

# Chronically fatigued patients face huge inequalities in accessing specialist services

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New research has identified the true extent of inequalities faced by adults who require access to specialist Chronic Fatigue Syndrome [CFS] or Myalgic Encephalopathy [ME] services in England. The findings, published in the journal *BMJ Open*, reveal a ‘postcode lottery’ whereby patients from more affluent postcode districts are more likely to be referred to specialist services than those from more deprived areas.

The research, led by academics at the University of Bristol, is the first study of CFS/ME service provision in England which has investigated whether access to services is linked to measures of social deprivation and [inequality](#).

In 2007, the National Institute for Health and Clinical Excellence [NICE] recommended that all patients should have access to CFS/ME specialist services, and that referral should be offered within six months of diagnosis for mild forms of CFS/ME, four months for moderate CFS/ME, and immediately for severe cases. However, in 2010 it was reported by the All Party Parliamentary Group (APPG) that the provision of specialist care was patchy and inconsistent and the APPG recommended that research be undertaken to remedy the ‘unacceptable’ variation in access to services.

The study analysed data from 46 (94 per cent) of the 49 specialist CFS/ME services in England, which between them received referrals from nearly 85 per cent of Primary Care Trusts (PCTs), representing 95 per cent of the adult population (33 million people). The team mapped

postcodes against clinic data to investigate whether assessment rates were related to PCT-level measures of deprivation and inequality.

The results showed that eight per cent (12/152) of PCTs did not provide a specialist CFS/ME service. Among the PCTs that did provide a service, the researchers identified a six-fold variation in assessment rates. In some areas, patients from more affluent postcode districts were more likely to access specialist CFS/ME services than patients from more deprived postcode districts.

Dr Esther Crawley, lead author and Reader in Child Health at the University of Bristol's School of Social and Community Medicine, said: "Several million people in England are affected by this debilitating condition and only a small proportion (three to eight per cent) of CFS/ME patients are expected to recover fully if untreated. These findings reveal the magnitude of inequality faced by many patients in need of specialist care, and the consequences for those from some of the most deprived areas, who were half as likely to access specialist services compared with those from the most affluent areas."

Sir Peter Spencer, Chief Executive of Action for M.E, the UK's leading charity for people with Myalgic Encephalomyelitis (M.E.) and their carers, said: "This latest report dramatically underlines the fact that local commissioning has failed people with M.E., a key finding that was also highlighted in Action for M.E.'s recent survey of secondary care [service](#) provision across the UK.

"The Secretary of State for Health needs to take action now to ensure that he personally holds local healthcare providers and Care Commissioners to account. Relying solely on 'local accountability' does not work for small patient groupings. It simply nurtures the insidious post code lottery so clearly revealed by Dr Crawley's excellent paper."

Colin Barton, Chairman of the Sussex & Kent ME/CFS Society said: "Although we have two specialist CFS/ME multidisciplinary teams in our region that are doing a fairly good job, they are very overstretched due to financial restraints meaning that there are very long waiting times and occasionally limited medical input. Early diagnosis and good management can often lead to improvements and better outcomes for those affected by CFS/ME so adequate NHS services are essential."

Mary-Jane Willows, Chief Executive of the country's leading ME/CFS charity for young [adults](#), The Association of Young People with ME (AYME) said: "It's unacceptable that those living in affluent postcodes have an improved chance of recovery, whilst those in deprived areas are more likely to be condemned to a life of chronic pain and disability."

"We need to raise awareness, among GP's and Commissioners, of the devastating impact of this condition and increase commitment to developing existing services and establishing more experienced multi-disciplinary teams."

"We also need to find appropriate ways to reach out to those suffering from ME/CFS amongst ethnic minority communities, most of whom currently remain unheard and unseen."

The study, entitled 'Equity of access to specialist [Chronic Fatigue Syndrome](#) (CFS/ME) services in England (2008-2010): a national survey and cross-sectional study, by Esther Crawley, Simon M Collin, Jonathan Sterne, William Hollingworth and Margaret T May, from the University of Bristol's School of Social and Community Medicine is published in the journal *BMJ Open*.

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