



The National

Myeodysplastic Syndromes Natural History Study

<sup>1</sup>Baseline BM required, otherwise collected when medically indicated.

<sup>2</sup>Baseline Germline required; 12 and 24 mo optional.

<sup>3</sup>For follow-up visits, current visits occurred + visits missed + visits pending + visits terminated = previous visits occurred + visits missed.

Visit Occurred: Any clinic data, QOL, or specimens collected. Data submitted table includes number of ppts with partial and complete forms/samples.

<u>Visit Pending</u>: No clinic data, QOL, or specimens submitted; no termination forms submitted; next visit within (± 60 days of target date) or ahead of visit window.

Termination: Death, lost to follow-up, consent withdrawn, transplant, or AML.

## Current as of data entered 31AUG2023

| 24 Mo Termination (N=70) |                       |  |
|--------------------------|-----------------------|--|
| Reason                   | N (%) of Terminations |  |
| Endpoint (Death,         | 40 (57%)              |  |
| transplant, AML)         |                       |  |
| Lost to follow-up or     | 30 (43%)              |  |
| withdrawal of consent    |                       |  |

| 24 Mo Visit                  |  |  |
|------------------------------|--|--|
| N (%) of Longitudinal Cohort |  |  |
| 376 (38%)                    |  |  |
| 6                            |  |  |
| 70                           |  |  |
| N (%) of Visits Occurred     |  |  |
| 288 (77%)                    |  |  |
| 228 (61%)                    |  |  |
| 33                           |  |  |
|                              |  |  |
|                              |  |  |

## 30 Mo Termination (N=36) Reason N (%) of Terminations Endpoint (Death, transplant, AML) Lost to follow-up or withdrawal of consent

| 30 Mo Visit               |                              |  |
|---------------------------|------------------------------|--|
| Visit Status <sup>3</sup> | N (%) of Longitudinal Cohort |  |
| Visit Occurred            | 274 (28%)                    |  |
| Visit Missed              | 6                            |  |
| Visit Pending             | 66                           |  |
| Submission Status         | N (%) of Visits Occurred     |  |
| Blood                     | 155 (57%)                    |  |
| Bone Marrow <sup>1</sup>  | 15                           |  |
| Done Mailow               | 15                           |  |

## Reason N (%) of Terminations Endpoint (Death, transplant, AML) Lost to follow-up or withdrawal of consent

| 36 Mo Visit               |                                       |  |
|---------------------------|---------------------------------------|--|
| Visit Status <sup>3</sup> | N (%) of Longitudinal Cohort          |  |
| Visit Occurred            | 204 (21%)                             |  |
| Visit Missed              | 7                                     |  |
| Visit Pending             | 45                                    |  |
|                           |                                       |  |
| Submission Status         | N (%) of Visits Occurred              |  |
| Submission Status<br>QOL  | N (%) of Visits Occurred<br>150 (74%) |  |
|                           |                                       |  |
| QOL                       | 150 (74%)                             |  |

| 42 Mo Termination (N=20) |  |  |
|--------------------------|--|--|
| 5                        |  |  |
|                          |  |  |
|                          |  |  |
|                          |  |  |
|                          |  |  |
|                          |  |  |

| 42 Mo Visit               |                              |
|---------------------------|------------------------------|
| Visit Status <sup>3</sup> | N (%) of Longitudinal Cohort |
| Visit Occurred            | 156 (16%)                    |
| Visit Missed              | 6                            |
| Visit Pending             | 29                           |
| Submission Status         | N (%) of Visits Occurred     |
| QOL                       | 38 (24%)                     |
| Blood                     | 89 (57%)                     |
| Bone Marrow <sup>1</sup>  | 20                           |

## 48 Mo Termination (N=18)

| Reason                | N (%) of Terminations |
|-----------------------|-----------------------|
| Endpoint (Death,      | 11 (61%)              |
| transplant, AML)      |                       |
| Lost to follow-up or  | 7 (39%)               |
| withdrawal of consent |                       |

| 48 Mo Visit               |                              |  |
|---------------------------|------------------------------|--|
| Visit Status <sup>3</sup> | N (%) of Longitudinal Cohort |  |
| Visit Occurred            | 87 (9%)                      |  |
| Visit Missed              | 4                            |  |
| Visit Pending             | 53                           |  |
| Submission Status         | N (%) of Visits Occurred     |  |
| QOL                       | 61 (70%)                     |  |
| Blood                     | 52 (60%)                     |  |
| Bone Marrow <sup>1</sup>  | 5                            |  |

| 54 Mo Termination (N=10)   |   | 54 Mo Visit   |
|--|---|---|
| Reason N (%) of Terminations   | Visit Status <sup>3</sup>   | N (%) of Longitudinal Cohort                          |
| Endpoint (Death, 8 (80%)   | Visit Occurred  | 55 (6%)   |
| transplant, AML)  Lost to follow-up or 2 (20%)   | Visit Missed  | 4   |
| withdrawal of consent  | Visit Pending   | 22  |
|  | Submission Status   | N (%) of Visits Occurred                              |
|  | QOL   | 16 (29%)  |
|  | Blood   | 32 (58%)  |
|  | Bone Marrow <sup>1</sup>  | 4   |
|  |   |   |
|  | 4   | <b>—</b>  |
| 60 Mo Termination (N=2)  | 6   | 60 Mo Visit   |
| Reason N (%) of Terminations   | Visit Status <sup>3</sup>   | N (%) of Longitudinal Cohort                          |
| Endpoint (Death, 1 (50%)   | Visit Occurred  | 35 (4%)   |
| transplant, AML) Lost to follow-up or 1 (50%)  | Visit Missed  | 3   |
| withdrawal of consent  | Visit Pending   | 19  |
|  | Submission Status   | N (%) of Visits Occurred                              |
|  | QOL   | 24 (69%)  |
|  | Blood   | 19 (54%)  |
|  | Bone Marrow <sup>1</sup>  | 1   |
|  |   |   |
|  | 4   | <b></b>   |
| 66 Mo Termination (N=4)  | 6   | 6 Mo Visit  |
| Reason N (%) of Terminations   | Visit Status <sup>3</sup>   | N (%) of Longitudinal Cohort                          |
| Endpoint (Death, 4 (100%)  | Visit Occurred  | 21 (2%)   |
| transplant, AML) Lost to follow-up or 0 (0%)   | Visit Missed  | 1   |
| withdrawal of consent  | Visit Pending   | 12  |
|  | Submission Status   | N (%) of Visits Occurred                              |
|  | QOL   | 3 (14%)   |
|  | Blood   | 12 (57%)  |
|  | Bone Marrow <sup>1</sup>  | 21  |
|  |   |   |
|  | 4   | <del> </del>  |
| 72 Mo Termination (N=1)  | 72  | 2 Mo Visit  |
|  |   |   |
| Reason N (%) of Terminations   | Visit Status <sup>3</sup>   | N (%) of Longitudinal Cohort                          |
| Reason N (%) of Terminations Endpoint (Death, 1 (100%)                                     | Visit Occurred  | N (%) of Longitudinal Cohort<br>16 (2%)               |
| Reason N (%) of Terminations Endpoint (Death, transplant, AML)                             | Visit Occurred Visit Missed   | 16 (2%)   |
| Reason N (%) of Terminations Endpoint (Death, 1 (100%)                                     | Visit Occurred  | 16 (2%)   |
| Reason N (%) of Terminations Endpoint (Death, transplant, AML) Lost to follow-up or 0 (0%) | Visit Occurred Visit Missed   | 16 (2%)   |
| Reason N (%) of Terminations Endpoint (Death, transplant, AML) Lost to follow-up or 0 (0%) | Visit Occurred Visit Missed Visit Pending                             | 16 (2%) 0 5 N (%) of Visits Occurred 8 (50%)          |
| Reason N (%) of Terminations Endpoint (Death, transplant, AML) Lost to follow-up or 0 (0%) | Visit Occurred Visit Missed Visit Pending Submission Status QOL Blood | 16 (2%)<br>0<br>5<br>N (%) of Visits Occurred         |
| Reason N (%) of Terminations Endpoint (Death, transplant, AML) Lost to follow-up or 0 (0%) | Visit Occurred Visit Missed Visit Pending Submission Status QOL       | 16 (2%) 0 5 N (%) of Visits Occurred 8 (50%)          |
| Reason N (%) of Terminations Endpoint (Death, transplant, AML) Lost to follow-up or 0 (0%) | Visit Occurred Visit Missed Visit Pending Submission Status QOL Blood | 16 (2%) 0 5  N (%) of Visits Occurred 8 (50%) 9 (56%) |