Patient recruitment is one area where the Internet already offers a unique opportunity for sponsors, CROs and investigative sites to accelerate their enrolment rates and to more effectively manage communications between these parties and to the patient. The Internet offers:

1 A Unique Patient Population
Today, it is estimated that 15% of all searches conducted on the Internet are for health-related information. Patients suffering from chronic or terminal illnesses and their caregivers or family-members are highly motivated to find sources of information well-beyond their immediate health provider network in order to make educated decisions about their treatment options. Given such a high level of motivation, information on the Internet reaches well beyond the physician-referral network. The Internet reaches even beyond electronic boundaries as users conduct searches, and print and distribute material for others. The Internet's reach will continue to grow as usage increases.

2 Interactivity
Unlike other advertising and promotional medium, the patient is not passively informed. Rather, the patient is an active recipient both in terms of finding information and in responding to that information through electronic mail and discussion/chat groups. Patients on the Internet can provide immediate feedback and response; and they may have a higher likelihood of qualifying to participate in clinical trials as they more actively self-select.

3 Unlimited Exposure, Content and Accessibility
Whereas traditional advertising and promotional media offer finite exposure (e.g. a television or radio spot), the Internet is accessible to a highly motivated audience 24 hours a day, seven days a week. In addition, an Internet browser can return to the same page of information as often as needed. With the appropriate design, the amount of information provided can be almost unlimited in length.

4 Greater Recruitment Promotion Control and Co-ordination
Without exception, advertising and promotion for patient recruitment must follow GCP guidelines and must receive approval by ethical review committees. The Internet is no exception. But more so than any other medium, the Internet offers far greater centralisation and coordination with regard to the management of promotional material following approval. A Web site is not bound by geography — a patient can access the Internet almost anywhere — therefore eliminating the potential for variability across research centres in a multi-centre study.

In addition, several weeks to even months are often required to produce and place recruitment advertisements in newspapers, radio and television. Advertising and promotional information can be placed on the Internet almost immediately and this information can be easily edited and modified almost instantaneously.

Based on these benefits, the Internet represents an exciting and potentially powerful promotional medium. The purpose of this study was to test the viability and cost-effectiveness of using the Internet to recruit patients in clinical studies.

Methods
In the summer of 1995, CenterWatch developed and launched a World Wide Web site called the CenterWatch Clinical Trials Listing Service, and in late September 1995, CenterWatch introduced the service to industry through a variety of marketing programs. Throughout this service introduction period, CenterWatch has monitored traffic and usage of its Web site. Rather than record 'hits' to its pages, CenterWatch counts 'visits' or unique domain addresses.

Results
Overall, the CenterWatch Internet service has had promising results to date — both in terms of industry receptivity and patient/health provider usage. Since September 1995, over 2,000 international trials have been posted on the CenterWatch Web site by more than forty sponsors and CROs and approximately one hundred research centres. While the majority of studies are being conducted in North America, a growing number of studies are being conducted throughout Europe.

With few exceptions, sponsors, CROs and investigative sites are seeing good traffic to their approved study descriptions. For example, each month a study on a treatment for thrombocytopenia receives approximately 3,000 visits or 68 visits per research centre listed. An asthma study receives 660 visits per month or an average of 42 visits per research centre. And a pancreatic cancer study receives 700 visits or 25 visits per research centre. Presently, CenterWatch is working with sponsors and CROs to determine how traffic to the Web site translates into enrolled patients.

Patient and health provider traffic to the CenterWatch Web site has steadily increased by 15% each month since the service was introduced. At this time, approximately 27,000 patients are visiting the Web site each month. Moreover, patients are representative of most major therapeutic areas including cancers, skin diseases, diabetes, AIDS, and neurological and psychiatric illnesses.

The cost to use the CenterWatch service is significantly less than those associated with other promotional medium. Based on the average cost to run a newspaper or television ad, the Internet service is three to five times less expensive.

Discussion
To date, our experience using the Internet to recruit patients into clinical studies has been very encouraging. The Internet offers a unique promotional vehicle at an attractive price point. Most importantly, patients and their support network are responding to this medium. As such, the Internet appears to be a viable resource whose potential to accelerate patient enrolment will continue to increase as the medium gains more wide-spread acceptance.

More needs to be understood about the effectiveness of the Internet in terms of the number of Web browsers who are screened and then enrolled in clinical studies. Our ongoing experience using the Internet for patient recruitment will be very telling with regard to optimal usage and effectiveness.

As sponsors and CROs more actively assist their investigative sites in managing patient enrolment responsibilities, however, there is no question that the Internet will become a viable supplemental recruitment resource. As part of a portfolio of advertising and promotional medium utilised, the Internet will prove to be extremely valuable in meeting the growing challenges of patient recruitment.

Paper CA10 11:45 - 12:00

DESIRE for Medical Research

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Introduction
"Development of a European Service for Information on Research and Education" (DESIRE) takes as its starting point the burgeoning use of World Wide Web (WWW) technology as a means of locating, co-ordinating and publishing research data. For example an Orthopaedic Information Server (OIS) has been set up to provide an expert knowledge base that can be contributed to or used by researchers world-wide.

The aims of DESIRE include: Validation of Advanced Authoring and Information Management Tools, Information Services and Navigation Tools, Applications for Access to Research Results and Management of Research Networking Services.

The goal is to provide an integrated information service infrastructure for researchers in Europe so that it may comprehensively address the areas in which existing services fail to adequately meet their needs. The project aims to provide: a sustainable approach to making searching, finding, browsing, accessing and retrieving multimedia resources as easy as possible, tools for the creation, maintenance, quality, cost-recovery and description of information resources security mechanisms to control access to information resources, for reasons of confidentiality or charging quality mechanisms to permit the quality of information and information services to be monitored and reported performance features to reduce the international bandwidth requirements of access to multimedia information across the European continent.

Methods

The approach adopted has been to build on existing initiatives and to take advantage of existing tools and services. Prototyping has been employed for the purpose of establishing user requirements, technical feasibility, the user interface and the user friendliness of the system, in the following way:

1. Adoption of a coding system as a classification tree (Hamilton 1990). The coding scheme is possibly the single most important component in the makeup of the system.
2. The filtering and scanning of a large (60,000) collection of 35mm slides.
3. The provision of a suitable interface for the viewing of the scanned images (singly or in sequence) plus any associated textual information.
4. Introduction of indexing of all information objects enabling 'deep' searching of the resource so that all meaningful information related to a particular keyword is identifiable. This is accomplished primarily with the use of the <META> tag.
5. Provision of forms interfaces for the submission of comments about any object already in the knowledge base.
6. Establishment of a subject matter review panel to monitor and 'approve' additions/modifications to the resource.
7. Establishment/maintenance of mailing lists

The user may use different approaches to finding the information, based on the adopted coding system (Hamilton, 1990) in which every image has a unique identifiable number which is derived from manually traversing of a predefined tree-structure. Thus images are grouped by an increasingly specific subject based category. At the lowest level of categorisation the images are grouped and stored in an appropriately named directory. Along with each image is an associated text file with relevant information.

Although the mechanism for establishing the unique identifiers employs a tree structure the storage structure is a one dimensional string of directories within a single retaining directory. The directory name for a group is derived from the image group name. This makes it a relatively straightforward job to develop search scripts which appear to traverse a tree but which in actual fact move across a one-dimensional search space.

Frames-based HTML provides an excellent user interface whereby a group (sequence) of images may be viewed, in thumbnail format, in one frame with a single larger image in another frame and its associated text information in yet another. Drawbacks with using frames are that they are not universal yet and they are resource hungry.

All of the large images are held in GIF format so that the highest quality may pertain. Given that there may be as many as 20 thumbnail images being viewed at any one time these are held in compressed JPG format. Holding images in GIF format causes problems with bandwidth but a bottom line for the project has been to deliver the highest quality image possible.

A requirement of any good research based WEB site is the facility to link to other sites offering similar material. Thus, the OIS includes a comprehensive list of links to other Orthopaedic sites.

Results

The following services are provided:

1. Delivery of 35mm slides via WWW.
2. The inclusion of servers from other sites, providing fuller information to increase the value of the resource while maintaining 'seamless' use.
3. A facility to allow the user to compile sequences of resource pages of their choice for specific teaching or research purposes. 'On the fly' production of new HTML documents for specific applications, such as a lecture, self learning session, student tutorial.
4. 'Deep' searching of the resource.
5. Casual browsing of the resource
6. Browse the resource using an agreed classification scheme (Hamilton, 1990)

Several of the pilot services which are established during the validation phase are planned to continue subsequently as production services.

Component technologies have clear exploitation possibilities by providers of information services and by network operators, although the legal problems of providing secure information services, particularly across national boundaries, will remain. The DESIRE team will exploit the technical infrastructure to deliver a new information service.

Discussion

Research has always been an international activity in which collaboration takes place across national boundaries. The collection of subject-based information wherever it occurs has importance for ensuring the consideration of local and national cultural and linguistic requirements. Equally, the wide availability of research information services brings opportunities to less-developed regions and reduces the costs of unnecessary replication at the national level. Effective access to research information increases the opportunity for its commercial exploitation.

Pan-European collaboration increases expertise in the provision of information services. Significant contributions will be made to the provision of tools and procedures for the development and maintenance of information services which will not only reduce costs to the research community, but have exploitation paths in the commercial information economy.

References

Hamilton, J.J. *Orthopaedic Slide Management System.* AAOS. 1990.