



ASSOCIATION OF
COMMUNITY HEALTH COUNCILS
FOR ENGLAND & WALES

HEALTH NEWS BRIEFING

PUBLIC PARTICIPATION IN SETTING PRIORITIES

ACHCEW's Evidence to the Health Select Committee

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genuine consultation in decision-making. There is also a strong practical case: local people, from all walks of life, will always know more about their felt health needs and about their experience of local health services than professional NHS planners.

This is not to say that all NHS purchasing decisions should be determined by referenda or opinion-polling, any more than decisions about other public services. It is also necessary to take on board the policies and priorities of the elected national government, the experience of health care professionals, the expertise of health care planners and the requirement to assess all needs and demands for health care in a way consistent with equal opportunities and natural justice.

Health Authorities do need to carry out exercises which bring them into direct contact with individuals living in their areas. But they also need to find organisations to consult about rationing decisions which: (a) are drawn from the local community; (b) can voice the health needs of ethnic and other minorities; and (c) are well-informed on health issues. If Community Health Councils did not exist they would have to be invented.

Official Guidance

The Government has stressed on many occasions the need for purchasers to consult CHCs and the local community generally.

1. The December 1990 document, Consultation and Involving the Consumer, pointed out: "True consumer involvement is more than just a consultation exercise to 'rubber stamp' a decision a DHA has, in effect, already taken". Consultations should "cover broad strategies for providing health care". "The principle should be to ensure a full degree of involvement by interested parties, including consumers, at all stages of strategic and operational change."

2. The January 1992 document, Local Voices, mentioned contact with CHCs as one way in which Health Authorities could exercise their "need to listen" when assessing health need.

3. This was followed in February 1992 by the letter from Stephen Dorrell MP, then the Minister responsible for CHCs, to Regional and District Chairs (ML(92)1). Mr Dorrell wrote:

The NHS reforms deliberately attach CHCs to the purchasing function in order to encourage them to engage in a realistic dialogue with health authorities about local health priorities. Ministers have stressed to CHC leaders the fact that we believe their contribution to the NHS will be significantly enhanced if they...contribute to the evolution and monitoring of the purchasing function...Ministers have repeatedly stressed that health authorities should use their purchasing role to assess the relative priorities of competing claims for health service resources and to shift resources to reflect those priorities. If CHCs are to make their full contribution to the purchasing process, they must be in a position to assess competing claims and to express an opinion about the relative, as well as the absolute, value of a particular proposal.

4. Mr Dorrell's letter was followed by a circular to District General Managers from the Deputy Chief Executive of the NHSME (EL(92)11). This stated that DHAs should "involve CHCs in the purchasing process. DHAs should agree locally with CHCs how they should contribute to the assessment of relative priorities, development of quality standards, target-setting and monitoring arrangements". DHAs should also "ensure CHCs have access to information such as DHA contracts with providers, purchasing plans, data about local health needs and services".

circumstances this CHC would choose to advocate for all needs identified and would reserve the right to be critical of all or any of the priorities selected by the Health Authority". Similarly, another CHC reports: "Last year, the commissioners asked that we agree the priorities set in their commissioning strategy but members felt they would compromise their relationship with local people if they were seen to be actively involved in decisions about priorities of health care services".

2. Commenting on Consulting on Purchasing

CHCs may regard it as invidious for them to endorse the priorities set out in a purchasing plan and yet feel it quite in order to assess the purchasers' consultation process. One CHC protests: "much more attention must be given as to how community values and priorities can be taken into consideration in the formulation of health plans". CHCs can act as information brokers for the wider community, empowering and enabling user groups and indeed individual patients to understand what is happening and express their views if they wish to do so.

3. Discussions with Purchasers

Purchasers are continually assessing and reviewing the scope for increasing or reducing the quantity of each service they purchase as part of the annual cycle of purchasing decisions. They may wish to involve CHC representatives in these discussions. Cardiff and Vale of Glamorgan CHCs report: "Both CHCs in South Glamorgan have been heavily involved in the development of [Local Strategies for Health], with members of staff serving on all ten strategy teams. These have made enormous demands upon the time and costs of the people involved". Participation by a CHC member or Chief Officer in strategy discussions need not imply endorsement by the CHC as a whole of the conclusions reached.

4. Responding to Rationing Proposals

Purchasers may wish to consult CHCs and other organisations about particular proposals to cease purchasing particular services altogether or to impose access restrictions ("protocols"). The CHC may decide to respond to an invitation to comment even if it feels unable to support the proposal. Possible responses include: rejection of the proposal; casting doubt on the arguments used by the purchaser to justify the proposal; laying down conditions (eg one CHC "decided not to oppose the policy provided that the listed procedures would be available to patients when clinically necessary"); or accepting that, given the resource constraints, and the alternative options for releasing money, the proposed restriction should be supported.

5. Priority-setting Exercises

Some Health Authorities have attempted to involve CHCs and others in exercises involving the listing of health services in priority order. This may be done partly in order to help the purchasers gain a feel for public values which can be incorporated into their decision-making; and/or it may be seen as intended to legitimate decisions to restrict the range of NHS services. A variety of different techniques have been used but it is likely that interest will generally be focussed on the areas where public support for services could prove a major consideration for purchasers wishing to avoid 'noise' and on the vulnerable areas at the other extreme.

6. Taking the Message Out

Some CHCs have actively sought to assess local opinion or to involve voluntary sector groups or individual members of the public in priority-setting exercises. There is an issue here about the appropriate division of labour between the CHC and the purchaser although the CHC may feel obliged to seek out views where the purchaser is failing to do so.

Making Progress

There is a long way to go before purchasers can be said to be effectively involving CHCs and local people generally in their decision-making. Attached is a summary of local issues which have arisen across England and Wales. In many of these 'rationing' decisions or discussions, CHCs and other patients' representatives have been barely involved, if at all. The Government's frustration is evident from their continuing reiteration of the need for progress.

The following steps would help ensure that genuine consultation takes place in the development of priority-setting in the Health Service:-

1. Health Authorities should continue to seek direct contact with local people through surveys, public meetings, etc. However, they need to make it clear before these exercises are conducted how the results will feed into their own deliberations. There is little point in conducting surveys if the results are then dismissed as revealing that the public are 'ill-informed' - ie that they do not agree with professional NHS planners. Health Authorities also need to ensure that their attempts to make contact with local people have legitimacy in those people's eyes through external validation of the process by the relevant Community Health Council(s).
2. Health Authorities will, however, also need to make more efforts to make the public aware of the factors involved in priority-setting. The documents they produce and the presentations they give will need to be 'balanced' and 'fully represent the facts', to quote the recent Code of Conduct. This means that these documents and presentations cannot be part of any communications strategy which is designed to avoid controversy or 'noise' or to 'get a good press' for the Health Authority.
3. Purchasers need to seek the direct involvement of Community Health Councils in their discussions before formal consultation documents are issued. For this purpose the CHCs' representatives will need adequate servicing by the purchaser. This would include providing relevant papers generated within the purchasing authority and useful documents produced by the NHSME/Department of Health and other agencies as well as prompt, full and frank responses to questions raised.
4. Similarly, purchasers need to seek the involvement of CHCs in the formulation of any 'protocols' restricting access to any form of NHS treatment. Virginia Bottomley has stated: "Good clinical guidelines should reflect all three criteria: views of patients, clinical and cost-effectiveness".
5. The reports on consultation demanded from purchasers by the Health Minister (in EL(94)4) should be produced annually. They should be public documents and should be circulated automatically to the appropriate CHCs. The CHCs should be invited to include statements to be attached to these reports setting out their view of the consultation process; the changes made to purchasers' plans as a result of patient input; and outstanding differences of view between the CHC and the purchaser.
6. Purchasers should be required to publish their purchasing plan each year and CHCs should be invited to include a statement to be attached to these plans - again, these should set out the CHC's view of the consultation process; the changes made to purchasers' plans as a result of patient input; and outstanding differences of view between the CHC and the purchaser.
7. Fundholding GPs are becoming increasingly important purchasers. Along with the contracts they reach with providers, fundholders' annual reports and purchasing plans should be public documents and copies should be automatically

sent to the local CHC. Fundholders should be obliged to consult before their purchasing plans are finalised, by seeking the views of their patients and of the local CHC.

8. The medical profession will need to make sure that patients have an input into their own deliberations on setting standards for health care which may be incorporated into protocols which in turn may restrict access to NHS care. The Royal Colleges, for example, need to be involved in a genuine dialogue with patients' organisations.

Conclusion

The responsibility for a decision is not automatically shared by consulting about it. The responsibility for rationing decisions will lie with the purchasing authorities which lay down ECR protocols or say that certain procedures will no longer be available. Responsibility will be ultimately with the Government for determining a level of resources within the NHS that requires the rationing decision to be made in the first place.

It is not acceptable for these decisions to be taken secretly without the opportunity for public debate. People have the right to know what choices are being made in their names, to express their views and to expect that those responsible are held properly accountable for the decisions being made. Consulting the public will not provide easy answers, nor will it provide an easy get-out when things go wrong, but it is an essential part of the democratic process.

East Surrey HA has been devising a system to rank patients on waiting lists from 0 to 9 to denote priority.

SOUTH AND WEST

Bristol HA's Public Health Consultants carried out a Nominal Group Technique exercise with the four CHCs. CHC Members are asked: "What are the key service changes that would have the greatest beneficial influence on the health of the population the Council represents?" The prioritisation, which takes an hour or two, may typically consist of 6 stages: (i) Silent generation of ideas in writing; (ii) 'Round-robin' feedback of ideas; (iii) Serial discussion of ideas; (iv) Preliminary vote; (v) Discussion of preliminary vote; (vi) Final vote. Bristol CHC members concluded that the highest priorities were "sufficient community support for those recently discharged from hospital" and "re-direction of resources to health promotion and preventive medicine". Issues which individual members "silently generated" but which received no votes in the priority-ranking included the "availability of speech therapy in nursery schools" and "recognition of the benefits of alternative and complementary medicine". Bristol CHC has reported its intention to repeat the Nominal Group Technique exercise with representative voluntary groups and geographical forums.

In March 1993, North Devon HA issued a consultation document on Non-Priority Clinical Procedures which might "not normally be purchased by the Authority". These were in the areas of Plastics and Reconstructive Surgery, General Surgery (reversal of vasectomy and female sterilisation, and removal of varicose veins for cosmetic reasons), Oral Surgery (eg extraction of non impacted teeth), Orthodontics and Others (IVF and gender re-assignment surgery).

In its 1992/93 Purchasing Intentions (SPIs), Exeter HA proposed not normally to purchase cosmetic varicose veins treatment, tattoo reversal or reversal of sterilisation (male or female). The CHC reported: "The 93/94 SPIs states that referrals are made for a number of other cosmetic or minimal health benefit operations in plastic surgery and some other surgical specialities. These are being identified...with a view to their exclusion from 93/94 contracts. The HA...also intends to maintain its policy of declining to pay for in-patient homoeopathic treatment and has undertaken to review its present policy of not purchasing in vitro fertilisation (IVF) in the light of responses to proposals contained in their draft 93/94 SPIs." The HA has also co-ordinated a number of strategy groups to look at common conditions such as asthma, incontinence and back pain.

Plymouth HA provides no sex-change surgery.

In August 1993, it was reported that a ranked waiting list was being piloted across a handful of specialties. Patients were allocated a score between 0 and 4 in five respects: speed of the disease, pain or distress, disability or dependence on others, loss of occupation and time waiting. The scheme was devised by Dr Alastair Lack, director of resource management at Salisbury Hospital, who said: "If we've only got the funds to treat patients who score 2 or 3 or more we're not going to put patients with minor conditions on the list". The scheme has not been subject to public consultation: "It is too sophisticated a concept for the uninformed public to understand", according to Dr Lack.

Somerset CHC has endorsed the Health Authority's proposal for a two-year programme of research and development on 'Public Opinion and Health Care Planning', to be undertaken jointly with the CHC. A research social scientist would be appointed to establish appropriate methods of community consultation.

Southampton HA's list of procedures not being purchased includes: IVF/donor insemination, cosmetic plastic surgery, reversals of sterilisation, asymptomatic

wisdom teeth, tattoo removal, asymptomatic varicose veins and certain orthopaedic procedures.

In June 1993, Pulse reported that Torbay HA was considering restricting extra-contractual referrals for some forms of mental illness such as anorexia nervosa and other eating disorders because of the expense.

Winchester and Central Hampshire CHC has reported that the HA was looking at rationing plastic surgery.

Purchasing Guidance issued to DHAs by the **Wessex Purchaser Consortium for Plastic & Reconstructive Surgery** is clear that: "purchasers will wish to define a range of procedures which will not normally be purchased in future". A list was included of Cosmetic Plastic Procedures which the Consortium was suggesting would no longer generally be purchased: "This list has been derived from those conditions for which patients have already waited for two years or more (ie low priority from the Clinicians' point of view), those which are not funded by private insurers and the views of a number of plastic surgeons, other clinicians and GPs". The list included: pinnaplasty (pinning back ears), tattoo removal, liposuction/lipectomy (removal of fat deposits), mastopexy (repositioning of nipple), breast augmentation, repair of nipple, buttock lift, blepharoplasty (repair drooping eyelids) and rhinoplasty (nose restructuring).

NORTH WEST

Blackpool, Wyre and Fylde CHC has reported: "The position within Blackpool, Wyre and Fylde Health District is that the Community Health Council have contributed a lay member to service review teams looking at particular Health Care Services. In 1992 reviews were made of:

1. Maternity and Neo Natal Services
2. Services for the Mentally Ill
3. Services for Elderly people.

Through this process and other means the CHC is able to bring forward matters which we consider require service developments." Blackpool, Wyre and Fylde CHC participated in a written exercise conducted by their Health Authority. Each respondent is first given 100 points to be allocated to 12 listed service areas. Secondly, within each service area, the respondent is asked to score individual specialties, so that the scores add up to 100 for each area.

South Manchester HA issued a proposal that a range of plastic surgery treatments would not normally be available at Withington Hospital. The list includes tattoos, adult bat ears, cosmetic augmentation mammoplasty, cosmetic abdominal lipectomy, facelifts and cosmetic blepharoplasties, split earlobes, liposuction for cosmetic purposes and most cosmetic rhinoplasties, other than those arising as a result of trauma.

In August 1993, the treatment of smokers was widely debated following the death of Harry Elphick who had been denied treatment by a cardiologist at Wythenshawe Hospital in Manchester. Dr Colin Bray insisted: "The best thing for patients who smoke is to stop smoking. We don't have anything as effective at reducing risk as simply stopping smoking". However, the British Cardiac Society said in a statement: "The society does not believe that it is possible to justify a clinical policy which systematically denies the right of access to treatment for individuals on the basis of a specific risk factor, even if this is self-induced". Alison Ryan, Chair of **South Manchester CHC**, commented: "If we are going to have a policy to deny people treatment on the NHS because of their lifestyle that has to be a decision made by politicians, not local doctors".

Oldham HA funds cosmetic surgery only for psychological reasons.

As part of their Local Voices work, **Salford HA** and **FHSA** "carried out a 'Priority Search' survey of over 1000 people. Priorities were: access to services, especially waiting lists; services for older people; community care and support, and the need for independence; and prevention of ill health."

Stockport HA's document 'Preparation for Purchasing Plan 1993/94' stated that further work was required to agree referral protocols with GPs in relation to 'Unnecessary' Hospital Admissions/Investigation (their quotes). It was proposed to draw up Cost and Protocol Contracts involving criteria for access to services. The types of cases treated would be reviewed leading to "a prioritisation for the service based on an order of cases allowing to the degree of health gain. Depending on the resources available a line would have to be drawn at some point below which access to the service would be denied...it is intended to pilot the approach in only a very small number of services or sub-specialities this year." Dr Steve Watkins, the HA's Director of Public Health, explained: "We will pay for the number of people the provider treats - if they treat the people who need the care...Cost and protocol contracts will become the normal model of contracting".

Tameside & Glossop introduced revised criteria for chiropody treatment. Approximately 1500 patients were then assessed. 486 of them were discharged as not meeting the revised criteria, under 350 were given a planned programme of care leading to discharge when completed and over 300 were assessed as needing ongoing treatment.

WALES

Cardiff and Vale of Glamorgan CHCs report: "Both CHCs in South Glamorgan have been heavily involved in the development of [Local Strategies for Health], with members or staff serving on all ten strategy teams. These have made enormous demands upon the time and costs of the people involved..."