**Follow-up questionnaires**

| **Questionnaire section** | **Field** | **Description** |
| --- | --- | --- |
| Background | UPN | Unique person number |
| Background | DOB | Date of birth |
| Background | Questionnaire date | Date of follow-up questionnaire |
| Background | Education | Education undertaken in the last 3 years |
| Background | Marital status | Current marital status |
| Background | Weight | Weight in kg |
| Background | Income | Approximate household income (fortnightly) |
| Background | Genetic test date | Date of genetic testing |
| Background | Gene mutation | Type of gene mutation: BRCA1, BRCA2, ATM, p53, CHEK2, PALB2, Other |
| Background | FCC date | Date last attended a familial cancer centre |
| Screening (unaffected) | Self Breast Examination confidence | Confidence in self breast examination to find a breast cancer |
| Screening (unaffected) | Self Breast Examination frequency | Frequency of self breast examination in the last 3 years |
| Screening (unaffected) | Doctor confidence | Confidence in doctor's ability to find a breast cancer |
| Screening (unaffected) | Doctor examination | Doctor’s examination in the last 3 years? |
| Screening (unaffected) | Doctor frequency | Frequency of doctor examination in the last 3 years |
| Screening (unaffected) | Doctor number | Number of examinations in the last 3 years |
| Screening (unaffected) | Doctor's examination reason | Reason for doctor's examination: screening, investigating a problem, other |
| Screening (unaffected) | Mammogram confidence | Confidence in a mammogram's ability to find a breast cancer |
| Screening (unaffected) | Mammogram | Mammogram in the last 3 years? |
| Screening (unaffected) | Mammogram frequency | Frequency of mammogram in the last 3 years |
| Screening (unaffected) | Number of mammograms | Number of mammograms in the last 3 years |
| Screening (unaffected) | Mammograms organised | Mammogram organised by: GP; breast surgeon; cancer specialist; gynaecologist; Breastscreen; Family Cancer Centre; other; don't know |
| Screening (unaffected) | Mammogram reason | Mammogram reason: screening; recall; investigate a problem; other |
| Screening (unaffected) | Mammogram date | Date of last mammogram or don't know date |
| Screening (unaffected) | Ultrasound confidence | Confidence in the ability of an ultrasound to find a breast cancer |
| Screening (unaffected) | Ultrasound | Ultrasound in the last 3 years? |
| Screening (unaffected) | Ultrasound frequency | Frequency of ultrasounds in the last 3 years |
| Screening (unaffected) | Ultrasound number | Number of ultrasounds in the last 3 years |
| Screening (unaffected) | Ultrasound organised | Ultrasound organised by: GP, breast surgeon; cancer specialist; gynaecologist; breastscreen; Family Cancer Centre; other; don't know |
| Screening (unaffected) | Ultrasound reason | Ultrasound reason: screening; recall; investigate a problem; other |
| Screening (unaffected) | Ultrasound date | Date of last ultrasound |
| Screening (unaffected) | MRI confidence | Confidence in the ability of MRI to find a breast cancer |
| Screening (unaffected) | MRI | MRI in the last 3 years? |
| Screening (unaffected) | MRI frequency | Frequency of MRI in the last 3 years |
| Screening (unaffected) | Number of MRI | Number of MRI in the last 3 years |
| Screening (unaffected) | MRI organised | MRI organised by: GP; breast surgeon; cancer specialist; gynaecologist; breastscreen; Family Cancer Centre; other; don't know |
| Screening (unaffected) | MRI reason | MRI reason: screening; recall; investigate a problem; other |
| Screening (unaffected) | MRI date | Date of last MRI or don't know date |
| Screening (unaffected) | Both ovaries removed | Both ovaries removed: yes, no, don't know |
| Screening (unaffected) | TVU confidence | Confidence in the ability of TVU to find ovarian cancer |
| Screening (unaffected) | TVU | TVU in the last 3 years? |
| Screening (unaffected) | TVU frequency | Frequency of TVU in the last 3 years |
| Screening (unaffected) | Number of TVU | Number of TVU in the last 3 years |
| Screening (unaffected) | TVU organised | TVU organised by: GP; breast surgeon; cancer specialist; gynaecologist; breastscreen; Family Cancer Centre; other; don't know |
| Screening (unaffected) | TVU reason | TVU reason: screening; IVF; pregnancy; heavy bleeding; other |
| Screening (unaffected) | TVU date | Date of last TVU or don't know date |
| Screening (unaffected) | CA125 confidence | Confidence in the ability of CA125 to find ovarian cancer |
| Screening (unaffected) | CA125 | CA125 in the last 3 years? |
| Screening (unaffected) | CA125 frequency | Frequency of CA125 in the last 3 years |
| Screening (unaffected) | Number of CA125 | Number of CA125 in the last 3 years |
| Screening (unaffected) | CA125 organised | CA125 organised by: GP; breast surgeon; cancer specialist; gynaecologist; breastscreen; Family Cancer Centre; other; don't know |
| Screening (unaffected) | CA125 date | Date of last CA125 or don't know date |
| Screening (unaffected) | Hysterectomy screening | Have you had a hysterectomy? |
| Screening (unaffected) | Cervical screening test confidence | Confidence in the ability of Cervical screening test to find ovarian cancer |
| Screening (unaffected) | Cervical screening test | Cervical screening test in the last 3 years? |
| Screening (unaffected) | Cervical screening test frequency | Frequency of Cervical screening test in the last 3 years |
| Screening (unaffected) | Number of Cervical screening test | Number of Cervical screening test in the last 3 years |
| Screening (unaffected) | Cervical screening test organised | Cervical screening test organised by: GP; breast surgeon; cancer specialist; gynaecologist; breastscreen; Family Cancer Centre; other; don't know |
| Screening (unaffected) | Cervical screening test reason | Cervical screening test reason: routine screening; previous abnormality; other |
| Medical history | Benign breast | Benign breast disease in the last 3 years |
| Medical history | Benign breast date | Date of benign breast disease |
| Medical history | Biopsy | Breast biopsy in the last 3 years |
| Medical history | Biopsy date | Date of breast biopsy |
| Medical history | Biopsy laterality | Breast biopsy laterality |
| Medical history | Biopsy result | Biopsy result: benign or malignant |
| Medical history | Malignant type | Invasive; DCIS; LCIS; don't know |
| Medical history | Benign type | Fibroadenoma; Fibrosystic disease; Atypical ductal hyperplasia; other; don't know |
| Medical history | New cancer | New cancer diagnosed in the last 3 years |
| Medical history | New cancer date | New cancer date |
| Medical history | Right breast removed | Right breast removed |
| Medical history | Right breast removed date | Right breast removed date |
| Medical history | Right breast removed reason | Right breast removed reason |
| Medical history | Right breast cancer found | Was cancer found when the right breast was removed |
| Medical history | Left breast removed | Left breast removed |
| Medical history | Left breast removed date | Date left breast was removed |
| Medical history | Left breast removed reason | Left breast removed reason |
| Medical history | Left breast cancer found | Was cancer found when the left breast was removed |
| Medical history | Right breast reconstruction | Right breast reconstruction? |
| Medical history | Right breast reconstruction date | Right breast reconstruction date |
| Medical history | Left breast reconstruction | Left breast reconstruction? |
| Medical history | Left breast reconstruction date | Left breast reconstruction date |
| Medical history | Right ovary removed | Right ovary removed in the last 3 years? |
| Medical history | Right ovary removed date | Right ovary removed date |
| Medical history | Right ovary removed reason | Right ovary removed reason: ovarian cancer; preventative oophorectomy; breast cancer, cyst, other, don't know. |
| Medical history | Right ovary removed cancer found | Was cancer found when the right ovary was removed? |
| Medical history | Left ovary removed | Left ovary removed in the last 3 years? |
| Medical history | Left ovary removed date | Left ovary removed date |
| Medical history | Left ovary removed reason | Left ovary removed reason: ovarian cancer; preventative oophorectomy; breast cancer, cyst, other, don't know. |
| Medical history | Left ovary removed cancer found | Was cancer found when the left ovary was removed? |
| Medical history | Hysterectomy? | Hysterectomy in the last 3 years? |
| Medical history | Date of hysterectomy | Date of hysterectomy |
| Medical history | Hysterectomy reason | Reason for hysterectomy: cancer of the uterus; cancer prevention; cancer of the cervix; ovarian cancer; other; don't know |
| Medical history | Hysterectomy cancer found | Was cancer found when the uterus was removed? |
| Medical history | Tubal ligation | Tubal ligation in the last 3 years? |
| Medical history | Tubal ligation date | Date of tubal ligation |
| Medical history | Fallopian tubes removed | Fallopian tubes removed in the last 3 years? |
| Medical history | Fallopian tubes number | Number of tubes removed |
| Medical history | Fallopian tubes date | Date fallopian tubes were removed |
| Medical history | Fallopian tubes removed reason | Reason fallopian tubes were removed: cancer prevention; cancer treatment; non-cancerous condition; ectopic pregnancy; contraception; other |
| Treatment (affected) | Breast cancer | New breast cancer diagnosed in the last 3 years |
| Treatment (affected) | Breast cancer date | New breast cancer date |
| Treatment (affected) | Breast cancer found | New breast cancer found by: mammogram; doctor examination; breast self-examination; nipple discharge or changes to breast appearance; breast ultrasound; prophylactic mastectomy; other; don't know |
| Treatment (affected) | Breast cancer locations | Which areas of the body did this breast cancer involve: left breast; right breast; both breasts; lymph nodes under the arm; other; don't know |
| Treatment (affected) | Breast cancer surgery | Surgery for this breast cancer? |
| Treatment (affected) | Breast surgery date | Date of breast cancer surgery |
| Treatment (affected) | Breast surgery type | Type of surgery: lumpectomy; mastectomy; removal of lymph nodes; other; don't know |
| Treatment (affected) | Radiation treatment | Radiation treatment for this breast cancer that started within 12 months of diagnosis? |
| Treatment (affected) | Radiation treatment start | Date radiation treatment started |
| Treatment (affected) | Radiation treatment where | Radiation treatment location/s: breast, chest, lymph nodes, other, don't know |
| Treatment (affected) | Chemotherapy | Chemotherapy that started within 6 months of diagnosis? |
| Treatment (affected) | Chemotherapy date | Date chemotherapy started |
| Treatment (affected) | Chemotherapy type | Chemotherapy type: Adriamycin; Carboplatin; Capecitabine; Cyclophosphamide; Docetaxel; Epirubicin; Fluorouracil; Gemcitabine; Lapatinib; Methotrexate; Paclitaxel; Pertuzumab; Traztuzumab; Vinorelbine; other; don't know |
| Treatment (affected) | Hormone | Anti-hormone treatment that started within 12 months of this diagnosis? |
| Treatment (affected) | Hormone type | Type of anti-hormone treatment: tamoxifen; arimidex; femara; zoladex; exemestane; other; don't know |
| Treatment (affected) | Hormone start | Date anti-hormone treatment started |
| Treatment (affected) | Hormone stop | Date anti-hormone treatment stopped |
| Treatment (affected) | Hormone current | Currently taking anti-hormone treatment |
| Treatment (affected) | Bone strengthener | Taken a bone strengthener/biophosphonate? |
| Treatment (affected) | Recurred | In the past 3 years have you had a recurrence of your cancer? |
| Treatment (affected) | Recurred date | Date of this recurrence |
| Treatment (affected) | Recurred where | Cancer came back: same breast; lymph nodes on same side; other lymph nodes, skin or subcutaneous; bone; liver; lung; brain; other; opposite breast; don't know |
| Treatment (affected) | Current situation | Cancer is: in remission; still present; don't know |
| Treatment (affected) | Medications | In the last 3 years taken any of these medications (all that apply): tamoxifen; anastrozole; letrozole; zoladex; exemestane |
| Treatment (affected) | Medications duration | Duration taken medications in months |
| Reproductive | Period weeks | Weeks since last period or more than 10 years indicated |
| Reproductive | Period stop reason | If last period more than 12 months ago the reason period stopped: natural menopause; pregnancy; medications; hormonal contraception; both ovaries removed; hysterectomy; IUD; other |
| Reproductive | Post-menopausal? | Do you consider yourself to be post-menopausal |
| Reproductive | Pregnancies | Number of pregnancies |
| Reproductive | Pregnancy date | Date of end of pregnancy (for each pregnancy) |
| Reproductive | Pregnancy outcome | Currently pregnant; single live birth; stillbirth; miscarriage; ectopic; induced termination; don't know |
| Reproductive | Pregnancy duration | Duration in weeks |
| Reproductive | Child Sex | Boy or Girl |
| Reproductive | Breastfed? | Baby was breastfed? |
| Reproductive | Breastfeeding duration | Duration in months or currently breastfeeding |
| Contraceptive | Taken contraceptive | Taken hormonal contraceptive in the last 3 years |
| Contraceptive | Contraceptive type | Type of hormonal contraceptive taken: combined oral; progesterone pill; injectable; implant; IUD; other |
| Contraceptive | Age first taken | Age first taken hormonal contraceptive |
| Contraceptive | Age last taken | Age last taken hormonal contraceptive |
| Contraceptive | Currently taking | Currently taking hormonal contraceptive? |
| Contraceptive | Contraceptive duration | Duration of use in months |
| Contraceptive | Use before pregnancy | Time using hormonal contraception before first full-term pregnancy (if applicable) |
| HRT | Used HRT | Used HRT in the last 3 years? |
| HRT | HRT type | Type of HRT used: cream; tablet; combination; IUD; synthetic; other |
| HRT | HRT first time | First used in last 3 years? |
| HRT | HRT current | Current use |
| HRT | HRT age first used | HRT age first used by type |
| HRT | HRT age last used | HRT age last used by type |
| HRT | HRT duration use | HRT duration used by type in months |
| Medication | Medication | During the last 3 years, taken medication at least twice a week for more than one month? |
| Medication | Medication type | Medication type: aspirin, low dose aspirin, paracetamol; NSAID; COX2 inhibitor |
| Medication | Medication duration | Duration taken in months or years |
| Medication | Medication current | Current taking medication |
| Medication | Medication quantity | Tablets taken per week |
| Preventative medication (unaffected) | Trial | During the last 3 years, participated in a preventative medication trial? |
| Preventative medication (unaffected) | Trial type | Name of preventative medication trial: IBIS I; IBIS II; other |
| Preventative medication (unaffected) | Trial start date | Trial medication start date |
| Preventative medication (unaffected) | Trial stop date | Trial medication stop date |
| Preventative medication (unaffected) | Trial current | Currently taking trial medication |
| Preventative medication (unaffected) | Trial duration | Duration trial medication taken in months |
| Preventative medication (unaffected) | Preventative medication | During the last 3 years, taken preventative medication? |
| Preventative medication (unaffected) | Preventative medication type | Type of preventative medication taken in the past 3 years: tamoxifen; anastrozole; letrozole; exemestane; goserelin. |
| Preventative medication (unaffected) | Preventative start | Preventative medication start date |
| Preventative medication (unaffected) | Preventative stop | Preventative medication stop date |
| Preventative medication (unaffected) | Preventative current | Currently taking preventative medication |
| Preventative medication (unaffected) | Preventative duration | Duration taken in months |
| Preventative medication (unaffected) | Preventative reason | Reason medications prescribed: prevent breast cancer; prevent osteoporosis; treat cancer; other; don't know |
| Exercise | Strenuous hours | During the last 3 years, hours per week participating in strenuous exercise |
| Exercise | Strenuous months | Months per year participating in strenuous exercise |
| Exercise | Moderate hours | During the last 3 years, hours per week participating in moderate exercise |
| Exercise | Moderate months | Months per year participating in moderate exercise |
| Smoking | Smoke | During the last 3 years, you smoked regularly? i.e. at least one cigarette per day for at least 3 months |
| Smoking | Smoke number | Over this period, how many cigarettes did you smoke per day? |
| Smoking | Smoke duration | Number of months where you smoked regularly |
| Smoking | Smoke current | Currently smoking regularly? |
| Smoking | Smoking start age | Age started smoking |
| Smoking | Smoking stop age | Age stopped smoking |
| Alcohol | Drink | During the last 3 years, drink alcoholic beverages regularly (at least once a week for a period of 6 months or longer)? |
| Alcohol | Drink months | Period over the last 3 years drank regularly in months |
| Alcohol | Drink type | Type of drink (all that apply): Beer; wine; spirits; alcoholic soda |
| Alcohol | Drink current | Do you currently drink regularly? |
| Alcohol | Drink stop age | Age when you stopped drinking regularly |

**Pathology collection**

| **Table** | **Fields** | **Description** |
| --- | --- | --- |
| Tumour | UPN | Unique person number |
| Tumour | Hospital | Hospital where procedure took place |
| Tumour | Stage | Stage of cancer |
| Tumour | T | T |
| Tumour | pN | pN |
| Tumour | M | M |
| Histopath | Diagnosis Date | Date of diagnosis from path report |
| Histopath | Laterality | Laterality for histopath results |
| Histopath | Procedure | Procedure noted on histopath |
| Histopath | Anatomic site | Site of procedure |
| Histopath | Histopath\_type | Histology on path report |
| Histopath | Surgeon | Surgeon noted on histopathology |
| Histopath | Tumour\_Grade | Grade of tumour |
| Histopath | Size of tumour | Tumour size in mm |
| Histopath | Total number of lymph nodes examined | Total number of lymph nodes examined |
| Histopath | Total number of lymph nodes positive | Total number of lymph nodes positive |
| Histopath | Oestrogen Receptor | Positive, Negative, Equivocal, not tested |
| Histopath | ER% stained summary | Absent, <1%, 1-10%, >10%, not reported |
| Histopath | ER staining intensity | Weak (1+), Moderate (2+), Strong(3+), not reported |
| Histopath | ER actual % stained number | Percentage stained |
| Histopath | Progesterone Receptor | Positive, Negative, Equivocal, not tested |
| Histopath | PR% stained summary | Absent, <1%, 1-10%, >10%, not reported |
| Histopath | PR staining intensity | Weak (1+), Moderate (2+), Strong(3+), not reported |
| Histopath | PR actual % stained number | Percentage stained |
| Histopath | HER2 Receptor | Positive, Negative, Equivocal, not tested |
| Histopath | HER2 staining intensity | Absent, <1%, 1-10%, >10%, not reported |
| Histopath | HER2 % stained summary | 1+, 2+, 3+, not reported |
| Histopath | HER2 testing type | IHC, IHC and ISH, ISH, not reported |
| Histopath | HER2 copy number | HER2 copy number |
| Histopath | HER2 ratio | HER2 ratio |
| Histopath | HER2 actual % stained number | HER2 percentage stained number |
| Histopath | Amplified | Amplified or non-amplified |
| Histopath | Ki67 | % reported, not reported |
| Histopath | C5 & C6 cytokeratins | Positive, negative, not reported |
| Surgery | Outcome | Reason for surgery, e.g. prophylactic |
| Surgery | Surgery date | Date of surgery |
| Surgery | Laterality | Reported laterality for surgery. |
| Surgery | Hospital | Hospital where surgery took place |
| Surgery | Surgeon | Surgeon named on the pathology report |
| Surgery | Right\_Breast\_Removed | Right breast removed |
| Surgery | Right\_breast\_type | Type of surgery |
| Surgery | Right\_breast\_reconstruction | Type of reconstruction |
| Surgery | Right\_breast\_immed\_recon | Immediate reconstruction |
| Surgery | Right\_breast\_path | Histopathology outcome |
| Surgery | Left\_Breast\_Removed | Left breast removed |
| Surgery | Left\_breast\_type | Type of surgery |
| Surgery | Left\_breast\_reconstruction | Type of reconstruction |
| Surgery | Left\_breast\_immed\_recon | Immediate reconstruction |
| Surgery | Left\_breast\_path | Histopathology outcome |
| Surgery | Mutation\_Status\_reported | Mutation status reported on pathology report |
| Surgery | Pelvic\_surgery\_type | Type of pelvic surgery, e.g. abdominal, laparoscopic |
| Surgery | Pelvic\_surgery\_reason | Reason for type of surgery |
| Surgery | Right Ovary Complete | Right ovary fully removed |
| Surgery | Right Ovary Partial | Right ovary partially removed |
| Surgery | Left Ovary Complete | Left ovary fully removed |
| Surgery | Left Ovary Partial | Left ovary partially removed |
| Surgery | Right Tube Complete | Right tube fully removed |
| Surgery | Right Tube Partial | Right tube partially removed |
| Surgery | Left Tube Complete | Left tube fully removed |
| Surgery | Left Tube Partial | Left tube partially removed |
| Surgery | Uterus Complete | Uterus fully removed |
| Surgery | Uterus Partial | Uterus partially removed |
| Surgery | Cervix | Cervix removed |
| Surgery | Other complete | Other completely removed |
| Surgery | Other partial | Other partially removed |
| Surgery | Pelvic histopath outcome | Outcome from histopathology for pelvic surgery |