Biobank recruitment in head and neck cancer patient cohorts: Culturally and linguistically diverse (CALD) considerations

Joseph W. Po [1,2,3,5], Anshuli Razdan [2,3], Tanzila Khan [2,3], Hei Lan Byun [6,10], Tony Pang [2,7,8], Fred Azimi [2,5,9], Nicole Caixeiro [1,2,3], Cheok Soon Lee [1,2,4,6]

[1] Centre for Oncology Education and Research Translation (CONCERT) Biobank, 1 Campbell St, Liverpool, 2170, NSW, Australia; [2] Ingham Institute for Applied Medical Research, 1 Campbell St, Liverpool 2170, NSW, Australia; [3] Western Sydney University, School of Medicine, Campbelltown 2560, NSW, Australia; [4] Discipline of Pathology, Western Sydney University, School of Medicine, Campbelltown 2560, NSW, Australia [5] Ingham Melanoma Skin Research Centre (IMSRC), Ingham Institute for Applied Medical Research, Liverpool 2170, NSW, Australia; [6] Department of Medical Oncology, Liverpool Hospital, Liverpool 2170, NSW, Australia; [7] University of New South Wales, School of Medicine, Kensington 2052, NSW, Australia; [8] Pancreatic Research Group, South West Clinical School, University of New South Wales, Liverpool 2170, NSW, Australia; [9] Department of Surgery, Liverpool Hospital, Liverpool 2170, NSW, Australia; [10] Department of Head and Neck Surgery, Liverpool Hospital, Liverpool 2170, NSW, Australia

Background

Biobanks have become a recognized research support tool, facilitating the acquisition of biomaterials for researchers and improving research engagement between researchers and clinical/surgical teams. However, many barriers to recruitment exist including logistical issues and importantly culturally and linguistically diverse (CALD) status of patients.

Head and neck cancer patients were screened for Biobank suitability and approached by clinical or Biobanking staff for informed consent. In total, 338 head and neck cancer patients were recruited between 2017-2018, and a questionnaire completed detailing nationality, country of birth and language spoken at home. Patient clinical data and histological reports were collected from electronic medical records and anatomical pathology departments.

Here, our data from the head and neck cancer patient cohort show that the CALD status of Biobank-recruited patients is consistent with local government area CALD statistics for the Liverpool population, indicating an overall well represented population of patients. Importantly, our data suggests that logistical issues as well as CALD status may be a critical barrier for Biobank recruitment.

Aims

• Determine if the local area CALD status / demographic is well-represented in the Head and Neck Biobank-recruited cohort

• Determine the impact of CALD status in the consenting process

• Identify logistical barriers to entry for Biobank recruitment

Methods

• Informed consent is obtained prior to surgery by health care professionals including nursing, medical or biobanking staff

• Demographic data were routinely collected as part of a questionnaire during the consenting process

• CALD status / ethnicity of Liverpool local government area (LGA) were acquired from the Australian Bureau of Statistics

• Audit was performed in all cases of missed recruitment and declined consent

Clinical Data

Surgery Type	n
Excision	93
Thyroidectomy	52
Hemithyroidectomy	27
Neck Dissection	11
Mandibulectomy	8
Laryngectomy	8
Glossectomy	7
Thyroidectomy and Neck Dissection	6
Parotidectomy	5
Maxillectomy	3
Others	17

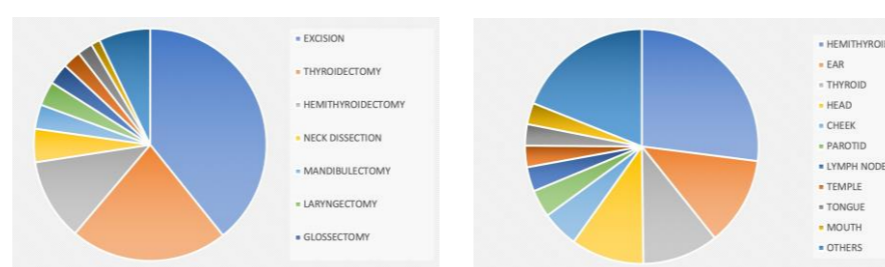| Site	n
Hemithyroid	64
Ear	29
Thyroid	25
Head	24
Cheek	12
Parotid	9
Lymph Node	8
Temple	7
Tongue	7
Mouth	7
Others	45

Figure 1: Clinical data of all head and neck cancer patients recruited from 2017-2018. Summary of clinical data showing the major surgical procedures performed (left) and surgery sites (right) (n=237).

CALD Status of Patient Cohort

COUNTRY OF BIRTH				
BIOBANKED PATIENTS			LGA (2016)	
COUNTRY	n	%	COUNTRY	%
Australia	172	61.0	Australia	51.7
Iraq	22	7.8	Iraq	4.8
Vietnam	18	6.4	Vietnam	3.3
Croatia	7	2.5	Fiji	3.2
England	7	2.5	India	2.6
India	7	2.5	Lebanon	2
Lebanon	6	2.1		

LANGUAGE SPOKEN AT HOME				
BIOBANKED PATIENTS			LGA (2016)	
Lang	n	%	Lang	%
English	254	82.5	English	41.4
Arabic	18	5.8	Arabic	11.4
Vietnamese	17	5.5	Vietnamese	4.9
Assyrian	13	4.2	Hindi	4
Spanish	6	1.9	Spanish	2.5
Indonesian	3	1.0	Serbian	2.4

INTERPRETER REQUIRED				
BIOBANKED PATIENTS			LGA (2016)	
Lang	n	%	Lang	%
Arabic	15	34.9	Arabic	11.4
Vietnamese	11	25.6	Vietnamese	4.9
Assyrian	6	14.0	Hindi	4
Spanish	5	11.6	Spanish	2.5
Croatian	3	7.0	Serbian	2.4
Khmer	2	4.7		
Serbian	1	2.3		

Table 1: CALD data between Biobank-recruited patients and the Liverpool LGA statistics. Comparison of CALD data between Biobank-recruited patients to the LGA statistics including country of birth (top), language spoken at home (middle) and interpreter requirements (bottom).
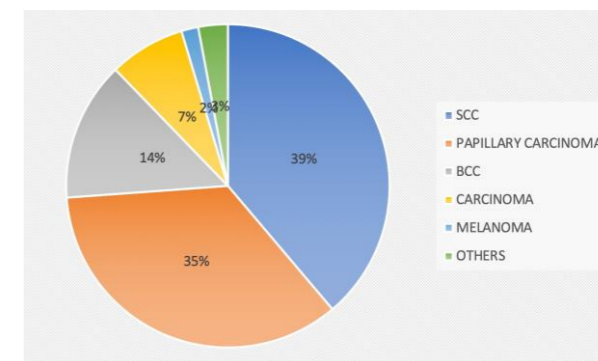
Histopathological Subtypes

Figure 2: Histopathological subtypes of biobank head and neck cohort. Five major histopathological subtypes of head and neck cohort including squamous cell carcinoma (SCC), papillary carcinoma, basal cell carcinoma (BCC), carcinoma and melanoma (n=237).

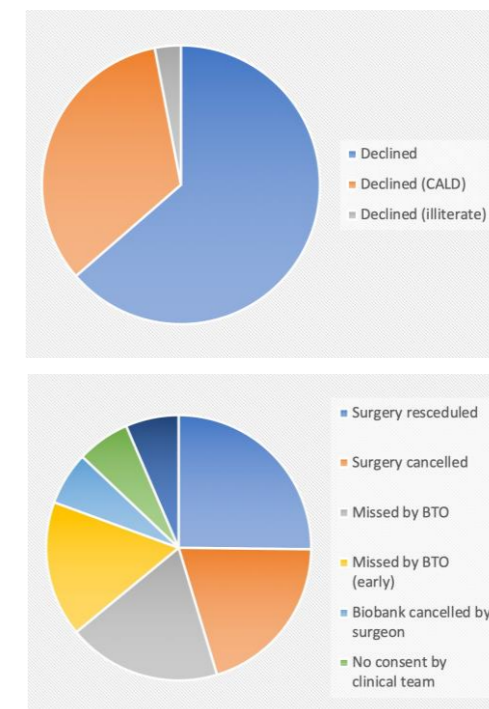## CALD and Logistical Barriers for Recruitment

Figure 3: Causes of missed recruitment and decline consents. Missed recruitment causes including proportion of CALD patients in cases of declined consent (top) and logistical barriers (bottom) (n=33 and n=139 respectively) (BTO = Biobank Technical Officer)

Conclusions

• CALD status of Biobank-recruited patients is consistent with LGA statistics

• Many patients deemed suitable for Biobanking were missed due to logistical barriers

• CALD status is a potential barrier during the consent process

Acknowledgements