

BRCA1/2 Collaborative Study on Genetic Modifiers (CIMBA) – Data Fields and Format as at 22 January 2009

- Format: Access (preferred) or Excel tables
- Preferred coding in parentheses.
- Leave blank if unknown or not applicable (unless stated otherwise below)
- Ideally provide dates in dd/mm/yyyy format but if complete information does not exist please provide at least year. If day and month are missing indicate date as: 01/07/yyyy. If day only is missing indicate date as: 15/mm/yyyy.

Required fields:

1. Study/Group
2. CIMBA Id (if one exists)
3. Country of residence
4. Ascertainment (1= Clinic, 2=Population, 3=Community)
5. Clinic or Registry of origin
6. Family id
7. Individual id
8. 1st Mutation: 1=BRCA1, 2=BRCA2 (EXCLUDE UVs)
9. BIC genomic nomenclature for 1st Mutation
10. HGVS genomic nomenclature for 1st Mutation
11. 2nd Mutation (if applicable): 1=BRCA1, 2=BRCA2 (EXCLUDE UVs)
12. BIC nomenclature for 2nd Mutation (if applicable)
13. HGVS genomic nomenclature for 2nd Mutation (if applicable)
14. Gender (Females only initially - code as 2)
15. Ethnicity (1= Caucasian, 2= African American, 3=Asian, 4=Hispanic, 5=Ashkenazi Jewish, 6= French Canadian, 7=Other-please specify)
16. Interview date (dd/mm/yyyy) or
17. Age at interview
18. Date of birth (dd/mm/yyyy)
19. Date of last follow up (dd/mm/yyyy) or
20. Age at last follow up
21. Date at diagnosis of first breast cancer (dd/mm/yyyy) or
22. Age at diagnosis of first breast cancer
23. First Breast Cancer type (1 = invasive, 2 = DCIS)
24. Date at diagnosis of contralateral breast cancer (dd/mm/yyyy) or
25. Age at diagnosis of contralateral breast cancer
26. Second Breast Cancer type (1 = invasive, 2 = DCIS)
27. Date at diagnosis of ovarian cancer (dd/mm/yyyy) or
28. Age at diagnosis of ovarian cancer
29. Prophylactic bilateral mastectomy (0=No, 1=Yes, 2=unknown)
30. Date at bilateral mastectomy (dd/mm/yyyy) or
31. Age at bilateral mastectomy
32. Bilateral Prophylactic oophorectomy (BPO) (0=No, 1=Yes, 2=unknown)
33. Date at BPO (dd/mm/yyyy) or
34. Age at BPO

- 35. Menopausal status (0=premenopausal, 1= postmenopausal, 2=unknown)
- 36. Age at menopause

Additional fields to be provided if available:

- 37. Parity (number of full term pregnancies)
- 38. Age at start of first full term pregnancy
- 39. Age at Menarche