Final

Our Care, Our Choice Advisory Group (OCOC)

Kinau Hale Boardroom, 1250 Punchbowl St., Honolulu HI 96813
July 31, 2018
1:00 p.m. to 3:00 p.m.

Members Present:
   Bruce S. Anderson, Lee Buenconsejo-Lum, M.D., Brenda Ho, Malachy Grange, Rae Seitz, M.D,
Members Absent:
   None
Guest(s)/Public Present:
   DOH- Alvin Onaka, M.D, Representative Della Au Bellati, Heath Williams (representing Senator Baker), Daniel Fischberg, M.D., Jeannette Koijane; DCCA Employees: May Ferrer, Ahlani Quiogue, Charlene Tamanaha, Lee Ann Teshima
   Attorney General Office: Angela Tokuda, Chris Flanders, M.D., Caryn Ireland

Staff Present: Lorrin Kim and Laura Arcibal

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<th>Agenda Item</th>
<th>Discussion</th>
<th>Recommendations/Actions/Conclusions</th>
<th>Person(s) Responsible</th>
<th>Date Due</th>
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<td>I. Call to Order</td>
<td>Meeting was called to order at 1:06pm. Quorum was established.</td>
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<td>II. Welcome and Introductions</td>
<td>Director Bruce S. Anderson opened the meeting and welcomed members of the advisory group, recognized</td>
<td>Board packet was distributed for each of advisory group members. Extra</td>
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| Rep. Bellati and Heath (Senator Baker’s representative) and guests present. | packets were distributed to the guests in attendance.  
Director Anderson provided comments on measure. Stated that this is the inaugural meeting.  
Director Anderson stated that the bill allows for terminally ill adults with six months to live to take medications to end their life peacefully.  
Director Anderson stated that prognosis must be confirmed by two doctors, patient must be found mentally competent, patient must make two oral requests twenty days apart, one written request witnessed by two people and one final attestation. Stated that there are safeguards in place in the bill.  
Director Anderson noted that legislation requires the Department to form an advisory group consisting of a designee from the Department, and no fewer than five group members to include one palliative care specialist, a hospice care specialist, a medical educator and a non-medical member of the community.  
Director Anderson noted that Act 2 is law and that we are not here to |
relitigate, and here to work to implement what is here in law.

Director Anderson noted that the advisory group are subject to Sunshine Law, open meetings.

Individual members of the advisory group and those present at the meeting introduced themselves.

Dr. Rae Seitz introduced herself as the Palliative Care Specialist. Received her palliative care experience through the Harvard School. She noted that she built home based palliative care programs and built palliative care service programs at Kaiser.

Malachy Grange introduced himself as the Non-Medical Community Member of the advisory group. He indicated that he is a retired nurse and worked in Oregon for 25 years both before and after the death with dignity law came into effect.

Brenda Ho introduced herself as the CEO of Hawaii Care Choices formally Hospice of Hilo worked for 27 years.

Dr. Lee Buenconsejo-Lum introduced herself from the medical school, is a
family physician, 20 years as an educator, oversee all the residency at UH JABSOM.

Lorrin introduced himself as an employee of the Department of Health, Chief of Planning, Policy, and Program Development. Will be staff for the advisory group.

Laura Arcibal introduced herself as Program Specialist and State Telehealth Coordinator for the Department of Health in the Planning, Policy and Program Development Office. Also will be serving as Staff to the Advisory Group.

Other guests and attendees introduced themselves.

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<th>III. Review of Agenda and Items for Discussion</th>
<th>A. Ground Rules</th>
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<td>B. Act 2, Session Laws of Hawaii 2018, “Our Care, Our Choice Act”</td>
<td>Lorrin indicated for Chapter 92 related to the Sunshine Law that members of the advisory group cannot speak in private about matters involving the OCOC Advisory Group.</td>
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<td>C. Roles and Responsibilities</td>
<td>Deputy Attorney General, Angela Tokuda, noted that outside of the advisory group meetings only 2 members are allowed and not more than 2 which is called Permitted Interaction Group (PIG). Lorrin noted that we must identify what is needed for us to implement this by January 1, 2019 and what must be avoided. A list is needed. Noted again that we are not here to relitigate this.</td>
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<td>D. Election of Advisory Group Chair</td>
<td>Election of Chair remains undecided. To be added to next agenda.</td>
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<td>E. Chapter 92, Hawaii Revised Statutes, “Sunshine Law”</td>
<td>Group discussion began to identify what is needed to effectively implement by January 1, 2019. Dr. Seitz responded and asked how providers are going to have these conversations to help empower the individual and families to make a more informed choice. Advisory members focused on “communications” to enable providers to have these conversations. Dr. Buenconsejo-Lum commented that it would be good for providers to have a</td>
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“resource” place to turn to for training and information such as ECHO which offer web-based educational sessions to providers. Recommended ECHO (Extension for Community Healthcare Outcomes) as it is already established, and it could include training (a series of trainings) Geriatric training includes many of the aspects related to palliative care.

Dr. Seitz commented that communication may be broken down into two buckets: 1) technical and 2) competencies (soft skills, skill building, feedback and practicing)

Lorrin commented that it is mentorships.

Dr. Buenconsejo-Lum responded that it is workshops such as a series to include non-physicians. Train the trainer. Pick a few champions from different practices.

Brendo Ho noted that we have assumptions that doctors will “step-up”.

Lorrin indicated we’ve talked about providers now let’s now switch to patients. How do we connect patients with providers?
Dr. Seitz commented that we should provide patients options and advice. Where patients can go for information.

Dr. Seitz recommended that DOH have a website for physicians and patients to access as a resource.

Lorrin noted the recommendation and the need for funding to support it.

Dr. Lee Buenconsejo-Lum seconded the recommendation for a DOH website.

Dr. Seitz recommended that a list be created that identifies providers and recommended a name for it such as “Physicians Aid in Dying” or something like that. She also noted that recruiting of physicians is needed for the list.
Dr. Anderson noted that we should have resources for families in addition to the patient.

Lorrin noted that we are assuming people have access to websites. Noted that there should be some non-
Malachy Grange noted that we are assuming physicians want to get involved. Where’s the data to show? Let’s hone in on access for January. People should know and can access it.

Lorrin noted what must we have on January 1 and what must be avoided. Noted that realistically there’s only 3 or 4 things we can work on.

Kat West noted that it must be integrated as much as possible as a standard of care. And noted that most hospitals have a system in place. A patient navigator system or internal referral systems. Kaiser model. We have fact sheets and are here for you to take. We are here to help.

Lorrin noted that documents are not endorsed by the state. Referred to the group that you are welcome to take one with you.

Kat West stated that implementation has a 3 year ramp up period.

Dr. Seitz stated that Kaiser does have a list internally.
Rep. Bellati stated that knowing there is a patient cadre out there who will be asking their doc, to hone in on likely patients such as cancer patients, who will likely be referred to palliative care, focus on hospice organizations and find out from them who are wanting to participate. She noted that organizations may opt out and that a public list may not be the way to go.

Dr. Anderson stated that it would be good to have a list of places so we can outreach where we can target.

Dr. Buenconsejo-Lum noted that for outreach to include spectrum such as supportive, palliative and hospice care. It would be important that on the website it should be clear that all of these options are available to the patient.

Lorrin summarized take away as to stratify providers, levels of care and benefits. Recapped. Talked about patient and provider communication.

Jeannette Koijane noted that 90% of these patients are in hospice care and to make sure we keep this in context. Didn’t see in Oregon report. Noted of the 100 patients who ask only 1 moves
forward. In the community people don’t know what hospice care is or what palliative is or supportive care. Don’t have an advance directive. Yet they may leap forward to medical aid in dying. Noted that pieces of the continuum be a part of the education to the community.

Lorrin acknowledged that education on the continuity of care be a part of the communication to the public. Discussion moved to data and medication.

Kat West noted that they have clinical data that was published related to medical aid in dying.

Malachy Grange noted that access to the community is important.

**Summary of recommendations are:**

1. Communication is needed to both providers and consumers.
   - Website for provider and consumer resources e.g. what consumer need to know, spectrum of care on supportive, hospice and
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<th>IV. Resources</th>
<th>A. Medical Aid in Dying in Other Jurisdictions (State Annual Data Reports)</th>
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<td>palliative care, applicable laws, related information</td>
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<td>• ECHO series training to include non-providers</td>
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<td>• Identify Champions – Train-the-Trainer</td>
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<td>• Identify providers – need a list</td>
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<td>• Consumer information on the spectrum of care benefits prior to – include supportive, palliative, and hospice care</td>
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<td>• Targeted approach to both providers (not all providers) and consumers e.g. oncologists, home hospice, palliative care, pharmacy, payers</td>
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<td>2. Training to providers on 1) technical requirements and 2) competencies.</td>
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<td>3. Infrastructure: Community access is needed by January 1, 2019. What if providers opt out? Where do consumers go?</td>
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<td>4. Policy: Disposal of leftover drugs (e.g. how secured in home, how meds are packaged, who to dispose?)</td>
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<td>V. Public Input</td>
<td>Kat West offered resources from Compassion and Choices.</td>
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<td>VI. Announcements</td>
<td>Next meeting is scheduled on August 31, 2018, 9am to 11am at Kinau Hale Boardroom 1250 Punchbowl St., Honolulu HI 96813</td>
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<td>VII. Adjournment</td>
<td>The advisory group adjourned at 2:57pm</td>
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