

Management of osteogenesis imperfecta (OI): self-reported funding sources for healthcare, consumables and services across the EU5 and Nordics

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Background

- Osteogenesis imperfecta (OI) is a rare, heritable connective tissue disorder of variable severity associated with low bone mass, skeletal fragility, and varying secondary features¹
- The IMPACT Survey explored self-reported experiences of the clinical, humanistic and economic impact of OI on the OI community, and generated the largest, most comprehensive dataset to date
- Here, we present data on funding sources for healthcare, consumables and services for adults with OI across the UK, France, Italy, Spain, and Germany (EU5), and Nordic countries

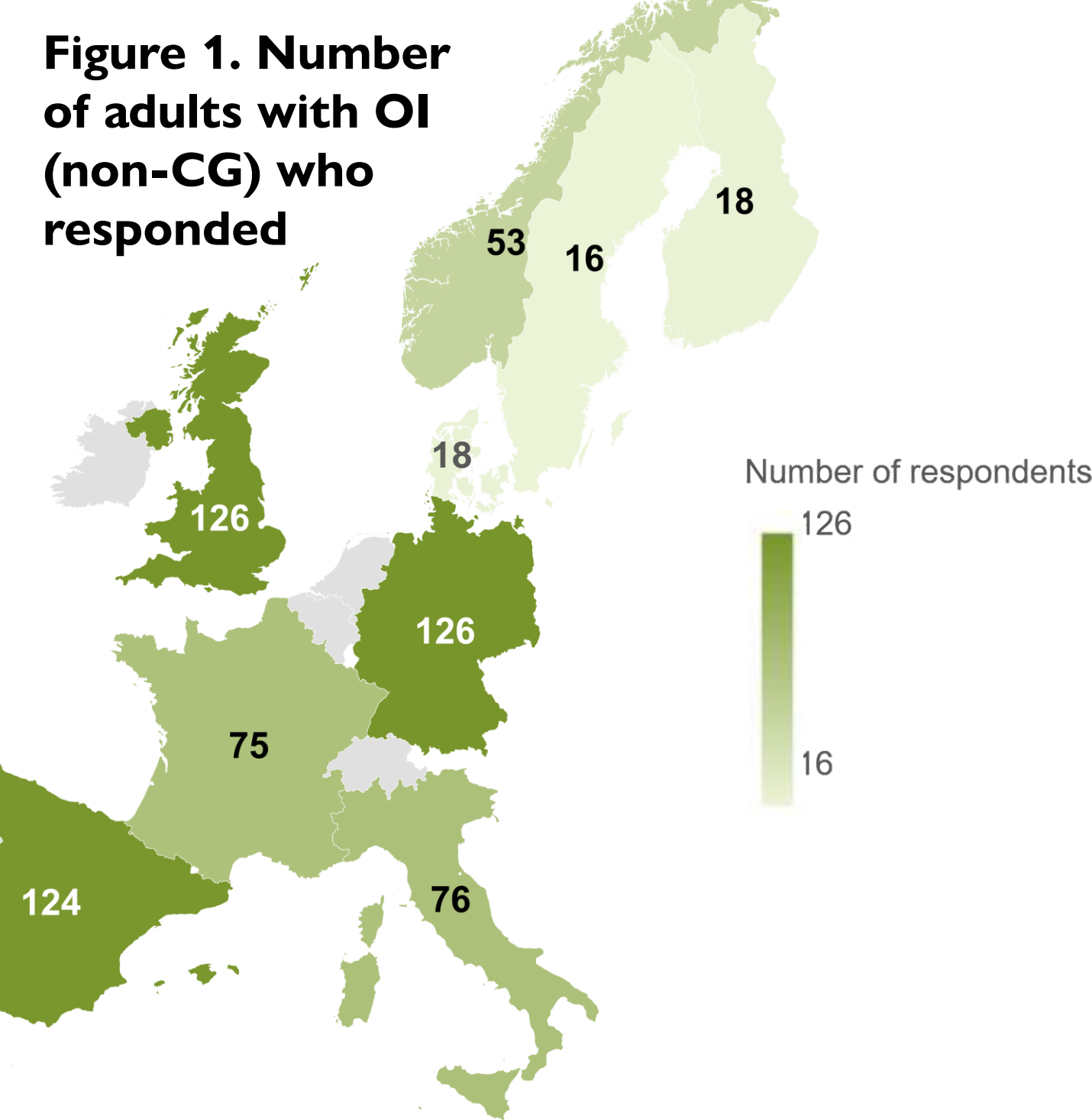
Methods

- The IMPACT Survey
- Developed by the Osteogenesis Imperfecta Federation Europe (OIFE), the Osteogenesis Imperfecta Foundation (OIF) and an international steering committee of OI clinical experts

Results

Demographics and respondent characteristics

- In total 2,208 individuals responded across 66 countries, of whom 1,440 were adults with OI
- Across the EU5 and Nordics, 632 adults with OI (non-CG) participated (Figure 1)
- Women were more highly represented across all countries (50–73%)
- In six countries, (UK, France, Italy, Germany, Sweden, and Denmark) most respondents reported moderate OI (43–62%), fewer reported mild (17–39%) or severe OI (13–23%). In Spain, Norway, and Finland most respondents reported mild OI (44–50%), fewer reported moderate (33–38%) or severe OI (15–17%)



Methods (continued)

- Open to adults or adolescents (aged ≥12–17 years) with OI, caregivers (CG; with or without OI), and relatives
- Included up to 102 questions on the clinical, economic and humanistic impact of OI
- Was professionally translated from English into French, European Spanish, Latin American Spanish, Portuguese, Russian, German, Italian, and Dutch, and fielded online July–September 2021

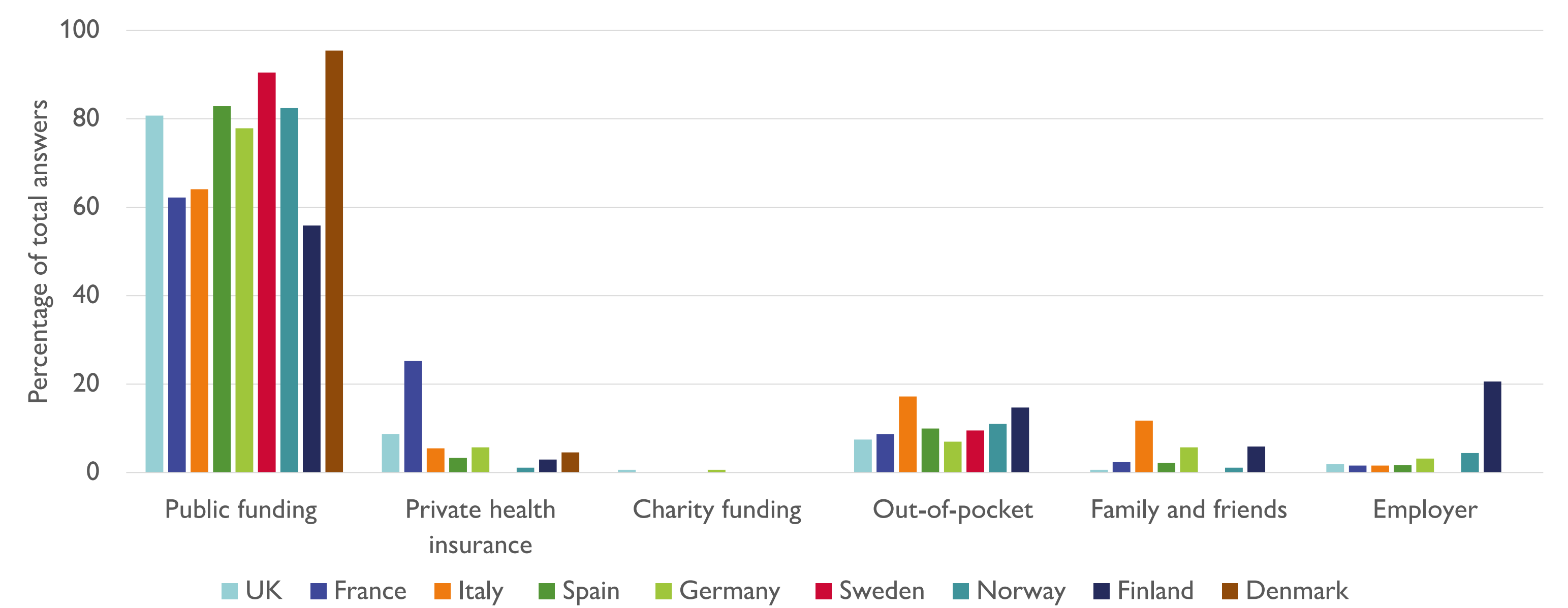
Recruitment

- Advertised through emails, meetings, and social media engagement by the OIFE, and OIF

Analysis

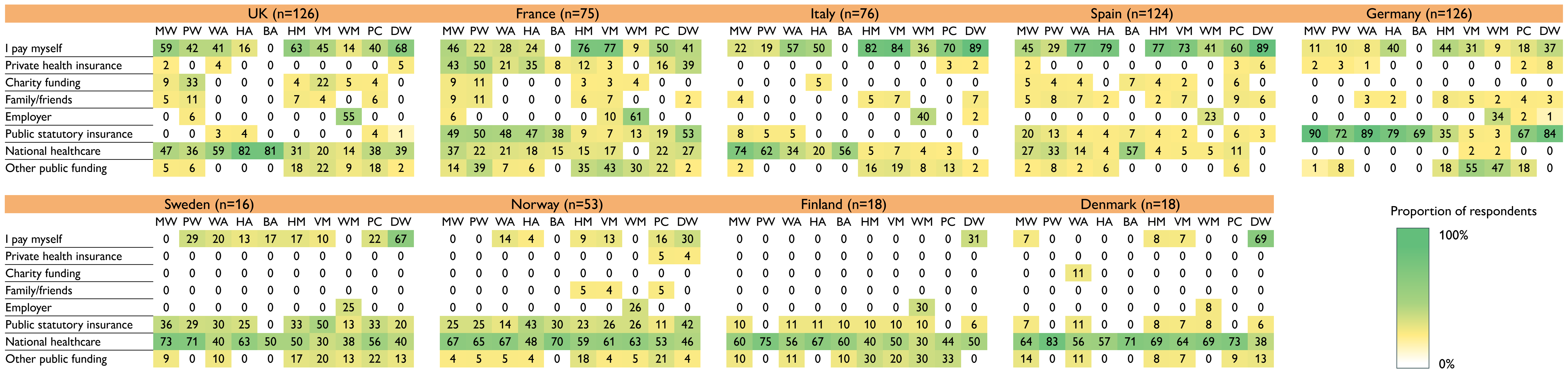
- Responses from all languages were professionally translated into English
- Microsoft Excel was used to clean, code, and analyse data
- Proportions are relative to the proportion of adults with OI reporting the need for a device or service unless otherwise stated
- Data are reported as provided by respondents who may be unaware of their country's public healthcare scheme

Figure 2. Funding sources for healthcare costs



- Public funding was the major healthcare funding source in all countries (56–95%; Figure 2)
- Countries with fewer respondents receiving public funding (<65%) had higher levels of private health insurance (France, 25%), out-of-pocket spending (Italy, 17%; Finland 15%), or employer funding (Finland, 21%)

Figure 3. Funding sources for consumables and services

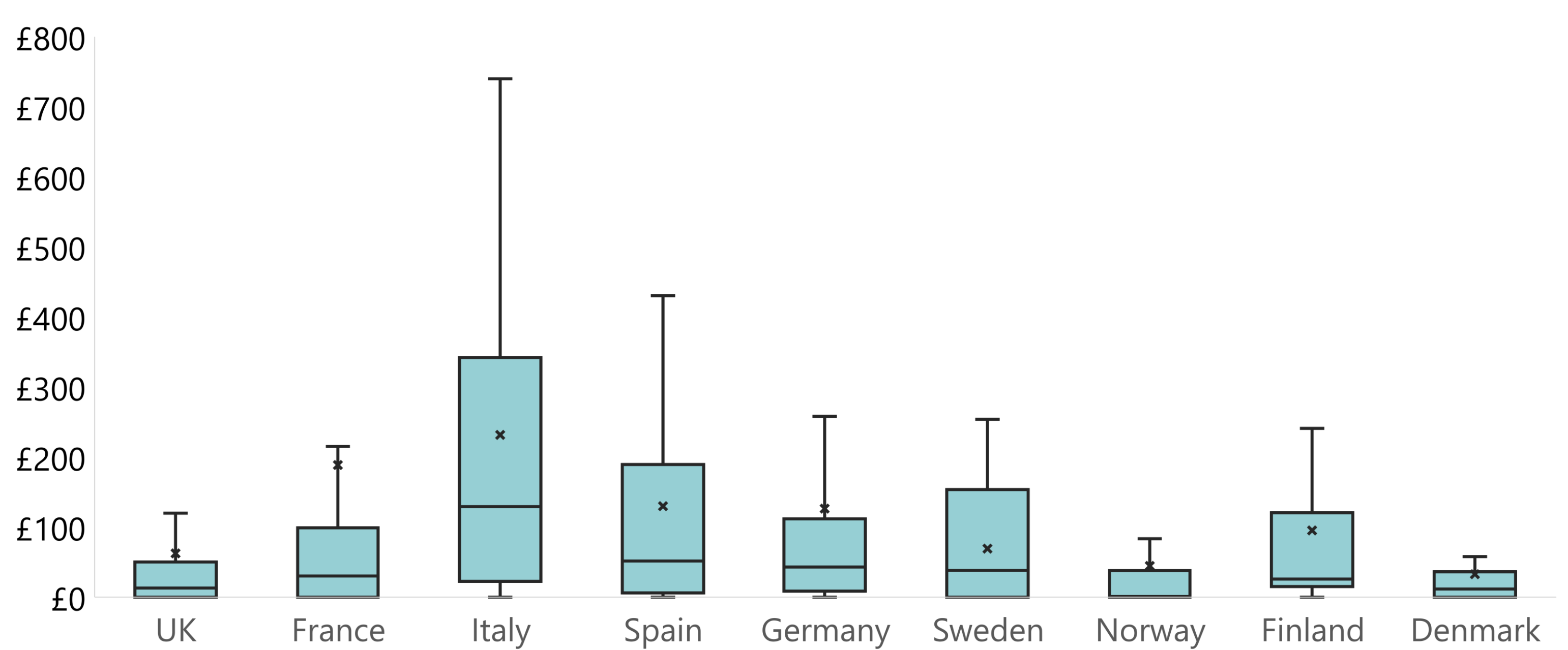


Key

Manual wheelchair	MW	Home modifications	HM
Powered wheelchair	PW	Vehicle modifications	VM
Walking aids	WA	Modifications at work	WM
Hearing aids	HA	Personal care/support assistance	PC
Breathing aid/machine	BA	Dental work	DW

- Public funding covered all consumables, yet the median number of respondents receiving public funding was ≤50% in UK, France, Italy, Spain, and Sweden, and ≤71% in Germany, Norway, Finland, and Denmark (Figure 3)
- Fewer respondents in Italy and Spain (<40%) received public funding for ≥7 consumable categories
- Other funding sources compensated a potential public funding shortfall, notably charity funding (typically <20%, except for UK with 33% of respondents access funding for powered wheelchairs, and 22% for vehicle modifications), and private insurance in France (3–50%, except work modifications)
- Employers covered some work modifications in all countries (23–61%)
- Respondents in all countries (≥30%) covered consumables out-of-pocket; this was higher in countries where public funding was lower

Figure 4. OI-related out-of-pocket expenses in a four-week period



- In a four-week period, respondents in all countries paid OI-related out-of-pocket expenses (Figure 4)
- Respondents in Italy had a notably higher median total out-of-pocket spend (£129.10) compared with other countries (from £0.80 in Norway to £51.60 in Spain)
- Respondents in France had the highest variability in out-of-pocket expenses (standard deviation 653.1); the least variability was observed in Denmark (standard deviation 48)

Conclusions

- Despite all countries having public healthcare provision for healthcare costs and consumables, many respondents used sources other than public funding for healthcare and consumable costs
- Non-public funding was more prevalent for consumables than for healthcare costs
- When countries had lower levels of public funding, without other sources to compensate, more respondents had out-of-pocket expenses, and at a higher cost, and highly variable within some countries
- Funding is variable across healthcare costs, consumables, and markets and a multi-pronged approach may address the shortfall in public funding access, improve other compensatory funding sources, and reduce out-of-pocket expense

Acknowledgments

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References

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