Information to accompany patients undergoing nuclear medicine procedures

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Claire Greaves¹, Victoria Senior², Julie Barnett², Marie Clark², Joanna Pope² and Paul Hinton¹

Royal Surrey County Hospital
¹Medical Physics Department
Royal Surrey County Hospital
Guildford
Surrey GU2 7XX

University of Surrey
²Department of Psychology
University of Surrey
Guildford
Surrey GU2 7XH

The aim of this research was to investigate information on restricting the exposure to radiation from nuclear medicine patients following diagnostic and therapeutic procedures. It comprised an audit of current practice in UK departments and interviews and focus groups exploring the views and experiences of patients and professionals. The majority of departments provide verbal and/or written information on restricting contact with others, particularly pregnant women and children. Fewer departments give instructions about minimising contamination. On the whole, information provided complies with or, in the case if diagnostic procedures, goes beyond the restrictions specified in the Medical and Dental Guidance Notes. Information is rarely produced in formats for people with disabilities or people who do not have English as a first language. We identified a need to communicate more effectively with patients the rationale for restrictions and the consequences of non-adherence. We also identified a need to raise awareness of radiation protection issues and disseminate information more effectively with professionals outside of nuclear medicine departments. Ways in which both of these needs can be addressed are discussed.

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EXECUTIVE SUMMARY

AIMS OF THE RESEARCH

The overall aims of this research were to -

- audit current practice in UK departments conducting diagnostic and therapeutic nuclear medicine procedures regarding the provision of information to patients (to restrict radiation exposure to others) and professionals who come into contact with these patients
- investigate the experiences and views of patients and professionals regarding the content and implementation of such information.

Achieving these aims will enable the HSE to develop guidelines for the production and implementation of information that effectively increases understanding of radiation hazards and successful restriction of exposure.

COMPONENTS OF THE RESEARCH

The research comprised two main components. The first component comprised an audit of current practice in UK departments conducting nuclear medicine procedures regarding the provision of information for patients undergoing diagnostic and therapeutic procedures. A questionnaire survey of current practice was completed by UK departments conducting diagnostic (n=108) and therapeutic (n=57) nuclear medicine procedures. In addition, these departments were asked to supply copies of written information disseminated to patients and professionals. A total of 92 departments supplied us with some form of written information which primarily comprised of written information disseminated to patients. An evaluation of the quality and content (contact and contamination restrictions and explanation of the rationale for restrictions) was conducted on written information for patients undergoing diagnostic (bone, heart, lung, and parathyroid scans) and therapeutic (radioiodine therapy for thyrotoxicosis) procedures. The second component comprised of qualitative studies of the views and experiences of patients and professionals who come into contact with patients following nuclear medicine procedures. Semi-structured interviews with 24 patients undergoing diagnostic and therapeutic procedures were conducted and analysed. Five focus groups with different relevant groups of professionals (including nuclear medicine staff, other hospital staff, staff working in the community (e.g. practice nurses, nursing home staff, carers and a general practitioner), and professionals who may handle a radioactive corpse) were conducted and analysed.

MAIN FINDINGS

The 109 departments who responded to the questionnaire survey conducted a wide range of different diagnostic and therapeutic nuclear medicine procedures. Most departments relied on verbal and written information leaflets and very few provided information in alternative formats, such as for patients with disabilities. The majority of departments only supplied written information in English and depended on other means of communicating with non-English speaking patients (such as interpreters and family members). Both patients and professionals supported more information on sources of reputable information such as websites. The majority of departments across both diagnostic (94%) and therapeutic (98%) procedures give patients verbal and/or written information on restricting contact with others. Fewer departments (57%) performing diagnostic procedures provide information to patients with the aim of minimising contamination, whereas the majority of departments (93%) performing therapeutic procedures...
do provide this information. The evaluation of written information suggests that there is large variation in specific advice for minimising contamination (for similar procedures) and greater consensus on appropriate advice seems warranted.

On the whole it appears that many departments are providing advice about restrictions that is in line with or goes beyond guidance in the Medical and Dental Guidance Notes (MDGN). The departments conducting diagnostic procedures primarily presented advice about restricting contact with pregnant women and children, typically for up to 24 hours following the procedure. However, only 72% reported restricting breast-feeding. For departments conducting therapeutic procedures, there was quite large variation in the restriction period specified although mean times were typically equivalent to the MDGN. Some written information presents very specific advice about contact restrictions (e.g., distance and time per day) and this format was preferred by patients who were interviewed. Explanations in written information of the rationale for restrictions (i.e., risk to self and others) were rather minimal and appeared to be presented with the aim of downplaying risks and, as a result, reassuring patients (an interpretation that was supported in discussions in the focus groups). Only one leaflet presented absolute risk information and no leaflet gave information on the possible consequences of not adhering to restrictions. Patients were aware of this gap in communication and wanted more information about this. Ways of communicating this information more effectively need to be found. The professionals in the focus groups recognised that information provided to patients varied across different departments and there was support for a consensus on how best to communicate with patients.

Most departments conducting nuclear medicine procedures provide information for hospital staff and other professionals who come into contact with patients, typically using an information pack. Departments reported problems with the information reaching the correct people and this was supported in the focus groups where many non-nuclear medicine professionals reported being unaware of radiation protection issues. Whilst staff with direct responsibility for the clinical care of patients appear to be aware of these issues, other staff who come into contact with the patients have little to no awareness of nuclear medicine procedures. They perceived this to be an important gap in knowledge. This research highlights a need to find ways of raising awareness of radiation protection issues in general to professionals who come into contact with patients and to find more effective ways of disseminating information both inside and outside the hospital. Including information about nuclear medicine procedures in staff training and use of the intranet were particular suggestions from the focus groups.

Departments reported a total of 32 deaths of patients shortly after a nuclear medicine procedure over the past five years (19 following diagnostic procedures and 13 following therapeutic procedures). Most departments do not have a written protocol for dealing with the repercussions of such an event and stated that they would provide ad-hoc advice if the situation arose. Professionals who come into contact with corpses were largely unaware of the issues involved when a patient dies following the administration of radioactive materials and they were concerned that they should have more information. The use of national associations as a means of raising awareness and achieving effective dissemination of information was emphasised.

This project has provided a valuable insight into nuclear medicine practice within the UK and has demonstrated variation in the advice on restrictions given to patients following nuclear medicine procedures and in the quality and content of information leaflets. It has also highlighted a number of areas where improvements can be made in terms of information provision and dissemination for nuclear medicine patients as well as hospital and non-hospital staff.
1. MAIN REPORT

1.1. INTRODUCTION

Patients administered with radioactive materials for diagnosis or treatment represent a potential radiation hazard. The patient acts as a radioactive source and may constitute both an external dose rate and a radioactive contamination hazard, depending upon the type and activity of radioactive material administered.

The radiation doses received by members of the public and employees due to patient administrations are subject to the requirements of the Ionising Radiations Regulations 1999 (IRR99) (HMSO, 1999). Adults who knowingly and willingly incur radiation dose in the comfort or care of the patient are not subject to dose limits but are subject to dose constraints, a value of 5 mSv per procedure being quoted in guidance to the regulations. Employees are subject to an annual dose limit of 20 mSv. Other persons (including children of patients) are subject to an annual dose limit of 1 mSv. In all cases, however, there is a duty on the hospital administering the radioactivity (as radiation employer) to implement measures that restrict exposures of such persons to a level that is as low as reasonably practicable (regulation 8).

Appropriate measures include keeping some patients (usually those undergoing therapy procedures) in the hospital until the radiation hazard they present has reduced significantly. However, the length of time which patients would be required to spend in hospital in order that they present no radiation hazard when discharged would be impracticable. Patients undergoing diagnostic procedures are not usually kept in hospital following the procedure. It is therefore necessary for hospitals to issue instructions to patients when they leave hospital following administration of radioactive materials, detailing restrictions such as limits on contact time with other persons (children and adults).

In some cases patients are not discharged following the procedure, but sent back to a hospital ward (either at the same or other hospital) or to a nursing home. In this case, the information would be sent to the ward / nursing home to enable the employer to restrict exposures of his employees accordingly (while providing care to the patient) and thus comply with the requirements of IRR99.

In order for the information provided to patients to be effective (and exposures of other persons thus restricted to a level which is as low as is reasonably practicable), the information must be provided in a format that is easily understood by the patient (or accompanying person if the patient is not capable of understanding). The level of information should be appropriate to the hazard presented (and indeed following some diagnostic tests, there is negligible radiation hazard associated with the patient and no information is required). Hospital nuclear medicine departments are known to produce very varied instructions to patients.

A related problem is that of radioactive corpses (ie patients who die shortly after administration of radioactive material). In this case, potential exposures of mortuary workers, embalmers, crematorium personnel etc must be restricted. There is therefore a need to assess information provided to such employees.

The Health and Safety Executive and the Department of Health wish to provide guidance on when written instructions are appropriate and which format may result in greater understanding and thus successful restriction of exposure. This research was undertaken to help in this process.

This piece of research comprises of:
• an audit of current practice of UK departments conducting diagnostic and therapeutic nuclear medicine procedures concerning information provided with the aim of minimising the radiation hazard (through external exposure and contamination) from nuclear medicine patients

• an investigation of the experiences and views of patients and staff coming into contact with patients following nuclear medicine procedures

• current practice concerning handling radioactive corpses and the experiences and views of professionals who may come into contact with patients who die shortly after the administration of radioactive materials.

1.2. CURRENT ADVICE

Current advice regarding these restrictions are summarised in the Medical and Dental Guidance Notes (MDGN) (IPEM, 2002). For diagnostic procedures, the MDGN advise that potential risks should be assessed by reviewing published data or in-house measurements. Calculation from first principles, making realistic or, if that is not possible, conservative assumptions about the behaviour of the patient and other persons, may be necessary if no other data are available. Estimates of potential doses to other people should be compared with a relevant dose constraint set by the employer. If the potential doses are significant compared to the constraint, then the advice must reflect this. Any advice should be validated by the medical physics expert (MPE) or radiation protection advisor (RPA).

The MDGN also advise that, in general, the quantities of radioactivity currently administered for diagnostic procedures do not necessitate any special precautions or restrictions to be placed on the patient. Known exceptions fall into 3 categories:

1. Patients who provide the majority of close care to babies and have been administered any of the following – at least 10 megabecquerels (MBq) In-111 labelled white blood cells; 120 MBq In-111 octreotide; 200 MBq Ga-67 citrate (this is above the diagnostic reference level); 150 MBq Tl-201 chloride or 800 MBq Tc-99m myocardial perfusion agent
2. Breastfeeding mothers or
3. Patients administered 30 MBq or more of I-131

Restrictions may also be necessary after administration of positron-emitting radionuclides.

If the patient works with radioactive materials, or their work is radiation-sensitive, the patient should be advised to inform his or her employer.

Current advice regarding restrictions for patients returning home following therapeutic procedures with unsealed sources is also summarised in the MDGN. A risk assessment should be performed and each patient assessed individually prior to any therapeutic administration. Guidance from the MPE or RPA should be sought. For I-131 patients further detailed restrictions are given regarding contact times for patients following administration of I-131 for hyperthyroidism. The times for patients treated with I-131 for thyroid cancer are likely to be shorter but verified measurements were not available at the time of writing of the MDGN. Contamination risks are considered to be low for the majority of patients administered I-131. For all patients the advice may need to be individually tailored where the risk assessment shows unusual patterns of contact or increased likelihood of a risk from contamination. Advice regarding therapeutic emitters using radionuclides that only emit beta particles is also provided.
in the MDGN. Up to 200 MBq of Sr-89, P-32 or Y-90 may generally be administered without placing any restrictions on the patient. The possibility of contamination and the generation of radioactive waste must however be considered and some precautions may be required.

1.3. COMMUNICATION AND RESTRICTIONS

In order for contact and contamination restrictions to be applied effectively it is necessary that both patients and staff have an understanding of the restrictions and the reasons they are advised to minimise exposures of others persons. Related to this is the need for patients to have an understanding of radiation and any attendant risks. In a recent commentary, Picano (2004) suggests that risk communication strategies can be conceptualised as one of three types in relation to nuclear medicine procedures. The first strategy is to give no information about risk. The second is to downplay risk with the apparent aim of reassuring patients. The third strategy is full disclosure of risk information which is, Picano suggests, typically only used in research protocols rather than routine clinical practice. As an example of the second strategy of downplaying risk, Picano highlights the practice of comparing the risk associated with the use of radioactive materials to that used in a “common radiological examination” which he suggests is disingenuous because many would consider this to be comparable to a chest x-ray whilst many nuclear medicine procedures use doses considerably higher than this (e.g., greater than 50 chest x-rays). This commentary, however, was not based upon empirical research and was particularly concerned with ethical principles underlying informed consent to nuclear medicine procedures. However, communication of radiation risk also has important implications from a behavioural perspective. Research in health psychology has demonstrated that patients are more likely to adhere to medical advice when they have an understanding of the reasons for this advice, particularly one which fits with their commonsense understanding of the problem (e.g., Cameron and Leventhal, 2003). For example, an understanding that a condition is chronic is related to greater adherence to long term medication. Whilst, advice about radiation exposure is a novel area for this type of research, the psychological mechanisms that guide behaviour are likely to be very similar. As a result of this it is suggested that patients are more likely to implement contact and contamination restrictions as advised if they have an understanding of the reasons for these restrictions including an understanding of radiation risks. If departments are indeed primarily using risk communication strategies of either not communicating risk or downplaying risk, as suggested by Picano, then this is likely to have implications for behavioural adherence. First, it is necessary to quantify the communication strategies of departments conducting nuclear medicine procedures and then it is necessary to investigate the impact of these different strategies on the beliefs and behaviour of patients.

Little research concerning people’s understanding of radiation and nuclear medicine procedures appears to exist. Although using rather simplistic methodologically, one American survey (not conducted on people undergoing nuclear medicine procedures) suggests that most people do not have a good understanding of radiation risks and nuclear medicine procedures (Ludwig & Turner, 2002). There is clearly a need for research that investigates these concepts in greater depth and in populations for whom the issues are salient, such as patients undergoing nuclear medicine procedures and the staff and professionals who come into contact with these patients.

It is also possible to draw some conclusions about what is likely to constitute an effective communication strategy for departments conducting nuclear medicine procedures from wider research on risk communication. The level of risk posed by diagnostic and therapeutic nuclear medicine procedures is acceptable provided a number of conditions are met, including that the individual knows what the risk is (UK Royal Society, 1983). However, many people have difficulty in understanding risk information. Gigerenzer and Edwards (2003) suggest that many problems encountered with risk communication in clinical practice are primarily due to poor
communication and suggest ways in which absolute, conditional, and relative risk information can be communicated more effectively. Edwards, Elwyn, and Mulley (2002) advise that both absolute and relative risk information should be communicated and that absolute risks should be given greater prominence than relative risks. Given the paucity of research about these issues in relation to nuclear medicine procedures, it is thought that initial investigations should be exploratory and make use of qualitative methodologies in order to investigate how people conceptualise radiation, radiation risk, contact and contamination restrictions, and experiences of such restrictions. This would lay the foundations for empirical research aimed at addressing any problems with communication and improving understanding of, and adherence to, contact and contamination restrictions.

1.4. AIMS AND OBJECTIVES

The overall aims of this project were to:

1) Audit current practice in UK departments conducting nuclear medicine procedures regarding the provision of information for patients undergoing diagnostic and therapeutic procedures and the professionals who come into contact with these patients.

2) To investigate the experiences and views of patients and professionals regarding the content and implementation of such information.

Achieving these aims will enable the HSE to develop guidelines for the production and implementation of information that effectively increases understanding and successful restriction of exposure.

The audit of current practice had the following specific objectives:

- To assess for which particular therapeutic and diagnostic procedures nuclear medicine departments provide written instructions to patients, for the purpose of restricting exposures to other persons.
- To assess what specific instructions are included and particularly to:
  - evaluate the quality of written patient information;
  - assess how the rationale for contact and contamination restrictions is communicated in written patient information;
  - assess which contact restrictions are specified and how these restrictions are communicated in written patient information;
  - assess which contamination restrictions are specified and how these restrictions are communicated in written patient information.
- To assess the format in which instructions are produced
- To assess whether instructions are produced in languages other than English when appropriate.
- To assess what written instructions are provided when patients are sent to wards or nursing homes.
- To assess what written instructions are provided when corpses are sent to funeral directors/embalmers/mortuaries/crematoria.
- To assess what problems nuclear medicine staff encounter in relation to communicating with patients, relatives, hospital and non-hospital staff.

The investigation of the experiences and views of patients and professionals regarding the content and implementation of such information had the following objectives:
To explore how patients undergoing diagnostic and therapeutic procedures with radioactive materials perceive currently used verbal and written information and the procedures for its dissemination

To explore any perceived shortfall in information provision and perceptions of how these information needs can best be met

To explore what patients think and feel about these procedures, their understanding of advice regarding reducing exposure to others and what difficulties they encountered in adhering to this advice

To explore how carers, professionals coming into contact with corpses, and professionals responsible for the development and dissemination of written information perceive currently used information and the procedures for its dissemination.

For the groups specified above, to explore experiences of adhering to advice regarding exposure risks and the organisational and individual barriers to adhering to the advice.

1.5. FORMAT OF THE REPORT

This report is based upon an audit of current nuclear medicine practice in UK departments regarding the provision of information for patients undergoing diagnostic and therapeutic procedures. There were two components to this research:

1) A questionnaire survey of current practice completed by UK departments conducting diagnostic and therapeutic nuclear medicine procedures. The methods and findings are reported in Annex 1.

2) An evaluation of written information given to patients undergoing diagnostic and therapeutic nuclear medicine procedures. The methods and findings of this research are reported in Annex 2.

This report is also based on research involving qualitative interviews and focus groups. The findings of the interviews with patients undergoing diagnostic and therapeutic nuclear medicine procedures are reported in Annex 3. The findings of the focus groups with staff and professionals who come in to contact with patients undergoing nuclear medicine procedures and with radioactive corpses are reported in Annex 4.

The main report amalgamates and summarises the findings from these four different components of the research. The report is presented in relation to the aims and objectives specified above. Ways in which to take forward the findings from this research in terms of further research and practical implications are made, both in the main body of the report and in the individual annexes.

The draft findings of this research were presented and discussed in workshops to two relevant groups (nuclear medicine specialists and patient information specialists) and feedback obtained. The results of these workshops are presented in Annex 5.

The questionnaire, patient information sheet and consent form for the patient interviews, and stimulus materials for the focus groups are included as appendices.
1.6. METHODS

Below is a brief synopsis of the methodology of the research. For a more detailed description of the methodology employed, see Annexes 1 to 4.

1.6.1. Annex 1: Survey of current practice
A questionnaire was developed assessing which diagnostic and therapeutic procedures nuclear medicine departments perform, what verbal and written information is provided, and how this is disseminated to patients, carers, and health professionals. The questionnaire also included a section on the department’s procedure for dealing with radioactive corpses. The questionnaire was sent to nuclear medicine departments in the UK. Responses were obtained from 109 departments. Of these, 108 departments performed diagnostic procedures and 57 of the departments performed therapeutic procedures. A detailed account of the methods and findings of the survey is presented in Annex 1.

1.6.2. Annex 2: Evaluation of the quality and content of written information
Departments conducting nuclear medicine procedures who responded to the survey of current practice were asked to supply copies of written information regarding restricting exposure to patients and staff. A total of 884 pieces of written information from 92 departments (84% of participating departments) were received. The majority of this information consisted of information presented to patients and comprised patient information sheets, letters, and yellow instruction cards. This study evaluated the quality and content of written patient information for some of the most commonly performed diagnostic and therapeutic procedures identified in the survey (comprising bone, heart, lung, and parathyroid diagnostic scans and radioiodine therapy for thyrotoxicosis). Evaluation of written information comprised two aspects. The quality of written information was evaluated using the ‘ensuring quality information for patients’ (EQIP) tool (Moult, Franck, & Brady, 2004) a reliable and valid tool for evaluating patient information. A new coding frame for the specific research questions of this study was developed, which assessed how departments explain the rationale for restricting exposure of others and the specific contact and contamination restrictions provided for patients. A detailed account of the methods and findings of this evaluation of written information is presented in Annex 2.

1.6.3. Annex 3: Experiences and views of patients undergoing diagnostic and therapeutic nuclear medicine procedures
Semi-structured interviews were conducted with 24 patients undergoing diagnostic (n=10) and therapeutic (n=14) nuclear medicine procedures. The interviews investigated the patient’s satisfaction with the verbal and written information they were given, their understanding of any contact and contamination restrictions and the reasons for these restrictions, and their experiences of implementing these restrictions and any problems they encountered. The interviews were audio-taped, transcribed and analysed using interpretative phenomenological analysis (IPA) which is an inductive approach to the analysis of qualitative data. A detailed account of the methods and findings of the interviews with patients is presented in Annex 3.

1.6.4. Annex 4: Experiences and views of professionals involved in the production, dissemination, and receipt of information from nuclear medicine departments
Five focus groups were conducted with:
- health professionals working within nuclear medicine,
- health professionals working within hospitals who may have contact with patients following therapeutic procedures,
- health professionals working within hospitals who may have contact with patients following diagnostic procedures,
• hospital and non-hospital staff who might have contact with a nuclear medicine patient outside the hospital
• staff who might come into contact with a radioactive corpse

A detailed account of the focus groups is presented in Annex 4.

1.7. RESULTS

1.7.1. Information provided to patients for the purpose of restricting exposure to other persons.

The 108 responding departments who undertook diagnostic nuclear medicine performed a large range of procedures, most commonly bone, lung, renal, thyroid and parathyroid studies.

Of the 57 departments performing therapeutic procedures the most commonly used radioisotope was I-131, particularly in the form of sodium iodide for thyroid therapies but also in MIBG therapy. Other commonly performed therapies are P-32 for polycythemia vera, Y-90 for the treatment of arthritic conditions and Sr-89 for palliative treatment of metastatic bone disease.

On the whole, information to patients was disseminated prior to the administration of radioactive materials with the appointment letter and verbally on the day of the procedure. Specific advice about restrictions was presented on the day of the therapy for patients undergoing therapeutic procedures. Most departments relied on verbal information and written information leaflets and very few provided information in alternative formats, such as for patients with disabilities. The evaluation of written information also highlighted the fact that very few departments provide information on alternative sources of information, such as reputable websites. In addition, the majority of departments only supplied written information in English and depended on other forms of communicating with non-English speaking patients (interpreters and family members). The majority of departments gave patients both written and verbal advice regarding contact restrictions (66% of departments performing diagnostic procedures and 98% of departments performing therapeutic procedures). For departments performing diagnostic procedures, there were slightly more who presented contact restrictions verbally (85%) compared with in writing (74%) and 6% of these departments did not provide contact restrictions either verbally or in writing.

Fewer departments (54%) performing diagnostic procedures provide information to patients with the aim of minimising contamination, although the majority of departments (89%) performing therapeutic procedures do provide this information. This was more likely to be given verbally than in a written format (24% of departments conducting diagnostic procedures and 79% of departments performing therapeutic procedures). The evaluation of written information demonstrates that there is rather large variation in what departments mean by contamination restrictions. In particular the content of this advice for therapeutic procedures, where it was presented, ranged from very minimal advice to rather complex advice. The focus groups also highlighted the recognition that this advice is very variable across different departments.

On the whole it appears that many departments are providing advice about restrictions that is in line with or, in the case of diagnostic procedures, goes beyond what is advised in the MDGN. As stated above the departments conducting diagnostic procedures gave advice about restricting contact with pregnant women and children. The analysis of written information supported the finding of the survey that most instructions concerned restricting contact with pregnant women and children and fewer departments presented written advice about minimising contamination. The analysis of written information also demonstrated that contact restrictions with pregnant
women and children were advised for up to 24 hours following the procedure. Surprisingly, however, only 72% of departments reported that they issue instructions to restrict breast-feeding following diagnostic procedures.

The same conclusion, that most departments are operating within the guidance of the MDGN, is also supported for departments conducting therapeutic procedures. The analysis of written information for radioiodine therapy for thyrotoxicosis demonstrated that although there was quite large variation in restriction periods, these typically appeared to average at around the period specified in the MDGN. In the evaluation of written information, the majority of therapy leaflets gave information about sleeping arrangements, the possibility of taking time off work because of the restrictions, and avoiding public transport for long journeys. Whilst the majority of leaflets mentioned avoidance of breast-feeding and pregnancy after the therapy, not all gave this advice. In addition, only half of the leaflets stated that female patients should not be pregnant at the time of the procedure.

The evaluation of written information suggested that many information leaflets should be reviewed and revised in the near future in order to meet all the criteria for high quality patient information. Some, but not all, patient information leaflets presented clear, unambiguous advice about restrictions such as providing definitions of close contact in terms of distance from other people and the amount of time per day. The participants in the interview study preferred this type of specific advice, although there was sometimes some confusion about whether time restrictions of 15 minutes referred to contact on one occasion or per day. The focus groups also demonstrated that health professionals perceive patients as preferring clear, unambiguous advice. Clarifying that restrictions refer to 15 minutes per day and for all departments to present such clear advice about what constitutes close contact would help with improving understanding of contact restrictions.

One interesting finding from the evaluation of written information related to the ways in which departments communicate the rationale for contact and contamination restrictions in terms of risk posed by the radiation to patients themselves and the necessity of protecting others. The leaflets for diagnostic procedures appeared to be attempting to reassure patients by describing the risk as low or very low and comparing risks, typically, with “many similar x-ray procedures” but also with specific x-ray procedures such as an x-ray of the lumber spine or with more complex radiographic techniques such as computed tomography (CT). The interviews with patients suggest that most people conceptualise a typical x-ray procedure as being equivalent to an x-ray of a limb and many do not know what a CT scan actually is. Only one leaflet made a statement about absolute risk. Surprisingly perhaps, given the higher activity levels, the radiiodine therapy for thyrotoxicosis leaflets typically either did not mention risk to the patient or stated that there was no risk. This finding supports the conclusion of Picano (2004) that many departments conducting nuclear medicine procedures are either not discussing risk or are downplaying risk. Across both types of procedure, where a rationale was actually presented, the rationale for restricting contact with others was often simply stated as “to avoid exposing them to unnecessary radiation”. Some leaflets presented the concept of the use of radiation being of benefit to the patient but not to others and it is tentatively hypothesised that this would be a useful way of communicating with patients. No leaflets gave advice on the consequences of non-adherence to restrictions. The findings from the focus groups also suggest that health professionals are concerned with not raising anxiety in patients and this may explain why information on the rationale for restrictions is presented in these ways. However, the interviews with patients highlighted that many were aware of this gap in information between the restrictions they were advised to adopt and the reason for these restrictions and this emerged as a strong theme in many interviews. The interview study also suggests that patients are not overly concerned about the risks involved for themselves with the use of radiation and that they see it as necessary. On the whole the people interviewed were very conscious of adhering to the
restrictions even if they did not fully understand the reasons for them. Similarly, the focus groups demonstrated that health professionals believe patients understand the restrictions that they are given, even if they do not fully understand the reasons for these restrictions. One conclusion from this research is that the rationale for restrictions together with accurate risk information (both absolute and relative risk) should be presented in ways that makes sense to people (Edwards, Elwyn, & Mulley, 2002; Gigerenzer and Edwards, 2003). Whether or not this presentation of information does increase patient anxiety should be established and ways of presenting information that lead to optimal levels of understanding and adherence, without increasing anxiety, should be found.

The findings from the focus groups show that many professionals put more emphasis on the value of verbal information over written information. Verbal information, it was believed, allowed them to judge the information needs and desires of the specific patient and to match this advice to their lifestyle. However, written information was also perceived to have an important role, particularly as it was recognised that patients may not take in everything they are told in the consultation. The patients interviewed did report reading and thinking about the written information they were given and, indeed, seeking out more information from books, personal contacts, and the internet. The focus groups and interviews highlight the fact that communication between health professionals and patients is a dynamic, interactive process in which understanding of information can be discussed and clarified. The professionals recognised that information to patients varied across departments and there was support for a consensus on what information should be given to patients and the best method of communicating this (although this was thought to be a difficult aim to achieve in practice).

**Recommendations**

- It may be useful to develop a more unified approach to issuing restrictions for diagnostic procedures for the ‘standard’ nuclear medicine patient (although, patients who have different needs or contact patterns will still require tailor made instructions).
- Improve methods of communication with non-English speakers and people with disabilities. The availability of a centralised bank of information in different formats and languages could help facilitate this.
- Nuclear medicine professionals could use reliable quality coding tools such as the EQIP to reach consensus on what criteria need to be applied to written information for patients undergoing diagnostic and therapeutic nuclear medicine procedures.
- Review and revise current patient information leaflets in line with these agreed quality criteria. It is suggested here that these criteria might include:
  - On information leaflets indicate date they were compiled and be clear that leaflet content is reviewed regularly.
  - Patient information should include reputable sources of further information such as a website address
  - Patient information should include details of who to contact if patients had concerns following the procedure or required further information or clarification
  - For patients undergoing therapeutic nuclear medicine procedures a standardised approach to the provision of advice regarding contact with pets, giving blood and food preparation is desirable.
  - Acknowledge in leaflets areas where patients may well find conflicting information (for example in making links between activity levels and practical advice); acknowledge that advice changes as new treatments start or over a period of time. Explain that this is the reason that advice may vary slightly between hospitals.
Consider including specific behavioural instructions for patients on the meaning of close contact (e.g., distance from other people, amount of time per day that contact is permitted).

- Nuclear medicine professionals to consider what is important and practicable advice regarding restrictions to minimise contamination in order to facilitate more consistent information being presented to patients on this issue.
- Conduct further research on how patients conceptualise radiation risk and what constitutes everyday language in the context of nuclear medicine procedures.
- Provide information in relation to the consequences of radiation exposure to others, patients did not on the whole know what would happen to people they came into contact with.
- Develop patient information that presents radiation risk and the rationale for restrictions in ways that are both accurate and understandable. This should include information about both absolute risk and relative risk.
- Conduct empirical studies to evaluate the impact of new patient information on understanding, level of anxiety, and adherence to restrictions in order to find ways of communicating that maximise positive outcomes and minimise risk.

1.7.2. Information for staff for the purposes of restricting exposure

The survey of departments conducting nuclear medicine procedures demonstrated that most departments do provide information for hospital and other staff. The provision of an information pack (for example, for a ward receiving nuclear medicine patients) was a common system for disseminating this information. What became clear in the focus groups was that this information does not uniformly reach the staff who need to implement the advice. In the survey, departments did report that they believed it was quite common that this information did not reach other hospital staff, for staff to perform other procedures without knowing that the patient was radioactive and, occasionally, for pregnant staff to care for radioactive patients. These problems with information dissemination were thought to be less common for patients undergoing therapeutic procedures and were rated as rare to non-existent problems. However, the survey also highlighted the fact that many departments did not think they would necessarily be aware of any problems that did occur. As well as finding effective systems for the dissemination of information, effective systems for reporting problems also need to be found.

The focus groups highlighted the fact that most nursing staff with direct responsibility for the care of patients undergoing therapeutic nuclear medicine procedures are aware of radiation protection issues. However, a wide range of other staff come into contact with nuclear medicine patients (e.g. cleaners, porters, drivers, nursing home staff, and general practitioners). Many of these people did not feel they were fully aware of the issues necessary for effectively restricting exposure. This was perceived to be an important gap in knowledge as non-nuclear medicine staff, such as porters, reported being asked for information from patients. They thought that patients often feel able to ask them questions which they are hesitant about raising with clinicians. What became clear in the focus groups was that our aim of establishing the views of non-nuclear medicine staff on the content of information was unrealistic as many staff reported being largely unaware that this was even an issue. Thus, finding ways in which information can be more effectively disseminated to, and implemented by, non-nuclear medicine staff needs to be the first step in this process. It was suggested that radiation protection issues should be highlighted in training at induction of new staff and the use of the intranet in disseminating information was suggested. Barriers to achieving effective dissemination to staff were thought to be the high turnover of NHS staff, the reliance on agency staff and staff who do not have English as a first language.
Both nuclear medicine staff and patients were aware of problems with the understanding of non-nuclear medicine staff. Nuclear medicine staff were aware that staff from outside the department sometimes acted in ways which was not commensurate with nuclear medicine procedures, such as disregarding restrictions when patients were on the ward or else having an overly cautious approach to radiation protection issues. Patients also reported problems with responses of health professionals, such as stating that approaching a radioactive patient on the ward would cause infertility or else disregarding the advice contained on instruction cards. This is important because patients are likely to form judgements on the content of information, and its importance, on the basis of their observations of the behaviour of health professionals. Thus, if health professionals disregard restrictions they may conclude that the restrictions are unnecessary or overly cautious and change their behaviour accordingly.

Another related issue highlighted in the survey was the increasing need for departments to provide information when patients are planning to travel overseas for the purposes of showing to customs officers and police. At the present time, 36% of departments conducting therapeutic procedures provide such information. Whilst only four departments were aware of any specific problems encountered by patients, it was recognised that there is no established mechanism for reporting of any problems. In addition, limited details are available regarding the sensitivity of detection equipment, making it difficult to develop evidence-based guidelines concerning travel across borders.

**Recommendations**

- More effective methods of communicating with referrers are required to make sure that they are aware of the implications of nuclear medicine procedures and of any restrictions that might need to be placed upon a patient. Referrers need to be able to provide the patient with sufficient information to give informed consent.
- Methods of dissemination of information between the nuclear medicine departments and other hospital and non–hospital staff need to be improved. The use of induction packs for staff groups is suggested as a mechanism of providing information for new staff but this does not address the problems of communicating with existing staff and of disseminating new information. Wider access to computers would aid this process. Improved handover processes for individual patients are also required both within hospitals and with staff working outside the hospital.
- Current methods of identification of radioactive patients to other staff groups both inside and outside the hospital are not effective. Improved methods of identification of radioactive patients (in-patients and out-patients) need to be considered. Develop protocols for communicating radiation protection information verbally.
- Increase the role of the intranet in providing staff with radiation protection information.
- Further information and advice regarding the sensitivity of detection equipment and the types of information required by police/customs officers would allow the nuclear medicine community to provide the relevant advice in the appropriate format. This would minimise problems for both patients and officials.
1.7.3. Information for professionals who come into contact with radioactive corpses

A minority of departments had a written procedure for handling a radioactive corpse (24% of departments conducting diagnostic procedures and 33% of departments conducting therapeutic procedures) with others stating that they would provide ad-hoc advice. Instructions are also more likely to be issued verbally than in writing. The majority of these would make staff aware of the procedure in the event of death rather than prior to death. Whilst the majority of departments had never had to issue any advice about a patient who died following the administration of radioactive materials, departments reported this as occurring 19 times following a diagnostic procedure and 13 times following therapeutic procedures in the past five years. Information was provided more frequently to staff within the hospital than to other professionals who may handle a corpse. A few departments reported problems, albeit rare or infrequent ones, with information dissemination or staff unknowingly coming into contact with a radioactive corpse.

The focus group with professionals who may handle a radioactive corpse highlighted a number of pertinent issues; in particular that most of the participants were unaware that exposure to radiation could be an issue. Indeed, gathering information on the issue was a primary motivation for participating in the focus group. Two particular issues emerged from this group. First, how these professionals would know if a corpse was radioactive and second, what procedures were in place should they need to deal with this issue. On the first issue, it was felt that the crematorium form was one method of flagging up information, although this would not be applicable for a burial and is only applicable to patients who die in a hospital. The gap between a person dying and the forms being drawn up also presented a problem. Most participants felt that the industry was largely unequipped to handle the issue of radioactive corpses effectively or to be aware when they encountered a radioactive corpse. The use of the radionuclide instruction card to indicate that a corpse was radioactive was felt to be inadequate. There is clearly a need to raise awareness of this rare but important event for professionals who handle corpses and the use of national associations as a means of raising awareness and achieving effective dissemination was emphasised.

Recommendations

- Develop generic procedures to be implemented following the death of a patient as many departments rely on drawing up ad-hoc advice in such an event. Generic procedures drawn up and distributed to relevant staff groups prior to such an eventuality will reduce alarm and increase the likelihood of the correct action being taken in the event of a patient death. It may be useful to have an example set of procedures available for departments to modify for their own use.
- Further consultation is needed with crematoria/funeral directors in order to understand how to communicate radiation risk appropriately and to consider the most effective ways of disseminating information.

1.8. OVERALL CONCLUSIONS

This project has provided a valuable insight into nuclear medicine practice within the UK and has demonstrated variation in the advice on restrictions given to patients following nuclear medicine procedures and in the quality and content of information leaflets. It has also highlighted a number of areas where improvements can be made in terms of information provision and dissemination for nuclear medicine patients as well as hospital and non-hospital staff.
1.9. REFERENCES


UK ROYAL SOCIETY Study Group, 1983 *RISK ASSESSMENT* LONDON. UK: Royal Society.
2. ANNEX 1: NATIONAL SURVEY OF RADIATION PROTECTION INFORMATION PROVIDED IN ORDER TO MINIMISE THE HAZARD FROM NUCLEAR MEDICINE PATIENTS

2.1. INTRODUCTION

2.1.1. Overview
A questionnaire was designed to assess which instructions nuclear medicine departments produce for patients in order to minimise the exposure of others (hospital and non-hospital staff as well as the general public). The questionnaire looked separately at instructions following diagnostic nuclear medicine procedures, therapeutic procedures and information for handling a radioactive corpse.

The questionnaire was sent out to 257 departments and generated 109 responses (42%) and 884 information leaflets and documents. 108 (99%) of departments performed diagnostic procedures and 57 (52%) performed therapeutic procedures. A wide range of diagnostic and therapeutic procedures were performed.

Information provided relating to diagnostic procedures
Written advice and verbal advice is provided by the majority of departments (74% and 85% respectively). This is provided predominantly by a mixture of administrative staff and radiographers/technicians using appointment letters and information leaflets. Use of other media such as the internet is rare. Only 7% of departments provide information for non-English speakers and there is a strong reliance on family members and interpreters. There is wide variation surrounding which diagnostic procedures departments choose to provide advice for. However, the advice provided across these groups seems fairly consistent; with the majority of departments providing advice regarding contact with children and pregnant women (written - 65%, verbal - 70%) and breastfeeding (written - 58%, verbal - 72%). Few departments provide information for patients travelling abroad (12%) following diagnostic procedures although 2 departments did report incidents where patients had been detected by customs/police. Information for hospital staff is predominantly provided via information packs on wards (67%) and backed up with further written and/or verbal information. Information for staff outside the hospital is most frequently sent with the patient (71%). Incidents of missing information and unwitting contact were reported and problems with handover were highlighted.

Information provided relating to therapeutic procedures
Written and verbal advice is provided by almost all the departments (79% and 89% respectively). This is provided by a more diverse group of staff (than for diagnostic studies) and frequently by more than one person but the Physicists (36%) were most strongly identified with information provision. The information leaflet was the main method of communication (91%). As with the diagnostic procedures, provision of information for non-English speakers was poor (5%). The types of instructions provided were consistent and similar to those given in the medical and dental guidance notes (MDGN) (IPEM, 2002). 36% of departments provided information for patients planning to travel abroad although only 7% were aware of problems relating to patients they had treated. The use of information packs for wards was again common (73%) as is the provision of additional written or verbal information. Information for therapeutic procedures tends to be given in advance of the procedure (78%) as well as sending information back with the patient or carer. Incidents of missing information and unwitting contact were infrequent.
Information for handling a radioactive corpse

24% of departments performing diagnostic nuclear medicine have a written procedure for dealing with a radioactive corpse. 20% would make staff aware of these prior to a patient’s death. Only 13 departments reported being contacted for advice regarding a radioactive corpse over the last 5 years (19 incidents).

33% of departments performing therapeutic nuclear medicine have a written procedure for dealing with a radioactive corpse. 37% would make staff aware of these prior to a patient’s death. Few departments provide information for staff other than ward staff that may have contact with a radioactive corpse (e.g. mortuary staff, crematoria staff). Only 7 departments reported being contacted for advice regarding a radioactive corpse over the last 5 years (13 incidents).

It is reassuring to see that the majority of departments provide written information backed up with verbal information. The responses to the questionnaire did highlight the need for some improvements in a number of areas: education of referrers, communicating with patients whose first language is not English or with patients with disabilities, variation in provision of advice, identification that a patient is radioactive, generic procedures for handling a radioactive corpse and information for patients travelling across borders.

2.2. AIMS AND OBJECTIVES

The questionnaire was designed to assess the following key points:

- For which therapeutic and diagnostic procedures do nuclear medicine departments provide written instructions to patients for the purpose of restricting exposures to other persons?
- What specific instructions are included (e.g. contact times with children / adults, sleeping arrangements, restrictions on work activity)?
- In what format are instructions produced?
- Are instructions produced in languages other than English when appropriate?
- What written instructions are provided when patients are sent to wards or nursing homes?
- What written instructions are provided when corpses are sent to funeral directors/embalmers/mortuaries/crematoria?
- What problems nuclear medicine staff encounter in relation to communicating with patients, relatives, hospital and non-hospital staff?

A copy of the questionnaire is given in Appendix 1.

2.3. DEFINITIONS

2.3.1. Diagnostic procedures

A table of diagnostic procedures was generated based on those listed in the Administration of Radioactive Substances Advisory Committee (ARSAC) notes for guidance (ARSAC, 1998).
Participants were also given free text fields to indicate other procedures performed within their departments.

2.3.2. Therapeutic procedures
A table of therapeutic procedures was generated from those listed in the ARSAC notes for guidance. Participants were also given free text fields to indicate other procedures performed within their departments.

2.3.3. Departments
Participants did not make it clear on the questionnaire whether they were completing the questionnaire on behalf of one individual department or for several departments. In the results section the term ‘departments’ has been used. This term refers to one completed questionnaire.

2.4. METHOD

2.4.1. Participants
A list of hospitals with nuclear medicine departments was generated using information available from the Institute of Physics and Engineering in Medicine (IPEM) and British Nuclear Medicine Society (BNMS) members websites. Consultation with the Health and Safety Executive (HSE) and the Department of Health (DH) revealed that no definitive list of hospital departments performing nuclear medicine procedures is held. In order to maximise the number of replies, where possible the questionnaire was addressed to a specific named member of staff. Where this was not possible the questionnaires were addressed to the superintendent radiographer of a department. In this way, it was hoped to maximise the number of responses and also to make sure the person filling in the questionnaire was sufficiently involved with the departmental practice to be able to provide accurate answers.

The questionnaire was sent out to 257 hospitals within the UK. Literature advising the nuclear medicine community about the project was circulated through the IPEM, Nuclear Medicine Special Interest Group (NMSIG) newsletter and the Medical Physics and Engineering Mailbase.

2.4.2. The questionnaire
A questionnaire was developed which comprised of 3 sections:

- Diagnostic procedures,
- Therapeutic procedures
- Information for handling a radioactive corpse.

The questionnaire was piloted locally and also through the NMSIG. Amendments were made as appropriate. Hardcopies of the surveys were sent out along with a freepost reply envelope. For ease of completion and data handling, the survey was also translated into a web based format. Departments were asked to complete the questionnaire and also to send copies of the information that is provided to patients, relatives and staff (either electronically or in the freepost envelopes).

The majority of questions used a tick box format. For some questions a single response was requested. For others any number of boxes could be ticked. This allowed participating departments to reflect a mix of practices and staff groups involved with dissemination of information. Consequently, the cumulative totals of percentages for a given question may exceed 100%.
2.5. RESULTS

2.5.1. Response rates
In total 109 (42%) responses were received (90 paper and 19 web responses). Follow-up phone calls to try and improve the response rate revealed that in some cases, the person completing the questionnaire did so on behalf of two or more hospitals but had not specified this on the questionnaire and therefore the 42% response rate represents a minimum. The survey responses came from hospitals covering a wide geographical area and from a range of hospital sizes (small general hospitals as well as large teaching hospitals).

As part of the survey copies of written information used to provide information to patients were requested and this resulted in 884 documents and leaflets being returned. The number sent from each site varied from 1 to 40. Leaflet evaluation is discussed in detail in Annex 2.

DIAGNOSTIC PROCEDURES

2.5.2. Types of diagnostic procedures performed
Departments were asked whether they performed any diagnostic nuclear medicine procedures and if so to indicate which ones on the table provided in the questionnaire. One hundred and eight (99%) departments performed diagnostic nuclear medicine procedures and completed this section of the questionnaire. The diagnostic procedures performed by these departments are summarised in Table 1.

It is perhaps, unsurprising that the results show that the most commonly offered procedures are bone, myocardial perfusion, lung, renal, thyroid and parathyroid studies. In the recent NRPB survey of Nuclear Medicine activity in the UK (Hart and Wall, 2005) these procedures contributed over 75% of the collective dose to patients undergoing nuclear medicine procedures.

<table>
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<tr>
<th>Radio-nuclide</th>
<th>Chemical Form</th>
<th>Investigation</th>
<th>Number of centres</th>
<th>% of departments</th>
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<td>Chemical Form</td>
<td>Investigation</td>
<td>Number of centres</td>
<td>% of departments</td>
</tr>
<tr>
<td>---------------</td>
<td>--------------------------------</td>
<td>----------------------------------------------------</td>
<td>-------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Tc-99m</td>
<td>Sestamibi</td>
<td>Breast imaging</td>
<td>21</td>
<td>19</td>
</tr>
<tr>
<td>Tc-99m</td>
<td>Arcitumomab (CEA scan)</td>
<td>Tumour imaging</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Tc-99m</td>
<td>Dcpeptotide (Neospect)</td>
<td>Lung tumour imaging</td>
<td>24</td>
<td>22</td>
</tr>
<tr>
<td>In-111</td>
<td>Pentetreotide</td>
<td>Somatostatin receptor imaging</td>
<td>42</td>
<td>39</td>
</tr>
<tr>
<td>Lu-177</td>
<td>m-Iodobenzyl-guanidine (MIBG)</td>
<td>Neuroendocrine tumour imaging</td>
<td>54</td>
<td>50</td>
</tr>
<tr>
<td>I-131</td>
<td>Iodide</td>
<td>Thyroid metastases imaging (after ablation)</td>
<td>31</td>
<td>29</td>
</tr>
<tr>
<td>I-131</td>
<td>m-Iodobenzyl-guanidine (MIBG)</td>
<td>Neuroendocrine tumour imaging</td>
<td>16</td>
<td>15</td>
</tr>
<tr>
<td>Tc-99m</td>
<td>Ti+</td>
<td>Non-specific tumour imaging</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Tc-99m</td>
<td>Ti+</td>
<td>Thyroid tumour imaging</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>I-123</td>
<td>Iodide</td>
<td>Thyroid metastases imaging (after ablation)</td>
<td>18</td>
<td>17</td>
</tr>
</tbody>
</table>

**Imaging – Vascular**

<table>
<thead>
<tr>
<th>Radio-nuclide</th>
<th>Chemical Form</th>
<th>Investigation</th>
<th>Number of centres</th>
<th>% of departments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tc-99m</td>
<td>Human albumin</td>
<td>Peripheral vascular imaging</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Tc-99m</td>
<td>Normal erythrocytes</td>
<td>Peripheral vascular imaging</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

**Imaging – PET**

<table>
<thead>
<tr>
<th>Radio-nuclide</th>
<th>Chemical Form</th>
<th>Investigation</th>
<th>Number of centres</th>
<th>% of departments</th>
</tr>
</thead>
<tbody>
<tr>
<td>F-18</td>
<td>FDG</td>
<td>Tumour Imaging</td>
<td>12</td>
<td>11</td>
</tr>
<tr>
<td>F-18</td>
<td>FDG</td>
<td>Brain imaging</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>F-18</td>
<td>FDG</td>
<td>Infection-inflammation</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>F-18</td>
<td>FDG</td>
<td>Differential diagnosis of dementia</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>F-18</td>
<td>FDG</td>
<td>Focal epilepsy</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>F-18</td>
<td>FDG</td>
<td>Myocardial imaging</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>F-18</td>
<td>Fluoride</td>
<td>Bone imaging</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

**Non imaging**

<table>
<thead>
<tr>
<th>Radio-nuclide</th>
<th>Chemical Form</th>
<th>Investigation</th>
<th>Number of centres</th>
<th>% of departments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Se-75</td>
<td>23-Seleno-25-homo-tauro-cholate (SeHCAT)</td>
<td>Bile salt Absorption</td>
<td>38</td>
<td>35</td>
</tr>
<tr>
<td>Cr-51</td>
<td>Normal erythrocytes</td>
<td>Sites of sequestration</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Cr-51</td>
<td>Normal erythrocytes</td>
<td>Red cell volume</td>
<td>26</td>
<td>24</td>
</tr>
<tr>
<td>Cr-51</td>
<td>Normal erythrocytes</td>
<td>Red cell survival</td>
<td>12</td>
<td>11</td>
</tr>
<tr>
<td>Co-57</td>
<td>Cyanocobalamin</td>
<td>GI absorption</td>
<td>19</td>
<td>18</td>
</tr>
<tr>
<td>I-125</td>
<td>Human albumin</td>
<td>Plasma volume</td>
<td>18</td>
<td>17</td>
</tr>
<tr>
<td>Tc-99m</td>
<td>Pertechnetate</td>
<td>Thyroid uptake</td>
<td>14</td>
<td>13</td>
</tr>
<tr>
<td>I-123</td>
<td>Iodide</td>
<td>Thyroid uptake</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>I-131</td>
<td>Iodide</td>
<td>Thyroid uptake</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>C-14</td>
<td>Urea</td>
<td>H Pylori detection</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Cr-51</td>
<td>Normal erythrocytes</td>
<td>GI blood loss</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Cr-51</td>
<td>EDTA</td>
<td>GFR measurement</td>
<td>39</td>
<td>36</td>
</tr>
<tr>
<td>Tc-99m</td>
<td>DTPA</td>
<td>GFR measurements</td>
<td>9</td>
<td>8</td>
</tr>
</tbody>
</table>

2.5.3. Information for patients undergoing diagnostic procedures

**What advice is provided?**

Departments were asked to indicate whether they provide any written or verbal advice to patients regarding contact with others following diagnostic nuclear medicine procedures and whether they provide any written or verbal advice to patients with the aim of minimising any contamination risks.

Most departments provide advice about restricting contact with other adults or children following a diagnostic procedure. This information is provided in writing in 80 (74%) of cases and given verbally in 92 (85%). Seventy two (66%) departments provide both written and verbal information and 7 (6%) departments reported that they do not provide any written or verbal information.
Fewer departments provide information to patients with the aim of minimising contamination - 26 (24%) written and 58 (54%) verbal. Forty seven (43%) departments report that they do not provide any written or verbal information.

Only 36 (33%) of departments have a written protocol governing what verbal advice is given.

Departments were asked to group together procedures where they issue the same advice according to the following list of restrictions:

The restrictions were:
- restrictions on contact with children and pregnant women
- restrictions on contact with adults
- restrictions on radiosensitive work
- restrictions to breast-feeding
- restrictions to minimise contamination

The method of grouping studies with similar restrictions varied widely from department to department. Some departments grouped all diagnostic procedures together, some grouped all technetium procedures together and some grouped various subsets of technetium and non-technetium procedures together (the maximum was from 1 department who had different restrictions for each of 14 subgroups of diagnostic procedure). Although the majority of departments grouped by procedure, others grouped by activity and others by radionuclide. A detailed breakdown of this is given below:

- All diagnostic procedures (n = 29)
- All technetium procedures (n = 16)
- Subsets of technetium procedures (n = 252)
  - Split by test (n = 246)
  - 21 separate procedures specified as well as a variety of combinations of procedures
  - Split by activity (n = 6)
  - 4 different methods were used
- Subsets of non-technetium procedures split by radionuclide (n = 78)
- Subsets including all radionuclides (n=12)
  - Split by test (n=8)
  - Split by activity (n=1)
  - Split by radionuclide (n=3)
- Non-imaging procedures (n = 8)
  - All non-imaging (n = 3)
  - Split by radionuclide (n = 5)
- Miscellaneous (n = 18)
- Unclear data entry (n= 8)

A breakdown of the restrictions employed is given in Table 2. Two thirds of departments provide information with the aim of restricting contact with children and pregnant women (65% written and 70% verbal). A similar proportion of departments provide information regarding interruption of breast-feeding (58% written, 72% verbal). Provision of information regarding advice to minimise the risk of contamination, to restrict contact with adults or to avoid radiosensitive work is given by a much lower proportion of departments. Detailed results are given in Table 2
Table 2. Total number and percentage of responses for all diagnostic procedures

<table>
<thead>
<tr>
<th>Restrictions</th>
<th>Percentage of departments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children and pregnant women (written)</td>
<td>65.1</td>
</tr>
<tr>
<td>Children and pregnant women (verbal)</td>
<td>69.8</td>
</tr>
<tr>
<td>Adults (written)</td>
<td>13.5</td>
</tr>
<tr>
<td>Adults (verbal)</td>
<td>14.0</td>
</tr>
<tr>
<td>Radio-sensitive work (written)</td>
<td>10.7</td>
</tr>
<tr>
<td>Radio-sensitive work (verbal)</td>
<td>13.3</td>
</tr>
<tr>
<td>Breast-feeding (written)</td>
<td>57.7</td>
</tr>
<tr>
<td>Breast-feeding (verbal)</td>
<td>71.7</td>
</tr>
<tr>
<td>Contamination (written)</td>
<td>18.8</td>
</tr>
<tr>
<td>Contamination (verbal)</td>
<td>32.3</td>
</tr>
</tbody>
</table>

Table 3 shows a further breakdown of the types of restrictions different departments place on patients. Although many departments use different methods of deciding which procedures it is necessary to provide restrictions for, the frequencies between groups are similar. The majority of departments issue restrictions regarding contact with children and pregnant women and breast-feeding. There is much greater variation in the number of departments who issue instructions to minimise contamination. For imaging procedures this varies from 7 to 40 per cent for written restrictions and from 28 to 60 per cent for verbal restrictions. In the miscellaneous group, the reason for this was largely due to advice provided following procedures on paediatric patients. For the other groups, the reason for the variation is unclear. Further analysis splitting the data into the further subsets did not highlight any additional information.
Table 3. Type of restrictions placed on the patients under the different categories used by the departments (as a percentage of the number of departments grouping using that category)

<table>
<thead>
<tr>
<th>Category</th>
<th>Contact with children and pregnant women</th>
<th>Contact with adults</th>
<th>Radio-sensitive work</th>
<th>Breast-feeding</th>
<th>Restrictions to minimise contamination</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Written</td>
<td>Verbal</td>
<td>Written</td>
<td>Verbal</td>
<td>Written</td>
</tr>
<tr>
<td>All diagnostic procedures</td>
<td>59</td>
<td>59</td>
<td>14</td>
<td>21</td>
<td>10</td>
</tr>
<tr>
<td>All technetium procedures</td>
<td>75</td>
<td>87</td>
<td>0</td>
<td>7</td>
<td>13</td>
</tr>
<tr>
<td>Subsets - technetium procedures</td>
<td>67</td>
<td>71</td>
<td>13</td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td>Subsets - mixed radionuclides</td>
<td>67</td>
<td>75</td>
<td>25</td>
<td>25</td>
<td>8</td>
</tr>
<tr>
<td>Subsets - excluding technetium</td>
<td>72</td>
<td>86</td>
<td>19</td>
<td>21</td>
<td>14</td>
</tr>
<tr>
<td>Non imaging procedures</td>
<td>25</td>
<td>13</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Other methods of grouping data</td>
<td>15</td>
<td>20</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Unclear data entry</td>
<td>75</td>
<td>63</td>
<td>13</td>
<td>13</td>
<td>13</td>
</tr>
</tbody>
</table>
Who provides the advice and at what point?
Information might be given to a patient at a number of different time points by a number of different members of staff. For example: by the referring doctor at the point of referral, by nuclear medicine staff (e.g. clerical staff, radiographers, technicians) when making an appointment, or by nuclear medicine staff on the day of the procedure.

Information is given to the patient at various points during the patient’s journey and sometimes at more than one point (departments were invited to tick more than 1 box here). Sixty one (57%) departments use the appointment letter and 65 (60%) use a patient information leaflet. Ninety five (88%) departments give the information verbally. A radionuclide instruction card (yellow card) is rarely used for diagnostic studies (seven departments (7%)) and although 17 (16%) departments use posters to provide information, only 4 (4%) use any other audio-visual medium (e.g. website, CD Rom). Only 4 (4%) departments provide information at the point of referral.

A variety of staff are involved with dissemination of information to patients and the responsibility for this is often shared between disciplines. However, two main staff groups stand out as having the primary role here – administrative and clerical staff 47 (44%) and technologists/radiographers 37 (34%). Verbal information for diagnostic studies is predominantly given by the technologist/radiographer 90 (>83%). The referrer was not identified with the provision of patient information by departments.

Information for patients who do not speak English
Only 7 (7 %) departments provide information in languages other than English. The languages available varied depending upon the geographical location of the hospital – two hospitals commented upon the requirement to have leaflets translated into Welsh. The choice of languages from other hospitals depended upon the availability of interpreters and the local language needs. Of the 97 (90%) departments who do not provide information in other languages, the main reasons were a) no requirement due to small number of non-English speaking population and b) availability of family members or hospital interpreters to translate directly to the patient. Hospital interpreters and family members are the main methods of communication with patients who do not speak English (93 (86%) and 91 (84%) respectively).

Information for patients who have a disability
Sign language interpreters are available in 34 (32%) of departments but other methods of communication with patients with disabilities are not commonly available e.g. large print – 2 (3%) and audio cassette – 1 (1%). No departments had information available in Braille. Again family members or friends are relied upon to communicate in difficult circumstances.

Information for patients planning to travel abroad
Only 13 (12%) hospitals provide written information for patients who are planning to travel abroad following a diagnostic nuclear medicine procedure for the purpose of showing to customs/police or other officials. Only 2 (2%) hospitals were aware of problems that patients had had when travelling following their test. One department reported knowledge of this from a patient that was picked up two weeks following an In-111 white cell scan. Other departments comment that they verbally tell patients to tell customs officials about their scan and ask them to phone the individual department or that they advise patients to take their appointment letters with them when travelling.
2.5.4. Information for staff/carers following diagnostic procedures

What advice is provided?
Ninety eight (97%) hospitals provide information regarding restrictions given to staff within their hospital. Of these, 66 (67%) have general information provided for each ward, 70 (72%) departments give information to a named nurse (verbally – 43 (44%), written – 27 (28%)). 45 (46%) departments given information to the ward clerk or nurses station (verbally - 20 (20%), written – 25 (26%)). Fifty three (54%) departments attach information to the front of the patient’s notes and 15 (15%) write inside the patient’s notes. Approximately one third (35) of departments who provide information to staff within the hospital do so 24 hours or more prior to the test. One third (36) provide information on the day of the test. Fifty eight (59%) departments provide information immediately prior to departure from the department. Departments were also asked about other methods of information dissemination: 5 (5%) departments provide information via the hospital intranet, 6 (6%) attach wristbands to patients and 3 (3%) use the radionuclide instruction card.

Seventy two (67%) departments provide information for staff outside the hospital (e.g. nursing homes, hospices). Of these, 22 (30.6%) departments provide written information in advance, 51 (71%) send written information back with the patient, 36 (50%) send written information back with the carer, and 52 (72%) give information over the telephone. In terms of the timing – 40 (56%) departments who provide information (written and verbal) to staff outside the hospital do so at least 24 hours prior to the procedure, 26 (36 %) do so prior to the administration and 44 (61%) provide information immediately prior to departure from the department.

Problems with dissemination
Departments were asked to assess how often problems with information dissemination occur. The results of this are given in Table 4. The main point which emerged here was that patients do not always inform the nuclear medicine staff about particular care needs, such as incontinence. Problems with the handover of information were also highlighted with 32% of departments reporting that other staff groups sometimes have contact with patients without knowing that they are radioactive and 26% of departments reporting problems with information not being received by the staff groups to which is sent.
Table 4 Details of problems with information dissemination to staff following diagnostic procedures (percentages)

<table>
<thead>
<tr>
<th>Details of problems with information dissemination to staff</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very often</th>
<th>No data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Written information regarding restrictions not being provided to staff</td>
<td>26</td>
<td>45</td>
<td>16</td>
<td>2</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Verbal information regarding restrictions not being provided to staff</td>
<td>25</td>
<td>50</td>
<td>10</td>
<td>2</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Written information not being received by staff groups to which it is sent</td>
<td>15</td>
<td>39</td>
<td>26</td>
<td>3</td>
<td>1</td>
<td>17</td>
</tr>
<tr>
<td>Staff performing other procedures not knowing a patient is radioactive (e.g. sonographers, carers)</td>
<td>11</td>
<td>38</td>
<td>32</td>
<td>6</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Pregnant staff unknowingly caring for a radioactive patient</td>
<td>24</td>
<td>47</td>
<td>16</td>
<td>2</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>Patient doesn't inform department about particular care needs e.g. incontinence</td>
<td>2</td>
<td>19</td>
<td>50</td>
<td>21</td>
<td>4</td>
<td>6</td>
</tr>
</tbody>
</table>

Many departments commented here that they would not necessarily know if these problems occur as there is no formal feedback mechanism. However, they believed that as the risks are low there would be no particular reason for concern. Specific issues that departments reported related to questions from wards regarding clinical procedures (e.g. insertion of a Hickman line or taking blood samples). Further comments that problems occurred when patients are moved between wards because the information does not go with them were reported.

Departments were also asked to give details of any ad-hoc instructions that they had had to provide and invited to add any comments. Ad hoc instructions covered: travel abroad, renal dialysis, and patients who work at power stations and may set off alarms.

THERAPEUTIC PROCEDURES

2.5.5. Types of therapy procedures performed

Fifty seven departments indicated that they perform therapeutic nuclear medicine procedures (53%). The types of therapies performed are detailed in Table 5. The most commonly used radionuclide is I-131 mainly in the form of sodium iodide for thyroid treatments but also for MIBG therapy. Other commonly performed therapies are P-32 for polycythemia vera, Y-90 for the treatment of arthritic condition and Sr-89 for palliative treatment of metastatic bone disease.

The recent NRPB survey of Nuclear Medicine activity in the UK (Hart and Wall, 2005) showed that 87% of therapies performed were I-131 treatments for thyrotoxicosis and thyroid cancer.
Table 5  Types of therapies performed by respondents

<table>
<thead>
<tr>
<th>Radionuclide</th>
<th>Chemical Form</th>
<th>For treatment of</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I-131</td>
<td>Iodide</td>
<td>Thyrotoxicosis</td>
<td>52</td>
<td>92.9</td>
</tr>
<tr>
<td>I-131</td>
<td>Iodide</td>
<td>Non-toxic goitre</td>
<td>31</td>
<td>55.4</td>
</tr>
<tr>
<td>I-131</td>
<td>Iodide</td>
<td>Carcinoma of thyroid</td>
<td>25</td>
<td>44.6</td>
</tr>
<tr>
<td>P-32</td>
<td>Phosphate</td>
<td>Polycythemia vera and related disorders</td>
<td>25</td>
<td>44.6</td>
</tr>
<tr>
<td>Y-90</td>
<td>Colloidal silicate in aqueous solution</td>
<td>Arthritic conditions</td>
<td>23</td>
<td>41.1</td>
</tr>
<tr>
<td>Y-90</td>
<td>Colloidal silicate in aqueous solution</td>
<td>Malignant disease</td>
<td>3</td>
<td>5.4</td>
</tr>
<tr>
<td>Er-169</td>
<td>Colloid</td>
<td>Arthritic conditions</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>Sr-89</td>
<td>Chloride</td>
<td>Bone metastases</td>
<td>30</td>
<td>53.6</td>
</tr>
<tr>
<td>I-131</td>
<td>m-Iodo benzyl guanidine (MIBG)</td>
<td>Malignant disease</td>
<td>9</td>
<td>16.1</td>
</tr>
<tr>
<td>Sm-153</td>
<td>Ethylenediaminotetramethylene phosphoric acid (EDTMP)</td>
<td>Bone metastases</td>
<td>5</td>
<td>8.9</td>
</tr>
<tr>
<td>Re-186</td>
<td>Hydroxy ethyliden diphosphonate (HEDP)</td>
<td>Bone metastases</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>Y-90</td>
<td>Ibritumomab tiuxetan</td>
<td>Non-Hodgkins lymphoma</td>
<td>5</td>
<td>8.9</td>
</tr>
<tr>
<td>Others (Please specify below)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I-131</td>
<td>Lipiodol</td>
<td>Malignant disease</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>Y-90</td>
<td>Lanreotide</td>
<td>Malignant disease</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>Y-90</td>
<td>DOTATOC</td>
<td></td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>Y-90</td>
<td>SIR spheres</td>
<td>Palliative treatment of liver cancer</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>Ra-223</td>
<td>Radium chloride</td>
<td>Bone metastases</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>Sr-89 and Y-90</td>
<td></td>
<td></td>
<td>1</td>
<td>1.8</td>
</tr>
</tbody>
</table>

2.5.6. Information for therapy patients

What advice is provided?
Departments were asked to indicate whether they provide any written or verbal advice to patients regarding contact with others following diagnostic nuclear medicine procedures and whether they provide any written or verbal advice to patients with the aim of minimising any contamination risks.

The majority of departments who perform therapeutic nuclear medicine procedures provide information about restricting contact with other adults or children (verbal – 56 (100%), written 55 (98%)). One department gives no information about restricting contact but this department only performs Y-90 administrations and external exposure is not an issue.

Similarly most departments provide information about minimising contamination following the procedure (verbal – 50 (89%), written – 44 (79%)). This does however leave 11 departments who report giving no written information about minimising contamination. Four
departments provide no written or verbal information to restrict contamination with three of these performing therapies using I-131 (2 for thyrotoxicosis and 1 for thyroid cancer).

A more detailed breakdown of the restrictions issued is shown in Table 6. Most departments performing therapies using I-131 place restrictions on patients regarding close contact (with adults, pregnant women and children), pregnancy/fathering a child and breast-feeding. Noticeably, fewer departments using Sm-153 (which is also a beta/gamma emitter) issued written or verbal restrictions. Fewer departments issue restrictions regarding radiosensitive work.

For the pure beta emitters such as P-32, Y-90 and Sr-89, approximately one third of departments issue restrictions regarding contact with children and pregnant women and one fifth issue restrictions regarding contact with adults.
### Table 6  Types of restrictions placed on the patients (as a percentage of the number of departments performing therapies)

<table>
<thead>
<tr>
<th>Name of Therapeutic procedure</th>
<th>Type of restrictions placed on patient</th>
<th>Contact with children and pregnant women</th>
<th>Contact with adults (e.g. work, travel, socialising, sleeping arrangements)</th>
<th>Breastfeeding</th>
<th>Radiosensitive work</th>
<th>Restrictions to minimise contamination</th>
<th>Restrictions to avoid becoming pregnant</th>
<th>Restrictions to avoid fathering a child</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Written</td>
<td>Verbal</td>
<td>Written</td>
<td>Verbal</td>
<td>Written</td>
<td>Verbal</td>
<td>Written</td>
<td>Verbal</td>
</tr>
<tr>
<td>I-131 Thyrotoxicosis N=52</td>
<td>98</td>
<td>94</td>
<td>96</td>
<td>94</td>
<td>77</td>
<td>83</td>
<td>42</td>
<td>64</td>
</tr>
<tr>
<td>I-131 Ca Thyroid N=27</td>
<td>93</td>
<td>89</td>
<td>93</td>
<td>89</td>
<td>74</td>
<td>70</td>
<td>44</td>
<td>67</td>
</tr>
<tr>
<td>I-131 Non-toxic goitre N=32</td>
<td>84</td>
<td>81</td>
<td>78</td>
<td>69</td>
<td>75</td>
<td>38</td>
<td>56</td>
<td>66</td>
</tr>
<tr>
<td>P-32 N=26</td>
<td>27</td>
<td>31</td>
<td>19</td>
<td>19</td>
<td>23</td>
<td>31</td>
<td>8</td>
<td>19</td>
</tr>
<tr>
<td>Y-90 Arthritic N=23</td>
<td>22</td>
<td>35</td>
<td>13</td>
<td>26</td>
<td>22</td>
<td>26</td>
<td>4</td>
<td>17</td>
</tr>
<tr>
<td>Y-90 Malignant N=3</td>
<td>33</td>
<td>33</td>
<td>0</td>
<td>0</td>
<td>33</td>
<td>33</td>
<td>0</td>
<td>33</td>
</tr>
<tr>
<td>Sr-89 N=31</td>
<td>19</td>
<td>23</td>
<td>7</td>
<td>13</td>
<td>19</td>
<td>29</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>I-131 MIBG N=9</td>
<td>67</td>
<td>67</td>
<td>67</td>
<td>67</td>
<td>56</td>
<td>56</td>
<td>44</td>
<td>56</td>
</tr>
<tr>
<td>Sm-153 N=5</td>
<td>40</td>
<td>40</td>
<td>20</td>
<td>20</td>
<td>20</td>
<td>20</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Re-186 N=1</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>0</td>
<td>0</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Y-90 Non-hodgkins lymphoma. N=5</td>
<td>20</td>
<td>20</td>
<td>20</td>
<td>20</td>
<td>20</td>
<td>20</td>
<td>0</td>
<td>20</td>
</tr>
<tr>
<td>Er-169 N=1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Ra-223 N=1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>I-131 Lipiodol N=1</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>0</td>
<td>100</td>
</tr>
</tbody>
</table>

31
In addition to the restrictions detailed above, departments also issued restrictions/advice on the other activities, detailed below.

- **I-131**
  - Providing blood/tissue samples (range 4 – 6 weeks post administration)
  - Presenting yellow card to medical and dental staff (1 month post administration)
  - Food preparation (no time details)
  - Travel abroad/holidays (no time details)
  - Waste disposal – catheters etc (no time details)

- **Ra-223**
  - Using a condom (8 weeks post administration)

- **Y-90**
  - Avoid fluid aspiration (4 weeks post administration)

- **Sr-89**
  - Blood/tissue samples (2 weeks post administration)

**Who provides the advice and at what time point**

Information might be given to a patient at a number of different time points by a number of different members of staff. For example: by the referring doctor at the point of referral, by nuclear medicine staff (e.g. clerical staff, radiographers, technicians, physicists, ARSAC holder) when making an appointment, during a pre-therapy appointment by nuclear medicine staff or by nuclear medicine staff on the day of the procedure.

Information is provided to the patient in a number of ways and at a number of different time points. Many departments use a combination of methods involving different staff groups at different time points.

The most popular method of providing the patient with information was verbally - 54 (96%), via a patient information sheet - 51 (91%), using a radionuclide instruction card - 43 (77%) and via the appointment letter - 22 (39%). As with diagnostic studies other methods of communication (posters, websites, CD Rom) were rarely used (<10% in total).

Information is given to patients prior to the procedure in the majority of cases. This might be: at referral - 22 (39%), at pre-procedure assessment - 32 (57%) or with the appointment letter - 35 (63%). Fifty (89%) departments provide information in the department prior to the procedure and 12 (21%) provide information following the administration.

For therapeutic administrations, written information is predominantly provided by the physicist - 20 (36%) but also by technologists/radiographers - 7 (13%) and administration and clerical staff - 9 (16%). The provision of verbal information demonstrates a similar pattern: physicist – 25 (45%), technologist/radiographer – 9 (16%), ARSAC holder - 4 (7%). Here, as with the diagnostic procedures, the referrer has a limited involvement - 2 (4%). In many cases a combination of staff groups might be involved in the provision of information e.g. ARSAC holder and Physicist and this was reflected in the general comments where in one instance four different people might give the information. Again a picture emerges of the provision of written information which is then backed up by verbal information given by appropriately qualified groups of staff.

**Information for patients who do not speak English**

Only 3 (5%) departments provide information in languages other than English. The reasons for this were either because of the small number of non-English speakers in the local
population or because of the ready availability of hospital interpreters 51 (91%), family members 50 (89%) or telephone translation services such as ‘Languageline’.

**Information for patients who have a disability**
52 (93%) of departments do not make information available in other formats for people with disabilities. Two (4%) produce large print leaflets and 15 (27%) departments have access to a sign language interpreter. Other hospitals rely on carers and family members and would seek solutions to an individual patient’s situation.

**Information for patients planning to travel abroad**
Twenty (36%) departments providing a therapeutic nuclear medicine service provide written information for patients planning to travel abroad for the purposes of showing to customs officers/police. Only 4 (7%) were aware that their patients had had specific problems.

These problems were:
- ‘patient returning home following radioiodine ablation was stopped at Moscow airport <30MBq retained activity when discharged from ….’
- ‘written information is provided, but not specifically for customs/police. A few patients have travelled abroad soon after the therapy without reported difficulties’
- ‘AWARE of 1 patient triggering alarms at an airport following an I-131 MIBG therapy. Interesting to note that this was on the return journey at a European airport. UK airport had not pulled him up on outward journey’
- ‘Following I-131 MIBG therapy treatment patient travelled to America a few weeks later. Patient activated a radiation alarm in airport but was able to produce his Radionuclide instruction card as proof of treatment’

There is no established mechanism for feedback from patients or police/customs to the department where the treatment took place and so we cannot be sure how many patients trigger alarms. It seems likely that this will become more common. As limited details are available regarding the sensitivity of detection equipment this makes it difficult for the nuclear medicine community to provide evidence based advice regarding travel across borders.

Other comments were that ad-hoc advice would be given by the Physicist tailored to individual circumstances, and that patients are screened as part of the prior risk assessment completed prior to administration. Some departments write a letter and some rely on the standard radionuclide instruction cards (yellow card). As a rule therapies are planned to avoid any impending flights/long journeys on public transport.

**2.5.7. Information for staff/carers following therapeutic procedures**

**What advice is provided?**
Forty five (80%) departments performing nuclear medicine therapies provide information regarding restrictions to other staff working within their hospital.

Thirty three (73%) of these departments stated that information was available on the ward. A large number of departments give information to a named nurse (34 (76%) - verbal, 30(67%) - written). Departments also disseminate information through the ward clerk (verbal – 10 (22%), written – 9 (20%)). 11 (24%) of departments attach information to the front of the patient’s notes and 12 (27%) of departments write inside the patient's notes.

The timing provision of information varies and some departments will provide information to more than one staff group within the hospital via more than one method. Thirty six of the 45 departments who provide information for staff within the hospital (80%) do so at least 24
hours in advance of the procedure, 18 (40%) provide information on the day of the procedure prior to administration and 15 (33%) provide information immediately prior to departure from the department.

Departments who routinely give therapies to in-patients in designated rooms commented that they also place information on the door of the isolation room, provide ward guidelines and give appropriate training to nursing staff.

Forty one (73%) departments provide information regarding restrictions following therapeutic procedures to staff outside the hospital. Twenty nine (71%) provide written information in advance, 32 (78%) send written information back with the patient and 20 (49%) send information back with the carer. Thirty five (85%) provide verbal information by telephone. Further comments were that patients from nursing homes would be admitted to the hospital where the therapy was being given. Information is usually given at least 24 hours prior to the procedure - 39 (95%) but this is also given on the day of the procedure, either prior to administration - 17 (41%) or prior to departure - 13 (32%)

Problems with dissemination
Departments were asked to assess how often problems with information dissemination occur. The results of this are given in Table 7. Problems with dissemination are not as frequent for therapeutic as for diagnostic procedures but there are still some infrequent occurrences of written instructions not being provided or received and of other staff groups unknowingly having contact with a radioactive patients.

<table>
<thead>
<tr>
<th>Written information regarding restrictions not being provided</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbal information regarding restrictions not being provided</td>
<td>67</td>
<td>28</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Written information not being received by staff groups to which it is sent</td>
<td>56</td>
<td>30</td>
<td>4</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Staff performing other procedures not knowing a patient is radioactive (e.g. sonographers, carers)</td>
<td>49</td>
<td>35</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Pregnant staff unknowingly caring for a radioactive patient</td>
<td>75</td>
<td>19</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Patient doesn’t inform department about particular care needs e.g. incontinence</td>
<td>25</td>
<td>49</td>
<td>19</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Individual comments here related to the low likelihood of finding out if an incident had happened due to lack of a feedback mechanism. Other comments were that information is mislaid during staff handover and that staff realise that the patient is radioactive but cannot find the instructions

Departments were also asked to give details of any ad-hoc instructions that they had had to provide and invited to add any comments on this section of the survey.
Ad-hoc instructions and advice have been given covering the following topics:

- travel to the Falkland islands
- insurance claim for flight cancellation
- a blind patient
- a patient who only spoke Arabic and could not read or write in any language
- incontinence (use, storage and disposal of pads)
- dialysis
- comforters and carers
- in-patient therapies
- carer for a wheelchair bound husband
- ileostomy patient referred for I-131 therapy
- local rules for a nursing home
- instructions for home carers
- laboratories for patients who need regular blood tests

2.5.8. Information for handling a radioactive corpse

**Diagnostic**

*Which departments have procedures for dealing with a radioactive corpse?*

Twenty six (24%) departments had a written procedure for handling a radioactive corpse following a diagnostic procedure and 65 (60%) did not. Of those departments who had a written procedure, 21 (81%) would make relevant professionals aware of it in the event of a death rather than prior to a death - 5 (20%).

*How many times has advice been provided?*

Over the last 5 years the majority of departments - 77 (71%) had never had to issue advice regarding the handling of a radioactive corpse. Nine (8%) departments had had to issue advice on one occasion, three (3%) on two occasions and one (1%) on four occasions. This means that out of the 109 departments who responded to this survey, advice has been given regarding 19 radioactive corpses following diagnostic administrations over the last 5 years.

**Therapeutic**

*Which departments have procedures for dealing with a radioactive corpse?*

Nineteen (33%) departments performing therapeutic nuclear medicine have a written procedure for handling a radioactive corpse following a therapeutic procedure. Seven (37%) of these departments would make relevant professionals aware of this information prior to a patient’s death. The remainder do so in the event of a death.

*How many times has advice been provided?*

Over the last 5 years, the majority of departments - 37 (65%) performing therapeutic nuclear medicine procedures had never had to issue advice regarding handling a radioactive corpse. Two (4%) had had to issue advice on one occasion, four (7%) on two occasions and one (2%) on three occasions. This means that advice has been given regarding 13 radioactive corpses over the last 5 years by therapy centres.

*Who is provided with information in the event of the death of a patient following a therapeutic procedure?*

More detailed information regarding the type of instructions provided are given in Table 8. Information is provided to staff within the hospital (ward staff and mortuary staff) more
frequently than to other staff that might handle a corpse. Verbal information provided in the event of the death of a radioactive patient is most common.

**Table 8** Information provided regarding exposure to radioactive corpses

<table>
<thead>
<tr>
<th>Staff group</th>
<th>Written Information</th>
<th>Verbal Information</th>
<th>No information provided</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Prior to death of patient</td>
<td>After death of patient</td>
<td>Prior to death of patient</td>
</tr>
<tr>
<td>Ward staff</td>
<td>9 47</td>
<td>6 32</td>
<td>6 32</td>
</tr>
<tr>
<td>Mortuary staff</td>
<td>5 26</td>
<td>6 32</td>
<td>3 16</td>
</tr>
<tr>
<td>Funeral directors</td>
<td>0 0</td>
<td>7 37</td>
<td>1 5</td>
</tr>
<tr>
<td>Embalmers</td>
<td>1 5</td>
<td>5 26</td>
<td>1 5</td>
</tr>
<tr>
<td>Crematoria staff</td>
<td>0 0</td>
<td>5 26</td>
<td>1 5</td>
</tr>
<tr>
<td>Other</td>
<td>0 0</td>
<td>1 5</td>
<td>0</td>
</tr>
</tbody>
</table>

Details about specific problems that departments have encountered are given in Table 9. Experience in this area is limited. Approximately 10% of departments reported that problems with information dissemination or staff unknowingly coming into contact with a radioactive corpse were rare. Five percent of departments reported that problems occur ‘sometimes’.

**Table 9** Problems with dissemination of advice regarding handling of radioactive corpse.

<table>
<thead>
<tr>
<th>Problem</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Written information about handling radioactive corpses not being provided to staff</td>
<td>19 33</td>
<td>4 7</td>
<td>1 2</td>
<td>1 2</td>
<td>2 4</td>
</tr>
<tr>
<td>Verbal information about handling radioactive corpses not being provided to staff</td>
<td>20 35</td>
<td>5 9</td>
<td>2 4</td>
<td>0 0</td>
<td>2 4</td>
</tr>
<tr>
<td>Written information about handling radioactive corpses not being received by staff groups to which it is sent</td>
<td>19 33</td>
<td>4 7</td>
<td>2 4</td>
<td>1 2</td>
<td>1 2</td>
</tr>
<tr>
<td>Staff unknowingly coming into contact with radioactive corpses</td>
<td>19 33</td>
<td>6 11</td>
<td>3 5</td>
<td>0 0</td>
<td>1 2</td>
</tr>
<tr>
<td>Corpses being removed from the mortuary without knowledge that the corpse is radioactive</td>
<td>18 32</td>
<td>6 11</td>
<td>1 2</td>
<td>0 0</td>
<td>1 2</td>
</tr>
</tbody>
</table>

Departments were invited to make any general comments about dealing with the death of a patient following administration of a radioactive substance. These comments covered:

- The provision of information in: the local rules, the general ward information, all wards and departments, the mortuary, internal notification via a specific form (if have received administration within 36 hours) and the intranet
• The low risk presented by diagnostic nuclear medicine patients would not require any action in the event of a death.
• The need for a risk assessment and information provision tailored to specific circumstances which means no generic procedure is available.
• Referral of the problem to: the radiopharmacy, the medical physics department, the medical physics expert (MPE) or to the Radiation Protection Advisor (RPA) in the event of a patient death.
• Referral to the medical and dental guidance notes (MDGN) for advice.
• The use of yellow wrist bands to highlight that a patient is radioactive. Although, some departments commented that patients wearing yellow wrist bands presented problems when wrist bands were either removed too early but also when they had not been removed even though it was after the stated restriction period and the patient had died.
• A number of departments commented that they were now intending to write a procedure.

2.5.9. General Comments
The final section of the survey allowed participants to make general comments and these are given below:

• A number of departments expressed concerns about giving advice and creating anxiety where the risk does not justify this. A need for a sense of proportion governing information provision was requested.
• The importance of training hospital staff so that they have the necessary underpinning knowledge to understand any restrictions.
• Problems with turnover of ward nurses and use of overseas staff leading to difficult communication. Problems with handover of information and written information getting lost or not being read.
• Problems identifying therapy patients who are discharged and then readmitted. Such patients should carry an instruction card but this does not always work. Similar problems identifying a patient who dies at home and may be radioactive.

2.6. DISCUSSION

2.6.1. Procedures performed
Departments provided information regarding the types of procedures performed in their departments. It is important to note that the data here relates to the number of departments who perform a procedure but does not give an indication of the frequency with which the particular procedures are performed. This may have some bearing on the information provided.

2.6.2. Restrictions

Diagnostic procedures
Current advice regarding the restrictions that might be necessary for patients following diagnostic nuclear medicine procedures are summarised in the MDGN which advises that potential risks should be assessed by reviewing published data or in-house measurements. Calculation from first principles, making realistic or, if that is not possible, conservative assumptions about the behaviour of the patient and other persons, may be necessary if no other data are available. Estimates of potential doses to other people should be compared with a relevant dose constraint set by the employer. If the potential doses are significant compared to the constraint, then the advice must reflect this. Any advice should be validated by the medical physics expert (MPE) or radiation protection advisor (RPA).
The MDGN also advise that, in general, the quantities of radioactivity currently administered for diagnostic procedures do not necessitate any special precautions or restrictions to be placed on the patient. Known exceptions fall into 3 categories:

1. Patients who provide the majority of close care to babies and have been administered any of the following – at least 10 MBq In-111 labelled white blood cells; 120 MBq In-111 octreotide; 200 MBq Ga-67 citrate (this is above the diagnostic reference level); 150 MBq Tl-201 chloride or 800 MBq Tc-99m myocardial perfusion agent
2. Breastfeeding mothers or
3. Patients administered 30 MBq or more of I-131

Restrictions may also be necessary after administration of positron-emitting radionuclides. If the patient works with radioactive materials, or his or her work is radiation-sensitive, the patient should be advised to inform his or her employer.

It is not clear from the results of the questionnaire why such a large number of departments chose to provide advice restricting contact with children and pregnant women following diagnostic nuclear medicine procedures. This may be related to a) in-house calculations or b) the application of the ‘as low as reasonably practicable (ALARP)’ principle.

It is important to balance any restrictions against the real risk involved and the anxiety they may cause the patient and his/her relatives.

There was great variation in the ways different departments used to decide which restrictions to place on which patients (section 3.2.2). Despite this, the majority of departments issue similar restrictions i.e. restrictions regarding contact with children and pregnant women and restrictions to breast feeding.

**Therapeutic procedures**

Current advice regarding restrictions for patients returning home following therapeutic procedures with unsealed sources is summarised in the MDGN. A risk assessment should be performed and each patient assessed individually prior to any therapeutic administration. Guidance from the MPE or RPA should be sought. For I-131 patients, further detailed restrictions are given regarding contact times for patients following administration of I-131 for hyperthyroidism. The times for patients treated with I-131 for thyroid cancer are likely to be shorter. Contamination risks are considered to be low for the majority of patients having I-131. For all patients the advice may need to be individually tailored where the risk assessment shows unusual patterns of contact or increased likelihood of a risk from contamination.

Advice regarding therapeutic emitters using radionuclides that only emit beta particles is also provided in the MDGN. Up to 200 MBq of Sr-89, P-32 or Y-90 may generally be administered without placing any restrictions on the patient. The possibility of contamination and the generation of radioactive waste must however be considered and some precautions may be required.

The majority of departments are in-line with this. However a small number apparently do not provide appropriate written or verbal information.

**2.6.3. Information provision**

**Information for patients**

The referrer was not strongly identified with the provision of information. Nuclear medicine departments have obligations under the ionising radiations (medical exposure) regulations [IR(ME)R 2000 (HMSO 2000) to make referrers aware of the radiation dose to the patient associated with procedures. Although there is no requirement for the referrers to have detailed knowledge regarding the risk to others from a nuclear medicine patient, knowledge of any
restrictions would be an important component of information provision as part of the consent process.

However, despite strenuous efforts to provide referrers with information regarding the procedures available, many referrers have a limited knowledge of what is involved with a procedure and of what the risks are. This was also commented upon in the focus groups (see Annex 4).

The ARSAC certificate holder did not have a direct involvement with the provision of written or verbal information but this is not necessarily a significant concern. An ARSAC holder has a responsibility to ensure that patient receives good quality accurate information rather than a direct involvement in providing information to individual patients.

The provision of good quality written advice in advance of the procedure backed up by verbal advice given by appropriately qualified healthcare professionals on the day of the procedure followed by an opportunity for the patient to ask questions is practical way of making sure the patient is fully informed and is an important component of obtaining consent. It is reassuring to see that the majority of departments demonstrate this good practice.

In some cases, a number of staff groups were involved in providing information and advice on restrictions to patients and different time points. In cases where multiple staff groups are involved clear lines of communication need to be established to ensure information is provided and also a means of ensuring consistency of information provision.

Very few departments provided information in languages other than English, relying instead on family members or interpreters to translate. Similarly, few departments provide information for people with disabilities. Mechanisms to improve communication in these areas need to be found.

Provision of information for patients travelling across borders is likely to become an increasing issue. No formal advice is available regarding the type of information that is acceptable to customs/police or the sensitivity of the detection equipment. This makes it difficult for departments to provide advice regarding what documentation to carry and how long supporting documentation might need to be carried for. Departments cannot assume that this is only an issue for patients following therapeutic procedures as one hospital reported an incident two weeks following an In-111 white cell study.

In addition to the categories listed in Table 6 some departments reported providing additional advice regarding giving blood, food preparation and contact with pets. A standardised approach to these types of concerns is desirable.

**Information for staff**

The responsibility for information provision for hospital staff, other staff and the general public lies with the employer who will need input from the RPA and MPE.

The provision of some kind of information pack in order to inform other hospital staff was common. However, evidence from the focus groups suggests that ward staff may not be aware that this exists (see Annex 4).

Handover of information between staff within the same ward and also different staff groups was highlighted in the questionnaire as being a problem especially in situations where a patient was transferred from one ward to another. This theme also emerged in the focus groups (see Annex 4). Few departments reported frequent problems due to missing information but it is of some concern that the mechanisms to protect staff working in the hospital do not always work effectively.
Providing information to staff (hospital and non-hospital) before and after a procedure is likely to decrease incidents involving unwitting contact with a radioactive patient. This is common practice for therapy procedures but less so for diagnostic procedures, possibly because of the logistical difficulties involved with this.

**Information regarding radioactive corpses**

Departments reported having to issue advice regarding 19 corpses following diagnostic procedures and 13 corpses following therapeutic procedures. This is a very low incidence especially given the numbers of procedures that will have been performed across the country during this time. The NRPB survey (Hart and Wall, 2005) showed that 656,000 diagnostic procedures and 14,000 therapeutic procedures were performed in the UK in 2003/4. The reported incidence is likely to be an underestimate as staff may be unaware that a corpse is radioactive. Even if they are aware that a corpse is radioactive, they may not know that they need to seek further advice.

Some departments, who do not perform therapeutic procedures, reported providing advice regarding radioactive corpses following therapeutic administrations. This suggests that a radioactive patient may die and advice may be requested (and given) from a department other than the one administering the therapy.

Many departments do not have generic procedures for handling a radioactive corpse and stated that they would provide ad-hoc advice in the event of a patient death conflicting with advice in the MDGN. Instructions are more likely to be issued verbally than in writing which is also of some concern. Problems with radioactive corpses are rare but departments were aware of problems with information provision or with other staff groups having unwitting contact with a radioactive corpse. A more stringent mechanism to highlight that a corpse is radioactive is desirable especially following therapeutic procedures. This issue was also reiterated in the focus groups (see Annex 4).

### 2.7. CONCLUSIONS

Provision of information to patients is predominantly by appointment letter and/or information leaflet backed up by verbal communication. Information is given prior to the test and followed up with further information on the day of the test. This is good practice as it is likely to increase understanding and compliance with any restrictions but also as part of making sure that the patient is informed about the procedure. The use of other media, such as the internet, is rare.

The main staff groups associated with provision of information are radiographers/technicians and clerical/administrative staff. Referrers have a limited involvement and this is of some concern.

Communication with non-English speakers and patients with disabilities is poor. The main reason given for this was the low demand.

The majority of departments issue restrictions following some diagnostic procedures but there is a wide variation in terms of which procedures. The main restrictions issued are close contact with children and pregnant women and restrictions regarding breastfeeding. This is more stringent than the guidance issued in the MDGN. Practice for therapies is much more unified and similar to that advice issued in the MDGN.
Problems with dissemination of information to staff and with the loss of information during handover were highlighted. Some incidences of unwitting contact were reported. These were more frequent for diagnostic procedures than for therapeutic procedures.

Current methods of identification of radioactive patients to other staff groups both inside and outside the hospital are not effective. Improved methods of identification of radioactive patients (in-patients and out-patients) need to be considered.

The reported incidence of issuing advice regarding handling a radioactive corpse is rare for both diagnostic and therapeutic procedures. Few departments have generic procedures and most would issue ad-hoc advice in the event of a patient death.

Few departments issue instructions for patients travelling abroad with the aim of showing to police/customs officers and some (rare) incidences were reported of patients triggering alarms both for diagnostic and therapeutic procedures.

2.8. PRACTICAL IMPLICATIONS

2.8.1. Communication with referrers
More effective methods of communicating with referrers are required to make sure that they are aware of the implications of nuclear medicine procedures and of any restrictions that might need to be placed upon a patient. Referrers need to be able to provide the patient with sufficient information to give informed consent.

2.8.2. Standardisation of practice on restrictions following diagnostic nuclear medicine procedures
A more unified approach to issuing restrictions for diagnostic procedures is desirable for the ‘standard’ nuclear medicine patient. Obviously, patients who have different needs or unusual contact patterns may still need tailor made instructions. A consensus view on the appropriate restrictions following diagnostic procedures is needed.

2.8.3. Standardisation of practice on restrictions following therapeutic nuclear medicine procedures
A standardised approach to the provision of advice regarding contact with pets, giving blood and food preparation is desirable.

2.8.4. Communication with non-English speakers and with patients with disabilities
Improved methods of communication with non-English speakers and patients with disabilities are important (for both staff and patients).

2.8.5. Policy for patients travelling across borders
Further information and advice regarding the sensitivity of detection equipment and the types of information required by police/customs officers would allow the nuclear medicine community to provide relevant advice in the appropriate format. This would minimise problems for both patients and officials.

2.8.6. Dissemination of information
Methods of dissemination of information between the nuclear medicine departments and other hospital and non–hospital staff need to be improved.

2.8.7. Identification of radioactive patients
Improved methods of identification of radioactive patients (in-patients and out-patients) need to be considered.
2.8.8. Generic procedures for the death of a patient

Many departments rely on drawing up ad-hoc advice in the event of a patient’s death. Generic procedures drawn up and distributed to relevant staff groups prior to such an eventuality will reduce alarm and increase the likelihood of the correct action being taken in the event of a patient death. It would be useful to have an example set of procedures available for departments to modify for their own use.

2.9. REFERENCES

ADMINISTRATION OF RADIOACTIVE SUBSTANCES ADVISORY COMMITTEE (ARSAC), 1998. Notes for Guidance on the Clinical Administration of Radiopharmaceuticals and Use of Sealed Radioactive Sources


3. ANNEX 2: EVALUATION OF DIAGNOSTIC AND THERAPEUTIC PATIENT INFORMATION LEAFLETS

3.1. SUMMARY

An evaluation of the quality and content of information provided to patients undergoing diagnostic and therapeutic nuclear medicine procedures was conducted. This evaluation was performed on 126 information leaflets for bone, heart, lung, and parathyroid scans and on information provided by 34 departments performing radioiodine therapy for thyrotoxicosis. Quality of patient information was evaluated using the Ensuring Quality Information for Patients (EQIP) tool. Information about contact and contamination restrictions was assessed using a coding frame specifically devised for the present study. The majority of leaflets were evaluated as being in the “good” or “having some serious problems” categories of the EQIP. This evaluation suggests that many leaflets should be reviewed and revised in the near future. The EQIP evaluation suggested that the therapy leaflets were generally of higher quality, than the leaflets for diagnostic procedures. The majority of diagnostic scan leaflets presented contact restrictions, typically of up to 24 hours following the procedure and aimed at restricting contact with pregnant women and children. The majority of radioiodine therapy leaflets presented contact restrictions, again with restrictions being particularly emphasised for children and pregnant women. Across both diagnostic and therapeutic procedures, restrictions to minimise contamination were less likely to be included in written information. The communication of information concerning the reasons for the restrictions raised some issues about what patients may perceive about these and suggests a need to test new ways of presenting this information.

3.2. OVERVIEW

There is an increasing recognition of the positive contribution that good quality evidence-based written patient information can make to healthcare (Ley, 1988; Shepperd, Charnock, and Gann, 1999). For example, patients who are well informed are more likely to comply with medical advice. Thus, the use of written information has a substantial role to play in improving effective communication between health professionals and patients. Patients are often anxious in consultations and anxiety can negatively impact on their ability to remember and understand medical advice. In addition, written information can also effectively supplement and reinforce the verbal communication of health professionals. The Audit Commission (1993) has recommended that written information should be reviewed periodically with the aim of improving the overall quality of information that is disseminated in the NHS.

3.3. AIMS AND OBJECTIVES

In order to complement and supplement the data from the survey of UK nuclear medicine departments (see Annex 1), departments were asked to supply copies of written information pertaining to contact and contamination restrictions. Our original aim was to evaluate written information provided for both patients and for hospital staff, carers, and other professionals. However, we received insufficient data of the second type of written information in order to perform any sort of meaningful analysis. Thus, the overall aim of this evaluation was to evaluate the quality and content of written patient information disseminated by UK nuclear medicine departments. The specific objectives were:

1. To evaluate the quality of written patient information;
2. To assess how the rationale for contact and contamination restrictions is communicated in written patient information;
3. To assess which contact restrictions are specified and how these restrictions are communicated in written patient information;
4. To assess which contamination restrictions are specified and how these restrictions are communicated in written patient information.

3.4. METHOD

3.4.1. Written information evaluated
A total of 884 leaflets or pieces of written information (e.g. instruction cards, letters, guidelines) were received from 92 (84%) of the departments who responded to the survey. These consisted of between one and 40 pieces of written information per department. Of this written information, 701 (79%) pieces of were specifically produced for patients. Patient information for both diagnostic and therapeutic procedures were evaluated as specified below.

Written patient information for diagnostic procedures
The content of 126 patient information leaflets from 49 different departments was evaluated, comprising 55 bone scans from 40 departments, 34 heart scans from 21 departments (myocardial perfusion scans using technetium tracers), 26 lung scans from 19 departments, and 11 parathyroid scans from 10 departments. The choice of which type of diagnostic scan leaflets to analyse was guided by the fact that these were commonly performed diagnostic procedures by the departments who participated in the survey (see Annex 1), they comprise a wide range of levels of administered activity some of which are likely to be sufficiently high to involve contact and contamination restrictions, and last, but not least, there were sufficient numbers of leaflets for each of these diagnostic procedures in order to conduct a meaningful analysis. It should be noted that this data is not independent in that in some cases the coding was performed on different leaflets from the same department. This meant that written patient information from the same department was very uniform across the four different types of diagnostic scans. For this reason the quality of the information (see below) was applied solely to the most common diagnostic scan leaflet, namely the 55 bone scan patient information leaflets. As information pertinent to contact and contamination restrictions was more variable across leaflets, this information was evaluated for all 126 patient information leaflets.

Written patient information for therapeutic procedures
The content of patient information for radioiodine therapy for thyrotoxicosis was chosen to be evaluated as the results of the survey indicated that this therapy was performed in 53 (93%) departments performing therapies. In addition, radioiodine emits both beta particles and gamma rays, leading to potential hazards from both external exposure and contamination, which necessitate complex restrictions. This analysis was conducted upon written patient information from 34 departments. This information primarily consisted of patient information leaflets, but also included letters that contained information pertinent to the objectives (e.g. information about restricting contact with others) and yellow instruction cards.

The evaluation of quality of patient information was performed specifically on patient information leaflets and excluded instruction cards and letters. This evaluation was performed on 29 patient information leaflets from different departments.

The assessment of the rationale for the restrictions (i.e. risk to self and others) was performed with information grouped by department and could comprise information leaflets, yellow instruction cards and relevant accompanying letters. Thus, this analysis was performed on information from 34 departments, comprising 29 information leaflets (including accompanying yellow radionuclide instruction cards and letters) and, in the case of five
departments, solely on the yellow radionuclide instruction card as no information leaflet was obtained from these departments.

The assessment of contact and contamination restrictions was performed on 55 restriction periods in information from the 34 departments. This was because different restriction periods were sometimes contained within one leaflet or instruction card (e.g. in the form of a table) or else we received a number of different leaflets from one department which were the same in all respects except that different activity levels and restriction periods were specified. Of the written information that was obtained, in 24 cases no activity was specified and in 31 cases an activity level was specified. Even where activity levels were specified, this covered rather a large range of possible activities (e.g., less than 400 MBq; 401-600 MBq, etc). These activity levels were therefore categorised as follows: activity level unspecified, less than 400 MBq; 401-600 MBq; and 601-800 MBq).

3.4.2. Criteria for the evaluation of written patient information

Quality of written patient information
The Ensuring Quality Information for Patients (EQIP) tool (Moult, Franck, & Brady, 2004) was used to evaluate the overall quality of the 55 bone scan patient information leaflets and the 29 radioiodine therapy for thyrotoxicosis patient information leaflets. The EQIP is a reliable and valid tool which was developed to provide a comprehensive evaluation of a wide range of written healthcare information. The EQIP evaluates written information in terms of its completeness, appearance, understandability, and usefulness. It does not establish the accuracy of the information and this needs to be established via other means (e.g. establishing an evidence base and through the consensus of experts). The tool as it was applied in the present leaflet evaluation comprised of rating 21 aspects of the written information (see Table 1 below) in order to establish overall quality. Each question was rated as whether the information leaflet addressed the issue well (“yes”) which was rated 1, “partly” rated 0.5, or “no” rated 0. Total quality was calculated by summing these 21 answers and dividing by the number of relevant questions, then calculating a percentage total quality score. Reliable coding was established with three researchers initially coding the 11 parathyroid leaflets, discussing any discrepancies, and reaching agreement. This preliminary evaluation was then discussed with one of the authors of the EQIP.

Information about contact and contamination restrictions
The patient information was assessed for information concerning contact and contamination restrictions, comprising three specific aspects:

1. Rationale for the restrictions: the rationale for restricting contact and minimising contamination was assessed in terms of whether, and how, the written information communicated the risk the radiation posed to the patient and to other people they came into contact with.

2. Contact restrictions: the written information was assessed for contact restrictions and included restrictions on contact with family and friends (e.g., who was specified, length of time in days and minutes, distance to maintain from others), sleeping restrictions, restrictions on working, other contact restrictions.

3. Contamination restrictions: the written information was assessed for contamination restrictions and included advice about personal hygiene, food preparation, and intimate contact.
3.5. RESULTS

3.5.1. Quality of written patient information leaflets

The 55 bone scan leaflets and 29 radioiodine therapy for thyrotoxicosis leaflets were analysed using the EQIP. Table 1 shows how the leaflets performed for each of the 21 individual questions. Total quality scores were calculated, converted into percentages, and then categorised into quartiles (as recommended by Moult et al, 2004). Table 2 shows the total quality scores for both sets of leaflets.

Table 1  Evaluation of information leaflets by individual dimensions of quality

<table>
<thead>
<tr>
<th>Category</th>
<th>Bone scan leaflets (n=55)</th>
<th>Thyrotoxicosis leaflets (n=29)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does it tell you what it will cover?</td>
<td>46 4 5</td>
<td>6  Partly 13  Yes</td>
</tr>
<tr>
<td>Does it use everyday language?</td>
<td>4  23 28</td>
<td>3  7  19</td>
</tr>
<tr>
<td>Does it use short sentences of less than 15 words?</td>
<td>2  22 31</td>
<td>2  4  23</td>
</tr>
<tr>
<td>Does it personally address the reader?</td>
<td>1  22 32</td>
<td>1  4  24</td>
</tr>
<tr>
<td>Is the tone respectful?</td>
<td>4  18 33</td>
<td>1  8  20</td>
</tr>
<tr>
<td>Is the design and layout of the document satisfactory?</td>
<td>0  16 39</td>
<td>3  15 11</td>
</tr>
<tr>
<td>Does it contain relevant understandable pictures?</td>
<td>4(^1) 1 1 2(^2) 3 5</td>
<td></td>
</tr>
<tr>
<td>Is information presented in a logical order?</td>
<td>17  24 14</td>
<td>6  14  9</td>
</tr>
<tr>
<td>Does it have a named space for making notes?</td>
<td>10  45 0</td>
<td>8  19  2</td>
</tr>
<tr>
<td>Does it contain relevant contact details?</td>
<td>6  18 31</td>
<td>2  4  23</td>
</tr>
<tr>
<td>Does it contain the date it was produced?</td>
<td>38  1 16</td>
<td>14  0  15</td>
</tr>
<tr>
<td>Does it contain name of person/department that produced it?</td>
<td>24  26 5</td>
<td>1  13  15</td>
</tr>
<tr>
<td>Were patients and families involved in its production?</td>
<td>54  1 0</td>
<td>29  0  0</td>
</tr>
<tr>
<td>Does it use generic names for medications/products?</td>
<td>0  0 55</td>
<td>0  2  27</td>
</tr>
<tr>
<td>Does it address quality of life issues?</td>
<td>8  12 35</td>
<td>0  4  25</td>
</tr>
<tr>
<td>Does it contain details of other sources of info?</td>
<td>49  3 3</td>
<td>27  0  2</td>
</tr>
<tr>
<td>Is the purpose of the procedure described?</td>
<td>24  12 19</td>
<td>1  6  22</td>
</tr>
<tr>
<td>Are the benefits of having the procedure described?</td>
<td>36  13 6</td>
<td>1  14  14</td>
</tr>
<tr>
<td>Are any risks described?</td>
<td>21  16 18</td>
<td>2  17  10</td>
</tr>
<tr>
<td>Are side effects described?</td>
<td>18  4 33</td>
<td>9  4  16</td>
</tr>
<tr>
<td>Are alternatives described?</td>
<td>54  1 0</td>
<td>24  1  4</td>
</tr>
</tbody>
</table>
48 bone scans leaflets and 24 thyrotoxicosis therapy leaflets did not contain pictures or illustrations and were not analysed in this category.

As Table 1 shows, the leaflets performed at least reasonably well in many of the dimensions. Also, the thyrotoxicosis leaflets generally performed better than the bone scan leaflets. However, there was room for improvement along many of these dimensions as evidenced by the areas where leaflets were scored as “partly” addressing the dimension. This large number of “partly” scores for many leaflets contributed to rather poor overall quality scores for the bone scan leaflets (see Table 2). In addition, the areas where at least half of the leaflets scored particularly poorly were:

1. not starting by informing the reader about what would be covered in the leaflet,
2. not containing a date of production
3. either not consulting patients in the development of the leaflet or else not explicitly stating that patients were consulted
4. very few leaflets contained explanatory illustrations or photographs and, those that did, were generally of poor quality or difficult for the patient to understand
5. not containing details of other sources of information such as websites.
6. not describing the potential benefits of having the bone scan
7. not describing any alternatives to having a scan or having radioiodine therapy

Table 2  Total quality scores for bone scan and thyrotoxicosis therapy leaflets

<table>
<thead>
<tr>
<th>Quality level</th>
<th>Score range</th>
<th>Bone scan leaflets (n=55) Frequency (%)</th>
<th>Thyrotoxicosis leaflets (n=29) Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High quality</td>
<td>75-100</td>
<td>4 (7.2%)</td>
<td>8 (27.6%)</td>
</tr>
<tr>
<td>Good quality</td>
<td>50-74</td>
<td>19 (34.5%)</td>
<td>18 (62.1%)</td>
</tr>
<tr>
<td>Some serious problems</td>
<td>25-49</td>
<td>32 (68.2%)</td>
<td>3 (10.3%)</td>
</tr>
<tr>
<td>Severe problems</td>
<td>0-24</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

As shown in Table 2, the majority of bone scan leaflets fell into the third quartile which indicates some serious problems with the quality of the information. Only a small number of thyrotoxicosis leaflets fell into this category. In this category the authors of the EQIP (Moult, Franck, & Brady, 2004) recommend that leaflets should be reviewed and revised immediately with a view to replacing them within six months to a year. No leaflets fell into the last quartile indicating that they should be “removed from circulation immediately”. The leaflets in the top two quartiles indicate good to high quality leaflets, with the second category perhaps containing some minor problems. It is recommended that high quality leaflets should be reviewed and revised within two to three years, and good quality leaflets within one to two years. As so few of the leaflets actually contained the year of production, it is difficult to estimate whether institutions are revising their leaflets on a regular basis.

3.5.2. Diagnostic scan leaflets: analysis of contact and contamination restrictions

Rationale for restrictions
The diagnostic scan leaflets were assessed for whether and how they communicated information about the risks associated with the use of radiation. First data pertaining to the risk to the patient themselves is presented and then data about contact and contamination restrictions and the rationale for these restrictions is presented.
Table 3 presents the extent to which the leaflets made any mention of risk to the patient and whether this was described using a verbal descriptor about level of risk (e.g. high risk, low risk).

### Table 3  Number of diagnostic leaflets mentioning risk to patient

<table>
<thead>
<tr>
<th>Scan</th>
<th>Bone</th>
<th>Heart</th>
<th>Lung</th>
<th>Parathyroid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of leaflets</td>
<td>55</td>
<td>34</td>
<td>26</td>
<td>11</td>
</tr>
<tr>
<td>Number of sites</td>
<td>40</td>
<td>21</td>
<td>19</td>
<td>10</td>
</tr>
<tr>
<td>Mention risk</td>
<td>37 (67%)</td>
<td>23 (68%)</td>
<td>18 (69%)</td>
<td>5 (45%)</td>
</tr>
<tr>
<td>Descriptive statement of risk</td>
<td>27 (49%)</td>
<td>22 (65%)</td>
<td>12 (46%)</td>
<td>4 (36%)</td>
</tr>
</tbody>
</table>

As shown in Table 3, a total of 84 (66.7%) leaflets made some mention about potential risk to the patient of the radiation. The majority, 65 (51.6%) of leaflets, used some descriptive statement about the level of risk posed to the patient. Typically these statements referred to small or very small doses of radiation being used for the scan. Although these statements were often preceded by a question such as “is the radiation dangerous?” the word “risk” was rarely used. Rather the statement was often phrased as “the amount of radiation you receive is small”. One leaflet also stated that “nuclear medicine procedures are among the safest diagnostic imaging tests available”, one stated “you should not be unduly worried” and one leaflet referred to legally-determined levels of radiation dose, stating “the amount of radioactivity is always the lowest we can possibly use and there are set legal limits which cannot be exceeded”.

In addition to descriptive statements, about the risk to the patient, the leaflets also presented comparative and (in one case) absolute risk information. As shown in Table 4, the risk posed by the specific diagnostic scan was compared with: other x-ray procedures, background radiation, travel, and smoking. Some leaflets used more than one form of comparative risk.

### Table 4  Use of comparative and absolute risk information in diagnostic scan leaflets

<table>
<thead>
<tr>
<th>Presented comparative risk information</th>
<th>Bone</th>
<th>Heart</th>
<th>Lung</th>
<th>Parathyroid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compared with:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. X-rays</td>
<td>27 (49%)</td>
<td>15 (44%)</td>
<td>14 (54%)</td>
<td>5 (45%)</td>
</tr>
<tr>
<td>2. Background radiation</td>
<td>24</td>
<td>12</td>
<td>13</td>
<td>3</td>
</tr>
<tr>
<td>3. Travel</td>
<td>7</td>
<td>4</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>4. Smoking</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Presented absolute risk information</td>
<td>1 (2%)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Where the leaflets used x-rays procedures as the means of comparison, the level of risk was described as:

- “Similar to many x-ray procedures” (bone, heart, lung, parathyroid);
- “Similar to that from an x-ray examination of your lower back and hips” (bone, lung, parathyroid);
- “The dose from this is considerably less than from equivalent x-rays” (bone);
- “The amount of radiation is similar to an x-ray CT scan” (bone, lung);
- “The same as six x-rays of your back” (bone);
- “The amount of radiation is similar to an x-ray CT scan of the abdomen” (heart);
- “Similar to a chest x-ray” (lung)
- “CT scan of the head” (lung)
- “The same as 100 x-rays of your back” (parathyroid)

Where background radiation was used as the means of comparison, the level of risk was described as being equivalent to between “half a year” and “a few years” additional background radiation. One parathyroid leaflet described the amount of radiation as equivalent to “50 years” of background radiation. This was the same leaflet that gave the comparative amount of radiation as the “same as 100 x-rays of your back”.

Where risks incurred by travel were the means of comparison, the statements were as follows:

- “Taking 100 transatlantic flights” (bone);
- “Driving a car for 75 miles a week” (bone, heart, lung)
- “Taking 25 transatlantic flights” (lung)

None of the leaflets stated the risk of what (e.g. exposure to radiation, having an accident).

The three leaflets that compared the risk with that of smoking cigarettes, compared it with the lifetime risk of smoking 40 cigarettes (bone), 10 cigarettes (lung), and 1000 cigarettes (parathyroid). None of the leaflets stated whether this was risk of developing cancer.

Only one leaflet (a bone scan) made any sort of statement concerning absolute risk. This leaflet stated that the amount of radiation “could lead to you eventually developing a related illness (the chance is less than 1 in 10,000)”. It did not state what would constitute a “related illness”.

Thirteen leaflets (10%) made some reference to the benefit of the scan outweighing the risk of the radiation. For example:

- “The benefits of the scan far outweigh any potential risk from the radiation”;
- “All scan requests are checked by the doctors before booking and it has been decided that the benefits of the scan far outweigh the small risk from the radiation”; 
- “The isotope scan is necessary to help make the right treatment decision so the benefit from the scan should usually outweigh the small radiation risk”; 
- “Your physician will not consider carrying out the investigation unless he believes that the risk is outweighed by the potential benefit of the study” (NB: note use of sexist language).

Whether, and how, the leaflets explained the rationale for restricting exposure of other people was also assessed. As this can be best understood in the context of whether or not these leaflet gave contact and contamination restrictions, these data are presented together.

**Contact and contamination restrictions**

5 presents the data concerning the number of leaflets advising that contact with others is restricted, who to restrict contact with, and advice on minimising contamination. In addition,
this table includes information on whether a definition of contact is presented in the leaflet (e.g. amount of time or distance) and whether it gave an explanation of the rationale for these restrictions.

Table 5  Contact and contamination restrictions in diagnostic scan leaflets

<table>
<thead>
<tr>
<th></th>
<th>Bone</th>
<th>Heart</th>
<th>Lung</th>
<th>Parathyroid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Restrict contact</td>
<td>45 (82%)</td>
<td>22 (65%)</td>
<td>17 (65%)</td>
<td>7 (64%)</td>
</tr>
<tr>
<td>Restrict contact with:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Children</td>
<td>45</td>
<td>22</td>
<td>17</td>
<td>7</td>
</tr>
<tr>
<td>2. Pregnant women</td>
<td>25</td>
<td>14</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>3. Other people</td>
<td>3</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Definition of close</td>
<td>18</td>
<td>11</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>contact</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contamination restrictions</td>
<td>10 (18%)</td>
<td>1 (3%)</td>
<td>1 (4%)</td>
<td>1 (9%)</td>
</tr>
<tr>
<td>Explanation of reason for restrictions</td>
<td>27</td>
<td>17</td>
<td>13</td>
<td>5</td>
</tr>
</tbody>
</table>

Eighty six leaflets (72%) gave advice on restricting contact with others. All 86 mentioned restrictions on contact with children (although there was variation in the recommended age limits), 49 leaflets advised on restricted contact with pregnant women, and five leaflets mentioned restricting contact with other people (e.g., women of child-bearing age, avoiding public transport and places of entertainment).

Advice on the length of time that contact should be restricted for varied. Eight leaflets only mentioned restrictions during the hospital appointment (i.e., asking that children and pregnant women did not accompany the patient). Forty eight leaflets stated that contact should be restricted for “the rest of the day” and two did not specify a timeframe. The remaining leaflets gave a specific amount of time ranging from 8 hours to 24 hours.

Thirty four leaflets (40% of those with contact restrictions) defined what was meant by restricting prolonged close contact. Typically, this stated “close contact means having a child sit next to you or on your knee for more than half an hour” and there was little variation in this advice. A small proportion of leaflets also stated that “normal contact is fine”. One leaflet defined contact as “sitting next to the same person for more than one hour” and one simply said “no cuddling children under 8 years”.

Thirteen leaflets (10%) gave advice on minimising contamination: nine referred to flushing the toilet and washing hands, three stated that the patient should avoid blood and urine tests, and one gave advice on the disposal of nappies.

Sixty leaflets (70% of those with contact restrictions) gave an explanation about why contact with others should be restricted. In 41 cases this explanation was typically stated as “to avoid exposing them to unnecessary radiation” and in 19 cases there was some variation on this theme (e.g., “as the test involves small amounts of radiation”; “to minimise the risk to others”; “because you will stay radioactive for 12 hours”, “with all procedures involving radioactivity we have to give advice that keeps radiation doses as low as reasonably practicable to all persons involved”).

A total of 27 leaflets (21%) made some reference to the fact that radioactivity would decay over time. This ranged from quite simple statements that did not mention half-life explicitly (e.g., “after the injection it will gradually fade away”, “After 24 hours the radioactive tracer will have passed out of your body”) to more detailed explanations (e.g., “the injection of
radiopharmaceutical will leave you slightly radioactive for about 24 hours”; “...has a half life of 6 hours meaning that every 6 hours the amount of active tracer in your body has reduced by half. So after 24 hours there is very little left of the original amount”

3.5.3. Radioiodine therapy for thyrotoxicosis written information: analysis of contact and contamination restrictions

Rationale for contact and contamination restrictions

The written information from 34 nuclear medicine departments was analysed in terms of whether, and how, risk to the patient and to others was addressed as this provides the rationale for contact and contamination restrictions provided. First, data pertaining to risk of the radiation to the patient themselves is presented and then data concerning risks to other people.

The information provided by 18 departments (53%) made no mention of whether the therapy posed any risk to the patient themselves. Leaflets from 14 departments (42%) stated that the therapy was safe. Typically this was the statement “Can radioiodine treatment cause cancer? No. radioiodine has been used for over 50 years to treat thyrotoxicosis. Patients treated this way have been studied carefully. There is no increased risk of developing thyroid cancer or other cancers as a result of treatment”

There was some slight variation in this statement in that some said there is no increased risk (as above) and others said “no evidence of increased risk”. In the other cases the leaflet simply said that the therapy is “a very safe form of treatment” or that the “radioactive iodine administered is at a level such that you are no danger to yourself or the general public”

For the final two leaflets, one stated “Don’t worry. The risks to you from the radioactivity are extremely small compared with the benefit you receive from this treatment” and the other stated “the radioactivity from this treatment will benefit you, but not other people”.

In addition, three leaflets gave comparative risk information, stating that the radiation dose to the rest of the body was similar to having an x-ray, three x-rays, or a few x-rays.

Information from seven departments (20%) stated that the radiation posed no risk to others, with five of these stating that precautions should be followed. Examples of these statements are:

- “Can the radiation from this treatment harm other people? No, but please take the simple precautions which we will tell you about”.
- “Will there be any danger to my family? No, but please take the simple precautions that we will tell you about when you come for the treatment. They are to help avoid any unnecessary radiation to members of your family and other people”

Information from 20 departments (57%) went somewhat further than this and explained that the precautions were designed to minimise the dose to others or prevent any harm. Examples of these statements are:

- “It is important that you take the following precautions to limit the radiation dose to people you come into contact with”.
- “The following precautions will ensure that the effect on other people is kept to an absolute minimum and is below all recommended limits”
- “Will there be any danger to my family and friends? You will be giving off radiation for several weeks. You must follow these restrictions for 2-3 weeks and then the risk to others will be very low”

Information from two departments (6%) suggested that other people could be put at some risk:
• “The iodine capsule which your doctor has prescribed emits a small amount of radiation which can be a minor hazard to other people if you are in close contact with them for a long time”

• “As you may be aware exposure to ionising radiation is a potential hazard to us all, and should be kept to a minimum – but do bear in mind that we are exposed to natural sources of radiation in our everyday lives”

Information from five departments (14%) made no mention of risk to others, although four of these were yellow instructions cards with no accompanying information leaflets. One leaflet spoke about the fact that the radioiodine benefited the patient but not other people and two used comparative risk information to explain the level of risk to others. This comparative risk was stated as equivalent to 0.5 to 1 year of natural background radiation.

Information from 10 departments (26.5%) addressed whether the use of radiation posed a threat to future children. All of these stated that there was no risk/no evidence of any risk, e.g.: “Are there any risks in having children afterward? No. fifty years of experience of using radioiodine shows no effect on the health of children of patients who have had radioiodine”.

**Contact and contamination restrictions**

From the 34 departments, 55 individual contact and contamination restrictions were available for analysis. Of these, 31 (56%) pertained to a specific activity level and 24 (44%) did not specify the activity level. First data from all leaflets are presented and then contact restrictions, broken down by activity level are presented. Maximum possible restriction times ranged from 7 to 42 days in 45 leaflets, with a mean = 21.7 days, standard deviation = 6.3 days, and median = 21 days. For the 9 leaflets that did not specify a time period, 7 referred the reader to the date specified on the yellow card and 2 did not mention a restriction period at all.

Definition of close contact: 35 leaflets (66%) stated that others should be kept at a distance of more than 1 metre, one specified the distance as sitting next to the patient, four others gave distances between two arms lengths and 2 metres. The other 15 gave vague instructions such as “avoid over close contact” and “non essential close contact”. Time restrictions for contact in minutes were specified by 15 leaflets (28.3%) and this was uniformly to restrict contact to less than 15 minutes per day. The other leaflets did not specify an amount of time in minutes.

The majority of leaflets, 52 (98%), made a distinction between different groups of people to restrict contact with. These were typically, children, pregnant women, partner, and other people. In many cases the leaflet specified the age group of children and these were in the categories or children under 3 years, children aged 3 to 5 years, and children over the age of 5. Where leaflets did not specify such a breakdown, we coded a statement that said simply “avoid contact with children” as up to the age of 18, but where it said “young children” this was categorised as up to the age of 5. Table 7 presents data on the number of days contact restrictions were imposed, specific to these different groups of people.
As shown in Table 7, the leaflets that specified a time frame did appear to distinguish between groups who were differentially at risk from radiation exposure. However, the table also shows a large range in restriction periods from 1 day to 30 days. In addition 7 leaflets specified two time periods, the first where there should be no contact and the second where there should be minimal close contact.

For the 31 leaflets that gave an indication about activity levels, the maximum number of days for contact restrictions were analysed for each group specified. This data is presented in Table 8.

### Table 7  Contact restrictions for different groups of people

<table>
<thead>
<tr>
<th>Group to restrict contact with</th>
<th>Number of leaflets</th>
<th>Maximum number of days if specified mean (SD) range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children aged 0-3 years</td>
<td>48 (87.3%)</td>
<td>21.5 (5.6) 7 – 30 (n=42)</td>
</tr>
<tr>
<td>Children aged 3-5 years</td>
<td>48 (87.3%)</td>
<td>19.7 (5.7) 7 – 30 (n=42)</td>
</tr>
<tr>
<td>Children over 5 years</td>
<td>40 (72.7%)</td>
<td>15.3 (7.4) 1 – 30 (n=37)</td>
</tr>
<tr>
<td>Pregnant women</td>
<td>44 (80%)</td>
<td>18.0 (8.0) 1 – 30 (n=38)</td>
</tr>
<tr>
<td>Other adults</td>
<td>29 (52.7%)</td>
<td>9.3 (5.9) 1 – 21 (n=26)</td>
</tr>
</tbody>
</table>

Kruskal-Wallis tests revealed that there were differences in the restriction period by activity level for children aged 0-3 years, chi-square=16.8, df=2, p<.001; children aged 3-5 years, chi-square=12.5, df=2, p<.01; children aged over 5 years, chi-square=7.4, df=2, p<.05. Therefore, restriction times increase significantly with increasing activity levels for these age groups. There were no significant differences for pregnant women or other adults, although these findings should be interpreted with caution given the small sample sizes.

With respect to sleeping arrangements, 46 leaflets (83.6%) gave instructions regarding contact with others whilst sleeping. Of these 41 stated that the patient should sleep in a separate bed, one gave a distance of 2 metres (even in different rooms) and four did not specify a distance. For the 39 leaflets that specified a specific time frame for this restriction the mean time was 13.3 days (SD=7.7 days) and ranged from 1 day to 26 days. This was then analysed for the 31 leaflets that presented information about activity levels and this data is presented in Table 9.
Table 9  Sleeping restrictions by activity level

<table>
<thead>
<tr>
<th>Activity Level</th>
<th>Less than 400 MBq (n=13)</th>
<th>401-600 MBq (n=9)</th>
<th>601-800 MBq (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean number of days sleeping restriction (SD)</td>
<td>12.5 (7.4)</td>
<td>14.2 (9.1)</td>
<td>16.2 (8.7)</td>
</tr>
</tbody>
</table>

A Kruskal-Wallis test found no statistically significant difference in the number of days sleeping restrictions in relation to activity level, although once again caution is needed when drawing conclusions given the small sample size.

Of the 46 leaflets that presented sleeping restrictions, a total of 33 leaflets mentioned specific groups that the patient should avoid sleeping with, comprising 22 leaflets mentioning not sleeping with children, 25 stated your partner, 6 stated pregnant women explicitly and 7 stated “other adults”. Four leaflets stated that partners were exempted from any restrictions if they were aware of, and accepted, the risks and one exempted partners over the age of 60.

With respect to travel there were restrictions specified by 35 (63.6%) leaflets. Where the number of days was specified (18 leaflets) this ranged between 1 and 14 days, with a median of 7 days (12 leaflets). Maximum journey times ranged from 0.5 hours to 7 hours with a median of 1 hour. Given the small number of leaflets that presented a specific number of days or journey times, it was not possible to analyse this data by activity level.

With respect to contact restrictions at work, 53 leaflets (96.4%) said something about the necessity of taking time off work. Many of these simply said that it would depend on the specific job and referred to the yellow card. For the 23 leaflets that gave a specific time to take off, this ranged from 1 day to 8 days with a median of 1 day. Again it was not possible to analyse this data by activity level. Of the 53 leaflets that mentioned work restrictions, 39 also mentioned special circumstances when the restriction period would be longer. These were working with pregnant women and children and also working with radiosensitive materials. When mentioned, the extended restriction period ranged from 7 days to 30 days.

Other contact restrictions were also presented in 32 (58%) leaflets, particularly avoiding places of entertainment. Eleven stated that the patient should avoid visiting doctors and dentist or other appointments (e.g. hairdressers). One leaflet said not to nurse young invalids, one said to only smoke in well ventilated areas, and only two mentioned anything about the possibility of setting off sensors when crossing through border controls.

Turning to restrictions to minimise contamination, 39 leaflets (71%) gave some form of guidance. This comprised of 28 (51%) that gave advice about personal hygiene (e.g., flushing the toilet twice), 13 (23.6%) that advised not to kiss or have sexual contact, 21 (38%) that gave advice about the preparation and handling of food, 10 (18%) that gave guidance about separating crockery and cutlery, and 10 that gave restrictions regarding donating blood. There was a lot of variation in how contamination restrictions were presented. This ranged from fairly minimal advice, such as “for the first 48 hours after treatment, we advise you to flush the toilet twice after passing urine (it is quite safe to use normal toilet facilities)” to very detailed advice, with the most extreme from one leaflet being:

“Wash your hands carefully after going to the toilet and rinse the basin. Ensure the toilet is properly flushed (flush twice to be sure) Use disposable handkerchiefs and dispose of them carefully Do not prepare food for others using bare hands Wash all your crockery and cutlery carefully and separately from those used by other people”
If there is spillage of body fluids on your clothes, wash them separately.
If there is spillage of body fluids on the floor, wipe it up carefully with a damp cloth. Wash the cloth separately.
Make sure no-one else uses your towels and facecloths. Wash them afterwards in the normal way.
Bathroom hygiene is the main way you can avoid contaminating other people.

Finally, the leaflets were assessed as to whether they stated that women undergoing treatment should not be breastfeeding and whether patients should avoid pregnancy. For the 55 leaflets, 44 (80%) mentioned that women should not be/should stop breastfeeding, 27 (49%) stated that women must not be pregnant at the time of undergoing the therapy, and 52 (94%) said that pregnancy or fathering a child should be avoided after receiving radioiodine therapy. The timeframe for avoiding future pregnancy was as follows: one leaflet stated 3 months, 40 leaflets stated 4 months, and 11 leaflets stated 6 months. This variation in time was not explained by the leaflets specifying different activity levels.

3.6. DISCUSSION

The aim of the evaluation of diagnostic and therapeutic patient information leaflets was to evaluate the overall quality of patient information leaflets, to assess which contact and contamination restrictions are communicated in written patient information, and to assess how the rationale for these restrictions is communicated.

With respect to quality, the leaflets were evaluated using the Ensuring Quality Information for Patients (EQIP) tool (Moult et al, 2004). The majority of the leaflets were categorised within the “good” and “some serious problems” categories, with the radioiodine therapy for thyrotoxicosis leaflets being more likely to be categorised as good quality and the bone scan leaflets being more likely to be categorised as somewhat problematic. This difference may well reflect a different weighting in the importance of providing high quality information that is given to diagnostic and therapeutic procedures. These total quality scores suggest that there is a need to revise many of these leaflets within the next one to three years (Moult et al, 2004). There are some simple ways in which the quality of the leaflets could be improved such as including information on who produced the leaflet and when (which will help with building in periodic reviews and revisions), including information on other sources of information such as websites. On the positive side, many of the leaflets performed well with respect to the criteria assessing how understandable they were, such as using short sentences, personally addressing the reader, and using a respectful tone. In addition, many leaflets did reasonably well with using fairly simple language. However, for this analysis it was necessary to make assumptions about what constitutes “everyday language”, with the term “radiation” being considered as a familiar term for most but “tracer” and “radiopharmaceutical” being considered as probably less familiar. There is a need to investigate what does indeed constitute everyday language for patients in the context of nuclear medicine procedures. Such consultation with patients and their families would be beneficial in improving the quality of these leaflets. The authors of the EQIP (Moult et al, 2004) are very clear that consideration of the quality of information leaflets should be performed once the accuracy of the information has been confirmed. The current analysis makes no claims about the veracity of much of the information within these leaflets.

For many diagnostic procedures there is no absolute requirement in the Medical and Dental Guidance Notes (MDGN) to present patients with contact and contamination restrictions given the lower activity levels involved (see Annex 1 for an overview of this guidance). Despite this 72% of diagnostic scan leaflets presented contact restrictions which were typically aimed at restricting contact with children and, to a slightly lesser degree, with pregnant women. The length of time contact was restricted for ranged between solely at the
appointment for the scan to up to 24 hours after the scan. It is interesting to note that 40% of
the leaflets with contact restrictions defined what was meant by close contact (e.g., having a
child sit next to the patient for more than half an hour). From a behavioural perspective, such
clear unambiguous instructions are likely to both reassure patients about what is being asked
of them and to lead to higher adherence to restrictions. It would be useful to test this in
empirical studies. Rather fewer leaflets presented restrictions to minimise contamination,
some 10%, which was primarily concerned with personal hygiene when using the toilet but
also included avoidance of giving blood. It is unclear why there is this discrepancy between
the relative frequency of contact and contamination restrictions in written information.

As might be expected, given the higher activity levels and the MDGN guidance, contact and
contamination restrictions were given much greater importance in the radioiodine therapy for
thyrotoxicosis leaflets. A rather complex array of different restrictions was apparent across
the different leaflets. Detailed analysis highlights some areas where there is consistency
between the leaflets and other areas where there is considerable variation. This analysis must
be treated with some caution as in some cases departments sent leaflets for different activity
levels with accompanying instruction cards, some departments sent only leaflets with no
instruction card, and some sent only the instruction card. Thus, rather than providing a
definitive analysis of what restrictions are presented to patients, this analysis provides an
overview of these restrictions. There was some consistency, in that contact restrictions were
primarily aimed at restricting contact with children and pregnant women, with less than half
the leaflets mentioning other adults explicitly. The majority of leaflets also provided a
definition of close contact, which was typically a distance of 1 metre. For the minority of
leaflets (28%) that presented a contact in minutes per day this was always stated as 15
minutes. It would perhaps be useful for all leaflets to give such specific advice. There was
quite a large variation in the length of the restriction period although there was a discernable
pattern in that longer restriction periods were given for younger children and pregnant women
and for higher activities of radioiodine. As not all information leaflets gave an activity level
and those that did usually incorporated a broad range of activity levels (e.g. in 200 MBq
ranges or more), it was not possible to rigorously compare restriction periods with the MDGN
guidelines. However, from a simple inspection of these figures it would appear that many
departments are indeed basing restriction periods on these guidelines or, indeed, taking a
more precautionary approach and recommending rather longer restriction periods than
specified in the MDGN. The majority of leaflets gave advice about sleeping arrangements
(83.6%), contact with others at work (96.4%), contact with others whilst on public transport
(63.6%), and other forms of one-off contact such as avoiding places of entertainment (58%).
Many of these leaflets also mentioned special circumstances were further or longer
restrictions could be advised, such as when working with children and pregnant women. For
the radioiodine for thyrotoxicosis therapy leaflets, the majority (71%) did present restrictions
to minimise contamination. However, there was much variation in the nature of these
restrictions and the complexity of the advice.

Finally, the leaflets were assessed as to how the rationale for contact and contamination
restrictions was communicated. The majority of diagnostic scan leaflets made some mention
of the potential risk of the radiation to the patient themselves. This was typically to state that
the risk was low or some variation on this phraseology. About half of these leaflets also
compared the risk of the radiation to other risks, primarily risks associated with other types of
x-ray or with background radiation. A few also compared the risk with risks incurred by
travelling by air or car or by smoking cigarettes. Only one leaflet gave any estimate of
absolute risk. The presentation of this risk information appears to be seeking to downplay risk
and reassure the patient. For example, many leaflets compare the risk to “many x-ray
procedures” or some variation on this. A few compare the risk to having a CT scan. However,
little is known about what comes to mind when a patient thinks of “x-ray procedures” or
whether they have any conceptualisation of what a CT scan is. This needs to be investigated
as it seems likely that many people will think of chest or limb x-rays and will therefore

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underestimate the risk. Risk of fatal cancer from a chest x-ray is estimated at 1 in 1,000,000, whereas or a bone scan using 600MBq it is estimated at 1 in 6,666 and for a parathyroid scan using 900 MBq Sestamibi it is estimated at 1 in 1,818 (NRPB, 1998). Therefore, if patients are indeed conceptualising the risk information that is typically used as equivalent to an x-ray of a limb or chest, they cannot be said to be fully informed about the risk.

Despite the fact that activity levels are higher and restriction periods are recommended, the radioiodine for thyrotoxicosis leaflets generally either did not mention any potential risk of the radioiodine to the patient or stated that there was no risk. All leaflets give minimal information about potential risk to others. In addition, no leaflet says what to do or what the consequences of not-adhering are. Most leaflets simply say that the restrictions are to minimise the radiation dose to others. One interpretation of these findings is that this information is presented in order to reassure patients that there is no risk and to prevent any anxiety. It seems possible that unless patients understand the rationale for the restrictions they may not adhere to them. Research in other areas of health psychology demonstrates that patients are most likely to follow medical advice (such as taking medications as prescribed) if they perceive a logical relationship between the behaviour (in this case restricting contact with others) and the reason for this behaviour (i.e. minimising the potential risk of the radiation to others). A few of the leaflets stated that the benefit to the patient made the small risk an acceptable risk but that as others received no benefit they should not be exposed to any radiation if possible. It is recommended that the leaflets include more detailed and understandable information on the level of risk and the rationale for the restrictions. These communications could include information on both absolute risk and comparative risk in a format that is understandable to the patient (Picano, 2004; Edwards et al, 2002). Ways of communicating this information that does not unduly raise anxiety but does facilitate the understanding and adherence of patients should be tested in future studies.

3.7. PRACTICAL IMPLICATIONS

- Nuclear medicine professionals could use reliable quality coding tools such as the EQIP to reach consensus on what criteria need to be applied to written information for patients undergoing diagnostic and therapeutic nuclear medicine procedures.
- Review and revise current patient information leaflets in line with these agreed quality criteria
- Patient information should include reputable sources of further information such as a website address
- Conduct further research on how patients conceptualise radiation risk and what constitutes everyday language in the context of nuclear medicine procedures
- Consider including specific behavioural instructions for patients on the meaning of close contact (e.g., distance from other people, amount of time per day that contact is permitted).
- Nuclear medicine professionals to consider what is important and practicable advice regarding restrictions to minimise contamination in order to facilitate more consistent information being presented to patients on this issue.
- Develop patient information that presents radiation risk and the rationale for restrictions in ways that are both accurate and understandable. This should include information about both absolute risk and relative risk.
- Conduct empirical studies to evaluate the impact of new patient information on understanding, level of anxiety, and adherence to restrictions in order to find ways of communicating that maximise positive outcomes and minimise any harm.
3.8. REFERENCES


4. ANNEX 3: EXPERIENCES AND PERCEPTIONS OF PATIENTS UNDERGOING DIAGNOSTIC AND THERAPEUTIC NUCLEAR MEDICINE PROCEDURES

4.1. SUMMARY

Semi-structured interviews with patients were conducted in order to investigate patients’ perceptions and experiences of undergoing diagnostic and therapeutic nuclear medicine procedures. Written information is primarily sent to patients with the appointment letter, prior to arrival in the department, and further information, either verbal and/or written is given in the department prior to the procedure. Semi-structured interviews were conducted with ten patients undergoing diagnostic procedures and fourteen patients undergoing therapeutic procedures. The main findings were that, in general, patients were satisfied with both the written and verbal information that they were given although some would have liked more relevant information for their particular case. A strong theme that emerged was a perceived lack of information, either written or verbal, regarding the consequences of radiation exposure to others; patients did not on the whole understand what might happen to people they came into contact with. Many patients accessed further information regarding their procedures from the internet. However, they did recognise the need for caution in this regard and expressed a desire for health professionals to provide information regarding alternative credible, reliable sources of information. A number of patients would have welcomed information which reflected the realities of what they would experience when undergoing the procedures. Most patients stated that they had some basic understanding of radioactivity and did not feel that they needed an in-depth understanding. Although many participants stated that they did not understand the rationale for the restrictions, most appeared to be happy to adhere to the restrictions that they were given. There was however concern that other staff in the hospital didn’t really understand the restrictions or the reasons behind them which could be seen to have the effect of undermining the importance of this information. The implications of these findings in terms of clinical practice and information provision are highlighted.

4.2. AIMS AND OBJECTIVES

As a first step towards gaining a greater understanding of the experiences and views interviews were conducted with patients undergoing diagnostic and therapeutic nuclear medicine procedures. The use of qualitative methods, in this case semi-structured interviews, allows for exploration of the way in which patients themselves conceptualise and talk about radiation and restrictions and their experiences of undergoing nuclear medicine procedures and implementing these restrictions. Therefore, the overall aim of this study was to investigate patients’ perceptions and experiences of undergoing diagnostic and therapeutic nuclear medicine procedures. The specific objectives were:

- To explore how patients undergoing diagnostic and therapeutic procedures with radioactive materials perceive currently used verbal and written information and the procedures for its dissemination;
- To explore any perceived shortfall in information provision and perceptions of how these information needs can best be met;
- To explore what patients think and feel about these procedures, their understanding of advice regarding reducing exposure to others and what difficulties they encountered in adhering to this advice.
4.3. METHOD

Semi-structured interviewing is the most widely used method of data collection in qualitative research and provides an opportunity for the researcher to hear the participant talk about their particular experiences and perceptions. This style of interviewing is sometimes described as non-directive, however the questions asked by the interviewer function as triggers that encourage the participant to talk and generate novel insights for the researcher.

4.3.1. Participant Selection

Patients who had an appointment at the Nuclear Medicine Department for therapeutic and diagnostic procedures with radioactive materials were given information about the study at their appointments (information sheet attached in Appendix 2). Those who agreed to be contacted about their possible involvement in the interview study were telephoned by the researcher. This telephone contact occurred towards the end of their restriction period, which was up to three weeks for patients undergoing therapeutic procedures. During the telephone contact the researcher further explained and clarified the study details, and negotiated individually with each patient the date, time and location of the interview. Ethical approval was obtained from the relevant local research ethics committee and each patient gave informed consent to be interviewed.

4.3.2. Participants

Ten patients (five women and five men) undergoing diagnostic nuclear medicine procedures were interviewed. These procedures comprised five bone scans, four heart scans, and one thyroid scan. Fourteen patients (seven women and seven men) undergoing therapeutic procedures were interviewed, comprising four patients with thyroid cancer and ten patients having radioiodine therapy for thyrotoxicosis. Patients’ ages ranged from 34 to 67 years and were predominantly white, married, with high academic achievement and working in professional or skilled occupations.

4.3.3. Procedure

Semi-structured interviews were conducted during which patients were encouraged to answer as expansively as they desired. The questions focused on their experiences and perceptions of information needs and provisions, what patients think and feel about the particular procedures that they were undergoing, their understanding of the use of radiation in the procedure and the advice regarding reducing exposure to others and what difficulties they encountered in adhering to this advice. Questions were open-ended and currently available written material was also used as stimulus material. The interviews, which were tape-recorded and fully transcribed, lasted up to one hour each and were conducted by trained interviewers. The majority of the interviews took place in the participants’ homes or at the hospital whenever possible. The full interview schedule for both the diagnostic and therapeutic procedures and stimulus materials used are shown in Appendix 3.

The interview transcripts were analysed in accordance with the principles of Interpretative Phenomenological Analysis (IPA; Smith, 1996). IPA is a widely used and rigorous technique for analysing qualitative data and constitutes an inductive form of data analysis. That is, it is a bottom-up form of analysis in which analysis is driven by themes in the data rather than attempting to fit the data into pre-determined categories (deductive or top-down analysis). Interview transcripts were analysed individually and themes identified. Themes were then integrated across transcripts in order to identify shared themes which captured the essence of the participants’ perceptions and experience.
4.4. RESULTS

The analysis has identified three main themes and a number of subordinate themes.

- Provision of information for patients’ undergoing therapeutic and diagnostic procedures with radioactive materials
  - Information from health professionals
  - Explanation of reason for restrictions
  - Other sources of information
- Understanding of radiation
- Adherence to advice regarding reducing exposure to others and what difficulties they encountered in adhering to this advice
  - Patient undergoing procedure
  - Friends and family
  - Other health care professionals

4.4.1. Provision of information for patients’ undergoing therapeutic and diagnostic procedures with radioactive materials

**Information from health professionals**

All patients’ stated that they had been given information in the form of leaflets with the appointment letters, which told them what they needed to know in terms of where to come and what time to come in for treatment, how long they would be in for if they were being hospitalised, whether or not visitors were allowed and the particular restrictions to them when they came out of hospital. The participants were generally satisfied with both the written and verbal information they were given. Generally, participants thought that the written information was communicated in a sufficiently comprehensible manner, as the following quotes show:

*It was simply laid out. I just needed a bit of time to sit and read it and absorb it. But no, I don’t think they missed anything out. It was very, very good*  
(therapy patient)

*It was quite straightforward. It sort of explained things in general, wasn’t frightening, wasn’t written in a technical fashion. It was quite straightforward*  
(therapy patient)

The information was generally perceived as containing the information that the patient needed to know

*It was pretty good. It told me basically what I wanted to know which was how long I would be in for, whether I could have visitors, or if you’re working how much time off afterwards I would need and there were restrictions to me coming out of hospital. That was one of my main concerns really and it told me all about that*  
(therapy patent)

*I read the leaflet and that seemed to explain everything I needed anyway*  
(therapy patent)

One issue that did arise for many participants about information provision was related to their understanding of the restrictions and the rationale for these restrictions. This is considered in the next section. Aside from this there were a few criticisms about the written information from a minority of participants about the content concerning specific aspects of the procedure or the style of presentation
The only point at which I felt there was a slight lack of information was concerning the scan. It was just basically "right we're going to give you a scan of your thyroid now" end of story
(therapy patent)

Probably too much writing, bearing in mind that I like things with different colours, headlines, short paragraphs, very clear and for a person that was less well literacy, that sort of person, they would not have been able to read it very well.
(therapy patent)

However, participants who queried the comprehensibility of the information for others, also reported that they had not experienced any problems understanding the written information themselves.

All patients stated that they were given verbal information when they came for their procedures. This additional verbal information could be seen to serve two purposes. Firstly, it helped to clarify issues that were specific to the individual participants’ situation and concerns, as shown below

He went through it all again…he went through it all again so, you know, made perfectly clear that I understood and I then signed the consent form...So, yes, every step of the way, you were talked through it, and I’m assuming it will be the same today.
It was very good
(diagnostic scan patient)

he went through it all again but I don’t think I learnt anything that I didn’t know other than I just did check up because I found the leaflet just slightly confusing as to how near and for how long people could come into contact with you
(therapy patent)

Secondly it acted as a source of reassurance about any concerns the patient had.

P They just reassured me.
IV Reassured you about?
P Well, that there was nothing to worry about, that it was a tablet, that if it didn’t work the first time possibly the second time it would work and if it went below under-active, then thyroxine was fine for the rest of May. So it didn’t really bother me
(therapy patent)

Some patients also stated that they would have particularly liked more information that reflected more fully the realities of what would happen when they attended for their procedures and that this would have helped them to be more prepared (such as information on side-effects that matched their experience or information on about having the scan).

Actually having a scan I think is a bit nerve-wracking if you don’t quite know what to expect
(therapy patent)
They bring the camera down there sort of thing...about an inch above you and then it sort of moves slowly across you and for about ten minutes it’s...you can’t lift your face. It slowly goes over you
(diagnostic scan patient)

Although not directly related to the use of radiation and experience of restrictions, these experiences are likely to influence their response to the situation as in some cases patients perceived that the information they received did not fully prepare them for the actual procedure itself or its consequences. It is now generally acknowledged that patients who attend hospitals for medical procedures or treatment often experience anxiety and stress. However, many studies have demonstrated that patients who are carefully prepared and given full information about the ‘events’ of the procedures, their order of occurrence and the sensations that they might expect afterwards are less anxious about the procedures and feel more in control. Further this has a beneficial effect on the patients’ emotional reactions and consistently reduces anxiety.

**Explanation of reasons for restrictions**

A major theme to emerge from the interview transcripts was that there was no information provided, either written or verbally, on what could potentially happen to people if the patients’ did get into close contact immediately after the procedure and/or did not adhere to the suggested restrictions, nor indeed what ‘exposed’ people should do if they felt concerned.

I suppose the one thing that actually made me laugh is the fact that the actual radioactive injection, it says, you know, the amount...the amount you will receive is small, similar to a doses in x-ray, there’s no risk to other members of your family but if there are small children or babies, you know, don’t cuddle them, and that just made me laugh because I thought, well, on the one hand they’re saying there’s no risk and on the other hand they’re saying but don’t go near young children
(diagnostic scan patient)

It was very good [the information leaflet] about what precautions you had to take, but it didn’t really explain why. So it was basically, stay away from, over a metre away from adults for ten days, and it’s obviously because you’re radioactive, but it didn’t go into the implications if you didn’t follow the advice.
(therapy patent)

I think if you’re told to do something or not to do anything then you should have full explanations on the reasons why.
(therapy patent)

This is a potentially important issue since much of the research (Ley 1981;1989) suggests that adherence to recommendations can be predicted by patients understanding of the information given. If individuals understand the information that they are given and the reasons behind it, then they are much more likely to be able to recall this information which in turn impacts on their satisfaction with the health care process and predicts higher levels of adherence to treatment recommendations. It might also be speculated that this would increase the patient’s ability and self-confidence in relating this information to others.

That this perceived lack of information and understanding in relation to the potential risk to others might be a barrier to adherence to restriction guidelines was also apparent in the interviews in that it led to the necessity of adhering to restrictions being questioned:

Just that I was or could be radioactive. That was all but nothing as to the extent of what, if you didn’t comply with the instructions, what it might do to anybody or what
the percentage of risk was, which sort of makes me think everybody’s hedging their bets here
(therapy patent)

On a related note, two patients were concerned as to how they would know if others had been ‘affected’, and expressed concerns as to whether the whole family should be checked, but did not feel that sufficient information was given to them in this regard.

Other sources of information
Many patients reporting seeking out information from other sources, such as books, family and friends, or via the internet.

I had a friend that we knew years ago .... and she had similar experiences to what I’ve had and that turned out to be her parathyroid; I rang her up to ask her what happened, and apparently it is an operation that you have to have; it can’t be treated otherwise. So, I’ve got quite a lot of information, from outside
(diagnostic scan patient)

One patient (therapeutic procedure) said that ‘I was advised to look on the internet…’. However, a strong theme to emerge was that because of the amount and diversity of information available on the internet, there needed to be caution when doing this and therefore

It would have been useful to direct patients to a really reputable site for further information
(therapy patent)

In line with this, some patients expressed concern regarding discrepancies between the information they retrieved from the internet and the information that they were given from the department. This was highlighted as follows by a patient undergoing a diagnostic bone scan in response to the stimulus material (Appendix 3).

P I’d understood [from the internet] that the amount of radiation was equivalent to about 200 X-rays, but maybe my information is wrong
IV There is a kind of discrepancy……
P Yes, there is. There’s the one which says its just like an X-ray
IV Yes, example two: ‘the radiation dose is usually similar to that from an X-ray’
P and then that one saying it’s like 6 x-rays

4.4.2. Understanding of radiation
Most participants stated that they were unconcerned about the use of radiation in their diagnostic procedure or therapy, as demonstrated by the following quotes

IV Did it bother you that there was radiation in the procedure?’
P No, not at all (therapy patent)

Initially when my consultant first suggested it, it was then, well, okay, what’s involved? But once he’d gone through that to start with, then I realized a), it was a very small dose, and b) it was sort of fairly low risk
(therapy patent)

Although occasionally some slight concern was expressed about the use of radiation
I think you’re always slightly anxious if you’re going to have some sort of new treatment especially when the words, radioactive, come into it
(therapy patient)

The concept of ‘low risk’ was also linked to perceptions of the risk being necessary in light of individual circumstances. For example, one participant having a diagnostic bone scan, who had already been diagnosed with cancer stated:

So one knows it’s not good for you but you don’t have any choice when you’re fighting cancer. So you have to, all you can think about is you want to stay alive
(diagnostic scan patient)

On the whole participants trusted health professionals to make the best decisions about their care and, indeed, the fact that there were restrictions was seen as reassuring by at least one patient

I did put my trust in people rather than querying, maybe I shouldn’t but if the powers that be tell me that’s the right thing then I’ll go for it
(therapy patient)

I certainly wasn’t anxious, really at all about it, and yeah, obviously it shows that the hospital’s actually thought out all the possibilities, I suppose that gives you more reassurance than anything
(therapy patient)

Some patients thought they did not know anything about radioactivity whilst others perceived themselves to have, at least, some understanding.

Probably the biggest question mark is what exactly is radioactivity?
(therapy patient)

Sometimes it [radioactivity] can have an effect on your body. Because it is like something strong isn’t it? Exactly because it is like, I don’t know a chemical or something in there, it’s like electricity or something like that, isn’t it?  It’s like the x-rays
(diagnostic scan patient)

He basically explained the type of radioactivity dividing one to one or something and he explained what it does but sometimes it can be a bit too technical to actually understand about gamma rays and one ml or some thing, or something, I mean I understood the basics of it and that sort of thing
(therapy patent)

Well I did Physics ‘A’ level, things like that, so vaguely remembered sort of half-lives and things like that
(therapy patent)

However, most did not feel that they needed an in-depth understanding as demonstrated by the following quote from a patient undergoing a diagnostic bone scan

I like to know what’s going to happen, but I don’t really find I need to know the ins and outs of it all
(diagnostic scan patient).
Most participants felt familiar enough with the term “radioactivity” for the use of this term in written and verbal information not to cause them any alarm. It was interesting to see the use of the phrase “glow in the dark” in a large number of the interviews. This was introduced by the participants themselves, usually referring to a response they had had from other people.

*I think I found it amusing. I mean, my colleagues at work, I got all the glow, being radioactive you know, glow in the dark and all this sort of thing*
(diagnostic scan patient)

Almost without exception participants used the phrase “glow in the dark” jokingly. Towards the start of the interviews participants sometimes expressed a view that they understood the basics about radiation in relation to their diagnosis or treatment. Later in the interviews some more idiosyncratic views were expressed by participants.

*I still don’t because to me it’s not radiation. Radiation to me is like beams, to me radiation is putting a beam on you, to me. But I’m getting no radiation at the moment, it’s going through my veins, it’s just a little bag”*
(diagnostic scan patient)

*but then again when you think that the radiation that you’re getting from this is the same as what they were pushing into you to kill the cancer, isn’t it? So it’s more or less the same, isn’t it, as it wouldn’t do you any harm, it would do you more good than harm because that’s what they’re trying to kill the cancer with, isn’t it, radiation*
(diagnostic scan patient)

One patient undergoing therapy for thyrotoxicosis thought that as the radioactivity was concentrated in her thyroid, the risk of radiation for others would be an effect on their thyroid.

*Well I suppose if there’s radioactive something within the body, even though it’s… I mean I was told that it only affected the thyroid, well presumably it could affect the thyroid of the growing baby if the stuff is still there in the body, it’s how I would read it*
(therapy patent)

These thoughts and images are difficult to access because patients are often aware that they may have misperceptions or erroneous beliefs and do not want to communicate a lack of knowledge or understanding. Often these remarks were “let slip” towards the end of the interview. This has obvious implications for health professionals communicating with patients as the patients are likely to be even more concerned about presenting a knowledgeable front to their clinician.

Although many participants stated that they did not understand the rationale for the restrictions, most appeared to be happy to adhere to the restrictions that they were given. They particularly liked being given explicit instructions (e.g. 1 metre distance) and more problems occurred where patients misinterpreted information when the instruction was rather vague.

Some had a complete understanding:

*I was definitely told clear instructions about not being close to people for 15 minutes, very clear it wasn’t 15 minutes per time, it was 15 minutes per day. They spelt it out and very clear about if I knew the instructions and what it meant and everything else. So they were very adamant*
(therapy patent)

Others expressed confusion in terms of their understanding. In particular the guideline regarding contacts with others which states “Avoid prolonged (greater than 15mins/day) close contact….” led to different interpretations such as
In my actual information, the way I read it I thought, no longer than 15 minutes, more than a metre, fine, didn’t realise that it was 15 minutes a day, I thought it was periods of 15 minutes and then if you go off
(therapy patent)

Still went to the gym/pub, just made sure not on the equipment for more than 15 minutes
(therapy patent)

Further, the challenge of how best to present risk information in terms of patient understanding was also evident. At the end of the interview, participants were asked for their reactions to stimulus materials, comprising risk statements from information leaflets currently in use in the UK. The patients undergoing diagnostic procedures were generally favourable towards a statement saying that the amount of radiation was equivalent to other x-ray procedures (“I think that’s quite good because I think most people will have an x-ray… whether it’s on their teeth or whether it’s on a full body”). They found this easy to understand and reassuring, although as discussed earlier at least one patient was confused about why he had read elsewhere that it was similar to about 200 x-rays. In addition, comparing the amount of radiation to a CT scan was not generally thought to be informative.

For a start I don’t know what an x-ray CT scan is so that doesn’t tell me anything
(diagnostic scan patient)

Whilst some participants had a positive attitude towards a comparison in terms of background radiation, some patients for example, felt that a majority of people would not understand what ‘background radiation’ was in terms of trying to interpret their risk. This was highlighted by the following quotes from two patients undergoing diagnostic bone scans, when shown the stimulus material (Appendix 3)

Background radiation, I don’t think a lot of people would know what you’re talking about there, they wouldn’t know what background radiation is. Is radiation dangerous, no. You receive an injection - I know, well any reasonable person, a lot of people wouldn’t know, they wouldn’t know that you can walk over an old factory dumping ground somehow or another and receive radiation
(diagnostic scan patient)

I suppose they mean by natural background radiation, is what’s sort of in the air all the time? But it doesn’t actually explain it properly
(diagnostic scan patient)

Similarly comparing the risk from the radiation was not perceived as particularly helpful by some participants, although otherwise liked it as a means of explaining risks as it made sense to them

I don’t quite understand the last bit. I mean, we all know that every time we get in our car there is a chance of having an accident but you don’t really go out and think that that’s going to happen and I suppose they’re trying to say that there is a risk but it’s like winning the lottery; it’s very unlikely to be you. I find that a bit strange. I think they’re trying to be a bit too helpful and not succeeding.
(diagnostic scan patient)

Well, people drive 75 miles so often and you just don’t think about it, do you? People are more familiar with driving 75 miles than the background radiation, aren’t they?
(diagnostic scan patient)
Different ways of framing risk communication and the value individuals place on the various gains and losses perceived may have an effect on the choices they make. This has ethical implications for information providers and the expression of risk communication may need to vary according to the needs of individual patients. This promotes the provision of accurate honest information in the context of the individual situation, in keeping with trends towards ‘patient-centredness’ and patient choice in health care.

Patients also expressed concern about ‘assumptions’ being made in the information leaflets in terms of individuals’ understanding regarding the precautions that they should take to limit the radiation dose to others. For example, it was suggested that there may be wide variations in what different people understood to be ‘normal standards of hygiene’ or ‘plenty of fluids’. These quotes are further examples of how people are aware of individual differences in understanding and interpretation of the information that they are given. People make sense of the information in terms of their individual experiences which includes the individual’s background, social and cultural determinants. This highlights the need for more and clearer information.

Maybe that should be clearer then. Because everybody’s idea of normal hygiene is different and when you’re in there they do ask you to double-flush the toilet which I got into a routine of doing so I did it even when I got home. I think after 48 hours the plates were cut I was using. I made sure that they didn’t sit on the side and they went into the dishwasher immediately. But they went in with everybody else’s anyway. But I suppose you would need to clarify what’s meant by that (isolation room - therapy patient)

4.4.3 Adherence to advice regarding reducing exposure to others and what difficulties they encountered in adhering to this advice

Patient undergoing procedure
The majority of patients tried very hard to adhere to the guidelines regarding what they could and could not do after the procedures. Some patients said that they actually moved out of the family home during the restriction period, others did not see any family or friends during that time and kept up the restrictions for longer than they had been advised.

It would have been very difficult to do that for my two children, seven and four, and so basically I arranged to go away for the period (therapy patent)

For some patients, adhering to restrictions was fairly easy, for example…

It was very easy to follow. But half the time my daughters are on the Internet upstairs anyway so it wasn’t particularly a problem for me. I suppose it would have been for people with small children; I don’t know how you’d get round that. But that wasn’t an issue here as they’re both grown up. There wasn’t a sleeping issue so it was quite easy for me (therapy patent)

However, others found it more difficult and indeed distressing because of their particular circumstances, as highlighted by the following quote from a patient undergoing a therapeutic procedure.

I found it difficult, obviously just being in the one bedroom flat with a partner, it was difficult, sleeping on the couch and things, you know I found it quite emotionally
distressing, I felt, because you know I am a friendly, cuddly, affectionate person and just to keep myself away from people I found quite difficult (therapy patent)

Concern regarding the potential risk to animals was also evident.

Also with animals, I have a dog who sits with me the whole time and she sleeps on my pillow, she’s a lovely dog sleeping on the sofa she’s next to me and we’re always stroking and cuddling, obviously I didn’t know what the risk to her was (therapy patent)

Friends and family
Although the majority of patients found their friends and relatives supportive, a number reported that their families and close relatives found the ‘stay away’ restriction difficult.

People don’t understand because you don’t have a green face or anything (therapy patent)

In some circumstances relatives and friends chose to ignore the advice

Only one that was a friend of my parents, said, it doesn’t matter. I said I’ll have to leave, if you carry on. (therapy patent)

Well, he [husband] just said “what a load of bunk” and completely ignored. I said “that’s entirely up to you, if you want to glow in the dark as well” (therapy patent)

Although in other cases, other people appeared to be quite concerned

My first day out I went to church on Sunday and everyone was going, sit over there! (therapy patent)

Hospital staff
A number of patients were particularly concerned that other staff in the hospital didn’t really understand the restrictions or the reasons behind them which had an impact on adhering to the guidelines. One patient undergoing a therapeutic procedure reported

When I showed it into that department [thyroid clinic in general medicine] all I got were blank looks...I said “I’m not supposed to sit close to anybody”. A nurse says “well, I suppose you’ll be alright there” and there were kids running up and down which are the ones you are supposed to avoid (therapy patent)

This caused her to consider whether the restrictions were really that important and whether the Nuclear Medicine Department were just being over cautious. She felt particularly ‘cross’ because she was off work for such a long time and therefore decided that ‘Work wise biggest problem, next time I won’t say anything to anybody’. This has obviously important implications in terms of the credibility of information provided.

The theme regarding a lack of understanding by other hospital staff was further reinforced by patients undergoing inpatient therapeutic treatments in terms of the reality of the patient experience contrasting with what they had expected from the information given. One example in particular related to the administration of their food. Contrary to information that they
received prior to admission about their food being served on paper plates, ward staff brought in trays with ordinary crockery, which then could not be removed from the ‘special room’ and resulted in

\[
\text{by the time I’d finished, I had about six trays and umteen plates and cups and saucers lying around the room}
\]

(patient admitted to isolation room for therapy)

Further it was suggested that awareness of radiation protection issues in for example temporary staff was not always adequate

\[
I \text{ had one male healthcare worker who came striding in on the second day and said I’ve come to change bed sheets. And I said go away, go away and he didn’t understand}
\]

(patient admitted to isolation room for therapy)

or indeed accurate

\[
P \text{It was a bit strange, I have to admit. My only complaint was that my daughters, who are 21 and 19, and they’d rung me and asked where do we go? I said they should go out to the main [hospital] ward and say that they were here to visit me because they had to put on these overshoes and gloves and the nurses would show you what to do. And apparently one of the nurses said to the one daughter, oh, obviously you don’t value your ovaries then?}
\]

\[IV \text{ Really?}
\]

\[
P \text{So they came in dressed in these really strange aprons. I mean they are not that strange but they were strange to them really, if you see what I mean – going, you’ll never guess what she said! And they were absolutely terrified and it took me the whole hour just to calm them down. The physicist had said, I’m not going to be daft – if you want to give them a hug then that’s fine but I don’t want lots and lots of close contact. They will have to sit at the other end of the room. Well they wouldn’t come anywhere near me so I did think that was a stupid thing to say.}
\]

This provides an interesting example of the importance of all staff being informed, and about increasing patient confidence in themselves once they have been informed. The other aspect of this is that contradictory information may have implications and may lead people to question the validity and authority of things they have been told previously.

4.5. PRACTICAL IMPLICATIONS

- Provide information in relation to the consequences of radiation exposure to others, patients did not on the whole know what would happen to people they came into contact with.

- Ensure patients have relevant information for their particular case and understand the information they are given. This also becomes particularly relevant in terms of whether or not patients can be said to have given ‘informed’ consent to a procedure, if they have not got the information or do not understand what they have been told.

- Experts to provide information regarding alternative credible, reliable sources of information such as internet sites and books, taking into account issues of social exclusion/minority populations.
• Provide details of who to contact if patients had concerns following the procedure or required further information or clarification

• Information should link to patients real life dilemmas, for example - one bedroom apartments

• Information should reflect/acknowledge in a reassuring manner the realities of what the patient will experience when undergoing the procedures, i.e. accurate reflection of the patient journey e.g. scanning machine proximity to face

• Provide information and training for staff in other areas that may come into contact with patients undergoing nuclear medicine procedures

• Have systems in place to ensure adherence to radiation protection procedures by other staff in other areas of the hospital to ensure that information provided by the nuclear medicine department is not undermined when patients are visiting/being treated in other departments.

• Delivery of information and risk communication should be patient-centred and reflect the diversity and complexity of individual interpretations.

4.6. REFERENCES


5. ANNEX 4: UNDERSTANDING AND ACTING ON RADIATION PROTECTION INFORMATION: THE PERSPECTIVE OF HEALTH CARE PROFESSIONALS

5.1. SUMMARY

A series of five focus groups were carried out with health professionals and other occupations that are potentially involved with radiation protection issues. The aim of the focus groups was to obtain an in-depth understanding of how health professionals view written and verbal radiation protection (RP) information that is provided to both nuclear medicine patients and to staff. There were four main themes of the focus groups that address these aims. The main findings in each of these areas are as follows

5.1.1. Expert Provision of Radiation Protection Information

Nuclear medicine staff recognised the value of written information. Verbal information however was seen as more effective in

- Being matched to patient needs
- Allaying patient concerns
- Increasing likelihood of adherence with RP advice

Nuclear medicine staff recognised

- the value of RP information being coherent and, as far as possible, consensual although for practical reasons this was seen as being difficult to achieve.
- that patients understand and respond to clear, practical and unambiguous information.
- that many patients will be active in seeking out information from alternative sources
- that people make sense of the information that they are given in the context of the realities of their lives, their own experiences and of the people they know.

5.1.2. Communication of RP information to patients by non-specialist staff

- Nuclear medicine staff believed RP information provided by non-specialist staff could lead to patient concerns being heightened
- Non-specialist staff often felt uncomfortable and ill equipped to provide reassurance and advice to patients around RP issues
- Staff recognised potential mismatch between information provided by experts and patient experiences
- Staff recognised that patients may have prefer information to be provided by more accessible, thus possibly less ‘expert’ sources

5.1.3. Communication of radiation protection issues to staff

- Nuclear medicine staff believed that non-specialist staff understandings of radiation was often patchy. They inferred this from their behaviour; from the content of their communication with patients and because they were unsure what information staff received about RP issues.
- Non-specialist staff generally felt that they knew little about RP but were not sure what they should know, or how they would get to know.
- Little concern was reported by nursing staff; even if they knew little, they believed that appropriate safety procedures were in place.
- Staff in less direct contact with patients were generally not aware of having received any information at all about RP issues; exploring these issues in focus groups often led to heightened risk awareness and preference for information.
• Staff who work with corpses
  o were not aware of the existence of a radiation hazard nor were they aware of any practical procedures that would enable them to manage this
  o felt there were considerable organisational and physical barriers to becoming aware that a particular corpse may present particular radiation issues and to the practicalities of dealing with this

5.1.4. Signalling radiation protection issues
• Within the hospital environment the presence of a yellow wrist band was generally seen to be an effective way of signalling RP issues.
• Outside the hospital, a yellow wrist band was not known to be a signal for RP issues
• It was difficult for staff to envisage a coherent system for signalling RP issues outside the hospital.

5.2. AIMs AND OBJECTIVES:
The aim of the focus groups was to obtain an in-depth understanding of how health professionals view written and verbal radiation protection information that is provided to both nuclear medicine patients and to staff
This would involve exploring beliefs about the information provided to both staff and patients and how this information is understood; an assessment of adherence to the advice regarding exposure risks and the organisational and individual barriers to this. Finally, methods of providing more effective information were considered.

5.3. METHOD
Focus groups have unique value in unravelling the everyday understandings of an issue, in identifying areas of agreement and conflict, and providing insights into the ways in which people make sense and meaning of both the familiar and unfamiliar in everyday life (Flick, 2002). As in ‘real life’, group dynamics facilitate discussion and opinion formation (Burningham and Thrush, 2004) and help make clear the everyday understandings of the issue (Horlick-Jones et al., 2004).

Five focus groups were conducted. Each group contained different types of health professionals and other workers. The aims of each group varied slightly because of the particular interest and expertise of the group participants.

**Group 1: Health professionals working in nuclear medicine**
All participants in this group were in some way responsible for passing on radiation protection information both to patients (undergoing both therapeutic and diagnostic procedures) and to staff that might come into contact with them. Participants in this group were not asked about the way in which they protect themselves. There were five participants in this group from three different hospitals including three physicists with nuclear medicine and radiation protection experience, one nuclear medicine radiographer and a senior nurse leading on clinical effectiveness for nuclear medicine in the Trust.

**Group 2: Health professionals in contact in the hospital with patients receiving radiation exposure (mainly for therapeutic purposes)**
This group was asked about the radiation protection information that both patients and they themselves receive. There were eight participants in this group from two hospitals including
a Sister in x-ray, a Senior Staff Nurse, a Housekeeper Supervisor, a cleaner, and Nurses in the Oncology Department

**Group 3: Health professionals in contact in the hospital with patients receiving radiation exposure (mainly for diagnostic purposes)**
This group was asked about the radiation protection information that both patients and they themselves receive. There were 6 participants in this group including three staff nurses, head of portering, a porter and a radiologist with a special interest in nuclear medicine

**Group 4: Health professionals and others in contact outside the hospital with patients receiving radiation exposure**
This group was asked about the radiation protection information that both patients and they themselves receive. There were 7 participants in this group including the day care manager of an ambulance service, a GP, district nurse, nurse specialists, a community nurse and a home care supervisor

**Group 5: Health professionals and others that may be involved in handling corpses that have been exposed to radiation**
This group was asked about the radiation protection information that they themselves receive. There were six participants in this group including a senior representative of the Federation of British Cremation Authorities, a Specialist Registrar in Pathology, a senior mortuary technician, a funeral director, a health and safety officer and a manager for a national funeral care company.

5.4. **PROCEDURE**

All the focus groups were held at the Royal Surrey County Hospital. The groups lasted between 60 – 90 minutes. Participants were introduced to the aims of the project and specifically to the aims of the focus group. They were assured that their identities would be kept confidential and that nothing would be attributed to them as individuals. The group facilitator explained that if no-one objected the discussion would be recorded in order that it could be reported accurately. All groups were recorded and full transcripts made. A copy of the interview schedule can be found at the end of this Chapter.

Where quotes are included in the report, IV indicates speech by the interviewer. F and M indicates female and male speakers respectively. In a passage of text the same speaker is indicated by the same number.

Four main themes that address the aims above emerged in the focus groups.

- Expert provision of radiation protection information
  - The role of written information provision
  - The role of verbal information provision
  - Matching information to patients needs
- Communication of radiation protection information to patients by non-specialists
- Communication of radiation protection information to staff
- Signalling radiation protection issues

Before dealing with these main themes two more generic issues can be noted

To some extent the aim of considering how effective the information that staff receive could not be addressed as many participants were not aware that information about radiation protection was provided to staff. It is also worth noting here that many participants commented that they had learnt something about radiation protection by being part of the
focus group. Of course this does not lead us to infer that the information had not been made available to them, indeed other areas of this research clearly indicate that information is distributed. One of the aims of this report is, therefore, to highlight processes that might be responsible for this and to suggest ways in which information provision might become more effective.

A further linked issue is that where participants felt that they had little understanding of radiation and radiation protection issues, the group discussions themselves sometimes appeared to heighten concerns about possible risks. This was particularly evident in Group 5. One of the particular aims of the HSE is to understand information dissemination about radiation protection to people who work with corpses. None of this group were aware of such information, and understandably in the light of the focus group being carried out, they believed this to be an important issue that they needed to know more about.

5.4.1. Expert Provision of Radiation Protection Information

A strong theme in the nuclear medicine staff group was the importance of verbal information in supplementing written information.

Although written information was given out, participants stressed that it was the way in which letters and pamphlets were used and how they were embedded and supported by verbal information that was important in maximising patient understanding and minimising anxiety. 

There is much more freedom of information to patients and hence we have to be careful that what we say is not inappropriate and too difficult for them to understand because I think that’s the problem, that you shove nuclear medicine into a sentence and they will freak and then you won’t be there to sort it out. ..... I think the difficult situation is always the nervous patient in hospital who has to have rapid investigations who doesn’t take it all in no matter how many times you tell them and that’s almost impossible. All you can do is explain it as best you can, document that you’ve explained it in the notes and give them means to ask again. But they will always ask. And some people will ask because they want a different answer because they didn’t like the answer they received.

(Group 3: Health Staff – Diagnostic - group)

Role of written information

Participants believed that written information had a particularly important role insofar as patients could re-read it and go back and refer to it at any time.

The other thing it’s actually part of your treatment and you are thrown so much information and it is incredibly difficult to take it all in. The advantage of having it written down is you can go and revisit it.

(Group 2: Health Staff – Therapeutic - group)

The nuclear medicine staff group (Group 1) argued that it was hard to make a judgement about whether the content of written information communicates radiation protection information effectively. This in part seemed to be because of the strong reliance on verbal information to tailor this to the needs of a particular patient. It was thus difficult to judge the adequacy (in terms of effectiveness) of the written information and how well it met patient needs for information.

The group noted that content of written information varies widely between different hospitals and trusts. Although staff recognised the value of having a consensual body of radiation protection advice in many ways this was felt to be an unrealistic aim.
• It was thought that it would be much too difficult to obtain the levels of agreement (e.g. across trusts) that would be required in order to have standardised information. The focus would move to the minutiae of terminology and to the obtaining acceptability of particular terms. There was some ambivalence around the value of having standardised information – it can be useful in terms of ‘singing from same hymn sheet’ but the process can be slow. Some staff noted the value of generic information leaflets produced by outside organisations.

• Staff were very aware that there was often a wide range of patient responses to radiation protection information – in their experience this would not change even if the same information was held constant.

“For example, I had a lady ring up the other day and she sent the child away for a week but she’s still scared about the dog. The child has already gone to somebody for a week and the dog is now about to go to the kennels and then you get somebody else who is a bit more blasé about it, don’t you? That’s how we have to deal with it at the time. Some people take it very, very seriously, the word radiation or anything; some people think of it in the context that it is, other people are blasé, so you get a combination”.

(Group 1: Nuclear medicine staff)

• Some patients are keen to seek out multiple sources of information and so even if information was standardised patients would often be aware of different sorts of advice about radiation protection.

F5 I don’t know if it’s going to come up but one of the biggest problems we have is if a patient is getting information off the internet, and misinformation; they’ve picked up an American site; ‘well, why don’t you do that here’? The protection issues in America and Australia and Europe, particularly America, are very different.

F4 Yes, and they’re very selective about what they read and what they actually pick up off the internet and that is usually the biggest problem. I had an instance a couple of weeks ago of a patient who insisted being discharged at a level that we considered unsafe and then having her husband saying you’re being too strict; in America they do it like this. This isn’t America.

(Group 1: Nuclear medicine staff)

I think it would be useful to have a national sort of resource but that still won’t stop patients from looking at other sites and saying why are you doing it this way? If they’re just .. enquiring as to why you do it, then that’s fine but it normally comes not as a question but an accusation.

(Group 1: Nuclear medicine staff)

**Role of verbal information**

Verbal information was seen to be crucial in supplementing written information. Staff recognised that for a variety of reasons patients do not read written information. Alternatively patients may become ‘overloaded’ with written information and require simplification and clarification. Patients may ignore or seem unaware of the advice provided through written information. Verbal information can therefore be used to highlight and emphasise aspects of written information.
I think the cancer patients very often need the written information as well because quite often they are in such an emotional state at the time that they've been told about this that they're not taking in what you tell them and certainly they would be spoken to by a physicist at least once, perhaps more, a few weeks or a few days before the treatment and then actually on the day of the treatment again but we have found that with some of the written information that they will pick a bit of it and they will make a meal out of that.

Most patients if they have young children, they definitely don’t want any harm to come to their children so whatever we tell them, if we say to them stay away for three days, they’ll say, oh, I’ll stay away for a week but every now and again you’ll get somebody who is the complete opposite.

And discounts any possible risk, do you mean?

Yes, they bring the whole family.

(Staff indicated that verbal information is routinely used to clarify that the written information has been understood. Indeed verbal communication about radiation protection can be part of the process of obtaining consent and of establishing the extent to which the person is able to look after themselves after treatment.)

Patient concern was an important cue for giving verbal information – this could be communicated directly by the patient or via other staff. Verbal information was seen to have a greater capacity to reassure than written information. Staff recognised that sometimes verbal information was used to heighten and buttress the written information that had been provided. On other occasions they were ‘softening’ written information, re-interpreting it and providing reassurance. Verbal information was seen as more able than written information to take account of individual differences between patients.

Verbal information provides an opportunity to relax the letter of the law and communicate what will actually occur in practice.

In the face of an urgent and unforeseen incident within the hospital, the provision of verbal information to other staff had an important role. One physicist noted that:

Sometimes if something happens as an emergency, then you would have to actually prepare things on the spot. We’ve had patients who’ve had therapies who’ve then had to go into critical care. There has been time to decide what’s appropriate to treat and so we have managed to put together quick instructions from elsewhere so that they have got some written instructions quickly. They may not be perfect but most of it will be done verbally with the staff.

(Staff indicated that verbal information is routinely used to clarify that the written information has been understood. Indeed verbal communication about radiation protection can be part of the process of obtaining consent and of establishing the extent to which the person is able to look after themselves after treatment.)
In summary, staff that were responsible for communicating information saw that careful negotiation was required around the balance of written and verbal information. Quite independent of the content, there were dangers from too much or too little written information. Verbal information has the capacity to take account of this and of the range of individual reactions and balance these appropriately. Participants in the group saw themselves as being part of a network of expertise such that, if they did not know the answer to a query, that they could find someone else that could help.

There was also some discussion of the availability of guidelines about how best to provide verbal information. There was little awareness of protocols for verbal communication of radiation protection information. It was generally felt that this is something that would be helpful.

**Matching information to patient's needs/the realities of their lives**

Those responsible for communicating radiation protection information recognised that people make sense of the information that they are given in the context of what they already know: they make sense of it in the light of their lives, their experiences, and the experiences of other people that they know.

> Our policy (is to) say nothing about cooking meals and normal standards of hygiene where some of the other hospitals say they shouldn’t cook meals or they’ve got to wear gloves and even that could cause somebody else anxiety. “I heard from somebody down the road and they had to do this, why haven’t I got to do this?” The restrictions have changed over the years. Their mother may have had it ten years ago and they had no restrictions and why have I got restrictions?

(Group 1: Nuclear medicine staff)

The difficulties of giving clear unambiguous radiation protection information were recognised. The Nuclear Medicine staff group recognised that information about levels of radiation were difficult to translate into measured practical advice. It was seen as important that such advice should be clear and concrete and link with the realities of people’s lives.

> The question that I usually get is, well, what will happen? If there was something tangible happening then they would accept it much more easily. If they said, well, your husband’s hair will fall out, then they would be quite happy to go and sleep in a separate bed. If you say something may not happen, it’s a possibility and that’s what they find difficult.

IV Would you agree with that?

F2 I would.

IV So you’re saying that’s a difficult thing to communicate when it is invisible and you don’t know if it’s going to happen or will there be a neutral effect or not?

F2 It seems as if they need to have a definite answer. You could say don’t have long contact with your child. That doesn’t mean anything to them really. You have to be more specific and say close contact means having a child on your lap for half an hour so then they understand that so they can relate to that rather than vague descriptions.

F4 We do give that because of phone calls with people saying should I keep away from my child for a week, what do I do? Should I get a babysitter? We say close contact means half and hour on your lap and it gives them a bit more perspective

(Group 1: Nuclear medicine staff)

Staff in the group noted that the sorts of questions that were addressed to them bore a direct relationship to the resumption of their lives after treatment. They too felt that patients understood best when information linked with their lives and was clear and unambiguous.
They just want to get on with the rest of their lives, really. The information is very clear. It says can you be in the same bed as your partner? Yes/No. All these things. It’s quite specific and clear and the patients, they understand that. They’ve spent five days in a room knowing that there’s precautions with regards to time that people can stay with them. They can transfer that on through to home then. They do understand.

(Group 2: Health Staff – Therapeutic - group)

Participants in the Nuclear medicine staff group felt that in the light of the wide variations in advice that patients could come across that it would be very helpful to have an accredited source of information, possibly on the Department of Health website, that those who wanted more information could seek out. One participant drew on her own experiences to illustrate the value of this.

F2 I think it’s overkill and a lot of people think it’s overkill as well. People just don’t want to read five pages. They just pick little bits out but I think you really have to have a good website because I personally needed some information that had nothing to do with nuclear medicine, it’s was to do with some very serious surgery, and I went onto the internet and some of the things they were telling me were so upsetting, it wasn’t for myself; it was for my sister, so I went and found the perfect website from a consultant who said the website for this is this, it’s a wonderful website. It told me exactly, because you can pick up all sorts of things from the web. I think something like you were saying about the Department of Health guidelines would be really good.

F3 I think it would be excellent.
F1 Yes, an excellent idea.
F2 We could put it at the bottom of our letters, couldn’t we?

(Group 1: Nuclear medicine staff)

The value of tailoring information towards different levels of patient interest and concern was also recognised. There is a need for coherence alongside a recognition that if the patient seeks advice elsewhere this may well be different.

The following quote reflects the dilemma about what and how much information to provide – especially in relation to written information.

I think it’s because we’re very cautious about what we put in written information on patients’ information leaflets. Obviously you’re dealing with a whole variety of people and some people don’t want to know anything, some people want to know everything so you have to have a balance there. That’s what causes some patients going on the internet and trying to find out information and other patients don’t want to know anything.

(Group 1: Nuclear medicine staff)

**Communication of radiation protection information to patients by non-specialist staff**

Many of the non-specialist staff in the focus groups said that they knew almost nothing about radiation and what patients would be told about radiation protection. Of course, this did not necessarily indicate that the information had not been provided.

Nuclear medicine staff believed that patients could inadvertently be given misleading information by other staff. This had sometimes confused or worried patients.

Participants in Group 1 provided examples of non-specialist staff passing on information where this had led to increased patient concern.
The only time we’ve had problems with people being absolutely frightened out of their life with clerical staff, it’s...

Yes, absolutely. Or the volunteers, they get asked a question, you want to hear what they’re saying, that’s when you get the problems because they’ve only picked up snippets and things. They do talk; everyone talks and they just try to be polite and answer and it’s not quite...

Even with the diagnostics, I feel that some of the nurses don’t know what they are saying on the wards. You get examples of patients coming down here and they are absolutely really scared about what’s going to happen from what’s been told to them on the ward so you’ve got to look at a way that we can actually get that information to the wards as well even if it’s just a very simple solution.

So are you saying sometimes patients are given information by nursing staff that is inappropriate?

Inappropriate because, for example, you have a lady who comes down and she’s got a catheter in, why did they catheterise me? Well, I’m not quite sure why they catheterised me but I was told that if I weed out after I’d had my scan, I was going to burn myself, my skin would all be burned. All these situations. These are inappropriate. I went back to the ward and explained that this doesn’t really go on, she didn’t really need to be catheterised, etc., etc. That nurse, felt at the time, it was what her knowledge was.

Staff generally recognised that if they needed help in advising a patient, the nuclear medicine staff were best suited to do this and were willing to be called on.

I am not an expert in radioactive treatment for patients. I do have a knowledge base but I’m a nurse. I have a broad knowledge of oncology of various types but sometimes, for the questions, we do get the physics department. If they want to know exactly how this treatment works within them, I will get someone down and that’s not a problem. They’re the experts.

Other staff were clear that sometimes patients asked questions that they did not feel able to answer and knew of nowhere on the ward where they could obtain information about nuclear medicine procedures that patients might undergo. One nurse recounted:

Well, they do go and have their VQ scans and then they come back but we don’t know what is involved here, what they actually had done. We don’t actually know what is going on during that scan. Nobody really explained to us. We don’t know the whole procedure and it’s quite awkward sometimes when patients ask us. We’re not actually sure.

Non-nursing staff too were asked by patients about which procedures they were being taken to have. The following quote is from a hospital porter.

Also, the patients are not informed. You’re taking the patient and you need to take them over to nuclear medicine. First question, nuclear. The next thing, the health. What happened is that I had to explain to the patient first this is a kind of test that you’re going to have, this is the kind of things that you’re actually going to go through in that test and by the time that I go to get the patient, he should be well aware of what’s going to happen to him or her. But that doesn’t happen because they ask me what are you taking me for, what are they going to do about me, what is that.
In this instance, the porter clearly gave the patient some information based on understandings of hospital procedures. In the quote above he tended to assume that because the patient had asked him, this meant that they had not been told anything. The next speaker suggested that one problem was that different names are used for the same procedure. This is important, again it relates to the importance of the information being given, mapping on to existing patient understandings. Future information provision should take account of this.

F1 They do explain to the patients exactly what they’re going to do, how they’re going to do it and sometimes when you come and pick them up you say nuclear medicine. They don’t know it under that name. They know you’re going to have a scan. That’s all what they know. They’ve been explained what they’re going to do to them and they wonder, well, why do I have to go there when the doctor said that, you know if there is two, three different names for perhaps one department procedure and I think that’s why patients get a bit confused.

F4 I think the doctors may well explain it as an isotope bone scan or a bone scan and they won’t mention nuclear medicine.

F1 And then a porter comes along and says I’m taking you to nuclear medicine department.

(Group 3: Health Staff – Diagnostic - group)

Importantly though, the focus groups also indicated possible drawbacks of verbal radiation protection communication simply being the provenance of doctors. The following quote draws attention to the connotations that the word ‘nuclear’ can often have. Importantly however, this leads on to a consideration of how patients can be reticent about asking doctors questions and how, paradoxically, they are likely to be much more forthcoming about concerns with people to whom they can relate more easily but who may be less ‘expert’.

F4 And I think nuclear is something that frightens people.

F2 It is.

F4 You mention nuclear medicine and it’s the nuclear. Radioisotopes doesn’t invoke the same anxiety and I think that’s the trouble. We have to be aware that patients’ perceptions of words may be completely different to ours.

M1 There’s different terminology.

F4 Yes. It’s different terminology and I think you’re right. The other thing is that I think whereas the doctors may explain, as far as we’re concerned, the procedure to the patient fully, you’re accessible to them. You’re a friend. You’re an ally. We’re a doctor. They don’t ask us questions. You’ll say everything’s fine. Do you have any questions? No. Then they’ll turn around to the nurse the minute we’re gone and say now what did they mean?

(Group 3: Health Staff – Diagnostic - group)

Another of the groups contained some interesting reflections about how the people that patients often see as experts, that is doctors, also have only partial understandings of radiation issues

F4 As a radiologist I have seen many patients come down who are either unsuitable for the test or unable to co-operate with the test that we’ve been asked to perform and that is partly because the doctors are not aware what it involves because imaging, the actual process, doesn’t form much of the doctors’ training. ... So, there are things that make patients unsuitable for various tests and the doctors may not be aware of those things because they may not have ever seen the test done. ...It’s rather depressing.

IV What do you mean, how much they know?
Yes, of the radiation dose that they’re inflicting on their patients. How many chest x-rays is a CT? It’s 200 to 400 chest x-rays and yet they say, oh, I’ll just have a CT chest instead of a chest x-ray. … It isn’t just the housemen that don’t know that because a lot of these technologies have come in and some of the senior consultants have been in post and so they haven’t received any training.

Along similar lines, the GP participating in Group 4 said that he may know which procedures his patients had undergone but not what the practical implications of these tests are. Other staff in this group explained how to some extent they relied upon patients themselves to say what treatment they had had. Participants suggested that this was problematic insofar as patients would generally expect health professionals to know this information. In addition it was felt that by the time the patient was back home to some extent they had regained control over their illness and were less reliant on their relationship with health professionals. This too may lead to a more restricted flow of information from patient to health professional.

This provides an interesting example of the blurred boundaries between medical experts and patient expertise. Those that patients might consider as most expert (i.e. doctors) not necessarily knowing the exposure implications of procedures that they prescribe; experts working from their non-expert/lay understandings of radiation risks; patients being relied on by health professionals outside the hospital to enhance expert knowledge by sharing information about procedures that they have undergone.

**Communication of radiation protection issues to staff**

From the point of view of participants in the nuclear medicine staff group, the awareness of other staff of radiation protection issues was often patchy.

> We do staff training on the ward because we have a specific group on the ward where patients go so we supposedly train staff but the staff there are so paranoid they won’t go anywhere near or are so blasé that they’ll walk past any notices that are on the outside; that’s a sweeping generalisation, a lot of them comply nicely and particularly when they have training, but we do get two extremes of staff. We’ve tried all different sorts of signs but they are so used to seeing signs on doors, which they are then allowed to go through because they’re staff.

**IV So what does it say?**

> It says controlled area, do not enter, must wear gloves and over shoes, and they just walk straight in or they will not go within 100 miles of the patient.

(Group 1: Nuclear medicine staff)

This sort of problem was seen to be particularly acute with bank staff (‘We had one bank nurse who actually climbed over the lead barrier to go into a room having been told not to go and do anything there’). Participants in the nuclear medicine group believed that some staff training in these issues did take place but the effectiveness of this could be undermined both by high staff turnover rates and language problems. However, it was generally believed that appropriate training was the key to improved practice in this area.

Nuclear medicine group participants were unsure what information was available and accessible to nursing and other staff across their hospitals.

> I know from a previous hospital I worked at, they had a leaflet, a poster in each ward, and the department sent up a protocol for each test of what. … there was a protocol that they had in their book of their patients and I’m not sure whether that’s in place here.

(Group 1: Nuclear medicine staff)
Clearly radiation protection did form part of training procedures for new staff.

When new staff start the designated radiation protection person for the ward, there’s two on our ward, one of them will go through the guidelines with the member of staff and the precautions to take and order their badge and just go through all the procedures – the foodstuffs, the scanning equipment that has been taken out of the room, all those things – and then twice a year there’s a full study day held. It’s for trained staff and for healthcare assistants. It doesn’t cover domestics but ours is a different hospital…. the one day study day covers different treatments, different precautions, what to do in an emergency with different scenarios. Physics have an input in that on the different treatments.

(Group 2: Health Staff – Therapeutic - group)

Domestic staff said that they had no information regarding any radiation protection issues. The excerpt below suggests that lack of clear information was producing more concern that radiation protection issues themselves.

F4 Dave, who’s up there now, he has only been told by word of mouth. It would be a good thing for us to have something in black and white because obviously when he is sick or goes on holiday we would put other people up there and it would be beneficial to our department, I think.

IV Do you mean in terms of understanding both what the rules are and the reasons for those rules?

F4 Yes. Exactly.

IV What do you understand are the reasons at the present time? I know you’ve not been told but what do you presume is the reason you can’t go in those rooms?

F4 Because they are receiving treatment for radiation. That’s about it.

IV And that that would be dangerous to you?

F4 Well, it could be. I think they issue out these little orange (badges) but some people have said to us, oh, it’s not necessary and other people have said you should have. Some people want to wear them, some don’t, some say do we have to? During the course of the years some people have said, well, why haven’t I got one of those and then we go along and ask and some say, well, it’s not actually necessary because they’re barely in there or what have you.

IV I see.

F4 And others say, well, if you feel like you would like to have one, then you may. So, it’s something I think we would like in black and white.

(Group 2: Health Staff – Therapeutic - group)

Portering staff also reported not having any information about radiation protection issues. They felt that the inclusion of some written information in their induction package would be an effective way of understanding radiation protection information better.

I think for health and safety and just for a bit of knowledge it would be useful because everyone’s trying to be politically correct nowadays. So, I think we should have some information on whatever risk there is. You should at least know.

(Group 3: Health Staff – Diagnostic - group)

So, it’s mostly ignorance than anything else here because I don’t know how much protection we need with one of us handling it. You see, if we transfer patients, yes. We take patients away. Well, we don’t know the amount of exposure they’ve had. Nobody will actually say, look, in this particular area there should be this amount of exposure and things could happen later on in life. I’ve never heard anything.

(Group 3: Health Staff – Diagnostic - group)
Staff outside the hospital that are potentially in contact with nuclear medicine patients said that they had never been given any information about radiation protection issues – indeed that was one of the reasons that they were interested in participating in the focus group. It is clear in the extract below that, for these staff, patients are an important source of information about the procedures that they have undergone and the possible implications of this.

F4 A lot of our referrals will come in via specialist nurses from the hospital, but as far as information if concerned, it’s very much asking the patient what they’ve been told, rather than information being directly to us.

F2 We do end up questioning the patients, about the treatment

F5 They’re the main source of information, yeah.

IV And do they ever say anything about, this is possibly your limit contact? Or is that not something you think they ever say?

F5 No.

[Consensus].

F5 I think some people are aware of, or worried about side affects, and sometimes we might have contact with the patients perhaps, or the carers, before, and then generally it’s after the treatment that we come into contact with them. But I have had a few, not many, that would be worried about not knowing, not having the information. More so beforehand. And are concerned about others around them.

(Group 4: Health care workers outside the hospital)

Ambulance workers also felt – in part on the basis of the group discussion – that more information was needed and that the exposure of ambulance staff may not be insignificant especially in a double-crewed ambulance where staff could be sitting in close proximity to a patient for some time – almost always for more than 15 minutes.

It’s probably too late, but it’s a good time to bring us up to speed, on the implications. Patients can be in the vehicle for up to an hour. It’s not only our staff, potentially at risk, but our other patients. Because we don’t have one patient, one vehicle. So there are implications that we do need to do a bit of research on.

(Group 4: Health care workers outside the hospital)

Nursing staff in Group Two were not concerned around radiation protection issues and were satisfied with the procedures in place for ensuring awareness of their exposure levels

F3 No. It doesn’t appear to be an issue. I think they’re very conscientious, the nursing staff. If you’re expecting or whatever, then obviously they take special care but, no, it’s not a real big issues on the ward. They know that the results come through of their exposure. So, nobody’s ever exceeding the limits.

F1 Everything’s fine until you get your sick patients and then, obviously, you’re in there for a while and you just need to be aware, in instances like that, that you’re actually wearing a counter that’s going to let you know if you have exposed as you have reached your limit for the day. Then that’s handed over to someone else.

(Group 2: Health Staff – Therapeutic - group)

This lack of concern was in the context of knowing what the possible implications of radiation exposure are.

IV What are you told about what could happen if those levels are exceeded? What’s your understanding of what the implications are?
Well, I think the implications with some of our patients would be the children that have had treatment for cancers and are now adults. People that have had radiation as a child and they come back presented with another primary, say, 10, 15 years later. It’s not just coincidence. It’s a fact that overexposure to radiation, as we’ve seen with Chernobyl and all the rest of it, can lead to other cancers but we’re talking massive doses. We’re talking huge doses that are treatment doses that aren’t ones that we’re going to come across as staff. I don’t think anybody has ever reached their limit for the year or whatever. Even in the physics department people who are working with these things all the time don’t even come near to it. It’s an awareness, yes, but people forget about it.

(Group 2: Health Staff – Therapeutic - group)

It was also clear that staff thought that the fact that they were working in this area was an indication that they were generally unconcerned.

It’s self-selection, isn’t it, in a way? The people who are overly concerned wouldn’t be working in radiotherapy.

(Group 2: Health Staff – Therapeutic - group)

Many participants believed that an Intranet could be an effective way of making available relevant information about (e.g.) the precautions and preparations necessary around scans. This would also have the advantage of being able to be easily and regularly updated. However this group also felt that this was a resource that was not routinely used in many hospitals and that access to it and awareness of it may be limited.

One particular group of health professionals to whom radiation protection may be an issue is the people who work, in various capacities, with corpses. Group 5 explored this issue with them. None of this group had ever received any information about this and most of them did not know that there was a possible issue in this area. Two issues emerged – firstly how these professionals would know if a corpse was radioactive and secondly, what procedures were in place should they need to deal with a radioactive corpse. Both of these questions were discussed in a context of some uncertainty; participants found it hard to believe that they had not come across these issues in many years working in their respective industries and were unsure whether this was evidence that this issue was not relevant to them or rather that it was something that did happen sometimes and had taken place without them being aware of it.

Across the [ ] funeral company there’s hundreds of outfits and I spoke to my manager about it and, no, we’ve got nothing in place, not come across it, it’s new to us. So somewhere at some point we must have put one in the ground.

Yes. Must have done. And I’m an embalmer. So, I must have come across it.

(Group 5: professionals working with corpses)

It was also felt that disposing of body waste through incineration or drainage as well as the ashes were also issues for which there must be implications.

1. How you would know if a corpse was radioactive?
In this group there was considerable discussion of the way in which particular issues relating to a corpse could most effectively be flagged up. It was felt that the crematorium form was one possibility for passing on information (such as whether the body contained a pace maker) but this form was not applicable where the corpse was being buried. Also, for corpses being cremated, there was still a gap between the person dying and those papers being issued and during this time many other people came into contact with the body.
2. What you would do if you knew that it was radioactive?
The mortuary worker drew attention to a particular incident where the mortuary was alerted to the possibility of a radioactive patient dying. It was suggested to him that they would ‘have to cordon off half the mortuary’ and this was seen as totally impractical. The mortuary worker said that they just crossed their fingers that the person would not die and they didn’t on that occasion.

One of the funeral directors explained how this was a new issue for them too and that they were not equipped to deal with radioactive corpses

And certainly within the group there’s no procedures in place either. It’s not anything that’s anticipated and so the procedures aren’t in place and if we did have a body come through, then as soon as it’s identified there’s no set procedures. So, we’ll be phoning up frantically to ask what are we going to do.

(Group 5: professionals working with corpses)

It’s all very well knowing that it’s radioactive but it’s what they’ll do about it. As a company we just haven’t got the facilities to isolate the body. It’s the same as the morgue. You just can’t say, right, use a corner of the room because you’re talking specialist rooms.

(Group 5: professionals working with corpses)

Participants in the group generally considered that if the body was in a closed box that the radioactivity would not be a problem. They were interested and surprised by the explanation of the physicist that this was not the case and moreover that there were particular levels of radioactivity that had to be reached before a corpse could be buried or cremated. The group participants were also unaware that the permissible levels of radiation for burial were much higher than those for cremation.

The representative from the Federation of British Cremation Authorities was concerned that in the past he had given the wrong information to one of the members and was aware that if and when this occurred in the future he had no idea what the correct guidance was. The pathologist was similarly unsure what the position was in relation to exposure to either corpses or organs. When consultants had been asked they had simply said that they would it expect there not to a problem at that stage.

The physicist in the group (and one of the research team) explained that a risk assessment was carried out on any patient likely to die and advice would be issued to the relevant departments on the basis of this. Clearly the practical implications of this were problematic; an example was given of a radioactive corpse being taken from a fridge even though a note was left that this should not be done. It was potentially even more problematic however, if a person was radioactive and died outside the hospital environment.

In order to try and explore in more detail the possibilities for communicating radiation protection information the participants talked about whether there were any ways in which they deal with infectious diseases might serve as a model. It was clear that in this instance it is a rare occurrence but they do have guidelines to deal with it.

Well, it depends on what the infectious disease is but we have guidelines from our society of not embalming or allowing embalming, restrictive viewing, , no viewing in extreme cases. It’s very rare but there are extreme cases.

(Group 5: professionals working with corpses)

Funeral directors are informed via the coroner of the presence of infectious disease. It seemed that within the hospital, issues of patient confidentiality still clouded what mortuary
staff could be told about the reason why a body might be in sealed bag. Sometimes it could be the accompanying hospital notes that would inform mortuary staff as to the disease status, sometimes staff do not know until the body is processed. It was suggested that for both infectious disease and radiation risk, the corpse could be classified as, say A, B or C. The key to this would be that particular actions would then follow from this classification of the corpse. Of course the problem of reliable communication remains.

A clear concern was generated for all the participants in Group 5 by the discrepancy between their lack of information and procedures in this area and the fact that it is clearly, to some degree, an issue for the HSE. The need for early advice was stressed as was the potentially important role of using national associations to achieve effective dissemination of information.

**Signalling radiation protection issues**

At one of the hospitals represented, a ‘yellow card/wrist band’ system was in place. The presence of a yellow card or yellow wrist band was generally seen to be an effective way of signalling patient status around radiation protection.

> Now they give the patient a yellow card which tells them what they’ve had and what they should be careful with for 24 hours. If they’re inpatients or patients who are remaining in the hospital for a period, they’re also given a plain yellow band.

(Group 1: Nuclear medicine staff)

The system had emerged as a way of making staff aware of the particular issues pertaining to waste disposal and contact with other staff, patients and departments. It was seen that there was less necessity for such a signal where there was a lower proportion of inpatients.

> Ours came about not so much for informing staff, it was an issue of waste disposal. Waste was put into the wrong stream because somebody didn’t know that the patient was red lighted. It came about that way. When we sort of looked into it, we found that a lot of patients were being booked in nursing, particularly if they were having a bone scan, where you had this nice two to three hour gap between injections and scanning so they’d then be sent off to other departments in the hospital for other tests; for stem cells to be taken, and so they were exposing people all over the place who were completely unaware of it as well as possibly samples being sent to labs that were not licensed to have radio active material.

(Group 1: Nuclear medicine staff)

In some hospitals issues around patient confidentiality had limited the way in which wrist bands might be used (e.g. band on its own used to signal radiation exposure rather than information being written on the band). Generally wearing yellow bands was not seen by staff in the focus groups as compromising confidentiality. No one knew of any instances where this had been an issue for patients.

The yellow card was discussed in some detail by the group of ‘outside the hospital staff’. None of them had ever seen a yellow card or heard of this system.

> M2 Is the message on that yellow card to the professionals?
> CG Well it says who we are, that’s what the patient’s given, and it’s got all those restrictions written in, but nothing more than that.
> IV So is it that none of you have ever seen such a yellow card?
> [All] No.
> IV Have you ever heard there is such a thing?
> [All] No.
On further discussion it seemed that for some this signalled a greater level of risk, thus a greater necessity for changed behaviour, than nuclear medicine experts would suggest is necessary. It was also clear that people felt that for patients who are very unwell, it was an unrealistic and unnecessary burden to expect them to produce a yellow card or for health care workers to notice the wrist band.

A key issue for the GP in the group was exactly what the level of risk was from patients that had been exposed to radiation. He had always presumed it to be very small. However, he partly inferred this from not having any recent or up to date information. He felt that a routine information sheet or an annual update about the latest procedures and the recommended radiation protection recommendations would be read by GPs or referred to. At the present time staff outside the hospital may be aware of some information about the patient from the details of their referral, however no links are made between this and possible radiation protection issues.

Staff said that they would expect any information about radiation protection issues to be communicated at the point of referral but were unsure in reality if this would happen. They suggested that a sticker could be put on the referral form to flag up the presence of radiation protection issues. One way of communicating more generic issues would be to give information that would be part of the ‘Policy Folder’.

Although staff in the group were mildly anxious about the implications of their lack of knowledge or information in this area, they were also aware that they may never have treated a patient about whom there were radiation protection issues. The point was however, that they would not know the implications of providing personal care to such a patient, or, in advance of this, they did not know what the generic issues were. Staff identified that both issues need to be dealt with

- To improve general levels of information about nuclear medicine procedures and the accompanying radiation protection issues. Staff outside the hospital suggested that

- To effectively signal the presence radiation protection issues in respect of particular patients. An effective signal is one where the required action is proportionate to the risk. Staff were wary of this concern for information leading to too much information. They did not want to be in the position of asking hundreds of extra questions to pick up one or two cases in a year.

There was also a discussion of the yellow card/wrist band system in Group 5: professionals working with corpses. Again, no members of the group had heard of this system which was in place in the area that they were working in, and none of the group had ever seen a yellow card. It was felt in the group that if a patient who was radioactive died outside the hospital that there was very little chance that the yellow card would constitute an immediate and effective signal that the corpse was radioactive.

5.5. PRACTICAL IMPLICATIONS

- Structure information provision so that those who want minimal information are not overwhelmed; provide further information for those that want to know more.

- Provide credible alternative sources of information on the internet (possibly on Department of Health website or a credible independent site such as the British Nuclear Medicine Society). Provide links to site on information leaflets and on Trust websites to enable that those who are interested to obtain further information.
• Consider developing a Frequently Asked Questions section where ‘real life’ information can also be given.

• Acknowledge in leaflets areas where patients may well find conflicting information (for example in making links between activity levels and practical advice); acknowledge that advice changes over time as new treatments start; over time etc. Explain that this is the reason that advice may vary slightly between hospitals.

• Further consultation is needed with crematoria/funeral directors in order to understand how to communicate radiation risk appropriately and to consider the most effective ways of disseminating information.

• Develop protocols for communicating radiation protection information verbally.

• Increase the role of the intranet in providing staff with radiation protection information.

5.6. REFERENCES


6. ANNEX 5: WORKSHOPS TO DISSEMINATE RESEARCH FINDINGS AND OBTAIN FEEDBACK

6.1. INTRODUCTION

Two workshops were arranged with the aim of disseminating the information contained within this report and obtaining feedback about the contents of the report and the recommendations contained therein. The draft report was sent to all participants prior to the workshop. Presentations of the key components of the research were given at the start of the day followed by a structured discussion. Participants in Workshop 1 were professionals with expertise in Nuclear Medicine and Radiation Protection. Participants in Workshop 2 were patient representatives or experts in the provision of patient information.

Although the research brief was primarily aimed at information provided with the aim of protecting other people from a radioactive patient, the research has highlighted that in order for patients to understand and adhere to restrictions they first need to understand the risk to themselves and that it was not completely possible to treat each area in isolation. At the outset, it was planned that the structured discussion would be centred around the protection of others from a radioactive patient, but discussions about explanation of risk to patients would not be excluded. The findings of the workshops are detailed below.

6.2. WORKSHOP 1 PROFESSIONALS WITH EXPERTISE IN NUCLEAR MEDICINE AND RADIATION PROTECTION

Participants attended with expertise in this field. Members of the following groups were present:

- Medical and Dental Guidance Notes Working Party
- Radiation Protection Special Interest Group
- British Institute of Radiology Nuclear Medicine
- British Nuclear Medicine Society
- Health Protection Agency
- Nuclear Medicine Special Interest Group

In the light of the research findings participants highlighted recommendations within the following areas.

1) Importance of consensual information nationally
2) Dose constraints
3) Advice for therapeutic procedures
4) Advice for diagnostic procedures
5) Leaflet design
6) Travel across borders
7) Educating other health care professionals
8) Corpses
9) Further research

6.2.1. Importance of consensual information nationally

The survey (see Annex 1) and leaflets (see Annex 2) showed a wide range of approaches to the provision of instructions for patients. The workshop participants agreed with the recommendations in the report that a unified approach to patient information provision is vital and that clear, co-ordinated advice endorsed by the Health and Safety Executive (HSE) would be one important way of facilitating this. Any guidance should emphasise the importance of a unified approach to restrictions and state that it is not necessary to impose any more stringent...
restrictions and that to do so might actually be detrimental to patient care/wellbeing (although further research in this field is required).

As well as the HSE providing clear guidance about what each leaflet should contain, it would be beneficial to create a set of leaflets which departments could download and use. These leaflets could then be made available in other formats (other languages, Braille, large print). It was recognised that this exercise had been performed previously by the British Nuclear Medicine Society (BNMS) but that an update was appropriate.

Written information is usually backed up with verbal information but in order to maintain consistency a protocol for the provision of verbal information or alternatively a checklist detailing the important things to cover would be useful.

6.2.2. Dose Constraints
The group were not aware of any new evidence which has been published which would invalidate the recommendations and dose constraints used in the Medical and Dental Guidance Notes (MDGN) (IPEM, 2002) and felt that this guidance should be used. The move towards a greater emphasis on dose constraints (draft proposals for replacement of ICRP 60) (ICRP, 2005) was discussed but it was felt that the arguments used to determine the constraints used in the MDGN still held true and that levels were unlikely to change. In order to achieve more unity in practice across the UK it is important for the Health and Safety Executive (HSE) to endorse the dose constraints used and the guidance issued prior to the generation of any statements which might be used in information leaflets.

6.2.3. Advice following diagnostic procedures
The group felt that the advice provided in the MDGN should remain unchanged. The main concern here was that many departments go beyond this advice and that in the interests of providing unified information across the country they should be dissuaded from doing so.

Some concern was raised about the number of departments who did not provide written information to restrict breast-feeding following diagnostic studies. The survey did not explore whether these departments did indeed restrict breast-feeding and it might be that verbal advice is provided. However, it was felt that this was an important issue and, again, that national guidelines in this area should be followed (ARSAC notes for guidance) (ARSAC, 1998).

Contamination hazards are considered low for diagnostic procedures and again no restrictions are advised in the MDGN. If the risk from the microbiological hazard is greater than that from the radiation and normal hygienic precautions would protect staff from this risk, then effectively there is no radiation risk and no additional precautions are required. Again it was felt that in order to encourage consistency across departments, the HSE would need to officially support this position.

6.2.4. Advice following therapeutic procedures
There was general agreement amongst participants that the table provided in the MDGN detailing restrictions necessary following radiiodine therapy for thyrotoxicosis was overly complex. This chart currently divides the restrictions into five activity levels (with advice to interpolate between levels as required). Five different types of behaviour restriction are then given for each activity level. The group felt that this table could be simplified. This would have benefits both for the patients and the Healthcare Professionals (HCP) who need to explain the restrictions.

The consensus was that splitting children into different age groups was unhelpful. Contact patterns have been assumed alongside dose rate data in order to predict doses and consequent restrictions. In practice contact patterns are unknown and unpredictable. Peoples own
estimates of time and distance may not be accurate. Assumptions that most people have similar contact patterns to our own may be inaccurate and there are also cultural differences and influences which we may not appreciate.

A review of this section of the MDGN was felt appropriate.

**6.2.5. Leaflet design**

The group recognised that written information did not often provide patients or staff with reasons for any recommended restrictions. In order to keep leaflets short, explanations are often removed. It was considered important that the emphasis should be changed to give precise instructions as well as the rationale for the advice. An alternative format would be to keep the information sheets simple but offer a further source of information for ‘frequently asked questions’ (FAQ).

The group recommended that a working party should be set up to design a set of leaflets or alternatively a set of templates which individual departments could customise. It would be beneficial for these to be endorsed by the HSE and be placed on a relevant website. It was recognised that it would be important to do this in conjunction with other groups involved in nuclear medicine such as the British Nuclear Medicine Society (BNMS) and the Royal College of Radiologists (RCR). It was also recognised that there are difficult issues to overcome in terms of:

- How we explain radiation risks
- Explaining risk where there is no risk-benefit equation
- Calculating and explaining the absolute risk.
- Explaining the uncertainty of the risk calculation
- What are the risks i.e. what could happen if the patient ignores the advice?
- The use of relative comparators such as background radiation.

**6.2.6. Travel across borders**

The research team raised the paradox of patients setting off alarms at international borders after the restriction period had ceased at which time they had been informed that they posed a minimal risk to others. After discussion, it was felt that the majority of patients would be comfortable with this if the reasons were explained clearly.

The main issue here was that the length of time when patients might trigger alarms could not be assessed as the detector sensitivities were unknown. The detection of diagnostic patients as well as therapy patients was highlighted, as this has been previously not been appreciated by many departments. What documentation is acceptable? The consensus was that further work on an agreed format along with guidance for nuclear medicine departments is desirable.
6.2.7. Educating other Healthcare Professionals (HCP)
Information given to other HCP (e.g., referrers or ward staff), who may need to explain nuclear medicine issues to patients, should be consistent nationally and also consistent with that given to the patient by nuclear medicine staff. Again, the availability of information on websites supplemented with a FAQ approach might be helpful.
It would be useful for HCP requesting a procedure to provide information to a patient with the rider that they will see people with more expertise further down the line so that if the information differs slightly then the patient should not worry and follow the instructions provided by the nuclear medicine experts. This would remove the conflict of patients receiving inconsistent information from different groups which is likely to have a detrimental effect on adherence to advice regarding restrictions and may unnecessarily intensify patient concerns.
It would also be valuable for referring HCP to ask the patients to read the information that is provided to them by the nuclear medicine professionals.

6.2.8. Corpses
Although this seems to be a relatively rare problem, it was felt that a more detailed set of generic procedures would be useful in order to provide a national resource which all groups involved with handling a radioactive corpse can access. Although some information and advice is provided in the MDGN there has been very little guidance published and this needs to be reviewed in light of new nuclear medicine therapies which are becoming available. This is particularly important as different cultures have different approaches to dealing with a corpse and great sensitivity is needed at this time. Again, HSE endorsement of any resulting recommendations is desirable.

6.2.9. Further Research
Further research into methods of describing radiation risk, explaining restrictions and the rationale for these is necessary in order to inform the text used in patient information leaflets and to maximise adherence. It is likely that experimental research designs will be necessary to address these questions effectively.

The research indicated that patients feel comfortable following the restrictions especially if they are explained well. However, we only interviewed patients who had chosen radioiodine therapy as a treatment choice. Is there any data to suggest that some patients are not taking up I-131 treatment due to concerns about restrictions? Further research in this area is vital.

6.3. Workshop 2 Patient Representatives or Experts in the Provision of Patient Information
Participants attended with expertise in this field. Patient representatives from the following groups were present:
- Royal College of Radiologists
- Royal College of Physicians
- Commission for Patient and Public Involvement in Health
- North Wales Patient Liaison Group

In the light of the research findings, participants highlighted recommendations within the following areas.

1) Provision of information other than in written English
2) Formal approach to designing leaflets
3) Reinventing the wheel
4) Consensus
5) Leaflet design
6.3.1. Provision of information other than in written English

The participants in this workshop felt that it was extremely important for the information provided to be made available to all patients. Communication with minority groups is frequently a resource and logistics problem rather than a lack of will. The use of generic leaflets which could be made available in different formats (possibly via the internet) for HCP and patients would facilitate this. The importance of back-translation was emphasised.

6.3.2. Formal approach to designing leaflets

Many trusts have guidelines for staff writing patient information and systems of evaluation and kite-marking. Although these were felt to improve the quality of information the group did not feel that this always resulted in leaflets that patients could understand. A formal written approach to developing and evaluating written information was felt to be valuable.

6.3.3. ‘Reinventing the wheel’

The importance of collaboration with other groups when writing generic leaflets was emphasised to avoid ‘reinventing the wheel’.

6.3.4. Consensus

There was support for a consensus on what information should be given to patients.

6.3.5. Leaflet design

The workshop participants felt that difficult and complex ideas can be put in leaflets as long as they are explained clearly in plain English but that it was important that the leaflets should not be condescending. The group felt that patients are generally well informed, have a grasp of risk/benefit and don’t mind references to cancer or to links between radiation and cancer. However, the workshop was made up from people predominantly involved with provision of cancer information who had also had cancer themselves and it is important to recognise that this statement may not be true for other groups. As noted above, further research relating to the communication of the reasons for restrictions is needed.

It was recognised that different patients have different needs in terms of information provision but that it was important that information should be made to fit the needs of all. The group advised that the leaflets should be designed in such a way as to give key information which it is essential for the patient to read, followed by additional information which can be read by patients/relatives who want further information. This additional information might be in the form of FAQ or some sort of glossary of terms.

The group advised that ‘jargon busters’ or ‘acronym busters’ were useful tools which made patients feel that it is acceptable not to understand and to ask questions. The use of patients’ personal experiences and questions followed by the answers or comments from the relevant HCP was also suggested as a non-threatening way of providing information. The provision of a contact number for further information was also considered important.

Although the workshop participants recognised the advantages of information provision via the internet they felt it was important to recognise that this systematically disadvantages certain groups. Other non-written formats can also be used such as audio or video tapes and CDs. These would be useful for some situations but have cost implications.
6.3.6. Relatives
Participants in the workshop felt that the provision of a leaflet for relatives might have some advantages but a simple paragraph with example text that a patient might find useful in explaining their restrictions and risks to others would be a better option. Ideally, any referenced sources of further information should also include information for relatives.

6.3.7. Explaining risk
The workshop participants agreed that explaining risks to patients was very difficult and that these difficulties were exacerbated where there is no clear risk-benefit argument (as is the case for relatives of nuclear medicine patients).

They agreed with the use of absolute risks but were wary of the use of risk comparators such as other diagnostic tests or background radiation. They felt this information would be meaningless for the majority of patients. They agreed that further research in this area is important. One important area was to explain what is meant by risk and to if necessary to be clear that the risk we are talking about might relate to cancer.

They felt that patients can cope well with uncertainty in terms of the information provided (especially if the reasons are explained clearly) and suggested that HCP may overestimate the difficulties that patients have with this.

The group agreed with the research team that it was extremely important to explain the rationale behind the restrictions.

The groups also mentioned that it is very offensive to patients to be treated as though they are not capable of understanding and that this is considered a very paternalistic, old fashioned approach.

6.3.8. Identification of radioactive patients
Methods of identifying that a patient is radioactive were discussed. The use of wrist bands was not considered good practice as they would infringe a patient’s confidentiality and possibly stigmatise the patients. It was felt that better communication between staff groups and between primary care and secondary care would avoid the need to label patients. Improvements in handover procedures are required. It was recognised that as well as protecting the rights of the patient, there was also a need to protect staff and the public as well and that this was difficult. More creative methods of labelling a patient in ways which would be invisible to others such as markers that only show up under a certain light were also discussed.

6.3.9. Communication skills
Poor communication skills were highlighted as a major area of concern and many HCP who regularly deal with patients have little or no training in this area. Specific training in this area would be desirable.

6.4. CONCLUSIONS AND FURTHER RESEARCH
Participants in both workshops welcomed the results of this research programme and the implications for national practice that were raised. The extensive leaflet evaluation and the qualitative work exploring patient and HCP perceptions of radiation risk has identified the value of experimental work that compares the impact of different leaflet contents (e.g. use of risk comparators and the provision of rationales for contact restrictions). Future work that explores the perceptions of radiation risk and contact restrictions of those who refuse radiation treatment, rather opting for alternative, often surgical, treatments that carry a greater risk of negative health outcomes would be extremely useful.
6.5. REFERENCES


National survey of radiation protection information provided in order to minimise the hazard from nuclear medicine patients
If you have any queries regarding this research, please do not hesitate to contact us:

For Technical Queries, contact:          For Scientific Queries, contact:
Joe Pope                                 Claire Greaves,
Research Fellow                        Principal Physicist
Department of Psychology               Department of Medical Physics
University Of Surrey                   Royal Surrey County Hospital
Guildford, Surrey                      Guildford, Surrey
GU2 7XH                                 GU2 7XX
Tel: 01483 xxxxxx                       Tel: 01483 xxxxxx

Information for completion of survey

The purpose of this questionnaire is:

i) To determine what advice nuclear medicine departments provide to patients, carers, and others in order to minimise the hazard from radioactive patients following nuclear medicine procedures.

ii) To determine how information is disseminated

Throughout the questionnaire the term “restrictions” is used, this term is used for brevity and refers to any information given to people advising them of appropriate behaviour to minimise radiation exposure and contamination.

We are only asking for details of restrictions which apply following nuclear medicine procedures. This survey is not asking about restrictions placed on patients prior to any nuclear medicine procedures (e.g. fasting, avoiding caffeine, etc).

Please answer all of the following questions unless directed otherwise.

Some of your answers to tick box questions may differ slightly depending on what nuclear medicine procedure you are describing. In these instances we would ask you to think of the most common practice in your department. Please give details of more unusual practices in the 'others' boxes or in the general comments box on p.20.

Confidentiality
Details of your experiences in this area are important in order for us to draw up realistic and practical guidance. We ask for your contact details in order to facilitate follow-up telephone or e-mail queries. You can be assured that all information will be treated in the strictest confidence. Our findings will be anonymised prior to being passed on to the HSE/DH.
PART 1 – DIAGNOSTIC PROCEDURES

Your name: ______________________________________________
Your job title: _____________________________________________
Institution: _______________________________________________
Department: _______________________________________________
Your email address: ________________________________________
Your contact telephone number: ______________________________

If we need any further information can we contact you?

☐ Yes
☐ No – If No, please could you provide the name and contact details of another key contact in your department

Key Contact: _____________________________________________
_____________________________________________
_____________________________________________
_____________________________________________

1. Do you perform any diagnostic nuclear medicine procedures in your department?

☐ Yes – Please continue to next question
☐ No – Please go straight to Part 2 Therapeutic procedures p.11
2. Please indicate all of the diagnostic tests performed in your department
(Please tick all that apply).

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<th>Imaging – Vascular</th>
</tr>
</thead>
<tbody>
<tr>
<td>$^{99m}$Tc</td>
</tr>
<tr>
<td>$^{99m}$Tc</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Imaging – PET</th>
</tr>
</thead>
<tbody>
<tr>
<td>$^{18}$F</td>
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<tr>
<td>$^{18}$F</td>
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<tr>
<td>$^{18}$F</td>
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<td>$^{18}$F</td>
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<td>$^{18}$F</td>
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<tr>
<td>$^{18}$F</td>
</tr>
<tr>
<td>$^{18}$F</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Non imaging</th>
</tr>
</thead>
<tbody>
<tr>
<td>$^{75}$Se</td>
</tr>
<tr>
<td>$^{77}$Cr</td>
</tr>
<tr>
<td>$^{77}$Cr</td>
</tr>
<tr>
<td>$^{77}$Cr</td>
</tr>
<tr>
<td>$^{64}$Co</td>
</tr>
<tr>
<td>$^{123}$I</td>
</tr>
<tr>
<td>$^{99m}$Tc</td>
</tr>
<tr>
<td>$^{123}$I</td>
</tr>
<tr>
<td>$^{123}$I</td>
</tr>
<tr>
<td>$^{131}$I</td>
</tr>
<tr>
<td>$^{123}$I</td>
</tr>
<tr>
<td>$^{131}$I</td>
</tr>
<tr>
<td>$^{18}$Cr</td>
</tr>
<tr>
<td>$^{99m}$Tc</td>
</tr>
<tr>
<td>$^{99m}$Tc</td>
</tr>
</tbody>
</table>

103
A – Information for patients

A1. Are patients given written information about restricting contact with other adults or children following diagnostic procedures?

☐ Yes
☐ No

A2. Are patients given verbal information about restricting contact with other adults or children following diagnostic procedures?

☐ Yes
☐ No

A3. Are patients given written information about minimising contamination following diagnostic procedures?

☐ Yes
☐ No

A4. Are patients given verbal information about minimising contamination following diagnostic procedures?

☐ Yes
☐ No

A5. Do you have written protocols for nuclear medicine staff governing verbal information given to patients following diagnostic procedures?

☐ Yes
☐ No

If you have said no to ALL FIVE of the above questions, please go straight to PART B (Information for Staff/Carers) on page 9.

If you have said yes to any of the above questions please proceed to the next question.
A6. Please detail in the table below all the diagnostic procedures performed in your department where patients are advised of restrictions, and tick the appropriate boxes to indicate which restrictions are placed on patients.

For ease of completion please group any procedures where the same radiocnuclide is used and the restrictions are common e.g. 'all Tc-99m renal scans'.

<table>
<thead>
<tr>
<th>Name of Diagnostic Procedure</th>
<th>Type of restrictions placed on patient (Please tick boxes)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>RESTRICTIONS ON:</td>
</tr>
<tr>
<td></td>
<td>Contact with children and pregnant women</td>
</tr>
<tr>
<td></td>
<td>Written</td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

A7. In addition to the restrictions named above, do you provide details to patients of any other restrictions?

☐ Yes – please provide details in the table below
☐ No – please continue to next question

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Restrictions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

105
A8. How is information regarding restrictions given to the patient?  
*Please tick all that apply*
- [ ] Within appointment letter
- [ ] Patient information sheet/ leaflet
- [ ] Radionuclide instruction card (Yellow card)
- [ ] Verbally / spoken
- [ ] Posters
- [ ] Audio-visual
- [ ] Website (please provide URL) 
- [ ] CD Rom
- [ ] Other *(please specify)*

A9. When is the information regarding restrictions most commonly given to patients?  
*Please tick all that apply*
- [ ] At referral
- [ ] With appointment letter
- [ ] At pre-procedure assessment
- [ ] In the department, prior to the procedure
- [ ] On day of test post- administration
- [ ] Other *(please specify)*

A10. Who is the person most likely to provide the patient with *written* information regarding restrictions?  
*Please tick one box only*
- [ ] Admin / Clerical Staff
- [ ] ARSAC holder
- [ ] Nurse
- [ ] Physicist
- [ ] Referrer
- [ ] Technologist
- [ ] Other *(please specify)*

A11. Who is the person most likely to provide the patient with *verbal* information regarding restrictions?  
*Please tick one box only*
- [ ] Admin / Clerical Staff
- [ ] ARSAC holder
- [ ] Nurse
- [ ] Physicist
- [ ] Referrer
- [ ] Technologist
- [ ] Other *(please specify)*

A12. Is the information regarding restrictions available in languages other than English?  
- [ ] Yes
- [ ] No

**IF YES:**  
Which languages do you provide information in?  
Why did you choose these languages in particular?

**IF NO:**  
What is the main reason you don’t provide information in other languages?
A13. How do you communicate with patients who do not speak English?

Please tick all that apply

☐ Written information in the patient’s first language
☐ Hospital interpreter(s)
☐ Family member/friend
☐ Other (please give details)

A14. Is information regarding restrictions following diagnostic nuclear medicine procedures available in other formats for patients with disabilities?

☐ Yes
☐ No

A15. In communicating with patients with disabilities does your department use any of the following?

Please tick all that apply

☐ Braille
☐ Audio cassette
☐ Large print
☐ Sign language interpreter
☐ Others (please provide details)

A16. Do you provide any written information for patients planning to travel abroad following a nuclear medicine procedure for the purposes of showing to customs/police or other officials?

☐ Yes
☐ No

A17. Are you aware of any problems that patients from your department have had when travelling abroad (e.g. activating radiation alarms in airports, etc) following a diagnostic nuclear medicine procedure?

☐ Yes (please provide examples in box below)
☐ No
### B – Information for Staff/ Carers
(of patients who have undergone a diagnostic nuclear medicine procedure- information given to wards, care homes, sheltered housing, relatives acting as carers, etc.)

**B1. Is information regarding restrictions given to staff within hospitals?**
- [ ] Yes
- [x] No

**IF YES:**
Which ways are commonly used to convey information about restrictions to staff within the hospital? 
*(Please tick all that apply)*
- [ ] General information is available on the ward
- [ ] Verbal information is given to the named nurse
- [ ] Written information is given to the named nurse
- [ ] Verbal information is given directly to the ward clerk/nurses station
- [ ] Written information is given directly to the ward clerk/nurses station
- [ ] Left to discretion of porter/escort
- [ ] Information is attached to the front of patient notes
- [ ] Information is written inside patient notes
- [ ] Other (please provide details)

**IF NO:**
Please continue to question B3.

**B2. When is information given to staff within the hospital?**
*Please tick appropriate boxes*
- [ ] At least 24 hours in advance of procedure
- [ ] On day of procedure prior to administration
- [ ] On day of procedure immediately prior to departure from department

**B3. Is information regarding restrictions given to staff outside the hospital?**
- [ ] Yes
- [ ] No

**IF YES:**
Which ways are commonly used to convey information about restrictions to staff outside the hospital? 
*(Please tick all that apply)*
- [ ] Written information is provided in advance
- [ ] Written information is sent back with the patient
- [ ] Written information is sent back with the carer
- [ ] Verbal Information is given over the telephone
- [ ] Other (please provide details)

**IF NO:**
Please continue to question B5

**B4. When is information given to staff outside the hospital?**
*Please tick appropriate boxes*
- [ ] At least 24 hours in advance of procedure
- [ ] On day of procedure prior to administration
- [ ] On day of procedure immediately prior to departure from department
B5. To your knowledge, how often do the following events occur in your department?

*Please tick one box for each*

<table>
<thead>
<tr>
<th>Event</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Appropriate <strong>written</strong> information regarding restrictions not being provided to staff</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Appropriate <strong>verbal</strong> information regarding restrictions not being provided to staff</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Written information regarding restrictions not being received by staff groups to which it is sent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Staff performing other procedures not realising patient is radioactive (e.g. sonographers, social workers, carers etc)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) Pregnant staff unknowingly caring for patients</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) Patient doesn’t inform nuclear medicine staff about particular personal care needs (e.g. incontinence)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g) Other (please specify)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Ad-hoc instructions**

Have you ever had to write instructions for a particular radioactive patient, or person coming into contact with them, in circumstances not covered in this section on diagnostic procedures? Please give details below and, where possible, provide copies of instructions.

**Information Leaflets – Restrictions following diagnostic procedures**

It is important for us to collect as many examples of written information as possible in order to complete this project. **Please send us copies of the following information either in the Freepost envelope provided, or electronically (preferred) to joe.pope@surrey.ac.uk:**

**ALL information given to patients with the purposes of restricting exposure or contamination of others, including:**

- Information your department has in other languages
- Information for patients with disabilities
- Information for radioactive patients travelling abroad

**ALL information provided for staff/ carers who may come into contact with radioactive patients, for example:** information given to wards, care homes, sheltered housing, relatives etc

**ALL written protocols governing verbal information given to patients following diagnostic nuclear medicine procedures**
PART 2 – THERAPEUTIC PROCEDURES

Your name: ______________________________________________
Your job title: _____________________________________________
Institution: _______________________________________________
Department: _______________________________________________
Your email address: ________________________________________
Your contact telephone number: ______________________________

If we need any further information can we contact you?

☐ Yes
☐ No – If No, please could you provide the name and contact details of another key contact in your department

Key Contact: _____________________________________________
_____________________________________________
_____________________________________________
_____________________________________________

1. Do you perform any therapeutic nuclear medicine procedures in your department?

☐ Yes – Please continue to the next question
☐ No – Please go straight to Part 3 – Information for handling a radioactive corpse, p18

2. Please indicate all of the therapeutic procedures performed in your department
(Please tick appropriate boxes)

<table>
<thead>
<tr>
<th>Radioisotope</th>
<th>Procedure Description</th>
<th>Clinical Applications</th>
</tr>
</thead>
<tbody>
<tr>
<td>^131^I</td>
<td>Iodide</td>
<td>Thyrotoxicosis</td>
</tr>
<tr>
<td>^131^I</td>
<td>Iodide</td>
<td>Non-toxic goitre</td>
</tr>
<tr>
<td>^131^I</td>
<td>Iodide</td>
<td>Carcinoma of thyroid</td>
</tr>
<tr>
<td>^32^P</td>
<td>Phosphate</td>
<td>Polycythemia vera and related disorders</td>
</tr>
<tr>
<td>^90^Y</td>
<td>Colloidal silicate in aqueous solution</td>
<td>Arthritic conditions</td>
</tr>
<tr>
<td>^90^Y</td>
<td>Colloidal silicate in aqueous solution</td>
<td>Malignant disease</td>
</tr>
<tr>
<td>^153^Sm</td>
<td>Colloid</td>
<td>Arthritic conditions</td>
</tr>
<tr>
<td>^90^Sr</td>
<td>Chloride</td>
<td>Bone metastases</td>
</tr>
<tr>
<td>^186^Re</td>
<td>m-Iodobenzylguanidine (MIBG)</td>
<td>Malignant disease</td>
</tr>
<tr>
<td>^1^8^O^4^Sm</td>
<td>Ethylenediaminotetra-methylene phosphoric acid (EDTMP)</td>
<td>Bone metastases</td>
</tr>
<tr>
<td>^1^8^O^4^Re</td>
<td>Hydroxy ethylenediphosphonate(HEDP)</td>
<td>Bone metastases</td>
</tr>
<tr>
<td>^90^Y</td>
<td>Ibritumomab tiuxetan</td>
<td>Non-Hodgkins lymphoma</td>
</tr>
<tr>
<td>Others</td>
<td>Please specify below</td>
<td></td>
</tr>
</tbody>
</table>
C – Information for patients

C1. Are patients given *written* information about restricting contact with other adults or children following therapeutic procedures?

☐ Yes
☐ No

C2. Are patients given *verbal* information about restricting contact with other adults or children following therapeutic procedures?

☐ Yes
☐ No

C3. Are patients given *written* information about minimising contamination following therapeutic procedures?

☐ Yes
☐ No

C4. Are patients given *verbal* information about minimising contamination following therapeutic procedures?

☐ Yes
☐ No

*If you have said no to ALL FOUR of the above questions, please go straight to PART D (Information for Staff/Carers) on page 16.*

*If you have said yes to any of the above questions please proceed to the next question.*
C5. Please detail in the table below all the therapeutic procedures performed in your department where patients are advised of restrictions, and tick the appropriate boxes to indicate which restrictions are placed on patients.

<table>
<thead>
<tr>
<th>Name of Therapeutic procedure</th>
<th>Type of restrictions placed on patient (please tick boxes)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>RESTRICTIONS ON:</td>
</tr>
<tr>
<td></td>
<td>Contact with children and pregnant women</td>
</tr>
<tr>
<td></td>
<td>Contact with adults (e.g. work, travel, socialising, sleeping arrangements)</td>
</tr>
<tr>
<td></td>
<td>Breast-feeding</td>
</tr>
<tr>
<td></td>
<td>Radio-sensitive work</td>
</tr>
<tr>
<td></td>
<td>Restrictions to minimise contamination</td>
</tr>
<tr>
<td></td>
<td>Restrictions to avoid becoming pregnant</td>
</tr>
<tr>
<td></td>
<td>Restrictions to avoid fathering a child</td>
</tr>
<tr>
<td></td>
<td>Written Verbal</td>
</tr>
</tbody>
</table>

C6. In addition to the restrictions named above, do you provide details to patients of any other restrictions?

☐ Yes – please provide details in the table below
☐ No – please continue to next question

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Restrictions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
C7. How is information regarding restrictions given to the patient?

*Please tick all that apply*

- [ ] Within appointment letter
- [ ] Patient information sheet/ leaflet
- [ ] Radionuclide instruction card (yellow card)
- [ ] Verbally / spoken
- [ ] Posters
- [ ] Audio-visual
- [ ] Website (please provide URL)
- [ ] CD Rom
- [ ] Other *(please specify)*

C8. When is the information regarding restrictions most commonly given to patients?

*Please tick all that apply*

- [ ] At referral
- [ ] With appointment letter
- [ ] At pre-procedure assessment
- [ ] In the department, prior to the procedure
- [ ] On day of test post- administration
- [ ] Other *(please specify)*

C9. Who is the person most likely to provide the patient with written information regarding restrictions? *Please tick one box only*

- [ ] Admin / Clerical Staff
- [ ] ARSAC holder
- [ ] Nurse
- [ ] Physicist
- [ ] Referrer
- [ ] Technologist
- [ ] Other *(please specify)*

C10. Who is the person most likely to provide the patient with verbal information regarding restrictions? *Please tick one box only*

- [ ] Admin / Clerical Staff
- [ ] ARSAC holder
- [ ] Nurse
- [ ] Physicist
- [ ] Referrer
- [ ] Technologist
- [ ] Other *(please specify)*

C11. Is the information regarding restrictions available in languages other than English?

- [ ] Yes
- [ ] No

**IF YES:**
Which languages do you provide information in?

Why did you choose these languages in particular?

**IF NO:**
What is the main reason you don’t provide information in other languages?
C12. How do you communicate with patients who do not speak English?

Please tick all that apply
- Written information in the patient's first language
- Hospital interpreter(s)
- Family member/friend
- Other (please give details)

C13. Is information regarding restrictions following therapeutic nuclear medicine procedures available in other formats for patients with disabilities?

- Yes
- No

C14. In communicating with patients with disabilities does your department use any of the following?

Please tick all that apply
- Braille
- Audio cassette
- Large print
- Sign language interpreter
- Others (please provide details)

C15. Do you provide any written information for patients planning to travel abroad following a nuclear medicine procedure for the purposes of showing to customs/police or other officials?

- Yes
- No

C16. Are you aware of any problems that patients from your department have had when travelling abroad (e.g. activating radiation alarms in airports, etc) following a therapeutic nuclear medicine procedure?

- Yes (please provide examples in box below)
- No
### Therapeutic procedures

#### D – Information for Staff/Carers

(of patients who have undergone a therapeutic nuclear medicine procedure - information given to wards, care homes, sheltered housing, relatives acting as carers, etc.)

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>D1. Is information regarding restrictions given to staff within hospitals?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] No</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>IF YES:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Which ways are commonly used to convey information about restrictions to staff within the hospital?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Please tick all that apply)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] General information is available on the ward</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] Verbal information is given to the named nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] Written information is given to the named nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] Verbal information is given directly to the ward clerk/nurses station</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] Written information is given directly to the ward clerk/nurses station</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] Left to discretion of porter/escort</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] Information is attached to the front of patient notes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] Information is written inside patient notes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] Other (please provide details)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>IF NO:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Please continue to question D3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>D2. When is information given to staff within the hospital?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Please tick appropriate boxes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] At least 24 hours in advance of procedure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] On day of procedure prior to administration</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] On day of procedure immediately prior to departure from department</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>D3. Is information regarding restrictions given to staff outside the hospital?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] No</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>IF YES:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Which ways are commonly used to convey information about restrictions to staff outside the hospital?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Please tick all that apply)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] Written information is provided in advance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] Written information is sent back with the patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] Written information is sent back with the carer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] Verbal Information is given over the telephone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] Other (please provide details)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>IF NO:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Please continue to question D5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>D4. When is information given to staff outside the hospital?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Please tick appropriate boxes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] At least 24 hours in advance of procedure</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] On day of procedure prior to administration</td>
<td></td>
<td></td>
</tr>
<tr>
<td>[ ] On day of procedure immediately prior to departure from department</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
D5. To your knowledge, how often do the following events occur in your department?

*Please tick one box for each*

<table>
<thead>
<tr>
<th>Event</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Appropriate <em>written</em> information regarding restrictions not being provided to staff</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Appropriate <em>verbal</em> information regarding restrictions not being provided to staff</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Written information regarding restrictions not being received by staff groups to which it is sent</td>
<td></td>
<td></td>
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<tr>
<td>d) Staff performing other procedures not realising patient is radioactive (e.g. sonographers, social workers, carers etc)</td>
<td></td>
<td></td>
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<tr>
<td>e) Pregnant staff unknowingly caring for patients</td>
<td></td>
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<tr>
<td>f) Patient doesn’t inform nuclear medicine staff about particular personal care needs (e.g. incontinence)</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>g) Other (please specify)</td>
<td></td>
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</tr>
</tbody>
</table>

**Ad-hoc instructions**

Have you ever had to write instructions for a particular radioactive patient, or person coming into contact with them, in circumstances not covered in this section on therapeutic procedures? Please give details below and, where possible, provide copies of instructions.

**Information Leaflets – Restrictions following *therapeutic* procedures**

It is important for us to collect as many examples of written information as possible in order to complete this project. Please send us copies of the following information either in the Freepost envelope provided, or electronically (preferred) to joe.pope@surrey.ac.uk:

**ALL** information given to patients with the purposes of restricting exposure or contamination of others, including:

- Information your department has in other languages
- Information for patients with disabilities
- Information for radioactive patients travelling abroad

**ALL** information provided for staff/carers who may come into contact with radioactive patients, for example: information given to wards, care homes, sheltered housing, relatives etc
PART 3 – INFORMATION FOR HANDLING A RADIOACTIVE CORPSE
(Information for ward staff, funeral directors, mortuary staff, etc)

E1. Do you have a written procedure for handling a radioactive corpse following a \textit{diagnostic} procedure?

\begin{itemize}
  \item [\square] Yes \hspace{1cm} \square No
\end{itemize}

\textbf{IF YES:}
When are people generally made aware of the procedure?

\begin{itemize}
  \item [\square] Prior to a death
  \item [\square] In the event of a death
\end{itemize}

\textbf{IF NO:}
Please continue to next question.

E2. How many times has your department had to provide advice about handling a radioactive corpse following a \textit{diagnostic} procedure in the last 5 years?

\begin{itemize}
  \item [\square] None \hspace{1cm} \square 1 \hspace{1cm} \square 2 \hspace{1cm} \square 3 \hspace{1cm} \square 4 \hspace{1cm} \square 5 \hspace{1cm} \square More than 5 times
\end{itemize}

E3. Do you have a written procedure for handling a radioactive corpse following a \textit{therapeutic} procedure?

\begin{itemize}
  \item [\square] Yes \hspace{1cm} \square No
\end{itemize}

\textbf{IF YES:}
When are people generally made aware of the procedure?

\begin{itemize}
  \item [\square] Prior to a death
  \item [\square] In the event of a death
\end{itemize}

\textbf{IF NO:}
Please continue to next question.

E4. How many times has your department had to provide advice about handling a radioactive corpse following a \textit{therapeutic} procedure in the last 5 years?

\begin{itemize}
  \item [\square] None \hspace{1cm} \square 1 \hspace{1cm} \square 2 \hspace{1cm} \square 3 \hspace{1cm} \square 4 \hspace{1cm} \square 5 \hspace{1cm} \square More than 5 times
\end{itemize}

E5. For each group of staff in the table, please indicate what information is given about exposure to radioactive corpses (following therapeutic procedures), and when this information is given.

\textit{Please tick boxes}

<table>
<thead>
<tr>
<th></th>
<th>Written Information</th>
<th>Verbal Information</th>
<th>No information is provided</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Prior to death of patient</td>
<td>After death of patient</td>
<td>Prior to death of patient</td>
</tr>
<tr>
<td>a) Ward staff handling a radioactive corpse</td>
<td></td>
<td></td>
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<tr>
<td>b) Mortuary staff</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>c) Funeral directors</td>
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<td></td>
<td></td>
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<tr>
<td>d) Embalmers</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>e) Crematoria Staff</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) Other (please give details)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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E6. To your knowledge, how often do the following events occur in your department?

*Please tick one box for each*

<table>
<thead>
<tr>
<th>Event</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Appropriate written information about handling radioactive corpses not being provided to staff</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Appropriate verbal information about handling radioactive corpses not being provided to staff</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>c) Written information about handling radioactive corpses not being received by staff groups to which it is sent</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>d) Staff unknowingly coming into contact with radioactive corpses</td>
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</tr>
<tr>
<td>e) Corpses being removed from mortuary without knowledge that corpse is radioactive</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>f) Others (please give details)</td>
<td></td>
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</tr>
</tbody>
</table>

E7. Please provide any comments about the information procedures in place for staff handling radioactive corpses in the box below.

**Information Leaflets**

It is important for us to collect as many examples of written information as possible in order to complete this project. Please send us copies of the following information either in the Freepost envelope provided, or electronically (preferred) to joe.pope@surrey.ac.uk.

ALL information provided to people who may come into contact with a radioactive corpse, for example: information given to ward staff, funeral directors, mortuary staff etc
Comments

Please feel free to comment on any aspect of this questionnaire. In particular we would be interested in hearing about effective methods of communication with patients and staff and effective ways of disseminating information in your hospital.

REMINDER: Information Leaflets

It is important for us to collect as many examples of written information as possible in order to complete this project. Please send us copies of the following information either in the Freepost envelope provided, or electronically (preferred) to joe.pope@surrey.ac.uk.

ALL Information given to patients with the purposes of restricting exposure or contamination of others, including:
- Information your department has in other languages
- Information for patients with disabilities
- Information for radioactive patients travelling abroad

ALL written protocols governing verbal information given to patients following diagnostic nuclear medicine procedures

ALL information provided for staff/ carers who may come into contact with radioactive patients, for example: information given to wards, care homes, sheltered housing, relatives etc

ALL information provided to people who may come into contact with a radioactive corpse, for example: information given to ward staff, funeral directors, mortuary staff etc

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE
The Royal Surrey County Hospital
NHS Trust

Information Sheet

Patients’ Views of Information and Advice from the Nuclear Medicine Department

Invitation

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of this study?

The aim of this study is to find out what people think of the information we have given to them about their visit to the Nuclear Medicine department. We are also interested in finding out about the experiences of people who are referred to the department. This study is one part of our research looking at ways to improve what information is given to patients. This research is funded for one year and the interview study is taking place over five months.

Why have I been chosen?

We are hoping to interview about 40 people about their views and experiences of the information they have been given when attending the Nuclear Medicine department. We are therefore inviting all those who have had an appointment during the last few months to take part in this study.

Do I have to take part?

It is up to you whether or not you decide to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw from the study at any time, or a decision not to take part, will not affect the standard of care that you receive.

What will happen to me if I take part?

If you agree to take part in the study we would like to ask you some questions. During the interview you will be asked about your experiences of the appointment and visit to the Nuclear Medicine department. We are particularly interested in what patients think about the information that we provide - both written and verbal, and so you will be asked about these in some detail.

What do I have to do?

We will arrange a time to come and interview you. We will ask you if we can tape-record the interview. The interview will take place at a time and place that is convenient for you (such as in your own home). We do not expect you to travel to the hospital in order to take part. If you would prefer to be interviewed at the Hospital or University we will reimburse your travelling expenses.

What are the possible disadvantages and risks of taking part?

Talking about a hospital visit or treatment can be upsetting for some people. If you do become upset during the interview you can ask to stop at any time. You have the option of continuing later, at another time or finishing the interview altogether.
The Royal Surrey County Hospital
NHS Trust

What are the possible benefits of taking part?
Although talking about an illness can be difficult, some people find it valuable to discuss their experiences. The information we get from this study will also help us to improve the service we provide for patients in the future.

Will my taking part in this study be kept confidential?
Yes. If you do want to take part, the audiotape of your interview will be used for this research project only. It will be kept secure and we will make a transcript of the conversation. We will remove any information that could be used to identify you from the transcript in order to keep the information confidential.

What will happen to the results of the research study?
The results will be used to help us improve the information we give to our patients. The results will be published in a scientific journal so that the wider community can benefit from them.

Who is organising the research?
The research has been funded by the Health and Safety Executive. The researchers conducting the research are Paul Hinton and Claire Greaves from the Nuclear Medicine Department at the Royal Surrey County Hospital together with Vicky Senior, Marie Clark, and Julie Barnett in the Psychology Department at the University of Surrey.

Who has reviewed the study?
This study has been approved by the South West Surrey Local Research Ethics Committee and the University of Surrey Ethics Committee.

Contact for further information
If you have any questions please contact Claire Greaves on 01483 xxxxxx or Dr Vicky Senior on 01483 xxxxxx.

Thank you for taking the time to consider taking part in this research.
Consent Form

Title of Project:

Information to accompany patients undergoing Nuclear Medicine Procedures – a qualitative study to assess perceptions of current information provision and information needs.

1. I confirm that I have read and understand the information sheet dated Jan 2004 (version 1) for the above study and have had the opportunity to ask questions

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected.

3. I agree to take part in this study

Name of Patient ___________________________ Date ____________ Signature ______________

Name of person taking consent (If different from researcher) ___________________________ Date ____________ Signature ______________

Researcher ___________________________ Date ____________ Signature ______________

3 copies:
1 for patient
1 for researcher
1 for hospital notes
APPENDIX 3  STIMULUS MATERIALS
Example 1

The radiation dose is usually similar to that from an x-ray.

Example 2

Is the radiation dangerous? The dose received from the injection is similar to 2 years background radiation.

Example 3

The risk associated with a Nuclear Medicine procedure is equivalent to the risk involved in driving a car for 75 miles in a week.

Example 4

The amount of radiation we give you is the same as six x-rays of your back or two years of natural background radiation. The risk is the same as smoking 40 cigarettes during your lifetime or taking 100 transatlantic flights.
Examples of Restrictions – Bone Scan Leaflets

Example 5

Patients are advised to avoid non-essential physical contact with children for twelve hours after their injection.

Example 6

As a precaution you will be asked to avoid close prolonged contact with pregnant women and children for 24 hours after your scan. This is to avoid exposing them to small amounts of radiation unnecessarily.

Example 7

You are advised to avoid close contact with expectant mothers and small children for 24 hours following the injection (close contact means having a child sitting next to you or on your knee for more than 30 minutes. This avoids exposing them to unnecessary radiation.)
Radiation Risk Examples – Myocardial Perfusion Imaging Leaflets

Example 1

The amount of radiation you receive is small. It is similar to that from an x-ray examination.

Example 2

This is a nuclear medicine procedure, which means it involves a small quantity of radiation. The amount of radiation is similar to an x-ray CT scan. The risk associated with a nuclear medicine procedure is equivalent to the risk involved in driving a car for 75 miles in a week.

Example 3

The radiation dose is low. To put this in context, we are all exposed to natural radiation every day. This test gives you 1.5 times the average yearly natural radiation dose. The doctor who requested this test is aware of the radiation risk. He/ she considers that the benefit of finding out what is wrong with you outweighs the small risk from the radiation.
Examples of Restrictions – Myocardial Perfusion Imaging Leaflets

Example 4

It is also advised that for 12 hours following the radio pharmacological injection you should avoid close contact with pregnant women, babies and children.

Example 5

However, we do advise that for 24 hours following the test, where possible you minimise close prolonged contact with small children or expectant mother (prolonged contact would be nursing a small child on you lap for 10-15 minutes)

Example 6

Please avoid close, prolonged contact with children or pregnant women for the rest of the day. This is to avoid exposing them to unnecessary radiation.

Example 7

As you will be slightly radioactive after the test, please avoid close contact with children for the rest of the day. This is to avoid exposing children to unnecessary radiation. Close contact means having a child sitting next to you or on your knees for more than half an hour.
Radiation Risk Examples – Parathyroid Imaging Leaflets

Example 1

The level of radioactivity used is extremely low.

Example 2

The amount of radiation you receive is small, it is similar to an x-ray examination of your lower back and hips.

Example 3

The amount of radiation dose received is very small. It is comparable to approximately 2 years background radiation.

Example 4

The risk is the same as smoking 1000 cigarettes during your lifetime.

Examples of Restrictions – Parathyroid Imaging Leaflets

Example 5

You should avoid close contact with small children and pregnant women for 24 hours after the injection.

Example 6

Please avoid close contact with children and pregnant women on the days that you are undergoing these examinations (close contact means having a child sit next to you or on your knees for more than half an hour).
Example 7

As you will be slightly radioactive after the test, please avoid close contact with children for the rest of the day. This is to avoid exposing children to unnecessary radiation. Close contact means having a child sitting next to you or on your knees for more than half an hour.
Stimulus Materials for I-131 Therapies

Example 1

Females should not become pregnant, and males should not father children for 4 months after radioactive iodine.

Example 2

Because of the possibility of unnecessary radiation exposure to the hospital staff and your relatives and friends, certain safety measures are taken while you are in hospital.

Example 3

What restrictions are there when I go home? You should stay at least 1 metre from children 5 years old and under and pregnant women for a week.

Example 4

May I have visitors? Visitors should sit across the room from you. They should wear over shoes and monitor themselves when they leave the room (the nurses will show them how to do this).

Example 5

When at home, normal standards of hygiene will prevent any contamination under normal circumstances.