PE1552/B

Scottish Parliament Public Petitions Committee:

CONSIDERATION OF PETITION PE1552

Cancer Research UK Response

About us

Cancer Research UK is the world's leading cancer charity dedicated to saving lives through research. Cancer is the leading cause of death in Scotland[i] and one in two people will develop cancer at some point in their lives.[ii] Together with our partners and supporters, our vision is to bring forward the day when all cancers are cured. We support research into all aspects of cancer through the work of over 4,000 scientists, doctors and nurses. In 2012/13 we spent £351m on research, about £34m of which was in Scotland. The charity's pioneering work has been at the heart of the progress that has already seen survival rates in the UK double in the last forty years. We receive no government funding for our research.

Evidence based treatments

Cancer treatment in all parts of the UK is underpinned by evidence based medicine. New treatments must be backed up by evidence that they are safe and effective before they pass into mainstream use via the NHS. To allow the use of unproven treatments risks serious harm to patients and waste of finite resources on treatments that may offer no benefit. In many cases evidence is provided from records of laboratory studies and trials that have been published in scientific journals, and reviewed by experts. For medical treatments, pharmaceutical companies must also supply evidence of new drugs' effectiveness to relevant health service departments before the drugs are made available for use.

Chemotherapy, radiotherapy and surgery are all proven treatments that benefit cancer patients – surgery and radiotherapy still cure more patients than any other type of treatment. (Around half of all patients whose cancer is cured have surgery as part of their treatment.[iii] And about four in ten of cancer patients who are cured receive radiotherapy as part of their treatment.[iv]) And all three of these cornerstone treatments are continuing to be advanced through scientific research. Radiotherapy is becoming more precisely targeted, sparing more healthy tissue; surgery less invasive and better at removing more of the cancer cells; and chemotherapy combinations less severe and more effective.

Any new drug will begin with preclinical testing – scientists will first study the drug in a laboratory setting, to procure evidence that it is effective at killing or slowing the

growth of cancer cells grown in the lab. They will then move on to testing the drug in animals, to ensure that it is effective and safe for further testing in humans. The next steps are clinical trials, where any new drug, new combination of treatments, or new technique is tested in patients or healthy volunteers.[v] The trials go through stages, first assessing the new cancer treatment for safety, and then to compare it to the current best treatment, also known as the gold standard of care.

Based on the results of the clinical trials, any new drug must first be licensed by the Medicines and Health Regulatory Authority or the European Medicines Agency to confirm the evidence demonstrates it's safe and effective. The final hurdle in Scotland is for the SMC to weigh up the drug's benefit compared to its cost, to decide if it offers value for money for the NHS.

This system, whilst not without flaws[vi], ensures that cancer patients receive treatments that are safe and likely to either prolong their life, or save it.

We can't comment on the statistic that is given in the statement- *"In fact, a report that came out recently said that breast cancer patients who reject all conventional treatments survive four times longer than women who follow the system"*- without reviewing the report the statement is based on. However we do know that statistics available are not detailed enough to tell you about the different treatments people may have had for breast cancer, and they don't tell us how treatment worked for them. Many individual factors will affect treatment and prognosis. For breast cancer, there are more and more tests that specialists take into account both to decide treatment and to estimate how well it will work. What we do know from the statistics is that survival for breast cancer is related to stage of the disease at diagnosis and that the majority of breast cancer patients are diagnosed at an early stage and therefore can begin treatment earlier, and have a better chance of survival.

Comparing cancer survival between counties is complex but likely explanations include: differences in stage at diagnosis, accessibility to good care, different diagnostic intensity and screening approaches, and differences in cancer biology[vii]. The EUROCARE study identified survival differences between countries in Europe, which has prompted further investigation by the International Cancer Benchmarking Partnership (ICBP) to explain the differences in survival[viii]. ICBP is restricted to those countries with full population coverage for cancer registration and similar healthcare systems to try and remove some of the possible explanations related to different survival results. Cancer survival in the UK has doubled in the last 40 years – over all types of cancer, ten year survival is at 50 per cent.[ix]

Alternative treatments

There was mention of several alternative treatments during the petition, the first of which was the Photon Genie. There is no credible scientific evidence to show that

the Photon Genie is of any benefit to cancer patients. The claims on their website[x] advertising the device are not based on any sound scientific principles.

There is no published evidence that cells have ideal “vibrational frequencies” (or that the Photon Genie can affect these levels), or that the Photon Genie has any anti-pathogen or disease reversing properties, or can affect fluid balance within tissues of the body. “Detoxifying” is a pseudoscientific concept – the liver, kidneys and other organs remove harmful substances from the body very efficiently and there is no evidence the Photon Genie enhances these functions or supports nutrient absorption.

Medical equipment based on energy emissions does exist. Devices that emit ultrasound, infrared, ultraviolet, X-rays, and gamma radiation are all approved medical treatments for a diverse range of pathologies (including medical imaging, cancer, acne, muscle injuries, and blood vessel blockages). But each of these devices has been rigorously tested for particular indications – and there is solid evidence from years of peer-reviewed medical research and clinical trials that they are effective tools.

Based on the absence of published evidence to back up the claims made by the company selling the Photon Genie, our opinion is that the device should not be considered as a credible cancer treatment. Other similar devices (like the Rife machine) have already been exposed as fraudulent cancer therapies, and the people selling them sued or jailed.[xi] Furthermore, claims that the Photon Genie can treat swine ‘flu were deemed to contravene the Public Health Service Act by the FDA.[xii]

The other ‘alternative treatments’ mentioned throughout the petition were “intravenous vitamin C, laetrile, Essiac, ozone therapy and immunotherapy”.

Most of these treatments are alternative and unproven, if not potentially harmful – there are comprehensive lists available online.[xiii] There is no evidence that Essiac[xiv] or laetrile[xv] have anti-cancer properties when taken by people with cancer: a review of published research into laetrile by the Cochrane library[xvi] found that it had no proven benefits but there is serious risk of cyanide poisoning, and oxygenation therapies like ozone therapy likewise have no benefit but can cause serious harm to patients.[xvii]

High dose vitamin C given intravenously is still being tested in early stage clinical trials to determine its safety. Clinical trials where vitamin C was given alongside one particular chemotherapy drug had to be stopped early due to side effects and the cancers growing more aggressively,[xviii] so there are signs that it is not safe for all cancer patients. Because the trials have been small and focused on determining the safety of vitamin C, there is little evidence that it has any benefits yet. Some studies reported an alleviation of some of the side effects experienced by patients

undergoing treatment, but due to the small size of the trials, the evidence is far from solid. And critically, there is certainly no evidence as yet from any clinical trial that vitamin C improves survival rates.

There is some data that indicate ozone therapy[xix] could be beneficial for patients suffering a complication caused by radiotherapy damaging the jawbone (osteoradionecrosis), but this needs further testing in clinical trials.

The mention of immunotherapy is interesting, because this is a very active area of research and new immunotherapy treatments are becoming available for cancer patients. Ipilimumab (Yervoy) was approved by the SMC[xx] for people with advanced melanoma, and pembrolizumab is now available to patients in the UK with the same disease via the Early Access to Medicines Scheme.[xxi] Drugs with a similar mechanism of action are being evaluated in clinical trials, or have already been licensed in some countries for cancer patients (for example nivolumab (Opdivo) is approved in the US by the FDA).[xxii] These treatments are being approved for use as and when there is sufficient evidence to show that they are safe and can offer benefits for patients.

The Oasis of Hope Cancer Hospital[xxiii] is a centre offering alternative cancer treatments with no proven efficacy, with a particular focus on laetrile. When asked by the FDA to provide evidence[xxiv] of his success with laetrile, Dr Contreras put forward 12 case studies, of whom six had died, one still had cancer, one had conventional treatment, and one died of an unrelated disease – the remaining three couldn't be located. Further coverage on this topic can be found here.[xxv]

In general, alternative treatments are described as such because they lack evidence of efficacy, and may even have the capacity to cause harm[xxvi] to cancer patients. Because of this lack of evidence of effectiveness, they are not provided on the NHS. This means they are often costly, and can lead to vulnerable people spending large sums of money and travelling long distances in poor health for treatments that have no proof of being effective. They can also take a huge emotional toll, offering false hope to patients via misleading advertising. The treatments themselves can be harmful (as mentioned, there is a serious risk from cyanide poisoning caused by taking laetrile, and products sold as black salves or cancer salves can burn the skin and leave permanent scarring and disfigurement).[xxvii] And finally, alternative treatments may lead the patient to postpone or avoid evidence-based treatments, which might otherwise have prolonged or even saved their lives.

Cancer Act 1939

The 1939 Cancer Act was brought in to try to stop the advertisement of fraudulent cancer cures to the general public in the UK and to control direct-to-consumer advertising of cancer treatment and services. It is very important to emphasise here

that it does not prevent the release of information about scientifically-proven treatments, affect genuine scientific research into cancer treatments, or hamper patient access to evidence-based therapies for cancer. However, it does aim to protect patients from being exploited by people selling therapies for which there is no good evidence, and several successful prosecutions have been made by Trading Standards against practitioners offering fraudulent and/or potentially harmful cancer treatments.[xxviii] See here for further reading.

Our relationships with the pharmaceutical industry

We have been very candid about our relationships with the pharmaceutical industry, and why we need to work with pharmaceutical companies to get treatments to patients as quickly as possible.

We form partnerships with pharmaceutical companies because we need their expertise and resources in order to fulfil our goal of getting lifesaving discoveries to patients as quickly as possible. Because drug development is so expensive – particularly the large scale clinical trials – the total amount of money we spend on research every year would fall short of developing even a handful of potential drugs. We simply can't afford to bear this cost, nor would it be the most effective use of our supporters' donations.

Working with pharmaceutical companies means we can support bigger, more ambitious projects. But we will only enter a joint venture if it will help us achieve our goal of improving the outlook for cancer patients and meets our high scientific standards. Furthermore, we never directly give pharmaceutical companies money, but co-fund specific projects with them based on the scientific merits of grant applications submitted by researchers.

If a new drug is developed based on our research, we have a subsidiary company, Cancer Research Technology (CRT), that ensures we have intellectual property rights to these discoveries. CRT staff work with scientists to identify promising research projects, finding the best commercial partner to take development forward. The legal agreements put in place ensure that a fair share of any royalties comes back to Cancer Research UK (and these profits are ploughed back into life-saving research), and that research into the drug is not halted for commercial reasons.

Because we are a charity and not constrained by making profits for shareholders, we are also free to support research and clinical trials testing promising drugs that might not be expected to make money. One good example is the research we're funding into aspirin – a very old drug with potentially important benefits for preventing and possibly even treating cancer, as well as reducing side effects from chemotherapy. But like all the other research we fund, it needs to be based on solid evidence. We

also fund a large amount of research into non-drug based treatments, like surgery and radiotherapy. You can read more here.

The pricing of new drugs is not controlled by research organisations such as Cancer Research UK. Instead it lies with drug manufacturers. There are many reasons why drugs can cost a lot of money, which we have explored in detail on our blog.

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[i] http://www.isdscotland.org/Health-Topics/Heart-Disease/Topic-Areas/Mortality/
[ii] http://www.nature.com/bjc/journal/v112/n5/full/bjc2014606a.html
[iii] http://www.cancerresearchuk.org/about-us/we-develop-policy/our-policy-on-access-to-cancer-treatments/our-policy-on-cancer-surgery
[iv] http://www.cancerresearchuk.org/our-research/our-research-by-cancer-subject/our-research-on-radiotherapy
[v] http://www.cancerresearchuk.org/about-cancer/cancers-in-general/cancer-questions/how-long-does-it-take-for-a-new-drug-to-go-through-clinical-trials
[vi] http://scienceblog.cancerresearchuk.org/2014/12/08/a-welcome-review-of-how-treatments-get-to-patients/
[vii] De Angelis R, Sant M, Coleman MP et al. Cancer survival in Europe 1999-2007 by country and age: results of EUROCARE-5 – a population-based study, . Lancet Oncol, 15 (Jan 2014), Pages 23-34. http://www.sciencedirect.com/science/article/pii/S1470204513705461 Accessed: 27/03/2015
[viii] MP Coleman, D Forman, H Bryant, et al. Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995–2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data, The Lancet, Volume 377, Issue 9760, 8–14 January 2011, Pages 127-138, ISSN 0140-6736, http://dx.doi.org/10.1016/S0140-6736(10)62231-3. (http://www.sciencedirect.com/science/article/pii/S0140673610622313) Accessed 01/04/2015
[ix] http://www.cancerresearchuk.org/health-professional/early-diagnosis-activities/international-cancer-benchmarking-partnership-icbp
[x] http://www.edskilling.com/photongenie.html
[xi] http://www.quackwatch.org/04ConsumerEducation/News/rife.html
[xii] http://www.fda.gov/ICECI/EnforcementActions/WarningLetters/ucm163693.htm
[xiii] http://en.wikipedia.org/wiki/Alternative_cancer_treatments#Ineffective_treatments; http://www.cancerresearchuk.org/about-cancer/cancers-in-general/treatment/complementary-alternative/therapies/; http://www.fda.gov/Drugs/GuidanceComplianceRegulatoryInformation/EnforcementActivitiesbyFDA/ucm171057.htm

[xiv] http://www.ncbi.nlm.nih.gov/pubmed/19476742
[xv] http://www.cancer.gov/cancertopics/pdq/cam/laetrile/patient/Page2#Section_24
[xvi] http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD005476.pub3/abstract
[xvii] http://www.cancernetwork.com/oncology-journal/oxygen-therapies
[xviii] http://www.cancer.gov/cancertopics/pdq/cam/highdosevitaminc/healthprofessional/page1/AllPages#Reference5.18
[xix] http://www.ncbi.nlm.nih.gov/pubmed/24487948; http://www.ncbi.nlm.nih.gov/pubmed/22825522 http://www.ncbi.nlm.nih.gov/pubmed/21310650

[xx] https://www.scottishmedicines.org.uk/SMC_Advice/Advice/997_14_ipilimumab_Yervoy/ipilimumab_Yervoy
[xxi] https://www.gov.uk/government/publications/early-access-to-medicines-scheme-eams-scientific-opinion-pembrolizumab-mk-3475
[xxii] http://www.fda.gov/Drugs/InformationOnDrugs/ApprovedDrugs/ucm427807.htm
[xxiii] http://www.oasisofhope.com/
[xxiv] Laetrile: The political success of a scientific failure. Consumer Reports 42:444-447, 1977. http://www.cancertreatmentwatch.org/alt/laetrile1.shtml

[xxv] http://www.theguardian.com/society/2005/may/21/cancercare.internationalnews; http://www.aljazeera.com/programmes/peopleandpower/2012/01/201211115241516455 8.html

[xxvi] http://whatstheharm.net/alternativemedicine.html
[xxvii] http://www.cancer.org/treatment/treatmentsandsideeffects/complementaryandalternativemedicine/manualhealingandphysicaltouch/cancer-salves
[xxviii] https://www.westminster.gov.uk/trading-standards-cancer-cure-claims-prosecuted