HORIZONS

UNIVERSITY OF Southampton

Understanding the impact of cancer diagnosis and treatment on everyday life

6 MONTH NON HODGKIN LYMPHOMA (NHL) CRF

FOR STAFF USE ONLY

CRF Completion Instructions

- **Please complete as much of the CRF as possible**
- **Please refer to your copy of the baseline CRF when completing this 6 month CRF: the questions marked with a RED ASTERISK need only be answered if they were marked "not currently known", "unknown" or left blank at baseline**
- **If you have any queries, please contact the HORIZONS Co-ordinating Centre, email address HORIZONS@soton.ac.uk**
- **Please tick boxes when appropriate**
- **When you have completed the CRF, please keep a copy for your own records and return a copy to us, by post, fax or email, along with the completed return cover sheet**

Participant's Study ID ☐☐ / ☐☐ / ☐☐☐☐

Participant's date of birth d d m m y y y y

Participant's lymphoma type (please tick one box below, or tick to indicate the question was answered at baseline)*

This question was answered at baseline ☐

Type	Sub-type	
High Grade B-cell non Hodgkin Lymphoma	Diffuse large B-cell lymphoma	
	T cell rich large B-cell lymphoma	
	Primary mediastinal (thymic) large B-cell lymphoma	
	High grade B-cell with MYC and BCL2 and/or BCL6 rearrangements	
	Other (please describe on line below) ……	
	Not currently known	

Date of participant's current cancer diagnosis (please add details or tick to indicate the question was answered at baseline)*

This question was answered at baseline ☐

Date of current cancer diagnosis d d m m y y y y

(date that histological diagnosis was reported)

Participant's Study ID ☐☐ / ☐☐ / ☐☐☐☐

Participant's tumour number stage at diagnosis (please tick one box below, or tick to indicate the question was answered at baseline)*

This question was answered at baseline ☐

IMPORTANT—YOU SHOULD HAVE ENTERED STAGING INFORMATION FOR EACH PARTICIPANT, EITHER IN THIS CRF OR IN THE BASELINE CRF

Stage 1 - One group of lymph nodes affected either above or below diaphragm	
Stage 1E (Extranodal Lymphoma) - Started in a single organ and is contained within organ	
Stage 2 - Two or more groups of lymph nodes affected either above or below the diaphragm	
Stage 2E (Extranodal Lymphoma) - Started in one organ and also in one or more groups of lymph nodes	
Stage 3 - Lymph nodes affected on both sides of the diaphragm	
Stage 3E (Extranodal Lymphoma) - Lymph nodes affected on both sides of the dia-	
Stage 4 (treated with curative intent)	

Does the participant have bulky disease, ie a nodal mass > 7.5cm—often marked as 'X'

Yes		No		Unknown	

Participant's letter stage (please tick one box OR tick to indicate the question was answered at baseline)*

This question was answered at baseline ☐

A	Absence of B symptoms	
B	One or more of: • Unintentional weight loss • Night sweats • Fevers	

Participant's Study ID ☐☐ / ☐☐ / ☐☐☐☐

Participant's cell of origin subtype classification (please tick one box below, or tick to indicate the question was answered at baseline)*

Germinal centre B-cell like (GCB)	
Activated B-cell-like (ABC) or non-GCB	
Cell of origin subtype not currently known	

This question was answered at baseline ☐

Participant's LDH level at diagnosis (please give reported level OR tick the box indicating the LDH level is not currently known)*

LDH Level _____ U/L

LDH level at diagnosis not currently known ☐

Participant's Study ID ☐☐ / ☐☐ / ☐☐☐☐

Has the participant had any genetic tests for inherited cancers? (please tick one box)

Yes (already recorded in baseline CRF)	
Yes (but not recorded in baseline CRF)	
No	
Unknown	

If you answered "Yes (but not recorded in baseline CRF)" to the above question, please provide some information about the participant's genetic test(s) by completing the table below

Name of genetic test for cancer (1)	Result of genetic test	
	Positive	
	Negative	
	Ambiguous/uncertain	
	Awaiting result	
	Unknown	

Name of genetic test for cancer (2)	Result of genetic test	
	Positive	
	Negative	
	Ambiguous/uncertain	
	Awaiting result	
	Unknown	

Participant's Study ID ☐☐ / ☐☐ / ☐☐☐☐

Has the participant developed any NEW co-morbidities (which were not recorded in the baseline CRF)? (please tick one box)

Myocardial infarct	
Angina/coronary artery disease	
Congestive Heart Failure	
Cardiac Arrythmias	
Hypertension	
Venous Disease (PE/DVT)	
Peripheral Arterial Disease	
Restrictive Lung Disease or COPD (chronic bronchitis, emphysema, asthma etc.)	
Liver Disease (portal hypertension, chronic/acute hepatitis, cirrhosis etc.)	
Stomach Ulcers or Inflammatory Bowel Disease	
Acute or Chronic Pancreatitis	
End-stage Renal Disease (chronic renal insufficiency, dialysis etc.)	
Thyroid problems (hyperthyroidism, hypothyroidism etc.)	
Diabetes Mellitus Type 1	
Diabetes Mellitus Type 2	
Stroke/TIA	
Dementia	
Paralysis (paraplegia or hemiplegia)	
Neuromuscular Condition (multiple sclerosis, Parkinson's, myasthenia gravis, other chronic neuromuscular disorder)	
Clinical diagnosis of anxiety	
Clinical diagnosis of depression	
Other psychiatric diagnosis (eg. schizophrenia, bipolar disorder etc.)	

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Participant's NEW co-morbidities continued (please tick all that apply)

Osteoarthritis	
Rheumatoid Arthritis	
Other Rheumatological Disease (systemic lupus, mixed connective tissue disorder, polymyositis, rheumatic polymyositis, scleroderma etc.)	
HIV/AIDS	
Alcohol Abuse (or history of, must be accompanied by social, behavioural or medical complications)	
Drug/Substance Abuse (or history of, must be accompanied by social, behavioural or medical complications)	
Morbid Obesity	
Other (please give details) _____	

Participant's Study ID ☐☐ / ☐☐ / ☐☐☐☐

What was the participant's route to diagnosis (please tick one box)

The participant was diagnosed:	
1. During/following a hospital outpatient appointment which resulted from:	
i) An urgent GP referral for suspected cancer ("Two-week wait")	
ii) A routine GP referral (for symptoms which don't arouse suspicion of cancer but need investigating)	
iii) A referral from a different outpatient specialty (eg. ENT)	
2. During/following an admission to hospital which was:	
i) An inpatient elective	
ii) An emergency (after an emergency GP referral, during an A&E visit, whilst in hospital due to an emergency)	
3. Other (please describe below)	
4. Unknown	

Participant's Study ID ☐☐ / ☐☐ / ☐☐☐☐

What treatments for NHL has the participant received, please tick ALL that apply and write details in the spaces provided (table continued overleaf)

Treatment type	Specific treatment details	Tick if patient has received	Start date of treatment (dd/mm/yyyy)	End date of treatment (if finished) (dd/mm/yyyy)	If course of treatment was not completed as planned, please give a reason why
Pre-phase steroids	Prednisolone		__ / __ / 20___	__ / __ / 20___	
Combination chemotherapy	CHOP		__ / __ / 20___	__ / __ / 20___	
	Other (please describe) _____		__ / __ / 20___	__ / __ / 20___	
	Chemotherapy number of cycles , please enter on line _____ If there were any amendments to chemotherapy dose during treatment , please give a reason why _____				
Intrathecal chemotherapy	Methotrexate		__ / __ / 20___	N/A	
	Other (please describe) _____		__ / __ / 20___	N/A	
	Chemotherapy number of cycles, please enter on line _____				
Monoclonal Antibody	Rituximab		__ / __ / 20___	__ / __ / 20___	
	Other (please state) _____		__ / __ / 20___	__ / __ / 20___	
	Monoclonal antibody number of cycles, please enter on line _____				
Radiotherapy	Radiotherapy		__ / __ / 20___	__ / __ / 20___	
	Radiotherapy site, please enter on line _____				
	Number of radiotherapy fractions, please enter on line _____				
	Dose for each radiotherapy fraction, please enter on line _____				

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Is the participant taking part in a clinical trial? (please tick one box)

Yes		No		Unknown	

If you answered "yes" to the above question, please give the NAME of the clinical trial the participant is taking part in

Name of clinical trial _____

Since the participant's diagnosis of non-Hodgkin lymphoma, have they been diagnosed with another new primary cancer? (please tick one box)

Yes		No		Unknown	

If you answered "yes" to the above question, please provide some information about the participant's new cancer diagnosis by completing the table below

Details of participant's new cancer diagnosis

Type of cancer	
Date of diagnosis	__ / __ / 20___
Treatment received	
Date treatment ended (if finished)	__ / __ / 20___

Participant's Study ID | | / | | / | | | | |

Has the participant had a relapse of their non-Hodgkin lymphoma? (please tick one box)

Yes		No	

If the participant has had a relapse, on what date was the relapse diagnosed?

d	d	m	m	y	y	y	y

If the participant has had a relapse, was the relapse at the original site or at a new site? (please tick one box)

Original site	
New site	

Has the participant's lymphoma become refractory (failure to respond/resistance to primary treatment)? (please tick one box)

Yes		No	

If the participant has had a refractory or relapsed lymphoma, has any further treatment been given? (please tick one box and if "yes" provide details in the table below)

Yes		No	

What second line treatments for NHL has the participant received, please tick ALL that apply and write details in the spaces provided (table overleaf)

Participant's Study ID ☐☐ / ☐☐ / ☐☐☐☐

Treatment type	Specific treatment details	Tick if patient has received	Start date of treatment (dd/mm/yyyy)	End date of treatment (if finished) (dd/mm/yyyy)	If course of treatment was not completed as planned, please give a reason why
Combination chemotherapy	ICE		__ / __ / 20___	__ / __ / 20___	
	DHAP		__ / __ / 20___	__ / __ / 20___	
	Other (please describe) _____		__ / __ / 20___	__ / __ / 20___	
	If there were any amendments to chemotherapy dose during treatment , please give a reason _____				
	Chemotherapy number of cycles, please enter on line _____				
Monoclonal Antibody	Rituximab		__ / __ / 20___	__ / __ / 20___	
	Other (please state) _____		__ / __ / 20___	__ / __ / 20___	
	Monoclonal antibody number of cycles, please enter on line _____				
Stem Cell Transplant	Autologous transplant/ High dose therapy and stem cell support		__ / __ / 20___	__ / __ / 20___	
	Allogenic transplant		__ / __ / 20___	__ / __ / 20___	
Radiotherapy	Radiotherapy		__ / __ / 20___	__ / __ / 20___	
	Dose for each radiotherapy fraction, please enter on line _____				
	Number of radiotherapy fractions, please enter on line _____				
	Radiotherapy site, please enter on line _____				

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If the participant has had a refractory or relapsed lymphoma, and has not yet received second line treatment, is any further treatment planned? (please tick one box and if "yes" give details)

Yes		No	

Please describe any planned treatment

_____

What type of follow-up care is the participant receiving? (please tick ONE box)

Routine/regular hospital clinic based follow-up (medical or nurse led, face-to-face or by telephone)	
Primary care based follow-up	
Patient initiated follow-up (also known as patient triggered follow-up (PTFU), open access follow-up, or supported self-managed follow-up)	
If the participant is receiving patient-initiated follow-up, on what date were they discharged to this? d d m m y y y y	

Participant's Study ID ☐☐ / ☐☐ / ☐☐☐☐

Has the participant been referred to any of the following services and/or had a Holistic Needs Assessment? (please tick all that apply)

Participant has been referred to palliative care services	
Participant has been referred to psychological services	
Participant has been referred to community services	
Participant has had an HNA (holistic needs assessment)	

If the participant has died please give the date and cause of death:

Participant's date of death

d d / m m / y y y y

Cause of participant's death

1) a)	
1) b)	
1) c)	
2)	

Cause of death not known ☐

Please add your name and signature and the date that you completed this CRF

Name _____ Signature _____

Date CRF completed d d / m m / y y y y