



ALL-PARTY PARLIAMENTARY GROUP ON M.E.

Chair: Tony Wright MP
Vice Chairs: Paul Burstow MP
Rev Martin Smyth MP
Secretary: Steve McCabe MP
Treasurer: David Amess MP

MINUTES OF THE ALL-PARTY PARLIAMENTARY GROUP ON M.E. HELD ON TUESDAY 28 OCTOBER 2003 AT THE HOUSE OF COMMONS

PRESENT

- Tony Wright MP
- Tom Clarke MP
- Ivan Henderson MP
- Steve McCabe MP
- Andrew Stunell MP

- Professor Anthony Pinching, Chair of Service Implementation Group (advising Department of Health), Associate Dean for Cornwall and former Deputy Chair of CFS/ME Working Group
- Chris Clark, Chief Executive, Action for M.E. (Secretariat)
- Samantha Radford, Action for M.E. (Secretariat)

1. MINUTES OF THE LAST MEETING

The minutes of the last meeting were agreed

2. APOLOGIES

Apologies for absence were noted

- Doug Henderson MP
- David Copper MP
- Dennis Turner MP
- Christine Russell MP
- Colin Pickthall MP
- Peter Duncan MP
- David Drew MP
- Helen Clark MP
- Andrew Hunter MP
- Mrs Betty Williams MP
- Lord Tim Clement-Jones
- Annabelle Ewing MP
- Lady Hermon MP
- Damian Green MP
- Howard Flight MP
- Dr Brian Iddon MP
- Anne Begg MP
- Janet Dean MP

- Mrs Marion Roe MP
- Mark Todd MP
- Nigel Jones MP
- David Rendel MP
- David Cameron MP
- David Amess MP
- Win Griffiths MP

3. PRESENTATION: Development of NHS Services in England – Policy and Progress

Following introductions Professor Pinching briefly covered recent major developments in the field. These include the publication of the Chief Medical Officer's Working Group report on CFS/ME in January 2002. This was followed by a request for the Medical Research Council to develop a broad strategy for researching CFS/M.E. The result was a thoughtful report by a group of non-M.E. specialists. Amongst other things, it was recommended that clinical and epidemiological research should be linked with services.

On the 12th of May 2003, Jacqui Smith, the then Health Minister announced £8.5m ring-fenced funding to pump prime services for people with CFS/M.E. in England. Professor Pinching was asked to Chair the CFS/ME Service Implementation Group (CSISG) that is overseeing the programme.

At present, services are patchy and planning is inconsistent with many gaps to be filled. Service networks need to be established. There is a lack of domiciliary services for the severely affected. An application process has been established for Providers and Primary Care Trusts (PCTs) to bid for the funding. Patients are being involved in the bidding process. When the Chief Medical Officer's Report was published in 2002, there was no specific funding available and newly formed PCTs although sympathetic were mostly not in a position to respond.

The £8.5m will introduce basic services that in future can compete for funding with others, on a more level playing field. The funding will be released over the next two years, first £2.5m in 2004 and remaining £6m in 2005. Thereafter the funding will continue, being directed to the PCTs hosting the services.

The proposal is to establish two levels of provision:

- Clinical network co-ordination centres to champion services and offer training and support to local multidisciplinary teams. The centres will also provide patient care.
- Local multi-disciplinary teams, each normally servicing 5-10 local PCTs. The teams may, for example, include physician, OT and nurse support.

GPs need greater awareness on how to diagnose and manage the condition and when to refer patients on. Training will be developed through the centres and local teams.

Originally it was thought that 6 - 10 centres would be adequate but 12 - 15 centres have been found to be more appropriate to ensure effective network start-up and development. Some are being developed from existing services, some new. The centres will form a national group to take the lead in research, training, development and provision of patient care.

The bidding process is under way and bids are being received from different areas, encouraging collaborative bids amongst those who have expressed interest from any area, but accepting that some may bid competitively. The criteria include demonstrating local responsiveness and access for patients, provision for young people and children, training of frontline staff and research capability. The details are set out on the Department of Health website. There are two deadlines:

- 1) 10 November 2003
Bids for clinical network co-ordinating centres (CNCCs). The first year funding will provide support for CNCCs across the country. There was only one geographical gap in the expressions of interest, and a local team was approached to bid. The remainder of the first year funding would be for those local multidisciplinary teams (LMDTs) with well advanced plans. The CNCCs, when established, will actively manage the process of developing plans by other LMDTs to cover the remaining areas in their patches.
- 2) April 2004
The majority of LMDTs will bid for second year funding by this deadline date. The aim is that by June funding for the whole programme will have been set out and designated for the next two years.

Making clear the funding is ring-fenced eliminates attempts to use it for other services. The funding will be tracked real time to ensure that maximal usage is achieved. Thereafter the funding of functional teams and centres will be rolled into host PCT baseline budgets as an additional allocation. Continuing allocation to services for people with CFS/ME will need to be achieved by performance management and by clear guidance about the need to continue these services, so long as they are showing themselves to be effective.

The application process is clearly set out on the NHS website. Two bid panels are split geographically (north/south) and will make recommendations to the main group.

The investment steering group includes PCT representatives, an SHA representative, a General Practitioner, a patient representative, an MRC

representative, physicians and therapists. Two meetings have been held so far, the first to establish the bidding process and second on long-term strategy development.

The implementation group recommends consistency of practice and dispersing of information through the centres to the front line, and sharing of good practice between teams and centres. The bulk of the funding is being pumped into local teams as that is where it will have more impact on patients.

So far there have been over 80 expressions of interest from a range of teams and professionals. Feedback has generally been very positive. Concerns expressed to date include reservations over the long-term security of funding and the short time period allowed for the exercise.

4. Questions and Debate

Tony Wright MP noted that up until now services have been a postcode lottery. He enquired whether an existing local service such as Great Yarmouth which is under funding pressure could place a bid.

Professor Pinching acknowledged that the few existing services are overstretched through lack of provision elsewhere and new centres will therefore help relieve pressure. A bid from an existing service could be successful if they can demonstrate the need to expand. In addition, a change from a uni- to multi-disciplinary team could be supported. Disinvestment in existing teams to bid for reinvestment by this process will not be allowed. The objective of the programme is that there will be no postcodes without a service.

Andrew Stunell MP enquired how far in the future the teams and centres can be expected to be up and running.

Professor Pinching outlined that following January announcements to lead PCTs the funding will be available at the beginning of the financial year. Allowing three months for recruitment means the first new services could be ready to go in April 2004. The services must demonstrate that they do see patients and provide a service which is needed. Plans will be reviewed if necessary and programme management will continue past the initial two years.

Andrew Stunell MP asked if this means there will be services across England from April onwards. Professor Pinching responded that it will take a year and a half before all areas will be covered by centres and teams. The first should however be running from April.

Tom Clarke MP noted that DWP covers all of the UK but DoH only England. The service development is marvellous but is the Scottish Executive following suit?

Professor Pinching said he advised the Short Life Action Group in Scotland in developing their policy document and also on progress of this investment process in England. There is no reason why the same sort of programme could not be done there. The Scottish office is aware of the issue. And he hoped they would follow suit.

Steve McCabe MP raised the point of follow up monitoring and the scale of need; He asked whether tension between clinicians and patients about terminology might prevent the services being used.

Professor Pinching noted that the CMO Report indicated the likely number of patients and there would be no epidemiological basis for any gaps in the country. Some areas may have relative over-representation of patients, but it is also possible that patient needs are being met in other ways. Often patients may be appropriately referred, but their needs are not being met and they face a brick wall - e.g. a patient of his was sent around the houses for two and a half years and ended up doing his own care plan; his could have been done within a couple of months, with appropriate professional help. As for tension, the vast majority of patients want a service and are not worried about the label.

Professor Pinching then outlined that the first task of a multidisciplinary team in a new area is to capture the patients, giving clear diagnosis and establishing a management plan. Complex cases will be referred to the centres. Care of patients in itself will provide the best experience and training for frontline staff. Eventually some patients won't need the 'safety net' of special services. GPs will be able to carry out a management plan but many are frightened off by lack of knowledge.

Professor Pinching added that the limit to setting up new services is £8.5m - if there were more funding available more could be done. An option to improve care provision for severe patients is to graft new services onto existing ones such as community domiciliary teams. It is far easier for clinicians to travel than patients.

Tony Wright concluded by thanking Professor Pinching.

5. Correspondence Received

6. Date, Time and Subject of Next Meeting

A debate is being planned to encompass insurance and benefits problems and a request for research funding.

The next APPG meeting will be in the New Year before the end of January and will be the AGM.