

The Good Thinking Society's submission to the Charity Commission, regarding CAM charities

Background

The current consultation arose, in part, due to correspondence between the Charity Commission and the Good Thinking Society (a registered charity) in 2016. Our involvement began after we became concerned that complaints made between 2012 and 2015 regarding a number of CAM charities seemed to have little effect on the actions of those charities or the misleading claims they were making to the public.

Some of the complaints in question concerned charitable organisations which promoted homeopathy to sufferers of HIV and victims of rape in Botswana, and organisations which claimed to be able to reverse cancer using homeopathy – the demonstrable harm of such claims to vulnerable members of the public concerned us greatly.

Below we offer our response to each of the six questions posed by the Commission, with our rationale for each response, followed by our concluding thoughts on how we believe the Commission ought to proceed so as to best ensure charitable status is not lent to organisations which offer no benefit to, and may even be actively harmful to, the public.

Consultation Questions

1) What level and nature of evidence should the Commission require to establish the beneficial impact of CAM therapies?

The beneficial impact of CAM therapies should be demonstrated in the same manner as the benefit of any other therapy – via well-conducted trials published in peer-reviewed literature. There is no justification for introducing a double-standard or any exemption for CAM therapies.

Rationale:

- For a treatment to be in the public benefit, it must have reliable or evidence likely of effectiveness.
- The more implausible a therapy is, the higher the standard of evidence that is required before that therapy can be accepted as effective. This point is sometimes misunderstood, especially by some CAM practitioners, but can be explained by way of an analogy: if someone claimed to have a pet cat, it would be reasonable to believe them, because the existence of cats is widely accepted, plenty of people have pet cats, and most people have seen prior evidence that cats exist. If, however, that person claimed to own a pet dragon, it would be unreasonable to accept their claim without first seeing the dragon or otherwise getting more evidence, as we have no reason to believe that dragons exist. The dragon claim

has a higher level of implausibility, and therefore a higher standard of evidence must be met before the claim should be accepted.

- The Charity Commission's current guidelines state that acceptable evidence includes peer-reviewed research in recognised medical journals, and recognition by the Department of Health or other health regulatory or health provision body; while unacceptable evidence includes anecdotal evidence, and non-scientific articles and features – that is a good standard of evidence to have, and if that policy standard were kept and action were taken by the Charity Commission to enforce it, we believe this would be very reasonable.
- The current guidelines state that evidence must be “independent and authoritative” – again, this is a good standard of evidence, which we support.

2) Can the benefit of the use or promotion of CAM therapies be established by general acceptance or recognition, without the need for further evidence of beneficial impact? If so, what level of recognition, and by whom, should the Commission consider as evidence?

The benefit of any therapy, conventional or CAM, cannot be judged merely by its acceptance or popularity – instead, for a therapy to be beneficial, there must be robust and reliable evidence of its likely effectiveness. Recognition and acceptance of a therapy should only be taken into account where that recognition and acceptance is based on a good standard of evidence.

Rationale:

- Acceptance or recognition by the public is not sufficient to accept a therapy as effective; nor is it necessary. Support can be found for all manner of unproven beliefs which should not be the basis of a charity; equally, there may be therapies which are not widely recognised but have their basis in sound evidence, which could be appropriate for promotion by a charity.
- The current policy states “In making these assessments the Commission relies on evidence, whether provided by the applicant organisation or from other sources.” – while the evidence provided by a prospective charity is a starting point, the Commission should be sure to seek external advice on evidence, as the prospective charity will always necessarily believe their evidence to be strong, and may present only the evidence which best represents their point of view, regardless of whether it is the most rigorous, robust or reliable evidence available. The judgement of external, independent sources has to be the benchmark – the input of objective health expertise.
- Acceptance or promotion of a therapy by CAM practitioners should not be given undue weight (and indeed should be given very little weight) when assessing charitable status, because (by definition) those practitioners will have a prior assumption that their therapy is effective. If, for example, the Commission needs to understand whether homeopathy or spiritual healing are effective therapies, the opinions of homeopaths or spiritual healers on the subject are unlikely to be free from bias; instead peer-reviewed literature and qualified and independent medical expertise should be relied upon.
- Bodies such as NICE, NHS Choices and the Cochrane Collaboration are good, independent sources, whose acceptance of a therapy is typically based on the best available evidence.
- Some of the concern regarding CAM charities rests in the claims they make for CAM therapies – with regard to such claims, the CAP Code for advertising is a good guideline for what is an acceptable claim, and organisations such as the ASA can make reliable independent judgements on whether claims are based on good evidence. The ASA has

recently been undertaking extensive assessments of CAM therapies, and ruled, for example, that claims for homeopathy should not be made as they are not supported by a robust evidence base.

3) How should the Commission consider conflicting or inconsistent evidence of beneficial impact regarding CAM therapies?

If the evidence for a therapy is conflicting to a point that it does not convincingly show the therapy is effective, it cannot be clearly stated that the therapy is of benefit and therefore it should not be promoted by charitable organisations.

Rationale:

- To be registered as a health charity, an organisation must promote treatments which have a public benefit. If the evidence for a therapy is conflicting or unclear to the point that the evidence no longer convincingly demonstrates the therapy to be effective, it can not be said to have demonstrated to have a public benefit. This is especially the case where a therapy has little or no biological plausibility.
- If a therapy is unable to demonstrate with good evidence that it is effective, its benefits are at best unproven, at which point it does not pass the public benefit test.
- These therapies rarely come without risk: some treatments can be expensive, some have direct risks and side effects associated with them, and others are promoted in lieu of well-established treatments which are based in sound evidence. Where the evidence for a therapy is conflicting or inconsistent, these risks mean it is likely unethical for the therapy to be promoted, particularly by a charitable organisation.
- Charitable organisations should not promote the therapy until such time, should it occur, that the evidence is more demonstrably and reliably positive. If the evidence base for a therapy develops, it may pass the public benefit test in future; however, with therapies that are based on notions with no biological plausibility, this is highly unlikely.

4) How, if at all, should the Commission's approach be different in respect of CAM organisations which only use or promote therapies which are complementary, rather than alternative, to conventional treatments?

If there is no reliable evidence for a treatment, it should not be promoted – either as an alternative to conventional treatments, or to complement conventional treatments. Without evidence of effectiveness, a treatment does not have therapeutic value and therefore no public benefit. There is also a danger that an organisation may be 'complementary' on paper, but 'alternative' in practice.

Rationale:

- Although some consider complementary therapies to be less harmful than alternative therapies, as the former is given alongside and the latter is given instead of conventional medicine, neither alternative nor complementary medicine organisations deserve charitable status if they promote a therapy for which there is little evidence of benefit to the patient.

- The behaviour in practice of a charity is a key concern – it is plausible that a charity whose stated goal is to offer treatments on a purely complementary basis may, in practice, discourage conventional treatment or may advise patients not to use conventional treatment alongside the ‘complementary’ treatment offered.
- Allowing charities to promote a therapy as ‘complementary’ based on a lower standard of evidence sends a signal to the public that the therapies promoted must be in some way effective – this conferred credibility could then lead the public to use those CAM therapies as alternative, rather than complementary.
- Allowing charities to promote any therapy as ‘complementary’ rather than ‘alternative’ presents an unacceptably high risk where that therapy has not been shown to be beneficial through good, reliable evidence.

5) Is it appropriate to require a lesser degree of evidence of beneficial impact for CAM therapies which are claimed to relieve symptoms rather than to cure or diagnose conditions?

If there is no reliable evidence for a treatment, it should not be promoted – either to cure or diagnose conditions, or to relieve symptoms. The threshold for what constitutes good evidence does not change depending on the application of the therapy. There is also a danger that an organisation may register to relieve symptoms but claim diagnostic or curative abilities in practice or that the difference in perception by the public of the difference between relieving symptoms and curing disease is actually nugatory.

Rationale:

- Treatments that have not been shown to be effective are no more likely to be beneficial in symptom relief than in cure or diagnosis – the first hurdle for any therapy must be that it demonstrates a beneficial effect. Without evidence of benefit, it should not be promoted within the framework of regulated charity.
- Once again, the behaviour of a charity in practice is a key concern – it is plausible that a charity whose stated goal is to offer therapies for the treatment of symptoms may, in practice, go beyond that remit when speaking to patients and claim their therapies can have curative or diagnostic effects.
- Allowing charities to promote a therapy for relief of symptoms, based on a lower standard of evidence, sends a signal to the public that the therapies promoted must be in some way effective – this conferred credibility could then lead the public to believe those CAM therapies can be used as curative or diagnostic therapies, rather than for symptom relief.
- Allowing charities to promote any therapy for symptom relief rather than cure presents an unacceptably high risk where that therapy has not been shown to be beneficial through good, reliable evidence.
- There may be some alternative therapies that have been proven to be effective, and which may be appropriate for promotion by a charity. However, alternative therapies that are proven to be effective typically become part of mainstream medicine and are no longer considered alternative, such as hypnotherapy in the treatment of irritable bowel syndrome.
- In practice, there may be little difference between the alleviation of symptoms and the cure of a disease. For example, a treatment which deals with the symptoms of hayfever or another allergy does not cure the underlying allergy, but by relieving all symptoms the sufferer is effectively able to feel as if they no longer had the allergy. This may be particularly

pertinent, given that a wide range of CAM therapies are promoted as an effective treatment for allergies, despite a lack of evidence for any effectiveness.

6) Do you have any other comments about the Commission's approach to registering CAM organisations as charities?

Legal observations and interactions with other regulatory bodies

- Charity law says that for an organisation to be a charity it must have a charitable purpose, and a public benefit. Fundamentally, the promotion of a treatment which has no evidence of effectiveness, especially to people suffering from illnesses, is the very antithesis of a public benefit. Thus it is vital that therapies promoted by a charity are based in evidence.
- The use of the term 'charity' to describe an organisation or undertaking has been protected for centuries in this country in order to preserve its meaning as denoting objectively recognised good works. That protection has developed into a sophisticated system of regulation that the Commission is a guardian of. Allowing organisations which purport to advance health or save lives, which cannot prove in conventionally accepted terms their benefit to the public, to call themselves charities is giving those organisations the unwarranted endorsement of that term.
- Taxpayer money is currently being spent encouraging a higher take-up of the MMR vaccine and other vaccinations, in order to prevent outbreaks of preventable diseases. If, currently, a charity were to be demonstrably discouraging vaccination, it would be doing so while operating with the tax breaks a charity receives. Such an organisation is free to exercise its right to free speech, but it should not be effectively state-subsidised in its efforts to undermine public health policy.
- Under the 1939 Cancer Act, it is illegal to claim in advertising to be able to cure cancer; meanwhile, medicinal licensing means it is unlawful to sell without prescription medicines which have not been licensed. Bearing this in mind, an organisation promoting so-called alternative cancer 'cures' (such as black salve, for example) would be acting illegally with regards to the 1939 Cancer Act, and unlawfully with regards to medicinal licensing – yet, charities which promote such therapies to cancer patients are effectively currently allowed to do so without losing their charitable status.
- The ASA recently concluded that there is no reliable evidence to claim that homeopathy is effective for any condition – this means there are registered charities whose goal of promoting homeopathy to treat disease would, should it be stated in advertising materials, contravene guidelines on acceptable advertising.
- It would be quite unusual for the Charity Commission's policies to contradict the considered policies of bodies like the ASA, or contradict the advice given by professional medical bodies such as NHS Choices and the Cochrane Collaboration.

The Complementary and Alternative Medicine industry

- Almost by definition, treatments that are classed in the Complementary and Alternative Medicine category lack robust, reliable and scientifically accepted evidence of effectiveness. If such a treatment were proven to be effective, it would be adopted by conventional medicine and would cease being considered as an alternative. One such example often cited by CAM practitioners is willow bark, which was used as a herbal painkiller before the

painkilling element of the bark was identified, synthesised and standardised into the aspirin pills commonly used today.

- CAM organisations routinely overstate the use of CAM therapies in the UK in order to argue that there is widespread public acceptance of their benefits, with some organisations suggesting homeopathy use, for example, to be around 10%-20% of the population; [recent findings from the European Social Survey](#) shows homeopathy use, in fact, at just 1% of the population.
- NHS support for CAM has fallen significantly over the last decade: homeopathy has been identified by NHS England as a procedure of low clinical effectiveness and a “[perfect example of those sorts of things we want to see less of](#)”; in the last two years more [than a dozen CCGs have ceased funding homeopathy](#), so that nine in ten CCGs in England no longer fund the service. In November 2016, NICE updated their guidelines [to remove their recommendation of acupuncture for lower back pain](#) because “evidence shows it is not better than sham treatment”. Evidence and support for CAM therapies among credible health bodies and health professionals is almost universally diminishing, rather than getting stronger.
- While there is much discussion about the effectiveness of alternative treatments (but very little actual evidence), there is less discussion about the potential harms of alternative treatments (and a significant body of evidence revealing risks)¹. The risks include pain and bruising caused by some types of massage, bleeding and infection from acupuncture, a range of side-effects caused by herbal remedies, misdiagnosis for therapies such as reflexology and iridology and so on. Moreover, there is the indirect harm caused by alternative therapies when mainstream treatments are delayed or abandoned.
- CAM organisations often point to their self-regulation or the overseeing of their profession by bodies such as the Professional Standards Authority as evidence that their therapies are proven and reliable – in fact, self-regulation demonstrates (at best) that therapies are carried out relatively safely; it adds nothing to the question of evidence of efficacy.
- CAM organisations reluctant to meet the standard of evidence outlined in the Charity Commission’s current policies may argue that there is not enough money to conduct the kind of controlled tests required to establish evidence of efficacy – we dispute this assertion. In fact, the complementary therapy industry is a multi-billion-pound industry, so funds are available, to conduct thorough tests, if there was the willingness in the industry to understand whether or not their treatments were effective.
- There has been, however, significant independent research on the effectiveness of CAM therapies – for instance, the Australian Government’s National Health and Medical Research Council’s paper “Evidence on the effectiveness of homeopathy for treating health conditions” looked at 57 systematic review papers, which included 176 individual studies². The report found that “there are no health conditions for which there is reliable evidence that homeopathy is effective”. Many other studies on homeopathy exist, that were not within the scope of the systematic reviews. There are similarly large numbers of trials for many other therapies, such as acupuncture and herbal medicine, with no clear evidence of their effectiveness.

¹ <https://www.ncbi.nlm.nih.gov/pubmed/12859546>

² https://www.nhmrc.gov.au/files/nhmrc/publications/attachments/cam02a_information_paper.pdf

Conclusions

- The Charity Commission should maintain a policy on CAM that reflects the best available evidence from independent research.
- Treatments should not be promoted until there is reliable, robust and replicable evidence of its effectiveness.
- New organisations should not be given charitable status if they promote – either as alternative or complementary; either for the treatment of symptoms or the cure of disease – treatments which do not have such evidence.
- Complaints made about the practice of CAM charities should be judged against the new policy; organisations that fail to be able to offer evidence for the therapies they promote should be removed from the charities register until such time as good evidence is available
- The current guidelines regarding CAM therapies – namely that evidence must come from peer-reviewed journals and medical professionals, rather than from anecdote and media coverage – is actually very sound, and would stand the Commission in good stead if it were routinely and rigorously applied when considering new charities and when handling complaints against existing charities. In part, this consultation came about because that standard of evidence was not followed in dealing with complaints regarding CAM charities.
- Where a charity is registered or seeks to be registered for the promotion of therapies that do not meet the standards of evidence identified by the Commission’s guidelines, those charities should not be granted charitable status or should have their status revoked.
- Organisations which promote treatments with claims that break the 1939 Cancer Act, that promote the sale or purchase of unlicensed medicines without prescription from a GP, or that breach the CAP Code for advertising, should not be given charitable status or should have their charitable status revoked.
- There are likely to be some charitable organisations whose mission statement and general work is very good and reasonable, but who have one project or a small number of projects that involve the promotion of CAM therapies which are not based in sound evidence. The Charity Commission should offer guidance to these charities, and issue warnings or take action where needed when these charities continue with projects that promote therapies not demonstrated to be beneficial.
- Nobody is suggesting that organisations which would like to promote unproven or disproven therapies should be prevented from existing or from acting – they simply ought not to be granted charitable status.

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