

NHS Central Register (NHSCR) Governance Board Meeting 24th October 2013

NHS Central Register Performance Targets 2012-13 and Objectives 2013-14

1. This paper describes the work of the NHS Central Register (NHSCR) in 2012-13 and sets out its intended targets for 2013-14. Due to the timing of this meeting outcomes from projects undertaken so far in 2013-14 have been included. The Board is invited to comment.

Performance Targets

2. The NHSCR has a range of performance indicators to support the targets. The main throughput and indicators are set out below for years 2012-13 and (for comparison) 2011-12. All targets have been met or exceed in the business year.

2012-13	Total Number of Requests/cases	Achieved on Time
NHS updates	1,440,148	1,444,621
Medical Research updates	471,475	471,475
Notification of Events to Researchers	532,585	532,585
Local government updates - received	152	152
Local government extracts (12)	299,764	299,764
Local government updates – Unique Property Reference(UPRN)/Postcode received	9,639,629	9,639,629
National Records of Scotland (NRS) extract download (12)	108,642,313	108,642,313
NRS Migration Extracts (36)	593,462	593,462
Notification of death from Ministry Of Defence (MOD)	119	119
Notification of veteran data from NHS Central Register (NHSCR)	11,960	11,960
Notification of England /Wales (E/W) deaths from Office for National statistics (ONS)	200	200

2011-12	Total Number of Requests/cases	Achieved on Time
NHS updates	2,209,528	2,210,292
Medical Research updates	661,321	661,321
Notification of Events to Researchers	108,654	108,654
Local government updates - received	211	211
Local government extracts (12)	492,471	492,471
Local government updates - UPRN/Postcode received	3,140,159	3,140,159
NRS extract download (12)	106,625,967	106,625,967

NRS Migration Extracts (36)	358,672	358,672
Scottish Longitudinal Study (SLS) Events – 2010	18,671	18,671
Notification of death from Ministry of Defence (MOD)	120	120
Notification of veteran data from NHSCR	5,112	5,112
Notification of E/W deaths from ONS	226	226

National Records of Scotland (NRS) Key Business Objective 2012-13

For 2012-13 Strategic Object 4.

- To promote and extend the use of our records, data, expertise and statistical information, raising awareness, understanding and enjoyment of Scotland past, present and future.

Outcome: We are the secure custodians of large paper and electronic databases of personal information. Working in collaboration with other government departments to promote the secure and legal sharing of NHS Central Register (NHSCR) data for the benefit and efficiency of service delivery and meet the needs of the National Data Linkage Centre.

4. NHS Central Register (NHSCR) Business Improvement Targets 2012-13

To maintain our role as Custodian of NHSCR data we rigorously enforce and implement robust protocols and governance procedures.

On behalf of the SGHD, to maintain and improve the excellent standards of accuracy and probity by continuing the rigorous regime of on-going examination of data, by devising and issuing a comprehensive handbook of instructions covering all NHSCR processes and procedures.

Act as advisor to influence and produce solutions for the provision of Medical Research data to assist academic findings.

To influence, advise and manage the provision of NHSCR data updates for the Improvement Service and National Records of Scotland (NRS).

To continually manage and develop our experienced properly trained staff to deliver excellent data linkage and quality outcomes.

To explore widening our customer base and increase income for NHSCR.

To maintain our role as Custodian of NHS Central Register data we rigorously enforce and implement robust protocols and governance procedures.

Outcome:

- We have in place robust password protocols for users accessing the NHSCR system, providing restricted access levels appropriate to need. Users are required annually to sign Confidentiality Declarations.

Bi-annually we carry out Disaster Recovery on the NHSCR system with ATOS our Information Technology provider.

All requests for access to or disclosure of NHSCR data are scrutinised to ensure they meet the LEARS Scotland Act 2006, Data Protection Act and Caldicott Principles. We work closely with Information Security Branch to ensure all protocols, processes and procedures are compliant and up to date.

On behalf of the SGHD, to maintain and improve the excellent standards of accuracy and probity by continuing the rigorous regime of ongoing examination of data, by devising and issuing a comprehensive handbook of instructions covering all NHSCR processes and procedures.

Outcomes:

6. Data Quality Community Health Index/NHS Central Register

To improve data items of NHS Central Register, Community Health Index, Community and Preventative Care (CPC) systems and Census Area Statistics (CAS). We work continuously to improve the accuracy and quality of data on all systems any changes made are fed back.

7. Patients Over 115 Exercise

There are currently no living patients in Scotland over 115 years old. An exercise was carried out to try to trace deaths for these patients to complete their records as fully as possible and to ensure the accurate content for the NRS Extract. This exercise was completed in October 2012 with deaths for 53% of cases traced.

8. England/Wales Death Registrations

A system is now in place for the monthly update of Scottish connection deaths registered in England and Wales.

9. Provision of the Defence Medical Services (DMS) posting by NBO Southport

A manual workaround is in place until an IT development can be implemented.

10. Postcode histories added

Permissions were sought from the Community Health Index (CHI) advisory to take forward work to build postcode histories on the NHSCR database, 12.5 million postcodes were updated. Discussions are underway with Atos for a date to remove the duplicate postcodes created by this exercise.

Act as advisor to influence and produce solutions for the provision of Medical Research data to assist academic findings.

Outcomes:

11. Scottish Longitudinal Study/Census

Scottish Longitudinal Study /Census work completed. No events received, these will be carried out in 2013/2014.

12. Scottish Mental Health Survey 1947 - Professor Ian Deary

NHS Central Register (NHSCR) has completed automatic and manual matching on the sub groups relating to the Standardised Mortality Ratios (SMR) 1942 study, totalling 8,972.

Work has commenced on the remainder of the cohort of 65,025 by tracing on the 1939 registers. This will allow the linkage with Information Services Division (ISD standardised data in Scotland and HES data in England and Wales).

The electronic update has been carried out on the SMS1947 data with an automatic match rate of 52%, the manual matching of 31,792 records has commenced. To date 1283 (4%) record have been manually flagged.

13. Privacy Advisory Committee

Work with Dr Murray has been completed surrounding the Proportionate Review of the Privacy Advisory Committee (PAC) applications and interviews for the PAC members were completed.

To influence, advise and manage the provision of NHS Central Register (NHSCR) data updates for the Improvement Service and National Records of Scotland (NRS).

Outcomes:

14. Swaps and Merges

NHS Central Register (NHSCR) has implemented the functionality to apply the 'swaps and merges' from the monthly updates supplied to the Improvement Service. From July 2012 the CAS system has benefited from the data quality work carried out at NHSCR with correct citizen details being attached to the Unique Citizen Reference Number (UCRN). We have undertaken the IT work required to provide updates nightly - on hold until Improvement Service are ready to take forward.

15. Resolution of temporary Unique Citizen's Reference Number (UCRNs) for the Improvement Service.

The Improvement Service (IS) requested NHSCR provide a high volume electronic resolution to the IS issue with temporary UCRNs (GUID) created on the Census Area Statistics (CAS) system and return valid UCRNs. This was delivered March 2013.

To continually manage and develop our experienced properly trained staff to deliver excellent data linkage and quality outcomes.

Outcomes:

16. Mothers Community Health Index (CHI) Number on Child's Record

NHS Central Register (NHSCR) linked the mothers CHI number to a child's record where Information Service Division (ISD) were unable to do so using their probability matching. NHSCR completed this exercise in June and traced a total 47,652 records for births from 1981 to 2011.

17. National Maternity Survey 2013

As part of the Scottish Government's Better Together Programme and Analytical Services Division, NHSCR are supporting the Scottish Government's (SG's) 2013 National Maternity Survey. 4,978 mothers' who gave birth in February and March 2013 were randomly selected and forwarded to NHSCR to manually flag and link to the child's record. There were 16 babies deaths identified.

To explore widening our customer base and increase income for NHS Central Register (NHSCR).

Outcomes:

18. North Lanarkshire Matching Exercise

North Lanarkshire Council approached NHSCR to carry out a further matching exercise as part of their 'Golden Record' Project. They needed additional information on date of death and their LG Local Identifier returned to them.

North Lanarkshire Council submitted a file of 132,253 records for linkage, 120,995 were matched and returned with the Unique Citizen Reference Number. North Lanarkshire Council currently have 11,258 un-matched records and are seeking funding for NHSCR to carry out this manual work.

19. Population Estimates Comparison Project Board Greater Glasgow and City

NHS Central Register has been involved in this work to look for ways to help explain some system differences. One outcome failed to fully confirm long held perceptions surrounding people born in Scotland not registered with NHS General Practitioner services. Report at [Appendix A](#).

Key Business Objectives 2013-14

20. Strategic objectives for 2013-14 NRS has five overarching strategic objectives deriving from the four key themes:

To preserve the nation's records in our care, ensuring that the security of the information they contain is maintained, and to promote the preservation of records held elsewhere.

To promote improvements in the management of records including digital formats, by the public sector in Scotland in order to support good governance, accountability and efficient use of public resources.

To produce statistics and gather and record historical and contemporary information, about Scotland and its population.

To promote and extend the use of our records, data, expertise and statistical information, raising awareness, understanding and enjoyment of Scotland past, present and future.

To improve the effectiveness and efficiency of our organisation.

21. NHS Central Register (NHSCR) Business Improvement Targets 2013-14

To maintain our role as Custodian of NHSCR data we rigorously enforce and implement robust protocols and governance procedures.

On behalf of the SGHD, to maintain and improve the excellent standards of accuracy and probity by continuing the rigorous regime of on-going examination of data, by devising and issuing a comprehensive handbook of instructions covering all NHSCR processes and procedures.

Act as advisor to influence and produce solutions for the provision of Medical Research data to assist academic findings.

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Outcomes of new projects undertaken from April to September 2013

22. NHS Central Register Audit – refer to appendix

NHS Central Register (NHSCR) underwent an internal audit in July 2013 to evaluate and report on controls established to manage the risks relating to the efficient and effective operation of NHSCR within National Records of Scotland (NRS). The final report has awarded NHSCR an Substantial Assurance on risk management, control and governance arrangements.

23. Extension of uses for NHS Central Register data

To continue to improve the quality of data held on NHS Central Register and feed back to National Services Scotland / Practitioner Services Division, Information Services Division and the IC (Southport). NHS Central Register data has successfully been used as a sampling frame for Research and other purposes. We plan to raise the profile of this analysis and linkage work, building on the recent recommendation from Privacy Advisory Committee (PAC) that NHS Central Register be promoted as best practice for the sampling frame.

24. Master Data Management Linkage

Work is underway to further develop data linkage and cleaning for the NHS and Local Government. Meetings have started to take this forward, including work under the title of 'Population Estimates Comparison Project Board'. There is a specific project underway involving Greater Glasgow and North Lanark.

Discussions have taken place to develop closer working between NHS Central Register and Alternative Sources on matching with very poor and/or incomplete data.

25. Glasgow Housing Association Pilot

NHS Central Register (NHSCR) have been approached by Glasgow Housing Association (GHA) to provide them with Unique Citizen's Reference Number, date of death and date of birth/gender for anomalies in missing data. They have over 100K records requiring matching. A pilot of 550 cases was undertaken by Alternative Sources using the NHSCR Extract, with a 75% match rate. NHS Central Register and GHA are taking forward the data sharing agreements before this work can progress.

26. Scottish Mental Health Survey 1947

Privacy Advisory Committee previously approved an application whereby cohort members from the above study are to be linked with the 1939 National Register. NHS Central Register will carry out manual tracing to link members, their parents and update a database with historical vital events.

27. Health and Care Experience Survey

This is a repeat of the 2011/12 GP Patient Experience Survey, with the scope being widened to include social care. Discussions have taken place with Health Analytical Services Division, for Electronic and Manual Matching of 600,000 records to take place in advance of the surveys being sent out at the beginning of November. NHS Central Register will carry out death checks with any patients who have died since the sample was extracted being notified to the contactor and removed.

28. Northern Ireland Death Registrations

We explored the provision of civilly registered death details for Scottish resident persons who die in Northern Ireland with General Register Office Northern Ireland. Due to the small number, 1 to 8 per year, cost implication and we currently receive this number of deaths through our usual channels, we will not pursue this.

29. Resolution of temporary Unique Citizen's Reference Numbers for the Improvement Service.

In June 2013 a pilot matching exercise of 1000 records was completed with 903 (90.3%) records electronically matching. We are awaiting the Improvement Service decision on how they wish to progress with the un-match records.

30. Provision of the Defence Medical Services posting by NBO Southport

Information Technology development is in progress now that National Services Scotland Practitioner Services Division and National Records of Scotland Alternative Sources needs have been confirmed.

31. NHS Central Register development scoping proposals with PMG/ATOS

To handle the new Defence Medical Services(DMS) posting provided by NBO, Southport, including 2 new files from LASCA(MOD) segmenting the DMS posting into AF and SMO.

Amendment to PNP file - to capture matched NI moves - approved at PMG 11th June 2013 at no cost to National Records of Scotland

Removal of Duplicate Postcodes (created from the Historical Postcode from Information Services Division)

Amendment to Matching Job Parameters on NHS Central Register

Appendix A

NHS Central Register Birth Registration Paper (July 2013)

NHS Central Register (NHSCR) was asked to investigate the reasons where a person was on the NHSCR database but subsequently as a result of Civil Registration no Health Board postings were recorded.

The assumptions were:

- ◆ Visitors having babies then leaving Scotland
- ◆ Private Health Care Patients (this has not been proven)
- ◆ Person was born and civilly registered in Scotland but never registered with a Scottish General Practitioner
- ◆ Person died in Scotland but never registered with a Scottish GP (visitors)

To enable the analysis to be taken forward it was important to look at the story behind the people identified. Using my extensive knowledge of the data held I identified categories for resolution.

There were several aspects of identifying the records affected that required working in partnership with Atos out IT providers. The records identified had Dates of Birth ranging from 1920 to February 2013.

In total we started with 2 files containing -

Alive	18,763
Deceased	7,653
Total	26,416

Risks

If these records were not investigated, there was a potential risk of an over count of persons contained on the NHS Central Register system.

Analysis

Deceased Persons Born in Scotland with no postings - 7,653 records

Investigation carried out identified - Current posting prior to Death was

8%	Scottish	627
<1%	England/Wales/Northern Island	28
6%	No Postings were traced	459
85%	Infant deaths	6539

No postings were traced for 6998 records - it was intended that these records would be flagged on completion of the exercise for identification purposes, however due to current technical constraints with death outputs, this is currently not possible.

>>>> it is intended that these records will be flagged NOPOST <<<<<

Following investigation of the deceased records I returned to investigating the records where the person was 'Alive' on the NHS Central Register. The records identified had Dates of Birth ranging from 1920 to February 2013. The bulk of births from April 2011 to date are not included in this analysis as it takes time for a patient to register with a General Practitioner (GP) and analysis confirmed the majority of these births have not yet been GP registered.

Persons Born in Scotland with no postings - 14,404 records**Analysis for the total 'Alive' records**

- 42% Current Postings is Scotland
- 38% No postings traced **
- 14% Current Posting is England/Wales/Northern Ireland/IM
- 3% Current Posting is AF/SMO/DMS/Embark/Cancelled
- 1% Sensitive cases (now removed)
- 1% Deceased

**** No Health Board Postings Breakdown**

- 39% Reason not identified - possible Private Health Care cases
- 35% Parent was in Forces (*)
- 17% Parents married Abroad
- 6% Usual Residence on birth entry was Abroad
- 3% Duplicate Records, patient registered with an allocated at General practitioner (GP) registration, at time original NHS number was not traced (plus cancelled and fictitious registrations)

(*) Forces Breakdown (a sample of the forces cases DOB 1974 & 1975) -

- 78% US Navy
- 11% UK Forces
- 9% Chilean Navy
- 1% Iranian Navy
- 1% Mexican Navy

Further Investigation

Analysis has also identified that duplicate re-registrations appear on the NHS Central Register (NHSCR) from 1994 when a birth is civilly re-registered, the NHSCR is not notified of the re-registration however the new birth record is added to the NHSCR. NHSCR receive a file daily from Registration Branch (Forward Electronic Record - FER) detailing all births that were registered with at a Scottish Registration office the previous day. These records are then electronically added to the NHSCR awaiting GP registration.

A sample of 638 Duplicate records (for births from 1994 to 2012) identified

- 64% Duplicate record on NHSCR - Re-Registered Births
- 30% Duplicate record on NHSCR - Person also has Allocated NHS number
- 7% Duplicate on NHSCR - entry cancelled at NRH (blank certificates)
- 2% Duplicate record on NHSCR - wrong NHS number being used

The Registration Branch confirmed that re-registrations are the creation of a new birth entry to add the natural father's/parent's details, alter parentage details or add the parents' marriage or civil partnership details if that marriage or civil partnership took place after the birth was originally registered.

Some birth entries have a Correction and are subsequently re-registered because to add a father's/parent's details to a new entry a correction declaring that person the father/parent must be recorded against the original entry. Re-registrations have been carried out since 1965, so the reason why they appear on the NHS Central Register (NHSCR) from 1994 are not known.

FER have confirmed it is possible to highlight these Duplicate Registrations to the NHSCR to prevent this issue continuing. However given the relatively small numbers involved, the IT changes required and the fact that NHSCR will continue to investigate

'No Postings' on an annual basis, the decision was taken not to pursue this.

The FER file currently reports discrepancies where the a birth registration is created where the year of birth is not equal to the current year or current year - 1. NHS Central Register will record these re-registered NHS numbers as Alternative NHS numbers in the future.

A sample of 1667 records from 1994 to 2012 have identified -

- 41% No postings traced (reasons as before)
- 40% Current posting is England/Wales/Northern Ireland - first GP registration is not Scotland
- 16% Current posting is Scottish
- 2% Current posting is Embark
- 1% sensitive cases (now removed)

Current Posting is England/Wales/Northern Ireland -

The NBO at Southport occasionally e-mail forms DUP106 to NHS Central Register (NHSCR) requesting verification that a patient is not currently registered in Scotland. This implies that the patient is registering in England and Wales. NHSCR will retain these requests for a period of time and then use the access we have to the England/Wales system to update the NHSCR with the patients new England/Wales posting and 10 digit NHS numbers. Analysis carried out over a period of 6 weeks (July - August 2013), identified 4 such records. This will ensure that if we are notified of the likelihood of a posting out with Scotland it is captured at the first opportunity.

Current posting is Scottish -

There are several reasons why duplicate records were added to the NHSCR and why some Scottish postings were not recorded on the NHSCR. The main reason being that the NHSCR was on a VME platform - this had tracing limitations, from 2008 the NHSCR moved to a sequel server. The VME system required users to trace using exact details, which were not necessarily known or recorded on the NHSCR. In 2008 NHSCR staff gained access to Community Health Index (CHI)²⁴ and the NHSCR also added previous names from CHI which has resulted in the duplicates being identified. There were also issue with names that were registered with accents, these are now reported as errors on the daily FER file to ensure that original NHS numbers are retained where possible.

As an ongoing measure NHSCR work on reducing the number of duplicate records, from 2012 demographic searches take place for all records accessed, this has resulted in the reduction of duplicates.

Current posting is Embark or Cancelled -

The current matching rules from CHI to NHSCR require that a record has a current posting before an Embark or Cancelled postings is captured. There is an opportunity to investigate the possibility of changing the 'rules' however further analysis is required to confirm this is the best approach.

Opportunities

While investigating the reason why a person had no GP registration, one source of information were their parents. We identified that some parents were on the NHSCR as being Scottish GP registered however the CHI system showed the person being Cancelled, whereabouts unknown or as having Embarked - both within 5 years of the child's birth. These transfers out of Scotland occurred before the CHI system was rolled out (1992). In 2010, NHSCR carried out an exercise to identify where the CHI had a person as 'Cancelled' but the NHSCR did not. 37K historic CAN postings were added to the NHSCR. This new exercise identified 5,018 records were missed, the script used for

this original job was amended and run on the 16th June 2013.

There are 21,588 records where the CHI shows the person with an Embark posting, the script for the Cancelled scenario can be re-used and amended to allow the NHSCR to be updated with these postings. If these postings do not get updated there is a risk that there will be an over count of registrations if the NHSCR data is used. This enhancement will require funding (this was raised at the NHSCR Extract Working Group on the 18th June 2013, for consideration) and Portfolio Management Approval.

There are approximately 1600 records where a person has no health posting on the NHSCR, however the person is not recorded as Scottish born. These records are currently being investigated.

Final Analysis

In total 22,057 records were manually investigated

57% a posting was traced and added to the NHSCR

43% the patient was deceased and no posting were traced

	Alive	Deceased
Posting Traced	61%	9%
No Posting	39%	81%

A 'NOPOST' flag was created on the NHSCR database to identify records for alive persons where no GP posting could be traced. On the 15th July 2013, 5355 such flags were added. During the period of the analysis, 223 patients subsequently registered with a GP and therefore no flag was added.

The NOPOST flag will be adopted for these cases going forward to prevent the duplication of this exercise.