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## Meeting the needs of Young Adults with Inflammatory Kidney Diseases – A Service Evaluation

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### Introduction

We set up a Young Adult Clinic at our hospital in 2014 for patients with inflammatory kidney diseases aged 16 to 24 years. This aims to meet the healthcare needs of young adults; easing the transition from paediatric to adult healthcare; supporting patients' understanding and management of their condition; building confidence with managing their medication and prescriptions, and addressing any impact of their condition on work, education and family planning. A key aim is that all patients should be in employment, education or training within 12 months of diagnosis. The multidisciplinary team comprises doctors, nurses, psychologists and a youth worker. In 2018 we undertook a service evaluation of the clinic.

### Aims

1. To assess how useful patients find the clinic.
2. To assess patient experience of the support provided by the clinic staff.
3. To assess to what extent patients manage their own conditions.
4. To assess whether patients need additional support to (re)enter education or employment.

### Methods

Patients attending the clinic completed an anonymous survey in the waiting room prior. The survey was approved by the hospital Patient Experience team and the service evaluation registered with the Clinical Governance team.

### Results

26 patients complete the survey; 50% were female; 10 were white ethnicity and 9 South Asian; 38% had SLE; 50% had previously attended paediatric renal clinics.

54% preferred to attend Young Adult rather than the main clinic with 42% not expressing a preference. Increased confidence in managing their condition was reported by 65%, whilst 27% reported they were confident before attending the clinic. 92% reported managing their own medication at home, although only 77% managed their repeat prescriptions.

All patients reported getting the opportunity to ask any questions they wanted. 77% reported receiving answers in a way they understood from doctor and 75% from nurses. All patients who wanted to, had had the opportunity to discuss fertility, future parenting and drug and alcohol use. 95% felt it was important for them to be able to contact the Specialist Nurse and 100% felt able to do so.

45% had discussed employment or education plans with the clinic team with only 12% reporting having to make minor changes as a result of the illness; no-one reported making major changes. All but one patient reported being in employment, education or training.

Although fostering peer support had been an intention of the clinic only 30% reported benefit from speaking to other young adults with similar conditions. 65% do not talk to other patients, although several reported they would like to do so.

### Conclusion

The Young Adult clinic is largely meeting the needs of the patients. Patients are continuing their educational or career journeys, whilst gaining confidence managing their conditions. The value patients place on access to a nurse is clear. Interestingly, despite being a key element of the clinic design, peer to peer engagement is low. Further work is required to better facilitate peer support.