

Abstract: “A Patient Coordination Portal and Care App”

In 2017 the 22q Foundation Australia & NZ began development of a 22q patient coordination web portal and app. Although there are 22q specific clinics across the globe many people do not have access to them. Services are often accessed across multiple disciplines in multiple locations and often the different teams may not communicate with each other making coordination difficult and time consuming.

The app will empower families and people with 22q to coordinate and control all their records, appointments, treatment centers, physicians, therapists, medications and assessment reminders. This app encourages independence and is part of the planning for people with 22q living in adulthood. www.22q.org.au

The App allows the user to :

- Set up a personal profile for yourself and your loved ones
- Tick off the assessment checklist and receive annual reminders for the recommended assessments due each year (*The Assessment Checklist was formulated and published in the Practical Guidelines for Managing Patients with 22q11.2 Deletion Syndrome*)
- Create a list of emergency contacts
- Create a list of medications with dosage and reminder (it also allows you to keep a history of your medications)
- Set up a list of care, medical and treatment centers including physicians, therapists or anyone who works with you or your 22q person and includes Google Maps
- Store a list of your immunization records
- Create a list of appointments, meetings, events etc... and be reminded via notifications
- Create a list of symptoms and allergies including treatment, severity and the ability to upload photos, reports and files
- Create a list of surgeries, treatments and helpful information
- Send the personal medical profile including reports or files directly from the portal and App to any person via email
- Join the community directory and connect with people near you (optional)
- Join the 22q Registry and be a part of research (optional)(Privacy Policy Applies)