Proposing a 'Consent Commons' in open education

Balancing the desire for openness with the rights of people to refuse or withdraw from participation

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Abstract

A new 'Consent Commons' licensing framework is proposed, complementing Creative Commons, to clarify the permissions given for using and reusing clinical and non-clinical digital recordings of people (patients and non-patients) for educational purposes. Consent Commons is a sophisticated expression of ethically based 'digital professionalism', which recognises the rights of patients, carers, their families, teachers, clinicians, students and members of the public to have some say in how their digital recordings are used (including refusing or withdrawing their consent), and is necessary in order to ensure the long term sustainability of teaching materials, including Open Educational Resources (OER). Consent Commons can ameliorate uncertainty about the status of educational resources depicting people, and protect institutions from legal risk by developing robust and sophisticated policies and promoting best practice in managing their information.

Keywords

consent, digital professionalism, ownership, copyright, licensing, consent commons, good practice, risk management, educational resources

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Introduction

In order to effectively and openly share educational resources we need to establish and routinely adhere to legal and ethical good practice in relation to the rights inherent in original works, and to educate colleagues and students in the principles and behaviours of 'digital professionalism' (Ellaway & Topps, 2010). The long term usability of OER in healthcare education has been affected by changes in policy, technology and public opinion whereby some shared resources containing recordings of people (which complied with good-practice guidelines at the time of collection e.g. CyberAnatomy at Newcastle University, and the Bristol Biomed Image Archive) have since been 'locked down' to local virtual learning environments (VLEs) or completely withdrawn due to concerns firstly about the clarity of how the people depicted wanted their recordings to be used, and secondly about the clarity of ownership and licensing of copyright. Creative Commons (http://creativecommons.org/) has revolutionised sharing digital recordings/media by explicitly identifying author ownership and licensing of copyright works and how copyright works may be attributed, used and reused (e.g. cc: by-sa (Attribution-ShareAlike)), and supports the concept of 'fair use' by being explicit about how copyright works can be used for educational purposes.

In most disciplines attaching a Creative Commons licence to a copyright work is enough to safeguard the original author rights, but in the clinical field the rights of people/data subjects (particularly patients) also have to be taken into account, such as privacy (consent to take) and confidentiality (consent to disclose) (General Medical Council [GMC], 2008). These concepts are often conflated with copyright, leading to confusion regarding the status of use and reuse of educational resources in healthcare where copyright status may be clear, but consent is not (or *vice versa*). Consent is bound by principles and ethics, and practice may be improved with awareness and education (leading to permanent culture change). We also need new tools to help manage and communicate the importance of consent.

Past research has identified some excellent practice but a high degree of variability and a lack of clarity around how existing (as opposed to new) recordings can be made (Ellaway et al., 2006; Common Healthcare Educational Recordings Reusability Infrastructure [CHERRI3], Organising Open Educational Resources [OOER] funded by the Higher Education Academy and Joint Information Systems Committee [JISC] with support from the Higher Education Funding Council for England, and international experiences e.g. MedEdPORTAL and the Health Education Assets Library [HEAL]), citing, for example:

- A very wide range of awareness of the issues involved when recordings of patients are used in education, as opposed to the patient's care programme or in research;
- Clinical providers do not feel that they have responsibility for or control over the issues that arise once recordings of their patients are transferred into the HE sector;
- Universities are unaware of the risks posed by clinicians employed by the clinical provider, and with an academic honorary contract to deliver education in non-clinical (i.e. educational) settings, with materials which may have unclear consent;
- Many clinical providers declare ownership/copyright of recordings of their patients acquired on their premises, but do not have pre-written licensing agreements;
- Staff in universities are not always able to keep track of every project in their institution that involves the acquisition and/or use of patient recordings;
- It is currently very difficult for any teacher to find out what responsibilities, to the patient, to clinical providers and to their medical school, they are taking on as an individual;
- There is no easily accessible source of information, policy documentation or guidelines;
- Students and teachers increasingly use pre-existing patient images from the web without adequately considering its copyright or how it was consented.

Here we argue that copyright and consent should be treated separately, necessitating the development of a 'Consent Commons' framework to support digital professionalism recognising the rights of people to be treated fairly and with respect. This will help institutions to develop standardised policies and practice (Huston, 2004) around the creation and deployment of educational resources containing recordings of people, and better manage legal risks (OOER, 2010). It balances a desire for sustainable open access with protecting patients' and other peoples' rights and expectations of how recordings of them, especially if captured in a clinical setting, may be used.

Definitions

Digital recordings are defined here as any digital file (including but not limited to photographs; images such as scans, ECGs and X-rays; audio; video and patient data such as blood pressure or case histories) derived from people (patients and non-patients). The terms digital media, recordings and clinical recordings are used interchangeably in this document.

Patients and non-patients are defined as:

- Patients, carers, patient families and friends, etc;
- Teachers: academics, clinicians, practice/work based learning tutors;
- Clinicians, care workers, support staff, etc;
- Students;
- Role players, actors, performers, contractors (including members of a recording crew);
- Owners of products (where commercial products or brands/logos, etc., appear in recordings)..

Rationale

The Data Protection Act (1998) in the United Kingdom (http://www.legislation.gov.uk/ukpga/1998/29/contents) requires **"***anyone who handles personal information to comply with a number of important principles***"** (Information Commissioner's Office) and gives "*data subjects*" (individuals) rights over their personal information. A person's "*physical or mental health condition*" captured as part of healthcare treatment is considered to be "*sensitive personal data*" (placing additional requirements on data controllers and processers) under the terms of the Act (part 1.2). The Act also gives data subjects the "*right to prevent processing likely to cause damage or distress*" (part 2.10), and has parallels in EU legislation through the European Parliament (1995) Data Protection Directive 95/46/EC and the Organisation for Economic Co-operation and Development (OECD) 1980 (accepted 1981) guidelines.

The Act also states that **"***'personal data' means data which relate to a living individual who can be identified—(a) from those data, or (b) from those data and other information which is in the possession of, or is likely to come into the possession of, the data controller*", which has been used by some to argue in favour of anonymising personal data (General Medical Council [GMC], 2002). This may not be possible in the case of clinical recordings, or may not be able to be future-proofed if data from different sources is amalgamated in such a way as to recreate identification of the data subject. Making recordings available as OER would conceivably fall within "*organisation, adaptation or alteration of the information or data*" and "*disclosure of the information or data by transmission, dissemination or otherwise making available*" (part 1.1) there seems little choice but to ensure that all data subjects have given (and continue to give) their informed consent. When gaining consent we enter into a contract promising to respect that person's wishes at the time of collection, taking responsibility for the storage, use and reuse of recordings, and renewing consent, if necessary. Responsibilities apply at both organisational and individual level, and are transferred when recordings move across boundaries hence the consent status needs to be an explicit part of the recording and, in a clinical context, signed consent forms for treatment, research and/or education should be stored with the patient record (OOER, 2010).

Authentic patient encounters are vital to good teaching and learning within the healthcare professions. Patients, their families and healthcare workers are often willing to collaborate with educators by sharing their story as told in a podcast, video or acted out by a role player; allowing recordings including photographs and x-rays to be taken for teaching purposes; or agreeing to their 'case' (medical history/patient record) being adapted for presentation to students, etc. Healthcare workers, academics, students and other people (such as contracted film crews and actors) often participate in the development of such resources. All of these are entitled to be treated with respect and in some cases (actors) professional bodies or guilds may have their own rules about how recordings of that person may be used and reused.

Equally there are many reasons why a person may wish to refuse or withdraw consent. They may not want digital recordings of them (whether anonymised or not) appearing in educational resources distributed openly via the Internet; they may become well and prefer to avoid a continuing reminder of a time when they were poorly; they may die and it is a family request that the recording is removed or replaced. Risk-aversion predicts that organisations will want to have policies covering what they will and won't do to comply with such requests, regardless of their legal obligations.

We need flexible and accessible tools to help people to review how their recordings have been distributed and sophisticated 'take down' policies so that data subjects can take responsibility for monitoring how recordings are used and reused (otherwise the practicalities of renewing consent where recordings are used in educational materials may become overly burdensome). Where a person wishes to withdraw their consent it may not be possible to remove all copies of that recording from the Internet, but it may be possible to alert users to the fact that a recording has been 'taken down', removed or replaced.

In the United Kingdom those who consent patients for recordings (employed by NHS) are not always the same as those who wish to use the recordings in education (academic institutions). Responsible users of educational materials containing recordings of people will want to satisfy themselves that the recordings have been captured, consented, kept and transmitted in accordance with best practice and respect, even if they don't have access to copies (because of data protection).

A Consent Commons licensing framework would clarify the policies and terms under which consent was managed. Consent Commons extends the concept of a 'Clinical Commons' originally proposed by Ellaway, et al. (2006), which recommended an additional licensing necessary to ensure the sustainability and 'openness' of online teaching materials involving clinical recordings.

> "Clinical recordings (such as images, videos and scans) have long been one of the mainstays of healthcare education. In recent years the subject matter of such images has remained largely constant but increasingly they are recorded digitally and viewed online. This new format and medium has so enabled duplication and onward transmission of recordings that processes and guidelines created to safeguard patients' interests and guide the practice of clinicians, teachers and technicians no longer fulfil their purpose" (Ellaway, et al., 2006 p1).

Consent Commons

The proposed Consent Commons licensing framework is a data subject version of Creative Commons and has the following characteristics:

- Complements Creative Commons to identify the consent status of recordings of people appearing in educational resources;
- Is a set of principles reflecting best practice, not an automatic right (like copyright);
- Accepts a basic human right for people to refuse digital recordings of themselves appearing and, where they have previously consented, their right to withdraw that consent;
- Works like Creative Commons in that educational materials would be hallmarked with a licence illustrating the consent status, and when consent needed to be reviewed or withdrawn;
- Has levels of release (e.g. closed, 'restricted', open but review [date]; fully open, etc.);
- Requires technology to enable data subjects to review recordings, and OER to be able to 'check for updates/status' and warn users if resources have been withdrawn or updated/replaced (OOER, 2010).

Future Developments and Changing Culture

While guidance and toolkits are being developed to influence policy regarding reusing medical images (CHERRI3) and good practice in creation of digital education resources (OOER, 2010) there is a fundamental requirement to promote continuous improvement in digital professionalism. Further work is taking place in the United Kingdom through a '*reusing medical images*' project (Williams and Jacobs, 2009) which has created a taskforce of stakeholder organisations expected to generate consensus around high-level standards and guidance. The GMC has consulted on their 2002 guidance on *making and using visual and audio recordings of patients* which is due to be published in 2010 and is reviewing their 2008 guidance on consenting the use of clinical recordings to be used in teaching (in addition to clinical treatment and research).

Ellaway et al. (2006) recommended "*all creators and users of clinical recordings be better educated and supported in the use of such recordings and that this training and support is normalised as much as possible both for quality assurance and economies of scale purposes*". The Higher Education Academy MEDEV Subject Centre is running workshops on applying digital professionalism when creating and using educational resources as part of the dissemination of the good practice risk management toolkit developed in OOER (2010). Some of these are aimed at encouraging best practice behaviours among role models in programmes teaching clinicians to teach as "*most learners are still strongly led by tutors and course practices: tutor skills and confidence with technology are therefore critical to learners' development*" (Beetham at al., 2009 p2). Two new OER projects will continue to develop the concepts of Consent Commons in collaboration with the United Kingdom national repository JorumOpen.

Conclusions

Creation of a Consent Commons licensing framework is a radical proposal to safeguard the long-term sustainability of OER containing recordings of people arising from the clinical education community in the United Kingdom. The concept requires further discussion at an international level and we would welcome input from the international OER community. Here we have argued the need for a Consent Commons as a tool supporting the development of policy and process around the rights of people to refuse or withdraw their consent, and the need for permanent culture change and the growing concept of digital professionalism. We also need new technologies around OER to enable users to take responsible decisions about using or reusing OER containing recordings of people.

For such a proposal to be accepted widely, it must have at its core, common principles and standards but ones which enable organisations to take into consideration local contexts and accountability. Consent Commons, to be successful, must work at a level that incorporates and supports national policy and guidelines where they exist, enables institutions to mitigate risk and enact robust policies and codes of practice and help individuals be clear how resources can or can not be reused.

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Jane has worked in the field of technology enhanced learning for over 20 years. She currently leads the adoption and development of digital technologies to support undergraduate medicine at the University of Bristol and manages a wide-ranging portfolio of local and national projects and initiatives. Her research interests include: staff-student partnerships in the co-development of online educational resources; the role of technologies to develop effective e-learning practice, and developing working solutions in the areas of copyright and patient consent for educational materials. Jane was a partner in the Organising Open Educational Resources (OOER) one-year pilot project where she led the development of a toolkit for managing patient and non-patient consent. She is currently a subject expert to the Common Healthcare Educational Recordings Reusability Infrastructure (CHERRI3) project developing high level standards and advice on issues relating to reusing medical images.

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Megan has worked with the Subject Centre since 2000, prior to which she was Deputy Director in the Faculty of Medicine Computing Centre at Newcastle University. She gained her PhD in the use of educational technology and has research interests in hypermedia. She has led >£10M educational development projects at Newcastle and contributed to >£40M led by others. She was awarded a Newcastle University Teaching Fellowship in 2005 and serves on many local and national committees such as the Higher Education Academy/JISC joint operational group. She is an inaugural Fellow and founding member of the Academy of Medical Educators and has run many international and national workshops including for IMS-Global and the eUniversity project in the

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