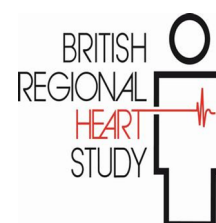# Follow-up non-fatal and fatal events (Q40Qr-RR24)

collected through the BRHS General Practice (GP) Record Review (RR)
and death notifications through Central Registries

Derived dataset: BRHS EventOutcomes Q40Qr_RR24.dat

Follow-up period Q40Qr-RR24:
40-year follow-up Questionnaire (Q40Qr) to 2024 GP Record Review (RR24)

Dataset description

A total of 1,009 cohort participants completed the 40-year follow-up questionnaire and are included in this dataset.

The dataset includes data on morbidity and mortality events (listed below) identified through the BRHS General Practice (GP) Record Review (RR) and death notifications from central registries. Events refer to those that occurred for the first time (first events) during the follow-up period.

To protect confidentiality, dates of death have been perturbed by adding a random number of days between 1 and 14 to each original date.

What is included in the dataset:

Event types for which data are available in this follow-up period and are included in this dataset are:

1) Myocardial Infarction (MI)	(non-fatal + fatal events)
2) Angina	(non-fatal events)
3) Heart failure	(non-fatal events)
4) Stroke	(non-fatal + fatal events)
5) Transient Ischaemic Attack	(non-fatal events)
6) CVD (MI or Stroke)	(non-fatal + fatal events)
7) Diabetes	(non-fatal events)
8) Atrial fibrillation (AF)	(non-fatal events)
9) Peripheral Vascular Disease (PVD)	(non-fatal events)
10) Pulmonary Embolism (PE)	(non-fatal events)
11) Deep Vein Thrombosis (DVT)	(non-fatal events)
12) Coronary artery bypass graft (CABG) or Percutaneous transluminal coronary angioplasty (PTCA)	(non-fatal events)
13) Vascular Dementia	(non-fatal events)
14) Alzheimer's disease	(non-fatal events)
15) Other Dementia (Mixed type dementia, Lewy body, Parkinsons, Alcohol related, Other type, Type not known)	
16) Any Type of Dementia (any of Vascular, Alzheimer's + Other Dementia)	

Data variables included for each event type are:

1) start and end date of the follow-up period
2) event prevalence at start of follow-up period
3) event occurrence status in follow-up period (none, non-fatal, fatal)
4) event date of the first non-fatal or fatal event occurring in the follow-up period
5) death date from any cause of death (for censoring)
6) censoring date (date of death or of exiting the study)

Detailed information can be found in table 1 below.

1. The follow-up period (Q40Qr-RR24)

Each BRHS participant's follow-up period <u>begins</u> on the date they completed the 40-year follow-up questionnaire (Q40Qr; 2018–2019) and <u>ends</u> on the GP Record Review (RR24) end date, 30 July 2024.

2. Prevalence

Prevalence data are based on GP Record Review events occurring prior to the date of completion of the 40-year follow-up Questionnaire (Q40Qr) in 2018-2019.

3. First events (combined non-fatal and fatal events)

The events included in this dataset refer to the **first occurrence** of a non-fatal or fatal event during the follow-up period. Some event types, such as myocardial infarction (MI), may occur more than once (multiple non-fatal events) for a participant during follow-up. However, only the **first event—whether non-fatal or fatal—is included under the first event data**.

4. Non-fatal events

The GP Record Review process and diagnostic criteria

The GP Record Review process and the **diagnostic criteria** for different types of non-fatal events are described in Section 2 of **Appendix A** (*BRHS Baseline (1978–80) to 2024 GP (Primary Care) Record Review.pdf*).

Reference - British Regional Heart Study cohort profile:
The British Regional Heart Study 1975-2004. Walker M, Whincup PH, Shaper AG. International Journal of Epidemiology, Volume 33, Issue 6, December 2004, Pages 1185–1192, https://doi.org/10.1093/ije/dyh295.

5. Fatal events

Follow-up of fatal events has been through central registers (the Office of Population and Census Surveys (OPCS), Health and Social Care Information Centre (HSCIC) and more recently NHS Digital). All BRHS cohort participants (n=7735) have been flagged for death notifications through Central Registries in England and Scotland since the study baseline (1978-80). Information is received on the date of death, and coded cause of death - International Classifications of Disease codes (ICD9, ICD10).

Fatal events MI, Stroke and CVD (combined MI and CVD) are derived based on the following ICD 9 codes:

Myocardial Infarction (MI):	(ICD9 410 – 4149)
Stroke:	(ICD9 430 – 4389)
CVD (MI or Stroke):	(ICD9 (ICD9 410 – 4149) or (ICD9 430 – 4389)

6. Date of death

Date of death from any cause. To reduce the risk of re-identification, dates of death have been perturbed by adding a random number of days between 1 and 14 to each original date.

7. Cause of death categories – see categories in table below

8. Censoring date

Date when the participant was lost to follow-up, withdrew from the study, or died from any cause.
Dates of death, where included, have been perturbed to reduce the risk of re-identification.

9. Non-fatal and fatal event date

This variable contains the date of a combined outcome—either a fatal or non-fatal event. To protect confidentiality, the dates of fatal events have been perturbed by adding a random number of days between 1 and 14 to each original date.

Table 1: Follow-up non-fatal and fatal events: 40-year follow-up Questionnaire (Q40Qr) 2018-19 to 2024 GP Record Review (RR24)

Variable description	Units/Category labels	BRHS Variable name
Start of Follow-up period Q40Qr to RR24		
Start date: 40year follow-up Questionnaire Completion Date: Day	Start date (Day) of Follow-p	Q40Qr_day
Start date: 40year follow-up Questionnaire Completion Date: Month	Start date (Month) of Follow-p	Q40Qr_month
Start date: 40year follow-up Questionnaire Completion Date: Year	Start date (Year) of Follow-p	Q40Qr_year
End of Follow-up period Q40Qr to RR24		
End date: GP Record review end date: Day	End date (Day) - End of follow-up	RR24date_d
End date: GP Record review end date: Month	End date (Month) - End of follow-up	RR24date_m
End date: GP Record review end date: Year	End date (Year) - End of follow-up	RR24date_y
Cause of death		
Cause of death category	1= Major CHD/MI death (ICD-9 codes :410 – 4149)	cdeath
	2= Stroke death (ICD-9 codes: 430 – 4389)	
	3= Other CVD death (ICD-9 codes: 390 – 459	
	(excluding 410-4149 and 430-4389))	
	4= Non-CVD deaths all other ICD-9 codes	
	(i.e. excluding all ICD codes listed in 1-3)	
	8 = Died abroad - Cause unknown	
	9 = Alive	
	10 = Lost to follow-up	
Death date during follow-up period Q40Qr to RR24 **(Note: Dates of death have been perturbed)**		
Death date (from any cause): Day	Day	PdeathQ40Qr_RR24_d
Death date (from any cause): Month	Month	PdeathQ40Qr_RR24_m
Death date (from any cause): Year	Year	PdeathQ40Qr_RR24_y
Censoring date during follow-up period Q40Qr to RR24 (Date when was lost to follow-up, withdrew from the BRHS study or died from any cause) **(Note: Dates of death have been perturbed)**		
Censoring date: Day	Day	PCensoredDate_d
Censoring date: Month	Month	PCensoredDate_m
Censoring date: Year	Year	PCensoredDate_y

BRHS (first) non-fatal and fatal event events Q40Qr-RR24 - Derived dataset: BRHS EventOutcomes Q40Qr_RR24.dat

Myocardial infarction (MI) fatal and non-fatal events	Units/Category labels	BRHS Variable name
MI prevalence at Q40Qr (MI event prior to Q40Qr (Questionnaire completion date))	0=No MI event prior to Q40Qr 1=Prevalent MI. (An MI event occurred prior to Q40Qr)	Q40QrRRprevmi
MI status in period Q40Qr to RR24	1=No MI event during Q40Qr-RR24 2=Non-fatal MI event occurred during Q40Qr-RR24 3=Fatal MI event occurred during Q40Qr-RR24 4=non-fatal event followed by a fatal MI event during Q40Qr-RR24	miQ40Qr_RR24
Note: Dates for fatal events have been perturbed		
First MI event during period Q40Qr to RR24 Date: Day First MI event during period Q40Qr to RR24 Date: Month First MI event during period Q40Qr to RR24 Date: Year	Day Month Year	fmiQ40Qr_RR24d fmiQ40Qr_RR24m fmiQ40Qr_RR24y
MI death during Q40Qr-RR24 (MI deaths= Cause of death: ICD9 codes: 410 – 4149)	0=No, 1=yes	mideathQ40Qr_RR24
MI death event during period Q40Qr to RR24 Date: Day MI death event during period Q40Qr to RR24 Date: Month MI death event during period Q40Qr to RR24 Date: Year	Day Month Year	mideathQ40Qr_RR24_d mideathQ40Qr_RR24_m mideathQ40Qr_RR24_y
Stroke fatal and non-fatal events		
Stroke prevalence at Q40Qr (i.e. Stroke event prior to Q40Qr (Questionnaire completion date))	0=No Stroke event prior to Q40Qr 1=Prevalent Stroke. (A stroke event occurred prior to Q40Qr)	Q40QrRRprevST
Stroke status in period Q40Qr to RR24	1=No Stroke event during Q40Qr-RR24 2=Non-fatal Stroke event occurred during Q40Qr-RR24 3=Fatal Stroke event occurred during Q40Qr-RR24 4=non-fatal event followed by a fatal Stroke event during Q40Qr-RR24	STQ40Qr_RR24
Note: Dates for fatal events have been perturbed		
First Stroke event during period Q40Qr to RR24 Date: Day First Stroke event during period Q40Qr to RR24 Date: Month First Stroke event during period Q40Qr to RR24 Date: Year	Day Month Year	fSTQ40Qr_RR24d fSTQ40Qr_RR24m fSTQ40Qr_RR24y
Stroke death during Q40Qr-RR24 (Stroke deaths=Cause of death: ICD9 codes: 430 – 4389)	0=No, 1=yes	STdeathQ40Qr_RR24
Stroke death event during period Q40Qr to RR24 Date: Day Stroke death event during period Q40Qr to RR24 Date: Month Stroke death event during period Q40Qr to RR24 Date: Year	Day Month Year	STdeathQ40Qr_RR24_d STdeathQ40Qr_RR24_m STdeathQ40Qr_RR24_y

Transient ischaemic attack (TIA) events	Units/Category labels	BRHS Variable name
Definite TIA status in period Q40Qr to RR24	0=No definite TIA event prior to Q40Qr 1=Prevalent definite TIA. (An event occurred prior to Q40Qr) 2=Incident definite TIA event after Q40Qr	DefTIAQ40Qr_RR24
First Definite TIA event during period Q40Qr to RR24 Date: Day First Definite TIA event during period Q40Qr to RR24 Date: Month First Definite TIA event during period Q40Qr to RR24 Date: Year	Day Month Year	fDefTIAQ40Qr_RR24d fDefTIAQ40Qr_RR24m fDefTIAQ40Qr_RR24y
CVD (MI or Stroke) fatal and non-fatal events		
CVD prevalence at Q40Qr (CVD event prior to Q40Qr (Questionnaire completion date)) (CVD is defined as an MI or a Stroke event)	0=No CVD event prior to Q40Qr 1=Prevalent CVD. (A CVD event occurred prior to Q40Qr)	Q40QrRRprevCVD
CVD status in period Q40Qr to RR24	1=No CVD event during Q40Qr-RR24 2=Non-fatal CVD event occurred during Q40Qr-RR24 3=Fatal CVD event occurred during Q40Qr-RR24 4=non-fatal event followed by a fatal CVD event during Q40Qr-RR24	CVDQ40Qr_RR24
Note: Dates for fatal events have been perturbed		
First CVD event during period Q40Qr to RR24 Date: Day First CVD event during period Q40Qr to RR24 Date: Month First CVD event during period Q40Qr to RR24 Date: Year	Day Month Year	fCVDQ40Qr_RR24d fCVDQ40Qr_RR24m fCVDQ40Qr_RR24y
CVD death during Q40Qr-RR24 CVD deaths=Cause of death: ICD9 codes: 410 – 4149 or 430 - 4389	0=No, 1=yes	CVDdeathQ40Qr_RR24
CVD death event during period Q40Qr to RR24 Date: Day CVD death event during period Q40Qr to RR24 Date: Month CVD death event during period Q40Qr to RR24 Date: Year	Day Month Year	CVDdeathQ40Qr_RR24_d CVDdeathQ40Qr_RR24_m CVDdeathQ40Qr_RR24_y
Angina events	**Units/Category labels**	**BRHS Variable name**
Angina status in period Q40Qr to RR24	0=No Angina event prior to Q40Qr 1=Prevalent Angina. (An event occurred prior to Q40Qr) 2=Incident Angina event after Q40Qr	ANGINAQ40Qr_RR24
First Angina event during period Q40Qr to RR24 Date: Day First Angina event during period Q40Qr to RR24 Date: Month First Angina event during period Q40Qr to RR24 Date: Year	Day Month Year	fANGINAQ40Qr_RR24d fANGINAQ40Qr_RR24m fANGINAQ40Qr_RR24y

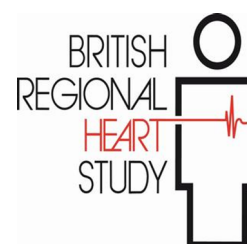| **Heart failure (HF) (non-fatal events)**		
Heart failure (HF) status in period Q40Qr-RR24	0=No Heart failure event prior to Q40Qr 1=Prevalent Heart failure. (An event occurred prior to Q40Qr) 2=Incident Heart failure event after Q40Qr	HeartFailQ40Qr_RR24
First Heart Failure (HF) event during period Q40Qr to RR24 Date: Day	Day	fHeartFailQ40Qr_RR24d
First Heart Failure (HF) event during period Q40Qr to RR24 Date: Month	Month	fHeartFailQ40Qr_RR24m
First Heart Failure (HF) event during period Q40Qr to RR24 Date: Year	Year	fHeartFailQ40Qr_RR24y
Diabetes events		
Diabetes status in period Q40Qr to RR24	0=No Diabetes event prior to Q40Qr 1=Prevalent Diabetes. (An event occurred prior to Q40Qr) 2=Incident Diabetes event after Q40Qr	DIABQ40Qr_RR24
First Diabetes event during period Q40Qr to RR24 Date: Day	Day	fDIABQ40Qr_RR24d
First Diabetes event during period Q40Qr to RR24 Date: Month	Month	fDIABQ40Qr_RR24m
First Diabetes event during period Q40Qr to RR24 Date: Year	Year	fDIABQ40Qr_RR24y
Atrial fibrillation (AF) events		
Atrial fibrillation (AF) status in period Q40Qr to RR24	0=No AF event prior to Q40Qr 1=Prevalent AF. (An event occurred prior to Q40Qr) 2=Incident AF event after Q40Qr	AFQ40Qr_RR24
First Atrial fibrillation (AF) event during period Q40Qr to RR24 Date: Day	Day	fAFQ40Qr_RR24d
First Atrial fibrillation (AF) event during period Q40Qr to RR24 Date: Month	Month	fAFQ40Qr_RR24m
First Atrial fibrillation (AF) event during period Q40Qr to RR24 Date: Year	Year	fAFQ40Qr_RR24y
Coronary artery bypass graft (CABG) or Percutaneous transluminal coronary angioplasty (PTCA)		
(CABG)/(PTCA) status in period Q40Qr to RR24	0=No (CABG)/(PTCA) event prior to Q40Qr 1=Prevalent (CABG)/(PTCA). (An event occurred prior to Q40Qr) 2=Incident (CABG)/(PTCA) event after Q40Qr	CABGPTCAQ40Qr_RR24
First (CABG)/(PTCA) event during period Q40Qr to RR24 Date: Day	Day	fCABGPTCAQ40Qr_RR24d
First (CABG)/(PTCA) event during period Q40Qr to RR24 Date: Month	Month	fCABGPTCAQ40Qr_RR24m
First (CABG)/(PTCA) event during period Q40Qr to RR24 Date: Year	Year	fCABGPTCAQ40Qr_RR24y

Pulmonary Embolism (PE) events		
Pulmonary Embolism (PE) status in period Q40Qr to RR24	0=No PE event prior to Q40Qr 1=Prevalent PE. (An event occurred prior to Q40Qr) 2=Incident PE event after Q40Qr	PEQ40Qr_RR24
First Pulmonary Embolism event during period Q40Qr to RR24 Date: Day First Pulmonary Embolism event during period Q40Qr to RR24 Date: Month First Pulmonary Embolism event during period Q40Qr to RR24 Date: Year	Day Month Year	fPEQ40Qr_RR24d fPEQ40Qr_RR24m fPEQ40Qr_RR24y
Peripheral Vascular Disease (PVD) events		
PVD status in period Q40Qr to RR24	0=No PVD event prior to Q40Qr 1=Prevalent PVD. (An event occurred prior to Q40Qr) 2=Incident PVD event after Q40Qr	PVDQ40Qr_RR24
First PVD event during period Q40Qr to RR24 Date: Day First PVD event during period Q40Qr to RR24 Date: Month First PVD event during period Q40Qr to RR24 Date: Year	Day Month Year	fPVDQ40Qr_RR24d fPVDQ40Qr_RR24m fPVDQ40Qr_RR24y
Deep Vein Thrombosis (DVT) events		
DVT status in period Q40Qr to RR24	0=No DVT event prior to Q40Qr 1=Prevalent DVT. (An event occurred prior to Q40Qr) 2=Incident DVT event after Q40Qr	DVTQ40Qr_RR24
First DVT event during period Q40Qr to RR24 Date: Day First DVT event during period Q40Qr to RR24 Date: Month First DVT event during period Q40Qr to RR24 Date: Year	Day Month Year	fDVTQ40Qr_RR24d fDVTQ40Qr_RR24m fDVTQ40Qr_RR24y

Vascular Dementia events (BRHS event code H1)		
Vascular Dementia (VD) status in period Q40Qr to RR24	0=No VD event prior to Q40Qr 1=Prevalent VD. (A VD event occurred prior to Q40Qr) 2=Incident VD event after Q40Qr	VDEMENTQ40Qr_RR24
First Vascular Dementia (VD) event during period Q40Qr to RR24 Date: Day	Day	fVDEMENTQ40Qr_RR24d
First Vascular Dementia (VD) event during period Q40Qr to RR24 Date: Month	Month	fVDEMENTQ40Qr_RR24m
First Vascular Dementia (VD) event during period Q40Qr to RR24 Date: Year	Year	fVDEMENTQ40Qr_RR24y
Alzheimer's disease events (BRHS event code H2)		
Alzheimer's (ALZH) status in period Q40Qr to RR24	0=No ALZH event prior to Q40Qr 1=Prevalent ALZH. (An ALZH event occurred prior to Q40Qr) 2=Incident ALZH event after Q40Qr	ALZHQ40Qr_RR24
First Alzheimer's (ALZH) event during period Q40Qr to RR24 Date: Day	Day	fALZHQ40Qr_RR24d
First Alzheimer's (ALZH) event during period Q40Qr to RR24 Date: Month	Month	fALZHQ40Qr_RR24m
First Alzheimer's (ALZH) event during period Q40Qr to RR24 Date: Year	Year	fALZHQ40Qr_RR24y
Other Dementia (BRHS event codes: HO, H3, H4, H5, H6, H8)		
Other Dementia status in period Q40Qr to RR24 (see note 1 below)	0=No Other Dementia event prior to Q40Qr 1=Prevalent Other Dementia. (Other Dem event occurred prior to Q40Qr) 2=Incident Other Dementia event after Q40Qr	OTHDEMENTQ40Qr_RR24
First Other Dementia event during period Q40Qr to RR24 Date: Day	Day	fOTHDEMENTQ40Qr_RR24d
First Other Dementia event during period Q40Qr to RR24 Date: Month	Month	fOTHDEMENTQ40Qr_RR24m
First Other Dementia event during period Q40Qr to RR24 Date: Year	Year	fOTHDEMENTQ40Qr_RR24y
Any Dementia events		
Any Type of Dementia status in period Q40Qr to RR24 (Any Type = BRHS event codes: H0, H1, H2, H3, H4, H5, H6, H8) See Note 1 below for codes	0=No "Any" Dementia event prior to Q40Qr 1=Prevalent "Any" Dementia. (An event occurred prior to Q40Qr) 2=Incident "Any" Dementia event after Q40Qr	ANYDEMENTQ40Qr_RR24
First Any type of Dementia event during period Q40Qr to RR24 Date: Day	Day	fANYDEMENTQ40Qr_RR24d
First Any type of Dementia event during period Q40Qr to RR24 Date: Month	Month	fANYDEMENTQ40Qr_RR24m
First Any type of Dementia event during period Q40Qr to RR24 Date: Year	Year	fANYDEMENTQ40Qr_RR24y

Note 1

H1=Vascular Dementia, H2=Alzheimer's, H3=Mixed Type Dementia, H4=Lewy Body Dementia, H5=Parkinsons Disease Dementia,

H6=Alcohol Related Dementia, H8=Other Type of Dementia, H0=Dementia - Type Not Known.

APPENDIX A

Follow-up of BRHS cohort participants through

General Practice (GP) records
(i.e. primary care records)

The GP (primary care) Record review

Baseline (1978-1980) to 2024 (30 July 2024)

Contents

Appendices

Follow-up of BRHS participants through primary care records. Baseline (1978-80) to 2024

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1. Follow-up of BRHS participants through primary care records

The General Practice (GP) record review

The GP record review is a review of BRHS participants' GP records (i.e. primary care records) for specified events mostly related to non-fatal cardiovascular disease, although this has subsequently been extended to include additional cardiovascular events and treatment, diabetes, cancer, dementia and frailty (table 1). The aim of the GP record review has been to identify and record the date of these events. The reviews have been carried out since baseline (1978-80) at intervals of typically every one or two years. A list of events including their definitions is provided for undertaking the review (Appendix 1). The reviewers are asked to search through the participants' medical records, identify events that match the definition terms, and record the first date of the events' occurrence on a form supplied for each participant (Record review form in Appendix 2). The start of data collection varied for different events, as shown in table 2.

Reference: The British Regional Heart Study 1975-2004. Walker M, Whincup PH, Shaper AG. International Journal of Epidemiology, Volume 33, Issue 6, December 2004, Pages 1185–1192, https://doi.org/10.1093/ije/dyh295

Table 1 Events included in the GP record review

Event type	Alternative terms used in the search	Other points noted in review
*Myocardial infarction	Heart attack, coronary thrombosis	
*Acute Coronary Syndrome	ACS	
Angina	Angina pectoris	Exertional or stress related chest pain
*Stroke	Cerebrovascular accident, CVA, cerebral thrombosis, embolism, or haemorrhage	
Transient ischaemic attack	TIA, Little / Minor Stroke	Transient cerebrovascular event (Complete recovery within 24 hours)
Diabetes	NIDDM, IDDM, Type 1 diabetes, Type 2 diabetes	
*Heart Failure	Congestive heart failure (CCF) Left ventricular failure (LVF) Pulmonary oedema	
Peripheral arterial disease	Peripheral vascular disease (PVD) Intermittent claudication Lower limb ischaemia Gangrene of foot/toes	
Abdominal Aortic aneurysm	Including complications (rupture and dissection)	
*Deep vein thrombosis (DVT)	Blood clot in the leg	
*Pulmonary embolism (PE)	Blood clot in the lung	
Atrial fibrillation (AF)		
Procedures for: Coronary Artery Bypass Graft (CABG) Coronary Angioplasty (PTCA)	Percutaneous coronary angioplasty, balloon treatment. Insertion of stents	
Cancer diagnosis and site		
Dementia - Vascular Dementia – Alzheimer Dementia - Other type Dementia - Type not known	Mixed typed, Lewy body, Parkinson's disease, Alcohol related, other type	
COVID-19		
Frailty/Frailty score	Electronic frailty index (eFI), other frailty assessment systems	

* Events requiring additional information. Reviewers are asked to complete a further enquiry form (validation form) and/or send a photocopy of the hospital summary sheet or discharge letter.

Follow-up of BRHS participants through primary care records. Baseline (1978-80) to 2024

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Table 2 Year data collection commenced for each event type

Event type	BRHS Event code	Year when data collection for events commenced*	Additional confirmatory information collected
Myocardial infarction (MI)	1	Baseline (1978)	Yes, since 1978
Angina	2	Baseline (1978)	
Stroke	3	Baseline (1978)	Yes, since 2000
Transient ischemic attack (TIA)	4	Baseline (1978)	
Coronary artery bypass graft (CABG)	5	1983	
Percutaneous transluminal coronary angioplasty, (PTCA)	7	1983	
Diabetes	6	1988	
Heart failure (HF)	D	1996	Yes, since 2000
Cancer	8	1996	
Peripheral vascular disease (PVD)	A	1998	
Deep vein thrombosis (DVT)	B	2000	Yes, since 2000
Pulmonary embolism (PE)	C	2000	Yes, since 2000
Abdominal aortic aneurysm	X	2000	
Atrial fibrillation (AF)	G	2014	
Dementia	H	2014	
Dementia - Type not known	H0		
Dementia - Vascular	H1		
Dementia - Alzheimer	H2		
Dementia - Mixed typed	H3		
Dementia - Lewy body	H4		
Dementia - Parkinson's disease	H5		
Dementia - Alcohol related	H6		
Dementia - Other type	H8		
COVID-19	Z	2020	
Frailty/Frailty score		2020	

*This is the year when data collection commenced and continued prospectively.

Note: events that occurred prior to the specified year were collected retrospectively but could only be collected for those participants who were still alive and whose GP records were available. GP records of deceased participants are not kept by the General Practices once a patient dies and therefore retrospective data collection was not possible on deceased participants.

Follow-up of BRHS participants through primary care records. Baseline (1978-80) to 2024

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2. Diagnostic criteria – definitions of non-fatal events identified through the GP record review

2.1. Myocardial Infarction

Non-fatal Myocardial Infarction events are classified as definite or possible. The case criteria for each are described below.

Definite Myocardial Infarction:

Criteria for definite Myocardial Infarction included: A history of typical features including chest pain, supported by ECG evidence consistent with MI, and/or abnormal cardiac enzyme (or troponin) levels (WHO criteria). Presence of two out of three of these criteria were classed as definite MI.

Possible Myocardial Infarction:

The criteria for a possible MI are met when only one of the following characteristics is present: a clinical diagnosis only, based on typical features including chest pain, MI picked up by routine ECG without typical history, and, cardiac enzyme/troponin changes.

2.2 Stroke

Non-fatal stroke diagnosis is based on an acute disturbance of cerebral function of presumed vascular origin lasting 24 hours or more as reported from GP records. Include subarachnoid haemorrhage, cerebral haemorrhage or thrombosis. Excludes cases where another diagnosis (e.g. cerebral neoplasm) is made.

2.3. Angina

Typical effort or stress-related chest pain.
Diagnosis was based on a doctor-confirmed diagnosis of Angina from General Practice (primary care) records.

2.4 Transient ischaemic attack (TIA)

Disturbance of cerebral function of vascular origin, lasting < 24 hours and leaving no residual deficit
Diagnosis was based on a doctor-confirmed diagnosis of Transient ischaemic attack (TIA) from General Practice (primary care) records.

2.5 Heart Failure

Diagnosis was based on a doctor-confirmed diagnosis of heart failure from General Practice records (including hospital and clinic correspondence). All cases were verified by a review of clinical information from primary and secondary care records to ensure diagnosis was consistent with current recommended heart failure diagnosis.

2.6 Diabetes (NIDDM Type 2 / IDDM Type 1)

Diagnosis was based on a doctor-confirmed diagnosis of diabetes from General Practice (primary care) records.

2.7 Atrial fibrillation (AF)

Diagnosis was based on a doctor-confirmed diagnosis of Atrial fibrillation from General Practice (primary care) records.

2.8 Peripheral Arterial Disease (PAD, PVD)

Intermittent claudication or lower limb ischaemia.
Diagnosis was based on a doctor-confirmed diagnosis of PVD from General Practice (primary care) records.

Follow-up of BRHS participants through primary care records. Baseline (1978-80) to 2024

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2.9 Deep Vein Thrombosis (DVT)

Blood clot in the leg.
Diagnosis was based on a doctor-confirmed diagnosis of Deep Vein Thrombosis (DVT) from General Practice (primary care) records.

2.10 Pulmonary Embolism (PE)

Blood clot in the lung.
Diagnosis was based on a doctor-confirmed diagnosis of Pulmonary Embolism (PE) from General Practice (primary care) records.

2.11 Aortic Aneurysm

Rupture or dissection.
Diagnosis was based on a doctor-confirmed diagnosis of Aortic Aneurysm from General Practice (primary care) records.

2.12 Coronary artery bypass graft (CABG)

Recorded CABG procedure in General Practice (primary care) record.

2.13 Percutaneous transluminal coronary angioplasty (PTCA)

Recorded PTCA procedure in General Practice (primary care) record.

2.14 Cancer

Diagnosis was based on a doctor-confirmed diagnosis of Cancer (including cancer site) from General Practice (primary care) records.

2.15 Dementia

Diagnosis was based on a doctor-confirmed diagnosis for different types of Dementia from General Practice (primary care) records. Types of dementia included:

Vascular dementia

Alzheimer's disease

Mixed type dementia

Lewy body dementia

Parkinsons disease dementia

Alcohol related dementia

Other type of dementia

2.16 COVID-19

Diagnosis was based on a doctor-confirmed diagnosis of COVID-19 from General Practice (primary care) records.

Follow-up of BRHS participants through primary care records. Baseline (1978-80) to 2024

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3. Events with additional confirmatory information

For specific non-fatal cardiovascular disease events, an extended enquiry is carried out where additional confirmatory information relating to the events is collected from the GP records. General practices are asked to complete a separate enquiry form (validation forms in Appendix 3) and/or send a copy of the hospital summary sheet or discharge letter to help validate events. This process is carried out for the following types of events:

Myocardial infarction (MI)

Stroke

Heart Failure

Deep Vein Thrombosis

Pulmonary Embolism

3.1 Myocardial infarction (MI)

Additional confirmatory information used for MI event validation.

Questions included in the additional enquiry form (MI event validation form in Appendix 3**)**

Re: Myocardial Infarction

1. Did he have prolonged chest pain lasting at least half an hour?   Yes   No
   If not, how did he present? _____

2. Did he have an ECG?   Yes   No
   If yes, what was the result? _____

3. Did he have cardiac enzyme levels measured?   Yes   No
   If yes - what were these results? _____

4. Did he have troponin levels measured?   Yes   No
   If yes - what were the results? _____

Follow-up of BRHS participants through primary care records. Baseline (1978-80) to 2024

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3.2 Stroke event - additional confirmatory information

The additional confirmatory information has been collected since 2000.

Questions included in the additional enquiry form (Stroke event validation form in Appendix 3**)**

1. Did signs/symptoms last for longer than 24 hours?   1= Yes 2=No 3=Don't know

2. Did he have definite hemiparesis or hemiplegia (weakness affecting one side on the body)?
   If No, how did he present? _____

3. Did he have a CT/MRI scan?   1=Yes 2=No 3=Don't know

   If yes, what was the CT/MRI Scan result?

Ischaemic stroke	1
Haemorrhagic stroke	2
Normal scan	3
Other pathology	4
Not a stroke	5
Results unavailable / Not known	6

4. What was the final diagnosis?

Ischaemic stroke	1
Haemorrhagic stroke	2
Subarachnoid haemorrhage	3
Stroke of uncertain pathological type	4
Not a stroke at all	5
Possible stroke	6
Transient Ischaemic Attack	7
Aneurysm/ Arteriovenous malformation	8
Vascular Dementia	9
Chronic Cerebrovascular Disease	10
Subdural Haematoma	11

5. Was he admitted to hospital?   1=Yes   2=No 3=Don't know

Follow-up of BRHS participants through primary care records. Baseline (1978-80) to 2024

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3.3 Heart Failure – additional confirmatory information collected since 2000

Questions included in the additional enquiry form (Heart Failure event validation form in Appendix 3)

1. Was an echocardiogram (cardiac ultrasound) performed?   Yes No
2. If yes, did it show a diminished left ventricular ejection fraction?   Yes No
3. Left ventricular ejection fraction (if available)   _____%
4. If other factors were important in making the diagnosis of heart failure, please indicate which ones:
    Good response to diuretic treatment
    Chest X-ray result
    Radionuclide scan result
    Cardiac catheterisation result
    Other (please give details)_____

5. Cause of heart failure   _____
6. *Is there a hospital diagnosis of heart failure?*   Yes No

3.4 Deep Vein Thrombosis (DVT) - additional confirmatory information collected since 2000.

Questions included in the additional enquiry form (DVT event validation form in Appendix 3)

1. Was the Deep venous thrombosis investigated by?
    Duplex ultrasound scan   Yes No
    Venogram   Yes No
    D-dimer test   Yes No

2. Did the results of the test show evidence of DVT?
    Duplex ultrasound scan   Yes No
    Venogram   Yes No
    D-dimer test   Yes No

3. What was the D dimer result (if available)_____

3.5 Pulmonary Embolism (PE) - additional confirmatory information collected since 2000.

Questions included in the additional enquiry form (PE event validation form in Appendix 3)

1. Was the Pulmonary Embolism investigated by:
    Ventilation-perfusion scan   Yes No
    CT scan   Yes No
    Pulmonary angiogram   Yes No
    D-dimer test   Yes No

2. Did the results of the test show evidence of PE?
    Ventilation-perfusion scan   Yes No
    CT scan   Yes No
    Pulmonary angiogram   Yes No
    D-dimer test   Yes No

3. What was the D dimer result (if available)

Follow-up of BRHS participants through primary care records. Baseline (1978-80) to 2024

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4 Data collection process of the GP record review (i.e. primary care records)

General Practices

The BRHS cohort participants were recruited from their General Practice, most of whom have remained with that practice over the study period. Those who moved ("removals"/migrants) were traced to their new General Practice using data from Primary Care registration services and NHS Digital and continued to be followed.

The General Practice record review procedure

1. The BRHS clinical director (Peter H Whincup) writes to the GP Partners and Practice Manager of the original 25 General Practices from where BRHS participants were recruited, seeking

   a) ongoing consent for the GP Record Review of BRHS participants within their practice, and
   b) a named person who can liaise with the BRHS team about the undetaking of the review.
   This person is normally the Practice Co-ordinator.

2. A BRHS Record Review pack is sent to the General Practice Co-ordinator.

The BRHS Record Review pack includes:
- Cover letter to the General Practice Co-ordinator with instuctions on how to carry out the review
- A list of the specified events with agreed definitions to be used in the medical record search for events. (Appendix 1).
- A Record Review form for each participant registered at the General Practice. The review forms include some necessary personal identifiers such as the BRHS study identifier, name, address, NHS number and date of birth to ensure correct participant identification (Appendix 2).
- Blank event validation forms for Myocardial Infarction (MI), Stroke, Heart Failure (HF), Deep Vein Thrombosis (DVT), Pulmonary Embolism (PE). The validation forms are used to collect additional confirmatory event information for event validation (Appendix 3).
- Labelled tamper proof envelope for the return of the record review and validation forms back to the BRHS Study Co-ordinator.

3. The General Practice Co-ordinator completes the record review form confirming:

   1. the participant is still registered at the General Practice
   2. the participant's contact details are correct
   3. the participant has consulted at the practice in the specified time frame as shown on the record review form
   4. whether any of the specified health outcomes (events) listed on the record review form have occurred
   5. Attaches **event validation forms/ additional confirmatory information form** or any other necessary additional documents such as hospital summaries, and discharge letters related the following events:

      1) Myocardial infarction (MI)
      2) Stroke
      3) Heart Failure
      4) Deep Vein Thrombosis
      5) Pulmonary Embolism

Participants who moved home or General Practice

Participants no longer registered at their GP practice because they moved home or genral practice are traced through Primary Care registration services/ NHS Digital to their new General Practice. Contact is made with their new practice and follow-up is arranged/continues with the new practice.

Follow-up of BRHS participants through primary care records. Baseline (1978-80) to 2024

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Non-response from General Practices

Reminders to the General Practices are sent four weeks after the initial mailing.

Data update and storage

On completion of the GP record review process, information is updated on the BRHS database held on the university's (UCL) Data Safe Haven (DSH). The date of completion of the record review is recorded. Identifiable information on paper records is redacted and the paper records are filed in a locked BRHS storeroom.

Follow-up of BRHS participants through primary care records. Baseline (1978-80) to 2024

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BRITISH REGIONAL HEART STUDY RECORD REVIEW 2022

FURTHER DETAILS OF DIAGNOSES

NOTE: If the patient has had a diagnosis of Heart Attack, Acute Coronary Syndrome, Stroke, Heart Failure, Pulmonary Embolism or Deep Vein Thrombosis please complete the relevant coloured validation sheet or send a copy of the hospital summary sheet or discharge letter.

	ALTERNATIVE TERMS USED	OTHER POINTS
HEART DISEASE AND STROKE		
*Myocardial infarction	Heart attack, coronary thrombosis	
*Acute Coronary Syndrome	ACS	
Angina	Angina pectoris	Exertional or stress related chest pain
*Stroke	Cerebrovascular accident, **CVA**, cerebral thrombosis, embolism, or haemorrhage	
Transient ischaemic attack	**TIA**, Little / Minor Stroke	Transient cerebrovascular event (Complete recovery within 24 hours)
Diabetes	NIDDM, IDDM, Type 1, Type 2 diabetes	
*Heart Failure	Congestive heart failure (CCF) Left ventricular failure (LVF) Pulmonary oedema	

OTHER CARDIOVASCULAR DISEASES		
Peripheral arterial disease	Peripheral vascular disease (PVD) Intermittent claudication Lower limb ischaemia Gangrene of foot/toes	
Aortic aneurysm	including complications (rupture and dissection)	
*Deep vein thrombosis (DVT)	Blood clot in the leg	
*Pulmonary embolism (PE)	Blood clot in the lung	

* If Yes, please complete the appropriate coloured forms or send a photocopy of the hospital letter or discharge summary

NAME: :		
Address:	Please tick if address is correct ☐	New address:
DOB:		
NHS No:		

Serial No: xxxxx   BRHS (men) Record Review 2022

<u>THE QUESTIONS ON THIS PAGE RELATE TO THE PERIOD FROM 1ST JULY 2020 TO PRESENT</u>

                                                                                          YES NO

1   Is the above patient still registered with you?   ☐ ☐

2   Has he **consulted** you since 1st July 2020?   ☐ ☐

3   Was any consultation for a **new episode** of: (day, month, year)

Myocardial Infarction (MI)   ☐ ☐   Date: ………………………….
Heart attack, Coronary thrombosis

Acute Coronary Syndrome   ☐ ☐   Date: ………………………….

Angina   ☐ ☐   Date: ………………………….
Exertional or stress related chest pain

Stroke   ☐ ☐   Date: ………………………….
Cerebrovascular accident (CVA), cerebral thrombosis, haemorrhage embolism

Transient Ischaemic Attack (TIA/ TCIA)   ☐ ☐   Date: ………………………….
Cerebrovascular disturbance (<24 hours); leaving no residual damage

Diabetes   (NIDDM Type 2 / IDDM Type 1)   ☐ ☐   Date: ………………………….

Heart Failure   ☐ ☐   Date: ………………………….
Congestive Cardiac Failure (CCF) or Left Ventricular Failure (LVF)

Other Cardiovascular disease:

Peripheral Arterial Disease (PAD,PVD)   ☐ ☐   Date: ………………………….
Intermittent claudication, lower limb ischaemia

Aortic Aneurysm- rupture, dissection   ☐ ☐   Date: ………………………….

Deep Vein Thrombosis (DVT)   ☐ ☐   Date: ………………………….
blood clot in the leg

Pulmonary Embolism (PE)   ☐ ☐   Date: ………………………….
blood clot in the lung

* If Yes, please send a <u>copy of the hospital letter or discharge summary</u>

                                                                                          YES NO

4   Has he been referred to a Consultant for any new cardiovascular condition?   ☐ ☐   Date: ………………………….
Diagnosis: ……………………………………………………………………………………..

5   Have any of the following procedures taken place: YES NO

Coronary Artery Bypass Graft (CABG)   ☐ ☐   Date: ………………………….

Coronary Angioplasty (PTCA)   ☐ ☐   Date: ………………………….
Percutaneous coronary angioplasty, balloon treatment. Insertion of stents ☐

6   Has he had a Cancer diagnosis?   ☐ ☐   Date: ………………………….
Site: ………………………………………………………………………………….

7   Has there been a diagnosis of: YES NO

COVID-19   ☐ ☐   Date: ………………………….

Atrial Fibrillation   ☐ ☐   Date: ………………………….

Dementia   ☐ ☐   Date: ………………………….

If yes, please give details of the type of dementia:

Vascular dementia   ☐

Alzheimer's disease   ☐

Other   ☐ please give details …………………………….

Dementia type not known   ☐

8   **Frailty**   Has a frailty score been calculated?   Yes, eFI score ☐   Yes, other score ☐   No frailty score calculated ☐

If yes, please provide details – enter **last** frailty score recorded in each year.

Date of Frailty Score	**Electronic *frailty* index (eFI)**	**Other** Frailty Assessment System		Do you consider this patient to be clinically frail?		
Month / Year	**eFI Score**	Name of score	Grade/value	**YES**	**NO**	**NOT ASSESSED**
…………./2020				☐	☐	☐
…………./2021				☐	☐	☐
…………./2022				☐	☐	☐

Signed ……………………………………………………………   Date:……………………………………………………………..

VALIDATION FORM: HEART ATTACK / MI / ACUTE CORONARY SYNDROME

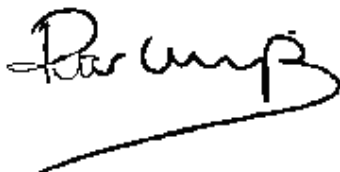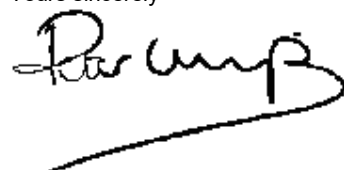|	
Study No:	
Name:	
Address:	
DOB:	
NHS:	

BRITISH REGIONAL HEART STUDY
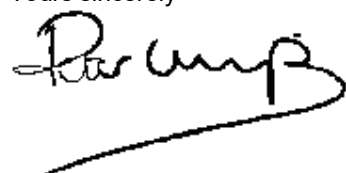
Dear Doctor,

Thank you for supplying information on the above patient who took part in the British Regional Heart Study. We note that he has had a major IHD event recently and would be most grateful if you could complete the following brief enquiry to provide documentation for our record, **OR send us a photocopy of the hospital letter or discharge summary.** This information is critical for the validation of our case criteria.

Re: Myocardial Infarction   **Date of event: _____**

		Yes	No
1.	Did he have prolonged chest pain lasting at least half an hour?	☐	☐
	If not, how did he present?		
	History of typical features including chest pain? Yes/No		
	....		
2.	Did he have an ECG?	☐	☐
	If yes, what was the result?		
	Is ECG evidence consistent with MI? Yes/No		
	....		
3.	Did he have cardiac enzyme levels measured?	☐	☐
	If yes - what were these results?		
	Abnormal Cardiac enzyme (WHO criteria)? Yes/No		
	....		
4.	Did he have troponin levels measured?	☐	☐
	If yes - what were the results?		
	Abnormal Troponin level (WHO criteria)? Yes/No		
	....		

We are extremely grateful for the co-operation we have received from so many GPs and hope to provide valuable information for the treatment and prevention of IHD in the future.

Yours sincerely

[signature]

Prof Peter H Whincup
Professor of Cardiovascular Epidemiology

British Regional Heart Study | Department of Primary Care & Population Health | Institute of Epidemiology and Health Care | UCL Faculty of Population Health Sciences | UCL Medical School | Royal Free Campus | Rowland Hill Street | London NW3 2PF
DDI: +44 (0) 20 7830 2335 | F: + 44 (0) 20 7472 6871 | E: l.lennon@ucl.ac.uk |W: http://www.ucl.ac.uk/pcph/research-groups-themes/brhs-pub

VALIDATION FORM: STROKE

Study No:

Name:

Address:

DOB:

NHS:

Dear Doctor,
Thank you for supplying information on the above patient who took part in the British Regional Heart Study. We note that he has had a major CVA event recently and would be most grateful if you could complete the following brief enquiry to provide documentation for our record, **OR send us a photocopy of the hospital letter or discharge summary.** This information is critical for the validation of our case criteria.

RE: STROKE   **Date of Event _____**

		Yes	No	Don't Know
1.	Did signs/symptoms last for longer than 24 hours?	☐ 1	☐ 2	☐ 3
2.	Did he have definite hemiparesis or hemiplegia?	☐ 1	☐ 2	☐ 3

(weakness affecting one side on the body)

2.1   If No, how did he present? _____

		Yes	No	Don't Know
3.	Did he have a CT/MRI scan?	☐	☐	☐

3.1   If Yes, what was the CT/MRI Scan result?

Ischaemic stroke	☐ 1
Haemorrhagic stroke	☐ 2
Normal scan	☐ 3
Other pathology, not a stroke	☐ 4
Results unavailable / Not known	☐ 5

4.   What was the final diagnosis?

Ischaemic stroke	☐ 1
Haemorrhagic stroke	☐ 2
Subarachnoid haemorrhage	☐ 3
Stroke of uncertain pathological type	☐ 4
Not a stroke at all	☐ 5
Possible stroke	☐ 6
Transient Ischaemic Attack	☐ 7
Aneurysm/ Arteriovenous malformation	☐ 8
Vascular Dementia	☐ 9
Chronic Cerebrovascular Disease	☐ 10
Subdural Haematoma	☐ 11

		Yes	No	Don't Know
5.	Was he admitted to hospital?	☐	☐	☐

We are extremely grateful for the co-operation we have received from so many GPs and hope to provide valuable information for the treatment and prevention of strokes in the future.

Yours sincerely

Prof Peter H Whincup
Professor of cardiovascular Epidemiology

VALIDATION FORM: HEART FAILURE

Study No: _____	BRITISH REGIONAL HEART STUDY
Name: _____	
Address: _____ _____	
DOB: _____	
NHS: _____	

Dear Doctor,

Thank you for supplying information on the above patient who took part in the British Regional Heart Study. We are seeking further information about diagnoses of heart failure, particularly to take account of the results of investigations (particularly echocardiograms) performed. We note from our records that this patient has had a diagnosis of heart failure and would be most grateful if you could complete the enclosed brief enquiry to provide documentation for our records, **or send us a photocopy of the hospital letter or discharge summary**. This information is critical for the validation of our case criteria.

RE: Heart Failure   **Date of Diagnosis: _____**

                                                                      Yes   No

1. Was an echocardiogram (cardiac ultrasound) performed?   ☐   ☐

2. If yes, did it show a diminished left ventricular ejection fraction?   ☐   ☐

3. Left ventricular ejection fraction (if available)_____%

4. If other factors were important in making the diagnosis of heart failure, please indicate which:-

                                                    (please tick if important)

          Good response to diuretic treatment ☐

                              Chest X-ray result ☐

                     Radionuclide scan result ☐

                 Cardiac catheterisation result ☐

                   Other (please give details)_____

5. Cause of heart failure
    Please write the cause of heart failure below if known - if not known please write `not known'

    _____

                                                                                Yes   No

6. Is there a hospital diagnosis of heart failure?   ☐   ☐

We are extremely grateful for the co-operation we have received from so many GPs and hope to provide valuable information for the treatment and prevention of cardiovascular disease in the future.
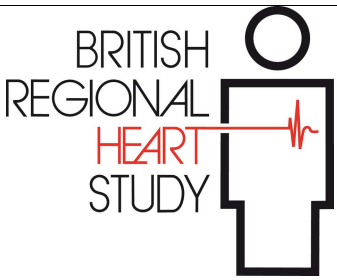
Yours sincerely

Prof Peter H Whincup
Professor of cardiovascular Epidemiology

VALIDATION FORM: DEEP VEIN THROMBOSIS and / or PULMONARY EMBOLISM

Study No: _____

Name: _____

Address:
_____

_____

DOB: _____

NHS: _____

Dear Doctor,

Thank you for supplying information on the above patient who took part in the British Regional Heart Study. We are seeking further information about diagnoses of a Deep Vein Thrombosis and / or Pulmonary Embolism that have occurred since the re-examination 1998-2000, particularly to take account of the results of investigations performed.

We note from our records that this patient has had a diagnosis of Deep Vein Thrombosis and / or Pulmonary Embolism and would be most grateful if you could complete the enclosed brief enquiry to provide documentation for our records, **or send us a photocopy of the hospital letter or discharge summary**.
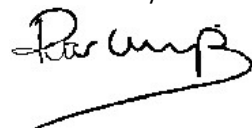
This information is will be very helpful for the validation of our case criteria.

RE: DEEP VEIN THROMBOSIS	**Date of Diagnosis:** _____		
		Yes	**No**
1 Was the deep venous thrombosis investigated by	Duplex ultrasound scan	☐	☐
	Venogram	☐	☐
	D-dimer test	☐	☐
2 Did the results of the test show evidence of DVT?	Duplex ultrasound scan	☐	☐
	Venogram	☐	☐
	D-dimer test	☐	☐
3 What was the D dimer result (if available)_____			

RE: PULMONARY EMBOLISM	**Date of Diagnosis:** _____		
		Yes	**No**
1 Was the Pulmonary Embolism investigated by	Ventilation-perfusion scan	☐	☐
	CT scan	☐	☐
	Pulmonary angiogram	☐	☐
	D-dimer test	☐	☐
2 Did the results of the test show evidence of PE?	Ventilation-perfusion scan	☐	☐
	CT scan	☐	☐
	Pulmonary angiogram	☐	☐
	D-dimer test	☐	☐
3. What was the D dimer result (if available)_____			

We are extremely grateful for the co-operation we have received from so many GPs and hope to provide valuable information for the treatment and prevention of cardiovascular disease in the future.

Yours sincerely

[signature]

Prof Peter H Whincup
Professor of cardiovascular Epidemiology