

An Overview of Cancer Genetics Services in New South Wales

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AN OVERVIEW OF CANCER GENETICS SERVICES IN NEW SOUTH WALES

1. Introduction to Cancer Genetic Services in NSW

Knowledge surrounding the hereditary basis of cancer has improved rapidly over the past 10 years with the identification of faulty genes which increase a person's risk of developing certain types of cancer (eg breast, ovarian, bowel). While inheriting one of these faulty genes does not automatically predict that a person will develop cancer, it does increase the risk substantially. Knowing that a person is at a higher risk allows for increased surveillance or risk-reducing treatment.

The general role of cancer genetics services is to support individuals who have an increased risk of cancer. The services help individuals understand their personal risk status, their options for cancer risk management, and to explore feelings regarding their personal risk status. Counselling focuses on obtaining and giving information, promoting autonomous decision making and facilitating informed consent if genetic testing is pursued.¹

In July 2006, the Cancer Institute NSW, supported by the New South Wales Oncology Group – Cancer Genetics, conducted a review of the cancer genetic services in NSW. The aim of the review was to provide information and baseline data about the current cancer genetic services that people at risk of familial cancer are able to access in NSW.

This paper provides a brief summary of challenges and issues facing cancer genetics services in NSW; and includes key data and information that will help identify demand for cancer genetics services, prioritise needs and inform the basis of future program development in this area.

2. Methodology

Data items were collected using a three-pronged approach:

- *A written questionnaire asking about each service's characteristics.* These were completed by the director of each service.
- *Semi-structured interviews regarding participants' views on their roles and services.* Qualitative information regarding participants' views on their roles, their services and the broader Cancer Genetics system was obtained through from key members of the Family Cancer Clinics, general outreach genetic counsellors, molecular genetics laboratories, the Hereditary Cancer Registry and the Centre for Genetics Education.
- *A written questionnaire regarding service provision at each of the Family Cancer Services and laboratories for 2005 and 2006.* Services were asked to provide information on numbers and types of patients, occasions of service, and laboratory tests ordered. They were also asked about the Area Health Service of residence of those who attended their services.

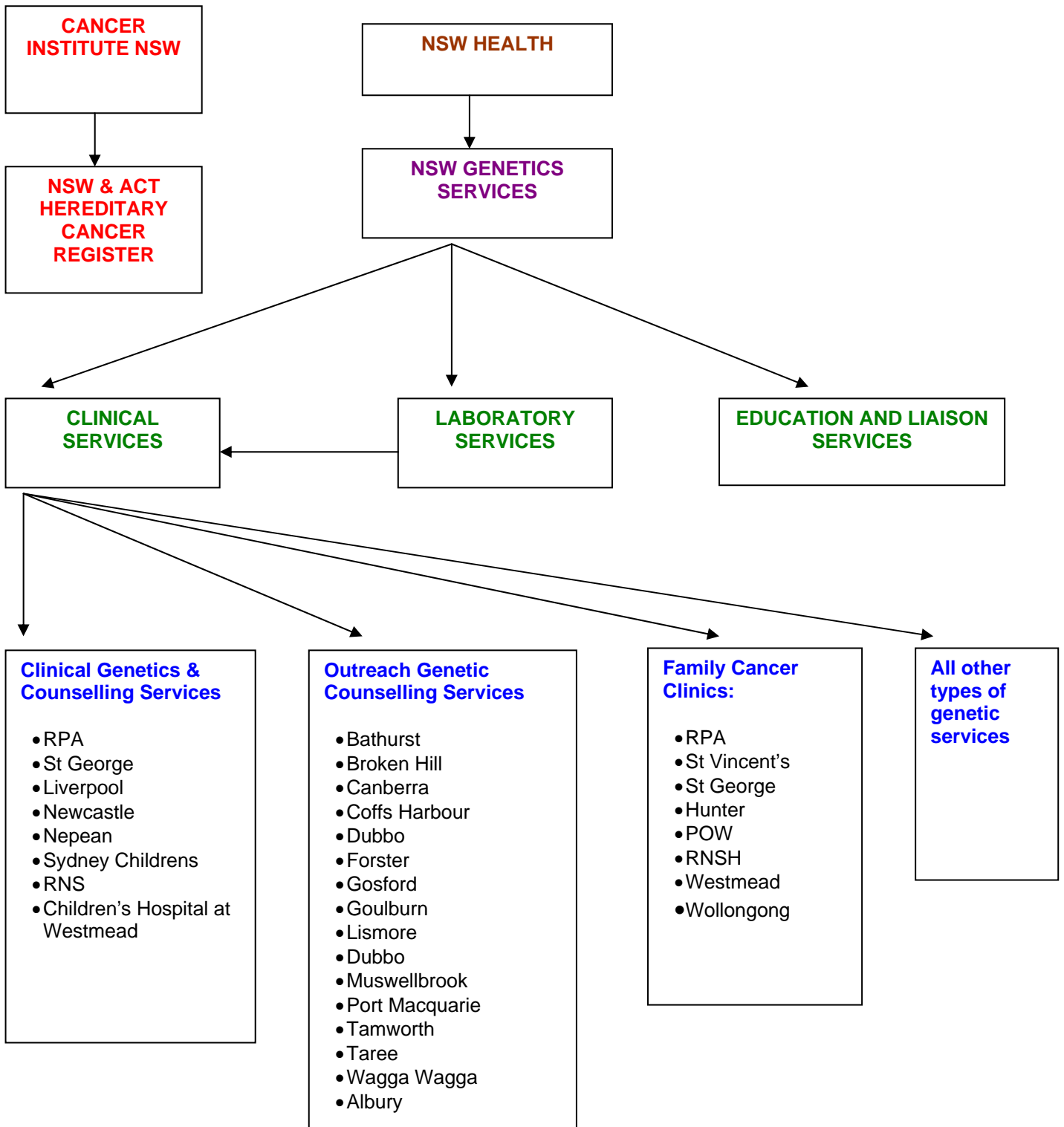
¹ National Cancer Institute. Retrieved from website 19 December 2008.

<http://www.cancer.gov/cancertopics/pdq/genetics/risk-assessment-and-counseling/HealthProfessional>

A service-level model was created, which places Cancer Genetics Services in a broader context within NSW Genetics Services and NSW Health. Figure 1 illustrates the different types of services involved in providing family cancer services in NSW.

Family Cancer Services are part of NSW Health’s statewide Genetics Service, and are supported by three molecular genetics laboratories, Area Health Service-level pathology laboratories, the Hereditary Cancer Registry, and the Centre for Genetics Education.

Figure 1: Cancer Genetics Services in NSW



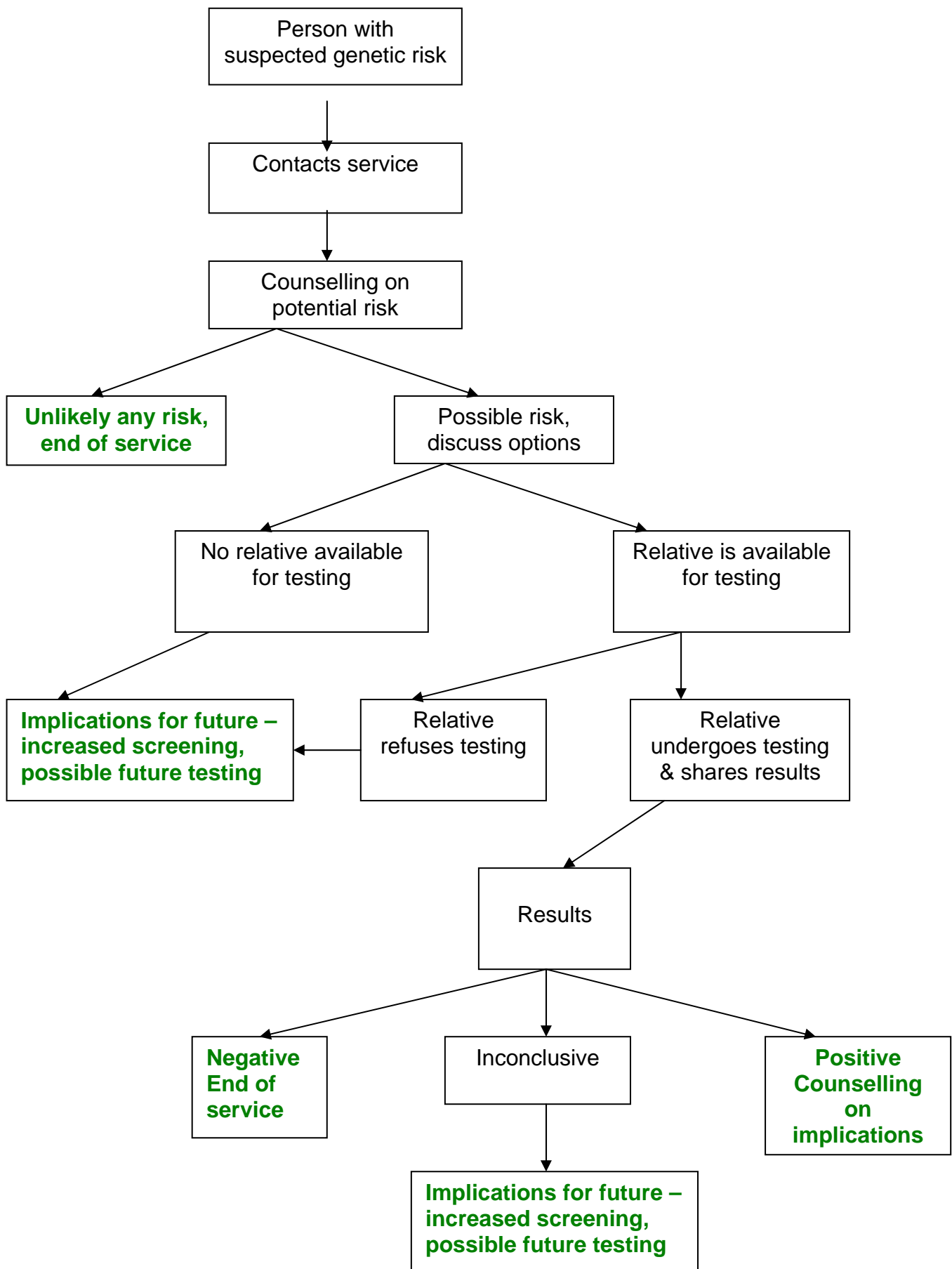
3. The Cancer Genetics Patient Journey

The review identified a number of ways that a patient may interact with cancer genetic services. Figure 2 shows the journey from the perspective of a person with a suspected genetic risk for cancer. It demonstrates the complexity in navigating the system and the factors that may impact on the pathway undertaken.

The major factors identified as impacting upon the service received were:

- The knowledge level of the person, their family and General Practitioner will determine whether a referral to cancer genetics services is considered.
- Where the person lives, where services are provided and the knowledge and links of the referrer with a service will determine which service a person accesses. This may be outside the Area Health Service of residence.
- Staffing levels and composition will determine the waiting time to receive services and the discipline providing the service.
- The availability and willingness of a relative to be tested will determine whether testing is undertaken or evidence-based screening guidelines and risk reduction strategies are provided.
- The resourcing of laboratories will impact on the waiting time for results.

Figure 2: Conceptual Framework – Perspective of Person with Suspected Genetic Risk



4. Statistics

The review collected a range of data on the numbers and types of patients using Cancer Genetics Services, those employed in Cancer Genetic Services, and the number and types of cancer genetic tests ordered.

For the following tables the number of employees in NSW Cancer Genetic Services is current as at 2007, while all other data are 2005 and 2006 figures.

Table 1: NSW Genetic Cancer Services Staffing

Occupation	Full-Time Equivalents	Head Counts
Senior Clinicians	4.95	8 (7 senior, 1 fellow)
Genetic Counsellors	9.6	11
Administration	4.1	5
Data Managers	1.6	3
TOTAL	20.25	27

There are five dedicated Family Cancer Services staffed onsite by senior clinicians and genetic counsellors, along with two dedicated Family Cancer Services staffed by genetic counsellors with senior clinician support. The cancer genetics workforce included seven senior clinicians, 11 genetics counsellors, five administrative positions, and three data managers. Table 1 provides details of the full-time equivalents for each of these groups.

Table 2: NSW Genetic Cancer Services Patient Profiles

Patient Group	2005	2006	% Change
New patients	1110	1186	6.8
New family members	532	515	-3.2
Patients return/follow up	890	1148	29.0
TOTAL	2532	2849	12.5
Breast / Ovarian Cancers	1143	1284	12.3
Bowel Cancers	642	589	-8.3
Other Cancers	161	183	13.7
TOTAL	1946	2056	5.7

The seven Family Cancer Services in NSW saw 2,532 patients in 2005 and 2,849 patients in 2006. More than 1,100 of those patients in each year were new to the service, and just over 500 new family members of patients who had already been seen by the service, with the remainder of patients returning for follow-up. The per cent of patients in each Family Cancer Service who come from within the Area Health Service varied from a low of 41 per cent to a high of 90 per cent, depending upon the service and the year.

In 2006, the majority of patients presenting to the Family Cancer Services were concerned about breast/ovarian cancers (62 per cent), followed by bowel cancer (29 per cent), and other cancers (8 per cent).

Table 3: Time Spent on Patient Contacts

		Mean (mins)	Min (mins)	Max (mins)
Genetic Counsellors				
Intakes		45.7	5	120
First Clinic	Face to face	47.1	15	120
	Telehealth	41.3	10	60
Follow Up	Face to face	41.3	10	120
	Telehealth	42	20	60
	Telephone	20.7	10	75
Senior Clinicians				
Intakes		28.3	15	60
First Clinic	Face to face	42.4	15	120
	Telehealth	49.7	15	85
Follow Up	Face to face	39	5	120
	Telehealth	36	14	60
	Telephone	21.3	10	60

In 2005, the Family Cancer Services had a minimum of 4385 occasions of service, including: telephone calls; formalised intakes; face-to-face and telehealth clinic consultations; ward visits; and counselling. That number increased to 5,194 in 2006.

The average time spent on an intake by genetic counsellors was about 45 minutes, with some intakes taking as long as two hours. The intakes included everything from brief conversations reassuring people at average risk, to counselling those at high risk. Some services include an education session as part of the intake process. Depending on the service, most intakes are conducted by telephone, while others are done face-to-face. On average, senior clinicians who undertake their own intakes spend less time on them than genetic counsellors.

Time spent on first consultations averaged between 40 and 50 minutes for both genetic counsellors and senior clinicians, with follow-up visits/telehealth consultations slightly shorter for senior clinicians. Average follow-up telephone consultations lasted about 20 minutes.

Table 4: Cancer Genetics Service Referral Sources

Patient Type	Referral Source	2005	2006	% Change
Patient	GP	28.2	26.6	-5.7
	Specialist/Other Health Professional	61.9	62.4	0.8
	Self Referred	9.9	10.9	10.1
Family	GP	36.6	41	12.0
	Specialist/Other Health Professional	20.9	30	43.5
	Self Referred	42.6	29	-39.9

The majority of new patients were referred to the Cancer Genetics Service by either a specialist or other health professional in both 2005 and 2006. The referral pattern for family members changed from a majority of self referrals in 2005 to a majority of GP referrals in 2006.

Table 5: Laboratory Tests Ordered

	2005	2006	% Change
Mutation search	486	556	14.4
Predictive tests	311	309	-0.6
Limited search	30	33	10.0
TOTAL	827	898	8.6

The services arranged for 827 genetic tests in 2005 and 898 genetic tests in 2006. The majority of these tests (~60 per cent) were genetic mutation searches, with the remainder predictive and limited searches.

5. Qualitative Findings

Analysis of the interviews with Cancer Genetics Staff yielded a number of key themes relating to Cancer Genetics Services across NSW.

General themes

- Services have developed on the basis of clinical interest, perceived need and the availability of funding.
- The current workforce appears low relative to the identified and future demand.
- While each service operates differently, all face similar constraints.
- Clarification is required around whether cancer genetics services should be part of general genetics services or cancer services.
- The distribution of services across NSW is inequitable.
- Laboratory testing is costly and time consuming.
- The role of the Hereditary Cancer Registry needs further definition.

Key themes relating to the specific cancer genetics disciplines

Senior clinicians raised the following concerns:

- The small nature of the field of cancer genetics services created feelings of isolation.
- There are limited training and job opportunities for upcoming senior clinicians.
- The availability of relief to cover staff leave is limited.
- The potential for burnout is high.

Genetic counsellors raised the following concerns:

- Advancement opportunities within Cancer Genetics Services are not defined.
- Pay scale award differences exist between disciplines.
- Roles and responsibilities vary across services.
- The potential for burnout is high.

Strengths identified

In reviewing Cancer Genetic Services in NSW a number of strengths were identified:

- The Cancer Genetics workforce is highly qualified and dedicated to evidence-based practices within their services.
- In general, the relationships between staff members within the services, as well as between the services, are highly collegial.
- Cancer Genetics staff members have made significant contributions to research, and continue to translate those research findings into improved practices for their patients.
- Working within multidisciplinary teams, they provide much needed expertise and assistance to those people with suspected or identified risks of familial cancer.

The further development of Cancer Genetic Services will enable staff to deliver those services to a likely increased number of future clients in a more supportive environment.

6. Future Directions

Based on the findings of this report, the Cancer Institute NSW is currently planning to undertake a number of activities to further develop Cancer Genetics Services in NSW. These activities will be undertaken in conjunction with stakeholders and include:

Development of a Cancer Genetics Statewide Services Plan

Options will be developed for an evidence-based structure for statewide Cancer Genetics Services (clinical and laboratory) that will meet current and future demand, be accessible to all potential clients across the state, and be timely and cost-effective. The strategy will give appropriate consideration to the critical dependence of the provision of safe and high quality cancer genetics services on an adequate and well trained workforce.

Building an Appropriate Workforce

Strategies will be developed to grow capacity in the NSW cancer genetics workforce. This will include consideration of the numbers of positions required to meet future demand (clinical and laboratory), the development of appropriate training pathways for cancer geneticists and counsellors, training, career opportunities and pathways, and equitable employment awards for counsellors including pay and responsibilities. An assessment will also be made of other barriers to developing capacity in the cancer genetics workforce, particularly funding of training, education and positions.

Development of an Appropriate Patient Management System

It is anticipated that, in conjunction with the NSW Department of Health, one database in which all services could input data will be established. This would increase the ease of use and reliability of the data collected. If consent issues are overcome, a centralised database could reduce unnecessary duplication.

Review of the Hereditary Cancer Registry

The Hereditary Cancer Registry has the potential to be an enormous support to the Family Cancer Services in NSW with both a clinical and research role. A review of the registry will be undertaken to clearly define its role.

The ultimate objective of the above activities is to further the development of cancer genetics services to enable staff to deliver services to the increasing number of clients in a more supportive environment.