Nevada Rare Disease Advisory Council (RDAC)

Council Member Survey

Summary of Findings

Submitted by Annette Logan-Parker, Chair of the RDAC

Presented on February 13, 2023, During a Regularly Scheduled Meeting

Background: The NV-RDAC was formed under SB 315 during the 2019 session of the Nevada Legislature. The council was assigned several specific duties that range from performing a statistical and qualitative examination of the incidence, causes, and economic burden of rare disease in Nevada; including the development of a registry of rare diseases diagnosed in Nevada to determine the genetic and environmental factors that contribute to such rare diseases. As well as responsibility of increasing awareness of the burden caused by rare disease; including improving awareness among health care providers of the symptoms and care required for patients with rare diseases. As well as many other extremely lofty assignments. Unfortunately, the state of Nevada did not provision their RDAC with the required resources to be effective in their efforts: apart from the Nevada DMV Specialized License Plate for childhood cancer initiatives – which has failed to raise a meaningful amount of resources to provide any level of significant financial assistance to the RDAC's assignments. https://dmvnv.com/platescharitable.htm.

Regardless of the complexities of the assignment and the extremely challenging environment within the RDAC must navigate; the members of the NV RDAC remain committed to the task at hand- which is to improve the lives of Nevadans with rare diseases.

Although the RDAC enjoys extremely engaged and driven council members, as well as an immensely supportive team of NV- DHHS employees assigned to assist the RDAC; for the most part we have been unsuccessful at accomplishing the any of duties assigned to the council under SB 315. The RDAC's less than desirable outcomes are a direct result of limited resources coupled with the complexities of a volunteer start-up council and the absence of a well-defined strategy.

The current Chair of the Nevada Rare Disease Council, Annette Logan-Parker, requested that RDAC council members participate in an anonymous survey to help her understand the primary objectives of the individuals who volunteer their time to the efforts of the RDAC, as well as to gain perspective of where the council members feel our limited resources should be used, The information gathered through this exercise will ensure that the collective efforts of the NV-RDAC are productive in action, as well as rewarding in experience. The secondary objective of the survey is to provide the new Chair with the information required to understand how to best lead the NV-RDAC through her term as Chair. The survey was conducted in an anonymous format, and orchestrated by Ashlyn Torres, Health Program Specialist I, from the Nevada Department of Health and Human Services, this document summarizes results of these efforts.

Summary:

The survey confirms that the members of the RDAC are not only engaged and willing to serve the state Nevada on behalf of people with rare disease, but they are also equally aligned in their personal and collective agendas to improve the overall landscape of rare disease management in Nevada; including access to high quality medical care, improving the knowledge base of the states healthcare providers, influencing positive change with payers who provide coverage for people with rare diseases, and educating the state's law makers to create new and improved regulations that positively impact people with rare disease(s) and the families who love them.

To establish a strategic action plan for the NV RDAC the survey listed the 13 duties assigned to the council by SB 315 and placed them into 5 groups and as a council we ranked them in order of priority based on our current capabilities. The survey has determined that the top priorities should be as follows, in the order of importance:

(1) Collection & Analysis of Data (Data collection and the analysis of the data tied for the position top priority)

(2) Funding for RDAC operations

(3) Awareness Campaigns

(4) The Establishment of a Comprehensive Rare Disease Plan for Nevada

The survey confirms that the council members have identified several additional areas of focus including, but not limited to the following:

1. Health Equity and Disparities- understanding the obstacles to high quality medical care, the current laws & benefits protecting people with rare diseases, and how to best communicate these topics with government officials in order to influence increased funding for services (for example genetic testing and bio-markers) and meaningful programs for people with rare diseases.
2. Improved understanding of what other Rare Disease Advisory Councils are doing across the country and how they operate, as well as orientation to the NV RDAC goals and objectives with ongoing conversations on the progress of RDAC's.
3. Improved understanding of the complexities of rare diseases, statewide; including rural and underserved communities; including addressing improvement opportunities and communication with healthcare providers who treat people with rare disease.

This survey process has been helpful in identifying how to plan the future areas of focus required for the NV RDAC to establish a 2- year strategic plan and has also provided the incoming Chair with adequate information and suggestions to formulate a draft pan for approval.

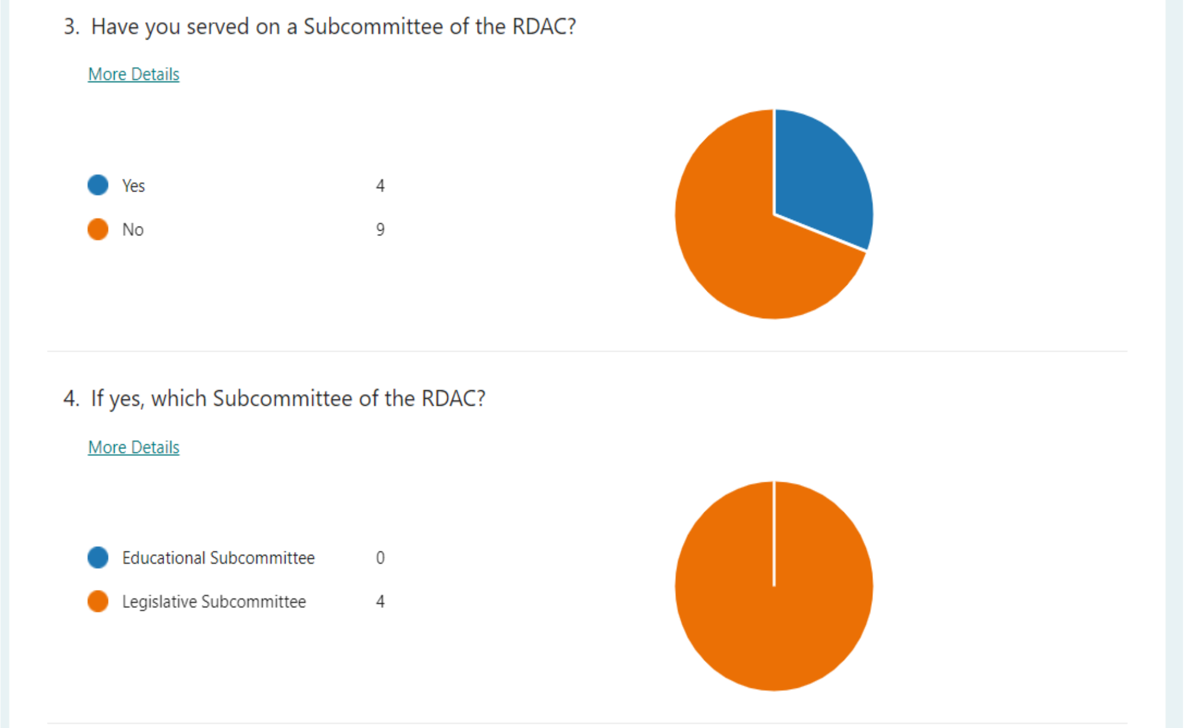
The remainder of this document showcases the questions asked and answers provided by the council members through this survey process.

Actual Survey Results:

The survey was sent out in January 2023 and was sent to all Nevada RDAC Members.

13 of the 16 members of the RDAC participated in the survey.

1. The members who participated in the survey have a varying degree of tenure on the council that range from 2 months (I member) to 3 plus years when the council was first formed (6 of the participants members are original RDAC members).
2. The participating RDAC members became aware of the opportunity to serve through a word-of-mouth process, and a few were approached by representatives of the state of Nevada- generally the current RDAC members have all been recruited by someone they know.

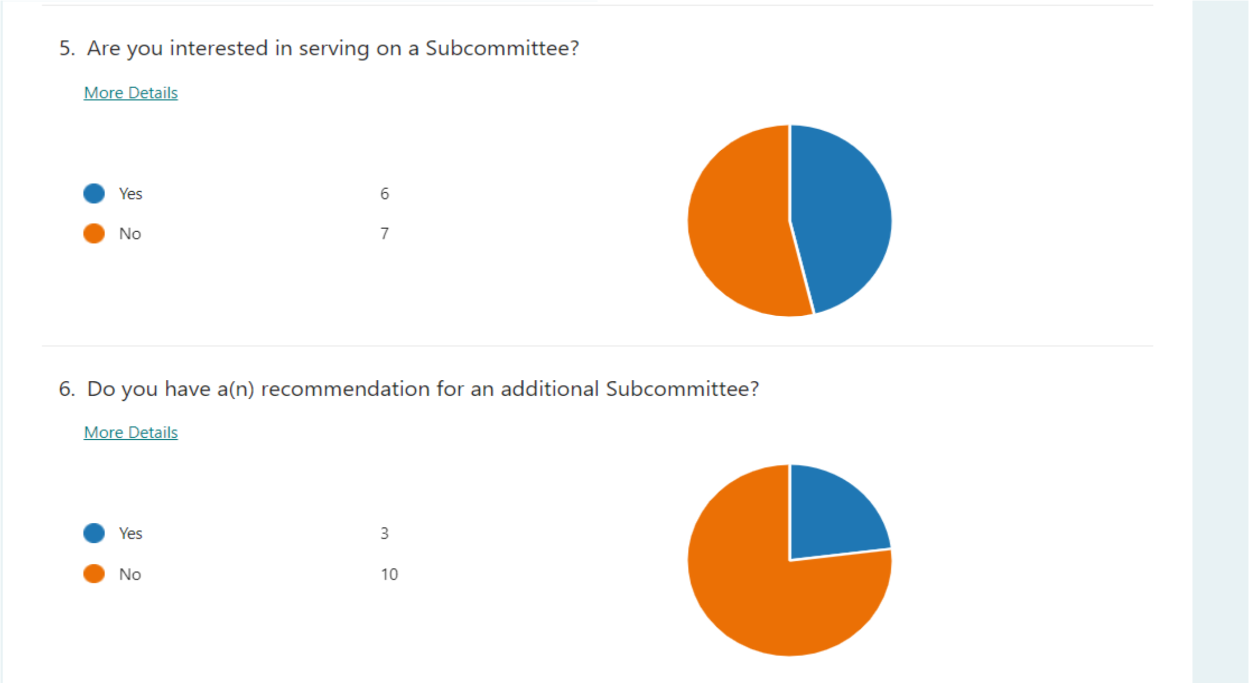


3. Have you served on a Subcommittee of the RDAC?

●	Yes	4
●	No	9

4. If yes, which Subcommittee of the RDAC?

●	Educational Subcommittee	0
●	Legislative Subcommittee	4



5. Are you interested in serving on a Subcommittee?

More Details

● Yes	6
● No	7

6. Do you have a(n) recommendation for an additional Subcommittee?

More Details

● Yes	3
● No	10

#7 Recommendations for additional sub-committees

1. State Cancer Data Reporting to ensure inclusion in the CDC reporting.
2. Health Equity
3. Medical or Scientific Committee

#8 What do you wish to accomplish through your involvement with the RDAC?

Responses:

“Improve patient outcomes”

“I hope the Nevada RDAC would help improve early detection, diagnosis, follow-up, and timely ongoing case management of rare diseases in Nevada and will improve the quality of life for patients and their families”

“I would like to truly provide resources to the families and patients who need them. I don't want to create a website that has dead ends to the links. I would also like to have an educational track for those that need it. It would be wonderful to have the RDAC committee partner with UNLV school of medicine or departments from the college and partner with UMC or a hospital that can close the loop on questions and needs.”

“I want to improve the state’s data collection efforts in order to the understanding of the issues facing the state specifically.”

“Increasing access to genetic services to the patients in NV.”

“Buy in to rare disease from Nevada governmental institutions to assist in better regulating commercial payors with significant rare disease care gaps.”

“Help facilitate more funding for RDAC initiatives”

“Make changes in the medical field”

“Greater access to care for NV AYA cancer patients, increase state's ability to provide specialized cancer care”

“Public policy that aligns with the needs of patients and their caregivers - and that avoids unintended consequences.”

“Cont. to get the word out on RDAC and bring families and other providers to the table.”

“I wish to contribute to long term changes in Nevada which benefit those with Rare Disease, through participating in talks, providing recommendations, and advocating locally and legislatively for individuals with Rare Diseases”

“Improve access to treatment in Nevada for patients with rare diseases”

#9 Is there an area of education regarding a specific topic or issue that relates to the goals and objectives of the Nevada RDAC that you feel you or the council as a whole could benefit from?

Responses:

“Better understanding of what other state RDACs are tracking and how they operate”

“Probably the area of communication especially with provider to improve communication with clinicians who provide care for patients with rare disease/s”

“I would have to think on that more and let you know.”

“I think the council needs an orientation to the RDAC goals and objectives. The goals are not clear and are rarely discussed.”

“Communication with government officials to increase funding to services for these patients”

“No as we have no authority”

“Registry of Rare Disease Practitioners in Nevada and neighboring states; better understand whether NV legislators truly want to fund RDAC or only give minimum funding”

“Sickle Cell Disease”

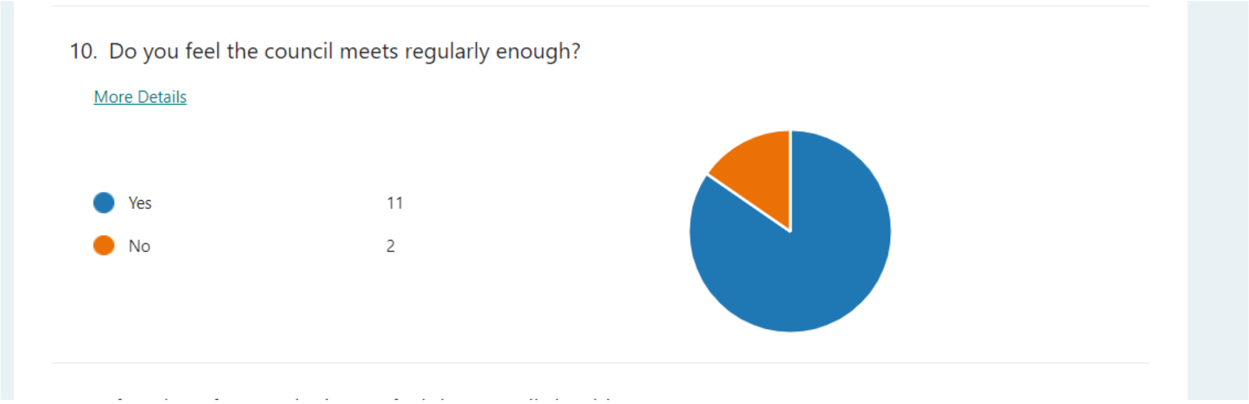
“National database for sharing cancer information”

‘Understanding the complexities of rare diseases, especially in rural, remote, and underserved communities. Also, the importance of all stakeholders communicating and building solutions to the challenges together.”

“None at this time.”

“Health Equity for patients with rare disease addressing disparities such as access to care and quality of care.”

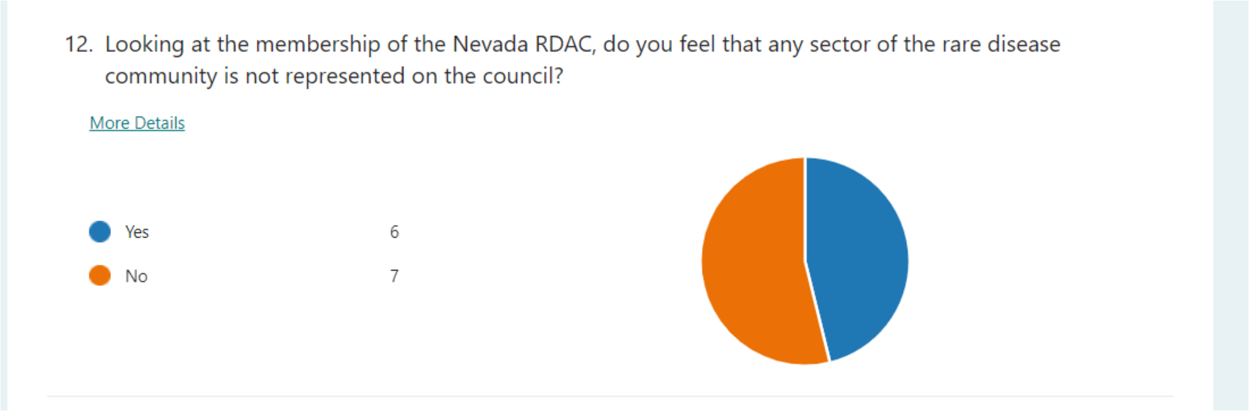
“What are the current laws protecting people with rare disease's access to medical care e.g.; SSI, Medicaid, Medicare coverage, etc.”



10. Do you feel the council meets regularly enough?

#11 Recommendations for meeting frequency

1. Monthly
2. Monthly until a cohesive goal/strategy and/or plan is developed and acted upon.



12. Looking at the membership of the Nevada RDAC, do you feel that any sector of the rare disease community is not represented on the council?

More Details

● Yes	6
● No	7

#13 If yes, what type of representative do you think would improve the collective efforts of the RDAC?

Responses:

“Adult patients with rare diseases”

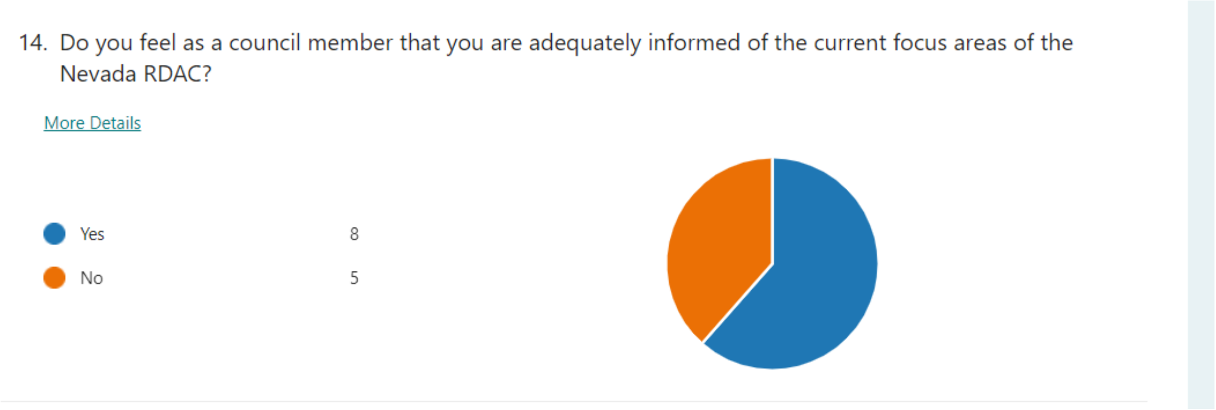
“Representatives of Medicaid and managed Medicare commercial payors”

“Need more data to accurately know prevalence of different types of rare disease in Nevada to answer question.”

“Perhaps someone from the extended provider sector … specialty pharmacies, long term/sub-acute care, etc. I also wonder if someone from the legislative branch would be good to include - a champion.”

“A representative that is not focused on any one Rare disease but all rare diseases in general

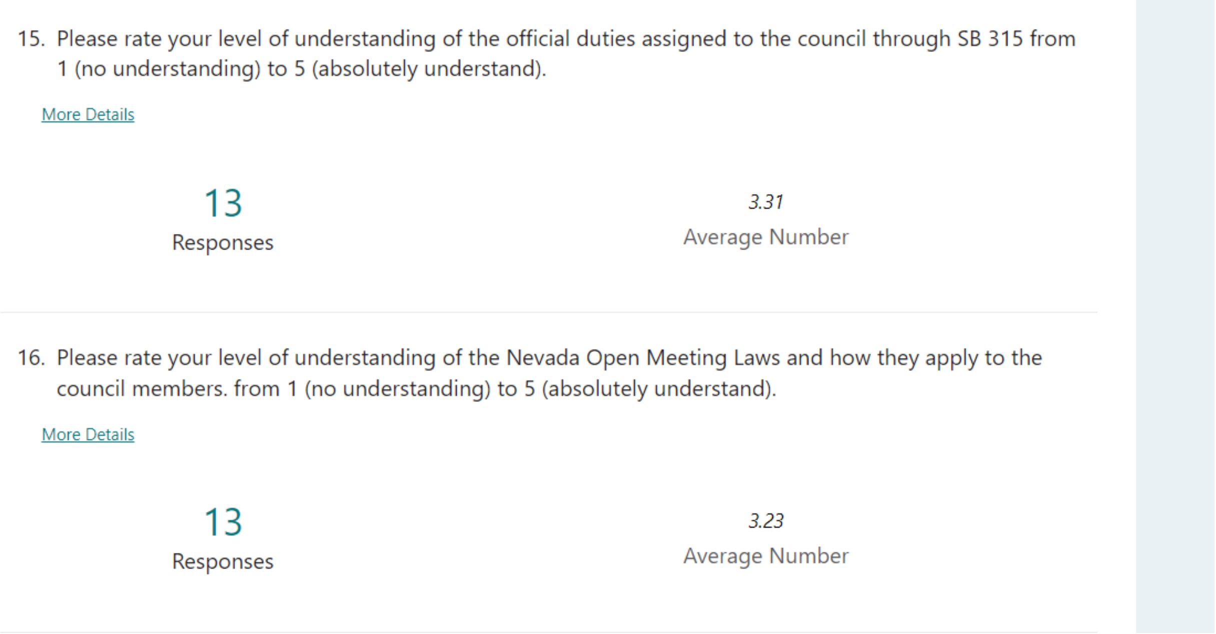
Metabolic diseases specialist and the Nevada Newborn Screening Program.”



14. Do you feel as a council member that you are adequately informed of the current focus areas of the Nevada RDAC?

More Details

● Yes	8
● No	5



15. Please rate your level of understanding of the official duties assigned to the council through SB 315 from 1 (no understanding) to 5 (absolutely understand).

More Details

13
Responses

3.31
Average Number

16. Please rate your level of understanding of the Nevada Open Meeting Laws and how they apply to the council members. from 1 (no understanding) to 5 (absolutely understand).

More Details

13
Responses

3.23
Average Number

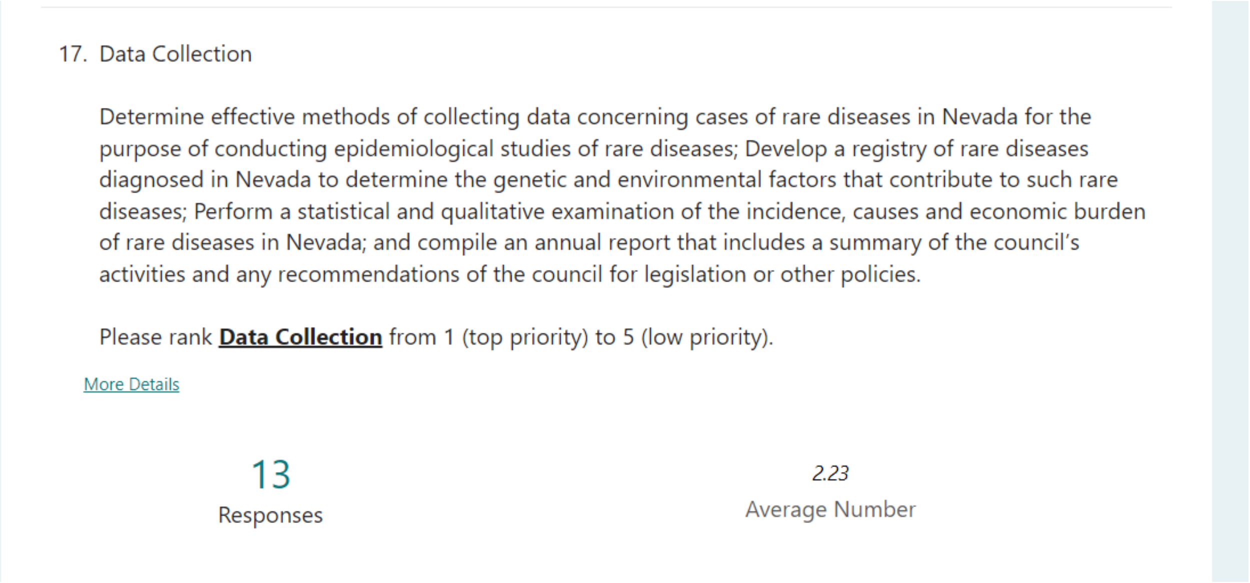
Determining the Primary area of focus as a council: The duties of the RDAC were placed into 5 categories to be rank in order of importance with 1 being a top priority and 5 being the lowest priority. In order of priority the categories are ranked as follows- with 1 and 2 resulting In a tied score.

Data Collection & Analysis of Data: 2:23 TIED SCORE

Funding for the RDAC 2.46

Awareness: 2.69

Comprehensive Rare Disease Plan for Nevada: 2.92



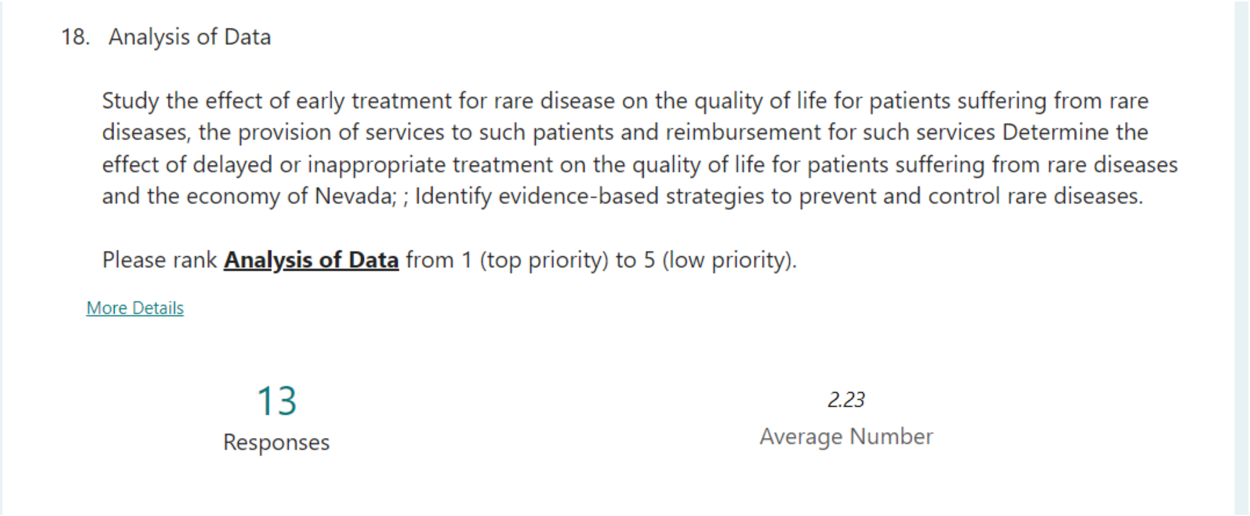
17. Data Collection

Determine effective methods of collecting data concerning cases of rare diseases in Nevada for the purpose of conducting epidemiological studies of rare diseases; Develop a registry of rare diseases diagnosed in Nevada to determine the genetic and environmental factors that contribute to such rare diseases; Perform a statistical and qualitative examination of the incidence, causes and economic burden of rare diseases in Nevada; and compile an annual report that includes a summary of the council's activities and any recommendations of the council for legislation or other policies.

Please rank **Data Collection** from 1 (top priority) to 5 (low priority).

13
Responses

2.23
Average Number



18. Analysis of Data

Study the effect of early treatment for rare disease on the quality of life for patients suffering from rare diseases, the provision of services to such patients and reimbursement for such services Determine the effect of delayed or inappropriate treatment on the quality of life for patients suffering from rare diseases and the economy of Nevada; ; Identify evidence-based strategies to prevent and control rare diseases.

Please rank **Analysis of Data** from 1 (top priority) to 5 (low priority).

13
Responses

2.23
Average Number

19. Awareness

Receive and consider reports and testimony concerning rare diseases from persons, the Division, community-based organizations, providers of health care and other local and national organizations whose work relates to rare diseases; Increase awareness of the burden caused by rare diseases in Nevada; Increase awareness among providers of health care of the symptoms of and care for patients with rare diseases. Evaluate the systems for delivery of treatment for rare diseases in place in Nevada and develop recommendations to increase the survival rates and quality of life of patients with rare diseases.

Please rank **Awareness** from 1 (top priority) to 5 (low priority).

More Details

13
Responses

2.69
Average Number

20. Comprehensive Rare Disease Plan for Nevada

Establish a comprehensive plan for the management of rare diseases in Nevada, which must include recommendations for the state and local health authorities, public and private organizations, businesses, and potential sources of funding, and update the comprehensive plan as necessary.

Please rank **Comprehensive Rare Disease Plan** for Nevada from 1 (top priority) to 5 (low priority).

More Details

13
Responses

2.92
Average Number

21. Funding for the RDAC

Determine how to best utilize the funds associated with the specialized license plate that was established to support the Rare Disease Advisory Council and research and treatment for childhood cancer that can be purchased through the Nevada DMV Specialized License Plates website.

Please rank **Funding for RDAC Operations** from 1 (top priority) to 5 (low priority).

More Details

13	*2.46*
Responses	Average Number