

UK Kidney Association: Transition to Young Adult (TYA) Specialist Interest Group

Aim: To optimise the care of young people transitioning care to adult services in the UK, to ensure shared decision making, limit avoidable harm and improve patient outcomes.

Composition and Members

The TYA Specialist Interest Group (SIG) will have delegated leadership responsibility, on behalf of the UK Kidney Association (UKKA), for AKI. It will be led by two *overall SIG chairs*, one medical and one multi-professional. The chairs will be members of the UKKA Executive Council and will be responsible for producing written reports for the UKKA Executive Committee and Board. They will usually serve for three years and no more than four years.

The SIG chairs, or delegated nominees, will be responsible for keeping the Committee's website up to date with information about current SIG workstreams and membership. They will also keep the wider UKKA membership informed of the SIGs activities. They will convene full meetings of the TYA SIG every 4 months by videoconferencing, plus an annual face to face meeting at UK Kidney Week. As this is a new group the two TYA SIG chairs will work with the SIG members identify the initial priorities of the SIG. Three months after establishing the SIG the co-chairs will submit to the Executive Council an outline of 3-5 priority areas and proposed workstreams and potential outputs from these workstreams.

The membership of the SIG will be based on calls for EOIs to all the UKKA membership. We will look for representation from EOIs that are consistent with the Equality, Diversity, and Inclusion principles of UKKA. Broad geographical representation will be encouraged to ensure representation from across the UK, including membership from the devolved nations, and English regions. The SIG will have seconded membership from: BAPN, Patient safety, KQuIP, Renal Registry, Education Committee, UKKRC Clinical Study Group. Members will serve for a 3-year term. It is recommended that no member will serve more than two back-to-back terms

Rationale and remit

The TYA SIG will work towards establishing the following core workstreams:

1. Improvement and implementation – based around service delivery and setting standards for an appropriate workforce
2. Patient experience, patient information and shared decision making
3. Data and measurement
4. Educating the workforce (working with the education committee)

Improving kidney outcome of young people and young adults with kidney conditions through Quality Improvement, Standard setting, Service Review and Implementation.

Repeated studies have demonstrated patient outcomes (e.g. transplantation and CKD) are poor in the cohort of kidney patients undergoing transition from paediatric to adult care and in young adults. This is a great opportunity to meet the need of this unique patient group (including sexual, mental and reproductive health, work and education needs, among many), and address how disease and treatment affects them differently. Published QI have shown tangible improvement in outcome with novel ways of working and engagement.

We will identify key stakeholders and promote partnership across professions, specialties, care settings and patient groups. Stakeholders will include but not be limited to the multi-professional workforce across paediatrics and adult services and identify champions and experts in this field, as well as patients and carer representatives. It will engage and maintain a positive culture of reaching out and inclusiveness across this diverse high-risk population.

National, regional and local partnerships will be supported by integration across *Kidney Quality Improvement Partnership (KQuIP)* networks. We aim to secure collaboration at all levels of NHS leadership including the new Integrated Care Services. It will utilise QI to limit unwarranted variation between services, to join up care, and identify barriers and enablers to implementation, including adverse outcomes and care costs associated with poor transition care. We will encourage best practice pathways to transition patients into adult services.

Patient experience, patient information and shared decision making

The SIG will use the strong existing links with patient groups and the wider kidney community to ensure patient information appropriate to them is available in formats and spaces most accessible to this group. We will work with patient groups to scope for and address unmet needs.

Data and Measurement

The SIG will use the UK Renal Registry and other registries such as Rare Radar and Transplant registry as well as work with clinical and research leaders to ensure patient care, treatment, outcomes, research, information, and service delivery are tailored to this unique population. We will ensure Kidney Patient Reported Experience Measures (PREM) meets their needs and findings relevant for them are acted on.

Educating the workforce

We will scope and address the education and training needs to serve this patient population, coproducing with multi-professional and patient groups. The aim will be that all young people will have high quality developmentally appropriate care and encouraged and empowered to make shared decisions wherever they live, whichever unit they attend and whatever kidney disease they have.

We will be delivering on the below:

NICE Pathways
and
Personalised
Care Agenda

ICB CYP 0 – 25yrs

Quality Improvement

Shared decision making
Information (4, 5)

- Ask 3 Questions
- Health literacy

Maintaining usual activities,
Advocacy + support (6,7)
Social Prescribing

- Youth workers
- Family therapist
- MDT

Transition (10),
SIG transition/YP

- 16+ pathway
- Adult directory of MDT supporting YP in adult services