Appendix 1. Survey

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| [Company Name] We are interested in how living with INOCA (Ischemia with No Obstructive Coronary Arteries) has impacted your medical care, health and life. Your responses will remain anonymous. Thank you for your time in responding to our questions.Question 1Do you have Ischemia with No Obstructive Coronary Arteries (INOCA)? Yes  No  (if No, no further questions) Question 2Would you say that your general health is: Excellent  Very Good  Good  Fair  Poor Question 3Which of the following forms of INOCA were you diagnosed with? (Check all that apply) Coronary Microvascular Dysfunction  Coronary Artery Spasm  Nonobstructive Atherosclerosis  Heart Failure with Preserved Ejection Fraction (HFpEF)  Takutsubo’s Syndrome (also known as Stress Cardiomyopathy/”Broken Heart” Syndrome)  I was not given a diagnosis aside from INOCA  I don’t know Question 4How long did it take from the onset of your symptoms to getting a diagnosis of INOCA? Less than 1 months  1-12 months  1-3 years  3-5 years  5-10 years  >10 years Question 5Prior to your diagnosis of INOCA were you ever told your symptoms were due to Reflux or GERD (gastroesophageal reflux disease)? Yes  No Question 6Prior to your diagnosis of INOCA did you undergo an endoscopy to assess for reflux/GERD based on your symptoms? Yes  No Question 7Prior to your diagnosis of INOCA were you ever told your symptoms were not cardiac? Yes  No Question 8Prior to your diagnosis of INOCA were you seen in the Emergency Room/A&E for your symptoms of INOCA and discharged without any treatment? Yes  No Question 9Prior to your onset of symptoms of INOCA, which of the following could you **previously** do? (Check All That Apply) Take Care of Yourself (ie. dress, eat, bathe, use toilet)  Walking Indoors  Walk 200 yards (182 meters) on level ground  Climb a flight of stairs or walk up a hill  Run a Short Distance  Do light work around the house (ie. dusting, washing dishes)  Do moderate work around the house (ie. vacuuming, sweeping floors, carrying groceries)  Do heavy work around the house (ie. scrubbing floors, lifting or moving heavy furniture)  Do yardwork (ie. raking leaves, weeding, pushing a lawn mower)  Have Sexual Relations  Participate in Moderate Recreational Activities (ie. golf, bowling, doubles tennis, throwing baseball, kicking football)  Participate in Strenuous Sports (ie. swimming, singles tennis, football, basketball, skiing) Question 10With your diagnosis of INOCA, which of the following can you **currently** do? (Check All That Apply) Take Care of Yourself (ie. dress, eat, bathe, use toilet)  Walking Indoors  Climb a flight of stairs or walk up a hill  Run a Short Distance  Do light work around the house (ie. dusting, washing dishes)  Do moderate work around the house (ie. vacuuming, sweeping floors, carrying groceries)  Do heavy work around the house (ie. scrubbing floors, lifting or moving heavy furniture)  Do yardwork (ie. raking leaves, weeding, pushing a lawn mower)  Have Sexual Relations  Participate in Moderate Recreational Activities (ie. golf, bowling, doubles tennis, throwing baseball, kicking football)  Participate in Strenous Sports (ie. swimming, singles tennis, football, basketball, skiing) Question 11How many consultants/specialists/doctors did you see prior to your diagnosis of INOCA? 0 (meaning diagnosed right away)  1-2  3-5  >5 Question 12How many cardiologists have you consulted for treatment of your INOCA? 1  2  3-5  >5 Question 13Prior to your diagnosis of INOCA were you ever referred to a psychiatrist for your symptoms or was such a referral suggested to you by your doctor? Yes  No Question 14Have you ever been started on, or been recommended to start, an antidepressant or antianxiety medication for your INOCA symptoms? Yes  No Question 15Are you under the care of a specialist in INOCA? Yes  No  Awaiting Initial Appointment  I Don’t Know Question 16If you under the care of a specialist in INOCA, how did you get to them? Self-Referred (I found the specialist myself)  My Family Doctor/GP referred me to the INOCA specialist  Another cardiologists referred me to the INOCA Specialist  Another doctor referred me to the INOCA Specialist  AI have never been under the care of an INOCA Specialist   |  |  | | --- | --- | | Question 17How many years have you had symptoms of INOCA for? Less than 1 year  1-5 years  5-10 years  10-20 years  >20 years Question 17At What Age were you Diagnosed with INOCA? Less than 30  30-40  40-50  50-60  60-70  >70 years Question 18Have you ever had a Heart Attack? Yes  No  Unsure Question 19Have you ever been told that although your symptoms of INOCA may be unpleasant, you cannot die from it and cannot have a heart attack? Yes  No Question 20Have you ever had to call an Ambulance for your symptoms of INOCA? Yes  No Question 21When you have called an Ambulance for your symptoms of INOCA, have you experienced any of the following? (choose all that apply) Taken to the Hospital and Cardiac Monitor Attached and ECG performed  No Ambulance dispatched  Assessed by Ambulance Crew but not taken to the hospital  Taken to the Hospital but No Cardiac Monitor or ECG performed despite symptoms  Ambulance Crew Understood the Diagnosis of INOCA  Ambulance Crew DID NOT Understand the Diagnosis of INOCA  I have never had to call an Ambulance  I do not call the Ambulance because they do not take my symptoms seriously Question 22As a patient living with INOCA, do you know when to call for an ambulance or go to the hospital for your INOCA symptoms? Yes  No |  |  Question 23Which diagnostic tests have you had related to your INOCA symptoms? (Check all that apply) ECG  Echocardiogram (also called Echo)  Exercise Stress Test  Stress Echocardiogram (Also called Stress Echo)  CT Angiogram  Cardiac MRI  PET Scan  Cardiac Catheterization (Also called Angiogram)  Cardiac Catheterization (Also called Angiogram) with Acetylcholine Testing  None of the Above Question 24Which symptoms do you experience related to INOCA? (Check all that apply) Chest Pain/Chest Pressure/Chest Discomfort  Fatigue/Exhaustion  Shortness of Breath  Back Pain  Shoulder or Arm Pain or Pressure  Neck/Jaw Pain  Palpitations/Racing of the heart  Sweats  Lightheadedness, Dizzyness  Nausea, reflux-like symptoms  Confusion, Brain Fog  Vision Changes  Other Question 25Have You Ever Left any Doctor’s Appointment and come away thinking they did not understand INOCA? All the Time  Often  Occasionally  Never Question 26Have You Ever Had to Stop Working because of INOCA? Yes  No Question 27Did You Had to Retire Early because of INOCA? Yes  No Question 28Have You Ever Had to Reduce Working Hours because of INOCA? Yes  No Question 29Have You Ever Had to Change Jobs or Roles for a Less Stressful Position because of your symptoms from INOCA? Yes  No Question 30Have You Ever Had to Change Jobs or Roles that Resulted in Lower Pay Because of your Symptoms with INOCA? Yes  No Question 31Have You Ever Had to Apply for Disability Benefits because of your symptoms with INOCA? Yes  No Question 32If You Had to Apply for Disability Benefits because of your symptoms with INOCA, was your application successful? Yes  No  I have never applied for disability benefits Question 33Do You Ever Worry about being home alone? Yes  No Question 34Do You Ever Worry about going out alone? Yes  No Question 35Do You Drive? Yes,  No, stopped due to INOCA symptoms  Never Drove Question 36Did you have any of the following conditions during pregnancy? (check all that apply) Hypertension During pregnancy  Preeclampsia or Eclampsia  Gestational Diabetes  Preterm Delivery  Miscarriage  Does Not Apply To Me, I have Never Been Pregnant Question 37Do you have any of the following conditions? (check all that apply) Migraines/ Frequent Headaches  Raynaud’s  Thyroid Disorder  Rheumatoid Arthritis  Lupus/ Systemic Lupus Erythematosus  Other Autoimmune Disorder  History of Stroke  Kidney Disease  None Question 38Do You Have Any of the Following Triggers for Your Symptoms of INOCA? Stress  Exercise/Exertion  Excitement or High Emotional State/Anger  Cold Weather  Change in Temperature or Weather Change  Triggered during Menstruation  Other  No Known Triggers Question 39Did Your Symptoms Change at Menopause? Yes  No  Unsure  Have not Undergone Menopause Yet  Male (Not Applicable) Question 40Has INOCA Adversely Affected Your Home Life? Yes  No Question 41Has INOCA Adversely Affected Your Relationship with Your Partner/Spouse? Yes  No  Not applicable Question 42Has INOCA Adversely Affected Your Work Life? Yes  No Question 43Has INOCA Adversely Affected Your Social Life? Yes  No Question 44Has INOCA Adversely Affected Your Sex Life? Yes  No  Not applicable Question 45Has INOCA Adversely Affected Your Mental Health? Yes  No Question 46Has INOCA Negatively Affected Your Outlook on Life? Yes  No Question 47Thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good? \_\_ (no number >30 will be accepted) Question 48Thinking about your mental health, which includes stress, depression and problems with emotions, for how many days during the past 30 days was your mental health not good? \_\_(no number >30 will be accepted) Question 49During the past 30 days, for how many days did poor physical health or mental health, keep you from doing your usual activities, such as self-care, work or recreation? \_\_(no number >30 will be accepted)  IF YOU WOULD LIKE TO SHARE ANY OTHER COMMENTS WITH YOU ABOUT YOUR EXPERIENCE LIVING WITH INOCA, PLEASE FEEL FREE TO WRITE ANY COMMENTS HERE: |  |