

Attachment 6

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

**Patient Interview Guide
(draft)**

HSC-SPH-07-0187

PATIENT INTERVIEW GUIDE (draft)

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Introduction:

Many advances have been made in cancer screenings and treatments. The best way that these advances can benefit patients is if they are implemented quickly and correctly. Our goal is to improve the quality of care for patients. By talking with patients about their experiences and ideas, we hope to gain valuable information that may help us develop an educational program for patients and health care providers. We are conducting interviews with patients and doctors to better understand their experiences with cancers of the blood (i.e., Multiple Myeloma, Chronic Lymphocytic Leukemia, Lymphoma, Chronic Myelogenous Leukemia, and Myelodysplastic Syndrome). We are specifically interested in your experience with being diagnosed with a cancer of the blood and your health care experience during this time.

Health Care Source:

1. Please start by telling me a little bit about yourself and your regular health care.

Probes:

- What is your usual source of health care?
Such as:
 - Primary Care Physician, Family Physician, Nurse Practitioner, Physician Assistant, Other, Etc.Location:
 - Clinic, Emergency Room, Etc.
- Is this outside of Houston (for example in a surrounding county? Elsewhere?)

Experience with Cancer:

2. I'd like to hear about your experience with cancer. Please, tell me about the first time you noticed something was wrong.

Probes:

- What happened first?
- When was that?
- What initially lead you to the doctor?
- How long did you wait before seeking health care, and why?
- When did you or your doctor first notice anything unusual?
- What happened then?
- At what point did the doctor first mention the possibility of a problem? When was that?
- What type of doctor was it (for example primary care doctor, gynecologist?)
- What did you do next? When was that?
- Was this a pretty smooth process or did you have problems (or delays) with care or services along the way? How did it go?
- Did you need to do anything to get things going? What did you do?
- What questions did you have along the way?
- How were your questions addressed?

Note: If the patient expresses any unaddressed questions, the interviewer will refer them to the MDACC Patient Advocate for questions to be addressed.

3. Tell me about your experience with referral (the steps taken in order for you to get seen by another doctor).

Probes:

- When did you first get referred?
- Did you have insurance?
- Did financial issues play a role in this?
- Did you have to fill out any forms?
- Did you have to contact your insurance company?
- Tell me about this process. Was it easy, hard, etc.?

4. Now, let's talk about the diagnosis and how you ended up at MD Anderson. Please tell me about that process.

Probes:

- When were you first diagnosed?
- Where were you first diagnosed?
- Who diagnosed your cancer?
- What happened after that?
- When was that?
- Was the diagnosis a pretty smooth process? How did that go?
- Why did you choose to come to MD Anderson? Probe: MD recommendation, location, reputation, research, access to clinical trials, insurance plan coverage?
- Did your diagnosis change at any point? What about once you got to MD Anderson?
- Did your Primary Care Provider (Nurse, PA, etc.) ever follow-up with you?

5. Now let's talk about treatment – how has that gone?

(Note: Patient may not be in treatment, but under surveillance – ask about the process.)

- When and where did you start treatment?
- What happened after that?
- When was that?
- Has treatment been a pretty smooth process? How did that go?
Clarification if needed: So you started/did not start treatment before MD Anderson?
- Under whose care did your treatment begin?

6. What have you discussed about your cancer with your family, friends, or other care givers?

Probes:

- Were they involved in decisions about the course of your care?
- What were their recommendations?
- How did they influence your decisions and/or the process in general?

7. What about the **time** everything took, including when you actually arrived at MDACC?

Probes:

- What about each part of the process from first noticing, to diagnosis, to treatment?
- How long did everything take?

- Did you need to do anything to get things going?
- Was there anything you think that may have made your experience longer than usual, regarding the diagnosis and/or referral?

8. Overall, please tell me your level of satisfaction with care at different points in time.

Date: _____ Interview #: _____

PICTORIAL TIMELINE

Interviewer: _____



