

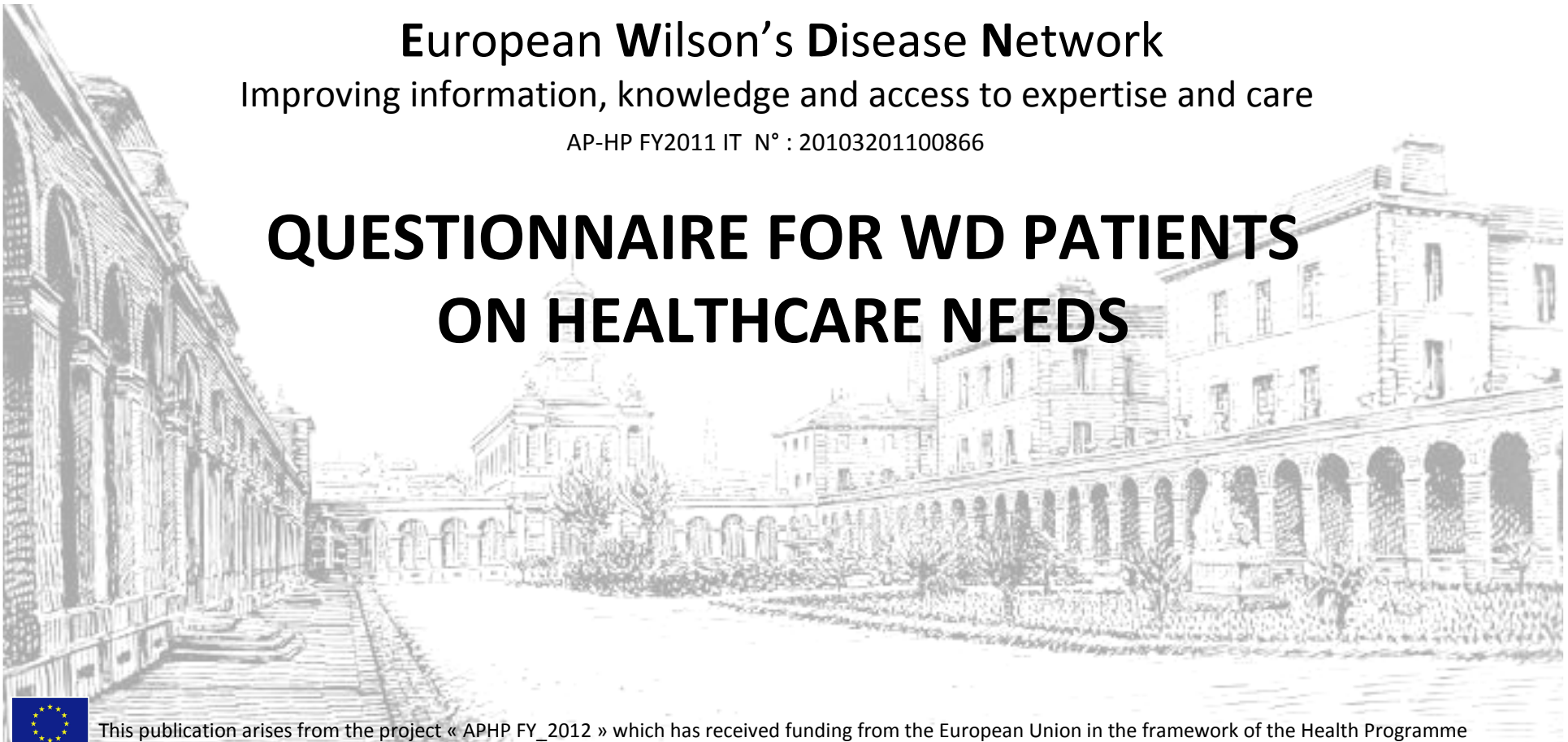
Health Program 2008-2013
Operating Grant 2010



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



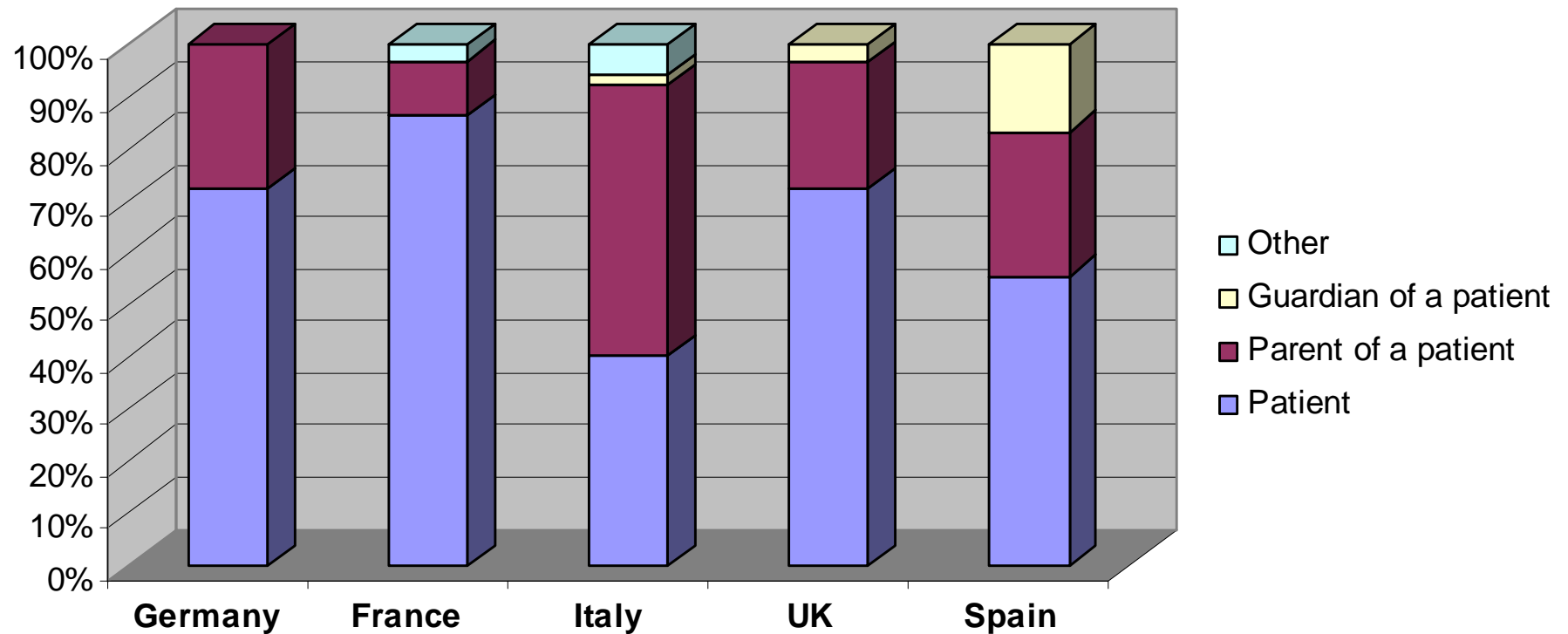
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Number of participants

Germany	France	Italy	UK	Spain	TOTAL
104	68	51	29	17	269

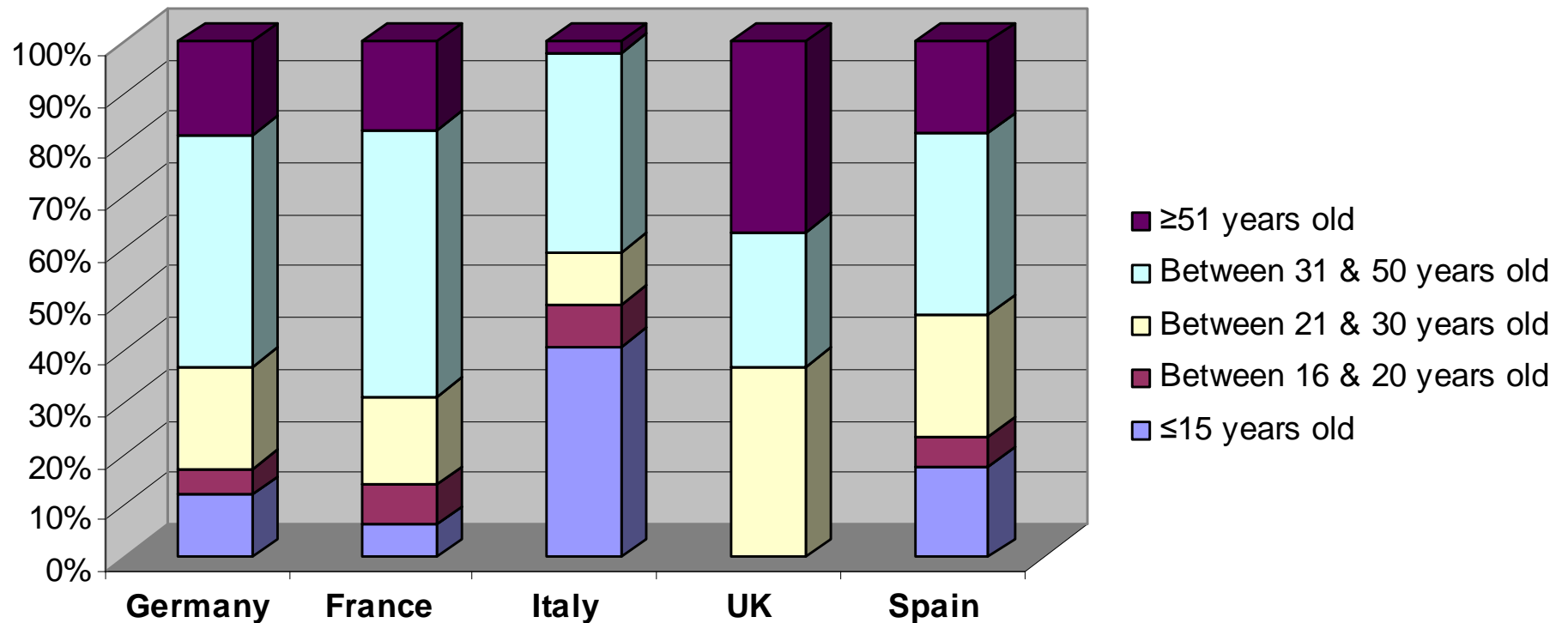
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Question n°3: Who are the participants?



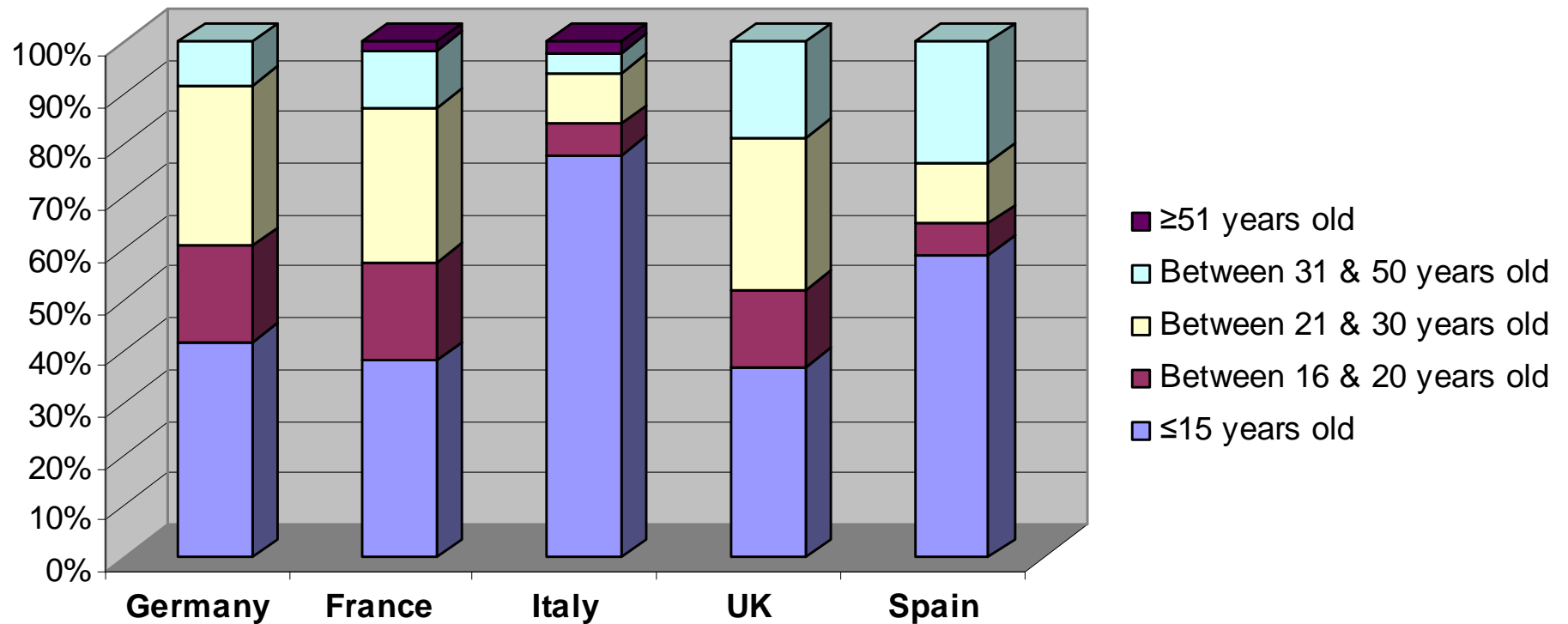
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Question n°4: Actual age of patient



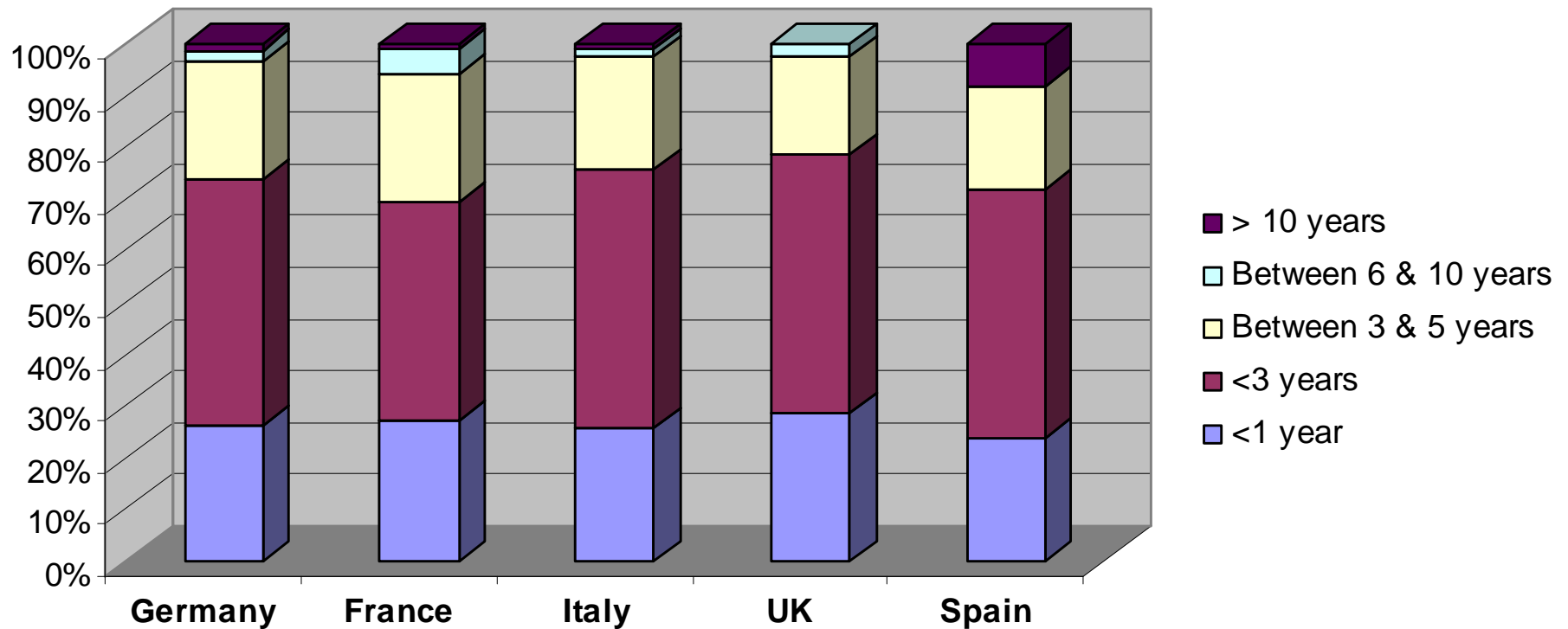
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Question n°6: How old were you or the patient when you (s/he) were diagnosed?



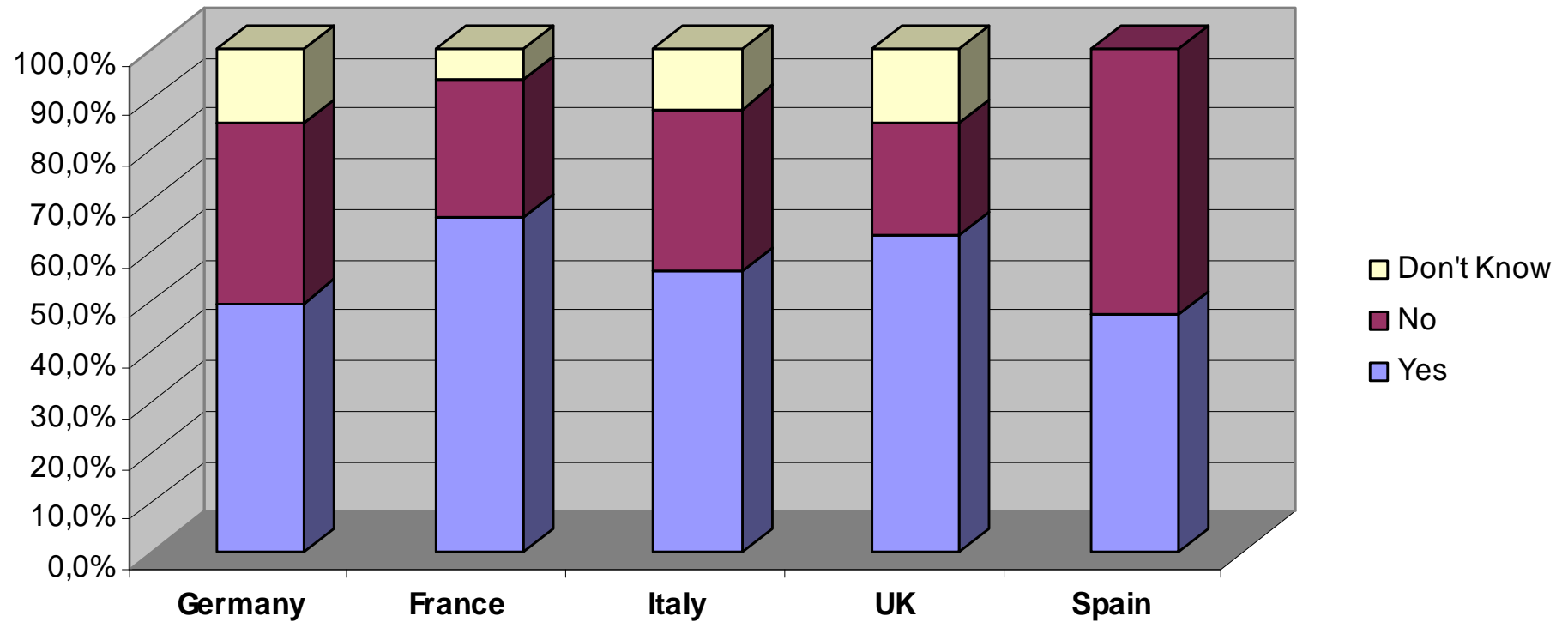
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

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



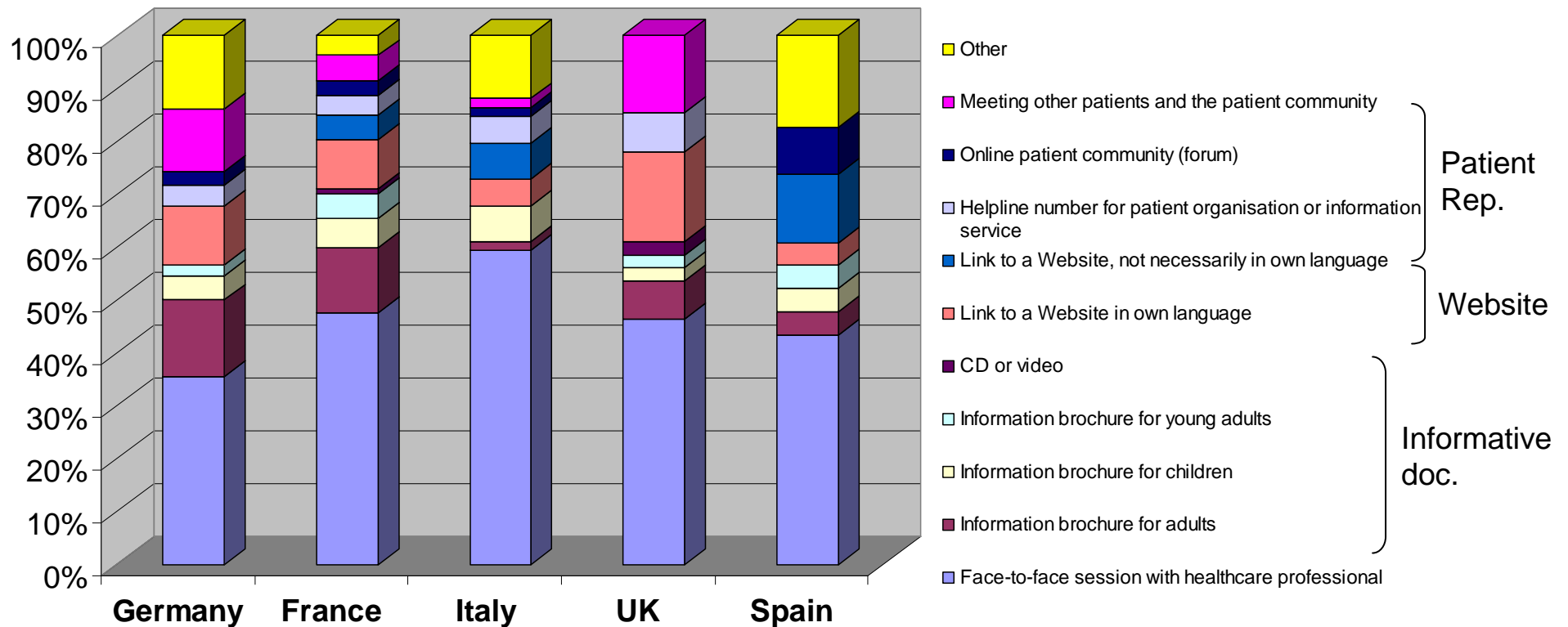
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Question n°9: Upon receiving your diagnosis, were you provided with adequate sources of information to understand your disease?



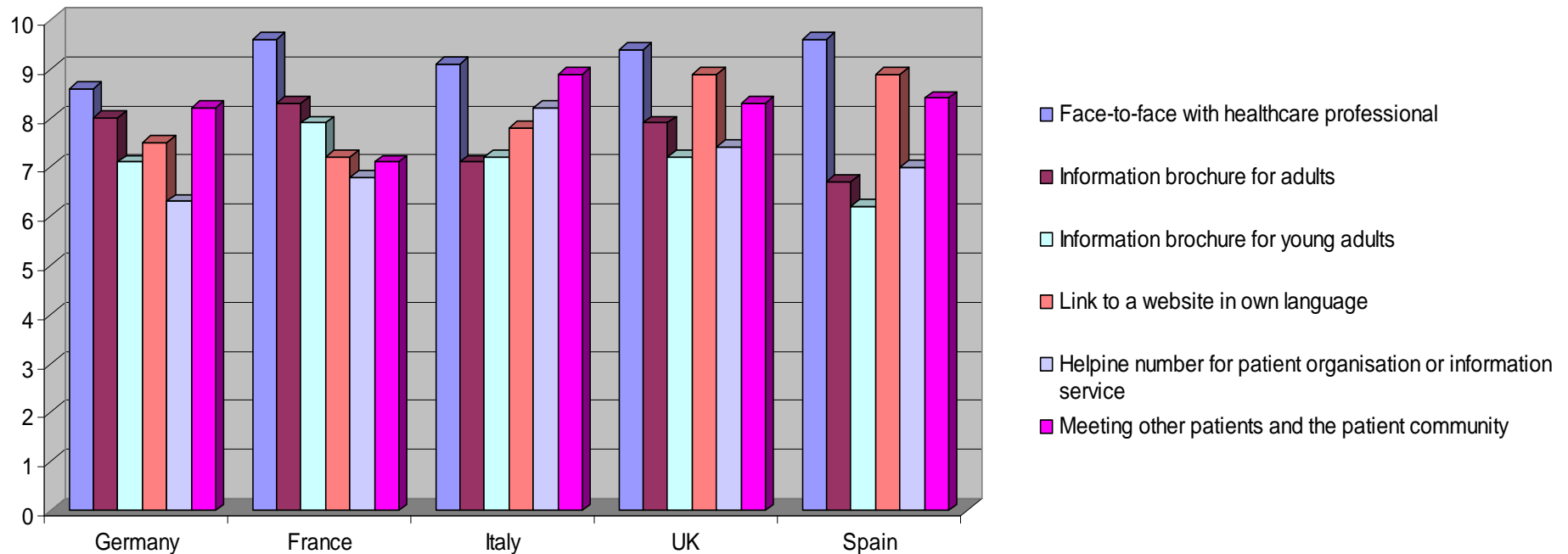
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Question n°10: If you did receive information about the disease, please specify the format/type?



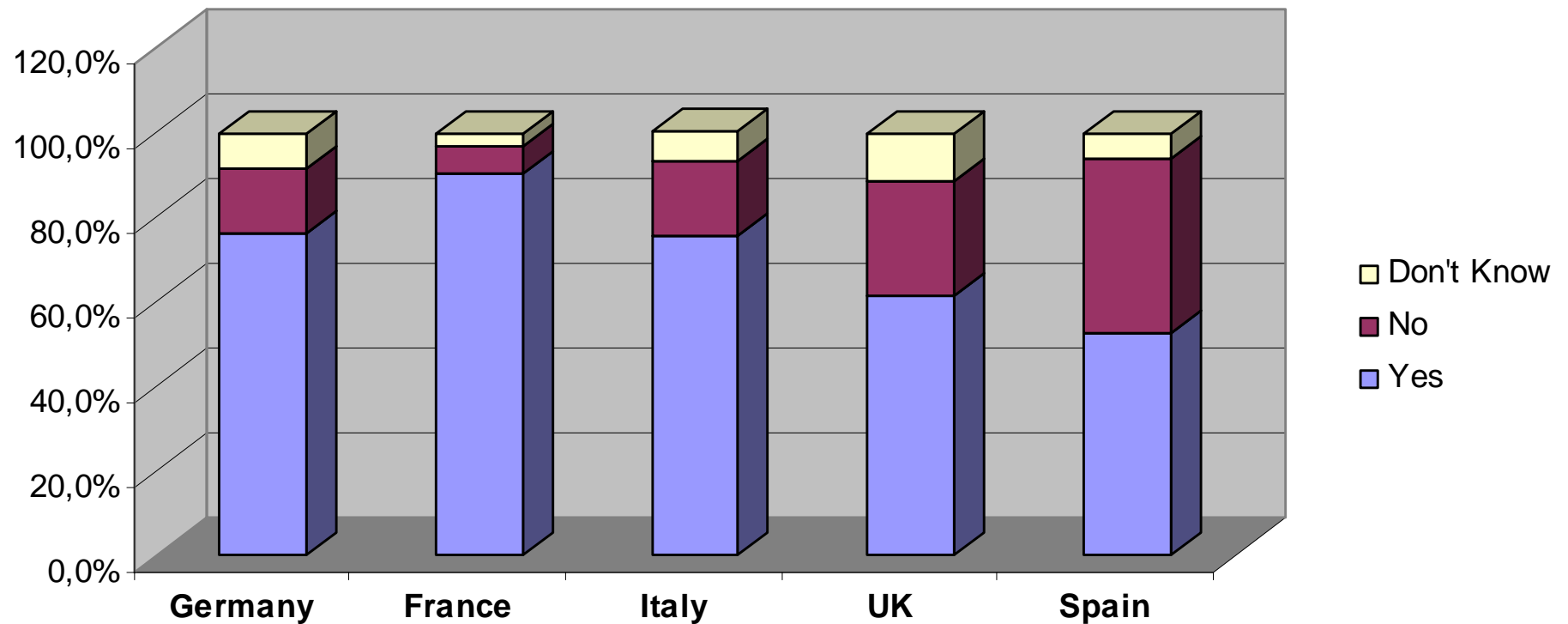
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

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?



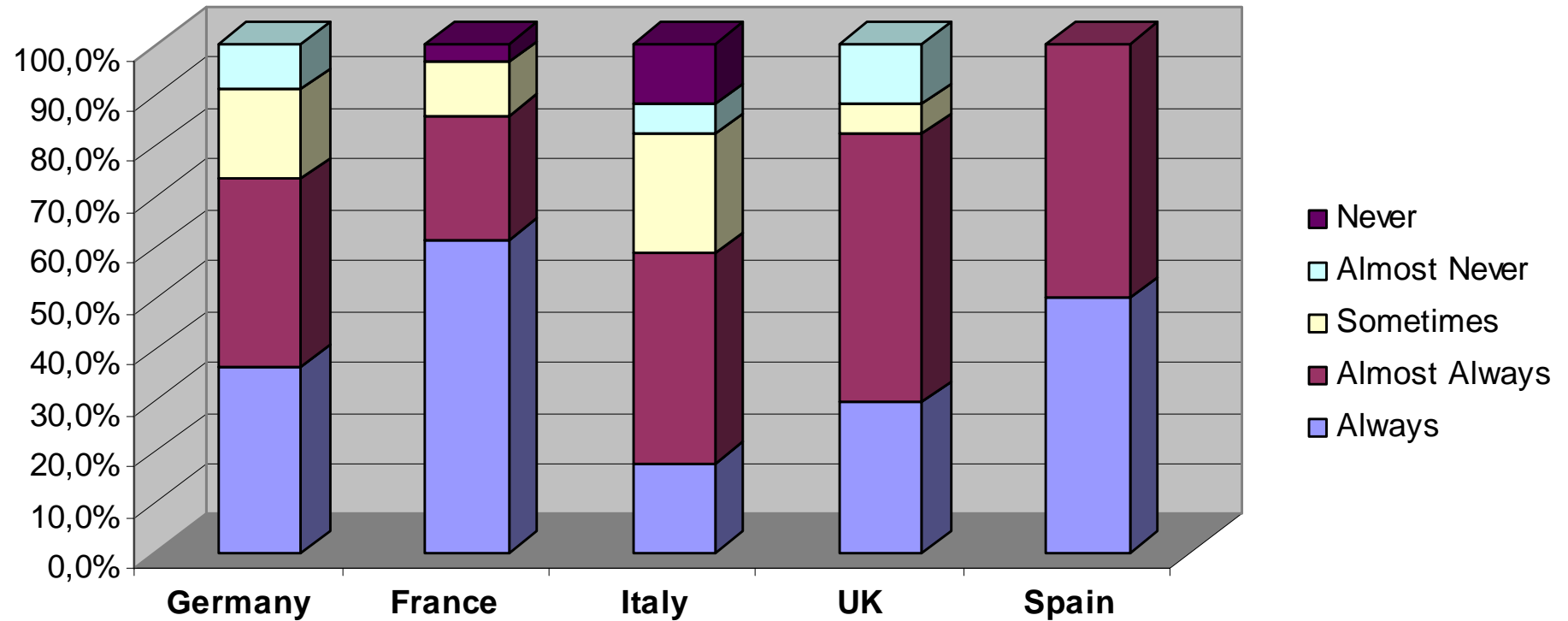
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

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



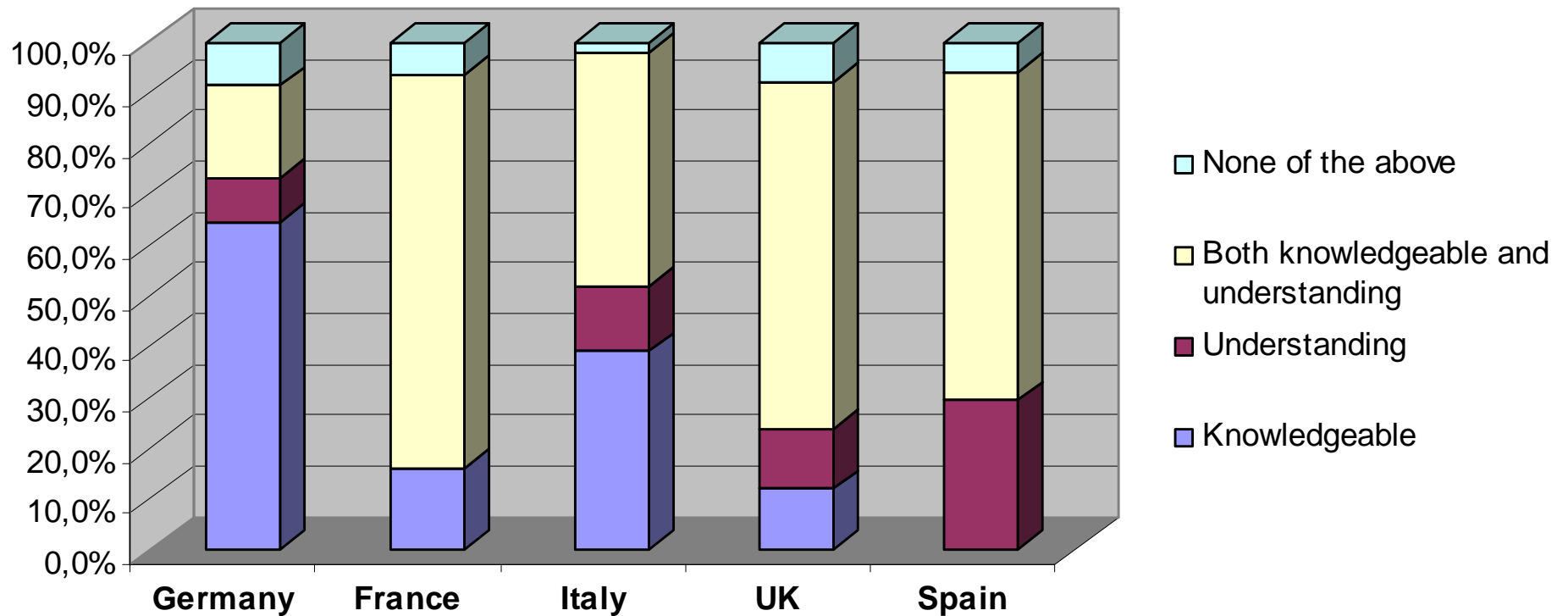
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Question n°14: Are you able to meet healthcare professionals at the centre as often as you would like to?



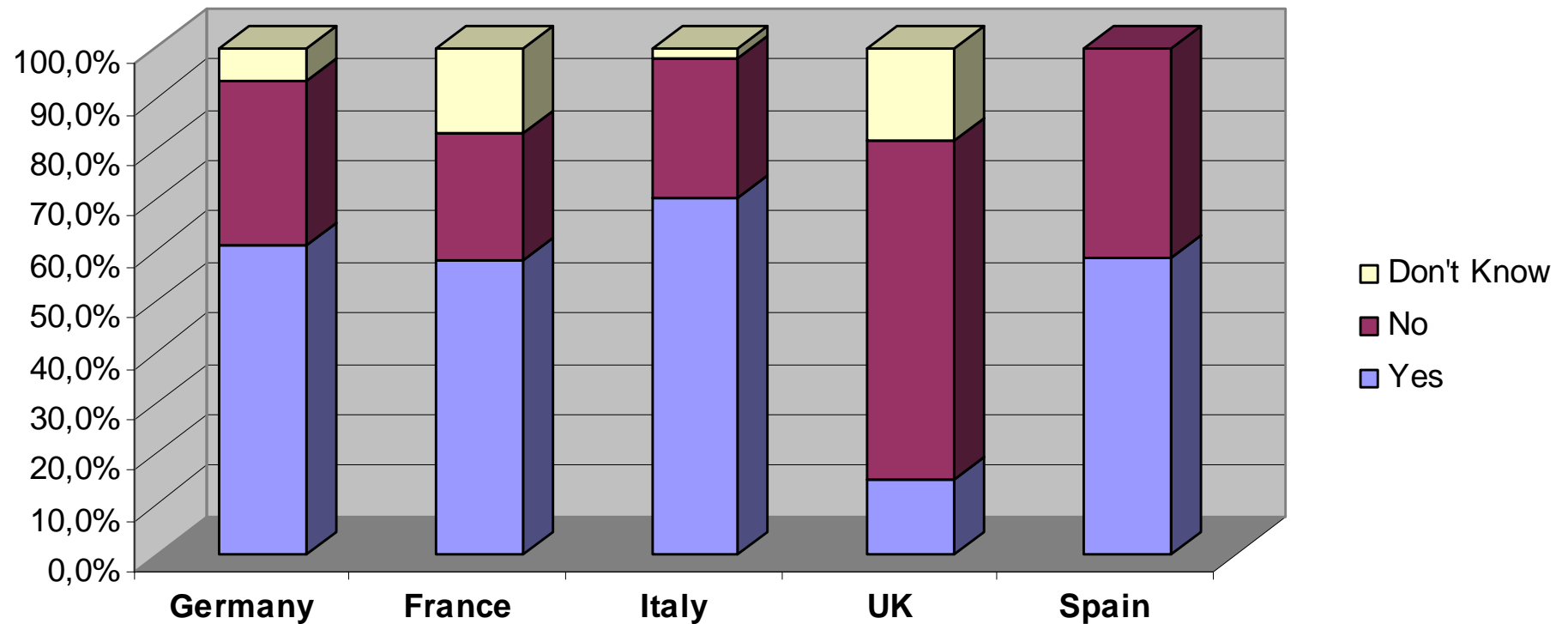
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Question n°15: The healthcare professionals in the centre responsible for your care are:



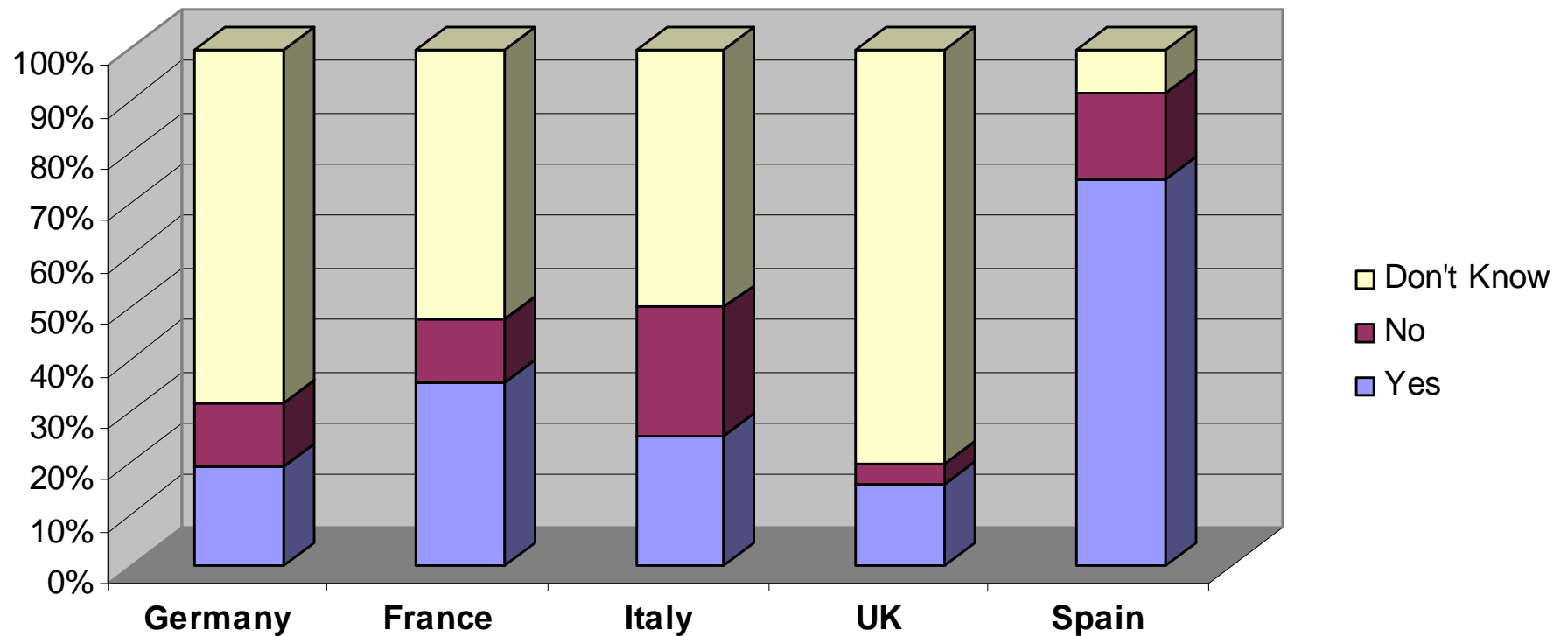
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Question n°16: Have you or your family been offered genetic counseling?



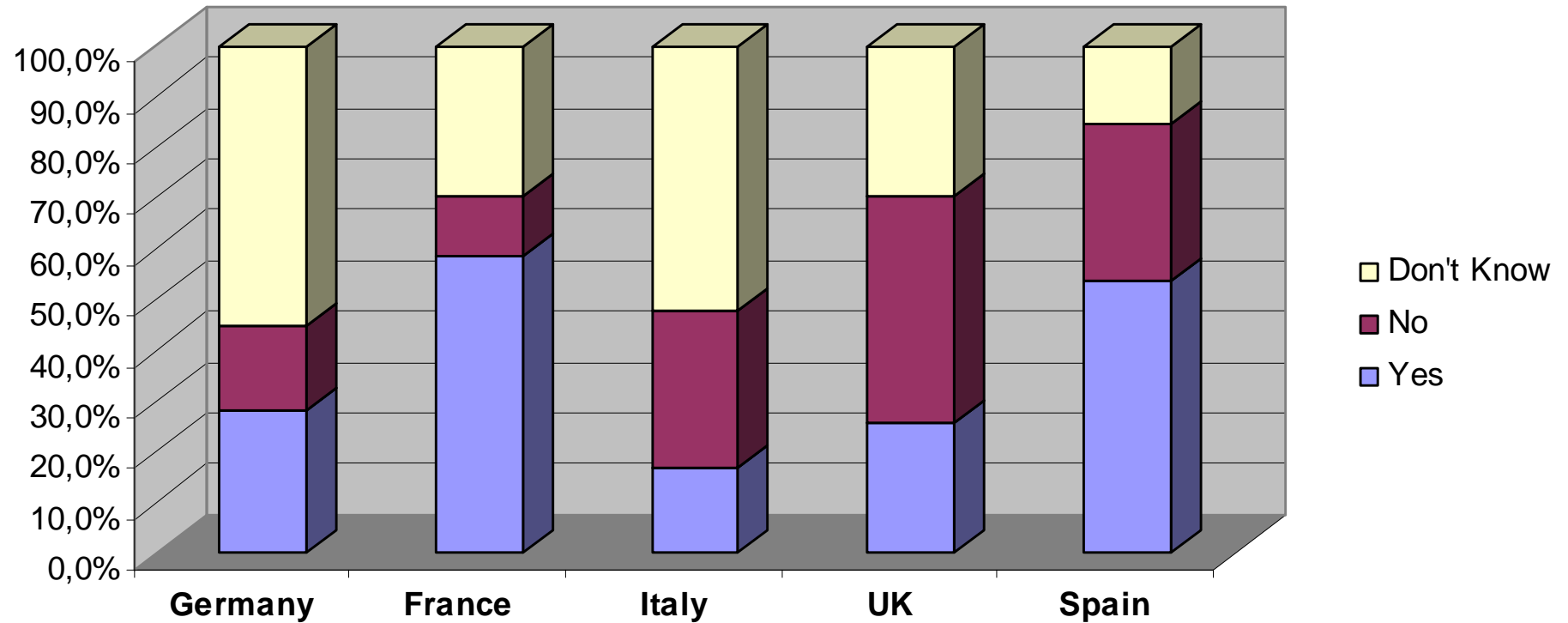
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Question n°17: Is the transition of care from childhood to adulthood satisfactory in your centre?



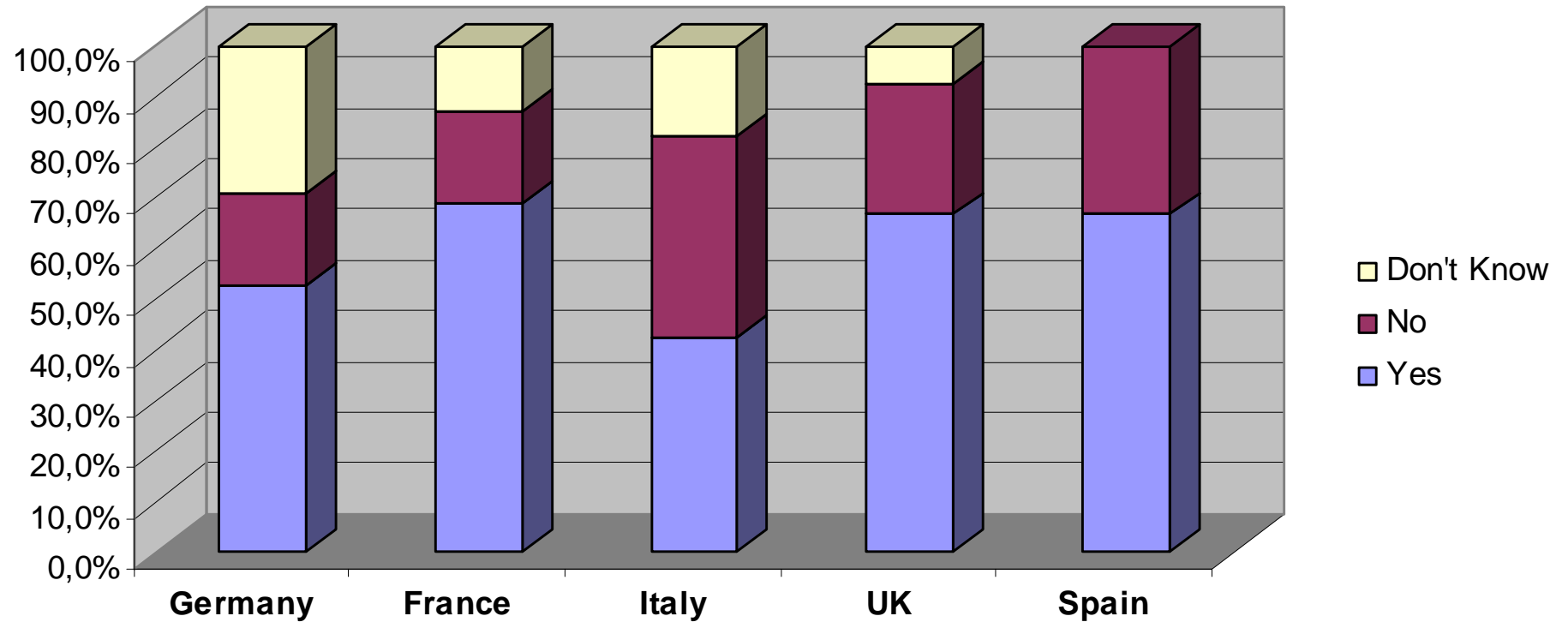
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

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



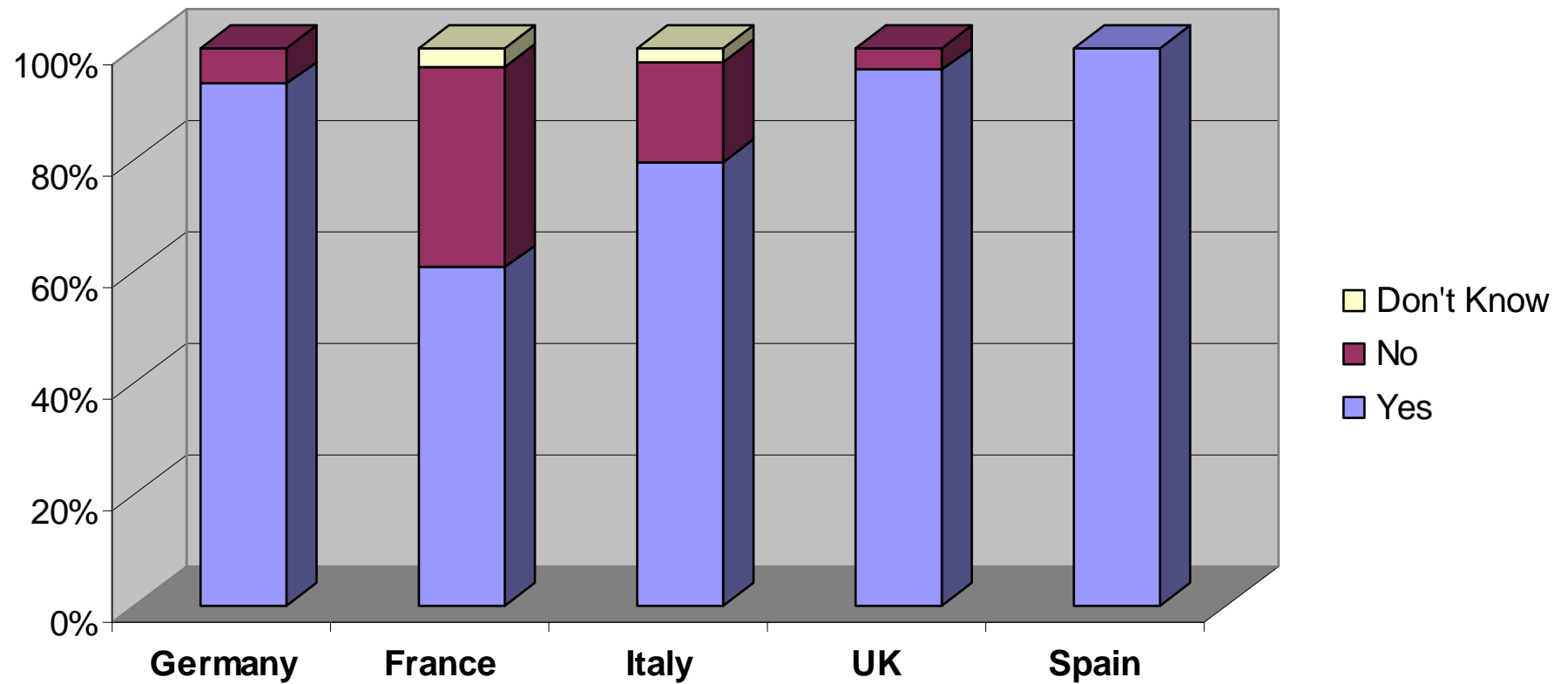
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

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



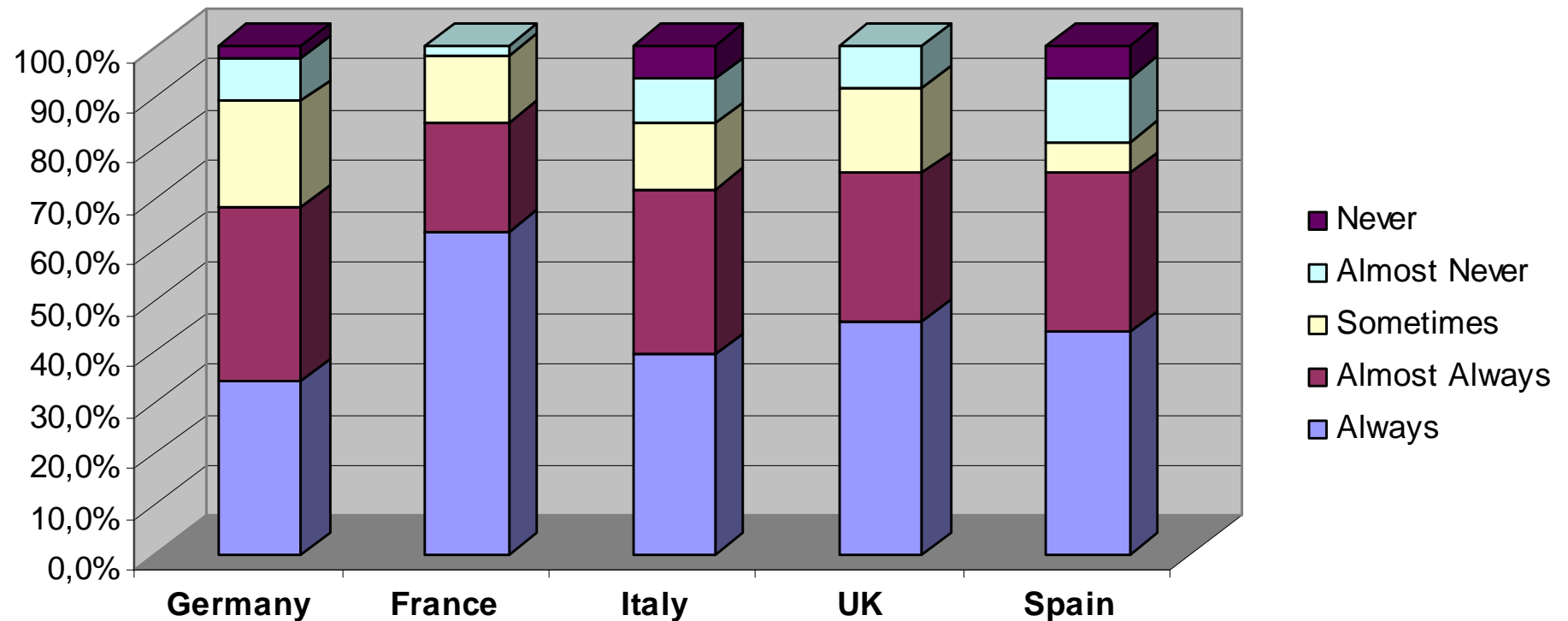
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

Question n°20: Did you contact or become a member of a patient group or association?



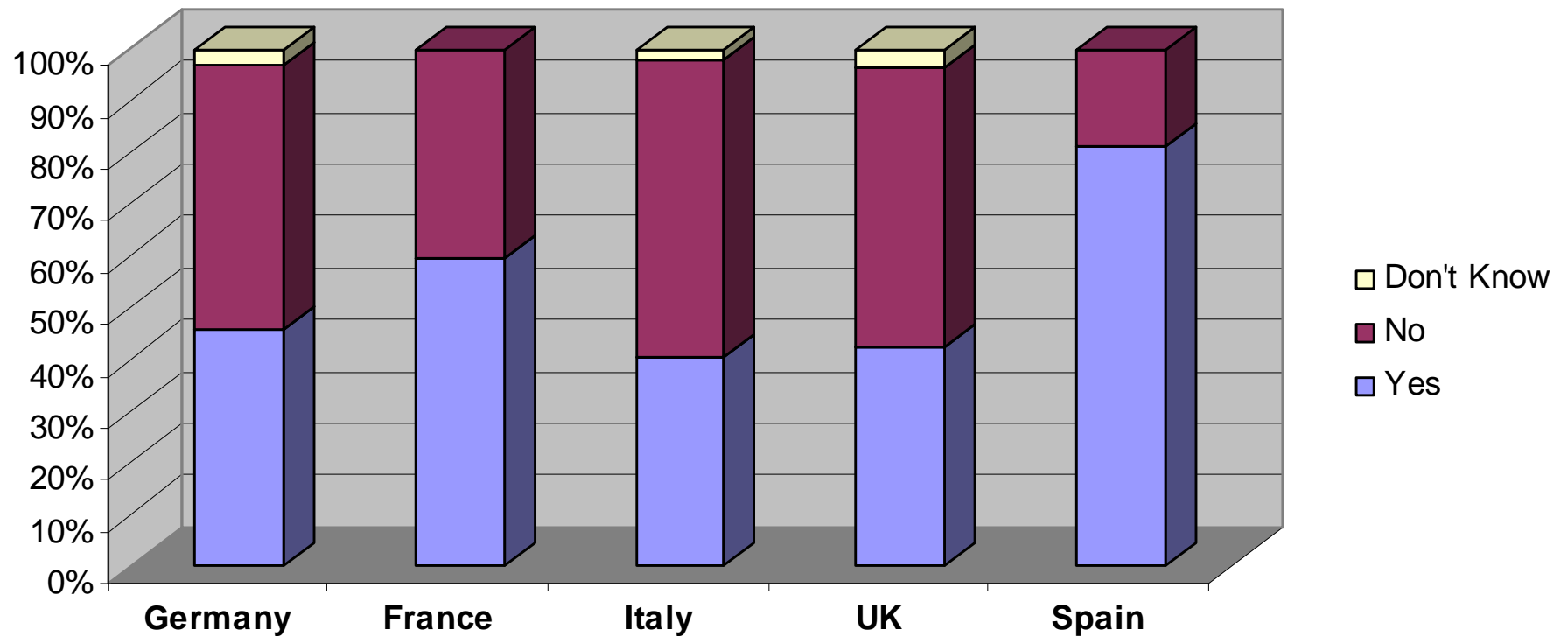
QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

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?



QUESTIONNAIRE FOR WD PATIENTS ON HEALTHCARE NEEDS

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?

