



HQIP

Healthcare Quality
Improvement Partnership



BRITISH SOCIETY OF
GASTROENTEROLOGY

UK Multicentre Autoimmune Hepatitis (AIH) Outcome Audit

AIH is a chronic non-infectious liver disease. It affects both women and men, people all ages and races and has nothing to do with lifestyle. Although it can usually be treated successfully, it may sometimes progress to liver cirrhosis and may even result occasionally in the need for a liver transplant.

We are conducting the first audit of management and outcome of AIH over a large part of the UK. The Audit is coordinated by Dr Vikki Gordon (Clinical Fellow) and Professor Dermot Gleeson (Consultant Hepatologist) of Sheffield Teaching Hospitals. It already includes 29 hospitals (see list below). We would like extend it across the whole of the UK but are currently resource-limited (we currently have some funding from the Health Quality Improvement Partnership and the British Society of Gastroenterology and are looking at further funding sources).

There is a real need for a project like this audit as only a few hospitals have published their experience of treating AIH. We hope our audit will provide more comprehensive information regarding management, outcome and patient experience of AIH in the UK.

We hope to include every patient with AIH diagnosed since January 2000 to date who is currently being looked after at each of the participating hospitals. We will look at how patients did on treatment and how often they needed a liver transplant. We also hope to ask patients what their experience has been with regard to quality of life.

Having identified patients and confirmed the diagnosis of AIH we then ask to hospitals to enter data relating to initial severity of AIH, treatment and outcome into a web-based system (which can only be accessed via a hospital-specific password). No patients name, hospital number or 'identifiers' are entered; thus the information is anonymous.

We have been given permission to conduct the audit without seeking prior permission from patients, as each centre is in effect, auditing its own practice. However, all patients currently attending a participating hospital diagnosed since 2000 should be receiving an information letter from their Consultant and have the right to "opt out" should they wish (although obviously, we hope very much that they will participate).

Thus, from a patient's perspective, all that is needed is that they (a) allow their local Hospital team to extract information relevant to their AIH from their records and enter it **anonymously** it into a secure database and (b) fill out two questionnaires on how they are feeling.

We are including in the Audit only patients who are currently over 18 years and who were diagnosed with AIH since 2000. The reason for excluding patients diagnosed before then is purely a practical one. We have found that it is increasingly difficult to extract information from the notes the further back in time one goes. Thus, given our currently limited resources, we have decided not to go back prior to 2000 and we are very sorry that some patients thus might feel excluded from the process.

The Audit took much longer to get underway than anticipated, however data entry has now commenced in 15 of centres and we anticipate others will start over the next few weeks.

We are very keen to make patients with AIH aware that this Audit has started, especially if they have been diagnosed since 2000 and are receiving their hospital care from one of the hospitals participating in the Audit. If so, they should be getting an information letter over the next few months. Indeed if they do not, we would encourage patients to contact their local hospital consultant (unless of course they don't wish to participate).

If patients (or carers) have any questions about this audit they are welcome to e mail us and we would be happy to try and answer them.

Dr Vikki Gordon (Clinical Fellow)

Victoria.gordon@sth.nhs.uk

Prof Dermot Gleeson (Professor of Hepatology)

Dermot.gleeson@sth.nhs.uk

Hospitals Involved - 29

