

Supplementary C. Neurologist questionnaire

Section 1: Demographics

1. In which location (i.e. name of hospital or practice) do you primarily see children with known or suspected developmental and epileptic encephalopathies (DEE)? *DEE are the most severe group of epilepsies. They usually begin in infancy or childhood with drug-resistant seizures, epileptiform EEG patterns, developmental slowing or regression, and cognitive impairment. For further information about DEE, please see the PENNSW.org.au website.*
2. Please indicate your primary role (can indicate more than one):
 - General Practitioner
 - Consultant Paediatrician
 - Paediatric Neurologist
 - Other: _____
3. How long have you been in the role specified above?
 - <6 months
 - 6 months – 2 years
 - 2 years – 10 years
 - > 10 years
4. How many patients have you cared for with DEE in your primary role?
 - 1-2
 - 3-5
 - 6-10
 - 10+
5. How confident do you feel in caring for children diagnosed with DEE?
 - Not at all (0) – 10 (very)

Section 1: Your thoughts on GenE Compass

	Question	4	3	2	1
1	How would you rate the quality of the reports/information you received with GenE Compass?	Excellent	Good	Fair	Poor
2	Did you get information that was useful to you/your patient and their family?	Yes, definitely	Yes, generally	No, not really	No, definitely not
3	To what extent has GenE Compass met your information needs?	They helped a great deal	They helped somewhat	They really did not help	They seemed to make things worse
4	If a parent were in need of information about their child with DEE, would you recommend GenE Compass to them?	No, definitely not	No, not really	Yes, generally	Yes, definitely
5	How satisfied are you with the amount of information you received within the GenE Compass reports?	No, definitely not	No, not really	Yes, generally	Yes, definitely

6	Has GenE Compass helped you care for your patients with DEE more effectively ?	Yes, they helped a great deal	Yes, it helped somewhat	No, it really did not help	No, it seemed to make things worse
7	In an overall, general sense, how satisfied are you with GenE Compass (<i>including the process and reports, while acknowledging that this is currently an intervention with parents as the primary audience</i>)?	Very satisfied	Mostly satisfied	Indifferent or mildly dissatisfied	Quite dissatisfied
8	If you were to receive another report from GenE Compass, would you use it?	No, definitely not	No, not really	Yes, generally	Yes, definitely

9. We sent all reports to the neurologist, GP and paediatrician that the caregiver nominated. Please share your thoughts about **this pathway**: _____
10. Please share **why** GenE Compass was **beneficial** to you or your patient/s, if at all: _____
11. Please share any thoughts or recommendations of how we could **improve** GenE Compass, for either you or your patient/s: _____

Section 2: Information searching and provision

Thinking about the **past 6 months**

	Question	Response
1	Please estimate how much time, in total, you spent searching for information related to all of your patients with a confirmed or suspected DEE diagnosis (in regard to their treatment, symptoms or general care):	<ul style="list-style-type: none"> • <30 minutes • 30 minutes - 1 hour • 1 hour – 5 hours • 5-10 hours • 10-20 hours • 20+ hours
2	What, if any, are the barriers to searching for information on your patients with DEE? (select as many as relevant)	<ul style="list-style-type: none"> • Didn't have time • Didn't know what was relevant / most accurate • Didn't know how to or where to look • Was too overwhelmed or stressed • Didn't understand the information • Other: _____ • None
3	Where did you seek information related to DEE from? (select as many as relevant)	<ul style="list-style-type: none"> • Google • Academic literature (i.e. peer-reviewed journals, GeneReviews) • Medical websites (e.g. UpToDate)

		<ul style="list-style-type: none"> • Please share the preferred websites that you use: _____ • A healthcare professional • A non-profit organisation (e.g. GETA) • Support group and/or peer support network • Colleagues • Other families with a child with DEE • Other, please specify: _____
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6. How often are you contacted with questions about your patients with a suspected or confirmed diagnosis of a DEE (*by the family, allied health, or other medical professionals*)?
- More regularly than once a fortnightly
 - Once a fortnight to monthly
 - Once every 1-3 months
 - Once every 3-6 months
 - 1-2 times per year
 - Less than once a year

Section 2: Final questions

	Question	Response
1	Would you be willing to participate in a 15-30-minute interview about your experiences with GenE Compass?	Yes / No
2	What is the best contact number for you?	Open
3	What is your email address?	
4	Please provide at least three availabilities for your interview. We will then send you a meeting invite. Thank you!	Open