

HealthWatch AGM 29th October 2019

- 1) **Present:** David Bender, Susan Bewley, Kenneth Bodman, Malcolm and Diana Brahams, Rupert Fawdry, Jolene Galbreath, Sofia Hart, Alan Henness, Keith and Jenny Isaacson, John Kirwan, Richard Lansdown, James May, Anne Raikes, Caroline Richmond, Nick Ross, Les Rose, Andrew Walsh. Including student prize winners, 37 people took the dinner.
- 2) **Apologies for absence:** Walli Bounds, Philippa Pigache, Dick and Janice Taverne
- 3) **Chair's report:**

Welcome to this evenings AGM. Healthwatch is a small charity with its roots in the Campaign against Health Fraud in 1989, and formally set up in 1991, reliant entirely on the voluntary work of its Trustees to whom we are all grateful. Looking at the first undated CAHF newsletter (in 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

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 trying to be more professional and proactive, but concentrating our limited resources to where there is a special Healthwatch contribution.

Communications

Internal

The committee continues its 21st century internal working, meeting largely by teleconference, but also in the old-fashioned face-to-face way as 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 google group 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 did not open an Instagram account. Although this means speedier communications and being part of an influencing network along with many previous HW award winners, it also takes time and judgement. We need to reflect on why we don't attract and retain the young. This is why we have produced a job description for a social media editor role and are looking for applications of interest and will give mentoring and support.

External

At an informal level, we've kept up our links, communications and meetings with a number of other external charities such as Sense about science, Transparimed, Good Thinking society and others, and have made representations to bodies such as the Charity commission, Royal College of Surgeons and others. Our president is very well connected, and this 'networking' is invaluable, and could maybe be capitalized upon further.

Last year we celebrated that HW and TranspariMED were 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 HW 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 for such a small charity to continue to be effective and we need to think about this more in the future.

Roger Fisker 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 is a very important role and means he's also been able to keep an eye on the final reports on government to judge the impact. They include topics such as the Research Integrity Concordat, NHSE Implementing Long term plan and changes to legislation, European Medicines Agency draft Regulatory science to 2025 strategy, and MHRA's relationship with the public.

Awards – student and annual (see separate reports) It's very good news that we continue to be spoiled for choice as to who we can recognize with our award. We have many volunteers organizing and marking the important student prizes, which has been a springboard to many students in their general and HW careers.

Specific projects

Age X Healthwatch-UK 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 on project through the months and years it takes. For example, with respect to the UK AgeX trial breast screening trial which HW has supported, we finally got a full Analysis feature in April 2019 BMJ. The article was ignored by all responsible authorities. Sarah Woollaston MP (last years award winner and Chair of the Health and Social Care Select Committee) did write to Matt Hancock, and disappointingly, he gave a stock reply. Specifically, he failed to answer questions about the cost and oversight. Mandy and I have been invited to write an open letter to him in the BMJ and various drafts are going backwards and forwards.

Trading standards/ Charity Commission Les Rose has moved beyond Trading Standards to the Charity Commission itself, producing four excellent evidence based complaints, that they replied to with standard letters. HW has challenged this. Les was approached by the CEO of the Charity Commission at their annual public meeting and managed to ask a question, so it seems there is an open door to our views as they modernize their approaches to improving the sector.

Puberty blockers for gender dysphoria Questions about the quality of evidence, particularly for puberty blockers in gender dysphoric children and young people have been discussed on the google group. The Chair appeared in a newsnight documentary and BMJ feature by Deborah Cohen (another previous HW award winner) talking about the uncertainties in this field, and calling for better quality evidence. Although there have been discussions about whether this is an ideal topic for a Healthwatch debate or campaign, we haven't progressed this, for three main reasons (a) the toxicity of the debates, (b) the paucity of our own deep knowledge and compassion, (c) the fact that lots of other people are getting involved and networks are forming.

Devices

The key main new project we have concentrated on has been devices and this has been the highlight of the HW 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 17th June ably led and facilitated by John Kirwan and HW 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 hope. Following today's committee meeting, we are ready to launch the strategy, but the key headlines are here: (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 and what are its constituents; How it is identified and tracked; How the evidence shows that it works; What risks are involved; What to do if things go wrong. (3) Regulators, academics and professional bodies should work together to achieve these aims. The Chair and Vice Chair had a productive meeting with Derek

Alderson, the President of the Royal College of Surgeons. We understand that there is some time before the delayed Cumberledge/Chantler report early in 2020 into the Mesh scandal to finalise our views and press our demands.

Outreach

Student prize 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). The responsibility for evidence-based teaching and development of critical thinking skills lies with the medical and other healthcare schools, yet we must continue to press for this in an era where 'fake news' and empiricism are so pervasive. Membership stays stable but we hope to have more specific responsibilities for committee members on tasks involving students and recruitment with a forthcoming social media editor which will relieve some of the load on Mandy Payne.

Annual Award We look forward to hearing from our latest Annual Award winner, Faye Kirkland.

Although we've had a stable number of members and healthy finances, there is always an ongoing tension in small charities like Healthwatch between growth on the one hand, and sustainability as older members moves on. To maintain the reputation of the organisation we may have to be more reflective about our ability not to languish in the backwaters of Dinosaurland all talking to the already convinced. To these ends, we have been doing some thinking:

Funding some options have been put together by Roger Fiskin

Governance the committee is considering the question of whether we should merge or affiliate with other charities. Full refreshing takes time and effort – we are limited by our numbers and welcome any contributions however small. Pleased to report that there has been an improvement in papers being tabled before meetings, and giving specific tasks & 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.

The 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 Fiskin 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, 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 google group. There are financial resources to spend on projects in line with our aims, so do apply and particularly if you have ideas that student groups can 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, though more 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

4) Membership report

To be appended to the final minutes

5) Treasurer's report

The Balance Sheet and Statement of Financial Activities for the period 1st June 2017 to 31st May 2018 are available at the AGM. The complete Financial Statements will be provided on request.

In the year to 31st May 2018, HealthWatch's general (unrestricted) reserves rose by £1,613 (2018, 2,573) to £23,608.

Total running costs were £3,884, not much more than last year's £3,480

Members of the Committee continue to give their time and effort at no cost to HealthWatch. The level of subscription income of £3,414 a little down on last year's £3,841 which, together with Gift Aid, now still covers the cost and distribution of the Newsletter and costs associated with holding the AGM.

During the year £1,524 (£876) was expended on the HealthWatch Student Prize. Last year's lower cost of £876 is simply there being fewer prizewinners. There remains £3,491 in this fund for this year after the generous award from the Royal College of Physicians of £4,000 towards this annual student prize.

There remains a need to maintain Healthwatch's level of reserves, not only for the Newsletter but also in case of libel defence (insurance being impractical) and for future projects that the Committee would like to implement.

The Research fund stood at £38,015 as at the end of May 2019 after a payment to Till Bruckner of £2,000 for initial research for this year's symposium on Evidence, Healthcare and Medical Devices & Implants.

Healthwatch reserves, excluding the Student Prize Fund and the Healthwatch Research Fund, totalled £23,608 at end May 2019, the bulk of which is held in a COIF Charities Deposit Fund.

Anne Raikes

- a) It was agreed to reappoint Lawrence Melinek as independent examiner of the accounts.
- b) It was agreed to allow the committee to explore conversion of HealthWatch from a simple charity to a charitable Incorporated Organisation.

6) Changes to the Constitution

- a) It was agreed *nem con* to delete Paragraph 3d, which reads as follows: "Corporate Membership: Corporate membership shall be open to companies and professional bodies, provided that they satisfy the Committee of HealthWatch and that they are interested in promoting the aims and interests of HealthWatch. Subscription fees paid by Corporate members will be subject to negotiation with the Executive Committee of HealthWatch", on the grounds that HealthWatch has never had any corporate members, and we prize our independence, so would not wish to attract corporate members.
- b) It was agreed *nem con* to amend Paragraph 6b to read "The Committee shall consist of the officers of HealthWatch and between eight and twelve other members", so as to permit us to recruit committee members (Trustees of the Charity) who have expertise lacking among other committee members (eg, we currently have no Trustee with medico-legal expertise, nor any representing nursing, midwifery and professions allied to medicine).

7) Election of officers and Trustees:

The following were elected *nem con*:

Chair: Susan Bewley
Vice-Chair: Keith Isaacson
Treasurer: Anne Raikes
Secretary: David Bender

Trustees: Roger Fiskin, Andrew Fulton, Jolene Galbreath, Sofia Hart, Alan Henness, John Illman, Keith Isaacson, Tom Moberley, Philippa Pigache, Les Rose (nominated by the committee), and Leeza Osipenko (nominated by Susan Bewley, seconded by David Bender).

8) Student prize competition for critical appraisal of clinical research protocols, supported by a grant from the Royal College of Physicians.

Winner, Nursing, Midwifery and Professions Allied to Medicine section
Sylvester Odame-Amoabeng, King's College London

Winner, Medical and Dental Students section

Nicholas Heng, Dundee (unable to attend AGM)

Runners up, Medical and Dental Students section

Robert Grant, Leicester University

Pavithran Maniam, Dundee University

Nadeer Raafat, Oxford University

Charles Southey, King's College London

9) Presentation of the HealthWatch Award 2019 to Dr Faye Kirkland