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| **Domain:** | Reproductive Health |
| **Measure:** | Causes and Treatments of Known Infertility |
| **Definition:** | Questions to assess participant's experience with infertility |
| **Purpose:** | These questions are used to determine the cause of the participant's or their partner's infertility and the treatments that they may have sought. It is important to measure because it can be related to birth outcomes (e.g., multiple births). Infertility may also be associated with gene/environmental interactions. |
| **Essential PhenX Measures:** | Current AgeDifficulty in ConceivingGender |
| **Related PhenX Measures:** |  |
| **Collections:** | Infertility and Sexual DysfunctionPregnancy and Fertility HistoryMedical Risks to Pregnancy |
| **Keywords:** | Reproductive health, cause and treatments of known infertility, fertility, fibroid tumors, myomas, endometriosis, National Survey of Family Growth (NSFG), drugs to improve ovulation, artificial insemination |

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| **Protocol Release Date:** | February 26, 2010 |
| **PhenX Protocol Name:** | Causes and Treatments of Known Infertility - Female |
| **Protocol Name from Source:** | The Expert Review Panel has not reviewed this measure yet. |
| **Description:** | The interviewer asks the participant questions about whether the participant or partner has needed medical assistance with having a baby, the type of assistance, and the type of infertility problems. |
| **Specific Instructions:** | Questions 1-3 are asked of both males and females.The NSFG provides a card of response categories to the respondent. For example, in question 2, an investigator would provide the respondent with a card listing the categories "advice, infertility testing, drugs to improve ovulation," "surgery to correct blocked tubes," "artificial insemination," "treatment for varicocele," and "other types of medical help." A card was also provided in question 3. RTI has removed references of the card from the questions.The male NSFG questions (questions 1-3) have been modified to indicate partner instead of wife.Below are some lay definitions from the Mayo Clinic website that researchers may find helpful in using the toolkit:* Uterine fibroids are noncancerous growths of the uterus that often appear during childbearing years. Also called fibromyomas, leiomyomas or myomas, uterine fibroids aren't associated with an increased risk of uterine cancer and almost never develop into cancer. (Mayo Clinic. http://www.mayoclinic.com/health/uterine-fibroids/DS00078 accessed February 15, 2010.)
* Endometriosis is a disorder of the female reproductive system. In endometriosis, the endometrium, which normally lines the uterus, grows in other places as well. Most often, this growth is on the fallopian tubes, ovaries or the tissue lining the pelvis. When endometrial tissue is located elsewhere in your body, it continues to act as it normally would during a menstrual cycle: It thickens, breaks down and bleeds each month. Because there's nowhere for the blood from this displaced tissue to exit your body, it becomes trapped, and surrounding tissue can become irritated. Trapped blood may lead to cysts, scar tissue and adhesions - abnormal tissue that binds organs together. This process can cause pelvic pain, especially during menstruation. Endometriosis also can cause fertility problems. (Mayo Clinic. http://www.mayoclinic.com/health/endometriosis/DS00289 accessed February 15, 2010.)

The PhenX Working Group recommends this measure should be preceded by "Difficulty in Conceiving" for a more complete assessment of infertility. |
| **Protocol:** | 1. Did you or your partner\* ever go / Have you or your partner\* ever been to a doctor or other medical care provider to talk about ways to help you have a baby together?[ ] 1 Yes[ ] 5 No (Skip to end)NOTE: Do not code yes if main purpose of visit was for something other than seeking help to have a baby.2. Which of the services (did / have) you or your / partner\*) (have / had) to help you have a baby together? ENTER all that apply: [ ] 1 Advice[ ] 2 Infertility testing[ ] 3 Drugs to improve ovulation[ ] 4 Surgery to correct blocked tubes;[ ] 5 Artificial insemination[ ] 6 Treatment for varicocele[ ] 7 Other types of medical help3. When you and your partner\* went for medical help to have a baby together, was your partner ever told that he had any of the following male infertility problems? ENTER all that apply: [ ] 1 sperm or semen problems[ ] 2 varicocele[ ] 3 other[ ] 4 none of the above\*Note: The questions have been modified by the PhenX Working Group to indicate partner instead of wife.4. Has a doctor or other medical care provider ever told you you had fibroid tumors or myomas in your uterus?[ ] 1 Yes[ ] 5 No5. Has a doctor or other medical care provider ever told you you had endometriosis?[ ] 1 Yes[ ] 5 No |
| **Selection Rationale:** | The National Survey of Family Growth Cycle 6 includes questions that address the causes and treatment of infertility. Cycle 6 includes both male and female respondents and represents the household population of the U.S. between the ages of 15-44 years. |
| **Source:** | Centers for Disease Control and Prevention (CDC). National Survey of Family Growth (NFSG) Staff Division of Vital Statistics, National Center for Health Statistics. National Survey of Family Growth (NSFG) 2003 Cycle 6 Male. Questions INFHELP IE-1 (question 1), INFSVCS IE-2 (question 2), NSFG INFRTHIS IE-7 (question 3). Notes: The male NSFG questions have been modified to indicate partner instead of wife. Centers for Disease Control and Prevention (CDC). National Survey of Family Growth (NFSG) Staff Division of Vital Statistics, National Center for Health Statistics. National Survey of Family Growth (NSFG) 2003 Cycle 6 Female. Questions UF HD8 (question 4), ENDO H9 (question 5). |
| **Life Stage:** | AdolescentAdult |
| **Language of source:** | English |
| **Participant:** | Participants 15-44 years of age |
| **Personnel and Training Required:** | The interviewer must be trained in the use of CAPI-lite questionnaires for the NSFG. |
| **Equipment Needs:** | If a computer-assisted instrument is used, computer software may be necessary to develop the instrument. The interviewer will require a laptop computer/handheld computer to administer a computer-assisted questionnaire. |
| **Standards:** |

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| **Standard** | **Name** | **ID** | **Source** |
| Common Data Element (CDE) | Male Known Infertility Reason Assessment Description Text | 3007421 | [CDE Browser](https://cdebrowser.nci.nih.gov/CDEBrowser/search?elementDetails=9&FirstTimer=0&PageId=ElementDetailsGroup&publicId=3007421&version=1.0) |
| Common Data Element (CDE) | Female Known Infertility Reason Assessment Description Text | 5067197 | [CDE Browser](https://cdebrowser.nci.nih.gov/CDEBrowser/search?elementDetails=9&FirstTimer=0&PageId=ElementDetailsGroup&publicId=5067197&version=1.0) |

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| **General references:** | Lepkowski JM, Mosher WD, Davis KE, Groves RM, van Hoewyk J, Willem J. (2006). NationalSurvey of Family Growth, Cycle 6: sample design, weighting, imputation, and variance estimation. Vital Health Stat, 2(142):1-82. PubMed PMID: 16999003.Martinez GM, Chandra A, Abma JC, Jones J, Mosher WD. (2006). Fertility, contraception, and fatherhood: data on men and women from cycle 6 (2002) of the 2002 National Survey of Family Growth. Vital Health Stat, 23(26):1-142. |
| **Mode of Administration:** | Interviewer-administered questionnaire |
| **Derived Variables:** | None |
| **Requirements:** |

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| **Requirement Category** | **Required** |
| Major equipment | No |
| Specialized training | Yes |
| Specialized requirements for biospecimen collection | No |
| Average time of greater than 15 minutes in an unaffected individual | No |

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| **Process and Review:** | The Expert Review Panel has not reviewed this measure yet. |