# Interview guide MEET-AML (revised version)

## Before the interview

See this interview guide as a structured way to make sure that you have talked about all topics of interest. We aim to achieve rich and exhaustive answers about patients thoughts, feelings and experiences and therefore probe-questions such as “in what way” and “could you tell me more about that” are good to use. However, if the patient has already covered a topic before you got the chance the pose the question, feel free to go to the next question instead. Make sure that you have printed a consent form, and a ranking-sheet, and have a pen with you.

The patient is welcomed and provided with written information about the study (same information as provided when the patients are invited). The written information is also reviewed verbally. Emphasize that the participant’s answers in this interview will not affect the therapy of the participant. Patient sign a consent form*.* Underline that there are no wrong or right answers. Ask if the patient have any questions.

*(Turn on audio recorder)*

Warm up questions

*(These responses will be presented in the final paper to describe the study population at an aggregated level)*

* How long have you been living with AML?
* How old are you?

## Part 1. Tradeoff between benefits and risks associated with treatment options

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| I would like to hear about your thoughts on drug treatments: |
| **Main questions** |
| - If you were proposed 2 different treatments, what would be important for you to know in order to choose ?  -Can you think of other aspects besides the ones you just mentioned that makes a treatment choice more preferred over another? |
| **Optional probing questions, use to achieve more exhaustive and detailed answers** |
| * *You have already mentioned some, could you think of other positive aspects of a treatment that you find important?* * *Are there more aspects of treatments that affect you and your life in a negative way, which you dislike or wish to avoid?* * *What makes these features important to you? In what sense do these features influence your life?* * *Could you tell me more about that?* |

## Ranking exercise:

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| **Introduction and instruction to ranking exercise** |
| You have mentioned several things that are important to you when it comes to drug treatments. You will now get to rank these features against each other. Here is a list of things that could be important when deciding between treatment options, based on previous literature and conversations with patients and physicians *(hand over the separate ranking sheet and a pen to the patient).* There are also empty spots on the list where you can write things that are missing from the list, e.g., the things you mentioned earlier. I would like you to rank these features from the most important to the least important based on what matters to you personally. Remember that there are no wrong or right answers. Take your time. |
| **Main questions** (*When patient have completed the ranking*) |
| -Please tell me what you put as number one on the list? *How come this is the most important thing to you?* |
| -Please tell me what you put as number two on the list? *How come this is the second most important thing to you? Tell me about your decision?* |
| -(Etc. depending on how many features the patient added on the list) |
| -Please tell me what you put last on the list? How come this feature is the least important to you? |
| -These treatment features that you just ranked, to what extent do you think these have been considered in treatments decisions? |
| To what extent do you perceive that you have you been involved in decisions regarding your treatment? |
| **Optional probe questions** |
| * *Could you tell me more about that?* * *Could you elaborate on that?* * *Could you give an example?* |

## Part 2. Personalized medicine

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| -What do you know about using algorithm to predict which treatment will be the best option for the patient? |
| **Information about personalized medicine** |
| I would like to tell you shortly about the personalized medicine and the ongoing research project that these interviews are a part of: Currently the personalized treatment of acute myeloid leukemia (AML) relies on a few genetic changes present in the cancer cells that can be targeted by specific drugs. The main objective of the MEET-AML study is to develop an integrative model of personalized medicine that includes the disease characteristics, therapeutic opportunities and preferences of AML patients and that can be used for selecting the best treatment option. For this purpose, samples from 150 AML patients will be collected from four different study sites in Europe and analyzed for changes that have occurred in the leukemia cell genes and metabolism. Using machine learning methods, the data will be integrated into a predictive model to identify disease specific markers or “biomarkers” and potential drug targets. The biomarkers and drug targets will be validated in laboratory settings and the patients’ perspectives regarding their treatment selection will be integrated into the model. The final aim of the model is to guide future clinical practice and help physicians in selecting the best therapy for the patient, as well as identifying potential cancer cell specific targets that can be developed for future personalized therapies.  *Emphasize to the participant that although the information from these interviews will be integrated into the described model aiming to guide AML treatment decisions in the future, the participant’s answers in this interview will not affect the therapy of the participant.* |
| *Investigate understanding and the need for elaboration;*  Is there something that you did not understand? Is there any words or concepts that you wish me to explain further? |
| **Main questions** |
| -What are your spontaneous thoughts about this new technology? |
| -What are your thoughts about the pros and cons of using this new technology/tools in treatment decisions? (compared to the traditional routine?) |
| -To what extent would you trust an algorithm to select the best treatment for you? And how does it compare to not using an algorithm? |
| -Do you have any thoughts about how patients’ priorities should be considered when using these new technologies/ decision tools? |
| -To be able to build and create these algorithms, there is a need of a lot of data from many patients. For this to be possible, there is a need to collect data from different countries. What is your thought about sharing your health data for this purpose? Do you have any concerns regarding this? |
| -Data that have been collected from patients in previous research project may be useful in new research projects in personalized medicine with a different purpose. What are your thoughts about re-using data for the purpose of enabling personalized medicine for other patients? |

Thank you! That were all the questions that I had. [*Summarize what you have been talking about].* Do you wish to add or comment something? Is there something that you find important that we have not talked about?

*Thank patient for participation. Turn off audio recorder.*

*Collect and save the ranking sheet and consent form.*

Probe questions to use throughout the interview:

* *Could you tell me more about that?*
* *In what sense?*
* *What are your feelings about that?*
* *In what way is that important to you?*
* *How is that affecting your everyday life?*