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Original Paper

The U.K. National Registry for Radiation Workers: Design, Development and First Analysis

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INTRODUCTION

THE NUCLEAR industry is probably unique in that quantitative records of exposure to its occupational hazard, ionising radiation, have been kept since its inception [1]. Nevertheless, while radiation has been recognised as a carcinogen since well before the start of the nuclear industry, in the earliest days there was a belief that the risk of cancer was zero if doses were held low enough. Even when the 'linear no threshold' hypothesis was accepted there was a belief that no effect of radiation would ever be detected in practice because the required sample size would be too large [2]. However, by the early 1970s it came to be recognised that direct evidence on the health of occupationally exposed persons would be of use, even if the quantitative estimates of radiation risks were so imprecise that the lower bound of the confidence interval was to be indistinguishable from zero. Accordingly, after consultation with employers, the Trades Union Congress and other interested parties, the National Radiological Protection Board (NRPB) set up the National Registry for Radiation Workers (NRRW) on 1 January 1976 [3]. The plans for the NRRW were described in a protocol [4] and the results of the first analysis have recently been published [5, 6]. This paper outlines the design of the study, data collection and validation (with special reference to practical problems) together with a brief outline of methods for analysis and results.

DESIGN OF THE STUDY

The NRRW is a cohort study, i.e. one in which data are collected on a large group of radiation workers and analyses are then carried out to see whether mortality and incidence of cancer differ between those who incurred different doses. In order to ensure the absence of bias it is important that epidemiological studies should achieve a very high coverage of the groups studied. The protocol for the NRRW specified at least 95% (although for the first analysis a coverage of over 98% was achieved).

The study population for NRRW was originally defined, very widely, as all those exposed to ionising radiation in the course of their work and for whom radiation dose records were kept. This was intended to exclude workers who occasionally wore a dosemeter, but for whom no systematic dose record was maintained. It would, however, include workers who were monitored regularly and for whom dose records were kept, even if they were not 'classified radiation workers' and subject to the detailed provisions of legislation.

Practical considerations determined the groups who were first enrolled in NRRW. The nuclear industry contained the largest numbers of workers and also those who tended to accumulate the highest doses; for this reason attention was first concentrated on British Nuclear Fuels (BNFL), the electricity supply industry (Nuclear Electric and Scottish Nuclear) and the U.K. Atomic Energy Authority (UKAEA). Other large employers of radiation workers were the Ministry of Defence (MOD), including both the Atomic Weapons Establishment (AWE) and those monitored by the Defence Radiological Protection Service (DRPS), and also Amersham International (AIL). A number of other medium and small organisations have since been added and the development of the database has been documented [7–9]. The additions include research laboratories, engineering firms and industrial radiographers. It was a condition of the participation of the sites that individuals should be allowed to refuse to be included in NRRW. In practice, relatively few workers have exercised this option. Practical considerations also dictated that at some organisation (e.g. Nuclear Electric) the population included in NRRW, at least for the time being, was restricted to classified workers.

When the NRRW was set up it was realised that it would be easier to ensure that data were complete and accurate for those who were still in radiation work than for those who had left employment. For this reason, and at the request of the participating organisations, radiation workers at each site were divided into four categories:

- A — those continuing radiation work on 1 January 1976;
- B — those continuing in employment on 1 January 1976, and who had undertaken radiation work in the past, but no longer did so;
- C — those who had left employment before 1 January 1976;
- D — those who started radiation work after 1 January 1976.

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Those in categories A and D were enrolled in the first phase. If records for those in category B were equally accessible then they too were included (this decision might vary on a site-by-site basis). Otherwise category B workers were held back to be included in a second phase. The latter was subject to a feasibility study, which confirmed that at most sites the historical records relating to category C (and B) workers were of sufficient quality for their inclusion in the analysis. Nevertheless, collating these historical data is a very substantial task and one that has not yet been completed at all sites.

COLLECTION OF PERSONAL AND DOSE INFORMATION

The data collected from employers are described in detail in Appendix A. They fall into three categories, although some information has more than one function, e.g. date of birth — both an identifier and a determinant of mortality rates:

(a) information to identify the individual, either in communications with the employing organisation or with flagging organisations, or to recognise successive employments of the same individual (e.g. name, date of birth, National Insurance Number);
(b) information that affects the expected pattern of mortality (e.g. date of birth, sex, industrial category, employment history);
(c) radiation dose history — for purposes of the first analysis this is limited to recorded exposures to external radiation with neutron and pro rata notional dose components identified separately.

Wherever possible data transfer to NRRW has been by computer-compatible medium, generally magnetic tape. This is an efficient method and also reduces the possibility of transcription errors. After the initial data transfer, updates have been transferred on an annual basis. Each annual data transfer includes personal and dose information for those starting dose record keeping and also an update of dose and personal information for those already on NRRW. Changes in personal details of participants (e.g. name) occur more frequently than might be supposed. This complicates the processing of the annual updates. However, the receipt of annual data transfers, with queries being referred back to the sites, assists in the process of ensuring that the database has been properly scrutinised.

Problems with historical dose records

It must be recognised that historical dose records were kept with the aim of controlling the immediate exposures of individual workers and (usually) to build up a dose record. The information kept was enough to allow the dosemeters to reach their intended wearer and to allow the results of the dosemeter assessment to be credited to him or her. Information not needed for this purpose would very probably not be kept and, if it were, data quality would probably be poor. At least in the U.K. it is almost certain that historical dose records will not contain all the information needed for an epidemiological study. Additional information will have to be collected from, for example, personnel or medical records.

This leads on to the question of how individuals are identified. A common practice in the U.K. was to assign a serial number for this purpose. If the same serial number was used elsewhere in the employing organisation it will be very helpful, when records are assembled for epidemiological studies. If not, the number may be of very little use except to bring together health physics records for the same individual. Even here, great problems can arise if individuals can change their number as they move around the plant or if numbers are reassigned to new individuals when an individual leaves employment. It is likely that records for the same individual will sometimes have to be brought together by matching on name and date of birth. Quite apart from random transcription errors there are well-known problems with variants of surnames (Gardener, Gardner) and with forenames (William, Bill) and their number and order. Computerised Record Linkage techniques are available to assist with this task although, in our hands, they are used only to assist human intelligence.

The physical format of the historical records may give problems. If handwritten, there are the inevitable problems of legibility and inconsistency in the degree of detail provided. Even computerised records can present problems with idiosyncratic punching conventions. It may also be that the records themselves are not sufficient, the file header may contain information or the ordering of the records may be important.

A few guidelines may be of use for those setting up databases for radiation epidemiology using results from programmes of personal monitoring.

(a) Check as much as you can as early as you can in the data acquisition process.
(b) Find out how many of the stored data items are used and how many are simply stored and printed on reports. The latter are likely to have a high level of inaccuracy.
(c) Identifiers are vitally important.
(d) It is worth discussing the available data sources in detail with those who were concerned with its day-to-day use. They will not only know of some of the pitfalls, they may also think of other data sources (e.g. lists of those leaving the record-keeping system).

Follow-up information

As is usual with epidemiological studies in Great Britain, the NRRW obtains mortality information from the National Health Service Central Registers (NHSCRs) at Southport (for England and Wales) and Edinburgh (for Scotland). The records of study-group members were flagged on the NHSCRs [10]. This was done by sending a card containing the personal details of each study-group member to NHSCRs. When a flagged individual dies, NRRW receives a copy of the death certificate, with the causes of death coded to selected International Classification of Diseases (ICD) Revisions [11]. Slightly different arrangements are made for those resident in Northern Ireland, the Isle of Man or the Channel Islands. If a study-group member emigrates and leaves the area covered by the National Health Service then this mechanism for obtaining mortality information is likely to fail, and the individual is taken to leave the study on the date of emigration. NHSCRs obtain information about some emigrations and pass this on to the appropriate researchers. However, it is known that the coverage of emigrations by NHSCRs is incomplete. If individuals emigrate, unknown to the researchers, and die abroad, they will continue to be regarded as alive and the death rates calculated will be too low. This is a recognised problem and one which does not have a completely satisfactory solution. A similar problem might arise if individuals left the National Health Service for any other reason. This would be the case for members of the Armed Services whose health care is provided by Service Medical Offices rather than by the National Health Service. To try to overcome these problems, and also to combat the small number of cases in which NHSCRs may establish a trace to the wrong person (for example, to father rather than son, or to the wrong twin, particularly if living at the same address), NRRW has also made use of the tracing facilities of the Records Branch of the Department of Social Security (DSS) at Newcastle. This office will, for properly approved studies, conduct a vital status check and, in the case of study members who have died, give whatever information is available on date and place of death.

Validation of personal and dose data

Data on Category B and C workers was transferred in a one-off exercise (at least in principle; frequently the exercise was repeated with successively refined datasets). Data on Category A and D individuals have been received on an annual basis from the participating organisations. As data were added to the database, checks were carried out by specially written software. These involved:

(a) checks on the identity of the individual and that personal details were in agreement with the information given in previous years;
(b) checks on the completeness of essential items of information;
(c) checks for plausibility of dose and employment histories.

Statistical summaries of the data held were returned to each site every 6 months and this allowed an opportunity for erroneous data to be identified and corrected. Nevertheless, complete reliance could not be placed on this on-going data validation. This was for a number of reasons:

(a) the sites not infrequently made annual returns which were known to be incomplete or inaccurate in some non-essential respect with the intention of correcting the deficiency in a later return;
(b) during the data collection phase, only limited efforts were made to correlate information from successive employers;
(c) the checks undertaken would often not have detected information which was plausible, but incorrect. Errors in certain important items, eg sex or date of birth, would usually have been queried by the flagging organisations (or have caused the flagging to fail), but this would not apply to, say, dates of employment or radiation work.

Accordingly, special validation checks had to be undertaken before the database was analysed. NRPB was fortunate in that the cohorts which were the subject of published reports on the UKAEA [12], Sellafield [13] and AWE [14] workforces had largely been checked already by staff from the London School of Hygiene and Tropical Medicine (LSHTM). The exception was radiation dose histories at Sellafield which had been checked by NRPB on behalf of both LSHTM and NRRW. With the agreement of the NRRW Advisory Committee it was decided that these blocks of data did not need to be checked again. However, special checks against data that had not been independently validated were needed before analysis.

The study population for NRRW is defined in terms of those for whom dose records are kept. Accordingly checks were generally carried out against each employer's health physics records. These, by definition, held the appropriate records of exposure to external radiation. They also held sufficient information to identify the individual: name, sex and date of birth. National Insurance Number was sometimes held as an identifier. National Health Service Numbers were never used by personal monitoring services, although all sites made an attempt to collect this information so as to assist the flagging of participants at NHSCRs.

At some organisations the master copy of the dose record is held on a computerised database. Where the records relate to radiation workers in the legal sense, the Health and Safety Executive will have satisfied itself of the security and integrity of such computer-based systems. At all the sites included in this analysis of NRRW, any individuals for whom records were kept, but who were not radiation workers in the legal sense, would have been included on the same footing as other radiation workers. Thus there are arguments for accepting the validity of such computerised dose record-keeping systems. Where computerised systems held the master copy of the radiation dose record they were used as the basis for the data validation exercise. This was done either as a 1% sample check or else by complete data interchange. The former was preferred where the raw records supplied by sites had undergone significant amalgamation with data from other sources. Where the master copy of the radiation dose record was not computerised it was necessary to check the card or paper record. This was done on a 1% sample basis.

Table 1. Breakdown of study population by lifetime dose and employer

Employer	Number of individuals in dose range (mSv)				Total workers	Collective dose (man Sv)	Mean dose (mSv)
	<10.0	10.0–50.0	50.0–100.0	100+			
BNFL	10,223	7464	3083	4847	25,617	1805	70.4
MOD-AWE	8599	1249	239	154	10,241	85	8.3
MOD-DRPS	20,717	4635	1018	876	27,246	381	14.0
Nuclear Electric	4490	2553	696	480	8199	198	24.1
UKAEA	14,916	5455	1631	1912	23,914	730	30.5
TOTAL	58,945	21,336	6667	8269	95,217	3196	33.6

Table 2. Status of participants at the end of follow-up

Alive	86,638
Dead	6660
Emigrated	1850
Untraced	69
TOTAL	95,217

A description of the validation of follow-up information prior to analysis is given in Appendix B.

Population studied for the first analysis

The population studied for the first analysis is summarised in Table 1; the precise definition of the study population can be found in the published report [5, 6]. Rather more than 40,000 of the 95,000 participants have been included in other published studies of radiation workers and these groups contribute two-thirds of the collective dose and two-thirds of the deaths. It is therefore important to appreciate that NRRW includes substantial data additional to that in the separately published studies.

Table 2 shows the status of the study population at the end of the follow-up period. This was 31 December 1988 for most participants, although the Board agreed, for the first analysis of the NRRW, not to include certain subgroups beyond the dates of the previously published analyses.

METHODS OF ANALYSIS

Two types of analysis were undertaken: an external or standardised mortality ratio (SMR) analysis and an internal analysis or test for trend with dose.

In the external analysis, mortality of the study population is compared with that of a reference population. For the first analysis of the NRRW, the reference population was the general population of England and Wales. Death rates by age, sex and calendar years are compared using the standardised mortality ratio (SMR). The SMR takes the value of 100 if the overall death rate in the population studied is the same as in the reference population. SMRs below 100 mean that the death rates are generally lower in the study group than in the reference population and vice versa. However, it is usually found that SMRs are below 100 in occupational groups (the 'Healthy Worker Effect') and this makes the SMR analysis hard to interpret — if the SMR is 85, how can we know whether it would have been 80 in the absence of radiation exposure?

For this reason, more attention is usually concentrated on the internal analysis. Here, the study population is divided into 'strata' in which individuals are of the same age, sex, social class and place of occupation. Mortality patterns for separate calendar periods are compared for those in different dose groups and the results are summed over all strata.

RESULTS OF THE ANALYSIS

Selected results from the external (SMR) analysis are presented in Table 3. This shows the expected healthy worker effect. The SMR for all causes of death is 85, significantly below 100 at the 0.1% level. The SMR for all malignant neoplasms (86) is similarly below 100. Both the SMR for lung cancer (76) and also that for other diseases associated with smoking (89) are significantly below 100.

The group of diseases in which any effect of radiation would most easily be detected are neoplasms of the haematopoietic systems; within this grouping special attention should focus on the subset of leukaemias excluding chronic lymphatic leukaemia (CLL). The SMR for all neoplasms of the haematopoietic system is 88 and that for leukaemias except CLL 93. The figures thus give no support to the idea that death rates are generally elevated in radiation workers. Other diseases of interest are prostate cancer and multiple myeloma for which the SMRs are 110 and 65, respectively. While the former is above 100 it is far from a statistically significant elevation.

Only for one type of cancer is there an SMR significantly above 100. This is thyroid cancer, SMR 303, significantly elevated at the 1% level. There is no trend in risk with external radiation dose, and those who had died of thyroid cancer had not worked at the same place. This result may be a chance finding.

The main results from the test for trend with dose are shown in Table 4. These take the form of an estimated excess relative risk (RR) per Sv, together with the probability (p) that an excess RR as large as the value observed would arise if there were no effect of radiation. A positive excess RR reflects an increase in the level of disease in the higher dose groups; a negative value would be found when the death rates were lower in high dose groups (a protective

Table 3. Standardised mortality ratio (SMR) for selected causes (lagged by 2 years for leukaemias, 10 years otherwise)

Disease	Observed deaths	SMR/100	95% Confidence interval
All causes	4884	0.85†	0.83–0.87
All malignant neoplasms	1363	0.86†	0.81–0.90
Diseases other than malignant neoplasms related to smoking	2085	0.89†	0.85–0.93
Cancer of the trachea, bronchus, lung and pleura	478	0.76†	0.69–0.83
Prostate cancer	80	1.10	0.87–1.36
Thyroid cancer	9	3.03*	1.39–5.76
All lymphatic/haematopoietic			
Lag = 10 years	100	1.00	0.81–1.21
Lag = 2 years	130	0.88	0.74–1.05
Multiple myeloma	12	0.65	0.33–1.13
Leukaemia	52	0.91	0.68–1.19
Leukaemia except chronic lymphatic leukaemia	44	0.93	0.67–1.24

*$p < 0.001$. †$p < 0.01$.

Table 4. Results of selected tests for trends in risk with dose

Disease	One-sided p-value	Excess RR (Sv^{-1})	90% Confidence limit	
			Lower	Upper
All known causes except cancers	0.49	0.01	−0.30	0.36
All malignant neoplasms	0.10	0.47	−0.12	1.20
Bladder cancer	0.070	3.6	−0.11	13.9
Thyroid cancer	0.30	1.0	−1.1	12.3
Multiple myeloma	0.064	6.9	−0.029	45.8
Prostate cancer	0.28	1.5	−1.4	10.7
Lymphatic/haematopoietic	0.30	0.61	−0.87	3.4
Leukaemia	0.10	2.3	−0.32	8.4
Leukaemia (except CLL)	0.0345	4.3	0.40	13.6

effect of radiation). All p values quoted for the internal analysis are one sided.

For all known causes of death except cancers the excess relative risk is almost exactly zero with a 90% confidence interval approaching symmetry in its coverage of negative and positive values. For all malignant neoplasms, the estimated excess RR is above zero, and although the excess does not reach the conventional level of statistical significance, the chance that an estimated excess RR as high as the observed value would arise in the absence of a radiation effect is 10% (i.e. $p = 0.10$). For all neoplasms of the haematopoietic system the estimated excess RR is positive, but not significant ($p = 0.30$). For all leukaemias the estimated excess RR is again positive and closer to statistical significance ($p = 0.10$). When attention is focused on leukaemias except CLL the positive excess RR reaches statistical significance ($p = 0.0345$).

There is trend with dose in the death rates from multiple myeloma that approaches significance ($p = 0.064$); however, this result is largely due to individuals included in the study of the Sellafield workforce, so the two observations are not independent. No significant association was found between prostate cancer and radiation dose. This is in contrast to two of the earlier individual studies despite the fact that data from these two studies are included in NRRW.

DISCUSSION

In order to make comparison with the familiar lifetime risk estimates of ICRP [16], the values of excess relative risk presented above can be incorporated in projection models to allow the data to be extrapolated to lifetime risks for a working population. Table 5 shows estimates of excess relative risk derived from NRRW, the Japanese atomic bomb survivor data [17], and a combined study of American nuclear workers [18]. This table also shows the corresponding lifetime risk estimates, of which the ICRP values were derived by applying a DDREF (dose and dose rate effectiveness factor) of two to the Japanese data. It can be seen that, while the risk estimates from NRRW are above those of ICRP, the statistical uncertainty in the NRRW data is large (for all cancers the 90% confidence interval includes a protective effect of radiation). It can also be seen that the

Table 5. Comparison of risk estimates from studies of the Japanese atomic bomb survivors, NRRW and the combined cohort of American nuclear workers

	Atomic bomb survivors*	NRRW	American nuclear workers†
Cohort size	75,991	95,217	35,933
Person years	2,185,000	1,218,000	705,000
Collective dose (man Sv)	10,000	3213	1140
Range of doses (Sv)	0–4+ 0–0.5	0–0.5+	0–0.5+
Excess relative risk (Sv^{-1}) (90% CI)			
All malignant neoplasms	0.41‡ 0.38‡	0.47	−0.99
	(0.32, 0.52)	(−0.12, 1.20)	(<1.6, 0.38)
Leukaemia	5.2§ 2.4§	4.3	<-1.5
	(3.8, 7.1)	(0.40, 13.6)	(<-1.5, 3.4)
Lifetime risks (%Sv^{-1}) (90% CI)	ICRP		
All malignant neoplasms	4¶	10	<0
	(3, 5)	(<0, 26)	(<0, 8.2)
Leukaemia	0.4¶	0.76	<0
	(0.3, 0.55)‖	(0.07, 2.4)	(<0, 0.60)

*Shimizu and associates [17] (note that results are presented both for the whole cohort and also for those receiving doses of 500 mSv or less).

†Workers at Hanford, Oak Ridge and Rocky Flats (Gilbert and associates [18]).

‡Value of all malignant neoplasms excluding leukaemia, based on all ages.

§Value for all ages at exposure.

¶Derived by applying a DDREF of two to the Japanese data.

‖Approximate values based on Japanese data.

American study failed to find an association between radiation and either all cancers or leukaemias, although the statistical uncertainties are again large. In fact, if the American data are pooled with NRRW, the resulting risk estimates are very close to those of ICRP, although the confidence intervals are still wide. The lifetime risk estimate from the combined studies for all malignant neoplasms is 4.9%/Sv (with 90% confidence interval <0, 18) and for leukaemias 0.30%/Sv (<0, 1.04).

The combination of NRRW with the American data has wide confidence intervals, and does not provide evidence to support a revision of the new risk estimates recommended by ICRP in Publication 60.

NEXT ANALYSIS OF NRRW

The NRPB intends to carry out a second analysis of NRRW shortly. This will include both longer follow-up and also groups of radiation workers not included in the first analysis. This second analysis should provide more powerful evidence on the risks of occupational exposure to radiation.

1. Kendall GM. Computerised dose records and database applications. *J Radiol Prot* 1989, **9**, 197–201.
2. Hems G. Detection of effects of ionising radiation by population studies. *Br Med J* 1966, **1**, 393.
3. Goodwin P. Registry for UK Radiation workers. *Nature* 1975, **255**, 517.
4. Darby SC (ed.) *Protocol for the National Registry for Radiation Workers*. Chilton, NRPB-R116. London, HMSO, 1981.
5. Kendall GM, Muirhead CR, MacGibbon BH, *et al.* Mortality and occupational exposure to radiation: first analysis of the National Registry for Radiation Workers. *Br Med J* 1992, **304**, 220–225.
6. Kendall GM, Muirhead CR, MacGibbon BH, *et al. First Analysis of the National Registry for Radiation Workers: Occupational Exposure to Ionising Radiation and Mortality*. Chilton, NRPB-R251. London, HMSO, 1992.
7. Darby SC, Saw GMA. *Summary of Data held by the NRRW*. Chilton, NRPB-R116, First Supplement. London, HMSO, 1982.
8. Saw GMA, Kendall GM. *Summary of Data held by the NRRW*. Chilton, NRPB-R116, Second Supplement. London, HMSO, 1985.
9. Kendall GM, O'Hagan JA, Rees S, Walker SM, Muirhead CR. *Summary of Data held by the National Registry for Radiation Workers*. Chilton, NRPB-R219. London, HMSO, 1988.
10. Office of Population Censuses, Surveys (OPCS). *The National Health Service Central Register as an Aid to Medical Research. A Guide for Potential Applicants*. London, OPCS, 1982.
11. World Health Organisation. *International Classification of Diseases, Injuries and Causes of Death*, 9th Revision. Geneva, WHO, 1977.
12. Beral V, Inskip H, Fraser P, *et al.* Mortality of employees of the United Kingdom Atomic Energy Authority, 1946–1979. *Br Med J* 1985, **292**, 44047.
13. Smith PG, Douglas M. Mortality of workers at the Sellafield plant of British Nuclear Fuels. *Br Med J* 1986, **293**, 845–854.
14. Beral V, Fraser P, Carpenter L, *et al.* Mortality of employees of the Atomic Weapons Establishment. *Br Med J* 1951–82, **297**, 757–770.
15. Binks K, Thomas DI, McElvenny D. Mortality of workers at the Chapelcross plant of British Nuclear Fuels. In Goldfinch EP, ed. *Radiation Protection — Theory and Practice. Proceedings 4th International Symposium*. Malvern, June 1989. Bristol, Institute of Physics, 1989, 49–52.
16. International Commission on Radiological Protection. 1990 Recommendations of the International Commission on Radiological Protection. *Ann ICRP* 1991, **21**, 1–3.
17. Shimizu Y, Kato H, Schull WJ. Studies of the mortality of A-bomb survivors. 9. Mortality, 1950–1985: Part 2. Cancer mortality based on the recently revised doses (DS 86). *Radiat Res* 1990, **121**, 120–141.
18. Gilbert ES, Fry SA, Wiggs LD, *et al.* Analysis of combined mortality data on workers at the Hanford site, Oak Ridge National Laboratory and Rocky Flats nuclear weapons plant. *Radiat Res* 1989, **120**, 19–35.

APPENDIX A

Summary of data required by NRRW

Personal

1 Name
2 Date of birth
3 Sex
4 National Insurance Number
5 National Health Service Number
6 Personnel number
7 Date employment began
8 Date employment ceased
9 (a) Year of commencement as a radiation worker during this period of employment with this organisation
(b) Year of commencement as a radiation worker in any employment (if available)

10 Date of entry to NRRW
11 Industrial classification
12 Update status

Exposure

13 Body-penetrating external radiation dose
(a) Dose history on an annual basis
(b) Dose in year

14 Notional component of dose
(a) Dose history on an annual basis
(b) Dose in year

15 Neutron dose
(a) Dose history on an annual basis
(b) Dose in year

16 Internal contamination
(a) Monitored for plutonium?
(b) Monitored for tritium?
(c) Monitored for any other nuclide?
(d) Known body content?

17 Involved in radiological accident or incident?

Notes on data

Personal

1 Name—Preferably this should consist of surname and full forenames, e.g. John Frederick Smith. If the full name is unavailable then surname and initials should be given, e.g. Smith, J.F. If an individual has changed his or her name then previous names should be notified.

2 Date of birth—The exact date should be given, e.g. 230254 or 23 Feb 1954. (Special arrangements should be made for dates of birth in the nineteenth century.)

3 Sex—Male or female.

4 National Insurance Number—e.g. AB 123456. This item is very important since it is the main index used to identify individuals in the records. If there is a letter at the end of the National Insurance Number, e.g. AB 123456A, this last letter is not needed. The National Insurance Number commonly appears on pay records.

5 National Health Service Number—e.g. PZKK234. This item is needed in order to flag the individual on the National Health Service Central Registers. For any individual this number will appear on his or her medical card. For people born before the end of the Second World War it will be the same as their wartime identification number. If any individual is unable to supply a National Health Service Number, then it is possible to flag him or her using alternative information. This can be either full forenames (see note 1) and last permanent address (i.e. address when last registered with a doctor) or place of birth or current doctor's name and address.

6 Personnel number—From the point of view of NRRW this item does not constitute an essential piece of information. However, many participating organisations find it convenient to include the personnel number or other personnel identification whenever any data concerning that individual are transferred. It can then be used as a reference in any queries.

7 Date of employment—This should correspond to the date of employment with the participating organisation as a whole rather than at any particular site. The exact date should be given as in note 2. If the individual has had more than one period of employment with an organisation and been a radiation worker during any previous periods, then the employment dates (both beginning and end) for these periods should also be notified to NRRW.

8 Date employment ceased—When an individual who is listed on NRRW leaves the employment of the participating organisation the date that employment ceased should be supplied, even if the individual was not a radiation worker at the time. The exact date should be given as in note 2.

9 Year of commencement as a radiation worker—This should be the year of commencement as a radiation worker during the present period of employment with the participating organisation as a whole. If the year of first commencement as a radiation worker in any employment is known this should also be notified.

10 Date of entry to NRRW—For positive entry systems this should be the date on which the consent form was signed. For positive refusal systems this should be the date on which the list of eligible personnel was compiled. The exact date should be given as in note 2.

11 Industrial classification—e.g. industrial or non-industrial. The classification of employees as industrial or non-industrial is a routine measure carried out by the nuclear industry. For those organisations which do not use this classification, individual arrangements can be made based on either method of payment of the employee (e.g. weekly or monthly) or occupational coding.

12 Update status—This item should accompany the annual exposure data.

N—New radiation worker, i.e. an individual for whom there should not be exposure data from that site for the preceding year.

U—Update for worker continuing radiation work, i.e. an individual for whom there should be exposure data from that site for both the preceding and following years.

R. L.—Individuals who have either retired (R) or left (L) radiation work (the latter while continuing in employment) during that year, i.e. for whom no exposure data from that site are to be expected the following year.

Where the information is available it would be helpful if sites would code 'D' instead of 'R' or 'L' for individuals who died during employment. If it is possible to distinguish those who retired (on grounds of age or ill-health) from those who moved on to another employment, 'R' should be coded for the former and 'S' for the latter. If an individual commences and ceases radiation work within a single calendar year, then R or L, etc, as appropriate, should be indicated rather than N.

Exposure

13, 14, 15 Dose data—The dose data can be supplied using any units of dose equivalent provided these are clearly stated. Dose histories should be given going as far back in time as the records permit. It should also be stated whether notional and neutron components are included in the body-penetrating totals. Preferably they should be included in note 13 and given separately in notes 14 and 15, if relevant. The threshold dose, the procedure regarding recording of doses below threshold and whether or not allowance for background radiation has been made should be clearly indicated for every year for which dose data are supplied. For notional doses it should also be stated whether the dose is a realistic estimate of dose received or whether the appropriate fraction of the dose limit for the period has been assigned. In some cases it may not be possible to supply detailed neutron dose histories on an annual basis, and special arrangements will be needed.

16 Internal contamination—Yes or No.

The answers to these questions should show the entire lifetime experience of the individual. For example, the answer to 16a should be 'yes' if monitoring for plutonium is known to have been carried out at any time in the past. It should also be stated whether an estimate of dose due to internal contamination has been included in the whole-body total dose. If it has been included, details should be given. If a person is likely to have a significant radiation dose from internal contamination as a result of being involved in a radiological accident or incident, individual arrangements as to further data collection will be made as necessary. It is thought that the numbers of people involved will be very small. However, if the group is large enough to merit further analysis, sufficient details will be sought on the nuclides involved and their distribution within the body to permit all calculations to be carried out as far as possible on the same basis. When the data are available, flags for 'monitored for internal emitters' are requested on a year-by-year basis. In the longer term, estimates of dose from internal emitters would be desirable.

17 Involvement in radiological accident or incident—Yes or No.

Has the individual been involved in an incident which led to an effective dose equivalent or effective dose equivalent commitment of more than 50 mSv?

APPENDIX B

Validation of follow-up information

Checks on cause of death codings. Death certificates were checked by the NRPB Assistant Director (Medical) for any errors in the cause of death codings. Very few codings were queried and these nearly always proved to be correct interpretations of the complex coding rules. Follow-up information was double punched in order to eliminate transcription errors. Nevertheless this could not detect errors in flagging or in the transmission of follow-up data to NRPB. Accordingly, a number of checks were carried out.

Checks at the National Health Service Central Registers. A 1% sample of NRRW participants was sent to NHSCRs where staff were asked to check:

(a) that a study card was held for the individual;
(b) if so, whether the individual was in one of the groups which should have been notified to NRPB, ie died, emigrated or not registered with an NHS doctor.

Of the sammple of 930, there were 3 individuals who had died within the follow-up period and whose deaths were not recorded on NRRW. In 2 cases it was recognised that the death should have been reported to NRPB but in the third case records at NHSCRs indicated that it had already been notified. NHSCRs also reported that 38 records in the sample were not flagged for NRRW; in 3 instances the individual had died. NHSCRs could not trace 10 individuals in the sample. The reasons for this are not known.

Although there was general agreement between the NRRW records and the NHSCR records it was felt that in order to ensure that the follow-up was as complete as possible, NRPB staff, with the assistance of staff from NHSCRs, should carry out a check on mortality information held at NHSCRs for NRRW participants. Although a further 5 deaths were at first identified from this check, upon further investigation only 1 of these was confirmed to be a death (in 1988) which had been omitted for the relevant follow-up period. Of the other 4, 1 death had occurred outside the follow-up period (in 1989) and 3 were incorrect matches.

Checks at the Department of Social Security. A 1% sample of all other NRRW participants was sent to DSS Newcastle. Of the total of 1146 records, 1035 individuals were reported to be alive, 103 dead and 8 untraced. Of the 103 dead, 2 were not known to NRRW. However, 1 of these was a recent death and, as such, outside the study period.

In addition, in an earlier exercise, all those without a National Insurance Number (NIN) had also been referred to the DSS. This was in order to check that follow-up was satisfactory for individuals for whom this important identifier was missing. Despite the absence of NINs, the DSS was able to trace over 90% of this group. Of the 589 individuals who could not be traced, 101 had been at or close to retirement age when the DSS system was set up in 1948. It is known that such individuals may not be included in DSS records. NINs tended to be missing for older individuals and about 20% of the group had died. Of these, 36 deaths in the follow-up period have not been traced at NHSCRs.

Checks on members of the Armed Services.

As described above, members of the Armed Services are not covered by the National Health Service, but rather by specific arrangements for servicemen and their families. This means that the normal method for obtaining follow-up information via the National Health Service Central Registers may be less reliable than usual. This would be especially so for deaths in service, but it is also probable that it is less easy to flag a record reliably at a time when an individual is in the Services and not registered with an NHS doctor. NRPB was therefore fortunate to be able to make use of data held by the MOD Medical Statistics Department to check for missing deaths in NRRW participants in the Armed Services. A further 7 deaths were identified for the Royal Navy and 8 for the Royal Air Force. No extra deaths were found for the Army whose records had already been checked at the DSS.

Summary of the validation exercises. The audits of records held at the sites generally showed that the data quality was good. There was often some ambiguity in dates of employment and of radiation work, particularly for those with complex employment or radiation work histories. As a general rule, for the NRRW the earliest date of employment or of radiation work was sought. A low level of errors in doses and personal information was found. Random errors were relatively few and unlikely to affect an analysis but in a few cases more serious systematic errors were found (e.g. omission of all doses incurred in the last quarter of a particular year). In these cases a special data transfer exercise was undertaken to rectify the error.

As for most epidemiological studies in the U.K. NRPB has relied mainly on the National Health Service Central Registers for its follow-up information. Given the size, complexity and duration of the study, it is probably not surprising that there was a degree of incompleteness in the follow-up data held by NRRW, albeit at a low level. To a large extent this was corrected by intercomparisons with data held by other research groups and by NHSCRs themselves. However, other deaths were identified in checks at the Department of Social Security, Newcastle, and MOD Medical Statistics. It was encouraging that, when records for Army participants were checked at the DSS and then with the MOD, the second check found no extra deaths.

It is known that NHSCRs do not hold complete information on emigrations and shortage of skilled staff prevented the DSS from identifying probable emigrations from the records held at Newcastle. About 2000 NRRW participants are known to have emigrated. The available data do not allow the authors to be confident that this is not an underestimate. The magnitude of any such underestimation cannot be known with certainty, but it is perhaps unlikely to exceed 50%.