



Specialised Healthcare Alliance

NHS CONFEDERATION ANNUAL CONFERENCE, 20 JUNE 2008 SHCA WORKSHOP – 'WHOSE MONEY IS IT ANYWAY?'

The SHCA's workshop at the NHS Confederation Annual Conference in Manchester again sparked an interesting discussion about specialised healthcare among delegates. The session was well-attended, with fairly even numbers of commissioners and providers in attendance.

The speakers were Mark Cooke, Chief Executive of Dudley PCT and Dr Stephen Waldek, Medical Director, Salford NHS Foundation Trust and a specialist in inherited metabolic disorders.

Mark Cooke

Mark began the session with an overview of specialised commissioning and then discussed some of the tensions within the system. Among the issues he covered were:

- The primary responsibility PCTs have to their local populations and the need to judge competing claims on expenditure in that light;
- Whether the public could be more involved in decisions about specialised services;
- The NHS's poor record at decommissioning outdated services, which led to resources being misused which could otherwise fund newer, high cost treatments;
- Whether the National Commissioning Group could have greater representation of PCT commissioners;
- How Primary Care Trusts can better influence and invest in research and development of new treatments;
- The need to recognise that many decisions around specialised healthcare are political, resting with ministers, and the possibility that the flow of funding should be adjusted accordingly.

Dr Stephen Waldek

Stephen gave a more detailed view of the patient experience for those with a rare condition, focusing on Lysosomal Storage Diseases. He discussed:

- How Britain's record of designating specialist providers was better than other European countries with reference to people he had come across in Italy and Spain who were being expensively and wrongly treated with enzyme replacement following misdiagnosis;
- The role Primary Care Trusts should play in research and development;

- How innovative treatments for rare conditions may also benefit patients with more common illnesses in the future;
- How funding for specialised services should come directly from the centre, rather than top-sliced from PCTs;
- How specialist providers had the advantage of being better able to decommission outdated services, therefore saving the NHS money.

Discussion

A number of issues central to the SHCA's agenda were raised in the open discussion among delegates. Issues raised included:

- One delegate explaining that funding the health service is about pooling risk; it is similar to an insurance model. There is therefore no need to focus on the one-off high cost treatments because these are already anticipated and the costs shared;
- One delegate was concerned that 'really rare' conditions were privileged over 'rare' conditions, although others countered that this was not the case: rarity only determined what levels decisions were made at, with severity being the more important consideration;
- Delegates agreed that PCTs should seek to influence research and development, and also questioned whether they could influence the manufacturers' drug prices;
- Others explained that one of the benefits of collective commissioning stems from greater bargaining power, although the high development costs of orphan drugs and small patient numbers may limit room for manoeuvre;
- Delegates discussed the issue of decommissioning, agreeing that the NHS spends a great deal of money on outdated services for more common conditions that could be better spent elsewhere;
- One delegate argued that some money spent on high cost treatments was inappropriate; for instance the money spent on a costly intervention for a terminal patient could instead be used to fund high quality palliative care;
- One delegate argued that specialised commissioners needed to move the debate away from discussion of the 'opportunity cost', that is, the money that cannot be spent on common conditions if rare conditions are treated: this is misleading because treating rare conditions is cost-effective, and has wider benefits.