

**Minutes of meeting of the
Cochrane Skin Group UK Contributors
Oxford, 3 April 1998**

Present

Anne Eady, Steve Ersser, Sarah Garner, Andrew Herxheimer, Peter Lapsley, Alain Li Wan Po, Barbara Meredith, Sam Majumdar, Cath Milwain, John Newton, Terrence Ryan, Hywel Williams (Chair), Kayode Adetugbo (minutes)

1. Opening

Hywel welcomed members to this the first meeting of UK Contributors to the Cochrane Skin Group (CSG) after the Group's registration in December 1997. He explained all the work that the editors and other members had to do before formal registration and that it was now time to get on with the work of the Skin Group. He further explained that the main purpose of this meeting of UK collaborators was to set the agenda for the Cochrane Skin Group's Annual Meeting in June.

2. Progress Report on the Cochrane Skin Group

Hywel also gave information that the Trent NHS Executive R&D had provided infrastructure support to kick-start the Skin Group. This enabled the appointment of a Coordinator who started work in February. Since then, the National NHS R&D has approved further infrastructure support for the next 2 years, which will also enable the Group to employ a part-time Trials Search Coordinator. There is a Business Plan which spells out the anticipated output from the Group (in terms of numbers of registered titles and completed protocols and reviews, and other bench marks), and against which the progress of the Group will be monitored and evaluated. A progress report is due in 18 months.

Action: Hywel and Kayode

There have also been two research grants to members of the Group that will potentially boost the work of the CSG. The grants are for conducting systematic reviews; one is for work on eczema, and the other is for reviews on treatments for severe psoriasis. Both awards were in open competition from the National R&D Health Technology Assessment Board.

It is anticipated that some of the Protocols being developed within the Group will get into the July issue (No 3 of 1998) of the Cochrane Library, and that at least one review will be completed this year.

3. International Involvement

The meeting reiterated its commitment to firmly pursuing and facilitating international involvement in the Group right from the outset. Hywel informed that there is an effort to hold a Skin Group event at the 1999 March meeting of the American Academy of Dermatology. In addition, the editors are submitting a paper to the special evidence-based dermatology issue of the *Archives of Dermatology* to publicise the Group and its work.

The meeting advised that we should also negotiate such publication in third world dermatology journals, and also collaborate with the International League of Dermatological Societies to bring information to all those interested in all parts of the world. Moreover, the Group should build a web site to disseminate its activities and products.

Resolution:

To liase with Terence Ryan about placing a short article on the CSG in the newsletter of the International League of Dermatological Societies;

Kayode to set up a CSG website to publicise the Group's titles, protocols, reviews, meetings, and educational activities.

4. Prospective Register of Trials

The rationale for a prospective register of trials was developed and accepted. To be able to produce the best evidence, there must be timely access to all trials and their results. This includes published, unpublished, and on-going trials. The suggestions from the meeting included that the Skin Group should:

- 4.1.1. Liase with industry to get it to release its data before publication (Both Schering Healthcare

and Glaxo-Wellcome have agreed to this)

4.1.2. Negotiate with the British Journal of Dermatology (BJD) to declare a Trials Publication Amnesty, and to agree to publish trials protocols
Action: Hywel will discuss at next meeting of the BJD editorial board.

4.1.3. Work with the National Research Register, as all publicly funded research in England and Wales must be prospectively registered (Mark Starr of UKCC will be administering it).

5. Involvement of Consumers

It was agreed that the Group should continue to develop a systematic approach to involve consumers. Some of the tasks as outlined by Barbara Meredith include:

- Describing to consumers what the CRG is doing and what the Collaboration is about
- Openness and clear communication with consumers
- An outreach programme targetting consumers and their organisations
- Identifying the training needs of consumers, for example, for handsearching
- Identifying key people to act as coordinators/facilitators for consumer input
- Finding funds for consumer activities

Peter Lapsley indicated that patient groups such as the Skin Care Campaign may be in a position to provide resources (for training, transport, accommodation) for consumer participation in the work of the Group. It was also suggested that the Group should link up with other consumer groups internationally, such as the Mothers Union and the Acne Support Group, and also subscribe to consumer magazines.

Resolution: *Barbara, Peter and Hywel will work together on developing a more systematic way of involving consumers.*

Dr Ersser volunteered to facilitate the involvement of nurses as a group in the work of the Skin Group. He reckoned that, as nurses are always communicating with patients, they are in a good position to assist the Group with communication with consumers.

6. Other Items that were mentioned (to be discussed fully at the Annual CSG Meeting)

6.1. Quality Assessment and Outcome Measures in Dermatology

It was agreed that there was need to develop quality assessment tools that could be generic for the Cochrane Skin Group. To facilitate this, the editorial base should put in place an e-mail discussion group.

Resolution: *Hywel and Alain to draft quality assessment guidelines
Kayode to set up an e-mail discussion list*

6.2. Support for Reviewers

There was the suggestion that the editorial base should identify how it can support reviewers, for example, with space, statistics and other technical support, training. This is apart from the training at the Cochrane centres and resources available both within the Collaboration and in other evidence-based-medicine formations and sites.

Resolution: *To be discussed as an agenda item in the June meeting*

6.3. Rare Diseases

This concerns the issue of how to cover rare diseases and not to neglect systematic reviews of them.

Resolution: *To be discussed at the June meeting after further feedback from Luigi Naldi and the Mario Negri Institute in Italy*