

Evaluating the role of Cardiac Genetics Nurses in inherited cardiac conditions services using a Maturity Matrix

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Abstract

Background: Cardiovascular disease is a leading cause of death worldwide and genetic risk factors play a role in nearly all such cases. In the UK, health service capacity to meet either current or future estimated needs of people affected by inherited cardiac conditions (ICCs) is inadequate. In 2008 the British Heart Foundation funded nine three-year Cardiac Genetics Nurse (CGN) posts across England and Wales to enhance ICC services. The CGNs were experienced cardiac nurses who had additional training in genetics and acted to coordinate cardiac and genetics service activities.

Aim: To create and apply a framework against which progress in ICC service improvement could be measured over time following the CGN appointments.

Methods: A performance grid (Maturity Matrix, MM) articulating standards in five domains against stages of ICC service development was created by stakeholders through a consensus approach. The MM was used to guide staged self-assessments by the CGNs between 2009 and 2011. A six-point scale was used to locate progress from 'emerging' to 'established', represented graphically by spider diagrams.

Results: Progress in all domains was significant for new, emerging and established services. It was most notable for effective utilisation of care pathways and efficient running of clinics. Commitment to family-centred care was evident.

Conclusion: The ICC-MM provided a comprehensive framework for assessing ICC services and has merit in providing guidance on development. CGNs can help integrate care across specialisms, facilitating the development of effective and sustainable ICC services at new, developing, and more established ICC service locations.

Keywords

Cardiac genetics, nurses, maturity matrix, consensus techniques, inherited cardiac conditions services, ICC services

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Introduction

Cardiovascular disease is a leading cause of death worldwide and whilst genomic technologies are elucidating the role that genetic variants play in nearly all such diseases,¹ including common conditions such as coronary artery disease,² the individual effect on risk of most variants is modest. However, the monogenic inherited cardiovascular conditions (ICCs) are associated with much greater risk. There are over 50 of these, the four main categories comprising the cardiomyopathies, arrhythmia syndromes, for example, Long QT, inherited arteriopathies such as Marfan syndrome and muscular dystrophies.³ Collectively they represent a substantial burden of disease, with a prevalence in the United Kingdom (UK) estimated to be around 340,000.³

For some ICCs, the first indication of disease is sudden cardiac death. Most of these conditions are associated with dominant inheritance, with a 50% risk to first-degree relatives.⁴ Cascade screening plays a vital role in identifying such individuals via cardiac tests such as electrocardiography and by DNA testing.⁵ Healthy individuals whose DNA test is mutation negative can be excluded from further follow-up. High success rates in identifying affected family

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members demonstrate the importance of this approach in initiating appropriate prophylaxis to ameliorate risk.⁶⁻⁸ Cascade screening for conditions such as hypertrophic cardiomyopathy and familial hypercholesterolaemia has been shown to be acceptable and cost-effective.⁹⁻¹²

Effective service provision is crucial for identifying and managing families affected by ICCs. The expertise of genetics services in routinely investigating family units and the potential complexity of clinical and genetic findings requires a multidisciplinary approach.¹³ With sudden cardiac death, the UK National Health Service (NHS) is required to make provision for identifying family members at risk, providing 'personally tailored, sensitive and expert support, diagnosis, treatment, information and advice to close relatives'.¹⁴ A comprehensive review of NHS ICC services identified 20 specialist services, most offering a variety of joint specialist clinics but with variable provision across all measures of activity surveyed, including range of specialist roles, number and range of outpatient clinics and new patients seen. The balance between cardiology and genetics consultant sessions also varied, with most ICC services tending to be dominated by one specialty or the other, rather than an integrated service.³ Whilst most covered the four main ICC categories, significant inequities were noted and capacity to meet either current or future estimated needs deemed inadequate, with a 3-4-fold increase in regional provision for new patients needed to meet the shortfall.³

The survey noted the valuable role that Cardiac Genetics Nurses (CGNs) can play within the multidisciplinary ICC team, although only 10 services employed them. Such nurses can act as a bridge between cardiology and genetics specialist services, serving as the identified contact for the family, providing information and support, organising tests and contributing to clinical care.³

The British Heart Foundation (BHF), a UK charitable organisation, funded two CGN posts in 2006. Following the success of these, in 2008, after competitive tender, they funded nine ICC services, each to appoint a full-time CGN for three years, to help develop new service initiatives or to develop existing services further. The aim was to improve the quality of provision to patients and families through improving access, support and communication with and between cardiac and genetics services. The authors were commissioned to conduct an independent evaluation of the contribution of the new CGN posts to the ICC services where they were based. In this paper we report the creation and application of a framework to assess progress in service development over time following their appointment.

Methods

The authors adopted a case study approach for the wider evaluation, treating CGNs as a single case, guided by an independent advisory group of medical consultants and

nurses from cardiology and genetics, along with health policy, education and patient representatives. For this study, we needed to ascertain:

- What does an effective and sustainable ICC service look like?
- To what extent are its features achieved over time?

One challenge in measuring impact was the absence of nationally agreed ICC service benchmarks. A two-stage approach was taken to develop and apply an ICC Maturity Matrix as a framework to assess service development following the CGN appointments.

The CGNs were appointed between October 2008 and March 2009 across England ($n=8$) and Wales ($n=1$), working in multidisciplinary teams, each with a medical consultant lead in genetics and/or cardiology. As experienced cardiac nurses, their roles incorporated reviews of referrals and test results, ordering additional tests and conducting clinical assessments. Following a minimum genetics training of 30 hours at Master's level, they were competent to undertake family history collection and risk assessment, to triage patients and provide genetic and cardiac-related information and support, liaising with other specialist cardiac nurses and genetic counsellors as appropriate. Initially, the ICC services were at varying stages of maturity and individual CGN roles were tailored according to the specific service needs of each site.

Stage 1: developing the Maturity Matrix

A Maturity Matrix (MM) is a two-dimensional instrument to evaluate organisational development over time (Figure 1(a)), used widely in health service settings¹⁵ and primary care in Europe.^{16,17} The common underpinning concept of identifying features of an organisation assessed over time partially dictates MM structure, but content varies and many are developed as new.¹⁸ It can be presented as a number of core concepts or domains, each with associated descriptors (individual components of a domain) comprising a series of indicators (describing items that can be measured) (Figure 1(b)). Appropriate indicator measures are grouped into stages of maturity, creating a matrix of cells against an ordinal scale (e.g. from 'new' to 'established'). Progress is identified through self-assessment with a facilitator.

The development process is summarised within Figure 2. A consensus approach was adopted at a one-day meeting of multidisciplinary stakeholders from cardiology, genetics, education, charitable organisations and patient groups. Before the meeting, participants (selected for their expertise and/or role) were invited by email to nominate essential elements for an effective ICC service. Items generated were categorised into themes by one researcher, verified independently by a second, and overarching domains agreed. The meeting followed a structured programme with a participative thematic

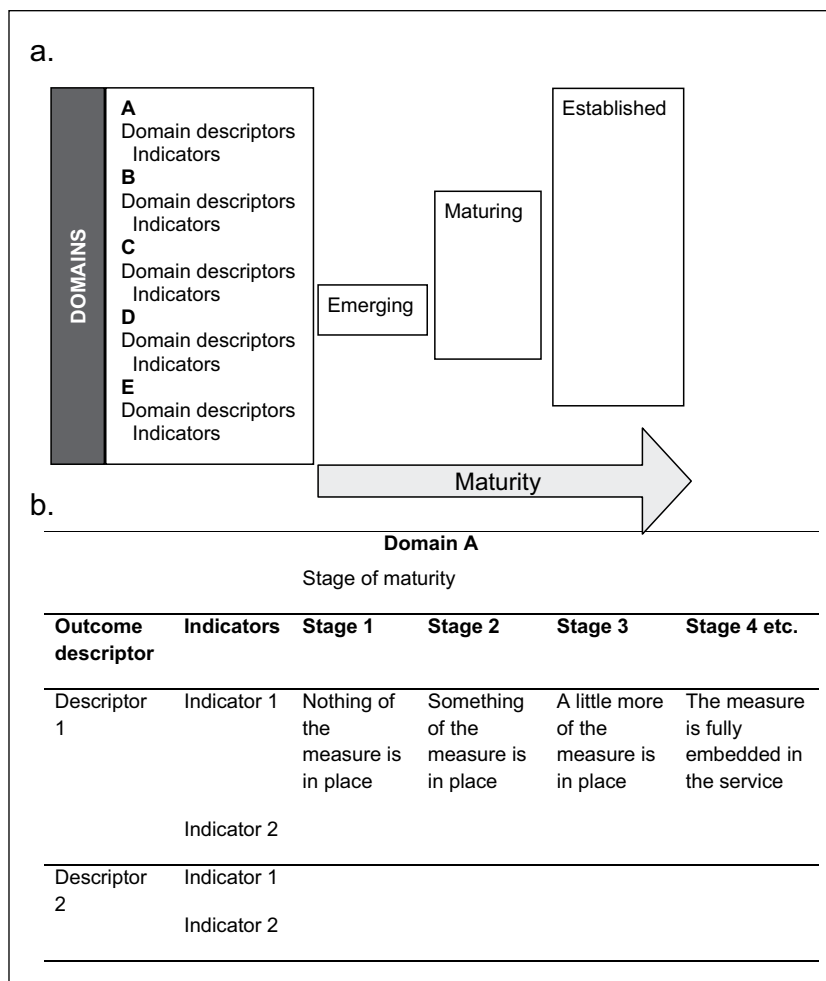


Figure 1. A Maturity Matrix. (a) Over time the organisation is able to identify performance that meets the expected measure for the appropriate stage of maturity (three stages shown for simplicity). (b) The working document is presented as a grid for self-assessment.

analytical approach whereby the stakeholders were involved in shaping the emerging framework by discussion throughout the day managed by an expert facilitator. Following review of the domains, participant groups considered three questions per domain in an iterative process (Figure 3). Electronic voting technology was used to agree the domains, outcome descriptors and indicators as a basis for further development. Participants were emailed for comments on the draft ICC-MM developed following the meeting. Further revision was made following consultation with the advisory group, ICC clinical leads at the host sites and the CGNs (Figure 2).

Stage 2: applying the MM

The ICC-MM was piloted at three sites, interviewing the CGNs for feedback on acceptability and the scope of measures appropriate as evidence for each indicator. The process was then discussed with all CGNs in a focus group (Figure 2). Refinements were made prior to the first self-assessments,

which incorporated brief narratives from the CGNs against each matrix cell. Continuity was maintained by the same researcher visiting sites to clarify and audit evidence. Clinical leads at each site were asked to verify the completed report. Two interim 'exception report' self-assessments were conducted in 2010, with a final full assessment in 2011. One CGN resigned in late 2010 and this site was subsequently excluded from further analysis.

Analysis

Self-assessments were coded and analysis was conducted blind. Two researchers independently analysed responses for each domain with disagreement resolved by discussion. We assigned a number to the maturity stages of a six-point ordinal scale, ranging from 'not yet emerging' (=0) to 'established' (=5) for ease of locating sites on the ICC-MM. Each self-assessment was scored for each indicator. Spider plots were produced for the baseline (2009)

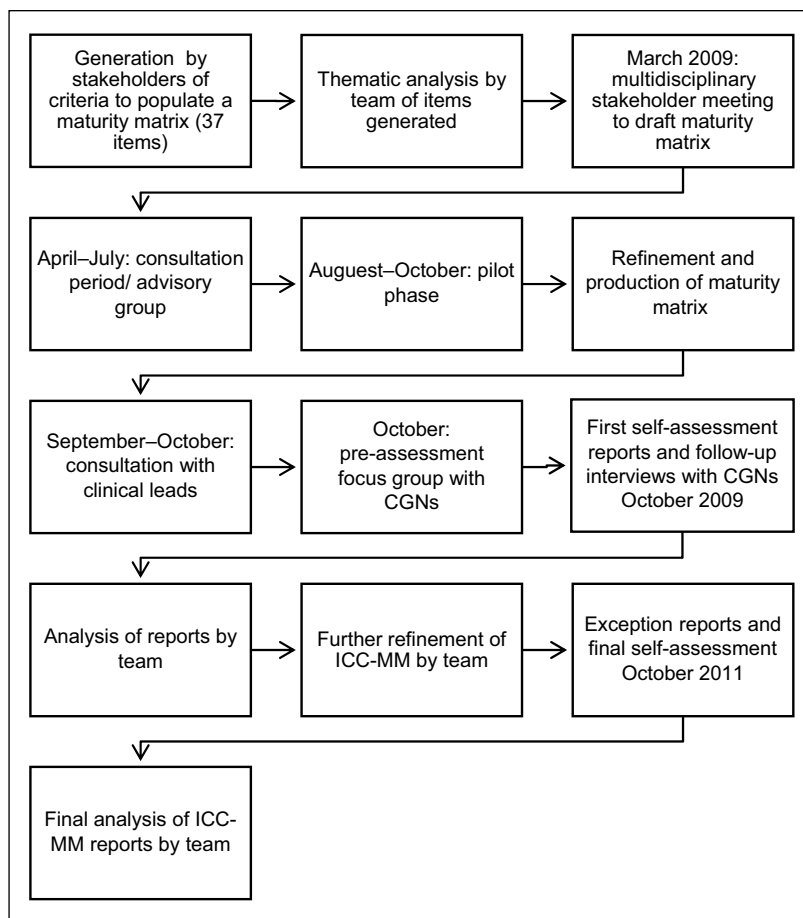


Figure 2. Stages of development and use of the ICC-Maturity Matrix (ICC-MM).
ICC: inherited cardiac condition

and final (2011) assessments to visualise progress, using the mean scores for each indicator. The direction of change in scores over time was examined using the Wilcoxon signed-rank test, with descriptive statistics used to compare rate of change. A repeated measures ANOVA was performed to identify interaction effects between how long the ICC services had been established and changes observed over time.

Ethical considerations

The investigation conforms with the principles in the Declaration of Helsinki.¹⁹ Ethics approval was given by the University of Glamorgan Faculty Ethics Committee on 22 February 2009. Offices overseeing governance at the host sites were notified of the evaluation programme.

Results

Stakeholders generated 37 items, categorised into five themes. Twenty-eight participants attended the meeting, including six CGNs. None disagreed with the descriptors

and indicators developed, although strength of agreement varied and two people rated two domains neutral (Table 1). Fourteen subsequently commented on the draft ICC-MM and all advisory group members ($n=14$) contributed to further refinement. The final ICC-MM outlined five domains accompanied by outcome descriptors, indicators (Table 2) and expected measures for stage of development (Table 1 in supplementary material online).

Comparison of means between 2009 and 2011 showed progress across the five domains (Figure 4), significant for all indicators bar four (supplemental Table 2). Spider plots based on the mean scores for indicators in each domain are presented in Figures 5–9.

Domain A: accessibility

Domain A is underpinned by documented, effective care pathways, multidisciplinary team (MDT) working and engagement of wider networks. By 2011 all sites reached the ‘Maturing’ stage as a minimum for all indicators (Figure 5). ‘Effective utilisation of individualised care pathways’ (A1.2) was one of four indicators showing the highest rate

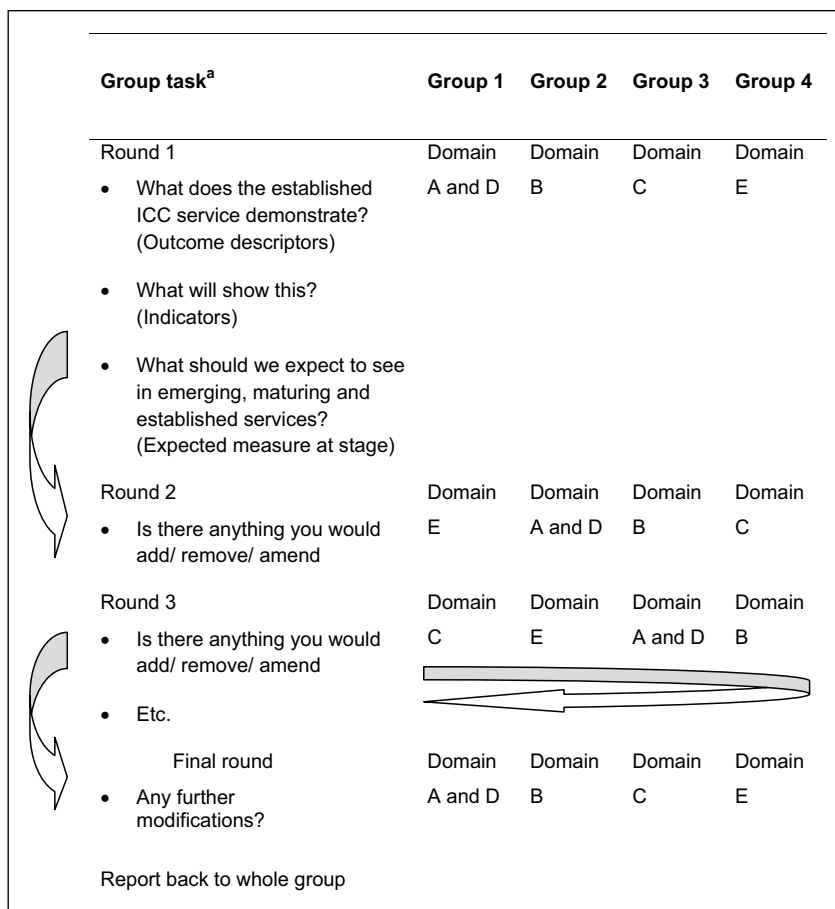


Figure 3. The iterative review process to develop the ICC-MM.

^aParticipants were allocated to multidisciplinary groups.

ICC-MM: inherited cardiac condition-Maturity Matrix

Table 1. Strength of agreement from participants ($n=26$) on domains, descriptors and indicators identified as a basis for MM development.

Domain ^a	Strongly agree	Agree	Somewhat agree	Neutral	Somewhat disagree	Disagree	Strongly disagree
A	5	17	4	0	0	0	0
B	2	15	7	2	0	0	0
C	6	15	4	1	0	0	0
E	5	11	10	0	0	0	0

^aDue to time constraints, votes were not cast for Domain D.

of change (supplemental Table 2). Most CGNs cited triaging and referral trends as evidence of effective use of care pathways:

Patients are triaged according to individual need by utilisation of pre-assessment telephone call. Inappropriate referrals can be intercepted...and the appropriate 'at risk' family members who need to be referred can be identified and a referral requested. High risk patients once identified are prioritised according to need and not waiting lists. (CGN-F, A1.2)

Commitment to audit and review of pathways was evident from the self-assessment narratives, such as CGN-G commenting 'At present we are auditing 100 consecutive families'. Progress in establishing effective working relationships was steady, with regular MDT meetings and network development to include paediatric cardiologists, primary and secondary care colleagues and coroners. In the latter case:

These links result in speedier referrals of patients following a sudden death – hopefully reducing their anxiety levels. (CGN-H, A3.1)

Table 2. ICC-Maturity Matrix domains and descriptors.

Domain	Outcome descriptors
A. An accessible inherited cardiac conditions service, with a clearly articulated model of service provision	A1. Integrated care pathways A2. Identify and facilitate key professionals to implement seamless care pathways A3. Clearly defined network at local and national levels
B. A communicated and coordinated service, where the structure of the service is understood by all	B1. Effective coordination of ICC service by CGN B2. Effective communication of ICC service
C. Family-centred care	C1. Empowered and supported to manage their own situation. C2. Patients feel they are treated as individuals C3. Patients/families know who they should expect to see and what to expect from the service C4. Access to external services and support is clear
D. A sustainable and ethical service	D1. Plans are in place for a sustainable ICC service, supported by the host organisation D2. Host organisation invests to secure adequate and appropriate access to facilities and equipment
E. Valuing the knowledge base, with a philosophy that embraces qualitative and quantitative evidence	E1. Delivering evidence-based services in line with national standards E2. Monitoring evidence-base and keeping service updated E3. Education initiatives in place E4. Collaborative engagement in ICC research programmes that value the patient voice E5. Host organisation values the CGN role, providing effective continuing professional development, training, clinical supervision and resources

ICC: inherited cardiac condition; CGN: Cardiac Genetics Nurse

Formal establishment of wider interest groups (A3.2) was less widespread, but there were examples of good practice; one site (G) conducted a needs analysis with patients before establishing their pathway.

Domain B: communication and co-ordination

Initially, most sites clustered around point 2 on the ordinal scale, ‘emerging/maturing’ in Domain B (Figure 6). By 2011, services were ‘bedded down’; efficient running of clinics (B1.2) showed one of the highest levels of change (supplemental Table 2). CGN-F detailed the role of pre-clinic telephone calls in preparation (B1.1):

A family history is taken and any other relevant information collated;

Clinic slots are booked according to patient’s risk;

Patients are booked in to see the most appropriate member(s) of the MDT clinic;

A one-stop shop is coordinated.

Coordinating clinic appointments, whereby separate cardiology and genetics consultations and assessments could be conducted on the same day (‘one-stop shop’), was found important but not possible at all sites. One CGN explained that ‘unfortunately there doesn’t appear to be any

scope (clinic space and time) for this within my clinical team’ (CGN-D, B1.1).

There was a clear focus on information provision, with CGNs using a variety of media before and at clinics (B2.1). One site involved patient groups and the regional clinical governance team in reviewing leaflets prior to use. Gaps in literature provision were noted, such as ‘age appropriate literature for teenagers and children’ (CGN-E, B2.1). CGN-D established a patient support group, and six sites had conducted patient satisfaction surveys.

Domain C: family centred

Most sites were initially assessed as emerging/maturing (point 2) against many indicators. There was clear commitment to facilitating family-centred care (Figure 7). By 2011, most sites were assessed as maturing (point 3) as a minimum. One site (G) reported how feedback from patients, families and the consultant geneticist indicated that patients were well informed about the service and their condition. There was evidence that patients’ and families’ views were actively sought and acted upon to try to accommodate their needs:

Families seen together whenever practical for them, even if it means overbooking for us. (CGN-B, C2.1)

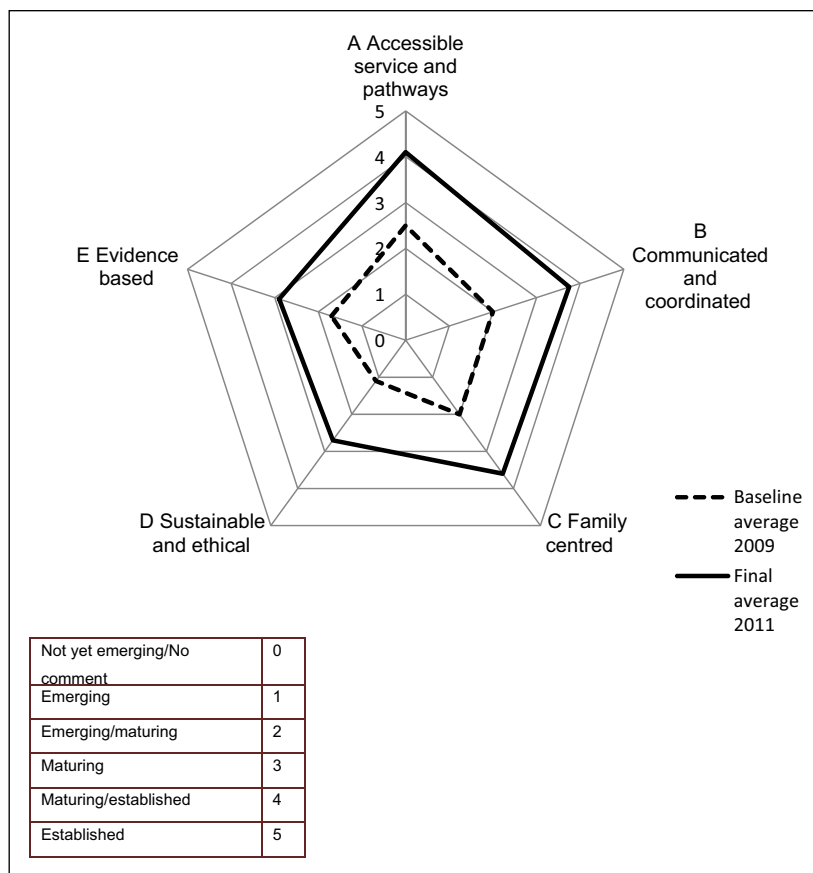


Figure 4. Mean scores across all sites for all domains 2009 and 2011.

Children's needs were handled sensitively:

Plans can be made with parents prior to clinic as to how best to deal with children that are particularly traumatised by hospitals, especially if there has been a death in the family. (CGN-F, C2.1)

However, CGNs also used the self-assessment narrative to note concern around gaps in provision, including 'a desperate lack of bereavement support for children in our area' (CGN-J, C2.3).

CGNs took steps to provide appropriate and up-to-date information about support groups with evidence of good follow-up practice. CGN-F commented that s/he will 'often ask them if they accessed the support group and how it helped'.

Domain D: sustainable and ethical

In 2009, with one exception, sites were at the early stages of planning and implementing new services, or new developments within existing services. By 2011, all were actively pursuing, or had secured, future funding for the service (Figure 8, D1.1). There was some evidence of support from the host organisations in terms of governance frameworks

and audit (D1.2) although this was not significantly changed:

Everyone helps wherever possible given the present limit of NHS resources. (CGN-B, D1.2).

A new indicator (D1.3) was introduced after the baseline assessment. Waiting times were generally well within national and local targets. Investment in the ICC service varied (D2.1), particularly in more recently established services and change here was not significant. Clinic space was an issue at one site, and administrative support very limited at others. Two sites were especially constrained by resources for genetic testing. Even so, CGNs were positive about the impact of their role as an integral part of ICC services:

...with me in post this certainly improves the care trajectory for this patient group. (CGN-D, D2.1)

Domain E: continuous improvement

In the early stages, CGNs were not as involved in research, nor in educating professionals or the public (Figure 9). Only two sites were 'maturing' for these first two indicators and none for the latter. By 2011, effective monitoring arrangements had

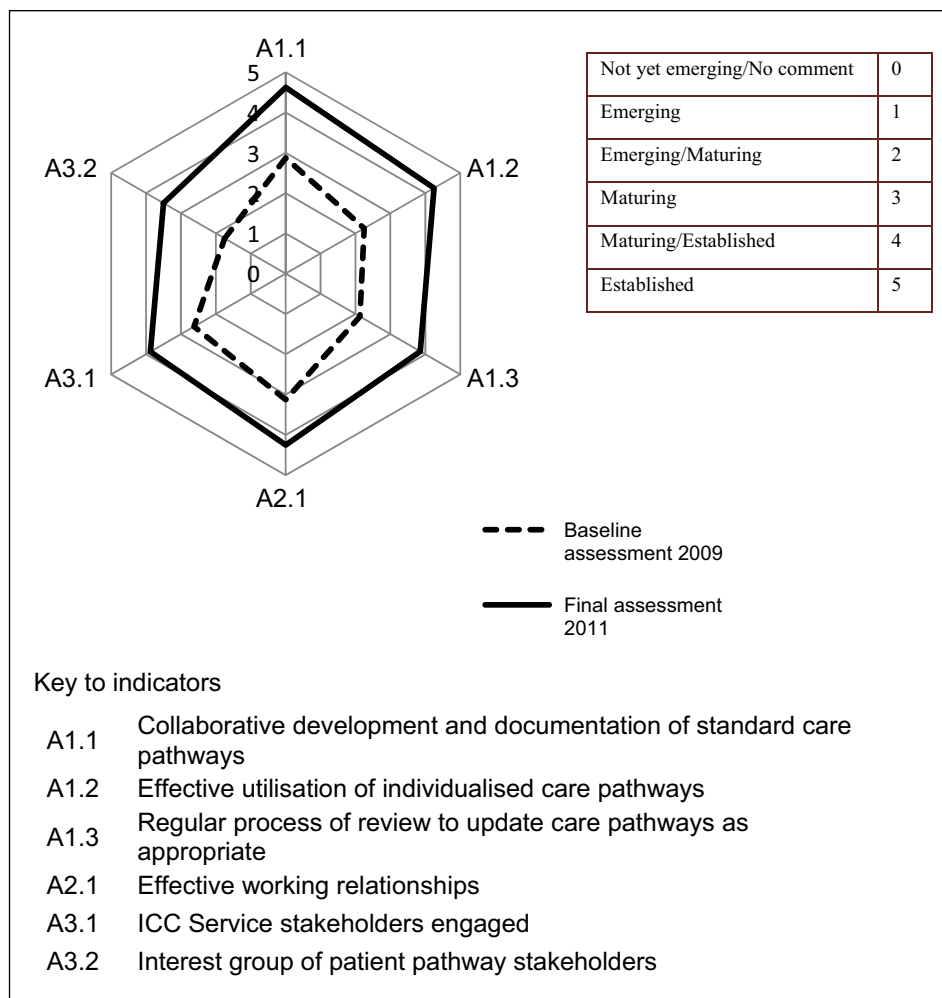


Figure 5. Domain A, an accessible inherited cardiac conditions service, with a clearly articulated model of service provision: mean scores across all sites for each indicator.

been developed with sound awareness of, and contribution towards, national guidelines although change was not significant for E1.1. CGNs were involved in formal teaching sessions across a range of audiences, within workload constraints. Sites were using the research evidence base and some CGNs were actively contributing through participation in multi-centre research studies and publishing in professional journals. Progress in patient/public participation in research (E4.2) was not significant.

CGNs were actively engaged in the BHF's comprehensive training programme and benefited from 'in house' mentoring and support:

...I have benefited tremendously by being mentored intensively by both the cardiology and genetics departments... [this] has helped patients get appropriate care and advice in a timely manner. (CGN-E, E5.2)

One of the fastest rates of change was in establishing clinical and counselling supervision (E5.4).

Overall maturation

Comparing rate of progress of established sites (A, B, E and F) with the other sites (D, G, H and J) using mean total scores in 2009 and 2011 across all domains showed increased scores for both established and new/emerging sites, with a faster increase for newer services. The repeated measures ANOVA showed that, overall, increase from baseline to final score was significant ($F=141.075, p<0.01$); however, there was no significant interaction with the type of site ($F=2.276, p=0.182$).

Discussion

The ICC-MM developed for this study aimed to capture progress in service development following the CGN appointments to the nine ICC services. The framework incorporated the concepts of accessibility, communication and coordination of services, family-centred care, sustainability and continuous improvement, for new through to

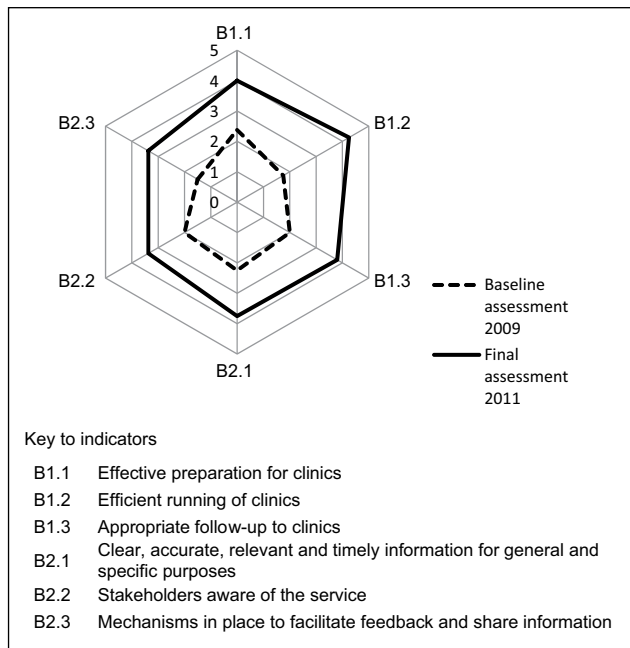


Figure 6. Domain B, a communicated and coordinated service, where the structure of the service is understood by all: mean scores across all sites for each indicator.

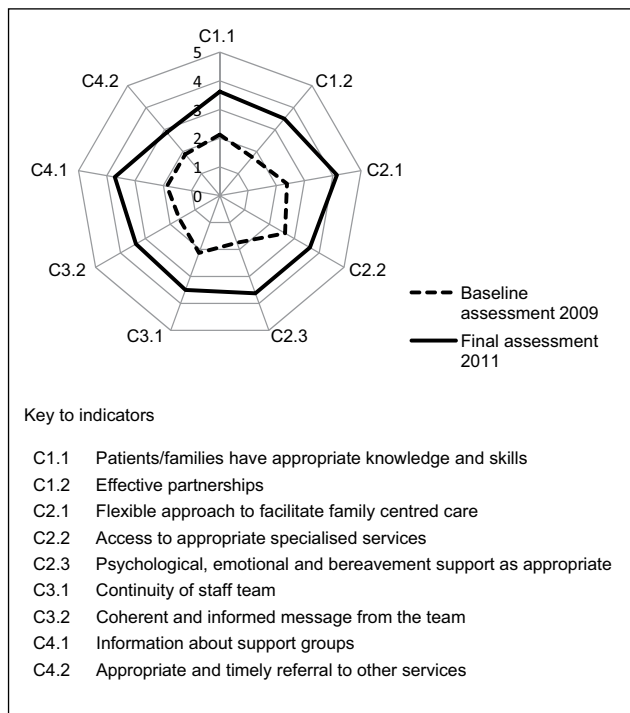


Figure 7. Domain C, family-centred care: mean scores across all sites for each indicator.

established services. Without any existing benchmarks, the ICC-MM, developed with stakeholders, provided an indication of how services might be expected to progress as new initiatives became embedded in ICC service provision (supplemental Table 1). Significant progress was noted in

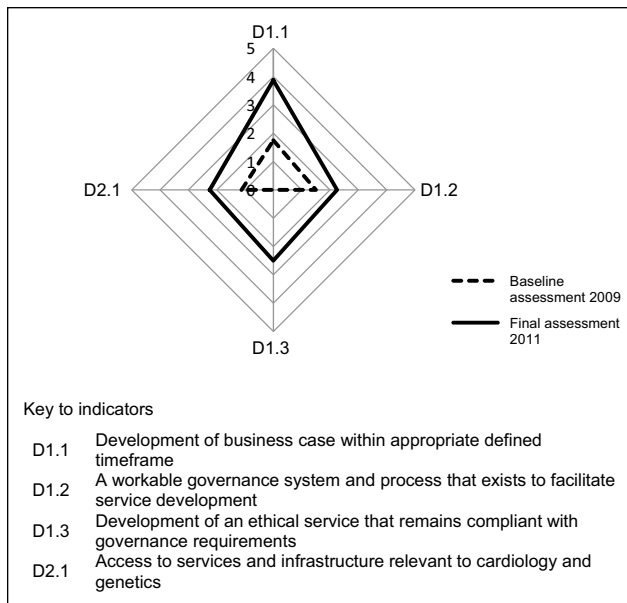


Figure 8. Domain D, a sustainable and ethical service: mean scores across all sites for each indicator.

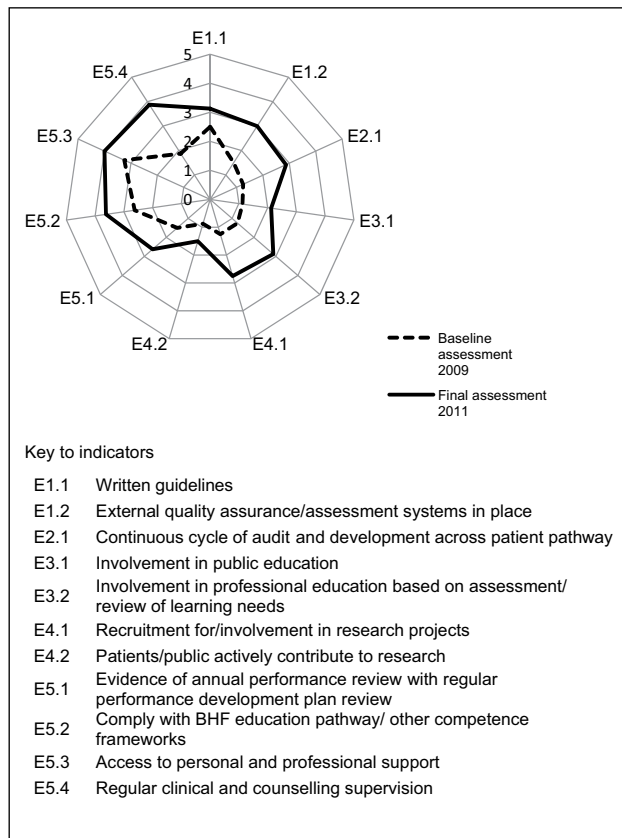


Figure 9. Domain E, valuing the knowledge base, with a philosophy that embraces qualitative and quantitative evidence: mean scores across all sites for each indicator. BHF: British Heart Foundation

all domains, for all but four of the 37 indicators and at both established and new or emerging sites. Self-assessments

demonstrated that CGNs have strategic insight into their service, identifying gaps in provision, offering solutions and achieving significant progress irrespective of the site's initial stage of maturity.

Most progress was noted in Domains A–C and this is perhaps to be expected in terms of the CGN's potential to contribute to service development. Promoting an accessible service, underpinned by effective care pathways, multidisciplinary working and wider networks (Domain A) represents the culmination of the initiative. The post is considered to be a timely addition to the multidisciplinary cardiac genetics team, including at established sites.²⁰ The CGN, in bridging genetics and cardiac services, is core to promoting 'A communicated and coordinated service' (Domain B). Family-centred care (Domain C), is a core nursing concept,²¹ empowering patients and families to share or make decisions and manage their condition, with care planned around the family. The increasing importance of CGNs in providing support and psychosocial care has been noted.^{20,22} CGNs appeared committed to this concept and concerned about the constraints of both service arrangements and gaps in provision.

Progress in Domains D and E was more limited for some indicators, suggesting that initial efforts were focused on the clinical service. The non-significant changes in securing sustainability and support (Domain D) with attendant uncertainty on the continuation of employment post-BHF funding reflect the challenges of NHS commissioning during severe fiscal constraint. Even so, considerable effort was made to inform commissioners about the CGN posts. Domain E relates to continuous improvement, incorporating research and education. The importance of the CGN in education has been highlighted²² and progress against the ICC-MM indicators related to this (E3.1, E3.2, E5.2) showed commitment to this role. Progress in relation to establishing written guidelines (E1.1) and patient involvement in research (E4.2) was not significant, again perhaps indicating that immediate service demands were a greater priority.

Limitations of the case study approach centre largely on generalisability of findings. Circumstances surrounding this study were unusual, if not unique, with the appointment of nine CGNs to ICC services at different levels of maturity and some inconsistency of the specified roles of the CGNs. Reliance on self-assessment could have introduced bias, since revealing limited progress might have prejudiced further funding. However, the researcher's site visits, interviewing and reviewing evidence, counterbalanced this potential.

The sample was small, therefore results should be treated with caution and firm conclusions cannot be drawn. Furthermore, each CGN worked as part of a multidisciplinary team and, although seen as catalysts for development, progress cannot be ascribed solely to their efforts. However, we believe the ICC-MM captured the general direction of service improvement and the accompanying narratives indicated the CGNs' contribution to this.

Although CGN roles and ICC services were not identical, there were common features, including challenges,

such as in raising awareness of the service and, paradoxically, coping with increasing demand. The application of the primary care MM across Europe assumes practices have common characteristics, develop along similar pathways and quality improvement processes are linear so levels can be defined at stages along a pathway.²³ We believe the ICC-MM developed in this study has relevance to ICC services in the UK and internationally. However, account must be taken of the context, with a rigorous approach to translation and training to ensure MM concepts are interpreted and applied consistently.¹⁶

We believe this is the first study to use a MM to evaluate ICC service development. Although the NHS National Service Framework outlined the services needed for families at risk of sudden cardiac death,¹⁴ detail to inform commissioning was not available until 2010.²⁴ The commissioning guide does not capture how ICC services might evolve although components show consistencies with ICC-MM domains and descriptors. We suggest that as well as marking progress, the ICC-MM provided a framework to inform service development targets and could be of value to cardiac nurses in other centres nationally and internationally who are involved in developing ICC services, although the engagement of the whole ICC team with this is important.

The integration of genetics and genomic technologies into medical specialisms like cardiology has been proposed as the future paradigm, with professionals developing expertise in the genetics aspects of the specialty and close relationships with genetics specialists an essential element of reconfigured services.¹³ In this context, the appointment of a cohort of CGNs to help develop ICC services provided an opportunity to explore their contribution to this evolving paradigm. The findings suggest that, after appropriate genetics training, cardiac nurses can apply their new knowledge and skills successfully to help integrate care across the two specialisms, facilitating the development of effective and sustainable ICC services at new, developing, and more established ICC service locations. Having a firm grasp of genetics knowledge and skills applied to their specialist area will also provide these cardiac nurses with a foundation on which to build as the new genomics paradigm gradually unfolds.

Implications for practice

- Cardiac nurses gaining additional skills in genetics can play a valuable role in integrating services across specialties.
- The ICC-MM may provide a useful framework for cardiac nurses involved in developing ICC services.
- Genetics is of relevance to cardiac nurses; relevant knowledge and skills in this field provides a foundation for integration of genomics advances as they impact on healthcare.

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Conflict of interest

The authors have no conflict of interest to declare.

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