Why are we copyrighting science?

PERSONAL VIEW Varuni de Silva, Raven Hanwella

Looking for a rating scale to screen for depression, we realised that many commonly used scales were under copyright and that researchers have to pay for their use.

Rating scales are an integral part of research in psychiatry. Most psychiatry diagnoses do not have external validating criteria, so scales help in structured gathering of information and in use of standard criteria for diagnosis. Scales are also used to assess patients’ levels of functioning, quality of life, satisfaction with services, and burden on carers. Of the many hundred scales developed for use in medicine only a few gain wide acceptance among researchers. Scales used in many specialties, such as the general health questionnaire and the mini-mental state examination, have been copyrighted. Some copyrighted scales are first published in journals and are available free to researchers. However, once a rating scale is accepted by the scientific community an updated version is copyrighted, a process similar to “evergreening” of drugs whereby patent periods are extended by licensing them for a practice that has resulted in loss of much important knowledge.

Patents have been issued on genetic material. Genes are products of nature and therefore should not be considered as patentable. But patents have been granted for modified genes. Gene tests for diagnosing illness caused by diseased genes are patentable too. So are stem cell lines used to treat illness. The case of the BRCA genes, which act as a tumour suppressor, illustrates how close we are to the edge. Mutations of the BRCA genes are linked to breast cancer and ovarian cancer, and tests can be carried out to identify mutations. The company Myriad Genetics held two patents for the diagnosis of mutations in the BRCA1 and BRCA2 genes and carries out the genetic screening test, which is very costly. The patent prevented any other laboratory from doing the test for a lesser cost. The American Civil Liberties Union and the Public Patent Foundation filed a lawsuit charging that patents on two human genes associated with breast and ovarian cancer are unconstitutional and invalid. On 29 March 2010 a New York federal court ruled that the patents on the BRCA1 and BRCA2 genes are invalid (BMJ 2010;340:c1870).

Extreme commercialisation of science can lead to patents on medical procedures and techniques. Companies can patent new surgical techniques and other procedures, and we may end up paying royalty fees every time a particular surgical technique is used. Recognising the implications of such action the American Medical Association has expressed its concerns in a document titled Ethical Issues in Patenting of Medical Procedure and has concluded that it is unethical for doctors to seek, secure, or enforce patents on medical procedures.

The scientific community is reacting to the increasing commercialisation of science. All genome sequences generated by the human genome project have been deposited into GenBank, a public database that is freely accessible by anyone. SNP Consortium, a collaboration involving the Wellcome Trust, leading academic centres, and 13 pharmaceutical and technological companies, has identified and mapped 1.5 million single nucleotide polymorphisms (SNPs) that have been made publicly available to researchers over the internet. (SNPs can alter our sensitivity to drugs or our susceptibility to diseases.) Legal means have also been used to protect the rights of the public, as in the case of the BRCA genes. Organisations such as the US National Institutes of Health and the United Kingdom’s Wellcome Trust insist on open access to publication resulting from research funded by them. Outside the medical sciences, computer software developers are challenging commercial software by developing open source software.

The fundamental philosophy of Western science is sharing knowledge. In some non-Western medical systems knowledge is closely guarded and handed down from teacher to student, a practice that has resulted in loss of much important knowledge.

Patenting provides a strategy for protecting inventions without secrecy. While it is a useful tool for protecting investments in industry, we need to rethink its role in science. Can we consider health and science as commodities? Countries that regard health as a basic human right provide universal, free health care for their citizens. It appears that scientific knowledge originating from these countries, such as the United Kingdom and Canada, is more readily shared. Their scientific journals provide more open access. Countries that regard health as a commodity are more likely to view scientific discovery too as a commercial opportunity.

Although those who consider science as a commodity are willing to invest in research and development, much medical research is still carried out by non-profit organisations using public money. It is only right that such knowledge is freely shared. This is possible because academic scientists still consider the prestige of discovery more important than monetary reward.

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The death of Dylan Thomas: a conspiracy theory

The idea of the “poète maudit”—the cursed poet—who drinks, drugs, and misbehaves his way to an early grave is one that is now deeply engraved on our consciousness. Of course, nowadays there are a lot of maudits who are by no means poètes: and where everyone is a bohemian, no one is. But still the image lives on.

Dylan Thomas (1914-53) was a perfect poète maudit. He spent much of his short life in dark bars, inhaling smoke and imbibing beer, often at other people’s expense. Until I read David N Thomas’s book Fatal Neglect: Who Killed Dylan Thomas? I (like most people) had always assumed that he had more or less drunk himself to death. But Mr Thomas’s theory is that he died from medical incompetence, and his case is a good one.

Thomas was asthmatic and at post mortem examination was found to have chronic obstructive pulmonary disease also. (Did he have α1 antitrypsin deficiency? He was well on his way to cirrhosis of the liver as well, with oesophageal varices developing and a somewhat enlarged spleen.)

Thomas was not a well man when, towards the end of October 1953, he went to the United States for another reading tour. He had an exacerbation of bronchitis, his breathing was laboured, and he often felt obliged to take the air outside his room.

At 2 am on 4 November Thomas left his hotel room to seek a drink. He famously boasted on his return an hour and a half later that he had drunk 18 double whiskies, that is to say more than a bottle. But this is unlikely: his tolerance had declined, and he was not drunk. At lunchtime he had two beers.

Later in the day he felt unwell—more unwell than usual—and his American doctor, Milton Feltenstein, visited. In fact he visited him three times in the hotel room on 4 November, each time injecting him with corticotropin and morphine, on the last occasion with 30 mg of morphine. It was after that injection that Thomas sank into the coma from which he never awakened.

Dr Feltenstein appears never to have examined Thomas’s chest or to have taken any notice of his cough, breathlessness, and fever but to have assumed that his restlessness was caused by the amount of alcohol he believed, mistakenly, that the poet had drunk and that he was now withdrawing. (Even in 1953 morphine was not the treatment of alcohol withdrawal.)

On Thomas’s admission to St Vincent’s Hospital Dr Feltenstein insisted that his diagnosis was the correct one, though x ray pictures and the autopsy showed pneumonia. Whether Thomas would have survived were it not for Dr Feltenstein’s ministrations cannot be known for certain, but surely it is unlikely that his libidinality with morphine can have improved the prognosis, to put it mildly.

The author of Fatal Neglect alleges a cover-up of Dr Feltenstein by other doctors and by the hospital. I am always somewhat reluctant to accept conspiracy theories . . . we all know that cover-ups are completely alien to the medical temperament.
Working 9 to 5.20

The NHS is trying to save money. There have been many suggestions, like cutting numbers of pin-striped management consultants and petty, jobsworth bureaucrats—nice easy scapegoats that make us all feel better. But time is money. We doctors are all busy, running at 110% and clamouring for ever more resources. The NHS needs to look at time management. Could a time and motion study, with clip-boarded observers, be the answer? This would be pointless, because we would run around like headless chickens during the study period, claiming to be always busy. In truth our time is something only we control, and we could be more efficient.

Doctors’ clinical practice, not the demands of patients, generates much of the workload in the NHS. Historically in general practice contraceptive drugs were given out every six months, for example. But a review of the evidence shows nothing to support this practice. These contraceptives are expensive, and the greatest consideration is the prevention of unwanted pregnancy. Therefore it seems logical and desirable to issue a year’s prescription. This change in practice saved some 500 appointments a year in our clinic. Likewise, it would be possible to scrap arbitrary, non-evidence based review appointments for hypertension, asthma, and the rest, to free up resources, encouraging doctors to stop the “routine” follow-up of patients after illness. Indeed we could offer more appointments simply by lengthening surgeries’ times by 20 minutes.

General practitioners are self-employed, non-unionised labour, so we have strong incentives to change clinical practice. But it is in the hospitals where most NHS resources lie, and here there is much scope to save time. We GPs should reduce outpatient referrals. Many referrals from general practice have poor results, so the time has come to end the denial that they don’t. Hospital doctors should order fewer investigations, fewer internal referrals, and fewer reviews. Also, one or two additional new patient referrals to each clinic wouldn’t hurt. The impossible slow trundling treadmill of the ward round could be sped up by cutting the “self-important, nobody listening anyway” monologues.

And why do doctors need to attend exotic international conferences? Why is it always the same doctors? The information gained can be got on a mobile phone screen at coffee break, and all conferences should be held in Middlesbrough. Is there really any justification for “parental leave” in these days of short working? In truth most of this time is spent golfing and shopping, not bonding. What are doctors actually doing during administration and research sessions? Lastly, surely anaesthetists could do something more productive during operations than shouting out crossword clues. Making our time 10% more productive: no problem. Don’t ask what the NHS can do for you, but ask what you can do for your NHS.

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Just a song at twilight

Like me, the Edinburgh International Festival was born in 1947 as a result of the second world war. My parents met during the Allied invasion of Italy. The festival was part of the effort to replace pan-European carnage with something better. Its organiser, Rudolf Bing, had fled Germany in 1934 and helped to found Glyndebourne Festival Opera—now, ironically, perceived as quintessentially English.

Edinburgh still has an international feel during its annual cultural jamboree, though nowadays aesthetes are outnumbered by fans of alternative theatre. Last month there were over 2500 fringe shows, and the streets were full of backpackers, clutching maps as they dashed from venue to venue.

Of which means profit to the canny locals. The city’s academic institutions hire out their premises to entrepreneurs. The university graduation hall hosts stand-up comedians. The Royal College of Surgeons squeezes actors from across the world into its lecture theatres, but its teaching suite for minimal access surgery remains off limits, at least for now.

College fellows who wish to perform must pay the going rate. It’s worth it, because the symposium hall’s acoustics are ideal for cabaret—and indeed for classics. When we arrived, a huge, piano shaped package was being manhandled up the stairs. Within 90 minutes it had been unwrapped, played, encored, and whisked off to its next concert. Follow that, boys.

Since our days as junior doctors in Edinburgh we’ve returned to play the fringe festival a dozen times. It’s hard to explain why, but, dash it, a hobby shouldn’t need explaining. Some people climb mountains, some restore steam engines, and some write songs. Because they’re there, OK?

Songwriters are roped together in pairs, like mountaineers. The composer is the creative artist (where on earth does a new tune come from?), but lyric writing is also a tricky craft—part emotion, part crossword puzzle. Without a deadline we would never get the job finished, and without an audience we would never know whether the thing worked.

For a song to have international appeal it should be wistful or downright miserable. Proper operas have tragic tenors and suicidal sopranos. After a lifetime in medicine we’ve had quite enough sadness, thanks, but perhaps our jokes are holding us back. Without them, who knows? We might be sitting on the lawn at Glyndebourne letting others do the work.

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