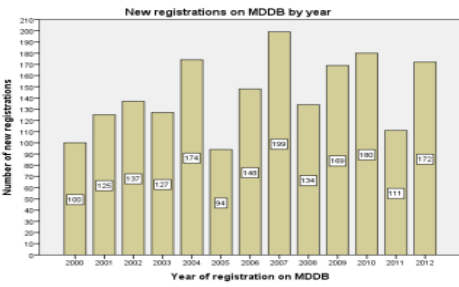
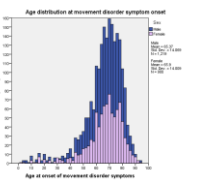
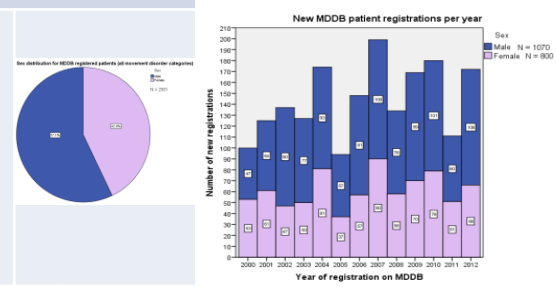


Long-term collaboration reaps dividends for clinical research in chronic movement disorders

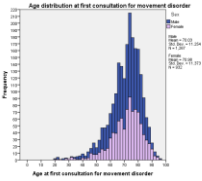
T. J. L. Malone, C. E. Clarke*, G. M. Fenwick, R. Gray*, V. R. Pearce, C. E. Rick*, R. P. Sheridan
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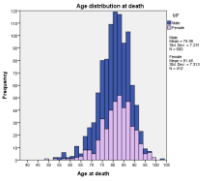
Each year about 140 new adult movement disorder patients, more men than women, are registered on the Exeter Movement Disorders Clinic Database (MDDB).



Mean patient age at first hospital consultation is 70 years for men and 71 for women, but there is a very wide range for both sexes.



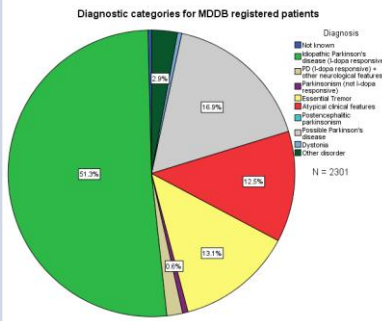
Most patients have had symptoms for about 5 years before first seeing a specialist, but some have been symptomatic for decades.



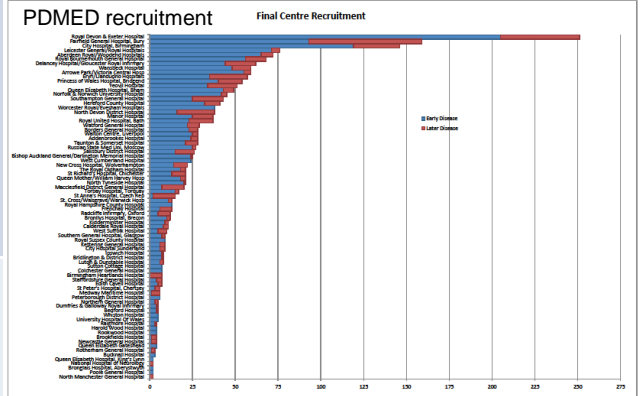
Most movement disorders are chronic neurodegenerative disorders requiring regular specialist reassessment and adjustments to treatment over many years, so patients are followed-up for life.

Long-term follow-up gives the opportunity for patients and their carers to participate in long-term trials.

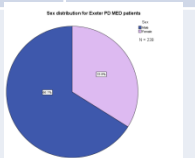
Although a wide range of disorders are seen, 70% of registered patients have idiopathic or probable Parkinson's disease.



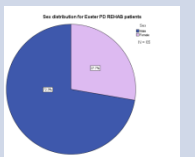
Involvement with research from an early stage is vital if the more meaningful longer-term research questions are to be answered.



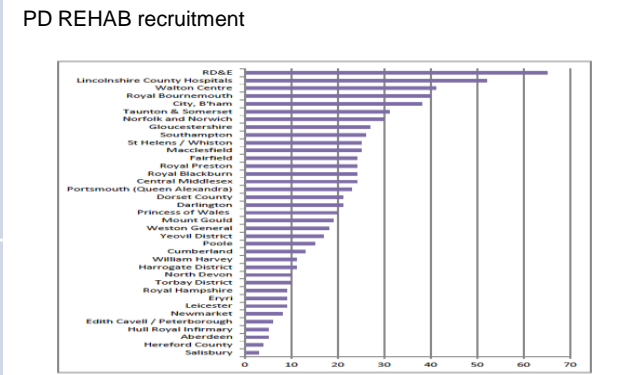
A large randomised assessment of the relative cost-effectiveness of different classes of drugs for Parkinson's disease



A large, pragmatic, multicentre randomised controlled trial to assess the clinical and cost-effectiveness of physiotherapy and occupational therapy in Parkinson's disease



A national Parkinson's disease DNA bank



Patient, carer and clinician engagement requires education about, and understanding of, longer-term goals in terms of patient quality of life whilst avoiding a 'quick fix' approach to treatment of chronic disorders.



Successful long-term collaboration, over more than a decade, between Royal Devon and Exeter Hospital and Birmingham Clinical Trials Unit has enabled south-west patients and carers to make significant contributions to three of the largest ever Parkinson's studies. Exeter has topped recruitment tables for PD MED and PD REHAB trials and PD GEN DNA bank.