Clinical practice in medical genetics

Contracting for clinical genetic services: the Welsh model

H E Hughes, J K Alderman, M Krawczak, C Rogers

Abstract

In a time of increasing competition for clinical services resources, it is imperative that health professionals actively participate in the commissioning process in order to ensure that established clinical standards are not compromised. Introduction of the NHS reforms in the UK in the early 1990s highlighted the difficulties in contracting for a specialised service such as clinical genetics, especially in the absence of a consensus regarding the contract currency. An average block contract price for each new family referred was introduced in Wales in 1992, and data from the subsequent five years show that this charging system is economically feasible and has the advantages of (1) recognising the contribution to care of non-medical personnel on the genetics team, (2) covering follow up including the counselling of relatives, (3) protecting the service from loss of income owing to non-attendance, and (4) providing a basis for negotiation when new services are being proposed to purchasers. Activity data show that while the majority of conditions incur below average cost, the mean cost is influenced by a small number of autosomal dominant and X linked disorders. The cost risk to the provider for seeing families over an extended period is minimal, as the data establish that family files experience an exponential decrease in activation probability over the early years, but this becomes constant later on. The robustness of the system is dependent on accurate baseline data on referral patterns to the

service, recording of activity, and staff costs.

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Clinical services face increasing competition for resources in virtually all countries. The "purchaser", be it government, health insurer, or private client, justifiably demands accurate accountability for any financial transfer. In the United Kingdom, changes in the NHS organisation in the early 1990s introduced a "purchaser/provider" split, which included general practitioner purchasing via fund holding, and these changes have highlighted the potential difficulties in contracting for a specialised regional service such as clinical genetics.

Unlike most other hospital based specialties, clinical genetic consultations or "patient episodes" usually deal with families (proband, consultands, and extended relatives) as opposed to individual people. Furthermore, the length of face to face contact hardly ever reflects the time and effort taken to address the families' concerns,¹ and the contribution to care by specialist nurses and genetic associates is not normally recognised as a chargeable outpatient service. Therefore contracting for clinical genetics poses particular problems, especially as there is no general consensus regarding the contract currency, and levels of manpower and the patterns of service delivery vary substantially between centres.² In the UK, this situation has forced each of the regional genetic services to develop and agree with the purchasers its own method of commissioning and contracting. In this paper, we present the contracting system introduced in Wales in 1992. Data from the subsequent five years show that the Welsh contracting system is both economically viable and cost effective to administer.

Contract currency

The clinical genetic service in Wales (population 2.9 million) was established in Cardiff, the regional centre, in 1970, with continuing development of outreach services and locally based nurse specialists (co-workers) from the early 1980s (fig 1). All standard counselling

Institute of Medical Genetics, University of Wales Healthcare NHS Trust, Heath Park, Cardiff CF4 4XW, UK
H E Hughes
J K Alderman
M Krawczak

North Wales Health Authority, Mold, Flintshire, UK
C Rogers

Correspondence to:
Dr Hughes.

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Table 1 Wales clinical genetic services staff (whole time equivalent) 1996-1997

	Centre	Outreach
Medical		
Consultants*	3.8	0
Trainees	3.5 (+1 research funded)	0
Clinical assistants	1.2	1.0
Nurses/co-workers†	4.5	9.5
Administration		
Manager	0.5	0
Secretaries	5.0	1.5
Computer officer	1.0	0

*66% of required staffing level (2 wte/million) - Royal College of Physicians' Report 1996.²

†Fulfilling staffing requirement (4 wte/million) - Royal College of Physicians' Report 1996.²

Figure 1 Map of Wales to show location of outreach services and boundaries of five purchasing districts.

and diagnostic services are provided³ with the exception of prenatal genetic assessments at a population level (screening), teratogen information, and the acute management of metabolic disorders. The increasing demand for

services related to breast cancer has been addressed through research funding and therefore is excluded from the data in this paper.

The direct regional funding status of the service was discontinued in 1992 and responsibility for purchasing was passed to nine District Health Authorities, later reduced to five, each covering a population ranging from approximately 470 000 to 715 000. In common with the data collected for the Report of the Royal College of Physicians 1996,⁴ the referral rate to the clinical genetic service in Wales in the early 1990s was 350–400 new families/million/year, with an approximate follow up rate for clinic consultations of 50%. It was agreed with each of the purchasing health authorities that the contract currency would be the cost for each new family referred, irrespective of the diagnostic category. This contract currency has the advantage of (1) recognising the contribution to care of non-medical personnel on the genetic team, (2) covering continuing follow up including counselling extended family members, and (3) protecting the service from loss of income owing to non-attendance at clinic. Furthermore, the price includes only a minimal administrative charge, provided that activity data are accurately recorded by the clinical staff. Charges for laboratory (molecular and cytogenetic) services are not included as these are contracted for separately.

In order to determine the cost per unit of contract currency, the total baseline cost (95% being staff cost, table 1) of the clinical genetic service at the time of loss of regional status in

Table 2A Activity profiles, costs – medical consultations (M)

Code	Activity	Cost
A	First visit, new referral. Includes data gathering, taking/reviewing family pedigree, frequently physical exam, interpretation of data, counselling, letters	1.0 unit M
B	Complex follow up, includes relatives Family seen for further counselling following investigations. Includes relatives for discussion of genetic implications of same condition in them	0.5 unit M
C	Re-referral 1st visit of "known" family Family not in follow up system (discharged) but re-referred with same disorder. Includes review of information, counselling, etc	0.5 unit M
D	Simple follow up Usually short follow up visit not requiring much in the way of preparation	0.3 unit M
E	Supervising consultation by senior staff. Where a "senior" physician has face to face contact with a family primarily managed by a "junior" colleague	0.3 unit M
F	Written report, no direct patient contact Clinical interpretation of lab data, counselling information when report submitted in writing. No patient contact	0.3 unit M
NAN	Non-attendance new	0.3 unit M
NAF	Non-attendance follow up	

Table 2B Activity profiles, costs – specialist nurse/co-worker (N)

Code	Activity	Cost
A	First visit, new referral. First face to face contact. Includes data gathering, taking family pedigree, assessment of needs and priorities, consent for records	1.0 unit N
B	Complex follow up Usually contact when family seen for further counselling, reinforcement of information obtained in clinic. Includes counselling of relatives, support, and bereavement counselling	1.0 unit N
C	Nurse managed, not seen by doctor Nurse assumes prime responsibility for face to face contact, counselling, and letters	1.0 unit N
D	Simple follow up Usually brief contact for venepuncture, arranging other forms of testing. Excludes formal counselling	0.5 unit N
E	Sitting in on clinic consultation	0.2 unit N
F	Written report, no direct patient contact as for F in medical consultation table	0.3 unit N
NAN	Non-attendance new	0.3 unit N
NAF	Non-attendance follow up	

Table 3 Audit activity: computerised data

Family genetic number
Date of first referral of new family
Date seen
Speciality of referring physician (eg paediatrics)
Name of purchasing district
Name of geneticist/co-worker generating activity
Activity code (see table 2A, 2B)
Where seen (either centre, outreach clinic, in patient, or home)
Type of clinic (general or speciality)
Clinic speciality (eg neurogenetics, dysmorphology, muscle)
Selected diagnostic category: HD, CF, NTD, etc

1992 had to be agreed with all the purchasers. The extrapolated cost for each new family was derived from dividing the total cost of the service at that time by the number of new families referred to the service in the previous financial year. Together with the purchasers, measures of activity were determined in order to allow accurate accountability for the clinical services provided to each family (table 2A, B). Since it is neither practical nor cost effective to identify all telephone calls and enquiries related to a given family, these data are not coded in the activity profile. However, for purchaser information, a representative work week is selected periodically by each health professional during which all telephone calls and their duration are recorded.

A computerised work activity profile was devised for completion by all health care professionals involved in the delivery of care (table 3). Each activity code (table 2A, B) was accurately priced (different cost unit for physicians and co-workers) so that the total cost of activity to all families during the financial year was equal to the actual cost of the service. In addition to measuring activity, this computer program can be used to record other data (for example, the purchasing district, source of referral, waiting time for new referrals, diagnostic category), which allow different types of clinical activity to be related to each family referred, and comparison of demand associated with specific genetic disorders, such as

Table 4 Proportion of active files under two models of file reactivation: the Welsh data

Year	Observed	Model A	Model B
Outreach			
7	0.266	0.185	0.282
8	0.253	0.185	0.263
9	0.258	0.201	0.270
10*	0.223	0.161	0.230
Centre			
22	0.090	0.092	0.091
23	0.097	0.101	0.097
24	0.098	0.097	0.097
25*	0.100	0.098	0.096

*Data not included in regression analysis.

Model A: constant annual activation probability, independent of age.

Model B: exponential decrease in activation probability with time.

Huntington's disease, muscular dystrophy, cystic fibrosis, etc (fig 2).

Risks to purchaser

With a block contract of the above nature, one of the main risks to the purchasers is payment for services which are not actually delivered. Therefore, confidence is required that the average cost per family referred is accurately represented by the contract price and that the activity generated is appropriate for a given family. Fig 2 shows that, while the majority of conditions incur below average price, the mean cost is influenced by the significant demand on resources of a small number of key genetic disorders (Huntington's disease, muscular dystrophy, and other similar autosomal dominant and X linked disorders). These conditions occasionally present with an extensive family history and a large number of at risk relatives. Although purchasers could decide to contract by disease category, this would be a disadvantage to both purchaser and provider: administrative costs could increase and, since referrals of cost intensive families are difficult to predict, uncertainties in budget planning and setting

Figure 2 Disease cost profiles, 1993-1997.

Figure 3 Active files proportionate to accumulated files, 1993/1994-1996/1997.

would result, especially when the population covered by an individual purchaser is relatively small.

Risks to provider

The main risk to the provider is the responsibility for follow up which may involve care for extended family members over long periods of time, sometimes even a generation. Families are not discharged, they become "inactive". Therefore, the service provider has to estimate carefully the probability of a file being reactivated, and the contract price has to take into account the proportion of follow ups in any one financial year. Various mathematical relationships can be presumed to hold between the age of a file and the probability of the file becoming active in a given year. Knowledge of this relationship would allow both purchasers and

providers to make reliable predictions about the work load expected from reactivated and newly opened files. Fig 3 shows the ratio between the active files in any one year and the accumulated number of files generated by a clinical genetic service over time. Data from three outreach clinics established in 1987/1988 are compared to data from the centre established in 1971/1972, and two mathematical models have been explored in more detail for these data (see Appendix). Model A assumes a constant annual activation probability, independent of age, while model B assumes an exponential decrease in activation probability with time. Over short periods of time, model B is by far more likely to be correct, but model A appears to perform equally well over longer time periods (table 4). Therefore, it may be that a combination of both models would be most meaningful, with activation probability decreasing exponentially up to a certain age of a file and staying constant thereafter.

With a referral rate of 350-400 new families/million/year, as observed over the past five to six years, and an overall medical consultation follow up rate of approximately 50%, average costing per new family referred can sustain follow up in a kindred with multiple affected relatives. Furthermore, despite a highly significant variability in the activity profiles, as shown for Huntington's disease, cystic fibrosis, neural tube defects, and the muscular dystrophies (fig 2), average costing for a new family referred is sensible since the relative distribution of work activity per year by disease has been fairly constant (table 5).

A further concern for the provider could be that, with a fixed population base, linking families together with time would lead to a net decrease in the number of new families referred. However, this theoretical possibility is unlikely to have a significant impact on income in practice, especially since clinical genetic services over the next 20 years are likely to face overwhelming and increasing demand from families with complex disorders.

Discussion

In a time when the demand for medical care has outstripped the available resources, it is imperative that health professionals actively participate in the process of commissioning in order to ensure that established clinical standards are not compromised. Without their involvement, it is inevitable that costing mechanisms will be introduced by governments or other agencies who may not be acquainted with the complexities of a highly specialised service such as clinical genetics. Since care is delivered to families rather than to individual people, clinical genetics does not fit traditional schemes of activity measurement and costing.

In partnership with the purchasers, the contracting system devised in Wales is simple to administer and provides the purchasers with a detailed breakdown of most clinical activities. It also makes transparent how the average cost per new family referred (the contract currency) is determined, and eases negotiation when new

Table 5 Work activity (% of total) by disease (physicians and co-workers combined)

	93/94	94/95*	96/96*	96/97*
Xp21 muscular and myotonic dystrophy	14.5	11.0	10.5	11.8
Cystic fibrosis	3.0	2.9	2.6	2.5
Huntington's disease	10.1	12.3	10.5	9.4
Neural tube defect	2.1	1.4	0.7	1.0
Total	29.7	27.6	24.3	24.7

*The increasing demand for genetic services for breast cancer has been addressed through research funding and therefore is not included in the above activity data. Breast cancer will be costed as a new service in the 97/98 financial year.

clinical services are being considered. The robustness of the system is dependent on accurate baseline data on referral patterns to the service, staffing requirements, and costs.

This method of costing clinical components of genetic services was implemented in Wales in 1992, and experience over the past five years suggests that it is satisfactory to both purchasers and providers. The model shows that it is equal to the task of transforming a complex process into one that is relatively simple and one in which the purchasers can have confidence. The key determinants to the success of the model depend on outcome data and these now will have to be addressed. Challenges to the contracting method will emerge over the next few years when new services, such as those for breast cancer and other complex disorders, will be proposed to purchasers. However, in Wales there is now a firm basis established for future negotiation.

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Appendix

Two mathematical models have been explored in more detail for the Welsh data on clinical genetic file activation. Model A assumes a constant annual activation probability q , independent of age, while model B assumes an exponential decrease in activation probability, that is, $q(i)=q^i$ where i denotes age in years. If a referral rate of r_k is assumed for time period $i(k-1)$ to $i(k)$, $k=1, \dots, m$, $i(0)=0$, $i(m)=n$, then the number of active files in year n is

$$(1) (1-q) \cdot r_m + q \cdot \sum_{k=1}^m r_k \cdot [i(k)-i(k-1)]$$

for model A, and

$$(2) q^n \cdot (1-q)^{-1} \cdot \sum_{k=1}^m r_k \cdot [q^{i(k)} - q^{i(k-1)}]$$

for model B. Regression analysis was performed for equations (1) and (2), using the data depicted in fig 3. To this end, constant annual referral rates were assumed for the starting periods 0 to 7 years (outreach) and 0 to 22 years (centre), respectively, while the final years (10 and 25) were not included in the regression analysis. Least squares estimates of q were $q=0.048$ for model A and $q=0.496$ for model B. Percentages of active files predicted by the two models are summarised in table 4.