

European Tourette Syndrome Research Survey 2017 -2018

Dr Seonaid Anderson

Research manager

Tourettes Action



European Tourette Syndrome Research Survey 2017-18



Dutch survey. The patient's perspective: Dutch member research

- Expanding our knowledge
- Improving the quality of life of patients with TS
- How to improve the QoL
- What do patients want?
- What do patients need?
- The patients' perspective



Recruitment

- Via Patients Associations in EU countries.
- Closed ESSTS patients FB page
- Contacts made via ESSTS
- Verify translation
- Circulate in their countries.
- Liaised re translation
- Surveys went 'live' on SurveyMonkey



European Tourette Syndrome Research Survey 2017

- first time ever patients and their families with Tourette Syndrome across lots of EU countries
- 13 different languages
- invited to help us tell researchers what they would like Tourette Syndrome research to focus on.
- collect as many views across Europe and share the results with the researchers at this year's ESST conference and beyond....!!!



European Tourette Syndrome Research Survey 2017

- Survey translated into 14 languages
- 13 for all results as Swedish withdrew support
- 2,269 responses
- Survey opened since October 2017, open for six months.



Advantages/Difficulties

Advantages

- First ever time multi-language survey done for TS
- Simple, 7 questions only

Difficulties

- Translations, not done professionally! No budget
- Some members may not have understood the survey
- Based on Dutch survey, not reviewed since then



Particularly low numbers from

- **Finland**
- **Sweden** Declined to be involved because of cannabis mentioned (cannabis mentioned in 3 times in 2/7 questions)
- **Greece** no association there and people didn't want to complete it



Number of responses per language (13):

Country	No. of responses
English	535
Dutch	402
Norwegian	393
French	160
Italian	138
German	125
Hungarian	120
Spanish	101
Danish	96
Finnish	65
Polish	62
Czech	56
Greek	16



Results & analysis

- to save time I will go through the questions and present results from each as we go.

No statistics carried out – just an overview of the figures.



Only 7 questions

Question 1: What country are you from?



Question 1: What country are you from?

English language responses: 535

UK based: 478 said UK (includes responses)

UK (224),

Great/Britain (8),

England (172),

Wales (8),

Northern Ireland (4)

Scotland (54).

There were 22 other countries mentioned 65 times.



English language survey

There were 22 other countries mentioned 64 times. Ireland had the highest, then the USA, Canada and Belgium.

Albania (2), **Australia (2)**, Austria (1), Bahamas(1), Belgium(4), Canada (7), Croatia (2), Cyprus (1), Denmark (2), Finland (1), Germany (1) Holland (1), **India(1)** Ireland (16), Italy (2) Malaysia (1) Poland(1) Portugal(1) Slovenia(2) Spain (3) **Tanzania (2)** and **United States (10)**.



Country	N	Responses to Question 1
English	535	See previous slide!
Dutch	402	341 from Netherlands, 54 from Belgium (Dutch and Flemish similar); 7 other countries mentioned – Germany, Austria, Slovakia, Switzerland, Spain, UAE and Japan!
Norwegian	393	386 from Norway; 5 from other countries Poland, Sweden, Denmark, Germany and India!
French	160	150 from France; 6 other countries mentioned – Belgium (French speaking area), Germany, Switzerland, Israel, India and Reunion Island (in the Indian Ocean)!



Italian	136	131 from Italy; 4 other countries Switzerland, Germany, Spain and Romania
German	125	115 from Germany; 4 other countries Austria, Luxembourg, Italy and Slovakia
Hungarian	120	117 from Hungary; 3 other countries, Ukraine, Slovakia and Serbia
Spanish	101	95 from Spain; 3 other countries – UK, Argentina and Mexico!
Danish	96	95 from Denmark and 1 from Faroe Islands
Finnish	65	All from Finland.
Polish	62	61 from Poland and 1 from Germany
Czech	56	49 from Czech Republic; 1 other country – Slovakia
Greek	16	All 16 from Greece



Question 2: What is your age?

General trends

61-80% generally in 35 to 44 or 55 to 64 groups English, Dutch, Czech, Norway, French, Italian Hungarian, Spanish, Danish.



Question 2: What is your age?

Younger groups

German 54% from either the 35 to 44 or 55 to 64 groups, younger completing

Not answering

Finland 38 people skipped this question (out of 65)!!!

89% of those who did complete were 18 to 24 or 25 to 34 – something cultural???

Poland 17 people skipped this question (out of 62).

82% of those who did complete were 18 to 24 or 25 to 34

Greece 62% (out of 16). of those who did complete were 18 to 24 or 25 to 34



Question3 : What is your relationship to Tourette?

- I have TS myself
- I am a parent
- Family member, partner of someone with TS



Instruction:

In relation to this person with TS, please complete the following questions:

(If you are an adult with TS yourself please complete this questionnaire in regards to yourself first, then come back and complete it a second time if it is for your child or someone else with TS)



Question 4. If you are a parent – what is the age of child? (If you are not a parent please go to Q5).

Blank box given – mistake?

DOB's given, not analysed, something for the future?

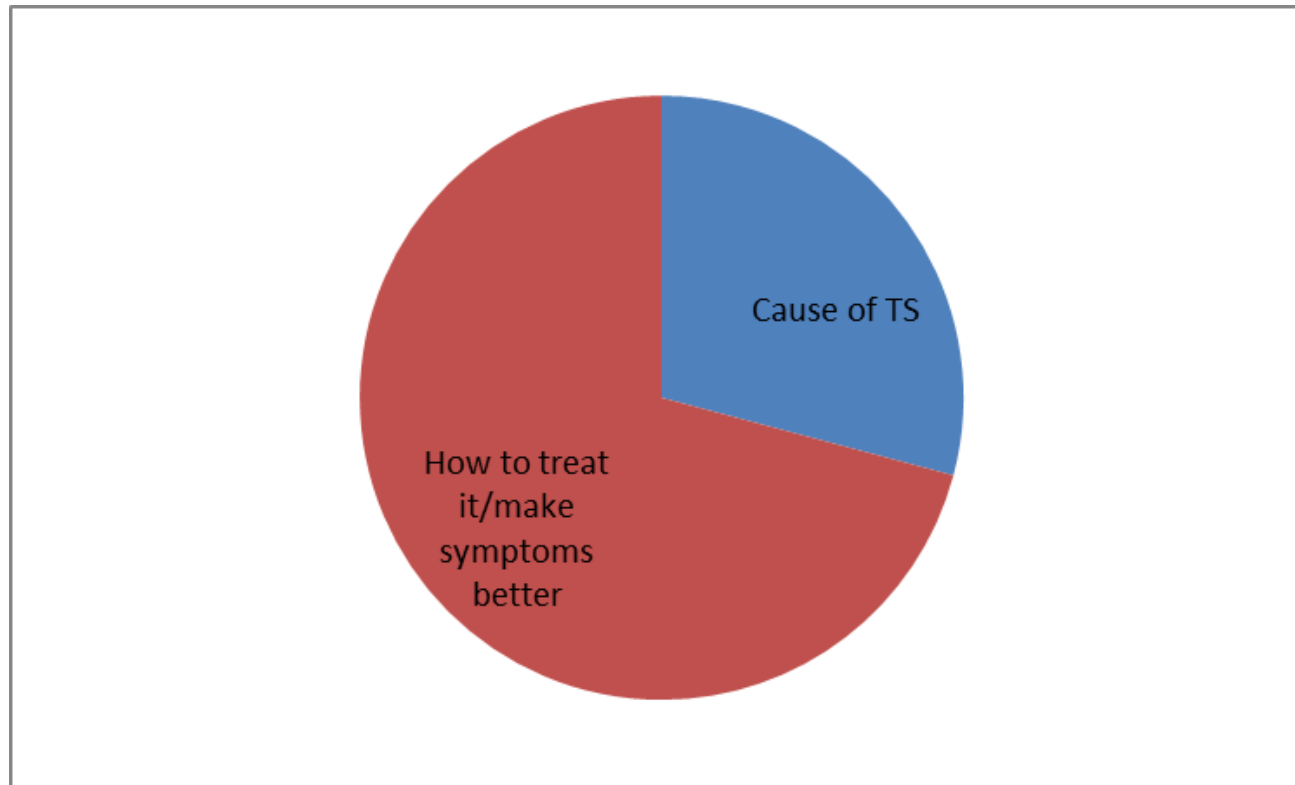


Question 5: If you had to choose, which would you prefer to see research on the cause of TS or looking for treatment?

- a. To find out what causes TS or
- b. How to treat it/make symptoms better?



Which would you prefer to see research on?



661

1608



Question 6. Can you prioritise the most important areas to do research on? Please indicate 1st choice, 2nd choice and 3rd choice?

Genetics/hereditary

Brain (structure/circuits/brain scanning)

Medication

Cannabis

Behavioural therapy

Botox

DBS

Problems other than tics related to TS (other symptoms/co-occurring conditions) for example: sleeping, anger, panic etc.

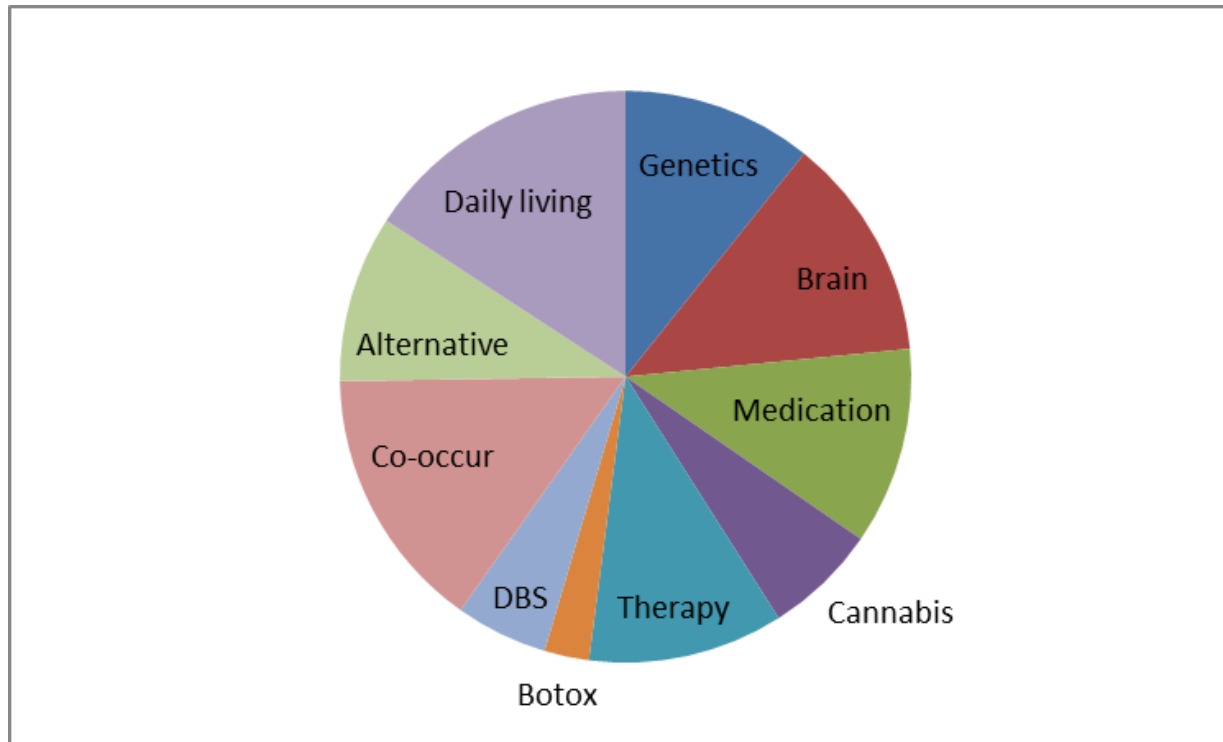


Most important areas to do research on?

Daily living issues (dealing with TS at home, work and school)	1570
Problems other than tics related to TS (other symptoms/co-occurring conditions) for example: sleeping, anger, panic etc.	1485
Brain	1261
Medication	1109
Behavioural therapy	1098
Genetics/hereditary	1067
Alternative treatments e.g. Acupuncture, diet	937
Cannabis	635
DBS	518
Botox	252

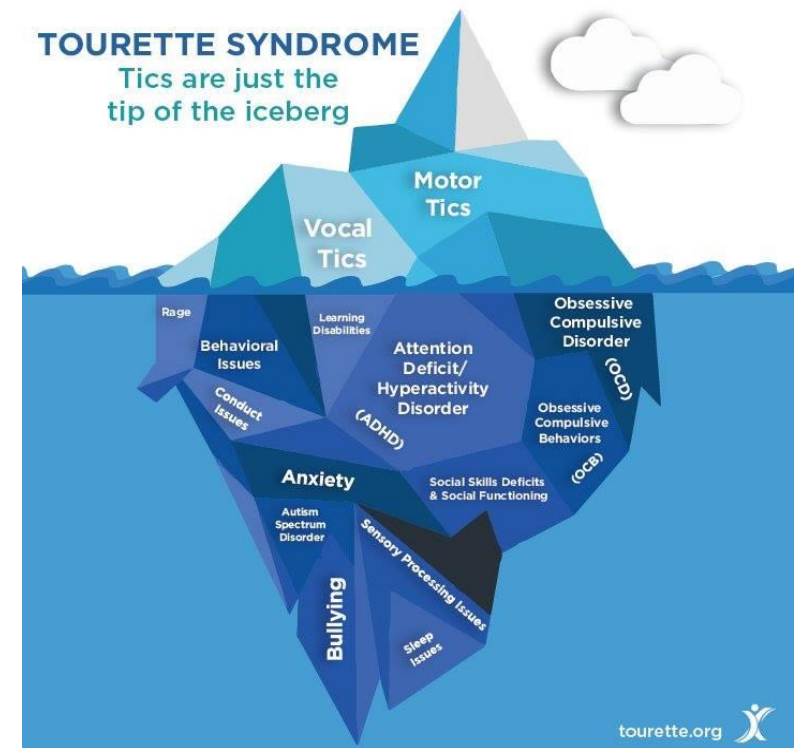


The most important areas to do research on?



Have we mentioned co-morbidities yet?

- Daily living issues (dealing with TS at home, work and school) (1570)
- Problems other than tics related to TS (other symptoms/co-occurring conditions) for example: sleeping, anger, panic etc. (1485)



Question 7: In your country..... Known/offered

Medication (risperidone, haloperidol etc)

Cannabis

Behavioural therapy (ERP, HRT, CBITS)

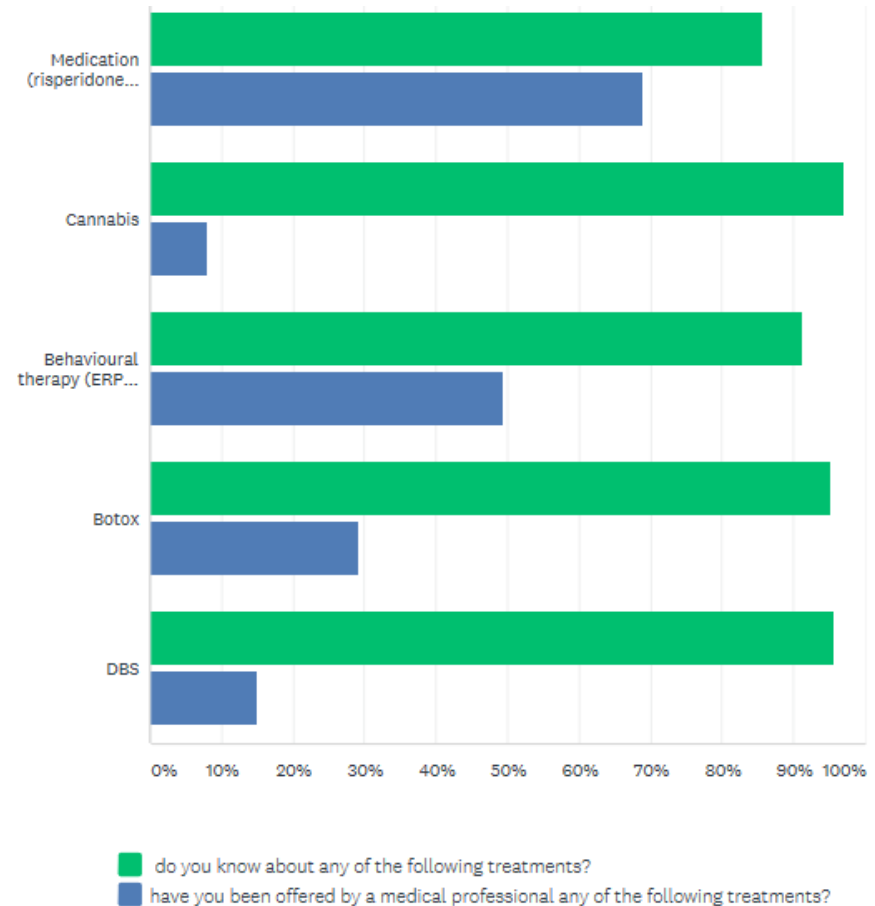
Botox

DBS

Other - I sought out alternative treatments by myself – e.g.
acupuncture, diet, **cannabis**



Known/offered



Of those who have heard of a treatment, what % offered:

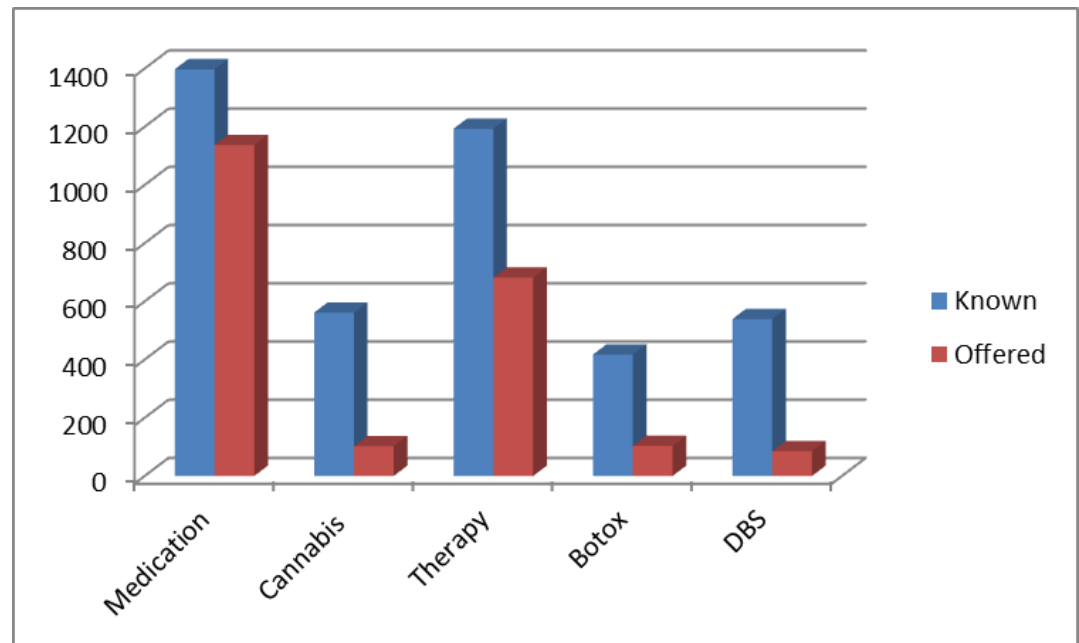
Medication 81%

Cannabis 18%

Therapy 57%

Botox 24%

DBS 16%



Other - I sought out alternative treatments by myself – e.g. acupuncture, diet, cannabis

CBT Manage Hypnotherapy Clonidine Relaxation Research
Offered Heard Medication Antibiotics Treatment
DBS Acupuncture School Diet CAMHS
Cannabis Reflexology Tried Magnesium Therapy Child
Homeopathy Health CBD Oil Support



Diet was mentioned 24 times, some examples of text, quotes:

'Attempted diet changes without success'

'I have focused on diet , eliminating triggers and testing at bio-chemist'

'Good balanced raw/whole-food diet , monitor calorie and liquid intake'

'Diet and have heard probiotic enemas are helpful'

'My son gets two massages a month for relaxation and we are looking into acupuncture to help reduce the tics and monitor his diet'

'Paying close attention to diet, especially artificial sweeteners & additives'



Criticisms of this research survey

- translation issues
- cannabis highlighting cultural issues
- questions genuinely reflect patients' concerns
- questions too vague and open-ended to be helpful?
- perhaps need a more scientific method
- no control over dissemination of surveys in EU countries



What to do next?

Compile the data from each country & send to the patient associations so they can use

Make a research paper/report

Can help inform researchers and the potential to create guidelines for researchers from collaboration of patients groups and researchers at ESSTS – Laura speaking on this...



Many thanks to people in each country who helped translate and circulate the survey links:

Olivier Marechal, Laura Beljaars, Michele Dunlap, Donatella Comasini, Dr. Tárnok Zsanett, Mario Martín Álvarez, Ondrej Fiala, Maciej A. Soborczyk, Melina Malli, Anne-Line Evenrud Gausdal, Tuula Savikuja, Lene Trier, Najah Khalifa & Henrik Pelling

And others...and the patients who responded to the surveys!



Tourettes Action currently running two surveys – the results of which are going to be very useful indeed in raising awareness with the public, medical professionals, funders and policy makers.

Why Tourettes Matters? Tourettes Action has created a survey about having Tourette Syndrome (TS) or a Tic Disorder. Please allow 10-15 minutes to complete this survey.

<https://www.surveymonkey.com/r/5QLY7JK>

Pain? Complete a short survey by Tourettes Action about injuries, physical problems or pain due to tics. Help us understand the issues facing people with TS.

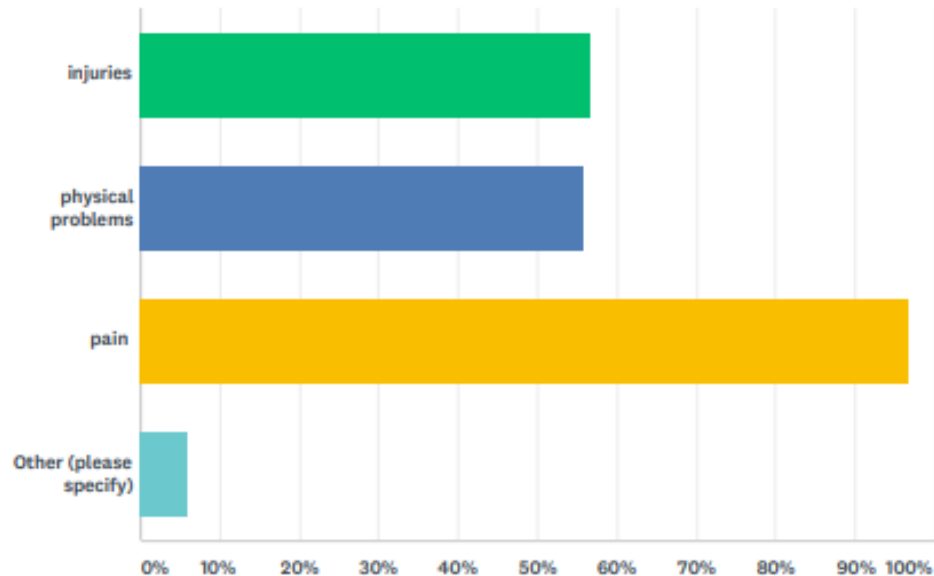
<https://www.surveymonkey.com/r/LMDRLTS>

Physio 122, Why TS matters 277



Q2 Due to your tics have you ever suffered from:

Answered: 118 Skipped: 0

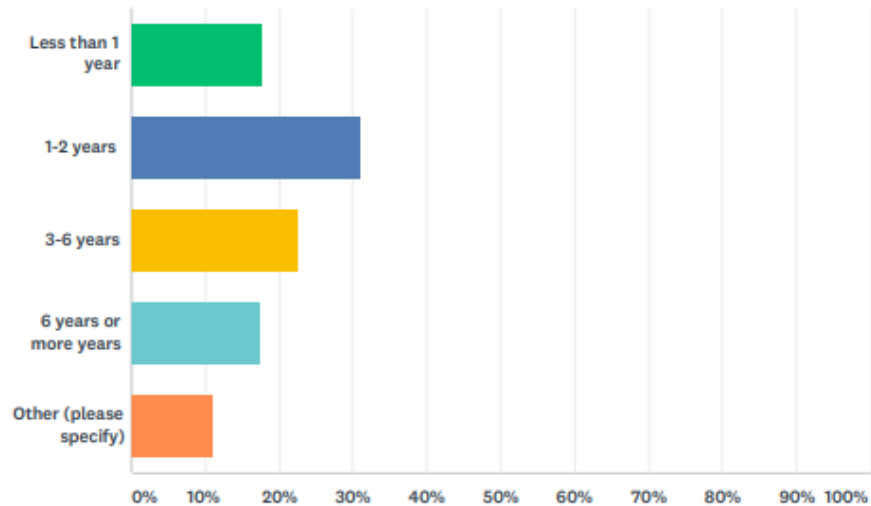


ANSWER CHOICES	RESPONSES	
injuries	56.78%	67
physical problems	55.93%	66
pain	96.61%	114
Other (please specify)	5.93%	7
Total Respondents: 118		



Q6 How long did it take from when you first noticed symptoms to receiving a diagnosis?

Answered: 225 Skipped: 46



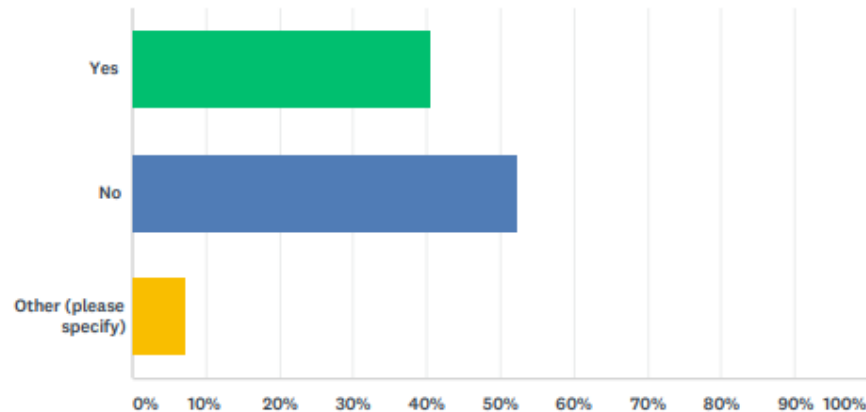
ANSWER CHOICES	RESPONSES	
Less than 1 year	17.78%	40
1-2 years	31.11%	70
3-6 years	22.67%	51
6 years or more years	17.33%	39
Other (please specify)	11.11%	25
TOTAL		225



Why Tourettes Matters?

Q12 Did you receive information from the health professional who diagnosed you about TS or tic disorders? (e.g. leaflets, directed towards Tourettes Action etc)

Answered: 224 Skipped: 47

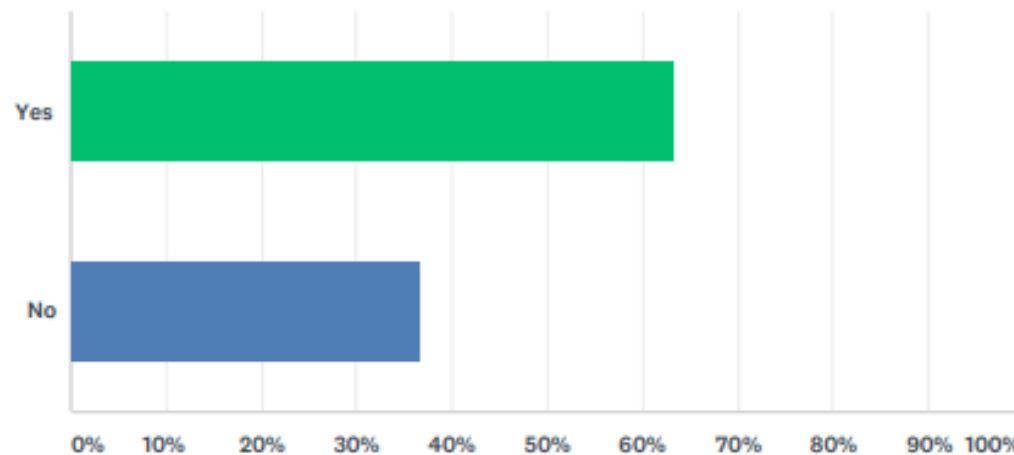


ANSWER CHOICES	RESPONSES	
Yes	40.63%	91
No	52.23%	117
Other (please specify)	7.14%	16
TOTAL		224



Q14 Do you feel that your journey through accessing a diagnosis and any treatment has affected your mental health?

Answered: 224 Skipped: 47

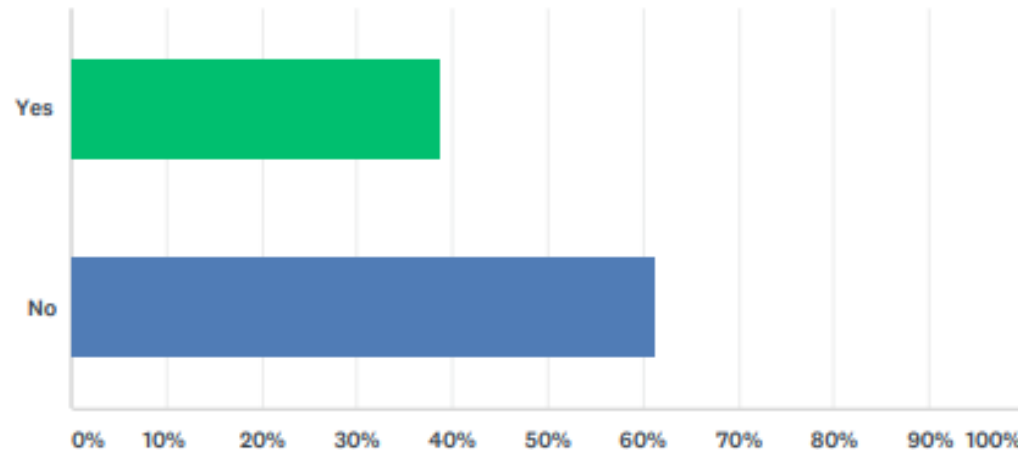


ANSWER CHOICES	RESPONSES	
Yes	63.39%	142
No	36.61%	82
TOTAL		224



Q26 Have you ever tried Behavioural Therapy?

Answered: 214 Skipped: 57

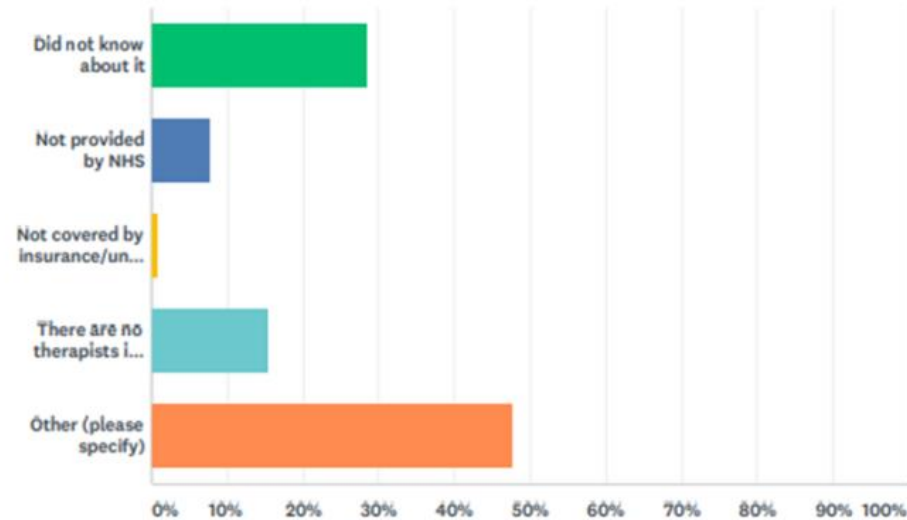


ANSWER CHOICES	RESPONSES	
Yes	38.79%	83
No	61.21%	131
TOTAL		214



Q28 If you have not tried Behavioural Therapy, why not?

Answered: 130 Skipped: 141

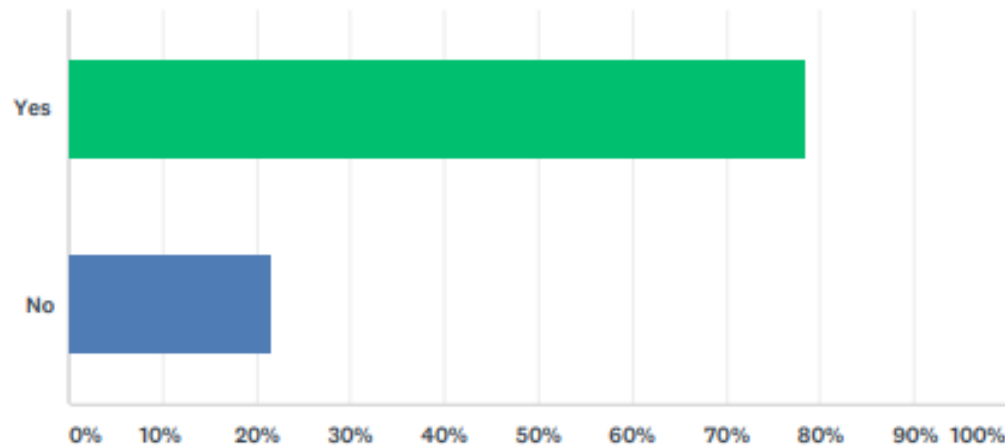


ANSWER CHOICES	RESPONSES	
Did not know about it	28.46%	37
Not provided by NHS	7.69%	10
Not covered by insurance/unable to pay	0.77%	1
There are no therapists in my area/geographically accessible to me	15.38%	20
Other (please specify)	47.69%	62
TOTAL		130



Q34 Do you feel that your TS has affected your mental health?

Answered: 208 Skipped: 63

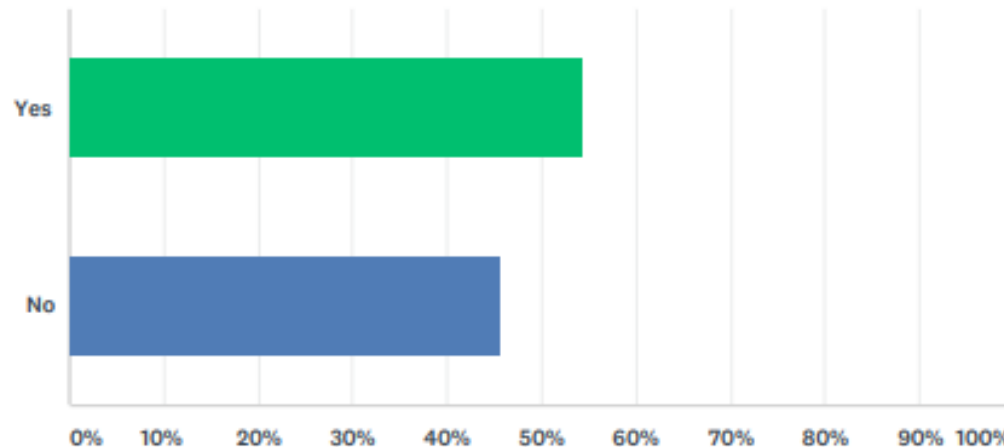


ANSWER CHOICES	RESPONSES	
Yes	78.37%	163
No	21.63%	45
TOTAL		208



Q36 Sometimes people with TS have described that they feel there is stigma around a diagnosis of having TS. Do you feel that any stigma surrounding TS has affected your mental health?

Answered: 206 Skipped: 65



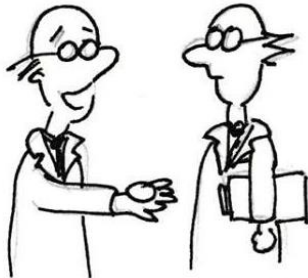
ANSWER CHOICES	RESPONSES	
Yes	54.37%	112
No	45.63%	94
TOTAL		206



“No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.” Professor Dame Sally Davies Chief Medical Officer (Foreword in Staley, 2009)

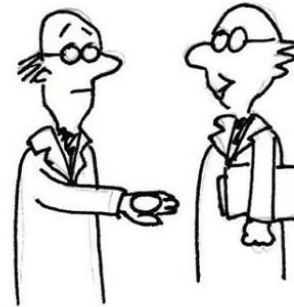


LABORATORY



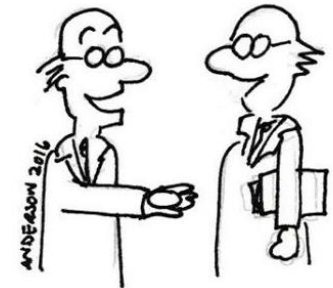
I'VE JUST INVENTED
A NEW DRUG FOR
TOURETTES SYNDROME!

LABORATORY



WILL IT STOP PEOPLE
WITH TOURETTE SYNDROME
HAVING TICS?

LABORATORY



NO! IT'S AN
'ACCEPTANCE' PILL
FOR EVERYONE ELSE!!





Helpdesk: 0300 777 8427



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