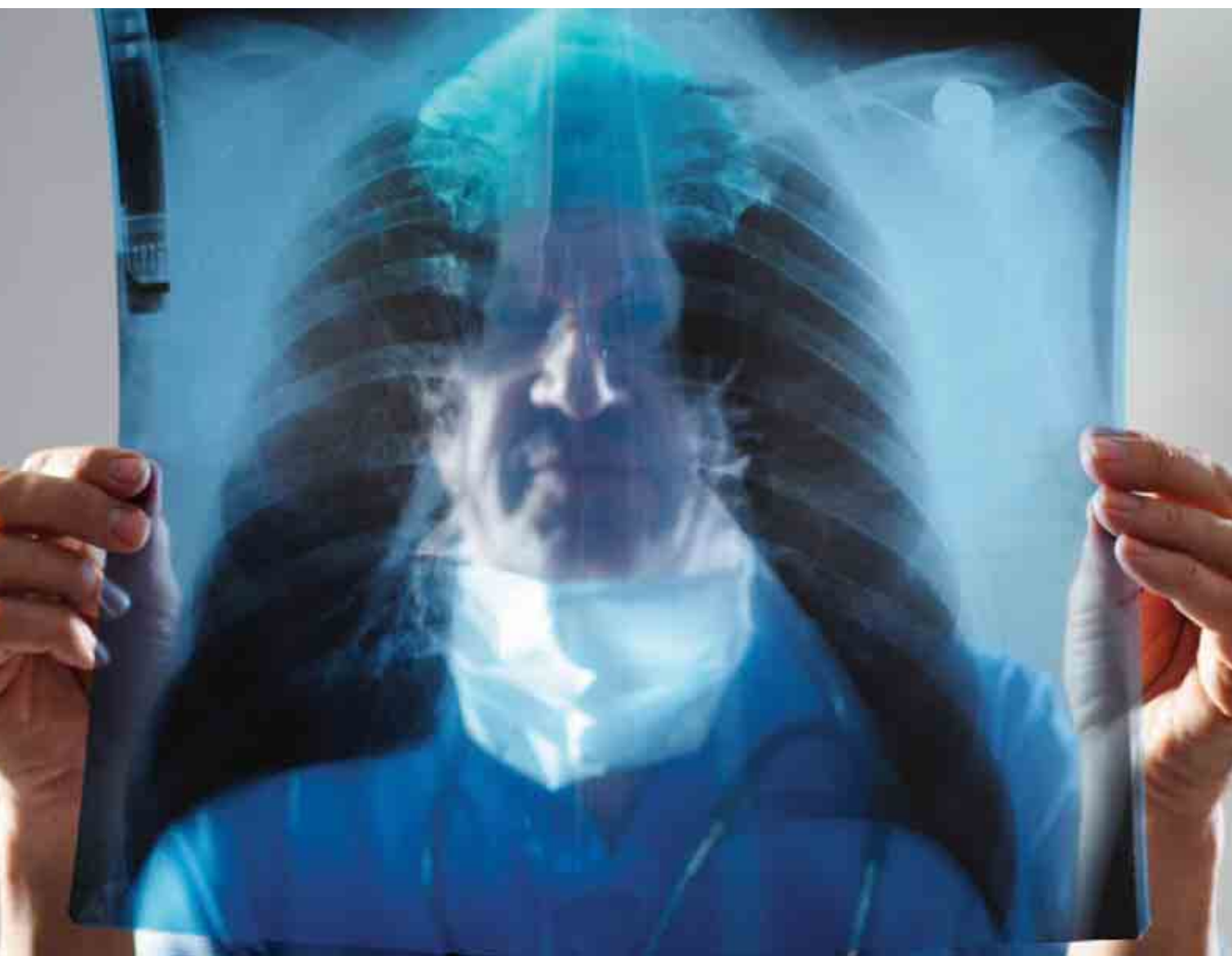


NEWSTATESMAN



WORLD-CLASS STRATEGY FOR CANCER



New ideas on therapies and care for living with cancer

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New Statesman
52 Grosvenor
Gardens,
London SW1W 0AU
Tel 020 7730 3444
Fax 020 7259 0181
E-mail info@
newstatesman.co.uk

Editor

Caroline Stagg

Round table

photography

Joel Chant

Sub-editor

Sue Laird

Front cover pictures

Mariusz Szachowski/
dreamstime

Participants in this recent Policy Forum discussion, a collaboration between the *New Statesman* and Pfizer, discussed the progress that may be expected on the newly released Cancer Reform Strategy and that of its predecessor, the 2000 Cancer Plan.

Between the publication of these two documents, many new drug therapies became available – expensive therapies that have led to disparities between primary care trusts about patients’ eligibility for them.

The discussion centred on the issues of what we need to do on prevention, early diagnosis, better treatment, living with and beyond cancer, and the whole new survivorship agenda.

Reducing inequalities, managing more patients as day cases, better commissioning for services such as radiotherapy and aligning drug licensing with NICE guidance – to widen the range, and speed up the rate, of new drugs reaching patients – were all debated. However, the topic that seemed closest to many participants’ hearts was that of the psychological, social and spiritual aspects of living with a diagnosis of cancer. This aspect of care involves not just the patient, but their carers and families and the NHS workforce that delivers their treatment too.

This and the other reports in the long-running series are available from the website: www.policyforum.co.uk. Your comments are welcome.

Round table participants



Liz Butler
Senior nutritional therapist, Penny Brohn Cancer Care



David Gillen
Senior research director, Worldwide Medical Pfizer



Emma Ream
Senior lecturer in nursing, Florence Nightingale School of Nursing and Midwifery, KCL



Prof David Cameron
Director, National Cancer Research Network



Dr Ian Gibson MP
Chair, All party parliamentary group on cancer



Prof Mike Richards
National cancer director, NHS



Simon Chapman
Ethics adviser, cancer policy group, National Council for Palliative Care



Ann Keen MP
Parliamentary under-secretary of state, Department of Health



Prof Karol Sikora
Medical director, Cancer Partners UK



Richard Davidson
Director of policy and public affairs, Cancer Research UK



Prof Jane Maher
Chief medical officer, Macmillan Cancer Support



Dr Jayant Vaidya
Senior lecturer and consultant surgeon, International Steering Committee TARGIT, Ninewells Hospital & Medical School



Dr Mark Emberton
Senior lecturer in oncological urology, Institute of Urology and Nephrology, UCL



Vivienne Parry (chair)
Scientist, writer and broadcaster



Prof Leslie Walker
Chair, cancer rehabilitation; clinical lead director, division of cancer, University of Hull Institute of Rehabilitation

Achieving a world-class cancer service in the UK

Vivienne Parry takes us through the recent history of cancer strategies in the NHS and the effects of a rapidly ageing population

The Cancer Plan did not take into account the projected doubling over the next 15 years of those aged over 65. Age is the single greatest risk factor for cancer

There are few more emotionally loaded words than cancer. Despite the fact that more people in Britain now survive a diagnosis of cancer than die from it, cancer is still a disease that inspires dread. In a recent poll, some 25 per cent of people said they feared cancer more than terrorism, Alzheimer's or a heart attack. With one in three people affected by cancer, everyone knows someone who has had it.

During the 1980s and 1990s, Britain had a shameful record, with one of the poorest cancer survival rates in Western Europe. Patients waited long periods for diagnosis and treatment, and there were widely varying standards of care across the country, with services fragmented and poorly resourced.

In 1999, Professor Mike Richards was appointed as the first cancer "tsar". He developed the first comprehensive cancer strategy the NHS Cancer Plan. At its launch in 2000, Alan Milburn promised it would mean UK cancer survival rates would be among the best in Europe "within ten years". Key elements of this ambitious strategy were improvements to cancer screening, the establishment of cancer networks, improvements in supportive and palliative care and reductions in waiting times.

Two-week referral

Rigorous targets were imposed, which ensured that 99 per cent of suspected cancers were seen by a specialist within two weeks of referral. Some in the medical profession claim such targets distort clinical priorities, incentivising the solution of one problem at the expense of another. The public saw them as lifesavers.

Fast forward five years. It was clear that the plan had succeeded in reducing waiting lists and improving access to services and there had been spectacular progress on some fronts; anti-smoking legislation for instance. But the landscape had changed more rapidly than anyone had predicted. Inequalities had become more glaringly apparent, the importance of prevention more pressing and patient experience more variable. Poor awareness



of symptoms still meant many presented too late for effective treatment. The need for radiotherapy services had been woefully underestimated.

Moreover the Cancer Plan did not take into account the projected doubling over the next 15 years of those aged over 65. Age is the single greatest risk factor for cancer and, by 2020, there will be 300,000 new cases of cancer each year instead of 230,000. Nor had the impact of obesity in pushing up cancer rates been appreciated. However, for the public, it was access to the new cancer drugs that had become the rallying cry.

New drugs

Since the 2000 plan was written, many costly, but very effective new cancer drugs had appeared. The fruits of 20 years of research into the molecular basis of cancer, they include, Glivec, Avastin and of course, Herceptin for breast cancer. Herceptin costs £20,000 for a year's treatment. These are not one-off treatments – they may need to be taken for years at a time.



Access to these drugs is controlled by the National Institute for Health and Clinical Excellence (NICE), which makes decisions about cost effectiveness. NICE has been much criticised for delay. Even when a favourable decision on a drug is made, not every patient appears to get access to it.

UK survival

In May this year, researchers from the Karolinska Institute in Sweden controversially linked poor cancer survival in the UK to its poor access to new drugs. France, which spends £900m on cancer drugs, has the highest five-year survival rate in Europe at 71 per cent for women and 53 per cent for men, compared to 53 per cent and 43 per cent respectively in the UK, which spends less than half this at £400m.

But drugs are not the only cancer treatment. They are just one part of a greater whole, which includes surgery and also radiotherapy, a service in which Britain has been noticeably lacking. Nor are European comparisons that helpful. The much-quoted 2007 Eurocare study of cancer

survival, which ranks Britain so poorly, is based on data from 1999. Access to cancer drugs has to be part of a wider debate about what the NHS can afford.

Demand for new strategy

The cancer charities were in full cry, demanding Cancer Plan 2. Cancer Research UK collected 250,000 signatures to a petition. In December 2006, Patricia Hewitt announced that there would be a new Cancer Reform Strategy but warned that there would be no new money. Cancer had been generously funded already. A year later, Alan Johnson announced the Cancer Reform Strategy (CRS), a five-year plan developed, once again, by Mike Richards. There are four new national initiatives, many new targets and, to the surprise of all, some £400m in additional funding.

There are two firsts; a section on living with cancer (unthinkable in 2000) recognises that many people now survive cancer but may be disadvantaged by it, financially, emotionally and medically; and a two-page patient pledge that sets

out what patients should expect of cancer services.

Recognising that half of all cancers could be prevented by changes to lifestyle, there is greater emphasis on prevention through further anti-smoking measures, action on obesity, alcohol and the use of sunbeds. There is emphasis on screening using new technologies to prevent breast, bowel, cervical and lung cancer and, to tackle the problem of late presentation, a national awareness and early diagnosis initiative. On drugs, all new cancer drugs (and 50 per cent of new drugs in the pipeline are anti-cancer treatments) are to be referred to NICE and there are promises to ensure that primary care trusts (PCTs) take up agreed drugs.

Darzi Review

The CRS travels with Lord Darzi, whose recent interim review of the NHS marks a shift from the command and control of old to localised services. Cancer services are to be centralised where necessary to improve outcomes but locally delivered where

possible. It is clear that savings are expected in moving cancer care out of hospitals. More rigorous analysis of variations in service quality will be made possible through a National Cancer Intelligence Network and the inequalities in care caused by deprivation, race and gender will be tackled through a National Cancer Inequality Initiative.

The strategy contains much of value, but its success will be judged on implementation. There is great reliance on PCTs to action it and, to many, this requires a greater rather than lesser degree of command and control if services are not to fragment once again.

There are some major NHS workforce issues to address to deliver the diagnostics required and many people are questioning the burden that may be placed on carers as more cancer care takes place in the community.

As the leading cause of premature death in those under 75, cancer demands comprehensive action. Optimism that Britain may indeed have a world-class cancer service by 2012 is at an all-time high.

Round table: a new perspective on cancer

Vivienne Parry Welcome everybody. I want to start by asking Mike, as National Cancer Director, to tell us where the UK stands at the moment.

Mike Richards In 1995, when the original Calman-Hine Report came out, we had poor survival rates, but we also recognised that we had a very fragmented service. Even within hospitals, surgeons, oncologists, radiologists, pathologists and others were not talking to each other. Equally, there was little communication between primary care, secondary care and tertiary care. We needed teamwork, multidisciplinary teams and networks of care. That started during the late 1990s but there was a recognition at the end of the 1990s that we needed to increase the pace. That is when we published the Cancer Plan – in the year 2000 – which gave a major commitment on new resources for cancer care and a change in the way we deliver it. There has been a discussion and debate recently about whether we have made progress since the Cancer Plan. We have – the National Audit Office came to the conclusion in 2005 that we had made substantial progress, although they also said, which I agree with, that more needed to be done.

Part of the dilemma is around survival rates. The Eurocare studies compared survival in different European countries. France, Italy, Spain and Germany do not have comprehensive cancer registration as we do, so you cannot be certain whether some countries' results are accurate. Having said that, I would trust the results from countries such as Sweden, Finland and Norway and their results are better than ours are. Let us acknowledge that these results were taken during the 1990s, up to and including 2000 and 2001. They do not tell us whether we have closed the gap during this century. I believe that we have, knowing what we have done in terms of cancer services, although nobody can prove what has actually happened yet.

During the past seven years, we have expanded the workforce considerably. The number of doctors has risen, taking all specialties that contribute to cancer together, by about 36 per cent. We have invested in new MRI and CT equipment. We still have a major gap before we get world-class services in radiotherapy. We have seen waiting times cut, major improvements in breast screening and multidisciplinary team working, but none of us are complacent.

We also know that there are new challenges and opportunities ahead. In particular, the number of cases of cancer is going on going up, largely because we are

all living longer, to the age where cancer is common. The figures for England are about 230,000 new cases of cancer each year. By 2020, that will be 300,000, based on predictions of what we know will happen to the population and trends in cancer incidence.

The pharmaceutical industry tells us that more than half of the drugs in the pipeline are targeted at cancer. We do not know how many of those will be successful, but some will and that will lead to better outcomes.

One of the things we learned from the Eurocare studies was that a major part of the reason that we had low survival rates was that patients in this country had more advanced stages of the disease by the time they got to treatment. So, we need to make sure that we put sufficient emphasis on early diagnosis. Equally, we know that over one-half of all cancers in this country are potentially avoidable, preventable if we can do more to reduce smoking. One-third of all cancer deaths are due to smoking. We can do more on obesity, physical activity and diet, and more in terms of avoiding over-exposure to sunlight. There are a number of different things we need to do.

At the beginning of this week, we published the Cancer Reform Strategy. It sets out what we need to do on prevention, early diagnosis, better treatment, living with and beyond cancer, the whole new survivorship agenda. What we need to do is reduce inequalities and also look at what we can do in relation to inpatient care. In the US, they manage far more patients in an ambulatory care setting, so they would not be sitting in hospital beds unnecessarily. They are managed as day cases, and that even includes patients who might have pain or might have a febrile neutropenia following chemotherapy. That frees up resources for areas that we all want to invest in.

The strategy sets out how we will do this within the NHS. It puts great emphasis on the importance of information collection. It puts emphasis on how we can commission services better and on funding, particularly that the government will fund world-class cancer services, but expects the NHS to deliver value for money. So, we have the strategy and now the fun begins, as we have to start implementing it.

Vivienne Parry Minister, what do you see as the challenges of the Cancer Reform Strategy and how would you monitor implementation?

Ann Keen I think the most important role I can play is in the development of the workforce. To implement

The number of cases of cancer is going on going up, largely because we are all living longer, to the age where cancer is common
Mike Richards

Patients say time and again that they struggle during and after treatment, that their psychological needs are not addressed
Emma Ream



this strategy, it is critical that we have the right people to deliver it. For example, patients say they want specialist nurses; they want access to all different forms of therapists who can assist in their journey. Also the social side is very important – the cost of cancer to a family, the way that cancer patients are viewed in the workforce, how employers react, your body image at work, how your work colleagues relate to you, and the whole family experience of that.

Vivienne Parry Emma, would you like to comment on that as a nurse specialist?

Emma Ream While it is great to have such a good commitment to increasing access to different treatments, wider treatments and much better treatments, my gut feeling is that we also need to work on the experience of care. Patients say time and again that they struggle during and after treatment, that their psychological needs are not addressed, that they are not systematically assessed well enough. Patients have a lot of outstanding needs.

The push to get people out of hospital more quickly is right, from both a cost-saving and a social point of view but carers and families need a lot more support in caring for the people who are unwell and facing difficulties. The role may be unfamiliar to them, and often has financial implications. They can feel very isolated. So I would like to see an effort put into that aspect.

Nurse specialists are key to a lot of this, the psychological care and the assessing of need. I think in talking about workforce issues, there is a gap there.

Jane Maher Experience of cancer is so important. About 1.2 million people are living with a diagnosis of cancer. Some of those will have active treatment, active disease, but many will not. Some of those will also be suffering the consequences of their treatment. When we focus on treatment, it is important to recognise that treatment has consequences that also affect people's lives. We may have the image of Kylie Minogue but it is much more likely to be a 76-year-old woman with diabetes who is looking after her

husband with dementia and has any number of other problems. When balancing the war against cancer with treatment, we have to think of it more as guerrilla warfare with a lot of other things going on in life.

Leslie Walker If you look at the psychological and psychiatric studies that have been done in the past 25 years, they do not make sanguine reading. Psychological and psychiatric morbidity in patients and relatives remains a major problem. If we take breast cancer as an example, in the late 1970s and early 1980s, Professor Peter McGuire showed that 25–33 per cent of women developed clinically significant anxiety, depression or sexual problems in the year following diagnosis, which at that time meant mastectomy. More recent studies here in London, by Professor Lesley Fallowfield's group and Professor Amanda Ramirez's group, suggest that the prevalence of these difficulties has actually increased. For example, Professor Ramirez found that 48 per cent of patients were anxious and depressed in the first year, which is an increase, and Professor Fallowfield's group found that 50 per cent were anxious and 38 per cent were depressed in the first three months. That is a major issue.

We have had a very significant increase in the workforce in psychological input, in clinical nurse specialists, in the NHS and in the voluntary sector yet, if anything, the problem is getting worse. We need to think about why that is. Burnout in the workforce is an issue. We recently completed a study of the 501 colorectal and vascular surgeons in the UK and found that 33 per cent of these individuals scored in the clinically significant range of anxiety and depression in the general health questionnaire. We found that 32 per cent are burned out and 76 per cent want to retire early. Our study of colorectal nurses found almost identical figures. If we are going to deliver high-quality cancer services, we not only have to look after patients and families, but must improve the working lives of our medical and nursing staff.

I have recently done eight weekend training sessions all over the UK for breast-care nurses. While they are enthusiastic about communication skills training, an issue that comes up time after time is that, when someone talks about personal matters, depression, ideas of self-harm or whatever, these nurses really do not know how to handle it. So communication skills are fine but we need to support the nurses with an infrastructure so that, when they have concerns that arise from their improved communication skills, they know what to do.

David Cameron How much of this is about cancer and how much is it an issue right across the NHS? The NHS is a very frustrating place to work, to try to implement change, which is either driven from clinicians, from research or from patients' feedback. The NHS is very resistant to changes that may improve the way you run clinics, do ward rounds, get information to patients.

On top of that you are dealing with a disease about which there is a very negative expectation that things will improve. Many of us who are breast cancer

doctors have seen things change, but there is still an expectation that nothing is really changing in lung cancer, or pancreatic cancer. If you go on treating those cancers year after year, you do not see much change. You are dealing with a disease that people do not want to talk about, which has a huge impact on patients and families. I am not surprised people get depressed.

Mike Richards Wearing my burnout hat, if you like, as opposed to national cancer director, I have been part of a research team looking at this. We deliberately looked at clinicians who are predominantly working in cancer and clinicians who work in other fields. We looked at gastroenterologists and at radiologists, at people who are giving clinical support services; cancer surgeons, clinical oncologists and medical oncologists. We measured it first in 1994 and then again in 2002 and, worryingly, burnout levels have gone up – particularly with those involved in cancer. I think clinical oncologists and cancer surgeons are those for whom the changes have been greatest. One of the key things is not only to look at what causes job stress but also to look at what causes job satisfaction.

The reason why most of the people around this table are not burned out, I would suggest, is because they have job satisfaction, and job satisfaction protects you against job stress. You need to make sure that you are keeping that job satisfaction. Part of the problem is that we have wanted people to work in more limited areas, to focus on this cancer or that cancer, so we have taken away variety, and variety is a source of job satisfaction.

To a certain extent, autonomy is a major factor. We expect people to work in an organised system, so we need to replace that aspect of satisfaction in other areas. Teaching and the intellectual satisfaction from research, are also major sources of satisfaction. Strangely, the biggest cause of satisfaction is dealing well with patients. We must not forget that. It is highly important.

On the stress side, dealing with patient suffering does not come as high up as you might think. It is more about overload, dealing with colleagues and all of that. We need to do more research on that. We need to take action to improve working lives.

We have a silo mentality in the NHS. We have radiographers, nurses, social carers, healthcare assistants and receptionists all working to different agendas
Karol Sikora



Ian Gibson People have high expectations now. We build it in their heads that we have Nobel Prizes, are doing more research, spending more money. That is good at one level, but it builds expectations in people that they are going to get the best treatment and the best care. That does not always happen and people like Ann and I get battered by the constituent who has had a bad time. The hundreds who have a good experience never come and see us, so we have to be careful.

Karol Sikora The NHS does not think of itself as customer focused. When I was clinical director, if our department over-performed – in other words, did more work, saw more patients – it got told off and financially penalised. No industry works like that. We have a silo mentality in the NHS. We have radiographers, nurses, social carers, healthcare assistants and receptionists all working to different agendas. The royal colleges each have an agenda, for their own members, the same as trade unions.

We need to get much more patient focus. Patients want the support we are talking about here. To them, that is more important than the latest wonder drug and it is very cheap to get.

The other problem in the NHS with this silo mentality is that it is impossible to change. Look at the delivery of radiotherapies. Some departments are highly efficient and are giving good-quality care, but others are hopeless. They have machines idle and they have half the number in volume through.

At Pizza Express you can see how businesses get things through so the customer is happy. A radiographer should not think, “I am a radiographer and I do this,” but “we have a patient, at certain times the department is busy, so a bit of multitasking outside of our comfort zone can only be helpful.”

Also, we have to get a distributed model. That is going to cost. We are short of radiotherapists.

Vivienne Parry Explain “distributed model” for us.

Karol Sikora For example, you have ten new bunkers at St. James’s but nothing at York. Some people live 60 or 80 miles away from where their treatment is. We can plan radiotherapy down the line. I think we need a little bit of independent-sector help to track people and redesign. In the same way that the hospices came out of a non-NHS body, you could look at ways to change the system from within by using an outside group.

Vivienne Parry Is there not a danger if you take all the volume, the easy stuff, off the system that specialist hospitals will not have enough cases to do the job?

Karol Sikora You do a joint venture partnership rather than work independently. The independent cancer sector currently deals with 20,000 cancer patients a year and it gets all the drugs it wants from Pfizer. So you have got a two-tier system.

This is all going to come to an end in the next four years. BUPA is going to have to raise its premiums for cancer dramatically.

One of the real barriers for the workforce is not being able to transfer information. The workforce does not know what happens before and after they see a patient
Jane Maher



Mike Richards On radiotherapy, we know we need more capacity. I think we do now have agreement that we want a “distributed model” – we need radiotherapy closer to home for a lot of patients. Why did we not do that before? It was largely because we did not have enough capacity in clinical oncologists and therapy radiographers. We are now building that number up. We are looking at having satellite units, or whatever you want to call them. It may well be that the independent sector has a role to play here. We have taken a completely neutral view of that by saying that the NHS should decide locally about that. Where the independent sector can be useful, let’s put it in, as long as we make sure that it is integrated within a cancer network – otherwise, we will have chaos.

The NHS can change its service models. If you look at what has happened over the past seven years, cancer is a very good example of where that has happened. In the past, it would have been impossible to think of anybody except a medically qualified radiologist reporting a mammogram but we now have advanced practitioner radiographers reporting mammograms.

In the UK, we have nurses doing flexible sigmoidoscopy, colonoscopy and endoscopy in the NHS. A lot of other countries say, “How have you achieved that?” So it is not true that you cannot change the service model within the NHS.

Ann Keen I think we do a disservice to the NHS staff who have worked so hard to achieve this change. It has not been easy in a very hierarchical structure to get them to agree that there is a skill mix that we can change but they have.

Mark Emberton One of the recurrent impediments to seamless care is that, if I have a problem or a big delay, for example, with MRI scanning, I have no financial control over that because that is a different directorate. Outpatients is a different directorate, a different hierarchy of management. It is very difficult for me to influence them because they have different priorities and agendas. We could contemplate models that would be built around the patient journey.

Jane Maher One of the real barriers for the workforce is not being able to transfer information. The workforce does not know what happens before and after they see a patient. At the moment you cannot transfer imaging data within the NHS. In New Zealand, every patient is given a memory stick with all their information on it that they can take wherever they want.

Vivienne Parry Let’s move on to one of the central planks of the Cancer Reform Strategy – prevention. We have done an enormous amount on smoking but the other areas that we would like to act on – obesity, for instance – involve cross-government involvement, not just the Department of Health (DoH). How will government deliver cancer prevention?

Ann Keen We are actively working with all the departments you would expect us to, such as education and culture, media and sport, and are also looking to outside organisations to help us in the plan. We already have the Football Foundation’s commitment; football can send a powerful message to all age groups, in encouraging activity and sport.

We need to look at how we advise on diet without being nanny-state about it, which is what we get blamed for. The incidence of children’s obesity is so worrying. At Alder Hey Hospital in Liverpool, they are looking to build a new wing and are taking advice on whether they should have wider doors because they will need wider beds for children. I was absolutely horrified. My colleague, Dawn, is working actively with the Department for Children, Schools and Families to see how we can assist with this.

Richard Davidson The forthcoming obesity strategy, is a great opportunity.

Ian Gibson But there is a cynicism in the public. You hear that bread is good for you one day and bad for you the next day. People think, “here we go again”.

Mike Richards Because smoking is so directly related to such a large number of cancers, we made the new commitments on consultation on where to go next. Smoking is part of the Cancer Reform Strategy. Obesity, physical activity and diet are important factors in cancer. We know far more about the link between obesity and cancer than we did in 2000, but we also recognise a greater importance in their involvement in diabetes, heart disease and so on. This is why the cross-government strategy that is going to come in shortly is going to be the main area of activity there.

Richard Davidson Mike is right that tobacco should not be seen as a tick box, “Right, we have got ‘smoke free’ in. Now we can move on to other things”. It is really important that we look at a wider, comprehensive strategy on tobacco, which could include vending machines, taxation and smuggling.

Jayant Vaidya I think it is vital to raise the legal age for buying tobacco to 21. This is what was done in

Goa, India. Twenty-one is the minimum age for buying tobacco, but most people start smoking before they are 21. If they have not smoked by the time they are 21, usually, they do not start. That would make a difference without having to raise tax.

Simon Chapman The long-term impact of obesity in the generation coming through means they will be able to do less and will place a greater demand on the sorts of services we are talking about.

Vivienne Parry Can we move on to the better treatment part of the Cancer Reform Strategy and the new therapies that are coming up, drugs in particular, where there is a major question about affordability.

Mike Richards The Cancer Reform Strategy very deliberately reminds people that, at the moment, surgery cures more people with cancer than any other treatment; this is followed by radiotherapy and then by drugs. High-quality surgery saves more lives than less-good-quality surgery, so making sure that we get good-quality surgery is important. We are doing that in two ways. First, we are making sure the complex surgery is in the hands of expert teams, centralising where necessary to get good outcomes. For example, in oesophageal cancer, we have seen 31-day mortality drop from 9.4 per cent to 4.9 per cent. A large part of that is because we have been centralising services. Equally, we need to make sure that surgeons are given the training they need because new techniques come along after they have reached consultant status.

If I was going to have my colorectal cancer dealt with surgically, I would want it to be done by somebody who was trained in laparoscopic surgery so that I could get back to an active life more quickly. So we need to make sure that people are trained in that. Actually, that is very cost effective and does not cost big bucks to do.

Second is radiotherapy and we have talked about that already. We do need investment there – radiotherapy is needed with over half of all cancer patients.

There are lots of exciting new drug treatments coming through. Some of the concerns have been about the

interval between licensing and NICE coming to a yes or no verdict. What we have said there is that, in future, all cancer drugs will go to NICE unless there is a really good reason to the contrary. This will mean that we can get a verdict from NICE almost in parallel with the licensing. That should eradicate a lot of the problems.

Long-term affordability, that is something society will have to discuss but, in the short-to-medium term, if we make the efficiency savings we know we can, that will give us the headroom for a lot of the new treatments we need, radiotherapy and chemotherapy. We reckon that there is £350m worth of inpatient care that could be eradicated, giving headroom for the new treatments that are going up by approximately £100m a year.

Karol Sikora It is great to get NICE to do the evaluation but they must be given the direction to look differently at drugs for cancer compared to drugs for other diseases. That is the ethical problem we all have when we try to have a reasonable system that works.

Mike Richards There is a legitimate debate about whether the cost per QALY [quality-adjusted life year] is the right measure. That debate can be had partly in the context of a much wider debate on pharmaceutical pricing that is going to be going on over the next year, which is why we did not attempt to cover it in the Cancer Reform Strategy. If people want to raise issues about value-based pricing, that is the context, not the Cancer Reform Strategy.

David Gillen From a research and development (R&D) standpoint, Pfizer welcomes the Cancer Reform Strategy. We also welcome the recognition that medicines have a part to play appropriately in the treatment of patients, along with surgery and radiotherapy. We want to work with NICE and the government to see how we can reform the way that NICE looks at oncology medicines and looks at medicines in general. There are obviously a lot of positives for bringing forward the evaluation of any medicine, but perhaps it is not an absolute panacea to bring it forward right to the time of licensing. I think that is an overly simplistic view.

Mike Richards I would like to come back to you on that and say that, if you did the right trials in the first place, that would not be a problem. If that pushes industry along with organisations like the National Cancer Research Network (NCRN) to do the right trials so that we have the right information at the time of licensing, then we will all be better off.

Vivienne Parry Simon Chapman, can I come to you on ethics because some people, particularly those with rarer cancers, are disadvantaged because they are never going to be appropriate for funding.

Simon Chapman The starting point is a quality judgement of what healthy people think it is like to have cancer. You cannot really anticipate the response of the individual until you are actually living with the

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We need to take end-of-life care aspects at least as seriously as the decisions we take about where to resource drug allocations

Simon Chapman



condition. Wearing my palliative care hat, there is also a wider point about how you allocate different resources. Do you focus it entirely on survivorship and on cure? Or are we also going to have a greater recognition in society – commended by the care strategy that is coming in the summer of 2008, I think, – in terms of end-of-life care. Sometimes people die of cancer – that is an inevitability in many cases. Yes, we can do a great deal about survivorship. Yes, we can do the screening, prediagnosis and all the rest of it and that is terribly important. But, if we are not giving psychological care and recognising that people have psychological, social and spiritual needs throughout their time on the cancer trajectory, then we are failing them in the end. We need to take end-of-life care aspects at least as seriously as the decisions we take about where to resource drug allocations within the survivorship aspect as well.

Mike Richards I absolutely agree. The reason I had not specifically gone into it before is because we are developing an end-of-life care strategy that will apply not just to cancer patients but to 100 per cent of people dying in this country, whether they are dying in hospital, at home, in care homes, in hospices or in prisons. That strategy is due to be published next summer because we want to do it in parallel with the Darzi Review [a wide-ranging review of the NHS] and I think that will make sure that end-of-life care is central to the next phase of development of healthcare in this country. Strategic health authorities (SHAs) are looking at where we have got to on end-of-life care, and are developing it locally. They will come back to us next week about that, so we are making progress.

We have been looking at different models; for example, Marie Curie has done some extremely good work in Lincolnshire where it has increased the number of people dying at home and done it at a lower cost per patient. A lot of that is because they have invested in better co-ordination of care and made sure that services in the community are there to support patients, thereby saving hospital costs, in particular.

Simon Chapman All of that is absolutely right but, with the two strategies coming separately, it is important that we do not get the workforces in different institutions thinking, “OK, we are part of the Cancer Reform Strategy and the end-of-life care strategy is for other people,” and vice versa. There needs to be cross-boundary working and integration.

Ian Gibson A lot of this care is provided locally by charities, where there is no real central control. They do good work but they are not kind of part of the movement, as it were. I would like to pull them in. At the moment, they decide what they want to do, a breast cancer unit, whatever; they are not part of the National Cancer Research Institute (NCRI) strategy nationally and they do not go through networks.

Mike Richards That may be because, in the past, the NHS, the primary care trusts (PCTs) and local authorities have not given priority to end-of-life care. I have been a clinical director for both cancer and palliative care at St Thomas’s Hospital. When I went to talk to the then equivalent of PCTs about cancer, I got to see somebody senior and got movement because it was a priority. When I went to talk to them about palliative care, I got somebody with no authority to move things on. That is what we have to change, if PCTs and local authorities need collective strategic commissioning, involving the voluntary sector and recognising its important role. This has happened in Lincolnshire. It was not just Marie Curie; it was St Barnabas Hospice and others. Part of what they did was to get the whole community together in the way we have on cancer. We need to repeat that in end-of-life care.

Vivienne Parry I did want to open it to you all whether, with the Darzi Review, we are moving towards localism rather than a national top-down approach, and whether that would mean you develop worse postcode lotteries.

Karol Sikora Already there is a 4:1 spend ratio between the best spending PCT and the worst spending PCT within your document, That can only get worse unless PCTs are given the money to cover the NICE guidance. Currently they are not, and they are struggling. Where will they get the money?

Ann Keen I wanted to come in on palliative care. Having worked for quite a number of years as a community and district nurse and been involved with what patients and families wanted, what the hospital consultant (who maybe felt ownership of the patient) wanted, and then what the GP was prepared to do, I do think the audit of primary care is so important. GPs are afraid to nurse a terminally ill patient at home; they feel inadequate. I have had first-hand experience of this, as the nurse with the GP who said, “Will you just get on with it, Ann, and if you want some prescriptions, whatever you want...” There can be great reluctance to be involved in end-of-life care because it is not easy.

Emma Ream From families' perspective as well, it is very scary to have your loved one at home and not have the structure to enable you to care for them properly, and if there is some kind of variability in that...

Vivienne Parry Is there a way, though, to add to that variability and is it through targets?

Ann Keen It could be but we need more openness – transparency in relation to skills and what we are able to do. What do we need more help on if we are to deliver this very specialist care that requires a multitude of skills? Who is the best person to do it?

Vivienne Parry Are you looking at a particular model of cancer care?

Mike Richards We are looking at lots of different models. Going back to the localism versus central push on cancer, we considered this very carefully in developing the strategy, with the NHS, the SHAs and PCTs, and also internally within the DoH. The first message is that the strategy comes as a very high priority – it is not chance that both the prime minister and the secretary of state for health launched it.

We have, where necessary, extended targets or standards, for example, the 31-day target for the interval between seeing a physician and getting treatment. This previously only applied to first treatments for cancer and now we are applying it to all treatments for cancer, and that will include all radiotherapy treatment. The strategy sets out very clearly to PCTs what they are expected to do; it also tells them how they can deliver on it, often by working through networks.

We do now know that there are variations in the spec. We did not know that when we published the Cancer Plan. We could have guessed it but we did not have the measurement. We now need to refine that. We now need to look at the reasons behind it. Then we can show people where they could be saving money to reinvest in other areas.

A combination of better information and better

We need more openness – transparency in relation to skills and what we are able to do
Ann Keen



commissioning will drive a lot of the changes we want to see but, where necessary, we have used targets in this strategy and have been up front about it.

Karol Sikora We have to get rid of difficult decision panels. The classic case is one where a lady bought herceptin, demonstrated a response, went to the panel, they still turned it down, so she went to the High Court and got a judicial review and they were forced to pay out. That is an inequity. You have to decide whether you are going to use this drug, yes or no. If it's no, then no one has it.

Mike Richards That is why we want to get decisions from NICE as close to the time of licensing, so that we do not have variations around the country.

Vivienne Parry One of the reasons our survivor rates fall behind other European countries is that people in Britain present later stages of disease, so diagnosing earlier is a fundamental part of the Cancer Reform Strategy. Part of diagnosing early is making people aware of symptoms and getting them to present earlier.

David Cameron If a woman has a lump in her breast, it is expected that she will go to the GP quickly. It is expected that the GP will refer her quickly, it is expected that a consultant will see her quickly, and she will probably get a diagnosis the day she goes into hospital. If the same patient develops a different symptom, a cough, a bit of breathlessness, a bit of fatigue, she will not go to the GP straight away, she will not be referred to a consultant straight away, and she will not get the diagnosis straight away. It is a different culture for some other conditions where the expectation is completely different, from the patient before they get to the GP, right through to the hospital system, and the scan and the diagnosis is not made the day the patient goes to the clinic.

Now, some of the models in some cancers are much more difficult to implement than others. A patient turning up to a clinic with a positive pancreatic cancer will not necessarily get a biopsy done the same day. Some of that thinking could transfer across to speed up all aspects of it. I am worried that there is a sort of negativity in certain areas, [a view that] it is not worth pushing faster because it will not make any difference.

Mike Richards Lung cancer is an example of that. Our five-year survival rates are about 7 per cent; other European countries are nearer to 17 per cent. It is partly because patients are stoical and do not seek help. We need to work at community level saying, it is right to go to the GP with your cough.

Ann Keen They also feel ashamed, do they not? They feel it is their own fault and they will somehow deal with this cough because they are going to be blamed.

Mike Richards We have to work at community level to change people's attitudes towards early help-seeking behaviour. We need to work with GPs. It is

The audit we are setting up in primary care will help us identify the patients most at risk in a particular minority ethnic group or certain age range
Mike Richards



difficult for GPs to spot which patients need to present for a chest X-ray, but we need to work with them on that. We have plans in the strategy to do that, as well as making more rapid transit at the hospital. We have some good pilots running in that area, and at GP level.

Ian Gibson There was going to be a general medical for everybody, I seem to remember. That could include cancer, could it not?

Ann Keen Yes, it could.

Mike Richards We are in discussions with the people who are developing that part of the programme across the whole of the department and are talking about how to make sure cancer gets adequately represented.

Ian Gibson We can do things like look after people of 50, and so on, have tests, and that could become part of the British way of life.

Ann Keen We do now...

Ian Gibson We could extend it.

Mike Richards It is not just GPs that have a role here. High-street pharmacists can do a lot when people come back for cough mixture the second time to say, "Do you think you should go and see your GP about that?"

Emma Ream Some of the groups who do not come forward are people who do not hear any of these messages – people from minority ethnic groups, the socially deprived and the elderly. These groups would not come forward for screening because they think a lot of health information and a lot of risks are not applicable to them. We need to do a lot more work to find out why they have a completely different cultural view to the health system that we provide.

Ian Gibson There are patient groups that are very active in this field and they know there are people who do not go to see the GP for all sorts of reasons.

Our PCT in Norfolk suddenly decided a week ago to put some of its instruction into Portuguese and Lithuanian in response to realising that there were changes in the community.

Jane Maher Two genetics programmes that were for black and minority ethnic groups demonstrated how this can be done. We have a strong group of primary care leads around the country, 120–130 GPs, who have had five years of working in this area. They are a good group to mobilise on this new work.

Vivienne Parry Many people complain that they keep going to their GP and presenting with a symptom and no notice is taken of them.

Jane Maher There are on average 800 symptoms, so 800 people will come with a symptom which could be cancer, of whom eight may turn out to be somebody who has something. All of those may come up with all sorts of different symptoms.

Mike Richards We have done some very good work over the past few years in trying to identify which clusters of symptoms in which age groups do help a GP to say that a patient has a serious chance of having cancer. We can build on that and we may well build so-called decision-support tools, in the same way that GPs assess somebody's risk of having cardiac disease by knowing the patient's age, their cholesterol levels, their blood pressure and their smoking status.

Also, the audit we are setting up in primary care will help us identify the patients most at risk in a particular minority ethnic group or certain age range. One-third of teenagers who have had cancer tell us that they went to their GP six or more times before they were referred. We may need to get to the point that, if you go to the GP a third time, that should be a trigger in itself. Some people have suggested the motto, three strikes and you are in.

Karol Sikora Technology is going to help with prevention because the problem with preventive medicine is that it is too general. I think there are technology solutions. What the government has to do is make sure that it is not just the middle-class worried well who get them. Liz has not said anything so I think we should see what nutrition could do for prevention.

Liz Butler The World Cancer Research Fund report came out just a couple of weeks ago. I think we do know what diet we should be eating to prevent cancer and it is a shame that the media picks up on some of the more controversial things, such as the bacon sandwich, and sometimes twists things a bit.

This was the biggest ever report into nutrition – in any disease, let alone cancer – and the advice is the same as we have been talking about for ten years. A plant-based diet with minimal animal products and limited fats is what people should be eating. I think education is the absolute key – educating children – but we should also be educating our health

professionals to be talking about diet to their patients more. Doctors get very little training in nutrition but they are the professionals that really have more time and energy to put into passing on those messages. A lot of nurses we work with want to pass on that information but they do not have the training.

Vivienne Parry Is there a worry that education is seen as the solution to these problems and yet what we really want to see is behaviour change? There seems to be relatively little research around the psychology of behaviour change in relation to diet.

Liz Butler This is the million-dollar question. My work is focused on survivors. Cancer survivors are very motivated to make changes for the sake of their health, whereas, for people that do not have any sort of symptoms or disease, it is much more difficult. You just have to get in as young as possible and you have to keep giving those messages all the way through school and beyond. There has to be more emphasis in training health professionals, not just on nutrition but on lifestyle in general. If people are getting these messages from health professionals they trust, they will listen.

Mike Richards Awareness of the lifestyle factors associated with cancer is very poor – other than smoking – in terms of the association between, say, obesity, diet, physical activity and cancer.

In terms of research, there has been a lot of research into the causes of cancer and very little research into behaviour change. This is something that the National Cancer Research Institute identified. As soon as we put research portfolios of all the major funders together, we identified that none of us was spending much money on research into prevention. We responded to that by setting up the National Prevention Research Initiative and it now goes beyond cancer, with Diabetes UK, the British Heart Foundation, the Foods Standards Agency, and others involved.

Now we are channelling research efforts into finding out how we can help those who want to develop healthy lifestyles.

Biological and pathological rationale for using radiotherapy only around a tumour is quite well rehearsed and one way of doing that is to do it in the operating theatre
Jayant Vaidya



Richard Davidson I was going to say two things. One was about Cancer Research UK's reduce-the-risk programme, which does a survey every year. One thing that came up very starkly was that people did not know the connection between obesity and cancer. The second thing was around what the government can do. Individuals can do things, but in terms of the 9pm watershed and advertising to children, that is key to cutting obesity rates. If we stop certain industries advertising to children, that will go a long way.

Emma Ream Industry has a part to play here because convenience foods, such as cheap pizzas, are far cheaper than fresh vegetables, unfortunately. So, if you are a bit strapped for cash, you are more likely to go and buy cheap pizzas than cook something fresh.

Ian Gibson Richard, did you think we would get to where we are today on cigarettes?

Richard Davidson There was a recent report that looks across the different tobacco laws in every country and the UK for the first time came out top.

Ian Gibson I am just worried about the 20 years it took, it has taken all that time to get it into the system and when it happens it hits you between the eyes.

Jayant Vaidya It is not a lot different from how new technology could save money and be better for the patients. One example is the new approach to breast cancer, which is to give radiotherapy to the area around the tumour. Normally, radiotherapy takes about six weeks and it is quite a burden for patients to come every day for six weeks to the hospital – some people even choose a mastectomy in order to avoid that.

The biological and pathological rationale for using radiotherapy only around a tumour is quite well rehearsed and it looks like one way of doing that is to do it in the operating theatre. So, the patient has the operation, the lung is removed; radiotherapy is given in the operating theatre, and that is the only treatment they get. If patients were suitable for breast cancer surgery and suitable for entropic radiotherapy, and if trials show it is as effective as we want, we could see a 20-22 per cent reduction in the amount of radiotherapy, in total, not just breast cancer, so that would be about £50m.

We are randomising patients in the target trial just now – 1,000 patients already randomised. Patients are happy to take part but are sad when they are randomised to have normal electric treatment and it feels bad to do that, but we have to in order to prove that they are equal.

Mark Emberton It is worth highlighting the role of technology both in precision diagnostics and in the use of new energy sources: radiotherapy, laser, sound waves and electroporation, because they render treatments into outpatient therapy. That means they can do it locally. You do not have to train for 20 years so that you can cut the organ out, a technician can be trained to do the therapy. It is happening in kidney

I am optimistic because of all the new technologies and because survivorship and living with diseases seems to be finally on the agenda
Liz Butler



cancer, prostate cancer and in many other solid organs. It does not have the same regulatory constraints as drug therapy. A lot of it comes through the back door and happens almost too quickly for it to be monitored or evaluated in the formal manner.

Jane Maher It is very important to think about the long-term consequences of this. It took us about 30 years to develop safe radiotherapy techniques. We have very severe late consequences of treatment as the Radiation Action Group Exposure, can testify. It may seem safe at the time but, eight years down the line, the treatment may be viewed quite differently.

Vivienne Parry As we get towards the close, Do you all feel optimistic about future cancer services in Britain.

Emma Ream Overall, yes. I still worry that the massive advances mean professionals are seeing a lot of people on a much shorter-term basis. What does that mean from the experience of care point of view? We need to address that rather than play catch-up later.

Leslie Walker I think we can be optimistic on the psychological and psychiatric side. There is increasingly good evidence that we can reduce the incidence of psychological and psychiatric morbidity down to at least a quarter.

Jayant Vaidya I am definitely optimistic that we can expect to see reducing mortality from breast cancer over the coming years because of incremental benefit from each of the new treatments we are starting. We need to facilitate researchers in getting new treatments and ideas. If every patient went on a trial, we would have new treatments faster and faster.

Karol Sikora I think it is positive; you have to reform the NHS. Choice and competition is the way forward. If you have a choice of provider, you can choose to have your diagnosis tomorrow or wait three months for your CT scan. Whether your patient can make that assessment is key.

David Cameron I am very optimistic. The UK now recruits a higher proportion of patients with cancer to trials than any other country in the world. Trials help you overcome some of the local variations because they require standardisation of treatment.

Richard Davidson Yes, I am very optimistic, too. The ten-year survival rate is now over 46 per cent – double that of 30 years ago. I will be more optimistic if we can get the survival rate of the harder to reach cancers up to the same levels as those of breast or even testicular cancer, and if we can reduce inequalities across awareness, diagnosis, and treatments.

Jane Maher I am optimistic that living with cancer is on the agenda. Not just the treatment, the experience. Aligning health and social care is a challenge.

Liz Butler I am optimistic because of all the new technologies and because survivorship and living with diseases seems to be finally on the agenda. If people are guided around lifestyle, they can enhance treatments and also reduce occurring morbidities.

Simon Chapman There are real grounds for optimism, but the challenge is to make sure good intentions are translated into action, particularly in palliative care. It has not actually happened yet. The way we can do that is by making PCTs report annually on progress against an annual strategy.

David Gillen I am relatively confident that the UK will maintain a vibrant clinical-trial environment and, with more appropriate funding and better uptake, the advances of the past ten years will continue.

Ian Gibson I am optimistic because of what has happened in the past 10 years but the public will not forgive us unless we pick up the challenges and move on.

Mark Emberton I am very optimistic about the future – largely because of the pace of technology and energy.

Mike Richards There are extremely good grounds for optimism. Death rates are falling and patients report that their care is better. We are world leaders in trial participation and that is leading to new technologies in diagnostics and treatment. I am also optimistic because of the partnership we have with stakeholders, the political will that there is, the commitment on funding, and that we have a new comprehensive strategy.

Ann Keen Being here has made me feel privileged to be a health minister. We know what has to be done, patients are saying what they are expecting of us. I still say that my responsibility is to make sure you have the workforce to support you through this. I look forward to working with you and am incredibly optimistic.

Vivienne Parry Thank you all for coming and thanks to Pfizer and the *New Statesman*.



New Statesman
3rd Floor
52 Grosvenor Gardens
London SW1W 0AU
United Kingdom

Tel: +44 (0)20 7730 3444

Fax: +44 (0)20 7259 0181

www.newstatesman.co.uk

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