

Development of a national Ménière's disease registry: a feasibility study

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Abstract

Objectives To examine the methods and infrastructure necessary to establish a national Ménière's disease registry Design Observational study. Four NHS Trusts and four independent hospitals or clinics, within three distinct urban and rural regions within the UK ("Blinded for review"). **Participants** Patients with Ménière's disease. **Main outcome measures** Data related to the number of participants recruited, method of recruitment, participant demographics, completeness of data, and proportion of participants with bilateral disease. **Results** 411 participants were recruited into this study, 263 from NHS Trusts, and 148 from independent hospitals or clinics. Online recruitment was used for 73% participants and 27% were recruited via paper. 57% of participants were female and 96% of participants were white. There was no clear advantage to data completeness from either online or postal data collection. Around 20% of participants had audiological evidence of bilateral Ménière's disease. **Conclusion** This feasibility study has demonstrated that hundreds of participants with Ménière's disease can be successfully recruited to enter data into a large data collection platform. It is hoped that this initial feasibility study will pave the way for expansion of the registry to answer fundamental and complex questions alike, regarding the nature of Ménière's disease.

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