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FEBRUARY 2008

IN PARTNERSHIP WITH MEPs AGAINST CANCER MAC

EUROPEAN CANCER PATIENT COALITION

MEPs against cancer: Leading the campaign

Europe in wide screen

A PARLIAMENT MAGAZINE SPECIAL SUPPLEMENT ON CANCER SCREENING

DODS

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POLITICS, POLICY AND PEOPLE MAGAZINE
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MEPs AGAINST CANCER
MAC

Europe in wide screen

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Europe in wide screen

Cancer screening saves lives, but the EU has some way to go to ensure that population-based cancer screening programmes are fully implemented across member states, writes the Parliament Magazine's managing editor **Brian Johnson**

The statistics on cancer make sober reading: over two million new cases of cancer will be diagnosed in the EU over the next year, one in three Europeans will be diagnosed with cancer, and the disease will kill one in four people. As EU health commissioner Markos Kyprianou told a packed audience at the recent cancer screening event organised by MEPs against cancer and the Parliament Magazine, cancer "represents one of the greatest burdens of ill-health throughout the EU and shows why our strategy of prevention and early diagnosis is so important".

Over the following pages, it becomes clear that the Cypriot commissioner, MEPs, academics and health experts from across the EU are in agreement that preventative measures, particularly population-based cancer screening programmes, can save lives and are economically viable. The half-day event in the European parliament, 'Europe in wide screen', saw an in-depth and at times lively debate on the need to improve EU-wide cancer screening, with sessions that included all three MEPs against cancer (MAC) co-founders, Liz Lynne, Adamos Adamou and Alojz Peterle.

Screening programmes can help reduce death rates on a number of cancers. Yet according to the MAC group, member states' screening programmes are often poorly implemented or non-existent, despite a council recommendation on screening for colon, cervical and breast cancer, adopted by EU health ministers in 2003. Central to the event was the status of the European commission's long awaited report on the progress of the 2003 council recommendations.

That report, which has unfortunately been delayed, is now expected towards the end of spring, and Kyprianou told the event's audience in a keynote speech that "from the preliminary results, I can already say that there is recognition of the importance of breast, cervical and colorectal cancer screening as a public health policy throughout the EU". However, as Liz Lynne also told the audience, "all member states need to fully implement the 2003 recommendation" to counter the "shocking" differences that exist among member states.

Two themed sessions saw debates on screening best practice across Europe and on future political action. German MEP Karin Jöns kicked off the first session, chaired by Liz Lynne and Adamos Adamou, arguing that although a lot has been achieved in reducing breast cancer mortality rates, there is still a lack of proper screening across the EU. Lithuanian MEP Jolanta Dičkuté outlined the latest developments on cervical cancer and said it was scandalous that only seven EU member states had fully implemented cervical cancer screening programmes.

UK TV consumer champion and president of the European cancer patient coalition, Lynn Faulds Wood, called for more action to break the taboo on talking about colorectal cancer, and invited MEPs to come forward and set an example by being screened for colon cancer using a specially adapted mobile colonoscopy vehicle. Christa Maar from the Felix Burda foundation ended the first session by outlining what had been achieved over recent years in Germany to create awareness of the need to screen for colon cancer.

The second session, chaired by Alojz Peterle, saw Greek MEP Antonios Trakatellis analysing the parliament's recent draft cancer resolution and heard updates on the current state of play on the commission's cancer screening report by the European commission's Karl Freese and Lawrence von Karsa from the Lyon-based international agency for research on cancer.

Professor of oncolologic biotherapy at the world renowned Karolinska institute, Håkan Mellstedt, explained the crucial role that oncologists can play in raising public awareness of cancer screening, while Panos Kanavos of the London school of economics gave the audience an idea of the economic costs and benefits of implementing EU-wide screening programmes.

The day's final speaker, Ljubljana's director general for health, Marija Seljak, provided a detailed review of the recommendations of the Slovenian presidency's February high-level cancer conference. Alojz Peterle rounded off the event with a personal call to EU member states. "As a cancer survivor I have a very strong personal interest in fighting cancer: helping my fellow citizens to prevent getting cancer and supporting cancer patients in their often difficult journey. Remember, cancer affects us all. Let's reinforce our cancer control strategy to fight against it effectively."

"Commissioner Kyprianou told the audience at the MAC event, 'From the preliminary results, I can already say that there is recognition of the importance of breast, cervical and colorectal cancer screening as a public health policy throughout the EU'"

The Parliament Magazine would like to thank commissioner Kyprianou, the MAC group, the panel speakers, and all who attended for giving up their time and for their strong contributions to the success of the event. Special appreciation goes to Hildrun Sundseth of the European cancer patients coalition, without whose help this event would not have been possible. Thanks are also extended to our commercial sponsors who have enabled this Parliament Magazine special supplement to be produced. ★

On screen

Cancer remains one of the greatest burdens of ill-health in the EU, the audience at the MAC event heard from EU health commissioner **Markos Kyprianou**

We all know that cancer is one of the most long-standing areas of community action on public health. It represents one of the greatest burdens of ill-health throughout the community and shows why our strategy of prevention and early diagnosis is so important.

There are three very clear messages: Certain cancers may be avoided – and health in general can be improved – by adopting healthier lifestyles; exposure risks to carcinogens in the environment, which include exposure risks via the human food chain, should be minimised by legislation and control action undertaken by the regulators; and cancers may be cured, or the prospects of cure greatly increased, if they are detected early. But more effort is needed at all levels – local, regional, national and European – so as to bring these messages home to our citizens.

As far as my portfolio is concerned, I will not lessen my determination in improving food safety by regulation and enforcement in continuing our efforts in food safety and control to avoid carcinogens entering the human food chain. Prevention is better than cure and has a dual cause.

On the one hand we should prevent the disease by addressing the determinants, and on the other hand we should promote early diagnosis through screening, not ignoring the fact that vaccination for certain types of cancer is also nowadays possible. When talking about determinants let me just give you one example – tobacco. Our last Eurobarometer on tobacco reveals that about a third of EU citizens are daily smokers. Over 650,000 die each year as a result of their habit. A further 80,000 adults are killed by second-hand tobacco smoke.

"There are simple actions that can be taken to reduce the toll that cancer takes on our societies"

These deaths could be avoided, so progress in reducing smoking is still disappointing. That is why a coordinated effort towards a tobacco-free Europe will remain one of the top priorities for the commission. That is why I have acted as health commissioner to put a constant emphasis on prevention. There are simple actions that can be taken to reduce the toll that cancer takes on our societies. ⇨

A short guide to commission policy on cancer

In 1985 the EU launched the Europe against cancer strategy to help member states coordinate the fight against the disease and reduce the number of cancer deaths. A committee of cancer experts was formed, made up of representatives from each of the then 12 EU countries.

The EU-funded strategy reduced deaths by nine per cent by the year 2000, and found that prevention and screening were two of the areas where concerted European efforts could be most effective.

Under the EU's strategy, the European code against cancer was published, which advised practical ways to prevent the disease by adopting a healthier lifestyle.

A subcommittee on screening was also formed under the group of cancer experts to select and fund pilot screening projects in the member states.

In 1992 the subcommittee on cancer screening published its first set of guidelines (on mammography) to help health professionals in the member states standardise their diagnostic procedures in order to implement population-based screening programmes.

In 1999 the commission's advisory group on cancer prevention prepared recommendations on cancer screening in the EU, which was followed in 2003 by a set of council recommendations.

The commission's guidelines have now been published for breast and cervical screening, with colorectal guidelines to follow in 2009.

And these actions will also reduce other important chronic diseases such as heart disease and stroke. To tackle a wide range of determinants, including tobacco, alcohol and nutrition, effectively we need to integrate health concerns into other policies such as education, environment and social policies.

At the EU level we will seek to provide added value to the action of our partners and pursue synergies at international, European, national and regional levels. This calls for stronger cooperation with international organisations on health and for opportunities for regional involvement, too. Implementing this requires action by a range of partners.

Clearly, we need a high level of commitment and involvement from member states and strong political leadership to drive these agendas forward, as well as the involvement of international organisations. One example of this commitment is seen through the contribution of the WHO's international agency for research on cancer (IARC). The commission is working closely with the experts in IARC, and I think that this is a good example of collaboration with international organisations.

Unfortunately, primary prevention alone is not enough. We also need effective programmes for screening and early detection to enable prompt diagnosis, and treatment to reduce the overall burden of breast, cervical and colorectal cancer in the population. This has been a long-standing area of EU action. The commission has worked with experts from the member states to develop best practice in cancer screening, published and known as the series of EU guidelines for quality assurance of cancer screening and diagnosis.

This was complemented in 2003 by the council recommendation on cancer screening, which was based on the recommendations of the advisory committee on cancer prevention. Continuing this tradition, the second edition of the European guidelines for quality assurance in cervical cancer screening was published on 7 February. This is testimony to the unique role the EU can play in assuring the efficient delivery of safe and effective services to maintain and improve the health of Europe's citizens.

During the next few months we will also issue our report on the implementation of the council recommendation on cancer screening.

From the preliminary results, I can already say that there is recognition of the importance of breast, cervical and colorectal cancer screening as a public health policy throughout the EU. Programmes reflecting the recommendation are currently running in most member states.

This report will therefore provide a useful opportunity to learn from the leading programmes, and to ensure that the recommendation is implemented in a way that reflects best practice throughout the entire EU. ★

Room for improvement

MAC co-chair and MEP **Adamos Adamou** told the audience that Europe needs to do more to tackle the burden of cancer

Cancer is one of the major causes of diseases, morbidity and mortality in the world. The last few decades have seen considerable progress in cancer control in the EU. Nevertheless, cancer remains an enormous public health challenge and a tremendous threat.

An estimated 3.2 million persons were diagnosed with cancer in 2006 (a significant increase from the 2.9 million in 2004). Cancer is responsible for 1.7 million deaths each year and accounts for four out of ten deaths in the 35-65 age group. Every day, 5214 Europeans are diagnosed with cancer and 3185 die from their disease. Cancer will affect one in every three Europeans and will kill one in four. The number of cancer cases will increase dramatically over the next 20 years due to the ageing of the European population.

Prevention is the key component in a comprehensive approach to cancer control. Patients and physicians strongly endorse the importance of preventive or periodic health examinations, including screening. An integrated approach and coordinated actions by member states, as far as risk factors and underlined determinants are concerned, is deemed essential to tackle cancer.

Measures need to be accelerated in order not only to reduce the levels of exposure of individuals, specific risk groups and the population in general to key risk factors (such as tobacco consumption, unhealthy diet, physical inactivity, UV exposure and harmful and hazardous alcohol consumption), but also to reduce occupational and environmental exposure to carcinogens.

In the field of screening, the commission is taking a leading role by issuing guidelines, the aim of which is to coordinate the activities of member states in the field. In particular, the fourth edition of EU guidelines for quality assurance of breast cancer screening and diagnosis is issued, as well as the second edition of the cervical cancer guidelines.

The first edition of the EU guidelines on quality assurance in colorectal cancer screening and diagnosis is foreseen in 2009. The council has also been active in this area, and on December 2003, it released its recommendations on cervical, breast and colorectal cancer screening.

These recommendations include, amongst others, that pap smear screening for cervical cancer should start not before the age of 20 but not later than the age of 30; mammography screening for breast cancer in women aged 50 to 69 should be made in accordance with the European guidelines on quality assurance in mammography; faecal occult blood screening for colorectal cancer should be made in men and women aged 50 to 74. ⇨

All these initiatives and activities have had a profound impact on breast cancer screening and treatment, but I strongly believe that Europe needs to do much more in tackling this disease. Altogether, patients, health professionals, politicians and authorities, we have to continue developing the efforts needed to ensure that all these recommendations will be implemented everywhere in Europe and that all cancer patients have an equal access to cancer treatment independently from where they live and from the hospital where they are treated.

Former oncologist Adamos Adamou is MAC's co-chair

For instance, the specialisation of medical oncology still needs to be recognised at a European level. The management of cancer patients has undergone major changes over the last couple of decades thanks to a steady increase in the knowledge of the pathology of the disease and a concomitant better treatment strategy, using both local therapy, for example surgery and/or radiotherapy, combined with medical treatment. Moreover, the development of new drugs requiring new mechanisms of action that are usually related to the molecular biology of the tumour and the increasing importance of pharmacogenomic considerations in the optimisation of treatment require a very specific education in medical oncology in order to ensure an extensive knowledge of drugs handling. Medical oncologists as professionals providing optimal care to patients and ensuring the management of associated treatment toxicity have here a relevant role to play.

> *"In Europe, there is an asymmetry between the extent of the burden caused by cancer and the resources allocated to address this burden"*

To guarantee in the future this crucial role of providing patients with best care, medical oncology must be recognized by the European member states. This would ensure optimal qualification of physicians using drugs for cancer treatment where continuing education, clear criteria, and guidelines are needed.

The burden of cancer in Europe is increasing and given the ageing European population, this burden will continue to increase. Cancer is a major public health challenge for Europe. However, in Europe, there is an asymmetry between the extent of the burden caused by cancer and the resources allocated to address this burden.

Of particular concern are the wide-ranging inequities in the burden of cancer, the scope and quality of cancer services and innovative medicines and the outcomes enjoyed by different European citizens with cancer.

Member states must realise now that public spending used in preventing cancer through screening or other methods constitutes a necessity in our societies. It is not a waste of money: On the contrary, it is a long-term investment that pays back.

MEP **Liz Lynne** warned that shocking differences in the way cancer screening is applied exist among member states

The statistics speak for themselves: cancer screening does save lives. But with greater cooperation at EU level and between member states many more could be saved. To ensure this happens, all member states need to fully implement a council resolution adopted in 2003 that calls for implementation of screening programmes in all member states.

I believe information campaigns are badly needed, so that citizens are more aware of the dangers of cancer and of the modern screening programmes that are available and which can save lives. All countries need to do more at national level, to extend and improve their screening programmes and participation in them.

However, the individual also has a responsibility. We know, for example, that screening for cervical cancer can reduce mortality by 60 per cent, so the message is simple – if you belong to a

risk group or are invited for a test, go. It could save your life.

Here are some more statistics to ponder. According to a study by the international agency for research on cancer, between 2004 and 2006 the number of new cases of cancer diagnosed each year in Europe increased by 300,000. That means that there are more than two million new cases and more than 1.1 million cancer deaths in the EU each year. From these figures it is clear that cancer remains a public health priority for Europe.

What I find particularly shocking is the differing levels of cancer screening in EU member states and differing levels of participation in screening programmes. Take, for example, the test for colorectal cancer. A recent EU-wide survey showed that in Germany, 19 per cent of those surveyed had had a test over the year preceeding the survey. Compare this to Romania and Croatia, where only two per cent of those surveyed had been tested, and in Cyprus only one per cent.

The same worrying disparities can be seen for both breast and cervical cancer screening. In Austria, 72 per cent of women surveyed last year had had a manual breast examination and 53 per cent a mammogram. By contrast in Romania, only 23 per cent had had a manual breast examination and six per cent a mammogram.

It is clear to me that many more deaths could be prevented in the EU each year by more consistent, extensive and effective cancer screening and a more effective sharing of best practice. But how can we make this a reality? I fully support the 2003 council recommendation and would point out that parliament has drafted a resolution on combating cancer, which itself requests member states who have not yet done so to implement the recommendation. It also calls on the commission and EU countries to promote information campaigns on cancer screening to the general public and all healthcare providers.

"If you belong to a risk group or are invited for a test, go. It could save your life"

I am also encouraged that Slovenia has made cancer their EU presidency priority and we must push to ensure that cancer screening remains firmly on their agenda. We must also push future presidencies to make cancer a priority of their presidencies.

The commission has been asked to produce a report on how EU nations have implemented the recommendation on cancer screening. Unfortunately, this report has been delayed. My hope is that the commission will publish this vital report as soon as possible so that cancer screening programmes can continue to be developed and many more European lives can be saved. ★

MEP Liz Lynne is MAC's co-chair

Prevention is the only cure

Early detection of cancer is pointless if the subsequent treatment is inadequate, MEP **Karin Jöns** writes

It has to come to an end that it is still often like a lottery, whether a cancer is detected early or not. It is also unacceptable that different kinds of cancer very often are not treated properly or even wrongly.

If we want to save some hundred thousands more lives of cancer patients every year, we have to push forward further EU guidelines for quality assurance in screening as they already exist for mammography and cervical cancer screening.

Screening leads the way! The European guidelines for quality assurance in breast cancer screening and diagnosis are a wonderful example of how effective the development of high-quality EU standards in early detection and treatment can be: However, only if they are implemented properly.

But where do we stand 16 years after the first edition of the EU guidelines for mammography screening? On one side we achieved a lot by reducing the breast cancer mortality rate by up to 35 per cent in those countries or regions where screening has been implemented in a correct way – that means organised and population-based screening for women aged 50 to 69. On the other side, we do still have opportunistic screening in a lot of member states, or even no screening at all – referring not only to the new member states.

This is already a shame, but there is another often neglected point: Screening in accordance with EU guidelines also leads the way to better treatment. It has become the door opener for the multidisciplinary approach which covers all aspects of an optimum of individual and evidence-based treatment and aftercare. It is obvious that if both screening and treatment are done correctly, 90 per cent of breast cancer could be cured.

The EU guidelines have set worldwide standards for quality assurance in early diagnosis and treatment. Therefore, it is really urgent to stop lip service in Europe. Every member state should take the screening recommendations seriously, which the council adopted unanimously in 2003. They should implement early detection of breast cancer and its treatment only in specialised breast services according to EU guidelines. Because failure to implement these guidelines correctly does not only prevent progress; it makes the situation even worse!

Just to explain it: There must be one screening unit for every one million inhabitants so that the critical mass of women to be screened is reached. Screening must also be organised and population based. Otherwise you would not reach every single woman in the required age group between 50 and 69 years, regardless of her social status, her level of education and where she lives. ⇨

"If both screening and treatment are done correctly, 90 per cent of breast cancer could be cured"

Breast cancer: The facts

One in nine women is diagnosed with breast cancer in her lifetime.

In the EU-27 more than 330,000 women are diagnosed with breast cancer and 90,000 die from it every year.

The incidence of breast cancer is increasing. Breast cancer remains the main cause of death in women aged between 35 and 59.

The number of younger women diagnosed is increasing: 35 per cent are under 55 and 12 per cent are under 45.

According to the WHO, mammography screening can reduce deaths from breast cancer by up to 35 per cent.

90 per cent of all breast cancer cases could be cured if detected early and treated in quality-assured specialist breast units.

Source: European parliamentary group on breast cancer

Karin Jöns is the President of the European Parliamentary Group on breast cancer (EPGBC)

X-rays should only be taken in dedicated screening centres, in order to guarantee the least possible radiation exposure and an optimum resolution as well as a blind double-reading of the mammograms. If women were allowed to visit any X-ray unit they like, there is a big risk that far too many will be treated following false positive results, not to mention the large number of overlooked carcinomas.

But the best early detection is pointless if the subsequent treatment is either inadequate or even wrong. To behave in such a way is actually unethical. That is why the European parliament initiated EU guidelines for breast units where only benign and malignant disorders of the breast should be treated. But these units should not spring up like mushrooms across Europe, like what is happing nowadays.

We only need one breast unit for every 250,000 to 300,000 inhabitants to be a genuine centre of competence. Otherwise it would not be possible to ensure that a critical mass of 150 operations of primary carcinomas a year is achieved.

A crucial point is that every case of breast cancer has to be discussed in a multidisciplinary case conference. The fact that in some member states only 20 to 40 per cent of cases of breast cancer have to be consulted in such a multidisciplinary team is totally unacceptable.

If the EU guidelines will not be implemented to a full extent in every member state, there will only be just a little change in the current situation in which the mastectomy rate varies among member states by up to 60 per cent. Only if the quality of both early diagnosis and treatment is assured, the mortality rate from member state to member state will stop varying by over 50 per cent.

That is the reason why the European parliament asked the commission to develop EU guidelines for a uniform quality-assured accreditation procedure which standardised certification and recertification of screening centres and breast units across the whole EU. Such an accreditation procedure for the implementation of the EU guidelines for quality assurance in breast cancer screening and diagnosis would also pave the way for EU guidelines for other types of cancer.

By the way, this would not at all encroach upon national competences. The principle of subsidiarity would be entirely respected, the costs in public healthcare and social services could be reduced and, above all, more patients would survive.

Jolanta Dičkutė told the MAC conference that it's a scandal that only seven member states have fully implemented cervical cancer screening programmes

Why should we speak out loud about cervical cancer? Every year 50,000 women develop and 25,000 women die from cervical cancer in Europe. High rates of cervical cancer can be observed in eastern Europe, particularly in Lithuania and Hungary, with the lowest rates in Malta and Finland.

Cervical cancer is also unique in that it has an earlier age of onset than most other cancers, with a peak incidence in the range of 35 to 45 years of age, the time when most women are raising their children, pursuing their careers or both, and the effect of this disease is therefore very substantial, obviously for the women involved, but also for their families and for society as a whole.

Cervical cancer is not the most common cancer among the women of Europe, but what is unique about this cancer is that we know exactly how to prevent almost every case of this deadly disease. We have known since the 1960s that organised cervical cancer screening programmes can prevent up to 80 per cent of cervical cancers and it is a scandal that only seven European countries have put these programmes in place.

The introduction of high-quality screening of cervical cancer in all member states could save the lives of over 14,000 women every year. The recent parliament motion for a resolution on combating cancer in the enlarged EU states that

"there are currently inequalities in cancer screening and follow-up within the EU". A major barrier, however, to addressing and treating this preventable cancer has been lack of the resources available to implement national and/or regional cancer screening guidelines and cervical cancer screening programmes, particularly in new member states.

The compiling and registration of relevant statistical information is not comprehensively undertaken in many countries of eastern Europe and limited information is available on cervical cancer prevention and treatment. New member states should be encouraged to make greater use of structural funds for investing in the health sector, such as supporting the implementation on the council recommendations on cancer screening.

"We have known since the 1960s that organised cervical cancer screening programmes can prevent up to 80 per cent of cervical cancers and it is a scandal that only seven European countries have put these programmes in place"

And now, we have new technologies such as liquid-based cytology, HPV testing and the HPV vaccination, that if implemented within comprehensive organised cervical cancer prevention programmes, will give us even greater reductions in cervical cancer, even to the point that this cancer could be virtually eliminated in Europe.

Increased access to cervical cancer screening has important implications for all women in Europe, has the potential to save lives, to control the disease and at the same time to reduce healthcare costs. Of vital importance is the commitment of national governments to public health information and education programmes aimed at women (particularly the disadvantaged) and men, doctors and patients. I also think that one of the most effective ways to deliver a comprehensive information and education programme in all member states is to ensure coordination at a European level.

There are at least two main reasons why the prevalence and mortality of cervical cancer is so high. First, women have not been made aware of what they need to do to prevent cervical cancer. As a result, they do not take advantage of the programmes where they exist and they do not advocate for the implementation of these programmes where they do not exist.

Second, many politicians are not aware of the health and economic benefits that these programmes would bring to the countries they serve and therefore they do not prioritise their implementation. Clearly, the last remaining front in the battle against cervical cancer is awareness.

So, we have this remarkable potential to reduce disease and death and yet the majority of women in Europe have no access to it. This is the challenge that I set before all of you: we know what we have to do, the technologies are available, but actually we need the political motivation to make sure that all women in Europe have access to proper cervical cancer prevention. ★

Cervical cancer: The facts

Cervical cancer is the second most common cancer after breast cancer affecting women aged 15-44 in the EU.

Each year, there are around 33,000 cases of cervical cancer in the EU, and 15,000 deaths.

The primary cause of cervical cancer is a persistent infection of the genital tract by a high-risk human papilloma virus (HPV) type.

Genital HPV infections are very common and acquired soon after the onset of sexual activity. Most infections are spontaneously cleared.

However, persistent HPV infections with a high risk HPV type can cause cellular changes in the cervix that can result in cervical cancer.

Source: Guidance for the introduction of HPV vaccines in EU countries, European cancer patient coalition

Lithuanian MEP Jolanta Dičkutė is co-chair of the European cervical cancer interest group

Breaking the taboo

Colon cancer is the most common cancer in the EU, but as **Lynn Faulds Wood** said, most people are either unaware of it or unwilling to talk about it

Colon cancer is now the most common cancer in the EU, but who knows this? I'm an award-winning investigative TV presenter in the UK, yet when I was diagnosed 16 years ago with colon cancer, I had never even heard of the disease.

Worse, after nearly a year of being fobbed off by my GPs that it was "nothing to worry about at my age, probably piles", I was shattered to discover I had advanced stage C cancer in the lymph nodes. I was female, 40, with a three-year-old child, no family history of cancer – and no piles.

When I was diagnosed, the UK had one of the worst survival records in Europe. I was lucky; I had a well-trained surgeon who audited his results and knew he was twice as good as the average surgeon. When I finally got the all-clear, I decided to give up most TV work and campaign to save others from this cruel, common cancer.

Over the years I've helped to create a huge symptoms database, produce new research-based symptoms advice (officially adopted for the UK in 2000) and set up formal diagnostic training courses in colonoscopy (No more "see one, do one, teach one" which seemingly used to be the principal training method in my country.)

I've also helped to break the taboo of talking about colon cancer (confusingly also known as bowel and colorectal cancer across Europe) with a number of awareness campaigns.

TV programmes I've made about colon cancer show the public really want to know about this cancer, which currently kills almost half the people across Europe who develop the disease. 'Doctor knows best', an investigation into GP training in cancer symptoms, attracted an audience of over 10 million people. 'Bobby Moore and me', an investigation into bowel cancer, got nearly seven million viewers and 28,000 letters poured in.

When GMTV (a UK breakfast TV programme) launched our recorded symptoms hotline – three minutes of me talking about the symptoms of bowel

"I asked the MEPs present whether they would be screened for colon cancer (they would!) and whether they thought a mobile colonoscopy vehicle parked in the European parliament was a good idea (they did!) Watch this space ..."

cancer – on the first day, it received an astonishing 156,000 attempted calls! And the department of health, agreeing to distribute our first symptoms leaflet, received 30,000 requests to their freephone line on day one.

It's time to break the taboo about this common cancer, which affects one in 10 of our families across Europe. This year over 100,000 European citizens will die unnecessarily of colon cancer. They will die because the European commission recommendation on cancer screening has been poorly implemented in most countries – if implemented at all. They will die because the populations of many countries do not know that this common cancer is preventable, treatable and curable. They will die because we don't talk about it, don't push for screening and don't know the symptoms.

European research has been the biggest driver for change in the UK. Back in the late 1990s, the Eurocare research project across Europe, comparing cancer survival in the then EU15, showed that Britain had among the lowest survival chances. This led to the appointment of a national cancer director (who has done a great job) and the redesign of cancer services.

MEPs could take the lead in ensuring the commission's recommendation on cancer screening is implemented, the aim being screening from the age of 50 by 2015. Congratulations to the Slovenian EU presidency for putting their health focus on cancer. They have brought about an important shift in emphasis on cancer, now the biggest scourge of our age as the death rates from heart disease and strokes are coming down across Europe.

The decision to place the focus on the prevention of cancer is important to stem the future cancer tide. With the emphasis on screening and early detection for cancers that can be prevented we will free up valuable resources for those that cannot. At the same time it is clear that we cannot abandon cancer patients for whom prevention is not possible or has come too late.

Congratulations too to MEPs against cancer for holding a landmark meeting on screening in the European parliament and for inviting me to speak about the need for screening for colon cancer and how we are trying to break the taboo surrounding this common cancer. I asked the MEPs present whether they would be screened for colon cancer (they would!) and whether they thought a mobile colonoscopy vehicle parked in the European parliament was a good idea (they did!) Watch this space … ★

Lynn Faulds Wood is president of the European cancer patient coalition and heads the UK-based charity Lynn's Bowel Cancer Campaign

No debate: Colorectal cancer screening saves lives

Christa Maar told the MAC audience that a deep personal tragedy has driven her campaign on colon cancer

Because colorectal cancer – with 400,000 newly diagnosed cases and 200,000 fatalities every year – is the second most common cause of cancer and cancer death in Europe, saving lives is eminently important. Additionally, the treatment costs of 800,000 patients who are currently alive with colorectal cancer in various stages represent a huge burden on the health budgets of European countries.

Concerning colorectal cancer incidence, mortality and survival rates there are great inequalities in the European countries. Since therapy cannot heal patients with advanced disease, the inequalities can only be overcome by the implementation of population-based, quality-assured national screening programmes in the member states. But to date, no more than 14 countries have implemented a national screening programme for the detection of carcinoma and its pre-stages.

One of the aims of the European conference on colon cancer prevention, which the Felix Burda Foundation organised last May, was to create awareness for this priority issue on the EU healthcare agenda as well as to press for urgency in developing an EU action plan to fight colon cancer on a pan-European level.

The participants from 28 different countries adopted a Brussels declaration 'Europe against colorectal cancer' which urges the European commission to lobby for implementation of colon cancer screening programmes in all member states.

"Screening can be a powerful tool to prevent European citizens from developing and dying of colon cancer, provided that the countries implement standardised, quality-assured screening"

The declaration is officially supported by all relevant scientific societies and cancer organisations in Europe as well as by MEPs and the Slovenian government. The Foundation has distributed 2000 copies to all relevant stakeholders in the EU member states, including scientific societies, politicians, health insurers, patient organisations and cancer leagues.

What then is the foundation's special interest in promoting colon cancer prevention and what exactly does it do to increase the awareness for this disease? The foundation was founded in 2001 after the person it is named after died from a colon carcinoma at the age of 33. Its main goal is to educate the public about the means and methods for the prevention and early detection of colon cancer and to increase the motivation of people to participate in screening procedures.

Being part of the large German media company Hubert Burda Media, the foundation uses all the media at its disposal to create awareness for this very topic through media campaigns. Together with a network of potent partners it has established the national colon cancer awareness month every March which has turned into a joint endeavour with the many different German players in this field of healthcare.

Main recommendations of the Brussels declaration on colorectal cancer

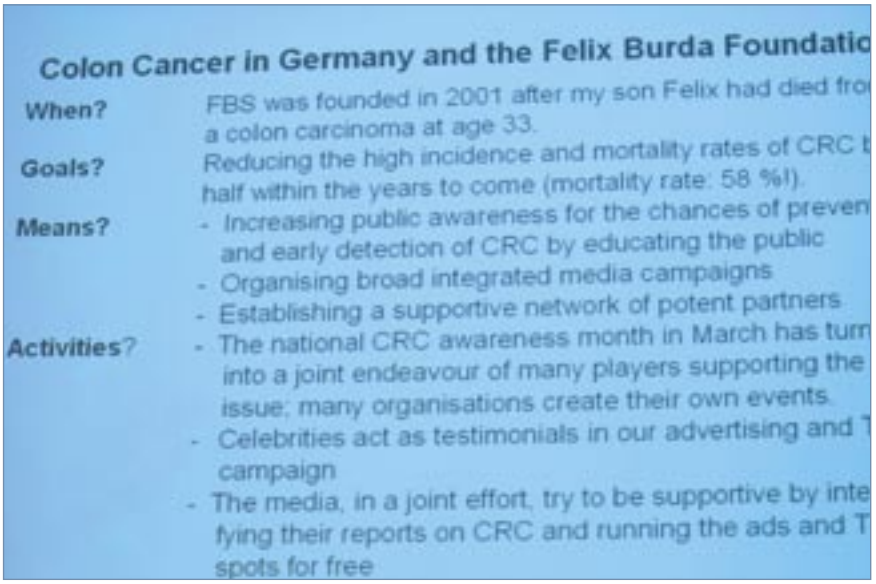
- **Action plan and European guideline**
  The European commission should set up a European action plan making the prevention of colorectal cancer a high priority task on the European healthcare agenda. The health ministers should, as soon as possible, be provided with a European guideline supporting the introduction and quality-assured implementation of national screening programmes. In addition, the guideline should include measures for the screening and handling of high-risk groups with an inherited susceptibility of contracting the disease.
- **Information and education campaign**
  The European guideline should advise member states to include a national awareness campaign in any national screening programme they are about to launch. This campaign should inform the public as well as doctors about the benefits of colorectal cancer screening.
- **Quality assurance of the colorectal cancer screening programme**
  The European guideline should advise member states to implement any national screening programme they are about to launch on the basis of a quality-assured and quality-controlled infrastructure.
- **Training of personnel**
  The European guideline should advise member states which are about to introduce a national screening programme to provide appropriate training to the personnel, involved in the screening procedures. This includes personnel involved in pre-screening consultation, the screening itself and, if necessary, the subsequent diagnosis.

- **Promotion of research programmes**
The European commission should establish a designated research programme to evaluate the methods of the prevention and early detection of colorectal cancer which have not yet been evaluated sufficiently and to investigate new screening methods which have a potential for the future.
- **Establishment of a pan-European network**
The European commission should use the panel of European experts from the Brussels conference on colon cancer prevention as a platform for the establishment of a pan-European network against colorectal cancer". In addition, the network should also feature representatives of health politics, health insurance providers, patients' organisations and high-risk groups from different European countries. Only with such a joint effort will it be possible to level the extensive inequalities in the colorectal cancer survival rates in the foreseeable future.

Looking at what has been achieved in Germany so far with the help of the foundation's campaign, the facts tell the tale. Shortly after the first national colon cancer awareness month in March 2002, Germany's public health insurers decided to extend the existing stool test programme by offering a preventive colonoscopy for all citizens older than 55, free of charge.

To date, three million people with no symptoms underwent a preventive colonoscopy. The results are encouraging: a high percentage of the carcinoma (70 per cent) which were detected during this procedure were in early stages and could be cured and about 150,000 persons in whom preliminary stages of cancer were found could be prevented from developing a carcinoma. The result is that Germany's mortality figures of colon cancer which were at a top range in Europe in 2002 came down from 58 per cent to 41 per cent.

However, Germany's participation rate in colon cancer screening does not match with Europe's best rates. The German rate suffers from the opportunistic scheme which does not allow for addressing the eligible persons directly and invite them for screening, like some other European countries do.



Despite this obvious failing in the screening system, every year more than half a million German people under 55 undergo a screening colonoscopy. The larger part of it is owed to the work of the foundation and its partners who always try to come up with innovative ideas, new co-operations, and new partnerships to raise awareness and address people in settings.

One million people have been educated by their companies about colon cancer, offering them a free of charge test-kit. About 100 of the largest German corporations in the meantime have integrated colon cancer screening into their regular healthcare programme for employees. Since men traditionally participate much less in screening programmes than women though developing colon cancer some years earlier than women, a partnership with a company providing car certification has been established and stool test kits will be handed out to men while they wait for their cars to be certified.

The exchange of innovative ideas and projects to overcome the natural barriers of people towards colon cancer screening is the lead motif of a transatlantic workshop the Felix Burda Foundation will be organising later this year in New York. It is a small group of experts and private institutions from both sides of the Atlantic which will gather to exchange best practice projects and learn from each others practical experiences.

Screening can be a powerful tool to prevent European citizens from developing and dying of colon cancer, provided that the countries implement standardised, quality-assured screening and inform their citizens about the chances of screening and staying healthy. European countries have to work on that. ★

Christa Maar is president of Felix Burda Stiftung

High resolution

MEP **Antonios Trakatellis** told the MAC event that up to two-thirds of cancer can be prevented

Prevention and screening should be at the centre of the fight against cancer in the enlarged EU. Last year I tabled a written declaration on the need for a comprehensive strategy to control cancer.

Two months later the European parliament put forward a resolution on combating cancer in the enlarged EU, which calls on the commission to revise the existing recommendation on cancer screening in order to take account of the rapid development of new technologies and to include more types of cancers and additional techniques of early diagnosis. I am pleased to say that in January the committee of environment, public health and food safety adopted the draft motion for a resolution on combating cancer in the enlarged EU.

As health spokesman for the EPP-ED group I really want to stress the following issues: The need for the commission to encourage and support initiatives with the aim of preventing cancer through promotion of healthy lifestyles, in particular as regards the major risk factors such as tobacco, alcohol, unhealthy diets and lack of physical activity and sun protection, putting a strong emphasis on children and adolescents; the promotion of the recommendation on cancer screening and its effective implementation in all member states as well as the setting up of population-based screening programmes according to European quality assurance guidelines; the allocation of funds within the seventh framework programme (FP7) in order to encourage research and innovation in the area of primary prevention, of screening and early detection, and of new anti-cancer medicines and treatments. I would also like to further stress the need to continue to fight the inequalities of access to anti-cancer medicines and treatments.

"I want to see a comprehensive strategy against cancer based on prevention, early diagnosis, therapy and palliative care"

After the powerful support the written declaration got from all sides and after the oral question tabled by the environment and public health committee, another important step has been made in the battle against cancer. The Slovenian presidency has pledged to make cancer a priority by revising the existing actions in the field of prevention and control of cancer, so they are in synergy with the progress of science and technology. I believe it was important to bring up these issues – and the resolution – at the MAC event in parliament because that was the perfect forum to highlight current failings. I want to see a comprehensive strategy against cancer based on prevention, early diagnosis, therapy and palliative care.

Cancer can be beaten. Indeed, up to two-thirds of cases can be effectively tackled but only through early diagnosis and prevention. Most people probably know someone who has died from cancer and I am no different. My mother's brother was a big smoker and had lung cancer, while a cousin of mine also died from cancer. We need to continue in our fight to make sure that cancer does not remain the leading cause of death in Europe. ★

Motion for a resolution on combating cancer in the enlarged EU

The parliament's motion for a resolution on combating cancer, released in November last year, calls on the commission to consider making improvements in the way cancer prevention is handled at EU level. It followed a previous written declaration on the need for a comprehensive strategy to control cancer tabled by Antonios Trakatellis in September 2007.

A cancer task force
The commission should set up an inter-institutional task force to coordinate best practice for prevention, screening and treatment.

Better information
There should be more information available to patients with cancer and better promotion of the council's 2003 recommendations on cancer screening.

Support for research
EU legislation should contain incentives for industries to innovate, and funding should be dedicated to primary prevention screening and developing anti-cancer medicines.

A patients' rights charter
Member states should adopt national charters of patient rights according to European guidelines.

Antonios Trakatellis is the EPP-ED group's health spokesman and member of the parliament's public health committee

Cooperation is essential

Laurence von Karsa said that the EU needs more resources and increased collaboration to successfully implement proper screening programmes

According to the international agency for research on cancer, over 250,000 deaths due to breast, cervical and colorectal cancers were reported in the EU in 2006. The annual rates of these cancers vary widely across the EU, reflecting a substantial increase in the health burden in various member states. This applies particularly to cervical cancer, the rates of which have markedly risen in all but one of the member states that acceded to the EU in 2004 and 2007.

Substantial knowledge and experience of screening has been acquired through screening networks established under the Europe against cancer programme. The networks have shown that achieving and maintaining high quality at every step in the screening process requires an integrated, population-based approach to health service delivery. This approach is essential in order to make screening accessible to those in the population who may benefit and in order to adequately monitor, evaluate and continuously improve quality.

The European commission is currently preparing a report on the implementation of the 2003 council recommendations, based on a written survey of the 27 member states conducted in the second half of 2007. The official report will be published after completion of the internal consultation process. The preliminary results of the report, based on the currently available data, show that substantial numbers of women and men in the EU are affected by breast, cervical and colorectal cancer screening programmes that are currently running or being established.

Based on present estimates, over 50 million people attended screening programmes in 24 member states in 2007. Furthermore, there is substantial agreement between member states and the council on the health policy priority of establishing population-based cancer screening programmes.

The widely shared consensus is reflected in the number of member states currently running or establishing population-based programmes for breast, cervical, and colorectal cancer.

Despite substantial efforts, however, there is still a great disparity in the implementation of screening across the EU. This is reflected in the number of member states in which nationwide rollout of population-based screening programmes is still ongoing, or has yet to begin because breast, cervical and colorectal screening programmes are currently in the piloting or planning phase.

The need for further action is also reflected in the number of states in which non-population-based screening programmes are still conducted or in which no programme implementation of any kind is currently known or planned.

Experts and policymakers agree that the current situation illustrates the need for support for member states seeking to implement or improve population-based screening programmes and they pointed out obstacles which should be overcome and priorities for further action. These can be summarised thus: Policymakers should be aware of the inefficiency and ineffectiveness of non-population-based screening; population-based screening programmes should be introduced where they are lacking, and non-population-based screening programmes should be replaced with population-based programmes; and non-evidence-based screening should be discouraged and evidence on how to improve existing programmes should be developed, including investigation of new screening tests.

"Despite substantial efforts, however, there is still a great disparity in the implementation of screening across the EU"

In the light of the large volume of breast, cervical and colorectal screening examinations currently performed in the EU (over 50 million per year), action is urgently needed in the following areas: Development and implementation of an EU-wide accreditation-certification scheme for screening, diagnosis and treatment according to EU guidelines; professional, organisational and scientific support for member states seeking to establish and improve population-based screening programmes; a European initiative for schools of screening management; improvement of screening performance and results by application of scientific methods and studies in service screening; and regular, systematic monitoring, evaluation and EU-wide status reporting is needed to promote an exchange of information on successful developments and to identify weak points requiring improvement.

Substantial additional resources are also required to plan, pilot and successfully implement population-based screening programmes, particularly in member states that have not yet implemented respective programmes. Cooperation between member states in these efforts is essential. ★

Laurence von Karsa is head of the screening quality control group (ECN) at the international agency for research on cancer in Lyon, France

Key players

The MAC debate heard from **Håkan Mellstedt** that oncologists can play a crucial role in raising public awareness of cancer screening

"We believe oncologists should take part in the development of cancer screening programmes, providing the scientific insights necessary to guarantee that screening has a positive impact and that drawbacks are kept to a minimum"

Cancer is to a large extent a preventable disease. Screening and education to promote early diagnosis are two major components for early detection of cancer and to improve the prognosis.

The European society for medical oncology (ESMO) is recognised as a highly qualified professional, scientific and educational society aiming to create a wider community of professionals providing optimal care to cancer patients. As a key player in the field of cancer, ESMO provides education and information to health professionals, cancer patients, the general public, policy-makers and every other stakeholder.

ESMO educates doctors on early diagnosis; encourages people to accept mass screening programmes and take them with a positive attitude and urges policy-makers to take responsibility for an effective fight against cancer which starts with screening and prevention.

ESMO has strengthened its commitment to cancer prevention and screening by establishing the 'ESMO cancer prevention working group' responsible for all activities that concern both prevention and screening. ESMO has recently launched the 'ESMO handbook of cancer prevention', a state-of-the-art, practical guidance on reducing cancer risk and screening for tumours.

So far oncologists have not been centrally involved in prevention and screening activities, with most of their work devoted to cancer treatment only.

However, there is a clear willingness to change the situation, firmly supported by ESMO. We believe oncologists should take part in the development of cancer screening programmes, providing the scientific insights necessary to guarantee that screening has a positive impact and that drawbacks are kept to a minimum. We also believe oncologists could play an important role by contributing to and participating in awareness campaigns to inform the population about the importance of screening programmes and disseminate information about how to prevent cancer.

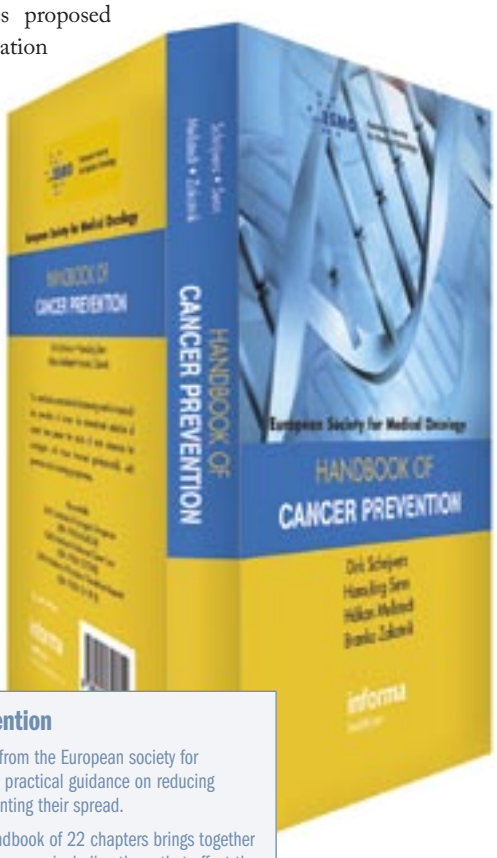
Before launching new screening campaigns, it is mandatory to assess the availability of effective treatments. Screening a large population for a disease that cannot be treated effectively is a waste of resources, to which we must add the sense of frustration and psychological side-effects for individuals. Implementation of screening programmes needs, therefore, to be based on the evaluation and prediction of effects, side-effects and costs. ESMO could help in four areas by:

- lobbying governments to implement screening programmes or improve existing ones
- raising public awareness through information and education
- training and educate health professionals and others on prevention and screening issues and
- supporting research to design more efficient screening strategies, new technologies and screening evaluation

ESMO strongly encourages the investment of funds for more research on prevention and screening. Considering the high number of new cancer cases, the terrifying estimates for the future and the fact that for most tumours earlier detection means better prognosis. It is clear that a larger proportion of investments should be dedicated to prevention and screening. Priorities include identification of new screening technologies and the search for biomarkers to help improve cancer prevention and screening strategies. In Europe cancer screening is at present definitely a competence of member states. Article 152 provides that EU action is merely to complement national policies.

The commission has been invited by the council to report on the implementation of cancer screening programmes on the basis of the information provided by member states. It is evident that the measures proposed by the council in its recommendation are not working fully effectively and we may consider the need for further action. ESMO, therefore, calls upon the many stakeholders in cancer screening to encourage the adoption and/or improvement of cancer screening programmes by member states; encourage the cooperation between countries in research and exchange of best practices and to support research on cancer screening.

It is clear to us that by failing to make cancer screening a priority, member states are missing important opportunities to reduce the burden of cancer among their citizens. ★



ESMO handbook of cancer prevention

- The ESMO handbook of cancer prevention, from the European society for medical oncology, contains state-of-the-art, practical guidance on reducing cancer risk, screening for tumors and preventing their spread.
- In order to increase awareness, ESMO's handbook of 22 chapters brings together vital information on preventing a range of cancers, including those that affect the lungs, cervix, breast, prostate and colon. Chapters devoted to tobacco, alcohol, nutrition, workplace risks and hereditary cancer provide recommendations on the best ways to reduce cancer risk.
- The handbook is part of a wider commitment from ESMO to promote the importance of cancer prevention.
- The ESMO handbook of cancer prevention is one of a series of handbooks ESMO has been producing since 2005. The ESMO handbook series provides comprehensive, easy-to-read guides in a format that is comfortable to carry and which offers concise first-hand advice on specific treatment and prevention strategies in the realm of oncology, making them a practical educational tool.
- The complete list of handbooks published to date, as well as sample pages are freely available at www.esmo.org/resources/books.

Håkan Mellstedt is professor of oncologic biotherapy at the Karolinska Institute, Stockholm and former president of ESMO

Completing the picture

Europe's colorectal cancer screening programmes are often opportunistically rolled out and subject to huge waiting times, writes the LSE's **Panos Kanavos**, with Willemien Schurer and Candida Owusu-Apenten

With levels of colorectal cancer (CRC) incidence and mortality presently amounting to a large proportion of the disease burden, the need for early and effective screening programmes presents itself now more than ever. The argument for CRC screening rests primarily on the early diagnosis of disease.

However, the overall performance of screening initiatives seems to be dependent upon whether such programmes fulfil the basic conditions needed for optimum performance. Indeed, CRC screening in Europe presents several challenges: first, the coverage of screening activity; second, which screening method is initiated and for whom; third, the modalities used within the process of screening; fourth, restrictions in human resources and additional capacity needed to ensure timely diagnosis and treatment; and fifth, assessing the cost, effectiveness and cost-effectiveness of different screening options.

In order for CRC screening initiatives to effectively fulfil the objective of improving health status for the whole population, screening needs to be available for all targeted individuals. Given the very nature of screening processes in general, the number of cases detected is inextricably linked to population coverage.

While the majority of countries within Europe have some form of informal CRC screening activity, very few member states can attest 100 per cent population coverage. Of the 13 responses received from a questionnaire conducted in 2007, only Slovakia, Poland, Finland, the Czech Republic, Germany, the UK and Italy reported the use of national CRC screening programmes. Furthermore, pilot screening initiatives or no CRC screening at all was

"Even if national governments switched overnight from a partial to a full screening policy of eligible individuals, this could not be implemented due to human resources and available facility limitations"

seen within Denmark, France, Greece, the Netherlands, Spain and Sweden. Evidence indicates that opportunistic screening is used within Belgium, the Czech Republic, Germany, France, Italy (partially), Slovakia and Poland, whereas in the UK, the national screening programme is rolling out gradually.

With the exception of Germany, many countries have failed to use methods of mass communication to secure participation. Within countries that performed opportunistic screening on a national level, values of participation were 10 per cent (Poland), 15 to 35 per cent (Germany) and 37 per cent (Slovakia). Even beyond the dimensions of opportunistic screening/formal invitation, a large proportion of countries have yet to implement prevention campaigns specifically designed to improve CRC awareness. Such programmes are reported as being implemented within the Czech Republic, Greece, the Netherlands, Slovakia and Spain.

Of the three modalities (faecal occult blood test (FOBT), flexible sigmoidoscopy and colonoscopy) frequently used to initiate screening, FOBT is the least invasive. While the lack of invasiveness, should, in principle, ensure relatively high levels of participation and limited risk to the individual, in practice the nature of the test increases the likelihood of CRC false negatives and participation screening rates are notoriously low and can range significantly (for example, partcipation rates for FOBT range from 15 to 60 per cent, 13 to 70 per cent for flexible sigmoidoscopy and 55 per cent for colonoscopy).

One of the main consequences of national screening programmes is the increase in the number of cases diagnosed in early stages. In such events it is important ethically, medically and economically that diagnosis and treatment is offered in a timely manner. In order to accommodate for such numbers, health systems need to invest in the appropriate facilities, skill-set and technology in order for screening to be truly effective.

However, long waiting times are a persistent problem within Europe. Beyond given health system targets, actual diagnostic waiting times were seen to be one month or more in Germany, Greece, the Netherlands, Spain, Sweden and the UK. In addition to this, insufficient endoscopic staffing was seen within the Czech Republic, Denmark, France, Greece, the Netherlands, Poland, Romania, Slovakia and Spain. It would be fair to say that even if national governments switched overnight from a partial to a full screening policy of eligible individuals, this could not be implemented due to human resources and available facility limitations, resulting in increased waiting times.

The decision of what screening policy to implement based on effectiveness, cost, and cost-effectiveness is an additional challenge facing payers as it has significant implications for the resources to be deployed for an effective screening policy. Available studies on cost-effectiveness of different CRC screening techniques focus mostly on FOBT and different age thresholds at implementation, and need to be supplemented with additional hard data on colonoscopy in order to provide decision-makers with a more complete picture. ★

Panos Kanavos is a senior lecturer in health policy at the London school of economics

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Shouldering the burden

Alojz Peterle and **Marija Seljak** tell the MAC conference how their country is intensifying efforts in the fight against cancer

"The fight against cancer should become a regular subject of the European council agenda"

Slovenia, fresh from hosting a conference on reducing the burden of cancer, is navigating a course towards an EU cancer strategy, and has made the disease a top health priority during its EU presidency term. According to Alojz Peterle, MAC's co-chair and a Slovenian MEP, "The fight against cancer is one of the priorities of the Slovenian presidency.

"The ambition is not aimed only at improvements in various areas as far as research, palliative care, screening programmes, etc. The Slovenian presidency would like to respond to citizens' calls for action also with a step forward at the EU level. The fight against cancer should become a regular subject of the European council agenda". He told the Parliament Magazine last month that cancer is on the rise. "One in three European citizens should today expect to get cancer. The world health organisation (WHO) even forecasts that there will be an increase in the number of new patients. How can the EU become the most competitive economy in the world when the health indicators are only worsening?"

His fellow Slovenian, Marija Seljak, director general for public health in Slovenia's health ministry, told the MAC conference that a report published after the Brdo cancer conference recommends a solution: integrated national plans, embracing the elements of prevention, early detection, treatment, rehabilitation, palliative care and research, and a system of population cancer registries. "The responsibilities for preventing cancer are within member states," she said. "But many things could be better dealt with at the EU level, including collecting evidence, developing guidelines and legislating in certain areas." Her aim is to close the gaps in screening and treatment between member states, and with this in mind, Slovenia is leading the EU towards a coordinated strategy on cancer. ⇨

Reducing the burden of cancer

Slovenia's recommendations from the cancer conference in Brdo, 7-8 February

Screening

- EU-wide accreditation-certification scheme for screening units
- Professional, organisational and scientific support for member states establishing population-based screening programmes
- Improve screening performance and results by applying scientific methods and studies in service screening
- Improve the accessibility of EU structural funds for screening programmes
- Regular systematic monitoring, evaluation and EU-wide status reporting to identify weak points in screening

Cancer strategy

- Use the EU health strategy to create a momentum for developing cancer plans with adequate commitment
- Create a task force on cancer within the commission
- Sustainable collaboration in HTA between member states, commission and others
- Develop a holistic approach to cancer, where quality of life as well as medical treatment is valued
- Develop and train staff in order to build multidisciplinary teams for cancer care
- Develop centres and networks of reference to support treatment and research

Cancer research

- More clinical/translational research across member states' boundaries
- Closer collaboration between different research centres in Europe and the formation of a network of cancer research centres
- More EU money dedicated to unified pan-European research activities that add European value
- Higher transparency on clinical cancer research with publicly available information on ongoing clinical trials and results

"Cancer research in Europe is still very fragmented and heterogeneous. Most of the member states and the commission need to increase their investment in cancer research"

Peterle and his fellow MAC members have long been calling for a cancer task force, something they urged the commission to create last year by tabling a motion for a resolution on combating cancer in the enlarged EU. "I myself have been pushing for the creation of an EU inter-institutional cancer task force composed of commission, council and parliament members, a group which will provide political leadership for fighting cancer, and insist that the knowledge and best practice for prevention , screening and treatment are better shared and implemented in Europe."

Seljak thinks the European code against cancer is a "valuable tool" for cancer prevention, but she says that not only does it need to be adapted, but its use in member states needs to be improved. The code dates back to 1987 and was drawn up by a group of cancer experts under the commission's Europe against cancer programme. It lists practical ways to improve health in an effort to prevent cancer.

But it must be used as a basis for prevention, along with practical measures including an EU-wide accreditation scheme for screening units, support for member states in establishing population-based screening programmes, the use of structural funds for screening and regular monitoring and evaluation to identify weak points in the various national plans. "Use the EU health strategy to create a momentum for developing cancer plans with adequate commitment," she told the audience of MEPs, commission officials and journalists at the MAC conference.

She also called for more money for research. "Cancer research in Europe is still very fragmented and heterogeneous. More clinical/translational research needs to take place across member states' boundaries. Most of the member states and the commission need to increase their investment in cancer research."

Peterle, who has a vested interest in the issue as a cancer survivor, welcomed the progress being made by campaigning MEPs and the MAC and Slovenian conferences. "It is clear that we have made a great step forward. We are now addressing cancer once more at the highest political level.

"The message I took from the Slovenian cancer conference is that we now have a new opportunity to intensify efforts to reduce the burden of cancer. And we are heading the right way. If we want to tackle the increasing cancer burden that experts tell us lies ahead as our citizens age, then surely the best strategy is to invest in prevention to stem the cancer tide."

He added, "As a cancer survivor I have a very strong personal interest in fighting cancer: helping my fellow citizens to prevent getting cancer and supporting cancer patients in their often difficult journey. Remember, cancer affects us all. Let's reinforce our cancer control strategy to fight against it effectively." ★

Screening matters

Governments, the voluntary sector and the public all have a part to play in ensuring that screening becomes an essential tool in the fight against cancer, argues **Richard Davidson**

We warmly welcome the initiative by the MEPs against cancer group (MAC) and the Parliament Magazine to focus on the important issue of cancer screening. Screening matters because it saves lives.

In the UK, as advocated by the 2003 council recommendations on cancer screening, women can be screened for breast and cervical cancer and both men and women for bowel cancer. In fact, the UK (specifically England and Scotland) was one of the first EU member states to set up a national screening initiative on bowel cancer in line with the recommendation. This new screening programme has the potential to save the lives of thousands more men and women in future years.

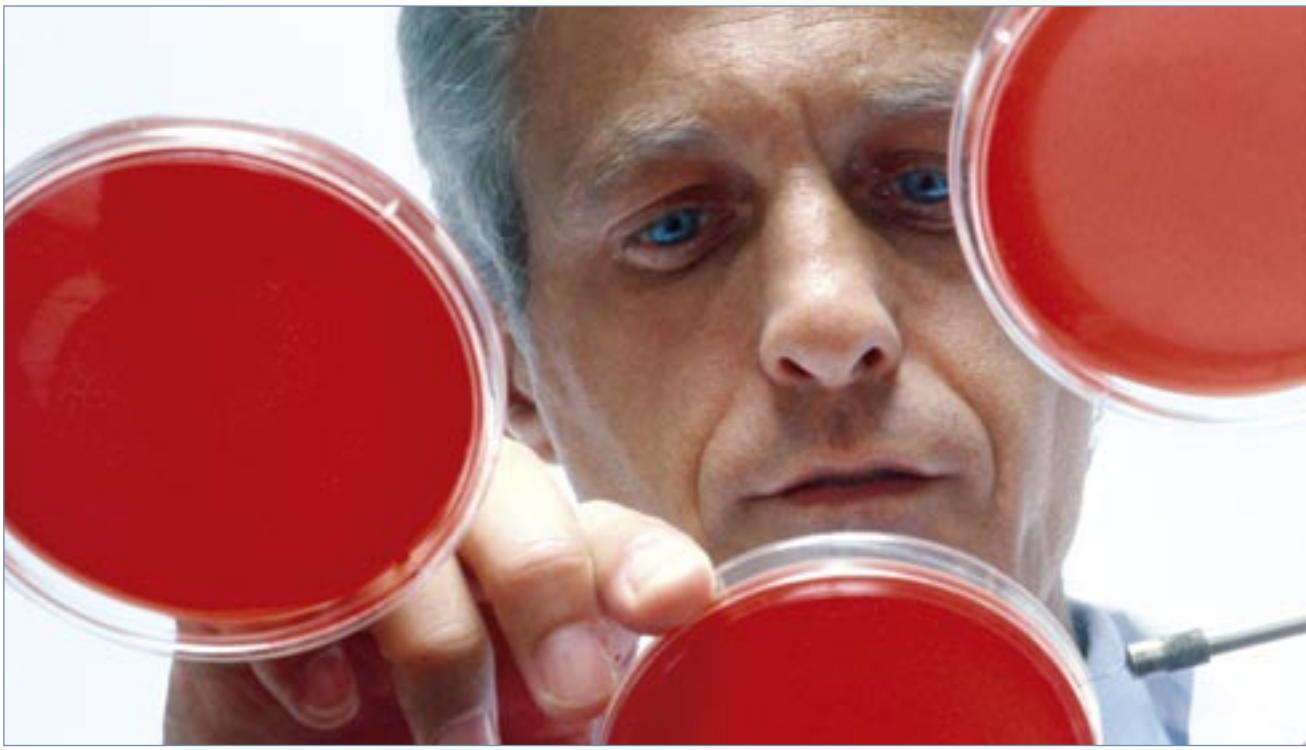
However, there is still room to do more. As highlighted during the MAC meeting, it is not enough to just have organised screening programmes in place: the general public must be made more aware of the potential lifesaving benefits of attending screening.

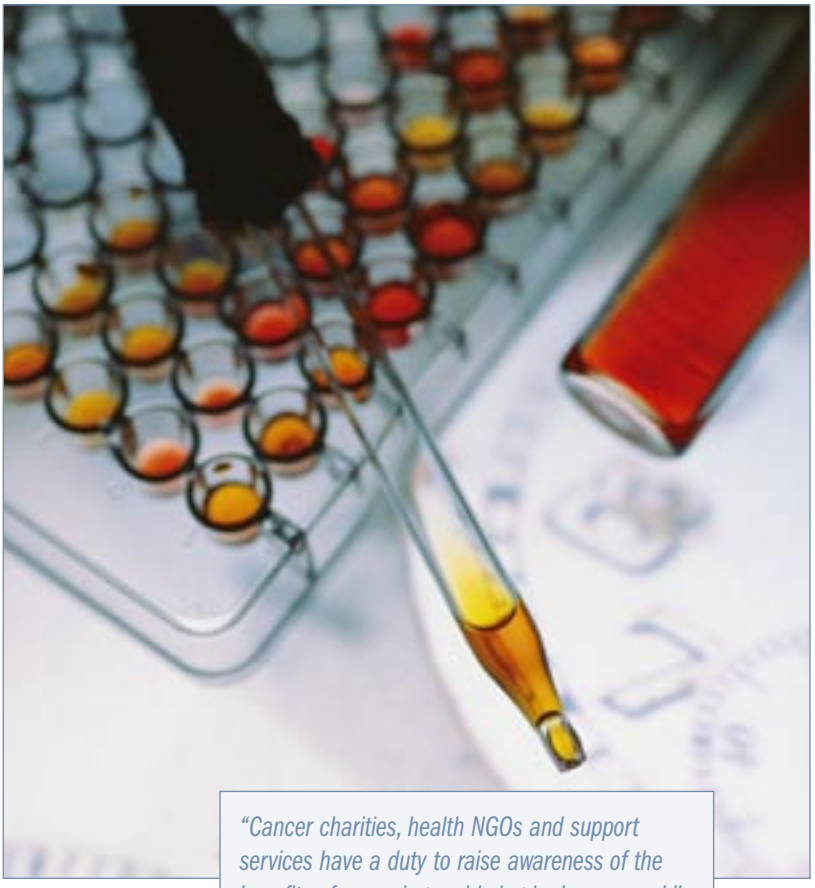
Governments have a major role to play in ensuring the ongoing success of cancer screening programmes. But it would be unfair to place the onus entirely on politicians. Cancer charities, health NGOs and support services have a duty to raise awareness of the benefits of screening and being body-aware, while the public themselves should take a measure of responsibility for prioritising their own health.

Analysis by Cancer Research UK statisticians shows that at least six million eligible people in the UK aren't taking up their invitations to attend screening.

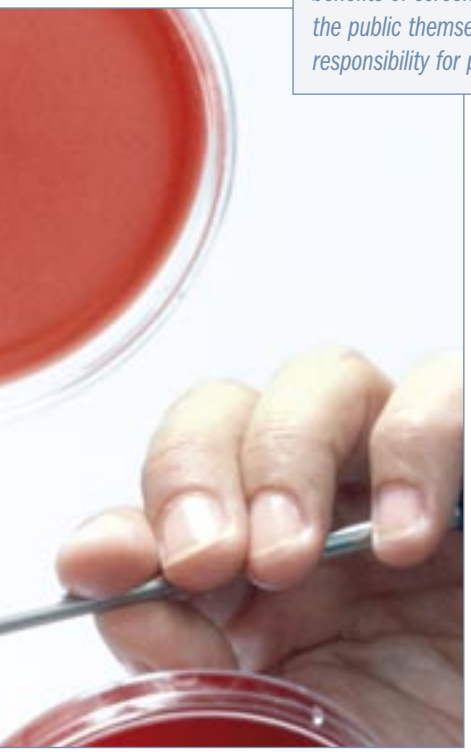
The reasons behind this problem of uptake are complex and include the accessibility of screening centres and the awareness and acceptability of screening in different communities. There have been examples across the UK where shortages of radiographers or radiologists have meant women were not invited to breast screening as often as they should be.

An extreme example of this was seen recently in Northern Ireland, where staff





"Cancer charities, health NGOs and support services have a duty to raise awareness of the benefits of screening and being body-aware, while the public themselves should take a measure of responsibility for prioritising their own health"



shortages led to the breast screening programme being temporarily suspended in a number of areas.

Running a screening programme is no small undertaking. Consistent, long-term funding and staffing are vital in maintaining effective screening. Making the often difficult decisions on investment and recruitment would be made more effective with the help of robust evaluation procedures, but this requires more advanced databases and a coordinated audit system.

We know cancer screening could save even more lives if uptake of screening services could be increased. For example, research by professor Max Parkin at the Wolfson Institute, London, calculates that there will be 20,000 fewer deaths from bowel cancer in the UK over the next 20 years thanks to the roll-out of the colorectal cancer screening programme.

It was with these thoughts in mind that Cancer Research UK launched its Screening Matters campaign in July 2007, ultimately hoping to influence both politicians and the general public. The campaign is supported by many of the UK's other cancer charities.

Already, 100,000 of the charity's supporters have signed a dual campaign pledge, backing the political aims of the campaign and making a personal commitment to attend screening if invited.

We are now moving the campaign on to its next stage: engaging with politicians and policymakers in all four UK administrations. Our more detailed policy shaped into a set of brief sheets will form the backbone of this work. There are four things Cancer Research UK wants the four UK governments to commit to:

- Screen at least three million more people over the next five years
- Reduce the variation in screening across the UK
- Reach out to people eligible for screening who aren't taking part
- Provide the best possible screening programmes through funding, staffing and measuring success.

Screening Matters can only succeed with the combined support of the public, the cancer community and politicians across the UK. This campaign is a tangible embodiment of Cancer Research UK's vision that together we will beat cancer.

Along with the Screening Matters campaign we are carrying out projects aiming to improve tests used currently in the UK's national screening programmes for breast, cervical and bowel cancer.

We are also investigating ways of detecting other types of cancer, which could form the basis of new screening programmes in the future. You can show your personal support for the campaign by signing the pledge at www.cancercampaigns.org.uk. ★

Richard Davidson is director of policy and public affairs at Cancer Research UK

Out of the shadows

There is an urgent need to bring brain tumours and other rare and less common cancers into the light, says **Kathy Oliver**

It is a place often cloaked in half light and shadows – the relatively uncharted corners of the cancer map. Turn left just after the "Big Four" of breast, lung, prostate and colorectal. Travel along a rocky, isolated terrain to the forest where money certainly doesn't grow on trees. Take another left, then a right and continue on to an arid region, desperately crying out for the rain of more research and the sunshine of hope. And there you have it – the place where rare and less common cancers dwell. It is a landscape in turmoil.

A desperate lack of funding for research; inequity in accessing promising new therapies, misdiagnosis and late diagnosis; a paucity of specialists and specialist centres, incomplete registries – these are just some of the problems encountered with the rare and less common cancers.

Governments, as well as major international and national cancer control organisations, have prioritised prevention, screening and healthy living campaigns in the fight against cancer. These are all excellent initiatives. But not every cancer can be helped by this approach. The worry for those living with a rare or less common cancer is that the focus on prevention, screening and lifestyle options may displace the equally important activities of research, awareness raising, support and advocacy.

Take the example of brain tumours. This devastating disease can affect a person's cognitive, emotional and physical abilities. A brain tumour strikes at the very core of one's being. It can affect everything that makes that person who he or she is. Despite some advances in treatment over the last few decades, brain tumours remain one of the most lethal,

most challenging of cancers. While brain tumours are not a major cancer in terms of incidence they shoot high up the list in terms of "average years of life lost" which is a measure of the burden of cancer to the individual patient.

Prevention? The causes of most primary brain tumours are largely unknown. For instance, despite continuing controversy and numerous studies, there appears to be no agreed firm evidence yet that mobile phones cause brain tumours. Without knowing their causes, there can be no prevention programmes for brain tumours.

Screening? Brain tumours do not discriminate by sex, race, geography, religion, class or age. They mostly appear to attack at random. Universal screening for brain tumours is unrealistic. Lifestyle options? Anti-smoking campaigns surely save more lives from lung cancer. Weight control and healthy eating might also help cut some cancer deaths. But there appears to be no such lifestyle shift to avoid a brain tumour.

So we must now ask: "What is being done for the rare and less common cancers, like brain tumours, which are stubborn, intractable and which are not affected by prevention, screening and lifestyle programmes?" There is an urgent need to bring brain tumours, and indeed other rare and less common cancers, out of the shadows on the cancer map, and to put them on the political and cancer control organisation agendas.

"The worry for those living with a rare or less common cancer is that the focus on prevention, screening and lifestyle options may displace the equally important activities of research, awareness raising, support and advocacy"

A coalition of over 30 rare and less common cancer groups in the UK called "Cancer 52" (so named because 52 per cent of cancer mortality is due to rare and less common cancers) has recently helped to raise their profile by participating in the UK department of health's cancer reform strategy consultation.

On February 29th – cleverly chosen to fall on the leap year's rare date – the European organisation for rare diseases (EURORDIS) is spearheading the inaugural "European rare disease day" which will further highlight the plight of people affected in this way. In addressing the challenges of the rare and less common cancers, we must be careful to ensure that the road signs do not only point to prevention, screening and lifestyle options.

Brain tumour patients and other rare and less common cancer sufferers – for whom there has been far too little for far too long – must travel a different path. This path should lead to increased government funding into the development of cutting edge therapies; as well as greater public awareness; additional support and determined advocacy.

We very much hope that the commission communication on rare diseases, expected in 2008, will shine a bright light into the darkness. It's time for brain tumours and other rare and less common cancers to emerge from the shadows. ★

Kathy Oliver is secretary of the international brain tumour alliance (IBTA)

Finding the right mix

Europe is a major contributor to the global cancer research effort, but bureaucracy and over-management are still serious problems as the Parliament Magazine's Martin Banks reports

"Contrary to public perception, a phenomenal amount of cancer research is carried out in Europe." So says professor Richard Sullivan, chair of the European cancer research managers forum (ECRM). As evidence of this, he cites the "huge" amount of cancer research papers currently being published in Europe.

"This is important," he says, "As many policy makers assume the global funding for cancer research is overwhelmingly concentrated in the USA. Our data indicate that this is not true and the effort is a truly global one. The possibilities for fruitful partnerships not only exist, but should be the basis for future long-term policy. We should not fail next generations in losing this opportunity."

Sullivan says there are over 100 major funders in both Europe and the USA, who each spend more than €1m a year on cancer research, as well as a number of important representative bodies. "In light of this, I think you can say there has never been such a golden opportunity for a more cooperative approach in the field, particularly towards the funding of trans-national research programmes," he says. Sullivan adds that while global levels of expenditure on cancer research (as a percentage of GDP) continue to show differences between the USA and Europe, this gap has "substantially" narrowed.

His comments are timely as the ECRM recently published the results of its major survey analysing how the overall €3.2bn spent on cancer research in Europe is funded. It identified 155 non-commercial funding organisations in Europe, spending €1971m on direct funding of cancer research compared to ⇨

€5158m by the USA. In Europe this represents a 38 per cent increase since the last ECRM survey whereas funding in the USA has remained relatively static. It also revealed that the average spend per capita across Europe was €3.42, a 34 per cent increase since it last survey in 2005, and that, in the USA, per capita spend was €17.61, five times greater than Europe. The ECRM is quick to point out, however, that in 2005, this gap was seven times greater.

The survey also found that public cancer research spending in Europe is evenly balanced between charitable and government organisations (47 per cent and 53 per cent respectively). In comparison, US government organisations are the dominant source of cancer research funding, with 96 per cent of all funds coming from ten federal funders. Despite these relatively healthy comparisons with the situation in the USA, Sullivan still makes an urgent plea for "less bureaucracy" which he says is stifling cancer research in Europe. "The impact of regulatory policy on research funding and productivity remains, as it was for the first survey, a critical issue for all countries.

"Over the last decade the fashion for ever increasing regulation across all domains – clinical trials, healthcare data, human tissue – has led to an undesirable increase in the unit cost of research in the absence of any tangible social benefit from many of these regulations. Good research governance is essential but bureaucracy is absorbing too much of the global investment in cancer research. Bureaucracy and over-management remain constant dangers to progress. Funding organisations and government policy makers must guard against these dangers and, where necessary, simplify and harmonise."

He goes on to say that, "Since our first survey was published two years ago, nearly 60 per cent of member states have increased their funding of cancer research in real terms, yet 30 per cent have not. Indeed, the major policy issue is the difference in cancer research investment between EU member states themselves, rather than the prevailing gaps in cancer research funding between Europe and the USA, which have been a driving force for EU policy-making to date."

"Good research governance is essential but bureaucracy is absorbing too much of the global investment in cancer research. Bureaucracy and over-management remain constant dangers to progress"
–professor Richard Sullivan

He also makes a special plea to those EU countries which lag behind the 15 member states which carry out the majority of the research. "It is clear that some governments are still failing to appropriately support cancer research. For these countries the need for specific policy actions to ensure a limited core of high quality research within their institutions is crucial if these member states have aspirations to become major locations for cancer research in the future."

A recently-published ECRM report attempts, for the first time, to estimate the direct annual expenditure of the major pharmaceutical companies involved in cancer research. Sullivan ends on an upbeat note, saying, "We estimate that the top drugs companies spend some €3095m, or 22 per cent of the estimated annual global spend on cancer research. "Traditionally, Europe has been considered weak in attracting industry R&D funding. However, when one considers the geographical origin of pharmaceutical publications, Europe is very much an equal partner with the USA in cancer research." ★

Fresh thinking

We need to rekindle political will in the fight against cancer, writes the ECPC's **Hildrun Sundseth**, who says she has found allies in MAC and the Slovenian presidency

After the Europe against cancer programme came to an end in 2002 – an inspired commission initiative covering prevention, research and information and which produced the European code against cancer – there was a political vacuum.

We urgently needed new Europe-wide political will and thinking to step up action against cancer. And this is why the European cancer patient coalition (ECPC) came into being – to unify the voices of European patients from different cancer groups such as lung, colon, prostate and breast, and including the rare cancers, into one strong single voice to improve cancer control across the EU and its member states. "Nothing about us without us" is our leitmotif.

Over 5000 EU citizens are diagnosed with cancer each day and almost half – 3000 people a day – die from the disease. We know that many of those lives could be saved and argue for improved outcomes for all of those citizens who will be diagnosed with cancer at one time in their life.

This is one third of the entire European population. Our organisation also covers cancer patients whose voices would otherwise go unheard – those with rarer cancers. Did you know that there are over 200 forms of cancer and many of them are rare? On their own, patients with rare cancers not only face the struggle of getting a diagnosis for their rare condition, but also have little chance to be heard in the political arena.

It can be hard to convince governments that allocating resources to the few will be transposed into political capital. But, when united under the ECPC umbrella, a patient with a rare Hodgkin's disease can

have as powerful a voice as a breast cancer patient. Almost every one of us has a family member, friend or neighbour who has faced the tragic misfortune of being diagnosed with some form of cancer. Patients who have gone through this ordeal want others to be spared the experience. This is why we vigorously argue that fresh thinking is needed to step up the fight against cancer.

Much could be done to stem the cancer tide if our countries invested more in prevention, screening and early detection. But again – this takes political will. It is ECPC's ambition to muster this political will, together with the help of MEPs against cancer (MAC) and now the Slovenian presidency. We have already found open ears with MEPs – Alojz Peterle, Liz Lynne and Adamos Adamou – who set up the cancer interest group MAC in order to rekindle the political will to action. There are now over 60 MAC members, spanning all major political groups. One of MAC's chief aims is to encourage the EU to tackle inequalities in cancer prevention and care.

"Cancer is too devastating a health burden to leave it to only one country to be our champion. Subsequent presidencies will bear the responsibility of consolidating and building upon this work"

Given the complexity of cancer, it is a shock that some member states still have no cancer control plan, nor a strategy for creating one. Some of our EU countries even today lack population-based screening programmes. We know the evidence – cancer screening can save lives. There is no excuse for such lack of planning and foresight, especially since we have a council recommendation on cancer screening.

It is difficult for patients to understand the existing inequalities in cancer prevention, treatment and care within and between member states. We have therefore taken heart that the Slovenian presidency cancer initiative will place the whole spectrum of cancer control under the microscope, including importantly, the need for continued research for all those cancers where currently there is no treatment. Importantly, their presidency conference in Brdo in early Februrary has given patients a seat at the table, reflecting the chapter "Patients as partners for change" that ECPC wrote in the Slovenian cancer report (Responding to the challenge of cancer in Europe).

ECPC, together with our friends and allies, will do all we can to support the Slovenian cancer efforts. For six months, a bright light will shine on our complex set of diseases. However, cancer is too devastating a health burden to leave it to only one country to be our champion. Subsequent presidencies will bear the responsibility of consolidating and building upon this work. We thank the Slovenian presidency for their support and take heart from their health theme that "today's seeds are tomorrow's flowers". We hope that the fruit of our collective labour means that soon we will have fewer patients and more survivors. Fewer cancer patients will be dying. ★

Hildrun Sundseth is head of EU policy at the European cancer patient coalition (ECPC)

Prevention programme

A new report by the European centre for disease prevention and control says that vaccination of adolescent girls could help reduce the number of women developing cervical cancer, writes **Johan Giesecke**

Following the authorisation of two human papillomavirus (HPV) vaccines, the European centre for disease prevention and control (ECDC) was asked by the commission and member states to review available scientific evidence on their likely public health impact.

In response, ECDC set up a panel of independent experts to conduct a thorough analysis of issues relating to HPV vaccination programmes, including the impact on existing cervical cancer screening programmes, the target populations, delivery options, cost effectiveness and the need for monitoring and evaluation. The conclusions of this panel were then reviewed by ECDC scientists and our advisory forum which brings together senior scientists from member states. Finally, on 21 January the agency published a report on "guidance for the introduction of human papillomavirus (HPV) vaccines in EU countries".

Its key finding is that vaccinating young adolescent girls against the HPV is likely to reduce the number of women who develop cervical cancer, providing that national cervical cancer screening programmes are maintained. Importantly, HPV vaccination programmes do not eliminate the need for cervical cancer screening, even for women who have been vaccinated.

Cervical cancer is the second most common cancer (after breast cancer) affecting women aged 15-44 in the EU. Each year, there are around 35,000 cases of cervical cancer in the EU, and 17,000 deaths. The primary cause of cervical cancer is persistent infection of the genital tract by one of the high-risk types of HPV (only a few of the HPV

Trends in cervical cancer in the EU

- In the EU, the incidence of cervical cancer per 100,000 females (all ages) per year ranges from less than 8.0 to 29.9 in the EU's eastern member states.
- Analysis of cervical cancer mortality in the then 25 EU Member States showed that the burden was lowest in Finland and highest in Lithuania.
- The risk of developing cervical cancer increases with age and reaches a peak at about 35 to 55 years of age in unscreened populations.
- Although cervical cancer incidence and mortality have been declining in many European populations in the past few decades, upward trends have been reported in younger women in several countries.
- Human papillomaviruses
- HPV infects the skin and mucous surfaces of the body. More than 40 types of HPV have been identified which can infect the human genital tract, and these are highly adapted to their human hosts.
- Transmission of genital HPV types usually occurs during sexual intercourse, although penetration of the penis into the vagina is not necessary. Transmission has been shown to also occur via skin-to-skin contact.
- HPV infections are the most commonly diagnosed viral sexually transmitted infections among women and men. Studies have detected asymptomatic

- HPV infection in 5-40% of women of reproductive age and most sexually active women and men will become infected with at least one type of HPV during their lifetime.
- Prevalence peaks soon after the start of sexual activity and remains high in the 20-29 year age group before sharply declining.
- HPVs can be classified as 'low risk' or 'high risk' in terms of their potential to cause cancers. There are at least 13 of these 'high-risk' types which are known to cause cervical cancer.

Source: ECDC report on guidance for the introduction of HPV vaccines in EU countries: Stockholm, January 2008

virus types are capable of causing cervical cancer). Genital HPV infections are very common and acquired soon after onset of sexual activity.

Most of these infections clear up on their own and cause no serious harm. However, persistent HPV infections with a high-risk HPV type can cause cellular changes of the cervix that can result in cervical cancer. Two prophylactic HPV vaccines have been licensed in Europe: Gardasil and Cervarix. Both vaccines have a good safety profile and protect against the high-risk HPV types 16 and 18, the two virus types that are responsible for an estimated 73 per cent of cervical cancer cases in Europe. In large phase three trials, both vaccines have been shown to prevent more than 90 per cent of precancerous lesions associated with HPV types 16 or 18 among women who are not already infected with HPV.

"The HPV vaccine offers a new, complementary tool to improve the control of cervical cancer. However, it does not eliminate the need for cervical cancer screening even for women vaccinated against HPV types 16 and 18, who will still be at risk from other high-risk HPV types"

Well organised cervical cancer screening programmes that achieve high coverage and include effective follow-up and treatment of women who show abnormal results have been proven to reduce cervical cancer incidence by over 80 per cent. The HPV vaccine offers a new, complementary tool to improve the control of cervical cancer. However, it does not eliminate the need for cervical cancer screening even for women vaccinated against HPV types 16 and 18, who will still be at risk from other high-risk HPV types.

The primary target group to consider for routine vaccination is girls at the age just before sexual activity (and therefore HPV infections). The exact age range of this group will vary from country to country, depending on the average age at which girls become sexually active, but will typically be in the range of 12-15 years old. Targeting slightly older girls and young women with catch-up vaccination at the start of a routine vaccination programme is likely to accelerate the impact of the vaccination programme and increase vaccination benefits in the short term.

School based immunisation is likely to be the lowest cost option for delivery of HPV vaccines to young adolescent girls. However local issues, such as whether there are school based health services, funding arrangements for vaccine purchase and administration and obtaining parental consent may affect the feasibility of this approach. Clinic or practice based immunisation is a universally available additional or alternative option for HPV vaccine delivery.

HPV vaccination should be evaluated not only for its efficacy, but also from an economic point of view. There is evidence from some countries that introduction of HPV vaccination programmes may be cost effective as a cancer prevention measure. However, healthcare costs vary across Europe, so this analysis needs to be done by individual member states.

As with any other vaccine, the consequences of the HPV vaccines, favourable and unfavourable, will need to be evaluated systematically. Post-licensure evaluation will need to determine uptake, compliance, long-term efficacy, effectiveness and safety of the vaccines, as well as the integration of vaccination with other strategies such as organised cervical cancer screening. Coordination between vaccine monitoring and cancer control programmes will be critical to assess the impact of the vaccine and its benefits compared with other existing prevention interventions such as screening.

While the ECDC report provides evidence on when and how HPV vaccination programmes could be effective, decisions on whether to introduce them lie with member states. A number of countries are considering introducing HPV vaccination programmes, and some have already done so. ★

Johan Giesecke is chief scientist at the European centre for disease prevention and control (ECDC)