

Table S4.1 – Outcomes suggested after R1 of the Delphi survey

Additional outcome suggested	Stakeholder & Score	Score	Notes
Frequency of hospital out-patient attendance for BECTS review	Professional	7	New outcome identified Outcome: Attendance for medical appointments in outpatients Domain: Seizures Description: Routine attendances for medical epilepsy management
seen by consultant with specialist expertise in epilepsy	Professional	7	No new outcomes represented in free-text response/already covered in outcomes.
seen by consultant paediatric neurologist	Professional	7	No new outcomes represented in free-text response/already covered in outcomes.
seen by paediatric epilepsy specialist nurse	Professional	7	No new outcomes represented in free-text response/already covered in outcomes.
taking anti-convulsant for BECTS	Professional	8	No new outcomes represented in free-text response/already covered in outcomes.
Hospital attendances	Professional	4	New outcome identified Outcome: Unplanned hospital attendances at Accident & Emergency Domain: Adverse events Description: Visiting the hospital

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			due to an acute medical emergency
Hospital admissions	Professional	4	New outcome identified Outcome: Unplanned epilepsy-related admission to hospital as inpatient Domain: Adverse Events Description: Unexpectedly needing to be admitted to hospital
Change in medication; e.g. withdrawal or addition of AED	Professional	5	New outcome identified Outcome: Drug treatment failure (adverse events or poor seizure control) Domain: Adverse Events Description: stopping medication because it's not working or causing problems
Epilepsy in this person drug resistant (by ILAE criteria)	Professional	4	No new outcomes represented in free-text response/already covered in outcomes.
list comorbidities	Professional	7	No new outcomes represented in free-text response/already covered in outcomes.
Evidence of parasomnia with awakening at night	Professional	7	No new outcomes represented in free-text response/already covered in outcomes.
Percentage of diagnosed	Professional	9	No new outcomes represented in

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comorbidities in children with RE			free-text response/already covered in outcomes.
The types of seizures seen in the child with the diagnosis	Professional	6	No new outcomes represented in free-text response/already covered in outcomes.
The percentage of children with RE whose epilepsy evolves or becomes uncontrollable.	Professional	9	No new outcomes represented in free-text response/already covered in outcomes.
speech regression / aphasia	Professional	9	No new outcomes represented in free-text response/already covered in outcomes.
Awareness of SUDEP	Parent	8	No new outcomes represented in free-text response/already covered in outcomes.
TICS	Parent	8	No new outcomes represented in free-text response/already covered in outcomes.
Improvement of deterioration of school work after starting treatment	Professional	6	No new outcomes represented in free-text response/already covered in outcomes.
Ability to play Sport	Parent	4	No new outcomes represented in free-text response/already covered in outcomes.