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Education paper

Sickle cell in the university curriculum: a survey assessing demand for open-access educational materials in a constructed community of interest

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What is known on this subject

- Sickle-cell disease is increasingly recognised as a major and global public health issue, although university graduates in health professions appear to be ill prepared on the subject.
- Sickle cell is an important topic within university curricula, offering an entry point to the study of anatomy, physiology, biochemistry and genetics, and an exemplar for exploring the role of diverse scientific technologies.
- Lack of knowledge about sickle cell among health professionals has contributed to tensions in delivering appropriate healthcare.

What this paper adds

- There is growing interest in the concept of open educational resources (OERs), which provide a way of making educational resources available to university educators.
- There is a demand for OERs about sickle cell, providing the quality assurance of such materials is addressed.

ABSTRACT

Successive UK governments have sought to support expanded teaching of science, technology, engineering and mathematics (STEM) subjects within university curricula. There is an increased expectation that the education of health professionals will enhance their knowledge of genetics. Sickle-cell disease is both a genetic condition and a major public health issue globally that is neglected in university curricula. An Internet survey involving 226 respondents from sickle-cell communities of interest (science educators, health professionals and voluntary groups for sickle cell) found greater awareness of educational resources on popular Internet sites than on formally constituted academic repositories for open education resources. Sickle cell was widely seen as an important topic for open education resources. These began in the USA in the 1990s but have only more recently received attention in the UK. A project developing such sickle-cell resources within a repository of open education resources has been proposed to and funded by the UK's Higher Education Academy (HEA) and Joint Information Systems Committee (JISC). From 2011, 'Sickle Cell Open: Online Topics and Education Resources (SCOOTER)' will develop sickle-cell open education resources, which can be found on its website (www.sicklecellanaemia.org).

Keywords: genetics, health professional education, open education resources, sickle cell, STEM subjects, university curriculum

Introduction

With the growth of the Internet has come a paradox for educators. The volume of available electronic resources that could be used for learning has grown exponentially, but much of the material is copyrighted to commercial publishing companies, making it expensive to download and impossible to adapt without securing permission. It has been estimated that, in 2007, 'publisher costs relating to UK-authored publications probably amounted to around £575 million' (Houghton *et al*, 2009, p. xi). As a result there is now increasing interest in the potential of open-access materials for UK universities (Friend and Swan, 2010).

In this article, we outline the meaning of open educational resources (OERs). We report on initiatives by the Joint Information Systems Committee (JISC) and the Higher Education Academy (HEA) in the UK to promote the concept of OERs and to begin the complex task of laying down resources for future use by the Academy and other communities of educators. We then introduce the topic of sickle-cell disease as an example of a themed collection that could be developed for open access. We outline why sickle cell is a topic of growing global importance. We also examine how and why the unique character of this disease could and should be embedded not only in the education of health professionals for diversity, and in the science, technology, engineering and mathematics (STEM) subjects, but also in social sciences and the humanities. We then report on an Internet survey of university lecturers, health educators and communities with an interest in sickle-cell disease. The aims of this survey were to assess perceived needs for OERs and to help to construct a community of interest in developing sickle-cell resources. We conclude with some thoughts on the implications of OERs for working with diversity in healthcare.

Open educational resources

The concept of building learning communities and sharing resources first emerged in the late 1990s. MERLOT (Multimedia Educational Resource for Learning and Online Teaching) originated in 1997 from the California State University Center for Distributed Learning with the purpose of making available a tool to share learning materials and form a community of users (California State University, 2011). Resources are licensed under Creative Commons, and there are processes for peer review. Learning resources range from assignments and animation to tutorials and training materials.

The term 'open education' emerged slightly later, in 2001, with the Massachusetts Institute of Technology (MIT) making educational materials freely available on the Internet. This initiative grew into the OpenCourseWare Consortium (OCWC). This consortium publishes quality educational materials which are structured either as courses (such as health sciences and technology, humanities, arts and social sciences, and science) or as cross-curricular subjects (for example, energy or the environment). The consortium now operates in collaboration with over 200 global educational institutions. Materials include syllabi, lecture notes, assignments and exam questions (OpenCourseWare Consortium, 2011).

OERs are materials that are thus open in the sense that they are made available to a wider community to draw upon free of charge, although in all cases the author/copyright holder is acknowledged. One such example is the notion of Creative Common Licences (Creative Commons, 2010), which enables creators of intellectual and artistic work to denote their authorship but to define the conditions under which their work may be freely shared, drawn upon and modified. It could be argued that the emergence of Creative Commons in 2002 was itself a catalyst for change, as it made available a range of simple-to-use copyright licences warranting various degrees of use. Some OERs may also subscribe to broader principles, such as wide participation in updating content based on asynchronous contributions from a network of volunteers. OERs can consist of a range of granularities. The smaller the portion of information that it contains, the more granular an educational resource is said to be. For instance, a single learning object, such as a diagram or graphic used in a lecture, is more granular than a complete course presented in a format which prevents it from being broken down. It is argued that content in granular pieces of information at the lowest level of aggregation can be more readily used and reused in educational initiatives (Jonassen and Churchill, 2004). For example, exposing the raw programming code behind a computerised animation resource gives the user of the open educational resource maximum flexibility to take the resource and adapt it to their specific educational purpose.

The UK was approximately a decade behind global developments in OERs by the time the Open University launched OpenLearn in 2006, offering a full range of academic content packaged as learning units that are openly available for use on the Internet via their OpenLearn portal (Open University, 2011). Two national bodies have now demonstrated an interest in the concept of OERs through recent funding initiatives. The Joint Information Systems Committee (2009) promotes best use of information and communications technology (ICT) by colleges and universities, and the Higher Education Academy (2009) aims to improve

research and evaluation of the learning experiences of university students, including the University Teaching Fellows Scheme. Some of the current authors have participated in the early stages of these initiatives. For example, VR participated as project partner with the UK Bioscience Centre in the OER pilot phase. The Virtual Analytical Laboratory (VAL) project released laboratory skills resources in the form of video, animations, audio files and text (Rolfe, 2010). VAL is routinely used by De Montfort University science undergraduates (Rolfe, 2009), and has had an impact on the UK bioscience community. VAL engaged a small staff team in the university's Faculty of Health and Life Sciences (HLS) to produce open content, and this in turn initiated a strategic change at the university, leading to OERs becoming part of the university's Technology-Enhanced Learning Strategy. The outputs of the VAL project and other OER pilot projects (Ellis, 2009; Caledonian Academy, 2010) point to two fundamental challenges for the OER agenda, namely how to lead and manage a cultural shift towards a more open way of working, and how to provide support for staff with the discovery, production, use and reuse of OERs. Meanwhile, the current educational policy focus is on generating suitable OER material that accords with other, wider priorities for higher education.

The ongoing aim of the UK JISC/HEA Open Educational Resources programme is to make available a wider range of academic content in a range of granularities, from complete courses to individual raw asset files. This will serve to encourage users to disaggregate the content and reuse it in new educational contexts. The Jorum service in the UK, funded by JISC, was launched in 2006 to encourage educational institutions to share learning materials, and to maintain interoperable standards. Resources in JorumUK are licensed free to UK education institutions only. JorumOpen was introduced more recently, in 2010, to make resources deposited there freely available, on a global scale, under Creative Commons, and since its launch it has amassed over 10 000 items (Joint Information Systems Committee, 2011). The growing academic interest in OERs also dovetails with wider developments in which the cultural explosion of Internet mass media has facilitated the distribution of user-generated content via services such as YouTube and iTunes, which have added educational components. On YouTube EDU institutions apply for a channel on which to submit video content (YouTube, 2011), and on iTunes U institutions apply for and enter into a service agreement (Apple, 2011).

In the UK, the broader societal priorities set by successive governments for higher education include the expressed strategic need of government support for universities in producing more STEM graduates (Department for Business, Innovation and Skills, 2010), and promoting interest in and engagement with science more generally (Confederation of British Industry and Universities UK, 2009). In addition, the pharmaceutical sector needs support in high-priority educational areas, including pathology and toxicology (Association of the British Pharmaceutical Industry, 2008). Within these priorities, genetics education has emerged as an important issue for the healthcare sector, with action required to 'get genetics incorporated into curricula' at all levels (Department of Health, 2008, p. 117), both in the UK (Atkin and Anionwu, 2010) and globally (World Health Organization, 2006). In the section that follows, we outline the rich potential of sickle cell to function as an exemplar for the development of OERs.

Sickle-cell disease

The year 2010 marked the 100th anniversary of the first scientific publication on 'peculiar elongated cells', or what we now term sickle cell, by James Herrick in the *Archives of Internal Medicine* (Herrick, 1910, p. 517). Sickle-cell disease (SCD) is now the most common inherited single-gene condition in England, where one in every 2300 births, across all ethnic groups, is a child with SCD, and one in every 540 white British infants carries a sickle-cell-relevant gene. Although it affects all ethnic groups, SCD is more prevalent in those self-classifying in UK Census categories as black African or black Caribbean (Streetly *et al*, 2010). SCD is thus vulnerable to being framed within wider societal racism (Bediako and Moffitt, 2011). The interface between people with SCD, health professionals (Elander *et al*, 2011) and health researchers (Benjamin, 2011) is characterised by distrust between professionals and clients who are often from different ethnic groups. This suggests that social science education, as well as scientific educational materials, is vital for improving health professionals' understanding of SCD.

The incidence of SCD is worldwide, and 400 000 affected children are born every year (Weatherall and Clegg, 2001), predominantly in sub-Saharan Africa (Modell and Darlison, 2008). Hitherto, it was estimated that 95% of these children died before the age of five years (Fleming, 1989). With new-born screening programmes about to be implemented in a number of African countries (Kafando *et al*, 2009; Rahimy *et al*, 2009; Tshilo *et al*, 2009), and a 95% survival rate reported in pilot programmes for such interventions (Dennis-Antwi *et al*, 2008), sickle cell is set to become a leading issue of the twenty-first century. Prior to 2010, sickle cell had only had six citations within JorumOpen, the JISC-funded open repository service, and was central to none of these.

SCD is notable for its relevance to all of the STEM subjects. In genetics, for example, it provides an

excellent exemplar of the complexities of inheritance. The terms 'dominant' and 'recessive' refer, strictly speaking, not to the *genotype* but to the *phenotype*, and sickle-cell anaemia provides a useful illustration of this distinction (Griffiths *et al*, 2002). There are several different outcomes in terms of structure and function of the organism associated with the gene encoding sickle haemoglobin. These outcomes are not all inherited in the same way. The gene encoding sickle haemoglobin is associated with a range of phenotypic features. These include the extent to which resistance to malaria is conferred, the tendency of red blood cells to sickle (i.e. to take on the characteristic sickle-cell shape), the presence of chronic anaemia and the alteration of the electric charge of the beta-globin molecule (which means that it moves at different rates when placed in gel and an electric current is passed across it) (Griffiths *et al*, 2002).

An analysis of the causes of sickling actually reveals a complex interaction between irritation of the walls of the blood vessels, the adhesiveness of cells to the walls of the blood vessels, the extent to which red blood cells break open, and the extent to which cells are dehydrated and have higher concentrations of sickle haemoglobin (Embury *et al*, 1994). SCD is also remarkable in that it affects almost every system in the body, thus causing strokes, silent strokes, retinopathy, acute chest syndrome, aplastic crisis, splenic sequestration, necrosis of joints, damage to kidneys, priapism and recurrent leg ulcers (Serjeant and Serjeant, 2001). It could thus be used as a starting point for consideration of many aspects of anatomy and physiology. Indeed there is an ongoing debate about the possible role of sickle-cell trait in exercise physiology and sudden death in athletes (Connes *et al*, 2007; Le Gallais *et al*, 2007).

Techniques for the investigation of SCD have included haemoglobin electrophoresis (Pauling *et al*, 1949), polymerase chain reaction (Clark and Thein, 2004), mass spectrometry (Daniel *et al*, 2005), and analysis of the globin chains by reversed-phase liquid chromatography (Wajcman and Riou, 2009). In all such cases SCD is arguably an appropriate exemplar for understanding the science behind these technologies. Moreover, appraisals of technologies pertinent to the sickle cell not only have direct relevance to scientific learning about SCD, but also offer a broader applicability to screening and diagnosis programmes and health technologies (Durosinmi *et al*, 1995). In addition, SCD is a useful vehicle for exploring emerging technologies behind pre-implantation genetic diagnosis (Harteveld *et al*, 2009).

However, SCD has traditionally been a neglected part of the curricula of medicine, nursing and midwifery (Dyson *et al*, 1996; Okpala *et al*, 2002), and has attracted accusations that it has been marginalised in the development of health services because it has been constructed as an ethnic issue rather than a health issue (Anionwu and Atkin, 2001). In the UK, the health services recently failed to prevent the death of a three-year-old boy with SCD, who was turned away from hospital with advice to take the mildest of painkillers (*London Evening Standard*, 2010). A 21-year-old woman with SCD who was undergoing a sickle-cell painful crisis died after ambulance staff reportedly refused to take her to hospital (*London Evening Standard*, 2011). Such episodes may be indicative of a lack of competence in caring for diverse populations, and suggest an ongoing need for resources to support student-centred learning in those university subjects that lead to health services employment.

SCD has yet to feature strongly within either social sciences or the humanities, but there is much potential to work through the example of sickle cell in these subjects, too. In the social sciences, there is a small but growing body of work on the sociologies of ethnicity (Dyson, 2005), health (Atkin and Ahmad, 2001), education (Abuateya *et al*, 2008), crime (Dyson and Boswell, 2009) and science (Martin, 1999). Sickle cell has been studied within psychology in relation to stigma (Burnes *et al*, 2008), quality of life (McLellan *et al*, 2008), risk of depression scales (Kelch-Oliver *et al*, 2007), and the utility of cognitive behavioural approaches (Anie *et al*, 2002). In social policy and social work it has featured in the issue of black carers (Ahmad, 2000).

In humanities, the work of Donald Rodney, an artist who had SCD, and whose work is archived in Tate Modern, has been analysed in art history for its place in anti-racist installation art (Hylton, 2003). In history, the spread of the sickle-cell gene can be associated with cross-Saharan migrations BCE, the transatlantic slave trade, and post-Second World War global migrations. Sickle cell was a central issue, too, in the history of the American Civil Rights Movement (Tapper, 1999). There are other subjects that could draw on sickle-cell exemplars. For example, film studies might consider sickle cell in films such as *A Warm December*, *To All Those on Shore*, *Full Metal Jacket* and *Crooklyn*. And analysis of contemporary music might consider the various artists who had SCD, including Miles Davis, Georgeanna Tillman of the Marvelettes, Paul Williams of the Temptations, Sean Oliver of Rip, Rig and Panic, Tionne Watkins of TLC and Prodigy of Mobb Deep (Johnson and Checkoway, 2011).

The purpose of the SCD OERs initiative would be to create a resource that would promote the study of the disease as a distinctive subject, of likely growing interest and concern in the university education of health professionals working with increasingly diverse ethnic communities in the UK, Europe and North America. The resource would benefit all of the STEM subjects, including those leading to health services employment and future employers. It would encourage symbiosis of ideas within the STEM subjects and

open up productive channels for the cross-fertilisation of ideas between STEM subjects, arts and humanities subjects and social sciences.

Methods

The aim was to conduct a survey of current perceived need for SCD OERs among educators. There is currently no community of interest that could form a sampling frame. A database of 1040 email addresses was constructed through a non-systematic global Internet search for the following types of peoples:

- health professionals involved with SCD ($n = 312$)
- academics, who had either previously published on haemoglobinopathies, or who taught in potentially relevant subject areas within science (e.g. genetics) or social science (e.g. racism and social policy) or who were associated with vocational courses in the health and welfare professions ($n = 576$)
- non-government organisations for people with SCD ($n = 76$)
- people living with SCD known to the authors of this paper ($n = 21$)
- people working for government or federal agencies ($n = 55$).

This process might best be conceptualised as illustrating the points made, respectively, by Bateson (1984), namely that a survey asserts as much about the social world (that sickle cell education is important) as it describes, and by Pawson and Tilley (1997), namely that surveys do not simply reflect a cross-section of a reality, but involve an imposed framework of the researchers creating the conditions of types of knowledge. The research was approved by De Montfort University Human Research Ethics Committee.

All 1040 members of this group of people were emailed using blind carbon copy so as not to reveal a list of addresses to those contacted. With regard to informed consent, an explanation of the purposes of the survey and the identities of those conducting the survey was included in the covering email. Consent was taken to be implied by virtue of completing the questionnaire, and participants were able to remain anonymous by simply choosing not to take the active step of supplying their contact details. The recipients of the email were asked to complete a short survey at the online survey facility SurveyMonkey.com. The survey consisted of open-ended questions or those based on a five-point Likert scale. Recipients were invited to submit their email address if they wished to be involved in future discussions.

Results

Respondent details

A total of 226 responses were received, with 41% of respondents being UK based ($n = 93$), and 59% being based outside the UK ($n = 133$). Of this second group, 87 respondents were located in North or South America, with smaller numbers from Africa, Europe, the Middle East and the Asia-Pacific region. The majority of the respondents were health professionals (57%, $n = 129$), with university lecturers representing the next largest group (17%, $n = 39$), and a range of others, including members of non-government agencies for sickle cell (15%, $n = 34$), people from government agencies (3%, $n = 6$), people living with SCD (1%, $n = 3$), and those who were not identifiable by their responses (7%, $n = 15$).

Stated awareness of OERs and repositories

In total, 42% of the respondents had heard of OERs. Awareness of OERs was approximately equal, with 44% of respondents in the UK and 40% elsewhere claiming to have heard of the term. Of the different role categories, not surprisingly it was found that more university lecturers had heard of the term OERs compared with health professionals (62% and 38% respectively). In general, respondents who were patients, school teachers or from voluntary groups had not heard of OERs. In total, 80 respondents (35%) had not heard of any of the repositories and sources of OERs indicated, but 146 respondents had heard of one or more sources (see Table 1). YouTube EDU and iTunes U were the most familiar, with the UK Open Universities OpenLearn reasonably well known in the UK and elsewhere. The OpenCourseWare Consortium from the Massachusetts Institute of Technology, which facilitates open sharing in the USA, and the UK's JorumOpen were less well known.

Interest in OERs about SCD

In total, 88% of respondents ($n = 199$) suggested that they would be interested or very interested in freely available resources about SCD. Only 11 respondents from the health professionals group, eight university lecturers and eight of the other respondents expressed a preference otherwise. A wide range of resource types appeared to be of equal interest, including research data and publications, video, animation and audio, and lecture slides with audio and stimulus questions. Images, diagrams and photographs were equally popular (see Table 2). The subject matter of interest was just as diverse, with medicine being the most popular (76%

Table 1 Awareness of open content repositories (total number of responses, respondents were asked to select all that applied)

	JorumOpen	YouTube Edu	iTunes U	OpenCourseware Consortium	OpenLearn
Elsewhere	0	21	13	4	7
USA	2	32	26	7	6
UK	6	36	22	4	16
Total number of responses	8	89	61	15	29
Total percentage of responses	5	61	42	10	20

Table 2 Level of interest expressed in each type of open education resource on sickle cell

	Numbers of respondents interested in type of resource				
	Not at all	Not particularly	Moderately interested	Interested	Very Interested
Research data	5	14	22	80	108
Research reports	6	11	18	81	114
Photos	9	20	40	73	76
Fixed images	8	11	38	87	81
Animations	11	14	39	75	85
Audio files	16	24	52	72	58
Talking heads with experts	10	21	48	76	70
Videos of people with SCD	7	23	55	56	85
Learning objects	7	21	37	77	85
PowerPoint with commentary	4	9	32	66	117
Stimulus questions	6	14	28	74	102

of total responses), and here was also an indication of the importance of genetics (61%). Other cross-curricular material, including the social sciences, the humanities and the arts, also attracted some degree of interest (see Table 3).

Additional comments

Of the 226 participants in the survey, 145 indicated an interest in future discussions, and 75 left additional comments. Of these comments, only one was negative, and that comment suggested that the respondent did not have time to respond to a questionnaire, although in fact even in these circumstances the person chose to be a respondent and returned a complete set of data (see Box 1). Other suggestions for subject matter

Table 3 Total number of responses for each of the subject categories (with respondents able to make more than one choice)

Medicine	180
Biomedical science	93
Genetics	143
Biochemistry	62
Pharmacy	86
Nursing	105
Social work	100
Psychology	129
Social science (sociology, social policy, politics)	101
Humanities (history, literature, music, art)	47
Other	35

Box 1 Indicative comments on proposal for open education resources on sickle cell

A Sickle Cell Voluntary Organisation, USA
'It would be good to have materials suitable for both medical education, as well as for patients and families'.

NHS Consultant, UK
'I believe there is a need for such resources for healthcare professionals, patients and families'.

University Lecturer, USA
'This would be an excellent resource because so many educational programs do not contain info on SCD'.

NHS Midwife, UK
'I think that this is a wonderful idea because I am the specialist haemoglobinopathy midwife for the Trust and I teach on antenatal women with Hb Variant on the maternity staff mandatory training every month. I am always looking for ways to improve or change my training'.

Doctors.org.uk
'Animations to visually demonstrate what is happening during a sickling crisis would be useful for patients to see and make it easier for doctors to explain things'.

included the experiences of people with the condition, making the resources available in other languages, and making the resources free to use. Several people commented on open-content repositories in general, and expressed the view that it was essential to ensure that the content was accurate and up to date, and that it was carefully monitored and approved by specialists in the field. Other people requested guidance and an orientation on how best to access and take advantage of the SCD resources or open content.

Discussion

In this online survey of academics, health professionals and those involved or living with SCD, the majority of the respondents from around the world expressed a need for resources. Although it is not surprising that medicine and biomedical sciences were high on the list, other subjects, such as social sciences and humanities, were also of interest. This suggests that generating a cross-curricular body of materials would offer an interesting means of widening the appeal of an OER. For example, using arts to promote sciences is already well established in the UK through organisations such as the Wellcome Trust. The fact that some UK university lecturers outside science expressed

interest in a topic more usually delineated as a scientific one may also indicate a new willingness to engage with scientific subjects. This may in turn reflect cuts in higher education budgets and the privileging of funding of university science education over both the social sciences and humanities.

The respondents were reportedly more aware of OERs that were developed as sections of commercial websites such as YouTube and iTunes than they were of repositories developed specifically by academics. This could imply that academics who are engaged in promoting OERs need to make greater use of existing sites that are flourishing within wider popular culture, and/or that they need to find ways to make academic-led sites for resources more high-profile and more accessible.

The minority of health professionals and academics who were unenthusiastic about OERs on SCD may reflect interest in SCD but a concern about the quality of OERs, or, conversely, interest in OERs but not a specific interest in SCD. Health professionals in the field of SCD are likely to be interested in education resources. However, given concerns that the Internet may proliferate inaccurate information, there have been numerous attempts to promote regulatory frameworks for appraising the quality of health information on the Internet, although most are transient and remain unvalidated (Gagliardi and Jadad, 2002). Lack of enthusiasm on the part of some health professionals may therefore reflect a concern not about OERs per se, but rather about their quality and accuracy. Likewise, the minority of lecturers who were ostensibly not interested may reflect an implicit disagreement that SCD as a specific potential topic fits within the broader frame of their work, rather than a rejection of OERs.

There is no specific discernible pattern to the types of resources that appear to merit consideration for inclusion in a repository of OERs about SCD. All potential types of resources, from simple photos to raw data, research reports, fixed diagrams, animations and PowerPoint presentations, attracted some interest. The diversity of resources sought appears to be an important lesson for those engaged in establishing OERs. Perhaps it is more important to facilitate the engagement of multiple learning communities with the same topic, while retaining overall coherence of the domain and at the same time enhancing the interface between learners and educators and the repository and the mechanisms that are put in place for editing and updating the repository (Dicheva and Dichev, 2006).

Historically at least, one complaint of people with SCD is that they may know more than the professionals who are caring for them (Hill, 1994; Anionwu and Atkin, 2001). This suggests that there are theoretical debates to be entered into about whether and how the same repository can make OERs available to meet the needs of, say, medical education and patient groups, as suggested by quotations 1 and 2 in Box 1. Quotation 3 at least implies that generic curricula may not contain sufficient details and specific resources for education about SCD, and echoes calls for sickle cell to be brought more fully into nursing curricula, for example Anionwu (1996). Quotation 4 suggests that although there are resources specifically developed to help individual health professionals in their work (see NHS Sickle Cell and Thalassaemia Screening Programme, 2011), educators continue to seek diverse resources that either fit their contextual needs or which they can adapt to such needs. Quotation 5 suggests a specific animated resource that a professional believes would help in patient education. The vaso-occlusive crisis and the associated excruciating pain is indeed one of the most contested sites in health professional–patients relationships (Anionwu and Atkin, 2001). The idea that animation would aid patient education is intuitively appealing, but social science cautions that wider antagonisms of racism in society (Rouse, 2009), and the social origins of distrust between the service provider and the SCD patient, would also need to be addressed (Benjamin, 2011).

Conclusion

In this study we have identified an expressed need for resources on the subject of SCD. This apparent demand dovetails into policy statements, made by a number of professional organisations, for increased scientific materials in key areas, including genetics, and also for materials in support of widening public awareness of science and on promoting health. A project has now been initiated as part of Phase 2 of the JISC/HEA Open Educational Resource Programme (2010–2011). This SCOOTER (Sickle Cell Open, Online Topics and Educational Resources) project involves universities, hospitals, charities and industrial partners in the UK in planning to release a wide range of OERs in a range of granularities. From photographs to interactive learning resources, to the digitisation of an historic textbook (Livingstone, 1985) and a 1000-item slide collection, OERs will be released on to a website (www.sicklecellanaemia.org) and also placed on JorumOpen. In order to develop an active online community, information is also disseminated using Web 2.0 technologies, including Posterous, Facebook and Twitter. Building communities of users to evaluate, discuss and develop OERs is a key element in ensuring the sustainability of OER projects (Downes, 2007).

The neglect of SCD and thalassaemia in the university curriculum has been noted to have had an adverse impact on subsequent practice (for example, within nursing) (Anionwu, 1996). Our global survey revealed

a reasonable level of awareness of the term 'OER', but a concomitant lack of familiarity with where to find resources. University educators, health professionals and sickle-cell community members agreed that an SCD OER repository was needed. The SCOOTER project that has been initiated now aims to address the needs of these communities of interest through a project website. Project goals include making the resources discoverable and visible on the Internet, and building an online community to own the project beyond the duration of the funding. In this way it is hoped to enhance diversity in two complementary ways, namely by enhancing educational materials on a neglected subject with ramifications for the care of minority ethnic groups, and by broadening access to educational materials to sickle-cell communities of interest.

REFERENCES

Abuateya H, Atkin K, Culley LA *et al* (2008) Young people with sickle cell disorder and education: a knowledge review. *Diversity in Health and Social Care* 5(2):123–35.

Ahmad WIU (ed.) (2000) *Ethnicity, Disability and Chronic Illness.* Buckingham: Open University Press.

Anie K, Steptoe A, Ball S *et al* (2002) Coping and health service utilisation in a UK study of paediatric sickle cell pain. *Archives of Disease in Childhood* 86(5):325–9.

Anionwu EN (1996) Sickle cell and thalassaemia: some priorities for nursing research. *Journal of Advanced Nursing* 23(5):853–6.

Anionwu EN and Atkin K (2001) *The Politics of Sickle Cell Anaemia.* Buckingham: Open University Press.

Apple (2011) *iTunesU.* www.apple.com/education/itunes-u (accessed 11 January 2011).

Association of the British Pharmaceutical Industry (2008) *Skills Needs for Biomedical Research.* www.abpi.org.uk/our-work/mandi/Documents/2008–10%20STEM%20Skills%20Review%20Report%20FINAL%20amended2.pdf (accessed 7 June 2011).

Atkin K and Anionwu EN (2010) *The Social Consequences of Sickle Cell and Thalassaemia: improving the quality of support.* London: Race Equality Foundation.

Atkin K and Ahmad WIU (2001) Living a 'normal' life: young people coping with thalassaemia major or sickle cell disorder. *Social Science and Medicine* 53(5):615–26.

Barden EM, Zemel BS, Kawchak DA *et al* (2000) Total and resting energy expenditure in children with sickle cell disease. *Journal of Paediatrics* 136(1):73–9.

Bateson N (1984) *Data Construction and Social Surveys.* London: Allen & Unwin.

Bediako SM and Moffitt KR (2011) Race and social attitudes about sickle cell disease. *Ethnicity and Health* 16:423–9.

Benjamin R (2011) Organized ambivalence: when sickle cell disease and stem cell disease converge. *Ethnicity and Health* 16:447–63.

Burnes DPR, Antle BJ, Williams CC *et al* (2008) Mothers raising children with sickle cell disease at the intersection of race, gender, and illness stigma. *Health and Social Work* 33(3):211–20.

Caledonian Academy (2010) *OER Synthesis and Evaluation Project.* https://oersynth.pbworks.com/w/page/29595671/OER-Synthesis-and-Evaluation-Project (accessed 7 June 2011).

California State University (2011) *Multimedia Educational Resource for Learning and Online Teaching.* www.merlot.org/merlot/index.htm (accessed 7 June 2011).

Clark BE and Thein SL (2004) Molecular diagnosis of haemoglobin disorders. *Clinical and Laboratory Haematology* 26(3):159–76.

Confederation of British Industry and Universities UK (2009) *Future Fit.* www.cbi.org.uk/pdf/20090326-CBI-FutureFit-Preparing-graduates-for-the-world-of-work.pdf (accessed 7 June 2011).

Connes P, Hardy-Dessources M and Hue O (2007) Sickle cell trait should/should not be considered asymptomatic and as a benign condition during physical activity. *Journal of Applied Physiology* 103:2138–40.

Creative Commons (2010) *Creative Commons.* http://creativecommons.org (accessed 7 June 2011).

Daniel YA, Turner C, Haynes RM *et al* (2005) Rapid and specific detection of clinically significant haemoglobinopathies using electrospray mass spectrometry–mass spectrometry. *British Journal of Haematology* 130:635–43.

Dennis-Antwi JA, Dyson SM and Ohene-Frempong K (2008) Healthcare provision for sickle cell disease in Ghana: challenges for the African context. *Diversity in Health and Social Care* 5(4):241–54.

Department for Business, Innovation and Skills (2010) *New Industry, New Jobs: one year on.* http://webarchive.nationalarchives.gov.uk/+/http://www.bis.gov.uk/policies/new-industry-new-jobs (accessed 7 June 2011).

Department of Health (2008) *Our Inheritance, Our Future: realizing the potential of genetics in the NHS Progress Review.* www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_084280.pdf (accessed 7 June 2011).

Dicheva D and Dichev C (2006) TM4L: creating and browsing educational topic maps. *British Journal of Educational Technology* 37(3):391–404.

Downes S (2007) Models for sustainable open educational resources. *Interdisciplinary Journal of Knowledge and Learning Objects* 3:29–44. http://ijklo.org/Volume3/IJKLOv3p029–044Downes.pdf (accessed 7 June 2011).

Durosinmi MA, Odebiyi IA, Adediran NO *et al* (1995) Acceptability of prenatal diagnosis of sickle cell anaemia (SCA) by female patients and parents of SCA patients in Nigeria. *Social Science and Medicine* 41(3):433–6.

Dyson SM (2005) *Ethnicity and Screening for Sickle Cell and Thalassaemia.* Oxford: Elsevier Churchill Livingstone.

Dyson SM and Boswell GR (2009) *Sickle Cell and Deaths in Custody.* London: Whiting and Birch.

Dyson SM, Fielder A and Kirkham M (1996) Midwives' and senior students' knowledge levels of the haemoglobinopathies. *Midwifery* 12:23–30.

Elander J, Beach MC and Haywood C Jr (2011) Respect, trust, and the management of sickle cell disease pain in hospital: comparative analysis of concern-raising behaviors, preliminary model, and agenda for international collaborative research to inform practice. *Ethnicity and Health* 16:405–21.

Ellis H (2009) *Approaches to the Delivery of Anatomy and Physiology Teaching (ADAPT)*. Preston: University of Central Lancashire. www.jisc.ac.uk/whatwedo/programmes/elearningcapital/reproduce/adapt.aspx (accessed 7 June 2011).

Embury SH, Hebbel RP, Steinberg MH *et al* (1994) Pathogenesis of vasoocclusion. In: Embury SH, Hebbel RP, Mohandas N *et al* (eds) *Sickle Cell Disease: basic principles and clinical practice*. New York: Raven Press. pp. 311–26.

Fleming AF (1989) The presentation, management and prevention of crisis in sickle cell disease in Africa. *Blood Reviews* 3:18–28.

Friend F and Swan A (2010) *Publishing Research Papers: which policy will deliver best value for your university?* www.jisc.ac.uk/media/documents/publications/briefingpaper/2010/bppublishingresearchpapersv1final.pdf (accessed 7 June 2011).

Gagliardi A and Jadad AR (2002) Examination of instruments used to rate quality of health information on the internet. *British Medical Journal* 324:569–73.

Griffiths AJF, Gelbart WM, Lewontin R *et al* (2002) *Modern Genetic Analysis: integrating genes and genomes*. New York: WH Freeman and Company.

Harteveld CL, Kleanthous M and Traeger-Synodinos J (2009) Prenatal diagnosis of hemoglobin disorders: present and future strategies. *Clinical Biochemistry* 42(18): 1767–79.

Herrick JB (1910) Peculiar elongated and sickle cell red blood corpuscles in a case of severe anemia. *Archives of Internal Medicine* 6:517–21.

Higher Education Academy (2009) *HEA Bioscience Bulletin No. 28*. www.bioscience.heacademy.ac.uk/ftp/newsletters/bulletin28.pdf (accessed 7 June 2011).

Hill S (1994) *Managing Sickle Cell Disease in Low Income Families*. Philadelphia, PA: Temple University Press.

Houghton J, Rasmussen B, Sheehan P *et al* (2009) *Economic Implications of Alternative Scholarly Publishing Models: exploring the costs and benefits*. www.jisc.ac.uk/media/documents/publications/rpteconomicoapublishing.pdf (accessed 7 June 2011).

Hylton R (ed.) (2003) *Donald Rodney: Doublethink*. London: Autograph.

Johnson A and Checkoway L (2011) *My Infamous Life: the autobiography of Mobb Deep's prodigy*. New York: Touchstone.

Joint Information Systems Committee (2009) *Open Educational Resources Programme*. www.jisc.ac.uk/oer (accessed 7 June 2011).

Joint Information Systems Committee (2011) *Jorum: learning to share*. www.jorum.ac.uk (accessed 7 June 2011).

Jonassen D and Churchill D (2004) Is there a learning orientation in learning objects? *International Journal on E-Learning* 3(2):32–41.

Kafando E, Nacoulma E, Ouattara Y *et al* (2009) Neonatal haemoglobinopathy screening in Burkina Faso. *Journal of Clinical Pathology* 62:39–41.

Kelch-Oliver K, Oyeshiku Smith C, Diaz D *et al* (2007) Individual and family contributions to depressive symptoms in African American children with sickle cell disease. *Journal of Clinical Psychology in Medical Settings* 14(4): 376–84.

Le Gallais D, Lonsdorfer J, Bogui P *et al* (2007) Sickle cell trait should/should not be considered asymptomatic and as a benign condition during physical activity. *Journal of Applied Physiology* 103:2137–8.

Livingstone FB (1985) *Frequencies of Haemoglobin Variants*. New York: Oxford University Press.

London Evening Standard (2010) Sick boy, three, dies waiting for an appointment. *London Evening Standard*, 15 November 2010. www.thisislondon.co.uk/standard/article-23897542-sick-boy-three-dies-waiting-for-an-appointment.do (accessed 7 June 2011).

London Evening Standard (2011) Student died 'after ambulance crew refused to treat her.' *London Evening Standard*, 26 January 2011. www.thisislondon.co.uk/standard/article-23917565-student-died-after-ambulance-crew-refused-to-treat-her.do (accessed 7 June 2011).

Martin PH (1999) Genes as drugs: the social shaping of gene therapy and the reconstruction of genetic disease. *Sociology of Health and Illness* 21(5):517–38.

McLellan CB, Schatz J, Sanchez C and Roberts CW (2008) Validity of the pediatric quality of life inventory for youth with sickle cell disease. *Journal of Pediatric Psychology* 33(10):1153–62.

Modell B and Darlison M (2008) Global epidemiology of haemoglobin disorders and derived service indicators. *Bulletin of the World Health Organization* 86(6):417–96.

NHS Sickle Cell and Thalassaemia Screening Programme (2011) *About Sickle Cell and Thalassaemia*. Available at: http://sct.screening.nhs.uk/cms.php?folder=2435 (accessed 16 January 2012).

Nzewi E (2001) Recurrent reincarnation or sickle cell disease? *Social Science and Medicine* 52:1403–16.

Okpala I, Thomas V, Westerdale N *et al* (2002) The comprehensive care of sickle cell disease. *European Journal of Haematology* 68:157–62.

OpenCourseWare Consortium (2011) *OpenCourseWare Consortium*. www.ocwconsortium.org/index.php (accessed 7 January 2011).

Open University (2011) *LearningSpace*. http://openlearn.open.ac.uk (accessed 7 June 2011).

Pauling L, Itano H, Singer SJ *et al* (1949) Sickle cell anemia: a molecular disease. *Science* 110(2865):543–8.

Pawson R and Tilley N (1997) *Realistic Evaluation*. London: Sage Publications.

Rahimy MC, Gangbo A, Ahouignan G *et al* (2009) Newborn screening for sickle cell disease in the Republic of Benin. *Journal of Clinical Pathology* 62:46–8.

Rolfe V (2009) *Development of a Virtual Analytical Laboratory (VAL) Multimedia Resource to Support Student Transition to Laboratory Science at University*. Higher Education Academy Bioscience Case Study. www.bioscience.heacademy.ac.uk/ftp/casestudies/VRolfe.pdf (accessed 18 June 2010).

Rolfe V (2010) *Virtual Analytical Laboratory (VAL)*. http://hlsweb.dmu.ac.uk/ahs/elearning/RITA/index.html (accessed 7 June 2011).

Rouse CM (2009) *Uncertain Suffering: racial health disparities and sickle cell disease*. Berkeley, CA: University of California Press.

Serjeant GR and Serjeant BE (2001) *Sickle Cell Disease*, 3rd edn. Oxford: Oxford University Press.

Streetly A, Latinovic R and Henthorn J (2010) Positive screening and carrier results for the England-wide universal newborn sickle cell screening programme by ethnicity and area for 2005–07. *Journal of Clinical Pathology* 63:626–9.

Tapper M (1999) *In the Blood: sickle cell anaemia and the politics of race.* Philadelphia, PA: University of Pennsylvania Press.

Tshilo L, Aissi LM, Lukusa D *et al* (2009) Neonatal screening for sickle cell anaemia in the Democratic Republic of the Congo: experience from a pioneer project on 31,204 newborns. *Journal of Clinical Pathology* 62:35–8.

Wajcman H and Riou J (2009) Globin chain analysis: an important tool in phenotype study of hemoglobin disorders. *Clinical Biochemistry* 42(18):1802–6.

Weatherall D and Clegg JB (2001) Inherited haemoglobin disorders: an increasing global health problem. *Bulletin of the World Health Organization* 79(8):704–12.

World Health Organization (2006) *Sickle Cell Anemia.* http://apps.who.int/gb/ebwha/pdf_files/WHA59/A59_9-en.pdf (accessed 7 June 2011).

YouTube (2011) *YouTube EDU.* www.youtube.com/education?b=400 (accessed 7 June 2011).

CONFLICTS OF INTEREST

None.

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