Submission Number:	063
Submission Received from:	Torres Strait Community Health Council
Email Received:	10 September 2008

Author: Maria Mene
Position: Policy Coordinator
Date: 19/08/2008

ANALYSIS OF ORGAN AND TISSUE DONATION PROCEDURES SELECT COMMITTEE – ISSUE PAPER
JULY 2008

Due:- 2nd September 2008

Abstract

The Review paper discussed Organ and Tissue donation processes, and is in response to The Select Committee's request for public comment, specifically from Aboriginal & Torres Strait Islander representatives, on issues raised within the Terms of Reference of the Review of Organ and Tissue Donation Procedures Select Committee (the Select Committee).

The Select Committee requires advice and guidance on the following issues:

1(a) Given the relatively low organ and tissue donation rates in Queensland, should a system of presumed consent or 'opt-out' for organ and tissue donation be introduced in Queensland?

1(b) If so,

- should presumed consent for removal of organs and tissue:

  (i) be absolute, or should further recourse be required to the wishes of relatives and/or legal guardians in this decision?

  (ii) apply to all persons, specifically considering the age, decision making capacity, cultural and religious beliefs of the person? If not, what exemptions and safeguards should apply?

  (iii) allow these organs and tissue to be used for other purposes such as research?

- what mechanisms should be put in place to enable persons to explicitly register their objection to their organs and tissue being removed?

- what would be the implications, including financial implications, of introducing a system of presumed consent for organ and tissue donation on the operation of all existing legislative, administrative and governance frameworks, including in other jurisdictions?

- what, if any, other matters should be considered in the regulation of this issue?

2. In addition to the issue of presumed consent for removal of organs and tissue, are there any additional options that should also be considered to increase public awareness of and improve the organ and tissue donation rate in Queensland?

In order to address these issues Aboriginal & Torres Strait Islander representatives need to ensure that all cultural, traditional lore, religious and personal beliefs are recognised, represented and direct this Policy with regards to the following:-

[1]Ailan Kastom

"Many Torres Strait Islanders refer to their culture in Melanesian terms as Ailan Kastom which is in fact a blend of the original culture and that of these same South Sea Islanders who were brought to the region in the nineteenth century as part of the pearl shell industry and during the process of Christianisation (Mullins 1995; Ganter 1994) (see Chapter 4). The two words of the term Ailan Kastom allows Islanders on one hand to reinforce their connection with the islands of the Strait and

on the other to make a clear distinction between themselves, Aboriginal people and other Australians.

Island culture in the form of dance, song, and customs is vibrant and is regarded as a cornerstone of contemporary Islander life in the Strait. *For instance, Islanders, particularly those living in Torres Strait, are more likely to speak either Creole or a traditional language than are their Aboriginal counterparts across Australia.* ***They are also more likely to identify with a clan or traditional grouping and to be active in cultural activities*** *(see Tables 5.1, 5.2 and 5.3).* ***Initiation of young men remains important with some being brought from the mainland to take part in initiation ceremonies*** *(Davis 1998:238). Ailan Kastom is also officially recognised in some government policies such as the Queensland Land Act 1991 (Davis 1998: 19). The importance of this culture is apparent in policy statements. In its second review of its Act in 1998, ATSIC noted that the TSRA's corporate plan states that its first function is:*

> *…to recognise and maintain the special and unique Ailan Kastom of Torres Strait Islanders living in the Torres Strait area (ATSIC 1998: 9).*

In a similar vein, the TSRA newsletter has as its banner:

> *Our Vision: Empower our people to determine their own affairs based on unique Ailan Kastom bilongTorres Strait from which we draw our unity and strength.2"*

The sensitivity and cultural protocols associated with Organ and Tissue donation is not a 'straight forward' matter from a Aboriginal & Torres Strait Islander consumer's perspective. The processes utilised through select committees interprets community perceptions in a western concepts as opposed to Aboriginal & Torres Strait Islander concepts of life, which entails a wholistic *(mind, body, spirit and environment)* viewpoint. Upon consultation with the Meriba Dhoeynidhay Yabu District Health Community Council Chairperson, Mr Napau Pedro Stephen, stated the following:-

> [2]*"The lack of Torres Strait Islander inclusion and consultation in this 'body parts donation' discussion to date speaks for itself.*
>
> *It is our spiritual belief system – I am not referring to the church's spiritual belief system no! It is our (Torres Strait Islander) traditional beliefs regarding life and its relationship with time and creation. Where our life has no beginning and no end.*
>
> *When our loved ones leave us we do not refer to this process as death, but as Sleep. We* ***do not interfere with our loved ones body*** *– we respect them and prepare them for their next journey totally intact."*

[3]The World Health Organisation defines Health *"a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."* This definition has directed and influenced the standards of Health Care provided to Aboriginal & Torres Strait Islander people throughout Australia.

[a]The Cultural Respect Framework for Aboriginal & Torres Strait Islander Health 2004 – 2009 these explanations for Aboriginal & Torres Strait Islander people and cultures and the inherent differences between the two races:-

> *"Aboriginal culture is one of the oldest surviving cultures in the world. Aboriginal cultures are numerous and diverse, made up of hundreds of different kinship and language groups that have adapted to diverse living conditions throughout Australia over many thousands of years. Torres Strait Islanders are a separate people with distinct identity and culture. Aboriginal cultures and Torres Strait Islander cultures are still dynamic and evolving and, for Aboriginal and Torres Strait Islander individuals and communities form the context for the development of health policy.1*

---

[1]Arthur, W.S., *Torres Strait Islanders and Borderline Case,* The Australian National University, Crawford School of Economics and Government. Policy and Governance Program, 2006.

[2] Stephen, N.P., Meriba Dhoeynidhay Yabu District Health Community Council Chairperson, Thursday Island, 20/08/2008.

[3]Geneva: World Health Organization. 1966. p.1.

[a]Australian Health Minister's Advisory Council, *Cultural Respect Framework for Aboriginal & Torres Strait Islander Health 2004 – 2009*, Department of Health South Australia, 2004.

> *Health is not just the physical wellbeing of the individual but the social, emotional and*

> *cultural wellbeing of the whole community. This is a whole-of-life view and it also includes the cyclical concept of life-deathlife.2*
>
> *Health, defined by the World Health Organization as a state of complete physical, mental and social wellbeing, is recognised as both a fundamental human right and an important worldwide social goal.3 That recognition is embodied in Australia in the Council of Australian Governments' commitment in November 2000 to an agreed set of reconciliation principles and priorities.*

The NHMRC Guidelines (as referenced in the Paper) – Ethical Conduct Standards are based on the following principles:-

1. Donation of organs and tissues is an act of altruism and human solidarity that potentially benefits those in medical need and society as a whole;

2. **Organs and tissues for transplantation should be obtained in ways that:**
   - **demonstrate respect for all aspects of human dignity, including the worth, welfare, rights, beliefs, perceptions, customs, and cultural heritage of all involved;**
   - **respect the wishes, where known, of the deceased;**
   - **give precedence to the needs of the potential donor and the family over the interests of organ procurement;**
   - as far as possible, protect the recipients from harm; and
   - **recognise the needs of all those directly involved, including the donor, recipient, families, carers, friends and health professionals;**
3. Organs and tissues should be allocated according to just and transparent processes; and
4. **The choice not to donate should be respected and the family shown understanding for the decision.**

Points two and four identify the internationally recognised principles of *"free and informed prior consent",* and are critical to "*1(b) (iii) allow these organs and tissue to be used for other purposes such as research?"*

This type of consent recognises principles which Aboriginal & Torres Strait Islander people believe are essential in ensuring best practice protocols and standards for Research, and need to be adhered to as they assist in achieving quality and sustainable outcomes for Aboriginal & Torres Strait Islander Communities. Aboriginal & Torres Strait Islander people should be able to:-

1. Make informed choices.
2. Making decisions which preclude pressure from Researchers, e.g., Researcher's submitting a proposal and requesting approval the following week, Researcher's constantly contacting appropriate Community based representatives to request approval etc.
3. Refuse to participate in research.
4. Withdraw consent if a research project will produce a detrimental outcome for the Community.
5. Apply self-determination principles to research projects.
6. Access to all necessary information regarding research projects, which include roles of project staff, gathering of information, implementation phases etc.
7. Direct research projects to ensure outcomes are enhancing community's sustainability and economic prospects.

Under the [1]Queensland Health Code of Conduct, the following ethical obligations are required to be adhered to by staff:-

Public Sectors Ethics Act 1991
The Code is developed under the *Public Sector Ethics Act 1994*
The Act sets out five ethics principles and their related ethics obligations.

---

[1]Queensland Health, Queensland Government, *Code of Conduct,* 2006.

Principle 1 Respect for people
ethics obligation
Queensland Health employees should treat members of the public and other employees honestly and fairly, and with proper regard for their rights and obligations. Employees should also act responsively in performing official duties.

Principle 2 Integrity
ethics obligation
In recognition that public office involves a public trust, each Queensland Health employee should seek to maintain and enhance public confidence in the integrity of public administration, and to advance the common good of the community. With regards to these obligations, employees: should not improperly use their official powers or position, or allow them to be improperly used should ensure that any conflict that may arise between their personal interests and official duties is resolved in favour of the public interest should disclose fraud, corruption and maladministration of which they become aware.

Principle 3 Respect for the law and the system of government
ethics obligation
Each Queensland Health employee should uphold the laws of the State and Commonwealth and carry out official public sector decisions and policies faithfully and impartially. Employees should act independently of government if independence is required by legislation or government policy, or is a feature of their work.

Principle 4 Diligence
ethics obligation
In performing official duties, each Queensland Health employee should exercise proper diligence, care and attention and seek to achieve high standards of public administration.

Principle 5 Economy and efficiency
ethics obligation
In performing official duties, every Queensland Health employee should ensure that public resources are not wasted, abused, or used improperly or extravagantly.

These principles strengthen and underpin the identified need to consent consumers and ensure that they have all the necessary information to select choices which they feel comfortable with making and also maximise their health outcomes, whilst treating them with respect, courtesy and dignity.

Introduction

The Review paper identifies the following points:

"Organ and tissue donations are important and often life saving treatments for people with end stage organ failure and other conditions. While people with kidney failure can be treated with dialysis until a kidney becomes available, there is no interim treatment for people with end stage heart, liver or lung failure. Some of the conditions that can be treated with organ and tissue transplantation are: heart transplant for dilated cardiomyopathy; lung transplant for cystic fibrosis; liver transplant for autoimmune disease, genetically transmitted haemocromotosis, and hepatitis C; replacement of bone after tumour removal; and rectifying defects in the cornea of the eye.

Transplant organ success rates in Australia are among the highest in the world. Survival rates for kidney transplants are around 90% in the first year after transplantation and over 75% after five years. Heart and liver transplant survival rates are around 90% in the first year and 85% after five years. Pancreas transplants have the highest survival rate of 94% after one year and 87% after five years.4

Australia's low organ donation rate is often remarked on. About 90% of Australians support organ donation in principle, and many have registered their consent or intention to donate on driver's licences or the Australian Organ Donor Register. However, only about 1% of deaths in Australia occur in circumstances where donation of the person's organs such as kidneys is possible. More people are able to donate tissue such as corneas or bones.

---

[1] Queensland Health, Queensland Government, *Code of Conduct*, 2006.

At the end of 2007 there were 1,748 people on the national organ transplant waiting list, 1,388 of whom were waiting for kidney donations. During 2007 there were 633 organ transplantations performed in Australia from 198 donors. The shortage of organs for donation is an issue that has been examined by taskforces, expert committees and governments in Australia and overseas on many occasions. Like Australia, most countries have fewer organs available for transplantation than people waiting for an organ transplant.

Expert commentators suggest a variety of ways that organ and tissue donation could be improved. Spain has higher organ donation rates than other countries and the "Spanish model" is often proposed as best practice. Some features of the Spanish approach are included in the recently announced national reform package (see 2.2 below), and are described in Section 3.3, Presumed consent, and in Section 4, Other Options to Improve Organ and Tissue Donation in Queensland."

Whilst this view is inherently a Western world view, we as Aboriginal & Torres Strait Islander people must consider:-

1. The cultural, traditional, religious and personal beliefs which influence Organ & Tissue donation.
2. The Burden of Chronic Disease experienced by Aboriginal & Torres Strait Islander people.
3. The increased rates of Type II Diabetes in young people in the Torres Strait.
4. The rates of Aboriginal & Torres Strait Islander people attending Renal facilities.
5. The financial impact of being an Organ & Tissue donor recipient.

We are faced with an issue that creates discomfort and angst for many, however we must responsibly provide recommendations and feedback to ensure that Aboriginal & Torres Strait Islander people and communities have an accessible range of health care options available.

Discussion of Literature

The Select Committee requests comments on six sections of the paper. Outlined herein are the subject headings and analysis of these sections.

"2.5.2 Legal requirements - Transplantation and Anatomy Act 1979

Like other Australian states, organ and tissue donation in Queensland requires the express consent of the deceased person or their family. Organ and tissue donation is regulated by the Transplantation and Anatomy Act 1979 (Qld) and in other states by similar legislation.

In practice, the potential donor's family is approached to ascertain whether the deceased person has consented to donation, or may have revoked their consent. If the deceased person's next of kin object to donation, it does not proceed. *Consent may be given to retrieve specific organs, or multiple organs and tissues. Consent may be for transplantation, or also to use retrieved tissue for other therapeutic, medical or research purposes."*

This is current Legislation.

6 The AODR can be contacted by telephone on 1800 777 203 or at: www.hic.gov.au.

Consent System Options

3.2 Types of decision-making or consent systems

The Committee offers the following systems as consumer consent mechanisms:-

3.2.1 Express consent or 'opt-in'

Currently the Organ/Tissue donation decision-making system in Australia is an express consent system, where the deceased person or their family are able to consent or decline. The deceased person's family is always consulted, and family objections are respected.

If you wish to be an Organ/Tissue Donor you can record this on your Driver's Licence. The Committee identifies that Driver's licences are not considered to be an adequate means of legal consent for donation.

In 2005, all Australian Health Ministers decided that the Australia Organ Donor Register would be the sole register for consent to donation. Following this announcement Queensland Transport ceased to record information about Organ & Tissue donation on new or renewed licences.

The Transplantation and Anatomy Act 1979 authorises the following:-

- removal of organs and tissue if the deceased person gave signed consent while they were alive, and their consent has not been revoked;

- before authorising removal of tissue, a designated officer in the hospital is required to make reasonable inquiries to ensure that the deceased person has not expressed an objection to donation, and the senior available next of kin has consented;

- the senior available next of kin may consent to removal of organs and tissue for transplantation or for other therapeutic, medical or scientific or research purposes

The Act (section 4) defines the senior available next of kin as follows:

senior available next of kin means—

(a) in relation to a child—the first of the following persons who in the following order of priority, is reasonably available—
 (i) the spouse of the child;
 (ii) a parent of the child;
 (iii) a brother or sister, who has attained the age of 18 years, of the child;
 (iv) a guardian of the child; and

(b) in relation to any other person—the first of the following persons who, in the following order of priority, is reasonably available—
 (i) the spouse of the person;
 (ii) a son or daughter, who has attained the age of 18 years, of the person;
 (iii) a parent of the person;
 (iv) a brother or sister, who has attained the age of 18 years, of the person.

Identify kinship systems which also operate and need to be covered legislatively.

3.2.3 First person consent

"If a person has registered their consent to donate organs and tissue while alive, first person consent means that donation would proceed. The donor's family could not have a role in the decision and any objections they had could be overridden. This approach ensures that the deceased person's wishes are respected, but does not take account of family views at the time of bereavement. Clinical staff are likely to be reluctant to proceed with organ retrieval if family members object."

At this time it is critical to identify the issue of individual choice e.g., if a person provides express written permission to remove Organ/Tissues from their bodies after death, however family members contest this matter, whose wishes should be adhered to? First person consent identifies that the rights of the person consenting are upheld.

However if the consenting person identifies to a family member verbally that they have changed their mind, legally how is this choice evidenced, qualified and adhered to? Do Aboriginal & Torres Strait Islander people really understand what they are consenting to?

3.2.4 Mandated choice

Consumers are required to make an individual choice about Organ/Tissue donation either when *completing a licence, health card or other government form*. This effectively means that a deceased person's family would not have a role in the decision process.

The advantages of mandated choice ensure that individual choices are known and respected. For the mandated choice system to be successful would require that people are well informed about the choice they were required to make.

3.2.5 Presumed consent or 'opt-out' systems

"Presumed consent operates on the assumption that everyone is an organ donor unless they have opted out or declined to consent in advance, subject to medical suitability for donation."

The assumption under this system is that people wish to donate Organs/Tissues. The key difference between approaches to opt-out or presumed consent policies are whether clinicians are required to consult with the family of the deceased person.

"The key difference between approaches to opt-out or presumed consent policies are whether clinicians are required to consult with the family of the deceased person."

Legislatively, Queensland operates under the system that "signed written consent" is required for Organ & Tissue donation.

"3.3 Presumed consent and opt-out in other countries

One of the possible ways to increase donations may be to change from our current system of express consent or 'opt-in', to presumed consent. There is debate about the advantages and disadvantages of presumed consent, and whether it would have a positive impact on the number of organs and tissues available for transplantation."

Access to opt out option – on the proviso that all educational resources are available to Aboriginal & Torres Strait Islander people.

Issues for comment

- ***What requirements for consent to organ and tissue donation should apply? If possible, please outline your reasons.***

There should be a range of options available to suit individual Aboriginal & Torres Strait Islander consumers needs. Choices should be inclusive of:-

1. Express consent or 'opt-in' – this system is reliant on Authorities understanding and being informed of Aboriginal & Torres Strait Islander kinship systems which need to consider traditional adoption arrangements, verbal directions from elders etc.

2. First person consent – is a system which provides the option for individuals to determine this choice, and will only be successful if the consumer's consent status is monitored on a biennial or triennial basis.

- ***Should the role of next of kin or family be different if a person has given written consent to organ and tissue donation?***

No, only if the person has identified to the next of kin that their consent status has changed.
If a person's has changed their mind about organ and tissue donation then the First Person Consent principles must demonstrate allowances for this.

- ***What is the best way to use a donor register in connection with consent when donation is being considered?***

The donor register must encompass:-

1. Free and informed prior consent.
2. Appropriate education and information resources.

3. Method if information delivery for Aboriginal & Torres Strait Islander people in rural or remote locations.
4. Biennial, triennial or quarterly mail outs to identify changes to consent status.
5. Ability to track transient populations such as Aboriginal & Torres Strait Islander people.

- ***Do you support introduction of an opt-out or presumed consent system?***

No.

- ***What reasons do you have for supporting or not supporting an opt-out or presumed consent system?***

This system does not provide consumers with appropriate choices. It is also incorrect for clinicians to assume they have the right to make decisions about a deceased person without the consent of next of kin.

- ***What role should a deceased person's family or next of kin have in consent to organ and tissue donation?***

If no consent can be identified for organ and tissue donation then the next of kin are the authorised person who can provide consent.

- ***If a presumed consent system was to be introduced, what mechanisms should be introduced for people to opt-out?***

The mechanisms need to include:-

1. Appropriate levels of resourcing to fund initiative in a sustainable and long term manner in languages and media sources which can be distributed and accessed by Aboriginal & Torres Strait Islander people in Rural & Remote geographical regions.
2. Ensure education and promotion of initiative is disseminated language appropriate to Aboriginal & Torres Strait Islander people in Rural & Remote geographical regions.
3. Available to all Primary, Secondary and Tertiary State Health Service providers, NGO Health Service Providers and other relevant Health stakeholders who may play a role in educating or disseminating the information to Aboriginal & Torres Strait Islander consumers.
4. Development of an education package for Medical Officer's, with special emphasis on Aboriginal & Torres Strait Islander cultural sensitivities, customs and practices, to ensure that the message delivered is consistent with medical options.
5. Annual or biennial consumer updates to ensure community remains informed about their choices.

- ***How could simple and reliable access to an opt-out mechanism be ensured?***

The system could be simply upon accessing any Health Service the "opt-out" question is asked of Aboriginal & Torres Strait Islander consumer's as a component of standard health care service/screening processes.

- ***If presumed consent was introduced, should the family be asked if they object to organ donation if the deceased person has not opted out of donation?***

Yes, the question and deference should **always** be exercised with an Aboriginal & Torres Strait Islander deceased member's family.

- ***Should children and people with impaired decision making capacity be part of a presumed consent system?***

No, we must ensure that the system and education and promotional activities covers all Aboriginal & Torres Strait Islander consumer groups, especially people with disabilities or impaired capacity to make informed decisions.

- ***Should particular categories of people be automatically excluded and not presumed to consent to donation?***

No, this is a question that must be posed to all Aboriginal & Torres Strait Islander consumer's.

- ***When should children be able to opt-out of presumed consent?***

This is dependant on the age of the child, ultimately Legislative statues must guide this process regarding minors and their ability to make educated and informed choices.

- ***What support would be required for clinical staff if a presumed consent system was introduced?***

The following mandatory staff training requirements are necessary:

- Aboriginal & Torres Strait cultural sensitivities, customs, practices and language/communication barriers.
- How to provide all available choices to ensure Aboriginal & Torres Strait Islander consumer's are making qualitative informed decisions.
- How Aboriginal & Torres Strait Islander people deal with Grief, eg. when can you appropriately ask the question of organ/tissue donation etc?
- How consent is given and recorded.

- ***What safeguards and limitations should apply to a presumed consent system?***

If Aboriginal & Torres Strait Islander consumer's have not "opted out" we must not presume that consent is authorised or indeed present.

It is important to note again here that many Aboriginal & Torres Strait Islander consumer's when approached by medical staff will often respond affirmatively to any question or request, however this ultimately is done for one of the following reasons:-

1. **Don't understand what information is being given, due to language barrier, or intellectual understanding of medical jargon.**
2. **Agree under pressure or out of obligation to please or appease Medical Officer's or professionals which Aboriginal & Torres Strait Islander consumers perceive as "experts".**
3. **Agree with medical request/advice to expedite departure of medical staff.**

- ***Are there specific religious or cultural issues that should be addressed in consent to donation or organs and tissue?***

Yes there will be and the Issues Committee needs to gather this information from the relevant groups to ensure that these religious or cultural practices are respected and adhered to in the process of trying to gain Aboriginal & Torres Strait Islander consumer's consent for organ/tissue donation.

- ***If an opt-out or presumed consent system is introduced, should it apply only to transplantation to another person, or also to other purposes such as research?***

The issues of removing biological tissues or samples from Aboriginal & Torres Strait Islander consumer's should follow in the same processes advised in the recommendations contained herein, and also abide by existing National and International principles and ethics which involved research of any Indigenous people's.

- ***In an opt-out or presumed consent system, should it be possible to opt-out of donating for one purpose, but continue with presumed consent for another purpose?***

Again these need to be options which are presented to individual consumers.

- ***If an opt-out or presumed consent is not introduced, is the current system of consent appropriate?***

Any changes to the current system need to be consultative and appropriately capture and cover appropriate Legislative requirements, cultural and religious practices.

- ***Are there changes you consider should be made to the decision-making or consent system?***

The options need to be decisive enough to allow Aboriginal & Torres Strait Islander consumer's to make qualitative informed decisions.

- ***What action should be taken to improve organ and tissue donation in Queensland?***

  Ultimately any improvement will depend on how education and promotion strategies are communicated to Aboriginal & Torres Strait Islander consumer's.

- ***Are there particular hospital-based strategies that should be considered in Queensland to improve organ donation rates?***

  As above.

- ***Should any incentives be offered to potential donors for organ and tissue donation?***

  Again this is a matter which should be investigated by the Issues Committee.

- ***What are your main reasons for supporting or opposing incentives? If you support incentives, what type of incentives do you consider may be appropriate?***

  This is should be based on individual participation.

- ***What action should be taken to promote better public awareness of organ and tissue donation?***

  All promotional material should be geared to suit all the differing ethnic cultures being targeted, with respect to appropriate language, understanding of cultural practices and sensitivities, and geographical region where information or campaign is to be delivered/disseminated to.

Conclusions

In conclusion the views presented here are a sample of individual Aboriginal & Torres Strait Islander consumer's, and we recommend the Issues Committee consider and seek further consultation, with the group identified, on the following:-

1. The cultural, traditional, religious, spiritual and personal beliefs which influence Organ & Tissue donation.
2. The consultative and inclusion process for gathering cultural, traditional lore, religious and personal beliefs information.
3. The Burden of Chronic Disease experienced by Aboriginal & Torres Strait Islander people.
4. The increased rates of Type II Diabetes in young people in the Torres Strait.
5. The rates of Aboriginal & Torres Strait Islander people attending renal facilities.
6. The financial impact of being an Organ & Tissue donor recipient.
7. Aboriginal & Torres Strait Islander consumer's right to make informed choices.
8. Aboriginal & Torres Strait Islander people's ability to make decisions which preclude pressure from Researchers, e.g., Researcher's submitting a proposal and requesting approval the following week, Researcher's constantly contacting appropriate Community based representatives to request approval etc.
9. Aboriginal & Torres Strait Islander people's right to refuse to participate in research.
10. Aboriginal & Torres Strait Islander people's right to withdraw consent if a research project will produce a detrimental outcome for the Community.
11. Aboriginal & Torres Strait Islander people's right to apply self-determination principles to research projects.
12. Aboriginal & Torres Strait Islander people's right to access to all necessary information regarding research projects, which include roles of project staff, gathering of information, implementation phases etc.
13. Aboriginal & Torres Strait Islander people's right to direct research projects to ensure outcomes are enhancing communities sustainability and economic prospects.