

# Transition and Shared Decision-Making Special Interest Group

Making the move from paediatric to adult services can be a difficult time for patients with kidney disease, and there are a lack of national data on this in the UK. Rachel Gair reports on the initiatives being implemented by the Transition and Shared Decision-Making Special Interest Group, and discusses how their outcomes might impact on patient care for young adults.

■ young adult ■ shared decision-making ■ person-centred care ■ quality improvement ■ communication

**T**he British Renal Society Transition and Shared Decision-Making Special Interest Group (TSDM SIG) is a multiprofessional body that was formed in 2014. TSDM SIG was developed from two networks with a longstanding interest in person-centred care: a network of renal clinicians who had previously participated in projects relating to shared decision-making (SDM), and a collective of health professionals working on improving the experience of young adults as they move from paediatric to adult services.

Membership of the TSDM SIG includes:

- Young adults with kidney disease
- Representation from patient charities
- A clinical research fellow
- A youth worker
- Specialist nurses in transition and SDM
- Adult and paediatric nephrologists with an interest and expertise in the transition of young adults
- Adult nephrologists with an interest and expertise in person-centred care and SDM.

TSDM SIG comprises a circle of passionate experts, including patients, who would like to improve services for young people (and others) using a person-centred approach. The group promotes the sharing of good practice by facilitating communication between different members of the multidisciplinary team.

## Rachel Gair

Person-Centred Care Facilitator,  
UK Renal Registry, Bristol

Email: [rachel.gair@renalregistry.nhs.uk](mailto:rachel.gair@renalregistry.nhs.uk)

It also links people with an interest and with examples of successful work in the following areas:

- The care of young adults (12–30 years) with chronic kidney disease and their families/carers as they transition from paediatric to adult renal services
- The care of young people who present directly to adult services without transitioning from a paediatric service
- Partnership between paediatric and adult services so as to present a consistent and collaborative approach from professionals working in the field
- SDM and supported self-management for patients with kidney disease
- Person-centred care and partnership working using principles and values of coproduction to plan future services.

## Key priorities

There has been a lot of talk in recent years about patient involvement and person-centred care. These are important priorities, and clinicians know how challenging it can be to work within existing systems and budgets to deliver truly person-centred care. Patients perhaps know this even better.

The purpose of the TSDM SIG is to enable sharing of best practice by helping clinicians to learn from each other's experiences. TSDM SIG also aims to make people aware of existing excellent practice, ongoing projects and useful resources.

## Variation in young person's services across the UK

There has been increasing recognition over the past few years that transition is a risky

time for young people. In fact, national policies have been developed which acknowledge this.

There is plenty of excellent work being undertaken and examples of outstanding practice; however, this enthusiasm has yet to translate into meaningful action in some centres. Good examples have holistic care at their core and offer a person-centred approach.

In February 2016, guidance was published by the National Institute for Health and Care Excellence (NICE) on the transition of young people using health services (NICE, 2016; Singh et al, 2016). At present, there are no national data regarding transition and young adult services in UK renal units.

## National survey

TSDM SIG believes that data collection is important to compare caseload and service provision, and to demonstrate the value of young adult services. To gain an understanding of the provision and services available to young adults across the UK, TSDM SIG supported the development of a short survey to send to all UK renal units.

The survey included questions on the delivery of specific transition clinics, the key worker role and the use of assessment tools. TSDM SIG also wanted to gain an understanding on whether staff involved in young adult services had received training in SDM and motivational interviewing.

The results of this data collection will offer insight into the variation in the provision of young adult services across the UK, and also help to inform a consistent approach to future service developments.



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## Transition to adult services has been recognised as a particularly risky time for young people

At the same time, TSDM SIG has supported the development of a minimum data set on transition services that is being piloted in an adult renal unit. This will be reviewed in 2017 by TSDM SIG and ratified with a view to recommending it as a template for data collection of young adult services across the UK. Data will be non-identifiable and in the first instance will be owned by the trusts or renal units.

### Key worker focus group

Several units across the UK have key worker roles in place. These comprise specialist nurses or youth worker positions and in the main provide non-clinical support. The roles identify and support young adults, coordinating implementation of interventions to reduce risk and increase empowerment. One of the most powerful tools is peer support, and for the past 5 years, an activity weekend funded by the British Kidney Patient Association (BKPA) has been held at a youth hostel in the Peak District. This has been organised and coordinated by several of the key workers supported by the TSDM SIG. The weekends are available for 18–30-year-olds and have proved so successful that TSDM SIG is planning on a larger venue and the potential of additional weekends for the forthcoming year. Commenting on the benefits of these weekends, a young person from Scotland said:

*'Being a renal patient for 21 years, from a very young age, it is very easy to feel alone in your situation. However, having*

*weekends like the one in Derby makes you feel part of a community of other young people who are going through the same things. It is so important to be able to talk about what you are going through and meet other people who you can lean on, support and become friends with. It was an incredible weekend all round and I thank the BKPA hugely for their funding to make the weekend happen.'*

### Young adult focus group

The young adult focus group has developed as a result of the TSDM SIG peer support weekends. It is run by young adults who have agreed to:

- Develop a network of peer support for other young people
- Become a credible voice for young people with kidney problems and ensure that this voice will develop and grow as the group gains confidence
- Provide a service to support research and quality improvement nationwide (e.g. provide test surveys, patient information and an expert voice into planning of young adult services).

The group has also set up a Facebook page (<http://tinyurl.com/pzzyhjn>) and is developing different ways of communicating and engaging with other young people.

### Annual events

TSDM SIG holds an annual meeting each year during UK Kidney Week and also aims to run a yearly education conference. There have been a number of

these highly successful learning events, incorporating topics such as peer support, communication skills and motivational interviewing, writing letters directly to patients, care planning and patient decision aids. This year, TSDM SIG's annual event, 'Setting up services for young people: perspectives, practice and planning', will be held on 1 December 2016 in Salford. The programme incorporates the young adult perspective alongside the key worker standpoint, supported by examples of person-centred care in practice.

### Useful resources

TSDM SIG can also help signpost clinicians to some helpful resources from key organisations. Some examples are:

- The Transforming Participation in Chronic Kidney Disease programme (<http://tinyurl.com/ouy86sq>)
- Shared Haemodialysis Care (<http://tinyurl.com/q4vd962>)
- National Voices (<http://tinyurl.com/o8nsw26>)
- The Ready Steady Go Transition Programme (<http://tinyurl.com/of46zae>).

### Conclusion

TSDM SIG maintains that there are huge opportunities to improve the experience of patients by sharing good practice. There is particular inequality across the UK in the provision of services focused on young people with these conditions. TSDM SIG is providing data and learning opportunities so that renal teams can improve services without having to reinvent the wheel. **JKC**

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*If you would like to join our network to help improve the provision of shared decision-making and the experience of young adults, please contact [rachel.gair@renalregistry.nhs.uk](mailto:rachel.gair@renalregistry.nhs.uk).*

### References

- National Institute for Health and Care Excellence (2016) *Transition from Children's to Adults' Services for Young People Using Health or Social Care Services*. <http://tinyurl.com/o985pd7> (accessed 8 November 2016)
- Singh SP, Anderson B, Liabo K, Ganeshamoorthy T (2016) Supporting young people in their transition to adults' services: summary of NICE guidance. *BMJ* **353**: i2225