



MAKING SENSE OF CANCER:

A JOURNALIST'S GUIDE

ANNA WAGSTAFF WITH THE ESO MEDIA TEAM



Acknowledgements

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Finally, it is a pleasure to acknowledge the efforts of the many journalists across Europe who remain committed to providing accurate, incisive, evidenced-based reporting at a time when the profession is facing immense pressures. Some of these journalists have been recognised over past years with Best Cancer Reporter Awards, and links to many of their stories are given throughout the Guide.

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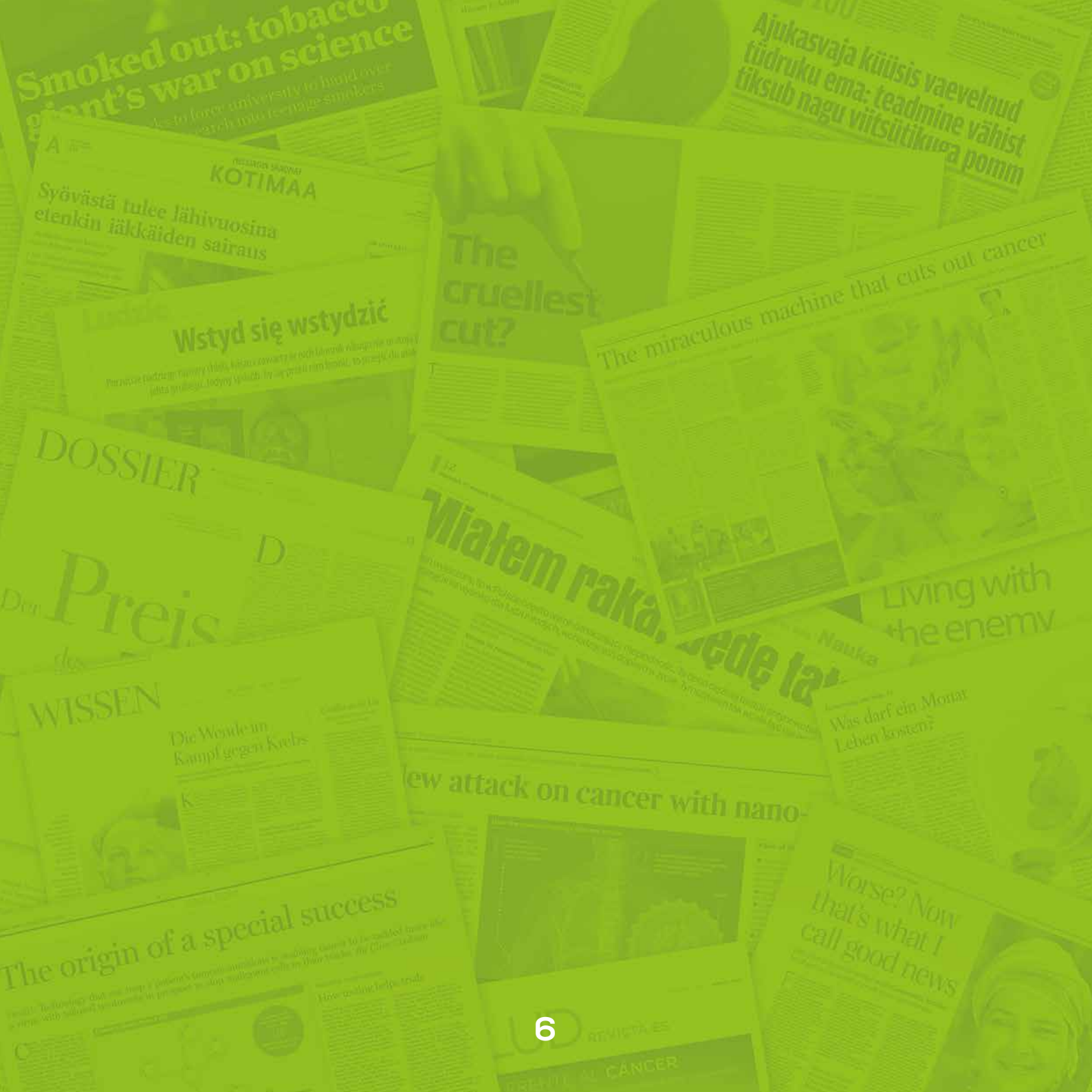
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Preface

Whether the angle is human interest, health, lifestyle, science, medicine, socio-economics, policy or politics, cancer is a topic that offers endless opportunities for rich and varied journalism.

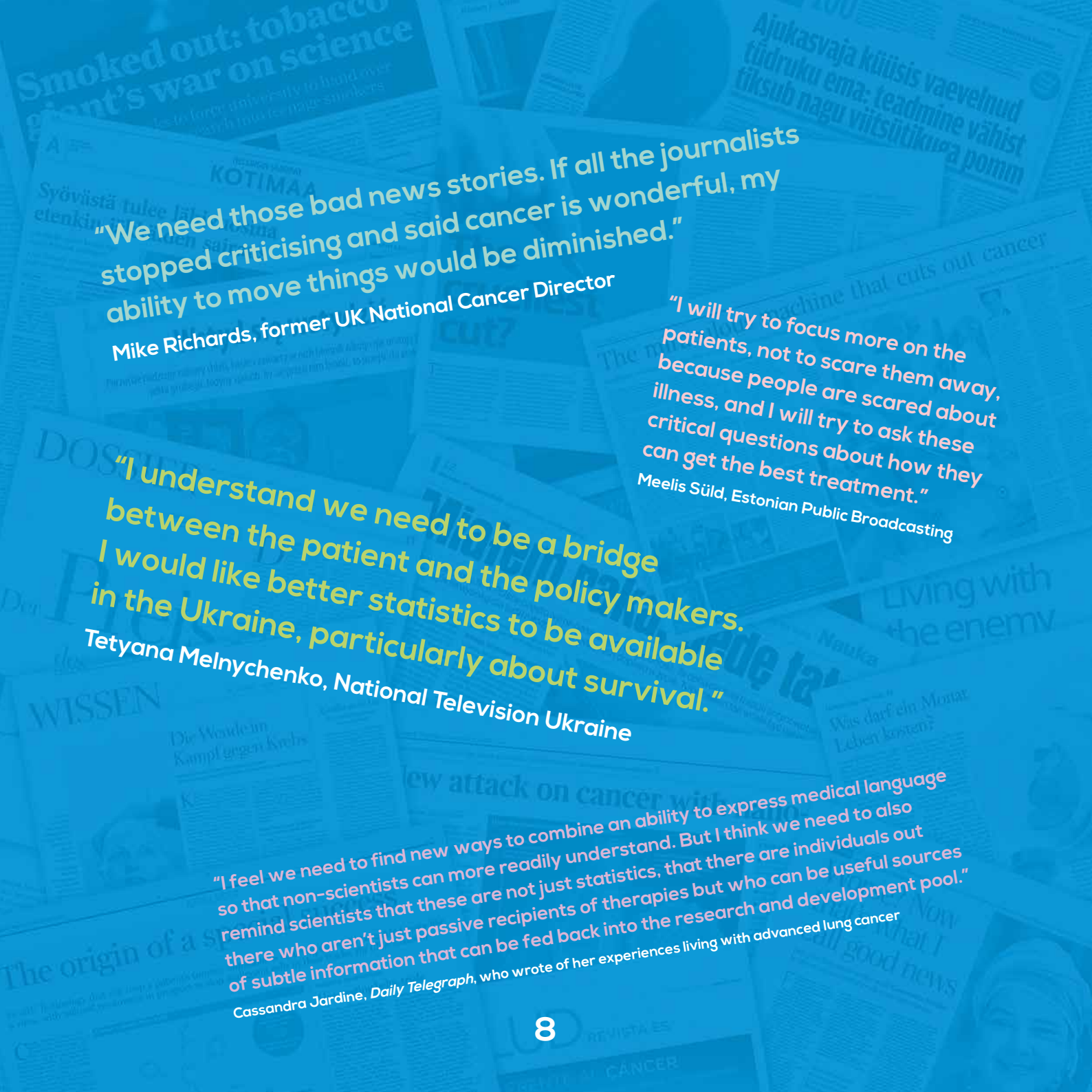
And rich and varied journalism is what is needed to give a voice to people affected by cancer and promote informed discussion about how to tackle the disease and support those who have it.

With the rate of new cases rising, the cost of treatment escalating, and people living longer with cancer than ever before, the need for accurate, incisive, and critical coverage has never been greater.

However, covering cancer effectively is a challenge because the disease and its treatment are complex, it is hard to get across concepts of risk and uncertainty when the subject carries such a burden of fear, and it is difficult to obtain accurate information about the quality and effectiveness of cancer services. The dominant role played by ideology, rather than evidence, in discussions about health policy does not make the journalist's task any easier – but it may make it more important.

This Guide to making sense of cancer was developed to help and encourage journalists to engage with this issue and play a part in helping improve the way we deal with the threat and reality of cancer as individuals and societies. It offers an overview of the key issues, with suggestions of important angles to explore, and tips for sources of information or comment. It is aimed principally at a European audience. While the examples quoted come mainly from the UK media, the Guide draws on training sessions done with broadcast, print and online journalists from all over Europe.

This Journalist's Guide arises from the EPAAC Joint Action, which has received funding from the European Union in the framework of the Health Programme.



"We need those bad news stories. If all the journalists stopped criticising and said cancer is wonderful, my ability to move things would be diminished."

Mike Richards, former UK National Cancer Director

"I will try to focus more on the patients, not to scare them away, because people are scared about illness, and I will try to ask these critical questions about how they can get the best treatment."

Meelis Süld, Estonian Public Broadcasting

"I understand we need to be a bridge between the patient and the policy makers. I would like better statistics to be available in the Ukraine, particularly about survival."

Tetyana Melnychenko, National Television Ukraine

"I feel we need to find new ways to combine an ability to express medical language so that non-scientists can more readily understand. But I think we need to also remind scientists that these are not just statistics, that there are individuals out there who aren't just passive recipients of therapies but who can be useful sources of subtle information that can be fed back into the research and development pool."

Cassandra Jardine, Daily Telegraph, who wrote of her experiences living with advanced lung cancer

Making sense of cancer: the Guide

Every country and every culture has its own version of "the C-word" – ways of referring to a disease that commands so much fear that it cannot be named.

Cancer is not the only disease that can be life threatening. But people fear it because they don't understand it, and they don't know how to protect themselves against it.

It is a very common disease. For journalists working in Europe, more than one in three of your audience will develop cancer at some point in their lives.

The number of new cases is still rising in Europe, more people are living longer after being diagnosed with cancer, the cost of cancer treatments is rising steeply, and public spending cuts are putting pressure on health budgets. Helping your audience make sense of cancer has never been more important:

- **It can help them make informed decisions** on matters affecting their risk of getting the disease or surviving it with a good quality of life.

- **It can engage them in debates** about the quality of and access to services, from prevention and early detection to the care and support of people diagnosed with cancer.

- **It can give a voice to people living with cancer** or whose lives have been touched by cancer, ensuring their experiences are represented in those debates, and challenging the discrimination and stigma that can blight lives as much as the cancer itself.

This Guide aims to help journalists understand cancer and offer some tips on how to handle cancer stories in a way that enables your audience to make sense of the information, rather than increasing their confusion.

It is divided into six modules:

1. What is cancer? Making sense of the disease
2. What gives you cancer? Making sense of risk factors
3. What can be done about it? A critical look at cancer control policies – with separate sections on Preven-

tion, Early detection, and Treatment, care and support

4. Measuring the size of the problem and monitoring progress
5. New treatments and discoveries: understanding, evaluating and reporting on the evidence
6. Reporting on complementary or alternative therapies: a test of responsible journalism

A detailed contents page should make it possible to pick out the sections of relevance to any given story. A list of useful resources can be found at the back of the guide.

"Key Issues" and "How do I cover this?" sections

This guide is for working journalists, who may not be very familiar with writing about cancer, and may be working under pressure. For ease of use, colours have been added to the text to highlight **"Key issues"** (text in blue) – subjects that are of particular interest to patients, the public and society – and **"How do I cover this?"** (text in red) – sections that suggest ways of covering the topic.



THE HALLMARKS OF CANCER

The 'hallmarks' of cancer is a term coined by Douglas Hanahan and Robert Weinberg to designate the 'acquired functional capabilities' of cancer cells, which they first characterised in 2000 (*Cell*100:57–70) and later updated in 2011 (*Cell*144:646–674)

Adapted from D Hanahan and RA Weinberg (2011)

Hallmarks of Cancer, the next generation

Cell 144:646–674

Courtesy of D Hanahan and RA Weinberg

What is cancer? Making sense of the disease

Understanding some basic points about cancer biology is important whether you are covering the disease from a scientific, personal, health, or policy perspective.

When cells go rogue

Cancer happens when some of the body's cells mutate in a way that makes them stop following the rules that normally govern their behaviour:

- They start proliferating out of control.
- They become "immortal" – immune to the mechanisms that would normally kill off damaged and old cells.
- They detach from their normal site and spread around the body, where they seed new cancers (metastases), they invade normal tissue, turning healthy parts of the body cancerous.
- As cancers develop they gather an increasing number of mutations, so the cells in the metastases can dif-

fer markedly from those in the "primary" tumour, and there can also be wide variation between cells that are part of the primary itself.

Classifying cancers: what type, how aggressive, how advanced?

One of the big challenges for journalists writing about "cancer" is that cancer is not one disease, but more than 200, and the number is growing as we learn more about the biology of different cancers. "Complex" is a word that tends to crop up a lot.

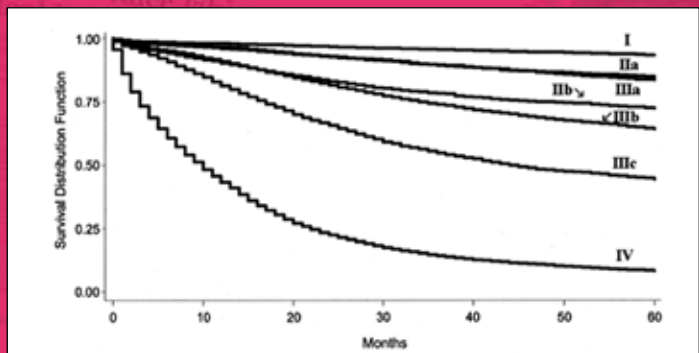
Science and medicine have many words for cancer. These include: "neoplasms" and "neoplasia" (from the Greek words meaning "new" and "formation"), "tumours" (usually "solid tumour", meaning a hard mass) and "malignancy". Because most tumours are not cancerous (but can still present a major hazard to health as they grow and disrupt surrounding tissue) it is best not to refer to a cancer simply

as a "tumour" without making it clear that it is a "malignant tumour" or "cancerous tumour".

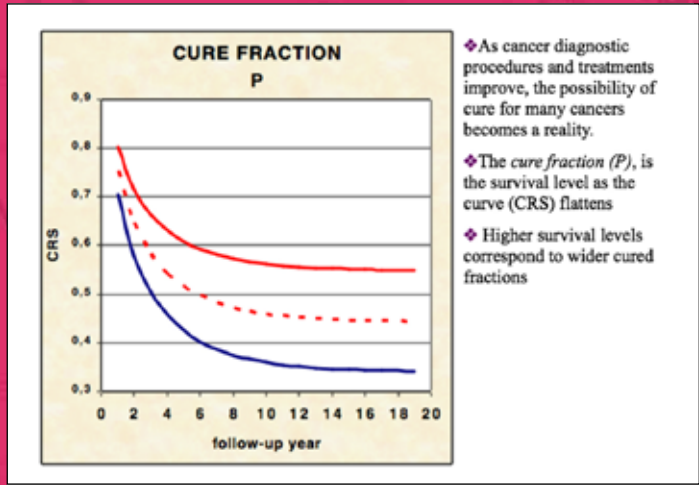
Some cancers are **named** from the tissue from which they are derived, such as lymphomas which come from lymph tissue, or from the type of cell they are composed of, such as astrocytoma, which originates in star-shaped brain cells called astrocytes.

Cancers are **classified** according to the type of tissue where they originate (histology), where in the body they are located – lung, breast, colon etc – and increasingly by their molecular subtype, which refers to gene mutations that drive the cancer or possibly render the cancer resistant to certain treatments.

They are **graded** from 1 to 4, based on the appearance of the cells and how different they are from normal tissue. "Poorly differentiated cells" bear a low re-



JB O'Connell et al, (2004) Colon Cancer Survival Rates With the New American Joint Committee on Cancer Sixth Edition Staging *JNCI* 96:1420–25, by permission of Oxford University Press



Courtesy of Silvia Fracisci, Istituto Superiori di Sanità, Rome

Prognosis depends heavily on how early the cancer is detected

This graph shows survival of people diagnosed with colon cancer according to the stage of the cancer. Five years (60 months) after diagnosis, fewer than 1 in 10 people diagnosed at stage 1 had died from the cancer, while fewer than 1 in 10 diagnosed at stage 4 had survived.

Can you talk about cancer being cured?

Doctors tend to talk about patients being “cancer free” or “in remission” rather than using the term “cured”. They talk about treatments as “curative” rather than cures, because the hope and intention is to cure, but there are never any guarantees, and cancers can return even 20 years after apparently successful treatment. But the concept of ‘cure’ is meaningful at a population level and with hindsight. Epidemiologists can model the fraction of patients diagnosed at a specific time point who can be deemed to have been cured (P), based on the proportion who show no extra risk of death with respect to a comparable group in the general population (statistical definition of cure).

semblance to their tissue of origin, which indicates a more aggressive cancer.

Cancers are **staged** according to how far they have developed and spread. The way this is done differs between cancers, but there are generally five stages. Stage 0 is a very early cancer that has not yet invaded other tissue, and stage 4 is an advanced cancer that has spread around the body. In between, stage 1 is usually a cancer limited to the organ where it has developed, stage 2 is a cancer that has invaded the adjacent lymph nodes, and stage 3 is a “locally advanced cancer”, that has spread to nearby tissue or lymph nodes.

All of this information contributes to determining the **prognosis** of a given cancer and choosing the most appropriate treatment.

Cancers that are diagnosed at a very early stage are generally easier to treat and have a very low risk of recurring, particularly if they are low grade, or “indolent”. Once solid tumours have already spread around the body, they cannot be cured, but they can often be held at bay, sometimes for many years.

Living and coping with the risk

Most cancer diagnoses fall somewhere in between these two extremes, and the risk of recurrence and spread varies accordingly. People diagnosed with cancer have to find ways of living with the uncertainty of this risk. They may also need to get a good sense of the implications of this risk in order, for instance, to make good decisions about treatment options.

The widespread adoption of breast conserving surgery for low-grade early breast cancers, for instance, required a development in public attitudes, to accept that not all cancers need to have every possible type of treatment to be used against them, no matter how damaging. Patient-led pressure was also needed to convince reluctant surgeons to change their ways.

The same sort of public discussion is now beginning to take place, for instance, about the use of active surveillance rather than interventional treatment for some prostate cancers, or dealing with ductal carcinoma in situ – a precursor of breast cancer often picked up in screening, which appears often to resolve itself without intervention.

Making sense of the disease

Writing about cancer in a way that helps people develop a more nuanced understanding that some cancers pose a far greater threat than others can:

- *Help reduce people’s anxiety about finding they may have the disease*
- *Help reduce the stigma attached to people who do have cancer*
- *Encourage people to be more aware of early signs and symptoms, and less afraid to go to a doctor if they are worried*
- *Help mediate a discussion between the health professionals and the public they serve about a more risk-sensitive approach to treatment.*



What gives you cancer?

Making sense of risk factors

The great majority of cancers arise from an accumulation of harmful mutations caused by a variety of risk factors – and lack of preventive factors.

Judging by media reports it can often seem as if almost everything has the potential to either cause or prevent cancer – sometimes both.

This may not be so far from the truth. However, there are only a limited number of factors that present a meaningful threat to most people at levels of exposure they are likely to be exposed to.

The International Agency for Cancer Research (IARC), part of the World Health Organisation, is responsible for researching and publishing evidence about things that cause cancer. In the past 30 years, the IARC has evaluated more than 900 likely candidates, around 100 of which have been reliably shown to cause cancers in humans, with the rest classified as “probably carcinogenic”, “possibly carcinogenic”, “unclassified” and “probably not carcinogenic”.

The main risk factors

Factors known to pose a cancer risk include “external” carcinogens, such as:

- **Chemicals in tobacco** (the single biggest cause of cancer), and in other products such as alcohol, and certain industrial, agricultural or even household agents.
- **Ionising radiation** from the sun or other sources of radiation, such as naturally occurring radon or radiotherapy.
- **Infections** such as hepatitis, which can cause liver cancer, or the HPV virus, which can cause cervical and throat cancer.

Certain personal and lifestyle factors are also associated with cancer risk:

- **Genetic inheritance** – a history of two or more close blood relatives with cancer indicates a heightened genetic risk for certain cancers, particularly if the cancers were more aggressive, struck at an unusually early age, and belong to groups of

cancers known to be linked to a common genetic mutation. The best known inherited harmful mutations are on the BRCA gene.

- **Hormonal processes** – age of first childbirth, breastfeeding, age of starting/ending menstruation, all impact on the risk of breast and some other cancers, as does hormone replacement therapy and some contraceptive pills.
- **Being overweight**
- **Lack of exercise**
- **Poor diet** – evidence shows that high levels of red meat and processed food, and low levels of fruit, vegetables and pulses raise the risk of cancer.
- **Age** – cancer is more common in old age; the older you are, the more time you have had to accumulate DNA damage.

Details about which factors are important for which common cancers can be found on the World Cancer Research Fund website (www.wcrf-uk.org), where you can also find full references to the scientific and epidemiologic evidence.



The risk of developing cancer depends heavily on individual risk factors. It is misleading to present statistics about the average – or ‘population’ – risk of developing a particular cancer without making clear to your audience how that average might apply to them



Reliable information about risk factors can also be found on the websites of major national cancer organisations such as:

- Cancer Research UK – www.cancerresearchuk.org
- Deutsche Krebshilfe – www.krebshilfe.de/
- Ligue contre le cancer – www.ligue-cancer.net

Advice on lowering risk

Evidence shows that more than one-third of cancers common in developed countries could be prevented if exposure to risk factors were reduced to optimal levels.

The advice given by the World Cancer Research Fund is:

- Be as lean as possible without becoming underweight.
- Be active for at least 30 minutes every day.
- Avoid sugary drinks. Limit consumption of energy-dense foods (particularly processed foods high in added sugar, or low in fibre, or high in fat).
- Eat more of a variety of vegetables, fruits, wholegrains, and pulses
- Limit consumption of red meats (such as beef, pork and lamb) and avoid processed meats.
- If consumed at all, limit alcoholic

drinks to two a day for men and one for women.

- Limit consumption of salty foods and foods processed with salt (sodium).
- Don't use supplements to protect against cancer.
- For mothers: it's best for mothers to breastfeed exclusively for up to six months.
- For cancer survivors: after treatment, cancer survivors should follow the Recommendations for Cancer Prevention (see www.wcrfuk.org).

Making sense of risk statistics

Writing well about risk helps people interpret what the story means to them in the context of their own personal risk profile, so they can make informed choices about how to manage their overall cancer risk, for instance by taking steps to lower their exposure to risk factors, and/or increase their chances of spotting it in time if cancer does develop.

Population risk or individual risk?

Websites such as www.cancerresearchuk.org or www.cancer.org provide tables showing the risk for males and females of developing different types of cancer at some point in their lives. For instance for a female, the risk of getting breast cancer at some point in life is given by Cancer Research UK

as 12.9%, or roughly 1 in 8 ($100 \div 12.9 = 7.75$); for a male the risk of getting colorectal cancer is 7.18% or 1 in 14.

These figures are accurate as a population average, but they cannot be applied to individuals, because risk varies greatly from person to person, according to individual risk factors. The average (UK) population risk of getting lung cancer is 5.77% for a woman and 7.63% for a man, but no one ever cites these figures because risk levels vary so greatly according to smoking history. The same principle applies to the risk for all cancers. The genetic, environmental, infectious, lifestyle and metabolic/hormonal risk factors listed above all contribute to an individual's personal risk, with their relative importance varying according to the cancer in question.

Age: The biggest risk factor

Age is the biggest single risk factor for cancer in general. This means that, for most types of cancer, the risk of being diagnosed before the age of 50 is well below the population average, whereas the risk of being diagnosed above the age of 65 is above average. Figures for the UK show that fewer than 1 in 1900 women aged 30 or under will have been diagnosed with breast cancer – by 85 years it is around 1 in 8.

Women need access to good information about the pros and cons of different options for contraception, so they can choose the right option for them. This article, however, was both misleading and wildly inaccurate (see Example)



Be clear about the difference between population risk and individual risk so your audience can understand what the story means for them. When writing stories about a particular risk factor for particular types of cancer, where possible, provide information about who is at highest risk. Ask for expert comment from cancer researchers, epidemiologists, clinicians, cancer NGOs and public health agencies.

Failing that, information about risk factors for the most common cancers can be found on the websites of Cancer Research UK (www.cancerresearchuk.org), Macmillan Cancer Support (www.macmillan.org.uk), the US National Cancer Institute (www.cancer.gov) and the American Cancer Society (www.cancer.org).

Lifetime risk or instantaneous risk?

Stories about risk factors, such as this example of taking hormonal contraceptive pills, often compare cancer incidence between groups of people with different levels of exposure, which gives a snap shot of differences in risk levels (relative risk), say, after 5 years of use. This relative risk applies at the time of measurement, and cannot be extrapolated to differences in lifetime risks between the groups being compared..

Current or lifetime risk?

Example: Cervical cancer risk and the contraceptive pill

On 9 November 2007 the *Daily Mail*, a leading UK paper, published a story under the headline "Pill can double risk of cancer". The story related to a study in the *Lancet* (370:1609–21) looking at the association between cervical cancer and patterns of oral contraceptive use. The study had indeed found that current users who had been on the contraceptive pill for more than 10 years had twice the risk of being diagnosed with cervical cancer compared with women who had never been on the pill.

However, the article then went on to draw conclusions about the impact on lifetime risk of getting cervical cancer:

"Generally, women are thought to have a one in 80 chance of developing cancer of the cervix - the neck of the womb - during their lifetime" [This figure is very high, so presumably included high-risk pre-cancers.] "[Therefore] Women who have been on the Pill for 10 years or more have twice the risk of developing cervical cancer, with odds of 1 in 40."

This is untrue. The doubled risk for long-term users of the pill does not apply over

the woman's lifetime. In fact, the *Lancet* study had been designed with a key aim of exploring how long the heightened risk of cervical cancer continued after women stopped taking the pill, and the published results showed that the heightened risk dropped off quite quickly:

"The risk declined after use ceased, and by 10 or more years had returned to that of never users."

Though the *Lancet* study gave no figures for lifetime risk, it did give figures for risk of being diagnosed before the age of 50:

"10 years' use of oral contraceptives from around age 20 to 30 years is estimated to increase the cumulative incidence of invasive cervical cancer by age 50 ... from 3.8 to 4.5 per 1000 in more developed countries."

This increase of 0.7 per 1000 represents a difference of 18.4% by age 50. As the impact of having been on the pill was known to fall away, that difference would decrease further with time. This is a far cry from the "doubling" of lifetime risk that had been reported in the *Daily Mail*.



Be clear about the difference between current risk and lifetime risk to avoid making the same error as the Daily Mail.

Risk versus benefits

Some of the biggest cancer risk stories in recent years have focused on things that people choose to expose themselves to for the benefits they bring. The story about the link between certain contraceptive pills and cervical cancer is one example. The story about the heightened risk of breast and ovarian cancer from hormone replacement therapy (HRT, below) is another. Covering stories like these requires putting the information about increased risk into the correct overall risk-benefit picture.

Be clear about how risks and benefits balance out for different groups of people, or you could end up misleading your audience about what is in their best interests. Always suggest that people should see their doctor if they are worried and want to understand more about what the story means for them.

Relative risk or excess risk?

When writing stories about things that increase or decrease the risk of getting certain cancers, it is good practice to focus on “excess” or “attributable” risk rather than relative risk.

Pitfalls when covering the balance between risk and benefit
Example: HRT and breast and ovarian cancer

The media coverage in 2002 of the findings of the Women’s Health Initiative study on the risks and benefits of hormone replacement therapy in older women provides an example of what can happen when the risk-benefit picture is inaccurately presented.

The study had been designed to look at the risk-benefit of long-term use of HRT therapy in women up to the age of 79 – well beyond the age of menopause. But, as a review published 10 years later, in a special issue of the peer-reviewed journal *Climacteric* (2012; 15:205–293) pointed out, the media coverage generalised the findings to younger age groups, who were at lower risk of breast cancer because of their younger age, and who stood to benefit more from HRT because they were closer to the age of menopause.

The result was a precipitate and prolonged drop in the use of HRT among women who could have benefited from the therapy, with an estimated drop in use by women aged 40–59 from around 30% in 2000 to 8% in

2011. In the 2012 *Climacteric* special issue, the International Menopause Society talked about how the coverage at the time had engendered “*excessive conservatism*” that “*has disadvantaged nearly a decade of women who may have unnecessarily suffered severe menopausal symptoms and who may have missed the potential therapeutic window to reduce their future cardiovascular, fracture and dementia risk.*” Their assessment was supported by mainstream medical opinion, which continues to support the use of HRT for women suffering serious menopausal symptoms.

A review of the media coverage of the WHI study, published in the *Climacteric* special issue under the title “Shock, terror and controversy: how the media reacted to the Women’s Health Initiative”, concludes that: “*the evidence suggests that more emphasis was placed on risk than on benefit, but that those risks were inadequately quantified.*” (*Climacteric* 2012; 15:275–280).

Los Angeles Times

CT scans in childhood can triple brain tumor, leukemia risk: study

June 06, 2012 | By Thomas H. Maugh II

As few as two CT scans of the head in childhood can triple the risk of developing brain tumors, while five to 10 such scans can triple the risk of leukemia, British researchers reported Wednesday. The absolute risk of developing the cancers remains small, but the study illuminates the dangers of unnecessary use of X-ray imaging in diagnosis.

The development of CT (computed tomography) scanning was one of the major developments of 20th century medicine because it allowed physicians to look inside the body more accurately than a conventional X-ray. But it also provides a much higher dose of radiation than a conventional X-ray. Based on extrapolations of data from survivors of the atomic bomb attacks in Japan at the end of World War II, some scientists have warned that such scans could increase the risk of cancer, especially in children, whose growing bodies are more sensitive to the effects of radiation. Others, however, have dismissed this as speculation because of the differences between bomb radiation and CT scans. In particular, a bomb affects the whole body, while a CT scan is focused on a small area. But there have been no previous epidemiological studies examining the risks.

A team headed by epidemiologists Mark S. Pearce and Dr. Alan W. Craft of Newcastle University studied nearly 186,000 children who underwent at least one CT scan between 1985 and 2002 in the radiology departments of 70% of the United Kingdom's hospitals. They estimated the dose of radiation absorbed in each scan, then linked the data to cancer incidence and mortality reports in the UK National Health Service Registry and calculated excess incidence of brain tumors and leukemia.

The team reported Wednesday in the British journal *Lancet* that 74 of 176,604 patients were diagnosed with leukemia and 133 of 176,604 were diagnosed with brain cancer. They concluded that two to three CT scans of the head among children under the age of 15 (a cumulative dose of about 100 milligray of radiation) tripled the risk of brain tumors, while five children under the age of 15 (a cumulative dose of about 500 milligray) tripled the risk of leukemia. The researchers also found that a single CT scan of the head in children under the age of 15 (a cumulative dose of about 100 milligray) tripled the risk of leukemia. The researchers also found that a single CT scan of the head in children under the age of 15 (a cumulative dose of about 100 milligray) tripled the risk of leukemia.

Is this really news?

If this story has any news value at all, it is probably because many people might be pleasantly surprised at how little cancer risk is incurred when children undergo CT scans of the head – 1 additional case of leukaemia per 10,000 children exposed to radiation from 1 CT scan, over the following 10 years, with even lower excess risk for brain tumours. That is not the impression given by the headline, however, which presents a highly misleading impresson by using relative risk figures

- **Relative risk** shows how much a risk is increased in terms of its original size, e.g. doubled. But it gives no information about whether the risk is major or negligible.
- **Excess risk**, in contrast, shows the difference exposure to a particular risk factor makes to a person's overall (or "absolute") risk of 'getting it'. If the absolute risk increases from 2 in 1000 to 3 in a thousand, the risk factor in question has an excess or attributable risk of 1 in 1000 (of every 1000 people exposed, 1 additional person will 'get it').

Headlines will always use the relative risk figure, because it sounds more dramatic.

People will tend to respond with alarm to the words "cancer risk" and "doubled", regardless of whether the cancer in the story is common or very rare. The very fact that it is presented as a news story implies it must be important – the bigger the typesize or the higher up the running order, the more important it must be.

When covering stories about risk factors, give prominence to figures showing excess risk, which provide a clear picture of how the risk factor impacts on overall risk levels. Avoid leading with the relative

Excess risk is more informative than relative risk Example: CT scans in childhood

On 6 June 2012 the *Los Angeles Times* ran a story under the headline "*CT scans in childhood can triple brain tumor, leukemia risk*" (<http://articles.latimes.com/2012/jun/06/science/la-sci-sn-ct-cancers-20120606>). The opening paragraph stated:

"As few as two CT scans of the head in childhood can triple the risk of developing brain tumors, while five to 10 such scans can triple the risk of leukemia, British researchers reported Wednesday."

Reading further down the story, it becomes clear that, as brain tumours and leukaemia are both rare events, even when the risk is tripled the threat re-

mains low. Quoting from the original report, which was published in the *Lancet*, the article said:

"For every 10,000 people younger than 20 who receive 10 milligray from a CT scan, the authors said, physicians can expect one excess case of leukemia; one excess brain tumor would be expected among every 30,000 people who received the same dose."

In other words, while this story may contain important information for clinicians, the impact is so small that it is hard to argue that it really counts as news. Focusing on the relative risk figure misleads people into thinking that it does.

risk figure, which gives an exaggerated impression of the true impact.

Research shows that the most effective risk communication uses a combination of excess risk, relative risk, personal risk factors and prevention advice. Using graphics also helps people understand risk statistics.

Evaluating stories about cancer risk

When good quality research shows an impact on cancer risk, particularly relating to something where exposure is frequent and widespread, such as the examples of HRT, the contraceptive pill, or mobile phones, it is clearly a news story of public interest, even if

Pictograms like this one are very effective at conveying information about excess risk, i.e. how many people out of every 100 (or 1000, or 10,000) would be expected to develop cancer under a variety of different scenarios





Vested interests

Stories like this one seem to confirm many people's worst fears that cancer is caused by all manner of seemingly innocuous things. Not only do they cause unnecessary anxiety, they confuse the important message about what the main risk factors for cancer really are.

This story was funded by a grant supporting soy farmers, and provided no evidence to indicate that anyone has ever suffered any ill-effects from these candles, let alone contracted cancer

the findings of the study are not particularly dramatic.

However, many stories that get picked up by all sections of the media about things that may raise or lower a person's risk of developing cancer are speculative at best, offering no evidence of any observable impact on cancer rates nor any compelling scientific reason to lend credibility to the story.

Be clear about the credibility of the story, about where it comes from, any vested interests, how strong the evidence is, and whether it shows what the researchers claim it shows.

Where do the stories originate?

The press releases that trigger these stories tend to be strong on headlines but flimsy on scientific content. Often they relate to research that is so speculative that it is abandoned before ever finding its way into the formal academic peer-reviewed literature. The researchers generating these press releases, however, benefit from getting into print because it shows public impact, which is good for their careers and grants. There is also a proven causal relationship between research being mentioned in mass media and the number of times the paper is cited

Public interest, or vested interests?

Example: The cancerous candles

On 20 August 2009, a story about candles was picked up by media in many different countries. In the UK, the *Daily Telegraph* reported that:

"Researchers have found that the fumes from paraffin – the most common and cheapest form of candlewax – can be poisonous and even cause cancer."

The same study also reported that no such dangers were posed by burning candles made of beeswax or soy.

The story was based on a brief press release from the researchers about an Abstract they had published at the American Chemical Society conference.

Not reported was the declaration of interest that had been published with the Abstract – but did not feature in the press release – that showed the study had been funded by a US Department of Agriculture grant entitled, "Soybean Candles for a Healthy Life and Well Being". No data were provided to back up their conclusions.

in the academic literature, which is very important to researchers.

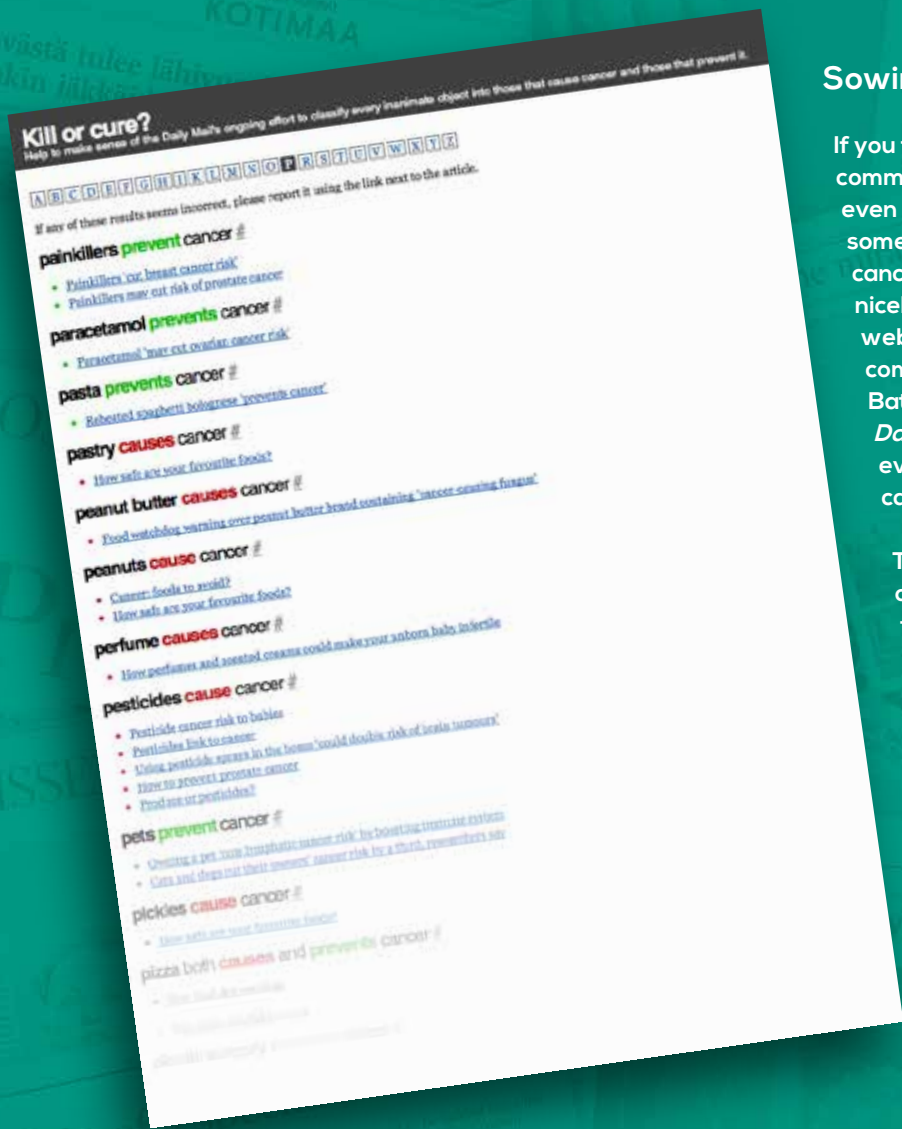
Vested interests, for instance in the food, nutrition, or health and fitness markets, are also frequently behind these stories, though their involvement may be hidden.

To sell their story the press releases often offer a quirky or newsy angle. For instance, research suggesting chocolate can reduce the risk of cancer may be press released just before Easter. This spin can be quite effective, to the ex-

tent that newsrooms may decide to run a story – "Good news, Easter Eggs are Healthy" – even if they have doubts that the report has any real substance.

Adopting a critical approach, armed with some knowledge of the basic principles, is the best key to guarding against this. If you can, argue against running stories that are essentially baseless.

Many of these stories may be seen as light-hearted "infotainment", but they can do real damage because they



Sowing confusion

If you try hard enough, almost every commonly encountered substance, or even behaviour, can be shown to link in some way to a raised or lowered risk of cancer – frequently both – as has been so nicely demonstrated by this “Kill or Cure” website (<http://kill-or-cure.herokuapp.com/>), which was set up by blogger Paul Battley to “help to make sense of the *Daily Mail*’s ongoing effort to classify every inanimate object into those that cause cancer and those that prevent it.”

The website presents an A–Z listing of every cancer threat or preventive that has featured in the pages the *Daily Mail*, parts of which have now been put to music (www.youtube.com/watch?v=UPEzM2oV-PY).

Though there may be more than a grain of truth behind most of these stories, the net effect is to make people more rather than less confused about the main cancer risks they face and how to mitigate them

add to public confusion about what the real threats, and preventives, are. The sheer quantity of stories, the tendency to overstate their significance, and the failure to put them in the wider context of what is known with some certainty about cancer risk and protection factors can give the impression that we either don’t really know what causes or protects against cancer, or that it is too complicated to make sense of.

Put the story in context

When covering stories speculating about cancer risk, put it into context of what is known with certainty.

A good example is this expert comment added at the end of the *Daily Telegraph* “romantic candles” story, which quoted a spokesperson for Cancer Research UK saying:

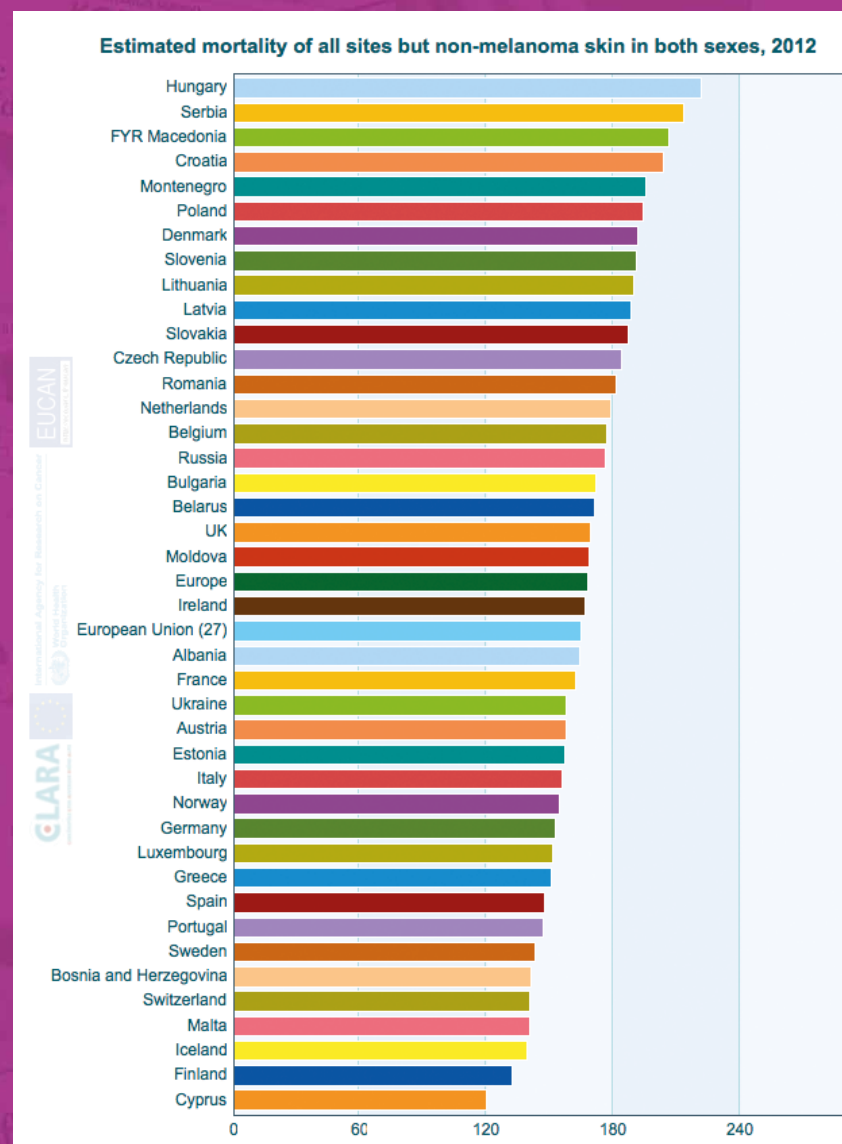
“There is no direct evidence that every-day use of candles can affect our risk of developing cancer. In terms of cancer, a far more significant type of

Behind the Headlines: a credibility checklist

Behind the Headlines – a service run by the UK NHS (www.nhs.uk/news/Pages/NewsIndex.aspx) – provides “an unbiased and evidence-based analysis of health stories that make the news” on a daily basis. It is a service to the public, helping them make sense of stories that have already been published, rather than a service that journalists can turn to for advice on particular stories that have just hit the news desks.. However, it does offer the following helpful advice on how to analyse the credibility of scientific reports:

- Does the article support its claims with scientific research?
- Is the article based on a conference abstract [as opposed to a peer-reviewed report]?
- Was the research in humans?
- How many people did the research study include?
- Did the study have a control group?
- Did the study actually assess what’s in the headline?
- Who paid for and conducted the study?

indoor air pollution is second-hand cigarette smoke. When talking about cancer risk, it’s important to focus on things we have hard evidence for. Life-style factors such as smoking, alcohol, obesity, unhealthy diets, inactivity and heavy sun exposure account for a much larger proportion of cancers.”



Cancer is a bigger killer in some countries than in others

Reducing the number of new cases, diagnosing cancers earlier, and treating them more effectively, all contribute to lowering mortality from cancer

What can be done about it? A critical look at cancer control policies

Despite many decades of sustained research, cancer remains the second or even first cause of premature death across Europe. However, a person's chances of dying of cancer are markedly lower in some countries than in others, and there are also marked disparities between countries in the chances of surviving for five years after being diagnosed with cancer.

Cancer control

The term "cancer control" refers to policies that contribute towards minimising death and suffering from cancer.

The key elements of cancer control are:

- **Preventing preventable cancers:** between a third and a half of all cancers could be prevented if exposure to avoidable risk factors was reduced to optimum achievable levels (*British Journal of*

Cancer 2011; 105, S2–S5).

- **Detecting early** any cancers that do develop: stage of diagnosis (see "classifying cancers" (page 11)) is generally the most important factor determining the likelihood of a cure.
- **Diagnosing and treating** cancers as effectively as possible.
- **Caring** for the health, psychosocial and other needs of people with cancer throughout diagnosis, treatment, survivorship and/or end of life.

This means that a very wide range of agencies and professions have a role to play in controlling cancer, including:

- Public and environmental health, health and safety, food standards, education and recreation services, genetic counsellors.
- A variety of people working in medical and allied professions

at primary (GP, pharmacy, community healthcare), secondary (screening, diagnostics) and tertiary (hospital-based specialist) levels, health service managers and administrators and auditors.

- Social services, patient advocacy and citizens'/workers' rights bodies, and other support organisations.
- Universities, research foundations and charities.

In line with EU recommendations, and following the lead of England, France, and Denmark, most European countries have now drawn up cancer plans that are designed to give a joined-up approach to all these aspects of cancer control.

The texts of these national plans are available at www.epaac.eu/national-cancer-plans



Effective cancer control requires joined up action by many players. Ulrich Bahnsen won a Best Cancer Reporter Award for a series of articles he wrote for the leading German paper *Die Zeit*, taking a broad look at what can – and what cannot – be achieved by changing lifestyles, screening and investing in the search for a cure. One of these was republished in translation in *Cancer World* www.cancerworld.org/pdf/4775_pagina_34-39_bestreporter.pdf

Mike Richards, England’s first National Cancer Director, presented a summary of his experiences planning, implementing and evaluating the first two English Cancer Plans at an ESO journalists’ training course, in Rome 2012. His presentation, entitled **How can my country get the best results in Europe?** can be downloaded from the Media Training page of the Cancer World website: www.cancerworld.org/Media/Media_Training.html – scroll down to the end of the Downloads section.

Journalists have an important role to play in helping promote informed public debate about cancer control policies. Important questions to ask include:

- Does cancer control get the resources it deserves given the impact it has on people’s lives and on economic productivity?
- Is there a formalised plan?
- Does it have a protected budget?
- Does it include all aspects of cancer control, including, for instance,

palliative care, psychosocial care, rehabilitation and survivorship?

- What voice do patient advocates have in formulating and evaluating the plan
- Who has responsibility for overall implementation and evaluation?
- Are there explicit published targets and for what indicators?
- How will progress be evaluated and reported?



A platform for debate

Vaccinating girls against strains of the HPV virus that can cause cervical and throat cancer is seen as controversial by some, because HPV is a sexually transmitted disease. By giving a platform to all sides in the argument, the UK media helped the public understand the issues and make up their own minds, leading to uptake rates of around 80% (www.gov.uk/government/publications/hpv-vaccine-uptake-1-september-2012-to-31-may-2013)



Prevention

Investing in prevention makes good sense for a disease that is life-threatening and very costly, both to the individual and to the economy in terms of lost productivity and the cost of treatment and care. Many of the lifestyle factors important for cancer are also important for diabetes, heart and circulatory disease and other serious conditions.

Traditional wisdom has it that prevention will never rate high on political agendas because the immediate impact is not always welcome (eg using taxation to influence spending on tobacco and alcohol), while it can take many years, or even decades for the 'pay off' to be felt in terms of a drop in the number of new cases.

But experience has shown that, given credible information, and space for informed debate, attitudes and behaviours can change significantly over a relatively short period. A positive example is the way attitudes towards tolerating exposure to other people's smoke

have changed in countries that now ban smoking in public places. The media has a key role to play in promoting such informed debate.

The lack of informed debate, on the other hand, can sink a sensible prevention policy. An example was the introduction of the HPV vaccine in Romania, where a failure to challenge historically entrenched public scepticism led initially to hopelessly low uptake rates, even though the country has the highest rates of HPV infection in Europe – with a death rate from cervical cancer that is more than 10 times higher than the best in Europe – and the vaccine was offered for free.

Healthy lifestyles: promoting informed debate

The media does not have a public health promotion remit, and journalists can come to dread the advent of yet another tobacco free week or obesity awareness week, wondering how to find a new angle on an old story.

But while the messages about smoking, diet, alcohol, exercise and weight may sound familiar, the reality is that the public remains deeply confused about risk and prevention factors, and as the previous chapter shows, the media has to bear some responsibility because of the sheer quantity of 'kill or cure' stories it covers, and the failure to put those stories into the context of what is known about the major risk factors.

In addition to being clearer about the information it presents on risk and prevention, the media also has a role reporting from the perspective of their audience. The risk of developing cancer doesn't only vary from person to person, but also from one social group to another. Changing to more healthy behaviours is easier for some sections of the population than others. Eating healthily can be more expensive and take more time than relying on fast food. Getting children involved in physical exercise is easier for those who have access to sports fa-



DAILY EXPRESS
THE WORLD'S GREATEST NEWSPAPER



Whose interests are you serving?

This front page of the *Daily Express* is serving the interests of the makers of a new 'health supplement'. It is betraying its own audience by lending credibility to a piece of advertising that is backed by no credible evidence. By contrast, the series of investigative reports the *Independent* ran on inappropriate and hidden influence exerted by the tobacco industry served the interests of its readers, and earned reporter Steve Connor a Best Cancer Reporter Award (www.cancerworld.org/pdf/2013_pagina_30_34_Best_Reporters_web.pdf)

cilities and clubs. Some people assume greater responsibility for safeguarding their own health than others: women typically take more care than men; teenagers have a greater tendency to regard themselves as invulnerable. These differences raise important questions about how and where prevention policies should be focused.

The media has an important role to play in:

- Raising awareness among all sections of the population about the consequences of exposure to avoidable risk factors, and about how people can protect themselves.
- Exploring attitudes to, and the challenges of, adopting healthier lifestyles among all sections of the population.
- Taking a critical look at prevention policies – who is benefiting, who is missing out?
- Promoting informed debate about the appropriate use of regulation, taxation, education and investment to promote healthy lifestyles.

Vested interests: resisting the spin

The importance of the media as a source of credible, accurate and understandable information is all the greater given the huge investment made by 'cancer causing' industries (including

those involved in tobacco, fast-food and alcohol), not just in advertising to individual consumers but also in trying to muddy the public debate and influence policy making – often in clandestine ways that only ever come to light thanks to investigative journalism.

The nutrition and health supplements industry are another vested interest that often try to market themselves on their impact on preventing cancer. But while strong claims have been made, for instance, for the preventive effect of anti-oxidants or vitamins C or E, research has not found good evidence of such an effect and some studies have found they may in fact increase the risk of certain cancers.

*"Don't use supplements to protect against cancer," is the specific advice of the World Cancer Research Fund (www.wcrf-uk.org) in its "10 ways to prevent cancer". So when the *Daily Express* runs the headline "Wonder pills pack all the goodness you need" (1 July 2011) they are seriously misleading their readers.*

The growing influence of public relations (PR) 'spin' in promoting misleading or exaggerated information from these industries is something that journalists need to guard against.

Getting a comment from an independent expert is always the gold-standard, but may not always be possible due to time constraints. However, all journalists should be able to avoid misleading their audience if they:

- Keep their 'spin sensors' alert
- Treat relative risk figures – eg "double" or "half" – with suspicion (see page 23)
- Use the Behind the Headlines credibility checklist (page 27). If the story is not credible, you may still have to write it, but you can flag up to your audience why there is room for scepticism.

Targeted prevention

Growing knowledge about genetic susceptibility to cancer is opening up new possibilities for tailoring prevention strategies for those believed to be at particularly high risk. However, it also presents individuals with the challenge of how to deal with the new-found knowledge that a heightened risk of cancer may run in their family.

The ability to identify people at high risk also raises policy issues about whether greater priority should be given to researching and testing interventions that could lower the risk of developing cancer in the same way that statins, for



Daily Mail

Articles like this one (1 February 2012) are important in raising awareness about genetic risk, but care should be taken to avoid frightening people into precipitate action that they may later regret. The message to individuals is: seek expert advice if you think you may be at heightened genetic risk. The question to health service administrators and policy makers is: are genetic counselling services in place with the capacity to provide that advice to everyone who may need it?

instance, are used to lower the risk of heart attack and stroke.

Currently preventive medical therapies account for less than 5% of money spent on cancer research, and there are no therapies approved for use in preventing cancers in Europe, though tamoxifen and raloxifene have been approved for this type of use in the US, and are used preventatively “off-label” in some European countries including the UK.

The media has an important role to play in:

- *Giving individuals and families the information and understanding they need to make informed decisions about managing their cancer risk*
- *Promoting discussion about policies for the provision of genetic counselling and testing services; regulation of commercial, direct-to-consumer testing services; and use of preventive medicine, particularly by people at higher risk.*

Celebrity stories such as the decision of film star Angelina Jolie to undergo preventive double mastectomy because of her genetic predisposition to breast cancer can provide a good hook for covering this issue. However, journalists should avoid the pitfall of presenting such a story as an example of what women in her position should do – it is rather an example of the value of understanding your level of risk, so you can seek advice on the best option for managing that risk.

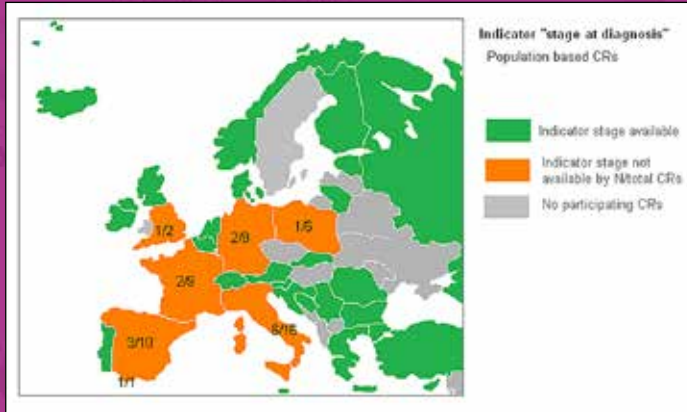
Not all countries collect data about the stage of detection of all cancers

Indicator "stage at diagnosis"
Population based CRs

- Indicator stage available
- Indicator stage not available by Ntctal CRs
- No participating CRs

Country	Indicator stage available	Indicator stage not available by Ntctal CRs (Fraction)	No participating CRs
Iceland	Yes		
Denmark	Yes		
Finland	Yes		
Sweden	Yes		
Norway	Yes		
Poland	Yes		
Czechia	Yes		
Slovakia	Yes		
Hungary	Yes		
Romania	Yes		
Bulgaria	Yes		
Greece	Yes		
Turkey	Yes		
Cyprus	Yes		
Portugal	Yes		
Spain	Yes		
France	Yes		
Belgium	Yes		
Netherlands	Yes		
Germany	Yes		
Austria	Yes		
Switzerland	Yes		
Italy	Yes		
Slovenia	Yes		
Croatia	Yes		
Serbia	Yes		
Bosnia and Herzegovina	Yes		
Montenegro	Yes		
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Ukraine	Yes		
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Ukraine	Yes		
Belarus	Yes		
Latvia	Yes		
Lithuania	Yes		
Malta	Yes		
Malta	Yes		
United Kingdom	Yes		
Ireland	Yes		

Most population-based cancer registries in Europe routinely collect data on stage of diagnosis for some tumour sites, but less than half do so for all tumour sites, and the information from regional registries is not always collated at a national level, according to a Eurochip report on cancer registry indicators published in 2012 (www.tumori.net/eurochip/material/WP5/EUROCHIP3_WP5_Report.pdf)



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Poorer early detection rates are a major contributor to the very poor survival rates in developing countries. Within Europe, they have been found to account in part for the relatively poor survival rates for some cancers, for instance, in Denmark and the UK.

Awareness, attitudes and access

Public/political discussion about early detection tends to focus on cancer screening – which refers to routine checks for cancer conducted in people with no symptoms. However, while the evidence does support screening pro-

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Awareness, attitudes and access

Public/political discussion about early detection tends to focus on cancer screening – which refers to routine checks for cancer conducted in people with no symptoms. However, while the evidence does support screening pro-

grammes for some cancers and some age groups (see below), most cancers are still detected by GPs, or in accident and emergency departments, after they give rise to symptoms.

- Recognising suspicious symptoms early – an issue of education and awareness.

- Recognising suspicious symptoms early – an issue of education and awareness.
- Taking prompt action to get checked out by a medical professional – potential barriers include financial impediments (if GP visits have to be paid for, if you suffer loss of earnings, travel costs), logistical impediments (if no GPs are available at a convenient time or place), and also attitudes (surveys have shown, for instance, that willingness to get concerns checked out by a GP vary according to gender, socio-economic level, and between countries and cultures)
- Getting quick access to the appropriate diagnostic tests and procedures – potential barriers include inappropriate pressure on GPs to act as ‘gate keepers’ to restrict access to over-stretched diagnostic services, or lack of training and guidelines to help them

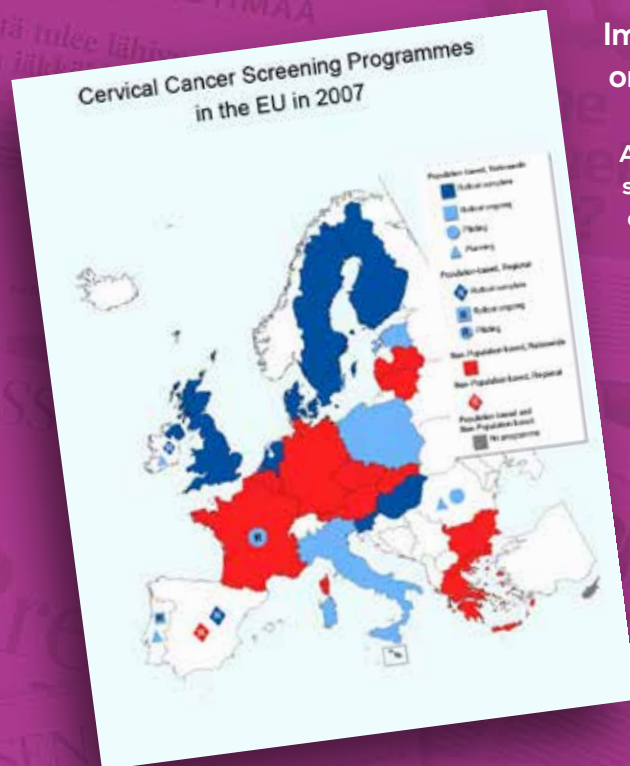
make the often difficult judgements about which symptoms are sufficiently worrying to merit further investigation.

An EU briefing on Primary Healthcare Services compiled by the London School of Economics in 2009 gives very interesting comparative data on the organisation and financing of primary care services across Europe, including data on 'gatekeeping' and payment for services – ec.europa.eu/social/BlobServlet?docId=4739&langId=en (Appendix Tables 1 and 3).

Data on the number of GPs per 100,000 head of population are available from the EUROSTAT database <http://epp.eurostat.ec.europa.eu>

Effective media coverage can contribute to improving early detection rates in a number of ways:

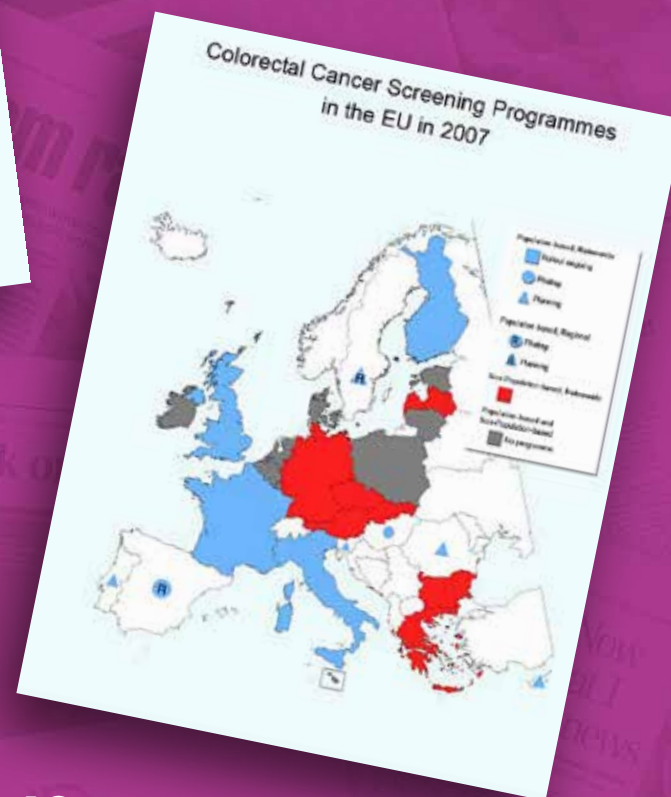
- *The media can, and does, help educate the public about suspicious symptoms to look out for, though inevitably perhaps, attention tends to focus most on cancers with the most active advocacy campaigns, such as breast cancer. By contrast*



Implementation of EU recommendations on cancer screening has been patchy

A 2007 report into the implementation of EU cancer screening recommendations showed a wide variation across Europe. The picture will have changed somewhat since that date, particularly for colorectal cancer screening.

The full report can be found at http://ec.europa.eu/health/ph_determinants/genetics/documents/cancer_screening.pdf



head and neck cancers, for instance, rarely get a mention, despite a far greater public ignorance of their symptoms and the crucial importance of early detection.

- *It has an equally valuable part to play in raising awareness of the benefits of early detection (and the risks of delaying detection), and promoting discussion and reflection about social attitudes with respect to being proactive in safeguarding one's own health.*
- *It can also promote informed public debate about the cost-effectiveness of investing in a primary care service that is accessible, well trained and able to refer patients promptly to further diagnostic tests as appropriate.*

Population screening

Population screening involves checking healthy people on a regular basis for signs that might be suspicious for cancer, and following up with further tests and treatment where necessary.

It plays a role in early detection, but it can only work for cancers that are:

- relatively common;
- generally curable if picked up at an early stage; and
- can be identified by tests that are:
 - affordable

- safe
- acceptable to the population
- reasonably accurate, i.e. don't give too many false-positives (acceptable specificity) and don't give too many false-negatives (acceptable sensitivity).

The EU recommends national screening programmes for cervical, breast and colorectal cancer. http://ec.europa.eu/health/major_chronic_diseases/diseases/cancer/index_en.htm#fragment3

These recommendations are based on a strong body of evidence showing that, when conducted according to the stipulated quality assurance guidelines, and used in appropriate age groups in a way that makes them truly accessible to the population as a whole, these screening programmes make an effective contribution to reducing deaths from cancer.

Opportunistic screening

Screening tests that take place at the suggestion of individual doctors or their patients, outside such national quality controlled programmes, are of questionable value for populations as a whole. Apart from the lack of quality control, inevitably many people who need screening don't get it; and many who do get it are screened more often

than makes sense. This sort of screening is known as 'opportunistic screening'.

Covering screening stories

Journalists are often contacted by advocacy groups and screening services urging them to help raise awareness about the importance of attending screening checks, and they are often happy to oblige. The ready access to willing individuals via such groups who can give poignant stories about 'their' cancer readily appeals to news values, making it relatively easy to write compelling copy reflecting those values in the little time available.

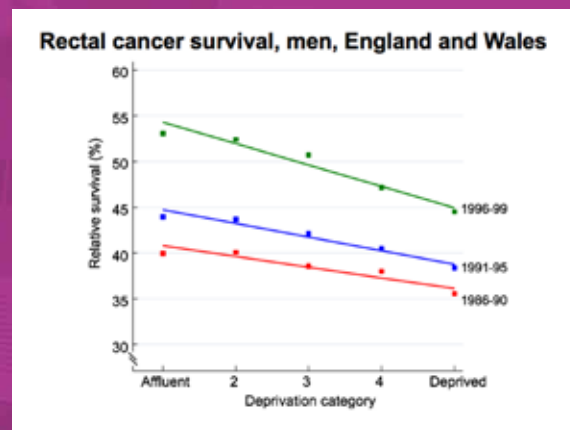
However, as with any story offering information about health interventions, journalists need to ensure they provide accurate information about the pros and cons, and take a critical approach to the services available.

There are downsides to screening (apart from the time, travel, possible cost and discomfort of the procedures), which need to be explained. In addition to clear signs of cancer, they also pick up potentially suspicious signs which can turn out to be of no consequence.

As a result, many healthy people go through great anxiety and further



1999
HELSINGIN SANOMAT
Helsingin Sanomat -lehti



Equal access is an important element of quality in a cancer care system

(Above) Figures from a UK study published in the *British Journal of Cancer* in 2008 (99: S30–S32), covering successive time periods, show that the chances of surviving rectal cancer are markedly higher for men from more affluent backgrounds compared to their more deprived counterparts.

Graph courtesy of Michel Coleman, London School of Hygiene and Tropical Medicine

(Left) Elderly patients can face discrimination because of assumptions made about their ability to tolerate aggressive cancer therapies based on their age rather than their frailty. Päivi Repo won a Best Cancer Reporter Award for addressing this issue in an article for Finland's leading daily paper, *Helsingin Sanomat*, titled "Everyone deserves the best chance to survive", which was republished in translation in *Cancer World* (www.cancerworld.org/pdf/6218_pagina_40-42_bestreporter.pdf)

Treatment care and support

Getting the treatment right the first time is important for achieving the best possible outcome in terms of both survival and quality of life – cancer is harder to treat once it has recurred.

Getting it right first time also makes economic sense because of the very high costs associated with treating and caring for patients with more advanced cancers.

But quality of care is about more than the treatment of the disease. It is about:

- Providing care that corresponds to the needs and priorities of each patient, including supportive/palliative care to help alleviate the symptoms of the disease and the side-effects of the treatment.
- Psychological support to help with the emotional impact of having cancer.
- Providing the information people need in a way they can understand to help them and their family find the best way of coping and reaching decisions on treatment options.
- Providing help to maximise patients' survival and quality of life after treatment ends.

Equal access to quality care

Delivering quality care to patients with cancer requires the right set of healthcare professionals, facilities and equipment. But it also requires that all patients should have access to that quality care. Studies from a variety of countries have shown that survival for many cancers differ according to socioeconomic factors, indicating, for instance, that people from less privileged backgrounds face greater barriers to accessing high-quality care, and the barriers are getting higher as the cost of cancer care is rising. There is also widespread evidence to show, for instance, that older patients are often denied therapies that give them the greatest chance of the best possible outcome, even when they are fit and healthy enough to undergo the treatment.

The need for a "radical shift in cancer policy" to address this inequity was one of the key calls arising from the 2010 report on delivering affordable cancer care in high-income countries, commissioned by the *Lancet Oncology* (2011; 12:933– 980; behind a paywall).

In their summary conclusions, the authors argued that:

"Political toleration of unfairness in access to affordable cancer treatment is unacceptable. The cancer profession and industry should take responsibility and not accept a substandard evidence base and an ethos of very small benefit at whatever cost; rather, we need delivery of fair prices and real value from new technologies."

In a Cover Story in *Cancer World* (issue 53, March April 2013), Richard Sullivan, lead author of the *Lancet* report, calls for much greater public debate about the affordability of cancer care so the public gets the chance to decide where the priorities should lie.

The media has a key role to play in promoting this debate.

Health systems with national cancer plans that require all patients to be diagnosed/staged and managed only at designated specialist facilities are likely to deliver better outcomes than health systems that leave decisions about whether or not to refer patients in the hands of GPs or local hospitals.

NÉPSZABADSÁG

Health reporter Victória Kun won a Best Cancer Reporter Award for an in-depth article, published in the leading Hungarian daily paper *Népszabadság*, which took a critical look at the structure of Hungary's cancer services, highlighting disincentives to referring patients to specialist hospitals. The article was republished in English in *Cancer World* (www.cancerworld.org/pdf/3667_50_53_cw8_Ace%20Reporter.pdf)

Stories like this one about proposals in 2007 to close a cancer unit in Sligo, in the north west of Ireland, can be highly emotive from the perspective of the local community, but also loaded with vested interests, among politicians and health professionals at national and local levels. By asking the right questions, journalists who have a basic grasp of the evidence relating to the organisation of cancer services can provide their audience with informed and reasoned debate rather than a series of counterposed assertions



Factors in effective treatment

Evidence points to a range of factors that play a key role in securing the best possible outcomes for cancer patients. Understanding what they are and how to evaluate them will help journalists take a critical look at the quality of their cancer services.

Organisation of services

A multidisciplinary approach to planning treatment and care

Cancer treatment is highly complex, with multiple options of different treatment combinations to choose from. It is therefore widely accepted that decisions about a patient's treatment and care should be taken with input from a team of specialists, usually including the pathologist and radiologist involved in doing the staging and diagnosis, and a surgeon, radiotherapist, medical oncologist, and specialist cancer nurse, with other specialists involved as necessary. Gerontologists, for instance, can offer advice with patients who are particularly frail, or cardiologists if the patient has a pre-existing heart condition, and so on.

Consideration by a multidisciplinary team is now mandatory in some countries, including England and France, though not all teams necessarily work as well as they

might. In many other countries, treatment decisions are often still taken by the first specialist who gets involved, particularly outside the main treatment centres.

Minimum volumes

Evidence shows – and logic dictates – that a minimum caseload of any given type of cancer patient is important at least for some aspects of diagnosis, staging, treatment and care:

- The evidence is strongest for surgery, where a relationship has been shown for many procedures between outcomes and the annual caseload of the surgeon or institution.
- Smaller treatment centres with low caseloads are also less likely to be able to sustain all the specialists needed for different types of cancer, or some of the more expensive specialist equipment.
- The evidence is unclear on exactly where the threshold for minimum volumes should lie. In general, it should be higher the more risky or tricky is the procedure or treatment, and the more frail the patient, or greater the number and/or severity of their other medical conditions.

Many European countries have taken steps to stop cancer treatments being handled at smaller hospitals, where case-

loads are too low, or they do not have the specialist staff they need to work in a proper multidisciplinary approach.

In many others, however, the decision to refer a patient to a more suitable hospital is left to the discretion of individual doctors or hospital management, who may well resist doing so because of financial pressures or professional pride.

This will impact on patients' chances of survival with a good quality of life. Patients who have the least access to information about where to get the best treatment, or who are unable to access the best treatment, perhaps because they live in the wrong area, are being disproportionately affected.

Closing cancer units or radiotherapy facilities and centralising treatments in fewer hospitals comes with downsides, however. It can be controversial, and there is no blueprint:

- People prefer being treated closer to home unless they are convinced of the need to travel. Difficult journeys are particularly unwelcome for people who are feeling tired and sick, or when they have to travel frequently.
- Evidence shows that some people turn down treatments that could



(Left) The pros and cons of centralising cancer services were explored in the pages of *Cancer World* in a debate between Susan O'Reilly, Director of the Irish National Cancer Control Programme, and Renée Otter, former Director of the Northern Comprehensive Cancer Centre in Groningen, the Netherlands (www.cancerworld.org/pdf/5722_pagina_23_26_Crosstalk.pdf)

(Below) The current paradigm of 'personalised' or 'precision' medicine is putting increasing demands on pathology and imaging (radiology) departments to deliver a wider variety of tests to more precise standards than ever before. In *Testing the Testers*, *Cancer World's* Marc Beishon looked at issues in building capacity to carry out standardised testing for new biomarkers (www.cancerworld.org/pdf/8468_pagina_14-20_cutting_edge.pdf)



help them if accessing them is too arduous – providing transport or supportive accommodation close to the treatment centre can help address this.

- People may question the motivation behind the closures: is quality being used as a cover for a cost-cutting exercise or to suit the interests of the specialists at larger centres?

When these stories arise, journalists have an important role to play in promoting informed public discussion, which goes beyond presenting assertions and counter assertions.

They should ask the main protagonists to provide evidence for their arguments, and take the time to check that evidence if possible.

The case of rare cancers

The issue of minimum volumes is particularly acute for patients with rare cancers. Their rarity means cases have to be drawn from a very large population in order to reach a minimum volume threshold – in extreme cases, smaller countries may not have enough patients to sustain even a single specialist centre.

To get the best care, patients may need to get their diagnosis double-checked

and get treatment advice from specialist centres beyond their borders, or may even need to travel abroad for treatment. Facilitating this was one of the reasons behind the European Directive on Cross Border Healthcare, which is set to come into force sometime in 2014.

Enough trained, up-to-date specialists

The term “specialist” does not denote any specific qualification or experience, and different countries have different traditions on who should do what. Medical oncology (which emerged as a cancer subspecialty of internal medicine) was only recognised as a specialty at European level in 2011.

Some countries still combine the role of medical oncologist and radiotherapist (or radiation oncologist), under the title ‘clinical oncologist’, but in practice clinical oncologists will specialise in one or the other. In some countries surgeons (eg urologists or gynaecologists) make decisions about certain cancer drugs given before or after surgery, which remains a highly contentious issue.

Medical oncologists claim those from a surgical background have too little knowledge of medical therapies to be trusted with those decisions, while the

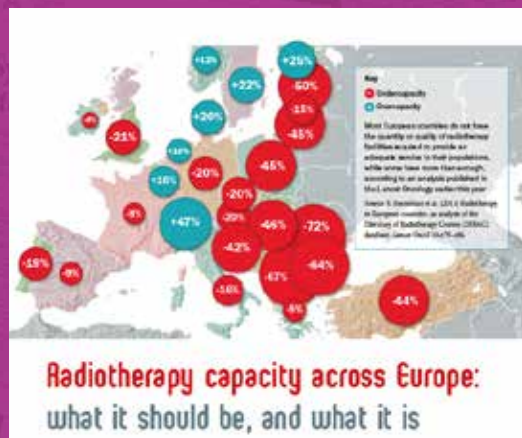
surgeons claim they know much more about the organ in question than do medical oncologists, and that is what counts. What the argument highlights is the importance of both types of specialist knowledge.

Very little information on numbers or training of specialists is available. However, professional oncology societies often do their own surveys, sometimes at a pan-European level. A list of European societies of cancer professionals is given on page 115. Some of these have a system of national representatives, who can be useful sources as they are familiar with their own country, but also have a perspective on how it relates to the situation elsewhere.

Enough well-maintained, up-to-date equipment

- **Pathology and imaging.** Getting the staging and diagnosis right, and understanding how a cancer is responding to a given treatment, are essential to getting the best outcomes. Insufficient capacity in many countries means many patients do not have access to all the tests they need.

This aspect of cancer management is becoming increasingly important



(Above) *Cancer World* published this infographic to illustrate the serious lack of radiotherapy capacity in large parts of Europe – and the potentially wasteful overcapacity in other parts (www.cancerworld.org/pdf/5184_pagina_30_33_Spotlight_On.pdf)



(Left) Simon Crompton won a Best Cancer Reporter Award for this article, which pointed out that while the world waits for science to deliver a miracle cure, surgery delivers cures every day, and it therefore makes sense to invest in improving standards of cancer surgery (www.cancerworld.org/pdf/8117_pagina_35-38_bestreporter.OK.pdf)

(Right) Nicola Kuhrt won a Best Cancer Reporter Award for her article in the *Frankfurter Allgemeine*, which explored the implications of the rising cost of cancer drugs. Her article was republished in translation in *Cancer World* (www.cancerworld.org/pdf/2704_pagina_30-33_bestreporter.pdf)



Frankfurter Allgemeine SONNTAGSZEITUNG

THE TIMES

as treatments are becoming more precisely targeted at individual cancers. However, it doesn't always get the public or policy attention it merits. Data on MRI and CT scanners per head of population are available from the OECD health site (www.oecd.org/health/health-systems/oecdhealthdata2013-frequentlyrequesteddata.htm)

■ **Radiotherapy.** Radiotherapy is one of the backbones of curative treatment for cancer (the other being surgery). Quality treatment, particularly for tumours in tricky locations, requires the ability to focus beams precisely, from any angle, and calibrate required intensities. The equipment needed for imaging the location of the tumour and planning the distribution of the dose is as important as the equipment that delivers the beam.

A study of radiotherapy capacity in Europe published in 2013 provides the most detailed data published so far. It shows shortfalls in capacity varying from minor to very serious, with particular problems in eastern and southern Europe. (See: Radiotherapy capacity in European countries: an analysis of the Directory of Radiotherapy Centres (DIRAC) database. Lancet Oncology 14:e79–e86)

Access to medical therapies (cancer drugs) Medical therapies, including chemotherapy, targeted biological therapies and immunotherapies are widely used in treating cancer. Though they rarely deliver a cure alone, they can improve the cure rates of surgery and radiotherapy. Used **neoadjuvantly** (preoperatively), medical therapies can shrink tumours to make it easier to surgically remove them or kill them with radiotherapy. Used **adjuvantly**, they can help mop up stray cancer cells after curative surgery or radiotherapy.

Medical treatments are the principal treatment used in metastatic cancer, and can delay the progress of the disease. In some cancers, such as breast cancer, some people are now living with cancer for up to 10 years (though 3–4 years is more common), prompting talk about turning cancer into a chronic disease.

Access to medical therapies – and the 'rationing' of cancer drugs – tends to get greater coverage in the media than other aspects of cancer treatment, such as surgery or radiotherapy, even though the latter are more important for curative treatment.

On the other hand, medical therapies also tend to be singled out by policy makers and the media for scrutiny

over their cost and whether they represent value for money, while other aspects of cancer treatment tend to escape such scrutiny.

One reason for this may be that it is easy to see the per-person cost of medical therapies, whereas the cost of new imaging, radiotherapy or surgical equipment is less obvious, as it is spread over thousands of patients over many years. It also comes out of hospitals' capital spending programmes, which are not often in the public domain. The cost of cancer therapies may become an even greater issue if treatment moves towards using "cocktails" of three or four medical therapies.

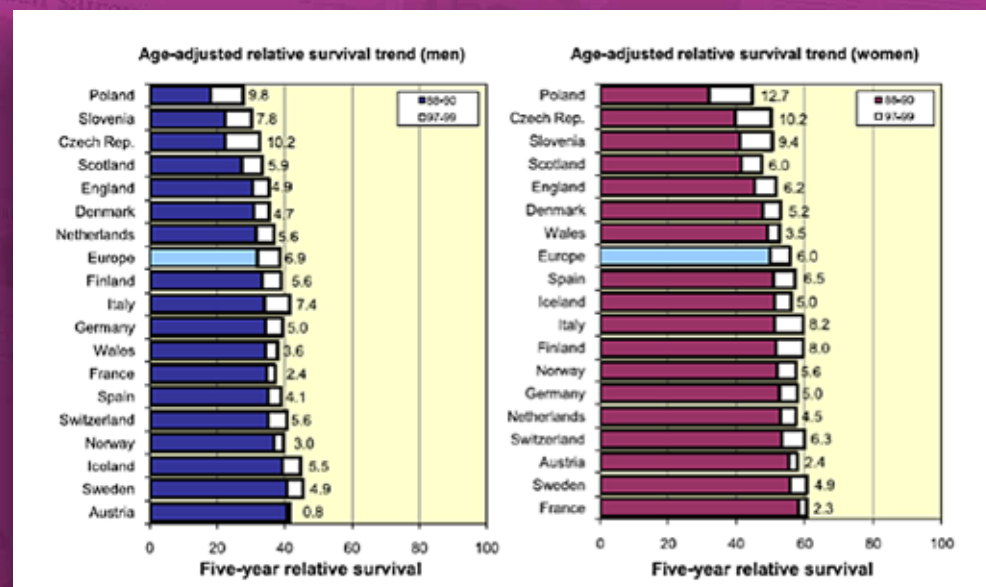
When covering these stories, journalists should perhaps take a wider look at the value for money achieved from other aspects of spending on cancer care as well.

Clinical research

Standards of care are known to be better in treatment centres that participate in clinical trials, not least because the robustness of the trial requires quality control procedures to ensure care is delivered according to protocol.

Patients also get the chance of much quicker access to experimental therapies where they have the option of partici-

Five-year relative survival 1988–1999 all cancers by country



Courtesy of Silvia Francisci, Istituto Superiore di Sanità, Rome

The EUROCARE reports offer a snap shot of how survival rates compare across Europe, but they can also show how survival rates change over time, providing important feedback on the impact of policies and investment. This graph is based on data from the EUROCARE-4 study. Some slides based on the EUROCARE-5 results, which were published in January 2014 in *Lancet Oncology* (paywall) are available at www.eurocare.it/LinkClick.aspx?fileticket=ehyt9B3OD6c%3d&tabid=64

The future of this survival information is currently in jeopardy (Spring 2014), because of a proposed EU directive on privacy that would make it illegal to access the personal data needed without individual consent. The media has an important role to play in examining where the public interest lies, and flagging up the likely consequences of this directive.

pating in a clinical trial. The shift towards more targeted “personalised” therapies means that new drugs tend to be tested in selected groups of patients who are most likely to respond, which means an increasing proportion of patients are benefiting from experimental treatments even in the early phase of trials.

Increasing the proportion of patients treated within clinical trials is likely to have an impact on both survival rates and on the general quality of care. Participation in clinical trials is very patchy across Europe. The barrier is often a question of culture, organisation and leadership. France is now very well geared towards enrolling patients in cancer clinical trials – particularly those with rare cancers or important molecular subtypes. In the UK, efforts to boost clinical trial enrollment led to a quadrupling in participation over a decade, from 1 in 26 to about 1 in 6. In many other countries, however, rates of participation remain pitifully low.

Access to clinical trials in an issue that merits wider media attention.

Reporting on the effectiveness of treatment

Reporting on the quality of healthcare can be difficult because health systems can be poor at collating and analysing data on

outcomes, and where they do, they are seldom keen to publish the findings.

Cancer is a partial exception to this rule, because of the existence of cancer registries, which in Europe now collate information not only on new cases and deaths, but also on survival – the time from diagnosis until death.

Comparative data on survival – ‘avoidable deaths’

Survival figures are usually given as **relative survival**, which shows observed survival of the people who had been diagnosed with cancer compared with the expected survival in a similar group in the population (same age, sex, year, area, socio-economic class).

Inevitably these data appear with an apparent time lag, because they indicate the success of treatment given around the time of diagnosis, which can only be known after enough time has passed to give a five-year (sometimes two-year or one-year) survival rate.

This information is available by country (though in some countries the registries cover only certain regions) and by type of cancer, gender and age. Since 1999, the EUROCARE project has published comparative studies of survival rates across

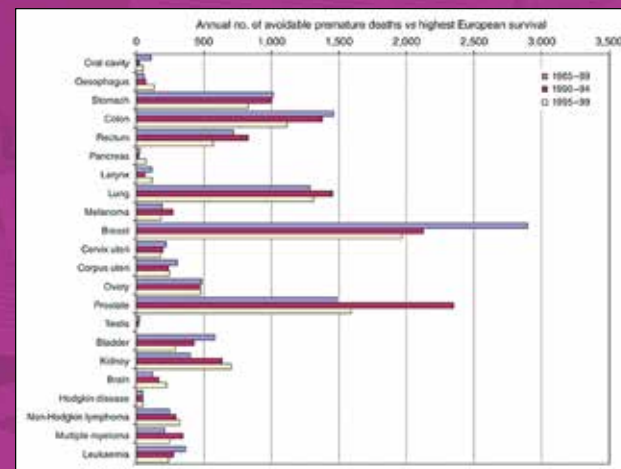
Europe every four years. This is very valuable information for journalists looking at the quality of cancer care in their own countries, and strong media coverage of these figures has helped propel the issue of quality cancer care up the political agenda in a number of instances.

The surprise relatively poor results for England in the first EUROCARE report prompted the then Prime Minister Tony Blair to create the first post of National Cancer Director in 1999, with a remit to develop a strategy for improving the situation. This pioneering move was later followed by President Jacques Chirac in France, and has now led to cancer plans being developed all over Europe. The EUROCARE studies also drew attention to the significantly poorer survival in eastern European countries in the 1990s, which prompted concerted action to catch up with the rest of Europe, the success of which has been charted in subsequent EUROCARE reports.

The early EUROCARE studies covered only a handful of countries, as the majority could not provide reliable survival statistics. Today almost all European countries provide that data, though in some countries the data are generalised from registries covering only part of the population.

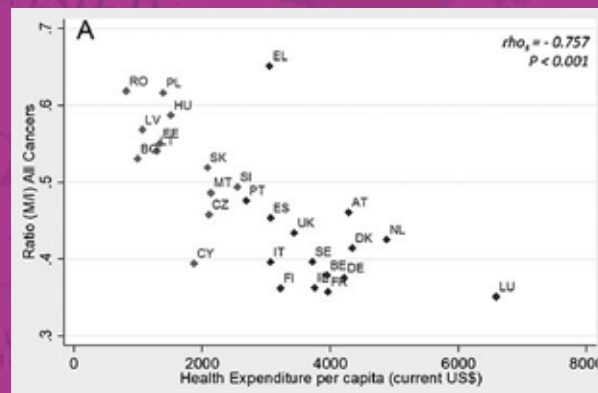
Avoidable deaths

The concept of “avoidable death” is useful to highlight the number of deaths that could be avoided in any given country if cancer control policies were as effective as in the best of comparable countries. The graph (right) shows the picture for the UK, for 22 common cancers, for patients diagnosed in 1985–1989, 1990–1994, 1995–1999



Reprinted from M Abdel-Rahman et al (2009) *British Journal of Cancer* 101:S115–S124, by permission from Macmillan Publishers Ltd on behalf of Cancer Research UK

Who gets the best value for money?



This scatter plot shows how the ratio of mortality to incidence (ie deaths to new cases) drops with increasing per capita expenditure on health across Europe. But some countries are clearly getting better results from the resources they put in than others

Reprinted from F Ades et al (2013) *Ann Oncol* 24:2897–2902, by permission of Oxford University Press

Headlines like this one in the *Daily Telegraph* (10 May 2007) can help galvanise political will behind efforts to improve services



Publication of the EURO-CARE reports provides the media with an opportunity to raise awareness about how survival rates in their country compares with those in other countries. The concept of “avoidable deaths” – the number of lives that could have been saved had services been equal to those in the best countries, is a useful one here.

It is a chance to ask questions about what is needed to bring survival rates up to the level of the best in Europe, with particular reference to the different factors in quality of cancer treatment listed above.

The EURO-CARE data also provide an important opportunity to look at how survival rates have changed since the previous results were published, and to draw conclusions about the effectiveness of cancer care policies.

Regrettably, most EURO-CARE studies are behind a paywall. However, slides presented at a roundtable at the European Parliament, *Key Determinants of Inequalities in Cancer Survival Across Europe: The Latest Results of the EURO-CARE-5 Study*, are available at www.eurocare.it/LinkClick.aspx?fileticket=ehyt9B30D6c%3d&tabid=64.

A very helpful overview of the different

types of statistical data that can help make sense of differences in cancer burden between countries and over time can be downloaded from the media training page of the Cancer World website www.cancerworld.org/Media/Media_Training.html (see *The Best and the Worst in Europe – What are They Doing That We are Not?* under the Downloads heading in the report on Past Training Sessions: *Off-The Record: Can Europe cope with the rising burden of cancer?*)

It's not all about money

Differences in average rates of cancer survival across Europe strongly reflect differences in the per capita expenditure on healthcare. In countries like Romania, Poland and Hungary, which spend less than \$2,000 per capita in healthcare, around 60% of people who are diagnosed with cancer die from the disease. This falls to between 40% and 50% in countries spending \$2,500–3,500, such as Portugal, Spain and the United Kingdom, and falls below 40% in countries like France, Belgium and Germany, where per capita health spending is closer to \$4,000.

However, a lot also depends on how effectively the resources are used. Some countries achieve markedly better out-

comes for less money. As ever greater demands are placed on health budgets, and policy makers are under pressure to reduce public spending, the need to ensure health services deliver care efficiently and in line with the needs and priorities of the people they serve becomes increasingly important.

Providing informed and critical coverage on the quality and value for money provided by health services is one of the most important jobs the media has as a public watchdog. All the more so because political debate about healthcare provision tends to be dominated by ideological agendas, rather than on evidence of what works well and what does not.



Finding the right balance between the drawbacks and benefits of different treatment options is a key part of quality care

The physical side-effects of medical cancer therapies range from nausea and vomiting, hair loss, fatigue and pain, through to painful, itchy and unsightly conditions of the skin, nails and inside of the mouth, impaired sense of touch, loss of fertility, suppressed immune system, chronic heart disease and a raised risk of new cancers. Surgery and radiotherapy can impair control of bladder or bowel, the ability to talk or swallow. Lymph node removal can lead to swollen arms and legs, and treatment can also affect people's sex lives, the way the look, their self-image and more.

Patients can be left feeling angry and bitter if they are not given the chance to decide for themselves how they want to balance the benefits a treatment might bring against the associated side-effects, as Peter McIntyre reported in this *Cancer World* article (www.cancerworld.org/pdf/6864_CW19_56_62_patientvoice.pdf)

Factors in quality care and support

Being diagnosed with cancer is among the most traumatic events likely to happen to anyone, and often leads to big life changes. Studies have found that almost one in four women diagnosed with breast cancer suffer post-traumatic stress disorder shortly after their diagnosis (eg JNCI 105:563-572 - paywall).

Particularly stressful points include the wait to hear how serious a diagnosis is, how well the treatment has gone, and whether follow-up shows any signs of a recurrence,. This fear takes a long time to recede, because while the chance of a cancer recurring in some form usually drops dramatically over a period of a few years, it never disappears entirely, and the raised risk period is extending as treatments become more effective. Breast cancer researchers, for instance, are now advising that the traditional 5-year follow-up given in study results needs to be extended to 10 years, to get a full picture of recurrences.

In addition to this stress, the disease and its treatment can impact on almost every aspect of a person's life, from the way they feel, to the way they look, what they can do, their fer-

tility, their self-image and self-confidence, even their relationships.

The support and care given to patients to help them cope with the physical and emotional impact of being diagnosed with cancer, going through treatment and picking up their lives again, is therefore as important as treating the cancer.

Psychological support and shared decision making

Helping patients cope in their own way with the uncertainty, anxiety and stress is an important aspect of quality care. Central to this is an ability to listen and communicate well, to give patients the information they want in a way they can understand, and to involve them to the extent they wish, in reaching decisions about their treatment and care.

Routinely checking patients' distress levels and offering counselling and support when needed is also important. Communication training and the role of specialist cancer nurses and psycho-oncologists and also patient advocacy and other support groups are important here.

The Salzburg Statement on Shared Decision Making ([http://e-patients.net/archives/2011/03/the-salzburg-state-](http://e-patients.net/archives/2011/03/the-salzburg-state-ment-on-shared-decision-making.html)

[ment-on-shared-decision-making.html](http://e-patients.net/archives/2011/03/the-salzburg-state-ment-on-shared-decision-making.html)) addresses these issues.

Managing side-effects

In addition to these psychological burdens, cancer treatments can be very harsh. Side-effects range from the irritating to traumatic and potentially life-threatening, and can have a life-long impact (see opposite).

This means there are often difficult choices to be made about how to balance the chances of benefiting from a given therapy option against the risk of its side-effects.

Patients need to be given the chance to decide for themselves where this balance lies; they can end up feeling very bitter if, for instance, long-term side-effects of aggressive therapy make their life miserable, and they feel retrospectively that they had never been properly warned or given a real choice.

Routinely checking for the impact of side-effects, and alleviating them as far as possible, is important for patients' quality of life, but it may also push up survival rates by enabling patients to receive more aggressive treatments, and reducing problems with adherence.



María Valerio Sáinz won a Best Cancer Reporter Award for an online piece she wrote for the Spanish newspaper *El Mundo* about men who are trying to find the best way to support their partners going through mastectomy. The piece was republished in translation in *Cancer World* (www.cancerworld.org/pdf/7183_bestreporter.pdf)



Talking about the ending of life – how to manage it, what are the priorities – can make a big difference to the experience of the last months of life. But it is hard for the person whose life is ending, and also for clinicians, friends and family. Some societies do it better than others. Journalists can play a key role in opening up public conversations on this topic, which was tackled by Simon Crompton in this *Cancer World* article (www.cancerworld.org/pdf/1080_pagina_22_27_Patient_Voice_final.pdf)

When treatment ends

After treatment ends people can often feel lost and abandoned and find it hard to get back on their feet and pick up their lives again. They may have health and functional problems of varying durations, and they may need help coping with the emotional and psychological impact of what they have been through. The transition to ending active anti-cancer treatment is particularly hard for people whose cancers cannot be cured, and have stopped responding to existing treatments. Many of them will want help and support in accessing any experimental therapies that could help them, and they need continuing health-care and support as they approach the end of life.

Quality care involves routinely assessing the needs of each patient as they finish treatment and helping them secure the continuing care and support that they need. A good example of how health systems are attempting to address these issues is the National Cancer Survivorship Initiative in England and Wales (www.ncsi.org.uk/).

In many countries, however, the quality of care given to patients after the end of their anti-cancer treatment is patchy at best.

Supporting people living with cancer

People whose cancers do come back in an incurable form, or whose cancer is already far advanced before it is first diagnosed, are faced with one of the biggest challenges anyone can face: how to get the most out of life, in terms of quantity but particularly quality, knowing they have an illness that will eventually kill them unless more effective treatments are found.

Telling a cancer patient that their disease is no longer responding to any available treatments is the hardest thing for doctors, and they don't always do it as well as they would like, with the result that, as patients near the end of their life, they are sometimes given treatments that do them more harm than good and they are unaware of their impending death.

Conversely, patients often worry that they are being taken off anti-cancer treatments too soon, particularly the very expensive treatments, to save money rather than for their own benefit, eg if their disease has started to progress, but they feel the treatment may still be of some value either in slowing progress or making them feel better.

For these people, being offered the chance to join a clinical trial testing a

new therapy can be very important, offering the possibility of an added lease of life before their time runs out.

However, access to clinical trials is very patchy across Europe. Doctors often don't ask patients if they would be interested in joining one; and it can be hard for patients themselves to find out about what trials are recruiting that they may be eligible for. Public suspicion of clinical trials can also be a barrier.

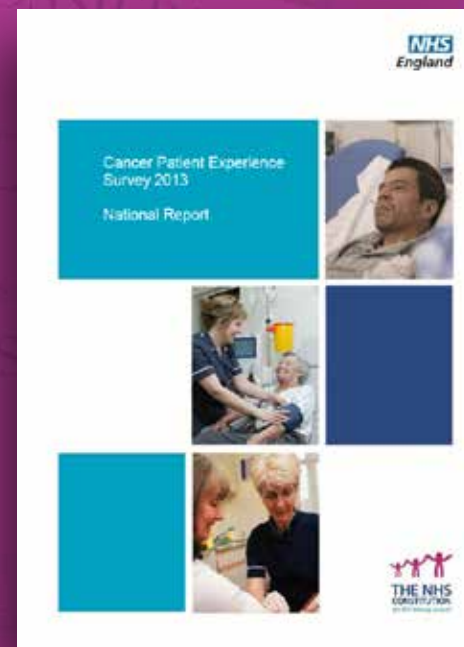
Attitudes in the community

Care and support from family, friends and colleagues is very important, but people with cancer can find themselves shunned and isolated because some of those around them don't want to, or don't know how to, relate to people facing possible life and death issues. The term 'relationship toxicity' has been coined to refer to the strains that having cancer can put on personal and family relationships. But while it can be the trigger for relationships breaking up, it is equally often a cause for bringing people closer together. Being diagnosed with cancer can also affect your chances of, for instance, getting a job, or keeping your job, getting a mortgage or adopting children.

Journalists have an important role to play in telling the stories of people with

Patients' experience of care

Care and support are important aspects of quality from a patients' perspective, yet they are rarely included in the criteria for judging the performance of doctors and hospitals. This makes it all the more important that the media picks up on these issues, as the *Daily Mail* did in this story (right), which it published on 1 February 2012



In 2010 the NHS in England became the first health service to gather and publish patient feedback from every hospital treating cancer patients, in an annual Cancer Patient Experience Survey (www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports). The survey gives a picture of patient satisfaction based on responses to almost 70 questions, covering a range of areas, including:

- Were they given enough information at all stages of their journey?
- Was it provided in a sensitive and understandable manner?
- Were they listened to and their views taken into account?
- Were they offered the opportunity to participate in research?
- Did they get the support and care they felt they needed?

cancer and flagging up issues relating to their treatment, care and support:

- They can shine a light on important aspects of people's lives that often remain hidden even though so many people are affected.
- They can help people with cancer feel less isolated and give them – and their friends and family – helpful insights into how others cope with the experience.
- They can also help inform and mediate change and development in public attitudes towards cancer and dealing with life and death issues.

- They can open up discussion about the relationship between the medical profession and patients – about the challenges of combining compassion with honesty, and practising shared decision making within the context of the time pressures, financial pressures, and health system priorities of daily practice.
- They can develop the public debate around the implications of cancer becoming more of a chronic disease: how can we support the growing number of people who are living longer with cancer, in terms of the cost to healthcare systems?

- They can highlight important gaps in the provision of care and support.
- They can promote discussion about opportunities and risks associated with clinical trials.
- They can explore how far the priorities of healthcare providers correspond to the priorities of patients – in 2010 the National Health Service in England became the first to gather and publish patient satisfaction surveys for every hospital treating cancer patients [http://www.ncin.org.uk/cancer_information_tools/cancer_patient_experience].



Guidelines are key to quality care

Doctors, nurses and other health professionals have built up a wealth of evidence about the best way to treat and care for cancer patients, which are laid down in clinical practice guidelines. Guidelines are also important to ensure patients are treated safely. Health systems with a strong culture of compliance with guidelines will get better outcomes and fewer 'scandals' than those where compliance is patchy



Factors in good governance of healthcare

Having robust systems to ensure things are done right first time, and a culture of quality control and quality improvement built in to every aspect of cancer care, is essential to the delivery of high-quality healthcare in general.

Atul Gawande, a surgeon and leading proponent of a systems approach to safety and quality argues in favour of widespread use of checklists, to ensure all the components of guidelines are routinely complied with. In his 2010 book, *The Checklist Manifesto*, he argues:

"We have accumulated stupendous know-how. Nonetheless, that know-how is often unmanageable. Avoidable failures are common and persistent. And the reason is increasingly evident: The volume and complexity of what we know has exceeded our individual ability to deliver its benefits correctly, safely, or reliably."

Nowhere is this more true than in caring for cancer patients, because of its complexity, the toxicity of treatments, and the number of different professionals and services involved.

Guidelines

Studies consistently show that cancer patients have better outcomes when they are treated in accordance with evidence-based clinical guidelines.

Guidelines have been developed by a variety of bodies – often at international or European level – for diagnosing and treating different types of cancer, administering different types of therapy, managing side-effects, breaking bad news, and more.

Adapting them to local conditions, and ensuring they are complied with in practice, needs to be done at national, regional and even hospital level. Developing national guidelines is seen as an important aspect of national cancer plans, but many countries still lack national guidelines on treating and caring for cancer patients, or systems for promoting and monitoring compliance.

Guideline compliance

Data on treatment – type of surgery, post/preoperative radiotherapy and/or chemotherapy – are recorded by cancer registries in a very few countries (see Figure 9 in the Eurochip report www.tumori.net/eurochip/material/WP5/EUROCHIP3_WP5_Report.pdf).

Analysed together with diagnosis and stage, this information gives an indication of the level of compliance with clinical practice guidelines, which makes it valuable for monitoring and improving standards, and for patients looking for the best treatment centres. The fact that this information is not gathered and analysed more widely is probably as much to do with resistance from doctors, who may not want to be monitored in this way, as with the added bureaucratic burden on hospitals.

Monitoring performance and outcomes

Knowing how well every part of a care system is working, and the standard of outcomes, doesn't prevent problems from occurring, but it does help ensure that when they do, they are picked up so they can be addressed.

Monitoring compliance with guidelines is one way of doing this, but currently only a small minority of countries gather the information needed to do this.

Another way is to look at key outcomes, such as survival. However, while this can be done at a national level – eg the EUROCORE survival analyses – there is an argument that it cannot be done in a



meaningful way at the level of individual hospitals or practitioners, because there are so many inputs into cancer treatment and care that it is hard to assign responsibility for outcomes. Patients may be diagnosed at one facility, have their treatment planned at another, have different bits of treatment carried out in different places, and then if the cancer returns they may be managed by an entirely different set of people.

This argument should be less valid now that the planning and delivery of cancer care is increasingly the responsibility of multidisciplinary teams, where evaluating outcomes as part of a policy of continuous quality improvement could and should be possible at a team level.

Currently, however, health systems tend to rely more on “surrogate” indicators for the quality of care, such as surgical complications and treatment delays.

Surgical complications

Data on surgical outcomes – mortality rates and complications – are commonly recorded, though they are rarely made public. In 2013 England became the first health service to legally require surgeons to publish their mortality and complications data. These can now

be freely accessed (www.nhs.uk/choices/yourchoices/consultant-choice/pages/consultant-data.aspx).

Treatment delays

Information on the time lapse between diagnosis and first treatment is more frequently gathered and made available. While this time lapse often has little impact on outcomes, it can be very stressful for patients, and because it is easily measured, it tends to attract attention, and is often included in lists of patients’ rights or hospital performance targets.

Figure 7 of the Eurochip report on cancer registry indicators in various countries (www.tumori.net/eurochip/material/WP5/EUROCHIP3_WP5_Report.pdf) shows the countries that use cancer registries to gather the relevant data; however, there are many other countries that gather similar data using different systems.

Patient reported outcomes

Healthcare systems exist to meet the needs of patients, so it would make sense to gather information about patient satisfaction as a key element in quality control and improvement programmes. However, this is very rarely done – the exception being the NHS in

England, which now publishes the results of annual surveys of patient satisfaction with cancer care in a way that makes it possible to see not only how each hospital is ranked for patient satisfaction, but how far its score has improved (or deteriorated) over the past year. Their results for 2013 can be seen at www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey-reports.

Accreditation systems

In an effort to address shortcomings in quality assurance, and encourage cancer units and cancer centres to strive for the highest standards, the Organisation of European Cancer Institutes now runs an accreditation service, which allows individual cancer institutes, centres or units to seek accreditation as a mark of quality assurance, on the basis of a defined set of quality standards <http://oeci.selfassessment.nu/userfiles/file/empty%20qualitative%20questionnaire.pdf>.

As a voluntary system, which has associated costs in time and money, it is uncertain how much of an impact this can have on assessing and approving quality at a system-wide level. In Italy, how-

How do we know it isn't happening elsewhere? What will be done to stop it happening again?

When things go badly awry, it is up to journalists to pose questions on behalf of the public they serve, not just about why it happened and who was responsible, but what safeguards there to prevent it happening again, and what guarantees can be given that similar problems aren't happening unreported elsewhere in the health system

Le Monde

ever, the government has now committed to funding all its cancer institutes to go through accreditation. As the procedure involves an in-depth audit and offers detailed feedback and suggestions for improvement, this will amount to an independent national audit of the country's cancer centres.

Voluntary schemes are also in place for breast centres, such as the one run by the International Breast Centre Network, as part of an initiative to get centres to work together and push up standards of breast care. It publishes an international directory of breast centres where people can find accredited breast centres in their own country (www.breastcentresnetwork.org/).

Beyond the 'scandal': reporting on quality and governance of healthcare

Poor decisions and substandard or negligent healthcare are more common than is generally appreciated. Health services themselves often don't have a clear picture of the standard of healthcare they deliver, and when things do go wrong, various overlapping interests tend to combine to ensure the press and the public don't get to hear of it until the problem has assumed "scandal" proportions – and often not even then.

So when stories about the quality of healthcare do hit the headlines, it tends to appear as if some disastrous mishap or misdemeanour has occurred within an otherwise well-functioning system.

Examples of cancer "scandals" that have hit the headlines include:

"The Epinal radiotherapy patients: jail sentences for two doctors and a radiologist"

Le Monde 30 January 2013

"GMC suspends 'rogue surgeon' accused of unnecessary breast operations"

The Guardian 7 November 2012

"Third party to oversee diluted chemo- therapy drug investigation"

Toronto Sun 4 April 2013

Typically these stories will focus on apportioning blame and looking at what went wrong in the case in question. This is important from a news perspective, but the issue of greater public importance is why did the system fail, how do we know it is not failing elsewhere, and what can stop it failing again?

The French radiotherapy scandal was about a failure to take into account previous treatments when calculating dos-

es, aggravated by attempts at a cover-up. The UK story was about a surgeon who was believed to have performed 'unnecessary or inappropriate' breast surgery on more than 1,000 women. The diluted cancer drugs – this one from Ontario, Canada – was another story of errors in preparation, which continued for a year before being picked up.

In every case – and this applies equally to stories about the quality of pathology or delivery of care in the areas of supportive, palliative and psychosocial care, and rehabilitation – there will be the same questions to be asked: about guidelines, checklists and quality control, about the mechanisms to promote and monitor compliance and pick up problems, about where these failed, whether these same failures may be happening elsewhere, and what can stop it happening again.

When stories about things going wrong do emerge, journalists should take the opportunity to ask the hospital management questions about:

- *What safeguards are operating to ensure things go right?*
- *Are there national guidelines?*
- *If so what measures are in place to promote and monitor compliance?*



- *Why did these measures not work?*
- *Are guidelines being complied with elsewhere?*
- *How do we know?*
- *What can stop this happening again?*

While individuals do have to be held accountable for their actions, journalists should bear in mind that delivering quality healthcare requires a culture of openness and responsibility at every level of the service.

The way you choose to cover stories when things go wrong can help expose weaknesses that need to be addressed, but it can also contribute to a climate of blame and retribution that leads to fear, defensiveness and cover-ups.

Effective reporting on the quality of healthcare has to be one of the most important areas of journalism, given the importance of healthcare to our lives, and the proportion of tax or social insurance money spent on it.

It is also one of the most challenging areas to cover, for a number of reasons:

- Politicians tend to treat every healthcare story as a chance to score political points.

- Health services are often the least transparent of any area of public service.
- Management don't like to advertise when things have gone wrong. If they have to go public, they prefer to delay the revelation until they are able to claim the problem has already been fixed.

- The requirements of medical confidentiality are important to protect patients, but they can also be used as an excuse to withhold awkward and embarrassing information.

- Medical professionals tend not to welcome public scrutiny of the quality of their work, and don't trust the media/public to interpret data for themselves; they can also be wary about criticising the quality of services in case they add to the anxiety of their patients or jeopardise their own careers.

- Patients and their families may welcome press publicity when it can help them, for instance, get access to a therapy they think will benefit them, but when treatment and care has been seriously mishandled, people can often feel too bruised and bitter to cope with the consequences of going public.
- Conversely, a family or patient can "go to the media" when distressed

and angry about an incident or treatment which in fact was appropriate and timely, perhaps spurred on by false claims of "miracle cures" elsewhere. Reporting this at face value can again create a 'scandal' that is baseless.

Journalists need to know what information about quality and outcomes is publicly available and how to get access to unpublished information. They can ask questions about whether the most relevant information is being gathered and whether more information should be made publicly available.

They need to understand the principles of good governance and ask critical questions when stories about the quality of cancer care arise.

They need to understand the different pressures and agendas of everyone involved in the organisation, administration and delivery of healthcare services, and promote informed debate about how to improve the accountability and transparency of this most important public service.

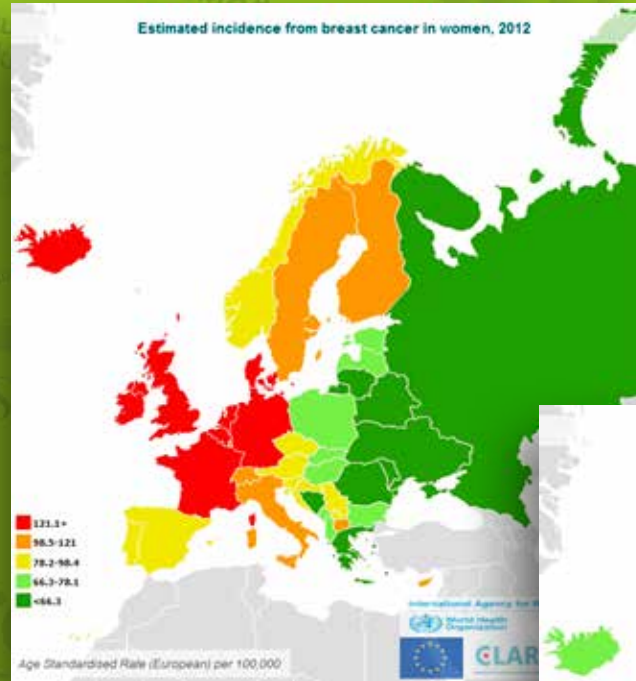
Helpful online resources for a more general grounding in the skills of health reporting can be found at the website of



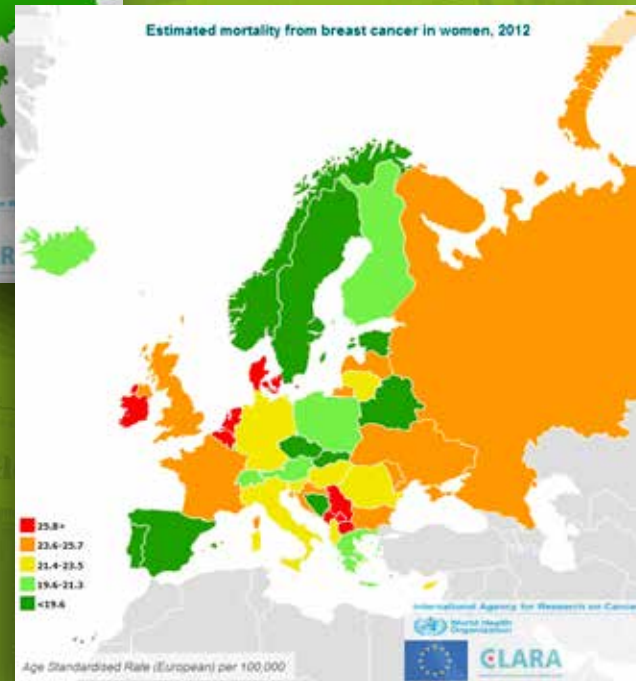
the EU HeaRT project – a pan-European initiative to help raise the standards of health reporting in Europe (www.project-heart.eu).

The European Health Journalism website (www.europeanhealthjournalism.com) also offers useful resources and information about training for health journalists.

The two documents under the EU HeaRT project's Health Care Quality and Performance heading – www.project-heart.eu/index.php/projectheart/elearning + click the UK flag + click "UK modules" at the end of the list – are particularly relevant to the topics covered in this guide.



The European Cancer Observatory (eco.iarc.fr) provides downloadable maps, graphs and data on incidence, mortality and prevalence for different cancers and different European countries. Countries that have relatively low mortality despite a relatively high incidence are better at picking up and treating cancer than those for which the reverse is true



Describing the size of the problem and evaluating progress

Data are available to throw some light on the extent of cancer in a population and how it is changing over time thanks to national/regional cancer registries, which record key information on cancer diagnoses and deaths from cancer. The effectiveness of prevention, early detection, and treatment policies and practices can be inferred by analysing changes in the data over time or comparing data from different countries.

Every European Member State now has a cancer registry covering all or part of its population, which gathers information on:

- New cases of cancer (incidence), classified according to the WHO's International Classification of Diseases (ICD) code
- Deaths from cancer (mortality)
- Survival rates

Incidence and mortality figures are usually presented in the form of numbers of

new cases/deaths per 100,000 head of population. The data are usually adjusted to account for differences in age profile.

The European Cancer Observatory website provided by the International Agency for Cancer Research (eco.iarc.fr) now provides tables and charts of the latest incidence and mortality data by cancer and country as well as estimates of prevalence, within its EUCAN database. You can also access cancer registry data as charts and tables showing incidence by age group, one- to five-year survival statistics by country and age group, and changes in incidence and mortality over time by country and cancer within its EUREG site. .

This is a superb resource for journalists looking to compare data over time or between countries, but it is important to take note of the warning on the EUREG site that a minimum knowledge in descriptive epidemiology is required

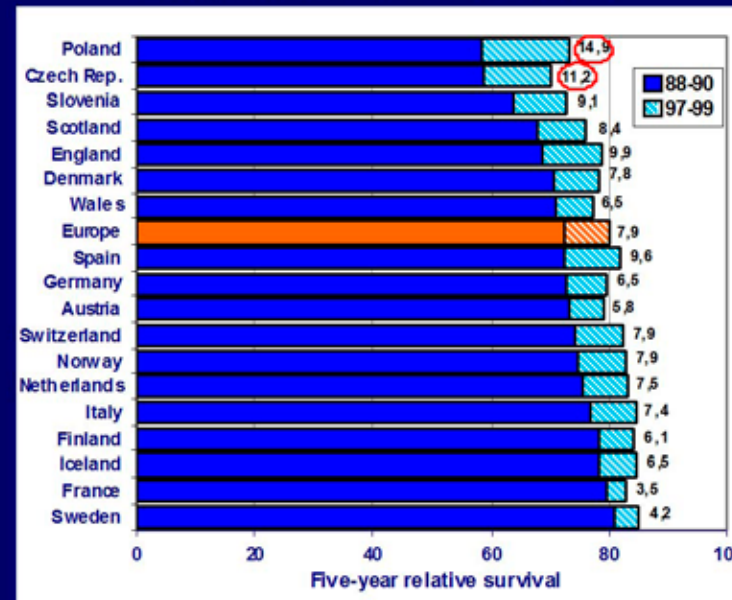
to correctly interpret the statistics. The following sections provide such a basic overview.

A very helpful introduction to the key statistics and graphs showing aspects of the burden of cancer across Europe can be downloaded from the media training page of the Cancer World website (www.cancerworld.org/Media/Media_Training.html) – See *The Best and the Worst in Europe – What are They Doing That We are Not?* under the Downloads heading in the report on Past Training Sessions: Off-The Record: Can Europe cope with the rising burden of cancer?)

Incidence data

Incidence data reflect exposure to risk factors, including preventable risk factors, and are therefore important in monitoring the effects of prevention policies, such as campaigns to cut smoking rates, lower alcohol intake, screen for

Change in 5-year relative survival (%) breast cancer, women Europe from 1988-90 to 1997-99



Reprinted from A Verdecchia et al. (2009) Survival trends in European cancer patients diagnosed from 1988 to 1999. *Eur J Cancer* 45:1042–66, with permission from Elsevier

Monitoring success

Differences in survival between European countries, highlighted in successive EUROCORE studies, focused politicians' attention on the importance of an effective cancer policy. It prompted the UK to draw up and implement the first cancer plan, and convinced many countries in eastern and central Europe to make concerted efforts to improve their cancer services. The results of those efforts can be seen in this graph, which shows the greatest improvement in five-year survival occurred in countries with the poorest survival rates for those diagnosed in 1988–89

cervical pre-cancers, vaccinate against the HPV virus, legislate on industrial carcinogens, promote healthier lifestyles and so on.

Some care should be taken when interpreting incidence data, because the number of new cancers that are diagnosed depends in part on how hard you look for them. Countries that routinely screen (check apparently healthy people) for prostate cancer, for instance, appear to have exceptionally high incidence rates, because they are picking up many cancers in elderly men that would otherwise have gone undetected.

As older age is the biggest risk factor for cancer, 'raw' incidence rates will also increase where people are living longer. Conversely, falling life expectancy, for instance among Russian men who are dying younger due to alcohol-related illness, will slow cancer incidence rates. To take into account differences in age profiles, incidence rates are often presented as 'age standardised', which allows rates to be compared between populations as if they all had a standard age profile.

Mortality data

Mortality data could be seen as the best overall indicator of the effectiveness of cancer control policies, as they meas-

ure the effects of prevention policies (fewer cases of cancer will lead to fewer deaths) and also the effects of early detection and successful treatment. Mortality rates, like incidence rates, tend to be presented in age standardised form to account for the impact of different age profiles.

Prevalence data

The prevalence of cancer is usually defined as the proportion of people alive on a certain day who previously had a diagnosis of the disease, regardless of how long ago the diagnosis was, or whether the person is still under treatment or is considered cured. It increases as more people get cancer, as more people are cured, and as more people live longer with the disease. The data provided on the EUCAN site are estimates for "limited-duration prevalence", i.e. the proportion of people alive on a certain day who had a diagnosis of the disease within the past 1, 3 and 5 years. Prevalence figures are important as an indication of how many people are living with the after effects of cancer, or are still coping with the disease and treatment.

Survival data

European cancer registries also link records of new cases of cancer to data from death certificates, in an anonymised

way, to provide information on how long people survive after being diagnosed with cancer.

Survival data give an indication of the success of treatment, which in turn gives an indication of how quickly cancers are picked up and diagnosed, and the quality of the treatment planning and implementation, and follow-up. These figures are usually given as **relative survival**, which shows *observed survival* of the people who had been diagnosed with cancer compared with the *expected survival* in a similar group in the population (same age, sex, year, area, socio-economic class).

Survival data from Europe have been published every four years by the EU EUROCORE project (www.eurocare.it/), alongside a detailed analysis. Key results for EUROCORE-5 were published in December 2013, in *Lancet Oncology* (15:23–34).

Regrettably, as with most EUROCORE studies, this is behind a paywall. However, slide presentations from the press launch at the European Parliament on 5 December 2013 contain some useful information, and can be accessed at www.eurocare.it/LinkClick.aspx?fileticket=ehty9B3OD6c%3d&tabid=64.



Survival statistics for some cancers can be distorted by the impact of screening programmes (checking apparently healthy people), so they need to be interpreted with caution.

This is because survival is measured from the time of diagnosis, and picking cancers up at a very early stage will increase the recorded survival time, whether or not the person actually lives any longer than they would have had their cancer been diagnosed at later stage.

This is known as the 'lead time effect'. It means that where widespread screening is in place, the statistics will show better survival than where there is no

screening, whether or not the screening is saving or extending lives.

Care should also be taken in interpreting survival statistics derived from data covering limited sections of a population. The standard of treatment and therefore the survival rates in centres or regions that are organised enough to produce survival statistics may not be representative of the whole country.

Stage of diagnosis

Some registries also gather information on the stage of diagnosis. These data are important for monitoring how quickly cancers are being detected and diagnosed.

This information is important to understand how far differences in survival rates can be attributed to differences in the timeliness of diagnosis; or whether poorer quality of treatment planning and implementation are the problem.

Data coverage

Details about what parts of the population are covered by cancer registries in different countries, and the indicators they gather can be found at www.tumori.net/eurochip/material/Report/EUROCHIP3_Final_Report/D03_-_WP5_CR_indicators.pdf

HOW SCIENCE REPORTING WORKS:



A scientist's perspective on the media

This cartoon presents researchers as the good guys and journalists as the bad guys. In reality, when stories are overhyped, the fault can often be traced back to press releases, editorials and quotes from the researchers themselves. Researchers will feel they have made a breakthrough when a new treatment approach that they believe in and have spent a lot of time and energy developing finally shows some evidence of effect. Clinicians working in hard-to-treat cancers will feel they have a breakthrough when survival increases, for instance, from a median of four months to eight months. To the public, 'breakthrough' means a marked improvement in cure rates. It is up to journalists to take a critical look at the claims being made, so their audience can understand the true implications of the story

New treatments and discoveries: understanding, evaluating and reporting on the evidence

The media frequently stands accused of being interested only in reporting bad news.

When it comes to stories about curing cancer, however, the pressure is in the opposite direction.

The public wants to hear good news, about cancer, so the media wants to supply it. Doctors want patients and families to hear a positive message; researchers want positive coverage of their work; and pharmaceutical companies, biotechs and manufacturers of medical equipment want good publicity.

As a result, stories about progress in understanding, diagnosing and treating cancer consistently overstate what it means in practical terms for people with cancer now and in the near future.

Progress: the story so far

Hopes of a "magic bullet" that will cure cancer have risen and fallen in recent decades, as new concepts of treatment have emerged with high hopes, which are only partially realised.

Some of the greatest benefits to patients in recent decades have resulted not from new therapies, but from much more selective use of existing therapies, which has allowed hundreds of thousands of patients to avoid surgery or chemo- or radiotherapy that would do them more harm than good.

The slow but steady improvement in survival rates in developed countries over recent decades owes as much to organisational factors such as better delivery of existing treatments, and catching more cancers at an earlier stage, as it does to new therapies –

something that is rarely reflected in the media coverage.

More incremental than breakthrough

Progress has tended to be incremental and patchy: survival rates in childhood cancers, testicular cancer, lymphoma, and breast cancer, for instance, have improved much faster than those in lung, ovarian and pancreatic cancer.

Perhaps the closest thing to a magic bullet was the development of Glivec (imatinib) in the late 1990s, the first of the new generation of targeted biological drugs, which controls (but doesn't cure) the rare cancer chronic myelogenous leukaemia (CML) in the majority of patients, possibly indefinitely.

But the high hopes that this era of 'personalised' or 'precision' medicine, where every cancer is controlled by biological

How the tale gets twisted

This front page of the *Sunday Express* (25 September 2011) makes two wild claims about Kadcyla, a new therapy for patients with advanced or recurrent HER2-positive breast cancer, one of which is profoundly misleading and the other simply untrue. The researchers were understandably enthusiastic about the treatment, as it is the first one to use a targeted therapy – in this case Herceptin – to deliver ‘old-fashioned’ cytotoxics (cell-killing agents) directly to cancer cells (the stealth-bomber concept). In theory this means that highly toxic drugs can be safely delivered to their target without damaging the rest of the body – hence the quote about the Holy Grail.

In practice, the drug comes with a warning of side-effects that include liver toxicity, heart toxicity and death, as well as possibly leading to severe life-threatening birth defects if taken while pregnant. So much for ‘no side-effects’. Does it destroy disease? The trial results showed a median progression-free survival of 9.6 months compared with 6.4 months in patients on the comparator arm, giving a median overall survival of 30.9 months in the Kadcyla group and 25.1 months in the comparator group. Good news, but no Holy Grail.



SUNDAY EXPRESS

drugs targeted to block the cell signalling that drives them, making cancer a “chronic” disease, have not materialised so far.

Current hopes are resting on many different approaches, which are likely to be used in different combinations. These include combinations of cytotoxics, targeted (‘personalised’) therapies and immunotherapies. More targeted ways of delivering physical or chemical attacks directly to cancer cells, eg by nanotechnologies or interventional radiology, are also in various stages of clinical trials.

Unrealistic expectations

A study into ‘cancer breakthrough’ reporting in Australia (*Med J Aust* 2003, 179:639–43), showed that, of 31 “cancer breakthroughs” reported between 1992 and 1994 in the *Sydney Herald*, 10 years down the line, 43% were judged as not having been supported by further research in the following decade, 10% had been refuted, 53% were judged to remain ‘potential’ breakthroughs, pending further research, and only 27% had been, or were about to be, incorporated into medical practice.

This matters, not least because it gives people an inaccurate perception of

what a new therapy is really likely to offer them.

It is not uncommon to hear of people getting into serious debt or selling their house to raise funds to get treatment abroad or pay privately for a therapy they have heard about that is not yet approved for sale or reimbursed in their own country.

Media reports that “hype up” the likely benefit a new therapy can often give patients a false idea about how much they stand to gain from taking such drastic action, and can add to the stress and other pressures they already face.

The Salzburg statement on Shared Decision making includes a call for journalists to play their role in helping people make informed decisions about their health by ensuring “that the information that they provide is clear, evidence-based, and up to date, and that conflicts of interest are declared.” (<http://e-patients.net/archives/2011/03/the-salzburg-statement-on-shared-decision-making.html>).

When covering stories about new therapies, diagnostics or research, many journalists say they feel part of their role is to offer hope. This is obviously important: cancer frightens people, and they want to hear that it is being “beaten”. Cancer

research also relies heavily on fund raising, so giving a hopeful message can help. However, the information journalists provide should be trustworthy, and not raise unrealistic expectations.

Most new cancer drugs are first trialled in patients with incurable cancers, where the benefit is measured in terms of extended survival. If approved in that setting they may then be trialled for use in a ‘curative’ setting, usually used ‘adjuvantly’, to kill remaining cancer cells after the main tumour(s) has been dealt with by surgery or radiotherapy, or “neoadjuvantly”, to shrink the tumour(s) in advance of surgery or radiotherapy.

It is misleading and unethical to describe new therapies as “wonder drug”, “breakthrough”, “life-saving” or “cure”, unless research reliably shows a significant proportion of patients eligible for the treatment derive enough benefit to merit that description.

Evaluating claims about new research

Press releases about potential new treatments may relate to findings from any point in a research process that typically spans more than a decade. Sometimes there is not even an actual

A story of incremental progress

Linda Geddes received a Best Cancer Reporter Award for her article, *Living with the Enemy*, which took a critical look at advances in cancer treatment, concluding that the longed-for breakthrough may never happen, and that progress will continue in the steady incremental way it has been going over recent decades. The article was first published in the *New Scientist* and was republished in *Cancer World* (www.cancerworld.org/pdf/3709_pagina_24-28_bestreporter.pdf)



agent involved, but just the discovery of a mutation believed to play an important role in driving a cancer or rendering it resistant to existing treatments, which could be a target for biological drugs yet to be developed.

Journalists need to know how to make sense of research studies, how to evaluate the strength of evidence, and how to convey this information in a way that people can understand.

This is not easy, given that journalists may have only a few hours to work on it. Following a few basic principles should help avoid sending out the wrong message.

Be critical

Ask questions about claims for new discoveries or treatments, rather than taking them at face value and looking for ways to maximise the impact of the story based only on face value.

Always seek an independent comment

The gold-standard with stories like this is always to get comments from at least one independent expert. However, this is not always possible given the time constraints. Even if you can get hold of an expert, they may not be aware of the report in question or have had time to read and digest it. Some-

times journalists have to rely on their own judgement.

Where does the report originate?

The 'quality mark' of medical/scientific research has always been publication in a high-quality peer-reviewed academic journal, where a respected editorial board and team of peer reviewers scrutinise papers before publication and effectively vouch for the paper as a valid piece of research.

While this remains the case today, pressure for getting results out quickly, and huge competition for media attention, means that a lot of research is published first as 'interim reports' in the form of abstracts presented at prestigious international conferences, such as ASCO and ECCO. These abstracts will have gone through a selection process that acts as some form of quality control, but interim reports can only speculate about what the final results of a study might be.

With social media making it easy to communicate and discuss research without recourse to official publication channels, an increasing amount of research is also finding its way into the public domain that has not been through a pre-publication quality assessment and is not aimed at a mass audience.

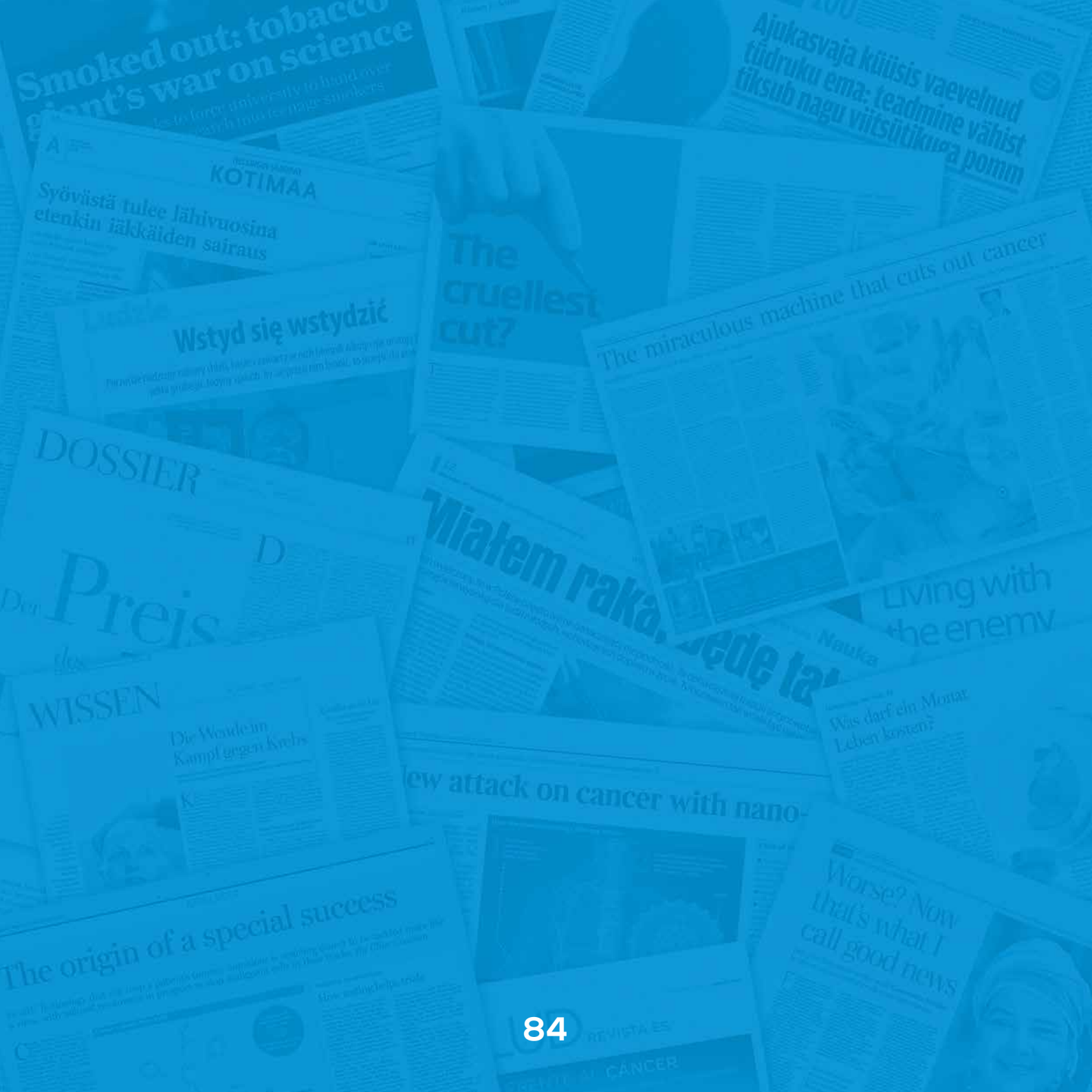
Journalists need to be aware of the differences between different sources of information and what that means for its credibility. If it has not been presented at a major conference or published in a peer-reviewed journal, they need to ask the question: why not?

Beware of 'presentational bias'

Reports published in peer-reviewed journals will have been checked for the integrity of the scientific process, but journalists are advised not to rely on reading only the abstract, discussion and conclusions.

A (peer-reviewed) study of reports of a series of recent clinical studies in treatments in breast cancer showed marked presentational bias (systematic error) in reports of studies which had failed to demonstrate what the researchers had hoped to demonstrate. In many cases, the report authors gloss over the failure while focusing instead on outcomes that had not been of primary importance in the trial design, but had shown better results.

Your audience may be more interested in hearing about positive results, but the main question addressed by the study will be the most important one, and if the results are negative, it is important to say so.



Ask the “So what?” question

Stories about potential new cancer therapies can hit news desks at any point in their development, from basic research that gives rise to a new concept of treatment, to proof of concept tests and preclinical tests of novel therapies, to the results of large trials in patients.

Killing cancer cells in mice or Petri dishes is not the same thing as curing cancer. How much benefit real cancer patients will ever derive from the experimental therapy cannot be known until the therapy has been developed and properly tested in clinical trials, which may take 5-10 years or more. Most preclinical studies are never taken forward into clinical trials in real patients.

Make sure your audience is clear about whether the story has practical implications for people with cancer today or in the near future, or whether it is a story of interest and hope for the future.

Be aware that researchers are likely to overstate the implications of their own research. They believe passionately in what they are doing, they want it to succeed, and they want to convince funders to keep backing them.

Evaluating and interpreting clinical trials

Stories about the results of studies of novel therapies in clinical trials in actual cancer patients are of relevance to patients of today and tomorrow, but here again journalists need to be clear about exactly what the trial claims to show and how strong the evidence is.

What is the trial designed to show? Trial phases

All medical therapies for cancer have to be approved by the European Medicines Agency before they can be marketed in EU member states. Traditionally this involved going through three phases of clinical trial:

- **Phase I:** Testing how safe it is, and at what doses.
- **Phase II:** Testing whether it is active against cancer, and merits being taken further.
- **Phase III:** A much larger trial aimed at providing convincing evidence that the benefit to patients is clinically relevant, that it outweighs the risk posed by toxic side-effects, and that it is better in some way than existing therapies.

This model for clinical trials is now being adapted to the needs of developing

personalised, or ‘precision’, medicines. Phase II trials, or sometimes combined phase I/II trials are increasingly used to try to tease out which patients respond best to the experimental therapy, at which dose and which stage of the disease.

New imaging techniques also mean much more can be learned about the biological impact of an experimental drug without having to wait for that impact to show up in scans showing tumour shrinkage or the halting of tumour growth.

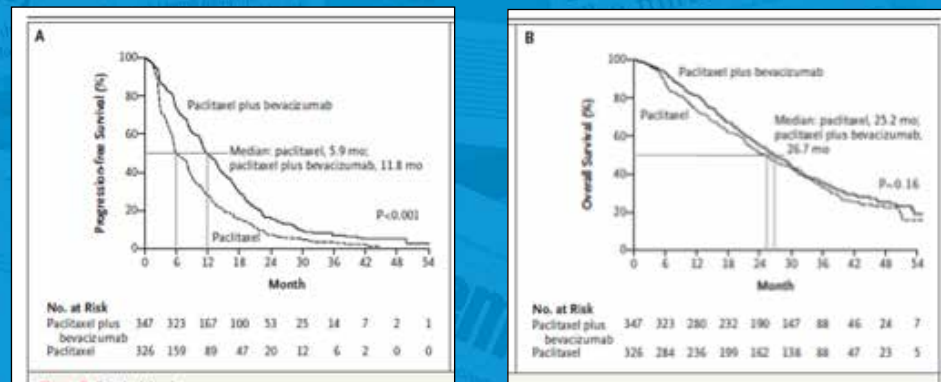
New knowledge about potentially relevant molecular mutations means it makes sense to try to find mutations that are associated with a particularly strong (or weak) response to the experimental therapy.

With the current focus on using “cocktails” of therapies, early phase trials may be used increasingly to try out different combinations, before taking the most hopeful contender on to a large phase III trial.

For all these reasons, the results of exploratory early phase trials are increasingly getting picked up and reported in the mass media.

Progression-free survival or overall survival?

Avastin (bevacizumab) was approved for use in advanced breast cancer on the basis of evidence that it delayed progression of the disease. However, when the overall survival statistics became available, they showed the therapy did not result in patients living any longer



K Miller et al (2007) Paclitaxel plus Bevacizumab versus Paclitaxel Alone for Metastatic Breast Cancer. *N Engl J Med* 357:2666-76, reprinted with permission

Usually regulators will require evidence generated from large phase III trials to examine an application for marketing approval. Trials that are used as a basis for applying for marketing approval are known as 'pivotal' trials.

When reporting on the results of clinical trials, journalists need to distinguish between trials that are designed to produce strong evidence about clinical benefit, and those that are merely designed to learn more about the experimental therapy and how best to use it.

What are the clinical endpoints?

When designing clinical studies, researchers choose "endpoints" – the measurements by which they intend the outcome of the study to be judged.

Patients want new therapies to show that they will help them live longer and feel better, but many clinical trials measure "surrogate endpoints" rather than the real thing.

Studies that use endpoints that measure a biological or physiological impact – the drug hits the target, a change in the tumour's metabolic rate, a change in blood flow – may show a therapy is behaving as intended but do not show the patient is deriving any benefit. Some-

times the impact can be quite dramatic, and researchers can be understandably excited.

These sorts of studies cannot be used to get a new therapy approved for market. They may be newsworthy, but reporters should bear in mind the poor history of translating these hopeful results into 'breakthrough' therapies, and should not raise expectations by overstating the implications for patients in the near future.

Overall survival vs progression-free survival

The most common endpoints for phase III trials are **overall survival (OS)** and **progression-free survival (PFS)**.

Studies with overall survival as an endpoint are designed to show that patients in one arm of the trial (the part of the study in which the treatment being investigated is given) live longer than those in a comparator arm (the part of the study in which the treatment under study is not given – usually this group of patients will be on the current 'standard of care' ie the standard treatment given to patients outside the trial).

An alternative measure, used as a surrogate for survival, is progression-free

survival, which shows how long, during and after the treatment, a patient lives with the disease but the cancer does not progress.

Overall survival is the more convincing endpoint, because a new therapy may be more effective at keeping the cancer at bay for longer, but once progression starts those patients may die as quickly as those on the other arm – or even quicker.

The European Medicines Agency accords value to progression-free survival as an endpoint in its own right, on the basis that patients can feel better, both psychologically and physically, if their cancer is being kept at bay. Reimbursement authorities, on the other hand, sometimes cite the lack of evidence on overall survival benefit as a reason to refuse or restrict reimbursement of new drugs.

However, improved overall survival can be hard to prove, for ethical reasons.

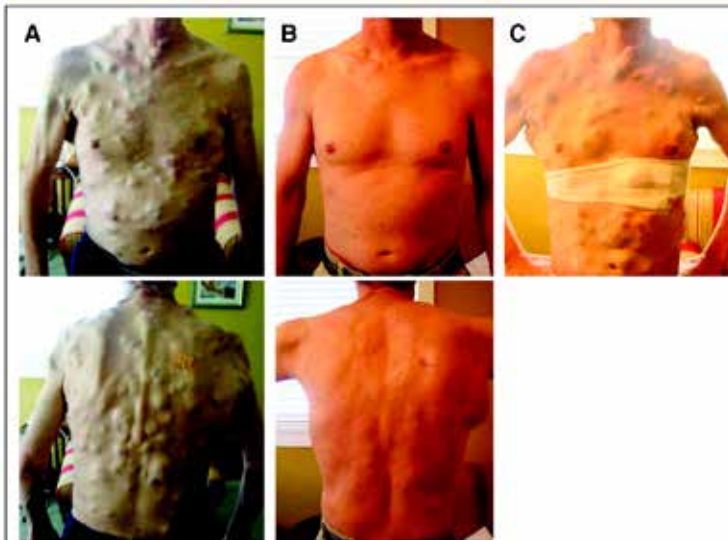
If an early look at the trial data shows that patients in one arm of the trial are doing better than those on the other in terms of delayed progression, trial participants will understandably want to change to the arm that seems to be doing better.

It's a dramatic response, but how significant is it for patients?

When researchers began seeing responses like the ones in panel B, they had every reason to be excited. Used in patients with advanced melanoma who had a mutated BRAF gene, the BRAF inhibitor vemurafenib seemed to make the tumours “melt away”. A few weeks or months later, however, the cancer typically becomes resistant to the treatment (panel C). As is so often the case, the new treatment is an important step forward, but more work has to be done before it can be translated into real progress for patients.

Asking the “so what?” question is a way journalists can ensure they do not give their audience an overblown impression of what a new treatment can actually deliver

BRAF inhibitors: SUCCESS AND FAILURE



They won't want to be kept on the apparently inferior treatment for the sake of providing stronger evidence that early progression-free survival results really do translate into convincing proof of longer overall survival.

This presents the researchers with an ethical dilemma: do they ignore the patient's request for a different treatment, or do they switch the patient to the apparently better arm, thereby weakening the trial and lessening the chances of gaining meaningful results?

Overall survival benefit can also be difficult to demonstrate when there are a variety of therapies available that trial participants can move on to once their disease has begun to progress. This is a bigger problem in testing new therapies for advanced breast cancer, for instance, than pancreatic cancer, where very few therapeutic options are available.

Overall survival also takes longer to demonstrate, particularly in settings where patients can stay alive for a long time with active disease. This has implications for cancer patients who need quick access to new therapies, and for pharmaceutical companies who have limited years of patent protection.

Journalists need to be clear about the difference between showing improved progression-free survival, and showing that patients actually live longer.

They need to understand the issues surrounding the choice of endpoint, as these are controversial, particularly when it comes to decisions on reimbursement.

These choices are often a question of balancing conflicting interests – something that should not be left up to the medical profession, regulators and reimbursement authorities alone. How do you balance the interests of trial participants and current patients outside the trial, for whom speed is the priority, against the interests of future cancer patients and the health system as a whole, for whom the priority is robust evidence of the benefit (and risk)?

Journalists can help explain the issues and give a voice to all sides.

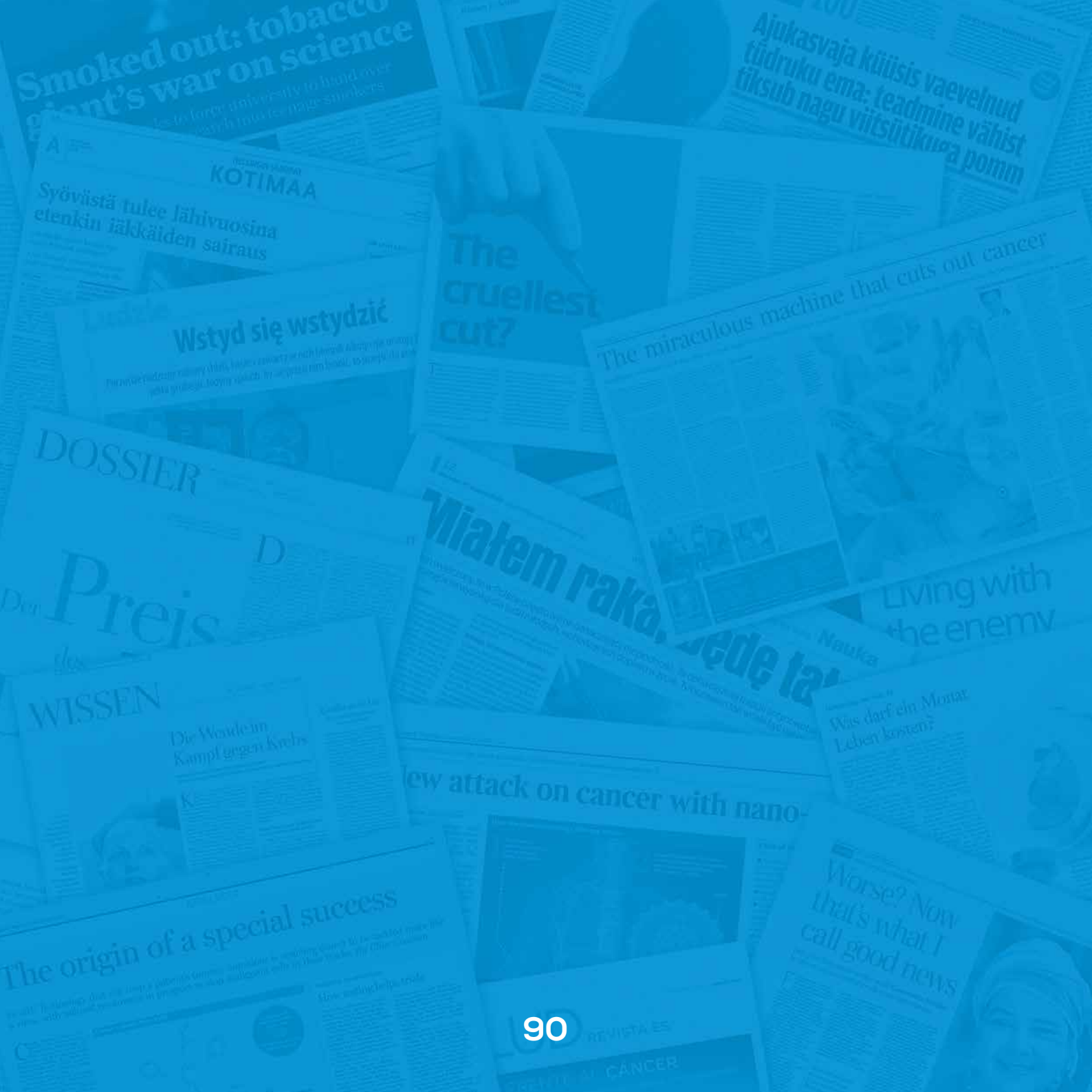
Side-effects and quality of life

Cancer therapies are notorious for their side-effects, which range from the irritating and unpleasant to potentially life-limiting and life-threatening. Even less-threatening side-effects can be fatal if patients find them so hard to bear that they give up on the treatment.

Long-term side-effects remain an especial problem in treatments for childhood cancers, as patients may feel the effects for the rest of their lives. A recent study of 1700 survivors of childhood cancer found that by the age of 45, about eight out of ten had at least one life-threatening, serious or disabling condition. This puts the 'good news' story about an 80% survival rate for childhood cancers in developed countries into sobering perspective.

Side-effects are also a particular issue for therapies that are taken for very long periods of time, like Glivec for chronic myeloid leukaemia (CML). Studies have revealed that a surprisingly high number of people on Glivec do not take the medicine as prescribed, which can limit its effectiveness.

Side-effects with therapies used adjutantly raise a different set of issues. Adjuvant therapies are given as a sort of “insurance” after the cancer has apparently been cleared by surgery or radiotherapy. While it does bring down overall rates of recurrence, many who receive the treatment would have remained cancer free anyway. They therefore suffer the side-effects without deriving any benefit.



Reports of clinical trials will always give data on side-effects. Journalists should take this information seriously. A significantly increased risk of heart attack or stroke may seem irrelevant if the therapy is going to save people dying of cancer, but it becomes very meaningful when the data shows only an incremental improvement in survival rates, or perhaps evidence only of improved progression-free survival.

More recently, largely in response to demands from reimbursement authorities, researchers have also started to measure quality of life indicators, which are intended to measure how the patient feels, as opposed to the more clinical measure of ‘side-effects’, which tends to focus on medically serious problems. A disfiguring rash or chronic diarrhoea may not be worth reporting as a medically significant side-effect, but could seriously affect someone’s quality of life if it puts them off going out. Quality of life measures may also register, for instance, the convenience offered by therapies that require fewer visits to hospital.

In some cases approval for a new therapy is sought with the primary endpoint of offering better quality of life with no worse survival than the existing standard of care.

The question of how much importance should be accorded to quality of life issues when evaluating cancer therapies is one that routinely arises when reimbursement authorities consider whether to reimburse a new drug, and at what price. People living with cancer often feel that decision makers do not understand how much “little things matter”, when you have only a short time to live, or when you face many years trying to live a normal and fulfilling life on cancer medications.

Public discussion about what extra life and quality of life are worth is essential to ensure that the proportion of money spent on health and how that money is allocated accurately reflects social priorities.

Journalists can help ensure that all sides are represented in this debate, including the voice of people who are living with cancer.

Selection criteria: Who is being studied? Clinical trials sponsors define the sort of patient they want to test their drug in by setting “selection criteria”. They may also specify “exclusion criteria” to define the sort of patient they do not want included.

For understandable reasons, drug developers tend to want to trial their drugs

in patients who are generally younger and fitter and have been through fewer previous treatments. However, most cancer patients are elderly, and many will not be very fit and may suffer from other conditions such as diabetes or heart disease.

When evaluating the significance of trials findings, journalists should bear in mind that the closer the selection criteria correspond to the profile of patients outside the trial, the more likely that benefits seen within the trial will still be evident when the drug is in wider use.

With the new ‘personalised’ therapy paradigm, a new issue has arisen of how precisely drug developers have identified which subset of cancer patients are expected to benefit from the new therapy.

What is the comparator arm? Is the experimental drug being compared against the best available alternative? Drug developers may prefer to go head-to-head with something they feel their drug can outperform. Sometimes the comparator arm is a valid choice when the trial is designed, but is later superseded by a new and more effective treatment after the

The 'personalised' or 'precision' therapy paradigm is all about dividing cancers and patients into ever smaller subsets. This could possibly make the traditional large phase III trials increasingly difficult, expensive and slow. At the same time, developments in imaging in particular are allowing much more biological information to be gathered during trials, which could make up for weaker statistical levels of proof. The question of what constitutes an acceptable level of evidence has implications for access to new medicines, progress in science and public faith in evidence-based medicine, and is therefore of considerable public interest. *Cancer World* explored this topic with particular reference to therapies for people with rare cancers
www.cancerworld.org/pdf/6386_pagina_24-30_cuttingedge.pdf



trial commenced, by which time it is too late to make changes.

Types of study and the strength of evidence they yield

Details of the study design are usually detailed in the "Methods" section of a study report. Journalists should take the time to read this section so they can evaluate how convincing the evidence really is.

Studies are considered to provide stronger evidence if:

- They are prospective – designed to answer specific questions in a specific way in advance of enrolling patients, rather than seeking to draw conclusions about treatment outcomes retrospectively.
- They test experimental therapies against one or more comparator or 'control' arms – often the existing standard of care – rather than using no controls, or comparing against retrospective outcomes from earlier cohorts of patients ('historic controls').
- They use randomisation to allocate patients to the experimental or comparator arms in preference to other allocation procedures which can introduce bias (systematic error).
- Neither doctors nor patients know

who is on which treatment arm, to avoid bias being introduced from the expectations of either side.

- Enough patients are enrolled to show with a high degree of certainty that the difference in outcomes between the trial arms is due to the differences in the treatment they received and not simply a matter of chance. A probability (measured as a "P-value") of less than 0.05, equivalent to a 1 in 20 chance, is generally taken as an acceptable level of evidence.
- The smaller the difference between the outcomes of the trial arms, the larger the number of patients needed to show the difference could not have come about by chance.
- Studies enrolling too few patients to demonstrate a difference in outcomes to an acceptable level of certainty are said to be 'underpowered'. Though underpowered studies are not ideal, they may be seen as acceptable in evaluating new therapies for very rare cancers or cancer subtypes, where it can be difficult to recruit enough patients. In these cases, alternative approaches are often advocated, including "Bayesian" approaches which allow underpowered studies to be supplemented by additional evidence rated in a transparent and systematic way for its relevance

and strength. So far (February 2014) Bayesian approaches have never explicitly been used to approve a new drug, though they are being used in some phase II trials.

What is an acceptable level of evidence?

The regulators responsible for approving new therapies, and the reimbursement authorities responsible for deciding whether and to what extent they are funded, make judgements about the quality of the evidence in front of them. Their judgements have an impact on the speed of access to new therapies – but also on the pace of progress in treating cancer, which is not just about the number of new therapies but whether, and by how much, they actually improve outcomes.

These issues belong in the public domain. Journalists can help explain the issues, and why they matter, and promote informed discussion.

Is it affordable, is it value for money?

This is a question that will not be covered in clinical trial reports or by the European Medicines Agency, but it will increasingly be the most important question that determines which new therapies patients get access to.

A resource for journalists

www.testingtreatments.org is a website dedicated to issues in testing treatments and what constitutes a fair test. Part of the site is devoted to providing resources for journalists (www.testingtreatments.org/category/resources-for-journalists-and-science-writers).

A free download of the book *Testing Treatments* (2nd edn), by Imogen Evans, Hazel Thornton, Iain Chalmers and Paul Glaziou is available on www.jameslindlibrary.org/pdf/testing-treatments.pdf



Decisions about whether newly approved therapies will be reimbursed – in total or with a co-payment – and which patients will be eligible for reimbursement are made by government agencies (national or regional) or social insurance bodies.

As a result, who gets access to what differs between and often even within countries.

Every member state has its own system for assessing the value of new therapies and negotiating prices. Some countries conduct thorough and transparent health technology assessments, taking evidence from all stakeholders, and use standardised procedures for determining the value of new therapies. In others the process is more opaque. Some countries negotiate hard over prices, while others link the price they pay to an average of what other countries pay.

For a good background guide on the concepts used in health technology assessment see the *Guide to Understanding Health Technology Assessment* produced for patients by Health Equality Europe. (<http://img.eurordis.org/newsletter/pdf/nov-2010/58-1%20HEE%20Guide%20To%20HTA%20for%20Patients%20English.pdf>)

With health budgets under pressure as never before, journalists have a role to play in promoting informed debate about how best to spend limited resources. This debate is especially urgent in the case of cancer, because of the high price of new therapies – particularly if they are to be used in combination – and the growing number of people who are living longer with cancer.

People living with cancer can often feel they are viewed as “hopeless cases”, and spending money on new therapies that extend or improve their lives is a poor use of resources. They question why they contributed all their lives to the health system, via taxes or health insurance, if they are denied care they need when they need it.

Journalists can ensure their voices get heard, and can take a critical look at the factors determining the price of new therapies, and the people and processes involved in decisions about reimbursement and the allocation of healthcare resources.

Understanding and reporting the statistical data

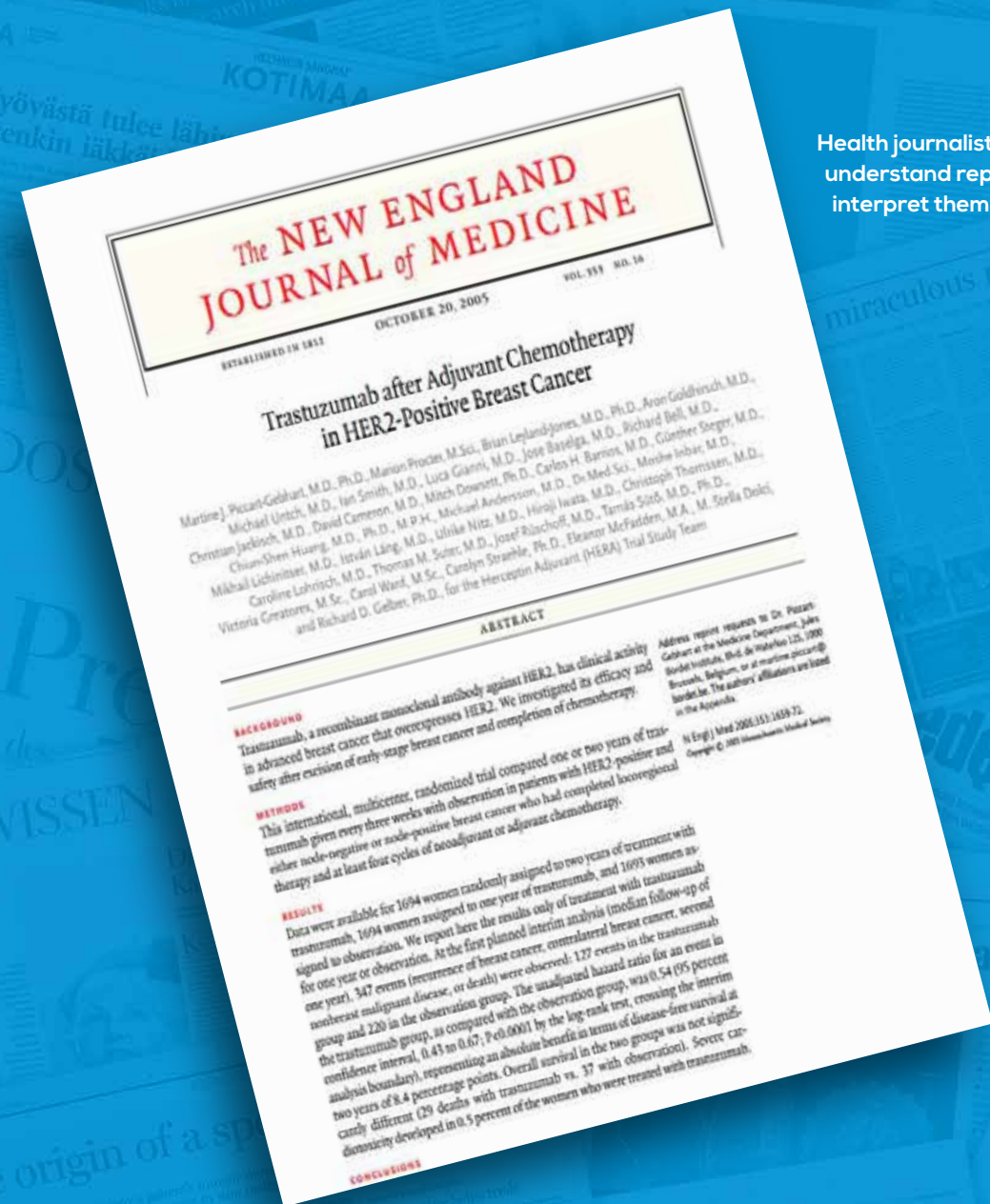
Research reports are written for scientists. Journalists need to be able to understand the statistics and present

them in a way that their audience can make sense of.

Example: the HERA trial

This example given below of the report of the results of the HERA (Herceptin as Adjuvant) trial, published in the *New England Journal of Medicine* in 2005 (www.nejm.org/doi/full/10.1056/NEJMoa052306), is typical. The trial compared one or two years of Herceptin (trastuzumab) with observation (ie no further therapy) in patients with HER2-positive early-stage breast cancer who had already undergone surgery followed by standard adjuvant (or neoadjuvant) chemotherapy. It had disease-free survival as its primary endpoint and cardiac safety and overall survival among a number of secondary endpoints. It summarised its results as follows:

“347 events were observed: 127 events in the trastuzumab group [n=1694] and 220 in the observation group [n=1693]. The unadjusted hazard ratio for the risk of an event in the trastuzumab group, as compared with the observation group, was 0.54 (95 percent confidence interval, 0.43 to 0.67; P<0.0001 by the log-rank test...) which corresponded to an absolute benefit in disease-free survival of 8.4 percentage points at two years (95 percent confidence interval,



Health journalists need to know how to understand reports like this one and interpret them for their audience

2.1 to 14.8). ... With 29 deaths in the trastuzumab group and 37 in the observation group, the estimated reduction in the hazard ratio for death (24 percent) was not statistically significant. ... [There was] a higher incidence of NCI-CTC grade 3 or 4 adverse events and serious adverse events in the trastuzumab group than in the observation group. There were six fatal adverse events in the trastuzumab group and three in the observation group. (NEJM 2005, 353:1659-72).

This is what it means: As the primary endpoint was disease-free survival, an ‘event’ in this case meant the recurrence of disease in some form (“recurrence of breast cancer, contralateral breast cancer, second nonbreast malignant disease, or death”). In terms of the secondary endpoint, overall survival, an ‘event’ meant a patient death from any cause. The number of events is important for the credibility of the results. The fewer the ‘events’ the more likely any difference may have come about by chance. We are told that the results for disease-free survival were based on 347 events, whereas the results for overall survival were based on 66 events (29 + 37). This means the results for overall survival are less reliable.

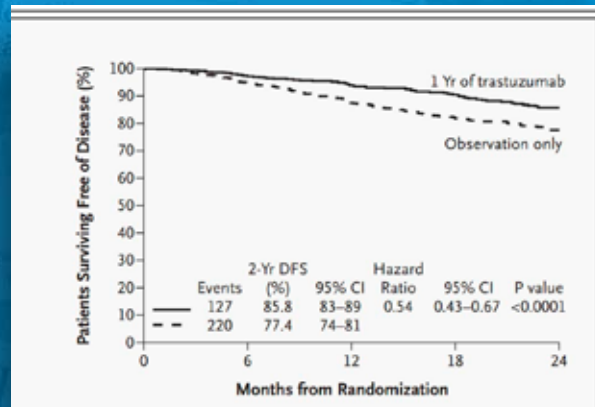
A **hazard ratio** (HR) is a measure of how often the event being measured happens in one group compared with how often it happens in another group, over time. A hazard ratio of 1 means that there is no difference between the two groups. A hazard ratio of greater than 1 or less than 1 means that survival, progression-free survival (or another endpoint) was better in one of the groups.

The hazard ratio of 0.54 means that the ratio of the rate of cancer recurrence between the Herceptin group and the standard treatment group is 0.54:1. This means that for every 1 recurrence in the standard treatment group there was (statistically speaking) 0.54 recurrence in the Herceptin group, which can be better expressed as 54 recurrences in the Herceptin group for every 100 in the standard group. In other words, the reported results showed an almost halving of recurrence rate at that point in time.

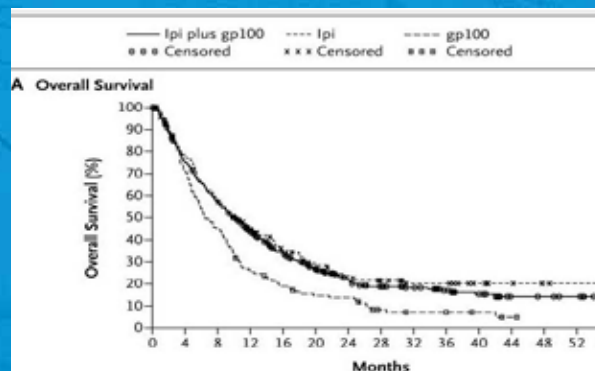
The hazard ratio for death was given (in Figure 2c of the report) as HR=0.76 – in other words for every 100 deaths in the observation arm you would expect 76 in the Herceptin arm. In the Results text, quoted above, this was presented as a 24% reduction in the hazard ratio for death.

The **95% confidence interval** is a measure of certainty that the hazard ratio, calculated on the basis of the observed events, represent the true size of the difference between the two groups. In this case, for the primary endpoint disease-free survival, there is 95% certainty that the true hazard ratio lies between 0.43 to 0.67. This means that if the same trial was done again and again with the same groups, in 95 out of 100 cases the hazard ratio would come out at between 0.43 and 0.67. For overall survival, the 95% confidence interval is given (Figure 2c of the report) as ranging from 0.47 to 1.23. This is not only a much wider range than for disease-free survival, but it doesn’t guarantee with 95% confidence that the statistical likelihood of dying, based on the relatively few deaths recorded at that point, may not even be higher in the Herceptin group than the observation group (because the upper limit is above 1).

The **probability** or **P-value** is a similar measure, in that it indicates what the chances would be of getting the observed pattern of events if, in reality, Herceptin conferred no benefit for disease-free survival, and the differences shown in the trial had happened merely by chance. In this case the P-value for disease-free survival was 0.0001 – a one



M Piccart-Gebhart et al (2005) Trastuzumab after Adjuvant Chemotherapy in HER2-Positive Breast Cancer. *NEJM* 353:1659–72. Republished with permission



S Hodi et al. (2010) Improved survival with ipilimumab in patients with metastatic melanoma. *NEJM* 363:711–723. Reprinted with permission

Kaplan-Meier survival curves

The impact of new treatments on progression-free or overall survival is often presented in curves like these. Where the treatment is adjuvant (used to mop up stray cancer cells after the tumour has supposedly been entirely removed), as for the HERA trial (*top*), the curve should flatten out at a level that indicates the long-term survival rate – in this case between 75% and 80% of patients. Where the treatment is for advanced cancer – as for the trial of ipilimumab in advanced melanoma (*bottom*) – the curve will tend towards zero, as these cancers are not currently curable. The long tail indicates that the treatment is particularly effective in a small subgroup of patients. When this happens, it typically prompts further research to find ways to distinguish between strong and weak responders, so the treatment can be used only in those who are likely to benefit – the personalised medicine paradigm

in 10,000 chance that Herceptin offered no benefit at all. The P-value for overall survival, by contrast, was only 0.26 (see Figure 2c), which represents a one in four chance and is not statistically significant. (A follow-up study published in 2012, after many more deaths had occurred on both arms, did in fact confirm a hazard ratio for death of 0.76 for women taking Herceptin for 1 year compared to observation. The higher number of ‘events’ meant the statistical significance of the findings had increased from P=0.26 in 2005 to P=0.0005, or one in 2000.)

The **absolute benefit** indicates the difference between the rates of disease-free survival between the two groups. In this case the Herceptin group had a 85.8% rate of disease-free survival at 2 years follow-up compared with 77.4% in the observation group (Figure 2a), giving an absolute benefit of 8.4 percentage points (with a 95% confidence that this value lay between 2.1 and 14.8 percentage points). In other words, for every 100 women with HER2+ early breast cancer who take Herceptin as adjuvant, an additional 8.4 will still be disease free at two years after diagnosis.

Kaplan-Meier (survival) curves

The HERA report also presented the data as a Kaplan-Meier curve (top

curve opposite), which shows the percentage of survivors in a step-wise fashion as time progresses for the comparator arms. The wider the gap between the two curves, the greater the difference between the treatment arms.

As this was a trial of adjuvant treatment, ie given to people who were apparently disease free after undergoing curative surgery, the Kaplan-Meier curves tend toward the 70–80% long-term survival rate.

(Where the experimental therapy is given to patients with advanced disease, by contrast, the curve will tend drop to zero over time, as it does in the lower graph, which shows the results of a trial of ipilimumab in patients with advanced melanoma. The long tail of the curve indicates that there is a small subset of patients who show long-term responses. When this happens, it tends to trigger an investigation to find a molecular (or other) marker that can help identify in advance the patients who are most likely to respond well.)

Side-effects

Side-effects were reported using the NCI-CTC (US National Cancer Institute common terminology criteria) for ad-

verse events, each of which is graded for severity, with grades 3 and 4 indicate the most severe. Table 2 shows the trastuzumab group had a higher incidence than the observation group of NCI-CTC grade 3 or 4 adverse events (7.9% vs 4.4%) and serious adverse events (7.7% vs 4.7%) and there were six fatal adverse events in the trastuzumab group and three in the observation group.

Interpreting it for your audience

This was a good news story in the effort to cure cancer, and in particular breast cancer, but the practical implications applied only to a relatively small group of people with the disease.

Who stands to benefit?

It is important to spell out early on exactly who stands to benefit.

In this case, as is stated in the background to the report, it is women with early-stage breast cancer of a particular molecular subtype (HER2-positive) that occurs in 15–25% of breast cancers, who have already undergone surgery and chemotherapy.

How good was the news?

The most accurate way to convey benefit is by using the statistical data on ‘ab-

Conveying complex statistical information

Using pictograms like this one is the best way to get across statistical information about how different treatment options can lower the risk of different 'events' eg the risk of dying from the disease or of the disease recurring within a certain time period, or the risk of suffering a serious side-effect from treatment



solute benefit', because this gives an idea of what would be expected to happen without the new treatment, and what difference the new treatment makes to that expected outcome. Try to use whole numbers in preference to percentages, fractions or decimals. If possible use a pictogram like the one opposite.

In this case, the results indicated that among women who stand to benefit from the drug, taking Herceptin would increase the number who are cancer free two years after diagnosis from 77 out of every 100, to 86 out of 100 – an additional 9 women out of every 100.

How strong is the evidence?

Journalists should always flag up to their audience how credible the report's findings are. This involves making a judgement based on the criteria detailed above in the section above on Evaluating and interpreting clinical trials

In this case the study produced very strong evidence. It was a large trial, conducted in a well-defined patient group. It was a prospective, randomised, controlled trial. The results showing improved disease-free survival were highly statistically significant ($P=0.0001$). The results showing improved overall survival, by contrast could not be relied on

from a statistical point of view ($P=0.26$) because so few deaths had occurred in either arm at that point. However, as most recurrences happen within the 2-years of the initial diagnosis (as stated in the Background to the study report), it is reasonable to speculate that the significantly lower recurrence rate would go on to translate into better survival – as proved to be the case in the 2012 follow-up report.

The credibility of the HERA trial was all the greater because the results closely resembled those of a similar trial which was reported in the same issue of the *New England Journal of Medicine*.

Side-effects

When looking at a treatment for a life-threatening disease like cancer, it is easy to dismiss side-effects as of minor importance. This might be fair enough if the treatments in question were highly effective. However, in most cases the benefit is incremental, and the toxic side-effects can in themselves be life-threatening. It is also worth making clear that toxic effects aren't always fully picked up in trial reports, because they can take decades to become apparent.

This means any story about a new treatment is incomplete unless it gives

proper attention to the side-effects, particularly side-effects that may be long-lasting or irreversible.

In the case of Herceptin, it was already known that the drug could lead to serious heart problems. The HERA trial confirmed this to be the case, but also showed no deaths from heart disease on the Herceptin arm, with symptomatic congestive heart failure reported in 2%, but graded as serious in less than half a percent. So in this case, the message was more about the need to manage that risk by checking for heart problems before treatment and monitoring patients' heart health during and after treatment.

The issue of side-effects is particularly important when considering treatments given adjuvantly, as in the HERA study, because, most of the women given Herceptin would never have had a recurrence even without the drug, and they therefore get all the toxic side-effects without the benefits. One of the ways used to quantify this problem is using the concept of "number needed to treat."

In this case, where the figures for absolute benefit show that for every 100 women with early-stage HER2-positive



breast cancer who take Herceptin an additional 8.4 women are free of cancer two years after diagnosis, the number needed to treat in order for one additional woman to be cancer free is $100/8.4 = 12$ women.

This sort of statistic is a way of looking at the benefit compared with the cost of side-effects felt by the 11 out of 12 who do not benefit (and the economic costs to the health system).

Reporting Herceptin – a case study of hype

In the event, this good news story of the reduction in recurrence among women with early-stage HER2-positive breast cancer become hugely overhyped in the mass media, which focused heavily on the relative statistic – the number of

recurrences was almost halved – rather than the absolute figures which showed an additional 9 women remained free of cancer for every 100 who were given the new drug. As often happens, part of the problem originated with a comment by made by one of the lead researchers in an editorial published alongside the two adjuvant Herceptin trials in the *New England Journal of Medicine*, which talked about “a dramatic and perhaps permanent perturbation in the disease, and perhaps even a cure.” Naturally the media picked up on the c-word.

Because of the way the story was covered, the public got the impression that the chances of dying without Herceptin were much higher than they really are, and that the impact of Herceptin was much greater than it actually is, and that

HER2-positive breast cancer was now the most curable form of breast cancer – which is far from the truth. The result was to create unrealistic expectation,s and also unnecessary anxiety, with stories of women taking extreme measures to secure access to a drug that was not available in many countries at that time. Many women turned to the media for support, and the media was happy to oblige, which further amplified the hype.

It was a legitimate story, and the media was not wrong to highlight the plight of women who were desperately seeking access to the drug, but all of that could have been achieved with much greater clarity about the level of benefits that the drug really offered.



Life and death consequences
Bernhard Albrecht won a Best Cancer Reporter Award for this article, first published in the leading German magazine *Der Spiegel*, about why 'Renate Mulofwa' decided to shun evidence-based medicine in favour of alternative treatments for her breast cancer, and as a result lost her chance to be cured.

Entitled 'In the Jungle of the Miracle Healers', the article was subsequently republished in translation in *Cancer World* (www.cancerworld.com/pdf/1070_pagina_28-33_bestreporter.pdf)

People who make claims about anti-cancer effects that are not borne out by credible evidence published in peer-reviewed journals tend to play on other people's fears and 'gut instincts'. Journalists need to guard against this and subject the claims to critical questioning.

Reporting on complementary or alternative therapies

When you are diagnosed with cancer, it is natural and sensible to want to do everything possible to feel better and improve your chances of survival. It is very common for people to look around for therapies that are not part of conventional medicine, but that they believe could help them feel better or even help combat the cancer.

Some therapies, including for instance massage, t'ai chi or acupuncture, have been shown to help in various ways by alleviating certain symptoms including pain or even nausea, or reducing anxiety and stress and promoting emotional well-being. And any diet that promotes well-balanced healthy eating is always good for general health. However, there is a vast array of different types of treatments, diets, nutritional supplements and psychospiritual therapies that claim to be able to help people with cancer, without any evidence that they actually do so.

These tend to play to widespread beliefs about cancer and the nature of

conventional medicine, according to which cancer is the result of some sort of physiological imbalance that has to be restored by 'natural' means, or that there is an emotional or spiritual cause that needs to be addressed. Conventional medicine, meanwhile, is distrusted on the grounds that treatments based on cutting, radiating or poisoning cannot be healing. There is also a widespread belief in a grand conspiracy to suppress knowledge about simple and cheap cures for cancer that have long existed, in order to bolster the profits of pharmaceutical companies.

For people with cancer, there is a lot at stake here. At worst, people can – and do – miss their chance to be cured if they shun conventional treatments in the belief that alternative medicine may be more effective. Even when taken on a 'complementary' basis – ie alongside conventional medicines – some therapies can impact on the efficacy of the conventional treatment, or they may be harmful in themselves, or simply a con and a waste of money. It

can be hard to tell the helpful from the harmful.

Journalists have a responsibility to take a critical approach to claims made about the benefit of alternative or complementary therapies for cancer patients. They should avoid being complicit with people who make a living by offering false hope to people with cancer.

Look at the evidence

Conventional cancer medicine uses therapies that have been shown to work according to objective, transparent, fair and reliable tests, which will be published in peer-reviewed academic journals (see "Evaluating claims about new research", page 81).

Alternative medicines that claim they have an anti-cancer effect can offer no such evidence. There may be anecdotal evidence, there are often attempts at giving a pseudo-scientific explanation of how it works, and there may be a number of case reports. What there won't be is evidence from a properly conduct-



Sorting the helpful from the dodgy and the dangerous

People with cancer use a wide variety of complementary therapies to help them feel better physically or mentally. Journalists can help alert their audience to the possibility that some therapies may be harmful, or just a waste of money. They can help people understand the sorts of questions they need to be asking about claims and assertions made for these therapies, so they can make informed choices

ed trial showing an anti-cancer effect in cancer patients.

New cancer treatments take years to develop, they have never just appeared overnight. The idea that a journalist can scoop a true story about an unknown new anti-cancer treatment is therefore absurd.

However, it can sometimes look convincing on the face of it. People with cancer may seize on any explanation that seems to confirm their greatest hope – a ‘cure’ – and ignore any evidence that contradicts this view. They can also become outspoken and vocal in their convictions, presenting a ready-made ‘human interest’ angle to their story. This has obvious attractions as news. But it is founded on fear and false hope – and that is what reporting it without looking at the reliability of any claims will yield. Real harm can be the result. So this is an important matter of journalistic ethics.

Look at the credentials and vested interests of your sources

Anyone can call themselves an “expert”, and anyone with a PhD in anything, from anywhere, can call themselves “Dr”. Journalists should be clear about the true credentials of

their sources – as should the sources themselves, if they are legitimate. No genuine academic should be willing to risk their future reputation on knowingly giving false information (though they can overstate their case through over-enthusiasm, see for example page 79). A misleading or fraudulent claim, in contrast, depends on false or unreliable information.

Journalists should always ask the sources they use about vested interests, financial or otherwise, they may have related to the story. Vast amounts of money are made every year by unscrupulous people selling unsubstantiated hope to vulnerable patients.

‘Balance’ doesn’t mean everyone is equally credible

It is misleading and therefore unethical to give equal weight to alternative opinions when one source is making assertions that cannot be substantiated by credible evidence, while the other offers strong evidence and represents the views of the main body of research.

Being in the mainstream doesn’t make you right, but people in a tiny minority should be expected to show strong evidence before they are given credibility.

What role should non-conventional therapies play in cancer?

Taking a critical approach to stories about non-conventional therapies does not mean acting as a cheerleader for mainstream cancer medicine.

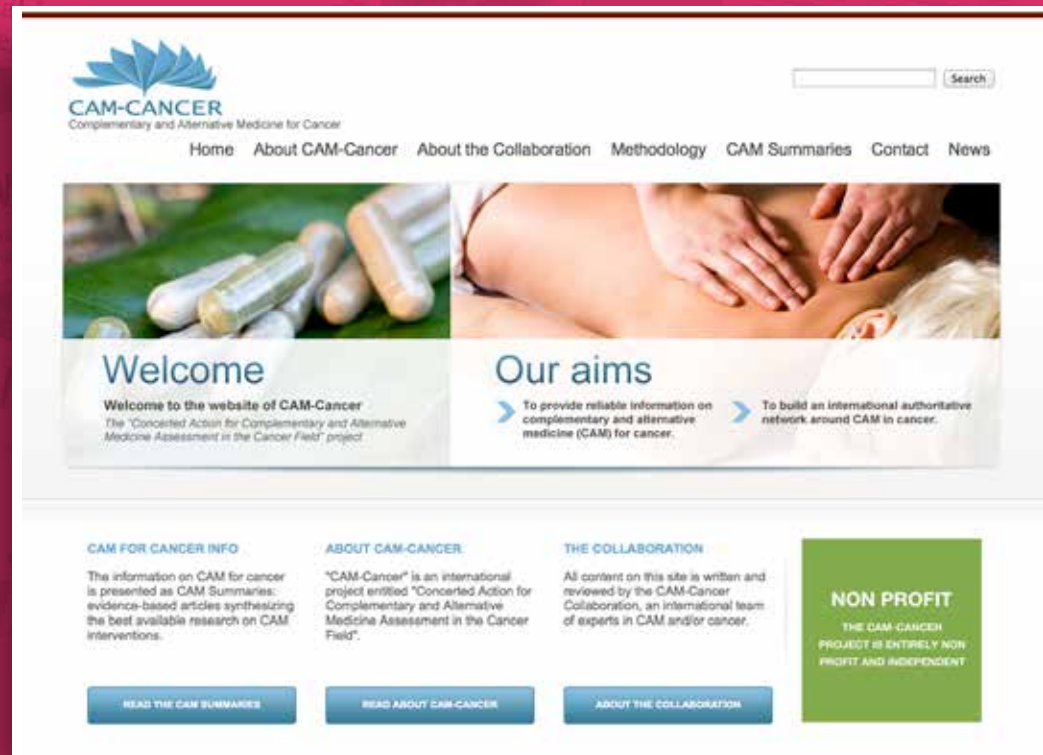
Around one in every three people living with cancer in Europe is estimated to be taking some form of complementary therapy, with the proportion being closer to three out of four in some countries.

The media has an important role to play in giving a voice to these people, and their efforts to find things that work for them.

While robust scientific research must be the arbiter of what works against cancer and what does not, the people who have the disease are the arbiters of what makes them feel better and what does not. Many of them spend a lot of time researching complementary therapies and swapping tips and experiences via their many networks, and they are a valuable and valid source of information.

Promoting dialogue with the medical profession

Patients frequently opt not to tell their doctors about other things they may be



What does the evidence say?

A good source of information on the current level of evidence behind many complementary and alternative therapies claimed to be effective for cancer patients is the website of the EU CAM-Cancer project (www.cam-cancer.org), which is hosted by the National Information Center for Complementary and Alternative Medicine (NIFAB) at the University of Tromsø, Norway.

taking or doing, often because they fear being ridiculed, or asked to stop. Many doctors, meanwhile, fail to ask their patients about their use of complementary therapies, or ask in a way that is unlikely to generate an open response.

This can lead to a variety of problems, some of them serious. Complementary therapies that have any form of biological activity can have a major impact on conventional cancer therapies that may be taken at the same time. Typically it can either decrease the effective dose (in which case doctors may assume the patient is not responding and could take them off the medication) or increase the dose (which can lead to dangerous toxic effects). Some extreme diets that lead to significant weight loss can lead to a dangerous increase in the effective dose of anti-cancer medication unless

it is adjusted to account for the change in body mass.

The media can help engage the medical establishment in conversations about non-conventional treatments. It can raise awareness among patients of the need to tell their doctors about what they are doing or taking, and raise awareness among the medical profession of the need to earn the trust of their patients and to learn about the potential effects of commonly used complementary therapies, so that they are in a position to offer them helpful and informed advice.

Questions for mainstream healthcare

The choices people make about turning to complementary or alternative therapists can also raise important questions

about what may be lacking in mainstream services.

Time, attention, a willingness to listen, hope, the 'human touch', fear of the damage done by mainstream therapy options are all cited as reasons why people choose to shun conventional medicine.

Giving a platform for these views to be aired can help promote discussion about whether these aspects of care are given sufficient priority in health-care systems, for instance in the training that doctors are given, in the allocation of specialist nurses with the time to provide advice, care and support, or in the quality criteria by which a clinician or hospital's performance is assessed.



Resources

1 Tools for health journalists

Testing Treatments – www.testingtreatments.org
The section for science writers and journalists provides a range of resources for:

- Conducting evidence-based analysis of current news stories.
- Sources of information about specific clinical conditions.
- “Ray Mohynihan’s” tip sheet for unravelling the story.

EU Heart project – a pan-European initiative to help raise the standards of health reporting in Europe (www.project-heart.eu)
The website contains a range of general training resources for health reporting. The two documents under the Health Care Quality and Performance heading are particularly relevant to the topics covered in this guide. They can be found at www.project-heart.eu/index.php/projectheart/elearning + log on + click the UK flag + click “UK modules” at the end of the list. Visitors to the site need to register, but it is free.

The European Health Journalism website (www.europeanhealthjournalism.com) also offers useful resources and information about training for health journalists.

Cancer World – www.cancerworld.org
Cancer World is a freely accessible bi-monthly European magazine that takes a broad look at how to reduce the unacceptable number of deaths from cancer that are caused by late diagnosis and inadequate cancer care. It covers key issues in the provision of cancer care, with perspectives from health professionals in all fields and at all levels, health policy makers, administrators and those for whom quality of care matters most – patients. *Cancer World* is published by the European School of Oncology (www.eso.net)

2 Resources on cancer policy

National cancer plans www.epaac.eu/national-cancer-plans
Details of European national cancer plans are available in English and native language – these are plans, not necessarily descriptions of reality.

How can my country get the best results in Europe? *The story behind the creation of the post of Cancer Czar and the development, implementation and evaluation of England’s Cancer Plan* Powerpoint presentation by Mike Richards, England’s first National Cancer Director (www.cancerworld.org/Media/Media_Training.html – scroll down to the end of the Downloads section)

3 Publications

Richard Sullivan et al (2011) **Delivering affordable cancer care in high-income countries (The Lancet report)** *The Lancet Oncology* 12 : 933– 980
The full text is behind a paywall. ([www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(11\)70141-3/fulltext](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(11)70141-3/fulltext))

Many of the issues are discussed in an interview with lead author Richard Sullivan, published in *Cancer World* (www.cancerworld.org/pdf/5476_pagina_4_10_CoverStory.pdf)

A seven-minute video overview with lead author is available at www.thelan-



cet.com/commissions/delivering-affordable-cancer-care-in-high-income-countries

Michel P Coleman et al (eds) (2008) **Responding to the challenge of cancer in Europe**, published by the European Observatory on Health Systems and Policies in connection with the 2008 European Cancer Conference held during the Slovenian Presidency of the Council of the EU. (http://ec.europa.eu/health/ph_information/reporting/docs/cancer_en.pdf)

Jose Martin-Moreno, Tit Albreht and Sandra Radoš Krnel (eds) (2013) **Boosting Innovation and Cooperation in European Cancer Control: Key findings from the European Partnership for Action Against Cancer**, published by the Slovenian National Institute of Public Health and the WHO on behalf of the European Observatory on Health Systems and Policies. (www.euro.who.int/en/about-us/partners/observatory/studies/boosting-innovation-and-cooperation-in-european-cancer-control) This book explores some of the innovative strategies being deployed against cancer in Europe, and how international collaboration has assisted in combating the cancer burden.

Health Systems in Transition series (www.euro.who.int/en/about-us/partners/observatory/health-systems-in-transition-hit-series). Published by the European Observatories on Health Systems and Policies, these reports provide a detailed description of a country's health system and of reform and policy initiatives in progress or under development. Mainly Europe. Some available in translation, including Russian

Cancer Care – Assuring Quality to Improve Survival: OECD Health Policy Studies (www.oecd.org/els/health-systems/Focus-on-Health_Cancer-Care-2013.pdf) This report explores policy trends in cancer care across countries over the past decade, identifies which policy approaches are associated with the best cancer survival and makes recommendations for creating and supporting high-quality cancer care systems.

Interpreting statistics

An easy to read guide, **Sense about statistics** (by former *Times* health editor Nigel Hawkes, 2010), is downloadable (in English) from www.straightstatistics.org/resources/making-sense-statistics

A discussion article in the *New England Journal of Medicine* by Susan Dentzer **Communicating Medical News – Pitfalls of Health Care Journalism**, *N Engl J Med* (2009) 360:1-3 (www.nejm.org/doi/full/10.1056/NEJMp0805753)

A WHO equivalent (in WHO Bulletin) **Making sense of health statistics**, Gerd Gigerenzer Bulletin of the World Health Organization 2009;87:567-567. www.who.int/bulletin/volumes/87/8/09-069872/en/

4 Information on cancer risk factors, prevention, symptoms and treatment options

Vast quantities of inaccurate information on risk factors, symptoms and treatment options are readily available on the internet, so it is important to only use well-established sources. Reliable sources include:

- World Cancer Research Fund – an international network of charities aimed at preventing cancer www.wcrf-uk.org/
- Cancer Research UK – www.cancerresearchuk.org
- Krebshilfe – www.krebshilfe.de/
- Ligue contre le cancer – www.ligue-cancer.net



Also some US sites such as:

- US National Cancer Institute – www.cancer.gov
- American Cancer Society – www.cancer.org

5 Data resources

IARC– International Agency for Research on Cancer (WHO) – www.iarc.fr/
IARC **country factsheets for Europe on incidence, mortality and prevalence** for different types of cancer are available at EUCAN – <http://eco.iarc.fr/EUCAN/Default.aspx>

OECD Health at a Glance – www.oecd.org/health/health-systems/health-at-a-glance.htm
provides data on health expenditure, health resources, healthcare activities, health status (mortality) and risk factors

6 Expert Sources

Patient advocacy groups

European Cancer Patient Coalition – www.ecpc.org
Provides details of around 300 national and regional patient advocacy groups for different types of cancer across Europe.

Other major European advocacy groups with national membership organisations include:

- Europa Donna – the European Breast Cancer Coalition – www.europadonna.org
- Europa Uomo – the European Prostate Cancer Coalition – www.europa-uomo.org/
- Myeloma Patients Europe – www.myelomapatientseurope.org/
- CML Advocates Network – www.cmladvocates.net

European cancer professional organisations

Some of these are more equipped to deal with the media than others. Web-sites will give contact details for national groups or national representatives where these exist.

- ECCO – the European CanCer organisation (an umbrella group for professional cancer societies) www.ecco-org.eu
- ESMO – European Society for Medical Oncology – www.esmo.org
- ESTRO – European Society for Radiotherapy and Oncology – www.estro.org
- EONS – European Oncology Nursing Society – www.cancernurse.eu
- ESSO – European Society of Surgical Oncology – www.essoweb.org
- SIOPE – European Society of Paediatric Oncology – www.siope.eu/
- EANO – European Association of

- Neuro-oncology – www.eano.eu/
- EUSOMA – European Society of Breast Cancer Specialists – www.eusoma.org
- EAU – European Association of Urology – www.euroweb.org
- ESGO – European Society of Gynaecological Oncology – www.esgo.org
- ESOP – European Society of Oncology Pharmacy – www.esop.eu
- EORTC – European Organisation for Research and Treatment of Cancer – www.eortc.be

Organisations of cancer centres

- **OECI – Organisation of European Cancer Institutes** – www.oeci.eu/
An organisation of cancer institutes, aiming to improve the quality of cancer care and translational research in Europe from an organisational viewpoint.
- **The Network of Breast Cancer Centres** – www.breastcentresnetwork.org
Breast Centres Network is the first international network of clinical centres exclusively dedicated to the diagnosis and treatment of breast cancer.

Other cancer organisations

- Association of European Cancer leagues – www.euroeapcancer-leagues.org



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