NHS SERVICE DELIVERY AND ORGANISATION R&D PROGRAMME

PROGRAMME OF RESEARCH ON PATIENT AND CARER CENTRED SERVICES

CONCORDANCE, ADHERENCE AND COMPLIANCE IN MEDICINE TAKING

SCOPING EXERCISE

Introduction

As part of its continuing programme of work on Patient and Carer Centred Services, the SDO programme is now inviting proposals to conduct a scoping exercise on **concordance in medicines taking.** Its aim is to identify future research priorities in this area. It will consist of a literature review and conceptual map of the field.

The concept of concordance in medicine taking has been the subject of increasing interest in recent years. This follows a greater focus on 'shared decision making' in clinical practice, and earlier concerns about levels of adherence and compliance.

Research has suggested that "compliance" may be poor: approximately 50 per cent of patients may be non-compliant in their medicine-taking.[1] Non-compliance with medicine taking produces significant costs, which include:

- Costs to patients and families, in terms of increased morbidity and mortality which could be prevented.
- Costs to the NHS, in terms of wasted medicines at a time of increasing pressure on prescribing budgets, and in terms of unnecessary expenditure on preventable illness.
- Costs to society, in terms of lost working days and productive life, as well as carer costs.

There is reason to believe that these costs are rising.

Increasingly effective medicines are being made available for chronic conditions. Some of these need to be taken on a preventative basis over a long period of time to be effective: in these cases patients may not see or feel an immediate benefit. Examples of such drugs include statins and anti-hypertensives.

The increasing interest in "shared decision making" in the clinical consultation has occurred alongside ideas about the "autonomous" or "resourceful" patient and the Expert Patient Programme.[2] There is now a considerable literature on concordance and adherence, and much of it has already been collated by the Medicines Partnership.[3 4 5 6 7 8 9 10 11 12]

A variety of meanings have been attached to the terms 'compliance', 'adherence' and 'concordance'. 'Compliance' and 'adherence' are generally used to describe the extent to which patients take medicines as prescribed or recommended by a health professional. It is therefore possible to talk about adherence or compliance in terms of a percentage. For practical purposes 'compliance' and 'adherence' are interchangeable terms, although some researchers and practitioners prefer to use the word 'adherence' over 'compliance'

because it emphasizes the patient's right to choose whether or not to follow a recommendation, and may avoid a connotation of blame.[13]

'Concordance' is a more complex term but is generally used to describe two things:

- first, the ***process*** by which a health professional and patient negotiate a joint agreement about diagnosis and treatment, one in which the patient's views and beliefs about illness and treatment are explored and respected;

- secondly, the ***outcome*** in terms of the extent to which the patient agrees with, or 'buys into' the prescribing decision.

The rise of consumerism in health care has had effects in a number of areas, including concordance. Patients increasingly expect to be more involved in decisions about treatment. There is substantial evidence[14] to suggest that concordance is the key to achieving better compliance or adherence.

In addition, concordance may have other positive outcomes beyond better compliance or adherence. It may enhance patient safety, it may result in different prescribing decisions (more, less or different medications) which are more closely matched to patient needs, and it may result in better health through patients having a greater ability to manage their own condition, and a greater sense of responsibility for self-care. However, these hypotheses have proved difficult to test systematically.

Current call for proposals

The SDO Programme now wishes to commission a scoping exercise with two main aims: to produce a conceptual map of the area of compliance, adherence and concordance, and to make proposals for future research.

The conceptual map (or framework) should encompass the available literature, and also current major issues in the areas of compliance, adherence and concordance with medicines taking. It needs to embrace both relevant theory and evidence.

The conceptual map will need to take account of the various bodies of literature on compliance, adherence and concordance, including

- the prescribing consultation process

- the relationship between patients' beliefs, perceptions and attitudes, and compliance, adherence and concordance

- roles of different professionals including nurses, doctors and community pharmacists in enhancing compliance, adherence and concordance

- relationships between users and professionals, and the changing dynamic/ balance of power between users and professionals

- the expert, resourceful or autonomous patient, and self management

- the volume and the quality of medicines information provision, and where relevant, of information provision in general; relevant innovations in information provision and in decision support techniques

- patient/user communities and peer to peer support

- patients' information needs

- psychological/sociological theories of behaviour change and their relevance to compliance, adherence and concordance

- equity and differential compliance, adherence and concordance in relation to different patient/user groups contributing to a "health divide."

- internet access and effects on peoples' compliance, adherence and concordance with medication

- the economics of compliance, adherence and concordance

- methods for measuring concordance

- the outcomes or results of concordance and how these might be measured

The second aim of the scoping exercise is to provide a clear indication of areas and themes for further research (both primary and secondary) that:

- will fit with the aims of the SDO Programme as a whole,
- build on ongoing and previous research and evidence in the area,
- are relevant to the current NHS policy context.

The scoping exercise should cover all relevant aspects of compliance, adherence and concordance and important relevant associated bodies of literature.

Lessons from sectors other than health and social care may be relevant, but need to be presented in such a way as to indicate their relevance to the brief. Evidence from countries outside the United Kingdom should be included where relevant. Differences between different sectors (i.e. the public sector, the for-profit sector and the voluntary sector) should also be discussed, where relevant.

It will also be important to be aware of current ongoing research in the area and databases of research including; Department of Health National Research register: http://www.update-software.com/nrr/, RD Info: a comprehensive research register: http://www.rdinfo.org.uk/, and those held by the ESRC, MRC and Wellcome Trust.

Methods

Applicants should clearly outline their proposed methods for carrying out the scoping exercise. They should take account of the following points:

- It is expected that applicants will plan to use a variety of methods including: the research team's prior knowledge; search of electronic databases; and advice from key researchers and practitioners in the field.

- Methods for synthesising and mapping the findings should be described.

Applicants should bear in mind that our commissioned scoping exercises are not systematic reviews. They intentionally cover too broad an area. However systematic methods for assembling, collating, analysing and presenting relevant bodies of literature including grey literature will need to be described.

The topic is complex. A wide range of academic disciplines is required. Researchers from different paradigms will approach this challenge differently. SDO research requires a broad range of disciplines and approaches.

The applicants for this scoping exercise should assemble a team with the necessary range of disciplines, including for example: information sciences, communications research, organisational studies, economics, psychology and sociology.

Outputs

The principal output of this scoping exercise will be a final report that should provide a clear agenda for the SDO Programme on priorities for commissioning a programme of substantive research in this area.

The report should:

- Discuss the relevant conceptual framework or frameworks and provide a conceptual map of current major issues in the area of compliance, adherence and concordance

- Report the literature review findings

- Describe relevant theory and evidence relating to the conceptual map; which might include for example: relationships between users and professionals, the volume and the quality of health care information provision, innovations in information provision, ongoing patient support, equity and differential compliance, adherence and concordance in relation to different patient/user groups

- Clearly identify areas for further research and how they might be addressed. This could include both further reviews of the literature and/or primary research. Needs for methodological research or capacity building should also be described if they arise, although these would form recommendations to other NHS R&D programmes.

The report will be used to inform the SDO Programme on the approaches to take when commissioning substantive research in this area.

Successful applicants may also be required to make a short oral presentation of their completed report to the SDO Programme Board.

Guidance Notes

Applicants are asked to submit proposals by **Wednesday 28th January 2004 at 1pm to:**

Mr Damian O'Boyle
Commissioning Manager,
National Co-ordinating Centre for Service Delivery and Organisation R&D
London School of Hygiene and Tropical Medicine,
99 Gower Street,
London
WC1E 6AZ.

25 copies of the proposals should be submitted (minimum font 10pt), including:

Cover sheet	(Stating the title of project, reference number of the advertisement, names and contact details of the lead researcher and all other applicants)
Scoping Proposal	(**Maximum of 5 sides of A4 paper**, stating the aims and objectives, background, methods and project timetable)
CVs	(Brief one-page CV of each applicant, stating relevant knowledge and experience to undertake the work)
Costing	(Complete with staff inputs, equipment, consumables, travel and overheads)

The project should cost no more than **£80,000**.

The project should start no later than **April 2004** and be completed in **9 months.**

Please clearly label the outside of the envelope in which you submit your proposal with the following: **'Tender Documents'**. This will enable us to identify proposals and keep them aside so that they may all be opened together after the closing date and time.
Teams should ensure that their proposal complies with the Research Governance Framework, which can be found on the Department of Health website, or via a link on the SDO website under the 'Call for Proposals' page.

The successful team will be required to provide proof of research ethics committee approval for their project, if this is required (information regarding this can be found on the SDO website under the 'Calls for Proposals' page).

We anticipate that there will be informal discussions with NCCSDO during the period during which the report is prepared to clarify issues as they arise.

Applicants should visit the SDO website: http://www.sdo.lshtm.ac.uk
to familiarise themselves with the work of the SDO Programme in general and with previous scoping exercises in other topic areas.

REFERENCES

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[9] Cochrane Library February 2002, also summarised in the Journal of the American Medical Association JAMA 2002;288:2868-2879

[10] Bond Christine (Editor) *Concordance Reader* (in press)

[11] Royal Pharmaceutical Society of Great Britain From Compliance to Concordance: achieving shared goals in medicine taking (1997)

[12] Horne, R and Weinman J: Concordance: The research perspective in Christine Bond (ed) Concordance Reader (in press)

[13] For example, in Royal Pharmaceutical Society of Great Britain 'From Compliance to Concordance: achieving shared goals in medicine taking' (1997), the report of the working group at the Royal Pharmaceutical society which enquired into the causes of medicine taking problems.

Addendum

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk.