

PLANET Registry and Mobile Application

Why is the Registry and App so important?

The Unicorn Foundation, in collaboration with the eResearch department at Melbourne University, have developed a world class Neuroendocrine Tumour (NET) registry and mobile app. Initial support has been provided by IPSEN Australia, and the project has been made possible by the PLANET Registry Committee, in consultation with patients, our Consumer Advisory Group.

The PLANET Registry and app have progressed through a rigorous ethics and governance approval process over the last 12 months and we are pleased to report that we are now ready to roll out at all the key NET hospitals in each state. Patient data is currently being imputed at each site and we are now at the stage to pilot the associated app, an app which gives the patient the power to provide data directly into the registry.

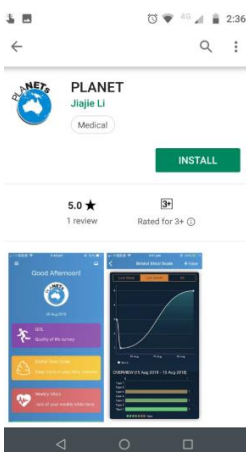
How the process will work, is once patients give permission to join the PLANET Registry, they will be given a unique authentication code to access the app. The mobile app can then be downloaded, activated and accessed from both iOS and Android devices. This will enable patients to enter information relevant to their ongoing care provided by their health professionals.

To download the PLANET application for iOS:



- Go to the App Store and search for **“PLANET medical”**
- Click on **“install”** and wait until the **“PLANET”** icon appears on your device
- Tap the icon to open the app then enter your activation code (App ID)
- Click on **“activate”** and you have successfully connected your device to the study

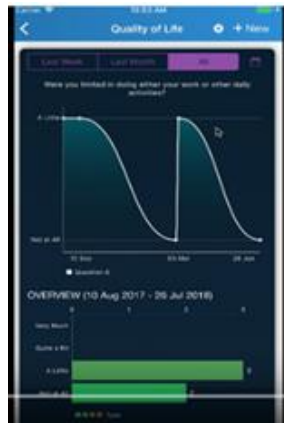
To download the PLANET application for Android:



- Go to the App Store and search for **“neuroendocrine NET registry”**
- Click on **“install”** and wait until the **“PLANET”** icon appears on your device
- Tap the icon to open the app then enter your activation code
- Click on **“login”** and you have successfully connected your device to the study server.

If you receive any error message, please make a note of the error and the time of the error and give the information back to the clinician that gave you these instructions.

Types of information that are entered in the app include:



- Quality of Life survey
- Bristol Stool Scale
- Monthly Vitals
- ECOG

How often should I be filling in the surveys on the app?

This is a discussion to have with your clinician or nurse, however, we suggest this simple guide based on your treatments:

Treatment	App Use Frequency
SSA	Monthly
PRRT	Monthly
Chemo – Carbo / Etop	3 weekly
CAPTEM	4 weekly
Everolimus	Initially 1-2 weeks, then 4 – 6 weekly
Sunitinib	Initially 1-2 weeks, then 4 – 6 weekly
Telotristat	Variable depending on other treatment
Immunotherapy	Monthly
Other	Monthly

To change your notification frequency, go to **“Settings”**, click on **“Reminders”**, enable notifications, and set the time and frequency you want to be sent an alert.

From time to time you may receive a message from your clinician. It is the hope of this project, to be able to easily identify patients for clinical trials so that we can improve NET research into the future.

We would like to thank our wonderful patients for being involved in this vital project, and only by working together can we look forward to a better future.

For more instructions and videos please visit the Unicorn Foundation at www.unicornfoundation.org.au