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Foreword

Welcome to the Annual Report of the South Wales South West Managed Clinical Network for Cleft Lip and/or Palate for calendar year 2011. Publication is later than we would normally aim for. The initial delay was due in large part to the demands of hosting the 2012 Annual Scientific Conference of the Craniofacial Society of Great Britain and Ireland in Bristol. Happily, this was an extremely successful event.

The Managed Clinical Network covers a population of around six million people across the whole of South and parts of Mid-Wales (~2.5m), and the South West of England (~3.5m). The two designated surgical centres are hosted by Abertawe Bro Morgannwg University Health Board in Morriston Hospital, Swansea and by North Bristol NHS Trust in Frenchay Hospital, Bristol. The Welsh Health Specialised Services Committee (WHSSC) has commissioning responsibility in Wales; in England, as a result of the Health and Social Care Act 2012, responsibility is transferring to the NHS Commissioning Board, currently via the newly formed South of England Specialised Commissioning Group.

Cleft lip and/or palate surgery for children and adults takes place at Frenchay and Morriston Hospitals, except for very occasional high-risk cases who are treated at the Children's Hospital for Wales in Cardiff or the Bristol Royal Hospital for Children. Patients are seen by the Lead teams for review, orthodontics, speech therapy, audiology or psychology either at the surgical centres or at Cardiff (South Wales) and Gloucester, Taunton, Exeter, Torbay, Plymouth and Truro (South West). Network clinicians work to a number of standards in a Network Clinical Service Specification which are audited on a regular basis.

As well as patients born with a cleft, the teams also see significant numbers of patients with speech problems caused by a non-cleft velopharyngeal dysfunction. This may be due to a range of causes, including an occult cleft palate, 22q11 deletion, neurological impairment affecting the palate or other structural problem such as previous excision of a tumour.

As always, whilst we may focus largely on the activities of the core clinical teams in the surgical centres, we are mindful that the Managed Clinical Network depends on the wide range of clinicians working outside the surgical centres (especially in the South West). We are grateful that although (in many cases) cleft work forms a small part of their job they nonetheless work with enthusiasm and dedication, as do the administrative teams who co-ordinate clinics throughout the Network and who are often the first point of contact for parents and patients.

Once again, we are pleased to acknowledge and thank the two CLAPA branches and Max Appeal for their continuing support of this Network.

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2011: Review of Objectives and Achievements

The 2010 Annual Report listed a range of objectives for 2011. The following paragraphs summarise progress against these objectives.

• Meeting the patient care standards set out in the updated clinical service specification, and the respective national patient access targets, where applicable. Largely this has been achieved across the Network. Some work needs to be done to achieve the referral times to the Cleft Team at prenatal diagnosis in the South West.

• Collaborating with and meeting national audits of cleft care in the UK. The Network has participated in national audits for orthodontics, speech, and nursing.

• Participating in major national and international research studies (TOPS, Cleft Care UK). Both Bristol and Swansea are active participants.

• Reducing waiting times for alveolar bone grafts in the South West. Waiting times have improved but are still not acceptable. Bed availability has been a factor in this.

• Appointing and working with Lead(s) in Restorative Dentistry in South Wales. Agreed appointment of Karl Bishop (Swansea) and Will McLaughlin (Cardiff).

• Seeking to progress a new South Wales Cleft Unit in Swansea. The next phase (1B) of the redevelopment of Morriston Hospital, planned to complete in mid 2014, includes clinical facilities designed to meet the needs of the cleft service.

• Clarifying the future for the services and accommodation housed in the South West Cleft Unit at Frenchay Hospital. It is hoped that the Outpatient Service can be located in the Dental Hospital when the Inpatients move to the Children’s Hospital. This has not progressed in 2011 and is a high priority for 2012. The possibility of remaining on the Frenchay site in the medium term is being explored.

• Seeking to secure capital funding in the South West for a 3D surface scanner. This is ongoing.

• Further develop care pathways, guidelines and protocols for the service. Some Network clinicians attended a day held by the DH to formulate national Fetal Anomaly Screening Programme (FASP) guidelines for antenatal care. These have recently been completed and will be adopted.

• Finalising patient and parent information leaflets. More leaflets have been developed, and this work continues.

• Establishing a patient panel in South Wales. This remains an objective.

• Reviewing the options for acquiring or developing an improved database, compatible with national and local Trust IT plans. This is a goal in Bristol, but with the problematic implementation of Cerner Millennium by North Bristol NHS Trust late in 2011, and still emerging changes associated with the transfer of specialised commissioning to the NHS Commissioning Board, it has been difficult to make progress.

• Extending the range of data being inputted, with consent, onto the national CRANE database. This started in 2011 but is an area we still aim to improve in.

• Submitting a bid for additional revenue funding for the South Wales service to meet significant shortfalls. Discussions with the Welsh Health Specialised Services Committee about funding levels have continued.

• Preparing to host the Annual Scientific Meeting of the Craniofacial Society of Great Britain and Ireland in Bristol in 2012. Conference held, with extremely positive evaluation and feedback.
• Continuing to enjoy a close working relationship with CLAPA and MaxAppeal. CLAPA and MaxAppeal both given complimentary stands and places at the 2012 Craniofacial Society conference. Clinicians attend CLAPA meetings and CLAPA have bought equipment and sponsored activity days for a number of children.

• Striving to be truly patient-centred and deliver our service always taking into account the needs and wishes of our patients and parents. Very few complaints were received about the service. Those that were received were around waiting too long for surgery, or bed/admission cancellations. These are Trust-wide rather than Cleft-specific problems.

**Looking ahead**

As indicated above, some of the objectives from 2011 remain relevant. Our objectives for 2012 and beyond include:

• Continuing to meet and monitor the patient care standards set out in the updated clinical service specification, and the respective national patient access targets, where applicable

• Collaborating with and meeting national audits of cleft care in the UK

• Continued participation in major national and international research studies (TOPS, Cleft Care UK). The South West (Bristol) will explore becoming a Pilot Site for the Cleft Collective Gene Cohort Study.

• With the appointment of a new surgeon, to reduce further waiting times for alveolar bone grafts in the South West

• Preparing for the new South Wales Cleft Unit at Morriston Hospital, including detailed planning for office accommodation as well as clinical facilities

• Clarifying the future for the services and accommodation housed in the South West Cleft Unit at Frenchay Hospital.

• Seeking to secure capital funding in the South West for a 3D surface scanner.

• Further develop care pathways, guidelines and protocols for the service. South Wales (Swansea) will revise its Orthognathic Care Pathway and information as well as developing new information on alveolar bone grafting; also develop revised Patient Journeys for each cleft diagnosis, as well as Baby Packs for every family.

• Finalising patient and parent information leaflets/DVD

• Establishing a patient panel in South Wales

• Reviewing the options for acquiring or developing an improved database, compatible with national and local Trust IT plans

• Extending the range of data being inputted, with consent, onto the national CRANE database.

• Submitting a bid for additional revenue funding for the South Wales service to meet significant shortfalls

• Hosting the Annual Scientific Meeting of the Craniofacial Society of Great Britain and Ireland in Bristol in April 2012.

• Contribute to the national Clinical Reference Group for Cleft chaired by Adrian Sugar in formulating a Quality Dashboard and a National Service Specification.

• Continuing to enjoy a close working relationship with CLAPA and MaxAppeal.

• We strive to be truly patient-centred and deliver our service always taking into account the needs and wishes of our patients and parents, so we will also be looking to improve the ways in which we gather their views about our services.
Babies born with a cleft in 2011

In 2011 there were 115 new babies with cleft lip and/or palate born across the Network; a record 54 in South Wales and a more normal 61 in the South West. Figure 1 below shows these figures in a historical context. Once again, within the individual centres we see large year-to-year fluctuations that represent a challenge to capacity and service planning in the surgical centres.

Figure 1:
Total numbers of babies born with a cleft in the Network, 2003-11

All Cleft Centres also have a significant workload associated with suspected submucous cleft palates and non-cleft velopharyngeal dysfunction. Whilst most of these cases are young children, adults of all ages are also referred. Historically, data collection for this group of patients has not been as robust, partially due to the limitations of ICD-10 codes. The number of additional new referrals, including other miscellaneous referrals, remains at least in part an estimate, but continues to be a broadly similar total to the number of new cleft cases.

In the South West, there is an emphasis on working through local teams, with clinics held in seven areas, including Bristol (where all Bath patients are now seen for MDT clinics). The distribution of babies born with a cleft within those areas over the period 2002 to 2011 inclusive is shown in Figure 2 below:

Figure 2:
Mean numbers of babies born with a cleft in the South West, 2002-11

The number of new babies in South Wales in 2011 was unusually high at 54 (equivalent to around 1 in 520 live births). This does seem to be part of an upward trend in numbers since the middle of the last decade. The population birth rate has gone up in Wales over this period, but not to the same extent. The Office for National Statistics has published birth data by Local Health Board for 2009 onwards. Figure 3 sets the average number of new cleft births by LHB over the last three years in this context (by applying the usually quoted assumption of 1 cleft in 700 live births.)
Speciality Reports

Nursing

Wilma Adams joined the Bristol team of specialist nurses in October, working 15 hours per week, allowing an increase in the support given to babies born in Devon. This meant that at the start of 2012, the teams at the Cleft Centres were – based at Morriston Hospital: Lisa Phillips, Michaela Rowe (Lead) and Michelle Wooldridge (total 1.4 wte); based at Frenchay Hospital: Wilma Adams, Cathy Marsh (Lead) and Lisa Thompson (total 1.8 wte).

Michaela is working with colleagues to re-introduce pre-assessment clinics, to allow a move to day-of-surgery admission. She is also teaching on the Midwifery course in Cardiff and the Newborn Screening course, trying to target paediatricians and teach on their inductions.

Related to this, the Lead Nurses nationally collaborated to produce a credit card-sized aide-memoire ‘Cleft Palate – what to look for’ and this has been circulated to maternity units.

Cathy and Michaela attended a National Fetal Anomaly Screening Programme (NHS FASP) stakeholders day to develop an antenatal care pathway following the diagnosis of a cleft lip. This will be consulted on and finalised in the course of 2012.

Cathy has continued teaching to allied health professionals including the university midwifery course, and regularly mentors and supports nursing students in their second year of their degree course. Lisa has completed the FLAP course (Facilitating Learning and Assessment in Practice), so will be able to take on some of this work in future.

Standard 9 of the Clinical Service Specification requires that “A Clinical Nurse Specialist or an appropriately skilled member of the cleft team should visit within 24 hours of receiving the referral”. The table below shows the performance against this standard.

<table>
<thead>
<tr>
<th>Babies born in</th>
<th>South Wales</th>
<th>South West</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–24 hours</td>
<td>98%</td>
<td>100%</td>
</tr>
<tr>
<td>24–48 hours</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>48 + hours</td>
<td>-</td>
<td>0%</td>
</tr>
<tr>
<td>Other reasons (incl. medical conditions)</td>
<td>2%</td>
<td>0%</td>
</tr>
</tbody>
</table>

The expected development of a national dashboard as part of revised commissioning arrangements is likely to bring this into sharp focus for the South West team, where a number of the new baby first visit are done by ‘an appropriately skilled member of the cleft team’ rather than a clinical nurse specialist. The dashboard is likely to report only those
visits carried out by cleft nurses, with the effect that the reported performance in the South West will be lower.

The new baby folders – produced with the support of CLAPA South West – have been well received and the production of other leaflets including Pierre Robin and sub mucosal cleft are almost complete.

The regular coffee mornings for new babies (and their parents!) held at the Frenchay Cleft Unit continue to attract positive feedback, so we have expanded and have held coffee mornings in Plymouth and Gloucester. The toddler groups are also receiving good reviews and we have expanded to 3 a year, these groups also have input from the speech and language therapists and a dental nurse. We have also commenced a preschool group in Gloucester with the local speech therapists and psychology, so lots of on going support available for these families.

The Specialist Nurse play a key role in the initial recruitment, assessment and support of babies into the TOPS trial (see page 7). In the South West, we are well on the way to meeting the target recruitment figures and have randomised 13 patients. South Wales joined the trial later and did not start recruiting until the end of 2011.

Lisa Thompson will be attending the national Nursing SIG Research and Audit Group representing the South West.

As well as mandatory training, CPD has included an Attachment study day and Baby-friendly Initiative awareness training.

**Paediatric Dentistry**

Our consultants are Mechelle Collard and Deborah Franklin. Lucy Williams (FTTA in Paediatric Dentistry) attends audit clinics at Frenchay.

Mechelle Collard regularly teaches Dental therapy and Hygiene students, and Foundation Dentists in Cardiff on the subject of Cleft Lip and Palate. She spoke at the Network Day 2011 held in Princess of Wales Hospital, Bridgend on ‘Bottles, Babies and Babble therapy’.

Deborah Franklin teaches on dental care for children with cleft lip and palate to both undergraduate and on the Postgraduate Advanced Revision Course, Bristol.

The service standard for Paediatric Dentistry states that “All children born with a cleft lip and/or palate will receive advice and be offered treatment to ensure that their level of dental disease is the same as or better than the average in their local community.” The main measure of this is the dmft score (decayed, missing, filled, deciduous teeth). The table below shows the most recently collated data for 5 year olds.

**Dental health outcome at aged 5 years, children born in 2001-05**

<table>
<thead>
<tr>
<th>Birth year</th>
<th>South Wales</th>
<th>South West</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>dmft</td>
<td>% caries free</td>
</tr>
<tr>
<td>Benchmark*</td>
<td>2.38</td>
<td>47%</td>
</tr>
<tr>
<td>2001</td>
<td>5.19</td>
<td>35%</td>
</tr>
<tr>
<td>2002</td>
<td>3.77</td>
<td>37%</td>
</tr>
<tr>
<td>2003</td>
<td>1.47</td>
<td>59%</td>
</tr>
<tr>
<td>2004</td>
<td>1.89</td>
<td>59%</td>
</tr>
<tr>
<td>2005</td>
<td>2.10</td>
<td>47%</td>
</tr>
</tbody>
</table>

* 2005/06 BASCD survey of 5 year olds
  dmft – lower is better
  % caries free, % records taken – higher is better

Mechelle had a research paper accepted by the British Dental Journal February 2012 ‘Access to primary dental care for cleft lip and palate patients in South Wales’ S. K. Bhatia and M. M. Collard.

A national audit in collaboration with the Nursing SIG looking at dental decay and prolonged bottle feeding in cleft children took place in
2010/11 and the results have led to the Feeding nurses providing increased preventative advice at an earlier age. Deborah’s submission for an oral presentation at the 2012 Craniofacial Conference - Is Bottle Feeding Prolonged in Children with Cleft Lip and Palate? – was accepted. The bottle feeding audit will be re-audited in 2013.

In South Wales, joint clinics with psychology for 2 year olds took place during 2011 and were found to be useful and so will be continuing for the next year.

Dental nurses Rachel Yemm (Cardiff) and Sarah Francis (Swansea) have been attending babble therapy sessions to give parents early preventive advice. A book has been developed to aid the session which won a Cardiff and Vale University Health Board Trust innovative award in 2011.

**Surgery**

With a vacant post in Bristol, 2011 was a challenging year for cleft surgery in the South West side of the Network. David Drake filled as much of the gap caused by this as he could, initially on an ad hoc basis and then formally as a part-time locum consultant for 12 months from April 2011. This has prevented a large backlog from building up, but a number of babies were still a little older at time of surgery than we would normally plan for. The impact was perhaps greater on outpatient services, where the normal pattern of clinics across the region was considerably disrupted. This will continue to be the case until our new surgeon, Alistair Cobb, becomes well established alongside Nigel Mercer in the second half of 2012. David has throughout this time continued to work as cleft surgeon in Swansea alongside Adrian Sugar.

Cleft surgery for alveolar bone grafts (ABGs), fistula repairs, osteotomy/distraction procedures as well as the use of osseointegrated implants continues to be carried out by Adrian Sugar and Peter Revington, in addition to their general maxillofacial workload.

The Timing of Palate Surgery (TOPS) is an international, multi-centre study on timing of palate repair has been progressing through the Research and Ethics system. David Drake and Nigel Mercer have been calibrated in using the Sommerlad technique. Recruitment of patients began at the end of 2010 in Bristol, with Swansea gaining approval later in 2011.

The adjacent table summarises the surgical activity of the four surgeons in 2011 for both cleft and non-cleft VPD cases. Please note that the figures report the main operation for each episode only. It is quite common to carry out multiple procedures in the course of an operations, for example surgery to the anterior hard palate at the time of lip repair, and palatal fistula repair at the time of alveolar bone grafting. Note also that some dento-alveolar and other minor procedures may not be captured in this data.

<table>
<thead>
<tr>
<th>Cleft Surgery in 2011</th>
<th>Drake (Swansea)</th>
<th>Drake (Bristol)</th>
<th>Mercer</th>
<th>Revington</th>
<th>Sugar</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial lip repairs</td>
<td>27</td>
<td>13</td>
<td>21</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Initial palate repairs†</td>
<td>36</td>
<td>25</td>
<td>35</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Further palatal/speech surgery*</td>
<td>34</td>
<td>12</td>
<td>13</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Lip revisions</td>
<td>15</td>
<td>1</td>
<td>6</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Nasal surgery</td>
<td>13</td>
<td>0</td>
<td>14</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Alveolar bone grafts</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>45</td>
<td>13</td>
</tr>
<tr>
<td>Orthognathic surgery</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Other (cleft-related)</td>
<td>19</td>
<td>0</td>
<td>1</td>
<td>8</td>
<td>15</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>145</strong></td>
<td><strong>51</strong></td>
<td><strong>90</strong></td>
<td><strong>57</strong></td>
<td><strong>30</strong></td>
</tr>
</tbody>
</table>

* The figures for further palatal/speech surgery only include cases where the operation on the palate or pharyngeal wall is the primary procedure. Both Mr Sugar and Mr Revington regularly perform secondary palatal surgery as an additional procedure at the time of the main procedure reported above.
Standard 25 states “All clefts involving the alveolus will be grafted before the age of 11 years unless there is a specific reason e.g. medical considerations, very delayed dental development or hypodontia.” In 2011, 43 ABGs were to patients aged under 11 years, whilst 8 were on adults aged from 18 to 60 years. Of the 7 who were aged 11 to 18 at the time of their graft, 4 were repeat procedures; 1 had moved to the UK from overseas; 1 was delayed due to a medical condition; and 1 was referred late by a local unit.

The success rate of ABGs is audited each year using an x-ray image to assess the extent of the bony infill 6 months after the operation. This was reviewed for the CSAG report in 1998 (using a slightly different measure) when the success rate across the 57 UK units assessed was only 58% (compared with 90% reported by the Oslo unit). Figure 4 shows that over the last five audited years, the South Wales results have bettered 90% in every year (a score of 1 or 2 being deemed a successful outcome). The South West results have been more varied, but across the same five years averages a 91% success rate.

Speech and Language Therapy

South Wales SLT Department has seen more staff changes in 2011. Having reached full establishment in 2010, Judith Saunders, Deputy Lead SLT, left the department for a promotion in December 2011. Rhian Hoccom returned from her maternity leave to part time hours and the remainder of those hours has been filled by Siwan Cassidy.

In the South West, the SLT Department has been stable in terms of trained SLTs at the “hub” and also all the Link Therapists in the region. Annabel Hancock plans to row the Pacific in 2013 and is going part-time (3 days a week) in 2012 to prepare for this.

We have had a number of volunteers—both trained SLTs and others—who have helped with therapy and preparing therapy materials.

All babies born with CLP throughout South Wales are now invited to attend a babble workshop, either in Swansea or Cardiff. Dental advice is also given at the workshop. Following an audit in South Wales of 126 cases, bilateral CLP was shown to score the worst speech outcomes. As a result of this, the SLT department has now introduced additional speech reviews at 2 and 4 years of age for children born with a BCLP.

Summer intensive group therapy sessions were provided at the Hub. Annabel Hancock helped with an intensive week’s therapy course run by the West Midlands Centre.

Helen Extence and David Drake are attending the multidisciplinary clinic for patients with chromosome 22q11 deletions held at the University Hospital of Wales on a quarterly basis. All newly diagnosed patients and complex patients are invited to attend as well as those families who request an appointment. Anne Roberts attends the 22q11 clinic held at Frenchay Hospital and now also at Derriford Hospital Plymouth; Anne is undertaking research on the speech outcomes for patients with 22q11. Judith Saunders and Shirley Williams attended training in the Spires Centre for the use of the nasometer in preparation for its use with patients in South Wales. Sharon Baker attended EPG training in Edinburgh enabling us to offer this type of therapy to
patients in South Wales. Siwan Cassidy commenced her MSc in Speech and Cleft Palate in September 2011.

We have participated in the Cleft Care UK and TOPS multi-centre research studies. We are continuing a study looking at the speech outcomes following Furlow palate repairs. All SLTs attend and contribute to regular journal clubs held by the Cleft Team.

Regular consensus listening sessions are taking place within the centre and inter centre meetings in order to maintain specialist listening skills for assessment and audit. This is the first year in South Wales that all cases have been listened to in line with National standards.

We contributed data to the Tri-Centre Audit day held in Birmingham in June 2011 (for example, see Figures 5 and 6). Audits of 3 and 5 year old speech outcomes are ongoing, as is an audit of speech results following speech surgery in patients with 22q11 deletion syndrome.

Figure 5 – Speech Outcomes (Resonance) at aged 5 years, children born in 2004 (relates to palate function)

Helen Extence completed her first year as an external lecturer for the UWIC Undergraduate Speech and Language Therapy degree course. Liz Albery is an external lecturer for the Marjon Undergraduate Speech and Language Therapy degree course and has also contributed to the Sheffield Postgraduate Course. Anne Roberts has given teaching presentations for the Plastics South West Regional Teaching Day and the Cleft Care Study Day for FTTA orthodontic trainees. We continue to offer training to Community Therapists throughout the Network.

Helen Extence and David Drake presented at the Network Day, results of 40 consecutive palate repair cases and the speech surgery care pathway (November 2011).

Helen Extence along with other team members presented at the Welsh Hospital Dental Specialties annual meeting (March 2011).

Figure 6 – Speech Outcomes (Cleft-type characteristics) at aged 5 years, children born in 2004
Angie Westwood (medical student), David Drake and Helen Extence presented at the Craniofacial Society of Great Britain and Ireland meeting in York, Prognostic indicators for speech following repair of cleft palate (April 2011).

**ENT/Audiology**

Miss Sinéad Davis is the Lead ENT Consultant for the South Wales service. The ENT SpR working with her attended some MDT clinics held between April and Oct, 2011.

Following on from discussions in the previous year, audiology clinics were introduced in 2011 at Morriston Hospital supporting the Cleft MDT clinics. These allow for four patients attending MDT clinic to have their hearing assessed on the day of clinic, offering considerable benefit to patients as well as allowing full record of results required as part of the National audit standards.

Provisional discussions took place, via email, with the Audiologist in UHW / The Vale regarding the introduction of audiology support services for the Cleft MDT clinics at UHW Cardiff. It is hoped that a formal meeting will enable agreement to be reached for the introduction of this element of the ENT service to commence during 2012.

An audit of ENT/Audiology records in the notes of South Wales cleft palate patients born in 2008 and 2010 was undertaken. The provisional results of this audit were included in a presentation by Miss Davis at the 2011 Network Day on the Hearing Loss in Cleft Palate children. These highlighted the lack of ENT/Audiology records in the ‘cleft notes’, making it impossible to determine with any degree of accuracy what patients are being seen and who have been lost to follow-up. This has been set as a target to be address in 2012.

Participation in the CSAGII study was facilitated by the provision of audiology services at Morriston Hospital.

There were no significant changes within the South West in 2011.

**Clinical Psychology**

Vanessa Hammond and Jenny Hunt have been the Lead Consultant Clinical Psychologists for the South Wales Team on a job share basis, supported by a full time Assistant Psychologist, Nicola Clabon.

2011 saw some changes in personnel and a reorganisation of the service. Jenny Hunt left the service in October to take up a full time post in another service in the hospital. Nicola Clabon, left the service in September to take up a place on the Clinical Psychology Doctorate Training Course in Oxford. Vanessa Hammond has now increased her hours slightly as the Lead Consultant to 0.7 wte. We welcomed Charlotte Russell, Assistant Psychologist (0.9 wte) in September and have appointed Danielle Dummett, Clinical Psychologist (0.5 wte) who will take up the post in early 2012.

In the South West, Link Clinical Psychologists Elene Robson (Plymouth) and Rachael Carrick (Exeter) have both been on maternity leave over the past few months and we welcomed Sadie Thomas-Unsworth to the Taunton post following Vineeta Gupta’s departure. We have also welcomed two volunteers Hazell Thomas and Gemma Smith who are helping us to collate and organise research papers and to analyse the psychology database with support from Rosemarie Winter.

During 2011, the role of psychology in the Cleft MDT clinics in South Wales was extended to include follow up immediately after the team consultation to ensure concerns and questions have been addressed and to assess patient and family experience of and satisfaction with the team and clinics. This includes involvement in videofluoroscopy clinics and subsequent follow up. A joint clinic for 2 year olds with Dr Mechelle Collard, Consultant in Paediatric Dentistry, was also established.

During 2011, both parts of the Network have been developing and improving leaflets and information sheets for families. In the South West, issues covered have included ‘Pierre Robin Sequence’, ‘Encouraging Oral Feeding’, ‘Coming to a SPIN clinic’, ‘Distraction Osteogenesis’ and a leaflet based on Cognitive-Behavioural Therapy principles called ‘Thinking,
Feeling, Doing’. The work in South Wales has included ‘Dealing with comments and questions’, ‘Teasing and bullying’, ‘Talking to your child about having been born with a cleft’, ‘Useful information for people with 22q11 microdeletion syndrome and their families’, and ‘Helping babies and young children learn to settle themselves to sleep’.

A package of outcome measures for psychological therapy/intervention has been developed. A number of audits & evaluations have been carried out including:

- Audit of parent satisfaction with the Cleft Team and experience at clinics for children age 0-5
- Evaluation of the information and resource pack sent to children and families in Year 6 on the transition from primary to secondary school
- Audit of referrals to psychology and psychology involvement with patients and families

A transition group for children in Year 6 and their parents was held and their art work has been installed in the South West Cleft Unit. A further piece of art work painted by another group of children was donated to the newly refurbished paediatric outpatient department at Frenchay.

We are collaborating with the Centre for Appearance Research (UWE) in the development of an on-line cognitive behavioural therapy programme for young people with appearance-concerns.

The South Wales and South West cleft psychology services, led by Psychology Assistants, Irena Morgan and Charlotte Russell, are in the process of finalising ethical approval to proceed with a joint research project, ‘Growing up with a cleft: exploring hopes, fears and challenges’. The study aims to recruit a small number of young people (aged 19-22) and parents (of children aged 15-18) into focus groups. The purpose of the study is to generate qualitative evidence to inform national audit and research as well as clinical practice.

Activity days

Thanks to a generous donation from CLAPA South West, we were able to run two pilot activity days at the Castle Quarry activity centre in Tytherington, near Bristol, for children with clefts. The aim of the days was to give children aged 8-11 the opportunity to get together and have fun, to meet other children with clefts, and to help build their confidence around making new friends and communicating. Group activities and building body confidence are effective ways to help children gain confidence and social skills.

The children were able to try climbing and abseiling on an indoor climbing wall, zip wiring across a lake and canoeing and kayaking in the lake (with a bit of swimming for the braver ones!). Members of the psychology and speech therapy teams supported the children on the day, encouraging them to try out the activities and get to know each other.

In order to find out whether we achieved our aims, children were asked to complete feedback questionnaires. The feedback indicated that although many of them were nervous at the start of the day, by the end they felt much more confident and had a really good time. Feedback from parents was also very positive, suggesting that the children had really benefitted from the opportunity to have an exciting day out with others like them.

Following the success of the pilot days, CLAPA have agreed to fund more activity days this year in Bristol, Torbay and a location in Cornwall.
Trainee Clinical Psychologist, Amy Fletcher, completed her Doctoral research on ‘Mothers’ experience of their babies undergoing cleft lip and/or palate repair surgery’. The findings were presented to the South Wales Cleft MDT and will be presented at a future Craniofacial Society of Great Britain and Ireland Annual Conference. The research is being written up to be submitted for journal publication.


At the South Wales South West Cleft Network day, Vanessa Hammond presented on ‘Psychology in the New Baby Clinic’ and Tina Owen on ‘Activity Days for children with cleft conditions’.

Vanessa Hammond presented at the Welsh Dental Hospital Specialties meeting on the role of psychology within the South Wales Cleft Service. She also presented at the ABMU Psychology in Health Conference on ‘The role of Psychology with families of a baby born with a cleft lip and/or palate’. The South Wales Cleft MDT received presentations by Amy Fletcher, Trainee Clinical Psychologist, on the outcomes of her research on ‘Mothers’ experience of their baby undergoing cleft lip and/or palate repair surgery’ and Nicola Clabon on the ‘Satisfaction with Service’ audit.

Activities supporting continuing professional development (CPD) have included attending: the CFSGBI Annual Conference; meetings and a clinical day organised by the Cleft Psychology SIG; the South West UK tri-centre audit meeting; the South Wales South West Network Day.

Other opportunities for CPD in South Wales have included attendance at the ‘South Wales SIG for psychologists working with children’ training events, the South Wales Faculty of Clinical Health Psychology meetings and events organised by the South Wales Assistant Psychologists Group. The Psychologists attended, and were involved in organising, the ABMU Psychology and Health conference.

Vanessa Hammond and Jenny Hunt have attended workshops organised by the South Wales Clinical Psychology Doctorate Training Programme including advanced supervision skills and Resilience.

Plans for the Coming Year
- Continue to develop range of leaflets and information sheets
- Extend the follow up and resources available for parents following attendance at New Baby Clinics
- Complete focus group research and write up for conference and journal publication
- Further explore with Cleft Nurses the possibility of organising parent and baby ‘coffee morning’ events
- Joint working with the Cleft Team and the surgical wards to develop protocols and resources in relation to procedural anxiety
- Provision of placements for Trainee Clinical Psychologists where appropriate

Orthodontics

The Lead Consultants are Scott Deacon for the South West and Jeremy Knox for South Wales. The specialist dental nurses are Diane Bell and Sarah Boulton (Bristol), Rachel Yemm (Cardiff) and Lyn Ashford (Swansea). Rhiannon Jones is the Specialist Dental Hygienist with the Bristol team. Diane Bell was successful in her National Orthodontic Nursing Certificate and with the highest mark in the final exam has won the “Orthodontic Dental Nursing Award”. Sarah Boulton is undertaking further training in impression taking through a recognised program from the South West Dental Deanery.

Scott Deacon and Jeremy Knox organised a successful teaching day for Senior Orthodontic trainees in 2012, which received excellent feedback from all the participants.
Study models for UCLP and BCLP cases at 5 years and UCLP cases at 10 years were scored to assess facial growth. The results were fed into the anonymous national audit with the Orthodontic SIG of CFSGBI.

Scott Deacon has been invited to sit on the National Clinical Reference Group for Cleft Lip and Palate services in 2012/3. He is Co-Reviewer for the Cochrane Systematic Review: "Pre-surgical orthopedics for infants with complete cleft lip and palate". The Protocol has been published and data extraction is in progress.

Publications in 2011:

- CRANE Annual Report 2011
- CRANE Progress Report 2011

Oral and poster abstracts for conferences

- Ourvinder Chawla, Scott Deacon, Nikki Attack, Anthony Ireland, Jonathan Sandy “Use of 3D digital models for rating dental arch relationships” UTG session BOS Conference September 2011
- Scott Deacon, Lynn Copley, Jan van der Meulen “Does the primary surgical care for cleft births with syndromic/additional anomalies differ from non-syndromic births?” Annual Conference of the Craniofacial Society of Great Britain and Ireland April 2011
- Ourvinder Chawla, Scott Deacon, Sam Leary, Anthony Ireland, Jonathan Sandy “3D digital models for rating dental arch relationships in unilateral cleft lip and palate” European Craniofacial Congress September 2011 (Poster)

Scott Deacon gave presentations to the following:

- British Orthodontic Society - Orthodontic Specialists Group Spring Meeting March 2012;
- Wessex BDA Hospitals Group Study Day May 2011;
- CRANE Project Update Craniofacial Society of Great Britain and Ireland Conference, York 2011;
- North Devon Dental Care Professional Study Group, March 2011

Scott Deacon authored the following textbooks:

- Postgraduate Notes in Orthodontics Sixth Edition revised and updated chapter on Clefting in 2011
- National British Orthodontic Society VLE Teaching Module "Module: Cleft Lip and Palate and Craniofacial Anomalies" Author completed 2011

**Restorative Dentistry**

Paul King is the Lead Consultant in Restorative Dentistry for the Network based at Bristol Dental Hospital. Matthew Jerreat provides treatment based in Plymouth and Taunton as well as cover for Truro and Exeter. A recent agreement has been reached for services in South Wales with Karl Bishop (Morriston Hospital) covering the SW and Will
McLaughlin (Cardiff Dental Hospital) the SE of the region. Karl Bishop will act as clinical lead. This welcome arrangement will take effect from the 1st April 2012 and aims to coordinate and standardise care across S Wales.

An ongoing audit of patients treated in the SW (PK; MJ) between Apr 2010 – Mar 2012 continues to highlight a range of restorative treatment needs and age groups. 65% of patients are age 25 years and above illustrating the ongoing treatment demands on Restorative Dentistry for the ‘older’ Cleft patient.

In conjunction with colleagues based at the Bristol Dental Hospital Paul King has successfully completed the first stage of a pan-European prospective clinical trial assessing the clinical performance of narrow diameter titanium dental implant fixtures designed to replace missing upper lateral and lower incisor teeth (50K Research Grant sponsored by Astra Tech, Sweden). Published:


The Bristol Dental Hospital team were also successful in securing a 10K grant from the Faculty of Dental Surgery, RCS England to facilitate a 10 year treatment outcome project assessing the performance of resin-bonded bridges used for the replacement of missing teeth. The results demonstrated mean survival figures of 80% over a 10 to 15 year observation period. Published:


Clinical audit, quality improvement & clinical effectiveness activity

Orthodontic/Dental

Comparison of the 5 year old, Goslon and Eurocran indices for assessing dental arch relationships in 5 year olds. (SpR research project).

Evaluation of the occlusal outcomes of patients who have completed their orthodontic treatment at the South West Cleft Unit (SHO project).

Evaluation of the occlusal outcomes of patients who have completed their orthodontic treatment in combination with orthognathic surgery at the South West Cleft Unit (Dental undergraduate elective project).

National growth outcome of UCLPs at 5, BCLP at 5 and UCLP at 10.

Dental Nursing/Hygienist

An Orthodontic Retainer reminder sticker system: does this have an impact on reducing patient SOS appointments? An orthodontic retainer reminder sticker system has been introduced, by which patients will be given a pot with a "REMEMBER ME" encouraging them to bring retainers with them at their 3/12 review appointment.

A protocol has been introduced to check intra-oral dental radiographs against standards set by the National Protection Radiology Board and Royal College of Radiology 1994.

Dental hygienist has raised awareness of cleft care and dental hygiene in general dental practice through lectures to the final year dental hygienist students at the BDH and the Cardiff School of Dental Hygiene Therapy.

Following the study to measure the clinical effectiveness of the dental hygienist, a poster has been accepted for display at the Conference of the Craniofacial Society of Great Britain and Ireland in April 2012.

Surgery

Nasal symmetry in unilateral cleft lip and palate patients: a comparison of primary surgery techniques. (Medical student).
A clinical effectiveness study has commenced to evaluate the effectiveness of Kelocote® for healing of scars following cleft surgery. (SpR).

Following the previously conducted audit on leg bandaging of Alveolar Bone Graft patients, the positive results of this previously conducted audit have been sustained, and have led to a shorter length of stay and reduced use of PCAs and bandages. Savings of one night’s hospital stay amount to approximately £9680 per annum and savings in the use of PCA (currently being costing) are estimated to be significant.

Psychology

An audit was undertaken to assess the prevalence of trauma symptoms in children presenting at services offering appearance-related psychological support. This was a joint project between Outlook, the South West Paediatric Burns Service and the South West Cleft Unit.

A proposal has been submitted to undertake focus groups to understand patient views on various aspects of the audit process and to inform our questionnaires. Ethical approval is expected shortly.

A DNA audit has been instigated following concern about persistent non-attenders and the disparate nature of information collected on them. This will be an ongoing audit taking into account staff detailed knowledge of family circumstances in conjunction with outcome data recorded on computer systems.

The questionnaire for parents of babies aged 0-3 months, encompassing many aspects of the patient experience in the first few months, has been analysed using data from Oxford and the South West, and it is intended to present this at the tri-centre audit conference in June 2012.

The 22q11 service is continuously trying to enhance communication between health professionals involved with children affected by 22q11 DS, by ensuring copies of the reports are distributed to all those identified by the parents. The 22q11DS service is being extended to cover the southern part of the South West region through the setting up of clinics at Derriford Hospital twice a year with the support of Dr Sharon Glass, Consultant Paediatrician.

Speech

A new database is being set up in order to track cleft patients’ speech outcome at the ages of 2 and 3. It will look at parameters of cleft-type speech and airflow measures and can be used to track individual patients or groups such as palate only, surgeon-specific patients, syndromic patients etc. A proforma is completed by all specialist therapists at age 2 and GOS.SP.ASS assessment at age 3 to collect the data to be used.

In order to inform our understanding of osteotomy on speech outcome, perceptual speech assessments for osteotomy patients both pre and post-op are being collated. This is linked to both structural outcome and satisfaction and will promote awareness about the potential of osteotomy on speech.

Data was submitted to the national speech audit on outcomes for 5 year-olds.

Record-keeping

Is the South West Cleft Regional Network collecting the complete 5 yr record set for every patient as per the clinical Standards Advisory Group guidelines? The results of this national audit will be presented to Managers/Clinical Directors at the CFS Conference in April 2012.

Tri-centre Audit Day (2004 births): data submitted

Aesthetic outcomes at 5 years of age.
Speech outcomes at 5 years of age.
Missed diagnosis of cleft palate
Ante-natal diagnosis of cleft lip
Postnatal standards 2 and 3 (response times)
What is the decay experience of children in South West England with Cleft Lip and Palate?
National Bottle audit for children aged 12 to 36.
Psychology (10 and 15 year data).
Annual Cleft Network Day

The programme for the 2011 event, hosted for the first time in the excellent Multi-Professional Education Centre, Princess of Wales Hospital in Bridgend, is reproduced to the left. The presenters’ backgrounds (clinical psychology, radiology, clinical genetics, clinical immunology, restorative dentistry, paediatric dentistry, ENT surgery, cleft surgery and speech & language therapy) demonstrate clearly the importance of multidisciplinary care and shared learning by professionals associated with the managed clinical network.

Finally…

Many thanks to everyone who contributed to this report. We promise that the next annual report (for the year to 31 December 2012) will made available much earlier in 2013 than has proved to be possible with this report in 2012.