Submission No 25

THE PROMOTION OF FALSE OR MISLEADING HEALTH-RELATED INFORMATION OR PRACTICES

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Executive Secretary
Committee on HCCC

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Dear Sir/Madam,

I am writing on behalf of this Society to convey our concerns at the proposals to remove freedom of speech about medical and health matters. In particular we are concerned with several of the terms of reference of the Committee.

(a) The publication and/or dissemination of false or misleading health-related information that may cause general community mistrust of, or anxiety toward, accepted medical practice;

We would argue that the major threat to the health of the community comes from the lack of use of evidence based medicine by the medical profession. The number 3 cause of deaths in NSW after cardiovascular deaths and cancer is deaths occurring as a result of inappropriate medical interventions, mainly in hospitals. This part of the problem is known and documented. However there is an additional area of serious harm and many deaths resulting from overdiagnosis and overtreatment for cancer that is not widely known. Details of this are given below under **Part (a)**.

When the medical profession is causing much harm and operating against the community interests it is important for the public to be able to hear about it. It becomes the responsibility of community groups such as ours to point this out. This would not be possible if this proposal were accepted. Although the wording refers to ***misleading*** information, cancer authorities have shown that any information conflicting with their statements is considered to be misleading the public.

(b) The publication and/or dissemination of information that encourages individuals or the public to unsafely refuse preventative health measures, medical treatments, or cures;

We believe there are many areas where it is important for the public to be able to refuse treatments where there is clear evidence that they cause more harm than good. Examples of this are given below in **Part (b)**. It is therefore important for groups such as ours to be able to provide information about the potential harm from particular cancer treatments to people with cancer so they can obtain informed consent before proceeding with any recommended treatment. The medical profession has consistently failed to provide informed consent over the past seventeen years in relation to mammography screening. The same situation applies to prostate cancer screening. Providing such accurate information would not be possible if this proposal were

accepted. Although the wording refers to ***unsafely*** refuse treatment, cancer authorities have claimed that any such information likely to encourage people with cancer not to accept such screening or medical treatment would put their lives at risk.

(c) the promotion of health-related activities and/or provision of treatment that departs from accepted medical practice which may be harmful to individual or public health;

We believe there are many examples where accepted medical practice is not only contrary to evidence based medicine but also causes more harm than good. In contrast with this we believe there are several cancer therapies with much better evidence for their efficacy and without serious side effects. Although the wording refers to treatments that are **harmful**, the medical profession have shown that they often describe safe treatments as harmful if they wish to suppress their use. Examples of safe and effective alternative cancer treatments are given in **Part (c)**. It is important to retain the right to point this out and be able to promote evidence based medicine. This would not be possible if this proposal were accepted.

(d) the adequacy of the powers of the Health Care Complaints Commission to investigate such organisations or individuals; and

(e) the capacity, appropriateness, and effectiveness of the Health Care Complaints Commission to take enforcement action against such organisations or individuals;

We believe that powers such as this belong more in a police state than in a democracy such as Australia. If there are clear cases of suspected criminal activity it is the role of police and the courts to examine and act on any alleged breach of the law.

We believe it is not the role of governments to act to restrict competition between health services, especially when one branch of these services, the allopathic school of medicine, has such a poor track record in the cancer area and there is clear evidence that it is causing much harm to the community.

Because our Society has been operating for over thirty years to provide evidence based information to people with cancer, we will focus on the above concerns where they relate to the treatment of cancer.

It is rather ironic that if the first of these proposals is accepted, it would no longer be possible to lodge a submission such as this to the Parliament or to lodge similar petitions on this subject in Parliament.

In addition if the above proposals become accepted and the HCCC is given powers to investigate and penalise individuals or organisations for providing such information or carrying out such activities we will have no choice but to act on behalf of our members by challenging any such legislation in the courts as a breach of the Constitution, a breach of the concept of free and fair trading and a breach of free speech.

Yours sincerely,

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Part (a) Dissemination of information critical of the medical profession that may cause general community mistrust of, or anxiety toward, accepted medical practice

(a) (i) Information to support out claim

There is a group of medical researchers and medical practitioners in most Western countries who question the claims of cancer authorities that most cancer treatments are effective, and that improvement in treatment is resulting in an increase in survival for most types of cancer. This group has special expertise in evaluating results of clinical trials and most of them use and promote evidence based medicine.

The main groups and medical researchers that question the medical consensus and accepted medical practice in relation to health in general and cancer in particular are

- *the International Cochrane Collaboration.* This group was established in 1992 to promote evidence based medicine. They had found this was necessary because only about 15% of medical interventions were based on good scientific evidence, such as a randomised controlled trial (RCT)[1].
- *The Nordic Cochrane Group.* This is part of the Cochrane Collaboration. It has recommended a review of mammography screening because it clearly does more harm than good[2];
- *the British Medical Journal's Clinical Evidence Group.* Their evaluations have found that the number of medical interventions *proven* to be beneficial is 11% with an additional 23% *likely* to be beneficial[3]. This is a total of 34%. In other words a majority of medical interventions based on "accepted practice" are not beneficial and could do more harm than good. (Our Society has examined the figures for cancer and found them to be ~3% proven to be beneficial in RCTs and an extra ~4% likely to be beneficial, ie a total of ~7%[4]. In other words ~93% of interventions for cancer are not beneficial and could do more harm than good)
- *a group of medical researchers in Australia, the UK, Europe and the US*. This group recently organised an international conference on Overdiagnosis in the US in September 2013 to see what could be done to minimise the increasing harm from overdiagnosis of many conditions[5] including breast, kidney, prostate, lung and thyroid cancers, melanoma, hypertension, diabetes, high cholesterol, osteoporosis and gallstones[6]. The problem with this overdiagnosis is that it leads to overtreatment, much of which is unnecessary and causes harm[6]. In Australia this group includes Professor Paul Glasziou and Ray Moynihan at Bond University and Alex Barratt, Professor of Epidemiology at University of Sydney; in the UK it includes the Cochrane Group and the British Medical Journal; in Europe it includes the Nordic Cochrane Group; in the US it includes a team at Veterans Hospital led by Gilbert Welch and professors of medicine at The Dartmouth Institute for Health Policy & Clinical Practice. Other researchers include Graeme Morgan, Ralph Moss and Ulrich Abel.

A summary of their findings in relation to cancer is that

- most screening for cancer is not beneficial[2,7-9] and does more harm than good;
- most radiotherapy does not produce any significant increase in overall survival yet causes harm[10];
- most chemotherapy has little benefit, providing an increase of only about 2.3% in 5-year survival for people with malignant tumours who receive it[11] and causes much harm and no benefit to most of the others who receive it[12,16,17].

These facts show that most claims by the medical profession about "accepted medical

practice" being beneficial are incorrect. It is therefore essential for the community to be able to question such claims. Any attempt to stop such criticism only serves to entrench an unscientific group within the medical profession.

A minority of this group believes that surgical interventions for cancer have not been shown to be beneficial in any randomised controlled clinical trials (RCTs). This and the above findings in relation to cancer are probably because the "accepted" medical treatments are based on an unproven paradigm that assumes that cancer starts locally as a tumour that later spreads.

This minority believes that the evidence from the most effective treatments shows that cancer starts as a systemic disease with tumours being late stage symptoms. Some of this group also believes that the most effective treatment for cancer, as shown in RCTs, is a form of psychotherapy and various types of immunotherapy[4] all of which are systemic treatments. It is therefore essential for organisations and members of the public to retain the right to discuss and promote a more valid paradigm of what cancer is.

Evidence from RCTs over the past 15 years has supported the above findings. For example

- There has been no RCT carried out to prove the efficacy of cancer surgery[4,13]
- RCTs evaluating the benefits of screening for breast[2,7], bowel[7], lung[7], prostate[8] and ovarian[9] cancers show that there is no overall saving of lives from screening for these cancers yet harm is done, including deaths, by post screening treatments. If earlier surgery made possible by early detection through screening does not provide any saving of lives, the current paradigm of what cancer is and how it should be treated must be invalid[4,13-15].
- Radiotherapy has been shown to shrink tumours but this has not been accompanied by increased survival except for a small number of immediately life-threatening tumours, such as those obstructing the bowel or pressing on the brain[10].
- Chemotherapy has been shown to beneficial in a small number of relatively rare cancer types, notably acute childhood leukemia, but overall it extends 5 year survival by only about 2.3%[11-12]. Yet it is widely used by oncologists for cancers for which RCTs have shown no or only minimal survival benefit. At the same time it often causes a serious reduction in the quality of life and many deaths[12,16-17].
- Claims of benefits from cancer treatments are often based on an invalid use of the term 'cure'[4].

The media in Australia has not aired the views of these medical researchers, mainly because journalists believe that the "consensus of experts" must be correct. They are not to know that this consensus is not based on evidence of efficacy from randomised controlled trials but on the opinion of specialists with a vested interest. Journalists are also told by cancer authorities that airing dissenting viewpoints will cause harm by encouraging people with cancer to reject treatments that could save their lives.

Appendix 1 gives an example of news about important developments about the lack benefits of cancer treatment that the Australian media essentially ignored.

This withholding of important news and information deprives people with cancer of critical information necessary for them to decide whether to undergo treatment for their cancer and, if so, what treatment(s) to accept[18] so-called "informed consent". Many people with cancer come to our Society for information after they have accepted a particular treatment. They express surprise when they discover there is a second opinion about

cancer therapies among a minority of doctors and researchers. Some of them become angry when they conclude that they were given incorrect information by their doctor or specialist on which to decide which treatment to accept.

What the proposed changes foreshadowed by terms of reference **(a)** represent is preventing charities like ours from providing accurate and up to date information to our members and the general community about cancer therapies and pointing out in the media the valid views of the minority of medical researchers who question the current medical consensus about what is "accepted medical practice".

When groups like ours point out in the media that claims by cancer authorities are invalid, we are accused of publishing and/or disseminating false or misleading health-related information that may cause general community mistrust of, or anxiety toward, accepted medical practice. The terms of reference **(a)** sets out to suppress the publication of such valid criticism of the cancer authorities. In the cancer field it would therefore entrench harmful practices, suppress their exposure and lead to many avoidable deaths.

For example in 1996 our Society published a paper claiming that mammography screening doesn't save lives and causes more harm than good[19]. Ours was the first group in the world to highlight this issue by publishing a review of clinical trials.

In 2001 the Nordic Cochrane group published a paper confirming most of our findings[20]. Cancer authorities in Australia tried to suppress this information and to discredit the Nordic Cochrane Group. In 2003 our Society complained to the ABC that had been promoting mammography screening, that they were being biased by not airing the views of the Nordic Cochrane Group. The ABC claimed that allowing such views that criticised the consensus of experts to be broadcast would lead to the public questioning the need for mammography screening thereby leading to unnecessary deaths. The Independent Complaints Review Panel upheld out complaint[21] but stated that the ABC had expressed a valid concern for the implication of such criticism. It recommended that both sides of the debate be aired in the future. The ABC has ignored this recommendation ever since.

In 2013 The Nordic Cochrane Group published an update of its earlier Cochrane Review confirming the rest of our Society's findings that there have been no saving of lives from cancer screening[2]. So the ABC and other media have been responsible for much unnecessary anxiety, much overtreatment of breast cancer and many deaths that have taken place over the past 17 years as a result of this overtreatment.

The proposal to prevent dissemination of information that may cause general community mistrust of, or anxiety toward, accepted medical practice will only serve to entrench the invalid views of the consensus of cancer experts and those in the media.

(a) (ii) Possible explanation for the misunderstanding of the results of clinical trials by experts outlined above

Most medical researchers do not understand the basic principles of running or interpreting the results of randomised controlled critical trials (RCTs). The interpretation of the results of such trials requires not only an understanding of statistics but also of the principles underlying the proper running of such trials.

The *first rule* for running a RCT is that both groups, the group offered treatment and the control group, must be closely matched[22]. This requires very careful randomisation procedures. For example in one of the six RCTs evaluating mammography screening the

randomisation was done so badly that the base line characteristics of the treated and control groups before the trial began differed by up to 20%. This meant the results of the trial lasting many years were later ruled invalid.

A *second rule* is that the treated group must be offered only one extra treatment – the treatment under evaluation - that the control group is not offered. No other changes in treatment are allowed that could result in these other treatments being applied differently in the two groups[22]. This could 'confound' the results.

The six RCTs evaluating mammography screening all used a 'common protocol' in the treated and control groups. This was designed to ensure that all women with breast tumours detected early, eg at a particular size, all received the same treatment in both groups. This protocol required radiotherapy for smaller tumours and chemotherapy for larger tumours. However because mammography screening is designed to detect tumours earlier than normal, it meant that women in the treated group (offered screening) had many more smaller tumours detected than women in the control group (not offered screening). As a result, the protocol guaranteed that screened women received much more radiotherapy than women in the control group. Similarly women in the control group had more tumours detected later so received more chemotherapy than the women in the treated group. Since both radiotherapy and chemotherapy can cause serious harm, including death, these unevenly provided treatments 'confounded' the results in all trials making any conclusions from the trials doubtful. Such protocols are inconsistent with properly run RCTs[22].

A *third rule* states that if a person dies as a result of treatment he or she must be listed as dying from the disease for which the treatment is being evaluated[7]. For example many women in the treated group who received radiotherapy died as a result of heart failure from the post-surgical radiotherapy. These were often listed as "deaths from other causes", whereas, according to the third rule, they should have been listed as deaths due to breast cancer. As a result of this poor methodology, fewer of the women offered screening died of breast cancer creating the false impression that they had not died.

As an indication of the knowledge of RCT trial leaders, the Principal Investigator of the most quoted (Swedish Two Counties) trial did not understand this requirement. During an analysis of his trial in 1995 I identified the uneven use of radiotherapy in the two arms of his trial. I pointed out in correspondence to him that there was an increase in deaths due to other causes among screened women, presumably due to the harm from radiotherapy, and asked him how he had dealt with this confounding factor. He stated bluntly that radiotherapy does not cause harm so its effect could be ignored. This is despite the fact that, at the time of my question to him the serious harm from radiotherapy had already been identified along with the mechanism for the radiotherapy causing the deaths[23]. It was mainly due to the results of this flawed trial that cancer authorities were able to claim that mammography screening reduced the deaths from breast cancer by up to 30%.

A *fourth rule* of RCTs is that it is only valid to compare deaths of the two entire groups: those offered screening (the treated group) vs those not offered screening (the control group)[7]. This ensures that the two groups being compared are properly matched. This also overcomes the problem of confounding factors such as wrongly classifying treatment-related deaths as "deaths from other causes". In breach of this rule, for each of the six RCTs, the trial leaders compared the deaths from breast cancer in the two groups, rather than total deaths in the two groups, an invalid comparison for reasons given above. This comparison of unmatched sub-groups is invalid in RCTs[7].

Some medical researchers not only completely ignore this rule by comparing unmatched subgroups but introduce a further bias by comparing women who were actually screened (among those offered screening) with those who were actually not screened (among those not offered screening). This is because some women offered screening did not attend, whereas some women not offered screening did seek out screening. Earlier research has established that women who seek out screening come from a higher socio-economic background and are therefore healthier compared to those who choose not to be screened. So women actually screened would live longer as a group than the whole group offered screening. Similarly those who did not attend screening would not live as long as the whole group not offered screening. So this becomes a comparison of survival of healthier women with less healthy women. This completely undermines the purpose of the RCT to ensure a comparison of accurately matched groups. Manipulating the data in this way creates the false impression that screening is more beneficial than it really is.

After the publication of the results of the Nordic Cochrane Group in 2001 questioning the benefits of mammography, a Working Group was convened of the International Agency for Research on Cancer (IARC) (part of the World Health Organization) to counter the Nordic Cochrane Group's findings. 24 experts from 11 countries (representing vested interests in cancer from these countries) took part. They used this invalid comparison of women actually screened with women not screened. Their press release dismissed the findings of the Cochrane Group and claimed that the "consensus" among these experts was that the trials showed that there was a reduction of mortality of 35% among women aged 50-69 who chose to participate in screening[24]. No peer-reviewed paper was published to substantiate this claim so from a scientific viewpoint this statement has no scientific status.

Australian cancer authorities then quoted the "consensus" statement from this conference which also stated that the Nordic Cochrane Group's findings were flawed. When local media reported the IARC findings the Nordic Cochrane Group was not afforded an opportunity to respond and point out why the IARC statement was invalid.

So the 24 cancer experts from 11 countries, a "consensus" of experts, showed an ignorance of the basic principles of medical science. As a result the "accepted medical practice" in Australia continues to include recommending mammography screening for breast cancer, a practice that has been shown to cause more harm than good.

This group of experts might have been influenced by the pressures of vested interests, representing a cancer industry worth about $500 billion a year. So it is difficult to state that ignorance of basic scientific principles is the only or main reason for this situation.

In January 2013 the pioneer of mammography screening in the UK, Emeritus Professor of Surgery Sir Michael Baum admitted that the mammography screening trials that he had helped to set up in the UK had been a failure. In 2004 he had called for them to be stopped because he believed that they caused more harm than good[25]. However in his 2013 comment he admitted there had been no saving of lives at all[26], thus confirming the rest our Society's findings that the apparent reduction in deaths from breast cancer was due mainly to the deaths from other causes as a result of the harmful post-screening treatments such a radiotherapy. It was therefore only valid to compare the deaths from all cause in the two arms of the trial, as Our Society had pointed out in 1996. None of the trials had shown any reduction in deaths from all causes.

The point is that the "accepted medical practice" is not evidence based, yet this is exactly what terms of reference (a) would make it an offence to criticise.

Part (b) Dissemination of information likely to encourage persons to refuse accepted treatments or cures

This Society supports and encourages evidence based medicine. We evaluate all cancer therapies, both conventional and alternative to determine the level of evidence supporting them. We do not advise our members about what cancer treatments they should use. We simply provide them with accurate information then provide them with support irrespective of which therapy they choose to use. Most of our members use a combination of conventional and alternative cancer therapies.

We base our evaluations for each therapy on a set of criteria that determines the level of reliability of the claims for efficacy. The following summarises the level of reliability of eight different types of evidence followed by details and examples of each type of evidence:

1. Properly run randomised controlled trials supported by epidemiological evidence – BEST
2. Properly run randomised controlled trials - GOOD
3. Poorly run randomised controlled trials - FAIR
4. Comparison of incidence and mortality over time - FAIR
5. Comparison of 5-year survival with current best results - FAIR
6 Epidemiological evidence - FAIR
7. Increasing percentage 5-year survival - POOR
8. Anecdotal/Clinical evidence - POOR

1. Randomised controlled clinical trials, supported by epidemiological evidence.

A good example of this is breast cancer screening trials. About seven such trials have been held over the years. None have shown any overall saving of lives among women offered screening compared with those not offered screening.

However in addition to this an analysis of breast cancer mortality in particular countries with similar population characteristic has shown that the introduction of mammography screening has had no measurable impact on mortality rates in those countries or areas where such screening was introduced. In fact the mortality from breast cancer has fallen more rapidly among the age group of women not offered screening both in Europe[27] and the UK[28].

The combination of these two findings place the conclusion that mammography screening has no impact on mortality in the highest level of evidence.

For this reason our Society concludes that there is no reliable evidence to support offering breast cancer screening to women of any age group.

2. Properly run randomised controlled clinical trials not supported by epidemiological studies

Many RCTs have been carried out evaluating radiotherapy, chemotherapy and hormone therapy.

Except for those chemotherapy trials involving "surrogate endpoints" such as tumour shrinkage, the results of these trials are fairly reliable. Generally it can be concluded that:

- Chemotherapy can result in a small increase in survival in some types of cancer. However, with the exception of acute childhood leukemia, for which there have not been any RCTs held, the increase in survival is in weeks or months rather than years[16].
- Radiotherapy trials generally involve the ability to shrink tumours. There has rarely been any correlation between tumour shrinkage and increase survival, so any claims about increased survival are in some doubt[10]. Radiation oncologists generally base their claims for efficacy of radiotherapy on the ability of radiotherapy to shrink tumours[10]. They also often use the term "cure" incorrectly in the same way as do cancer surgeons. For this reason their claims are invalid.
- Hormone therapy for breast cancer has shown significant increases in survival[10] but comparable therapies for prostate cancer appear to have serious side effects[29].

3. Poorly run randomised controlled trials

Most of such trials evaluating mammography screening did not produce any significant reduction in deaths from all causes among those offered screening compared to those not offered screening. The trial protocols guaranteed that several post-screening treatments would be used differently in the two arms of the trial in breach of the principles for properly run RCTs. This resulted in confounding factors that make it difficult to interpret results other than comparison of deaths from all causes in the two groups. See item 1 above.

4. Comparison of Incidence and Mortality over time.

This is normally a fairly reliable measure of benefits. It requires mortality rates to fall faster than incidence rates or rise more slowly over time[30]. The incidence rate measure here must be the rate observed with people presenting with symptoms. It is not a valid measure of benefits where the incidence suddenly increases as a result of the introduction of widespread cancer screening. Unfortunately most cancer authorities compare changing incidence following screening, or diagnoses during investigations for other conditions, with changing mortality and wrongly interpret this as evidence for progress in cancer control[29]. Prostate cancer diagnosis is an example of this[31].

5. Comparison of 5-year survival with current best results

Survival statistics are available for different types of cancer following accepted treatment. If a new treatment produces markedly better results this can be reliable if the group treated closely matches those in the past and the technology used for the diagnosis is similar. The latter avoids the possibility that survival only increased due to earlier diagnosis. For example for Acute childhood leukemia (ALL) percentage 10-year survival is claimed to have increased from around 10% in 1960 to 60% in 1985[32]. Although some of this increase was clearly due to comparison of unmatched groups and improved diagnostic technology, the magnitude of the increase suggests progress.

6. Epidemiological evidence

This can be useful information once a cause and effect has already been been established. An example of this is cigarette smoking and lung cancer. However there are some remaining doubts with this interpretation when so many heavy smokers don't get

lung cancer and many who don't smoke get lung cancer. This suggests other intermediate factors play a part.

A similar correlation applies to the link between exposure to asbestos and mesothelioma where up to 40% of those exposed to the most dangerous form of asbestos (crocidolite) contracted mesothelioma up to 40 years later.

However compared to these two, most carcinogens have a relatively minor impact on mortality and would be unlikely to affect mortality statistics.

There is some evidence that the introduction of the Pap test has had an impact on mortality from cervical cancer. However there are claims that the mortality had begun to fall many years before the introduction of the Pap Test and the rate of fall was not affected by the widespread introduction of the Pap test[10,13].

7. Increasing 5-year survival over time

This apparently obvious measure can be easily shown to be unreliable[13]. A study headed by Welch[33] calculated the change in 5-year survival from 1950 to 1995 for the 20 most common solid tumour types and these changes in survival were correlated with changes in incidence and mortality for each tumour type. They found that from 1950 to 1995 there was an increase in 5-year survival for each of the 20 tumour types. The absolute increase ranged from 3% for pancreatic cancer to 50% for prostate cancer. During the same period mortality rates declined for 12 types of cancer and increased for the remaining 8 types. There was little correlation between changes in 5-year survival for a specific tumour and the change in tumour-related mortality. On the other hand the change in 5-year survival was positively correlated with the change in the tumour incidence rate. This suggested that the increased survival was due mainly to overdiagnosis following screening. So increasing 5-year survival is not a reliable measure of progress in cancer control. Most cancer authorities use this to support their claims about progress in cancer control.

8. Observational studies, anecdotal studies, clinical observation

Treatment of cancer using surgery is based on the observation that surgery can remove tumours that often do not reappear until many years later. This primary treatment for cancer has never been proven in an RCT to increase survival or reduce mortality for any type of cancer[13]. It would therefore appear that this apparently obvious conclusion is incorrect and that, if left untreated, such cancers would not have been life-threatening[13].

Most claims by cancer authorities relating to cancer treatment are therefore based on evidence at Levels 3 to 8 with none at the two most reliable levels. The primary treatment for cancer, surgery has evidence only at Level 8.

In addition, cancer authorities often use the word "cure" in relation to accepted medical practice. This is incorrect as there is no type of cancer that has been shown to be cured by accepted medical practice. Cancer authorities use a special definition of "cure" based on the absence of a return of symptoms (tumours) after 5 years. This is not a valid definition of cure that is accepted anywhere else in the medical profession.
When the correct definition is used it was found that treatment for breast cancer for those women with the greatest survival did not provide evidence of cure[34-35].

So if our Society provides our members with accurate, up to date evidence based information about conventional cancer therapies based on the above criteria, we would be in breach of the proposal (b)

Part (c) the promotion of health-related activities and/or provision of treatment that departs from accepted medical practice

We believe there are several cancer therapies that depart from accepted medical practice with much better evidence for their efficacy and without serious side effects. When community groups point these out, cancer authorities claim that pointing out these alternative cancer therapies to the public might encourage people to use such therapies *instead of* accepted medical practice. They then claim that, because accepted medical practice provides the only effective and safe treatment for cancer, any others will by definition be both ineffective and probably unsafe. Using this reasoning such alternative cancer treatment, if used by cancer patients instead of accepted medical practice, must therefore result in harm including an increase in deaths.

As mentioned in Parts (a) and (b) above, such claims are invalid. Therefore claims that therapies outside accepted medical practice must be ineffective or less effective and more harmful are also invalid.

Examples of some alternative cancer therapies follow, together with their level of their effectiveness. None of them produce any significant harm.

Alternative cancer paradigm

According to an alternative paradigm the tumour is a late-stage symptom or element of a systemic disease resulting from a gradual breakdown of several body systems including metabolic, endocrine, digestive and immune system triggered of by several factors, including some prior to birth[4].

There are more than 150 alternative cancer therapies being used throughout the world whose evidence for efficacy ranges from well-run RCTs (level 2) to anecdotal evidence (level 8). The following are just three examples from within this range that are based on this alternative paradigm

Psychotherapy and Immunotherapy

Recent research has suggested that chronic stress is a major contributory factor not only to cancer but also to other degenerative diseases such as coronary heart disease[4]. The mechanism for this would appear to include shortening of telomeres and other weakening of the immune system[36-37].

Several RCTs by Eysenck and Grossarth-Maticek have evaluated treatments based on this paradigm. Those with positive results show benefits far exceeding those achieved using treatments based on the orthodox paradigm. For psychotherapy the suggested increased 5-year survivals range from 32% to 64%.[38] Similar but lower increases were observed with immunotherapy.[39] These are both examples of Level 2 evidence. Despite this fact the medical profession rejects the claim that psychotherapy can affect survival of people with cancer.

Issels' Wholebody therapy

Josef Issels' Wholebody Therapy in Germany in the 1960s based on this paradigm produced better survival results treating late stage cancer than with any other therapy anywhere in the world. It is claimed to have produced 16.7% 5-year survivals and 15% 15-year survivals among late stage cancer patients (with a typical prognosis of 12 months) 5 to 8 times higher than could be achieved at the time using surgery or other therapies based on the orthodox paradigm[40]. This is Level 5 evidence. Despite Dr Issels' remarkable success in treating cancer his medical colleagues succeeded in destroying his career.

Homeopathy

Another area of medicine that the medical profession is strongly opposed to, despite strong evidence for its efficacy, is homeopathy. Most clinical research conducted on homeopathic medicines that has been published in peer-review journals has shown positive clinical results, especially in the treatment of respiratory allergies, influenza, fibromyalgia, rheumatoid arthritis, childhood diarrhea, post-surgical abdominal surgery recovery, attention deficit disorder, and reduction in the side effects of conventional cancer treatments. In addition to clinical trials, several hundred basic science studies have confirmed the biological activity of homeopathic medicines. In *in vitro* studies, 67 experiments (1/3 of them replications) and nearly 3/4 of all replications were positive[41].

In relation to cancer treatment in particular, The University of Texas MD Anderson Cancer Center (MDACC) in Houston offers homoeopathic remedies as part of their cancer treatment. This followed after they had conducted clinical trials of two homoeopathic remedies on 15 patients with brain tumours. Six of their 7 patients with gliomas had experienced a complete regression. This is Level 5 evidence.

The US National Cancer Institute (NCI) evaluated a particular homoeopathic cancer protocol on 10 patients with different types of cancer. In four cases of lung and esophageal cancer they observed partial responses.[42]

Our Society has members whose children have completely recovered from brain tumours using a combination of homeopathy and herbal treatments.

There is increasing support for the principles underlying homeopathy in Europe, including from two Nobel Prize winners, Luc Montagnier, the French virologist who shared the Nobel Prize in Physiology or Medicine in 2008 for discovering the HIV virus, and Brian Josephson PhD, an emeritus professor at Cambridge University, who shared the Nobel Prize in Physics in 1973. A third leading researcher, immunologist Jacques Benveniste also supported the principles underlying homeopathy but his career was also destroyed.

Other alternative cancer therapies

Apart from these three examples there are many other alternative cancer therapies that are claimed to have resulted in complete recovery from late stage cancer. Yet the medical profession is strongly opposed to these and many other alternative cancer therapies, claiming they are unsafe and ineffective.

In this Society's submission to the Senate Inquiry into services and treatment options for persons with cancer in March 2005[10] we provided detailed examples (pages 51-62) of how the work of 20 people working in the cancer field throughout the world had their views or work suppressed by cancer or medical authorities. In one case in the United States this suppression was exposed in a Congressional Inquiry that resulted in the Congress requiring the US National Cancer Institute to desist from their suppression of

cancer therapies[43]. The Inquiry led to the setting up in the US of the Office of Alternative Medicine (OAM) that later led to establishment of the National Center for Complementary and Alternative Medicine (NCCAM).

So contrary to Terms of Reference (a) it is the criticism of many types of effective alternative medicine, such as psychotherapy, immunotherapy and homoeopathy, by the medical profession that is depriving many cancer patients of recovery from cancer.

Yet if our Society provides our members with accurate, up to date evidence based information about alternative cancer therapies based on the criteria in Part (b), we would be in breach of the proposal (c).

REFERENCES

1. Smith, R (Editorial). Where is the wisdom…the poverty of medical evidence. BMJ (5 October) 1991; 303: 798-799.
2. Gøtzsche PC, Jørgensen KJ. Screening for breast cancer with mammography. Cochrane Database Syst Rev. 2013 Jun 4; 6:CD001877.
3. Clinical Evidence http://clinicalevidence.bmj.com/x/set/static/cms/efficacy-categorisations.html.
4. Benjamin, Don. The role of psychotherapy in the treatment of cancer. Journal of Alternative Medicine Research 2010; 2 (4): 429-438. https://www.novapublishers.com/catalog/product_info.php?products_id=26210.
5. www.preventingoverdiagnosis.net.
6. Welch GH. Overdiagnosed: making people sick in pursuit of health. Beacon Press, Boston, 2011.
7. Black W, Haggerstrom D and Welch HG. All-cause Mortality in Randomized Trials of Cancer Screening. J Natl Cancer Inst, 6 Feb 2002; 94(3):167-73.
8. Boyle P and Brawley OW. Prostate Cancer: Current Evidence Weighs Against Population Screening (Editorial). CA Cancer J Clin (Jun 29) 2009; 59:220-224.
9. Buys SS et al. Effect of screening on ovarian cancer mortality: the Prostate, Lung, Colorectal and Ovarian (PLCO) Cancer Screening Randomized Controlled Trial. JAMA. (Jun 8) 2011; 305(22):2295-303.
10. Cancer Information & Support Society. Submission #15 to Senate Inquiry into services and treatment options for persons with cancer, 2005. http://www.aph.gov.au/Senate/committee/clac_ctte/completed_inquiries/2004-07/cancer/submissions /sub15.pdf.
11. Morgan G, Ward R, Barton M. The contribution of cytotoxic chemotherapy to 5-year survival in adult malignancies. Clin Oncol (R Coll Radiol). (Dec) 2004; 16(8): 549-60. Review.
12. Moss, RW. Questioning Chemotherapy. Equinox Press, New York 1995 (p. 56).
13. Benjamin, DJ. The efficacy of surgical treatment of cancer. Medical Hypotheses 1993; 40 (2): 129-138.
14. Devitt JE. Breast cancer: have we missed the forest because of the tree? Abstract In: Proceedings of The Lancet Conference: "The challenge of breast cancer", 21-22 April 1994, Brügge, Belgium; and Lancet 1994; 344: 734-35.
15. Retsky MW, Demicheli R, Hrushesky WJ, Baum M, Gukas ID. Dormancy and surgery-driven escape from dormancy help explain some clinical features of breast cancer. APMIS. 2008 Jul-Aug; 116(7-8): 730-41.
16. Abel, U. Chemotherapy of advanced epithelial cancer: a critical review. Biomedicine & Pharmacotherapy 1992; 46: 439-452.
17. Mayor, Susan. UK audit shows need for greater caution with chemotherapy in very sick patients. BMJ 2008; 337:a2498.
18. Cancer Information & Support Society. Submission to Independent Inquiry into The Media and Media Regulation. October 2011.
19. Benjamin, DJ. The efficacy of surgical treatment of breast cancer. Medical Hypotheses 1996; 47 (5): 389-97.

20. Olsen, O and Gøtzsche, P. Cochrane review on screening for breast cancer with mammography. Lancet 2001; 358: 1340-42. Full report: Systematic review of screening for breast cancer with mammography. 134 refs. Cochrane Database Syst Rev. 2001.
21. http://about.abc.net.au/reports-publications/2003-2004-annual-report/ Appendix 18, p.172.
22. Kendall, JM Designing a research project: randomised controlled trials and their principles. Emerg Med J 2003;20:164–168.
23. Cuzick J, Stewart H, Rutqvist L et al. Cause-Specific Mortality in Long-term Survivors of Breast Cancer Who Participated in Trials of Radiotherapy. J. Clin Oncol 1994; 12 (3): 447-453.
24. IARC. Mammography Screening Can Reduce Deaths From Breast Cancer. Press Release 19 March 2002. http://www.iarc.fr/en/media-centre/pr/2002/pr139.html.
25. Baum M. False premises, false promises and false positives--the case against mammographic screening for breast cancer. Int J Epidemiol. 2004 Feb;33 (1):66-7.
26. Baum M. Harms from breast cancer screening outweigh benefits if deaths caused by treatment is included. BMJ (23 Jan) 2013; 346: f385.
27. Autier, P et al. Breast cancer mortality in neighbouring European countries with different levels of screening but similar access to treatment: trend analysis of WHO mortality database. BMJ (28 July) 2011; 343: d4411.
28. Mukhtar Toqir K, Yeates David RG, and Goldacre Michael J. Breast cancer mortality trends in England and the assessment of the effectiveness of mammography screening: population-based study. J R Soc Med. (June) 2013; 106(6): 234–242.
29. Efstathiou JA, Bae K, Shipley WU, et al. Cardiovascular mortality after androgen deprivation therapy for locally advanced prostate cancer: RTOG 85–31. J Clin Oncol. 2009; 27:92–99.
30. Enstrom, JE & Austin, DF. Interpreting cancer survival rates. Science 1977; 195: 847-851.
31. Cairns, J. The Cancer Problem. Sci Am. 1975; 233 (5): 64-78.
32. Lilleyman, JS. Childhood leukemia, The facts. OUP, Oxford, 1994.
33. Welch HG et al. Are increasing 5-year survival rates evidence of success against cancer?. JAMA (14 June) 2000; 283 (22): 2975-8.
34. McKay J and Langlands AO, Prognostic Factors in Breast Cancer. N Engl J Med 1992; 327: 1317.
35. Brinkley D, Haybittle JL. The curability of breast cancer. World J Surg. 1977 May; 1(3): 287-9.
36. Epel, ES, Blackburn EH, et al. Accelerated telomere shortening in response to life stress. Proc Natl Acad Sci USA (Dec 7) 2004; 101(49):17312-5.
37. Cawthon RM et al. Association between telomere length in blood and mortality in people aged 60 years or older. Lancet. (Feb 1) 2003; 361 (9355): 393-5.
38. Eysenck, HJ & Grossarth-Maticek, R. Creative Novation Behaviour Therapy as a Prophylactic Treatment for Cancer and Coronary Heart Disease: Part II - Effects of Treatment. Behav Research and Therapy 1991; 29 (1): 17-31.
39. Grossarth-Maticek R, Kiene H, Baumgartner SM, Ziegler R. Use of Iscador, an extract of European mistletoe (Viscum album), in cancer treatment: prospective nonrandomized and randomized matched-pair studies nested within a cohort study. Altern Ther Health Med. (May-Jun) 2001; 7(3): 57-66, 68-72, 74-6.
40. Issels, J. Immunotherapy in Progressive Metastatic Cancer - A Fifteen-Year Follow-up. Clinical Trials Journal, August 1970: 357-365 with editorial by Phillips S. Dr Joseph Issels and the Ringberg Klinik. Clinical Trials Journal. August 1970: 355-56.
41. Kassab S et al. Homeopathic medicines for adverse effects of cancer treatments. Cochrane Database of Systematic Reviews 2009, Issue 2.
42. Banerji P, Campbell DR, Banerji P. Cancer patients treated with the Banerji protocols utilising homoeopathic medicine: a Best Case Series Program of the National Cancer Institute USA. Oncol Rep. 2008 Jul; **20** (1):69-74.
43. US Congress. Congressional Public Hearing: A hearing on the Immuno-Augmentative Therapy of Dr. Lawrence Burton. January 15, 1986 before Congressman Guy V. Molinari.

Appendix 1.

The following are examples of how media in the UK and the US have provided widespread and impartial coverage of recent developments in the cancer field. It shows the validity of our claims and how Australian medical practice has fallen behind that in the rest of the Western world. The Australian media's lack of coverage of this issue, or its biased presentation, has contributed to the Australian public's lack of awareness of these issues.

In August 2011 the New York Times had the following report:

"August 1, 2011
Screening: Mammograms Seen Ineffective in Europe
By NICHOLAS BAKALAR
An analysis of data from six European countries suggests that mammography screening has had no effect on breast cancer mortality.

Deaths from breast cancer have declined substantially in most industrialized countries, but it is difficult to know how much of the decline is due to early detection, treatment, or the efficiency of health care systems.

Researchers took advantage of a natural experiment in three pairs of countries. Some had instituted regular mammography screening significantly earlier than the others, but their health care systems and socioeconomic levels were nearly identical. The countries matched for comparison were Northern Ireland and the Republic of Ireland; the Netherlands and Belgium; and Sweden and Norway.

The study, published online July 28 in the British medical journal BMJ, found that in all three cases, earlier implementation of screening had no effect on mortality. For example, in Northern Ireland, screening was introduced in the early 1990s, and by 1995, 75 percent of the women were getting mammograms. In the Republic of Ireland, screening was not introduced until 2000, and it was not until 2008 that 76 percent of the population was screened. Yet from 1989 to 2006, breast cancer mortality decreased by 29.6 percent in Northern Ireland and by 26.7 percent in Ireland.

"We were surprised and quite sad to find that breast cancer screening doesn't work," said Dr. Philippe Autier, the lead author. "We were expecting to find the reverse."

A version of this article appeared in print on August 2, 2011, on page D6 of the New York edition with the headline: Screening: Mammograms' Value Questioned in Europe."

There was little if any reporting of this in the Australian media or on the ABC so most women would not be aware of the situation.

The national breast cancer screening program in the UK is at last under review. And the views of the minority of medical researchers are at last beginning to be more widely discussed.

On 25 October 2011 The Archives of Internal Medicine published the following report:

"Mammography Questioned Again, British Program Under Review

Zosia Chustecka

October 25, 2011 — Once again, the benefits and harms of mammography are being discussed in public forums, in a major medical journal, and in an entire country, now that the national breast screening program in the United Kingdom is officially under review.

In an analysis published online October 24 in the Archives of Internal Medicine, 2 American academics focus on the claim that "mammography saves lives." This powerful slogan, and the story it doesn't tell, was discussed in detail in a special Medscape Medical News report last year. The new analysis, carried out by Gilbert Welch, MD, MPH, and Brittney Frankel, from the Dartmouth Institute for Health Policy and Clinical Practice, Hanover, New Hampshire, addresses this specific claim once again.

"Most women with screen-detected breast cancer have not had their lives saved by screening," the authors conclude. "They are instead diagnosed early (with no effect on their mortality) or overdiagnosed."

Questions about mammography have been circulating for some time across the Atlantic, where the British

national breast screening program is currently being reviewed. The national program — which offers mammography every 3 years to women 47 to 73 years of age — has previously come under attack for not representing the harms of screening as adequately as the benefits. Some of these concerns, as well as many others, have resurfaced in a letter published online October 25 in BMJ from Susan Bewley, MB BS, MRCOG, professor of complex obstetrics, division of women's health, at King's College London, United Kingdom. A reply from the UK cancer tsar Mike Richards, CBE, MD, FRCP, DSc(Hon), national clinical director of cancer at the Department of Health, London, accompanies the letter.

"The ongoing controversy should, if at all possible, be resolved," Dr. Richards writes.

An independent review of the research evidence for breast cancer screening (including both randomized controlled and observational studies) was initiated a few weeks ago, Dr. Richards writes.

He will be leading the review (Dr. Richards was formerly a consultant medical oncologist at Guy's Hospital, specializing in breast cancer), along with Harpal Kumar, MA, MEng, MBA, chief executive officer at Cancer Research UK. They are trying to find "independent advisers who have never previously published on the topic of breast cancer screening," he notes.

Once the review is complete, the evidence will be presented at a workshop hosted by Cancer Research UK; experts from both sides of the argument will be invited.

In addition, the information issued to the public, such as the leaflets sent out with the invitation to screening, is also under review, Dr. Richards notes. This is being carried out for all the cancer screening programs currently operating in the United Kingdom (including colorectal and cervical cancer) — but the breast cancer leaflet will be the first to be revised, he notes. Again, this review will be undertaken by an independent team, and it will take into account current thinking on how to synthesize information on the benefits and harms to offer an informed choice, he explains.

Saving Lives

The British national program is based on advice from the independent Advisory Committee on Breast Cancer Screening. This committee concludes that "breast screening saves lives and...the benefits considerably outweigh the harms," Dr. Richards notes.

This is in line with the stance taken by the World Health Organization's International Agency for Research on Cancer, he notes.

However, it is this central message — that screening saves lives — that is questioned in the analysis by Dr. Welch and Ms. Frankel. They address the "enthusiasm for screening" and the cancer survivor stories — particularly those of celebrities — that have created a presumption among the general public that every survivor whose cancer was detected by screening has had her "life saved" by screening.

"Our analysis suggests this is an exaggeration," they write, adding: "In fact, a woman with screen-detected cancer is considerably more likely not to have benefited from screening."

An accompanying commentary points out that all preventive healthcare services, not only breast cancer screening, can result in tremendous benefits but can also cause harms such as overdiagnosis and overtreatment. The piece is authored by Timothy Wilt, MD, MPH, and Melissa Partin, PhD, from the University of Minnesota, Minneapolis. Dr. Wilt is also a member of the US Preventive Services Task Force.

They urge clinicians to be a "reliable source of information" for their patients, and say that the message about any preventive procedure needs to be tailored to the individual. In some circumstances, the message might be negative, with the clinician recommending against a test, they point out.

Arch Intern Med. Published online October 24, 2011."

The Times, London reported on this development on 26 October 2011 with the headline “Doubt cast on breast cancer screening”. The Times report covered most of the information given in the Archives Report.

So 17 years after our organisation published a paper in 1996[19] showing that mammography screening for breast cancer had not been shown to save lives, the cancer industry is being forced to confront the scientific evidence. But again there has been little or no reporting of this situation in the Australian media or on the ABC.