

SUPPLEMENTARY MATERIAL

Perspectives of Adult Patients and Caregivers on the Management and Challenges Associated with Neurofibromatosis Type 1 and Plexiform Neurofibromas: A Multinational Qualitative Survey

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Table S1 Number of patients or caregivers approached and methods to source participants in study, by country

Country	Number of patients or caregivers approached for inclusion in study	Methods used to source patients or caregivers in study
Italy	12	Patient organizations and HCP referrals
Germany	10	HCP referrals
Spain	17	Patient organizations and HCP referrals
Japan	12	Patient organizations
Canada	20	Patient organizations
UK	16	Patient organizations and patient databases
France	9	HCP referrals
China	8	Patient databases

HCP, healthcare professional.

Table S2 List of PN symptoms patients must have experienced at least one of in the past 3 months to be eligible for participation in the study.

List of PN symptoms patients must have experienced at least one of in the past 3 months
Chronic pain
Chronic headache
Hearing impairment
Vision impairment
Bladder and/or bowel dysfunction
Muscle weakness and/or paralysis
Seizures/epilepsy
Disfigurement
Airway/respiratory problems
Neurocognitive issues (learning delays)

PN plexiform neurofibroma

Table S3 Number of patients/caregivers who were approached but ineligible to participate in the study due to not having at least one of the PN-related symptoms listed in Table S2 in the past 3 months, by country.

Country	Number of patients/caregivers who were approached but ineligible due to not having at least one of the PN-related symptoms listed in Table S2 in the past 3 months
Italy	0
Germany	0
Spain	4
Japan	3
Canada	0
UK	1
France	0
China	0

PN plexiform neurofibroma

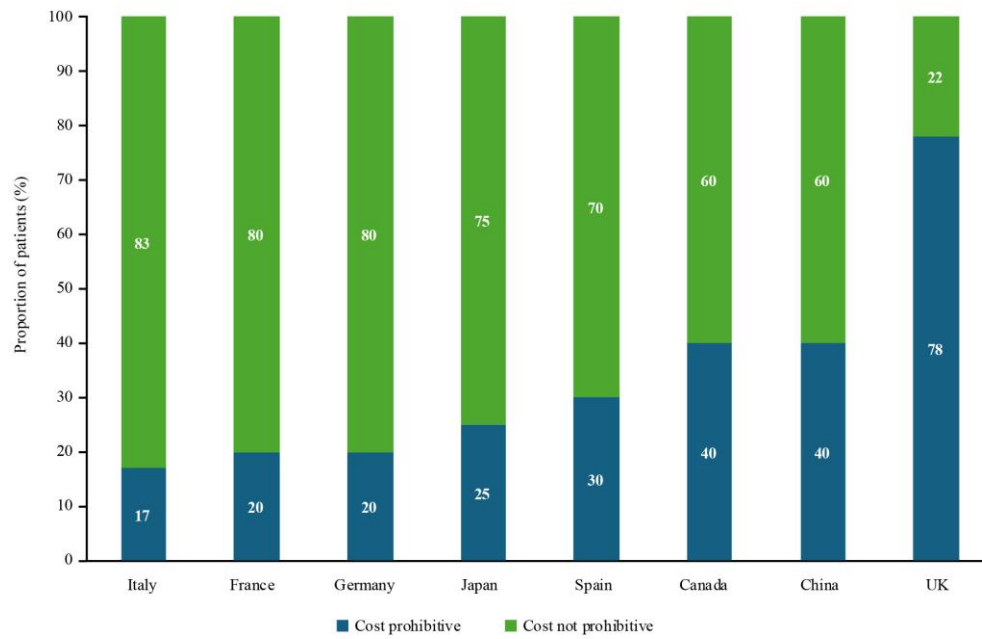


Fig. S1 NF1-PN treatment costs by country.

NF1 neurofibromatosis type 1, *PN* plexiform neurofibroma

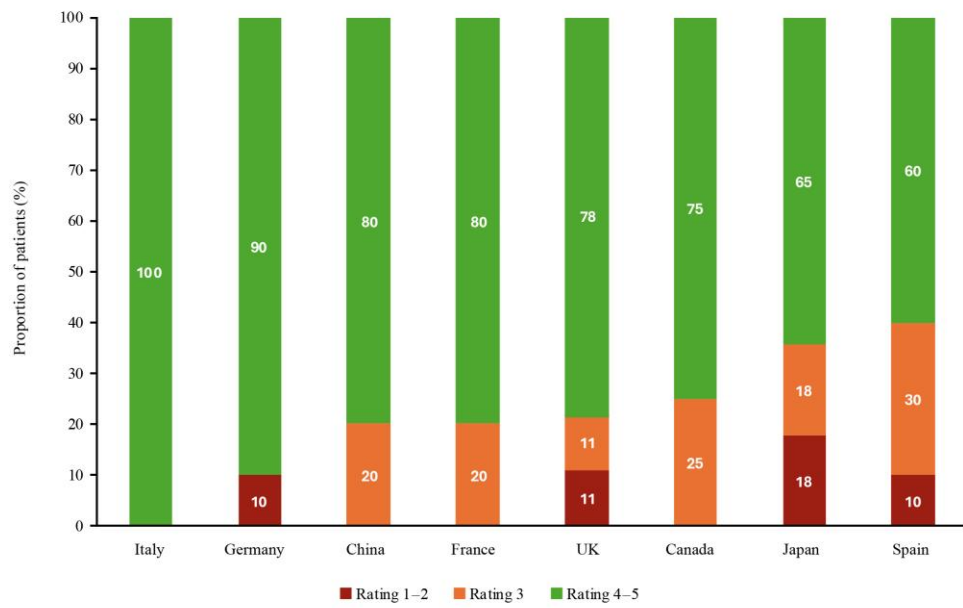


Fig. S2 Satisfaction with current physician for NF1-PN management by country. Rating scale: 1 = not at all satisfied; 5 = extremely satisfied.

NF1 neurofibromatosis type 1, *PN* plexiform neurofibroma



	School	Work	Relationship	Mental Health	Quality of Life
Germany (n=10)	75%	60%	60%	80%	89%
UK (n=9)	78%	78%	75%	44%	67%
Italy (n=10)	88%	78%	44%	67%	64%
Spain (n=10)	89%	100%	30%	44%	50%
China (n=10)	50%	50%	40%	60%	40%
Japan (n=10)	40%	44%	40%	44%	38%
France (n=10)	50%	40%	33%	22%	50%
Canada (n=10)	20%	13%	0%	40%	30%

Fig. S3 Impact of NF1-PN on daily life by country.

**Percentage of patients/caregivers rating a 4 or 5 on a 5-point scale where 1 = No impact and 5 = Extremely impactful. Shading represents patients/caregivers by country who rated their NF1-PN as having higher impact. Red: 80–100% of patients/caregivers report high impact; dark pink: 70–79% of patients/caregivers report high impact; light pink: 60–69% of patients/caregivers report high impact.*

Country: n = School, Work, Relationships, Mental Health, Quality of Life:

Germany: n = 8, 5, 10, 10, 9; UK: n = 9, 7, 8, 9, 9; Italy: n = 8, 8, 9, 9, 8; Spain: n = 9, 5, 10, 9, 10; China: n = 10, 7, 10, 10, 10; Japan: n = 10, 6, 10, 9, 8; France: n = 8, 7, 9, 9, 8; Canada: n = 10, 8, 10, 10, 10.

NF1 neurofibromatosis type 1, *PN* plexiform neurofibroma

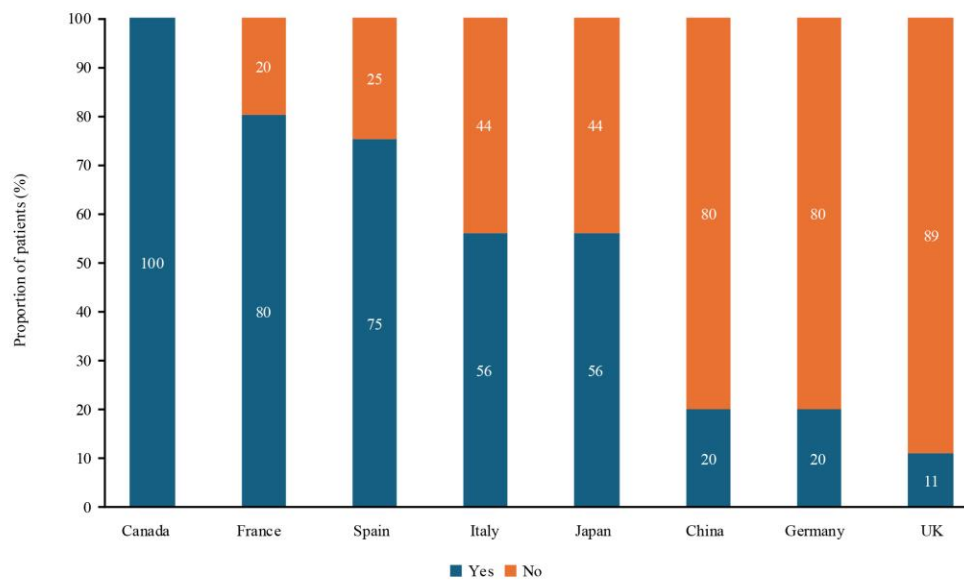


Fig. S4 Involvement in NF1 associations/patient support programs by country.

NF1 neurofibromatosis type 1

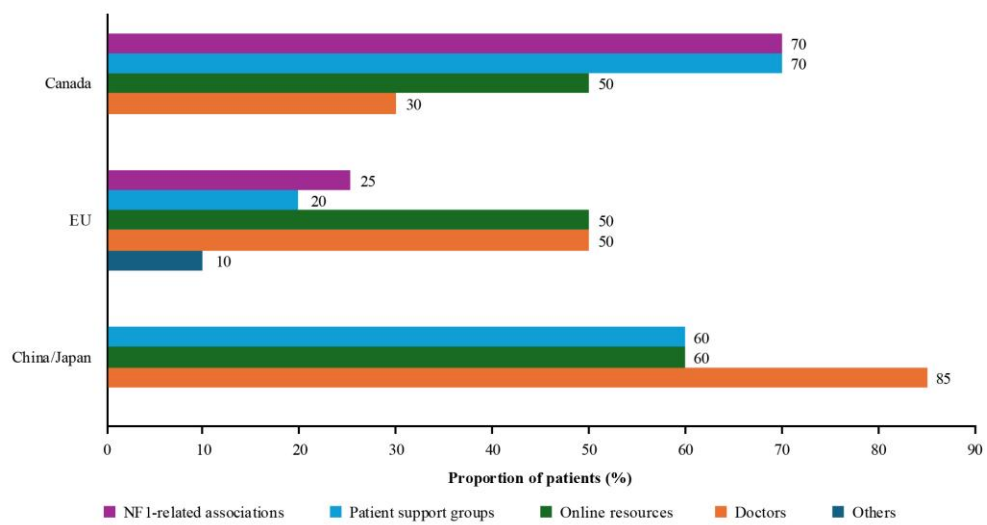


Fig. S5 Sources of NF1-PN information by country.

EU European countries (Italy, France, Germany, Spain, the UK), *NF1* neurofibromatosis type 1, *PN* plexiform neurofibroma