**MASSACHUSETTS RARE DISEASE ADVISORY COUNCIL (RDAC)**

**Steering Committee Meeting Minutes**

Friday, May 27, 2022, 1:30-2:30 pm

**REMOTE MEETING:**    <https://zoom.us/j/98529449282?pwd=djZMVE9LM2dYT1gvbGhsbXJQVkJKQT09>

* **Welcome**

Dr. Tierney welcomed members to the first meeting of the RDAC Steering Committee (SC). SC was established to create a leadership group to set agendas for RDAC meetings. I hope to work through how SC will operate. Also joined today by Kevin Cranston, Assistant Commissioner and BIDLS Bureau Director. Kevin will discuss the RDAC’s place in BIDLS and within DPH, which frames what can be achieved through RDAC meetings.

* **Roll Call**

|  |  |
| --- | --- |
| Member | Present |
| Representative Hannah Kane | X |
| Dr. Jeff Livingstone | X |
| Jenn McNary | X |
| Dr. David Miller | X |
| Michele Rhee | X |
| Dr. Ryan Thompson | X |

* **Discussion: operation of the Steering Committee**

Dr. Tierney said he would like to use this time to determine how the SC will operate regarding setting an agenda for the full RDAC. Dr. Tierney explained that he is an infectious disease physician, and although some rare diseases are infectious, the vast majority are not, and he needs the SC to help him guide the full Council. He asked the SC what an RDAC can accomplish in general? The legislature mandates the MA RDAC to provide a forum for discussing rare diseases. The RDAC is responsible for conducting a comprehensive list of charges outlined in the legislative language. Other states have RDACs that do not operate out of a state health department. These RDACs have been able to engage in other activities like conducting research, advocacy, and outreach to the rare disease community. How expansive should the MA RDAC be?

Dr. Tierney indicated that Kevin Cranston was invited to speak to provide his thoughts on the RDAC and its role within DPH BIDLS and asked Mr. Cranston to speak.

* **Guest Speaker:**

**Kevin Cranston, MDiv**

**Assistant Commissioner**

**Director, Bureau of Infectious Disease and Laboratory Sciences (BIDLS)**

**Massachusetts Department of Public Health**

Dr. Livingstone indicated that any scope that is too large initially would find it hard to get anything done. The MA RDAC is large and perhaps should consider taking the first half of the year looking at specific areas of a rare disease that have more need than others.

Dr. Tierney appreciated the comment and said he would like the RDAC to address as many issues as possible, for example, telehealth. What can the MA RDAC achieve given its makeup – member needs to do the work.

Dr. Livingston, it may be helpful to lay out a high-end vision for the Council and then peel away at the layers that will make it work.

Rep. Kane indicated that the RDAC duties are outlined in the enabling legislation.

Mr. Cranston said it is beneficial to have a clarifying legislative framework as public bodies can struggle without it. Mr. Cranston thanked all the SC members for their commitment to the RDAC and to the SC itself. He indicated he had been a member of other advisory bodies. His experience is that the busiest individuals always take on extra duties like this. He stated the Department is responsible for coordinating and making meetings useful, so everyone’s time is well spent.

BIDLS is appropriate Bureaus to house the RDAC, as the Bureau has the experience of monitoring 90+ infectious agents and diseases (some rare) through surveillance and other funded services. The Bureau invests in health care delivery, clinical care, policy, screening, laboratory diagnostics, and epidemiology. Bureau-funded delivery systems at the community level are not necessarily applicable to the rare disease community, but the experience is analogous and informative. BIDLS is also legislatively authorized (through the Commissioner) to manage the work of the MA Newborn Screening Program (this operates under the UMASS Medical School) and the work of the Newborn Screening Advisory Program. Some diseases will overlap between this and the RDAC. Mr. Cranston described Dr. Tierney and Ms. Meehan as dedicated to public service, with both deep clinical and policy experience. Mr. Cranston has worked with Ms. Meehan for two decades focusing on policy, regulatory, and community advisory issues with a focus on HIV and HCV. Mr. Cranston wants to be clear that the RDAC is assigned to DPH to host and manage meetings, but DPH is not the implementor of the RDAC recommendations, except as the RDAC work falls into DPH’s governmental role.

DPH’s role is to convene and support. Some members of the RDAC have most likely been involved in other governmental advisory work before this, some have not. To state the obvious, the Council’s job is to collect information, deliberate the meaning and significance, and make recommendations. Sometimes being close to the government can give a false sense of being able to direct government in a certain way. Recommendations need to be directed to the correct audience. For the RDAC, the most important audience is the legislature, and next, if appropriate, recommendations should be shared with medical bodies/audiences or other aspects of state government. DPH will support this work. Mr. Cranston opened the discussion to questions.

Dr. Tierney suggested taking Mr. Cranston’s comments relative to the nine responsibilities identified in the legislation. Mr. Cranston said it is a good idea to review these now and repeat the review over time.

Dr. Tierney read the responsibilities:

(d)  The rare disease advisory council shall advise the governor, the general court, and the department on the incidence of rare diseases within the commonwealth and the status of the rare disease community. To achieve its purpose, the advisory council shall:  
(i) coordinate the performance of the rare disease advisory council's duties with those of other rare disease advisory bodies, community-based organizations, and other public and private organizations within the commonwealth for the purpose of ensuring greater cooperation regarding the research, diagnosis, and treatment of rare diseases. The coordination shall require, when appropriate: (A) disseminating the outcomes of the advisory council's research, identified best practices, and policy recommendations; and (B) utilizing common research collection and dissemination procedures;  
(ii)  using existing publicly available records and information, undertake a statistical and qualitative examination of the prevalence and causes of rare diseases to develop a profile of the social and economic burden of a rare disease in the commonwealth;  
(iii)  receive and consider reports and testimony from expert individuals, the department, community-based organizations, voluntary health organizations, health care providers, and other public and private organizations recognized as having expertise in rare disease care to learn about their contributions to rare disease care and possibilities for the improvement of rare disease care in the commonwealth;  
(iv)  develop methods to publicize the profile of the social and economic burden of a rare disease in the commonwealth to ensure that the public and health care providers are sufficiently informed of the most effective strategies for recognizing and treating rare diseases;  
(v)  determine the human impact and economic implications of early treatment of rare diseases versus delayed or inappropriate treatment of rare disease as it pertains to the quality of care, the quality of patients’ and their families lives, and the economic burdens, including insurance reimbursements, rehabilitation, hospitalization, and related services, on patients, families and the commonwealth;  
(vi)  evaluate the current system of rare disease treatment and available public resources to develop recommendations to increase rare disease survival rates, improve quality of life and prevent and control risks of co-morbidities for rare disease, based on available scientific evidence;  
(vii)  research and determine the most appropriate method for the commonwealth to collect rare disease data, including a database of all rare diseases identified in the commonwealth along with known best practices for the care of said diseases and such additional information concerning these cases as the advisory committee deems necessary and appropriate to conduct thorough and complete epidemiological surveys of rare diseases, subject to all applicable privacy laws and protections;  
(viii)  examine the feasibility of developing a rare disease information and patient support network in the commonwealth to aid in determining any genetic or environmental contributors to rare diseases; and  
(ix)  develop and maintain a comprehensive rare disease plan for the commonwealth utilizing any information and materials received or created by the advisory council pursuant to this subsection, and that shall include information directed explicitly toward the general public, state and local officials, state agencies, private organizations and associations and businesses, and industries.  
estimate of any cost savings on the part of individuals and the commonwealth that will occur upon full implementation of the comprehensive rare disease plan and accompanying programs.

Mr. Cranston commented that the list of responsibilities is expansive.

Dr. Tierney asked the question, with DPH as a facilitator, who does this, and how does this work happen within the makeup of the RDAC and meeting schedule?

Mr. Cranston indicated that identifying the scope of the Council is important and identifying the work that happens in face-to-face meetings vs. outside of meetings.

Ms. Rhee Asked the group to think about the order in which the RDAC approaches the nine activities as it may make sense to approach some items before others. Ms. Rhee also asked the SC to ask members to think about how activities can be executed based on the makeup of the RDAC, for instance, can individuals who work in the industry perhaps leverage access to data and information.

Rep. Kane stated the RDAC is under the Commissioner of DPH, with Dr. Tierney as the Commissioner’s designee. The legislative language indicates the RDAC shall meet no less than four times a year so that the Council could meet more than four times a year. Rep. Kane also commented that she assumed the Council would establish subcommittees and that all members would be familiar with the activities written in the legislation. The SC needs to help prioritize the activities and then take a recommendation back to the full Council.

Dr. Tierney agreed that the SC meeting is a first step toward developing smaller working groups. Dr. Tierney reminded everyone that all smaller working groups are also subject to the Open Meeting Law (OML).

Rep. Kane shared her experience with the Local & Regional Public Health Commission. The group was similar to the RDAC and had a Steering Committee and four subcommittees. Minutes were taken at each meeting by administrative support, and each subcommittee had a chair who coordinated and kept the group moving. Some of these subcommittees functioned on their own; all took minutes.

Mr. Cranston thanks Rep. Kane for the useful history, also indicated that BIDLS would consult with their general counsel on the operation of smaller subcommittees, as policy deliberations can only occur under the OML, including any subcommittees. Mr. Cranston also indicated that the RDAC would be getting additional administrative support.

Rep. Kane reminded the group that the RDAC legislation allows the group to accept funds as the RDAC. If the RDAC can get funds, it can underwrite other supports such as graduate students to assist with work.

Ms. Rhee asked if the council could solicit pro bono work? Dr. Tierney will bring this to the Bureau’s counsel. Ms. Rhee commented that pro bono assistance would help understand epidemiological data.

Dr. Tierney agreed, saying that a subcommittee could be focused on research and oversee that work. Subcommittees may also engage academic and medical centers. Dr. Tierney asked Mr. Cranston if there are any resources from BIDLS beyond convening meetings, for example, an epidemiologist? Mr. Cranston said he would need a detailed written request of what is needed to respond to.

Dr. Tierney commented that a subcommittee could also focus on a specific issue such as insurance coverage. Dr. Tierney explained that the next full RDAC meeting in June would have a panel of three RDACs from other states discussing their work. Dr. Tierney said that before the meeting, he would send out the authorizing legislation and ask members to start to think about subcommittees based on the nine activities. A vote will need to be taken at a future meeting to form subcommittees.

Ms. McNary asked if, at the next meeting, the panel discussion could happen as well as a discussion of the RDAC’s mission and deliverables? Or is it possible to add another meeting as the group seems to run out of time? Dr. Tierney responded that the RDAC could meet as frequently as the group would like. The next meeting is on June 23, 2022. There was a suggestion to add another full RDAC meeting in July, with another SC meeting held before that time.

Rep. Kane asked everyone to read the legislation carefully and have the SC help to prioritize the nine activities. For example, could the SC recommend a list of reading materials for all members?

Dr. Tierney said he drafted an email to the full RDAC asking them to read/review the legislative language and think about how each member can contribute to the activities. Dr. Tierney asked if this could be done through email based on the OML. Rep. Kane said she thought that would be fine. Mr. Cranston commented that groups could not deliberate recommendations in secret, they must be public, but that administrative tasks, such as this, are not deliberations. Dr. Tierney will check with counsel.

Ms. Rhee said she has heard from other state RDACs that it can be a struggle to get anything done and is happy MA has established an SC to help make things happen. Rep. Kane wants the MA RDAC to have something visible to the patient community.

Dr. Tierney appreciated the positive attitude and said he would send out dates for the next SC meeting, a full RDAC meeting (after the June meeting), and an email with the legislation. Dr. Tierney will also draft some ideas/topics for subcommittees. Dr. Tierney thanked everyone, including Mr. Cranston, then ended the meeting.