Q&A BANNFU WEBINAR SEP 24 2020

Question / Topic Suggestion	Answer / Response
There is CoLab partnership which is established in recent years to improve healthcare of children with medical complexity. Preterm and neonatal cohort of infants will form a substantial group of these infants. How do we link these two groups to establish collaborative working and avoid duplication within these two special interest groups.	Thank you very much for your question. We would love to hear from you. (There is CoLab partnership which is established in recent years to improve healthcare of children with medical complexity. Preterm and neonatal cohort of infants will form a substantial group of these infants. How do we link these two groups to establish collaborative working and avoid duplication within these two special interest groups.).
CoLab is established by coming together of Dr Hilary Cass, Dr Ronny Cheng and other similar interest groups to look after and support families with 'child with medical complexity'. Together for short lives have collaborated with CoLab as well. Though the aims and objectives of each group (ie CoLab and BANFFU) will be different, however I do believe that around the transition at 2 year developmental check both the work streams will benefit. I'm trainee with neonatal interest and a member of CoLab. Rashmi Mehta.	Thank you so much Rashmi. We will be in contact with you.
Are you actively looking for parents? NeoMates parents group is a great source of knowleadgeable, motivated parents.	Yes we would definitely be looking for parents that may want to join us. Please ask NeoMates to make contact with us by emailing bapm@rcpch.ac.uk
How do we register for the study day?	The study day will advertised via BAPM and social media to begin with. Registration will be via BAPM.
A model of best practice that would improve patient care and experience from neoantal unit to neurodevelopmental follow-up in community. More adivce on developmental care can be improved in a DGH setting.	Thank you. Yes, you are absolutely correct. This is the model of care we want to practice. Hopefully, with our streams on education and service provision we may raise awareness and provide recommendations.
Are we also looking at separate functional hearing screening beyond OAE and ABR for all babies receiving intensive care and neonates with meningitis?	Thank you. This is important and very specific and will need revision of the specific guideline from the National Screening Committee.
How should we ensure that autistic features that do not fit the full diagnositic criteria are recognised for educational needs? Many esprems do not acquire the ASD label and so may not recieive the approach to learning that they need.	That is correct - we are currently looking at how outcomes can be captured in the way you describe in routine neonatal data collection.

My clinical experience would indicate that a 4-year-old should be for all kids with early hospitalisation, not just <28 weeks. Also, we see emergent diffs at about 7 years, so I think LT FU is essential. Welcome your views.	Thank you so much. We would like to go all the way to 4y. Further to this would probably be beyond our neonatal experience which is why we need other groups to join us. We also need to consider the resource implications of expanding routine follow-up to 4 years for all early hospitalised infants, not just those born <28 weeks.
I think if we get it right in the earliest years, we will see less emergent needs at 7 year. At the minute, the lack of awareness/understanding especially in education impacts significantly on these young people and their families. Happy to join.	Wonderful. We would like to hear from you. Please contact BAPM with your interest and you will be redirected to BANNFU. Also, please take a look at the free PRISM preterm birth e-learning resource for education professionals (www.pretermbirth.info). This can be shared freely to raise awareness of preterm birth among schools and teachers.
How can we influence NICE to include follow-up guidance for term babies with HIE 2+, ECMO/ECLS, PPHN requiring iNO, hydrops...	Yes, this is an important question. We must think about it. Many thanks.
Is research planned on the impact on infant mental health related to separation from parents and parental anxieties related to Covid restrictions pre intra and post delivery?	Yes. There is already some groups looking into this and papers have been published on the subject.
Would BANNFU be looking to advising early general movement assesment in NNU and would it be possible to organise training for interested HCP?	Yes, we will be advocating this. We would refer you to the GM course, as you need to be certified and your reliability assessed for using this test.
Is there a role for ND follow up of babies born to substance misusung mothers ie. Neonatal Abstinence syndrome? Would BANNFU be interested?	Substance abuse would be categorised as high risk, therefore we believe that full neurodevelopmental follow-up should be offered to these children.
Do you see a role for neonatal nurses becoming involved in neurodevelopmental assessment/follow-up at term or on discharge from the neonatal unit?	Yes, definitely. There are already nurses doing developmental assessments like NBO in Neonatal Units. You just need the correct training.
Who carries out the PARCA-R assesment?	Parents complete the PARCA-R questionnaire.
PARCA-R doesn't match when you see the patients. Parents find it really difficult to complete.	We are aware of this but it has been very useful for the majority and some services are attaining 100% follow-up rates. We will be sending out a parent survey soon to capture this and to feedback to the PARCA-R team.

You say yes to nurses doing assessments. Doesn't NICE say certain assessments have to be by a doctor? And can we get that changed (corrected!)?	It should be a MDT that may include nurses - It depends on the assessments and the specifications of the manufacturers. However, if nurses have the correct training, experience and knowledge, there is no reason to prevent them form supporting the ND teams.
I am the mother of a very preterm baby and I would be happy to be involved.	Thank you, we would love to have you. Please contact Kate Dinwiddy about BAPM membership by emailing bapm@rcpch.ac.uk
For Badger 2 year follow up/outcome data, PARCA-R is not recognised as a standardised assessment and there is nowhere to officially document results. During COVID this then meant that NNAP audit data was not recorded and classed as a 2 year outcome not done. Can Badger have a box for PARCA-R?	We are working on adding the PARCA-R scores to the 2y questionnaire, but this should not prevent you from using its results. 1- For the Development question, you may use the Cognitive-Nonverbal scale 2- For the communication questions you may use the answers from the questionnaire 3- You may use the free text section to say that you used the PARCA-R and provide the results here.
Are there any plans to include motor assessment in PARCA-R?	Prof Johnson and her team are currently exploring options to develop a patient-based motor outcome assessment.
Can PARCA-R be used for babies with brain injury?	Yes, the PARCA-R can be used to assess the develpment of all children in the general population as it is norm-referenced.
Are people using the PARCA-R as well as the Bayley at 2 years?	Before Covid most units were using Bayley and some were using both. During Covid mostly using PARCA-R, as it doesn’t need to be face-to-face. At present, very few are still doing face-to-face assessments.
Thank you, we have been using it during Covid too, as the Bayley looks at cognitive and communication. I was just wonedring if this is duplication? (Are people using the PARCA-R as well as the Bayley at 2 years?).	Yes, it would be duplication. For the units using both, their approach was to use PARCA-R first and refer to Bayley if the child has problems, if the child is outside the age range for PARCA-R at assessment, or if the parent is not able to complete it, for example if they do not speak English.
I would be interested in training to use PARCA-R calculations and how to interpret.	Please contact Prof Sam Johnson by emailing parca-r@le.ac.uk

If PARCA-R shows delay, would you recommend doing Bayleys or Griffiths?	In Covid times, the first option would be to go through the questionnaire with the parents and confirm that there is delay. Depending on the results and if there is a possibility for a face-to-face then yes, we probably would recommend a referral for a formal test by a professional before embarking on other referrals.
With research highlighting an increase in safeguarding issues in preterm babies, which I understand can impact on neurodevelopment, are there plans for any research in relation to this and is it seen as a factor in assessing babies and children?	You are correct. These children should be classified as high risk and therefore should be having ND FU services.
Question re: the PARCA-R - is there any effect of socio-economic or cultural background on the results, for example the language and vocab?	Please see our latest report Johnson S, Bountziouka V, Brocklehurst P, Linsell L, Marlow N, Wolke D, Manktelow BN. Standardisation of the Parent Report of Children's Abilities-Revised (PARCA-R): a norm-referenced assessment of cognitive and language development at age 2 years. The Lancet Child and Adolescent Health2019 Oct;3(10):705-712
Question re: 4 year followup, does BANNFU know who is doing it? As a trainee, I've seen it done by community paediatrician. Is this the case elsewhere?	A good amount of community paediatricians are already seeing 4-year-old ex premature children, and some neonatal units are planning on starting by joining the community paediatricians.
How do you get involved in the research?	Please contact BAPM bapm@rcpch.ac.uk and, from there, you will be directed to our research stream.
Any plans for having PARCA-R in Arabic?	The PARCA-R team are looking into producing futher versions.
I completely agree about the value of the later 4yr and beyond assessment and that 28 eeek	Thanks.
Sorry, continued.....that the 28 week cut off is at arbitrary. The major challenge is resources.	You are correct. These children should be classified as high risk and therefore should be having ND FU services.
Is there a local guideline on neurodevelopmental follow-up or would you be happy to produce one?	Yes, a NICE guideline has already been published. Our local guideline adds one more review.
During these COVID times what score would you recommend we use to assess fine and major motor function either by telephone or video when face-to-face is not possible please?	Neurodevelopmental assessments are better done F2F. However given the situation, age dependent checklists, really good observant parents with good cameras on their laptops. Not as if you are there, but it has worked for some.

Thank you, we do struggle with lack of video.	Faced with the impossibility to do F2F, questionnaires and checklists confirmed by video are the next best option. Telephone is probably unreliable. You may ask parents for their consent to contact them via FaceTime which is pretty safe or others, like Telegram, but you do need to confirm their consent by phone first.
We have been told there is no guidance or evidence for doing 3 months or 6 months or 1 year follow-ups hence not necessary. Is there any support?	It all depends on the outcomes you are measuring and the reason for looking at those outcomes. On one side, there is plenty of evidence now on the effects of prompt diagnosis and implementation of early intervention with babies and families. The NICE guideline has more than 800 references in all about follow up and assessments. On the other side, early outcomes (3, 6, 12 months) are more effective in changing practice in Neonatal Units faster than 2y or 4 years. Outcomes involving parents (psychosocial interventions) are effective throughout.
Do you have Welsh translation please?	Yes, a Welsh translation of the PARCA-R will be released in October 2020.
I think it was mentioned earlier - given unit variations - are you looking to develop a consistent strategy/pathway for neurodevelopmental support for those babies still on the NICU? Early intervention and parental engagement even before they leave our units?	Indeed, our core group is majority of Neonatologists with a special interest in Neurodevelopment. We start our ND FU pathway right from pregnancy and all the way through to 4 years.
I would like to know how to set up across various LNU in UK is. We are one of the busy LNU, but struggling to develop neurodevelopmental care service. Any advice/ideas would be highly welcome.	A short scoping exercise will identify your local therapists (OT / Physio / SALT) with interest in neurodevelopment and developmental care. Invite them to form a group with a Lead Consultant and a Coordinator. We would be happy to advice if required. Please contact BAPM referring to BANNFU.
Who is best placed to highlight which babies need follow-up and then coordinate neurodevelopmental follow-up and for how long.	Please refer to the NICE guidelines on developmental care of the high risk infant to begin with. A paper by us on ADC about the review of the guideline is also available for discussion of the issues in your local centres. (McKinnon K, Huertas A).
What is the best discharge planning and follow up for a floppy baby?	As high risk, this baby should be placed on the ND follow-up. As a baby with an already defined neurological diagnosis a joint with a neurolgy service would be advisable, and as already defined impairment then CDT with full therapy should be in place from early on.

Is BANNFU aware of music therapy in neonatal care and its Lon-term effects on neurodevelopmental outcomes and would they be interested in supporting its use in neonatal care in the UK? Neonatal management of grade 4 IVH to reduce poor neurological outcome. Consider low dose phenobarbitone? Neonatal seizure - babies with anticonvulsants at discharge. How to wean and what parameters to consider. Recent consensus please. Use of levitaracetam in first line neonatal seizures.	On interventions in general, outcome data should provide good quality evidence of benefit before being endorsed by the Neonatal Community. From BANNFU we would be able to advise once we have enough data collected by the Neonatal Units (i.e. outcomes of babies using phenobarbitone vs outcome son babies from units not using phenobarbitone, or exposed to music vs not exposed, or using family integrated care vs nor using family integrated care). We will depend on the data that is collected and the outcomes we are interested.
Where do you see the future of Bayley III in follow up?	Bayley III will be upgraded into Bayley IV. Different views about how to use it are: 1- with the use of PARCA-R, free of use, completed by parents, reliable according to research, we may not need the Bayley at 2 years unless the child is not in the window of age for PARCA-R, or language is a problem in which case Bayley could be an option, 2- Bayley IV for the units and networks already using Bayley with the purpose of developmental trajectories, and 3- for more detailed information for research purposes or QIPP matching MRI/MRS/EEG.
Please give us a risk/benefit of not restarting 2-y assessment in the current climate.	1- Not starting at all: RISK- not identifying children at risk, no early dx, no early intervention, less good outcomes, no audit of NICU service, no support for families, no planning of services, BENEFIT- No benefit. 2- Starting Virtual with Video and good quality questionnaires: RISK- May not be able to identify problem in children for who the questionnaire is not completed or is partly completed, not able to examine and get objective measures. BENEFIT- None.

Top tips for the 2year assessment by video	Yes, good question. 1- You need a coordinator to book the clinic ideally by video. The child must be available and awake for observation. 2- Send the PARCA-R in advance and have it reviewed and scored on time for the clinic. 3- Make sure you know the case including parents and child's names before you meet the family. 4- Ideally ask for measures of OFC height and weight in advance. 5- Ask to have a few toys, books, blocks, cups, small objects, a ball, crayons and paper. 6- At the clinic ask for concerns first, then follow the questions on the Badger Outcomes questionnaire (use PARCA-R for questions on cognitive and communication). 7- Use HINES or other structured assessment for Neurology observation (ask the parents to examine while you instruct).
The 4 year assessment How to achieve it, what teams and resources will be needed and how to address the gaps in services to achieve this.	NICE guideline is already recommending the 4 year assessment. You may want to start with a scoping exercise to find out who is doing what in your area (include therapists, clinical and educational psychologists, community paediatricians, etc) and start from there. We believe that a neonatologist should be included in the MDT assessing the child so that outcomes that matter in NICU are fed back to NICU. Parents should be included at all levels so outcomes that matter to them are feedback to them. Create the need by demonstrating that is cost effective and start slowly one at a time.
As a child psychiatrist, I'm interested in infant mental health, including that of babies who have spent time on neonatal units. I would be interested in how the impact of their neonatal unit experience, especially negative and traumatic ones, might affect how parents/carers view and assess their baby's progress and ability especially if they haven't had a chance/been able to process what they experienced in a helpful way.	This is an extremely relevant topic for families, which has been addressed in many ways by different authors. Nowadays the aim in NNU is to try and reduce the impact of prematurity in the family by improving care, supporting families in NNU and in follow-up, This is an area most OT would be trained in and interventions like Kangaroo care, Family Integrated Care, Brazelton, etc. Outcome data is key to be able to measure the size of the problem and if enough data is available would allow comparisons between units in UK.