

# DATA IS POWER: REGISTRY EXPERIENCE AT AN ENETS CENTRE OF EXCELLENCE

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## Introduction

The collection of anonymised data for patients with neuroendocrine tumours is necessary for quality assurance, monitoring patient pathways and disease characteristics and the ongoing improvement of patient care and research.

## Aim

To develop a registry from an in-house database

## Timeline of Data Management Strategies at Peter MacCallum Cancer Centre (PMCC)

2009	<ul style="list-style-type: none"> <li>MS Access NET Database developed to run PRRT Therapy Program</li> <li>Entry of Paper Quality of Life Surveys.</li> </ul>
2017	<ul style="list-style-type: none"> <li>NeuroEndocrine Cancer Australia established as Sponsor and Study Coordinator</li> <li>Committee established and PLANET Registry developed based on MS Access NET Database</li> <li>Beta Testing PLANET Registry</li> </ul>
2018	<ul style="list-style-type: none"> <li>Ethics submission for 5 sites across Australia via the Mutual Acceptance Program</li> <li>Addition of Treatment Planning Fields to NET Database to satisfy ENETs requirements</li> <li>289 of 616 Database fields chosen for data upload to Registry</li> <li>Surrogate ID added to avoid use of known identifiers and allow opt out model of consent for PLANET Registry</li> <li>Accreditation of PMCC as ENETs COE</li> </ul>
2019	<ul style="list-style-type: none"> <li>Recruitment of patients to Registry</li> <li>Upload of Encrypted Data from MS Access to PLANET Registry</li> <li>Patients record Quality of Life data, Vital Signs and Bristol Stool Scale via PLANET Mobile App replacing paper records</li> </ul>

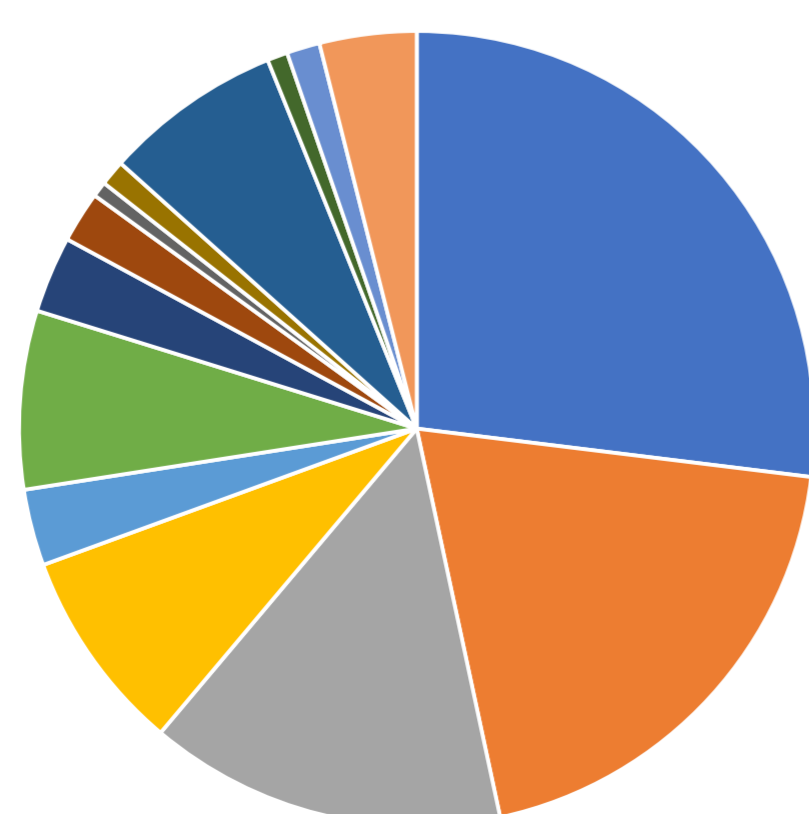
## Entity Relationship Diagram



Data is recorded in the MS Access Database and PLANET Registry for the entities shown in the diagram. A One to many relationship is specified for each entity relative to the Patient entity.

## NET Database Patient Characteristics PMCC

Tumour Type (Primary Site or Rare Type), (n=1178)



- Pancreas
- Lung
- Appendix
- Neuroblastoma
- Phaeo
- Small Bowel NOS
- Duodenum/Ampulla/Prox/Jejunum
- Gastric
- Unknown
- PGL
- Lower Jejunum/Ileum
- Colon/Rectum
- MEN1
- Merkel
- PGL=Paraganglioma, Phaeo=phaeochromocytoma NOS=Not otherwise specified

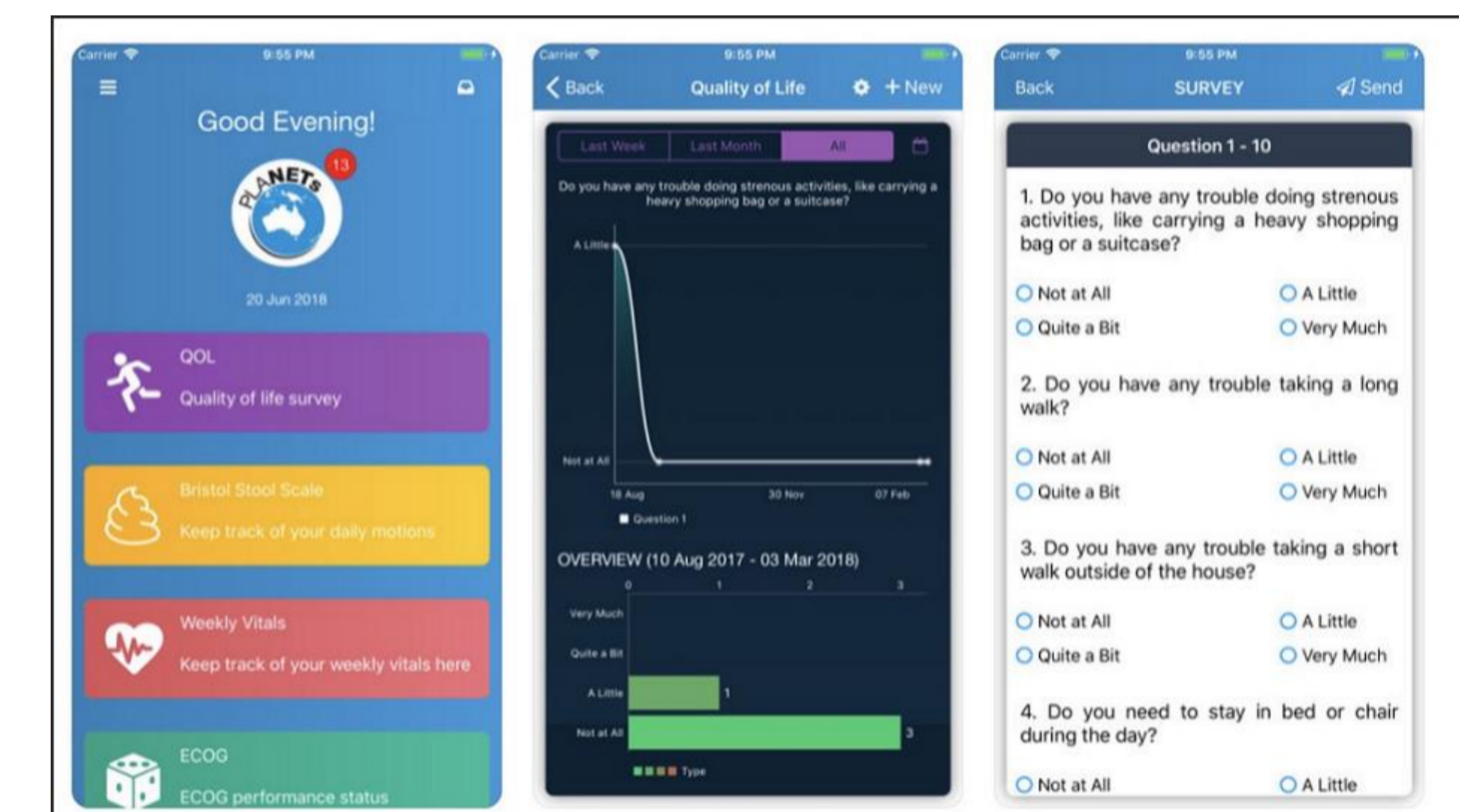
## Methods

- A MS Access NET Database was developed in 2009 to provide a means of capturing NET patient data
- The NET Database was expanded in 2016 to provide the data necessary for the ENETS Centre of Excellence requirements
- The PLANET Registry was developed to allow national recording of NET patient data and use of a mobile phone app to record Patient Recorded outcome measures
- Additional fields and modification of fields was required to align the NET Database with the PLANET Registry.
- Data was extracted from the NET Database, encrypted and uploaded to the PLANET Registry.
- Patients were invited to enter the following data using the Mobile App associated with the PLANET Registry.

## PLANET Mobile App for Patient Data

The PLANET Mobile App (shown at right) allows patients to enter:

- Quality of Life
- Bristol Stool Scale
- Vital Signs
- ECOG

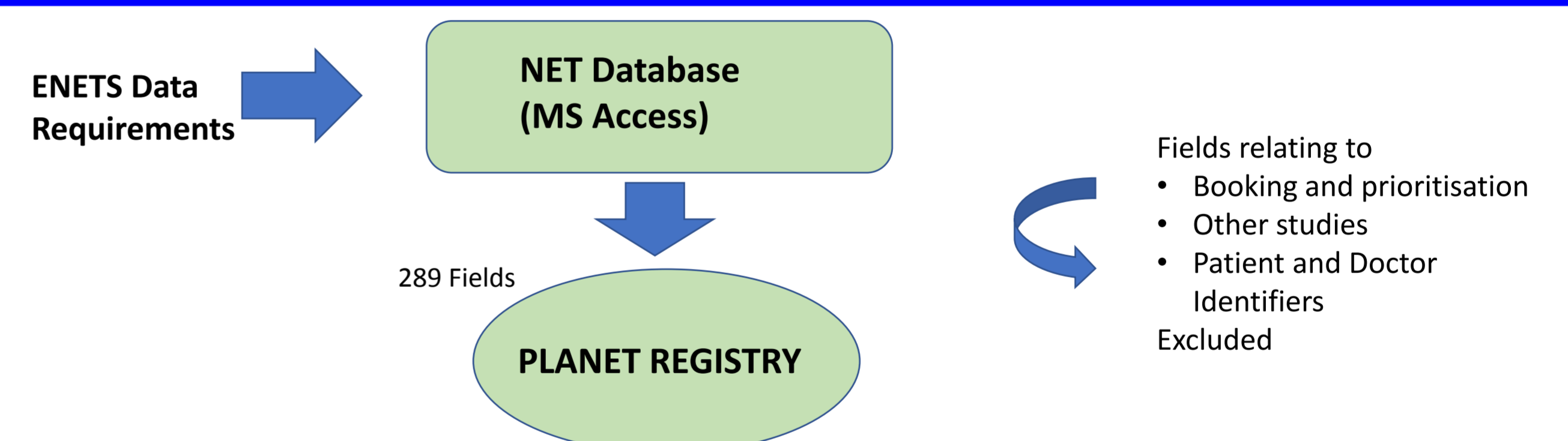


## Uptake of Mobile App for Patient Data

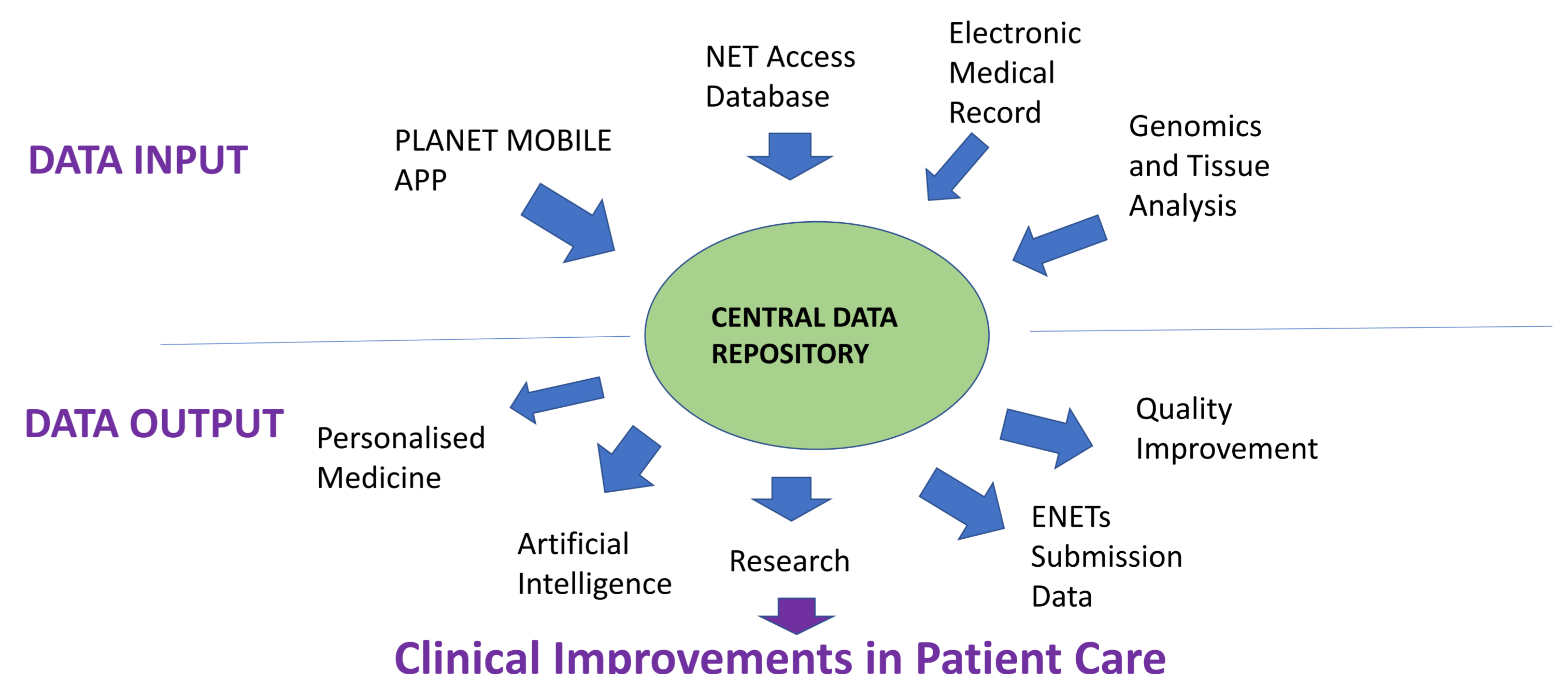
Time from Registry consent to use of Mobile App	% Patients
<2 weeks	40
2- 5 weeks	26
>5 weeks	26
Not used	7

- To date, 95 patients at PMCC have been provided with the information required to download the Mobile App and 74 have been given access codes.
- 36 (48%) have downloaded and registered the Mobile App

## CREATING A CENTRAL DATA REPOSITORY



The PMCC NET Database (containing identified data) and National PLANET Registry (containing anonymised data) form a central data repository to house NET patient data including mobile App data. Creation of this resource involved addition of fields required for Annual ENETS Data Submissions, assigning of Surrogate Identifiers, mapping of fields to PLANET Registry and encryption and uploading of data. Fields not required for the PLANET Registry were excluded from the upload process.



## Discussion and Conclusions

The transition of an institution-based data repository to a national registry with remote entry of patient-reported outcome measures is a feasible and effective mechanism for the collection of NET patient data