4th Open Science Forum

Sharing with Care: Data Stewardship in Cancer Biobanking

Dr. Karen Ng Lee Peng
Oral Cancer Research & Coordinating Centre (OCRCC)
Faculty of Dentistry, Universiti Malaya

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Setting the Scene

- Cancer biobanks = *cornerstone of precision medicine*
- Contribute >40% of cancer research outputs globally
- Key question: *How do we share responsibly while protecting trust?*
- Tension: Access vs Protection

Why data stewardship matters?

- End-to-end responsibility for biospecimen data: collect – store – curate – share – reuse
- Biospecimen metadata + clinical/ genomic data
- Ensuring FAIR principles: Findable, Accessible, Interoperable, Reusable
- Goes beyond compliance – ensures ethical + scientific quality
- Balancing **openness** and **protection**

Why It Matters in Cancer Biobanking?

- Highly sensitive data: genomics, imaging, clinical data
- High stakes: diagnosis, treatment development, prognosis
- Social impact: equity in representation & benefit-sharing
- Trust is the foundation – participation depends on confidence in stewardship

Cancer Biobanking Landscape

- National Cancer Registry, MOH
- Institutional-based
  - » Malaysian Oral Cancer Database & Tissue Bank System (MOCDTBS)
  - » UM Biobank
  - » Biobank Unit, IMR
- Collects cancer tissues for research purposes
- Strength: diverse population, global relevance

Case: Malaysian Oral Cancer Database & Tissue Bank System (MOCDTBS) vs UM Biobank

	MOCDTBS	UM Biobank
Established	2005	2010
UM-based led by	Oral Cancer Research & Coordinating Centre (OCRCC), UM	UM Cancer Research Institute (UMCRI), UM
Partnership/ collaboration	MOH, NGO, UM, UKM, USM	Faculty of Medicine, UM
Samples collection	Tissues, blood, saliva	Mainly tissues
Type of consent	Broad	Broad
Collection method	Centralised biospecimen collection	Centralised biospecimen collection

Case: Malaysian Oral Cancer Database & Tissue Bank System (MOCDTBS) vs UM Biobank

	MOCDTBS	UM Biobank
Access to biospesimen	Open to all researchers	Limited to collaborators within the same research group
Data sharing	Strict anonymization before sharing	Strict anonymization before sharing
Collection protocol	Different SOPs for different type of sample collection	SOP for tissue collection

Open Access Implementation

- OA principles increasingly adopted
- NIH Malaysia study: researchers open to OA, but barriers remain
- OA in cancer biobanking limited
- Lacks visibility and existence

Key Challenges

- Fragmented governance & inconsistent SOPs
- Static consent models
- Limited QC & digital infrastructure/ infrastructure disparity
- Low public awareness
- Sustainability & funding

Best Practice Recommendations

- Governance: Established Biobank Act/ **clear guidelines**
- Adopt **flexible/ dynamics consent models**
- Harmonise **metadata standards** across biobanks
- Build **capacity** – infrastructure, train data stewards
- Promote **equity & community trust** – engage the public transparently

Conclusion

Sharing with Care = Sharing with Trust

- Stewardship ensures open access is ethical, equitable and impactful
- By balancing openness with protection, cancer biobanks can drive precision medicine
- OA not just about data release; it's about **trust, governance and sustainability**

Thank you