British Nuclear Test Veterans Health Needs Audit

Commissioned by the UK Ministry of Defence

MILES AND GREEN ASSOCIATES

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Disclaimer

This health needs audit was commissioned by the UK Ministry of Defence. This report has been prepared for the commissioner and is not to be relied on for any other purpose, or by any other party.

The audit was undertaken by Miles and Green Associates ltd, an independent consultancy specialising in public health research, health-care management and public services planning and policy.

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The data and information presented in the report on specific disease categories or specific conditions is purely a reflection of the information provided by the respondents. This information has not been independently validated, and verification and validation of the data and information provided was not within the remit of the audit.

This report is based on the information and material referred to above, and not on any other information. This information provided may not be complete or accurate.

We strongly advise that the data on disease prevalence should not be used to make comparisons with the prevalence of disease in the wider UK population (or any other population), as this would be misleading and would not be statistically valid.

If any conclusions are drawn from the contents of the report which are not expressly stated in the report then neither the authors nor the UK Ministry of Defence may be associated with such conclusions.

The views and beliefs presented in this report are those expressed by the respondents. They are not necessarily those of the authors. This health needs audit cannot and does not attempt to address in any way the issue of causality.

This report is not intended to be a comprehensive review of all potentially relevant health issues relating to the respondents. It is intended to draw attention to those issues which have been identified by the respondents and which the authors consider to be material.

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CONTENTS

FIGURES AND TABLES

Executive Summary

British Nuclear Test Veterans Health Needs Audit

- The overarching aim of the health needs audit was to identify the health experiences, concerns and health and social care needs of British nuclear test veterans.
- Data were collected between November 2010 and March 2011 using a questionnaire-based postal survey, sent to all British Nuclear Test Veterans Association veteran-members resident in the UK, and via a series of discussion groups with a sub-set of survey respondents. The survey response rate was 71% (633 respondents) and eight discussion groups involving 84 veterans were held in different parts of the UK.
- The survey asked respondents to report on serious illnesses and long term conditions diagnosed by a doctor since their participation in the nuclear tests. The definition of ‘serious’ was left up to the respondents to define for themselves.
- It is important to note the limitations of the data. First, the illnesses listed are self-reported and not verified from health records. Second, respondents expressed their individual conditions in many different ways (for example ‘heart trouble’, ‘heart’, ‘angina’, ‘chest-pain’), making robust disease-specific analysis and comparison problematic. Third, there is no age-sex specific data on prevalence or incidence of the various conditions in the general UK population. Therefore, no comparisons can be made or conclusions drawn about whether the nuclear test veteran survey respondents’ health status is better or worse than might be expected.
- Respondents were also asked to report on how many children and grandchildren they have had, and to say whether they thought their descendants’ health had been affected by their test participation.
- In terms of service experience, survey respondents were broadly similar to the nuclear test population as a whole, with 45% RAF, 38% Army and 17% in the Navy and Royal Marines, although with more army, and fewer RN and Royal Marines. The average length of service varied by service with over half serving for less than six years and a higher proportion of national servicemen among the respondents than among the nuclear test population overall.
- 91% of respondents reported having been diagnosed (by a doctor) with a serious or long term condition since their participation in the nuclear tests. Five disease categories, musculoskeletal, cardiac, diseases of the digestive system, cancers and genitourinary disorders represented over 60% of all the reported conditions. Conditions were mainly diagnosed in later life and the most common conditions are also very common in older men in our society.
- To assess their current overall health, respondents were asked to complete a simple and validated health-status assessment questionnaire. This asked people to rate themselves on five ‘domains’ of health or social care functioning; mobility; self-care;

performing usual activities; pain and discomfort; and anxiety and depression. An overall measure of an individual's 'health status' was also calculated.

- Of those who fully completed this part of the questionnaire, 18% (108) reported current good health (no problems on any of the five domains), 57% (336) had some problems on at least one domain and 19% (111) reported being in 'poorest' health category, meaning they had severe problems on all five domains.
- Respondents were also asked to provide information about their use and experience of health and social care services over the past 2 years, together with their suggestions for improving these services.
- Whatever their health needs, most respondents indicated that, in general, they felt their health care needs were being met, and met very well, by the NHS. There was not quite the same level of satisfaction regarding social care services, although the group of respondents who had tried to access social care services was much smaller.
- Veterans were also asked about their own view of the possible causes of their ill-health. Of the 2,801 conditions reported, a third of conditions were attributed by the respondents to radiation, either alone or in combination with another causal factor. 16% of conditions were considered to be due completely to other causes (such as smoking, poor diet or work-related factors) and for 51% (1,425) of conditions, no specific cause was identified by the respondents.
- Views amongst respondents about whether their health was affected by their participation in the nuclear tests was mixed, with 51% saying that they were certain or thought their health had been affected by their participation, but an almost equal number (49%) saying that they were either unsure, didn't know, or felt their health had not been affected.
- Although not all believed that their participation in the nuclear tests has affected their health, amongst those who did, this belief is in itself a cause of significant stress for some, and is causing ongoing worries about their own health and their descendants' future health.
- In terms of children and grandchildren, 86% of respondents said that they had fathered children, and in total they reported having 1321 biological children and 2021 grandchildren. 29% of respondents were certain or thought there was a link between their participation in the nuclear tests and descendants' apparent ill-health. 42% were less certain (saying 'maybe', or that they didn't know). 19% stated that they did not believe there to be a link, and 10% did not answer the question.
- Finally, based on their recent experience, the veterans made a number of suggestions for future improvements to health and social care, and for improved communications with the MOD.

Veterans' suggestions for the future

Suggestions made by the participants in the audit included the following:

General improvements to health and social care services

- Improve access and waiting times by making the system for booking GP appointments more user-friendly and flexible. Improve waiting times for hospital appointments.
- Improve access to wider therapies provided by the NHS – such as physiotherapy, podiatry, etc.
- Improve access to a range of social-care services, both for patients and also their carers, to enable continued mobility, independence and ability to maintain activities of daily living.

Improvements to health and social care services specific to nuclear test veterans

- Increase awareness of priority NHS treatment for veterans amongst both veterans and NHS staff - where relevant or appropriate.
- Improve understanding and knowledge of the nuclear tests amongst doctors.
- Provide access to a 'centre of expertise' on the health effects of radiation – for both doctors and patients.
- Develop a system to 'flag' nuclear test veteran status in health records.
- Introduce a health screening system specifically for nuclear test veterans – possibly annually.

Improving relations and communications with MOD

- The MoD should bring together in one easily accessible place, a set of high-quality evidence-based information sheets, written in clear lay language, to help inform lay people and veterans. It should specifically include:
    - Information on what documents about the tests are in the public domain and how to obtain them
    - Information on how veterans can obtain their own service history and service medical records
    - Clarification of the MoD's position on any future research that could be done regarding the health impact of the nuclear tests.

Introduction

In September 2010, the UK Ministry of Defence (MoD) commissioned a health needs audit of British veterans who took part in the nuclear tests in Australia and the Pacific during the 1950s and 1960s. The intention to carry out this audit was first announced by the then Veterans Minister, Kevan Jones in April 2009[1] and subsequently confirmed by Andrew Robathan, the present Minister for Defence Personnel, Welfare and Veterans. This health needs audit also forms part of an on-going commitment to review the healthcare needs of all British veterans'[2].

The audit was carried out between October 2010 and July 2011 by Miles and Green Associates - an independent research group specialising in public health research, health service planning and policy based in Oxford. The audit consisted of a postal survey completed by 633 veterans together with 8 discussion groups involving 84 veterans held in different locations around the UK.

This report presents the findings of the health needs audit and is structured as follows:

Chapter 1 provides a brief summary of the health needs audit itself, including its scope, aims and the research methods used. It also outlines specific limitations and concerns about the data and its wider interpretation and misuse.

Chapter 2 provides a brief general overview of the wider historical background context in which the audit was carried out.

Chapter 3 presents respondents' demographic characteristics and military service history.

Chapter 4 presents respondents' self-reported health-history and current health status.

Chapter 5 presents respondents' use and experience of health and social care services.

Chapter 6 presents respondents' views and beliefs about the causes of their ill-health.

Chapter 7 explores respondents' views on the health of their descendants.

Chapter 8 outlines conclusions and recommendations.

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[1] House of Commons debate 21st April 2009, c6 6-7WS (cited in Standard note: SN/SC/5145)

[2] Set out in the MOD's Service Personnel Command Paper, *The Nation's Commitment: cross-government support to our armed forces, their families and veterans*, published in July 2008

1 About the Health Needs Audit: Aims, Scope and Methods

1.1 Aims and objectives of the Health Needs Audit

The overarching aim of the health needs audit was to identify the health experiences, concerns and health and social care needs of British nuclear test veterans.

The objectives were to gather and record veterans':

- Experience of health and illness since the nuclear tests to the current day
- Perceptions of the health impact of their service in the forces during the nuclear tests
- Experiences of health and social care services and how these services have or have not responded to their needs
- Suggestions for improving health and social care services to better meet their needs
- Examples of good practice that could help improve services specifically for nuclear test veterans and/or other veterans in the future
- Views about whether and how veterans think that their health, or that of their descendants, has been affected by their taking part in the nuclear tests.

1.2 Scope and methods

The audit used both quantitative and qualitative research methods to look at the experience of a self selected sample of individuals. Analytical techniques commonly used in qualitative research were used to identify common issues, themes and experiences.

1.2.1 Scope and inclusion criteria

The health needs audit focussed on veterans' self-reported experience of serious or major illness, including both short and long term conditions, but only those conditions diagnosed by a doctor; and only conditions diagnosed since their participation in the nuclear tests. The definition of 'serious' or 'major' was left up to the respondents to define for themselves.

It also explored and recorded veterans' beliefs and views, where they held any, about what they thought might have caused their ill-health.

Although the audit report records the personal self-reported experience of ill health of a group of nuclear test veterans and whether and how they think their health was affected by taking part in the nuclear tests, it does not, and cannot, draw any links or conclusion about whether the nuclear tests had any direct or indirect impact on the health of the veterans, or the health of their descendants.

For practical reasons, only UK based British nuclear test veterans were included in the audit.

The following inclusion criteria were applied to individuals wanting to take part in the audit:

- Individuals must have been serving in one of the four British armed forces (Army, Navy, RAF or Royal Marines) and stationed at one or more test sites in Australia and the Pacific during the tests or clean-up operation
- Individuals must be resident in the UK.

Consequently, the following groups were excluded:

- Widows and descendants of nuclear test veterans
- Individuals with civilian status who were present at the nuclear test sites during the testing and clean-up operations.

Following discussion and agreement with management of the British Nuclear Test Veterans Association (BNTVA) and the MoD, it was assumed, in good faith, that members of the BNTVA could be considered bona-fide nuclear test veterans. However, the survey did ask respondents to provide their armed service number as a deterrent to non-genuine nuclear test veterans. A sample of 10 anonymised service numbers was sent to the MoD in January 2011 for verification.

1.2.2 Data collection

Data for the audit were collected using a questionnaire-based postal survey and via a series of discussion groups with a sub-set of survey respondents.

The postal survey collected both quantitative data and qualitative information about:

- The veterans’ characteristics and demographics
- Self-reported episodes of doctor-diagnosed serious or long term illness in the years since participating in the nuclear tests
- Their assessment of their current health status, quality of life and self-reported disabilities
- Their recent use and experience of health and social care services in the last two years
- Their beliefs about whether and how their health may have been affected by their involvement in a nuclear test
- Any serious illnesses they believe have been experienced by their descendants (children and grandchildren); and whether they believe that their children and grandchildren’s health has been affected by their participation in a test.

Discussion groups were semi-structured and enabled the collection of purely qualitative information. They allowed for a more detailed examination of some of the common themes raised in the questionnaire-survey and more in-depth discussion of issues raised in the survey. The information gained in the discussion groups proved particularly useful in contextualising and enhancing the data gathered through the survey on veterans’ beliefs about their health problems.

In total 891 questionnaires were sent and 633 returned, a response rate of 71%.

1.2.3 The questionnaire

Details about the questionnaire development, piloting and administration are given in Appendix 1. The questionnaire was divided into six sections:

Section A: "About You"- collected information on basic demographic characteristics.

Section B: "Your Service History" - collected information about respondents' armed services history including the nuclear test sites where they were stationed.

Section C: "Your health history" - collected information about self-reported serious or long term conditions diagnosed by a doctor at any time since the nuclear tests. Respondents were also asked to identify what they thought were the possible cause(s) of their most serious or major conditions.

Section D: "Your current health and care needs" - collected information on current health status via the EQ-5D questionnaire and asked for information on any disabilities they may have, and what help and support they felt they needed with specific aspects of daily living.

Section E: "Your use and experience of health and care services"- collected information on veterans' recent usage of specific health and social care services (over the past 2 years) together with their views on ease of access and overall satisfaction with these services. This section also gave respondents the opportunity to provide information on services they had not received, but felt they needed, and finally, it asked for examples of good practice and suggestions for service improvement.

Section F: "Your views on your descendants' health" provided the opportunity to provide details on the health of their descendants and respondents' own views on whether their descendants health has been affected by their involvement in the nuclear tests, and why.

1.2.4 Discussion groups

Questionnaire respondents were offered the opportunity to participate in one of eight discussion groups held in different parts of the UK. Overall 84 veterans took part, with 13 participants in the largest group and 8 in the smallest. The discussion groups followed a semi-structured format, lasted between 3-4 hours and all were facilitated by two members of the project team. Further details about the discussion groups can be found in Appendix 1.

1.2.5 Data analysis

Information from the questionnaires and discussion groups was collated and stored in an anonymised form, in compliance with the requirements of the Data Protection Act 1998. The information and data were reviewed and cleaned prior to analysis. Data on the reported conditions was analysed firstly into ICD-10 disease categories at what is called the 'chapter' level, and secondly, at a condition-specific level. The latter has a much lower level of accuracy for reasons described below. Respondent's current health status was analysed using the EQ-5D quality of life assessment tool, stated disabilities, and an analysis of respondents' concurrent conditions.

1.3 Methodological limitations and data warnings

In common with other studies of this kind, it is important to note that there a number of features of the audit methodology which limit the overall generalisability of the findings.

The data presented in this report must be carefully interpreted and not used out of context.

1.3.1 Limitations of the recruitment process

Because of the significant difficulties inherent in obtaining current contact details of ex-service personnel who had participated in the nuclear tests, a decision was made early in the audit to use the BNTVA database of members as the primary source for recruitment. As a result, over 96% of survey respondents were BNTVA members. BNTVA members represent only a relatively small proportion of the total nuclear test veterans estimated to be alive today, and their experience or views may not be representative of nuclear test veterans in general.

1.3.2 Limitations of the analysis of the health history data

The survey asked respondents to report on serious illnesses and long term conditions diagnosed by a doctor, and these are reported in subsequent sections of this report. However, it is impossible to draw any definitive conclusions about whether the level of illness amongst respondents is higher or lower than might be expected. There are several reasons for this.

First, the illnesses listed are self-reported and have not been verified by checking respondents' health records. This would have only been possible via a much larger and considerably longer-term study; and would have required resolution of a great many ethical, practical and other data-access permission issues.

Second, the many different ways in which respondents expressed or described their individual conditions (for example 'heart trouble', 'heart', 'angina', 'chest-pain') made condition/disease-specific analysis problematic. There will therefore be an unavoidable, but unquantifiable degree of inaccuracy in this data.

Third, there is a lack of comparable data about the rates of prevalence or incidence of individual conditions or diseases the general UK population. Whilst there is a comprehensive and reliable UK cancer registration system which records both cancer incidence and mortality (and indeed this was used in the NRPB studies of nuclear test veterans' health), there are no similar comprehensive population based registries for other common diseases (other than for notifiable diseases – largely infections). It is therefore impossible to say whether the rate of disease in our sample is different from what would be seen in an age and socio-economically matched group of British men who had not taken part in the nuclear tests. In addition, this audit does not use age standardised rates, just numbers and crude rates (or percentages within our sample).

Even with the summary EQ-5D measure of health status, which has been used extensively as an outcome measure in clinical trials, it was not possible within the scope of this audit to identify an age-matched group of men against which to compare respondents' scores.

1.3.3 Limitations of reporting on descendants' health

Respondents were asked to report on how many children and grandchildren they have had, and to list major health conditions with which these descendants have been diagnosed. The same limitations apply to these data as to veterans' reports on their own health, but the fact that it is reported at a step or two removed made it even more difficult to verify or validate. It was not within the remit of this health needs audit to collect information directly from descendants themselves. Indeed, a study which did this would be very difficult undertake, and would require highly complicated ethical approval and consent processes, and access to confidential medical records. In addition, the tracking of progeny (who are likely to be dispersed across many countries) would be very difficult, costly and take a great deal of time.

Overall, the information and accuracy provided by respondents about their descendants' conditions or ill-health was so limited, that it was reluctantly concluded that it was not possible to undertake any meaningful analysis at a condition-specific or even disease-category level. The information presented in Chapter 7 is therefore purely a record of veterans' individual views and beliefs about there being a causal link (or not) between their participation in the nuclear tests and the health of their descendants.

2 Wider Background Context

This section covers:

- An overview of the British nuclear tests
- Overview information on the personnel who took part
- Information on the nuclear test participants today
- A brief summary of previous research looking at the health of nuclear test veterans

2.1 The British nuclear tests

Between 1952 and 1958 the UK carried out a series of 21 atmospheric nuclear tests. Twelve tests took place in Australia. Nine tests took place at Christmas Island (now called Kiritimati) and Malden Island in the South Pacific, as follows[3]:

Figure 2-1 Summary of the British Nuclear Tests

Australia

Codename	Date	Location	Yield
Hurricane	3 Oct 1952	Monte Bello Island	25 Kt
Totem	14 Oct 1953	Emu Field	10 Kt
	26 Oct 1953		8 Kt
Mosaic	16 May 1956	Monte Bello Island	15 Kt
	19 Jun 1956		60 Kt
Buffalo	27 Sep 1956	Maralinga Range	15 Kt
	4 Oct 1956		1.5 Kt
	11 Oct 1956		3 Kt
	21 Oct 1956		10 Kt
Antler	14 Sep 1957	Maralinga Range	1 Kt
	25 Sep 1957		6 Kt
	9 Oct 1957		25 Kt

Pacific Ocean

Codename	Date	Location	Yield
Grapple	15 May 1957	Malden Island	0.3 Mt
	31 May 1957		0.72 Mt
	19 Jun 1957		0.2 Mt
Grapple X	8 Nov 1957	Christmas Island	1.8 Mt
Grapple Y	28 Apr 1958		3 Mt
Grapple Z	22 Aug 1958		24 Kt
	2 Sep 1958		1 Mt
	11 Sep 1958		0.8 Kt
	23 Sep 1958		26 Kt

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[3] Source: MOD factsheet accessed at http://www.mod.uk/NR/rdonlyres/470D247F-7615-460C-9829-DDAF99F88D39/0/Key_Events.pdf

In addition, a number of minor trials were conducted in Australia between 1953 and 1963. Major clean-up operations involving British personnel took place at Christmas Island in 1964 and Maralinga in 1964 and 1967.

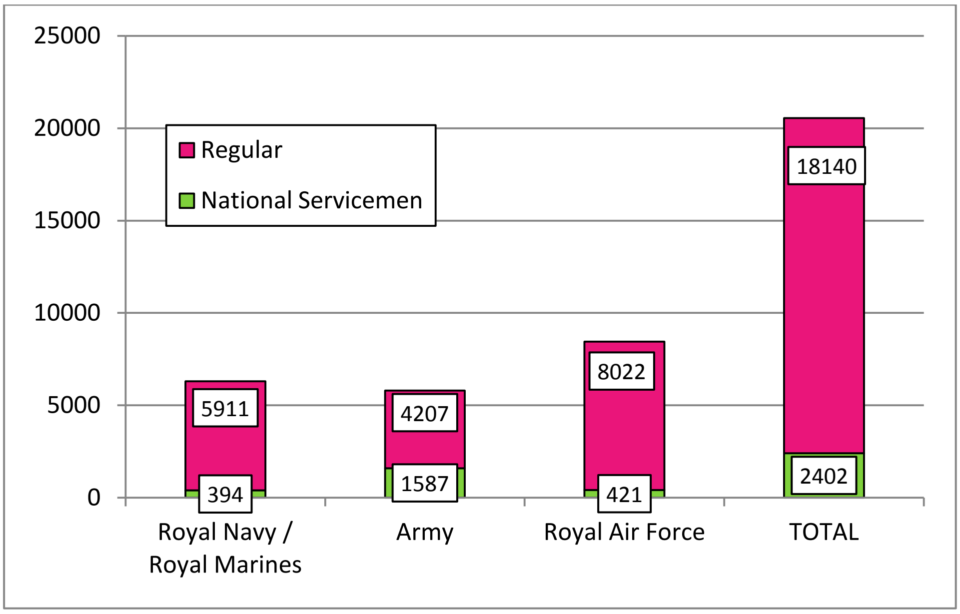
UK personnel also participated in US nuclear weapons tests based at Christmas Island in 1962.

2.2 The service personnel who took part

Over 20,000 British service personnel were involved in the tests, though not all were present at a detonation. The range of duties they carried out was extremely wide, covering every aspect of preparing for and executing the tests but also creating and managing the infrastructure and logistics at the sites in order to support the large number of personnel living and working there.

The demographics of the service personnel who took part are described in detail in the three reports by the National Radiological Protection Board (NRPB). The most recent (2003) NRPB report[4] identified 20,542 service personnel (together with 815 civilians) involved in the nuclear tests in some way, in that they either visited at least one of the test locations at the relevant times, or had sampled radioactive clouds. Of these, 12% (2,402) were undertaking national service. The total number of men who took part, by service type, is shown in Figure 2-2.

Figure 2-2 Participants in the nuclear tests, by type of service



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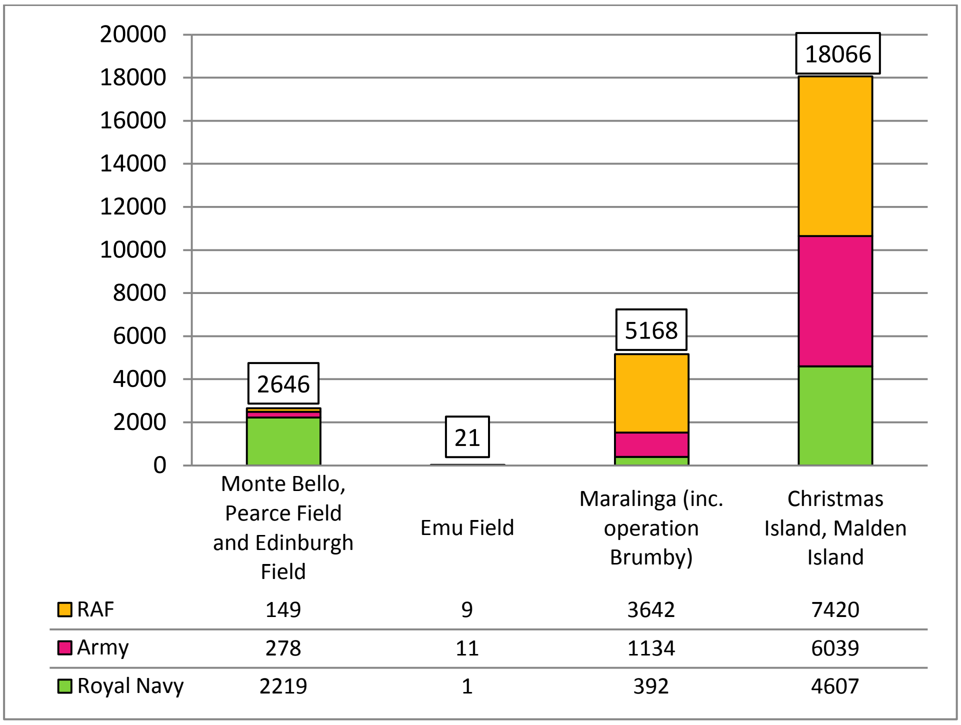
[4] **Follow Up Of Mortality And Incidence Of Cancer 1952–98 In Men From The UK Who Participated In The UK's Atmospheric Nuclear Weapon Tests And Experimental Programmes** C R Muirhead, D Bingham, R G E Haylock, J A O'Hagan, A A Goodill, G L C Berridge,M A English, N Hunter, G M Kendall *Occup Environ Med 2003;60:165-172* doi:10.1136/oem.60.3.165, updated version (published March 2004) accessed at http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1194947308572

Figure 2-3 Operational involvements in the nuclear tests, by site



	Monte Bello, Pearce Field and Edinburgh Field	Emu Field	Maralinga (inc. operation Brumby)	Christmas Island, Malden Island
🟨 RAF	149	9	3642	7420
🟥 Army	278	11	1134	6039
🟩 Royal Navy	2219	1	392	4607

Some service-personnel took part in more than one operation. The same 2003 NRPB report identified 25,901 "operational involvements" by military personnel (an average number of operational experiences per serviceman of 1.26), split between the test-sites as shown in Figure 2-3.

2.3 The nuclear test participants today

On 1 January 1999, the date at which the test participant population was traced for the last NRPB report, 4,857 (23%) of the original 21,357 participants identified (including the 815 non military personnel) had died. The MoD has estimated that between 8,000 and 10,000 nuclear test veterans are likely to be living today.

The MoD has stated that almost all the British servicemen involved in the UK nuclear tests received little or no additional radiation exposure as a result of their participation[5], with only around 10% of personnel exposed to measurable levels of radiation[6]. Nevertheless, in 1983 and in response to the on-going concerns of some nuclear test veterans, the MoD commissioned the independent National Radiological Protection Board (NRPB), now part of the Health Protection Agency, to look at cancer incidence rates and mortality amongst nuclear test participants. The NRPB study linked data on over 20,000 nuclear test participants with data kept by the NHS Central Cancer Registry on cancer incidence and mortality and compared the results to a matched control group of a similar number of ex-servicemen who had served around the same time but had not participated in the nuclear

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[5] Source: MOD Atmospheric Nuclear Weapons Tests Factsheet 1 accessed at http://www.mod.uk/NR/rdonlyres/357B9CB8-B3E8-45C1-A966-8460907A0AF7/0/ntvfactsheet1.pdf

[6] Source: MOD Atmospheric Nuclear Weapons Tests Factsheet 5 accessed at http://www.mod.uk/NR/rdonlyres/D1BD228E-2E55-4254-8BB6-D083F50E7321/0/ntvfactsheet5.pdf

tests. The first report was published in 1988[7]. The analysis was extended and updated papers were published in 1993[8] and 2003[9]. The 2003 report concluded that overall levels of mortality and cancer incidence among nuclear test participants continued to be similar to those in the matched control group, and that overall mortality rates in the nuclear test veterans was lower than national (England and Wales) mortality rates in men. An exception was a possible slight increase in the incidence of certain types of leukaemia in the early years after the tests.

More recently, a study frequently mentioned by the veterans who took part in this audit, undertaken by Professor R.E. Rowland and his team from Massey University in New Zealand, looked at genetic damage amongst New Zealand naval veterans of the British Grapple series nuclear tests on Malden and Christmas Islands[10]. This was published in 2008. In the study, 50 veterans (who had been stationed on two New Zealand weather ships located between 34 km and 150 km up wind from the centre of the detonations) and 50 carefully age-matched controls (who had also undergone military or police training as young men) gave blood for analysis. The study showed a significant increase in the number of chromosome translocations (where fragments of chromosomes are broken off and attached to other chromosomes) in the DNA of the nuclear test participants when compared with the DNA of the controls. The authors concluded that this finding was “evocative of radiation” most likely to be attributed to radiation exposure. However it was acknowledged that study numbers were very small. There are different types and multiple known causes of translocation, notably ageing and some life style factors. It has been noted[11] that the veterans who participated in the study were volunteers, and may not be representative of New Zealand veterans as a whole. It is also important to note, as the report itself concludes, that the clinical significance of these findings in terms of presence or prediction of diseases is simply unknown to date. So far Professor Rowland’s findings have not been replicated in any other population.

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[7] **A summary of mortality and incidence of cancer in men from the United Kingdom who participated in the United Kingdom's atmospheric nuclear weapon tests and experimental programmes**, S C Darby et al, Br Med J (Clin Res Ed) 1988;296:332 doi:10.1136/bmj.296.6618.332

[8] **Further follow up of mortality and incidence of cancer in men from the United Kingdom who participated in the United Kingdom's atmospheric nuclear weapon tests and experimental programmes**, SC Darby et al, BMJ 1993 Dec 11;307(6918):1530-5.

[9] **Follow up of mortality and incidence of cancer 1952–98 in men from the UK who participated in the UK's atmospheric nuclear weapon tests and experimental programmes** C R Muirhead, D Bingham, R G E Haylock, J A O'Hagan, A A Goodill, G L C Berridge,M A English, N Hunter, G M Kendall *Occup Environ Med 2003;60:165-172* doi:10.1136/oem.60.3.165, updated version (published March 2004) accessed at http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1194947308572

[10] **Elevated chromosome translocation frequencies in New Zealand nuclear test veterans**, MA Wahab et al, Cytogenet Genome Res. 2008;121(2):79-87

[11] **Comments on “New Zealand Nuclear Test Veterans’ Study - A Cytogenetic Analysis” by RE Rowland et al [A Report by the Institute of Molecular Biosciences, Massey University,presented to the New Zealand Nuclear Test Veterans’ Association (2007)],** Radiation Protection Division of the Health Protection Agency, accessed at http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1284473852692

3 Respondents' Demographic Characteristics and Military Service History

This section covers:

- Respondents' demographic characteristics and current living arrangements
- Respondents' armed services history, including the number and location of nuclear test sites at which they were stationed

3.1 Introduction

Respondents were firstly asked to provide some basic demographic information about themselves and about their current living arrangements and to provide brief information about their military service history at the time of the nuclear tests.

This chapter presents a summary of the following data about the survey respondents:

Demographic Characteristics

- UK region currently living in
- Date of birth and age
- Current and previous marital status
- Current living arrangements
- Education attainment

Service History

- Which armed forces respondents served in
- How long they served
- Which and how many of nuclear test sites respondents were stationed at

Where data were readily available, comparison has been made with the wider test population as reported in the most recent NRPB report[12].

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[12] **Follow up of mortality and incidence of cancer 1952–98 in men from the UK who participated in the UK's atmospheric nuclear weapon tests and experimental programmes** C R Muirhead, D Bingham, R G E Haylock, J A O'Hagan, A A Goodill, G L C Berridge,M A English, N Hunter, G M Kendall *Occup Environ Med 2003;60:165-172* doi:10.1136/oem.60.3.165, updated version (published March 2004) accessed at http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1194947308572

3.2 Demographic characteristics

3.2.1 UK Regions where respondents currently live

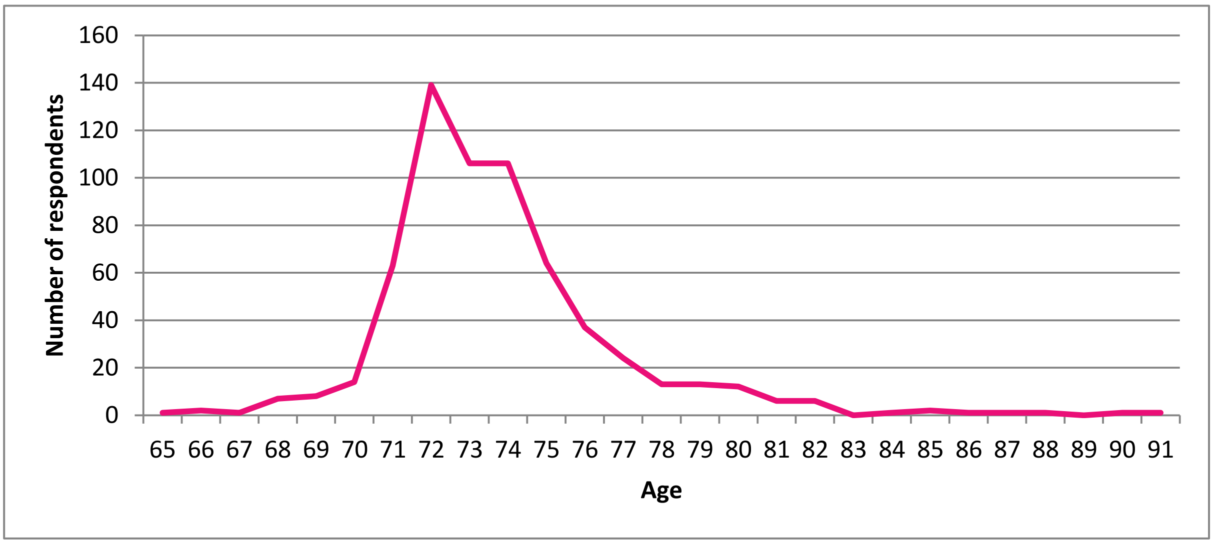
Of the 633 respondents, 533 (84.2%) currently live in England, 46 (7%) in Scotland and 43 (7%) in Wales. A very small numbers of respondents live in Northern Ireland (4) or in the Isle of Man, Guernsey, or didn't indicate where they live (7).

Within England, the largest number of respondents live in the South West (88) followed by the East of England (79) and then the North West (67). London and the North East were regions with the fewest respondents (21 and 31 respectively). In Scotland, there was a cluster of respondents living in Greater Glasgow and the Clyde (13) with the remaining respondents distributed in small numbers across the country. In Wales survey respondents were widely distributed across the county and no specific clusters were visible.

3.2.2 Age of survey respondents

Respondents were aged between 65 and 91 years old, with an average age of 74 years old. The large majority (81% or 515) of respondents were between 71 and 76 years old. Figure 3-1 shows the distribution of survey respondents' ages[13].

Figure 3-1 Distribution showing the age of survey respondents



3.2.3 Marital status

The majority of respondents (81%) reported being currently married or living with a partner. Only 5% (29) said they were divorced. Widowers made up 10% (69) of respondents. Of the widowers currently living alone 2% had been widowed for more than 10 years and 6% had been widowed less than 10 years.

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[13] Age is based on the age of survey respondents on 17th December 2010, the original closing date for Health Needs Audit postal survey.

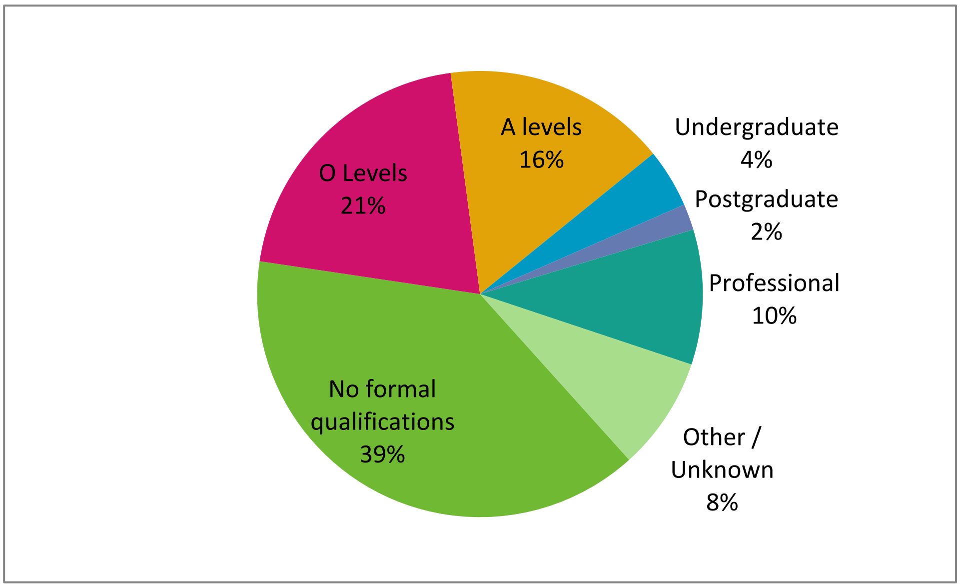
3.2.4 Living arrangements

91% of respondents (579) continue to live independently in a house or flat that they rent or own. A small number (15 or 2%) live in sheltered accommodation or with relatives or friends (14 or 2%). Only three people reported living in a residential care or nursing home.

3.2.5 Educational attainment

Respondents were asked to provide information about their highest level of qualifications and this was then compared with the most recently available (2001) census data for men in England and Wales of a similar age[14]. 39% of survey respondents reported having no formal qualifications, somewhat fewer than the census figure of 49% for men of a similar age in the general population. 21% of respondents had an 'O' level or equivalent vocational qualification compared to 18% in the census. 16% of respondents reported higher level qualifications (this includes degree level, postgraduate, and professional and vocational qualifications) very similar to the census figure of 15% [15].

Figure 3-2 Survey respondents' highest reported level of qualification



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[14] 2001 Census data, ONS: Standard tables - men aged between 60 to 64 (to reflect the average age of respondents at the time the data was gathered) by their highest level of qualification.

[15] The 'A level' description covers A' levels, Highers (Scotland), Apprenticeship qualification, NVQ level 3 or A.C.E. (1st class). The 'O'level' description covers O' levels, CSEs, Standard Grades (Scotland), NVQ level 2 or A.C.E. (3rd or second class).

Figure 3-3 Summary Table - Respondents' Demographic Characteristics

Demographic Characteristics	**Health Needs Audit Respondents**		**2001 Census males of similar age**
	Number	**%**	**%**
Total Respondents	**633**	**100**	n/a
Age			
Average age (years)	73.8		n/a
Aged 71-76 years - Number (%)	515	81%	n/a
Marital Status			
Married of living with a partner - Number (%)	512	81%	n/a
Widowers - Number (%)	69	10%	n/a
Divorced - Number (%)	29	5%	n/a
Housing			
Living in own or rented home - Number (%)		92%	n/a
Sheltered accommodation - Number (%)	15	2%	n/a
Living with relatives/friends - Number (%)	14	2%	n/a
Place of Residence			
England	**533**	**84%**	n/a
East Midlands	45		
East of England	79		
London	21		
North East England	31		
North West	67		
South Central	57		
South East Coast	57		
South West	88		
West Midlands	36		
Yorkshire and the Humber	52		
Scotland	**46**	**7%**	n/a
Glasgow/Clyde	13		
Wales	**43**	**7%**	n/a
Northern Ireland	4		n/a
Elsewhere and/or blank	**7**		
Educational Attainment			
No formal qualifications		39%	49%
O level or equivalent		21%	18%
Higher level qualifications		16%	14%

3.3 Service History

Respondents were asked to provide information on which armed forces they had served in, the year they joined, how many years they had served and the rank they were when they left service. The latter question was not analysable because of the wide varieties of ways in which ranks were described. They were also asked which nuclear test site or sites they had been stationed at and when.

Figure 3-4 summarises the information returned by survey respondents on their service history and, where data are available, comparison is made with the data reported in the 2003 NRPB study for the total nuclear test service population.

Figure 3-4 Summary Table – Respondents' Service History

Service History	**Notes**	**Health Needs Audit Respondents**		**All British Service Personnel Involved in the Tests**	
		Number	**%**	**Number**	**%**
Number of survey respondents / test participants		**633**		**21,357**	
Armed Services		633	100%	20,542	96%
Civilians		0	0%	815	4%
Armed Force served in					
RAF		285	45%	8443	41%
Army		242	38%	5794	28%
Navy & Royal Marines		106	17%	6305	31%
Total		**633**		**20542**	
Type of service					
National Service	1[16]	152	24%	2,402	12%
Professional Armed Service personnel		481	76%	18140	88%
Nuclear test sites where stationed					
Christmas Island or Malden Island	2[17]	532	80%	18066	70%
Maralinga (inc. operation Brumby)		69	10%	5168	20%
Monte Bello, Pearce Field and Edinburgh Field		63	10%	2646	10%
Emu Field		2	0.3%	21	0.1%
Number of test sites served at					
1 nuclear test site - Number (%)		571	90%		
More than 1 nuclear test site - Number (%)		59	9%		
Average length of time (years) at nuclear test sites					
RAF		1.8			
Army		1.8			
Navy		1.6			
Royal Marines		2.1			

3.3.1 The armed services in which respondents served

Survey respondents served in the following armed services:

- 45% served in the RAF,
- 38% served in the Army and

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[16] (1) National Service – amongst the survey respondents, the no. and % given is those who reported that they served less than 2 years in the armed forces.

[17] (2) The total does not reconcile to total respondents / test participants, because some were stationed at more than one site.

- 17% in the Navy and Royal Marines[18].

Whereas for the total nuclear test service population

- 41% served in the RAF,
- 28% served in the Army and
- 31% in the Navy and Royal Marines.

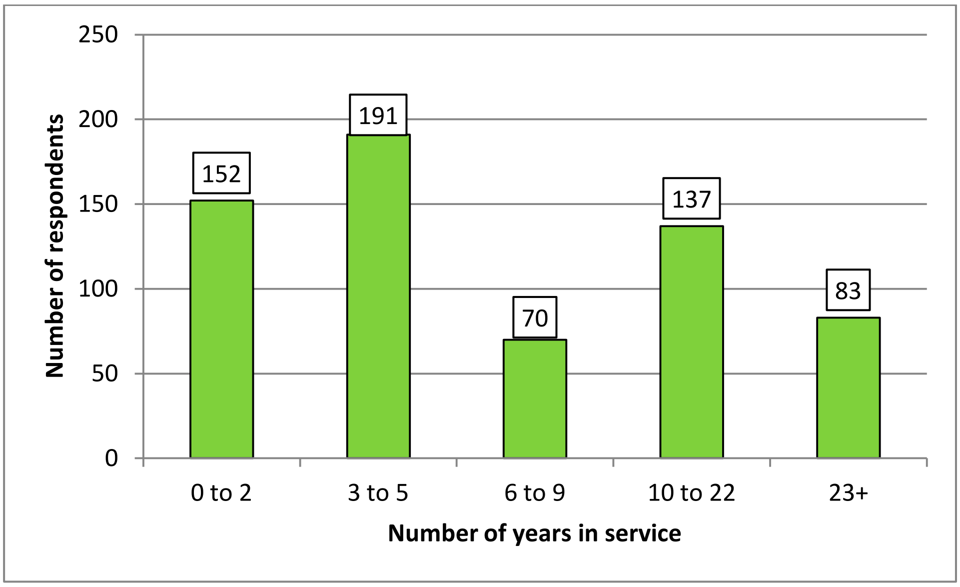
3.3.2 Length of service by type of armed force

For survey respondents, the average length of service varied by armed force in which respondents served.

- Those in the RAF served on average 9.4 years
- Those in the Army had the lowest average length of service, at 6.4 years.
- Those in the Navy served on average 10.5 years, and
- Those in the Royal Marines served on average 7.2 years.

Many survey respondents served for much shorter periods with over half (54% or 343) serving for less than 6 years.

Figure 3-5 Number of years served in the armed forces by survey respondents



Comparison with the published data on all nuclear test participants suggests that there was a larger proportion of those on national service amongst the audit survey respondents than amongst the test population as a whole. The survey did not specifically ask respondents whether they were on national service, but 12% of the overall test population were on national service, compared with 24% of survey respondents who said they served in the forces for less than 2 years.

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[18] For the purpose of comparison with NRPB data, Royal Marines are grouped under 'Navy'. 15 survey respondents reported themselves as members of the Royal Marines

3.3.3 The nuclear test sites at which respondents were stationed

80% of survey respondents were stationed either on Christmas Island and/or on Malden Island at some time during the period of nuclear testing and clean-up. This compares with 70% of the total nuclear test population. 10% were stationed at Maralinga (including operation Brumby), compared to 20% of the total nuclear test population and 10% reported being stationed at either Monte Bello, Pearce Field and/or Edinburgh Field (a similar number to the total test population). A very small number (2) were stationed at Emu Field.

90% of survey respondents (571) reported being stationed only at only one nuclear test site during the period of nuclear testing/clean-up and 9% (59) reported being stationed at more than one test site. Half of those reporting being stationed at two sites were respondents serving in the RAF at the time. A very small number of respondents reported being stationed at three or four sites (3 and 5 survey respondents respectively).

4 Respondents' Health History and Current Health Status

This section covers:

- The information which survey respondents were asked for, and warnings about the validity of the data collected
- Respondents' health history and reported serious and long term conditions, grouped by ICD-10 disease category
- The age of diagnosis by disease category
- Prevalence of specific conditions within each disease category
- Respondents' current health status as measured by the EQ-5D survey tool
- Respondents' current disabilities

4.1 Introduction

Survey respondents were asked to provide details of any serious or long-term health conditions which had been diagnosed by a doctor, at any time since their participation in the nuclear tests, up to the present. Respondents were left to define for themselves what conditions they considered 'serious'.

In order to assess their *current* health and social care needs, respondents were also asked to complete the EQ-5D questionnaire - a simple and validated "quality of life" or health-status assessment questionnaire. This asks people to identify how they feel they are (on the day they are completing the questionnaire) across five 'domains' of health or social care functioning; mobility; self-care; performing usual activities; pain and discomfort; and, anxiety and depression. An overall measure of an individuals' 'health status' can then be calculated using their individual scores to each domain.

Finally, survey respondents were also asked if they considered themselves to have a disability and, if so, to provide more details.

Throughout the remainder of this report, use the term 'condition(s)' as a substitute for all other relevant terms, e.g. illnesses, disease, serious illness, or long or short-term condition, etc.

Data validity issues

It is important to highlight that, for a number of reasons, there are significant validity issues attached to the data presented in this chapter. Great caution needs to be taken when interpreting these data. It is not possible or appropriate to try to make comparisons about the reported levels of ill-health of the survey respondents with that of the wider population or even with males in the same age-band.

The reasons for this are outlined fully in the methods chapter or linked appendices. However, the key points about data quality are:

- Respondents' definition and description of "serious illnesses or long-term conditions" (referred to hereafter for ease as 'conditions') are wholly ***self-defined and self-reported***. It was not within the scope of this audit to verify the information provided and the data on the prevalence of different conditions presented in this report have therefore not been independently validated.
- The respondents determined for themselves what they considered to be a (doctor diagnosed) serious illness or long-term condition. Some conditions reported are very clearly identifiable as 'serious' whilst others may not be classified as such. However, they may well be serious for the individual concerned.
- There was considerable variation in the level of detail and the accuracy in describing their conditions and/or medical terms. There were many different ways in which respondents described potentially similar individual conditions. Overall disease-specific classification and analysis was in some cases problematic.

4.2 Respondents' health history and reported conditions

Respondents were asked whether they had been diagnosed by a doctor with a serious illness or long term condition, at any time since their participation in the nuclear tests.

If they had, they were invited to provide brief details about each condition, including its name (and a brief description if they wished), the year first diagnosed, whether the condition was now resolved (and if so when) or whether they still suffered from the condition currently.

For analytical purposes, respondents were asked to list their conditions in broad disease categories or groups, using the internationally recognised WHO disease-classification system known as ICD-10. [19]

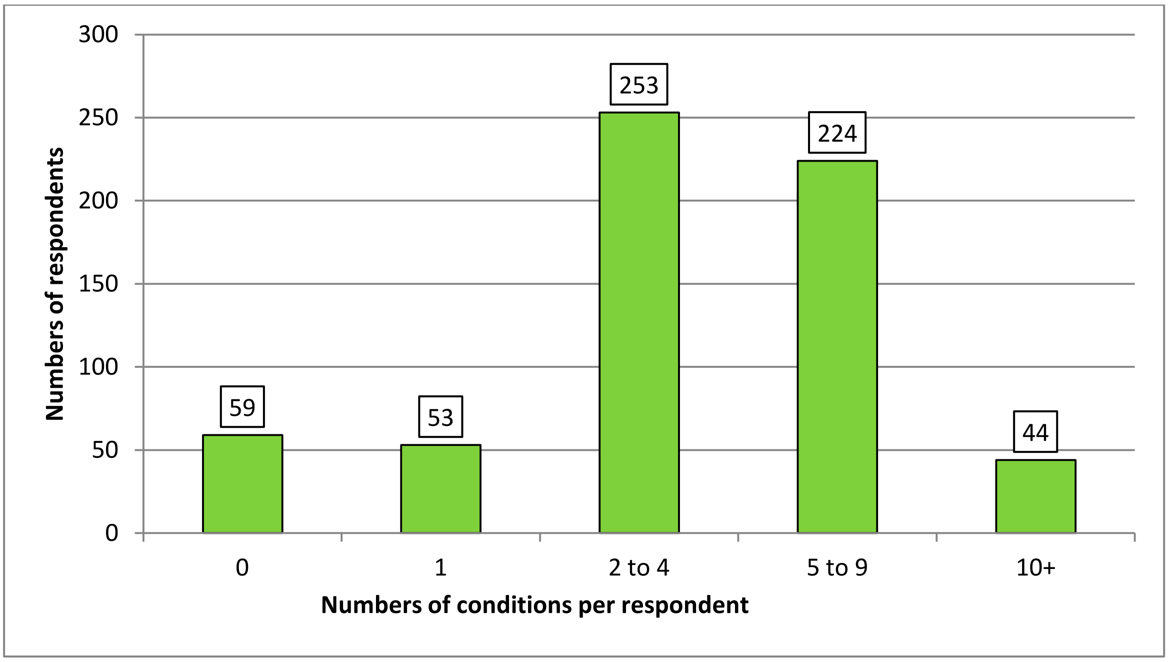
4.2.1 Number of respondents who have had a condition since the tests

Of the 633 survey respondents, 574 (91%) reported having been diagnosed (by a doctor) with what they considered to be a serious or long term condition since their participation in the nuclear tests, and 59 (9%) reported having never had a serious condition.

4.2.2 Number of concurrent conditions per respondent

Of the 574 who reported a serious or long term condition, 53 respondents (9%) reported having had just one condition, 253 (44%) reported having had 2 to 4 conditions, 224 (39%) reported having had 5 to 9 conditions and 44 (8%) reported having had 10 or more conditions (see Figure 4-1)

Figure 4-1 Numbers of serious or long term conditions reported by respondents since the tests (ever had)



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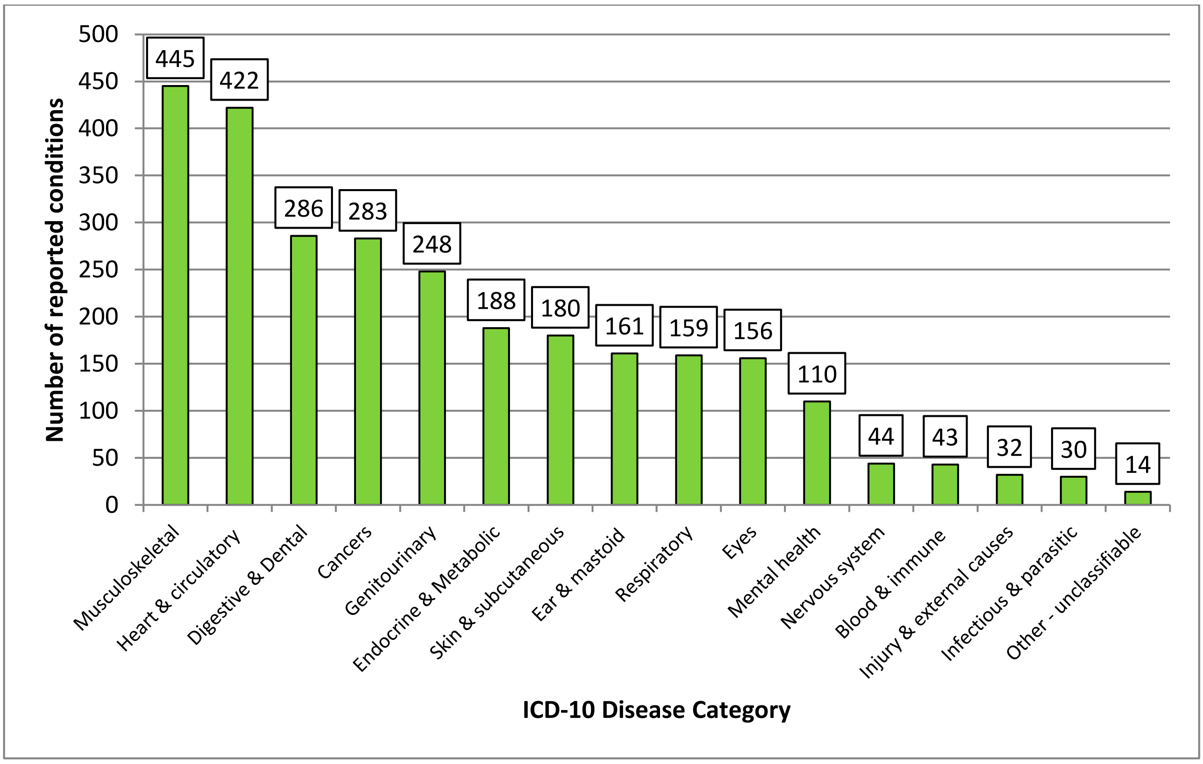
[19] See http://www.who.int/classifications/icd/en/

4.2.3 Number of conditions (ever had) by ICD-10 disease category

Amongst the 574 respondents who provided information on their conditions, a total of 2,801 different conditions were reported (including both current and resolved conditions – called 'ever had' in this report). Figure 4-2 shows the numbers of reported conditions by the broad ICD-10 'chapter level' disease categories.

Figure 4-2 Number of reported conditions diagnosed since nuclear tests (ever had) by ICD-10 disease category



N.B. This is a count of the different reported diseases or conditions and is NOT a count of individual respondents. A single respondent could have reported more than one condition in the same, or any other, disease group or category.

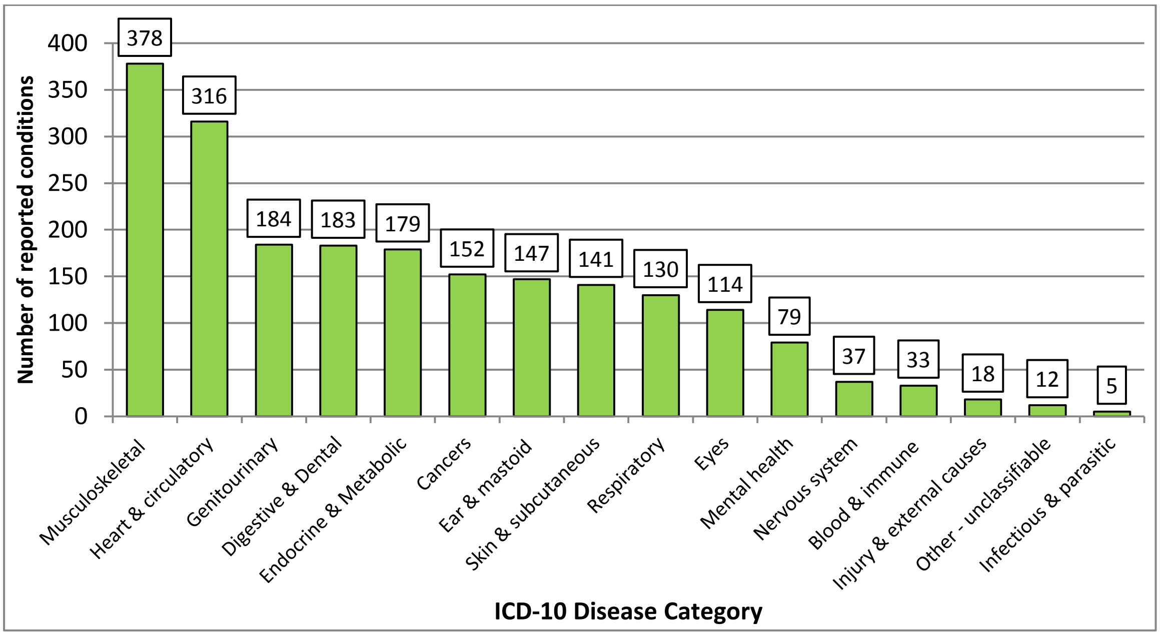
Five disease categories represented over 60% of all the reported conditions, with:

- 445 (16%) were diseases of the musculoskeletal system,
- 422 (15%) were diseases of the heart or circulatory system,
- 286 (10%) were diseases of the digestive system (which include serious dental problems)
- 283 (10%) were cancers (including non-melanoma skin cancers)
- 248 (9%) were genitourinary conditions (which include benign prostate problems).

4.2.4 Number of current conditions by ICD-10 disease category

Figure 4-3 shows the numbers of current reported conditions by ICD-10 disease category. Diseases of the musculoskeletal system and diseases of the heart or circulatory system continue to predominate with musculoskeletal problems reported having more than twice the prevalence of the 3rd most prevalent group of conditions (genitourinary). There is a similar prevalence in the genitourinary, digestive (and dental) and endocrine and metabolic diseases.

Figure 4-3 Number of current conditions - by ICD-10 disease category

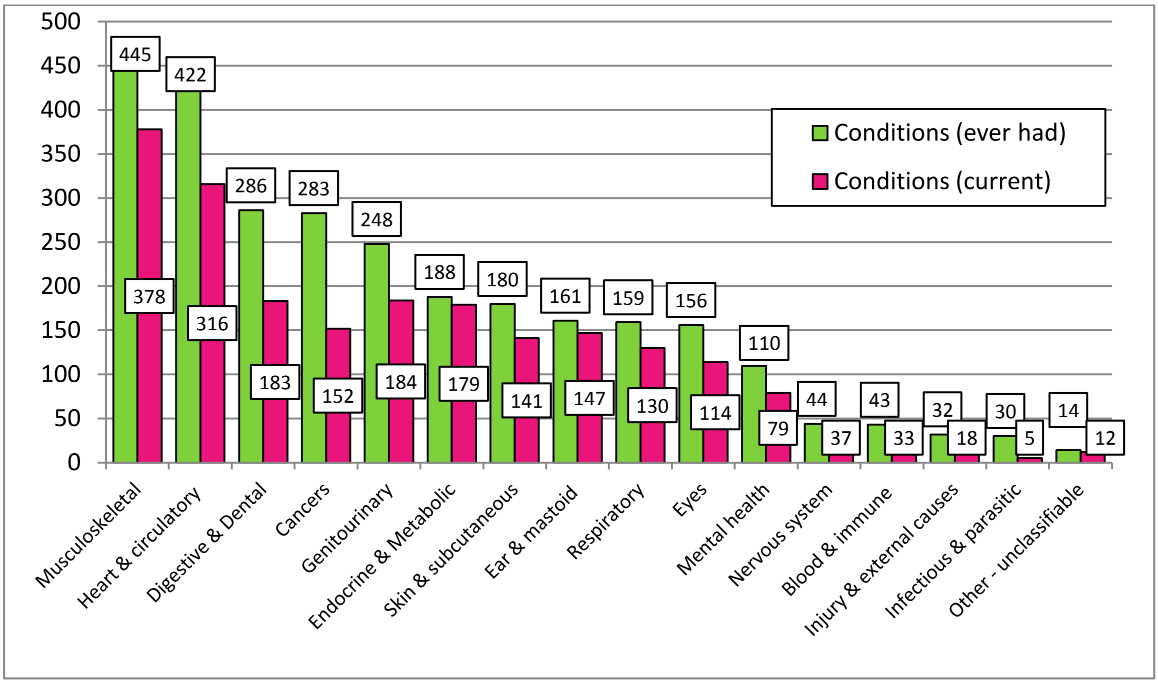


4.2.5 Comparison of current conditions and all conditions (ever had) since tests

Respondents also provided information on whether their conditions had resolved and if so when.

Figure 4-4 shows both the numbers of 'ever had' conditions and current conditions side by side. This provides a clear picture of how different diseases have resolved over the period, whilst others continue to be a major burden of disease in this group.

Figure 4-4 Comparison of current and 'ever had' conditions - by ICD-10 disease category

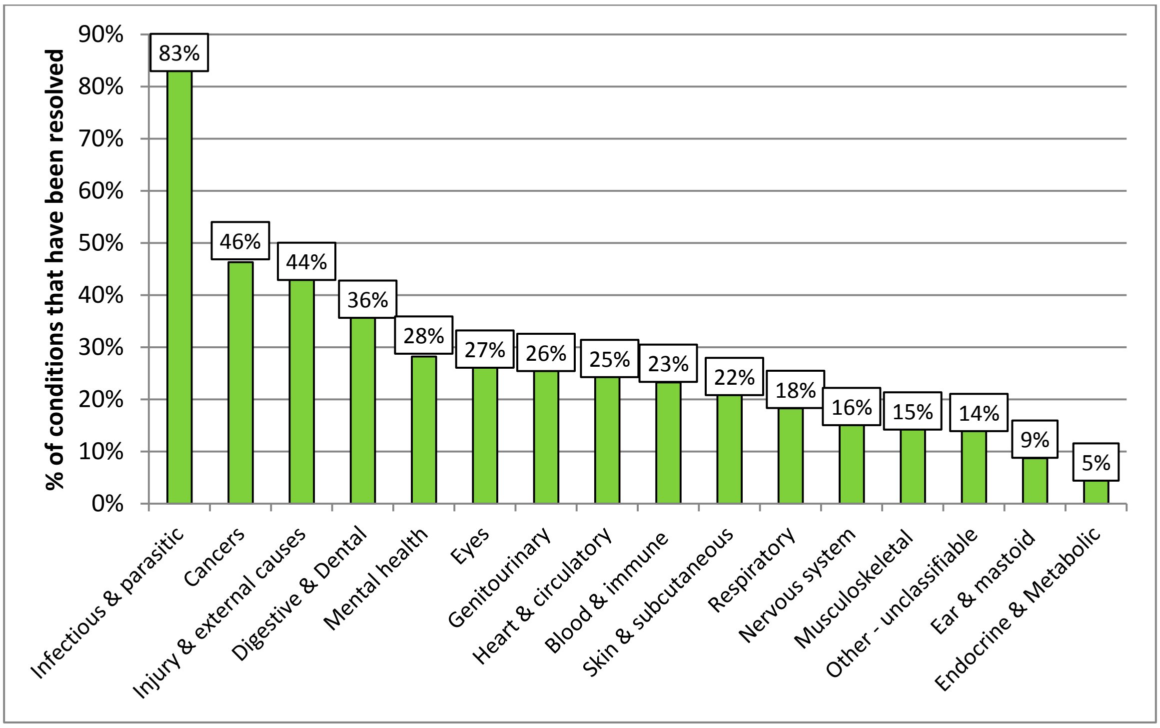


- Musculoskeletal problems, diseases of the heart and circulatory system, and diseases of the digestive system (including serious dental) continue to be the most prevalent - both currently and 'ever had' the conditions respondents have 'ever had'.
- However, diseases of the genitourinary system are reported to be the 3rd most prevalent group of 'current' conditions, whereas they were the 5th most prevalent in the 'ever had' conditions. This is likely to be a feature of ageing – particularly with the increase prevalence of benign prostate problems in men of this age-group.
- Cancer, is ranked as the 4th most prevalent in the 'ever had' conditions (representing only 10% of all serious reported conditions), and interestingly is then ranked 6th in the 'current conditions'. The current reported prevalence of cancer is nearly half of the 'ever had' numbers – implying many respondents with cancer are now 'cancer survivors' and their cancers have resolved or been treated effectively.
- Mental health problems, diseases of the nervous system, blood disorders and immune conditions, injury, poisonings, or other external forces, infectious and parasitic diseases, and 'other unclassifiable' conditions – together only represent 10% of the current conditions.

When looking at the proportion (or percentage) of conditions reported by respondents as 'resolved', some categories (as might be expected) show a higher proportion of recovery or resolution than others (see Figure 4-5). For example, only 5% of endocrine conditions (primarily diabetes) have been resolved (or have been stabilised with treatment), 9% of ear and mastoid processes conditions (mainly to do with hearing) and 15% of musculoskeletal conditions diseases have resolved. At the other end of the spectrum, 83% of infectious and parasitic diseases are reported to have resolved, and (perhaps less obviously) 46% of the cancers are reported as having been resolved. But the proportions are affected by the size of the original numbers of conditions reported in the first place. So – although 83% of infections and parasitic diseases are reported as resolved – there were only 30 reported in total (ever had) and only 5 conditions currently classifiable in this group – so very small numbers both currently and ever had.

Overall, 693 (25%) of the 2801 conditions which the respondents had ever had, had resolved at the time of the audit.

Figure 4-5   Proportion of conditions within each disease category that have been resolved



4.2.6 The age of diagnosis by disease category

The ICD-10 disease categories were also analysed by the decade of reported diagnosis and grouped into three broad age-bands:

- Early life (age 20 – 45 years)
- Mid-life (age 45– 64 years)
- Later life (age 65 years and over)

Only conditions for which respondents had provided a year of diagnosis could be included in this analysis, therefore 592 conditions are excluded from this analysis because they did not report a date of diagnosis. A further 21 were excluded because they were conditions diagnosed prior to the date that respondents reported being stationed at a nuclear test site.

Figure 4-6 presents the percentage of conditions in each of the broad disease categories, which were diagnosed in early life (20-45 years), mid-life (45-64 years) and later life (65 years plus). Green shaded cells denote the stage of life in which the disease type was predominantly diagnosed amongst the audit respondents.

Figure 4-6 Table showing percentage of conditions diagnosed in each age band

	Early Life	**Mid-life**	**Later Life**	**All Ages**
Disease Chapter	**20-44 years**	**45-64 years**	**65 years plus**	**Numbers**
Blood & immune	9%	30%	61%	33
Cancers	9%	28%	63%	257
Digestive & Dental	41%	33%	26%	227
Ear & mastoid	23%	56%	21%	110
Endocrine & Metabolic	6%	52%	41%	170
Eyes	17%	23%	59%	111
Genitourinary	24%	31%	44%	192
Heart & circulatory	9%	44%	47%	342
Infectious & parasitic	70%	10%	20%	20
Injury & external causes	58%	25%	17%	24
Mental health	47%	38%	15%	79
Musculoskeletal	22%	47%	31%	344
Nervous system	24%	24%	51%	37
Other - unclassifiable	56%	11%	33%	9
Respiratory	26%	34%	41%	113
Skin & subcutaneous	56%	27%	18%	120
All Diseases	**23%**	**37%**	**40%**	**2,188**

Overall, across all the reported conditions, 40% of disease onset was in later life, 37% in mid-life and 23% in early life. The disease categories with the highest onset in early life were:

- Infectious and parasitic diseases - 70% in early life, and
- Injury, poisoning and other external forces - 58% in early life.

The disease categories with the highest onset in mid-life were

- Ear and mastoid process - 56% in mid-life, and
- Endocrine and metabolic - 52% in mid-life.

The disease categories with the highest onset in later life were

- Cancers - 63% in later life
- Blood and certain immune disorders - 61% in later life, and
- Eyes - 59% in later life.

Figure 4-7 shows these data graphically - ranked by the percentage diagnosed in later life.

Figure 4-7 Percentage of cases diagnosed within each condition by each 20-year age-band

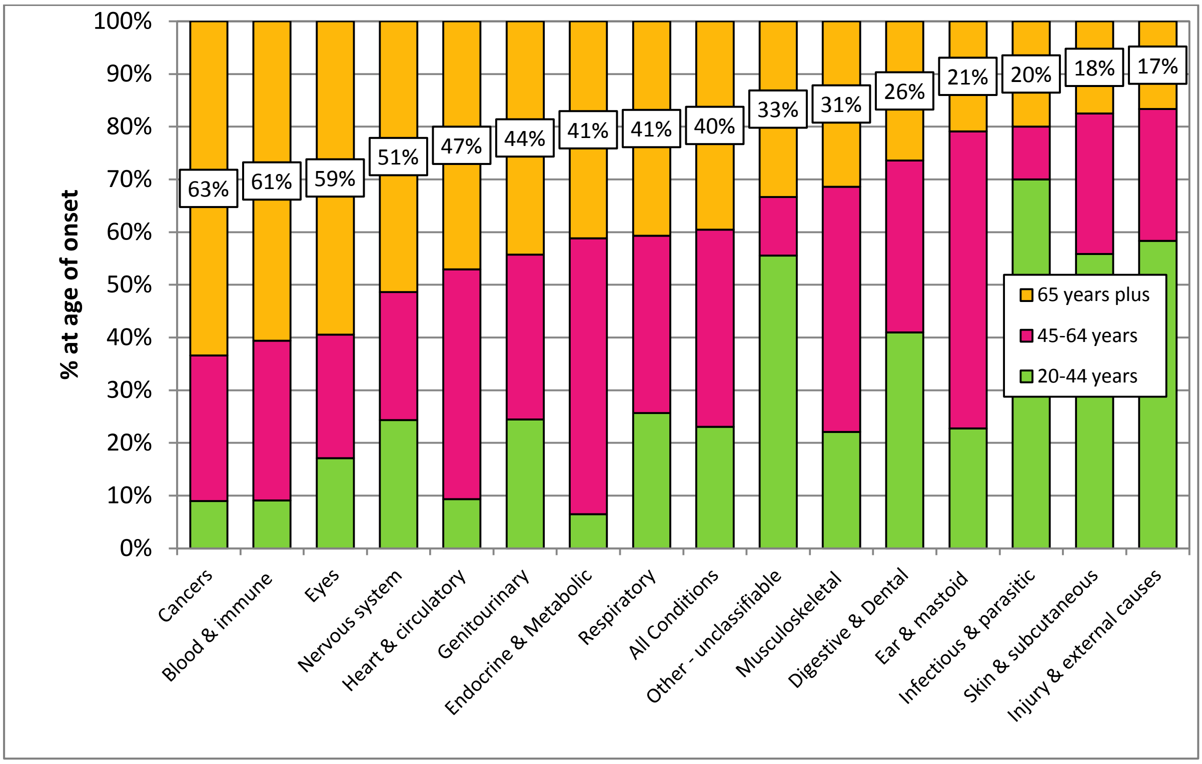
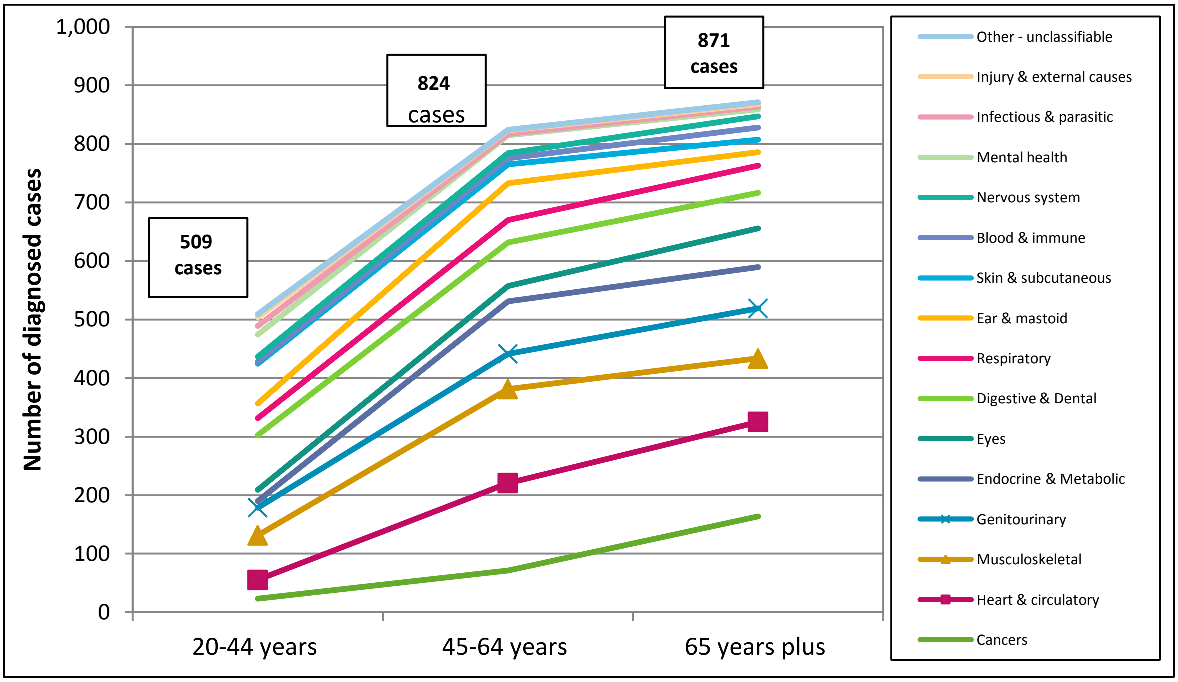


Figure 4-8 shows all the reported numbers of diagnosed cases (ever had), by broad disease category, grouped into the 3 age-bands in which they were first diagnosed.

This shows how the incidence of different diseases rises and/or falls in different age-groups. It also clearly shows clearly how the overall burden of disease has increased as respondents have aged.

Figure 4-8 All reported diagnosed cases (ever had) by disease category - cumulative number

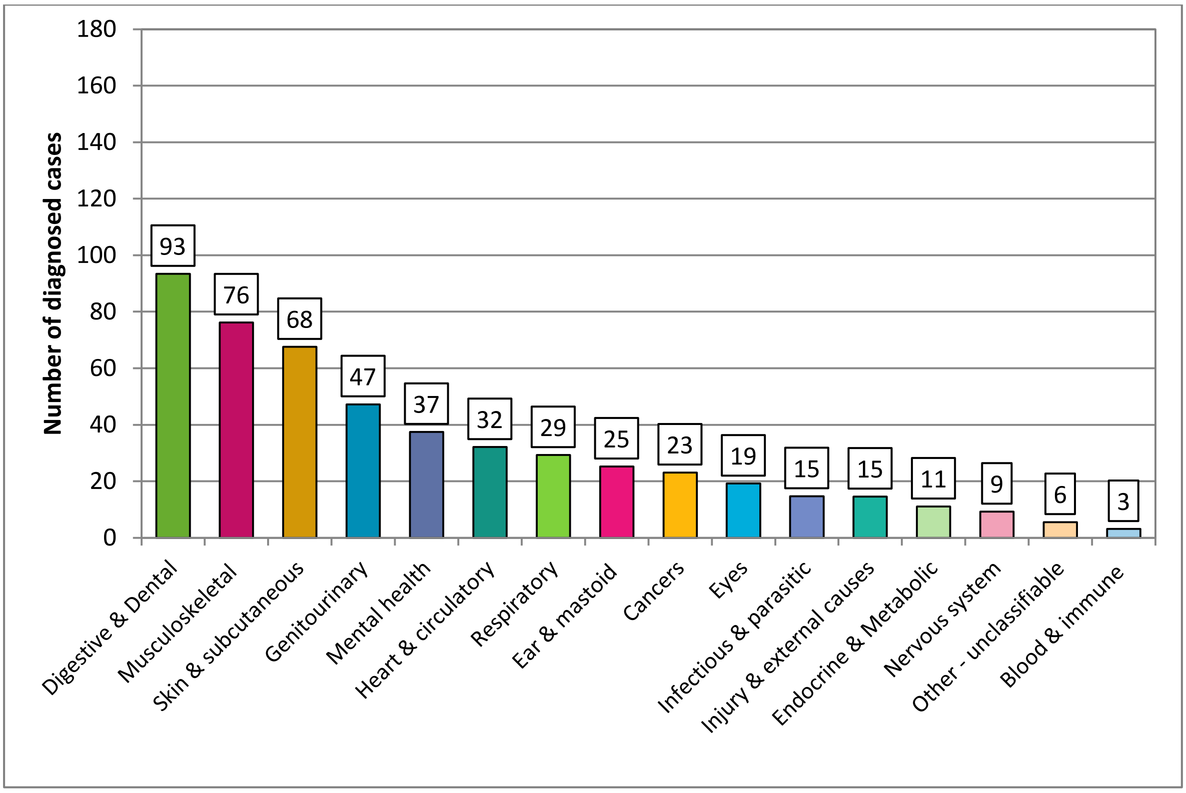


In total, across all the conditions, there were

- 509 diagnosed cases in the early life age-group
- 824 diagnosed in the mid-life age-group, and
- 871 diagnosed cases in the later life age-group.

Figure 4-9 shows the diseases most commonly diagnosed when respondents were aged 20-44 years.

Figure 4-9 The numbers of diagnosed cases by disease group in respondents in early life (20-44 years)

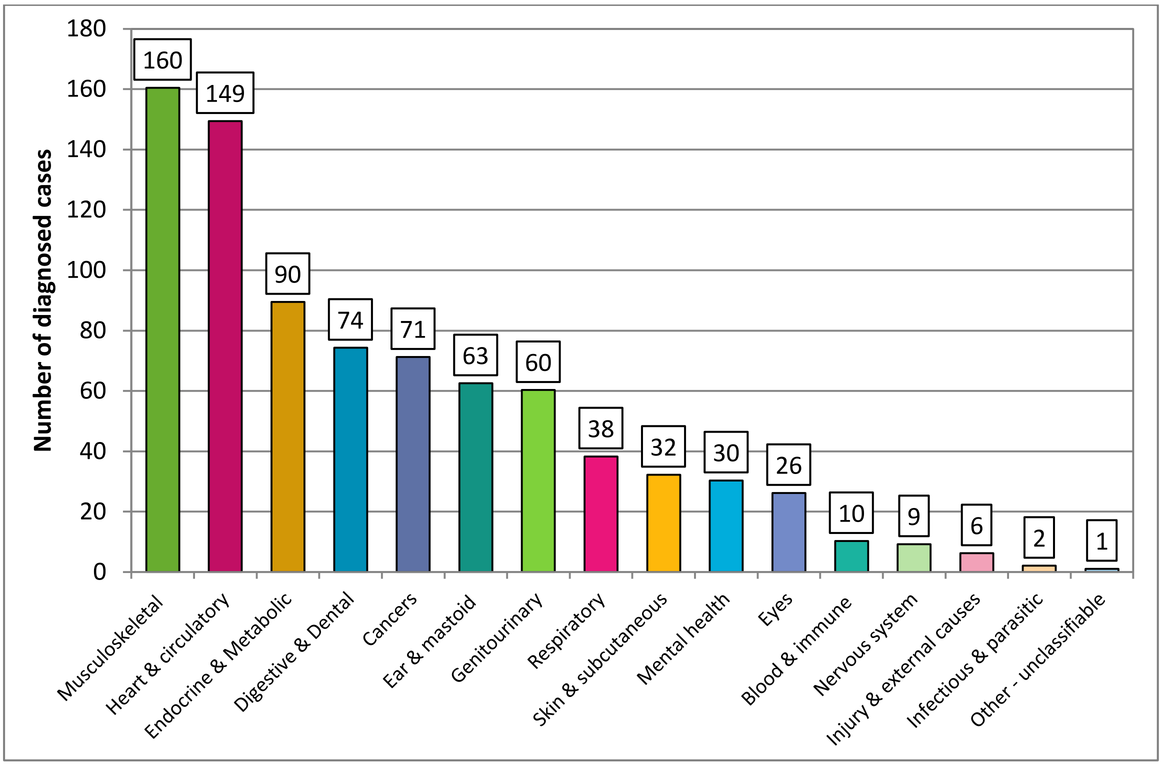


The diseases most commonly diagnosed when respondents were aged 20-44 years were:

- Digestive system and dental problems (93 cases)
- Musculoskeletal system and connective tissue (76 cases), and
- Skin and subcutaneous tissue (68 cases).

Figure 4-10 shows the diseases most commonly diagnosed when respondents were aged 45-64 years.

Figure 4-10 The numbers of diagnosed cases by disease group in respondents in mid-life (45-64 years)

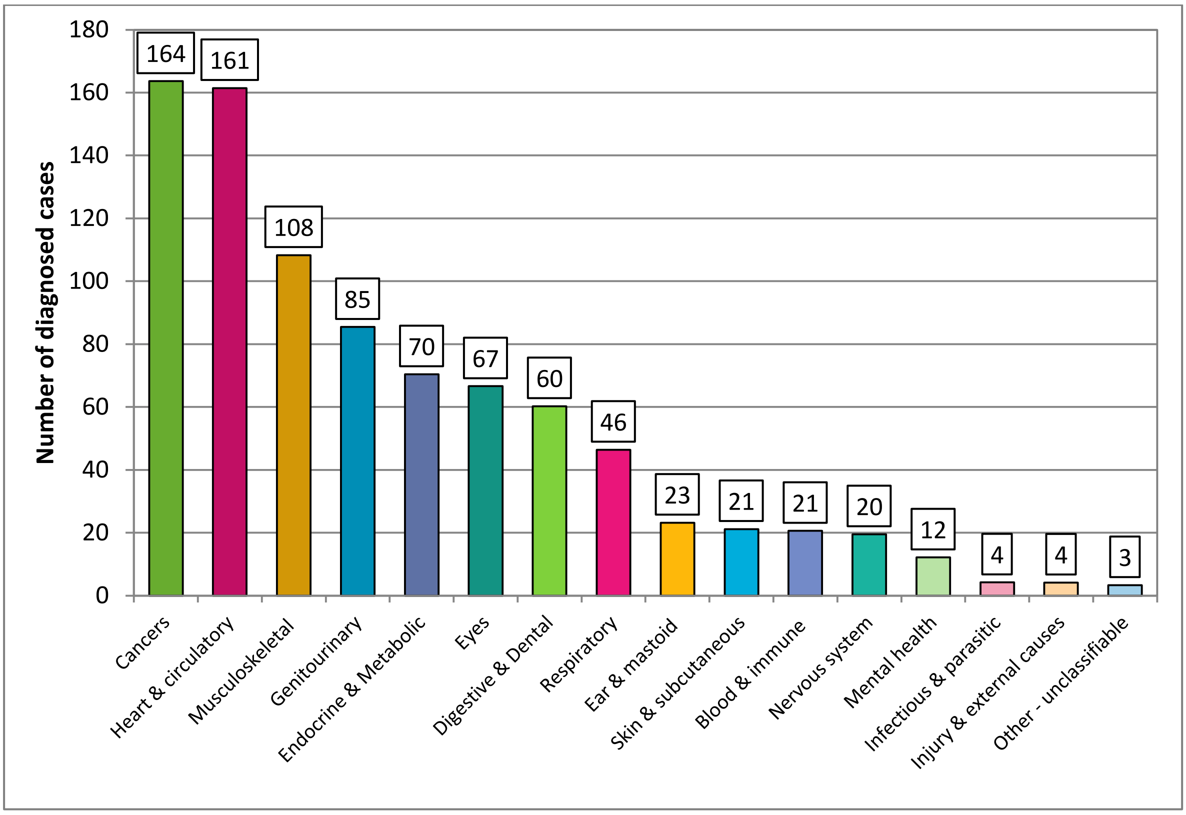


The diseases most commonly diagnosed when respondents were aged 45-64 years were:

- Musculoskeletal system and connective tissue (160 cases)
- Heart and circulatory system (149 cases) and
- Endocrine and metabolic (90 cases).

Figure 4-11 shows the diseases most commonly diagnosed when respondents were aged 65 years and over.

Figure 4-11 The numbers of diagnosed cases by disease group in respondents in later life (65 years and over)



The diseases most commonly diagnosed when respondents were aged 65 years and over were:

- Cancers (164 cases)
- Heart and circulatory system (161 cases) and
- Musculoskeletal system and connective tissue (108 cases).

4.2.7 Prevalence of specific conditions within the ICD-10 disease categories

As explained in the introduction, more detailed analysis of the specific conditions reported by respondents proved problematic, due to the considerable variation in the accuracy of the names and descriptions of individual diseases. However, despite the concerns about the accuracy of some the information, a break-down of the conditions within each ICD-10 category is provided in Figures 4-12 and 4-13 below. Only conditions where there are four or more reported conditions are listed. Figure 4-12 shows the current conditions respondents report living with now and Figure 4-13 shows the conditions that respondents report having ever had since the nuclear tests.

Disease or condition names used by respondents have been corrected where there were simple or obvious errors.

Figure 4-12 Respondents' Current Reported Conditions – grouped by ICD-10 Disease Category

Broad disease category			Illness / condition category		
Disease category	**Total number of diseases reported in each category**	**% of all diseases reported**	**Illness / condition**	**Total number of illnesses / conditions reported**	**% of disease category total**
Musculoskeletal system and connective tissue	378	18%	Arthritis	196	52%
			Spondylosis/ spondylitis	39	10%
			Osteoporosis	37	10%
			Spine problem	13	3%
			Knee replacement	7	2%
			Pain - in back	7	2%
			Prolapsed vertebrae	7	2%
			Nerve damage and sciatica	5	1%
			Polymyalgia Rheumatica	5	1%
			Dupuytren's contracture	4	1%
			Pain - in neck	4	1%
			Hip replacement	4	1%
			All Others	50	13%
Heart and circulatory system	316	15%	Heart Attack	60	19%
			Hypertension	56	18%
			Arrhythmia	37	12%
			Angina	34	11%
			Coronary Artery Disease	32	10%
			Stroke	29	9%
			Vascular disease	8	3%
			Heart Failure	8	3%
			Aneurism	6	2%
			Poor circulation	6	2%
			TIA	5	2%
			Varicose veins	5	2%
			Circulatory disease	4	1%
			All Others	26	8%
Genitourinary system	184	9%	Prostate - enlarged	87	47%
			Bladder problems	32	17%
			Kidney disease	30	16%
			Infertility	21	11%
			Erectile dysfunction	4	2%
			All Others	10	5%
Digestive System and Dental	183	9%	Dental - Gum disease, decay & tooth loss	36	20%
			Diverticular disease	20	11%
			Hernia	17	9%
			Peptic ulcer	14	8%
			IBS	12	7%
			Gastric Reflux Disease	9	5%
			Gall bladder	8	4%
			Ulcerative Colitis	7	4%
			Duodenal ulcer	7	4%
			Digestive - Other not specified	6	3%
			Diarrhoea	5	3%
			Polyps	5	3%
			Pancreas problems	4	2%
			Liver disease	4	2%
			All Others	29	16%
Endocrine & Metabolic	179	8%	Diabetes	132	74%
			Hypothyroidism	21	12%
			Thyroid problems	11	6%
			High cholesterol	7	4%
			All Others	8	4%

Broad disease category			Illness / condition category		
Disease category	**Total number of diseases reported in each category**	**% of all diseases reported**	**Illness / condition**	**Total number of illnesses / conditions reported**	**% of disease category total**
Cancers	152	7%	Urological Cancers	49	32%
			Skin cancers (inc BCC, SCC & other)	47	31%
			Haematological Cancers	17	11%
			Colorectal Cancer	11	7%
			Head and Neck Cancer	6	4%
			Lung cancer	5	3%
			All Others	17	11%
Ear and mastoid processes	147	7%	Hearing loss	114	78%
			tinnitus	20	14%
			All Others	13	9%
Skin and subcutaneous tissue	141	7%	Rash or Dermatitis	52	37%
			Psoriasis	19	13%
			Growths, Warts and Cysts	18	13%
			Infections - bacterial and fungal	16	11%
			Keratosis and/or sun damage	11	8%
			Dry skin	10	7%
			Vitiligo	5	4%
			All Others	10	7%
Respiratory system	130	6%	Asthma and/or breathing problems	51	39%
			COPD	28	22%
			Plural plaque	6	5%
			Lung disease	5	4%
			Obstructive sleep apnoea	4	3%
			Bronchitis	4	3%
			Pneumonia	4	3%
			Emphysema	4	3%
			Asbestosis	4	3%
			All Others	20	15%
Eyes	114	5%	Cataracts	27	24%
			Poor eyesight	24	21%
			Glaucoma	22	19%
			Macular degeneration	11	10%
			Blepharitis	6	5%
			Retinal problems	5	4%
			All Others	19	17%
Mental health	79	4%	Anxiety, depression or stress	64	81%
			Dementia	6	8%
			All Others	9	11%
Nervous system	37	2%	Parkinson's disease	7	19%
			Epilepsy	7	19%
			Headaches	6	16%
			Neuropathy	5	14%
			All Others	12	32%
Blood and certain immune disorders	33	2%	Anaemia	12	36%
			Blood disorder - General	6	18%
			All Others	15	45%
Injury, poisoning and other external forces	18	1%	Injury - back	4	22%
			Coral poisoning	3	17%
			All Others	11	61%
Other - signs, symptoms unclassifiable elsewhere	12	1%	All Others	12	100%
Infectious & parasitic diseases	5	0%	All Others	5	100%

Figure 4-13 Respondents' reported 'ever had' conditions – grouped by ICD-10 Disease Category

Broad disease category			Illness / condition category		
Disease category	**Total number of diseases reported in each category**	**% of all diseases reported**	**Illness / condition**	**Total number of illnesses / conditions reported**	**% of diseases category total**
Musculoskeletal system and connective tissue	445	16%	Arthritis	217	49%
			Spondylosis/ Spondylitis	41	9%
			Osteoporosis	38	9%
			Spine problem	16	4%
			Pain - in back	11	2%
			Hip replacement	9	2%
			Prolapsed vertebrae	9	2%
			Knee replacement	8	2%
			Dupuytren's contracture	7	2%
			Nerve damage and sciatica	6	1%
			Polymyalgia Rheumatica	6	1%
			Bone spurs	6	1%
			Pain - in neck	5	1%
			Bone fractures & dislocations	4	1%
			Knee Cartilage damage	4	1%
			Gout	4	1%
			All Others	54	12%
Heart and circulatory system	422	15%	Heart Attack	78	18%
			Hypertension	60	14%
			Stroke	50	12%
			Coronary Artery Disease	41	10%
			Angina	40	9%
			Arrhythmia	39	9%
			Aneurism	15	4%
			Heart Failure	11	3%
			Vascular disease	9	2%
			TIA	9	2%
			Varicose veins	7	2%
			Poor circulation	7	2%
			Circulatory disease	4	1%
			Carotid Artery Disease	4	1%
			DVT	4	1%
			Ulcers	4	1%
			Haemorrhoids	4	1%
			Pulmonary embolism	4	1%
			All Others	32	8%
Digestive System and Dental	286	10%	Dental - Gum disease, decay & tooth loss	60	21%
			Gall bladder	35	12%
			Hernia	24	8%
			Diverticular disease	21	7%
			Peptic ulcer	19	7%
			Duodenal ulcer	16	6%
			IBS	12	4%
			Gastric Reflux Disease	10	3%
			Ulcerative Colitis	9	3%
			Polyps	9	3%
			Digestive - Other not specified		0%
			Liver disease	7	2%
			Pancreas problems	6	2%
			Diarrhoea	5	2%
			All Others	53	19%

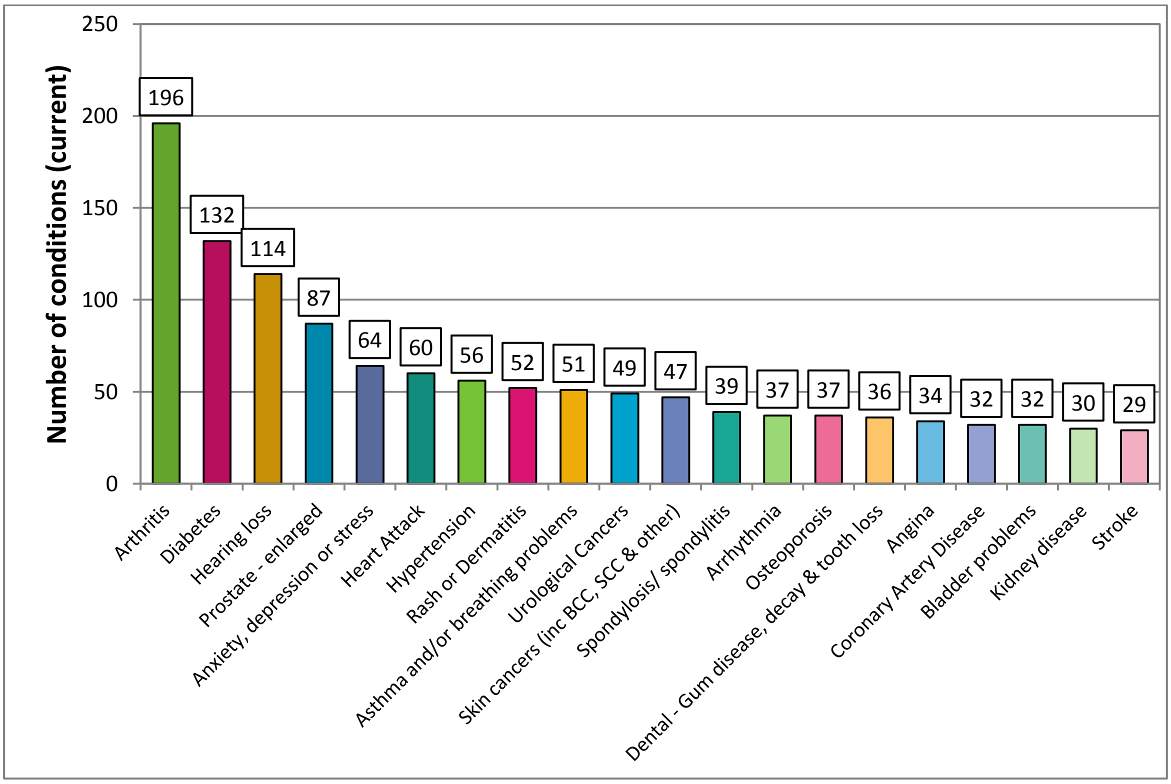
Broad disease category			Illness / condition category		
Disease category	Total number of diseases reported in each category	% of all diseases reported	Illness / condition	Total number of illnesses / conditions reported	% of diseases category total
Cancers	283	10%	Skin cancers (inc BCC, SCC & other)	94	33%
			Urological Cancers	78	28%
			Colorectal Cancer	35	12%
			Haematological Cancers	23	8%
			Head and Neck Cancer	14	5%
			Lung cancer	7	2%
			Bone & Soft Tissue cancers	5	2%
			Upper GI Cancer	4	1%
			Brain tumour	4	1%
			All Others	19	7%
Genitourinary system	248	9%	Prostate - enlarged	117	47%
			Bladder problems	40	16%
			Kidney disease	38	15%
			Infertility	31	13%
			Erectile dysfunction	5	2%
			All Others	17	7%
Endocrine & Metabolic	188	7%	Diabetes	136	72%
			Hypothyroidism	22	12%
			Thyroid problems	14	7%
			High cholesterol	7	4%
			All Others	9	5%
Skin and subcutaneous tissue	180	6%	Rash or Dermatitis	66	37%
			Growths, Warts and Cysts	25	14%
			Infections - bacterial and fungal	24	13%
			Psoriasis	21	12%
			Keratosis and/or sun damage	12	7%
			Dry skin	11	6%
			Blistering	6	3%
			Vitiligo	5	3%
			All Others	10	6%
Ear and mastoid processes	161	6%	Hearing loss	125	78%
			Tinnitus	23	14%
			All Others	13	8%
Respiratory system	159	6%	Asthma and/or breathing problems	57	36%
			COPD	30	19%
			Pneumonia	19	12%
			Plural plaque	6	4%
			Lung disease	5	3%
			Emphysema	4	3%
			Asbestosis	4	3%
			Bronchitis	4	3%
			Obstructive sleep apnoea	4	3%
			All Others	26	16%
Eyes	156	6%	Cataracts	54	35%
			Poor eyesight	26	17%
			Glaucoma	25	16%
			Macular degeneration	12	8%
			Retinal problems	7	4%
			Blepharitis	6	4%
			Blindness	5	3%
			All Others	21	13%
Mental health	110	4%	Anxiety, depression or stress	87	79%
			Dementia	6	5%
			All Others	17	15%
Blood and certain immune disorders	43	2%	Anaemia	14	33%
			Blood disorder - General	7	16%
			All Others	17	40%

Broad disease category			Illness / condition category		
Disease category	**Total number of diseases reported in each category**	**% of all diseases reported**	**Illness / condition**	**Total number of illnesses / conditions reported**	**% of diseases category total**
Nervous system	44	2%	Epilepsy	10	23%
			Neuropathy	7	16%
			Headaches	7	16%
			Parkinson's Disease	7	16%
			All Others	13	30%
Injury, poisoning and other external forces	32	1%	Coral poisoning	6	19%
			Injury - back	4	13%
			All Others	22	69%
Infectious & parasitic diseases	30	1%	Malaria	11	37%
			Tuberculosis	4	13%
			Septicaemia	4	13%
			All Others	11	37%
Other - signs, symptoms unclassifiable elsewhere	14	0%	All Others	14	100%

Figure 4-14 charts the top 20 current conditions in ranked order and Figure 4.15 does the same for the 'ever had' conditions.

It is perhaps unsurprising that the conditions which feature in the top 20 ranked current conditions, including many diseases which are very commonly experienced in males of this age group and are largely linked to ageing.

Figure 4-14 Top 20 Current Reported Conditions

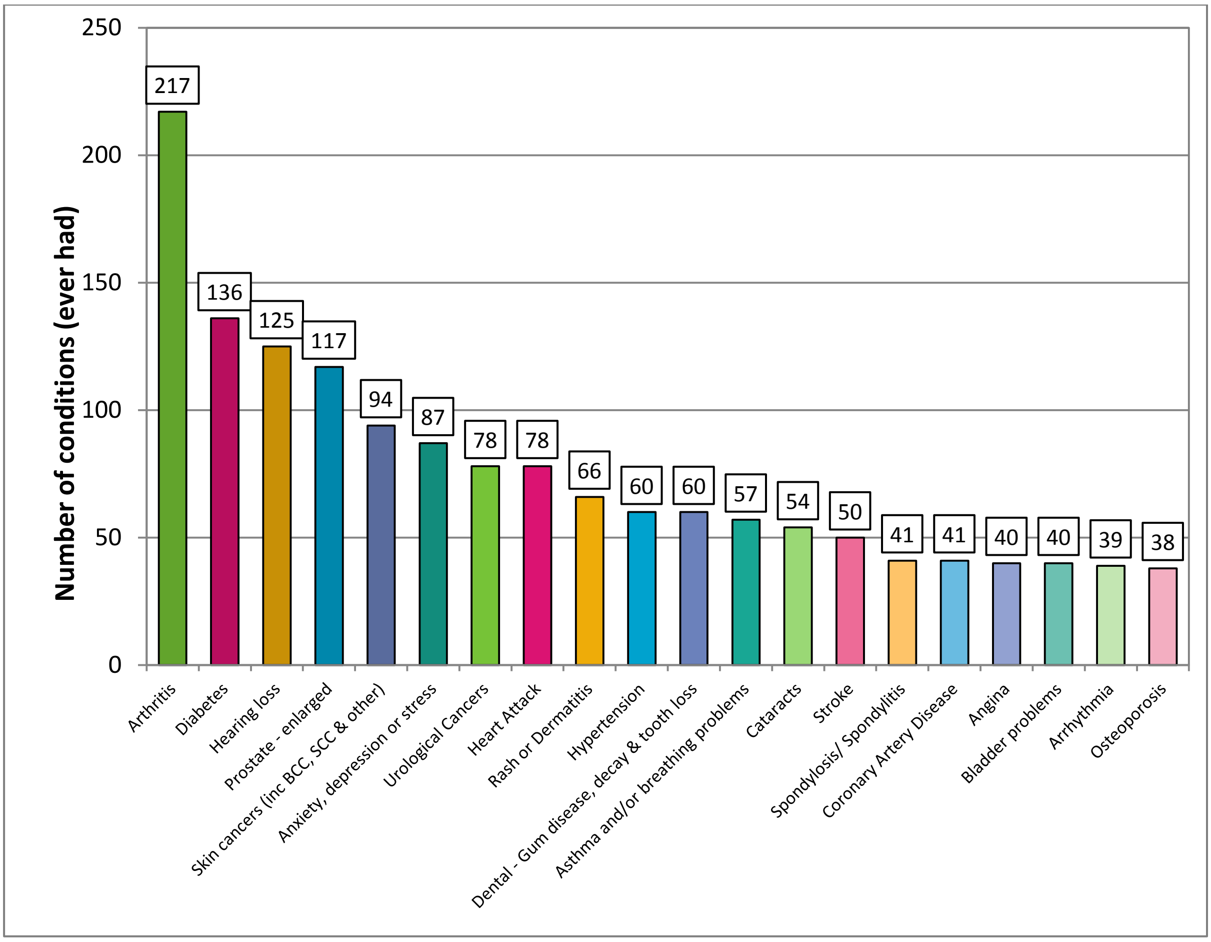


However, of note is that "anxiety, depression or stress" is ranked fourth, with 64 respondents reporting currently having these conditions. This is a slightly higher prevalence than heart attacks or hypertension. There is a strong predominance of musculoskeletal problems, diabetes and heart and circulatory system diseases.

Amongst the 'ever had' conditions, most of the same specific conditions feature in the top 20 most commonly reported. The rank order is slightly different, and of note is that cataracts feature in the 'ever had' top 20 list, and presumably do not appear in the current top 20 list because they are a highly treatable condition and will have been resolved.

Of note, perhaps, is that the only cancers that feature in the top 20 (in both the current and 'ever had' lists) are the skin cancers (which include the more common "non-melanoma" skin cancers) and urological cancers – the majority of which are cancer of the prostate – again a common, and often non-invasive, malignancy in this age-group.

Figure 4-15 Top 20 'Ever Had' Conditions



4.3 Current health status of respondents

To obtain an up to date picture of respondents' overall current health and social care needs, respondents were asked to complete a brief health-related quality of life questionnaire - known as the EQ-5D. This is a standardised and validated survey instrument used in many different health and social care surveys and in studies to measure health status of populations or groups. It asks about self-assessed levels of functioning across five domains:

- Mobility
- Self-care (defined as washing and dressing)
- Ability to perform usual activities
- Pain; and
- Anxiety/depression.

Respondents are asked to rate or score themselves in each of the five domains on a three-point scale: 1 (no problems), 2 (some problems) or 3 (extreme problems); as they are feeling at the time of completing the questionnaire.

An overall summary health index for each respondent can then be generated using the scores for each domain (for those who completed all five domains). This overall health index is calculated using a ‘value set’ which assigns a weighting to the different EQ-5D health states (the weighting is based on the preferences of a large sample of the UK population)[20]. Using this ‘value set’ gives each respondent a summary health index of between -0.073 and 1, where -0.073 is the index for someone with a score of 33333 (extreme problems in all five domains) and 1 is the index of someone with a score of 11111 (no problems in any of the five domains).

The health index scores from the survey respondents can then be grouped into three overall health status groups:

- **‘Top’ health status** - the respondents who scored an index of 1 (i.e. had no problems on any of the five domains and with the best health status)
- **‘Middle’ health status** - respondents who scored an index of 0.5 and 0.99. (All but two of these respondents scored a mix of 1s and 2s in the domains. Two of these respondents scored four ‘1s’ and one ‘3’)
- **‘Bottom’ health status** - respondents who scored an index of below 0.5. (These were respondents in the worst state of health and who scored at least one ‘3’. Only one of these respondents scored ‘3’ in all five domains).

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[20] **Co-efficients for the estimation of the EQ-5D index values based on VAS valuation studies,** in *EQ-5D Value Sets, inventory, comparative review and user guide*, EuroQuol Group Monographs Volume 2 by A. Szende et al

4.3.1 Summary Health Status Results

Overall, there were 585 respondents (92%) who completed the EQ-5D section of the audit in full and 78 who only partially completed it or chose not to complete this section at all. These 78 have therefore been excluded from the composite score analysis.

Of these 585:

- 108 (18%) of the 585 respondents reported being currently in good health (reporting no problems on any of the five domains of the EQ-5D) and therefore fall into the 'top' health status group.
- 336 (57%) were within the middle health status group (see Figure 4.14).
- 111 (19%), were in the bottom health status group representing those in the poorest health.

Figure 4-16 Number of respondents by overall health status group

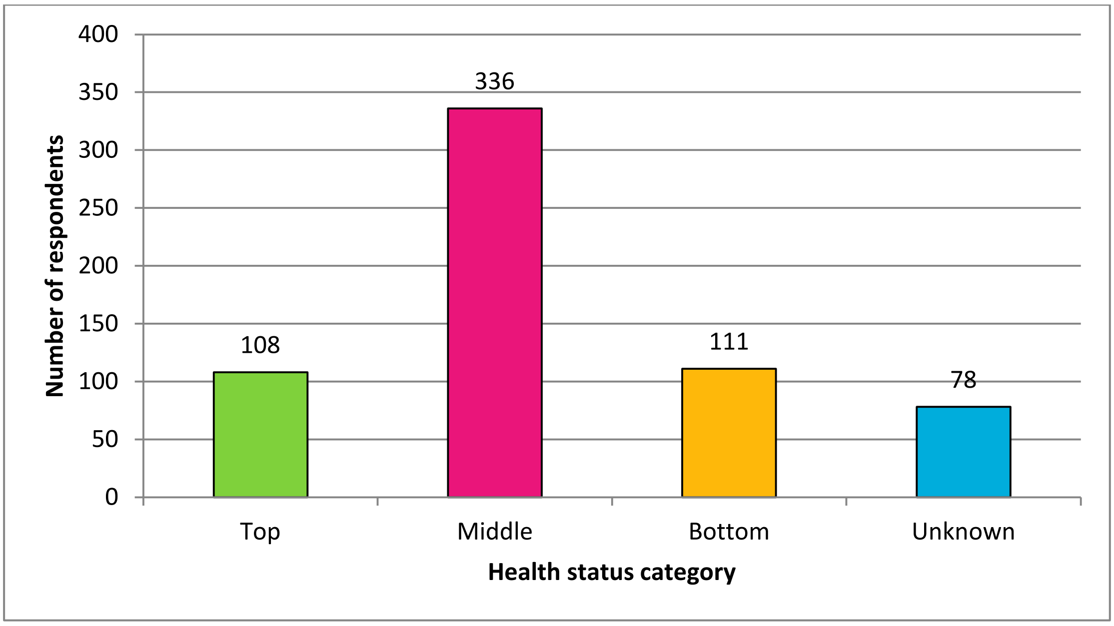
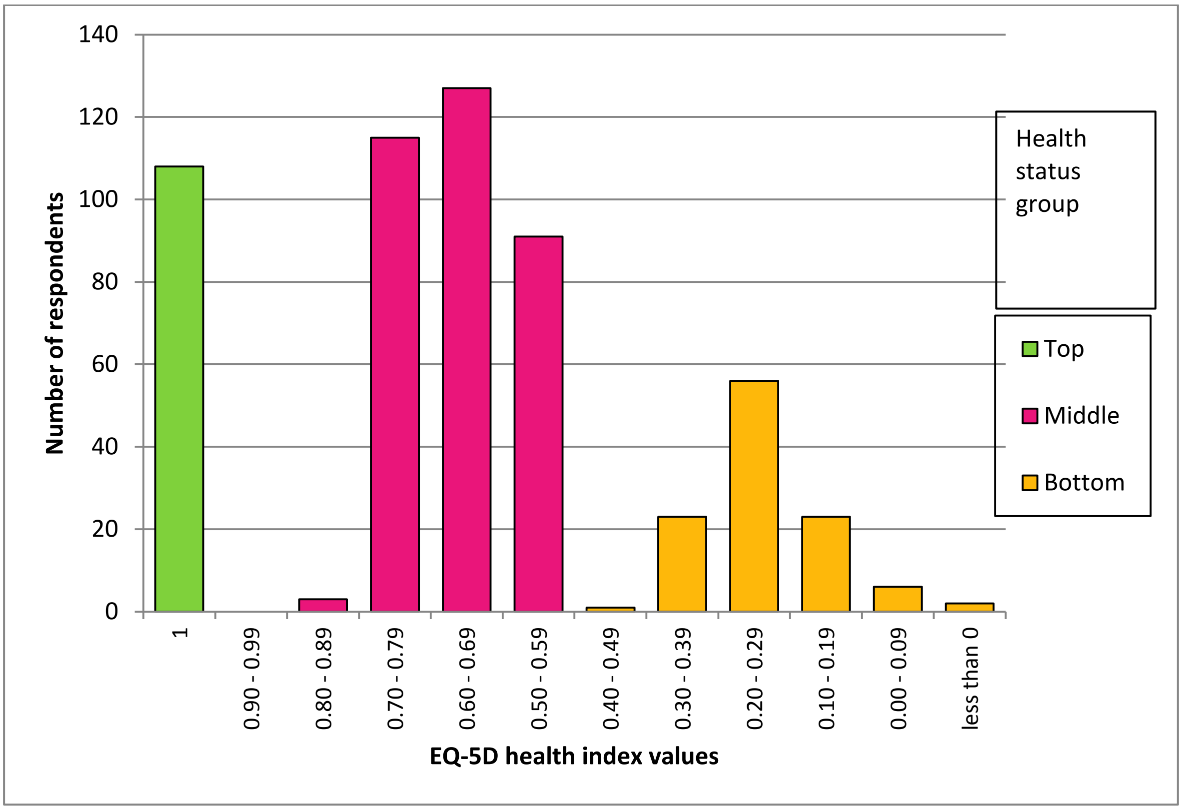


Figure 4-17 gives a more detailed breakdown of respondent numbers across the range of possible EQ-5D summary health index values.

Figure 4-17 Distribution of respondents by overall health index score



4.3.2 Health status by individual EQ-5D 'Domain'

Figures 4-18 – 4-22 present the responses to each of the separate domains within the EQ-5D questionnaire.

- Pain or discomfort was the problem most affecting survey respondents' quality of life with a total of 72% reporting living with some pain or discomfort (either extreme or moderate). Of this 72%, 91 (14%) reporting living in extreme pain or discomfort, 368 (58%) in moderate pain and only 23% in no pain or discomfort (figure 4-22).
- 332 (52%) said they had some trouble with mobility (figure 4-18), whereas 43% had no problems with mobility.
- 326 respondents (51%) reported problems with performing their usual activities (figure 4-20), and 282 respondents (42%) reported having no problems with usual activities.
- 222 respondents (35%) described themselves as either moderately or very anxious or depressed (figure 4-21).
- Managing self-care was the problem least affecting survey respondents' quality of life (specifically washing and dressing) with 443 (70%) reported having no problems with self-care (figure 4-19).

It is not possible to compare the health status of the audit respondents with that of the general male population, as there is no standardised age-matched male EQ-5D population data for England or the UK. Therefore, no conclusions can be drawn about whether the nuclear test veterans survey respondents' health status is better or worse than might be expected.

Figure 4-21 Survey respondents' EQ-5D scores for anxiety or depression

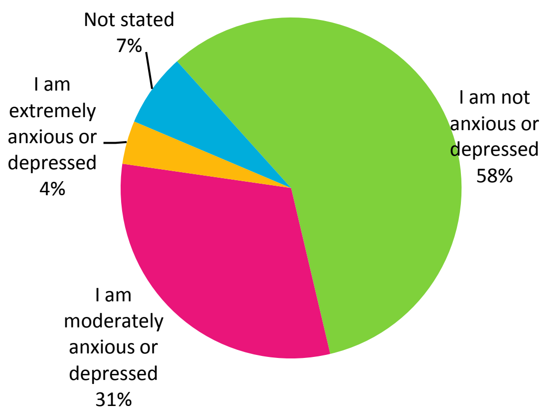


Figure 4-22 Survey respondents' EQ-5D scores for self-care

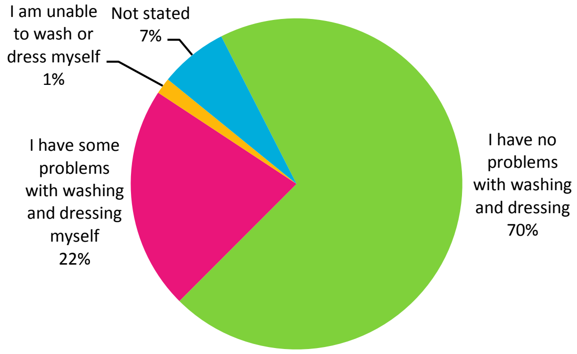


Figure 4-20 Survey respondents' EQ-5D scores for mobility

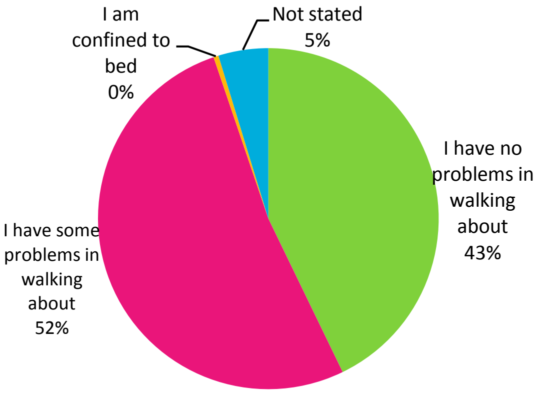


Figure 4-19 Survey respondents' EQ-5D scores for usual activities

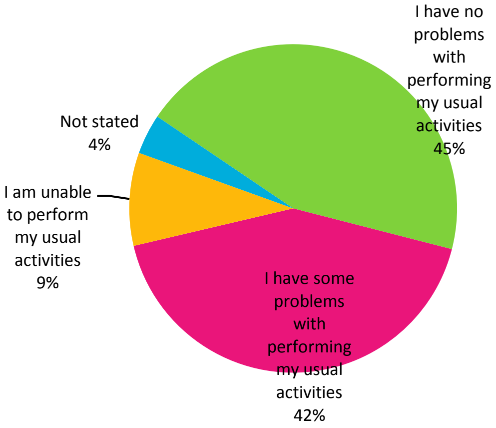
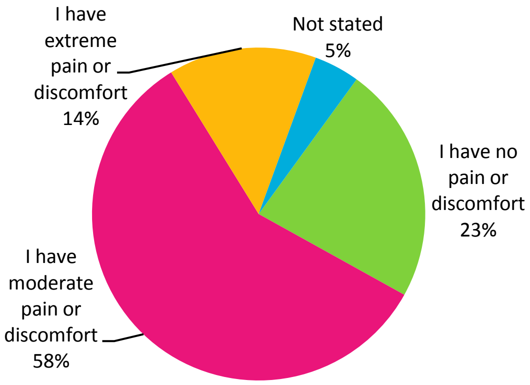


Figure 4-18 Survey respondents' EQ-5D scores for pain and discomfort



4.4 Survey respondents' level of disability

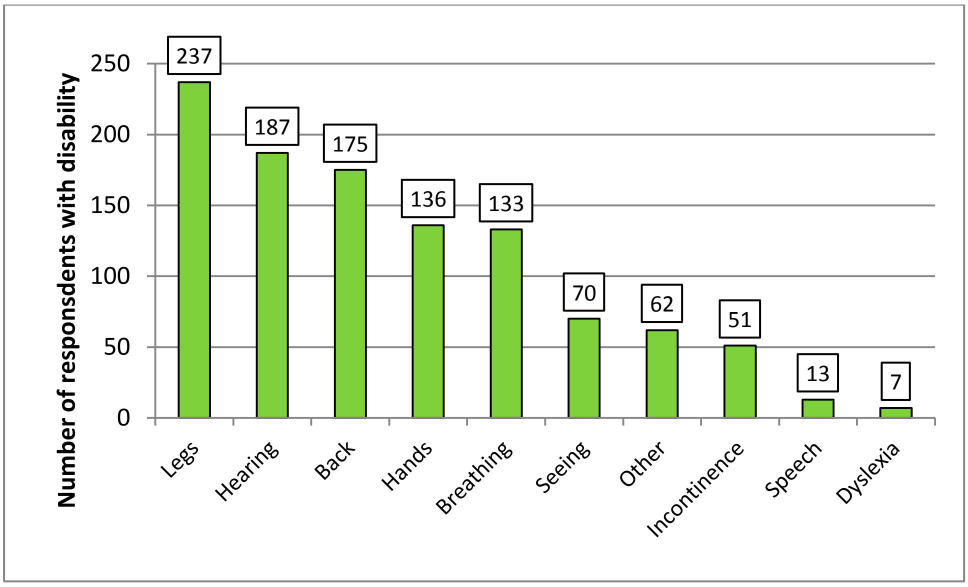
Respondents were asked if they considered themselves to have a disability. If so, they were asked to identify what sort of disability they had from a short list of the more common disabilities[21], together with the length of time they have been affected and to provide more details if they wished.

Overall, out of the 633 survey respondents 379 (60%) considered themselves to have a disability.

As figure 4-23 shows, the most commonly reported disabilities were problems relating to legs or feet (237 or 37%) followed by hearing problems (187 or 29%) and then back or neck problems (175 or 28%).

Only 13 respondents (2%) reported having problems relating to speech and 7 reported having a problem with dyslexia (1%).

Figure 4-23 Number of disabilities reported by respondents, by type



When looking at the level of disability in the three EQ-5D summary health status groups (top, middle or bottom),

- Of the 111 respondents in the lowest or 'bottom' health status group, 108 (97%) reported having a disability
- Of the 336 in the 'middle' health status group, 208 (62%) reported having a disability
- Of the 108 in the 'top' (least ill) health status group, only 17 (16%) reported a disability.

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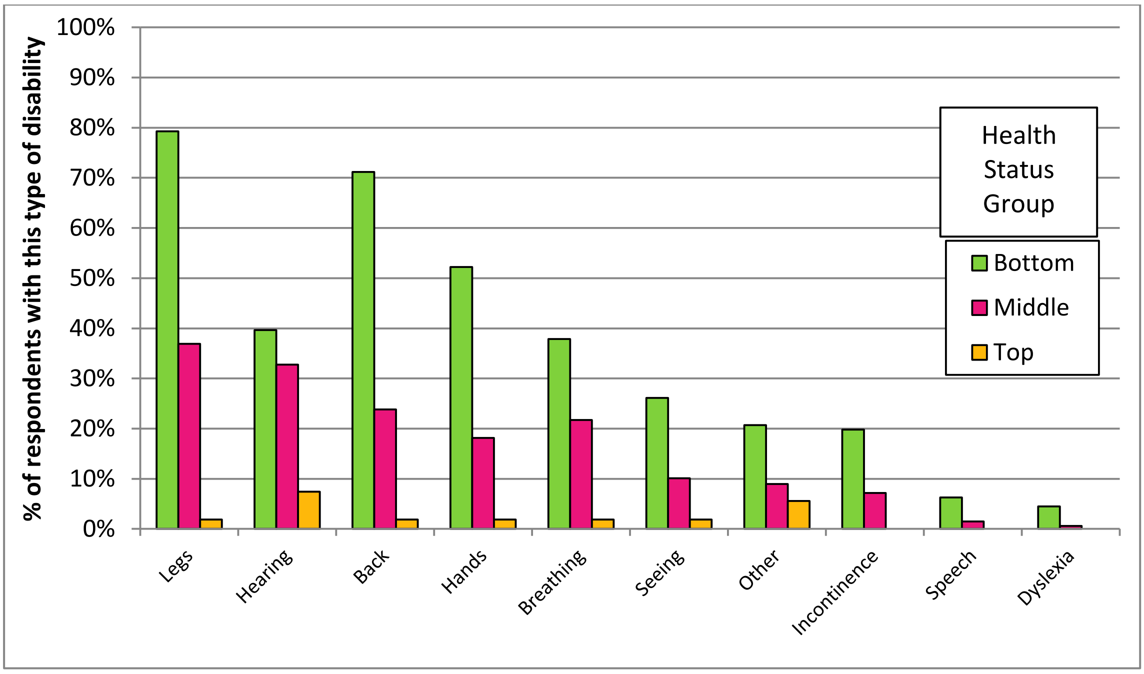
[21] Options given were: Speech impairment, Difficulty hearing, Difficulty seeing (even when wearing glasses or contact lenses), Dyslexia, Breathing problems, Incontinence, Problems or disabilities related to arms and hands, Problems or disabilities relating to legs and feet, Problems or disabilities relating to back or neck, and 'Other'.

Figure 4-24 shows the percentage of each health status group living with different types of disability[22]. For example, 79% of respondents in the 'bottom' (least healthy) group have problems with their legs, compared with only 2% of those in the 'top' group.

Figure 4-24 The percentage of respondents with a disability, by disability type and health status group



It is clear from this analysis that having a disability has a direct impact on overall health-related quality of life (as would be expected). Also, certain types of disability (for example problems with legs, backs and hands) seem to have a relatively greater impact on this than other types of disability.

Figure 4-25 shows how long, on average, respondents have been living with disabilities of different types, and figure 4.26 shows the number of years respondents report having lived with each type of disability.

Dyslexia appears to be the only disability predominantly identified in younger life (over 30 years ago). For most types of disability, the majority of respondents report having had them for up to 10 years. Disabilities related to legs, hands and incontinence stand out as having increased rapidly in the last ten years of respondents' lives.

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[22] N.B. some respondents did not provide information on how long they had lived with a disability – and these are therefore not included in the numbers above.

Figure 4-25 The average number of years with a disability, by disability type

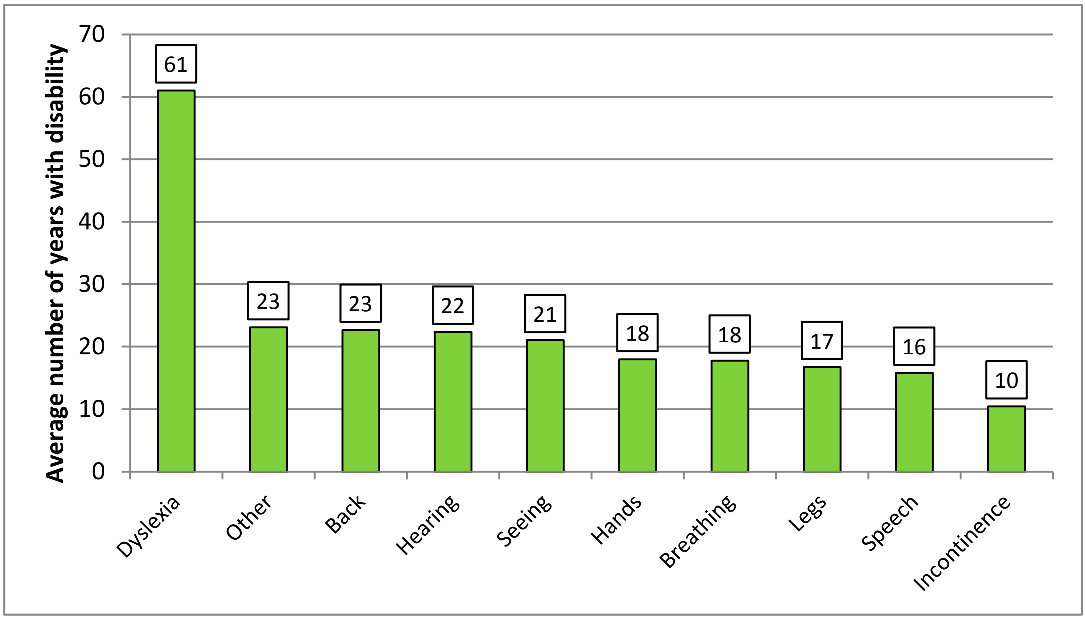
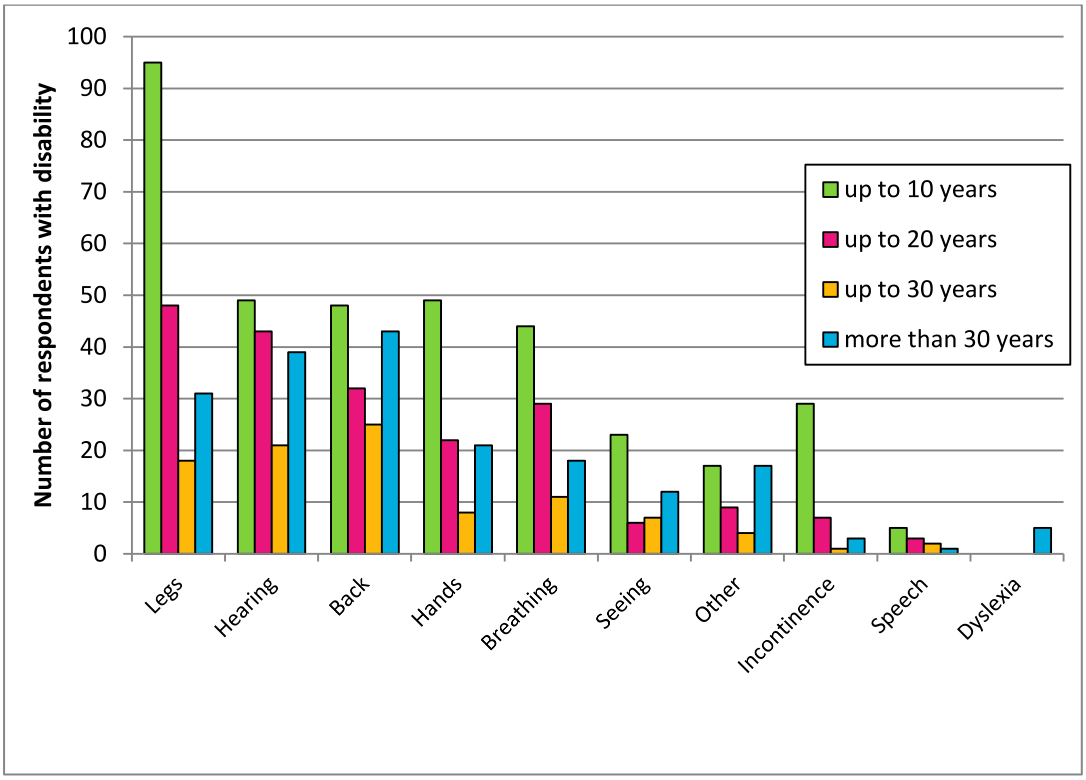


Figure 4-26 Distribution of length of time with a disability, by type of disability

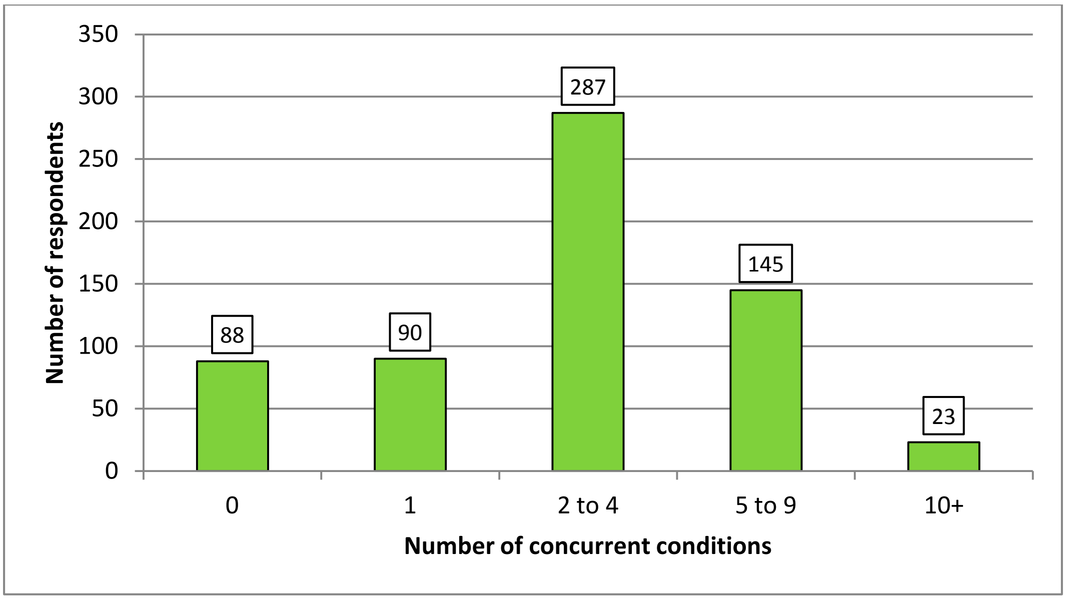


4.4.1 Numbers of concurrent conditions currently suffered by respondents

A significant number of respondents also reported currently suffering from more than one serious or long term condition concurrently (see figure 4-27) – contributing to significant co-morbidity.

- 23 (4%) reported currently having over 10 conditions
- 145 (23%) reported having 5-9 conditions
- 287 (45%) reported having between 2-4 conditions
- 90 (14%) reported having one condition, and
- 88 (14%) reported having no current conditions.

Figure 4-27 Numbers of concurrent conditions suffered by each respondent currently



Further analysis was undertaken to compare the respondents' overall summary health status (as measured by the EQ-5D) with the average number of conditions they were living with concurrently.

Those respondents in the 'bottom' (worst) EQ-5D health status group were living with an average of 5.7 different concurrent serious or long term conditions. This is over five times the average number of conditions for those respondents in the 'top' (most healthy) EQ-5D health status group, where the average number of concurrent conditions was 1.1 (see figure 4-28).

Figure 4-28 Average number of concurrent illnesses by health status group

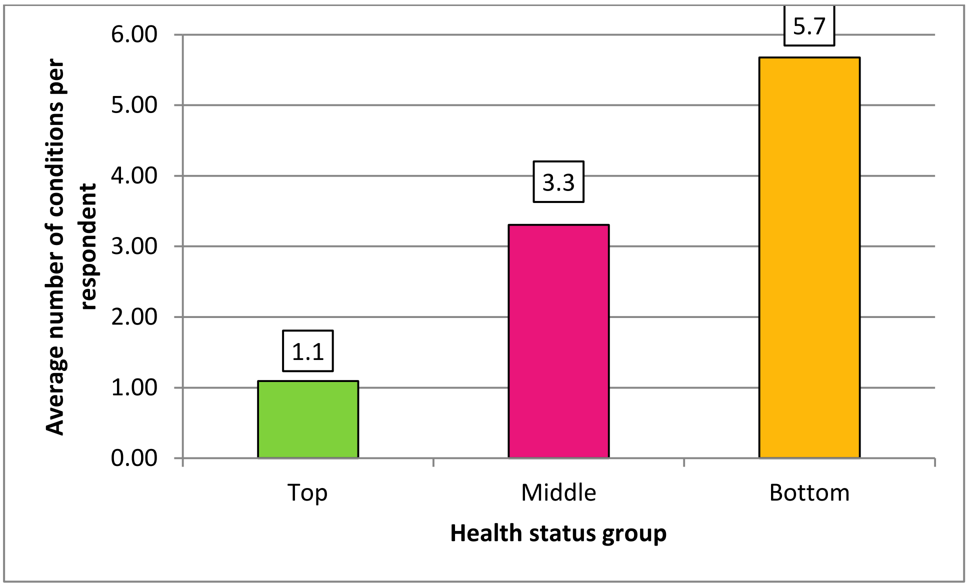
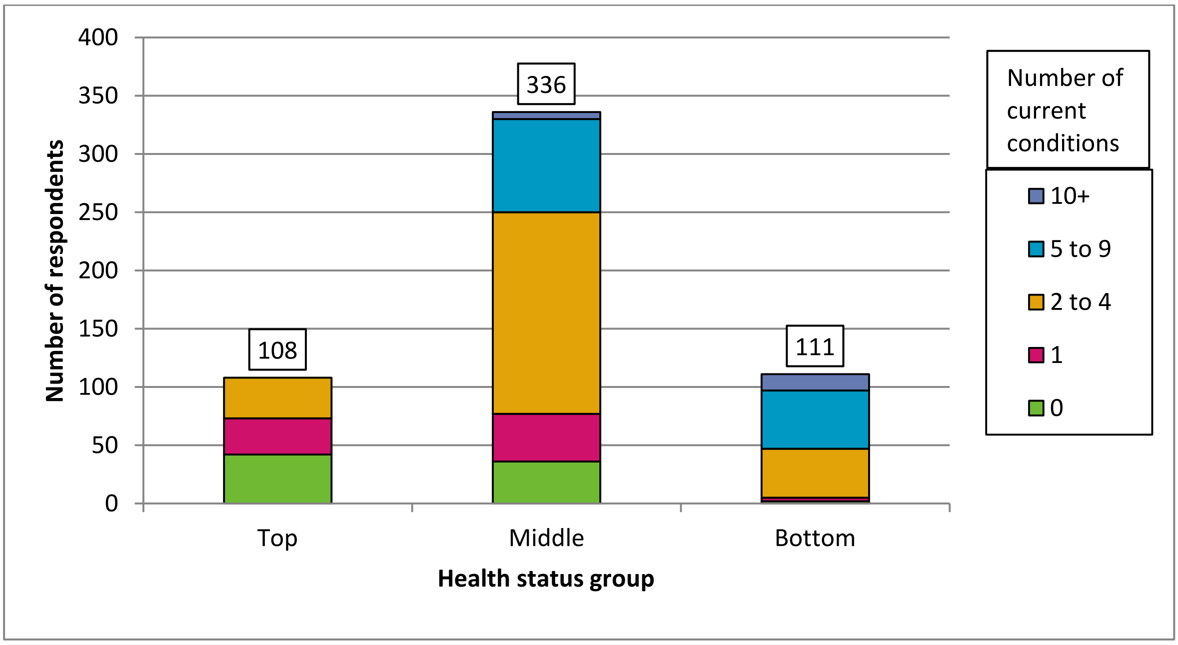


Figure 4-29 shows the distribution of number of conditions reported by respondents in each of the health status groups.

Figure 4-29 Number of concurrent conditions, by health status group



Although there are more people living with 5 or more concurrent conditions in the 'middle' health status group (86) compared to 64 in the 'bottom' health status group, they make up 25% of the middle group, but 58% of the bottom group. The people in the bottom group therefore are experiencing a higher intensity of disease burden than in the other groups – alongside disabilities which may or may not be associated with the conditions which they have.

5 Use and Experience of Health and Social Care Services

This section covers:

- Respondents' use of health and social care services
- Respondents' of access to health and social care services
- Respondents' overall experience of health and social care services

5.1 Introduction

Respondents were asked to provide information about their use and experience of health and social care services over the past 2 years, together with their suggestions for improving these services.

Respondents were presented with a list of 16 types of health and social care services and asked to:

- State how frequently they had used each service (if at all) using a five point scale ranging from 'very often (at least once a week) to 'not at all',
- State how easy they had found them to access (on a four point scale ranging from 'very easy' to 'very difficult', with an additional option 'I haven't needed it'); and to
- Rate their overall experience of each service they have used (on a four point scale ranging from 'very good' to 'poor', with an additional option 'I haven't needed it').

Respondents were also invited to add any comments or suggestions about any health and/or social care services they had **not** received but they felt they needed, or should have had.

Finally, in this section of the audit, respondents were invited to provide examples of particularly good practice or good experiences of care they have received, and to offer any ideas as to how they feel their health and social care services could be improved, or how things could have been done better.

The themes raised in the survey responses were later explored in greater depth during the eight discussion groups held throughout the country.

The analysis revealed that the majority of respondents have been very satisfied with the healthcare services they have received in recent years and many provided stories and examples to illustrate the excellent and timely care they had experienced.

Views of social care services were more mixed, with many respondents saying they had found these services harder to access. Some expressed their concerns about their dependence on getting help and support with daily living from their partners, many of whom were also ageing and had their own health-needs.

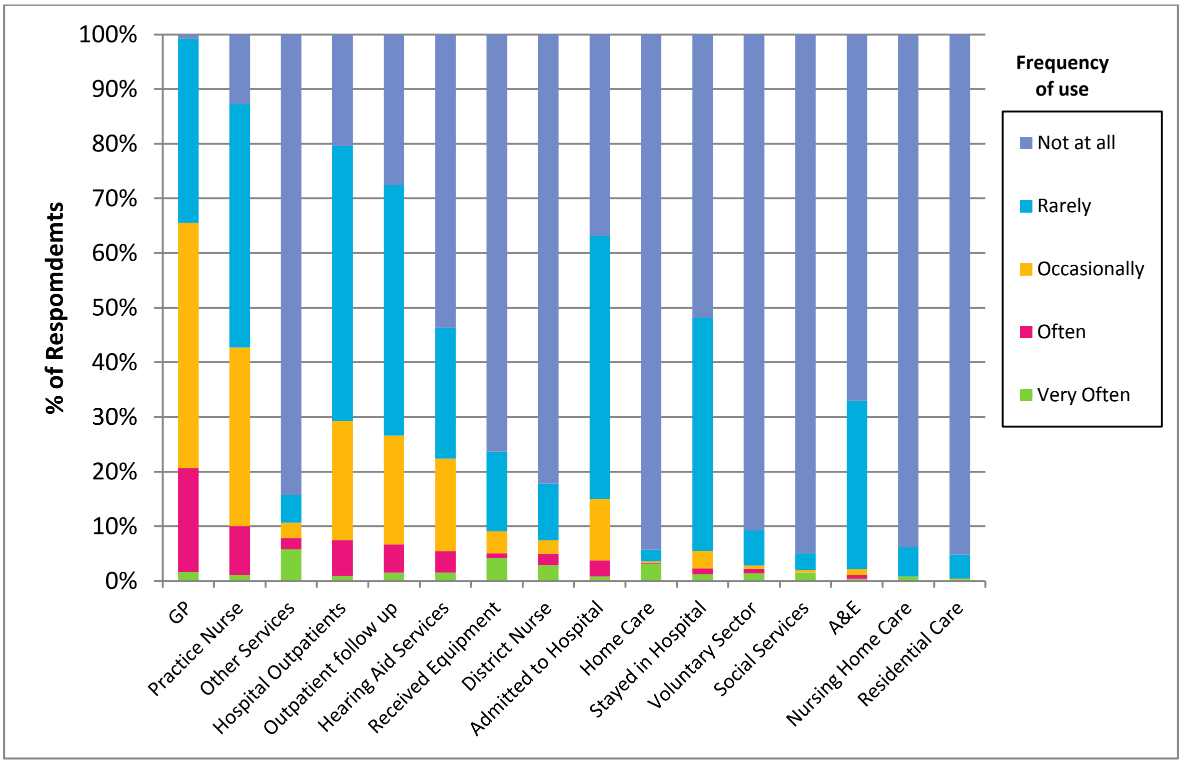
Although they were not specifically asked for improvement suggestions related directly to their status as nuclear test veterans, nearly half of respondents' ideas for improvements were about how the particular needs of veterans could be better met by health or social care services.

5.2 Use of health and social care services

Respondents were asked to indicate how frequently they had recently used health or social care services from a choice of 16 types of health or social care service. Recently was defined as within the past 2 years. Figure 5.1 provides an overview of the frequency of use of services, ranked from the service most frequently used (GP services) to the least frequently used (residential care).

As might be expected, primary care services have been the most frequently used with 627 (99%) of respondents having consulted their GP and 551 (87%) their practice nurse in the last 2 years. Nursing home care and residential care were the least used (used by 6% and 5% of respondents respectively). 63 respondents (10%) stated that they had used 'other' services, and provided details of these – these included opticians, and also frequently mentioned were respondents' wives, or other family members, who were providing care which might otherwise have been provided by a statutory or voluntary organisation.

Figure 5-1 Frequency of use of health and social care services in the past two years, by service



For analytical purposes, the 16 health and social care services are grouped into four care-type groups:

- Primary care (comprising GP, district nurse, practice nurse and hearing aid services)
- Hospital care (comprising A&E, hospital inpatient and outpatient services)
- Social care (comprising social services, home care, the provision of home-based equipment and/ or aids, residential and nursing care and care provided at home by the voluntary sector)
- 'Other' services, defined by respondents themselves, including self-organised, paid-for help and help by family members.

The frequency of use of these four grouped service areas[23] was then analysed by the overall health status of each respondent[24] (see figures 5-2 – 5-4).

*Figure 5-2 Frequency of use of **primary care services**, by EQ-5D health status group*

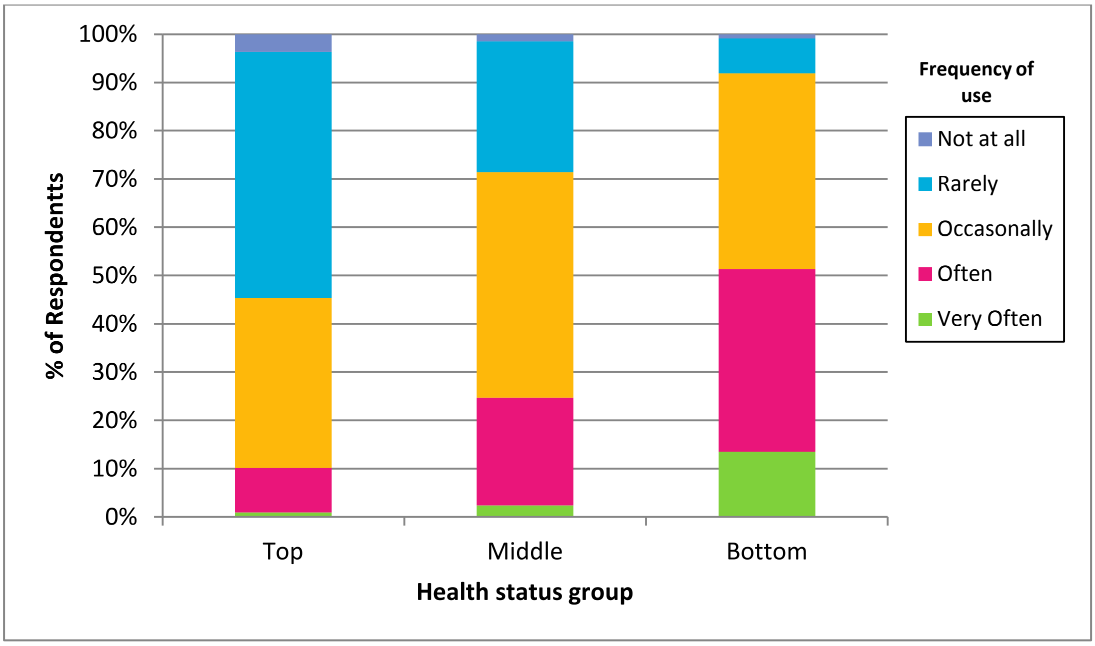
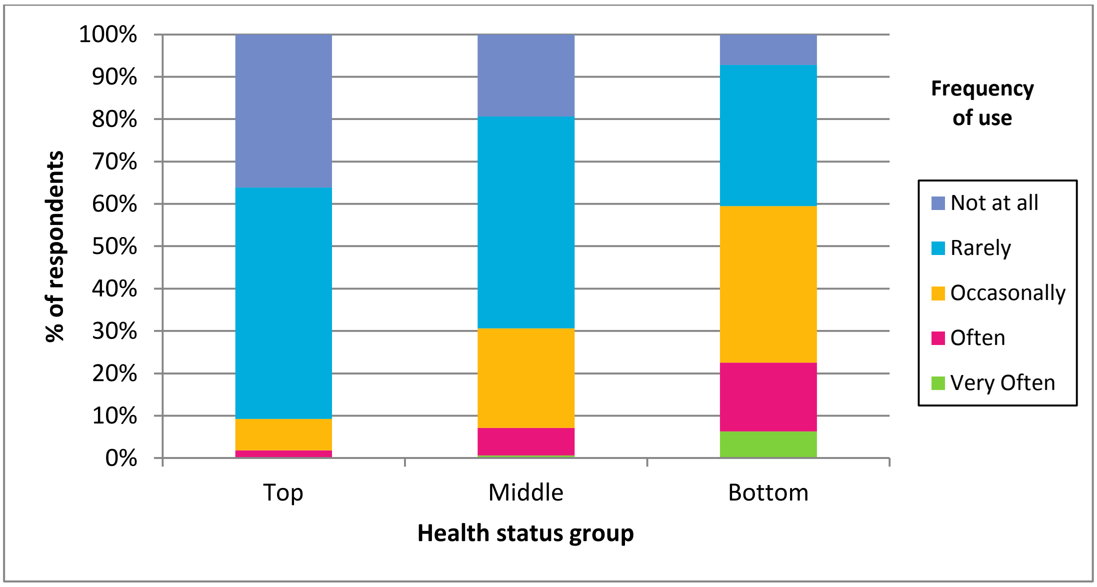


*Figure 5-3 Frequency of use of **hospital care services**, by EQ-5D health status group*



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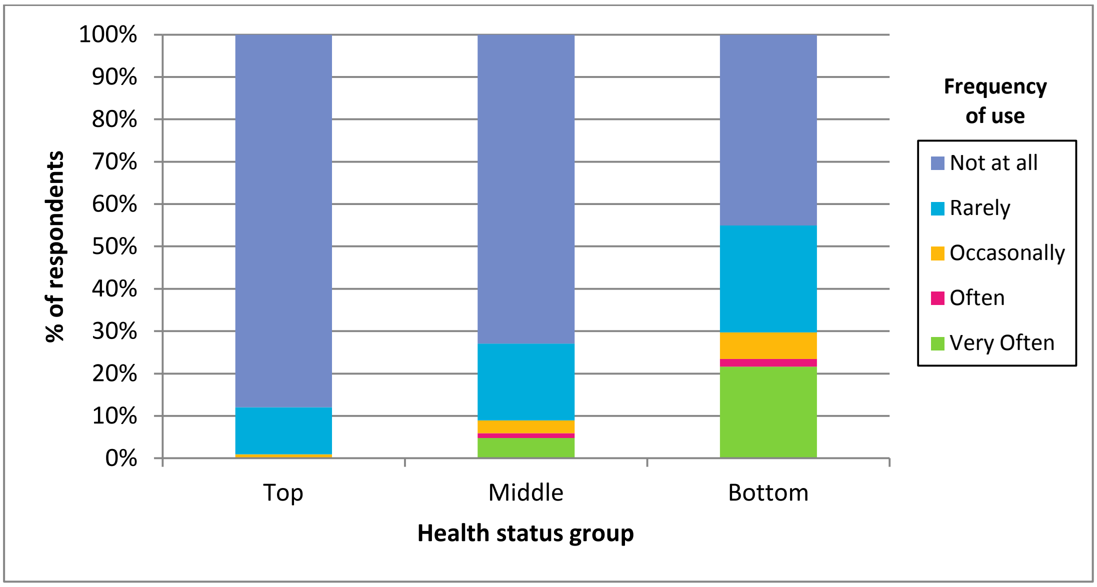
[23] For each respondent, frequency of use of each group of services was defined as the frequency with which they had used the service which they used most.

[24] See Appendix 1 for details of how the summary index was calculated and used to generate the three overall health status groupings.

Figure 5-4 Frequency of use of ***social care services****, by health status group*



As would be expected, those respondents in the 'bottom' (least well) health status group used all four groups of service more frequently. However, of note, was that of those in the 'bottom' health status group, 45% (50 out of 111) respondents reported that they had not used social care at all, and a further 25% (28 out of 111) that they used it 'rarely' (figure 6.4) – despite there being clear levels of need for the types of services and support provided by social care services. This is discussed further in the section on access to care below.

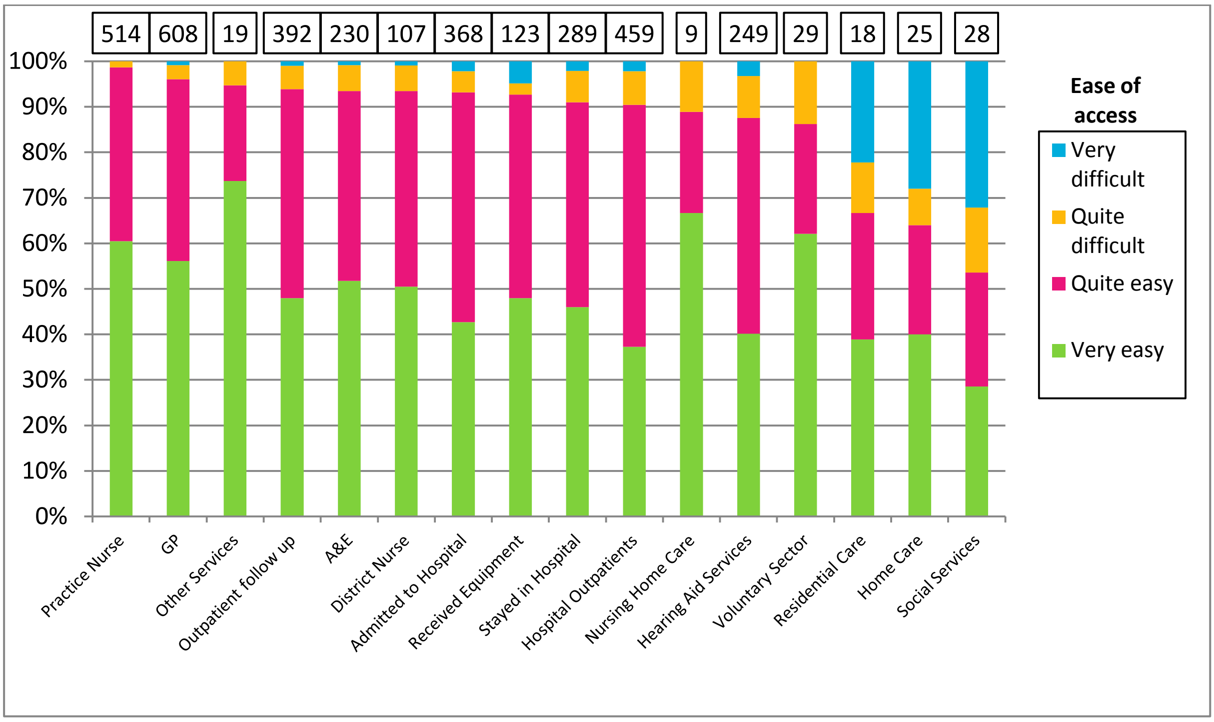
5.3 Ease of access to health and social care services

Respondents were asked to rank how easy they had found it to access the different health and/or social care services, using a four-point scale.

Figure 5-5 summarises the responses received (the number of these respondents is shown above each bar), with the service-types ranked from the most easy to access (practice nurses) to the least easy to access (social services) based on the proportion saying access was 'very easy' or 'easy'.

The services reported as most easy to access were practice nurses and GPs, followed by 'other' services, which typically included for example a family member care or paid-for, self-organised help. Social services, home care and residential care were rated as hardest to access.

Figure 5-5 Ease of access to health and social care services, by service type



5.3.1 Access to healthcare services – Experiences and suggestions for improvement

The questionnaire survey and the discussion groups enabled respondents to provide a more detailed commentary about their views and experiences of ease of access to services and offer suggestions for improvement.

There were 188 comments or suggestions made for improving services in the survey responses.

Waiting Times

Twenty-seven of the 188 (14%) were suggestions for improvements to waiting times. There was a broad spread of issues raised, from waiting times for elective surgery or other specialist appointments, to the time waited whilst in A&E and outpatient clinics, or the time having to wait for the results of tests.

> *Frequent cancellations for treatment in the larger hospitals allied to long hours in waiting rooms forced me to seek other avenues for treatment.*
>
> *Hospital waiting lists could still be improved (from diagnosis of my heart problem to actual surgery - I waited 9 months - very stressful times).*
>
> *I find it annoying, frustrating and in this day and age unnecessary to have to wait up to 2 weeks for 'the result' - blood test - X ray etc.*
>
> *My concern is the waiting time to see a specialist. As you come closer to your appointment, you get a letter saying it's been put back two or three months. That's the only concern I've got.*

GP Appointments

Six survey respondents suggested changes to the way in which GP appointments were booked, and this was also a much discussed topic in several of the discussion groups. The lack of 'same-day' appointment systems were a particular source of frustration.

> *I would like to eliminate the difficulty of getting appointments to see our local GP at our 'palatial' new health centre.*
>
> *It is difficult to make an appointment with the doctor (have to phone same day and the phone lines are busy) and it takes a long time to come to myself in the morning.*
>
> *To get a doctor's appointment you have to phone at 8 AM. You wait 45 minutes and then eventually get through to be told, 'oh sorry it's booked up - ring up again at 11'. Then at 11 you can't get through. It happens day after day: you have to book on that day that you want to be seen, but there's no way that you can because it engaged.*
>
> *There are seven or eight doctors at our practice…But you can only make a booking on the day. You have to be there at 8.30 as all the appointments are gone by nine. If you phone you will never get through.*

Travelling for specialist treatment

Five survey respondents expressed concerns about the distance that they have to travel to access specialist care.

> *Would like to have all treatment at Hospital X only 2 miles away. Too far to travel to Y or Z more than 20 miles; in heart emergency it would be too far.*

Access to therapy services

Five survey respondents mentioned their un-met need for additional therapy input: two wanting better physiotherapy, two chiropody and one audiology/lip reading support.

> *Due to hip replacement unable to cut toe nails, therefore I visit chiropodist every 2/3 months at my own expense, never been offered help by GP.*

But overall, the commentary and responses regarding access to health treatment was that respondents felt that generally they had very good access to the care they needed.

Access to health and social care services – Examples of good practice

95 respondents provided written examples of particularly good practice or experience. Their comments ranged in scope from providing specific occasions where they had had rapid access to care when they needed it, being very satisfied with on-going access to follow-up treatment, to very short waiting times (which had often surprised them).

> *2009. Optician sent me to hospital for 2nd opinion re eye pressure. Appointments in short time. Drops prescribed. Further appointments as needed. Pressure dropped with treatment. No complaints.*

> *999 emergency calls were always good when I kept falling over at home. The doctor would call the same day when urgent which was good. Also Home Carers (Adult Care Services) always came despite the dreadful weather, such as snow, as I was a priority.*
>
> *Double hernia from diagnosis to operation very short time. Quick reaction from GP and Health Authorities when I have had health problems.*
>
> *From the GP checking my blood pressure, he sent me immediately to North Tyneside General Hospital for ECG and was actioned within one hour.*
>
> *With my liposarcoma, the doctor insisted that it had to come out. He cleared his schedule. I can't speak highly enough.*
>
> *I went to the hospital about my eye and the appointment was half past nine and before I could even sit down they said come through. I saw three people and I was out by 10am. It does happen sometimes.*

5.3.2 Access to Social Care services – Experiences and suggestions for improvement

Social care services and home-care were reported to be the two most difficult services to access by those who had needed them.

The survey asked in more detail about the needs of respondents with disabilities for help with day to day activities. The responses of the 375 respondents who reported that they had a disability are shown in figure 5-6. The vast majority of these respondents said either that they didn't need help, or that they had enough help to meet their needs, but a minority said they would like more. The most commonly reported need for additional help was with going out and about, cited by 24 respondents (6% of those with a disability), followed by moving around, cited by 12 respondents (3% of those with a disability) and getting up, cited by 10 respondents (3% of those with a disability).

Figure 5-7 looks at the overall health status of those saying they would like more help. As would be expected, the majority were in the 'bottom' health status group, and none in the 'top' health status group.

Figure 5-6 Need for help with activities of daily living for all respondents with a disability

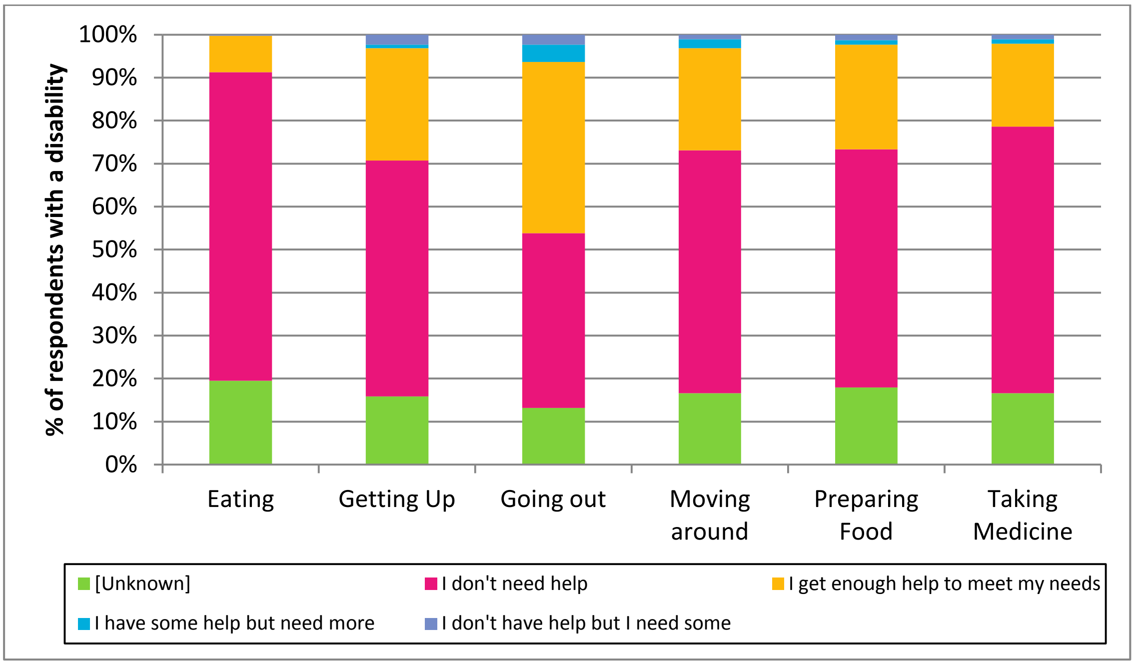
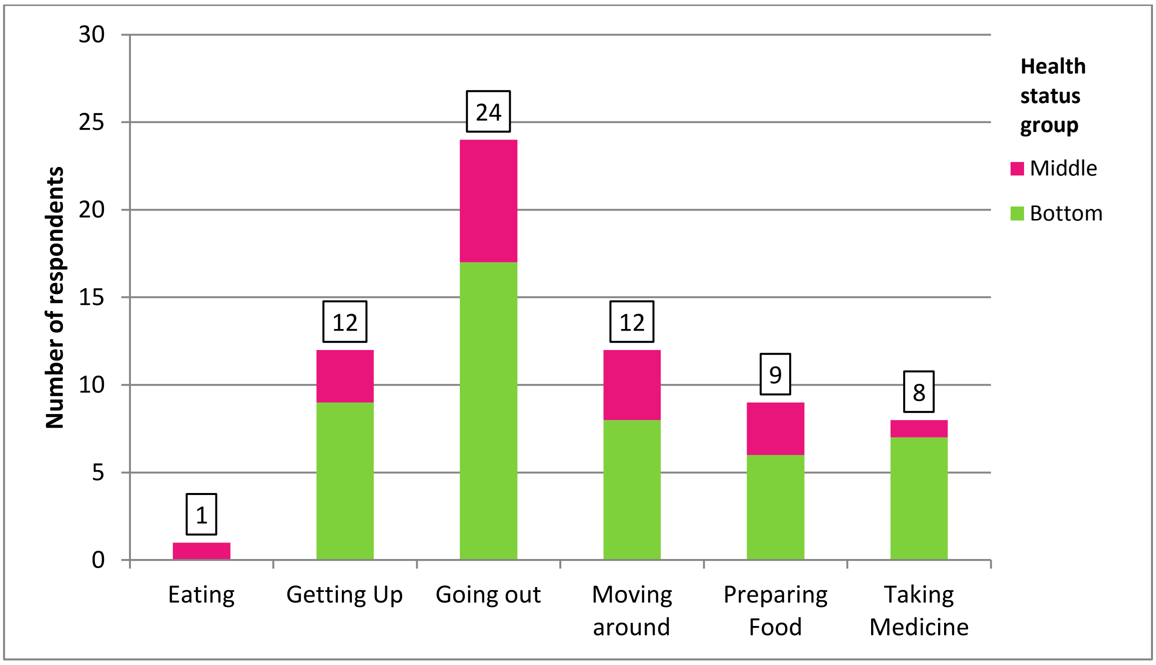


Figure 5-7 Health status group of those needing additional help, by type of help



Nine survey respondents provided more detail about the need for more home-based equipment and/or mobility aids (and 2 of these also mentioned it under improvement suggestions).

A common theme was that some respondents felt they were 'on their own' both logistically and financially when it came to acquiring aids and equipment, and they need more support.

> *I tried the Red Cross, SSAFFA and British Legion also the hospital, to get a mobility scooter to no avail. I had to hire one. I was in a full plaster to my leg for four months.*

> *During early years - 1993, 1994 - I received little or no help / advice. Even today, particulars concerning help with mobility problems (the acquirement of 'scooters' etc.) have had to be solved by myself.*
>
> *I paid for a walk in shower for assistance while bathing. I bought my own electric wheelchair (scooter). I bought my own walking stick.*

Five survey respondents mentioned the need for more financial benefits or assistance with meeting the costs of social care.

> *I get no benefits from the government or local council or help from any other services. I have to pay privately for all outgoings. My state pension and very small private pension is not enough for me to live on.*

A commonly cited issue during the discussion groups was a concern amongst the veterans about the additional strain their care needs was having on their wives, or other family members. Many respondents talked about their fears about would happen if family members were no longer there to offer care or support.

> *More help for my daughter who has cared for me and my wife, both disabled. She has done it since she was at school and is now 30. Is now saying she has missed out on life. We couldn't manage without her.*
>
> *Social services have been aware that my wife has been in hospital (30 miles away) twice in recent months but have not contacted me to see if I needed help during the present bad weather. I asked my housing association and was refused help to clear snow.*
>
> *It is likely that from now on (having only in the last few days ceased to own a car) my wife, who will reach the age of 91, and I will have increasing difficulty in accessing GP, dentist, day-to-day shops, bank, Post Office, etc., especially in bad weather: threatened cuts by National and Local Government on health and social services give us cause for anxiety.*
>
> *Currently my wife, an ex-nurse assists me in dressing. As she's in her late 70s, I dread to think what would happen if she was unable to help me.*
>
> *The thing I find with social services is that if you can get time to explain to them then they will put things together. But it's trying to find out what's available and what the package can be. My wife is nearly 80 and she lugged me all over the place and when she had problems through helping me – no one wanted to know*

Priority treatment for veterans

All UK service veterans are entitled to priority access to NHS hospital care for any condition, as long as the condition is related to their period of service, whether or not they receive a war pension. Details of the scheme are given on the Veterans UK website[25]. Veterans are encouraged to tell their GP about their veteran status in order to benefit from priority

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[25] http://www.veterans-uk.info/vets_issues/healthcare.htm

treatment. However, priority access is decided by the clinician in charge and is also dependent on clinical need relative to other patients.

Fifteen respondents commented that the implementation of this policy should be improved. Some respondents felt that many NHS staff seemed unaware of the policy or how it worked. Also, because it can be difficult to clearly establish which conditions were directly related to service, priority treatment should extend to any veterans' conditions. This topic was explored further in the discussion groups, although it was notable that many participants had never heard of the policy themselves, or there was considerable confusion about how the policy should be being implemented.

> *"Fast track" is non-existent. It's there on paper from politicians but when you go to it, it's non-existent.*
>
> *As a disabled ex-serviceman I am entitled to preferential treatment connected to my disability. It would seem that very few people in the NHS are aware of this.*
>
> *All veterans when seeking medical treatment should have it on GP and hospital notes. That they should be treated as a Veteran, as laid down by Parliamentary Law.*
>
> *I think that once a doctor, surgeon etc. knows one is a veteran, more priority should be given to that patient. It should be standard for GP to ask if one is a veteran. They should not be kept waiting as many illnesses and injuries stem from active service.*
>
> *This came to me through the letter from the Veterans Agency for the gratuity war pension is that if I've got any more problems from the skin cancers, I've to inform my GP and I will get preferential treatment. I'd like to see that across the board. Regardless of whether a veteran is ill or not it should flag up on his hospital notes and he should get preferential treatment.*
>
> *Relatively few health professionals know about priority access for veterans. Very few health professionals have ever seen the Department of Health directive. The only way I knew about it is through the British Legion – no one else knows about it.*

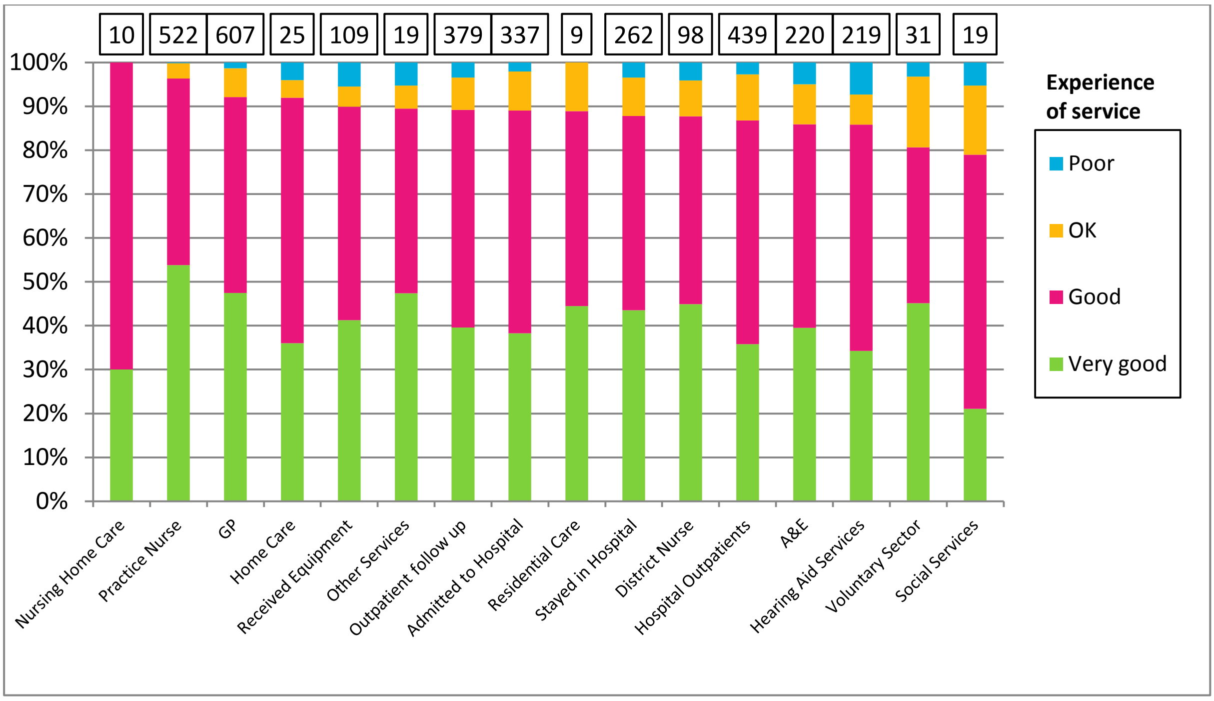
5.4 Overall experience of health and social care services

5.4.1 Overall ratings of health and social care services

Respondents were asked to rate their experience of health and social care services using a four-point scale ('Very good - it couldn't be improved'/ 'Good' / 'OK - but it could be improved'/ 'Poor-it could be improved a great deal').

Figure 5-8 shows the services ranked from best to worst (based on respondents' rating them 'good' or 'very good'). The number of respondents who rated each service is shown above each bar.

Figure 5-8 Distribution of experience of services, by service

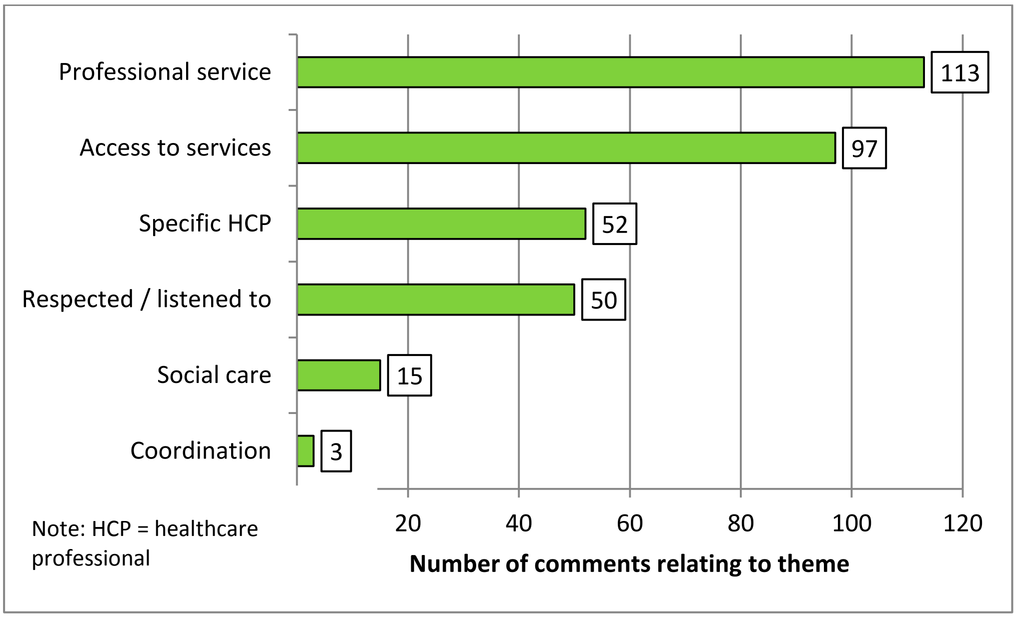


Perhaps surprisingly, the top rated service was nursing home care, but this was used and reported on by only 10 respondents. Practice nurses and GPs received generally positive ratings. Interestingly, home care and equipment received in the home were also rated highly, despite the difficulties in accessing them reported above. But experience of social care provided services again came out as the least well regarded service, but with still 80% reporting they thought it 'good' or 'very good'.

5.4.2 Health and social care services - Examples of good practice

Survey respondents were asked 'Can you give some examples of health or care services that you've been very pleased with? Tell us what was so good about them'. 330 respondents (50%) gave examples. These were analysed thematically and grouped as shown in figure 5-9.

Figure 5-9 Thematic grouping of examples of good health and social care experiences



Note: HCP = healthcare professional

"A Professional Service"

113 (out of 330) of the survey comments praised what they often called an 'all round professional service' from different parts of the NHS – often citing all of the NHS or many different services within a single comment.

> *Doctors are first class in every way when I need help.*
>
> *GP and practice nurse, almost like a private practice*
>
> *All services from cleaners to the top. All do a very good job.*
>
> *Because our health service is run from the Welsh Assembly, we have very few problems with the hospital service. Our G.P. and Practice Nurse services are excellent.*
>
> *District nurses visited daily, quick access to wheelchair and other aids, prompt scans and hospital appointments and excellent transport to hospital.*

The 'all round professional service' offered by many NHS services was also a dominant theme in the discussion groups. The story below from a discussion group participant who had had a head and neck cancer illustrates this theme well.

> *My experience was excellent, from the time my GP identified what this was to getting to hospital to have it removed at Hospital X – they saw me more or less straightaway. I had three or four operations there and radiotherapy, and they found that they couldn't do more about it. I then went to Hospital Y, which is the regional centre for ENT. The guy there told me exactly what the problem was and if I didn't have something done the cancer would eat into the skull and brain, and all that kind of thing. It took me a month to make the final decision. In the meantime I spoke to another consultant, my GP and the facial surgeon and decided, yes, to go ahead with it. From then on it was absolutely brilliant what they did. They took the cancer out*

> *but damaged my face, put in a prosthetic ear, a hearing aid this side, a bone-anchored hearing aid here, which is attached to the skull, and they've rebuilt my face to some extent. I'm still in contact with the facial surgeon – I'm not discharged – he said I'll never really be discharged as they need to keep an eye on things. I'm in fairly constant touch with the guy who made the ear, in fact they made me a spare one a well. I've been in touch quite often with the surgeon who did the facial work. The guy who took the cancer out and the neurologist, I see occasionally. The guy who did the facial work did an absolutely fantastic job... Two or three weeks ago we had a call from one of the specialist nurses at Hospital Y. She said, "We wonder if you can help?" and I thought I'd got to go in again. No, it wasn't that, she said: "We've got a guy here who has to have a very similar operation and he's absolutely terrified about it, he's on his own. I wonder if you could come and have a chat with him?" So my wife and I went in and we sat with him on his own, and we explained what had happened and all the rest of it. I hope we were able to placate him. I can't criticise the care and attention I had. The consultant, the doctors, nurses and even the district nurses who came in to do the dressings – first class. People talk about the NHS…. but there's no way, it's great.*

Ease of Access to services

95 survey respondents commented on specific occasions where they had had rapid access to care or treatment when they needed it, and praised on-going access to follow up treatment, or short waiting times (which had often surprised them).

Specific healthcare professionals (HCPs)

52 survey respondents mentioned by name a specific healthcare professional or team who had delivered outstanding care.

> *The Parkinson's consultant and clinic have been excellent. Always ready to listen and help - especially the Parkinson's nurse, Liz M.*
>
> *'Acute stroke unit' Glasgow Western Infirmary, follow up very good, Dr H in particular.*
>
> *I cannot thank the surgeon Mr M enough when he did my bypass. I did find out a little later he saved my life and that's good enough for me.*
>
> *I would also like to mention the treatment and help by Combat Stress, Hollybush House, Ayrshire for my war disablement condition, post-traumatic stress disorder which as plagued me for many, many years, caused by nuclear explosions.*
>
> *My best experience was attending the Party Day Centre, an Alzheimer's Day Centre. One carer, Cliff, took a special interest in me, looking online for aircraft information and showing me DVDs on the same theme.*
>
> *My GP (Dr D) always available, explained and advised, very good (now retired). My GP now Dr H, just as good.*

Information, communication - being respected and listened to

50 survey respondents cited examples of times when they had been listened to, given information and kept informed, or been particularly involved in decisions about their care.

> *I have had eight operations (2 major) during the past six years. I was informed at each stage what the surgery consisted of and the possible outcomes. Consultants, surgeons, and nursing staff were excellent in the treatment and encouragement given.*
>
> *The prostate cancer – they explain it to you: what it was, what they will do, what will happen afterwards. Brilliant really. I never came away worried as they put me at ease. Even on the day I went in, the chap was talking to me.*
>
> *In the last 12 months I've found out I've got this short lung. My doctor now, takes interest, when I talk to him about something, even when he got the report back from the CT scan, when the specialist said 'oh it's all down to asbestos', I said 'I don't believe that because I was never in enclosed areas with asbestos we were always out in the open so we didn't ingest. But he was the first one to say, 'I don't agree with that'. He said 'I can't go against the specialist, but we'll keep it in mind'. In the last 12 months I've got a doctor who listens.*

Several respondents highlighted the role played by patient organisations in providing information and support.

> *Stroke Association aftercare was excellent. Myasthenia Gravis Association was and still is brilliant with regular updates on new treatments and care programmes.*

Social care

15 survey respondents highlighted examples of prompt access to social care, (although this was also most often cited as an area for improvement – see section 6.3.3 above). All but two of these positive comments related to the provision of aids and adaptations around the home.

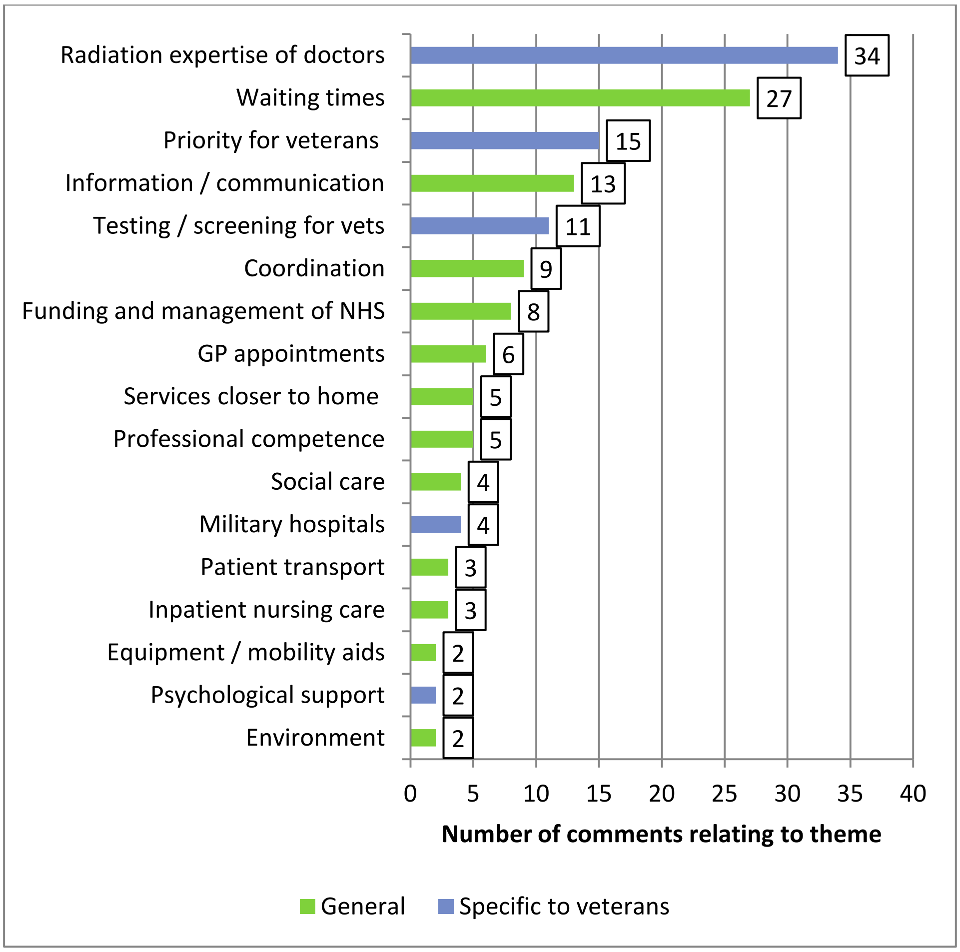
> *With being disabled myself, my wife had a nasty fall down stairs and was in hospital for a month, since then for both of us; we have rails up the steps outside, double stair rail special seats for toilet and bath, panic alarms, stair lift in the pipeline.*
>
> *Care services - adaptation of bungalow - very quick assessment and implementation.*
>
> *Received equipment promptly i.e. hand rails, bath, and lift.*

5.4.3 Suggestions for improvements to health and social care services

We asked survey respondents 'Do you have any ideas about how the health and care services you have received could be improved?' Overall, 188 survey respondents answered this question. 15 respondents said specifically that they thought nothing could be improved in the NHS and social care – it was all excellent. 20 of the 188 made comments related to compensation, war pensions and their treatment by the MoD – these are not included here.

This left 153 specific improvement suggestions (24% of respondents) which were grouped thematically as shown in figure 5-10. Almost half (64) of the suggestions were specific to meeting the needs of veterans.

Figure 5-10 Thematic grouping of suggestions for improving health and social care services



The comments made about waiting times, priority treatment for veterans, GP appointments, social care and equipment / mobility aids all relate to access to services and have already been discussed in section 5.3.2 above. The remainder are discussed in more detail below.

5.4.4 Improvement suggestions specific to nuclear veterans' needs

Greater understanding or knowledge of the impact nuclear tests amongst doctors

34 respondents highlighted their wish for medical staff to have a greater understanding of the nuclear tests and more expertise on the effects of radiation on the human body. This was also a dominant theme within the discussion groups. Respondents reported that doctors frequently "don't know anything about the nuclear tests", or even that they took place, and seem lacking in knowledge and in interest about possible effects on veterans' health. The result of this is that veterans were unable to get answers to their questions and concerns about the causes of their ill-health and frequently have to repeat the same information and explain their service history.

This lack of knowledge amongst medical staff in some cases increased their levels of anxiety about the impact of the tests on their health.

> *I have brought to the attention of my doctor my concerns regarding being used for nuclear testing and the effects it has had on me, and especially my son. They all confirmed to me it was beyond their expertise to offer me any answer to my concerns.*
>
> *It would be helpful to receive a more sympathetic response to nuclear test veterans' concerns from the NHS, rather than the simple dismissive stance taken by some practitioners. Some take our concerns more seriously, but not always.*
>
> *Surely GPs and the related health services could be empowered to ask and record if patients have had personal experience at nuclear test or trial sites. Much information useful for planning, gauging numbers and potential needs could be gleaned this way*
>
> *Wife asked dermatologist if my skin problems could be result of radiation: said he knew nothing about radiation.*
>
> *As my attendance at a nuclear test was over 50 years ago, the current crop of specialists etc. are largely ignorant of what took place on the likes of Christmas Island.*
>
> *I don't know if you can improve the health care for nuclear test veterans as none of our doctors seem to know anything about nuclear radiation, and when you tell them that you are a nuclear test veteran they look at you as if you're an alien.*
>
> *Yes it would be nice to get some comments from all the practitioners that I have dealt with. When I ask the question, do you think that the illness has any bearing on the fact I was involved with nuclear test, they go silent and I never get an answer.*
>
> *It all happened before most doctors of today were born. They have no idea what radiation is. You say, 'I was subject to radiation'. They say, 'What?'*

Access to a "centre of expertise" on the effects of radiation – for both doctors and patients

It was suggested that doctors might benefit from having access to a "centre of expertise" to whom they turn to for additional advice on radiation issues, or to which they could refer patients for information.

> *Should be a specialised unit where problems could be dealt with by people who know what they are dealing with?*
>
> *[There should be] acceptance from the medical profession that they have bitten off more than they can chew and there is a problem, and they should have access to a senior guy who has experience or is prepared to give some advice. I almost feel sorry for them sometimes. They don't know what to do next. We're just another patient in the queue. You've got this or that wrong, but they don't know what the cause is.*

> *Because there's so few of us left now, not every GP or hospital could have a nuclear specialist. But I'm sure they could have it central somewhere where they [the medics] could go for advice.*
>
> *We're just looking for a decision. If something happens, a rash or something, you want someone to go to ask is it or it isn't, you know. Not a GP, someone who can say as a knowledgeable person 'That could not have been caused by radiation or is more likely to be caused by excessive exposure'.*

Access to military health records / Veteran status 'flag'

During the discussion groups, many respondents suggested that their military health records should routinely be made available to their doctors, or that their veteran status should be flagged in their medical record.

> *Our nuclear test information should be available to GPs. It's not. The old GP knew all about it. Now I've changed the new one has no idea. I have my Christmas Island records now. It took a long time. It's all detailed but not on GP's notes.*
>
> *I wrote to the MoD [for my military health record] and they wrote back and said my GP to request them for a specific reason and then it would be up to him if he discussed it with me.*
>
> *Anybody who has been a serviceman, there should be a box on the form and it should indicate whether you've had nuclear exposure.*

Health screening for veterans

11 survey respondents suggested that all nuclear veterans should have undergone some kind of health screening following their service at a nuclear test site, so that potential problems could be identified, or that their minds could have been put at rest. This was a dominant theme in the discussion groups. 10 survey respondents mentioned this as a current need when asked what services they have not received that they would have liked.

> *Follow up tests from the MOD on my health was non-existent, unlike other countries who looked after their test veterans.*
>
> *I believe military personnel should be checked for medical problems thoroughly before leaving the service and at stages in time after.*
>
> *I would like the Government to take responsibility for putting all veterans in harms way. My health has never been checked with regard to me being a nuclear test veteran. This should be corrected.*
>
> *The only way for the health services to be improved for myself and my son would be simply to test us.*

One survey respondent commented that children and grandchildren should also be subject to check-ups.

> *Monitor veterans, their children and grandchildren over their lifetime.*

Linked to this, a number of respondents referred to cytogenetic testing and saw this as ‘the answer’ to all their questions or concerns about their ill health.

> *I suggest strongly that all surviving UK servicemen be given a newly developed DNA test for chromosome damage caused by their participation at nuclear test sites.*
>
> *Lift the ban on allowing nuclear test veterans to obtain cytogenetic blood tests.*
>
> *I have been trying to get a cytogenetic 'FISH' blood test to show the level of radiation I have received (radiation is cumulative).*
>
> *I would like to know if we could get blood tests done. There must be someone that could look and say whether there had definitely been damage done by nuclear radiation… It’s something we should all get.*
>
> *The mFISH study conducted in New Zealand showed that you could go back over 50 years with your DNA to see if you had been irradiated. When we put this to the MoD or the government they said we won’t go down that road because we admit that you will get some results from that but all it will do is multiply by 10 or 20 because there are more participants in England. We are aware of what the answers will be, we are aware of the amount of radiation over there and we are aware of what we’ve had. So they’re not saying you’re not, all they’re saying is we’re not paying you!*

Psychological support

Two survey respondents made suggestions for improving the psychological support offered to veterans, and this was also mentioned by 2 survey respondents (with one respondent in common) as a need for additional services.

> *Physical manifestations of the ‘nuclear situation’ (skin disorder, cancer, etc.) might be relatively straightforward. The psychological less so. I have had anxieties over the years. As a young man returning from Christmas Island I suffered emotional stress over personal relationships. People wanted to know of my experience, but were not able to ‘hear’ or appreciate what was described. With advancing years, when aches, pains and ailments occur, it nags that there may be a connection with the past. I recognise that health professionals generally are more aware of and sympathetic to ‘post-traumatic stress’ these days. So, to an extent is the MOD, although their first reaction seems always to deny all possibilities, whatever the concern… It would be helpful to receive a more sympathetic response to nuclear test veterans’ concerns from the NHS, rather than the simple dismissive stance taken by some practitioners. There are those who take our concerns more seriously than others, I am sure, but not always in my experience.*
>
> *'War pensions' should pay 'Combat stress' for at least twice per year residential treatment. The forces together are a good thing, especially mental welfare.*

Psychological care also came up in the discussion groups, with one respondent highlighting how the psychological impact of taking part in the nuclear tests had affected his mental health, and how psychiatric care had helped.

> *Psychologically, I still sometimes have nightmares about the bombs; I get panic attacks with thunder and lightning activity. I'm 72 years old and I've suffered from it all my life. I can't shake it off. I've had treatment for it [The psychiatric care] has been very good yes. I was treated by a psychiatrist from X and she sorted me out, with medication to help save me from panic. I'm convinced that the first heart attack was caused by the psychological effects. There was a thunder and lightning storm… and I woke up in the morning and that was it heart attack.*

5.4.5 General health and social care improvement suggestions

Information and Communication

Thirteen survey respondents mentioned the need for improvements in the way in which NHS organisations and/or staff communicate with their patients and 6 respondents wanted more information about their illness, treatment or self-care.

> *It's been left to me to find out any information, until I've phoned I've been left in the dark, even after asking to be kept informed.*

> *After my first heart problems 2009, several consultant appointments were cancelled resulting in another emergency admission as I had not been given specific dietary advice.*

> *Never had support following heart op. Jan 1990. One check-up, then discharged. Support for me & wife would have been helpful, especially when had bad angina. Both needed reassurance & how to cope, when to call for help etc.*

One discussion group member highlighted the lack of information available to enable patients to make informed choices about where they should be treated.

> *Its life threatening, it's first class; they shift the world for you. If it's something you can get along with and put up with… then they come back and say, 'here's the choice'. Then they list three places you can go to. So you start ringing around to ask who'll be treating you, they don't know. Is he any good? They don't know that either. So the only thing they can tell you to inform your choice is the length of time you'll have to wait to meet some surgeon, who you wouldn't know from Adam anyway and he may not do the job anyway if you do go there.*

A particular frustration was automated telephone systems.

> *Contacting hearing aid services is via a general (0845) number: one is then offered a choice of buttons. This leads to an (unspecified) queue, with alternate 'music' and largely irrelevant messages, before eventually being connected.*

Co-ordination of care

Nine survey respondents made suggestions for improving co-ordination between different parts of the health system. Many of these described having to repeat the same information time and time again, and some commented that doctor turnover leads to a lack of continuity of care.

> *May I suggest a far better method to record a patient's medical history. At present it is incumbent upon the patient to supply this information during every new appointment with a specialist - causing undue frustration and confusion in an elderly person.*
>
> *My details of medication are on the various computer systems and yet each visit to the hospital no-one has my details and levels of medication. Why have they not got one database system with all the details on.*
>
> *We seem to have a quick turnover of doctors, so continuity is not what it should be. My regular doctor is excellent.*
>
> *You get played about so much. You go to the doctors and after two or three times you are then referred to a specialist. You get a letter one month later with an appointment three months later, see the man, he sends you round the hospital and have some tests and then another appointment in three months' time. During that time you can get another letter cancelling the appointment and another three months goes by – I have been delayed by 15 months to get back to the man – I go back and see my GP and he can't do anything because I have been referred to a specialist. You are on a merry go round.*
>
> *When specialists recommend you to another specialist they should pass information on. Went you see them it's like starting with a blank sheet every time.*

Funding and management of the NHS

Eight survey respondents expressed general concerns over the way in which the NHS is run.

> *There is an acute shortage of nursing staff and too many administrative staff. It may seem retrogressive thinking but I firmly believe there is a place for the Matron to come back into the hospital system.*
>
> *Free car parking at hospitals, reduce managers and employ more front line nurses, doctors etc. Ensure that attractive items i.e. computers are not stolen or lost etc. Run NHS on military lines.*

Professional competence

Five survey respondents highlighted specific episodes of care where they felt that they had been poorly diagnosed or treated.

> *An improvement in the diagnostic skills of GPs [is needed]. Normally GP is good, but wrong diagnosis made in May 2010 resulting in major surgery in Nov 2010*

Three survey respondents talked about poor experiences of inpatient nursing care, although this was counterbalanced by many more positive comments (see section 6.4.1 above).

> *Annual re-training for nursing staff on the care and attention of patients. I have not received the care and attention on a daily basis from nursing staff while in hospital. (Always appear too busy).*

Patient transport

Three survey respondents highlighted deficiencies in patient transport.

> *Arranging transport should be made easier.*

Environment

Finally, two survey respondents talked about the hospital environment in terms of parking and food. One discussion group participant also talked about mixed sex wards.

> *As far as I'm concerned [Hospital X] cardiac unit is the best. I cannot fault it. The only trouble with it, it could do with more parking spots.*
>
> *If you are in hospital, better food to recover by should be paramount to getting better.*
>
> *The only gripe I've got about the health service is mixed sex wards. I felt embarrassed. It's like a third world hospital. Blair, Cameron, they all said the same thing. It's very embarrassing.*

6 Respondents' Beliefs about the Cause(s) of their Ill-health

This section covers:

- Respondents' views on the causes of their most serious or major conditions
- Respondents' beliefs about the whether the nuclear tests have affected their health
- The influences and external factors associated with respondents' beliefs that their participation in the nuclear tests has affected their health.

6.1 Introduction

Respondents were asked what they thought were the possible causes or cause of their most serious or major conditions and to select the possible cause(s) from a list of 12 common possible causes of ill-health, including life-style behaviours (such as smoking and alcohol consumption), genetic factors, socio-economic factors (such as bad housing), or work-related factors.

They were also asked specifically to state their beliefs or views about whether they thought their health had been affected because of their having been stationed at a nuclear test site; choosing from five options: No [it hasn't been affected] / maybe it has / I think it has / I am certain it has / I don't know.

If they did think their health had been affected, they were given the opportunity to say, in free text, why they thought this was the case, for example because of the type of work they were doing at the time, the things they saw, etc..

Respondents expressed a wide range of different views about whether (or not) they believed their health had been affected by their presence at the nuclear tests and why. They also provided useful free-text commentary about what they believed might be other causes of their ill-health. Importantly, it became clear that there was a range of different factors that have influenced veterans' beliefs in their being a causal link between their experience of ill-health and their participation in the nuclear tests.

6.2 Respondents' views on the causes of their most serious or major conditions

Figure 6-1 shows respondents' views about the possible cause, or causes of their most serious or major conditions. Of the 2,801 conditions reported, 33% (922) of conditions were attributed to radiation, of which 24% (665) of conditions were attributed to radiation alone (i.e. no other possible causes were suggested) and the remaining 9% (257) attributed to both radiation and another cause.

Only 16% (454) of conditions were attributed to other causes of ill-health (such as smoking, poor diet, work-related factors).

However, in 51% (1,425) of conditions, no causes or cause was identified. It has therefore been presumed that the respondents were therefore unsure.

Figure 6-1 Respondent's views on causes of their serious conditions, (based on number of conditions)

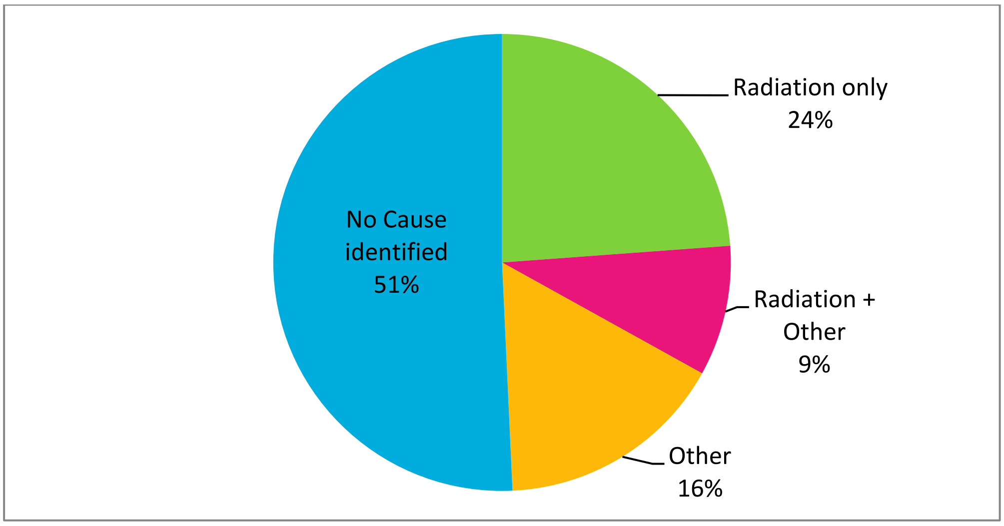


Figure 6-2 shows respondents' views about the possible causes of their serious or major conditions by disease category.

Respondents were most likely to link cancers and wider skin conditions to having been exposed to radiation. Radiation (exposure) was mentioned as a possible cause in 65% (184) of the reported cancers and in 49% (88) of the reported skin conditions. In contrast, it was only mentioned as a possible cause of 23% (95) of heart/circulatory diseases and 15% (28) of endocrine diseases.

Figure 6-2 Causes attributed by respondents to their conditions - by disease category

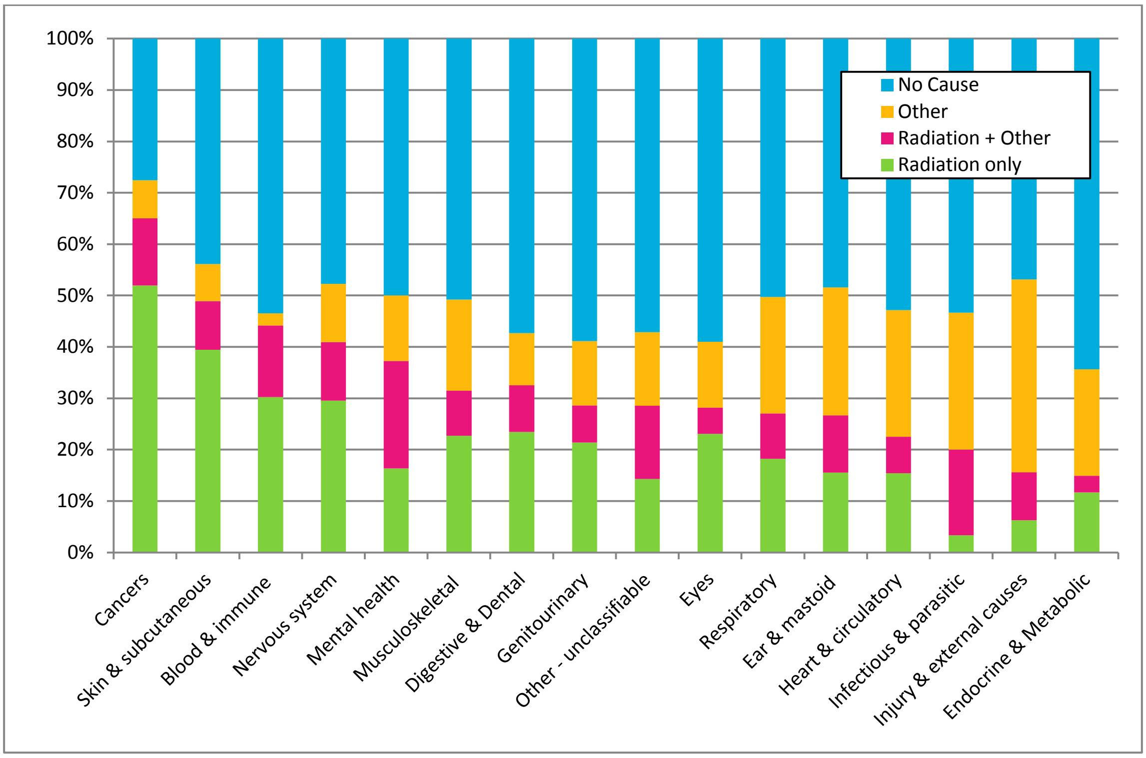
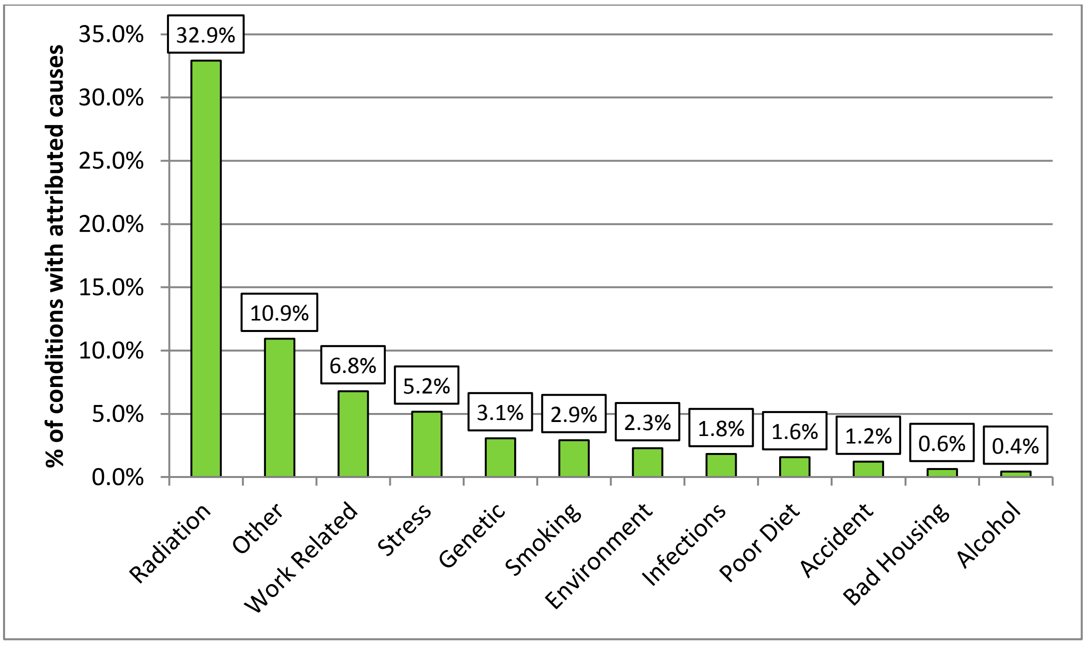


Figure 6-3 shows the weight given by respondents to different possible causes of ill-health. The other causes besides radiation most commonly cited as causing their conditions were 'other causes' (cited in 11% of conditions), 'work related' causes (cited in 7% of conditions) and 'stress' (cited in 5% of conditions). Of note was the weight attributed by respondents to radiation (considered a cause in 33% of conditions) in comparison with smoking (only mentioned as a cause in 3% of conditions) and alcohol (in only 0.4% of conditions).

Figure 6-3 Causes mentioned in relation to respondents' conditions



The discussion groups further highlighted the breadth of respondents' views regarding the range of possible causal links to their serious ill-health, together with their views or understanding of the potential impact of radiation exposure. The quotes below reflect some of these differing viewpoints.

> *Exactly 40 years later I got leukaemia. A specialist said low level radiation can take 40 years to come out. Then I got ulcerative colitis – both of these are related to immunity. I've also had heart problems, but a lot have this. I'm pretty damn sure the low level radiation caused it.*
>
> *I don't think I've been affected. Well I haven't been ill with anything that could be associated with Christmas Island. I've been diabetic for 20 years but never connected it.*
>
> *The problem is that some of the conditions of which we're complaining are things as a result of old age as well as radiation, so it's very difficult to make sense of it all.*

6.3 Overall beliefs about nuclear tests affecting their health

Survey respondents were asked the specific question: 'Do you think that your health has been affected because you were stationed at a nuclear test site?' The results are shown in figure 6-4.

- 28% (175) of respondents said they were certain their health had been affected by the nuclear tests
- 23% (147) said they thought it had been.

Therefore half of the respondents (51%, 322) indicated positively that they believed their health has been affected in some way by their participation in the nuclear tests

However,

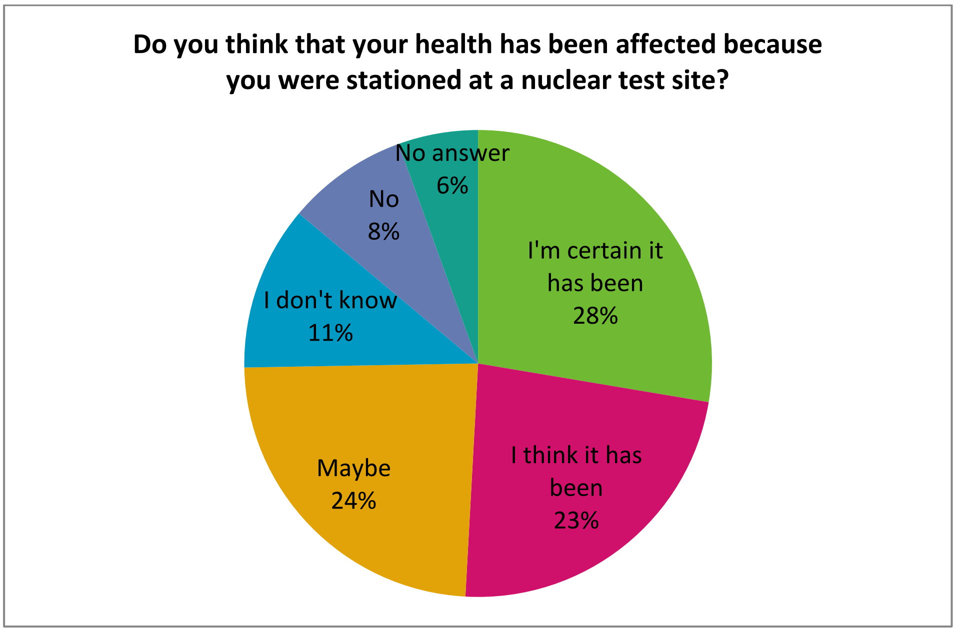
- 24% (151) were unsure if it had (replying 'maybe')
- 11% (72) replied that they didn't know.

So 35% (223) were much less certain about direct causation.

Finally,

- 8% (53) said a clear 'No' they did not think their health had been affected.
- 6% (35) of survey respondents did not reply to this question at all.

Figure 6-4 Beliefs about whether involvement in nuclear tests affected their health



6.4 Factors associated with respondents' beliefs that the nuclear tests affected their health.

There was a range of factors which seemed to be associated with, or be influencing respondents' beliefs that their health had been affected by their participation in the tests.

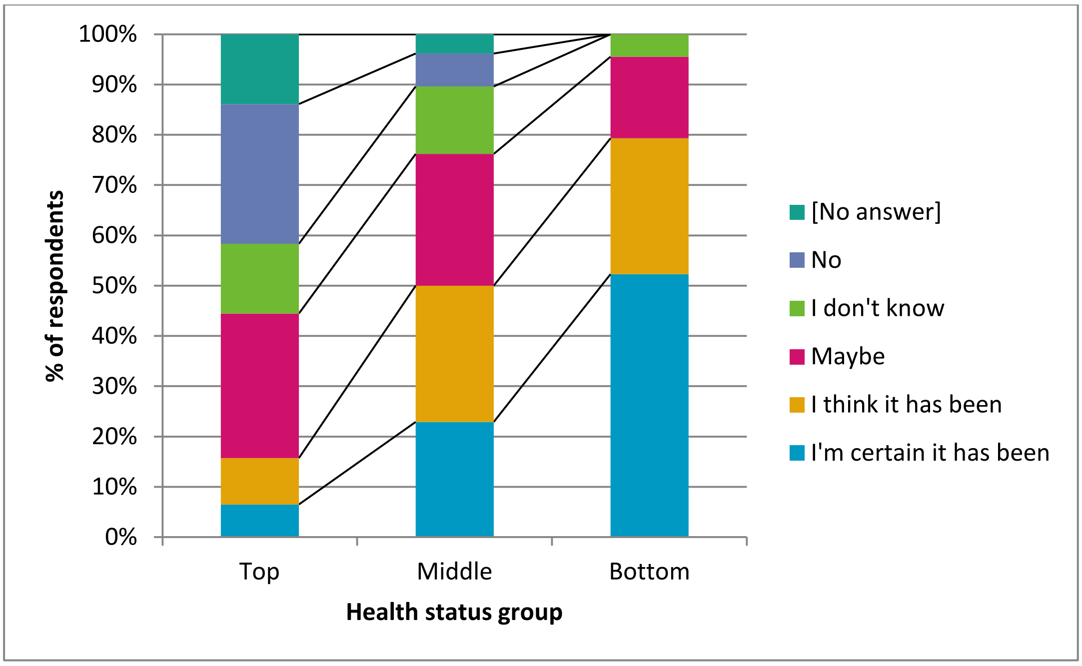
6.4.1 Respondents experience of ill-health and health status

The first and unsurprising association was that more of the respondents who are currently in the poorest health (i.e. those in the 'bottom' health status group) believed that their ill-health had been caused by their participation in the nuclear tests, than those who were currently in better health (see Figure 6-5).

Of the 111 respondents in the 'bottom' health status group, 88 (79%) were either certain, or thought that their health had been affected by the nuclear tests, whereas, of the 108 respondents in the 'top' health status group, only 17 (16%) respondents were either certain or thought their participation had affected their health.

Those in the 'top' health status group were those most likely to think there was no causal link (28% or 30 respondents).

Figure 6-5 Respondents' own health status and their belief in a link between their health and the nuclear tests



This association is also replicated across all the individual domains of the EQ-5D quality of life assessment. Those respondents reporting the greatest difficulties with mobility, self-care, ability to perform usual activities and pain are also more likely to believe their health has been affected by their participation in the nuclear tests. This link is even more pronounced for respondents reporting the highest level of anxiety and depression. 22 (85%) of respondents reporting themselves as extremely anxious or depressed said that they were certain of a link.

Below are examples of the types of comments respondents made in the discussion groups when asked why they think their ill-health is linked to their nuclear test involvement.

> *It was 25 years ago. I was okay but then things started to go wrong. Basically skin problems and that's been continuous for 25 years to the present moment. Even last year, a specialist discovered something else wrong with me. The biggest thing was that I had a horn growing from my forehead and I have a scar still there.*
>
> *I witnessed 25 explosions in three months… The panic attack situation - thunder and lightning sets me off… My first major heart attack came the day after a big panic attack which was triggered by thunder and lightning.*
>
> *In the 1980s I went for a blood test and learned I had leukaemia… where your bone marrow stops working and the spleen takes over. Then I read up that it can be contributed to by being irradiated as well.*

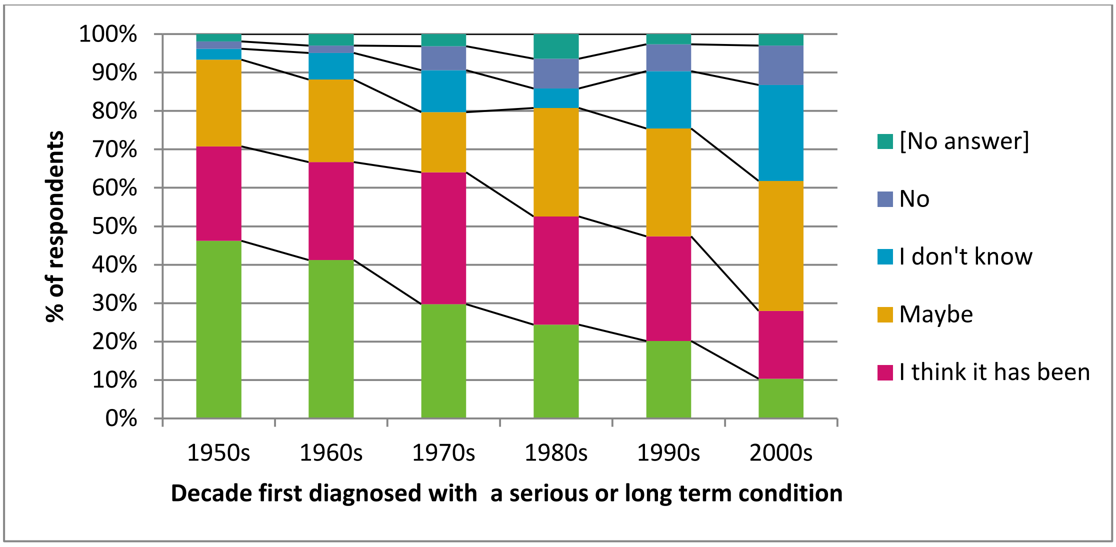
6.4.2 How soon first diagnosed with serious condition after participation in tests

There is also a clear association between respondent's belief in a causal link and how soon after the tests they were diagnosed with a serious of long term condition.

Those whose first serious or long-term condition was diagnosed immediately, or soon after, their participation in the nuclear tests (i.e. in the 1950s and/or 1960s), were four times more likely to believe in a causal link than those respondents diagnosed in later decades (see Figure 6-6).

46% (49 out of 106) of those who had their first serious or long-term condition in the 1950s believed in a causal link, whereas only 10% (7 out of 68) of those first diagnosed with a serious or long-term condition between 2000 -2009 believed there to be a link.

Figure 6-6 Decade first diagnosed with a serious or long-term condition and belief in a link between their health and the nuclear tests



In the additional free text narrative provided by respondents as to why they thought their health had been affected by the nuclear tests, 38 survey respondents mentioned experiencing serious health problems during or very soon after the tests – and with conditions which they had not suffered previously.

This was also a dominant theme in discussion groups.

> *I think that my general health did suffer after my period on Christmas Island. When I went into the Army I was passed A1, however, within 12 months of returning from Christmas Island I had to leave the army on medical grounds.*

> *In 1959 I started to get severe pain in my right side. I was reporting sick every day and given a green fluid to drink. It didn't do any good. I was flown back to the military hospital where I had an operation to remove the stones.*

> *I got de-mobbed in 1959… A year or two later I started getting bouts of uncontrolled vomiting. I and the doctor couldn't put it down to anything…This went on for 4 – 5 years. It was really terrible. Even the hospital couldn't say what it was… I'm no medical man but it keeps flashing in my mind: radiation sickness.*

Further analysis was carried out to look for other potential factors that might be associated with veterans' beliefs. However, there were no particular associations found in relation either to their current living arrangements (e.g. married, widowed, etc.), their length of service in the armed forces, or to their levels of educational attainment or qualifications.

6.4.3 **Other possible or perceived health hazards at nuclear test sites**

Respondents also identified a range of other perceived health hazards (not just possible radiation exposure) which were present at the test sites and which they believed had, or might have, affected their health subsequently. These included things like exposure to DDT insecticide, exposure to excessive sun and noise, and work-related accidents and injuries. Although comments on these other potential health hazards were fewer in number than comments about radiation exposure, they are nevertheless important in the overall picture of the veterans' beliefs about a wider range of potential causal factors.

DDT (Dichlorodiphenyltrichloroethane)

Most common was the perceived health risk of exposure to DDT - mentioned in 25 survey responses. Respondents talked of the frequent spraying of the insecticide from RAF Auster planes. Some perceived a direct link between this exposure and specific illnesses they have suffered, citing the fact that DDT is now a banned substance, and in several instances providing information on research papers they had read that linked DDT to specific illnesses.

> *The main camp where I was billeted was subjected to an aerial dusting of DDT every two or three weeks by a small crop dusting aircraft. This was to keep the mosquitoes from breeding. This insecticide has since been banned worldwide.*

> *Main camp sprayed daily from the air over Main Camp. It came down like a stinking yellow /grey cloud and settled on everything and everybody.*

> *My main chronic illness, myasthenia gravis, is a rare condition of the immune system, this may or may not be due to the nuclear tests, but a study by the Americans have*

> *linked this illness to Vietnam and the use of DDT. This was sprayed on us daily on Christmas Island by a RAF spray plane.*

Sun exposure

Fifteen respondents mentioned excessive and obvious exposure to sun. For many test participants, service at nuclear tests in the Pacific or Australia would have been their first exposure to strong sun over a prolonged period. This is reflected in a number of survey comments where they also raised the lack of precautions they had taken to protect themselves from sun exposure.

> *[This was my] first continual exposure to tropical sunshine.*
>
> *No advice [was given] on dealing with very hot sun.*
>
> *Was working as an instrument fitter in the RAF in extreme sun and heat with no sun protection creams supplied and a very poor diet!*

Exposure to loud noise

The effects of being exposed to loud noise was mentioned by 13 survey respondents, all of whom also reported varying degrees of hearing impairment. In addition to the loud sound of blasts during the detonation of bombs, respondents also cited constant exposure to aircraft noise as a reason for their belief that their hearing had been affected.

> *I have permanent tinnitus, which the audiologist thought was due to the explosions at Christmas Island. They very rapidly gave me a war service pension for being over 20% deaf.*
>
> *Christmas Island 1958 saw five nuclear tests, hence in my opinion have resulted in high tone deafness, tinnitus and low platelet count. Worked in the airfield area around aircraft.*
>
> *I think my hearing damage (across the speech spectrum) was initiated by the proximity to four nuclear blasts and exacerbated by working on aircraft radios in fighter aircraft assembly pans.*
>
> *In defence of the RAF, they didn't start looking after your hearing until the mid-1960s… it wasn't until the late 1960s early 70s that they came in with ear defenders for those working with planes.*

Accidents, injuries and other external causes

Accidents and injuries were mentioned in very small number of the survey comments. However, there were many anecdotes shared in discussion groups about their occurrence. Among those mentioned were injuries to limbs caused by falling equipment, back problems through heavy lifting and infections caused by coral poisoning contracted when swimming or playing football on pitches made of coral sand.

> *I have bad arthritis in my feet, trouble walking. I mentioned they got trapped under a bulldozer on the island. I spent a fortnight in hospital on Christmas Island. He said*

> *see if you can get hold of your medical records and we'll see if it's related. I emailed and asked. A year later, it's all in there. I haven't done any more about it as my feet have improved.*
>
> *Coral was in fact one of the main problems with ear infections. If you looked at the hospital on Christmas Island the number of people reporting with coral poisoning was very high.*
>
> *I had coral poisoning through an abrasion on the ankle. Penicillin powder had to be applied. Purple scar for several years and it ached.*

6.5 Reasons why respondents think their health was affected by the nuclear tests

Survey respondents were asked, 'If you think your health may have been affected, why is this?' Respondents were prompted to consider things they saw, things they were told at the time or since, as well as details of the types of work they were involved in. Their answers were wide-ranging, reflecting their diverse experiences both at the tests and the things which have influenced them over the years since.

This section looks specifically at respondents personal interpretations of what happened at the nuclear test sites which possibly gave rise to the later beliefs of some that their health has been affected. Comments made are grouped into those relating to respondents' beliefs that they were exposed to radiation, and comments made about other health hazards at the test sites.

6.5.1 The reasons respondents believe they were exposed to radiation

294 comments were made in the survey responses about why respondents believed that they had been exposed to radiation. These have been thematically grouped as follows:

- Proximity to the blast site(s) and/or work undertaken at blast sites
- Lack of protective clothing or other forms of protection
- Experiencing 'the flash'
- Information given at the time about risks of radiation exposure
- Issues relating to 'radiation badges'

Proximity to the blast site and work undertaken at blast sites

The belief that proximity to the blast site and/or the work that respondents did at the test sites led to radiation exposure featured in 96 comments. Respondents explained that they believed that in many instances they had been too close to the site of detonation, or that they had been exposed to radiation by sailing through contaminated seas, or flying through clouds after a blast.

A common theme in the discussion groups, as well as the survey responses, was respondents' work on machinery, and aircraft in particular, that may have been contaminated. Others talked directly about their work to clean equipment and areas after detonations had taken place, and in some instances the requirement to work in or visit 'forward' or 'restricted areas'. Accompanying these comments were descriptions by some respondents of steps taken to ensure decontamination of military personnel, including vigorous and repeated washing, and nail and hair cutting.

> *After the tests, we were required to hose down aircraft which had flown through the resulting clouds. Even as a young man I sensed the danger in these experiences, feeling I was a 'guinea pig'. As a result I was always worried about my health.*
>
> *I was working in the weapons compound on Christmas Island and so in constant closeness to whatever was happening.*
>
> *Involved washing down and servicing aircraft that flew through mushroom cloud collecting air samples. Resulting in some personal contamination at the time.*
>
> *I was a member of the island laundry unit and therefore in contact with all units' clothing and dress.*
>
> *Because of close proximity to the actual nuclear testing areas which had obvious risks of radiation (no matter what anyone else says).*
>
> *Anyone who was doing anything to active material, there were special showers. You had a crew cut for a start - that was sensible, and kept your nails exceedingly short. You went into decontamination and were scrubbed, washed down, checked and told 'OK, on your way'.*

Lack of protective clothing or other forms of protection

76 comments related to witnessing the detonations. In these, survey respondents talked about their personal beliefs that 'being out in the open' caused them to be exposed to radiation. Seeing the after-effects on wildlife (e.g. blinded birds) and the land (described as "scorched and burnt") also influenced the views of some that they had been exposed. Some respondents expressed concerns about whether the environment in which they were living had been contaminated. Many felt that they should have been issued with more protective clothing than they were.

> *Tops of trees nearby us were on fire… thousands of trees and lagoons vanished.*
>
> *I was stationed at Christmas Island working as a plant operator. Witnessed 5 atomic blasts without wearing ANY protective clothing of any kind. After blasts witnessed bushes burning and dying birds in certain areas.*
>
> *Admittedly the explosions were 30 miles distant but radiation must have polluted the air for days if not weeks.*
>
> *[I was on] Christmas Island, printing newspaper. I saw 2 A- and 2 H-bombs while there. Told to turn back on bombs and not to look directly at them. We were offered no protection at all.*

The information and advice received at the time

The information and advice about radiation and other health risks (or lack of it) given at the time was the subject of 52 comments in the survey and a topic raised frequently in the discussion groups.

Some respondents reported that, at the time of the nuclear tests, they were not told about the potential dangers of radiation exposure, or that they were informed that the bombs were 'clean' or 'safe'. Discussion group participants reflected that at the time, this was not of great concern. However, looking back some respondents now feel they were naïve to have taken the information provided at face value.

> *We were not informed of any health risks at the time of the detonations or anything since.*
>
> *I worked in many areas on the island including what was called the forward area. Little did I know that this was not a very nice area to be in. In my time on this island we was never told of any dangers of radiation.*
>
> *The nuclear bomb cloud expanded in the sky so much it eventually was above our heads on the ship and daylight was dimmed by the dense cloud. We did not worry too much when this was happening because we were instructed to believe that these were the clean nuclear bombs.*
>
> *Served on HMS Campania throughout Operation Hurricane at Monte Bello Islands and exposed to radiation. This was not just at the time of the test/explosion, but for several weeks/months after. This was without knowledge, explanation or awareness of the possible dangers at the time. One just did what one was told to do.*
>
> *We were given a talk by – I don't know if it was an officer – about radiation and the effect it could have and how much the body could take. He assured us we would never get anywhere near this level.*
>
> *We were young guys. Even if you saw a sign saying 'don't go there' you can guarantee that the first thing you would do was to go.*
>
> *We're judging a lot of the actions of yesteryear. I think, going out to Christmas Island as a 20 year old, if someone had said to me 'there's something out there which is going to harm you' I would have said 'well I'm invincible'. I think there was an element of warning given. I think there was an element of disregarding it.*
>
> *While we were there, nobody told us what the radiation level was. But this week in the papers [because of the nuclear incident in Japan] here have been all these helpful guides which tell you about the different radiation levels and what they mean. It's very helpful. We never had anything like that.*

Experiencing 'the flash'

The perception that experiencing 'the flash' was evidence of radiation exposure was described in 44 comments.

> *During test we put our hands over our face - it was as if our whole body lit up - and we were being x-rayed. Something I will remember for the rest of my days.*
>
> *Watched bomb go off. Could see bones in hands over eyes when bomb detonated. Surely this can't be normal.*
>
> *We had our backs to the bomb. The heat was tremendous. With our eyes covered with our fists (as instructed) we could still see the skeleton of our hands.*
>
> *Felt blast, heat surge and experienced blinding light through hands.*
>
> *I witnessed first Grapple test from the flight deck of HMS Warrior offshore from Malden Island with our backs to the detonation the flash showed the bones in our hands which were over our eyes, so what went through our bodies?*

Issues relating to radiation badges (dosimeters)

26 comments related to the use of 'radiation badges' to measure exposure to ionizing radiation. 13 respondents mentioned that dosimeters or badges had not being issued to them, leading to concerns about the failure to monitor possible radiation. Others who had been issued with dosimeters or badges reported that that they had not been told the results at the time or since, or were told that results had been lost. Several reported occasions when dosimeters had failed to record a reading.

Similar comments featured in discussion groups and it was clear from these that such experiences were interpreted by some, as evidence of radiation exposure.

> *The dosimeters where taken off us straight after the blast. The results never shown.*
>
> *My radiation film badges are reported as missing.*
>
> *I never heard about, or even saw a personal dosimeter or other radiation exposure device until the 1960s.*
>
> *I actually started to ask questions of the Veterans' Association and the MoD about how much radiation we'd actually received. I asked for my medical records. I had four film badges and they were all lost – they fell off into the water. I got a reply back that 'yes, you are listed as being issued with one badge'. I actually received a printout… it says that my film badge was missing so I was given an 'average' dose 0.5 mSv over the period I was there, same as someone will see in the UK.*

6.6 Wider external factors influencing respondents' beliefs

The discussion groups revealed a range of wider external factors that have contributed to influencing respondents' beliefs in there being a link between their health and the nuclear tests. These are summarised below.

The views of health professionals on the causes of respondents' ill-health

How health professionals have responded to veteran's concerns or questions about having been at the nuclear test sites and the effects on their health of radiation exposure, was a topic of major debate in all the discussion groups. Many respondents have been influenced in their views by doctors either saying there was likely to be a link between their illness and their nuclear test service history, or by their refusal to rule one out. Equally, if their expressed concerns about their radiation exposure have not been supported or even ignored or dismissed by health professionals, some still assumed the worst – and even in some cases – led them to conclude that there medical staff were involved in a complicit 'cover up'.

> *I must have been affected, not just because I saw the bombs when I was on Christmas Island, but because the doctor at the hospital said that. I had a cancer on the face and had it removed.*
>
> *I have chronic kidney disease and I've always thought it was the flash. If I ever mention anything about Christmas Island or nuclear they clam up. I'm sure the medical profession have been told not to say anything. They're not all ignorant. They all read the newspapers and medical journals.*
>
> *I've had numerous stomach operations and they just can't determine what cause my problems. I've seen Profession C.I. for years, but he says we can't go down the road of what cause this because there's not been enough scientific research. Strangely enough there was an Australian doctor assisting him and he knew quite a bit about Maralinga and all that, and he says 'I wish I could have some time with you but Professor C.I. won't allow it. He said 'If I'm not mistaken, your problems do stem from Christmas Island'.*
>
> *I've had lots of skin cancers removed – so often that the doctor asked me if I sunbathed. I said no. We chatted and I mentioned I was on Christmas Island. Something clicked with him and it was about the time that everything was in the papers about nuclear test veterans, the claims and all the rest of it. As soon as he heard that, the shutters went down. He wouldn't talk about anything.*
>
> *I suffered an abscess at the base of my spine in the early 60s. I was in good health until six years ago, when it got to the point where I could hardly walk. I had a CT scan and they found that one lung was curled up. As soon as you mention you are a nuclear vet, their eyes glaze over and they don't want to know. They asked about what else I had done and I said I had been a builder so they put it on the report that I would have been near asbestos.*

The influence of the media

The media, but newspapers in particular, have played an influential role in shaping perceptions from the time the nuclear tests took place right up to the present day. Some respondents remembered, indeed reminisced, about media coverage at the time of the nuclear tests that speculated about future health problems for servicemen and led some young women to write 'Dear John' letters to loved ones. However, most often mentioned was the long standing campaign in support of nuclear test veterans run by the Daily Mirror. In particular the front page headline run by this newspaper in the early 1980s urging nuclear test veterans to seek medical advice.

It was clear from discussion groups that reading about possible health effects in newspapers had given some respondents cause to start raising concerns in a possible link to their own health. For others, media coverage has reinforced concerns they already had.

Over the years, the news media has continued to follow developments relating to veterans of the nuclear tests, and this had continued to impact on respondents, furthering health worries for some, and fuelling disappointment and resentment at successive governments' responses for others.

What is clear from respondents' comments is that the media has been a key source of information that is easy to access and easily understood by them – and importantly, in the absence of any credible or trusted alternative sources of information.

In some of the discussion groups respondents referenced 'facts and figures' from newspaper articles they read over the years, and in some instances brought along copies of these articles.

> *We got the newspapers late out there, but a few weeks after a lot of fellas got 'Dear John' letters as their wives and girlfriends had read that children would be deformed.*
>
> *When I finished my national service, in the local paper I read of the deaths of several people who had been in Christmas Island. It starts to sink home then.*
>
> *The Daily Mirror in 1983 had a full page: it said 'Anyone who served in Maralinga or Christmas Island - go and see your doctor now'. I went to the skin hospital and next thing I was in the Christie Hospital (for removal of cancerous lump on ear).*
>
> *There's something in the papers about nuclear veterans almost every day. Like there's this chap he says his name is on a list, his body will be checked after his death.*
>
> *Well it was in the newspapers that this can rear its ugly head in children's, children's children for the next 500 years.*
>
> *There is so much in the press about the French, the Americans, and the Australians. You'd think there'd be some justice. I know everyone's case is different but as far as I'm concerned I don't want much…*

Views of others

Some respondents described how their perceptions have been influenced by other individuals. Respondents talked about comparing their own experience to the experience of other veterans and being made aware of possible effects of radiation by friends, or colleagues. Membership of groups, including the BNTVA, has also played a part in respondents' understanding and perception of the issues.

> *Four years ago, I passed out and was taken to hospital. I was there for three or four weeks. They couldn't work out what was wrong with me. Every bodily function went. I couldn't walk, my bladder packed up. I never made the link at first but then my mother started talking to me. She said 'this is all to do with Christmas Island'. But the doctors won't admit it; they say there's no connection'.*
>
> *I've had two bouts of depression or three in the last 25 years. When I talk to other mates I thought it was just natural, you know, but I talk to other people and I think it could be the bombs.*
>
> *After the explosion I had to drive a lorry of men to an explosion site and the dust caused from the tyres at the site was breathed in. Since I have belonged to the BNTVA and they have informed all members re the high risk of radiation exposed to at that time, and continue to campaign re exposure illness.*
>
> *In about the early 1980s I heard that there was a British Nuclear Veterans Association and I joined it. I thought I was joining a group to get together with the lads and have a chat about the old days. I had a questionnaire asking me whether I had warts and deformed fingernails and I thought, 'of course, yes, I did, hang about!'*

Concerns about the responses from the MoD

All the discussion groups featured often strongly expressed views about veterans' feelings of having been treated, or communicated with, by the MoD in an unsatisfactory manner (both in the past and currently). 20 respondents used the section of the questionnaire survey on "health service improvements" to air their views about their perceived treatment by the MoD. Some of the issues raised included:

- A perceived lack of recognition of the contribution that nuclear test veterans made through their participation in the tests.
- A perceived 'blocking of access' to information, either about themselves as individuals (for example access to their service medical records and information on individual levels of radiation exposure) or about the tests more widely.
- Lack of pro-active direct communication from the MoD about nuclear test issues, either when they were discharged from the armed forces or since.
- Puzzlement at why the MoD is spending money defending legal action rather than using these funds to offer a degree of compensation to nuclear test veterans, as other countries have done.

- Lack of understanding of why more resources have not been invested in scientific research either in the form of a full epidemiological analysis or cytogenetic study of nuclear test veterans.
- A perception that over many years politicians have used the nuclear test veterans story for political gain when in opposition, but have not followed this support through when in government.
- A view that MoD needs to change how it relates to its veterans in general.

The MoD should be more aware of what we did for the sake of the nuclear deterrent which I feel is quite important. Especially the younger generation who don't really know what it is all about.

We need a voice, someone to listen. Not pie in the sky excuses. I've got letters from MPs for the last 20 odd years and every single one said they will do their upmost and then when they get in they don't do anything.

I can sum it up in three words: openness, frankness and honesty.

Regardless of what may in fact be the case, the perception that facts are being withheld is believed by many. Requested is a more straight forward approach towards answering questions.

I don't know how it's affected my health. How can a layman know what a medic doesn't know, and the MOD won't tell you.

54 year ago people didn't realise radiation was a problem

There was a lack of communication in the first place and it's compounded all these years later by an on-going lack of feedback.

I'd like them to be a bit more open. At the very least we'd like an apology. We were treated appallingly. They've told so many lies over the years about how we were checked for radiation, had badges, Geiger counters, protective clothing.

Well its one word respect. There seem to be a total lack of it. Once you're out of the forces it's good luck and goodbye.

7 Respondents’ Beliefs and Views about Health of Descendants

This section covers:

- The number of descendants reported by respondents
- Respondents’ beliefs about their descendants’ health
- Factors associated with beliefs about descendants’ ill-health
- The impact on respondents of concerns about their descendants’ health

7.1 Introduction

Nuclear test veterans have, for some time, expressed concerns about there being a possible link between their participation in the nuclear tests and ill-health amongst their descendants (children or grandchildren). Although, to date, there is no generally accepted scientific evidence which clearly demonstrates such a link, as this was such an important issue to the veterans themselves, it was agreed that the health needs audit would explore in more depth, their beliefs or concerns about the potential health impact on their descendants.

The audit questionnaire asked respondents to provide:

- Details about the number of all their (biological) children and grandchildren they have had and their gender
- Information about the conditions of those descendants whom they thought had experienced any serious illnesses, together with the year of birth of the relevant descendant, the year of diagnosis of the serious conditions, and whether these conditions were now resolved
- Information on any descendants who had died including year of death and what they believed was the cause of death.

They were also asked to outline further their views and beliefs about whether their own participation in the nuclear tests had or had not affected the health of their descendants.

It was not within the remit of this health needs audit to collect information directly from descendants themselves. Such a study would be very difficult, time-consuming and costly to undertake, as it would need highly complicated ethical approval and consent processes, and require access to confidential medical records. In addition, the tracking of progeny (who are likely to be dispersed across many countries) would also be difficult.

The information presented in this chapter is therefore purely a record of what the veterans described in their survey responses and during the discussion groups about their descendants’ health or about their concerns about their descendants’ health. It has not been validated and it would be impossible to do so.

Often, people may not necessarily have a detailed or comprehensive understanding about the ill-health or conditions (sometimes kept private) of wider family members. As reportedly earlier, there were already problems with the accuracy or level of detail which some respondents were able to provide about their own conditions. It became evident that for many, the information they could provide about their descendants' ill-health or serious conditions had additional problems with accuracy, both in terms of the descriptions of conditions, the numbers or frequency reported, and age of onset. It was therefore reluctantly decided that the information provided was of too variable quality to be able to produce any meaningful analysis.

This chapter therefore simply presents an analysis of the qualitative comments regarding the respondents' stated beliefs about whether their descendants' health has been affected by their participation in the nuclear tests, and the impact that this has had on them.

7.2 The number of descendants

Of the 633 survey respondents, 545 (86%) said that they had fathered children. 473 (75%) of the respondents also reported having grandchildren.

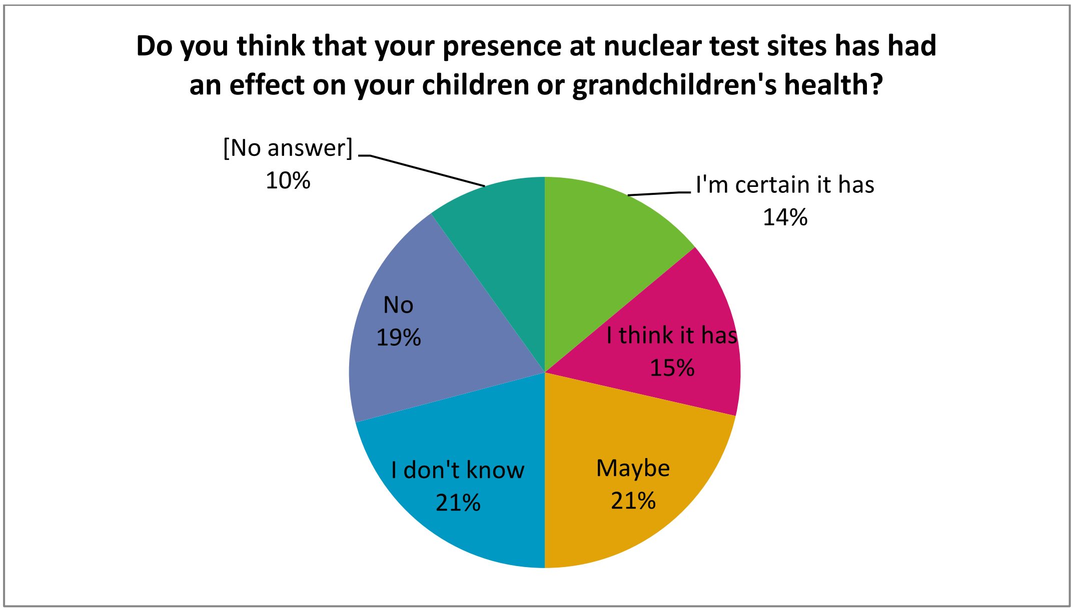
In total there are 3,342 descendants, 1,321 of whom are children and 2,021 of whom are grandchildren. 88 survey respondents either have not had children, or chose not to complete this section of the survey questionnaire.

7.3 Respondents' beliefs about their descendants' health

Survey respondents were asked the question 'Do you think that your presence at nuclear test sites has had an effect on your children or grandchildren's health?'

Figure 7-1 shows the beliefs of the 546 respondents who reported that they had biological children (whether or not their descendants had had a previous or current condition).

Figure 7-1 Respondents beliefs about whether their involvement in the nuclear tests has had an effect on their children's health



- 159 (29%) believed that the health of their descendants had either been definitely affected by their own participation in the nuclear tests (76 or 14%), or they thought it had been (80 or 15%).
- 117 (21%) were less sure – answering 'maybe', whilst 114 (21%) said they definitely didn't know.
- 105 (19%) said a clear 'No' - they did not think their children's health had been affected by their involvement in the tests.
- 54 (10%) respondents with children did not answer this question at all.

Although opinion on this matter was clearly mixed, respondents expressed much less certainty about there being a link between their nuclear test participation and their descendants' ill-health than they did about their own ill-health.

As reported earlier, 51% of respondents were either certain their own health had been affected or thought it had, whereas only 29% of respondents were certain or thought their descendants health had been affected.

7.4 Factors associated with beliefs about descendants' ill-health

When restricting the analysis to the 546 respondents who reported having descendants, 267 reported that their descendants had had a past or current serious condition.

Of these 267:

- 56 (21%) were certain that their descendants' condition(s) was/were due to their participation in the tests
- 68 (25%) thought it had
- 83 (31%) said it may have
- 44 (16%) said they didn't know
- 14 (5%) said no, they didn't think it had.

This shows that where respondents' descendants have had a serious condition, they are more likely to attribute their participation in the tests as a key causal factor.

Additional analysis was undertaken to look for possible associations between respondents' demographic characteristics and their beliefs about the possible link with their participation in the nuclear tests and their descendants' health. The following characteristics were examined but no correlations were found.

- Education attainment of respondents
- Length of service in the armed forces
- How soon after the tests their own serious condition was diagnosed (which does correlate with their views about their own ill-health).

Both the free text in the survey and discussion groups provided more detail about some of the reasons behind some of the respondents' beliefs in a causal link between their participation in the nuclear tests and their descendants' ill-health. These reasons included:

- Diagnosis of an unusual or rare condition
- Diagnosis of a condition where there had been no previous family history
- Diagnosis of a serious condition at a young, or very young age
- Conditions which respondents believed to be generally associated with radiation exposure
- Conditions which they believed were associated with genetic translocation.

The comments below reflect some these beliefs:

> *It seems strange that both my daughters had cancer and there is no incidence of cancer in my family.*
>
> *My grand-daughters are presently under investigation for health issues. One of them has a heart murmur, the other bowel problems. The biological mother and myself sill have general good health. For some reason some of our children and grandchildren have developed health issues which are inconsistent with family medical history. I think this is the result of my national service spent on a nuclear test site.*
>
> *My last wife had numerous miscarriages before finally giving birth to my daughter. My son was born three years later, after two more miscarriages. He was born with cataracts to the eyes, very rare in children, but an after-effect of radiation exposure. This I feel sure was due to my service on Christmas Island.*
>
> *My daughter had an underactive thyroid and it's a common complaint among young people who were at Chernobyl. My grandson has this strange deformity in his ankles. These things seem to crop up more often than they do in the general population, but they won't do any proper research so we'll never really know… our DNA needs to be independently checked, or we'll never know the answer.*
>
> *I took my son to consultant specialist aged 12 because we noticed that one knee was lower than the other. It's not only the length of his leg, but the entire length of his skeleton. And he called it congenital haematrophy. When I asked him if being on Christmas Island had any bearing on it, he said I haven't the expertise to tell you. And he wouldn't commit himself either way. And I'm absolutely convinced that I've pass this onto him.*
>
> *My daughter was born with a restricted aorta and two extra ribs, rheumatoid arthritis, diabetes type 1, hypertension. She's had her spine fused and she has bone growth on her foot that she's had cut back a few times and its arthritis. Granddaughter aged 22 born with a heart murmur that has since disappeared, psoriasis, arthritis since the age of 11, not believed to be rheumatoid. Grandson autistic, knee problem caused by his legs not straightening properly. Other granddaughter, perfectly fit just eczema, asthma and Reynaud's syndrome. There is a Finnish doctor who has tied up radiation with arthritis.*

However, other respondents whose descendants had experienced ill health expressed clear doubt of there being a causal link:

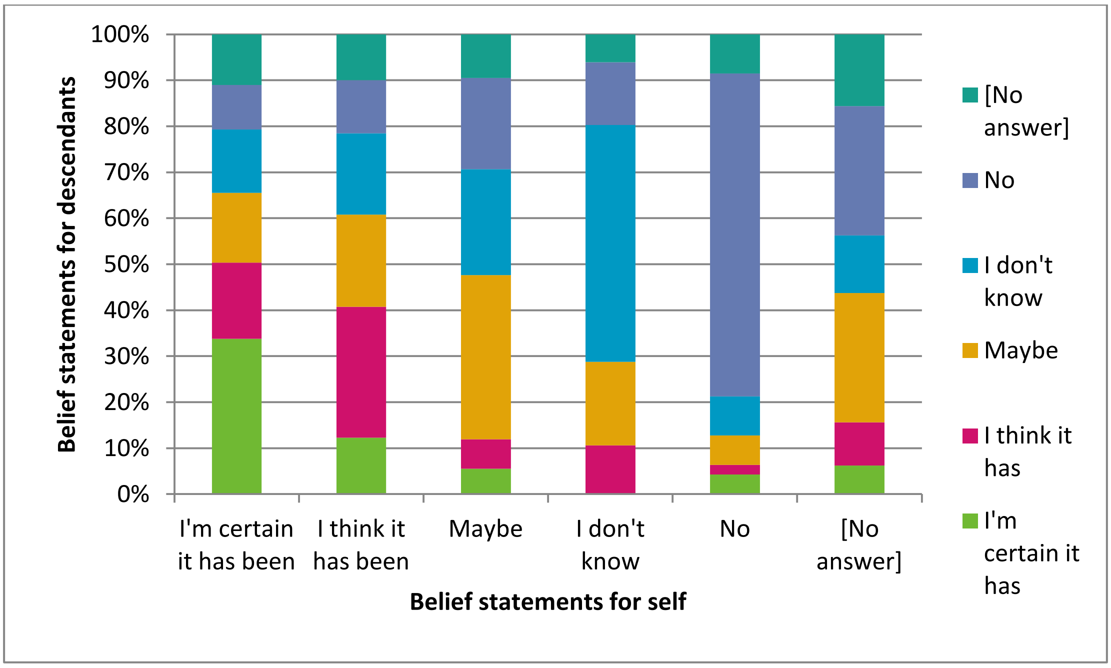
> *One grandson has Down's syndrome. We did some research into it and there doesn't appear to be any correlation.*
>
> *I don't think there's been any worry. My eldest daughter was born with a couple of defects. She's deaf and we didn't know about it for four years… she went to see the specialist and it was all sorted out. He operated on her ear drum and put it back together and she's been fine. We did worry and wonder but she was fit enough to join the army for three years. She was born ten years after I was there. I say no. The changes are so slim.*
>
> *My eldest son was born with a defective hip and spent the first 9 months of his life in a splint the full length of his back. He recovered all right. It's difficult to describe. There could be some connection but I couldn't put it down to it.*

Respondents with a clear stated belief that their own health had been affected by their involvement in the nuclear tests (saying 'I think it has' or 'I'm certain it has') were also more likely to believe that their descendants' health had also been affected than those who were less certain about the causal link to their own ill-health.

Of those who said they were certain their own health had been affected, 43% of these also said they thought or were certain that their descendants health had been affected.

Conversely, of those that gave a definitive 'No' about their own health, only 6% expressed a clear belief that their descendants' health had also been affected.

Figure 7-2 Veterans beliefs about the impact of the nuclear tests on their own health and the health of their descendants



7.5 The impact on respondents of living with concerns about their descendants' health

The discussion groups revealed a degree of ongoing anxiety amongst respondents that their participation in the nuclear tests could affect the health of their descendants in the future. The uncertainty about causation and 'not knowing' was an issue often raised during the discussions. Below is a selection of some of the remarks reflecting this anxiety.

> *It's always in the back of your mind. The incubation period is so long. It could come out in a grandchild years later.*
>
> *When my children had our grandchildren I wanted to be the first to see the baby to check its fingers and toes and everything was in the right place. It became an obsession. I used to fear when my kids said they were pregnant… I was on tenterhooks. That in itself puts a strain on your health every time.*
>
> *My son is also very convinced that his condition it is to do with my present of the test. My granddaughter, at the moment, there is nothing wrong with her, but as everyone knows here that this can be an on-going thing, it can skip a generation. Low level contamination can go on for years and years and years and keep coming out in future generations.*
>
> *Well it's difficult. The dilemma you're in is that you can put two and two together and get 10, but you don't want to transfer that on to your family. The problem is with us. But our interest in the BNTVA is being reinforced because you see these things happen to our families. And also as we get older we learn more, there's more information coming in – like this New Zealand study which has convinced a lot of people that something went wrong out there. So all l these things begin to accumulate in your mind. But at the end of the day, you're in a position – like in my case – our daughter had everything go wrong with her. She had a mild form of spina bifida. Her children have problems. So a picture begins to build up that there's more to it.*

8 Summary and Suggestions

8.1 Introduction

This report presents a high-level picture of the apparent 'burden of disease' or disease prevalence, health status and health-needs of a group of 633 British nuclear test veterans, in December 2010 and January 2011. These 633 represents 3% of the 21,542 British servicemen who it is believed participated in the British nuclear tests in the Pacific in the 1950s. It is estimated that between 8 -10,000 are still alive today, meaning that the audit sample may represent around 8% of the current living nuclear test veterans.

The information presented in this report is derived from a questionnaire-based postal survey, together with eight discussion groups held around the UK. The respondents were a self-selected group of individuals from amongst the UK-resident membership of the British Nuclear Test Veterans' Association, and not a random sample. The information they have provided does not necessarily reflect the experience of the wider group of nuclear test veterans, and also cannot be compared in any respect with the health needs of the wider population. It simply describes their individual experiences of ill-health, their health needs, their use and experience of health and social care services and their beliefs and concerns about the causes of their ill-health.

8.2 Data warnings and the dangers of misinterpreting the data presented in this report

Great care must therefore be taken in the interpretation of the data and information presented in this report. There are a number of very important 'health warnings' associated with the accuracy of the data collected and reported, in part due to inherent bias of having a self-selected sample of respondents, and reporting unverified (and unverifiable) information about disease prevalence.

The authors strongly caution against the misuse of the data presented in this report for 'political' or campaigning purposes. This is likely to be counterproductive. Such misuse would only add to the anxiety and concerns expressed by elderly, and in some cases quite vulnerable, men and their families.

The data warnings are discussed more fully in Chapter 3 and in Appendix 1 - but include the following main points:

- The data presented on serious or long-term conditions and disabilities is self-reported and has not been validated through independent checks of respondents' health records.
- The definition of 'serious' has been left up to the respondents to decide for themselves.
- The data presented in this report are, and can only be, representative of the reported experience of the group of people who kindly completed the survey.

- There was considerable variation in the accuracy and level of detail in which respondent's expressed disease names, making analysis challenging.
- The prevalence or 'burden' of disease presented is therefore **not comparable** with any other reported statistics on wider population health status or burden of disease.
- It is **not possible** to make any comparisons with, nor draw any conclusions about whether the burden of disease reported by this group of veterans is 'higher' or 'lower' than the general population (of same age or sex), or compared to any other group of nuclear test veterans (or other non-nuclear veterans).
- It is also **not possible** to make any correlations or draw any conclusions from these data about whether the nuclear tests have had any direct or indirect impact on the respondents' health.

8.3 Reported serious or long term conditions (by broad ICD10 disease category)

Respondents provided details of what they considered serious or long term conditions, diagnosed by a doctor, since their participation in the nuclear tests to the present day. They were also asked to state when they had been diagnosed, and if (and when) any of their conditions had resolved.

The conditions are reported at both the broad ICD-10 chapter disease category level, and then (where possible) listed by individual conditions. In summary the burden of disease amongst this group of 633 veterans is as follows:

- 59 (9%) reported never being diagnosed with a serious or long-term condition since the nuclear tests up to the current day
- 574 (91%) respondents reported between them total of 2,801 separate conditions diagnosed since the nuclear tests up to the current day
- 25% (692) of these conditions had been resolved (at the time of completing the survey) - therefore 75% of reported conditions were still current.
- At the ICD-10 disease category chapter level, the most commonly reported current conditions were
  - Musculoskeletal diseases (accounting for 18% of the reported conditions)
  - Heart and circulatory system (15%)
  - Genitourinary (9%)
  - Digestive and dental (9%)
  - Endocrine and metabolic (8%)
- Many reported currently suffering from multiple conditions, with 287 reporting 2 to 4 concurrent conditions, 145 reporting 5 to 9 concurrent conditions, and 23 reporting 10 or more concurrent conditions.
- The analysis revealed a clear (and unsurprising) association between the number of reported conditions and respondents' overall health status as measured by the EQ-5D.

8.4 Summary of respondents' current health status and levels of disability

Respondents' health status was measured using a standard validated quality of life instrument called the EQ-5D. This measures quality of life across 5 domains using a 3- point scale. An overall health status index can be calculated from responses, putting respondents in either a 'bottom' (worst health status) category, 'middle' category or 'top' category (best health status).

Amongst the 585 respondents who fully completed the EQ-5D:

- 108 (18%) reported no problems on any of the five EQ-5D domains
- 336 (57%) had some problems on at least one domain
- 111 (19 %) reported some problems or severe problems on all five domains

In terms of broader self-assessed experience of disability:

- 379 (60%) of respondents considered themselves as having a disability
- The most commonly reported disabilities related to legs or feet, followed by hearing problems, followed by back or neck problems.
- Unsurprisingly, there was a clear association between reported levels of disability and health status (as measured by the EQ-5D)
- Disabilities relating to legs, backs and hands had the greatest impact on overall health status.

8.5 Respondents' experience of health and social care services

The audit gathered information on respondents' recent use of health and social care services (over the past two years). Questions were asked about frequency of service use; ease of access to services; areas of unmet need for services; experience and satisfaction with services; examples of good practice; and suggestions for improving health and social care services.

In summary:

- Primary care services were the most frequently used (accessed by 97% of respondents over the past 2 years), followed by hospital services and then social services.
- Predictably, those in the poorest health ('bottom' health status category), or with more than one current condition, used services more than those in the other health status groups and across all service types.
- Regarding ease of access to services, the majority of respondents rated nearly all services as being 'easy' or 'very easy' to access. However, residential care, home care and social services were rated as harder to access than all other services.
- A relatively small group of respondents with disabilities said they needed more help with activities of daily living, with the most stated need being for help with going out and about (24 people).

- Overall, maybe surprisingly, most respondents were very pleased with the services that they had received, with all service types rated ‘good’ or ‘very good’ by over 78% of respondents. Primary care services were particularly well regarded. Social care provision was the least well regarded.
- Over 330 examples of good or excellent practice or experience were provided and there were numerous accounts of the NHS, in particular, providing an overall, outstanding and professional service and many examples of excellent care being offered by named individuals and clinical teams.
- GPs and practice nurses were rated particularly highly in terms of both ease of access and patient experience.
- Social services provision was viewed both as hardest to access and least well regarded, although only 28 respondents (4%) said they had tried to access social services in the past 2 years.

8.6 Respondents’ views and beliefs about the cause or causes of their ill-health

The audit examined in some detail veterans’ views and beliefs about the possible cause or causes of their conditions or ill-health and their perceptions of links between their participation in the nuclear tests and the impact on their health.

Respondents were asked specifically whether they thought their health had been affected by being stationed at a nuclear test site.

As the majority of respondents (96%) were members of the BNTVA (a group originally set up to raise awareness and campaign for financial compensation for perceived damage to nuclear test veterans’ health) it was anticipated that most would strongly believe there to be a direct causal link between their participation in the nuclear tests and their (or others’) ill health. Perhaps surprisingly therefore, views were more or less equally divided about the issue of causation.

- 322 respondents (51%) said that they were either certain or thought their health had been affected by their participation in the nuclear tests.
- 311 (49%) were much less certain or didn’t express an opinion – saying they were either unsure (24%), didn’t know either way (11%), that the tests definitely had not caused their ill-health (8%), or didn’t express an opinion (6%).

The audit also asked respondents to express their views about a range of possible causes of their ill-health, including radiation exposure. These included other factors present at the nuclear test sites; wider life-style or health-behaviours (such as smoking, stress, etc.); socio-economic factors (such poor housing, work-related injury, etc.); or other factors (such as genetic factors etc.).

Perhaps notably, respondents raised a number of additional perceived health hazards at the test sites which they believed may have affected their health, aside from possible radiation exposure. These included exposure to DDT insecticide, exposure to sun and noise, and accidents and injuries.

- Respondents cited radiation as the *only cause* of 24% (665) of their conditions
- In addition, respondents cited radiation ***but in combination*** with another causal factor of 9% (257) of their conditions
- In total, therefore, radiation was cited as a cause of 33% (922) of their conditions
- In contrast, the other most commonly cited other possible causes of their ill-health were work related issues (cited in 6.8% of conditions), stress (cited in 5.2%) and genetic factors (cited in 3.1%).

8.7 Factors associated with respondents' beliefs that their health has been affected by the nuclear tests

The audit also looked at possible factors associated with respondents' beliefs in a link between ill-health and participation in the nuclear tests (51% of respondents held this belief).

Unsurprisingly, respondents were more likely to believe there was a causal link if they had experienced more serious illnesses or long term conditions, or were generally in poorer health currently.

Those diagnosed with a first serious or long term condition sooner after the tests were also more likely to believe in a causal link.

Respondents also described a range of wider external influences which seem to have contributed to their beliefs in a link between ill health and test participation. These included:

- Health professionals' comments (or conversely refusal to comment) when asked about a link between illness and radiation
- Media reporting about there being a causal link
- The views or opinions of other individuals or groups, particularly members of veterans' organisations such as the BNTVA.

For some of the respondents who believe there to be causal link, there was a noticeable impact on their overall sense of wellbeing. In this group, there was more reported anxiety and depression, and a higher level of concern expressed both about their own health and wellbeing and about the possible impact on the health of their family-members, both currently and in the future. Some respondents stated that even if they had not experienced any specific illness which they could associate with the tests, they had a general sense of anxiety or fear that something 'might' happen to them, or to a member of their family, in the future.

8.8 Concerns about descendants' health

The health needs audit was not initially designed to include a survey about descendants' health. But because this issue was of such great importance to some veterans, it was agreed to include a section on respondents' views, beliefs or concerns about the potential health impact on their descendants.

However, when analysing the information provided, it became apparent that the level of detail and degree of accuracy provided about specific conditions in descendants was highly variable and often clearly inaccurate. This sadly meant that any meaningful analysis of descendants' conditions proved impossible.

The analysis could therefore only report on whether or not respondents believed that their descendants' health had been affected by their own participation in the nuclear tests; and more general or wider concerns respondents had about their descendants' health.

When asked about their beliefs about the causes of their *descendants*' ill-health, respondents generally expressed much less certainty of there being a link to their participation in the tests than they did in relation to their own ill-health.

- Of the 633 survey respondents, 545 (86%) said that they had fathered children, and they reported having 1321 biological children and 2021 grandchildren. Some also reported on great-grandchildren.
- 29% were certain or thought there was a link between their participation in the nuclear tests and their descendants' ill-health.
- 42% were either less certain ('maybe') or said they didn't know
- 19% stated that they did not believe there to be a link and 10% didn't answer the question.

Nevertheless, the comments made by respondents showed that, for some, the ongoing uncertainty about the possible effects of their participation on their descendants' health is a cause of continuing anxiety.

8.9 Summary of health and social care needs

- This group suffers from a wide range of conditions and disabilities. Some respondents, however, are evidently in excellent health, whilst others are clearly struggling with poor health across a range of domains and often with concurrent conditions.
- It is not possible to determine whether this group's level of health or health needs are the same, more, or less, than males of the same age in the general population, for reasons explained fully in the report.
- Whatever their health needs, nearly all respondents indicated that, in general, they felt their healthcare needs were being met, and met very well, by the NHS.
- Levels of satisfaction with the health services were extremely high. There was not quite the same level of satisfaction with the care provided by social services.
- However, there were also some respondents in the lowest health status group and therefore probably the most in need who were not getting sufficient, or any, access to the range of support services that they could benefit from. This might be through lack of information about service availability, or not asking for services, or simply lack of local provision.
- Veterans want health professionals to be more aware of their status as veterans and issues to do with being a nuclear test veteran in particular.

- Awareness of priority NHS treatment amongst both veterans and NHS staff - where relevant or appropriate - was limited. This should be improved.
- Although a wider policy issue, consideration should be given whether priority access could be provided to veterans to the range of social care services.
- Not all believe that their participation in the nuclear tests has affected their health, but amongst those who do (51%), this belief is in itself a cause of significant stress for some, and is causing ongoing worries about their own health and their descendants' future health.

8.10 Veterans' suggestions

As well as identifying the broad burden of disease and the health needs of this group of veterans (including their access to health and social care), an important part of the health needs audit was to gather suggestions or recommendation for improving health and social care services in order that they might better meet their, or other veterans' needs in the future.

Although there were high levels of satisfaction with the health services received by the respondents (across all sectors of the health service), and to a lesser extent with social care services, there were still 153 recommendations made by respondents specifically relating to their health or social care needs. These are summarised below.

Secondly, despite the audit asking specifically for suggestions to improve health and social care services, many respondents decided to explicitly include a number of comments or suggestions relating to their concerns about general veterans' issues, or issues specific to nuclear test veterans, or specifically about their communications or relationship with the MoD.

Despite these issues not being strictly relevant or directly related to the health needs audit itself, they were clearly so important to the respondents, it was decided to include them in this section of the report.

8.10.1 Suggestions for improving health or social care services

Improvement suggestions for health or social care - generally

- Improve access and waiting times by
    - Making the system for booking GP appointments more user-friendly and flexible
    - Improving waiting times for hospital appointments
- Improve access to wider therapies provided by the NHS – such as physiotherapy, podiatry, etc
- Improve access to a range of social-care services – to enable continued mobility, ability to maintain activities of daily living and maintain independence
- Improve support to family carers

- Improve access to home-based equipment and aids – or information on where to access these
- Improve health professionals' communications skills
- Improve information provided on conditions and health services
- Improve the co-ordination of care between health professionals and between organisations

Improvement suggestions for health or social care - specific to nuclear test veterans

- Improve understanding or knowledge of the nuclear tests amongst doctors
- Improve awareness of priority NHS treatment for veterans - both amongst veterans and NHS staff - where relevant or appropriate.
- Although a wider policy issue, consideration should be given whether priority access could be provided to veterans to the range of social care services.
- Provide access to a "centre of expertise" on effects of radiation – for both doctors and patients
- Improve access to military health records
- Develop a system to 'flag' nuclear test veteran status in health records
- Introduce a health screening system specifically for nuclear test veterans – possibly annually
- Improve access to psychological support services specific to the experience of nuclear test veterans

8.10.2 **Suggestions for improving relations and communications with the MoD**

Improve the information currently available about nuclear tests for veterans and their families

The MoD website currently has a number of factsheets available which describe various aspects of the British nuclear tests, including the MoD's position on how many veterans were exposed to measurable radiation and the relationship between radiation exposure and health. However, these fact sheets are rather difficult to find, and could be re-written in perhaps more user-friendly language. They could be aimed at the veterans themselves, rather than a wider readership (presuming the media and politicians also).

It would be helpful if the MoD compiled a set of high-quality evidence-based information sheets in one easily accessible place, written in clear lay language, providing accurate information for lay people and veterans and help to dispel the many myths that can easily influence non-experts. This could specifically include:

- Information on what documents about the tests that are in the public domain and how to obtain them
- Information on how veterans can obtain their own service history and service medical records

Clarify the MoD's position on any future research that could be done regarding the health impact of the nuclear tests.

Many respondents in the audit wanted access to cytogenetic testing. The HPA suggested in 2007[26] that consideration should be given to repeating the Massey University study with a larger group of British veterans. It would be helpful if the MoD clarified their current view about the feasibility or desirability of commissioning a larger cytogenetic study of nuclear test veterans. It would also be useful to clarify their position regarding the feasibility of undertaking a wider epidemiological population-based study.

Improve general communications between veterans and the MoD

Many veterans told us that this audit was the first time they felt anyone 'official' had talked to them, or listened to them about their experience of having participated in the nuclear tests, or their concerns, let alone their fears about their descendants' health.

The opportunity to record their health history and their concerns about their service history has therefore been greatly welcomed.

A final observation

Although the initial remit and scope of the health needs audit was to look only at health and social needs and experiences of this group of veterans, it became clear that it was also going to be important to widen the scope in order to capture the concerns and beliefs about the possible causes of their ill-health (and that of their descendants).

It was made quite clear to participants from the outset that the audit was neither designed nor intended to be able to address or provide any helpful information to the issue of there being a causal link between ill-health and participation in the nuclear tests.

It is clear that this issue will continue to be debated and for some time to come. However, what was strongly apparent throughout this audit was that in the middle of what is often a highly inflamed debate, there is a group of now ageing ex-service men, some of whom continue to be very worried about their health and the health of their descendants. They are not scientists, lawyers or health professionals. Getting access to, understanding and critically appraising complicated scientific evidence (particularly of this nature) is not easy.

There is a great deal of room for the misinterpretation, misunderstanding and even misrepresentation of the 'scientific evidence' (on either side of the argument). For some of the veterans the mere continuation of this debate, the lack of resolution and the lack of independent and accurate information which they feel they can trust will further exacerbate their stress and anxiety and in some cases could adversely affect their mental health. This is regrettable.

Miles and Green Associates, Oxford, October 2011

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[26] **Comments on "New Zealand Nuclear Test Veterans' Study - A Cytogenetic Analysis" by RE Rowland et al [A Report by the Institute of Molecular Biosciences, Massey University, presented to the New Zealand Nuclear Test Veterans' Association (2007)]**, Radiation Protection Division of the Health Protection Agency, accessed at http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1284473852692

Appendix 1 – Further information on the Health Needs Audit methodology

The audit was undertaken in three stages. The main elements of each stage are summarised below.

Stage 1 – Project inception (October – November 2010)

This included; the development of detailed risk assessment and project plans; inception meetings with the MoD steering group for the audit and initial discussions and meetings with members of the British Nuclear Test Veterans' Association (BNTVA); the development and piloting of questionnaire and production of information for veterans about the audit;

Stage 2 – Data collection (November 2010 – March 2011)

This included the planning and administration of the postal questionnaire and discussion group events

Stage 3 – Analysis and report drafting (April 2011 – July 2011)

Data Collection

Data for the audit were collected using a questionnaire-based postal survey and via a series of discussion groups with a sub-set of survey respondents.

The postal survey collected both quantitative data and qualitative information about:

- The veterans' characteristics and demographics
- Self-reported episodes of doctor-diagnosed serious illness (short or long-term) in the years since participating in the nuclear tests
- Their assessment of their current health status and quality of life and self-reported disabilities
- Their recent use and experience of health and social care services in the last two years
- Their beliefs about whether and how their health may have been affected by their involvement in a nuclear test.
- Whether they believe that their children and grandchildren's health has been affected by their participation in a test.

Discussion groups were semi-structured and enabled the collection of purely qualitative information. They allowed for a more detailed examination of some of the common themes raised in the questionnaire-survey and more in-depth discussion of issues raised in the survey. The information gained in the discussion groups proved particularly useful in contextualising and enhancing the data gathered through the survey on veterans' beliefs about their health problems.

In total 891 questionnaires were sent and 633 returned - a response rate of 71%.

The Questionnaire

Development and piloting of the survey questionnaire

The project team drafted an initial survey questionnaire, drawing on a range of survey literature and exploring the use of various validated tools as part of this process. Following review by the MoD steering group and BNTVA, changes were made to the questionnaire where appropriate. The questionnaire was laid out by a professional designer experienced in creating and testing user-friendly questionnaires and patient information. The questionnaire was then piloted with a group of volunteer respondents who were all BNTVA members eligible to take part in the audit. A member of the audit team visited the respondent in their own home and left the questionnaire with them to complete, and then returned to find out how easy they had found it to do so. Further modifications were then made to the questionnaire, leading to a third and final version completed on 15th November 2010.

The questionnaire was divided into six sections:

Section A: "About You"- collected information on basic demographic characteristics.

Section B: "Your Service History" - collected information about respondents' armed services history including the nuclear test sites where they were stationed.

Section C: "Your health history" - collected information about self-reported serious or long term conditions diagnosed by a doctor at any time since the nuclear tests. Respondents were also asked to identify what they thought were the possible cause(s) of their most serious or major conditions.

Section D: "Your current health and care needs" - collected information on current health status - via the EQ-5D questionnaire and provide information on any disabilities they may have, and what help and support they felt they needed with specific aspects of daily living.

Section E: "Your use and experience of health and care services"- collected information on veterans' recent usage of specific health and social care services (over past 2 years) together with their views on ease of access and overall satisfaction with these services. This section also gave respondents the opportunity to provide information on services they had not received, but felt they needed, and finally, it asked for examples of good practice and suggestions for service improvement.

Section F: "Your views on your descendants' health" provided the opportunity to provide details on the health of their descendants and respondents' own views on whether their descendants health has been affected by their involvement in the nuclear tests, and why.

Recruitment of audit participants

The BNTVA provided the main channel through which nuclear test veterans were informed of and invited to participate in the audit. An article publicising the work was placed in the November issue of the BNTVA's newsletter 'Campaign'. Following this, the postal questionnaire was sent to all BNTVA nuclear test veteran members resident in the UK, together with a leaflet explaining the audit and a covering letter from the BNTVA's President encouraging participation. A dedicated phone line, project email address and project website (www.nuclearvetsaudit.com) were set up to manage enquires about the audit.

Leaflets about the audit were also supplied to the COBSEO annual general meeting that took place on 27th October 2010 together with an announcement during the plenary session.

In total, 891 questionnaires were distributed to veterans in the week commencing 22nd November 2010. Of these, 866 were sent to BNTVA members with the remaining 25 sent to veterans hearing about the survey through word of mouth and via other ex-service organisations.

Inclusion criteria

Capturing veterans' direct and most recent experience of health and social care services together with their current health history were key aims of the audit. For this reason, the following inclusion criteria were applied to individuals wanting to take part in the audit:

- Individuals must have been serving in one of the four British armed forces (Army, Navy, RAF or Royal Marines) and stationed at one or more test sites in Australia and the Pacific during the tests or clean-up operation
- Individuals must be resident in the UK.

Consequently, the following groups were excluded:

- Widows and descendants of nuclear test veterans
- Individuals with civilian status who were present at the nuclear test sites during the testing and clean-up operation.

Following discussion and agreement with management of the BNTVA and the MoD it was assumed, in good faith, that members of the BNTVA could be considered bona- fide nuclear test veterans. However, the survey did ask respondents to provide their armed service number as a deterrent to non-genuine nuclear test veterans. A sample of 10 anonymised service numbers was sent to the MoD in January 2011 for verification.

Administration of the survey

The questionnaire was sent out between 25th and 29th November 2010 to 891 nuclear test veterans, with a response deadline of Friday 17th December.

Exceptional weather conditions followed, leading to delays in the mail, and it was therefore decided to extend the deadline to Christmas, and thereafter on a case by case basis to the end of January for participants who said that they had been away during the response period. By that time, 633 completed questionnaires had been received. This represents a 71% response rate, exceptionally high for this type of audit.

Between November 26th and January 28th the project team responded to approximately 30 calls to the dedicated helpline by veterans and other interested parties.

Data processing and analysis

An Access database was developed to store and analyse responses. Data has been stored in an anonymised form in line with requirements of the Data Protection Act 1998.

Data was reviewed to ensure consistency and enable effective analysis of responses to take place. This process included:

- Standardisation of the self-reported serious or long terms conditions entered by respondents in free text (for example, unifying ‘cancer of the prostate’ and ‘prostate cancer’ as simply ‘prostate cancer’)
- Reclassification of self-reported serious or long terms conditions into the correct ICD-10 disease category, if entered incorrectly or under ‘other’, where possible
- Reclassification of highest level of educational attainment entered as ‘other’ where the description of the qualification provided allowed the level of qualification to be identified.

Survey respondents were asked to complete the EQ-5D scale[27], a standardised, validated survey instrument which gives an overall picture of current quality of life and health status, scoring quality of life across 5 domains: mobility, self-care, ability to perform usual activities, pain, and anxiety/depression. On each of these domains, respondents could rate themselves, as they are today, as either 1 (no problems), 2 (some problems) or 3 (extreme problems).

Using respondents’ scores for each domain, we generated an overall summary health index measure for each respondent using a ‘value set’ which assigns weights to the different EQ-5D health states based on the preferences of a large sample of the UK population[28]. Using this value set gives each respondent a summary health index of between -0.073 and 1, where -0.073 is the index for someone with a status of 33333 (extreme problems on all five domains) and 1 is the index of someone with a status of 11111 (no problems on all five domains).

Respondents fell naturally into one of three overall health status groups, which were then used for a number of the other analyses:

- ‘Top’ respondents had an index score of 1 (no problems on any of the five domains) so in the best health
- ‘Middle’ respondents had an index score of 0.5 and 0.99 (typically a mix of ‘1’ and ‘2’ scores on all domains)
- ‘Bottom’ respondents had an index score of below 0.5 (typically respondents with one or more domains scoring ‘3’) – in the worst health.

A fourth category of respondents had an ‘unknown’ overall health status, since they had not completed all parts of the EQ-5D survey. These respondents (who numbered 78 out of 633, 12% of the sample) did not provide an answer for all five ED5D questions. Where analyses on individual domains of the ED5D were undertaken, respondents from the unknown group were included in analysis if they had provided a response on that domain.

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[27] See http://www.euroqol.org/eq-5d/what-is-eq-5d.html

[28] **Co-efficients for the estimation of the EQ-5D index values based on VAS valuation studies,** in *EQ-5D Value Sets, inventory, comparative review and user guide*, EuroQuol Group Monographs Volume 2 by A. Szende et al

Discussion groups

Recruitment and planning

Survey respondents were offered the opportunity to indicate if they wished to participate in a discussion group to be held after the survey phase of the audit had been completed.

Of the 633 respondents, 180 indicated they would be interested in taking part in one of the eight planned discussion groups.

These respondents' addresses were plotted on a map of the UK, using postcode mapping software, in order to establish where any geographical clusters might exist. The mapping revealed a wide spread of respondents, with the majority living outside major cities. The project team identified 10 potential locations; all within around an hour's travelling time of at least 10-15 possible respondents. Within each of these locations, venues were identified that offered ease of access by car and public transport, good disabled access, and appropriate rooms for the discussion group itself and an area for partners and wives accompanying veterans to wait in.

All 180 interested participants were contacted listing the possible venues and dates, and asking them to indicate whether they would be able to attend one (and whether they had a second choice). The 112 veterans that responded indicated a preference for one of the groups. Gloucester and Newcastle were the least popular locations so veterans that had expressed an interest at attending groups at these locations were informed that groups would not be proceeding and where possible offered their second choice. Veterans that could not be accommodated were offered a phone interview with a member of the project team; however none took up this offer.

Eight discussion groups took place between mid-February and mid-March in the following locations:

- Windsor, Berkshire
- New Forest, near Southampton
- Sale, Greater Manchester
- Hockley Heath, Birmingham
- Dartford, Kent
- Pollokshields, Glasgow
- Mansfield, Nottinghamshire
- St. Mellion near Plymouth, Cornwall

Great efforts were made to accommodate as many veterans as possible who wanted to attend a discussion group, and in the end 84 veterans took part (considerably more than the 64 originally planned for). Eleven veterans had to cancel in advance; however this provided others who had expressed an interest, the chance to participate. Some participants were accompanied by their wives, but they were not allowed to join the group discussions. The largest group had 13 participants; the smallest had 8. Participants were telephoned three days prior to each group to confirm their attendance and travel arrangements, and as a result there were no 'no-shows' on the day of the groups.

Approach used in discussion groups

Discussion groups followed a semi-structured format and ran from 11am to 2.30pm, including a break for lunch. All groups were facilitated by two members of the project team. Each participant signed a consent form and confidentiality agreements prior to the group taking place. A detailed introduction to the day was given by one of the facilitators outlining the aims and scope of the audit and the ground rules for the day, and emphasising the complete independence and impartiality of the facilitators. The discussion was divided into three sessions:

- Session 1: Your health and your beliefs about the impact of the nuclear tests on your health
- Session 2: Your descendants' health
- Session 3: Your experience of health and social care services

At the start of each session, participants undertook a simple task to align themselves to a statement most closely matching their experience. This was designed to reduce the possibility of 'group-think' whereby a few participants are unduly influenced by the expressed views of the others. Great care was taken to draw out the opinions of all participants.

Qualitative Data analysis

The groups were recorded and later transcribed. In addition, extensive notes were kept by one of the project team during each session.

Immediately after each session, the project team held a de-briefing to discuss summary impressions and emergent themes arising from the discussion. The team was thereby able to use the Constant Comparative approach; seeking to find additional examples in subsequent groups to test the emerging hypotheses. Once all the groups had been completed, the transcripts were thematically analysed, grouping all comments against the range of issues covered in the survey questionnaire and also a range of additional emerging themes.

Qualitative data from the discussion groups was used mainly to augment findings from the survey, and care has been taken to use only those verbatim quotes which are representative of the views expressed over the duration of one or more discussion groups. Specific attention has also been given to avoiding the use of sensational remarks and remarks that were not substantiated through further discussion.

Methodological Limitations and Data Warnings

In common with other studies of this kind, it is important to note that there a number of features of the audit methodology which limit the overall generalisability of the findings.

The data presented in this report must be carefully interpreted and not used out of context.

Limitations of the recruitment process

Because of the significant difficulties inherent in obtaining current contact details of ex-service personnel who had participated in the nuclear tests, a decision was made early in the audit to use the BNTVA database of members as the primary source for recruitment. As a result, over 96% of survey respondents were BNTVA members. BNTVA members represent only a relatively small proportion of the total nuclear test veterans estimated to be alive today, and their experience or views may not be representative of nuclear test veterans in general.

Limitations of the analysis of the health history data

The survey asked respondents to report on serious illnesses and long term conditions diagnosed by a doctor, and these are reported in subsequent sections of this report. However, it is impossible to draw any definitive conclusions about whether the level of illness amongst respondents is higher or lower than might be expected. There are several reasons for this.

First, the illnesses listed are self-reported and have not been verified by checking respondents' health records. This would have only been possible via a much larger and considerably longer-term study; and would have required resolution of a great many ethical, practical and other data-access permission issues.

Second, the many different ways in which respondents expressed or described their individual conditions (for example 'heart trouble', 'heart', 'angina', 'chest-pain') made condition/disease-specific analysis problematic. There will therefore be an unavoidable, but unquantifiable degree of inaccuracy in this data.

Third, there is a lack of comparable data about the rates of prevalence or incidence of individual conditions or diseases the general UK population. Whilst there is a comprehensive and reliable UK cancer registration system which records both cancer incidence and mortality (and indeed this was used in the NRPB studies of nuclear test veterans' health), there are no similar comprehensive population based registries for other common diseases (other than those which are notifiable diseases – largely infections). It is therefore impossible to say whether, the rate of disease in our sample is different from what would be seen in an age and socio-economic ally matched group of British men who had not taken part in the nuclear tests. In addition, this audit does not use age standardised rates, just numbers and crude rates (or percentages within our sample).

Even with the summary EQ-5D measure of health status, which has been used extensively as an outcome measure in clinical trials, it is not possible in the scope of this audit to identify an age-matched group of men against which to compare respondents' scores.

Limitations of reporting on descendants' health

Respondents were asked to report on how many children and grandchildren they have had, and to list major health conditions with which these descendants have been diagnosed. The same limitations apply to these data as to veterans' reports on their own health, but the fact that it is reported at a step or two removed made it even more difficult to verify or validate. It was not within the remit of this health needs audit to collect information directly from descendants themselves. Indeed, a study which did this would be very difficult undertake, and would require highly complicated ethical approval and consent processes, and access to confidential medical records. In addition, the tracking of progeny (who are likely to be dispersed across many countries) would be very difficult, costly and take a great deal of time.

Overall, the information and accuracy provided by respondents about their descendants' conditions or ill-health was so limited, that it was reluctantly concluded that it was not possible to undertake any meaningful analysis on a condition-specific or even disease-category level. The information presented in Chapter 7 is therefore purely a record of veterans' individual views and beliefs about there being a causal link (or not) between their participation in the nuclear tests and the health of their descendants.

Appendix 2 – Glossary of terms

Term	Definition
Access database	A database program used to enter and store information on the completed health needs audit questionnaires and analyse this.
BNTVA	The British Nuclear Test Veterans Association
Composite EQ-5D score or Summary Health Index	An overall score which shows an individual's health related quality of life based on their answers to the EQ5D questionnaire. It is calculated using a formula, and can fall between -0.073 (worst imaginable health) and 1 (best imaginable health).
Congenital condition	A condition which is present at birth
DDT Dichlorodiphenyltrichloroethane	An insecticide which was used to kill mosquitoes at the nuclear test sites
Demographic Characteristics	The characteristics of a person. In this audit demographic details asked for included age, marital status, region lived in and living arrangements
Domains of the EQ-5D	The five areas of life measured by the EQ5D: mobility, self-care, ability to perform usual activities, pain and anxiety/depression
Epidemiological study	A study looking at health patterns in a population, sometimes compared to a 'control group', to identify causes of ill health and suggest approaches to treatment
EQ-5D	A questionnaire based tool which measures a person's health related quality of life by asking them 5 simple questions. This tool has been used in large groups of people and found to be a reliable measure
Health status group	Three groups of people who answered the survey who were identified based on their composite EQ5D score. The groups are 'top' (best health), 'middle' and 'bottom' (worst health)
Hypothesis	A suggested theory or explanation which can be tested by gathering evidence
ICD-10 disease categories	The 10th version of the International Classification of Diseases system of the World Health Organisation. This is a system for grouping diseases into broad categories to make them easier to analyse. For more information, see http://apps.who.int/classifications/apps/icd/icd10online/index.htm?ki00.htm+
National service	A period of compulsory service (or conscription) in the armed forces for men leaving school which operated in Britain during the 1940s, 1950s and 1960s.
Primary Care	In this audit, primary healthcare is healthcare provided locally by GPs, district nurses, practice nurses and hearing aid services - the first point of contact with the NHS
Qualitative information	Information based on what people say, the stories they tell, the recollections they have, which can be analysed using a theme based approach.

Term	Definition
Quantitative information	Information based on numbers such as percentages, scores etc, which can be analysed by using statistical methods
Self-reported illness	Illness that was reported by the respondent themselves, not checked against medical records
Social care	In this audit, social care is defined as access to equipment to help with mobility or in the home, home care, residential and nursing home care, social services (such as meals on wheels) and help provided by the voluntary sector
Survey respondents	Someone who sent back the completed health needs audit survey questionnaire
Test participant	Someone who was either directly involved in a Nuclear Test by being present at a detonation, or involved in the clean up operation afterwards

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