

NATIONAL INSTITUTE FOR CLINICAL EXCELLENCE

SPECIAL HEALTH AUTHORITY

RESEARCH AND DEVELOPMENT PROGRAMME

FIRST PROGRESS REPORT TO THE BOARD

The Board is asked to note this first report from the newly established Research and Development Programme.

Peter Littlejohns
Clinical Director

May 2003

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1 Background to the programme

1.1 From its inception, the Institute has recognised that it has a role to play in identifying and stimulating work in those aspects of health services and clinical research which support its guidance programmes. This interest falls broadly into three categories:

- Clinical research topics identified by the Institute's advisory committees and groups: the Institute seeks to refine research questions and promote interest by appropriate organisations in getting the research done;
- Methodological research into the analysis and interpretation of evidence: NICE will form partnerships with research funders, including NHS R&D and researchers to undertake this work and will commission some directly;
- Research into the impact of the guidance issued by NICE: work likely to be commissioned by NICE, often in partnership with NHS R&D.

1.2 A R&D committee was established in 2000 as a sub committee to the board. Its purpose was to:

- (i) Advise the board on strategic developments required to support the research base that underpins the Institute's recommendations to the NHS
- (ii) Establish good working relationships with other agencies which sponsor and commission R&D of relevance to the NHS
- (iii) Review and monitor quality control procedures for the R&D commissioned by and for the Institute, including R&D by Institute staff.
- (iv) Encourage the development of external research capacity upon which the Institute depends and to support and develop the research interests of the Institute's own staff
- (iv) Address other such matters related to R&D which may from time to time be referred to the committee by the board.

1.3 The membership of the committee was appointed by the board and comprised of 2 non executive members of the board, the clinical director, 3 members of the Partner's Council, a representative of the NHS R&D Programme and co-opted other members as deemed necessary. These

included all the Institute Programme Directors. It was chaired by Professor Tony Culyer

- 1.4 The committee was to meet not less than once a year and the minutes would be received by the board at its public meetings.
- 1.5 The committee has met on 5 occasions and supervised the commissioning of a range of research projects in conjunction with the Methodological Section of the NHS R&D Programme. These include the evaluation of the impact of the Institute's appraisal programme and the evaluation of the Citizen's Council. It is currently involved in commissioning an extensive programme of research into the public perception of QALYS. It has also commissioned directly a project to model the cost-effectiveness of beta interferon and glatiramer acetate.. It has forged links with the various arms of the NHS R&D Programme and hosted a session at the 2002 Clinical Excellence Conference which initiated discussion on how the uptake of NICE research recommendations in its guidance could be encouraged. It has supported a range of international workshops in Health Economics and Guidelines Methodology. It has not had the opportunity to forge as close links as it would have liked with research commissioners other than the NHS R&D programme because of lack of resources.
- 1.6 It has become apparent that while the Institute's prime function is the production of guidance on clinical and cost-effectiveness to the NHS, it has a lot to offer in supporting research and development in the relevant health economic and health services research disciplines.
- 1.7 Two events have taken place that have required the Institute to place a greater emphasis on R&D. Firstly the Institute has now completed the restructuring of the Confidential Enquiries. The new Confidential Enquiry in Maternal and Child Health, the National Confidential Enquiry into Patient Outcomes and the Confidential Enquiry in Suicide and Homicides are now in a position to concentrate on further developing their methodology in order to ensure they make a major contribution to the evidence base underpinning the Institute's Guidance. Secondly it is now an opportune time to explore more actively how the Institute could support research commissioning organisations and the NHS in responding to the research recommendations included in all NICE guidance - the results of which are required for subsequent updating of the guidance.
- 1.8 In seeking to ensure that these two challenges can be met, the Institute has established a new Research and Development Programme, with the appointment of two, part time, Research and Development Programme Directors, and is seeking Board approval for the establishment of an advisory Research and Development Committee to replace the existing Board sub committee. This advisory committee will work in parallel with the Confidential Enquiries Advisory Committee, chaired by Professor Catherine Peckham. Each committee will be supported by one of the new Associate R&D Directors: Professor Louise Parker – Associate R&D Director (Confidential Enquiries) and Professor Jeremy Wyatt – Associate

R&D Director. These posts will be supported by the newly appointed R&D Project manager, Magnus Anderson

- 1.9 The Clinical Director will be the Executive Director responsible for this programme and will represent the programme at Board and Senior Management levels.

2 Priorities for the research and development programme

- 2.1 An early priority will be to establish a database listing and characterising research suggestions identified by the appraisals, guidelines and interventional procedures programme. Part of this assessment will be an exploration of which suggestions have been taken up.
- 2.2 The Associate Directors and Project Manager will spend time over the next months establishing relationships with appropriate R&D bodies and forming an understanding of their work whilst promoting this new area of work for NICE.
- 2.3 The recruitment of members of R&D committee.
- 2.4 Preparation of an R& D strategy for the Institute.

3 Update from the confidential enquiries arm

- 3.1 The Confidential Enquiry into Maternal and Child Health (CEMACH) has now been successfully established, replacing the Confidential Enquiry into Maternal Deaths (CEMD) and the Confidential Enquiry into Stillbirths and Deaths in Infants (CESDI). The new enquiry was launched on 1st April. Professor Michael Weindling has been appointed to chair the new Enquiry. Professor Weindling is a Fellow of the Royal College of Paediatrics and Child Health and his clinical practice is as a consultant neonatologist at the neonatal intensive care unit at Liverpool Women's Hospital. He is also Professor of Perinatal Medicine in the Department of Child Health at the University of Liverpool
- 3.2 Work continues on the existing projects of all three enquiries. The Confidential Enquiries Advisory Committee (CEAC) continues to meet at quarterly intervals, and it is anticipated that work on improving the enquiries' methodologies will accelerate with the appointment of the new Associate Director.

4 Future arrangements for Research and Development

- 4.1 The Board will receive regular progress reports from the R&D Programme at its future meetings. These reports will detail the progress made by both the R&D and confidential enquiries arms of the programme.

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