Electronic “Form A” and “Form B”

There have been longstanding calls from the organ retrieval community for an electronic replacement for the HTA Form A and Form B. The potential advantages of electronic forms over paper include:

- improving data capture
- validating the reporting of retrieval injury and other anomalies
- providing more rapid feedback to retrieval surgeons as part of a robust quality cycle
- reducing the burden of form completion by eliminating duplicated data vs multiple paper forms

The Netherlands uses a system of electronic forms with the implanting surgeon’s assessment of the organ directly compared to the retrieval surgeon’s, which can then be used to provide robust performance data for quality control and to guide training. This system under development has absorbed some of the functions of the Dutch system, modified to meet the needs identified by the UK transplant community.

Electronic is not always better. Most people can write faster than they type – although they may be able to type more quickly than they can write legibly! When then, should we go to the trouble of developing electronic forms when we could just use paper?

Transplant operations, both retrieval and implantation, are long, technically difficult and have a depressing tendency to be done late at night, possibly following a full normal working day. At the end of a long, and possibly fraught, operation at 3am or 4am, the transplant surgeon’s efforts are rewarded by a pile of tedious paperwork. Much of the paperwork is accepted as professionally necessary, but the tedium arises from the repetition of the same information:

- there is a large overlap in data collected on the organ-specific HTA-A forms for liver, pancreas and kidney
- for each individual surgeon, much of the content of the HTA-B form is the same for every transplant

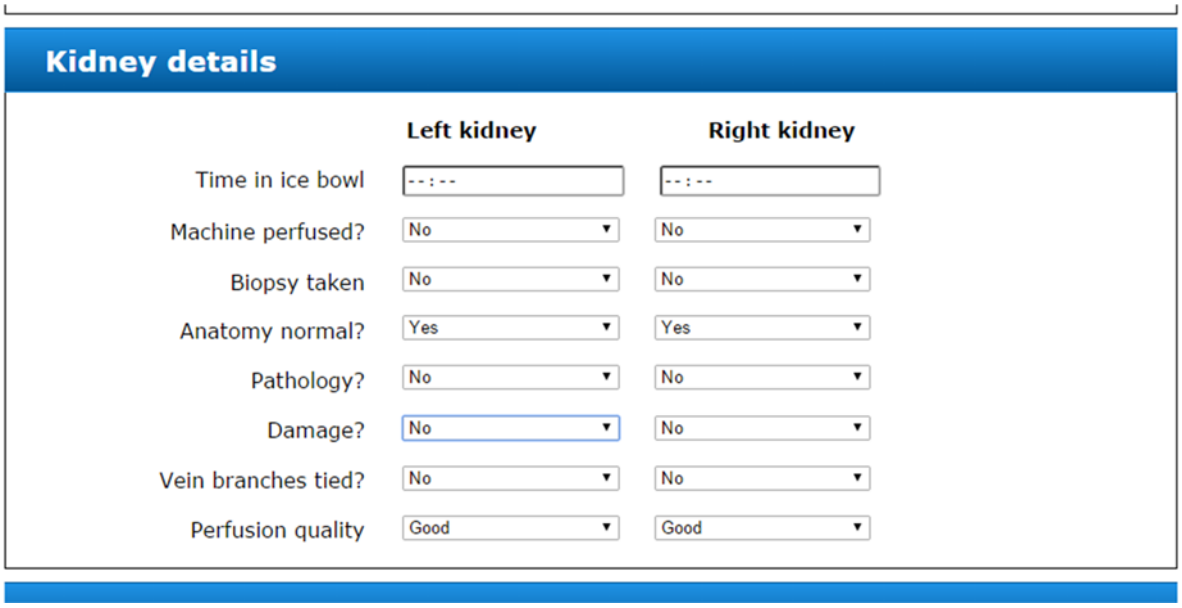
Any effort to collect more data on the forms must be set into this context. To be acceptable to overstretched surgeons, the effort to record more detail must be offset by a system that reduces repetition and unnecessary detail.

The existing paper HTA-A form collects details on a number of anatomical anomalies, pathology and damage, mostly as binary yes/no answers, and many as counterintuitive numerical codes such as 1 for no and 2 for yes. It does not seek more granular detail on those anomalies, pathology or damage, and it is often on that detail that a decision regarding suitability for transplant is made. Nor do the existing forms include pertinent information on novel preservation technologies such as normothermic regional perfusion.

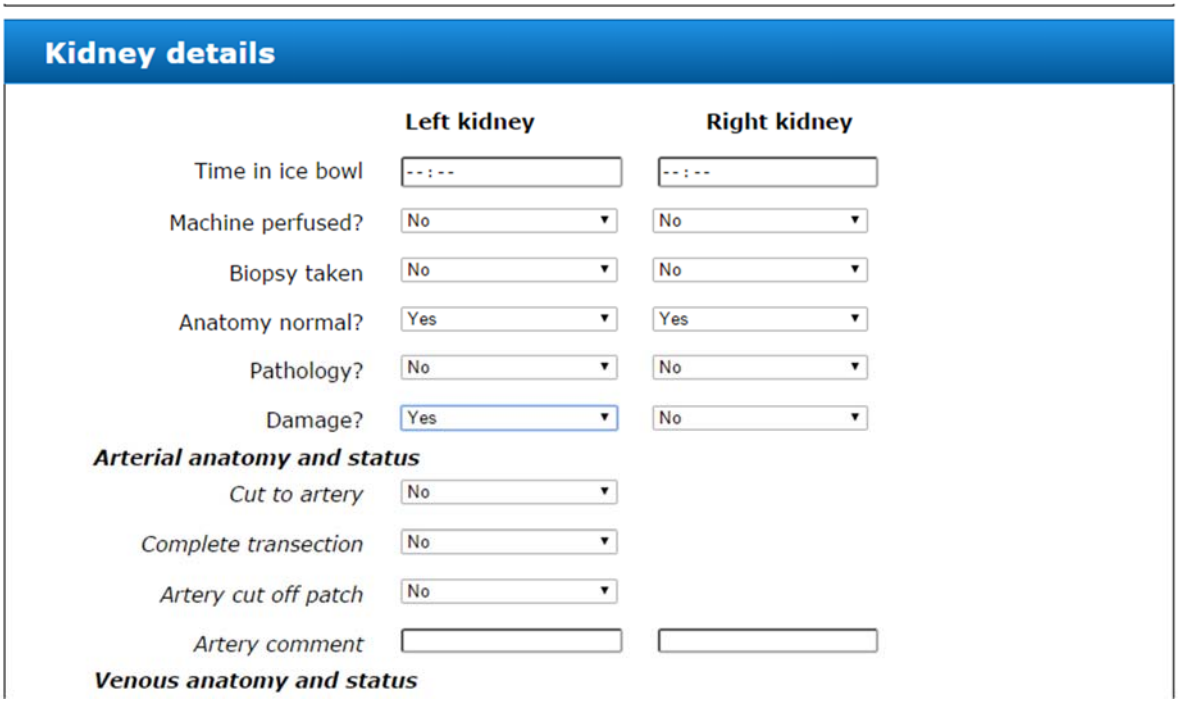
The proposed electronic form avoids repetition as the donor details, timings and perfusion details are asked once for all organs, and where an answer affects more than one organ simultaneously, e.g. a replaced right hepatic artery which impacts both liver and pancreas, the answer given in the sub-form for one organ can be replicated automatically on the other sub-form, saving effort and avoiding inadvertent discrepancies.

The burden of form filling is reduced on the electronic form by showing and hiding form fields so that more detail is only sought when relevant. For example, the form asks if there is any kidney damage, and if so, further fields are revealed to ask whether the damage is arterial, venous, ureteric or parenchymal; then, depending on which categories of damage are selected, further questions about the nature of the damage are revealed. If there is no damage, then none of these additional questions appear.

The form is designed to minimise the work required for form completion by automatically populating fields from the database whenever possible and by hiding fields until they become relevant. For example, the basic view of the kidney-specific fields is:



If any of the options for machine perfusion, biopsy, abnormal anatomy, pathology or damage are selected, additional fields appear to capture specific information. For example, if damage is selected:



Using this approach, it should be able to capture more detail than currently as the detail will only be requested when relevant. For example, if “Pathology” is changed to yes, the additional fields that appear include one for “Cysts”, and if this is selected then additional fields appear to further characterise the cysts.

The protype interface has been built to test usability, while the working version will be based within DonorPath for eForm A, to provide offline data entry capabilities, and the eForm B will be based within the Microsoft Dynamics CRM platform which in future will be used for transplant centre interaction with ODT such as patient registration, waiting list management and follow-up data reporting.

Functional structure

The basic paper form completed by the SNOD is intended to confirm the organ and provide three pieces of patient-identifiable information to confirm the donor identity matches the hard copy donor blood group report. This form is sent with the organ, can be completed before the retrieval, and allows the organ to be dispatched as soon as it is packaged and in an ice box or on a perfusion machine, so that the dispatch of a heart or super-urgent liver is not delayed by the need to finish the retrieval or complete documentation.

The Form A will be available to view online at the recipient within minutes of its completion by the retrieval surgeon and would also be available for viewing with any transplant offers made after the retrieval, e.g. if a kidney originally matched for a kidney and pancreas transplant is reoffered when pancreas found to be unsuitable.

In an analogous way, if a recipient centre decides not to transplant an organ after receipt, their assessment of the organ and reasons for non-use will be documented on the electronic Form B and when the organ is

offered to other centres, the offer can include access to review both the retrieval and recipient centre surgeons' assessments of the organ to inform a decision on acceptance.

Consultations

To ensure usability and relevance of the eForms, clinical consultations around the dataset, design and processes were performed with both the retrieval community and transplant surgeons from non-NORS centres through the National Retrieval Group, Clinical Retrieval Forum, Advisory Group Chairs Committee, Advisory Groups and volunteer reviewers for each organ. There has also been internal consultation with representatives for ODT Statistics, Information Services, Hub Operations, Specialist Nurses in Organ Donation, IT and Quality.

Taking this further

The full functional plans and architecture and now being decided by a working group within the ODT Hub Project with development work of the working application due to start in July. The Scaled Agile method of IT development has a dynamic approach to planning so the exact date or order of release will depend on which parts of this complex project can be developed first, but the current plans are to start the working application with the eForm B within a single organ, then rolling out to eForm A and B for all organs.

John Asher
National Clinical Lead for Health Informatics, ODT