

Tricks to Improving Teenage Adherence

Transitioning the Paediatric Patient to Adult Services

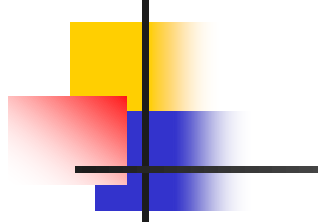
Mignon McCulloch

Paediatric Nephrologist/Intensivist
Red Cross War Memorial Children's Hospital
University of Cape Town

Paul Harden

Consultant Nephrologist and Transplant Physician, Oxford
University Hospital Honorary Senior Lecturer
University of Oxford







What we are good at?

- Looking after really sick...Children
- Not Good at....Looking after Adults
- Where do Adolescents fit in....





Who has lived with an Adolescent?

- Who is currently living with an Adolescent?
- What age do you consider maturity?



AGE OF TRANSITION ?

AYA – Adolescents & Young Adults





Adolescents

- Normal adolescent behaviour plus...
- Chronic illness delayed maturity
 - MRI scan delayed development of frontal lobes
- Body image
- Desire not to be 'Different' vs 'Being Different'
- Compliance/Adherence
 - Medications, Fluid, Diet and Dialysis



Adolescent Challenges

- Groan !!!
 - Patients & Parents
 - Paediatricians
 - Adult Physicians
- Adolescent Clinic started in 2002 at Adult Hospital
 - Graduation ceremony from Paeds with tea
 - Combined Clinic - Paeds went to Adults
 - **Psychologist** and Champion on Adult service

Paediatric Kidney Patient

- Antenatal diagnosis of Posterior urethral valves (Congenital malformation of the bladder) – family devastated
- End stage renal failure with dialysis at 3 years
- Transplant from Mom at 5 years of age – ‘miracle in itself’
- Well known to children’s renal team for 15 years – ‘model patient’ – family always attend.
- 30 patients in clinic – 5 doctors
- Transferred to Adult unit
 - Seen by nurses/different docs 1-2
 - Lots of OLD people
 - Doesn’t know anyone, ‘Mom’ not allowed into room, Where is Pharmacy
 - Doesn’t return to clinic – no phone calls. 300 patients in clinic
 - Doesn’t take medicine – returns in renal failure





Paediatric Kidney Patient

- 'Over'-molly coddled

Young Adult Kidney Patient

- 18 year old scholar just finished Matric – great marks.
- Sports scholarship to university – swimming – junior olympics
- Tired but thought to be due to exams – swelling of legs
- Nephritis undiagnosed and renal failure requiring urgent dialysis
- Loses place at university
- No appetite
- No sport
- No friends
- Depressed – not attending hospital and no medication





Young Adult Kidney Patient

- 'Under' molly coddled

Integrated Paediatric to Adult Transition combined with a Young Adult Transplant Clinic Service reduces Kidney Transplant Failure Rates

**Paul Harden, Daniel Lonsdale, Nikki Bandler, Suzanne Bradley, Stephen Marks,
Judy Taylor, Mignon McCulloch, Grainne Walsh
Oxford Transplant Centre, Oxford; Departments of Paediatric Nephrology
Great Ormond Street Hospital and Evelina Childrens Hospitals, London**

Dr Paul Harden

Consultant Nephrologist / Transplant Physician
in Adult Medicine,
Oxford Radcliffe Hospital, UK

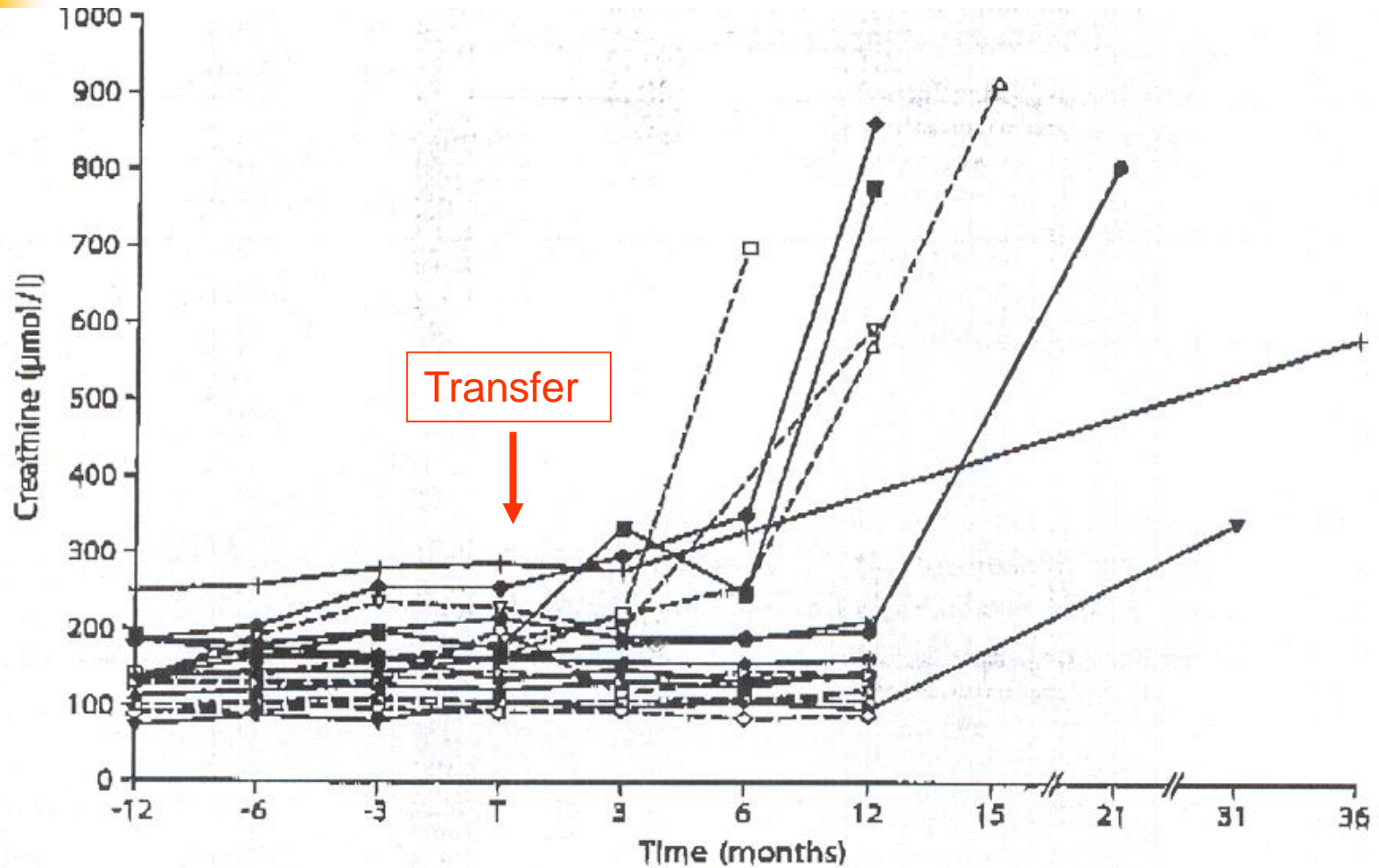
Dan Lonsdale

Youth Support Worker,
Oxford Kidney Unit and Transplant Centre

Oxford Radcliffe Hospitals
NHS Trust



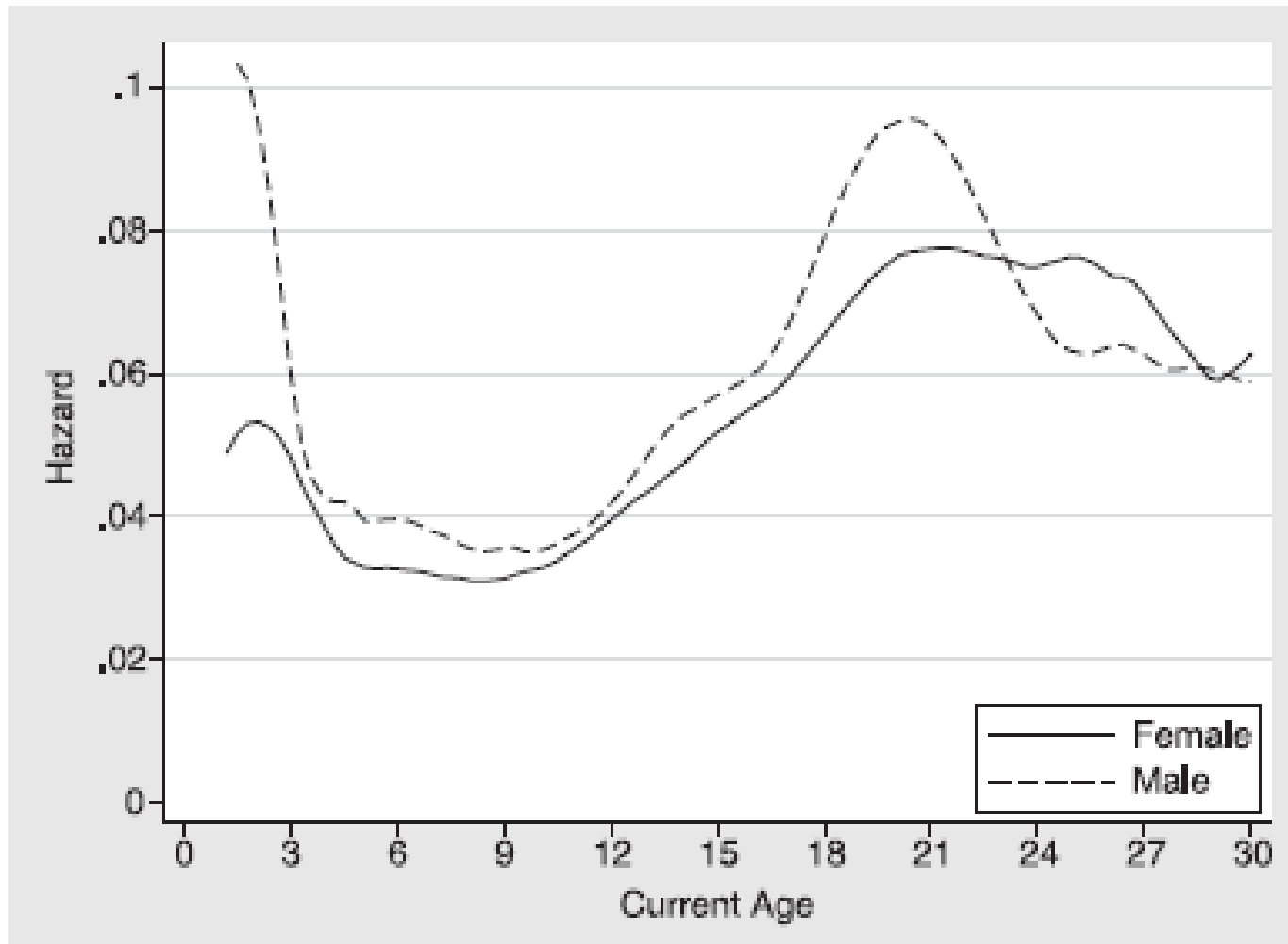
Transfer of Adolescents to Adult Units



35% unexpected transplanted kidney loss (non-adherence)

Watson AR et al (2000) *Pediatr Nephrol* 14:469-472

Kidney loss after Paediatric Kidney Transplantation



Slit



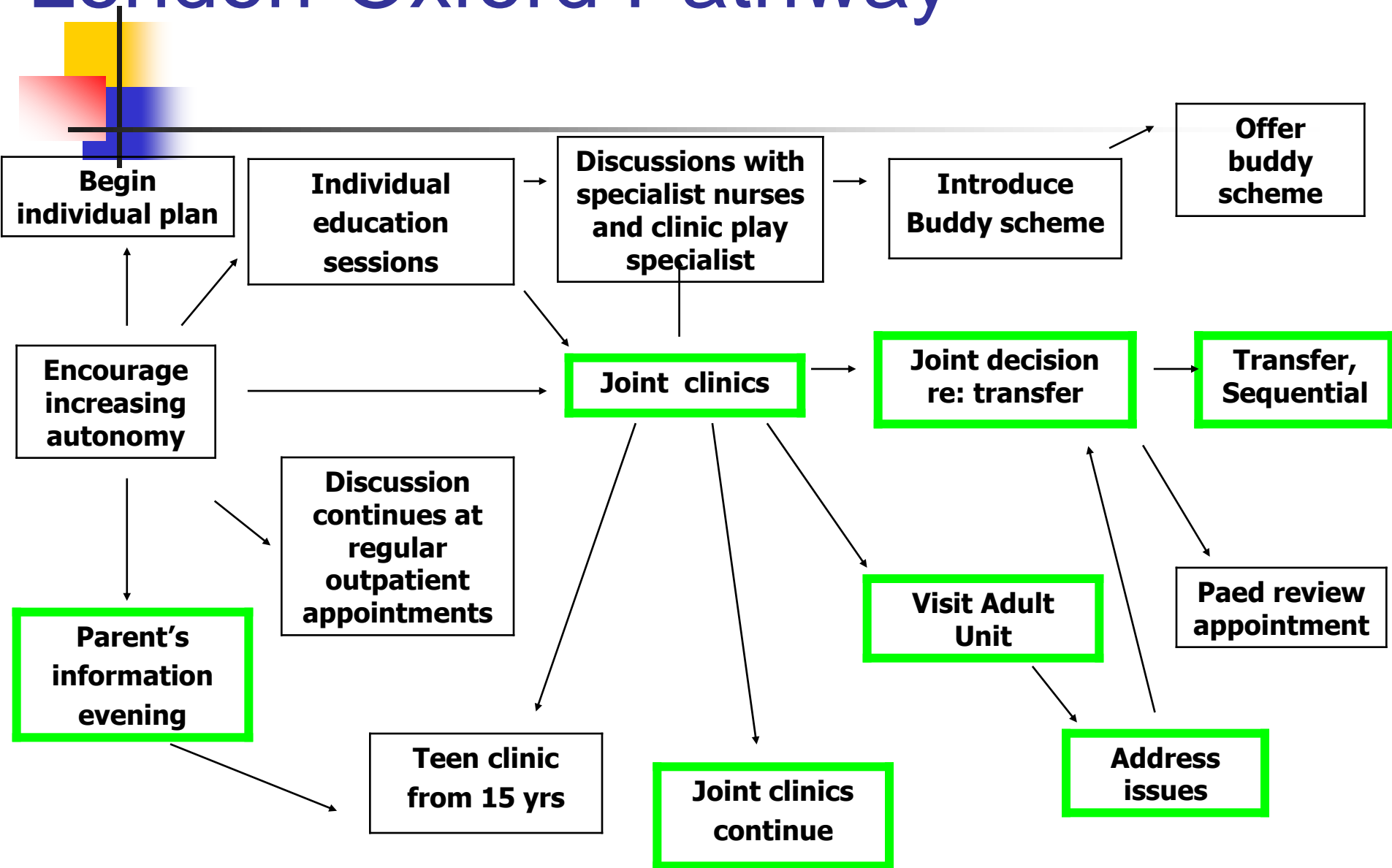
Van Arendonk et al CJASN 2013;8:1019-26



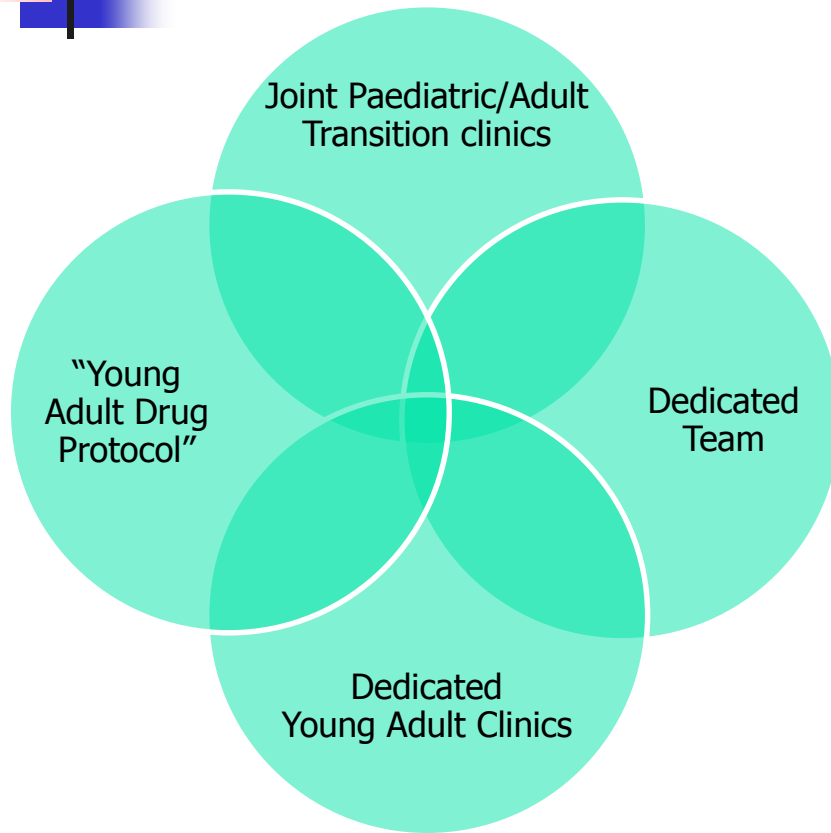
Paul Harden

- Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure.
 - *Harden PN1, Walsh G, Bandler N, Bradley S, Lonsdale D, Taylor J, Marks SD. BMJ. 2012 Jun 1*
- Adolescents are paediatric and adult physicians shared 'challenge'
- Watch unique clinic in action

London-Oxford Pathway



Oxford Young Adult Services



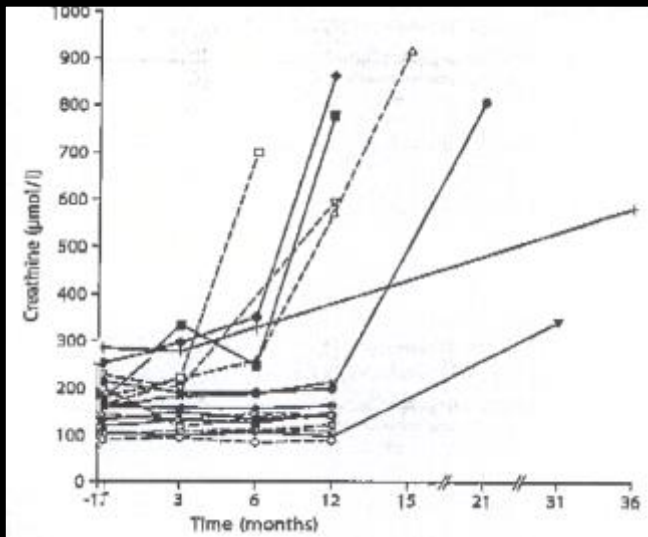
Oxford Model



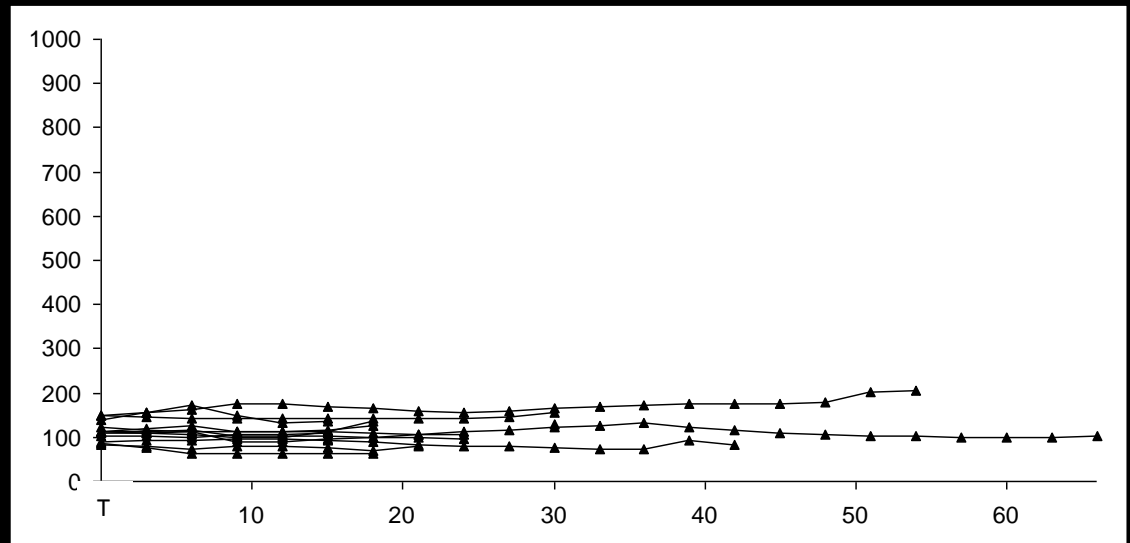
OXFORD YOUNG ADULT CLINIC

Transition patients serum creatinine post transfer

UK Nottingham cohort



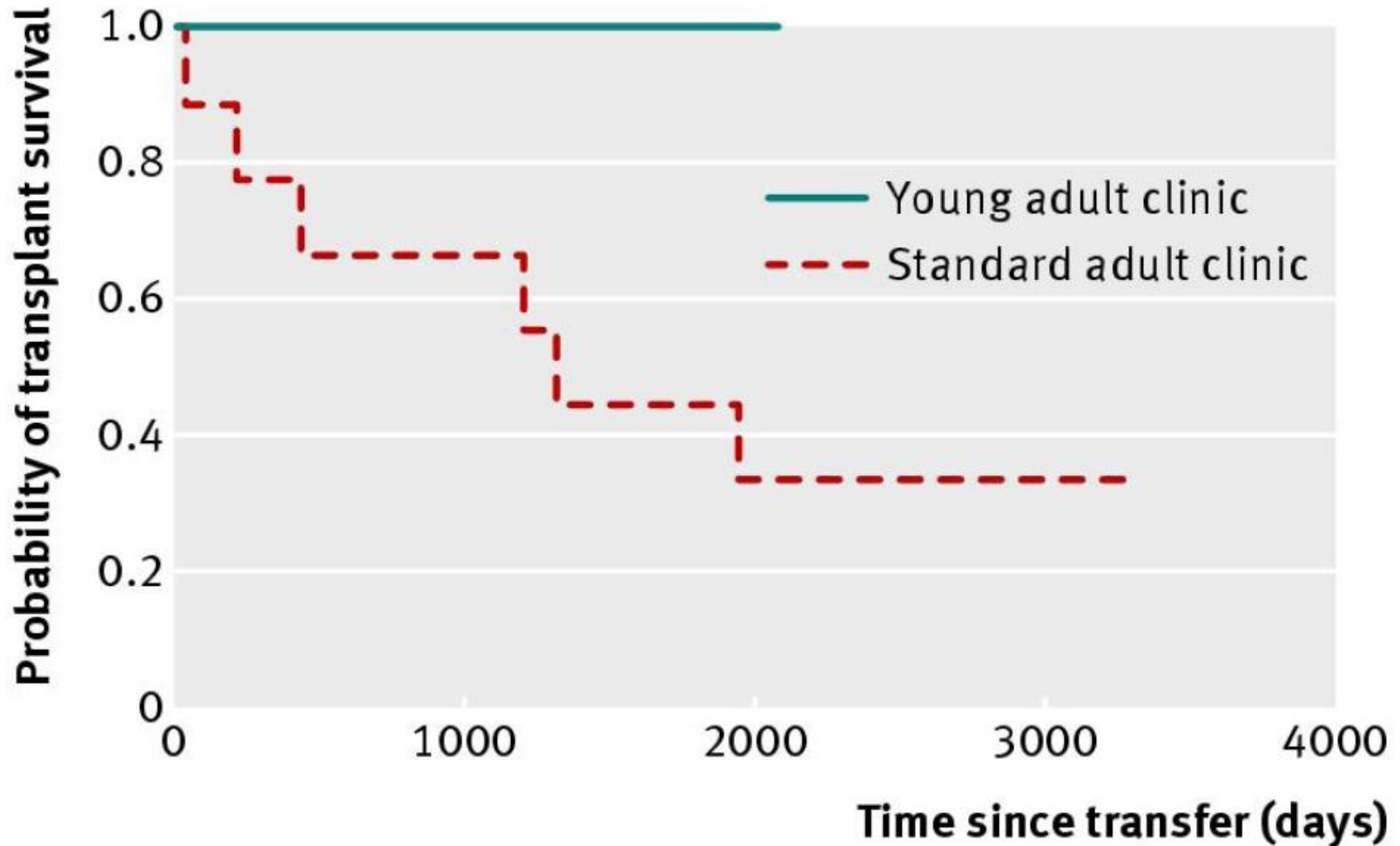
Oxford - London Integrated transition cohort



No of patients = 12

Total months in follow up = 401

Transplant survival post transfer



BMJ 2012;344:e3718

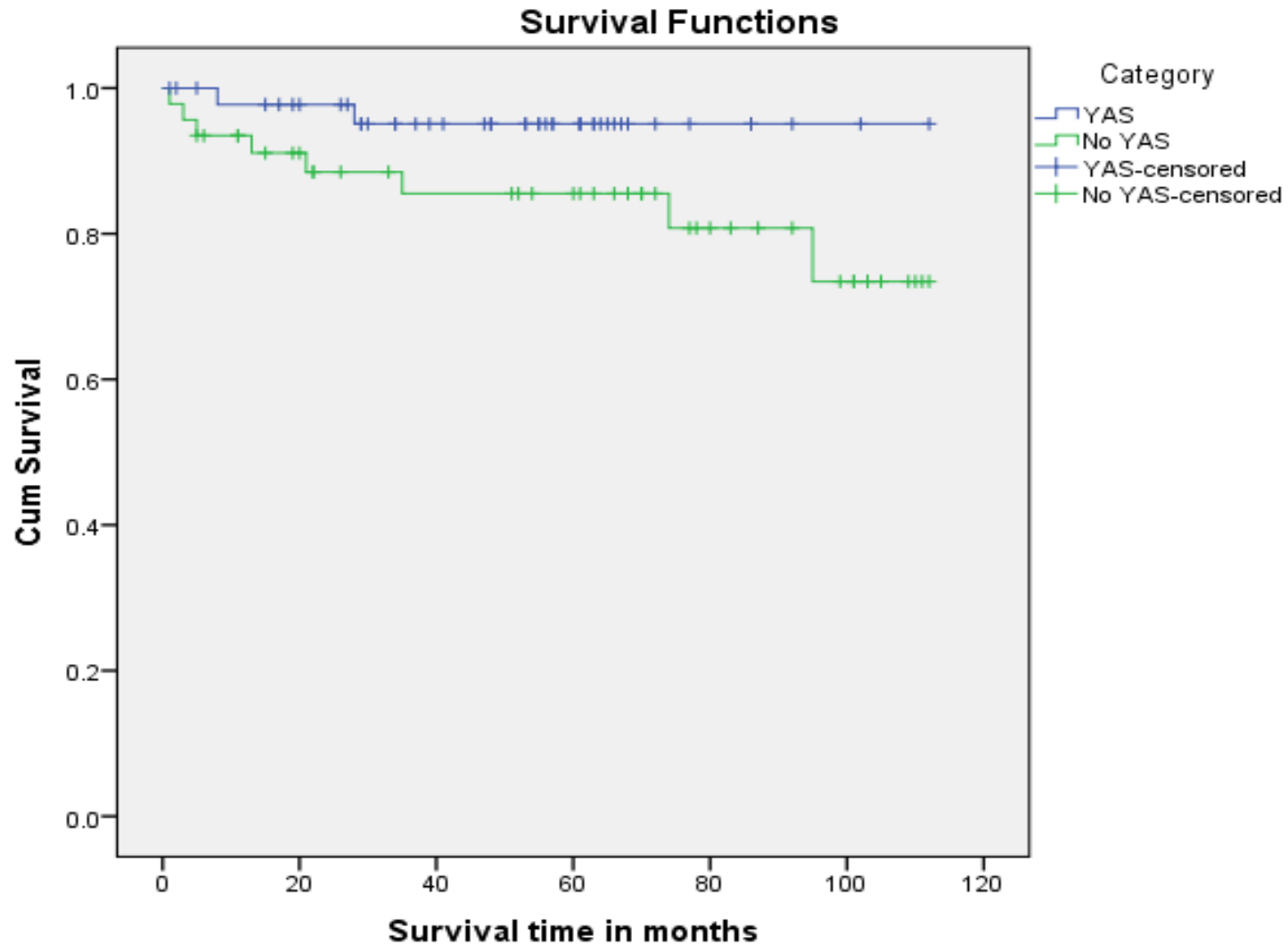
No: of YAC patients (2006-2011) = 12
No: of pre-YAC patients (2002-2006) = 9
Median Follow-up = 24 months



Outcome of Young Adult Service(YAS) in Adult Presentation Group

- 2005-2014: **93 Kidney Transplants age 17-30 in Oxford**
- 60m;33f: 84.9% White: Mean age at Tx: 24.2(17-29) yrs
- **47 (51%)** were involved in the Young Adult Service (YAS)
- YAS pts: late rejection (>3 m) **1/47 (2%) v 6/46 (13%), p= 0.046**
- YAS pts: graft loss **2/47 (4%) v 8/46 (17%), p= 0.041**

Transplant survival: Conventional care versus Young Adult Service





Key Messages

- *Individualise* transition plans
- *Integrated partnership* between paediatric and adult centres
- *Youth Friendly* Young Adult Service
- Utilise *peer support* – group interaction / mentorship program
- *Youth Worker* to provide 1:1 and group support
- *Simplify Medication Regimens* : once daily / dosette boxes / mobiles
- *Young Adult Patient COMMUNITY* : Facebook / social events/

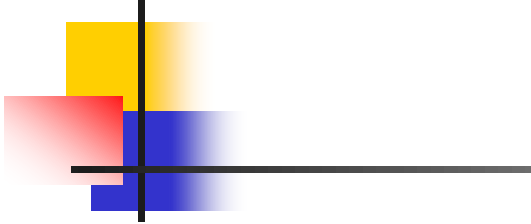


What happens in Cape Town?



Not everyone gets dialysis

- Adult service starts at 13yrs
 - 12yrs and many months
- Cape Town limited number of dialysis slots in state practice
 - Vetting committee chooses best 'candidate'
 - Adolescents may not fall into that category
- Non-adherence may result in death
 - First kidney transplant or subsequent
 - If no living related donor



Warrior - Fight for cause

- You owe it to your young adult patients
- Affects all adolescents with chronic illness
- NHS Kidney Care:
 - *New Supporting Young Adults Project*





Thanks to:

- Paul and his team of patients came to share their experience with our doctors
 - Ride the Argus as well as fund raise for a psychologist for our young adult service
 - Paeds colleagues – hard work
 - Adult Colleagues – vision and commitment



9th Congress of the
International Pediatric Transplant Association

IPTA

2017

BARCELONA, SPAIN

May 27-30, 2017

www.ipta2017.org

IPTA President

Burkhard Toenshoff
University Children's Hospital
Heidelberg, Germany

IPTA 2017 Congress Chair

Anne I. Dipchand
The Hospital for Sick Children
Toronto, Canada



International Pediatric
Transplant Association



IPTA is a Section of
**The Transplantation
Society**

