BACCH National Trainees’ Study Day

Friday 20th May 2016
Royal College of Paediatrics and Child Health
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<tr>
<th>Time</th>
<th>Event</th>
<th>Speaker/Details</th>
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<tr>
<td>08:50 – 09.15</td>
<td>Registration and Coffee/Tea</td>
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<tr>
<td>09.15 – 09.30</td>
<td>Welcome</td>
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<tr>
<td>09.30 – 10.30</td>
<td>The deaf blind child</td>
<td>Catharine Infield, Sense</td>
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<td>10.30 – 11.00</td>
<td>Getting familiar with the British Paediatric Surveillance Unit</td>
<td>Richard Lynn, BPSU Scientific Coordinator</td>
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<td>11.00 – 11.20</td>
<td>Coffee break and poster display</td>
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<td>11.20 – 11.50</td>
<td>Handling the Media</td>
<td>Lauren Snaith, RCPCH Media &amp; Campaigns Officer</td>
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<tr>
<td>11.50 – 12.50</td>
<td>How does the NHS work?</td>
<td>Dr Venkat Reddy, Consultant Community Paediatrician, Clinical lead and Associate Clinical Director, Cambridge</td>
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<td>12.50 – 13.45</td>
<td>Lunch</td>
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<td>13.45 – 14.45</td>
<td><strong>Workshops: Session 1</strong></td>
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<td></td>
<td><strong>Behaviour and its management</strong></td>
<td>Dr Max Davie, Consultant Community Paediatrician and Paediatric Mental Health Association (PMHA) Chair</td>
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<td></td>
<td><strong>Attachment disorders: How do I recognise them?</strong></td>
<td>Dr Georgie Siggers, Consultant Community Paediatrician, Kent</td>
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<td><strong>CSAC: training update</strong></td>
<td>Drs Brindha Dhandapani, Consultant Community Paediatrician and CSAC Assessments advisor, Manjari Tanwar We will focus on the CSAC guidance on SLEs for Level 3 trainees. We will also discuss the new GMC guidance with regards to the ARCP outcome for sub speciality training and what this would mean for CCH trainees.</td>
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<td></td>
<td><strong>Achieving child public health competencies through a local immunisation campaign</strong></td>
<td>Dr Kati Hajibagheri, Consultant Community Paediatrician, Chelsea &amp; Westminster</td>
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<td>14.45 – 15.00</td>
<td>Coffee and change over</td>
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<td>15.00 – 16.00</td>
<td><strong>Workshops: Session 2</strong></td>
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<td></td>
<td><strong>Behaviour and its management</strong></td>
<td>Dr Max Davie, Consultant Community Paediatrician and Paediatric Mental Health Association (PMHA) Chair</td>
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<td><strong>Developmental exam in visual impairment</strong></td>
<td>Drs Ngozi Oluonye and Jenefer Sargent, Consultant Paediatricians, GOSH</td>
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<td><strong>START for community trainees</strong></td>
<td>Drs Brindha Dhandapani &amp; Sarah Mills An interactive workshop outlining information on START (Specialty Trainee Assessment of Readiness for Tenure) including assessment format, domains assessed &amp; marking, examples of scenarios, feedback and trainee experience</td>
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<td>16.00 – 16.15</td>
<td>Trainees prize presentation</td>
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<td>16.15 – 17.00</td>
<td>Sleep</td>
<td>Dr Michael Farquhar, Consultant in Paediatric Sleep Medicine, Evelina Children’s Hospital</td>
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<td>17.00</td>
<td>Closing remarks</td>
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Competencies we aim to achieve today

Media
- Have developed a range of skills to enable them to respond effectively to journalists and media colleagues on issues of public interest and controversy.

BPSU
- Be familiar with the work of the National Screening Committee and The British Paediatric Surveillance Unit (BPSU).

Attachment
- Understand the concept of attachment and its expression at different ages and developmental stages;
- understand how attachment difficulties may present at different ages and developmental stages.

Immunisation
- Be able to contribute to the implementation of an immunisation initiative;
- be aware of the factors which contribute to low immunisation uptake and some of the interventions which can improve these;
- be able to support immunisation programmes by contributing to training and auditing outcomes.

How NHS works
- Be able to recognise the opportunity costs of introducing a new service.

Behaviour
- Be able to offer advice on behavioural difficulties to parents and young people;
- be able to provide individual behavioural treatment with parents and young people in straightforward cases and to recognise when to liaise with specialists;
- be able to recognise the nature and severity of behavioural difficulties in the context of developmental stage and social context;
- know the range of treatments for children with mental illness and behavioural disorders and when referral to a specialist may be appropriate;
- be able to involve colleagues appropriately to help with assessment and provide complex interventions for anxiety and depression in both parents and children.

Sleep
- Be aware of the association of sleep disorder in developmental disorders such as ADHD, ASD, learning disability.

Visual impairment
- Be able to assess, investigate and diagnose a broad range of developmental, visual and hearing disorders, explain the outcome and management plan to parents, carers and young people;
- be able to identify infants and children at risk of sensory impairment and be able to recognise when that impairment might contribute to developmental difficulties and refer appropriately;
- be able to recognise when a child with other disabilities may have a visual or hearing impairment and be able to investigate and refer appropriately;
- be able to assess the child with suspected visual and/or hearing impairment, undertake and interpret a range of visual and hearing tests and be able to establish the likely extent of impairment in conjunction with specialist colleagues;
- be able to explain the results of the tests and their implications to the child or young person, parents, carers and other professionals.
Speaker Biographies

Lectures

Catharine Infield (Sense – for deafblind people)
Sense is a national charity that supports and campaigns for children and adults who are deafblind or have sensory impairments. They have been supporting people who have sensory impairments to enjoy more independent lives for the last 60 years.

Catharine is a qualified MSI teacher and Teacher of the Deaf, who previously worked at GOSH in the Cochlear Implant department.

Richard Lynn (BPSU Scientific Coordinator)
The British Paediatric Surveillance Unit (BPSU) enables doctors and researchers to find out how many children in the UK and Republic of Ireland are affected by particular rare diseases or conditions each year.

The Unit was set up in 1986. It is a joint initiative of the Royal College of Paediatrics and Child Health (RCPCH), Public Health England (PHE) and the Institute of Child Health (ICH) to support research into rare childhood disorders.

Lauren Snaith (RCPCH Media & Campaigns Officer)
Lauren trained in journalism and began her career as a reporter working for the regional newspaper Kent on Sunday. Prior to joining the RCPCH, Lauren worked as a Senior Press Officer and was the Editor of a community magazine for a Kent council which won the Highly Commended CIPR Award for Publications.

Since joining the College in 2011 Lauren has led high profile project launches and provided media training for senior College Officers, briefed the Chief Executive and President on key areas of media activity and drafted briefings and press releases accordingly in a bid to grow the College's profile externally.

Dr Venkat Reddy (Consultant Community Paediatrician, Clinical lead and Associate Clinical Director, Cambridge)
Dr Reddy has clinical expertise in acute, community and mental health care of children and young people. He has special interest in clinical management, leadership and large scale service transformation. Dr Reddy has held a number of management and leadership positions including National Clinical Programme Lead for Children with the NHS Institute for Innovation and Improvement. He currently works as a Consultant Community Paediatrician in Peterborough and is the Associate Clinical Director for the Children’s Directorate (Community child health and CAMH) in Cambridgeshire and Peterborough NHS Foundation Trust. Dr Reddy is involved in developing new integrated models of care for children in Cambridgeshire and Peterborough.

Dr Michael Farquhar (Consultant in Paediatric Sleep Medicine, Evelina Children's Hospital)
Dr Farquhar trained in general children's medicine, children's respiratory medicine and children's sleep medicine at the Royal Hospital for Sick Children Glasgow, Nottingham Children's Hospital, The Children's Hospital at Westmead (Sydney), Sydney Children's Hospital and Great Ormond Street Hospital.

Dr Farquhar has been a consultant in the Evelina London children's sleep medicine department since 2012.
Workshops

Dr Max Davie (Consultant Community Paediatrician and Paediatric Mental Health Association (PMHA) Convenor)

Max is a Consultant Community Paediatrician in Lambeth, London's angriest borough. He runs a school age developmental clinic, and has thus accumulated a massive ADHD cohort, to whom he is much attached. He is Convenor of the Paediatric Mental Health Association, which you should really join. He is a sceptic, but not, quite yet, a cynic.

Dr Georgie Siggers (Consultant Community Paediatrician, Kent)

Georgie has been a Medical Advisor for Adoption since 2009, a role she is passionate about. More recently with a move to the country she has taken on the additional role of Designated for Looked After Children for part of Kent. The Looked After Children and Adoption work in Kent is particularly challenging given geographical reasons and the fact that three different NHS Trusts provide health services for a single Local Authority.

Dr Brindha Dhandapani (Consultant Community Paediatrician and CSAC Assessments Advisor)

Brindha Dhandapani is a Consultant Community Paediatrician at Lewisham and Greenwich NHS Trust. She is the London Deanery lead for CCH isthe Assessment advisor for the Community Child Health CSAC.

Dr Kati Hajibagheri (Consultant Community Paediatrician, Chelsea & Westminster)

Bio not available at time of printing

Drs Ngozi Oluonye & Jenefer Sargent (Consultant Paediatricians, Great Ormond Street Hospital)

Ngozi Oluonye – Bio not available at time of printing

Jenefer Sargent completed clinical medical training as a mature student and has worked as a Consultant Paediatrician in the department of Neurodisability at Great Ormond St hospital since 2001. She works predominantly in an outpatient, multidisciplinary setting within the Developmental Vision Clinic and the Developmental Communication service. She has particular interests in the developmental consequences of severe visual impairment, and the developmental and communication needs of children with severe motor speech impairment. She has expertise in the visual assessment of children with known or suspected visual difficulties, including those with complex disability.

She is the paediatric representative on the Royal College of Ophthalmologists' paediatric sub-committee, the Chair of the Visual Impairment Paediatric Special Interest Group, and a Trustee of the Mary Kitzinger Trust, which furthers education, training and research in the field of childhood visual impairment. She is also currently a member of the Seeability Task and Finish Group for the Children in Focus Campaign, and paediatric advisor to the British Childhood Visual Impairment Study 2.
Background Female genital mutilation (FGM) is a harmful practice deeply rooted in many cultures. It is a form of child abuse in the UK, has no health benefits and can cause lifelong consequences to physical and psychological health. It is estimated that over 137,000 women and a further 70,000 girls under the age of 15 have either had or at risk of FGM. (1) It has been a crime in the UK since 1985. The GMC updated guidelines in October 2015 about mandatory reporting duty to safeguard girls and women at risk. (2) Healthcare professionals (HCP’s) require comprehensive, up to date knowledge to identify, treat and prevent FGM.

Aim To assess gaps in knowledge about FGM among HCP’s at a district general hospital. This will allow identification of educational and training needs.

Methods A cross-sectional survey was conducted over two weeks in March 2016 exploring HCP’s knowledge about FGM demographics, the law, health impacts, and cultural beliefs.

Results The survey was completed by 48 HCP’s (15 midwives, 13 paediatric nurses and 20 paediatric doctors). The results are presented in Table 1.

<table>
<thead>
<tr>
<th>Question</th>
<th>Answered Correctly (%)</th>
<th>Answered Incorrectly (%)</th>
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<tbody>
<tr>
<td>1. Prevalence in UK</td>
<td>38%</td>
<td>62%</td>
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<tr>
<td>2. No. of practising countries</td>
<td>48%</td>
<td>52%</td>
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<tr>
<td>3. Is it a crime?</td>
<td>52%</td>
<td>48%</td>
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<tr>
<td>4. Different types of FGM</td>
<td>48%</td>
<td>52%</td>
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<tr>
<td>5. At risk age group</td>
<td>31%</td>
<td>69%</td>
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<tr>
<td>6. Religious support for FGM</td>
<td>54%</td>
<td>46%</td>
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<td>7. Medicalisation of FGM</td>
<td>19%</td>
<td>81%</td>
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<tr>
<td>8. Associated health benefits</td>
<td>77%</td>
<td>23%</td>
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<tr>
<td>9. How FGM is performed</td>
<td>71%</td>
<td>29%</td>
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<tr>
<td>10. Aware of Mandatory reporting duty</td>
<td>58%</td>
<td>42%</td>
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Conclusion This study identifies key knowledge deficits surrounding FGM amongst HCP’s, particularly around the legal status of FGM. The majority of HCP’s were unaware that FGM is occurring in early childhood and the increasing trend towards medicalisation. (3) HCP’s are not adequately informed about the non-religious basis for FGM and that there are no associated health benefits. This may result in under-detection and inappropriate management.

There is an urgent need to address the knowledge gaps identified. Increasing HCP recruitment, focussed teaching strategies, highlighting Trust policies and signposting referral pathways are required to enhance current training programmes. Further studies evaluating training targets by assessment of ongoing knowledge gaps will aid HCP’s to promote the abandonment of FGM and ensure accurate management of its health consequences.

References
1. UNICEF Female genital mutilation/cutting A statistical overview and exploration of the dynamics of change. July 2013
Absent CNKSR2: A Rare Cause of X-Linked Intellectual Disability and Seizures
Lottie Mount, ST6 (Genetics)

X-linked intellectual disability (XLID) accounts for 10% of intellectual disability (ID) in males. Causes for this have been studied, with over 100 responsible genetic mutations being identified so far.

We report on the mutation of CNKSR2 in a male who presented with myoclonic jerks from 5 weeks of age. This deletion, associated with intellectual delay, speech difficulties and seizures, has only been reported twice before in literature. CNK2 protein, the gene being located on X chromosome, is integral for post synaptic function and is highly expressed in the brain.

The proband was born at term, following a normal pregnancy. He was jittery from 4 days old, especially when being carried. At 5 months, during admission for bronchiolitis, myoclonic jerks were observed. These jerks, documented by video EEGs, were found to be non-epileptic in nature, and triggered by movement and loud sudden noises. Neurological examination also revealed dystonic movements.

Extensive neurological and metabolic testing revealed normal or negative results. Neurophysiological and radiological investigations were unremarkable. Standard EEG showed discharges supportive of epilepsy. He was enrolled into multiple trials including international research on hyperekplexia and movement disorders, to aid a diagnosis. He was also consented for Deciphering Developmental Delay (DDD) at 18 months of age.

At 5 years of age, our child got a positive DDD result, revealing a de novo CNKSR2 absence.

Today, at 6 years old, our boy has severe learning difficulties and absent speech. He has clinical features of both ASD and ADHD. He suffers with generalised tonic-clonic epilepsy (well controlled with Epilim) and myoclonic jerks.

The main features of CNKSR2 deficiency are highlighted in this case; however, we may see this genetic finding, a very rare cause for XLID, replicated further in future.

Using Simulation to Teach Child Protection.
Emily Payne¹, Torsten Hildebrand², Matthew Obaid³
¹Community Paediatrics, Cardiff and Vale Health Board, Cardiff, ²Paediatrics, ³Community Paediatrics, Princess of Wales Hospital, Bridgend, United Kingdom

Background Addressing child protection concerns is a daunting task but there often is little opportunity to practice required skills. We felt this challenge could be aided using simulation. Simulation is used frequently and effectively to improve management of resuscitation situations but is rarely used for child protection.

Aim To develop a simulation course for paediatric junior doctors to develop and practice skills in child protection.

Methods The course was aimed at paediatric trainees in the latter SHO years or early middle grade years. The faculty consisted of a Senior Social worker, a Consultant Community Paediatrician, a Consultant General Paediatrician and two paediatric community grid trainees. The programme incorporated two structured talks and table top exercises in the morning.

The afternoon consisted of simulation scenarios conducted in a simulation suite, arranged mimicking a paediatric assessment unit. Three medical actors took various roles with one candidate actively running the scenario. The scenario was observed by all other participants in an adjacent seminar room linked via audio-visual stream from the simulation suite. The scenarios lasted approximately 15 minutes with feedback for 30 minutes. Scenarios covered were: seeing a baby with bruising, sexual abuse disclosure and a strategy meeting. The bruising scenario was divided into three parts; meeting the family for the first time and history taking, discussing the child
protection process and then discussing results of investigations. This case was then discussed at a simulated strategy meeting.

**Results** Thirteen paediatric trainees attended the course. The overall feedback was very positive. Using a scale from 1-5 with 5 being positively “completely agree”, 12 out of 13 participants rated all feedback questions 4-5.

**Conclusions** Child protection is a challenging issue for trainees to address. The skills required can be taught and practiced using simulation. We found simulation to be a popular way to teach child protection to our trainees.

**References**

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**Parental knowledge of risk factors for Sudden unexpected death in infancy (SUDI)**
Dr H Unsworth (ST8 community Paediatrics), Dr R Zoualghina (ST8 Paediatrics), Dr M Sutcliffe (Consultant Neonatologist)

We present results of a service evaluation determining education given to parents of infants discharged from the neonatal unit in Wolverhampton regarding risks for SUDI. We suggest ways to improve support given to families to reduce the risk.

There has been a much slower decline in incidence of SUDI following the initial success of the ‘back to front’ campaign in 1991. Epidemiological studies continue to identify risk factors including prematurity, low birth weight and maternal smoking.

Wolverhampton has one of the leading infant mortality rates in England with 3.2% attributed to SUDI between 2004 and 2012. In the majority of cases at least one modifiable risk factor associated with SUDI was identified.

NICE guidance for postnatal care specifies advice regarding the known risk factors for SUDI should be given to parents.

Using questionnaires we asked parents of infants less than six months corrected gestational age about education they received around SUDI and we asked the neonatal nurses about what education is currently offered. We asked for suggestions for improvement.

The majority of parents were English speaking, but there are many different languages spoken in Wolverhampton. One parent was unable to read.

Most parents received information from a health professional, however only 50% of parents recalled information being provided by neonatal staff. 40% recall information from Health visitors and 50% from a midwife. Most parents knew some of the main risk factors and no parent said anything unsafe.

Neonatal nurses reported giving varied information including factors unrelated to SUDI. There was no standardised guidance for provision of accurate and appropriate information to these higher risk infants.

Suggestions for improvement include more education for health professionals and group education for parents. These suggestions have been taken forwards as part of the service development. Following full implementation there will be a re-audit.
Retrospective audit of children referred to Community Paediatrics for aetiological investigations of their hearing loss

E.Wilson and S.Sivakumaran
Lewisham and Greenwich NHS Trust

**Aims** To ensure that children with hearing loss are offered the appropriate investigations according to British Association of Paediatricians in Audiology guidelines.

**Methods** Medical notes of all patients diagnosed with a sensorineural hearing loss referred for aetiological investigations by Audiology, in 2014 were reviewed. There were 31 referrals, 4 of whom were discharged after multiple DNAs and 5 notes were unavailable. Number of notes studied were 22.

**Results** A total 3 of 22 patients were offered all the correct investigations; 13 of 22 had unnecessary additional investigations requested with no explanation and 19 of 22 were not fully investigated.

Results showed that of those with congenital hearing loss 1 of 10 were offered all the required investigations offered; 1 of 3 with unilateral hearing loss were offered all the required investigations; 1 of 2 of those with bilateral mild hearing loss were offered all the required investigations; 0 of 6 of those with bilateral mild to moderate were offered all the required investigations and 0 of 1 of those with bilateral severe to profound were offered all the required investigations.

**Discussion** The most commonly missing investigation for all categories was CMV testing in 7 of 22. The most common additional investigation requested without an explanation was ECG in 12 of 13 patients.

Congenital CMV causes 10-20% of childhood sensorineural hearing loss and so is potentially being missed. Extra unnecessary investigations will have a cost implication, put patients under unnecessary stress and may identify incidental findings.

Following this audit we identified that more thorough education to those requesting investigations needs to be done. We have created template letters for CMV testing and to request results back from allied professionals. We have created a pro-forma for medical staff to use when assessing a patient with hearing loss.

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Microarray testing in Autism Spectrum Disorder (ASD) assessment

Jessica Slater
ST5 Paediatrics, Yorkshire and Humber Deanery

**Aims** NICE recommend considering genetic tests in autism assessment, especially if there are dysmorphic features, congenital anomalies or intellectual disability. The association between abnormal genetics and ASD is not completely understood.

A service evaluation of our new ASD pathway investigating the frequency of microarray testing and our positive results was performed.

**Methods** A retrospective notes audit. Cases identified using ASD database.

**Results** 167 total patients referred for an ASD assessment; of which 87 confirmed ASD and 49 not ASD. 31 unclear diagnoses, for which the multi-disciplinary team panel meeting is awaited or further information is being gathered.
Notes for 134 patients were obtained. Of these, 78 had confirmed ASD, 52 had microarray results, 3 with abnormalities (3.8%). The 3 abnormal results were on chromosome 15 q11.1 &q11.2, interstitial deletion of chromosome 20 p11.21 and p11.1, interstitial duplication of chromosome 16 p13.11 and p13.12.

In 15 cases there was no microarray requested (11.1%) and in 11 cases it was requested but not done (8.2%).

39 patients did not receive an ASD diagnosis, 22 had microarrays, and 7 had genetic abnormalities (17.9%).

There were 17 cases of unclear ASD diagnosis; 5 had microarrays with 2 showing abnormalities (11.7%).

Conclusion We performed microarray testing in 58.9% of total patients. In 18.7% of all cases it was documented for a request for a microarray however no result was obtained.

Of the children tested, only 8.9% had positive genetics, and only 2% were positive in the confirmed ASD group. The 3 positive results in ASD all had different genetic abnormalities.

This service evaluation highlights the importance of considering a genetic testing is ASD, however finding a significant abnormality is rare and each child should be individually assessed as to whether it is indicated.
Speaker handouts

Dr Venkat Reddy
*How does the NHS work?*

Other presentations not available at time of printing.

It is hoped they will be available via the BACCH website after the event.
How does the NHS work?
Dr Venkat Reddy
Community Paediatrician
Cambridgeshire and Peterborough FT

What matters to You?
• What is your context?
• One thing you always wanted to find out
• What problem you might solve?

Junior Doctors strike as a symptom
• What are the root causes?
• What does it teach us about how NHS works?
• How can we influence the working of NHS?
Micro Level
- Your Team
- Your service
- Your Directorate
- Your organisation

Local Health System
- Primary Care
- Community Care
- Hospital care
- Mental Health

Commissioning
- Central
- Local
- Joint with Local Authority
Finance
- Devolution in NHS
- Autonomy for devolved nations
- Funding flows
- Resource allocation

Performance Monitoring
- Quality
- Activity
- Business

Workforce
- Health Education England
- Royal Colleges
- GMC / NMC
Reforms and the future

- Integration
- Vanguard pilot sites
- Sustainability and Transformation Plans

Pulling it all together

- Understand your local system
- Be prepared for more change