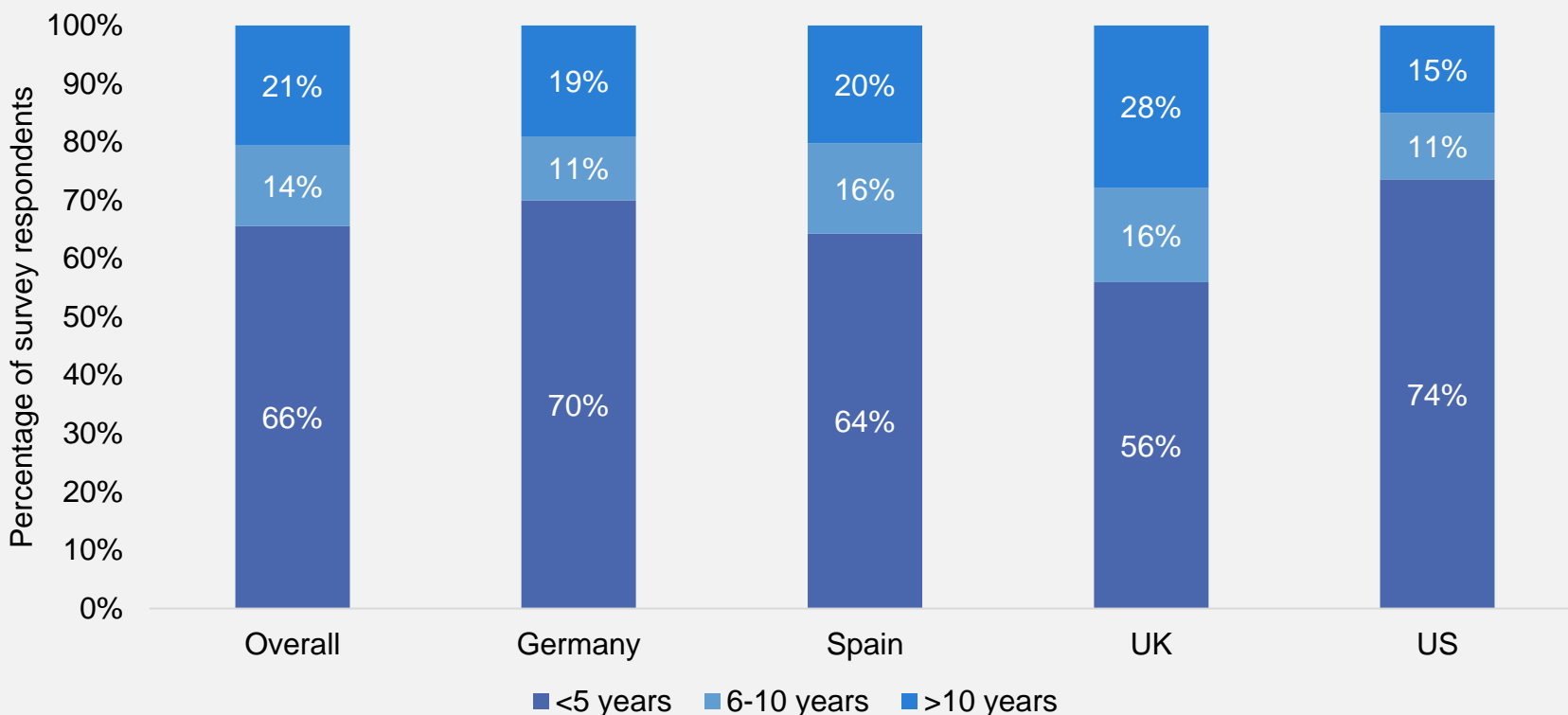


# Rare Disease Panel Survey

## February/April 2024

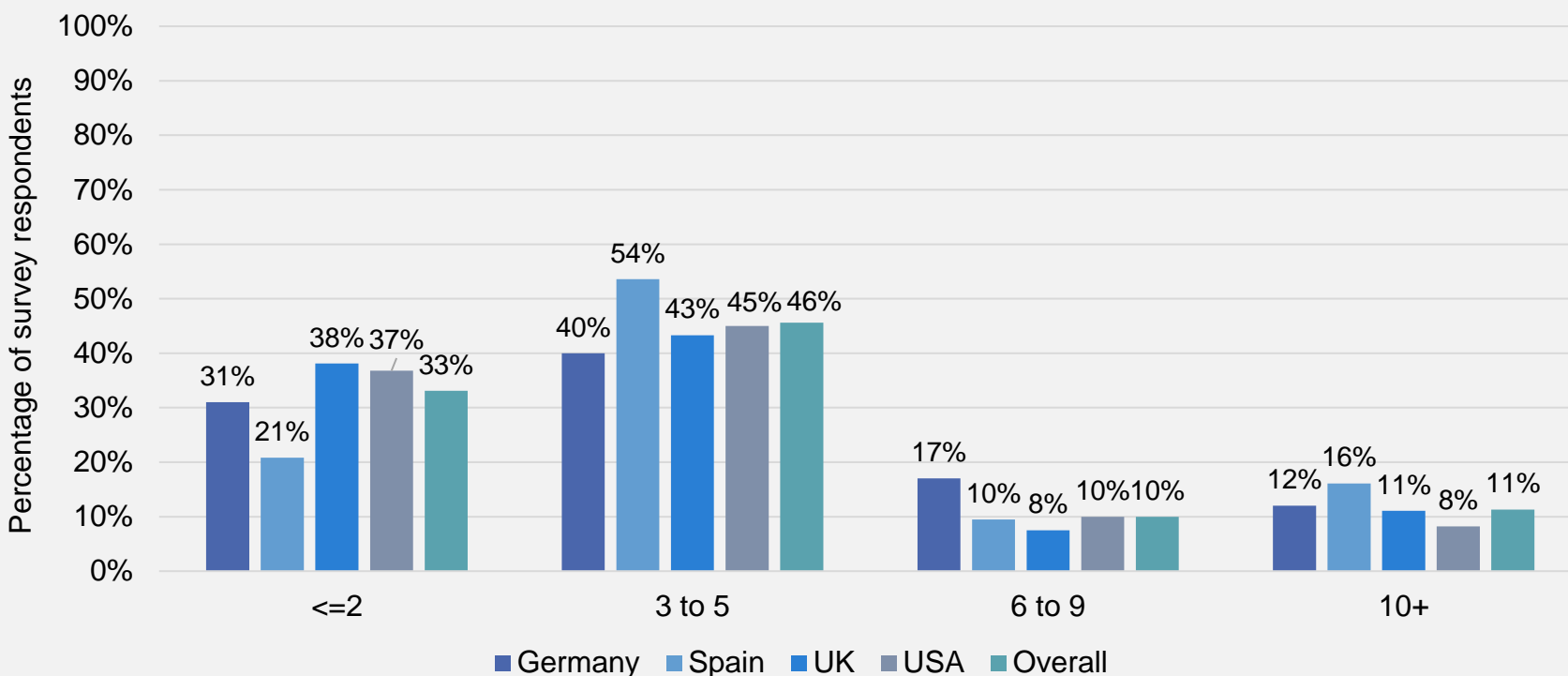
Results depicted here are from a survey of 800 rare disease patients and their caregivers across Germany, Spain, the UK and the U.S. In February/April 2024, participants completed an online survey asking their opinions about their rare disease diagnostic journey, access to healthcare, and perspectives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

### Number of years to receive a confirmed diagnosis



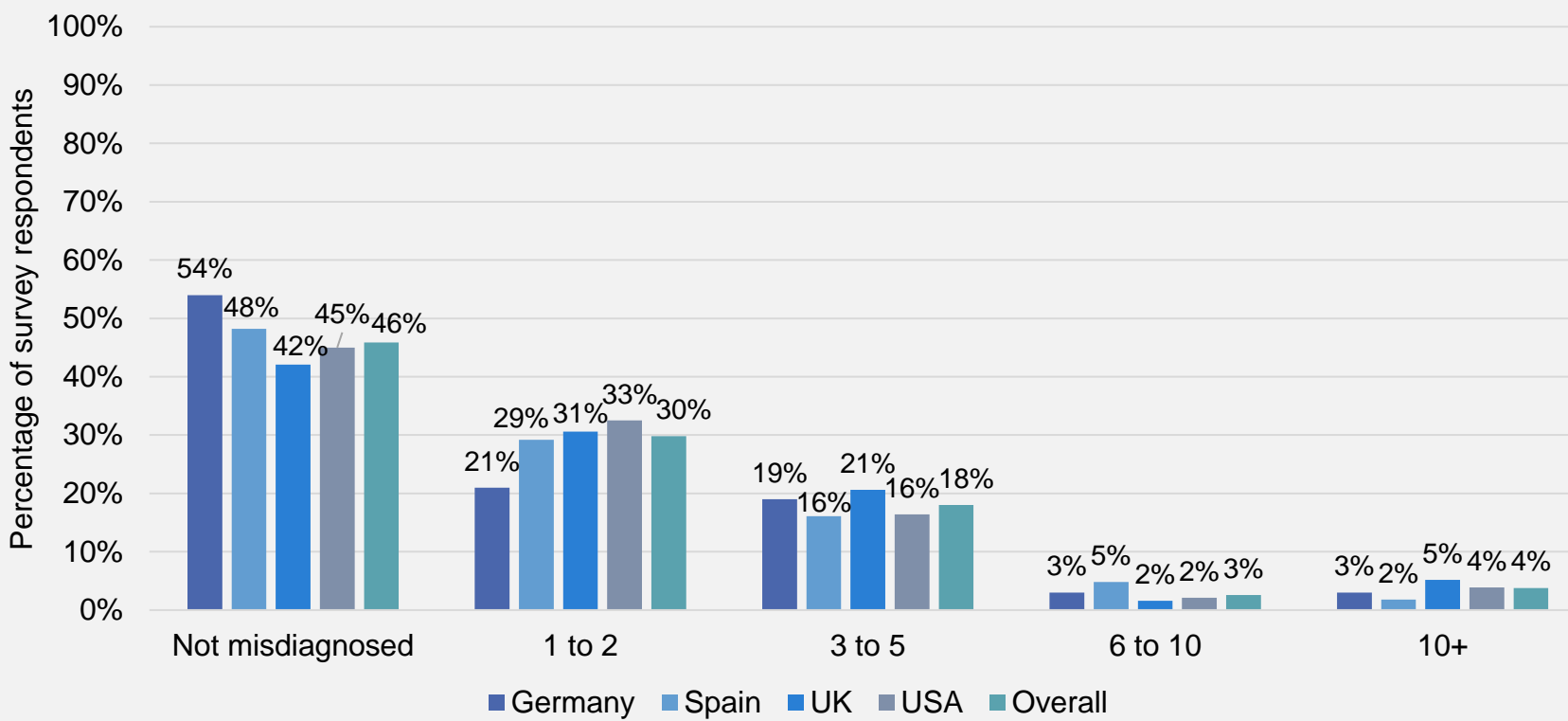
It took up to five years for 2/3<sup>rd</sup> of patients to reach a rare disease diagnosis, while one in five patients (across the countries) took more than 10 years.

### Number of specialists patients consulted before their confirmed diagnosis



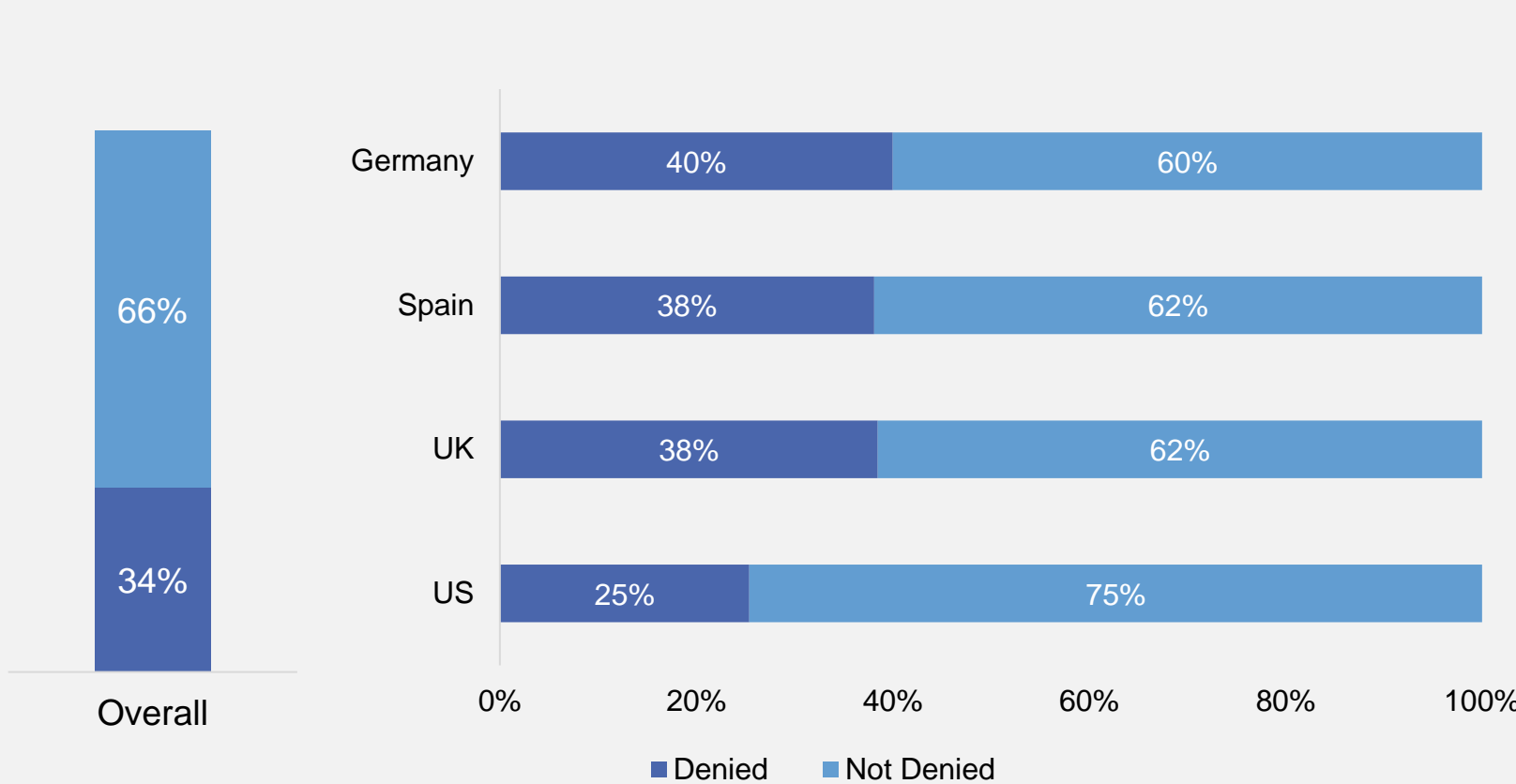
Majority of participants needed to see 3 or more specialists before receiving a rare disease diagnosis.

## Number of times patients were misdiagnosed



Across the countries, majority of rare disease stakeholders reported being misdiagnosed at least once.

### Proportion of Patients denied a diagnostic test



RD Stakeholders had diverse perspectives on how their disease diagnostic journey could have been better.

A word cloud visualization of the top 100 terms from the survey. The central and largest text is "Listen to the patient" in dark blue. Other prominent terms include "Improvement in doctor education" (orange, top left), "Increase access to specialist" (dark blue, right), "Earlier disease intervention" (dark blue, bottom center), and "Doctors willing to take a second look" (dark blue, bottom center). Smaller terms include "Need access to mental health support" (orange, right), "Financial improvements" (dark blue, top right), "Increased acceptance" (orange, top right), "Honesty from Doctors" (dark blue, top right), "Reduce unnecessary care" (dark blue, top right), "Need social services" (dark blue, top right), "Find a cure" (dark blue, top right), "Consequence for doctors" (dark blue, top right), "Increased support in healthcare" (dark blue, right), "Create better treatments" (dark blue, right), "Need access to mental health support" (orange, right), "Increased awareness" (dark blue, right), "Decrease costs" (dark blue, left), "Needed help from family" (dark blue, left), "Mental health impacts" (dark blue, left), "Decrease waiting times" (dark blue, left), "Access for rural communities" (orange, left), "Psychological impact on patient" (dark blue, left), "Doctors working with other doctors" (dark blue, left), "Improvements in Government" (orange, left), and "Doctors willing to take a second look" (dark blue, left). The words are arranged in a circular pattern around the central text, with varying sizes and colors (dark blue, orange, and light blue) used to distinguish different categories or themes.

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