

Dr Cynthia Lean¹, Ms Catherine Bullivant¹, Dr Deanna Pagnini², Ms Elizabeth Tracey¹, Ms Anthea Hepburn¹, Ms Sue Sinclair¹, Prof James Bishop¹

¹Cancer Institute NSW, ²Consultant

AIM

The aim of this review is to support Program 18.2 of the NSW Cancer Plan (2004-2006) by providing information and baseline data about the current Cancer Genetics Services that people at risk of familial cancer are able to access in NSW. The review will provide information to the Cancer Institute NSW that will help it identify key trends, prioritise needs, and inform the basis of future service development in NSW.

DATA AND METHODS

Data were collected using a three-pronged approach:

1. A written survey asking each Service about its characteristics and staffing levels. These were completed by the Service Director.
2. Qualitative information regarding staff views on their roles, their services, and the broader Cancer Genetics System obtained through a series of semi-structured interviews with key members of the Family Cancer Clinics, General Outreach Genetic Services, Pathology Laboratories, the Hereditary Cancer Registry, and the Centre for Genetics Education.
3. 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.

FINDINGS AND DISCUSSION

Participation

A total of 27 interviews were conducted including staff from:

- Every Family Cancer Service
- Three Pathology Laboratories:
 - HAPS (Hunter Area Pathology Service)
 - SEALS (South Eastern Area Laboratory Services)
 - Westmead Hospital
- Hereditary Cancer Registry (HCR)
- Centre for Genetics Education
- Three of the Rural Outreach Genetic Services

Location of Cancer Genetics Services and Incidence of Cancer

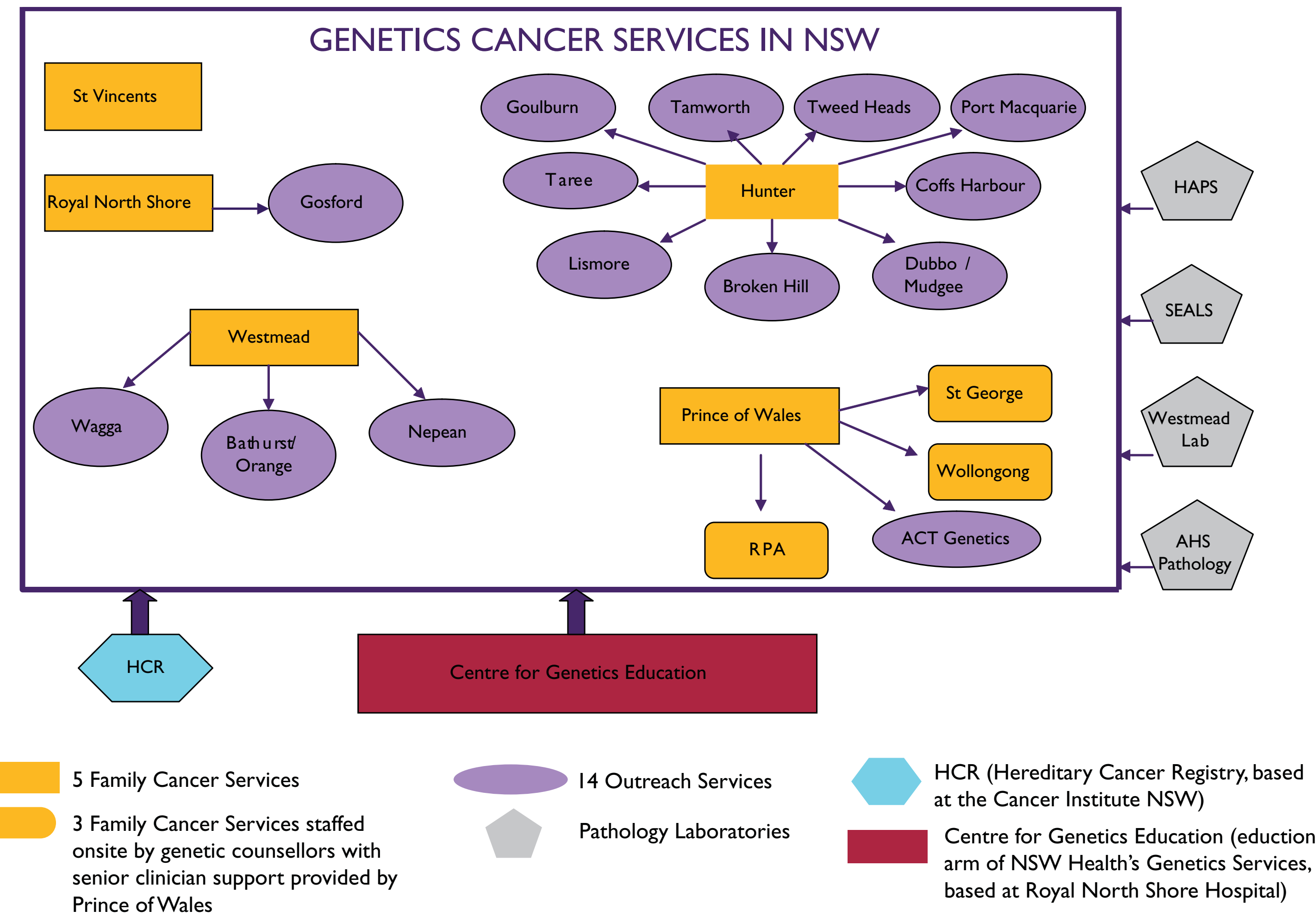
FIGURE 2: Cancer genetics services and incidence of breast and bowel cancer in NSW

AREA HEALTH SERVICE	BREAST	BOWEL	CANCER GENETICS SERVICE(S)
Sydney South West	690	652	RPA
SESAHS	713	809	POW, St Vincent's, Wollongong, St George
Western Sydney	553	493	Westmead, Nepean
Northern Sydney Central Coast	827	812	RNS, Gosford
Hunter New England	432	657	Hunter, Tamworth, Taree
North Coast	415	538	Lismore, Coffs Harbour
Greater Southern	290	397	Wagga Wagga
Greater Western	209	397	Orange/Bathurst, Broken Hill
Total	4124	4611	

Figure 2 compares the location of Cancer Genetics Services and the incidence of breast and bowel cancers (the two cancers with 5-10% known genetic components).

Profile of Cancer Genetics Services in NSW

FIGURE 1: Genetics Cancer Services in NSW



The Cancer Genetics Workforce

The Cancer Genetics workforce includes:

- 7 senior clinicians (4.15 FTEs), 1 clinical fellow
- 10 cancer-specific genetic counsellors and 11 regional general genetic counsellors
- The counsellors cover the majority of workload including a reported 25-45% of patient administration, attendance at multidisciplinary team meetings and data collection
- Data managers and administrative support are able to provide only a low level of support.

Service Provision

FIGURE 3: Service Provision – Family Cancer Services

CATEGORY	2005	2006
Number of patients seen	2797	3168
Number of occasions of service	4384	5193
Laboratory tests:		
- Mutation searches	491	557
- Predictive searches	311	309
% by type of cancer:		
- Breast/ovarian	62.1	60.1
- Bowel	31.2	33.7
- Other	6.7	6.4
% patients presenting at Family Cancer Service with AHS of residence	65.8 (41.7–90.3)	64.1 (40.8–78.8)

NB: Numbers in Figure 3 are preliminary and do not take into account 100% of the services

- Prince of Wales, Hunter, and Westmead services saw the highest number of patients.
- The percent of patients in each Family Cancer Service who come from within that AHS was from 41%–90%, depending on AHS and year.
- The extent to which people stay within their area varies by:
 - geographic availability of services
 - personal preferences
 - referral patterns
- Patient numbers by themselves misrepresent the amount of work and actual patient contact the services provide.

Themes and Structural Issues

Overall themes:

- Services have developed on the basis of clinical interest, perceived need and where funding has been available.
- The current workforce is low relative to the identified and growing demand.
- While each service operates differently, all face similar constraints.
- The evidence base and emerging need is expanding rapidly
- Where Cancer Genetics is further developed needs to be defined, i.e. as part of General Genetics or Cancer Services

Structural issues:

- Variable distribution of services in NSW
- Staffing and funding levels low for developing demand
- Continuing role of the Hereditary Cancer Registry needs to be well defined

Issues related to the nature of Cancer Genetics

- Amount of non face-to-face work including Multidisciplinary care meetings, research, committee work, records searches and data entry
- Data and privacy issues including different databases, an inability to share data due to privacy constraints and different definitions and a lack of resources

Service Implications

PATIENTS	SENIOR CLINICIANS	GENETIC COUNSELLORS
Inequity of access	Isolation (little peer support)	No defined career ladder
Extended waiting times for appointments and results	Limited training	Pay scale award inequities
Inadequate follow-up	Limited relief	Roles and responsibilities spread widely
The need for retesting as information is not shared	Potential for burn-out	Potential for burn-out

CONCLUSIONS

- ⇒ Using both quantitative and qualitative data, this review has summarised Cancer Genetics Services in NSW including distribution of services and workforce.
- ⇒ Collaboration between the Cancer Institute NSW; NSW Oncology Group Cancer Genetics, State-wide Services, NSW Health and the Hereditary Cancer Registry will ensure optimal development of an effective and coordinated state-wide strategy.