



Europe's Ageing Population:  
Healthy and Working, or  
a Burden on Society?  
*A Case Study*

**Gisela Kobelt**  
**Maarten de Wit**

26 February 2008

## Europe's Ageing Population: Healthy and Working, or a Burden on Society?

---

### About the Speakers

**Gisela** Kobelt is the founder and president of European Health Economics SAS. She is the author of an introductory guide to economic evaluation for non-specialists that is now available in several languages. Since 2003, she has organized and directed an annual intensive training course Health Economics of Pharmaceuticals and other Medical Interventions in Southern France. Previously, she was course director of the executive course in "Strategic Health Economics" at the Stockholm School of Economics.

Dr Kobelt created and headed the Health Economics department at Sandoz (now Novartis) in Basel (Switzerland). She holds a Master's degree from the University of Strasbourg (France), an MBA from the Institute for Management Development (IMD/IMEDE) in Lausanne (Switzerland) and a PhD in Health Economics from the Karolinska Institute in Stockholm (Sweden).

**Maarten de Wit** is Vice President of EULAR, representing people with arthritis/rheumatism in Europe. He has been active in organisations of patients with rheumatic diseases at local, national and international levels for many years. He was involved in the Dutch Steering Committee of the Bone and Joint Decade from 1999 till 2005. He is currently responsible for scientific research and international contacts within the Dutch Arthritis Patient League. In OMERACT (bi-annual conference on "Outcome Measurement in Rheumatology Clinical Trials") as well as other international projects he has been actively involved in promoting patient participation in scientific research.

In 2006 he founded Tools2use, a non profit corporation, based in the Netherlands, aiming at increasing the competences of patient advocates. Maarten studied Social Sciences at the University of Amsterdam and worked as a HRM consultant and company trainer. Maarten has experienced psoriatic arthritis for over 25 years and has therefore a personal as well as professional outlook on the condition. Since 2002 he has

been successfully treated with a new generation of disease modifying drugs also known as "biologicals".

---

### **Gisela Kobelt**

Thank you very much. Good afternoon.

It's a very great honour to be invited. Today I will present some work which has really been fascinating to do, led by professor Göransson from the Stockholm School of Economics, and with the help of Professor Josef Smolen, who is one of the most distinguished rheumatologists in Europe. I'm going to focus on the burden of the disease and on access to the latest, most effective treatments, but let me start with some historical anecdotes, for those of you – I assume that most of you are not really working in or with rheumatoid arthritis (RA) all the time.

I think it's been of the most fascinating scientific developments that we have seen in terms of treatments. [*referring to slides*] You certainly all know Auguste Renoir; if you look at the middle picture, he had very, very severe rheumatoid arthritis. He got it at 54, and this was at the end of the 19<sup>th</sup> century. He obviously got it in a time when there was literally nothing that could be done. It was really just moving into being disabled. You can certainly spot the difference in those two paintings, the one on the left being one of his last ones that is hanging in the Musée d'Orsay.

Raoul Dufy: same story, but we start to see the scientific progress and if you look at one his last paintings, in 1950, which was 15 years into the disease – he was disabled, but much better off because he got cortisone. The first treatment that actually did something for the disease had come in and help was on its way.

You all remember Christiaan Barnard, the South African heart surgeon. He had to stop surgery, because of rheumatoid arthritis. He went back into surgery because he got methotrexate, the next step on the ladder of better treatment. I have yet to find a picture of a celebrity using the current biologic treatment, but I will find one. I can tell you the story of a friend who could hardly walk because of the disease; he got one of the biological treatments and three months later, he put his motorbike on a boat to Finland from Southern Sweden, crossed all of Finland on a motorbike and went to help counting eagles by putting rings on eagles' feet.

So, we have veered into a field where the scientific progress has just been incredible, incredible. But obviously, it comes at a given cost and what we are talking about today is how much of this progress there is, how can we afford it, and who should get these treatments. So, the objective of the study that we have done was really to look into how access to these new biological treatments is both in Europe and in other countries – but I do focus on Europe here. Also, I focus on the three TNF inhibitors, because we ran the analysis

over a time series, and the two most recent biologicals in this field only came onto the market in 2006 and 2007, so they're not included. And then we'll try to analyze what determines access – what causes the differences in who gets the drugs, and how many patients get the drugs?

In the study, we obviously also look at the medical aspects of the disease. We look at health technology assessment. We look at cost effectiveness analysis to see whether these drugs are cost effective to be used or not, and for whom. I will skip all that and really focus today on the cost and the health burden of rheumatoid arthritis and on the use of biological drugs.

Let's start with the disease burden. The World Health Organization together with the World Bank and Harvard University have developed a concept which is called DALY, it means Disability Adjusted Life Years. So this is year of lives that are kind of indexed or weighted with an index that represents disability. And this was done in a way, with the objective to be able to compare the burden of different diseases across the world. If [referring to slide] we look at rheumatoid arthritis we can see that about 1% all DALYs lost in the countries that we have studied are due to RA. Considering that the highest prevalence is probably around 0.6-0.7, this means that the disease has a very strong impact on morbidity but also about 1% on mortality. The impact of the disease is stronger on the morbidity although rheumatoid arthritis does have a higher mortality – patients assume that rheumatoid arthritis has a higher mortality risk than the normal population but it comes very late in the disease so people live with the morbidity for many, many years and that's what we're going to look at.

Health economists prefer the term "QUALY" to "DALY", and I'm not going address why. I'm obviously comfortable with this concept, where we look at the same ideas, we use life years and we adjust them with the patients' or the people's quality of life. [referring to slide] Measured on an index between 0 and 1, where 1 means full health and 0 means death. And if you look at the first column here, you can basically see that rheumatoid arthritis and rheumatic diseases rank really at the bottom. Quality of life of people is severely diminished (you can see only other chronic diseases), but it's not just 0.5. 0.5 might not be so bad. If you want the reference of the 0.5, "blind" is usually rated as about 0.4-0.5 as a comparison. But it's not just that, it's the point that as the disease progresses, this gets really, really bad.

What I have here on this axis is the measure of the functional capacity of RA patients. A patient with a score a score of 0.3 is a patient basically in a wheelchair who can't really use his or her hands, while here there is no or limited disability. And you can just see how on this quality of life index – and we have the mean here; you can see that as the disease progresses, quality of life just plummets very, very severely. There are few diseases where you see the curve going down like this: MS, multiple sclerosis, would have the same type of curve. And it's consistently the same findings. Nobody would believe that the Swedes and the French are the same people but people with rheumatoid arthritis they are, whether they are Swedes or French. It is the same impact on quality of life.

We then try to look at the economic burden of the disease and there is very little data available. For some reason, there seems to be very sketchy data on the cost of RA; only pieces – partial small samples, particular patient groups, particular treatments were analyzed...but not very many studies that have a population sample and look at all costs. So what have we done from the literature? We have taken all studies that we could identify

with acceptable methodology, and we used whatever we could from those studies from any given country and then imputed the costs to countries where there was no data by using economic indicators like wage rates, purchasing power parity, and so forth.

These are not data that we have collected; this is an estimate, using data that are available and imputing them to countries where there is no data, using the economic and health environment of those countries. What do we get? We get an annual cost per patient with rheumatoid arthritis in Europe of about 13,000-13,500 euros per year – clearly very different between Western Europe and Central and Eastern Europe, which you would expect. And you can see that we have one big cost here, which is the indirect cost: productivity losses. People with RA have to leave the workforce earlier than one would like to. If we compare these 13,000 euros, what at first seems quite much is, in fact, quite little; if we compare them with a study that I have also been involved in, in which we looked at the disorders of the brain, you can see that with the 13,000 euros, we are at the higher end of diseases, of brain disorders – exceeded only by, basically, stroke, multiple sclerosis and tumours. But when we consider that patients with strokes and tumours do not have a very long life expectancy after the event, while people with MS or people with RA live 20, 30 or 40 years, you can see that we are talking about a very, very high cost to society.

I've said that the large cost is in the indirect cost and you can see it here presented as a proportion of costs. We have estimated the cost in Europe to be about 45 billion euros, for a little bit fewer than 3 million patients overall. So the big cost is here. How does this cost arise? Just like quality of life, things gets worse as the disease gets worse, in other words, we have the same development: as the functional capacity of the patient decreases, we have costs increasing.

These [*referring to slides*] are healthcare costs, the light blue. The white cost is help by the family. This are things paid by nobody else than the family, not direct non-medical costs. And then we have the indirect costs. And here is where it happens. As patients get in to the middle of the disease, they have to leave the workforce. Early in the disease, they will have to take sick leave, because they have inflammatory periods that simply make it impossible for them to work. Here is where patients have to leave the workforce and you can see here the proportion of indirect costs. In the later stages, it is lower. Why? Clearly, because the disease progression is also correlated with age. So by the time most patients get into these very, very severe stages of the disease, they are also over retirement age. They are over 60 for France, this is a French study, or 65 in normal countries [*laughter from audience*]. Sorry, I couldn't resist. So, how does this come about?

Here is another way to look at exactly at the same problem. Here is, again, the French sample. This is the largest sample we've had to work with; it has 1500 patients, and we have the details of this population sample. Again, grouped by advancing functional capacity – and you can see the proportion of patients under 60, so here are actually people who are of working age in France. Early in the disease, participation is about normal. In the age group 40-60, we should have about 70% of women and men in the workforce. But this is about the norm for a group between 50-60 years of age, which is the patients in this sample. So, many should work; we should have strong participation in jobs at this level. But we have hardly 10%. People with this disease will not be able to continue working. And this is an enormous

loss to society. It is a cost to the pensions system, sure, but that's not the whole story. These people no longer produce, at an age where they should produce more than they consume. When we are 80, we all consume more than we produce. At this age, we should produce more than we consume, and these patients cannot participate at that level. Again, it happens at this level here. *[referring to slides]* We have to keep patients here; we have to keep them at that level, where they can continue to work.

With this I go over simply to end the talk with differences in the update of the biological drugs. The way we have done that, the only data that are available across the world are sales data of the IMS. They have their issues, which I'm not going to discuss here. We have based all our estimates on prices from the manufacturer to the wholesale market and the public – so this is not the price a patient would pay. This is simply because the manufacturer prices in the IMS dataset are quite accurate, while the public prices had a lot of difficulties with them. So, calculating the sales per 100,000 in each country, we could then obviously also use prevalence to look at how many per 100,000 patients.

Before I do that, however, I would like to immediately take one step towards explaining the differences. We have tried to calculate how well different countries could afford these drugs with a type of affordability index. You will find the details in the booklet. What we have done, we have used the health expenditure per capita adjusted to purchasing power parity in each country by the average price (and when I say *price*, I actually mean the annual cost of treating one patient). So we have divided the health expenditure by this unweighted price average. We have used an index where Germany was set to 100, such that a low number means that you can afford it easily, whilst a high index means that you really have difficulty to pay for those drugs. And I show you the difference that we find: we find, with Germany being 100, that most of Western Europe is representing a rather good affordability for those drugs; but clearly when we walk to Central and Eastern Europe, we have a difficulty to pay. The US spends \$6,000 per capita per year on healthcare. Romania, at this end, spends \$600 per capita on healthcare. It is quite obvious that in a system with \$600 per capita, you have less ability to afford innovative drugs than a country with the means to spend \$6,000. And it shows up here that if we invert this curve and look at what share of RA patients are on treatment, we obviously find exactly the opposite curve. We find most patients in the US, then we have Western Europe, then we have Eastern and Central Europe with far more difficulties paying for these treatments. Now this does not explain everything, because although Western European countries really have a similar affordability – they're not that different – we find differences in Western Europe in uptake as well.

So I go over to this now *[referring to slides]*, what you can see here, is the sales series from 2000, first quarter of 2000 to the last quarter of 2006 and this is the sales of these three anti-TNF drugs per 100,000 population, so this is not adjusted to eventual differences in prevalence in the disease. In the US, there's about three times the level of the average of Western Europe. Canada is very much similar to Western Europe and Eastern Europe is at the very bottom.

If we look into the five large markets in Europe, here it is adjusted for prevalence because the prevalence is higher in Northern Europe than it is in Southern Europe. We can see that we're doing well in France and Spain compared to the average of Europe. And we have the

UK, which is difficult to see, and Italy and Germany lagging behind. So although these countries have theoretically about the same levels of affordability, we see enormous differences in uptake. So there are other things at work here. If we look at the smaller European markets (so this is all the smaller European markets), it's actually amazing to see that all small European countries are above the average. Meaning that countries like Germany, Italy and the UK drag the average downwards. The highest are Norway and Sweden; the Scandinavians are very generous with these drugs. They have also assessed the cost effectiveness of these drugs very thoroughly and decided for which patient these drugs are cost effective, and then they get used. So we can maybe see a bit of an effect there.

If we look at Central and Eastern Europe, the picture is scattered. The reason why they jump up and down is because data is sometimes missing for a quarter or so. You can see, I can't even put Europe and the US on this graph because they would kind of hit the ceiling.

So, to conclude, clearly affordability is one of the major factors in the uptake of expensive biological drugs and particularly in Europe where we have single, global prices across Europe to avoid parallel trade. It is difficult for lower income countries to afford those drugs. But this does not explain everything. Prices will update influence; this is perfectly normal and we can see that Germany has a relatively high price. Whereas the US has a relatively low price, so we do have an influence of price. But there is no systematic influence; the difference between Italy and Germany in uptake is very small. But in Europe, Italy has almost the lowest price and Germany has the highest, so we cannot explain those differences. So most of the variation remains unexplained, other than that every country has put in place very stringent rules for which patient group can get access to those treatments: how bad you have to be, how high the inflammation has to be, how many drugs you have to have tried before you can get access to the very effective drugs.

I'm not saying that every patient should get access, by no means. These drugs are not meant for all patients, but there is a large group of 20%, 25-30% of patients that really should have them. So these policies influence things as well. But as a true health economist, for me, the most important thing is that if we want to change that picture, we have to treat early. We have to avoid the costs going up as the disease progresses. We have to keep people in our productive workforce and we have to avoid that their quality of life just plummets to the basement. Early intervention is therefore the key. And that is what I wanted to say here today.

*[applause]*

### **Stephen Pollard**

I'm delighted to welcome our next speaker, Maarten de Wit. Maarten is Vice President of EULAR, representing people with rheumatoid arthritis. He's a tireless campaigner for the issue. As you'll see in his biography, he spends almost all his time representing the rights of the patients and patients with rheumatoid arthritis and will set up a company which is designed to help others to do the same job, which is of course a hugely necessary task. So without further ado, let's hear the patients' perspective.

## **Maarten de Wit**

Thank you very much for the introduction and also of course for the invitation to speak to you. I have changed the title of my presentation slightly, to "Europe's ageing population: healthy and working or still a silent agony?". And in a way, it will be a little bit another case study.

I was really impressed by the first speaker – particularly by the outcomes and the research that she has been doing. It seems this has been an issue that has been neglected for a long time. And maybe because we can't find the right instruments to measure it – but I would like to compliment you on this outcome, with these studies and also with the booklet which is very nice – because you have published in an economic journal but you have also made a layman's publication – and I think that's an example that more researchers should follow, just to make their own outcomes more accessible to patient organizations. These data are absolutely necessary to get a clear picture of the enormous size of the challenge we have to face, which is: how to improve the lives of people affected by rheumatoid arthritis (RA) and how to reduce the huge economic burden on society. And in a way, it sounds a little bit like a paradox, because we have made, as Gisela also introduced to you, major scientific progress in the last decade and we have seen a new generation of effective drugs entering the field of rheumatology.

Let me just say a little bit about my personal background. After 30 years of suffering, I am experiencing the great benefits of these new innovative developments. Before that, my life dramatically changed when confronted with a disease, like psoriatic arthritis. This diagnosis was only made after a period of 7 years of uncertainty and treatment with only pain-killers and physiotherapy. At the time I saw my first rheumatologist, one of my knees was irreversibly damaged and I had my first joint replacement. Ten years ago, as result of continuous joint pain, long lasting stiffness, and a tremendous lack of energy, I had to say farewell to my job and career prospects. In this sense, arthritis is a good case study, I think, for showing the impact of a highly debilitating disease that forces people out of work into early retirement. Until 5 years ago, when I regained a new perspective, starting to use these new drugs made a difference equivalent to day and night. All the work I currently undertake for EULAR, and also for my own association, would not have been possible without these new so-called biologicals.

So let's go back to the first question: How can we improve the quality of life of people with arthritis and prevent them from leaving the labour market and entering a situation of stigmatisation and isolation? It seems the answer is quite easy to give now: Keep the period between first symptoms until referral to a rheumatologist as short as possible. Promote early diagnosis (Gisela also told us that this is the key), educate general practitioners on how to recognize first symptoms of arthritis. Create a quick start of appropriate treatment, make use of the new generation drugs, appoint a sufficient number of rheumatologists and educate them to be more proactive. Don't wait till the first signs of irreversible damage occur. Educate employers; create good work places that provide appropriate ergonomics. And then you will see that they are able to participate in society and, like everybody else, pay taxes; they can live full and independent lives, and their quality of life will not be very different from other healthy persons. So it seems very simple. In conclusion, if you want people to

stay active and productive, the key is, early detection and a quick start of the appropriate treatment.

Well, but why are we not doing this, you might ask? Is it really that simple? Why is there today such an enormous gap between the best possible outcomes and reality? And why do we still accept that there is still this huge economic burden for society?

50-60% of people with RA are unemployed within 10 years. I think this is also shown on one of Gisela's slides. We have the data, not only this latest data. But it's also published by the AAO burden report on musculoskeletal diseases. You can find it in the *Eurobarometer* and also in the report of the *Bone and Joint Decade*, which gave an overview of prevalence and incidence of all musculoskeletal diseases in Europe. But there are barriers, and if you think of an answer to the question, "why don't we just get the rules or the solutions implemented?", then the answer to the question is, of course, because they are so expensive. But the report from Gisela will also show that price is not the only determinant for the use of these new therapies. There are other aspects that we have to take into account. First of all, I would mention, a lack of clear vision and strategy to answer the needs of people's long term conditions. Access to treatments is neither equally guaranteed within the individual European member states, nor between them.

For people that do respond positively to the drugs, we should try harder to achieve equal provision of these drugs all over Europe. It is our duty to make these drugs available to those citizens who are eligible to receive these kinds of treatments. After many decades without any progress at all in the field of rheumatology, it is legitimate to make an extra effort to guarantee good access, to avoid having people ending up in a wheelchair – which was, only 10 years ago, a very realistic prospect for most people with rheumatoid arthritis. So therefore we are extremely happy also with the current written declaration in the European Parliament which is started by Edite Estrela. It includes a call to develop national action plans to fight rheumatism. We support this declaration and, on behalf of EULAR, we also want to offer our help in getting these action plans into place. At the moment we are developing European standards of care for rheumatic diseases, and we will begin with standards of care for rheumatoid arthritis. We believe that this can be a very helpful and powerful tool for national member states to focus their arthritis healthcare policies.

There are other aspects: other than prices and the lack of national action plans, there are uncertainties about the long term side effects. It's not really whether the new drugs are splendid; it is that they are not suitable for everybody. And we're not sure of what the long term side effects may be. This is something new research should give a clearer picture of. A lot of rheumatologists are not used to starting immediately with new therapies of "combination therapies". They are very reluctant to start what we call "very aggressive" therapies. In fact, they see patients going backwards. But we must realize that their reluctance is not justified. Most joint deterioration occurs in the first two years of the disease and therefore a quick start is really the appropriate treatment and this is the key to preventing irreversible joint deformities. And then we have found out that these new drugs are not effective for all patients with RA and other inflammatory diseases. So we need more research into why some people do not respond to this new generation of drugs. We also need to identify new targets and to promote innovative arthritis-specific studies of the

disease – with self-management options and individually tailor-made therapies. Hopefully, there will be cheaper options found in the future.

Of course, it's not only a matter of medicines. Educating general practitioners and establishing so-called "early arthritis clinics" would be a very good thing to do. Early arthritis clinics are clinics set up by rheumatologists where general practitioners can send people with first symptoms directly to a specialized rheumatology centre and they will be seen, for example, within two weeks. Ergonomic adjustments in the workplace are often not considered; rehabilitation programs and – specifically in my country, the Netherlands, they are not always successful, specifically because they don't take into account that people with arthritis do have specific ergonomics needs that differ from those of other patients.

So, what could the European Union and its member states do, to increase the quality of life of people with musculoskeletal diseases – as we saw also on one of Gisela's slides, one of the most debilitating of all chronic conditions? How can we enable people with arthritis to remain in the labour market? One might think about following recommendations, providing appropriate access to treatments – for example, by promoting the establishment of national strategies for improving the arthritis healthcare provision as stated also in the written declaration that's now before Parliament. This also includes support of the development of standards of care for rheumatic diseases in which early diagnosis, a fast start of therapy and an expansion of the number of rheumatologists as well as orthopaedic surgeons will be prominent targets. Promote innovative research for new, effective treatments – not only for RA, but also for other rheumatic conditions like osteoarthritis.

Well, this is what I've said: start educational programs for RA, to go or to stay at work; self management programs. We should also think about more flexibility in work contracts than we have now. People with chronic diseases, as you know, their energy levels, but also their limitations – they need to be able to influence their own working conditions, and by creating more flexibility in working contracts, they can achieve this. Think about tailored working, e-working, etc. And then of course, establish networks of support groups and self-help groups. In a lot of countries, organizations are taking over this role; they support and start their own rehabilitation program for their members. And last, abandon stigmatisation and discrimination by new legislation. And that has also to do, of course, with raising awareness of the whole problem that we are facing. In conclusion, and with these recommendations, I hope to have shown you that many rheumatic diseases like RA are nowadays avoidable causes of disability and early retirement. I can work again full time and I enjoy life within certain limitations. I also wish that people with rheumatic diseases could experience the same benefits.

Thank you for your attention.

*[applause]*

## Q&A

---

### **Stephen Pollard**

Thank you very much for that, Maarten. I'm sure it's given rise to a number of questions and thoughts and so on. This is where I get to pretend to be Jerry Springer and walk around with a microphone.

Perhaps, if people have question and comments, if they can just indicate and I'll wander over and if you can just say who you are and where you're from as well, that would be helpful, please. So who'd like to kick off?

### **Question**

Somebody needs to kick off. Congratulations on your speeches. I'm Paul de Raeve, secretary-general of European Federation of Nurses (EFN), representing more or less 2 million nurses in Brussels. First of all to the organizers: In fact, I was thinking that my secretary gave me the wrong documents for the meeting. I read here: "Europe's ageing population". I'm little bit confused in this context to discuss this issue, and I think it's a shame that you classed it within an ageing population. In my environment, I have very young colleagues who have arthritis and they are totally out of possibilities, because we think that it is only for older people. So I want to get rid of that stigma and if you're giving this stigma already in this conference, then I'm very confused about this.

The other thing that I would like to say is, I feel a little puzzled with, and I can understand where you're coming from, but if you really want to make progress in health system reform – and I'm looking forward to WHO on that, because national plans – if you go to the Parliament and you go to the Commission and you see all these civil servants from all the DGs going back home with national plans, I think they become crazy a little bit. And I'm wondering if that is the real toolkit to make progress. I'm not 100% sure about that. But nevertheless, if WHO succeeds in taking health system reforms further, what I didn't hear in your speech, both of you, is the move from diagnosis and treatment to the concept of continuity of care. You highlighted a little bit at one point that families take over some care, but what about access to care? Why are families taking over? Why are not only the patients staying at home but also family members staying at home? Because there is no other choice. So it's about accessibility, and I don't want to make reference to the US because we don't want the same model in Europe as the US model, which is advertising and selling. This brings me to the last question: which companies are selling these medications? I don't have a clue and I want to know.

### **Gisela Kobelt**

That's the easy part to answer. The first drug that was launched is Etanercept, at the time of launch in the mid 90s, it was Immunex which then got purchased by Amgen, but in Europe, it's put on the market by Wyeth. Then we have Infliximab, also called Remicade, which is marketed in Europe by Schering-Plough. The originator of the drug is a biotech company in the US called Centocor, which is used for sales in the US whereas in Europe, it's sold under

license by Schering-Plough. The third one, Humira (or Adalimumab) is from Abbott, who markets it worldwide.

The drugs not involved here are not TNF inhibitors and they are, say, the next step. Currently, those two drugs, one is Rituximab or MabThera, which is from Roche, which is basically a drug which has been used in oncology, NHL and lymphomas and it has moved successfully into this arena but we don't have the data on this drug in our data set. The latest one to be approved is from Bristol-Myers.

I think most of your first part of the question is probably most addressed to the organizers. I have to admit that that most people get it (RA) around the age of 45, which I consider young. You got it earlier. You have many getting it much earlier, absolutely, but let's say the average is around 45 so that hits people full in their workforce, so it's a point well taken. We should stay away from saying this is a ladies disease and it's old age and therefore it will disappear. It doesn't. It is young people, it is active people, and we should put it on the map as such, I fully agree. I can give you an example I didn't mention, it's obviously one determinants of access that we will – this report is the first step. The easy parts to analyze are clearly the economic parameters; you can analyze determinants of access using economic parameters. The direct impact of the access to care is much more difficult to analyze in all those many, many countries that we have in the report. But it is clear that is has, for instance in France, where there is very good access, we have one rheumatologist for 150 patients, or about 1 per 30,000-35,000 population. In Germany, it's 1 per 300,000 of population, so there are far fewer rheumatologists in Germany – which explains part of the problem of the diagnosis.

To your last point, I think the family, that's another point very well taken, that's also on our agenda for more analysis. Why does the family have to take over? I can give you an example of a study we have run on multiple sclerosis with data from 10 Western European countries, that's 16,000 patients. We've actually looked at how much family health they require. And you can spot differences. It was a cross section study, so you cannot look for causalities, you cannot pretend that something is like this because something has happened in the past. You can only observe what there is. But what I would say is, for instance, the Swedish and Swiss systems provide much more help to handicapped people than the other countries in our sample. It can't be an accident that then when we look at how many stay in the workforce after 10 years of the disease, it's more in Sweden and Switzerland than in the other countries. So there's a relationship which needs further analysis, it's just a first step.

### **Maarten de Wit**

Well, to come back to the title, I had at first the same question: Ageing, but it's about ageing and employment and staying at work. So, I interpreted this as we're talking about people between, who are in a working age, and looking at rheumatic diseases, there are a lot of people, in the age of 25 and 65, that are affected, so... and I fully agree of course, that we don't like the suggestion that RA or rheumatic diseases are elderly diseases.

There are more things that I have not spoken about and you are quite right about. If we are talking about access to care, I think we should also mention the benefits of working with multi-disciplinary teams. These are now starting in hospitals. But also on the first line of

care, we see there is a growing role of nurses, whether they work with general practitioners or whether they work independently, there is a growing role in the care for people with RA for what we also call the “lighthouse professionals”. And to come back on your suggestion, and I’m very interested in hearing your opinion about this further – you said: “I don’t know whether the national action plans are the most appropriate means to get the health system changing”). And we are looking for ways. I think the written declaration is an initiative. In the UK for example, my impression is that they have now a very good strategic plan to fight rheumatism, accepted by the government. I think this is quite unique, this happened, if I am well informed, it happened last year, 2007. And it’s quite unique that the government should announce a national strategy to fight against rheumatism and come with concrete action. So I would like to see this happen in more countries.

### **Stephen Pollard**

If I can just explain the title: if you have a look at our website, for the last two years we’ve had a program called “Healthy ageing, Europe’s ageing population”. And this is simply one part of our program, it is a rubric. And this is an issue which is of relevance to Europe’s ageing population. I know full well that’s an issue for people who aren’t ageing, I’ve suffered from a mild form of arthritis since I was ten, so I don’t need to be told that it’s just for elderly people.

### **Gisela Kobelt**

I think there is a drug on the way of being launched, hyaluronic acid, which is fundamentally the old protein used in the cataract surgeries. So it’s a very large viscoelastic molecule that, I must say, was originally developed for racing horses (for helping the joints of racing horses). And it has only been launched in Europe, whether there were other treatments before... [inaudible] ...there’s probably not much data available. But also, it’s not really used in RA, it’s used in osteoarthritis.

### **Question**

I am David Magnusson from the Swedish Rheumatism association. I agree with you that it is more in the osteoarthritis, and I know that we are working on it in Sweden and that some are for it (and some are against it). There is some research going on. There are similar kinds of cases in glucosamine, and they haven’t agreed whether it’s good or not. It’s like normal research, which takes some time until you have the data to see if it’s really valid. When you can compare patient groups having the treatment and those who haven’t, only then you can get exact results, and that takes some years.

I think that your comment that the family is important, but Maarten’s point was very good. He pointed out that today there exists a new treatment, of biologics. And why wait using them? Because they have solved some of the family problem – I’ve seen Swedish patients being very affected by this rheumatic arthritis and seen them after 1 or 2 injections; they are like a new man. On the patients on whom it works, you have to have an infection which is active, so not everyone is helped by it. So we can do that today, we don’t have to wait for that. We can get them back to work. So if you look at, for instance, Sweden, it’s very interesting that Gisela had noticed in her research that we have accepted this; it’s cost effective, this is not a burden, this is an investment. Because if we were like a machine in a factory, every factory would use this drug as it would see that this machine is now

producing, not standing there and gaining dust and not producing. So I think we have to see people more like an investment and not always seeing the burden and the cost. Because they are really an investment in the future.

### **Question**

Thank you, I'm Rob Anderson from the European foundation in Dublin, and I'm delighted to see so much data being presented. But I feel sometimes, it leaves me with more questions than answers – which is what you might expect from some of the global data that you have. I would have thought in your presentation that you might have given us an estimate of the relationship between the expenditure on drugs and the benefits in terms of reduced costs of lost productivity and employment. But when I look at table 5 with data from Sweden, I see that half of all the costs in Sweden are indirect costs. And if these are workplace costs, that's interesting. It's a much lower proportion in France. My question is, of course, what kind of data do we have on the relationship between the use of these drugs and total indirect cost? If indeed, indirect costs are a good measure of lost productivity and employment. Because I don't really know what goes into indirect costs.

I think though, it is very important to acknowledge that the proportion of costs – or even the absolute costs – in the different European countries are very different for different items, and you've highlighted the difference in costs of drugs in different countries. I think we can also highlight the difference in indirect costs in different countries and ask why that may be the case.

I will conclude by saying that we've done quite a lot of work, looking at measures for retention in employment of people with chronic health problems and reintegration to employment for people with chronic health problems. And what you see are vast differences between the member states in the amount of energy that they put into reintegration. I think the two messages are very much like those of the last speaker: first of all, whatever can be said about treatment, attitudes to retention of employment of people when they get chronic illnesses are in the dark ages, they are overwhelmingly negative. They are full of low expectations on the part of employers and also people who get the condition, and also of many professional workers. So these positive actions that need to be taken, to respond to the diagnosis, to respond to the illness, are not being taken. People are not given the opportunities to stay at work. They're being given the option of incapacity benefit and a long exclusion from employment. Secondly, when actions are being taken – reference was just made to multidisciplinary teams – they do need to be coordinated in relation to employment. Bringing together people from the health and rehabilitation arena with employment guidance and employers, what we find is that coordination, often, doesn't work at all well, because the bridges between work place and life outside work are very weak.

### **Gisela Kobelt**

I didn't really want to bore you technically with the indirect costs, but you are obviously correct. We have them estimated for all countries; I'll try to take it in the order that you mentioned them. But first I think your point was also correct: why haven't we talked about this before? I did my first study on RA in '92 and since '92, I've been running around on every presentation on every congress, talking about productivity losses that are the driver

and that we should work. But it was the beginning and I think it was probably this aspect, of this being a disease of rather over 50s and 60s so we have no chance to do something about it. And we didn't. Until the biologicals, we literally didn't. I think two things have happened medically, and I'm not a physician, so I don't want to comment too much but what I have actually witnessed in the last five years is rejuvenation of cortisone and methotrexate, which, through developing the biologicals, in the clinical trials, have almost been redeveloped as drugs for RA. They work extremely well when given to the right patient, either in combination or not. And all of this has changed today. 15 years ago, telling a patient they had RA was like a death sentence, it's a horrible thing to get. But today, you're going to live with disability for many, many years to come. Today, that's totally different, today, there's actually a way to avoid those disabilities. We get patients into remission, into complete remission. So that's what has changed. Now, suddenly, we do think that we have means to affect productivity losses. So it may explain why things haven't really happened so much in the past, being at the European or at the member state level. This is my theory; I have no proof for what I'm saying. Retirement costs, I mean, indirect costs are different for each country for a number of reasons. One reason is they're obviously lower in France, because France has a retirement age of 60. In Germany, indirect costs are higher with a retirement age of 67, basically many more potential work years that you lose if you have to go out of the workforce at 55. So that's one of the big differences. Then obviously, there's the income level which also makes a difference, because indirect productivity losses are based on the national average wage rate in general. So those are the two things.

You talked about whether we can measure the effects of these drugs. I think we're not far from doing so. Because, if you remember, that's why all my slides are structured by progression and disease severity, because we have to see patients not developing the severe disability in order to be able to measure that they stay in the workforce. That takes years, it takes some time and I think with the registries that we're starting to analyze, what we can say today, the sick leave and early disease, get dramatically reduced, so patients on these short terms, 3-4 weeks, they have to leave the workforce for inflammatory bouts, they are very much reduced. They however will not offset the cost of those drugs, clearly.

When I did my first study with the Swedish registry to see what happens with patients who get those drugs, those were the very first patients. They did tremendously well. I have not (I work across all diseases, so RA is only one of the areas of my work), I have never, ever seen a quality of life improvement of that magnitude in year one. We're talking about something of 0.3 on a scale between 0 to 1, which is huge. You don't see that in other diseases. Yet, we couldn't show a difference in the productivity gains in one year. First, it was too short. Second, those patients who got those drugs were the very, very severe cases with 20 years of the disease, who had been on invalidity pensions 10 years. They were 55, 57 and 62 years old. Nobody wanted them back in the work market. It wasn't the disease that stopped them from going back; they could have. But there was no job. Because in all those years they had been out of the job; the work place had changed; their qualifications were no longer adequate; they had the wrong qualifications; they had not been able to keep up with the developments in the areas of their expertise. This is why I'm saying we've got to avoid them getting out of the workforce. That is where we have the effect. To measure the data for this, we have to have 10 years, to see it. I think we're not far from being able to show that it's moving in the right direction.

**Stephen Pollard**

Maarten, do you want a final word?

**Maarten de Wit**

To your last remark, also about the way that the workplace is quite isolated from the healthcare system, I think that's something that we also see in the Netherlands and I would support also the suggestion – I don't know if you have experience with this – that clinicians from hospitals, caregivers, health insurance consultants work in a more multi-disciplinary way, to create good conditions around the working place. I am not aware of rheumatologists going into companies just to look at the working place of his or her patients. But probably, if you take expertise within ergonomics, physiotherapists, just to look what is needed in this situation to stay at work. I think we should do some experiments around this. I know there are some, but they are rarely done and introduced more broadly.

**Stephen Pollard**

Thank you very much for coming.

I'd like to thank our two speakers for coming over and giving us such a fascinating talk with so many different shades of light on the issue. I've certainly learnt an enormous amount about it. And I'd also like to thank Roche for their donation to CNE, which has enabled this meeting to take place, so thank you very much to them. Hopefully, I'll see you all at a future CNE health event. Thank you for coming and thank you to our speakers again.

*[applause]*

*[end]*