

## Survey Questions

This question list aims to aid in understanding the methods and results of the 2022 Mito Community Survey. Questions not included in this list were related to:

- Establishing the respondent's link to mitochondrial disease (mito)
- Demographic data
- Consent and prize draw

The survey included complex internal logic to display only relevant questions and to repeat questions when necessary.

For more information on the survey, please contact Mito Foundation via [info@mito.org.au](mailto:info@mito.org.au).

### Bereavement

1. Thank you for telling us about your connection(s) to mito. You have told us that you have known someone with mito who has passed away. We are deeply sorry for your loss. Were you aware that Mito Foundation can provide bereavement support?
2. Is there anything you'd like to share about your experience with Mito Foundation's services as a part of your bereavement?
3. How likely are you to recommend Mito Foundation's services to others who have experienced a bereavement?

### Empowerment – for respondents who have mito themselves

4. We would now like to ask you about your experience as someone with mito. Overall, what impact does mito have on your day to day life?
5. Now thinking about your knowledge of mito, to what extent do you agree or disagree with the following statements?
  - I know how to manage my mito symptoms
  - I have learned so much about mito that I often educate others about it, including health professionals
  - I understand the medical tests that I need to have to monitor my mito
  - When I have questions about mito, I know how to seek answer
6. Which aspects of mito have you found most challenging to learn about?
7. Overall, how would you describe accessing health care for your mito?

8. Please answer the following questions about your health care.

- I have access to a key specialist doctor that is a mito expert
- I have a general practitioner (GP) that supports me to manage my mito, along with my other health needs
- I receive professional advice regarding the best diet for mito-such as from a dietitian
- I receive professional advice regarding the right amount and type of exercise for mito-such as from a physio therapist or exercise physiologist
- I have a management plan for my mito
- I have an emergency plan containing information about my mito to give staff at the hospital when I need urgent treatment.

9. Please use this space to tell us more about your experiences with these aspects of your health care.

10. Thinking about your medical specialists for your mito, where do you see them?

11. Thinking about the impact of mito, to what extent do agree or disagree that you have helpful support in the following areas of your life

- Mental health and wellbeing
- Finances
- Housing
- Employment
- Education
- Personal care/independent living
- Transport

12. What have been your major challenges in getting helpful support?

13. Now some questions about your confidence with managing mito. To what extent would you agree or disagree with each of the following statements?

- Overall, I am confident to manage my mito
- I actively share in decisions made about the management of my mito
- I am able to arrange appointments related to my mito
- I feel confident to stand up for myself about what I need regarding my mito
- When I need additional help, I am able to find someone to assist me

14. Now we would like you to think about your mental health and wellbeing

Please rate each of the following statements. In the last 4 weeks, I have

- Been a very anxious person
- Felt down hearted and blue

15. A few more questions about your mental health and wellbeing

To what extent do you agree or disagree with each of the following statements

- I often feel lonely because of my mito
- I feel hopeful about the future
- I often feel socially isolated because of my mito/because of my caring responsibilities

16. In regards to your response to the statement 'I feel hopeful about the future'. Can you tell us about the key things that lead you to feel this way?

17. In general, would you say your health is:

- Excellent
- Good
- Fair
- Poor
- Very poor

18. You told us that you are seeking a diagnosis of mito. We'd like to understand your experience in seeking a diagnosis.

To what extent do you agree or disagree with each of the following statements?

- I have a general practitioner(GP) who is helping me search for a diagnosis of mito
- I am able to access medical specialist care as a part of seeking a diagnosis of mito

## Empowerment - for respondents who provide regular care for one or more people with mito

19. Now we would like to ask some questions about your health and wellbeing in the context of being a regular carer for someone with mito. In general, would you say your health is

- Excellent
- Good
- Fair
- Poor
- Very poor

20. Now thinking about your knowledge of mito in the context of your experience as a regular carer, to what extent do you agree or disagree with the following statements?

- I know how to help those I care for manage their mito symptoms
- I have learned so much about mito that I often educate others about it, including health professionals
- I understand the medical tests that those I care for need to have to monitor their mito
- When I have questions about mito, I know how to seek answers

21. Now some questions about your confidence with managing mito for the person/s you provide regular care. To what extent do you agree or disagree with each of the following statements?

- Overall, I am confident to manage mito for those I care for
- I actively share in decisions made about the management of mito for the person/s I care for
- I am able to arrange appointments related to those I care for
- I feel confident to stand up for those I care for regarding what they need for their mito
- When I need additional help, I am able to find someone to assist me

22. Now we would like you to think about your mental health and wellbeing

Please rate each of the following statements. In the last 4 weeks, I have

- Been a very anxious person
- Felt downhearted and blue

23. A few more questions about your mental health and wellbeing

To what extent do you agree or disagree with each of the following statements

- I often feel lonely because of mito
- I feel hopeful about the future

- I often feel socially isolated because of my caring responsibilities

24. In regard to your response to the statement 'I feel hopeful about the future'. Can you tell us about the key things that lead you to feel this way?

25. We would now like to ask you some questions about your experience as a regular carer for \_\_\_\_.

Overall, what impact does mito have on \_\_\_\_'s day to day life?

- No impact
- Minor impact
- Moderate impact
- Significant impact
- Extreme impact

26. Still thinking about your experience as a regular carer for \_\_\_\_, how easy or difficult is it for you to access health care for them?

- Very difficult
- Difficult
- Neutral
- Easy
- Very easy

27. Now, thinking about accessing health care for \_\_\_\_, do they:

- Have access to a key specialist doctor that is a mito expert?
- Have a general practitioner (GP) that helps us to manage their mito, along with their other health needs?
- Receive professional advice regarding the best diet for mito, such as from a dietitian
- Receive professional advice about exercise, such as from a physiotherapist or exercise physiologist?
- Have a management plan for their mito?
- Have an emergency management plan containing information about their mito to give staff at the hospital when they need urgent treatment?

28. Please use this space to tell us more about your experiences with accessing health care for \_\_\_\_.

29. Thinking about the medical specialists that \_\_\_\_ sees for their mito, where do they see them?

30. Thinking about the impact of mito, to what extent do you agree or disagree that \_\_\_\_ has useful help in the following areas of life?

- Mental health and wellbeing
- Finances
- Housing
- Employment
- Education
- Personal care/independent living
- Transport

31. What have been your major challenges in getting helpful support for \_\_\_\_ ?

32. You told us that you are seeking a diagnosis of mito for \_\_\_\_\_. To what extent do you agree or disagree with each of the following statements?

- I understand what is involved in obtaining a diagnosis of mito
- They have a general practitioner (GP) who is helping us search for a diagnosis of mito

- They are able to access medical specialist care as a part of seeking a diagnosis of mito

## Support Service awareness and usage

33. How did you first learn about Mito Foundation?

34. At what point in your mito journey did you first learn about Mito Foundation?

35. Mito Foundation provides a variety of services to the mito community. Please indicate below which services you are aware of and if you have used them. You may have used services either for yourself or on behalf of another person with mito.

- Helpline
- Mito fact sheets, videos and other resources at [www.mito.org.au](http://www.mito.org.au)
- Patient Pathways Nurse Program
- Mito Connect Calls: video and voice calls that focus on one topic, usually with an expert speaker
- Mito Information Days: events in person or online that bring together mito community and experts to learn about mito
- Mito Meet-ups: Peer support groups facilitated by a member of the mito community

## Helpline

36. Thinking back to when you last used the Helpline, what was the reason you did so, i.e. what information or support were you seeking?

37. How would you rate the Helpline on each of the following?

- Meeting my immediate needs
- Listening to me
- Knowledge of staff
- Time taken to respond
- Helping me feel more confident in managing mito

38. How can Mito Foundation improve the Helpline?

39. How likely are you to recommend the Helpline to someone else in the mito community?

## Website

40. Thinking back to when you last used the information on Mito Foundation's website, what was the reason you did so? For example, what information or resources were you looking for?

41. How would you rate the information or resources on Mito Foundation's website on each of the following?

- Helping me to feel more confident in managing mito
- Improving my knowledge of mito
- Helping me to access health care or other support
- Improving my wellbeing
- Enabling me to find what I was looking for

42. How can Mito Foundation improve the information and resources on its website?

43. How likely are you to recommend the information and resources on Mito Foundation's website to someone else in the mito community?

## Mito Information days

44. In the last 2 years, did you attend a Mito Information Day/s

- Online
- In person
- Can't recall

45. Thinking back to the last Mito Information Day you attended, what was the key reason you had for attending?

46. How would you rate the last Mito Information Day you attended on each of the following?

- Covering topics relevant to me
- Improving my knowledge of mito
- Helping me to access health care or other support
- Improving my wellbeing
- Helping me to feel more confident in managing mito

47. How can Mito Foundation improve Mito Information Days?

48. Thinking about the last Mito Information Day you attended, how likely are you to recommend an event like this to another member of the mito community?

## Patient Pathways Nurse Program

49. Thinking back to when you last used the Patient Pathways Nurse Program, what was the reason you did so, i.e. what information or support were you seeking?

50. How would you rate the Patient Pathways Nurse Program on each of the following?

- Listening to my needs
- Meeting my immediate needs
- Time taken to respond
- Helping me to access health care or other support
- Improving my wellbeing
- Helping me to feel more confident in managing mito

51. How can Mito Foundation improve the Patient Pathways Nurse Program?

52. How likely are you to recommend the Patient Pathways Nurse Program to someone else in the mito community?

## Mito Connect Calls

53. Thinking back to the Mito Connect Call you attended, what was the key reason you had for attending?

54. How would you rate Mito Connect Calls on each of the following?

- Improving my knowledge of mito
- Helping me to access health care or other support
- Improving my wellbeing
- Helping me to feel more confident in managing mito
- Expertise of the presenter

55. How can Mito Foundation improve Mito Connect Calls?

56. How likely are you to recommend Mito Connect Calls to someone else in the mito community?

## Mito Meet-ups

57. Thinking back to when you last attended a Mito Meet-up, what was the main reason you did so? For example, what information or support were you seeking?

58. In the last 2 years, did you attend a Mito Meet-up

- Online
- In person
- Can't recall

59. How would you rate the Mito Meet-up on each of the following?

- Felt welcoming
- Making me feel comfortable to share my experience
- Sense of connection to other people impacted by mito
- Improving my wellbeing
- Helping me to feel more confident in managing mito

60. How can Mito Foundation improve the Mito Meet-ups?

61. How likely are you to recommend Mito Meet-ups to someone else in the mito community?

## Medical Professionals Directory

62. In the last two years, have you sought help from Mito Foundation to find a health professional to assist you, or a person with mito?

63. Was Mito Foundation able to connect you with a health professional

64. Can you tell us a bit more about your experience in trying to get help from Mito Foundation in connecting with a health professional?

65. What type of specialist or health professional were you seeking?

66. How likely are you to recommend the service to connect to a health professional to someone else in the mito community

67. Mito Foundation plans to build on the success of their Exercise Physiology Network by connecting mito community members to more allied health professionals. This involves building up a list of mito-aware health professionals. Which of these would be most useful to you:

- Psychologist
- Physiotherapists
- Dietitians
- Occupational therapists
- Speech therapists
- Other professional (please specify)

68. Do you know a mito-aware health professional that you would recommend to others? Mito Foundation will reach out to see if they would be interested in joining our health professionals directory.

## Mito Foundation Patient Registry (Mito Registry)

69. Are you / a person you care for registered on the Mito Foundation Patient Registry (also called the Mito Registry)?

- Yes and have been involved in at least one research study
- Yes not involved in a research study
- No but interested in finding out more
- No, not interested
- Unsure
- Prefer not to say

70. How can Mito Foundation improve the Mito Registry?

71. How likely are you to recommend the Mito Registry to someone else in the mito community?

72. You told us you were not interested in joining the Mito Registry for yourself or someone you provide regular care for. Can you share the reason/s why?

## The National Disability Insurance Scheme (NDIS)

73. Are you, or the person you care for, receiving or have received support through the National Disability Insurance Scheme (NDIS) in the last 2 years?

- Yes
- No need for any disability services
- No – applied but was found to not be eligible
- No – have a need for disability support but haven't applied
- Prefer not to say

74. What kind of support are you (or the person/s you are caring for) receiving through the NDIS?

75. Mito Foundation is strengthening the help it provides to the mito community with accessing the NDIS. If you'd like the Mito Foundation to assist you with the NDIS, how would you like to access that service?

- - Understanding the NDIS and how it could help me
- - Applying for access to the NDIS
- - Preparing for my first meeting with the NDIS to ask for what I need
- - How to best use my NDIS plan
- - What to do if my circumstances or needs change
- - Help with NDIS decisions and review process
- - Another type of help (please specify)

## Likelihood to use services & service improvements

76. You indicated that that you were aware of but hadn't recently used the Helpline. Could you share with us the reason/s why?

77. You indicated that that you were aware of but hadn't recently accessed mito fact sheets, videos and other resources at [www.mito.org.au](http://www.mito.org.au). Could you share with us the reason/s why?

78. You indicated that you were aware of but had not recently used the Patient Pathways Nurse Program. Could you share with us the reason/s why?

79. You indicated that that you were aware of but had not participated in Mito Connect Calls recently. Could you share with us the reason/s why?

80. You indicated that that you were aware of but had not attended Mito Information Days recently. Could you share with us the reason/s why?
81. You indicated that you had not recently attended Mito Meet-ups. Could you share with us the reason/s why?
82. Mito Foundation is interested in your feedback on some specific projects and services. Would you be happy to be contacted by Mito Foundation via email about any of the below topics?
83. Mito Foundation is always looking for ways it could improve the services and support it provides the mito community. Do you have any other suggestions?
84. Would you like Mito Foundation to follow up with your or provide any further support or information? If yes, please indicate how Mito Foundation can help.

## Recommendations and brand attributes

85. How likely are you to recommend Mito Foundation to someone else in the mito community?

## Stories

86. Sharing your story is a powerful way for you to help us understand your life with mito. Can you tell us about some of the biggest challenges you have faced in your mito journey and what has helped you most?



[mito.org.au](http://mito.org.au)