

Supplementary File 2

Survey & Topic Guide

1. Health professional survey

Emotional and psychological support for people diagnosed with Blood Cancer: understanding current practice, experience and views of healthcare professionals

Thank you for considering taking part in this questionnaire study. We are interested in health professionals' current practice and views of the emotional and psychological support services for patients with blood cancer

We will also be interviewing patients and the information we collect will be used to inform future service provision and policy in this area.

Please read the [Participant Information Sheet](#) before completing the questionnaire. The questionnaire should take approximately 5-10 minutes to complete. Participation is entirely voluntary. There are no right or wrong answers.

If you have any questions about any aspect of completing the questionnaire please contact

Thank you very much for your help!

CONSENT Section – participant will be required to complete this before can enter survey

I confirm that I have read and understand the participant information sheet for the above study. I understand that my participation is voluntary. I understand that all the study documentation whether hardcopies or electronic will be kept for up to 10 years and will be disposed of securely if it is confirmed that they are no longer required. Data may be accessed by staff at Oxford Brookes University and regulatory bodies for audit and monitoring purposes. I agree to take part in the survey.

Yes

I agree that data gathered for this study may be stored in a secure data repository and will be available through open access for other researchers to use. However I understand that no data that identifies me will be stored.

Yes
 No

I agree to the use of anonymised quotes (from open response questions in the survey) in the reporting of the findings

Yes

No

QUESTIONNAIRE**Section 1 Background Information****1. What is your current role?**

- Consultant Haematologist
- Consultant Oncologist
- Specialist Registrar
- Nurse Specialist / Advanced Nurse
- Practitioner -Specialist (please provide details)

- Haematology or Oncology Sister / Deputy Sister
- Haematology or Oncology Staff Nurse
- Other (please specify) _____

2. Please tell us which blood cancer patient group(s) you mainly work with? (Please tick all that apply)

Hodgkin Lymphoma

- Non-Hodgkin Lymphoma
- Indolent Lymphoma
- Symptomatic Myeloma
- Smouldering Myeloma
- Chronic Lymphocytic Leukaemia (CLL)
- Acute Lymphoblastic Leukaemia (ALL)
- Acute Myeloid Leukaemia (AML)
- Myeloproliferative Neoplasms

3. Do you look after patients who have had the following treatments (please tick all that apply)

- Stem cell transplant
- CAR-T cell therapy
- Other (please specify) _____

3. Where do you work? (Please tick all that apply)

- Cancer Centre
- District General Hospital
- Primary Care
- Other (please specify) _____

4. How many years have you been working in oncology haematology?

- 0-5
- 6-10
- 11-15
- >15

5. Which one of the following geographic regions represents the area where you practise *most of the time*? [Single response]

London

- London

South of England

- South East Coastal
- South Central
- South West

Midlands and East SHA

- West Midlands
- East Midlands

North of England

- Yorkshire & Humber
- North East
- North West

6. What is your gender?

- Male
- Female
- Non binary/other
- Prefer not to say

Current Practice**7. How many patients with a newly diagnosed blood cancer would you typically see each month?**

- 1-20
- 21-50
- >50
- Not sure

8. How many patients with a previously diagnosed blood cancer would you typically see per month?

- 1-20

- 21-50
 >50
 Not sure

9. Are the emotional / psychological needs of your patients with blood cancer routinely assessed?

- Yes
 No
 Don't know

10. At what time point(s) is assessment for emotional / psychological needs usually done, and how often? (please tick frequency for each stage of patient care)

	Always or nearly always	Often	Some- times	Infrequently	Rarely or never	Don't know
Diagnosis	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
During treatment	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
On Watch and Wait	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
After treatment	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Recurrence / Disease progression	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other (please specify) _____	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

11. How often are the following used in assessing emotional/ psychological needs? (please tick frequency for each stage of patient care)

	Always or nearly always	Often	Some- times	Infrequently	Rarely or never	Don't know
Health Needs Assessment	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Screening tool (please specify)	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Clinical Judgement	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
After treatment	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other (please specify) _____	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

Other (please specify) _____

12. How often are the following health professionals involved in providing support for emotional / psychological problems?

	Always or nearly always	Often	Some- times	Infrequently	Rarely or never	Don't know
Doctor	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Nurse Specialist	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Allied Health Professional (please specify) _____	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other (please specify) _____	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

13. To what extent do you agree with the following statements

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
The emotional / psychological wellbeing of blood cancer patients is comprehensively assessed in my centre	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Patients are well supported in terms of emotional/psychological well-being	<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Please add any additional comments:

14. What do you think are the main barriers to providing blood cancer patients with emotional and psychological support? (please tick all that apply)

- Clinical Time Pressure
- Lack of resources eg staffing levels
- Lack of expertise
- Competing clinical priorities
- Patient factors (eg patient reluctance)
- Other (please specify)
- Don't know

15. What proportion of blood cancer patients you see do you think experience high levels of (disabling) emotional / psychological distress?

_____%

Don't Know

16. Do you have access to in house specialised psychological support for your **out patients**?

- Yes
- No
- Not applicable
- Don't know

17. Do you have access to in house specialised psychological support for your **inpatients**?

- Yes
- No
- Not applicable
- Don't know

18. If yes, what triggers a referral (please tick all that apply)

- Screening guidelines
- Clinician opinion
- Patient asking for referral
- Relatives asking for referral
- Other (specify)

If no, how do you support these patients? (please tick all that apply)

- Nurse specialist support
- Refer to charity service eg Bloodwise / Maggie's centres / Macmillan / MIND etc (specify)
- Refer to GP

- Refer to private sector services (specify)
- Other (specify)
- Don't know

19. For patients who you refer on / signpost to other services, how confident are you that their needs are met?

- Very confident
- Confident
- Neither confident or unconfident
- Not every confident
- Not at all confident

20. Are there particular groups of patients you feel are more likely to experience disabling emotional/psychological problems? (tick all that apply)

- Certain types of blood cancer diagnoses (specify)
- Patients with recurrence
- Females
- Younger patients
- Older patients
- Single patients
- Patients with co-morbidities
- Patients with previous mental health problems
- Patients with low socioeconomic status
- Patients with young children
- Patients with low social support
- No specific groups
- Other (please specify) _____
- Don't know

21. When do you think the need for emotional / psychological support is the greatest? (Tick all that apply)

- Diagnosis
- Treatment
- Survivorship
- Watch and wait
- Recurrence
- Other Please specify
- Don't know

22. Do you give patients written information about managing the emotional / psychological impact of blood cancer?

- Always

- Often
- Sometimes
- Rarely
- Never

Please specify what written information: _____

23. Do you signpost patients to online information

- Always
- Often
- Sometimes
- Rarely
- Never

Please specify what online information: _____

24. Do you feel providing psychological / emotional support is part of your role?

- Yes, definitely
- Yes, somewhat
- Not sure
- No

25. Have you received any training in assessing and managing psychological needs?

- Yes (please specify) _____
- No

If yes, how useful was this?

- Very useful
- Somewhat useful
- not very useful
- Not at all useful

Do you apply what you learned in your practice?

If no, is this something you think would be useful?

- Yes, definitely
- Yes, possibly
- No

26. How confident do you feel in providing psychological support?

- Very confident
- Confident
- Neither confident or unconfident
- Not very confident
- Not at all confident

27. Does your organisation have guidance on providing psychological support for patients with blood cancer?

- Yes
- No
- Don't know

28. Is there anything else you would like to add on this topic:

2. Topic Guide-Patient Interviews

Introduction: Thank you for agreeing to this interview. It should take around an hour to complete. If at any time, you wish to have a break or stop, please just let me know. If you want any questions repeated or clarified, please ask. I will be asking you about the emotional impact of your diagnosis and treatment and your experiences, if any, of emotional or psychological support since you were diagnosed with blood cancer. We want to understand how services for patients and their families can be improved in the future.

Before we start I need to record your consent to this interview (read out consent form).

- How long ago were you diagnosed and can you briefly describe what your treatment history has been.
- In relation to your cancer how are you feeling now about things emotionally?
- How has Covid-19 impacted on you? If possible, we would now like to ask you to try and think back to how things were before the Covid19 pandemic:
 - And how were you feeling in terms of emotions before the Covid-19 pandemic?
 - How does this compare to how you felt when you were first diagnosed?
- We are interested in what emotional or psychological support patients are offered / received:
 - Since diagnosis what sort of emotional or psychological support have you been offered
 - Did you take up this offer? ▪ Hospital Who, what, when – timing and content Have you been referred elsewhere – if so where and how was that
 - Friends and families
 - Peers
 - Charities – helplines etc
 - Forum
 - Support Groups

How useful has this been?

- If felt in need of support: Preferred mode of support (face-to-face, telephone, information online or printed, support group etc.) Main emotion you needed support for (anxiety, sadness, anger etc). In what way did the emotions restrict life?

Role of factual information about blood cancer and the treatment in managing emotions (what was helpful/unhelpful)?

- When in the course of illness/ treatment would you have wanted psychological support most? If got no support from hospital

- o How was that?

- o Would you have liked more?

- o How would it work best for you?

- How big an impact has diagnosis had on your mental health o Effect on working life, social life, normal activities

- Views towards information about managing the psychological impact of blood cancer - was there any? If so, in what form? How useful did you find this? Could anything be improved about this?

- Any potential improvements to the overall process of obtaining emotional/psychological support