



House of Commons  
Committee of Public Accounts

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# Services for people with rheumatoid arthritis

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**Tenth Report of Session 2009–10**

*Report, together with formal minutes, oral and  
written evidence*

*Ordered by the House of Commons  
to be printed 1 February 2010*

## The Committee of Public Accounts

The Committee of Public Accounts is appointed by the House of Commons to examine “the accounts showing the appropriation of the sums granted by Parliament to meet the public expenditure, and of such other accounts laid before Parliament as the committee may think fit” (Standing Order No 148).

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The following members were also members of the committee during the parliament:

Angela Eagle MP (*Labour, Wallasey*)  
Mr Philip Dunne MP (*Conservative, Ludlow*)

### Powers

Powers of the Committee of Public Accounts are set out in House of Commons Standing Orders, principally in SO No 148. These are available on the Internet via [www.parliament.uk](http://www.parliament.uk).

### Publication

The Reports and evidence of the Committee are published by The Stationery Office by Order of the House. All publications of the Committee (including press notices) are on the Internet at <http://www.parliament.uk/pac>. A list of Reports of the Committee in the present Session is at the back of this volume.

### Committee staff

The current staff of the Committee is Sian Woodward (Clerk), Emily Gregory (Senior Committee Assistant), Pam Morris and Jane Lauder (Committee Assistants) and Alex Paterson (Media Officer).

### Contacts

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## Summary

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Rheumatoid arthritis is a lifelong, progressive, musculoskeletal disease that causes severe pain, swelling and inflammation of the joints, and can lead to reduced joint function and disability. An estimated 580,000 people in England have the disease, with 26,000 new cases diagnosed each year. Annual healthcare costs to the NHS are £560 million, with costs to the economy of £1.8 billion in sick leave and work-related disability.

Too many people with the disease are not diagnosed early enough and, once diagnosed, they do not always get the services they need to help them live as well as possible with the disease. Starting treatment within three months can stop the disease getting worse and yet the time between experiencing symptoms and receiving treatment is typically nine months, unchanged since 2003. The barriers to gaining early treatment arise from people's low awareness of the disease, causing them to delay seeking medical help, and from GPs failing to spot the early symptoms and refer quickly enough for diagnosis by a specialist. People with rheumatoid arthritis visit a GP on average four times before referral, and a fifth visit a GP eight or more times before referral.

People don't always get the services they need once they have been diagnosed and, as for many long term conditions, there may be a postcode lottery of care. There are big variations in spending on rheumatoid arthritis across Primary Care Trusts and access to the range of services needed to manage rheumatoid arthritis varies. There are differences in the quality and breadth of services available, in particular significant gaps in access to psychological services. People also find it difficult getting timely access to help when they experience a flare-up.

Not diagnosing the disease early enough makes it harder for people to remain in work. Three quarters of people with rheumatoid arthritis are diagnosed when of working age, and one third of people stop working within two years of being diagnosed. People with the disease often lack the right support mechanisms to help them maintain their independence and make an economic contribution to society. In November 2008 the Government accepted the finding of a Review of the health of Britain's working age population<sup>1</sup> that steps were needed to help people with musculoskeletal conditions, but this has yet to filter through to action on the ground.

On the basis of a Report by the Comptroller and Auditor General,<sup>2</sup> we examined the Department of Health on: identifying and diagnosing cases of rheumatoid arthritis sooner; providing better support for people living with the disease; and how the NHS can work more effectively to improve services for people with rheumatoid arthritis.

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1 *Working for a healthier tomorrow, A Review* by Dame Carol Black, National Director for Health and Work, March 2008

2 C&AG's Report, *Services for people with rheumatoid arthritis*, HC (2008–09) 823



## Conclusions and recommendations

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- 1. Prompt diagnosis of rheumatoid arthritis is crucial in preventing irreversible damage yet delays arise from people failing to present promptly to GPs with symptoms.** The Department should run a campaign during 2010 to raise people's awareness of the symptoms of rheumatoid arthritis, highlighting the need to seek prompt medical attention.
- 2. GPs often fail to recognise the symptoms of rheumatoid arthritis, causing delay in referring to a specialist for a diagnosis.** The Department should, as a priority, launch a targeted campaign or guidance to raise the awareness of GPs and other primary care professionals of the importance of referring people promptly to a specialist, if rheumatoid arthritis or other forms of inflammatory arthritis are suspected.
- 3. GPs receive on average only two hours of teaching on musculoskeletal conditions during their training, including minimal coverage of inflammatory arthritis.** The Department should encourage the Royal College of GPs to provide more training on rheumatoid and inflammatory arthritis when it implements its plan to extend the duration of training for GPs. Such training should help trainee GPs identify the early signs of inflammatory arthritis and emphasise the importance of early referral to specialists.
- 4. In July 2009 a Commissioning Pathway for Inflammatory Arthritis was introduced but current services fall far short of this ideal.** The Department should write to this Committee by March 2010 setting out what it is doing to encourage take up of the Commissioning Pathway by Primary Care Trusts, and how it intends to evaluate its impact on patients.
- 5. People with rheumatoid arthritis can experience intense pain when they suffer a flare-up but rapid access to specialist care is not always available when they most need it.** The Department should review the evidence on the need for better access to flare-up and pain management services for people with rheumatoid arthritis and produce an action plan by March 2010.
- 6. Rheumatology specialists do not have sufficient flexibility to prioritise appointments for patients according to clinical need.** Strategic Health Authorities should clarify how they expect commissioners in primary care to ensure that sufficient follow-up appointments are available for people with rheumatoid arthritis in their local area, and should audit whether acute trusts are providing the number of follow-up appointments required to meet clinical need.
- 7. We are concerned about significant variations in the cost of providing services for rheumatoid arthritis.** Data presented by the National Rheumatoid Arthritis Society identified variations in spending by Primary Care Trusts on rheumatoid arthritis services of between £5.68 and £17.58 per head—a greater than threefold difference. The Department should identify the reasons for variations in Primary Care Trusts' spending, set national benchmarks, and require Strategic Health Authorities to hold Primary Care Trusts to account for the cost effectiveness of the services they provide.

- 8. The National Audit Office Report identified inconsistency between Primary Care Trusts in the provision of certain drugs for rheumatoid arthritis and the extent of multidisciplinary services.** For example, access to biological drugs varies widely and while depression is common with rheumatoid arthritis, there is often no access to psychological services. Primary Care Trusts should obtain much better information about the numbers of people with rheumatoid arthritis, decide what services, including psychological services, they need to provide, and take action to ensure their services are configured cost-effectively.
- 9. Support for people with rheumatoid arthritis to remain in or return to work is totally haphazard.** The Department should publish clear standards covering the support people can expect from the NHS to help them remain in or return to work. It should agree with the Department for Work and Pensions how they will ensure that assessors have the knowledge they need to make proper judgements about the ability of people with rheumatoid arthritis to work.

# 1 Early identification and diagnosis of rheumatoid arthritis

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1. Rheumatoid arthritis is a lifelong, progressive, musculoskeletal disease. An estimated 580,000 people in England have the disease, with around 26,000 new cases diagnosed each year. Each year it costs the NHS £560 million and the wider economy at least £1.8 billion. Three quarters of people with rheumatoid arthritis are diagnosed when of working age. Women are more than twice as likely as men to have the disease, and one third of people will have stopped working within two years of being diagnosed.<sup>3</sup> Almost half of people with rheumatoid arthritis are of working age, and over 60% have been living with the disease for more than ten years.<sup>4</sup>

2. To minimise damage to joints as a result of rheumatoid arthritis, treatment should start within three months of the onset of symptoms.<sup>5</sup> Aggressive treatment very soon after the onset of symptoms can lead to remission.<sup>6</sup> Early treatment can also prevent pain and disability, and help people go on working and producing an economic return to society.<sup>7</sup> Since 2003, however, the average time from onset of symptoms to diagnosis and first treatment has remained constant at around nine months.<sup>8</sup>

3. Between half and three quarters of people with rheumatoid arthritis delay seeking medical help from their GP for three months or more following the onset of symptoms, and around a fifth delay seeking medical help for a year or more.<sup>9</sup> There has been no real improvement between 1995 and 2005 in the number of people seeing their GP within three months of the onset of symptoms and there continues to be a general lack of understanding and awareness of the disease and its impact.<sup>10</sup> The Department accepted the need to raise public awareness of the symptoms of inflammatory arthritis, including rheumatoid arthritis, so that people who experience them visit their doctor more promptly.<sup>11</sup>

4. Public education campaigns using television, the internet, leaflets and GP practices have been successful at raising public awareness of specific diseases, but such a campaign had not yet been undertaken for inflammatory arthritis, including rheumatoid arthritis.<sup>12</sup> The Department believed that design of such a campaign would be challenging because of the lack of a clear target population.<sup>13</sup> Working with the Rheumatology Futures Group, it was

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3 Q 72

4 C&AG's Report, *Services for people with rheumatoid arthritis*, HC (2008–09) 823, para 1.7

5 C&AG's Report, para 2

6 C&AG's Report, para 1.2

7 Qq 43, 44 and 52

8 C&AG's Report, para 6

9 Q 25

10 Q 27

11 Q 3; C&AG's Report, para 18a

12 Qq 28, 36, 39 and 47

13 Qq 38, 40 and 42

considering a campaign, The S Factor, to help people recognise the symptoms (**Figure 1**).<sup>14</sup> The Department also acknowledged the need for better understanding amongst primary care staff, including GPs, practice nurses and NHS Direct.<sup>15</sup>

**Figure 1: 'The S Factor': Recognising the symptoms of inflammatory arthritis**

<b>S Factor</b>	<b>Recognising the symptoms</b>
<b>Swelling</b>	Swelling of the small joints, particularly the small joints of the hand.
<b>Stiffness</b>	Profound stiffness of the joints. People may be almost unable to move, and unable to fasten their buttons or bra.
<b>Squeeze test</b>	It is painful to compress across the knuckles of the hand or the same joints in the feet.
<b>Severe buttock pain</b>	Patients with ankylosing spondylitis—typically young adult males—develop quite severe buttock pain and morning stiffness in their back.

*Source: Qq 45 and 46; C&AG's Report, Figure 1*

5. The Department accepted that the route to diagnosis could be better.<sup>16</sup> People with rheumatoid arthritis visit a GP on average four times before being referred to a specialist for diagnosis, and 18% of patients visit eight times or more before being referred.<sup>17</sup> The Department argued that in part this is because early disease is difficult to identify.<sup>18</sup> Outcomes were better for patients whose GPs spotted the signs of suspected rheumatoid arthritis at an early stage and referred patients promptly to specialists for early diagnosis (**Figure 2**).<sup>19</sup> There was also scope for greater use of specialist nurses and early arthritis clinics.<sup>20</sup>

14 Qq 45 and 46; C&AG's Report, Figure 1

15 Qq 29 and 49

16 Q 4

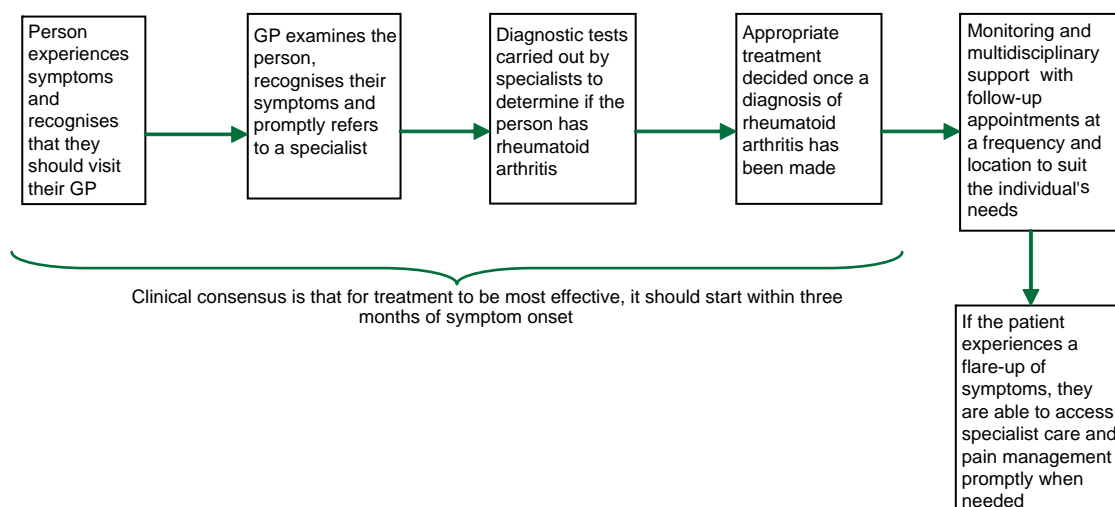
17 C&AG's Report, para 2.7

18 Qq 32 and 33

19 Q 2

20 Qq 34 and 35

**Figure 2: The diagnosis and treatment pathway for people with rheumatoid arthritis**



Source: C&AG's Report, Figure 2

6. With the annual number of new cases estimated to be 26,000 and the number of GPs in England around 34,000,<sup>21</sup> each GP may only see one new case or less a year. It is difficult for GPs to pick up new cases of rheumatoid arthritis from the thousands of musculoskeletal conditions that a GP sees.<sup>22</sup> GPs are not well informed about the disease, with a lack of education on rheumatoid arthritis during medical training.<sup>23</sup> Whilst around one fifth to one quarter of all GP consultations are musculoskeletal related, a trainee GP's tutorials on musculoskeletal conditions are on average just two hours of teaching, of which coverage of rheumatoid arthritis may be just a part.<sup>24</sup> A survey in 2004 found that teaching in musculoskeletal conditions was rated as inadequate by trainee GPs.<sup>25</sup>

7. The Department accepted that more extensive training was needed in musculoskeletal conditions,<sup>26</sup> and was working with the Royal College of GPs, the Rheumatology Futures Group and some patient groups to improve post graduate training for GPs. It expected to produce, by early 2010, educational material for GPs to help them spot the difficult-to-detect early warning signs of rheumatoid arthritis.<sup>27</sup> The Department was also looking at extending the training time required of GPs before becoming fully qualified principals in general practice, from the current three years post hospital work to at least four years and possibly five years, to reflect the complexity of conditions now seen in primary care, including rheumatoid arthritis.<sup>28</sup>

8. In June 2004, the Department made a commitment that by December 2008 no one would have to wait longer than 18 weeks from GP referral to the start of specialist

21 C&AG's Report, para 2.5

22 Qq 4 and 5

23 Q 31

24 Q 17

25 Q 18; C&AG's Report, para 2.12

26 Qq 52 and 54

27 Qq 18 and 53

28 Q 54

treatment—the 18 week ‘referral to treatment’ standard.<sup>29</sup> By December 2008, 97% of rheumatology patients were being treated within 18 weeks of GP referral. The average time from GP referral to being seen by a specialist was around six weeks, although acute trusts’ individual averages ranged from two to thirteen weeks.<sup>30</sup>

9. The Department published a Commissioning Pathway for Inflammatory Arthritis in July 2009 which emphasised that GPs should refer their patients to a specialist where they suspect inflammatory arthritis and not rely solely on the results of blood tests and x-rays which may not detect rheumatoid arthritis during its early stages.<sup>31</sup> The Pathway encourages commissioners in Primary Care Trusts and general practices to work with clinicians to redesign and deliver better services for people with inflammatory arthritis. A range of training events was taking place to encourage better design and management of services.<sup>32</sup> The Committee recognised that the Pathway was a positive step and offered the prospect of better services for patients, although its development also highlighted that the current reality fell far short of the ideal.<sup>33</sup>

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29 C&AG’s Report, para 2.16

30 Q 6; C&AG’s Report, para 2.17

31 Qq 30, 41 and 51

32 Q 7

33 Q 57

## 2 Supporting people to live with rheumatoid arthritis

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10. People with rheumatoid arthritis may suffer unbearable pain as a result of a flare-up of their condition, and when this happens they may not get access to the services they need promptly and easily.<sup>34</sup> There are gaps in the support and information available to help people with rheumatoid arthritis manage their condition. For example, 59% of people with the disease strongly agreed that a named person they could turn to when they had a flare-up would help them manage their disease better. The Department accepted that there were shortcomings in access to services to help manage flare-ups, particularly to specialists and at night.<sup>35</sup> As part of its programme for all people with chronic diseases, it had given people with complex rheumatoid arthritis access to a case manager, but that this would not be both day and night.<sup>36</sup>

11. The Department recognised that better planning and organisation of services could help with the management of flare-ups by releasing the time of consultants in the acute sector where patients currently seeing a specialist do not necessarily need to do so.<sup>37</sup> It envisaged a combination of services, with patients seeing both GPs and specialists and with a mixture of pain relief and anti-rheumatic drugs as the way forward.<sup>38</sup> Although there were examples where primary and community services worked effectively with specialists, the Department recognised that good practice in looking after patients to manage flare-ups in a systematic way was not widespread enough.<sup>39</sup>

12. The focus on implementing an 18 week 'referral to treatment' standard for new patients had meant that patients already in the system had had problems accessing the services they needed and had received slower or deficient treatment.<sup>40</sup> In its census of acute trusts, the National Audit Office found that two-thirds of acute trusts were not able to provide follow-up services to all people with rheumatoid arthritis who need them.<sup>41</sup> The Committee was concerned about instances where people needed to be referred again by a GP when they needed follow-up appointments or had suffered a flare-up and needed to see a specialist. The Department did not recognise this problem but agreed to look into it.<sup>42</sup>

13. Primary Care Trusts lack good information on the extent and costs of rheumatoid arthritis in their local populations which meant that the services they commissioned could be limited and deficient. The Department accepted that the effect of the National Institute for Health and Clinical Excellence guidelines, the National Audit Office Report, and the

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34 Qq 10, 21 and 24

35 Qq 11 and 65

36 Q 11

37 Q 65

38 Q 10

39 Q 65

40 Qq 19, 20, 63 and 64

41 C&AG's Report, para 4.6

42 Q 21 and 22

Commissioning Pathway for Inflammatory Arthritis would be to make Primary Care Trusts re-examine the services they were delivering and where they could be improved.<sup>43</sup>

14. While it did not recognise that existing patients were receiving a deficient service,<sup>44</sup> the Department acknowledged that services could be better planned, managed and delivered to make more efficient use of existing capacity and to deliver improvements in quality.<sup>45</sup> This meant improving commissioning so that primary and community services and hospitals worked more closely together in order to provide more effective management in the community, such as by making better use of specialist nurses in GP practices for the review and monitoring of people with rheumatoid arthritis.<sup>46</sup>

15. Evidence from the National Rheumatoid Arthritis Society suggested that there were variations in spending on rheumatoid arthritis between Primary Care Trusts ranging from £5.68 per head in Bexley to £17.58 per head in Gateshead, with an English average of £10.97.<sup>47</sup> The Committee was concerned that these spending variations could contribute to variations in service quality, and the risk of a postcode lottery.<sup>48</sup> In its census of acute trusts, the National Audit Office had found different levels of access to multidisciplinary services.<sup>49</sup> It also found that policies for funding new drugs for the treatment of rheumatoid arthritis varied across Primary Care Trusts.<sup>50</sup> The Department said it would investigate whether there was any correlation between levels of spending and service quality.<sup>51</sup>

16. An example of particular concern to the Committee was the variations in access to psychological services. Although depression is common amongst people with rheumatoid arthritis, just one in seven acute trusts provided access to psychological services for people with rheumatoid arthritis who needed help with depression.<sup>52</sup> The Department acknowledged that the relationship between physical and mental health had not been well understood nor supported in the past, but said that 75% of Primary Care Trusts now had access to psychological therapy services and that its 'Access to Psychological Therapy' programme would be introduced across the whole NHS. It also expected the forthcoming clinical guidelines from the National Institute for Health and Clinical Excellence to reinforce the importance of psychological therapy for people with rheumatoid arthritis.<sup>53</sup>

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43 Q 57

44 Q 64

45 Qq 61, 62 and 65

46 Qq 34 and 65

47 Ev 18

48 Qq 67 and 70

49 C&AG's Report, para 3.16

50 C&AG's Report, para 3.8

51 Q 69

52 Q 8

53 Q 8

## 3 Helping people with rheumatoid arthritis to be able to work

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17. Almost half of the adult population with rheumatoid arthritis is of working age. Three quarters of people with the disease are diagnosed when of working age, and one third of people with the disease will have stopped working within two years.<sup>54</sup> The wider costs to the economy of sick leave and work-related disability (lost employment) in respect of rheumatoid arthritis amount to an estimated £1.8 billion annually.<sup>55</sup>

18. If people were diagnosed with the disease earlier and had maintained treatment, their chances of continuing in work could be much improved.<sup>56</sup> The National Audit Office had identified in its economic modelling that increasing from 10% to 20% the number of people treated within three months of experiencing symptoms would increase NHS costs by £11 million over five years but could result in productivity gains of £31 million for the economy, due to reduced sick leave and work-related disability.<sup>57</sup> There is, however, no particular incentive on the NHS to fund earlier treatment.<sup>58</sup>

19. Effective support to remain in or return to work depends on dialogue between the Department of Health and the Department for Work and Pensions and in particular the views of medical assessors employed by the Department for Work and Pensions to determine the impact of a medical condition on someone's ability to work. The Committee was sceptical that in practice assessors had the necessary expertise to recognise and understand rheumatoid arthritis and the impact the disease can have on someone's working life. The Department, however, said that the Department for Work and Pensions was satisfied that assessors understood rarer conditions such as rheumatoid arthritis and could make proper judgements about people and their ability to work.<sup>59</sup>

20. Little progress had been made in improving access to services to help people with musculoskeletal conditions manage their return to work, despite the Government's commitments in its response to Dame Carol Black's March 2008 Review of the health of Britain's working age population, *Working for a healthier tomorrow*.<sup>60</sup> The Department recognised that Dame Carol Black's work envisaged more coherent working between the Department of Health and the Department for Work and Pensions, but acknowledged that progress had been poor.<sup>61</sup>

21. The National Audit Office Report identified a lack of coherence in the links between the NHS and organisations commissioned by the Department for Work and Pensions to

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54 Q 72; C&AG's Report, paras 1.7 and 1.2

55 C&AG's Report, para 1.10

56 Q 23

57 C&AG's Report para 17

58 Q 12

59 Q 24

60 Q 71; C&AG's Report, para 4.15

61 Q 71

help people get back to work. Just 56% of acute trusts were aware of Department for Work and Pensions schemes to help people back into work, and a third of these did not provide information about the schemes to people with rheumatoid arthritis.<sup>62</sup> Only 12% of GPs gave information about continuing in employment to patients newly diagnosed with rheumatoid arthritis. People with rheumatoid arthritis rated services to support them to remain in work as the least effective services compared with other aspects of their care, and just 20% of people with the disease considered they received sufficient information about employment issues.<sup>63</sup>

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62 C&AG's Report, para 4.19

63 C&AG's Report, para 4.18

# Formal Minutes

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**Monday 1 February 2010**

Members present:

Mr Edward Leigh, in the Chair

Rt Hon David Curry  
Rt Hon Keith Hill

Mr Austin Mitchell

Draft Report (*Services for people with rheumatoid arthritis*), proposed by the Chairman, brought up and read.

*Ordered*, That the draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 21 read and agreed to.

Conclusions and recommendations 1 to 9 read and agreed to.

Summary read and agreed to.

*Resolved*, That the Report be the Tenth Report of the Committee to the House.

*Ordered*, That the Chairman make the Report to the House.

*Ordered*, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

[Adjourned till Wednesday 3 February at 3.30 pm

## Witnesses

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**Monday 23 November 2009**

*Page*

**Mr David Nicholson CBE**, Chief Executive of the NHS, **Mr Gary Belfield**, Acting Director General, Commissioning and System Management, **Professor David Colin-Thomé OBE**, National Director for Primary Care and **Dr Alan Nye**, General Practitioner and Clinical Adviser for Elective Care, Department of Health

Ev 1

## List of written evidence

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1	Abbott UK	Ev 11
2	Arthritis and Musculoskeletal Alliance (ARMA)	Ev 13
3	Arthritis Care	Ev 17
4	National Rheumatoid Arthritis Society (NRAS)	Ev 18
5	Roche Products Limited	Ev 24

## List of Reports from the Committee of Public Accounts 2009–10

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First Report	A second progress update on the administration of the Single Payments Scheme by the Rural Payments Agency	HC 98
Second Report	HM Revenue and Customs: Improving the Processing and Collection of Tax: Income Tax, Corporation Tax, Stamp Duty Land Tax and Tax Credits	HC 97
Third Report	Financial Management in the Foreign and Commonwealth Office	HC 164
Fourth Report	Highways Agency: Contracting for Highways Maintenance	HC 188
Fifth Report	Promoting Participation with the Historic Environment	HC 189
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Ninth Report	The procurement of legal aid in England and Wales by the Legal Services Commission	HC 322
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Thirteenth Report	Excess Votes 2008–09	HC 360

# Oral evidence

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## Taken before the Committee of Public Accounts on Monday 23 November 2009

Members present:

Mr Edward Leigh, in the Chair

Angela Browning  
Keith Hill

Mr Austin Mitchell

**Mr Amyas Morse**, Comptroller and Auditor General, **Mr Rob Prideaux**, Director, Parliamentary Relations and **Karen Taylor**, Director, National Audit Office, gave evidence.

**Ms Paula Diggle**, Treasury Officer of Accounts, HM Treasury, gave evidence.

### REPORT BY THE COMPTROLLER AND AUDITOR GENERAL Services for People with Rheumatoid Arthritis (HC 823)

*Witnesses:* **Mr David Nicholson**, CBE, Chief Executive of the NHS, **Mr Gary Belfield**, Acting Director General, Commissioning and System Management, **Professor David Colin-Thomé OBE**, National Director for Primary Care, and **Dr Alan Nye**, General Practitioner and Clinical Adviser for Elective Care, Department of Health, gave evidence.

**Q1 Chairman:** Good afternoon. Welcome to the Committee of Public Accounts where today we are considering the Comptroller and Auditor General's Report on Services for People with Rheumatoid Arthritis. We welcome back to our Committee David Nicholson, who of course is the Department of Health's accounting officer and chief executive of the National Health Service. Would you like to introduce your colleagues please, Mr Nicholson?

**Mr Nicholson:** Yes. David Colin-Thomé, the national clinical director for primary care. Gary Belfield, the acting director general for commissioning and Dr Alan Nye, who has a variety of roles but he helps the 18 week team. He is a general practitioner and an expert in the field.

**Q2 Chairman:** If we look at this Report, Mr Nicholson, we can see that too many people with rheumatoid arthritis have not been diagnosed and treated early enough and that, once they are diagnosed with this debilitating disease, they do not always get the services they need. There are obviously value for money considerations here because many people find it very difficult to work, so if we could get them diagnosed and treated early enough it would both save money and of course help them enormously. We want to try and pursue these issues with you in as positive a frame of mind as we possibly can. What are you doing, Mr Nicholson, to try and make GPs better at spotting the signs of rheumatoid arthritis and referring the patients to specialists early enough?

**Mr Nicholson:** I think it is worth saying to begin with—I am sure my clinical colleagues at some stage will talk about this—that it is quite a difficult thing to do, the early diagnosis of rheumatoid arthritis. We can see that by the response of general practice and people in the clinical community. It is not through want of effort or trying that people have had

difficulties in this area. There are three areas that I think we would focus our attention on. The first one is recognition and diagnosis. There is a whole set of issues around information to patients through patient choices, through the various leaflets and documents that both ourselves and the voluntary sector put out. There is the work that the Royal College of GPs is doing around the training and education of general practitioners. There is a whole set of issues around public recognition of this particular illness. All of those things need to be pursued in terms of recognition and diagnosis. The second issue I think is in relation to timeliness that you describe and again it is very important for us to continue to drive forward the 18 week programme because of the effects that has on rheumatology generally; the publication of commissioning guidance, making sure that our commissioners are absolutely on top of it. The final issue is about the effectiveness of treatment, again focusing on the delivery of the various guidance that NICE has put out about what works and the commissioning guidance that they are about to put out later on this year. All of those things together I think, driven from the department, will have a significant effect in this area.

**Q3 Chairman:** Presumably you have no trouble, Mr Nicholson, with recommendation (a), paragraph 18 on page nine: "The Department of Health should explore the cost-effectiveness of options for raising public awareness of the symptoms of inflammatory arthritis, including rheumatoid arthritis, to encourage people to present to the NHS promptly after symptom onset." You have no difficulty with that?

**Mr Nicholson:** I think it is absolutely the right thing to do but that is not to underestimate how difficult it might be. There is not a particular time of the year

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 Department of Health
 

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when this particular condition comes about. There is not a particular patient group, so it is quite difficult to focus your attention and make it happen. We are considering, I think quite actively at the moment, a bid from Birmingham, as it happens, for research into the area of public awareness so we can absolutely focus our attention on things that will work. We are open to that.

**Q4 Chairman:** Have a look again at paragraph 2.6 on page 17 of this Report which describes how GPs may carry out diagnostic tests. It is still not clear to me why GPs are wasting resources and not getting people promptly to a specialist. They are risking people's health, unless you get this dealt with very quickly. As I understand it—correct me if I am wrong—with modern drugs it is possible on most occasions to arrest this or alleviate it but you have to start very quickly indeed. If you read paragraph 2.6, it seems that either GPs are not sufficiently trained in carrying out these tests or recognising what they do or they are simply not doing it. It is worrying, is it not?

**Mr Nicholson:** I am sure it can be done better. Just to put it in context—Alan might say something about this clinically in a minute—about a quarter of all the work that general practitioners do is in the area of musculoskeletal problems. Quite a lot of work that GPs do is in this area and it is quite difficult in that group of patients to identify specifically the ones that would benefit.

**Q5 Chairman:** Let us ask Dr Nye then. He is the expert in this. What is the problem?

**Dr Nye:** If I may try and put this in context for you, as David Nicholson says, around 20% to 25% of all GP consultations are musculoskeletal related. The average GP sees one new case of rheumatoid arthritis a year, so there is a real issue about sorting that one case out from the many hundreds, if not thousands, of musculoskeletal problems that a GP sees. Added to that there is not a single way in which rheumatoid arthritis presents. It can present in many, many different forms. Further complicating it, when a GP gives standard treatment for a patient with joint pain such as anti-inflammatories, patients with rheumatoid arthritis often respond very well in the initial stages, which can further cloud the issue as to what can be going on. As regards the diagnostic tests, there is a multitude of clinical conditions that can present with joint pain. I think it is often completely appropriate that GPs carry out a range of diagnostic tests to make sure there is not some other condition that requires prompt treatment for their patients.

**Q6 Chairman:** It says that you are doing quite well on meeting this 18 week standard but, as I understand it Dr Nye, ideally you should be in with a specialist in six weeks. Is that not right?

**Dr Nye:** That is what the Report—

**Q7 Chairman:** You really have to move fast. How could we incentivise GPs to refer people who are diagnosed more quickly, do you think?

**Dr Nye:** I think there is a number of steps that we have taken. We have published an inflammatory arthritis commissioning guide in the summer of this year, which is there to encourage commissioners, both PCT and practice based, and clinicians to work together to actually redesign and deliver better services to people with inflammatory arthritis and obviously rheumatoid arthritis is part of that. We are also carrying out a range of training events. I am in Leeds on Wednesday looking at shifting services into community settings, so we are trying to improve the services for local health communities, trying to encourage them to look at redesigning and managing this problem better.

**Q8 Chairman:** Can we talk about depression because this is often a very big problem with rheumatoid arthritis, is it not? If we look at 3.16 in this part of the Report here, we see that only one in seven trusts is providing help for people with depression. Are you doing enough to get this message down to the primary care trusts?

**Mr Nicholson:** There is no doubt that the relationship between physical and mental health has not been well supported in the past and not well understood, I do not think, in the past. It was one of the reasons that Lord Layard wrote his report in 2006 and it is one of the reasons why we have launched the whole set of issues around psychological therapies. That is why we are rolling it out across the NHS as a whole. You will no doubt know that 75% of our PCTs now have access to psychological therapies as part of a general picture. We do believe that the clinical guidelines set out by NICE that are coming this year will reinforce the importance of psychological therapy to people who have rheumatoid arthritis.

**Professor Colin-Thomé:** The other issue is that a lot of these patients would see their GPs as well. This often happens with chronic disease. It would be via access through their GP to the psychological therapies and some of the counsellors that we employ ourselves that patients could get access. Just measuring the acute trust referral patterns would not cover the whole picture of referral for depression.

**Q9 Chairman:** What about supporting people now once they have this disease? If we look at paragraph 4.18, we see that the help that they receive in trying to get them back to work is really totally haphazard. Is there any more progress you can make on this, do you think?

**Mr Nicholson:** I think this is a really important issue for us, not just for the general population but also for our own staff. We have 1.3 million people in the NHS, some of whom have long term conditions as well. Today we have announced the Bowman Report on staff health. I will ask David Colin-Thomé to talk about this and people with rheumatoid arthritis in general.

**Professor Colin-Thomé:** It is an area we have not done well in but I think Carol Black's review last year has given us the focus to do better. The work that generated from her is now rolling out. There are several things. We have had Pathways to Work,

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which is an opportunity funded by Jobcentre Plus for patients with issues about work to go and get a consultation and help to go back to work. We have found that the studies show that that produced a lot more people going back to work or staying in work than the control group. They were not as good for mental health problems and that is why we have this condition management programme which focuses more on mental health problems. We have a major bit of work. Since Carol Black's work, we also have the Fitness to Work pilots, because there are several bits. One is that Carol has recommended now that we should have a fit for work note for GPs rather than a sickness note to change the thinking about people's opportunities. We want to have more opportunity for occupational health and employment advisers to be based in general practice. This is the work that we will be producing from next year as a result of Carol Black's work. For people in work to stay in work, we need support which is what we are offering, but also for the workless some of these programmes will help them get them back to work when they have been out of work for some time.

**Q10 Chairman:** Some of these patients will be in unbearable pain. What work are you doing to try and ensure that they get the services they need promptly and easily, that they are specially helped, targeted and all the rest?

**Professor Colin-Thomé:** They are seeing their specialist but also their general practitioner and I think the mixture of the pain relief plus the anti-rheumatic drugs is the way forward.

**Q11 Chairman:** I mean help day or night.

**Professor Colin-Thomé:** We have both us available as well as our community nursing services, some of which maybe are not working overnight at the moment, but that is the area we will be looking to try and develop in the future. They would have access. What we have done in this particular group of patients, as with other people with chronic conditions, is at least give them access to a key worker, a case manager, so that, for the more complex end of these conditions, they can have access to somebody. That would not be day and night, but it would give them a tremendous amount of cover, more than they have had hitherto. That is part of our chronic disease programme for all people with chronic diseases.

**Q12 Chairman:** Could I ask the Treasury a question finally? If you look at paragraph 3.10, we do not want to get fixated on the costs to the economy because clearly people are suffering appallingly from this and what is important is to get them helped and treated, but as far as the Treasury is concerned we see that for those of working age the NAO's model suggests that this earlier treatment could result in productivity gains of £31 million for the economy due to reduced sick leave. A very high proportion of people who get rheumatoid arthritis have had to leave work, but there is no particular incentive on

the NHS, is there, to fund this? Do you take a view on this when you are funding the NHS? Do you say that this has an enormous impact on the economy and therefore we want to fund the NHS in such a way that they are incentivised to deal with it; or do you just wash your hands of it and say, "It is over to them"?

**Ms Diggle:** I had precisely the same reaction as you do. It seemed to me that if we could do something about earlier diagnosis it would be extremely welcome because it would mean less living on benefits, more tax coming in. That would almost certainly well cover the cost of extra treatment. However, the sad point of the story is that it is very hard to diagnose. Having talked to the people who are in front of you, I do understand that it is very, very hard to spot people with this disease any quicker. If it could be done, I think there would be a jolly good case for looking at that equation.

**Q13 Angela Browning:** Dr Nye, are you the clinical lead for the Department of Health in musculoskeletal conditions?

**Dr Nye:** No, I am not. I am clinical adviser for elective care for the department.

**Q14 Angela Browning:** Who is the clinical lead in the department?

**Mr Nicholson:** We do not have one.

**Q15 Angela Browning:** Why do you not have one?

**Mr Nicholson:** We do not have a clinical lead for every condition. If we did, there would be over 200 clinical leads in the department. It is not necessarily the case that, because you have a clinical lead, it means that focus is put on it. There are lots of other services that improve without having a clinical lead *per se* at national level.

**Q16 Angela Browning:** When we see that back in 2004 there were guidelines set down about the length of time between referral from GP to a consultant, has anybody taken the initiative within the department to review it, if there is no clinical lead? I am asking because obviously we have all read about this window of opportunity.

**Mr Nicholson:** Just because there is not a clinical lead does not mean there are not clinicians involved in all this. We put it into the pathway guidance that went out. We have strengthened it. It will be in the NICE guidance that comes out this year and we expect all organisations to follow that guidance.

**Q17 Angela Browning:** Could I just ask you to look at page 19, paragraph 2.12? We heard a little bit just now about the difficulty because the average GP would only see one case presented a year and obviously with patients like that one can understand it would be difficult to just pick up these odd cases. There is quite a damning paragraph there about the way trainee GPs are still being tutored in

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musculoskeletal conditions. It says here, “Seventy per cent of GPs had tutorials . . . receiving an average of two hours teaching” and the most common topics were back pain, joint injections and osteoarthritis. Just where does rheumatoid arthritis feature in all of this?

**Professor Colin-Thomé:** It would fit in with musculoskeletal conditions. When you are a GP registrar, a GP in training, which is a three year programme, it covers a wide range of the responsibilities. Musculoskeletal conditions cover a lot but rheumatoid arthritis is a part of that so it would be covered in that training. Then we have to learn about cancer, diabetes and all the others, so it is probably an area that maybe we should improve but everybody else has pressures as well as to what slice of the GP training programme they get.

**Q18 Angela Browning:** It does say in this paragraph that the GPs who were surveyed here felt that their training on musculoskeletal conditions was inadequate.

**Professor Colin-Thomé:** Completely. In fact, that is why we have the Royal College of GPs focusing on this—Alan is involved with working with them—looking at improving the curriculum around postgraduate education for GPs. The issue is that if you are a generalist, which I was until I retired, every condition is part of our responsibility so trying to allocate it sufficient training for all is quite a difficult area. Every condition comes to us, whether it is diabetes, angina and so on and so forth. In that, if there has been a highlighted need that GPs are identifying, that is why we are looking with the Futures Group at how we might get better training for GPs. I can see why in the past there has been so much conflicting pressure. Now we have some harder evidence I think your group, Alan, is going to be focusing on this.

**Dr Nye:** The Rheumatology Futures Group and myself, the Royal Colleges and some patient groups are working to help produce some educational material for GPs to help them spot those difficult to detect early warning signs. Hopefully, we will produce something by later this year or very early next year on that.

**Q19 Angela Browning:** I think, Mr Belfield, this is probably for you. We have heard that once a GP has made a referral, time is of the essence etc., but we understand—I must say I am a little confused by this—that because of the way commissioning is exercised once a consultant has seen the patient for the first time they go back into the care of the primary care field and that there is great difficulty for some consultants in being able to actually initiate follow-up appointments. Everybody is shaking their heads but we have this on very good evidence. It is something I really would like to be followed up, because I understand it is not to do with patient care *per se*; it is to do with the ramifications of how commissioning is carried out in this country. It is to do with money, I think.

**Mr Belfield:** I do not recognise that.

**Q20 Angela Browning:** You do not recognise it at all?

**Mr Belfield:** No, in the sense that PCTs do not dictate clinical practice. If somebody is seen in hospital for a first out-patient appointment, it is then up to the consultant in the hospital to decide whether the patient is brought back. The PCT will not stop that happening.

**Q21 Angela Browning:** We have been told quite emphatically by the charitable sector dealing with this condition that that does not happen. It is quite difficult. They sort of go back into the system and you have to initiate the whole thing from scratch for a second or follow-up appointment. If somebody is in crisis or something has flared up and they need to see a consultant, the fact is that they have to go through the whole system again. They are not as most hospital conditions would be. If someone is on the hospital register, they would be seen by that consultant again pretty quickly. There is a problem here and I have been quite convinced from what I have been told that you should be investigating this. I am asking, through you Chairman, whether you would investigate this.

**Mr Belfield:** I am happy to because I am concerned by what you have just said. I will definitely take that away. There are examples where PCTs, with their clinical colleagues, GPs, etc., are putting in place systems to make sure that the practice in hospital is not over-referring in terms of seeing people too many times, but that does not sound like what you are describing to me.

**Q22 Angela Browning:** No, it is not.

**Mr Belfield:** Outside the Committee I will take that away and look at that for you.

**Q23 Angela Browning:** Thank you very much indeed. Could I just finally come on to this question that has already been touched on? This is the question of people who are diagnosed and are of working age. We see from the statistics in the NAO Report that 45% of the 580,000 over 16s are of working age and it is a cost, estimated in this paper of £1.8 billion to the exchequer of loss of money in terms of people who are having to give up work. We understand after two years it is quite a common thing for people not to be able to carry on coping with this condition. If they were diagnosed earlier and had maintained treatment, they would certainly be able to have a much more fulfilling life and carry on working. One of the things that worries me enormously is where this fits into this new scheme of benefits that the DWP have responsibility for, because already we have seen with other conditions—I have to say I have not had a rheumatoid arthritis condition—I can easily see, if this is one of those conditions which is not really clearly understood, there is not a lot of expertise out there, let alone among DWP assessors. Certainly I have had some very harrowing accounts in my own constituency of DWP assessors recently in the way they have dealt with people recovering from cancer

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etc. I suppose, Mr Nicholson, this is for you. What dialogue are you having with the DWP about this condition?

**Mr Nicholson:** We have had dialogue with the DWP about it but of course the issue is not the condition itself. It is how it presents and the impact on individual patients. The thing you have described there was not part of those discussions, I have to say. Once the diagnosis is made, it is pretty clear that that is the condition. There is a lot of expertise around about its treatment and there is a lot of understanding about what the prognosis for individual patients is. It is not that kind of open ended thing that you might get with other conditions. If there is evidence to show that patients with rheumatoid arthritis are suffering potentially, then we would like to see it because we genuinely have not seen it.

**Q24 Angela Browning:** The reason I am flagging it up is because it seems to me that this is another one of those conditions where for example people get what they call "flare up". You could be properly managed in terms of medication and medical supervision, holding down a job and then you get a flare up and you are suddenly off work again. I just wonder how much these assessors and people who sit on tribunals actually understand this condition when it presents. I say that because there are so many conditions where you need a specialism to make a proper judgment about people and their ability to work.

**Mr Nicholson:** The DWP are satisfied that they have the expertise and we can certainly help and support them.

**Angela Browning:** I hope you will help them because I do not have your trust and faith in them having expertise in some of these rarer conditions.

**Q25 Mr Mitchell:** There seems to be a real problem of ignorance or, to use the proper medical term, lack of information on the part of the public and GPs about this issue which is leading to delays in referring to the doctor or doing anything about it. I see from paragraph 2.2 that between half and three quarters of people with rheumatoid arthritis delay seeking medical help from their GP for three months or more and around a fifth delay seeking medical help from their GP for a year or more. I can see from table one that there is a lack of information on the part of the public about the disease and from table ten that most people do not know much about it but the correct answers are usually under 40%. Why is this? Why the delay? They must be in pain. Do they just sit and grin and bear it or what?

**Mr Nicholson:** I think Alan Nye would be in a good position to be able to tell you because he sees those patients directly.

**Dr Nye:** I think what you say is true. Patients are generally sometimes quite stoical and they do not put aches and pains down to what can be a potentially very serious, and yet treatable, condition. What you also have to bear in mind is the very variable nature which rheumatoid arthritis can present in its very early stages. People can sometimes have problems for a day or two and then it can settle

down and they can be quite well for a period of time. They tend to forget almost that this happened. It is only when things tend to snowball and they have difficulty carrying out their job or other activities that they sometimes seek help. As I have previously mentioned, they may be going to their chemist and buying some over the counter medication which is really very helpful. Again, they put it down to a trivial problem rather than seeking help. It is unfortunately due to the nature of the problem in some ways.

**Q26 Mr Mitchell:** It is the intermittent impact?

**Dr Nye:** It can be, yes. There is a type of rheumatoid arthritis called palindromic which presents in exactly this way, where it is bad for a few days. Then it goes and it comes back again.

**Q27 Mr Mitchell:** I see from paragraph 2.3 that there has been no real improvement in the number of people referred to their GP within three months between 1995 and 2005. That is amazing. What public education have you been doing to encourage people to go to their GP?

**Dr Nye:** There is a number of steps. One is again this work of the Rheumatology Futures Group with the Department of Health and the Royal Colleges. We are looking potentially at some posters which may go up in GPs' surgeries and other areas which relate to the warning signs which they should take seriously.

**Q28 Mr Mitchell:** Have you anything on the internet? Most people seem to prescribe their treatment from the internet these days rather than going to their doctor. What is available on the internet?

**Dr Nye:** There is a wealth of high quality internet resources. There is the NHS Choice's website and something else we are developing as a development of the inflammatory arthritis commissioning pathway is a patient layer, a layer specifically designed for patients to be able to easily access high quality, validated information which will actually cover the whole of the patient journey from self-care, presentation in primary care, diagnosis and ongoing.

**Q29 Mr Mitchell:** If I ring NHS Direct, what will they tell me?

**Dr Nye:** I had a look at the web based decision tool before coming here. Their advice is to go and seek help from your GP.

**Q30 Mr Mitchell:** When you get to the GP, there seems to be a problem in the sense that GPs do not know enough about it and are tending to refer people for tests which are not necessarily useful. I see from 2.6 that the blood tests for rheumatoid factor detect less than half of people who will eventually be diagnosed with arthritis. The x-rays may well be normal and therefore do not present the symptoms. Is this because the tests need specialist interpretation?

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**Dr Nye:** No. I think there are a couple of points around the tests. Firstly, it is completely true to say that in early rheumatoid arthritis the blood tests and the x-rays are completely normal, but I think it is also fair to say that there are many other conditions which can present with general aches and pains, for which it is completely appropriate for the GP to carry out these investigations. I think it would be remiss of general practitioners not to thoroughly investigate their patients but to bear in mind that in rheumatoid arthritis they should not be unduly reassured by normal results. What the inflammatory arthritis commissioning pathway highlights is that they should refer on clinical suspicion and not rely on the results of tests.

**Q31 Mr Mitchell:** GPs do not appear all that well informed. They do not appear to be well educated in the matter at medical school from what I see in the Report. Would it not be better if people presenting were referred immediately to a specialist? Why do you not just instruct GPs to do that?

**Dr Nye:** I think you have to bear in mind that 20% to 25% of all GP consultations have this musculoskeletal element. If we were to tell GPs to refer a quarter of all the patients they saw, the services would be swamped and completely overwhelmed. Patients needing expert care—

**Professor Colin-Thomé:** It would be about 80 million people. GPs see about 300 million people a year so if a fifth of those were sent to hospital I think they would not cope. The volume that goes to general practice is huge.

**Q32 Mr Mitchell:** What proportion of those will have rheumatoid arthritis?

**Professor Colin-Thomé:** About 25% will have a musculoskeletal condition. As we were saying, for new rheumatoids, the GPs will see less than one a year. Some of them are more obvious. I think there is a mention in the NAO Report about 40% of patients going to see a doctor quite quickly and they get referred. I presume those are the ones with more extreme symptoms. Many of them do not have that severity early on and that is where it gets too difficult to differentiate that from all the other—

**Q33 Mr Mitchell:** It is a vicious circle, is it not? If they only have one or two cases a year and they do not recognise the need to refer them to a specialist, we will have more delays.

**Professor Colin-Thomé:** Yes. When you say GPs are not informed, I think most people would know about rheumatoid arthritis but it is the difficulty of diagnosis in the early days that is the issue. Yes, we need to do more as we have described about raising the profile and the information for GPs, but nevertheless in my knowledge of my consultant colleagues, it is not always easy for them to diagnose either. It is quite a difficult area in the early stages for many of these patients.

**Q34 Mr Mitchell:** I see the Report indicates that specialist nurses can make a big contribution here. How many specialist nurses are available? How many arthritis clinics do you have?

**Professor Colin-Thomé:** I do not have a figure. In the Report I think there are only about a couple of hundred specialist nurses.

**Dr Nye:** It is in the 400s, I believe, just relying on my memory.

**Q35 Mr Mitchell:** Is that going up?

**Dr Nye:** I believe it is. I think you have to bear in mind the NICE guidance on rheumatoid arthritis which highlighted the importance of multidisciplinary teams and nurses as a vital part of that team. It was only released in February of this year and there is a lag of about a year to 18 months to train these rheumatology nurse specialists. I would like to think that the numbers of nurses, as the NICE guidance is being implemented, are increasing.

**Q36 Mr Mitchell:** This looks like an area where there would be enormous advantage in spending quite a bit of money on a public education campaign through television, leaflets or surgeries or whatever, because the earlier you treat people the longer they can stay working and the less they need surgery and all the rest of it. Why do you not go in for that?

**Mr Nicholson:** I think we are exploring that as a possibility at the moment. If we are going to do it, we want to do it right.

**Q37 Mr Mitchell:** How much would it cost?

**Mr Nicholson:** It depends what you do, does it not? It depends whether you have television advertising.

**Q38 Mr Mitchell:** How long is a piece of string?

**Mr Nicholson:** Yes. You have all of those things and also what is effective because it is not a particular time of the year. It is not like 'flu or something like that where you have a particular time of the year when you would concentrate your activity. It is throughout the year on every occasion. I think we are exploring that as a possibility. We certainly have not ruled it out.

**Professor Colin-Thomé:** It is difficult though because if you look at cancer, where there has been a lot more publicity, one of the reasons why our outcomes were worse in this country was because patients were slower to go to their doctors. That is with a lot of public information. As David says, we need to find ways which are proven so that we can communicate. Otherwise we will spend a lot of money on unnecessary advertising which does not have the impact we want. For cancer it is improving but it has been very slow to get people to go to their GP. That is one of the gaps that we have in this country for instance.

**Q39 Mr Mitchell:** Cancer indicates the success and the possibilities of these disease campaigns. There has been a dramatic improvement in people getting quick opinions from doctors and they are quickly

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referred to specialists and to hospital and being quickly treated in cancer, which has not occurred in rheumatoid arthritis.

**Professor Colin-Thomé:** That is true but there is still a problem for us in this country of people who are getting the symptoms before they are seen in cancer as well. That has not changed much at all.

**Q40 Mr Mitchell:** The number of people treated quickly has changed.

**Professor Colin-Thomé:** I agree. All I am saying is we are looking at the public information approach to try and get the lay person's knowledge higher. Even in cancer we have found huge difficulty to make that effective on that particular area I am talking about.

**Q41 Mr Mitchell:** I would not discount the possibility of having a campaign on this issue, given the benefits which the Report indicates. Can I just move on to the question of referrals from the doctor to the specialist? What is the reason for the delays there? Is there a problem with the procedures of some primary care trusts?

**Dr Nye:** No. I think as soon as a GP suspects there may be inflammatory arthritis they will do a referral. I am not aware of any delays which would interfere with the process. It is actually raising the suspicion. It is making that initial diagnosis in primary care which is important. I am not aware of any other delays with the referral process.

**Q42 Mr Mitchell:** What is the potential for treatment? Unremittingly destructive, vroom. Relapsing and remitting is vroom, vroom, vroom. That seems to be in the majority of cases and then suddenly in 10% to 15% of the cases it is just a short impact. Do we know why those differences occur? Is it a failure of treatment?

**Dr Nye:** No, we do not know why. There are different patterns of presentation and progression of rheumatoid arthritis. We know certain patterns of symptoms and blood results are quite bad prognostically, but again as to why one individual with it has the relapsing form and another individual has the gradually progressive we do not understand why that is the case.

**Q43 Mr Mitchell:** Are the ones that are unrelentingly destructive the ones that are referred to surgery?

**Dr Nye:** No. If you manage to get patients controlled within the first year of their illness it is possible, with some of the modern drugs, to prevent much of the pain and disability that traditionally patients with rheumatoid arthritis have.

**Q44 Mr Mitchell:** They can carry on working?

**Dr Nye:** Yes.

**Q45 Chairman:** As this is being shown on the television, describe for the public what they should look for in these people. What signs are there? What should they be doing?

**Dr Nye:** Part of the campaign we are looking at with the Futures Group has borrowed something from the popular TV show, *The X Factor* and we are

calling it the S factor. It talks about swelling, which is swelling of the joints, particularly of the small joints of the hand.

**Q46 Chairman:** This happens quite quickly, does it?

**Dr Nye:** This can happen overnight. You can go to bed normal, so to speak, and wake up almost unable to move, unable to fasten your buttons or fasten your bra as a woman. Swelling is one. The other is stiffness. Patients with rheumatoid arthritis often complain of profound stiffness of the joints. The other is a test called the squeeze test. That is the third S. It is where you actually compress across the knuckles of the hand or the same joints in the feet and it is painful. That is the most validated examination test for an inflammatory arthritis. There is a final S factor point for patients with ankylosing spondylitis where young adult males develop quite severe buttock pain and morning stiffness in their back. The condition there is almost harder to diagnose than rheumatoid arthritis with average delays of two years before diagnosis. That is a real challenge to try and get patients to present and for doctors to identify and refer early.

**Q47 Chairman:** Given that this is in many cases an utterly debilitating disease, are you getting this message out to people with posters in surgeries and advertising campaigns? The signs we are talking about seem to me to be fairly clear and simple for the public to understand.

**Dr Nye:** I have simplified things quite significantly but I think what is important is to raise general awareness amongst primary care clinicians and for the patients that every ache and pain which they may have occasionally, if you have these other signs, can be serious. This is still work in progress and we would hope to be able to produce these posters and education within a few months. Hopefully in the near future we will be able to take this further.

**Q48 Chairman:** How many of these symptoms that you are talking about which can happen very quickly could just be ordinary arthritis?

**Dr Nye:** Quite a few.

**Q49 Chairman:** Like in the squeeze test?

**Dr Nye:** Yes, but what we would hope GPs or practice nurses would consider is that if they have a patient with these we want them to think to themselves: could this be an inflammatory arthritis? If they think that and there is a possibility, they should act and refer for a specialist assessment. Because the diagnosis is so hard to make in some cases, what is important is that GPs or practice nurses act on suspicion and do not rely on blood tests, x-rays or other things. We are trying to speed up that patient journey.

**Q50 Chairman:** As your colleagues said, GPs are seeing 80 million people a year with these sorts of aches and pains.

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**Dr Nye:** That is right.

**Q51 Chairman:** Presumably all the incentives are the other way, are they, because they are saying, “I cannot refer too many people”? That is the difficulty, is it not?

**Dr Nye:** Most GPs are incentivised to do the right thing for their patients. That is what most GPs are in the job to do. What we are trying to do is to get them to think about the possibility of an inflammatory arthritis. If they feel that exists, then we are asking them to act.

**Chairman:** Thank you very much for that. That is a very clear exposition. I wish all our witnesses were as impressive, Mr Nicholson, particularly permanent secretaries.

**Q52 Keith Hill:** Can I begin by saying how much I appreciated the NAO’s DVD called “*Patient Stories*” which is attached to the NAO Report? In this Committee we most often deal with just money but in this case we are actually dealing with human beings and a lot of pain. I thought the DVD brought home exactly the human dimension of this particular inquiry which is so important. Although we deal primarily with money in this Committee, there is a value for money angle in the appropriate treatment of rheumatoid arthritis because, I think as the NAO Report demonstrates, if there is one area of medicine where early intervention—making the investment to stabilise the condition—can produce an economic return to society, then this is the example above all. What was so obvious in the DVD and those courageous people, if I might say so, who agreed to go on the DVD was their desire to go on working and making a contribution to society. That is I believe something that we should want to encourage. I want to focus on the issue of relationships and communications between, as it were, the front line of those who treat rheumatoid arthritis and the commissioners. Let me just go back to one or two questions that have already been asked again. First of all, this issue about the extent of musculoskeletal problems presenting to doctors. This is probably one for David Nicholson. Let me ask again: are you satisfied that there is a proportionate amount of training in a GP’s education and degree which is devoted to musculoskeletal issues of which rheumatoid arthritis is one case?

**Mr Nicholson:** No.

**Q53 Keith Hill:** What are you going to do about it?

**Mr Nicholson:** In a sense, that is why we have asked Rheumatology Futures and the Royal College of GPs to give us some advice about how we might best do it. It is relatively easy to say no, it is not, and we need to do more. Unless you extend the amount of time you spend training people, something else has to go. That is quite a difficult set of issues to deal with. In principle, we think that is absolutely right. We want to encourage training to be changed in that way but we are asking for advice about how best to do that.

**Q54 Keith Hill:** I suppose the fact that, as we have heard frequently, up to 25% of cases presented to doctors are of that character would certainly suggest that more extensive training should be given in that area, because that is actually the best preparation for being a GP.

**Professor Colin-Thomé:** As a general point, we want to extend the years that GPs are in training, currently it is three years once you have left your hospital work. Certainly we are going to go to four years and the Royal College of GPs is recommending a five year programme because of the sheer complexity of most of the conditions that now are in primary care, to take your point. We are looking to extend the training before you become a fully qualified principal in general practice.

**Q55 Keith Hill:** That is extremely interesting and something new to me. That would make the British experience I think more comparable to that for example of our continental neighbours. That is a different matter. Let me come back to this issue of the musculoskeletal conditions. Perhaps this is one for Dr Nye. How does the severity of rheumatoid arthritis compare with the other conditions a doctor or GP is likely to come across in the course of his or her work?

**Dr Nye:** A doctor sees a full range of possible conditions from those who are terminally ill to those with quite trivial illness. Rheumatoid arthritis is a very disabling illness and often impacts on every aspect of a patient’s life. I think what is important in managing conditions like rheumatoid arthritis and the other life long, long term conditions is the concept of having a multidisciplinary team, primary care and the specialist services working together to deliver the best standard of care for the patient. I think rheumatoid arthritis is a great example where it is possible for specialist services and primary care to work in harmony together with patients receiving the best care on a day to day basis from their GP and, when things are not going well or when there are flare ups, maybe seeking expert help from a member of the specialist team, whether that is a consultant or a nurse specialist. What the Inflammatory Arthritis Pathway encourages is for commissioners, primary care and specialist services to work together to look at redesigning services. Rather than working in separate bunkers between GPs and hospitals, you are actually working together to deliver coherent services for your patients.

**Q56 Keith Hill:** You have anticipated some questions I wanted to ask about IAP, the Inflammatory Arthritis Pathway. That is supported by the Department of Health and I understand that you played a part in developing it. Can you say a little more about what it is and the benefits you expect it to confer?

**Dr Nye:** Sure. It is an 18 week commissioning pathway. Its primary purpose is to describe an idealised patient service. It covers the complete patient journey from self-care, initial diagnosis, the patient journey in primary care covering common presentations, investigations and treatments that

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can be managed in primary care. It then moves on into specialist services, again mirroring the presentation, investigations and treatments that are delivered from specialist services. Finally, there is a section on tertiary care where there are highly complex needs for patients because, as I am sure you are aware from reading the Report, rheumatoid arthritis can sometimes be a disease of the whole body involving the kidneys, the eye and other organs. Some patients can be highly complex and require a very, very skilled degree of clinical input. The pathway describes the whole possibility of what patients with inflammatory arthritis may need and actually encourages clinicians and commissioners to work together to look at redesigning services locally.

**Q57 Keith Hill:** I am sure it is absolutely the right way forward. Presumably the reason why you, others and the DoH have developed it is because actually the reality falls far short of that at the moment because there does seem to be a good deal of evidence that primary care trusts, for example, do not seem to have good information on the extent and costs of rheumatoid arthritis in their local populations. They seem to provide somewhat limited services on the whole and equally GP practices also seem to be deficient in commissioning rheumatoid arthritis services. Is that a kind of reality that you would recognise?

**Dr Nye:** I think the effect of NICE guidance, the National Audit Office Report, the Inflammatory Arthritis Pathway is that they are a force for good. They are a force to make local health communities look at the services they are delivering and ask themselves questions on where they can improve. I think it is definitely a force for change for the better.

**Q58 Keith Hill:** Would you be surprised to learn that some clinicians report that they have no direct communication with commissioning organisations as a result of which the complexity of the disease is simply not recognised?

**Dr Nye:** Speaking personally, in Oldham where I work I have a fantastic relationship with our commissioners. Aside from my role as a GP, I also run one of these early arthritis services covering rheumatology, orthopaedics and chronic pain. We have an excellent relationship with our commissioner. I think it is possible as a clinician to foster and develop good relations with your commissioner. I think the pathways encourage you to sit down and discuss problems together rather than again acting in silos.

**Q59 Keith Hill:** Lancashire seems to be rather good at this sort of thing because the Members of the Committee have received a rather impressive document about the rheumatology unit in Bolton. Lancashire is obviously a bit of a pace setter in this regard. Is it happening elsewhere?

**Mr Nicholson:** It is not happening elsewhere in quite the way we would want everywhere. I am sure Gary will talk a little bit about commissioning generally. In a sense, that is why the pathway is so important. That is why the NICE guidance is so important.

That is why the NICE commissioning guidance coming out at the end of this year will be so important because there we are setting a kind of national benchmark, in a sense, for commissioners about what we expect in the future.

**Mr Belfield:** In preparing for this, I looked around the country to see what PCTs were beginning to do because there is a degree of criticism in this Report. I think it is fair to say that last year we asked PCTs to do a needs assessment of their population about the things that were really affecting health. They chose things like stroke, cancer, heart disease, etc. to focus on in terms of their commissioning decisions, but we are seeing this year—certainly in the last six months—an increasing look with PCTs thinking about long term conditions. Just in the last month or so, I have heard of three PCTs that are actually changing their services for arthritis in terms of self-care education, for example in Norfolk and Portsmouth. Tameside and Glossop have a consultant led rheumatology service going into the community. If this Committee were to ask again, say, in 12 months' time, I think you would see a very different picture with PCTs beginning to reflect much more about long term conditions in their commissioning strategies.

**Q60 Keith Hill:** That is also encouraging. Is it the case that this kind of holistic approach is expensive and need it be expensive?

**Mr Belfield:** No, I do not think that it should be expensive. If you get this right first time, as the Report says, and you help identify the need early enough, then in the longer term it saves money. Certainly the Department of Health has a very strong view that quality should not cost because getting it right first time should save taxpayers' money.

**Q61 Keith Hill:** It sounds like a propitious development, Mr Nicholson. Is this something you are going to put your back into?

**Mr Nicholson:** Absolutely. Gary is absolutely right. This is not an issue about huge amounts of extra resource. This is about organisation, management, planning and execution.

**Q62 Keith Hill:** Smart solutions, in other words?

**Mr Nicholson:** Yes. It is all of those things. That is why it is so important we set national benchmarks and set out our expectations.

**Q63 Keith Hill:** This I think is one for Mr Nicholson: do you recognise the risk that the focus on getting the newly identified rheumatoid arthritis patients through the system can lead to slower or indeed deficient treatment of existing patients?

**Mr Nicholson:** No, I do not see the connection at all. We have grown capacity significantly in the NHS over the last few years. As you have heard me talk about on numerous occasions, before we had the capacity to deal with this, it is for relatively small numbers of patients.

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**Q64 Keith Hill:** It is mentioned for example in the DVD that patients already in the system seem to perceive they have problems in accessing the services they are looking for because of the concentration of units on meeting the 18 weeks target. That is not something that you recognise?

**Mr Nicholson:** No, I do not think so. To be honest, with the 18 week pathway and the way it is designed, we would not expect that to be one or the other.

**Q65 Keith Hill:** Could I ask the NAO to come in on this point?

**Ms Taylor:** If you look at paragraphs 4.6 and 4.7 and also to an extent 4.10, some of the evidence we collected is that people are having problems when they have a flare up or in continuing to get treatment after the initial diagnosis. There are a number of examples given there that were reported to us by both the acute trusts and through our patient survey.

**Professor Colin-Thomé:** The figure you have given for rheumatology is that about a fifth of the cases are for rheumatoid arthritis. If we could get, as we have in some places, primary and community services working with our hospitals, some of the repetitious work for people who are not having flare ups could be done quite well in primary care. Certainly in my practice—and I know in Alan's—we used to have a rheumatoid arthritis nurse working with us for the general reviews of patients once significant symptoms had settled. Working with our physiotherapy colleagues, we could obviate the need for a lot of referrals to orthopaedics or rheumatology because we needed an opinion about better care. One of the issues for us, which practice commissioners will have to major on, is how do we get that better system. A lot of the reason we have expense in our health care system is because of duplication. You find that a lot of patients are seeing the specialist when they are not acute and also seeing their GP and so on. That is the area where we could make a significant improvement in quality, release our consultants for more time for flare ups and acute care and yet still look after patients in a systematic way. I think that is the real test for us where there are examples already happening, but not widespread enough yet.

**Mr Nicholson:** I hear these comments about choose and book, which is the issue that is raised. I do not believe that these are reasons why we cannot organise the services better than we do. It is, at the end of the day, a mechanism for planning capacity and there is no short cut for PCTs and acute trusts planning their capacity properly. Choose and book makes you do things in a much more transparent way which I think is a good thing and I do not believe that choose and book is the reason why people are having problems with that service; I think we need better organisation.

**Q66 Angela Browning:** We have read that the average age for this condition to start is about 40, or people in their 40s; it is not necessarily a condition of old age. It seems to me increasingly that where people have developed it in their 40s or 50s—I have a certain personal interest, not that I have rheumatoid

arthritis—and where people present with chronic conditions, they get specialist treatment up to a point and then they pass a certain age barrier and they suddenly become the responsibility of geriatricians. I wanted your assurance that in a case like this, for rheumatoid arthritis, that people who are, say, over 65 or over 70, would continue to get the specialism from the consultants and not from a generalist?

**Professor Colin-Thomé:** The answer is yes, and in fact a key responsibility lies with the general practitioner deciding, once they are referred, who is the most appropriate. If you are a care-of-the-elderly specialist it is more to do with the organisation of care for people with lots of chronic problems, but for specific things like diabetes and so on they will need to see a specialist, and that generally happens. If there was a rule to say otherwise, I think you would find a lot of people like Alan and I would say that this was a nonsense and challenge it quite strongly. The answer is, you have to find the specialist who is most appropriate for the presenting problem, and to say you have to go off to a different system is not right. As Alan says, this report and the NICE guidance will reinforce that even more strongly.

**Mr Nicholson:** There should be no age cut-off, either implicitly or explicitly for rheumatoid arthritis.

**Angela Browning:** That is very encouraging, thank you.

**Q67 Chairman:** We have had a very helpful submission from the National Rheumatoid Arthritis Society and they have submitted an analysis to the Committee highlighting the difference in spending on rheumatoid arthritis between PCTs—£5.68 per head in Bexley and £17.58 in Gateshead; the English average is £10.97. What is going on? Are they just diagnosing it much better in Bexley and need to spend less, or are they just being mean in Bexley? What is happening?

**Mr Nicholson:** I think there is a whole set of issues. People are collecting the information and sharing it and looking at it for the first time, and you may find in those circumstances that people are collecting it and showing it in different ways.

**Q68 Chairman:** We need to get to the bottom of this, this is very important.

**Mr Nicholson:** I agree. That is one of the issues. The other issue is that the populations are different as well, in terms of the age structure of the population. What we have not done is connected those two things together.

**Q69 Chairman:** It is hard to think that there is such a difference in the age structure in Bexley and Gateshead. There is something else going on here, I suspect. The Society is unable, they tell us, "... to conduct an assessment to ascertain whether there is any correlation between levels of spending and service quality since the findings of the NAO's survey of the quality of acute care are anonymised. The Public Accounts Committee may wish to

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consider investigating this directly, or asking the Department of Health to do so.” I am now asking you to do so.

**Mr Nicholson:** We would be happy to investigate because it raises a whole series of issues.

**Q70 Chairman:** We do not want a postcode lottery here, do we?

**Mr Nicholson:** No.

**Q71 Chairman:** You mention Dame Carol Black, who is mentioned right at the back of the Report. Do you think she would be satisfied with progress if she were here?

**Mr Nicholson:** No.

**Professor Colin-Thomé:** No. Whenever you write a report, and we have all written our reports, you are frustrated by the pace of progress, and I think that is an issue. In answer to your previous point, of course Carol’s work straddled both the DWP and the Department of Health, to try and get more coherent working together, but in terms of the programme I think she would have expected more to have happened. We are putting a lot of store on these fit-for-work pilots, because that is a more comprehensive look at it, not just whether GPs have fit notes but getting more occupational health people working at earlier interventions and so on and so forth to see if that is possible. But the answer is, whenever any of us write a report, we are always frustrated by the pace of progress.

**Q72 Chairman:** That is a very honest answer. Thank you for that. I think that concludes our hearing, gentlemen, thank you very much. I think it has been

an important and interesting hearing. As I often say on these occasions, we are very proud of the fact on this Committee that we have managed to put a spotlight on certain conditions, such as hospital-acquired infections, dementia, stroke, over the years, and we are very grateful to Karen Taylor for all the wonderful work she does for this Committee in the field of health. She has done a lot of work over the years to bring these subjects forward. So we are very grateful to you, Karen. May I just say that although we were told that a GP may only see one case a year, this is still an enormous problem. There are, we are told, an estimated 580,000 adults in England who have rheumatoid arthritis, and there are 26,000 new diagnoses each year. It costs the NHS £560 million a year in health care costs but the cost to the economy is £1.8 billion a year. What is even more worrying is that three-quarters of people with rheumatoid arthritis are first diagnosed when of working age. Women are more than twice as likely as men to have the disease, and one third of people will have stopped working within two years of being diagnosed with rheumatoid arthritis. So I am sure you would agree, Mr Nicholson, this is a very serious problem indeed. It is extremely worrying that the public awareness of the disease is so very low. Before I got involved in this, my own personal awareness of this disease, I have to accept, was very low indeed. We need to ensure that diagnosis comes much quicker because it is undoubtedly true from what we have heard today that if you are diagnosed quickly you can arrest this disease. We expect to have a very helpful but hard-hitting report, Mr Nicholson, to encourage your efforts in this field.

**Mr Nicholson:** Thank you.

**Chairman:** Thank you.

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## 1. Memorandum from Abbott UK

### EXECUTIVE SUMMARY

Abbott welcomed the NAO report on Services for people with Rheumatoid Arthritis and believes that it is vital to undertake value-for-money analyses to examine the cost of ill-health to the Treasury as a whole rather than to individual government departments. The report contained a number of powerful recommendations: especially on the cost-effectiveness of earlier treatment; the creation of more Early Arthritis Clinics; and the use of multidisciplinary teams to support people remain in or return to work.

We were concerned by the NAO’s findings that there continues to be a lack of integration between primary and secondary care, and agree with other organisations that the Government should appoint a National Clinical Director for musculoskeletal disorders (MSDs) to provide enhanced strategic direction and oversight. At the same time, the 2010–11 NHS Operating Framework needs to prioritise rheumatology and MSD services due to their significant impact on incapacity benefit.

### ABOUT ABBOTT

1. Abbott is a global, broad-based health care company devoted to the discovery, development, manufacture and marketing of pharmaceuticals and medical products, including nutritionals, devices and diagnostics. The company employs more than 72,000 people and markets its products in more than 130 countries.

2. While Abbott’s expertise lies in the health sector, we have been particularly active over the past few years in supporting research into the relationship between health and work. We have sought to address key policy questions such as how to build a more “work-focused” NHS and ensure that patients’ health needs are well supported in the workplace.

3. Abbott's particular interest is in the field of MSDs such as rheumatoid arthritis (RA) and ankylosing spondylitis (AS). MSDs are one of the most common causes of work-limiting health problems and long-standing illness, and the second biggest cause of sickness absence.<sup>1</sup> In 2007 Abbott supported a Work Foundation study into the effect of MSDs on labour market participation—a project which is now being rolled-out across Europe.<sup>2</sup>

#### THE NAO REPORT

4. Abbott welcomed the National Audit Office report on *Services for people with Rheumatoid Arthritis*. Given the current financial climate and pressure on public spending, it is vital to undertake value-for-money analyses to examine the cost of ill-health to the Treasury as a whole rather than to individual government departments.

5. We welcomed the NAO's recommendation that treatment of RA should be started as early as possible, ideally within three months, and that initial cost increases to the NHS due to higher expenditure on drugs and associated costs would be offset by productivity gains of £31 million for the economy due to reduced sick leave and unemployment. The report noted that at present only 10% of patients with RA are treated within three months of symptom onset.<sup>3</sup>

6. As such, we strongly support the creation of more Early Arthritis Clinics (EAC), given that NAO modelling showed that the wider adoption of an EAC approach could result in an initial cost saving to primary care of about £3 million, with annual efficiency savings for the NHS of about £2 million. It should be noted that the NAO model did not account for the initial investment that might be needed for an EAC approach to be more widely established because its analysis of spending on RA patients by acute trusts with and without an EAC showed "no significant difference" in spending.<sup>4</sup>

7. We were concerned by the NAO's findings that there continues to be a lack of integration between primary and secondary care and little incentive for changing the way services are currently configured.<sup>5</sup> This follows a 2009 report by the Arthritis and Musculoskeletal Alliance (ARMA) which highlighted poor implementation of the Government's 2006 Musculoskeletal Services Framework,<sup>6</sup> and a King's Fund report in 2009 which found that "patients and professionals perceive an unacceptably wide variation in the level and quality of care currently available".<sup>7</sup>

8. Abbott endorses the recommendation that Primary Care Trusts should work with providers to ensure that all people with RA are offered a personalised care plan which should support them to remain in or return to work. We also support the recommendation that PCTs need to assess the number of people with RA in their population, and identify what specialist and multidisciplinary services they need.<sup>8</sup> An example of such a multidisciplinary service can be found at the Department of Rheumatology in Bolton, which aims to break down the boundaries between primary and secondary care settings and whose staff includes consultants, advanced rheumatology practitioners, physiotherapists, an occupational therapist, and counsellors. An article outlining the Bolton case study has been included with this submission.

9. Following Dame Carol Black's review of the health of the working age population, we encourage the swift implementation of "Fit Notes" to prompt GPs to take action which will directly support a patient's return to work, such as urgent referrals to a specialist rheumatologist, physiotherapist or occupational therapist. The NAO report recommends that the Department of Health and the Royal Colleges should cover RA in the ongoing continuing professional development of primary healthcare professionals, requiring the early referral of suspected cases and using tools such as the 18-week commissioning pathway for inflammatory arthritis.<sup>9</sup> The Government should now ensure that the pathway is implemented as quickly as possible so that all RA patients can be treated within three months.

10. Whilst we agree with the NAO's recommendation that there should be clearer links between NHS and Jobcentre Plus services, we believe that employment services should be a "one-stop shop", which include routine liaison with healthcare professionals, fast-track referral to occupational therapy services and employer "check-lists" to ensure employers are prepared to make reasonable adjustments where appropriate.

<sup>1</sup> Health and Safety Executive, Health and Safety Statistics 2007–08, p 6, p 23  
<http://www.hse.gov.uk/statistics/overall/hssh0708.pdf>

<sup>2</sup> The Work Foundation, Fit for Work Europe—<http://www.fitforworkeurope.eu/>

<sup>3</sup> National Audit Office, Services for people with rheumatoid arthritis, 2009, p 5  
<http://www.nao.org.uk/idoc.ashx?docId=3884f599-9c81-4976-aa4b-4ebbbf2dba3&version=-1>

<sup>4</sup> National Audit Office, Services for people with rheumatoid arthritis: Economic models of identification and treatment of early rheumatoid arthritis, 2009, p 16–17  
<http://www.nao.org.uk/idoc.ashx?docId=a5368598-d965-40f8-9ce6-0f9cfdc7b046&version=-1>

<sup>5</sup> National Audit Office, Services for people with rheumatoid arthritis, 2009, p 10.

<sup>6</sup> Arthritis and Musculoskeletal Alliance, Joint working? An audit of the implementation of the Department of Health's musculoskeletal services framework, 2009, p 3—[http://www.arma.uk.net/pdfs/MSF%20Review\\_FINAL1.pdf](http://www.arma.uk.net/pdfs/MSF%20Review_FINAL1.pdf)

<sup>7</sup> King's Fund, Perceptions of patients and professionals on rheumatoid arthritis care, 2009, p 24  
[http://www.rheumatoid.org.uk/download.php?asset\\_id=615](http://www.rheumatoid.org.uk/download.php?asset_id=615)

<sup>8</sup> National Audit Office, Services for people with rheumatoid arthritis, July 2009, p 10.

<sup>9</sup> National Audit Office, Services for people with rheumatoid arthritis, 2009, p 9.

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## NEXT STEPS

11. The NAO report found that 86 per cent of acute trusts are able to prescribe biologic medicines to all patients in accordance with National Institute for Health and Clinical Excellence (NICE) technology appraisal guidance. However, whilst the Department of Health's 2006 Musculoskeletal Services Framework acknowledges that year-on-year costs of prescribing "TNF alpha inhibitors" are likely to be offset by keeping patients with RA at work,<sup>10</sup> NICE is not yet tasked with considering the wider impact of its guidance on employment—a recommendation of the Health Select Committee in 2007.<sup>11</sup> In July of this year, a review by Professor Sir Ian Kennedy into this issue also called for more research to be carried out into how NICE might incorporate societal and employment costs into its appraisals.<sup>12</sup>

12. The Department of Work and Pensions has committed itself to reducing the flow of people out of work due to ill-health,<sup>13</sup> however the current NHS Operating Framework is noticeable for the lack of priority given to tackling MSDs.<sup>14</sup> The 2010–11 NHS Operating Framework needs to prioritise rheumatology and MSD services due to their significant impact on incapacity benefit—one of the key drivers of public spending. The new NHS Indicators for Quality Improvement should also include greater emphasis on the treatment of MSDs—especially on facilitating earlier intervention in order to increase productivity, in line with the findings of the NAO report.

13. The Government should appoint a "clinical champion", or National Clinical Director for MSDs to provide enhanced strategic direction and oversight—a call endorsed by a recent House of Commons EDM.<sup>15</sup> This would follow a recent move to appoint a National Clinical Director to lead the development of a National Strategy for Liver Disease, as announced by the Department of Health in October 2009.<sup>16</sup> A similar National Clinical Director for MSDs could coordinate the pilot of "Into-work" sessions across the country, with the aim of bringing together local NHS workforce development leads, commissioners and health professionals to discuss service re-design to more effectively and efficiently help people with MSDs such as RA remain in or return to work.

14. In order to help realise the potential savings to the Treasury as highlighted in the NAO report, the Department of Health should introduce new measures that include work as a clinical outcome for patients and which are considered when evaluating a PCT's performance. This could be supported by appropriate materials such as a Department of Health care pathway and the anticipated NICE commissioning toolkit on RA, due later this year.

*November 2009*

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## 2. Memorandum from Arthritis and Musculoskeletal Alliance (ARMA)

The Arthritis and Musculoskeletal Alliance (ARMA)—the umbrella organisation for the musculoskeletal community—welcomes the Public Accounts Committee's investigation into services for people with rheumatoid arthritis (RA).

The National Audit Office (NAO) report highlights a number of limitations in current services for people with RA and identifies range of improvements that could be implemented to improve both the efficacy and cost effectiveness of care for people with RA. These include complex solutions aimed at better delivery of care in appropriate settings (eg in primary care where possible and secondary care where necessary), and better integration of health and social care services

These limitations in the planning and delivery of RA services are not however peculiar to RA alone and ARMA, along with its 34 member organisations believes that the inefficiencies uncovered by the NAO are representative of musculoskeletal services as a whole. We contend that the current situation is the consequence of a lack of direction and a poor prioritisation of musculoskeletal conditions at the national level. We believe that the Department of Health could readily address this lack of national direction and ensure that all musculoskeletal services, including those for people with RA, are organised more effectively and efficiently for the benefit of patients.

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<sup>10</sup> Department of Health, The Musculoskeletal Services Framework, 2006, p 36

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4138412.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4138412.pdf)

<sup>11</sup> House of Commons Health Committee, National Institute for Health and Clinical Excellence, First Report of Session 2007–08, volume 1, 2007, p 6—<http://www.publications.parliament.uk/pa/cm200708/cmselect/cmhealth/27/27.pdf>

<sup>12</sup> Kennedy I, Appraising the Value of Innovation and Other Benefits. A Short Study for NICE, 2009, p 6  
<http://www.nice.org.uk/media/98F/5C/KennedyStudyFinalReport.pdf>

<sup>13</sup> Department for Work and Pensions, DWP: Three Year Business Plan 2009–2012, 2009, p 24  
<http://www.dwp.gov.uk/docs/three-year-plan-2009.pdf>

<sup>14</sup> Department of Health, The NHS in England: The operating framework for 2009–10, 2008

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_091446.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_091446.pdf)

<sup>15</sup> House of Commons, Early Day Motion 1930, tabled on 20 July 2009

<http://edmi.parliament.uk/EDMi/EDMDetails.aspx?EDMID=39156&SESSION=899>

<sup>16</sup> Department of Health—[http://www.dh.gov.uk/en/News/Recentstories/DH\\_107304](http://www.dh.gov.uk/en/News/Recentstories/DH_107304)

ARMA has uncovered a large body of evidence to suggest that musculoskeletal conditions are being delivered without effective planning. Earlier in 2009, for example, ARMA audited every single Primary Care Trust (PCT) in England to ascertain its progress in implementing the Department of Health's musculoskeletal services framework (MSF) of July 2006. The complete findings of our audit are contained in our report, *Joint working*<sup>17</sup>. Key findings from the audit include:

1. More than one in five (21%) PCTs do not operate a Clinical Assessment and Treatment Service (CATS) for musculoskeletal conditions, despite this being described as the “keystone” of the Government's policy in this area. There is a huge degree of confusion within the NHS over the best location, purpose and staffing arrangements of CATS.
2. Only 16% of responding PCTs had mapped their current resources and their use by people with musculoskeletal conditions.
3. Patients are still experiencing delays in obtaining an accurate diagnosis of a long-term musculoskeletal condition. One cause of this—a lack of awareness amongst GPs—is being exacerbated because less than half (43%) of PCTs offer education to GPs on how to manage patients with inflammatory arthritis.
4. 40% of PCTs do not work with voluntary and community organisations expert in the delivery of care to patients with musculoskeletal conditions.
5. Over half (57%) of PCTs have not made links with their local Pathways to Work scheme.
6. A review of the provision of NHS and social care rehabilitation services initiated by the Department of Health in 2006 is yet to be completed.
7. 60% of PCTs have not audited the outcomes of patients with musculoskeletal conditions. Of those that had, a variety of outcome indicators are used. The lack of nationally validated outcome measures is cited by a number of PCTs as a reason for not doing so.

ARMA has also uncovered evidence of widespread variations in the amount of funding provided to each person with a musculoskeletal condition, ranging from £204 per patient in Camden PCT to £632 per patient in Gateshead PCT. This analysis is at Annex.

In order to address the varied implementation of the Musculoskeletal Services Framework and the unjustifiable variations in spending between different PCT areas, ARMA is calling on the Government to appoint a National Clinical Director for Musculoskeletal services. More than 10 million people in the UK are living with musculoskeletal disorders and more than 10.8 million working days are lost as a direct consequence of these conditions. With an ageing population and increasing levels of obesity these figures will continue to rise. The appointment of a National Clinical Director would provide for the first time, clear leadership for musculoskeletal services, a line of communication between the musculoskeletal community and government and a mechanism for developing a coherent strategy to maintain the musculoskeletal health of the UK population as effectively and efficiently as possible.

We would be happy to discuss our work further with you if this would be of assistance.

## Annex

### ANALYSIS OF MUSCULOSKELETAL PROGRAMME EXPENDITURE

#### 1. BACKGROUND

The Department of Health published its programme budgeting data—which lists the expenditure on a range of different programme areas, including “problems of the musculoskeletal system”—on 16 July 2009.<sup>18</sup>

#### 2. ANALYSIS

- To assist policymakers in understanding how this expenditure breaks down at the Primary Care Trust (PCT) level, ARMA conducted an analysis of programme budgeting data to ascertain the average spend on a person living with a musculoskeletal condition in each area of the country, shown in the table below.

<sup>17</sup> [http://arma.uk.net/pdfs/MSF%20Review\\_FINAL1.pdf](http://arma.uk.net/pdfs/MSF%20Review_FINAL1.pdf)

<sup>18</sup> Department of Health, *Programme budgeting data*, 16 July 2009; available here: [http://www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/Programmebudgeting/DH\\_075743?IdcService=GET\\_FILE&dID=200999&Rendition=Web](http://www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/Programmebudgeting/DH_075743?IdcService=GET_FILE&dID=200999&Rendition=Web)

— The methodology used in the analysis is set out beneath the table.

— As the table shows, there is a huge variation in spending on musculoskeletal services: in 2007–08 for example, this stretched from £204 per patient per year in Camden PCT to £632 in Gateshead PCT.

<i>PRIMARY CARE TRUST</i>	<i>Total number of children (A)</i>	<i>Total number of adults (B)</i>	<i>Estimated number of children with musculoskeletal conditions (C)</i>	<i>Estimated number of adults with musculoskeletal conditions (D)</i>	<i>Expenditure on musculoskeletal conditions in 2007–08 (£000s) (E)</i>	<i>Estimated expenditure on musculoskeletal conditions per person with a musculoskeletal condition in 2007–08 (F)</i>
Camden PCT	44,410	188,066	43	47,017	£9,596	£204
Bexley Care Trust	54,012	156,834	53	39,208	£8,268	£211
Ealing PCT	75,638	244,609	74	61,152	£14,614	£239
Hammersmith and Fulham PCT	34,004	135,992	33	33,998	£8,409	£247
Westminster PCT	39,522	194,978	39	48,745	£12,072	£247
Hounslow PCT	54,036	166,803	53	41,701	£10,367	£248
Luton PCT	51,588	133,456	50	33,364	£8,311	£249
Brent Teaching PCT	65,457	214,374	64	53,593	£13,354	£249
Richmond and Twickenham PCT	40,899	132,068	40	33,017	£8,385	£254
City and Hackney Teaching PCT	58,525	161,954	57	40,488	£10,523	£260
Wandsworth PCT	52,942	227,203	52	56,801	£14,873	£262
Kensington and Chelsea PCT	36,141	154,373	35	38,593	£10,187	£264
South West Essex PCT	101,940	295,424	99	73,856	£19,575	£265
Redbridge PCT	64,247	175,730	63	43,933	£11,764	£267
Barking and Dagenham PCT	49,017	116,207	48	29,052	£7,867	£270
South East Essex PCT	79,381	253,967	77	63,492	£17,948	£282
Mid Essex PCT	87,171	269,110	85	67,278	£19,364	£287
Solihull Care Trust	51,871	154,681	51	38,670	£11,131	£287
Islington PCT	38,148	149,127	37	37,282	£11,079	£297
Bradford and Airedale PCT	140,136	357,499	137	89,375	£26,670	£298
Bedfordshire PCT	103,260	308,456	101	77,114	£23,096	£299
Wakefield District PCT	80,666	252,520	79	63,130	£19,045	£301
Leicester City PCT	81,833	226,866	80	56,716	£17,147	£302
West Hertfordshire PCT	135,910	400,480	132	100,120	£30,332	£303
Blackpool PCT	33,081	107,023	32	26,756	£8,173	£305
Suffolk PCT	135,856	452,116	132	113,029	£34,858	£308
Kirklees PCT	102,684	289,285	100	72,321	£22,372	£309
Berkshire East PCT	101,012	283,213	98	70,803	£22,056	£311
Leeds PCT	179,500	587,581	175	146,895	£45,813	£312
Calderdale PCT	50,651	149,770	49	37,443	£11,877	£317
Portsmouth City Teaching PCT	46,485	153,037	45	38,259	£12,231	£319
Telford and Wrekin PCT	42,760	118,150	42	29,537	£9,516	£322
Southwark PCT	57,921	200,324	56	50,081	£16,413	£327
Croydon PCT	87,459	247,683	85	61,921	£20,313	£328
Kingston PCT	40,098	131,915	39	32,979	£10,842	£328
East and North Hertfordshire PCT	137,526	412,267	134	103,067	£34,163	£331
East Riding Of Yorkshire PCT	68,583	235,713	67	58,928	£19,703	£334
Cambridgeshire PCT	136,171	440,903	133	110,226	£36,949	£335
Buckinghamshire PCT	128,080	368,542	125	92,136	£30,897	£335
Havering PCT	57,703	179,509	56	44,877	£15,276	£340
North Tyneside PCT	46,617	157,468	45	39,367	£13,504	£343
Hull PCT	68,040	212,004	66	53,001	£18,187	£343
Lambeth PCT	62,453	227,294	61	56,823	£19,502	£343
Doncaster PCT	72,908	220,235	71	55,059	£19,016	£345
Medway PCT	69,943	195,264	68	48,816	£16,975	£347
Manchester PCT	117,442	368,069	114	92,017	£32,085	£348
West Kent PCT	167,408	494,842	163	123,711	£43,203	£349
Liverpool PCT	104,838	339,150	102	84,787	£29,696	£350
North Lincolnshire PCT	38,070	120,189	37	30,047	£10,542	£350
County Durham PCT	118,272	391,219	115	97,805	£34,556	£353
Sheffield PCT	124,779	409,472	122	102,368	£36,525	£356
Darlington PCT	24,101	74,102	23	18,526	£6,631	£357
Greenwich Teaching PCT	60,090	170,372	59	42,593	£15,423	£362
Hampshire PCT	302,211	933,699	294	233,425	£85,266	£365
Enfield PCT	70,511	197,358	69	49,340	£18,076	£366
Derbyshire County PCT	161,760	530,936	158	132,734	£48,630	£366
Bristol PCT	94,019	334,105	92	83,526	£30,762	£368
Worcestershire PCT	128,557	416,820	125	104,205	£38,780	£372
Stoke On Trent PCT	62,671	195,446	61	48,862	£18,211	£372
Berkshire West PCT	114,311	340,790	111	85,198	£31,766	£372
South Staffordshire PCT	140,521	442,536	137	110,634	£41,309	£373
Torbay Care Trust	30,433	108,688	30	27,172	£10,211	£375
North Yorkshire and York PCT	175,861	591,483	171	147,871	£55,919	£378
West Essex PCT	65,556	196,100	64	49,025	£18,563	£378
North East Essex PCT	71,601	246,371	70	61,593	£23,355	£379
Sutton and Merton PCT	89,103	288,551	87	72,138	£27,511	£381
Great Yarmouth and Waveney PCT	50,292	170,382	49	42,595	£16,281	£382
Harrow PCT	49,719	148,786	48	37,196	£14,239	£382
Cornwall and Isles Of Scilly PCT	117,731	408,211	115	102,053	£39,395	£386

<i>PRIMARY CARE TRUST</i>	<i>Total number of children (A)</i>	<i>Total number of adults (B)</i>	<i>Estimated number of children with musculoskeletal conditions (C)</i>	<i>Estimated number of adults with musculoskeletal conditions (D)</i>	<i>Expenditure on musculoskeletal conditions 2007-08 (£000s) (E)</i>	<i>Estimated expenditure on musculoskeletal conditions per person with a musculoskeletal condition in 2007-08 (F)</i>
South Birmingham PCT	84,749	262,265	83	65,566	£25,331	£386
Rotherham PCT	60,677	183,211	59	45,803	£17,781	£388
Haringey Teaching PCT	57,328	183,075	56	45,769	£17,792	£388
Lewisham PCT	62,026	195,393	60	48,848	£18,996	£388
North East Lincolnshire Care Trust	41,888	121,663	41	30,416	£11,853	£389
Bromley PCT	74,592	228,912	73	57,228	£22,622	£395
Bournemouth and Poole PCT	70,168	251,067	68	62,767	£24,842	£395
Brighton and Hove City PCT	55,069	204,031	54	51,008	£20,263	£397
Tower Hamlets PCT	54,244	160,279	53	40,070	£16,073	£401
Nottingham City PCT	71,815	233,419	70	58,355	£23,709	£406
Isle of Wight NHS PCT	30,339	107,646	30	26,911	£10,947	£406
Northamptonshire PCT	166,990	493,518	163	123,379	£50,287	£407
Herefordshire PCT	39,811	134,967	39	33,742	£13,871	£411
North Staffordshire PCT	45,661	158,440	44	39,610	£16,342	£412
West Sussex PCT	180,823	593,033	176	148,258	£61,650	£415
Northumberland Care Trust	69,707	241,567	68	60,392	£25,165	£416
Wiltshire PCT	111,322	323,599	108	80,900	£33,732	£416
Bury PCT	47,120	134,996	46	33,749	£14,086	£417
Bassetlaw PCT	25,325	81,269	25	20,317	£8,517	£419
Warwickshire PCT	122,285	393,872	119	98,468	£41,377	£420
Barnet PCT	82,990	248,481	81	62,120	£26,126	£420
South Gloucestershire PCT	60,075	182,100	59	45,525	£19,257	£422
Leicestershire County and Rutland PCT	155,950	489,329	152	122,332	£51,892	£424
Gloucestershire PCT	138,784	440,314	135	110,079	£47,058	£427
East Lancashire PCT	98,287	275,232	96	68,808	£29,537	£429
Sandwell PCT	77,826	223,571	76	55,893	£24,054	£430
Norfolk PCT	155,748	567,890	152	141,972	£61,094	£430
Coventry Teaching PCT	81,824	240,947	80	60,237	£25,972	£431
Peterborough PCT	39,922	109,681	39	27,420	£11,884	£433
Lincolnshire PCT	161,373	537,262	157	134,316	£58,350	£434
Warrington PCT	47,953	144,825	47	36,206	£15,740	£434
Dudley PCT	72,860	228,437	71	57,109	£24,837	£434
Oxfordshire PCT	150,241	462,582	146	115,646	£50,412	£435
Walsall Teaching PCT	66,432	183,324	65	45,831	£20,099	£438
Shropshire County PCT	66,857	218,301	65	54,575	£24,050	£440
Surrey PCT	260,289	812,099	254	203,025	£90,124	£443
Heywood, Middleton and Rochdale PCT	55,164	148,799	54	37,200	£16,539	£444
Waltham Forest PCT	59,804	168,447	58	42,112	£18,725	£444
Dorset PCT	86,693	295,573	84	73,893	£32,906	£445
Halton and St Helens PCT	76,448	227,746	74	56,937	£25,512	£447
Swindon PCT	48,133	144,408	47	36,102	£16,195	£448
Birmingham East and North PCT	112,211	285,975	109	71,494	£32,196	£450
South Tyneside PCT	35,336	115,621	34	28,905	£13,037	£450
Central and Eastern Cheshire PCT	106,210	339,577	103	84,894	£38,943	£458
Hillingdon PCT	62,825	177,466	61	44,366	£20,365	£458
Trafford PCT	51,969	158,735	51	39,684	£18,223	£459
Wolverhampton City PCT	59,391	178,144	58	44,536	£20,463	£459
Devon PCT	161,852	570,349	158	142,587	£66,378	£465
Newcastle PCT	59,510	201,351	58	50,338	£23,711	£470
Tameside and Glossop PCT	57,270	167,989	56	41,997	£19,835	£472
North Tees PCT	47,695	140,827	46	35,207	£16,689	£473
Stockport PCT	68,393	213,095	67	53,274	£25,502	£478
Middlesbrough PCT	37,451	106,654	36	26,664	£12,781	£479
Bolton PCT	69,242	193,287	67	48,322	£23,404	£484
Derby City PCT	67,443	203,580	66	50,895	£24,729	£485
Cumbria PCT	113,340	388,763	110	97,191	£48,141	£495
Sefton PCT	64,598	206,041	63	51,510	£25,640	£497
North Somerset PCT	46,272	155,539	45	38,885	£19,373	£498
Sunderland Teaching PCT	64,335	209,655	63	52,414	£26,183	£499
North Lancashire PCT	72,655	253,686	71	63,421	£31,912	£503
Eastern and Coastal Kent PCT	176,343	539,556	172	134,889	£68,302	£506
Blackburn with Darwen PCT	45,260	105,927	44	26,482	£13,512	£509
Hartlepool PCT	23,477	67,655	23	16,914	£8,662	£511
Western Cheshire PCT	56,978	188,711	56	47,178	£24,205	£512
Nottinghamshire County PCT	149,704	489,231	146	122,308	£62,796	£513
East Sussex Downs and Weald PCT	74,852	251,880	73	62,970	£32,783	£520
Newham PCT	74,790	179,714	73	44,928	£23,604	£525
Knowsley PCT	39,563	110,723	39	27,681	£14,653	£529
Central Lancashire PCT	107,119	331,592	104	82,898	£43,959	£530
Heart of Birmingham Teaching PCT	90,215	191,941	88	47,985	£25,502	£530
Salford PCT	53,799	169,062	52	42,266	£22,473	£531
Redcar and Cleveland PCT	32,324	100,489	31	25,122	£13,359	£531
Milton Keynes PCT	62,036	170,412	60	42,603	£23,346	£547
Hastings and Rother PCT	39,076	132,322	38	33,081	£18,137	£548
Bath and North East Somerset PCT	42,632	143,386	42	35,847	£19,883	£554

<i>PRIMARY CARE TRUST</i>	<i>Total number of children (A)</i>	<i>Total number of adults (B)</i>	<i>Estimated number of children with musculoskeletal conditions (C)</i>	<i>Estimated number of adults with musculoskeletal conditions (D)</i>	<i>Expenditure on musculoskeletal conditions in 2007–08 (£000s) (E)</i>	<i>Estimated expenditure on musculoskeletal conditions per person with a musculoskeletal condition in 2007–08 (F)</i>
Plymouth Teaching PCT	59,905	190,392	58	47,598	£26,830	£563
Barnsley PCT	56,325	175,226	55	43,806	£24,698	£563
Ashton, Leigh and Wigan PCT	73,290	228,306	71	57,076	£32,870	£575
Southampton City PCT	54,733	190,878	53	47,720	£27,679	£579
Somerset PCT	122,782	390,326	120	97,582	£56,685	£580
Wirral PCT	76,537	233,284	75	58,321	£34,407	£589
Oldham PCT	61,936	160,426	60	40,107	£23,714	£590
Gateshead PCT	45,005	149,038	44	37,260	£23,570	£632

### 3. METHODOLOGY

The table above was calculated, as follows:

- Columns (A) and (B) are taken from the Department of Health’s estimates of the child and adult populations in each Primary Care Trust area (children are defined as males and females aged 0–19, and adults are defined as males and females aged 20+).<sup>19</sup>
- The estimate of the number of children with musculoskeletal conditions (column C) is derived from:
  - The Department of Health estimates that 12,000 children in England live with a musculoskeletal condition.<sup>20</sup>
  - Given that there are 12,318,410 children in England (NHS Information Centre, *Attribution dataset GP registered populations 2008*, 30 January 2009) this suggests that 0.097% of children in each Primary Care Trust on average live with a musculoskeletal condition.
  - Each value for the number of children in a Primary Care Trust area is multiplied through by 0.00097 to obtain the estimated number of children in each Primary Care Trust area living with a musculoskeletal condition (column C).
- The estimate of the number of adults with musculoskeletal conditions (column D) is derived from:
  - The Department of Health estimates that one in four adults in England live with a musculoskeletal condition.<sup>21</sup>
  - Each value for the number of adults in a Primary Care Trust area is therefore multiplied through by 0.25 to obtain the estimated number of adults in each Primary Care Trust area living with a musculoskeletal condition (column D).
- Expenditure on musculoskeletal conditions in 2007–08 (the latest year for which figures are available) (column E) is taken from the Department of Health’s National Programme Budgeting Project.<sup>22</sup>
- The estimated expenditure on musculoskeletal conditions per person with musculoskeletal conditions (column F) is calculated by dividing the overall spend on musculoskeletal conditions (column E) by the estimated total number of adults and children living with musculoskeletal conditions (columns C and D respectively)

November 2009

### 3. Memorandum from Arthritis Care

Arthritis Care is the UK’s leading organisation working with and for people with arthritis. Our mission is to offer the nine million people with arthritis in the UK the information and support they need to make informed choices about managing their arthritis, to channel their concerns to decision-makers and to seek to ensure that health services genuinely involve and meet the needs of people with arthritis.

<sup>19</sup> NHS Information Centre, *Attribution dataset GP registered populations 2008*, 30 January 2009; available here: <http://www.ic.nhs.uk/webfiles/publications/gpregpopulations2005/GP%20Registered%20Populations%20-%202008.xls>

<sup>20</sup> Department of Health, *A joint responsibility: doing things differently*, 12 July 2006; available here: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4138413?IdcService=GET\\_FILE&dID=11304&Rendition=Web](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4138413?IdcService=GET_FILE&dID=11304&Rendition=Web)

<sup>21</sup> Ibid.

<sup>22</sup> Department of Health, *Programme budgeting data*, 16 July 2009; available here: [http://www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/Programmebudgeting/DH\\_075743?IdcService=GET\\_FILE&dID=200999&Rendition=Web](http://www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/Programmebudgeting/DH_075743?IdcService=GET_FILE&dID=200999&Rendition=Web)

Arthritis Care warmly welcomes the NAO report on services for people with rheumatoid arthritis (RA) and supports its recommendations. Our Chief Executive, Neil Betteridge, has in fact been involved in the production of the report as a member of the report's steering committee.

The evidence presented by the NAO and its assessment of the prevalence of RA, far in excess of previous estimates, demonstrates the urgency for taking action.

#### WHAT PEOPLE WITH RA SAY THEY NEED

The many thousands of people with RA who have approached Arthritis Care for information, support and advice over recent years have expressed to us a series of key, recurring concerns and difficulties which they encounter in seeking assistance for their condition. These are:

- Health services for musculoskeletal conditions are not sufficiently joined-up, and community-based services are scarce;
- GPs are not always familiar with the symptoms of RA and therefore there is a gap before that vital referral onto a specialist for diagnosis and treatment;
- Arthritis is often dismissed as a few aches and pains, meaning that friends, family, colleagues and the public can underestimate its impact on people with RA. It can also mean that people often delay going to see their doctor as they do not recognise the symptoms as something serious; and
- many people with arthritis do not know where they can find information about their condition or about ways in which they can self-manage their condition.

#### WHAT WE ARE CALLING FOR

- The Department of Health should appoint a National Clinical Director for musculoskeletal services to lead on improving the quality of services for people with arthritis across England in line with the NAO recommendations.
- The Quality and Outcomes Framework should include a clear indicator on MSK conditions, arthritis or chronic pain in light of the fact that 30% of a GP's workload is musculoskeletal.
- The Department of Health should run a public health campaign to increase the number of people with symptoms of rheumatoid arthritis presenting early to their GP.

23 November 2009

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## 4. Memoandum from National Rheumatoid Arthritis Society (NRAS)

### INTRODUCTION

The National Rheumatoid Arthritis Society (NRAS) welcomes the recommendations of the National Audit Office report into *Services for people with rheumatoid arthritis*, many of which reflect the concerns raised in the King's Fund Report on behalf of the Rheumatology Futures Group.<sup>23</sup>

We agree with the NAO that action needs to be taken to improve overall outcomes for people with rheumatoid arthritis (RA), in particular by implementing the NICE Clinical Guideline on RA which was published in February 2009,<sup>24</sup> and to promote the commissioning of RA services in line with the IA commissioning pathway which is available on the DH 18 week website.

It is widely recognised that early diagnosis and appropriate treatment can decrease the risk of joint damage thereby maintaining the mobility of people with RA for longer and avoiding costly and unnecessary surgery.

The NAO's own modelling has identified that a person treated within three months rather than four months could see an improvement in quality of life by around 4% over the first five years, as measured by quality adjusted life years (QALY) gained.<sup>25</sup>

NRAS was therefore concerned but not surprised by the NAO's research which shows that delays in the system are contributing to late diagnosis and treatment and poorer outcomes for people with RA. These delays are also contributing to the inefficient use of health services resources and productivity losses for the economy.

We have outlined below our concerns and the recommendations from the NAO report that we believe require urgent attention and that the Public Accounts Committee should address in their inquiry.

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<sup>23</sup> The King's Fund, *A Consultancy Report by The King's Fund for the Rheumatology Future's Group: Perceptions of patients and professionals on rheumatoid arthritis care*, January 2009.

<sup>24</sup> National Institute for Health and Clinical Excellence, *Rheumatoid arthritis: The management of rheumatoid arthritis in adults*, February 2009.

<sup>25</sup> National Audit Office, *Services for people with rheumatoid arthritis*, July 2009, page 25.

## RECOMMENDATIONS

1. *The Department of Health, PCTs and Royal Colleges should improve GP awareness of RA to reduce costly delays in the system*

- GPs are the gatekeepers to specialist diagnosis and treatment yet, as the NAO recognises, people with RA visit a GP on average four times before being referred to a specialist and 18% more than eight times.<sup>26</sup> This is not only causing poor clinical outcomes for people with RA but is also costing the NHS £6 million a year in unnecessary, repeated visits.<sup>27</sup>
- The current management of people of RA, as revealed by the NAO's research, appears to be inconsistent with the Department of Health's policy to move treatment of long-term conditions into primary care rather than reactive acute care. *Supporting People with Long term Conditions* called for a move away from "reactive, unplanned and episodic approach to care" and for people to be treated, "sooner, nearer to home and earlier in the course of the disease."<sup>28</sup> It is however important that the Committee realise that whilst we welcome greater integration of services between primary and specialist care and there are some things which GPs are well placed to undertake such as CV risk assessment and monitoring of RA patients, people with RA will continue to require access to specialist care, as needed, throughout the lifetime of their disease.
- The Public Accounts Committee therefore may want to ask how the Department of Health plans to address poor GP awareness and what discussions officials have had with Royal Colleges regarding the inclusion of rheumatoid arthritis in continued professional education as recommended by the NAO.<sup>29</sup>

2. *The Department of Health should undertake a public awareness campaign on the signs and symptoms of RA to encourage early presentation.*

- Low public awareness is compounding the problem of late diagnosis and treatment for people with RA. As the NAO has identified, between half and three quarters of people with RA delay seeking medical help from their GP for three months or more following the onset of symptoms. A fifth of patients delay seeking help for a year.<sup>30</sup>
- The NAO has identified that this could be addressed by increasing the number of people diagnosed with RA in the first three months from the current 10%:  

*"Our economic modelling suggests increasing this to 20% could initially increase costs to the NHS by £11 million over five years due to higher expenditure on drugs and the associated costs of monitoring people with the disease (after around nine years, earlier treatment could become cost neutral to the NHS). This increase in earlier treatment could, however, result in productivity gains of £31 million for the economy due to reduced sick leave and lost employment."*<sup>31</sup>
- The Public Accounts Committee therefore may want to ask Department of Health officials what assessment the Department has made of the cost-effectiveness of an RA public awareness campaign in light of the NAO's estimate of the productivity savings that could be delivered through earlier diagnosis and treatment of people with RA.<sup>32</sup>

3. *Musculoskeletal services are an inefficient area of health service spending*

- In the last year, NHS expenditure on musculoskeletal conditions increased from £3.5 billion to almost £4.1 billion—an increase of over 15%—even though improvements in outcomes were not delivered by this extra spending.<sup>33</sup>
- One critical factor in the success of national frameworks in other therapeutic areas has been the presence of national clinical leadership to drive change (eg in cancer, diabetes, mental health, and cardiac care). However, there is no such National Clinical Director to drive progress in musculoskeletal services unlike in other areas. Even though liver disease consumes around half the NHS resources currently accounted for by musculoskeletal conditions, the Department of Health announced on 20 October that it was appointing a National Clinical Director for Liver Disease.
- The Public Accounts Committee may wish to consider asking Department of Health officials whether greater clinical leadership at the national level will improve the efficiency of resource spending for RA.

<sup>26</sup> *Ibid* page 5.<sup>27</sup> *Ibid* page 15.<sup>28</sup> Department of Health, *Supporting people with long-term conditions*, January 2005.<sup>29</sup> National Audit Office, *Services for people with rheumatoid arthritis*, July 2009, page 9.<sup>30</sup> *Ibid* page 9.<sup>31</sup> *Ibid* page 9.<sup>32</sup> *Ibid* page 9.<sup>33</sup> Department of Health, *Programme budgeting data 2007–08*, 16 July 2009.

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4. *Delays in referral to specialists should be addressed to improve timely access to appropriate treatment*

- NRAS recognises the importance of early and aggressive treatment for RA which can reduce the need for costly procedures such as joint surgery and maintain mobility for longer. Delays in referral to specialists are preventing people with RA getting access to appropriate treatment early enough.
- A study published in 2002, cited in the NAO report, found that 11% of people with rheumatoid arthritis on conventional drug therapy (ie not biologics) will need joint surgery within five years of treatment.<sup>34</sup> It also found that within five years of treatment, between 10 to 15% of people went into remission with no evidence of persistent disease.<sup>35</sup>
- The Public Accounts Committee therefore may want to ask Department of Health officials what plans they have to communicate to PCTs and health care professionals “the benefits to long-term health and the economy of early treatment of people with rheumatoid arthritis.”<sup>36</sup>

5. *Variations in the quality of RA Services should be urgently looked at*

- NRAS is concerned by the variations in quality of RA services identified in the NAO report. The NAO’s audit has revealed wide variations in provision of services, due to capacity issues around appointing staff in MDTs. Only 14% of acute trusts provided access to psychological services despite the fact that depression is common amongst people with RA.<sup>37</sup>
- RA services should be commissioned on the basis of a thorough assessment of local need. However, the NAO report revealed that 71% of PCTs had not carried out a local needs assessment for rheumatology services overall and 73% had not undertaken any assessment to establish the number of people with RA living in the locality.<sup>38</sup>
- The failure to conduct needs assessments may contribute to the wide variations in spending on RA services, which in turn may contribute to the variations in service quality. NRAS has undertaken an analysis of the level of spending on rheumatoid arthritis services in each PCT area (reproduced in the annex) which reveals that spending on RA services varies in different PCT areas from £5.68 per head in Bexley PCT to £17.58 per head in Gateshead PCT—a great-than-threefold variation—with an England average level of £10.97 per head.
- NRAS is unable to conduct an assessment to ascertain whether there is any correlation between levels of spending and service quality since the findings of the NAO’s survey of the quality of acute care are anonymised. The Public Accounts Committee may wish to consider investigating this directly, or asking the Department of Health to do so.
- Furthermore, the variable quality of services can be explained by the absence of musculoskeletal conditions from the national levers the Department of Health uses to influence the direction of local policy. For example, the Department of Health’s flagship *World Class Commissioning* programme list 54 national indicators—from which PCTs are able to pick and choose according to their local priorities, and against which their progress will be measured—but none relate to musculoskeletal conditions.<sup>39</sup>
- The Public Accounts Committee should consider asking Department of Health officials how it plans to measure the outcomes of local RA service delivery to ensure the consistent implementation of national guidance. The IA commissioning pathway, which references the NICE RA Guidelines published earlier this year, would be a suitable benchmark for PCTs to use here, but there will undoubtedly be PCTs who are unaware of its existence.

6. *People with RA are not being given sufficient support to stay in work creating a financial burden for both society and the individual*

- The NAO estimated that for the cost to the economy of sick leave and work-related disability for people with RA is £1.8 billion a year,<sup>40</sup> which is substantially more than the NHS costs associated with treating RA.
- NRAS believes that in addition to earlier diagnosis and treatment, people with RA could be better supported in staying in work. Only 20% of those surveyed by the NAO stated that they had received sufficient information about employment issues and that services to support patients in work were the “least effective services compared with other aspects of their care.” Only 12% of GPs surveyed offered people diagnosed with RA information on staying in work.<sup>41</sup>

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<sup>34</sup> *Ibid* page 4.

<sup>35</sup> National Audit Office, *Services for people with rheumatoid arthritis*, July 2009 page 4.

<sup>36</sup> *Ibid* page 10.

<sup>37</sup> *Ibid* page 26.

<sup>38</sup> *Ibid* page 34.

<sup>39</sup> Health Mandate, *National priorities, local action*, July 2009.

<sup>40</sup> *Ibid* page 5.

<sup>41</sup> *Ibid* page 32.

- Our own research has shown that once on Incapacity Benefit (now known as the Employment and Support Allowance) 80% of people with musculoskeletal conditions never return to work.<sup>42</sup>
- The Public Accounts Committee should therefore consider asking Department of Health officials how they plan to encourage PCTs to establish clearer links with Jobcentre Plus services and ensure adequate provision of holistic care for people with RA.<sup>43</sup>

7. *The NAO survey of 1,400 people with rheumatoid arthritis found there is a lack of coherence in the support and information available to help them self-manage their condition*

As with the findings of the earlier Kings Fund report, the NAO report found that people wanted more information about living with RA and 59% agreed that having access to a named individual to whom they could turn when in need and/or experiencing a flare would be extremely beneficial. One of the key NRAS priorities is to “empower” people with RA by teaching them more about their disease and providing them with timely information and support to enable them to self manage their disease more effectively. A key part of our strategy to improve patient self management in RA has been to partner with EPPCIC (Expert Patients Programme) to develop an RA specific self management programme which was successfully piloted in three locations in England in early 2009. It is anticipated that this programme will be ready for commissioning mid 2010.

## Annex

### ESTIMATED EXPENDITURE OF RHEUMATOID ARTHRITIS SERVICES PER HEAD OF POPULATION, BROKEN DOWN BY PRIMARY CARE TRUST AREA

The following is an analysis of expenditure on rheumatoid arthritis services per head of population in each Primary Care Trust area in England. It is calculated as follows:

- The second column shows the total amount each PCT spent on musculoskeletal services in the 2007–08 year, and is taken directly from the Department of Health’s programme budgeting data.<sup>44</sup>
- Across England, total programme spend on musculoskeletal conditions in 2007–08 was £3,848,281,000. The National Audit Office estimates that total expenditure on RA services in 2007–08 was £557,000,000<sup>45</sup>—suggesting that 14.5% of expenditure on musculoskeletal services was on rheumatoid arthritis services.
- The third column in the table below therefore multiplies each PCT’s expenditure on musculoskeletal services by 0.145 (ie a percentage of 14.5%) to find each PCT’s expenditure on RA services.
- The fourth column divides each PCT’s expenditure on RA services by its resident population,<sup>46</sup> giving each PCT’s spend per head on RA services
- The table shows that spending on RA services ranges from £5.68 per head in Bexley PCT to £17.58 per head in Gateshead PCT—a greater-than-threelfold variation—with an England average of £10.97.

Primary Care Trust	Expenditure on musculoskeletal services in 2007–08 (£000s)	Estimated expenditure on rheumatoid arthritis (£000s)	Total population	Estimated expenditure on rheumatoid arthritis services per head of population (£)
Bexley Care Trust	£8,268	£1,197	210,846	£5.68
Camden PCT	£9,596	£1,389	232,476	£5.97
Luton PCT	£8,311	£1,203	185,044	£6.50
Ealing PCT	£14,614	£2,115	320,247	£6.60
Hounslow PCT	£10,367	£1,501	220,839	£6.79
Barking and Dagenham PCT	£7,867	£1,139	165,224	£6.89
Brent Teaching PCT	£13,354	£1,933	279,831	£6.91
City and Hackney Teaching PCT	£10,523	£1,523	220,479	£6.91
Richmond and Twickenham PCT	£8,385	£1,214	172,967	£7.02
Redbridge PCT	£11,764	£1,703	239,977	£7.10
South West Essex PCT	£19,575	£2,833	397,364	£7.13

<sup>42</sup> National Rheumatoid Arthritis Society, *I want to work . . . Employment and rheumatoid arthritis, a national picture*, 2007 page 8.

<sup>43</sup> National Audit Office, *Services for people with rheumatoid arthritis*, July 2009, page 10.

<sup>44</sup> Department of Health, *Programme budgeting data*, 16 July 2009; available here: [http://www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/Programmebudgeting/DH\\_075743?IdcService=GET\\_FILE&dID=200999&Rendition=Web](http://www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/Programmebudgeting/DH_075743?IdcService=GET_FILE&dID=200999&Rendition=Web)

<sup>45</sup> National Audit Office, *Services for people with rheumatoid arthritis*, July 2009, page 15.

<sup>46</sup> NHS Information Centre, *Attribution dataset GP registered populations 2008*, 30 January 2009.

<i>Primary Care Trust</i>	<i>Expenditure on musculoskeletal services in 2007-08 (£000s)</i>	<i>Estimated expenditure on rheumatoid arthritis (£000s)</i>	<i>Total population</i>	<i>Estimated expenditure on rheumatoid arthritis services per head of population (£)</i>
Hammersmith and Fulham PCT	£8,409	£1,217	169,996	£7.16
Westminster PCT	£12,072	£1,747	234,500	£7.45
Wandsworth PCT	£14,873	£2,153	280,145	£7.68
Kensington and Chelsea PCT	£10,187	£1,474	190,514	£7.74
Bradford and Airedale PCT	£26,670	£3,860	497,635	£7.76
South East Essex PCT	£17,948	£2,598	333,348	£7.79
Solihull Care Trust	£11,131	£1,611	206,552	£7.80
Mid Essex PCT	£19,364	£2,803	356,281	£7.87
Leicester City PCT	£17,147	£2,482	308,699	£8.04
Bedfordshire PCT	£23,096	£3,343	411,716	£8.12
West Hertfordshire PCT	£30,332	£4,390	536,390	£8.18
Kirklees PCT	£22,372	£3,238	391,969	£8.26
Wakefield District PCT	£19,045	£2,757	333,186	£8.27
Berkshire East PCT	£22,056	£3,192	384,225	£8.31
Blackpool PCT	£8,173	£1,183	140,104	£8.44
Telford and Wrekin PCT	£9,516	£1,377	160,910	£8.56
Islington PCT	£11,079	£1,604	187,275	£8.56
Calderdale PCT	£11,877	£1,719	200,421	£8.58
Suffolk PCT	£34,858	£5,045	587,972	£8.58
Leeds PCT	£45,813	£6,631	767,081	£8.64
Croydon PCT	£20,313	£2,940	335,142	£8.77
Portsmouth City Teaching PCT	£12,231	£1,770	199,522	£8.87
East and North Hertfordshire PCT	£34,163	£4,945	549,793	£8.99
Buckinghamshire PCT	£30,897	£4,472	496,622	£9.00
Kingston PCT	£10,842	£1,569	172,013	£9.12
Southwark PCT	£16,413	£2,376	258,245	£9.20
Medway PCT	£16,975	£2,457	265,207	£9.26
Cambridgeshire PCT	£36,949	£5,348	577,074	£9.27
Havering PCT	£15,276	£2,211	237,212	£9.32
East Riding Of Yorkshire PCT	£19,703	£2,852	304,296	£9.37
Doncaster PCT	£19,016	£2,752	293,143	£9.39
Hull PCT	£18,187	£2,632	280,044	£9.40
West Kent PCT	£43,203	£6,253	662,250	£9.44
Manchester PCT	£32,085	£4,644	485,511	£9.57
North Tyneside PCT	£13,504	£1,955	204,085	£9.58
North Lincolnshire PCT	£10,542	£1,526	158,259	£9.64
Liverpool PCT	£29,696	£4,298	443,988	£9.68
Greenwich Teaching PCT	£15,423	£2,232	230,462	£9.69
Lambeth PCT	£19,502	£2,823	289,747	£9.74
Enfield PCT	£18,076	£2,616	267,869	£9.77
Darlington PCT	£6,631	£960	98,203	£9.77
County Durham PCT	£34,556	£5,002	509,491	£9.82
Sheffield PCT	£36,525	£5,287	534,251	£9.90
Hampshire PCT	£85,266	£12,341	1,235,910	£9.99
Berkshire West PCT	£31,766	£4,598	455,101	£10.10
Derbyshire County PCT	£48,630	£7,039	692,696	£10.16
Stoke On Trent PCT	£18,211	£2,636	258,117	£10.21
South Staffordshire PCT	£41,309	£5,979	583,057	£10.25
West Essex PCT	£18,563	£2,687	261,656	£10.27
Worcestershire PCT	£38,780	£5,613	545,377	£10.29
Harrow PCT	£14,239	£2,061	198,505	£10.38
Bristol PCT	£30,762	£4,452	428,124	£10.40
North East Lincolnshire Care Trust	£11,853	£1,716	163,551	£10.49
Sutton and Merton PCT	£27,511	£3,982	377,654	£10.54
North Yorkshire and York PCT	£55,919	£8,094	767,344	£10.55
Rotherham PCT	£17,781	£2,574	243,888	£10.55
South Birmingham PCT	£25,331	£3,666	347,014	£10.57
Torbay Care Trust	£10,211	£1,478	139,121	£10.62
North East Essex PCT	£23,355	£3,380	317,972	£10.63
Great Yarmouth and Waveney PCT	£16,281	£2,357	220,674	£10.68
Lewisham PCT	£18,996	£2,749	257,419	£10.68
Haringey Teaching PCT	£17,792	£2,575	240,403	£10.71
Bromley PCT	£22,622	£3,274	303,504	£10.79
Cornwall and Isles Of Scilly PCT	£39,395	£5,702	525,942	£10.84
Tower Hamlets PCT	£16,073	£2,326	214,523	£10.84
Northamptonshire PCT	£50,287	£7,279	660,508	£11.02
Bournemouth and Poole PCT	£24,842	£3,596	321,235	£11.19
Bury PCT	£14,086	£2,039	182,116	£11.20

<i>Primary Care Trust</i>	<i>Expenditure on musculoskeletal services in 2007-08 (£000s)</i>	<i>Estimated expenditure on rheumatoid arthritis (£000s)</i>	<i>Total population</i>	<i>Estimated expenditure on rheumatoid arthritis services per head of population (£)</i>
Wiltshire PCT	£33,732	£4,882	434,921	£11.23
Nottingham City PCT	£23,709	£3,432	305,234	£11.24
Brighton and Hove City PCT	£20,263	£2,933	259,100	£11.32
Barnet PCT	£26,126	£3,781	331,471	£11.41
East Lancashire PCT	£29,537	£4,275	373,519	£11.45
Isle of Wight NHS PCT	£10,947	£1,584	137,985	£11.48
Herefordshire PCT	£13,871	£2,008	174,778	£11.49
Peterborough PCT	£11,884	£1,720	149,603	£11.50
South Gloucestershire PCT	£19,257	£2,787	242,175	£11.51
West Sussex PCT	£61,650	£8,923	773,856	£11.53
Sandwell PCT	£24,054	£3,482	301,397	£11.55
Bassetlaw PCT	£8,517	£1,233	106,594	£11.56
North Staffordshire PCT	£16,342	£2,365	204,101	£11.59
Warwickshire PCT	£41,377	£5,989	516,157	£11.60
Leicestershire County and Rutland PCT	£51,892	£7,511	645,279	£11.64
Coventry Teaching PCT	£25,972	£3,759	322,771	£11.65
Walsall Teaching PCT	£20,099	£2,909	249,756	£11.65
Northumberland Care Trust	£25,165	£3,642	311,274	£11.70
Birmingham East and North PCT	£32,196	£4,660	398,186	£11.70
Heywood, Middleton and Rochdale PCT	£16,539	£2,394	203,963	£11.74
Gloucestershire PCT	£47,058	£6,811	579,098	£11.76
Warrington PCT	£15,740	£2,278	192,778	£11.82
Waltham Forest PCT	£18,725	£2,710	228,251	£11.87
Oxfordshire PCT	£50,412	£7,297	612,823	£11.91
Dudley PCT	£24,837	£3,595	301,297	£11.93
Lincolnshire PCT	£58,350	£8,446	698,635	£12.09
Halton and St Helens PCT	£25,512	£3,693	304,194	£12.14
Surrey PCT	£90,124	£13,045	1,072,388	£12.16
Swindon PCT	£16,195	£2,344	192,541	£12.17
Shropshire County PCT	£24,050	£3,481	285,158	£12.21
Norfolk PCT	£61,094	£8,843	723,638	£12.22
Hillingdon PCT	£20,365	£2,948	240,291	£12.27
Dorset PCT	£32,906	£4,763	382,266	£12.46
Wolverhampton City PCT	£20,463	£2,962	237,535	£12.47
South Tyneside PCT	£13,037	£1,887	150,957	£12.50
Trafford PCT	£18,223	£2,638	210,704	£12.52
Central and Eastern Cheshire PCT	£38,943	£5,637	445,787	£12.64
Tameside and Glossop PCT	£19,835	£2,871	225,259	£12.74
North Tees PCT	£16,689	£2,416	188,522	£12.81
Middlesbrough PCT	£12,781	£1,850	144,105	£12.84
Bolton PCT	£23,404	£3,387	262,529	£12.90
Blackburn with Darwen PCT	£13,512	£1,956	151,187	£12.94
Heart of Birmingham Teaching PCT	£25,502	£3,691	282,156	£13.08
Stockport PCT	£25,502	£3,691	281,488	£13.11
Devon PCT	£66,378	£9,608	732,201	£13.12
Newcastle PCT	£23,711	£3,432	260,861	£13.16
Derby City PCT	£24,729	£3,579	271,023	£13.21
Newham PCT	£23,604	£3,416	254,504	£13.42
Sefton PCT	£25,640	£3,711	270,639	£13.71
Hartlepool PCT	£8,662	£1,254	91,132	£13.76
Eastern and Coastal Kent PCT	£68,302	£9,886	715,899	£13.81
Sunderland Teaching PCT	£26,183	£3,790	273,990	£13.83
Cumbria PCT	£48,141	£6,968	502,103	£13.88
North Somerset PCT	£19,373	£2,804	201,811	£13.89
Knowsley PCT	£14,653	£2,121	150,286	£14.11
North Lancashire PCT	£31,912	£4,619	326,341	£14.15
Nottinghamshire County PCT	£62,796	£9,089	638,935	£14.23
Western Cheshire PCT	£24,205	£3,503	245,689	£14.26
Central Lancashire PCT	£43,959	£6,363	438,711	£14.50
East Sussex Downs and Weald PCT	£32,783	£4,745	326,732	£14.52
Milton Keynes PCT	£23,346	£3,379	232,448	£14.54
Redcar and Cleveland PCT	£13,359	£1,934	132,813	£14.56
Salford PCT	£22,473	£3,253	222,861	£14.60
Hastings and Rother PCT	£18,137	£2,625	171,398	£15.32
Oldham PCT	£23,714	£3,432	222,362	£15.44
Barnsley PCT	£24,698	£3,575	231,551	£15.44
Bath and North East Somerset PCT	£19,883	£2,878	186,018	£15.47
Plymouth Teaching PCT	£26,830	£3,883	250,297	£15.52

<i>Primary Care Trust</i>	<i>Expenditure on musculoskeletal services in 2007–08 (£000s)</i>	<i>Estimated expenditure on rheumatoid arthritis (£000s)</i>	<i>Total population</i>	<i>Estimated expenditure on rheumatoid arthritis services per head of population (£)</i>
Ashton, Leigh and Wigan PCT	£32,870	£4,758	301,596	£15.77
Somerset PCT	£56,685	£8,205	513,108	£15.99
Wirral PCT	£34,407	£4,980	309,821	£16.07
Southampton City PCT	£27,679	£4,006	245,611	£16.31
Gateshead PCT	£23,570	£3,412	194,043	£17.58
<b>England Average</b>				<b>£10.97</b>

#### INFORMATION ABOUT NRAS

NRAS is the only charity in the UK dedicated to working towards a better quality of life for people with RA specifically (as opposed to other forms of arthritis).

NRAS has a national network of volunteers (400), people living with RA, who support the charity in a wide variety of ways and provide peer to peer telephone support.

NRAS has helpline which operates Monday—Friday, a comprehensive and informative website and a range of publications and information sheets available for both people with RA and the health professionals who treat them.

November 2009

#### 5. Memorandum from Roche Products Limited

As the manufacturer of the treatments rituximab and tocilizumab for people with rheumatoid arthritis (RA), Roche Products Ltd welcomes the Public Accounts Committee's investigation into services for people with RA. The National Audit Office (NAO)'s report into services for people with RA has made clear that, "there are opportunities to increase efficiency by addressing the delays in obtaining formal diagnosis and treatment for many people with RA".<sup>47</sup>

Following the oral evidence session of 23 November 2009, there are a number of points to which Roche would like to draw the Committee's attention as it finalises its report. These focus on economy (the minimising of costs of resources used for an activity, having regard to appropriate quality), and efficiency (the relationship between the output in terms of goods, services or other results and the resources used to produce them).

First, with respect to efficiency, Roche would like to highlight the information in the Department of Health's programme budgeting data, and in particular the increase in expenditure on musculoskeletal conditions. Although the musculoskeletal conditions category does not capture expenditure on RA explicitly, it shows that net NHS expenditure on musculoskeletal conditions more generally has increased from £3,531,277,000 in 2006–07 to £4,085,030,000 in 2007–08 (an increase of almost 16%).<sup>48</sup> It is difficult to quantify whether this increase in spending has witnessed concomitant improvements in outcomes for patients, since there is a lack of nationally-validated outcome measures.<sup>49</sup> In order to measure the efficiency of RA services, this gap needs to be addressed.

Second, with respect to economy, Roche would like to draw the Committee's attention to the potential efficiencies which could be made if the mandatory technology appraisal issued by the National Institute for Health and Clinical Excellence (NICE) in relation to rituximab was fully implemented by the NHS. NICE's guidance on rituximab, published in August 2007, states that:<sup>50</sup>

"Rituximab, when given together with methotrexate (another drug used to treat rheumatoid arthritis), is recommended as a possible treatment for adults with severe active rheumatoid arthritis only if:

- the person has already tried drugs known as disease-modifying anti-rheumatic drugs to treat their rheumatoid arthritis, one of which must have been an 'anti-TNF' drug, but these haven't worked or weren't suitable,
- it clearly improves the person's condition, and doesn't need to be given more often than every six months, and
- treatment is supervised by an experienced doctor who specialises in rheumatoid arthritis."

<sup>47</sup> P 9 NAO, *Services for people with rheumatoid arthritis*, 15 July 2009.

<sup>48</sup> Department of Health, *Programme budgeting data 2007–08*, 16 July 2009.

<sup>49</sup> ARMA, *Joint working?*, July 2009.

<sup>50</sup> NICE, *Rheumatoid arthritis (refractory)—rituximab*, August 2007.

The essence of the guidance is that rituximab should be given to patients who have had an inadequate response to an “anti-TNF” treatment. Given that rituximab is 39% less costly than an anti-TNF treatment (the cost of rituximab per average patient per year is £6,127.68, compared to the cost of an anti-TNF per average patient per year of £10,086.45, inclusive of drug, outpatient, tariff and community costs), the full implementation of NICE guidance has the potential to deliver both savings to NHS organisations and improved outcomes for patients. The NAO’s report and the findings it contains allows, for the first time, a national calculation to be made of the potential efficiencies which could be realised:

- The NAO’s report estimates that there are 17,419 people with RA being treated with a biologic (either an anti-TNF or rituximab) in England every year.<sup>51</sup>
- Of these, it is estimated that 36.7% are patients who have had an inadequate response to one anti-TNF and are being treated with subsequent biologic therapies (ie 6,393 patients).<sup>52</sup>
- However, Hospital Episodes Statistics data suggest that only 1,759 of these patients are being treated with rituximab across the country.<sup>53</sup>
- This leaves an estimated 4,634 patients who have had an inadequate response a first anti-TNF, but are still being treated with them, even though if NICE guidance was being correctly implemented then they should be being treated with rituximab.
- At an average cost difference of £3,958.77 between the two treatments, the potential savings across the country could total £18,344,175 per year, if the 4,634 patients were being treated in line with NICE guidance.

Roche considers these savings additional to the potential savings identified by the NAO in its report, which focus on increasing the number of people diagnosed within three months of onset of disease.<sup>54</sup>

The remit of the Public Accounts Committee focuses only on value-for-money criteria. However, a number of reports undertaken this year—for example by the Rheumatology Futures Group, and ARMA, in addition to the NAO—suggest that expenditure on RA services and musculoskeletal services more broadly is inefficient because services are inappropriately configured, and that this is itself a manifestation of a lack of national clinical leadership in government. In other areas, national clinical leadership has demonstrated the ability to drive efficiencies in the spending of public money, and has facilitated service change through the provision of appropriate commissioning guidance and performance-management measures. Although the appointment of a National Clinical Director in musculoskeletal services is a policy solution, it has value-for-money implications—given the National Audit Office’s finding that, “productivity gains could be achieved and patient quality of life improved through better integration and coordination of services, leading to quicker diagnosis and earlier treatment”—which the Committee may wish to consider in its report.<sup>55</sup>

*November 2009*

<sup>51</sup> Based on the NAO-estimated cost of biologic treatment of £160 million (page 8, NAO, *Services for people with rheumatoid arthritis*, July 2009), divided by an average cost of a biologic of £9,185.33. Roche data on file MabRA061.

<sup>52</sup> GfK Study Quarter 3 2008: % of Total Biologic Patients Receiving 2nd + line treatment.

<sup>53</sup> Hospital Episode Statistics MAT August 2008. MabThera patients estimated based on analysis of RA ICD-10 primary diagnosis codes and rituximab OPCS-4 code.

<sup>54</sup> P 9 NAO, *Services for people with rheumatoid arthritis*, 15 July 2009.

<sup>55</sup> P 8 NAO, *Services for people with rheumatoid arthritis*, 15 July 2009.