# Supplementary Material APPENDIX A. Health sTate Text

For the interviews, the health state letters used throughout this article were changed so that respondents could rank the health states without being biased by the organizational structure implied by the original letters. For example, health state A was renamed as O, and B1 was renamed as J. The letters seen by the respondents are included in parentheses below.

**Health State A: AML (O)**

**Symptoms**

* As a result of your condition, you have **anaemia**. This means your blood cannot carry as much oxygen as it usually does and you feel **very tired and fatigued**.
* You also have **shortness of breath** when exerting yourself (for example, climbing stairs).
* You **sometimes have infections** that cause fever and flu-like symptoms.
* You have **occasional** **nosebleeds**. Any cuts you get bleed more than normal. Your gums bleed when you brush your teeth.

**Impact**

* You are **not able** to work.
* You are **not able** to perform physically strenuous activities like running or walking up several flights of stairs.
* You need to sleep a lot.
* It is **difficult** for you to engage in your routine activities and household tasks.

**Treatment Process**

* You are **not** receiving treatment.

**Health State B1: Remission Following Induction or between Rounds of Consolidation (J)**

**Disease Status**

* You have **previously received treatment**, and now lab tests cannot detect any evidence of disease. You have almost normal levels of healthy blood cells.

**Symptoms**

* You have **mild anaemia**. This means your blood cannot carry as much oxygen as it usually does and you feel **a little** tired and fatigued.
* You **do not have** a fever.
* You **do not have** nosebleeds or gum bleeding. Any cuts heal normally.

**Impact**

* You are **not able** to work.
* You are **not able** to perform physically strenuous activities like running or walking up several flights of stairs.
* You need **more sleep than normal**, but not as much as before you started treatment.
* You can **engage in some** routine activities and household tasks.
* You are **worried** that your disease might come back.

**Treatment Follow-up**

* You have a **catheter**, which is a small tube inserted into a vein in your chest. This allows doctors to draw blood and give you treatment with fewer needle sticks.
* You have to flush the catheter with a saline solution to clean it **3 times each week**. It is covered with a bandage. You change the bandage **once each week**. You have to keep it dry and clean to prevent infection.
* You see your doctor **at least 2 times per month**.

**Health State B2: Durable Remission (e.g., following successful transplant or final round of consolidation) (G)**

**Disease Status**

* You **previously received treatment**, and now lab tests cannot detect any evidence of disease. You have normal levels of healthy blood cells.

**Symptoms**

* You **do not have anaemia**, and you **do not** feel tired or fatigued.
* You **do not have** a fever.
* You **do not have** nosebleeds or gum bleeding. Any cuts heal normally.

**Impact**

* You are **able to work full time**.
* You feel stronger than before you started treatment. You **can perform most** physical activities.
* You can **engage in most** routine activities and household tasks.
* You are **worried** that your disease might come back.

**Treatment Follow-up**

* You have regular follow-up visits with your doctor.

**Health State C1: Induction (7+3) + B1 (L+J)**

**Hospital**

* You stay in hospital for a total of **about** **4 weeks**.

**Treatment Process**

* You have a **catheter**, which is a small tube inserted into a vein in your chest. This allows doctors to draw blood and give you treatment with fewer needle sticks.
* You **receive treatment** by intravenous (IV) infusions into your blood stream through the catheter.
* A first treatment is administered with a **continuous infusion pump for 7 days**. You are connected to this pump **24 hours per day for all 7 days**. The pump is attached to a pole on wheels. **You can walk around the hospital with this pump**.
* A **second treatment** is administered in a **15-minute infusion on days 1, 2 and 3** of the 7 days.

**Side Effects**

* The side effects of this treatment include **complete hair loss** and **risk of infection**.
* This treatment makes you feel **very** fatigued and tired.

**Recovery from Treatment**

* After the week of treatment, you remain in the **hospital** for **3 more weeks** to recover.
* You need **blood transfusions** **about once per week** to give you healthy blood cells and help reduce symptoms. This is administered through the catheter.

*J for the Rest of the Year*

**Disease Status**

* You have **previously received treatment**, and now lab tests cannot detect any evidence of disease. You have almost normal levels of healthy blood cells.

**Symptoms**

* You have **mild anaemia**. This means your blood cannot carry as much oxygen as it usually does and you feel **a little** tired and fatigued.
* You **do not have** a fever.
* You **do not have** nosebleeds or gum bleeding. Any cuts heal normally.

**Impact**

* You are **not able** to work.
* You are **not able** to perform physically strenuous activities like running or walking up several flights of stairs.
* You need **more sleep than normal**, but not as much as before you started treatment.
* You can **engage in some** routine activities and household tasks.
* You are **worried** that your disease might come back.

**Treatment Follow-up**

* You have a **catheter**, which is a small tube inserted into a vein in your chest. This allows doctors to draw blood and give you treatment with fewer needle sticks.
* You have to flush the catheter with a saline solution to clean it **3 times each week**. It is covered with a bandage. You change the bandage **once each week**. You have to keep it dry and clean to prevent infection.
* You see your doctor **at least 2 times per month**.

**Timeline**



**Health State C2: Induction (Vyxeos) + B1 (I+J)**

**Hospital**

* You stay in hospital for a total of **about 5 weeks**.

**Treatment Process**

* You have a **catheter**, which is a small tube inserted into a vein in your chest. This allows doctors to draw blood and give you treatment with fewer needle sticks.
* You **receive treatment** by intravenous (IV) infusions into your blood stream through the catheter.
* The treatment is administered with an infusion pump in a **90 minute infusion on days 1, 3, and 5**. Other than these three 90-minute periods, you are not connected to the infusion pump, and you can **move around freely**.

**Side Effects**

* The side effects of treatment include **thinning hair** and **risk of infection**.
* This treatment makes you feel **a little** fatigued and tired.

**Recovery From Treatment**

* After the week of treatment you remain in the **hospital** for about **4 more weeks** to recover.
* You need **blood transfusions** **about once per week** to give you healthy blood cells and help reduce symptoms. This is administered through the catheter.

*J for the Rest of the Year*

**Disease Status**

* You have **previously received treatment**, and now lab tests cannot detect any evidence of disease. You have almost normal levels of healthy blood cells.

**Symptoms**

* You have **mild anaemia**. This means your blood cannot carry as much oxygen as it usually does and you feel **a little** tired and fatigued.
* You **do not have** a fever.
* You **do not have** nosebleeds or gum bleeding. Any cuts heal normally.

**Impact**

* You are **not able** to work.
* You are **not able** to perform physically strenuous activities like running or walking up several flights of stairs.
* You need **more sleep than normal**, but not as much as before you started treatment.
* You can **engage in some** routine activities and household tasks.
* You are **worried** that your disease might come back.

**Treatment Catheter**

* You have a **catheter**, which is a small tube inserted into a vein in your chest. This allows doctors to draw blood and give you treatment with fewer needle sticks.
* You have to flush the catheter with a saline solution to clean it **3 times each week**. It is covered with a bandage. You change the bandage **once each week**. You have to keep it dry and clean to prevent infection.
* You see your doctor **at least 2 times per month**.

**Timeline**



**Health State D1: Consolidation (5+2) + B1 (K+J)**

**Hospital**

* You stay in hospital for **about 1 week**.

**Treatment Process**

* You have a **catheter**, which is a small tube inserted into a vein in your chest. This allows doctors to draw blood and give you treatment with fewer needle sticks.
* You **receive treatment** by intravenous (IV) infusions into your blood stream through the catheter.
* A first treatment is administered with **a continuous infusion pump for five days**. You are connected to this pump **24 hours per day for all five days**. The pump is attached to a pole on wheels. **You can walk around the hospital with this pump**.
* A **second treatment** is administered in a **15-minute infusion on days 1 and 2** of the 5 days.

**Side Effects**

* The side effects of this treatment include **complete hair loss** and **risk of infection**.
* This treatment makes you feel **very** fatigued and tired.

**Recovery From Treatment**

* After the week in hospital, you go home. For **2 weeks**, you attend outpatient follow-up appointments twice per week for physical exams and blood draws to check your blood counts.
* You also need **blood transfusions** **about once per week** to give you healthy blood cells and help reduce symptoms. This is administered through the catheter.

*J for the Rest of the Year*

**Disease Status**

* You have **previously received treatment**, and now lab tests cannot detect any evidence of disease. You have almost normal levels of healthy blood cells.

**Symptoms**

* You have **mild anaemia**. This means your blood cannot carry as much oxygen as it usually does and you feel **a little** tired and fatigued.
* You **do not have** a fever.
* You **do not have** nosebleeds or gum bleeding. Any cuts heal normally.

**Impact**

* You are **not able** to work.
* You are **not able** to perform physically strenuous activities like running or walking up several flights of stairs.
* You need **more sleep than normal**, but not as much as before you started treatment.
* You can **engage in some** routine activities and household tasks.
* You are **worried** that your disease might come back.

**Treatment Follow-up**

* You have a **catheter**, which is a small tube inserted into a vein in your chest. This allows doctors to draw blood and give you treatment with fewer needle sticks.
* You have to flush the catheter with a saline solution to clean it **3 times each week**. It is covered with a bandage. You change the bandage **once each week**. You have to keep it dry and clean to prevent infection.
* You see your doctor **at least 2 times per month**.

**Timeline**

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**Health State D2: Consolidation (HiDAC) + B1 (R+J)**

**Hospital**

* You stay in hospital for **about 1 week**.

**Treatment Process**

* You have a **catheter**, which is a small tube inserted into a vein in your chest. This allows doctors to draw blood and give you treatment with fewer needle sticks.
* You **receive treatment** by intravenous (IV) infusions into your blood stream through the catheter.
* The treatment is administered with an **infusion pump in a 4-hour infusion, twice each day on days 1, 3, and 5**. Other than these six 4-hour periods, you are not connected to the infusion pump, and you can **move around freely**.

**Side Effects**

* The side effects of treatment include **thinning hair** and **risk of infection**.
* This treatment makes you feel **very** fatigued and tired.

**Recovery From Treatment**

* After the week in hospital, you go home. For **2 weeks**, you attend outpatient follow-up appointments twice per week for physical exams and blood draws to check your blood counts.
* You also need **blood transfusions** **about once per week** to give you healthy blood cells and help reduce symptoms. This is administered through the catheter.

*J for the Rest of the Year*

**Disease Status**

* You have **previously received treatment**, and now lab tests cannot detect any evidence of disease. You have almost normal levels of healthy blood cells.

**Symptoms**

* You have **mild anaemia**. This means your blood cannot carry as much oxygen as it usually does and you feel **a little** tired and fatigued.
* You **do not have** a fever.
* You **do not have** nosebleeds or gum bleeding. Any cuts heal normally.

**Impact**

* You are **not able** to work.
* You are **not able** to perform physically strenuous activities like running or walking up several flights of stairs.
* You need **more sleep than normal**, but not as much as before you started treatment.
* You can **engage in some** routine activities and household tasks.
* You are **worried** that your disease might come back.

**Treatment Follow-up**

* You have a **catheter**, which is a small tube inserted into a vein in your chest. This allows doctors to draw blood and give you treatment with fewer needle sticks.
* You have to flush the catheter with a saline solution to clean it **3 times each week**. It is covered with a bandage. You change the bandage **once each week**. You have to keep it dry and clean to prevent infection.
* You see your doctor **at least 2 times per month**.

**Timeline**



**Health State D3: Consolidation (Vyxeos inpatient) + B1 (H+J)**

**Hospital**

* You stay in hospital for **about 1 week**.

**Treatment Process**

* You have a **catheter**, which is a small tube inserted into a vein in your chest. This allows doctors to draw blood and give you treatment with fewer needle sticks.
* You **receive treatment** by intravenous (IV) infusions into your blood stream through the catheter.
* The treatment is administered with an **infusion pump in a 90-minute infusion on days 1 and 3**. Other than these two 90-minute periods, you are not connected to the infusion pump, and you can **move around freely**.

**Side Effects**

* The side effects of treatment include **thinning hair** and **risk of infection**.
* This treatment makes you feel **a little** fatigued and tired.

**Recovery From Treatment**

* After the week in hospital, you go home. For **3 weeks**, you attend outpatient follow-up appointments twice per week for physical exams and blood draws to check your blood counts.
* You also need **blood transfusions** **about once per week** to give you healthy blood cells and help reduce symptoms. This is administered through the catheter.

*J for the Rest of the Year*

**Disease Status**

* You have **previously received treatment**, and now lab tests cannot detect any evidence of disease. You have almost normal levels of healthy blood cells.

**Symptoms**

* You have **mild anaemia**. This means your blood cannot carry as much oxygen as it usually does and you feel **a little** tired and fatigued.
* You **do not** **have** a fever.
* You **do not have** nosebleeds or gum bleeding. Any cuts heal normally.

**Impact**

* You are **not able** to work.
* You are **not able** to perform physically strenuous activities like running or walking up several flights of stairs.
* You need **more sleep than normal**, but not as much as before you started treatment.
* You can **engage in some** routine activities and household tasks.
* You are **worried** that your disease might come back.

**Treatment Follow-up**

* You have a **catheter**, which is a small tube inserted into a vein in your chest. This allows doctors to draw blood and give you treatment with fewer needle sticks.
* You have to flush the catheter with a saline solution to clean it **3 times each week**. It is covered with a bandage. You change the bandage **once each week**. You have to keep it dry and clean to prevent infection.
* You see your doctor **at least 2 times per month**.

**Timeline**

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**Health State D4: Consolidation (Vyxeos outpatient) + B1 (M+J)**

**Hospital**

* You **do not stay in hospital**.

**Treatment Process**

* You receive this treatment at an **outpatient clinic**.
* You have a **catheter**, which is a small tube inserted into a vein in your chest. This allows doctors to draw blood and give you treatment with fewer needle sticks.
* You **receive treatment** by intravenous (IV) infusions into your blood stream through the catheter.
* The treatment is administered with an infusion pump in a **90-minute infusion on days 1 and 3**. Other than these two 90-minute periods, you are not connected to the infusion pump, and you can **move around freely**.

**Side Effects**

* The side effects of treatment include **thinning hair** and **risk of infection**.
* This treatment makes you feel **a little** fatigued and tired.

**Recovery From Treatment**

* After completing this treatment, you gradually recover **at home** over a period of **three weeks**.
* During this time, you attend outpatient follow-up appointments twice per week for physical exams and blood draws to check your blood counts.
* You also need **blood transfusions** **about once per week** to give you healthy blood cells and help reduce symptoms. This is administered through the catheter.

*J for the Rest of the Year*

**Disease Status**

* You have **previously received treatment**, and now lab tests cannot detect any evidence of disease. You have almost normal levels of healthy blood cells.

**Symptoms**

* You have **mild anaemia**. This means your blood cannot carry as much oxygen as it usually does and you feel **a little** tired and fatigued.
* You **do not have** a fever.
* You **do not have** nosebleeds or gum bleeding. Any cuts heal normally.

**Impact**

* You are **not able** to work.
* You are **not able** to perform physically strenuous activities like running or walking up several flights of stairs.
* You need **more sleep than normal**, but not as much as before you started treatment.
* You can **engage in some** routine activities and household tasks.
* You are **worried** that your disease might come back.

**Treatment Follow-up**

* You have a **catheter**, which is a small tube inserted into a vein in your chest. This allows doctors to draw blood and give you treatment with fewer needle sticks.
* You have to flush the catheter with a saline solution to clean it **3 times each week**. It is covered with a bandage. You change the bandage **once each week**. You have to keep it dry and clean to prevent infection.
* You see your doctor **at least 2 times per month**.

**Timeline**

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**Health State E1. Best Supportive Care (N)**

**Disease Status**

* Previous treatments have not worked for you.
* You receive ongoing treatment in an **outpatient facility** to manage your symptoms. You return home after each treatment.

**Symptoms**

* As a result of your condition, you have **anaemia**. This means your blood cannot carry as much oxygen as it usually does and you feel very tired and fatigued.
* You also have shortness of breath when exerting yourself (for example, climbing stairs).
* You sometimes have infections that cause fever and flu-like symptoms.
* You have **occasional** nosebleeds. Any cuts you get bleed more than normal. Your gums bleed when you brush your teeth.

**Impact**

* You are **not able** to work.
* You require more sleep than you used to.
* It is **difficult** for you to engage in your routine activities and household tasks.

**Treatment Process**

* You have a **catheter**, which is a small tube inserted into a vein in your chest. This allows doctors to draw blood and give you treatment with fewer needle sticks.
* You have to flush the catheter with a saline solution to clean it **3 times each week**. It is covered with a bandage. You change the bandage **once each week**. You have to keep it dry and clean to prevent infection.
* You need **blood transfusions about once per week** to give you healthy blood cells and help reduce symptoms. This is administered through the catheter.
* You receive **treatment with antibiotics**.

**Health State E2. Non-intensive Therapy: Hypomethylating Agents (Q)**

**Disease Status**

* Previous treatments have not worked for you.
* You are receiving a **low-dose medication treatment.**
* You receive this treatment in an **outpatient facility**. You return home after each treatment.

**Symptoms**

* Your treatment has helped **reduce your symptoms slightly**, but you still have symptoms.
* As a result of your condition, you have **anaemia**. This means your blood cannot carry as much oxygen as it usually does and you sometimes feel tired and fatigued.
* You also have shortness of breath when exerting yourself (for example, climbing stairs).
* You have **occasional** nosebleeds. Any cuts you get bleed more than normal. Your gums bleed when you brush your teeth.

**Impact**

* You are **not able** to work.
* You require more sleep than you used to.
* It is **difficult** for you to engage in your routine activities and household tasks.

**Treatment Process**

* You have a **catheter**, which is a small tube inserted into a vein in your chest. This allows doctors to draw blood and give you treatment with fewer needle sticks.
* You have to flush the catheter with a saline solution to clean it **3 times each week**. It is covered with a bandage. You change the bandage **once each week**. You have to keep it dry and clean to prevent infection.
* You are receiving low-dose medication by intravenous (IV) infusions through the catheter for **one week each month**.
* The side effects of this treatment **include fatigue and diarrhoea**.
* You need blood transfusions about **once per week** to give you healthy blood cells and help reduce symptoms. This is administered through the catheter.

**Health State F. Transplant + B2 (P+G)**

**Hospital**

* You stay in hospital for a total of **about 4–6 weeks**.

**Blood Cell Infusion**

* **Healthy blood cells from another person**, a donor, will be transplanted into your blood stream. These healthy blood cells will then go to your bone marrow. Your bone marrow will then produce more of these healthy blood cells.

**Treatment Process**

* You have a **catheter**, which is a small tube inserted into a vein in your chest. This allows doctors to draw blood and give you treatment with fewer needle sticks.
* You receive **high doses of medication** **treatment** to prepare for the transplant. You receive this treatment by intravenous (IV) infusions into your blood stream through the catheter. You receive this treatment for **about a week**.
* After the week of medication treatment, you receive the transplant. The healthy blood cells are given to you through the catheter. This **lasts for up to 3 hours**.

**Side Effects**

* The side effects of the high-dose medication treatment include **complete hair loss, mouth sores, nausea, vomiting, diarrhoea, and high risk of infection**.
* During the treatment, you feel **very** fatigued and tired.

**Recovery From Treatment**

* Following the transplant you remain in the **hospital for** **about 3–4 more weeks** to recover.
* You have lingering side effects from the medication you received previously. These include hair loss, nausea, vomiting, fatigue, low appetite, mouth sores, and risk of infection. These go away **after 30 days**.
* After you leave the hospital, you have appointments for blood draws and medication adjustment at least 2 times per week.
* After about **3 months** the catheter is removed.

*G for the Rest of the Year*

**Disease Status**

* You have **previously received treatment**, and now lab tests cannot detect any evidence of disease. You have normal levels of healthy blood cells.

**Symptoms**

* You **do not have anaemia**, and you **do not** feel tired or fatigued.
* You **do not have** a fever.
* You **do not have** nosebleeds or gum bleeding. Any cuts heal normally.

**Impact**

* You are **able to work full time**.
* You feel stronger than before you started treatment. You **can perform most** physical activities.
* You can **engage in most** routine activities and household tasks.
* You are **worried** that your disease might come back or that there may be later complications of transplant.

**Treatment Follow-up**

* You have regular follow-up visits with your doctor.

**Timeline**



**Full Health**

* You are healthy.
* You do NOT have any health problems.
* You are happy and relaxed.
* You can perform your usual activities without difficulty (getting around the community, work, school, social, family, and physical activities).