

Attachment 8

Assessing Problem Areas in Referrals for Chronic Hematologic Malignancies and Developing Interventions to Address Them

Primary Care Provider Survey (draft)

Public reporting burden of this collection of information is estimated to average 20 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-XXXX)

Referrals for Chronic Hematologic Malignancies

(Draft) Primary Care Provider Survey

The Dana-Farber Cancer Institute and
the Centers for Disease Control and Prevention

The CDC and its partners are studying ways to improve timeliness of care to improve patient outcomes. One area of interest is the care of patients with hematological malignancies. Your participation will help us understand the current practice patterns for these patients, and help us construct tools to help providers care for these patients in the future.

Before beginning, please review the cover letter describing the purpose of this study. All of your answers will be kept secure.

If you have any questions about this survey, please call 617-632-2304 and ask for Gregory A. Abel, MD or e-mail gregory_abel@dfci.harvard.edu.

Survey Instructions

Please answer each question by choosing the answer that best describes your opinion, feelings or experience.

- Answer all the questions that apply to you by marking an “X” in the box for your answer or writing in the information requested.
- You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this: → *skip to question 1*

Part I. Your Professional Background

1. Which of the following specialties do you primarily practice? *(Please check all that apply)*

- Family Practice
- General Practice
- Internal Medicine
- Obstetrics/Gynecology
- Pediatrics
- Other: *(please specify)*

2. What professional degree do you hold?

- Medical Doctor (MD)
- Doctor of Osteopathy (DO)
- RN with prescription privileges
- RN without prescription privileges

3. Do you have any board certifications or board eligibilities? *(Please write in)*

4. Are you regular faculty, adjunct faculty, have no relationship at all, or some other relationship with an academic medical center? *(Please mark one)*

- Regular faculty
- Adjunct faculty
- No Relationship
- Other relationship: *(please specify)*

5. Does your current practice referral network include any physicians in the following specialties with whom you are on a first-name basis? *(Please mark yes or no for each)*

	Yes	No
Hematologist	<input type="checkbox"/>	<input type="checkbox"/>
Medical Oncologist	<input type="checkbox"/>	<input type="checkbox"/>
Surgical Oncologist	<input type="checkbox"/>	<input type="checkbox"/>
Radiation Oncologist	<input type="checkbox"/>	<input type="checkbox"/>
Gynecological Surgeon	<input type="checkbox"/>	<input type="checkbox"/>
Gynecological Oncologist	<input type="checkbox"/>	<input type="checkbox"/>
General Surgeon	<input type="checkbox"/>	<input type="checkbox"/>

6. To the best of your knowledge, in the past 12 months, what was the total number of patients for whom you provided care?

_____ (number of patients)

7. To the best of your knowledge, in the past 12 months, how many patients did you see that you suspected might have a hematological malignancy?

_____ (number of patients)

If you saw none → skip to Part II

8. In the past 12 months, of those patients you suspected might have had a hematological malignancy, how many did you refer to a specialist? *(Please write in number of patients in each age group)*

Less than 21 years old	
21-44 years old	
45-64 years old	
65 or older	

Part II. Signs and Symptoms

1. If you were to see a previously healthy patient during a routine physical with **mild anemia (Hg 80% of normal) and no other symptoms**, which of the following would you do? *(Please check all that apply)*

- Differential on CBC
 - CT scan of chest or abdomen
 - Fe studies
 - B12/Folate
 - Reticulocyte count
 - SPEP
 - Stool guaiac
 - EGD
 - Colonoscopy
 - 2-week follow-up
 - Referral to hematologist
 - Referral to surgeon
 - Reassurance
 - Other: *(please specify)*
-

2. If you were to see a previously healthy patient during a routine physical with **non-specific constitutional symptoms (malaise and ten pound weight loss) and no other symptoms**, which of the following would you do? *(Please check all that apply)*

- CBC with differential
 - Antibiotics
 - 2-week follow-up
 - Stool guaiac
 - EGD
 - Colonoscopy
 - CT scan of chest or abdomen
 - Referral to hematologist
 - Referral to surgeon
 - Reassurance
 - Other: *(please specify)*
-

3. The patient with **mild anemia** presents two weeks later. The anemia is unchanged, but the patient has **one** new sign/symptom in the following list. For each of these as an isolated new finding, what would you do next? *(Please check all that apply. If you would have already referred to a specialist in question 1 → skip to question 4)*

Sign/Symptom	Imaging	Follow-up in 2 weeks	Refer to specialist
Fever	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Weight loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lymphadenopathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Night Sweats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thrombocytosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thrombocytopenia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leukopenia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leukocytosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non-pigmented cutaneous nodule	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pancytopenia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient says "I just don't feel well..."	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Insistent family member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. The patient with **non-specific constitutional symptoms (malaise and ten pound weight loss)** presents two weeks later, no worse, but with **one** new sign/symptom in the following list. For each of these as an isolated new finding, what would you do next? *(Please check all that apply. If you would have already referred to a specialist in question 2 → skip to part III)*

Sign/Symptom	Imaging	Follow-up in 2 weeks	Refer to specialist
Fever	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Night sweats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lymphadenopathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anemia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thrombocytosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leukopenia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leukocytosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Polycythemia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non-pigmented cutaneous nodule	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pancytopenia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient says "I just don't feel well..."	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Insistent family member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part III. Flow of Referral Information

1. For hematological cases that you refer to a specialist, do you...

	Always	Usually	Sometimes	Rarely	Never
...write a formal referral letter to specialist?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...write a referral email to specialist?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...provide patient a copy of test results to bring to specialist?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...contact patient to ensure he or she attended appointment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...contact specialist to follow-up on suggestions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...give patient a copy of resulting consultation report?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. When you receive feedback from a specialist after a referral, how often does the specialist...

	Always	Usually	Sometimes	Rarely	Never
...provide diagnosis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...provide citations from relevant literature?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...provide treatment plan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...assume complete care of patient?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...provide no feedback at all?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. How often do you refer a patient you suspect may have a hematological malignancy to a hematologist or a surgeon, and find at a subsequent clinic visit...

	Always	Usually	Sometimes	Rarely	Never
...the patient has not been to see the specialist?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...your office has not arranged an appointment with the specialist?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...the patient has cancelled his or her appointment with the specialist?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. For a chronic hematological malignancy, the ideal consult note contains: *(Please choose only one)*

- Diagnosis only
- Diagnosis and treatment plan only
- Diagnosis, treatment plan, and brief review of associated literature
- Diagnosis, treatment plan, and extensive literature review
- Diagnosis, treatment plan, literature review and invitation to take over care of the patient for the referral issue

Part IV. Deciding to Refer and Choosing a Specialist

1. When you are deciding to make a referral of a patient for evaluation for a possible hematological malignancy, on a scale of 1 to 5, how important is each of the following factors in choosing a consultant?

	Not Important At All				Extremely Important
	1	2	3	4	5
Patient preferences for site of care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Possibility of losing patient to specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal relationship with specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Availability of clinical trials at referral site	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Distance from patient's home to site of care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reputation of specialist/facility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your affiliation with that provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist's affiliation with a cancer center	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient's ability to pay for specialist care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Ideally, the specialist I would choose for a patient who I suspect of having a possible chronic hematological malignancy...

	Strongly Agree	Disagree	Neutral	Agree	Strongly Agree
...is affiliated with a cancer center.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...offers the patient the opportunity to enroll in a clinical trial.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...takes over care of my patient as it relates to the hematological problem.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

...has taken care of my patients before.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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3. Please record your level of agreement with the following statements regarding referrals of patients with suspected hematological malignancies.

	Strongly Agree	Disagree	Neutral	Agree	Strongly Agree
There is a lack of specialists to whom I can refer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is poor infrastructure to schedule or follow-up on referrals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There is poor patient compliance with referrals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many of my patients cannot afford to see a specialist.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When I suspect a hematological problem for which there are few treatments, such as CLL or MDS, I am less likely to refer to a specialist.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can recognize and diagnose most patients with chronic hematological malignancies myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can manage most chronic hematological malignancies myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. Please note in the space below the one most important factor that could improve the process of early diagnosis and referral of patients with hematologic malignancies.

Part V. Case Vignette One

A 63 year old [**African American versus do not specify**] woman presents with several weeks of fatigue and a 2.0 cm mobile mass in her cervical chain that she associates with an upper respiratory syndrome. She is otherwise well-appearing. This is her first visit for this complaint. Her CBC is normal except that her white cells are slightly elevated (12.5 k/microL) with 85% lymphocytes.

1. At this point, what would be the top three choices on you differential diagnosis? (Please write in)

I. _____

II. _____

III. _____

2. Please answer the following questions on a scale of 1 to 5, where “1” is “extremely unlikely” and “5” is “extremely likely.”

	Extremely Unlikely				Extremely Likely
	1	2	3	4	5
How likely is it that this patient has a hematological malignancy at this time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How likely is it that you would refer this patient to a surgeon?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How likely is it that you would refer this patient to a hematologist?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How likely is that this patient needs rapid diagnosis/treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The woman is given three days of azithromycin and scheduled for follow-up in two weeks. She cancels because of a work conference and reschedules for one month later (six weeks from her last visit). At that appointment, she says the mass is smaller; however, on exam, it seems unchanged. She otherwise feels well, but you find a .5 cm “shotty” groin node on exam. A repeat CBC shows mild anemia (32.5%), normal platelets, and white cells are now 15.5 with 83% lymphocytes.

3. At this point, what would be the top three choices on your differential diagnosis? (Please write in; please write “unchanged” if they are unchanged)

I. _____

II. _____

III. _____

4. Please answer the following questions on a scale of 1 to 5, where “1” is “extremely unlikely” and “5” is “extremely likely.”

	Extremely Unlikely				Extremely Likely
	1	2	3	4	5
How likely is it that this patient has a hematological malignancy at this time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How likely is it that you would refer this patient to a surgeon?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How likely is it that you would refer this patient to a hematologist?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How likely is that this patient needs rapid diagnosis/treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part VI. Case Vignette Two

A [70- versus 45-] year old male with diabetes presents with a new complaint of low back pain and fatigue. He usually presents with his wife, but informs you that she died recently. A CBC shows a hematocrit of 36.7% (previously 42.2%), but is otherwise normal. Physical exam is non-revealing, and labs are stable from the prior visit, including a creatinine of 1.4. A serum protein electrophoresis shows no monoclonal protein.

1. At this point, what would be the top three choices on your differential diagnosis? *(Please write in)*

I. _____

II. _____

III. _____

2. Please answer the following questions on a scale of 1 to 5, where “1” is “extremely unlikely” and “5” is “extremely likely.”

	Extremely Unlikely				Extremely Likely
	1	2	3	4	5
How likely is it that this patient has a hematological malignancy at this time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How likely is it that you would refer this patient to a hematologist?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Would the presence of serious comorbidities make you more likely to refer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How likely is it that this patient needs rapid diagnosis/treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

You obtain a plain film of the spine, which is read as “small lytic lesion versus bowel shadow in pelvis, follow-up imaging recommended in six months.” The test is arranged. Despite NSAIDs, the patient’s back pain becomes worse and he presents again four months later. He hasn’t been eating and expresses that he misses his wife terribly; repeat creatinine is slightly elevated at 1.6.

3. At this point, what would be the top three choices on your differential diagnosis? (Please write in, please write “unchanged” if they are unchanged)

I. _____

II. _____

III. _____

4. Please answer the following questions on a scale of 1 to 5, where “1” is “extremely unlikely” and “5” is “extremely likely.”

	Extremely Unlikely				Extremely Likely
	1	2	3	4	5
How likely is it that this patient has a hematological malignancy at this time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How likely is it that you would refer this patient to a hematologist?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Would the presence of serious comorbidities make you more likely to refer?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How likely is it that this patient needs rapid diagnosis/treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part VI. Final Questions About You

1. In what year were you born? *(Please fill in year)*

_____ (Year)

2. Are you... *(Please mark one)*

- Male
- Female

3. Are you of Hispanic or Latino origin or descent? *(Please mark one)*

- Yes, Hispanic or Latino
- No, not Hispanic or Latino

4. What is your race? *(Please mark one or more)*

- Black or African-American
- Asian
- White
- Hawaiian or Pacific Islander
- American Indian or Alaska Native

5. What year were you graduated from medical or nursing training? *(Please fill in year)*

_____ (Year)

6. In the past 12 months, what percentage of your patients were:

Less than 21 years old	%
21-44 years old	%
45-64 years old	%
65 or older	%
Total =	100 %

Thank you for taking the time to answer these questions!

Please return this questionnaire using the postage-paid envelope.

