Q1 About you

Answered: 31 Skipped: 1

ANSWER CHOICES	RESPONSES	
Job role	100.00%	31
Number of years in post	96.77%	30

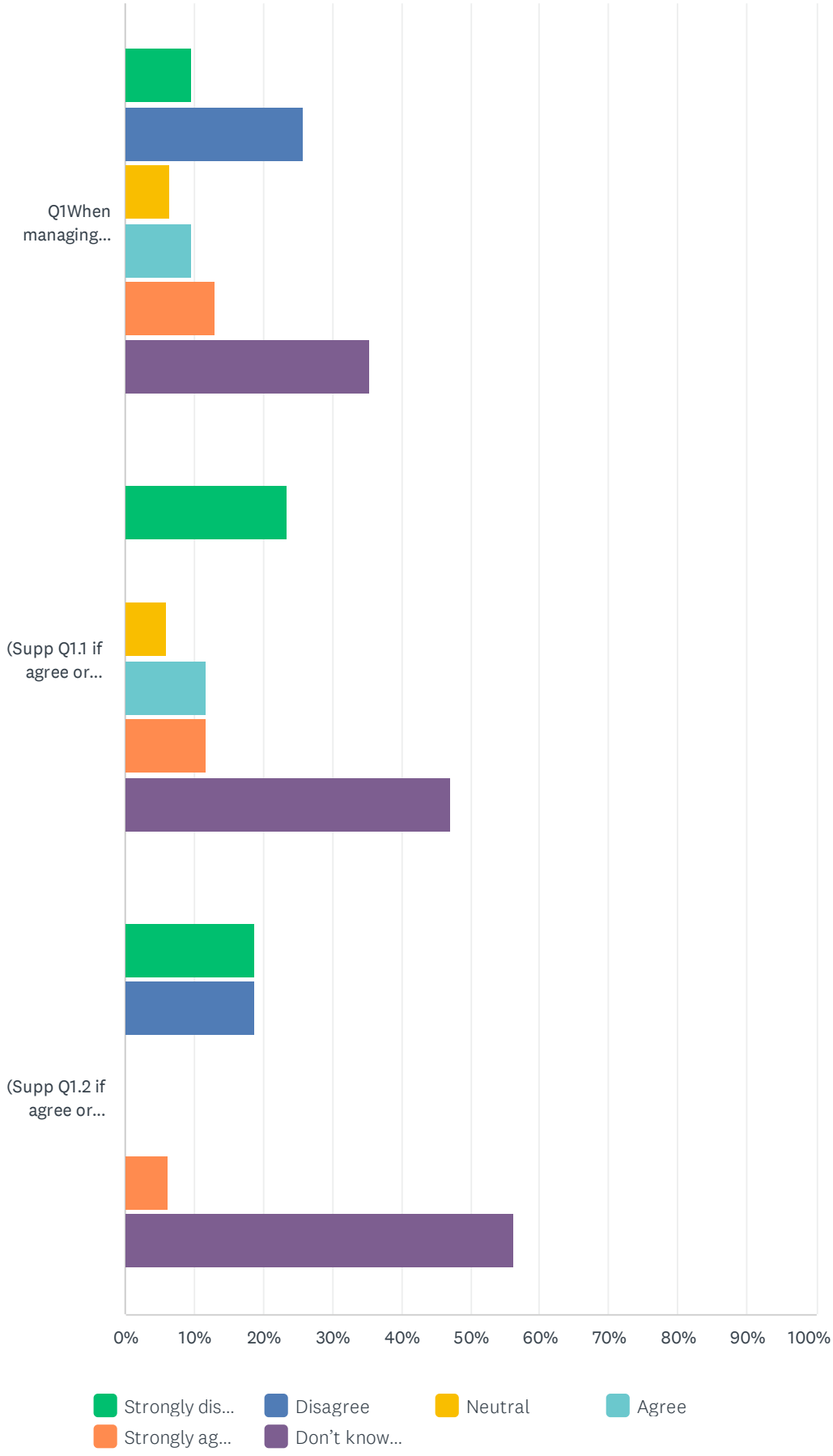
#	JOB ROLE	DATE
1	staff nurse	3/10/2022 12:58 PM
2	Community Nurse	3/10/2022 10:43 AM
3	Consultant Paediatrician with Specialist Interest in PPC	3/9/2022 6:41 PM
4	Clinical Nurse Specialist	3/8/2022 10:29 AM
5	consultant paediatrician	3/7/2022 2:38 PM
6	Clinical Nurse Specialist	3/7/2022 1:36 PM
7	Palliative Care CNS	3/7/2022 9:19 AM
8	consultant paediatrcian	3/4/2022 6:53 PM
9	consultant	3/3/2022 6:31 PM
10	Consultant Paediatrician	3/3/2022 3:27 PM
11	Consultant Palliative medicine	3/2/2022 5:16 PM
12	Consultant paediatrician	3/2/2022 4:01 PM
13	Consultant in PPM	2/23/2022 10:16 AM
14	Grid trainee- ppm	2/9/2022 11:03 AM
15	Clinical Nurse Specialist	2/6/2022 12:36 AM
16	Retired Hospice Director	2/5/2022 10:58 AM
17	CCN	2/3/2022 10:30 PM
18	Hospice Medical Director and Palliative Care Paediatrician	2/3/2022 9:54 PM
19	consultant paediatric palliative medicine	2/3/2022 5:33 PM
20	Clinical Nurse Specialist	2/3/2022 3:17 PM
21	Paediatric Neurodisability Nurse	2/3/2022 11:04 AM
22	Ppm consultant	2/3/2022 8:00 AM
23	consultnat community paediatrician	2/2/2022 11:31 PM
24	Consultant in PPM	2/2/2022 12:25 PM
25	paediatrician	2/2/2022 12:17 PM
26	Consultant Paediatrician (Disability)	2/1/2022 4:33 PM
27	Clinical Nurse Specialist	2/1/2022 3:50 PM
28	Palliative care consultant	2/1/2022 2:48 PM
29	Consultant	2/1/2022 1:46 PM

30	Consultant Paediatrician s.i. Paed Pall Medicine	2/1/2022 1:01 PM
31	Consultant in Paediatric Palliative Medicine	2/1/2022 12:44 PM

#	NUMBER OF YEARS IN POST	DATE
1	3	3/10/2022 12:58 PM
2	4	3/10/2022 10:43 AM
3	8	3/9/2022 6:41 PM
4	8.5	3/8/2022 10:29 AM
5	12 years	3/7/2022 2:38 PM
6	0.5	3/7/2022 1:36 PM
7	2.5	3/7/2022 9:19 AM
8	1	3/4/2022 6:53 PM
9	15	3/3/2022 6:31 PM
10	1	3/3/2022 3:27 PM
11	11	3/2/2022 5:16 PM
12	15	3/2/2022 4:01 PM
13	4	2/23/2022 10:16 AM
14	2	2/9/2022 11:03 AM
15	6 months	2/6/2022 12:36 AM
16	28	2/5/2022 10:58 AM
17	9yrs	2/3/2022 10:30 PM
18	Have worked in PPC for 12 years	2/3/2022 9:54 PM
19	20 years	2/3/2022 5:33 PM
20	2	2/3/2022 3:17 PM
21	6	2/3/2022 8:00 AM
22	3	2/2/2022 11:31 PM
23	1/2	2/2/2022 12:25 PM
24	25	2/2/2022 12:17 PM
25	28	2/1/2022 4:33 PM
26	7	2/1/2022 3:50 PM
27	19	2/1/2022 2:48 PM
28	21	2/1/2022 1:46 PM
29	11	2/1/2022 1:01 PM
30	2 years	2/1/2022 12:44 PM

Q2 Please read the following statements and place a tick on the rating scale

Answered: 31 Skipped: 1


Q1When managing...
(Supp Q1.1 if agree or...
(Supp Q1.2 if agree or...
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%
Strongly dis...
Disagree
Neutral
Agree
Strongly ag...
Don't know...

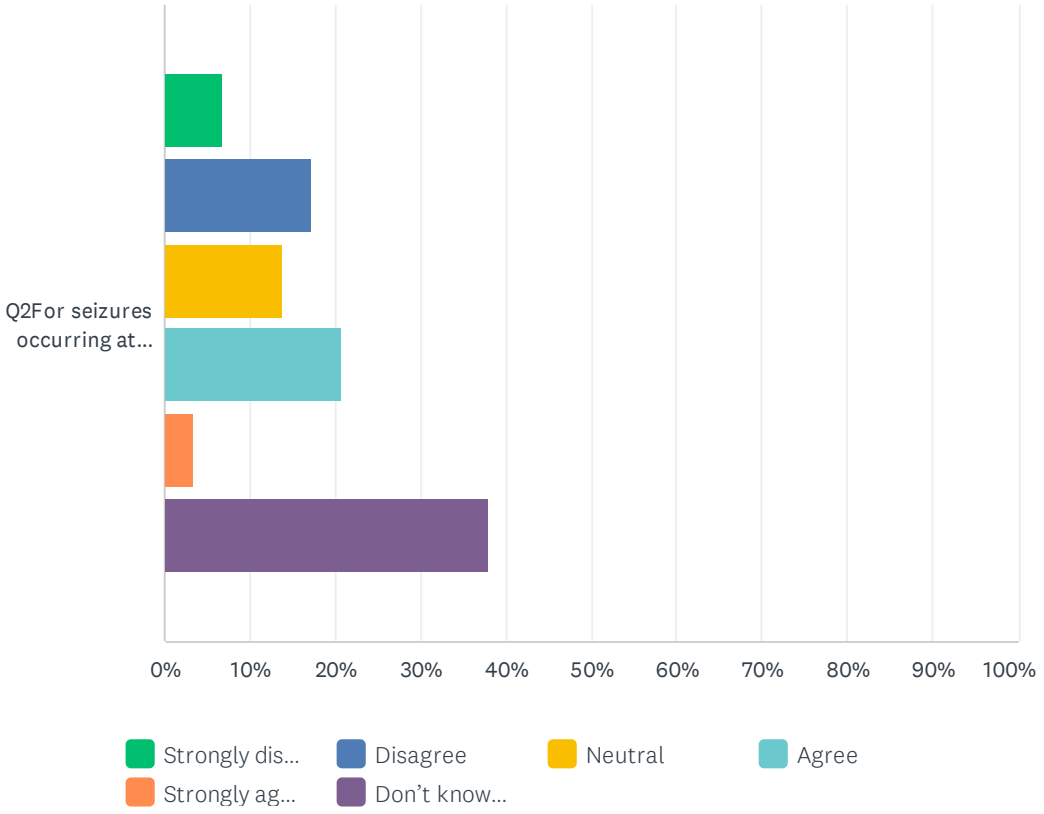
	STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE	DON'T KNOW/NOT WITHIN MY EXPERIENCE	TOTAL	WEIGHTED AVERAGE
Q1When managing seizures occurring at EOL: I have prescribed Phenobarbitone at a dose higher than that recommended in the APPM formulary	9.68% 3	25.81% 8	6.45% 2	9.68% 3	12.90% 4	35.48% 11	31	1.84
(Supp Q1.1 if agree or strongly agree to Q1) When managing seizures occurring at EOL: I have prescribed Phenobarbitone at a dose higher than that recommended in the APPM formulary only with the advice of a Paediatric Neurologist	23.53% 4	0.00% 0	5.88% 1	11.76% 2	11.76% 2	47.06% 8	17	1.47
(Supp Q1.2 if agree or strongly agree to Q1) When managing seizures occurring at EOL: I have prescribed Phenobarbitone at a dose higher than that recommended in the APPM formulary only with the advice of a subspecialist in Paediatric Palliative Medicine	18.75% 3	18.75% 3	0.00% 0	0.00% 0	6.25% 1	56.25% 9	16	0.88

#	(SUPP Q1.3 IF AGREE OR STRONGLY AGREE TO Q1) DOSE PRESCRIBED, AGE & DIAGNOSIS OF CHILD, OTHER MEDICINES PRESCRIBED AT THE TIME AND ANY ADVERSE EFFECTS OBSERVED	DATE
1	max 20mg/kg/day	3/3/2022 6:31 PM
2	2years old approx 13kg. Genetic Encephalopathic epilepsy experiencing regular seizures presenting with apnoeas - expected to die at 9 months. Already on high doses of phenobarbitone alongside ketogenic diet. Failing to respond to multiple other antiepileptic drugs. Combination of Phenobarbitone and midazolam reduced apnoeas during end of life care without causing excessive drowsiness. Survived with growth and development for many months beyond expected prognosis, but required regular titration of background medication. Phenobarbitone gradually titrated with advice from consultant neurologist overseeing her care to 85mg bd	3/2/2022 5:16 PM
3	died aged 10 months MOPD1 (neurogenetic syndrome), died 7 months WWOX (epileptic encephalopathy) both also had midazolam in a separate driver. 8 yr Retts syndrome (oral dosing)	2/23/2022 10:16 AM
4	Dependent on condition of child. Seen too numerous to remember all details	2/5/2022 10:58 AM

5	I can't remember all the details as it was a long time ago but I think we did go above APPM doses for a child once, only once all other options considered and tried, shared decision making between hospice doctors and hospital pall care team. For terminal seizures secondary to a brain tumour. My experience is that for terminal seizures the neurologists are sometimes less confident in prescribing advice than pall care colleagues	2/3/2022 9:54 PM
6	Not needed outside of usual range. Have experienced challenges in not being able to use loading dose in a teenager with s/c access only and poor enteral absorption - so phenobarb was not especially effective in her case of agitation/delirium at EOL & haloperidol and levomepromazine used in addition.	2/2/2022 11:31 PM
7	I don't use phenobarbital for seizures at end of life as have found the child or young person's usual medication (enteral or IV) and midazolam (buccal, subcut or IV) together effective as anticonvulsants.	2/1/2022 4:33 PM

Q3 Please read the following statements and place a tick on the rating scale

Answered: 29 Skipped: 3



	STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE	DON'T KNOW/NOT WITHIN MY EXPERIENCE	TOTAL	WEIGHTED AVERAGE
Q2For seizures occurring at EOL I would prescribe Phenobarbitone at a dose higher than that recommended in the APPM formulary**	6.90% 2	17.24% 5	13.79% 4	20.69% 6	3.45% 1	37.93% 11	29	1.83

Q4 (Supp Q2.1 if agree or strongly agree to Q2)Do you have a max dose of Phenobarbitone that you would prescribe to? What influences your decision to prescribe higher than the recommended APPMF dose range? What factors limit the dose prescribed?

Answered: 12 Skipped: 20

#	RESPONSES	DATE
1	As per APPM	3/8/2022 10:29 AM
2	20mg/kg/day not check blood levels. Limit is related to ability to give SC infusion volumes	3/3/2022 6:31 PM
3	I would take advice	3/3/2022 3:27 PM
4	Patient response is major factor. I would not prescribe above recommended dose without consulting widely with my own team and neurologists	3/2/2022 5:16 PM
5	This would be a gradual titration from starting doses within APPM range. Titration would also include increasing other medications (eg. midaz, chloral). Aim to	2/23/2022 10:16 AM
6	As per APPM	2/9/2022 11:03 AM
7	1. response to RX 2. stage to EOL 3. response to other seizure management drugs 4. I would normally only see children who had not responded to other treatments	2/5/2022 10:58 AM
8	I would consider it if all other options explored and ongoing seizures that require treatment. I would consult others and not make an isolated decision. I would only increase the dose if dose adjustments were proving helpful.	2/3/2022 9:54 PM
9	n/a	2/3/2022 11:04 AM
10	would do so following discussion with specialist PPM colleagues and lower dosing ineffective but tolerated.	2/2/2022 11:31 PM
11	I don't usually use Phenobarb at EOL	2/2/2022 12:25 PM
12	As above, I do not choose phenobarbital at end of life	2/1/2022 4:33 PM

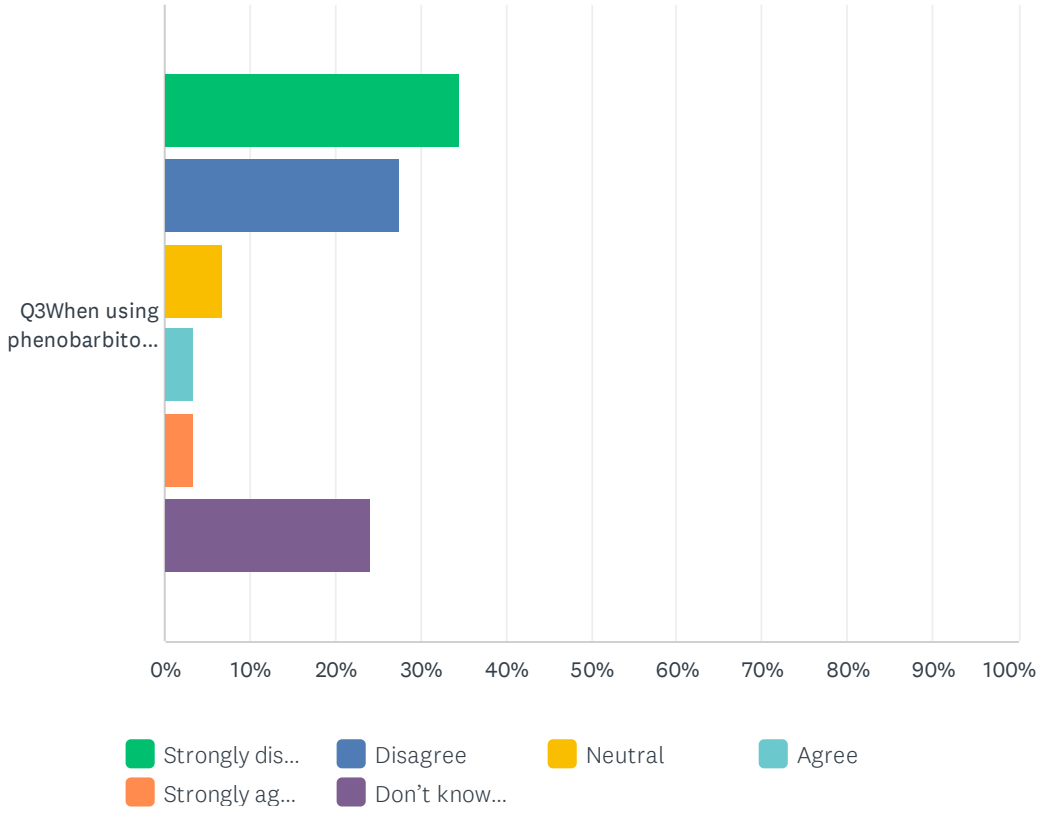
Q5 (Supp Q2.2 if disagree or strongly disagree to Q2)Assuming that the patient is receiving maximum tolerated doses of benzodiazepine medication and phenobarbitone what additional steps would you take to manage uncontrolled seizures at EOL?

Answered: 13 Skipped: 19

#	RESPONSES	DATE
1	I would consider Levetiracetam as an alternative drug if the maximum dose of Phenobarbitone was ineffective	3/8/2022 10:29 AM
2	Try levetiracetam (keppra)	3/4/2022 6:53 PM
3	might change the benzo Consider triggers eg pain, agitation Use paraldehyde and Keppra infusion	3/3/2022 6:31 PM
4	Change of benzo Actively manage secondary symptoms (distress, pain, secretions) Addition of chloral hydrate/other adjuvants that would introduce an element of sedation whilst still able to maintain airway. Advice from L4 consultant	3/3/2022 3:27 PM
5	consider subcut levetiracetam, rectal paraldehyde, rectal chloral hydrate	2/23/2022 10:16 AM
6	Discuss with neurology Consider keppra	2/9/2022 11:03 AM
7	1. Titrate up standard anti-epileptics 2. Consider using Keppra	2/5/2022 10:58 AM
8	Consider adding levetiracetam. Ensure any trigger symptoms well treated - eg pain. Consider ketamine (n=1 for us), phenytoin if have iv line, pr options (carbamazepine, possibly gabapentin - neurologists once recommended we try this but literature is scarce and we didn't need to try it in the end) DW neurologists for their advice	2/3/2022 9:54 PM
9	n/a	2/3/2022 11:04 AM
10	appropriate sedation to treat agitation/distress if not already sedated by benzo/phenobarb. consider any reversible causes (although unlikely in this scenario). Counselling of parents regarding seizure activity being more distressing to them than to child (if unaware.) Sufficient support around the family ?consider transfer to hospice/hospital for closer symptom control input.	2/2/2022 11:31 PM
11	Keppra po/subcut (if in community)	2/2/2022 12:25 PM
12	Depends on the situation and what the child is on already. Ensure appropriate route of administration for the situation. Discuss with epilepsy expert paediatric neurologist as need be.	2/1/2022 4:33 PM
13	Increased midazolam infusion	2/1/2022 12:44 PM

Q6 Please read the following statements and place a tick on the rating scale

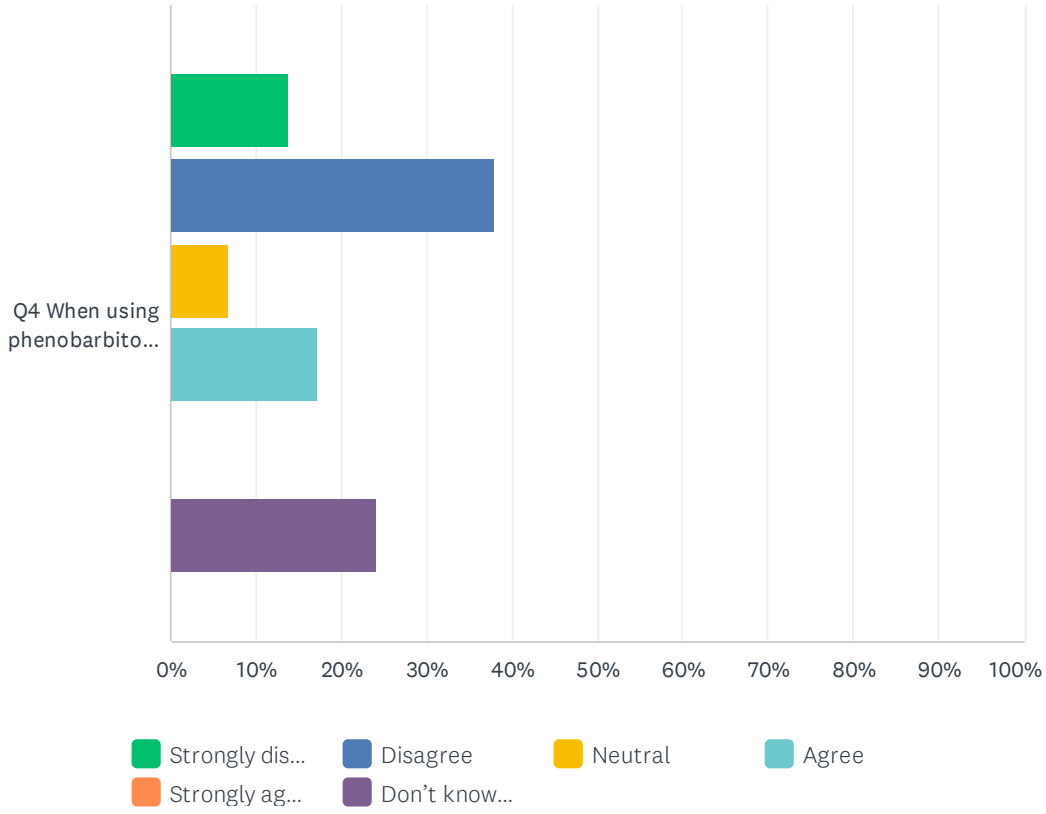
Answered: 29 Skipped: 3



	STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE	DON'T KNOW/NOT WITHIN MY EXPERIENCE	TOTAL	WEIGHTED AVERAGE
Q3When using phenobarbitone to manage seizures at EOL I would monitor plasma phenobarbitone levels as part of my usual practice	34.48% 10	27.59% 8	6.90% 2	3.45% 1	3.45% 1	24.14% 7	29	1.41

Q7 Please read the following statements and place a tick on the rating scale

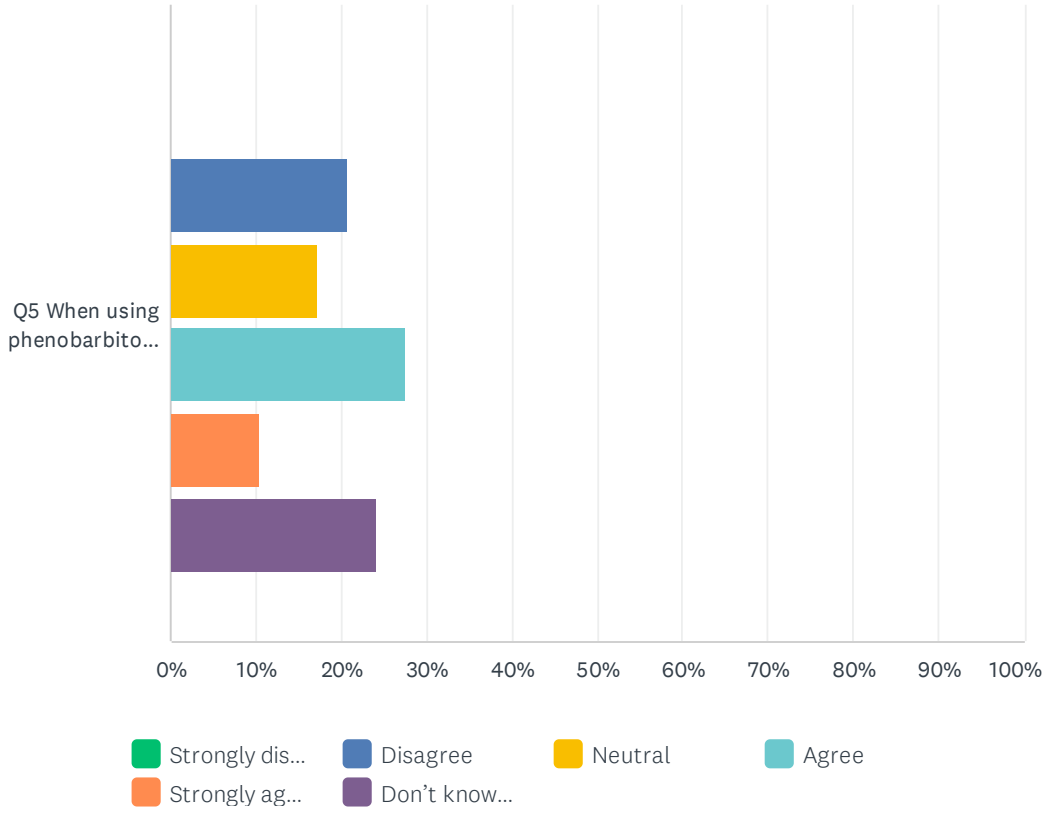
Answered: 29 Skipped: 3



	STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE	DON'T KNOW/NOT WITHIN MY EXPERIENCE	TOTAL	WEIGHTED AVERAGE
Q4 When using phenobarbitone to manage seizures at EOL I would monitor plasma phenobarbitone levels sometimes	13.79% 4	37.93% 11	6.90% 2	17.24% 5	0.00% 0	24.14% 7	29	1.79

Q8 Please read the following statements and place a tick on the rating scale

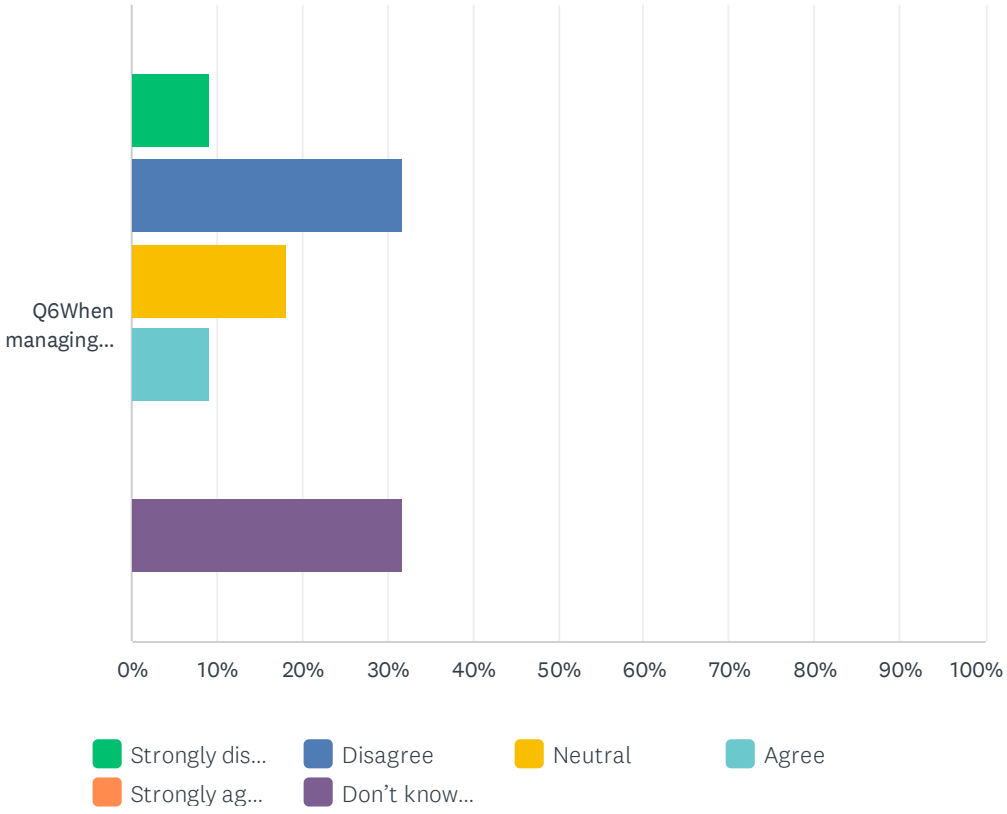
Answered: 29 Skipped: 3



	STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE	DON'T KNOW/NOT WITHIN MY EXPERIENCE	TOTAL	WEIGHTED AVERAGE
Q5 When using phenobarbitone to manage seizures at EOL I would never monitor plasma phenobarbitone levels	0.00% 0	20.69% 6	17.24% 5	27.59% 8	10.34% 3	24.14% 7	29	2.55

Q9 Please read the following statements and place a tick on the rating scale

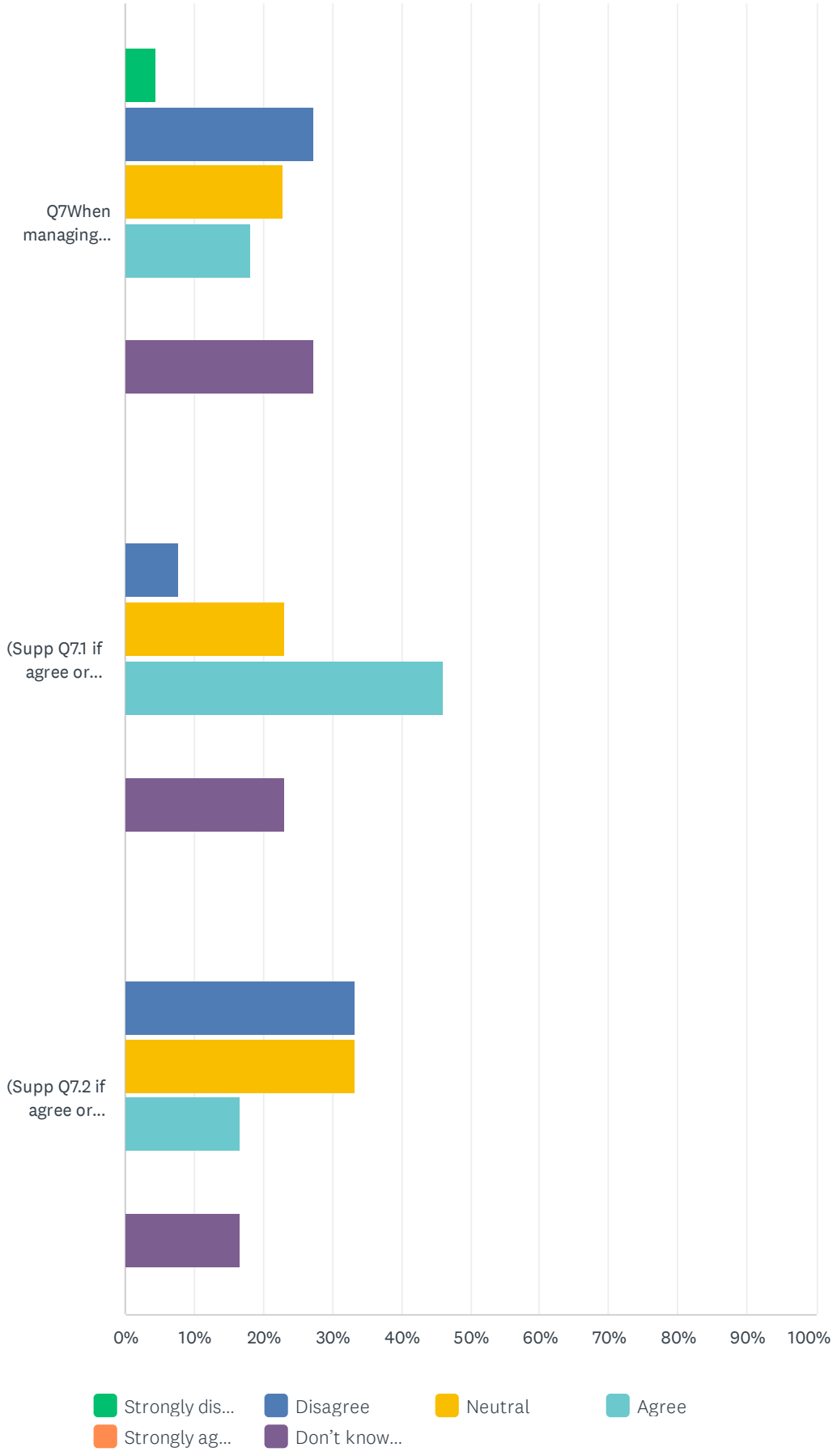
Answered: 22 Skipped: 10



	STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE	DON'T KNOW/NOT WITHIN MY EXPERIENCE	TOTAL	WEIGHTED AVERAGE
Q6When managing seizures occurring at EOL: I have prescribed a pulse (3-5 day course) of steroids to improve seizure control	9.09% 2	31.82% 7	18.18% 4	9.09% 2	0.00% 0	31.82% 7	22	1.64

Q10 Please read the following statements and place a tick on the rating scale

Answered: 22 Skipped: 10

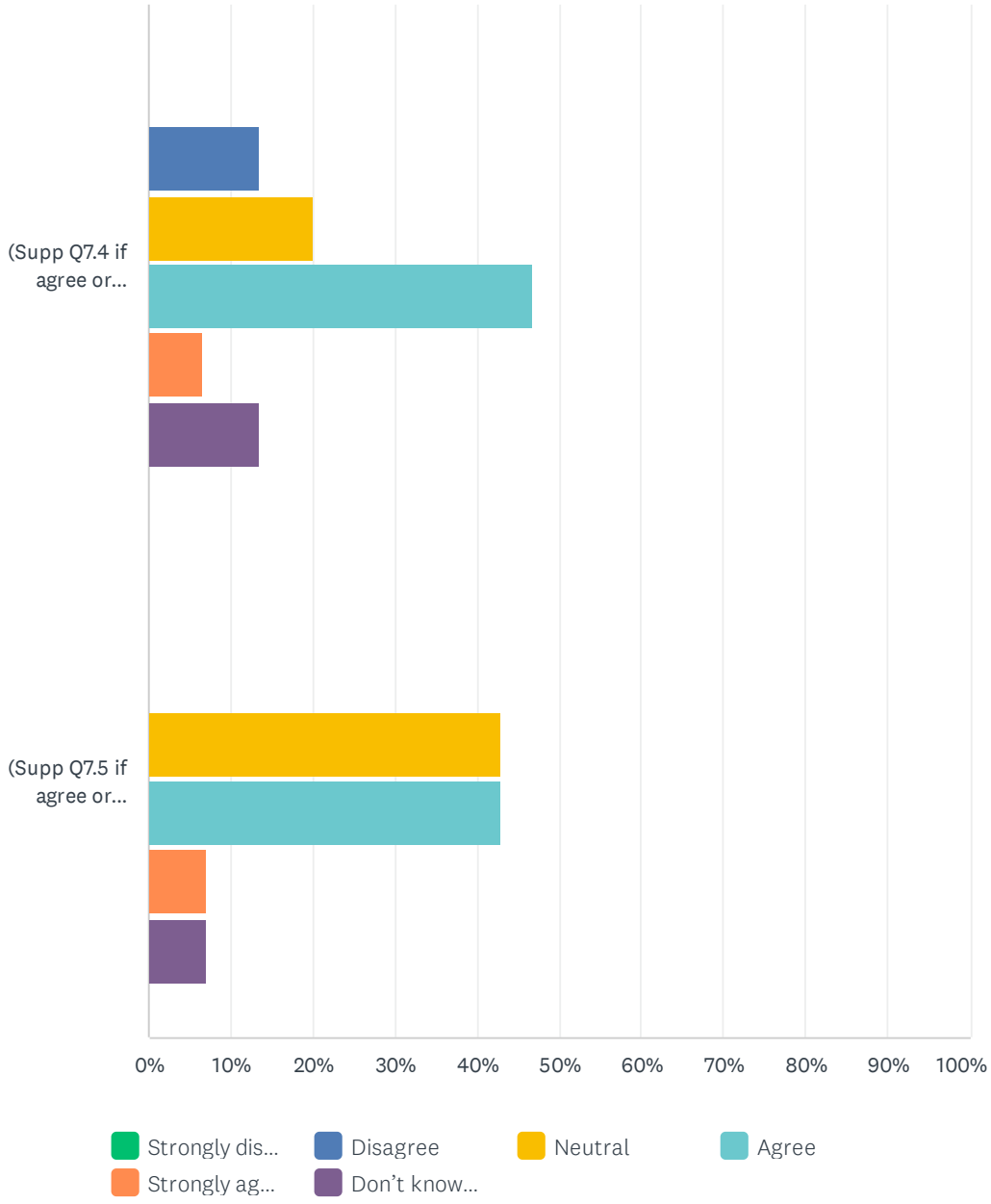

Q7When managing...
(Supp Q7.1 if agree or...
(Supp Q7.2 if agree or...
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%
Strongly dis...
Disagree
Neutral
Agree
Strongly ag...
Don't know...

	STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE	DON'T KNOW/NOT WITHIN MY EXPERIENCE	TOTAL	WEIGHTED AVERAGE
Q7When managing seizures occurring at EOL: I would prescribe a pulse (3-5 day course) of steroids to improve seizure control	4.55% 1	27.27% 6	22.73% 5	18.18% 4	0.00% 0	27.27% 6	22	2.00
(Supp Q7.1 if agree or strongly agree to Q6 or 7) If prescribing a pulse of steroids for seizures at EOL I would choose dexamethasone as first line	0.00% 0	7.69% 1	23.08% 3	46.15% 6	0.00% 0	23.08% 3	13	2.69
(Supp Q7.2 if agree or strongly agree to Q6 or 7) When prescribing a pulse of steroids for seizures at EOL I would choose prednisolone as first line	0.00% 0	33.33% 4	33.33% 4	16.67% 2	0.00% 0	16.67% 2	12	2.33

#	(SUPP Q7.3 IF AGREE OR STRONGLY AGREE TO Q6 OR 7) MY CHOICE OF STEROID (DEXAMETHASONE OR PREDNISOLONE) IS INFLUENCED BY:	DATE
1	dexamethasone since mix in some infusions and more experience in PPC setting	3/3/2022 6:32 PM
2	Discussion with neurologist and L4 consultant	3/3/2022 3:31 PM
3	experience	2/5/2022 10:59 AM
4	I am interested to hear more about this approach	2/3/2022 9:56 PM
5	experience of prednisolone usage in infantile spasms/difficult epilepsy management. However I am more familiar with using Dex for all other pall care indications.	2/2/2022 11:33 PM
6	Mainly practice originating in oncology. Dexamethasone is thought to cross blood-brain barrier better. I am not aware of any evidence in encephalopathy that argues against that although the blood-brain barrier is probably defective anyway. Not sure my argument is convincing even to me.	2/2/2022 12:30 PM
7	familiarity with use of dex for brain tumours	2/2/2022 12:19 PM
8	Not needed to use steroids in this situation at EOL.	2/1/2022 4:35 PM
9	Previous experience	2/1/2022 3:52 PM
10	Experience with its use	2/1/2022 1:49 PM

Q11 Please read the following statements and place a tick on the rating scale

Answered: 16 Skipped: 16



	STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY AGREE	DON'T KNOW/NOT WITHIN MY EXPERIENCE	TOTAL	WEIGHTED AVERAGE
(Supp Q7.4 if agree or strongly agree to Q6 or 7)When using steroids for seizures close to EOL: I would do this only with advice from a Paediatric Neurologist	0.00% 0	13.33% 2	20.00% 3	46.67% 7	6.67% 1	13.33% 2	15	3.07
(Supp Q7.5 if agree or strongly agree to Q6 or 7)When using steroids for seizures close to EOL: I would do this only with advice from a Subspecialist in Paediatric Palliative Medicine	0.00% 0	0.00% 0	42.86% 6	42.86% 6	7.14% 1	7.14% 1	14	3.36