Waitematā
District Health Board

Best Care for Everyone

Consumer Council

Wednesday

18 March 2020

2:00pm – 4:00pm

Venue
Nikau Meeting Room
Waitakere Hospital

Waitematā
District Health Board
Best Care for Everyone

CONSUMER COUNCIL
18 March 2020

Venue: Nikau Meeting Room, Waitakere Hospital
Time: 2:00pm – 4:00pm

Consumer Council Members	Ex-officio - Waitematā DHB staff members
David Lui (Council Chair) DJ Adams Neli Alo Boyd Broughton (Te Rūnanga o Ngāti Whātua) Lorelle George Insik Kim Angela King (Healthlink North) Jeremiah Ramos Kaeti Rigarlsford Ravi Reddy Lorraine Symons (Te Whānau o Waipareira) Vivien Verheijen	Dr Dale Bramley – Chief Executive Officer David Price – Director of Patient Experience Other Waitematā DHB staff members Brenda Witt – Complaints and Adverse Events Manager Jacky Bush – Quality and Risk Manager Amanda Mark – Legal Counsel Emily Dwight – Care Redesign Fellow

APOLOGIES

AGENDA

Disclosure of Interests (see page 5 for guidance)

- Does any member have an interest they have not previously disclosed?
- Does any member have an interest that might give rise to a conflict of interest with a matter on the agenda?

KARAKIA

	1.	**AGENDA ORDER AND TIMING**
	2.	**CONFIRMATION OF MINUTES**
2:00pm	2.1	Confirmation of the Minutes of Meeting 19 February 2020 Actions Arising from Previous Meeting
	2.2	Confirmation of 05 February 2020 Strategy Session Notes
	2.3	Summary of recommendations : Engagement with the Youth
	3.	**DISCUSSION ITEMS**
2.05pm	3.1	Expectation from the complaints process (Brenda Witt and Jacky Bush)
2.30pm	3.2	End of Life Care (Emily Dwight)
2.55pm	---	Break
3.00pm	3.3	Informed Consent (Amanda Mark)
3.25pm	3.4	Waitematā DHB Website
3.40pm	3.5	Presentation to the WDHB Board
	4.	**INFORMATION ITEM**
For noting	4.1	Patient Experience Report
	5.	**ANY OTHER BUSINESS**
3:50pm	5.1	Agenda for next meeting
3.55pm	5.2	Community concerns

Waitematā District Health Board

Consumer Council

Member Attendance Schedule 2019-2020

NAME	Jul 2019	Aug 2019	Sep 2019	Nov 2019	Feb 2020	Mar 2020	Apr 2020	Jun 2020
David Lui (Chair)	✓	✓	✓	✓	✓			
DJ Adams	✓	✓	✓	✓	✓			
Neli Alo	✓	✓	✓	✓	✓			
Boyd Broughton	✓	✓	✓	×	✓			
Lorelle George	✓	✓	×	✓	×			
Insik Kim	✓	✓	✓	✓	✓			
Angela King	✓	×	×	✓	✓			
Jeremiah Ramos	✓	✓	✓	✓	✓			
Ravi Reddy	✓	✓	✓	✓	✓			
Kaeti Rigarlsford	✓	✓	×	✓	✓			
Lorraine Symons	×	×	✓	✓	✓			
Vivien Verheijen	✓	✓	✓	✓	✓			
+Dale Bramley	✓	✓	✓	×	✓			
+David Price	✓	✓	✓	✓	✓			

✓	*attended*
×	*absent*
*	*attended part of the meeting only*
^	*leave of absence*
+	*ex-officio member*

WAITEMATĀ DISTRICT HEALTH BOARD
CONSUMER COUNCIL

REGISTER OF INTERESTS

Board/Committee Member	Involvements with other organisations	Last Updated
David Lui (Chair)	Director, Focus on Pacific Limited Chair, Consumer Advisory Committee, PHARMAC Board Member, Walsh Trust Board Member, Mental Health Foundation Chair - Board of Trustees, Henderson High School	18/09/19
DJ Adams	No declared interest	02/09/19
Neli Alo	No declared interest	24/09/19
Boyd Broughton	No declared interest	03/07/19
Lorelle George	No declared interest	03/07/19
Insik Kim	No declared interest	03/07/19
Angela King	An employee of Royal District Nursing Service which has a contract with Auckland District Health Board	03/07/19
Jeremiah Ramos	No declared interest	03/07/19
Ravi Reddy	Board Member – Hospice West Auckland Senior Lecturer – Massey University Honorary Academic – University of Auckland	19/02/20
Kaeti Rigarlsford	No declared interest	03/07/19
Lorraine Symons - Busby	MOU Liaison – Waipareira Trust	24/09/19
Vivien Verheijen	No declared interest	03/07/19

Conflicts of Interest Quick Reference Guide

Under the NZ Public Health and Disability Act 2000, a member of a DHB Board who is interested in a transaction of the DHB must, as soon as practicable after the relevant facts have come to the member's knowledge, disclose the nature of the interest to the Board.

A Board member is interested in a transaction of a DHB if the member is:
- a party to, or will derive a financial benefit from, the transaction; or
- has a financial interest in another party to the transaction; or
- is a director, member, official, partner, or trustee of another party to, or person who will or may derive a financial benefit from, the transaction, not being a party that is (i) the Crown; or (ii) a publicly-owned health and disability organisation; or (iii) a body that is wholly owned by 1 or more publicly-owned health and disability organisations; or
- is the parent, child, spouse or partner of another party to, or person who will or may derive a financial benefit from, the transaction; or
- is otherwise directly or indirectly interested in the transaction.

If the interest is so remote or insignificant that it cannot reasonably be regarded as likely to influence the Board member in carrying out responsibilities, then he or she may not be "interested in the transaction". The Board should generally make this decision, not the individual concerned.

A board member who makes a disclosure as outlined above must not:

- take part in any deliberation or decision of the Board relating to the transaction; or
- be included in the quorum required for any such deliberation or decision; or
- sign any document relating to the entry into a transaction or the initiation of the transaction.

The disclosure must be recorded in the minutes of the next meeting and entered into the interest register.

The member can take part in deliberations (but not any decision) of the Board in relation to the transaction if a majority of other members of the Board permit the member to do so. If this occurs, the minutes of the meeting must record the permission given and the majority's reasons for doing so, along with what the member said during any deliberation of the Board relating to the transaction concerned.
Board members are expected to avoid using their official positions for personal gain, or solicit or accept gifts, rewards or benefits which might be perceived as inducement and which could compromise the Board's integrity.

IMPORTANT

Note that the best course, when there is any doubt, is to raise such matters of interest in the first instance with the Chair who will determine an appropriate course of action.

Ensure the nature of the interest is disclosed, not just the existence of the interest.
Note: This sheet provides summary information only.

2. CONFIRMATION OF MINUTES

2.1 Confirmation of the Minutes of Meeting 19 February 2020
Actions Arising from Previous Meeting
2.2 Confirmation of 05 February 2020 Strategy Session Notes
2.3 Summary of recommendations : Engagement with the Youth

DRAFT Minutes of the meeting of the Consumer Council

of the Waitematā District Health Board

Wednesday, 19 February 2020

held at the Waitematā Room, Whenua Pupuke North Shore Hospital
commencing at 2.05pm

CONSUMER COUNCIL MEMBERS PRESENT:

David Lui (Chair)
DJ Adams (Ngati Maniapoto, Ngati Kahungunu)
Neli Alo (*present from 2:14pm*)
Boyd Broughton
Insik Kim
Angela King
Jeremiah Ramos
Kaeti Rigarlsford
Ravi Reddy
Lorraine Symons (Te Whānau o Waipareira)
Vivien Verheijen

ALSO PRESENT:

Judy McGregor (WDHB Board Chair) *present from 2.15pm*
Warren Flaunty (WDHB Board Member) *present until 3.17pm*
Dr Dale Bramley (Chief Executive, Ex-officio member) *present from 2.25pm*
David Price (Director of Patient Experience, Ex-officio member)
Dr Dean Manley (Consumer and Whānau Consultant)

PUBLIC AND MEDIA REPRESENTATIVES:

There were no public or media representatives present.

APOLOGIES:

Apologies were received and accepted from Lorelle George and late arrival from Neli Alo.

WELCOME:

The Consumer Council Chair welcomed everyone to the meeting. The members acknowledged the presence of Warren Flaunty to the meeting.

DISCLOSURE OF INTERESTS

There were no interests declared that might involve a conflict of interest with an item on the agenda.

The Chair reminder the members of the Council to submit an updated Declaration of Interest Form should there be changes from the last declaration made.

1 AGENDA ORDER AND TIMING

Items were discussed in same order as listed in the agenda. Discussion for Agenda Item 4.3 was deferred due to time constraints.

The meeting started with a Karakia.

2 CONFIRMATION OF MINUTES

2.1 Confirmation of Minutes of the Consumer Council Meeting held on 6 November 2019 (agenda pages 6-11)

Resolution (Moved Ravi Reddy/Seconded Angela King)

That the Minutes of the Consumer Council Meeting held on 6 November 2019 be approved.

Carried

Actions arising from previous meetings (agenda page 12)

The council noted the updates and no issues were raised.

3 INFORMATION ITEM

3.1 Patient Experience Report (Agenda pages 13-22)

David Price (Director, Patient Experience) noted the report as read highlighting that the DHB achieved its highest Net Promoter Score of 81 since the survey began in 2013.

Matters covered in the discussion and response to questions included:

- The Asian Health Services team provides cultural support to patients and whānau as well as an interpreter service. They also provide cultural/clinical support within the Mental Health Services Division of the DHB.
- David Price noted that payment of parking fee could be a barrier for patients to attend appointments. This is recognised by the DHB and it has adopted a 'compassionate parking policy' to address it. Information and posters are available on the website and are posted on the car park pay machines.

- A request was made for the next report to provide more visual presentation of information in the report.

3.2 Strategy Meeting Updates

David Price (Director, Patient Experience) provided an update on the discussions and actions points following the Strategy Meeting.

Matters covered in the updates included the following:

- Strategic Plan is in progress. This is being framed within the TOR of the Council to align activities within and in support of its responsibilities. A draft will be sent to Council members in the following week.
- A tracking list of recommendations made by the Council is also being drafted and will be sent to Council members in the following week.

3.3 **PHARMAC** presentation

David Lui (Chair, Consumer Council) presented an overview of the functions of PHARMAC. He highlighted the following items:

- PHARMAC's many functions include managing price of medicines and devices on behalf of New Zealand by reducing cost of medications using a variety of strategies and create savings.
- PHARMAC also promotes the proper use of medicine.
- Pharmac recently released its new strategy with 3 bold goals. Equity is an important focus for the organisation noting representation from Māori and Pacific. One of its goals is to eliminate inequities in access to medicines by 2025.
- The organisation's Consumer Advisory Committee ensures that PHARMAC has strong connection and engagement to the community.

Matters covered in the discussion and response to questions included:

- The PHARMAC website has a list of FAQs related to Lamotrigine and how the organisation is responding to issues with respect to this particular brand of medicine.
- The Consumer Advisory Committee are able to provide suggestions and recommendations on questions and concerns presented to them by PHARMAC as well as ask questions that are relevant to the communities they represent or engage with.
- There is focus on engagement with community and improving health literacy. The funding approval process involves extensive consultations with clinical experts as well as the public.

The Chair encouraged the members to email him if there are specific questions related to PHARMAC and he will be happy to respond as appropriate.

4 DISCUSSION ITEMS

4.1 Consumer and Whānau Advisory Team – Lived Experience Leadership (Agenda pages 23 - 32)

Dr Dean Manley (Consumer and Whānau Consultant) was present for the discussion of this item. He presented an overview of the team, in particular, its advocacy services for the consumer and whānau; the contribution to quality improvement of services provided through networking and feedback; provision of advice on policy and innovation strategies to achieve better outcomes and improve patient experience. Dean requested the Council's feedback and suggestion on how they can increase engagement and cooperation with the consumer council.

Matters covered in the discussion and response to questions included:

- In response to a question, Dean clarified that they work with the Patient Experience Team collaboratively. This can be through work streams or through co-designing of services with both community and whānau advisors.
- The team also provide inputs/support to investigations by the Coroner's office.
- In response to a question on ethnicity data of patients with mental health conditions, Dean noted that the team has a priority programme in place for Māori and Pacific to reduce inequities.
- No current strategy is in progress with respect to the proposed Cannabis Legalisation and Control Bill.
- Vaping in the youth is an issue for many communities but research on this is in its early stages.
- The team is working on different ways of working to support and improve outcomes. A particular focus is to identify ways to be able to communicate effectively to the youth community (12-29 year olds). Related to this, the WDHB Board Chair requested the members of the Council to provide their thoughts and inputs to David Lui and David Price on how the DHB can address this.
- The team also adopts a 'transition programme' called 'citizenship project' to prepare patients when they are ready to live back in the community.
- Community and consumer advisors are also being 'up-skilled' to assist in policy review.
- Some consumers/clients will be involved with a volunteer programme to provide peer and whānau support.
- There is also existing work on working with families and whānau for provision of continued support and recovery.
- A suggestion was made to consider people with intellectual disabilities on the team's plans and work streams.
- A section on Mental Health Services was requested to be incorporated into the next Patient Experience Report with particular focus on statistics for Māori and Pacific and quality improvements in place.

The council members also extended an invitation to the Senior Management Team of the Specialist Mental Health and Addictions Team to attend a future meeting of the consumer council to link and discuss areas of collaboration.

Dean thanked the members for their comments.

3.02 to 3.13pm – Session on break
3:07pm Warren Flaunty retired from the meeting

4.2 Outpatient Experience

David Price (Director, Patient Experience) provided an overview of the challenges of the outpatient process. David also tabled a previously drafted information sheet as well as a sample 'Guide Sheet' to help patients prepare for a doctor's visit.

Discussions, comments and suggestions received from the council include the following:

Information for Outpatients

- Form is helpful and informative, however, consumer lens need to be applied and will need to be developed within the health literacy policy. It was also suggested to consider 4Q's (questions) to ask the clinicians (*Do I really need it?; What are the risks?; Is there a safe option?; What will happen if I don't have the procedure?*). This is in line with the HQSC's 'Choosing Wisely' Programme.
- In line with the HQSC's 'Choosing wisely' the patients should be made aware that they have options and this should be promoted or made explicit to the patient.
- A checklist for clinicians should also be developed. A clinician's checklist aligned with the Outpatient's checklist could also be developed (for example 4Q's key takeaways for patients).
- Easy-read format (with more visual messages/pictures) should also be considered for information to be given to patients. This will address needs of patients with intellectual, visual as well as language barriers.

The appointment process

- There are different appointment systems adopted between NSH and WTH which could make it difficult for patients to navigate.
- There is also inconsistency in terms of advice and information given on phone calls. This could be very confusing to older people.
- There should be a consideration of convenience and accessibility to patients when setting schedule of appointments and location of appointments.
- The council provided examples of community members given appointments that do not consider a patient's condition (letters too small for patients with visual impairment/issues, appointments set over the phone for elderly patients, more youth-friendly approach to language for youth patients). Appointment letters and discussion with patients should consider these aspects.
- A suggestion was made to look into a process where in the clinical team can record a patient's needs during their appointment and a system that can capture this, so that in future appointments, the system will prompt the staff with this

information when making calls or preparing letters - this could enhance patient experience.
- Suggestions were also made into providing automated copies of letters to carers, whānau or support persons for patients with disabilities and/or language barriers.
- In response to a question on paper based appointments, it was clarified that the DHB also have an on-line booking process.

- A suggestion was made to highlight if a response is required from the patients on appointment letters. This will make it clearer for patients if there is a need to respond. This may reduce possibility of missing or inadvertently cancelling appointments by missing 'to respond' 'messages.

<u>During the appointment</u>

- There is a need to recognise the condition of the patient and the relationship. Patient could be confused and/or scared, as such, delivery of the message should be with empathy. Clinicians should also ensure that the patient has understood what has been communicated.
- The need for continued staff training on cultural competency was also highlighted. There was also a suggestion to consider utilising the volunteer ushers in the hospital as support persons or a Kaumatua to assist patients during and after an appointment.
- 'SOS cards' are given to patients. This will enable them to call in, if their condition changes prior to their next appointment.

<u>After the appointment</u>

- A letter (digital or paper based) to be provided to the patients similar to a discharge summary for in-patients was suggested. The challenge however for this is ensuring that this summary would be useful to patients as information is currently 'designed' for GPs. While a patient's GP could assist in providing more information, this is a barrier for patients who are not registered to a GP or attend their GP regularly.
- In relation to the above, it was suggested that a consideration is made for a 'contact centre' for outpatients wherein they can ask questions if there are aspects of the letter they do not understand.

David Price thanked the members for their suggestions.

4.3 Expectations from the Complaints Process

The discussion of this Agenda Item was deferred at the next meeting due to time constraints.

5 OTHER BUSINESS

5.1 Agenda for the next meeting

The following topics were identified to be included in the succeeding meetings of the council:

- End of life care – the DHB would like to improve the experience of patients (and their whānau) to make the end of like journey easier.
- Care for Bariatric patients

5.2 Community Concerns

In response to a suggestion for discussion of the health of Lesbian Gay Bisexual Transgender Transsexual Intersex (LGBTTI) community, the Chair suggested that the council can also out forward their recommendations for this subject or request a paper from the DHB.

David Lui thanked the members and attendees for their time.

The meeting concluded with a Karakia.
The meeting adjourned at 4.13pm.

SIGNED AS A CORRECT RECORD OF THE MEETING OF THE WAITEMATĀ DISTRICT HEALTH BOARD – CONSUMER COUNCIL MEETING HELD ON 19 FEBRUARY 2020.

________________________________CHAIR

ACTIONS ARISING FROM THE MINUTES OF THE MEETING OF THE CONSUMER COUNCIL AS AT 10 MARCH 2020

Minutes ref.	Topic	Person responsible	Action / Status
25/09/19	The council requested WDHB to review the procedures on the return of body parts (particularly for those patients who were in tragic events and accidents)	David Price (Director, Patient Experience)	- An update is provided below
19/02/20	The council requested that more visuals are used to present information related to the Patient Experience Report	David Price (Director, Patient Experience)	- Noted for action. Update will be reflected on the April Agenda
	A section on Mental Health Services was requested to be incorporated into the Patient Experience Report with particular focus on statistics for Māori and Pacific and quality improvements in place	David Price (Director, Patient Experience)	- Noted for action. Update will be reflected on the April Agenda
	The council was requested to submit their recommendations with respect to increasing engagement with the youth population.	Consumer Council Members	- Comments and suggestions have been received. A summary is included in this agenda

Waitemata DHB's policy on the return of body parts (version dated October 2019 attached at the end of this agenda)

The Waitematā DHB's policy exists to ensure all legal and cultural aspects pertaining to the storage, return to patient and disposal of body parts/tissue are complied with. Key points include the following:

Patients (or their representatives and/or parents /guardians for children) must receive sufficient information regarding body parts / tissue management to give informed consent. This discussion and consent must be recorded in the clinical record. However, In the case of an acute or emergency surgery where no 'Body Part/Tissue Release' form or 'Agreement to Treatment' form has been filled out, or where the form 'Authority to treat without consent' has been completed, then any body part/tissue removed is to be treated as if the patient has requested it to be returned.

The Ward staff/Medical staff will discuss with the patient his/her wishes regarding the return and/or retention of body part/tissue. The tissue that the patient wishes for return is either returned to the patient at the time (A delegate may collect on the patient's behalf as requested by the patient and on presentation of some form of identification) or held by Surgical Pathology and returned to the patient via the Director of Nursing who then writes to patients or their family to ask them where they wish for it to be picked-up.

On reply, arrangements are made to return the tissue in a discreet and respectful manner.

- The Maori Health staff may assist with this process.
- The Director of Nursing prepares the packages to main reception at North Shore of Waitakere Hospitals for pick up by the patient. They are advised of the process.
- The Director of Nursing delivers to the patient's home at times by special arrangement.

DRAFT Consumer Council Strategy Session Notes

Wednesday, 05 February 2020

held at the Waitematā Room, Whenua Pupuke North Shore Hospital
commencing at 12.00pm

CONSUMER COUNCIL MEMBERS PRESENT:

David Lui (Chair)
DJ Adams (Ngati Maniapoto, Ngati Kahungunu)
Neli Alo
Boyd Broughton
Lorelle George
Insik Kim
Angela King
Jeremiah Ramos
Kaeti Rigarlsford
Ravi Reddy
Lorraine Symons (Te Whānau o Waipareira)
Vivien Verheijen

ALSO PRESENT:

Judy McGregor (WDHB Board Chair)
Dr Dale Bramley (Chief Executive, Ex-officio member)
David Price (Director of Patient Experience, Ex-officio member)
Mark Allen (Facilitator, Community Waitekere)

Purpose

- Advocacy
- Development in health care (buildings, new services)
- Prioritisation
- System co-redesign

Objectives

- Equity access to treatment and services (this should be overarching objective/principle for the Council)
- Conduit for the community
- Improving Patient Experience.
- Strategise to assist in prioritising key issues

Risks – Consumer Council to advise when it comes to organisational risks rather than take them on.

How is the organisation using the Consumer Council advice?

- Action tracker is required for papers that were presented are required to report back how their feedback was used
- Create a feedback loop for all issues and agenda items discussed.

Important to have an example of how the Council have supported/influenced and changed something within the organisation – to assist with communication of our purpose to the community/organisation

Patient Experience feedback

- Core business – conduit for the community both inwards and outwards
- Council does not have capacity to take on individual experiences
- Themes of complaints and feedback
    - Provide information on the themes to understand effectively
    - Could assist with the Council focus
- Who is complaining?
    - Ethnicities of feedback
    - Other demographics of where feedback is coming from
- Patient experience information presented as a snap shot – to bring out key themes that members need to be aware of– do not overwhelm with too much information.

Key focuses over next 1-3 years and potential agenda items for discussion and exploration

- Bariatric Surgery
    - Targets not being met – high level of Maori accessing this service (50%)
    - Pathway in – disqualification process (does not support equity of access)
    - Long burning issue – would like to hold the DHB to account and maintain pressure
- Mental Health
    - underspend in this space?
    - Current areas of focus
    - Connection with Consumer Advisors in Mental Health
    - Prevention – upstream focus
- Oral Health
    - Equity of access to services
- Transgender Health
    - Fear of doctors
    - How are they coping overall?
    - Rainbow tick – work towards – ADHB doing well in this space
    - Training for staff
    - Medical and management support for recognition
- Disability
    - Staff training
    - Unconscious bias
    - Reading platforms to ensure documents/website are accessible to those with vision impairments
    - Don’t make assumptions
    - Access to buildings/facilities
- Youth
    - Lack of representation within the Council

    - How do we ensure their voices are heard?
- Rural Health
    - Supporting those particularly in the North of the DHB to access health care
- Communication
    - Access to the right services at the right time
    - Website development
    - Improve communication with ethnic communities – not just translated documents
        - Other social media options for ethnic communities.

    - Improve communication with all communities - especially North Shore and Rodney, who lack a vehicle such as Waitakere Health Link for communicating information from and to the DHB

Identifying further priorities for Council

- Health Needs Assessment
    - Data available – key priorities have already been identified – this may assist with council prioritising key areas of focus.
- Areas within the organisation that are stuck – advocate for change.

How do we communicate and ensure our voice is heard by the Board?

- There may be a political need to show support for the organisation
- We are a key part of the organisational governance – therefore should report to the Board.
- We should be mobilised and be a part of key discussions outside of the Council meetings – to advocate and be at the table.
- We are a conduit for the community
- Currently the Patient Experience information and hence the Consumer Council information is embedded as part of the Quality Report – this needs to be pulled out at least twice a year and the Council Chair is responsible to talk to a Consumer Council report.
- Informal combined lunch with the Board
- Involved and invited to any strategic planning sessions
- Review of key policies for endorsement
- Engaged with key projects coming up – rather than at the end after key decisions are made and limited opportunity to influence/change

Ecology of Consumer Engagement

- Connection with community networks
- Connection with the Board
- Connection with staff
- Connection with the community
- Communication vehicle for the DHB (to be further defined)
- Communicating our successes with the community and the DHB
- Monitoring our contribution to the DHB – Action Tracker

Working together as a Council?

We want to be dynamic!

David Lui and David Price are current gate keepers – however as a Council we want to be communicated with about what is being managed at this point. Priorities in relation to triage at this point should be around inequity, patient experience and influencing key policy.

David Lui conduit for member agenda items, David Price conduit for DHB agenda items. David L and David P meet a fortnight out from each meeting to ensure agenda is managed effectively and information meets the needs of the members to enable robust discussion.

When an agenda item is presented – staff experts are used to explain and be a part of the discussion, if a gap is highlighted by the Consumer Council within the discussions – this must be highlighted and presented to the Board.
Email burden – we do not want too many emails – however would like regular updates about what is happening within the DHB. Happy for things to be sent through for discussion via email – but do not overburden.

Use of other technology options can and should be consider to support access to meetings and other opportunities eg; skype, teleconference, zoom platforms.

Sub committees can be formed with Consumer Council members – these are ad hoc for areas of interest and not mandatory.

Two way street of engagement – agenda not just set by the DHB. Council members have an influence of topics of discussion – present issues that have been highlighted within their community.

At end of each meeting – agenda for next meeting is discussed to agree what should be given priority for discussion and how it should be presented. This will also assist members in how they present agenda items at future meetings.

A process for engaging with the Consumer Council should be developed.

- How we prioritise and when key topics should come to them ie: not for tick boxing at the end of a process.
- Consumer Council engagement as part of project Gantt charts in early stages of planning.

What does a successful Consumer Council look like?

- Consumer Engagement is BAU (Business as Usual)
- Tangible evidence of success – impact of making change
- Add value to the DHB
- Strong links to Board, ELT and SMT

- Feedback is implemented
- Inequity on all agendas – accountability, action plan and framework
- Regular items on agenda – are at a strategic level

ACTIONS

- Strategic plan to be simple to start – based on Hawkes Bay Model
    - A living document
    - Assists with framing
    - 2 pages maximum
- Action Tracker to be developed
    - To keep track of all agenda items presented to Consumer Council and enable the Council to be updated on how their feedback/advice has been used and influenced changed
    - Regularly updated by those who present agenda items
    - Aim for 6 month updated feedback loop
- 'Rules' of Consumer Council Engagement
    - List of questions to answer prior to considering Consumer Council engagement
    - Do not want to be tokenistic ie; sign off of brochures
    - Embed into project Gantt charts to ensure timing is appropriate
    - Ensure agenda items are discussion items not just information sharing
    - Questions for the council are presented within the agenda to enable effective preparation and engagement with the community.
    - Feedback loop integration
- Communication increase
    - More relevant and succinct information to be sent to Consumer Council
    - Specific newsletters and CEO updates will be sent for the Council to consider what information they are interested in receiving
- Elevator pitch development
    - A pitch to assist in promoting role within the community and enabling a clear understanding of Consumer Council roles
    - Council members can be a communication vehicle for the DHB.
- Future Agendas
    - To be discussed 6 weeks in advance at end of each meeting – to support council members in gathering more information and preparing for upcoming agendas
    - In addition, it assists with prioritising the agenda items
- 12 month timetable of agenda items
    - Assist with planning and prioritising
    - However this can be dynamic and flexible – given some items may become more topical throughout the year – therefore priorities will change.
    - Enables DHB services to prepare papers as required

2.3 Recommendations : Engagement with the Youth

The following are the themes gathered from the recommendations from the Consumer Council to increase engagement with the youth.

1. **Align policies and activities of the DHB to make it relevant and "matter" to the youth.**

   Making any kaupapa relevant, in alignment with what matters to them

   When I was with Healthlink North we held/organised x 2 Health Expos at Mahurangi College and Kaipara College. We had numerous health and social service related booths with talks and some fun stuff too. They were very interactive. At the Mahu one, there was a stand that had a push bike that when the students worked the pedals it made/squeezed fruit juices. From what I recall both of these Expos were a great success and were open during school time and I believe after school as well. There were also presentations. The students openly discussed their issues etc. with stall holders and took away key information. Wiki Shepherd organised one of them and would be a great person to talk to about it. Very involved and did a great job.

   To increase efforts to use social media to connect with young people.

   WDHB can start a social media campaign to get youth feedback. There may be opportunities to tag onto existing social media activities.

   WDHB can from time to time go out to the youth community (schools, tertiary institutions) to conduct targeted survey or similar on a specific issue. WDHB can also use other youth organisation website, newsletters, FB pages and other social medias platforms as a means to engage with youth.

   Kai; Technology; Social Media; Safety – this is probably huge; Confidentiality (which I guess is part of safety); Music

   Performing Arts e.g., music, dance, spoken word; working with some well-known local celebrities who the youth look up too, to run events etc.; offering Koha for their time and contribution; social media apps which are popular at the moment, tik tok, snapchat, instagram, etc.

   Sports event, like a fun run within the hospital compounds. This will make the public and the youth familiar with the hospital facilities; a beneficiary concert for the hospital held at the hospital grounds, with guest celebrities like Stan Walker. This will help the youth understand what the hospital does for the community; Celebrities have scheduled visits to the hospitals and is announced in social media, so the public can have a chance to mingle with them as well.

2. Consider a dedicated program or ‘hub’ to cater to youth

Employment of young person - if the youth issues are important enough and substantial WDHB can consider investing in employing someone to specifically focus on youth involvement and engagement with WDHB

Volunteer hospital work for the youth, like apprenticeship and the like, so they would be aware of the work involved in running a hospital.

Interactive community hub, where the public and the youth can just go to the computers, setup in a public space, if they have any inquiries.

I think teenagers and young adults may have little understanding about WDHB and its services. WDHB also may have little knowledge or awareness of teenagers and young adults. Teenagers and young adults know their issues and problems. My suggestion is to form a focus group (or other proper name) comprised of college students, university students and young working adults. This focus group may be operated for short-term or can become a sub-committee of CC depends on its progress and/or results. The member candidates may be recommended from schools (Colleges and universities) and community organizations such as CAB(Citizens Advise Bureau), TANI (The Asian Network Inc.) or Various ethnic group associations, etc.

Numbers of members could be between 5 to 10 people who are willing to participate and actively involved. The starting of the group task might be:

- *Gathering the members’ current state of knowledge about NZ healthcare system and WDHB services and their expectations from WDHB. Get their opinion about their issues and problems;*
- *WDHB to provide information about NZ health system, scope of WDHB services and direction of the desired target/expected results about 12-29 years age group's engagement etc.;*
- *Let members discuss and get some questions and their initial thoughts and the following process may be progressed as how WDHB guides or co work with them.*

My opinion is that their, teenagers and young adults, participation from initial stage is necessary, and they may contribute well if DHB selects the right members. I attach here some articles which I searched in short time and think might be helpful for this kinds of approach.

> *Advancing patient engagement: youth and family participation in health research communities of practice | Research Involvement and Engagement*

https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-018-0094-2

The Power of Prevention and Youth Voice: A Strategy for Social Work to Ensure Youths' Healthy Development
https://academic.oup.com/sw/article-abstract/63/2/135/4823231

3. Increase/formalise relationships with youth and other organisations

To engage with the Youth Advisory Panel, Auckland Council which will be confirmed shortly. It is made up of 21 young people - one from each of Auckland's local board areas - aged 14 to 24 (I know the contact person who is looking after the panel and can help to connect with them).
https://www.aucklandcouncil.govt.nz/about-auckland-council/how-auckland-council-works/advisory-panels/Pages/youth-advisory-panel.aspx

To contact and engage with local youth board [such as]
https://www.facebook.com/DevonportTakapunaYouthBoard/
https://www.facebook.com/pg/WhauYouthBoard/about/

To contact AUT and Massey University' students' associations, in particular, health-related facilities; and also offer placement opportunities for some students who are passionate about social services and health care.

To engage with local high school students who are interested in the health sector.

To contact some youth social groups and organisations, such as the North Shore youth innovation hub and Youthline:

https://ourauckland.aucklandcouncil.govt.nz/articles/news/2019/10/north-shore-youth-innovation-hub-to-open-early-2020/
https://www.youthline.co.nz/community-collaborations.html

Open days, activities at schools and events that are happening in the community which the WDHB can join and "piggy back" on to get views on specific issues from time to time.

Formalised relationships - teaming up with youth organisations through agreement (MOU) or other mechanism such as with Auckland Council as suggested already, Zeal (youth hub) in Henderson or other youth organisations, schools churches to establish a relationship to receive views and feedback and on the other hand provide them with information that may benefit them. It was brought to our earlier meeting that the DHB already has some established relationships with schools.

Working together with schools' Health Academies.

[To approach] All Universities have student associations (can get a diverse mix).

[To] approach the youth parliament and the Ministry of Youth Development (contacts and advice).

The following organisations/groups/connections might be useful in terms of increasing engagement:

- *Community Coordinators (North Shore) Youth connections, for example:*
    - *Jill Nerheny, Kaipatiki Community Facilities Trust Coordinator, eg Youth Board*
    - *Sarah Thorne,Takapuna North Community Trust Coordinator, including Inter-generational dialogue*
    - *Maria Teape, Devonport Community Coordinator, a variety of links with youth in the community, http://devonportdirectory.co.nz/devcom.htm*

- *YMCA Akoranga Drive*

"Rise Up" programme, https://www.raiseup.co.nz
Raise Up is YMCA's youth development programme run by youth for youth and operates from locations across New Zealand. Established in 2002, Raise Up has built on the long and successful history YMCA has had working with youth in local communities.

- *Bays Youth, Windsor Park, https://baysyouth.co.nz*

We help young people make positive changes in their own lives and become involved in their community. Our programmes and services provide positive early intervention and support to 11-18 year-olds and we help them develop the skills, confidence and experience they need to overcome challenges and create plans and steps towards achieving a bright future!

- *YES Disability Centre, Albany, through Sonia Thursby*

https://yesdisability.org.nz a range of youth connections, including the new centre being established in Shea Terrace, Takapuna

- *Northcote Baptist Church (and probably other large churches, eg Windsor Park), https://nbc.org.nz/ministries/youth*

- *Hibiscus Coast Youth Centre, https://kidslink.co.nz/services-view/hbc-youth-centre*

- *Public Health Nurses, Warkworth: strong linkages with youth through the Colleges (Orewa, Mahurangi)*

- *Other Colleges across the Waitemata area, through their senior students and leadership groups*

3. DISCUSSION ITEMS

3.1 Expectation from the complaints process
3.2 End of Life Care
3.3 Informed Consent
3.4 Waitematā DHB Website
3.5 Presentation to the WDHB Board

3.1 Discussion: Expectations from the Complaints Process

Recommendations:

The recommendations are that you:

a) Discuss your expectations from the Complaints process **Yes/No**
b) Discuss how we can 'close the loop' of the complaints process **Yes/No**

Background
All feedback (complaints and compliments) from patients, clients and their whānau are received by the Feedback Team and redirected to the appropriate service for investigation and response. Feedback can be given by telephone, in writing or by email (feedback@waitematadhb.govt.nz) , via *contact us* on the DHB website. You will be able to submit a complaint on behalf of a patient or family member. A complaints/compliments box is also situated in the main foyer of the hospital for patients to submit their feedback. It is DHB policy that all complaints are responded to within 14 calendar days of receipt. The team also encourages the service to phone complainants and ensure a patient-centred response.

Resource Persons

Brenda Witt – Complaints and Adverse Events Manager
Jacky Bush – Quality and Risk Manager

3.2 Discussion: Last days of life in WDHB hospitals: Te Ara Whakapiri

Recommendations:

The recommendations are that you:

a) Review the report regarding the last days of life in WDHB and the attached documents "Care in the last days of life" and "Ongoing care of the dying person" (Also known as the ACE chart) **Yes/No**

b) Prepare answers to the listed questions. **Yes/No**

Key Issues

There have been a number of complaints, adverse events, and negative experiences relating to adult inpatient care in the last days of life at North Shore and Waitakere Hospitals. The feedback received suggests that we do not explore the preferences and priorities of our patients and that we are missing opportunities to enhance comfort and peace while dying.

Key stakeholders from WDHB agree that there is an urgent need to improve the quality of care provided for patients in their last days of life. WDHB is initiating a piece of work to better recognise and meet the needs of people in their last days of life on our adult inpatient wards. Our aim is to put in place a bundle of care which is compassionate, holistic, and makes room for exploring patient and whānau priorities and preferences.

We are seeking 30 minutes of Consumer Council time to help us understand how to improve our care in the last days of life for patients and whānau. Our discussions will centre around the attached documents from the Te Ara Whakapiri Toolkit. We would like to know what you think of this pathway as a starting point for providing excellent care in the last days of life in WDHB and your ideas of how we translate this into practice on our wards.

Contacts for further discussion (if required)

Name	Position	Telephone	Suggested first contact
Emily Dwight	**i3 Fellow**	**021309704**	**Emily.dwight@waitematadhb.govt.nz**

End of Life Care in New Zealand:

Due to an ageing population the number of deaths in New Zealand is anticipated to markedly increase.[1] From a healthcare planning perspective this means an integrated system promoting high quality end-of-life care is a key priority area.[2] An important component of end-of-life care is the care provided someone's last days of life. Despite many people citing that home would be their preferred place of death, New Zealand data shows that the second most common place of death for New Zealanders is in a public hospital.[1]

The Last Days of Life in Waitematā DHB

There have been a number of complaints, adverse events, and negative experiences relating to adult inpatient care in the last days of life at North Shore and Waitakere Hospitals. The feedback received suggests that we do not explore the preferences and priorities of our patients and that we are missing opportunities to enhance comfort and peace while dying. Key stakeholders from WDHB agree that there is an urgent need to improve the quality of care provided for patients in their last days of life.

WDHB is initiating a piece of work to better recognise and meet the needs of people in their last days of life on our adult inpatient wards. Our aim is to put in place a bundle of care which is compassionate, holistic, and makes room for exploring patient and whānau priorities and preferences. Although we acknowledge that hospital would not be the preferred setting of many people who are dying, and we need to do our best to meet our patients' preferences, we want to make sure that while patients are in our hospitals they have a good experience in the last days of their life.

Te Ara Whakapiri

In New Zealand the standard of care for the last days of life has been outlined in a care pathway called *Te Ara Whakapiri* (Ministry of Health, 2017).[3] Te Ara Whakapiri is intended to guide end of life care provided in any setting including hospital, aged residential care, and home. The pathway centres around seven principles to promote the provision of individualised, holistic, person-centred care. To help translate the principles into practice, the expert working panel developed a toolkit of resources, including a "Care in the last days of life" pathway and observation chart equivalent (the ACE chart).

After Te Ara Whakapiri was developed by the Ministry of Health, it was left to each DHB to implement the pathway, including adaptation according to the needs of each DHB and integration into existing models of care. Although there is currently some awareness of Te Ara Whakapiri in WDHB, it is not being used routinely.

Due to WDHB's commitment to continuous improvement and person-centred care, we are proposing to re-implement Te Ara Whakapiri in WDHB. This process will include co-design of the pathway with groups of consumers and clinicians to ensure it meets our consumers' needs, digitalisation of the pathway so that it is built into clinical work streams and is therefore universally used, and piloting the pathway on a small number of wards using quality improvement and co-design methodologies with the aim of scaling across all wards.

<u>What we are seeking from the consumer council:</u>

We are seeking 30 minutes of Consumer Council time to help us understand how to improve our care in the last days of life for patients and whānau. Our discussions will centre around the attached documents from the Te Ara Whakapiri Toolkit. We would like to know what you think of this pathway as a starting point for providing excellent care in the last days of life in WDHB and your ideas of how we translate this into practice on our wards.

<u>Te Ara Whakapiri toolkit</u>

Please review the attached documents and see the brief explanations below. Please note that these documents are designed for healthcare professionals to complete with input from the person and their whānau

"Care in the last days of life" document

This document is designed to guide healthcare professionals to recognise and address physical, emotional, cultural, spiritual, and whānau needs in the last days of life. The current forms include parts of the process which are nurse-led, and a part which a doctor or nurse prescriber needs to complete (in order prescribe relevant medications, for example). It is a pathway of continuing care and not intended to be completed all at once.

The ACE chart

The needs of someone who is dying are different than other patients we care for in the hospital. The focus shifts from monitoring blood pressure, heart rate, and respiratory rate (for example), to monitoring for signs of discomfort and/or distress. The Te Ara Whakapiri ACE chart would be the equivalent of an observations chart to make sure we are identifying and meeting patient's health needs in the last days of life.

<u>Questions</u>

1. Do these resources encapsulate all the elements of care which would matter to you and your whānau in the last days of life?
2. From a consumer perspective, how would you like to see this pathway translated into practice? What would excellent care in the last days of life look like in the hospital setting?

References:

1. McLeod H. The Need for Palliative Care in New Zealand [Internet]. Tas.health.nz. 2016. Available from: https://tas.health.nz/assets/Health-of- Older-People/Technical-Report-Need-for-Palliative-Care-vF2-June-2016-H- McLeod.pdf
2. Ministry of Health. Palliative Care Action Plan [Internet]. Wellington; 2017. Available from: https://www.health.govt.nz/system/files/documents/publications/palliative- care-action-plan_0.pdf
3. Ministry of Health. Te Ara Whakapiri: Principles and guidance for the last days of life. (2nd edn) [Internet]. Wellington: Ministry of Health; 2017. Available from: https://www.health.govt.nz/system/files/documents/publications/te-ara- whakapiri-principles-guidance-last-days-of-life-apr17.pdf

Local logo

Patient name:
NHI:
DoB:

Care in the last days of life

Baseline assessment

Recognition that the person is dying or is approaching the last days of life

Is the *Recognising the Dying Person Flow Chart* available to support decision-making? Yes ☐

Diagnosis: Ethnicity:

Lead practitioner name: Designation:

Lead practitioner's contact no: After-hours contact no:

Note: The lead practitioner is the person's GP, hospital specialist or nurse practitioner.

The person's awareness of their changing condition

Is the person aware they may be entering the last few days of life? Yes ☐ No ☐

The family/whānau's awareness of the person's changing condition

Is the family/whānau aware that the person may be entering the last few days of life? Yes ☐ No ☐

Family/whānau contact

If the person's condition changes, who should be contacted first? Name:

Relationship to person: Phone (H): (Mob):

When to contact: At any time ☐ Not at night-time ☐ Staying overnight ☐

Is an enduring power of attorney in place? Yes ☐ No ☐

Has it been activated? Yes ☐ No ☐ N/A ☐

Advice to relevant agencies of the person's deterioration

Has the GP practice been contacted if they are unaware the person is dying? (If out of hours, contact next working day.) Yes ☐ No ☐ N/A ☐

Note: Consider notifying the person's specialist teams, district nursing services, residential care and other agencies involved in their care.

Has this assessment been discussed with the person and family/whānau and priorities of care been identified? Yes ☐ No ☐

If not, discuss reasons:

Taha tinana – *Physical health*

Assessment of physical needs

Is the person: Conscious ☐ Semi-conscious ☐ Unconscious ☐

In pain	Yes ☐	No ☐	Able to swallow	Yes ☐	No ☐	Confused	Yes ☐	No ☐
Agitated	Yes ☐	No ☐	Continent (bladder)	Yes ☐	No ☐	Experiencing respiratory tract secretions	Yes ☐	No ☐
Nauseated	Yes ☐	No ☐	Catheterised	Yes ☐	No ☐			
Vomiting	Yes ☐	No ☐	Continent (bowels)	Yes ☐	No ☐	Skin integrity at risk	Yes ☐	No ☐
Dyspnoeic	Yes ☐	No ☐	Constipated	Yes ☐	No ☐	At risk of falling	Yes ☐	No ☐

Is the person experiencing other symptoms (eg, oedema, myoclonic jerks, itching)? Yes ☐ No ☐

Describe:

Patient name:
DoB:

Availability of equipment

Is the necessary equipment available to support the person's care needs (eg, air mattress, hospital bed, syringe driver, pressure-relieving equipment)? Yes ☐ No ☐

Provision of food and fluids

Is clinically assisted (artificial) nutrition in place? Yes ☐ No ☐

If yes, record route: NG ☐ PEG/PEJ ☐ NJ ☐ TPN ☐

Ongoing clinically assisted (artificial) nutrition is:

Not required ☐ Discontinued ☐ Continued ☐ Commenced ☐

Is clinically assisted (artificial) hydration in place? Yes ☐ No ☐

If yes, record route: IV ☐ Subcut ☐ PEG/PEJ ☐ NG ☐

Ongoing clinically assisted (artificial) hydration is:

Not required ☐ Discontinued ☐ Continued ☐ Commenced ☐

Doctor or nurse practitioner to complete

Review of current management and prescribing of anticipatory medication

Has current medication been assessed and non-essentials discontinued? Yes ☐

Has the person's need for current interventions been reviewed? Yes ☐

Anticipatory prescribing of medication completed (refer to relevant symptom management flow charts (links):

Pain	Yes ☐	Nausea/vomiting	Yes ☐
Agitation	Yes ☐	Dyspnoea/breathlessness	Yes ☐
Respiratory tract secretions	Yes ☐		

Have additional treatment and/or care-related issues been discussed with the family/whānau if needed (eg, food, fluids, place of care, ceiling of care, cardiopulmonary resuscitation)? Yes ☐

Consideration of cardiac devices: If a person has a cardiac device (eg, cardioverter defibrillator (ICD) or ventricular assist device), a conversation should take place with the person and/or the family/ whānau to discuss what can occur in the last days of life, whether the cardiac device should be deactivated and, if so, how and when this would take place.

Has the cardiac device been deactivated? Yes ☐ No ☐ No ICD in place ☐

Full documentation in the clinical record is required for any issues identified.

Doctor's / nurse practitioner's name (print): ……………………

Signature: …………………… Date: …………… Time: ……………

Taha hinengaro – *Psychological and mental health*

Assessment of the person's preferences and wishes for care

Does the person have an advance care plan (ACP) / or other directive? Yes ☐ No ☐

Has the person expressed the wish for organ/tissue donation? Yes ☐ No ☐

Has the person expressed a preferred place of care?

No preference ☐ Home ☐ ARC ☐ Hospital ☐ Hospice ☐

Does the person have a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) order in place? Yes ☐

Does the person have any cultural preferences? Yes ☐ No ☐

If yes, describe: ……………………

Does the person have any emotional or psychological symptoms or concerns? Yes ☐ No ☐

If yes, describe: ……………………

Patient name:
DoB:

Te wairua – *Spiritual health*

Provision of opportunity for the person and their family/whānau to identify what is important to them

If able, has the person been given the opportunity to express what is important to them at this time (eg, wishes, feelings, spiritual beliefs, religious traditions, values)? *(Refer to the person's ACP for personal wishes if completed)* Yes ☐ Not able ☐

Specify if applicable: ....

Has the family/whānau been given the opportunity to express what is important to them at this time? Yes ☐

Specify if applicable: ....

Has the person's own spiritual advisor/minister/priest been contacted? Yes ☐ N/A ☐

Name: .... Contact no: .... Date/time: ....

Are there other needs to address (such as access to outdoors, pets, touch therapy, music, prayer, literature, etc)? Yes ☐ No ☐

....

Te whānau – *Extended family health*

Identification of communication barriers and discussion of needs

Is the person able to take a full and active part in communication? Yes ☐ No ☐

Have the cultural needs of the family/whānau been identified and documented? Yes ☐

Has the person and/or the family/whānau expressed concern about previous experiences of death and dying? Yes ☐ No ☐

Provision of information to the family/whānau about support and facilities

Has the family/whānau received information about support and facilities available to them? Yes ☐

Has the *When Death Approaches* information sheet been offered to the family/whānau? Yes ☐

If the person is being cared for at home, has the family/whānau received information about who to contact after hours or if the person's condition changes? Yes ☐

Has the *Dying at Home* information sheet been offered to the family/whānau? Yes ☐

Has advice been given to the family/whānau on what to do in an emergency? Yes ☐

Full documentation in the clinical record is required for any issues identified in this assessment.

Nurse's name (print): .... Date: ....

Signature and designation: .... Time: ....

Care after death

It may be appropriate to complete some of this section before the person's death.

Taha tinana – *Physical health*

Verification of death

Time of death: .... Date of death: ....

Is the person to be buried or cremated? Burial ☐ or Cremation ☐

Name of doctor informed of person's death: ....

Name of funeral director: .... Tel no: ....

Date and time death verified: .... Who verified the death? ....

Patient name:
DoB:

Taha tinana – ***Physical health*** (continued)

Is the coroner likely to be involved? Yes ☐ No ☐

Has a medical certificate been completed? Yes ☐ Doctor's name: ……………………

Note: Relevant members of the multidisciplinary team (MDT) should be advised of the person's death in a timely fashion (eg, district nurses, hospice, GP/specialist).

The person/tūpāpaku is treated with dignity and respect.

Ensure the wishes and cultural requirements of the deceased person and their family/whānau are met in terms of after-death care.

Are valuables to be left on the person/tūpāpaku? Yes ☐ No ☐

……………………………………………………

Note: Support the family/whānau to participate in after-death care if they wish to be involved, undertake after-death care according to local policies and procedures and return personal belonging to the family/whānau in a respectful way.

Te whānau – ***Extended family health***

Has the family/whānau been given the opportunity to express spiritual, religious and cultural needs? Yes ☐

Note: Provide an opportunity to talk with the family/whānau about their spiritual, religious or cultural needs.

Has a private space been made available for the family/whānau? Yes ☐

Note: Respect the family/whānau need for privacy, ensure a private space is available for prayer, karakia or other cultural or spiritual needs and arrange for blessing of the room/bedspace as appropriate.

The family/whānau is provided with information about what to do next.

Has a conversation been held with the family/whānau to ensure they have adequate information about what to do next? Yes ☐

Has written material been offered (this may include information regarding local funeral directors, funeral planning, etc)? Yes ☐

Note: Additional support should be offered at the time of death if needed. This may include a social worker, cultural support and/or chaplain support.

Taha hinengaro – ***Mental health***

The family/whānau is able to access information about bereavement support and counselling if needed.

Was the family/whānau present at the time of death? Yes ☐ No ☐

If not, has the family/whānau been notified? Yes ☐ No ☐

Name of person notified: …………………… Relationship to the deceased person: ……………………

If no one was notified, explain why not.

……………………………………………………

Did the family/whānau appear to be significantly distressed by the death? Yes ☐ No ☐

Was there evidence of conflict that remained unresolved within the family/whānau? Yes ☐ No ☐

Note: Written bereavement information should be offered as available.

If Yes was ticked to either of the last two questions AND/OR the family/whānau expressed distress at being unable to say goodbye, complete the Te Ara Whakapiri Bereavement Risk Assessment Tool.

Nurse's name (print): …………………… Date: ……………………

Signature and designation: …………………… Time: ……………………

MINISTRY OF HEALTH
MANATŪ HAUORA

Local logo

Patient name:
NHI:
DoB:

Ongoing care of the dying person

Use the ACE coding below, initial each entry and record details in the progress notes. Seek a second opinion or specialist palliative care support as needed.

A C E codes:	**A = Achieved** No additional intervention required	**C = Change** Intervention required and documented	**E = Escalate** Medical or senior nurse review required and documented

Domains and goals	**Date**	/ /						/ /					
	Time												
Te taha tinana – *Physical health*													
Pain The person is pain free at rest and during any movement.													
Agitation/delirium/restlessness The person is not agitated or restless and does not display signs of agitated delirium or terminal anguish.													
Respiratory tract secretions The person is not troubled by excessive secretions.													
Nausea and vomiting The person is not nauseous or vomiting.													
Breathlessness/dyspnoea The person is not distressed by their breathing.													
Other symptoms (document fully in clinical notes) The person is free of other distressing symptoms, eg, myoclonic jerks, itching.													
Mouth care The person's mouth is moist and clean.													
Nurse initials each set of entries													
		AM		PM		N		AM		PM		N	
Elimination (bowels and urination) Outputs are managed with pads, catheters, stoma care, rectal interventions, etc. *Note: Observe for distress due to any of the following: constipation, faecal impaction, diarrhoea, urinary retention.*													
Mobility/pressure injury prevention The person is in a safe and comfortable environment. Repositioning and use of pressure relieving equipment is effective.													

Ongoing care of the dying person

Person's name:
DoB:

A C E codes:	**A = Achieved** No additional intervention required	**C = Change** Intervention required and documented	**E = Escalate** Medical or senior nurse review required and documented

Domains and goals	**Date**	/ /			/ /		
	Time	AM	PM	N	AM	PM	N
Te taha tinana – *Physical health*							
Hygiene/skin care The person's personal hygiene needs are met. The person's family/whānau has been given the opportunity to assist with the person's personal care.							
Food/fluids Oral intake is maintained for as long as the person wishes. If in place, artificial hydration and feeding is meeting the person's needs.							
Te taha hinengaro – *Psychological / mental health*							
Emotional support Any emotional distress such as anxiety is acknowledged and support is provided.							
Cultural The person's cultural needs are acknowledged and respected.							
Te taha wairua – *Spiritual health*							
Addressing spiritual needs Religious and spiritual support is offered to the person and to their family/whānau as per the person's wishes.							
Te taha whānau – *Extended family health* (these items refer to the health of the carers, not the person)							
Emotional support Any distress relating to issues such as grief and anxiety is acknowledged and addressed. The need for privacy is respected.							
Practical support Advice and guidance are offered according to the needs of the person's family/whānau.							
Cultural support The cultural needs of the family/whānau are reviewed and care is mindful of these needs.							
Communication Communication is open to address any fears or concerns about the dying process.							
Nurse initials each set of entries							

Waitematā
District Health Board
Best Care for Everyone

3.3 Discussion: Agreement to Treatment / Consent Form

Recommendations:

The recommendations are that you:

a)	Note that key aspects of the consent form have been revised	**Yes/No**
b)	Endorse the proposed changes to the Agreement to Treatment / Consent Form	**Yes/No**

Background

Before a patient is provided a procedure or treatment, permission needs to be given for a healthcare provider to proceed lawfully. Informed consent is the process of providing sufficient information for a patient to understand, rationalise the benefits and risks, and voluntarily provide permission for the procedure or treatment based on their informed decision. One aspect of the informed consent process involves going through the Agreement to Treatment / Consent form. The purpose of this form is to facilitate a two-way conversation between the clinician and the patient and their whanau and to summarise and confirm the informed consent made by the patient and acknowledge what has been agreed.

In July 2019, a formal complaint was made to the Health and Disability Commission relating to concerns with the current Waitematā DHB Agreement to Treatment / Consent form, February 2018 version. In particular, it sought further clarification about the role of students and health professionals in various stages of training, and what needs to be explicitly consented in terms of their involvement in procedures and any examinations they may be undertaking on patients. It also highlighted clarity was required for consenting the involvement of House Officers and Registrars, who are qualified registered health care professionals employed to provide clinical care in our hospital involved with an ongoing training programme.

An informed consent steering group reviewed the form and sought feedback from the Consumer Council in August and September 2019. The steering group found the Agreement to Treatment / Consent Form was of very good standard and is consistent with legal and ethical requirements. It was acknowledged that it could be made more user-friendly and clarified, taking on board the valuable input from the Consumer Council.

The Consumer Council recommendations in relation to clarity of language, cultural sensitivity, availability of patient information to improve the process leading up to the completion of the consent form are being addressed through the development of digital and non-digital resources with the Institute of Innovation and Improvement. The Consumer Council's comments relating to the content of the form (feedback from a workshop on 14 August 2019) are informative. It highlighted more information on the role of students / learners on the procedure would be useful and that the way the statements are presented is "confronting" and it "doesn't feel like there is an option to opt out". The word "present" is said to be misleading since it implies observation only. Also, it is not clear whether the reference to "training" refers to a different staff group to the students.

We sought advice from Prof Ron Paterson, expert in health law and the former HDC and Ombudsman. He also came to the conclusion that:

“The Consent form does not specifically seek consent to observation and/or hands on participation by trainees who are not yet qualified to do a procedure on their own, even though the Informed Consent policy says that ‘explicit permission’ is required in such circumstances. The form should be revised to be consistent with the policy. “

In view of this key aspects of the consent form have been revised, with detailed advice from Prof Paterson. The draft updated consent form is presented for your consideration today.

Resource Person

Amanda Mark – Legal Counsel

Overview of the Proposed Changes to the Agreement to Treatment / Consent Form

Current consent form (August 2018 version)	**Consumer Council Feedback on current consent form**	**Proposed changes to the consent form**	**Justification for change**
I agree that:	Perception that all aspects must be agreed to. Format doesn't indicate options for refusal	I agree that: *[Cross out anything you don't agree with]*	Make clear to patients / guardians that they can cross out any statement they do not agree with.
I have had adequate opportunity to ask questions and I have received all the information that I require.	No comments were made for this.	I have had adequate opportunity to ask questions and I have received all the information that I need.	Changed the work require to need to align with the word used in right 6(2) from the Code of Rights
I understand that during this procedure images or pictures relevant to my / the patient's care may be captured and incorporated into my / the patient's clinical record.	No comments were made for this.	To remove entire bullet point.	Decision to omit since images are part of clinical record and is lawfully and appropriately being collected.
I understand that in the event of an emergency, and as determined by my / the patient's medical team at the time, there may be other procedures undertaken to save my / the patient's life or prevent harm.	No comments were made for this.	In the event of an emergency, and as determined by my / the patient's medical team at the time, there may be other procedures undertaken to save my / the patient's life or prevent harm.	Removal of "I understand", which is implied with the statement I agree. This improves ease of reading.

I understand that my / the patient's care is occurring in a teaching hospital and there may be healthcare students (medical, nursing) present. I understand they will be appropriately supervised but at any time I can ask for them not to be present.	Felt misrepresentative using the term "present" for students. Group interprets this as only observing. Group would prefer an option to opt in to having a student.	My / the patient's care is occurring in a teaching hospital and healthcare students (medical, nursing) and clinicians in training may be present to observe and learn. I understand they will be appropriately supervised but at any time I can ask for them not to be present.	The form has been revised to be consistent with the policy. It is more specific regarding the observation and/or hands on participation by health care students or qualified health care professionals involved with ongoing training.
I understand that no assurance can be given that a particular clinician will be performing my / the patient's procedure but that the clinician will be suitably qualified and, if in training, will be appropriately supervised by a senior clinician.	It was not clear that 'in training' refers to a different staff group to the students. Further clarification was required.	My / the patient's health care will be delivered by a team, which may include registered doctors and nurses in training. On the day, so far as reasonably practicable, I / the patient will be introduced to the clinicians who will be performing my / the patient's procedure. They will be suitably qualified and, if in training, will be appropriately supervised by a senior clinician.	

INTERPRETER REQUIRED: Yes ☐ No ☐ LANGUAGE: ______________________________

SURGERY / OTHER PROCEDURE(S)

I, ____ (name of patient / parent or guardian / welfare guardian or attorney under enduring power of attorney)

Agree that the following procedure be performed for me / my child / person in respect of whom I am welfare guardian or attorney under an enduring power of attorney

____

____

____

____ If relevant specify side (***circle one***): **Right / Left**

I have discussed this with:

Name ________________________________ **Designation** ________________ **Signature** ____________________________

They have explained to me the reason for this procedure, the alternatives, and the possible risks.

Risks of the procedure include (but are not limited to):____

____

____

____

____

I agree that: *[Cross out anything you don't agree with]*

- I have had adequate opportunity to ask questions and I have received all the information that I need.
- In the event of an emergency, and as determined by my / the patient's medical team at the time, there may be other procedures undertaken to save my / the patient's life or prevent harm.
- My / the patient's care is occurring in a teaching hospital and healthcare students (medical, nursing) and clinicians in training may be present to observe and learn. I understand they will be appropriately supervised but at any time I can ask for them not to be present.
- My / the patient's health care will be delivered by a team, which may include registered doctors and nurses in training. On the day, so far as reasonably practicable, I / the patient will be introduced to the clinicians who will be performing my / the patient's procedure. They will be suitably qualified and, if in training, will be appropriately supervised by a senior clinician.

Blood accidents

- If a healthcare worker is accidentally exposed to my / the patient's blood or other body fluids, I agree to a sample of my / the patient's blood being taken and tested for transmissible diseases such as Hepatitis and HIV
- I understand I will be informed if this happens and test results will be discussed with me and if required treatment will be given.

Return of Body Parts

- I wish to have any body part / tissue removed during this procedure that is not required for diagnosis returned to me: Yes / No (***circle one***) if *yes ensure this is documented on the Laboratory form and Theatre staff have been informed.*

Patient / Welfare Guardian / Attorney's signature:____________________________________ **Date:**______/______/_______

Interpreter's signature:______________________________________ **Interpreter's name:**______________________________

ANAESTHESIA

AGREEMENT TO TREATMENT / CONSENT

Review Date: mmm yyyy

Waitemata
District Health Board
Te Wai Awhina

Waitemata DHB Wide

[*PLACE PATIENT LABEL HERE*]

First Name: ____________________________ **Gender:** ________
Surname: ______________________________ **Ph:** ____________________
Address: ____
Date of Birth: ______________ **NHI#:** _________________
Ward/Clinic: ______________ **Consultant:** _________________

Agreement to Treatment / Consent

I, ____(name of patient / parent or guardian / welfare guardian or attorney under enduring power of attorney)

Agree that the Anaesthetic for me / my child / person in respect of whom I am welfare guardian or attorney under an enduring power of attorney has been explained to me for the procedure discussed overleaf

- I agree to the following Anaesthetic as discussed: ____
  ____
- The possible benefits and risks of the Anaesthetic have been explained to me relating to my / the patient's clinical history and condition.

The risks include, but are not limited to: ____
____
____
____

I / the patient have been advised NOT to drive a motor vehicle, operate machinery or potentially dangerous appliances, drink alcoholic beverages or make important decisions for 24 hours after having a general anaesthetic or sedation agents administered.

Patient / Welfare Guardian / Attorney's signature:_________________________________ **Date:**_______/______/________

Interpreter's signature:______________________________________ **Interpreter's name:**______________________________

Anaesthetist's signature:____________________________________ **Anaesthetist Designation:** ________________________

Name of Anaesthetist:_______________________________________ **Date:**______/______/_______

BLOOD COMPONENTS AND PRODUCTS

☐ I have been advised that I / the patient may require blood, or blood product transfusion. I have been advised of the possible risks, benefits and alternatives to blood transfusion. I understand the risks of blood transfusion refusal.

☐ I have had the opportunity to ask questions and discuss this with the Clinician whose signature appears below.

☐ I **agree** to receive blood or blood products if these are considered necessary by the Doctors looking after me / the patient. I understand I / the patient may need to receive repeated transfusions.

OR

☐ I **DO NOT** agree to receive blood components and / or products under any circumstance and I understand the risks of this decision.

Patient / Welfare Guardian / Attorney's signature: _________________________________ **Date:** ______/______/________

Interpreter's signature: _____________________________________ **Interpreter's name:** ____________________________

Clinician's signature: _______________________________________ **Clinician's Designation:** __________________________

Name of Clinician: ____ **Date:** _______/________/________

AGREEMENT TO TREATMENT / CONSENT

Review Date: mmm yyyy

3.4 Discussion: Waitematā Website Wish List Development

Recommendations:
The recommendations are that you:

a)	Review the current Waitematā DHB website	**Yes/No**
b)	Review the current analysis of how website is currently used	**Yes/No**
c)	Respond to questions below to create website wish list	**Yes/No**

Key Issues

The current Waitematā DHB website was launched around 5 years ago and is no longer fit for purpose as there has been no dedicated FTE to support and update the website for a couple of years. As such there is content that is outdated and no longer needed. The scope and requirement for the website has also changed since it was first launched and there is a need to align it with what and how our consumers as well as staff use the information on the website.

The version of the content management system (CMS) that the website is developed in is also out of date, so this presents a good opportunity for us to rebuild the website and improve functionality. There are however some limitations for the scope of our development:

- We need to meet the highest level of security due to sensitive information potentially being sent through the contact forms on the website. The recommended CMS from the Department of Internal Affairs (DIA) is Silverstripe which must be hosted on the Common Web Platform managed by the DIA.
- The backend development and support for the DHB website is managed by healthAlliance, so they would need to approve of the any developer that we engage for the rebuild.

Recent analytics conducted for the current website highlighted growth in use of the website – however the highest users driving growth are staff. Consumer growth in website access is slower. From those that do access the site, around 70% do so from their mobile devices.

It is hoped that with the Consumer Councils support that a wish list can be developed to inform a business case for funding to be allocated to the development of a new fit for purpose website that meets the needs of our community.

To develop this wish list the following questions are posed for discussion.

- What information you are commonly looking for?
- What are the things that you find most frustrating/difficult when accessing the site?
- What content would you expect to find on the website that is not currently available?
- What other features would you like to see in the website?
- Do you generally just use the website search to find information?

Contacts for further discussion (if required)

Name	Position	Telephone	Suggested first contact
David Price	**Director of Patient Experience**	**021 715 618**	✓
Matthew Rogers	**Director of Communications**	**021 228 9432**	

3.5 Discussion: Presentation to the WDHB Board

Recommendations:

The recommendation is that you:

a) Discuss and agree on the topics and updates to be provided to the WDHB Board **Yes/No**

Background

The Waitematā District Health Board (DHB) Consumer Council works collaboratively with the Waitematā DHB Chief Executive, and Board to develop effective partnerships in the design, planning and delivery of high quality, safe and accessible health care services for the Waitematā community.

In line with the Council's focus and area of work related to governance through provision of advice and support, regular reports will be provided to the Board to ensure that the DHB is engaging with consumers at all levels of governance.

Since its initial meeting in July 2019, the Council has already put forward a number of recommendations and suggestions to various services that impact on patient experience.

The members are therefore asked to provide their insights on the topics and updates they wish to provide to the Board members of the Waitematā DHB.

4. INFORMATION ITEM

4.1 Patient Experience Report

4.1 Information Item: Patient Experience Report (January 2020)

Executive Summary

The Waitematā DHB Patient Experience Team is led by Director of Patient Experience. This team supports all divisions and services of the organisation by collecting, listening to and analysing patient, whānau, staff and community feedback to provide a better understanding of what matters to our diverse community. This informs organisational strategic direction and highlights local service improvements to enhance the patient experience and achieve better health outcomes for our community. The Patient Experience team works with divisions, teams and services to deliver innovative, responsive, accessible and flexible care that meets the individual needs of our patients and their whānau throughout the whole patient journey.

The Director of Patient Experience also supports Chaplaincy Services and the Asian Health Services Team. Waitematā DHB's Asian Health Services (AHS) provides a range of services and programmes for Asian patients, families and community members. These services include: iCare Health Information Line, Asian Breast Screening Support Service, Asian Patient Support Service, Asian Mental Health Service, WATIS (Waitemata Translation & Interpreting Service) and Health Promotions. The Asian Health Services Team has many aims including: providing communication (language) support to Waitematā DHB staff and non-English speaking patients/clients and their families; providing cultural, emotional and coordination support to Asian patients/clients. The Interchurch Council for Hospital Chaplaincy (ICHC) provide seven Chaplains and a part time Administrator across North Shore Hospital, Waitakere Hospital and Mason Clinic to support pastoral care and spirituality support for our inpatients, whānau and staff.

Highlights

- Volunteers feel more connected after attending Welcome to Waitemata workshops.
- Asian Health Services is working with Waietmata DHB’s communication team and Auckland Regional Public Helth Service (ARPHS) to provide accurate information about Coronavirus (COVID-19).
- Asian Health Services offered a Pacific Cultural Workshop for Asian staff and ethnic interpreters as part of the ***Let’s get real*** - Workforce Development Project

Key issues

- Long wait times, poor signage, poor service/care, short staffed, food and the environment are some reasons for patients giving a low score on the Friends and Family Test in January.
- Inaccurate information about Coronavirus (COVID-19) shown on Asian media contributed to increase fear and unnecessary panic in the community.

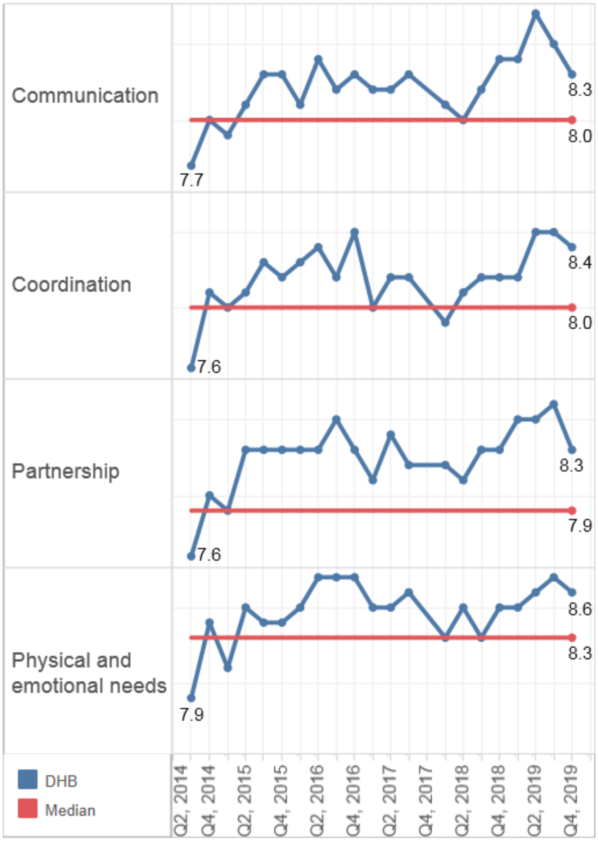
1.0 Patient Experience Feedback

1.1 NATIONAL INPATIENT SURVEY

HQSC weighted results			
Communication	**Partnership**	**Co-ordination**	**Needs**
8.3 **WDHB**	**8.3** **WDHB**	**8.4** **WDHB**	**8.6** **WDHB**
8.3 **National Average**	**8.4** **National Average**	**8.3** **National Average**	**8.6** **National Average**

Table 1: National Survey Quarter One (July - August 2019)

Quarter 4 (Q4) results include patients discharged between the 4th of November 2019 and 17th of November 2019. The response rate for Q4, 2019 was 33% . All surveys were distributed via email. The national response rate for this quarter was 24%. Waitematā DHB and National results were down on previous two quarter results. The Partnership domain decreased by 0.3 from the previous quarter, however all domains are broadly consistent across the last five years. There is limited variation between DHBs.



Graph 1: Waitematā DHB run chart for all domains, 2014-19

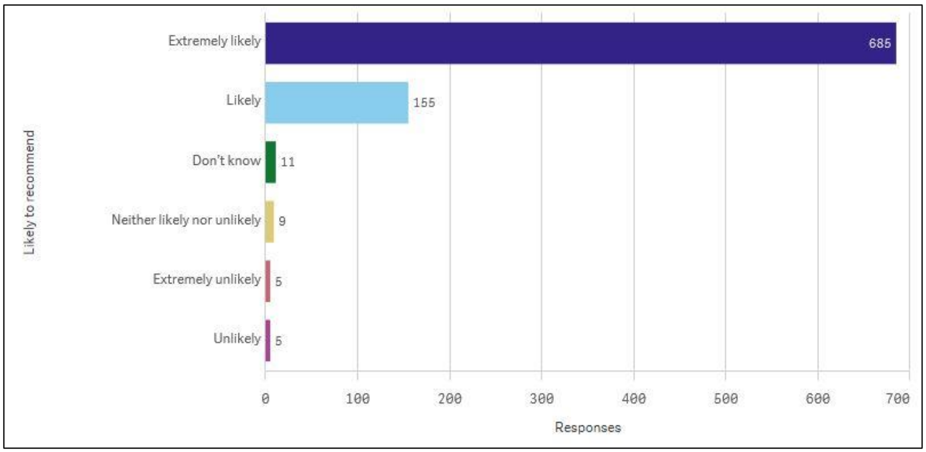
Cemplicity will stop providing the quarterly survey capture and reporting mechanism from the end of 2019. The new provider – Ispos was formally announced as the new provider by the Health Quality & Safety Commission in late January. A review of the current survey is in progress, with many changes predicted.

1.2 FRIENDS AND FAMILY TEST

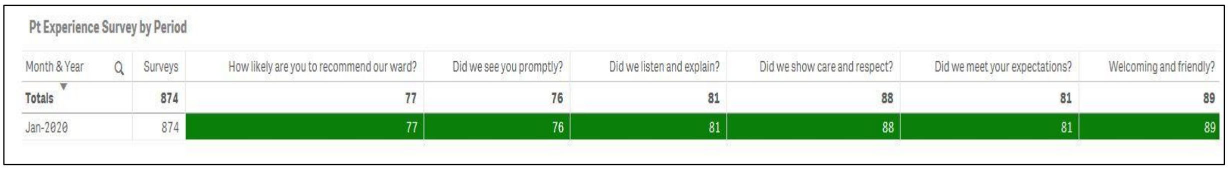
In January 2020 we achieved a Net Promoter Score (NPS) of 77. This is down slightly from the previous month where we achieved our highest ever score of 81. This month we received feedback from 870 people (down from 922 people the previous month). The NPS continues to consistently perform well and score above the DHB target of 65.

1.2.1 Friends & Family Test Overall Results

Figure 1: Waitematā DHB overall NPS



Graph 2: Waitematā DHB overall FFT results

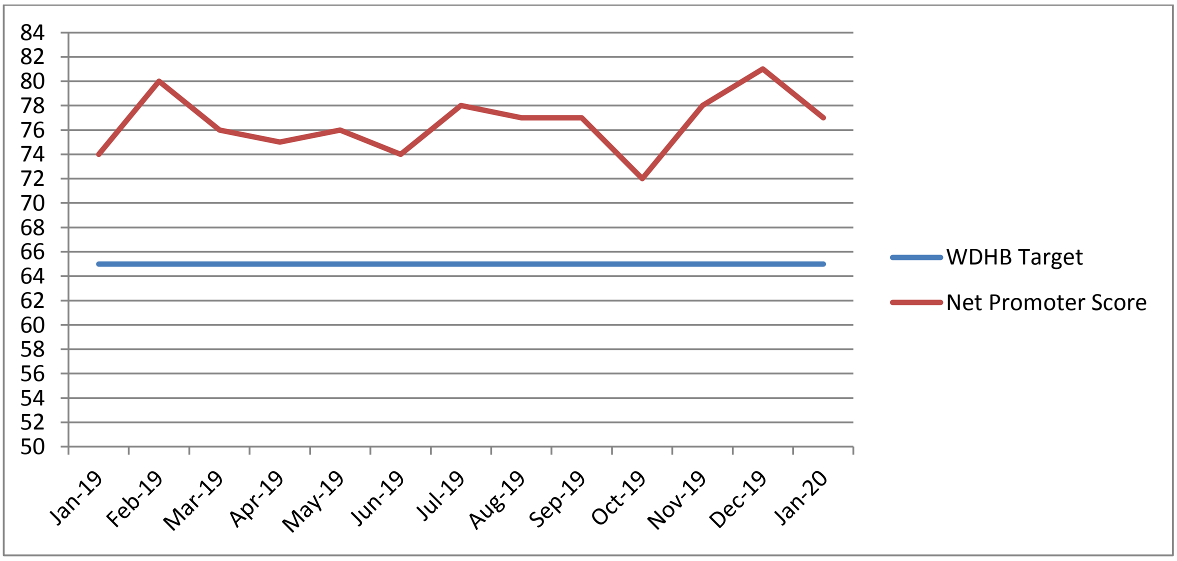


Pt Experience Survey by Period

Month & Year	Surveys	How likely are you to recommend our ward?	Did we see you promptly?	Did we listen and explain?	Did we show care and respect?	Did we meet your expectations?	Welcoming and friendly?
Totals	**874**	**77**	**76**	**81**	**88**	**81**	**89**
Jan-2020	874	77	76	81	88	81	89

Table 2: Waitematā DHB FFT results (each question)

The net promoter scores in January have met target for all Friends and Family Test questions. All measures are down on the previous month, however it should be noted that December scores were exceptional. The January scores all score above the target. The highest performers are once again ‘welcoming and friendly’ and ‘care and respect’ achieving scores of 89 and 88 respectively. An area for improvement is ‘did we see you promptly’ which scored 76.



Graph 3: Waitemata DHB Net Promoter Score over time

1.2.2 Total Responses and NPS to Friends and Family Test by ethnicity

January 2020	NZ European	Māori	Overall Asian	Overall Pacific	Other/ European
Responses	577	66	103	44	208
NPS	77	80	81	67	78

Table 3: NPS by ethnicity

In January, all ethnicities met the Waitemata DHB NPS target and score 65 and above.

January 2020	NZ European	Māori	Overall Asian	Overall Pacific	Other
Did we see you promptly?	75	80	87	61	81
Did we listen and explain?	81	85	89	62	83
Did we show care and respect?	89	88	91	71	87
Did we meet you expectations?	81	80	88	69	83
Were we welcoming and friendly?	90	94	92	77	90

Table 4: NPS for all questions by ethnicity

This month all measures, with the exception of two, score above the DHB target. The lowest scores were for Pacific for the following measures 'did we see your promptly' and 'did we listen and complain' where they achieved an NPS score of 61 and 62 respectively. 'Welcoming and friendly' once again achieved the highest scores across all ethnicities.

1.2.3 Friends and Family Test Comments

- *"Every team was compassionate, gentle and listened to my needs."* ***Short Stay Ward, NSH***
- *"Staff have been so amazing. Thank you all for your help – brining our boys smile back! You are all awesome."* ***Rangatira Ward, WTH***
- *"Had a surprise birth at 31 weeks. Everyone was amazing, so understanding and caring. Really explained everything to me. Looked after my baby and me with lots of attention."* ***Maternity, NSH***
- *"Your compassion and medical attention is commendable. Thank you very much."* ***Ward 3, NSH***
- *"The nurses are friendly and have taken care of me. The doctors clearly explained and the treatment for me is timely and effective"* ***Huia Ward, WTH***
- *"Absolutely a million percent. From the get go everythings been fantastic ."* ***Ward 8, NSH***
- *"Excellent service. The staff are so friendly, cheerful and happy and great to see us as if we are like their family."* ***Haematology Day Stay, NSH***

2.0 Patient Experience Activity Highlights

2.0.1 CONSUMER COUNCIL UPDATE & HIGHLIGHTS

The Consumer Council met in January for their strategy meeting which was externally facilitated by Mark Allen from Community Waitakere. The discussions focussed on:
- the upcoming challenges and opportunities for the DHB,
- key focus areas for the Council to focus on over the next three years,
- what the unmet needs, consumer's health preference and inequities that can be changed with the DHB,
- the areas the Council could contribute towards to ensure the DHB meet the needs of the community,
- how the Council could best connect and have its voice heard with the Board and the DHB,
- how the Council can work together effectively as a team.

The strategic session was a great success with all members highly engaged with many ideas and great commitments for the year ahead. The final strategy document is to be presented to the Board in April by the Consumer Council Chair.

Recent discussion areas that the Consumer Council have been involved with during their meetings are:
- informed consent,
- outpatient experiences,
- health literacy,
- Waitemata DHB communication with community,
- Partners in Care

Their ideas and discussions have led to significant changes to enhance services and design. Currently there is a wait list for agenda items with the Council as well as a priority list that Council members have identified for future meetings.

2.1.1 VOLUNTEER RECRUITMENT STATISTICS

Volunteer number has slightly decreased from previous month as few volunteers have resigned due to a change of circumstances. The number is expected to rise again as targeted recruitment continues.

Green Coats Volunteers (Front of House) **(A)**	**Other allocated Volunteers** **(B)**	**Volunteers on boarded awaiting allocation (C)**	**Total volunteers available (D)** **(A) + (B) + (C) =(D)**
50	90	3	143

Table 8: Volunteers Recruitment

2.1.2 VOLUNTEER ACTIVITY HIGHLIGHTS

- ***Recruitment***

Orientation for new volunteers continues on Ward 5. Volunteer service has recently started on Ward 10 with two new recruits volunteering on Wednesdays. The patient experience team is catching up regularly with staff and volunteers to provide support for effective integration. We continue expanding opportunities across all wards.

In addition, we have developed a new volunteer opportunity: ***Care Standard Patient Interviewer.*** This role will support gathering more information about the patient experiences on each ward and will contribute to the overall results for the Patient and Whānau Centred Care Standard Programme. Targeted recruitment supported by the Volunteering Auckland website continues and the average of new applicants remains high at 4 per week.

- ***Volunteer Recognition***

New volunteers have been attending Welcome to Waitemata workshops along with new employees and they have reported positive feedback. Volunteers state that they feel more welcomed into the organisation and connected.

In addition, we have commenced acknowledging volunteer birthdays due to the support of Better impact software – a central database of all volunteer information.

2.2 PATIENT EXPERIENCE TEAM HIGHLIGHTS

- ***Pilot of new Friends and Family Test and Youth Survey***

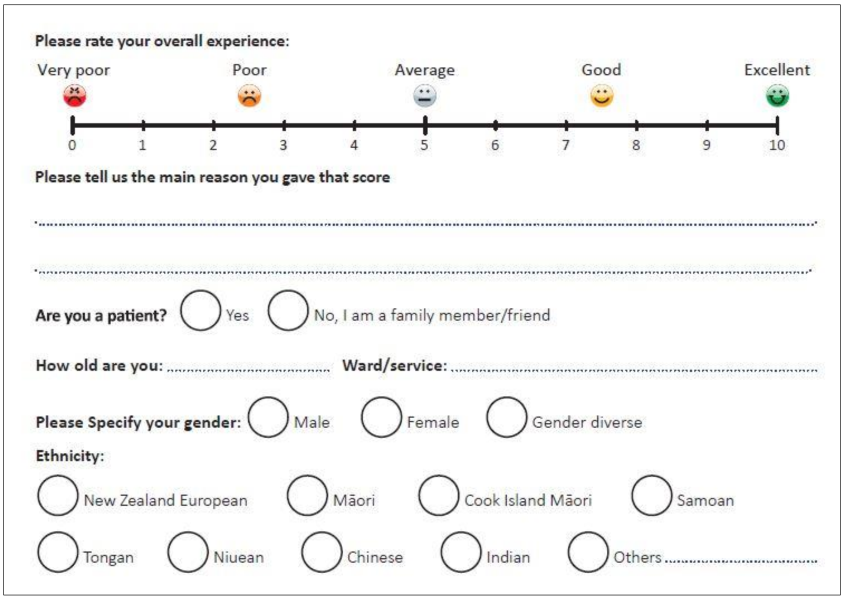
Patient Experience team will pilot new Friends and Family Test (FFT) questions in the following wards/services: ADU WTH, Ward 7, Renal and Radiology. The survey includes a new satisfaction rating and questions co-designed with patients, and the survey is aligned with our WDHB values. We will be applying a more sensitive 11 point scale which is in line with a true Net Promoter Score scale.

Tell us what you think

Waitematā District Health Board
Best Care for Everyone

	Strongly disagree		Disagree			Neither agree or disagree			Agree		Strongly agree
	0	1	2	3	4	5	6	7	8	9	10
The staff were welcoming and friendly											
I was treated with compassion											
I was listened to											
I was involved in decision making											
My condition/treatment was explained in a way that I understood											

Please turn over



Please rate your overall experience:

Very poor		Poor			Average		Good			Excellent
0	1	2	3	4	5	6	7	8	9	10

Please tell us the main reason you gave that score

....

....

Are you a patient? ○ Yes ○ No, I am a family member/friend

How old are you: .... **Ward/service:** ....

Please Specify your gender: ○ Male ○ Female ○ Gender diverse

Ethnicity:

○ New Zealand European ○ Māori ○ Cook Island Māori ○ Samoan

○ Tongan ○ Niuean ○ Chinese ○ Indian ○ Others ....

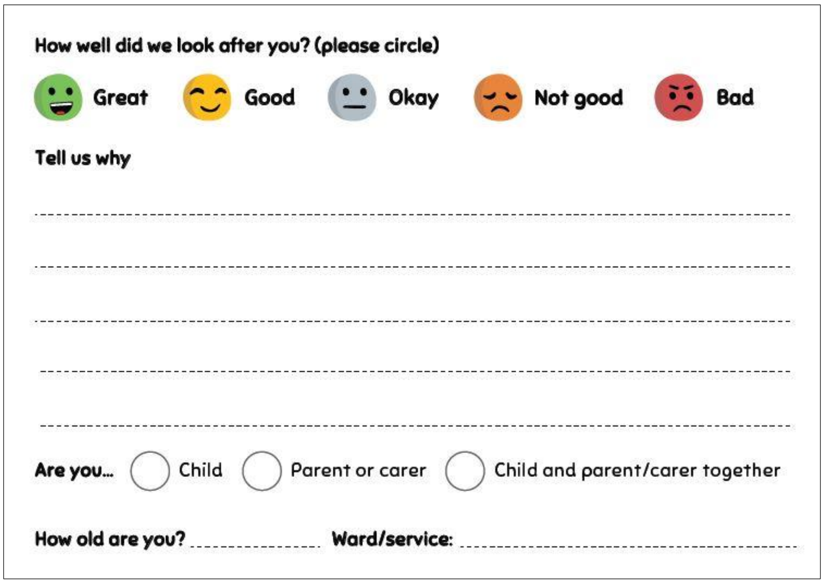
A new Youth Friends and Family Test survey has been created to capture feedback from our younger patients (aged 5 to 15). The trial will take place in Rangatira Ward and five Auckland Regional Dental Services.

Tell us what you think

	Always	Usually	Sometimes	A little	Never
We were friendly	○	○	○	○	○
We told you our names	○	○	○	○	○
We listened to you	○	○	○	○	○
You understood what was happening	○	○	○	○	○

Waitematā District Health Board
Best Care for Everyone

Please turn over



How well did we look after you? (please circle)

Great Good Okay Not good Bad

Tell us why

Are you... ○ Child ○ Parent or carer ○ Child and parent/carer together

How old are you? ______________ **Ward/service:** ______________________________

- ***Health Literacy Collaboration***

Susan Reid and Carla White from Health Literacy NZ – met with Leanne Kirton and David Price to collaborate on creating a training programme for Waitematā staff during Health Literacy month in October. Waitematā DHB have hosted a regional wide health literacy symposium over the past two years. Feedback from previous years have highlighted that a more practical approach to health literacy would be beneficial for future symposiums. With Health Literacy NZ – a more practical programme will be designed to support Waitematā DHB become a more health literate organisation.

(L:R - Leanne Kirton, Susan Reid, Carla White, David Price)

Policy - Body Parts, Tissue Storage, Cremation and Return

Body Parts, Tissue Storage, Cremation & Return

Contents

1. Overview

Purpose

This policy exists to ensure all legal and cultural aspects pertaining to the storage, return to patient and disposal of body parts/tissue are complied with.

Any specific issues that are not covered in the policy or fall outside of the policy should be addressed with the Waitematā DHB Legal Advisors or Director of Nursing in the first instance.

Scope

Covers all body parts/ tissues except for the following:

1	The current process for over 20 weeks stillbirths/neonatal deaths *NOTE: Hine Ora and Maternity have particular procedures for managing still births/neonatal deaths*
2	Placenta/ Whenua *NOTE: Maternity have a particular procedures for managing placentas*
3	Processes for obtaining Tissue/Organs for transplantation *NOTE: ICU and Theatre have particular procedures for managing donation*
4	Coroner's Cases *NOTE – See Death of a Patient policy*

Body Parts, Tissue Storage, Cremation & Return

2. Key Points

2.1 Tikanga / Cultural Respect

At all times body parts /tissue must be handled and stored with appropriate respect according to Tikanga best practice policy. It is recognised that tissue is part of the whole person. For some cultures they wish for the tissue to be buried in a way that acknowledges the spiritual significance.

2.2 Tissue is not held in Tissue Libraries

Waitematā DHB does not hold tissue as part of any tissue library. Tissue is either returned to the person if they request to retain it or disposed of using appropriate processes in accordance with appropriate regulations.

Tissue is retained by Surgical Pathology for eight weeks to ensure availability for diagnostic testing and where a patient has not indicated return of the body part/tissue. After which time the body part/tissue will be disposed of using appropriate processes or returned to the patient if requested.

Paraffin blocks which contain a very small quantity of tissue are required by the Royal College of Pathologists of Australasia to be retained for 20 years from the date of surgery. On request these can be returned to a patient.

Management of Placenta/Whenua is documented and managed separately by the Maternity Unit on each site

2.3 Handling of Tissue

Any body tissue taken into custody for testing or secure holding –

Refer to 5.1 if dealing with foetal or pregnancy tissue

- Must be placed in the appropriate sealed container to minimise loss or spill of body fluids. All containers must be suitable, leak proof and 'fit for the purpose' in regards to body parts /tissue/foetal/pregnancy tissue.
- Tissue is packaged by the Surgical Pathology staff for discrete removal from WDHB.
- Must be labeled **immediately** with the patient's name on the holding container to allow for accurate identification. The ID label must also be placed securely on the holding container (not on the specimen pot lid) and on all forms before placing in an appropriate bag for transport. **No specimen may leave the immediate clinical setting unlabeled**
- The specimen must be accompanied by the relevant documentation which must also have appropriate identification attached
- Must be taken/sent to the Laboratory as soon as possible if testing is required ***OR*** placed in the dedicated freezer or fridge to maintain the condition and security of the tissue before being uplifted or disposed.

Note: **No specimens may be placed in ward or unit fridges/freezers that contain food/drink.**

2.4 Consent

Patients (or their representatives and/or parents /guardians for children) must receive sufficient information regarding body parts / tissue management to give informed consent. This discussion and consent must be recorded in the clinical record.

Body Parts, Tissue Storage, Cremation & Return

Patients /family /whanau should receive the appropriate information leaflet prior to giving informed consent and this is to be documented in the clinical record.

The information to the patient /family /whanau regarding management of body parts /tissues [see page 10 below] includes an explanation on testing, storage, return or disposal, relevant to the patient's clinical management.

- It is the responsibility of the team carrying out the procedure to gain this consent and to ensure that the patient /family /whanau understand the information regarding the management of body parts /tissue.

If any issues or objections should arise with the family/whanau of an individual around consent, contact the WDHB Legal Advisors.

2.5 Laboratory Handling

The Laboratory staff will check the request form for the sticker affixed by the procedure staff to ascertain whether the patient has indicated that they wish to have the tissue returned after testing or not.

- *If indicated for return* to the patient, the tissue will be processed for return after diagnostic testing.

2.6 Collection of tissue for return

Tissue that the patient wishes for return is

- either returned to the patient at the time (A delegate may collect on the patient's behalf as requested by the patient and on presentation of some form of identification)
- or held by Surgical Pathology and returned to the patient via the Director of Nursing.

For any urgent collections after-hours please contact the Director of Nursing to assist with this process.

2.7 Disposal of tissue

Tissue, not for return to patients, is managed through a formal process with the contractor.

- Cremation of foetal tissue is actioned by a Funeral Director

After testing

If <u>not</u> indicated for return to the patient, the tissue is placed in the specified, secured Red Containers for holding tissue that is planned for disposal. The containers are secured at all times to prevent unauthorised access. This includes transport and storage prior to contractor removal.

2.8 Health and Safety/Infectious material

Safe handling of tissue/body parts that has been stored in formalin is outlined in the *"Information for handling of returned Body parts and tissue"* information sheet.

Body Parts, Tissue Storage, Cremation & Return

3. Processes for Return of patient Tissue

TISSUE RETURN

Tissue via Surgical Pathology [A*]

- Staff ask patient if want tissue returned
- Staff document in clinical record & on lab form
- Surgical Pathology receives tissue and documents RTP
- Surg Path prepares tissue for return
- 2 weekly [Friday], DoNM picks up tissue for return
- DoNM writes to patients . Advises to contact re: pick-up
- DoNM delivers packages to pick-up point.
- Note: if no reply, tissue disposed after 6 months

Miscarriage ED

- Tissue placed in approved containers
- If requiring laboratory assessment – sent to Lab . Note RTP
- Surgical Path release tissue as per [A*]
- [1] Tissue [< 20 weeks] given to patient on discharge in appropriate container. Patient offered support from CNS Early Pregnancy Given information pack
- [2] Tissue [< 20 weeks] not given to patient on discharge but want to be returned later Orderly places in Mortuary fridge [L] with form [*Dec 1] DoNM contacts CNS Early Pregnancy to return to patient
- Note: if not for return, DoNM arranges cremation

Foetal demise [Hine Ora]

- Foetus/tissue to ADHB Pathology
- ADHB Pathology returns to Hine Ora who will contact family
- CNM Hine Ora contacts family for pick up. CNM liaises with SW – support Contacts CNS Pregnancy Loss for support
- Documents return on clinical record
- Note: if not for return, CNM completes forms [*Dec 1]. Orderly places in Mortuary Fridge. DoNM arranges cremation

Foetal demise [Maternity] > 20 weeks

- Midwife and social worker support family
- Foetus/tissue to ADHB Pathology for autopsy
- ADHB Pathology returns to Hine Ora for return
- CNM Hine Ora contacts Midwife to arrange family for pick up. Midwife liaises with SW - support
- Documents return on clinical record
- Note: if not for return, CNM completes forms [*2]. Orderly places in Mortuary Fridge. SW arranges burial as per family wishes.

4. Storage of Tissue for Pick Up

The tissue to be returned is packaged by the Surgical Pathology staff or placed in appropriate containers. It is held in Surgical Pathology until pick up by the Director of Nursing or named service contact.

The Director of Nursing collects the tissue ready for patient return each fortnight. All relevant document is completed and the tissue placed in dedicated space in the Mortuary at North Shore Hospital.

Body Parts, Tissue Storage, Cremation & Return

All fridges/freezers holding tissue are

- Dedicated and labeled for this purpose
- Secure to prevent unauthorised access
- Managed by the Director of Nursing who manages the items and supervises cleaning in these fridges at North Shore Hospital.

The Director of Nursing documents all names are record on secure spread sheets. The patient is contacted by mail to offer the tissue back. *See 5 below*

Where tissue is placed in the Mortuary that has not gone through the Surgical Pathology service, the tissue must be in a secure, spill-proof containers prior to transport by the Orderly Service to prevent spillage or unauthorised access.

- Orderly staff are asked to transport/remove the containers to a Mortuary area.

Items are held securely until

- release to the patient/whanau
- disposal including transport and storage prior to contractor disposal.

4.1 Tracking

Records are kept of tissue held by the Surgical Pathology Laboratory from time of receipt to the time of disposal if not requested for return to the patient. Documentation of handover to the Director of Nursing is retained by the Surgical Pathology department. All body parts and tissue is tracked in and out of the laboratory.

- Tissue for return to the patient is signed for by the Director of Nursing
- This means that a series of 'registers' records tissue transfers from one area to another for audit purposes.

5. Notification of Readiness for Return

Where a service or the Director of Nursing advises the patient that tissue is ready for return, the patient is formally advised of the process for retrieval of tissue

- verbally at the time they sign the consent form
- in a copy of an approved pamphlet explaining the procedure and post discharge contact process

If the tissue is available to be handed over at the time of discharge i.e. Surgical Pathology has completed diagnostic testing

- the nurse/midwife/maternity social worker discharging the patient should contact Surgical Pathology to arrange pick up / hand-over of the tissue to the patient.
- If diagnostic process is not complete then they should be informed that they can expect a letter advising that the tissue is ready for pick-up. This may be up to 8 weeks after the procedure. If they have a query they may contact the DHB Feedback line – see internet webpage

Surgical Pathology hands the tissue as requested to the Director of Nursing who sends a letter advising the patient that the tissue is released and asks where they wish for pick up.

The patient is advised that the tissue can only be held for a specified period of time. The patient emails to arrange pick up.

On reply, arrangements are made to return the tissue in a discreet and respectful manner.

- The Maori Health staff may assist with this process.
- The Director of Nursing prepares the packages to main reception at North Shore of Waitakere Hospitals for pick up by the patient. They are advised of the process.

- The Director of Nursing delivers to the patient's home at times by special arrangement.

5.1 Identification

Any person receiving and removing tissue from the hospital, must

- Must have appropriate authority to consent
- show appropriate identification
- sign the form in the clinical record where they have requested return of the tissue indicating that they have received the tissue.

6. Body Parts /Tissue for Return

6.1 Return directly after the Procedure

Follow the steps below to ensure the management of body parts/tissue for return to patient is followed

Steps	Action
1	Before any procedure the medical staff discuss with the patient/family/whanau the return of body parts/tissue. The information leaflet is given and discussed.
2	Patient/family/whanau indicates that the decision of the patient on the '*Agreement to Treatment*' form, whether the tissue is to be returned immediately or after laboratory analysis. The consenting doctor completes the *'Body Parts/Tissue Release'* form (tba) according to information on Agreement to Treatment form.
3	Upon removal of body part/tissue, the tissue is placed in an appropriate container.
4	From the triplicate *'Body Parts/Tissue Release*' form - One sheet to accompany the body parts/tissue to the laboratory - One sheet to be placed in patient's clinical records - One sheet to be handed to patient/family/whanau
5	Once ready for release, the container and '*Body Part/Tissue Release*' form is signed and handed over to patient with the appropriate information leaflets
6	Tissue Management staff contact the patient/family/whanau and manage return.
7	On discharge or if an inpatient death occurs, the ward contacts Surgical Pathology to facilitate release of tissue to family. The front sheet of the patient's clinical records has the Body Parts label for reference.

6.2 Body Parts /Tissue for Laboratory Testing & later return to patient

Follow the steps below to ensure the management of body parts/tissue for laboratory testing is followed

Steps	Action
1	Before any procedure there is discussion with the patient /family/whanau regarding the testing and return/disposal of body parts/tissue. Information leaflets are given and discussed.
2	Patient/family/whanau indicates on *'Agreement to Treatment'* form that the tissue to be returned after Laboratory testing. Consenting doctor completes the '*Body Parts/Tissue Release*' form (tba) according to information on '*Agreement to Treatment*' form.
3	Upon removal of the body part/tissue, this must be placed in an appropriate container.

4	From the triplicate Body Parts/Tissue release form - One sheet to accompany the body parts/tissue - One sheet to be placed in patient's clinical records - One sheet to be handed to patient/family/whanau
5	All body parts/tissue that are to be returned to the patient must have a '*Body part to be returned to patient*' **sticker** fixed to - the laboratory request form - '*Body Parts/Tissue Release*' form accompanying specimen - and specimen container.
6	Send specimen and form to surgical pathology Specimen Reception
7	The yellow '*Body part to be returned to patient*' **sticker** to be placed on patient's front sheet in Clinical notes.
8	The staff in theatre/procedure area provides verbal handover to the ward staff regarding body parts/tissue sent to surgical pathology
9	After testing Surgical Pathology Tissue Management oversee return.

7. Foetal tissue /Pregnancy Tissue

Follow the steps below to ensure the management of baby/pregnancy tissue is followed

- If the foetus weighs less than 400g **and** issues from its mother within the first 19 weeks and 6 days of pregnancy then no Doctor's certificate is required.
- If the foetus weighs more than 400g **or** the pregnancy is of greater duration than 19 weeks and 6 days then a birth and Doctor's certificate is required. The required certificate is the Medical Certificate of Causes of Foetal and Neonatal Death (HP4721)
- If a foetus is over 19 weeks and 6 days then a perinatal autopsy is performed at Auckland City Mortuary. Refer to Miscarriage Management – 13 to 20 Weeks Gestation Policy Guidelines.
- If a foetus is over 20 weeks or weighs more than 400gms, then refer to the Stillbirth Policy Guidelines.

Step	**Action**
	See section 4 above
1a	**[1a] Weighs less than 400g and within first 19 weeks and 6 days of pregnancy** All products of conception, including the foetus, are collected and placed in an appropriately sized container and the container placed in a plastic bag and sealed to prevent spillage. • For early miscarriage, the tissue is placed in a specimen container. • The container is placed in a brown paper bag for discreet transport.
1b	**[1b] Weighs greater than 400g** or **the pregnancy is of greater duration than 19 weeks and 6 days** • The foetus is placed in a special basket and the family advised to contact a Funeral Service to arrange for Funeral Director to arrange for burial. If there is no post mortem intended, they may wish to take the fetus from the Hospital. • If for a post mortem, a foetus will be transported by a Funeral Director to Auckland City Hospital Mortuary and post mortem arranged at A+ Lab with the Technical Head of Forensic Pathology Department on 0800 522 7587 extn 23056. Family may accompany the foetus at all times.
2	Documentation • A patient ID label is placed on the container • The date and time the tissue/foetus is placed in the container is written in the container The "Consent – Investigations Following Death – Baby" form is to be completed and accompanying documentation attached to container indicating whether the woman wishes to receive the tissue/foetus back. If tissue sent for histology then the laboratory and "Consent – Investigations Following Death – Baby" form is attached and returned with the specimen.
	For forms check Nursing intranet page End of Life Care Policy

3	Laboratory • The Laboratory completes the assessment. • The specimen is transferred to the care of the Director of Nursing. • Contact is made with the woman and arrangements made for transfer of care/return to the woman. • The specimen is placed in the Mortuary until it is returned to the woman after discussion with the Director of Nursing.
4	**Non Laboratory specimens** Where a foetus/tissue has been transported by the Orderly staff to the Mortuary pending a decision by the woman, the orderly places it in the designated fridge. The presence of the foetus is identified by the Director of Nursing or social worker, contact and appropriate arrangements made.

7.1 Collection of Pregnancy Tissue/Foetus

Step	Action
1	If the woman has indicated that she wants return of the tissue/foetus, a copy of the Consent – Investigations Following Death – Baby form must be placed into the clinical record. - If the plan is to collect the tissue/foetus, the woman is provided with contact to the Early Pregnancy Clinic Nurse Specialist or the maternity social worker on ext. 42718 or 42533 - If the tissue has not been uplifted, the Director of Nursing will make contact with the woman to discuss her wishes. Unclaimed tissue/foetus is taken by the Director of Nursing to Dil's Funeral Services Ltd ph: 415 8720 for cremation. The consent for cremation is attached to the package to inform the Director of Nursing of patient decision. Document accompanies the containers to Dills confirming content. For a foetus of <20weeks or weights <400gms, if the woman **does not** want the tissue/foetus to take home at the time of discharge, the tissue/foetus will be held for 3 months. The woman is written to after 3 months has expired to confirm their decision if this is not already known. If there is no contact regarding collection it will be cremated.
2	Where the foetal tissue has been sent to North Shore Surgical Pathology for testing or for perinatal autopsy, the woman will be asked if they wish for return of the foetal tissue by the Director of Nursing
3	On receiving the tissue/foetus, the woman or authorised family/whanau signs the release form in the clinical record (name, signature, date, time) • that they have received the tissue or foetus • that they have the appropriate paper work • The paperwork will be sent to clinical records
4	The tissue/foetus should be carried out of the hospital in an appropriate container, in a discrete and respectful manner using the designated pathways. The Orderly or Maori Services staff can advise staff/families about an appropriate exit route.

8. Body Parts/Tissue in Acute/Emergency cases

Steps	Action
1	In the case of an acute or emergency surgery where no '*Body Part/Tissue Release*' form or '*Agreement to Treatment*' form has been filled out, or where the form '*Authority to treat without consent*' has been completed, then any body part/tissue removed is to be treated as if the patient has requested it to be returned. The staff must complete a '*Body Part/Tissue Release*' form The procedure is then followed as if the patient had requested that body part/tissue to be returned.
2	Ward staff/Medical staff will discuss with the patient his/her wishes regarding the return and/or retention of body part/tissue.
3	Ward staff to inform Surgical Pathology Tissue Management of the outcome of patient's wishes. The tissue will be held for 8 weeks to ensure all diagnostic testing completed then returned to the patient or disposed of.

9. Skin Management & Storage

Follow the steps below for correct storage and documentation of Skin.

Steps	Action
1	Scrub nurse to prepare skin as per surgeon's preference e.g. wrap in saline soaked non-raytex gauze swab.
2	Place in small dry sterile pot
3	Circulating nurse to label pot with patient label/date/time/surgeon/specimen type/expiry date (28 days)
4	Place into biohazard bag with body part/tissue release form or disposal of tissue form
5	Place in tissue/bone fridge
6	Fill in tissue book.

10. General

10.1 No Tissue to Retrieve

Where Surgical Pathology has received little tissue to test and therefore has little to return to the patient, the patient requesting return of tissue is advised that the tissue cannot be returned.

A letter is written as follows

> *"The tests undertaken on your tissue have been placed in paraffin blocks as required by the diagnostic test. This has only left a small amount that can easily be returned. The majority of the tissue is in the paraffin blocks. We're happy to show you the paraffin blocks so you can see what they look like and to explain 'face to face' why it is recommended by the Royal College of Pathologists of Australasia that we retain all tissue blocks and slides for 20 years from the time of surgery. By keeping the paraffin blocks, we could do further tests for you or your family in the future should this be needed for diagnostic and prognostic reasons. If the tissue is returned we may not have the blocks available to do the molecular studies if needed*".

If the patient insists on receiving the tissue after an explanation, this is released after the person has signed appropriate release documents.

Body Parts, Tissue Storage, Cremation & Return

10.2 Disposal where Tissue Not Wanted

Where the patient does not wish to have the tissue:

- The tissue is placed in the red containers provided by the contractor for disposal. These containers are secured
- The red secure container tissue will be disposed appropriately.

10.3 Tissue Not Collected

Tissue that has been identified as wanted by the patient, but has not been claimed after six months is disposed of appropriately

- The person is contacted in writing and advised that the tissue can be collected/returned. They are also advised that if they do not collect the tissue then it will be disposed of.
- Refer to 5.1 regarding foetal and pregnancy tissue

At six monthly intervals, the tissue that has still not been retrieved, is placed in the appropriate container and collected for disposal off-site by an approved contractor.

Associated documents

Type	Title/Description
Legislation	Births, Deaths & Marriages Act 1995 Burial & Cremation Act 1964 Hazardous Substances & New Organisms Act 1996 Health & Safety in Employment Act 1992 Health & Disability Commissioners Act 1994 Human Tissue Act 2008 Crimes Act Human Rights Act Resource Management Act Local by laws
Publications	Treaty of Waitangi Health & Disability Code of Consumer Rights Infection Control: Waste Disposal standards Consent process for the collection and use of human tissue under the Human Tissue Act 2008- Ministry of Health
Policy	Interrupted Pregnancy , Miscarriage Management – 13 to 20 Weeks Gestation Placenta/Whenua Management Death of a Patient Informed Consent Maori Values and Concepts [Tikanga]
Forms	Agreement to Treatment Authority to Treat Without Consent Body parts/Tissue Release form Yellow Body parts/Tissue Return to patient Sticker Consent – Investigations Following Death – Baby form: 11.5.001
Information Sheets	Information for handling of returned Body parts and tissue. Information regarding the Examination, Return and Cremation of Body Parts and Tissue.