>68</td>
<td>65</td>
</tr>
<tr>
<td>General purpose letters</td>
<td>28</td>
<td>29</td>
<td>27</td>
<td>21</td>
<td><strong>41 &gt;ZC</strong></td>
</tr>
<tr>
<td>Person-to-person letters</td>
<td>44 &gt;B</td>
<td>58 &gt;ZBD</td>
<td>23</td>
<td><strong>52 &gt;B</strong></td>
<td><strong>38 &gt;B</strong></td>
</tr>
<tr>
<td>Group meetings</td>
<td>70 &gt;D</td>
<td>81 &gt;D</td>
<td><strong>84 &gt;ZCD</strong></td>
<td>69 &gt;D</td>
<td>53</td>
</tr>
<tr>
<td>Newsletter</td>
<td>72 &gt;D</td>
<td>63</td>
<td>73 &gt;D</td>
<td><strong>84 &gt;ZABD</strong></td>
<td>53</td>
</tr>
</tbody>
</table>

> Z: results significantly higher than total
> A, B, C or D: results significantly higher than A, B, C or D
All possible information tools are largely used: the 8 main medias at organisations’ disposal are used by 55% to 84% of them. Only person-to-person letters, medical texts and general purpose letters are less frequently used.
Information services with salaried staff have more individualised medias

Information delivery more individualised for services with salaried staff

These organisations can probably dedicate more time to prepare tailored responses.
Some are more frequently used in some regions

Group meetings in Northern countries

Newsletter

Referring to an expert in Central/Eastern countries

Face to face meetings in Central/Eastern countries

Person to person letters in Western and Central/Eastern countries

Other are used more homogeneously

Written leaflets

Direct telephone advice

Website

Emailed advice
## Means used according to area of activity

**Q16 MEANS USED TO DELIVER YOUR INFORMATION**  **very limited data**

<table>
<thead>
<tr>
<th>Base</th>
<th>Total</th>
<th>Information</th>
<th>Services to patients</th>
<th>Care</th>
<th>Research</th>
<th>Lobbying</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Z</td>
<td>A</td>
<td>B</td>
<td>C</td>
<td>D</td>
<td>E</td>
</tr>
<tr>
<td>At least one mention</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>98</td>
<td>99</td>
<td>100</td>
</tr>
<tr>
<td>Specifically written leaflets</td>
<td>84</td>
<td>85</td>
<td>90</td>
<td>82</td>
<td>87</td>
<td>88</td>
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<tr>
<td>Direct One to one telephone advice</td>
<td>82</td>
<td>84</td>
<td>85</td>
<td>75</td>
<td>86</td>
<td>80</td>
</tr>
<tr>
<td>Newsletter</td>
<td>72</td>
<td>73</td>
<td>75</td>
<td>71</td>
<td>77</td>
<td>76</td>
</tr>
<tr>
<td>Website</td>
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<td>72</td>
<td>73</td>
<td>75</td>
<td>74</td>
<td>72</td>
</tr>
<tr>
<td>Group meetings</td>
<td>70</td>
<td>71</td>
<td>71</td>
<td>69</td>
<td>72</td>
<td>78 &gt;Z</td>
</tr>
<tr>
<td>Referring enquirer to an expert</td>
<td>69</td>
<td>70</td>
<td>74</td>
<td>75</td>
<td>76</td>
<td>70</td>
</tr>
<tr>
<td>Emailed advice</td>
<td>67</td>
<td>69</td>
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<td>69</td>
<td>72</td>
<td>66</td>
</tr>
<tr>
<td>Face to face meetings, one to one discussions</td>
<td>55</td>
<td>55</td>
<td>60</td>
<td>71</td>
<td>60</td>
<td>62</td>
</tr>
<tr>
<td>Person-to-person letters</td>
<td>44</td>
<td>44</td>
<td>49</td>
<td>43</td>
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<td>44</td>
</tr>
<tr>
<td>Relevant medical texts</td>
<td>43</td>
<td>44</td>
<td>47</td>
<td>43</td>
<td>51</td>
<td>47</td>
</tr>
<tr>
<td>General purpose letters</td>
<td>28</td>
<td>28</td>
<td>31</td>
<td>37</td>
<td>26</td>
<td>33</td>
</tr>
</tbody>
</table>

> Z: results significantly higher than total  
> A, B, C, D or E: results significantly higher than A, B, C, D or E
Medias are used for all activities, none is specific to one in particular

Specifically written leaflets

Direct One to one telephone advice

Website

Referring enquirer to an expert
### Q18 Is there a helpline in your organisation?

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Central / Eastern</th>
<th>Northern Europe</th>
<th>Western Europe</th>
<th>Southern Europe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base : Total</td>
<td>372</td>
<td>59*</td>
<td>74*</td>
<td>153</td>
<td>86*</td>
</tr>
<tr>
<td>Yes</td>
<td>82 &gt;B</td>
<td>90 &gt;B</td>
<td>57</td>
<td>90 &gt;ZB</td>
<td>85 &gt;B</td>
</tr>
</tbody>
</table>

### Q19 Are operators trained for the helpline?

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Central / Eastern</th>
<th>Northern Europe</th>
<th>Western Europe</th>
<th>Southern Europe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base : Help line</td>
<td>306</td>
<td>53**</td>
<td>42**</td>
<td>138</td>
<td>73*</td>
</tr>
<tr>
<td>Yes</td>
<td>53</td>
<td>45</td>
<td>43</td>
<td>49</td>
<td>71 &gt;ABC</td>
</tr>
</tbody>
</table>

### Q20 Availability of your helpline

<table>
<thead>
<tr>
<th></th>
<th>Base : Help line</th>
<th>306</th>
<th>53**</th>
<th>42**</th>
<th>138</th>
<th>73*</th>
</tr>
</thead>
<tbody>
<tr>
<td>24 hours</td>
<td>34</td>
<td>42</td>
<td>36</td>
<td>32</td>
<td>32</td>
<td></td>
</tr>
<tr>
<td>Office hours</td>
<td>43</td>
<td>40</td>
<td>36</td>
<td>47</td>
<td>42</td>
<td></td>
</tr>
<tr>
<td>Evening</td>
<td>29 &gt;D</td>
<td>21</td>
<td>36 &gt;D</td>
<td>38 &gt;AD</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>At weekend</td>
<td>19</td>
<td>19</td>
<td>14</td>
<td>26 &gt;D</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>In the morning</td>
<td>19 &gt;B</td>
<td>19 &gt;B</td>
<td>2</td>
<td>22 &gt;B</td>
<td>21 &gt;B</td>
<td></td>
</tr>
<tr>
<td>In the afternoon</td>
<td>20 &gt;B</td>
<td>23 &gt;B</td>
<td>7</td>
<td>25 &gt;B</td>
<td>16</td>
<td></td>
</tr>
</tbody>
</table>

** very limited data, cautious interpretation

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In Northern Europe, nation-wide helplines exist. Other organisations do not need to run their own. In Southern Europe, training is often a condition to receive funds. As organisations are younger, more training may be needed.
Unless created from the beginning, it takes more than 10 years to operate a helpline

Existence of an helpline, by age of organisations

Organisations of more than 10 year-old operate more often during office hours

Hours of operation according to age of organisations
And helplines operating during office hours also have more volunteers

Organisations with more than 15 volunteers

![Diagram showing hours of operation for organisations with more than 15 volunteers. The diagram includes the following hours:
- Office hours
- In the morning
- In the afternoon
- Evening
- At weekend
- 24 hours
- 60% and 40%]

63
Availability of helplines, by region

Lines operating 24 hours or during office hours: no difference between regions

Office hours

24 hours

For other periods, differences exist between regions

Evening

In the afternoon

At weekend

In the morning
Existence of a helpline, by activity

** very limited data, cautious interpretation

<table>
<thead>
<tr>
<th>Q18 Helpline in your organisation</th>
<th>Total</th>
<th>Information</th>
<th>Services to patients</th>
<th>Care</th>
<th>Research</th>
<th>Lobbying</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base: Total</td>
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<td>360</td>
<td>284</td>
<td>51**</td>
<td>151</td>
<td>193</td>
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<tr>
<td>Yes</td>
<td>82</td>
<td>84</td>
<td>87</td>
<td>86</td>
<td>91 &gt;ZAEF</td>
<td>83</td>
<td>80</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q 19 Operators trained for helpline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base: Help line</td>
</tr>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>

Existence of helpline, by activity

Operators trained for helpline, by activity

Medical training or training for social workers takes place at school, during their degree, not specifically within the information service: this may be why operators in groups that provide care are declared as more often trained.
Monitoring the helpline

Q20bis. Here are some questions about the monitoring of your help line. (Answer by yes or no)

Helpline monitoring (percentage positive answers)
Monitoring the helpline, by region

Do you use volunteers?

- Northern: 74%
- Central/eastern: 64%
- Western: 64%
- Southern: 53%

Do you hold directories of hospital and social services?

- Northern: 36%
- Central/eastern: 73%
- Western: 57%
- Southern: 78%

Do you hold directories of patient groups?

- Northern: 55%
- Central/eastern: 64%
- Western: 89%
- Southern: 84%

Do you use the information you collect from enquirers to promote improvement in care, policy, legislation?

- Northern: 52%
- Central/eastern: 85%
- Western: 73%
- Southern: 83%

Do you keep track of enquirers to call them back?

- Northern: 57%
- Central/eastern: 92%
- Western: 89%
- Southern: 93%
### Helpline according to status of staff – 9/12

**Q18. Is there a help line in your organisation? / Q19. Are the operators trained for this purpose? / Q20. How long is your help line available?**

<table>
<thead>
<tr>
<th>Q18 Helpline in your organisation</th>
<th>Total</th>
<th>No salaried staff</th>
<th>Salaried staff employed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base : Total</td>
<td>372</td>
<td>253</td>
<td>118</td>
</tr>
<tr>
<td>Yes</td>
<td>82</td>
<td>79</td>
<td>90</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q19 Operators trained for a helpline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base : Help line</td>
</tr>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q20 Availability of your helpline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base : Help line</td>
</tr>
<tr>
<td>Office hours</td>
</tr>
<tr>
<td>24 hours</td>
</tr>
<tr>
<td>Evening</td>
</tr>
<tr>
<td>In the afternoon</td>
</tr>
<tr>
<td>At weekend</td>
</tr>
<tr>
<td>In the morning</td>
</tr>
</tbody>
</table>

It definitely helps to employ paid staff to run a helpline, but still, 79% of organisations without salaried staff run a helpline.

The main difference lies in operating hours: fewer organisations employing paid staff are able to open the line in the evening or during weekends.

> Z: results significantly higher than total
> A or B: results significantly higher than A or B
Organisations with paid staff more often operate a helpline:

Existence of helpline according to paid/unpaid staff

Chi² test

p < 0.05

79% 90%

Organisations with a helpline:

No salaried staff Salaried staff

And their operators are more often trained:

Helpline operators' training according to paid/unpaid status

Chi² test

p < 0.001

42% 74%
Availability of helpline is significantly different when operated by paid staff

Availability of helplines according to operators’ status

- Office hours: 100%  \( p < 0.001 \)
- In the morning: 0%  \( p < 0.05 \)
- At weekend: 0%  \( p < 0.001 \)
- In the afternoon: 0%  \( p < 0.01 \)
- Evening: 0%  \( p < 0.01 \)
- 24 hours: 0%  \( p < 0.001 \)

Legend:
- \( \square \): No salaried staff
- \( \square \): Salaried staff
The monitoring of the helpline, by operators’ status

Q20bis. Here are some questions about the monitoring of your helpline. (Answer by yes or no)

Activity of helpline according to operators' status (% "yes")

- Are volunteers supervised? [29% paid staff, 42% no paid staff]
- Are volunteers trained? [29% paid staff, 44% no paid staff]
- Do you have procedures? [25% paid staff, 59% no paid staff]
- Do you have a guideline on confidentiality? [47% paid staff, 68% no paid staff]
- Do you hold directories of hospital and social services? [55% paid staff, 74% no paid staff]
- Do you use volunteers to operate the help line? [45% paid staff, 72% no paid staff]
- Do you use the information you collect? [72% paid staff, 84% no paid staff]
- Do you hold directories of patient groups? [76% paid staff, 84% no paid staff]
- Is the help line in a confidential area? [32% paid staff, 79% no paid staff]
- Do you keep track of enquirers? [83% paid staff, 92% no paid staff]
## Collecting and supervising Information

* limited data

<table>
<thead>
<tr>
<th>Q21</th>
<th>The collecting and supervising of your information</th>
<th>%Total</th>
<th>Central / Eastern Europe</th>
<th>Northern Europe</th>
<th>Western Europe</th>
<th>Southern Europe</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Z</td>
<td>A</td>
<td>B</td>
<td>C</td>
<td>D</td>
</tr>
<tr>
<td>Base: helpline 372</td>
<td></td>
<td>59*</td>
<td>74*</td>
<td>153</td>
<td>86*</td>
<td></td>
</tr>
<tr>
<td>Do you have a medical advisory board (MAB)?</td>
<td>63 &gt;B</td>
<td>73 &gt;B</td>
<td>50</td>
<td>65 &gt;B</td>
<td>63</td>
<td></td>
</tr>
<tr>
<td>Do specific advisors answer specific questions?</td>
<td>73</td>
<td>83 &gt;BD</td>
<td>65</td>
<td>75</td>
<td>67</td>
<td></td>
</tr>
<tr>
<td>Does your MAB assist in creating leaflets/web pages/e-mail responses?</td>
<td>55 &gt;B</td>
<td>59 &gt;B</td>
<td>42</td>
<td>56 &gt;B</td>
<td>63 &gt;B</td>
<td></td>
</tr>
<tr>
<td>Do you scan medical texts/journals for information?</td>
<td>74 &gt;B</td>
<td>88 &gt;ZB</td>
<td>54</td>
<td>78 &gt;B</td>
<td>76 &gt;B</td>
<td></td>
</tr>
<tr>
<td>Do you read other rare disease group newsletters?</td>
<td>83</td>
<td>75</td>
<td>78</td>
<td>86 &gt;A</td>
<td>85</td>
<td></td>
</tr>
<tr>
<td>Do you know how to do a web-search?</td>
<td>94</td>
<td>100 &gt;BD</td>
<td>89</td>
<td>94</td>
<td>93</td>
<td></td>
</tr>
<tr>
<td>Does your MAB regularly monitor your information?</td>
<td>42</td>
<td>56 &gt;ZBD</td>
<td>35</td>
<td>44</td>
<td>34</td>
<td></td>
</tr>
<tr>
<td>Do you tailor the information you send to enquirers according to their needs?</td>
<td>84 &gt;B</td>
<td>90 &gt;B</td>
<td>55</td>
<td>93 &gt;ZB</td>
<td>87 &gt;B</td>
<td></td>
</tr>
<tr>
<td>Do you have a volunteer to collate information?</td>
<td>46 &gt;B</td>
<td>59 &gt;BD</td>
<td>30</td>
<td>52 &gt;B</td>
<td>42</td>
<td></td>
</tr>
<tr>
<td>Do you have a paid staff member for information-delivery?</td>
<td>26 &gt;B</td>
<td>25</td>
<td>12</td>
<td>27 &gt;B</td>
<td>35 &gt;B</td>
<td></td>
</tr>
</tbody>
</table>

Central / Eastern Europe organisations scan medical journals more often, and their advisory board is more involved in reviewing information. Volunteers to collate information are also more frequent.

Western Europe organisations more often tailor the information they send to enquirers.
Collecting and supervising information

Do you have a medical advisory board (MAB)?

- Northern: 50%
- Central/Eastern: 73%
- Western: 65%
- Southern: 63%

Do you scan medical texts/journals for information?

- Northern: 54%
- Central/Eastern: 88%
- Western: 78%
- Southern: 76%

Does your MAB regularly monitor your information?

- Northern: 35%
- Central/Eastern: 56%
- Western: 44%
- Southern: 34%

Does your MAB assist in creating leaflets/web pages/e-mail responses?

- Northern: 42%
- Central/Eastern: 59%
- Western: 56%
- Southern: 63%

In Central/Eastern Europe, medical advisory boards are more involved in reviewing information.
Collecting and supervising information

Do you have a volunteer to collate information?

Central / Eastern Europe organisations more often use volunteers to collate information.

Do you tailor the information you send to enquirers according to their needs?

Western Europe organisations more often tailor the information they send to enquirers.

Do you have a paid staff member for information-delivery?

Northern Europe organisations less often employ paid staff to deliver information.
Information provided differs according to status of staff

When organisations can afford employing salaried staff, they can specifically develop some information domains like welfare benefits, psychological services, centres of excellence, special education needs, home care...
Collection and supervision of information differs according to status of staff

How do you supervise the collection of information?

- Know how to do a web-search
- Tailor the information
- Read other rare disease group news
- Specific advisors answer questions
- Scan medical texts
- Medical advisory board assists in responding
- MAB monitors information
- Volunteers collate information
- Paid staff member delivers information

<table>
<thead>
<tr>
<th>Supervision Activity</th>
<th>Salaried staff</th>
<th>No Salaried staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Know how to do a web-search</td>
<td>97%</td>
<td>91%</td>
</tr>
<tr>
<td>Tailor the information</td>
<td>89%</td>
<td>83%</td>
</tr>
<tr>
<td>Read other rare disease group news</td>
<td>81%</td>
<td>71%</td>
</tr>
<tr>
<td>Specific advisors answer questions</td>
<td>79%</td>
<td>69%</td>
</tr>
<tr>
<td>Scan medical texts</td>
<td>81%</td>
<td>71%</td>
</tr>
<tr>
<td>Medical advisory board assists in responding</td>
<td>70%</td>
<td>64%</td>
</tr>
<tr>
<td>MAB monitors information</td>
<td>59%</td>
<td>51%</td>
</tr>
<tr>
<td>Volunteers collate information</td>
<td>51%</td>
<td>48%</td>
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<tr>
<td>Paid staff member delivers information</td>
<td>48%</td>
<td>38%</td>
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<tr>
<td></td>
<td>2%</td>
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</tbody>
</table>
The most universally provided information is specific information on the disease, then expert doctors. 
Information provided differs by region.
## Kind of Information provided – 2/2

* limited data

<table>
<thead>
<tr>
<th>Q17 Kind of information provided by less than 50% of organisations</th>
<th>Total pays</th>
<th>Central / Eastern Europe</th>
<th>Northern Europe</th>
<th>Western Europe</th>
<th>Southern Europe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base</td>
<td>Z</td>
<td>A</td>
<td>B</td>
<td>C</td>
<td>D</td>
</tr>
<tr>
<td>Prognosis</td>
<td>41</td>
<td>58 &gt;ZBCD</td>
<td>39</td>
<td>39</td>
<td>35</td>
</tr>
<tr>
<td>Clinical trials</td>
<td>34</td>
<td>32</td>
<td>30</td>
<td>39</td>
<td>33</td>
</tr>
<tr>
<td>Medicinal products</td>
<td>44</td>
<td>39</td>
<td>39</td>
<td>47</td>
<td>48</td>
</tr>
<tr>
<td>Dietary products</td>
<td>20</td>
<td>24</td>
<td>23</td>
<td>20</td>
<td>14</td>
</tr>
<tr>
<td>Alternative medicine, herbal medicine</td>
<td>18</td>
<td>44 &gt;ZBCD</td>
<td>15</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>Aids and equipment, devices and small accessories</td>
<td>49</td>
<td>63 &gt;C</td>
<td>49</td>
<td>46</td>
<td>47</td>
</tr>
<tr>
<td>Home care</td>
<td>36</td>
<td>46</td>
<td>32</td>
<td>32</td>
<td>38</td>
</tr>
<tr>
<td>Transport, auxiliaries</td>
<td>24</td>
<td>17</td>
<td>34 &gt;AD</td>
<td>25</td>
<td>16</td>
</tr>
<tr>
<td>Genetic services</td>
<td>44</td>
<td>49</td>
<td>38</td>
<td>48</td>
<td>40</td>
</tr>
<tr>
<td>Special education needs</td>
<td>42</td>
<td>36</td>
<td>32</td>
<td>45</td>
<td>48</td>
</tr>
<tr>
<td>Community care</td>
<td>25</td>
<td>25</td>
<td>27</td>
<td>26</td>
<td>21</td>
</tr>
<tr>
<td>Respite care</td>
<td>26 &gt;B</td>
<td>47 &gt;ZBC</td>
<td>15</td>
<td>19</td>
<td>34 &gt;BC</td>
</tr>
</tbody>
</table>

> Z: results significantly higher than total
> A, B, C or D: results significantly higher than A, B, C or D
Information provided (% organisations)

Even though few questions are asked about some of these subjects (see section on Information needs), services still develop efforts to have it available. E.g., Information on orphan drugs and other medicinal products is important: 44% of organisations provide information on medicinal products.
Information provided, by region

Prognosis
- Northern: 39%
- Central/Eastern: 58%
- Western: 39%
- Southern: 35%

Central/Eastern p<0.01

Treatment/clinical management
- Northern: 57%
- Western: 73%
- Central: 80%
- Southern: 50%

Central p<0.05

Clinical trials
- Northern: 30%
- Western: 32%
- Central: 33%
- Southern: 30%

Medicinal products
- Northern: 39%
- Western: 47%
- Central: 48%
- Southern: 39%

Mechanics of the disease
- Northern: 53%
- Western: 67%
- Central: 66%
- Southern: 45%
Information provided, by region (continued)

- **Expert doctors:**
  - North (N): 76%
  - Centre (C): 92%
  - South (S): 84%
  - West (W): 75%

- **Respite care:**
  - North (N): 15%
  - Centre (C): 47%
  - South (S): 34%
  - West (W): 19%

- **Local support groups:**
  - North (N): 53%
  - Centre (C): 63%
  - South (S): 43%
  - West (W): 32%

- **Home care:**
  - North (N): 32%
  - Centre (C): 46%
  - South (S): 38%
  - West (W): 32%

- **Centres of excellence:**
  - North (N): 47%
  - Centre (C): 64%
  - South (S): 67%
  - West (W): 43%

Significance levels:
- **p<0.05** for Centre (C) in local support groups
- **p<0.01** for Centre (C) in local support groups
- **p<0.001** for Centre (C) in respite care and centres of excellence
Information provided, by region (continued)

Specific information on disease

Current research

Special education needs

Scientific conferences

Genetic services

p<0.01

p<0.05

p<0.001
Information provided, by region (continued)
2.3 Access to information
### How is your organisation reached?

**Q23.** Regarding access to information, how do people reach your organisation? (Answer by yes or no).

**Q24.** Do you have an outreach strategy?

* Limited data

<table>
<thead>
<tr>
<th>Q23 How do people reach your organisation?</th>
<th>% Total</th>
<th>Central / eastern Europe</th>
<th>Northern Europe</th>
<th>Western Europe</th>
<th>Southern Europe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base: Help line</td>
<td>372</td>
<td>Z: 59*</td>
<td>B: 74*</td>
<td>C: 153</td>
<td>D: 86*</td>
</tr>
<tr>
<td>Health professionals refer patients to you</td>
<td>86</td>
<td>93 &gt;BD</td>
<td>81</td>
<td>89</td>
<td>80</td>
</tr>
<tr>
<td>Patients reach you through other organisations</td>
<td>74 &gt;B</td>
<td>81 &gt;B</td>
<td>57</td>
<td>81 &gt;B</td>
<td>71</td>
</tr>
<tr>
<td>Patients reach you through a website</td>
<td>88 &gt;B</td>
<td>95 &gt;B</td>
<td>77</td>
<td>92 &gt;B</td>
<td>85</td>
</tr>
<tr>
<td>Clinics/hospitals display your information</td>
<td>70 &gt;D</td>
<td>81 &gt;D</td>
<td>76 &gt;D</td>
<td>71</td>
<td>58</td>
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<tr>
<td>Medical centres welcome the presence of a group representative</td>
<td>33</td>
<td>32</td>
<td>28</td>
<td>30</td>
<td>44 &gt;BC</td>
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</table>

<table>
<thead>
<tr>
<th>Q24 Outreach strategy</th>
<th>Base: Total</th>
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<th>59*</th>
<th>74*</th>
<th>153</th>
<th>86*</th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
<td>66</td>
<td>68</td>
<td>65</td>
<td>67</td>
<td>65</td>
<td></td>
</tr>
</tbody>
</table>

> Z: results significantly higher than total  
> A, B, C or D: results significantly higher than A, B, C or D
Websites, health professionals and patient organisations are key for accessing information services

Patients reach your organisation through...

Although websites and health care professionals constitute the main keys for accessing information services, other organisations and information displayed at clinics play an important role too.
Access to information services, by region

Patients reach you through a website

- Northern: 77%
- Central/eastern: 95%
- Southern: 85%
- Western: 92%

Health professionals refer patients to you

- Northern: 81%
- Central/eastern: 93%
- Southern: 81%
- Western: 89%

Clinics/hospitals display your information

- Northern: 76%
- Central/eastern: 58%
- Southern: 71%
- Western: 81%

Medical centres welcome the presence of a group representative

- Northern: 28%
- Central/eastern: 32%
- Southern: 44%
- Western: 30%

Patients reach you through other organisations

- Northern: 57%
- Central/eastern: 71%
- Southern: 81%
- Western: 81%

p<0.01
p<0.05
p<0.001
**How do you raise awareness ?**

*Q26. How do you raise awareness on rare diseases ? (Answer by yes or no).*

<table>
<thead>
<tr>
<th>Q26 How do you raise awareness?</th>
<th>%Total</th>
<th>Central / Eastern Europe</th>
<th>Northern Europe</th>
<th>Western Europe</th>
<th>Southern Europe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base</td>
<td>372</td>
<td>59*</td>
<td>74*</td>
<td>153</td>
<td>86*</td>
</tr>
<tr>
<td>At least one mention</td>
<td>96</td>
<td>97</td>
<td>95</td>
<td>96</td>
<td>97</td>
</tr>
<tr>
<td>Does your group target information to professionals ?</td>
<td>79</td>
<td>90 &gt;BC</td>
<td>69</td>
<td>78</td>
<td>83 &gt;B</td>
</tr>
<tr>
<td>Do you hold conferences for All Interested Parties ?</td>
<td>80 &gt;B</td>
<td>80</td>
<td>69</td>
<td>85 &gt;B</td>
<td>80</td>
</tr>
<tr>
<td>Do you offer workshops/information tools for non-specialist professionals ?</td>
<td>41 &gt;C</td>
<td>54 &gt; C</td>
<td>47 &gt;C</td>
<td>31</td>
<td>44 &gt;C</td>
</tr>
<tr>
<td>Do you offer workshops/information tools for decision-makers ?</td>
<td>25 &gt;B</td>
<td>41 &gt; ZBC</td>
<td>14</td>
<td>18</td>
<td>36 &gt;ZBC</td>
</tr>
<tr>
<td>Do you offer workshops/information tools for the media ?</td>
<td>42 &gt;BC</td>
<td>51 &gt;BC</td>
<td>24</td>
<td>31</td>
<td>69 &gt;ZABC</td>
</tr>
<tr>
<td>Do you liaise with medical schools to define university programmes</td>
<td>12</td>
<td>20 &gt;B</td>
<td>8</td>
<td>11</td>
<td>9</td>
</tr>
</tbody>
</table>

> Z: results significantly higher than total  
> A, B, C or D: results significantly higher than A, B, C or D

Rare diseases organisations mainly rely on conferences and information to professionals to increase awareness on their existence and on issues related to rare diseases.
How do you raise awareness?

Does your group target information to professionals?

- Northern: 69%
- Central/Eastern: 90%
- Western: 78%
- Southern: 83%

Do you hold conferences for All Interested Parties?

- Northern: 69%
- Central/Eastern: 85%
- Western: 80%
- Southern: 80%

Do you offer workshops/information tools for non-specialist professionals?

- Northern: 54%
- Central/Eastern: 47%
- Western: 31%
- Southern: 18%

Do you offer workshops/information tools for the media?

- Northern: 24%
- Central/Eastern: 51%
- Western: 31%
- Southern: 69%

Do you liaise with medical schools to define university programmes?

- Northern: 9%
- Central/Eastern: 11%
- Western: 8%
- Southern: 20%

Interestingly, there is very limited communication with medical schools.
Awareness strategies: salaried staff helps

More awareness strategies when organisation employs salaried staff

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Salaried staff</th>
<th>No salaried staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conferences for Interested Parties</td>
<td>87% *</td>
<td>75%</td>
</tr>
<tr>
<td>Target information to professionals</td>
<td>86% †</td>
<td>75%</td>
</tr>
<tr>
<td>Workshops for the media</td>
<td>58% *</td>
<td>34% *</td>
</tr>
<tr>
<td>Workshops for non-specialist professionals</td>
<td>60% *</td>
<td>32%</td>
</tr>
<tr>
<td>Workshops for decision-makers</td>
<td>42% *</td>
<td>17% *</td>
</tr>
<tr>
<td>Liaise with medical schools</td>
<td>15%</td>
<td>10% NS</td>
</tr>
</tbody>
</table>

*: p < 0.001
†: p < 0.05
3 Information Needs
Patients are actively searching for information: they represent 54% of enquiries, even though rare diseases are often disabling.

There is a clear difference between mother and father: roles are distributed between the mother as the carer and the father as a source of revenues for the family. Fathers may sometimes refuse to acknowledge the disease.

### Who’s the enquirer?

#### Q13. Who is the primary enquirer?

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Central / Eastern Europe</th>
<th>Northern Europe</th>
<th>Western Europe</th>
<th>Southern Europe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base</td>
<td>372</td>
<td>59*</td>
<td>74*</td>
<td>153</td>
<td>86*</td>
</tr>
<tr>
<td>The patient</td>
<td>54</td>
<td>53</td>
<td>57</td>
<td>58</td>
<td>47</td>
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<tr>
<td>The mother</td>
<td>40</td>
<td>42</td>
<td>32</td>
<td>37</td>
<td>52 &gt; Z</td>
</tr>
<tr>
<td>The father</td>
<td>2</td>
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<td>3</td>
<td>2</td>
<td>1</td>
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<tr>
<td>The brother</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>The sister</td>
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<td>0</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
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<td>The grandparent</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>The friend</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>The medical professional</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>2</td>
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</table>

* limited data

> Z: results significantly higher than total
> A, B, C or D: results significantly higher than A, B, C or D
What information is needed?

* Limited data

<table>
<thead>
<tr>
<th>Q14 Information needed: all needs</th>
<th>% Total</th>
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<th>Northern Europe</th>
<th>Western Europe</th>
<th>Southern Europe</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Base</strong></td>
<td></td>
<td>Z</td>
<td>A</td>
<td>B</td>
<td>C</td>
</tr>
<tr>
<td>Specific information on disease</td>
<td>94</td>
<td>92</td>
<td>93</td>
<td>97</td>
<td>92</td>
</tr>
<tr>
<td>Prognosis</td>
<td>65 &gt;D</td>
<td>81 &gt;ZCD</td>
<td>72 &gt;D</td>
<td>61</td>
<td>52</td>
</tr>
<tr>
<td>Treatment/clinical management</td>
<td>78</td>
<td>69</td>
<td>80</td>
<td>84 &gt;AD</td>
<td>72</td>
</tr>
<tr>
<td>Understanding of mechanics of the disease</td>
<td>41 &gt;D</td>
<td>36</td>
<td>46 &gt;D</td>
<td>48 &gt;D</td>
<td>27</td>
</tr>
<tr>
<td>Expert doctors</td>
<td>66</td>
<td>80 &gt;ZBC</td>
<td>61</td>
<td>59</td>
<td>74 &gt;C</td>
</tr>
<tr>
<td>Centres of excellence</td>
<td>49 &gt;C</td>
<td>69 &gt;ZBC</td>
<td>38</td>
<td>39</td>
<td>60 &gt;ZBC</td>
</tr>
<tr>
<td>Clinical trials</td>
<td>24</td>
<td>19</td>
<td>18</td>
<td>28</td>
<td>26</td>
</tr>
<tr>
<td>Current research</td>
<td>65</td>
<td>58</td>
<td>58</td>
<td>72 &gt;AB</td>
<td>65</td>
</tr>
<tr>
<td>Scientific conference dates/registration</td>
<td>22</td>
<td>12</td>
<td>18</td>
<td>24</td>
<td>28 &gt;A</td>
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<tr>
<td>Medicinal products</td>
<td>49 &gt;A</td>
<td>31</td>
<td>43</td>
<td>54 &gt;A</td>
<td>56 &gt;A</td>
</tr>
<tr>
<td>Dietary products</td>
<td>18</td>
<td>24 &gt;D</td>
<td>27 &gt;CD</td>
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<td>10</td>
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<tr>
<td>Alternative medicine, herbal medicine</td>
<td>20</td>
<td>36 &gt;ZCD</td>
<td>23</td>
<td>15</td>
<td>14</td>
</tr>
<tr>
<td>Aids and equipment, devices and small accessories</td>
<td>35</td>
<td>42</td>
<td>35</td>
<td>35</td>
<td>29</td>
</tr>
<tr>
<td>Home care</td>
<td>30</td>
<td>41 &gt;C</td>
<td>27</td>
<td>24</td>
<td>38 &gt;C</td>
</tr>
<tr>
<td>Transport, auxiliaries</td>
<td>20</td>
<td>27 &gt;D</td>
<td>24</td>
<td>20</td>
<td>13</td>
</tr>
<tr>
<td>Genetic services</td>
<td>47</td>
<td>46</td>
<td>43</td>
<td>54</td>
<td>41</td>
</tr>
<tr>
<td>Psychological services</td>
<td>62 &gt;B</td>
<td>64</td>
<td>50</td>
<td>71 &gt;BD</td>
<td>57</td>
</tr>
<tr>
<td>Welfare benefits</td>
<td>48 &gt;B</td>
<td>56 &gt;B</td>
<td>31</td>
<td>55 &gt;B</td>
<td>45</td>
</tr>
<tr>
<td>Special education needs</td>
<td>34</td>
<td>24</td>
<td>35</td>
<td>39 &gt;A</td>
<td>31</td>
</tr>
<tr>
<td>Community care</td>
<td>21</td>
<td>20</td>
<td>19</td>
<td>27 &gt;D</td>
<td>13</td>
</tr>
<tr>
<td>Respite care</td>
<td>26 &gt;B</td>
<td>44 &gt;ZBC</td>
<td>11</td>
<td>21</td>
<td>35 &gt;BC</td>
</tr>
<tr>
<td>Local support groups</td>
<td>51 &gt;BD</td>
<td>61 &gt;BD</td>
<td>38</td>
<td>62 &gt;ZBD</td>
<td>37</td>
</tr>
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</table>
Information provided does not always match information needed

Information needed compared to information provided

Organisations are not comfortable with information on prognosis
Information provided does not always match with information needed

Secondary information

Information needed compared to information provided (continued)
Where it corresponds well

Specific information on the disease

Mechanics of the disease

Current research

Experts doctors

Local support groups

Welfare benefits
Where it corresponds well (continued)
Where information provided is well over what is needed

Scientific conferences

Equipment and small accessories

Special education needs

Clinical trials

- Provided
- Needed
Where needs are greater than what is provided

Treatment and clinical management: the demand for information exceeds the offer, reflecting the limited knowledge on rare diseases.

Prognosis is a delicate issue: the demand for information is much greater than what organisations provide, in all regions.
Other types of information

Respite care

Transport auxiliaries

Alternative and herbal medicines

Dietary products
Frequently asked questions: about what? By region

Specific on disease
- Northern: 82%
- Central/Eastern: 74%
- Western: 78%
- Southern: 74%

Treatment/clinical management
- N: 46%
- S: 30%
- C: 38%
- W: 48%
p<0.05

Current research
- N: 10%
- S: 23%
- C: 12%
- W: 23%
p<0.01

Expert doctors
- N: 18%
- S: 31%
- C: 43%
- W: 20%
p<0.001

Centres of excellence
- N: 14%
- S: 24%
- C: 24%
- W: 9%
p<0.001

Psychological services
- N: 14%
- S: 24%
- C: 12%
- W: 22%
p<0.05
Frequently asked questions: about what? By region

Prognosis

Medicinal products

Genetic services

Home care

p<0.001
Enquirers target their questions according to the type of organisation

For some types of information, enquirers more often contact services that employ salaried staff: this may be due to specific advertising from information services on these subjects.
Impact of a lack of information

* Limited data

<table>
<thead>
<tr>
<th>Q15 Impact of insufficient / late information</th>
<th>%Total</th>
<th>Central / Eastern Europe</th>
<th>Northern Europe</th>
<th>Western Europe</th>
<th>Southern Europe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Base</td>
<td>372</td>
<td>59*</td>
<td>74*</td>
<td>153</td>
<td>86*</td>
</tr>
<tr>
<td>At least one mention</td>
<td></td>
<td>98</td>
<td>97</td>
<td>99</td>
<td>99</td>
</tr>
<tr>
<td>Inappropriate care of child</td>
<td>63 &gt;D</td>
<td>64</td>
<td>59</td>
<td>71 &gt;D</td>
<td>50</td>
</tr>
<tr>
<td>Insufficient financial support</td>
<td>36</td>
<td>32</td>
<td>49 &gt;ZD</td>
<td>35</td>
<td>30</td>
</tr>
<tr>
<td>Distraction from the needs of other family members</td>
<td>24 &gt;D</td>
<td>20</td>
<td>24 &gt;D</td>
<td>33 &gt;ZD</td>
<td>12</td>
</tr>
<tr>
<td>Negative impact on career</td>
<td>27 &gt;A</td>
<td>10</td>
<td>27 &gt;A</td>
<td>33 &gt;A</td>
<td>27 &gt;A</td>
</tr>
<tr>
<td>Isolation</td>
<td>63 &gt;B</td>
<td>58</td>
<td>50</td>
<td>75 &gt;ZABD</td>
<td>58</td>
</tr>
<tr>
<td>Anger</td>
<td>32</td>
<td>22</td>
<td>30</td>
<td>38 &gt;A</td>
<td>29</td>
</tr>
<tr>
<td>Frustration</td>
<td>58</td>
<td>51</td>
<td>57</td>
<td>58</td>
<td>62</td>
</tr>
<tr>
<td>Powerlessness</td>
<td>49</td>
<td>41</td>
<td>42</td>
<td>54</td>
<td>52</td>
</tr>
<tr>
<td>Incompetence</td>
<td>24</td>
<td>31</td>
<td>19</td>
<td>22</td>
<td>26</td>
</tr>
<tr>
<td>Fear</td>
<td>48</td>
<td>69 &gt;ZBCD</td>
<td>47</td>
<td>45</td>
<td>41</td>
</tr>
<tr>
<td>Wrong decision-making</td>
<td>59</td>
<td>66</td>
<td>62</td>
<td>54</td>
<td>60</td>
</tr>
</tbody>
</table>

> Z: results significantly higher than total
> A, B, C or D: results significantly higher than A, B, C or D
Hypotheses to explain regional differences include more family assistance in Southern Europe, or the hypothesis that welfare is maybe more developed in Western Europe where you can claim for support provided you have the information (exact diagnosis): the absence of a diagnosis is an obstacle to obtain full support.
Perspectives 1/3

Q27. Here are statements regarding some perspectives/additional points. For each of them, please tell us whether you agree / disagree /or if you do not know.

Percentage of organisations in agreement with the following statements

- The Internet and the need for training strengthens the utility of Eurordis PARD II and PARD III projects.
- Telemedicine and telematics are certainly not a priority for rare disease organisations. On the contrary, only 20% declare patient mobility not to be a problem in Europe.
## Perspectives – 2/3

Q27 Responses above 60%

<table>
<thead>
<tr>
<th>Response</th>
<th>Z</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Internet is an alternative and a useful tool for information on rare diseases.</td>
<td>95</td>
<td>97</td>
<td>92</td>
<td>95</td>
<td>95</td>
</tr>
<tr>
<td>The Internet is an alternative and a useful tool for communication.</td>
<td>92</td>
<td>93</td>
<td>86</td>
<td>93</td>
<td>94</td>
</tr>
<tr>
<td>The Internet is helpful as an open, free and large source of information.</td>
<td>90</td>
<td>92</td>
<td>92</td>
<td>90</td>
<td>88</td>
</tr>
<tr>
<td>Training is necessary for operators to respond to sensitive questions accurately</td>
<td><strong>84&gt;B</strong></td>
<td>85</td>
<td>73</td>
<td><strong>85&gt;B</strong></td>
<td><strong>93&gt;ZB</strong></td>
</tr>
<tr>
<td>Sharing internally validated information with other patients’ groups helps ensure quality.</td>
<td>80</td>
<td>75</td>
<td>78</td>
<td>78</td>
<td>87</td>
</tr>
<tr>
<td>The Internet should not be used exclusively as a source of information.</td>
<td>78</td>
<td>83</td>
<td>69</td>
<td>78</td>
<td><strong>84&gt;B</strong></td>
</tr>
<tr>
<td>Isolated patients with no group for their disease can benefit from belonging to a group representing other rare diseases.</td>
<td><strong>73&gt;B</strong></td>
<td>75</td>
<td>61</td>
<td><strong>75&gt;B</strong></td>
<td><strong>80&gt;B</strong></td>
</tr>
<tr>
<td>Language is an obstacle to access information on the Internet</td>
<td>70</td>
<td>69</td>
<td>65</td>
<td>65</td>
<td><strong>83&gt;ZBC</strong></td>
</tr>
<tr>
<td>A unique European toll-free number for help lines would be helpful</td>
<td><strong>65&gt;B</strong></td>
<td><strong>71&gt;B</strong></td>
<td>43</td>
<td><strong>67&gt;B</strong></td>
<td><strong>77&gt;ZB</strong></td>
</tr>
<tr>
<td>The approach to the training of help line operators is different for those with professional education and those with patient or parent experience.</td>
<td><strong>62&gt;B</strong></td>
<td>61</td>
<td>46</td>
<td><strong>62&gt;B</strong></td>
<td><strong>74&gt;ZB</strong></td>
</tr>
</tbody>
</table>

> Z: results significantly higher than total
> A, B, C or D: results significantly higher than A, B, C or D

* Limited data
### Perspectives – 3/3

**Q27 Responses below 60%**

<table>
<thead>
<tr>
<th>Perception</th>
<th>Z</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel frustrated when I access a web site with restricted information</td>
<td>60 &gt;B</td>
<td>76 &gt;ZBC</td>
<td>43</td>
<td>58 &gt;B</td>
<td>69 &gt;B</td>
</tr>
<tr>
<td>The use of video-conferences would be a great benefit to NGOs.</td>
<td>59 &gt;AB</td>
<td>36</td>
<td>46</td>
<td>61 &gt;AB</td>
<td>81 &gt; ZABC</td>
</tr>
<tr>
<td>Partnership with other help lines could be useful to solve language issues</td>
<td>57 &gt;B</td>
<td>68 &gt;B</td>
<td>36</td>
<td>61 &gt;B</td>
<td>59 &gt;B</td>
</tr>
<tr>
<td>The use of telephone-conferences would be a great benefit to NGOs</td>
<td>57 &gt;AB</td>
<td>37</td>
<td>38</td>
<td>57 &gt;AB</td>
<td>72 &gt;ZABC</td>
</tr>
<tr>
<td>Workload can be increased with e-mail traffic/dialogue as compared to a telephone service</td>
<td>48</td>
<td>53</td>
<td>38</td>
<td>46</td>
<td>57 &gt;B</td>
</tr>
<tr>
<td>My organisation is advocating to improve patient mobility</td>
<td>47</td>
<td>64 &gt;ZBC</td>
<td>36</td>
<td>39</td>
<td>57 &gt;BC</td>
</tr>
<tr>
<td>The Internet is generating too much information and this creates confusion</td>
<td>43</td>
<td>36</td>
<td>35</td>
<td>48</td>
<td>44</td>
</tr>
<tr>
<td>There is more information available on US based web sites compared to EU ones</td>
<td>37</td>
<td>41</td>
<td>27</td>
<td>35</td>
<td>45 &gt;B</td>
</tr>
<tr>
<td>Data protection makes it impossible to recontact enquirers when needed.</td>
<td>29</td>
<td>23</td>
<td>34</td>
<td>28</td>
<td>30</td>
</tr>
<tr>
<td>My organisation is familiar with telemedicine1</td>
<td>20 &gt;C</td>
<td>17</td>
<td>19</td>
<td>12</td>
<td>36 &gt;ZABC</td>
</tr>
<tr>
<td>Patient mobility is not a problem in the European Union</td>
<td>20</td>
<td>24</td>
<td>22</td>
<td>22</td>
<td>14</td>
</tr>
<tr>
<td>My organisation plans to develop telemedicine services</td>
<td>11</td>
<td>15</td>
<td>7</td>
<td>8</td>
<td>16 &gt;BC</td>
</tr>
<tr>
<td>Information on European Court of Justice decisions on patient mobility is largely available</td>
<td>10</td>
<td>10</td>
<td>8</td>
<td>10</td>
<td>13</td>
</tr>
</tbody>
</table>

* Limited data

> **Z**: results significantly higher than total
> **A, B, C or D**: results significantly higher than A, B, C or D
Perspectives: do you agree with the following statements? By region

The use of video-conferences would be a great benefit to NGOs.

- Northern: 46%
- Western: 61%
- Central/eastern: 36%
- Southern: 81%

p<0.001

The use of telephone-conferences would be a great benefit to NGOs.

- Northern: 38%
- Western: 57%
- Central/eastern: 37%
- Southern: 72%

p<0.001

My organisation is advocating to improve patient mobility

- Northern: 36%
- Western: 39%
- Central/eastern: 64%
- Southern: 57%

p<0.01

Partnership with other help lines could be useful to solve language issues

- Northern: 36%
- Western: 61%
- Central/eastern: 68%
- Southern: 59%

p<0.001
Perspectives: do you agree with the following statements about the use of Internet? By region

I feel frustrated when I access a website with restricted information

The Internet should not be used exclusively as a source of information.

Language is an obstacle to access information on the Internet.

Use of the Internet

- The Internet is helpful as an open, free and large source of information
- The Internet is generating too much information and this creates confusion

I feel frustrated when I access a website with restricted information:

- **N**: 69%
- **C**: 76%
- **S**: 69%
- **W**: 58%

p<0.001

The Internet should not be used exclusively as a source of information:

- **N**: 69%
- **C**: 83%
- **S**: 84%
- **W**: 78%

The Internet is helpful as an open, free and large source of information:

- **N**: 83%
- **C**: 83%
- **S**: 83%
- **W**: 65%

p<0.01

The Internet is generating too much information and this creates confusion:

- **N**: 65%
- **C**: 69%
- **S**: 65%
- **W**: 65%

p<0.01
Perspectives: do you agree with the following statements? By region

My organisation plans to develop telemedicine services

My organisation is familiar with telemedicine

Patient mobility is not a problem in the European Union
4 Conclusions
Whichever the region, the organisations:

- mainly deal with information and services to patients
- are generally rare disease patient organisations focusing on one disease
- mostly work with volunteers
- are highly supported by their members and to a lesser extent, by private donors
- need funding for information leaflets, projects, meetings, and think national governments and European Commission should fund information services.
But there are clear differences between Northern, Central/Eastern, Western and Southern European countries in terms of age, area of activity, employment of staff, and funding sources/purposes. Region, maturity and activity are closely connected.

- Northern organisations are older, more mature and therefore more focused on raising money through lobbying. They do not work a lot with paid staff. They receive funding more from their national government and charitable bequests and successions and collect it more for meetings and networking.

- Central organisations are more focused on services to patients, like psychological support, and work more with volunteers. They are younger but still mature enough to cover their activity. They raise more money from health insurances.

- Southern organisations are the youngest ones. They are more focused on information and employ more paid staff. They also raise more funding from regional and local government, especially to raise awareness, especially in the medical community, and to develop their helpline.

- In Western countries, fundraising events are more often quoted; this is probably related to events like Telethon in France that benefits to many patient organisations. Research activities are more frequent than elsewhere.
The main sources every organisation relies on to gain information about the disease are scientific conferences and specialists practitioners. But the most reliable source remains the patient organisations.

There are two major reasons preventing people from giving information. The medical sphere is reluctant to provide the information, especially in Southern Europe, whereas social services, pharmacists or patient organisations suffer from a lack of information.

Specifically, written leaflets and Internet are common means used by the organisations to deliver information. Nonetheless there are differences according to regions and consequently to the area of activity. Those focusing on care use more face-to-face meetings or one-to-one discussions (+ Central Europe) whereas those concentrated on lobbying logically use more group meetings (+ Northern Europe).

Overall, information provided corresponds well to information requested by enquirers, except for prognosis for which information services are more embarrassed.
Most of the organisations have a helpline but they use it very differently according to their maturity, their activity. Northern European organisations do not use it as a major tool. Indeed being not focused on information delivery or help to patients they don’t make the most of it. A possible explanation is the existence of centralised information service run by one organisation, like CSH (the National Centre on Rare Diseases) in Denmark: other groups do not need to operate their own information service. Contrary to Central and Southern European countries where the helpline turns out to be a precious tool enabling them to implement their activity.

Moreover, Central/Eastern and Southern European organisations seem to be more active in the collection and supervising of the information and people are trained to manage it. Central organisations largely use Internet. Western European organisations publish more newsletters.
The kind of information delivered also differs according to the nature of the organisation. Central European organisations, as they are more oriented to psychological support, provide naturally more information on welfare benefits or treatment management. Southern European organisations, as they are less developed, are like a relay between the patients and other organisations in providing information on centres of excellence or scientific conferences.

The enquirer is mainly the patient or the mother. Patients are actively looking for information even though rare diseases are often disabling.

Other members of the family or relatives only rarely contact information services.

Websites, health professionals and patients’ organisations are key for accessing information services.
<table>
<thead>
<tr>
<th>Region</th>
<th>Southern Europe</th>
<th>Central Europe</th>
<th>Northern Europe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key area of activity</td>
<td>Information</td>
<td>Services to Patients</td>
<td>Lobbying</td>
</tr>
<tr>
<td>Main means</td>
<td>General letters</td>
<td>Direct, one-to-one relationship</td>
<td>Group meeting</td>
</tr>
<tr>
<td>Information</td>
<td>Trained/paid staff to deal with information</td>
<td>Tailor Information according to needs</td>
<td>Focused on the information on the disease</td>
</tr>
<tr>
<td>Helpline</td>
<td>Willing to develop it</td>
<td>Make the most of it</td>
<td>Is not an essential tool</td>
</tr>
<tr>
<td>Support</td>
<td>Self supporting, rely a lot on the network.</td>
<td>Supported by peers and private donors</td>
<td>Well known =&gt; complementary to the state involvement.</td>
</tr>
<tr>
<td>Needs</td>
<td>To raise awareness, especially by the medical sphere</td>
<td>To disseminate more and better information, specifically on care</td>
<td>To raise more money</td>
</tr>
</tbody>
</table>

Maturity scale:

- Young
- More mature
In terms of perspectives, the Internet seems to be an alternative and useful tool to increase awareness and improve communication between the organisations, although some problems of reliability and languages still remain.

A focus should also be made on the training on using the Internet and managing the helpline in order to better handle the information.

These improvements should enable organisations to better share information and then to be more efficient in its collection and delivery.