

## Case study 2: Team gains neutral leadership from non-profit's persistence

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*The dogged determination of the chief executive of a northern NGO led to him chairing a service-improvement committee he initially wasn't even invited to join.*

The **Long Term Conditions Clinical Alliance Team (CAT)** was set up as part of the **Greater Auckland Integrated Health Network (GAIHN)** initiative to improve primary care and reduce acute episodes that result in unplanned hospital admissions. Rex Paddy from the **Stroke Foundation Northern Region** heard about the project through his networks and knew he wanted to be involved.

GAIHN is an alliance of health providers and funders dedicated to delivering *Better, Sooner, More Convenient* care for approximately 1.1million patients across Auckland. Current partners include four Primary Health Organisations (Auckland, East Health Trust, ProCare Health Ltd, and Waitemata) and three District Health Boards (Auckland, Counties Manukau and Waitemata).

The Northern DHB Support Agency (NDSA) and ProCare were the driving energy setting up this and other GAIHN projects, but Rex kept in touch with the GAIHN people via calls and e-mails until he was invited to join the team. They then asked him to chair the group as a neutral party who wasn't from a hospital or general practice.

The CAT included a broad range of clinicians (GPs, senior consultants and allied health professionals), but Rex was the only NGO represented. Despite this and possibly because of his previous experience in hospital management, he said he felt part of the group and listened to. Everyone gave their time freely – both during work hours and outside them, and Rex says it was well co-ordinated, with an excellent project manager. At the height of its activity, there were meetings two or three times a week, and the organisers did make a financial contribution to Rex's organisation since he was the Chair.

Some participants were concerned that their efforts would result in a report and nothing would happen, but Rex is hopeful that the ideas and projects identified will get implemented. Things faltered a little when the group tried to find out where the money was coming from, as all the desired initiatives totalled around \$6million.

"The DHBs were great at freeing up time for their people to be involved in the planning, but they are not so forthcoming with money. They never say no, but they don't say yes," says Rex.

"In the health sector it is discouraging when you don't see the changes you want to, but progress is being made slowly. It's often a case of three steps forward and two steps back."

From Rex's perspective, his involvement was worthwhile for the Stroke Foundation, as he was there "beating the drum" to get stroke recognised separately from "just the abbreviations". Initially, it was lumped in as part of CVD (cardiovascular disease), but Rex says "to most people, CVD means heart attacks," so it was important that stroke was clearly identified, otherwise it was likely to be overlooked further down the track.

"It might be one line in a 100-page report, but at least it's there," says Rex.

A key question for Rex is why other NGOs didn't get involved in the CAT, as many have interests in long-term conditions.

“Perhaps they were wary of putting time into things that come to nothing, or they didn’t have the time, resources or people to make available,” muses Rex.

GAIHN’s Project Director, David Tucker says there were very tight timeframes around putting together the clinical alliance teams, as they were working to a deadline dictated by the DHBs.

“These were short term projects and we mostly put them together with organisations we knew. We had other non-profits, such as St John’s and Otara Health, involved in some of the other workstreams,” explains David.

“There was no deliberate strategy to involve or not involve NGOs – we just targeted those we knew.”

David says with such a large sector, GAIHN would value any help getting to NGOs and keeping them informed about integration of activities.

A long-held concern of many NGOs is that they are left out of key planning and decision-making processes. This can be due to the reasons Rex suggests, but often it’s because opportunities are not well-communicated or promoted and NGOs find out too late that work is already underway. Organisers often claim that “there are so many NGOs” they don’t know who to include, but often they don’t ask for guidance. A number of national bodies and umbrella groups, such as Platform (mental health) and the NZ Disability Support Network, exist to help. The Health and Disability NGO Working Group is funded by the Ministry of Health to advise and inform on such matters.

“It may be a bit cynical, but I don’t think there is an understanding in the Ministry or the DHBs of just what NGOs do,” says Rex, who is disturbed by the constant state of NGO services in decline due to funding cuts or no cost-of-living increases.

“Because of their size, PHOs can do more prevention work,” he says.

The Stroke Foundation Northern Region is one of four regional non-profits affiliated with the national office of Stroke Foundation – but each region operates autonomously.

While the national office has a focus on awareness and prevention, around 80% of the Northern region’s work is supporting families whose lives are turned upside-down when a member of the whānau has a stroke. This includes advocating for people to get the services they are entitled to such as a Disability Allowance, or helping them get back to work by sometimes paying for an assessment or referring them to the vocational counsellor, which the Stroke Foundation is funding from reserves.

“These people are usually stressed and fatigued, but our field workers don’t take ‘no’ so easily and can quote a clause that says what people are entitled to,” Rex explains.

“Often people say to our field workers ‘you’re the first person who’s had time to talk to me’. So we give people hope that there is a future for them.”

A major step forward for the Stroke Foundation – at a branch and national level – has been the introduction of Stroke Units in all hospitals.

“The international publications show the difference these make and the Ministry recognised this,” says Rex.

“Since then, we’ve fought hard to have our field officers recognised as part of the multi-disciplinary team, so they now go to weekly meetings. It was a huge battle to convince the DHBs that it wasn’t a breach of privacy to pass on the contact information for the next-of-kin or family. Now as part of the team, they can legitimately receive referrals.”

Ninety-five percent of referrals to the Stroke Foundation come from hospitals, rather than from general practice. Interestingly, Rex says most GPs tell him that they don’t see stroke patients, but he thinks that’s more likely a case of not seeing them as ‘stroke patients’, but for other medical conditions.

“Practice nurses are good at making referrals to the Stroke Foundation or other services,” says Rex, “and we have good relationships with other NGOs dealing with the same people we are.”

The work of the Stroke Foundation is complemented by the activities of the Heart Foundation, because as Rex puts it: “almost everything done to prevent heart attacks, prevents strokes.”

Like others on the CAT committee, Rex is now waiting to see what happens next. The aim is to reduce admissions to hospital and bed nights, so good stroke prevention programmes and knowledge can contribute a lot to this. Research has also established that early mobilisation and early SUPPORTED discharge produces better outcomes after stroke, and reduces bed days in hospital.

A key emphasis in the GAIHN approach is to put the patient at the centre of planning and action, and to empower GAIHN alliance partners to manage a greater proportion of people’s health care needs in community settings. For the GAIHN programme to have a sustained impact, changes to both clinician and patient behaviour are needed. A key driver of change will be to modify the current contracting environment – creating positive incentives and removing perverse incentives that encourage unsustainable behaviours.

GAIHN’s David Tucker says work is now refocusing around a workstream to target the 5,000-10,000 people who are frequent users of the hospital ED (Emergency Department), and there could be opportunities to include NGOs in these discussions as they develop.

**More information:** [www.gaihn.health.nz](http://www.gaihn.health.nz) or [www.stroke.org.nz/stroke-support-northern](http://www.stroke.org.nz/stroke-support-northern)

This is one of the 15 case studies profiled in *How NGOs Make a Difference to Health Care in the Community* – a 96-page report from the Health and Disability NGO Working Group, Jan 2012.

The case studies cover acute nursing services, health information services, virtual practices, youth one-stop-shops, mental health networks, community development approaches, cardiac rehab, Whānau Ora and Asiasiga models of care, and more – from North to South.

See [www.ngo.health.govt.nz](http://www.ngo.health.govt.nz) for more of the report.