Access to Transplantation

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UK Renal Registry
2012 Annual Audit Meeting
Overview

• Health inequalities & centre variation in access
• ATTOM – study design
• Qualitative study & survey
• Emerging Themes
• Benefits/outcomes
• Questions
Access to transplant in the UK

• Several studies have commented on healthcare inequalities and inequity
• Patient specific variables such as age and comorbidity affect access to renal transplantation
• Unexplained centre variation in access to the waiting list, time taken for activation and receipt of a transplant once activated*
• Patient and/or unit specific variables that explain such variation not clear

* BMJ 2010;341:c3451
Figure 1: Percentage listed prior to start of RRT or within 2 yrs of starting dialysis
(Excluding centres with <10 patients on RRT)

Non Tx vs Tx centre: OR 0.9 (0.82 to 0.99)
Figure 3  Percentage transplanted (LKD/DCD) within 2yrs of registration
(Excluding centres with <10 patients waitlisted)

Non Tx vs Tx centre: OR 0.69 (0.60 to 0.79)
Figure 4
Median time to waitlisting
(Excluding centres with <10 patients waitlisted)

The centre represented by an unfilled symbol has its final event time as the plotting position as the median time could not be estimated.
ATTOM

Access to Transplantation and Transplant Outcome Measures
ATTOM

- ATTOM – Access to Transplant and Transplant Outcome Measures

- Unexplained between centre variation in getting on the transplant list and getting a transplant once on the list – i.e. post code lottery

- Unexplained between centre variation in outcomes after transplant

- Is graft / patient survival the only way to measure ‘success’ after transplant? What about Quality of life (QoL)?

- Is the current organ allocation algorithm suitable for the next decade? Can we make it more intelligent to maximise benefit for patients?
Survival on dialysis and after transplantation

QoL on dialysis and transplantation

Health economics

Access to transplantation

Organ Allocation
The ATTOM group

Cambridge
Andrew Bradley  
Chris Watson  
Ms Ruth Summers (NHS manager)

Bristol
Charlie Tomson  
Chris Dudley  
Rommel Ravanan

Edinburgh
Gabriel Oniscu  
John Forsythe

UKRR
Damian Fogarty

SRR
Wendy Metcalfe

NHSBT
Rachel Johnson

Royal Holloway
Prof Clare Bradley (PROMs expertise)

LSHTM
Prof John Cairns (Health economic expertise)

Southampton University (Epidemiology & Qualitative research expertise)
Prof Paul Roderick  
Dr Gerry Leydon

+ Ethics & patients representatives
ATTOM Cohort 1

All patients\(^1\) < 75 commencing dialysis in the UK over 12 months
n = 5500\(^2\)
Baseline data on all patients

- Wait-listed on dialysis
  - Transplant
  - Continue on dialysis
  - Death

- Not wait-listed on dialysis
  - Continue on dialysis
  - Death

Qualitative centre level practice pattern assessments

- Enable access to waiting list
- Barriers to waiting list

- Enable receiving a transplant
- Barriers to receiving a transplant
ATTON Cohort 2

Incident transplant patients\(^1\) in the UK

- Functioning Transplant
- Death
- Return to dialysis

n = 2250

Prevalent wait-listed patients in the UK

- Transplant
- Death or removal from the list
- Remain on the transplant list

n = 2250
ATTOM - how

• Plan to have 22 nurses in 22 renal transplanting units across UK collecting data from 72 renal units across the UK; critical to achieving study outcomes (reflected in ~£1million of the grant spent on nursing salaries)

• PROMs (Patient Reported Outcome Measures) questionnaires help assess QoL and quality of health as perceived by patients – some PROMs questionnaires to be administered by nurses

• Plan for nurses to collect information on patients over a one year period – follow these patients for outcomes of interest over the subsequent 2-4 years by linking to the national renal registries (UKRR, SRR, NHSBT)

• Patients not subject to any clinical intervention of any sort. No change to routine clinical care of the patient.
Welcome To ATTOM

Access to Transplant and Transplant Outcome Measures (ATTOM) is an NIHR funded research programme, supported by the Department of Health, Renal Association, British Transplantation Society, UK Renal Registry, Scottish Renal Registry and NHS Blood and Transplant. ATTOM is a non-interventional, prospective, cohort study that aims to recruit all patients aged <75y starting dialysis, receiving a transplant and a similar number of matched patients active on the transplant waiting list, from all dialysis and transplant centres in the UK over a one year period. The study aims are

- To improve equity of access to kidney and pancreas transplantation across the UK
- To optimise organ allocation to maximise the benefit, including cost-effectiveness, from kidney and kidney-pancreas transplantation.

If you require any further information please contact your local renal unit.
Data Entry
ATTOM - when

• Patient recruitment commenced 13/12/11 in some centres and all centres recruiting by September 12

• Most nurses in post for 12-13 months

• Recruitment should be complete for majority by March 2013

• Results/reports from ATTOM published from summer 2013 onwards. ‘Major’ results due in late 2014/2015
Recruitment update (up to 31/08/12)

• All 22 centres now actively recruiting. St George’s last centre to join (21/08/12). Truro only centre not to have recruited patients.

• 3100 patients recruited

• ~700 MC, 1200 IT & 1300 ID patients

• ~350 detailed PROMs and 2750 normal PROMs
Recruitment update continued…

• ~1200 female, 2000 male

• 200 Afro-carribean, 250 Asian, 2150 Caucasian, 15 Chinese, 70 Irish, 300 ‘other’ (lots of Scottish + 2 ‘Yorkshire’ in other!), 200 mixed/missing

• 250 need help ‘always’ or ‘often’ with medical literature, 200 ‘sometimes’

• 850 ‘long term sick’, 800 ‘retired’, 250 ‘unemployed’, 800 ‘working’ (full or part time)
Recruitment update continued…

• PRD – 300 ‘uncertain etiology’, 550 DM, 700 GN, 350 PKD

• 400 had h/o IHD, 2600 did not

• 300 had h/o malignancy, 2700 did not

• 200 had h/o mental disorders, 2700 did not
Qualitative Study

• Semi-structured interviews: Staff & Patients. Exploring listing process and barriers
• Quantitative structured questionnaire / Survey
• Delphi technique
• Data combined with ATTOM results, to improve understanding
Qualitative Interviews

• >100 interviews completed nationally
• >4000 pages of transcribed interviews currently be coded.
• Quality Control, ‘Double coding’
Emerging Patient Themes

- Patients’ sources and understanding of information about treatment options
- Patients’ understanding of specific information on transplantation and transplant listing and view of specific info provided by the renal unit
- Pathways to care
- Patients’ perceptions about how kidney disease affects them
- Patients’ perceptions about the decision-making process and how final decision is made
Emerging Patient Themes

• Patients’ perceptions of treatments (especially dialysis)
• Patients’ attitudes towards live donations
• Ethnicity and Religion
• Patients’ perceptions of support available to them
• Patients’ meanings and feelings attached to transplantation
• Description of the assessment process for transplant listing
• Biographical disruptions and identity shifting
Emerging Staff Themes

- Variation in CKD care pathway/provision of services
- Perception of transplantation and different sub-types
- Staff attitudes towards live donation
- Staff perception of suitability for transplantation
- Staff perceptions about the decision-making process and how final decision is made
- Process mapping & organisational issues
Emerging Staff Themes

• Transplant work up criteria
• Staff perceptions of inequity
• Impact of ethnicity and religion
• Support
• Resources issues
• Interactions between transplanting and non transplanting units
ATTOM - output

• What’s in it for the units?
  Accurate benchmarking of unit level co-morbidity burden / transplant related resource availability
  Share ‘best practice’
  Near complete data returns to UKRR/SRR
  NIHR portfolio income

• What’s in it for the renal community in the UK?
  ‘Real world’ UK clinical evidence base to drive UK clinical policy
  Survival probability model to improve equity of access
  Understanding PROMs in renal patients
  Permanent complete dataset for many analyses by UKRR/SRR
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  • Scottish Renal Registry
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Any questions

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