# A Survey on Women's Experience with a Surgical Procedure called a Hysterectomy

## Data Dictionary Codebook

**Instrument:** Survey on Women's Experience with Hysterectomy

| # | Variable / Field Name | Field Label | Field Attributes (Field Type, Validation, Choices, Calculations, etc.) |
|---|-----------------------|-------------|---------------------------------------------------------------------|
| 1 | record_id             | Study ID    | text                                                                |
| 2 | date_of_survey        | What is today’s date? | text (date_dmy), Required Custom alignment: LV                      |
| 3 | hysterectomy_yes_no   | Have you had a hysterectomy (removal of the uterus/womb with or without the ovaries) in the last 2 years? If No, please do not continue completing this questionnaire | yesno, Required 1 Yes 0 No Custom alignment: LV Question number: 1 Stop actions on 0 |
| 4 | postcode               | What is your postcode? | text (postalcode_australia), Required Custom alignment: LV Question number: 2 |
| 5 | birth_year            | What is the year of your birth? | text (number, Min: 1900, Max: 2000), Required Custom alignment: LV Question number: 3 |
| 6 | height                | What is your height (cm)? | text (number, Min: 130, Max: 215), Required Custom alignment: LV Question number: 4 |
| 7 | weight                | What is your weight (kg)? | text (integer, Min: 35, Max: 200), Required Custom alignment: LV Question number: 5 |
| 8 | weight_at_hysterectomy| What was your approximate weight at the time of your hysterectomy (kg)? | text (integer, Min: 35, Max: 200) Custom alignment: LV Question number: 6 |
| 9 | marital_status        | What is your current marital status? | radio, Required 0 Single 1 Married 2 Defacto or living with partner 3 Separated or divorced 4 Widowed Custom alignment: LV Question number: 7 |
| 10 | household_income      | What is your household’s yearly income? | radio, Required 0 I'd prefer not to answer 1 $1-$4,159 2 $4,160-$6,239 3 $6,240-$10,399 |
Do you have private health insurance? radio, Required
0 No
1 Yes, hospital only
2 Yes, hospital plus extras
3 Yes, extras only
4 Other please specify

Other, please specify
text, Required

What is the highest level of education you have completed? radio, Required
0 I'd prefer not to answer
1 Did not complete primary school or have no formal schooling
2 Completed primary school (or Grade 6)
3 Completed junior high (or Grade 10)
4 Completed senior high school (or Grade 12)
5 Trade or technical certificate or diploma
6 University or college degree
7 Other please specify

Other please specify
text, Required

Had you gone through menopause or 'change of life' before your hysterectomy? yesno, Required
1 Yes
0 No
| Question number | Question                                                                 | Type                        | Required | Custom alignment |
|-----------------|--------------------------------------------------------------------------|-----------------------------|----------|------------------|
| 11              | pregnancies_yes_no: Have you ever been pregnant?                         | yes/no, Required            | Yes      | LV               |
| 12              | number_pregnancies: How many pregnancies have you had?                   | text, Required              | Yes      | LV               |
| 12a             | had_children: Have you had any children?                                 | yes/no, Required            | Yes      | LV               |
| 12b             | number_of_children: How many children have you had?                      | text (number), Required     | Yes      | LV               |
| 12c             | children_delivered_by: How were they delivered?                          | checkbox, Required          | Yes      | LV               |
| 12d             | svd_number: How many were by spontaneous vaginal delivery?               | text (number), Required     | Yes      | LV               |
| 12d1            | c_section_numbers: How many were by caesarean section?                  | text (number), Required     | Yes      | LV               |
| 12d2            | equipment_delivery_no: How many were by forceps delivery or other special equipment used by the doctor? | text (number), Required     | Yes      | LV               |
| 12d3            | morbidities_at_hyst: Below is a list of common health problems. Please select one or more of the following | checkbox, Required          | Yes      | LV               |
that were occurring at the time you planned to have the hysterectomy.

select all that apply

|   | morbidities_at_hyst___1 | No health problems |
|---|------------------------|--------------------|
| 2 | morbidities_at_hyst___2 | Heart disease      |
| 3 | morbidities_at_hyst___3 | High blood pressure|
| 4 | morbidities_at_hyst___4 | Lung disease       |
| 5 | morbidities_at_hyst___5 | Diabetes mellitus  |
| 6 | morbidities_at_hyst___6 | Ulcer or stomach disease reflux |
| 7 | morbidities_at_hyst___7 | Kidney disease     |
| 8 | morbidities_at_hyst___8 | Liver disease      |
| 9 | morbidities_at_hyst___9 | Anaemia other blood disease |
| 10| morbidities_at_hyst___10| Cancer             |
| 11| morbidities_at_hyst___11| Anxiety Depression |
| 12| morbidities_at_hyst___12| Osteoarthritis or degenerative arthritis |
| 13| morbidities_at_hyst___13| Back pain          |
| 14| morbidities_at_hyst___14| Rheumatoid arthritis |
| 15| morbidities_at_hyst___15| Other medical problem |

Custom alignment: LV
Question number: 13

25 other_med_probs
Show the field ONL Y if: [morbidities_at_hyst___15] = '1'

Please specify other medical problems
text, Required
Custom alignment: LH
Question number: 13a

26 public_or_pvt_pt
Did you have your hysterectomy as a:
radio, Required

1 Public patient
2 Private patient

Custom alignment: LV
Question number: 14

27 gp
General Practitioner

checkbox, Required

1 gp___1 First suggested
2 gp___2 and/or Informed me
3 gp___3 This info was very influential
4 gp___4 This info was moderately influential
| Question number: 15 |  |
|---------------------|---------------------------|
| 28 obsgyn Obstetrician or Gynaecologist | checkbox, Required |
| 1 obsgyn___1 First suggested |  |
| 2 obsgyn___2 and/or Informed me |  |
| 3 obsgyn___3 This info was very influential |  |
| 4 obsgyn___4 This info was moderately influential |  |
| 5 obsgyn___5 This info was not influential |  |
| 6 obsgyn___6 N/A |  |

| Question number: 16 |  |
|---------------------|---------------------------|
| 29 med_dr Other medical doctor | checkbox, Required |
| 1 med_dr___1 First suggested |  |
| 2 med_dr___2 and/or Informed me |  |
| 3 med_dr___3 This info was very influential |  |
| 4 med_dr___4 This info was moderately influential |  |
| 5 med_dr___5 This info was not influential |  |
| 6 med_dr___6 N/A |  |

| Question number: 17 |  |
|---------------------|---------------------------|
| 30 spec_nurse Specialist nurse | checkbox, Required |
| 1 spec_nurse___1 First suggested |  |
| 2 spec_nurse___2 and/or Informed me |  |
| 3 spec_nurse___3 This info was very influential |  |
| 4 spec_nurse___4 This info was moderately influential |  |
| 5 spec_nurse___5 This info was not influential |  |
| 6 spec_nurse___6 N/A |  |

| Question number: 18 |  |
|---------------------|---------------------------|
| 31 friend_family Friends or family | checkbox, Required |
| 1 friend_family___1 First suggested |  |
| 2 friend_family___2 and/or Informed me |  |
### Question number: 19

**Friend/Family**

|   |   |   |
|---|---|---|
| 3 | friend_family___3 | This info was very influential |
| 4 | friend_family___4 | This info was moderately influential |
| 5 | friend_family___5 | This info was not influential |
| 6 | friend_family___6 | N/A |

### Question number: 20

**Website**

|   |   |   |
|---|---|---|
| 1 | website___1 | First suggested |
| 2 | website___2 | and/or Informed me |
| 3 | website___3 | This info was very influential |
| 4 | website___4 | This info was moderately influential |
| 5 | website___5 | This info was not influential |
| 6 | website___6 | N/A |

### Question number: 21

**Internet Chat Forum**

|   |   |   |
|---|---|---|
| 1 | chat_forum___1 | First suggested |
| 2 | chat_forum___2 | and/or Informed me |
| 3 | chat_forum___3 | This info was very influential |
| 4 | chat_forum___4 | This info was moderately influential |
| 5 | chat_forum___5 | This info was not influential |
| 6 | chat_forum___6 | N/A |

### Question number: 22

**Yourself**

|   |   |   |
|---|---|---|
| 1 | yourself___1 | First suggested |
| 2 | yourself___2 | and/or Informed me |
| 3 | yourself___3 | This info was very influential |
| 4 | yourself___4 | This info was moderately influential |
| 5 | yourself___5 | This info was not influential |
| 6 | yourself___6 | N/A |
| Question number: 23 | Other specify | Other please specify | checkbox, Required |
|---------------------|----------------|----------------------|-------------------|
| 35                  | other_specify  | Other please specify | 1 other_specify__1 | First suggested |
|                     |                |                      | 2 other_specify__2 | and/or Informed me |
|                     |                |                      | 3 other_specify__3 | This info was very influential |
|                     |                |                      | 4 other_specify__4 | This info was moderately influential |
|                     |                |                      | 5 other_specify__5 | This info was not influential |
|                     |                |                      | 6 other_specify__6 | N/A |

Question number: 23a

| Question number: 23a | how_informed_were_you | Looking back now after you have had the hysterectomy, how well informed do you think you were at the time of making the decision to have one? |
|----------------------|-----------------------|----------------------------------------------------------------------------------------------------------------------------------|
|                      | radio, Required       | 1 Very well informed |
|                      |                       | 2 Fairly well informed |
|                      |                       | 3 Not very well informed |
|                      |                       | 4 Not informed at all |

Custom alignment: LV

Question number: 24

| Question number: 24 | health_reasons_for_hyst | What were the reasons behind your decision to have a hysterectomy? select all that apply |
|---------------------|-------------------------|--------------------------------------------------------------------------------------------|
| 38                  | health_reasons_for_hyst__1 | Fibroids cancerous growths inside the muscular walls of the uterus |
|                     | health_reasons_for_hyst__2 | Endometriosis condition in which the cells move from the lining of the uterus to other areas of the body |
|                     | health_reasons_for_hyst__3 | Prolapse uterus slips into the vagina |
|                     | health_reasons_for_hyst__4 | Pelvic disease inflammation/infection of the uterus, fallopian tubes and/or ovaries |
|                     | health_reasons_for_hyst__5 | Hyperplasia the lining of the uterus becomes too thick and causes abnormal bleeding |
|                     | health_reasons_for_hyst__6 | N/A |
| Question Number | Field Name                        | Description                                                                                   | Data Type              | Required |
|-----------------|-----------------------------------|-----------------------------------------------------------------------------------------------|------------------------|----------|
| 25              | health_reasons_for_hyst           | Reasons for hysterectomy. Please select all that apply.                                       | radiobutton            |          |
| 25              | other_reason_for_hyst             | Other reason please specify. Enter other reasons if none of the above apply.                  | text                   | Required |
| 26              | symptoms_b4_hyst                   | For how many months did you have symptoms or health issues (if any) before you decided you    | text (number)          | Required |
|                 |                                   | needed/agreed to have a hysterectomy? If none enter 0.                                        |                        |          |
| 27              | alleviating                        | How much did this alleviate symptoms?                                                          | radiobutton            |          |
| 28              | solving                           | How much did this solve your medical problems?                                                 | radiobutton            |          |
| 29              | lifestyle                          | How much did this change your lifestyle?                                                       | radiobutton            |          |

Show the field ONLY if: [health_reasons_for_hyst(15)] = '1'

Other reason please specify text if: [health_reasons_for_hyst(15)] = '1'

For how many months did you have symptoms or health issues (if any) before you decided you needed/agreed to have a hysterectomy? Enter 0 if no symptoms/health issues.

Alleviating symptoms: How much did this alleviate symptoms?

Solving medical problem: How much did this solve your medical problems?

Lifestyle: How much did this change your lifestyle?
| Number | Question       | Details                                                                 |
|--------|----------------|-------------------------------------------------------------------------|
| 29     | hormone_levels | Change to hormone levels radio (Matrix), Required                       |
| 30     | avoid_cancer   | Avoiding cancer radio (Matrix), Required                                 |
| 31     | treat_cancer   | Treating cancer radio (Matrix), Required                                 |
| 32     | other          | Other (please specify other reason if any) radio (Matrix)                |
| 33     | reason_for_hyst| Other reason for deciding to have a hysterectomy text, Required          |
| 33a    | aware_other_hyst_methods | Were you aware that there are several possible surgical methods by which a hysterectomy can be performed? yesno, Required |
| 34     | what_hyst_methods | If yes, what methods do you know about? select all that apply checkbox, Required |

https://redcap.health.uq.edu.au/redcap_v6.5.0/Design/data_dictionary_codebook.php?pid=94

28/10/2015
| Question number | Knowledge Code | Description | Text Required | Custom Alignment | Question number |
|-----------------|----------------|-------------|---------------|------------------|-----------------|
| 51              | knowledge_tah  | Open abdominal hysterectomy - what do you think or know are the advantages and disadvantages of this type of hysterectomy? | text, Required | LV               | 34a             |
| 52              | knowledge_vag_hyst | Vaginal Hysterectomy - what do you think or know are the advantages and disadvantages of this type of hysterectomy? | text, Required | LV               | 34a1            |
| 53              | knowledge_tlh   | Total Laparoscopic Hysterectomy - what do you think or know are the advantages and disadvantages of this type of hysterectomy? | text, Required | LV               | 34a2            |
| 54              | knowledge_lavh  | Laparoscopically assisted vaginal hysterectomy - what do you think or know are the advantages and disadvantages of this type of hysterectomy? | text, Required | LV               | 34a3            |
| 55              | knowledge_robotic | Robotic hysterectomy - what do you think or know are the advantages and disadvantages of this type of hysterectomy? | text, Required | LV               | 34a4            |
| 56              | pt_preference_hyst | Did you have a preference for a particular type of hysterectomy? | yesno, Required |                   |                 |
Which type of hysterectomy did you have a preference for? select all that apply

1. Open Abdominal Hysterectomy (long cut, either horizontal or vertical across abdomen)
2. Vaginal Hysterectomy (all performed through the vagina)
3. Total Laparoscopic Hysterectomy (all performed through tiny keyhole in the abdomen)
4. Laparoscopically Assisted Vaginal Hysterectomy (performed through tiny keyhole in the abdomen and through the vagina)
5. Robotic Hysterectomy (using tools attached to a robotic arm, the surgeon controls the arm with a computer)

Why did you have a preference for the Open Abdominal Hysterectomy?

Why did you have a preference for the Vaginal Hysterectomy?

Why did you have a preference for the Total Laparoscopic Hysterectomy?

Why did you have a preference for the Laparoscopically Assisted Vaginal Hysterectomy?
| Question Number | Field Name | Description | Type | Required | Custom Alignment |
|-----------------|------------|-------------|------|----------|------------------|
| 35a5            | pref_robotic_why | Why did you have a preference for the Robotic Hysterectomy? | text | Required | LV |
| 36              | choose_dr_on_hysts | Did you choose your Doctor based on what types of hysterectomy they perform? | yes/no | Required | LV |
| 37              | dr_recommend_hyst_type | What type/s of hysterectomy did your Doctor recommend? select all that apply | checkbox | Required | LV |
| 38              | second_opinion | Did you get a second opinion about your hysterectomy? | yes/no | | LV |
| 39              | second_opinion_options | What type/s of hysterectomy did the second doctor recommend? select all that apply | checkbox | Required | LV |
| Question number: | decision_surg_risks | Surgical risks | radio (Matrix), Required |
|------------------|---------------------|----------------|-------------------------|
| 38a              | 1                   | Very much      |                         |
|                  | 2                   | Somewhat       |                         |
|                  | 3                   | A little bit   |                         |
|                  | 4                   | Not at all     |                         |
|                  | 5                   | Don't recall   |                         |

| Question number: | decision_sex_fx | Sexual function | radio (Matrix), Required |
|------------------|-----------------|-----------------|-------------------------|
| 39               | 1               | Very much       |                         |
|                  | 2               | Somewhat        |                         |
|                  | 3               | A little bit    |                         |
|                  | 4               | Not at all      |                         |
|                  | 5               | Don't recall    |                         |

| Question number: | decision_body_image | Body image (e.g. scarring) | radio (Matrix), Required |
|------------------|----------------------|----------------------------|-------------------------|
| 40               | 1                    | Very much                  |                         |
|                  | 2                    | Somewhat                   |                         |
|                  | 3                    | A little bit               |                         |
|                  | 4                    | Not at all                 |                         |
| Question number | Description                                                                 | Response Options                                                                 |
|-----------------|------------------------------------------------------------------------------|-----------------------------------------------------------------------------------|
| 41              | decision_cost                                                                     | Cost radio (Matrix), Required<br>1 Very much<br>2 Somewhat<br>3 A little bit<br>4 Not at all<br>5 Don't recall<br> |
| 42              | decision_recovery                                                                | Recovery time radio (Matrix), Required<br>1 Very much<br>2 Somewhat<br>3 A little bit<br>4 Not at all<br>5 Don't recall<br> |
| 43              | decision_support                                                                  | Family or main support person's preference radio (Matrix), Required<br>1 Very much<br>2 Somewhat<br>3 A little bit<br>4 Not at all<br>5 Don't recall<br> |
| 44              | decision_surgeon                                                                 | Surgeon's preference radio (Matrix), Required<br>1 Very much<br>2 Somewhat<br>3 A little bit<br>4 Not at all<br>5 Don't recall<br> |
| 45              | decision_other                                                                   | Other (please specify other reason if any) radio (Matrix)<br>1 Very much<br>2 Somewhat<br>3 A little bit<br>4 Not at all<br>5 Don't recall<br> |
| 46              | specify_other_hyst_decision                                                      | Please specify other reason/s for your hysterectomy decision text, Required<br>Custom alignment: LV<br>Question number: 46a<br> |

Show the field ONLY if: [decision_other] = '1' or [decision_other] =
| Question Number | Question                                                                 | Sub-Questions                                                                                                                                          | Type        | Required |
|-----------------|--------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------|-------------|----------|
| 47              | How many nights were you in hospital after your hysterectomy?           |                                                                                                                                                    | text,       | 47       |
| 48              | Did any problems occur, whilst you were in hospital for your hysterectomy, before you were discharged home? |                                                                                                                                                    | yesno,      | 48       |
| 49              | What problems occurred whilst you were in hospital recovering from your hysterectomy? |                                                                                                                                                    | notes,      | 49       |
| 49a             | Did you need to go back to the operating theatre for these problems whilst you were still in hospital recovering from your hysterectomy? |                                                                                                                                                    | yesno,      | 49a      |
| 50              | When you left the hospital (discharged), were you well prepared and given enough information to recover at home? |                                                                                                                                                    | yesno,      | 50       |
| 50a             | What information do you think was missing that could have helped you more at home? |                                                                                                                                                    | notes,      | 50a      |
| 50b             | What did you find you were unprepared for after discharge from the hospital? |                                                                                                                                                    | notes,      | 50b      |
| Question Number | Field | Description | Response Options | Notes |
|-----------------|-------|-------------|------------------|-------|
| 84              | return_to_hospital | After you were discharged from the hospital, did you have to return to the hospital for any problems? | yesno, Required  
1 Yes  
0 No | Custom alignment: LV  
Question number: 51 |
| 85              | why_return_to_hos | What were the problems that caused you to have to return to the hospital after you were discharged home? | notes, Required  
Custom alignment: LV  
Question number: 51a |
| 86              | taken_back_to_ot | Were you taken back to the operating theatre after returning to the hospital with these problems? | yesno, Required  
1 Yes  
0 No | Custom alignment: LV  
Question number: 51a |
| 87              | bend_stretch | I could bend and stretch | radio (Matrix), Required  
1 Within 1 week  
2 Within 6 weeks  
3 Within 3 months  
4 Within 6 months  
5 Within 12 months  
6 Not resolved  
7 Don't recall  
8 Not applicable | Question number: 52 |
| 88              | usual_activities | I returned to my usual activities | radio (Matrix), Required  
1 Within 1 week  
2 Within 6 weeks  
3 Within 3 months  
4 Within 6 months  
5 Within 12 months  
6 Not resolved  
7 Don't recall  
8 Not applicable | Question number: 53 |
| 89              | returned_work | I returned to work | radio (Matrix), Required  
1 Within 1 week  
2 Within 6 weeks  
3 Within 3 months  
4 Within 6 months  
5 Within 12 months  
6 Not resolved |
| Question number | Description | Radio (Matrix), Required |
|----------------|-------------|-------------------------|
| 90             | no_pain     | I no longer had any pain |
| 91             | bowels_normal | My bowels worked normally |
| 92             | bladder_normal | My bladder worked normally |
| 93             | energy_normal | My energy levels were back to normal |
| Question number: 58 | 94 | moods_stable | My moods stabilised | radio (Matrix), Required |
|------------------|----|-------------|-------------------|-------------------------|
| 1 Within 1 week  | 2  | Within 6 weeks | 3 Within 3 months | 4 Within 6 months |
| 5 Within 12 months | 6  | Not resolved | 7 Don't recall | 8 Not applicable |

| Question number: 59 | 95 | accepted_body_image | I accepted the changes to my body image | radio (Matrix), Required |
|------------------|----|---------------------|--------------------------------------|-------------------------|
| 1 Within 1 week  | 2  | Within 6 weeks | 3 Within 3 months | 4 Within 6 months |
| 5 Within 12 months | 6  | Not resolved | 7 Don't recall | 8 Not applicable |

| Question number: 60 | 96 | sexual_function_return | My sexual function was back to normal | radio (Matrix), Required |
|------------------|----|------------------------|-----------------------------------|-------------------------|
| 1 Within 1 week  | 2  | Within 6 weeks | 3 Within 3 months | 4 Within 6 months |
| 5 Within 12 months | 6  | Not resolved | 7 Don't recall | 8 Not applicable |

| Question number: 61 | 97 | did_not_choose | I was not given the option to choose a type of hysterectomy | radio (Matrix), Required |
|------------------|----|----------------|--------------------------------|-------------------------|
| 1 Strongly agree | 2  | Agree | 3 Neither agree or disagree | 4 Disagree |
| 5 Strongly disagree | | | | |

| Question number: 62 | 98 | right_choice | It was the right choice made either by me or my Doctor | radio (Matrix), Required |
|------------------|----|-------------|---------------------------------|-------------------------|
| 1 Strongly agree | 2  | Agree | 3 Neither agree or disagree | |
| Question number | Description | Responses |
|-----------------|-------------|-----------|
| 63              | regret_choice | I regret the choice that was made either by me or my Doctor |
|                 |             | 1 Strongly agree |
|                 |             | 2 Agree |
|                 |             | 3 Neither agree or disagree |
|                 |             | 4 Disagree |
|                 |             | 5 Strongly disagree |
| 64              | same_choice | If I had to choose again or had been able to choose, the decision would remain the same |
|                 |             | 1 Strongly agree |
|                 |             | 2 Agree |
|                 |             | 3 Neither agree or disagree |
|                 |             | 4 Disagree |
|                 |             | 5 Strongly disagree |
| 65              | choice_did_harm | The choice did me a lot of harm |
|                 |             | 1 Strongly agree |
|                 |             | 2 Agree |
|                 |             | 3 Neither agree or disagree |
|                 |             | 4 Disagree |
|                 |             | 5 Strongly disagree |
| 66              | wise_choice | It was the wisest choice |
|                 |             | 1 Strongly agree |
|                 |             | 2 Agree |
|                 |             | 3 Neither agree or disagree |
|                 |             | 4 Disagree |
|                 |             | 5 Strongly disagree |
| 67              | prepare pt better | Looking back now, what information could have helped you prepare for your choice of hysterectomy better and how could this have been better provided to you? |
|                 | notes      | Custom alignment: LV |
| 68              | comments | Please provide any other comments that you would like to share about your hysterectomy experience |
|                 | notes      | Custom alignment: LV |
| 69              | survey_on_womens_experience_with_hysterectomy_complete | Complete? |
|                 | dropdown   | 0 Incomplete |
|                 |             | 1 Unverified |
|                 |             | 2 Complete |