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

**Workgroup 2 Subcommittee Meeting**

Wednesday, April 12th, 2023

11:00 AM – 12:00 PM

Meeting Minutes – Approved August 7, 2023

**REMOTE MEETING:**

https://us06web.zoom.us/j/84409482998?pwd=TzFSS09US2xSZkxIdTBHak9JMFdaQT09

**Welcome – Jenn McNary (chair)** welcomed all to the meeting at 11:02

**J McNary** conducted a Roll Call for attendance

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| **First Name** | **Last Name** | **Email** | **Present** |
| Jenn | McNary | [jenn@jmcnaryconsulting.com](mailto:jenn@jmcnaryconsulting.com) | X |
| Lisa | Deck | [lisadeck@gmail.com](mailto:lisadeck@gmail.com) | X |
| Guadalupe | Hayes-Mota | [guadamota@gmail.com](mailto:guadamota@gmail.com) | - |
| Diane | Lucente | [dlucente@partners.org](mailto:dlucente@partners.org) | - |
| Michele | Rhee | [michele.rhee@gmail.com](mailto:michele.rhee@gmail.com) | X |
| Ross | Zafonte | [rzafonte@mgh.harvard.edu](mailto:rzafonte@mgh.harvard.edu) | - |
| Janis | Creedon | [janiscreedon@gmail.com](mailto:janiscreedon@gmail.com) | - |
| Jay | Livingstone | [jay.livingstone@mahouse.gov](mailto:jay.livingstone@mahouse.gov) | X |
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Jenn asked if everyone had received the minutes from the last meeting. All stated yes. She then asked if there were any edits, corrections, or omissions to the minutes. No one responded. She then made a motion to accept the minutes from the last meeting as written.

**L Deck** made a second.

**J McNary** conducted a roll call vote

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| **First Name** | **Last Name** | **Email** | **approve** |
| Jenn | McNary | [jenn@jmcnaryconsulting.com](mailto:jenn@jmcnaryconsulting.com) | yes |
| Lisa | Deck | [lisadeck@gmail.com](mailto:lisadeck@gmail.com) | yes |
| Guadalupe | Hayes-Mota | [guadamota@gmail.com](mailto:guadamota@gmail.com) | NA |
| Diane | Lucente | [dlucente@partners.org](mailto:dlucente@partners.org) | NA |
| Michele | Rhee | [michele.rhee@gmail.com](mailto:michele.rhee@gmail.com) | yes |
| Ross | Zafonte | [rzafonte@mgh.harvard.edu](mailto:rzafonte@mgh.harvard.edu) | NA |
| Janis | Creedon | [janiscreedon@gmail.com](mailto:janiscreedon@gmail.com) | NA |
| Jay | Livingstone | [jay.livingstone@mahouse.gov](mailto:jay.livingstone@mahouse.gov) | yes |
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**Review workgroup progress**

**J McNary** thanked everyone for their work on the project. She then asked L Deck if she could summarize the progress to date.

**L Deck** stated that the work was ongoing. People added information to the Google doc. She stated that A Mahady had sent a list of resources, and Cassidy entered it into the spreadsheet, but it was very tedious work. She then asked if we needed to take the time to do this? She asked if it was the best way to collect this information. And what is our end goal?

**J McNary** stated that the end goal was to gather information from this list to address the legislative charges given to the group. She then asked the group if this was the best way to gather this information. She told the group that she is on Workgroup 3 also, and they had decided to use a survey tool to gather information on stakeholders. She asked if this may be the best way for workgroup 2 to gather information. She asked if anyone knew how to use this type of form.

**M Rhee** added that she knew how to use a Google form. She could create a Google form that would populate the spreadsheet.

**J McNary** stated that it sounded like a good idea. If we consider using a survey to collect the data we need, can we think about what we would want in the survey tool?

She asked if we should add information about the location of the resource. Could we ask where the resource is available?

**M Rhee** stated that we could use zip code or county and that using dropdown may be the best way for people to complete the survey.

**J McNary** asked if we should collect demographic data. We could ask by category, for example We could ask if the resource is medical, caregiving, housing, social, emotional, or recreational.

She asked if anyone had suggestions for other categories.

**M Rhee** added financial and insurance.

**J McNary** added that we should ask a question about whether or not they have used the resource and when; that way, we know if it is current.

**J Livingstone** added that we should try to keep it as simple as possible. It’s hard to get people to share information so the simpler we made it, the better.

**M Rhee** added that we could put dropdowns whenever possible, which may help.

**J McNary** added that we should know what demographic or population the resource is for. For example, is it for adults or pediatric, is it disease-specific, or for the disabled?

**M Rhee** asked which field we should have required.

**J McNary stated** that she thought that we should make them all required. In order to get a complete list, she thinks we need to require all the fields.

**M Rhee** said that she thought it made sense to ask their name at the beginning and if we could reach out to them if we needed verification or clarification on any of the information they submitted.

**L Deck** asked if we should allow people to enter more than one resource.

If so, how would we do that? Would people have to enter a new form for each resource?

**J Livingstone** added that it might be difficult to get people to enter all the information if it’s difficult to do it. Can we allow them to add many resources in one form? He stated that he looks at it a little differently. What if we centered the form around the people? First, ask where they live, then allow them to add more than one resource.

**M Rhee** stated that we could structure it that way. We could ask how many resources they wanted to enter, and then I could set it up so that it allowed them to enter all those resources by category. How many resources do we want to allow someone to enter?

**J McNary** asked if we could have ten. Could we allow people to add up to ten resources?

**M Rhee** stated that she would work on that. She wanted to talk with S Patel from workgroup 3 to see how he was creating theirs, but thought that it was possible.

**J McNary** asked if we could move on to the next item on the agenda. She wanted to revisit the legislative charges of the workgroup and see if we can develop a mission statement for the group.

**J Livingstone** asked why we needed a mission statement if we already had the legislative charges.

**J McNary** stated that she thought it was a way to let the public know what they were working on. She said she was thinking something like:

Evaluate and audit the current resources for the rare disease community and identify the gaps. We can then make recommendations based on our findings.

**J Livingstone** agreed that it made sense

**L Deck** recommended the following language

Audit and evaluate the current system of rare disease treatment and resources , Identify and determine the gaps in services, then provide recommendations to help the rare disease community.

**J McNary** then asked if we could think about timelines. When can we get this done?

**J Livingstone** asked if we could add another question to the survey. He asked if we could ask if there were any resources that they wished were available.

**J McNary** added that it was a great idea and then asked M. Rhee if she could add something like that.

**M Rhee** stated that she would work on the survey tool and could have a draft by the end of the week.

**J McNary** stated that if we get a draft sent to this committee and test the tool, we could then present it to the full council in May. Did everyone agree with that timeline?

**L Deck** asked if we were only collecting information for MA residents.

**M Rhee** added that she thought it would get to that question if we asked where the resource is located. I don’t think we care where the person lives, only where the resource is available, right?

**L Deck** then asked if we could send out the link to the survey through social media.

**J McNary** said we could ask that at the full council meeting in May.

**J McNary** asked how long we should plan to leave the survey open.

**L Deck** stated that she thought two months was a good timeframe. Especially because it was summertime.

**J McNary** summarizes by stating: if we launch the survey tool in May at the full council meeting and we leave it up for two months, that would put un into Mid-July or August. If we then review the data we collected for a month or so, we should be able to get our recommendations completed by the end of the year. Do people think that is a realistic goal?

**L Deck** asked what we do with the current data we have. We mostly only have lists of resources. Should we take the time to enter by cutting and pasting it into the spreadsheet? It’s a lot of work.

**J McNary** stated that it probably didn’t make sense to do that. We could always use that list as a reference, and it will be part of the data we collected. She didn’t think it would be productive to spend the time to re-enter the information at this point.

She then asked if anyone had any questions.

No one responded.

She asked if people were ok with the timeline we discussed.

All agreed.

She then asked if there was a motion to adjourn.

**J Livingstone** thanked Jen for her hard work and made a motion to adjourn.

**L Deck** Made a second

**J McNary** adjourned the meeting at 11:55.

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| [https://us06](https://us06web.zoom.us/j/83407469310?pwd=bW1WQlp6MkVCMkhLdGpqU1VaU3FSQT09) |