



UKTS Survey 2016:

# Quality of Life with Thalassaemia in the UK

The UK Thalassaemia Society is always interested to learn from your experiences; and the results of this survey will also be useful to medical professional groups, e.g. the UK Forum on Haemoglobin Disorders.

Our aim is for all patients to have a good quality of life. The information requested in this survey is used to highlight good and bad practice and its impact on patients' lives. Your input is extremely important: it will help to improve the quality and consistency of care offered to all patients, parents and carers and to ensure that we set good standards for care.

If you have questions or would like help in completing this questionnaire please call the UKTS Office on 020 8882 0011

Please feel free to add any comments on the last page of this questionnaire.

All information that you provide to us will be kept completely confidential. Resulting data will be anonymized and will not be linked back to you.

This questionnaire is for patients with thalassaemia who were aged 15 or over on 1 January 2016.

## Part 1: About You

1) Are you:

Male

Female

2) In what year were you born? \_\_\_\_\_

3) What are your parents' ethnicities?

a) Mother's ethnicity (please tick one only)		b) Father's ethnicity (please tick one only)
<input type="checkbox"/>	Pakistani	<input type="checkbox"/>
<input type="checkbox"/>	Bangladeshi	<input type="checkbox"/>
<input type="checkbox"/>	Indian	<input type="checkbox"/>
<input type="checkbox"/>	Other Asian	<input type="checkbox"/>
<input type="checkbox"/>	Black African or Black Carribean	<input type="checkbox"/>
<input type="checkbox"/>	Cypriot	<input type="checkbox"/>
<input type="checkbox"/>	Other Mediterranean	<input type="checkbox"/>
<input type="checkbox"/>	Middle East	<input type="checkbox"/>
<input type="checkbox"/>	White British	<input type="checkbox"/>
<input type="checkbox"/>	Other: (please specify below)	<input type="checkbox"/>

4) Where do you live?

Place name or first half of post code (e.g. "London" or "N14"): \_\_\_\_\_

**5) What is your diagnosis**

Beta thalassaemia major	<input type="checkbox"/>	Alpha thalassaemia major	<input type="checkbox"/>
Beta thalassaemia intermedia	<input type="checkbox"/>	HbH disease	<input type="checkbox"/>
Haemoglobin E/beta thalassaemia	<input type="checkbox"/>	Other (please specify:)	<input type="checkbox"/>

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**Part 2: About your Clinical Management and Annual Review**

**6) Have you had a bone marrow transplant?**

No  Yes

**7) Was the transplant successful (i.e. are you now transfusion free)**

No  Yes

Any comments:

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**8) How often are you transfused?**

Regularly (every few weeks)  Occasionally  Never  If "Never", jump ahead to question 14

**9) Where are you transfused? Please tick all that apply**

Adult ward	<input type="checkbox"/>	Children's day unit	<input type="checkbox"/>
Adult day unit	<input type="checkbox"/>	Specialist Thalassaemia Unit	<input type="checkbox"/>
Children's ward	<input type="checkbox"/>		

**10) When are you transfused?**

Daytime (weekday)  Evening or overnight  Weekend

**11) Is transfusion available out-of-hours (i.e. weekends and evenings)?**

Yes  No  Don't Know

**12) If you are transfused in the daytime/on weekdays would you choose out-of-hours transfusion if it were available?**

Yes  No

Any other comments about transfusion:

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**13) How old were you when you started iron chelation therapy (taking medicine to remove excess iron)?**

\_\_\_\_\_ years

**14) What is your current iron chelation regime?**

None	<input type="checkbox"/>		
Desferrioxamine (Desferal)		Combination	
with pump	<input type="checkbox"/>	Desferal + Deferiprone	<input type="checkbox"/>
with prepared infuser (e.g. Baxter)	<input type="checkbox"/>	Desferal + Exjade	<input type="checkbox"/>
Deferiprone (Ferriprox / L1)	<input type="checkbox"/>	Exjade + Deferiprone	<input type="checkbox"/>
Deferasirox (Exjade)	<input type="checkbox"/>		

**15) How regularly do you take your chelation treatment (be honest please!)?**

As prescribed  Less regularly

**16) What is your current ferritin (if known)?** \_\_\_\_\_

Any other comments about iron chelation therapy:

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**17) Have you had an annual review (check-up with thalassaemia doctor or specialist nurse to check that all monitoring tests are up to date, whether any specialist referrals are necessary and whether any prescriptions for medicines need to be adjusted) in the last 12 months?**

Yes  No  Don't Know

**17b) If "Yes", did your annual review include making a treatment plan for next year and discussing this with you?**

Yes  No  Don't Know

Any comments:

**18) What specialist(s) do you visit in addition to your main treating doctor and why?  
Please complete both columns**

Do you need treatment for...?		How many times in 2015 did you see...	
a) Heart problems	<input type="checkbox"/>	b) A heart specialist? (cardiologist)	_____
c) Diabetes	<input type="checkbox"/>	d) A diabetes specialist?	_____
e) Osteoporosis, bone pain or other bone or joint problems	<input type="checkbox"/>	f) A specialist in bone problems? (rheumatologist/orthopaedic doctor)	_____
g) Growth, development or fertility problems	<input type="checkbox"/>	h) A specialist in growth/puberty/fertility? (endocrinologist)	_____
i) Hepatitis B	<input type="checkbox"/>	l) A liver specialist? (hepatologist)	_____
j) Hepatitis C	<input type="checkbox"/>		
k) Other liver problems	<input type="checkbox"/>		
m) Psychological problems	<input type="checkbox"/>	n) A psychologist?	_____
o) Other medical problems	<input type="checkbox"/>	p) Another specialist doctor? (please specify): _____	_____

Any comments about complications, or additional complications not mentioned above?

**19) In what year was your last:**

	Year	Result (if known)
a) Scan of the Heart? (MRI T2*)	_____	_____
b) Scan of the liver? (MRI / Ferriscan)	_____	_____
c) Bone scan? (DEXA scan)	_____	_____

**20) Have you experienced bone or joint pain in the past year?**

No bone or joint pain <input type="checkbox"/>	Mild/moderate bone or joint pain (interferes little with normal life) <input type="checkbox"/>	Severe bone or joint pain (interferes a lot with normal life) <input type="checkbox"/> Age started _____
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**21) Have you had any bone fractures?**

No  Yes

**22) How well do you feel your bone problems are managed?**

Poorly  It varies  Well

Any comments about bone problems?

### Part 3: About your experience of regular care where you are usually treated

23) How well do you think your thalassaemia doctor understands and responds to your needs?

Very poorly  Poorly  Well  Very well

24) Do you think your treatment is correct?

No  Not sure  Yes

If "No" or "Not sure", why not?

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How well do you think your current GP understands and responds to your needs?

Very poorly  Poorly  Well  Very well

25) How do you find out what the correct treatment for thalassaemia is? Please tick all that apply

From my thalassaemia doctor  From the UK Thalassaemia Society   
From another doctor  From another source   
From treatment protocol  please state: \_\_\_\_\_

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### Part 4: About your experience of living with thalassaemia

	Never	Rarely	Sometimes	Usually	Always
26) You and your family can contact the treatment centre and speak to a knowledgeable doctor/nurse.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27) Your problems are always dealt with quickly enough	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28) Overall you are satisfied with the service you receive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29) You are treated with care, dignity and respect	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30) You are offered a choice of clinic times including outside the work or school day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Any comments:

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### Part 5: About your Quality of Life

31) Have you been educated at any of the following? (please tick all that apply):

School  University   
College  Vocational training/apprenticeship

32) If no longer in education, what is your present occupation?

Full time paid employment  Retired   
Part time paid employment  Not working (through choice)   
Voluntary work  Not working (unable to work)

33) If you are in paid work or were in paid work in the past, tell us more e.g. your area of work or job title?

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34) If not employed, how much do you think having thalassaemia contributed to this?

Not at all  Some  Quite a bit  Very much

Any comments:

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**35) Roughly how many days per year do you think you lose from education or work because of having thalassaemia?**

None  1-5 days  6-10 days  11-15 days  16 or more days  (please specify): \_\_\_\_\_

**36) What is your relationship status?**

Single  Living with partner  Married  Divorced  Widowed

**37) How many children do you have?** \_\_\_\_\_

**38) Do you have plans for (more) children**

Yes  No

**39) When do you meet other patients with thalassaemia (please tick all that apply)?**

Never  Socially   
At clinic  Via social media   
During transfusion  Through the UK Thalassaemia Society

**40) How easy do you find it to talk to friends and colleagues about having thalassaemia?**

Impossible  Very difficult  Difficult  Easy  Very easy

**41) Over the past year, how much has treatment for thalassaemia interfered with your normal social or recreational activities?**

Little or not at all  Quite a bit  Extremely

Please give examples:

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**42) Over the past year, how much has treatment for thalassaemia interfered with you forming or maintaining an intimate relationship (with boyfriend, girlfriend, spouse, sexual partner)?**

Little or not at all  Quite a bit  Extremely

Please give examples:

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**43) Over the past year, how much has your physical / emotional health (including emergencies, hospitalisations and treatment side effects) affected your school/job, daily or social activities?**

Little or not at all  Quite a bit  Extremely

Please give examples:

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**44) How much do you think thalassaemia has interfered with your physical growth and appearance?**

Little or not at all  Quite a bit  Extremely

Please give examples:

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**45) Have you experienced any problems arising from attitudes of society towards thalassaemia? (e.g. ignorance, prejudice, anxiety)**

Never  Rarely  Sometimes  Often

Please give examples:

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46) Do you feel you are fulfilling your hopes in relation to...

	Not at all	Partially	Mostly/ Completely	Not applicable
a) Building a family, including relationship with a partner, having children?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Having friends, taking part in social activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Employment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Education?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Sport and leisure activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please give examples:

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## Part 6: What would you change?

47) What more (if anything) could the medical or nursing staff do to help your treatment?

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48) What more (if anything) could the UK Thalassaemia Society do to help you?

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49) Is there anything else you want us to know? Please attach extra pages if needed.

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# Thank You for Supporting Your Society!

The information that you have given in this survey will help the UKTS to highlight good and bad practice and its impact on patients' lives.

Input from patients is extremely important: it helps to improve quality and consistency of care for all patients, parents and carers across the country; and to ensure that the right standards for care are set and met.

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