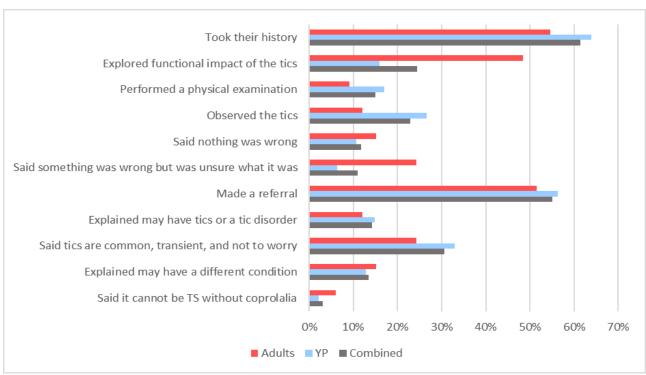
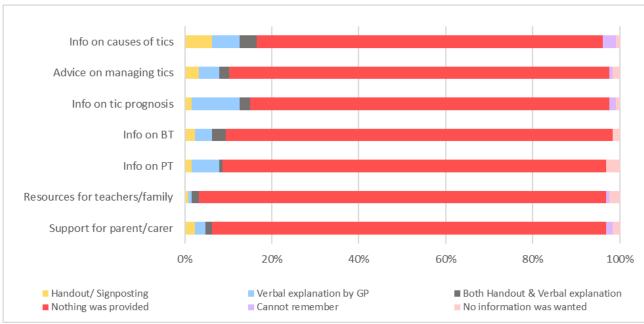
1 Figures

Fig. 1. What the GP did During the First Appointment



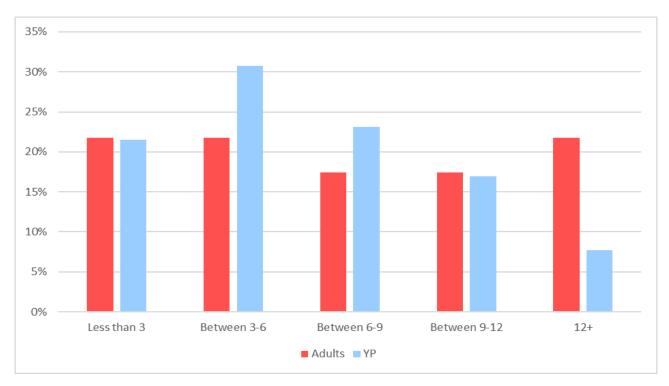
TS= Tourette syndrome; YP= young people.

Fig. 2. Immediate Management Provided in the First GP Appointment for Tics.



BT= behaviour therapy; PT= pharmacotherapy.

Fig. 3. Number of Months Spent on the Waitlist for Their Secondary Care Appointment.



YP=young people.

2 Tables

Table 1. Demographic Information Collected from the Participants.

Characteristic	Adult with tics (n=33)	YP with tics (n=94)	Combined (n=127)
UK location, <i>n</i> (%)			
England	25 (75.8)	74 (78.7)	99 (78.0)
Wales	3 (9.1)	13 (13.8)	16 (12.6)
Scotland	5 (15.2)	5 (5.3)	10 (7.9)
Northern Ireland	0	2 (2.1)	2 (1.6)
Gender, <i>n</i> (%)			
Man/Boy	10 (30.3)	51 (54.3)	61 (48.0)
Woman/Girl	20 (60.6)	42 (44.7)	62 (48.9)
Non-binary	3 (9.1)	1 (1.1)	4 (3.1)
Ethnicity, <i>n</i> (%)			
White	33 (100)	86 (91.5)	119 (93.7)
Mixed or multiple ethnic groups	0	7 (7.4)	7 (5.5)
Asian or Asian British	0	1 (1.1)	1 (0.8)
Tic Diagnosis, n (%)			
TS	23 (69.7)	41 (43.6)	64 (50.4)
CTD	0	3 (3.2)	3 (2.4)
PTD	0	3 (3.2)	3 (2.4)
FND (functional tics)	1 (3.0)	1 (1.1)	2 (1.6)
Co-morbidity (may be more than one condition	31 (94.0)	58 (61.7)	89 (70.1)
per participant), n (%)			
Anxiety	24 (72.7)	31 (33.0)	55 (43.3)
OCD	14 (42.4)	22 (23.4)	36 (28.3)
Autism	8 (24.2)	20 (21.3)	28 (22.0)
ADHD	7 (21.2)	14 (14.9)	21 (16.5)
ID	1 (3.0)	8 (8.5)	9 (7.1)
Depression	17 (51.5)	2 (2.1)	19 (15.0)

YP=young people; TS=Tourette syndrome; CTD=chronic tic disorder; PTD=provisional tic disorder; FND=functional neurological disorder; OCD=obsessive compulsive disorder; ADHD=attention deficit/hyperactivity disorder; ID=intellectual disability.

Table 2. Themes and Sub-themes

Themes	Sub-themes
Minimisation of Tics by GPs	Impact of Tics Not Taken Seriously
	Tics Misinterpreted as Other Conditions
	Having to Fight for a Referral
Feeling Supported by GPs	Pro-active and Compassionate GPs
	Easy Access to Referrals
	Working Collaboratively to Facilitate Care
Issues with the Provision of Support by Secondary Care	Poor Availability of Tic Services
	A Lack of Clear Referral Pathways for Tics

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Table 3. A Summary of our Findings and Recommendations

Key points and recommendations for primary care clinicians:

- Tics are common in school children and can persist into adulthood
- The impact of tics should be explored in all patients, even if tics are new-onset, as this informs the need for a secondary care referral
- Information about tics should be provided to patients (and parents/carers if appropriate), to include general tic prognosis and a brief overview of potential treatment options
- Tics are unlikely to completely remit in most people but typically prognosis is good. With time, tics often become less severe and have a smaller impact on quality of life and a minority experience worsening of their tics; manage patient and parental expectations accordingly

Key points and recommendations for secondary care services:

- Patients and family members raised the following concerns of secondary care:
 - o Long waitlist times, particularly for adults
 - o Being referred to multiple secondary care services (neurology, paediatrics, psychiatry) sequentially as each said they do not offer support for people with tics
 - o Being discharged from secondary care after diagnosis with no support provided
- There appears to be a paucity of NHS clinicians with a specific interest in tic management across the UK
- Greater clarity is needed on which secondary care services can receive referrals for tics and manage these patients appropriately consider formation of dedicated NHS tic services

- 98 3 Additional Files
- 99 **3.1 Additional File 1**
- 100 Adult Survey

Demographics

Which country in the UK do you live in?

- England
- C Wales
- Scotland
- C Northern Ireland
- C Prefer not to say

Which of the following best describes your gender?

- C Man
- C Woman
- Non-binary
- C Other
- Prefer not to say

Which of the following best describes your ethnicity?

- C Asian or Asian British
- C Black, Black British, Caribbean, or African
- C Mixed or Multiple ethnic groups
- C White
- C Other ethnic group
- Prefer not to say

Apart from	tics,	do	you	have	any	other	diagnos	ed	medical	conditions'	Please	select	all	that
apply.														

□ None
☐ Anxiety
☐ Attention Deficit/Hyperactivity Disorder (ADHD)
☐ Autistic Spectrum Condition (ASC)
☐ Conduct Disorder (CD)
□ Depression
☐ Intermittent Explosive Disorder (may also be called Rage Attacks)
☐ Learning Disability (may also be called an Intellectual Disability) (LD or ID)
□ Obsessive Compulsive Disorder (OCD)
□ Oppositional Defiant Disorder (ODD)
□ Prefer not to say
□ Other
If you selected Other, please specify:

Experiences of the first GP appointment

How old were you, in years, when your tics were **first** noticed? This could be by family members, teachers, classmates, or yourself. Please type in a number, for example 8 or 18.

The number should be 60 or lower.	Please enter a whole number (integer).	
	The number should be 60 or lower.	

How old were you, in years, when you had your first appointment with the GP about your tics? Please type in a number, for example 8 or 18.
Please enter a whole number (integer). The number should be 60 or lower.
What happened during the first appointment with the GP? Select all that apply.
□ Discussed your symptoms and general medical □ historyExplored the impact your tics were having on □ your life GP carried out a physical examination □ GP observed the tics, for example from a video recording of the □ ticsGP said nothing was wrong □ GP said something was wrong but was unsure what it □ wasGP made a referral to another healthcare professional □ GP explained that you may have tics, or a specific tic disorder (such as Tourette Syndrome) □ GP explained that you have tics which are common and will likely go away after a while and so not to worry about them □ GP explained that you cannot have Tourette Syndrome because your tics do not involve swearing (NOTE: this is a misconception) □ GP explained that you may have a different condition □ Other
If you selected Other, please specify:

How did you feel about how the first appointment with the GP went? Please explain.

GP's perceived knowledge

Please read the following statements and rate how strongly you agree or disagree with them. If you have seen more than one GP for the tics, please answer based on the **GP you have had themost contact with**.

More info

Please don't select more than 1 answer(s) per

row.Please select at least 5 answer(s).

	Strongly agree	Slightly agree	Slightly disagree	Strongly disagree	Does not apply to me
My GP appeared able to identify my motor tics well.	Г	Г	Г	Г	Г
My GP appeared able to identify my phonic tics well.	Г	Г	Г	Г	Г
My GP appeared able to identify my simple tics well.	Г	Г	Г	Г	Г
My GP appeared able to identify my complex tics well.	Г	Г	Г	Г	Г
Overall, my GP appeared able to identify my tics well.	Г	Г	Г	Г	Г

111 The More info section above contains the following message: "For reference: Motor tics are tics that involve movement of any body part. 112 Phonic tics are tics that cause sound (words, phrases, or any other noise). 113 114 Simple tics are tics that involve one muscle group such as sneezing, coughing, eye twitching, or tics that cause noises (not words or phrases). 115 Complex tics can be multiple simple tics occurring at the same time. They can also be 116 tics involving multiple muscle groups such as suddenly bending over, or tics where you say 117 words or phrases spontaneously." 118 119 120

How satisfied were you with the GP's **knowledge and understanding** of tics? If you have seen more than one GP for the tics, please answer based on the **GP you have had the most contact with**.

\/_r\/	satisfied
verv	Sausileu

Satisfied

Neutral

Dissatisfied

Very dissatisfied

GP's immediate management

During the first appointment with the GP, which of the following were offered to you?

Please don't select more than 1 answer(s) per row.

Please select at least 7 answer(s).

	Hand out/signposting to online websites only	Verbal explanation by GP only	Both hand out/signposting to online websites and verbal explanation by GP	Nothing was provided	Cannot remember	I did not want any information
Information about what causes tics	Г	Г	Г	Г	Г	Γ
Information and advice on how to better manage tics	Г	Г	Г	Г	Г	Г
Information on prognosis (how long the tics are likely to last)	П	Г	Г	Г	Г	Г

Information on behavioural therapy as a treatment for tics	Γ	Г	Г	Г	Г	Г
Information on medication as a treatment for tics	Γ	Г	Γ	Г	Г	Г
Resources to give to teachers/family members about tics	Γ	Г	Γ	Г	Г	Г
Support and advice for parents/carers	Γ	Г	Γ	Г	Г	Г

How satisfied were you with the **information and support offered** by your GP for your tics? If you have seen more than one GP for the tics, please answer based on the **GP you have had themost contact with**.

○ Very	satisfied
--------	-----------

Satisfied

Neutral

Dissatisfied

Very dissatisfied

Is there any information that you wish your GP had given you, but didn't? Please explain.

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The referral process and diagnosis

Have you been referred to a specialist for your tics?

C Yes	
C No	
C Don't know	

Have you accessed specialist support **privately** for the diagnosis or management of your tics? This could be with a doctor (psychiatrist, neurologist, paediatrician) or an allied health professional such as a psychologist, amongst others.

■ More info

C Yes	
C No	
C Prefer not to say	

- 127 The More info section above contains the following message:
- "NOTE: 'Privately' means that you had to pay directly for the appointment(s) with the tic specialist."

The referral process (continued)

At what age,	in years,	were you	referred to	a specialist	for your	tics?	Please	type in	a numbe	ŀr,
forexample 8	8 or 18.									

Please enter a whole number (integer). The number should be 60 or lower.
Which specialist have you been referred to? Please choose all that apply.
Please select at least 1 answer(s). General Psychiatrist (eg CAMHS or Adult Psychiatry) General Neurologist General Paediatrician Psychiatrist specialising in tics Neurologist specialising in tics Paediatrician specialising in tics (includes Paediatric Neurologists) Cannot remember. Other
If you selected Other, please specify:
How many GP appointments did you have about your tics before you got a referral to a specialist?

Roughly, how far from home did you have to travel for the appointment with the specialist?	f you
have not had the appointment yet, please answer based on how far you will have to travel.	

- C Less than 20 miles
- C 20-50 miles
- 51-80 miles
- O 81+ miles
- Cannot remember

How long did you have to wait for the appointment with the specialist?

- C Less than 3 months
- C Between 3-6 months
- C Between 6-9 months
- C Between 9-12 months
- Over 12 months
- C Have not had the appointment yet
- Cannot remember

Have you received a formal diagnosis for your tics?

- Yes
- No
- C Cannot remember

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Diagnosis (continued)

Please choose which diagnosis you have received.
 Transient / Provisional tic disorder Tourette Syndrome Chronic / Persistent motor or vocal tic disorder Functional Neurological Disorder (FND) Cannot remember Other
If you selected Other, please specify:
Which healthcare professional gave you the diagnosis? General Psychiatrist (eg CAMHS or Adult Psychiatry) General Neurologist General Paediatrician Psychiatrist specialising in tics Neurologist specialising in tics Paediatrician specialising in tics (includes Paediatric Neurologists) Cannot remember Other
If you selected Other, please specify:

In total, hov	many months	did it take	for you to	get your	diagnosis,	starting	from 1	the day	y you	first
went to you	r GP for your tic	s? Please	type in a	number, f	for example	e 3 or 15	i.			

Please enter a whole number (integer).
Overall thoughts of the care received from your GP
Overall, how satisfied are you with the care you have received for the tics from GPs? Please consider all GPs you have seen for the tics.
C Very satisfied C Satisfied C Neutral C Dissatisfied C Very dissatisfied
Please explain your answer to the previous question.

147 Parent/Carer Survey

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Demographics

Which country in the UK do you live in?

Fna	land
	iai ia

Wales

Northern Ireland

Prefer not to say

Which of the following best describes your child's gender?

C Boy

○ Girl

Non-binary

Other

Prefer not to say

Which of the following best describes your child's ethnicity?

C Asian or Asian British

C Black, Black British, Caribbean, or African

Mixed or Multiple ethnic groups

White

Other ethnic group

Prefer not to say

149

allthat apply.
 None Anxiety Attention Deficit/Hyperactivity Disorder (ADHD) Autistic Spectrum Condition (ASC) Conduct Disorder (CD) Depression Intermittent Explosive Disorder (may also be called Rage Attacks) Learning Disability (may also be called an Intellectual Disability) (LD or ID) Obsessive Compulsive Disorder (OCD) Oppositional Defiant Disorder (ODD) Prefer not to say Other
If you selected Other, please specify:
Experiences of the first GP appointment How old was your child, in years, when their tics were first noticed? This could be by family members, teachers, classmates, or yourself. Please type in a number, for example 8 or 12.
Please enter a whole number (integer). The number should be 17 or lower.

Apart from tics, does your child have any other diagnosed medical conditions? Please select

How old was your child, in years, when you made the first appointment with the GP about their tics? Please type in a number, for example 8 or 12.
Please enter a whole number (integer). The number should be 17 or lower.
What happened during the first appointment with the GP? Select all that apply.
□ Discussed your symptoms and general medical □ historyExplored the impact your tics were having on □ your life GP carried out a physical examination □ GP observed the tics, for example from a video recording of the □ ticsGP said nothing was wrong □ GP said something was wrong but was unsure what it □ wasGP made a referral to another healthcare professional □ GP explained that you may have tics, or a specific tic disorder (such as Tourette Syndrome) □ GP explained that you have tics which are common and will likely go away after a while and so not to worry about them □ GP explained that you cannot have Tourette Syndrome because your tics do not involve swearing (NOTE: this is a misconception) □ GP explained that you may have a different condition □ Other
If you selected Other, please specify:

HOW	ala you teel	about now	tne tirst app	pointment w	ith the GP	went?	Please expla	ain.	

GP's perceived knowledge

Please read the following statements and rate how strongly you agree or disagree with them. If you have seen more than one GP for the tics, please answer based on the **GP you have had themost contact with**.

■ More info

Please don't select more than 1 answer(s) per

row.Please select at least 5 answer(s).

	Strongly agree	Slightly agree	Slightly disagree	Strongly disagree	Does not apply to me
My GP appeared able to identify my child's motor tics well.	Г	Г	Г	Г	Г
My GP appeared able to identify my child's phonic tics well.	Г	Г	Г	Г	Г
My GP appeared able to identify my child's simple tics well.	Г	Г	Г	Г	Г
My GP appeared able to identify my child's complex tics well.	Г	Г	Г	Г	Г
Overall, my GP appeared able to identify my child's tics well.	Г	Г	Г	Г	Г

163 The More info section above contains the following message: "For reference: Motor tics are tics that involve movement of any body part. 164 Phonic tics are tics that cause sound (words, phrases, or any other noise). 165 166 Simple tics are tics that involve one muscle group such as sneezing, coughing, eye twitching, or tics that cause noises (not words or phrases). 167 Complex tics can be multiple simple tics occurring at the same time. They can also be 168 tics involving multiple muscle groups such as suddenly bending over, or tics where you say 169 words or phrases spontaneously." 170 171

How satisfied were you with the GP's **knowledge and understanding** of tics? If you have seen more than one GP for the tics, please answer based on the **GP you have had the most contactwith**.

Verv	satisfied
V C I V	Sausiicu

- Satisfied
- Neutral
- Dissatisfied
- Very dissatisfied

GP's immediate management

During the first appointment with the GP, which of the following were offered to you?

Please don't select more than 1 answer(s) per

row.Please select at least 7 answer(s).

	Hand out/signposting to online websites only	Verbal explanation by GP only	Both hand out/signposting to online websites and verbal explanation by	Nothing was provided	Cannot remember	I did no want ang information
Information about what causes tics	Γ	Г	Г	Г	Г	Г
Information and advice on how to better manage tics	Γ	Г	Γ	Г	Г	Г
Information on prognosis (how long the tics are likely to last)	Γ	Г	Γ	Г	Γ	Γ

Information on behavioural therapy as a treatment for tics	Г	Г	Г	Г	Г	Г
Information on medication as a treatment for tics	Γ	Г	Г	Γ	Γ	Г
Resources to give to teachers/family members about tics	Γ	Г	Г	Г	Г	Г
Support and advice for parents/carers	Γ	Г	Г	Г	Г	Г

How satisfied were you with the **information and support offered** by your GP for your tics? If you have seen more than one GP for the tics, please answer based on the **GP you have had themost contact with**.

0	Verv	satisfied
	,	00.1.000

Satisfied

Neutral

Dissatisfied

Very dissatisfied

Is there any information that you wish your GP had given you, but didn't? Please explain.

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The referral process and diagnosis

Has your child been referred to a specialist for their tics?
C Yes C No C Don't know
Have you accessed specialist support privately for the diagnosis or management of your child'stics? This could be with a doctor (psychiatrist, neurologist, paediatrician) or an allied health professional such as a psychologist, amongst others. More info
C Yes C No C Prefer not to say
The More info section above contains the following message: "NOTE: 'Privately' means that you had to pay directly for the appointment(s) with the tic specialise.

The referral process (continued)

At what age, in years, was your child referred to a specialist for their tics? Please type in a number, for example 8 or 12.

Please enter a whole number (integer). The number should be 17 or lower.
Which specialist was your child referred to? Please choose all that apply.
Please select at least 1 answer(s). General Psychiatrist (eg CAMHS or Adult Psychiatry) General Neurologist General Paediatrician Psychiatrist specialising in tics Neurologist specialising in tics Paediatrician specialising in tics (includes Paediatric Neurologists) Cannot remember. Other
If you selected Other, please specify:
How many GP appointments did you have about your child's tics before the GP referred your child to a specialist?

Roughly, how far from home did you have to travel for the appointment with the specialist? If youhave not had the appointment yet, please answer based on how far you will have to travel.

C 20-50 miles
C 51-80 miles
C 81+ miles
C Cannot remember
How long did you have to wait for the appointment with the specialist?
C Less than 3 months
C Between 3-6 months
C Between 6-9 months
C Between 9-12 months
C Over 12 months
C Have not had the appointment yet
C Cannot remember
Has your child received a formal diagnosis for their tics? C Yes C No
C Yes
C Yes C No

Diagnosis (continued)

Please choose which diagnosis your child has received.

C Transient / Provisional tic disorder
C Tourette Syndrome
C Chronic / Persistent motor or vocal tic disorder
C Functional Neurological Disorder (FND)
C Cannot remember
C Other
If you selected Other, please specify:
Which healthcare professional gave your child the diagnosis?
☐ General Psychiatrist (eg CAMHS or Adult Psychiatry)
☐ General Neurologist
☐ General Paediatrician
☐ Psychiatrist specialising in tics
☐ Neurologist specialising in tics
☐ Paediatrician specialising in tics (includes Paediatric Neurologists)
☐ Cannot remember
□ Other
Manage and acted Others related a second of the
If you selected Other, please specify:

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In total,	, how n	nany	months	did it	take	for	your	child	to	get their	diagnos	is, startin	g from	the	day
you firs	t went	to yo	ur GP fo	r their	tics?	Ple	ease	type i	n a	a numbe	r, for exa	mple 3 o	15.		

Please enter a whole number (integer).	

Overall thoughts of the care received from your GP

Overall, how satisfied are you with the care your child has received for their tics from GPs? Please consider **all** GPs you have seen for the tics.

- Very satisfied
- Satisfied
- Neutral
- Dissatisfied
- Very dissatisfied

Please explain your answer to the previous question.

205 3.2 Additional File 2

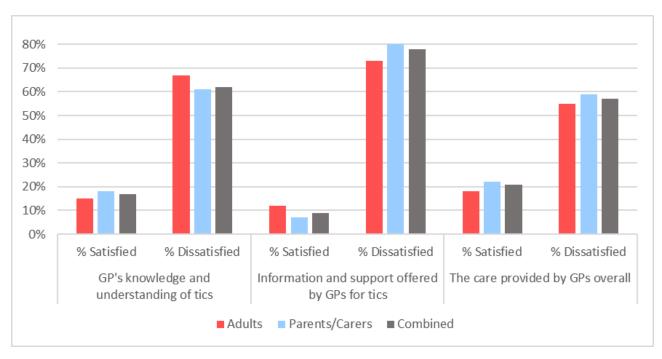
Mann Whitney U Tests Comparing (in Years) the Age at First Tic Onset, Age at First GP Appointment for Tics, Age at Referral to Secondary Care for Tics, and the Delay (in Years) Between Each of These, in Adults and YP with Tics.

		N	Mean (SD)	Mean rank	U	Z	<i>p</i> value
Age at First Tic							
Onset in	Adults	32	9.72 (5.54)	78.34	1029.00	-2.674	.007
	YP	94	7.02 (3.67)	58.45	1023.00	2.07.	.007
Age at First GP Appointment for Tics in							
1140 111	Adults	32	17.66 (8.57)	95.94	466.00	-5.832	<.001
	YP	94	8.29 (3.63)	52.46			
Age at Referral to Secondary Care for Tics in							
	Adults	27	25.19 (11.72)	81.46	149.50	-6.503	<.001
	YP	73	9.42 (3.42)	39.05			
Delay Between Age at First Tic Onset and Age at First GP Appointment for							
Tics in	Adults	31	7.48 (9.45)	80.37	794.00	-3.775	<.001
	YP	90	0.92 (1.18)	52.33			
Delay Between Age at First Tic Onset and Age at Referral to Secondary Care for Tics in	Adults	25	14.44 (12.40)	68.66	358.50	-4.411	<.001
for thes in	YP	70	2.31 (2.16)	40.62	330.30	7,711	<.001
Delay between Age at First GP Appointment for Tics and Age at Referral to Secondary Care for Tics in							
	Adults	25	4.88 (7.50)	53.24	744.00	-1.203	.229
YP=voung people.	YP	70	1.04 (1.48)	46.13			

YP=young people.

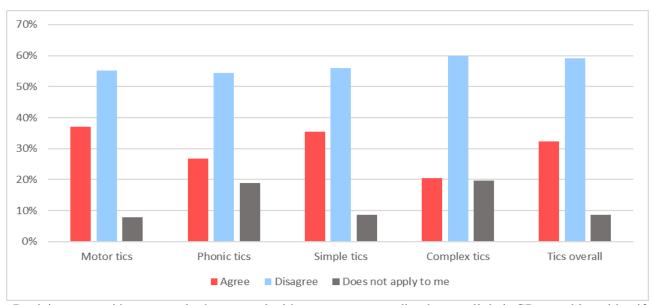
3.3 Additional File 3

208 Participants' Satisfaction With Various Aspects of the Care Received From GPs for Tics.



3.4 Additional File 4

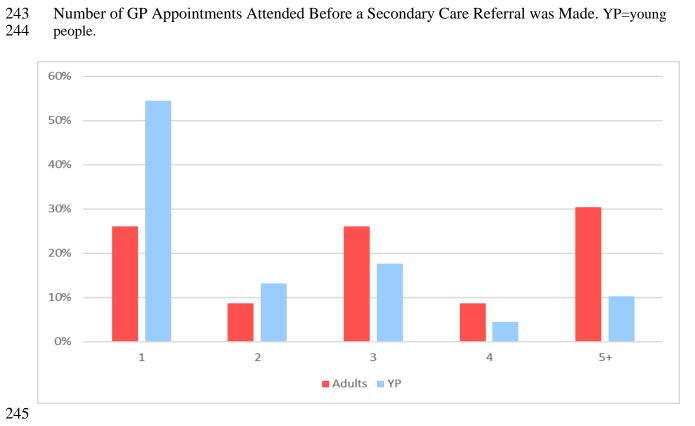
The Perception of Participants in how Able GPs Were in Identifying Tics.



Participants rated how strongly they agreed with statements regarding how well their GP was able to identify each type of tic and tics overall.

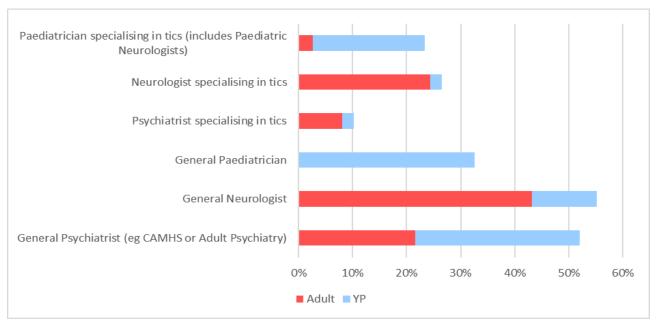
3.5 Additional File 5

Number of GP Appointments Attended Before a Secondary Care Referral was Made. YP=young people.



3.6 Additional File 6

Secondary Care Specialists Which the Participants Have Been Referred to.



Participants were able to select multiple options if they had been referred to more than one. YP=young people.

3.7 Additional File 7

- 276 Distance Travelled (in Miles) for the Specialist Appointment for Tics.
- 277 Participants who had not had the appointment yet answered based on how far they will have to travel.

YP=young people.

