

## SCOPPE - Scan of Pheochromocytoma and Paraganglioma Experiences

### Informed Consent

#### INVITATION

In my role as principal investigator, I am inviting you to participate in a survey of patients who have been diagnosed with a pheochromocytoma (pheo) or paraganglioma (para) or have a genetic mutation associated with these conditions. Caregivers of pheo para patients also may complete the survey on behalf of patients who are not able to complete the survey themselves.

This research is being conducted by the Pheo Para Alliance (PPA), which is an international nonprofit patient advocacy organization, and by researchers from Brock University and the University of Colorado. Please note that the principal investigator, Dr. Linda Rose-Krasnor (Secretary, PPA Board of Directors), as well as co-investigators Stephanie Arband (PPA Executive Director) and Dr. Lauren Fishbein (member of the PPA Medical Advisory Board), are affiliated with the Pheo Para Alliance.

The purpose of the study is to identify patients' perceptions of unmet needs for information about, and availability of, diagnosis, treatment and monitoring options for pheos and paras. We are also interested in possible gender, geographic, and other group differences in patient awareness of these options, as well as access to timely and effective health care services for this rare disorder.

#### WHAT'S INVOLVED

As a participant, you will be asked to complete a confidential online survey, taking approximately 20 minutes.

#### POTENTIAL BENEFITS AND RISKS

We hope the results will enable health care professionals to improve access to information and quality of care in the management of pheos and paras, increase the effectiveness of our patient support and education activities, and help direct funding to needed research. In addition, benefits of participation to you personally may include increased awareness of diagnostic and treatment options. Information about diagnosis, treatment and monitoring procedures can be found <https://pheopara.org/education/pheochromocytoma> and <https://pheopara.org/education/paraganglioma>. This information has been vetted by our Medical Advisory Board and is written in patient-friendly language. Additional diagnostic and treatment information is available on the NORD (National Organization for Rare Disorders) website.

There are no known or anticipated risks associated with participation in this study.

## SCOPPE - Scan of Pheochromocytoma and Paraganglioma Experiences

### Informed Consent, Continued

#### **CONFIDENTIALITY AND ANONYMITY**

All information you provide will be kept confidential; your name will not be included or, in any other way, associated with the data collected in the study. Furthermore, because our interest is in the average responses of groups of patients, you will not be identified individually in any way in reports of this research.

Data collected during this study will be stored on a secure server in the US, managed by SurveyMonkey. Although SurveyMonkey collects IP addresses as part of its standard procedure, that information will not be available to the researchers. Staff members of Survey Monkey can access IP addresses in exceptional situations where they are required to report information to law enforcement agencies or a court of law. Once the survey is complete, the Survey Monkey data will be deleted from its server, after the data are downloaded to the investigators' computers. The now anonymous data will be kept by the researchers in a secure password-protected location until all the research questions have been addressed and any data retention requirements established by journal publishers have been met. At that time, the data will be deleted.

Access to this anonymous data will be restricted to Dr. Linda Rose-Krasnor and co-investigators Stephanie Alband and Dr. Lauren Fishbein.

#### **VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If you wish, you may decline to answer any questions, except the initial question confirming your status as a pheo/para patient or caregiver. If you are not a pheo/para patient or caregiver answering for a patient who is incapacitated or unable to comprehend the questions, you will not be eligible for this study. You may decline to participate or answer any question without any penalty or loss of benefits to which you are entitled and your choice to participate will not impact affiliation with PPA or its services.

#### **PUBLICATION OF RESULTS**

Results of this study may be published in professional journals, shared on websites and social media, and presented at conferences. A summary of the results of this study will be available on the website of the Pheo Para Alliance in September 2022 and also by emailing the principal investigator at linda.rose-krasnor@brocku.ca.

#### **CONTACT INFORMATION AND ETHICS CLEARANCE**

If you have any questions about this study or require further information, please contact Dr. Linda Rose-Krasnor at linda.rose-krasnor@brocku.ca. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University [File #21-204]. If you have any comments or concerns about your rights as a research participant, please contact the Office of Research Ethics at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this study. Please keep a copy of this form for your records by printing it.

## SCOPPE - Scan of Pheochromocytoma and Paraganglioma Experiences

### Consent Form

\* Please enter:

today's date

Date

\* I agree to participate in the study described. I have made this decision based on the information I have read in the Consent Form. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time prior to submission of the survey. If necessary, I have given permission for a caregiver to complete the survey on my behalf.

- I agree
- I don't agree

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\* For parents/guardians completing the survey on behalf of a minor whom parents believe will not be able to understand the survey questions or caregivers of a pheo para patient who is unable to complete the survey on their own. I agree to participate in the study described above on behalf of a pheo para patient. I have received permission from the patient to complete the survey on their behalf, from their perspective, and will treat any information obtained from the patient as confidential. I have made this decision based on the information I have read in the Information-Consent Letter and Consent Form. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time prior to submission of the survey.

- I agree
- I don't agree
- Not applicable, I am NOT completing the survey on behalf of someone else

## SCOPPE - Scan of Pheochromocytoma and Paraganglioma Experiences

### Assent for minors

\* Please enter:

Today's date

Date

\* I understand that my parent/guardian or other caregiver will answer some questions about me as part of a research study. The answers to the survey may help people who have a pheo or para in the future. I have had a chance to ask questions about the study. I understand that I don't have to be part of the study and that nothing bad will happen if I don't want to.

- I agree
- I don't agree
- Not applicable, I am taking this survey on behalf of an adult

## SCOPPE - Scan of Pheochromocytoma and Paraganglioma Experiences

Please indicate whether you (or the person you are filling out this survey for) is a:

- Patient with pheochromocytoma or paraganglioma (currently have tumor(s) or they were surgically removed).
- Genetic mutation carrier - have a mutation but never had tumours

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Have you had genetic testing?

- Yes
- No
- I don't know

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When did you have genetic testing? Approximate year is ok.

Do you have a known pheo para genetic mutation?



## SCOPPE - Scan of Pheochromocytoma and Paraganglioma Experiences

Which genetic mutation syndrome do you have:

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### Genetic Mutation Status

When did you have genetic testing? Approximate year is ok.

Do you have a known pheo para genetic mutation?

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### Genetic Mutation Syndrome

Which genetic mutation syndrome do you have:

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### Obtaining Your Diagnosis

What type of pheo or para have you been diagnosed with? Select ALL that apply.

- |                                                                                        |                                                           |
|----------------------------------------------------------------------------------------|-----------------------------------------------------------|
| <input type="checkbox"/> Unilateral pheochromocytoma in the adrenal gland (one side)   | <input type="checkbox"/> Paraganglioma in the abdomen     |
| <input type="checkbox"/> Bilateral pheochromocytoma in the adrenal glands (both sides) | <input type="checkbox"/> Paraganglioma in the pelvic area |
| <input type="checkbox"/> Paraganglioma in the head/neck region                         | <input type="checkbox"/> Do not know                      |
| <input type="checkbox"/> Paraganglioma in the chest                                    |                                                           |

What was the state of your tumor(s) at the time of diagnosis?

- I was diagnosed with a tumor or multiple tumors, but it had not metastasized.
- It had spread/metastasized to other organs.
- I don't know. I cannot remember.

Which of the following **BEST** describes your experience in getting a pheo para diagnosis?

- After initial symptoms and tests, I was misdiagnosed twice or more with other conditions before a pheo para diagnosis was made.
- After initial symptoms and tests, I was misdiagnosed once with other conditions before a pheo para diagnosis was made.
- After initial symptoms and tests, pheo para was the first diagnosis received.
- I didn't have any symptoms. I was diagnosed after screening for another condition.
- I didn't have any symptoms. I was diagnosed after screening based on family history.
- I can't remember. I don't know.
- Other (please specify)

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### Obtaining Your Diagnosis, Continued

Which healthcare provider did you first see about your symptoms?

- General practitioner / Primary care physician
- Nurse
- Endocrinologist
- Hematologist/Oncologist
- Radiologist
- Surgeon
- Emergency room doctor
- ENT
- Cardiologist
- Other (please specify)

How many healthcare providers did you see before you received a diagnosis?

- 1
- 2
- 3
- 4
- 5
- more than 5

Regarding your pheo para symptoms, were you initially diagnosed with any of the following conditions before receiving a pheo para diagnosis? Select all that apply.

- anorexia
- another type of cancer
- another type of tumor
- anxiety
- depression
- diabetes
- gall bladder dysfunction
- hypochondria
- inflammatory bowel disease (crohn's disease, ulcerative colitis)
- irritable bowel syndrome
- menopause
- neuropathy
- pneumonia
- pancreatic disease
- pituitary disease
- thyroid disease
- I don't remember/cannot say.
- Other (please specify)

- None. I was diagnosed with pheo para right away.

What was the approximate length of time between your first symptom and pheo para diagnosis? Please indicate number of years and months.

Years

Months

Which healthcare provider made the pheo or para diagnosis?

- General Practitioner / Primary Care Physician
- Nurse
- Endocrinologist
- Hematologist/Oncologist
- Radiologist
- Surgeon
- Emergency Room Doctor
- Nuclear Medicine Specialist
- ENT
- Cardiologist
- Other (please specify)

Where did you receive your pheo para diagnosis?

- Individual medical practice (a family practitioner, primary care physician, etc)
- Regional medical center (small medical center that usually serves a region with some specialties available, but often limited)
- University or large medical center (a large hospital that may train doctors, with varied specialties, diagnostics & treatments available)
- Other (please specify)

In what country did you receive your diagnosis?

- United States
- Canada
- Mexico
- Great Britain
- Other (please specify)

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### Treatment & Monitoring

Which, if any, of the following pheo para treatments did you receive? Check all that apply.

- chemotherapy (such as temozolomide or CVD - cyclophosphamide, vincristine, dacarbazine)
- external beam radiation
- MIBG Therapy (such as Azedra)
- PRRT Therapy (such as Lutathera)
- radiofrequency or thermal ablation
- somatostatin analogues (such as octreotide or lanreotide)
- surgery
- clinical trial with another treatment not mentioned above
- wait and watch (no treatment recommended at time of monitoring)
- Other (please specify)

- None of the above

Were any of the following pheo para treatments recommended to you, but you were unable to receive? Check all that apply.

- chemotherapy (such as temozolomide or CVD - cyclophosphamide, vincristine, dacarbazine)
- external beam radiation
- MIBG Therapy (such as Azedra)
- PRRT Therapy (such as Lutathera)
- radiofrequency or thermal ablation
- somatostatin analogues (such as octreotide or lanreotide)
- surgery
- clinical trial with another treatment not mentioned above
- Other (please specify)

- None of the above

If you weren't able to receive treatments, why not?



Which, if any, of the following pheo para treatments have you heard of, even if not available to you? Check all that apply.

- chemotherapy (such as temozolomide or CVD - cyclophosphamide, vincristine, dacarbazine)
- external beam radiation
- MIBG Therapy (such as Azedra)
- PRRT Therapy (such as Lutathera)
- radiofrequency or thermal ablation
- somatostatin analogues (such as octreotide or lanreotide)
- surgery
- clinical trial with another treatment not mentioned above
- Other (please specify)

- None of the above

To the best of your knowledge, which, if any, of the following pheo para treatments are available in your country? Check all that apply.

- chemotherapy (such as temozolomide or CVD - cyclophosphamide, vincristine, dacarbazine)
- external beam radiation
- MIBG Therapy (such as Azedra)
- PRRT Therapy (such as Lutathera)
- radiofrequency or thermal ablation
- somatostatin analogues (such as octreotide or lanreotide)
- surgery
- clinical trial with another treatment not mentioned above
- Other (please specify)

- None of the above

Which of the following tests for ongoing monitoring of pheo para, have you heard of, even if not available to you at your institution? Check all that apply.

- Plasma/urine metanephrines and catecholamines
- Chromogranin A (CgA)
- Conventional imaging (e.g. CT or cat scan, MRI, Ultrasound)
- Gallium 68 DOTATATE or DOTATOC PET CT
- FDG-PET scan
- MIBG scan
- I don't know
- Other (please specify)

- None of the above

To the best of your knowledge, which of the following tests for ongoing monitoring of pheo para are available in your country? Check all that apply.

- Plasma/urine metanephrines and catecholamines
- Chromogranin A (CgA)
- Conventional imaging (e.g. CT or cat scan, MRI, Ultrasound)
- Gallium 68 DOTATATE or DOTANOC PET CT
- FDG-PET scan
- MIBG scan
- I don't know
- Other (please specify)

- None of the above

Which of the following tests for ongoing monitoring of pheo para do you receive regularly?

Check all that apply.

- Plasma/urine metanephrines and catecholamines
- Chromogranin A (CgA)
- Conventional imaging (e.g. CT or cat scan, MRI, Ultrasound)
- Gallium 68 DOTATATE or DOTANOC PET CT
- FDG-PET scan
- MIBG scan
- I don't know
- Other (please specify)

- None of the above. I am not regularly monitored.

How often are you monitored for pheo para?

- every six months or less
- every 7 - 12 months (approximately every year)
- every 13 - 24 months (approximately every other year)
- every 25 - 36 months (approximately every three years)
- I am not monitored
- Other (please specify)

Have you used any of the services or specialists below in the past 12 months? Check all that apply.

- Clinical nurse specialized in pheo para
- An experienced pheo para doctor of any specialty
- Emergency care
- Multidisciplinary team
- Palliative care
- Patient support group
- Caregiver paid to provide services to a pheo para patient
- Psychological care with a private consultant
- Ongoing therapies like massage, acupuncture, meditation
- Physical activities like yoga classes, trainings designed for cancer patients

How far do you travel to be treated or monitored by a specialist, if applicable, for your pheo para?

- 1-50 miles (1-80 km)
- 51-100 miles (81-160 km)
- 101-250 miles (161-400 km)
- over 250 miles (more than 400 km)
- N/A - I am not treated or monitored

Which of the following health care professionals are actively involved in the ongoing monitoring related to your pheo para? Please select all that apply.

- General Practitioner
- Nurse
- Surgeon
- Endocrinologist
- Internist
- Medical Oncologist
- Nuclear Medicine Specialist
- Nutritionist/Dietician
- Psychiatrist/Psychologist/Mental Health Worker
- Radiation Oncologist/Radiotherapist
- Nephrologist
- Hypertension Specialist
- Pediatrician
- Palliative Care Specialist
- Maternal/Fetal High-Risk Obstetrician
- ENT
- Other (please specify)

- None of the above. I am not regularly monitored.

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### Questions About Quality of & Access to Care

On a scale from poor to excellent, how would you rate the overall quality of healthcare your country currently provides to you as a pheo para patient? Select N/A if you aren't sure.

Poor	Fair	Good	Very Good	Excellent	N/A
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Which of the following issues, if any, have you experienced in the past 12 months? Select all that apply.

- Lack of access to information about my specific medical situation from experts
- Lack of access to educational information about pheo para
- Lack of access to diagnostic tests or treatments
- Lack of access to an experienced pheo para medical team
- Lack of communication between specialists
- Delays in receiving monitoring tests or results
- Delays in receiving treatment
- Delays in receiving specialists' opinions
- Other (please specify)

- None of the above

Please rate the importance of the issues you have experienced in the past 12 months from extremely important to not at all important. If you didn't experience some of the issues listed, please select N/A.

	Not at all important	Somewhat important	Important	Very important	Extremely important	N/A
Lack of access to information about my specific medical situation from experts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of access to educational information about pheo para	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of access to diagnostic tests or treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of access to an experienced pheo para medical team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of communication between specialists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Delays in receiving monitoring tests or results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Delays in receiving treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Delays in receiving specialists' opinions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of access to regular monitoring	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other important issues (please specify)

Please rate the level of support you receive from the following.

	not at all helpful	somewhat helpful	helpful	very helpful	extremely helpful	N/A
Paid caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Healthcare professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other patients, patient support groups, social media	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Significant other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medical journals, online research journals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Educational webinars	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other sources of support (please specify)

How important would each of the following be in helping you with the ongoing management of your pheo para? If you don't have ongoing management, then select N/A.

	Not at all important	Somewhat important	Important	Very important	Extremely important	N/A
More pheo para treatments available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Better access to pheo para experts/medical center that specializes in pheo para	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More information about/more opportunity to participate in pheo para clinical trials	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More knowledgeable pheo para healthcare professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Better coordination amongst my pheo para medical team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
More educational information about the illness from my medical team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other helpful resources (please specify)

Which of the following best describes your approach to the management of your pheo para or genetic mutation?

- I prefer my medical team guide me in order to make the best decisions for my care
- I prefer to make decisions in partnership with my medical team
- I prefer to make decisions about my care with some input from my team
- Do not know



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### Financial Impact of Pheo Para

Over the last 12 months, how much have health expenses related to your pheo para presented a financial difficulty for you?

- No current out-of-pocket expenses, all were covered by government health care/insurance
- Very little difficulty
- Moderate difficulty
- Severe difficulty
- Prefer not to say/I don't know

Over the past 12 months, what were your out-of-pocket expenses in the categories listed below related to your pheo para? Please report approximate U.S. dollar amounts.

	less than \$500	\$500-\$999	\$1,000- \$2,499	\$2,500- \$4,999	\$5,000- \$9,999	\$10,000 or more	Don't know
Diagnostic tests	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Treatment procedures	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Monitoring costs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Travel & accommodation expenses	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medications	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other types of care (clinical nurse, emergency care, palliative care, counseling, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health insurance costs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

Does your country have government-subsidized healthcare that covers expenses related to your pheo para?

- Yes
- No
- I don't know

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### Demographic Information

Gender: How do you identify?

- Male
- Female
- Non-Binary
- Prefer not to answer
- (Please specify)

What is your age (in years)?

What was your age (in years) at the time of pheo para diagnosis? Or, if have a genetic mutation but no tumors, at what age did you learn about your genetic mutation status?

In what country do you live?

- United States
- Canada
- Mexico
- United Kingdom
- Other (please specify)

Which of the following best describes where you live?

- Urban / City Center (1,000,000+ population)
- Suburban (100,000-999,999)
- Town (25,000-99,999)
- Rural (5,000-24,999)
- Remote (less than 5,000)

What is the highest level of education you have completed?

- Less than high school
- Completed high school
- Trade or apprenticeship certificate
- Some community/junior college study
- Completed community/junior college
- Some university
- Completed university degree
- Some post-graduate study
- Post-graduate degree

Which of the following do you identify with? (Select all that apply.)

- Black or African American/African Canadian
- Hispanic
- White
- Indian American or Alaska Native
- Canadian Indigenous
- Asian
- Native Hawaiian / Pacific Islander
- Prefer not to answer
- Other (please specify)

How would you rate your income level compared to the average income level of other people in your country?

- Lower
- Average
- Higher
- Do not know. Prefer not to say.

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### Final Thoughts

Is there anything else you would like us to know about your experience as a pheo para patient?

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SCOPPE Survey - I do not agree

**Thank you for your consideration in taking this survey. Your consent is required for participation. If you made this mistake in error, please hit the previous button and select 'I agree'.**

## SCOPPE - Scan of Pheochromocytoma and Paraganglioma Experiences

Thank You For Participating!

**Results will be available on the Pheo Para Alliance website (<https://pheopara.org>) in September 2022.**

**Information about diagnosis, treatment and monitoring procedures can be found at <https://pheopara.org/education/pheochromocytoma> and <https://pheopara.org/education/paraganglioma>. This information has been vetted by our Medical Advisory Board and is written in patient-friendly language. Additional diagnostic and treatment information is available on the NORD (National Organization for Rare Disorders) website, <https://rarediseases.org/rare-diseases/pheochromocytoma/>**