

OMB No. 0925-0766

Expiry Date 4/30/2023

Burden Statement: Public reporting burden for this collection of information is estimated to average 15 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the 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: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0766). Do not return the completed form to this address.

1. Name

* 2. Profession: (Select all that apply)

- Physician
- Dentist
- Advanced Practice Nurse / Physician Assistant
- Nursing
- Patient Care Coordinator
- Laboratory
- Nutrition
- Pharmacy
- Social Work
- Other (please specify)

3. What is your specialty? (ID, Hematology, Transplant, etc...)

4. Are you employed by Institute or the Clinical Center ?

- Institute (Contractors included)
- Clinical Center (Contractors included)

5. Years of experience working in bone marrow transplant

6. Primary Population (select all that apply)

- Pediatrics
- Adults
- Malignant Disease
- Non malignant Disease
- Other (please specify)

7. Where do you see outpatients? (select all that apply)

- Clinic
- Day Hospital
- NA
- Other (please specify)

The next section is divided by body systems and patient concerns that may be reviewed during an outpatient follow-up visit after their 100 day post-transplant visit. Please answer each section of the question with either always, usually rarely, never or N/A. There is also a comment section available to you for each body system and patient concern if you would like to add information to your response.

8. **Immune System:** chimerism, infection risk, vaccinations

	Always	Usually	Rarely	Never	N/A or addressed by consultant
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

9. **Vision:** visual changes and signs of eye GVHD

	Always	Usually	Rarely	Never	N/A or addressed by consultant
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

10. **Oral Care:** Dentition, and signs of oral GVHD

	Always	Usually	Rarely	Never	N/A or addressed by consultant
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

11. **Pulmonary:** smoking cessation, dyspnea, lung function tests, signs of lung GVHD

	Always	Usually	Rarely	Never	N/A or addressed by consultant
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

12. **Cardiovascular:** hypertension, hyperlipidemia, late effects of chemo/ radiation

	Always	Usually	Rarely	Never	N/A or addressed by consultant
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

13. **Liver:** iron overload, LFTs, signs of liver GVHD

	Always	Usually	Rarely	Never	N/A or addressed by consultant
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

14. **Kidneys & Bladder:** urgency, hypertension, AKI, late effects, medications to avoid

	Always	Usually	Rarely	Never	N/A or addressed by consultant
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

15. **Muscles & Joints:** Signs of GVHD, myopathy, muscle strength

	Always	Usually	Rarely	Never	N/A or addressed by consultant
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

16. **Bone Health:** Osteoporosis, fracture risk, physical activity

	Always	Usually	Rarely	Never	N/A or addressed by consultant
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

17. **Skin:** sun exposure, self exam for skin cancer, signs of skin GVHD

	Always	Usually	Rarely	Never	N/A or addressed by consultant
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

18. **Nervous System:** neuropathy, long-term neurological conditions

	Always	Usually	Rarely	Never	N/A or addressed by consultant
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

19. **Endocrine:** diabetic care and management, thyroid, growth and pubescent development in children, sex hormones in adolescents and adults

	Always	Usually	Rarely	Never	N/A or addressed by consultant
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

20. **Genitals, Sexual Health and Physical Intimacy:** signs of genital GVHD, libido, relationships

	Always	Usually	Rarely	Never	N/A or addressed by consultant
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

21. **Fertility and Family Planning:** access to fertility services or banked egg or sperm, contraception if applicable

	Always	Usually	Rarely	Never	N/A or addressed by consultant
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

22. **Diet and Nutrition:** Obesity, gastrointestinal signs of GVHD, failure to thrive

	Always	Usually	Rarely	Never	N/A or addressed by consultant
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

23. **General Health:** Connection to home physician, navigation of care, health literacy

	Always	Usually	Rarely	Never	N/A
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

24. **Secondary Malignancies:** prevention screenings

	Always	Usually	Rarely	Never	N/A
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

25. **Sleep and fatigue:** Insomnia, excessive sleep, sleep hygiene

	Always	Usually	Rarely	Never	N/A
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

26. **Cognitive Deficits:** Memory, concentration, decision making, executive functioning skills

	Always	Usually	Rarely	Never	N/A
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

27. Emotional Health and Wellbeing: body image, depression, anxiety, suicide risk, motivation, post traumatic stress symptoms

	Always	Usually	Rarely	Never	N/A
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

28. Physical Activity and Exercise: Development or modifications to exercise regimens

	Always	Usually	Rarely	Never	N/A
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

29. **Vocational Rehab and Returning to Work or School:** goal setting, shifting from sick role to goals for future

	Always	Usually	Rarely	Never	N/A
Do you currently address this in outpatient follow-up visits?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Are you comfortable addressing this topic area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Would you like your patients to have additional education about this topic or receive a referral to a Clinical Center or community resource?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

30. Are you interested in joining a work group to develop patient education and resources for topic area?

	Yes	No
Immune System: chimerism, infection risk, vaccinations	<input type="radio"/>	<input type="radio"/>
Comments:	<input type="text"/>	
Vision: visual changes and signs of eye GVHD	<input type="radio"/>	<input type="radio"/>
Comments:	<input type="text"/>	
Oral Care: dentition and signs of oral GVHD	<input type="radio"/>	<input type="radio"/>
Comments:	<input type="text"/>	
Pulmonary: smoking cessation, dyspnea, function tests, signs of lung GVHD	<input type="radio"/>	<input type="radio"/>
Comments:	<input type="text"/>	
Cardiovascular: hypertension, hyperlipidemia, late effects from chemo/radiation	<input type="radio"/>	<input type="radio"/>
Comments:	<input type="text"/>	
Liver: iron overload, LFTs, signs of liver GVHD	<input type="radio"/>	<input type="radio"/>

Yes

No

Comments:

Kidneys and Bladder: hypertension, AKI, late effects, medications to avoid

Comments:

Muscles and Joints: signs of GVHD, myopathy, muscle strength, Rheumatology

Comments:

Bone Health: osteoporosis, DEXA, physical activity

Comments:

Skin: sun exposure, self exam for skin cancer, signs of skin GVHD

Comments:

Nervous System: neuropathy, long-term neurological conditions

Comments:

Endocrine: diabetic care and management, thyroid, growth and sex hormones

Comments:

Genitals, Sexual Health, and Physical Intimacy

Comments:

Fertility and Family Planning: Access to fertility services or banked egg or sperm

Comments:

Emotional Health and Wellbeing: body image, depression, anxiety, suicide risk, motivation, post-traumatic stress symptoms

Yes

No

Comments:

Diet and Nutrition: obesity, issues related to GVHD, failure to thrive

Comments:

General Health: connection to home Physician, navigation of care, health literacy

Comments:

Secondary Malignancies: prevention screenings

Comments:

Fatigue

Comments:

Sleep: Insomnia, excessive sleep, sleep hygiene

Comments:

Cognitive Deficits: memory, concentration, decision making, executive functioning skills

Comments:

Physical Activity and Exercise: development or modifications to exercise regimen

Comments:

Vocational Rehab and Return to Work or School: shifting from sick role to development of goals for the future

Comments:



