| Question Number | Information Needed | Question                                                                 | Analyses Notes | Variable Name(s) | Skip Logic                                                                 | Programming Notes |
|-----------------|--------------------|---------------------------------------------------------------------------|----------------|------------------|-----------------------------------------------------------------------------|-------------------|
| 1               | Prescreen multiple myeloma patients in the United States or unknown location. [Screen all new patients to PLM via ad recruiting] | Where do you live?  
1. United States  
0. Outside the United States | country          | -If response is 0 United States → screen out, end survey                  |                 |
| 2               | How old are you (in years)? Numeric | How old are you (in years)? Numeric | age            | -If response <18 years → screen out, end survey                            |                 |
| 3               | Have you been diagnosed with amyloidosis by a physician or healthcare provider?  
1. Yes  
0. No | Have you been diagnosed with amyloidosis by a physician or healthcare provider?  
1. Yes  
0. No | amyloidosis       | -If response is 1 → screen out, end survey                                |                 |
| 4               | Have you been diagnosed with Multiple Myeloma by a physician or healthcare provider?  
1. Yes  
0. No | Have you been diagnosed with Multiple Myeloma by a physician or healthcare provider?  
1. Yes  
0. No | diagnosis         | - If response is 0 → screen out, end survey                              |                 |
| 5 | In the last 5 years, have you been diagnosed with and treated for any other cancer (other than Multiple Myeloma)?  
1. Yes  
0. No | other_cancer | - If response is 1 → screen out, end survey |
|---|---|---|---|
| 6 | There are many ways to treat multiple myeloma and its symptoms. We would like you to focus on those treatments or treatment regimens that you have taken to **treat the multiple myeloma itself** (such as stem cell transplants, medications, or combinations of medications) and not those treatments that you might have taken to help address any symptoms or complications such as bone problems, pain, nausea, vomiting, blood clots, or anemia.  
Which of the following best describes your history with multiple myeloma treatment(s)?  
1. I have never received treatment or I have not yet started treatment for my multiple myeloma.  
2. I am receiving treatment for multiple myeloma.  
3. I received treatment for my multiple myeloma before, but I am not on treatment now. | tx_status | - If response is 1 → skip to demographics then show NDx thank you after completion  
-If response is 3 → skip to demographics |
| 7 | How many times has the **return or progression of your multiple myeloma meant you had to** change and/or restart your multiple myeloma medication? Please indicate the number of times below in **numeric form**. If medication changes have always been for other reasons, such as side effects or cost, please answer '0'. | progressions | - If response is 0 → ND end of study message, else RR end of study message |
# Module 2a: Multiple Myeloma Treatment

Now we'll ask you a few questions about how you treat your multiple myeloma.

| Question | Options |
|----------|---------|
| 8 How are you receiving your multiple myeloma medication(s)? We would like you to focus on those treatments or treatment regimens that you are taking to **treat the multiple myeloma itself** (such as medications, or combinations of medications) and not those treatments that you might be taking to help address any symptoms or complications such as bone problems, pain, nausea, vomiting, blood clots, or anemia. | 1. I only take medications by mouth (oral) 2. I only receive injections (either under the skin [subcutaneous] or in a vein [intravenous]) 3. I receive medications both by mouth (oral) and by injections (either under the skin [subcutaneous] or in a vein [intravenous]) 4. None of the above [exclusive option] |

- If response is 1 then turn on → oral_meds
- If response is 2 then turn on → inject_meds
- If response is 3 → turn on module with oral_meds and inject_meds
- If response is 4 [none] → skip to SCT and then skip to demographics

| 9 You stated that you take medications by mouth (oral). Which of these oral medications are you taking to treat your multiple myeloma? Please select all that apply. | oral_meds |
|-----------------------------------------------|-----------|
| 1. Cyclophosphamide (Cytoxan) 2. Dexamethasone (Decadron, Baycador) 3. Etoposide (Toposar) 4. Ixazomib (Ninlaro) 5. Lenalidomide (Revlimid) 6. Melphalan (Alkeran, Evomela) 7. Panobinostat (Farydak) 8. Pomalidomide (Pomalyst) | If resp for tx_roa → only oral → then jump to prior_tx |
9. Prednisone (Deltasone, Rayos)
10. Thalidomide (Thalomid)
11. Vorinostat (Zolinza)
   -98. I don’t know
   -1: Other

You stated that you receive medication by injection. Which of these injectable (either under the skin [subcutaneous] or in a vein [intravenous]) medications are you taking to treat your multiple myeloma? Please select all that apply.
1. Bendamustine (Bendeka, Treanda)
2. Bortezomib (Velcade)
3. Carfilzomib (Kyprolis)
4. Cisplatin (Platinol-AQ, Platinol)
5. Daratumumab (Darzalex)
6. Doxorubicin (Adriamycin, Doxil)
7. Elotuzumab (Empliciti)
8. Etoposide (Toposar)
9. Interferon (Intron A)
10. Melphalan (Alkeran, Evomela)
11. Vincristine (Vincasar PFS)
   -98. I don’t know
   -1: Other
11 | Did you receive any medications for multiple myeloma before the medications you are taking now? We would like you to focus on those treatments or treatment regimens that you have taken to treat the multiple myeloma itself (such as medications, or combinations of medications) and not those treatments that you might have taken to help address any symptoms or complications such as bone problems, pain, nausea, vomiting, blood clots, or anemia.

1. I only took those medications by mouth (oral)
2. I only received those medications via injections (either under the skin [subcutaneous] or in a vein [intravenous])
3. I received these medications both by mouth (oral) and by injection (either under the skin [subcutaneous] or in a vein [intravenous])
4. I did not receive any medications before [exclusive option]

prior_tx | - If response is 4 → skip to sct_ever

12 | Continuing to think about the multiple myeloma medication(s) you received right before your current treatment regimen, when did you stop taking these medication(s)?

1. Within the past 2 months
2. 2 months to 6 months
3. 6 months to 12 months
4. More than 12 months ago

prior_when
Modula 2b: SCT Module

| Question | Response Options | Module | Notes |
|----------|------------------|--------|-------|
| 13       | Have you ever had a stem cell transplant for your multiple myeloma? | 0. Never, 1. Yes, within the past 2 months, 2. Yes, more than 2 months but within 6 months ago, 3. Yes, more than 6 months ago | SCT | If resp for tx_roa includes “none of the above” turn off all modules except “demographics” |

Module 3: Treatment Satisfaction

In the next few questions we’ll ask you questions about your current medication.

| Question | TSQM – 9 (9 questions) | VALIDATED MEASURE | TSQM_instructions |
|----------|-------------------------|-------------------|------------------|
| 14       | How satisfied or dissatisfied are you with the ability of your multiple myeloma medication to prevent or treat your condition? | TSQM_1 | https://www.ncbi.nlm.nih.gov/pubmed/16336491 |
| 2 | Very Dissatisfied |
|---|-------------------|
| 3 | Dissatisfied      |
| 4 | Somewhat Satisfied|
| 5 | Satisfied         |
| 6 | Very Satisfied    |
| 7 | Extremely Satisfied|

| 15 | How satisfied or dissatisfied are you with the way your *multiple myeloma medication* relieves your symptoms? |
|----|----------------------------------------------------------------------------------------------------------------------------------|
| 1  | Extremely Dissatisfied  |
| 2  | Very Dissatisfied      |
| 3  | Dissatisfied           |
| 4  | Somewhat Satisfied     |
| 5  | Satisfied              |
| 6  | Very Satisfied         |
| 7  | Extremely Satisfied    |

| 16 | How satisfied or dissatisfied are you with the amount of time it takes your *multiple myeloma medication* to start working? |
|----|----------------------------------------------------------------------------------------------------------------------------------|
| 1  | Extremely Dissatisfied  |
| 2  | Very Dissatisfied      |
| 3  | Dissatisfied           |
| 4  | Somewhat Satisfied     |
| 5  | Satisfied              |
| 6  | Very Satisfied         |
| 7  | Extremely Satisfied    |

Convenience
|   | Question                                                                 | TSQM   |
|---|--------------------------------------------------------------------------|--------|
| 17| How easy or difficult is it to use your **multiple myeloma medication** in its current form? |
|   | 1  Extremely Difficult                                                   |        |
|   | 2  Very Difficult                                                        |        |
|   | 3  Difficult                                                            |        |
|   | 4  Somewhat Easy                                                         |        |
|   | 5  Easy                                                                  |        |
|   | 6  Very Easy                                                            |        |
|   | 7  Extremely Easy                                                        |        |
| 18| How easy or difficult is it to plan when you will use your **multiple myeloma medication** each time? |
|   | 1  Extremely Difficult                                                   |        |
|   | 2  Very Difficult                                                        |        |
|   | 3  Difficult                                                            |        |
|   | 4  Somewhat Easy                                                         |        |
|   | 5  Easy                                                                  |        |
|   | 6  Very Easy                                                            |        |
|   | 7  Extremely Easy                                                        |        |
| 19| How convenient or inconvenient is it to take your **multiple myeloma medication** as instructed? |
|   | 1  Extremely Inconvenient                                                |        |
|   | 2  Very Inconvenient                                                     |        |
|   | 3  Inconvenient                                                         |        |
|   | 4  Somewhat Convenient                                                   |        |
|   | 5  Convenient                                                           |        |
|   | 6  Very Convenient                                                      |        |
|   | 7  Extremely Convenient                                                  |        |

Global Satisfaction
| 20 | Overall, how confident are you that taking your **multiple myeloma medication** is a good thing for you?  
1 Not at All Confident  
2 A Little Confident  
3 Somewhat Confident  
4 Very Confident  
5 Extremely Confident | TSQM_7 |
|---|---|---|
| 21 | How certain are you that the good things about your **multiple myeloma medication** outweigh the bad things?  
1 Not at All Certain  
2 A Little Certain  
3 Somewhat Certain  
4 Very Certain  
5 Extremely Certain | TSQM_8 |
| 22 | Taking all things into account, how satisfied or dissatisfied are you with your **multiple myeloma medication**?  
1 Extremely Dissatisfied  
2 Very Dissatisfied  
3 Dissatisfied  
4 Somewhat Satisfied  
5 Satisfied  
6 Very Satisfied  
7 Extremely Satisfied | TSQM_9 |

**Module 4: Medication Adherence**  
Next, we’d like to ask you about your experience remembering to take your medicine.  

When thinking of answers to the following 4 questions please think about the medication you are **currently** taking to treat your multiple myeloma.
| 23 | Do you ever forget to take your **multiple myeloma medication**?  
1. Yes  
0. No | **VALIDATED MEASURE**  
[Morisky Medication Adherence Scale – 4] | forget |
| 24 | Do you ever have problems remembering to take your **multiple myeloma medication**?  
1. Yes  
0. No | | miss |
| 25 | When you feel better, do you sometimes stop taking your **multiple myeloma medication**?  
1. Yes  
0. No | | cut_back |
| 26 | Sometimes if you feel worse when you take your **multiple myeloma medication**, do you stop taking it?  
1. Yes  
0. No | | stop_symptoms |

**Module 5: Adjustment to Illness (Multiple Myeloma)**  
These next questions are about how your multiple myeloma impacts your work productivity and daily activity.

| 27 | Are you currently employed (working for pay)?  
1. Yes  
0. No | **VALIDATED MEASURE**  
WPAI_1 | - If response is 0 [no]  
→ skip to annual_visits |
| 28 | The next questions are about the past **seven days**, not including today.  
During the past seven days, how many hours | WPAI_2 |
|   | Question                                                                 | Response | WPAI Code |
|---|--------------------------------------------------------------------------|----------|-----------|
| 29 | During the past seven days, how many hours did you miss from work because of any other reason, such as vacation and holidays. | [numeric] | WPAI_3    |
| 30 | During the past seven days, how many hours did you actually work?       | [numeric] | WPAI_4    |
| 31 | During the past seven days, how much did your multiple myeloma affect your productivity while you were working? | [numeric] | WPAI_5    |

*Include hours you missed on sick days, times you went in late, left early, etc. because of your multiple myeloma.*
| 0. 0 (Multiple myeloma had no effect on my work) |
|-----------------------------------------------|
| 1. 1                                           |
| 2. 2                                           |
| 3. 3                                           |
| 4. 4                                           |
| 5. 5                                           |
| 6. 6                                           |
| 7. 7                                           |
| 8. 8                                           |
| 9. 9                                           |
| 10. 10 (multiple myeloma completely prevented me from working) |

| 32 |
|----|
| During the past seven days, how much did your multiple myeloma affect your ability to do your regular daily activities, other than work at a job? |
| By regular activities, we mean the usual activities you do, such as work around the house, shopping, childcare, exercising, studying, etc. Think about times you were limited in the amount or kind of activities you could do and times you accomplished less than you would like. If multiple myeloma affected your activities only a little, choose a low number. Choose a high number if multiple myeloma affected your activities a great deal. |
| Consider only how much multiple myeloma affected your ability to do your regular daily activities, other than work at a job. |
| 0. 0 (Multiple myeloma had no effect on my work) |
| WPAI_6 |
10. 10 (multiple myeloma completely prevented me from doing my daily activities.)

**Module 6: Burden of Multiple Myeloma Management**
Now we'll ask you more about the burden of managing your multiple myeloma.

| Question                                                                 | Code       | Response Options                                                                 |
|--------------------------------------------------------------------------|------------|----------------------------------------------------------------------------------|
| In the past 1 month, how many times did you visit your doctor's office, clinic, or infusion center to receive **multiple myeloma medication**? There are many ways to treat multiple myeloma and its symptoms. We would like you to focus on those treatments or treatment regimens that you have taken to **treat the multiple myeloma itself** (medications, or combinations of medications) and not those treatments that you might have taken to help address any symptoms or complications such as bone problems, pain, nausea, vomiting, blood clots, or anemia. | annual_visits | Numeric |
| How do you usually get to your doctor's office, clinic, or infusion center to receive your multiple myeloma medication? | travel_how | If resp is 3 or 4 skip to distance |
1. I drive myself
2. Someone else drives me
3. I use public transportation
4. I take a taxi or rideshare (e.g., Uber)

| Question                                                                 | Answer |
|--------------------------------------------------------------------------|--------|
| 35 You said you drive to your doctor’s office or clinic, how much do you | park_cost |
| have to pay (in dollars), on average, for parking? [numeric, $$] -97      |        |
| Prefer not to respond -98 I don’t know                                  |        |
| 36 How long does it take you to travel (in minutes) from where you live  | distance |
| to the doctor’s office, clinic, or infusion center where you receive    |        |
| your multiple myeloma treatment? (a one-way trip) [numeric, min]         |        |
| 37 How many miles do you live from the doctor’s office, clinic, or      | miles  |
| infusion center where you receive your multiple myeloma treatment? (a   |        |
| one-way trip) [numeric, miles]                                           |        |
| 38 In the past month, what was the average time (in minutes) you spent  | average_time |
| in your doctor’s office, clinic or infusion center each time or at each |        |
| visit when you were receiving your multiple myeloma medication? (including |
| waiting time) [numeric]                                                 |        |
| 39 What is the cost you pay out-of-pocket (in dollars) on average for    | copay  |
| copays for visits to                                                     |        |
your doctor’s office, clinic or infusion center for multiple myeloma treatment? (excluding copays for medications) [Numeric, $$] -97 Prefer not to respond -98 I don’t know

| 40 | In the past month, how many times did a caregiver accompany you to your multiple myeloma treatment visits? [Numeric] | caregiver |

**Module 7: Groningen Frailty Index**

| 41-44 | Are you able to carry out these tasks single-handed without any help? (The use of aids such as a walking stick, walking frame, wheelchair, is considered as independent)  
1 Shopping,  
2 Walking around outside (around the house or to the neighbors)  
3 Dressing and undressing  
4 Going to the toilet  
Independent= 0; dependent= 1 | **VALIDATED MEASURE** [file:///C:/Users/Pronabesh/Desktop/For%20export/PLM_Stats/Takeda%20Multiple%20Myeloma/Documentation/Materials%20from%20Takeda/Groningen%20Frailty%20Indicator%20and%20the%20G8%20questionnaire%20for%20frailty%20in%20cancer_2012.pdf] | tasks |

| 45 | What score do you give yourself for physical fitness? (scale 0 (worst) to 10(best)) | fitness |
|   | Question                                                                 | Response Options | Category         |
|---|--------------------------------------------------------------------------|------------------|------------------|
| 46 | Do you experience problems in daily life due to poor vision?             | No= 0; Yes= 1    | vision           |
| 47 | Do you experience problems in daily life due to poor hearing?            | No= 0; Yes= 1    | hearing          |
| 48 | During the last 6 months, have you lost a lot of weight unwillingly? (more than 13 pounds in 6 months or more than 6.5 pounds in 1 month) | No= 0; Yes= 1    | weight_loss      |
| 49 | Do you take 4 or more different types of medicine?                       | No= 0; Yes= 1    | meds             |
| 50 | Do you have any complaints about your memory?                            | No = 0; Yes = 1; sometimes=2 | memory |
| 51 | Do you sometimes experience an emptiness around you?                     | No= 0; yes= 1; sometimes=2 | emptiness        |
| 52 | Do you sometimes miss people around you?                                 | No= 0; yes= 1; sometimes=2 | Miss_fragility   |
| 53 | Do you sometimes have the feeling of being left alone?                   | No= 0; yes= 1; sometimes=2 | alone            |
| 54 | Have you recently felt downhearted or sad?                               | No= 0; yes= 1; sometimes=2 | sad              |
| Question | Description | Possible Responses | Notes |
|----------|-------------|-------------------|-------|
| 55       | Have you recently felt nervous or anxious? | No= 0; yes= 1; sometimes=2 | Sometimes is same as yes anxious |
| 56       | Why are you not receiving treatment for your multiple myeloma now? | 1. My healthcare provider advised me not to take multiple myeloma treatment due to other health issues 2. My healthcare provider advised me to take multiple myeloma treatment but I decided not to 3. My healthcare provider thinks my multiple myeloma is under control (in remission) and I do not need treatment now 3. I have been recently diagnosed and have not begun treatment yet -1. Other (fill in the blank) | why_no_rx Show only for response 1 and 3 in Q6 or if resp to Q8 is 4 |
| 57       | Why did your healthcare provider advise not to take multiple myeloma treatment? Please select all that apply | 1. I am too frail 2. I have other medical comorbidities 3. Because of my age -1. Other (fill in the blank) | Why_hcp_no_tr eat If 1 on Q 56 |
| 58       | Why did you decide not to take multiple myeloma treatment? Please select all that apply | 1. I do not have insurance 2. I have insurance, but the cost of multiple myeloma medications is too expensive 3. I live too far from the treatment center 4. I do not have a caregiver to help me 5. I am not able to take time off work 6. I do not think multiple myeloma treatment | Why_you_no_tr eat If 2 on Q 56 |
| 59 | What is your sex?  
1. Male  
2. Female  
-97. Prefer not to respond | sex |
|---|---|
| 60 | What ethnicity do you consider yourself to be?  
1. Not Hispanic or Latino  
2. Hispanic or Latino  
-97. I Prefer to skip | ethnicity |
| 61 | What race do you consider yourself to be?  
1. White  
2. Black or African American  
3. Asian  
4. Native Hawaiian or other Pacific Islander  
5. American Indian or Alaskan Native  
6. Mixed race  
-97. I prefer to skip | race |
| 62 | What type of insurance do you have for medical services (doctor/clinic visits, | insurance |
hospitalizations)? (Select all that apply)
1. Commercial/Private Insurance
2. Medicaid
3. Medicare
4. Military Health Insurance (Veterans Affairs, Champus, Tri-care)
5. Indian Health Service
6. Not Insured
   -98: I don't know
   -99: Does not apply
   -97: I prefer to skip

63 | What type of insurance do you have for your prescriptions? Please select all that apply.
   | 1. Commercial/Private Insurance
   | 2. Medicaid
   | 3. Medicare
   | 4. Military Health Insurance (Veterans Affairs, Champus, Tri-care)
   | 5. Indian Health Service
   | 6. Not Insured
   | -98: I don't know
   | -99: Does not apply
   | -97: I prefer to skip
   | Insurance_rx

64 | What best describes your current living situation?
   | 1. I live alone
   | 2. I live with my spouse
   | 4. I live with at least one other adult
   | 5. I live only with young children
   | 6. I live in an assisted living facility or nursing home
   | housing

65 | What best describes your current
   | employment_p
|   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|
| employment status? |   |   |   |   |   | erf |
| 1. Employed full-time (≥ 35 hours) |   |   |   |   |   |   |
| 2. Employed part-time (<35 hours) |   |   |   |   |   |   |
| 3. Self-employed |   |   |   |   |   |   |
| 4. Student |   |   |   |   |   |   |
| 5. Homemaker |   |   |   |   |   |   |
| 6. Retired |   |   |   |   |   |   |
| 7. Medically unable to work |   |   |   |   |   |   |
| What is your highest level of education? |   |   |   | education |   |   |
| 1. 8th grade or less |   |   |   |   |   |   |
| 2. Some high school, but did not graduate |   |   |   |   |   |   |
| 3. High school graduate or GED |   |   |   |   |   |   |
| 4. Some college but less than a bachelor's/undergraduate degree |   |   |   |   |   |   |
| 5. College bachelor's/undergraduate degree |   |   |   |   |   |   |
| 6. Postgraduate degree (Master’s, doctorate, etc.) |   |   |   |   |   |   |
| -97 I prefer to skip |   |   |   |   |   |   |
| What type of treatment center do you go to for your multiple myeloma treatment? Please select all that apply. |   | treatment_center |   |   |   |
| 1. Academic center or university hospital |   |   |   |   |   |   |
| 2. Community hospital |   |   |   |   |   |   |
| 3. Comprehensive cancer center |   |   |   |   |   |   |
| 4. Community outpatient clinic |   |   |   |   |   |   |
| 5. Other (Please Specify) |   |   |   |   |   |   |
| What State do you live in? |   |   | residence |   |   |   |
| [drop down list of states] |   |   |   |   |   |   |
| -97. I prefer to skip |   |   |   |   |   |   |
| 69 | What is your total household income? | income |
|----|------------------------------------|--------|
| 1. Less than $23,000  
2. $23,000 to $42,999  
3. $43,000 to $69,999  
4. $70,000 to $119,999  
5. $120,000 or more  
-97. Prefer not to respond | VALIDATED MEASURE  
https://www.ncbi.nlm.nih.gov/pubmed/15908666 | physical_status |

| 70 | Would you say you are: | VALIDATED MEASURE  
https://www.ncbi.nlm.nih.gov/pubmed/15908666 |
|----|-----------------------|-----------------------------------------------|
| 1. I am fully active and able to carry out activities the same as before my cancer diagnosis, without any restrictions.  
2. I have difficulty with physically strenuous activity but I am able to walk and carry out work that is light or based in one location; such as light house-work or office-work  
3. I can walk and take care of myself, but I am not able to carry out work activities; I am up and about more than half the hours that I am awake  
4. I am capable only of limited self-care and spend more than half the hours that I am awake in bed or in a chair  
5. I am completely disabled, cannot carry on any self-care, and am totally confined to a bed or chair | |