Comprehensive Children's Epilepsy Centre

Alberta Children's Hospital

Alberta Health Services

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

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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

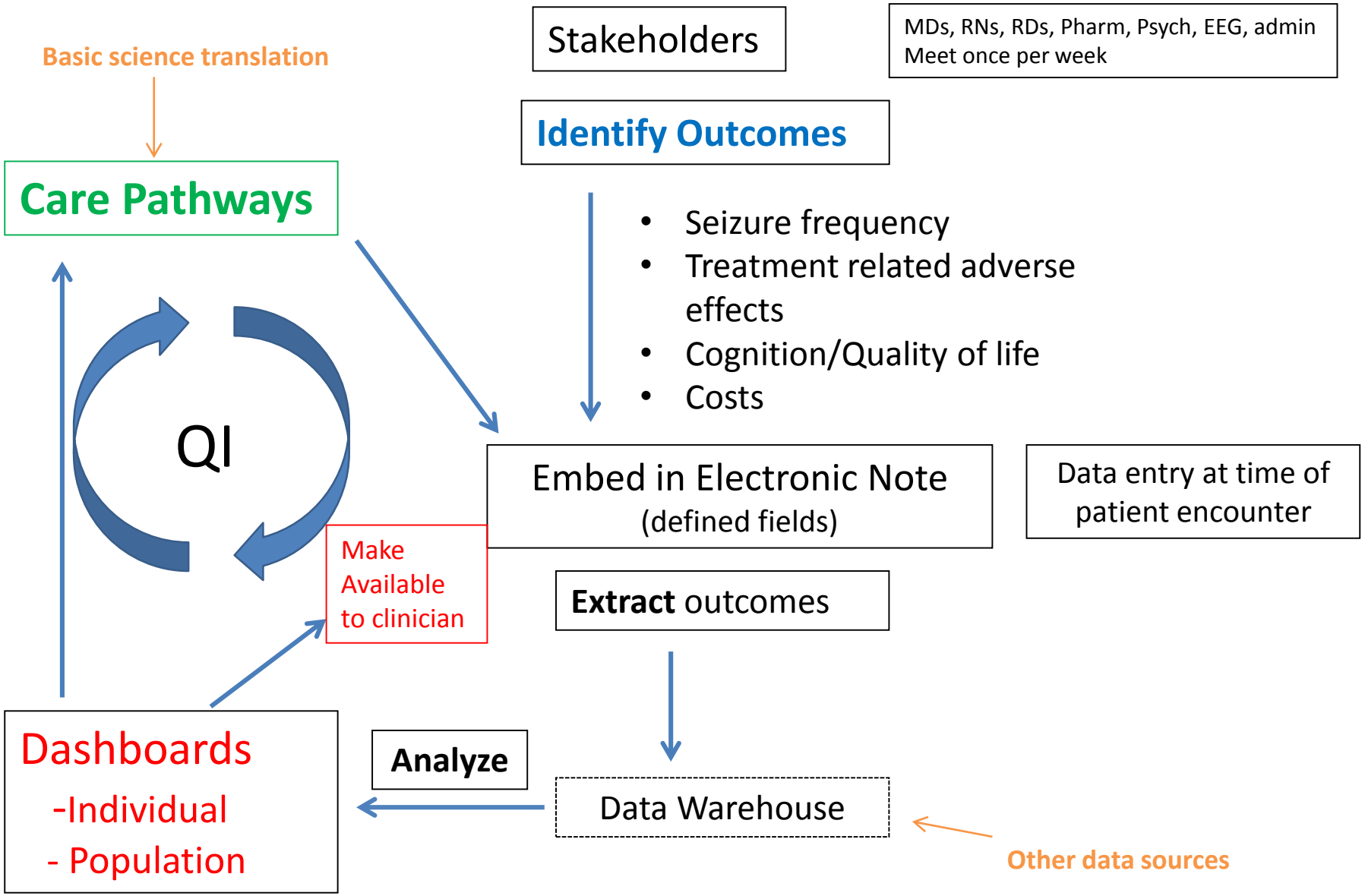
Pediatric Epilepsy Outcomes-Informatics Project

- 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



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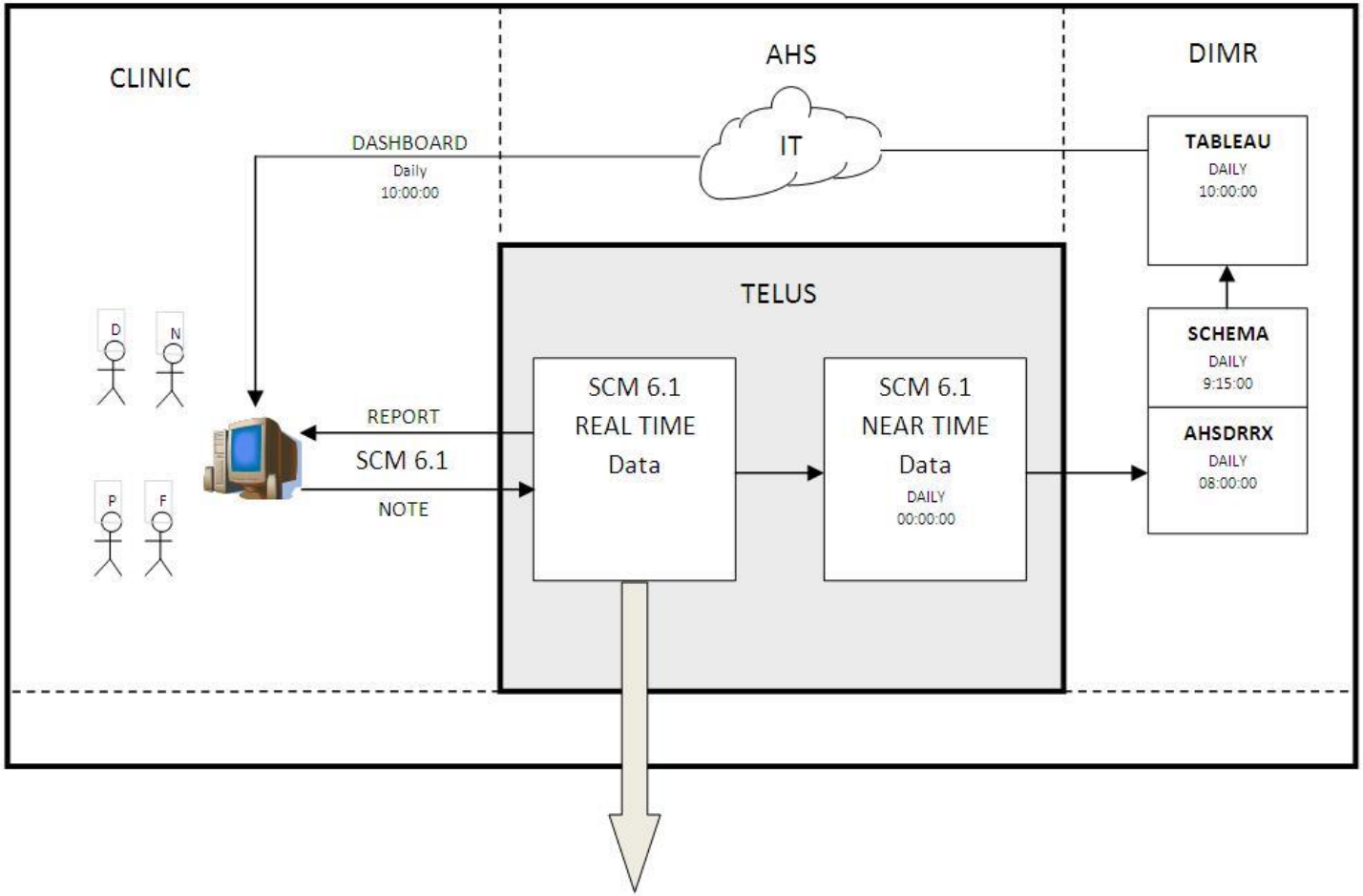
DATA ENVIRONMENTS



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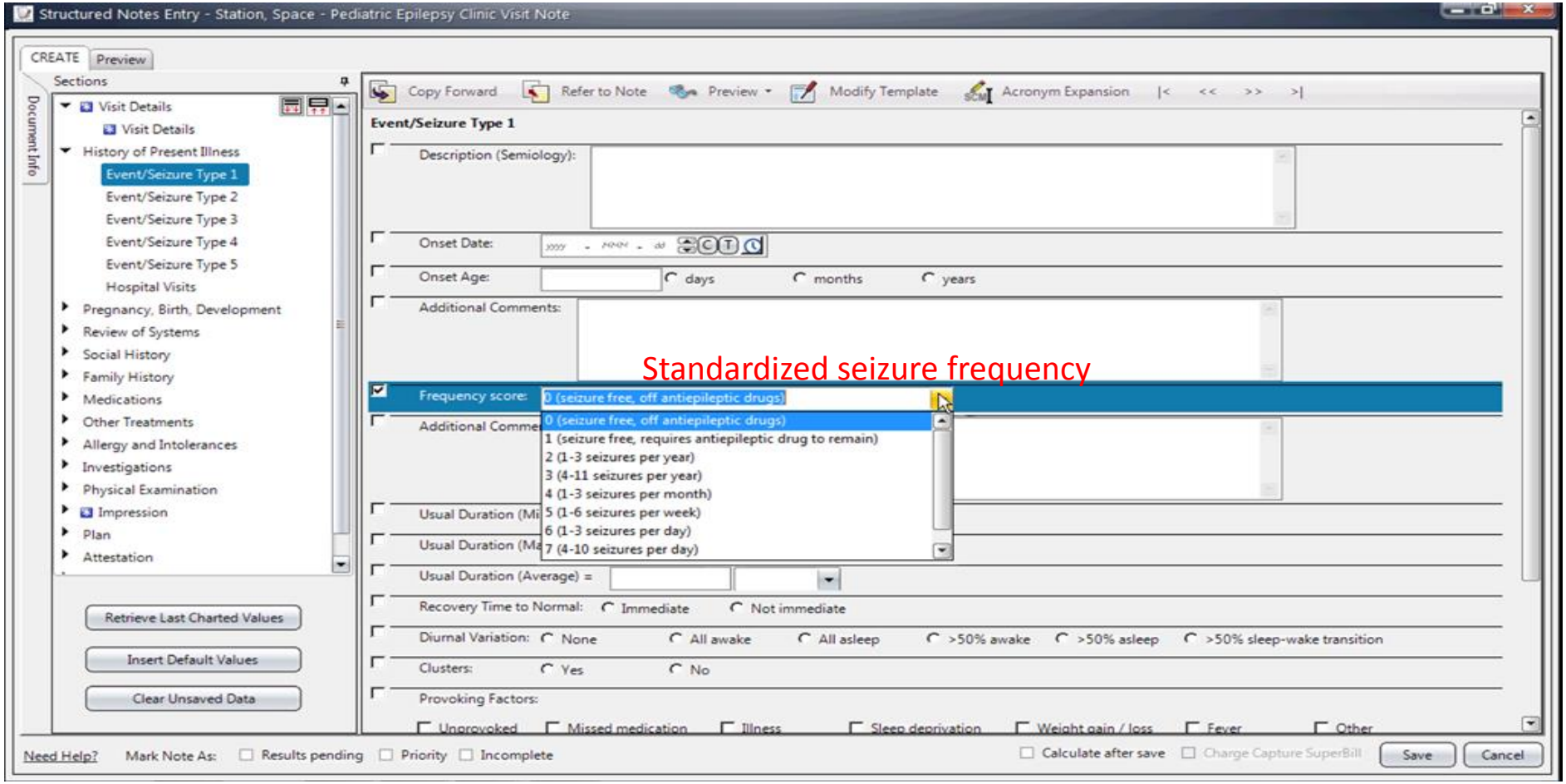
ELECTRONIC HEALTH RECORD - Symptomology



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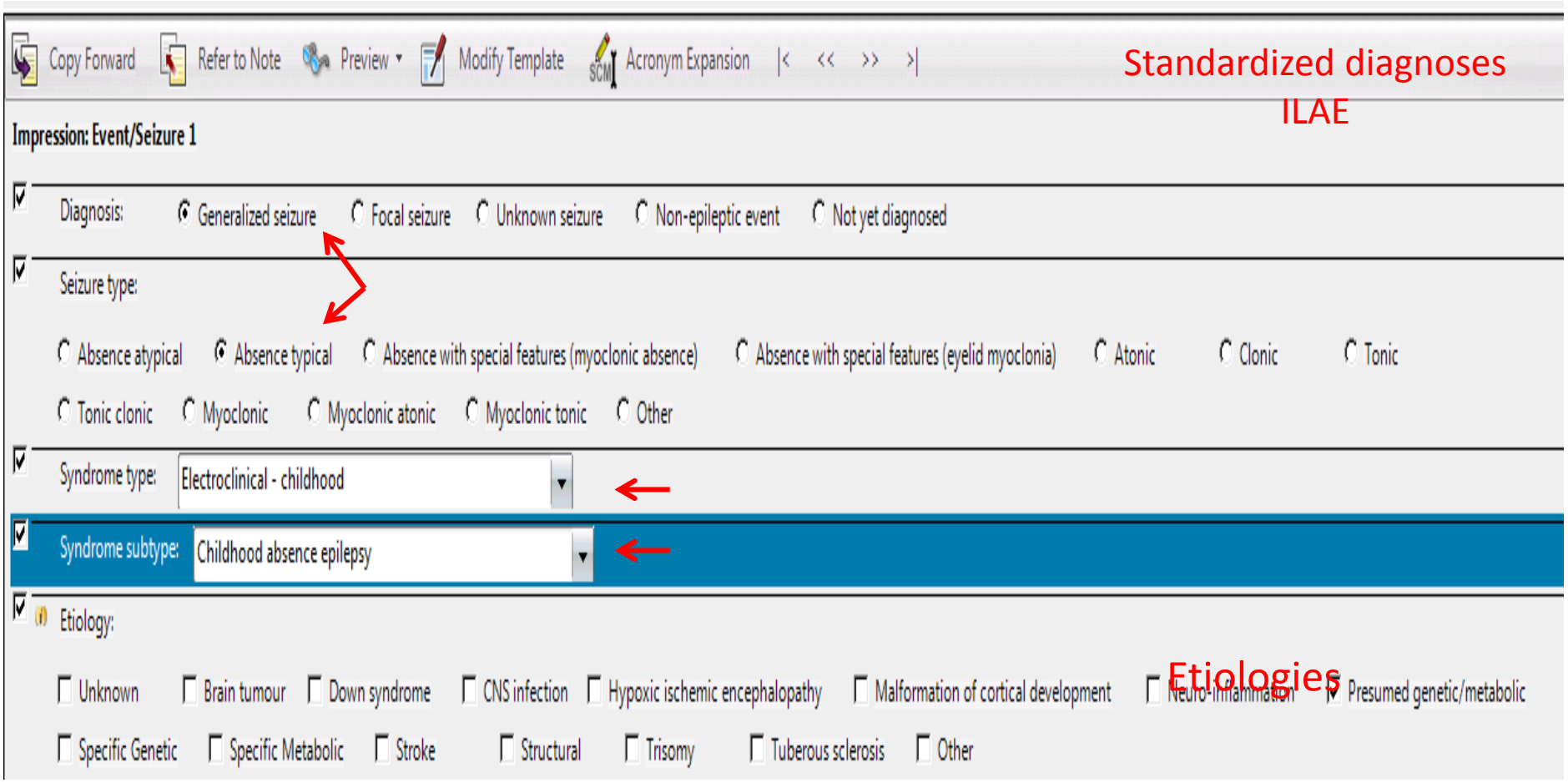
ELECTRONIC HEALTH RECORD - Diagnosis



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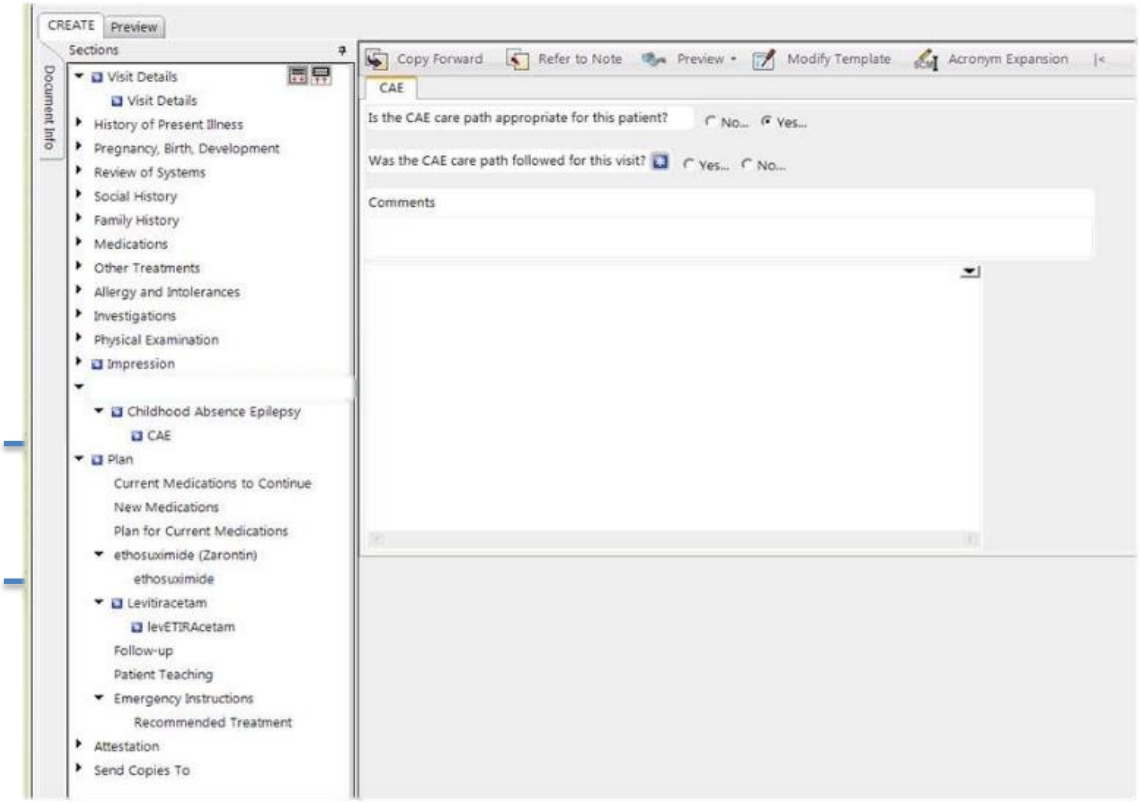

3. Childhood Absence Epilepsy Pathway: Initial visit

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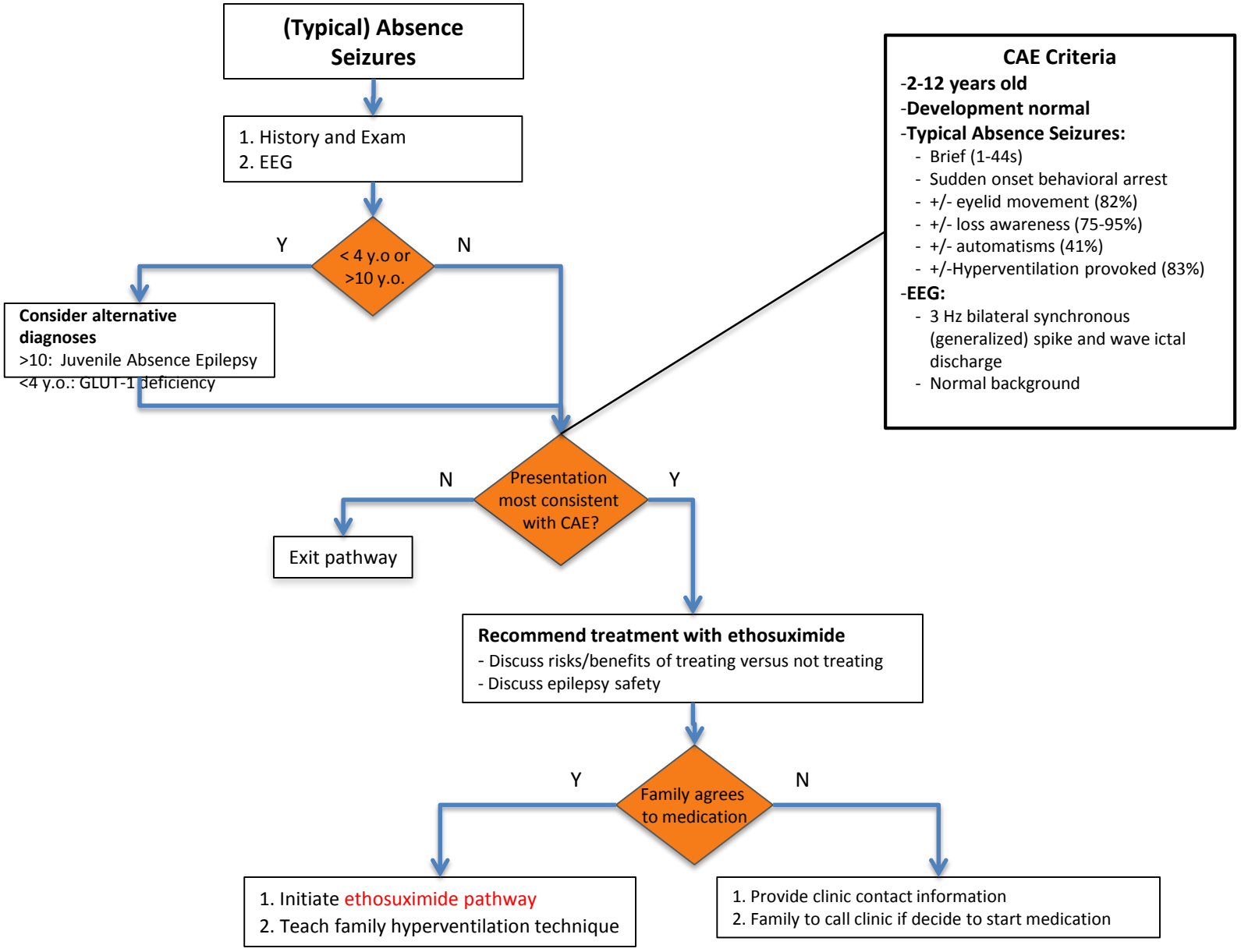
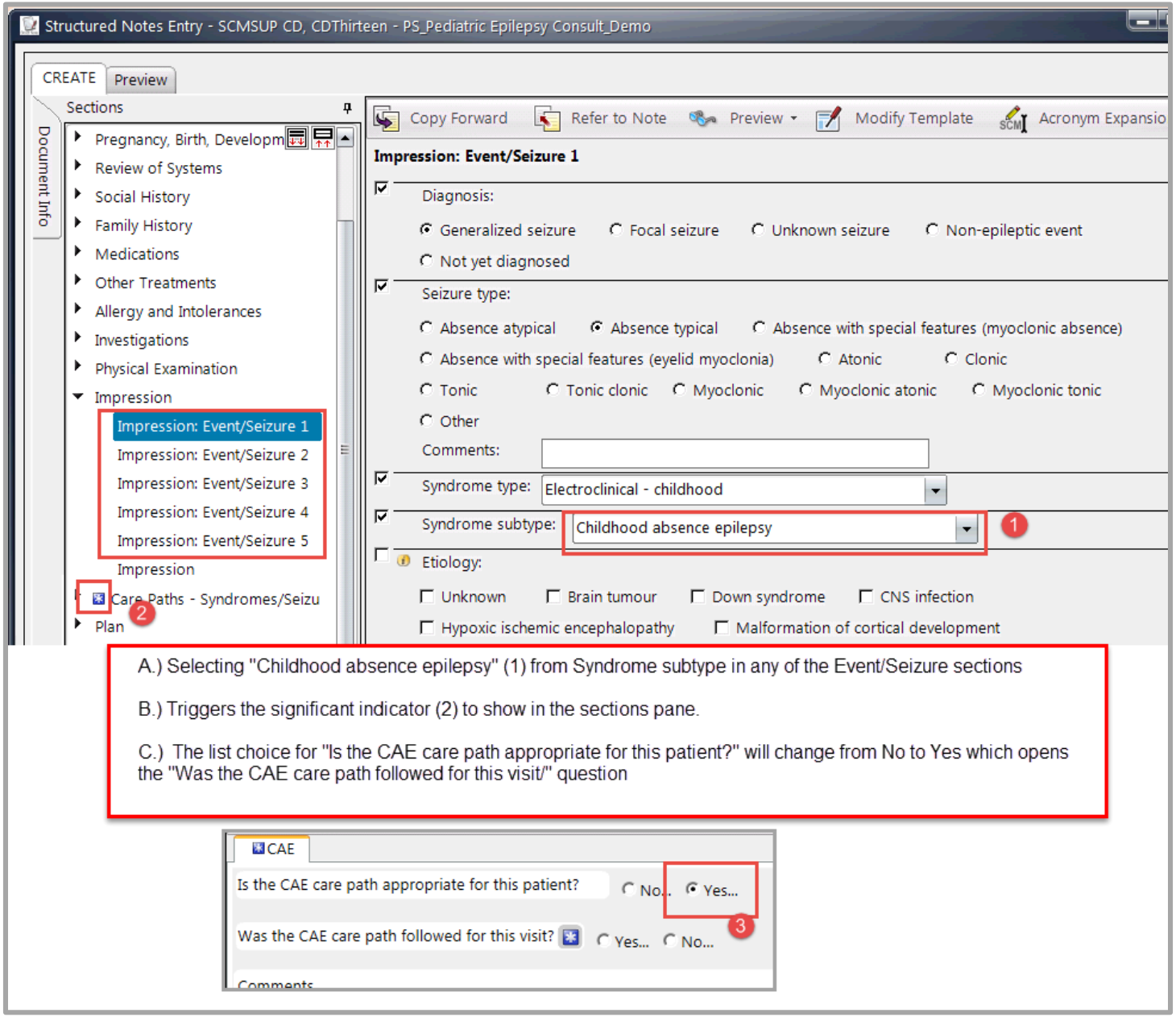


Individual physicians may refer to neurologist at any point in pathway

2015-04-09

Screen shot CAE pathway in EHR



4A Childhood Absence Epilepsy Pathway: Follow-up visit/Phone: Ongoing Clinical Seizures

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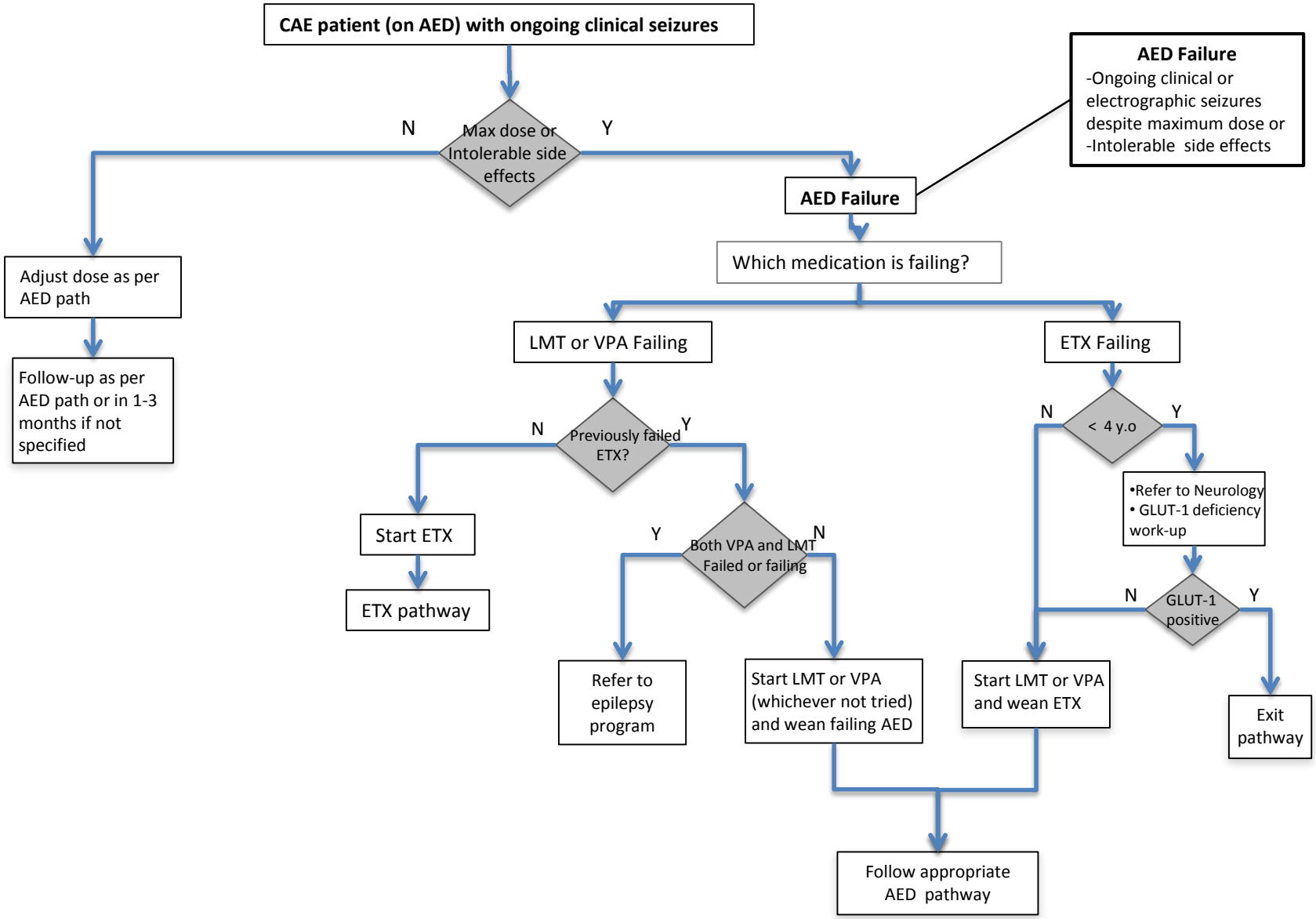

AED = Antiepileptic drug; ETX = ethosuximide
VPA = Valproic acid; LMT = lamotrigine

Individual physicians may refer to neurologist at any point in pathway

2016-03-03

4B Childhood Absence Epilepsy Pathway: Follow-up visit/Phone: No Clinical Seizures

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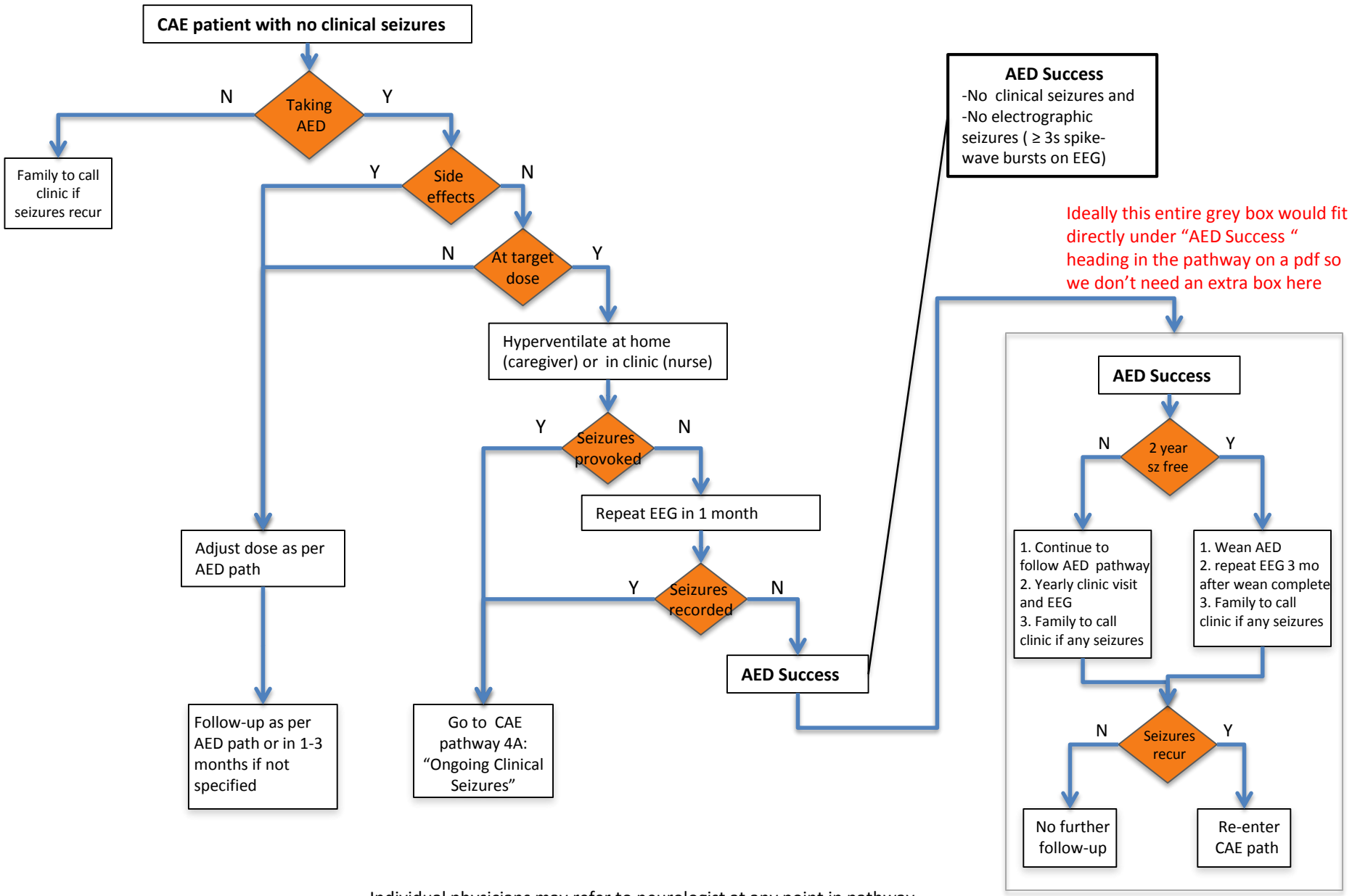

AED = Antiepileptic drug

Individual physicians may refer to neurologist at any point in pathway

2016-01-08

ETHOSUXIMIDE PATHWAY

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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 week[3]
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

Adherence
- N → Educate & restart pathway
- Y → At maximum dose
  - N → Increase by 10 mg/kg/day[3]; maximum 250 mg/day
  - Y → Ethosuximide Failure:
    1. Wean over 1 week
    2. Return to CAE pathway

Seizure free[4] + No disabling ADRs

Caregiver to hyperventilate at home (as per handout)

Seizures induced
- Y → At maximum dose
- N → Routine video EEG within 1 month

Seizures present
- Y → Ethosuximide Failure:
  1. Wean over 1 week
  2. Return to CAE pathway
- N → Ethosuximide Success: Return to CAE pathway

Disabling ADRs

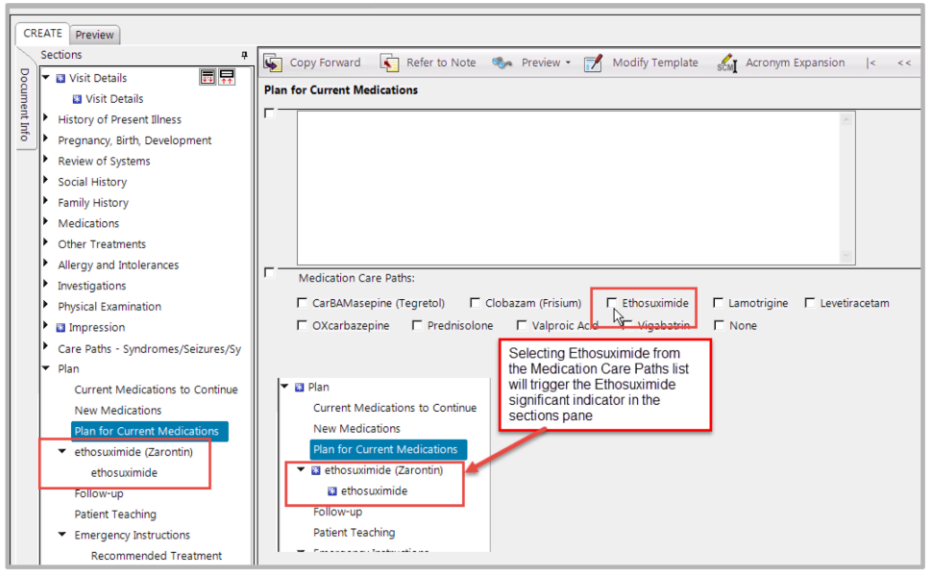
GI intolerance on liquid
- Y → Switch to oral capsules
- N → Seizures
  - Y → Ethosuximide Failure:
    1. Wean over 1 week
    2. Return to CAE pathway
  - N → ADR Strategies:
    1. Change AM/PM dosing balance, or
    2. Reduce dose by 5 mg/kg/day

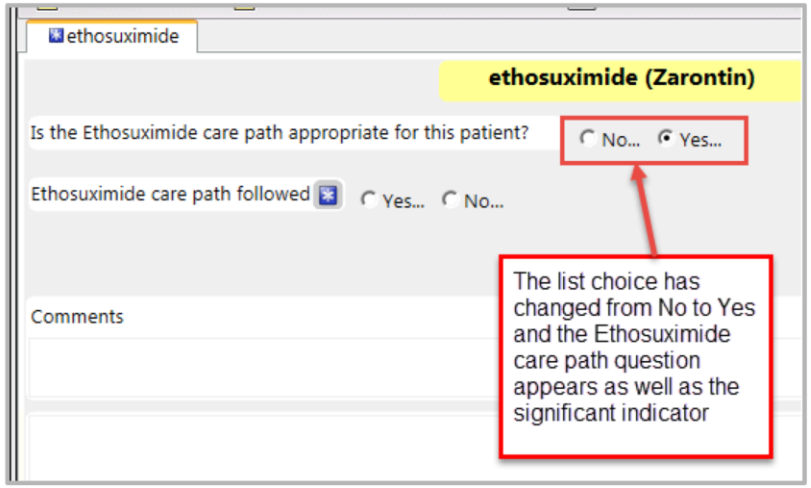
[1] consider modified dosing in obesity; [2] modify dosing in renal impairment
[3] to nearest full/part tablet, [4]seizure-free despite provoking factors (e.g. sleep deprivation, illness)
[5]crushable AED = anti-seizure medication; ADRs = adverse drug reactions; form provided at initial visit

2016-02-04

Screen shot of ETX pathway in EHR

Ethosuximide Aware Note Screen Prints





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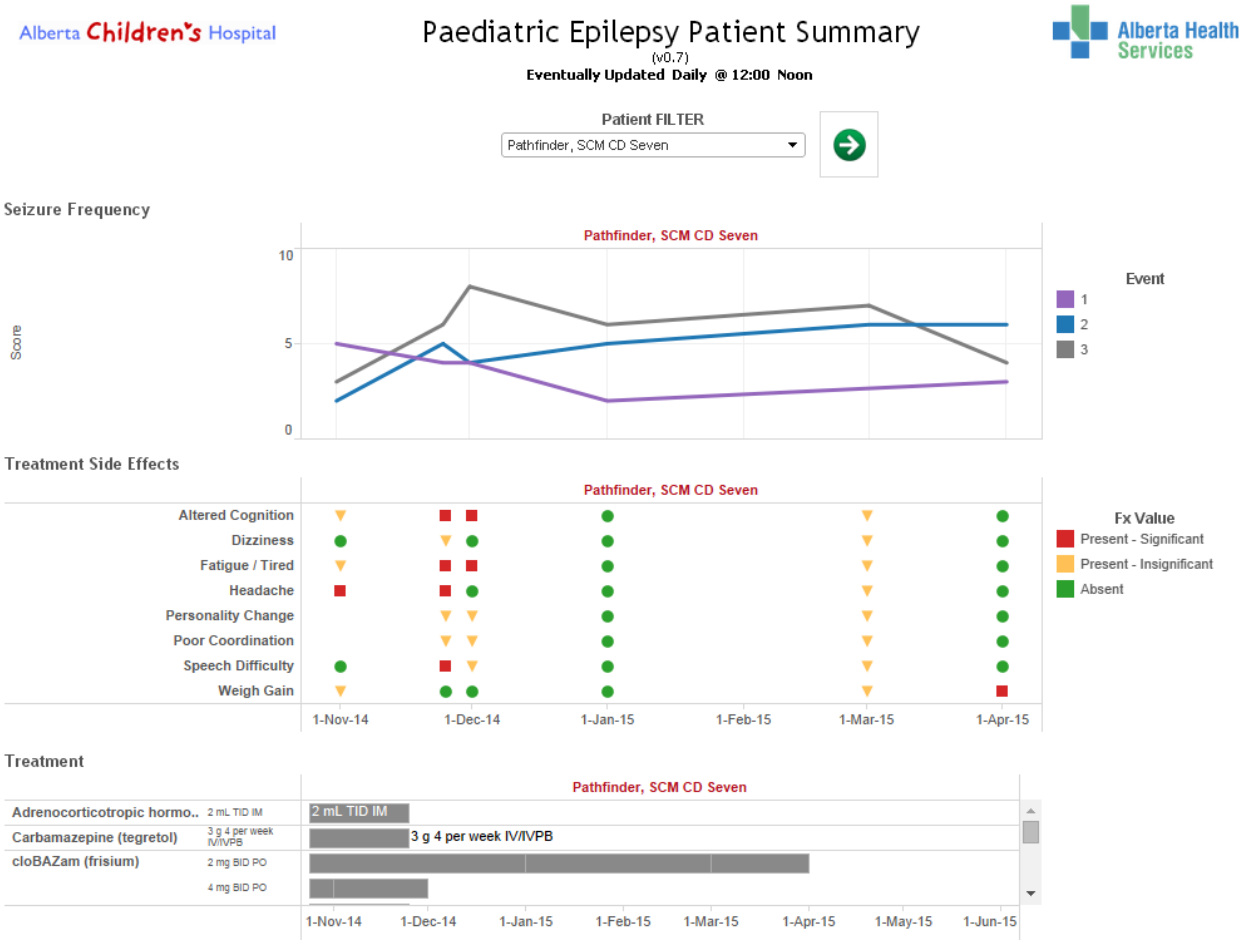
PATIENT DASHBOARD



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Paediatric Epilepsy - Population Summary

(v1.5)

Updated DAILY @ 12:00:00 (Noon)

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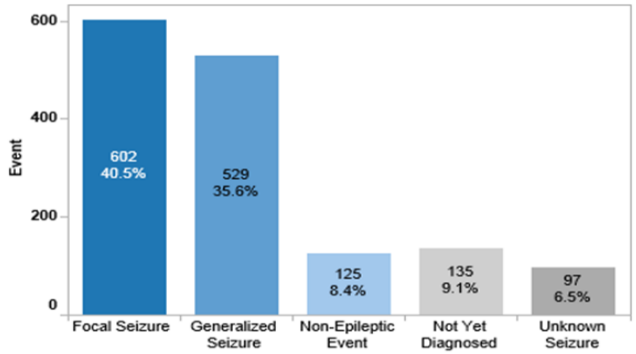
Start Date	End Date
1-Nov-14	31-Dec-15

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

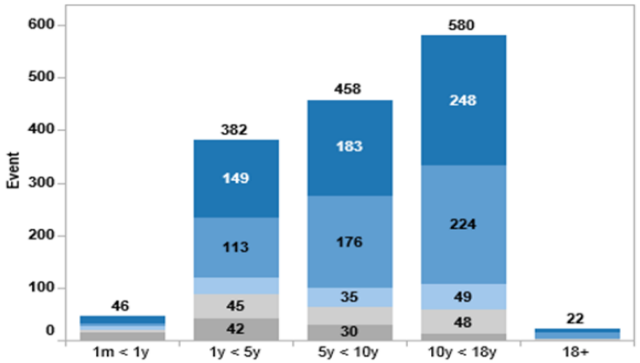
Data DATE

24-Aug-15
15:09:46

Event Diagnosis



Event Age



Patient COUNT

905

Visit COUNT

914

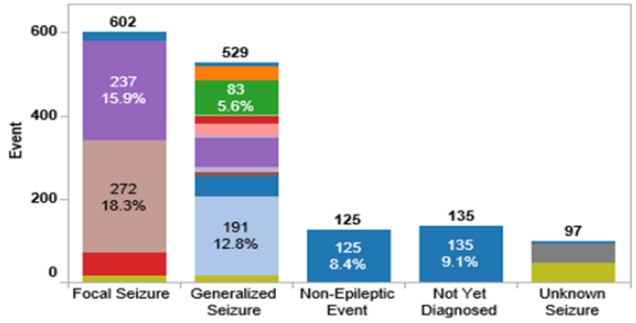
Note COUNT

1,148

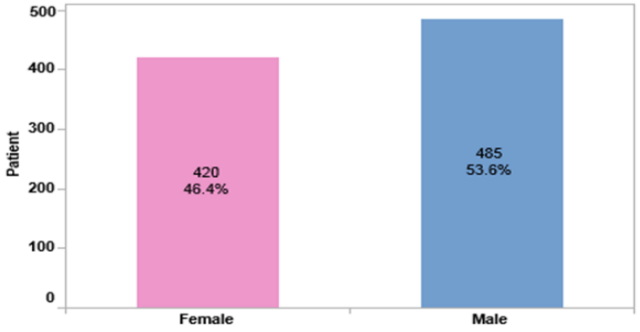
Event COUNT

1,488

Event Seizure Type



Patient Gender



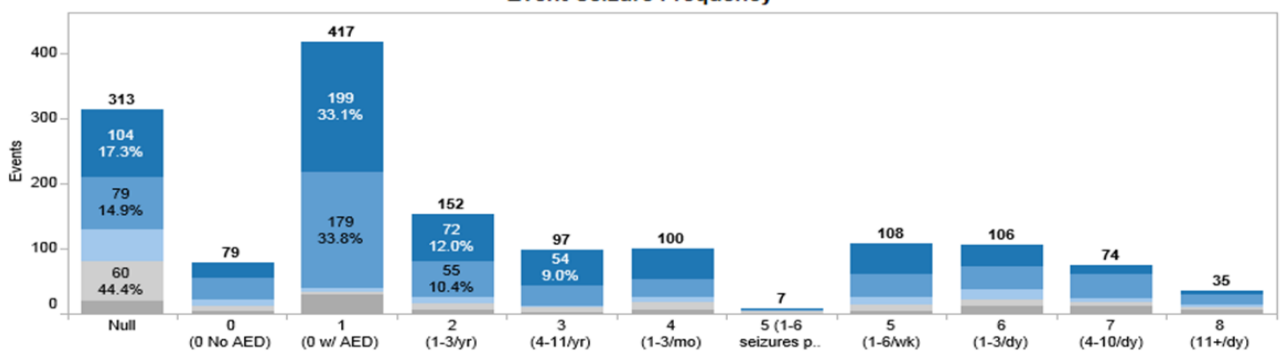
Diagnosis FILTER

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

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HOSPITAL
FOUNDATION

KINSMEN CARE
FOUNDATION