EQUALITY IMPACT SCREENING ASSESSMENT

Multiple Sclerosis Risk Sharing Scheme

The Multiple Sclerosis (MS) Risk Sharing Scheme (MS RSS) was agreed in February 2002 with the relevant patient and professional groups and the manufacturers of 4 disease-modifying treatments (DMTs) for MS.

The purpose of the scheme is to secure the provision of these treatments to patients in the UK, despite earlier concerns from NICE that they were not cost-effective at their existing UK prices. The scheme has two key elements:

i an initial cut in the UK price for 3 of the 4 products;

ii an agreement to monitor the actual benefits achieved by the 4 products over a ten-year period, in terms of their impact in slowing disease progression, compared with the expected benefits estimated using the economic model used by NICE. Actual and expected benefits are compared every 2 years and if there is a significant shortfall in actual compared to expected benefit for a particular product, the price of that product is reduced for the following 2-year period.

Around 12,000 people are now being treated under the scheme, and data are collected from a cohort of over 5,500 patients from around 70 UK prescribing centres. The monitoring data is collected by the MS prescribing centres, and collated and analysed by a "scheme coordinator", Parexel Ltd, a contract research company. The contract with Parexel is held, on behalf of the scheme partners (4 pharmaceutical companies and the UK health departments), by the MS Trust, a small charitable research organisation.

The first analysis of scheme data has been completed and a paper interpreting the results was published in the British Medical Journal on 2 December 2009. It concludes that it is premature to reach any conclusion about the cost-effectiveness of the drugs used to treat relapsing remitting MS from this first analysis. The independent Scientific Advisory Group, which provides advice to the scheme, is taking steps to address several important methodological issues which it is hoped will lead to more meaningful results at the next analysis.

Negative impact

We do not expect the risk-sharing scheme or the associated monitoring and analysis of anonymised patient data to have negative effects or impact on the six equality strands, namely, race, gender, disability, age, religion/belief and sexual orientation.

The risk-sharing scheme gives persons with relapsing-remitting MS eligibility for NHS treatment if their consultant says they meet the criteria set out in professional guidelines produced by the Association of British Neurologists. All eligible patients are treated, but a cohort of patients are monitored to assess the cost-effectiveness of the drugs. The scheme is effectively an observational study conducted as part of routine clinical practice. It has ethics committee approval.

Positive impact

The scheme is designed to provide access to NHS treatment for people with relapsing-remitting MS, and do so cost-effectively. In assessing the cost-effectiveness of the treatments we do not consider that the scheme will have any impact on existing inequalities – cost-effectiveness will be achieved by modulating the drugs prices; patients will not be affected.

The scheme has provided around 12,000 people with relapsing remitting MS, and in some cases with secondary progressive MS, access to the drugs they require in a cost-effective manner.

The Multiple Sclerosis International Foundation (www.msif.org) say that MS is at least two to three times more common in women than in men. Data from the MS Risk Sharing Scheme confirms this, showing that in the monitoring cohort the disease is three times more common in women than in men.

From the outset of the scheme information on the ethnicity of those patients in the monitoring cohort has not been collected and it is now considered too costly to do so. The MS Trust are a charity who are heavily involved with the Scheme. They are very confident that there is no discrimination by neurology departments on grounds of ethnicity, against patients who require access to drugs that are part of the scheme.

We understand that there is no backlog of patients waiting to receive treatment for their MS with any of the drugs included in the scheme.

The scheme has strengthened the development of a UK-wide network of over 70 MS specialist treatment centres. This has improved the care and support available to people with MS. The scheme has also led to an increase in the number of MS specialist nurses in the UK to over 200. Funding from the scheme has been used to support the creation of many of these posts.

The Multiple Sclerosis Trust is a member of the scheme's 'Steering Group', overseeing the implementation of the scheme. We keep in regular contact with them, addressing any issues they raise as best as we are able. To date they have voiced no concerns about the way in which the Scheme has been managed and access to the drugs.

Evidence

The attached health service circular (HSC 2002/004) sets out the background and purpose of the scheme.

More than 85,000 people in the UK have MS. A study in 2009 suggested it may be about 100,000. There are three main types of MS: relapsing remitting; primary progressive; and secondary progressive. It is not always clear what type of MS someone has, particularly when newly diagnosed and regardless of the type, health professionals will base symptom management on individual needs. For this reason it is not possible to say how many people with relapsing remitting MS are on the scheme.

The first analysis of scheme data was published in the British Medical Journal on 2 December 2009. The authors of the paper have concluded that it is too early to say, in a long-term study of this type, whether the drugs are cost-effective (or not). The next analysis of data will take place in Spring 2010.

Screening assessment

In light of the above assessment we have concluded that the risk-sharing scheme will have no impact, either positive or negative, on barriers or equalities that might currently exist. Therefore, we do not consider that the policy requires full equality impact assessment.