

Patient information leaflets.

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With contributions from the EANM Technologists Education Sub-Committee

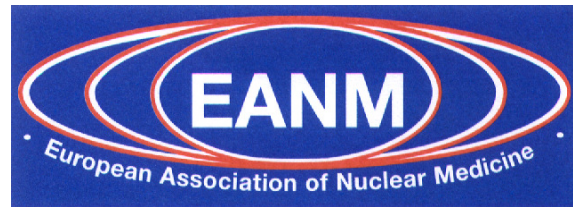
Many Nuclear Medicine services find patient information leaflets a useful and efficient way of conveying information to patients in good time for their studies. We have to be careful, however, not to frighten or confuse patients or overload them with more information than they can take in. These questions and suggested answers are intended to look at some of the things that need to be considered in patient information and also give some ideas of what should be included in it.

Why do patients need written information?

- It improves their understanding and recall of the things they have been told. It is rare to understand and remember everything you are told at once in any situation, patients under stress are even more likely to miss or forget things if they are only told once.
- It improves their compliance in any preparation for the study, or instructions on what to do on the day, e.g. loose clothing for any cardiac stress procedures. This helps the service run smoothly as well as helping the patient
- It reduces the stress of not knowing what will happen and may increase their satisfaction in their experience in the Nuclear Medicine department. If a consistent clear approach is taken before and throughout the procedure the patients are more likely to feel that have been dealt with properly.

What are the common causes of unnecessary stress?

- Too little understanding of why the study may be being performed – many patients think that if the study involves radiation it must in some way imply that their doctor suspects a cancer. They may need reassurance that Nuclear Medicine is used to detect or exclude other, easily dealt with, pathologies.
- Fear of the results - there is not much we can do about this but recognise that it may enhance other fears that **can** be allayed.
- Fear of the study procedure – we have probably all come across patients who think that a bone scan injection must be given into the bones or spine and have been needlessly worried about the possible pain involved for days or weeks. A clear description will prevent this sort of problem.
- Fear of making a fool of themselves – patients may worry about not understanding instructions and not knowing what to do or say, especially if they are elderly.
- Not speaking the language that the hospital staff will know and use - Information in a range of likely languages and/or clear directions to any translation resources can not only make things easy for the patient but also very much easier for the technologist.



What questions are you asked?

Asking yourself this is a good place to start building your own leaflet. It will give you an idea of what most patients want to know. You might like the idea of putting it in the form of common questions so that they can see it is of concern to many other patients

How can you best get over the information?

- Appointment letters or leaflets – the suggestions below have been broken into appointment letter and leaflet as one method of giving out information and may be more convenient if you have information leaflets printed or like to have them available for other purposes. You may choose to send each patient a long appointment letter including all the information. This isn't too difficult if you have a standard letter set up on a word processor to be individualised as required. Either way the patients will get the access to the information they require.
- Leaflets must be easily read – this can be achieved by having a simple writing style, though not too childish (except for paediatric leaflets). It's best to use quite large print – older people in particular often have reading difficulties. Pictures, like line drawings or cartoons, can be very helpful, save many words and make the effect light-hearted.
- Information on different studies could be on different coloured papers to help the clerical staff ensure the right ones are sent out.
- Some departments are setting up websites that can give information and show photographs of the department and its equipment. Patients would need to be given the web address and, as yet, it probably isn't reasonable to expect everyone to have access to the Internet but it can form a very useful addition.

What is the basic information an information leaflet could contain?

- A brief explanation of Nuclear Medicine, that it shows how parts and organs of the body are working and a comparison with X-Rays (radiographs) and how these are used may be useful, as most people are much more familiar with these.
- A brief explanation of the procedure - this may start with, for example: the use of radioactive substance, the method of administration, and the improbability of side effects.
- The practical details - like the time between administration and scan, the time the procedure takes and any necessity to bring food if the study is likely to be long and/or include delayed images.
- A brief description of the procedure- they may be reassured by a few words on what is happening at each stage and a warning of any pain/discomfort they may feel or reassurances for procedures that are painless.
- Who they can bring with them – many patients like to bring a family member or friend with them for company and support. You might like to suggest that it is not suitable to bring small children or pregnant women to the department unnecessarily.
- Standard radiation protection advice – Instructions on measures such as care with urine contamination and avoiding close contact with pregnant women or small children can be given. It should be made clear how long this restriction needs to last so that patients can then plan to deal with it in advance if necessary.
- How to get the results - if the study results are not available on the day of the study, it can save anxiety and annoyance if the patient knows this in advance, along with when and where they can get them.



What is the basic information an appointment letter could contain?

- Patient's Name, Date of Birth, Full address. You cannot start too early in making sure you have the right person on front of you when you administer the radiopharmaceutical.
- Which doctor or nurse has asked that the study should be done – A patient may have several problems at the same time. They need to know which one is relevant to the study
- The day and date – Putting both helps to reduce missed appointments from mistakes.
- The time and place – The name of the department should be clear and any extra instructions on finding it, particularly in a big hospital. A map may be useful
- Information on transport, local buses, rail/metro stations and parking facilities – they may be undecided on what mode of transport to use, how far they may have to walk from a car park or bus stop and how much it is likely to cost.
- Any preparation - obviously this is the time to detail any special preparation like fasting or stopping certain drugs for an interval before the study.
- A contact telephone number - patients need to know how to get advice in any special circumstances like diabetes or if they are worried about any aspect of the procedure. It can be useful to ask them to contact the department if they are pregnant or breast feeding so that the study can be reconsidered and advice given
- A request to be informed if the patient is unable to attend – an explanation of why gaps cannot be easily filled and that missed appointments waste precious time and resources may encourage patients to inform the department if they are not coming.

For children, there may be some extra points such as;

- Any possibility of pregnancy in carer – Mothers of young children are quite likely to be pregnant again and proper radiation advice needs to be given.
- Any attendance at a paediatric ward for cannula insertion and how long this will take – this could form part of the explanation as a whole.
- The possibility of sedation - if this is used in your department, a forewarning would allow the child's carers to raise any anxieties in advance.
- Favourite tapes, stories etc- carers can be asked to bring these to help with keeping a child calm and still.
- Any necessity to bring food and toys - if the study is likely to be long or include delayed images, amusement and any special food requirements are best dealt with by the carers as they know the child's likes and dislikes. In addition, it is useful to know if there are any hospital play workers or facilities that can be used.
- With children it can be a good idea for the carer to bring supply of clothing in case of contamination

This has been a collection of ideas from various sources and discussions with technologists. The intention is to share some ideas that could be found useful, especially if you are drawing up this sort of information service for the first time. Any additions or comments are always welcome. Good practice will only spread if ideas are communicated and used.

There are plenty of examples about. If you have one that you think works well perhaps you would like it to be used as an example on this website – any language welcome.