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Epilepsy service provision in the National Health Service in England in 2012[☆]

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ABSTRACT

Purpose: The National Health Service in the United Kingdom compares favourably on many international measures of quality and cost-effectiveness. It has many centres of excellence for epilepsy care and in some areas is a world-leader. However, for over twenty years there have been concerns that the provision of good quality care is variable and in many areas major improvements are required. We report the results of the latest major survey into the quality of epilepsy care in the NHS.
Methods: Four target groups were sent questionnaires: acute hospital trusts, Clinical Commissioning Groups, local authorities and patients. Each questionnaire was specifically designed by Epilepsy Action after reviewing national guidance and quality standards.
Results: We present the key results of the survey and we discuss them in the context of the latest national guidelines, quality standards, the organisational structure of the NHS and the research literature.
Conclusion: Although there are some examples of excellent services for people with epilepsy these results show that overall there has been little improvement in recent years and there continues to be significant geographical variability in quality with many areas offering sub-optimal care.

1. Introduction

1.1. Epilepsy services in the United Kingdom National Health Service

The National Health Service in the United Kingdom compares favourably on many international measures of quality and cost-effectiveness [1]. Despite frequent and ongoing reforms, the United Kingdoms' National Health Service (NHS) is intended to be a comprehensive service, available to all, in which access is based clinical need and not an individual's ability to pay. The NHS "aspires to the highest standards of excellence and professionalism" and to "put(ting) patients at the heart of everything it does" [2].

Just over 20 years ago, the Clinical Standards Advisory Group, an expert group established to advise United Kingdom (UK) health ministers, published their report into epilepsy and highlighted infrequent routine monitoring, a lack of coordination and poor communication between primary and secondary care. They emphasised that General Practitioners (GPs) need help and support with the clinical management of more complex aspects of epilepsy care [3]. The Epilepsy Needs Documents were published in 1993 [4] and 1998 [5], and since then, many published reports by governmental and non-governmental organisations and research studies have compared the clinical and social reality with the aspirations expressed in these official documents and suggested how services for people with epilepsy could be developed to match them better.

In 2002 the National Sentinel Audit of Epilepsy-Related Deaths [6] highlighted the mortality associated with uncontrolled epilepsy and that systemic inadequacies in the delivery of care meant that many of these deaths were potentially preventable. In response to this report, the Department of Health (DoH) published

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its action plan Improving Services for People with Epilepsy [7,8] which made specific recommendations including the decision to focus the National Service Framework (NSF) for long-term conditions on neurological conditions [9]. The DoH also provided additional funding of £1.2 million (€1.52/$1.93 million) [10]. The NSF consists of eleven quality requirements (QRs). QR2 for example, refers to "early recognition, prompt diagnosis and treatment". This QR stipulates that "people suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible". The eleven QRs are due to be fully implemented in 2015 via Clinical Neuroscience Networks led by Primary Care Trusts (PCTs) and Strategic Health Authorities (SHAs).

In the same year as the DoH's action plan (2002), the Scottish Intercollegiate Guidelines Network (SIGN) published their first clinical guideline on Diagnosis and Management of Epilepsy in Adults [11], followed in 2004 by the guideline of the National Institute for Clinical Excellence [12]. Both sets of guidelines were intended to provide evidence-based advice on the optimal treatment of epilepsy in NHS settings. Epilepsy also became part of the Quality Outcomes Framework for GPs, a system under which GP practices receive additional income for specified activities (such as carrying out annual reviews of patients with epilepsy) [13]. In 2005, the Action on Neurology Programme [14], which arose as a response to the challenge of delivering the NSF's QRs, illustrated some national examples of best practice. A proposal to develop a competency framework for GPs and other health care professionals with a special interest in epilepsy was published in 2007 [15]. In the same year the All Party Parliamentary Group on Epilepsy published The Human and Economic Cost of Epilepsy [16]. In 2009 Epilepsy Action published Time for Change [17] and in 2011 the Royal College of Physicians and the Association of British Neurologists published Local Adult Neurology Services for the Next Decade – all making specific recommendations, many already included in previous reports. The latest major reports into epilepsy care in the NHS are the National Audits of Seizure Management in Hospitals (NASH) [18,19] which highlighted highly variable care in emergency departments (EDs) when patients present with seizures.

1.2. Current organisation of the NHS in England

The NHS in the UK is organised differently in each of the constituent nations (England, Scotland, Wales and Northern Ireland). In England it is run by NHS England which is an independent organisation funded from tax revenue by the Department of Health in England. Its remit is to improve health outcomes and deliver high-quality care for people in England. This is achieved by direct commissioning of specialised services such as neurology and by funding and overseeing Clinical Commissioning Groups (CCGs) which are clinically-led organisations which commission services for local populations. There are 211 CCGs in England with a mean population of 251,693 (range 61,607–863,433) [20] and an average size of 618 km^2 per CCG [21]. CCGs replaced Primary Care Trusts (PCTs) which were previously responsible for commissioning local services, in April 2013.

In England, in-patient and most specialist outpatient services (including almost all outpatient epilepsy services) are currently provided by 160 acute hospital trusts. Emergency hospital care relating to epilepsy is commissioned by local CCGs, specialist care (which currently includes neurological outpatient care) is commissioned centrally by NHS England. Acute trusts differ considerably in size, and although they mainly serve their local population, they do not have geographical boundaries and are required to treat patients from any area. The Office for National Statistics mid-2013 population estimate for England was 53,865,800, therefore each of England's 160 acute trusts serves a nominal 336,661 people.

Local government in England also has responsibility for health. Local authorities are required to host Health and Well Being Boards (HWBBs) which must produce a Joint Strategic Needs Assessment (JSNAs) to inform the strategy of the local authority and the local CCG. HWBBs consist of representatives of the authority, the CCG, social services, children's services, public health, patients and other invited members. Their remit is to plan the best way to meet the needs of their local population and reduce inequalities in health.

1.3. A Critical Time

In January 2013 Epilepsy Action published their report entitled A Critical Time for Epilepsy in England. It was a survey of patients and organisations responsible for epilepsy service provision in England (the other devolved nations of the UK were not included). It was based on the responses of four target groups: acute hospital trusts, CCGs/PCTs, local authorities and patients. This paper is intended to present the key results of this snapshot of epilepsy care and to disseminate the findings of the survey to a wider audience national and internationally. We discuss the context of the results and draw conclusions about the quality of current epilepsy service provision in England.

2. Methods

Four separate questionnaires were designed for each of the target groups by Epilepsy Action, the largest membership-lead epilepsy organisation in the UK. The surveys were lead by their Policy and Campaigns team. Initial drafts were drawn-up after review of up-to-date national guidance including NICE Clinical Guidance, the National Service Framework for long-term conditions and in anticipation of the NICE quality standards which were at that time due to be published imminently. The Medical Advisory Board of Epilepsy Action reviewed and provided feedback on all four questionnaires. In addition to this, the patient survey was reviewed and user tested by six people with epilepsy. This process took place between February and May 2012.

2.1. Target groups

2.1.1. Acute hospital trusts

A list of the relevant acute hospital trusts in England was compiled from the NHS Choices website (specialised trusts that were known not to provide epilepsy care or treatments were not contacted). The initial requests were entered under Freedom of Information requests by email to Information Governance teams, on 4 May 2012. The trusts were given the option of supplying the data online or by email or by post. Two reminders were sent. A total of 152 trusts were contacted. 10/152 (6.6%) responded stating that they did not provide epilepsy services and 62/152 (40.1%) did not respond (or responded after the deadline). A total of 80/152 (53%) trusts responded with completed questionnaires.

2.2. Primary Care Trusts and Clinical Commissioning Groups

CCGs were set up by the Health and Social Care Act 2012. They began operating in shadow form in 2012 before taking on their full legal responsibilities in April 2013. The survey was therefore conducted during the transition period over which responsibility transferred from PCTs to CCGs. A list of the 208 CCGs was purchased from Specialist Info, a company who specialise in maintaining databases of doctors and health care providers. A total of 158/208 (75.9%) of the CCGs contacted responded to the survey.