The Nursing Terms project: progress and results

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In 1992 we began work on a scoping study which looked at the task of getting nursing, midwifery and health visiting terminology into Read Codes. This was followed by a major two year project, commenced in 1993. In this paper I wish to outline what we have achieved to date and what we hope to complete by April 1995 when the Project ends.

The background, aims and methods of the nursing terms project have been described in earlier presentations: reports are available on request from the NHS Centre for Coding and Classification (NHS CCC).

As a reminder of why so many people are working on this project I will give an example of the fundamental reason for doing the work: supporting clinical practice. Consider a small boy with a sore mouth doing his own mouth care. He uses a mirror and almost scientific detachment to view his condition. The nurse provides encouragement in a situation which may seem simple but is really quite complex - as is most nursing, midwifery and health visiting. This complexity needs to be recorded in whatever records we keep, whether on paper or on computer. How we express complex care in records is critical to whether we can use the information contained in those records.

It is no longer sufficient to say that the child has a sore mouth and is doing his own care. We are able to be much more precise in what we record so that we can use the information for audit, research into clinical effectiveness and to argue for resources.

The child has a sore mouth, currently rated at 16 on a paediatric oral assessment scale. His pain is well controlled, he has rated it at 1 on a faces analogue scale. This is not idealism, this is the way that nurses in this environment score the symptoms and problems of the children. The mouth care is sub-standard, it is going to take this little boy a while to be confident enough to do more than dab the anti-fungal agent on to the problem areas. However the paediatric nursing which is going on is excellent. So we have a description of the problem which suggests care is sub-standard in a context of excellent nursing. The overall outcomes for this child will be very good, although the recovery of his mouth may take a little longer than expected. All of this takes time, expertise and is based on the most up to date theory and research.
I came into the nursing terms project because I needed to be able to express just this kind of situation in computer systems. I needed to be able to use the computerised information to manage the care of this kind of patient, to demonstrate outcomes and compare them with those of other children with similar problems, and to justify the role of RSCNs in this environment. I felt the starting point was the terms which would allow me to express the complexity of nursing in a computer system.

What the project set out to do, two years ago, is summarised in the terms of reference:

1. develop a set of terms and synonyms commonly used in nursing, midwifery and health visiting records;
2. liaise with medical and PAMs project working groups to agree shared terms;
3. order the terms so they can be incorporated into the Read Codes;
4. communicate the work of the project to the profession and produce educational material;
5. produce a proposal for the further development and maintenance of the terms.

The original terms of reference included piloting the terms. However we will not now be conducting a full review in the field until after April 1995. Instead we are planning a comprehensive review of the terms by the working groups who produced them, so the terms are checked and refined before they are field tested.

**Working with the nursing professions**

A wide range of people have been directly involved in the project. Six working groups (representing the main branches of nursing) were increased by more than 60 specialist nurses: continence care, renal, oncology, intensive care etc. Each group included a full-time field worker. There was a Project Board and Quality Assurance Team with representation from the professional bodies and the other UK countries.

Such was the size of the task that we expected all these people to undertake, that they generally recruited local help: many other nurses, midwives and health visitors were indirectly involved. In particular groups (such as the learning disability and community groups) the nurses went back with the work they had to do and formed focus groups in their work areas to help them get through the task.

All these people are to be congratulated on the substantial achievement of this project, which is to get together all the terms and synonyms that we feel will be needed to construct nursing records on a computer.

**Comprehensive coverage**

The second term of reference was to produce terms and synonyms that would be comprehensive enough for use in computerised records, but which would also reflect the language that people wanted to use in those records. This forms the fundamental quality criteria for the terms produced. One hundred and thirty two separate lists of terms were delivered at the end of August 1994, covering all aspects of nursing, midwifery and health visiting. The topics covered in these lists included such diverse areas as advocacy, ante natal care, continence, health promotion, seclusion and restraint, and intravenous therapy: topics which members of the working groups, the Project Board and the Quality Assurance Team felt covered all of nursing.
There are over 250,000 clinical terms in the current Read Thesaurus. Our groups reviewed a substantial number of those terms to see whether they would suit the needs of the nursing professions. They then added terms which had been collected in the field by nursing fieldworkers. A quality assurance review was carried out by 20 independent reviewers, 3 or 4 for each working group. They were asked specific questions about comprehensiveness: "Does this list cover the topic in your opinion very well, quite well, not very well, poorly?" Many of the reviewers took the time to wade through the stacks of paper in great detail, noting where things should be added, commenting "inappropriately worded" or "doesn't reflect lay-language appropriately".

The second main review question was "Do these terms reflect nursing language - quite well, very well, not very well, poorly?" So far the comments have been very favourable. Only a few lists were felt not to reflect nursing language and this was because the full question said "the terms that nurses, midwives and health visitors would want to use in their records". The reviewers felt there was insufficient lay language included. So we shall go back and relook at those lists.

Of the 132 lists, comments for 82 have been received and only four have an unacceptable score. At present we are in the cycle of receiving review comments and asking the working groups to look at the individual comments, liaise with the reviewers if necessary, and revise the lists. Thus we are trying to make sure everybody has a say and that term coverage is comprehensive.

**Liaison with medical and PAM Groups.**

Terms projects for medicine and the professions allied to medicine (PAMs) have been proceeding in parallel. As we worked on the nursing project we attempted to resolve issues which crossed disciplines. However, it was not until we began to integrate the terms into the single clinical Thesaurus that many of the issues became visible. People word things differently and have different meanings for the same term, depending on their perspective.

To address these areas we have held joint topic meetings and some topics are still being worked on. One of the most difficult areas has been assessment of 'skills and abilities'. Physiotherapists, occupational therapists and nurses want to be able to say things about what patients are and are not able to do. To structure that area of terms and to agree everyone's perspective is taking some time. Other ongoing topics include 'communication', 'cognition' and many topics within the mental health field.

One of the major achievements of the project is the way that the professions have worked together. In the early stages we had nurses, midwives and health visitors taking their own 'tribal' views. They quickly came together into a single project and are now into joint working with others including doctors and PAMs.

Working with social services has been more of a problem. The NHS CCC has tried for two years to set up a working relationship with social services organisations to consider adding shared terms into Read Codes. The nursing working groups include several social workers. But establishing the right contacts at a high level has been difficult and so we hope to have a scoping study in the way we did for the nursing terms.
Another area which proved difficult is client and patient terms. Two years ago, when we announced our intentions to include them, I am sure many people laughed quietly. They were right - it has proved very complex. We asked patient and client representatives to join the various nursing groups and spent time trying to decide how we could tackle the term issues. They gave up on us, set up their own group and have collected patient leaflets from which they have extracted terms.

At the end of the project they will produce a report that will say what we need to do to make Read codes usable in shared and client-held records. The important thing that is emerging is that we do not need to add many more terms - most of them are already there with adequate synonyms. What patients and clients want are lay definitions or explanations of medical terms. For example when looking at their computer record in the future they could click on a term like "Myocardial Infarction" and see an understandable definition. This opens up a whole new range of issues.

Education and awareness

Another term of reference was to produce educational material and inform the profession about the project. Joyce Wiseman has conducted a series of road shows in hospitals across the country. Nurses had voiced their concern that it was not they who made decisions about what goes into systems. The NHS CCC has held regional road shows targeted at managers and information people which has helped raise awareness about what we are doing and why it is important to the professions. Regular progress reports are sent to a core group of over 1,000 interested people and there is a growing range of literature available from the NHS CCC.

Nick Hardiker helped to produce an education briefing pack which was widely circulated to educational institutions. NSG Education Focus Group members helped review this material and we appreciate their contribution. We will be producing further educational material towards the end of the project.

Overall the team has attempted to reach wide audiences, to share with others and to learn what is going on around the world. An awareness survey indicated that the main professional journals were the best way to get information about central initiatives to clinical staff. So communication plans include articles for 'Nursing Times', 'Community Outlook' and 'Midwives Chronicle'. It is proving challenging to explain the project to people who have had nothing to do with computers and don't like them anyway.

The most effective route for communication has been through the working group members. They have produced and distributed communication packs and set up local events in their areas. They have taken information which they have produced to make the whole thing understandable to their own professional conferences.

Where are we now?

The nursing terms were delivered by the working groups in August 1994 and the process of integrating them into the Read Codes has begun. This is proving to be the most difficult part of the project, which means that the planned release of a developmental set of terms in April 1995 will be incomplete.

There are four key areas which have contributed to the problem:
• the quarterly release of Read Codes;
• the evolution of a more holistic model which underpins the structure for Read codes;
• the moving target of version 3, and
• terming issues such as word form and word order.

The quarterly release of Read Codes is an important service so that the terms and codes are constantly updated. But every three months all work stops on the terms while the Codes are subjected to technical reviews and released to the service. Although the nursing project plan allowed for this, it has had a bigger impact than we expected, with only a small number of skilled 'authors' who are able to do the terms integration work.

As integration of nursing and PAM terms began it became apparent that there needed to be a move from a physical systems 'structure' in the old Read Codes to a much more holistic one. Many nursing and PAM terms were not comfortable in the old structures and some restructuring of sections such as signs and symptoms has become necessary. This is proving to be a major undertaking.

In addition, Version 3 of Read Codes has evolved so that the kinds of clinical detail required by clinicians in their records could be accommodated. With the old Read structures if you wanted to record preferences to do with maternity care, for example, you would have to select from a list of every possible combination of where, how and with whom the woman wished to deliver. Impractical, long 'picking lists' are not necessary because of the 'qualifier' structure of Version 3.

Another change has been the development of terms which add context, (for example timing, severity, causal links). These terms can add information which may change the meaning of a term. For example if you record the action of 'teaching': you might want to say that it is 'planned', 'done', 'started' or 'abandoned'. If you record an assessment finding such as 'rash' you may want to say whether it is 'present', 'absent', 'possible', 'potential'.

Nursing action terms were one of the most challenging areas to structure. It was necessary to link actions to terms that exist elsewhere in the Thesaurus: for example making it possible to record the action of 'observing' anything about a patient which is already listed in the 'signs and symptoms' section. This avoids the need to re-list huge sets of terms: the action term 'administer' is not listed alongside every drug in the drug list but instead the single action term can be linked to any drug.

Issues such as these have come up as Version 3 has evolved, as a direct result of the kinds of terms the nursing, medical and PAMs professions require. Some of the solutions which have been adopted have inevitably affected the 'naturalness' of the terms going into the Thesaurus.

One example is the 'form' of expression - the part of speech used. An example is the term observation (a noun). Nurses want to be able to record:

- a plan (observe for bleeding),
- a past act (observation completed),
- an act which is ongoing (observing for blood loss).
In the Thesaurus it would be impossible to list the three or more forms required for each action term. So the decision had to be made to select one and it was the gerund (..in) form which was chosen for actions. Such choices need to be tested and reversed if they do not meet the needs of those using record systems in the future.

Another example is word order: in a nursing record, a patient problem might be 'poor memory' but in a medical record as the doctor runs down the check list of the body he writes 'liver- enlarged', 'chest - clear', 'memory - poor'. Again it would be impossible to have both forms of expression for every sign or symptom. So there has had to be a degree of compromise. It is important that potential users of Read Codes know about these decisions because if their expectation is that everything will be as they want to see it, that may not be the case. The review and updating mechanisms for the clinical terms will make sure that if such compromises are unacceptable then changes can be made where necessary.

A balance has had to be found between a completely free text expression in natural language and the necessary constraints of trying to produce a practical solution to structuring clinical terminology.

**Next steps**

Beginning in February 1995 we plan to review the nursing terms that have been added into the Read Thesaurus. The working groups will be asked to give their views on what they delivered: this is how it looks in Read Codes; are you happy with the way it has been added? What else needs to be done before we use the terms in systems?

We plan to release a developmental set of terms in April 1995 which will be widely available for people to look at, including system suppliers. We believe we need to undertake a period of refinement before we release these developmental terms in the full set of Read Codes. Independent evaluation of what has been achieved will be needed once the terms are refined.

During the coming years we will need to demonstrate to the profession and the world at large, that Version 3 of Read Codes is capable of supporting entry, retrieval and messaging of patient information across care settings and over time. We also need to look at the development of clinically useful groupings and definitions of nursing information - should it be done, if so how and by whom? There is a clear indication from the professions that they not only want to capture complexity but to compare outcomes.

Going back to the example of the little boy with the sore mouth - his nurses need to be able compare whether his progress and outcomes were better or worse than those for children in other centres with the same problems. This means we have to take the development of our language beyond nursing terms. Only then will we be able to say that the quality of the child's care was as good as possible.

**Discussion**

**John Bryden,** Health Information Consultant, Scotland.

When one talks of integrated systems, one gets worried about separation within the Read Thesaurus, I was lucky enough to be involved with the cardiac surgery group.
When it comes out in its final form one hopes that the nursing terms will be as transparent within the codes as the cardiac surgery terms. Will this be the case?

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There will be one healthcare Thesaurus, so a nurse working in cardiac surgery will be able to access the cardiac surgery terms, the nursing terms, the equipment terms and so on. As the Read Thesaurus is huge we will also need sub-sets. There will be one for general practice, one for nursing and so on. So the nurse in cardiac surgery may use certain flagged subsets which will be the first terms that the nurse sees, this might take information from cardiac surgery and nursing terms. In such local implementations the paediatric oncology ward might have a paediatric oncology subset and a subset for paediatric nursing.

Reference

NHS Centre for Coding and Classification. Terms, Records and Information- A self-learning pack. (An introduction to using computerised information and the Read Coded Clinical Terms in nursing, midwifery and health visiting practice.) IMG Ref: F6123 Free from NHS Centre for Coding and Classification Woodgate LOUGHBOROUGH Leicestershire LE11 2TG