

## News

# Remembering two founder members

We were deeply saddened to learn of the deaths of two of our founder members in the final weeks of 2023. Full obituaries of Vincent Marks and Caroline Richmond are in this issue. There have been some brilliant ones in other media, for Vincent in [The Guardian](#), [The Times](#) and the [British Medical Journal](#); and for Caroline in [The Guardian](#), [The Times](#), the [British Medical Journal](#), the [British Association of Science Writers](#), and the [Medical Journalists' Association website](#).

Vincent Marks, world-leading expert on hypoglycaemia and a key witness in high-profile murder trials, was one of the [founder members](#) in the late 1980s of the group that became HealthWatch. His [account](#), written with Caroline, of how our charity came to be can be found on our website. Vincent Marks died on 6 November 2023.

In November last year, the Medical Journalists' Association (MJA) had voted unanimously to bestow

honorary membership on Caroline Richmond.

Thanking her for her services to medical journalism, MJA vice-chair Jane Symons described her as: "an extraordinary advocate for science and journalism throughout her life." Caroline was an outstanding and fearless journalist with a witty and elegant style. Caroline Richmond died on 24 December 2023.

*Caroline Richmond: it's an honour. MJA website, 3 Nov 2023. <https://mjauk.org/2023/11/03/caroline-richmond-its-an-honour/>*

## News in brief

**Our News in Brief section features latest achievements and news from our brilliant volunteers, trustees, past award winners and partners. Let us know what you are doing to promote good science and integrity in healthcare by emailing [newsletter@healthsense-uk.org](mailto:newsletter@healthsense-uk.org)**

### New research on its way to publication

HealthSense trustee Les Rose has recently completed a study of pseudoscience on offer via the UK NHS. His requests under the Freedom of Information Act 2000 (FOIA) revealed that many NHS trusts were offering treatments such as reiki, reflexology and chakra balancing. This is particularly concerning because it could bestow undeserved credibility on practices with no scientific basis. His research findings raise questions about the understanding of clinical evidence among some decision makers. The paper is complete and in process of being submitted for publication.

HealthSense members will look forward to reading his findings in full.

### Newsletter archive now online

Some of the earliest issues of this newsletter in all its previous incarnations can now be enjoyed in their original format in our online archive of past issue pdfs. Virtually all issues have been found, scanned and uploaded to the website. Go to: <https://www.healthsense-uk.org/publications/newsletter.html> and scroll from the current issue right down to the very first four-pager, then titled 'Campaign Against Health Fraud'. Take your time!

### Praise for latest research from Consilium

A new publication from researchers at our partner organization, Consilium Scientific, drew praise in an invited commentary when it was published in the prestigious journal JAMA Internal Medicine. The study, (1) led by HealthSense's vice chair Leeza

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Osipenko of the London School of Economics, had found that at best under 8% of new drugs offered a substantial added clinical benefit compared with existing medicines. Although industry invents nearly three times as many medicines as academia does, Osipenko et al's study of new drugs entering the French market found that drugs originating in an academic setting bring better clinical benefit than those from industry.

Joel Lexchin, emeritus professor at the Canadian universities of York and Toronto, is frequently critical of drug regulation. He praised the Osipenko-led study for helping challenge the beliefs that the pharma industry is responsible for all new medicines, and that all new medicines give patients more therapeutic choices: "Both are false."(2)

As well as reading their latest research, be sure to get notified of upcoming seminars from Consilium. They are online, free to join, and feature world-leading presenters from science and health policy in a one-hour format. Recordings and transcripts are available for catch-up afterwards. Go to <https://consilium-scientific.org/knowledge/seminars-2024> and sign up.

#### References

1. Osipenko L, Potey P, Perez B, et al. Provenance and Clinical Benefit of Medicines Introduced to the French Market, 2008 to 2018. *JAMA Intern Med.* 2024;184(1):46–52. doi:10.1001/jamainternmed.2023.6249 (20 Nov) <https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2811777>
2. Lexchin J. Therapeutic Benefit From New Drugs From Pharmaceutical Companies. *JAMA Intern Med.* 2024;184(1):52–53. <https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/2811785>

### Olivieri's courage championing patient safety wins her the John Maddox Prize

In 1996, Canadian haematologist Nancy Olivieri was lead investigator in a clinical trial of deferiprone. The drug is used to remove excess iron in patients with the blood condition thalassaemia major. But Olivieri suspected the drug was also harming patients. When she tried to inform trial participants of her concerns, Apotex, the drug's manufacturer, terminated the trials and threatened legal action if she made the findings public.

Olivieri believed patient safety should come first. So she shared her results at a scientific meeting and submitted them for publication. She was fired from her position at the hospital, charged with professional misconduct, and endured drug company lawsuits and harassment. Ultimately, when hauled before the College of Physicians and Surgeons of Ontario (CPSO), they turned tables on her persecutors by ruling that her advocacy for patients had been "commendable".

Nancy Olivieri was the worthy 2023 winner of The John Maddox Prize, awarded in October. The Prize is a joint initiative between one of our partner organizations Sense about Science, and the journal Nature. This important annual award recognizes the courage shown by individuals who stand up for science and advance

public discourse around difficult topics using sound evidence in the face of challenges or hostility.

Find out more and meet this year's winners and shortlist in a 3-minute video here: <https://senseaboutscience.org/activities/maddox-prize-2023/>

### Experimental treatments on a child result in Breakspear doctor suspension

The Medical Practitioners Tribunal Service has ordered a 12-month suspension against Dr Jean Monro, medical director of the private Breakspear Medical clinic in Hemel Hempstead. The Tribunal determined and found proven allegations against Dr Monro, including her referring a five-year-old for investigation with a 'Neuroscope' – a diagnostic tool that was experimental and not clinically indicated for the child's symptoms; and that she supported an intervention requiring the child to wear an oxygen facemask for hours a day even though its benefit was unproven and the treatment experimental in nature.

The Tribunal considered the fact that Dr Monro had not provided evidence of regret, apology, remediation or insight into the risks posed by her misconduct, to be an aggravating factor.

Dr Monro's promotion of unproven treatments under the umbrella term "clinical ecology" was one of the drivers for the [creation of the Campaign Against Health Fraud](#), which went on to become HealthWatch and is now HealthSense.

*Medical Practitioners Tribunal Service, decision published.* <https://www.mpts-uk.org/hearings-and-decisions/medical-practitioners-tribunals/dr-jean-monro--apr-23>

### Link up with us on LinkedIn

HealthSense now has a dedicated LinkedIn page where we can promote our activities within a more professional forum. Take a look and follow us. Search on LinkedIn for HealthSenseUK or go straight to the page at <https://www.linkedin.com/company/healthsense-uk/>

### Cancer workshop cancelled after complaint

We welcomed the news that a talk at University College London by author Jane McLelland was cancelled after Professor David Colquhoun (HealthSense Award winner 2010) wrote to the university's provost to question whether the university's reputation might be harmed by hosting an event for someone who advocates unproven and disproved treatments for cancer. McLelland, a physiotherapist, is the author of "How to starve cancer". Her December 10 event, "Metabolic Adaptations in Cancer", had been promoted on EventBrite as an educational workshop and was reportedly priced at £87.30 per seat.

### Kite flying incident

The General Chiropractic Council (GCC) has been inviting its members to download a "kitemark" featuring

the GCC logo as a way to show clients they are registered. Not wise. The term 'kitemark' is, of course, a registered trade mark of the British Standards Institute (BSI). The BSI noted the infringement and contacted the GCC, the term has now been removed.

*GCC relaunches 'I'm registered' scheme. GCC website, 4 Apr 2023. <https://www.gcc-uk.org/gcc-news/news/entry/gcc-relaunches-im-registered-scheme>*

### The King's homeopathic doctor

King Charles has attracted our attention recently with his choice for the position of head of the royal medical household. Dr Michael Dixon is a part-time GP with a special interest in complementary and alternative medicine, particularly homeopathy. The King's choice of Dixon as his top doctor was the subject of a feature in The Times in December, by Dr Mark Porter, our 2015 HealthWatch Award Winner. In the article Porter describes the demise of homeopathy in the NHS, and concerns over its continued use. He concludes: "If the King wants a homeopathic GP as his doctor, so be it. My only concern is that the appointment could be the thin end of a wedge he hopes to drive into NHS policy. What happens in the royal household should stay in the royal household." We tend to agree.

*Porter M. The King has a homeopathic doctor, but I don't recommend it. The Times, 11 Dec 2023. <https://www.thetimes.co.uk/article/king-charles-homeopathic-doctor-9dkrlrkt>*

### American psychologists join the fight against health-related misinformation

Misinformation could account for as much as 29% of overall news consumption, and may be even higher when it comes to health news, says the American Psychological Association. In November the group issued a 44-page consensus statement to advise on how scientists, policymakers, and health professionals should respond to the ongoing threats posed by health misinformation. The statement's eight recommendations include some useful tips about debunking and "pre-bunking" (try to discourage people from being likely to believe in misinformation before they are even exposed to it). It also, rather optimistically, suggests: "Collaborate with social media companies to understand and reduce the spread of harmful misinformation" and "Demand data access and transparency from social media companies for scientific research on misinformation." Good luck with those two.

*Using Psychological Science to Understand and Fight Health Misinformation: An APA Consensus Statement, American Psychological Association, November 2023. <https://www.apa.org/pubs/reports/health-misinformation>*

### Obituary



## Caroline Richmond: a force to be reckoned with

**Caroline Richmond, 1941 - 2023**

*By Nick Ross*

**During her long career as a medical journalist Caroline Richmond wrote enough obituaries of the great and good in healthcare to deserve one of her own, even if it were simply her journalism that has cause to be remembered.**

That in itself richly deserved the lifetime award she received in November from the Medical Journalists' Association. She was warm-hearted, but biting if a subject deserved it, and always, always, scrupulous about getting her facts right. But Caroline was more than a principled writer. Having broken the glass ceiling of science journalism herself she worked hard to help other women rise to the top of the profession (becoming coordinator of [Women in Media](#)) and was a passionate campaigner for scientific literacy (becoming vice chair of the [Association of British Science Writers](#)).

One attribute - which was perfect for a ginger group like HealthSense - is that Caroline was plainly not one to be naturally compliant.

Born in 1941, Caroline grew up in Richmond, Surrey, the daughter of Cedric Ivor Smith, an Indian civil servant, and his wife Kathleen (née Meeson). Caroline was expelled from Richmond Grammar School for Girls, thrown out of college two years into a zoology degree, and later quit a neuroscience PhD after a disagreement with her boss, before completing a masters in physiology at Birkbeck.

She apparently enjoyed her Masters, but abandoned academia to find her métier in journalism. Caroline contributed to the *BMJ*, *The Independent*, *New Scientist*, *The Spectator* and *The Oldie*. She was also European

correspondent of the *Canadian Medical Association Journal* and co-author with Professor Vincent Marks of *Insulin Murders*. She was a prolific obituarist. Caroline is survived by her husband Jim Edgar, an IT analyst. They met in 2010 and were married in 2015.

Of course what I knew Caroline best for was as the founder of HealthWatch (now HealthSense).

And here I have a confession to make. Back in 1991 I had thought that I was starting HealthWatch myself, having been persuaded by the oncologist Michael Baum who introduced me to some of his patients in late-stage cancer who had suffered terribly from so-called alternative health practitioners rather than seeking proper medical advice. But it turned out Michael had been busier than I realised. The initiative was already gathering momentum with Caroline providing most of the impetus, if not actually being panjandrum of the whole endeavour.

That original idea was to set up a UK version of the American CAHF, the Campaign Against Health Fraud, to tackle what Caroline called the ‘thriving and malignant relic’ of prescientific times. As she told our first meeting – a rather impromptu small gathering around a table in a pub – she was fed up writing about deficiencies in the law, misguided faith healers and persuasive fraudsters. Something needed to be done to stop such people preying on the worried well and especially on the worried sick.

I soon discovered that Caroline and I shared a corresponding passion for the flipside of CAM quackery: the flimflam in conventional medicine caused by commercial pressures on pharma, egoism in academe, and from medical professionals steeped in old-fashioned and often poorly evidence-based ways of doing things. Much of alternative medicine was harmless – other than debasing human intelligence and diverting some poor souls from getting proper care – but real medicine is powerful and, wrongly applied, it does tremendous harm. Caroline strongly believed that what was good for the goose was good for the gander. The same rules must apply whether to the mainstream or to the clearly bonkers, whether to self-appointed shamen or highly-qualified physicians. After CAHF was renamed HealthWatch in 1990 it was Caroline as much as anyone who helped us transition from a campaign *against* quackery into a campaign *for* evidence based medicine, or as we now describe ourselves, for science and integrity in healthcare.

For three decades Caroline was a driving force, despite several bouts of serious illness. At one time, some 20 years ago, she was so unwell that when I went to see her in a sterile room in hospital (the old Middlesex Hospital in London’s Fitzrovia which was demolished in 2005) she confided that if the experimental treatment didn’t work she was not long for this world. More recently she had persistent problems with hydrocephalus (so-called water on the brain) but the shunts to relieve the pressure didn’t work and yet again she faced the prospect of imminent death – now with a serenity that came from so many years of living with the prospect.

Even so, when she did die on Christmas Eve I found it hard to accept the news. I had come to see Caroline as indestructible – as durable as her love for impartial facts and her lust to save people from pseudoscience medical harm.

Come to think of it, the only time I ever doubted Caroline was when she told me she was dying. As always she was right.

We have lost a good journalist, a good campaigner, a good person.

*Nick Ross*  
Writer, journalist and broadcaster  
President of HealthSense  
London

## Obituary



## Vincent Marks: insulin expert and star witness

**Vincent Marks, 1930-2023**

*by John Illman*

**A world authority on insulin and hypoglycaemia, Professor Vincent Marks was a founder member of the Campaign Against Health Fraud (CAHF), forerunner of HealthWatch and then HealthSense.**

He was also its catalyst, thanks to a chance meeting with Caroline Richmond, with whom he later wrote the highly acclaimed *Insulin Murders* (2007).

Meeting her as a fellow-speaker at a meeting in 1987, over lunch he told her in his loud, booming voice about his membership of the US National Council against Health Fraud. Fired by characteristic passion and determination, Caroline set about launching a UK equivalent. CAHF was launched in 1989.

Vincent recalled: "The nascent organisation started quack-busting without delay. A tip-off by an anonymous

member led to the 'defrocking' of a bogus doctor; then another member, David Pearson, reader in medicine at Manchester University, pointed out dangerous and misleading errors in the *Women's Journal*.

Professor John Garrow, eminent nutritionist and later HealthWatch chair, and I individually complained to the BBC *Today* programme about "nutrition misinformation that included a bogus vitamin and perpetuation of the diet-hyperactivity myth."

In the world at large Vincent was a star expert witness. As befits one of our founders, he was renowned for rigorous pursuit of justice and good science; and great caution in framing observations about the mystery of insulin and hypoglycaemia with the word 'probably'. He aimed to eliminate the old idea that insulin was the perfect murder weapon — the poisoner's friend and the policeman's nightmare.

Vincent led nine expert witness in the first big televised US trial, of Danish born British lawyer and socialite, Claus von Bülow, who had been convicted of trying to kill his wife Martha ('Sunny') von Bulow by insulin injection. Vincent's evidence was critical in quashing the conviction and 30-year jail sentence.

In contrast, in evaluating evidence against Lincolnshire nurse and convicted child murderer Beverly Allitt, Vincent was sure about her guilt — unlike other authorities at a pre-trial meeting. He said: "It appeared that almost no one except me was prepared at the beginning of the conference to stick their neck out and say foul play had definitely been committed". Allitt was convicted of four murders and attempting to murder three other children. Insulin was implicated in two of the murders.

Documenting 50 years of legal cases and reading like a tense crime thriller, *Insulin Murders* – the 2007 book Vincent wrote with Caroline Richmond – underlines the deep complexity and elusiveness of the science that intrigued Vincent for more than half a century. The *BMJ* reviewer suggested that Vincent would be the perfect dinner guest, with 'stories of bigamous murders, serial killers and bungled miscarriages of justice until well after the last wafer thin mint had been eaten and the port bottle emptied'.

Vincent's illustrious reputation in the witness box evolved from innovative research. Developing a novel way to measure glucose at low concentrations in the blood, he discovered that, although people with diabetes are at the greatest risk from hypoglycaemia, many others are also susceptible. He detected hypoglycaemia 'masquerading' as neurological disorders — including brain tumours, dementia and panic attacks.

As with so many other successful careers, serendipity gave him an encouraging pat on the back. He came into the field during a period of critical discovery in the late 1950s and early 1960s when US researchers developed a means of measuring the quality of insulin in the blood. Vincent and Dr Ellis Samols, the distinguished South African researcher who introduced the US technique to Europe, conducted original research to diagnose hypoglycaemia with insulin measurements.

Born in the Grand Junction Arms pub in Harlesden, north London, Vincent was one of two sons of publican Lewis Marks, formerly Lewis Myer Kinishinski, and his wife Rose (née Goldbaum), a photographer's assistant. Vincent's brother John, a GP, became chair of the BMA Council.

Evacuated during World War Two to a Devon farm in Bishop's Minton, Devon, he came to love the wide open spaces, hay-making and milking. But his refusal to eat non-kosher food created an initial crisis. Big brother John was despatched to Devon to re-assure him that the rabbi had issued him with a dispensation to eat non-kosher food with a free conscience.

Rural life had a profound effect. Returning home in 1942 for a scholarship place at Tottenham Grammar School, he declared himself to be an atheist, and later, a humanist. His nephew, Richard Marks, also a doctor, said: "Speak to him about religion for five minutes and you'd wonder how anyone could believe in God. He was so convincing."

Vincent also obtained a scholarship to Brasenose College, Oxford. He was accused of being a communist when he proposed that the junior common room newspapers should include *The Daily Worker*, forerunner to *The Morning Star*.

He later recalled thinking: "If they're going to call me a communist, I might as well join the party". His commitment was short-lived. He left in disgust after the Soviet Union's savage response to the 1956 Hungarian uprising.

Graduating from Oxford in 1952, he did his clinical training at St Thomas' Hospital, London, qualifying in 1954, shortly before meeting his future wife. Trained at St Martin's College of Art, Averil became an accomplished sculptor.

Vincent developed his interest in hypoglycaemia at the Hospital for Nervous Diseases. After working in laboratory and metabolic medicine in London for several years, he spent eight years as the first consultant pathologist at Epsom district hospital. He then became foundation professor of clinical biochemistry at the newly-founded University of Surrey where he was 'an outstanding teacher, both entertaining and provocative', according to Dr John Wright, one of his 1980s students.

Vincent contributed to more than 300 research texts, wrote about 50 original papers and was the author, co-author or editor of nearly 20 other publications.

His first book, "*Hypoglycaemia*", co-authored with neurologist Frank Clifford Rose, appeared in 1965; and his last, "*The Forensic Aspects of Hypoglycaemia*", in 2019, nearly 25 years after his 'retirement.' He was talking about a forthcoming paper with his son Lewis the day before he died. Lewis said: "He just loved writing — he was so enthusiastic about it — as with anything he was doing. He really was one of the world's great enthusiasts. He was also a wonderful father."

His wife Averil and their two children, Lewis and Alexandra, survive him.

*John Illman  
Journalist and HealthSense trustee, London*

## HealthSense Award

## Another world is possible: awards for transparency leaders and top students

By Mandy Payne

**In his talk entitled "Another World is Possible", the 2023 HealthSense Award Winner Till Bruckner astonished us.**

He began with the story of Emma Yasinski, of Florida, who received a mesh heart implant in childhood as part of a clinical trial that was never registered. Now an adult, she will never know whether her implant is safe, how the other patients fared or even if they survived.

In another example of how non-publication of clinical trial data can directly harm patients, he described how a [classic 2008 study](#) revealed that 31% of registered trials of antidepressants, tested on nearly 3,500 study participants, had never been published.

Not surprisingly, most of the trials that investigators had chosen *not* to publish were the ones that had shown the drug under test did not work. This selective publication meant the research literature available to prescribers would mislead them to believe that in 94% of clinical trials the antidepressants had been proven effective.

The true figure should have been nearer 50%. "Patients are harmed because we don't know how effective treatments really are."

Till Bruckner started the [TranspariMED](#) initiative in 2017 to improve the public's and policy makers' understanding of how to effectively tackle the problem of hidden medical evidence. His energetic media advocacy has heightened public understanding of the human and financial costs of medical evidence gaps, while at the same time he has educated decision makers and come up with innovative solutions for how to solve the problem in practice. As a result of his efforts, the UK has now put into place the world's first comprehensive clinical trial monitoring system.

From left to right: Nick Ross, Nicholas DeVito, Till Bruckner



"Things are changing fast, and for the better," says Till. "And HealthSense has been a big part of that story throughout."

Till shared his award with fellow transparency pioneer Dr Nicholas DeVito, postdoctoral researcher at Oxford University's Bennett Institute for Applied Data Science, who has been a driving force behind the [EU Trials Tracker](#) and the [FDAAA Trials Tracker](#) which show how far funders are complying with transparency regulations. Since the trackers were launched, clinical trial reporting rates have increased from 50% to around 80%. Nick led an enthusiastic question and answer session.

Our 2023 HealthSense Awards Night was held in London's Victory Services Club on 15 November. It was opened by our president, the broadcaster and journalist Nick Ross, with a heartfelt toast to founder members Vincent Marks, who had died the previous month, and Caroline Richmond who had generously funded champagne for all. Caroline was too unwell to raise a glass with us in person, and later died on Christmas Eve.



From left to right: Nick Ross, Noelle Yau, Toni Oduwole, Sakshee Ramakrishnan

In this year's audience our guests included Tim Mitchell, president, and Ralph Tomlinson, director of research and quality improvement, both of the Royal College of Surgeons of England, who generously sponsor the HealthSense Student Prize. Nick emphasized how the Royal College of Surgeons of England have done so much more than other Royal Colleges to really put science on the map. He particularly commended their surgical trials clinical research initiative to examine the efficacy of surgical procedures – not just the innovative ones, but whether time-honoured procedures such as appendectomies are still the best way to treat? Follow the evidence!

Three star students received their [HealthSense Student Prize](#) cheques from Nick Ross in person. First prize in the Medical & Dental category, and a cheque for £500, were awarded for an outstanding entry from Sakshee Ramakrishnan, from London, who is in her third year at Lancaster Medical School. Her passion is for Population Health, a blend of epidemiology, study design and public

health. "The HealthSense prize captured exactly the aspects of the curriculum that I find so enjoyable, and relevant to evidence-based medical practice. I am really grateful to have stumbled across it, it was genuinely a lot of fun!" She has applied for a medical bursary from the British Army and aspires one day be a part of the humanitarian medical care effort.

Noelle Yau, who took the £500 first prize in Nursing, Midwifery & Professions Allied to Medicine, is studying Cancer Biomedicine at University College London but hails from Vancouver. As well as competing in evidence-spotting, she is also a competitive badminton player who has represented Canada. She told us: "I wanted to test the skills that I have learned from university and challenge myself to think outside the box. I found the competition fun but challenging at the same time."

We were delighted to meet Toni Oduwole, runner-up in Medical & Dental. Toni, from Essex, is also at UCL. She has just intercalated a BSc in Clinical Sciences as part of her medical degree, and has two more years of medical school. The competition was right up her street, because: "I have been interested in scientific writing since my iBSc last year. I also learnt a lot about study designs and clinical trials during the year, so I wanted to put my skills of assessing study protocols to the test!"

Nick also congratulated three runners-up in the Medical & Dental category who were unfortunately unable to attend in person: water sports enthusiast Lorenzo Verani of Monza, Italy, who has just graduated in medicine from Imperial College London; Matthew Lim of Penang, Malaysia, in his final year at the University of Glasgow Medical School; and aspiring oral and maxillofacial surgeon Oyeyemi Opeyemi Victor, who is studying at Ahmadu Bello University in Zaria, in his home country of Nigeria. We wish them all success.

The video [recording](#) of the evening's presentations is on our [YouTube channel](#). The 50-minute recording begins with the welcome by Nick Ross; the [Student Prize](#) presentations start from 12:30 minutes in; then the presentations by Till Bruckner and Nick DeVito from 16:30 onwards.

We are grateful once again to The [Royal College of Surgeons of England](#) for their generous support of this year's HealthSense Student Prize competition.

*Mandy Payne  
HealthSense Newsletter Editor*

## Overdiagnosis

### Saying "no" to overtreatment – not as easy as it sounds

*By Shavez Jeffers*

**Four years ago, I became aware of the terms overdiagnosis and overtreatment for the first time.**

As an individual with previous experience in health psychology and health promotion I had assumed that benefits always outweighed harms in all medical

interventions offered within the National Health Service (NHS).

However, when I came across a studentship titled 'Navigating perceived overdiagnosis & overtreatment' it immediately captured my attention and sparked a huge interest in an aspect of healthcare that I had not previously considered. My previous knowledge of wider influencing factors and patient-centred care focused on ways to promote healthcare services and medical interventions. I had not considered the potential harms of those medical interventions and I was previously unaware of the terms overdiagnosis or overtreatment.

Overdiagnosis refers to the identification of conditions that look like early diagnosis but are not destined to cause symptoms or death (1). It can lead to overtreatment, that is, unnecessary treatment for a condition that is not life threatening or would not cause any symptoms and may lead to harmful side effects (2). Both overdiagnosis and overtreatment have been identified as potential harms of the NHS Breast Screening Programme (BSP) because of the uncertainty around if or how breast cancers will progress. Therefore, women are encouraged to make a choice about whether to participate in screening, accept follow up tests or accept breast cancer treatment. But even though screening guidance documents explain that women have the freedom to choose, research shows that deciding to decline the offer can be viewed as problematic by others.

Therefore, the aim of my study was to explore the experiences of people who decline screening, treatment and/or breast cancer treatment after being invited to the NHS BSP.

When I began this project, I felt that my eyes had been opened to the other side of a coin that I had not previously considered. As part of my studies, I was able to immerse myself in the literature surrounding this topic; however, I did not fully understand the concepts, the complexities of medical uncertainty or the impact that it could have on individuals until I heard women's experiences as part of my research project. Through contacting online support groups, forums and posting on social media, 20 women voluntarily agreed to take part in my project by attending an interview over the phone or on Microsoft Teams, to answer questions about their experiences of declining either an invitation to the NHS BSP, follow up tests and/or breast cancer treatment.

Interestingly (and unintentionally), most of the women that I interviewed had health-related occupations so by interviewing a group of women whose occupations might have been assumed to encourage participation in medical interventions, I was able to gain a unique understanding of the impact that overdiagnosis and overtreatment can have on different parts of an individual's life. My findings revealed that even though this sample was identified by accident, even they talked about difficulty in having their decisions accepted, by healthcare professionals but also by friends and family.

These women did not regret their decision to decline, as they believed it was a way of avoiding overdiagnosis and/or overtreatment. That underlines that while

declining is a theoretical possibility, it isn't necessarily an easy one in the current system. Overall, I believe that this project has enabled me to recognise my lack of knowledge and consideration for the other side of the coin: there are uncertainties within medicine.

Now that I have finished my PhD, I plan to publish these findings to highlight that even though there is rhetoric about what informed choice should be and how it should be received, it is not clear what this looks like in practice and how healthcare professionals can facilitate this in a way that is perceived as supportive by individuals.

The project was an Economic and Social Research Council (ESRC)-funded PhD studentship based in the Department of Population Health Sciences at the University of Leicester. My research background includes Health Psychology, Social Science Research and Public Health. I currently work as a research assistant for the Global Health Research Centre based at the Leicester Diabetes Centre.

*Shavez Jeffers BA (Hons) MSc*

*Research Assistant, Global Health Research Centre,  
Leicester Diabetes Centre, Leicester General Hospital,  
UK; and University of Leicester*

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1. Ollila, D.W., Hwang, E.S., Brenin, D.R. et al. The Changing Paradigms for Breast Cancer Surgery: Performing Fewer and Less-Invasive Operations. *Ann Surg Oncol* 25, 2807–2812 (2018). <https://doi.org/10.1245/s10434-018-6618-z>
2. Kale M S, Korenstein D. Overdiagnosis in primary care: framing the problem and finding solutions *BMJ* 2018; 362 :k2820 <https://doi.org/10.1136/bmj.k2820>

### Meeting report

## Preventing Overdiagnosis

**Copenhagen, 14-16 August 2023**

*By Mandy Payne*

**Elspeth Davies was in her teens when she was diagnosed and treated for melanoma, a serious form of skin cancer. Her diagnosis became life-defining.**

She gave talks in schools as a 'success story'. She, and those close to her, learned to be hyper-vigilant to any new mark or lump on her skin, and she accumulated new scars from further mole removal. Isolated from her healthy peers, she sought solace in support groups, and faced an adulthood haunted by fear of the deadly disease recurring. Seven years later, as a social scientist at Cambridge University completing her PhD, Davies learned that most melanomas in situ are 'overdiagnosed'. She realized that instead of being a 'cancer survivor', it was highly likely that her condition might never have harmed her at all.

In the course of her moving 15-minute abstract presentation, we learned what this feels like, and how the ways we understand and communicate about overdiagnosis have consequences for a patient's trust in medicine and even in their own bodies. She called on health care professionals to find ways to build that trust while also admitting diagnostic uncertainty.(1)

This was only the first day of "Preventing Overdiagnosis", a three-day international medical conference featuring over 100 arresting presentations from scientists, doctors and journalists. For me, Davies' story stood out because it is so rare to hear a patient's perspective on overdiagnosis. Most individuals labelled with a life-threatening condition who find themselves healthy after treatment will believe themselves to be cured. But many will have been overdiagnosed and subjected to life-changing treatment needlessly. Their doctors, not surprisingly, are drawn into the illusion.

Overdiagnosis and the harms of too much medicine have long concerned HealthSense because they are examples of poor use of evidence in health care, they harm patients and are wasteful of human and financial resources. And they too-often result when treatments are promoted for reasons other than the best interest of the patient.

Our charity's interest in this field was reflected by the number of past HealthSense award winners both in the audience and behind the microphone. In one keynote speech our patron, Glasgow GP and author Margaret McCartney (2008 HealthSense Award), talked about the upstream dangers of the boom in unregulated private screening tests; in another, investigative medical journalist Deborah Cohen (2017 HealthSense Award) described the challenges of reporting the truth about overdiagnosis in the media.

The range of topics covered in the biennial Preventing Diagnosis conference, now ten years old and with over 300 delegates from around the world, went well beyond the dangers that overdiagnosis poses to individual patients. We heard about the extent of environmental damage and energy costs from wasted treatment; the financial burden on health care systems and cost to citizens; questions over methods and checklists devised to diagnose early signs of Alzheimer's Disease; and the bullying and professional harassment faced by two US researchers who dared to challenge their industry-connected senior academics. Encouragingly, we also learned that the word 'overdiagnosis' has now been recognized by the US National Library of Medicine as a medical subject heading (MeSH) in its own right, which will make it easier to engage with and search for research on this important topic.

#### Correcting health misinformation

What about solutions? Correcting health misinformation to nurture a better-informed and questioning public is a start. A team led by Dr Paula Byrne, senior post-doctoral researcher at the University of Galway in Ireland, has created iHealthFacts: <https://ihealthfacts.ie/>.(2)

This simple website invites the public to submit questions on any health claim they come across on social media or elsewhere. Do UV lamps in nail bars cause skin cancer? What about drinking alcohol? The university iHealthFacts team and their collaborators undertake rapid reviews of the evidence related to the question, also appraising the quality of that evidence. A bite-sized but accurate response is reviewed by a subject expert,



public and patient partners, and a health journalist before being published on the site.

Inevitably the process is labour-intensive, and for each individual question to have a response published may take weeks or even months. But, as the answers accumulate, iHealthFacts is building to be a useful resource for the public to get evidence-based answers to common health questions.

### Online training on breast cancer overdiagnosis

French non-profit [Cancer Rose](#) has developed an online course to teach health professionals how to better communicate complex information and support women to make informed decisions on breast screening.

'Breast Cancer Screening - Informing Women' takes 3 hours to complete and includes films, quizzes, and animations. It has been accredited by the French authority for medical training (DPC). It is accessible to French medical professionals via the e-learning platform 360Learning.

### Getting best evidence in front of GPs

Patients with long-term conditions are often prescribed drugs to be taken for months or years. What if it's not the right treatment? Research published in 2020 by Julian Treadwell, a general practitioner-turned-academic at the Nuffield Department of Primary Care Health Sciences, University of Oxford, showed that UK GPs' knowledge of the absolute benefits and harms of treatments for long-term conditions is poor. He found that 87% of GPs have an unrealistic expectation of how much their patient is likely to benefit from the drugs prescribed. This could be leading to overprescribing on a massive scale, not to mention the risks from avoidable drug interactions.<sup>(3)</sup>

The revelation guided Treadwell's four-and-a-half year PhD research programme, a monumental compilation of evidence-based guidance and research, co-designed with health care professionals and the public, followed by exhaustive user testing, all funnelled into a deceptively simple and speedily navigable online resource: [GPevidence.org](#). Thirteen common long-term conditions are presented with menus of treatment options for each, supported by colourful icon array graphics that instantly communicate risk and benefit data, tailored to individual patient characteristics. The resource is neatly presented so that a GP can gather key evidence for making prescribing decisions swiftly, or grab a coffee for a deep dive into the evidence around dilemmas such as options for glycaemic control. Take a look at: <https://gpevidence.org/> and use it.

*Mandy Payne*  
*HealthSense Newsletter Editor*

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## AGM 2023

# Chair's annual report 2022-23

*By Roger Fiskén*

### Core activities

**Formal meetings** For 2023 HealthSense again held an online AGM followed, three weeks later, by an (in-person) Awards Ceremony where we celebrated the achievements of our student prizewinners and of Till Bruckner of TranspariMED, the winner of the 2023 HealthSense Award for outstanding achievement. Till has made it clear that his work and achievements would not have been possible without the excellent work of his colleague Nick DeVito from Oxford.

**Annual Student Prize Competition** There was a substantial entry to the competition this year (just short of 100 entries) and there were considerably more high-quality submissions than in the recent past: 57 students placed the protocols in the correct order. A clear winner was identified in the medical and dental students' category and four students were runners up. A winner was also selected for the category of students of nursing, midwifery and professions allied to medicine. Three of the successful students, including both the winners, joined us at the Victory Services Club to receive their certificates. We are grateful to the Royal College of Surgeons who continue to support the student prize, and to the volunteers who contribute an enormous effort in running this unique and successful competition.

**Membership** Our total membership has remained in the range 200 to 220, managed by our membership secretary, Alan Henness, who also ably runs and maintains the HealthSense website.

**Newsletter** Mandy Payne, editor, has produced another tremendous four issues. Included in the content were a report on how companies are offering private blood tests for a range of conditions and deficiencies, with some making misleading claims, and leaving the overworked NHS to follow up 'abnormal' results, a report by Edzard Ernst on the way in which German medical experts are fighting pseudoscience and an article by last year's overall winner of the student prize competition, Lydia Shackshaft, on the parlous state of the teaching of EBM in UK medical schools. I would like, at this point, to thank Mandy for all the work that she does for HS over and above her work on the newsletter - she is full of energy and always engaged with what we do.

**Research Fund** The balance in the fund remains healthy. There have been no new projects funded this year but we have paid the final instalment of our support to TranspariMED for their project entitled "Unreported Clinical Trials: Medical research waste made in the UK". Rather pleasingly, the study showed that most major non-commercial research institutions in this country take

research waste seriously and intend to make as much use as they can of data from abandoned or incomplete trials.

**Student resources** An educational resource was launched on the website this year, with learning materials to help students read and critically analyse research protocols. Next, students will be invited to produce reports and videos of their results, which we hope to publicize under the title of 'Whack a mole'.

**Campaigning** Trustee Les Rose, with support of HealthSense and the Good Thinking Society, continues his personal dogged work to compel the Charity Commission to investigate charities that promote questionable treatments. He identified a consultation that the Commission had issued relating to the responsible use of social media by charities. Les is keen to recruit HealthSense members to help in his meticulous work.

Les has been investigating the issue of employment of 'alternative' practitioners in various parts of the NHS. He has written a paper which is being submitted for publication.

#### **Ad hoc activities and opportunities**

**Interactions with government and public agencies** In February I attended an MHRA webinar on changes to the regulation of medical devices as the result of various factors, including Brexit. To my dismay, the two questions that I submitted were not called, let alone answered, even although the webinar finished early! I have followed this up by way of a FOI request but I still haven't been able to get a straight answer to my query. It seems that, more and more, the MHRA is being seen by Government as a tool for facilitating the activities of pharmaceutical and medical device companies rather than, you know, regulating them.

In March I submitted a letter on behalf of HS to the Parliamentary Health and Social Care Committee, one of whose current work streams relates to the prevention of ill health. I pointed out that disease screening was likely to be of little value and that the government could achieve much more in preventing sickness if it paid attention to known determinants of ill health such as poverty, air quality, poor housing, insecure employment, etc.

In July we wrote to the National Screening Committee, suggesting that it should undertake a regular review of the evidence for all screening programmes with the aim of retiring those that have become obsolete.

During 2023 two parallel, but apparently unrelated, schemes have been put into action to gather data on various aspects of the health of the population. Both seem to assume that performing health checks and gathering data is an unqualified good. One of these schemes is the NHS Health Check programme which has been in place for several years. A lengthy report on their findings was published in 2019; however, the only information in that report which says anything about the effect of health checks on clinical outcomes is to be found in a pair of unpublished papers! The second scheme, entitled Our Future Health, is run by a private company but states that it is working in partnership with

the NHS and has the NHS logo on its paperwork. It is far from clear what, if anything, it has to do with NHS Health Check or why it seems useful to run two similar schemes at the same time. I have been writing to the DHSC to try and find out more about these programmes.

Susan Bewley has submitted a formal complaint to Public Health England concerning their campaign to encourage bowel cancer screening, pointing out the poor quality of their information leaflets.

**Media** I had a letter published in *The Times* on the dangers of uncritical acceptance of the idea that 'more means better' when it comes to breast cancer screening. In May, Susan and Leeza were quoted in a *BMJ* article on disclosure of industry payments to doctors. It's also pleasing to point out that in September we were quoted in the *BMJ* in an article on whether there should be a register of doctors' financial interests and who should hold such a register.

#### **Personal comment**

As one can see, we have continued to be active on a variety of fronts, thanks especially to the work of Les Rose, Susan Bewley, Mandy Payne, Alan Henness, and others. However, I do have concerns about the future of our charity: although we have over two hundred members, we have very few active members and no funding stream apart from our members' subscriptions and occasional donations. I am concerned that we don't seem to be very good at holding on to our young members – the student prize winners – or, if we do keep them in the fold, they don't appear to have the time to do very much (with honourable exceptions).

I would really like to work on increasing our membership and, in particular, our active membership, perhaps by recruiting people who are 50 plus and who, therefore, have built their careers and who no longer have the responsibility of looking after young families.

*Roger Fiskin, Chair of Trustees, HealthSense  
5th October 2023*

#### **Last word**

## **Where is Russia's medical research?**

*By Colin Brewer*

**A few years ago, I published a book about Alzheimer dementia and assisted dying.(1) Partly out of continued interest and partly in the hope of an updated second edition or translation, I scan the Alzheimer literature on Medline almost every day.**

The citations are surprisingly numerous with a daily average around 40 additions and sometimes over 100. Most of them don't interest me because my concern is with the way Alzheimer patients are mismanaged, perceived or perceive themselves. Few papers deal with those issues but I've recently noticed some interesting national differences in the output and focus of Alzheimer papers.

Given their size and the massive Westernisation of Chinese society in the past 40 years, both the USA and China are naturally well-represented. In proportion to their populations, so are Western Europe, Australia, New Zealand and Canada but some countries are under- or over-represented. As with military drones, Iran (population 88 million) produces more Alzheimer papers than Russia (147 million). Of 415 Alzheimer papers in ten consecutive days, there were six from Russia and seven from Iran, as well as 10 from South Korea (52 million) and six from Poland (38 million). It's not just the relative paucity of Russian research that is notable; so is the lack of world-famous names. We know about military innovators like Kalashnikov, Ilyushin and Tupolev but where are their modern medical equivalents? They used to be numerous. Several, like Korotkoff and Pavlov, gave their names to important medical advances.

Following the collapse of Communism and the USSR, Russia experienced a significant reduction in life expectancy seen in no other country but most Russians still live for long enough that Alzheimer's Disease could occur. In any case, it isn't just in Alzheimer research that Russia is almost invisible. Among the 200 most recent Medline citations under 'cardiac surgery', only one was Russian. 'Hypertension and diabetes' yielded five from Iran, two from Poland and one from Ukraine but none from Russia. The ordinary Russian citizen one sees on TV don't look underfed and even Communism didn't abolish diabetes. The explanation cannot be that Russian researchers are submitting papers only to home-grown journals because some Russian journals (presumably including the leading ones) are included in Medline and some Russian papers appear in English-language journals. It would seem that 73 years of Soviet Communism and three post-Soviet decades have produced no really new therapeutically useful drugs.

My perusal revealed several other interesting national differences in research publications and was made easier by the fact that surnames are still revealing. When all authors have typical Chinese names, it is likely that the paper is from China or Taiwan but migration means that it could also in fact be American. In contrast, hardly anybody from outside the former USSR migrates to Russia, so Russian papers should be easy to spot. For similar reasons, so are Iranian ones. Medical migration to countries like Poland, South Korea, India and Japan does occur but only on a small scale, so author surnames on papers from these countries are fairly homogeneous. Conversely, the few papers from South Africa still appear to have a predominance of British or Afrikaner surnames and few African ones.

The further east the papers originate from, the more likely they are to focus on the supposed therapeutic effects of local plants. As with acupuncture, that is particularly true of China and accounts for much of its over-representation on Medline. For every hard-nosed paper showing a proper regard for scientific method, scepticism and the importance of placebo effects, there are two or three that show none of these vitally

important qualities. For example, "Natural compounds and extracts offer several advantages, including the ability to target multiple pathways and exhibit high efficiency with minimal toxicity."(2) Really? Haven't they heard of bush-tea disease or toadstool poisoning? Others enthuse that "Deer antler velvet, with kidney tonifying, promoting the production of essence and blood, strengthening tendons and bones, not only has a thousand-year medicinal history ... "(3) or that "*Polygala tenuifolia* was documented to calm the mind and promote wisdom ... "(4) I would invite the reader to look at these referenced articles and decide on which side of the line they fall.

Despite increasing and overwhelming evidence that well-designed placebo acupuncture has exactly the same effects as the real thing,(5) much Chinese acupuncture research is characterised by assertions that "Acupuncture is an effective method to improve [fill in the disease you're studying]." (6) Most of the acupuncture studies don't have placebo controls. Many are animal studies and apart from wondering how they managed to identify the acupuncture points for laboratory animals when they can't be reliably identified in humans,(7) few authors seem aware that simply handling animals in laboratory or veterinary settings has large non-specific effects that can significantly improve or worsen outcomes.

There is also the little matter of academic corruption and malpractice. No country is immune but some are less immune than others and China's hyper-productivity in terms of research output helps to ensure that it tops the list.(8,9) One study found that "there were differences in responses between [US and Chinese academics] in willingness to report plagiarism (U.S. 95.65% vs. Chinese 40.21%;  $p < .0001$ ) and data falsification (U.S. 100% vs. Chinese 81.25%;  $p < .0001$ ) and in willingness to attend biomedical industry-funded promotional events (U.S. 11.0% vs. Chinese 74.0%;  $p < .0001$ )."(10) A *Lancet* editorial noted that: "fabrication, falsification, plagiarism, and unattributed ghost-writing threaten to overshadow China's achievements" and that "misconduct might not be limited to isolated individuals or institutions, but ... could have infiltrated the country's research culture more widely".(11) The Chinese government itself admits that corruption is a serious problem,(12) but are not its Maoist and Xi-ist autocracies another potential source of academic bias? Totalitarian states don't appreciate criticism of government-approved policies and treatments, especially China, where acupuncture and traditional Chinese medicine (TCM) are seen as specifically Chinese procedures. The only examples of real governmental censorship of academics in conventional medicine that I know of involved doctors working in totalitarian communist countries. I admire Cuba's health service but Cuban doctors don't question dubious claims about certain locally developed treatments(13) because that would be bad for their careers. Russian psychiatrists who questioned the existence of 'reformist delusions' and 'sluggish schizophrenia' (uniquely Soviet mental illnesses that supposedly afflicted Russian dissidents) were themselves compulsorily detained in psychiatric

hospitals. The USSR was expelled from the World Psychiatric Association in the 1980s for this sort of psychiatric abuse.(14)

Our imperfect democracy reflects an imperfect world but we should be grateful for its considerable freedom of speech and contemptuous of cancel culture warriors who act as if that freedom applies only to them.

*Colin Brewer  
Retired psychiatrist, London*

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- 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

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