Follow-up of BRHS cohort participants through General Practice (GP) records (i.e. primary care records)



Baseline (1978-1980) to 2022

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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.

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 dissed	ction)
*Deep vein thrombosis (DVT)	Blood clot in the leg	
*Pulmonary embolism (PE)	Blood clot in the lung	
Atrial fibrillation		
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 as	sessment systems

Table 1 Events included in the GP record review

* 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.

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)	В	2000	Yes, since 2000
Pulmonary embolism (PE)	C	2000	Yes, since 2000
Abdominal aortic aneurysm	Х	2000	
Atrial fibrillation	G	2014	
Dementia	Н	2014	
Dementia - Type not known	HO		
Dementia - Vascular	H1		
Dementia - Alzheimer	H2		
Dementia - Mixed typed	Н3		
Dementia - Lewy body	H4		
Dementia - Parkinson's disease	H5		
Dementia - Alcohol related	H6		
Dementia - Other type	Н8		
COVID-19	Z	2020	
Frailty/Frailty score		2020	

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

<u>Note:</u> 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.

2. Diagnostic criteria

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 <u>definite</u> 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 <u>possible</u> 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.

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.

Angina

Typical effort or stress-related chest pain.

Transient ischaemic attack (TIA)

Disturbance of cerebral function of vascular origin, lasting 24 hours and leaving no residual deficit

Heart Failure

Diagnosis of non-fatal heart failure is based on report of heart failure in GP records.

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.

Re: My	ocardial Infarction		
1.	Did he have prolonged chest pain lasting at least half an hour? If not, how did he present?	Yes	No
2.	Did he have an ECG? If yes, what was the result?	Yes	No
3.	Did he have cardiac enzyme levels measured? If yes - what were these results?	Yes	No
4.	Did he have troponin levels measured? If yes - what were the results?	Yes	No

3.2 Stroke event - additional confirmatory information

The additional confirmatory information has been collected since 2000.

Questi	ons included in the additional enquiry form	n (Stroke event validation form in Appendix 3)		
1.	1. Did signs/symptoms last for longer than 24 hours? Yes No			
2.	Did he have definite hemiparesis or hemiplegia If No, how did he present?			
3.	Did he have a CT/MRI scan?Ye	es No		
	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	on 8		
	Vascular Dementia	9		
	Chronic Cerebrovascular Disease	10		
	Subdural Haematoma	11		
5.	Was he admitted to hospital?	Yes No		

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 f	ailure, 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 CT scan	Yes No Yes No
Pulmonary angiogram	Yes No
D-dimer test	Yes No
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)

2.

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.

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.

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 <u>please complete the relevant</u> <u>coloured validation sheet</u> or send a <u>copy of the hospital summary sheet</u> or <u>discharge letter</u>.

	ALTERNATIVE TERMS USED	OTHER POINTS	
HEART DISEASE AND STRO	DKE		
*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

									APPENDIX 2
	ME: : lress:		Please ticl	c if address is correc	• + □	New a	ddress:		
DO						incir a	uur c55.		
NHS	5 No:								
<u> </u>	del Neu mana								
Serial No: xxxxx BRHS (men) Record Re				Review	2022				
THE QUESTIONS ON THIS PAGE RELATE TO THE PERIOD FROM 1 ST JULY 2020 TO PRE						TO PRESE	<u>NT</u>		
1	Is the above nati	ent still registered wi	th you?						
2									
3 Was any consultation for a <u>new episode</u> of:								(day	/, month, year)
				*Myocardial In			$\square \square$	Date:	*
			He	art attack, Coron	-				
	*Acute Coronary					Irome			*
	Exertional or stress related chest pain						Date:		
					*S	Stroke	\square	Date	*
	Cereb	rovascular accident (CV	•		-			Date	
		Cerebrovascular dist		schaemic Attac	• •		\Box	Date:	
				(NIDDM Type 2 /		-	\square	Data	
								Date:	
		Congestive Car	diac Failure (CCF)	or Left Ventricul	Heart Failure		$\Box \Box$	Date:	*
	Other Cardiovas	-				. ,			
			Peripher	al Arterial Dise	ase (PAI	D,PVD)	$\square \square$	Date:	
				udication, lower					
Aortic Aneurysm- rupture, dissecti *Deep Vein Thrombosis (DV									
	blood clot in the leg						Date:	*	
				*Pulmonary Er			$\square \square$	Date:	*
		* If Vac. places of			clot in th	-			
		* If Yes, please se	enu a <u>copy o</u>		ietter		YES NO	unnnary	
4	Has he been refe	erred to a Consultant	for any new cai	rdiovascular cor	dition?			Date:	
	Diagnosis:								
5	Have any of the	following procedures	-				YES NO		
			-	Artery Bypass (-	-		Date:	
		Percutaneous coronar		oronary Angiop				Date:	
6	Has he had a Car		, , , ,					Date:	
7	Has there been a	-					YES NO		
		COVI							
			l Fibrillation						
	Dementia			tails of the type	of dem	entia:		Date:	
			prese 8.10 de		ular dem				
				Alzhei	mer's di	isease			
				Domontio tru		Other	D please	give details	
				Dementia ty					
8	-	ailty score been calcul		Yes, eFI score		-	score 🗌	No frailty	score calculated
		ovide details – enter la	I						
			Assessment Sys	tem				consider this patient	
	Frailty Score Month / Year	index (eFl) eFl Score	Name of score	۹		6	rade/value	to be cli YES NO	nically frail? NOT ASSESSED
				-					
	/2021								
	/2022								
	Signed			Date:					

Additional confirmatory information

VALIDATION FORM: HEART ATTACK / MI / ACUTE CORONARY SYNDROME

Study No:	BRITISH (\mathbf{C}
Name:		
Address:	HEART	-1r-
		Ľ
DOB:	L	
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 IHD event recently and would be most grateful if you could complete the following brief enquiry to provide documentation for our record, <u>OR send us a</u> <u>photocopy of the hospital letter or discharge summary</u>. This information is critical for the validation of our case criteria.

Re: I	Re: Myocardial Infarction Date of event:			
1.	Did he have prolonged chest pain lasting at least half an hour? If not, how did he present?	Yes	No	
2.	Did he have an ECG? If yes, what was the result?			
3.	Did he have cardiac enzyme levels measured? If yes - what were these results?			
4.	Did he have troponin levels measured? If yes - what were the results?			

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

tor Un

Prof Peter H Whincup Professor of Cardiovascular Epidemiology

VALIDATION FORM: STROKE

Study No:	BRITISH O
Name:	
Address:	HEART T
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, <u>OR send us a photocopy of the hospital letter or discharge summary</u>. This information is critical for the validation of our case criteria.

RE: STROKE Date of Event _				
1. 2. 2.1	Did signs/symptoms last for longer than 24 hours? Did he have definite hemiparesis or hemiplegia? (weakness affecting one side on the body) If No, how did he present?	Yes	No 2 2 2	Don't Know 3 3 3
3. 3.1	Did he have a CT/MRI scan? If Yes, what was the CT/MRI Scan result? Ischaemic stroke Haemorrhagic stroke Normal scan Other pathology, not a stroke Results unavailable / Not known	Yes 1 1 2 3 4 5	No	Don't Know
4.	What was the final diagnosis? Ischaemic stroke Haemorrhagic stroke Subarachnoid haemorrhage Stroke of uncertain pathological type Not a stroke at all Possible stroke Transient Ischaemic Attack Aneurysm/ Arteriovenous malformation Vascular Dementia Chronic Cerebrovascular Disease Subdural Haematoma	1 2 3 4 5 6 7 8 9 10 11		
5.	Was he admitted to hospital?	Yes □	No □	Don't Know

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

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: I.lennon@ucl.ac.uk |W: http://www.ucl.ac.uk/pcph/researchgroups-themes/brhs-pub

VALIDATION FORM: HEART FAILURE

Study No:	BRITISH O
Name:	
Address:	HEART
	STUDY L
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, <u>or send us a photocopy of the hospital letter or discharge summary</u>. This information is critical for the validation of our case criteria.

	RE: Heart Failure	Date of Diagnosis:		
1. 2. 3. 4.	Was an echocardiogram (cardiac ultraso If yes, did it show a diminished left ventric Left ventricular ejection fraction (if availal If other factors were important in making	cular ejection fraction?	Yes	No
	Oth	(please ticl Good response to diuretic treatment Chest X-ray result Radionuclide scan result Cardiac catheterisation result er (please give details)		
5.	Cause of heart failure Please write the cause of heart failure be	low if known - if not known please wri	te `not	known'
6.	Is there a hospital diagnosis of heart failu	ıre?	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 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:	BRITISH O
Name:	
Address:	
DOB:	STUDY L P
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:		
1	Was the deep venous thrombosis investigated	Duplex ultrasound scan Venogram D-dimer test	Yes	No
2	Did the results of the test show evidence of DV	T? Duplex ultrasound scan Venogram D-dimer test		
3	What was the D dimer result (if available)			

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

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

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: <u>l.lennon@ucl.ac.uk</u> |W: <u>http://www.ucl.ac.uk/pcph/research-groups-themes/brhs-pub</u>