Systematic review of treatment of dry age-related macular degeneration and Stargardt's disease

Record Status
This is a bibliographic record of an ongoing health technology assessment being undertaken by a member of INAHTA. Links to the published report and any other relevant documentation will be added when available.

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Authors' objectives
As the Macular Society website says, age-related macular degeneration (AMD) is the commonest cause of visual impairment and blindness in the UK. The macula is part of the retina at the back of the eye. It is responsible for our central vision, most of our colour vision and the fine detail of what we see. The macula has a very high concentration of photoreceptor cells - the cells which detect light. They send signals to the brain which interprets them as images. AMD usually affects people over 60 but can happen earlier. In the UK over 600,000 people are affected. About half are registered as visually impaired. Macular degeneration affects different people in different ways. They may not notice any change in vision during the early stages. However, as macular cells deteriorate, the ability to see clearly changes. Straight lines such as door frames and lampposts may appear distorted or bent. Vision may become blurry or develop gaps. Objects in front of people may change shape, size colour or seem to move or disappear. Dark spots like a smudge on glasses could appear in the centre of vision. It may be difficult to recognise faces, read, watch TV, or read bus signs. The term macular dystrophies covers a large number of rare, inherited conditions. They can appear in childhood but they are often not diagnosed until later in life. They are a result of faulty genes inherited from one or both parents. Juvenile macular dystrophies cause the loss of central vision as a result of damage to the macula, the most sensitive part of the retina. Stargardt disease is one of the most common forms of macular dystrophies. AMD starts with fatty deposits in the eye called drusen and can then progress to two advanced forms dry AMD and wet AMD. Wet means that abnormal new blood vessels develop. It can be treated, usually with drugs injected into the eye. However at present only one treatment has been proven to be help at all in dry AMD. That is nutritional supplementation with the AREDS2 formula which delays progression by 25% over 5 years. So there is a great need for effective treatments in dry AMD. About 40 treatments have been suggested, including a lot of different drugs, and a range of physical treatments including lasers. There are very few good quality trials. We need those to see if the treatments really work or not, and if they work, to see what side-effects they might have. Some of the suggested treatments sound too good to be true, but are publicised on the Internet. We need to provide unbiased information for people desperate to find a treatment. The Health Technology Assessment Programme commissions research to meet the needs of the NHS. This research include clinical trials. But before the HTA Programme commissions any trials, it looks for a thorough review of all the existing evidence to see what is already known, and to identify research priorities. The aim of this proposal is to review emerging treatments for dry AMD and Stargardt's disease in order to see which looks most promising for testing in clinical trials. The bid is being submitted jointly by academic researchers and the Macular Disease Society. If successful, the main result would be information to help the HTA Programme decide on which trials to commission, but there would also be a report on the Macular Society website to give people reliable information. By 2017, NICE will develop a clinical guideline for AMD, but that will not cover experimental treatments

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