



21st October 2020

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HealthWatch AGM, 20th October 2020, held virtually (by Zoom)

- 1) Those attending: David Bender, Susan Bewley, Diana Brahams, Malcolm Brahams, Kenneth Bodman, Till Bruckner, Matthew Choy, Roger Fiskén, Andrew Fulton, Sofia Hart, Alan Hennes, John Illman, Keith Isaacson, Kevin Kane, Tom Moberly, Mandy Payne, Rahul Penumaka, Philippa Pigache, Anne Raikes, Caroline Richmond, Les Rose, Nick Ross (president and chair of the meeting), Edgar Wallner, Geoff Watts, Barbara Wesby, Peter Wilmshurst, Bridgette York.
- 2) Apologies for absence: Leeza Osipenko.
- 3) Minutes of the 29th AGM, October 2019: these were presented and agreed, *nem con*.
- 4) Matters arising: none.
- 5) Chair's report: see below. Thanks to David Bender. name change for next year's AGM.
- 6) Membership report: see below. Alan Hennes informed members that he was in the process of redesigning the website (mainly the home page). The new format will be visible in the near future.
- 7) Treasurer's report: see below. The sum for running expenses was greater in 2019-20 because of the costs of running the symposium on medical devices. The level of reserves in the research fund had gone down because the Executive Committee had agreed to commission a piece of research from Till Bruckner into unpublished research projects by UK academic and other non-commercial institutions. The report was approved by the meeting *nem con*.

It was agreed that Lawrence Melinek would be appointed as Independent Examiner.

8) Election of officers and trustees:

The following were elected *nem con*:

Chair: Susan Bewley

Vice chair: Leeza Osipenko

Treasurer: Anne Raikes

Secretary: Roger Fiskén

Trustees: Andrew Fulton, Sofia Hart, Alan Hennessey, John Illman, Keith Isaacson, James May, Tom Moberly, Philippa Pigache, Les Rose.

9) Co-options to the Executive Committee: the meeting noted the co-option of Nathan Hodson and Jolene Galbreath to the committee. The co-option of Robert Grant, Pavithran Maniam and Sylvester Odame-Amoabeng as student representatives on the committee was also noted.

10) Presentation of awards to winners of the winners of the student prize competition for critical appraisal of clinical research protocols, supported by a grant from the Royal College of Physicians: there were 80 entrants for the competition this year, 24 of whom ranked the protocols in the correct order. No correct entries were received from nursing students or students of professions allied to medicine, therefore the awards this year were given entirely to students of medicine or dentistry.

Winner: Matthew Choy, University of Cambridge

Runners up:

Edward Christopher, University of Edinburgh (unable to attend)

David Hewitt, University of Glasgow

Rahul Penumaka, Imperial College, London

11) Presentation of the HealthWatch Award for 2020 to Professor Jennifer Rogers.

HealthWatch Chair's report October 2020

Introduction

Welcome to the 2020 Chair's report, delivered at HealthWatch's first virtual AGM.

Last year I started with a reminder of the history of the charity that was rooted in the Campaign Against Health Fraud. We consciously moved from being 'against' things, to being 'for' fair testing, and 'for' science and integrity in healthcare. We have always been particularly concerned about people being deceived about illusions of cures from those posing as healers when people are at their most vulnerable - when ill or depressed.

Just as you thought bias, dishonesty, corruption and fraud couldn't get worse the pandemic (or syndemic) hit. This year's events with the pandemic and its aftershocks undoubtedly play into all our deepest fears, uncertainties and hope in science, and yet also into the hands of those who are fools at best, and greedy liars at worst. It's shown, more than ever, how hungry people are for trustworthy, reliable scientific information. Yet more than ever, misleading information flows around the internet faster, further and deeper than truth.

So, how is HealthWatch doing, in terms of its activities and effectiveness as we take the cool, calm long view? Although conceived two years earlier in 1989, and born or formally constituted in 1991, next year will be our 30th birthday.

Let's remind ourselves: HealthWatch, with its entire reliance on unpaid volunteer Trustees, has been foresightful, a kind of crucible or "think tank", set up before all of the following and yet with many overlapping aims and personnel: the Cochrane Collaboration started in 1993, Transparency International global coalition against corruption 1993, NICE 1999, Sense about Science 2003, James Lind Initiative 2004, Harding Centre for Risk Literacy 2009, Friends of Science in Medicine Australia 2011, AllTrials 2015, And so many others changed the landscape since the 1980s. Did HW spawn all this? No, but we spotted and celebrated many of the individuals, and we've been part of the fabric or glue between initiatives & institutions. Sometimes we're the 'awkward squad' raising concerns about the culture of institutional 'pass the parcel' of responsibility.

The problems haven't gone. Our work remains as vital as ever, notwithstanding limited people and resources, so we have to be targeted if we are to continue to 'punch above our weight', and to offer something

different – our ‘unique selling point’ or USP (which is not simply a lack of financial indebtedness to corporations).

The Work

We’ve continued with the three areas of strategic focus, (1) communications, (2) specific projects and (3) outreach, particularly trying to be professional and proactive, but concentrating limited resources to where there is a special HW contribution.

1. Communications

Internal

Trustees: We are reliant and indebted to the Trustees who continue to give their volunteer service. Clearly it’s been harder for those who do still have full time jobs, let alone small children, in a year dominated by the pandemic, lockdown and home-schooling on top of the usual pressures, but I particularly want to thank David Bender who is stepping down after many ‘tours of duty’ as a Trustee, Chair and Secretary. He’s been a fabulous support, holding us all to come up with action points, while acting as a ‘corporate memory’. I do hope we get a vaccine soon so he can enjoy many more years cruising.

Meetings: The committee has taken to Zoom like a duck to water, and met four times this year. We’ve embedded the roles of responding to consultations and parliamentary liaison. Although we’ve looked and invited a couple of observers, we’ve not yet appointed a Trustee with a patient-user background, and we have retained and had useful input from our students. We’ve started a process of writing job roles and tighter governance, but not lost the informal and enjoyable familiarity of meetings.

Googlegroup: The Googlegroup continues to be a great source of information and ideas without being too onerous, averaging just over one email a day, though often in bursts of discussion. Anyone who wants action can make suggestions to the committee, or better still offer to help – let’s say drafting a letter that might then go in HW’s name about your particular ‘bee in the bonnet’.

External

Newsletters: We rely, as our main benefit to members, on the news items and our seasonal newsletters. Tremendous thanks to Mandy Payne for this. Articles are now being published first online as the paper version is phased out. Highlights of articles this year have covered: drug safety & devices including unreported medical device trials; the Cumberlege Review; Ethics

concerns over student research activities; why nutrition needs a re-brand; why dental implants go wrong, the government's COVID-19 'vulnerable' list, bad analysis of science in the Caster Semenya case, the pelvic mesh scandal, why isn't dental practice more evidence-based?; what's next for clinical trials reporting & transparency. We've had book reviews of Sex Robots & Vegan Meat/ Alzheimer/ pharma's funding trap, the paradoxes of Mindfulness and why we need to talk about Alzheimer's. It would be very good if more members joined in the tasks of reading /reviewing books, and spotting new talent to write and work with us. Please could everyone commit to identifying and praising an up-and-coming young person, draw their words to Mandy's attention and invite them to join HW?

Twitter: the good news is that we have increased our followers by another 200 to 1185 (if not our hardcore membership), and benefit from some of the conversations.

Website: in Alan Hennes's capable hands this has been undergoing a refresh to modernise and make more attractive thanks to the feedback from committee observers and new trustees

	2019-20 AGM	2018-19 AGM	2017-18 AGM
Membership numbers (total)	232	212	231
Googlegroup members (total)	60	54	-
Twitter followers	1185	979	842
Cumulative HW Committee threads	2416	1845	460
Cumulative Tweets (~500/ year)	2648	2169	1630

Change of name – it has become clear that we have been drowned by the government's HEALTHWATCH, that we can't be found on the internet, and have to face a change. It is my hope that we don't do something superficial but that in our 30th birthday year, we change our name and up our game. I hope the membership agree with me, and with your committee, that it's time for a stocktake, revitalisation and revamp. We have been debating and voting on a long list [of potential names] and have come to a short list of: *Campaign for Health Evidence, Society of Evidence Based Medicine* and no change. We will continue to take soundings, but will refine this for a constitutional agreement at the next AGM.

2. Specific Projects in 2019-2020

Briefing papers These can be found on the website, and are looked at for their continuing relevance. I thank Roger Fiskén & James May for their excellent new briefing paper on statins.

Consultations: Roger Fiskén has continued with his work of anticipating relevant consultations (largely with government bodies), eliciting comments from the membership and writing our formal responses. This year has included the Parliamentary Select Committee on Health & Social Care; delivering core NHS and care services during the pandemic and beyond; the Competition and Markets Authority consultation on advice to be given to private-sector IVF clinics on consumer law; and the Department of Health and Social Care consultation on extending the storage periods for embryos, eggs and sperm. He has also looked at the final reports to judge HWs impact and we'll be reviewing this role and a handover to another trustee during the next year when he takes over as secretary.

Research: In March the HealthWatch-funded study by Till Bruckner led to publication of report comparing health technology assessment agencies. Overall, this found that NICE does a very good job, but we must keep an eye on transparency & redactions/influence, especially with new leadership. Although it did find transparency gaps, the study helped us NOT go further in that direction, but to concentrate on devices.

Devices: In November 2019 HW wrote a letter to Baroness Cumberlege to ask the Independent Medicines & Medical Devices Safety Review to demand that those who implant a device must know (and be able to explain to the patient): what it is and what its constituents are, 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. In March we published these five demands to keep patients safe from medical device harms, well in advance of the delayed Independent Medicines & Medical Devices Safety Review (Cumberlege report, 'First do no Harm'), — set up to examine historical harms to pregnant women from Primodos, the decades of valproate-damaged babies, and women with complications of vaginal mesh and breast implants. HW's submission led to myself, as HW chair, being invited both to the Today Programme & Press Release (sadly hitting the cutting room floor on both occasions). We must make more links with patient organisations and keep the pressure on the government to enact its recommendations in full. The key problem is how to put patients before profits.

Breast screening: In April NHS breast cancer screening stopped and Susan Bewley published a blog explaining why that's a good thing. HW noticed in August that the vast AgeX breast screening trial ended, ever so quietly. This is tremendously good news, but HealthWatch asked Jeremy Hunt (as Chair of the House of Commons Health Select Committee to ask his successor as

Secretary of State what the Age X trial cost and who approved the spend? We got no answer and were fobbed off, but will continue to investigate, ask questions and ensure that the results are not buried but examined independently as we do cannot trust the team in charge.

Trading Standards/ Charity Commission and the regulation of 'bogus' charities: our indefatigable committee member Les Rose continues to collate fantastic information about the most egregious of so-called alternative medicine charities. He has put in six complaints that have languished in the 'pending / under investigation' label for far too long. We've been working on strategy with the Good Thinking Society and were pleased to be able to ask a difficult question about their criteria of 'public interest' at the rather 'stage-managed' Charity Commission AGM, thanks to David Colquhoun's place becoming available. We are not achieving much rapidly, but continue on doggedly.

Puberty blockers for gender dysphoria: questions about the quality of evidence, particularly for puberty blockers in gender dysphoric children and young people, continue and the Chair has written to Hilary Cass and NHSE about the processes of the two Independent Reviews (initially just about drugs, now extending to the services), and our previous HW award winner Deborah Cohen continues to do features for the BBC.

Students: an enormous amount of work goes into running the Student Prize and I thank everyone for their continuing contributions to setting and marking this. We have had more input from students on the committee than before and know their teaching and training on critical analysis and evidence based healthcare remains improvable. I hope that we will identify tasks and work that are fulfilling, maybe within a separate work stream or subcommittee.

Annual Award: as usual we had a plethora of good candidates to choose between, and we look forward to hearing from our latest Annual Award winner, Jennifer Rogers

3. External outreach/ Partnerships

Good Thinking Society (as above)

Centre for Evidence-based Medicine, Oxford: HealthWatch volunteer Mandy Payne has been helping communicate best evidence about COVID-19, working with them to produce lay summaries of the Oxford COVID-19 Evidence Service reviews on important questions about the science of the pandemic which are being updated.

Transparimed

Royal College of Surgeons: Following the meeting of the Chair, and Vice-Chair Keith Isaacson with the Derek Alderson (the previous president of the RCS) regarding their attitude to devices, we noted a much better, more fulsome response from the RCS. We are delighted that they have taken up funding the HW Student Prize and maybe more educational links or joint activity will follow (especially about the teaching and training in appraising evidence at student and early academic career level)

French advocates for good science: HealthWatch has been at the forefront of raising concerns about breast screening programmes and joined a cross-European challenge to an EU-funded clinical trial over concerns about inevitable and avoidable harms to women, complaining about MyPeBS - a flawed RCT – more activity of some committee members on international Google group? HealthWatch has joined with three other groups who share concerns about women's health and human rights in research: Belgium's Group de Recherche et d'Action pour la Sante (GRAS), the Italian epidemiologists and scientists of NoGrazie, and the French group Cancer Rose.

The European Manifesto against Pseudoscience was launched yesterday, the day before the AGM. HW is an official organising supporter as well as having many individual members sign the manifesto.

Access Info Europe: in 2019 along with 27 other consumer and health related agencies, we signed a letter asking for better transparency from the European Medicines Agency. Although, of course, this is moot once we leave the EU next year as the EMA will not respond to requests that come from outside the EU, as they are not obliged to do so under Regulation 1049/2001. Nevertheless it resulted in more conversations about transparency within the EU that we will still want to support.

Future plans

This is something we hope that HealthWatch can do more of in the future – working with other like-minded organisations to 'get more bang for the bucks', whether supporting one another's initiatives or even getting grants for funded projects, as we've seen the value of using our Research Fund to generate ideas and evidence. Our president, Nick Ross is very well connected, and our applicant for Vice-Chair is also a keen 'networker' so again, next year we hope to capitalize further on these links.

Susan Bewley,
Chair of Trustees, HealthWatch UK

14 October 2020

Founded 1991 to promote evidence-based healthcare.
Patrons: Robin Ince, Prof Steve Jones FRS, Dr Margaret McCartney,
Sir Michael Rawlins, Lord Dick Taverne QC, Dr Sarah Wollaston

Membership Report, October 2020.

Year	Number of members
2017-18	231
2018-19	212
2019-20	232

Thus, membership numbers remain steady.

85 members pay their subscriptions by standing order and there are 6 life members, 8 complimentary members and 91 student members.

Treasurer's report: financial results for the year to 31st May, 2020.

	<u>2020</u>	<u>2019</u>
Total incoming resources	5,715	5,745
Total running expenses	5,655	3,884
Reserves		
Unrestricted reserves	23,668	23,608
Research fund	28,601	38,015
Protocol appraisal (student prize competition)	1,859	3,491
Total reserves	54,128	65,114