

# RESPONSE TO THE REPORT OF THE BRISTOL ROYAL INFIRMARY INQUIRY

## NATIONAL INSTITUTE FOR CLINICAL EXCELLENCE

### Introduction

The Report of the Bristol Royal Infirmary Inquiry is of fundamental importance to the NHS. It describes failures in the arrangements for securing high standards of care and makes recommendations for change and improvement which will effect everyone involved in the health service.

The Institute is committed to playing a full part in achieving the goals set out in the Report. We have considered carefully each of the recommendations which apply to NICE, in consultation with our Partners Council. This response was agreed by the Board of the Institute at a meeting held on 19 September 2001.

The Institute is currently constituted as a Special Health Authority with the responsibility to advise health professionals, working in the National Health Service (NHS), on measures to ensure that they are able to provide patients with the highest attainable standards of care. Its guidance takes several forms:-

1. It advises health professionals on the appropriate use, within the NHS, of specific health technologies (including pharmaceuticals, devices, procedures, diagnostic and health promotion techniques). In doing so it is required to take account of both the clinical and cost effectiveness of these technologies by the process of "technology appraisal".
2. It advises health professionals on the appropriate management of specific conditions (including both diseases such as hypertension, and symptoms such as acute breathlessness). Its guidance may also include advice on appropriate referral for specialist advice. In drawing up clinical guidelines it is required to take into account both clinical and cost effectiveness.
3. The Institute has inherited responsibility for a suite of service delivery guidelines, for cancer, that will be completed within the next 2 years. These are intended to advise commissioners and purchasers of health

care, in the NHS, on the infra-structure necessary to support health professionals provide high standards of care. The Institute has no plans to expand this programme at the present time. Instead, it proposes to incorporate service delivery issues within its clinical guidelines but there may be circumstances, in the future, when separate advice on service reconfiguration would be helpful to the NHS.

4. It advises health professionals with methodological advice on monitoring adherence to its technology appraisal advice, and its clinical guidelines, by means of clinical audit. This includes proposing audit criteria and audit methods.
5. It has responsibility for commissioning and supporting national clinical audits conducted by its National Collaborating Centres (NCCs).
6. It has responsibility for commissioning and supporting the National Confidential Enquiries and for disseminating, to the NHS, specific advice on reducing mortality and other serious adverse events.

**The Board's response to the relevant recommendations of the Report are (in bold) set out below.**

## The regulation of the quality and safety of healthcare

39. The framework of regulation must consist of two overarching organisations, independent of government, which bring together the various bodies which regulate healthcare. A Council for the Quality of Healthcare should be created to bring together those bodies which regulate healthcare standards and institutions (including, for example, the Commission for Health Improvement (CHI), the National Institute for Clinical Excellence (NICE) and the proposed National Patient Safety Agency). A Council for the Regulation of Healthcare Professionals should be created to bring together those bodies which regulate healthcare professionals (including, for example, the General Medical Council (GMC) and the Nursing and Midwifery Council); in effect, this is the body currently referred to in *'The NHS Plan'* as the Council of Healthcare Regulators. These overarching organisations must ensure that there is an integrated and co-ordinated approach to setting standards, monitoring performance, and inspection and validation. Issues of overlap and of gaps between the various bodies must be addressed and resolved.

**Response: The Institute welcomes the proposal to establish a Council for the Quality of Health Care. It would expect the Council**

**to help co-ordinate the work of its constituent organisations (including the National Institute for Clinical Excellence, the Commission for Health Improvement, and the National Patient Safety Agency). The Institute also believes that the NHS Modernisation Agency should play a full part as a member of the Council. The Institute, however, expects the Council to operate as a facilitative body; with a membership drawn from the chairs and chief executives of its participating organisations; a rotating chair; a secretariat of no more than two or three people; and a budget commensurate with its size.**

41. The various bodies whose purpose it is to assure the quality of care in the NHS (for example, CHI and NICE) and the competence of healthcare professionals (for example, the GMC and the Nursing and Midwifery Council) must themselves be independent of and at arm's-length from the DoH.

**Response: The Institute's guidance is prepared by the expert members of its advisory committees. They are drawn from the NHS and academia and although they seek the views of the Institute's stakeholders (the professions, patient and carer organisations, manufacturers and government) their advice is independent of any vested interests. The independence of its advisory committees is valued by the Institute and the wider community.**

**The Board is conscious that some consider the Institute to be too close to the Department of Health and the National Assembly for Wales. This needs to be addressed. However, the Board believes that its formal status as an NHS body has considerable advantages. NICE is proud to be part of the NHS and to use its logo as it seeks to secure improvements in the quality of care, for patients, from within the service. The Institute should continue to be seen as part of the NHS and for this to be visible in the way in which its guidance is presented to the NHS and the public.**

**The Board is also anxious that its current emphasis on achieving both clinical *and* cost effective care for NHS patients should continue. The Board draws a distinction, however, between advising on cost effectiveness within the resources available for health care, and affordability. The latter is properly the responsibility of government and to scrutiny by parliament.**

**Whilst the Board seeks to remain as part of the NHS, there are measures that would enhance its independence and improve its**

efficiency. Collectively, these would give the Institute the autonomy proposed in the Report:-

1. NICE's guidance (particularly its technology appraisals and clinical guidelines) has major implications for the NHS. Its advice must not only meet the tests of clinical and cost effectiveness, but must also be affordable and capable of implementation. Ultimate responsibility for the selection of NICE's work programme currently rests with the Department and the Assembly. This is intended to ensure that the government's priorities are met; and that the service can both afford, and implement, the guidance that the Institute may produce. Although the Institute is fully engaged in these deliberations the present arrangement is opaque, has yet to engage fully with the service itself, and has led some commentators to assume (incorrectly) that NICE's priorities are driven by political, not service, needs.

The Board therefore proposes a radical change to the process by which its work programme is constructed. These changes are designed to meet the requirements of openness and transparency, engagement with the service, and explicit sharing of the responsibility for topic selection. The Board therefore suggests that responsibility for gathering and developing proposals for its work programme be devolved to the Institute, and that final decisions on topic selection be taken jointly with the Department and the Assembly.

2. A number of appointments, in the Institute, are subject to prior ministerial agreement. These include the position of chief executive, the chair and members of the Appraisal Committee, and members of the Partners Council. The Institute proposes that the prior agreement of ministers, for all these appointments, be withdrawn and responsibility be devolved to the Board (or to the non-executive members of the Board in the case of the appointment of the chief executive). The appointment of the chair and non-executive Board members must, of course, continue to remain with ministers.
3. Powers to establish, or disestablish, committees of the Institute should (with the exception of those necessary to

**comply with NHS corporate governance arrangements) should rest solely with the Board.**

- 4. The Secretary of State's Directions covering the Institute's activities should be re-considered.**
- 5. In order for the Institute to meet the increased responsibilities envisaged in the Report, and the Board's response, a modest expansion of its size is proposed. This would amount to one additional executive director (making five in all) and two non-executive directors (making eight in all).**

42. All the various bodies and organisations concerned with regulation, besides being independent of government, must involve and reflect the interests of patients, the public and healthcare professionals, as well as the NHS and government.

**Response: NICE is already fully committed to involving all its stakeholders in its affairs. The membership of the Institute's Partners Council, which includes representation from the health professions (including management), health care industries, and patients and carers, reflects this. The Board and its advisory committees all include individuals with experience of patient and carer advocacy.**

## **Care of an appropriate standard**

122. One body should be responsible for co-ordinating *all* action relating to the setting, issuing and keeping under review of national clinical standards: this should be NICE, suitably structured so as to give it the necessary independence and authority.

**Response: The Board, broadly, accepts this challenge subject to two provisos.**

**First, further consideration needs to be given to the boundaries of the term "national clinical standards". Whist this clearly includes clinical practice guidelines, the extent of NICE's involvement with developing guidelines for service configuration (or re-configuration) needs to be explored. Similarly, the involvement of the Institute in developing generic, patient-centred guidelines (in areas such as interpersonal communications, provision of information, and the maintenance of individual respect and dignity) needs to be carefully considered. It is in this context, particularly, that the boundary between the responsibilities of the**

**professional regulatory bodies and those of the Institute must be clearly defined. It would be inappropriate for the Institute to develop standards for general management or administrative purposes.**

**Second, there are areas where further consideration is needed for the strictest interpretation of this recommendation:-**

- 1. The Board agrees that the Institute's clinical guidelines should become the sole basis for the management of conditions in the NHS. Their scope should ultimately be extended to cover the significant causes of morbidity and mortality in the UK as recommended in the Report (recommendation 127).**
- 2. Standard setting for screening (through the National Screening Committee) and immunisation (through the Joint Committee on Vaccination and Immunisation) is currently a national function exercised for the UK as a whole. These activities are closely linked to the public health responsibilities of the Chief Medical Officers. The Board sees no insurmountable difficulty in incorporating these functions under the umbrella of NICE, but recognises that it would need to develop appropriate relationships with the ministers and the NHS in Northern Ireland and Scotland as well as with all four chief medical officers and their staff.**
- 3. Some guidance to health professionals is offered by the Medicines Control Agency and the Medical Devices Agency in fulfilment of their statutory functions. The Board sees no case for change that, anyway, would probably be incompatible with the UK's legal responsibilities to the European Union. NICE already has excellent relations with both bodies, and the Board expects to continue working closely with them to ensure that consistent advice is given to NHS health professionals.**
- 4. The Human Fertility and Embryology Board, as part of its regulatory responsibilities, also offers guidance to health professionals. The Board, again, sees no case for change but will work closely with the Authority in areas of mutual interest.**
- 5. Some new organisations (the National Commission for Social Care, the National Patient Safety Agency and the Health Development Agency) may wish to develop**

**standards related directly to the clinical care of patients. NICE will work closely with all these organisations to ensure cohesion.**

123. Once the recommended system is in place, only NICE should be permitted to issue national clinical standards to the NHS. The DoH (as the headquarters of the NHS) while issuing, for example, National Service Frameworks and supplementary guidance, should not be able to rescind or detract from the standards issued by NICE.

**Response: The Board fully supports this proposal subject to the caveats raised in its response to 122 (above). In particular, it welcomes the proposal that systems should be in place to avoid conflict between National Service Frameworks and the clinical standards developed by NICE. Furthermore, the Institute's clinical standards should also apply to all providers offering health care, in whole or in part, at the expense of the public purse (e.g. palliative care centres, nursing and residential homes, and all private hospitals providing care under contract to the NHS).**

124. NICE should pursue vigorously its current policy of involving as wide a community as possible, including the public, patients and carers, in the work to develop and keep under review clinical standards. In particular, the special expertise of the Royal Colleges and specialist professional associations should be harnessed and supported. Account should also be taken of the expertise of the senior management of the NHS.

**Response: The Board welcomes the Report's endorsement of the arrangements that the Institute has put in place for the involvement of patient and carer organisations, and professional bodies, in the development of its guidance (see also the response to recommendation 42). In particular, the establishment of the Institute's six National Collaborating Centres, based on the Royal Colleges and professional societies, resonates fully with the "hub-and-spoke" arrangements recommended in the Report. The Institute has also established a National Guideline and Audit Patient and Carer Involvement Unit (in association with the College of Health) to help patient and carer organisations maximise their contributions to clinical guideline development groups. The Institute also provides financial support to organisations to patient/carer organisations which become involved in its work programmes. Senior NHS managers already sit on its advisory bodies.**

125. National standards of clinical care should reflect the commitment to patient-centred care and thus in future be formulated from the perspective of the patient. The standards should address the quality of care that a patient with a given illness or condition is entitled to expect to receive from the NHS. The standards should take account of the best available evidence. The standards should include guidance on how promptly patients should get access to care. They should address the roles and responsibilities of the various healthcare professionals who will care for the patient. They should take account of the patient's journey from primary care, into the hospital system (if necessary), and back to primary and community care, and of the necessary facilities and equipment.

**Response: The Institute's guidance, and particularly its clinical guidelines, reflects the quality of care that patients can expect from the NHS. In general, therefore, its clinical guidelines are accompanied by versions specifically written for patients and their carers. Where appropriate, they include advice on referral practice to specialist care and the urgency (on clinical grounds) with which this should be undertaken. The Institute's guidelines will form the basis of local "integrated care pathways" so that local health communities can decide for themselves the most appropriate approach to providing high quality care. The Institute is uncertain as to whether it is best placed to offer the NHS explicit guidance on access times and would wish to discuss this further with the Department of Health and the National Assembly for Wales.**

126. Such standards for clinical care as are established should distinguish clearly between those which are obligatory and must be observed, and those to which the NHS should aspire over time.

**Response: This recommendation is capable of two interpretations. Both are unacceptable. The Institute has always indicated that health professionals, when exercising their clinical judgement, should take its guidance fully into account; but that it does not override their responsibility for making appropriate decisions in the circumstances of the individual patient. This principle is important because even the best clinical guideline is unlikely to be able to accommodate more than around 80% of patients for whom it has been developed. Nor does the Institute believe that it is desirable for a distinction to be made between obligatory and optional standards at an institutional level. NICE accepts that, for some of its guidance the essential infra-structure may take time to prepare. All the Institute's formal guidance should have the same status. NHS organisations will need to**

**develop an implementation plan for each piece of guidance, identifying the resources, organisational changes as well as the timetable associated with its implementation.**

127 A timetable over the short, medium and long term should be published, and revised periodically, for the development of national clinical standards, so that the public may be consulted and kept aware of those areas of healthcare which are covered by such standards and those which will be covered in the future. Target dates should be set by which clinical standards will have been prepared for all major conditions and illnesses.

**Response: The Board welcomes this challenge. It, too, seeks to provide NHS health professionals with a comprehensive suite of clinical guidelines covering all significant areas of morbidity and mortality encountered in the UK. Effective and efficient planning of this programme will be greatly facilitated by the changes to the topic selection programme proposed in the Board's response to recommendation 41.**

**Although fully sharing the Report's objectives, however, the Board is anxious that a realistic time-scale is adopted. The national expertise in clinical guideline construction that incorporates both clinical and cost effectiveness is limited. The Institute must therefore increase the national capacity for clinical guideline production including the enlargement of its existing NCCs as well as possibly creating additional ones. Furthermore, there are finite limits to the rate at which the NHS can absorb, implement and resource enhancements to the quality of services given to patients. Careful planning, in close cooperation with the NHS and with the Department and the Assembly, will be necessary to achieve these goals.**

127. Resources, and any necessary statutory authority, must be made available to NICE to allow it to perform its role of developing, issuing and keeping under review national clinical standards.

**Response: Some changes in NICE's statutory basis will be required if the proposals for change are to be implemented. A very substantial increase in the Institute's funding (currently £12.5 million per annum) will be needed for its expanded roles. This will need to include provision for:**

- ?? The new topic selection programme**
- ?? An enlarged Board**
- ?? The expanded clinical guidelines programme**

**?? The expanded clinical audit programme**

**?? The Institute's associated infrastructure costs**

129. Standards of clinical care which patients are entitled to expect to receive in the NHS should be made public.

**Response: The Institute already places its guidance in the public domain and, in addition, routinely prepares versions of its advice (in plain English and Welsh) for patients and carers. It will continue to do so.**

## Monitoring standards and performance

### Local monitoring

143. The process of clinical audit, which is now widely practised within trusts, should be at the core of a system of local monitoring of performance. Clinical audit should be multidisciplinary.

**Response: Whilst the Board fully endorses this, it will require both effective leadership, and a major shift in clinical and managerial culture, if this goal is to be realised. First, clinical audit should be seen to include both the “process” of care, as well as the “outcome” of care, with the development of appropriate criteria and indicators for each. Second, the emphasis must be directed towards clinical audit as a learning tool, rather than a performance monitoring tool to enable health professionals to engage in it with enthusiasm (Pringle M, British Medical Journal, 2001;323:176). There needs to be recognition that effective clinical audit, including (as it must) both “process” and “outcomes”, requires the active cooperation of health professionals. Third, there is a real need for academic leadership in the field. The Board therefore proposes that the Department and the Assembly funds, by open competition either directly or indirectly through NICE, up to (say) six professorial chairs in clinical audit (with appropriate supporting staff) in English and Welsh Universities. This would give intellectual credibility in an area that is currently regarded, academically, with disfavour; it would stimulate research in a field where there is a real need for methodological development (e.g. indicators, case-mix); and it would provide a focus for education and training in the NHS. These chairs should preferably be sited in institutions with multi-professional undergraduate and postgraduate training**

**programmes, and with a geographical spread that maximises opportunities for interacting with the NHS.**

144. Clinical audit must be fully supported by trusts. They should ensure that healthcare professionals have access to the necessary time, facilities, advice and expertise in order to conduct audit effectively. All trusts should have a central clinical audit office which co-ordinates audit activity, provides advice and support for the audit process, and brings together the results of audit for the trust as a whole.

**Response: The Board, again, fully supports this. It is essential if local audit is to support the implementation of NICE's technology appraisal and clinical guidelines programmes. There is, though, a dearth of trained audit staff, in England and Wales, which requires the establishment of appropriate educational activities. The Board's proposals for the establishment of professorial chairs (as above) would go far towards meeting this need.**

145. Clinical audit should be compulsory for all healthcare professionals providing clinical care and the requirement to participate in it should be included as part of the contract of employment.

**Response: Whilst the Board supports this recommendation, it is dangerous to assume that a contractual requirement to participate in clinical audit will, of itself, achieve the objective of this recommendation. Compulsion should, rather, be a "back-stop" to ensure the engagement of (what will hopefully become) a very small minority of recalcitrant health professionals.**

### **National monitoring**

146. The monitoring of clinical performance at a national level should be brought together and co-ordinated in one body: an independent Office for Information on Healthcare Performance. This Office should be part of CHI.

**Response: CHI has a major role to play in ensuring that the standards of clinical care, as increasingly developed by NICE, are implemented in the NHS. The proposed Office for Information on Healthcare Performance would be an appropriate base for the Commission to undertake this.**

**The Board, however, has the gravest reservations about the proposal that the Institute's responsibility for clinical audit and the Confidential Enquiries be transferred to CHI. These anxieties are not based on a selfish desire, by the Board, for the Institute to retain its current portfolio of activities. Rather, it is because it**

does not believe that this recommendation would lead to the (implied) benefits. Since the issues relating to clinical audit and the Confidential Enquiries are different, they are considered separately.

### **Clinical Audit**

Under the current arrangements, NICE has responsibility for developing audit criteria, audit tools and audit data-sets arising from its guidance programmes (technology appraisals and clinical guidelines). These are provided, in part, to support local clinical audit but also to underpin the national audits carried out, on behalf of the Institute, by its national collaborating centres (NCCs). The Institute expects national audits to be designed, executed and analysed by the same NCC responsible for the original development of the guideline. The objectives of this strategy are as follows:-

1. It provides individuals, and groups (teams), of clinicians with a framework to monitor their own performance in relation to NICE's guidance (i.e. to facilitate local clinical audit).
2. It enables health groups (hospital and primary care trusts) to monitor their own performance in relation to NICE's guidance. This, again, facilitates local clinical audit.
3. It provides the essential elements for national clinical audits to be conducted for both comparative purposes, and to assess the overall quality of care in England and Wales.
4. It allows NICE, and the relevant NCC. To evaluate a particular clinical guideline for initial implementability.
5. It allows the particular NCC to define, and refine, the standard of care (sometimes described as a "benchmark") that can be expected in the real world of clinical practice. It should be appreciated that no clinical guideline, however well constructed, will be applicable to more than about 80% of patients with a specific condition. Since, at the time a clinical guideline is originally developed, it is impossible to predict with any degree of accuracy this figure, in routine practice, an iterative approach is needed to refine, and continuously improve, local and national performance. Moreover, it is the experience of every major clinical

guideline development group that some recommendations are found, *post hoc*, to be impossible to accomplish.

6. It is an important signal to alert the Institute and the relevant NCC that the particular clinical guideline requires revision.

**These objective will only be achieved by retaining the responsibility for clinical audit within NICE. If responsibility was to be transferred to CHI :-**

1. **The critical link between clinical guideline development and the subsequent clinical audit would be lost. This would lead to fragmentation of approach, and disappearance of the iterative link between the two.**
2. **Confusion between the roles and responsibilities of NICE and CHI would be inevitable. Who, for example, would take responsibility for deciding audit criteria, audit methods, audit data-sets, and for defining (and refining) standard “benchmarks”? For NICE these follow, both naturally and logically, from the development of its guidelines. For CHI, there would be a need to replicate the effort and expertise already expended in the development of the original clinical guideline.**
3. **Overall management by CHI would conflict with the Commission’s inspectorial function leading to clinical audit being regarded, primarily, as a component of performance management rather than (as this response has previously endorsed) a learning tool.**
4. **NICE has put in place arrangements for national clinical audits to be undertaken by its NCCs. The Institute believes that this arrangement is essential if the support and commitment of the professions is to be harnessed; and if the cohesion between audit and guidelines is to be maintained. The Board is convinced that neither local nor national clinical audits will succeed unless there is professional leadership. The Board fully accepts, and welcomes, the important role that CHI has to play supporting clinical audit. The Board believes that the Commission has the responsibility to ensure that local arrangements are in place to undertake clinical audit; that relevant clinical audits are being undertaken; that the audit “loop” is closed; and that there is universal participation**

in national audits. The Commission will also wish to access the results of local and national audits as part of its inspection programme.

### **Confidential Enquiries**

The Report seriously misunderstands the role and relevance of the four Confidential Enquiries by presuming that they are, or could become, part of performance monitoring. They are not. They are, essentially research tools for identifying patterns of practice, or service provision, that may be causally related to serious adverse outcomes (death or, in the future, near misses). The Institute has been working closely with the Enquiries, over the past two years, to create an environment that is capable and enhancing their potential to the NHS. Appropriate findings will, in the future, form the basis of new NICE guidance to the NHS. Given the status and broad acceptance of the Institute's guidance in the NHS and the fact that, in future, the product of the Enquiries will be issued to the NHS as NICE guidance, The Institute believes that their future contribution to improving standards of clinical practice can best be achieved by retaining the current management arrangements (which have only recently been put in place). The Institute would wish to explore, with CHI and the National Patient Safety Agency, how, jointly, the work of the Enquiries and their output can be best used to secure improvements in clinical practice.

147. The Office for Information on Healthcare Performance should supplant the current fragmentation of approach through a programme of activities involving the co-ordination of the various national audits. In addition to its other responsibilities, the new system should provide a mechanism for surveillance whereby patterns of performance in the NHS which may warrant further scrutiny can be identified as early as possible.

**Response: The Board, too, is unhappy at the fragmentation of approaches to clinical audit as it has explained in its response to recommendation 142. It welcomes the recognition that there should be a merger of both process and outcomes audit. The Office for Information on Healthcare performance would also have an invaluable role in examining correlates between the results of local and national clinical audits and other performance indicators. For reasons already discussed earlier, however, the responsibility for clinical audit should remain with NICE.**

## Information systems

149. Steps should be taken nationally and locally to build the confidence of clinicians in the data recorded in the Patient Administration Systems in trusts (which is subsequently aggregated nationally to form the Hospital Episode Statistics). Such steps should include the establishment by trusts of closer working arrangements between clinicians and clinical coding staff.

**Response: The Board agrees with the sentiment but emphasises that the requirement for both accurate data capture, and the development of scientifically robust approaches to issues such as outcome indicators and case-mix adjustment. In addition, it is essential that there is agreement, between those whose activities generate clinical data and those who use for management and planning purposes, on which data is meaningful to collect.**

150. The Hospital Episode Statistics database should be supported as a major national resource which can be used reliably, with care, to undertake the monitoring of a range of healthcare outcomes.

**Response: Subject to the caveats in its response to recommendation 149, the Board strongly supports this.**

151. Systems for clinical audit and for monitoring performance rely on accurate and complete data. Competent staff, trained in clinical coding, and supported in their work are required: the status, training and professional qualifications of clinical coding staff should be improved.

**Response: The Board strongly supports this but would also include the need to ensure the adequate training of audit staff.**

152. The system of incentives and penalties to encourage trusts to provide complete and validated data of a high quality to the national database should be reviewed. Any new system must include reports of each trust's performance in terms of the quality and time liness of the submission of data. The systems within a trust for producing data of a high quality, and its performance in returning such data in a timely manner to the national database, should be taken into account in the process of validating and revalidating the trust.

**Response: The Board believes that it is insufficient to merely provide incentives and penalties, to Trusts, for the provision of data to national audits and the Confidential Enquiries. Instead, requests to Trusts and their staff in relation to the provision of these data should be mandatory. This places an obligation on NIC to plan programmes in a manner that does not impinge unreasonably on individual clinicians' other activities.**

153. At national level, the indicators of performance should be comprehensible to the public as well as to healthcare professionals. They should be fewer and of high quality, rather than numerous but of questionable or variable quality.

**Response: The Board agrees.**

154. The need to invest in world-class IT systems must be recognised so that the fundamental principles of data collection, validation and management can be observed: that data be collected only once; that the data be part and parcel of systems used to support healthcare professionals in their care of patients; and that trusts and teams of healthcare professionals receive feedback when data on their services are aggregated.

**Response: The Board strongly endorses this. Indeed, unless such an investment is made, it is pessimistic about the prospects for fully effective clinical audit at either local or national levels.**

## **Publication of information about performance and standards**

155. Patients and the public must be able to obtain information as to the relative performance of the trust and the services and consultant units within the trust.

**Response: The Board agrees.**

156. As part of their Annual Reports trust boards should be required to report on the extent of their compliance with the national clinical standards. These reports should be made public and be made available to CHI.

**Response: The Board agrees**

## **Public involvement through empowerment**

157. The involvement of the public in the NHS must be embedded in its structures: the perspectives of patients and of the public must be heard and taken into account wherever decisions affecting the provision of healthcare are made.

**Response: The Board agrees and considers that its pioneering work in this respect is already providing the NHS with a benchmark.**

159. The processes for involving patients and the public in organisations in the NHS must be transparent and open to scrutiny: the annual report of every

organisation in the NHS should include a section setting out how the public has been involved, and the effect of that involvement.

**Response: The Board agrees**

161. Proposals to establish Patients' Forums and Patients' Councils must allow for the involvement of the wider public and not be limited only to patients or to patients' groups. They must be seen as an addition to the process of involving patients and the public in the activities of the NHS, rather than as a substitute for it.

**Response: The Board agrees and is already establishing a Citizen's Council to meet this need.**

162. The mechanisms for the involvement of the public in the NHS should be routinely evaluated. These mechanisms should draw on the evidence of what works.

**Response: The Board agrees**

164. Financial resources must be made available to enable members of the public to become involved in NHS organisations: this should include provision for payments to cover, for example, the costs of childcare, or loss of earnings.

**Response: The Institute already makes available financial support for patient/carer organisations to contribute to its work.**

165 The involvement of the public, particularly of patients, should not be limited to the representatives of patients' groups, or to those representing the interests of patients with a particular illness or condition: the NHS Modernisation Agency should advise the NHS on how to achieve the widest possible involvement of patients and the public in the NHS at local level.

**Response: Although the Board is sympathetic to this proposal, it has not found it possible to identify patients except through their associations and support groups.**

**National Institute for Clinical Excellence  
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