

Summary of WHI National Death Index (NDI) data

The purpose of utilizing the NDI resource is to augment the WHI reported fact and cause of death when study participants stop or become lost to follow-up, or when WHI death information is incomplete for known deceased participants. In addition, death information is obtained from NDI on WHI participants who chose not to enroll in the WHI Extension studies.

The first NDI submission took place in 2000. Included were all participants either lost or who requested absolutely no follow-up, plus a random sample of known alive and deceased participants. These latter two groups were included only for use in developing a matching algorithm based on social security number, first and last name, date of birth, and other factors. The algorithm was developed using test and training sets, and resulted in both a specificity and sensitivity of 98%. This same algorithm, with minor refinement, has been used for all subsequent NDI submissions.

Submissions also occurred in 2004 and 2005, and included only participants either lost or who requested absolutely no follow-up. Additional submissions occurred in 2010 and 2013 and annually or biannually starting in 2015. The 2010-2018 submissions included WHI participants not enrolled in the Extension studies and known to be alive at their last study contact. Also sent were participants known to be deceased but with a cause of death on Form 124 recorded as “unknown”, “other cancer” or “other cardiovascular”; “other injury” was added in 2016. Beginning in 2013, deceased participants with a Form 120 collected but no Form 124 were also included in the submissions for the WHI, Extension 1, and Extension 2 (SRC only) studies.

Starting in 2022, all WHI participants that were not marked as dead and had no contact in the past year were included in the early release searches.

The specific cause of death, obtained through the NDI search and matching algorithm, was then recorded on a Form 124 in the WHI database.

Below is a table of all NDI searches performed to date. “Search Years” are based on the last contact date or death date through the year of available NDI data.

Summary of NDI Searches

Submission Year	NDI Release	Search Years		Criteria for NDI inclusion	Number of participants sent	Number found dead*
		From	To			
2000	Full 1999	1993	1999	Known dead	467	
		1993	1999	Full follow-up	1252	1
		1993	1999	Lost or Absolutely no follow-up	2282	23
2004	Full 2002	1995	2002	Lost or Absolutely no follow-up	3647	70
2005	Full 2003	1995	2003	Lost or Absolutely no follow-up	4322	52
2010	Full 2008	1997	2008	Known dead	566	
		1994	2008	Not enrolled in Extension study; Lost or Absolutely no follow-up	35485	3287

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Submission Year	NDI Release	Search Years		Criteria for NDI inclusion	Number of participants sent	Number found dead*
		From	To			
2013	Full 2011	1995	2011	Known dead	2656	
		2004	2011	Not enrolled in Extension study; Lost or Absolutely no follow-up	44785	4480
2015	Full 2013	1995	2013	Known dead	3445	
		2004	2013	Not enrolled in Extension study; Lost or Absolutely no follow-up	44718	4526
2016	Full 2014	1995	2014	Known dead	2064	
		2011	2014	Not enrolled in Extension study; Lost or Absolutely no follow-up	43380	2137
2017	Full 2015	1996	2015	Known dead	2402	
		2012	2015	Not enrolled in Extension study; Lost or Absolutely no follow-up	42131	2443
2018 (Feb)	Full 2016	1996	2016	Known dead	3129	
		1996	2016	Not enrolled in Extension study; Lost or Absolutely no follow-up	36260	2229
2018 (Nov)	Full 2017	1995	2017	Known dead	2709	
		2016	2017	Not enrolled in Extension study; Lost or Absolutely no follow-up	46398	2469
2019	Full 2018	1996	2018	Known dead	3157	
		2016	2018	Not enrolled in Extension study; Lost or Absolutely no follow-up	38763	2402
2020 (Oct)	Early 2019	2019	2019	Known dead, MRC only, no Death Certificate	53	
		2019	2019	Lost	9779	181
2020 (Dec)	Full 2019	2019	2019	Known dead (2019 deaths only)	3231	
		2017	2019	Lost (all)	37885	2178
2021	Early 2020	2020	2020	Known dead	2609	
		2020	2020	Lost	35838	2433
2022 (Jan)	Full 2020	2015	2020	Known dead	874	
		2019	2020	Lost	33008	701
2022 (Apr)	Early 2021	2021	2021	Known dead	3283	
		2021	2021	Lost	70095	2928
2023 (Jan)	Full 2021	2010	2021	Known dead	716	
		1994	2021	Lost	31008	404
2023 (Mar)	Early 2022	2022	2022	Known dead	2229	
		2022	2022	Lost	71754	3370
2024 (Apr)	Full 2022	2022	2022	Lost (rerun of Early)	71754	377
2024 (Apr)	Early 2023	2023	2023	Known dead	3151	
		2023	2023	Lost	62265	2873
2024 (Nov)	Full 2023	2023	2023	Lost (rerun of Early)	62265	283

* Not previously known to be dead

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Using the data from NDI:

The NDI agreement allows WHI to obtain death information on those participants who did not re-consent to participate in the Extension studies. However, this “waiver of consent” does not allow any other retrospective data collection on these participants.

For use in statistical analyses, this data should only be used when death is the outcome of interest. Events from cause of death that occur after a participant’s consent period should not be incorporated into the corresponding outcome (e.g., breast cancer or CHD) since ascertainment of non-fatal outcomes after the consent period but prior to death is not possible.