

**HEALTH SCRUTINY PANEL**

A meeting of the Health Scrutiny Panel was held on 31 January 2017.

**PRESENT:** Councillors E Dryden (Chair), S Biswas (Vice-Chair), J G Cole, A Hellaoui, C Hobson, J McGee, G Purvis and M Walters

**ALSO IN ATTENDANCE:** Phil Archman - Service Manager Paediatrics - South Tees Hospitals NHS Foundation Trust  
Craig Blair - Director of Strategic Planning and Performance - South Tees CCG  
Mark Burdon - Commissioning Manager (Mental Health) - South Tees CCG  
Maria Catterick - FASD Network  
Dave Chadwick - Clinical Director for Urology - South Tees Hospitals NHS Trust  
Michelle Conley - Commissioning Manager (Health Inequalities) - South Tees CCG  
Brian Cox - Service Manager Clinical & Diagnostic Support Services - South Tees Hospitals NHS Foundation Trust  
Sarah Danieli - Service Manager Planned Care Centre - South Tees Hospitals NHS Foundation Trust  
Dr Maeve O'Sullivan - Consultant Paediatrician - South Tees Hospitals NHS Foundation Trust

**OFFICERS:** C Breheny and Graeme Nicholson - Health Improvement Specialist (Best Start and Families) Public Health Middlesbrough

**APOLOGIES FOR ABSENCE** Councillor B A Hubbard.

**DECLARATIONS OF INTERESTS**

None Declared

**16/17 MINUTES - HEALTH SCRUTINY PANEL - 20 DECEMBER 2016**

The minutes of the Health Scrutiny Panel meeting held on 20 December 2016 were approved subject to a minor adjustment being made.

**16/18 BREAST RADIOLOGY SERVICES**

In 2015 the panel was advised that owing to a number of challenges facing breast radiology services at James Cook University Hospital including a broken machine and recruitment issues (including the need to recruit Radiologists from the Netherlands) breast diagnostic services were to be temporarily carried out at North Tees General Hospital. This temporary measure had now been in place for approximately 18 months and the Chair reminded the panel that in November 2016 an update on this topic had been provided. However, at that point the panel had not felt reassured by the pace of progress taking place. It had therefore been requested that further information be presented at today's meeting to assure Members that breast diagnostic service provision would soon resume on the James Cook University Hospital (JCUH) site.

The Service Manager for the Planned Care Centre, Service Manager for Clinical and Diagnostic Support Services and the Clinical Director for Urology were in attendance at the panel meeting to provide an update. An update report, which detailed the timetable that the Trust was committed too and steps being taken to open a dedicated breast unit on the JCUH site from the 1st July 2017 2017/18 was presented. It was advised that in order to achieve this target significant work in the next few months was required in relation to estates and facilities planning, equipment and joint workforce planning.

During discussion the following points were made:

- The unit would be housed in the main outpatient department at JCUH and would consist of a dedicated L shape facility designed to protect the privacy of the patient whilst undergoing diagnosis. The plans were at the draft stage at present and the Architect was in the process of producing the final drawings, which were to be shared with North Tees colleagues for quality assurance purposes.
- Once the drawings had been approved the mammography equipment would be ordered and then quality assured by the staff at University Hospital North Tees. The mammography equipment would be used for x-raying breast tissue, undertaking ultrasounds / biopsies and would provide a much better arrangement for patients in the South Tees. It was confirmed that the JCUH would be a spoke unit and the funding was available to purchase the equipment. Once ordered it would take approximately twelve weeks for delivery.
- In May / June briefings with GPs would be undertaken to inform GPs that breast clinics would resume at the JCUH site from 1st July 2017. Public relations work would also be completed to ensure members of the public were aware of the changes.
- Reference was made to a breakdown in communication in respect of patient information being made available when patients were transferred from University Hospital North Tees to JCUH. Apologies were made for errors that had occurred and any appointments missed. It was explained that at present patient records are still retained on paper files and this type of error happens from time to time and was not reflective of this service in particular.
- The point was made that at present if ladies in Middlesbrough were undergoing surgical procedures at North Tees Hospital then they have chosen that hospital, as their preferred option through the choose and book system.
- Clinical Radiologists needed to see a large number of patients to retain their clinical standards approximately 5000 patients a year. It was confirmed that unfortunately the plan to recruit Dutch radiologists had been unsuccessful.
- Integrated working between hospitals was becoming more common place, as competing Trusts were competing for resources. All staff appointed in breast diagnostics were appointed Teeswide and North Tees and Hartlepool NHS Foundation Trust was the employing Trust.

Further recruitment would also be necessary to re-establish breast radiology services for South of Tees patients at the JCUH site. This would require collaborative agreement with North Tees and Hartlepool NHS Foundation Trust for the appointment of any staff related to the breast service at both Consultant and Advanced Practitioner (Radiographer) level. It was noted that recruitment specialists had been engaged to identify the required specialists to strengthen the South Tees / North Tees collaborative position.

Clarification was sought on the difference between a Radiologist and a Radiographer. It was explained that a Radiologist was a clinical doctor, with responsibility for diagnosis and at present this aspect of the service was carried out at North Tees Hospital. Advanced Radiographers specialising in breast radiography undertook a five year training programme to achieve advanced level qualification.

The Chair requested a summary of the discussion and it was advised that the plans for the unit would be finalised in the next few weeks, the site would be quality assurance checked prior to task and finish groups at North and South Tees working through any operational issues and an operational model would need to be agreed. Work was also ongoing to appoint a third breast surgeon and the mammography equipment would be ordered in March 2017. All of the funding for the building works was available and a go live date of 1st July 2017 was envisaged. The Chair queried whether there were any threats to the project and it was advised that the biggest threat was around completion of the physical works. An invitation would be extended to the panel to visit the unit once completed. The Chair welcomed that invite and thanked the relevant parties for their attendance.

AGREED as follows:-

1. That an invitation be extended to the Service Manager of the Planned Care Centre at South Tees NHS Foundation Trust to attend the panel's April 2017 meeting to confirm that plans remained on track.

16/19 **FOETAL ALCOHOL SPECTRUM DISORDER (FASD)**

The Democratic Services Officer reminded the panel that in agreeing to consider the topic of FASD the panel had requested that the review would focus on the scale of the problem in Middlesbrough and consider the support that was/needed to be provided. A number of representatives were in attendance at the meeting to provide evidence in the form of a round table debate on the topic. The Chair invited the FASD representative to outline for the benefit of all attendees the pertinent issues at this time. The FASD Network representative stated that the officers in the Public Health team had undertaken fantastic work over the last 18 months around promoting the message of no alcohol in pregnancy in an effort to prevent FASD. However, the area where families were having difficulties was obtaining a diagnosis of FASD, they often spent years going around in circles in order to get a diagnosis. In South Tees there appeared to be an obstacle on the health side, as parents reported that they had been on this journey for quite a few years. The FASD representative accepted that there were challenges in the diagnosis of FASD but obtaining a diagnosis and accessing post diagnostic support were important for children and families.

The panel advised that many of the children diagnosed with FASD were children in the care system and Looked After Children (LAC) Paediatricians were often the most familiar with this condition. For cases where there were very obvious facial characteristics the children tended to be diagnosed with FASD by a geneticist. Across the North East and North Yorkshire there were 1 or 2 named Paediatricians that would rule in or out FASD as a possible diagnosis. For example, there were 2 in North Tees, 2 in Durham, 1 in Gateshead and 1 emerging in Sunderland. The FASD Network expressed the view that a named Paediatrician in the South Tees would be helpful in moving issues forward.

The Director of Strategic Planning and Performance at the South Tees CCG confirmed that at present there was no formal care pathway for FASD and Community Paediatricians focussed on a broader range of attention and attachment disorders. The Consultant Paediatrician advised that in her view the lack of a formal care pathway was from the CCG's perspective not such an issue. The broader consultant body were aware of FASD and had attended training days and departmental days on the condition. It was advised that although she was a Consultant Paediatrician with a special interest in neurodevelopmental conditions all General Paediatricians and LAC Paediatricians regularly worked with children who had neurodevelopmental issues and this was already the pathway these children were taking.

It was confirmed that any child referred to a Paediatrician for neurodevelopmental delays, learning disabilities or specific problems with attention / memory and significant behavioural disturbances would be assessed in clinic. A normal part of a Paediatrician's role related to taking background information, family history and assessing whether there had been any nutritional deficiencies prior or following birth. Multi-disciplinary and multi-agency assessments by other agencies would also be undertaken including assessments by Speech and Language Therapists, Physiotherapists and Neuropsychologists. It was confirmed that this process holds true for all children seen in clinic. The Consultant Paediatrician advised that anecdotally she was aware that there were waiting lists for assessment by Children and Adult Mental Health Specialists (CAMHS) for autism, attachment disorders and ADHD. The FASD Network Representative stated that another difficulty was with children waiting for assessments only to be told it was not autism or ADHD. The question was posed as to where families were supposed to access support next.

The Consultant Paediatrician advised that FASD was not a straightforward diagnosis but a diagnosis of exclusion and several factors would be considered including behavioural problems, cognitive problems, poor maternal health, parental drug and alcohol misuse and many other issues that affected a baby's development. In addition, neglect, attachment disorder, genetic background and learning disabilities all needed to be considered. It was stated that there were no definitive biological markers for this condition. FASD and FAS were also an umbrella term for a spectrum of disorders and often it could not be qualified that this child's problems were due to the mother's consumption of alcohol during pregnancy. It was emphasised that very rarely was there only one issue and children coming through the looked after system had often experienced early neglect and childhood trauma. There were also two

versions of FASD AR and D. The Commissioning Manager (South Tees CCG) confirmed that at present there were also issues with the coding for the condition, as there was no register where the information was stored. Data on numbers of people with FASD was taken from those who had been through hospital with a diagnosis of FASD.

The Consultant Paediatrician made the point that what was important was to look at the difficulties faced by these children, find out what those difficulties were and how the children could be best supported. These children needed good access not just to Paediatricians but to appropriate Educational Psychologists. Having supporting documentation, assessments by an Educational Psychologist, CAMHS, education colleagues and the interface between professionals was needed to obtain the right information. The panel expressed the view that at present it appeared we were not getting to that point quickly enough, there was a real need to work with CAMHS, as there was no commissioned pathway to accommodate FASD. It was confirmed that efforts were being made to condense waiting times for autism and ADHD diagnosis. However, it was not necessarily the case that a specific pathway for FASD was the best solution it was more about how the CAMHS system could be best used to provide support for children with FASD.

Reference was made to the fact that the LAC CAMHS contract ensured that CAMHS workers sat within the LAC team and as a result of that direct pathway LAC children could be seen very quickly. It was queried how long it would take for a LAC child to go through the full system and obtain a diagnosis. It was confirmed that behavioural assessments took time and it would still be the case that a child would wait to see an Educational Psychologist as well as undergo other assessments to build up a picture of the child's needs. It was advised that these were children with complex needs and there was no quick fix.

A member of the panel queried whether there was any generic treatment whilst a child was awaiting / undergoing assessment. The Consultant Paediatrician stated that there was no generic treatment for FASD and all of these children presented with very individual needs. When undertaking a diagnosis it was confirmed that a Paediatrician would look back over different aspects and the child's other medical conditions, which could account for the child's presentation. The Paediatrician would also take into consideration whether the child had been seen by a geneticist, whether the child was experiencing significant learning disabilities in school and had the child been seen by an Educational Psychologist. It was confirmed that this process could easily take approximately one year.

The FASD Network representative advised that an Occupational Therapist assessment for a child with FASD was an ideal first step but yet a rare service. The real benefit of this assessment was around slower processing speeds and the impact this could have on regulating a child's behaviour at home, as well as in school. The point was made that in North Yorkshire the response from the commissioners was that there was no commissioned service for FASD. The panel queried where it should look for the gold standard in FASD diagnosis, care and support. It was advised that Canada is seen as an exemplar with Diagnostic Clinicians, Occupational Therapists, and Speech and Language Therapists working collectively. There were also Case Managers pulling all of the documentation together. The child would see each practitioner for an assessment, those practitioners would come together once a month and establish whether it was a diagnosis of FASD or not. The turnaround was quite quick and it would be followed up by a post diagnostic plan.

In response the Consultant Paediatrician expressed the view that there was still much debate as to whether FASD as a condition was accurately quantifiable and that these children needed to be looked at in the whole. It was stated that a lot of children assessed for ADHD or autism will not have FASD but we still need to ensure their needs were being met. Rather than focusing on diagnostic labelling the focus should be on meeting the child's needs and putting the child at the centre of the work. The Commissioning Manager South Tees CCG confirmed that at present there was not a lot of data available to the CCG and this needed to be revisited. It was a chicken and egg situation given the uncertainty of what a diagnosis looked like from a clinician's perspective. If a child was not deemed to be on the autism spectrum or ADHD what pathway of care was available? The child had arrived at the end of the journey, as could only be diagnosed with FASD through exclusion. The FASD Network representative advised that their organisation dealt with families in this situation on a daily basis. The child

may display some of the traits but not fulfil the diagnosis criteria. When no diagnosis was given the children and families were struggling and there was a limit to the support available in the community. The question was also raised as to whether these children received appropriate help at school, as the issue was much wider than meeting a set of diagnostic criteria for ADHD or Autism.

The benefit of receiving a diagnosis of FASD was queried and the point was raised as to whether there was any evidence to demonstrate better outcomes for a child diagnosed with FASD. The FASD Network representative expressed the view that a FASD diagnosis provided understanding for the family in the same way a diagnosis of autism or ADHD did. Children with FASD presented very different challenges for parents compared with those recommended to undertake the prescribed parenting courses and having an explanation also made a difference to the practitioners working with the child. Attachment therapy and art therapy could be provided and the treatment plan was tweaked as appropriate. It also made a difference to the child themselves. Prior to diagnosis it was stated that children often felt they were stupid, bad or a failure. However, the Consultant Paediatrician emphasised the point that evidence of FASD remained in its infancy, in five years' time more accurate data could be presented. The evidence referenced at present was anecdotal and there was not sufficient evidence to substantiate the claims. FASD was a very difficult diagnosis to reach. The Service Manager of Paediatrics at South Tees Hospitals NHS Foundation Trust informed the panel that there were also differences in the diagnostics criteria for FASD in different countries.

The panel expressed the view that irrespective of the diagnostic criteria for FASD it appeared at present post diagnostic support was commissioned from CAMHS and there remained a gap in the current level of provision. A cohort of these children may have learning disabilities / behavioural issues, which also impacted on schools and children's services. The Chair requested that a representative from CAMHS be invited to attend the panel's next meeting, as it was clear multiple systems needed to come into play. CAMHS was a pathway that schools could go down and depending on clinical presentation, even if FASD was not diagnosed, a child should still have an educational health care plan.

Reference was made to the work undertaken in schools and it was questioned how aware staff were of the condition. It was confirmed that a number of training sessions on FASD had been held in schools, however, the onus for management of the condition was not on teaching staff. The Executive Member for Education and Skills advised that there was a real concern around some of the teenagers currently coming through the Pupil Referral Unit. Some had severe behavioural problem and recognition needed to be given to the fact that this was not due to naughtiness but a case of early influences driving behaviour.

The Executive Member for Education and Skills advised that at present a lot of work was being undertaken by Public Health to produce a toolkit for schools, which addressed a number of issues. This 'extra life offer' for schools consisted of a number of short, evidential based, digital animation videos to support young people on a number of preventative issues. Reference was made to a school that had a child with FASD that had produced a short animation video to explain to other children in the school about the condition.

A query was raised in respect of the fact that the majority of children diagnosed with FASD were fostered or adopted and it was questioned whether GPs were able to access birth mother's medical records. It was confirmed that records could be traced, however, the quality of information provided was entirely dependent on the honesty of the mother at the time of the pregnancy. The point was made that it was often more difficult to ascertain medical records where the children remained with their birth parents. With children known to the Local Authority through the LAC system risk assessments would have been undertaken. These records contained the medical history of the child and would be provided to adoptive parents. It was confirmed that Middlesbrough did provide a full disclosure, although it was unknown whether this would have been the case nine or ten years ago.

During discussion the following points were made:

- In terms of commissioning it was evident that children were experiencing a number of problems and it was not easy for them to access support. There needed to be a service available where a child could have a behavioural and cognitive assessment

undertaken, which made recommendations on what support could then be provided if the child did not fit the prescribed pathways of care. Currently there was no other general pathway of care provided.

- Elsewhere across the region the condition was being diagnosed.
- Autism has had to prove its existence and there must have been benefits for children and families in obtaining a diagnosis.
- There needed to be a way of supporting the parents to navigate the system with some form of advocacy in place.
- Preventing FASD before it developed would be the most effective form of treatment for all children.

Reference was made to the preventative approach being taken and it was confirmed that a substantial amount of work had been undertaken by midwives with expectant mothers at 8 to 12 weeks. The Consultant Paediatrician confirmed that the information provided by Midwives in respect of alcohol consumption during pregnancy was much more substantial and the advice provided was unequivocal - FASD was both utterly preventable and incurable. The Chair thanked all of the guests for their attendance and valuable contributions.

AGREED as follows:-

1. That an invitation be extended to the Manager CAMHS, the Principal Educational Psychologist, the Looked After Children's Manager and FASD Network representative to provide further information on this topic at the panel's next meeting.
2. That the Executive Member for Education and Skills be invited to attend the panel's next meeting on this topic.
3. That a copy of the article from the January 2017 edition of the British Medical Journal on FASD be obtained and circulated.