

r(20) diagnosis and access to CBD survey

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Summary statistics



Survey emailed to 131 recipients by email, with follow-up reminder sent after 7 days for non-respondents.



Survey link shared on Facebook page and closed Facebook group.

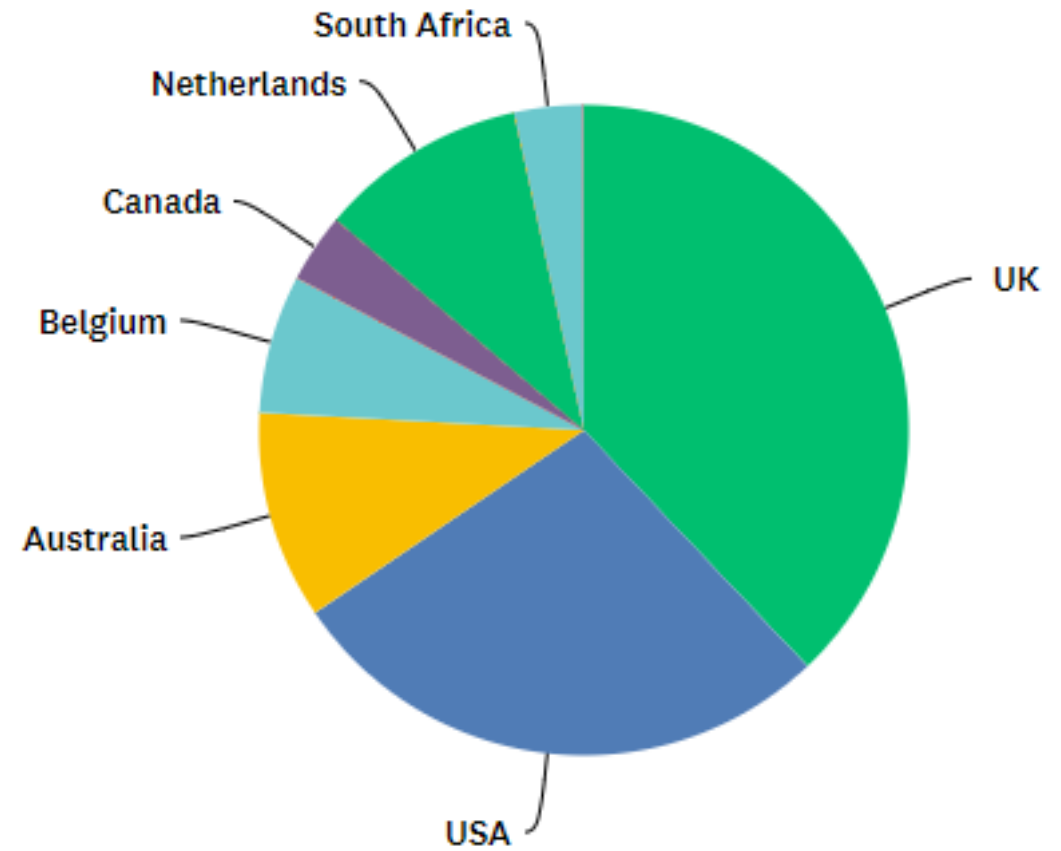


Survey open for > 2 weeks.



Total of 29 responses received.

Q1:What
country do
you live in?



Q2:How long did you wait to receive your r(20) diagnosis i.e. how many years between when your first symptoms (seizures) started and when you were advised you have r(20) syndrome? Please specify a number (of years)



Longest time to diagnosis
= 19 years



Least time to diagnosis
= 0 years



Average time to diagnosis
= 4.2 years

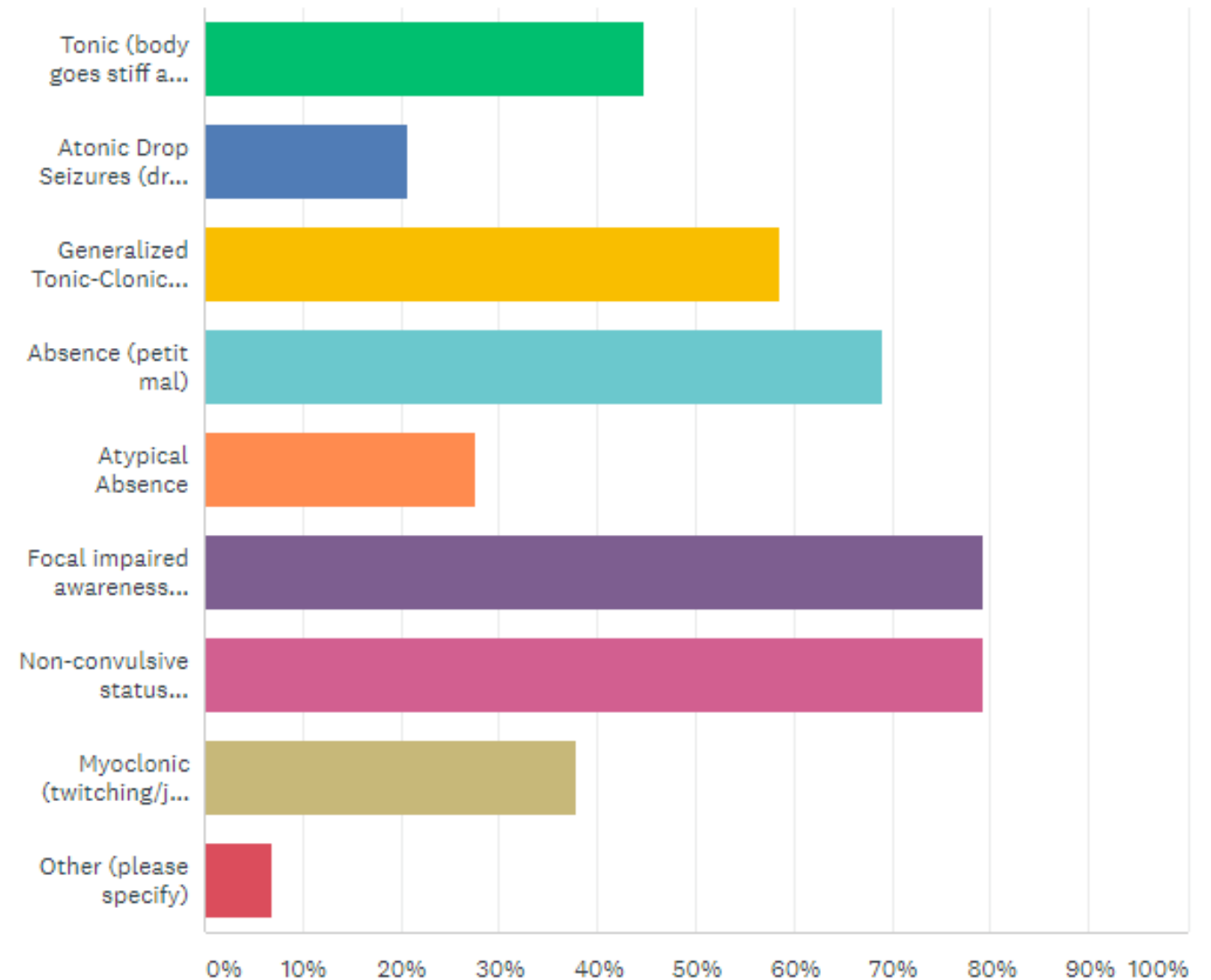
Q3: Before you received your r(20) diagnosis, did you receive an alternative cause for your epilepsy?

Nearly $\frac{1}{4}$ (24%) of respondents received an alternative diagnosis prior to r(20):

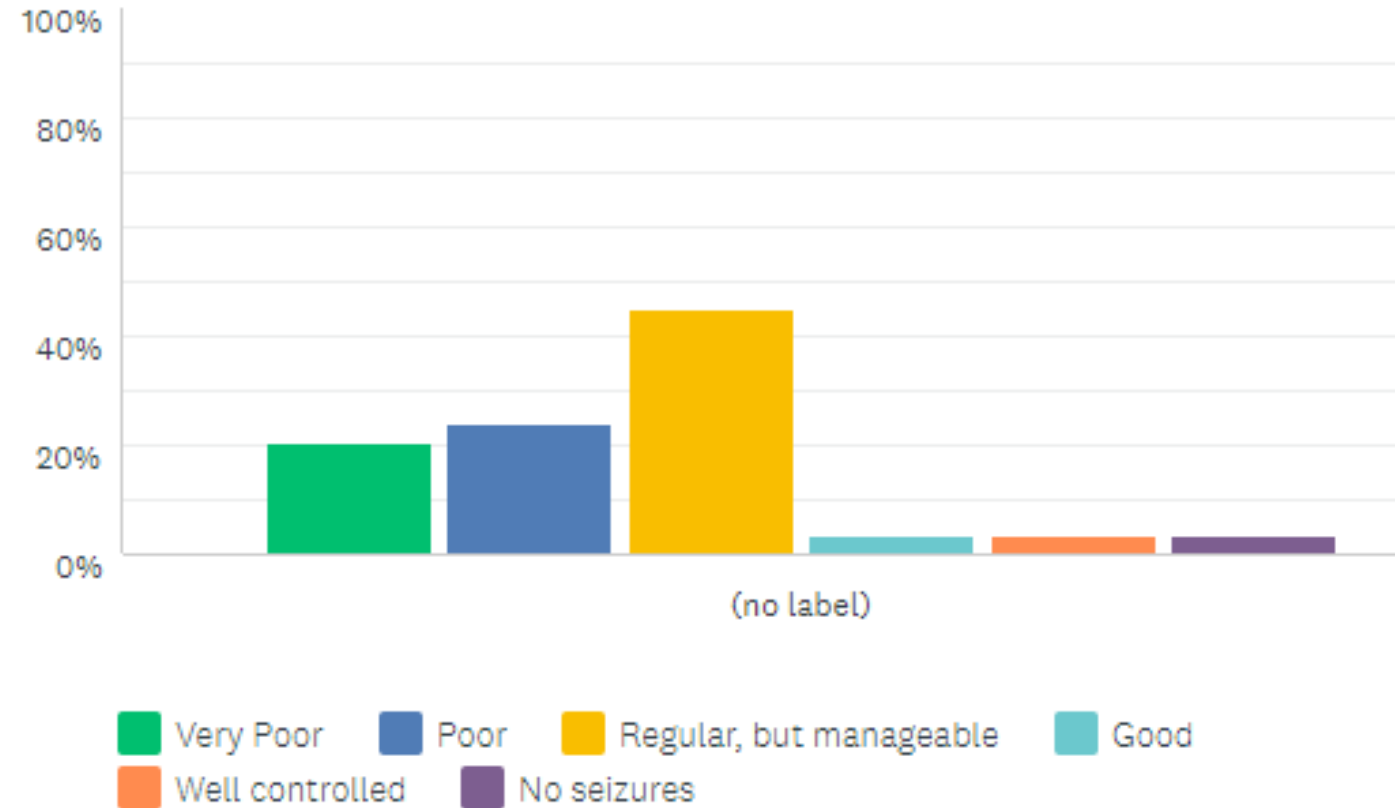
- 1x Lennox Gastaut Syndrome (LGS)
- 1x Landau Kleffner Syndrome (LKS)
- 1x Benign Rolandic Epilepsy
- 1x Left temporal lobe epilepsy nocturnal in nature
- 1x Idiopathic Complex partial with generalizations
- 1x Learning difficulties
- 1x Frontal lobe epilepsy

2x immediately received r(20) diagnosis

Q4: Which of the following seizure types do you experience?



Q5: How would you describe your level of seizure control currently?



Q6:Have you tried medicinal cannabis (CBD)?
Q9:Did your consultant prescribe medicinal cannabis (CBD) or did you have to obtain a private prescription yourself?

11 (38%) individuals have tried some form of medicinal cannabis treatment.

- 6 from USA of which
 - 5 are on Epidiolex (Consultant prescribed)
 - 1 Leafline Labs' "Cobalt Oral Suspension" (Private prescription)
- 2 Netherlands
 - 1 medical CBD (Consultant prescribed)
 - 1 from pharmacy with 10% CBD (Consultant prescribed)
- 1 UK
 - 1 Bedrolite (Private prescription)
 - 1 bought from internet
- 1 Australia
 - 1 (unspecified) (Private prescription)

Q7: If you have NOT ever been prescribed medicinal cannabis (CBD), if it was made available under prescription to you, would you consider trying it? Please tell us why/why not



67%

who haven't tried would like to try



16.5%

not sure/perhaps



5.5%

it has to be affordable



5.5%

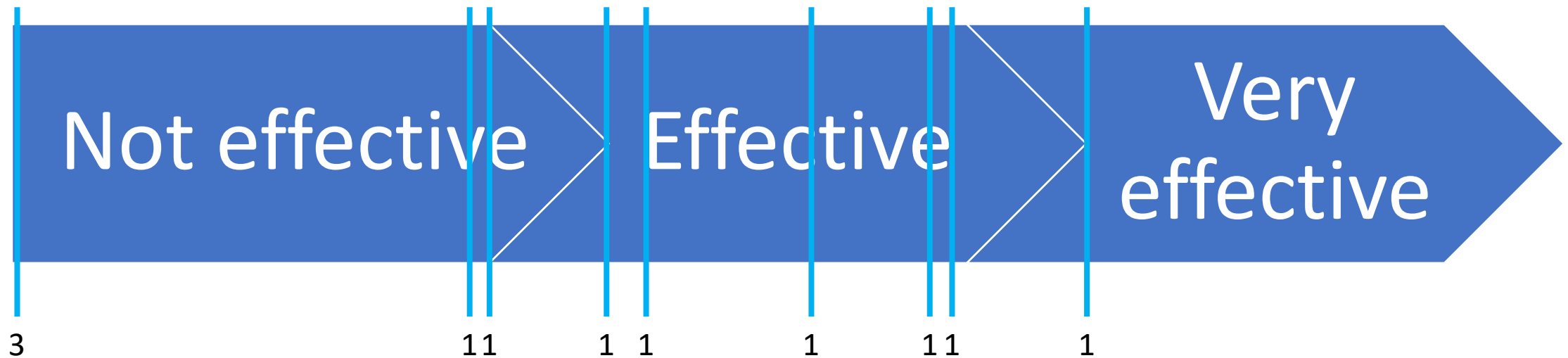
doubt it could control severe symptoms of r(20) on its own



5.5%

depends on past success with treating NCSE

Q9: How effective has medicinal cannabis (CBD) been on helping to control your seizures?



Number denotes no. of respondents who have tried medicinal cannabis and their rating

Q10:Has taking medicinal cannabis (CBD) made any difference to you e.g. Quality of Life, mood, behaviour, alertness, side effects? If so please explain the differences you've experienced



5 report improvements to behaviour, alertness, clear headed



1 reported improvement in generalised tonic clonic seizures

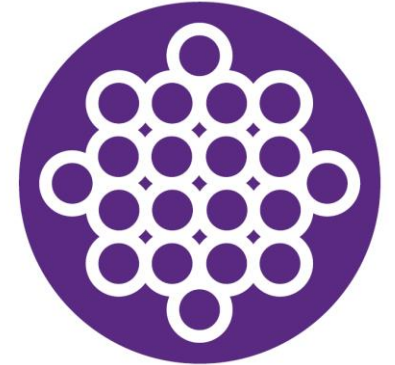


3 reported no additional benefits



1 'hard to judge as taken for a short period'

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