Welcome

Pat Ward - Programme Director of the NHS FASP

The NHS and the framework in which it functions are presently undergoing many changes in line with the government’s commitment to improve services for patients and drive forward locally led arrangements. For the NHS Fetal Anomaly Screening Programme (FASP) and the UK National Screening Committee (NSC) it is clear that we will become part of the new Public Health England (PHE), which takes effect formally from 1 April 2013, and transition arrangements are already taking place. Presently we are still unsure how this may affect NHS FASP in terms of staffing and future work commitments, but as ever will continue to ensure we have a robust system underpinning any changes to mitigate possible detrimental effects.

Also, along with the government’s overall strategy, we have to ensure that financially we are making as many savings as possible, and compete for that, demonstrating a lean and effective process.

This progress update concentrates on achievements we have made to date and provides the overview of a number of work streams, which continue to assist the service in making improvements, whilst being very aware of the changes taking place. Much work has taken place supporting sonography staff in their daily work of undertaking fetal measurements within the combined screening strategy. A great deal of improvement has been demonstrated, with very pertinent and new resources developed to support sonographers.

We continue to work with many stakeholders to develop clinical pathways throughout the screening, diagnosis and treatment areas of the 12 conditions that we screen for. Although we are very keen to emphasise that we are not responsible for services beyond screening, it is important that, where there is no one taking these initiatives forward, we work with everyone to improve the care along that pathway.

2012 onwards will bring many challenges and our objective will be to continue to develop initiatives which will support the service through these changes.

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The NHS FASP nuchal translucency training and support structure was launched in 2010 to support the universal implementation of combined screening for Trisomy 21 in England. The aim was to assist ultrasound practitioners in obtaining the requisite theoretical and practical skills to contribute to a high quality local screening programme for women.

In response to requests from service level, the appointment of 10 Regional Obstetric ultrasound Screening Coordinators (ROSCOs) working within the 10 Strategic Health Authority boundaries emphasised the NHS FASP's commitment to offering practical training and support.

The training structure and the ROSCO role, which supported improvements during the last year has provided practical support and statistical improvements (via the Down's syndrome Quality Assurance Support Service) to the accuracy of practitioner's measurements of the fetal nuchal translucency and crown-rump length, thus improving the accuracy of the combined screening test.

Resources have been developed or updated to support the training and quality improvement process. The “Manual for Sonographers – 2010” has been revised and re-named as “Measuring the NT and CRL as part of combined screening for Trisomy 21 in England: Manual for ultrasound practitioners”. Also, a new “Image Review Guidance” tool has been designed specifically to assist those responsible for auditing the quality of departmental NT and CRL measurements (usually the locally nominated Screening Support Sonographer or department lead). This resource is presented as a PowerPoint presentation and includes written explanations and example images to assist practitioners in the identification of a range of acceptable cross-section views.

Both resources are now available on our website.

The NHS FASP annual Screening Support Sonographers (SSS) conference was held at Aston University, Birmingham, on 7 March 2012 and was attended by 170 SSS, Regional Team members, Regional Obstetric ultrasound Screening Coordinators, ultrasound practitioner representation from Scotland and Wales and the Society and College of Radiographers.

Conference evaluation from previous SSS events indicated that delegates prefer information on practical aspects of their role to assist in clinical practice improvements. Consequently, the tabled programme had this emphasis and scheduled more discussion time than previously to encourage feedback and debate.

The overall delegate evaluation of the conference was excellent with many indicating they considered the information they received “invaluable”.

Key message
Be CLEAR on how to optimise the NT image. Under or overestimating the NT measurement can result in misleading risk information.

- Adjusting these controls appropriately will improve your NT image.
Developing integrated care pathways for Fetal Anomalies

Karen Toulalan - Programme Associate

Following the publication of the "18+ to 20+6 Weeks Fetal Anomaly Scan Standards and Guidance for England 2010", the NHS Fetal Anomaly Screening Programme was asked by the Department of Health to set out care pathways for the 11 Fetal Anomaly conditions screened for. Referral care pathways had been developed for Down's syndrome, Fetal Anomalies in general and prenatal diagnosis. We developed and published care pathways for fetal neural tube defects in 2011. During 2011, integrated care pathways have been under development for congenital diaphragmatic hernia, cleft lip and congenital heart disease and these will be published in 2012.

Congenital diaphragmatic hernia

The aim of developing a care pathway for congenital diaphragmatic hernia for health professionals was to set out best practice care for women whose unborn baby is diagnosed with congenital diaphragmatic hernia. The pathway should commence from the point of antenatal diagnosis and through to the first year of neonatal life. An integrated care pathway would enable greater standardisation and equity in England. Alongside this it would enable the health service to deliver more timely care for women in the antenatal and neonatal periods.

The stakeholder meeting was held on 11 October 2011, chaired by Mr Tim Overton who also represented the British Maternal Fetal Medicine Society. There were presentations in the morning by NHS FASP, Beverly Power from CDH-UK (formerly Cherubs UK), key stakeholders were identified to participate in a national meeting to identify best practice, any gaps in the service and to plan out key elements of a pathway.

Following the commission of a literature search and a review of current evidence and meetings with the charity CDH-UK (formerly Cherubs UK), key stakeholders were identified to participate in a national meeting to identify best practice, any gaps in the service and to plan out key elements of a pathway.

Fisher from Antenatal Results and Choices (ARC), Mr Bill Martin (Consultant in fetal maternal medicine at Birmingham Women’s Hospital), Ms Karen Luyt (Consultant Neonatologist at St. Michael’s Hospital, Bristol), Professor Paul Losty (Consultant Paediatric Surgeon at Alder Hey Children’s Hospital) and Mr Gregor Walker (Consultant Paediatric and Neonatal Surgeon at Glasgow Royal Hospital for Sick Children). The afternoon included small group work and an open forum discussion.

Following the event a meeting report was produced and work commenced on a first draft of the pathway. The meeting attendees have submitted comments as part of the first stage of the consultation process and the pathway is now under revision. Following the re-draft the pathway will be available on our website for a wide consultation later in the spring.

Cleft lip

NHS FASP has a long established relationship with the charity CLAPA, who have collaborated on the development of patient information. They identified much variation in service provision across England and the need for earlier referrals to the specialist cleft teams.

A stakeholder meeting was held on 6 December 2011, chaired by Dr Pam Loughna (Senior Lecturer and Consultant Obstetrician at Nottingham University Hospitals NHS Trust). Presentations were given by NHS FASP, Rosanna Preston (Chief Executive of CLAPA), Rachel (a parent describing her experiences of having a diagnosis), Sue Brown (Clinical Psychologist at Royal Victoria Infirmary, Newcastle), Trisha Bannister (Consultant Nurse for the North West Cleft Network), Andrew Rostron (Implementation Manager for NHS Newborn Infant Physical Examination Screening Programme) and Dr Alex Habel (Honorary Consultant Paediatrician for the North Thames Cleft Unit and representing the Royal College of Paediatrics and Child Health).

Following the event a meeting report was produced and a pathway drafted. The pathway has been revised following submission of comments from the stakeholder group. The pathway has been re-drafted and a wide web-based consultation will commence in April 2012.
Screening for congenital heart disease – an update

Sophie Bale - National Projects Midwife

Recent work in this area has been prioritised and recent work streams have included collaborative work with the NHS Newborn and Infant Physical Examination Programme (NIPPE), the British Maternal Fetal Medicine Society (BMFMS), the Safe and Sustainable review of congenital heart services for children in England and Wales and the British Congenital Cardiac Association (BCCA). Development of the integrated clinical care pathway and planning of future projects within this area has also continued.

Working with NHS NIPPE, BMFMS, Safe and Sustainable and the British Congenital Cardiac Association

A number of meetings have been held with these key stakeholders. This has ensured uniformity of the standards and literature produced, not only for the screening of CHD but also for use in diagnostic fetal cardiology units across England. A joint approach has been fostered to ensure high quality care is provided by successfully functioning, multi-disciplinary teams within the CHD networks.

Development of an integrated clinical care pathway for the screening and diagnosis of CHD

In accordance with the ongoing work within NHS FASP to develop clinical care pathways for the 11 identified conditions, work has begun on the cardiacl pathway. A stakeholder event was held on 1 March 2012 in London. The meeting was chaired by Mr Pranav Pandya, Director of Fetal Medicine, University College London Hospitals Foundation Trust. A wide range of stakeholders were present, including clinicians, charities/support groups and parents/lay representation. The event was extremely well received and the facilitated group work ensured the productivity of the day. The draft pathway will be released for national consultation in the coming months.

Congenital heart disease – leaflets for parents and professionals

These leaflets have been newly produced and are intended to function as a source of preliminary information prior to referral to a speciality unit and condition-specific information from charities such as the British Heart Foundation and Tiny Tickers. As work continues in this area further information will be produced. The leaflets can be found in the “Information to support parents and health professionals once a diagnosis of a congenital anomaly has been made”, which will be released shortly.

Public Voluntary Register for Sonographers (PVRS)

Donna Kirwan - National Projects Officer

Recently, NHS FASP was made aware that the College of Radiographers were upgrading the Public Voluntary Register of Sonographers (PVRS) from 1 March 2012. The voluntary register now has associated with it a Code of Conduct and Ethics, Standards of Proficiency and a supporting Policies and Procedures document. Voluntary registrants will be asked to confirm that they will follow these good practice guidelines.

All sonographers whose names are currently entered on the registers are being asked to renew their registration and the process of transferring current voluntary registrants to the upgraded register will take approximately six months. At that point the current register will be closed. An online re-registration form will also allow the College to update details and information on the range of sonography practice and the qualifications and statutory registration status of sonographers. New sonographers are also welcomed.

There will be no charge for re-registration for any sonographer whose name is listed on the current register. Registration will then be for a two-year period, apart from this first cycle where the College will allow three years. The next process for registration will be in March 2015.

Statutory regulation of sonographers remains the policy and ambition of the College of Radiographers and they will continue to support and argue the case for this, despite the publication of a command paper by the coalition government in February 2011 (Ref 1) preventing this action.

The College hope that sonographers will renew their registration – or, for new sonographers, consider registering if they have not done so before – as this will help to protect the public in an area of practice where statutory registration is not possible for all; it will also help support the continuing drive to obtain statutory regulation for sonographers and for “sonographer” and “ultrasonographer” to become protected titles.

The online application form for both new applicants and re-registration, along with the supporting documents, can be found at:


NHS FASP Consent Standards and Guidance – July 2011

We have developed a number of new resources since our last progress update of spring 2011. The updated NHS FASP Consent Standards and Guidance were published in July 2011. In addition to the standards and guidance, the group has developed additional resources for parents and health professionals. These include three pathways and a mini guide for health professionals responsible for each stage of the consent process. All of these documents are available within the standards booklet and as stand-alone documents. These resources are available from the website: http://fetalanomaly.screening.nhs.uk/consent.

Online resource for parents – Screening choices in pregnancy: for Down’s syndrome and Fetal Anomalies – February 2012

Our first parent-focused online resource for women and their partners is now available at: www.resources.fetalanomaly.screening.nhs.uk/parent/screening-choices. Created by the NHS Fetal Anomaly Screening Programme, the resource provides information on the antenatal screening tests for Down’s syndrome and Fetal Anomalies. It allows women to navigate a wide range of detailed information related to the Down’s syndrome screening tests and Fetal Anomaly screening. By the end of March 2012, this resource had already attracted 12,031 hits to its website address.

Information to support parents and health professionals once a diagnosis of a congenital anomaly has been made

The review of the information to support parents and health professionals once a diagnosis of a congenital anomaly has been made is now complete. This information will be published in a spiral-bound book and will contain updated leaflets covering the following conditions: Anencephaly, bilateral renal agenesis, serious congenital cardiac anomalies, congenital diaphragmatic hernia, cleft lip, exomphalos, gastroschisis, Trisomy 18, Trisomy 13, lethal skeletal dysplasia, and spina bifida. Two copies of each book will be sent out to every ultrasound department in England and the leaflets will also be placed on our website, available here: http://resources.fetalanomaly.screening.nhs.uk/.

The following additional resources have also been published:

- The Evaluation of the NHS FASP Nuchal Translucency (NT) Training Provision, written by Amber Butler, is available to download here: http://fetalanomaly.screening.nhs.uk/reports
- The NHS FASP 2010-2011 Annual Report is available to download here: http://fetalanomaly.screening.nhs.uk/reports
- A journal paper from BMUS entitled "A practical solution to combining dating and screening for Down’s syndrome" is available to download free from our website with kind permission from BMUS.

Relevant papers

The aim of this project is to develop a suite of first and second trimester Down’s syndrome screening clinical standards and guidelines for providers and commissioners in England. The national working group includes 30 stakeholders (some deputies) from a range of healthcare backgrounds (maternity, pathology, public health, education, research, imaging, some royal colleges and “user” charities). Since the inaugural meeting in July 2011, the group have met on another two occasions. The final meeting will be in September 2012.

In brief, the second edition of the T21 standards, produced in 2007, has undergone a substantial transformation over a period of nine months. To begin with, the task was to decide on whether all the standards were required, whether new standards should be introduced and what should be withdrawn. The first edit was undertaken by looking at the whole document as a group and the second edit by devolving specific sections of the document to individual sub-groups. The allocation of “work-packages” and editing of information was managed via a group-nominated member to coordinate comments via email.

The first of two national online consultations took place over a course of five weeks during the autumn of 2011 and generated plenty of feedback. Since this event, the group have met in November and February and edited the document again.

In respect to presentation, the UK NSC Office stipulated that all national screening programmes present their standards in a uniform way and this was for several reasons: in the past there have been too many standards, some of which are “true standards” but guidance; many standards are replicated by other programmes and, if of a similar nature, may oversaturate providers; standards should link into the “generic programme objectives” that are linked with the NSC QA themes and each set of standards should bear recognisable branding by having a tabulated grid with measurable targets which providers are able to monitor.

At the recent Fetal Maternal and Child Health (FMCH) meeting on 13 March, the T21 standards (in a tabulated grid) were presented to the group for review. The document received positive feedback. The next steps of the project are to:

- Substantiate each standard with a reference
- Apply targets for each standard
- Consult on the standards from 7 May to 8 June 2012.

Currently at least a quarter of all biochemistry screening laboratories in England also routinely report risk figures for T18 and T13 when markers used for T21 screening yield patterns significant for T18 and T13, albeit that a formal policy has not been approved by the UK National Screening Programme (UK NSC). The NHS FASP, in recognition of this disparity, decided that a project was required to explore this further in terms of the impetus behind reporting, clinical management and benefits to women.

A national working group commissioned by the Programme Centre has looked at the evidence and service implications for reporting incidental T18 and T13 markers of the T21 screening test. Additionally, during November to December 2012, a national consultation was undertaken to seek the views of stakeholders, the draft paper proposing that all women with either a single or multiple pregnancy be given a single composite risk result for T18 and T13, separate from the T21 risk result, and in the second trimester, reporting of a single T18 (but not a T13) risk from components of the Quadruple Screening Test (where Combined Screening cannot be undertaken). The consultation yielded a wealth of feedback with the majority of respondents in favour of the draft proposal and the draft paper now revised.

The UK NSC office is dovetailing the project by commissioning an external body to undertake another review of the literature and the proposal challenged against the 22 Wilson and Junger World Health Organisation (WHO) criteria (1968) to address the condition, the test, the treatment, viability, effectiveness and the appropriateness of introducing the reporting of the risk for T18 and T13.

The group will meet again in September.
311 sonographers throughout the 10 regions in England were sent the questionnaire via email by CFEP UK Surveys Limited. The questionnaire was active from 20 June to 21 July 2011; a response rate of 67.8% was achieved. Before November 2010, 78.6% were using one of the FMF theory training options and 56% received practical training from them. Since November 2010 onwards there has been a definite shift in the delivery of NT theoretical and practical training, with the majority reporting using the NHS FASP resources.

The main training providers were compared using a usefulness scale, where 1 was least useful. All training scored positively, demonstrating effective commission of NT training. 78.1% rated the usefulness of the FMF practical training 7 or above and 82.4% rated the usefulness of the FMF theory 7 or above. 87.5% rated the usefulness of the NHS FASP online NT training 7 or above and 86.4% rated the usefulness of the ROSCO 7 or above.

The questionnaire established that increased numbers of participants were aware of the NHS FASP resources to support sonographers to improve NT and CRL measurements; and with increased awareness and use of NHS FASP resources and support of the ROSCOs, sonographers reported an improvement in both confidence and competence scores.

The full report can be viewed on the NHS FASP website at: http://fetalanomaly.screening.nhs.uk/reports.
QC Group Update

Dr Angela Mallard - Independent Biochemist Consultant

The fourth Biochemistry Conference, which is organised by the QC Group, took place on the 18 and 19 April at the Innovation Centre, Exeter, and covered issues that have arisen within the group over the past year. Around 52 participants from 19 of the Down's syndrome screening laboratories in England, Scotland & Wales, plus associated manufacturers, attended the meeting.

On the first day, the agenda included an update on the random access analyser project that took place in the last year, plus a possible way forward for standardising internal QC protocols, with a presentation on IQC data. There were also roundtable discussions on the updated risk calculation software specification, and on risk reporting, including the reporting of T13 and T18.

Day two covered QA of CRL measurements, cycle reports from DQASS, a session on Serious Untoward Incidents plus short presentations on fb-hCG stability, with feedback on the recently issued questionnaire, the effect of smoking dose on Down’s syndrome screening analytes, and when “a risk is not a true risk”. The meeting was a great success and the evaluation of the day was very positive.