Study N	um	ber
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The Yorkshire and Humberside Haematology Network (YHHN) is a study that collects information from people of all ages, who have been diagnosed with a blood cancer or related disorder. This helps us understand why some people develop these conditions and others do not, and why they may respond differently to treatment.

This questionnaire is about what happened leading up to the diagnosis of your blood cancer or disorder, including your **symptoms**, and **where you went to look for help**. By completing it, you will help us to understand more about your experiences during this time, which may lead to better health services in the region.

We would be grateful if you, or someone acting on your behalf (e.g. parent, other relative or guardian) could complete this questionnaire. You can do this **yourself**, or if you are being contacted on behalf of a child, or need help for any reason, **another person** (e.g. a relative or friend) can do this for you.

Please write clearly, and if choices are given, tick the box you agree with.

If you need more space, please continue on page 6.

If you have any questions, or need help filling in this form, please contact us using the details on the back page.

Once you have completed the questionnaire, please return it in the stamped addressed envelope provided.

Questionnaire

Version 4 | July 2024 IRAS ID: 188782

About you

	Please write your address in the box belo details are correct. Please write any chang			nat the
	Address	Amend	ded details	
1.	Who is completing this form?			
	I am the patient			
	I am a parent / guardian of the patient, wh	no is a child or young p	erson	
	I am a relative / caregiver / friend of the p	atient		
Yo	ur diagnosis and symptoms			
2.	Looking back, did you have any sympton present illness?	ns before being diagno	osed with y	our/
	Yes			
	No			
	Not sure			
	If No or Not sure go to question 7 .			
3.	What symptoms did you have, and rough Symptom	nly when did you notic	e them? Month	Year
	i)			
	ii)			
	iii)			
	iv)			

How long was it from the time you first thought something might be wrong w you until you first contacted your GP practice to talk about it?	ith
Not applicable - I didn't contact my GP practice	
Not applicable - the GP first identified that something could be wrong	
Less than 3 months	
3-6 months	
6-12 months	
More than 12 months	
Don't know	
If Not applicable go to question 7 .	
Before you were diagnosed, how many times did you speak to a healthcare professional at your GP practice about health problems caused by your blood cancer or related disorder?	
Once	
Twice	
Three or four times	
Five or more times	
Don't know	
Overall, how would you rate your care from the GP practice before diagnosis? (Scale of 1 - 10; 1 = very poor; 10 = very good)	
Very poor 1 2 3 4 5 6 7 8 9 10 Very good	
How did you come to be diagnosed?	
Via a GP referral	
At a hospital visit / appointment for something else	
After a routine blood test	
Other (please specify)	
	Not applicable - I didn't contact my GP practice Not applicable - the GP first identified that something could be wrong Less than 3 months 3-6 months 6-12 months More than 12 months Don't know If Not applicable go to question 7. Before you were diagnosed, how many times did you speak to a healthcare professional at your GP practice about health problems caused by your blood cancer or related disorder? Once Twice Three or four times Five or more times Don't know Overall, how would you rate your care from the GP practice before diagnosis? (Scale of 1 - 10; 1 = very poor; 10 = very good) Very poor 1 2 3 4 5 6 7 8 9 10 Very good How did you come to be diagnosed? Via a GP referral At a hospital visit / appointment for something else After a routine blood test

8.	Did you go to an Accident and Emergency (A&E) department to get help for your symptoms? (Your own decision; sent by your GP; or taken by ambulance or someone else)
	Yes
	No
	Don't know
	If No or Don't know go to question 11 .
9.	How many times did you go to A&E to get help for your symptoms before your diagnosis?
	One
	Two
	Three or four
	Five or more
	Don't know
10.	Overall, how would you rate your care from the hospital before diagnosis? (Scale of 1 - 10; 1 = very poor; 10 = very good)
	1 2 3 4 5 6 7 8 9 10 Very poor
11.	Overall, how did you feel about the length of time it took for you to be diagnosed?
	It was about right
	It was a little too long
	It was much too long
	Don't know
12.	If there anything else you would like to tell us about your symptoms or diagnosis, please use the box below. If you need more space, please continue on page 6.

How do you feel today?



Under each heading, please tick the ONE box that best describes your health TODAY

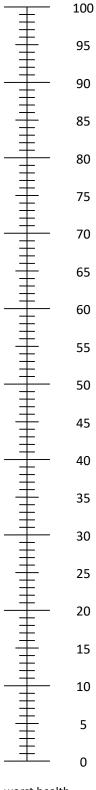
MOBILITY	
I have no problems in walking about	
I have slight problems in walking about	
I have moderate problems in walking about	
I have severe problems in walking about	
I am unable to walk about	
SELF-CARE	
I have no problems washing or dressing myself	
I have slight problems washing or dressing myself	
I have moderate problems washing or dressing myself	
I have severe problems washing or dressing myself	
I am unable to wash or dress myself	
USUAL ACTIVITIES	
(e.g. work, study, housework, family or leisure activities)	
I have no problems doing my usual activities	
I have slight problems doing my usual activities	_
I have moderate problems doing my usual activities	⊢
I have severe problems doing my usual activities	_
I am unable to do my usual activities	Ш
PAIN / DISCOMFORT	
I have no pain or discomfort	
I have slight pain or discomfort	
I have moderate pain or discomfort	
I have severe pain or discomfort	
I have extreme pain or discomfort	
ANXIETY / DEPRESSION	
I am not anxious or depressed	
I am slightly anxious or depressed	
I am moderately anxious or depressed	
I am severely anxious or depressed	
I am extremely anxious or depressed	



- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
 0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The best health you can imagine



The worst health you can imagine

If there anything else you would like to tell us about you or your illness, please use the space below.
Signed: Date form
completed:
Your contact telephone number: (in case we have any queries)

Contact us

Address

YHHN

Area 3, Seebohm Rowntree Building Department of Health Sciences University of York Heslington YORK YO10 5DD

Website

Scan the QR code to visit our website.

yhhn.org

For newsletters, our latest research, and more.



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