Continuing Care - Coming up short

The looming funding gap in the NHS over long-term care.

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THE LOOMING FUNDING GAP IN THE NHS OVER LONG-TERM CARE.

Background

1. In November 2002 Paul Burstow MP published Who Cares, Who Pays? which examined the rules the NHS were using to determine whether a person was entitled to full funding of their ongoing healthcare. The report drew together the answers to parliamentary questions and a review of the rules (eligibility criteria).

2. We found that many take a 'banded' approach, establishing three or four 'bands' and placing in the worst category of life threatening conditions – artificial respiration and feeding, double incontinence, total immobility, round the clock medical interventions etc in band one, and then specify that it is only this band which unambiguously qualifies for NHS funding. Many of the rules being used up and down the country were unlawful. Many still are.

3. In February 2003 the Health Service Ombudsman published a special report on Long Term Care. It was highly critical of the way in which the NHS had drawn up and applied the rules for continuing healthcare. The report called on the NHS to find an compensate those who had be unfairly treated.

4. This report examines what has happened since the Ombudsman report and how much it is costing.

Main Findings

5. **According to Strategic Health Authorities (SHAs) the cost this year alone of compensating people wrongfully denied NHS funding is £220 million. However, the financial risk to the NHS is put at £557 million**. Both these figures are based on assessments by SHAs and are likely to be conservative estimates of the cost.

6. **In addition to the cost of compensation there is the administrative cost of reviewing claims. This has been put at £100,000 per Primary Care Trust. For England as a whole the cost could be in the region of £30.3 million.**

The history

7. The DoH first issued guidance on continuing health care policy in 1995[i] requiring health authorities to develop and implement eligibility criteria for

access to fully funded NHS continuing health care by 1 April 1996. Resulting policies have varied across the country and have been subject to legal challenge most notable in the Coughlan case which found in 1998 that a health authority had acted unlawfully in requiring a local authority to pay for the ongoing health care needs of a patient in long term care. The significance of the Coughlan judgement was that all health needs qualify for NHS funding and where there are care packages with nursing tasks and carer's tasks which cannot be separated, it is the responsibility of SHAs/PCTs to fund. The implications of the judgement have never been spelt out in clear guidance and the eligibility criteria.

8. The DoH issued further guidance in 1999 requiring health authorities to review their policies to ensure they were lawful following the Coughlan judgement. Late in 2001 further guidance was issued requiring Health Authorities to develop eligibility criteria, jointly approved with local councils and PCTs, to replace the former health authorities.

9. Paul Burstow MP, in a report in November 2002 showed that the majority of Strategic Health Authorities and Social Services had illegal arrangements for assessing and meeting the continuing care health needs of their patients (the Coughlan ruling is based on the patient's condition and not their need for treatment; 'health needs', as opposed to 'need for health').

10. In February 2003, the Health Service Ombudsman (HSO) issued a report of her investigations into a number of continuing cases where she found, in some instances, that patients had been wrongly denied access to NHS fully funded continuing health care in nursing homes. Instead patients were wrongly funding their own care.

11. In May 2003, the DoH issued further guidance to the NHS accepting most of the recommendations made by the Ombudsman and instructing that the NHS should recompense patients, or their estates, where a financial injustice has occurred due to patients being wrongly denied access to NHS fully funded continuing health care. Claims for the reimbursement of care costs, potentially backdated to 1996, should be dealt with by 31 December 2003. But cases are certain to come to light after that date and the are question marks around the continuing use of illegal criteria.

How much is it all going to cost?

12. In July 2003 Paul Burstow MP wrote to all 28 Strategic Health Authorities asking them for their estimates of the numbers of people involved and the cost of compensation. By the closing date for the survey 23 replies had been received.

13. What the survey has revealed is a wide variation in the way in which SHAs are approaching the task, some have a very clear idea about the numbers and costs involved others appear to be working in the dark. Apart from the cost of compensation itself there is also the cost of running the compensation scheme. The costs surrounding the administration and investigation/research by the PCTs/SHAs into potential cases arising from the Ombudsman report have to be met by the PCTs and SHAs themselves. There is no new money to do this work with. This is placing additional strain on stretched resources.

14. One SHA noted that additional administration costs arising from the review process are likely to be in the region of £100,000 for each PCT in its patch. They also note that social services authorities are also likely to incur considerable cost in supporting the work of the clinical review teams and that no additional funding has yet been made to cover either of these risks. They also have identified the risk from key staff being diverted from operational practice to undertake clinical reviews and the potential for increase in legal costs relating to claims being dealt through the judicial system, another financial risk that has been identified but not quantified.

15. If every PCT had the same level of administrative costs the whole exercise will cost the NHS £30,300,000. Based on 303 PCTs at £100,000 each.

16. The main focus of the survey was finding out what Strategic Health Authorities believed the cost of compensation would be. Twenty SHAs supplied detailed answers to this question. These results would give a projected total for all 28 SHAs of £219,673,300 (approx. **£ 220 million**).

17. The survey also asked what SHAs view was of the overall financial risk to the NHS arising from Ombudsman report. Eleven SHAs supplied their estimates of the financial risk. These results would give a projected total for all 28 SHAs of £557,430,600 (approx. **£ 557 million**).

Implications of the Ombudsman report

18. There has been widespread on-going media coverage of the Ombudsman's report, which has raised public expectations as well as concern.

19. SHAs are responsible for establishing a special lay review panel. This will make recommendations to PCT chief executives about the validity of claims and how much should be paid.

20. PCTs are responsible for identifying and handling requests for reimbursement. NHS bodies locally are required to decide what is

reasonable and proportionate action to make people aware of the special review and reimbursement process?

21. SHAs are responsible for ensuring special reviews of claims are properly handled. A special review panel, with an independent chair, will recommend to PCTs whether recompense is justified and if so how much.

22. Legal advice concerning responsibility for the policy has been at odds with guidance from the DoH causing much debate. Although the legal guidance advises that local councils should 'approve' the criteria, the DoH have advised that PCTs have 'joint and shared' responsibility for the criteria with the SHA. One SHA's legal advice, for example, suggested that the SHA alone is required to 'approve' the criteria and subsequently direct the PCTs to adopt them.

23. Common and easy to understand SHA-wide eligibility criteria would enable more equitable access but it is the practical application of the criteria by multidisciplinary teams in hospitals and community settings that will have the greatest impact. The challenge is to spread and sustain a common interpretation and application of the criteria, to assure equitable access to comprehensive assessment, effective multidisciplinary team working and consistent commissioning. This is evidently not the case at the moment.

24. One CHC, for example, has formally written to the Secretary of State requesting that the draft SHA-wide criteria be subject to a public consultation on the grounds that the criteria represent a substantial variation in service.

25. SHAs and PCTs have a duty to involve patients and the public, in the development of policy (Section 11 of the health and Social Care Act) and the PCTs in one SHA have worked together with their local CHCs to plan and implement a programme of patient and public involvement to consider the draft eligibility criteria. Feedback from local events involving patients and the public will be used to inform the final version of the policy document along with comments from local councils and PCT boards.

Conclusions

26. Current eligibility criteria appears to be subject to varying degrees of local interpretation – still no clear national and transparent criteria. There is clearly a role for the Government to clarify this situation.

27. The costs involved in administering the complex and confusing eligibility criteria (together with the claim costs) only serve to underscore the value of having a simpler and more holistic approach to providing free long-term

care for all by taking up the main recommendation of the Royal Commission on Long Term Care.

28. The Government remains reluctant to act to clear this mess up and provide adequate support to the local NHS (only some PCTs have included a provision in their 2002/03 accounts for continuing care reimbursement claims and despite this the research shows a massive shortfall between projected financial provision and project financial risk – albeit with variation across the SHAs).

29. The way in which the Department of Health and NHS has handled the issue of long term health care for the elderly is a scandal. It is the health equivalent of the pensions mis-selling scandal.

Background material available on request

Burstow P, 2003, 'Whither continuing health care: How Labour sells the elderly short on health care'

Clements L, 2003 'Whatever happened to continuing care?', Parliamentary Seminar

Health Ombudsman, 2003, 'NHS funding for long term care', The Stationary Office: London

For a personal account of the real human cost of this debacle:
Please speak with Carole Denby on 01637 889051

[i] HC(95)8