Minutes

Pancreas Database Meeting

Friday 26th August 2016

10:00 am

Attendees: Carl Marshall (CM); Ally Bradley (AB); Shruti Mittal (SM)

Background:

The pancreas database has been a project under discussion since 2010. The aim is to collate clinical information for transplant patients in one place as currently it is stored in various electronic files and formats and also on paper. SM was involved in the project initially as part of a working group but then left OUH and during this time understands that there have been ongoing discussions about incorporating the database within Cerner but is not up to date with the outcome. SM has now returned to OUH and will be involved in the coordination of this project, which is to develop a clinical evaluation database to run alongside and until the Trust pancreas database is in operation.

CM will be responsible for technical and IT aspects and AB will provide project management support. In the long term, there are plans to incorporate clinical data relating to transplantation in the Electronic Patient Record (EPR) but this may not be for some time and a system is required in the meantime.

Current methods of data storage:

Pre-op data – Excel spreadsheet

In-patient data – paper

Discharge summary – Electronic Patient Record

Follow up (clinic) – paper

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| **ITEMS DISCUSSED** |
| 1. Uses for the data |
| * Service evaluation * Reporting to NHSBT * Information for OUH staff   The pancreas database will be used to store information which can then be extracted to provide clinical (service) evaluation. It is also a requirement of NHSBT to provide reports for transplant patients at the time of transplant, 3 months and 12 months. Also consultants often ask for specific information regarding transplant patients (e.g. rate of graft failures, delayed graft function) and this is not easily obtained or available electronically. A more efficient data storage and extraction facility is required.  Some information is stored in an Excel spreadsheet maintained by Shirley Lockhart and Simon Northover (Specialist Nurses in Transplantation). Another member of staff not currently involved in the pancreas programme (Rob Crookston) will be taking over from Shirley in the near future. At present, pre-op data is entered manually into this Excel spreadsheet and obtained from various sources including email correspondence and phone calls. When information for a particular patient is required by a clinician it is printed off as a hard copy and put in a folder. |
| 1. Migration of existing data |
| Several different data sets relating to OUH pancreas patients are currently held in different formats, for different time periods and by different people. Since 2002 data has been collected by SM, Anand Muthusamy, Sham Dholakia, Beth Royston and Ed Sharples, Shirley Lockhart and Simon Northover and possibly others within the transplant centre. This data will need to be collated and combined into one database. It was agreed that the best starting point for this would be to meet with Shirley Lockhart and Simon Northover and base the initial data set on the fields included in their Excel spreadsheet. Once this step has been agreed it will be necessary to meet with holders of the additional data sets and add extra fields as required. SM will obtain an anonymised version of the Excel spreadsheet currently used by Shirley and Simon and send this to Carl for initial review. CM will also need access to the renal drives.  ACTIONS  Arrange a meeting with Shirley and Simon  DONE – meeting arranged for 10am on Friday 2nd September 2016.  SM to provide CM with anonymised version of Excel spreadsheet.  CM to contact renal IT and obtain access to the renal drives |
| 1. Processes for adding new data/additional data fields |
| Once the initial database has been created it will be possible to electronically merge data from other sources (e.g. SM’s database, Shirley and Simon’s Excel spreadsheet) into it. If a case arises where this is not possible then some data may have to be entered manually. Some data, such as that of organ donors, is not stored by OUH but is obtained from NHSBT (for organ donors this is via EOS). James Gilbert and Ed Sharples are the leads for the pancreas programme and should be included in any discussions involving required data fields. |
| 1. Functionality |
| Functionality and tools for reporting and extracting data will need to be discussed with all users of the database. Reports (such as the one month, three month and twelve month reports for NHSBT) should be automated where possible.  ACTION: Define functionality and reporting requirements. |
| 1. Data fields/items |
| [see above] Data fields will be initially identified from the Excel spreadsheet held by Shirley and Simon. Additional data fields not included in this spreadsheet will need to be agreed with relevant transplant centre staff currently holding separate data sets and agreed with James Gilbert and Ed Sharples. |
| 1. Data dictionary/mapping of data fields |
| It will be necessary to create a data dictionary defining each field and the type of information to be held. This will need to be discussed in more detail at future meetings.  ACTION: Create data dictionary and process for mapping of data fields |
| 1. Clinical coding |
| The clinical data from existing data sets may have been coded in different ways. A single clinical coding method needs to be identified and implemented. Shruti will discuss this with Ed Sharples.  ACTION: SM to discuss clinical coding method with Ed Sharples |
| 1. NHS interoperability 2. Data standards |
| CM is currently researching interoperability and data standards. This will need to be discussed further at future meetings. |
| 1. Contact details for relevant staff |
| Relevant staff include all users of the single pancreas database. For the next steps contact details are required for Shirley Lockhart and Simon Northover. These details are already available. Contact details of all other relevant staff will be obtained as required. Staff from the tissue typing labs will also need to be involved at some point in the future. |
| 1. AOB |
| It would be useful for SM to have access to the Diakonia github repository.  ACTION: CM to provide SM with the github link and access to the repository |
| 1. Date of next meeting |
| To be confirmed |

Summary of next steps:

1. Map process with Shirley and Simon
2. Build system to support data storage requirements
3. Migration of data
4. Clinical reporting functionality