

Using images of patients for learning and teaching – The BioMed Image Archive experience

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Introduction to the BioMed Image Archive and a discussion on the ethics of using patient images

The BioMed Image Archive <www.brisbio.ac.uk/> is an established collection of freely-available images for use in learning, teaching and research in the medical, dental and veterinary disciplines. The archive contains about 8500 images that have been donated by practitioners and teachers from across the world. Agreements were negotiated with donors to allow the digital images to be published via the Web and used freely for non-profit educational purposes.

The original approach to making the images available involved project-based quality checking and enhancement of images, and the cataloguing of images by librarians using the Medical Subject Headings scheme (MeSH) <www.nlm.nih.gov/mesh/meshhome.html>. Although this approach resulted in an overall high quality for the archive, it was found to be too costly in terms of time and staff effort to be sustainable in the long term. Therefore, an approach that could realise a more sustainable resource was sought, whereby many of the processes involved with image donation would be automated, and ownership of and responsibility for the archive handed to its community of users.

This new development phase has been funded by the Joint Information Systems Committee (JISC) <www.jisc.ac.uk/>, under its Focus on Access to Institutional Resources (FAIR) programme. The overall project aim is to encourage members of the biomedical community to share resources via the development of an infrastructure that will allow

individuals to deposit their own images with the archive from their desktops, and to add their own descriptive keywords. However, offering the community this degree of autonomy could lead to a possible loss in quality control and credibility. Thus it is particularly important to provide potential image donors with clear legal and ethical guidelines on what image content is and is not appropriate.

In biomedical subject areas, the use of images of patients has a high educational value, being powerful and immediate methods of conveying information, ideas and concepts. Consequently, it is in the community's interest to ensure the continued use of all types of images in an appropriate way. A contentious, but pressing, issue currently facing those in biomedical education is how they should approach the legal, moral, ethical and professional challenges of using digital images of patients. Addressing these issues fully will have implications for currently accepted practices and behaviours. These are issues that must be addressed and all those who use images of patients, whatever the educational context, must be prepared to modify their behaviour and presumptions.

The ethics of using patient images

Many patient images continue to be collected and used in biomedical teaching contexts, often with little thought given to the human and

moral rights of those portrayed in those images or how they might go on to be used or re-purposed by others. Increasingly, however, those who use images of individuals in electronic format are being called on to justify their actions and motives.

Perhaps no environment has been so challenged regarding its use of images and other patient-derived material than the biomedical world. The whole issue of obtaining consent from patients or patient representatives for using material for education and research has been highlighted by a number of recent events. In 1999, it was revealed that three UK children's hospitals had been harvesting hearts, lungs, brains and other organs from dead babies without their parents' informed consent. Thousands of body parts had been removed and kept in hospital storage. The subsequent inquiry <www.rlcinquiry.org.uk/> looked at what information parents were given and what they understood by 'consent'. The inquiry report stated that major changes in the law were needed to ensure that parents, patients and relatives gave 'informed consent' to the removal of organs during post-mortem examinations.

In a similar vein, almost 35 babies under a year old died at the Bristol Royal Infirmary between 1991 and 1995 as a result of alleged sub-standard care. The subsequent inquiry <www.bristol-inquiry.org.uk/> again found that children's body parts had been removed and stored without parental consent. Parents were found to have been given 'partial,

confusing and unclear' information. It was stressed that healthcare professionals have a duty of candour to patients and that 'there must be agreed and published standards of clinical care for healthcare professionals to follow, so that patients and the public know what to expect'. These incidents have led to changes in UK law and it is now illegal for staff to ignore informed consent.

Partly as a result of the cumulative effect of these events, and the climate of uncertainty and fear that has been left in their wake, the medical profession has had to completely rethink its practices in creating and using images of patients. The public is becoming increasingly aware of its rights to privacy and to be treated with dignity. It can no longer be assumed that members of the public will be happy for their images, whether recognisable or not, to be used for educational purposes.

Major issues and concerns

The BioMed Image Archive is leading an investigation of current practices across biomedical subject areas regarding the ethical and legal aspects of publishing and using digital images of patients for learning and teaching. Initial investigations have found that current UK guidelines on ethical considerations deal in a generic way with research materials emanating from individuals, but are lacking in specific guidance on the publication and use of image-based materials. The various guidelines can also be interpreted in a number of ways.

When using an image of an identifiable person for educational purposes, there are a number of questions and potential consequences that need to be fully considered.

Did the lecturer get permission from the individual to use their image openly for learning and teaching purposes?

If permission was not obtained, what actions could be taken by the person portrayed to ensure the image ceases to be used?

What are the legal and moral rights of the subject of the image?

Who would be legally responsible – the lecturer or his/her institution?

Were efforts made to remove identifying factors such as patient data?

Does the lecturer's institution or department have a policy regarding the use of such images?

Who is the owner of the images – the lecturer or his/her institution?

What are the legal implications for those who may have used non-consensual images without knowledge of their background?

There does not appear to be clear, agreed upon, consistently applied solutions to many of these questions. As a consequence, there is confusion and uncertainty about how to handle and use images of patients.

Many are still of the opinion that consent to use an image for teaching is not required if a patient is considered to be unidentifiable. No clear definition of what constitutes identification exists, however. The ability to identify an individual is based on more than facial features. Additionally, accompanying metadata (*i.e.* descriptive text) may render a depicted individual immediately recognisable.

Until recently, consent was not considered an issue in the collection of veterinary images. However, in an increasingly litigious culture, many teaching veterinarians are now obtaining consent from the owners of pets and other animals.

An additional factor influencing the archive's approach to careful image selection is new and amended legislation including the Data Protection Act <www.dataprotection.gov.uk/index.htm>, copyright laws <www.patent.gov.uk/copy/index.htm>, and EU Directives such as Communication to the Public Rights <www.euclid.org/issues/euclid/euclid.html#main1>, part of the European Copyright Directive.

Archive initiatives

The archive is holding a number of focus groups and debates around the UK involving academics, practitioners and educational technologists from the tertiary

education community. The aim is to pool knowledge, expertise and experiences in the area of patient images and to disseminate this collected body of information through the BioMed Image Archive. The project team has also been collecting examples of current guidelines and consent forms.

The outcomes of this research will be particularly important not only for the future BioMed Image Archive, but also for the existing collection. At the time that most of these images were collected (mid-1990s), it was not always practice to obtain the permission of the patients involved. This was particularly the case where images were likely to be completely unrecognisable, for example, a tissue sample or an X-ray. There are, therefore, questions about the ethical status of some of the images held.

The team hopes that through this ongoing research and with the backing and support of the community and experts in the medical and imaging fields, we can suggest ways of moving forward consensually according to an agreed set of guidelines for good practice.

Anticipated outcomes

Our aim is to devise a policy for the acceptance and Web publication of images portraying or derived from patients. Anticipated archive policy will be to hold and allow to be distributed only those images where informed patient consent has been obtained. This policy, it is hoped, will:

- Ensure the best possible and fairest treatment for the image subject, their relatives, friends, colleagues, and so on.
- Respect the dignity and integrity of those depicted in images and protect their privacy and identity.
- Make the archive an exemplar for others concerning the gaining of consent for patient images.
- Protect the archive and the University of Bristol from any liability or adverse publicity that might result from identification of a patient or an image where consent has not been obtained.

- Allow the community to feel complete trust in the archive and that any images can be used for a variety of educational purposes without fear of repercussions.

Conclusions

At the time of writing, we do not have all of the answers to the questions that we and others have asked. There is much work to be done in raising awareness of the issues and arriving at an agreed set of principles for handling patient images. There is a danger that uncertainty and apprehension may lead to the removal and destruction of visual resources that are (by their very nature) sensitive. In this worst case scenario, medical education could be restricted and diminished. The BioMed Image Archive is concerned that these uncertainties do not deter members of the biomedical community from sharing their patient images with others. Far from discouraging the use of patient images in education, we see great value in encouraging the use of these images in a legal and ethical way, so that all can benefit.

The archive has organised a one-day conference to discuss the issues concerning biomedical images, consent and permission. The conference will be held on Tuesday 6 January 2004 at the University of Bristol. For more information visit the Web site at www.brisbio.ac.uk/conference/.

We are keen to hear from anyone who has an interest in or an experience to share in the area of patient consent, or would like to be involved as an image contributor.

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NeLH Update

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As this is the December issue, it seems a good time to review the last year for the National electronic Library for Health (NeLH).

It's been a busy year, which kicked off with the approval of our Final Business Case www.nhsia.nhs.uk/helth/pages/documents/FBC_Executive_Summary.pdf and a comprehensive procurement exercise. The year has seen a few changes to the site, previewed via our Lab pages www.nelh.nhs.uk/lab, including the launch of a new Resource Management System. As we draw to the end of the year, we are expanding the team with six new members of staff and finalising our strategy and roadmap for the medium-term future. Here are some of the highlights of 2003.

Partnership working

One of the highlights of the year has been the opportunity to work more closely with health librarians, as the following examples show.

Core Content for the NHS

Following a successful European procurement in April, the Core Content Group launched, a portfolio of electronic resources for the English NHS. The portfolio consists of seven bibliographic databases (Medline, Embase, CINAHL, British Nursing Index, DH-Data, PsycInfo and AMED) via Dialog; a range of full text journals via Proquest and EBSCO; and an NHS-wide subscription to Biomed Central.¹ The NeLH links to the Core Content resources and is working with the Core Content Group to promote seamless access and an integrated service.

Digital Libraries Network

June saw the launch of the Digital Libraries Network (DLnet), an informal network for librarians and

trainers. Designed to support marketing and training activities in relation to digital library services and resources, DLnet has brought together over 170 individuals so far. Via a virtual community, they are able to share tips, tricks and know-how. An online support resource provides downloadable materials, links to useful resources and a know-how section www.nelh.nhs.uk/dlnet. One of the most popular tools has been a collaborative Weblog <http://dlnet.blogspot.com> enabling the sharing of ideas and experiences. At the time of writing, we have over 50 contributors registered.

Online learning

Earlier in the year, the NeLH experimented with online learning for librarians, as part of its Librarian Development Programme. NeLH commissioned SchARR Information Resources, experts in delivering training to health librarians, to deliver a pilot programme, called FOLIO. The pilot consisted of three modules: project management, service evaluation and evidence-based librarianship. Although there were a few areas for improvement, the courses were very successful with delegates quoting the convenience as a major plus point. A tender to deliver a 2-year programme of online learning was issued in October 2003.

Developing NeLH

Resource Management System

There have been some subtle changes to the NeLH over the year. One of the key areas for development has been the Resource Management System (RMS), which enables NeLH to