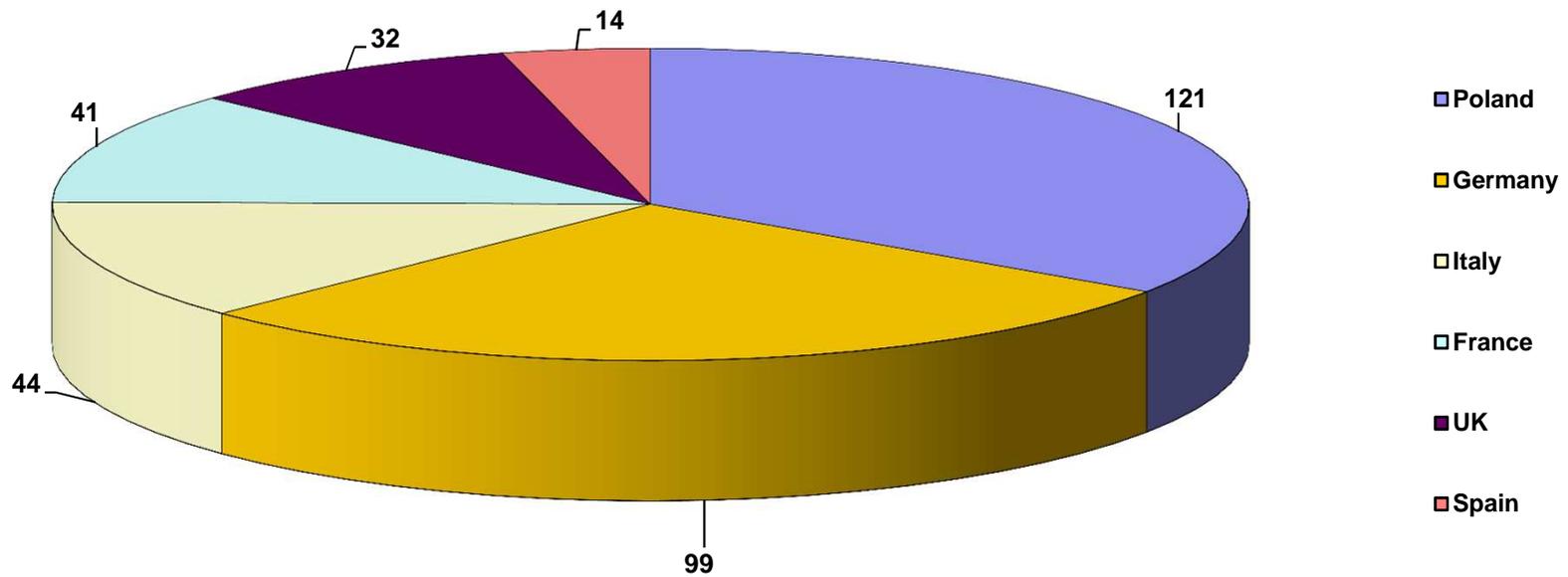


2012 Patient Survey

351 participants

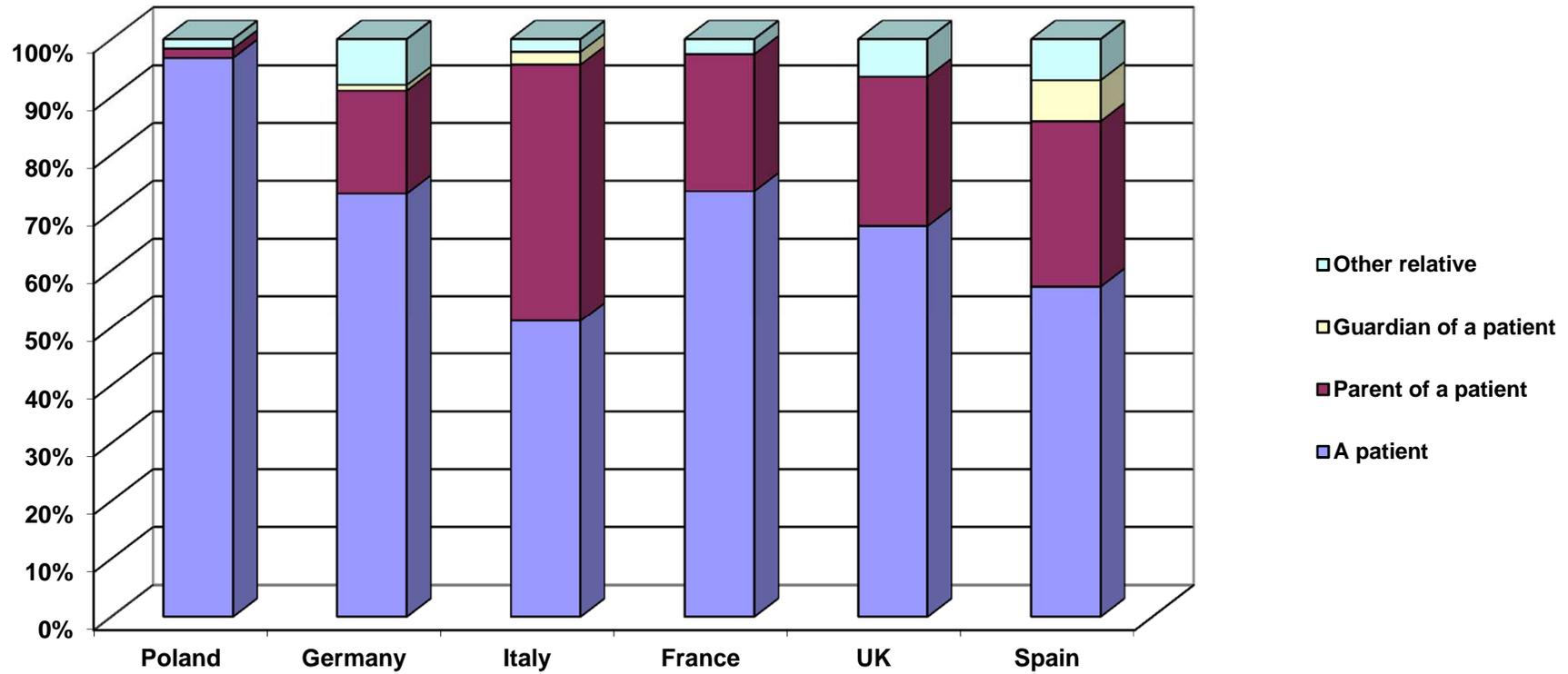
(In 2011: 269 participants)

New participating country in 2012: Poland



2012 Patient Survey

About the participants

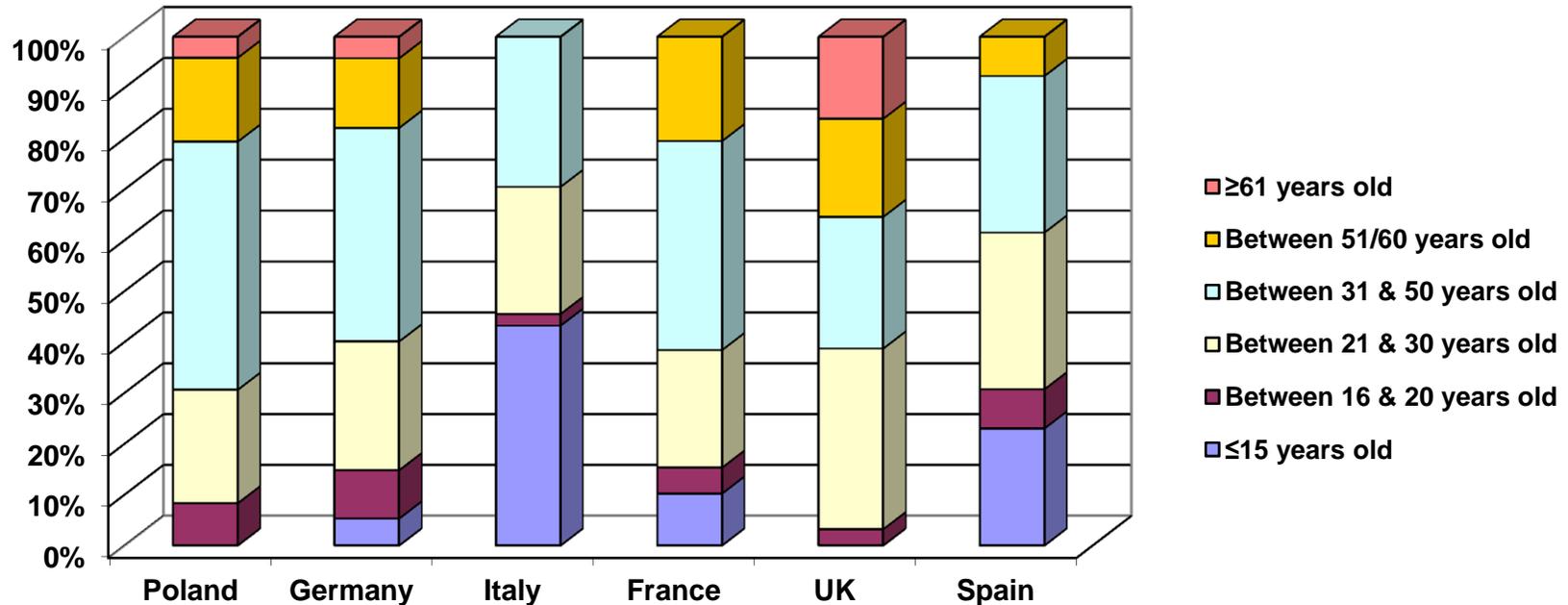


2012 Patient Survey

Current age of the patients

Younger patient: 5 years old (Italy) / Older patient: 78 years old (UK)

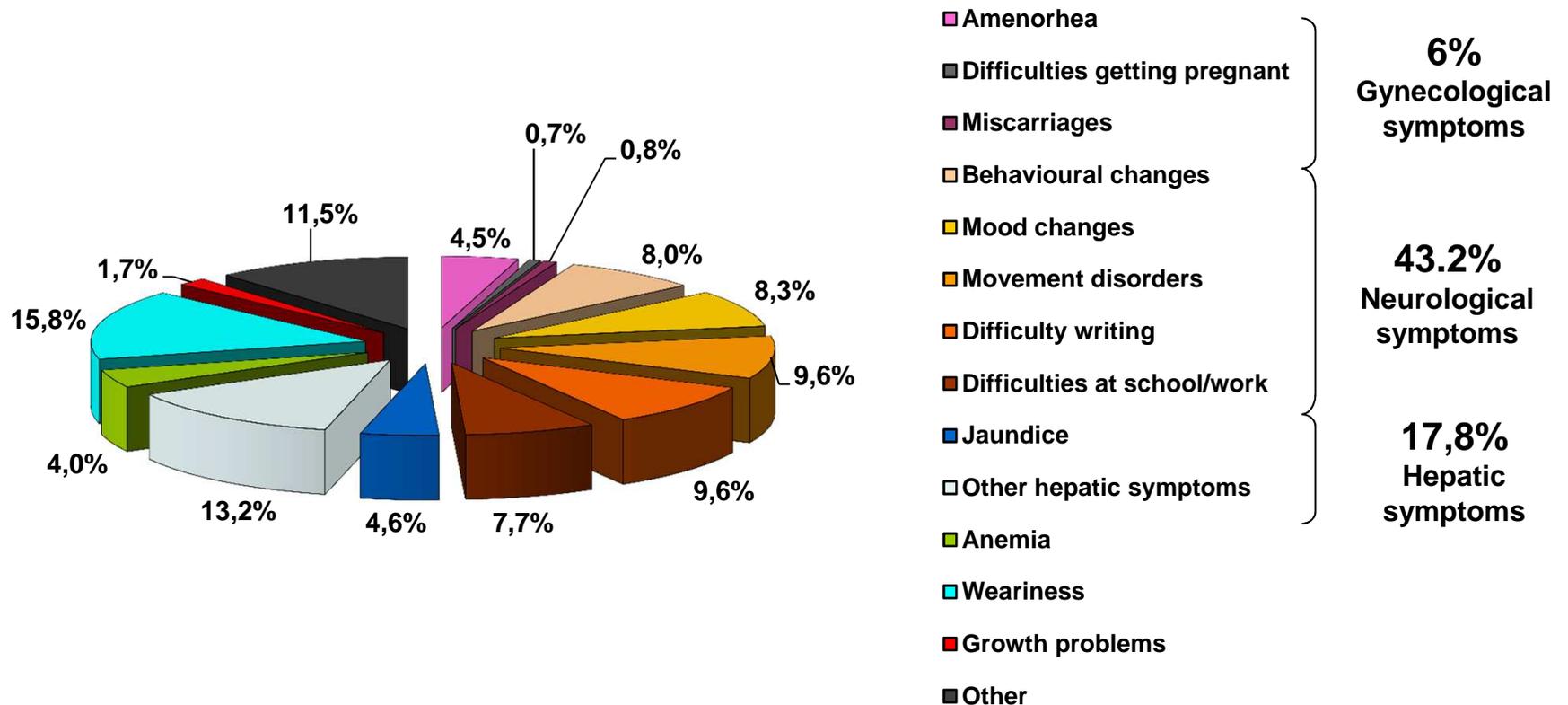
Mean current age of the patients in Europe: 33 years old



Countries	Poland	Germany	Italy	France	UK	Spain
Mean current age of the patients	38 years old	36 years old	22 years old	35 years old	40 years old	28 years old

2012 Patient Survey

What were your (her/his) first symptom(s)?

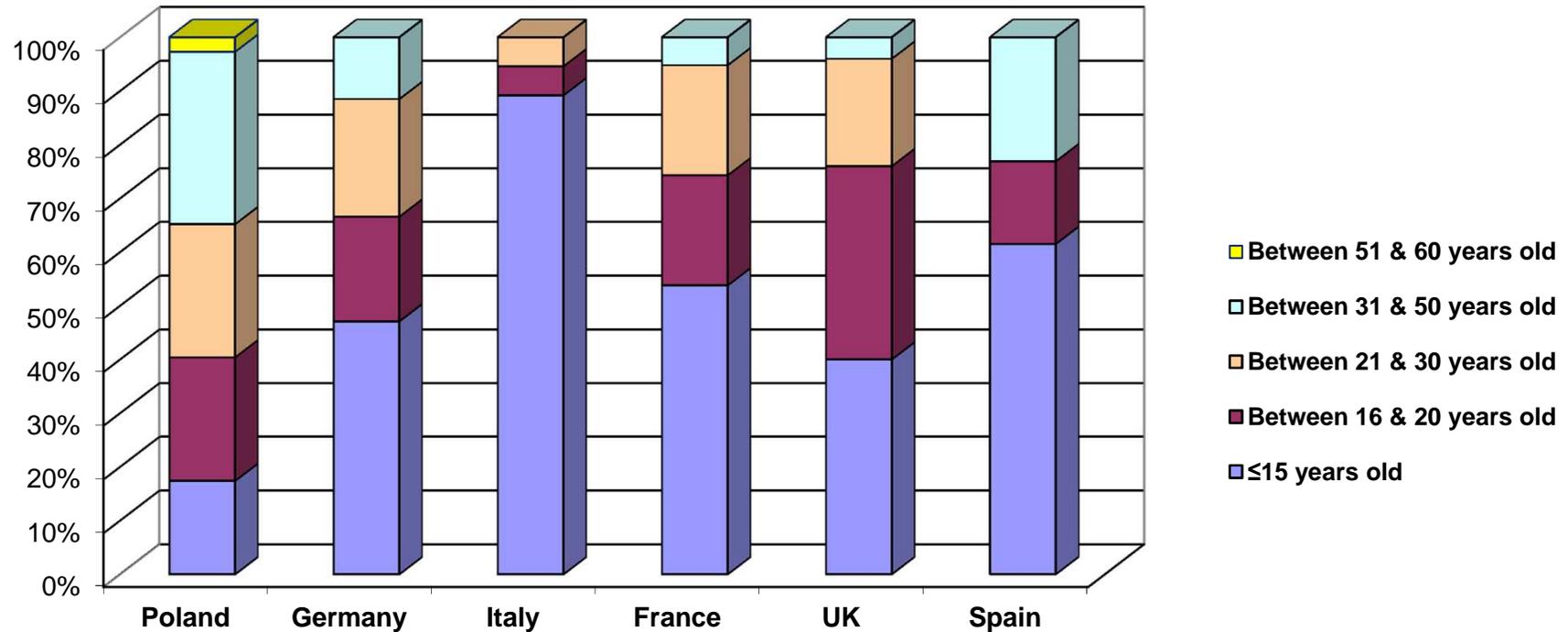


Others: Family screening, dermatological problems, speech difficulties...

2012 Patient Survey

How old were you (or the patient) when the first medical symptoms appeared?

Mean age in Europe: 16 years old

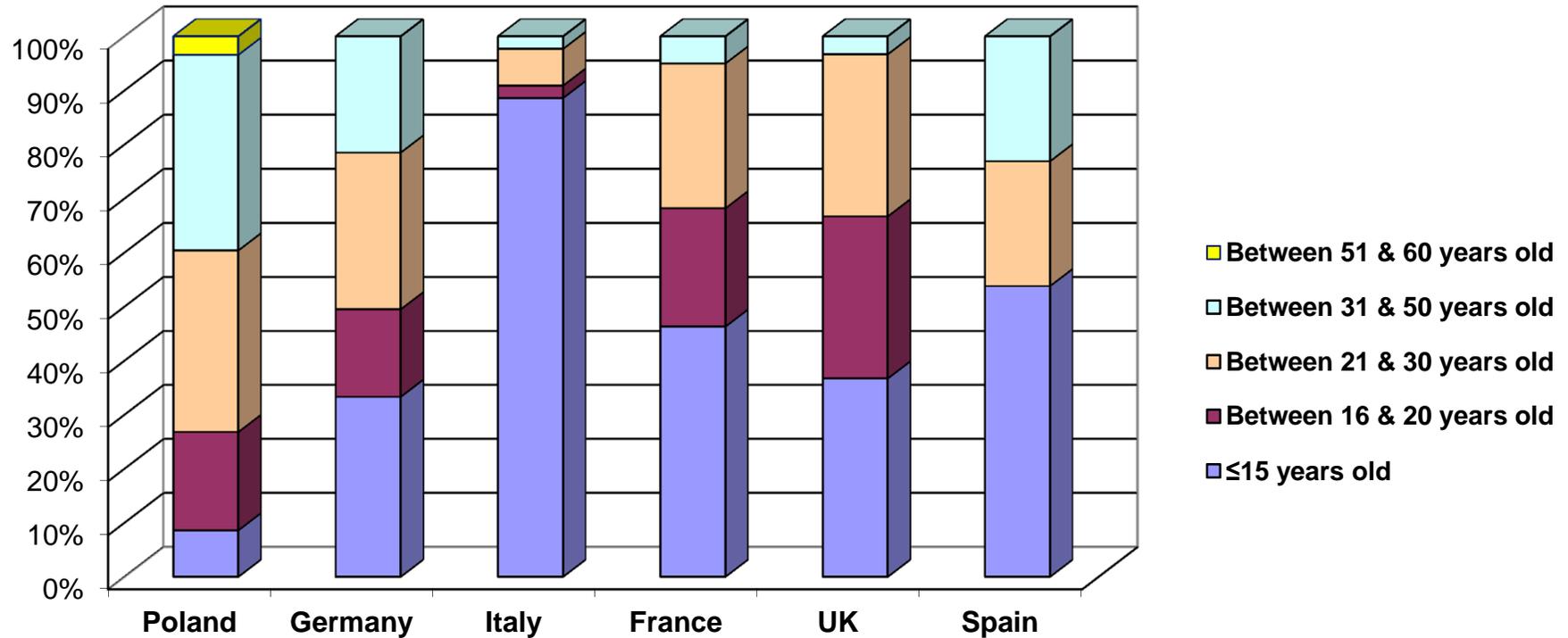


Countries	Poland	Germany	Italy	France	UK	Spain
Mean age of the patients	26 years old	18 years old	8 years old	16 years old	17 years old	15 years old

2012 Patient Survey

How old were you (or the patient) when you received a confirmed diagnosis of WD?

Mean age in Europe: 15 years old

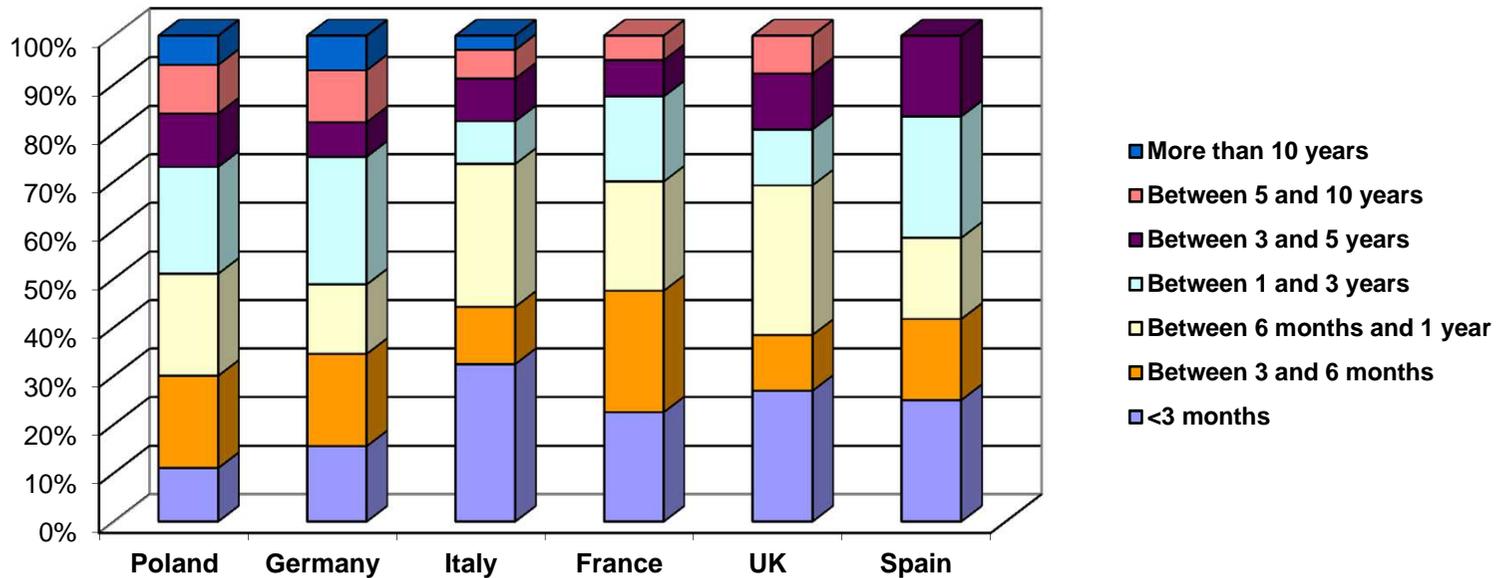
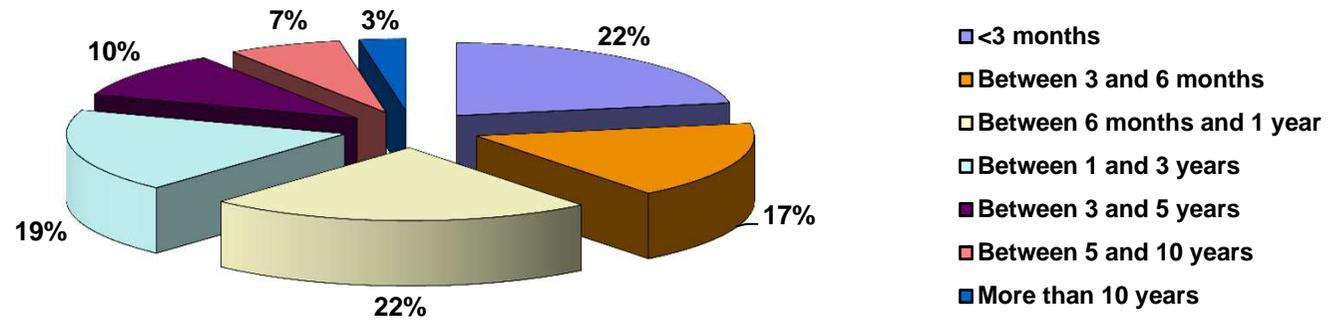


Countries	Poland	Germany	Italy	France	UK	Spain
Mean age of the patients	28 years old	21 years old	9 years old	17 years old	17 years old	18 years old

2012 Patient Survey

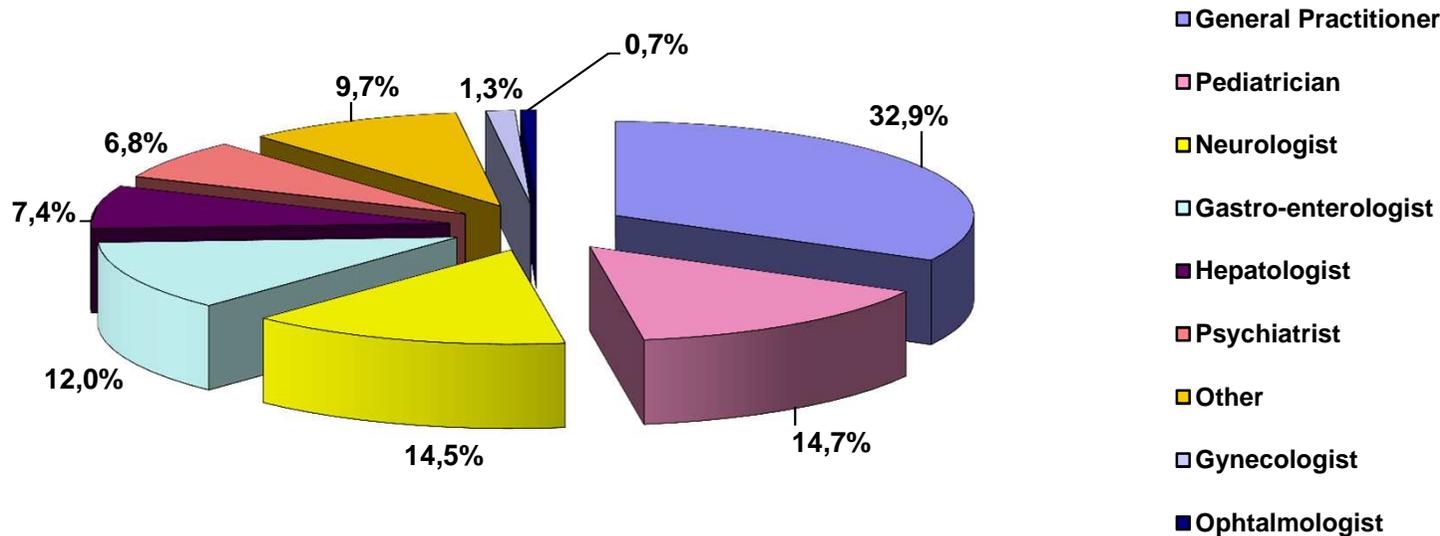
Could you state approximately the time between your (her/his) first symptoms and the diagnosis of Wilson disease?

In Europe



2012 Patient Survey

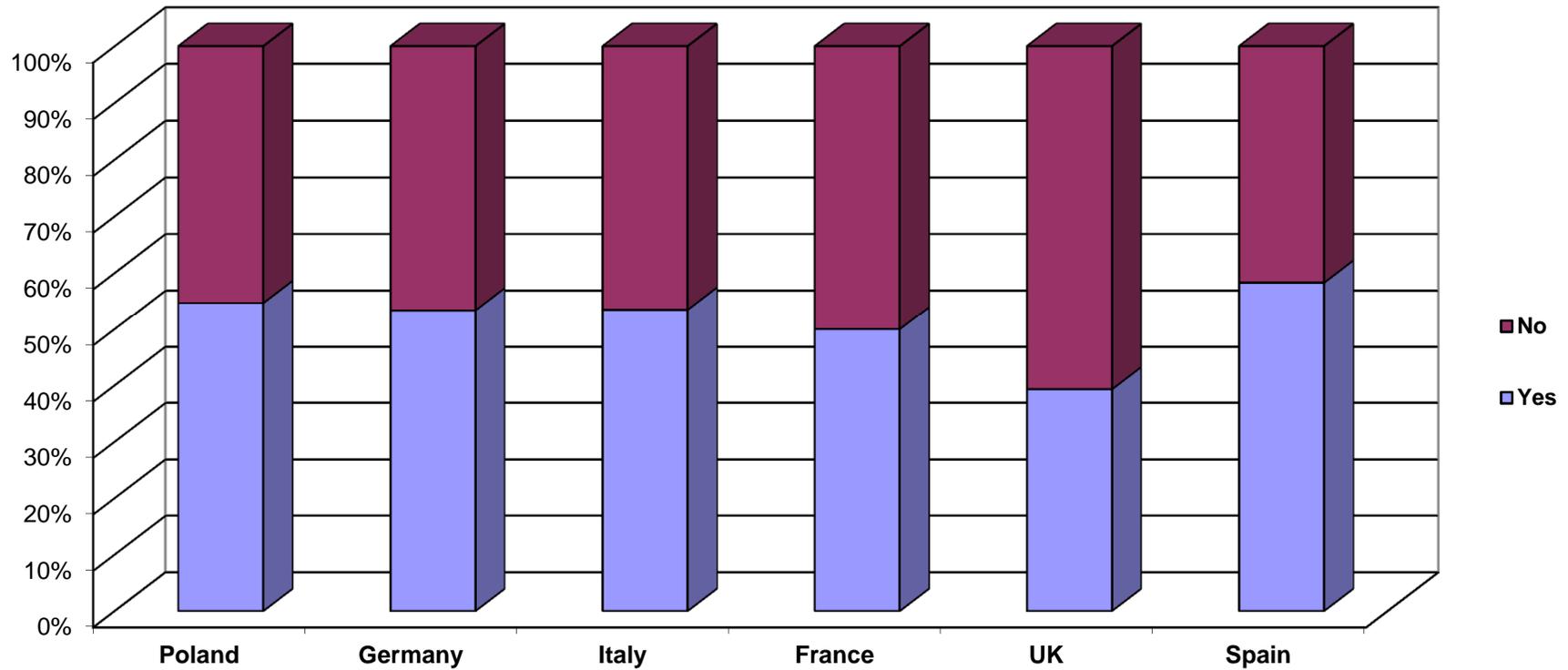
What was the medical specialty of the first doctor you (or the patient) consulted for these symptoms?



Others: Dermatologist, Endocrinologist, Hematologist, Oncologist, Physiotherapist, Pulmonologist, Psychologist.

2012 Patient Survey

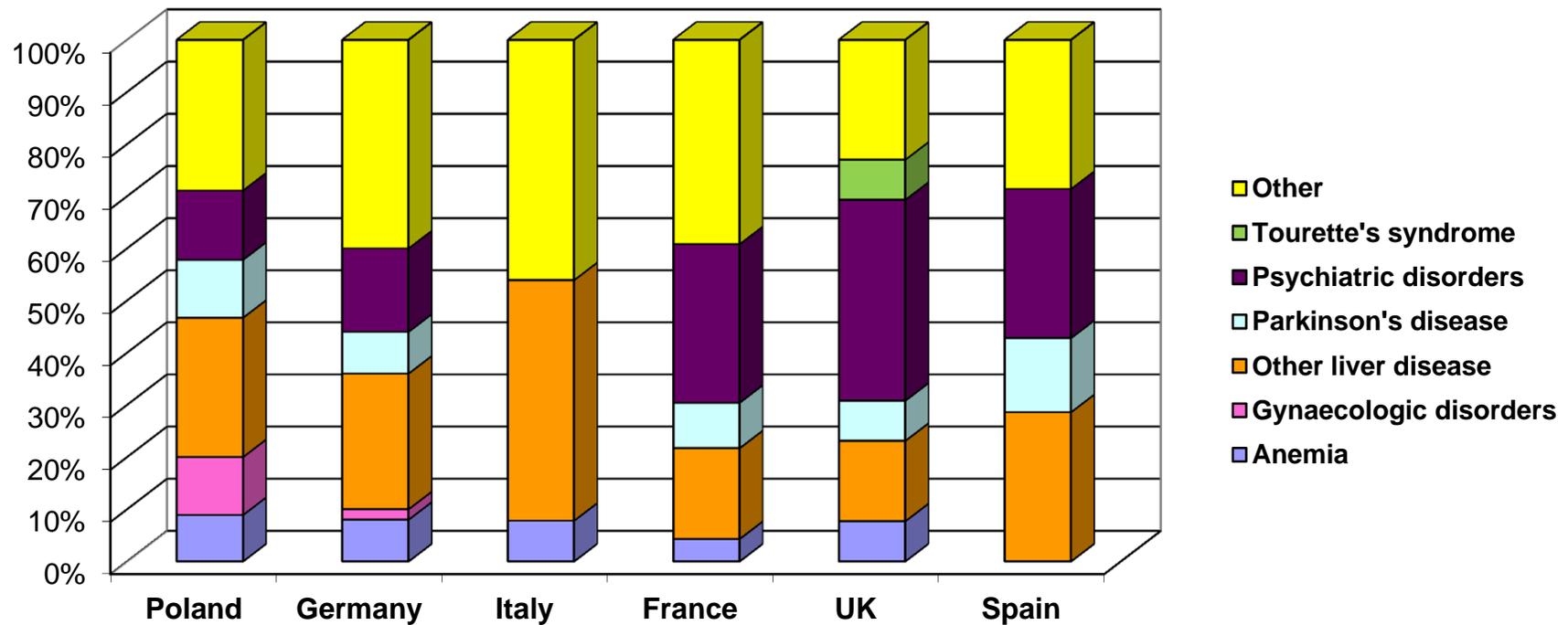
Have you (or the patient) been misdiagnosed?



2012 Patient Survey

Have you (or the patient) been misdiagnosed?

If yes, please state the disorder:

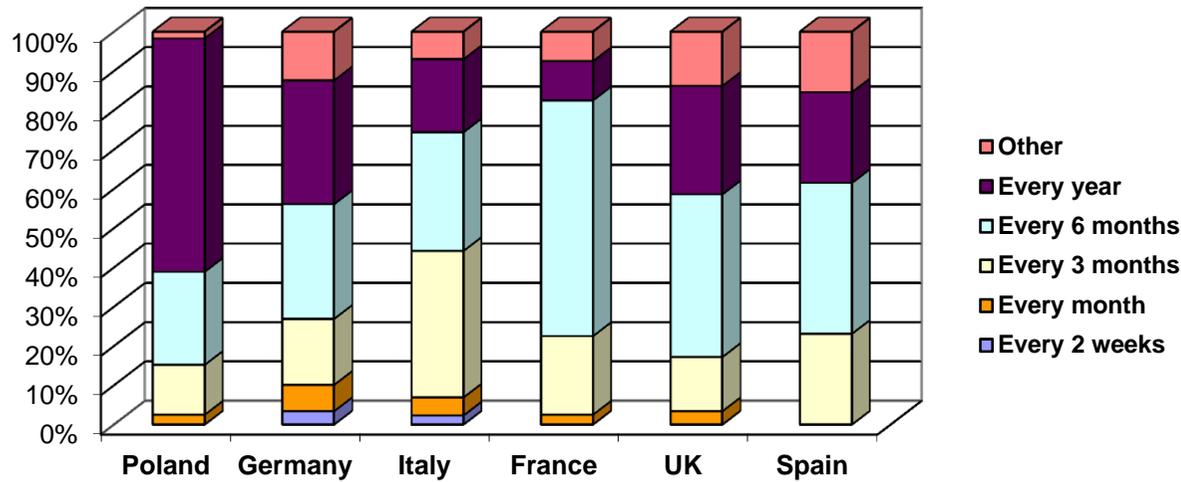
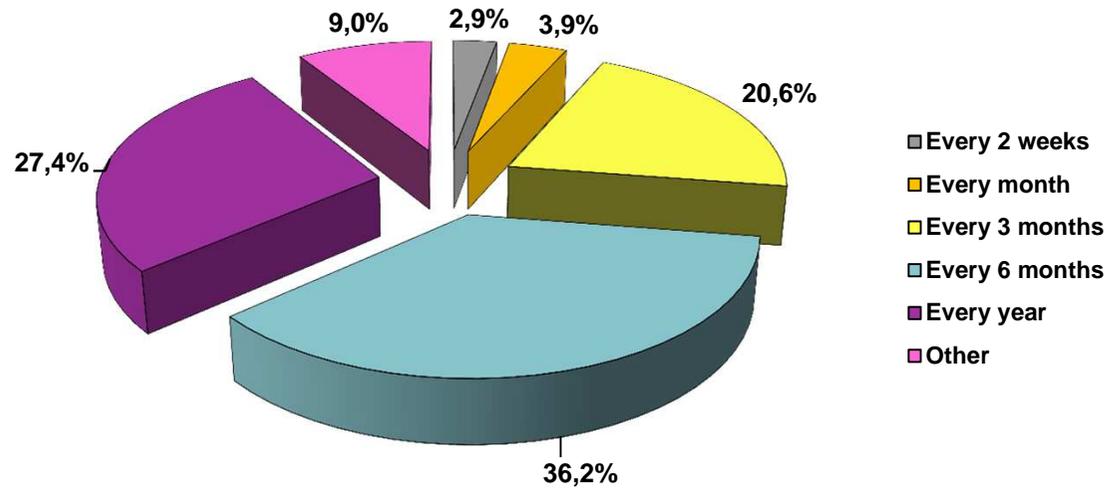


Others: Endocrinological problems, Hypertension, Leukemia, Leukopenia, Mononucleosis, Multiple Sclerosis...

2012 Patient Survey

Currently, how often do you (or the patient) see your specialist?

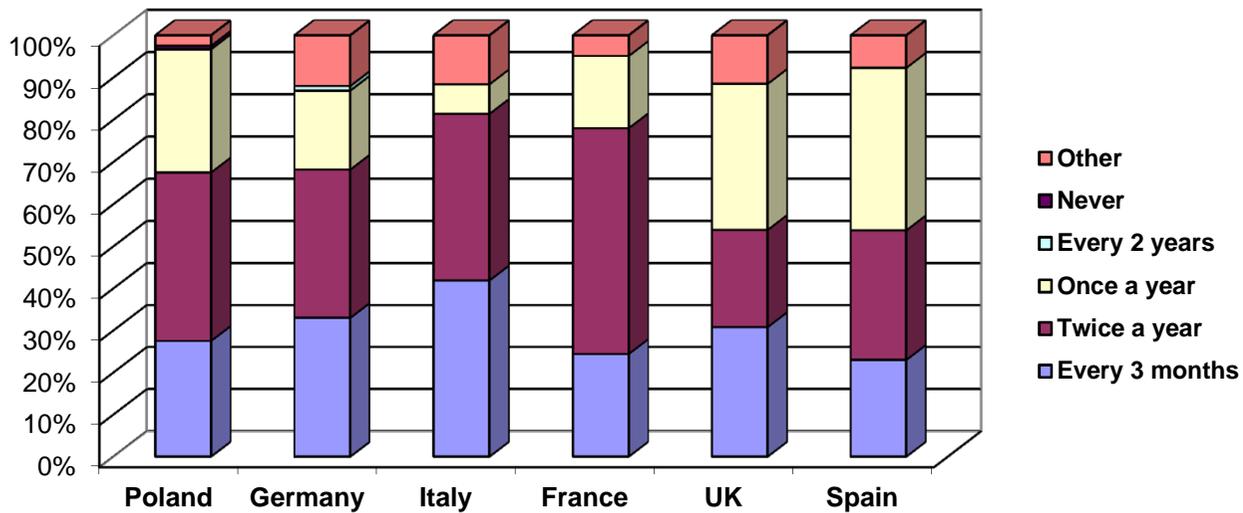
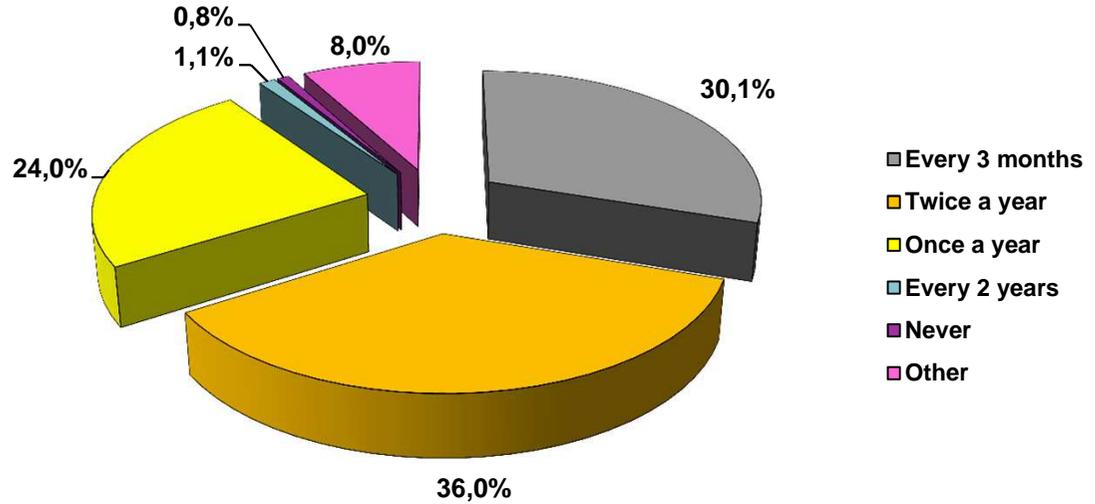
In Europe



2012 Patient Survey

Currently, how often do you (or the patient) have a blood test?

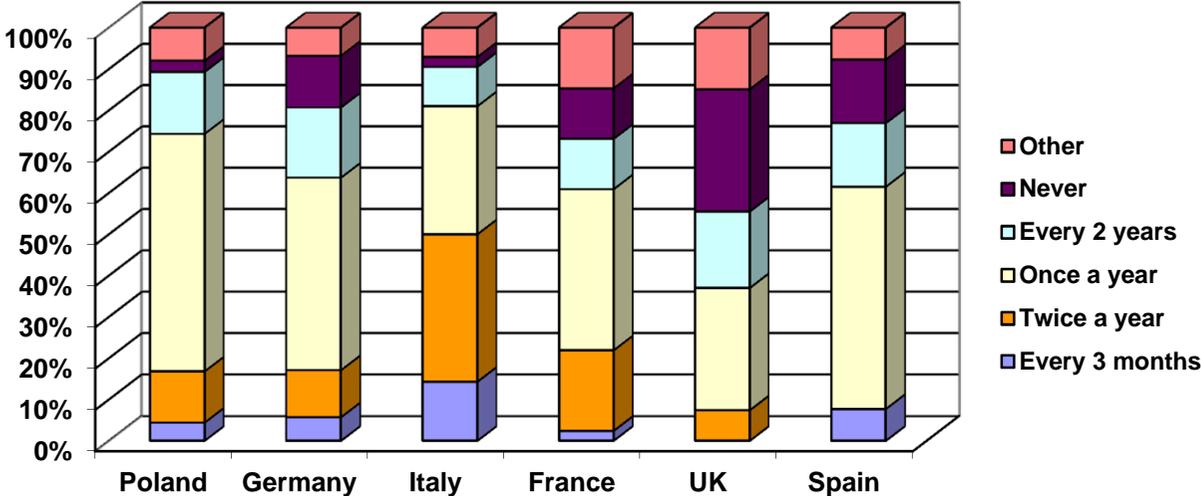
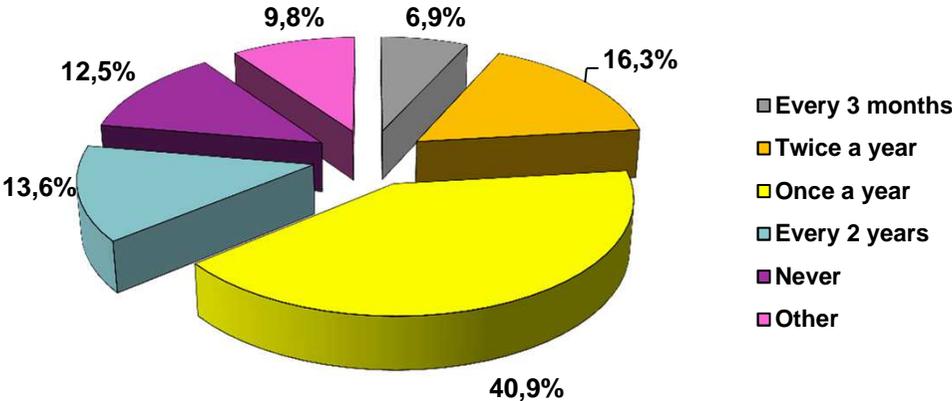
In Europe



2012 Patient Survey

Currently, how often do you (or the patient) have a liver ultrasonography?

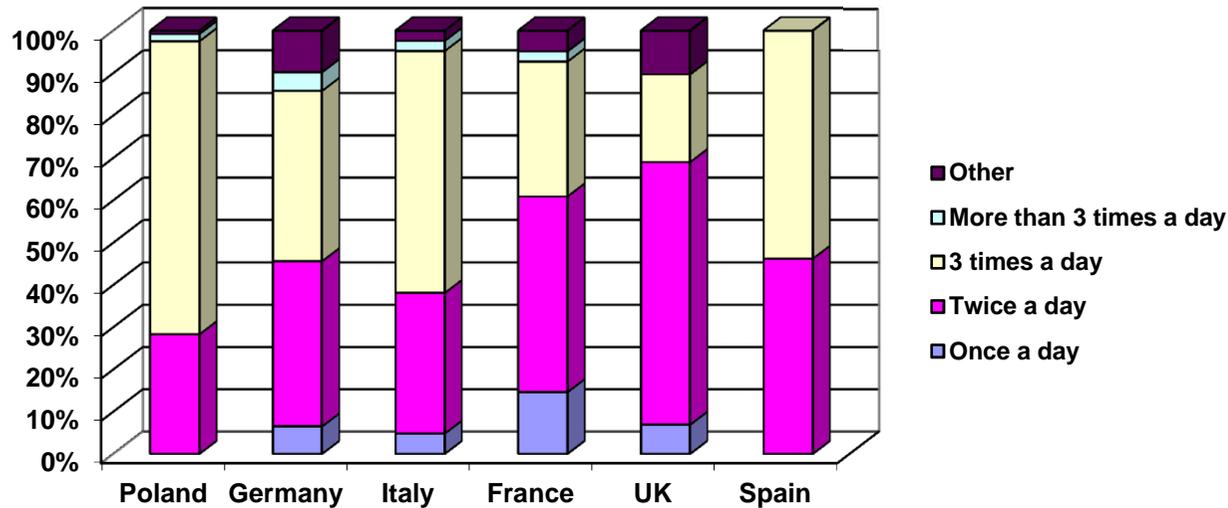
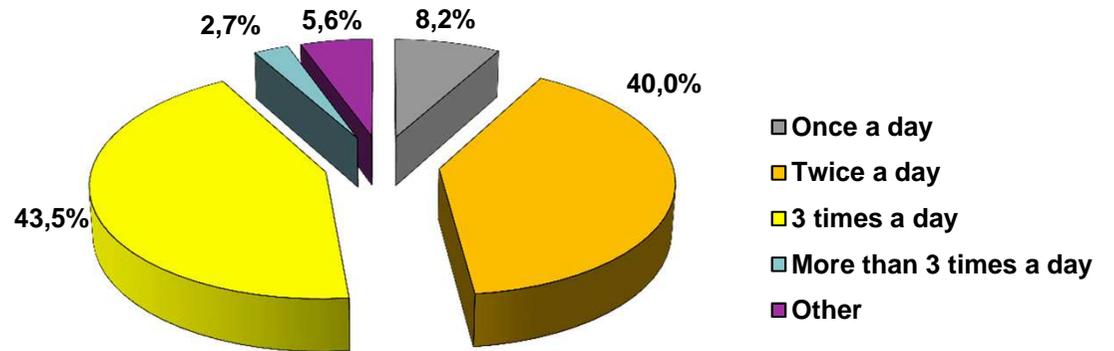
In Europe



2012 Patient Survey

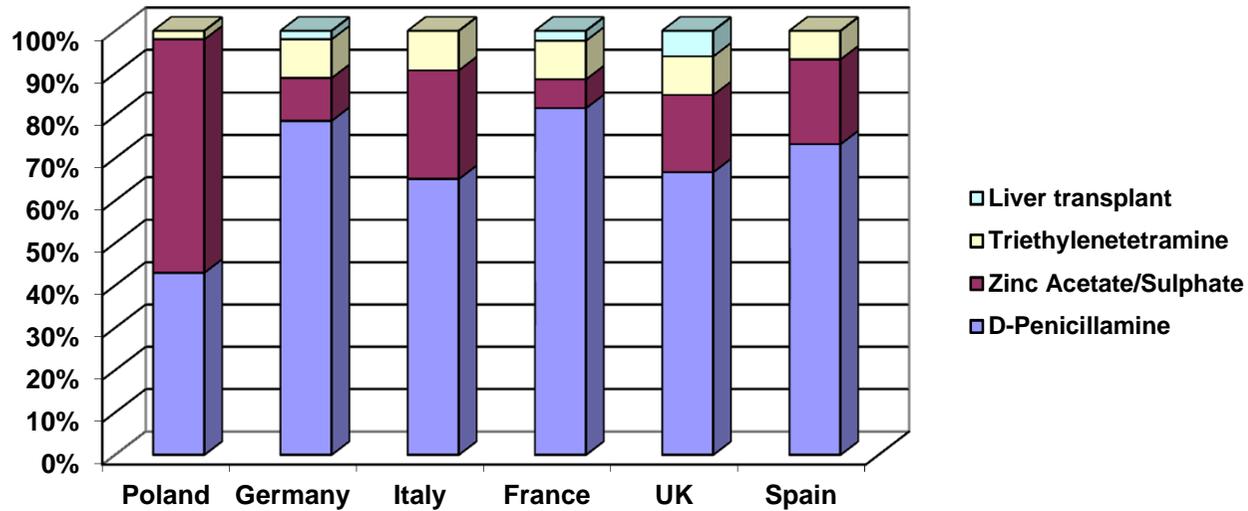
Currently, how many times a day do you (or the patient) take your medication for WD?

In Europe

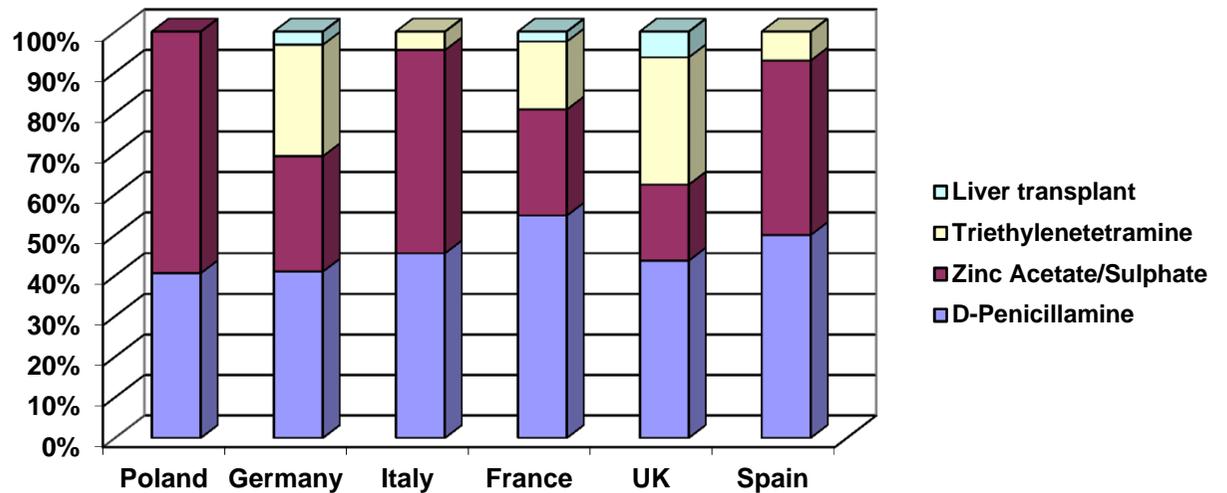


2012 Patient Survey

What was your (her/his) initial treatment for Wilson disease?

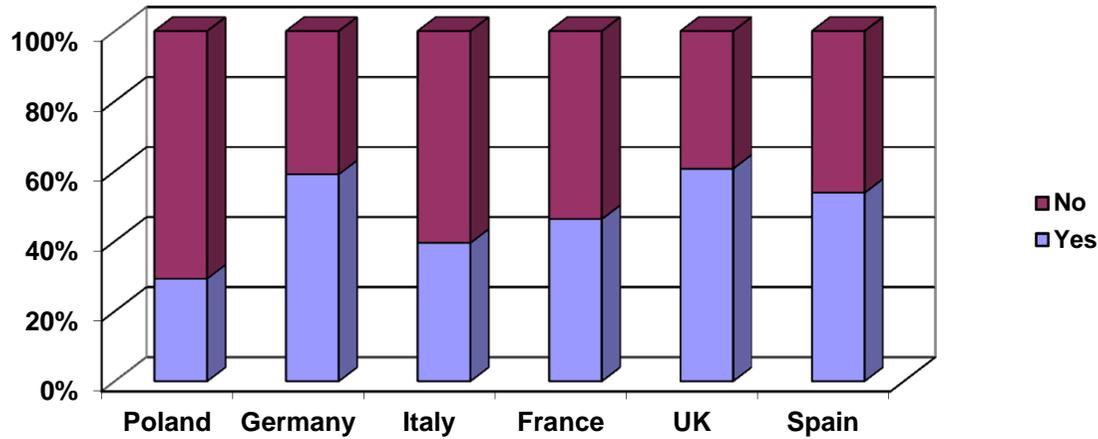


What is your (her/his) current treatment for Wilson disease?



2012 Patient Survey

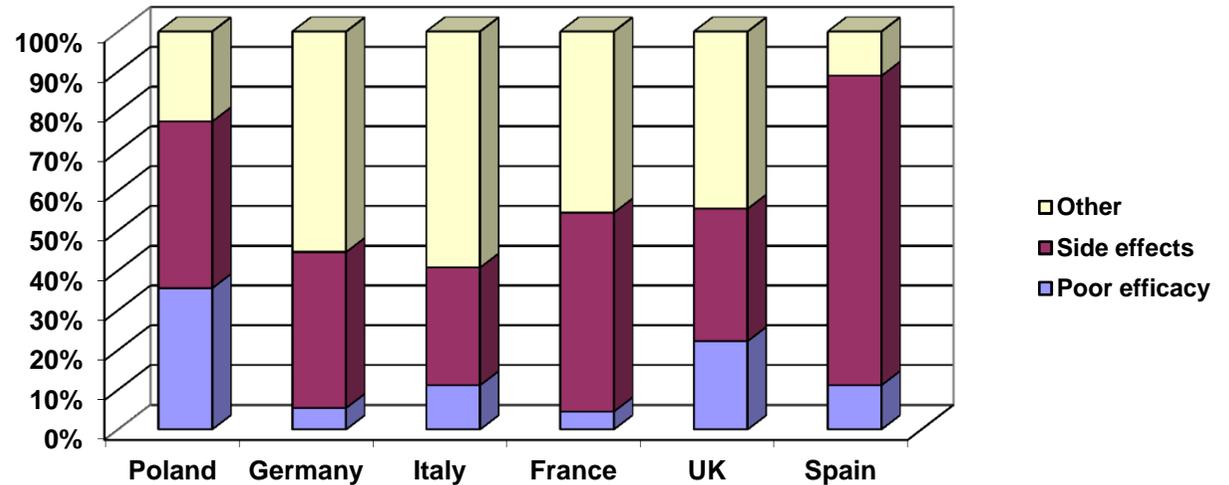
Have you (or the patient) changed your medication between the time of diagnosis and now?



If yes, please specify why:

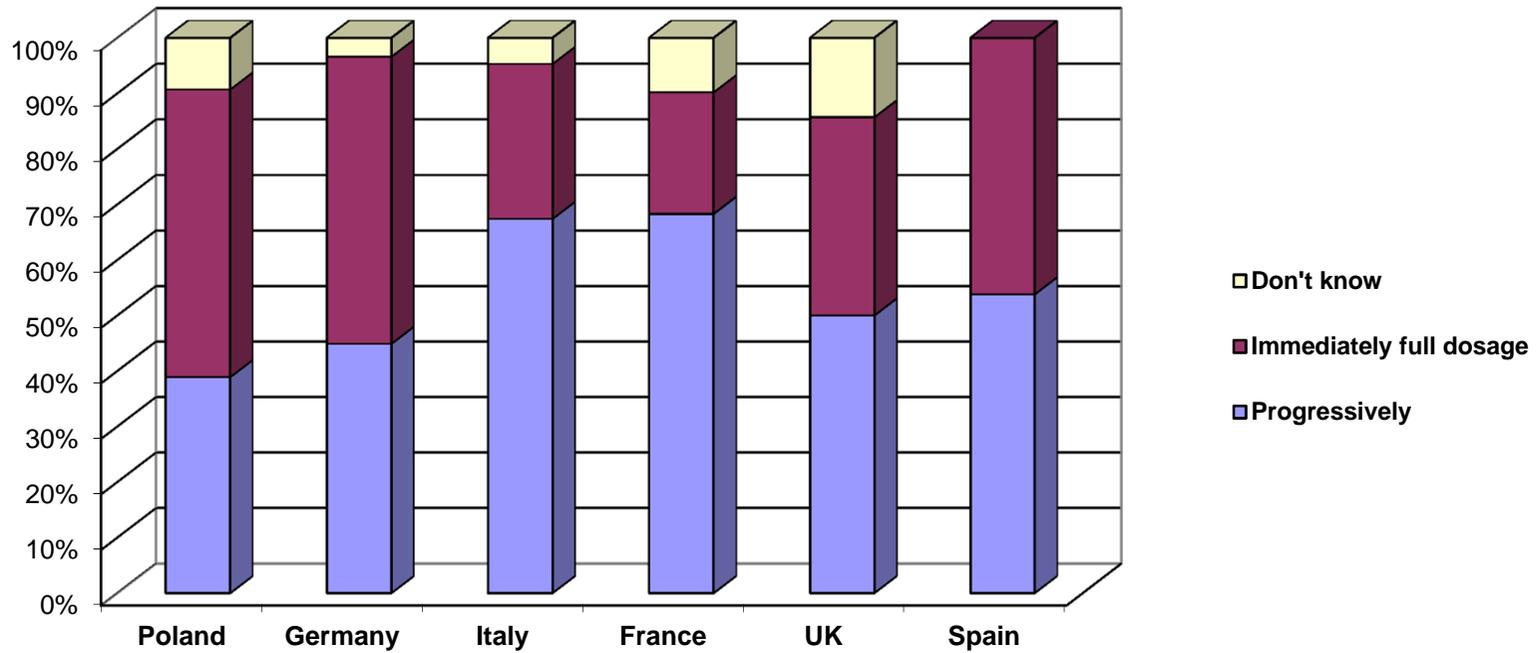
Others:

- Change of dosage
- Liver transplantation
- Pregnancy



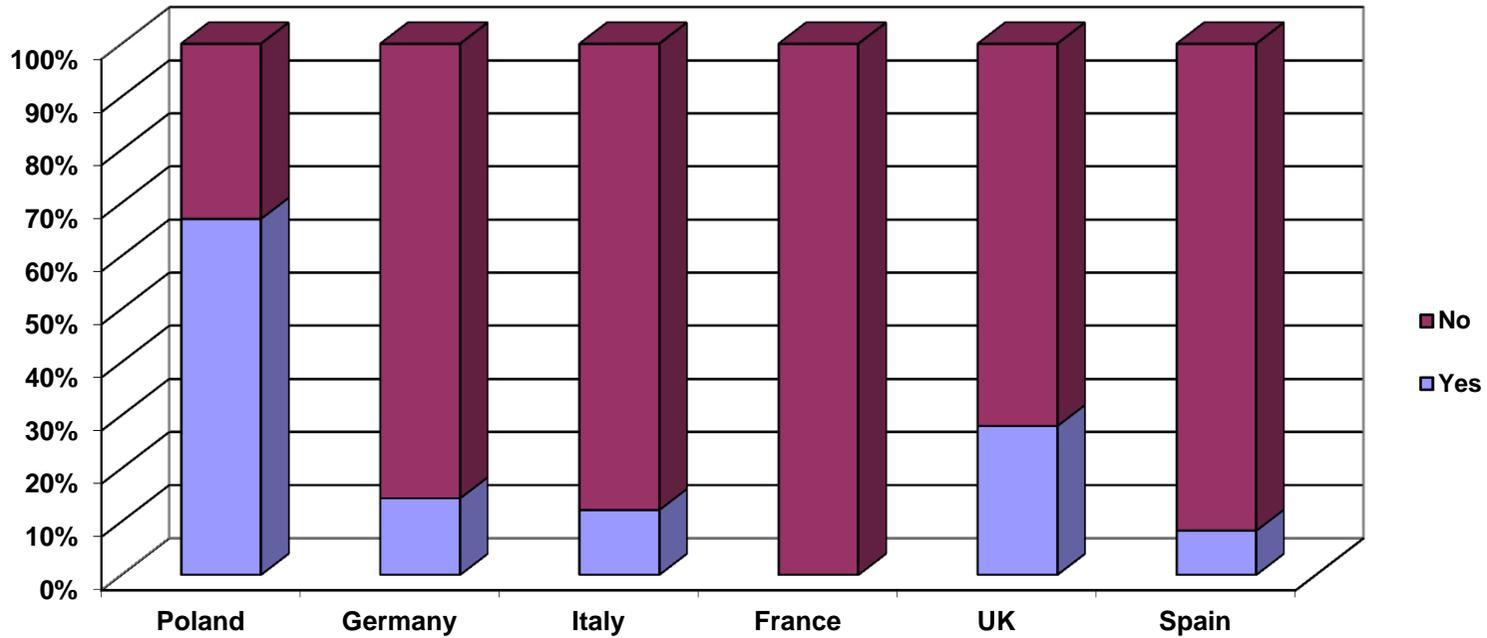
2012 Patient Survey

How was your (her/his) treatment started?



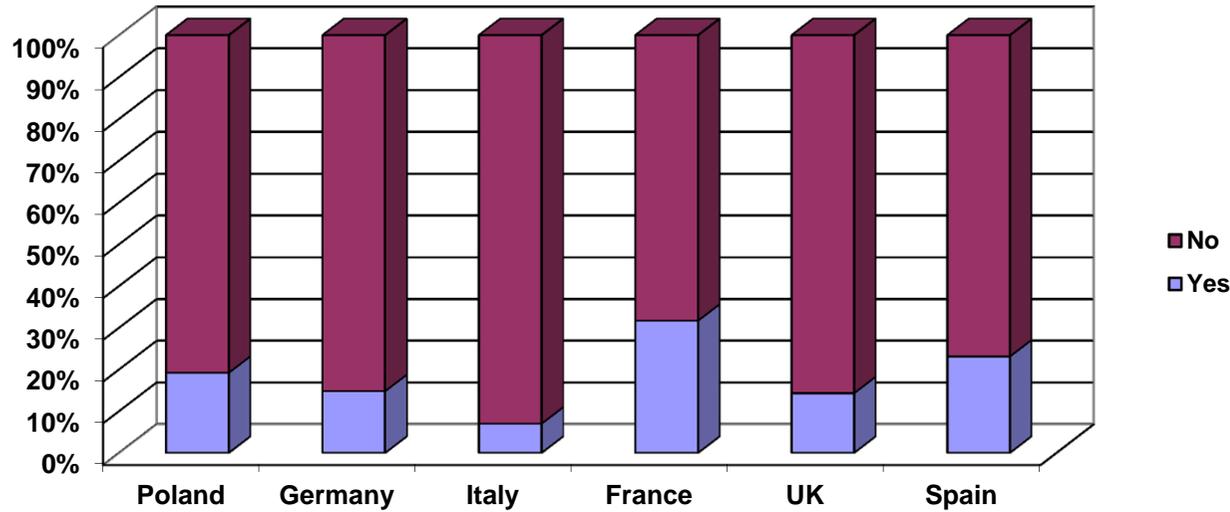
2012 Patient Survey

In your country, do you (or the patient) have difficulties getting reimbursed for your treatment?

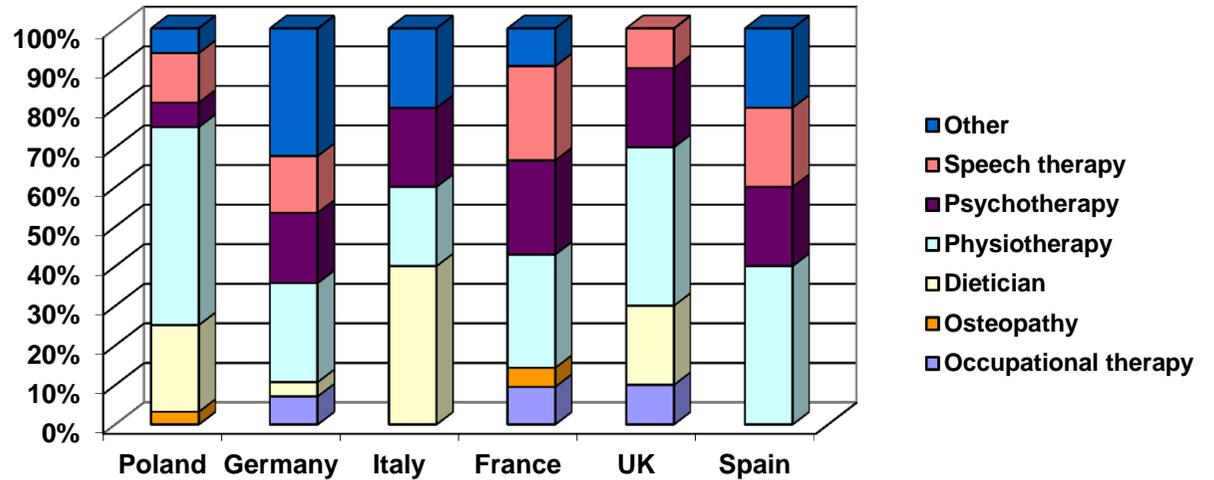


2012 Patient Survey

Are you (or the patient) in a programme of rehabilitation?

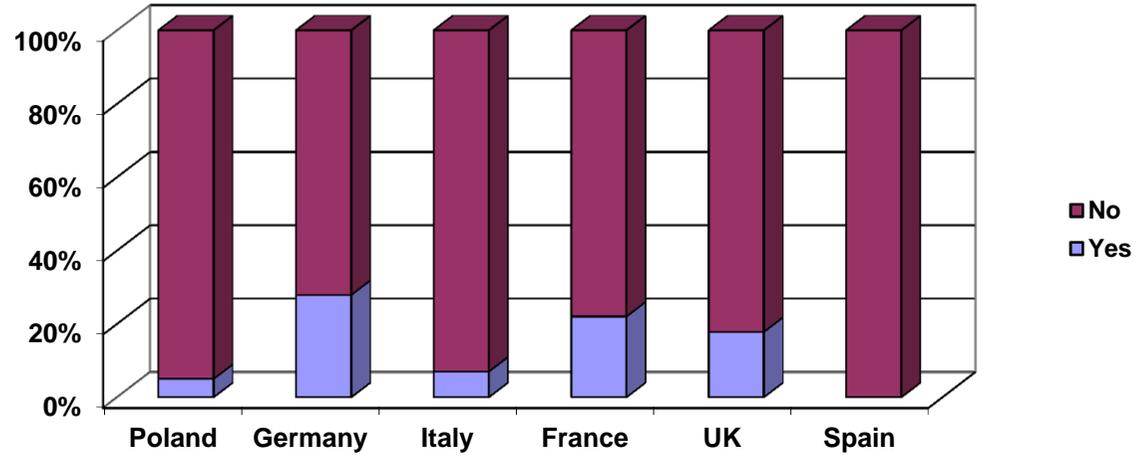


If yes:

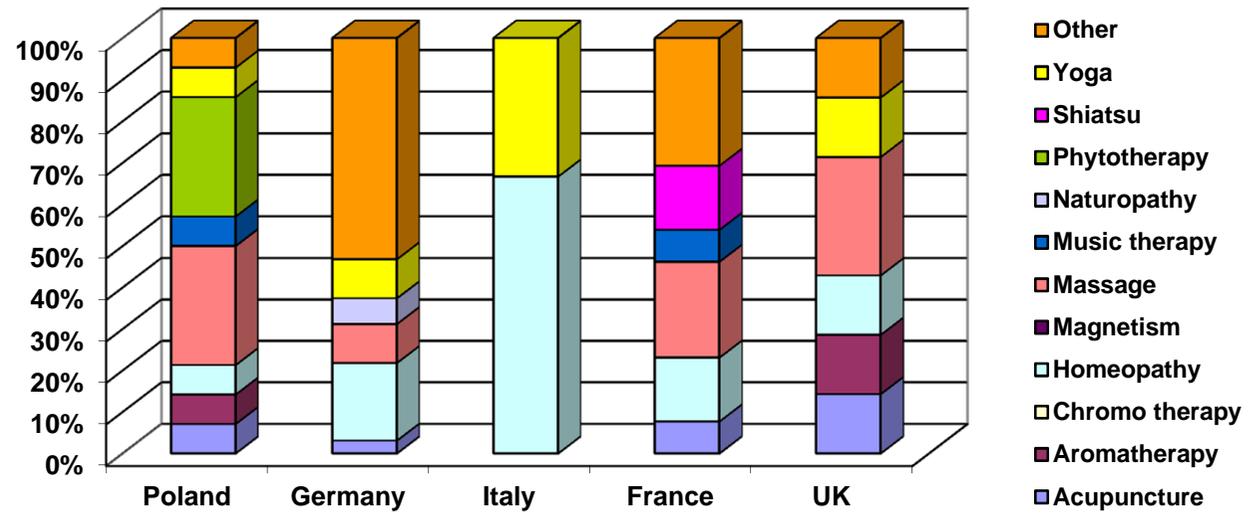


2012 Patient Survey

Do you (or the patient) use any forms of complementary medicine?

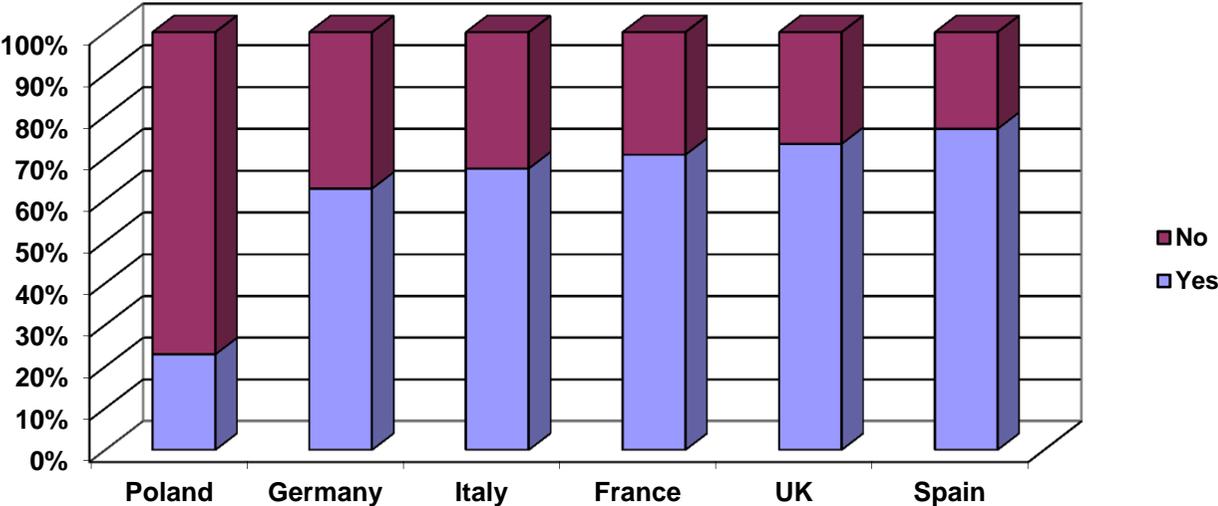


If yes:

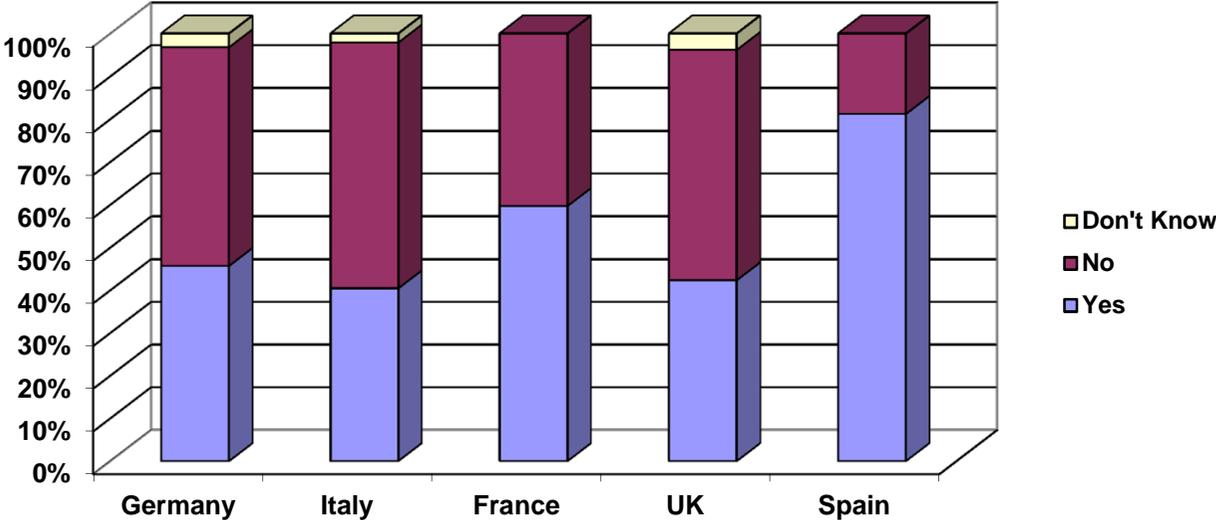


2012 Patient Survey

Before you answered this survey, had you heard about EuroWilson?



In 2011:



2012 Patient Survey

In your opinion, what should be the most important mission of EuroWilson?

