
Evidence Development from Clinical Interactions

Pediatric Epilepsy Outcomes-Informatics Project

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(for the CCEC Team)*

April 14, 2016

Mission

To create a system of excellence to provide comprehensive clinical care, research that leads to improved outcomes & education for all stakeholders in a manner that optimizes societal resources

Pediatric Epilepsy Outcomes-Informatics Project

GOALS

To produce **Measurable Outcome Improvements**
in the lives of Children & Families living with Epilepsy
while minimizing Waste & Treatment Cost

To improve efficiency of Patient Care by developing
consistent **Diagnostic & Treatment Pathways** with
Measured Outcomes

To extend the **Pathway Outcomes** approach to **non-experts**
who treat children with epilepsy

Pediatric Epilepsy

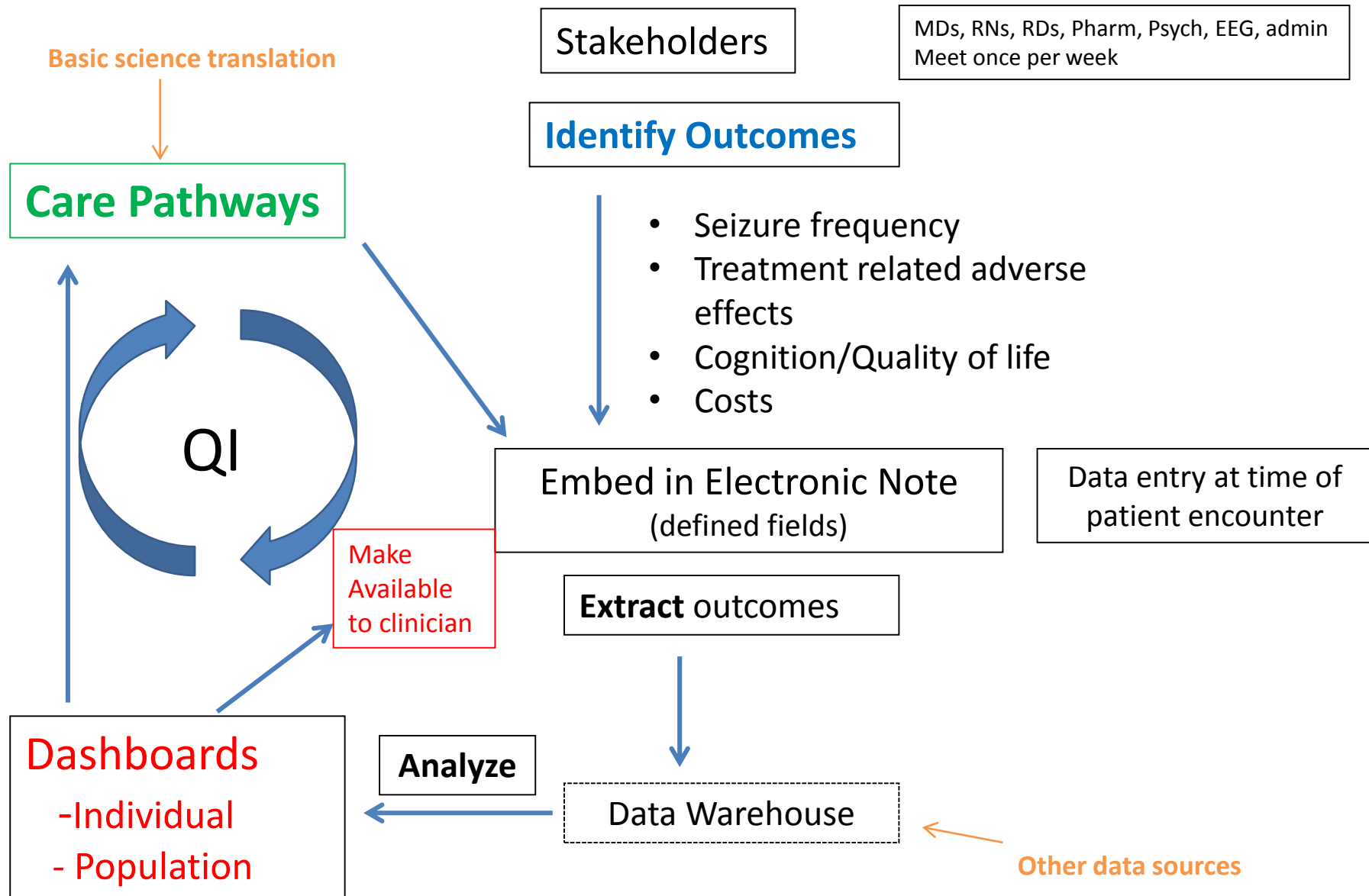
Outcomes-Informatics Project

- 30% of patients remain intractable
- Ultimately cures will come from labs
- What to do until then?
 - Consider other paradigms of basic & clinical research
 - Use Quality Improvement methodology
 - Reduced variation improves outcomes
 - Reduced variation reduces cost
 - Requires measurable outcomes (clinical, process, costs)
 - Requires a feasible informatics (data) platform

How is this different...?

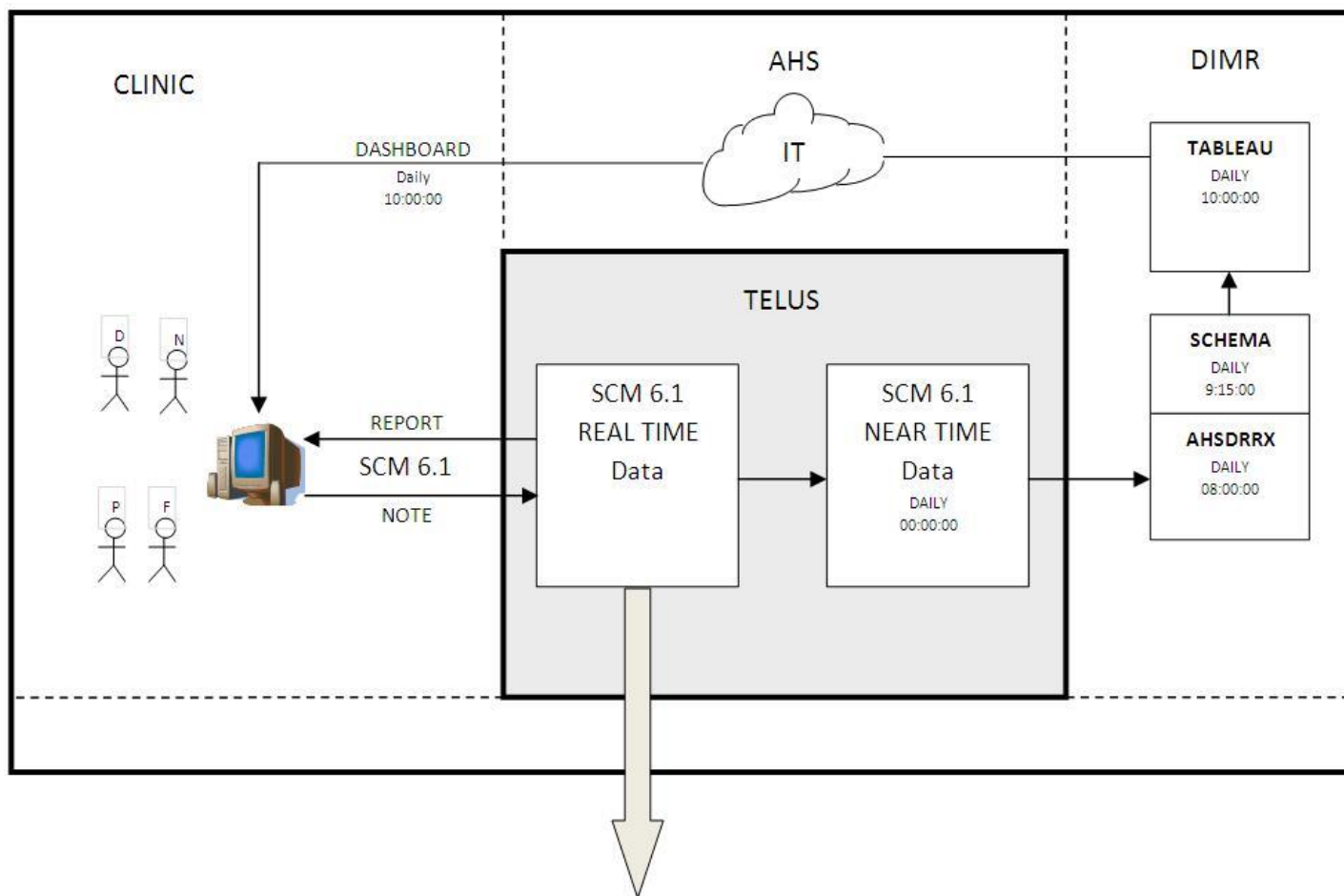
- Standard approaches
 - Compliments RCTs
 - Incorporated into standard work flow (learn from each patient)
 - Prospective
 - Standardized definitions, pathways, outcomes
 - Standardized data collection
- What others are doing
 - e.g. PERC
 - Limited conclusions can be made by combination of results from individual persons & places

Improve Outcomes & Reduce Costs by Standardization of Processes



Pediatric Epilepsy Outcomes-Informatics Project

DATA ENVIRONMENTS



Pediatric Epilepsy Outcomes-Informatics Project

ELECTRONIC HEALTH RECORD - Symptomology

Structured Notes Entry - Station, Space - Pediatric Epilepsy Clinic Visit Note

CREATE Preview

Sections

- Visit Details
 - Visit Details
- History of Present Illness
 - Event/Seizure Type 1
 - Event/Seizure Type 2
 - Event/Seizure Type 3
 - Event/Seizure Type 4
 - Event/Seizure Type 5
 - Hospital Visits
- Pregnancy, Birth, Development
- Review of Systems
- Social History
- Family History
- Medications
- Other Treatments
- Allergy and Intolerances
- Investigations
- Physical Examination
- Impression
- Plan
- Attestation

Document Info

Copy Forward Refer to Note Preview Modify Template Acronym Expansion

Event/Seizure Type 1

Description (Semiology):

Onset Date: 2009-10-01

Onset Age: days months years

Additional Comments:

Frequency score: 0 (seizure free, off antiepileptic drugs)

Additional Comments: 0 (seizure free, off antiepileptic drugs)

1 (seizure free, requires antiepileptic drug to remain)

2 (1-3 seizures per year)

3 (4-11 seizures per year)

4 (1-3 seizures per month)

5 (1-6 seizures per week)

6 (1-3 seizures per day)

7 (4-10 seizures per day)

Usual Duration (Minutes):

Usual Duration (Months):

Usual Duration (Average) =

Recovery Time to Normal: Immediate Not immediate

Diurnal Variation: None All awake All asleep >50% awake >50% asleep >50% sleep-wake transition

Clusters: Yes No

Provoking Factors:

Unprovoked Missed medication Illness Sleep deprivation Weight gain / loss Fever Other

Retrieve Last Charted Values

Insert Default Values

Clear Unsaved Data

Need Help? Mark Note As: Results pending Priority Incomplete Calculate after save Charge Capture SuperBill Save Cancel

Pediatric Epilepsy

Outcomes-Informatics Project

ELECTRONIC HEALTH RECORD - Diagnosis

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Standardized diagnoses
ILAE

Impression: Event/Seizure 1

✓ Diagnosis: ☒ Generalized seizure ☐ Focal seizure ☐ Unknown seizure ☐ Non-epileptic event ☐ Not yet diagnosed

✓ Seizure type:

☐ Absence atypical ☒ Absence typical ☐ Absence with special features (myoclonic absence) ☐ Absence with special features (eyelid myoclonia) ☐ Atonic ☐ Clonic ☐ Tonic

☐ Tonic clonic ☐ Myoclonic ☐ Myoclonic atonic ☐ Myoclonic tonic ☐ Other

✓ Syndrome type: Electroclinical - childhood

✓ Syndrome subtype: Childhood absence epilepsy

✓ Etiology:

☐ Unknown ☐ Brain tumour ☐ Down syndrome ☐ CNS infection ☐ Hypoxic ischemic encephalopathy ☐ Malformation of cortical development ☐ Neuro-Inflammation ☒ Presumed genetic/metabolic

☐ Specific Genetic ☐ Specific Metabolic ☐ Stroke ☐ Structural ☐ Trisomy ☐ Tuberous sclerosis ☐ Other

Etiologies

Pediatric Epilepsy

Outcomes-Informatics Project

CAE

ETX

CREATE Preview

Sections

Document Info

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 - Medications
 - Other Treatments
 - Allergy and Intolerances
 - Investigations
 - Physical Examination
 - Impression
- Childhood Absence Epilepsy
 - CAE
- Plan
 - Current Medications to Continue
 - New Medications
 - Plan for Current Medications
 - ethosuximide (Zarontin)
 - ethosuximide
 - Levetiracetam
 - levETIRAcetam
 - Follow-up
 - Patient Teaching
 - Emergency Instructions
 - Recommended Treatment
 - Attestation
 - Send Copies To

Copy Forward Refer to Note Preview Modify Template Acronym Expansion

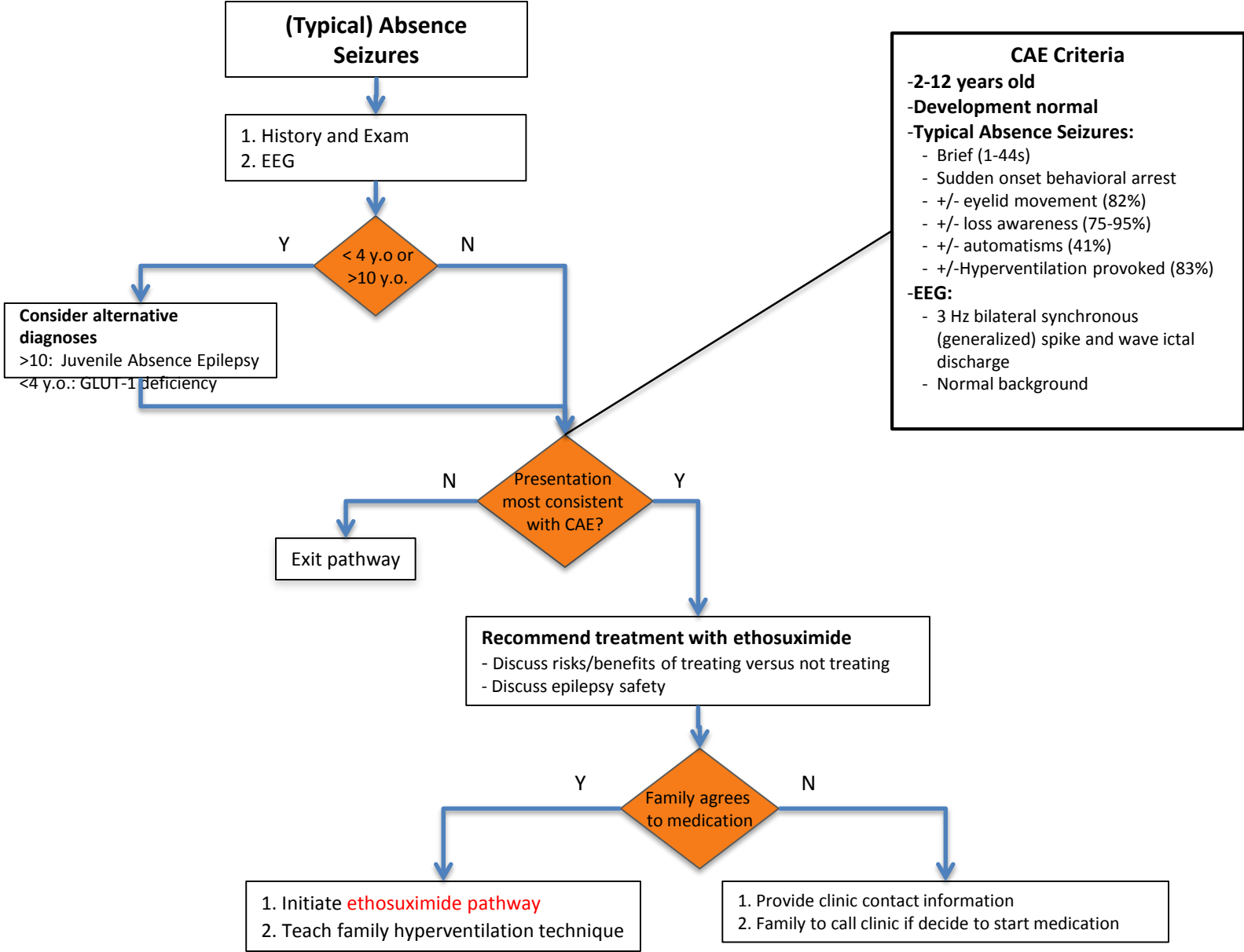
CAE

Is the CAE care path appropriate for this patient? ☐ No... ☐ Yes...

Was the CAE care path followed for this visit? ☐ Yes... ☐ No...

Comments

3. CHILDHOOD ABSENCE EPILEPSY PATHWAY: INITIAL VISIT



Screen shot CAE pathway in EHR

Structured Notes Entry - SCMSUP CD, CDThirteen - PS_Pediatric Epilepsy Consult_Demo

CREATE Preview

Sections

- Pregnancy, Birth, Development
- Review of Systems
- Social History
- Family History
- Medications
- Other Treatments
- Allergy and Intolerances
- Investigations
- Physical Examination
- Impression
 - Impression: Event/Seizure 1
 - Impression: Event/Seizure 2
 - Impression: Event/Seizure 3
 - Impression: Event/Seizure 4
 - Impression: Event/Seizure 5
 - Impression
- Care Paths - Syndromes/Seizure
 - Plan

Copy Forward Refer to Note Preview Modify Template Acronym Expansion

Impression: Event/Seizure 1

☒ Diagnosis:

☒ Generalized seizure ☐ Focal seizure ☐ Unknown seizure ☐ Non-epileptic event

☐ Not yet diagnosed

☒ Seizure type:

☐ Absence atypical ☒ Absence typical ☐ Absence with special features (myoclonic absence)

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☐ Tonic ☐ Tonic clonic ☐ Myoclonic ☐ Myoclonic atonic ☐ Myoclonic tonic

☐ Other

Comments:

☒ Syndrome type: Electroclinical - childhood

☒ Syndrome subtype: Childhood absence epilepsy

☐ Etiology:

☐ Unknown ☐ Brain tumour ☐ Down syndrome ☐ CNS infection

☐ Hypoxic ischemic encephalopathy ☐ Malformation of cortical development

A.) Selecting "Childhood absence epilepsy" (1) from Syndrome subtype in any of the Event/Seizure sections

B.) Triggers the significant indicator (2) to show in the sections pane.

C.) The list choice for "Is the CAE care path appropriate for this patient?" will change from No to Yes which opens the "Was the CAE care path followed for this visit?" question

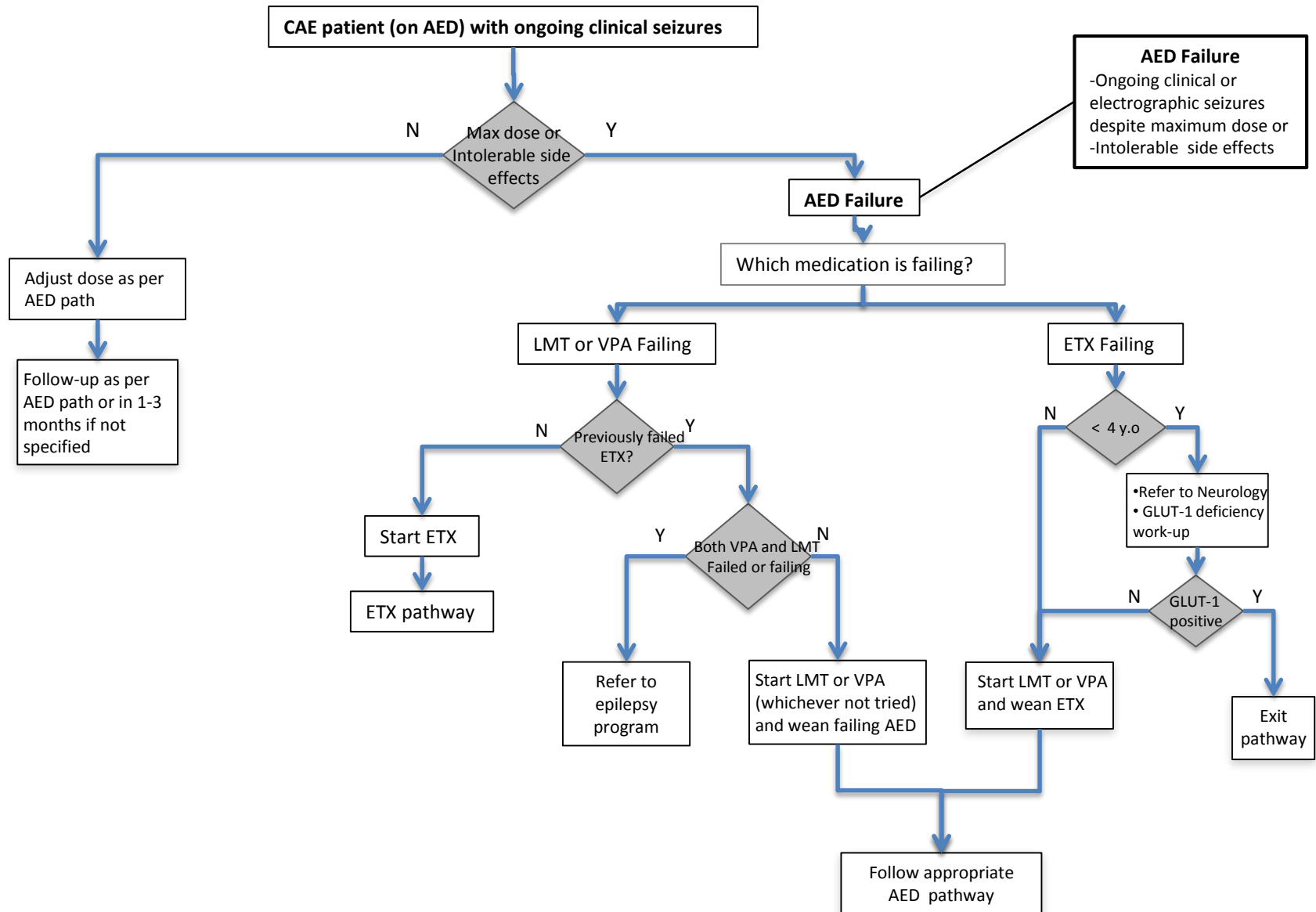
CAE

Is the CAE care path appropriate for this patient? ☐ No... ☒ Yes...

Was the CAE care path followed for this visit? ☒ Yes... ☐ No...

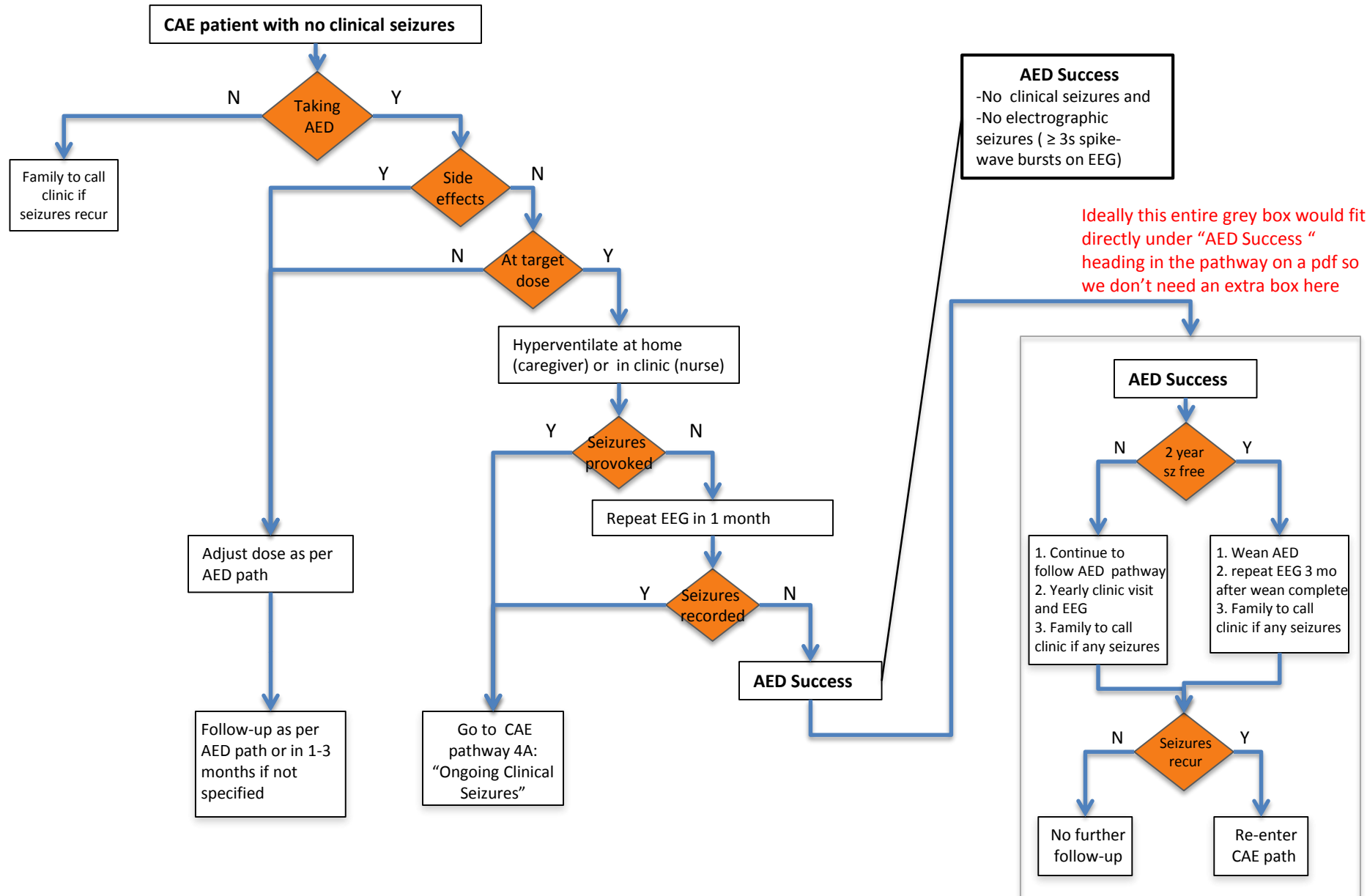
Comments

ONGOING CLINICAL SEIZURES



4B CHILDHOOD ABSENCE EPILEPSY PATHWAY: FOLLOW-UP VISIT/PHONE:

NO CLINICAL SEIZURES



ETHOSUXIMIDE PATHWAY

Individual physicians may refer to neurologist at any point in pathway

ethosuximide (Zarontin®)

Initiate dose at 10 mg/kg/day^{1,2,3}; maximum 250 mg/day
Increase by 10 mg/kg/day every week³
to initial maintenance dose 20 mg/kg/day; maximum 500 mg BID

DRUG INFORMATION:

Ethosuximide is available as:

- 250 mg capsules
- 50 mg/mL oral liquid, which is poorly tolerated due to GI effects

Maximum daily dose of 60 mg/kg/day or 2 g/day, whichever is less.


Caregiver to contact clinic by **day 14** after target dose reached or after any subsequent dose changes to report seizure frequency + ADRs

Continued seizures
+ No disabling ADRs

Seizure free⁴
+ No disabling ADRs

Disabling ADRs

Adherence

Caregiver to
hyperventilate at home
(as per handout) 

GI intolerance
on liquid

Switch to
oral capsules

Educate &
restart pathway

Seizures
induced

Routine video EEG
within 1 month

Seizures

ADR Strategies:
1. Change AM/PM
dosing balance, or
2. Reduce dose by 5
mg/kg/day

At maximum
dose

Seizures
present

Ethosuximide Success:
Return to CAE pathway

Ethosuximide Failure:
1. Wean over 1 week
2. Return to CAE pathway

Increase by
10 mg/kg/day³;
maximum 250 mg/day

¹ consider modified dosing in obesity; ² modify dosing in renal impairment

³ to nearest full/part tablet, ⁴ seizure-free despite provoking factors (e.g. sleep deprivation, illness)

⁵ crushable

AED = anti-seizure medication; ADRs = adverse drug reactions; form provided at initial visit

Screen shot of ETX pathway in EHR

Ethosuximide Aware Note Screen Prints

CREATE Preview

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Copy Forward Refer to Note Preview Modify Template Acronym Expansion

Plan for Current Medications

Medication Care Paths:

- ☐ CarBAMasepine (Tegretol)
- ☐ Clobazam (Frisium)
- ☒ Ethosuximide
- ☐ Lamotrigine
- ☐ Levetiracetam
- ☐ OXcarbazepine
- ☐ Prednisolone
- ☐ Valproic Acid
- ☐ Vigabatrin
- ☐ None

Selecting Ethosuximide from the Medication Care Paths list will trigger the Ethosuximide significant indicator in the sections pane

ethosuximide

ethosuximide (Zarontin)

Is the Ethosuximide care path appropriate for this patient? ☐ No... ☒ Yes...

Ethosuximide care path followed ☒ Yes... ☐ No...

Comments

The list choice has changed from No to Yes and the Ethosuximide care path question appears as well as the significant indicator

Pediatric Epilepsy

Outcomes-Informatics Project

PATIENT DASHBOARD

Alberta Children's Hospital

Paediatric Epilepsy Patient Summary

(v0.7)
Eventually Updated Daily @ 12:00 Noon

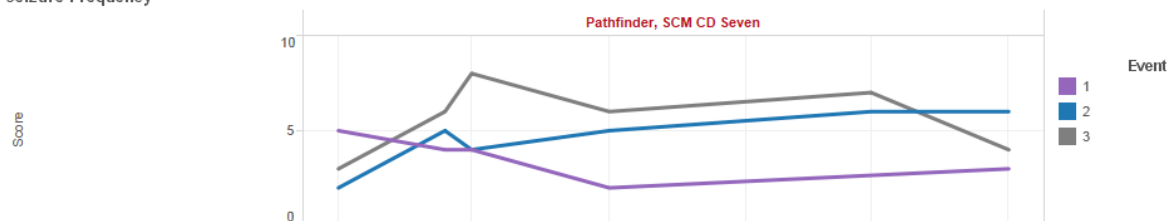
**Alberta Health
Services**

Patient FILTER

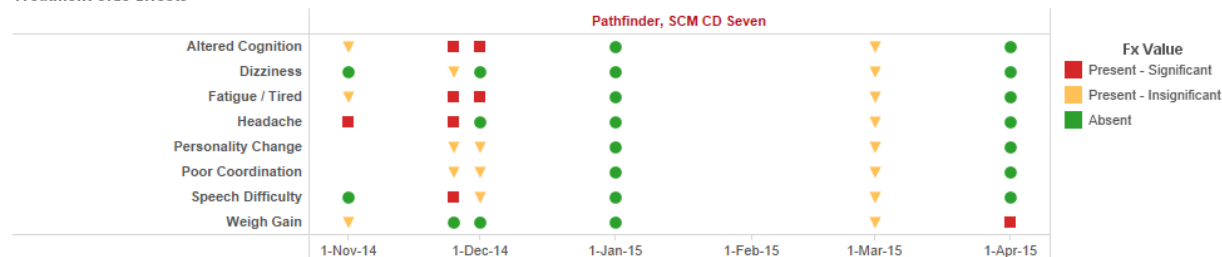
Pathfinder, SCM CD Seven



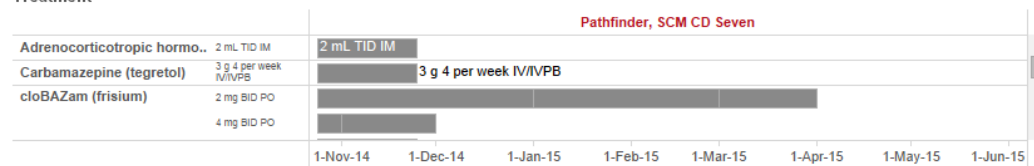
Seizure Frequency



Treatment Side Effects



Treatment



Paediatric Epilepsy - Population Summary

(v1.5)
Updated DAILY @ 12:00:00 (Noon)

Data DATE

24-Aug-15
15:09:46

Start Date

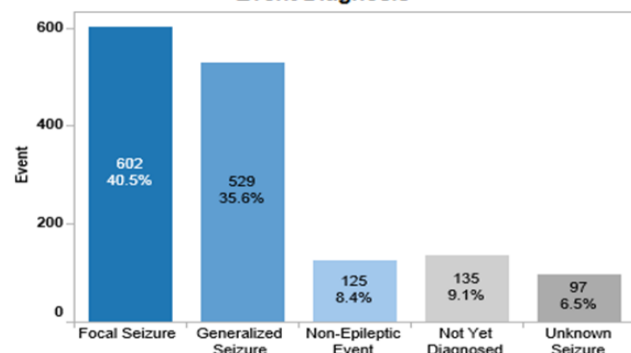
End Date

1-Nov-14

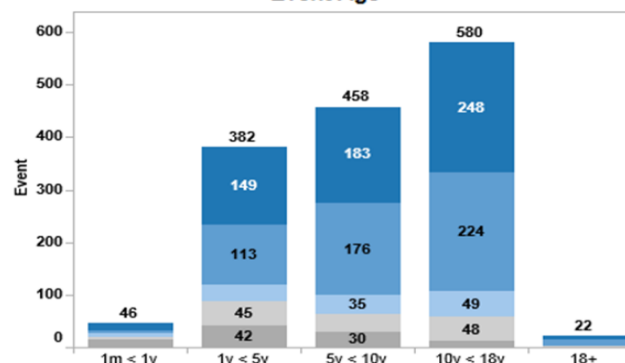
31-Dec-15

~ All values reflect specified Date Range. Data Date is last record updated before extract 00:00:00 ~

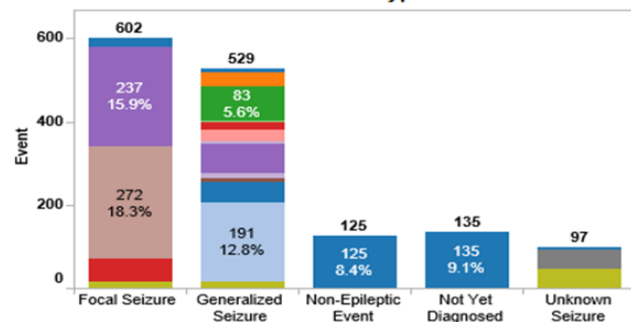
Event Diagnosis



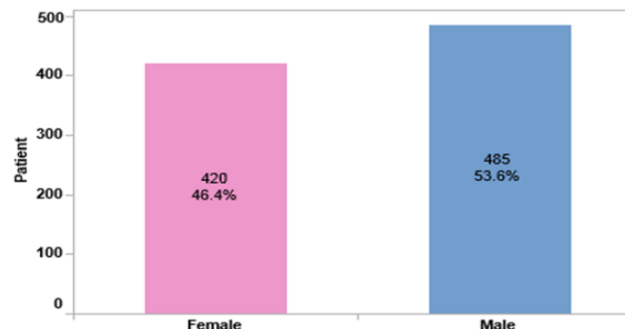
Event Age



Event Seizure Type



Patient Gender



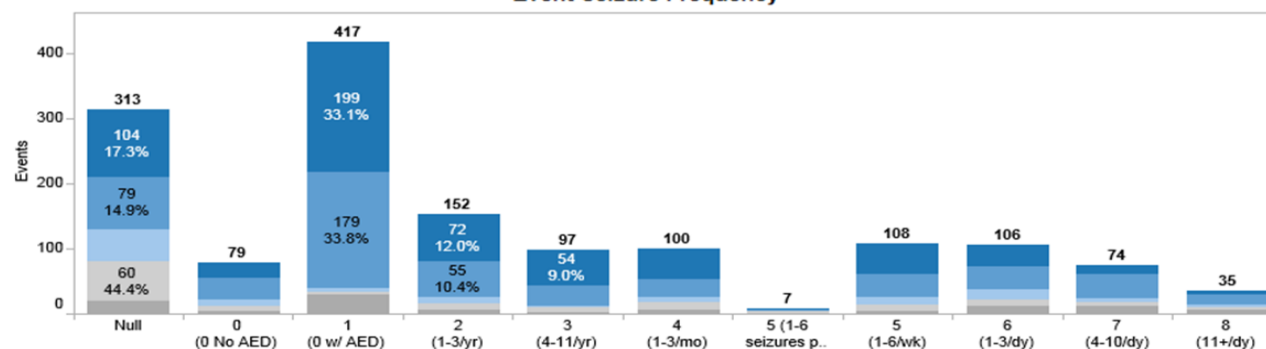
Diagnosis FILTER

Focal Seizure	602
Generalized Seizure	529
Non-Epileptic Event	125
Not Yet Diagnosed	135
Unknown Seizure	97

SeizureType FILTER

Null	297
absence atypical	36
absence typical	83
absence with special featur..	2
absence with special featur..	18
atonic	28
bilateral convulsive	237

Event Seizure Frequency



Age FILTER

1m < 1y	17
1y < 5y	204
5y < 10y	297
10y < 18y	373
18+	14

Gender FILTER

Male	485
Female	420

Live Dashboard Demo

- 1537- visit types
- 543- 3 events, drugs, other RX
- 1162- visit types, events, gen/focal/gen
- 1445- 3 events, Aes
- 1227- Dravet-like

Progress to Date

- Stakeholder group assembled, culture changed
- Outcomes & other data agreed upon
- Structured electronic note created
- Note available to system & family immediately
- Dashboards re-calculated every 24 hours
- Care pathways with compliance in note
- To do: demonstrate improved care with interventions

Potential Interventions

- Intractability pathway (e.g. outcome improvement due to more rapid referral for surgery or ketogenic diet)
- Process improvement (e.g. frequency of office visits, testing- EEG, MRI, blood)
- Discovery (e.g. phenotype-genotype)
- Clinical decision support

Take Home Messages

- Culture & engagement are everything
- Nothing special re: EHR required
- Consider analytics (back-end) when creating EHR note (front end)
- Decide what is really important for outcomes, avoid 'recreational data collection'
- Get feedback from patient & families

CCEC Core Team



Funding

