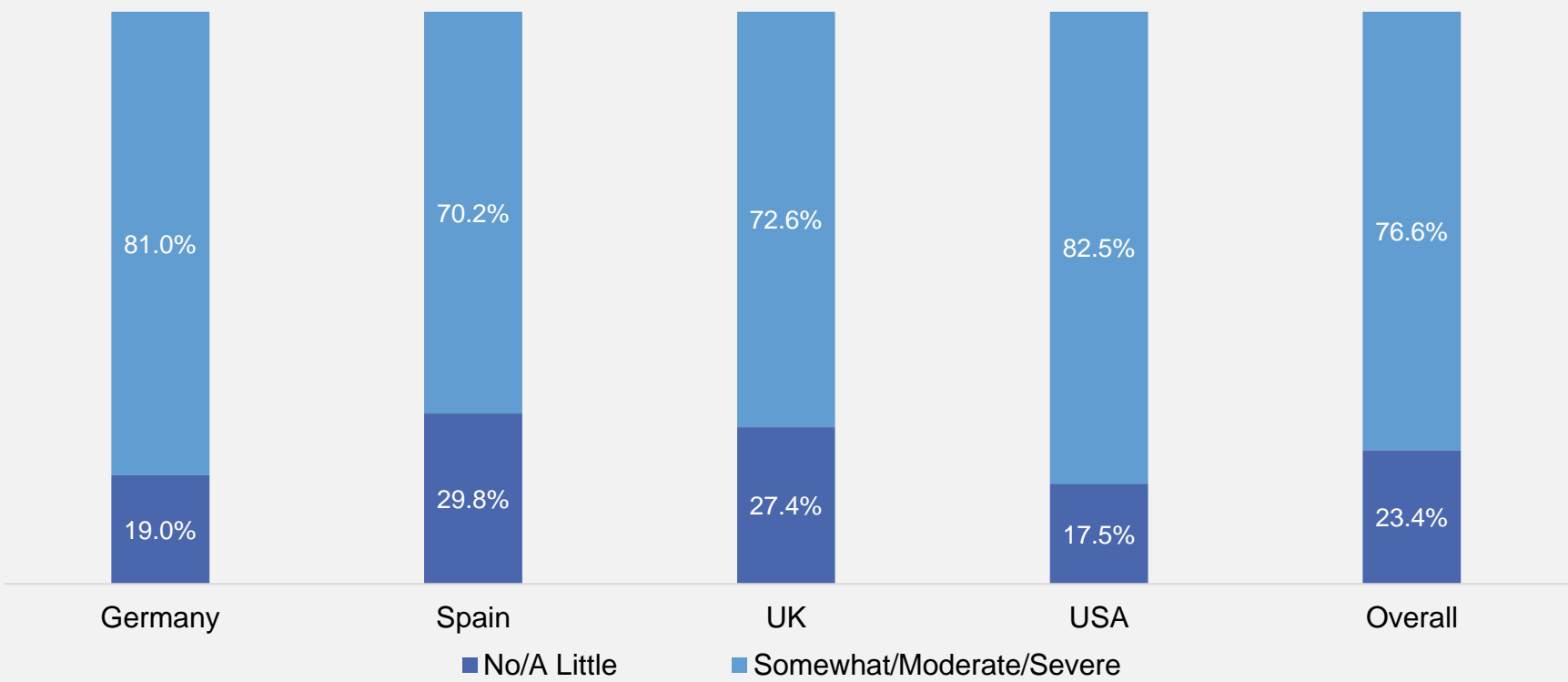


Rare Disease Panel Survey

February/April 2024

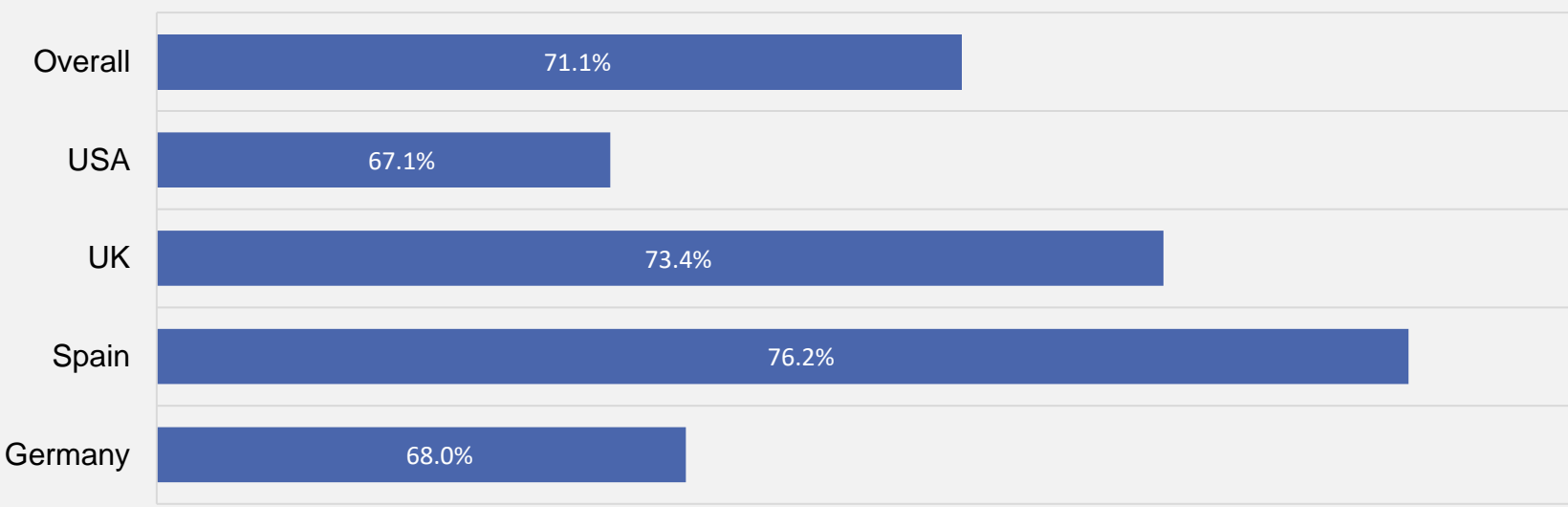
Results depicted here are from a survey of 800 rare disease patients and their caregivers across Germany, Spain, the UK, and the US. In February/April 2024, participants completed an online survey asking their opinions about their access to healthcare, diagnostic journey and perspectives on living with a rare disease. Over 300 rare diseases are represented in the study.

Impact of rare disease on family finances



Overall, 77% of respondents reported that rare disease related economic burden impacted their family finances; 27% reported spending over 10,000 EUR/USD out-of-pocket to manage the disease.

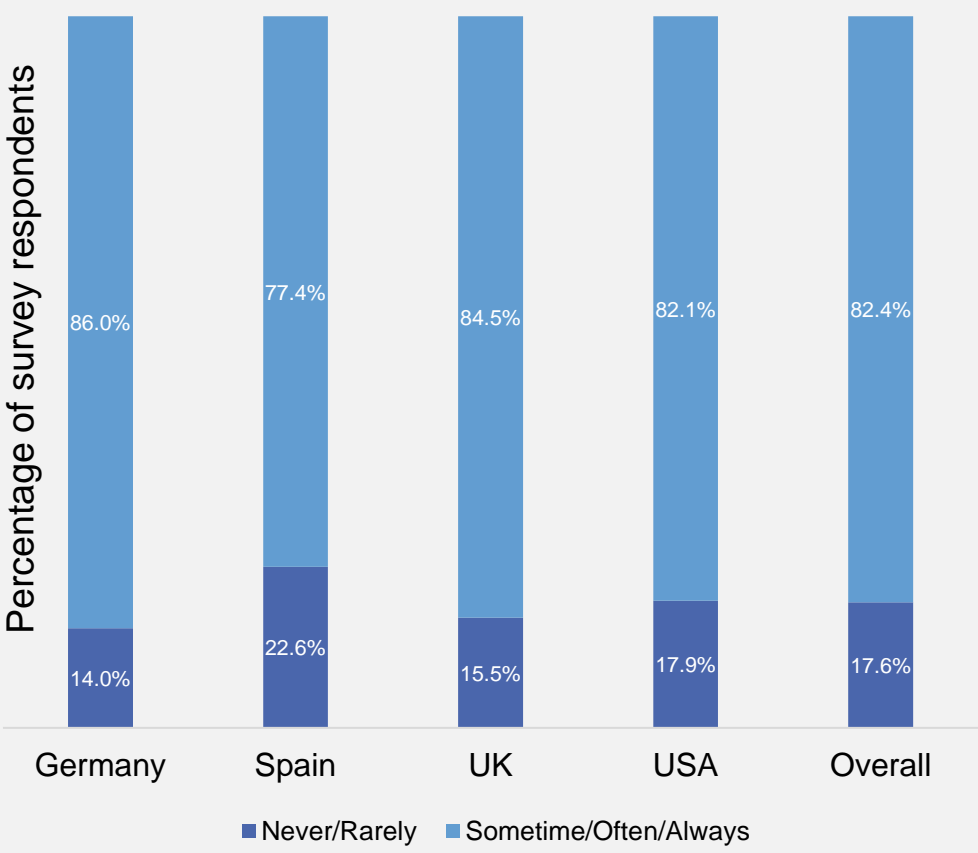
Rare disease impact on quality of life



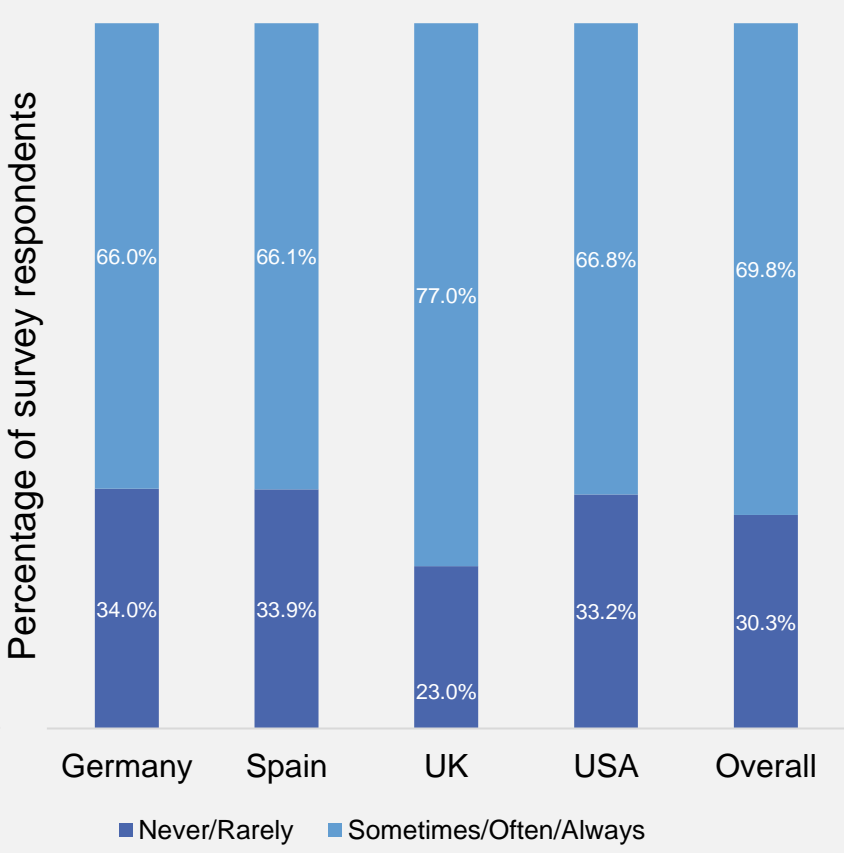
Percentage of survey respondents reporting severe impact

Over 2/3rd of survey respondents report severe impact of rare disease on (patient) quality of life.

Rare disease impact on preventing spending time with family and friends

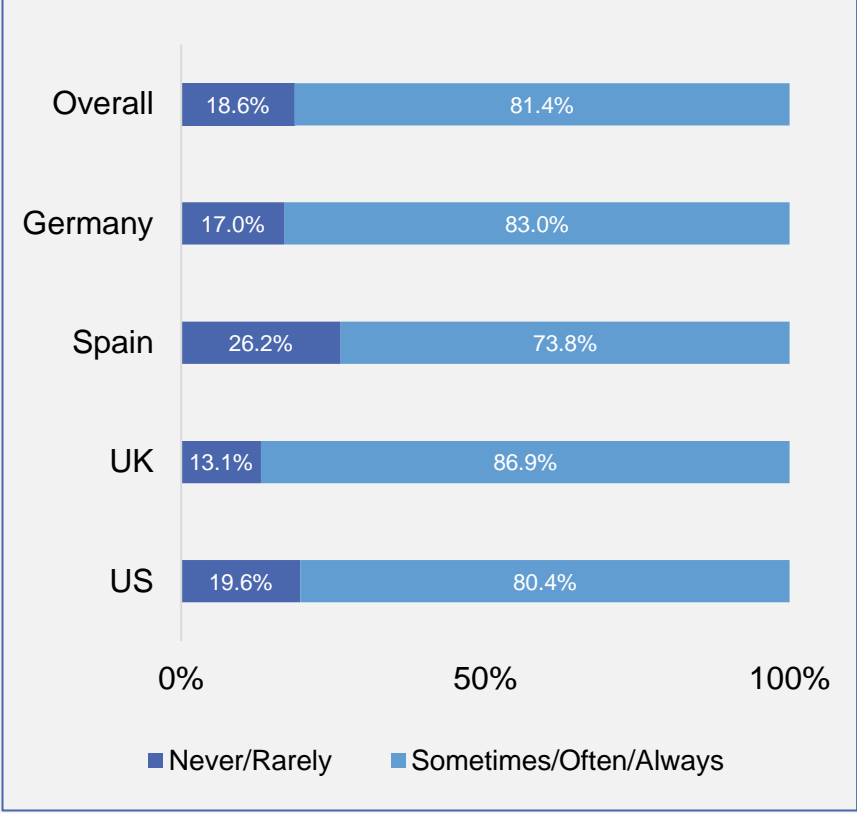


Rare disease impact on exclusion from social events

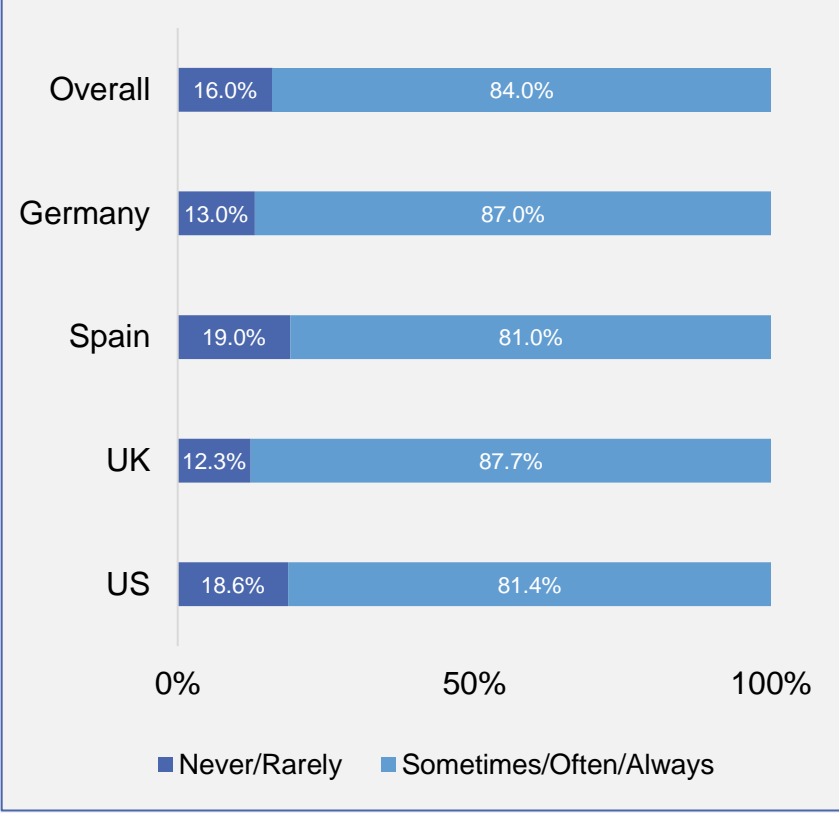


Overall, majority of participants report their rare disease prevents them from spending time with their friends and family, and they are excluded from social events.

Patients feel like a burden to family



Rare Disease impact on relationships



A vast majority of respondents reported that they feel like a burden to their family, and having a rare disease impacts their family relationships.

RD Stakeholders had diverse perspectives on how their disease misdiagnosis impacted their disease burden.

