Andrew Dillon: Apologised for delays in sight-saving drugs

The head of the NHS rationing watchdog has said he is 'genuinely sorry' for a delay in approving a new treatment for blindness.

But campaigners said Andrew Dillon's comments would be of little consolation to the thousands of Britons who have lost their sight in the two years it took NICE to make its final decision.

The watchdog has now approved Lucentis, which is used to treat wet age-related macular degeneration, a condition which affects 26,000 new sufferers every year.
NICE's original recommendation was that patients had to wait until they went blind in one eye before they would be given treatment to save the sight in the other.

The proposal caused a huge public outcry from doctors and campaigners, prompting a U-turn in December last year before further consultation resulted in the final decision today.

Mr Dillon, the chief executive of NICE, seemed to blame these protests for slowing the decision to make Lucentis more widely available.

He claimed that because NICE's rulings were not made behind 'closed doors' and were open to being challenged, lengthy delays often occurred.

But campaigners said the procrastination, which potentially cost the sight of 50 patients a day, was not their fault.

The Royal College of Ophthalmologists said the latest guidance was nearly identical to the suggestions it made two years ago and campaign groups pointed out that without their intervention, NICE might never have overturned its original decision.

Winfried Amoaku, of the Royal College, said: 'It has taken over two years for NICE to formally consult stakeholders on each stage of its deliberations - after which they have implemented all but one of the recommendations made by the College in its original submission in August 2006.

'In that time, around 50,000 patients have been diagnosed - and many hundreds of patients have gone blind - some of them needlessly.'

Tom Bremridge, of the Macular Disease Society, said: 'Those responsible for NICE should be aware that during the cumbersome two-year review process, 152 PCTs have individually had the power to decide whether to let patients go blind or to save their sight.

'The resulting stress and suffering has been cruel and unnecessary.'

Mr Dillon told the BBC Radio Four's Today programme that it was important that all parties had the opportunity to have their say.

He said: 'Everybody involved needs to look back to see if there was anything they could have done to have speeded up the process.

'It would be very easy to make decisions behind closed doors. Nobody would find that acceptable.'

'Once you start consulting, once you start giving people the opportunity to appeal, all these things add time.'
Victim: Joan Armstrong, 82, has been refused sight-saving drugs four times

But Steve Winyard of the Royal Institute of Blind People (RNIB) said: 'These are warm words from NICE but we now need action.

'The process is far too slow and thousands of people have gone blind unnecessarily because of this long wait. It put people in the impossible position of paying for private treatment or going blind, and understandably many were very upset and frustrated.'

He added: 'We asked NICE why there were long periods when nothing was happening, but never got a clear answer.

'At times things moved at a snail's pace and we'd like to see real urgency in the process. Our evidence and responses to consultation were delivered on time and it's difficult to see what lessons we have to learn.'

RAF war veteran Dennis Devier, who has very limited sight after being refused Lucentis when he started to go blind two years ago, also criticised the apology from Mr Dillon.

The 85-year-old from Henley-on-Thames in Oxfordshire, who is a full-time carer for his wife Frances, paid £10,000 to have the injections privately after a fundraising campaign by his local newspaper.

He lost sight in his left eye in 1994 due to wet AMD and was diagnosed with the condition in his right eye in May 2006.

He said yesterday: 'It's all very well to apologise now, but it's too late for those of us who have now lost their sight.

'While I was appealing the PCT's decision not to give me the injections on the NHS, I lost a crucial three
The new guidance recommends that all patients in England be offered Lucentis, which is already available in Scotland.

However, NICE has dismissed an appeal by drug maker Pfizer to fund NHS treatment with an alternative treatment called Macugen, for patients sensitive or allergic to Lucentis.

Mr Amoaku said: 'This unfairly penalises the 3 per cent of wet AMD patients who may be allergic to Lucentis, where a reaction to the drug can cause additional damage to the retina.'

The U-turn comes with an agreement between NICE and the drug's manufacturer Novartis which means the NHS funds only 14 injections of Lucentis, with the cost of further treatment topped up by the company.

This could increase pressure on the Government to remove restrictions on patients who pay privately for drugs on top of their NHS care.

• 'My wife has suffered while NICE dithers', says Major-General Bill Whalley

When my wife, Mary, was told in February that she had a condition that could blind her within months, we were horrified.

But we were assured that there were drugs that could deal with the condition and we were confident that the NHS, of which we have always been proud, would swing into action and see us through.

Loser in the health lottery: Mary Whalley, who needs the drug Lucentis, with her husband Bill

How wrong we were. What we have discovered is that Britain's brilliant doctors have their hands tied by bureaucracy, bureaucracy that costs some their sight, and others their lives.

There are 26,000 new cases of my wife's condition - wet age-related macular degeneration - every year.
Thankfully, the blindness it causes can be averted with a highly-effective drug, Lucentis.

The bad news is that this drug, so badly needed by my wife and thousands of others, was only made available to all yesterday.

Not because of clinical trials or even waiting lists, but simply because it has taken the National Institute for Health and Clinical Excellence more than two years to decide to compel our primary care trusts to supply it.

Unfortunately, in the absence of meaningful guidance from NICE - as has been the case with Lucentis - a postcode lottery is created as PCTs make their own decisions on whether to prescribe.

My wife was a loser in this lottery. While our neighbouring trust of Sandwell has been supplying Lucentis since January 2007, our local PCT, Birmingham East and North, has not. And my wife has suffered as a result.

Her sight has deteriorated over the months we have been waiting, but not nearly as quickly as it might have done. Wet AMD can blind you in as little as three months.

Many will not have been as fortunate and it is quite clear that the blame for that lies at the door of NICE.

Now Mary will finally get her sight-saving treatment. She can no longer see faces on the television, but with luck, she will not lose her sight completely.

When my wife was diagnosed with macular degeneration, our consultant at the Good Hope Hospital in Sutton Coldfield immediately prescribed Lucentis.

But her expert medical judgment was thwarted by a committee of bureaucrats at our PCT who wanted to save money and had been given the loophole to do so by NICE’s indecision.

But it's not just NICE’s fault. The PCTs also play a part in this debacle and often seem more interested in saving money and allocating funds to their own pet projects than helping patients.

Indeed, our PCT, which apparently didn't have enough money to save my wife's sight, has recently launched a £250,000 programme to educate its obese staff about overeating.

More than 200 of its employees will get pedometers and personal trainers. This is outrageous.

I am 78 now. I spent 38 years in the Royal Army Ordnance Corps. During that time my wife put her heart into voluntary work with Army wives and families and when I retired she continued to do voluntary work for Oxfam.

We believe in putting time and effort into society. But what happens when my wife needs something back?

Nothing. Huge amounts of money are poured into a swelling health bureaucracy that devours money which should be spent on patient care and also decides who gets what treatment, on financial and not medical grounds.
At the top of this bureaucratic heap sits NICE.

It is reckoned that during the two years that NICE has contemplated whether or not we can afford Lucentis, 20,000 have lost their sight.

It's an inhuman price for a system that puts paper-pushing above care, and apparently puts money above the one thing the whole institution was set up to protect: the patient.

• NICE was also under fire from terminally ill patients yesterday - for blocking drugs to treat advanced kidney cancer.

A 50-strong group of sufferers and their families, some in wheelchairs, staged a protest at central London headquarters of the National Institute of Clinical Excellence (NICE).

Four drugs which slow the progression of renal cancer will not be available on the NHS, Nice announced earlier this month.

The demonstrators said they felt 'angry and abandoned' after meeting with chief executive Andrew Dillon as part of the consultation process.

Protest organiser Clive Stone, from Witney, Oxfordshire, said: 'My personal message to him was that I'm dying and he's taking any hope away from me. I'm appalled.

'These drugs have been known to extend life for at least two years. Without that we're gonners. There's nothing else.'

Nice ruled that the medicines - Sutent, Avastin, Nexvar and Torisel - only extend a patient's life by an average of five to six months.

They therefore cost six times the NHS budgeting limit of £30,000 per patient per year, the committee said.

A group of 26 oncologists said in a letter to the Sunday Times that they were 'dismayed' by the ruling over the drugs, which are freely available in other countries.
Too late: After thousands of patients needlessly go blind, NICE boss says sorry for delays...