Background

- Childhood HPATs are complex and very rare, so experience in any single centre is limited.
- Their high survival carries with it high neuroendocrine morbidity.
- As there is currently no evidence-base, treatment is individualised on a case basis according to consensus (2005) guidance (ref 1).

Hypothesis: Centralised care or wider multi-professional decision making may improve neuroendocrine and visual outcomes.

- In 2011, a 6-month national HPAI advisory group pilot, was set up with a view to acquiring funding for centralising care from the UK Department of Health.
- Though centralisation was not ultimately funded, the pilot was well received.
- The Northern (Liverpool/Manchester) and Southern (London) 3-centre HPAI meetings subsequently continued independently, adding more national and international centres (Ireland and Australia) to their virtual meetings.

Aims

1. To facilitate multi-professional dialogue across centres nationally (including adult pituitary specialists) in a videoconference format.
2. To enhance diagnostic and treatment decision-making through education and sharing audits, knowledge and experience.

Methods

- Initially we undertook regular, minute monthly videoconference meetings between as many as 25 professionals across 3 sites. Multi-professional attendance at one meeting is shown on the right. Over the next few years, more centres and specialties.
- Despite significant high level IT input at all 3 sites and a (20k) IP based system at GOS, facilitating the provision of a live video conference with simultaneous high quality imaging initially proved challenging. These issues were subsequently resolved with time, with localized Cisco MCU in conjunction with ISDN Gateway.

Case summaries Table 2

<table>
<thead>
<tr>
<th>No.</th>
<th>Number of cases</th>
<th>Position</th>
<th>Diagnosis and Initial Work-up</th>
<th>Diagnosis and Viability of Endocrine/Diagnostic Indices</th>
<th>Diagnostic and Post HMI Management</th>
<th>Outcomes of HMI Meeting</th>
<th>Pilot HMI Meeting Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.5</td>
<td>18</td>
<td>Superintendent</td>
<td>table 1 (right)</td>
<td>Table 2 (right)</td>
<td>Table 3 (right)</td>
<td>Table 4 (right)</td>
<td>Table 5 (right)</td>
</tr>
<tr>
<td>1.5</td>
<td>18</td>
<td>Superintendent</td>
<td>Table 1 (left)</td>
<td>Table 2 (left)</td>
<td>Table 3 (left)</td>
<td>Table 4 (left)</td>
<td>Table 5 (left)</td>
</tr>
<tr>
<td>1.5</td>
<td>18</td>
<td>Superintendent</td>
<td>Table 1 (middle)</td>
<td>Table 2 (middle)</td>
<td>Table 3 (middle)</td>
<td>Table 4 (middle)</td>
<td>Table 5 (middle)</td>
</tr>
</tbody>
</table>

Results

- In 27 meetings spanning 2.5 years.
- 67 HAPIT clinical cases (including quality imaging) were discussed in relation to formulating management plans (Table 1).
- 16 discussed on multiple occasions.
- Table 2 shows type of cases discussed, questions posed & decision outcomes in 10 craniopharyngioma cases (most common tumour type discussed).
- In the first 7 cases, we focused on acute management decisions.
- The first 4 of these proceeded to surgery (3) or proton beam radiation (1).
- The following 3 cases were managed conservatively.
- All are in remission and doing well.
- The last 3 cases were brought to meetings late in their management, to demonstrate high morbidity, discuss future management, education and acquisition of long-term outcome data.
- Currently we have:
  - 7 participating centres.
  - 3-4 cases discussed per month.
  - Alternating with themed meetings.
  - Aiming to collect outcome data.

**Table 1** Summary of Meetings – Table 1

<table>
<thead>
<tr>
<th>Meetings</th>
<th>Number of new cases</th>
<th>Number of reviews from previous meetings</th>
<th>Types of new tumours discussed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pilot study</td>
<td>7 meetings</td>
<td>9 new</td>
<td>None</td>
</tr>
<tr>
<td>Jan → Dec 2012</td>
<td>12 meetings</td>
<td>33 new</td>
<td>14 reviews</td>
</tr>
<tr>
<td>Feb → Sept 2013</td>
<td>8 meetings</td>
<td>25 new</td>
<td>16 reviews</td>
</tr>
<tr>
<td>Overall</td>
<td>27 meetings</td>
<td>67 new cases</td>
<td>30 reviews</td>
</tr>
</tbody>
</table>

**Table 2** Attendance at a pilot meeting 9/8/11

**Table 3** Case summaries Table 2

- A national, regular, multidisciplinary consultation for discussing rare HPAIs is feasible and welcomed, facilitating dialogue amongst a wide specialist professional grouping and influencing management.
- With appropriate funding, such collaborative experience with outcome data collection, regular on-going audits, and an educational programme should enhance the management of this rare patient group, resulting in better outcomes and shaping the national standard of care.