HOUSE OF COMMONS

Science and Technology Committee

Oral evidence: National Health Screening, HC 244

Wednesday 11 June 2014

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Written evidence from witnesses:

- Advocates for Honesty and Transparency in Breast Screening
- Children Living with Inherited Metabolic Diseases (Climb)
- Muscular Dystrophy Campaign
- Dr Margaret McCartney
- Sense About Science
- UK Faculty of Public Health

Watch the meeting

Members present: Mr Andrew Miller (Chair); Mr David Heath; Stephen Metcalfe; David Morris; Stephen Mosley; Graham Stringer; David Tredinnick

Questions 53-152

Witnesses: **Robert Meadowcroft,** Chief Executive, Muscular Dystrophy Campaign, **Professor Michael Baum**, Professor Emeritus of Surgery, University College London, representing Advocates for Honesty and Transparency in Breast Screening, and **Steve Hannigan**, Executive Director, Children living with inherited metabolic diseases (Climb), gave evidence.

Q53 Chair: Good morning to the panel. Thank you very much for coming in this morning. It would be helpful, just for the record, if you would kindly introduce yourselves.

Steve Hannigan: I am Steve Hannigan, executive director of Climb.

Professor Baum: I am Michael Baum, professor emeritus of surgery and visiting professor of medical humanities at UCL.

Robert Meadowcroft: I am Robert Meadowcroft, chief executive of the Muscular Dystrophy Campaign.

Q54 Chair: In my experience when I have been treated by doctors, in hospitals in particular, the level of information one gets about the risks you are undergoing as a result of some intervention is communicated in a way that is unintelligible to most lay people. You sit down and sign consent forms with statistical data on them that mean nothing to most people, unless, I suppose, they happen to be expert gamblers. In the context of screening, do members of the public really understand that participating in screening programmes confers both benefits and risks?

Professor Baum: Your opening point gets to the very heart of the problem as far as I am concerned. I share your concern about how risk and benefits are described. The fundamental problem with screening for cancer—I would include all cancers—is that proponents of screening use relative risk reductions, which not only lay people but most of my professional colleagues do not understand. The fact that screening for breast cancer has a relative risk reduction of 15% in breast cancer mortality sounds very impressive. When you translate that into absolute terms, it means that you have to screen between 1,000 and 2,000 women for 10 years to avoid one breast cancer death. I think it is unethical to deny innocent lay women that knowledge when they come to make a decision as to whether or not to go for screening.

I would hope the very first thing you can grapple with is how on earth we are going to display risks and benefits in absolute terms which lay people can understand. There are many infographic methods of dealing with it. I hope that one of your recommendations would be to come up with clear infographic ways of explaining chances of benefit versus chances of harm, and then you would have done a good day's work. I am sorry. That sounds patronising.

Chair: Leave that to us.

Robert Meadowcroft: If I may echo part of that, I think there is a problem. We heard from families in Wales, who had been part of a newborn screening programme for Duchenne muscular dystrophy, that they were advised by health professionals, "Oh, don't worry; it always comes back negative." There is a sense in which the information they were being given was well intentioned and well meant but not helpful. The informed consent was very shallow; it was not really informed, so when the test came back positive and the diagnosis was given, the sense of devastation was perhaps greater than it otherwise would have been had it been talked through and explained. The risk is very low; one in 3,500 live births of boys will have Duchenne. Even so, virtually to dismiss the risk by saying, "Oh, it always comes back negative," is not engaging in a meaningful dialogue or discussion. I think that is regrettable.

Steve Hannigan: At our particular end, newborn screening, the benefits and harm are known to families but not really taken into consideration. They meet the midwife during the pregnancy at week 10 where the procedure for the heel prick test and what will be tested for is gone through and they are given a book full of leaflets. The leaflets normally end up in a handbag and are never read. At week 28 they are brought in again just to confirm that they have had the leaflets. They should go through the benefits and harm and what is going to happen on the heel prick test the day before, or the day the heel prick test is taken. A lot of people are completely unaware of what the test involves, or even if they

have a right to withdraw from that test. A lot of mothers we speak to feel it is a compulsory test. It is not.

Q55 Chair: Coming back to Professor Baum's observations, in terms of how the information is communicated you suggested an infographic approach. Is that something that can be applied universally?

Professor Baum: The infographic approach is improving again and again. I was a member of a panel advising a committee on how the new invitation for breast cancer screening should be put together. We urged infographics. Before me, there are no infographics; there are numbers, and even those are spun. I should preface my remark by saying that I am an architect of the screening programme; I was one who set it up in 1987-88. I would love it to be positive, but I had to resign from the national committee in 1997-98 on the issue of truth-telling. When the adverse effects of screening became known to the profession, and when we recognised that the estimates of benefit were half what we assumed they were at the beginning in 1988 after the Forrest report, I said that information had to be made known to the lay public. I was told at the committee that if we did so we would not reach our targets and women would not come. I said, "Well, so be it." They said, "No; we can't have that," so I resigned.

What I have witnessed first hand is an intention, no doubt a good one, by the people running these screening programmes to maintain a very high uptake, on the assumption that they know best. I am challenging this Committee to recognise that the individual lay person knows best, if given information for and against.

Q56 Chair: How are the numbers spun, to use your word?

Professor Baum: This is the latest version of the leaflet. We struggled for 10 years again and again to get the numbers right and include harms as well as benefits. The bottom line here is: "Saving lives from breast cancer. Screening saves about 1 life from breast cancer for every 200 women who are screened. This adds up to 1,300 lives saved." That is simply not true. It is not just a question of spinning; it is choosing estimates based on mathematical models that are simply not true. Truth-telling is also an ethical imperative, and that is something I feel pretty passionate about.

Q57 Graham Stringer: Following on from those questions, there is a debate going on about informed consent. The all-party group on muscular dystrophy said that they believe that "the process of informed consent is as strong and robust as possible." What does "strong and robust" mean in these circumstances?

Robert Meadowcroft: I think we are back to the relationship in which information is given to would-be parents early in pregnancy. Mothers would normally have their first antenatal visit at 12 or 13 weeks. There is no reason why one would not start a dialogue at that stage to make sure there is ongoing discussion about newborn screening and what it might mean for the parent. Looking at this in the round, in the rare case when it comes back as a positive, if the same professional is able to conduct that stage of the discussion about what it means and having that test confirmed, it is a pretty robust process. I take Professor

Baum's point. The information has to be accurate and delivered in a way that is part of a dialogue so that the parent can choose to take part or not take part in the test. That conversation needs to be open.

Q58 Graham Stringer: Where does the final responsibility lie for ensuring that people are able to make an informed choice?

Robert Meadowcroft: You use the word "choice," which we would certainly support. That choice lies with the parent; they should have the choice to opt in or out. It is a more difficult choice today because there are no effective treatments for children diagnosed at birth—as newborns—but the position is changing, because with the progress being made in research, we can see a situation, we hope in a matter of years, where there will be effective treatments. Then the imperative will be to identify boys who will benefit at the earliest possible age.

In the APPG inquiry we heard from Professor Muntoni. He pointed out that by the age of five a boy will have lost between 30% and 35% of muscle mass, and at the moment that cannot be restored. Therefore, the sooner you can start an effective treatment the better; it is about anticipation and prevention as well.

David Morris: Excuse my voice. Professor Baum, your organisation identified the need for change to the way expert advice on breast cancer screening is to be governed and delivered—

Professor Baum: I am sorry. Your voice is hoarse; my hearing is hard.

Q59 David Morris: I will start again. Your organisation identified the need for changes to the way expert advice on breast cancer screening is governed and delivered. Could you clarify what changes you are looking to see?

Professor Baum: It would be a good start if we could agree on the numbers. You can filter it down to two sets of numbers. What is the chance of an individual woman benefiting in absolute terms? How many women have to be screened for how long to avoid one breast cancer death? We need agreement on that number. The lay public needs to know the fact that there is disagreement on that number, so they should be given the range. I think the range is 1,000 to 2,000. That is number one.

The other is the estimate of harm. How many women are over-diagnosed and over-treated? There is a lot of disagreement, but the estimate is that for every one breast cancer death avoided either three or, as the upper limit, nine women are over-diagnosed and over-treated. Over-treatment carries risk—a rare risk—of death from toxicity. We need to agree on uncertainty. There is no problem in agreeing on uncertainty and expressing it to the lay public; they understand uncertainty. The group I represent are mostly lay people who are not trained in statistics or medicine, but they are wise enough to see the deception that is going on. They want it transparent: "Okay, you're uncertain. Give us the estimates, and then we can make a choice." That is the most important thing.

To go back to the infographics on the leaflet, I want to give you a successful example of how that can be achieved. I am now retired, but I used to be a surgeon dealing with breast cancer. I was also an expert on medical treatment called adjuvant systemic therapy. That

innovation in endocrine therapy and chemotherapy has reduced mortality by 30% to 50% over the last 20 years. It is a fantastic success, but we do not say that every woman must have it. We give them, with a technique on a computer screen, a printout showing their chance of dying over the next 10 years without this treatment and the chance of dying with the treatment, and what are the toxic side-effects. You choose. The vast majority of women faced with that—I have first-hand experience and can document this any way you like—say, "Thank you, doctor. This is the first time anyone has involved me in a choice. I think that on the balance of benefits and harm, I will go for the treatment." That is the way we should do it.

Q60 Chair: For clarity, while David gets his voice back, you used some strong words: "deception" and "deceiving." Who is doing the deceiving? Define the deception more clearly.

Professor Baum: Forgive me for using strong words. Maybe this is not the forum to use strong words.

Q61 Chair: Feel free. We want to be clear.

Professor Baum: I feel very passionate about this. I have been fighting a lonely battle on behalf of womankind for nearly 15 years, but it is not so lonely now; the women are getting wise. Is it a benign deception? I suppose it is a benign deception; there is no cabal out there to trick women into coming. There is a group of public health doctors and Department of Health officials who sincerely believe that the benefit outweighs the harm. The danger is that they select advisers who constantly reinforce that message. I am never invited to advise the Department of Health about the wisdom of screening. Even though I chaired the national prostate screening committee and I know a lot about screening, no one in the Department of Health ever listens to me. The Department of Health are electing their advisers to reinforce an existing prejudice.

David Morris: Chair, my voice has gone. I do not think I can manage it.

Q62 Chair: You have been fairly clear about where you see the responsibility, but who would you have involved in developing public information about screening programmes?

Professor Baum: Who have we involved?

Chair: In your ideal world, who would you have involved in developing public information?

Professor Baum: To begin with, I would choose the Cochrane Collaboration. The Cochrane Collaboration is a totally independent, no conflict of interest organisation that grinds the numbers and comes up with the details. They have no conflict of interest. It does not do them any harm or good; that is their job. By and large, most people respect the output of the Cochrane Collaboration so for getting the numbers right—in the passive tense—my group have already consulted with them to come up with what we think is the ideal leaflet. There is what we think an ideal leaflet out there.

Many of us go further than that, not advocating dismantling the screening programme but improving it. We are stuck in a time warp. What we are doing now is what was set up in

1988. Stuff has moved on since then. We know how to improve it, almost certainly with better outcomes, not by screening everybody—one size fits all—but by undertaking a risk assessment. You can do very accurate risk assessments for women these days and exclude the very low-risk from screening—they are five or 10 times more likely to die of cardiovascular disease; breast cancer is the least of their worries. You exclude the very high-risk from screening, because what they need is genetic counselling. After that triage, there is likely to be a group who, on balance, would have more benefit than harm. I advocated that at Portcullis House in 2010. I even have the paper in your journal "Science in Parliament" where I advocated it in 2009. It was well received, but nothing happened. I am still advocating it.

Q63 Chair: Turning to the two other witnesses, could similar approaches be adopted for other conditions?

Robert Meadowcroft: I understand the point about the Cochrane Collaboration, but from our point of view we would look at the professional bodies involved. The British Myology Society looks at muscle weakness and muscle wasting. Although these are rare conditions, there are lead professionals who I am sure would be delighted to advise on information for parents. There is international collaboration and TREAT-NMD—Treat neuromuscular diseases; and a patient group like ourselves would have credibility in adding to information and making sure the language was accessible to young parents. I see that coalition of groups coming together to make information accurate and accessible.

Steve Hannigan: We would support that. We would see the British Inherited Metabolic Disease Group, a professional body, clinical reference groups, patient advocates, the MCADD and PKU programme board and the national bloodspot screening unit all taking part in producing leaflets and information for parents.

Q64 Mr Heath: I am slightly worried listening to what Professor Baum said. It is a bit of a cop-out to have an independent body outside the Government validating statistics. We have the Office for National Statistics which is independent of Government. I just wonder whether there is any scope, at least on a statistical basis, to give an imprimatur as to whether these are legitimate and accurately described results.

Professor Baum: Thank you, Mr Heath. That is the first original idea I have heard in many years. Why not have an independent statistical review of the data? I think that is a terrific idea. Thank you so much.

Chair: It is a bit ironic because the new chief statistician is currently the Librarian here and the president of the Royal Statistical Society, so he might get that message a little earlier than some others.

Q65 Stephen Metcalfe: Professor Baum, you talked about the ideal leaflet. Was that specific to breast cancer screening?

Professor Baum: I have a lot of expertise with breast cancer screening so it is predominantly that, but the principles apply to whatever you screen for. I am very

knowledgeable about prostate cancer screening. We do not advocate PSA screening yet, until the results of our national trial of 400,000 men appear, probably late next year. Then we will know what the benefits and harms are with absolute accuracy and the leaflets can be designed, although at that time we may judge that it is really not worth going ahead, but the principles are the same.

Q66 Stephen Metcalfe: I am trying to establish whether or not there is an ideal leaflet across the board.

Professor Baum: Absolutely.

Q67 Stephen Metcalfe: Briefly, can you take us through the steps to arrive at the ideal leaflet? Where did you start, and how did you get to that?

Professor Baum: To produce the modern leaflet we went through a process where a committee was set up of experts in communication skills and leaflet writing. There were good people on that committee. I was one of a number who were advising the committee. I was very encouraged by one of the first drafts I saw. Somewhere along the line other people worked on it, and the final version was not the one that I thought was going out. We know what the process of designing and developing the leaflet should be, because the structures are there. I would like it to go up the line through completely independent bodies, not any body that has a political conflict of interest. Forgive me for saying that, but it would take a very brave Government, of whatever colour, to say we should stop screening. This is a very complex issue. The public outcry would be terrible. But there are steps where we could improve the national screening programme. The whole process has to be transparent and totally independent.

Q68 Stephen Metcalfe: Who is responsible at the moment for oversight of the information material given out about the benefits and risks of screening?

Professor Baum: It is very difficult to define the line of communication. It was very clear to me when Professor Sir Michael Richards was the director of cancer services and this brief was his. It went up the line and I knew who was ultimately responsible, but that responsibility has now shifted to the new director of public health. I visited him a year ago, and his in-tray was overloaded. It is quite difficult to define.

Q69 Stephen Metcalfe: What I think you are saying is that who has oversight is a bit hit and miss. I do not mean just cancer but all screening programmes.

Professor Baum: There is no transparency at the moment. I do not mean that, therefore, there are dirty dealings; it is not conspiracy, but I think it is a bit of confusion.

Steve Hannigan: I agree with Professor Baum on a lot of the points, but pushing a leaflet through professional body after professional body does not usually meet the needs of the patients. The expert is the family who have that disease, and I would much rather see the leaflet in its final stages going to the families affected by that disease for them to discuss

and give comments on it so they can have an input as to their family life and how it actually works.

Q70 Stephen Metcalfe: How can we improve the overall quality of the information that is provided? There are some good ideas, but presumably we want consistency so we can have confidence in the information being presented to us, and, regardless of the condition we are screening for, we know that it has been through a process of sorts. How do we get to that point? Where do we start? We start from here, but how do we get there? What are the steps that we need to take?

Steve Hannigan: Obviously one is to produce the leaflet and have as many people involved in producing it as you can, but the second one is training. Four new metabolic diseases will be added to the newborn screening list from January next year. Between now and then every midwife has to be trained on the benefits and harm in screening for those four diseases so they can advise families. It is a big task.

Q71 Stephen Metcalfe: But who should be designing that leaflet?

Steve Hannigan: Probably the national newborn bloodspot screening unit, with the involvement of other groups.

Q72 Stephen Metcalfe: Do they need guidelines to make sure they design it in line with other leaflets for other conditions?

Steve Hannigan: Yes. They are all contained in a large booklet. Whenever you turn up for a newborn screening you get a booklet of leaflets and hidden in there somewhere are all the ones on metabolic diseases, but there are other leaflets in there. Whether or not you read all of them is hit and miss.

Robert Meadowcroft: I agree with that. There needs to be consistency across the screening process. The patient voice is critical, although the information has to be accurate and verified by professional bodies and leading consultants.

Q73 Stephen Metcalfe: After someone has been screened and they get a positive result, what is the quality of the information they are given about the consequences of that diagnosis and the possible treatments?

Professor Baum: Speaking as a surgeon, at that point the patient with breast or prostrate cancer comes to the surgeon, and then it is a completely different code of conduct; it is a one to one. It is not a public health issue any more, which is the invitation to screening; it is an individual, personal relationship where the surgeon is duty bound and ethically bound to explain the pros and cons of treatment. I mentioned chemotherapy. I do not think that issue is a problem. I am not saying it is done well. Our medical schools have to teach communication skills and they do so. Our professional bodies demand certain standards. The GMC demands certain standards. I do not think that is the problem. The problem is, first, to agree what the numbers are; secondly, to agree the level of uncertainty around those numbers; and then to take that to a committee who are expert at designing leaflets,

like the group at King's College London, and involve consumer groups—I represent a very active one, and there are others like it—as witnesses to that. Then you draft it, test it out on the consumer groups, redraft it, and go up to an independent panel who will present it to the Department of Health.

Robert Meadowcroft: When I consider the points you have raised, quite a number of issues come into play from the point of view of Duchenne muscular dystrophy. Mr Stringer referred to the APPG inquiry. There we heard evidence from two parents in particular from Wales. Their experience was very different on being given a diagnosis within weeks of their little boys being born. One man, John from Cardiff, said that it was devastating. When you are given the diagnosis of Duchenne it is always devastating, but it was devastating because the person giving the diagnosis knew little or nothing about Duchenne and could not answer their questions and they felt abandoned. They had one appointment and had to wait six months for the second. The lack of support and information for him was devastating, and it had a huge impact on the family.

Then we heard from a lady called Jeanette, again from Cardiff—the same place—who had had a very different experience. She had been given the diagnosis sensitively and had been supported. She highlighted that there were seven medical appointments and information-giving sessions in six weeks. She felt well supported and prepared. When asked whether, if she could go back, she would still have newborn screening and so on, she said, "Yes. For us, it was the right thing; it helped us look at family planning and genetic counselling and plan the house and future adaptations," whereas John said, "No. It was the worst thing we did. We were told, 'It always comes back negative; you'll be fine.'" He felt abandoned.

Q74 Stephen Metcalfe: How do you eradicate that huge discrepancy between the two experiences? How do you get consistency into the way these things are dealt with?

Robert Meadowcroft: Without being simplistic, it is about training and having the right people giving the diagnosis—that they themselves understand the condition they are talking about and are trained to do that. The skills required are rare. The family then needs support straight away to go beyond that, and that is about neuromuscular care co-ordinators and care advisers. We are now seeing real progress in that across the country, which is marvellous news for families, and we have to drive that.

Steve Hannigan: With metabolic diseases and the bloodspot and the heel prick test, the disorder is only suspected. They have to see a clinician as soon as possible and have further tests before they are given a confirmed diagnosis.

Q75 Stephen Metcalfe: There is a period when there is a positive response but it has yet to be confirmed.

Steve Hannigan: It is suspected.

Q76 Stephen Metcalfe: What information are they given at that point?

Steve Hannigan: They are given as much information about the disease—on that suspected disorder—as is possible before they see a specialist, and then they have to see a specialist very quickly and go through further tests for their baby.

Q77 Stephen Mosley: That last chain of inquiry leads me to what I was going to ask. There are a number of issues around training and so on. Mr Meadowcroft, you started talking about training. Is there anything specific that you think is not being done at the moment, and how can you change that?

Robert Meadowcroft: I mentioned a moment ago that we are now seeing progress in health professionals having an understanding about muscular dystrophy and neuromuscular conditions. That is good news, but the services are still patchy. We are looking to strengthen, if you like, the network of professionals who understand these conditions and the impact they have on families. There is a role for professional bodies and for the NHS to look at the further developmental needs of regional community-based teams dealing with patients with these conditions. That is not to say it is a disaster. We are making progress, but there is more to do.

Q78 Stephen Mosley: Are the people doing the screening specialists in muscular dystrophy, in your case, or are they generalists who do not have that in-depth experience?

Robert Meadowcroft: In terms of antenatal classes, they are generalists. The experience in Wales where there was a newborn screening programme, which has now been halted, is that the first point of contact was with people who were generalists, as reported by John, to whom I referred. At the moment there is no newborn screening taking place for Duchenne muscular dystrophy. We think that there should now be steps to put it in place as treatments are starting to come through from clinical trials. When I say "starting to come through", I should make it absolutely clear that they are not coming through yet; they are on the horizon. Potential treatments are now looking more likely. You can imagine the situation. When you are given a diagnosis that is life-changing, of a life-limiting and life-shortening condition, your first question as a parent is, "What treatments are there?" There was almost no real treatment. That is changing, hence we are looking to anticipate that, but we will need a trained cadre of staff to deliver the information.

Professor Baum: There is a form of screening in my subject that I endorse; I am not anti-screening. It is screening for the BRCA1 and BRCA2 mutations. These are rare mutations, apart from the Ashkenazi Jewish community where one in 40 women carries them. The bad thing about this mutation is that 80% of those women will get breast cancer and may get ovarian cancer. They get it young and it is pretty deadly. There is a good argument for screening for that gene, but the issue is how do you deal with the service? It is complex and expert, but because it is rare, in this country we have managed to concentrate it in the hands of specialists. In London, if I encountered a family—say they were Ashkenazi Jewish—and every other female member of the family had developed breast cancer under the age of 40, I would send them either to Guy's or the Royal Marsden Hospital where they would get counselling before testing, knowing they were in safe hands. It is an underfunded but wonderful service.

Steve Hannigan: I would not totally agree with Mr Meadowcroft. One of the primary concerns about screening is that there is treatment at the end. There is no point in screening somebody for a disorder and then saying, "Sorry; we can't treat you." That causes an awful lot of harm to a family.

Robert Meadowcroft: This is a really interesting point, and one we can debate. In our inquiry, we heard from a mother from Worcestershire whose son was misdiagnosed. It was a very delayed diagnosis. He was not diagnosed until he was eight. She went to two paediatricians and a GP who missed the diagnosis of Duchenne. By the time he was eight he could have been on steroid therapy for three or four years. He missed part of that window and therefore he lost ambulation more quickly, and became a wheelchair user more quickly. She feels passionately that she would have preferred to know much sooner, even though there was no treatment to address the symptoms.

When we conducted a survey of families with Duchenne muscular dystrophy, 255 people took part. That was quite a large proportion of the Duchenne population. Of those, 82% said they would prefer to have screening and know, even when there was no treatment, and 96% said they would certainly choose screening when there was a treatment. Even so, 82% made that parental choice.

Q79 Stephen Mosley: Moving to something slightly different, the Academy of Medical Science was concerned whether information adequately met the needs of the less advantaged. The RNIB has pointed out that often information is not provided for blind and partially sighted people in a format they can access; and Public Health Wales highlighted concerns about groups of people with low levels of health literacy. How do we ensure that information on screening is delivered in such a way that it does not exacerbate health inequalities?

Robert Meadowcroft: It certainly has to be road-tested with different groups of parents and families. We will need it in different languages and formats as you suggest. We need to put a lot of care and thought into that to make sure it is entirely accessible.

Professor Baum: That is a very important and good question. There is expertise around; the important thing is to seek it out. There is expertise at King's College London and at the department of primary health care at Oxford University. I am sure there are other places where they do it equally well, but it certainly has to be done in a way that minority groups and underprivileged groups can cope with, and it has to be road-tested.

Steve Hannigan: We also need to consider audio tapes, especially for people who are blind or partially sighted, but also for minority ethnic groups who cannot read in either English or their native language. An audio tape would be a better medium for them.

Q80 Stephen Metcalfe: I want to look at how we decide what to screen for, and whether or not the criteria we are using are still relevant. As I understand it, the UK National Screening Committee uses an internationally recognised set of criteria to decide which areas to look at. Are those still fit for purpose? Is it the right set of criteria to use, or should we be looking at alternatives and designing our own system that perhaps has a slightly broader approach?

Professor Baum: I am familiar with the criteria; they have stood the test of time. That does not mean they are written in tablets of stone, and perhaps we should take a fresh look at them. They are the best we have got, but my concern is that these criteria are not met by most of our screening programmes. There has to be treatment. Two of the criteria are that it has to be a common cause of death and there has to be an adequate treatment. One thing that is missing is over-diagnosis. It would be good if we could write into these criteria the issue of over-diagnosis. There are ten commandments, and we add an 11th: "Thou shalt not be found out." The 11th commandment should be that there is some evidence that the benefit outweighs the harm of over-diagnosis.

Q81 Stephen Metcalfe: On that basis, is there anything we are screening for at the moment that if you applied your new criteria, or applied different criteria, we would stop screening for?

Professor Baum: I think we should stop screening an unselected female population for breast cancer—that is my bottom line—which is what we are doing. We should try to limit the harm and increase the benefits by being more selective.

Steve Hannigan: I can see more being added, especially on the newborn screening side.

Q82 Stephen Metcalfe: They would not be added under the current process.

Steve Hannigan: They would. Which ones do we go for? Which ones do we look at? How do we screen for them? What is the technology involved? What is the cost involved? Is there a treatment? That is the main thing at the end of the day.

Robert Meadowcroft: I may already have covered this, but I think the world in which people with Duchenne muscular dystrophy live is changing, with potential treatments on the horizon. Therefore, the balance of risk is changing, and the factors that might influence parental choice and would-be parents' choice are changing. On the need for support beyond the diagnosis being given, that is improving. It is being put in place too, so we are ticking those boxes, but we still need an absolutely reliable test that is internationally recognised. The test used in Wales produced quite a high proportion of false negatives, which was most unhelpful. I think there were 17 states or countries which had been screening for Duchenne since 1977. Only Ohio state currently screens, and they are trialling a new test. We would wish to see screening in place when the proposed criteria are met: a reliable test, support and a potential treatment.

Q83 Stephen Metcalfe: I gather from the point you are making that the criteria themselves are not the issue; it is that we now need to fulfil those criteria.

Robert Meadowcroft: Yes.

Q84 Stephen Metcalfe: You are happy with the way the criteria are applied at the moment, and the process that is used.

Robert Meadowcroft: In terms of my brief for muscular dystrophy, yes.

Q85 Stephen Metcalfe: Is there a broad enough range of stakeholders involved in that process? Is it a transparent enough process, which you all have confidence in?

Steve Hannigan: We come back to screening for metabolic diseases. A lot of European countries screen for an awful lot more disorders than we do; it is typically 15 to 25. We screen for two metabolic disorders, and we are about to add another four. They have the same information as us in access to technology and treatments, but some are different from us in that they have specialist committees to advise on newborn screening for metabolic diseases. Germany and Australia do that; New Zealand is just going down the same road; the USA and three or four other states in Europe do it. We could do it if we better employed people within the clinical reference group for metabolic diseases by putting forward a sub-committee to advise the National Screening Committee on metabolic diseases that should be screened for and being more pre-emptive than reactive.

Q86 Stephen Metcalfe: You said that one of the criteria was that it should be a common cause of death and a treatment should be available. Is there ever a case for screening where there is not a treatment available?

Robert Meadowcroft: When we conducted the survey we found that 82% would opt to go through screening for Duchenne muscular dystrophy, even though there is no effective treatment available. That is about planning. There are some families who have had two boys with Duchenne because the first boy was diagnosed only at four or five, and they have had a second son. In those situations it is about planning your home and the arrangements you need to cope with it, because somebody is going to become a wheelchair user, so there is that sense.

Steve Hannigan: If in screening somebody is identified as having a very mild case and the likelihood of developing the disorder is slim or non-existent, are you causing more harm than good by telling them?

Q87 Chair: The answer to that is that it depends on both the condition and the particular family.

Robert Meadowcroft: Indeed. To add one thought, it is the reliability of the test that is of major concern to us.

Q88 Mr Heath: Stephen was talking about the criteria that the National Screening Committee uses. I would like to touch a little on process. The observation is that the UK committee gives the go-ahead for a particular screening test and nothing happens for a long time. In a number of cases there is a long period between the agreement being reached and implementation. Therefore, when it is implemented in what is supposed to be a national health service, nevertheless different constituent nations and regions go at their own rate, so we have either incomplete or sporadic implementation. Are there good reasons for that, or is it an anomaly of bureaucracy and devolution, or what?

Steve Hannigan: It is not really an anomaly. We gave them their own health boards in Scotland, Northern Ireland and Wales. The UK NSC started looking at a project to screen for MCADD in 2000; it finally became screened for in England in 2009. Scotland implemented it in 2009, Northern Ireland in 2010 or 2011 and Wales in 2012. The UK NSC makes a recommendation to the other national health services for them to implement screening, but it is their decision when and if they can afford to implement it; whereas if there is a rejection by the UK NSC—with newborn screening for, say, biotinidase, which has recently gone through a review—it is automatically rejected by the other countries. There is certainly an anomaly there. In my view, it should all be implemented at the same time.

Professor Baum: On my subject, it was implemented far too quickly. After the Forrest report in 1987 I was one given the task of implementing it within 12 months, as well as having a daytime job. We did it. Within a year, the south-east of England started screening, and it had been rolled out across the country by 1990. I thought it was all a bit hasty at the time, and what is happening with prostate screening is the wise approach. Let's wait until all the data are in and are mature before even starting to roll it out, but when you roll it out you must be tooled up so that, if it is beneficial, everybody has access to it at the same time; otherwise, it is unfair and unjust.

Robert Meadowcroft: I would echo that. The phrase "tooled up" is interesting, isn't it, in terms of information being available and accurate and up to date with the right support. In our experience the newborn screening service in Wales was not part of a national screening programme. It was very much a pilot programme that started with a very committed consultant, but with hindsight perhaps there is not the infrastructure, support and training behind it to allow it to be delivered more effectively.

Q89 Mr Heath: I was going to come to that. You mentioned several times the Duchenne muscular dystrophy programme in Wales. Am I hearing that very often these decisions are political—with a small "p"—or allied to the enthusiasm of particular individuals who feel they have to push things forward?

Robert Meadowcroft: I cannot comment generally, but in terms of the Wales newborn screening service for Duchenne it appears that an enthusiastic geneticist clinician was keen to take it forward on a pilot basis.

Q90 Mr Heath: You criticised it in a number of ways in your evidence this morning. You feel that perhaps it was brought in without some of the details being quite right.

Robert Meadowcroft: From the evidence we took at the all-party group inquiry, those are legitimate questions to raise. We heard from families who felt their experience was not as it might have been. Let me leave it at that, if I may.

Q91 Mr Heath: Mr Hannigan, you mentioned experience in other countries. To what extent do we properly take into account evidence from screening programmes?

Steve Hannigan: We take some account, but we have to have a randomised controlled test or pilot project to satisfy ourselves that what other people have been telling us is right. I feel we should be taking their information into consideration, especially if they have been screening for a particular disorder for a number of years, and look for the differences in England and then do a randomised controlled test to make sure we have got it right, which would then cut it down. Four new disorders have just been added to the approved newborn screening list, probably from January next year. It took four years to get them through; it took nine years to get MCADD through. That is an awfully long time to get a disorder through for screening. We can look at the experience of other countries. Australia has a very strong newborn screening programme; so does the USA. They screen for up to 52 disorders. We should be looking at what they are doing, how they are doing it and how we can add to it or adjust it to make it better for us.

Q92 Mr Heath: Are you saying that the UK screening community will not be doing that?

Steve Hannigan: I think we have to provide our own evidence all the way down the line. We should be taking more and more into consideration what other countries in Europe are doing and looking for the loopholes, or the blind spots if you like. We should be looking to use those to make them better for ourselves.

Q93 Mr Heath: It sounds to me like a failure of analysis; it is quite surprising that we are not looking at all of the literature.

Steve Hannigan: I am not saying that we are not looking at it all. I am saying that we should look at it more closely, take the benefit of their experience and add to it, and use it for ourselves, rather than going down a four-year programme to introduce screening for a metabolic disorder.

Professor Baum: It is somewhat amusing that one country, Switzerland, has learned from the experience of other countries. The Swiss health board has just advocated closing down their breast cancer screening programme based on the experience of other countries. I think that is a bit radical because it might throw the baby out with the bathwater. What we have that is precious is a spin-off from the breast cancer screening programme: the infrastructure. We have a fantastic infrastructure. It would be tragic if we lost the expert pathologists and radiologists. I have little doubt that we could use that infrastructure to better effect. I would not go as far as the Swiss have gone.

Q94 Mr Heath: Knowing the Swiss political system, I am amazed they can do that without a national referendum.

Professor Baum: They probably will get to a referendum.

Mr Heath: I am not supposed to be saying things about Switzerland. I apologise.

Chair: Gentlemen, this has been really interesting. Thank you very much for your attendance this morning.

Examination of Witnesses

Witnesses: **Síle Lane**, Director of Campaigns, Sense About Science, **Dr Margaret McCartney**, Glasgow GP, and **Dr John Middleton**, Vice President for Health Policy, UK Faculty of Public Health, gave evidence.

Q95 Chair: Can I welcome you here this morning? Thank you very much for coming. Perhaps you would be kind enough to introduce yourselves for the record.

Dr McCartney: I am Margaret McCartney. I am a GP from Glasgow.

Síle Lane: I am Síle Lane, director of campaigns at Sense About Science, which is a charity that equips people to make sense of science and evidence. We work with groups across society, including community groups, women's groups, patient groups, policy makers and the media to help people make sense of science and evidence. In 2009 we worked with those groups to produce "Making Sense of Screening" in response to many of them telling us about the absence of good quality information about screening programmes.

Dr Middleton: I am John Middleton. I am vice president of the UK Faculty of Public Health, which is the body for professional standards in public health in the UK. We have about 3,500 members, including people in specialist and training grades.

Q96 Chair: Thank you very much for coming. We started the earlier discussion talking about public understanding of some of the messages that go out about screening. Can I ask the three of you where you think the responsibility lies for communicating risks and benefits to the public participating in screening programmes?

Dr McCartney: From my point of view, it should be the person who is inviting the citizen for a screening test. One of the problems we have is that invitations for screening are sent from a centralised body. They often appear to come from the general practitioner, but they actually come from the screening service.

Q97 Chair: They come from both, don't they?

Dr McCartney: In Scotland, where I work, invitations for cervical screening, for example, will appear to come from me, but I have nothing to do with the invitation letter. It has come from a centralised organisation, the screening office within the Scottish health directorate.

Q98 Chair: In England, for example, bowel screening for the over-60s just appears through the post with no reference to your GP practice.

Dr McCartney: Some screening programmes do; the letter appears to come from the general practitioner, but it comes from the screening office.

Síle Lane: I agree with Margaret. The National Screening Committee has a very evidence-based approach in looking at the benefits, harms and costs of screening programmes, but

sometimes those considerations are not clearly communicated in the information they produce, so they need to lay out that information in the leaflets they produce. Ministers and civil servants need to be better briefed on this as well. When we produced this document in 2009 the Committee might remember that it was a time when there was a lot of discussion about screening among the public, led by celebrity stories, I suppose. Kylie Minogue was diagnosed with breast cancer, and the TV personality Jade Goody was diagnosed with and died from cervical cancer around then. Politicians were hearing a lot of calls and clamouring for more and wider screening programmes. They need to be able to respond to those calls as well, and that means clearly setting out the considerations that go into making decisions about screening programmes.

Dr Middleton: The question you asked is right at the heart of the whole screening issue. I agree with Margaret that the person or organisation that is leading, running and implementing a screening programme has to be responsible for the quality of the information that is provided to the person who is likely to be receiving the screening. Where we have formally agreed and implemented national screening programmes, there is a national responsibility to get the information right. We heard earlier today about the breast screening materials. There has been a very strong and conscious effort to improve the quality and content of that patient leaflet, and not hide the harms. The notion that many of my colleagues may have had, including myself when running screening programmes as a director of public health in a primary care trust, was the complicit idea that, if you tell people the whole truth, getting them into the screening programme will somehow be jeopardised. We need a much more sophisticated, honest and open set of information to give people, to enable them to make informed choices.

Q99 Chair: Clearly, while multiple skills are needed in devising effective methods of communicating, the science and accuracy of the information has to be driven by clinicians. What would you do to improve the way this kind of topic is covered in the undergraduate medical syllabus?

Dr McCartney: The very first thing I would do is try to separate the targets that in UK screening are set to get people to go for screening tests from the aim of the information.

Q100 Chair: I was looking specifically at the people. I want to make sure that the people have the right skills to do the job you want them to do.

Dr McCartney: Sure, but you have to make sure that the practitioner is there for that individual and can help them make a good, informed choice, not that the person is working to a target or trying to get that individual to do something, or not do something, on the basis of the structures within which they work, but that they are able to advocate for that person's choices. Until you do that, it is almost irrelevant how you teach people, because they cannot put into practice what they learned as undergraduates.

Q101 Chair: I beg to differ on that. It seems to me you have to have the right skills before you can undertake the task.

Dr McCartney: True.

Q102 Chair: If you were back in medical school now, what would you change in terms of the process you went through to help you do the task that you clearly have to do as a GP?

Dr McCartney: When I was at medical school we learned about screening, and we learned about the Wilson and Jungner criteria written by the World Health Organisation to try to tell us what a good screening test is and is not. We were given that education, but it is difficult to put into practice. The knowledge is there, but we do not get a chance to use it properly because of the structures in which we work. Medical students are taught about screening. I teach screening to second-year students in Glasgow. We have a whole session devoted to the statistics, practice, ethics and difficulties of screening tests. I know you think I am not answering the question, but the problem is that it is very hard to put into practice when I do not get a chance to discuss with my patient whether or not she would like to go for breast screening, because the invitation comes centrally.

Q103 Chair: In your case, there was something in the syllabus not just about screening but about communicating risk associated with screening.

Dr McCartney: Absolutely. It is difficult. It is hard to do, but it was there.

Q104 Chair: Anybody else?

Síle Lane: It is difficult, because screening is not like any other kind of medical intervention. Talking about screening is not just setting out a list of instructions; it is not the same kind of material as telling somebody when the results of their blood test might come back. Screening comes along with a unique narrative and unique factors that need to be cut through. I am thinking of things like the direct campaigning pressure that is being exerted about screening, which is often not well thought out and not evidence-based, and does not take into account harms at all. The expectations people have about screening are not matched by what screening programmes can deliver, because our mental model of screening is diagnosis. We see the story lines in soap operas and read the personal stories in magazines and newspapers about people turning up for screening and being given a yes or no answer as to whether or not they have cancer, but screening tests are not diagnostic tests. Screening cannot do that. It aims to pick up people who are at higher risk of getting the disease so that they can go on to get more investigation and diagnostic tests and the disease can be caught earlier and treatment can be offered. Because screening programmes look at populations of healthy people, most of whom will never get the disease in question, they do not help the majority of people who turn up for them. In that context, what we ask of information about screening has to be higher; it has to cut through that narrative.

Dr Middleton: The question of undergraduate training is highly pertinent, but we need the same discussion about a higher level of knowledge in the general population. When you look at the 22 screening criteria of the National Screening Committee they seem self-evident; they seem to be things that people would expect. At the same time, looking critically at each one to see how few screening programmes meet particular criteria is crucial. In the Faculty of Public Health we are reviewing our curriculum generally for specialist training, but we have also entered into a new memorandum of understanding

with medical schools about undergraduate education in public health, and for us getting this into the undergraduate programme is very important.

Q105 Chair: I think there is a slight difference between the two of you. Dr McCartney seems to suggest that when she was at medical school she got some good training. My own experience—I expressed this to the last panel—is that, on the whole, doctors are not very good at explaining risk to members of the public.

Dr McCartney: I would concur with that.

Q106 Chair: What is missing in the training?

Dr McCartney: Training is a continuous process; it does not suddenly stop when you leave medical school.

Chair: I accept that.

Dr McCartney: You leave medical school, get postgraduate education and train to be a GP, and then you realise that you don't know anything properly, so you have to go back to the beginning and start it all again. It is a continuous, difficult process. That is matched by the fact that, when you look at the work statisticians have done about how well the public understand even basic statistics, it is pretty poor. You are starting from a difficult position. I have lots of information that I want to try to give my patients, but that information is quite difficult. It is not particularly expected information. The picture a lot of people have is that screening is easy and straightforward. It is sensible and logical; why would you not want to have it? When you come to a patient and say, "Actually, there are pros and cons, pluses and minuses," you are opening up a big box that perhaps people did not expect to be there, and it takes a lot of time and energy when there are lots of competing priorities in the consulting room. It is very difficult. We are not very good at it. There is evidence to show that doctors do not understand screening statistics very well. That is shared by midwives, nurses and members of the public, so we have our work cut out to try to explain screening properly. I can speak only for the medical school I teach in; I certainly do not know about curriculums elsewhere, but I think it is a known problem, as opposed to an unknown one.

Q107 Stephen Metcalfe: Following up on that, in your book "The Patient Paradox" you call not for more information but for better information. We heard from the previous panel about the wide discrepancy in the quality of the information provided. How do we produce better information consistently across the wide range of screening programmes there are? How do we physically get to that point?

Dr McCartney: It is a massive project. One of the problems just now is that it is being done by lots of well-intentioned people probably working quite separately from one another. To me, the overriding principle is that we should not talk about targets for screening in terms of how many people go for screening tests; we should talk about targets for how many people make good choices about screening. Once you start with that, you have a completely different sheet of paper and you can work out how best to do it. It is

immensely difficult fully to consent someone for many screening tests through a bit of paper. That is a really difficult thing to do, because screening is one of the most complex interventions in medicine. If someone is going for surgery, we sit down and explain the pros and cons; we check our patient's understanding; we see if there are any questions; and then we go ahead with it.

Screening tests do not work like that. For dementia screening—we are not allowed to call it that; we have to call it case finding—under the English GP contract, if you are in an at-risk group, and if you have high blood pressure, for example, and you see your doctor for an unrelated matter, you can be asked questions about your memory to screen you for dementia, but where is the consent given by the patient first? When did the patient get a chance to say whether or not they want this? Do they want to have a label that they have been diagnosed, for example, with mild cognitive impairment that might never lead to dementia? They could be given a label, so I do not think consent is being taken seriously enough. Once we do that, it then opens the door to say, "What information do patients need?" What level of information do patients need? Some people might just want a small amount of information—not very much at all; others might want to sit and work through an hour-long shared decision-making model on a computer. We should be able to cope with all kinds of people's needs for information in that scenario.

Q108 Stephen Metcalfe: How do we start that piece of work? Where should it start?

Dr McCartney: I think it should start with the UK National Screening Committee, who I respect highly as an evidence-based organisation. They make very thorough, careful judgments about things. Every few years they review their screening policy; they do a thorough review and present the pros and cons and try to make clear where the uncertainties are. Starting from that model, what do we need to translate for patients? My big concern is that sometimes when people write information leaflets their big fear is that they might put people off having screening tests, but we are talking about informed choice. That means some people will choose one particular set of risks compared with another. That is called autonomy, and we have to respect it. Until we get in place the principle that people must be allowed to make a free choice, based on good information and with support from professionals, we will not get it right.

Q109 Stephen Metcalfe: You have confidence that the National Screening Committee can do that.

Dr McCartney: I have always been impressed by them. What impresses me about them is that they are unafraid to express uncertainty. Very often when screening leaflets come through it seems quite certain and obvious what should happen, whereas the UK National Screening Committee usually produce reports that say, "We are not sure about this or that." That makes me have more confidence in them, because once we start talking about where the uncertainties are we can start to reduce them, and at least acknowledge them with our patients.

Q110 Stephen Metcalfe: Are there any advantages or disadvantages of information being produced about screening programmes outside the NHS?

Dr McCartney: There are huge problems. One of the really big ones is that we are screening but we are not calling it screening, and we are not calling it screening because it does not meet the scientific criteria for screening tests. But it is capable of doing harm. One of two big areas I would mention is dementia screening as part of the GP contract; it is called case finding, but Wilson and Jungner make no distinction between case finding and screening. I think it should have the same scientific basis and it does not. The UK National Screening Committee have made it clear that there is no evidence base for population dementia screening. The other area is health checks, which are now mandated in England. They have not been shown to be beneficial. The interim 1999 trial was published yesterday in the *BMJ* showing that a behavioural and risk reduction programme for cardiovascular disease does not produce a mortality reduction at 10 years. I would challenge the spending of money by Public Health England for these now mandated health checks when they cannot be sure they are going to do more good than harm. I really do not think so.

Q111 Stephen Metcalfe: What would the harm be?

Dr McCartney: There are several levels of harm. My biggest concern is that you are spending money on something that does not work and missing the opportunity to spend it on something that does. You have the healthy attender effect, where the most fit and the most healthy in society—the people who are already destined to live longer—turn up for these tests rather than the people who are not, in which case you are widening health inequalities. The first thing is the direction of public health travel.

The next thing is over-diagnosis: giving people lots of diagnoses that they do not necessarily benefit from. You end up treating someone with high blood pressure or high cholesterol, which on paper might look as though it is going to reduce risk, but in real life they have a small chance of benefit. They end up taking pills for life that they think will help them, but the real improvements in health lie elsewhere, outside medication.

Q112 Stephen Metcalfe: My final question is about where the National Screening Committee is located within Public Health England. Is that the right place for it?

Dr McCartney: I am quite confused about who answers to whom, particularly in England. Scotland, England, Northern Ireland and Wales take advice from the National Screening Committee. I do not know. I would like to feel that they are as independent as possible; that can only be to the population's advantage.

Dr Middleton: The National Screening Committee is clearly working for all four nations. It reports to a committee of the deputy chief medical officer that makes recommendations to the four chief medical officers. That much is independent and professional. The recommendations to the devolved nations about their country are clear enough. In England, NHS England is responsible for the money, the budgets and the implementation, but they are using Public Health England specialists seconded to them for the purpose and it all gets a lot messier. I doubt whether NHS England could implement a new screening programme without reference to the Secretary of State, but, strictly speaking, it is NHS England's responsibility.

Q113 Graham Stringer: I think everybody is agreed that we want high- quality information going to people in order that they can make a decision whether to participate in a screening programme, but what might be very high-quality information to you as a trained clinician might not be high-quality information to somebody going into it. Is the information in leaflets and in other forms regularly evaluated to see if it is effective? If it is not, should it be regularly evaluated to see that it is effective in delivering information about risks and benefits?

Dr McCartney: I am not sure that it is. It would be possible to do a randomised controlled trial of information.

Q114 Graham Stringer: It would be possible.

Dr McCartney: Absolutely. It has been done before. Several American trials have looked at the effect of information, usually in the form of shared decision models. Often, they find that people will decide not to go for a screening test, but are far better informed about it. There have been trials, particularly in the States, and it would be absolutely possible to do the same in the UK.

Q115 Graham Stringer: Decisions are made. It is whether the decision is made on the basis of really understanding the information, so it is effective communication, isn't it?

Dr McCartney: Absolutely.

Q116 Graham Stringer: That is what needs to be evaluated.

Síle Lane: That is right. It is not just the numbers, although whole numbers, real numbers and understandable numbers are vital in this information; it is also the other factors that help people understand what screening is, and what it can and cannot do. To underline what I said earlier, people have expectations of screening programmes that screening programmes just cannot deliver, so there are insights about what screening is—that it can identify some of the people who are going to get the disease, but cannot prevent it; that it can cause harms; that some false positives and false negatives are an unavoidable cost of screening populations of healthy people; and that it rarely benefits all sections of the population, so it needs to be targeted at those most likely to benefit. We found in our work with public health professionals, GPs and others that those are the insights that are most useful to the people who have to talk to other people about screening.

Dr Middleton: The pace of clinical innovation is far faster than any of the information resources in place. It has always been the case that the information and materials available to patients have not been seen as terribly high priority. We used to have a health education authority; we then had Health Education England producing stuff from a national level, but now we have a very ad hoc set of arrangements where some enthusiasts might do a one-off piece of work on bowel cancer or anything else, but sophistication about decision making—the social marketing part that makes information relevant to particular communities—is very under-resourced and unsupported.

Q117 Graham Stringer: Should the information focus on survival rates, reductions in mortality, quality of life or something else? If so, why?

Dr Middleton: That goes back to the ethical questions. Why are we doing screening? Presumably, we want to save lives and reduce disability. In some instances with some of the newborn screening it is preparing a child and a parent; for sickle cell thalassemia, it is more about preparing them for what to expect with bouts of the disease. But in each case we are obligated to do some good. We are also obligated first to do no harm. There has to be a big objective in relation to reducing disability, disease or death.

Q118 Graham Stringer: Does anybody else want to comment on whether the information should use survival rates or reduction in mortality?

Dr McCartney: One of the big problems is lead-time bias, where it can appear that a screening test is doing a lot of good but in effect is not. It has been described as two people who die of cancer in, say, 2015: one was diagnosed in 2013 through symptoms; one was diagnosed in 2010 because of screening, but they both die at the same time. It appears that one person survived for far longer through screening, and one person did not. That kind of lead-time bias can be very deceptive in the screening statistics and can often make screening look far better than it actually is. We need profound care around the kind of statistics we choose to use, because it is very easy to persuade people that screening is good rather than not.

Another problem—sometimes called the popularity paradox—is when a bad test produces lots of false positives. People go on to have diagnostic tests that show them not to have the disease. Instead of feeling angry about a false positive diagnosis they are relieved that they did not have the disease, so a bad screening test becomes even more popular, because people get reassurance that they did not need in the first place.

Q119 Graham Stringer: Cancer Research tells us that identifying reductions in all-cause mortality would be the ideal way of evaluating, but it is very difficult.

Dr McCartney: Absolutely.

Q120 Graham Stringer: Why is it so difficult?

Dr McCartney: It is difficult because you need big trials, but it is very important because you can harm someone because of the treatment as an outcome from a screening test for a diagnosis that you did not need and would never benefit from. You end up doing someone harm, but saying there's a reduction in mortality because of the treatment intervention for a positive screening test that would otherwise have gone undetected and would be unknown—so-called over-diagnosis and over-treatment. You have to anticipate that your screening intervention could do as much harm as not screening. Because of that you need all-cause mortality. You cannot just use cancer deaths as your outcome; it must encompass all possible outcomes, including the possibility that you have harmed people more through screening and interventions than through not doing that.

Q121 Graham Stringer: What is the difference in using disease-specific mortality? It is easier.

Dr McCartney: It is easier, and you can use smaller trials. That is the advantage. The disadvantage is that it is not going to pick up harms accumulated through the screening and treatment process.

Dr Middleton: The argument that with most medical conditions when we do trials we judge them against the outcome of that particular disease is more difficult with screening; saying, for instance, "We've stopped you dying of aortic aneurism but we haven't prolonged your life in any way." You have brought people into a screening programme when they did not know they had an aortic aneurism, and they make all of the choices that they are then obliged to make. It is not the same as somebody who knows they have a condition and then has a treatment, or no treatment. It feels to me that it is even more incumbent on people who are recommending a screening programme that those overall mortality results are looked at.

Q122 Mr Heath: As an aside, thinking back to my undergraduate career, such as it was, albeit in a pre-clinical degree, I do not think I was ever taught anything that related to a conscious, sentient patient, but there we are. Perhaps I missed those days. To continue the theme about evidence, what worries me about a lot of the screening programmes is that the test is in the efficacy. Is it doing more good than harm? It seems to me that in a lot of cases the evidence as to what the outcomes are is very limited. At least in the cancers we have the cancer registries; we have something that gives us evidence. We do not have that in some of the other conditions. Should that sort of approach be extended? I do not know who I am asking. Dr Middleton, would you like to pick that up?

Dr Middleton: Neonatal screening has quite sophisticated data returns from the labs that run that. As the new national screening programmes have come in there has been quite elaborate quality assurance, which has covered everything from the final outcomes through the process measures of how many people are required to go to second-stage assessments and so on—

Q123 Mr Heath: Can I interrupt you for a second? I do not know whether you were here during the previous evidence. Professor Baum directly questioned whether the statistics that accompanied the tests were accurate.

Dr Middleton: On the figures he quoted for the numbers needed to treat on screening for breast cancer, I am certainly familiar with the 2,000. Until more recently, that was the figure in my mind and in my professional practice. The figure in the breast cancer screening leaflets is that 200 women need to be screened to prevent one breast cancer death. I have seen only 84 as the number in an American journal. The range that Professor Baum described of 1,000 to 2,000 is even bigger. It means that for both monitoring and patient information it makes it extremely difficult.

Q124 Mr Heath: Dr McCartney, do you say the same?

Dr McCartney: A huge amount of quality assurance goes on within the screening programmes validated by the UK National Screening Committee. A huge amount of work goes on to ensure that it does what it says on the tin. What I am concerned about are the programmes that are screening but are not being looked after by the UK NSC, so you do not get the same quality assurance. Perhaps the audit going on is looking at the minutiae of what is going on day to day, which is incredibly important, but is perhaps not always looking at the bigger picture. Does this programme still do more good than harm? Are we still informing people properly? Did people who are now at the end stage of treatment know what they were getting into at the very beginning? Those kinds of questions are perhaps not being asked in the same way.

Q125 Mr Heath: Can I turn to what you just said? You think the monitoring is very carefully done, but if you haven't even got accurate figures on mortality, let alone morbidity, I cannot reconcile it.

Dr McCartney: I agree. For example, if someone has an interval breast cancer in the screening programme, all the radiographs are pulled up and looked at very carefully by other people. People are trying very hard to do the best they can within the programmes, but it is the bigger picture. You are right about mortality and morbidity. Did people know what they were consenting to at the beginning? Is it still doing more good than harm? Has our population changed? The breast cancer statistics we are now using are 20 years old, and treatments have changed hugely. I suppose the bigger picture I am concerned about is not fulfilling what we should be doing, rather than the people, who I think are working genuinely hard within the programmes themselves.

Síle Lane: I would like to add support to what Margaret said. Good evidence for screening programmes depends on them being continually or at least regularly monitored, and continually weighing up that they are doing what they set out to do, or doing what they aim to do. As soon as any part of the screening programme changes, whether it is the test, or a change in treatment, or a change in society, which means different kinds of people are attending for screening, that will change the balance of benefits and harms in the programme and change its effectiveness. That needs to be continually fed back in, monitored and weighed up, as well as continually weighing up other things that are not screening that might make a difference to the detection and treatment of disease, whether it is putting more money into educating GPs about symptoms, for example, or putting into place systems for speedier referral to specialists, which might be a more cost-effective route.

Q126 Mr Heath: Is somebody doing that work? Is somebody identifying the gaps?

Síle Lane: That is the National Screening Committee's role for the programmes they oversee. As Margaret said, there are other programmes that are not overseen by the NSC.

Dr McCartney: They do a very good job, but there are bigger questions. Who is holding them to account in terms of the bigger questions? I know they interact a lot with policymakers. I suppose it is a matter of always asking the question: are you doing more harm than good with this programme? Is it time to stop doing it? Is it time to change it

radically? I know that decisions like that have been made before—for example, raising the age of cervical screening based on evidence.

Dr Middleton: Looking at cervical screening, that is an example where modification and change to a programme has happened based on good evidence—raising the age and frequency of screening because there is no benefit in older women having it three-yearly. There is a constant process of refinement of screening programmes.

The commonest screening programme we all consent to is dental screening. The expectation that we have a six-month check is no longer the case. I certainly did not apply the screening criteria to dental screening, but there are holes in your teeth that can get better on their own. If 100 dentists look at your mouth, all of them will come up with a different range of work that needs doing. When we look back at the criteria for screening, the notion that we are doing good by finding it early is not always the case. Other kinds of screening are now being advocated—around domestic violence, for instance. A recent review says that universally asking women about domestic violence will not help, because we simply do not know enough about the natural history of it. Will you cause harm by meddling or investigating at that point? The criteria of screening really need to be probed in detail.

Mr Heath: I feel that I should leap to the defence of the dental profession, but I shan't.

Q127 Chair: Clearly, screening programmes can pick up something like a cancer earlier, but it does not necessarily change the point at which the person is likely to die. It might as medicine improves. In those circumstances does it make the screening a valueless proposition, or are there other benefits the patient gets from knowing they are being properly cared for?

Dr Middleton: That is where it is no longer a clinical scientific professional judgment; it is very much in the public domain, and we need that more sophisticated discussion with patients. I think it is a major burden to be informing people of something that you are not going to treat, or giving somebody knowledge that does not help. With things like aortic aneurism screening, for instance, there is an operative mortality. By definition, the outcome or the harm of a screening programme could be people dying. The people who are given the result that they have a small aneurism that does not need operating on are in effect being told about something that they may have until the end of their life and will not be the cause of their death. These are things that need to be rehearsed more with patients and the public.

Síle Lane: There is a tension, isn't there, between screening programmes, which are population-wide initiatives and are designed and evaluated against doing good across the population, and the fact that it is an individual who turns up for them? The programme may or may not do anything for that individual on that day; it may have no impact on their lives at all. That is a real tension.

Q128 Chair: Dr Middleton's example plays havoc with things like insurance.

Síle Lane: Yes. It can lead to things like increased anxiety if you are told, "There may be a risk factor, so we are going to send you for further interventions." Something that we have not yet discussed is the kind of false reassurance people can be given when they get a negative result. Another piece of information that I suggest needs to be included in any information about screening is clarity on what getting an all-clear at a screening test means. It does not mean you are never going to get that disease.

Q129 Chair: That leads me to questions about the ethical issues around screening. Should the National Screening Committee provide more explicit statements about what to consider when scrutinising the ethical acceptability of screening programmes? Is there a case for some sort of standing body to be looking at the ethics of screening programmes?

Síle Lane: I don't know.

Dr McCartney: You have to have ethical oversight. You have to have clear medical ethics embedded in invitations, such that it is crystal clear to people that there is a risk in coming and a risk in not coming, and what those different risks are. How best that would fit in, I do not know. The UK NSC talk about ethics in their reports; they talk about the ethical issues surrounding screening in different circumstances, but I am not sure how that is done currently. It has certainly not been tested. As Mr Stringer said, there are no RCTs behind the vast majority of leaflets that I can see, so what criteria are they being held to? There does not seem to be a set of criteria that says you must ensure x, y and z, and make that clear in your invitation leaflets.

Dr Middleton: Certainly, there is scope for a more formal ethical consideration through the National Screening Committee. That would involve some professional ethicist, but I think there should be wider public involvement as well. We tend to involve stakeholders about specific screening programmes. You might have an interest in prostate cancer and therefore you get asked about it. There is Healthwatch, for instance; shouldn't everybody who is a member of a local healthwatch understand something about the detail of screening programmes? On several occasions I did exercises on screening for elected members in the scrutiny committee. Raising the level of understanding and debate that is possible with elected members and other community interests that are not specific to a particular screening programme is important.

Síle Lane: You have to give people full and honest information. I do not know whether there is a need for another standing body to be set up to ensure that is happening. That is perhaps another discussion, but you need to give people full and honest information; otherwise, you are coercing them. You have to tell people about all the risks and all the benefits, with clear and full information about coming to screening programmes. If you cannot give someone an argument to attend a screening programme that is based on the truth, perhaps you need to look again at the screening programme.

Dr McCartney: You absolutely have to have citizen involvement wherever you go with this. The only thing I would caution about is that most people do not know if they are being harmed by screening tests. How can you represent that group of people? In the past, I worked closely with a group of women who felt they had been over-diagnosed in the breast cancer screening programme, and that they were not given proper information. It is difficult to find such people. It tends not to be vociferous members of charities speaking

out in those terms, so you really have to make sure you have adequate citizen representation, not just from people who believe they are being helped by screening but also people who accept that they may have been harmed by it.

Q130 Chair: Just to reinforce the point I made earlier, part of that message needs to be about some of the consequential effects, because, taking the minor condition that is identified, it has consequential effects on the size of your wallet; insurance costs go up and things like that. Insurance companies as yet are just useless at doing anything other than tick boxes on matters like this. You have a really key responsibility, haven't you, in communicating that risk to the public?

Dr McCartney: Absolutely. Quite often anxiety is talked about as though it is nothing. Anxiety is a horrible thing. I have met many people—there is evidence of it as well—that people who have a false positive prostate-specific antigen test are anxious even a couple of years after, compared with people who did not want to have the screening test. We really have not examined enough the psychological impacts of screening on a population. As a GP, it is the kind of thing you see all the time. Every few weeks someone comes in saying they've had a letter saying that their smear test is abnormal. They have been writing their will and contacting charities, and are absolutely terrified. It seems a real shame that it is only quite far down the process that someone says to them, "False positive tests are extremely common." You can almost expect to get one as a woman if you participate in the screening programme.

Q131 Chair: My final point, developing it further, is that, as we move towards a more personalised medical system, is mass screening on a population basis compatible with that general move?

Dr McCartney: No.

Q132 Chair: What is going to happen? Do you envisage that as we get to know more about the individual patient, mass screening will slide away into the distance?

Dr McCartney: I do not know, but certainly a vast amount of private screening companies would like you to believe that that is how it should be. You can go down Harley Street today and pay £5,000 for someone to scan every bit of your body in the belief that it is the ultimate check-up. Numerous companies are trying to get in on this. We have not made it clear enough to the population that screening is a matter of pros and cons; it comes with harms and it is not the be-all and end-all. Because of that, lots of private screening companies have tagged themselves on, with the idea that more information is always better information, and are offering it to private citizens, who often pay hundreds of thousands of pounds in the private sector, which is effectively an unregulated market, and the NHS has to mop up. The problem is that people come back from their BUPA health assessment, their Harley Street check-up, or one of the Life Line Screening clinics with vast amounts of information, none of which is terribly relevant or really helps the patient. What are they telling them? To reduce their cardiovascular risk is not to be overweight, to exercise regularly, to eat a good diet, not to smoke and not to drink too much: exactly the

same advice as I would have given them had they never had the screening test, but now they are 150 quid poorer for it.

Síle Lane: That is an important point. Those private screening tests are not a screening programme; it is not being run and overseen by the National Screening Committee, and it is not inviting specific people in a specific population to come along for a specific test. It is inviting everyone to come along, and I suspect that it is not people with symptoms, but mostly the worried well and healthy people who turn up for those programmes. They are offering direct consumer tests. There are lots of problems with that, as Margaret set out. Most tests were not designed to be used on well people with no symptoms. As Margaret said, tests are not regulated, so there is no need for the people offering them to have any evidence that a test will show what they say it will show. Anybody can set themselves up with a lab and start testing people. Should it be regulated?

Dr McCartney: Yes.

Q133 Stephen Mosley: Our Chairman talked about social and ethical issues. I am afraid I want to turn to money now. NICE suggests that a health intervention should cost less than about £20,000 to £30,000 per quality adjusted life year to be considered cost-effective. Should screening programmes be subject to the same threshold?

Dr Middleton: Yes. My last reading of breast cancer screening was that it certainly came within that range; I think cervical cancer is less expensive. The cost-effectiveness of screening programmes is less well evaluated, and it takes you back to the question of randomised trials. The only way you can tell that a screening programme is better than nothing, or better than the other best alternative, and to cost it, is by doing randomised trials. The answer to the question is that screening programmes should be capable of being measured on cost.

Dr McCartney: There is no reason why we should not have the same standards for cost-effectiveness of screening as for any other medical intervention, and I do not think it is being done thoroughly enough in the NHS at the moment. I am particularly concerned about programmes that are screening but claim not to be, such as dementia screening in health checks. I think they should be subject to rigorous cost-effectiveness analysis; otherwise, we are just going to keep pouring good money after bad.

Dr Middleton: To take you back to the criteria and an important health condition, syphilis in pregnancy is very rare, but the test is very cheap. Preventing syphilis in pregnancy and treating it saves a whole lifetime of disability. Those kinds of economic evaluations are not necessarily about things that are very common or that will kill you. Sometimes the rare conditions can be cost-effective, so that economic evaluation needs to be applied.

Q134 Stephen Mosley: You are saying it should be applied.

Dr Middleton: Yes.

Q135 Stephen Mosley: It needs to be applied. Can I ask you what weighting is currently given to economic factors by the UK National Screening Committee when they review evidence for a screening programme?

Dr Middleton: I cannot tell you the detail of how much economic evaluation they look at, but one of the criteria is a simple, cheap and acceptable test. Another criterion is about assessing randomised trial evidence, and there is also assessing the effectiveness of treatment. There are various points in the criteria at which cost-effectiveness can be judged. I would not say that I could tell you precisely what they do.

Q136 Stephen Mosley: Is it your impression that they are doing that, or do you think greater transparency needs to be in place in order to judge that?

Dr Middleton: I believe that they operate in a very rigorous way, but I cannot say I have seen it transparently on their website.

Stephen Mosley: I think we can deduce something from that, can't we?

Q137 Stephen Metcalfe: I would like to come back for a few moments to the issue of private health screening. I think you said there is very little regulation.

Dr McCartney: Absolutely. I have been trying to write about these concerns over the last decade, pretty unsuccessfully it would seem. Basically, lots of full-page adverts go out, often in the quality and tabloid press, saying, "Come along for these tests at your local church hall or scout hall. We can save your life." There is no evidence at all that that is the case. They are offering ultrasound scans, usually for the abdominal aorta and the carotid arteries in the neck; an ECG; and blood tests for cholesterol and glucose, which you could have got, had you needed them, from your GP. Therefore, the tests are available and could be done on the NHS, and the tests done are not those recommended by the UK National Screening Committee, or any other organisation. They are very poor screening tests that lead to lots of false positives. Then it flips over to the NHS, because patients come in and say, "I've had a leg scan done and it is a bit abnormal." They want to see a vascular surgeon. We set up a website called privatehealthscreen.org where there is testimony from vascular surgeons saying that whenever Life Line Screening is in town they get lots and lots of appointments. They are clogged up with people who have been for an unnecessary test, and want reassurance because of it. There is a big impact on the NHS from the private health screening sector. That is ridiculous. Why should the NHS have to pick up the pieces from unwarranted private sector testing that did not need to be done in the first place?

Q138 Chair: That sounds like a strong case for regulation.

Dr McCartney: I have been to the Advertising Standards Authority who have done what they can. In two judgments, from midnight last night companies are no longer allowed to say they have saved lives, because they have no evidence of doing so. Life Line Screening say that they have screened over 250,000 people in the UK and Northern Ireland in four years. That is a huge amount of testing. If there are any abnormalities, people are told to

go back to their GP. I have been to Trading Standards, who said the companies are doing what they have said they will do, so there is nothing they can do about it. I have been to the General Medical Council, because I believe that the doctors who run these clinics have been complicit in allowing misinformation and poor advertising to perpetuate. The GMC have not acted, so I would be really pleased if you would be interested in doing something about this.

Q139 Stephen Metcalfe: Regulate it or ban it?

Dr McCartney: Well—

Stephen Metcalfe: Be honest.

Dr McCartney: I think if people are going to have these things done they should know that they are paying for something that is not recommended by any reasonable evidence-based authority, and they should be responsible for paying for all follow-up tests that they wish to have as a consequence, and the NHS should be spared from having to do the private sector's leftover dirty work for them. That is one thing.

The second thing is that any advertising that these companies wish to do should be cleared by an independent group of evidence-based clinicians or researchers. I have been playing catch-up for the last decade. Every time they put up a new advert I have to make another complaint to the NSC, who usually uphold most if not all of the points I make. Then they produce a new advert and I have to go back again. They are even allowed to say that something "might" or "could" save your life when there is no evidence to suggest that is the case. We are pinning all these hopes on tests that really do not need to be done, and the big issues are the basic ones: smoking, drinking alcohol, being in work, and not being poor. All those kinds of things have a much bigger impact on your health than unnecessary screening tests.

Síle Lane: I do not know whether or not regulation is the answer, but it would perhaps help us move the information being given about these kinds of tests closer to where the National Screening Committee are moving with their evidence now, i.e. clearly laying out the benefits, harms and misconceptions about direct consumer health tests for well people. Selling tests to well people is usually not a good idea as most tests are not designed to be used on well people. They come along with all the same kinds of misconceptions as in screening programmes—that a test can give you a yes/no diagnosis immediately, whereas in reality tests are usually part of a much longer diagnostic pathway. They can give false reassurance from an all-clear. At the bottom of it is the fact that most tests were not designed to be used on well people, but these are the kind of people who are showing up for these health scans; in fact, these are the people they are being promoted to, with the message, "Wouldn't it be better to know?"

Q140 Stephen Metcalfe: I suppose the problem is that some who want to have these tests probably think they are doing the NHS a favour. They do not want to trouble you; they have a concern and they will get a test. How do you square that particular circle?

Dr McCartney: One of the things I picked up Life Line Screening on is the fact that they had a couple of anecdotes from people who said they had been hugely helped by it, but both those people had symptoms, and symptoms need sorting out by doctors. It could be even just making it clear that screening tests are meant to be for people who are asymptomatic. The second thing is to hold them to account. Every time they put out a new advert they should be required to evidence every single statement they make in it. I did some paid work for *Which?* We looked at private screening companies and what information they were offering. We found that almost none—I think one out of six or seven companies—was prepared to say that their screening tests could do harm when we asked them that specifically on the telephone. There are similar groups out there who are aware of the need for balanced information, but they struggle to get their voices heard, because we are up against big glossy adverts like, "Why don't you save your life? Come with us," and the evidence is left as a very small voice in the corner.

Q141 Stephen Metcalfe: Presumably, when these tests are conducted either in the NHS or privately, data are collected. How is that stored and shared?

Dr McCartney: I am sorry?

Q142 Stephen Metcalfe: Let's talk about breast cancer screening, where perhaps we end up with the figure of one in 100. There must be a result from all the screening programmes. Presumably, those data are held somewhere and then used to decide whether or not it is a valuable programme.

Dr McCartney: Yes. I think that is about quality assurance and the need for an internal audit to be consistently taking place, and it is one of the bigger questions not being offered. In the private screening sector there is none of that. They put claims on their website. One was, "We've saved thousands of lives." You have to go back and challenge them and say, "Where's your evidence?" Of course, they have no evidence because they have not followed up people in the long term. In the private sector the data disappear, as far as I can see, unless they are storing them. I have been told that BUPA store some information, but they have yet to make that available to me.

Q143 Stephen Metcalfe: Where data are collected, either privately or within NHS screening programmes, are patients made aware that the data will be collected and stored, and are they aware of how it might be used in the future?

Dr McCartney: I have no idea about the private screening sector. Within the NHS I presume it is just the same as any other information that is gathered as part of your medical record.

Q144 Stephen Metcalfe: Is there is a tiny box somewhere at the bottom that says, "We might store and use the data," or is it made clearer than that?

Dr McCartney: I do not know. In the private screening sector, in terms of data I presume it is all under their own code, which you submit to, but in the NHS it is presumed that your data will be used to investigate how well the programme is working.

Q145 Graham Stringer: Who, if anybody, gives information about risk and benefits on NHS Health Check?

Dr McCartney: The NHS Health Check website has recently been revamped. There are lots of things on it that they say can benefit you. There are benefits to be gained if you exercise more, if you stop smoking and drink sensibly, and if you are not overweight, but I cannot find any shared decision aids from the NHS Choices website. I cannot find any choice-based information that would help people decide whether or not to attend for a check.

Q146 Graham Stringer: Do you think these tests should have oversight by a body that can independently scrutinise their effectiveness?

Dr McCartney: Absolutely.

Síle Lane: Yes.

Q147 Graham Stringer: And that is not there at the present time.

Síle Lane: No, it is not. I saw a report published last year by the charity Diabetes UK. They looked at the effect of the NHS Health Check programme four years after it was rolled out. They discovered that four years after it was rolled out there were some PCTs—at least they were PCTs in 2009 when it launched—that had never offered anybody a diabetes check as part of the NHS Health Check programme. They found that diabetes checks were being offered sporadically, illogically and randomly. Their conclusion was that because of that not enough people were being offered the diabetes check, and the subsequent intervention and lifestyle advice that comes from it, to make any difference at all to the prevalence of diabetes.

Dr Middleton: The report Margaret referred to earlier, which is the Danish study of health checks, comes out virtually as close to one as you could be—there is no difference between the tested and the not tested. It says that elements within the general health check that work should be looked at and tested. Things like quit smoking advice are perfectly sound and evidence-based interventions, but whether you need a whole national mandated programme for somebody to get quit smoking advice is another question. The health checks crept in; it was not a National Screening Committee programme. It was implemented through the reforms that Lord Darzi put through when he was a Health Minister, but it is enshrined in legislation and is part of the NHS constitution, so that will need some change in law.

The Faculty of Public Health recognise that health checks do not comply with the criteria for screening programmes, but many of our service people have regard to a risk stratification approach using GP lists and trying to call up people at most risk of a heart attack in the next 10 years—people in Stoke, Haringey, Nottingham, Sandwell and

Cumbria. That more targeted approach does seem to offer a real opportunity to get to the people who are at most risk, but it is not a screening programme; it is using GP practice lists, identifying people directly and case finding.

Q148 Graham Stringer: Finally, Dr McCartney, we have touched specifically on some problems with NHS Health Check, and it has come up once or twice in the questions. Can you just finish by telling us generally what your concerns are about these checks?

Dr McCartney: My concerns are that they are not proven to work and they will attract only the most healthy who have the least to gain, and we widen health inequalities; and also there is the presumption that this will make a difference to public health, so we do not concentrate on the other things that we know work—for example, fair laws on smoking or tobacco, fair laws to do with children getting to school, not needing to be driven in cars but walking instead, social inequalities and social deprivation. These are the far bigger problems that are much more likely to help reduce health inequalities.

One of the big issues is that we should stop doing things that we know do not work. For example, we know that population screening for diabetes does not work; it was said in *The Lancet* in 2012, but it is now an integral part of the health checks. Rather than keep on doing something that does not work and trying to make it work better, just accept that we are not going to solve the problems with our health inequalities in the UK based on doing more of that. We have to do something else instead.

Graham Stringer: It is very useful to get that on the record.

Q149 Chair: To go back to Stephen Metcalfe's question about data, in the context of screening, to whom do the data belong: the individual or NHS?

Dr McCartney: Pass. I would not be able to answer that.

Chair: I know what the answer should be.

Síle Lane: I do not know. I assume it is the same as for any NHS appointment you attend when data are collected.

Dr Middleton: You are entitled to have your data. The simple answer is that it is within the NHS screening programme. There is a bigger issue about data sharing and linkage. In relation to breast cancer, for instance, we know from the big studies that the screening programme does have an impact on mortality. We know that treatment has had a spectacular effect on reducing mortality, but we cannot tell you which of the lives saved from breast cancer have been due to the screening programme or to the treatment. Part of that is tied up with the lack of availability of routine data links between hospital and GP. You will be aware of the problems over care data, but if we are to get a more sophisticated way of measuring outcomes we need linked data between GP and hospital.

Q150 Mr Heath: I have a very quick question on diabetic screening. Has any comparison been done of the effectiveness of population screening for diabetes as such and the simple use of the eye test and retinopathy as an effective means of screening out diabetes?

Dr McCartney: Retinopathy as?

Q151 Mr Heath: Diabetic retinopathy being something picked up as an ancillary result of a routine eye test, rather than asking people to go and have a diabetic test.

Dr McCartney: I am not aware of that.

Dr Middleton: We had that kind of situation before formal diabetic eye screening came in, and we regard the diabetic eye screening programme as one of the more successful screening programmes, and certainly much more successful than ad hoc eye tests where opticians might just pick it up.

Q152 Mr Heath: If they do not pick it up, they are seriously deficient in their testing.

Dr Middleton: Yes.

Dr McCartney: If someone has a diagnosis of diabetes they automatically enter the diabetic retinopathy screening programme. If you have a diagnosis of diabetes you go in for that, but in terms of opticians picking up diabetes when doing examination of eyes, I do not think there is any data on that. I do not think that would be a useful screening test, based on a quick thought about the Wilson and Jungner criteria.

Chair: Thank you very much for your attendance this morning. It has been extremely helpful.