

# Participant Profile (form A)

## REGISTRY INFORMATION

You have completed ... (of Form A - Participant Profile)

10%

A1.1 - Who will complete this survey?

- Participant (self, parent or guardian)
- Physician
- Anesthesiologist
- Anesthesiologist Assistant (AA)
- CRNA
- Nurse
- Biopsy/DNA Test Center Staff
- NAMHR Administrator
- Other (specify)

A1.1.1 - If other, please specify:

\_\_\_\_\_

A1.1.2 - If you are a medical provider who is filling out this survey, please leave your contact information so that we can get in touch with you regarding any questions pertaining to the survey. (NAME, PHONE, EMAIL, etc.)

\_\_\_\_\_

A1.2 - Registry Record Date

\_\_\_\_\_ (for example, if Dec 25th, 2017, please type in 2017-12-25)

A1.3 - Did you call the hotline for help?

- Yes
- No

A1.3.1 - Did the hotline call reassure you that you were doing the right thing?

- Yes
- No

A1.3.1x - If the above answer is 'No', could you tell us why?

\_\_\_\_\_

A1.3.2 - Did the hotline call change what you were doing when you called?

- Yes
- No

A1.3.2x - If the above answer is 'Yes', could you tell us what you would change in your management?

\_\_\_\_\_

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A1.3.3 - If you had a similar case scenario in the future, would you call the hotline again?

- Yes
- No

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A1.3.3x - If the above answer is 'No', could you tell us why?

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\_\_\_\_\_

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A1.9 - Has this case been written up for publication(s) or presented?

- Yes
- No
- I don't know

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A1.9.1a - If yes, please specify 1st publication:

\_\_\_\_\_

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A1.9.1b - If yes, please provide the 1st publication link below:

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\_\_\_\_\_

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A1.9.2a - If yes, please specify 2nd publication:

\_\_\_\_\_

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A1.9.2b - If yes, please provide the 2nd publication link below:

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\_\_\_\_\_

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A1.9.3a - If yes, please provide the 3rd publication link below:

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\_\_\_\_\_

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A1.9.3b - If yes, please specify 3rd publication:

\_\_\_\_\_

**PREVIOUS NAMHR NUMBERS**

**You have completed ... (of Form A - Participant Profile)**

**20%**

A2.1 - Did the participant have any previous NAMHR-assigned numbers?  Yes  No  
(if you do not know the previous numbers, please go to the next page)

A2.1.0a - Hotline call #: \_\_\_\_\_

A2.1.0b - Hotline Comment \_\_\_\_\_

A2.1.1a - AMRA report #: \_\_\_\_\_

A2.1.1b - AMRA Comment \_\_\_\_\_

A2.1.2a - AKA report #: \_\_\_\_\_

A2.1.2b - AKA comment \_\_\_\_\_

A2.1.3a - RSR report #: \_\_\_\_\_

A2.1.3b - RSR report comment \_\_\_\_\_

A2.1.4a - MHS report #: \_\_\_\_\_

A2.1.4b - MHS report comment \_\_\_\_\_

A2.1.5a - MHN report #: \_\_\_\_\_

A2.1.5b - MHN report comment \_\_\_\_\_

A2.1.6a - Biopsy report #: \_\_\_\_\_

A2.1.6b - Biopsy report comment \_\_\_\_\_

A2.1.7a - Relative's report #: \_\_\_\_\_

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A2.1.7b - Relative's report comment

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A2.1.8a - Registry Card Number:

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A2.1.8b - Registry Card comment

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A2.1.9a - GUID Number:

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A2.1.9b - GUID number comment

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**PARTICIPANT'S PERSONAL INFORMATION**

(some of questions are hidden due to lack of properly consent, such as names and birthday, etc.)

**You have completed ... (of Form A - Participant Profile)**

**30%**

A4.1 - Participant First Name

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A4.2 - Participant Last Name

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A4.3 - Participant Middle Name

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A4.4 - Participant Maiden or Prior Last Name

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A4.5.1 - Participant's year of birth

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(enter year only (e.g. 2017))

A4.5.2 - Participant's month of birth

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(enter month only (e.g. 12))

A4.5.3 - Participant's day of birth

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(enter day only (e.g. 25))

A4.6.1 - Street Address (line 1)

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A4.6.2 - Street Address (line 2)

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A4.7 - City

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A4.8 - State, Province, or Country of Participant's Residence

- Alabama
- Alaska
- American Samoa
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- District of Columbia
- Florida
- Georgia
- Guam
- Hawaii
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas
- Kentucky
- Louisiana
- Maine
- Marshall Islands
- Maryland
- Massachusetts
- Michigan
- Minnesota
- Mississippi
- Missouri
- Montana
- Nebraska
- Nevada
- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- North Dakota
- Ohio
- Oklahoma
- Oregon
- Palau
- Pennsylvania
- Puerto Rico
- Rhode Island
- South Carolina
- South Dakota
- Tennessee
- Texas
- Utah
- Vermont
- Virginia
- Washington
- West Virginia
- Wisconsin
- Wyoming
- Alberta
- British Columbia
- Manitoba
- New Brunswick
- Newfoundland and Labrador
- Northwest Territories
- Nova Scotia
- Nunavut
- Ontario
- Prince Edward Island
- Quebec
- Saskatchewan
- Yukon Territory

Other (international)

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If other, which international country:

\_\_\_\_\_

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A4.9 - Zip/Postal Code

\_\_\_\_\_

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A4.10 - Country of Participant's Residence

- USA
- Canada
- Mexico
- Other (specify)

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A4.10.1 - If other, please specify:

\_\_\_\_\_

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A4.11 - Home Phone Number

\_\_\_\_\_

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A4.12 - Cell Phone Number

\_\_\_\_\_

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A4.13 - Email Address

\_\_\_\_\_

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A4.14 - Additional information:

\_\_\_\_\_

**PARTICIPANT'S DEMOGRAPHIC INFORMATION**

**Some of the information contained in this section will be used to make a unique, de-identified code that may be used by investigators via the internet in the NIH/NCATS GRDR? Program, the Global Rare Disease Patient Registry Data Repository.**

**You have completed ... (of Form A - Participant Profile)**

**40%**

A5.1 - Age at the clinical encounter

\_\_\_\_\_ (please enter year in this field, and additional months in the field below (if younger than 1 year old, please enter 0))

A5.1.1 - How many months in addition

\_\_\_\_\_ (enter months only, e.g. 12)

A5.2 - Sex

- Male
- Female
- Unknown

A5.3 - Pregnancy status at the time of event

- Not pregnant
- Pregnant
- Peripartum - within 24 hours of delivery
- Unknown

A5.4 - Race/Ethnicity

- White/Caucasian
  - Hispanic
  - Black or African-American
  - American Indian/Native American
  - Hawaiian/Pacific Islander
  - African
  - East Asian
  - South Asian
  - Middle Eastern
  - Other (specify)
- (check all applicable)

A5.4.1 - If other, please specify:

\_\_\_\_\_

A5.5 - Body Build

- Normal
- Muscular
- Peripartum
- Lean
- Obese
- other (specify)

A5.5.1 - Specify other:

\_\_\_\_\_

A5.6 - Are you going to enter weight in kilograms or pounds?

- kilograms (kgs)
- pounds (lbs)



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A5.6kg1 - Weight in kilograms:

\_\_\_\_\_ (kilograms)

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A5.6kg2 - weight equivalent in pounds

\_\_\_\_\_ (lbs)

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A5.6lb1 - Weight in pounds:

\_\_\_\_\_ (lbs)

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A5.6.lb2 - weight equivalent in kilograms:

\_\_\_\_\_ (kilograms)

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A5.7 - Are you going to enter height in centimeters or feet?

- centimeters (cms)
- feet (ft)

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A5.7cm1 - Height in centimeters:

\_\_\_\_\_ (centimeters)

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A5.7cm2 - Height equivalent in feet:

\_\_\_\_\_ (feet)

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A5.7ft1 - Height in feet:

- 0    1    2    3
  - 4    5    6
- (feet)

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A5.7ft2 - additional inches

- 0    1    2    3
  - 4    5    6    7
  - 8    9    10    11
- (inches)

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A5.7ft3 - Height equivalent in centimeters:

\_\_\_\_\_ (centimeters)

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A5.8 - Body Mass Index (BMI)

\_\_\_\_\_

**PARTICIPANT'S MEDICAL HISTORY****You have completed ... (of Form A - Participant Profile)****50%**

A6.1 - Does the participant have any of the following?  
(check all applicable)

- muscle weakness interferes with daily activity at least once/week
- muscle cramps or pain interfere with daily activity at least once/week
- cola colored urine
- heat stroke or heat prostration
- oral (or rectal/axillary equivalent) fever >38.6 C or 101.4 F at least 6 times/year without medical cause
- recent generalized infection (specify how long ago)
- recent use of cholesterol lowering drugs (specify drugs and how long ago below)
- recent use of antipsychotic drugs (specify drugs and how long ago below)
- recent use of serotonin re-uptake inhibitors (specify drugs and how long ago below)
- recent use of monoamine oxidase inhibitors (specify drugs and how long ago below)
- recent use of illicit drugs (specify drugs and how long ago below)
- a regular regimen of strenuous physical activity (specify how long ago below)
- ingestion of any medicine to improve muscular performance
- intolerance to heat
- exercise intolerance due to muscle pain, weakness, or fever
- diabetes - unspecified
- diabetes - Type 1
- diabetes - Type 2
- more bleeding than expected from minor injuries or surgical procedures
- none of the above
- other (specify)
- unknown

A6.1.1 - If there was a generalized infection, how long ago was it?

\_\_\_\_\_ (days)

A6.1.2 - For Cholesterol drugs - which drugs?

\_\_\_\_\_

A6.1.3 - For Cholesterol drugs - how long ago was it last ingested?

\_\_\_\_\_ (days)

A6.1.4 - For antipsychotic drugs, which drugs?

\_\_\_\_\_

A6.1.5 - For antipsychotic drugs, how long ago was it last ingested?

\_\_\_\_\_ (days)

A6.1.6 - For serotonin re-uptake inhibitors, which drugs?

\_\_\_\_\_

A6.1.7 - For serotonin re-uptake inhibitors, how long ago was it last ingested?

\_\_\_\_\_ (days)

A6.1.8 - For monoamine oxidase inhibitors, please specify drugs:

\_\_\_\_\_

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A6.1.9 - For monoamine oxidase inhibitors, how long ago was it last ingested?

\_\_\_\_\_ (days)

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A6.1.10 - For illicit drugs, please specify drugs

\_\_\_\_\_

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A6.1.11 - For illicit drugs, how long ago was it last ingested?

\_\_\_\_\_ (days)

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A6.1.12 - If a regular regimen of strenuous physical activity, how long ago was the last work-out?

\_\_\_\_\_ (days)

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A6.1.13 - If other, please specify:

\_\_\_\_\_

**PARTICIPANT'S FAMILY MEDICAL HISTORY****You have completed ... (of Form A - Participant Profile)****60%**

A7.1 - Family history is positive for:  
(check all applicable)

- malignant hyperthermia
- masseter spasm
- intraoperative death not thought to be MH
- sudden infant death syndrome or cot death
- sudden death from unknown cause at less than 45 years, but greater than 1.5 years
- exercise-associated heatstroke
- environmentally induced heatstroke
- neuroleptic malignant syndrome
- intolerance to heat
- chronic muscle pain
- frequent muscle cramps
- chronic muscle weakness
- exercise intolerance due to muscle pain, weakness, or fever
- episodes of dark urine (myoglobinuria) and muscle pain
- myopathy (specify)
- idiopathic creatine kinase elevation
- diabetes - Type 1
- diabetes - Type 2
- diabetes - unspecified
- none of the above
- other (specify)
- unknown

A7.1.1 - If myopathy, please specify:

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A7.1.2 - If other, please specify:

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**PARTICIPANT'S PHYSICAL FINDINGS****You have completed ... (of Form A - Participant Profile)****70%**

A8.1 - Has the subject ever had physical findings of:  
(check all applicable)

- increased muscle tone
- decreased muscle tone
- generalized muscle weakness
- myopathy (specify type)
- ptosis
- strabismus
- hiatal hernia
- inguinal hernia
- umbilical hernia
- undescended testes
- clubbed foot
- joint hypermobility
- kyphoscoliosis (moderate or severe; curve >45 degrees)
- pectus carinatum
- winged scapulae
- skeletal fractures (e.g. possible osteogenesis imperfect; more than 2)
- gall stones
- kidney stones
- laryngeal papillomas
- none of the above
- other (specify)
- unknown

A8.1.1 - If myopathy, please specify type:  
(type 'unknown' if not known)

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A8.1.2 - If other, please specify:

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**PARTICIPANT'S ANESTHETIC HISTORY****You have completed ... (of Form A - Participant Profile)****80%**

A9.1 - How many times was this patient anesthetized prior to this case entered?

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(Enter a number or if unknown or unknown but greater than 0 please describe as relevant)

A9.2.1 - the year of possible or clear-cut MH episode

---

(enter year only (e.g. 2017))

A9.2.2 - the month of possible or clear-cut MH episode

---

(enter month only (e.g. 12))

A9.2.3 - the day of possible or clear-cut MH episode

---

(enter day only (e.g. 25))

A9.3 - Year of most recent anesthetic (excluding present episode):

---

(enter year only (e.g. 2017))

A9.4 - Were unusual metabolic or muscular responses (including myoglobinuria) noted during prior anesthetics?

- Yes  
 No  
 Unknown

A9.5 - Was there unusual delayed awakening from previous general anesthetics?

- Yes  
 No  
 Unknown

A9.6 - How many of these prior general anesthetics involved MH triggering agents?

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((please enter an integer. or leave blank if unknown.))

A9.6.1 - What was/were the triggering agents used?

- Isoflurane  
 Sevoflurane  
 Desflurane  
 Halothane  
 Ether  
 Methoxyflurane  
 Succinylcholine

A9.7a - Indicate the number of inhalational anesthetics without succinylcholine

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((This would be any anesthetic that included volatile agents from the list above, but did NOT include succinylcholine))

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A9.7b - Indicate the number of inhalational anesthetics with succinylcholine

\_\_\_\_\_  
((This would be any anesthetic that included volatile agents from the list above and DID include succinylcholine))

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A9.7c - Indicate the number of times succinylcholine without inhalational anesthetics:

\_\_\_\_\_  
((This would be any anesthetic that did NOT include volatile agents from the list above, but DID include succinylcholine))

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A9.8 - How many anesthetics were suspect for possible MH?

\_\_\_\_\_  
(medical provider or biopsy center director's opinion)

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A9.9 - How many fulminant MH episodes occurred?

\_\_\_\_\_

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A9.10 - Past anesthetic history positive for:  
(check all applicable)

- clear-cut clinical MH episode(s)
  - possible MH (not clear-cut MH)
  - masseter muscle rigidity only
  - delayed awakening from general anesthesia
  - positive caffeine halothane contracture test
  - positive calcium uptake test (performed in Boston)
  - none of the above
  - other (specify below)
  - unknown
- 

A9.10.1 - If other, please specify:

\_\_\_\_\_

**PARTICIPANT'S ATHLETIC HISTORY****You have completed ... (of Form A - Participant Profile)****90%**

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A10.1 - Do you currently have a regular exercise regimen?

- Yes  
 No

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A10.2 - Are you a competitive athlete?

- Yes  
 No  
 In the past

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A10.3 - What best describes your competitive athletic past and present?

- Competitive event training ie marathon, iron man  
 High school athlete  
 College athlete  
 Professional or Olympic athlete

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A10.4 - What is your best athletic achievement? i.e. high school state wrestling champion, completed a marathon

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\_\_\_\_\_

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Congratulations. You have completed ... (of Form A - Participant Profile)

100%