All-Party Parliamentary Group on Primary Headache Disorders

Oral Evidence Session

14 January 2014

Attendees:

Jim Fitzpatrick, MP for Poplar and Limehouse (JF) (Chair)

Virendra Sharma, MP for Ealing Southall (VS)

Stephen O'Brien, MP for Eddisbury (SOB)

Baroness Masham of Ilton (BM)

Jillie Abbott, Trigeminal Neuralgia UK (TNA UK) member (JA)

Dr Fayyaz Ahmed, Consultant Neurologist, Hull Royal Infirmary and Senior Lecturer, Hull York Medical School (FA)

Professor Peter Goadsby, Director, Wellcome Trust Clinical Research Facility, Kings College London (PG)

Dr Rachael Kilner, GP, member of the British Association for the Study of Headache (BASH) (RK)

Wendy Thomas, The Migraine Trust (WT)

Professor Joanna Zakrzewska, Facial Pain Consultant, Eastman Dental Hospital and Honorary Professor, UCL (JZ)

Introduction

JF welcomed those present and introduced the speakers for the event. In preparation for the event, each speaker had been supplied with four questions to consider. The discussion would take the form of a roundtable; following the contributions from speakers on each question there would be an opportunity for all attendees to provide their thoughts on the issues raised.

Roundtable Discussion

I. Do existing headache services in England present good value for money?

PG commented that while headache services in England presented extraordinarily good value for money, NHS England offered very little in relation to the size of the problem. Patients were seeking secondary services as they were 'worried' about their conditions; a degree of reorganisation

and investment was required in order to remove some of the burden from healthcare practitioners across the system. A&E staff in many parts of the country were 'on their knees' due to heavy workloads.

While FA agreed with PG that the NHS offered good value for money compared to other countries' health services, he noted that the health care system in general was very poorly organised. Services were 'patchy,' and headache treatment in particular varied according to the patient's proximity to a tertiary headache centre. As a result, many patients in need of neurological expertise were currently treated by physicians without specialist knowledge. The 'scattered' nature of headache services led to a lack of awareness in the health care system over who had responsibility for treating certain patients. There was a need for reorganisation and reallocation of resources.

JZ explained that although she specialised in facial pain, this was understood by headache specialists to belong to the same category as headache. However, problematically, both the public and the profession of dentistry considered facial pain to be a matter for dentists to treat. Dentists often did not look at patient history; they were taught to think 'mechanically' and did not consider the patient holistically. One of the largest causes of facial pain in the UK was temperomandibular disorder. While it was common for dentists to treat this with a splint, sometimes a more holistic approach was required. Furthermore, if dentists failed in their treatment they would refer patients to maxillofacial surgeons or to dental schools, instead of headache specialists. JZ agreed that the treatment for headache available in the UK was 'patchy', and often 'fell between two stools.'

WT also highlighted the regional disparities in headache services, and the variation in the services offered by different Clinical Commissioning Groups (CCGs). The majority of headache patients could be treated in primary care, yet many headache sufferers chose not to visit a doctor; this should be addressed. WT agreed with PG that the current headache services were good value for money, but that more could be offered.

JA remarked that there was a significant lack of communication between dentists and GPs. Dentists often performed unnecessary or harmful interventions, some of which were irreversible; this was a substantial cost. No concrete treatment pathways existed, and it was difficult to get information from healthcare professionals. JA said that focusing on improving local services could result in a 'postcode lottery'; a national focus was needed. Patients would receive more benefit from centres of excellence, even if these required travelling a long distance, than from attempts to ensure a good service locally. More patients should be referred by health care professionals to patient support groups, as these could offer 'invaluable' guidance.

RK stated that educating general practitioners on headache was essential. The number of headache cases referred to secondary care was problematic; this diverted resources away from more complicated conditions requiring specialist attention. More research should be conducted into the possible benefits of providing GPs with access to scanning facilities. RK suggested that the overcrowding of A&E could be seen as a 'cry for attention' from patients whose headaches were not being correctly managed.

FA commented that headache education should be included as part of neurology courses in medical school. Greater financial support for headache services would not overcome the problem unless health care professionals were equipped with expertise in this area. BASH and The Migraine Trust had pioneered the education of the general public in many UK cities as to the treatment available for different types of headache. GPs should receive training on common headache disorders before qualifying as practitioners, and further training should be provided throughout their careers.

SOB mentioned that few healthcare professionals specialised in this area, or regarded it as a worthwhile and important topic. It was necessary to increase the profile of these disorders from the medical professional's perspective. PG replied that politicians had the ability to raise the profile and standard of headache care in the UK, by setting an agenda through the Department of Health.

A member of the audience remarked that physiotherapists were often very interested in headache, yet were not given the opportunity to contribute to their treatment. With a small amount of money devoted to training, the physiotherapists working in the NHS could become specialists in the treatment of headache.

Another audience member suggested that physiotherapists were ready to treat patients, yet that there was a lack of awareness of this fact from other healthcare professionals.

II. What opportunities do you think exist to save NHS money, and to make better use of existing NHS resources (primary, secondary and tertiary) and patient experience of headache services in England?

PG noted that the size of the NHS made it difficult to attempt large changes. However, subtle changes were possible. GPs were very busy, and repeat visits from patients represented a waste of resources. An opportunity existed for GPs with a special interest (GPwSI) to remove some of the burden from routine GP practice. Employing a higher number of GPwSI could also reduce A&E attendance. Efforts should be made to build on existing headache centres in order to provide better resources for GPwSI.

FA said that the emphasis in headache treatment was currently placed on excluding a brain tumour. The proportion of headaches caused by tumours was very low. More emphasis should be placed on correctly diagnosing the headaches that required secondary care, and on ensuring adequate primary care for those which did not. FA highlighted the three-tier model proposed by Dr Timothy Steiner, where GPs treated simple cases and referred more complex ones to GPwSI and neurologists specialising in headache. Currently the problem was that GPs often referred complex cases to general neurologists, who excluded a brain tumour as the cause and did not proceed further.

JZ stated that all staff within primary care required more education. Clinical nurse specialists could have a large impact, while costing less than physicians. Patients should be empowered to self-manage. Dental practitioners were skilled in eliminating dental causes for headache, yet often referred into the secondary care sector when they should be referring to GPs. For difficult headache cases, a multidisciplinary approach including psychology and physiotherapy was crucial. On the other hand, simple headaches such as TMDs could be dealt with in primary care by a well-trained nurse.

WT commented that headache needed to become more 'sexy' as a topic, in order to encourage GPs to specialise. There was scope for increasing the number of headache nurses, as they had an important role to play in treating headache disorders such as migraine or TN. WT noted that although patients might not mind travelling a long way for treatment, it would be beneficial for more to be done locally.

JA suggested that once a diagnosis of a primary headache disorder was made, the GP or dentist should have instant access to online guidance on next steps. There should also be a fast-tracking process for those in extreme pain or distress as a result of their condition. This would save unnecessary visits to A&E, as would an increase in the number of pain management clinics available to patients.

JA stated that she did not think the right information was being given to patients regarding anti-epileptic drugs. Money was being wasted on drugs that were not used, as patients became confused over dosage and side-effects and chose not persevere with their course of treatment. The same was true of anti-depressants; patients often did not understand the reason these were prescribed.

JA said TN patients would benefit from having a high-resolution MRI scan. However, patients were not receiving MRI scans early enough in the process. GPs and dentists should be encouraged to visit the 'professionals' area of various headache-related websites, where they would find accurate and up-to-date information. Healthcare professionals should be encouraged to attend conferences, and NHS grants should be provided for this purpose.

JA stated that the NHS should collect evidence on the effectiveness of various drugs and on the outcomes of different surgeries; the success rates of various surgeries should be publically available.

RK agreed with the three-tier model comprising GPs, GPwSI, and neurologist headache specialists. However, she mentioned the need for integration. The system would benefit from a single point of referral, whether this was a hospital or a community service. A triaging service would also be useful, particularly for areas such as physiotherapy. Patients could be referred from the physiotherapist to a GPwSI, or to secondary or tertiary care.

SOB questioned whether enough research and development was occurring for headache disorders, given the number of people affected by headache and their purchasing power. SOB hoped that more research and development could be attracted to the field, in order to identify the causes of headache disorders and to simplify treatment regimes.

PG highlighted the need to ensure that the infrastructure was in place to promote the development of the next generation of compounds to treat headache. US companies in particular were keen to develop new drugs in the UK, due to its high standard of practice.

BM commented that from an employer's perspective cluster headaches were a serious issue, as employees often needed to take time off work. PG remarked that the UK led the rest of the world in cluster headache research. While some advances had already been made, more support was needed from the Department of Health on headache research.

JZ noted that even rare conditions were receiving some attention, and that clinical trials were ongoing. An audience member responded that during the last session, it had been stated that the UK was falling behind the rest of the world in terms of research and development due to a lack of funding.

Another member of the audience mentioned that the management of headache required a multidisciplinary approach, as patients often experienced more than one pain presentation at once. The creation of a joined-up group of specialists interested in headache as a region of pain would help to remove the 'blinkers' from individual health care professionals.

SOB noted the small number of his constituents who actively sought advice for headache, compared to other conditions. More needed to be done to educate the population on the availability of treatment for headache disorders.

III. What barriers exist to implementing the cost-saving improvements that you have indicated above? How can these barriers be overcome?

RK stated that leadership and management structures needed to be less location-based and more disease-specific. A wider range of professionals should be involved in headache care. The input of psychologists could be important in this area, and nurses were another area of untapped potential. RK highlighted that diabetes care had been 'vastly' changed in the UK, in part through the effective strategy of encouraging specialists to enter into general practice. Lessons could be learned from this in the treatment of headache disorders.

JA said that while there was a large volume of information available on headache disorders, a data collection system did not exist. Furthermore, patients were unsure how to access guidance and support with their conditions; health care professions should direct patients towards support groups. JA mentioned the fact that evidence-based guidelines were not always followed, and clearer communication to patients was needed. A 'carrot and stick' approach to the education of health care professionals was suggested. Financial support for charities would prove beneficial and lift the burden on the NHS. The information held by these charities was currently under-utilised.

WT expressed disappointment over the delay in the development of a neurological dataset covering resources, services, and outcomes, which had been planned for 2014. Primary headache disorders were not prioritised at a national level. The NICE headache guidelines were an important tool. A meeting had been held the previous March to discuss the lack of research, and there was now more positivity over the prospects for future research.

JK noted that evidence-based guidelines were in existence, yet were not being used. Data on prevalence and treatment outcomes was widespread, yet could not be accessed as it was not available electronically. Another barrier was the lack of clinical time, as complex disorders required more than a 10-minute appointment. Managers were unaware of the degree of empathy and trust-building necessary for healing to occur.

FA remarked that there was currently a lack of evidence to support the privileging of any particular model. When adopting a model, it was important to provide evidence for its efficacy. Therefore, piloting was the best option. A study had shown that services provided by a GPwSI could be as effective as those provided by a neurologist or other headache specialist. Another barrier was the indirect nature of the cost-savings that could be realised by improving headache care, which decreased the level of motivation for investment in this area.

FA commented that patients' perception of specialists needed to change, as many patients felt it necessary to see a neurologist or other specialist. Resistance to reform was a large barrier, yet this could be overcome through strong leadership. FA agreed that guidelines could be beneficial, although he thought issues remained over their implementation. Some GPs had difficulty interpreting the NICE guidelines. Patient organisations should be given greater ownership of

patient and physician education and networking. Currently, research was driven by the pharmaceutical industry and the government provided no financial support for education about headache disorders.

PG stated that the NIHR could aid in improving headache care through the setting of goals.

An audience member said that it was reassuring for patients to be seen by a neurologist, due to the fact most GPs lacked specialist knowledge regarding headache disorders. A national hub should be created where GPs or patients could receive additional information on headache. Once a patient was diagnosed with a rare headache disorder, an action plan should be agreed upon by the doctor and patient in order to guide treatment. JZ replied that she had received a leaflet from NHS England stating that 'better information means better care'; more work was needed on how to implement this.

BM asked the speakers whether food or drink could cause migraine. PG responded that alcohol could cause migraine. BM enquired if chocolate could act as a cause for migraine. PG answered that a study had demonstrated that chocolate was not a trigger. Overall, the evidence for food as a trigger was modest.

WT said that although she agreed with the audience member's point regarding patients wishing to see a neurologist, there were cases where GPs referred patients to the wrong neurologist. The Migraine Trust advocated the self-management of migraine, through efforts to understand and control triggers. PG commented that the chances of encountering a hemiplegic migraine were minute. Educating every GP on hemiplegic migraine would therefore be a waste of resources. Instead, GPs should be educated on when to refer patients.

BM asked if more specialist nurses were required. JZ agreed that specialist nurses could make a huge difference in reducing the burden placed on other health care professionals. PG added that specialise nurses could greatly improve the quality of care, allowing patient queries to be more confidently addressed over the phone.

An audience member noted that the NIHR had funded a study to compare the effects of acupuncture and exercise on neck pain and headache. However, this study would not be included in the NICE guidelines due to the lack of a placebo element. This was the result of a level of miscommunication on the part of NICE, which was seen as a problem.

IV. What are the overall benefits of improving headache services in England?

RK stated that patient benefits of improved headache services would include a reduction in disability and an improvement in their management of their condition. Another benefit would be a reduction in A&E admissions, which would bring cost benefits in the long term. The economy would benefit from a reduction in the number of days taken off work due to headache disorders.

JA commented that the amount spent on medication would be significantly lower if patients were given more information on their prescription. With regards to TN, adequate information and guidance from TNA UK could reduce the amount of time patients spent suffering from pain. An

improvement in headache services would lead to a better quality of life for those with headache and facial pain. There would be a reduction in GP and hospital visits and less time spent off work, as well as a reduction in the number of benefits claimed. JA suggested that fewer families would break up, and suicides would decrease, as a result of improved headache services.

WT also emphasised the days lost from school and work every year as a result of headache. The improvement of headache services would mean a reduction in the burden of headache for both the individual and the NHS.

JZ remarked that an important benefit of faster treatment for headache disorders would be to prevent chronic conditions and the development of co-morbidities. Particularly in TN, benefits could be gained from receiving surgery as early as possible. Early treatment had also been shown to reduce the risk of long-term symptoms in TMD.

FA said that it was necessary for care to be needs-driven. It was impossible to generalise when discussing headache care as every patient was different. There was a need for cost-effectiveness, which would be achieved through the training of more specialist nurses and GPwSI.

PG suggested that no-one would argue with the moral or medical case for improved headache services; however, the business case also had to be stated. The Chinese government had begun a programme to open 27 new headache centres. The Chinese had recognised the value of improved headache care to the community. PG highlighted the importance for the UK of keeping pace with the rest of the world on the provision of headache services. Improved headache services would benefit patients, physicians and the economy, yet leadership from politicians was required.

V. Questions and comments from the inquiry panel, speakers and audience

BM asked if there was an international network for headache. FA replied that both national and international networks existed. Headache UK was a group composed of both patient and professional organisations. The British Association for the Study of Headaches (BASH) was linked to the European Headache Federation (EHF). UK health care professionals had the ability to network throughout the world with regards to headache care. WT noted that the European Headache Alliance (EHA), a patient group, contained organisations from 19 European countries. JZ highlighted another organisation, the International Association for the Study of Pain (IASP), which this year had launched the Global Year for Increased Awareness of Orofacial Pain. The IASP provided fact sheets and other information for patients and health care professionals on their website, in addition to organising lectures. BM enquired if the government was providing enough support to events such as the lectures JZ had mentioned. JZ replied that clinicians were required to pay for their own travel to conferences.

BM asked the speakers how they would improve the situation for patients. FA answered that patients should be given ownership over their condition. This would require physicians to achieve a high level of confidence in diagnosis; at the moment this confidence was lacking. Benefits would be achieved if time could be spent on training, yet physicians did not have the spare time for this. Specialist nurses could take on responsibility for managing the patient's diet and lifestyle, and could perform telephone consultations when necessary.

An audience member commented that students were interested in headache disorders, and that there was scope to introduce teaching on headache disorders in undergraduate medical schools.

A member of the audience highlighted the low level of funding available for headache disorder research; most of this funding was provided by medical research charities.

WT stated that problems resulted from the widespread belief that there was no treatment for headache.

BM enquired whether a large number of children suffered from headache. PG replied that 6% of children under 12 suffered from migraine. There were a very small number of paediatric headache experts currently practicing in the UK. Higher levels of investment in NIHR research on headache would provide future benefits to children with migraine.

An audience member mentioned that while he had experienced willingness from GPs to undertake specialist training, CCGs were not interested in supporting this. Another audience member commented that commissioners were concerned that improving their headache services would produce an unmet need. It was suggested by an audience member that there was scope for physiotherapists to reduce the burden on consultants.

A member of the audience remarked that headache or orofacial pain provided a perfect model for an integrated and managed clinical network. This network would benefit from specialist input while also including other forms of support. Managed clinical networks involved inbuilt education, facilitated an ongoing rapport, and were able to cross the boundaries of care to better meet patient needs.

FA said he agreed with WT on the need to improve the perception of headache care among GPs.

An audience member expressed a lack of understanding with regards to the difference between GPwSI and the primary care neurology community. It was suggested that primary care physicians with an interest in neurology could be persuaded to specialise in headache care.

JZ stated that the role of dentists should not be forgotten. The ‘craze’ for implants among dentists was currently causing problems as these were sometimes placed wrongly, leading to neuropathic pain. Dentists should be encouraged to make enquiries concerning a patient’s medical history, and to refer patients for medical treatment; to this end, they should receive more education in orofacial pain.

BM enquired if teachers should be given training in order to identify cases where a child is missing school due to a headache disorder, as this could interfere with their exams. PG agreed that headache was disruptive for exams and for a child’s life in general. It was useful for school nurses to have some understanding of headache disorders.

An audience member highlighted the fact there were only 11 headache nurses in England. Headache nurses had reported feeling that their jobs were at risk due to budget cuts, and more effort was needed in order to protect these positions. One challenge the APPGPHD faced was in encouraging CCGs to invest in these specialised nursing roles.

Conclusion

JF explained that the APPGPHD was in possession of the report from the first oral evidence session, along with a number of written submissions. A report of the current session would be produced and circulated to guests and contributors, in order to ensure it accurately reflected proceedings. The inquiry panel would then draw together its conclusions and recommendations in an authoritative document, which could be submitted to the Department of Health, Public Health England and other relevant parties. JF stated that the purpose of the document was to improve the lives of people suffering from headache disorders. JF thanked the speakers and all who attended.

This Brief Summary was produced by Ubiqus UK ✆ +44 (0) 20 7269 0370
http://www.ubiqus.co.uk / infouk@ubiqus.com