

Summary

General aim of the project

The aim of the project is to improve the quality and dissemination of expert knowledge on an emerging group of patients: adults with rare metabolic diseases. Patients with these diseases hitherto often did not live to see adulthood in a reasonable condition, if at all. Expertise on this subject is limited and scattered among a few experts in the field.

This improvement is thought to occur through quality assessment of current expertise followed by presentation of the results in an accessible form on the Internet, a hard copy presentation and a set of training sessions. This means that there are four main ultimate products: A: Quality assessed body of knowledge; B: Internet site; C: Hard copy presentation; D: Training session.

There are 8 main operational parts in the project:

- (1): Formation of expert groups
- (2): Determination of relevant source material of sufficient quality
- (3): Quality assessment of current literature
- (4): Establishing the reviews for the dissemination process
- (5): Launch of the Internet site
- (6): Design of the hard copy
- (7): Design of the training session
- (8): Performance of the training session with presentation of the hard copy book.

Management

The contract period ran from December 15, 2000 to December 15, 2002. Operational management was done by the Co-ordinating Centre. Decisions were taken by the collective group of participants present at the meetings. Decisions were translated into practical policy by the Co-ordinating Centre.

Theoretical structure of the project

Source material

The review work is done by expert groups. They select relevant titles on the basis of literature searches done in databases by the Co-ordinating Centre. Abstracts from the selected titles are provided and the groups select the relevant abstracts. The papers from which these abstracts stem are provided to the groups as working materials. These working materials are subsequently used for analysis and writing of a review test. This review constitutes endproduct A (operational part 1-4), although it is a fluent and changeable product.

Dissemination

Dissemination first uses the Internet site, managed by the Co-ordinating Centre (UMC, Utrecht, The Netherlands); this is endproduct B. Second, the hard copy format is established and the hard copy produced by using the reviews of endproduct A; this is endproduct C. Thirdly, the design of the training session is made, filled with the endproduct A and performed; this is endproduct D.

Practical performance and adaptation of the project

Source material

In the two years of the project, 7 meetings have been held with partners in this project to initiate, monitor and adapt the process. During the first months of the first year, the six groups were formed, headed by an expert in the field as had been agreed in the design of the project. Each group had a distinct set of topics. These groups were to operate autonomously. The structure of the project as agreed started with the analysis of literature with identification of the sources of sufficient quality. At that point, a number of stumbling blocks occurred that necessitated adaptation of the project design and has delayed the development of the project. These stumbling blocks are:

Geographical spreading of members of a working group may be desirable from the prospect of Europe-wide initiatives, it severely slowed down the process. This meant that during the first year of the project, groups had to be rearranged. This also took time.

One group did not perform their task at all. This meant that the subjects and topics of this group has to be re-allocated and in the end the Co-ordinating Centre took on the major task of this group which means a long delay.

The autonomy of the groups was in practice too great for adequate functioning of the groups, reinforced by the fact that because it is a new field and because there is a limited number of experts, the members of the groups have an overloaded programme already and the credits are uncertain in this experiment. This means that currently the Co-ordinating Centre has a directive role in all the groups to ensure the optimal outcome.

The above-mentioned development have meant that there was a considerable delay in the course of the project and has also led to the investment by the Co-ordinating Centre of human and financial resources after the formal end of the contract period to allow the completion of the review process and the performance of the dissemination activities.

Dissemination

The three dissemination actions have been prepared. The Internet site for the TEAM-I project is available from December 1, 2003 with subsequent filling of the review spaces (endproduct B). The design of the hard copy has been agreed upon during the final contract-meeting on February 7-9, 2003 (endproduct C). The training sessions has been designed and agreed upon during the same meeting (Endproduct D). Due to the review delays, these three activities had to be postponed during the course of the project. The Internet site is launched but will be filled in the period January 1, 2004-July 1, 2004. The training sessions with presentation will be held for the first time from August 28-30, 2004, in connection with the meeting of the Society for the Study of Inborn Errors of Metabolism.

Presentations

The project leader has performed a number of activities to promote the TEAM-approach and products in general of the activities in this new patient group. There have been 15 activities, detailed in the General Report.

Outlook and perspective

There project now end the review stage and the dissemination structure for the use of the reviews is in place. This means that the aims of the project will be achieved in 2004. Thus, the objectives are achieved, but later then it was originally planned and agreed. The experience with such a project in a new field and in a network of collaborating partners throughout Europe has provided experiences that are used in the conduct and adaptation of the TEAM-2 project. By using these experiences in the TEAM-2 project, it will be possible to perform that project in accordance with the original design and within the time-framework of the contract of TEAM-2. A number of links has been established with other websites that can be found by visiting our site. The TEAM-1 products (hard copy and training session) will be available after the first performance.

Conclusion

The TEAM-1 project has met with difficulties in the first stage of the project (the reviewing stage) that required adaptation of the design of the project and considerably delayed the course of this stage. The second stage (the dissemination process) has been designed and is organised and can start with the completion of the review materials. The Internet site is launched; the hard copy will be presented at the first training session that will be held in August 2004.

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