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Hospital Name:	
Interviewer's name:	•••
Start time:	

INDIVIDUAL PATIENTE QUESTIONNAIRE

SENOVIE Île-de-France Study – Version 05/2024

GENERAL INFORMATION

Identification Number: |___| |___| |___|

Interviewer: the identification number is noted on the anonymity card

A1. You were diagnosed with breast cancer between 01/01/2014 and more than 3 years ?

1. Yes

2. No, it was before January 1, 2014 → [End of interview]

- 3. No, it was after December 31, 2020 → [End of interview]
- A2. Date of the interview: |___| |__| |___| |___|

A3. To begin with and to find your way in time, can you tell me in what way year you were born? |___|___|

Interviewer. Locate the year of birth in the biographical grid, write 0 in the "age" column for the corresponding row and fill in these columns going back to the current age.

A4. In which country were you born?

Interviewer: Note the name of the country of birth in column 1.1 on the year of birth row in CAPITAL LETTERS

A LIFETIME IN REVIEW

TO ALL WOMEN

GRID: RESIDENTIAL HISTORY - COLUMN 1

We'll start by talking about the places where you've lived for at least a year since you were a child and until now...

The stages of at least 1 year or equivalent to one year in the grid.

G1. <u>If the woman was born in sub-Saharan Africa</u>: Until when (how old) did you stay in the country where you were born?

If the woman was born in France: Have you always lived in France?

Yes → G4
 No

Interviewer: Locate the year of country change and draw an arrow to indicate the time spent in the country

G2. And then, in which country did you live?

Interviewer: Note the country in CAPITAL LETTERS on the year of arrival in the new country

G3. Until when (how old) did you stay in this country?

- Interviewer: Locate the year of country change and draw an arrow to indicate the time spent in the country
- Interviewer: For women born in sub-Saharan Africa, draw an arrow to mark the year of arrival in France

TO ALL WOMEN

GRID: RESIDENTIAL HISTORY - COLUMN 1

We will detail together the different accommodations where you have lived for more than a year in **France.** Some of these accommodations may be in the same city. Periods of frequent home change (less than one year in each dwelling) are considered periods <u>of residential instability</u>.

G4. <u>If the woman was born in sub-Saharan Africa</u>, from the time you arrived in France, did you live in the same home for more than a year or did you change homes frequently?

<u>If the woman was born in France</u>, from the moment you left your parents' home, did you live in the same home for more than a year or did you change homes frequently?

- Interviewer: If housing for more than one year, ask G5 to G7 to the current housing
- Interviewer: If there is frequent change, note <u>"INSTABRESID</u>" in column 1.3 for the year in which this period began. Draw an arrow to indicate the length of the period. Do not ask for the nature of the accommodation and ask G9 directly

G5. When you moved into this accommodation:

- 1. It was your own accommodation (regardless of the status: tenant/owner/roommate)
- 2. You were staying with your family or members of your entourage (with a financial contribution but without an exchange of services)
- **3.** You were hosted by your family or members of your entourage (with exchange of services but without financial participation)
- **4.** You were staying with your family or members of your entourage (with an exchange of services and with a financial contribution)
- 5. You were staying with your family or members of your entourage (without financial participation or services)
- 6. Other Specify
 Interviewer: code from 1 to 6 on column 1.3
- G6. In which department was this accommodation located?
 Interviewer: Note the department and the year of arrival in the accommodation in column 1.2

Interviewer: If the patient says "Paris": get confirmation "Paris itself?" or another department of Île-de-France

G7. How long did you stay in this accommodation?

- Interviewer: Identify the year of the change of accommodation and draw an arrow to indicate the time spent in the 1st dwelling.
- G8. And then, have you lived in the same home for more than a year or have you Changed accommodation frequently?
- Interviewer: For periods of frequent change of accommodation, note "<u>INSTABRESID</u>" in column 1.3 for the year in which this period began. Draw an arrow to indicate the length of the period. Do not ask for the nature of the accommodation and ask G9 directly
- G9. During this period when you have changed your accommodation frequently, are you arrived *(check directly in column 1.4)*
- *Therviewer: several possible answers:*
 - 3. To be hosted by associations or institutions? (115, Samu social, Médecins du Monde,...)
 - 2. To be hosted successively with several friends or family members?
 - 3. To sleep in a squat?
 - 4. To sleep on the street?

TO ALL WOMEN

WORKSHEET: ACTIVITIES - COLUMN 2

We will now talk about what you have been doing since your childhood: your periods of study, vocational training, work, periods at home or unemployment, etc. Let's talk about those that lasted at least 1 year.

- Interviewer: Note the main activities that lasted at least 1 year (or equivalent to one school year).
- Interviewer: If over a period, the person has accumulated two activities, note his or her main activity, and note the complementary activity. Indicate, if applicable, the shorter steps in the "Remarks and Clarifications" column: e.g. 5 months of unemployment after dismissal.
- Interviewer: if the person has changed activity frequently (following odd jobs of less than one year.), write "<u>INSTABPROF</u>" in column 2.1 for the year in which this period began. Draw an arrow to indicate the length of the period.
- G10. What did you do when you were 6 years old? What was your main occupation?
- Interviewer: Write down in full the main occupation at 6 years old: "school", "helping at home"..., in column 2.1

How long did you continue to go to school / help at home or whatever...? [Adapt]

æ	Interviewer: Identify the year of change of occupation and draw an arrow to the 2nd occupation. Column 2.1
P	Interviewer: If the person has been to school, do not differentiate between the different grade levels
G1 1	. And then, what did you do? And until when? whether this is declared or not.
æ	Interviewer: code for each activity the following code in column 2.1 and draw an arrow to indicate the beginning and end of this activity:
	 Odd jobs: <u>frequent changes</u> in occupation during the same year Cleaner, cleaning lady <u>in offices</u>
	 Childminders, childminders, live-in nanny ATSEM, teaching assistant <u>in a school</u>, childcare assistant
	 Nursing assistant Life assistant
	 Self-employed trader Self-employed craftswoman
	 Street vendor Saleswoman, cashier, store employee
	11. Employed in the direct service to individuals: hairdresser, beautician, cleaning lady in private homes, waitress, etc.
	 12. Employee in <u>a private company</u> 13. Employed in the <u>public</u> service : secretary, office worker, hospital worker,
	14. Skilled worker, in the workshop or in the factory 15. Labourer, unskilled worker, on the assembly line
	16. Farmer (self-employed): farmer 17. Subsistence farming
	18. Intermediate profession in health or social care: nurse, midwife, rehabilitation specialist, medical technician, pharmacy technician, educator, specialist in socio-educational intervention or socio-cultural and leisure worker, social worker, etc.
	 19. Intermediate profession in a company: technician, supervisor, etc. 20. Intermediate profession in the civil service: teacher, technician, supervisor, etc.
	 Administrative or commercial framework in the private sector Administrative or commercial manager in the civil service Artistic profession Technical executive, engineer in the private sector Technical executive, engineer in the private sector
	25. Technical executive, engineer in the civil service26. Professional
G12	 Other: Specify If it is a work activity in France, what type of contract did you have?

Interviewer: Note in column 2.2 the type of contract in the year in which the activity starts a permanent contract

- 2. a fixed-term or temporary contract
- 3. self-employed, self-employed, self-employed
- **4.** without a contract

G13. If it is a work activity in France, specify in column 2.3: Were you?

Interviewer: Note the type of activity in the year it starts

- **1.** Public sector employee
- 2. Private sector employee
- 3. Independent/self-employed status
- 4. Undeclared employment

A5. To recap your studies:

- 1. you have never been to school \rightarrow Skip to B1
- 2. You only went to Koranic school 🗲 Skip to B1
- 3. you went to school
- A6. What was the last class you took? |___|
- *Therviewer: See coding below.*
- Interviewer: Grade <u>97 if</u> the proposed school system does not match and describe the school system below.

01: Pre-school (kindergarten)

Elementary - Primary

- **02** : Cours d'Initiation Cl
- **03**: CP Preparatory Course
- 04 : Elementary Course 1 CE1
- **05**: Elementary Course 2 CE2
- 06 : Intermediate Course 1 CM1
- 07 : Intermediate Course 2 CM2

Secondary - Middle School

- **08**: 6th
- **09** : 5th
- 10: 4th / CAP 1
- 11: 3rd / CAP 1

Secondary - High School

12 :	2nd / BEP 1
13 :	1st / BEP 2

14 : Terminal

Upper

- 15: 1st year (DEUG 1, L1 or equivalent) / BTS 1
- **16**: 2nd year (DEUG 2, L2 or equivalent) / BTS 2
- 17: 3rd year (Bachelor's degree, L3 or equivalent)
- 18: 4th year (Master's, M1 or equivalent)
- 19: 5th year (DESS, DEA, M2 or equivalent)
- 20: Grade 6 and beyond (doctorate...)

97: If the school system is different, note in plain English:

.....

RELATIONSHIP STORIES & CHILDREN

We are now going to talk about the main stages of your emotional and family life: the relationships or unions, the children you have had.

Let's start with all the people you've been with for at least 1 year, whether or not they've had sex, including your current partner.

- Interviewer: whether there was marriage or not, whether there was cohabitation or not, whether it was a man or a woman, whether this partner is alive or deceased.
- B1. Have you had any relationships that have lasted at least 1 year?
 - Yes → Skip to G14
 No
 98. Don't wish to answer

	TO ALL WOMEN
GRI	D RELATIONS COLUMNS 3. 1
G14	Ist relationship: Let's talk about the first person you were with during the minus a year. Can you tell me a name to identify us?
	With "quoting the first name", when did you start to be together?
@	Interviewer: Note R (for relationship) then H for male and F for female, then the person's first name in column 3.1 to the year in which the relationship began. Ex: R H Claude.
<u>If ye</u>	 Are you still together? 25: → Upgrade to G16 2 : When did this relationship end? And how did it end?
æ	Interviewer: Identify the year the relationship broke up and draw an arrow to the breakup
æ	Interviewer: Note: S (separation), D (divorce) or DC (death) + first name of the PERSON in the year of the end of the RELATIONSHIP: ex "D Claude" in the year of the divorce with Claude.
G16	. 2nd relationship: have you had another relationship of more than a year?
()	Interviewer: REPEAT the same for each RELATIONSHIP: beginning and end (eventual) of the RELATIONSHIP + draw the arrow.
æ	Note: if there are two relationships with people with the same first name, differentiate them by a serial number: Claude 2 for the 2nd Claude

We will now talk about relationships that lasted less than a year or casual relationships, whether they lasted a few days, weeks or months. Whether it's relationships with women or men.

B2. Have you had any relationships that have lasted less than a year ?

Yes → Skip to G17
 No

98. Don't wish to answer

TO ALL WOMEN

COLUMNS RELATIONS GRID 3.2

G17. If so, can you tell me when it was?

Thereware: Note "RELCO" in the year it happened in column 3.2.

Interviewer: TAKE the question again and write down "RELCO" in all the years in which they occurred.

We will now talk about children, if you have any, regardless of their age.

B3. Have you had one or more children?

1. Yes

2.

- No **Switch to C1** if the woman was born in sub-Saharan Africa
 - Switch to C3 if the woman was born in France

TO ALL WOMEN

CHILDREN'S GRID - COLUMN 4.1 to 4.2

G18. If B3=1, when was your first child born?

Interviewer: Locate in column 4.1 and note E1, H for boy and F for girl: ex E1 H

G19. Where does this child live now? (Note in column 4.2 the code of the answer):

- Interviewer: Note the places where children live regardless of their ages
 - 1. In France with you
 - 2. In France but not with you
 - 3. In France in alternating custody (ego/other parent)
 - 4. At home
 - 5. In another country,
 - 6. The child is deceased (if the child is deceased, note DC E1 in column 4.1 in the year of death
 - 7. Other
 - 98. Don't want to answer
 - 99. Don't know anymore

G20. Have you had other children, whether with the same person or another?

Interviewer: If yes, write E2 when your 2nd child was born and ask question G19

Repeat the same for all children

NATIONALITY, ARRIVAL IN FRANCE AND STAY

WOMEN BORN IN SUB-SAHARAN AFRICA

We will now talk about the period of your arrival in France.

- Interviewer: Consider here the first arrival in France that counts for her as an arrival (not as a trip)
- C1. In which year did you arrive in France?
- Interviewer: Enter in numbers

(year). In the month of (_____ (month) [NSP possible on month,

grade 99] [MAX Year: 2024]

C2. Why did you come to France (at that time)?

- **1.** Try your luck, find work
- 2. Join a family member
- 3. Studying

Several possible

answers

- 4. To flee threats in your country
- 5. For medical reasons
- 6. Another reason, in plain text.....

GRID: NATIONALITY - COLUMN 5

G21. When you were born, what were your nationality(ies)?

Interviewer: Enter the nationality on the year of birth

- G22. Did that change after that?
 - **1.** Yes
 - 2. No → Skip to C3

G23. Can you tell me when?

- Interviewer: Draw an arrow to the year of the change in nationality. Note the year of change of the new nationality
- Interviewer: if dual nationality, note both

TO ALL WOMEN

We will now talk about your parents, their places of birth and nationalities.

9

C3. Was your father born:

- **3.** In metropolitan France
- 4. Overseas
- 5. In another country, specify.....
- 98. Don't wish to answer
- 99. Don't know

C4. What is your father's nationality?

- 1. French by birth
- 2. French by naturalization, marriage, declaration or option on reaching the age of majority
- **3.** Another nationality
- 98. Don't wish to answer
- 99. Don't know

C5. Was your mother born:

- 1. In metropolitan France
- 2. Overseas
- 3. In another country, specify.....
- 98. Don't wish to answer
- 99. Don't know

C6. What is your mother's nationality?

- 1. French by birth
- 2. French by naturalization, marriage, declaration or option on reaching the age of majority
- **3.** Another nationality
- 98. Don't wish to answer
- 99. Don't know

WOMEN BORN IN SUB-SAHARAN AFRICA

GRID: RESIDENCE PERMITS – COLUMN 6

The issue of papers can affect the possibilities you have to live and work in a country. This is why I would like to try to retrace with you the different types of papers, residence permits, that you may or may not have had while living in France. Can we try to retrace this together?

G24. The year you arrived in France, what type of document did you have?

- 1 Temporary residence permit or receipt ASYLUM APPLICATION: TS<1 year
- 2 Temporary residence permit or receipt OTHER REASONS: TS<1 year
- **3** A temporary residence permit: TS 1-3 years old
- 4 A resident card: TS 10 years old
- 5 No residence permit: Without TS
- 6 No need for a residence permit: No need for TS
- 7 Other: Specify

G25. And then, has your situation changed?

Interviewer: RELANCE: If the situation has not changed: "Currently, you have a ... "

Interviewer: If the situation has changed:

G26. In which year did it change? What type of document did you have then?

Interviewer: Draw an arrow to the year of document change. Note each new document type in the corresponding year

And then, has your situation changed?

WOMEN BORN IN SUB-SAHARAN AFRICA

- C7. Have you applied for a residence permit for a medical reason?
 - **1.** Yes
 - 2. No → Moving to D1
 - **98.** Don't want to answer → Moving to D1
- C8. Have you obtained a residence permit for medical reasons?
 - **1.** Yes
 - 2. No → Moving to D1

98. Don't want to answer → Moving to D1

TO WOMEN BORN IN SUB-SAHARAN AFRICA, ASK G27 if C8=1

RESIDENCE PERMIT GRID COLUMN 6

lf C8=1,

G27. And in what year did you obtain this residence permit for medical reasons? <u>for the first time?</u>

Interviewer: Note "MEDIC" the year in which the residence permit was obtained for medical reasons

HEALTH PROTECTION

<u>TO ALL WOMEN</u>

We will now talk about access to health coverage.

D1. If the woman was born in sub-Saharan Africa: Since you arrived in France, have you had health coverage?

If the woman was born in France: since you were 18 years old, do you have health coverage?

- **1.** Yes
- 2. No → Move to D4

Interviewer: different health coverage: social security; CMU (Universal Health Coverage), AME (State Medical Aid), PUMA (Universal Health Protection), Health Insurance...

GRID: HEALTH PROTECTION - COLUMN 7

G28. From what year did you have health coverage?

Interviewer: Note "COUV-MA" in the year of start of health coverage

G29. Subsequently, are there periods of at least one year when you have not had any more Health coverage?

- Interviewer: If the answer is "No", go to D2
- Interviewer: If the answer is "Yes", go to G30

G30. If G29=Yes, from when to when was it?

- Interviewer: Draw an arrow to the year of interruption. Note "FREE-COUVMA" in the year in which the interruption begins
- *Interviewer: Note "COUV-MA" in the year of resumption*

REMINDER: If there is no recovery, then you currently have no health coverage?

D2. Today, what type of health protection do you have?

Interviewer: Name all proposals

- 1. Classic social security
- 2. PUMA Social Security (Universal Health Protection)
- **3.** AME (State Medical Aid)
- 4. Other *Specify*
- 5. No health protection
- 98. Don't want to answer
- 99. Don't know

D3. Today, you have-Do you have a mutual health insurance / complementary health insurance?

- **1.** Yes
- **2.** No
- 98. Don't want to answer
- 99. Don't know

D4. Do you have a general practitioner?

- **1.** Yes
- 2. No → Upgrade to E1

98. Don't want to answer → Upgrade to E1
99. Don't know → Upgrade to E1

D5. In which department is his or her place of consultation?

TO ALL WOMEN

VIOLENCE

We are now going to talk about difficult experiences that you may have had during your life, in particular the violence that you may have faced.

E1. Has it ever happened that someone physically assaults you, hits you?

- **1.** Yes
- 2. No → move to E2
- 98. Don't want to answer → go to E2

G31. If so, can you tell me when this violence took place?

- Interviewer: Note "PHYS" in the violence column, for women born in sub-Saharan Africa, if the violence takes place in the year of migration, clarify with the respondent whether the violence took place before or after arrival in France (or both).
- Interviewer: If a long period of time, draw an arrow

E2. Has it ever happened that someone sexually assaults you, forces you to have Sex you didn't want?

1. Yes

2. No → move to F1

98. Don't want to answer → switch to F1

G32. If ves, can you tell me when this violence took place?

- Interviewer: Note "FORCES" in the violence column, for women born in sub-Saharan Africa, if the violence takes place in the year of migration, clarify with the respondent whether the violence took place before or after arrival in France (or both).
- Interviewer: If a long period of time, draw an arrow
- Interviewer: if the person reports past or current violence, call the following toll-free number to access the listening centre for women victims of violence: 3919. Line open Monday to Saturday from 9 a.m. to 7 p.m.

TO ALL WOMEN

BREAST CANCER

We will now talk about your breast cancer, diagnosis, treatment and your management.

13

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F1. Do you remember the year in which a DOCTOR first told you that you have breast cancer?

	(year) to the month of (month) [NSP possible on month,
grade 99]	
[MAX Year: 2020]	

Therewiewer: Note in column 9.1 of the grid, DIAG to the year of diagnosis

F2. Can you tell me what best fits the way you were diagnosed for your cancer?

Interviewer: Also note the answer in column 9.1 of the grid, according to the corresponding code (e.g., next to the mention DIAG: 1)

- **1.** You have participated in a generalized screening campaign (letter from the Social Security) and had examinations
- 2. You had had signs that something was wrong and you consulted
- **3.** You have been ordered an examination on another occasion
- 4. Other, specify.....

F3. Before diagnosis, did you notice the following signs:

Therviewer: ask the person to answer yes/no to each modality

- 1. Unusual fatigue?
- 2. A lump in the breast?
- Several possible answers
- **3.** Pain in the breast?
- **4.** A discharge from the breast?
- 5. A lump under the arm?
- 6. Redness, a pimple or a skin lesion on the breast?
- 7. Others, please specify.....

Interviewer: Capture in numbers

8. No sign \rightarrow go to F7

F4. When did you first notice these signs?

Interviewer: Enter in numbers

grade 99] [NSP possible on month,

[MAX Year: 2020]

The second seco

F5. When you noticed this sign(s), how long did it take before whether you are consulting a <u>first</u> health professional for this problem?

Interviewer: If the patient does not know, enter 9999 in the first field

Number of jours______ Number of semaines______ Number of mois______ Number of années_____

F6. Which professional was it?

Interviewer: only one possible answer

- 1. A general practitioner / general practitioner?
- 2. A gynaecologist?
- 3. An oncologist?
- 4. A homeopathic doctor or a naturopath?
- 5. Another doctor?
- 6. A midwife?
- 7. A nurse?
- **8.** A community health worker?
- **9.** A traditional healer?
- 10. Others, please

specify.....

F7. When the diagnosis was made, how long did it take for you to consult a <u>first</u> health professional to treat this problem?

Interviewer: If the patient does not know, enter 9999 in the first field

Number of jours	
Number of semaines	_
Number of mois	
Number of années	

F8. Which professional was it?

Interviewer: only one possible answer

- 1. A general practitioner / general practitioner?
- 2. A gynaecologist?
- 3. An oncologist?
- 4. A homeopathic doctor or a naturopath?
- 5. Another doctor?
- 6. A midwife?
- 7. A nurse?
- **8.** A community health worker?
- **9.** A traditional healer?
- 10. Others, please

specify.....

WOMEN BORN IN SUB-SAHARAN AFRICA

Interviewer: F9 = check on the grid and validate with the respondent

^{CP} Interviewer: if the year of diagnosis and migration are the same, take into account the order of events: diagnosis then migration or migration then diagnosis

F9. Did you diagnose cancer before you arrived in France?

- 1. Yes before
- 2. No after → Switch to F11

F10. Once you arrive in France, where the first medical consultation for your cancer?

- 1. At a general practitioner in town
- 2. At a specialist doctor in town
- 3. At a specialist doctor in a hospital/clinic
- 4. In a hospital emergency room / in a clinic
- 5. At the PASS of a hospital
- 6. In an NGO (Doctors of the World, etc.)
- 7. Other, specify.....

TO ALL WOMEN

F11. You...?

- 1. Right-handed
- 2. Left-hander
- 3. Ambidextrous

F12. Which side was your breast cancer on?

- 1. Right
- 2. Left
- 3. Both breasts

F13. Since the diagnosis, have you been told that you have to have breast surgery to remove the cancer?

- **1.** Yes
- 2. No → Switch to F21
- 99. Don't know how → to switch to F21

F14. Have you accepted this operation?

- 1. Yes, and it has already happened → Skip to G33
- 2. Yes and it is programmed → Switch to F21
- **3.** No, you have not accepted

F15. For what reason(s) did you wish you did not have breast surgery?

IN PLAIN LANGUAGE:

.....

.....

BREAST CANCER GRID COLUMN 9

lf **F14=1**

G33. In what year did the first operation take place? (Column 9.2)

Was this operation only to remove the cancer or to also do reconstruction?

Therefore the interviewer: For each operation, indicate whether it is a mastectomy (Note OP2 Ma) or reconstruction (example OP2 Rec) or both (OP2 MaRec).

Interviewer: WARNING!

Once the patient has listed all of her treatments, write them down in the order in which they were performed.

- Opération (questions F14 F15 F16)
- Chemotherapy (question F21)
- Radiation therapy (question F23)
- Hormone therapy (question F25)

F16. Did you then have another breast operation?

- 1. Yes to remove cancer
- 2. Yes for reconstruction
- 3. Yes for both
- 4. No
- 98. Don't wish to answer
- 99. Don't know

BREAST CANCER GRID COLUMN 9

lf F16=1, 2 or 3

G34. In which year did the other operation take place? (Column 9.2)

Therefore the interviewer: For each operation, indicate whether it is a mastectomy (Note OP2 Ma) or reconstruction (example OP2 Rec) or both (OP2 MaRec).

Interviewer: Check that there was no breast reconstruction from the first operation, if this is the case note Rec in the grid next to the 1st operation

Take the question again for each operation

F17. Can you tell me what breast surgeries you ultimately had as part of your cancer treatment?

Interviewer: adapt the vocabulary to the woman surveyed: the word "amputation" is often used by African patients, but not by women born in France. Another formulation: "part of your breast/all of your breast has been removed".

- 1. Partial mastectomy of one of the breasts (lumpectomy, quadrantectomy)
- 2. Partial mastectomy of both breasts (lumpectomy, quadrantectomy)
- **3.** Total mastectomy of one of the breasts
- **4.** Total mastectomy for both breasts
- 5. Partial mastectomy of one breast and total mastectomy of the second breast
- 99. Don't know

F17bis.Remind me, did you have breast reconstruction during your breast surgery(s)?

Interviewer: F17bis = check on the grid and validate with the respondent
 1. Yes -> Upgrade to F20

2. No → Skip to F18

Article 99. Don't know how → to switch to F18

F18. Have you been offered breast reconstruction that you have not done?

- 1. Yes and you have accepted it and it is programmed → Switch to F20
- 2. Yes, but you refused it
- 3. No, we didn't offer it to you → Switch to F20
- 99. Don't know how → to switch to F20

F19. For what reason(s) did you refuse breast reconstruction?

TIN PLAIN LANGUAGE:

.....

F20. Did you have any physical difficulties in the year following the operation(s)?

Interviewer: ask the patient to answer yes/no to each modality

	-
Several	
possible	
answers	

- 2. Pain?
- e **3.** Difficulties in carrying?

1.

- 4. Discomfort in everyday gestures?
- 5. Swollen arm?

Fatigue?

- 6. Other, please specify
- 7. No, no difficulty?

F21. Have you been told that chemotherapy should be done for cancer treatment?

- 1. Yes, we told you and you made it -> Go to G35
- 2. Yes, we told you and it's programmed → Switch to F23
- 3. Yes, you were told but you refused it
- 4. No, we didn't tell you Switch → to F23
- 99. Don't know how → to switch to F23

F22. Why did you refuse chemotherapy?

TIN PLAIN LANGUAGE:

.....

.....

BREAST CANCER GRID COLUMN 9

lf **F21=1**

G35. In which year(s) did chemotherapy take place? (Column 9.2)

Interviewer: Write down CHIMIO the years in which the respondent reports chemotherapy

F23. Have you been told that radiation therapy is required as part of your treatment?

Therviewer: Brachytherapy is a form of radiotherapy. Check yes if the respondent is talking about brachytherapy.

- 1. Yes, we told you and you made it → Go to G36
- 2. Yes, we told you and it's programmed → Switch to F25
- 3. Yes, you were told but you refused it
- 4. No, we didn't tell you Switch \rightarrow to F25
- 99. Don't know how → to switch to F25

F24. Why did you refuse radiotherapy?

TIN PLAIN LANGUAGE:

.....

BREAST CANCER GRID COLUMN 9

If **F23=1**

G36. In which year(s) did the radiotherapy take place? (Column 9.2)

- Interviewer: Note "RADIO" the years in which radiation therapy was received
- Interviewer: if there was Chemo and Radio in the same year, note in the order in which they were done: e.g. "RADIO-CHIMIO" if the X-ray preceded the chemo

F25. Have you been told that you need hormone therapy as part of your treatment?

- Interviewer: treatment to be taken every day for 5 to 10 years: Tamoxifen, Nolvadex, Aromasine, Arimidex, Femara, Zoladex, Decapeptyl, Anaxtrozole...
 - 1. Yes and you continue to take this treatment
 - 2. Yes, but it's over
 - **3.** Yes, but you stopped taking it before the scheduled date
 - 4. Yes and it is programmed → to switch to F28
 - 5. Yes but you refused to take this treatment → Switch to F27
 - 6. No, we didn't tell you Switch → to F28
 - 7. No because not concerned → Switch to F28
 - 98. Don't want to answer → Skip to F28
 - 99. Don't Know → How to Switch to F28

BREAST CANCER GRID COLUMN 9

If F25=1, 2, 3 G37. In which year(s) did the hormone therapy take place? (Column 9.2)

19

Interviewer: Write down "HORMO" the year in which hormone therapy began, indicate with an arrow the beginning and end of the period.

lf **F25=3**

F26. Why did you stop taking hormone therapy?

IN PLAIN LANGUAGE

.....

lf F25=5

F27. Why did you refuse to take hormone therapy?

IN PLAIN LANGUAGE

.....

.....

F28. Following your treatment (operations, radiotherapy, hormone therapy, chemotherapy, etc.), Have you been limited, <u>at least 6 months</u>, in the activities you usually did?

- 1. Yes severely limited
- 2. Yes, limited but not strongly
- 3. No, not limited at all → Switch to F29

BREAST CANCER GRID COLUMN 9

If F28=1 or 2,

G38. Can you tell me when these limitation periods took place? (Column 9.3)

Interviewer: Draw arrows for all the periods concerned: code 1 strong limitation, code 2 medium limitation

F29. Following your breast disease, have you had any rehabilitation or training sessions? Physiotherapy for your arm?

- **1.** Yes
- 2. No

Several

possible

answers

- 98. Don't want to answer
- 99. Don't know

F30. Following your breast disease, have you resorted to:

Therviewer: Ask the person to answer yes/no to each modality

- 1. A nutritionist?
- 2. A psychologist?
- 3. Social support?
- 4. Adapted physical activity?
- 5. Pain management?
- 6. A beautician?
- 7. Art therapy?
- 8. A support group?
- 9. A therapeutic education workshop?

10. To something else, *Specify*

11. No, none of that

F31. Have you been cared for only at this centre since your diagnosis (at follow-up with a doctor specializing in cancer)?

- **1.** Yes, only in this center
- 2. No, in another centre too
- 98. Don't want to answer
- 99. Don't know

F32. To come to the hospital today, have you had a reimbursement of your expenses for the transport ?

- **1.** Yes, you have received a paper from the hospital
- 2. Yes, it is covered by your mutual insurance company
- 3. No, you paid yourself
- 4. Not concerned (coming on foot)
- 98. Don't want to answer

F33. Have you ever had a doctor or medical staff treat you worse? or receive you worse than other patients?

- **1.** Yes
- 2. No → Skip to H1
- **98.** Don't want to answer → Skip to H1
- 99. Don't Know → How to Switch to H1

F34. In your opinion, was this behaviour related to...

- 1. Your gender?
- 2. Your state of health or a disability?
- 3. Your skin color?
- 4. Your origins or your nationality?
- 5. Your religion?
- 6. Your age?
- 7. Other Specify.....
- 98. Don't want to answer
- 99. Don't know

TO ALL WOMEN

COVID PERIOD

We will now talk about the COVID-19 period.

H1. Since the beginning of the Covid pandemic and until today, have you had some care that has been <u>Deferred</u> because of Covid (postponed to later, but which have had a good place):

- **1.** Medical consultations with your oncologist?
- 2. Medical consultations with your GP?
- 3. Medical consultations with other health professionals (psychologists, dieticians, nurses, etc.)?

21

Several possible answers

Several

possible

answers

- 4. Tests that you were prescribed?
- 5. Surgical operations that were scheduled?
- 6. Other Specify
- 7. No no care postponed

H2. Since the beginning of the Covid pandemic and until today, have you had some care that has been <u>Cancelled</u> because of Covid (which were scheduled but did not finally took place):

- Several possible answers
- 1. Medical consultations with your oncologist?
- **2.** Medical consultations with your GP?
 - 3. Medical consultations with other health professionals (psychologists, dieticians, nurses, etc.)?
 - 4. Tests that you were prescribed?
 - 5. Surgical operations that were scheduled?
 - 6. Other Specify
 - 7. No no treatment cancelled

H3. Have you been vaccinated against COVID-19?

- **1.** No
- 2. Yes, you have received one dose
- 3. Yes, you have received two doses
- 4. Yes, you have received three or more doses
- 98. Don't wish to answer
- 99. Don't Know

TO ALL WOMEN

ECONOMIC CONSEQUENCES

We will now talk about the economic consequences of the disease in your life.

11. Were you employed at the time of your diagnosis?

- **1.** Yes
- 2. No → Upgrade to I4
- 98. Don't want to answer → Switch to I4

12. Have you experienced one or more sick leaves related to the diagnosis of your disease?

- 1. Yes one stop → Proceed to G39
- 2. Yes, multiple stops → Skip to G39
- 3. No, no sick leave
- 98. Don't want to answer

ACTIVITIES COLUMN 2.4 WORKSHEET

G39. Can you tell me the years in which you had sick leave of 30 days or more?

Interviewer: Note the years "STOP"

Several possible

answers

13. Compared to the job you held at the time of your diagnosis, Have you experienced any changes to your schedule in terms of:

- **1.** Type of work
- 2. Working conditions
- 3. Working time (therapeutic part-time, part-time, etc.)
- 4. Working hours
- 5. Safety at work
- 6. Place of work (transfer)
- 7. Other
- 8. No, no changes
- 99. Don't know

TO ALL WOMEN

- 14. Do you think that since the diagnosis of your disease, your household income:
 - 1. Have increased significantly
 - 2. Have increased a little
 - **3.** Have not changed
 - 4. Have decreased a little
 - 5. Have decreased significantly
 - 98. Don't want to answer
 - 99. Don't know

15. Currently, would you say that financially:

- 1. You are comfortable
- 2. That's right, you have to be careful
- 3. You can hardly do it
- 4. You can't do it without going into debt
- 98. Don't want to answer
- 99. Don't know

16. In the <u>Last 12 months</u>, did you have any out-of-pocket expenses, i.e. concerning the management of your cancer, which have not been reimbursed?

- **1.** Yes
- 2. No → Upgrade to I8
- 98. Don't want to answer → Upgrade to I8
- 99 Don't know → Upgrade to I8

17. These expenses concerned:

- 1. Physiotherapy session
- 2. Psychological or social support
- **3.** Other so-called supportive care (acupuncture, pain management, nutrition, adapted physical activity, etc.)
- 4. Fee overruns
- 5. Prostheses
- 6. Medications
- 7. Analytics

Several

possible

answers

- **8.** An operation
- 9. Other, specify.....

18. That <u>Month</u>, is there any care that you have not been able to provide (consultations, examinations, drugs, prostheses, other) due to a lack of financial means?

- **1.** Yes
- 2. No → Upgrade to I10
- 98. Don't want to answer → Upgrade to 110
- 99 Don't know → Upgrade to 110
- 19. If yeswhich?

110. Do you currently have recognition of the status of disabled worker (RQTH)?

- **1.** Yes
- 2. No
- 98. Don't want to answer
- 99 Don't know

111. Following the diagnosis, do you receive the disabled adult allowance (AAH)?

AAH: financial aid granted to people over 20 years of age living in France who have a disability rate of at least 50% and a long-term restriction of access to employment that cannot be compensated for by workplace adaptation measures. Means-tested.

- 1. Yes, still in progress
- 2. Yes, touched but no longer touched
- 3. No, never
- 98. Don't wish to answer
- 99. Don't Know

TO ALL WOMEN

SEXUALITY, HEALTH, WELL-BEING

Day 1. Overall, do you think your health today is:

- 1. Very good
- 2. Good
- 3. Fairly good
- **4.** Bad
- 5. Very poor
- 99. Don't know

Day 2. Do you have any other disease or health problem that is chronic or Sustainability?

Interviewer: an illness that lasted at least 6 months

- **1.** Yes
- 2. No → Skip to D4
- 98. Don't want to answer → Skip to D4
- 99. Don't know how → to switch to D4

Day 3. If yes, which one/s?

- 1. Asthma
- 2. Other respiratory diseases (chronic bronchitis, etc.)
- 3. Hypertension

Several

possible answers

- 4. Heart disease (angina, heart attack)
- 5. Diabetes
- 6. Digestive disorders
- 7. Gynecological disorders
- 8. Joint problems, rheumatism
- 9. Anxiety
- 10. Depression
- **11.** HIV
- **12.** Chronic liver diseases
- **13.** Chronic kidney disease
- 14. Physical disabilities or physical problems
- 15. Mental disability or other psychiatric disorders
- 16. Obesity
- 17. Diarrhoea
- 18. Other cancer, please specify
- 19. Other pathologies, please specify

Day 4. Do you smoke, even if only from time to time?

Interviewer: concerns cigarettes, cigars, cigarillos, pipes, hookahs or shisha pipes, but not

electronic cigarettes.

- **1.** Yes, every day
- 2. Yes, less often
- 2. No, never

Day 5. How often do you currently drink alcohol, whether it's wine, Beer or hard liquor?

- 1. You never drink alcohol
- 2. 1 time per month or less
- **3.** 2 to 4 times a month
- 4. 2 to 3 times a week
- 5. At least four times a week

TO ALL WOMEN

RELATIONSHIP TO THE BODY: BODY IMAGE SCALE

I'm now going to ask you a few questions about how you perceive your physical appearance, your body. <u>During **the past week**</u>:

Interviewer: Present the rulers and emphasize the <u>last week</u> and the methods of response.

	Not at all	A little	Quite often	Often	
K1. Did you feel embarrassed by your physical appearance?					
K2. Did you feel physically less seductive because of the illness or treatment?					
K3. Did you feel unhappy with your appearance, once dressed?					
Remind them of the response procedures and the week	Not at all	A little	Quite often	Often	Refusal

	Did you feel less feminine because of of the disease or the treatment?					
K5. nake	Did you have trouble looking at yourself ed?					
К6.	Did you feel sexually less attractive because of the illness or treatment?					
K7.	Have you avoided people because your Appearance bothered you?					
Rem	ind them of the response procedures and the week	Not at all	A little	Quite often	Often	Refusal
K8.	Did you experience the treatment as one Harm to your body or mutilation?					
К9.	Did you feel unhappy with your body?					
K10	. If F14=1 (operation)					

TO ALL WOMEN

MENTAL HEALTH : PHQ4 SCALE

L1. Over the past few years, <u>Last 2 weeks</u>, how often have you been disturbed by the following problems?

Interviewer: Present the rulers and insist on the <u>last 2 weeks</u> and the methods of answers.

	Never	Several days	More than half the time	Almost every day	
L1.a. A feeling of nervousness, anxiety, or of tension					
L1.b. An inability to stop worrying or control worries					
L1.c. Little interest or pleasure in doing things					
L1.d. Being sad, depressed, or hopeless					

TO ALL WOMEN

LONG RELATIONSHIPS

We will come back to your relations.

Interviewer: M1 = check in the grid and validate with the respondent

M1. Remind me, you had a relationship of at least a year at the time of diagnosis?

- **1.** Yes
- 2. No → Upgrade to U15

M2. In XXX [year of diagnosis], when you found out you had cancer:

- 1. You lived in the same country as your partner, and you lived together
- 2. You lived in the same country as your partner, but not in the same accommodation
- **3.** You didn't live in the same country
- 98. Don't wish to answer

M3. During your relationship, did you live together:

- All the time
 Yes, but not all the time
- **3.** No, never
- **98.** Don't wish to answer

M4. In which country was "Partner First Name" born?

Specify..... 99. Don't know

M5. Is " Partner First Name" younger/older than you?

- 1. Younger
- 2. Older
- 3. Approximately the same age (+/- 2 years)
- 98. Don't want to answer
- **99.** Don't Know

M6. What was the level of education of "Partner First Name" at the beginning of your relationship?

- 1. Non-schoolchildren
- 2. Primary school
- **3.** Secondary education (middle school, high school)
- 4. Higher education
- 98. Don't wish to answer
- 99. Don't Know

M7. Did you get married with " Partner First Name "?

- Interviewer: adapt the wording according to whether the relationship is ongoing or not and do not list the answers
 - **1.** Yes
 - 2. No
 - 3. Not married but in a civil partnership
 - 98. Don't want to answer

M8. Did " Partner First Name " have other stable partners during your relationship?

- **1.** Yes
- **2.** No
- 98. Don't wish to answer

99. Don't Know

M9. Did you tell " Partner First Name " that you had breast cancer?

1. Yes

2. No → upgrade to U15

98. Don't want to answer **→** switch to M15

M10. What was the first reaction of " Partner First Name " when you told him?

- 1. He/she was understanding and helped you
- 2. He/she was sad and depressed
- 3. He/she has become more distant
- **4.** He/she got angry and yelled
- 5. He/she has left you
- 6. Other, specify.....
- 7. No particular reaction
- 98. Don't wish to answer

M11. Has " Partner First Name " ever accompanied you to medical consultations in the context of your illness?

- **1.** Yes
- 2. No
- 98. Don't wish to answer
- 99. Don't Know

M12. Have you discussed with " Partner First Name " the treatments concerning you?

- **1.** Yes
- 2. No, you didn't want to
- **3.** No, you wanted to, but [first name] was reluctant
- 4. No, neither he nor you wanted to discuss it
- 98. Don't want to answer
- 99. Don't know

M13. Would you say that during your illness:

- 1. "First name" supported you
- 2. "First name" has complicated your life
- 3. Neither
- 98. Don't wish to answer
- 99. Don't Know

M14. Would you say that since the beginning of your illness, your relationship with "First Name":

- 1. Has strengthened
- 2. Has been altered
- 3. Hasn't changed
- **4.** You have separated
- 98. Don't wish to answer
- 99. Don't know

M15. <u>Before diagnosis</u>, in your home who took care of household chores (cooking, shopping, cleaning, laundry, taking care of the children):

- 1. Always you
- 2. More often than not, you

- 3. Both you and your spouse
- 4. Most often your spouse
- 5. Always your spouse
- 6. Always or most often other members of the household
- 7. Other, specify.....
- 98. Don't want to answer

M16. Since diagnosis, in your home who took care of household chores :

- 1. Always you
- 2. More often than not, you
- 3. Both you and your spouse
- 4. Most often your spouse
- 5. Always your spouse
- 6. Always or most often other members of the household
- 7. Other, specify.....
- 98. Don't want to answer

M17. Have you also received help with household activities since the diagnosis?

- 1. Yes, from relatives who live with you
- 2. Yes, from relatives who don't live with you
- 3. Yes, from a paid person
- 4. Yes, from an association
- 5. No, you didn't need it
- 6. No, but you would have needed it
- 98. Don't want to answer

M18. Do you currently live alone?

- Yes, **→ move to N1**
- **2.** No

1.

Several

possible

answers

Several

possible answers 98. Don't want to answer

M19. If not, who do you live with?

- 1. With your spouse
- 2. With your child(ren)
- 3. With other people in your family
- 4. With other people who are not related to you (friends, buddies, roommates, etc.)

TO ALL WOMEN

SEXUALITY

Now we're going to talk about your sexuality in general.

N1. Have you had sex since your cancer diagnosis?

1. Yes → Upgrade to N3

2. No→ Upgrade to N2

98. Don't want to answer → Skip to N5

N2. Would you say it's related to your illness?

- 1. Yes → Upgrade to N5
- 2. No → Upgrade to N5
- 98. Don't want to answer → Skip to N5
- 99. Don't Know → How to Switch to N5

N3. Since the diagnosis, would you say that overall the frequency of your sexual intercourse:

- 1. Decreased
- 2. Remained unchanged
- 3. Has increased
- 98. Don't want to answer
- 99. Don't know

N4. Since the diagnosis, have you experienced any <u>Periods of at least 6 months</u> where you Have you not had any sexual intercourse?

- **1.** Yes
- 2. No
- 98. Don't want to answer
- 99. Don't know

SEXUALITY GRID, column 10

If N4=1

G40. Can you tell me when it happened?

Interviewer: mark ABS the year(s) of the period

REMINDER: Until when?

Interviewer : shoot an arrow

TO ALL WOMEN

N5. Since diagnosis, your sexual desire/libido:

- 1. Decreased
- 2. Remained unchanged
- 3. Has increased
- 98. Don't want to answer
- 99. Don't know

N6. Since diagnosis, your ability to orgasm:

- 1. Decreased
- 2. Remained unchanged
- 3. Has increased
- 98. Don't want to answer
- 99. Don't know

N7. Since the diagnosis, have you been to a consultation with a sexologist?

- 1. Yes
- 2. No, we didn't offer it to you
- 3. No, you were offered it but you didn't see the point/ you didn't want to
- 98. Don't wish to answer
- 99. Don't know

FAMILY, ENTOURAGE AND SUPPORT

We are now going to talk about your professional, friendly and family circles.

01. Are you currently employed?

- **1.** Yes
- 2. No → Skip to O3

98. Don't wish to answer → Skip to O3

02. In your current job, do you talk about your illness in your workplace?

- 1. Yes, often
- 2. Yes, from time to time
- 3. Yes, only once
- 4. No. never
- 98. Don't wish to answer
- 99. Don't Know

O3. Apart from doctors/caregivers, who are the people currently in the current of your cancer?

- 1. Your spouse
- 2. (One of your) children
- 3. Your mother Your father
- Several possible answers
- 5. Your sister(s)

4.

- 6. Your sibling(s)
- 7. Another member of your family
- 8. A friend
- 9. A social worker, an association
- **10.** Other person(s)
- 11. No one knows about it
- 98. Don't want to answer
- 99. Don't know

04. Have you ever spoken to members of associations of women living with breast cancer?

- 1. Yes
- 2. No → Skip to O6
- 98. Don't want to answer → Skip to O6
- 99. Don't know → Skip to O6

O5. Which country was it in?

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31

- 1. In your country of origin [ENQ: read only if immigrant]
- 2. In France
- Several possible answers
- 3. In another country
- **98.** Don't want to answer
- 99. Don't know

O6. In case of difficulty, do you have someone to count on?

- **1.** Yes
- 2. No → Switch to O8

98. Don't want to answer → Switch to O8

99. Don't know → Switch to O8

07. In which country is this person(s) located?

- 1. In your country of origin [ENQ: read only if immigrant]
- 2. In France
- 3. In another country
- 99. Don't know
- 98. Don't want to answer

O8. Currently, what is the importance of religion in your life?

- 1. Not at all important
- 2. A little importance
- **3.** Enough importance
- **4.** A lot of importance
- 98. Don't wish to answer
- 99. Don't know

O9. Since diagnosis, have you ever seen a psychologist to talk about your cancer?

- **1.** Yes, you were consulting him before the diagnosis
- 2. Yes, you started seeing a doctor after the diagnosis
- **3.** No
- 98. Don't want to answer
- 99. Don't know

O10. Since the diagnosis, have the doctors/caregivers suggested that you consult a psychologist?

- **1.** Yes
- 2. No
- 3. No, because they knew that you were already seeing a psychologist
- 98. Don't want to answer
- 99. Don't know

CHILDREN'S DESIRE

We are going to address the question of the desire for children.

- Interviewer: if 40 years of age or older, go to P1
- Interviewer: if under 40 years of age, go to P2
- P1. At the time of diagnosis, were you menopausal?
 - **1.** Yes
 - 2. No → Move to P2
 - 98. Don't want to answer

Several possible answers 99. Don't know

P2.	Do you think that your illness has had consequences on your project to have an (other)
	child?

- 1. Yes, by strengthening it
- 2. Yes, by reducing or postponing it
- 3. Yes by cancelling it
- 4. No
- 98. Don't want to answer
- 99. Don't know
- Q1. What are the projects that are close to your heart and that you would like to realize?

⇒ Comments of the interviewer

Identification Number: |___| |___| |___|

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End time: