

Development of a new software application (App) to enhance patient centred management of Nephrotic Syndrome.

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Young adults are a vulnerable group of renal patients who are unlikely to engage in traditional patient support networks. It is crucially important that we find ways to engage these young adults to optimally manage their condition and provide clinicians with a better understanding of the impact of disease on the patient's life. This includes aspects such as managing educational and work/career opportunities, often away from their home or local renal units, and forming relationships; little of which is understood by clinicians. It also involves the often difficult transition to adult units which can be a difficult time for the young patient. The Nephrotic Syndrome Trust (NEST) as part of the NURTuRE biobank initiative (<https://www.nurturebiobank.org/>) is developing a clinical application (App) for patients with Nephrotic Syndrome (NS) which will empower young adults to shape the way technology can improve the communication between patients, researchers and clinicians. This will give the patients the knowledge and confidence to share their lived experiences, so that they have a voice with clinicians and are able to find support networks that suits them. The app will ultimately help patients, particularly young adults, to become autonomous in managing Nephrotic Syndrome, will inform clinician consultation, support transition between paediatric and adult units and improve data capture to accelerate research. Importantly it will also increase the awareness of NS, help to inform better experiences and treatments, and ideally increase the number of young adults (16-25s) being registered within this and similar kidney disease cohorts.

The objective is to use technology to engage and encourage young adults; giving ownership of the project by involving them in the process. We have recruited young adults to become lead ambassadors for the project to contribute to the development of the App and to ensure its usefulness/appeal to this patient population by engaging with other young patients through a program of national, multi-disciplinary roadshows., Although initially the app will be trialled in NS it is hoped that it can be then be rolled out to other kidney disease groups. The app will be used by patient:

- to participate in their own care by keeping regular records of discrete health parameters and key aspects relating to their quality of life which can be actively used to inform their management and accelerate current research.
- develop an increase in awareness, current research and renewed understanding and treatments for NS and other renal diseases.
- ensure that quality of life indicators are taken into account during consultations so patients feel these important factors are taken into consideration.
- to feel less isolated and ensure that they have a vehicle for airing their experiences, which works with their clinicians and research.

The data captured from the App will feed directly into NURTuRE and will dovetail with capturing patient-centred data, resulting in increased quality data for research, resulting in better outcomes.