BACCHNEWS
BACCH
British Association for Community Child Health
Sept 23

Genomics for Community Paediatricians p9-13

Contents and Contacts

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BACCH is an organisation representing professionals working in paediatrics and child health in the community. It is a specialty group of the Royal College of Paediatrics and Child Health.

BACCH welcomes new members!

Benefits of membership

- 'BACCH News' BACCH's quarterly flagship magazine: paper copy posted to all members; e-version available to download for members only via the website. *(Student members will NOT receive a paper copy of the Newsletter.)*
- Monthly email updates.
- Reduced delegate rates to BACCH conferences.
- Option to subscribe to the Journal Child: Care, Health and Development, for the reduced rate of £20 per year. *(Not available for those who join as overseas members or student members.)*
- Regional coordinators organise local meetings and represents members' views to BACCH Council.
- Members' only content on the BACCH website.

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BACCH is an incorporated company (06738129) limited by guarantee and a registered charity 1129758 in England and Wales.

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Published by
CKN Print *www.cknprint.co.uk*

Publishing 2023/4

Editorial deadline	Publication date
15 November '23	15 Dec '23
15 February '24	15 March '24
15 May '24	15 June '24
15 August '24	15 Sept '24

Advertisement rates for 2023/4

	Commercial	Charity/Not for profit/NHS jobs advert rate
Back page	£585	£290
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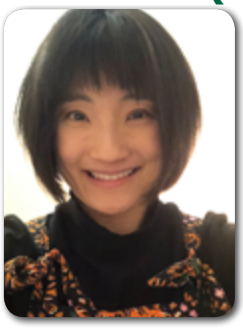
BACCH
British Association for Community Child Health

From the (Trainee) Editor



On behalf of the newsletter team, welcome to the September edition of BACCH News.

September for me has always felt like a transition point between endings and new beginnings. As Summer begins to fade, and the trepidation of a new rotation creeps in, I find myself trying to get my brain in gear, ready to learn and tackle the new job ahead. I hope you have all enjoyed a lovely Summer and had a chance to recharge your batteries. I feel hopeful that the following pages will enlighten you some new learning nuggets, refresh your memory on some key topics and offer a little helping hand to preparing you mentally, clinically and professionally, for the new season ahead.

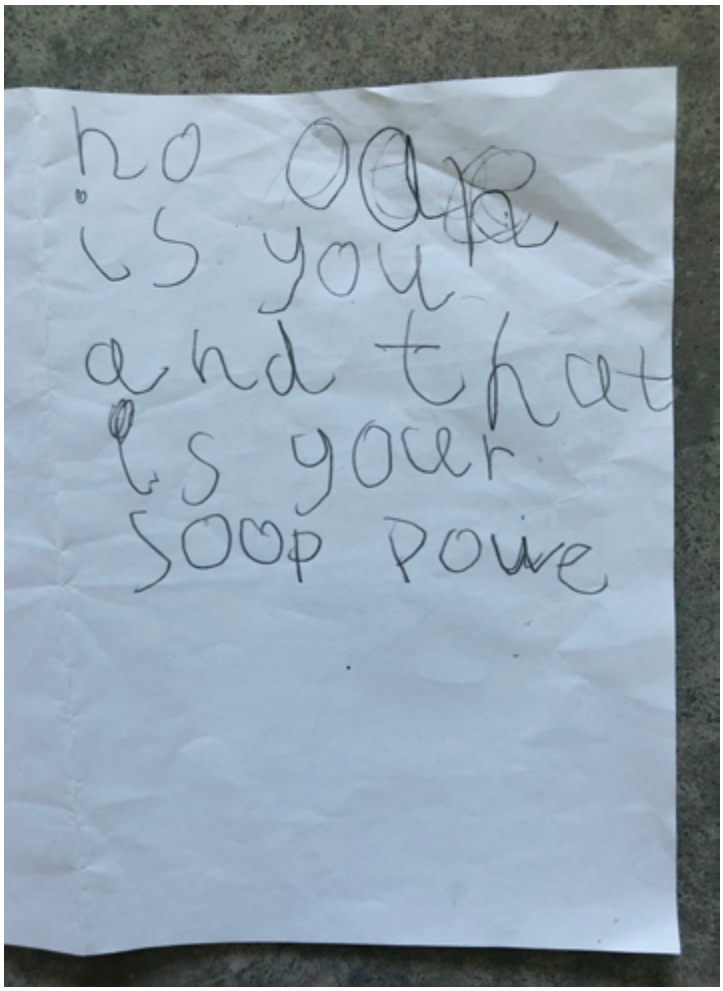
Just as my co-trainee editor, Thushara, glided seamlessly back into clinical work following maternity leave, I now write from the midst of my third maternity leave. Brainstorming ideas, networking with potential authors and overseeing this edition of the NEWS has been a key component in keeping me sane and feeling connected with the professional world whilst the other part of my life (aka juggling three young kids) is still adjusting to a new level of chaos!

This issue of the NEWS includes a number of clinically important topics, interesting projects, and ideas and resources to promote our wellbeing. Our cover feature is on genomics, specifically tailored for the community paediatrician. In this article, Elaine effortlessly summarises a vast topic that is rapidly advancing and gives practical tips on how to approach genetic testing in neurodevelopmental disorders, and when it might be appropriate to request whole genome sequencing. I have earmarked this article to re-read just before I go back to work next year! Suzi refreshes our memory on the child death review process which many of us, as community paediatricians, will be involved with at some point given the nature of our work with children with life-limiting conditions. Debbie provides us with the third helping of our four-part series in which she discusses the complexities of the 'social brain' and risk-taking behaviours of adolescents. In safeguarding, Tina summarises an important recent paper on how to approach evaluation of children presenting with bruising or bleeding who are undergoing child protection investigations for possible physical abuse.

Kidzmed is a project which I first heard about through listening to one of the RCPCH Podcasts on my way to work last year. It struck me then how ingeniously simple yet effective this QI project is. The benefits are really a no-brainer and Dimple summarises this for us and considers the relevance of training our own patients to take tablets within community paediatrics. The best QI projects are ones which really make an impact on our everyday practice and Jemma outlines her process in a project which came out of her personal experiences in clinic. In training, Florence gives some great practical tips in approaching the START assessment from the perspective of a community trainee (I wish I had this prior to my recent START assessment, although I did have the fortune of being part of her study group!). Nia, our CSAC chair, also gives us an informative update the brand new Progress Plus curriculum and its potential impact on community child health training as well as discussing the much debated 70:30 split in GRID training.

This month's spotlight features Dr Michelle Heys, chair of the new BACCH Strategic Research Group and a community paediatrician whose passion for working with the most vulnerable children shines through her reflections. She candidly shares with us some extremely tough moments in her career. Through it all, prioritising self-compassion and wellbeing has been central in helping her overcome adversities and come out even stronger – an inspiring read.

Speaking of compassion, this summer brought us as a family to the other side of the NHS when one of my kids underwent a surgical procedure. Every member of staff showed bucketfuls of kindness and I felt a renewed sense of gratitude for the NHS but mindful that self-care is so vital in being able to display compassion towards others. With this in mind, I encourage everyone to read Anna's latest instalment on wellbeing. With September being a fresh start for many, we should take heed of Anna's advice and prescribe ourselves our very own 'kit bags' with things that bring joy into our days. I had a 'wild strawberry' moment (again, read the article!) when my eldest presented me with a little handwritten note of a quote he had heard. I share this below with a 'translation' of his 5-year-old writing in the hope that it helps some of you as it does for me. I think I will pack this into my kit bag when I re-join the clinical world.



'No one is you and that is your super power' – Maxi, aged 5

Finally, this is the last edition that I will be actively involved with as I come to the end of my two-year term with BACCH News. Thank you to Isabelle for being so diligently helpful and knowledgeable, Paul our design guru for making every issue look so fabulous and Thushara for the creative ideas, the organisation and generally being a superwoman with a bigger brood than me! Thanks also to Deepak for being the king of cool and granting me liberty over editing this edition. Do consider putting yourself forward for trainee editor or encouraging the role to others; it is such a rewarding role and you get to work with a super friendly team! I will look forward to being surprised with quarterly paper copies of the NEWS and hopefully sharing some more ideas with you all in our wonderful network of community paediatricians.

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Continues overleaf

From the Editor

Hello September!

As Shuang said, she has had full liberty to edit and the pair (Thushara & Shuang) are fabulous. Think of them as the pair of registrars, whose presence on a night shift allows an on call consultant to rest peacefully! Shuang has covered article highlights in her editorial so, I am going off on a tangent now.

Have you ever felt you have not achieved anything? Since the last edition and this, I have been quite busy, life has been tough, but I don't think I have achieved anything! At least that's how I feel. Many emails have gone unread or unresponded, admin is piling up. Work has been "CTRL+ALT+REPEAT". How about you? Reading Michelle's Spotlight article, it makes sense. "Learn, Grow stronger, keep soldiering on". Going back to my moaning, it's all not mundane. To me, the recent conviction of Lucy Letby and the sad case of Sara Sharif highlight the importance of preventive and safeguarding work we do. So, hang in there and keep making a difference. There is a lot more to do and Doug has outlined this, in his writeup.

It is sad to see a talent such as Shuang leave. Dedicated, diligent, and determined, she saw things through, efficiently. If you feel you can be the next Shuang, write back to me.

So long until next time.

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From the Chair

I am writing this piece in the run up to the BACCH Annual Scientific Meeting (ASM) in Manchester. I really enjoy being with like-minded people and last year's meeting in Leicester was very reinvigorating; I commend the ASM to you. The first day of this year's ASM is also my first day as a retired Chief Medical Officer and NHS Trust Deputy Chief Executive; after 35 years in the National Health Service, this new phase will take some adjustment, but I am looking forward to being able to invest more time and energy into the second half of my term as your Chair. There is lots to do.

It was at last year's ASM that the idea was raised with me of BACCH creating a training programme for trainee Community Paediatricians. We have explored doing this with the Royal College of Paediatrics & Child Health (RCPCH) and I mentioned that discussion in my last column. I am clear that this is not an avenue that will deliver what trainees want. The trainees and I are discussing how BACCH can become the provider of choice of Continuing Professional Development for those parts of the Progress Plus curriculum that are not easily delivered on the job. I think this training could also be valuable to other professional groups such as Advanced Clinical Practitioners and Physician Associates. This will take time to develop and needs to build on the BACCH & BACAPH Improving Services Series (BBISS) material, but I have more time now. If you would like to join this enterprise, please let me or Isabelle know.

We all know that the number of children waiting for neurodevelopmental assessments, particularly for autistic spectrum conditions, is very high and into thousands in some places. Individual trusts and local systems need to create their own plans to address these backlogs, but there is an opportunity for BACCH to support commissioning bodies across health, education and social care. I was privileged to be in contact recently with the Chair of the Royal College of Psychiatrists Child and Adolescent Faculty, the NHS England National Clinical Directors for Children and Young People's Mental Health and Paediatrics to discuss this major challenge. We think now is the time to reimagine services for children with neurodevelopmental disorders and, using the best evidence we have available support commissioners develop services that provide early intervention into nurseries and schools without a diagnosis, join up Attention Deficit Hyperactivity Disorder and Autism Spectrum Disorder assessment processes and bring together the assessment and intervention functions that are spread across providers in too many places. We are seeking a mandate from the NHS across all four countries to do this work.

I am really encouraged that RCPCH recognises the specific neurodevelopmental and broader community child health service challenges we face and is planning a campaign that BACCH will support. Issues we will highlight are that:

- Community waiting times and service recovery sit outside of NHS & government-led recovery campaigns, and receive little national attention or investment compared to other health service activity. Likewise, the national NHS teams do not have the same level of oversight on community child health services as on acute services.
- Community paediatrics now has the longest waits of any part of the health system, with 13% of the waiting list waiting for over 52 weeks.
- Children are being left behind with children four times more likely than adults to wait for over a year for community health services. There are now more children waiting for over 52 weeks than adults, despite children being a much smaller population group.
- While 72% of adults on the community waiting lists are seen within 12 weeks, less than half of children are seen within the same timeframe.

We will be developing briefings for parliamentarians, with the aim of getting questions or a debate in parliament on children's community health services. The RCPCH media team will be working on a series of press articles to draw attention to the impact of long waits on children and their families, and we will also be working to highlight this issue with NHS authorities in the four nations.

There is still work to do to refine the specific actions asked of government, but the RCPCH suggestions include the following policy calls:

- Overarching call for greater investment on community child health services and workforce, reflecting that the NHS workforce plans outline a move towards community-based care, without adequate investment.
- NHS and government in the four nations to focus on and commit to addressing long waits across child community services. Community waits are outside of the scope of the NHS recovery campaign and data quality is poor.
- Action to address consultant gaps amongst community paediatricians (alongside the increase in sub-speciality Community Child Health (CCH) posts).
- Invest in wider community child health workforce by creating more Advanced Clinical Practitioner (ACP) roles in community services and ensuring community child nursing numbers keep pace with the 92% increase in adult nurses set out in the workforce plan.

Do share any thoughts you have on making this an effective campaign with me as this will be a focus for the next few months at least. Remember there are roles in BACCH that are vacant, please consider volunteering for a regional or national role as many hands make light work.

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CHILD HEALTH

Child Death Reviews in England: an overview

'The death of a child is a devastating loss that profoundly affects bereaved parents as well as siblings, grandparents, extended family, friends and professionals who were involved in caring for the child in any capacity. Families experiencing such a tragedy should be met with empathy and compassion. They need clear and sensitive communication. They also need to understand what happened to their child and know that people will learn from what happened. The process of expertly reviewing all children's deaths is grounded in deep respect for the rights of children and their families, with the intention of preventing future child deaths'.

Child Death Reviews Statutory & Operational Guidance 2018 p10[1]

Background

Following a series of high-profile miscarriages of justice involving mothers who were wrongfully imprisoned for the murder of their children, it was recognised that there was a need for a thorough multiagency response to unexpected child deaths, and a process to ensure each case is appropriately reviewed, both underpinned by evidence-based guidance. From 2008, Local Safeguarding Children Boards were responsible for setting up multiagency Child Death Overview Panels (CDOP) and putting the 'Rapid Response' and child death review process into place for their local area.

In England, the majority of child deaths are due to medical causes[2]. Since 2008, the wider landscape of learning from deaths has evolved: there have been a number of public inquiries where failings in care were identified. There is now a statutory Duty of Candour, Medical Examiners have been introduced, Perinatal Mortality Reviews assess obstetric and neonatal care, and there is an increasing focus on review of service provision & effective learning. Statutory guidance has been updated, and the process and breadth of reviews have expanded, becoming increasingly standardised. Family support, information, and involvement in the review process remain central.

Since 2018, the Child Death Review (CDR) process is commissioned by 'Child Death Review Partners' (Local Authorities & Integrated Care Boards) for a particular area, and is now overseen by the Department for Health and Social Care. There remains considerable variability across England in terms of the make-up and delivery of CDR services, but the underlying processes are consistent across the board, aligning to the statutory guidance.

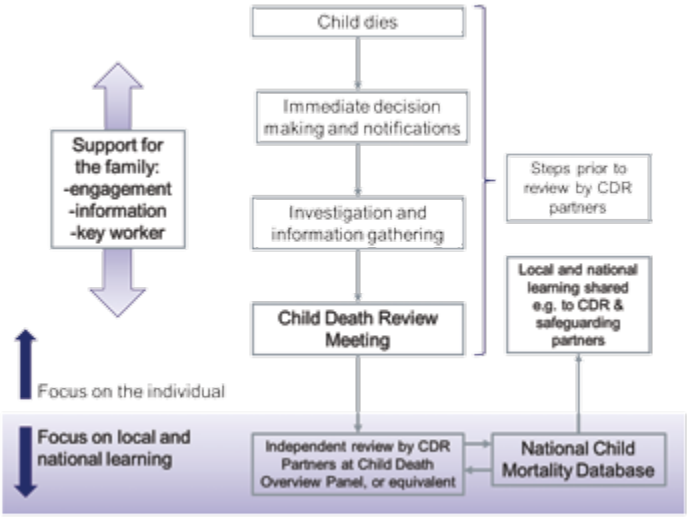
National Child Mortality Database

Since 2019, it is mandatory for local CDR data to be shared with the National Child Mortality Database (NCMD). The NCMD is the first scheme of its type in the world to collect detailed information and analyses for every child death at a national level. It publishes regular thematic reports using this data on topics such as suicide, deprivation and deaths due to trauma. It also collaborates with charity and research partners to provide training and resources for quality improvement in child death review, as well as information for professionals working with bereaved families.

Family support & involvement

Ensuring appropriate support for bereaved families is central to the CDR process. As set out in the latest statutory guidance[1], every family should be assigned a Key Worker – a single named professional who can offer them support, help them to access specialist resources, and provide information about the review process. The Key Worker also represents the voice of the family in meetings and supports the family with addressing any questions or concerns they may have.

The Child Death Review Process



The Child Death Review Process flowchart. Taken from Department for Education (DfE) (2018) *Working together to safeguard children: a guide to interagency working to safeguard and promote the welfare of children.* London: Department for Education (DfE)[2].

The process for reviewing deaths is set out in full in Child Death Reviews: Statutory & Operational Guidance England (2018)[1], building on the statutory requirements of Working Together 2018[2]. The essential steps in the process are as follows:

Phase 1: Child dies – immediate decision-making & notifications

If a child (liveborn of any gestation, up to the age of 18 years) dies, within the first couple of hours, decisions are taken based on the available facts about the circumstances of death:

- Are criteria met for a Joint Agency Response? (See below.)
- Can a death certificate be issued or does the case need referring to the Coroner?
- Are there any concerns for the immediate safety of others?
- Have there been any issues in care or service delivery that would warrant further investigation?
- How are the family best supported?

Following the death of a child, practitioners from all agencies should notify the local Child Death Review partners, using a standardised 'Notification Form'. In most areas across England, this is done via the online eCDOP portal, facilitating simultaneous notification to the NCMD.

The Joint Agency Response (JAR)

This is a joint, coordinated multiagency response that follows the guidance set out in 'Sudden unexpected death in infancy and childhood' (The 'Kennedy Guidance')[3]. It involves joint working between Police and Health Professionals, including taking a history from the family, examining the body and visiting the scene or home.

Continues overleaf

A JAR is activated in the following circumstances:
- Death due to external causes;
- Sudden and unexpected death (i.e. not anticipated in the preceding 24 hours, and with no immediately apparent medical cause);
- Death occurring during detention under the Mental Health Act, or while in custody;
- Medically unattended stillbirth;
- Death due to suspicious circumstances.

Where a child has collapsed due to any of the above, and has a poor prognosis, the JAR should be initiated at the time of collapse (not the time of death), to ensure that information around the scene and time of collapse is captured effectively.

Phase 2: Investigations & information-gathering

This is often the longest phase in the CDR process, as it can take many months (or years) for some investigations to reach a conclusion and for the findings to be shared.
- CDR teams will request 'Reporting Forms' from professionals involved in the life of the child, to provide detailed case information to both the local Child Death Overview Panel (CDOP) and the NCMD.
- Agencies involved undertake their own governance reviews, to review the quality of care they provided and identify any learning.
- There may be many parallel investigations taking place, including the Coronial investigation process, police investigations, Child Safeguarding Practice Reviews, and external governance reviews including Healthcare Safety Investigation Branch maternity reports.

Phase 3: Child Death Review Meeting (CDRM)

This is a professionals-only multiagency meeting, which involves those who cared for the child during their life and those investigating the death. The aims of the meeting are to review all the information gathered around the circumstances of the death, share, collate and identify any additional learning, review support for the family and staff, and start the case analysis. The standardised process of analysis involves identifying factors that may have contributed to the vulnerability or death of the child. Factors across four domains are considered:
1. Factors intrinsic to the child (including antenatal factors);
2. Factors in the family or social environment;
3. Factors in the physical environment;
4. Factors in service provision.

Any factors which could potentially be modified by means of a locally or nationally achievable intervention are noted ('Modifiable Factors'). The cause of death is then categorised, learning recorded and any necessary actions raised. The draft case analysis is sent on to the CDOP.

Phase 4: Child Death Overview Panel (CDOP)

This is a multiagency panel bringing together professionals from across Health (including Public Health, primary and secondary care), Local Authorities, Police and others. CDOPs meet and review all the deaths of children usually resident in their area, carrying out the final anonymised independent scrutiny for each case. They may identify additional local or national learning and raise any relevant actions to reduce the risk of future child deaths. To help identify learning, CDOPs may review cases together on a particular theme (e.g. neonatal deaths, deaths due to suicide, deaths of children with a Learning Disability), and may invite additional professionals with relevant expertise to participate and advise.

Learning from Child Death Reviews

Both local and national learning from child death reviews is key in informing local service design, priorities and practice. Locally this has included:
- Developing multiagency resources to support professionals talking with families about safer infant sleeping;
- Informing priorities tackling infant mortality including work on smoke-free homes and reducing smoking in pregnancy;
- Developing learning briefings for professionals on topics such as epilepsy safety, use of community defibrillators, awareness of guidance around private fostering, and recognising & responding to aerosol abuse in young people.

CDOPs produce Annual Reports which summarise their case review findings and learning for their area and may make local recommendations based on these.

Trainee involvement

The Child Death Review process provides a fantastic opportunity to engage with health promotion and illness prevention (Community Child Health Curriculum Domain 5). Trainees are very welcome to come to observe both Child Death Review and CDOP meetings (the vast majority of which are held virtually). For Community Child Health trainees, there may also be opportunities to participate in work related to health promotion programmes, and to link in with Public Health. Contact your local Designated Doctor for Child Death to find out more.

Further Resources:

The National Child Mortality Database ***www.ncmd.info***

Local CDOP Contacts:
https://www.gov.uk/government/publications/child-death-overview-panels-contacts

Working Together to Safeguard Children 2018, Chapter 5:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/942454/Working_together_to_safeguard_children_inter_agency_guidance.pdf

Child Death Review Statutory & Operational Guidance (England) 2018:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1120062/child-death-review-statutory-and-operational-guidance-england.pdf

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3. Royal College of Pathologists & Royal College of Paediatrics & Child Health. *Sudden Unexpected death in infancy & childhood: Multi-agency guidelines for care and investigation*. London: Royal College of Pathologists; 2016. 105. Available at: ***https://www.rcpath.org/static/874ae50e-c754-4933-995a804e0ef728a4/Sudden-unexpected-death-in-infancy-and-childhood-2e.pdf***

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Young Volun'teens Programme for Youth with Disabilities

Volunteering can make a significant contribution to the individual, the health and wellbeing of the community and to supporting health and care systems. This includes positive youth development and forming their own identity.[1] Similarly, youth are able to obtain and achieve vocational skills and educational attainment through the holistic work experience for future employment.[2] The enhancement of social capital and networks cultivates a community belonging where youth are encouraged to recognise their civic duty, moral principles, political responsibility and are empowered to contribute to society in a meaningful manner.[1] The benefits of volunteering amongst youth have been captured but remain less documented amongst young people with disability.[1] It is recognised that often those who could benefit most from volunteering are the least likely to be able to take part in it – mirroring the inverse care law affecting other types of health and social care interventions.[3]

The Young Volun'teens programme was established by the Alder Hey Academy to support young people with mental health, intellectual and physical disabilities access volunteering opportunities at Alder Hey. This group can experience many challenges and barriers to volunteering, including lack of awareness of opportunities to engage; accessibility; cultural differences; social expectations; time limits; lack of trust; and some may lack confidence, motivation, or resources (financial, knowledge or skills).[4]

A mixed methods review was undertaken to explore the evidence on the barriers to volunteering within a broader pattern of social, education, economic and health inequality amongst the disadvantaged population of youth with both mental health, intellectual and physical disability and considers the major determinants in volunteerism that encompass structural, institutional, and personal levels. While there is robust evidence exploring the barriers that hinder adults that have additional needs to engage with volunteer work, there is a paucity of studies specifically exploring the barriers and effect on quality of life amongst young people with disability.

Potential social benefits from the study include improved volunteer and parent/guardian experience and potentially improved quality of volunteering for the children and adolescents with additional needs and disability. It was recognised that the study results may also highlight some issues with the delivery of the Young Volun'teens programme, noting that barriers to delivery of good quality volunteering opportunities and unintended negative consequences can be remedied through focused co-designed improvement actions.

Community-level benefits included access to a wider range of opportunities if:

(i) changes are made to improve the quality-of-volunteering delivery in response to the results and
(ii) wider collaboration is achieved.

Potential programme benefits included the provision of new insights / information to better understand the strengths and weaknesses of the use of youth volunteering programmes and volunteering delivery tools and their potential for use in other NHS settings.

The review also evaluated the implementation of a pilot Young Volun'teens programme established by the Alder Hey Academy (AHA) in 2022/23, working in conjunction with two local education providers.

The new volunteering opportunities consisted of:
a) support to the medical education team with undergraduate medical student rotations (Meet and Greet role);
b) workshops with medical students from the University of Liverpool (UOL)
c) Micro-volunteering through the creation of podcasts.

The Young Volun'teens programme aimed to provide opportunities for young people to:
- develop increased confidence and self-esteem through taking part in a positive, accessible, and tailored volunteer experience.
- gain experience and skills in public speaking, working in a team, working with media & communications professionals, and working with wider staff groups, providing invaluable experience for future employment and volunteering opportunities.
- gain access to wider volunteering opportunities with Alder Hey Children's NHS Foundation Trust.

In addition, it was hoped that through role (b), medical students on placement at Alder Hey would gain an enhanced understanding of the challenges faced by children and young people (C&YP) with disabilities by listening to their first-hand experiences and perspectives and, through having increased contact and conversations, go on to develop a greater empathy with this group. The ultimate goal, subject to evaluation, would be for this type of initiative to be scaled up across other NHS Trusts.

18 young people were initially recruited for the pilot phase, 8 from ACE (Alder Centre for Education) and 10 from SPS (Sandfield Park School).

The exploratory qualitative study consisted of three focus group discussions, together with three in-depth key informant interviews with participants from ACE which is an alternative education provider for young people with mental and physical health needs and SPS which is a special needs school. In addition, stakeholder interviews were conducted with four staff from ACE, SPS and AHA.

A codebook based on grounded theory and a phenomenological framework were created to develop a contextually salient evaluation questionnaire on the experiences of these youth volunteers to identify:
1) barriers to volunteering
2) experiences with education and resources at school to prepare for career opportunities
3) experiences with the health system to better prepare future doctors
4) experience of the Young Volun'teens programme.

The young people reported that poor quality of life stemmed from social isolation both at home and school. Stigma in the form of being treated vastly differently from children who do not have additional needs and the general disregard for their difficulties with delayed recognition of their additional needs. Challenges

Continues overleaf

at mainstream school were anticipated in the form of bullying and segregation with the implied aspiration of 'normality' to be achieved. The resultant effect was lack of confidence and self-esteem with many experiencing poor mental well-being.

A number felt that mainstream schools do not understand how to manage student's additional needs and end up offering options that are not conducive to their well-being. Their educational development would be stunted whilst alternative education provision and special needs schools may not be tailored to the differing needs and limited resources for future career choices can undermine the goals of these young people. Many shared worries about leaving the safety of these educational institutions and feeling unprepared to live independently and contribute to society in a meaningful manner.

The Young Volun'teens reported a range of negative experiences with the health system and professionals - caused by mistrust, miscommunication of information and lack of understanding of their additional needs. They highlighted a lack of decision making in their health needs and independence during consultations which can be caused by their age and having additional needs. Some reported their recurrent hospitals admissions had worsened their quality of life and educational progress. Key barriers to volunteerism included lack of inclusive opportunities, accessibility, and provision of additional support such as a suitable environment, and appropriately trained staff. Additionally, there were preconceived notions that stigmatised these youth.

All respondents across both ACE and SPS rated the programme as useful for gaining new skills, experiences, and opportunities. Some found the different roles more/less challenging (with ACE pupils reporting that they found it more difficult). This may reflect the fact that the level of autonomy given to ACE pupils developed over time and, due to scheduling and some logistical challenges, the SPS students had a more limited experience at the time of the evaluation. Half of the ACE students stated that their confidence had increased as a result of their participation and more than two thirds of this group felt that this experience would support them in terms of next steps (College or other). ACE student volunteers particularly enjoyed the Volun'teens programme as they were 'able to try new things' and the SPS Volun'teens felt that they 'gained more skills, opportunities, and experiences' through the role. The level of support provided to students was rated positively, and the large majority of Young Volun'teens would recommend the programme to others.

The review highlighted several aspects associated with the organisation and management of such programmes – ranging from the benefit of close collaboration between all parties in the design through to some logistical challenges given the fixed schedule of the medical student induction.

This study provides a framework for inclusive NHS volunteering programmes for young people with additional needs. Recommendations include proposing a designated coordinator, whether this would be an oversight from the AHA with strong partnerships with the youth volunteers themselves to embody their needs and empower them to be a key representative within the decision-making process of the programme. Similarly, suggestions were made for broadening volunteering activities based on the interests of these volunteers and ensuring accessible transport and more flexible opportunities. Wider cross collaboration is also key to leverage local capacity with existing community volunteering programmes which would further support the needs of these young people.

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Association of Paediatric Palliative Medicine

Association for Paediatric Palliative Medicine

I am excited to announce that the Association of Paediatric Palliative Medicine (APPM) is now affiliated with BACCH. This is a very exciting development, which will only be of benefit to ourselves as community paediatricians.

The philosophy for children's palliative care is to promote the best quality of life and care for every child with a life limiting or life threatening condition for them and their families. Research suggests that numbers are growing and that there are at least 49,000 children in the UK.

Many of us look after children with complex neurodisability. We also all work within areas that have very different services to support these children and families. We know that palliative care is an active and total approach to care which starts at the point of diagnosis or recognition throughout the child's life and death. As Community Paediatricians, we are ideally placed to provide that active and total approach to care. The children and families have long standing relationships with us. We see them regularly in clinic and work alongside our allied health professionals to deliver care. We also work alongside education, child disability social work and respite provisions. We have a unique and privileged understanding into the lives of these children and their families.

Many of these children spend most of the lives within the 'neurodisability bubble'. We already provide a high standard of care of these children. Many of us will also be involved in the anticipatory care plans and resuscitation wishes of the families. However, at times in their journey the children and families will need the involvement and support of the paediatric palliative care teams. Likewise, ourselves as professionals will need their expertise and support.

That is where I hope that this affiliation will be useful going forward. We can work together to help to improve our training and knowledge base in this area, build and continue to build on joint working between the two specialities. I am the Community Paediatric representative for APPM. I want to hear your views and thoughts on this area. What are the challenges you are facing? Do you have access to paediatric palliative care support? Any areas of symptom management that we would benefit from more training or guidance in? Any other ideas, thoughts or suggestions you have would be welcome.

The APPM website is ***www.appm.org.uk.*** It is also very easy to become a member of APPM and the many benefits that offer you. **Our Conference is on the 16th and 17th November 2023** in Birmingham, which will be a very interesting and informative event. We have so far developed three national guidelines. My colleague and I delivered a workshop at the recent BACCH Annual Scientific Meeting (ASM) on the relevance of Gastro-intestinal Dystonia guidelines to Community Paediatricians. I look forward to meeting you all and please contact me with any questions or thoughts on how we can make the most of this exciting affiliation with BACCH.

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CLINICAL

Genomics for Community Paediatricians

Introduction

Neurodevelopmental disorders are now understood in the context of underlying differences in brain structure and function arising from diverse genetic, epigenetic, and environmental effects at critical sensitive time periods within the developing brain.

Continuing advances in genomic medicine are leading to significant increase in diagnostic yield for children with global developmental delay (GDD) and intellectual disability (ID), advancing understanding of pathophysiology and leading the way for potential treatments.

How Genetic Investigations have evolved in Community Paediatrics

Historically, research has shown that an underlying cause for GDD/ID can be determined form a thorough history and examination with targeted investigations in between 12.5% and 38.6% of children.[1]

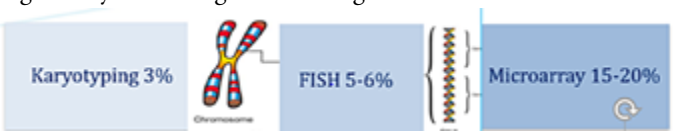
In the In the mid-20th century, Trisomy 21 was discovered as the underlying cause of Down Syndrome and in 1991, FMR1 was recognised as the gene involved in Fragile X syndrome.[2]

Genetic testing by karyotype was recommended as first-line testing in UK guidance from 2006 and by 2016, chromosome microarray was emerging as the single most efficient diagnostic test after history and examination.[3]

In 2003, the NHS was the first in the world in completing the first whole sequence of the 3.3 million letters of the Human Genome. This led to the 100,000 Genome Project aimed at sequencing the genomes of people affected by rare disease or cancer. Through this initial project there was an increase in diagnostic yield across a range of rare diseases[4] which in 25% of cases has led to support in management and clinical decisions.

The diagnostic yield from genetic testing for intellectual disability had increased with increasing resolution.[5] Moving from 3% with karyotyping, through 15 to 20% with microarray testing to yields of over 40% using new whole genome sequencing (WGS).

Diagnostic yield from genetic testing in GDD



Genes impacting early brain development and neuronal communication (synaptic function)[6] and those involved in epigenetic process are highly implicated in neurodevelopmental disorders.[7]

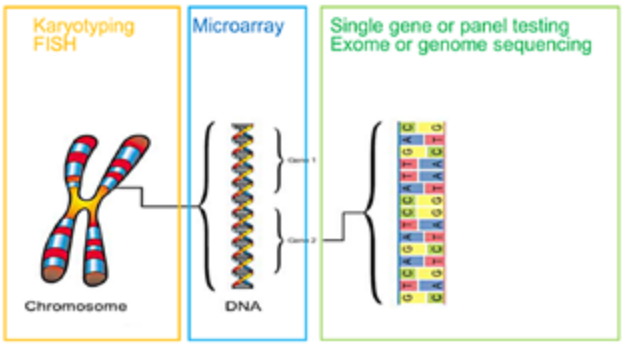
Epigenetics

Epigenetic processes affect the transcription of how and when genes are transcribed into proteins, enabling regulation of changes required at different stages of development. Deoxyribonucleic acid (DNA) methylation and *chromatin modification* are two mechanisms that regulate gene expression.[8] The human genome is tightly packaged with chromatin in the nucleus of the cell, with DNA sequences wrapped around histone proteins. Chromatin modification takes place via enzyme reactions to allow specific regions of DNA to be accessed. Methylation is a chemical reaction that enables sequences of DNA to be "silenced" to regulate expression.

Evolution of the genetic testing techniques

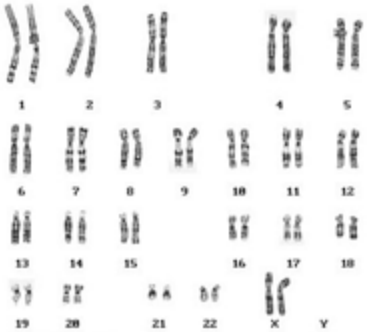
Genetic variation can occur within a chromosomal change, a copy number variation or a single nucleotide change.

Increasing resolution through advances in genomic testing



Karyotype

Karyotyping involves looking for chromosome changes through a microscope. This method can detect missing or additional chromosomes, large deletions, large duplications and variations in positioning of genetic material with inversions, translocations and ring chromosomes. The test is limited as it can only detect large genetic changes and has essentially been replaced by microarray for diagnostic purposes. It still has some use in looking for translocations and mosaicism.



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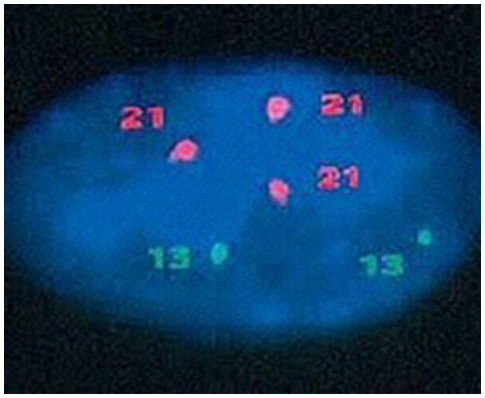
Fluorescence in situ hybridization (FISH) probes

As research began to correlate known clinical syndromes with specific variations in genetic material, Fluorescence in situ hybridization (FISH) probes were developed to identify these differences. However, this method relied on a high level of clinical suspicion and was limited to looking for variation in one region only. FISH has also largely been replaced now by microarray.

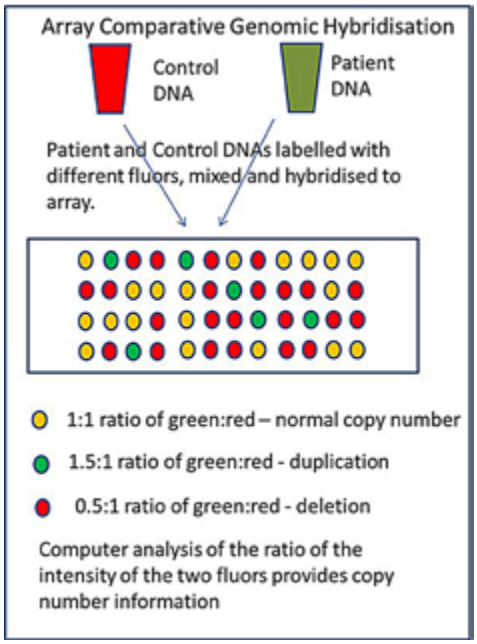


Microarray testing

Copy number variants refer to small segments within the chromosome (100-200 base pairs), which vary in number. Typically, we carry two copies of each chromosome. Areas where there is only one copy are referred to as deletions while those with more than two copies are called duplications.

Microarray testing provides the ability to test for a wide range of deletions or duplications at once for individuals where a genetic difference is suspected but no specific syndrome is evident clinically.

Array Comparative Genomic Hybridisation



SNP (single nucleotide polymorphism) array can also be used to look for differences in single base changes which can help with detecting uniparental disomy and mosaicism.

Current limitations of microarray testing are that it does not detect low level mosaicism, below 10%[9], single gene variants, balanced translocations, imprinting disorders due to methylation abnormalities (Beckwith-Wiedemann, Angelman) or Fragile X syndrome.[10,11] It provides information on how much genetic material is present at each genetic locus, but not where it is in the DNA strand.

Fragile X testing

Fragile X syndrome affects approximately 1/5000 births, typically causing moderate ID in boys and a variable phenotype in girls (unaffected to significant ID). The level of intellectual disability relates to the length of the triplet repeat. Phenotypic features evolve and are not as apparent in younger children.

The diagnostic yield of Fragile X in ID/GDD and/or Autism Spectrum Disorder (ASD) varies widely with study design with yields reported between 0.5 and 6%.[12] A large scale study has suggested that Fragile X is substantially underdiagnosed in the general population due to clinical heterogeneity.[13]

Fragile X testing involve looking for the triplet repeat on the X chromosome. This is not currently identified through microarray testing.

Whole Genome sequencing

Next Generation Sequencing

Each human genome is a unique sequence of about 3.3 billion letters. DNA sequencing is the process of determining the exact order of these base pairs. Sequencing an entire genome requires breaking the DNA of the genome into many smaller pieces which are called reads. These reads are loaded into a sequencing machine which places them in order using a reference sequence. A reference sequence has been created using large numbers of individuals and large number of reads. This reference template is updated regularly with new information. The latest reference is GRCh38- Genome Reference Consortium Human Build 38. Once a genome has been sequenced it can be stored for future testing.

Variations in the sequence of three base pairs enable the creation of amino acids which combine to form proteins. See video on BBC Bitesize for more information: ***https://www.bbc.co.uk/bitesize/guides/zys2v9q/video.***

A single letter change can therefore potentially alter protein formation. Through research variations in single letter changes have been linked with medical conditions.

Gene Panels

Scientists and clinicians work together to create panels to detect gene variants associated with different conditions. Using the template of a patient's whole genome sequence, a panel can be applied to look only at the genes related to a specific condition (for example, epilepsy).

Over time as new genes are identified, these are added to existing clinical panels. In future updated panels can be applied to stored patient data.

Variant classification

Not all variants are pathogenic, some account for the vast variability we see within our diverse population. Interpreting whether a variant may be pathogenic requires consideration of how prevalent this variation is within the general population and accessing current scientific research to discover whether this particular variant has been associated with a condition.

It is also important that the genetic variation correlates with the clinical phenotype. This can make interpretation challenging and in general the more specific features that can be described, the more certainty can be given to a genetic diagnosis.

The American College of Medical Genetics and Genomics (ACMG) recommend five variant classifications.

Benign Variant	Not thought to be associated with disease. Often present in phenotypically normal individuals or in the general population
Likely Benign Variant	Considerable evidence to suggest that this is not associated with disease but where additional evidence might influence this.
Variants of Uncertain significance	There is not enough information to determine whether the change is pathogenic or benign. Additional studies might be useful to provide additional information to clarify pathogenicity.
Likely Pathogenic Variant	Considerable evidence to suggest that they are likely to be associated with disease but where further evidence may be required.
Pathogenic	Thought to be associated with disease. These are known to be associated with a rare condition and explain the patient's phenotype.

Why test?

Genetic testing has the potential to offer a definitive diagnosis which may inform clinicians and patients about possible appropriate treatment options, any need for active surveillance or access to helpful support services. Certainty about a diagnosis can provide relief and information on prognosis and may help to reduce the number of sometimes invasive investigative procedures.

Genetic findings may help with predicting recurrence risks and provide options for prenatal testing. Individuals can have opportunities to get in touch with other similarly affected individuals or families or access research trials.[14, 15]

Genetic findings are key to understanding the proteins and processes underpinning neurodevelopmental differences. Such findings can help with the development of pharmaceutical treatments or gene therapies.

How to approach genetic testing in neurodevelopmental disorders[16,17]

Investigations for children with GDD/ID should still be guided by detailed medical and developmental history, clinical examination, and family history.

This approach is based on current guidelines. However, with rapid advances in discoveries through whole genome sequencing, this may change. It is possible that WGS will become the first line investigation for children with moderate to severe GDD/ID as the diagnostic yield is much higher than that for microarray in this group.

All individuals with intellectual disability, autism or epilepsy should be offered genetic testing with microarray to look for copy number variations.

Consider Fragile X testing in those with positive family history of intellectual disability, and autism spectrum disorder in both males and females. (Fragile X is unlikely in individuals with microcephaly).

When and how should WGS be requested?

In the absence of a genetic diagnosis from microarray and Fragile X testing it is important to consider whole genome sequencing. This can be requested by Community Paediatricians.

The diagnostic yield for WGS is higher in those with more severe intellectual disability, delayed motor milestones, macrocephaly, microcephaly, epilepsy, dysmorphism and congenital anomalies.[18] For those with mild developmental impairment and no dysmorphic features the likelihood of obtaining a diagnosis through whole genome sequencing is currently low and not recommended.

The diagnostic yield is highest when WGS information is also available for both parents (trio genetic analysis) and for families with a larger pedigree. For example, for those with intellectual disability, diagnostic yield was 25% in singletons, 41.7% for duos and 45.1% for trios.[19]

For children with GDD/ID we would currently recommend requesting the R29 intellectual disability panel which covers around 1000 genes.

There are a wide range of other panels available that may be more relevant including congenital malformations, epilepsy, microcephaly, hypotonia and specific motor disorders.

The Genomic Test Directory provides guidance on which panels are currently available for specific conditions.

The Full Genomic Test Directory can be accessed via the NHS England website:
https://www.england.nhs.uk/publication/national-genomic-test-directories/

The Test Selection Tool has been developed as a simple search function in which you can enter clinical features to establish whether this is an indication for whole genome sequencing
https://test-selection-private.genomics.nhs.uk/test-selection/

If uncertain, it is always helpful to talk with your local Genetics Team or Regional Genomics Laboratory Hub.

North East and Yorkshire: ***ney-genomics.org.uk***

North West: ***mft.nhs.uk/nwglh***

East: ***eastgenomics.org.uk***

Central and South: ***bwc.nhs.uk/west-midlands-regional-genetics-laboratory***

North Thames: ***norththamesglh.nhs.uk***

South West: ***nbt.nhs.uk/south-west-genomic-laboratory-hub***

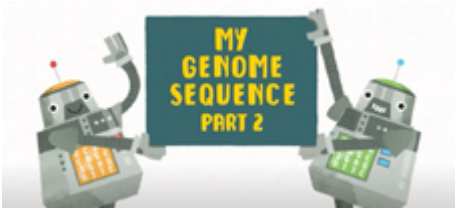
South East: ***https://southeastgenomics.nhs.uk/who-we-are/***

Where can I find patient information on whole genome sequencing?

Information leaflets should be available on your Regional Genomics laboratory website.

Continues overleaf

On the Great Ormond Street Hospital website (***www.gosh.nhs.uk),*** under 'Clinical Genetics support and information' you can find an animated resource for young people and individuals with intellectual disability. This video is also available in other languages on this website.



Consent for whole genome sequencing

Testing for WGS requires informed consent. The information to be shared is documented as a record of discussion which covers topics related to implications for family members, variants of uncertain significance and incidental findings.

In addition to providing clinical consent, individuals are invited to consent for their anonymised data to be made available for research purposes.

This is a video on research discussion for whole genome sequencing: ***https://vimeo.com/769641917/e20228cf22?***

Do genetic findings affect health assurance?

- Access to confidential patient information, including genetic data or genetic test results, will not be shared with an insurance company without patient consent.
- Anti-selection is a risk that insurance companies face. Anti-selection occurs when someone who is buying insurance has access to more information than the insurer and, as a result, the insurer underestimates the risk of insuring that person.
- If you are applying for life insurance over £500,000, you may need to disclose to an insurer if you have a predictive genetic test result for Huntington's disease.
- Further information can be found here: ***https://www.abi.org.uk/data-and-resources/tools-and-resources/genetics/genetics-faqs/***

What forms are required?

Contact your Regional Genomics Laboratory Hub for the relevant forms for your area.

Currently one test request form should be completed for all family members to be tested. One Record of Discussion form is required to be signed for each individual.

Test Order Form	**Record of Discussion**	**Consultee Declaration Form**
One form for whole family	One form for **each** family member e.g child and both parents = 3 forms	Nominated consultee consenting on behalf of a patient over 16 who lacks sufficient capacity. Only if patient lacking in mental capacity

What samples should I send?

- Peripheral blood samples (2-5ml EDTA tube) from child and both parents
- Saliva (in exceptional circumstances)

Where shall I send the forms and samples?

To your Regional Genomics Laboratory Hub.

Where can I find information about specific gene findings?

These resources are aimed at health professionals. Through these resources key facts can be found about each condition, plus detailed information on clinical features, diagnosis, management and treatment.

https://www.genomicseducation.hee.nhs.uk/genotes/

https://www.genomicseducation.hee.nhs.uk/doc-type/genetic-conditions/

https://www.rarechromo.org/

https://omim.org/

https://www.ncbi.nlm.nih.gov/pmc/

https://geneticalliance.org.uk

https://medlineplus.gov/genetics/

Additional Useful Resources

https://www.genomicseducation.hee.nhs.uk/

https://www.england.nhs.uk/blog/nhs-genomic-medicine-service-alliances-to-help-embed-genomics-into-patient-care-pathways/

https://www.undiagnosed.org.uk/ - SWAN "syndromes without a name" where testing has failed to identify a genetic cause in an individual thought to have a genetic condition

https://www.norththamesglh.nhs.uk/showcase-of-genomics-community-paediatrics/

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The Adolescent Social Brain & Risk-taking

Changes in the adolescent brain can significantly influence social behaviour and in particular risk-taking behaviours. The major changes which are taking place in brain development during this period affects how adolescents perceive and respond to social cues, interact with others, decision making and navigate their social environments. One of the main concerns seems to be the 'imaginary audience' which is a phrase coined by the psychologist David Elkind in the 1960s.[1] The feelings experienced by most adolescents that others are evaluating and judging them drives self-conscious and sometimes selfish behaviour which is often associated with this age and stage.

Leah Somerville at Harvard University carried out a brain scanning study in 2013 which asked participants to think that their face was being observed during periods when a red light flashed.[2] The adolescents in the study reported high levels of embarrassment and stress, in comparison to others in the group, at the anticipation of being observed as well as at the times when they thought they were being watched. The thinking was also noted in the activity levels in the medial prefrontal cortex of the adolescent brain, the part of the social brain involved in understanding other people and thinking about the self, concluding that this self-conscious thinking is more pronounced in the changing adolescent brain, something which is possibly more acute today with social media.

The partnership between biology and the environment is very strong with the biological side ensuring that there is optimal growth potential.[3] This interaction is often referred to as gene-environment interaction or nature-nurture interplay. The neuroplasticity of the adolescent brain means that it is highly malleable and capable of change. The synaptic pruning and strengthening of neural pathways and connections occur in response to experiences alongside genetic factors which influence the brains baseline structure and function. The plasticity of the brain allows it to adapt and rewire in response to environmental stimuli. The brain is therefore able to adapt to specific types of experiences such as language acquisition, skill development and social learning. However, this can be a particularly painful period where the brain can experience social pain similar to that of physical injury by being excluded from friend groups or receiving online bullying.

Matthew Lieberman's book 'Social' states that our brains spend a large amount of time considering our social world because having an understanding of ourselves and others is essential for us to survive and thrive.[4] The NHS talk about the five steps to mental wellbeing one of which is connection, developing relationships with friends, family, colleagues has been proven to be important for our overall health and wellbeing.[5] The Harvard researcher, George Valliant, tracked people over their lifetime and was able to determine, through questioning such as 'what keeps us healthy and happy as we go through life?' that people with good social connections live happier, healthier and often longer lives.[6] The need for social connection seems to be at its peak during the adolescent years therefore the opposite, social isolation, can be very damaging during this developmental phase.[3]

Sarah-Jayne Blakemore and Catherine Sebastian carried out a lab-based study using a computerised ball game which, at different times included and excluded individuals from the passing of the ball.[7] The individuals all believed that they were engaging in this online game with real people, however, this was not the case in reality. The study showed that, with both adults and young people, anxiety levels increased, and mood was lowered due to the exclusion phases. The adolescents reported much higher anxiety levels and a significantly lower overall mental state than the adult group. Blakemore also noted this in studies with rats placed in isolation during their short period of adolescence. Increased signs of depressive behaviour, as well as changes in the prefrontal cortex, indicating that social isolation affects brain development in adolescents more than it does in adults. Whilst similar isolation studies cannot be carried out with humans, evidence shows that adolescents growing up in unstable environments, moving between foster care and children's homes generally have poorer physical and mental health than young people with a stable upbringing.

The conclusion of these studies points to the fact that adolescents' risk-taking behaviour is often associated with the need to fit in and be included with their peer group. Peer pressure often leads to risk taking behaviours as individuals strive to fit in and be accepted by their social group with the fear of rejection often driving adolescents into engaging in activities they might not otherwise consider. It can serve to bond with peers with exciting or rebellious activities creating a sense of camaraderie with shared experiences fostering closer relationships within the group.

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The Kidzmed Project and its relevance to Community Child Health

The Kidzmed project is a simple yet fantastic initiative that was developed and set up by the team at the Great North Children's Hospital, Newcastle, to teach children and young people (CYP) how to swallow pills. Evidence from other studies indicating the benefits of tablets versus liquids for the CYP, carers and pharmacists formed one of the rationales behind this project. Some of those benefits include tablets being less sickly, containing less sugar thus less risk of tooth decay. Furthermore, tablet medications generally have longer expiry dates, are cheaper, and more convenient as they are more readily available in local pharmacies than liquid medications and do not require refrigeration. In addition, many liquid formulations are unlicensed and costly (Figure 1).[1] It is often the case that CYP remain on liquids due to habit, reluctance to change or staff and parents' lack of knowledge about how to switch to tablets.

This table compares several drugs on a £/unit basis between their suspension and tablet formulations.

Price per dose (£ per mg)			
Drug	**Suspension**	**Tablet**	**Relative cost**
Prednisolone 10mg	1.85	0.06	29.2x
Nitrofurantoin 50mg	14.90	1.12	13.3x
Ciprofloxacin 250mg	1.06	0.09	11.3x
Cetirizine 10mg	0.29	0.03	8.6x
Paracetamol 500mg	0.48	0.08	5.8x
Amoxicillin 250mg	0.21	0.08	2.6x

Figure 1: Adapted from the e-Learning for Healthcare training content: "Kidzmed – How to teach children to swallow pills."[1]

Source: BNF for Children Oct 2020

The Paediatric Renal and the Infectious Diseases Team at the Great North Children's Hospital, Newcastle set up a quality improvement (QI) project to train staff to embed a system of looking for and converting eligible children to tablet mediations. In one team, over a 3-month period, out of 90 CYP who were seen in 13 multi-disciplinary renal clinics, 25 were suitable for conversion to tablet medication. The initiative included working with families and multidisciplinary teams comprising of hour-long interactive training packages with a training video and comic poster (Figure 2).[2]

Figure 2: Comic poster teaching children how to swallow tablets [2]

Using positive reinforcement and play, the trainer sat facing the learner with sweets or dummy capsules filled with sweets of increasing sizes. By placing easily accessible 'switching kits' in clinic filled the necessary dummy pills, awards and certificates overcame some of the practical barriers. Twenty-one children were successfully converted with one patient requiring two sessions. Thirty-six medicines were converted, generating £46,588 per year of recurrent savings. Feedback from families included the ease of obtaining tablet medication compared to liquids.

This QI project has won numerous awards and is a great step ahead in improving families' experience of obtaining medication, teaching children an essential life skill from a young age of 5 and not forgetting the considerable cost savings.

The project encourages all paediatric units to set up pill swallowing training. The idea can be introduced by doing a 15-minute e-learning session on teaching CYP how to swallow pills using an evidence-based, six-step technique. By training staff in various paediatric departments, informing parents about the potential benefits in clinics and recruiting CYP for teaching sessions, we can bring about a cultural change.

This project could work well with CYP seen in the Community Child Health (CCH) Paediatric setting, particularly those with neurodevelopmental conditions who struggle to take tablets due to the texture or the fear of pills altogether. This is where inspiration from this project may help this cohort of CYP. A potential starting point would be to incorporate the e-learning package within CCH

departments and work within multi-disciplinary teams to train staff, informing parents about the potential benefits of taking tablet medications in clinics and obtaining feedback from parents. By recruiting CYP to teach them the life skills of swallowing tablets in CCH could potentially be a positive step ahead in reducing the consumption of liquid medications and promote an overall cultural change, benefitting the patient as well as the service provider.

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Further resources (including downloadable leaflets in different languages and YouTube tutorial videos):

1. Tse Y, Vasey N, Dua D, *et al*. The KidzMed project: teaching children to swallow tablet medication. *Archives of Disease in Childhood* 2020;105**:**1105-1107. Available at: ***https://adc.bmj.com/content/105/11/1105***
2. "Creating a Pill School: The Kidzmed Project" Available at: ***https://qicentral.rcpch.ac.uk/medsiq/patient-support/creating-a-pill-school-the-kidzmed-project***
3. "Swallowing pills (Kidzmed)" Available at: ***https://www.nenc-healthiertogether.nhs.uk/parentscarers/medicine-children/pill-swallowing-kidzmed***

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SAFEGUARDING

Haematological evaluation of bruising and bleeding in child protection cases: Who and how to investigate

Introduction

The aim of this article is to summarise the guidance presented in a *British Society for Haematology* Good Practice Paper published in 2022.[1] This was written to assist haematologists, paediatricians and laboratory scientists involved in the laboratory evaluation of children with bruising and bleeding undergoing child protection investigations for possible physical maltreatment.

There has previously been a lack of consistency in approach to this challenging area of practice, resulting in missed or delayed diagnoses in those with a bleeding disorder, or repeated blood sampling leading to distress or false positive results in those without a bleeding disorder. This can cause poor decision-making, delay in court proceedings and can compromise child safety.

1. Which children require haematological investigations?

Most children who present with bruising and/or bleeding due to possible physical maltreatment do not require haematological investigations. This is particularly the case for older children. However, testing may be required to diagnose or exclude a bleeding disorder. A bleeding tendency may be acquired or inherited. In addition, there are non-haematological disorders (e.g. Ehlers-Danlos syndrome, osteogenesis imperfecta) which are associated with a bruising or bleeding tendency but these are outside of the scope of this article.

A detailed history is required to assess bruising and bleeding in a child. It is important to consider what might be normal bruising. **Normal bruising** occurs in mobile children, particularly 1-9 years of age, and consists of small bruises over exposed areas at the front of the body such as the shins, knees, and over bony prominences. Toddlers may have bruising of the forehead, nose or back of the head due to falling. **Unusual sites of bruising** are of the softer or 'protected' areas such as the neck, ears, cheeks, back of the hands, abdomen, back of the legs, buttocks and genital area. Children with a bleeding disorder tend to have more bruises and larger bruises than normal children, but these usually remain limited to exposed areas unless they are due to known trauma. Unexplained bruising in a pre-mobile child should always raise concern as should bruising in the shape of an implement or hand.

The history should include symptoms of bleeding such as **epistaxis**, **gum bleeding**, **prolonged bleeding from minor wounds**, **menorrhagia**, **dental extraction bleeding** or **surgical bleeding**. For younger children, **bleeding in the neonatal period** can be relevant and can include cephalohaematoma, prolonged bleeding after umbilical cord separation, bleeding from Guthrie heel prick or immunisations or vitamin K injection, and post-circumcision bleeding. A **drug history** and history of **neonatal vitamin K administration** may provide a clue to an acquired bleeding tendency. Details of a **bleeding tendency or bleeding disorder diagnosis in family members** may indicate an inherited bleeding disorder diagnosis.

Unexplained intracranial haemorrhage (ICH) occurring in infancy can be spontaneous haemorrhage due to vitamin K deficiency bleeding (VKDB) or a severe inherited bleeding disorder, or bleeding because of physical maltreatment. In the absence of other physical injury, the distinction may be difficult.

Haematological testing should be considered in the following (**Table 1**):

A pre-mobile child with unexplained bruising
A child with bruising or bleeding that is out of proportion to the mechanism reported
A child with bleeding at a critical site, e.g. intracranial, retinal, gastrointestinal, haemarthrosis, with no other explanation*
A child with a personal or family history which raises suspicion of an inherited bleeding disorder

*Coagulation testing in children who have bleeding at a critical site is important. Identifying an acquired or inherited coagulopathy may lead to specific treatment which will reduce the extent of the bleeding therefore potentially reducing morbidity and mortality.

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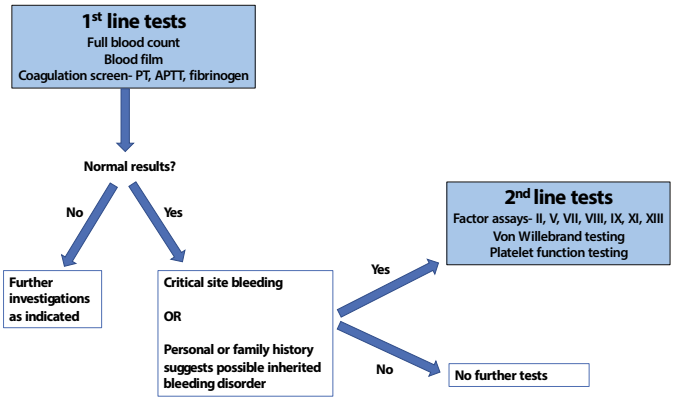
2. Which laboratory tests should be done?

Figure 1 shows a pathway for decision-making in relation to haematological investigations.



When haematological evaluation is required, first-line tests should be requested. These are full blood count (FBC), blood film and a coagulation screen which consists of a prothrombin time (PT), activated partial thromboplastin time (APTT) and fibrinogen level. These tests will identify any significant acquired condition, e.g. leukaemia, immune thrombocytopenia (ITP) or vitamin K deficiency. Although a normal coagulation screen does not rule out all bleeding disorders, severe disorders may be identified, e.g. isolated prolonged APTT indicating severe haemophilia.

Further investigation will only be indicated when there is critical site bleeding and/or a personal or family history which suggests the possibility of an inherited bleeding disorder diagnosis. Second-line tests include factor assays (factors II, V, VII, VIII, IX, XI, XIII), von Willebrand testing and platelet function testing (with platelet aggregation studies, platelet glycoproteins and platelet nucleotide analysis). This is a full set of investigations for a bleeding disorder diagnosis.

Platelet function testing should be avoided in children <1 year of age where possible. This is due to the large volume of blood (12-20 mls) that is required for accurate testing. It may be necessary in younger children to limit this to platelet glycoprotein testing (requiring 5-6 mls) which will identify the severe disorders of platelet function, i.e. Glanzmanns thrombasthenia, Bernard-Soulier syndrome.

3. Where and how should the samples be taken?

It is important to obtain a good quality blood sample of adequate volume for coagulation testing. Ideally this will be a free-flowing sample from a peripheral vein. Heparin contamination of samples from indwelling lines causes erroneous results and unfortunately isn't always prevented by removal of dead-space blood as heparin can 'stick' to the surface of the line.

Tips for taking blood samples from children for coagulation testing:

- **Inform the laboratory in advance** about sample arrival and which tests are required.
- If platelet function testing is required, ensure that the child has not received non-steroidal anti-inflammatory drugs, e.g. Ibuprofen, during the previous 7-10 days.
- Take a clean **venous sample from a peripheral vein**- avoid heparin contamination from lines.
- Fill the required number of citrated (coagulation) bottles **to the fill line** and not above.
- **Invert the tubes** five to six times gently.
- **Transport the samples by hand** to the laboratory as soon as possible, ideally within 2 hours.

First-line blood tests can be completed in primary care or a district general hospital. Second-line tests require analysis in a specialist coagulation laboratory. It may be necessary to refer the child to a tertiary care centre for blood samples to be taken. If the child is too unwell to be transferred, the samples should be prepared in the laboratory (e.g. by centrifuging and freezing) prior to urgent transport to the specialist coagulation laboratory.

4. How should the results be interpreted?

Coagulation test results in children should be interpreted by someone who has the relevant expertise. First-line tests taken in a District General Hospital setting can usually be interpreted by an 'adult' haematologist, but second-line test results may require input from a paediatric haematologist or expert in paediatric haemostasis.

Frequent pitfalls in interpretation are:

- *Developmental haemostasis:-* Coagulation factor levels are usually lower at birth and vary in the time taken to reach 'adult' levels. Results must therefore be interpreted with reference to age-related normal ranges. e.g. a 'low' level of factor IX or factor XI in an infant may be physiological for age. It should not result in a bleeding tendency but may need to be repeated once mature to rule out a genuine deficiency.
- *Acute phase response:-* Factor VIII, von Willebrand factor and fibrinogen are acute phase proteins levels which will increase in response to trauma, surgery, stress, infection, etc. This may 'mask' a mild deficiency of one of these factors.
- *Lupus anticoagulant:-* This occurs frequently as a consequence of viral infection in children. It causes an isolated prolonged APTT which does not correct when tested on a 50:50 mix with normal plasma. It does not result in a bleeding tendency.

It is worth noting that a bleeding disorder and physical maltreatment may co-exist in the same child. It is also important to recognise that a mild bleeding disorder diagnosis may not be sufficient to account for the severity of bruising or bleeding that is present.

Key points

- Most children who present with bruising and/or bleeding due to possible physical maltreatment do not require haematological investigation.
- In addition to a detailed history of the presenting findings, it is essential to take a history of other bleeding symptoms and a family history.
- Extensive coagulation testing is only required when there is:
  - bruising and a history suggestive of an inherited bleeding disorder.
  - bleeding at a critical site, e.g. intracranial, retinal, gastrointestinal or haemarthrosis.
- A blood sample of adequate quality and quantity should be transported to the laboratory by hand, by prior arrangement if required.
- Abnormal coagulation test results should be interpreted by someone who has the necessary expertise.

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Acknowledgements:

Dr Tina Biss would like to acknowledge her co-authors, along with the support of the British Society for Haematology (BSH) Haemostasis and Thrombosis Task Force, the BSH Guidelines Committee and The Royal College of Paediatric and Child Health (RCPCH) Child Protection Standing Committee in the development and publication of this guidance.

Reference:

1. Biss T, Sibson K, Baker P, Macartney C, Grayson C, Grainger J, Chalmers E, Dixon S. Haematological evaluation of bruising and bleeding in children undergoing child protection investigation for possible physical maltreatment: A British Society for Haematology Good Practice Paper. *Br J Haematol.* 2022;199(1):45-53.

TRAINING

START assessment for Community Child Health (CCH) trainees – tips and pointers

START stands for Specialty Trainee Assessment of Readiness for Tenure. It is a three-hour assessment with consultant paediatricians assessing trainees' abilities in clinical decision-making as a new consultant. This article is a rough guide based on my personal experience and reflections, which I hope readers will find helpful.

Step 1: Go through the resources published by RCPCH and London School of Paediatrics (LSP)

These include helpful information such as the latest format, logistics, themes and assessment criteria. The key ones are:

- RCPCH START – guidance for trainees ***https://www.rcpch.ac.uk/resources/rcpch-start-guidance-trainees***
- RCPCH START – guidance for trainees by trainees ***https://www.rcpch.ac.uk/resources/rcpch-start-guidance-trainees-trainees***
- RCPCH START – how it works (structure and specimen papers) ***https://www.rcpch.ac.uk/resources/start-how-it-works-structure-specimen-papers***
- LSP START Preparation YouTube channel – playlist of 6 videos ***https://www.youtube.com/playlist?list=PLD3UNdKzloDSO0c6tUNUvtRWS5auLYz1P***
  (NB: The August 2020 video has longer talks on specific topics like ethics, critical appraisal and quality improvement)

Step 2: Get access to the relevant WhatsApp groups and Trello boards

These may only be available to trainees in a certain deanery or specialty. The examples below are open for all:

- LSP START preparation WhatsApp group
- LSP START Trello board
- The Neurodisability Community (TNC) START Trello board

Step 3: Reach out to your local networks for support/resources

This may include:

- Colleagues or friends who have recently taken START – they can share their experiences, resources and feedback, and may also practise with you.
- Consultants or supervisors – they can clarify points of uncertainty, such as dealing with a colleague in difficulty, business cases and management structures.
- Mock START assessments held locally.

Step 4: Plan your time well

Have a good look at your schedule (e.g., rota, on calls, other commitments, childcare) and think about when you can fit in:

- Practice sessions – approximately 1-2 hours for evening sessions or longer on a day off.
- Reading – aim to read around 1-2 themes per week; this can be done in 20–30-minute bursts if spare time arises in between clinical commitments or even on your commute.

Step 5: Create or join a revision group of trainees taking START in the same sitting

- With solely CCH trainees or with other sub-specialties – one advantage of teaming up with CCH trainees is that you can cover general paediatric and CCH scenarios together, although there will be perks of practising with general paediatric trainees or other sub-specialty trainees to gain different perspectives.
- Geographical considerations – given the ease of meeting virtually and the current online format of START, your group does not have to be limited to those living or training near you. Despite this, additional in-person sessions with a smaller group who live near you may be beneficial – advantages include covering more scenarios, time away from screens, and an excuse to enjoy more hot beverages and nibbles than usual!
- WhatsApp polls – helpful to gauge availability and decide on session dates and times.
- Google docs – helpful for keeping track of progress and collating information.

Our group agreed on a time and date for the upcoming session and allocated scenarios one week in advance. Our sessions were in the evenings lasting 1-1.5 hours covering 3 scenarios each time (10 minutes for presentation and 20 minutes for feedback/discussion). During the first few weeks, we prepared our allocated cases before the group session. In the last few weeks, the whole group became involved in using the 4-minute preparation time during the group session to prepare for each case irrespective of whether they would be presenting the answer – this helped us ease into "exam mode" by honing our preparation and time management skills.

Step 6: Create tailored crib sheets to use on the day

This is best done in the last 1-2 weeks prior to START as you will have figured out and refined your own approach towards each scenario from previous practice. This will save you time on the day so you won't have to rewrite your structure or headings at the start of each 4-minute preparation slot.

Depending on the scenario, an A4 page could include the headings "Issues/approach" and those as part of the 'SPIES' structure ("Seek Information", "Patient Safety", "Initiative", "Escalate", "Support"); another page could include "Issues/approach", "Before", "During"

Continues overleaf

and "After". Make sure you leave enough blank space in between the headings for you to write your notes during the preparation time on the day.

Other pointers

- When to start preparation – 4-6 weeks is more than adequate (to avoid burning out).
- Timings – very important as the 4-minute preparation time and 8-minute answer time will feel much shorter on the day.
  - Example structure of 4-minute preparation – issues/approach (1 minute) > content > summary (1-2 minutes).
  - During practice – use a timer and be strict with time allocation.
  - On the day – a timer will be available on the screen throughout, so a separate timer will not be needed.
- Handover station – remember to count the number of patients and not miss anyone out (personal experience during practice and on the day!).
- Do not neglect general paediatrics scenarios – it is tempting to focus on CCH scenarios (which we are more familiar with and perhaps enjoy more) but they only make up 3 of the 10 stations in total.
- Examples of CCH-specific topics include Adoption and Fostering, Children with Medical Complexity, Palliative Care, Public Health/Health Promotion (e.g., immunisations, nutrition), Hearing and Visual Impairment, Safeguarding (including ethics, law, consent, competence).

Personal reflections/take home messages

1. Having a group of motivated and like-minded trainees to prepare is crucial.
2. The preparation process and START assessment itself will be better than expected – it is important to reiterate that we already know more than we give ourselves credit for, and instead it is more about refining and structuring our answers and having an overall approach.
3. The assessment was more informal, and, in many stations, it was like a conversation with the assessor – it may therefore be helpful to leave time for questions during practice sessions.

Lastly, huge credit is due to the amazing revision group I was lucky to be a part of – aside from being a huge source of support throughout, they also unknowingly contributed to my formulation of this article and were pivotal to the positive feedback I received.

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"Mother wants to talk to you about her child" – A project to improve our local responses to patient messages

The GMC tells us 'we must take part in systems of quality assurance and quality improvement to promote patient safety' in Good Medical Practice (Domain 2).[1] However other work commitments mean that Quality Improvement (QI) projects can be hard to fit in. Many doctors end up completing their yearly audit requirement as a 'tick box exercise' to pass their appraisal/Annual Review of Competency Progression (ARCP) without really embracing the opportunity to make a valuable impact at work. Therefore, I hope this article demonstrates that QI projects are a great way to improve your local service in a practical way. Rather than focusing on QI theory, which can be learnt via relevant courses, I am going to outline a recent QI project that has resulted in a notable reduction in the demands on my personal community paediatric workload.

Step 1: Identification of an Issue

This project started due to a personal irritation about the number of messages that I was receiving about my patients between appointments. Returning from annual leave to a large pile of patient messages was a real heart sink moment! As my patient list grew, these messages started to feel unmanageable, so I decided to do something about it.

Step 2: Initial Data Collection

In order to get a clearer idea of the size of the problem and possible solutions, I started to collect some data. Each time I got a message about a patient, I completed the paper log outlined below. This log helped me keep track of these messages and my response to them. I also logged the date and reason for the calls as well as the date and duration of my reply phone call.

Name	CC Number	Date of Message	Method	Person	Subject	Date of Response	Length of Response	Advice

Step 3: Initial 'Plan, Do, Study, Act' (PDSA) Cycles

Whilst I was collecting my initial data, I identified various ways to improve my responses, which I implemented via multiple informal PDSA cycles. A PDSA cycle is outlined in figure 1.[2] Current QI theory recommends doing repeated PDSA cycles to make small incremental changes in a 'trial and error' fashion.

Figure 1: PDSA Cycle

My first PDSA cycle was to start to filter the messages and actively think of alternative ways to address each message rather than automatically ringing every parent back. My second PDSA cycle was my decision to only ring parents back a maximum of twice when they did not answer.

Step 4: Data Analysis

I collected this initial data over a 4-month period between November 2022 – February 2023. During this period of 18 weeks, I received a total of 106 messages, which was equivalent to 5-6 messages per week. This log gave me a basic understanding of the frequency of the messages as well as valuable information about the reason for the messages.

Step 5: New Telephone Call Sheet

The initial finding from my data was the variable detail in messages from the secretaries due to the pressures on our secretarial team. The more vague messages made it difficult to determine the reason for the call or the urgency of the response needed. To improve the quality of the messages taken by the secretaries, a new telephone sheet was introduced by the clinical team; see before and after below.

Before:

Telephone Message Recording Sheet for Specialty Doctor/Nurse

DATE		**TIME**					
MESSAGE FOR							
MESSAGE	**Patient Name:** **COCH Number:**						
TAKEN BY							
LATEST CLINIC LETTER AVAILABLE?	**YES**		**NO**		**NOT APPLICABLE**		

Date:		**Time**		**Length of call**	
Outcome : (tick most appropriate – only one box to be ticked)					
Advice given		Bring forward OP clinic			
Keep previously arranged OP clinic					
Cancel OP clinic and discharge					

Summary of advice/ discussion (if relevant):

After:

Telephone Message Recording Sheet for Community Paediatrician/Nurse Specialist
(Doctor/Nurse to respond within 5 working days)

DATE:		**TIME:**		**CLINICIAN:**			
PATIENT NAME:							
HOSPITAL NO:							
CURRENT MEDICATION:							
LAST APPOINTMENT:		**NEXT APPOINTMENT:**					
REASON FOR THE CALL:	**Medication side effects** ☐ **Medication review** ☐ **Request to start medication** ☐ **Any other issues:** ☐ Tel						
Admin name:							
LATEST CLINIC LETTER AVAILABLE?	**YES**		**NO**		**NOT APPLICABLE**		

Date:		**Time:**		**Length of call:**	
Outcome : (tick most appropriate – only one box to be ticked)					
Advice given:		Bring forward/Postpone OP clinic:			
Medication altered:					

Summary of advice/ discussion (if relevant):

Step 6: More Data Collection

After the new telephone sheet was introduced in March 2023, I collected a further 5 weeks of data in late March – early April including an extra record of the overall time taken to address the messages. During this period, I received 32 messages from parents. My new filtering system meant that I rang 17 parents back. I brought 4 appointments forward and decided that 6 messages could wait for the next clinic review. I replied to 2 messages via email and 3 parents did not answer my calls. As a result of my calls, I wrote 9 additional letters and 6 additional prescriptions. In total, I spent 7.5 hours responding to the messages – 130 minutes calling parents back, 120 minutes dictating letters, and 200 minutes reviewing patient notes and writing prescriptions. This information highlighted the impact of the messages on my workload, which was useful when discussing the scale of the issue with my managers.

Step 7: New Standard Operating Procedure (SOP)

The other main finding from my data was that there was a high number of messages received that did not need to be answered by the clinician. I categorised the messages received into three categories depending on whether they could be addressed by the secretaries, by the secretaries with support from the clinician or by the clinician themselves. I wrote a list of potential responses to common messages received and gave this list to the secretarial team for feedback. This meant they could make practical suggestions about whether the responses were feasible. Once I adjusted the list based on this feedback, I took this list to the rest of the clinical team for their comments. This resulted in the new SOP outlined below.

Calls for Secretaries = Clinician will not call parents back

- If wants to start new ADHD medication = Review clinic letter + advise as per plan in letter OR offer next available face to face appointment if no clear plan on letter
- If wants additional copy of a signed clinic letter sent out = Action without informing clinician
- If wants a letter for housing/DLA applications = Inform the parent that they should use the last clinic letter
- If wants to provide further information for the clinician = Inform the parent to post information to Kingsway
- If WNB'ed (was not brought to clinic) without a good reason and wants appointment to be rescheduled = Inform the parent to ask school to re-refer if discharged
- If wants their clinic letter to be sent urgently = Type urgently and ask clinician to sign

Calls for Secretaries with Support = Clinician will not call parents back

- If wants an earlier clinic slot than scheduled = Discuss with clinician with stated reason
- If providing measurements (weight/height/blood pressure) = Send measurements to clinician and upload on Evolve
- If wanting a new Autism Spectrum Disorder (ASD) assessment = Ask school to make a new referral with the appropriate information, will be reviewed in the triage meeting.
- If asking about an ongoing ASD assessment = Discuss with ASD Pathway coordinator depending on age
- If requesting new prescription = Inform clinician with details of medication required
- If requesting alteration to clinic letter = Inform clinician of any changes required
- If want update about ASD meeting = Inform parents that the outcome will be discussed at next appointment
- If want update about QB test result (for Attention Deficit Hyperactivity Disorder [ADHD]) = Inform parents that the results will be discussed at next appointment

Calls for Doctors = Clinician will call parents back if needed

- If want ADHD/sleep medication review (next appointment <1 month) = Tell parent to wait for next appointment
- If want ADHD/sleep medication review (next appointment >1 month) = Bring appointment forward if possible, otherwise ask clinician whether it is clinically relevant to do an urgent telephone call instead
- (NB tell parents that any urgent telephone call counts as their 6 monthly F/U appointment so ask them to provide weight/height/BP when contacted and inform them that we will postpone their next face to face appointment by 6 months)
- If report ADHD/sleep medication side effects = Inform clinician
- If other query or feedback about ADHD/sleep medication = Inform clinician

Continues overleaf

- If want update about blood test/x-ray results = Inform clinician and tell parents that the results will be posted (NB will be updated via telephone if clinically indicated)
- If asking about behavioural/ Child & Adolescent Mental Health Service (CAMHS) issues = Inform clinician
- Any other issues = Inform clinician

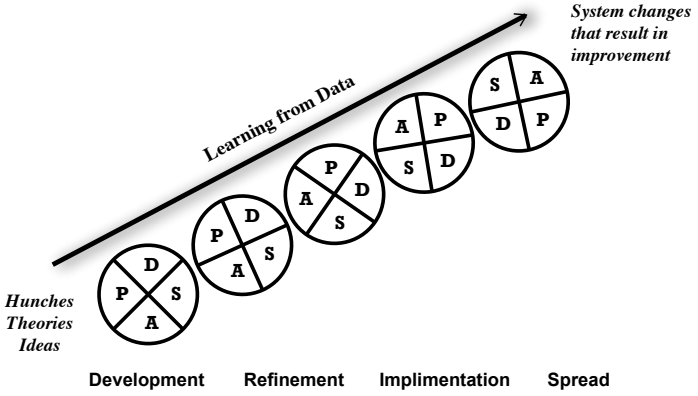
Step 8: Further Data Collection

The new SOP was finalised in May 2023 so I repeated my data collection in July 2023. Subjectively there has already been a reduction in the number of patient messages. I received a total of 10 messages during July. I only rang 2 parents back as I was able to address the other calls by alternative means. It is too early to determine if this improvement will be maintained so I plan to continue to monitor my patient messages over the next few months. Our team is also looking at the introduction of weekly 'masked clinics' to respond to these messages in a more scheduled and measurable way.

Summary

My main advice is to not be intimidated by QI projects as they do not necessarily require a lot of extra work. Ideally, they can be integrated into your daily work by regularly collecting small amounts of data and frequently reviewing this data to identify areas of possible improvement (Figure 2).[3] Making little changes in your routine practice over a prolonged period of time is far more manageable in the busy workplace.

Figure 2: Repeated PDSA Cycles



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Update from the Community Child Health College Specialty Advisory Committee (CCH CSAC)

From September 2023, all doctors undertaking paediatric training, apart from those completing training by September 2024, will be following the Progress Plus curriculum. Progress Plus, the Royal College of Paediatric & Child Health (RCPCH)'s response to the Shape of Training review, has received recent General Medical Council (GMC) approval and is the new two level, run-through specialty training in Paediatrics. This work has taken the RCPCH many years to complete and there is a real sense in the college that paediatric training will now be flexible and responsive to the needs of the trainees and their localities.

As community paediatricians we have faced this change with reservation, fearing a reduction in opportunity for trainees to work in community settings and a shortening of training time. We worry about those doctors who need the opportunity to consider other options or gather valuable experiences from working in more than one discipline. The CCH GRID curriculum has not changed but there is more focus on generic competencies in child mental health and public health from the start of training – all very relevant to community child health.

The main elements of Progress+ are that this will be a seven year, two level programme ST1-4 (Core training) and ST5-7 (Specialty Training). Theory exams will need to be completed by ST3 and the Clinical part of the MRCPCH exam will need to be completed by ST4, to progress to ST5 and specialty training. There will be a less prescriptive approach to placement requirements allowing some flexibility to reflect local needs and career intentions and trainees will be encouraged to incorporate Out of Programme (OOP) opportunities to enrich their training.

We therefore need to be mindful that trainees approaching subspecialty GRID training may not be as experienced as those applying in previous years and there is an onus to continue to highlight our concerns regarding exposure to Community Child Health opportunities in ST1-4, while trainees are still focussing on passing their clinical examinations. We have heard recently in some deaneries that ST1 and ST3 Community posts have been created and we know of a number of areas where F2 doctors are working in Community Child Health; but the number of posts are small and most are spending less than four months in each post, so the opportunities to experience the real value of a community placement is compromised. It would be valuable to hear from you of local plans to ensure CCH training opportunities.

The 70:30 Split and out of Hours Commitment

There have been a number of articles in the BACCH magazine over the years alerting readers to the difficulties faced by GRID trainees because of competing Out of Hours (OOH) work on the acute paediatric and neonatal wards. As a CSAC we insist that 70% of training time is spent in community training and though this is written into each GRID post job description, there is evidence to suggest that most trainees are spending 50-60% of their training time in their community posts because of leave commitments and OOH work. Since the inception of GRID training in CCH, we have been able to demonstrate the huge difference between community child health training and acute ward work and many feel that achieving competencies in acute paediatrics at CCT (Certificate of Completion of Training) will have no bearing on their work as consultant community paediatricians. As long as trainees achieve generic and higher specialty competencies, there is no requirement for CCH trainees to undertake general paediatric competencies or undertake out of hours work in the acute paediatric setting in order to achieve a CCT in Community Child Health. We know of some CCH trainees who because of geographical constraints and the need to take up hybrid consultant posts, will need to maintain general paediatric competencies; but this is not the case for most. A number of deaneries have been proactive in removing their community grid trainees from the acute paediatric rota in a step-wise manner over the three years of training so that by their final year, they spend 100% of their training time in the community setting. Wouldn't it be better if, in a flexible curriculum, we could facilitate a more bespoke approach to training so that doctors are enabled to train to do the work they will be undertaking as consultants? The decision to allow this change lies solely with each Deanery/Postgraduate school as there is naturally a need to

support acute paediatric rotas; but unless we highlight the effect that this is having on the quality of training, I fear that community child health work will start to become an unattractive career prospect to many trainees.

Sub-Specialty Recruitment

Following a reasonably successful recruitment round least year where we interviewed 50 doctors for 42 CCH grid posts, we found 45 appointable and filled all but 8 training slots. We noticed a reduction in applicants from London last year, where the interest is usually high. The reason for this is unknown and I hope that this is merely a 'blip' and that we will be able to continue to recruit to this area where the training opportunities are excellent and the need for Community Paediatricians is high. Though distressing to see training slots go unfilled, these may be used to support future grid applicants, where training can be prospectively approved for grid or be filled by trainees who may want to have some experience in community posts before deciding on their career options.

Thank you to all who contributed to last year's grid interviews. It's such an enjoyable process and very encouraging to see enthusiastic doctors do so well. Although face-to-face interviews are far preferable, it was great to see colleagues from all areas of the United Kingdom as interviewers and we wouldn't have been able to achieve this without remote access. I have sent invitations for the next round between January 31st and 2 February 2024 and am looking forward to hearing from any consultant community paediatrician who is able to help out for a day. As a CSAC we are working on preparing and benchmarking interview questions – a process that is taking much longer than it should! The programmes from across the county are being submitted to the CSAC for approval, so please get in touch if you have any specific queries about posts in your area.
Finally, Emma Bradley, deputy CSAC Chair, and I will be facilitating two CSAC workshops at the BACCH ASM in Manchester this year. In addition to providing a training update, we will be focussing on the GRID application and interview process. Hope everyone had a very happy summer and looking forward to seeing you in Manchester.

Dr Nia John | Consultant Community Paediatrician
Chair of CSAC for Community Child Health
Email: nia.john@wales.nhs.uk

PEOPLE

Spotlight on... Michelle Heys

Michelle is a University College London (UCL) and National Institute for Health and Care Research (NIHR) Professor of Global Child Health at the Great Ormond Street Institute of Child Health, University College London, UK. She is also a Community Paediatrician, providing care to children and young people with cerebral palsy and learning disabilities in Newham, East London, at the Specialist Children's and Young People's Services, East London NHS Foundation Trust.

Over the last 17 years she has combined paediatric and public health training in the UK, Australia and Hong Kong with research, working less than full time up until the start of the COVID-19 pandemic. She has three children, girls aged 11, 15 and 17.

Her research focuses on improving outcomes for children and young people in low resource settings, with ongoing projects in the UK, Zimbabwe and Malawi. Her work addresses the survive and thrive agenda - focusing on needs and inequities of priority populations such as sick and small newborns in low resource health facilities, children and young people with complex neurodisability and neurodiversity and unaccompanied asylum-seeking children and young people.

Michelle has secured multiple grants, including a recent 5-year NIHR Global Health Research Professorship. Michelle is the co-founder and trustee of Neotree charity, aiming to scale up the Neotree intervention to support health systems in Malawi and Zimbabwe. Neotree is a digital quality improvement system combining data capture, education and clinical decision support to optimise and standardise newborn care.

She is actively involved in teaching, supervising students, and mentoring PhD candidates. Michelle has a significant portfolio of enterprise and external engagement activities, collaborating with arts enterprises and engaging with policymakers to influence research strategy and policy in community child health and health systems.

She holds two UK roles to communicate and influence research strategy: a member of the NIHR Health Technology Assessment committee for Community and Social Care, and Chair of the strategic research group of the British Association for Community Child Health. Through these roles, she influences local, regional and national agenda setting for research in community child health and health systems.

1. Describe your job in three words.

An utter privilege.

2. Who has been your greatest inspiration and why?

My mum. She left school at 14, to take up a job in the local gas board. She was incredibly creative and worked in the home whilst our family lived in many places in the middle east due to my dad's job as a civil engineer. When I was a teenager, she went back to work training as a teaching assistant with interest and expertise in children with special educational needs (SEND) support. When I was studying for my GCSEs, she was studying for her SEND qualifications. She would always go the extra mile, or two, or more, in supporting children showing dedication, kindness, humour and enormous patience. Her ethos was always to support children to be the best that they could be, something I have always tried to embody with my own children and in my clinical practice and research.

3. What has been your biggest challenge of your career and how did you overcome it?

I have experienced many significant challenges in my career and it's hard to say which have been more difficult. The one I think shook me the most, but also the one that has probably been most influential in determining my career journey was when I was working in a core general paediatrics training post (ST3-4 equivalent). We had a full-time rota, staffed by only 5.5 middle

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grade doctors. We provided senior onsite cover for A&E (accident & emergency), a very busy ward (including a small high dependency unit) and a level 3 neonatal unit, supported by very junior SHOs (senior house officers) and a small number of consultants for a population with high levels of deprivation, diversity and complex pathology. Babies and children suffered unnecessarily from this - and myself and my colleagues raised the alarm. The consultants managed to convince the deanery I was a troublemaker, the ring leader, who had, and I quote, "too high standards". One of the neonatal nurses printed a private email off my account in which I had been discussing the situation with one of the previous doctors (I had left it open whilst I ran to an arrest call) and used it as evidence. The deanery made me repeat another 6-months of a general paediatrics ST4 post. I then ended up out of step with my training and so took 6 months out of programme to do a public health training post with the eastern region, explored general practice and took some time to regroup. Subsequent groups of trainees reported the same experience and in the end the unit was recognised for the dysfunctional, dangerous place it was. Now the same clinical areas are staffed by 20 registrars, 5 consultants resident on-call in addition to a second tier of consultants at home.

I am definitely stronger for the experience - I learnt so much about my ability to manage under significant stress and about what I was prepared to fight for - but also how important self-care is. And that self-care is just that - care provided and prioritised by yourself. How did I overcome this? Well, partly through the support of my husband, family and friends, partly through counselling, I took 2 weeks off to support my mental health, journaling and making sure from then on I always had a plan B (and even C, D and E). The experience taught me that my personal health and wellbeing is more important than any job, and that if I don't prioritise myself, no one else will; and that preventable mortality is always unacceptable - irrespective of how others might try to frame it. But it also kickstarted my career combining child public health with paediatrics and academic work - which has led me to very many exciting and interesting opportunities - and to my clinical academic post now.

4. What is the highlight of your working day?

The highlight of any of my working days is seeing my team succeed - in any way, big or small. One of the joys of academic work is supervising and mentoring early career researchers and clinicians. I get enormous pleasure out of watching them learn and grow and in supporting where I can. That, and of course, my early morning coffee where I set my intentions and plan for the day.

5. What is the best advice you have received so far as a doctor?

Four things. When I did my first house officer job (Foundation Year 1 equivalent) I remember doing my first 24 hour on call - and partway through the shift my SHO asking me if I had had anything to eat or drink. In fact, I hadn't (I was probably being hangry). He told me that in this job, no one is going to sit you down and tell you to take a break, you have to do that for yourself and not feel guilty for it. I think that's a hard lesson to put into action sometimes, especially when the work feels unending. Second, that it is ok to cry - that it's ok for families to see that you are emotionally affected by a death, or by a sad case - not to blub uncontrollably, but to let some of it out there and then. Then later, when in the privacy of your home, or in a safe space to let it go. Third, to remember to ask for help, to recognise when you need help and to ask. Finally, especially relevant to community paediatrics - to see a therapist regularly. The emotional toll of our work can be substantial, especially the safeguarding caseload. When I started as a consultant, I set up a monthly therapy session that has been invaluable in helping me balance the impact of work and ensure it doesn't seep into my family life.

6. What is the single, most encouraging thing that one of your colleagues can do to make your day?

To make me a cup of coffee and make sure the biscuit drawer is filled... No, seriously, to say thank you. We all need to feel appreciated and recognised sometimes and as you get more senior it can feel lonely sometimes. We all get imposter syndrome and it's nice to get feedback.

7. After a hard day at work, what is your guilty pleasure?

Decaffeinated Earl Grey, Green and Blacks dark chocolate with salted caramel and an episode of any one of a range of house tidying reality programmes - especially "Queer Eye".

8. If you had a superpower, what would it be and why?

To sort my house out. I dream of having Marie Kondo superpowers. We are a busy household of 3 teenage girls, dual-career couple, with older parent-carer responsibilities, hobbies, sports and travel. High energy and output, very little time and relatively poor tidying skills. I dream of offering up our house to the interior design masters crew…

9. What advice would you give to inspire the next generation of community paediatric trainees?

As a future UK community paediatrician, be a strong advocate for children and families, ensuring the needs of vulnerable children are met. Collaborate with diverse professionals for better patient outcomes. Prioritise preventive care and early intervention, educating families about healthy living. Medicine is constantly evolving, and new research and technology are continually shaping healthcare practices. Stay curious and open to learning. Get involved with research. Community paediatrics can be emotionally demanding. Remember to prioritise self-care and well-being. Seek support when needed and take time to recharge. A healthy and resilient paediatrician can provide better care to their patients. Get involved in advocacy and policy development to influence positive changes in child health. Foster a supportive work environment, address health inequalities, and leverage technology for improved patient care. **Never underestimate the value of your role and the positive change you can bring to your community**. Last of all, wear sunscreen.

10. Finally, if you were stranded on a desert island, what three luxury items would you take with you?

Coffee, Green and Blacks dark chocolate and a piano (I am learning the piano and just started working towards my Grade 6 - much practice is needed!)

REVIEWS AND REFLECTIONS

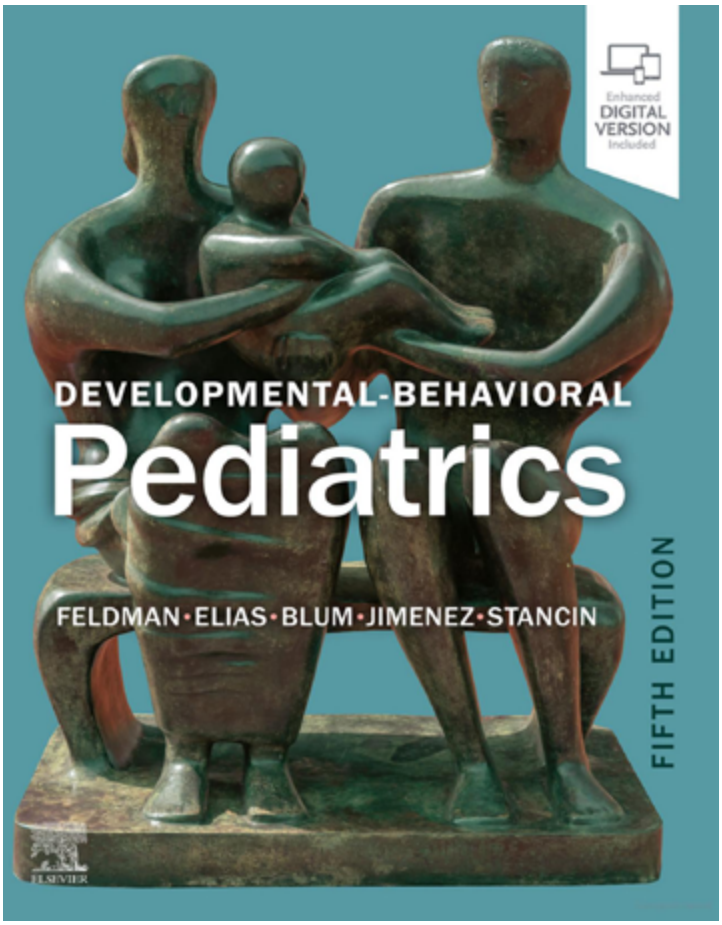
Book Review

Developmental-Behavioral Pediatrics (5th Edition)

Editors: Heidi M Feldman, Ellen Roy Elias, Nathan J Blum, Manuel Jimenez, Terry Stancin

Developmental-Behavioral Pediatrics has been updated and is now in its fifth edition. There is now a focus on an interdisciplinary approach in child development. This edition has been authored aptly by new set of professionals and experts. New sections on the theoretical foundation of knowledge about child development makes this edition even more authoritative.

This edition has kept up to date with current societal and influential topics, embracing subjects like the influence and impact of the digital world on child development and how it can be used to facilitate development, the nuances of maternal emotional health and experiences and the importance of gathering detailed information about over the counter medications. The wider aspects of child-parent relationship, from perinatal mental health to profound effects of early childhood experience have been covered from research to clinical levels, exemplified by vignettes at the opening of each chapter.



The eBook format allows one to access the entire book on a variety of devices for quick reference. It has a customised layout for easy readability and the ability to highlight sections of the text. It can also be narrated in the form of an audiobook.

This edition does not replace the previous ones but makes a valuable contribution to the advances in our understanding of child development, and should be held as compendium.

Dr Neel Kamal
Convenor, George Still Forum

WELLBEING: What do we need to pack in our bags for the new term?

I write this just before my summer holiday. I know that by the time you read these words, the days will be shorter, the air a little cooler and autumn will be just around the corner. I hope you have had a chance to unwind this summer. For many of us the summer months mean we can take a longer holiday that enables us to switch off and recharge our ailing batteries. Like the past few years, this year for many reasons has been tricky and has had a deep drain on our reserves. I often feel that September is a better month to perhaps make some resolutions for the new term ahead.

I used to love the start of a new school year. Perhaps a treat of a new school bag, a pencil case filled with new pens and then best of all - the thrill of having new exercise books. Writing your name on the cover and turning the page of a pristine book is something I still enjoy. It is the reason I keep a handwritten journal rather than a

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digital version. New school shoes and uniform that is on the larger side with room to grow. (I appreciate that as the older sibling, that was my privilege rather than the endless hand me downs my sister had.)

So, can we make some changes to our working days and weeks, to enable us to continue to feel recharged and energised as we enter another school year as paediatricians? Those who know me well will perhaps remember my challenge – how do we ensure the first patient of the shift and the last get the same kind, compassionate, safe, high-quality care? We have to be able to look after ourselves and our teams at work, during the working day.

What to put in our own pencil cases

So – let's start with what we pack in our own personal pencil cases. Talking with Cheryl Chambers Support and Psychological lead from our local HOPE (Haematology, Oncology, Palliative and End of Life care) counselling centre we realised we have both over the years built up own 'kit bags'. I have a larger tin that I keep in my office and a smaller portable one in my handbag. The contents include: rose hand cream, polos, a squeezy ball, jakemans aniseed lozenges and tissues. Also a few important tunes on my phone to listen to quietly or roar loudly and tunelessly when needed. Cheryl has a shoebox covered in some smart paper, inside there is a picture of some friends, some hand cream, her favourite book, a stone she collected from a beach, and always some chocolate (which needs replacing often).

Over a virtual cuppa, we decided it would be useful to write a bit more about this. The need to 'come to our senses' to enable us to soothe at points during the day, is arguably more pertinent now than ever. To recognise this in ourselves and others requires vulnerability. We need to reveal our authentic self, to enable understanding of our own needs and those in our teams. How can we show emotions in an environment that at work feels contained, dehumanised and at times disconnected? Our teams are still fractured. Some of us are able to work in our usual environments but these feel and look very different. Some of us have set up working from home – or living at work. We both feel fortunate to be able to do a mixture of both as it gives us valuable insight into the two environments. Many of us are trying to make sense out of the madness and chaos and for some of us that is easier than for others. It's quite exhausting keeping up a smiley face to others when inside we are feeling panicked and anxious. Our ability to spin many plates is being well and truly tested. We need to find ways to make sense and find some relief from this chaos and uncertainty. We also need to pause and remember that for many of our patients, families and colleagues, uncertainty has become the new normal.

The kit bag we carry with us needs to contain a few things that will enable us to pause and soothe. If we come down from the sympathetic overdrive of fight, flight, face and freeze we can reconnect to our own needs and be more available for our teams.

These kit bags are unique to us; we have shared this idea with many colleagues. Some have their grandma's perfume to remind them of her strength, some carry a gin bottle to enable a sniff (empty to avoid a swig), a jigsaw puzzle left on a table can be useful, and a squeezy ball, a punchbag, a skipping rope and an exercise bike have all been discussed. Some have certain books and pictures, little quotes to inspire and homemade drawing and cards. We often collect these on our desks without realising it – perhaps now is a good time to make these choices a little more conscious. All of these enable to us to return to parasympathetic system. Here we can restore ourselves ready for the next conversation, the next task or the next procedure. If we enable our window of tolerance to grow, we hold a bigger space to enable us to be more effective as individuals but also within our teams.

This insightful Sufi story is helpful too; this is how we remember it. One day a man was cycling the several miles he needed to in order to get some water for his family, on his way his bicycle developed a puncture, so he started to walk, he then tripped over and hurt his leg. Whilst limping on he came across some tigers that chased him into a pit. As he clung onto the roots of a tree, whilst hanging in the pit he saw venomous snakes at the bottom of the pit. Realising that life could not get any worse for him and that everything was against him, he turned his head and saw a wild strawberry growing. He took a bite and for an instant life was ok. We need to take time to find our "strawberries". Moments in life when things are ok even when they are not ok. So we encourage you, or perhaps challenge you all to go and grab some strawberries and keep those moments in your kit bag too. We would love to hear what you carry.

Many of us will be familiar with the latest NHS staff surveys. In general, they make for pretty eye watering reading. Burnout and colleague wellbeing are going in the wrong direction and

are compounding increasing staff shortages. Add in increased workload, a cost-of-living crisis and dissatisfaction fuelling NHS and wider strikes, we are in truly challenging times. In my reading around colleague wellbeing the evidence is striking. If we can lead our teams with inclusion, kindness, compassion and wellbeing as our core strengths then we are more likely to promote a working environment where we can all not just survive but also thrive. Shanafelt et al[1] discuss this in their article on Wellness-Centred leadership. They propose a model that at its foundation has 'care about people always', then adds in how important it is to cultivate relationships as individuals and teams. With these foundations, we enable change to be inspired. I would recommend reading their paper referenced below. The core leadership skills can be learned and comprise a broad set looking at inclusion, keeping colleagues informed, using humble inquiry, being motivated as leaders to develop individuals and empower individuals and teams. By focusing on intrinsic motivators rather than external rewards this further facilitates a sense of team.

Many of us will have read West and Coia's report 'Caring for doctors, Caring for patients'.[2] They describe 3 key features that we all need to enable professional satisfaction. These are: autonomy and control, a sense of belonging and meaning, and a sense of clinical competence (being able to do our jobs well). When we feel like we are simply cogs in a wheel working in a way that derives little sense of meaning and purpose this can be challenging. I will write more on these 2 articles and what they offer towards a sense of team in the next BACCH News. For now though, here are a few suggestions for supporting our teams:

What to put in the team kit bag

When we gather for team meetings we could include some time for a catch up. Can we look at a few minutes at the start of a meeting for a shared lunch, cup of tea and cake? These informal conversations are very powerful and go a long way to feeling reenergised as a team. If we only come together to discuss the agenda items that can be quite dry and challenging, we don't build those foundational relationships we often need to innovate and inspire change.

There is much evidence that reflective practice helps provide a space to explore the emotional cost of caring. Schwartz rounds ('About Schwartz Rounds – The Point of Care Foundation'[3]) provide a structured forum where all colleagues, clinical and non-clinical, come together regularly to discuss the emotional and social aspects of working in healthcare. The purpose of Schwartz rounds is to understand the challenges and rewards that are intrinsic to providing care, not to solve problems or to focus on the clinical aspects of patient care. If your trust doesn't yet do them do look up the link. We can also gather in smaller reflective groups; we can use our educational and clinical supervisor sessions in this way. We can also spend time when peer reviewing cases to think about the human aspects. Clinical supervision is well known to our psychology colleagues, we perhaps need to think about how we set aside some time to prioritise ourselves.

More informally locally, we have had great success with our #FriYAY lunchtime session. Instead of a formal teaching like the other weekday lunches, Fridays have the aim of connection, fun and getting together as a team. We have celebrated big birthdays, maternity leave, babies, achievements outside of work over shared lunch and cake. We also have a keen crafter and Sarah has entertained us with group sessions from watercolour cards, through macrame plant pots, key rings and origami. Always popular they also provide a vital function of connecting us.

Sending you all good wishes for a good term ahead, please do let me know what you have packed in your pencil case or team kit bag.

Dr Anna Baverstock | Paediatrician, Leadership and Wellbeing Lead, Somerset NHS Foundation Trust
Twitter: @anna_annabav

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Events Calendar

BACCH events

Date	Event
09-10 Oct 2024	Annual Scientific Meeting (Glasgow) – SAVE THE DATE *https://www.bacch.org.uk/events/bacch-asm-2024*

Affiliate group events

Date	Organisation	Event
05-06 Oct 2023	GSF	Annual Scientific Meeting – Masterclass & Study Day (London) *https://georgestillforum.org*
06 Oct 2023	BACD	Weigh to Go! (online) *www.bacdis.org.uk/events/weigh-to-go-2023*
09-10 Oct 2023	BAPA	Aetiological Investigations for Hearing Loss in Children (London) *https://tinyurl.com/whjk2kpa*
16-17 Nov 2023	APPM	Paediatric Palliative Care Conference (Birmingham) *https://www.appm.org.uk/events/*
09-10 Oct 2023	BAPA	Aetiological Investigations for Hearing Loss in Children (London) *https://tinyurl.com/whjk2kpa*

Events Calendar *(cont.)*

External events

Date	Organisation	Event
05 Oct 2023	RCPCH	How to Manage FASD in Community Paediatric services (London) ***https://www.rcpch.ac.uk/news-events/events***
11 Oct 2023	HC-UK	CAMHS National Summit 2023 (online)* ***https://www.healthcareconferencesuk.co.uk/virtual-online-courses***
16-17 Oct 2023	Alder Hey Academy	Paediatric Vestibular Course (Liverpool) ***https://www.alderhey.nhs.uk/academy/courses-events/***
16-17 Nov 2023	ACDRP	Association of Child Death Review Professionals Annual Conference (Manchester) ***https://partnersinpaediatrics.org/news-events/association-of-child-death-review-professionals-conference/***
23 Nov 2023	DSMIG	Winter Meeting & AGM (London) ***https://www.dsmig.org.uk/tc-events/dsmig-winter-meeting-2023/***
24-26 Jan 2024	BPNA	Annual Conference (Bristol & online) ***https://bpna.org.uk/conference/2024/***

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