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HealthWatch Newsletter

for Science and Integrity in Healthcare

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What's in a name? Change is coming

Newer members cannot fail to have noticed that we are not the only HealthWatch on the block. Since we registered as a UK charity in 1991, the name has been appropriated by fitness groups and commercial companies touting products such as food supplements and more recently (surprise, surprise) a smartwatch.

Rather cruelly, in 2012 the UK Government's Health and Social Care Act created a network of "Healthwatch" groups as a statutory service commissioned by local councils, to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf.

Initially their existence was a massive nuisance. Our press helpline was so awash with calls for the "other Healthwatch" that we had to cut it off. The media now rely on our e-mail media@healthwatch-uk.org to contact us.

We occasionally receive hurt or angry emails on our HealthWatch Enquiries e-mail, often with a lengthy screed of intimate personal and medical information, and we have to gently direct the enquirer to where they need to go. The team at the government's Healthwatch England are familiar with us, and there is a degree of friendly referring back and forth on twitter, too. So, from the admin point of

view, it is not a major issue. But is it an issue for our members? And could shaking off our old name inspire and invigorate under a new banner?

A new name would have to encapsulate our passion for evidence and healthcare. It would have to be unique (many good suggestions have already been taken by others). Importantly, the internet domain must be available.

In the coming weeks we will be encouraging discussions on the subject, and plan to poll suggested new names on the website. There will be a formal proposal at the next AGM in October. In the meantime, we would urge members who have views or ideas for new names to get in touch, either via the googlegroup or by e-mailing the editor at newsletter@healthwatch-uk.org

** Members who have not yet joined the googlegroup please write to membership@healthwatch-uk.org*

News

Heroes fighting fire and fake science

Olivier Bernard, a Canadian pharmacist, uses cartoons and comic strips to shatter health myths and make science fun on his website, The Pharmafist. He writes popular science books and has an award-winning television programme. But when he challenged the practice of high dose vitamin C injections for cancer patients, he was met with a smear campaign and death threats against him and his family.

"Science communication is incredibly fun. But scary," he said, accepting the early career researcher prize at the John Maddox Awards ceremony at the Wellcome Institute, London on 12 November. "Harassment, threats, and bullying of good people defending science must be condemned." His experiences led to the creation of a Quebec government taskforce to protect scientists who speak out on sensitive topics.

The main Maddox prize went to Professor Bambang Hero Saharjo, the fire forensics expert on illegal and environmentally catastrophic peatland fires in Indonesia. Not only is he one of the few who dares to testify as an expert witness defending the right of Indonesian people to a healthy environment, but he has done so more than 500 times. The fires are often started by companies to clear land cheaply and quickly for crops such as palm oil and

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paper. In 2018, one company sued him for the equivalent of US\$36 million after he gave evidence that incriminated them. “Using fire for land preparation is so destructive to the environment and destroys the health of local people. The evidence shows it,” he said. A humble and quietly spoken man, Dr Saharjo told HealthWatch he was amazed and grateful that his efforts had been recognised from the other side of the world, and believes the international attention from winning the John Maddox prize will give him more power to fight misrepresentation by companies who use fire so destructively.

“We have a responsibility to recognise those who communicate with commitment and bravery – we cannot

raise the standard of science without people who are prepared to speak up,” said Tracey Brown, director of Sense About Science, summing up the reason for the John Maddox Prize. The annual awards recognize those who promote evidence in the public interest despite difficulty or hostility. The judges report growing numbers of nominations – this year they had to choose between 206 nominations from 38 countries. The Prize, now in its eighth year, is a joint initiative of the charity Sense about Science and the international scientific journal Nature.

Mandy Payne

Editor, HealthWatch Newsletter

FDA under fire from transparency advocates

Fewer than half of clinical trials registered with the US Food & Drugs Administration (FDA) comply with legal requirements for timely disclosure of results, says a study published 17 January in the medical journal *The Lancet*.(1)

When clinical trials results go unpublished, the research resources are wasted, the evidence base of medicine is undermined, and patient participants will have been exposed to risk in vain. In an attempt to address under-reporting in the US, the Final Rule of the FDA Amendments Act (FDAAA) came into force in January 2017. FDAAA says that results from applicable clinical trials should be reported onto the FDA’s database ClinicalTrials.gov within 12 months of trial end – regardless of whether the results are positive or negative.

In the first comprehensive study of compliance with the law, scientists from Oxford University’s EBM DataLab found that only 41% of the 4209 clinical trials registered on ClinicalTrials.gov had met the legal deadline to report their results. More than a third had not reported results there at all. Trials with an industry sponsor were much more likely to comply with the law than the non-industry studies, while the worst offenders were US Government sponsors. Of concern is that the level of compliance has

remained unchanged since July 2018 – it seems the move towards transparency has now stalled.

The authors estimate that had the law been strictly enforced, over US\$4 billion in fines could have been collected up to the end of September 2019. “Over four decades since non-reporting of clinical trials was first reported, it is disappointing to see that we have only progressed to legislation being passed, and then largely ignored,” commented co-author Nicholas DeVito from the University of Oxford, UK. Sile Lane, head of international campaigns and policy for the charity Sense about Science, which runs the AllTrials campaign for transparency in medical research, said: “The FDA is responsible for monitoring the law and punishing those who flout it. The FDA has never taken action about unreported results.”

*DeVito NJ, Bacon S, Goldacre B. [Compliance With Legal Requirement To Report Clinical Trial Results On ClinicalTrials.gov: A Cohort Study](#). *Lancet* 17 January 2020*

Cochrane policy change raises eyebrows

As part of moves to boost trust in its work, the Cochrane Collaboration is to tackle bias by reducing the proportion of its authors whose independence could be compromised by conflicts of interest.

The international Cochrane organisation compiles reviews of research evidence, making a readily accessible and readable library of evidence-based reports that patients and health care professionals can access to make informed choices about treatment.

It is paramount that Cochrane reviews are produced by experts who are independent and unbiased. As currently, the new policy will not permit reviews for the Cochrane Library to be authored by anyone employed by a commercial organisation that might profit directly from the outcome of the review. First and, now, last authors must be completely conflict-free. But for any Cochrane Review with titles registered after January 2020, the proportion of authors in the review team who must be completely free from any conflicts of interest whatsoever is to be increased from half to two-thirds.

Does the new policy go far enough? Some have asked, how can something be considered wrong two-thirds of the time but OK the rest of the time?

Dr Peter Goetzsche was a co-founder of Cochrane but his membership was terminated in 2018 after he was outspoken about his concerns over commercial influence in the organization. On hearing of the new policy he tweeted: “Simmelweis never told doctors to wash one hand only. Wash both.” He went on to say: “Cochrane’s ‘strengthened’ commercial sponsorship policy is like eating the cake and still having it. It is like going from declaring to your spouse that you are unfaithful half of the days in a month to ‘improving’ by declaring that from now on you will only be unfaithful one third of the days.”

Readers’ views would be welcomed, whether by letter to the editor or via the HealthWatch googlegroup.

News in brief**Deb Cohen scoops BJA award**

Another award for quality journalism in the public interest has been presented to Deborah Cohen, BBC Newsnight's UK correspondent and ex-BMJ investigations editor. The Press Gazette's annual British Journalism Awards took place in London on 10 December, and she received the Health and Life Science Journalism prize. Deborah Cohen, known for her meticulous research of medical stories and courage in confronting injustice and vested interests, was previously winner of the 2017 HealthWatch Award. We congratulate her!

Welcome new student reps

One of our 2019 Student Prize winners and two of the runners-up have joined the HealthWatch committee as student representatives. Sylvester Odame-Amoabeng, in final year of his degree in Midwifery and Palliative care, King's College London impressed us all with his winning essay and his enthusiasm when we met him at the HealthWatch AGM in October. Pavithran Maniam, currently in the 5th year of his medical degree at the University of Dundee; and Robert Grant, 4th year medic at the University of Leicester, were also present. Read more about them on page 9. We look forward to fresh ideas.

Should you take statins? New briefing paper

If you're at low risk of heart attack and stroke, the benefit of taking statins will be modest at best, says HealthWatch's newest background briefing paper. Roger Fiskén (specialist in endocrinology and diabetes) and GP James May sifted through the evidence on this controversial subject to produce "Statins for the prevention of vascular events", which is now published on our website. HealthWatch briefing papers are a useful reference for journalists, healthcare professionals and patients. They now cover 11 healthcare topics. Find them all by looking under the "Publications" tab at <https://www.healthwatch-uk.org/>

How do you take your Newsletter?

Has hard copy had its day? Are pdfs past it? The HealthWatch Newsletter would be open to considering going online, but we want to hear from members. Would you read the Newsletter if articles were posted online as they happen? Or would you rather turn a printed page? With limited manpower, we probably couldn't manage to do both, so we'd very much like to hear your views and ideas as to which way you'd like the Newsletter to go. Let the editor know what you think about this, or indeed any other HealthWatch-related subject that's on your mind, by e-mailing newsletter@healthwatch-uk.org

Let's declare to fight research waste

Twenty-five years ago, British statistician Doug Altman declared that much medical research is unreliable because of the pressure to publish research without adequate controls on its quality. Now an international group of researchers and patients has created the [Declaration to](#)

[Improve Health Research](#) to call for simple but crucial measures to address the problems, by improving the quality and openness of medical research, and giving the public the right to access the research they fund. HealthWatch has signed the Declaration, and we suggest members take a look too and consider signing.

Do factual arguments always backfire?

A report claims that factchecking does help to inform citizens, and that backfire effects – in which people cling more firmly to false beliefs when presented with evidence to the contrary – could be rare rather than the norm. We just came across the short booklet published last year by Full Fact, an independent UK factchecking charity: [The backfire effect. Does it exist? And does it matter for factcheckers?](#) It summarises recent studies into the effect, including several that could not find evidence of backfire. However, it acknowledges that strongly held political beliefs can be a strong factor mitigating against the success of debunking.

Bringing 10:23 to Brazil

Homeopathy is taught as fact in medical and pharmacy degree courses in Brazil, but the practice is being challenged from within by the country's Question of Science Institute (IQC). Based in Sao Paulo, the IQC is a non-profit, non-partisan association which promotes evidence-based public policy. They held an [international seminar](#) in November where they were joined by like minds from opposite ends of the globe: Loretta Marron, CEO of the Australian group [Friends of Science in Medicine](#), and Michael Marshall, Director of the [Good Thinking Society](#) here in the UK, who also masterminded the [10:23](#) campaign which aims to raise awareness that homeopathy is ineffective.

NHS calls time on homeopathy

And while we are on the subject ... last November Simon Stevens, Chief Executive of NHS England, wrote to the Professional Standards Authority (PSA) to express concern that the Society of Homeopaths retains their accreditation. His letter made headlines in the newspapers, including a leader in *The Times*, and undercover investigations into homeopaths' anti-vaccine advice appeared in both the *Mail* and *The Telegraph*. Kudos to Michael Marshall and his team at the [Good Thinking Society](#) for their dogged work to expose the danger in PSA lending their legitimacy to organizations associated with vaccine misinformation. The [GTS' legal case](#) against PSA accreditation of the Society of Homeopaths continues.

Free webcasts on law, science and health

Some excellent lectures are made available online by the University of Minnesota. They are all free to register and attend via webcast, and include the spring series, Speaking Science in Public Controversies, and their annual research ethics day on 4 March on responsible data sharing. See: <https://consortium.umn.edu/news-events/events>

Erratum – and a new website to explore

For members who receive the hard copy version of the HealthWatch Newsletter, the editor apologises for an error in the Autumn issue. Norbert Aust, who authored the delightful article ‘Thank you, Mr Hevert!’ (pp 10-11) has pointed out that it was published with the affiliation of a completely different Norbert Aust. His sign-off is now correct in our online edition: ‘Dr, -Ing. Norbert Aust, Informationsnetzwerk Homöopathie, Schopfheim.’

The editor was pleased to have the error pointed out because it led her to Dr Aust’s website. ‘Homeopathy Information Network’ is an online resource by and for those committed to honest medicine and fair education about homeopathy. It can be read in English as well as German, and we invite HealthWatch members to take a look and enjoy: <https://netzwerk-homoeopathie.info/en/>

HealthWatch Award Winner 2019

Shining a light on areas of medicine that journalists – and patients – might not see

Investigative journalist and GP, Dr Faye Kirkland received the 2019 HealthWatch Award at the HealthWatch AGM in October. Here is her compelling presentation.

In my early 30s I was a GP partner in a practice I had wanted to join for years. A training practice, a very traditional surgery – where the doctors knew their patients and generations of families were all known by one doctor. This was the view of family practice I had been given as a medical student, seeing and treating people in the context of their families and communities.

But an internal voice started to grow in intensity. The pressure on the NHS, and the movement of care from hospital to GPs, often made continuity of care for patients more difficult. Qualified GP colleagues I knew left the UK altogether and went abroad, saying their quality of life was better, while I found myself staying at work later and later to provide the type of care I would want as a patient.

The nagging noise in my mind grew louder, and I started to wonder how I could use my knowledge in a different way. On a day off, I managed to get an interview at Cardiff University for a course in broadcast journalism, and to my surprise I got in. In just a week I had resigned from being a GP partner, moved my home into storage and my life from Brighton to Bristol, where I spent 18 months in my Dad’s spare room working as a GP at the weekend to fund the course in Cardiff.

I started to learn the craft of journalism, and realised I wanted to use investigative techniques and my knowledge to shine a light on areas of medicine that other journalists or patients might not see.

Access to diagnostic tests

A few years before starting the course, a close friend of mine had become seriously unwell. He had been to Accident & Emergency several times, collapsed at home and was even told by ambulance staff to pull himself together, that he had a virus. He was finally diagnosed with a brain tumour. Difficulty in accessing imaging, and people not recognising symptoms, were both major hurdles to him getting his diagnosis. The skills I had acquired allowed me to investigate whether his experience was reflected across the country. I knew from when I had worked as a GP that in some areas I couldn’t even refer for an MRI scan, but in others I could. Despite the Department of Health saying that all should be able to access this, different clinical commissioning groups had different rules. I established a picture that showed this post code



Faye Kirkland, speaking at the 2019 HealthWatch AGM

lottery. It was my final piece of work on my course but ended up as an hour of live radio for *BBC 5 Live Investigates*.(1)

Vitamin and mineral infusions

Within months of qualifying, I became interested in the world of vitamin and mineral infusions. While researching one programme I went to Harley Street undercover, posing as a patient.

I asked doctors if the vitamin and mineral infusions they advertised would treat my supposed eczema and anxiety. At one clinic a practitioner asked me to hold up my left hand, and with my right touch various organs of my body. The practitioner pressed down on my left arm and seemed to growl as if the diagnostic technique had revealed something about the state of my body. I was provided with

vials of different vitamins to hold against various organs, and again asked to repeat the arm test. This time, it seems, I was stronger. This diagnostic revelation meant I needed vitamins – and fast. An urgent infusion was offered. I politely declined.

The cost of this miraculous arm test ran to hundreds of pounds and the infusions which, apparently, I needed every few weeks were approaching £200 each time.

The importance of my investigative work became apparent to me as I looked in a room and saw a very frail man hooked up to two drips – one in each arm.

I found more than 100 webpages claiming that vitamin and mineral infusions such as these could help treat Parkinson's Disease, asthma, depression and hepatitis, with no evidence to support the claims.(2) It was clear at the time – this was 2015 – there were huge gaps in regulation. Were these infusions, which were straight into your vein, a medicine or not? Up to then, no one had decided. The drugs regulator, the MHRA, took the investigation seriously.

They had to write to each clinic, to analyse each of the vials to decide if these drugs were medicines or not. Eventually they decided medical claims could not be made against these products, as to do so,

might imply they were a medicine. The claims, they say, had to be removed. The majority of the medical claims for these infusions have now gone from the websites – in doing so I hope protecting patients. However, unfortunately, un-evidenced generalised claims of improving your well-being or giving you a glow persist.

Online health care

That was the year I came across a burgeoning new area of medicine: care online, ever accessible, at a click of a button and often at a price. Private, glossy websites often featuring celebrity doctors and well-known brands, offering care I would not give in the surgery. You filled in an online form with pre-set questions, send it off. A doctor reviews the form, prescribes medication for you without speaking or seeing you or having access to your NHS notes, and then a UK chemist would send the drugs to your home within 24 hours.

Four years ago, I found sites offering to cure sexually transmitted diseases after a few questions, with no warnings that their treatments were suboptimal and might not cure your infection.(3)

The familiar brand, Superdrug, was at that time making antibiotics available online for gonorrhoea, without the customer necessarily having proved they had it, and providing antibiotics which did not meet national guidelines. This was at a time when some patients were having to be treated for gonorrhoea in hospital, having acquired multi-resistant strains.(3) Following the investigation for *BBC 5 Live Investigates*, there was intervention from the British Association of Sexual Health and HIV, and a letter from The Chief Medical Officer and Chief Pharmaceutical Officer to all online clinics and GPs.(4) Since then there has been a massive change. Superdrug no longer provides antibiotics for this indication

– instead they advise you, correctly, to seek treatment at a suitable clinic.

This experience made me wonder what else you might be able to buy online.

As with all such things, digital health care has stayed one step ahead of the regulators. In 2016, again with *BBC 5 Live*, we went undercover posing as patients. My colleague was able to buy drugs for an ear infection, supposedly of three days' duration, therefore probably viral and hence not curable by antibiotics. Some halfway through the questionnaire we were abruptly asked about sexually transmitted disease and a vaginal discharge. Following this, drugs were prescribed that I have never given for an ear infection. This was all delivered to the house and was signed off by a practising UK doctor.(5)

How could this be allowed to happen?

We asked the company which had provided this medication. They blamed a computer problem saying the questionnaire about vaginal discharge had got mixed up

with the one for ears and actually we had been sent antibiotics for the wrong condition.

We asked the Care Quality Commission (CQC) – the health regulator in England – and the General Medical Council (GMC), the doctor's

regulator, to respond. The CQC brought forward a wave of inspections, with the clinic exposed being one of the first. It was suspended. The GMC investigated the doctors. Clear online health care standards for online companies were published by the CQC the following March.(6)

A step forward you may think? But last year, with the BBC's *Panorama*, I found the sites were once again one step ahead. Not only were they supplying antibiotics but often drugs of misuse, such as opiates.

Some sites moved their headquarters out of England and therefore avoided regulation by the CQC, most choosing to base their companies in Romania. Now their online doctors' care could not be regulated, and the prescriptions could be sent electronically from Romania to pharmacies in the UK and still delivered to your door.(7)

Panorama 'Online doctors uncovered'

Still with *Panorama*, I wanted to see these Romanian companies – the supposed hub for these online doctor sites – for myself. But instead of finding a hive of doctors doing online consulting, I found empty flats. Just an address, that means the CQC cannot regulate and keep patients safe.

After the *Panorama* programme was broadcast last year I was contacted by a family whose daughter had been able to buy codeine from 18 online UK pharmacies, as well as continuing to obtain these drugs from her GP, who had not been informed. She had collapsed and died behind her front door. She was in her early 40s. Her inquest is yet to take place but her family believe the codeine contributed to her death.(8)

Also following the programme, and in part as a result of it, the General Pharmaceutical Council has also moved to stop pharmacies in Great Britain from dispensing certain high-risk medications to patients without their family doctors being informed.

“They blamed a computer problem ... the questionnaire about vaginal discharge had got mixed up with the one for ears. We had been sent antibiotics for the wrong condition.”

Also in response to Panorama, the CQC asked the Government to change legislation. They are still waiting for this to happen.

Investigative journalism has taken me to places I never imagined, secret meetings, being given leaked documents and holding power to account. Continuing to be a doctor is a privilege but helping to create change on a national level can be an even greater one.

Faye Kirkland

Freelance investigative journalist and GP, London

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Report from the Chair

Still punching above our weight

Report from the Chair of HealthWatch, Dr Susan Bewley

Healthwatch is a small charity with its roots in the Campaign Against Health Fraud (CAHF) that was established in 1989, and formally set up in 1991. It is reliant entirely on the voluntary work of its Trustees to whom we are all grateful. Looking at the first undated CAHF newsletter (from the pre internet era) gave me a stark reminder of the continuing problem. As our president, Nick Ross, explained, we exist because the public are being deceived: “People are at their most vulnerable when they are ill or depressed, and it is a particularly offensive form of fraud when people pose as healers and exploit that desperate need for help by offering them illusions of cure that can never be fulfilled”.

In the past 30 years many, many other organisations and commentators have sprung up to deal with quacks, charlatans, and the problems with honesty, bias, corruption and fraud in health care and its sciences. Although there have been great gains in understanding, education, research and regulation, nevertheless our work remains as vital now as ever, notwithstanding we have limited people and resources, we must continue to ‘punch above our weight’, and to offer something different – our ‘unique selling point’ or USP.

The work we do

Last year I focused on the three areas of strategic focus (1) communications, (2) specific projects and (3) outreach. We’ve continued with these, and particularly on being more proactive, but limiting our resources to where there is opportunity to make a special Healthwatch contribution.

Internal communications

The committee continues its 21st Century internal ways of working, meeting largely by teleconference, but also in the old-fashioned face-to-face way today. Although we only had three newsletters this year, one of these was a bumper ‘double edition’. Mandy Payne has been indefatigable in continuing to produce excellent online newsletters with news, book reviews, updates from around the world and

such diverse topics as evidence based dentistry, pelvic mesh, prostate biopsy, intersex and sport, clinical transparency and bioresonance machines.

Although only a quarter of the membership are on the googlegroup* it continues to be a place of debate and information sharing. It’s reached thread number 1845 (460 in this last year, so your inboxes will not be overwhelmed). Twitter is an increasingly useful way of communicating what we are doing. As of today, HealthWatch has 979** followers (up from 842) and has tweeted 2169 times (539 this year). Our Facebook account has very little activity and we are not on Instagram.

Although social media means speedier communications and being part of an influencing network along with many previous HealthWatch award winners, it also takes time and judgement. We need to reflect on why we don’t attract and retain the young, which is why we have just taken on a volunteer in the role of social media editor and will give mentoring and support.

External communications

At an informal level, we’ve kept up our links, communications and meetings with a number of other external charities and organizations such as Sense About Science, TranspariMED, the Good Thinking Society and others, and have made representations to bodies such as



* Members who have not yet joined the googlegroup please write to membership@healthwatch-uk.org to enlist.

** At time of going to press @HealthWatchUK has 1028 followers on Twitter

the Charities Commission, the Royal College of Surgeons and others. Our president, Nick Ross, is very well connected and this ‘networking’ is invaluable, and maybe could be capitalized upon further?

Last year we celebrated HealthWatch and TranspáriMED being cited in the Science and Technology Committee of the UK’s House of Commons report calling for a “national audit programme of clinical trials transparency”. This is still on ongoing work, which HealthWatch doesn’t lead but supports Till Bruckner’s fantastic efforts to hold institutions and individuals to account for registering and reporting trial results. Working in joint collaborations is a way a small charity can continue to be effective, and we need to consider this more in the future.

Roger Fiskén has taken on the tremendously helpful task of anticipating consultations (largely with government bodies), eliciting comments from the membership and writing our formal responses.

This really important role means he’s also be able to keep an eye on the final reports being produced by government, and to judge their impact. Consultations we have contributed to include those on Universities UK’s

Concordat to Support Research Integrity; NHS Implementing Long Term Plan and Changes to Legislation; the European Medicines Agency’s draft Regulatory Science to 2025 Strategy; and MHRA’s relationship with the public.

Awards – student and annual (see also pp4, 8)

It’s very good news that we continue to be spoiled for choice in who to recognize with our annual award. We have volunteers organizing the important student prizes, which has been a springboard to many students in their general and HealthWatch careers.

Projects: AgeX

HealthWatch has been described as a group of people with ‘bees in their bonnets’ – I think this means people with the grit and determination to continue following through on projects for the months and years it takes. For example, with respect to the UK AgeX trial breast screening trial which HealthWatch has opposed since we first learned about it in 2011, we finally exposed its flaws in an Analysis feature published in the *British Medical Journal* in April 2019. Despite this being one of the world’s most influential medical journals and generating letters of support from many international experts, the article was ignored by all responsible authorities. Sarah Wollaston MP (2018’s HealthWatch Award winner) wrote to health secretary Matt Hancock to challenge him on the trial and, disappointingly, he gave a stock reply and specifically didn’t answer questions about its cost and oversight. Mandy Payne and I have been invited to write an open letter to him in the *BMJ* and various drafts are going backwards and forwards.

“Responsibility for teaching critical thinking skills lies with the medical schools, but we must continue to press for this in an era of ‘fake news’.”

Projects: Trading Standards/Charities Commission

Les Rose has expanded the scope of his investigations into misleading treatments targeting the public. This year he moved beyond Trading Standards to the Charities Commission, producing four excellent evidence-based complaints against charities who promote potentially dangerous treatments in violation of the charity’s public mission. The Commission replied with standard letters. HealthWatch challenged, and Les was later approached by the CEO of the Charities Commission at their annual public meeting. So it seems there is an open door to our views as they modernize their approaches to improving the sector.

Projects: puberty blockers for gender dysphoria

Questions about the quality of evidence, particularly for puberty blockers given to gender dysphoric children and young people, have been discussed on the HealthWatch

googlegroup. I appeared in a *Newsnight* documentary and a *BMJ* feature by Deborah Cohen, another previous HealthWatch Award winner, talking about the uncertainties in this field and calling for better quality evidence. Although there have been discussions as to whether it would

be an appropriate topic for a Healthwatch debate or campaign, we haven’t progressed this for three main reasons: (a) the toxic nature of much of the debate on this issue, (b) the fact that many other people and organizations are already involved, many with deeper knowledge of the condition than ourselves, and (c) our sincere compassion for those individuals affected. We welcome comment on this as a strategic approach; also of course suggestions for topics for a HealthWatch debate or further symposium.

Projects: Medical devices

The key main new project we have concentrated on has been medical devices and I think this has been the highlight of the HealthWatch year. We commissioned the wonderful Dr Till Bruckner to produce a background paper on the regulation of devices which, after lots of engaged peer review, formed the background material for the successful symposium on 17 June 2019, ably led by John Kirwan and HealthWatch facilitators. All the papers, participants, and responses were collated and uploaded on the website and a draft strategy produced by John. We consulted with the membership, although the level of response was smaller than we’d hoped. We are now ready to launch the strategy. These are the key headlines:

1. *Implant approval should be graduated, and supported by step-by-step evidence; the old ‘equivalence’ system of approval, using Notified Bodies, has failed.*
2. *Those who implant a device must know (and be able to explain to the patient): what it is; what are its constituents; how it is identified and tracked; how the evidence shows that it works; what risks are involved, and what to do if things go wrong.*

3. *Regulators, academics and professional bodies should work together to achieve these aims.*

Our vice chair, Keith Isaacson, and I have had a productive meeting with Derek Alderson, the President of the Royal College of Surgeons. The delayed Cumberledge & Chantler report into the surgical mesh scandal is now expected early in 2020. We await its publication before we finalise our views and press our demands.

Outreach

An enormous amount of work goes into running the Student Prize and I thank everyone for their continuing contributions to setting and marking this (see separate report, below). The responsibility for evidence-based teaching and development of critical thinking skills lies with the medical and other healthcare schools, but we must continue to press for this in an era where ‘fake news’ and empiricism are so pervasive. We hope to allocate more specific responsibilities to committee members, including our new volunteer social media editor, to involve and recruit students.

Although our membership has remained stable over some years, and our finances are healthy, small charities like Healthwatch always experience a tension between growth on the one hand, and sustainability as members age and move on. To avoid languishing in the backwaters of Dinosaurland, and to maintain the relevance of our organisation, we have to reflect on whether it is enough to talk mostly to the already convinced and converted. To these ends, we have been doing some thinking:

Funding: Some options have been put together by Roger Fiskén and will be subject to further discussion.

Governance: The committee is considering the question of whether we should merge or affiliate with other charities. Our impact is always limited by the fact that we are so few. We are pleased to report that members are

rising to the challenge of specific tasks and roles, but we are all busy people and we must nurture volunteers through difficult personal times, as well as challenging them to produce, or at least succession-plan.

Committee: Lastly, a charity and its chair is nothing without her committee and I am particularly indebted to David Bender, our stalwart secretary, Anne Raikes our prudent treasurer, Alan Henness our efficient membership secretary, Keith Isaacson a reliable vice-chair, and the hard working members Roger Fiskén who took on the role of consultation coordinator, John Kirwan for this year’s particular focus on devices, the indefatigable Les Rose who continues to work on trading standards and charitable status of dangerous alternative remedies, as well as John Illman, James May, Philippa Pigache, Tom Moberly, Andrew Fulton, Jolene Galbraith and Sofia Hart. We must also particularly thank the very hard working Mandy Payne, our Newsletter editor and Nick Ross, our inspiring president. We are sadly saying goodbye to John Kirwan who’s been a great force for *doing*, not talking.

In summary, it has been another positive year. Please look at the website, and join the googlegroup. We have financial resources to spend on research projects in line with our aims, so do apply (look for ‘Research fund’ under the ‘Projects’ tab on our website), particularly if you have ideas that student groups could work on. It cheered me up to realize just how much has been done this year, and how the focus on strategy and systems within HealthWatch has paid dividends in terms of wider impact. More still needs to be done to draw in a rejuvenated membership of students and new doctors who are as passionate about evidence as we are.

Susan Bewley

*Emeritus Professor (Honorary), King’s College London
Department of Obstetrics & Women’s Health*

Students

Our brilliant young winners

This year the HealthWatch Student Prize will come of age, as it reaches its 18th birthday. Since its launch in 2002 we have been cultivating evidence-spotting among the upcoming generation of health professionals, and handed over a combined total close to £20,000 to 28 first prize winners, and 58 runners up. The 2020 HealthWatch Student Prize is now open and we hope that by the time it closes at midnight BST on 30 April our judges will be once again snowed under with outstanding entries.

October’s HealthWatch AGM hosted many of the 2019 winners and runners up and we are delighted that three of these brilliant young people – Robert Grant, Pavithran Maniam and Sylvester Odame-Amoabeng – have agreed to join the committee as Student Representatives. Sylvester Odame-Amoabeng, our £500 first prize winner in the Nursing, Midwifery and Professions allied to Medicine category, bowled us all over with his enthusiasm and excitement when we met him at the AGM.

Sylvester was born in Ghana but relocated to the UK in 2013 where he is now in the final year of his BSc Adult Nursing Degree at King’s College London, currently on placement at University College London. “I have my

clinical placements at a Hospital Trust and belong to a faculty where clinical research is a big driver. I found out about this competition during my student elective exchange at the University of Sydney, Australia and I jumped at the opportunity to do some real critical appraisal of clinical research protocols right after a module in Evidence-Based Practice at University,” he said.

“As one interested in pursuing a career in academia, this is a propeller towards a career firmly founded on evidence – asking the right questions to know how things can be improved.” He will have plenty of opportunities to ask questions as one of our new HealthWatch Student Representatives.

Our first prize in the Medical and Dental category, another cheque for £500, went to Nicholas Heng, who was then about to qualify in medicine from Dundee University. Nicholas was also a runner up in the 2018 competition. He says taking part is rewarding and relevant to students, and recommends the competition to anyone involved in healthcare: “It not only gave me the opportunity to understand so much more about critical appraisal, but also pushed me to learn how to develop and apply these skills. They will go a long way towards providing quality care to patients in the future.” Nicholas could not make it to the AGM, as he was starting the first of his Foundation Year posts. His summer internships at various labs over the past few years have broadened his outlook on medicine and he looks forward to becoming a clinician scientist. We wish him well.

Runners-up each won a cheque for £100. Pavithran Maniam, also studying at Dundee, hails from Petaling Jaya in Malaysia. “I have been involved in a range of research projects previously, but I never had the opportunity to evaluate the quality of research protocols. This competition tested my ability to think critically and I learnt the importance of assessing the quality of a research protocol using a systematic approach.” Pavithran enjoys asking questions and would love to be part of a research team doing evidence based clinical and molecular research.”

Robert Grant, from Luton, used to be a professional golfer, but is now in his 4th year of Medicine at the University of Leicester. He gathered the confidence to enter thanks to the opportunity to attend events run by LUMRS, the Medical Research Society at his university, and his medical school’s excellent journal club. “I am going to be making an Academic Foundation Programme application next year and I see critical appraisal as an essential skill for my future clinical practice. I’m hoping for a career in academic surgery.”

Nader Raafat, from Cairo, is in the penultimate year of his course in Medicine at Oxford University. “I thought



Pavithran Maniam receives his certificate from Nick Ross



Four Student winners join Faye Kirkland for a photo. LtoR: Nader Raafat, Robert Grant, Sylvester Odamo-Amoabeng, Faye Kirkland, Charles Southey

“Interesting – critically appraising protocols on their methodological merits alone, without being confounded by how ‘worthy’ the trial’s aim was.”

the premise of the award was really interesting, as it was about critically appraising protocols on their methodological merits alone, without being confounded by how ‘worthy’ the trial’s aim was. It gave me a chance to apply what we’d been learning about evidence-based medicine in a systematic way, a skill (and scepticism) I’ll

hopefully use for my future clinical practice!” Nader hopes one day to return to Egypt with the skills and experiences learned here in the UK. “Particularly in the context of one of the last free at the point of care health services in high-income countries, to be able to improve health outcomes in Egypt. I’m

hoping to achieve this through a career in medical education or management (or both!) that gives me good exposure during my time here.”

Charles Southey from London studied closer to home, at King’s College London, where he qualified last year. Charles is getting his peers involved in critical appraisals and quality improvement projects now that he is a Foundation Year 1 doctor. “Universities could improve their curriculums with regard to teaching critical appraisal and how to tell good evidence from bad.”

We are, as always, extremely grateful for the generosity of the prize’s sponsors over the years – from the AJAHMA Charitable Trust, through the Medico-Legal Society, the late Professor John Garrow, Cambridge University Press and, since 2018, the [Royal College of Physicians of London](#), to whom we offer our heartfelt thanks for their continued support.

Mandy Payne
Editor, HealthWatch Newsletter

Book review

O, LET ME NOT GET ALZHEIMER'S SWEET HEAVEN: Why many people prefer death or active deliverance to living with dementia

Author: Colin Brewer, £8.64p Paperback, 272 pages. Published 17 October 2019 by Skyscraper Publications. Reviewed by Philippa Pigache

This book sits astride conventional genres. It is in part a detailed portrait of the illness – Alzheimer's – now the leading cause of death in England and Wales, according to the Office for National Statistics, with incidence, symptoms (especially the latter stages), treatment options and case histories. It is also in a way, a self-help book of the 'Living with ulcerative colitis' kind: 'Dying with Alzheimer's'?

Although at no point does Brewer supply instructions on how to end your life, he does include forms for the drafting of an Advance Directive, often referred to as a Living Will, plus useful contacts and further reading. But it is principally, a polemic. Medical detail plus a wide range of source material, from history, literature and religion are recruited to support the argument for a change in English law to permit assisted dying, or 'deliverance' as he calls it. He argues for an arranged and stress-free death to be permitted, not just to those terminally ill or suffering from cruel and intolerable illnesses like motor neurone disease, but even to those who are no longer mentally competent, as in the final stages of Alzheimer's, always provided that they have written an Advance Directive stating that this is what they want while still fully compositus.

The author has been here before. In 2015 he was co-author of the delightfully-named *I'll See Myself Out*,

Thank You: a collection of writings on the same theme.

This managed to be an entertaining read, despite being about disease, suffering and death. I would not claim this about his latest book. It's a tough, uncompromising, in-your-

face exposé about the experience of Alzheimer's for family, carers and for sufferers – and first person case histories are rare, for the obvious reason that in the latter stages rational thought is lost – and Brewer doesn't flinch from detailing how most end their lives under the present system. It is rarely stress-free, and can include involuntary feeding or even the voluntary withdrawal of food and hydration. (For this distressing quietus see the chapter called 'Will you still need me will you still tube-feed me when I'm 94?')

Brewer's chapter headings are vivid and help the reader in navigating the thorny issues he grapples with. The less painful sections of the book explore how social attitudes to suicide, and ergo, to assisted dying, have progressed throughout history. Brewer points out that many things abhorrent to previous generations: contraception, abortion,

cremation, have become legal and broadly acceptable in this country today.

Even the objections of religious groups to suicide are not universal: eastern religions like Buddhism, Confucianism and Hinduism take a more nuanced view. This also applies to cremation he notes, that was 'illegal in Britain (give or take the odd heretic) until late in the 19th century.' As an atheist and convert to Brewer's cause, I incline to the Greco-Roman view that suicide can be a brave or even noble act, as opposed to the Catholic classification as moral sin.

I enjoy Brewer's skirmishes with religious doctrine in the chapters entitled 'Worse than murder' and 'Slippery slopes: are they always a bad thing?'. They give him an opportunity to display his characteristic dry humour.



Philippa Pigache

Discussing the faith of Muslims and evangelical Christians who are among those most opposed to any form of assisted dying, demanding in all circumstances that 'everything must be done', he writes:

'Paradoxically, when on the brink of death, and even though both religions envisage an enjoyable afterlife (about which Islam gives the most confident, detailed and lyrical descriptions) it seems that the more faithful the adherents, the keener they are to keep their barely-functioning bodies and minds in this imperfect world rather than sampling the joys of the next, compared with those who have less or no faith.'

I fear Dr Brewer will not succeed in converting those with entrenched views with the elegance of his argument. He has been trying to do this in one way or another for some 40 years and has published widely on the subject. His experience as a doctor and psychiatrist informs his book. Although no longer practising, he is frequently called up to write the medical competence reports that are required for Advance Directives, and it is probably as an aid for those attempting to persuade the Westminster

"His skirmishes with religious doctrine in the chapters entitled 'Worse than murder' and 'Slippery slopes: are they always a bad thing?'. display his characteristic dry humour."

government to follow where public opinion leads (84 per cent in favour in the most recent survey) in liberalising the law related to assisted dying that this book will be most useful. The rich can afford to go to Switzerland; doctors have the means and the know-how to do it themselves. He argues that such an 'easeful death' should be available to all Alzheimer's sufferers who ask for it.

The book is thoroughly researched and comprehensively indexed and referenced. It tackles an important and difficult issue head-on, but is full of entertaining discursions and illuminating, if sometimes unpalatable, clinical detail. I believe HealthWatch members should read it.

Philippa Pigache
Medical Journalist and Author, East Sussex

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We stand for:

- The assessment and testing of all medical and nutritional treatments, products and procedures
- Consumer protection in regard to all forms of health care
- The highest standards of education and evidence-based health care by practitioners
- Better understanding by the public and the media of the importance of application of evidence from robust clinical trials

We are against:

- Misleading advertising of health products
- The sale of unproven remedies to the vulnerable and desperate
- Unethical marketing by pharmaceutical companies
- Misconduct in clinical trials
- Media misinformation on health and nutrition
- Government promotion of health and screening programmes unsupported by evidence

Our activities include public debates, symposia, awards, a student competition, and this quarterly newsletter. HealthWatch welcomes membership enquiries from those who share its aims. Join at <https://www.healthwatch-uk.org/join>



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