



**European School of Oncology
in partnership with EUROCHIP 3**

Cancer registries

USING THE MEDIA

**Making sense of the data
for policy makers
and the public**

**Media training for professionals from cancer registries
in European countries involved in EUROCHIP-5**

**Sunday 26 February &
Monday 27 February 2012
Hotel Europa - Ispra, Italy**

“Enabling cancer registries from different countries to provide the media and the public with accurate, interesting and easy to understand messages on epidemiological data on cancer”

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Introduction – Understanding the media agenda

As health professionals, you develop a vocabulary and a method of working that allows you to communicate with other professionals effectively and without misunderstandings. Your communication is often nuanced, based on explaining risk and uncertainty.

As media professionals, journalists have skills in communicating with the public which are based on the principles of simplicity and public interest. Journalists seek clarity, certainties and to some extent controversy.

As experts in your field, you have data with implications that the public and policy makers need to understand. The media provides the fastest and broadest avenue to reach these audiences so that your data can improve public awareness and policy decision making. To use the media effectively, you need to turn data into narrative – to tell a story. You also need some understanding of the way that journalists think and work. This guide will help you to do this and to approach the media and journalists with confidence. You have different agendas – but they are compatible agendas.

Journalists will ask questions that they or their editors or producers find interesting. They are especially interested in data on mortality and survival (although they may not fully understand the difference). These may not be the questions you would like them to ask.

However, part of your role is to be able to guide non-experts on how to read and interpret data. Media, policy makers and public have difficulty in interpreting figures and need them to be explained clearly. Indeed, one can argue that as cancer registries are funded with public money there is a duty to explain the data that is so carefully collected. If you are proactive and you prepare, you can set the agenda for this dialogue on your terms.

This pack gives you guidance on how to respond to media requests for information or interview, how to prepare a press release and how to make the most of an interview when you do one. The preparation described here is also useful if you are preparing to make a presentation to policy makers or to interested groups. Making sense of data, helping people to understand their strengths and weaknesses, and turning figures into a credible narrative are skills that can be universally applied. Those who take the next step and actively encourage media interest can open a path to the public understanding of health and cancer issues. By making the population more literate about health, you will help them to understand the meaning behind data on incidence, mortality and survival.

Part 1 What is news?

News tells you something new or interesting. It gives you information you did not have about a significant event or topic; something that has an impact on your life or the lives of other people you care about. News is something you want to pass on – to tell other people.

We do not always agree what is significant and we do not always agree what is news. However, news must be current ('new') and mean something to your audience (significant). You are competing in a crowded media space with everything else thought to be new or significant.

Media refer to each news item as a 'story'. Stories are packages of news, with a narrative structure, presented according to a convention, with one or more of the following qualities:

- **Immediacy:** Reporting something that has just happened or is about to happen.
'A new health care funding policy is announced today.'
- **Significance:** A story must have impact for the reader, listener or viewer. News may affect the audience in a personal way. It may cause feelings of sympathy or outrage. It may make the audience curious or moved to action.
'Big rise in breast cancer in women aged 30 to 50'
- **Proximity:** Facts and occurrences important in your country or neighbourhood.
'Lung cancer deaths twice as high in [my country] as in [neighbouring country].'
- **Prominence:** Public figures, holders of public office, people in positions of influence and celebrities or just those who stimulate our curiosity,
'TV star says "I've got cancer."'

What interests the media?

Netherland 21 Feb 2012: The sweaty feet of 48 Dutch men are central to efforts to reduce malaria, by luring mosquitoes into traps. Professor Willem Takken is to test his idea in field experiments in Kenya, using synthesised extracts of the smell from feet that proved most attractive to mosquitoes. 'If we can reduce 100 infections a day to one, then we have gone a very long way,' said Professor Takken.

Germany 21 Feb 2012: Hamburg's smoking ban has been ruled unconstitutional by Germany's highest court, forcing the city state to devise a new regulation. The Court ruled that smoking bans must be imposed on restaurants and bars alike, or not at all. Hamburg had said that bars that only offer drinks are allowed to keep a separate smoking room, while places that offer food are not.

Malta 21 Feb 2012: Multiple sclerosis patients suffering from intense muscle pain are calling on the Maltese government to approve the importation of Sativex, a cannabis based mouth spray that relieves painful muscles. The drug is marketed by Bayer and has been approved by EU governments including the UK, Spain, Germany, Denmark and Sweden. "We are being discriminated against," a patient told MaltaToday. The Medicines Authority has not yet received a formal marketing application.

Poland 17 Feb 2012: Shale gas mining will not damage water supplies or increase carbon emissions, according to the Polish Geological Institute. Warsaw wants to tap an estimated 5.3 trillion cubic meters of shale gas reserves, and the US Energy Information Administration, says that Poland is sitting on more than 300 years of domestic energy needs. Environmentalists say that 'fracking' will increase greenhouse emissions.

Bulgaria 21 Feb 2012: Bulgarian Deputy Health Minister Gergana Pavlova, who controlled Government policy on medical equipment and drugs, and liaised with the National Health Insurance Fund (NHIF), has been fired. Media accused drug distribution company Sopharma Trading, where Pavlova was once a top manager, of selling medication at inflated prices. NHIF managing director Neli Nesheva resigned on 17 February after authorising staff bonuses at a time when the Cabinet was calling for austerity.

- **Conflict:** Conflict dominates international, national and local media. Where there is controversy, different opinions should be represented in the media.
'Bulgaria Cancer Patient Wins Legal Battle against Health Ministry'
- **Suspense:** Suspense creates and expands news appeal.
'Eurozone crisis: Greek bailout in doubt'
- **Emotions:** 'Human interest' stories stir our interest by prompting sympathy, anger or other emotions.
Example: Young mother dies from cervical cancer
- **Oddity:** Oddity is often news. The bizarre, the unusual, the unexpected often make news. There is room for offbeat stories, small items and even humour.



The cancer registry

(Borrowed from Storm & E-B v Veen:
Data protection and ethical: obstacles to cancer registry research in Europe)

What interests the media?

Portugal 21 Feb 2012: A joint mission by Portugal's 'troika' from the International IMF, ECB and EC arrived in Lisbon to begin an assessment of the country's bailout programme. Thousands massed peacefully in Lisbon to protest. The collective level of debt by Portuguese non-financial sector companies stood at €303 billion, equivalent to 178% of GDP.

Spain 21 Feb 2012: The first man in Cataluña to be given an implanted artificial heart has died within hours of being told to go home and live a normal life. The operation was carried out last November at the University of Bellvitge Hospital in Barcelona. On Monday the hospital presented 57-year-old Eufemio García to the press and told him he could go home. 24 hours later he was dead. An autopsy is to be carried out.

Bulgaria 21 Feb 2012: More than six in ten Bulgarians are "ignorant" when it comes to their health, according to a study from Sofia Medical University. People aged 55 or over have twice as much difficulty in understanding what doctors are telling them, compared to young Bulgarians between the ages of 15 and 24. Bulgarians with college degrees and a higher social status have a better understanding. Bulgaria was ranked last of eight EU Member States.

Italy 20 Feb 2012: Renato Dulbecco, who shared the 1975 Nobel Prize in medicine for research on the interaction between tumours and cells, died in California aged 97 on 20 Feb 2012. Dulbecco's research gave the first clue to the genetic nature of cancer, showing how a virus could insert its genes into the chromosome of an infected cell, sparking uncontrolled growth.

Germany 21 Feb 2012: Residents across Germany are complaining of unwanted gifts from the heavens: giant chunks of frozen faeces and urine plummeting to the ground from passing aeroplanes. In Saxony, an 81 year-old pensioner heard something hitting his roof. He found 20-centimetre frozen balls in his garden that stank terribly. Earlier a 1.5-kilo chunk of urine crashed into a family's garden in Niefern, Baden-Württemberg. "I was relaxing in our living room. Suddenly there was a huge bang," 59-year-old Erika Keil told *Bild*. "I thought our roof was caving in."

France 13 Feb 2012: Patients with a history of heart disease will probably not reduce their risk for developing cancer by taking vitamin B and/or omega-3 fatty acid supplements, a new French analysis suggests. "We found no beneficial effects of either B vitamins or omega-3 fatty acids taken over five years on cancer occurrence or cancer-related death," noted study author Valentina Andreeva. The nutritional epidemiology research unit at the University of Paris XIII reported its findings in the *Archives of Internal Medicine*.

Media refer to news as ‘stories’. However, newspapers and radio also include longer more detailed items that they refer to as features. These offer a deeper insight into an issue, initiative or problem and give people a better opportunity to speak for themselves.

Media focus on audiences – you are in competition for media space

Good media are essential for democracy, but media are very focused on their audiences. All media – newspapers, radio, TV or Internet – seek to maximise audiences. Competition for readers, listeners, viewers or website visitors is intense. Although most media feel that they provide a public service, what they publish or broadcast is focused on what they believe to be of interest to their audience. One journalist put it like this: “Sometimes someone asks ‘Why did you emphasise that part of the story?’ The answer is simple. That is what I thought would most interest my readers.”

To change media perception of what is important, you have to persuade media that what you want to emphasise will interest their audience. To some extent, you have to put yourselves in the shoes of a journalist and be aware that you are competing with all other sources of news – some inside your sector, some that have nothing to do with it.

First-hand sources, diverse opinions

As far as possible, news stories are based on *primary sources* –people who take part in events or who observe events first-hand. Journalists will be more interested in your story if you were present or involved, or can lead them to someone who was. In terms of cancer registries and the figures they produce you are indeed the primary source. You are the expert who can speak with authority on this topic and who knows the strengths and weaknesses of the data and the stories they tell.

You should not be surprised if media also interview someone who has a different opinion from yours.

Diversity is part of good journalism. When facts are complex or controversial, there will be many different

versions of the same event or issue. One aim of your organisation should be to become a regular source of news and opinion on your special area of interest, but you are unlikely to be the only source.

Journalists will be more interested in your story if you were present or involved, or can lead them to someone who is.

Confidential sources

A source may offer information to the media in confidence, i.e. on the understanding that his/her identity will not be disclosed. Confidential sources may fear they will lose their job or be attacked, or may simply not want their names in the public domain. The media will respect a source's wish to protect his or her identity. However, an identified source is generally considered more credible. Any arrangement of this sort (e.g. a patient giving an interview about his or her experience) must be clearly agreed in advance.

'Off the record'

'Off the record' means that neither the source's identity, nor the information may be reported. Offering information in this way is only appropriate in exceptional circumstances. Never tell a journalist something 'off the record' unless you know the journalist well and he or she agrees, in advance, to hear it on these terms. It is not fair on journalists and is not safe for you. If you do not want them to publish it, why are you telling them?

Part 2: Interacting with journalists

What will journalists ask you?

Journalists will ask questions that they or their editors or producers find interesting. These will probably not be the questions you would like them to ask.

They will ask you things you cannot explain. They will ask you things that are not to do with cancer registries. They will ask you question you may consider to have 'political' overtones.

But they will also ask you things that you do know about and can explain. They may ask:

- Why are cancer rates are going up?
- Why are our rates worse than our neighbours' rates?
- Where do we rank in Europe for cancer deaths?
- Why are the latest drugs not being used?
- Why are we not seeing a greater reduction in mortality?

What you would like journalists to ask you?

If you are proactive and you prepare or go to the media before they come to you, you can set the agenda on your terms.

- You may want to talk about overall rates of cancer.
- You may want to highlight particular cancers where more attention is needed.
- You may want to talk about late diagnosis , and the role of cancer registries in encouraging early diagnosis, prevention and treatment
- You may want to talk about the role of the cancer registry in preparing and monitoring your national cancer plan.

With the help of clinical colleagues you can also organise sessions where journalists can learn how to understand data and how to ask better questions.

Part 3: Explaining data to journalists

In your field of expertise you need to be able to explain figures as well as to understand them. For the public and for policy makers it is important to keep the figures simple. If they are not clear to the journalist, he or she will not be able to make them clear to the public.

Part of your role therefore maybe to give journalists (and others) a quick guide as to how to read and interpret data. The public is not good at understanding figures and needs them to be explained clearly.

It may be better for journalists to give approximate figures and have them understood than to give exact figures and have them misrepresented. For example, it may be better to say “just over half” than 51%, or “almost a third”, rather than 32%, and then give the detailed figures a little lower down. If reporting on outcomes with very small numbers (n) then it is often misleading to use percentages “The number of deaths rose by more than 50% last year”, sounds very dramatic, but if it rose from 2 deaths in 100,000 to 3 in 100,000 people would be less alarming. You should advise journalists always to give absolute numbers as well as percentage increases or decreases.

Most journalists will not have a good understanding of the way you use terms that describe frequency or risk: They will need an explanation.

Unless they have a science background, the journalist may not have a clear understanding of the difference between:

- Incidence – the frequency with which new cases are found in the relevant population
- Prevalence – the proportion of the relevant population who are living with the condition

They may have only a vague idea of “statistical significance”.

Explaining about risk

MEASURE	DEFINITION	EXAMPLE
Absolute risk	The number with an outcome/ The number who could have had the outcome	10 of 100 people receiving treatment X with condition Y die over a period of five years Absolute risk of death is 10/100, one in ten or 10% over five years If 30 of 100 people receiving placebo for the same condition die over a period of five years Absolute risk of death is 30/100, three in ten or 30% over five years
Absolute risk reduction	The difference in absolute risk between one group and another as a percentage "percentage points lower"	$30\% - 10\% = 20\% = 20$ in 100 Over 5 years, treatment X lowered the chance of dying by 20 percentage points compared to placebo If 100 adults with condition Y took treatment X for five years there would be 20 fewer deaths
Relative risk	Absolute risk of those treated with A/ Absolute risk of those given placebo	$10\%/30\% = 0.33$ (one third) Over five years the chance of dying for those on treatment X was one third of those on placebo
Relative risk reduction	1 minus the relative risk	Relative risk reduction = $1 - 0.33 = 0.67$ or 67% Over 5 years, treatment X lowered the chance of dying by 67% (two-thirds) compared to placebo
Number needed to treat	$1 / \text{absolute risk reduction}$	$= 1/0.67 = 1.5$ 5 adults would have to take treatment X for five years to prevent 1 death

Given the above it is very likely the journalist will headline "Treatment cuts cancer deaths by 67%"

Advise journalists always to report absolute risks for each group in addition to any other numbers being used.

For all risks, be clear about 3 things:

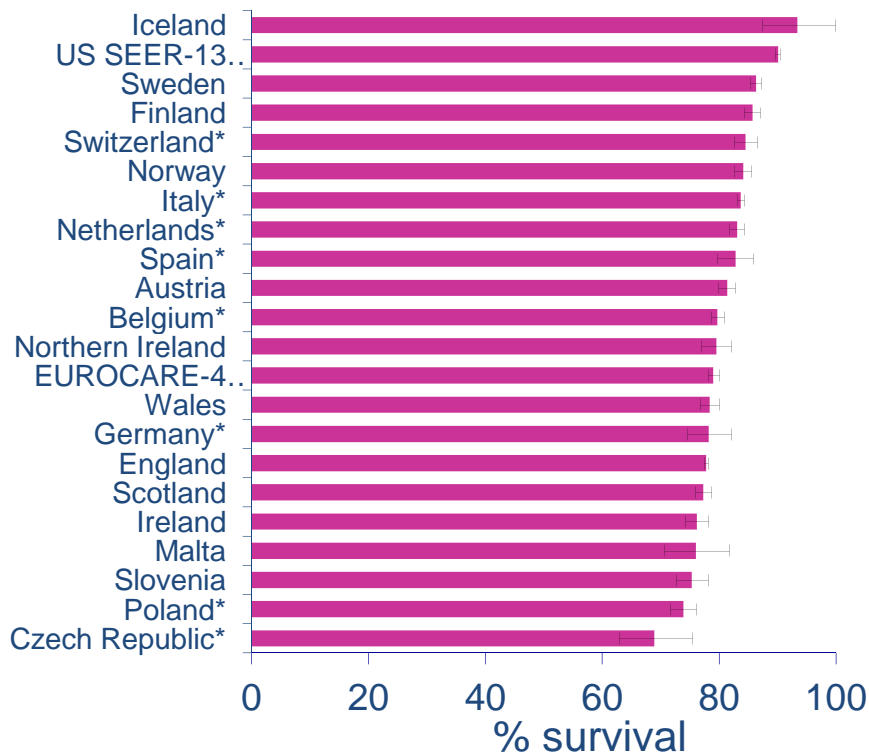
- **The outcome** (e.g. having lung cancer),
- **Over what time period** (e.g. 20 years) and
- **In whom** (e.g. adults who smoke more than 10 cigarettes a day).

Adapted from The VA Outcomes Group (<http://www.vaoutcomes.org>) Center for Medicine and the Media at the Dartmouth, New Hampshire, USA as quoted by JNCI, Journal of the National Cancer Institute

An example of comparison between countries

Breast cancer: age-adjusted five-year relative survival selected countries

(period of analysis, 2000-03)



Source: Verdecchia et al . Lancet Oncology 2007 8(9):784 / as cited by Cancer Research UK

Data show that women with breast cancer had 93.4% five-year survival in Iceland and 68.9% five-year survival in the Czech Republic.

The absolute chance of dying in the Czech Republic over five years was 31.1 in 100. Approximately 1 in 3 women diagnosed with breast cancer died within five years.

The absolute chance of dying in Iceland was 6.6 in 100. Approximately 1 in 15 women diagnosed with breast cancer died within five years.

The absolute risk difference between Iceland and the Czech Republic was 31.1% - 6.6% or 24.5 percentage points.

The relative risk of dying in Iceland compared to dying in the Czech Republic was $6.6\% / 31.1\% = 0.21$ (one fifth)

The relative risk difference between Iceland the Czech Republic was $1 - 0.21 = 0.79$ or 79%

A woman's chances of dying with breast cancer were 79% lower in Iceland than in the Czech Republic

Explaining about statistical significance

If you have used p values you need to help them to understand.

Explain that:

If $p=0.0004$, then we can say that there is only a 4 in 10,000 chance that these results could have been by chance

If $p > 0.05$, we say the results are "consistent with chance", and therefore "not statistically significant".

If $p < 0.05$ we say the results are "statistically significant"

However, even results that are "highly significant" can be wrong; if the study is biased (for example in the selection of patients in a study) or confounded (there could be another cause).

You may need to point out what a difference even a 5% margin can make. The first example above where the relative risk reduction was 67%, had a 95% confidence interval that ranges from 36% to 83%, due to its small sample size. 67% may be the most likely conclusion but the actual result could fall anywhere between those figures.

Comparative statistics

Journalists are very likely to ask you to explain why your figures are higher or lower than those of other countries or why they have improved or got worse over time. Comparing survival across time or place is possible if you are comparing like with like. However, comparison is difficult if methods of detection are different, or if cancers are generally found at different stages. If a country detects earlier cancers and treats them earlier then that can be a major reason for differences in survival rates. If one country manages to reduce smoking rates more quickly than another, that will lead to a lower incidence and, ultimately, to lower mortality.

Differences between countries may also be partly explained by the countries having a different age profile. Countries with an older demographic profile would be expected to see more cancers. The opposite is also true: countries with more deaths at an earlier age (for whatever reason) could be expected to have a lower incidence of cancer.

You may be asked about the benefits of screening. If a country introduces a screening programme, incidence figures would be expected to rise, because the programme is actively looking for cancers that might not otherwise have come to light. This is especially true for prostate cancer, where many cancers detected never need treatment, and to a lesser degree for breast cancer where some of the cancers detected would never have become known.

You will need to explain that the time between detection and death is not a good guide to these benefits (did the patient live longer, or were they simply diagnosed earlier?). You can however explain when trials show benefits from screening.

It may be tempting to retreat behind all these issues (and other such as socio-economic factors) and say that you cannot be sure why the figures are the way they are. However, if the public and policy makers are to understand the situation, then registries should give explanations, even if they are tentative. These might be in the form of alternative scenarios, based on the different factors involved. Explaining about difficulties and possible compounding factors should be an aid to understanding the figures, not an obstacle to doing so.

If the professionals do not help journalists to interpret the figures, then journalists are more likely to make errors in reporting.

Part 4: Press releases:

Contact the media when you have something topical and newsworthy to say. Examine the issue objectively to see how it will make a story that will interest other people.

What is a Press Release

A press release is an announcement of an event or newsworthy item that is issued to the media for publication.

A press release tells the media a story from your point of view and sets the agenda for a news item. It acts as a consistent record for what you tell the media, and gives journalists key facts (names, contact numbers etc.) in a reliable format.

Preparation is very important, especially if you are not experienced in pitching ideas to people you do not know. A press release helps you to prepare by assembling key facts before you make contact: Who is involved? What is happening? Where? When? Why? and How?

How to write a press release?

News is about getting up-to-date information to the public quickly and journalists are often short of time. A good press release makes the job of a journalist easier by minimising the work they have to do to turn your press release into a story.

Main points first

Important information should appear first, followed by the next most important information, and so on. This ensures that a journalist who reads only the first part of the press release has the most important information. This is quite different from, for example, a clinical trial report, which starts with the problem and works up to the conclusion.

The first paragraph should contain only key facts. Don't overburden the beginning with names. Put full titles lower down or in a note to editors at the end of the release.

State the most newsworthy aspects first. Additional paragraphs should provide supporting information in descending order of importance, so that you expand the story like a pyramid.

Headline

The headline should be short, to the point and in the present tense. Things that happened in the past may be perceived as old news.

Quotations

Include a comment from a senior person in your organisation (preferably the director or equivalent), which journalists may use as a quote. The quote should introduce something relevant and important that hasn't been mentioned in the rest of the release. Keep quoted material reasonably short. One or two sentences will do.

“The combining of these registries is a big step forward for the control of cancer. For the first time figures from all parts of the country will be collected in the same way. We will be able to see clearly whether the regional differences are real or reflect the different methods used until now.”

Avoid quotes that fail to add substance, such as “we are proud to announce” or that give purely factual information, “It begins at 2pm”.

Your press release should express facts objectively. The release might, for example, call on hospitals to give better data. The release would tell the story as if from a third party:

The Tratvonia Cancer Registry has urged the country's leading hospitals to give more information about cancer patients and their treatment, so that they can keep better records about what happens in the future.

Opinions can be given in quotations.

The head of the cancer registry said: “We need to know about the treatment so we can monitor which course of treatment leads to the best outcomes.”

Language and abbreviations

Simple language is preferable. Your press release will get more attention if it is easy to read and to the point. Use short sentences without many sub clauses. Where possible use the active rather than the passive voice. Write out full names on the first occasion with the acronym in brackets and use the abbreviated form thereafter. “The European Network of Cancer Registries (ENCR) today launched....”

Be careful about making claims for your organisation unless you know them to be true. Don't describe yourself as “Germisllavia's only source of high quality information about cancer incidence and survival ...” if there is another source that also believes it is high quality.

Minimise the use of jargon. To assure the public that you have high standards, you might say: *“Our data are cleansed according to agreed protocols that ensure international quality assurance (QA).”*

But it might be better to say: *“All our figures are checked to high standards agreed with leading European institutions.”*

You need to think about how to explain some key phrases in easy language. For example, how many members of the public (and journalists) understand the following?

Demographic trends

Pre-cancerous cervical lesions

Recurrent cancer

Mortality

Staging (Stage I-IV)

Metastatic cancer

How many journalists know the difference between incidence and prevalence?

Make it look good

Press releases should be clearly laid out on one or two pages of A4 paper, well-spaced, and on one side of the paper only. Use your headed paper and logo. Make sure they are spell-checked and grammatically correct. You may send them by email, fax, or by post. 'Press Release' should be clearly marked across the top, along with the date. Make a special place on your website where you put your press releases so that journalists (and others) can look them up. You can send an email, text message or Twitter message with the link.

Contact details

The full name, address, telephone/fax number and email address of your contact person should appear at the bottom of the release so journalists can contact you easily. Provide your website address. State whether you have photos and a logo available. Digital pictures are often preferred. *Make sure the contact person is available for interview.*

Notes to Editors

At the bottom of the press release, include any necessary background material in a note to editors. Background information can include details of your organisation –where it is based, its main areas of activity, website etc. – and additional relevant information not provided in the body of the release.

Embargo

If you need to, you can specify an 'embargo' date and time, which gives the journalist a 'not before' time to publish the story. This is only necessary when you need everyone to have the same information at the same time. An embargo will always be inconvenient for one or more media, and unnecessary use of embargos will reduce your coverage. But if you do set an embargo, stick to it. Do not give a 'favourite' journalist permission to break an embargo, or no journalist will respect it in future.

Following up your press release

Decisions on which stories to run are sometimes hard to call, and if a reporter has a pile of press releases it may help to bring yours to the top if you ring up and ask whether it has been arrived, and whether it is likely to be used. Be polite, rather than pushy. If it is 'not news', ask why not. At worst, you will learn something for next time; at best, you might move it up the pile. If you ring, try to pick a time of day that is not too busy. This will differ according to different news schedules, but mid-morning or early afternoon can be good times. (As you get to know your journalist contacts, find out from them when they do and do not like to be called). If you do not succeed at first, do not feel snubbed, but persist. You are not asking for a favour. When you have news you should expect the media to respond.

Pictures

Be prepared to provide photos of the subject of your announcement and the people involved. If it is a new initiative or project, have a selection of portrait and landscape shots with captions/details of the subject matter and/or those involved to hand, together with your organisation's logo. If you quote someone in your announcement, have photos of the speakers available, and be prepared to send them by email. They should be sent as jpgs and you should have high resolution version available (more than 1MB). One option is to send out low resolution copies with a link to the high resolution versions on your website. If you are taking your own photos, then ensure that they are clear and of reasonable quality. The pictures that the media will *not* want will be a row of 'important' people at an opening ceremony, shot from half a room away. Some newspapers prefer to take their own pictures, and TV will need opportunities to film. Think about what you can offer them.

Exclusives

When you have a good news story, it is usual to approach all your media contacts. However, you may develop an 'exclusive' with one journalist who has a special interest or you know will provide good coverage. This requires some sensitivity. You may make a friend at one newspaper or radio station by giving them an exclusive, but cause resentment at a rival organisation. Try to expand your range of contacts.

Respond to follow-up calls

Be prepared to respond positively to requests for interviews, photos or filming. Offer to go into the radio or TV station, or to be interviewed in a visually appropriate place. Do ensure

that your key contact is available for interview after you send a press release. If the person is away and unavailable you may lose your opportunity for coverage.

If journalists ask for more details, photos or logos, try to work to their deadlines. If you respond too slowly, you risk the media dropping your story. However, it is very important that you do not allow yourself to be rushed. Take time to get relevant materials together (such as your press release and data) and prepare yourself mentally.

Keep a record of your press releases; these are a valuable source for you to track your priorities at different times. Also monitor which journalists and media respond. Work on the ones that don't. Why are they not covering your issues? Don't only judge success by the size of the headlines. Small paragraphs or broadcast items can be valuable to your organisation, as well as larger 'splash' stories, or features. Being quoted briefly in a larger story means that you are regarded as a spokesman / spokeswoman for your area of interest.

Press officers are there to help you – not replace you

If your organisation has regular dealings with the media and you have a budget then you may have a formal press officer (or 'borrow' one from the Ministry of Health). If so, ensure that he or she is well informed about your organisation and about your policies, and how data are collected, cleansed and used. Your press officer should have authority to brief journalists, but not to do interviews. These should be done by the lead person in your registry. The person who speaks to the media should be enthusiastic and effective. This is a skill that can be practised and learnt.

The press officer should draw up a list or database of media contacts. This should include details of all health specialists. Keep a note of email addresses, fax and phone numbers for individuals, the paper/programme they work for and the frequency of production and deadlines. The individuals may change rather often, so it is important to stay up to date, noting when new journalists join or when a good journalist moves elsewhere. If it is possible to establish a computerised database, from which emails or faxes can be sent out in batches, it will save a lot of time in the future.

Be proactive about forming relationships with key journalists, including regional and local media. Contact media and introducing yourself and your organisation. Send out annual reports and significant releases. Ask if there are journalists who specialise in relevant issues and get their contact details. The press officer should suggest story ideas and build a relationship.

Read relevant publications, listen to and watch the news, and make others in the organisation aware when stories have been published. The press officer should circulate press cuttings or notes about programmes, and keep copies of all your press releases. They will act as an instant history when you need to review what you did last year.

Remember that for a newspaper you can also suggest feature stories. You have a duty of confidentiality that you must keep, but you may still be able to help a journalist find people willing to be interviewed, photographed or filmed, including doctors and advocacy or patient groups who may in turn lead them to relevant patients. Media always want to put a human face and voice to a story.

Legal issues

If you are publishing written material, such as in a newsletter or leaflet, or providing material to another news outlet, such as the local media, you need to be aware of any legal constraints, which will vary from country to country.

Avoiding libel is primarily the concern of the news media, but organisations that issue press releases and conduct interviews need to be aware that these also constitute publication. Libel is the publication of defamatory material that is not true – i.e. it unfairly damages someone's reputation. Material broadcast on radio or television can also be libellous as this constitutes publication. If you name an individual or organisation, including a company, or make it possible to identify an individual or organisation, then the article could be libellous if it damages the reputation of those identified and is factually incorrect. This is unlikely to be a problem for cancer registries, but be careful if you are criticising figures that you consider to be wrong to check your facts.

Normally if what you are saying is true and your comment is fair, you should be protected, but that is not always the case. In some countries criticising government can be dangerous even when the facts are true.

You also need to be aware of any legislation that affects what you can say about a legal case that is going through the courts. This varies widely between countries.

If you criticise commercial organisations they are likely to respond, so make sure that your criticism is based on verifiable facts and is well founded.

Part 5: Getting your message across – the interview

A media interview is a positive opportunity to present your news and views to the public, either in a live broadcast or through an edited broadcast or newspaper story. The best way to become good at interviews is to do them. Prepare in advance, be clear about your core messages, and try to get over two or three clear points. You cannot do more in a three minute interview. Remember that you are talking to the public, not to your colleagues, and that most of your audience are not experts.

Find someone in your organisation who is positive and who wants to put over your case. For broadcast interviews, a clear speaking voice is important but a ‘professional’ accent is not. For some issues you want the audience to identify with the person speaking – someone in their shoes. Be positive. If you prepare well, behave naturally and sound human, you will do an effective interview. Interviews go better if you approach them in a positive spirit. If you are going to do interviews regularly, attend or organise a media training course.

Preparing for an interview

Requests for an interview may arise from a press release you have sent out, or journalists may also approach you for your views on a story you did not initiate. When approached:

- Find out as much as you can about what they want and why they have chosen you.
- If a journalist is working from a press cutting or statement, ask for a copy.
- Think whether you are the right person to do the interview. If you are not the right person, who is?
- Be inclined to say yes, but do not allow yourself to be interviewed about something you know nothing about or have not the authority to speak about.
- Do not refuse just because your organisation or the work you are promoting is being criticised. Handling bad news needs experience and skill, but “refused to comment” is usually the worst option. If there is a debate your side needs to be heard.
- You need to prepare: take note of the journalist’s name and telephone number and find out their deadline. Collect your thoughts and look up relevant facts. If you have a relevant press release, find it and read it again!
- Don’t be rushed into doing an interview when you are not ready.
- Keep your promises. Ring back when you said you would.
- If possible, do the interview face to face. This is not always possible.

Broadcast interviews

- Ask whether you will be live or on tape. A live interview gives you more control, but you can't stop and start again. A recorded interview is less stressful, but you can't control the editing. (A live broadcast will be recorded and extracts may be used later.)
- Ask who else is being interviewed for the same item. This will give you an idea of what points you need to cover.
- Your pre-interview discussions may be with a researcher or producer rather than the reporter or presenter. He/she will not give you a list of questions but will tell you the general approach.
- Ensure the reporter or researcher knows who you are and what you do. If there are areas you cannot cover, tell them in advance.
- If your organisation or research is under attack, don't handle it alone. Get some advice and include your colleagues. Be honest and straight, and if something has gone wrong, say so, and what you are doing to put it right.
- TV and radio reporters often ask oppositional questions ("But surely, you should have known that..."). Do not become defensive. These often give you an opportunity to put your case more clearly.
- Remember that in the vast majority of cases you will not be under attack. The interviewer wants you to put your case well and will help you.

Getting ready

Whether the interview is for newspaper, radio or television, the principle is the same:

- Prepare the points you want to make,
- Speak to your (public) audience,
- Deliver your key message(s).

Before an interview, take a quiet moment to prepare.

- Jot down your (two or three) main points but do not work from a script.
- Practise your main points in your head or out loud, but do not over-rehearse. Be spontaneous.
- Take any relevant press releases with you.
- Think about how to present complex issues. How will you explain your figures in simple language?

NB: Your audience will only remember two or three points at most so discipline yourself to stick to these. If you try to make more, your audience will become confused.

Putting up other people for interview

If your organisation puts forward people in vulnerable positions (such as patients) for interview, make sure you discuss in advance what they are prepared to do. People may react badly when they see a story in print. Will they want their name used? Will they want their picture used? What is acceptable to the journalist and to their editor/producer? The time to negotiate is before the interview, not afterwards. Put any agreements in an email so all parties are clear.

Where does the interview take place?

Whenever possible, do interviews face to face. It takes more time, but can pay off in effectiveness. Even with print journalists, it is helpful to see who you are talking to and how they are reacting. Think about where you will be. A workplace can add atmosphere to a broadcast piece, or give context to a print journalist. You may be more comfortable in a studio where you can focus better. In your own environment, ensure that phones are not going to ring, and that people are not going to interrupt. Make sure that you are comfortable and relaxed. If you need to refer to a press release or notes (just headings) put them where you can see each sheet without moving or turning a page. Do not rustle paper near a microphone.

A TV crew may want you to stand or sit in front of something that adds colour to their piece. Co-operate but do not do something that makes you uncomfortable. Make sure there is nothing confidential in camera shot. The TV 'crew' may be one multitasking person acting as reporter, camera operator and sound technician. After the interview, the reporter may film him/herself asking the questions ('noddies'), or film you 'listening' to the question and will 'cut' those bits into the tape of your interview. They may also want to film you doing something that they will show with your voice over the top. These are known as 'cutaways'.

A newspaper interview is often done on the telephone, which means you must be aware that it is being recorded on tape or with shorthand (see below). A photographer may call afterwards with a limited idea of what the story is about. Co-operate, but don't do anything you are uncomfortable with. The picture may be used several times if the story continues to make news.

Doing the interview

An interview is not the same as a chat. Look alert but feel relaxed – it is useful to sit on the edge of your chair and lean very slightly forward. It is rare for a media interview to be aggressive. Usually, journalists want to help you to do a good interview. The following tips look like a lot of advice, but they boil down to being open, direct and down to earth.

- Make your main point early – preferably in your first answer. If the first question is completely off the point, say, “I think the most important thing to say is that” and then make your main point. Then go back to their question.
- Remember that health issues in general and cancer issues in particular are about people. Even when talking about the science, keep the people in the picture.
- Do answer the questions. If you dodge questions you sound like a politician!
- Make an effort to speak slowly. It is easy to gabble on air.
- Give basic information. Your audience has a hazy idea about things that are common knowledge to you.
- Use simple everyday language.
- Speak in a conversational and friendly voice.
- Talk about people and give examples if possible.
- Describe things. Be the eyes and ears for your audience.
- Be candid, honest and accurate. “Nobody is in favour of this,” is not convincing if you are followed immediately by interviews with five people who are. Never lie.
- Think about weak points in your case. How will you answer if asked about them?
- If you don’t know, say so. Don’t flannel.
- Resist the temptation to say too much. Make your point and then stop.
- Be careful about attacking other people. What you say may be quoted back at you afterwards. If you sound aggressive, you will probably not win over your audience.

Being interviewed for television

Think about how you look, but do not be obsessed. Lots of dangly jewellery may be distracting. If you wear all black, you will look severe. Too much white will reflect the lights. Patterns (stripy shirts, patterned ties, patterned tops) can look very busy and pulse on screen (known as strobing). Sometimes in a studio, you may be advised not to wear solid blue. Think about what image you want to project. Don’t be more formal or more casual than you want to be. If you are being interviewed at home or in your office think about what is behind

you and will be visible on screen. If it comes naturally, smile. Sit up and slightly forward. Look at the interviewer, not the camera. Don't look down, as this makes you look shifty. Don't wave your arms about or hit the table as this makes a very disturbing noise on air.

Being interviewed for newspapers

Be aware this is all on the record. However, journalists may quote only one sentence of what you say. Try to stay focused and be wary if the interview is going on too long. The more you say, the more scope there is for the article to go off at a tangent. Emphasise your main points. "My main point is..." "What we really think is essential is that..." Only say what you are happy to see in print. Reporters may agree to check your quotes back with you.

Telephone interviews are less satisfactory than face to face interviews, but they are common for print interview. Remember you are on the record and the reporter is taking notes. Be careful not to 'agree' with statements unless you mean to.

Interviewer: *"This cut in spending must make you pretty angry?"*

You: *"Yes, well we have to stay focused on doing the job."*

can become: *"Registry boss fury at funding cuts."*

or

Interviewer: *"So what you are saying is that patients will die because of this policy?"*

You: *"We provide data – but without good data it is possible that health resources will not be directed to the major problems and, yes, that could lead to sub-optimal outcomes."*

can become: *"Patients will die', says cancer registry boss"*

Be careful, even when contradicting.

Interviewer: *"Surely your pilot was a complete failure?"*

You: *"I wouldn't call it a complete failure at all."*

can become: *"Pilot not 'complete failure', says researcher"*

Use your own words and language:

"Surely your pilot was a complete failure?"

"We captured a lot of data and learnt what needs to be done. It was a great start."

These examples are exceptions – but things are more likely to go wrong with a telephone interview, especially if you do not know the reporter.

Afterwards

- Remember, you are still on the record when you think the interview is over. Don't make indiscreet comments while a tape recorder is running. If you spend three minutes denying there is a problem and then say as you shake hands, "This Ministry of Health doesn't understand the figures properly," that will be the story.
- Monitor what is used. Keep press cuttings or record radio programmes, or at least listen to the likely spot (ask when it will be broadcast).
- Give feedback. If the interview has been used well, ring up and say so to reinforce good journalism. Do not complain over trivia but do complain if there are serious errors.
- Develop a relationship with a journalist. If you respond positively to requests for interviews, you will become a valuable resource and develop mutual trust.

Complaints – what happens if something goes wrong?

Tell them what has gone wrong

Even well researched, well written or well filmed stories can contain errors. When reacting to publication or broadcast, try to think in broad terms. Did it go well or badly? Was the piece fair or unfair? One wrong fact may cause you anger, but seem insignificant to someone outside your organisation. Get a second opinion. What did a work colleague or your neighbour think?

If, on balance, the story was OK but there is a fact that needs to be corrected, make contact with the journalist. Start with the positive. Tell them what they did well and got right. Journalists may appear tough, but they are just like everyone else. They want to be seen as competent, and can go into their shells when criticised.

If it is one factual error, a wrong phone number, or position, then (for newspapers) a letter to the editor is very useful. *"Thank you for your very positive article on xyz. Unfortunately, you printed an incorrect number for our helpline. It should be 123456."*

This puts the error right, gives you a second bit of publicity, and maintains a positive relationship between you and the publication. A letter is more likely to be published if it states your case clearly, does not contain abusive language and does not attack the journalist or newspaper in personal terms. It must also be short or it will be cut (check with the publication for maximum length).

If the mistake was on radio, and it is important, then ask them to put it right on air. If an error or an offensive statement may be repeated in a later bulletin, ring up quickly. They may modify the item. The same is true for television.

If you approach a journalist, they may be a member of an association or union with a code of ethics. Make yourself familiar with this. Many associations and unions are affiliated to the International Federation of Journalists (based in Brussels). The IFJ Declaration of Principles on the Conduct of Journalists can be found at:

<http://www.ifj.org/en/articles/ifj-declaration-of-principles-on-the-conduct-of-journalists>

In all but the most serious cases it is better to contact a journalist or media output directly and try to get redress in the form of a correction or clarification. You need to keep a sense of proportion. If you always complain after a story, you may be being hypersensitive (or you may need to try a different media outlet next time). However, if the mistake is serious or you do not seem to be making any headway with the journalist or newsdesk, you may need to complain more formally.

Write to the editor or the station manager setting out your complaint and asking for a clarification or apology. If this does not lead anywhere then you will need to know if your country has a press complaints procedure or a media ombudsman/woman.

Prevention is better than cure

With media coverage, just as with health, prevention is better than cure. Getting fair media coverage is often a question of developing relationships and trust.

Peter McIntyre & Anna Wagstaff,
26 February 2012

IFJ Declaration of Principles

Some key clauses of the IFJ Declaration are:

- Respect for truth and for the right of the public to truth is the first duty of the journalist.
- The journalist shall report only in accordance with facts of which he/she knows the origin. The journalist shall not suppress essential information or falsify documents.
- The journalist shall only use fair methods to obtain news, photographs and documents.
- The journalist shall do the utmost to rectify any published information which is found to be harmfully inaccurate.

Appendix 1

Examples of press releases

Example 1: A clear press release in support of screening

Press Release

NHS Bowel Cancer Screening Programme News

8 December 2011

The NHS BCSP in England is on track to cut bowel cancer deaths by 16 per cent

An analysis of the first one million test results, published today in *Gut* reveals that the NHS Bowel Cancer Screening Programme in England is on track to cut bowel cancer deaths by 16 per cent.

The results show a much higher proportion of cancers detected were left sided, suggesting that different strategies may need to be deployed to pick up disease on both sides of the body, as right sided cancers are thought to be more aggressive, say the authors. They base their findings on an analysis of the first 1.08 million faecal occult blood tests, returned by patients invited for the first round of bowel cancer screening in England.

To date, around 12 million test kits have been sent out by the Programme and over 11,000 cancers have been detected.

Professor Julietta Patnick CBE, Director of the NHS Cancer Screening Programmes, said: "We are delighted to report these results on the first million people we screened in the NHS Bowel Cancer Screening Programme and are pleased to be on track to match the research findings and cut bowel cancer deaths by 16 per cent. Early detection is crucial to lowering the number of deaths from bowel cancer which is currently the second most common cause of cancer deaths in the UK. The earlier cancer is detected, the higher the chances of successful treatment.

"The paper also reports that a higher proportion of cancers detected were on the left side of the bowel compared with the right. This finding mirrors a general global trend and is subject to on-going evaluation and investigation into different screening strategies."

Press and media enquiries should be made to:

NHS Cancer Screening Press Office

70 Gray's Inn Road, London WC1X 8BT

Tel: 020 7400 4499 | Fax 020 7400 4481 | Email: press.office@nhscancerscreening.co.uk

Example 2: A clear press release resulting from data collection

Elderly breast cancer patients less likely to get surgery

Thursday 16 June 2011

National Cancer Intelligence Network Press Release



Older women in the UK are less likely to have surgery for breast cancer than younger ones. And this difference can't be fully explained by age-related ill health from other diseases, according to new data presented today at the National Cancer Intelligence Network (NCIN) conference (Thursday).

Researchers looked at the records of more than 23,000 women with breast cancer diagnosed in the West Midlands, Yorkshire and North East of England between 1997 and 2005 to investigate whether women aged over 70 in the UK are less likely to have surgery because of other illnesses.

They found that, overall, surgery rates dropped off with age and women who had other illnesses were less likely to have surgery. Even after taking other illnesses into account the chances of having surgery fell with age – over 85 per cent of women aged 65 to 70 had surgery, but this fell to 70 per cent in those over 70 and to only 50 per cent of the over 80s. Older patients were also less likely to have surgery if they were from a deprived area.

Dr Katrina Lavelle, lead study author from the University of Manchester, said: "Previous research has shown that older women are less likely to have surgery for breast cancer compared with younger patients. Surgery to remove breast tumours is one of the most effective ways to treat this cancer so it's important to get a better understanding of what lies behind these differences.

"This research suggests that the presence of other illnesses, which we know increases with age, does not fully explain the difference in treatment between older and younger patients.

"The good news is that over the time period we looked at, the numbers of women over 65 having surgery did rise from 68 per cent to 75 per cent.

"Our ongoing research, funded by the Breast Cancer Campaign and the National Institute for Health Research, is investigating the extent to which the lack of surgery amongst older women is due to things like overall frailty or patient choice. We are also developing statistical techniques to help to decide which treatment is likely to be the most appropriate based on patient choice, health and acceptable risk, rather than age."

Steven Oliver, study author from the Northern and Yorkshire Cancer Registry and Information Service (NYCRIS), said: "This study illustrates the important role the UK's cancer registry system plays in improving cancer care. By recording the patterns of treatment received by all patients with cancer we have a vital resource that can form the basis for research to understand why care varies."

FOR MEDIA ENQUIRIES PLEASE CONTACT THE CANCER RESEARCH UK PRESS OFFICE ON 020 3469 8300 OR, OUT-OF-HOURS, THE DUTY PRESS OFFICER ON 07050 264 059.

Example 3: A not so clear press release – perhaps not wanting to highlight the problem

Media Centre - IARC NEWS

[Launch of EPI-CT website](#) 30/01/2012 -

The International Agency for Research on Cancer (IARC) is the coordinating centre of "Epidemiological study to quantify risks for paediatric computerized tomography and to optimize doses (EPI-CT)", an international project supported by the European Union. The EPI-CT study uses cohort data from nine European countries: Belgium, Denmark, France, Germany, the Netherlands, Norway, Spain, Sweden, and the United Kingdom: 1 million patients will be enrolled. The study aims to evaluate the factors associated with the use of paediatric CT scans, to build evidence to understand risks vs benefits of CT procedures and to define strategies for dose reduction. A dedicated website, <http://epi-ct.iarc.fr> is the public interface of the study.

Diagnostic radiation represents an indispensable tool for modern medicine. Physicians see benefits of using computerized tomography (CT) scanning in their daily clinical practice. The growth of CT use in children has been driven primarily by the reduction in the time needed to perform a scan. As a consequence, it is now possible to perform more examinations in a given time, extend the scope of some examinations, as well as introduce new techniques and examinations. The ease of acquisition of images results sometimes in unnecessary exposure of patients to radiation, particularly in developed countries. Organ doses from CT scanning are considerably larger than those from corresponding conventional X-ray. A dose to the stomach from a conventional abdominal x-ray examination is approximately 0.25 mGy, which is at least 50 times smaller than the corresponding stomach dose from an abdominal CT scan (Brenner & Hall, 2007).

The growing use of CT technology despite the introduction and wider use of other modalities, such as magnetic resonance imaging, raises concerns in radiological protection, especially for children and adolescents. Children are generally more sensitive to the carcinogenic effects of ionizing radiation than adults. In addition, they may receive even higher radiation doses from a CT procedure than an adult. The long-term risk of radiation induced cancer or other health effects following CT scanning has not been directly assessed, although the scientific knowledge so far does not exclude that the ionizing radiation, which is emitted by CT, may cause cancer. No large-scale epidemiological studies of health risks associated with this procedure have been reported so far. The "Epidemiological study to quantify risks for paediatric computerized tomography and to optimise doses" (EPI-CT) was set-up to investigate the relationship between the exposure to ionizing radiation from CT scans in childhood and adolescence and possibly attributable late health effects. Eighteen centres from Belgium, Denmark, Germany, Finland, France, Luxembourg, the Netherlands, Norway, Spain, Sweden and the United Kingdom will cooperate in this project to enrol approximately one million patients. The knowledge gained on current and past CT examination practice will help to propose strategies for further dose reduction.

The EPI-CT study is coordinated by the Section of Environment and Radiation at the International Agency for Research on Cancer (IARC). The study received substantial financial support from the Seventh Framework Program of the European Commission (FP7-Fission-2010-3.2.1). Results are expected in 2015.

Appendix 2

What you can do with a web-site

NEW YORK STATE DEPARTMENT OF HEALTH

ABOUT THE NEW YORK STATE CANCER REGISTRY

WHAT IS THE CANCER REGISTRY?

Cancer is a reportable disease in every state in the United States. In New York State, Public Health Law Section 2401 requires that all physicians, dentists, laboratories, and other health care providers notify the Department of Health (the Department) of every case of cancer or other malignant disease. Through the New York State Cancer Registry, the Department collects, processes and reports information about New Yorkers diagnosed with cancer.

WHAT IS THE CANCER REGISTRY USED FOR?

Cancer Registry data are routinely used by programs within the Department of Health, county and local health departments, patient advocacy groups, public interest groups, researchers and the public. The data are used for public health planning and evaluation as well as for research. Because the Registry has collected statewide data since 1976, it can be used to monitor cancer incidence patterns and trends for all areas of New York State.

The Cancer Registry plays an important role in research to identify the causes of cancer. Researchers often use the data collected by the Cancer Registry to identify cancer patients who could be interviewed about possible exposures they had before they were diagnosed with cancer. These can be compared to interviews among people without cancer to determine if cancer patients had different exposures. Researchers can also use Registry data to determine whether groups of people with specific exposures, such as those who work in a particular occupation or with a particular substance, are more likely to develop cancer than people who do not have these exposures. Registry data are also linked to other data sources such as hospital discharge files to evaluate health services.

WHAT DOES THE CANCER REGISTRY DO TO PROTECT PRIVACY?

All information reported to the New York State Cancer Registry is confidential, and strict procedures are in place to protect patients' privacy. For example, access to the Registry offices is restricted. All employees are trained in handling confidential information. State law limits use of confidential cancer data to research. All research studies involving data with patient identifiers must be reviewed by the Health Department's Institutional Review Board, which protects rights of privacy and informed consent. Statistics for areas smaller than the county level are only released when there are enough cases in the area to guard against revealing confidential information about individuals.

HOW LONG HAS THE CANCER REGISTRY BEEN COLLECTING AND REPORTING CANCER DATA?

The New York State Cancer Registry is one of the oldest cancer registries in the country and has been collecting information on patients with cancer for more than 50 years. The first state regulation requiring reporting of cancer cases diagnosed in New York State, excluding New York City, was passed in 1939. In 1973, the law expanded the Registry to include reporting of information on cancer patients diagnosed in New York City. Evaluation of the reporting patterns shows that 1976 is the first year that is considered complete enough to use for analysis of statewide cancer trends.

In 1995, the Cancer Registry began receiving additional funding from the Centers for Disease Control and Prevention (CDC) under the federal Cancer Registries Amendment Act. These funds have allowed for many improvements in collecting and processing data and in expanding the number of data elements collected on each cancer patient, consistent with the standards of the National Program of Cancer Registries. All Cancer Registry data from 1976 to the present were converted into a new database for processing and storage. In September 1997, the Cancer Research Improvement Act of 1997 was signed into law in New York State. This law included new provisions requiring all reporting facilities with more than 100 diagnosed cases per year to have the abstracting and reporting functions performed by Certified Tumor Registrars starting in the year 2000. The law also specifies that reporting facilities must report within six months from the date the patients are diagnosed or examined.

WHAT INFORMATION IS COLLECTED ABOUT PATIENTS WITH CANCER?

When the Cancer Registry first started collecting data, only a minimal amount of information about patients and tumors were collected. Over the years, the volume of cancer cases has increased and the amount of data collected for each case has expanded. The Cancer Registry collects data on the anatomic sites of tumors, the stages at diagnosis, the cell types of the cancers and, more recently, some treatment information. When a person is diagnosed with more than one type of cancer, this information is collected for each separate tumor. The Cancer Registry also collects specific sociodemographic information (age, gender, ethnicity, race, residence, place of birth, etc.) on each individual diagnosed with cancer. Information about the date and cause of death of persons diagnosed with cancer is also stored on the database. In total, more than 100 different pieces of information on each person are contained in the Registry database.

The Cancer Registry includes reports of all malignant cancers, except selected skin cancers. Basal cell and squamous cell cancers of the skin are exempt from reporting. Malignant cancers include those with both in situ and invasive behavior. In situ cancers are very early cancers, while invasive cancers have more potential to spread. The Cancer Registry also collects data on brain and nervous system tumors classified as benign or which have an uncertain behavior. Benign tumors do not have the potential to metastasize beyond the tissue where they originated.

WHERE DO REPORTS OF CANCER CASES COME FROM?

Each time a person is diagnosed with a tumor, the hospital(s) where that person is diagnosed and/or treated reports information about the person and tumor to the Cancer Registry.

Reporting is not voluntary; Public Health Law Section 2401 requires reporting. Civil penalties can be levied for noncompliance with the law. The law specifies that reports will be submitted within six months of patient diagnosis. Although the law requires that all cancer cases be reported to the Cancer Registry regardless of where they are diagnosed, in practice, cancer reports have been received mainly from hospitals throughout the state. Other types of reporting facilities, such as pathology laboratories, physicians and ambulatory care centers, also report cases. Although veterans' hospitals and military hospitals are exempt from the reporting requirements, many voluntarily report cancer cases to the Cancer Registry. In addition, interstate reporting agreements with 22 states, including all neighboring states as well as Florida, help ensure the completeness of reporting. Another source of information about cancer patients is death certificates.

HOW IS THE QUALITY OF THE CANCER REGISTRY DATA ASSURED?

The New York State Cancer Registry participates in the North American Association of Central Cancer Registries (NAACCR) certification process. As part of this process, the Cancer Registry submits data annually to be evaluated for timelines, completeness and quality. The New York State Cancer Registry received Silver- level certification for 1997 data and Gold-level certification for 1998 through 2007 data. The majority of the data presented in this report, diagnosis years 2004 to 2008, meet the Gold standard for all NAACCR measures of data quality, including overall completeness, percent of cases with information on key data items (county of residence at diagnosis, race, gender and age), prevalence of unresolved duplicates, percent of cases reported from death certificates only and the percent of cases passing interfield data edits.

HOW LONG DOES IT TAKE TO PROCESS THE CANCER DATA?

The Cancer Registry receives almost two hundred thousand reports of invasive cancers per year, representing over 100,000 new tumors. It currently takes about two years beyond the end of each year for Cancer Registry data to be available. This time frame is in line with national standards and consistent with the availability of cancer data from other state registries.

ARE NATIONAL CANCER DATA OR DATA FROM OTHER STATES AVAILABLE?

The U.S. Congress passed the Cancer Registries Amendment Act in 1992, which authorized the National Program of Cancer Registries (NPCR) of the Centers for Disease Control and Prevention. The NYSCR has received support from the NPCR since 1996, which has enabled the New York State Cancer Registry to achieve 'gold' status for the quality and completeness of its cancer data. Through ongoing collaboration with the SEER program, the NPCR provides nationwide, regional, and state-based cancer incidence and mortality data published in the United States Cancer Statistics (<http://www.cdc.gov/Features/CancerStatistics/>) and also available in the CDC WONDER web-based query system (<http://wonder.cdc.gov/>) . The United States Cancer Statistics currently covers 99% of the United States population.

The New York State Cancer Registry is a member of the North American Association of Central Cancer Registries (NAACCR), which sets data standards and best practices for population-based registries. Thanks to the advent of federal funding for cancer registries, the NAACCR membership now includes central registries in all fifty states and the District of Columbia, as well as in the Canadian provinces, and in Puerto Rico and Guam. NAACCR compiles and

publishes Cancer in North America and associated data products, which are available at <http://www.naaccr.org/Research/CINAProducts.aspx>.

When the New York State Cancer Registry updated its database in 1996, it adopted the SEER and NAACCR standards for coding data. One major change in the collection and coding of multiple primary tumors was important for the interpretation of cancer incidence statistics. For cancer cases diagnosed prior to 1996, New York used the International Agency for Research on Cancer (IARC) rule for counting primary tumors, which allows only one primary per site per person per lifetime. Thus the Cancer Registry would count only one breast cancer or one lung cancer per person. The SEER coding rules allow for multiple primary cancers in an anatomic site, based on the histology, length of time between the two tumors and the oncologist's determination as to whether a second cancer represents a second primary or a recurrence. According to data from the SEER program, about five percent of breast cancers, for example, are second primary cancers among women previously diagnosed with breast cancer. Because all data for cancers diagnosed prior to 1996 were coded using the IARC rules, New York data for some sites of cancer are not directly comparable to the SEER or NAACCR data. The extent of the effect for each cancer site is dependent on the site-specific probability of multiple primaries. Beginning with cases diagnosed in 1996, New York State's data are comparable to both SEER and NAACCR data. SEER data, which currently represent 26% of the U.S. population, are available at <http://seer.cancer.gov/>.

WHAT KINDS OF DATA DOES THE CANCER REGISTRY RELEASE?

This report, *Cancer Incidence and Mortality in New York State*, is the Cancer Registry's principal publication. The printed volume provides the number of cancer cases or deaths and the age-adjusted rates by county, site of cancer and gender for the most recent five-year period. Five years of data are combined because the number of cases and rates for single years can vary considerably, particularly for most of the counties outside metropolitan areas and cities. Additional data are also provided in electronic format on the New York State Department of Health Internet site (www.health.ny.gov) and in printed format upon request. This includes detailed data on the number of cancer cases or deaths and rates by age, race and year of diagnosis, as well as the proportion of cases diagnosed at early stages. These data are made available for New York State, New York City, New York State exclusive of New York City, and the New York City Boroughs. Additional statistics available on the Health Department Internet site include incidence data for selected New York cities, New York City Neighborhoods and selected areas of Nassau, Rockland, Suffolk and Westchester counties, incidence and mortality for childhood cancers, and estimated prevalence for selected regions and counties. Users are referred to the SEER program Web site for classification rules of incidence (ICD-O-3), mortality (ICD-9 and ICD-10) and International Classification of Childhood Cancers.

As part of the New York State Department of Health's Cancer Surveillance Improvement Initiative, the New York State Cancer Registry has released data for breast, lung and bronchus, colorectal and prostate cancers by ZIP Code. These data and more information about this initiative can be found on the Health Department's Internet site.

The New York State Cancer Registry also releases a public use file for use with the National Cancer Institute's SEER*Stat program. This file contains cancer data for 1996 on and can be found on the Registry's web page (<http://www.health.ny.gov/statistics/cancer/registry/>).