



ICON: Babies Cry, You Can Cope
Minutes of Executive National Strategic Group (ENSG)
held on 19 July 2024

Attendees:

Jane Scattergood	(JS)	Chair
Suzanne Smith	(SS)	
Sue Anslow	(SA)	
Jenny Whyte	(JW)	
Scott McLean	(SM)	
Giles Haythornthwaite	(GH)	
Celia Balbernie	(CB)	
Andy Knox	(AK)	

Apologies:

Katie Clarke	Paul Havey
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No.	ITEM	ACTION
1	Minutes of Extraordinary meeting held on 15 April 2024 were approved as an accurate record.	
2	<u>Action Log</u> All outstanding actions complete, deferred or on target: Action 80: Complete. Scotland have come on board with ICON. Action 84: Deferred - Audits will be revisited when situation regarding ICON funding is clearer. Action 99: Deferred – to be discussed in terms of charity status as that is a change in our funding model to ensure a costed framework for auditing compliance and fidelity with the programme. Action 100: Complete. Meeting with Warrington has taken place. Action 102: Complete. KC has kept in touch with SS and Ali Kenner re: ICON. Actions 103 & 104: On target. SS provided updates on these: Scotland have agreed to adopt ICON. The Scottish government have approved this and the £20k fee. The ICON parent ambassador for Scotland has written a letter of thanks, and she	

	<p>is happy for herself and her son Jason, who was shaken as a baby, to be involved and support Scotland.</p> <p>The charitable status update is that they have agreed that ICON does meet all the criteria for a charity. We are just awaiting forms with the trustees signatures on and SS will send these forms off immediately. Once we have the number applications for funding will start. It is in the newsletter and it means that ICON can carry on.</p> <p>From 1 July, SA returned to her substantive role in HCRG, who are the providers that SA worked for prior to being seconded to ICON. HCRG have been very supportive in agreeing that SA can retain three days a week supporting ICON. This was originally going to be until the end of September, when HCRG were transferring to a different supplier but now that is not happening. Potentially we might have SA for three days a week until end of October 2025, although this hasn't been agreed to as yet. It is all positive even though we have come really close in terms of financial zero-ness. We now have sustainability and will have funds in the bank soon from charitable funding.</p> <p>JS updated they have been in contact with some people who are very experienced in working with and enabling the charity sector, and who have introduced us to people who have done some pro-bono work to tell us where ICON best fits with donors. We have been invited to apply, as soon as we have a number, to the Henry Smith Foundation who donate between £40m and £60m a year, and they have got a new theme which is called Change Makers. The head of their Trustees thinks he can get significant funding for us, and this could be obtained quickly and will give us some financial security. JS thanked everybody for volunteering to be trustees, and to SS for pursuing charitable status. SS thanked JS for getting us contacts with donors.</p> <p>SM commented that it might be more clear now to the NHS Trusts that we deal with where we fit now we have charity status, and this might facilitate more joint work. SS and JS agreed and JS mentioned the way that Lullaby have worked since they became a charity, which opens many avenues.</p> <p>GH asked who do we communicate this information to in the NHS and ICBs, so we can log ourselves as charity partners for the NHS? JS said NHSE probably for England, and then the devolved governments. For ICBs, all the providers of NHS Foundation Trusts have charity relationships and provider organisations. This can loop around to the royal colleges that all endorsed us previously and re-assert that we are now a charity, and that will change the relationship.</p> <p>SS agreed that once we have the number, we need an action plan of how to cascade the information. We will need to be reaching out to different organisations, and Kenny Gibson, who is one of the trustees, is a good link into NHSE, and the royal colleges are really important especially RCGP as they have been so supportive. Also people like Dorian Kennedy so we need a plan of who we tell and how we telling them. We will also have to review the number on our stationery, copywriting etc. JS advised that they have got some offers of help for that from the CVS and others, as they have a statutory relationship with local authorities</p>	<p>JS/SS</p> <p>JS/SS</p>
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	<p>that commission 0-19. This will help us position ourselves. There are links available to help us understand how we do that in the first instance, and the Cumbria CVS will help and link us to all sorts of pro-bono.</p> <p>SM commented that as we now have 335 new MPs, there might be an opportunity to share the message with them, even if only 10 of them re-tweeted. JS and SS agreed it was a good idea, and Mark Britten (MB) might have a lot of contacts for MPs through their social media. SA to speak to MB about this.</p>	SA/MB
3	<p><u>Commissions/interest update</u></p> <p>SA updated that there are still four areas that haven't commissioned, but perhaps when we get charity status their safeguarding boards may look at ICON differently, and they may decide to come on board.</p>	
4	<p><u>Parent/Families Slot</u></p> <p>SS updated that a child of a parent in the parents group, died recently, and he was a shaken baby. He lived until he was seven and had very severe disabilities, and his funeral was held on 18 July. Obviously all the parents are touched by this. We sent some flowers and a card and when Terry, Tristan's mum, is ready we will add an In Memorium tribute on our website. We are waiting to hear if the police are going to re-open the case, because it is now a murder enquiry.</p>	
5	<p><u>ICON Team Updates</u></p> <p>SA updated - team update papers as circulated.</p> <p><u>ICON Week</u></p> <p>ICON Week this year is going to be very much social media focussed, because of funding uncertainties, we could not plan anything. There will be a toolkit circulated and hopefully we will launch our new leaflet which is how friends and family can support parents/carers. We have also asked the NSG to keep us up to date with what they are planning for us to share on social media. If they are planning any training/conferences to invite us and we may be able to join them virtually.</p> <p><u>Resources</u></p> <p>We are awaiting some new resources – we have done and shared the cleft palate posters and we are awaiting the Friends and Relatives leaflet, and also the O and N posters.</p> <p>SS and SA had a meeting with some people from the cleft lip and palate association, CLAPPA, they saw the poster and assumed that we were suggesting that babies with cleft palate were more likely to cry. Even though the poster said – All babies are different, all babies cry, which was agreed with the parents. We fed back that we have had no negative feedback from any parent. CLAPPA even said that: <i>"We don't know how many people have looked at your poster and as a result have had an abortion, because they think that babies with cleft lip and palates are more likely to cry"</i>. This was a shocking thing to say. They</p>	SA/MB

	<p>suggested that we should do posters for other types of babies, and they also said we were portraying cleft lip and palate as a disability, although this word does not appear. We are not going to change the posters as the parents provided us with these pictures and we have had no complaints. We are going to look at getting a more diverse range of children on our posters, but that was always part of the plan.</p> <p>SS then received an email from the National Safeguarding Panel, who sent a Cleft Lip and Palate Safeguarding review from Rochdale. They put us in touch with Dr Sujata De, who is a specialist in Cleft Lip and Palate. SS has tried to engage with Dr Sujata De but without any response. SS is going to share the posters with them.</p> <p>GH suggested that CLAPPA may think that somebody is treading on their area and the posters are quite good, and that's probably why it annoys them. The posters are not asking for money to be put into the Cleft Lip and Palate Association - it just has a different message about crying and they are probably feeling a bit put out that they are not involved and it isn't their message. From the parents perspective it has been a very therapeutic situation for them putting their child out there, and maybe it's a learning curve for consulting these sorts of associations in future so they don't take offence. SS agreed. JS said that the overriding thing is the universal nature of the message for any family with any baby, and that's why we resisted doing targeted populations etc. It's because the cleft palate isn't special - that is the point.</p> <p>SS added that people may have seen the pictures of Betsy Mae, who has had a repair now, and we have got some lovely photos.</p> <p><u>Primary Care</u></p> <p>JS advised that recently GPs had been saying that ICON is not a thing anymore, and as AK is on the call, do they need to do some messaging to challenge that, and reassert ICON to GPs? SS said that when ICON was launched, they didn't have a problem getting GPs involved, and they had two named doctors in Hampshire who drove it, and got the RCGP involved. But we seem to have lost that drive, and GPs are now becoming a problem in terms of being open to complete that last touchpoint at the 6-8 week check, so we really need to do something in that space. AK to look at this and take as an action. JS added that there is a pop-up on EMIS now for GPs to complete, and for audit purposes, when they are doing the 6-8 week check.</p> <p>GH wanted to refer to the MPs point mentioned earlier: early years and prevention seem to be on the political agenda, and with our charity status, do we need to push with Dorian Kennedy the need to be inside some of the strategy or scoping of what will happen in health? We haven't quite got the evidence yet but the trauma database that we were hoping for the quantitative, has gone live again so hopefully the data that we need will be migrated across. GH has a contact in Manchester who has the PALM database, and their data has got all the trauma injured children. We want to compare areas where ICON has gone live, against areas which hadn't gone live, to see if there is a</p>	<p>AK</p>
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	<p>difference to the rate of injured shaken babies. The qualitative analysis has found very similar things to the Hampshire evaluation and it evaluates really well. The quantitative analysis will be useful for opening doors between the Government, so is Dorian Kennedy the right place to go for that? With GPs we have to be pretty careful on the messaging to make sure we're not looking like we're asking them to do something additional. They are asking for more pay on that at the moment, and some of that will involve working to contracts, so we have to be very careful in making it clear that ICON is actually a tool which speeds up their communication, and having it reduces their attendance. That also shows the benefits to their patients but also to their practices and business models.</p> <p>JS agreed and said it can reduce footfall in early weeks as well as preventing horrific injuries. It felt like the messaging was that ICON was not a thing anymore, and from that it looked like the repository of evidence wasn't maintained i.e. we did it and it was great but now we are not doing it. Certainly, the evaluative evidence you describe would be great. If Dorian Kennedy was retiring, we could find out who is in that place in DH but Lord Darzi is surely going to write about prevention in community as he did last time.</p> <p>SA advised that following on from the last NSG meeting, where it was brought up that ICON isn't really a thing, a lot more areas are starting to look into that. SA went to an ICON meeting in Lancashire recently and they are looking at how to engage and roll out the training to the GP's. Areas are starting to realise that the GP contact may not be being completed as it should and they looking at how to ensure this is being completed. JS said that was great and we could use that as a tester because AK is not only a GP but also the ICB, which includes all of those Lancashire Councils.</p> <p>JW added that they are getting multi-agencies attending this training and it's going well. One of their child death nurses is doing it. JW to send the up-to-date stats for this which will be put in the next newsletter</p> <p>SA also mentioned there was an article in the newsletter about Barnados. SS did a presentation there, and there were lots of people from different areas including from Ireland, Scotland, and Wales. That was really positive and they might be of some support for us.</p> <p>SS said she got into Wales through Barnados. They have been on board with us from the beginning, since 2017, and they did some of the early evaluations. More recently we have trained all their health and social care workers around ICON. The event that SS did recently was training everybody in Barnados, and that included all their shopworkers, so that was really positive. SS also had a meeting with Welsh Barnados, who do their own programme, and they are looking at taking the whole of ICON and adapting it to be served through those programmes. That might also be a way for ICON to get into the Health Board.</p> <p>SS added that Avon & Somerset Police have contacted her and came to a presentation, and they really want to make the delivery</p>	<p>JW/AB</p>
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	<p>of ICON a substantive and regular thing. So they are looking at us to make a programme for them. GH added that they have got a big HQ with good teaching facilities.</p> <p>JS advised they were talking to the Cumbria constabulary who are also interested in that, and also are introducing them to the police force leads who work on safeguarding and working with families, so maybe we can join something up. They share their HQ with the Fire & Rescue Service, so we can do a north of England and SW England programme.</p> <p><u>Men's Steering Group</u></p> <p>SA advised that Fabian Smith in West Sussex, has only just come on board but she is a really keen GP and she has adapted our PowerPoint 'Train the Trainer' for GPs. SA attended one of her sessions and she has also designed a 7-Minute Brief. She has offered to give some support if we need it as well. JS asked if we could link that together with Andy's social media presence and video shorts, that would be great.</p>	AK/SA/ MB
6	<p><u>Reachdeck</u></p> <p>SA updated that there are still quite a lot of people using the translation facility on Reachdeck and there is a demo video on the website. Some areas have translated a lot of leaflets and Harlow have got these, but there are too many to put on the website, so we still direct translation enquiries to Reachdeck or Harlow. JS commented that different areas have different language needs.</p>	
7	<p><u>Finance report</u></p> <p>JS updated that the financial report says we have got next to no money, but Scotland are now going to give us some money, and we will also be a charity. We might need to give HCRG some public recognition for supporting ICON with three days a week – they are a partner. This was agreed.</p>	JS
8	<p><u>Social Media report</u></p> <p>SA summarised the social media report: Compared with last quarters report numbers have gone up slightly, for members and downloads it's gone from 25,000 to 34,000. Social media reach has gone up as well. You now have to pay for these statistics on X (Twitter)..</p> <p>E-Learning for the last quarter was 445 who had completed it, and 1,479 completed in total for this quarter, and feedback has been very positive.</p>	
9	<p><u>Harlow Printing</u></p> <p>SA advised that we have had the reports from Harlow Printing but haven't received any payment for a while so AB and SA checked back on the reports to 2023 and saw that we were owed £1600 from them. So that will pay for the leaflets plus we will get some money paid to us, which is good news!</p>	

10	<p><u>AOB:</u></p> <p>GH said he was a bit worried that about a year ago we had flourished but then we were lagging. But now it feels organic because the language that has been invented is so good, because people are using it as their own which is fantastic and that's the real success. ICON has become a normal part of people's language now in a lot of places.</p> <p>The next step is have we enough evidence to do a national media campaign? The other thing is whether or not we have got enough to either: peer review ICON services, so people go from one ICON service to another so they review each other's and collect ideas; or embed ICON inside one of the statutory and mandatory reviews that people have to do for their ICB assurances or safeguarding boards, so we can add it in as a long term governance.</p> <p>JW advised they have got it in their Section 11 returns: Section 11 is where their providers have to give us the assurance as an ICB around safeguarding. JS added that ICON has been commented on in a number of maternity reports as a positive.</p>	
11	Date of next quarterly ENSG meeting is Wednesday 16 October 2024 at 10:00-11:30.	