

## BIOBANKING WORKSHOP ATTACHMENT-1

### Plenary feedback and clustering of the table top issues:

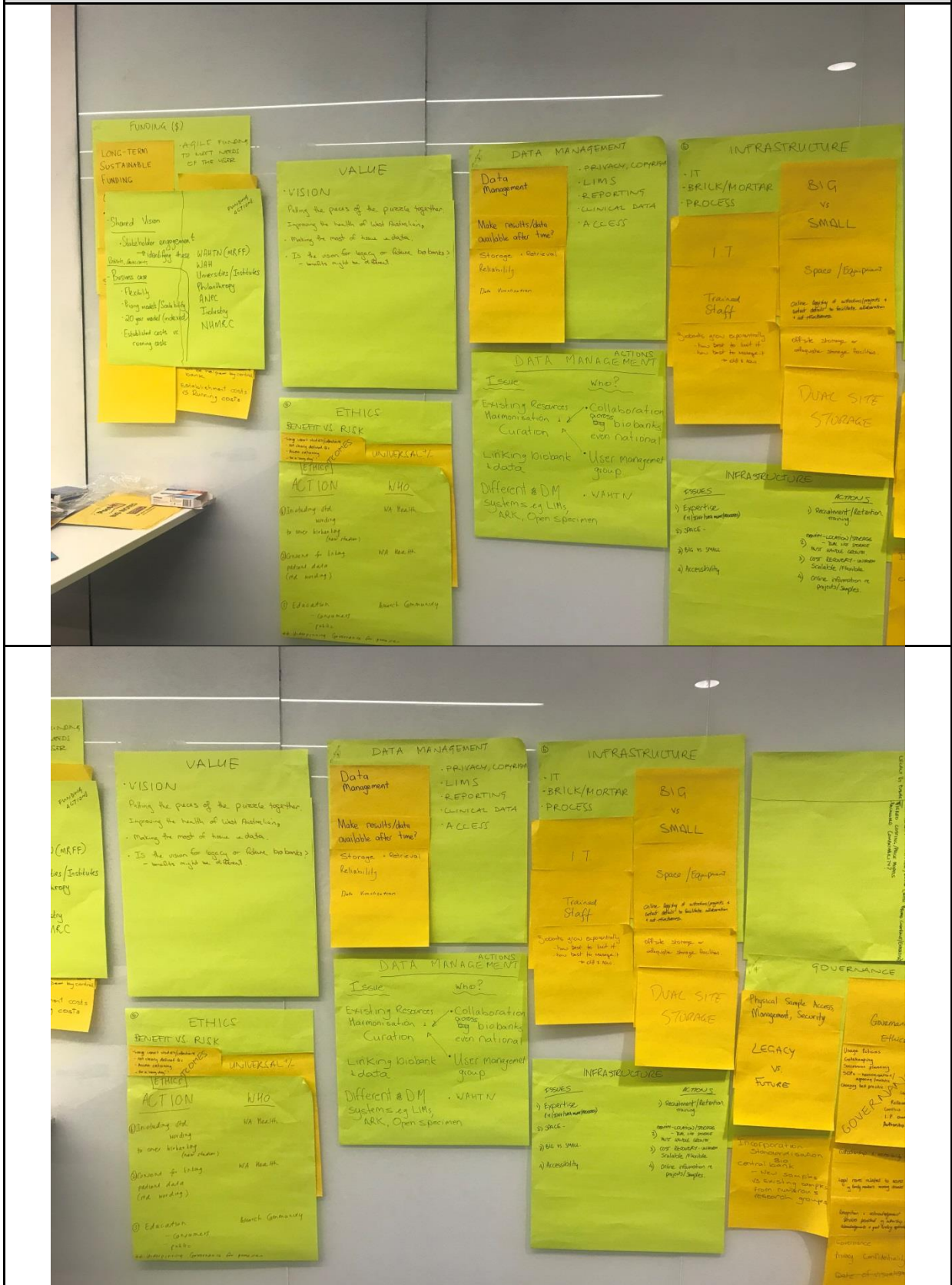
<ul style="list-style-type: none"> <li>• Long-term sustainable funding</li> <li>• Sample quality and testing over time (storage and assurance testing). QA issue on those samples</li> <li>• Long term vs short term users – access to samples</li> <li>• Infrastructure funding vs cost recovering funding</li> <li>• Funding models consistent</li> <li>• Agility in funding to allow different types of uses to access the biobank to meet the needs of the user</li> <li>• Data management</li> <li>• Making the data publically available after a certain number of years. Open access issue, IP issue and privacy issue.</li> <li>• Physical sample access</li> <li>• Management of samples</li> <li>• Security of samples (who can access and how it is looked after)</li> <li>• Accreditation</li> <li>• Consent</li> <li>• Legacy versus future</li> <li>• Big versus small (e.g. agile funding and mechanisms/key expertise and staff that can enable small groups)</li> <li>• Scalable flexible infrastructure</li> <li>• Harmony</li> <li>• Values and beliefs</li> <li>• Laboratory Information Management System (LIMS)</li> <li>• Reliable ongoing funding</li> <li>• Specialised space (e.g. liquid nitrogen)</li> <li>• Equipment</li> <li>• Automated</li> <li>• IT (e.g. private cloud, not commercial)</li> <li>• Metadata</li> <li>• Ethics</li> <li>• Governance</li> <li>• Staff- suitably trained and qualified</li> <li>• Infrastructure (e.g. processes and responsibilities)</li> <li>• Usage policies</li> <li>• Sustainable cost structure</li> <li>• Should it have an upper limit? What would that look like? Biobanks grow exponentially</li> <li>• Off-site storage and adequate storage facilities</li> </ul>	<ul style="list-style-type: none"> <li>• Gatekeeping</li> <li>• Succession planning</li> <li>• Rollover – move of PIs</li> <li>• Changing landscape that is best practice</li> <li>• Sample curation</li> <li>• Cold chain management and sample flow</li> <li>• Challenge of getting fresh tissue</li> <li>• Possibility of opt out</li> <li>• Waiver of consent if a patient is deceased and have previously opted in</li> <li>• One form for all hospitals</li> <li>• Cost will go up with the costs of new technology</li> <li>• Unclear outcomes</li> <li>• Access rationing</li> <li>• Benefit versus risk</li> <li>• Security</li> <li>• Sustainability</li> <li>• Expertise in the materials and data management (e.g. collection and scribing)</li> <li>• Custodianship and accessibility)</li> <li>• Legal issues related to the access of the samples (e.g. cancer patient deceased with family seeking access)</li> <li>• Online registry of custodians and projects serviced by such facilities to enhance usage – facilitates collaboration and cost effectiveness. (e.g. clinical trials.gov.au)</li> <li>• Recognition and acknowledgement of services provided</li> <li>• Storage and retrieval</li> <li>• Data visualisation – how it is produced</li> <li>• Marketing</li> <li>• Funding – starting off from scratch (e.g. universal Denmark model). What about all the existing samples, incorporating physically or from an infrastructure point of view</li> <li>• Export data in a meaningful way (biobanking tool that gives back the data back in a user friendly way)</li> <li>• How are you going to obtain the Clinical information? Efficient and in good quality.</li> <li>• Researchers to obtain customised data.</li> <li>• Dual site storage</li> <li>• Improving the provision of the healthcare</li> <li>• Key stakeholders</li> <li>• vision</li> </ul>
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### Q - Can issues by table be clustered into common issue streams?

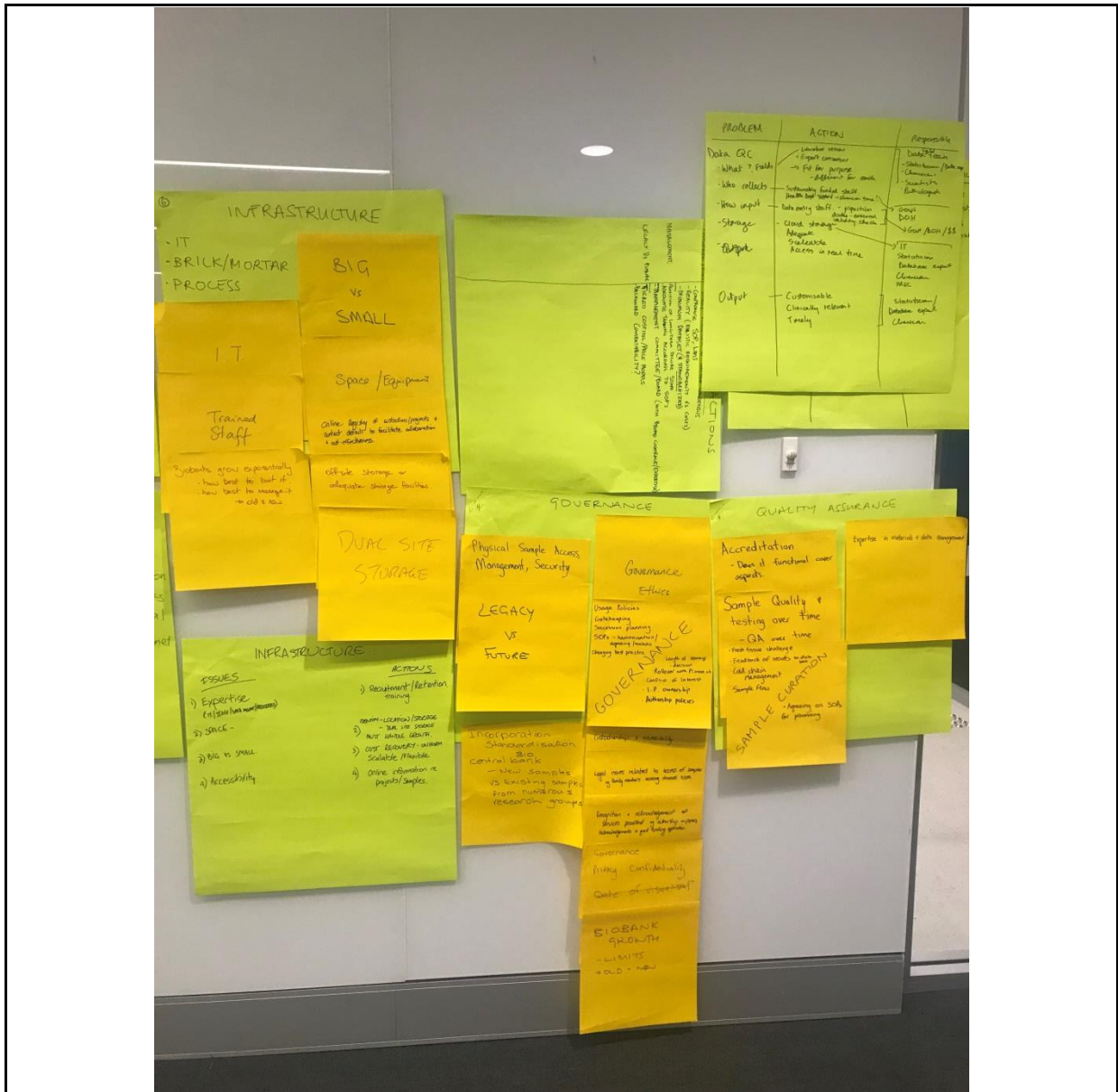
<ul style="list-style-type: none"> <li>• <b>Funding</b></li> <li>• <b>Quality assurance</b></li> <li>• <b>Data management</b></li> <li>• <b>Governance</b></li> </ul>	<ul style="list-style-type: none"> <li>• <b>Ethics</b></li> <li>• <b>Infrastructure</b></li> <li>• <b>Values</b></li> </ul>
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Activity: Table speaker provides feedback for table. Plenary discussion and clustering/streaming of issues on to a large A3 post it note as each table presents.



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