



Identification and referral pathways for people living with 'difficult to treat' epilepsy from primary care to Tertiary Epilepsy Centres in New South Wales: Preliminary findings

DR KAREN HUTCHINSON

PROFESSOR FRANCES RAPPORT

ASSOCIATE PROFESSOR GEOFFREY HERKES

Difficult to treat epilepsies

IMPROVING UNDERSTANDING OF EPILEPSY MANAGEMENT IN PRIMARY AND COMMUNITY HEALTH CARE THROUGH TO TERTIARY EPILEPSY CLINICS



Background

- Epilepsy is the most common neurological condition and affects people of any age
- Approximately one third of people have refractory epilepsy, a chronic and complex form of epilepsy (lack of seizure control with antiepileptic drugs (AEDs))
- Co –morbidities, drug side effects and social stigma add to the burden of living with epilepsy
- One third of refractory epilepsy patients can achieve seizure freedom through resective surgery, but delays occur in disease identification and referral to Tertiary Epilepsy Centres (TECs)
- It takes approximately 17 years in Australia to move through primary, community and TECs
- Refractory epilepsy has a great financial impact (estimated cost \$9.8 million per/yr NSW)

Study Aim

- To explore clinical practices around identification and referral of refractory epilepsy patients to TECs examining GPs, general neurologist and patient perceptions
 - Assess practices and perceptions of GPs and general referring neurologists
 - Disclose patients' understanding of the disease and referral process
 - Define routine clinical practices surrounding refractory epilepsy patients (surveys, interviews, observations of consultations)

Study design

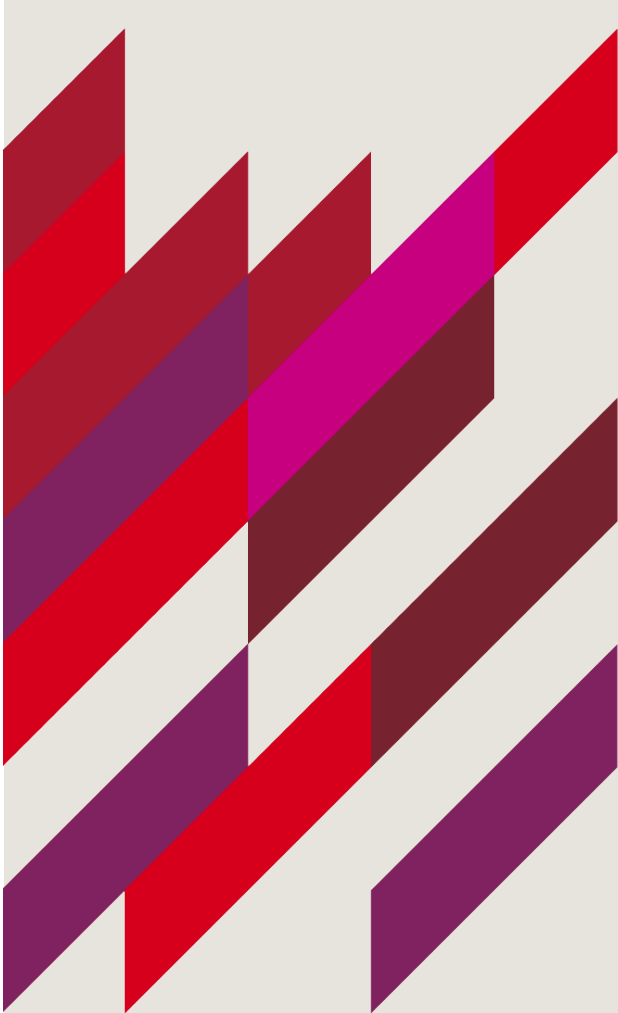
Mixed methods: qualitative and quantitative data; 3 main study groups

- **Neurologists** – 5 semi structured interviews completed, 3 general and 2 epilepsy specialists
- **Patients** – 10 semi structured interviews and observations of consultations
- **GPs** – online survey (North Sydney Primary Health Network and Hunter New England Central Coast Primary Health Network)

Random selection of GP practices in city, regional and rural areas – 5 responses only!

19 interviews to be completed by middle of July

Preliminary Findings



1. What understanding do we have of current clinical practices in primary and community contexts in NSW?
2. What are some of the barriers and enablers to decision making?
3. What understanding have we gained of the impact of relationships?

Seizure types

TYPE OF SEIZURE IMPACTS WHEN PEOPLE FIRST SEEK MEDICAL ASSESSMENT



Seizure

- The complexity and variability of seizure presentations and severity can range from transitory periods of inattention to prolonged convulsions.
- *“Going out for lunch for a bit of a walk and ended up 4 or 5 hours later on I discovered that I was at Circular Quay. I had a seizure of some sort.”*
- *“I just randomly had a bad seizure in the gym and really bashed up myselfso I was rushed to hospital in an ambulance”*

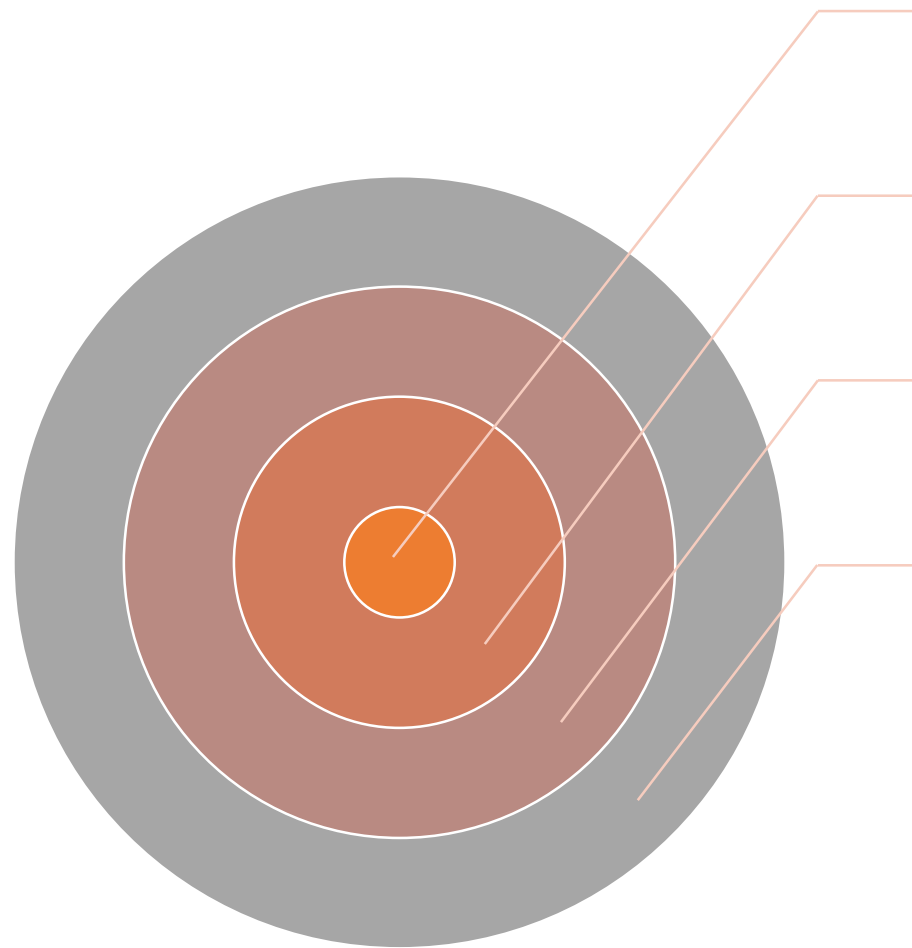


Initial presentation

In this research:

- People with an initial convulsive seizure presented at hospital emergency departments
- People with non-convulsive seizures, often delayed making initial contact with their GP due to the vagueness of their symptoms.
- After seeing a GP it could take some time to get a diagnosis and start treatment- they often needed a range of tests to exclude other conditions with similar presentations.

Informal shared care arrangement – people with uncontrolled epilepsy



Person with
epilepsy

General
practitioner

General
neurologist

Epilepsy
specialist

PWE

- To be understood and informed
- Shared decision making
- Negotiated care arrangement

GP

- Primary contact for epilepsy then all general medicine, co morbidities and drug side effects
- Initial tests
- Referral to neurologists- general and specialist

GN

- Tests and diagnosis
- Management plan
- Feedback/ support to GP
- Referral to epilepsy specialist

ES

- Specialised tests and diagnosis
- Access to epilepsy nurses and MDT
- Management plan
- Surgical assessment/ plan

Impacted by

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Current practise of general neurologists in the management of people living with 'difficult to control' epilepsy

General Neurologist – current clinical practice from initial assessment to TEC referral for patients living with refractory epilepsy



Assessment

Detailed history including family, physical examination, EEG, MRI, workup

Exclusion of other diagnosis presenting with similar signs and symptoms

Diagnosis of epilepsy

'Right diagnosis first and foremost'



Treatment

Start AED regime- small and increase slowly –adjust AED regime, trial new drugs

Promote/modify life style changes

Establish/ manage side effects or intolerances

Manage/ monitor comorbidities together with GP

Educate family

'Trying to find the medications or group of meds that work to control seizures'



Uncontrolled

Failure of 2 AED drugs to control seizures

Establish if uncontrolled/ drug resistant epilepsy may take 1-4 years

Discuss referral to TEC for further investigations, consideration of surgery

'Working out who is refractory early on'



Referral to TEC

Referral letter from neurologist to TEC

Phone call if urgent

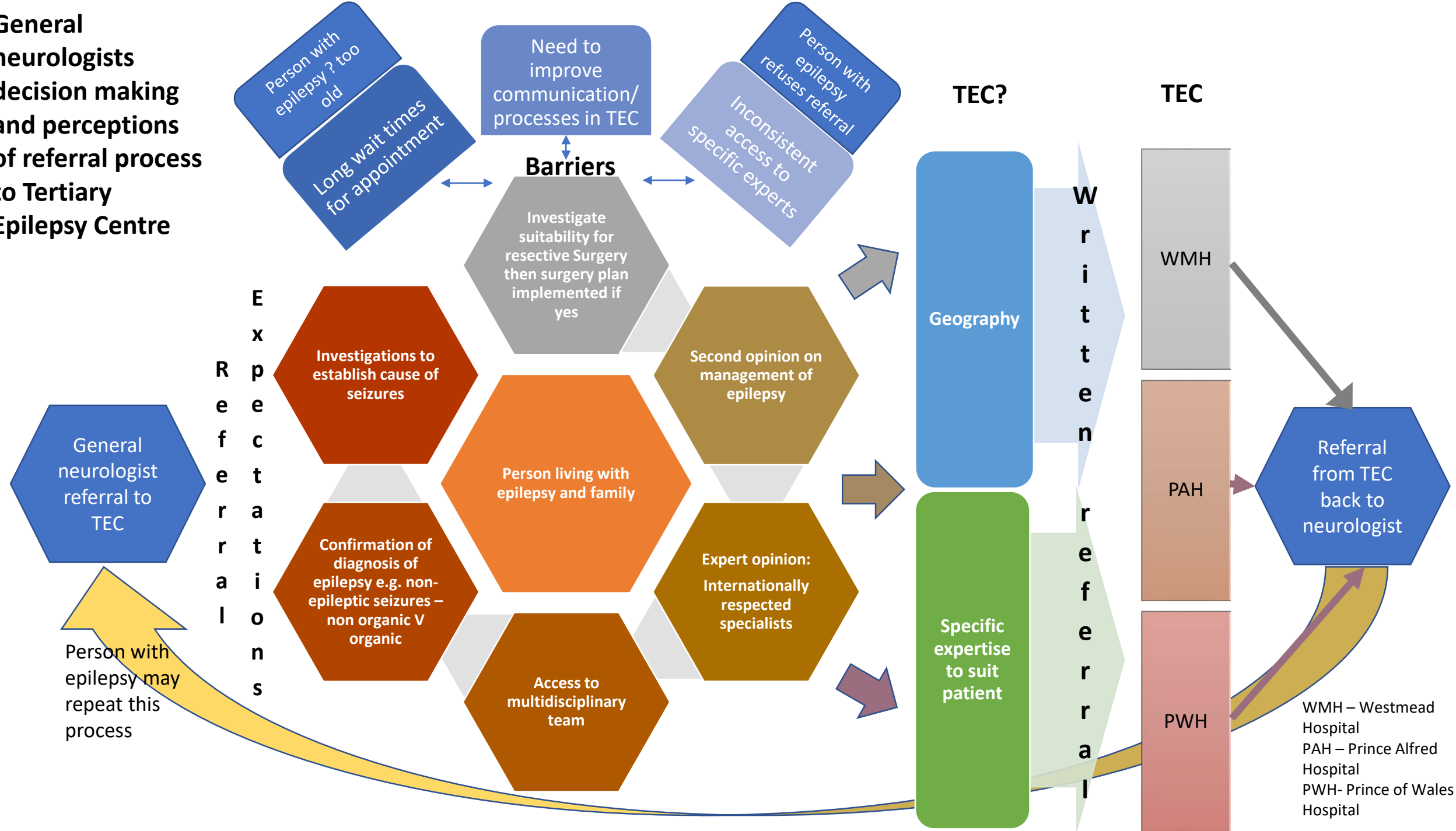
Explanation to patient & family of potential delay in receiving an appointment

Explanation of routine procedure in TEC

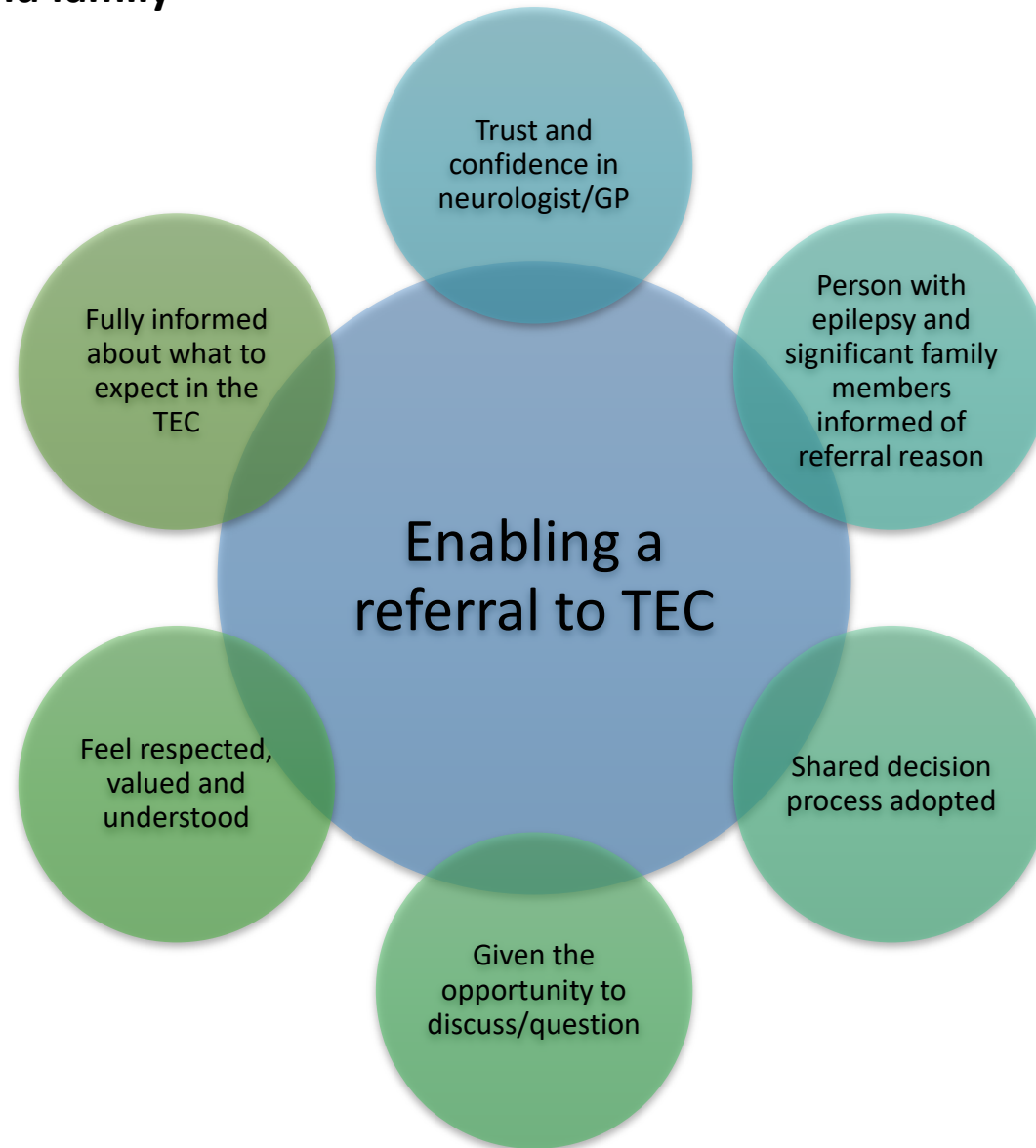
'Then referring them to specialised centres'

Common practice - Communication with GP throughout via letter, email and or phone after each appointment

General neurologists decision making and perceptions of referral process to Tertiary Epilepsy Centre



Enablers supporting a referral to the TEC from the perspective of the person living with epilepsy and family



Patients relationship with health professionals can impact identification of refractory epilepsy and onward referral to TEC



Enablers

- Supported/ shared decision making
- 'Approachable'
- Empathic
- Respectful
- Clinical expertise/ connection with specialists
- Personal recommendation of healthcare professional increases confidence
- Communicates in layman terms
- Interest in personal experiences
- Responsive to need
- Known history – comorbidities and family
- Choice and control
- Communicates well with other health professionals and family




Barriers

- Feels misunderstood
- Rude/abrupt communication style
- Using medical jargon – *'baffled me with medical terminology'*
- Loss of confidence and trust – PWE and family
- Limited clinical knowledge about epilepsy
- Failure to recognise signs and symptoms of epilepsy
- Disrespectful/ disconnected
- Lack of interest in comorbidities
- Changing healthcare professionals
- Lack of understanding of impact on life and family

Conclusion

Collaboration for change to improve the lives of people living with 'difficult to treat' epilepsy



Addressing concerns across the primary–tertiary interface



TO GUIDE APPROPRIATE SHARED CARE



TO IMPROVE QUALITY OF CARE



TO IMPROVE KNOWLEDGE AND UNDERSTANDING



TO REDUCE DELAYS AND GAPS IN THROUGHPUT





Thank you

Email: karen.hutchinson@mq.edu.au