

Evaluation of the British Heart Foundation Cardiac Genetics Nurses Service Development Initiative

Executive summary 2012



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1. The BHF Cardiac Genetics Nurse Initiative

Background

There are over 50 inherited cardiac conditions (ICCs), with a UK prevalence of around 340,000. However, there is considerable variation in ICC service provision and capacity is inadequate to meet current or future estimated need; with services markedly London-centred and highly unequal across the country. A 3-4 fold increase in regional provision for new patients is needed to meet the shortfall (Burton et al. 2009).

The government articulated its commitment to embedding genetic/genomic healthcare across the NHS, identifying heart disease as a priority in its genetics White Paper (Department of Health 2003). The revision of the National Service Framework for Coronary Heart Disease (NSF; 'Chapter 8') requires that the NHS should have systems in place for timely and effective identification, assessment, diagnosis, intervention and support for individuals and families who may be at risk from sudden cardiac death syndromes (Department of Health 2005).

In 2008 the British Heart Foundation (BHF) launched an initiative to enhance the care and services delivered to patients and their families with or at risk of an ICC through funding nine BHF Cardiac Genetics Nurse (CGN) posts across England (n=8) and Wales (n=1) for a period of three years, the first taking up post in October 2008. The British Heart Foundation had already funded two CGN posts in 2006 at Leeds and Belfast. The success of these posts, alongside rapid scientific and clinical advances, and policy developments to address the needs of families affected by ICCs, provided the impetus for the current initiative.

In appointing experienced, trained cardiac nurses who would then undergo additional training in genetics, the BHF were looking for CGNs who would coordinate care across the specialties of cardiology and genetics, facilitating communication across the multidisciplinary team. The CGN posts were thus to meet two primary objectives:

1. To improve the quality of service provision to patients with ICCs and their families by improving accessibility and communication with cardiac and genetics services.
2. To create a sustainable, fully funded cardiac genetics nursing service delivery model, whereby onward funding of the BHF CGNs is provided by other agencies at completion of the project.

Engagement with stakeholders and providing education and support to patients and families using ICC services are also important aspects of the CGN role.

Evaluation approach

An independent evaluation was commissioned to provide an assessment of the value added by the BHF CGN posts to patients and families affected by ICCs at the nine locations across England and Wales. Three questions were posed to evaluate the extent to which the objectives of the BHF CGN Project were met:

1. What does an effective and sustainable cardiac genetics service look like?
2. What is the most effective way for the nursing role to integrate cardiac and genetics services?
3. To what extent are the defined features being achieved over time?

A single case study approach was taken to follow the project over three years, using qualitative and quantitative methods to gather multiple sources of evidence. CGNs completed quarterly reports on caseload, activity levels and health economics data. Interviews with health professionals and patient

representatives focused on: establishing baselines; education; the patient and family; the CGN role and 'making a difference'. Staged self-assessment of ICC service development was conducted through completion by each CGN of a performance grid (a Maturity Matrix) that sets out standards over time as a service matures. The BHF CGN Maturity Matrix was generated by consensus with ICC stakeholders and comprises 5 core concepts or Domains (see Appendix 1 for more details):

- A. An Accessible Inherited Cardiac Conditions Service, with a clearly articulated model of service provision
- B. A Communicated and Coordinated Service, where the structure of the service is understood by all
- C. Family-Centred Care
- D. A Sustainable and Ethical Service
- E. Valuing the Knowledge Base, with a philosophy that embraces qualitative and quantitative evidence

These Domains describe an effective, sustainable ICC service, are cognisant of the NSF requirements and reflect the features of a specialist ICC service outlined by Alberg and Burton (2010). A 6-point scale was used by the evaluation team to assess progress from 'emerging' to 'established' against a series of indicators. Progress was then represented graphically by spider diagrams.

Ethics approval for the evaluation was given by the University of Glamorgan and offices overseeing governance at each host Trust were notified of the evaluation programme.

The case study cohort

ICC services at the 9 locations were at different stages of maturity at the outset of the BHF CGN Project. One site was launching a brand new service with the appointment of the CGN, bringing to 21 the total number of ICC services in the UK. The sites also adopt different service models, including 'hub and spoke' and centrally located tertiary services. The three London ICC services take national referrals. The 8 services in England are subject to different commissioning arrangements from the service in Wales, where there is no budget for cardiac genetic testing.

Each of the CGNs appointed took up their posts at different times between October 2008 - March 2009. One CGN resigned in late 2010 and was replaced in late 2011. As for all other BHF Specialist Nurses, the CGNs had access to a comprehensive package of funded education, training and support. One crucial additional element of this was the requirement for all CGNs to undertake a Master's level module in genetics run by Plymouth University, essential for their new role in helping to develop ICC services.

Clinically, the CGNs utilise their cardiology skills to review referrals and test results, order and oversee the interpretation of additional tests, conduct some clinical assessments and coordinate the care pathway. Following training in genetics they also undertake family history collection and risk assessment and are able to triage patients and provide genetic and cardiac related information and counselling as appropriate. Working alongside consultants, nurse specialists, genetic counsellors, electrophysiologists and others, in many ways they function as the lynch-pin within the multidisciplinary team, spanning the two specialties and acting as gatekeepers to the ICC service.

Policy drivers and benchmarks for ICC services

Although there are currently no agreed benchmarks for ICC services, in collaboration with NHS Improvement, the Public Health Genetic Foundation issued a Commissioning Guide for ICC services (Alberg and Burton 2010). It outlines nine key features of a specialist ICC services and cross-references the service components to the World Class Commissioning competences. The NHS Quality, Innovation, Productivity and Prevention (QIPP) initiative provides a broader framework in which to present evidence of improvements in efficiency and effectiveness of care. These and other policy initiatives informed the evaluation approach.

2. QIPP and the CGN role in ICC services

The Clinical Leads (CLs) could readily articulate the relevance of the NHS Quality, Innovation, Productivity, Prevention (QIPP) framework in relation to the CGN role. One CL captured how the CGN's impact mapped to the whole framework:

[CGN] brings all four to the table. There is quality of patient experience, innovation in terms of developing pathways to ensure it happens correctly and make changes that are necessary. Productivity – our numbers have increased and [CGN] is here to manage that. S/he ensures the correct families are seen... Focusing on those who do need to be seen and excluding those who don't. This is where it affects productivity. Prevention – identifying those at risk, a vital part of preventing. [CL-G3]

Quality

The BHF CGN Project can demonstrate an impact on all three elements of quality (Darzi 2008).

The quality of the patient and family experience

Interviews with the CGNs and Clinical Leads and data from patients and families show that there is congruence in the view that the CGNs have considerable influence in enhancing the quality of the patient experience. Three sub-themes emerged from the data:

Quality caring. This incorporates the CGN role in acting as a point of contact for information, providing support and continuity along the care pathway for the patient and family and across lifestages. *Time* is a factor in this and relates to the time the CGN makes available, talking with the patient and family and being accessible.

The last time I went to the hospital and saw [the CGN] I didn't feel rushed. Normally you go with a list of questions and half the time you don't even touch the surface of those questions. [Support group member D]

Having time to explain and to listen is fundamental to *Giving clarity*. CGNs can de-mystify the process, providing patient and families with the information they need in a language they understand, when they are ready to absorb it, at any point along the pathway. In preparing people for the consultant appointment, CGNs enable the doctors to spend time more meaningfully with the patient, reflecting a quality gain. *Managing anxiety and uncertainty* involves providing sensitive emotional and practical support to patients and families and signposting to other services such as bereavement counselling.

Coordinating care for the patient and family. Pre consultation work up or *Preparing* is a major remit of the CGN role, making the initial contact, introducing the service to patients, outlining their likely pathway, explaining tests and investigations and incorporating psychological preparation. *Knowing the patient* contributes to *Having the Bigger Picture*. The CGN is sensitive to family dynamics and is active in sharing this knowledge, pre-empting any difficult situations other staff might encounter

Facilitating seamless care between specialties. The CGN facilitates seamless care between the two specialties in a patient-focused integrated ICC care pathway.

The CGN provides a vital link between mainstream cardiology and genetics, facilitating exchange of knowledge. [The CGN] has done this brilliantly. The two units are working together much more coherently now. [CL-G3]

The CGNs also play an important role in coordinating care between the ICC service and primary and secondary care as well as liaising more broadly with coroners and the BHF Genetic Information Service.

Patient safety

The first tenet of quality is that no harm is done to patients, ensuring the environment is safe and reducing avoidable harm. The role of the CGN in relation to patient safety can be considered from a number of perspectives:

- CGNs are comfortable in acknowledging the limits of their knowledge and role; an important factor in ensuring that patients are given accurate information.
- The expertise of the CGNs as highly trained cardiac nurses, with additional genetics training contributes to safer care through being better placed to identify and address 'gaps'.
- The CGN role in triaging patients so that those potentially at highest risk are seen soonest.
- The CGN can also play an important role in reducing avoidable harm in terms of overseeing clinical interventions, particularly where other staff are less experienced.
- The CGN plays an important role in promoting 'safe' decision-making, with patients and families being appropriately prepared to make informed decisions.

Effectiveness of care

Clinical effectiveness is 'the application of best knowledge, derived from research, clinical experience and patient preferences to achieve optimum processes and outcomes of care for patients.'¹ CGNs can demonstrate how they help ICC services in meeting the five markers of good practice set out in 'Chapter 8' of the NSF:²

1. Rapid access to cardiac evaluation
 - CGNs can individualise care, facilitating quicker access for higher risk patients.
 - CGNs pre-assess new referrals, providing expert clinical intervention, sooner.
 - CGNs facilitate cardiac evaluation (sometimes prior to a consultant clinic), organising appropriate investigations in a timely and coordinated manner.
2. Suitable bereavement services are available for those who have lost a family member
 - All CGNs are able to provide their patients with quality nursing caring.
 - CGNs have built networks of specialist support, enabling them to provide information about and signpost patients to, relevant services (such as support groups and charities).
3. An expert post mortem and appropriate tissue retained if informed consent is given
 - CGNs have actively raised awareness of ICCs with coroners and pathologists, *to ensure that in sudden death, the appropriate samples are taken.* [CL-G3]
4. Evaluation of families in a dedicated clinic, with appropriately trained staff. Genetic counselling and further testing is available if appropriate
 - CGNs play a crucial role in identifying family members at risk and facilitating family centred care in a dedicated clinic.
 - CGNs are highly skilled professionals providing care across two specialities.
5. Suitable bereavement support and appropriate clinical assessment and treatment for children and young people
 - CGNs have improved multidisciplinary working between adult and paediatric services.
 - CGNs can coordinate transition care and family centred care.

¹ Department of Health (1996) Promoting Clinical Effectiveness.

² Department of Health (2005) National Service Framework for Coronary Heart Disease – Chapter Eight: Arrhythmias and Sudden Cardiac Death

Key points:

- CGNs enhance the quality of the patient/family experience through an holistic approach to care, offering clarity and continuity along a potentially complex pathway, often when patients and families are particularly vulnerable.
- The CGNs' overview of both cardiology and genetics is a factor in promoting a coordinated approach to care and service delivery.
- CGNs facilitate seamless care between two specialties in a patient-focused integrated ICC care pathway.
- CGNs make an important contribution to patient safety through having knowledge and skills that span two specialties, identifying potential gaps in care and in the knowledge to underpin care, providing continuity and producing protocols to enhance the safety of clinical interventions.
- CGNs have a key role to play in patient safety through supporting decision-making.
- CGNs have an important role in helping ICC services to meet the requirements set out in Chapter 8 of the NSF.

Innovation

Innovation is a key enabler for achieving quality and productivity gains. It can take place at different levels, such as from the translation of research into practice to improve patient outcomes and clinical effectiveness, to the development of new services and care pathways, or improving the skill mix. The BHF CGN Project itself is an innovative concept, providing capacity to catalyse innovation. This is reflected in the establishment of new services, new care pathways that span specialties and in new ways of working.

Establishment of new services and care pathways

One CGN post provided the capacity to establish a new ICC service at one site. This necessitated establishing new pathways. Other sites have seen the development of new or improved service components, including new care pathways.

Yes, the pathway of care is established now. It has been ratified through the clinical governance team. This was a new regional service and took approximately 6 months to get clinics established and 12 months for the guidelines to be ratified [CGN-G].

These new pathways often involve new nurse-led clinics. At one site, the CGN is leading the development of a pilot triage service, running a family history screening service through several weekly nurse-led clinics. As well as nurse-led clinics, other new clinics have also been piloted.

Establishment of new ways of working

By acting as a bridge across specialties, the CGN role provides the capacity and capability to develop new ways of working, both within the immediate multidisciplinary team and across the wider stakeholder group. One CGN outlined how s/he had driven change in order to conduct Ajmaline testing. Another described changes to service arrangements as a result of the CGN post:

Consultations for patients 'at risk' of an ICC, traditionally undertaken by the doctor are now undertaken by myself – apart from a clinical assessment and investigation I also ensure that a pedigree is completed for each patient and that appropriate cascade screening is facilitated where required. [CGN-D].

The CGNs provide a number of examples of new or improved services or ways of working resulting from links developed with the wider stakeholder group. These include the development of multidisciplinary teams such as to incorporate paediatrics, closer working relationships with those specialising in inherited neuromuscular conditions and improved communication with coroners.

Leading innovation in practice

The CGNs take the initiative as autonomous practitioners to bring about further developments in service components and for the benefit of patients. Examples include the establishment of Patient Support groups, counselling mentorship sessions for staff and leading grant applications for funding.

The BHF CGN cohort as an innovation

The appointment of the cohort of experienced trained cardiology nurses who have then been supported specifically to undergo further training in genetics has facilitated the acquisition of *a whole new skill set that most of them have never had before* [CL-C10]. For some sites in particular this has been in response to an identified gap in service provision and the addition of a trained cardiac nurse is clearly welcomed.

They're a new breed! The higher the knowledge base the more autonomous they become – run clinics, need less and less supervising. [CL-G3]

Key points:

- The BHF CGN Project is an innovative concept that has facilitated innovation in ICC services.
- The sites are demonstrating innovation in the development of new services, new care pathways and/or new ways of working.
- The CGNs as autonomous practitioners are proactive in promoting further developments in service components and for the benefit of patients.
- The CGN role is emerging as a 'new breed' of multi-skilled specialist nurse.

Productivity

The CGNs were appointed to help improve ICC services through a sustainable model that demonstrates 'value for money'. Productivity, 'doing more with the same,' is core to this. The CGNs' contribution to improved productivity of ICC services can be considered under four key themes:

1. Promoting greater clinic efficiency through coordination and reducing waste

The CGN has a key role in improving clinic (and service) efficiency throughout the pathway, from promoting more, and more appropriate, referrals, to pre-clinic preparation, the clinics themselves, and follow-up. A significant proportion of the CGNs' workload is around pre-clinic preparation which CGNs suggest can save time, or improve the quality of time, can perform a triage function, and lead to more efficient clinics, with a resultant cost saving. The Clinical Leads also note the impact this has on clinic efficiency and on their own roles, making them more efficient so that they can use their skills more effectively.

We get more people through. We can have more new appointments a week because they can be a little bit shorter than before... we're more likely to get everything wrapped up in one appointment... and we can increase the number of new patient slots. [CL-C9]

2. Freeing up the time of other professionals

A number of Clinical Leads identified that CGN saved them time enabling them to see more patients. The pre-clinic preparation and work up with patients can change the nature of the subsequent clinic consultation, particularly where consultants have been relieved of some tasks, enabling them to focus their expertise more effectively on the patients.

3. Taking a gatekeeping role

The CGN role contributes to productivity gains through promoting more appropriate referrals as well as helping to reduce the number of inappropriate referrals so *there isn't any waste* [CL-C14].

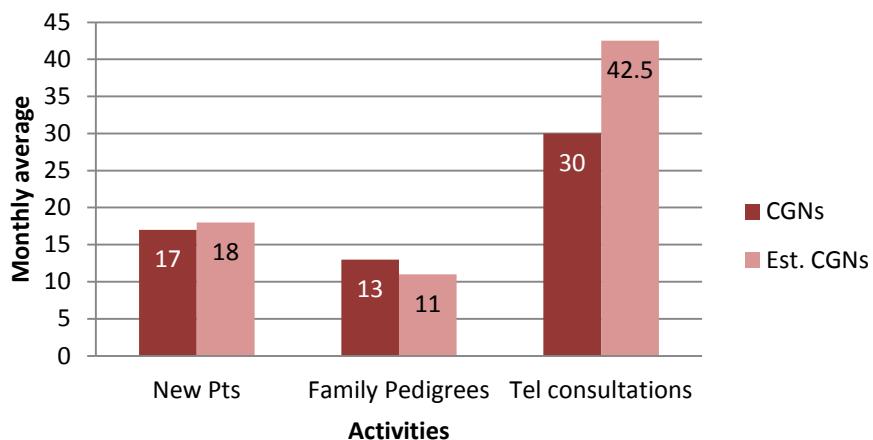
Referrals into the tertiary genetic service had substantially decreased since we put the CGN service in place and the referrals that we are now receiving... are much more appropriate than they used to be... The CGN service is effectively the gateway in to all of that. [CL-G5]

4. Adding capacity within the service through nurse led services and care

CGNs can enhance productivity through nurse-led services that allow the consultant and other MDT members to focus on other elements of their role, promoting a more effective skill mix. They demonstrate high levels of activity that contribute to improved efficiency. The activity levels captured provide a picture of the sustained activity of the CGNs since appointment. A total of 5931 patients were seen by CGNs between January 2009 and June 2011, including 4038 new patients. CGNs held a total of 5879 telephone consultations with patients up to March 2011, and during 2010, 518 genetic (blood) tests were ordered and 5593 medical tests.

A comparison of monthly averages of new patients seen, family histories completed and telephone consultations for the nine new BHF CGNs and the two established CGNs at other UK sites, shows that from baselines of zero activity at commencement of post in 2008/09, CGNs have rapidly built up a busy workload comparable with established CGNs on other sites.

Figure 2.1 Activity levels of new CGNs compared with established CGNs Jan –Dec 2010



CGNs add much appreciated capacity to the service and as highly trained nurses they bring a desirable skills set, further enhanced through the BHF Education programme.

Productivity, the CGN and increasing demand for ICC services

CGNs provide capacity to increase clinic efficiency, through efficient preparation, organisation, and follow-up, freeing up the time of consultants, not just to do 'more of the same' but also to 'do more, better', as patients and families are better prepared for consultant appointments. Nurse led clinics and the CGN gatekeeping role, through preliminary assessment and triaging contribute to productivity, so that more of the right patients can receive 'right care'. Their roles in raising awareness of the ICC service and identifying potentially at risk families through cascade referrals generate further referrals. In their Commissioning guide, Alberg and Burton (2010) reiterate their estimation of the shortfall in provision of 7000 new referrals per year, adding that upward trends in referrals (echoed by the Clinical Leads in this project) will continue. It is difficult to see how this increase in demand could be met without the CGNs, unless more doctors were to be employed.

Key points

- CGNs enhance productivity by enabling the ICC service to see more patients, more of the 'right' patients, and fewer of the 'wrong' patients.

- CGNs enhance productivity by preparing patients and families in the 'right' way, freeing up consultant time to spend more effectively with patients and families.
- CGNs can enhance productivity through nurse-led services that allow the consultant and other MDT members to focus on other elements of their role – promoting a more effective skill mix.

Prevention

Prevention is a fundamental aim of ICC services, through clinical management and lifestyle modification of those who are symptomatic and through screening of asymptomatic family members who may be at risk of a serious cardiac event or sudden death. The CGNs play their role in this, particularly in relation to identifying and contacting patients and family members who might be at risk, raising awareness about the service, and educating stakeholders.

Prevention, of course. Cascade screening, helping families and targeting people who might benefit from medication or devices. Secondary prevention as well of course... if you do a genetic test and the person has a mutation, that person needs to be supported for prevention of serious complications. We can minimise the risk. [CL-G2]

Identifying individuals at risk

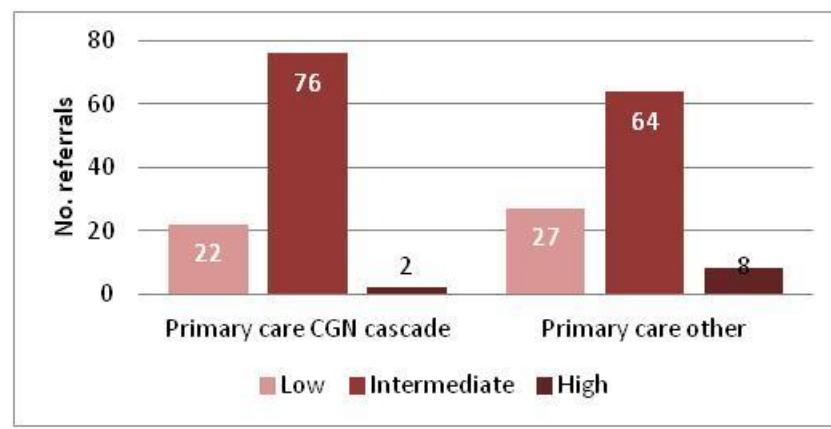
Taking a family history, cascade referral activities, and risk stratification to prioritise those at most risk are important components of the CGN role. Family history taking is a crucial first step in this. Over an 18-month period from January 2010 to June 2011, CGNs completed 2148 family trees. The family history provides the trigger for identification of other family members who may be at risk.

We will see a family member and then identify who else needs to be referred... A lot of the time [patients] will phone me and I will tell them what they need to tell their GP... [CGN F]

In their study involving 64 index cases of patients with hypertrophic cardiomyopathy (HCM), Finch et al. (2011) found that over 12 months, each new index case generated 3-4 at risk relatives requiring long-term surveillance. Fifteen new cases of HCM were diagnosed from 71 asymptomatic at risk relatives screened. Three patients at high risk of sudden cardiac death subsequently received primary prevention defibrillator implantation (one of which subsequently fired). They concluded that the CGN role was effective in facilitating pro-active screening.

Data collected by CGNs (n=6) from June-September 2011 demonstrate the contribution of the CGN to generating referrals via cascade letters, representing 50% of referrals received from primary care (Figure 2.2), and over 26% of all referrals. Data collected over the same period also illustrate how the service is able to identify those at low risk (and thus removed from the need for long-term care) as well as identify those at high risk who were initially assessed as being at lower risk.

Figure 2.2 Initial risk status of patient referred from Primary Care sources June-Sept 2011



Raising awareness about ICC services

The CGNs are proactive in raising awareness about ICC services through a range of formal and informal approaches. There is clear evidence of collaborative links being nurtured, particularly across primary care, cardiology (including

Arrhythmia and Heart Failure Specialist nurses), paediatrics, coronial services and relevant charities and support groups. Up to December 2010, 1438 new contacts were reported since the CGNs came into post and during 2010, they reported a total of 2016 telephone or email contacts with GPs or consultants. Their efforts in raising awareness are having an impact, with more, and more appropriate referrals, with some Clinical Leads commenting that the impact is 'dramatic'.

Educating others

The CGNs' role in education makes an important contribution to addressing the recommendations set out in *Heart to Heart* (Burton et al. 2009). They contribute at three levels:

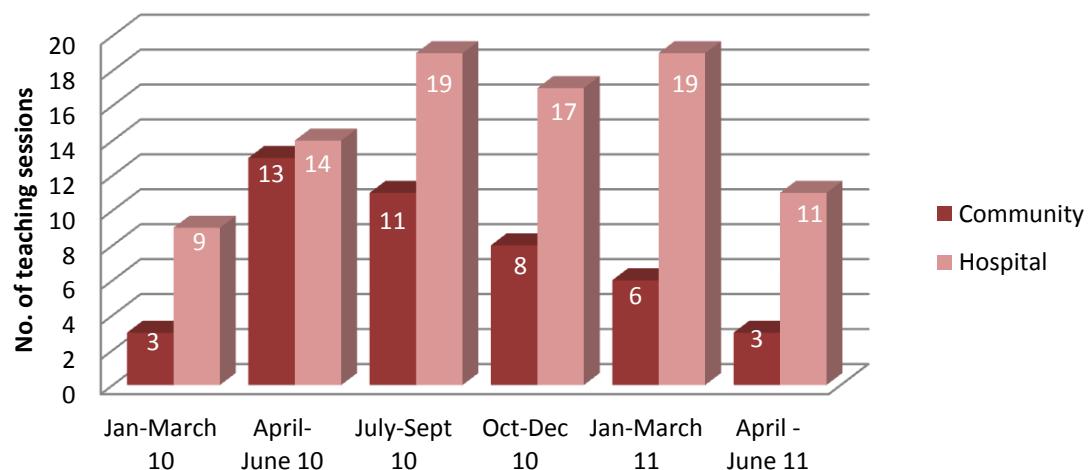
The multidisciplinary team

I mean [CGN's] got everybody together through a lot of hard work, and got the paediatric and adult cardiologist talking to each other, and genetics... And along to that meeting come the nurses and the echo team and the cardiac physiologist – so you know it's quite an extended team as well. So it's got an education base to it as well... [CL-E3]

Healthcare and other professionals

CGNs provide informal and formal teaching sessions, engaging healthcare professionals in a range of ways. During 2009, CGNs reported a total of 49 formal teaching sessions. From January 2010 – June 2011, the total was 133 sessions (Figure 2.3).

Figure 2.3 Teaching sessions provided by all CGNs per quarter Jan 2010 – June 2011



Patients and families

The patient-centred approach is a valuable factor in promoting compliance with lifestyle adjustments to ameliorate risk and other management advice for patients and families. Patient surveys conducted indicated very high levels of satisfaction (>90%) with the information and explanations provided by CGNs. This highlights the role of the CGN as an accessible educator, something particularly important for people with long term conditions.

Key points:

- Prevention is a fundamental aim of ICC services and CGNs play a core role in this.
- CGNs have an important role in identifying individuals and families at increased risk by taking family histories, cascade referral, and risk stratification to prioritise those at most risk
- CGNs are proactive and successful in raising awareness about ICC services through formal and informal networking activities and this has an impact on the number and quality of referrals.
- CGNs further contribute to prevention through formal education sessions.
- CGNs promote prevention by giving clear information and explanations to patients and families.
- CGNs play a useful role helping ICC services to address the recommendations in *Heart to Heart*.

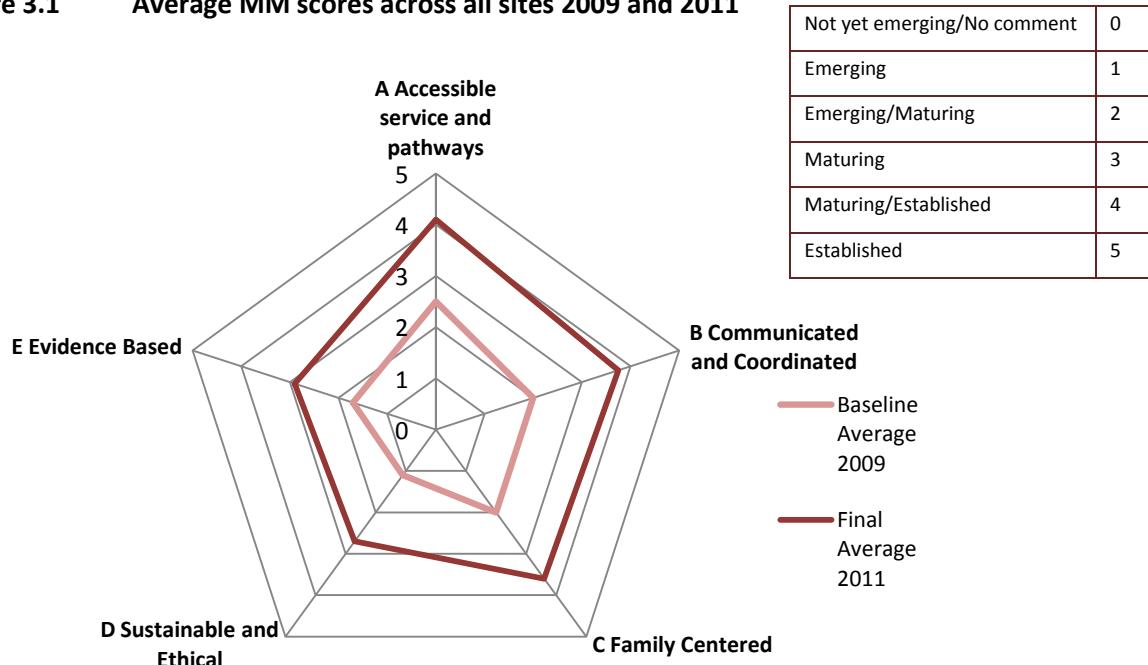
3. ICC services and the Maturity Matrix outcomes framework

The Maturity Matrix was developed in order to articulate *what an effective and sustainable cardiac genetics service looks like* and to assess *how the defined features are being achieved over time*. It provides an outcomes framework to benchmark performance across sites and over time and its components are consistent with many of the service specification requirements in the Commissioning guide (Alberg and Burton 2010).

Overall progress

Progress in the timescale has been marked across all five domains (Figure 3.1; see Appendix 1 for more details). The overall impression is the commitment of the CGNs to 'making this work', providing examples of good and excellent practice. Particularly significant progress has been in the efficient running of clinics (Domain B). Good progress has also been made in the development, implementation and review of care pathways (Domain A) and most quote triaging and referral trends as evidence of their effective utilisation. Commitment to personalised care and to facilitating family-centred care is also notable (Domain C).

Figure 3.1 Average MM scores across all sites 2009 and 2011



The self assessments captured in the Maturity Matrix demonstrate that the CGNs have good insight into their ICC services and are able to think strategically. They are aware of gaps in services and offer solutions. CGNs have demonstrated significant progress across all domains, with significantly increased scores by both established services and new or emerging services. Although the increase is faster for newer services, the difference between such sites and established services is not significant. Most importantly, this indicates that the CGNs have made a significant contribution to development in both new and existing ICC services.

Key points:

- The Maturity Matrix provides a framework to benchmark performance against the five domains of relevance to ICC services.
- Progress is significant across all five domains, in both established and new/ emerging services.
- CGNs have made a significant contribution to both new and existing ICC service development.

4. The CGN and 'value for money'

The CGNs are appointed to their posts to help improve ICC services through a sustainable model so it is important that the project can demonstrate 'value for money'. One difficulty in undertaking an economic evaluation of whole services is that the range of outcomes is very wide. It can also be difficult to attribute outcomes to specific members of the team. Furthermore, having a CGN in post may not be a requirement for introducing a service or service component, although it might provide the necessary increase in capacity to enable it to happen.

The economic element of this evaluation focused on the immediately identifiable resource impacts of having a CGN in post, limited to identifying the resources released or imposed directly by having a CGN in post. It is explicitly not a full cost benefit analysis.

CGNs reported their salaries and any associated London allowances. Any time released or imposed identified in the quarterly returns and questionnaire responses was valued by multiplying the number of hours by the relevant unit cost for the identified member of staff. Unit costs are mainly from Curtis (2010).

Table 4.1 shows the approximate average number of hours per week released or imposed by category of staff *at sites where these were identified*. Thus the 4.5 hours/week of released technical services manager time (in column 3) represents the impact of the CGN at the one site which reported an effect on technical services manager time.

Table 4.1 Mean hours freed/imposed per week* and mean net resource savings at sites where they were reported

Staff member	Number of sites reporting **	Hours freed	Hours imposed	Net hours freed	Unit cost (£)	Value of saving £
Consultant	5	2.4	0.9	1.5	169	253.50
Genetics counsellor	7	4.4	0.3	4.1	44	180.40
Heart Failure/SCD Nurse	3	4.6	0.3	4.3	46	197.80
Secretary	2	3.1	1.0	2.1	19	39.30
Technical services manager	1	4.5	0	4.5	38	171.00
Total	n/a	19.0	2.5	16.5	n/a	842.00

* = for sites reporting an impact on each type of staff

** = number of sites which identified each type of staff

At sites where the CGN reported and quantified an impact on GC time, the net value per site of freed GC time was £180.40/week or £9,381/year. At sites where the CGN reported and quantified an impact on consultant time, the net value per site of released consultant time was £253.50/week or £13,182/year. Combining these can illustrate potential overall savings i.e. a site which could achieve saving across all staff categories could release up to £43,784 of resources per year.

Financial Enquiry

An independent financial enquiry highlighted the differences between financial savings and productivity gains/increased efficiency and explained how additional revenue to ICC services from additional activity generated by the CGNs represents a financial cost to commissioners and hence to the NHS. It indicated that there are no net financial savings to the ICC service and the financial cost to the NHS is positive. However, the report stressed that improvements to the quality of ICC services

had been identified during the site contacts and concluded that the CGN posts represent good value for money even if they do not produce financial savings.

Observations

Apart from the direct cost of employing the CGN, all quantified results are based on recall and estimation. Nevertheless, the data suggest that the time of others released because of the CGNs being in post was greater than the time imposed by them by a significant factor in every case. Despite some caveats the conclusion is that the cost of employing a CGN is in part offset by the net releasing of other resources, although in no case was the value of the freed resources greater than the cost of the CGN. However, the objectives of the CGN initiative were to improve the quality of ICC services and to create a sustainable, fully funded CGN service delivery model. The relevant economic question thus concerns whether employment of a CGN improves service efficiency.

Within the QIPP framework, data gathered within this evaluation indicate that the CGN is having a considerable impact on pathways by increasing the likelihood of a patient being allocated to a more appropriate pathway than might otherwise have been the case. Similarly the data suggest that the CGN is improving 'right care' by separating those patients who need referral from those who do not. If efficiency savings are to be re-invested to support improvements in quality and outcomes, then this evaluation suggests that the CGN initiative can be seen as providing good value for money and hence being a good recipient of such re-invested savings. That seven Trusts so far have continued the funding for their CGN posts is a strong indicator of their perceived value.

In summary, the health economic assessment, together with other data from this evaluation, indicates three key elements where the CGN role provides 'value for money':

- Identifying unmet need, both in terms of providing health benefits to those identified as being at risk and appropriately put on long term surveillance and in terms of identifying those at low risk who might otherwise have presented themselves to the service and inappropriately be put on long term surveillance. The large number of quality adjusted life years associated with avoiding a single sudden cardiac death means the CGN could still be a cost effective use of NHS resources. Further research is needed to quantify the magnitude of these QALY gains and thus provide evidence that the new service model which identifies and treats patients at risk of SCD is a cost effective way of producing health outcomes.
- Promoting greater clinic efficiency, with potential increase in new patients slots and fewer unnecessary follow-ups and more appropriate use of other health professionals' time.
- Promoting more efficient use of resources overall, including through the exclusion of low risk patients from unnecessary testing.

Key points:

- The CGN post has increased the effectiveness of the service by facilitating more, and more appropriate, clinical activity (more total benefit).
- The CGN post has increased the efficiency of the service by allowing more to be achieved by existing resources (lower cost per unit of benefit).
- Through the efforts of the CGNs and others, there is an increase in newly identified unmet need which results in an increase in cost to the NHS. The CGNs are likely to contribute to savings on this from a reduction in unnecessary tests and inappropriate long term follow up.
- Increased activity made possible by the CGN has increased revenue to the service, although not by enough to fully recover the direct monetary cost of employing the CGN
- The data suggest that the time of others released because of the CGN is greater than the time imposed which partly offsets the economic cost of employing the CGN.
- The contribution of the CGN role to preventing SCD is likely to reflect a very substantial QALY gain and this would merit further evaluation.

Table 4.2 Summary of Impact of CGN set against the QIPP framework

The findings can be summarised to provide an overview of the impact the CGNs have had on ICC services, for the benefit of patients and families. These are mapped to the QIPP framework. Some of the QIPP subthemes in column 1 are those we have identified during the evaluation.

QIPP FRAMEWORK	IMPACT OF CGN	EXAMPLES
Quality		
<i>Patient and family experience (NHS Outcomes Framework Domain 4)</i>	CGNs facilitate a holistic approach to care, offering clarity and continuity along a potentially complex pathway, often when patients and families are particularly vulnerable	Maturity Matrix data for Domain C - Family Centred Care Patient focus groups and patient surveys Thematic analysis of qualitative data: <i>I felt I was being treated as an individual and as a human being with a mind and emotions – not just a set of symptoms.</i> [Patient B]
<i>Safety (NHS Outcomes Framework Domain 5)</i>	CGNs have knowledge and skills to underpin care that span two specialties, are able to identify potential gaps in care. They produce protocols to reduce any risk from clinical interventions.	Development of protocol for in-patient Ajmaline testing (CGN F). Thematic analysis of qualitative data: <i>[CGN] has knowledge we don't. When we ask about different tests or investigations, s/he has the knowledge to help us understand what they are used for.</i> [CL-G7]
<i>Effectiveness of care (NHS Outcomes Framework Domains 1-3)</i>	CGNs have an important role in helping ICC services to meet the requirements set out in chapter 8 of the NSF	One marker of good practice in Chapter 8 is that individuals who need it can have rapid access to cardiac evaluation. The CGN helps facilitate this: <ul style="list-style-type: none"> • In coordinating clinics, CGNs can individualise care, facilitating quicker access for higher risk patients • CGNs pre-assess new referrals, providing expert clinical intervention, sooner • CGNs facilitate cardiac evaluation (sometimes prior to consultant clinic), organising appropriate investigations in a timely and coordinated manner.
Innovation		
<i>A catalyst for service development</i>	Different sites are demonstrating innovation in the development of new services, new care pathways and/or different ways of working	Development of evidence-based protocol for CGN-facilitated predictive testing in LQTS ICC Referral letter pathway developed/established
<i>Leaders of innovation</i>	The CGNs as autonomous practitioners are proactive in promoting further developments in services for the benefit of patients	Development of an ICC Patient Support Group. Establishing new links with secondary care (CGN J) Initiating recurring audit of patient satisfaction (CGN B)
<i>Emergence of a new role</i>	The CGN role is emerging as a 'new breed' of multi-skilled specialist nurse	The BHF CGN Nurse is an experienced cardiac nurse with additional genetics education including practical genetics, genetics science and counselling skills

		and able to work across 2 specialties.
Productivity		
<i>Greater clinic efficiency</i>	CGNs promote greater clinic efficiency through coordination and reducing waste, enabling ICC services to see more patients: more of the 'right' patients; fewer of the 'wrong' patients	Maturity Matrix data for Domain B, indicator B1.2 Efficient running of clinics, showed greatest rate of significant change, with evidence of good practice in relation to preparation for clinics Thematic analysis of qualitative data shows clear indication of impact of CGN Increased activity generates increased revenue to the service
<i>Freeing up time of others</i>	CGNs prepare patients and families in the 'right' way, freeing up consultant time to spend more effectively with patients and families	Based on 5 sites reporting, the average net hours freed of consultant time per week was 1.5. Based upon 7 sites reporting, the average net hours freed of GC time per week was 4.1
<i>Adding capacity</i>	Nurse-led services add capacity within the service, allowing consultants and other MDT members to focus on other elements of their role	Two sites have nurse-led Family History Screening Clinics Thematic analysis of qualitative data: <i>What does the CGN bring? Firstly, a pair of hands which has allowed us to advance the service dramatically.</i> [CL-C16]
Prevention		
<i>Identifying those at risk</i>	CGNs have an important role to play in identifying individuals and families at risk by taking family histories, cascade referral, and risk stratification	Finch et al. (2011): From 64 index cases, 15 new cases of HCM were diagnosed from 71 asymptomatic at risk relatives screened
<i>Raising awareness</i>	CGNs are proactive and successful in raising awareness about ICC services through formal and informal networking activities and this has had an impact on the number and quality of referrals	<i>When we started, there was very little awareness, even amongst Cardiology. There was no awareness in primary or secondary care. This has changed dramatically. They all agree that there should be a first point of call and they now look to the CGN for that. It's a big achievement.</i> [CL-C12]
<i>Educating others</i>	CGNs further contribute to prevention through formal education sessions and by giving clear and helpful information and explanation to patients and families	Quarterly return detailing education sessions delivered: <i>Paediatricians – 20 (did presentation about role), Stakeholders at [Regional] ICC Service – 30 (did presentation about service and sat in on focus groups), Teachers at little girl's school – 15 (presentation on Long QT) [CGN H]</i>

5. The CGN model: Training, education, impact and scope

The CGN: a specialist nurse with genetics training

In her report, Burton (2011) recommends that the increasing need for genetics to be integrated into mainstream medicine should be met through specialist training to build capacity amongst the professionals within the medical specialty. For cardiology this would include cardiac nurses. At the same time and to complement this, regional genetics services should also continue to include specialists to provide the necessary tertiary and quaternary expertise and services.

The importance of the CGN being a trained nurse has been a consistent theme throughout the project, both in terms of the (specialist) clinical skills to underpin the role (for example in triage and clinical pre-assessment) and the transferrable nursing skills. The latter are exemplified through the theme of *quality caring*, captured by one of the CLs in cardiology who, when asked about the skills the CGN brings to ICC services, responded *empathy, being understandable, contactable, sympathetic – very much core nursing skills* [CL- C13]. The value of the CGNs being located and managed within cardiology, where their cardiology skills can be fully utilised alongside their genetics knowledge and skills is also highlighted. However, it was clear that colleagues in genetics also appreciate the specialist knowledge of the CGNs.

The nature and scope of the CGN role is such that it is difficult to see how it could be accomplished without the knowledge and skills of a trained specialist nurse. It is this foundation on which additional training in genetics and other areas, is built.

The BHF package of education and support for CGNs

The BHF Education package provided for the CGNs recognises that a wider range of skills other than those directly related to clinical practice (i.e. genetics and cardiology) is needed to underpin the role. As such, it provides a good template to apply to other roles incorporating genetics. On the basis of this, we suggest the following core elements need to be provided for cardiac nurses, although this could be adapted for other specialties:

- Genetics training, with a focus on practical skills but including 'basic' scientific concepts
- Communication and counselling skills, with a focus on bereavement support
- Cardiology updating, including pathology (depending on CGN background)
- Leadership and management skills, including transformational change.

This is best delivered through a range of approaches:

- Formal scheduled training
- Informal training, including as part of an induction programme
- Broader networking opportunities
- Formal scheduled access to counselling supervision

The BHF offers ongoing professional development funding to its supported healthcare professionals, but Trusts will be challenged to sustain this level of support in the current economic climate. However, the CGNs themselves may be able to play a useful role in the development of other staff.

Impact of the CGN on ICC services

The establishment of a CGN post represents a significant investment of resources. In the final interview round we asked about the difference the CGN had made to ICC services. Responses were overwhelmingly positive and generally reflect the four elements of the QIPP framework in terms of the impact the CGN was making on the ICC service. One Clinical Lead (CL) responded:

[Patients and families] get a far superior service. Now it is tailored to them. They used to be part and parcel of a normal cardiac service. Now they have access to a highly experienced

person on the phone who gets back to them with their results, explains things, talks to them about the interpretation of results, liaises with the family doctors. No doubt it improves the quality of life. [CL-C17]

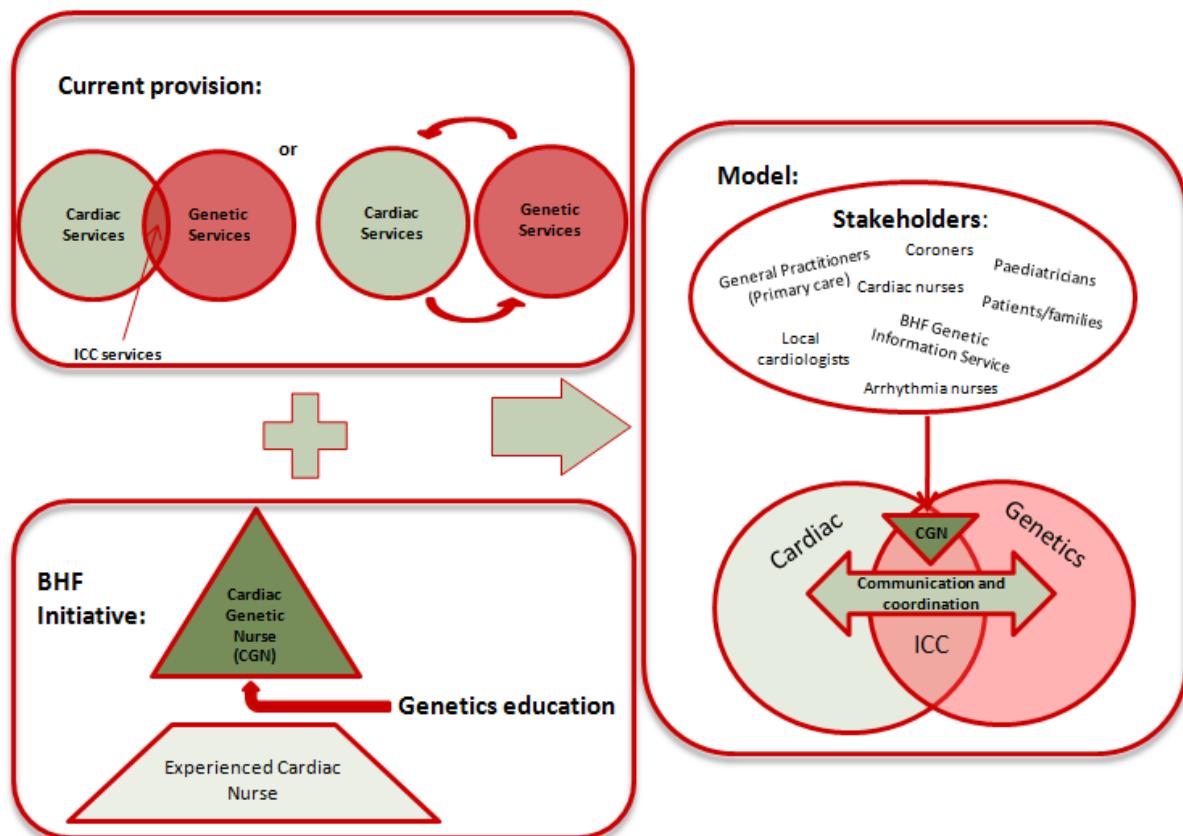
The Clinical Leads and other colleagues value the CGN role and the difference it has made to ICC services. They are clear that without the role now, quality of care and services would be affected. After a CGN resigned from post at one site and until a new appointment could be made, clinics were cut by about a third and capacity for development and innovation was stifled. The CLs clearly see value in continuing the role and when asked about how they would allocate the funding again, would choose the CGN role:

Another CGN. We now have a service we didn't have before. Excellent addition to the team and extension of service. We're providing something we weren't providing before. We've had lots of different pots of money provided before for different things. This has been the most fruitful. [CL-C17]

The CGN model

The model used in the BHF CGN Project is that of taking an experienced cardiac nurse and 'adding' education in genetics (and other areas) to develop a highly skilled nurse who could act as a bridge to facilitate accessible, seamless care between specialties, coordinating communication across the MDT, as well as engaging with the wider stakeholder group (Figure 5.1). The themes which have emerged about the model include its success, the importance of support in relation to this and the potential for blurring of professional boundaries between the CGNs and Genetic counsellors. The most powerful, and consistent theme however, has been the contribution of the specialist nursing background to the CGN model.

Figure 5.1 Development and scope of the CGN role



The CGN role in the context of other professional roles

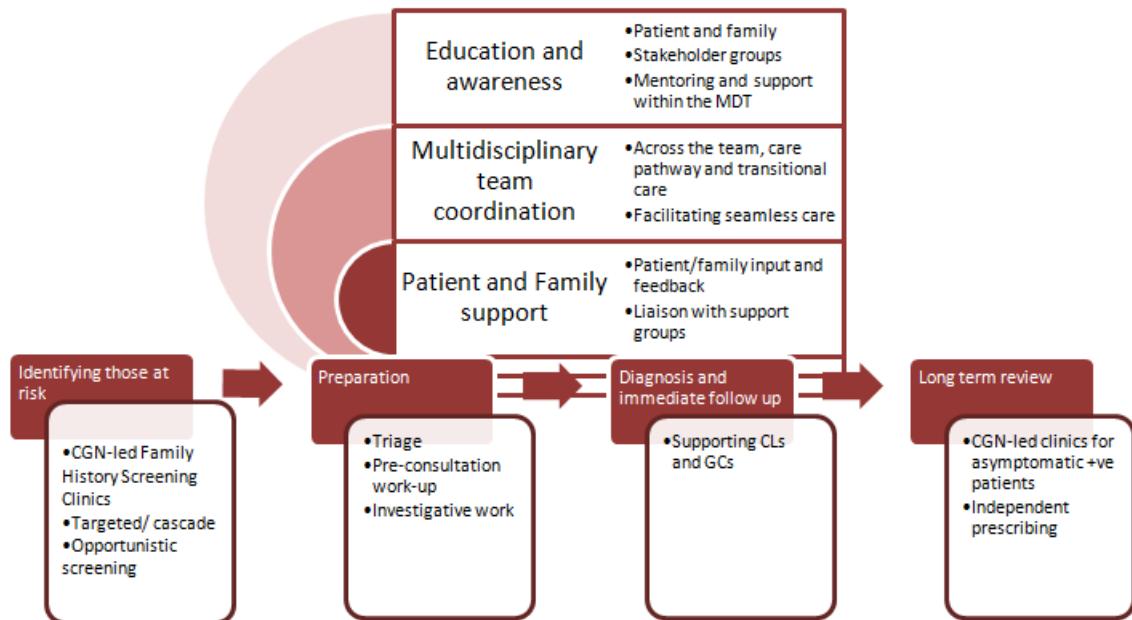
A key question that the model raises is whether the 'starting point' needs to be a cardiac nurse (or any other specialist nurse) rather than a Genetic counsellor. The balance of opinion amongst all those interviewed appeared to favour the broader clinical background in nursing as the basis for development. Although there was some support for Genetic counsellors developing the necessary specialist clinical expertise, the view was that acquiring this sufficient to the role would be more challenging than the reciprocal approach, particularly where clinical interventions are necessary, including devices and medications. However, the roles were also seen as complementary rather than substitutive. Some blurring of role boundaries was noted, but this was not problematic, with each bringing different strengths and experiences.

The model is also relevant to other cardiac specialist nurses or other clinical specialties. The Arrhythmia Specialist Nurse role in particular was felt to be well suited to this model and there was evidence of close working with these nurses at some sites. There appeared to be some consensus that the model could and should be applied to other areas of healthcare.

The scope of the CGN role

The scope of the CGN role encompasses three overarching functions in patient and family support, MDT coordination, education and awareness. We present a 'best case scenario' that seeks to illustrate how these functions can be realised in practice across the patient/family pathway, from initial identification of those potentially at-risk to follow-up and long-term review, with the CGN input leading to a more efficient, streamlined and patient/family-centred process (Figure 5.2).

Figure 5.2 A 'best case scenario' overview of the CGN functions



The autonomy of the CGN is an important factor in this; they can lead nursing clinics and take a key role in education, but they can also lead a team of nurses and other healthcare workers in supporting activities across the care pathway. Their capability to work strategically (as demonstrated in the Maturity Matrix self-assessments) should not be overlooked. Table 5.1 sets out how we believe CGNs contribute to achieving the World Class Commissioning competences. The focus is on those competences highlighted by Alberg and Burton (2010) as particularly relevant to ICC services. The ICC service provision outlined in column 2 is based on that which they identified.

Table 5.1 World Class Commissioning (WCC) competences in ICC services: CGN contribution

WCC competence	ICC service provision	How do CGNs contribute to this?
2. Work with community partners to commission services that optimise health gains and reductions in health inequalities	Enhanced long term management with good follow-up and robust links with other agencies	CGNs are core to an ICC service that delivers high quality caring, continuity of care and long term management. Their outreach activities help promote wider engagement across the geographic area.
3. Engage with public and patients to shape services and improve health	Improved overall quality of life, with provision of accurate, trusted information to support decision-making	CGNs are proactive in hosting support groups, patient focus groups and conducting patient satisfaction surveys. CGNs are proactive in developing high quality information resources.
4. Collaborate with clinicians to inform strategy and drive quality, service design and resource utilisation	<ul style="list-style-type: none"> • Increased patient satisfaction and trust; • Improved clinical outcomes; • More efficient and effective care; • Enhanced reproductive choice 	<p>CGNs can act as valuable members of a collaborative team as they:</p> <ul style="list-style-type: none"> • Act as the bridge across 2 specialties • Manage the MDT meetings • Build and foster strong whole community networks • Contribute to audit
5. Manage knowledge and assess needs to establish full understanding of current and future needs	Reduced inequalities through development of services accessible to all geographic areas and outreach	<p>CGNs develop broad networks across stakeholder groups, including patient support groups and voluntary agencies, to inform needs assessments 'from the grass roots'.</p> <p>CGNs contribute to audits and research, playing an important role in education.</p> <p>CGNs add capacity to extend services.</p>
6. Prioritise investment, developing systems of decision-making related to genetic testing.	Efficient and effective use of genetic testing	Through their roles in risk assessment and triaging, CGNs are promoting more appropriate referrals to genetics, also educating others (e.g. in primary care) about appropriate referrals for cascade testing.
8. Promote improvement in quality and outcomes through innovation and education to share best practice	Efficient and timely referral of patients to the most appropriate specialty	CGNs play an important role in raising awareness of ICC services and in educating health professionals and others about ICCs. CGNs provide capacity and capability to enhance innovation, including the development of new pathways and services.
10. Manage the local health system in partnership with providers to ensure continuous improvements in quality and outcomes	Continuity of care for family members at risk or affected by an ICC	<p>CGNs are proactive in promoting improved transitional care through strengthening links with paediatric care.</p> <p>CGNs can maintain links with patients and families across the pathway and across life stages.</p>

The CGN model as piloted in this project has been successful in the eyes of the key clinical stakeholders, with support expressed for its application to other nursing roles in cardiology and more broadly. The approach of building capacity from within the specialty of cardiology supports the recommendation that this is needed 'to provide the specialised elements of services for inherited diseases within the clinical specialties' (Burton 2011, p29).

The model has been underpinned by a very well supported education package from BHF, which has been responsive to the needs of the CGNs, with further support from other members of the multidisciplinary team

Key points

- An important element of the CGN model is that it seeks to build capacity from within the specialty to integrate care for people affected by inherited cardiac conditions.
- The knowledge and skills that CGNs bring to the role as specialist nurses are core to the success of the CGN model, forming an important basis on which to build further expertise.
- Education and training needs to encompass not only genetics but also counselling and communication skills, cardiology and leadership and management training.
- The education package needs to be delivered as a mix of formal scheduled courses and informal training, in which mentoring and counselling supervision play an important part.
- The Clinical Leads and others value the CGN role and without it, quality of care and services would be affected.
- The CGN and Genetic counsellor roles are complementary, not substitutive.
- The CGNs can contribute to ICC services at both operational and strategic levels.
- The CGN model provides a useful template to apply to other areas of nursing practice.

6. Challenges and lessons learnt

Challenges to service development, to the effective functioning of the multidisciplinary team and the CGNs themselves, have been identified during data collection throughout the evaluation. These range from practical, operational issues such as securing office and clinic accommodation, to the strategic challenges associated with funding, particularly in relation to genetic testing, and with managing increasing demand. The key issues raised during the final interview round focused on:

- Securing funding and demonstrating sustainability, compounded by difficulties in identifying appropriate outcome measures, particularly for long term conditions.
- Resources for genetic testing
- Workload and capacity to meet current and future demand
- Raising awareness and engaging others
- Organisational constraints and the importance of collaborative working
- Consistent and appropriate administrative support

Future challenges are also significant, with the pressures of reconfiguration and the harsh economic climate alongside technological advances and demographic changes increasing the burden of ill health. For cardiac genetics, the rapidly-advancing understanding of the genetic aetiology of common disorders is revolutionising how such conditions are conceived by modern healthcare and demanding clinical attention to the patient's family. Arithmetically, this is a huge challenge (many more people are now potential service users); it is also a new challenge for the knowledge, skills and attitudes of staff, having now to deal both with asymptomatic individuals, and a host of ethical, legal and social sequelae.

In this context, the contribution of the cardiac genetics nurse emerges as a vital additional dimension to care. Not only does the role increase the capacity of services to meet the needs of more people; it also provides a source of expertise and advice in dealing with those issues which are new and challenging for many staff.

Lessons learnt by interviewees which they felt would be of relevance to other services or specialties looking to establish a 'mainstream genetics' service came under two themes:

- The importance of building a supportive environment, with support from colleagues, managers and consultants, as well as the wider network, including the other CGNs. The nature of support includes opportunities for education, continuing professional development, and both clinical and counselling supervision.
- The approach and attitudes of individuals to engaging in a new initiative. Being open-minded, open to communication and being willing to be flexible are important to success.

Applying the lessons learnt

Funding a cohort of nine nurses over 3 years represents a substantial investment by the BHF. To maximise on this investment, it is apposite to reflect on the undoubted success of the project and on the lessons learnt. As advances in genetic technologies bring further developments to 'mainstream medicine', the impetus to integrate genetics into clinical specialties increases. The experiences captured through the evaluation of this project could therefore be valuable in informing other service developments, in cardiology and in other specialties. The 'checklist' is provided to help guide other services looking to integrate genetics through the enhancement of a specialist nurse role. Although the nine posts are located in England and Wales, the points raised in the checklist are applicable across the UK.

CHECKLIST to set up a Cardiac Genetic Nurse Service...

- 1. Induction period:** As for all staff taking on new roles, CGNs require a period of induction, to familiarise themselves with the Trust and their new teams in both genetics and cardiology. This should include scheduled opportunities for observation in genetics clinics.
- 2. Preliminary genetics education:** Practical, relevant training in core genetic concepts is essential to underpin the role. The introduction to genetics for healthcare professionals provides CGNs with a sound foundation of knowledge and skills in genetics to build upon.
- 3. Support and mentoring from clinical leads, genetic counsellors and others:** Commitment to formal and informal support for CGNs from all Clinical Leads and other colleagues within the immediate MDT is essential from the outset. There has to be flexibility and a willingness to 'make it happen'.
- 4. Administration support:** Dedicated administration support for the CGN allows for a more focused and efficient CGN service.
- 5. Cardiac training:** Although CGNs will have some background in Cardiology, CGNs should identify any gaps in their cardiac knowledge and experience. Any further training required must be prioritised appropriately, and be built into their ongoing development.
- 6. Management training:** CGNs should be equipped with the skills to function as autonomous, senior nurses who can provide leadership, support and education to others. Forward planning should consider how their expertise can best be utilised once the new service is embedded.
- 7. Counselling supervision:** as for Genetic Counsellors within the team, counselling supervision should be available to CGNs on a formal scheduled basis. This should be provided in addition to clinical supervision and more general support and mentorship.
- 8. Lead time to set up new clinical services:** Service planning activities can take longer than anticipated, from the strategic planning around care pathways and evaluation to practical issues of securing clinic space and appropriate office accommodation. CGNs themselves must also receive the appropriate induction, support and training. In new or developing ICC services, the lead time may be significantly longer and this must be factored into planning.
- 9. Wider network and support:** In a new and developing role, wider networking and support from others is fundamental. Organisations and groups such as BHF and the Association for Inherited Cardiac Conditions can facilitate this.
- 10. Lead time to raise awareness of the service:** Particularly in new or developing services, it will take time to raise awareness of the new role/service. It should be an ongoing part of the CGN role to promote and educate people about the service and foster ongoing engagement. This must be factored into workload planning.

7. Recommendations and conclusions

The five Domains of the BHF Maturity Matrix have provided a useful framework to describe an effective, sustainable ICC service. The Domains are consistent with NSF requirements and reflect the features of a specialist ICC service (Alberg and Burton 2010). Assessment of performance of ICC services in which the CGNs are involved has demonstrated significant progress both in new and well established ICC services. It has also highlighted inequities in provision, compounded in Wales in particular by the lack of funding for cardiac genetic testing. Nonetheless, other data have corroborated that the CGNs make substantial contributions to enhancing the quality of the patient/family experience and play a core role in prevention. They also enhance productivity and contribute to and facilitate innovation. On this basis, the CGN model is successful and adaptable to other specialist nurse roles.

Education & support

The robustness of the BHF Education package, and further support from BHF and host organisations for additional training, has been a critical feature of the project. We make the following observations and recommendations in order to build on this for other ICC services.

- a. Appropriate and accessible education and training is a vital component of the role which needs to be sustainable at Trust level. Work-based learning and the application of new technologies to support learning and promote networking, can play an important part in this.
- b. There needs to be some thought given as to how genetics education can best be consolidated in the CGN's own location, through clinic observation and mentoring, as part of a structured programme that starts with induction.
- c. Continuing professional development within the specialist field needs to be addressed alongside the acquisition of genetics knowledge and skills.
- d. A broader, more formal support package is needed that incorporates education for changing roles, mentoring and provision for counselling supervision.
- e. There should be some consideration as to how the leadership potential of CGNs can be maximised in terms of the contribution they can make to the education, training and professional development of others, both within the specialty and the wider NHS workforce.

The CGN Specialist Nurse model

The CGN model, whereby the specialist nurse receives appropriate education and training in genetics to enable the nurse to work across two specialties, acting as the linchpin in doing so, is a successful one that is applicable to other specialist nursing roles.

- a. Further consideration needs to be given to the optimal skill mix and appropriate training that would be required to make best use of the CGN's expertise within the healthcare team.
- b. There needs to be further examination of the factors that may contribute to the success of nurse led clinics.

Conclusion

The CGN role and impact can be articulated against the QIPP framework, can be mapped to the five markers of good practice set out in 'Chapter 8' of the NSF and the seven WCC competences applied to ICC services (Alberg and Burton 2010). The CGN role can also help ICC services to address the recommendations in *Heart to Heart* (Burton et al. 2009), providing capacity to help meet the identified current shortfall in provision and the anticipated increase in demand. We conclude that the CGN model is fit for purpose and that the CGNs can make an effective, value for money contribution to ICC services, facilitating efficient service delivery across two specialties.

The Clinical Leads and CGNs are very clear about the possible consequences of the CGN no longer being in post, with an adverse impact on waiting times and capacity to meet increasing demand. Most importantly, the quality of the patient and family experience would be compromised. Our conclusions on the CGN contribution can be summarised in five distinct and complementary themes.

Five key reasons to appoint a CGN to ICC services

1. The CGN plays a core role in facilitating seamless care between specialties in a patient focused integrated ICC care pathway

As highly skilled cardiac nurses, with further training in genetics, CGNs act as a bridge, facilitating care and services between cardiology and genetics. Their broad skill set promotes flexibility, enabling them to adapt to change as services develop as well as allowing them to contribute directly to clinical care. Their role makes a direct contribution to enhancement of quality, capacity for innovation, increased productivity and prevention.

2. The CGN role enhances the quality of the patient/family experience

CGNs enhance the quality of the patient/family experience through the holistic, family-centred care they deliver. They act as a point of contact, providing continuity along a potentially complex pathway, often when patients and families are particularly vulnerable. CGNs spend time helping patients and those at risk of an ICC to understand their condition, its management and the patient pathway. They take time to listen and respond to concerns and queries, support decision-making, and empower patients through education and advocacy.

3. The CGN adds capacity to innovate and enhance or develop aspects of (new) services

CGNs act as catalysts to further development, helping to develop new services, care pathways and new ways of working, building links across the MDT and wider networks. CGNs take the initiative in improving aspects of services through activities such as establishing patient support groups and forums, and providing opportunities for staff development.

4. CGNs enhance productivity, providing a value for money contribution to ICC services

CGNs enhance productivity through increasing the effectiveness of the ICC service and the identified productivity gains represent a clear improvement in efficiency. They enable increased throughput together with a reduction in the number of inappropriate patients seen, with a resulting increase in patients' capacity to benefit, especially for those at highest risk. Effectiveness is further increased through the release of consultant and Genetic Counsellor time from activities not requiring their expertise and by ensuring that families are better prepared to communicate with these health professionals. The value of released resources partly offsets the cost of employing the CGNs.

5. The CGN plays an important role in prevention

CGNs play an active role in prevention, identifying unmet need through their activities in raising awareness, family history and clinical assessment, triaging and cascade referrals. They increase capacity to see higher risk patients sooner and their patient-centred approach helps promote compliance. Their role in education further promotes prevention by extending knowledge into primary and secondary care and the wider community.

It could also be said that the implications of this model go beyond cardiology and genetics and inform broader implementation. In her report on mainstreaming genetics, Burton (2011) suggests that it is time for detailed policy work with commissioners and stakeholders in other clinical fields to consider how best they can develop an integrated, specialty led service. The BHF CGN project would make a valuable case study to inform those policy discussions.

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Appendix 1 Maturity Matrix Domains and Descriptors

Domain	Outcome Descriptors
A. An accessible Inherited Cardiac Conditions Service, with a clearly articulated model of service provision	<p>Pathways A1. Integrated care pathways</p> <p>Multidisciplinary core team working A2. Identify and facilitate key professionals to implement seamless care pathways</p> <p>Wider networks A3. Clearly defined network at local & national levels</p>
B. A communicated and coordinated service, where the structure of the service is understood by all	<p>Coordinated care B1. Effective coordination of ICC service by CGN</p> <p>Communication B2. Effective communication of ICC service</p>
C. Family-centred care	<p>Advocacy C1. Empowered and supported to manage their own situation.</p> <p>Personalised care C2. Patients feel they are treated as individuals</p> <p>Consistent service C3. Patients/families know who they should expect to see and what to expect from the service</p> <p>Further support C4. Access to external services and support is clear</p>
D. A sustainable and ethical service	<p>Sustainability D1. Plans are in place for a sustainable ICC service, supported by the host organisation.</p> <p>Investment D2. Host organisation invests to secure adequate and appropriate access to facilities and equipment</p>
E. Valuing the knowledge base, with a philosophy that embraces qualitative and quantitative evidence	<p>Benchmarked services E1. Delivering evidence-based services in line with national standards</p> <p>Currency of service E2. Monitoring evidence-base & keeping service updated</p> <p>Education E3. Education initiatives in place</p> <p>Research E4. Collaborative engagement in ICC research programmes that value the patient voice</p> <p>Developing the expertise of practitioners E5. Host organisation values the CGN role, providing effective Continuing Professional Development (CPD), training, clinical supervision and resources</p>