OER IN HEALTHCARE - LEGAL AND ETHICAL CHALLENGES

DESCRIPTION

Suzanne Hardy, Senior Advisor, MEDEV Subject Centre, Newcastle University, talking about solutions to the licensing issues encountered in OER projects.

http://tinyurl.com/6wvzjj5

Transcription

Who are you and where do you come from?

My name is Suzanne Hardy and I am from Newcastle University in the North East of England. I work in the School of Medical Sciences Educational Development and previously have been senior advisor for the Higher Education Academy Subject Centre for Medicine, Dentistry and Veterinary medicine.

Can you describe your OER project?

I have been involved in several OER projects. The first one was in the OER phase 1 pilot projects and we had a project called 'Organising Open Education Resources' with 18 institutions involved. That was quite a big project and quite difficult to coordinate, but it gave us a really good grounding in what the particular problems were in healthcare education, which is where we were coming from specifically with that project. That led onto PORCHE which was Pathways to Open Resource Sharing in Healthcare Education…. thorough *Convergence* in Healthcare Education sorry.... that one was a collaboration between the University of Newcastle primarily and the London deanery and enabled us to explore in some detail some of the problems that had come out of the phase one project. The particular ones that were of interest, through the collaboration with the London deanery, were the differences in NHS and academic settings and looking to explore issues of consent more. That was something we came across quite a lot. And concurrently with that one we had the project called ACTOR which was one of the OMAC projects and we have recently been funded through Phase three to do 'Publish OER' . So that one is underway now and that one is working with publishers to explore how we can look at content from publishers and how that might be incorporated more easily into Open Education Resources.

What from your perspective, make/makes your project special or different, particularly with reference to licensing OERs?

I think what is special in healthcare education; there are two things that are special. The first thing is that we work across both NHS setting and academic settings on a day to day basis. So students are not always based on campus and staff often have more than one role. They can be academics who have an honorary contract to deliver clinical work in NHS. Conversely they could be clinical people employed by the NHS with an honorary contract to deliver education for universities. And that gives us all sorts of problems for access for a star. The NHS net and JANET are separate networks. There is a N3 gateway that bridges across the tow of them. However, the priority of the traffic across that gateway is patient centred so education falls down the list. The other thing that is particular to clinical education and Medicine, Dentistry and Veterinary medicine is that we have the involving of patients in the delivery of education. The recordings of patients are used quite extensively in healthcare education. Therefore we didn't just have issues of IPR and copyright to deal with. We had the same issues as everybody else with those. People were applying cc licences wrongly, they were unsure about what they were, they didn't know who owned the copyright to the materials and that's replicated equally in both the NHS and in academic settings. But we also had the additional challenge of thinking about schedule 2 in the data protection act and how that affected consent for patients who had given their permission for their recordings to be used in healthcare education but possibly hadn't given their permission or consent for those recordings to be used more widely and shared outside of the immediate setting that they were originally intended for. So that was a big area that needed exploration I think for us.

What are the IPR issues and Challenges you have faced in your project?

Some of the IPR and licencing challenges that we have faced in the projects that we have done so far in Medicine, Dentistry and Veterinary medicine have I think probably been similar to other peoples. We have the same problems in that people don't know which content is theirs, they cannot remember where the content came from. We have problems of orphaned works, that we haven't a clue where they have come from but they still on the VLE somewhere. There are the challenges that material might have been openly licenced incorrectly, is therefore shared when perhaps it shouldn't be. And we cannot of course revoke those licences, so there are some challenges in trying to find out where that stuff had originally been made. If its NHS licenced materials, often the department where it was originally created, because of the numerous shake ups that have happened in the NHS over the years, has actually disappeared. So it is quite difficult to find the person that originally commissioned that material or who made that material. So that material was really challenging to find out where the rights lay with it. The issues of consent, which aren't directly to do with IPR or copyright, but we kind of think of them in a third strand when we talk about the projects that we work with because it is very difficult, conceptually, to divorce the ideas of IPR and copyright from the issues of consent. Because the person who made the material, that might have a recording of a person in it, has the copyright but there is an ethical question there. I think the ethical side is something that is something that has been more easy to explore in healthcare related projects. However I think the

issues of consent go beyond healthcare education and they are very pertinent to everybody in fact. If we think of it as a continuum where we have patient at one end of the continuum, who are protected by schedule 2 of the datd protection act, and we have performing rights at the other end of the spectrum, where actors and performers are protected by performance legislation. But there are people in the middle, they are becoming increasingly aware through the media, that their images can be used and reused and images of them can be captured and used in things like news broadcasts and appear on things like Facebook without their consent. So there is something about the ethics of whether that is right or not. And of course we are all people and sometimes we are patients so we have extra rights when we are patients which somehow disappear again when we become well. Plus the fact that patients, when they give their consent for their recordings to be made of them in a clinical environment, are often quite vulnerable and may not very well. And therefore when they are well again they may change their mind about whether they want that material to be used in education or shared. It's very rare that that happens, most patients are incredibly supportive of having their material used in medical education and they want to help other people. They want other people to benefit from the service that they have had from their clinicians and they are very aware of the fact that education has to happen and their involvement is crucial in it. But there are occasions, when for example somebody might die and the family would want the material to be taken down it to be taken down and therefore there is another ethical side, another question that we might want to explore there. I think ethics and consent are something that have been particularly pertinent to the clinical education OER programmes that we have been involved in.

How have you overcome them? Can you indicate the tools you have used?

So in order to overcome the challenges that the OER projects that I have been involved in have faced, around consent and copyright. We have used the tools that have been provided and developed during the course of the projects. And the IPR support toolkits have been really helpful in that, there are other tools that have come from elsewhere, for example the General Medical Council have released some new guidance on making and using audio and video recordings of patients. Which wasn't incorporated into any of the other IPR and copyright tools. And therefore we felt the need to bring all that kind of guidance's together to form our own toolkit which we called the 'Risk-kit', which is to help people evaluate the risk in their learning and teaching materials. It also incorporates all the stuff around consent and what to do if you have got recordings of people or recordings of animals in your learning and teaching resources. And they may not always be patients they could be other members of healthcare staff, other members of academic staff, other students, families, carers, all kinds of things; so what to do when you have got those people, and also what to do if you have got cadaveric materials. Again that is not covered anywhere else. It is quite easy to know what to do with cadaveric materials… you don't share them. The rest of the, the alive people there is a lot of guidance incorporated into the Risk-kit, which also incorporates the guidance from JISC legal and the tools they have funded, and places like the General Medical Council. What we have tried to do is bring that all together, and we are still constantly updating that as we think it is important to do so.

How did the OER IPR support Team tools make a difference?

I think the OER IPR support team tools have been absolutely invaluable in helping us to put the Risk-kit together. We used the, for the decision support risk kit that we developed, we used the work flow diagrams that had come out of the OER IPR support team. We also used seven of the templates we looked at the model release letters and things like that. They have helped us form the basis for the kind of patient consent materials that we have developed from those in the Risk-kit. Without the stuff that had gone before through Web2Rights and OER IPR more latterly I don't think we would have been able to develop the kits we have.

As well as working with ideas of consent we really wanted to come out with something practical. So Jane Williams, from Bristol, who worked with us on both the OOER project and PORSCHE, Jane and I were asked to go down to the general medical council to help them with their new version of making and using audio and visual recordings of patients. And one of the biggest outcomes, I think of those two projects, is that learning and teaching is actually explicitly mentioned in that GMC guidance. What came out of that was another project funded by the JISC, via a workshop that was held back in November 2010. To bring together a task force to look at how we might put together some guidance that went beyond the simple GMC guidance, which is in itself useful. There is other stuff out there form places like Welcome Images, the Institute for Medical Illustrators. Which are bodies that are well respected within areas that we work in in health care education, but it was quite disparate, all of that material was quite disparate. And so the task force, which was run from and via the Strategic Content Alliance of the JISC brought together people from the MEDEV Subject Centre, where I work, Jane Williamson from Bristol and some clinicians from Bristol who she has done a lot of work on IPR and consent on, Welcome Images the Institute for Medical Illustrators and the General Medical Council. We put together some guidance in the form of a tool kit, which is available from the JISC digital media website. That's something that doesn't exist anywhere else and without those projects I don't think the Strategic Content Alliance would have been able to have funded that material. There is still alto of dissemination on it but I think that together with the new guidance of the GMC we are really proud that the have come out of the OER projects that were funded through the UK OER programme, and really pleased that we were able to extend that funding from beyond that programme into the work that the Strategic Content Alliance does.