

# CYNet



Health of our children: Wealth of our nation

Newsletter of the Advisory Group for New Zealand Child and Youth Clinical Networks

Issue 1 - 2017



## From the Chair

Welcome to the new edition of the CYNet newsletter for 2017.

This edition includes an article contributed by Prof Steve Cropper following his visit to New Zealand last

year. Many of the New Zealand network leaders met Steve at our joint networks meeting in Wellington and at the PSNZ annual conference. It was very useful to compare Steve's extensive experience with clinical network development in the UK with our program in New Zealand, and in his article, he describes in detail the UK position. A key point which he raises in his commentary is the relationship between the New Zealand Child and Youth Clinical Networks (NZCYCN) program and DHB leadership and service commissioning systems. New Zealand has a small number of nationally funded child health services, but the most child health services are funded and managed by individual DHBs with some regional networking and agreements around referral criteria for tertiary services.

NZCYCN seek to improve quality and access to care through guideline development, health professional education, and dissemination of information for both health professionals and parents. There is a sense that much of this activity is occurring under the radar for DHB leadership. The program is producing a lot of quality improvement activity

and accessible resources at remarkably low cost. The NZCYCN program does not have a mandate to direct the commissioning of new child health services nor to change the way in which agreements between DHBs are set up regarding centralisation of more complex aspects of child health. Regardless of this, NZCYCN is well supported by the Ministry of Health and issues which are identified by Network clinical leads can be raised for consideration at ministry level. There is an opportunity for NZCYCN to assist DHBs in achieving Ministry health targets and the Better Public Services aims which include several child health priorities.

The NZCYCN program has recently commissioned an independent external review of the network program by Quigley and Watts, who have considerable experience in program evaluation. This was a high-level review of the Network program governance rather than a review of the progress of individual networks. The objectives of the review were:

- 1) To understand how effectively the program has been established
- 2) To understand the key features of the program, including those that are critical to its success and sustainability
- 3) To understand how effectively the program is being implemented and managed
- 4) To identify the areas that the program is working well and those that could be improved.



The work has been completed, and the Clinical Advisory Group have received a draft report for initial consideration before it is finalised. The findings will be published in the near future.

The NZCYCN program is approaching the end of the current contract between PSNZ and the Ministry of Health at the end of this financial year. We are optimistic regarding renewal of the contract and looking forward to discussions with the Ministry about how a new contract can be focussed. The visit and subsequent reflections from Prof Cropper, and the independent review by Quigley and Watts will both be invaluable to inform our discussions with the Ministry.

As in previous newsletters I am pleased that we able to include articles which highlight the real benefits which are being achieved by our clinical networks, in this case from the Gastroenterology and Eczema networks. I also note that PSNZ has been redesigning its website and this should help with more dedicated web based links for CNs. Information will be on the PSNZ Listserver regarding changes.

The Kidshealth web site has also been re-designed, and is well worth visiting for NZ designed parent information material.

Regards,

**Richard Aickin**

Chair, Paediatric Clinical Networks Advisory Group.

## Clinical Network websites

For more information on what is happening with the 11\_NZ (national) Clinical Networks check out the front page below or go directly to the specialist CN

[www.starship.org.nz/for-health-professionals/national-child-and-youth-clinical-networks/](http://www.starship.org.nz/for-health-professionals/national-child-and-youth-clinical-networks/)

[www.starship.org.nz/diabetesnetwork](http://www.starship.org.nz/diabetesnetwork)

[www.starship.org.nz/gastroenterologynetwork](http://www.starship.org.nz/gastroenterologynetwork)

[www.starship.org.nz/newbornnetwork](http://www.starship.org.nz/newbornnetwork)

[www.starship.org.nz/childprotectnetwork](http://www.starship.org.nz/childprotectnetwork)

[www.starship.org.nz/palliativecarenetwork](http://www.starship.org.nz/palliativecarenetwork)

[www.starship.org.nz/cysticfibrosisnetwork](http://www.starship.org.nz/cysticfibrosisnetwork)

[www.starship.org.nz/sleepnetwork](http://www.starship.org.nz/sleepnetwork)

[www.starship.org.nz/tubefeedingnetwork/](http://www.starship.org.nz/tubefeedingnetwork/)

[www.starship.org.nz/neuronetwork](http://www.starship.org.nz/neuronetwork)

[www.starship.org.nz/eczemanetwork](http://www.starship.org.nz/eczemanetwork)

[www.starship.org.nz/allergynetwork](http://www.starship.org.nz/allergynetwork)

# Out of the Gate:

## Reflections on the New Zealand Child & Youth Clinical Networks

**Steve Cropper,**

Keele University, and Partners in Paediatrics, UK

It was an absolute privilege, towards the end of last year, to visit the Paediatric Society of New Zealand, to learn about the Child and Youth Clinical Networks and to do some pondering on the ways in which clinical networks in New Zealand compare with those I know in the UK. I had several bites at the cherry – hearing from Chairs of the Special Interest Groups, attending the annual scientific meeting (in Tauranga), and meeting with the Child and Youth Clinical Networks advisory board, the network leads and managers, and with other national network leads at the Ministry. Lots of food for thought<sup>1</sup>.

First things first. I was forcibly struck by the energy and commitment of members of the multi-professional groups that convened as the visible front of the networks, and by the achievements to date. This impressive and ambitious programme reminded me very



strongly of the explosion of activity in the early years of paediatric networking in the UK. Then, networking had added significance because it signalled a way of mitigating the effects of the market on children's health services. Professionals working in those services found time and energy from somewhere to pool for the purposes of collaborative service planning and improvement.

I observed something important about the swapping of notes across the Child and Youth Networks at the meetings, and about the openness to the evaluation of the programme, which will soon be reporting its findings. Like any form of organizing, you have to work at it, thoughtfully and respectfully – it is based on relational practices that demand this.

As a member of the core team of Partners in Paediatrics<sup>2</sup>, which

has supported networking in one region of England, I was also acutely aware of the quiet professionalism of the PSNZ central team, the network facilitators and leads, and the supportive feel evident from the sponsor – the Ministry – for the development of the network approach to service improvement. It is clear that services for children and young people are visible in a strategic sense at national level.

There is always more that can be done, but children and young people in New Zealand have a committed set of champions here. These are all important ingredients that help to explain the progress that has been made in the work to secure quality and equitable services. From the UK, 2017, there is much to envy.

### History and some lessons from the origins of managed networking

History may be bunkum, but it is important bunkum. In the UK, the ‘clinical network’ was an idea that made sense, when, in 1995, Kenneth Calman and Deirdre Hine set out a strategy to improve the organisation of cancer services in England and Wales. The following year, David Carter, leading a review of Acute Services in Scotland also saw that clinical networks could improve the accessibility and quality of care in a geography and demography that has rather greater similarity to those of New Zealand.

The definition of the managed clinical network, devised in Scotland and then widely adopted, is of an integrated system of care: “linked groups of health professionals and organisations from primary, secondary and tertiary care working in a co-ordinated manner, unconstrained by existing professional and existing [organisational] boundaries to ensure equitable provision of high quality services” (Scottish Acute Services Review, 1998; Baker and Lorimer, 1999).

This set a high bar ... Since then, there has been a gradual accumulation of experience with networks, and evidence about networks.

Further points have been added to the general specification – the involvement of patients and the public in the work of the network, and requirements for strong network accountability for performance, to name but two. The Royal College of Paediatrics and Child Health (2012) report ‘Bringing Networks to Life’ found twenty principles to govern network operations and a range of benefits that networks could bring to a locality or region. It is the bit in the middle – between principles and benefits – that has been the tricky bit.

In Scotland, a review of national and Scotland-wide managed clinical networks, looked for performance and added value against network costs to the national budget (NHS Scotland, 2010). Despite a range of rationales and practices, the review found good value (NHS Scotland, 2011). On my reading, the New Zealand networks



*Out of the gate  
and off for a walk  
went Hairy Maclary  
from Donaldson's Dairy*

with thanks to Lynley Dodd and members of PSNZ.

would more than match up. Three recommendations made by the Scottish review may, however, be points to consider.

First, the review noted that some ‘mature networks’ (some 10 years old) had (likely) come to the end of their productive life, having made ‘an enormous contribution’ in the first few years of their life. It also suggested that the structures in place for some networks in areas of high potential service improvement were not yet fit for purpose and recommended a further three years of investment. Active attention to the life cycles of networks is important to ensure the resources invested are used to best effect. PiP’s experience is that networks don’t necessarily perform evenly through time – life cycle management is

necessary, but it requires careful judgement.

Second, the review recommended a more formalised governance arrangement and sharing good practice across the networks and this led to establishment of a national network management service to provide strategic direction, operational management and support to the 25 nationally commissioned networks in Scotland (<http://www.mcns.scot.nhs.uk>). Here, Scotland follows the New Zealand lead.

Thirdly, the question of who values and uses (engages in) the networks is key. The Scottish review argued that greater stakeholder engagement was needed to maximise network impact. “The extent to which the network engages with its main stakeholders is fundamental to its success; this should include engaging with patients, carers, and the voluntary sector as well as the variety of professional disciplines involved in providing care, and other relevant bodies.” (NHS Scotland, 2011: 2).

I found little talk, during my time in New Zealand, of the widening of participation to include such ‘experts by experience’. In the UK, engagement with children and young people is proving, for a centrally-initiated push, to be inspiring and productive. There is much to be gained from consultation and engagement on service planning, review and delivery with young people and their parents/carers – knowledge and understanding of how they experience services – good and bad – and what they see as important. They are powerful representatives and self-advocates. But Partners in Paediatrics has also explicitly defined ‘involvement and advocacy’ as part of its formal objectives. It has been working to engage commissioners in a network for purposes of shared learning about children’s services. This is in the context of a ‘struggle’ over twenty years or so to redress a form of neglect of children and young people in service planning and in service resourcing.

On the English scene, regional Strategic Clinical Networks were set up, in 2012, for each of four ‘priority’ service areas – cancer, critical care, mental health, and ... hoorah, children and maternity. In 2016,

cuts in the budget to the shared network support units meant that children's networks were written out of the agenda – maternity survives and it will be important for children's services somehow to pin themselves to maternity as reconfiguration and integration of services proceeds to extract efficiency savings and deliver sustainable services.

Forty four, recently published Sustainability and Transformation Plans cover England and represent a move away from competition between providers, and a conflictual contracting regime, to a place-based 'whole system' approach – 'all in it together'. Children's services do not feature heavily in the plans, apart from the national priority of CAMHS, but it should be possible (and may turn out to be essential) to maintain networks to inform and challenge the planners.

### **What the networks do and what they achieve**

The PSNZ networks have been set up to become 'the go-to place for expertise'. Designation helps. A central capacity to support recognised networks also helps. Ferlie and colleagues (2013), in their assessment of managed clinical networks, suggest that the role of strong network management teams was, they concluded, key to making the cancer networks effective. The New Zealand Child and Youth clinical networks have those advantages. The Paediatric Diabetes network, alone, has nine workstreams: though there were clearly some differences in level of network activity, there is no lack of ambition.

In the UK, we have a type of mandated network (commissioned centrally and with comprehensive coverage of the population, generally by region or sub-region). This type includes cancer, critical care, and newborn networks. These have (some/much) delegated responsibility for the planning and governance of services including oversight of the operation of the services. They are dubbed 'Operational Delivery Networks'. Like the New Zealand networks, these are formally constituted and accountable for performance, improvement vehicles that are allowed very close influence over practice.

The New Zealand networks clearly have come into being, courtesy PSNZ and the Ministry of Health, with DHB contributions, for excellent reasons – to ensure equity of access, standardisation of service and practice, and evenness of outcome across the child and youth population. This speaks to the ambitions of the networks. But they are advisory. Expert groups come together to assemble evidence where it exists and to pool opinion towards a consensus on standards, protocols, guidelines and pathways.

The presentations at the Wellington meeting shows this is substantial work. Investment in project organisation and support is essential and so, too, is investment in dissemination and support, and in follow-up to see whether and how the tools are being used by clinical colleagues in their services, and to what benefit. I was unclear how evenly and determinedly this second set of activities are being pursued.

The same issue arises in Partners in Paediatrics. Reach into the clinical community(ies) to promote take up of guidance is one thing; reach into the executive chambers and the levers available there – contracts with different professional groups about responsibilities, workload and time; the availability of professionals with the necessary experience, skills and expertise, and the right health care facilities/technology - is another.

This is where the networks may have some constitutional work to do. An issue for the New Zealand networks that is perhaps not

completely resolved is the relationship between the national clinical networks and more local planning arrangements, including the DHBs and their Regional Alliances. The bulk of network resource – clinical and manager time - is spread around and contributed by the DHBs. But DHB 'sign-up' to the Networks and their terms of reference seems to be a gap. And DHBs may not even be aware of their contributions if clinicians use, for example, CME time and are recruited via professional associations and interest groups for their expertise rather than chosen by the DHBs and given 'representative' status. It might narrow the range of networks and it might limit their ToRs, but this might ensure that the time and energy going into the networks is the more valued.

Ferlie and colleagues found that the clinical networks they examined (which included cancer networks) fell short of the performance expected. Even on 'soft measures' of learning and knowledge translation, where networks should, in theory, do well, they found a generally disappointing pattern' (p208).

I didn't see that at all in the New Zealand networks – quite the reverse – but I had limited insight into the networks' reach into the DHBs themselves. In one of the more carefully constructed efforts, in which a UK managed clinical network was used to improve quality of diabetes care, Greene et al (2008) found that improvement was achieved, attributable to the network's use of multiple quality improvement strategies (guideline development and dissemination, education, clinical audit, support for multidisciplinary working and task redesign).

Most important, however, was the depth and breadth of clinical engagement that was built up over sustained network presence and activity. For the New Zealand networks, the balance between engaging professionals in collaborative development work and a focus on building impact on the ground is perhaps one to watch carefully. Supporting members in work to translate and implement 'back home' may be a crucial network task.

The most tabled question of my visit concerned the question of how to keep networks going. The members judge, the sponsors and stakeholders judge, and the prime beneficiaries – children, young people and their families – need to remain in close focus.

For any network, there seems to be a natural ebb and flow of energies from an initial period of enthusiasm in which members of the network contribute, cooperate and produce. The presentations of workplans, outputs, achievements and for each of the networks at the Wellington airport meeting was extraordinary. With the networks' careful leadership and the emerging governance systems, that commitment will make important differences for children and young people across the country.

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1 I would like to thank the many people who showed me the quality of New Zealand hospitality and have me much to think about. I was royally looked after. A special thanks to Mollie Wilson, David Newman, Richard Aiken and Denise Tringham who sponsored and organized the visit, saw me in and off the premises, and gave much in-between. And thank you, Rosie Marks, for a kind and instructive lift from Auckland to Tauranga.

2 <http://www.partnersinpaediatrics.org>

# A case study: finding the needle in the haystack

## History

Following an uneventful pregnancy, with associated good antenatal care that included normal maternal screening bloods and anatomy scans, Baby X was born at 41 weeks and the case notes record Baby X as “Good condition at birth”.

It was also noted that Baby X passed meconium like stools initially, but over subsequent days the stools had become increasingly pale. At one week of age the stools were very chalky and pale although sporadically some stools did have some colour.

General observations recorded as; baby alert, breastfeeding well, regular wet nappies noted. However mild scleral jaundice was also observed.

Based on the above at one week of age the Lead Maternity Carer, who observed the pale stools and jaundice, referred Baby X to a Paediatrician.

## Treatment and care.

A split bilirubin (conjugated and unconjugated bilirubin) was ordered and this identified conjugated hyperbilirubinaemia, an indicator of biliary cholestasis.

Baby X was immediately referred to tertiary specialists for further investigation of possible biliary atresia. The diagnosis was confirmed as biliary atresia and Baby X had a Kasai Portoenterostomy corrective surgery at five weeks of age.

## Comments

This is a positive case of finding a ‘needle in the haystack’.

Baby jaundice is a common occurrence in newborn babies. In New Zealand however, around 12 babies annually (approximately 0.02% of annual deliveries) develop obstructive jaundice that requires urgent referral for immediate and ongoing treatment.

The timing of corrective surgery is important for positive health

outcomes for these babies. If surgery is performed earlier the need for liver transplant is potentially delayed or even avoided.

The later the diagnosis is made the less successful the surgery and transplant is not only more likely to occur but will be required often as an infant.

To reduce the age of diagnosis for new babies with this condition, a quality improvement activity of the New Zealand Paediatric Gastroenterology Network has been the development of (1) a referral pathway and (2) the “beware yellow” campaign. These activities seek to raise awareness of early signs of the condition for health professionals who provide care for mothers and new born infants.

During subsequent conversations with the Lead Maternity Carer, who referred the baby, it was identified that she had recently seen the ‘beware yellow’ video as part of a Midwifery education day. This update reinforced her knowledge about the importance of making an early referral when jaundice with pale stools or dark urine were observed.

The fast action of this Midwife resulted in a positive outcome for Baby X and the family.

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NZ Clinical Networks



# A radiant young woman an eczema story

by Annie Judkins

A radiant young woman bounced up from her seat in the waiting room when I called her name. She had a beaming smile, a shining complexion, luxurious long black hair, dressed in t-shirt and sports shorts and wrapped completely in confidence.

Had I not asked a nurse to book her an appointment to see me, I would not have recognized this young woman as the same 11 year old I met 18 months ago.

That girl was downtrodden; her hands and wrists were cracked, dry and covered in green pustules. Her face was raw, her lips were tight and it hurt to move. She walked slowly and didn't make eye contact. She had only worn long sleeved shirts and track pants for years. She had never played sports.

In the previous five years she had been prescribed 40 courses of oral antibiotics.

She had been hospitalised twice in that time for several days, for infected eczema – the discharge records included: *“Pustular discharge from elbows. Very denuded skin over L upper thigh posteriorly. Sloughy tissue around R forehead. Scalp dry + + +. Otherwise NAD”. Swabs were “Multi-Resistant MRSA”.*

What we did was not rocket science. Initially we cleaned and dressed her hands, after lancing a couple of nasty pustules. I gave her antibiotics and a week off school and got her back a week later. Then we re-taught her how to use her emollients, creams, steroids and how to identify when she need “Bleach and Emollient Baths.” A week later I reviewed her and she was well, her skin was improving.

Two months later, in December 2015, I phoned and asked her to come and see me, because I was worried that things may be worse.

They weren't. She came in, on her own. She was well, she was wearing a t-shirt and shorts and she acknowledged that this was the first summer for years that she had done that. Her skin was still scarred, but not dry, not infected and not inflamed.

In 2016 she only presented once; she was in tears, she had pustules on her hands and back; it hurt and she felt unwell. She had forgotten that she used to feel like this all the time. We treated her with antibiotics just that once in 2016.

I asked this Radiant Young Woman how managing her eczema had changed her life:

“I didn't use to play sports because it hurt, now I play basketball and volleyball and I am in the school junior team. Swimming used to sting but it doesn't any more. For the last two summers I have been wearing t-shirts and shorts, but I never used to do that.”

I also asked her “what advice would you give the younger you?”  
“Keep putting on your creams all the time”

This Radiant Young Woman still uses steroids and emollient every day – she showers in emulsifier and her daily treatment in 1% hydrocortisone in emulsifier.

She's heading off to her first high school camp – and she knows that she needs more of her hydrocortisone ointment for the trip. She doesn't want to come home with bad skin.

In 2015 we established an Eczema Clinic at Ora Toa Cannons Creek Porirua. This clinic was set up to improve eczema management in a high need community, which is predominantly Maori and Pacific, decrease our referrals to secondary care and further develop a model of cross-sectorial care.

It is hosted by myself and Debbie Rickard; Nurse Practitioner. We usually also have GPEP1 registrars attend as part of their community outreach learning.

We work like a tag-team. I lather every child in emollient, so I can model application and observe effect while Debbie revisits the history. We then share the eczema education process.

What the clinic has brought to our community is a sense of confidence that we are taking their skin health seriously and that they do have a caring team to support them. We have had mothers in tears, as their children stop scratching in the room with us. Our patients are engaged.

What it has brought to Debbie and myself is a sense of support and shared commitment to our goals. We both learn from each other in each clinic. We both feel like our workload is decreased because we are able to be proactive, and mostly timely, in our patient care

**New national clinical network resources** and information are frequently being loaded on to the web site.

Check out [www.starship.org.nz/for-health-professionals/national-child-and-youth-clinical-networks](http://www.starship.org.nz/for-health-professionals/national-child-and-youth-clinical-networks) to see if your speciality interest has new information.

**Your contributions** We welcome thoughts, contributions and articles and notices of upcoming events.

We anticipate publishing updates around every six months. Please email the editor, Lauren Young on [lauren@laurenyoung.co.nz](mailto:lauren@laurenyoung.co.nz)