Original article

A head and neck cancer database for the 21st century

Elliot Benjamin, Ghassan Alusi

Department of Otolaryngology, St Bartholomew's Hospital, London, UK

A versatile, hand-held computerised database is described. Its use for general patient management, audit and as a tool for clinical governance is illustrated.

Key words: Cancer – Database – Personal digital assistant

The use of cancer databases has been demonstrated for research and audit in many surgical fields, including breast,¹ prostatic,² pancreatic³ and oesophageal malignancies.⁴

In 1998, it was noted that the single most major deficiency in the UK in the management of head and neck cancer had been the absence of accurate systematic prospective data collection, hence the genesis of a dedicated head and neck cancer database.⁵

The concept of such a database was to aid prospective audit, allow more accurate prognosis, help give information to establish dedicated cancer service providers and provide long-term, population-based observational studies.

Unfortunately, much of the data collection and data entry has been retrospective with a third party entering data to a computer database from either a review of the medical notes or from a completed hand-written data form. It has been shown⁶ that where surgeons are involved with prospective data acquisition of operative records, complications and re-admissions, the accuracy and completeness of such a record will exceed that of a medical notes audit. The use of a third party, often, non-medical for the data retrieval has obvious cost and efficiency implications.⁷

These computerised databases may well have achieved some of the aims set out above, but with all the data held on a single desk-top computer the information is then separate from the point of source, *i.e.* it is rarely used to aid the actual

management of the patient on whom the data is collected.

The answer to these problems is in the use of the rapidly developing hand-held computers or Personal Digital Assistants (PDAs). PDAs have been used for data acquisition in orthopaedics,^{8,9} management of clinical trials in breast cancer treatment,¹⁰ in radiological diagnosis for neurosurgical cases,¹¹ and for surgical log books.¹² The St Barts Head and Neck Cancer Database was developed using the PalmVx PDA (Fig. 1) and a database software package (ThinkDB, thinkingBytes Technology). The fields used were chosen to both provide data for audit purposes but also to aid the on-going management of any particular patient; they are loosely based on the British Association of Head and Neck Oncologists' National Minimum Dataset.

Each page of the database contains the name, hospital number and date of birth of the patient. The operative pages provide information on diagnosis, operation (including a free text operative note), date of operation (including a calculation of the number of days postoperatively) and any postoperative complications (Fig. 2).

Pathology and radiology pages list reports of histology and cytology findings and MRI and CT results. The database can be further developed to scan in the actual radiological images, but the usefulness of this is yet to be assessed. A tumour map is entered into the PDA at the time of the diagnostic panendoscopy with its TNM

Figure 1 The St Barts' head and neck database on the PalmVx PDA.

staging (this can either be hand drawn or entered on to a previously downloaded tumour map). This has proved very useful along with printouts from the database in multidisciplinary meetings for the management of patients (Fig. 3).

A radiotherapy record is kept on the database and updated in the combined radiotherapy clinics allowing discussion on treatment modalities for a particular patient or looking at treatment options for a particular stage of tumour from an audit point of view. Prospective audit pages can be concurrently run on the database, including,

Figure 3 Tumour map on the database.

Figure 2 Operative page of database.

for example, an audit into the use of bone scans in the work up of head and neck cancer patients (Fig. 4).

The database also has the facility to record secondary and subsequent operations along with the ability to add any further fields required by a particular user. These fields may contain the full British Association of Head and Neck Oncologists' National Minimum Dataset or can be further added to for particular patient management or research needs. Hierarchical data (*i.e.* multiple neoplasms or multiple operations) can be collected by linking new data records on the same patient. The database is able to provide its own instant reports such as a catalogue of operations performed by a unit, complications reports or average bed-stay reports (Fig. 5).

More complex reports and audit enquires can be set up by integrating the database with Microsoft Access or

Figure 4 Audit page on database showing audit of bone scans.

thinkDB	
Statistics for:	Operation
Apply filter:	none
----- Results -----	
Commando	1
Direct laryngoscopy	4
Laryngectomy	4
Laser debulking	0
Maxillectomy	4
Oesophagoscopy	0
Panendoscopy	3
Parotidectomy	1

Done [Σ %]

Figure 5 Report page – operations performed.

Excel on the downloadable and fully synchronised version of the database on the departmental personal computer. The present version of the software does allow integration with commercially available head and neck databases such as Infoflex, but via a conversion process within Microsoft Access. A new version of the software called Adesso (Adesso Systems, USA) will allow direct integration with Infoflex, as well as allowing web service integration and so is likely to be able to provide a full hand-held version of the new DAHNO (Data for Head and Neck Oncology) – the system being set up to collect uniform head and neck data nationally.

In the daily running of the database, all members of the head and neck team (*i.e.* the consultant, two registrars and SHOs) had a copy of the software on their PDAs allowing instant access to up-to-date information retrieval and data input. This information could then be shared by the department, either by infrared transfer between PDAs or by synchronisation with the departmental computer. This ensured that at all times an up-to-date version of the complete database was available in the department for clinical and research use.

One problem with this hand-held portable database is its position under the 1998 Data Protection Act.¹² This states that all personal data should be 'processed fairly and lawfully', 'be kept up to date' and 'technical and organisational measures should be taken against unauthorised or unlawful personnel processing of personal data'.

Medical personnel are allowed, under the act, to collect 'sensitive personal data' but as with all data collectors, a

notification should be made to the Data Protection Commissioner. It remains unclear as to whether separate users of the PDA database need to notify or all users are covered by the hospital notification system. What is clear, is that the data must be protected from unlawful access and so a two-level password protection system (one to switch on the PDA and one to open the database) has been included.

Conclusions

We have presented details of a versatile, hand-held computerised head and neck cancer database. This has been used not only for prospective audit and research data collection and hence as an invaluable tool for clinical governance, but also in the on-going clinical management of our patients.

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