European Wilson's Disease Network
Improving information, knowledge and access to expertise and care
AP-HP FY2011 IT N° : 20103201100866

QUESTIONNAIRE FOR WD PATIENTS
ON HEALTHCARE NEEDS
# QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Number of participants

<table>
<thead>
<tr>
<th>Germany</th>
<th>France</th>
<th>Italy</th>
<th>UK</th>
<th>Spain</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>104</td>
<td>68</td>
<td>51</td>
<td>29</td>
<td>17</td>
<td>269</td>
</tr>
</tbody>
</table>
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Question n°3: Who are the participants?

The graph shows the distribution of participants from Germany, France, Italy, UK, and Spain. The categories include:

- Other
- Guardian of a patient
- Parent of a patient
- Patient

The graph indicates that the majority of participants are patients in all countries, with variations in the proportions of other categories.
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Question n°4: Actual age of patient

- ≥51 years old
- Between 31 & 50 years old
- Between 21 & 30 years old
- Between 16 & 20 years old
- ≤15 years old
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Question n°6: How old were you or the patient when you (s/he) were diagnosed?
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Question n°7-8: Time between symptoms and diagnosis

- Germany: >10 years (40%), Between 6 & 10 years (20%), Between 3 & 5 years (10%), <3 years (30%), <1 year (10%)
- France: >10 years (30%), Between 6 & 10 years (20%), Between 3 & 5 years (10%), <3 years (40%), <1 year (10%)
- Italy: >10 years (30%), Between 6 & 10 years (20%), Between 3 & 5 years (10%), <3 years (40%), <1 year (10%)
- UK: >10 years (40%), Between 6 & 10 years (20%), Between 3 & 5 years (10%), <3 years (30%), <1 year (10%)
- Spain: >10 years (30%), Between 6 & 10 years (20%), Between 3 & 5 years (10%), <3 years (40%), <1 year (10%)
Questionnaire for WD patients on healthcare needs

Question n°9: Upon receiving your diagnosis, were you provided with adequate sources of information to understand your disease?
QUESTIONNAIRE FOR WD PATIENTS
ON HEALTHCARE NEEDS

Question n°10: If you did receive information about the disease, please specify the format/type?
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Question n°11: What format of disease information do you think would be the most useful for a patient or the family of a patient newly diagnosed?
QUESTIONNAIRE FOR WD PATIENTS
ON HEALTHCARE NEEDS

Question n°12: Do you have access to a national expert or specialized centre for WD?

Germany: 80.0% Yes, 20.0% Don't Know, 0.0% No
France: 100.0% Yes
Italy: 80.0% Yes, 20.0% Don't Know
UK: 100.0% Yes
Spain: 80.0% Yes, 20.0% Don't Know
QUESTIONNAIRE FOR WD PATIENTS
ON HEALTHCARE NEEDS

Question n°14: Are you able to meet healthcare professionals at the centre as often as you would like to?
Question n°15: The healthcare professionals in the centre responsible for your care are:

- Germany: Knowledgeable (80%)
- France: Both knowledgeable and understanding (90%)
- Italy: Understanding (60%)
- UK: Knowledgeable (70%)
- Spain: Both knowledgeable and understanding (90%)

Total: 400 patients

100.0%
QUESTIONNAIRE FOR WD PATIENTS
ON HEALTHCARE NEEDS

Question n°16: Have you or your family been offered genetic counseling?
Question n°17: Is the transition of care from childhood to adulthood satisfactory in your centre?

Don't Know
No
Yes

Germany  France  Italy  UK  Spain
Questionnaire for WD Patients on Healthcare Needs

Question n°18: Do you think cooperation between your national expert centre and local healthcare provider is satisfactory?

Graph showing the distribution of responses by country.
Questionnaire for WD Patients on Healthcare Needs

Question n°19: Do you have access, in your region/country, to all the services needed for best care?

![Bar chart showing the percentage of patients in different countries who have access to all the services needed for best care.](chart.png)
Question n°20: Did you contact or become a member of a patient group or association?
Questionnaire for WD Patients on Healthcare Needs

Question n°21: During consultations at your expert centre, do you feel sufficiently informed/knowledgeable to make an informed decision without force or intimidation in deciding about care/treatment?
Question n°22: Before answering this survey, have you heard about EuroWilson?
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Question n°23: In your opinion, how can EuroWilson help you?