

NHSCR Data Sharing FOI 1500377 part 1

NHSCR Background

Background information on the NHS Central Register is available from National Records of Scotland's website - <http://nationalrecordsofscotland.gov.uk/statistics-and-data/nhs-central-register/about-the-register>

The Register is confidential, accessible only to a list of bodies approved by the Scottish Parliament and set out in the Local Electoral Administration and Registration Services (Scotland) Act 2006 (LEARS Act). The act and its associated schedules sets out the information that the Registrar General can hold in the NHSCR and who this information can be shared with. The information provided to these bodies is the minimum necessary for them to do their work. So, for example, local authorities are not provided with the indication of cancer.

Section 1: Requests Granted

Table 1: Medical Research - Provision of Events to approved Researchers

	Requests Received/ Events Provided	Updates made/ events Provided	Type of data	Additional Information
2006-2007	15,463	15,463	cancer registrations, changes of name, movement between health boards	This is a automated system. So in any given year a large number of individuals are flagged as part of research studies. These are all externally approved by NHS medical research approvals process (Calidcott Guardian) sometimes with the advice of NHS National Services Scotland Privacy Advisory Panel. When part of an individuals record changes as agreed in the approved research specification (eg if a study member dies or there is an instance of cancer) the researchers are automatically informed.
2007-08	10,396	10,297	death registration	
	26,365	26,365	cancer registrations, changes of name, movement between health boards	
	8,420	8,329	death registration	

2008-09	52,221	52,221	cancer registrations, changes of name, movement between health boards	
2009-10 ¹	7,270 32,846	7,260 32,846	death registration cancer registrations, changes of name, movement between health boards	Information regarding individuals included in their research is shared with bona fide researchers, to assist in measuring long term outcomes. Researcher may also receive information regarding death with cause and new diagnosis of cancer. Links below to: - PAC terms of reference (ToR) - Q&A page for applicants to PAC - CHAIG terms of reference (ToR) - Caldicott Guardians http://www.nhsnss.org/pages/corporate/about_pac.php http://www.nhsnss.org/pages/corporate/for_applicants_to_pac.php
2010-11	7,628 112,209	7,615 112,209	death registration cancer registrations, changes of name, movement between health boards	
2011-12	8,503 100,126	8,484 100,126	death registration cancer registrations, changes of name, movement between health boards	http://www.nhsnss.org/pages/corporate/about_pac.php http://www.nhsnss.org/pages/corporate/for_applicants_to_pac.php
2012-13	8,528 53,368	8,528 53,368	death registration changes of name,	http://www.shsc.scot/meetings/chi-advisory-group/ http://www.knowledge.scot.nhs.uk/caldicottguardians.aspx
2013-14	7,742 57,633	7,742 57,633	death registration cancer registrations, changes of name, movement between health boards	
2014-15	9,419 66,239	9,419 66,239	death registration cancer registrations, changes of name, movement between health boards	
	<u>9826</u>	<u>9,826</u>	death registration	

1. October 2009/10 figures are significantly higher due to an update of historical cancers which was carried out during this month

Table 2: Improvement Service acting on behalf of Local Authorities

Year - Financial year	Total No of Records Requested	No of Records Provided	Type of Data	Additional Information
2006/07 ²	780,814	1,563	May receive up to but no	Under existing powers of Schedule 2 of the LEARS Act 2006
2007/08 ³	9,200,000	9,200,000	more than name, date of	Section 57. Updates ensure the myaccount is kept up to date and
2008/09	126,036	126,036	birth, date of death, gender,	mirrors the NHSCR. Restricted demographic data and retention
2009/10	374,872	374,872	place of birth, mother's birth	policy is in place to comply with Caldicott and Data Protection
2010/11	284,589	284,589	surname and UCRN.	principals.
2011/12 ⁴	546,452	515,522	Middle name, place of birth	The Improvement Service received in 2007/08, an NHSCR extract
2012/13	302,354	302,051	and mothers birth surname	for use in automated processing on behalf of the Registrar General.
2013/14	801,161	642,896	only included in 2014 when	The extract is a cut down subset of the full NHSCR, with the data
2014/15 ⁵	7,850,573	7,810,598	the new myaccount system	fields provided outlined in the 'Type of Data' column. These are the
			replaced the old citizens	minimum number of fields required and doesn't include things like
			account	CHI number or Health Board, which are primarily for administering
				health services. This was refreshed in 2014/15 and it is now
				updated daily with changes to NHSCR.
				The Local Authority data is matched against the NHSCR extract
				and where discrepancies are identified, records are passed on to
				NHSCR for checking. NHSCR pass back the cleansed records to
				the Improvement Service.
				The NHSCR extract contains over 7 million records because it
				includes information on deceased individuals and individuals who
				have left the country. It is important that the Local Authority knows
				about dates of death for the provision of services.

2. The number of records provided is considerably less than the number requested because the request was for screening for deaths only
3. This estimate includes 1,391,932 records provided through quality assurance and an estimated 7.8 million records provided in a full extract to the Improvement Service
4. Figures from 2011/12 onwards include records transferred as part of data quality improvement projects. From 2011/12 North Lanarkshire provided data to IS / NRS to be cleansed against the NHSCR before being returned to them. From 2013/14 GHA provided IS / NRS with an extract of their customer records to match against NHSCR to prove the use of the matching service with their data . A limited number of UCRNs and notes of death were temporarily shared with GHA as a proof of concept. The data was subsequently removed from the their systems.
5. A significantly higher number of records were transferred in 2014/15 as these transfers include both business as usual and 7,447,275 records transferred for data quality work in preparation for myaccount

Table 3: Police Enquiries

Year - Financial year	Total No of Records Requested	No of Records Provided	Type of Data	Additional Information
2006/07	37	25	Anything except cancer	Requests from Police under section 29(3) of the Data Protection Act 1998. This is also allowed under the LEARS Act. Any entry information requested in relation to the prevention or detection of serious crime (within the meaning of section 93(4)(a) or (b) of the Police Act 1997(3)), to the apprehension or prosecution of those suspected of having committed such crime or to national security, except the entry information described in entries 4 and 5 in Schedule 1. Where there is uncertainty over whether a crime is
2007/08	52	39		
2008/09	42	30		
2009/10	75	20		
2010/11	61	46		
2011/12	28	19		
2012/13	10	7		
2013/14	21	14		

2014/15

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'serious' it is referred to lawyers for confirmation. This is a tracing service and the NHSCR will only provide information in cases of serious crime and if the individual is on the register.

Table 4: Tracing for Other Organisations

Year	Name of Organisation	Total No of Records Requested	Type of data	Additional Information
2006/07	MoD - Veterans Agency	2	Fact that the person is on the NHSCR	To trace next of kin for payment of benefit from Armed Forces Pension Scheme
	Legal Tracing	9	Fact that the person is on the NHSCR and fact of death.	To trace the whereabouts of the person for probate or for court attendance.
	NHS National Services Scotland	8	Person demographic data	To trace person for medical care
	NHS England and Wales (Southport)	6	Person demographic data	To trace person for medical care - referred to NHS National Services Scotland
	Charity - Anthony Nolan	21	Fact that the person is on the NHSCR and fact of death.	To trace the whereabouts of people registered on their donor register.

	NHS - Welsh Bone Marrow Agency Department of Work and Pensions - Fraud	1 Fact that the person is on the NHSCR and fact of death.	To trace the whereabouts of people registered on their donor register.
		1 Person demographic data	Confirmation of person demographic details.
2007/08	Ministry of Defence - Veterans Agency NRH - Presumption of Deaths (scotland) Act 1977	1 Fact that the person is on the NHSCR	To trace next of kin on the death of MoD personnel so they receive payment of benefit from Armed Forces Pension Scheme
		1 Last known Health Board or fact of death	Declaration of death under section 12 of the Presumption of Death (Scotland) Act, 1977. After at least 7 years a missing person, presumed dead, NRS NHR can check on the behalf of the family to see if the person appears alive, if they are not this allows the person to be presumed dead for probate. NHSCR assists by checking if there is a live entry on the register.
	Legal Tracing	12 Fact that the person is on the NHSCR and fact of death.	To trace the whereabouts of the person for probate or for court attendance.
	NHS National Services Scotland	1 Person demographic data	To trace person for medical care
	NHS England and Wales (Southport)	1 Person demographic data	To trace person for medical care - referred to NHS National Services Scotland

Charity - Anthony Nolan Police Counter Fraud - Section 29/3 (EW) Welsh Bone Marrow Agency	26	Fact that the person is on the NHSCR and fact of death.	To trace the whereabouts of people registered on their donor register.
	1	Person demographic data	Confirmation of person demographic details.
	2	Fact that the person is on the NHSCR and fact of death.	To trace the whereabouts of people registered on their donor register.
2008/09	NRH - Presumption of Deaths (scotland) Act 1977	2 Last known Health Board or fact of death	Declaration of death under section 12 of the Presumption of Death (Scotland) Act, 1977. After at least 7 years a missing person, presumed dead, NRS NRH can check on the behalf of the family to see if the person appears alive, if they are not this allows the person to be presumed dead for probate. NHSCR assists by checking if there is a live entry on the register.
	Legal Tracing	10 Fact that the person is on the NHSCR and fact of death.	To trace the whereabouts of the person for probate or for court attendance.
	NHS National Services Scotland	2 Person demographic data	To trace person for medical treatment
	Charity - Anthony Nolan	15 Fact that the person is on the NHSCR and fact of death.	To trace the whereabouts of people registered on their donor register.

Business Services Organisation - Northern Irish Blood Transfusion Service

7 Fact that the person is on the NHSCR and fact of death.

To trace the whereabouts of people registered on their donor register.

Welsh Bone Marrow Agency Child Exploitation (CEOP) police

5 Fact that the person is on the NHSCR and fact of death.

To trace the whereabouts of people registered on their donor register.

2 Person demographic data

To confirm person demographic information and trace the whereabouts of persons

2009/10

NRH - Presumption of Deaths (scotland) Act 1977

5 Last known Health Board or fact of death

Declaration of death under section 12 of the Presumption of Death (Scotland) Act, 1977. After at least 7 years a missing person, presumed dead, NRS NHR can check on the behalf of the family to see if the person appears alive, if they are not this allows the person to be presumed dead for probate. NHSCR assists by checking if there is a live entry on the register.

Legal Tracing

7 Fact that the person is on the NHSCR and fact of death.

To trace the whereabouts of the person for probate or for court attendance.

NHS National Services Scotland

1 Person demographic data

To trace person for medical care

NHS
 England
 and Wales
 (Southport)
 Charity -
 Anthony
 Nolan
 Business
 Services
 Organisatio
 n - Northern
 Irish Blood
 Transfusion
 Service

- | | | |
|---|---|---|
| 1 | Person demographic data | To trace person for medical care - referred to NHS National Services Scotland |
| 5 | Fact that the person is on the NHSCR and fact of death. | To trace the whereabouts of people registered on their donor register. |
| 5 | Fact that the person is on the NHSCR and fact of death. | To trace the whereabouts of people registered on their donor register. |

2010/11

NRH -
 Presumptio
 n of Deaths
 (scotland)
 Act 1977

- | | | |
|---|--|---|
| 3 | Last known Health Board or fact of death | Declaration of death under section 12 of the Presumption of Death (Scotland) Act, 1977. After at least 7 years a missing person, presumed dead, NRS NHR can check on the behalf of the family to see if the person appears alive, if they are not this allows the person to be presumed dead for probate. NHSCR assists by checking if there is a live entry on the register. |
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Legal
 Tracing

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| 1 | Fact that the person is on the NHSCR and fact of death. | To trace the whereabouts of the person for probate or for court attendance. |
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NHS
 National
 Services
 Scotland
 Charity -
 Anthony
 Nolan

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| 3 | Person demographic data | To trace person for medical care |
| 1 | Fact that the person is on the NHSCR and fact of death. | To trace the whereabouts of people registered on their donor register. |

	Business Services Organisation - Northern Irish Blood Transfusion Service	2 Fact that the person is on the NHSCR and fact of death.	To trace the whereabouts of people registered on their donor register.
2011/12	Legal Tracing	2 Fact that the person is on the NHSCR and fact of death.	To trace the whereabouts of the person for probate or for court attendance.
	NHS National Services Scotland Counter Fraud - Section 29/3 (NHS National Services Scotland)	4 Person demographic data	To trace person for medical care
		54 Person demographic data	Confirmation of person demographic details.
2012/13	NRH - Presumption of Deaths (Scotland) Act 1977	1 Last known Health Board or fact of death	Declaration of death under section 12 of the Presumption of Death (Scotland) Act, 1977. After at least 7 years a missing person, presumed dead, NRS NHR can check on the behalf of the family to see if the person appears alive, if they are not this allows the person to be presumed dead for probate. NHSCR assists by checking if there is a live entry on the register.
	Legal Tracing	3 Fact that the person is on the NHSCR and fact of death.	To trace the whereabouts of the person for probate or for court attendance.

	NHS National Services Scotland Charity - Anthony Nolan	3 Person demographic data	To trace person for medical care
		2 Fact that the person is on the NHSCR and fact of death.	To trace the whereabouts of people registered on their donor register.
2013/14	Legal Tracing	2 Fact that the person is on the NHSCR and fact of death.	To trace the whereabouts of the person for probate or for court attendance.
2014/15	NRH - Presumption of Deaths (scotland) Act 1977	3 Last known Health Board or fact of death	Declaration of death under section 12 of the Presumption of Death (Scotland) Act, 1977. After at least 7 years a missing person, presumed dead, NRS NHR can check on the behalf of the family to see if the person appears alive, if they are not this allows the person to be presumed dead for probate. NHSCR assists by checking if there is a live entry on the register.
	Legal Tracing	1 Fact that the person is on the NHSCR and fact of death.	To trace the whereabouts of the person for probate or for court attendance.

Table 5: Letter Forwarding Summary⁵

Year - Financial year	Total No of Records Requested	No of Records Provided	Type of Data	Additional Information
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2006/07	57	2	The fact that the individual's NHSCR offer a tracing service for specific types of organisations
2007/08	N/A	N/A	information is on the including charities. This allows NHSCR to identify individuals and
2008/09	N/A	N/A	register, fact of death or the pass on letters to them via Practitioner Services Divisions (PSD). A
2009/10	N/A	N/A	fact that the family letter letter will only be forwarded to an individual if they explicitly consent
2010/11	257	7	has been sent to the to receiving the letter.
2011/12	575	2	individual.
2012/13	634	0	On receiving a request to forward a letter, NHSCR will first attempt
2013/14	711	2	to trace the intended recipient on the NHSCR database. If the
2014/15	962	4	individual can be traced, is in Scotland and is still alive, NHSCR will
			pass to the relevant PSD details of the individual, a letter to
			individual and pre paid envelope for the individual to reply stating
			whether or not they wish to receive the letter. If the individual
			replies, action will be taken in accordance to their response. No
			information that would allow a person to be identified or traced
			without their consent is ever released. The number of records
			provided column indicates the number of individuals who have
			consented to receiving a letter.
			Some examples of the reasons for this are
			British Red Cross - To facilitate re-establishing contact for families
			who have lost contact through conflict. Part of the International
			British Red Cross Service.
			Missing People and the Salvation Army - Families trying to trace
			missing relatives

6. Under the DPA NHSCR reviews retention of documents regularly and confidentially destroys those past their retention period - unfortunately the statistics for 2007/08-2009/10 were destroyed too.

Table 5.1: Letter Forwarding - British Red Cross⁷

Financial Year	Records Requested	records provided	Additional Information
2006/07	17	1	To facilitate re-establishing
2007/08	N/A	N/A	contact for families who
2008/09	N/A	N/A	have lost contact through
2009/10	N/A	N/A	conflict. Part of an
2010/11	211	0	International British Red
2011/12	557	0	Cross Service.
2012/13	613	0	
2013/14	700	1	NHSCR write to the sought
2014/15	936	0	person once via Practitioner Service Division, no follow up contact is made if there is no response from sought person. Family letters are only forwarded to the sought person with their written consent at an address of their choosing.

7. Under the DPA NHSCR reviews retention of documents regularly and confidentially destroys those past their retention period - unfortunately between 2007 and 2009 the statistics were destroyed too.

Table 5.2: Letter Forwarding - Missing People⁸

Year - Financial	Number of Records	Number of records	Additional Information
2006/07	29	1	To facilitate re-establishing
2007/08	N/A	N/A	contact for families who
2008/09	N/A	N/A	have lost contact.

2009/10	N/A	N/A
2010/11	14	4 NHSCR write to the sought
2011/12	3	0 person once via Practitioner
2012/13	5	0 Service Division, no follow
2013/14	2	0 up contact is made if there
2014/15	5	0 is no response from sought person. Family letters are only forwarded to the sought person with their written consent at an

8. Under the DPA NHSCR reviews retention of documents regularly and confidentially destroys those past their retention period - unfortunately between 2007 and 2009 the statistics were destroyed too.

Table 5.3: Letter

Year - Financial	Number of Records	Number of records Additional Information
2006/07	11	0 To facilitate re-establishing
2007/08	N/A	N/A contact for families who
2008/09	N/A	N/A have lost contact.
2009/10	N/A	N/A
2010/11	32	3 NHSCR write to the sought
2011/12	15	2 person once via Practitioner
2012/13	16	0 Service Division, no follow
2013/14	9	1 up contact is made if there

2014/15

21

4 is no response from sought person. Family letters are only forwarded to the sought person with their written consent at an

9. Under the DPA NHSCR reviews retention of documents regularly and confidentially destroys those past their retention period - unfortunately between 2007 and 2009 the statistics were destroyed too.