

## Supplementary B1. Caregiver Questionnaire 1

## Section 1: About you

	Question	Response
1	What is your gender?	<ul style="list-style-type: none"> <li>Female</li> <li>Male</li> <li>Other (<i>please specify</i>) _____</li> </ul>
2	What is your date of birth?	<i>Open text</i>
3	What is your postcode?	<i>Open text</i>
4	What is your highest level of education?	<ul style="list-style-type: none"> <li>Year 10 or below</li> <li>Year 12</li> <li>Apprenticeship</li> <li>Certificate/Diploma</li> <li>University degree</li> <li>Postgraduate degree</li> </ul>
5	What is your employment status?	<ul style="list-style-type: none"> <li><b>Employed:</b> Full-time / part-time / casual</li> <li><b>Not employed:</b> actively seeking work / not seeking work / retired / student / home duties</li> </ul>
6	Marital status	<ul style="list-style-type: none"> <li>Never married / never de facto</li> <li>Currently married or de facto</li> <li>Separated / divorced / previously de facto</li> <li>Widowed</li> </ul>

## Section 2: About your child

	Question	Response
1	How many children do you have with a suspected or confirmed diagnosis of developmental and epileptic encephalopathy (DEE)?	<i>Open text</i>
2	What is the full name of your child/ren?	<i>Open text</i>
3	What is their date of birth?	<i>DD/MM/YY</i>
4	Do they have a genetic diagnosis?	<i>Yes (please specify) / no</i>
5	We will send you a report for each question you submit to GenE Compass. Please provide the name of your child's paediatric neurologist, paediatrician and GP (if they don't have one, please write 'none')	<i>Open text</i>

## Section 3: Perception of illness

For the following questions, please circle the number that best corresponds to your views:

	Question	Response
1	How much does your child's illness affect your life?	0 (no affect at all) – 10 (severely affects my life)
2	How long do you think your child's illness/symptoms will continue?	0 (a very short time) – 10 (forever)
3	How much control do you feel you have over your child's illness/symptoms?	0 (absolutely no control) – 10 (extreme amount of control)
4	How much do you think your child's treatment (e.g. anti-seizure medications, physiotherapy, diet) can help his/her illness/symptoms?	0 (not at all) – 10 (extremely helpful)
5	How much does your child experience symptoms from his/her illness?	0 (no symptoms at all) – 10 (many severe symptoms)

6	How concerned are you about your child's illness?	0 (not concerned at all) – 10 (extremely concerned)
7	How well do you feel you understand your child's illness?	0 (don't understand at all) – 10 (understand very clearly)
8	How much does your child's illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?)	0 (not at all affected emotionally) – 10 (extremely affected emotionally)

#### Section 4: Information searching

On average:

	Question	Response
1	On average, how much time do you spend a month personally searching for information related to your child's diagnosis, treatment, symptoms or general care:	<i>Open text</i>
2	Over the past month, where have you sought information from? (select as many as relevant)	<ul style="list-style-type: none"> <li>• Google</li> <li>• Academic literature (i.e. peer-reviewed literature)</li> <li>• Medical websites</li> <li>• A healthcare professional</li> <li>• A non-profit organisation (e.g. GETA)</li> <li>• Support group and/or peer support network               <ul style="list-style-type: none"> <li>• Please share any that you find particularly useful:</li> </ul> </li> <li>• Family/friends</li> <li>• Other: _____</li> </ul>
3	What, if any, are the barriers to searching for information? (select as many as relevant)	<ul style="list-style-type: none"> <li>• Didn't have time</li> <li>• Didn't know what was relevant / most accurate</li> <li>• Didn't know how to or where to look</li> <li>• Was too overwhelmed or stressed</li> <li>• Didn't understand the information</li> <li>• Other: _____</li> </ul>

#### Section 5: Understanding health information

Please circle the answer that best represents your response.

	Question	Response
1	How often do you have someone help you read hospital materials?	1. Always 2. Often 3. Sometimes 4. Occasionally 5. Never
2	How often do you have problems learning about your medical condition because of difficulty understanding written information?	
3	How often do you have a problem understanding what is told to you about your medical condition?	
4	How confident are you filling out medical forms by yourself?	

#### Section 6: Caring for your child

There are no right or wrong answers. Each parent navigates their child's illness in the best way they can at the time. These questions indicate your knowledge, skills and confidence in managing your child's health. It **does not** indicate your ability to parent well.

	Question	Response
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1	When all is said and done, I and/or my partner are responsible for managing my child's health condition	<ul style="list-style-type: none"> <li>• Disagree strongly</li> <li>• Disagree</li> <li>• Agree</li> <li>• Agree strongly</li> <li>• N/A</li> </ul>
2	Taking an active role in my child's health care is the most important factor in determining my child's health and ability to function	
3	I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my child's health condition	
4	I know what each of my child's prescribed medications do	
5	I am confident that I can tell when my child needs to go get medical care and when I can handle a health problem myself	
6	I am confident I can tell my child's health care provider concerns I have even when he or she does not ask	
7	I am confident that I can follow through on medical treatments my child needs to do at home	
8	I understand the nature and causes of my child's health condition(s)	
9	I know the different medical treatment options available for my child's health condition	
10	I have been able to maintain my child's lifestyle changes for their health	
11	I know how to prevent further problems with my child's health condition	
12	I am confident I can figure out solutions when new situations or problems arise with my child's health condition	
13	I am confident that I can maintain my child's lifestyle changes, like diet and exercise, even during times of stress	

### Section 7: Your quality of life

These questions will help us understand more about the parents who are responding to our questionnaires. They will also help us evaluate the impact of GenE Compass on you and your family.

1. Which of the following statements best describes how you spend your time? (please select one box)

When you are thinking about how you spend your time, please include anything you value or enjoy, including leisure activities, formal employment, voluntary or unpaid work, and caring for others.	
1	I'm able to spend my time as I want, doing things I value or enjoy
2	I'm able to do enough of the things I value or enjoy with my time
3	I do some of the things I value or enjoy with my time, but not enough
4	I don't do anything I value or enjoy with my time

2. Which of the following statements best describes how much control you have over your daily life? (please select one box)

1	I have as much control over my daily life as I want
2	I have adequate control over my daily life
3	I have some control over my daily life, but not enough
4	I have no control over my daily life

3. Thinking about how well you look after yourself – such as, getting enough sleep or eating well – which statement best describes your present situation?

1	I look after myself as well as I want
2	I look after myself well enough
3	Sometimes I can't look after myself well enough
4	I feel I am neglecting myself

4. Which of the following statements best describes how safe you feel?

By 'feeling safe' we mean feeling safe from fear of abuse, being attacked or other physical harm, such as accidents, which are a result of your caring role.	
1	I feel as safe as I want
2	Generally I feel adequately safe, but not as safe as I would like
3	I feel less than adequately safe
4	I don't feel at all safe

5. Thinking about how much contact you have with people you like, which of the following statements best describes your social situation?

1	I have as much social contact as I want with people I like
2	I have adequate social contact with people
3	I have some social contact with people, but not enough
4	I have little social contact with people and feel socially isolated

6. Thinking about the space and time you have to be yourself in your daily life, which of the following statements best describes your present situation?

1	I have all the space and time I need to be myself
2	I have adequate space and time to be myself
3	I have some of the space and time I need to be myself, but not enough
4	I don't have any space or time to be myself

7. Thinking about feeling supported and encouraged in your caring role, which of the following statements best describes your present situation?

This question is asking about feeling supported and encouraged, rather than how you are supported and encouraged by particular people or organisations.	
1	I feel I have the encouragement and support I want
2	I feel I have adequate encouragement and support
3	I feel I have some encouragement and support, but not enough
4	I feel I have no encouragement and support

## Supplementary B2. Caregiver Questionnaire 2

## Section 1: Your thoughts of GenE Compass

	Question	4	3	2	1
1	How would you rate the quality of the service you received with GenE Compass?	Excellent	Good	Fair	Poor
2	Did you get the kind of service you wanted?	Yes, definitely	Yes, generally	No, not really	No, definitely not
3	To what extent has GenE Compass met your needs?	Almost all of my needs have been met	Most of my needs have been met	Only a few of my needs have been met	None of my needs have been met
4	If a friend were in need of similar help, would you recommend GenE Compass to him or her?	No, definitely not	No, not really	Yes, generally	Yes, definitely
5	How satisfied are you with the amount of help you received with GenE Compass?	Very satisfied	Mostly satisfied	Indifferent or mildly dissatisfied	Quite dissatisfied
6	Has GenE Compass helped you to deal more effectively with your problems?	Yes, they helped a great deal	Yes, they helped somewhat	No, they really did not help	No, they seemed to make things worse
7	In an overall, general sense, how satisfied are you with GenE Compass?	Very satisfied	Mostly satisfied	Indifferent or mildly dissatisfied	Quite dissatisfied
8	If you were to seek help again, would you come back to GenE Compass?	No, definitely not	No, not really	Yes, generally	Yes, definitely

9. Please share why GenE Compass was of **benefit** to you, if at all: *Open text*

10. Please share any thoughts/recommendations of how we could **improve** GenE Compass: *Open text*

## Section 2: Information searching

Over the past 3-months:

	Question	Response
1	Please estimate how much time, on average, you spend a month personally searching for information related to your child's diagnosis, treatment, symptoms or general care:	<i>Open text</i>
2	Where have you sought information from? (select as many as relevant)	<ul style="list-style-type: none"> <li>• GenE Compass</li> <li>• Google</li> <li>• Academic literature (i.e. peer-reviewed literature)</li> <li>• Medical websites</li> <li>• A healthcare professional</li> <li>• A non-profit organisation (e.g. GETA)</li> <li>• Support group and/or peer support network               <ul style="list-style-type: none"> <li>• Please share any that you find particularly useful:</li> </ul> </li> <li>• Family/friends</li> </ul>

		<ul style="list-style-type: none"> <li>• Other (<i>please specify</i>) _____</li> </ul>
3	What, if any, are the barriers to searching for information yourself? (select as many as relevant)	<ul style="list-style-type: none"> <li>• Didn't have time</li> <li>• Didn't know what was relevant / most accurate</li> <li>• Didn't know how to or where to look</li> <li>• Was too overwhelmed or stressed</li> <li>• Didn't understand the information</li> <li>• Other (<i>please specify</i>)</li> </ul>

#### Section 4: Perception of illness

For the following questions, please circle the number that best corresponds to your views

	Question	Response
1	How much does your child's illness affect your life?	0 (no affect at all) – 10 (several affects my life)
2	How long do you think your child's illness/symptoms will continue?	0 (a very short time) – 10 (forever)
3	How much control do you feel you have over your child's illness/symptoms?	0 (absolutely no control) – 10 (extreme amount of control)
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It **does not** indicate your ability to parent well.

	Question	Response
1	When all is said and done, I am the person who is responsible for managing my child's health condition	<ul style="list-style-type: none"> <li>• Disagree strongly</li> <li>• Disagree</li> <li>• Agree</li> <li>• Agree strongly</li> <li>• N/A</li> </ul>
2	Taking an active role in my child's health care is the most important factor in determining my child's health and ability to function	
3	I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my child's health condition	
4	I know what each of my child's prescribed medications do	
5	I am confident that I can tell when my child needs to go get medical care and when I can handle a health problem myself	
6	I am confident I can tell my child's health care provider concerns I have even when he or she does not ask	
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2. Which of the following statements best describes how much control you have over your daily life? (please select one box)

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<b>4</b>	I have little social contact with people and feel socially isolated
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6. Thinking about the space and time you have to be yourself in your daily life, which of the following statements best describes your present situation?

<b>1</b>	I have all the space and time I need to be myself
<b>2</b>	I have adequate space and time to be myself
<b>3</b>	I have some of the space and time I need to be myself, but not enough
<b>4</b>	I don't have any space or time to be myself

7. Thinking about feeling supported and encouraged in your caring role, which of the following statements best describes your present situation?

This question is asking about feeling supported and encouraged, rather than how you are supported and encouraged by particular people or organisations.	
<b>1</b>	I feel I have the encouragement and support I want
<b>2</b>	I feel I have adequate encouragement and support
<b>3</b>	I feel I have some encouragement and support, but not enough
<b>4</b>	I feel I have no encouragement and support

### Section 7: Final questions

	Question	Response
<b>1</b>	If possible, would you like to continue having access to the GenE Compass service?	Yes / No / Unsure
<b>2</b>	Would you be willing to participate in a 30-minute telephone interview about your experiences with GenE Compass?	Yes / No
<b>3</b>	<i>If yes:</i> What is your best contact number?	<i>Open text</i>
<b>4</b>	<i>If yes:</i> When is the best day/time to call you? We will first call to answer any questions you may have and to book in your interview.	<i>Open text</i>