NHS Information Authority

DSC Notice: 25/99/P18

Date of Issue: January 2000

CRIR

Committee for Regulating Information Requirements

Subject:
Cervical Screening Statistics – Revision of Central Statistical Returns: KC53 & KC61

Implementation date: **1 April 2000**

DATA SET CHANGE CONTROL PROCEDURE

This paper gives notification of changes approved by CRIR which will be included in the NHS Data Dictionary, the NHS Data Manual and the NHS CDS Manual in due course.

Summary of change:

Enhancements to KC53 & KC61 including the collection of data by relevant population (PCG based) in place of resident population, to improve the information available for monitoring the NHS Cervical Screening Programme.

Summary of impact:

KC53:
Changes to Health Authority computer systems and familiarisation training for HA administrative staff.

KC61:
Changes to computer programmes to enable extraction of additional information. Awareness training for laboratory staff on the changes to the forms and computer systems.

Change Proposal Reference No:CP31/99

Please address enquiries about this DSCN to the CRIR Secretariat, NHS Information Authority, 15 Frederick Road, Birmingham B15 1JD Tel: 0121 335 4461 or to the nominated enquiry point.

Data Set Change Notices are located on the Internet in the Electronic Library at **http://www.standards.nhsia.nhs.uk/library/index.htm** and on the NHSnet at **http://nww.standards.nhsia.nhs.uk/library/index.htm**

DSCN numbering format = sequence number/year of issue/service identifier and service sequence number. The service identifier and sequence number enables you to check that you have a complete set of service-specific DSCNs.

Key to Service Identifier:
A = All Services
P = Patient (Hospital, Community, Cross Sector Services)
F = Finance
E = Estates
W = Workforce
T = Transport

DATA SET CHANGE NOTICE 25/99/P18

Reference:	CP31/99
Version No:	V1.1
Subject:	Cervical Screening Statistics – Revision of Central Statistical returns: KC53 & KC61
Type of Change:	Revisions to existing Central Returns
Reason for Change:	Recommendations of Expert Working Group set up to perform triennial review of central returns KC53 and KC61
Effective Date:	1 April 2000

Effect on Central Returns Various enhancements to KC53 & KC61 including the collection of data by relevant population (PCG based) in place of resident population. Copies of the returns are attached for information.

1. Introduction:

Central Statistical Returns KC53 and KC61 have been revised to improve the information available for monitoring the NHS Cervical Screening Programme.

2. Background:

The central statistical returns Working Group confirmed the continuing need for returns KC53 and KC61 because they are necessary to monitor the NHS Cervical Screening Programme (NHSCSP) which contributes to the Government's target of reducing the incidence of invasive cervical cancer. The changes affect the detail of the information already collected. Those to the KC53 are to report additional information, which is available from the current database, for monitoring the effectiveness of cervical screening programme particularly among older women.

The KC61 has been amended to collect information about the test results in more detail. Full details of the changes are in Annex 1 to this change notice. Annex 2 contains the revised forms for information.

3. Timing:

The revised returns are introduced for the collection of data for the financial year 2000-2001.

4. Argument:

Cervical screening started in the 1960s when a number of local screening programmes were implemented. By the 1980s it was clear that an effective, well managed, national screening programme was required to replace the many local programmes that had been developed on an ad hoc basis. In 1988 the Department required each health authority to introduce a cervical screening programme to offer all women aged 20 to 64 a smear at least every 5 years.

Both existing returns are required, as they are used for different purposes. The KC53 monitors the call and recall system established by health authorities for women aged 20 to 64 and shows the percentage of women tested and those who have some abnormality identified. The KC61 relates to laboratory activity and gives some indication of whether or not laboratories are following the criteria for the identification of different types of abnormality. The results of the latest analysis of these returns were published in January 1999 by the Department in the Statistical Bulletin "Cervical Screening Programme, England: 1997-98".

A number of meetings of the Working Group were held. The group included representatives from the Department's statistical and policy sections responsible for cervical screening, the National Co-ordinator of the NHS Cervical Screening Programme, 2 consultant pathologists and a representative from a cytology laboratory, a regional QA co-ordinator, representatives from health authority cervical screening programmes, a representative of the British Society for Colposcopy and Cervical pathology, and members of the NHS Information Authority. The group therefore had representation from both Departmental and NHS users, and from the computer unit responsible for implementing changes to KC53.

5. Impact:

<u>KC53</u>

All HAs in England use the same computer system for producing the KC53 return. Developments to the system are planned and funded centrally and are carried out by the NHS Information Authority.

The NHS Information Authority representatives on the Central Statistical Returns Working Group confirmed that the changes to the KC53 will have little impact on the collection of data at a local level.

KC61

It is not appropriate for the NHS Information Authority to undertake reprogramming of the KC61 as there is no common computer programme used in the 170 pathology laboratories in England. Many individual and proprietary systems have been developed.

Unlike the KC53 changes, which will involve rewriting the software programme, the KC61 changes involve extracting additional information already held on laboratory computer systems.

Data collection in laboratories is carried out by a combination of administrative, scientific and clinical staff, and varies from laboratory to laboratory. In addition to the changes to the computer programmes, staff will have to learn the revisions to the forms and changes to their computer systems.

6. Summary:

There is considerable interest in the NHS Cervical Screening Programme and the KC53 and KC61 statistical returns are essential for monitoring the progress of the programme and its quality. The revisions will improve the information that is available for monitoring the call and recall programme and the outcomes of tests

7. Clearance:

ROCR and PS(H) have agreed the revised data collection.

8. Additional Information:

For further information contact:

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Skipton House
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ANNEX 1

DETAILS OF CHANGES RECOMMENDED BY WORKING GROUP

KC53

1. A sample copy of the revised return is attached. (Annex 2)

Part A2 (New): status of health authority relevant population

2. The existing Part A2 has been split into 2 parts, the first part (new Part A2) to include existing columns (2), (3), (4) and (5), and a further column (6) headed:

> "Eligible population" (to be calculated from column (2) less (3) only i.e. women with recall ceased for clinical reasons).

3. It was confirmed that health authorities will need to estimate their population base to the relevant population composed of Primary Care Groups. That is: ALL those patients resident within the health authority boundary; PLUS all patients registered with GPs who form part of PCGs for which the health authority are responsible, but who are resident elsewhere; MINUS residents registered with GPs who form part of PCGs responsible to another health authority. It was noted that CIC returns would be completed on this basis in the future. Column 2 has therefore been amended to refer to:

> "Number of women in Health authority relevant population."

The NHS Information Authority and NHSCSP confirmed that the change could be financed and completed in the financial year 1999-2000.

4. There was interest in the testing of older women and it was agreed to identify separately the age group 75-79.

Part A3(New): Number of women screened by time since last test

5. The screening programme has been running for a number of years and NHSCSP require information about women "ever" screened in their lifetime to judge the effectiveness of the screening programme. Present records went back to 1988. A new Part A3, therefore, has been introduced to collect information specifically about the number of women screened by the time since last test. It includes information already collected about number of women tested in last 3 years. The column about number of women tested in the last 5 years has been modified to collect information about the number of women tested:

> "more than 3 years ago but not more than 5 years ago."

Additional columns have been included to obtain information on the number of women last tested -

> "more than 5 years ago but not more than 10 years ago;
> more than 10 years ago but not more than 15 years ago; and
> more than 15 years ago."

Part C

6. A minor change only; the words "…and may include some clinically indicated screens.", to be deleted from Notes for column 8.

Part E (New): Notification of result – waiting times

7. There is considerable ministerial interest in the time that women have to wait from having a test to the time they received their result. This matter has also been raised by the NAO, at PAC hearings, and in Parliamentary Questions. The difficulties in providing this information is understood but the delay in advising results needs to be monitored in order to reduce anxiety among women who have had a cervical smear test. Part E has therefore been introduced to ensure that this information is available.

8. The national standard to be achieved is that women should be advised in writing of the result of their test 4 weeks from the date the test was taken. The time taken is based on calendar days. The return counts all tests and not just the most severe result. Only screening programme smears are included. Details on the length of delays would provide information on how well screening programmes were working locally and also the performance of laboratories. (Information about the time taken to authorise laboratory reports will also be collected on KC61 – see para 15 > below.)

9. There is considerable variation in the dates used for receipt of tests and the organisation of the notification of results. Generally health authorities should be responsible for sending out result letters. But where laboratories are responsible for notifying results the health authority would not have information about the delay between the women having the test and receiving the result. Also some laboratories hold back results in order that the GPs could be advised of the result before the woman. The Department will be issuing instructions later this year to health authorities about the notification of test results including the maximum time from producing the report to sending it out and, avoiding women receiving an abnormal result on a Saturday.

10. The KC53 software reports information about delays from the system if the arrangements locally are that the health authority sends out the results.

Part F (New): Test/recall status of women following most severe screening test result in the year.

11. An additional part has been included in the KC53 to collect information about the action taken following a woman's most severe test result in a year. The information about the numbers of women classified by each result and action code will be helpful to the NHSCSP to establish a national picture of action taken.

12. The action codes to be monitored are Recall (A), Suspend (S) and Repeat (R) against result codes 1 to 8 from HMR 101/5. Form HMR 101/5 is an operational document used by most laboratories on which they code the results of cervical smears. The women to be included in this return are those from the NHSCSP only, age 20-64.

KC61

13. A sample copy of the revised return is attached. (Annex 2).

Part A

14. Existing Part A has been renumbered Part A1.

Part A2: Laboratory processing: from receipt of smears to authorisation of report

15. Part A2 has been introduced to collect information about the backlog of smears in laboratories. This information has been collected in the past but because of problems in collecting the data it had been dropped. However the information is required to monitor the performance of laboratories. It is recognised that there are various reasons why laboratories accumulate a backlog.

16. Information for each quarter is required. The interval to be reported is from the date of receipt of smear at laboratory and date of authorisation of final report. Guidance will make clear that the smear should be dated immediately on receipt at laboratory.

Part A3: Number of smears primary screened for/by another laboratory.

17. As some smears are sent from one laboratory to another for examination this information is required. Part A3 has therefore been introduced to record information about the numbers of imported and exported smears dealt with by laboratories and also the number of instances where more than one sample was checked from a single smear prepared

18. Current guidance is that the receiving laboratory should count and report on the smear. Information is to be recorded about smears “processed” and not “primary screened”. The Department will ensure that the guidance is strengthened in connection with the treatment by laboratories of imported smears.

Part C

19. The year 1998 has been removed from the heading. The amended heading is "Outcome by 31 March yyyy for women recommended for gynaecological referral where the smear was registered during April- June yyyy". The actual date will be stated on the form when it is distributed by SD2B in the Department.

20. The screening programme is primarily concerned to detect cervical cancers and line 0001 has been amended to read;

“Cervical cancer (including micro-invasive)”.

An additional line 0011 has been included to record

“Non cervical cancers detected”.

This allows specific reporting of gynaecological cancers as an outcome of a positive smear even though these findings were incidental to the Cervical Screening Programme.

21. For clarity line 0010 has been amended from "Result not known" to "Result not known by laboratory".

22. Part C also includes the formula to calculate the Positive Predictive Value of smears reported as moderate dyskaryosis or worse to enable the laboratory to calculate whether or not they are reaching an achievable standard. Calculation of PPV is subject to change by the ABC (Achievable standards, Benchmarks for reporting and Criteria for evaluating cervical cytopathology) Group. The Department, in consultation with NHSCSP, would write direct to laboratories should the formula for calculating PPV change.

ANNEX 2

DH FORM ADULT SCREENING PROGRAMMES: CERVICAL SCREENING KC53

Year ending 31 March yyyy

Health Authority code | Q | | |

Health Authority name _____

Name of contact _____

Telephone _____

If you have any queries regarding completion of this form, please contact SD2B

Telephone 0171 972 5697

FAX 0171 972 5662

Return to Department of Health
Statistics Division 2B
Room 430B
Skipton House
Elephant and Castle
London
SE1 6LH

For NHS use. Please use this space to record anything relevant to the quality or consistency of the data.

DH FORM PART **A** CERVICAL SCREENING PROGRAMME **KC53**

STATUS OF HEALTH AUTHORITY RELEVANT POPULATION

PART **A1**

Routine recall interval in use in the Health Authority (TICK ONE BOX ONLY)

		(1)
0001	5 YEARS	
0002	4 YEARS	
0003	3 YEARS	
0004	3 AND 5 YEARS MIXED	
0005	OTHER	

Please specify:.....

PART **A2**

(1)	(2)	(3)	(4)	(5)	(6)
Line number	Age of woman at 31 March	Number of women in Health Authority relevant population	Number of women with recall ceased for			Eligible population
			clinical reasons (no cervix)	age reasons	other reasons	
0001	Under 20					
0002	20-24					
0003	25-29					
0004	30-34					
0005	35-39					
0006	40-44					
0007	45-49					
0008	50-54					
0009	55-59					
0010	60-64					
0011	65-69					
0012	70-74					
0013	75-79					
0014	80 & over					

0015	Target age group (25-64)					

9999	Total all ages					

In column (6) record women in the Health Authority relevant population less those who are recall ceased for clinical reasons, i.e. col.2 - col 3

DH FORM PART A3

CERVICAL SCREENING PROGRAMME

NUMBER OF WOMEN SCREENED BY TIME SINCE LAST TEST

KC53

(1) (2) (3) (4) (5) (6) (7)

Line number	Age of woman at 31 March	Number of women last tested in the last 3 years	Number of women last tested more than 3 years ago, but not more than 5 years ago	Number of women last tested more than 5 years ago, but not more than 10 years ago	Number of women last tested more than 10 years ago, but not more than 15 years ago	Number of women last tested more than 15 years ago	Number of women with no cytology record
0001	Under 20						
0002	20-24						
0003	25-29						
0004	30-34						
0005	35-39						
0006	40-44						
0007	45-49						
0008	50-54						
0009	55-59						
0010	60-64						

0011	65-69						
0012	70-74						
0013	75-79						
0014	80 & over						

0015	Target age group (25-64)						

9999	Total all ages						

DH FORM PART B CERVICAL SCREENING PROGRAMME NUMBER OF WOMEN INVITED **KC53**

(1)		(2)	(3)	(4)	(5)	(6)
Line number	Age of woman at 31 March	Number of women invited in the year as a result of:				
		Call	Routine recall	Repeat in <3 years for reasons of		
				Surveillance	Abnormality	Inadequate smear
0001	Under 20					
0002	20-24					
0003	25-29					
0004	30-34					
0005	35-39					
0006	40-44					
0007	45-49					
0008	50-54					
0009	55-59					
0010	60-64					
0011	65-69					
0012	70-74					
0013	75 & over					
0014	Target age group (25-64)					
9999	Total all ages					

Notes:

In column (2) record those women invited for screening in the year as a result of a first call for screening (these women will not have been screened before).
In column (3) record those women invited for screening in the year as a result of a routine recall. These women will have had a previous negative result and been recalled after the usual interval (normally 3 or 5 years).
In columns (4) and (5) record those women invited for screening because their last smear was adequate, but a repeat was advised. Normally these women will have had a previous abnormal smear.
In column (6) record those women invited for screening because their previous smear was inadequate.

DH FORM	PART C	CERVICAL SCREENING PROGRAMME NUMBER OF WOMEN TESTED	**KC53**

		(2)	(3)	(4)	(5)	(6)	(7)	(8)
Line number	Age of woman at 31 March	Number of women tested in the year -						
		as a result of:		Repeat in <3 years for reasons of			While recall suspended	Opportunistic screen
		Call	Routine recall	Surveillance	Abnormality	Inadequate smear		
0001	Under 20							
0002	20-24							
0003	25-29							
0004	30-34							
0005	35-39							
0006	40-44							
0007	45-49							
0008	50-54							
0009	55-59							
0010	60-64							
0011	65-69							
0012	70-74							
0013	75 & over							
0014	Target age group (25-64)							
9999	Total all ages							

In column (2) record those women screened in the year as a result of a first call for screening, within the 12 months following the original invitation being issued (these women will not have been screened before).

In column (3) record those women screened in the year as a result of a routine recall within the 12 months following the original invitation being issued. These women will have had a previous negative result and been recalled after the usual interval (normally 3 or 5 years).
In columns (4) and (5) record those women screened in the year because their last smear was adequate, but a repeat was advised, within the 12 months following the recall invitation being issued. Normally these women will have had a previous abnormal smear.
In column (6) record those women screened in the year because their previous smear was inadequate, within the 12 months following the recall invitation being issued. These women will have a Recall Type of "Inadequate".
In column (7) record those women screened in the year who were suspended from the call and recall system.

In column (8) record those women screened opportunistically in the year. These will be all women whose Recall Status was "No action", "GP not informed", "GP informed" "ZZZ GP" and those women whose recall status was "Final non-responder" -where the initial invitation was generated more than 12 months ago.

DH FORM KC53 PART D CERVICAL SCREENING PROGRAMME RESULT OF TEST KC53

(1) (2) (3) (4)

Line number	Age of woman at 31 March	Woman's most severe test result in the year (see categories in box 22 of form HMR 101/5)			
		Negative (cat. 2)	Borderline/ Mild dyskaryosis (cats. 3/8)	Moderate dyskaryosis (cat. 7)	Severe dyskaryosis (cats. 4/5/6)
0001	Under 20				
0002	20-24				
0003	25-29				
0004	30-34				
0005	35-39				
0006	40-44				
0007	45-49				
0008	50-54				
0009	55-59				
0010	60-64				
0011	65-69				
0012	70-74				
0013	75 & over				
0014	Target age group (25-64)				
9999	Total all ages				

Notes: This part concerns women for whom a test result was recorded during the year. Inadequate smears are not included.

DH FORM PART E CERVICAL SCREENING PROGRAMME KC53

NOTIFICATION OF RESULT - WAITING TIMES

(1) Line number	(1) Number of weeks between date smear is taken and date result is sent from the Health Authority	(2) Number of tests
0001	Less than or equal to 4 weeks	
0002	>4 weeks up to 6 weeks	
0003	>6 weeks up to 8 weeks	
0004	>8 weeks up to 10 weeks	
0005	>10 weeks up to 12 weeks	
0006	Over 12 weeks	
0007	Total	
0008	Letter not sent by Health Authority	

NHS Screening Programme smears only

Line 8 - for use only where letters are sent directly by laboratory or by some other agency which is not the Health Authority

DH FORM PART F

Cervical Screening Programme
Test Recall/Status of women following most Severe Screening result in the year

Woman's most severe test in result in the year	Recall/Test action codes		
	Normal (A)	Suspend (S)	Repeat (R)
Inadequate (cat. 1)			
Negative (cat. 2)			
Mild dyskaryosis (cat. 3)			
Severe dyskaryosis (cat. 4)			
? Invasive cancer (cat. 5)			
? Glandular neoplasia (cat. 6)			
dyskaryosis (cat. 7)			
Borderline changes (cat. 8)			

NHS Screening Programme women, (aged 20-64) only

DH FORM

PATHOLOGY LABORATORIES - CERVICAL CYTOLOGY AND OUTCOME OF GYNAECOLOGICAL REFERRALS.

KC61

Year ending 31 March yyyy (1)

NHS Trust Name

NHS Trust Code R (2)

A separate return is required for each pathology laboratory that carries out gynaecological cytology

Pathology Laboratory Code (3)

Pathology Laboratory Name _____

Name of contact _____

Telephone _____

If you have any queries regarding completion of this form, please contact SD2B
Telephone: 0171 972 5538 Fax : 0171 972 5662

Return to: Department of Health
Statistics Division 2B
Room 430B Skipton House
Elephant and Castle
London SE1 6LH

For NHS use. Please use this space to record anything relevant to the quality or consistency of the data.

I confirm that these data are, to the best of my knowledge, an accurate representation of the results obtained from the cervical screening carried out at this laboratory.

Signed _____ **Date** _____

Consultant Pathologist

PART A1 NUMBER OF SMEARS EXAMINED BY SOURCE OF SMEAR **KC61**

(1)		(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)
		Results of test (See categories in box 22 of form HMR 101/5)								
Line No.	Source of smear (Box 9 of form HMR 101/5)	Inadequate (cat. 1)	Negative (cat. 2)	Borderline changes (cat. 8)	Mild dyskaryosis (cat. 3)	Moderate dyskaryosis (cat. 7)	Severe dyskaryosis (cat. 4)	Severe dyskaryosis/ ?Invasive carcinoma (cat. 5)	?Glandular neoplasia (cat. 6)	Total number examined
0001	GP									
0002	NHS Community Clinic									
0003	GUM									
0004	NHS Hospital									
0005	Private									

0006	Other									

0007	Total of GP and NHS Community Clinics Line 0001 + 0002									

0008	Grand Total									

PART A2 LABORATORY BACKLOG

	TOTAL NUMBER OF SMEARS REGISTERED	NUMBER REPORTED (TO WOMAN OR HA) WITHIN				
		0-2 weeks	3-4 weeks	5-6 weeks	7-8 weeks	9 weeks or more
QUARTER 1 As at 30 June yyyy						
QUARTER 2 As at 30 September yyyy						
QUARTER 3 As at 31 December yyyy						
QUARTER 4 As at 31 March yyyy						

PART A3

NUMBER OF SMEARS PROCESSED FOR/BY ANOTHER LABORATORY

NUMBER OF SMEARS SENT TO ANOTHER LABORATORY	
NUMBER OF SMEARS RECEIVED FROM ANOTHER LABORATORY	

WHERE MORE THAN ONE SMEAR IS TAKEN

NUMBER OF INSTANCES WHERE MORE THAN ONE SAMPLE IS CHECKED FROM A SINGLE REPORT	

DH FORM | PART B | RESULTS OF SMEARS FROM GP AND NHS COMMUNITY CLINICS ONLY BY AGE GROUP OF WOMEN | **KC61**

(1)		(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)
Line No.	Age	Results of test (See categories in box 22 of form HMR 101/5)								Total number examined
		Inadequate (cat 1)	Negative (cat 2)	Borderline changes (cat 8)	Mild dyskaryosis (cat 3)	Moderate dyskaryosis (cat 7)	Severe dyskaryosis (cat 4)	Severe dyskaryosis/ ?Invasive carcinoma (cat 5)	Glandular neoplasia (cat 6)	
0001	Under 20									
0002	20-24									
0003	25-29									
0004	30-34									
0005	35-39									
0006	40-44									
0007	45-49									
0008	50-54									
0009	55-59									
0010	60-64									

0011	65-69									
0012	70-74									
0013	75 and over									

0014	Total 20-64 Lines 0002 - 0010									

0015	Grand Total									

NB: Total number examined as recorded in Part B should equal row 0007 in Part A

DH FORM PART C OUTCOME BY 31 MARCH YYYY FOR WOMEN RECOMMENDED FOR GYNAECOLOGICAL REFERRAL WHERE THE SMEAR WAS REGISTERED DURING APRIL - JUNE YYYY **KC61**

(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)
Line No.	Outcome of referral *	Most significant result (See categories in box 22 of form HMR 101/5)					Total
		Inadequate (cat. 1)	Borderline changes (cat. 8)	Mild dyskaryosis (cat. 3)	Moderate dyskaryosis (cat. 7)	Severe dyskaryosis (cats. 4/5/6)	
0001	Cervical cancer (including micro-invasive)				x	x	
0002	Adenocarcinoma in situ				x	x	
0003	CIN3				x	x	
0004	CIN2				x	x	
0005	CIN1				y	y	
0006	HPV only				y	y	
0007	No CIN / No HPV				y	y	
0008	Inadequate biopsy						

0009	Colposcopy NAD no biopsy taken						
0010	Result not known by laboratory						
0011	Non cervical cancers detected						

* Where more than one specimen is taken from the same woman the most severe result only should be recorded

Positive Predictive Value (PPV)

$$\frac{\text{Total x}}{\text{Total x + y}} \times 100 = \quad \%$$

PPV should be regarded as a guide for the audit of histology and cytology and is not a precise measure of accuracy