Appendix

Project Overview

1. The enactment scenario for sensitization

Patient's:

Day 1: The patient has already consulted with their GP who suspects a potential case of Melanoma and has referred them for a further examination to a dermatologist. Meanwhile, the patient is also required to wear a Data Collector (DC) widget which is a meaningful tool that will serve the medical team by collecting vital data about the patient's skin condition. The patient is instructed to wear the DC for one hour on the first night, during which it will conduct an automatic skin scan. The DC should be strategically placed over the mole to collect its data.

Day 2: As the interaction between the patient and the DC evolves, the patient is expected to participate more actively in data collection. At this point, they are required to submit unique data about themselves to the DC. A questionnaire in the booklet solicits information from the patient about observable symptoms and any recent alterations in the size, colour, or shape of a mole. The responses to these questions should be inputted into the DC. This information assists medical teams in preparing the patient for a biopsy, a procedure that involves removing cells, tissues, or fluids for examination by a medical pathologist. Biopsies are conducted when areas of concern are identified or when symptoms or signs of certain conditions are reported by the patient. Traditionally, such questions would be asked in-person and data would be collated by medical staff. In our envisaged healthcare of tomorrow, patients are empowered and equipped to answer these questions at their convenience and upload the responses directly to medical databases through their DC.

Day 3: On this day, the focus centres around the receipt of the biopsy results. In an effort to increase the authenticity of the scenario, even though the participants are not actual patients, we've provided sample test results styled in the format and arrangement of Erasmus M.C. documents. These test results come brimming with specific medical terminologies and figures, steering participants closer to a realistic medical environment. Each test result, for ease of access and personalised interaction, is assigned a unique numerical code that enables it to be uploaded onto patients personal DC. Within this envisioned realm of data-driven healthcare, the sanctity of data privacy stands paramount. To that end, we allow patients to decide whether or not to share their results with other practitioners in the field of healthcare. This is aimed at promoting an environment where patients feel not just like mere receivers of care, but active contributors with autonomy over their health

information. Patients can choose to share their results with other medical practitioners. So the reason behind putting a hare number is to give the patients this feeling that they have autonomy in deciding what to share with others.

Day 4: This final day, scheduled post-enactment session, revolves around an introspective exercise for participants. Its focus is to engage participants in reflecting upon their emotional experiences during the decision-making process.

Attention will be paid to their sense of empowerment, or lack thereof, when choosing treatment options within a data-centric care path, a possible departure from the experiences provided by traditional contemporary healthcare systems. This reflection process aims to highlight the differentiated impact of data-driven healthcare on patients' healthcare experiences and decisions.

To enhance the actors' immersion in their roles, we incorporated an imaginary test result to allow the participants better connect with their characters and the scenario they were portraying.

Erasmus MC
Universitair Medisch Centrum Rotterdam

Pathology laboratories
Erasmus Medical Center
Rotterdam, The Netherlands

Biopsy Result - 4D Laboratory

DC Share number: 153-298305-44

Laboratory Name: 4D - EMC
Patient Name:
Patient ID:
Date of Birth:
Gender:
Doctor:

Test Result: Sentinel Lymph Node Biopsy (SNB)

Procedure Details: The sentinel lymph node biopsy (SNB) procedure was performed on [Date] for staging and evaluation of melanoma in accordance with standard clinical guidelines. The aim of the SNB is to identify and assess the regional lymph nodes that are most likely to be involved in the spread of melanoma.

Procedure Description: Under sterile conditions, the patient received local anesthesia at the primary melanoma site located on [Location]. A radiopharmaceutical agent [Name of Agent] was injected intradermally around the site. Additionally, [Blue dye name] blue dye was administered to aid in the localization of the sentinel lymph node(s). The migration of the tracer and dye was monitored using a gamma probe and visual observation.

Findings: During the SNB procedure, [Number] sentinel lymph node(s) were successfully identified and excised. These sentinel lymph nodes were identified based on their radioactivity and/or blue staining characteristics. The excised sentinel lymph nodes were labeled and sent for pathological examination.

Pathology Results: Histopathological examination of the sentinel lymph node(s) was performed by an experienced pathologist. The following findings were noted:

- Sentinel Lymph Node #1:
  - Gross Examination: A single lymph node measuring 1.5 cm in greatest dimension was received.
  - Microscopic Examination: Metastatic melanoma involving the lymph node is observed. The melanoma cells exhibit irregular nuclear contours and prominent nucleoli, consistent with a diagnosis of melanoma.
  - Immunohistochemistry: Immunostains for melanocytic markers (S-100, Melan-A, HMB-45) show strong positive staining, confirming the presence of melanoma cells.
- Sentinel Lymph Node #2:
  - Gross Examination: A single lymph node measuring 1.2 cm in greatest dimension was received.
  - Microscopic Examination: Metastatic melanoma involvement is identified within the lymph node. The melanoma cells demonstrate epithelioid morphology and brisk mitotic activity, supporting the diagnosis of melanoma.
  - Immunohistochemistry: Immunostains for melanocytic markers (S-100, Melan-A, HMB-45) exhibit intense positive staining, indicating the presence of melanoma cells.

Impression: Based on the findings of the sentinel lymph node biopsy (SNB), there is histological evidence of metastatic melanoma in the excised sentinel lymph nodes. The presence of melanoma cells within the sentinel lymph nodes suggests regional lymph node involvement at this stage.

Clinical Recommendation: Given the negative SNB results, further lymph node dissection or adjuvant therapies may not be warranted at this time. However, it is important to discuss these results with your dermatologist or oncologist to determine the most appropriate follow-up plan and ensure ongoing monitoring of your melanoma status.

Please note that this is a fictional sample test result provided for illustrative purposes only. Actual test results may vary depending on the specific circumstances and individual patient cases. It is crucial to consult with a qualified healthcare professional for accurate interpretation and personalized management of test results.

Erasmus MC

As we speculate about the future of data-driven healthcare, patients assume a more proactive role in their diagnosis, leveraging AI tools that enable them to independently scan moles to determine their malignancy status.

Day 2 - Action A

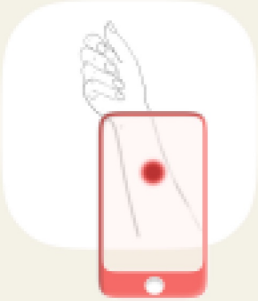
Put the bandage on your mole area.

Armin
Dermatologist

Hi . This is your dermatologist. Today you came to me for doing the biopsy, we removed a wide part of your skin around your mole. I hope you were not that much annoyed with the blade. We already sent the sample to laboratory for pathological analysis and it may take a day to receive the result. I can imagine waiting for the result will be an stressful time. But overthinking about it does not help. So be patient! You can do some assignments if you want:

A good practice would be to store some of your data in your DC. By providing this data, doctors will be able to offer you more personalized care and take into account your values, preferences, and concerns.

- Fill out the next page, its a hypothetical smart page and whatever you write there, will be uploaded to your DC.
- Take picture of the mole area, and share it with AI-client using the QR code on the DC.
- If you have anything that you want to let your doctors know, (It can be your values, preferences or ..), you can write them there as well.



Note: The one who answers you on Whatsapp is the researcher (Samrad) , im enacting the dataset AI admin. You can skip if you do not want to do this for any reason!

Day 3 - Action B

DC Share number: 153-117325-14

	I don't know
1. Medical History:	
• Have you had any previous melanomas or skin cancers?	○
• Do you have a family history of melanoma or other skin cancers?	○
• Have you had any previous treatments for melanoma or other cancers?	○
• Are you currently taking any medications or supplements?	○
2. Lymph Node Involvement:	
• Have you noticed any swelling or changes in your lymph nodes?	○
• Have you experienced any unexplained weight loss or fatigue?	○
• Have you had any other symptoms that may indicate the spread of cancer?	○
3. Imaging and Diagnostic Tests:	
• Have you had any imaging tests, such as ultrasound or MRI, performed on the melanoma or surrounding area?	○
• Have you undergone a biopsy or excisional biopsy to confirm the diagnosis of melanoma?	○
• Are there any additional tests or scans that need to be performed prior to surgery?	○

The actors had the freedom to openly contemplate the medical condition and cancer history of the fictional patient they were portraying.

Significant others':

Day 1: For participants who act as the significant other, the function of their DC is defined differently. They are encouraged to adopt the mindset that they are stressed about what happened to their partner, friend, or loved one with cancer. They consider the DC as a device that records their concerns, mood, and emotional ups and downs regarding what happened to their beloved one. Since the significant others are often affected by the patient's situation, it may not always be the best idea to directly express their concerns to the patient. So, by using the DC, they can be supported to have their concerns into consideration. They will be further guided on how to do this. They are asked to link their DC with the one that belongs to the patient to enable decision support tools to consider the significant others' concerns when providing support to the patient. The purpose of this practice is to instil the notion that in future data-driven healthcare, emotional needs will also be considered & there will be consistency between the medical data related to the patient and the emotional aspects of their life.

Day 2: On this day, participants will be supported in reflecting on their concerns and sharing them with the medical team. They are encouraged to freely write down the factors that are causing them to worry about the situation. They become aware that they can load more specific data on their DC widget by simply writing their thoughts down on paper.

Day 3: It is critical for the patient to have the support of their significant other both before and after surgery. As a result, on this day, significant others are asked to communicate with the patient to determine the best time for them to perform the surgery. Indeed, the significant other is making their availability clear to the medical team for providing a tailored treatment plan for the patient, taking into account their own medical time limits and the significant other's availability for supporting the patient.

Day 4: As with the patient, the activity for the final day (which occurs after the enactment session) for the significant other is about reflecting on how experiencing this hypothetical data-driven healthcare differs emotionally from the existing healthcare system.

Significant others could imagine about the concerns they could have about their partner. They were supposed to load the most important concerns of them on them on the DC.

Day 2 - Action A

Here I can stick the main concerns of mine from as a significant other to the patient from next page.

#1 #2 #3 #4

If you want to reflect more on your concerns, use the space below ....

Day 2 - Action A

Armin
Dermatologist

Hi,

Thanks for following the patient for the Biopsy. I can imagine it might be stressful to see your beloved one in that condition where we remove a part of their skin. But that will help us a lot to understand the stage and type of the cancer. I can imagine you might be concerned about so many things. What will happen to them? How you can help? how that might affect their life....

A good practice would be to write down all your concerns and questions and store them in your DC. Im aware that you have a different perspective toward this issue as you may think more rational compared to the patient not being directly affected be cancer. That's why Im asking you to put as much data as you can on your DC. You can fill in the page and then take a picture of the page.

Fill out the next page by sticking the , its a hypothetical smart page and whatever you write or stick there, will be uploaded to your DC.

A set of cards with probable concerns of patients' partners where provided to assist the actors and make them informed about the potential concerns of the character they enact!

Day 3 - Action B

March 2023

S	M	T	W	T	F	S
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25

rather not say

How long do you know the patient?

How much time do you spend with your partner everyday?

Do you think there is anything that we should be aware of?

The individuals enacting the roles of prospective significant others had the opportunity to engage in a practice to discuss and decide on a timeline for important clinical appointments and treatments with the patient.

Doctor's:

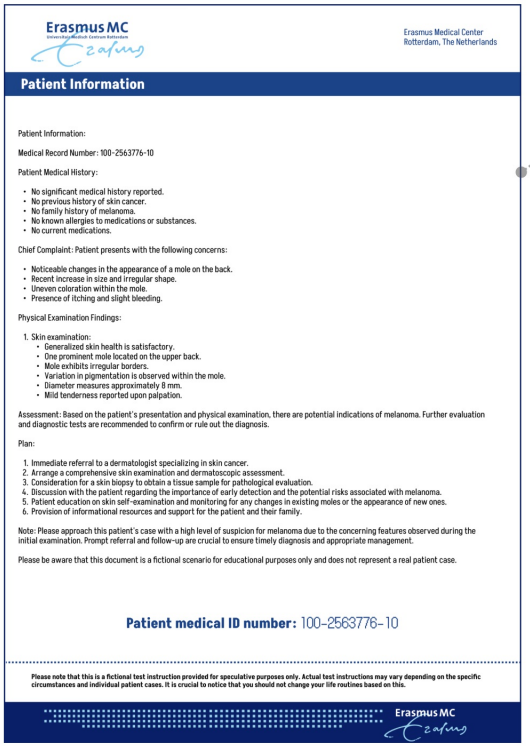
Day 1:
On this initial day, the participant embodying the role of the doctor is informed of the latest changes at Erasmus M.C., particularly the transition from traditional healthcare to a data-driven model. The doctor understands the essence of the tiny widget they receive–a proactive data collector that utilizes NLP based models and other interactive mediums. These compact data-collecting devices are capable of storing a wide range of information, including patient test results, consultation notes, and other Electronic Health Records within the medical centre. They have to activate their personal DC to be able to use them as data collectors.

Day 2: The doctor's experience expands on the second day as they learn that patient biopsy test results are uploaded directly to their Data Collector (DC). The trail of paper-based test results becomes obsolete.

Day 3: As the third day unfolds, the doctor discovers a new facet to the DC–the ability to place it near clinical displays to visualize the tissue analysis results. The doctor also receives a list of potential topics for the following day's discussion with the patient, serving as a guide for the participant to effectively navigate the session.

Day 4: The final day is dedicated to reflection. Doctors assess their experiences, considering their level of autonomy and engagement throughout the enactment. They ponder on how these factors may have influenced their role-play and what implications this may suggest for real-world scenarios.

To enhance the actors' immersion in their roles, an imaginary pathology result is made which provides more information on patients Melanoma state.



Erasmus MC

Erasmus Medical Center
Rotterdam, The Netherlands

Patient Information

Patient Information:

Medical Record Number: 100-2563776-10

Patient Medical History:

- No significant medical history reported.
- No previous history of skin cancer.
- No family history of melanoma.
- No known allergies to medications or substances.
- No current medications.

Chief Complaint: Patient presents with the following concerns:

- Noticeable changes in the appearance of a mole on the back.
- Recent increase in size and irregular shape.
- Uneven coloration within the mole.
- Presence of itching and slight bleeding.

Physical Examination Findings:

1. Skin examination:
   - Generalized skin health is satisfactory.
   - One prominent mole located on the upper back.
   - Mole exhibits irregular borders.
   - Variation in pigmentation is observed within the mole.
   - Diameter measures approximately 8 mm.
   - Mild tenderness reported upon palpation.

Assessment: Based on the patient's presentation and physical examination, there are potential indications of melanoma. Further evaluation and diagnostic tests are recommended to confirm or rule out the diagnosis.

Plan:

1. Immediate referral to a dermatologist specializing in skin cancer.
2. Arrange a comprehensive skin examination and dermatoscopic assessment.
3. Consideration for a skin biopsy to obtain a tissue sample for pathological evaluation.
4. Discussion with the patient regarding the importance of early detection and the potential risks associated with melanoma.
5. Patient education on skin self-examination and monitoring for any changes in existing moles or the appearance of new ones.
6. Provision of informational resources and support for the patient and their family.

Note: Please approach this patient's case with a high level of suspicion for melanoma due to the concerning features observed during the initial examination. Prompt referral and follow-up are crucial to ensure timely diagnosis and appropriate management.

Please be aware that this document is a fictional scenario for educational purposes only and does not represent a real patient case.

Patient medical ID number: 100-2563776-10

Please note that this is a fictional test instruction provided for speculative purposes only. Actual test instructions may vary depending on the specific circumstances and individual patient cases. It is crucial to notice that you should not change your life routines based on this.

Erasmus MC

The actor who plays the role of future doctor, receives a checklist on how to approach the patient in the appointment

Day 3 - Action B - **How to approach patient**

1. **Empathy and Compassion:** Approach the patient with empathy and sensitivity, acknowledging the emotional impact of the diagnosis. Create a safe space for the patient to ask questions and express their concerns.
2. **Explanation of Diagnosis:** Clearly communicate the diagnosis of stage 2 melanoma, explaining what it means in terms of the extent of the cancer and potential risks associated with it. Provide information about the staging system and what stage 2 signifies.
3. **Treatment Options:** Discuss the available treatment options for stage 2 melanoma, which may include surgical interventions, such as wide excision or sentinel lymph node biopsy (if applicable), as well as adjuvant therapies like immunotherapy or targeted therapy. Explain the goals, benefits, and potential side effects of each treatment option.
4. **Prognosis and Risk Assessment:** Discuss the patient's individual prognosis based on factors such as tumor thickness, ulceration, mitotic rate, and lymph node involvement (if any). Explain the potential for disease recurrence or spread and the importance of ongoing surveillance.
5. **Shared Decision-Making:** Engage the patient in shared decision-making, allowing them to actively participate in the treatment planning process. Provide balanced information about the potential benefits, risks, and expected outcomes of each treatment option. Consider the patient's preferences, values, and goals when formulating a treatment plan.
6. **Multidisciplinary Approach:** Emphasize the importance of a multidisciplinary approach to treatment, involving a team of specialists, such as surgical oncologists, dermatologists, pathologists, and medical oncologists, to ensure comprehensive and coordinated care.
7. **Supportive Care and Resources:** Offer information about support services, patient resources, and advocacy groups that can provide additional support, information, and assistance throughout the treatment journey.
8. **Follow-up and Monitoring:** Outline the importance of regular follow-up appointments and monitoring to assess treatment response, detect any signs of recurrence or new lesions, and address any concerns or side effects that may arise.
9. **Addressing Emotional and Psychological Well-being:** Acknowledge the emotional impact of the diagnosis and provide resources for counseling or support groups that can help the patient cope with the emotional challenges associated with their diagnosis.

Day 4 - Action C

How do you think the qualities of communication can be affected by using a Magic ball?

Regarding having autonomy, how do you think using magical ball influenced it?

The actor who plays the role of future doctor, can assess their experiences of data-driven care, considering their level of autonomy and engagement throughout the enactment.

DESIGNING A DECISION SUPPORT TOOL FOR ONCOLOGY

SPECULATIVE ENACTMENT

THE SCENARIO OF SIGNIFICANT OTHER

FOR A STORY ABOUT

MELANOMA

PARTICIPANTS NAME:

TU Delft

4D

Erasmus MC Cancer Institute

Day 1 - Action A

Eva, GP

Hey there.

I hope you are doing good. Yesterday, you came to our clinic as a companion to the patient. As we talked about, it seems that the behaviour of the moles the patient has, is representing the features of a serious type of skin cancer, but nothing is yet curtain.

Btw, tomorrow, the patient has to do a biopsy for analysing the mole to see if the mole is benign (non-cancerous) or if it shows any signs of malignancy (cancerous). We need to remove a wide part of the skin, so it would be really helpful if be there to support him/her.

Im so aware how this can be stressful for you and I wish you stay strong all through this with them. You received a device called **DC,** a smart device that records your concerns and mood, emotional ups and downs regarding what happened to your beloved one. I can imagine you might be concerned about the situation of the patient and you do not want to open it up with patient. The DC will help you to record your concerns whenever you want. Today you are only supposed to activate you device. When It's activated, you can use it to share your feelings. emotions and concerns with it. You will probably need your partner medical code to set link it to her DC, you can find the code below:

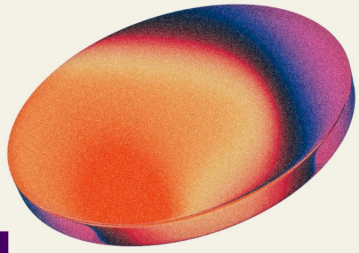
1- Simply scan the QR code on your DC.
2- Open the WhatsApp chat option, Its a fake chat representing the server that controls the DCs.
3- Write down your partner medical code and send it to the server .
4- You will receive a confirmation that your device has been contacted to the patient.

Patient medical ID number: 100-2563776-10

Note: The one who answers you on WhatsApp is the researcher (Kamran) . Im enacting the dataset AI admin. You can skip if you do not want to do this for any reason!

I am

and this is the scenario that I should enact.



The parts written in black text are intended to assist me in immersing myself in my role and better understanding the character I am portraying. I do not need to perform any specific actions related to these parts. They are solely provided to enhance my ability to believe in and embody the character effectively.

The sections highlighted with white text on colored boxes indicate that there are specific actions I need to take. This could involve completing an assignment or sending a submission to DC. These sections serve as clear indicators of tasks or requirements that require my attention and follow-through.

Day 2 - Action A

Armin
Dermatologist

Hi,

Thanks for following the patient for the Biopsy. I can imagine it might be stressful to see your beloved one in that condition where we remove a part of their skin. But that will help us a lot to understand the stage and type of the cancer. I can imagine you might be concerned about so many things. What will happen to them? How you can help? how that might affect their life....

A good practice would be to write down all your concerns and questions and store them in your DC. Im aware that you have a different perspective toward this issue as you may think more rational compared to the patient not being directly affected be cancer. That's why Im asking you to put as much data as you can on your DC. You can fill in the page and then take a picture of the page.

Fill out the next page by sticking the , its a hypothetical smart page and whatever you write or stick there, will be uploaded to your DC.

Day 2 - Action A

Here I can stick the main concerns of mine from as a significant other to the patient from next page.

#1 #2 #3 #4

If you want to reflect more on your concerns, use the space below ....

Day 3 - Action B

March 2023

S	M	T	W	T	F	S
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25

rather not say

How long do you know the patient?

How much time do you spend with your partner everyday?

Do you think there is anything that we should be aware of?

Day 3 - Action B

Annemiek
Dermatology nurse practitioner, EMC

Hi, you are probably by now aware that the case with your partner is **Melanoma**. It's a serious type of skin cancer and should be treated as soon as possible.

Im sorry about this. The patient needs more of your support from now on. We meet tomorrow for planning a treatment. I can imagine that patient might be super stressed today, so you have to do nothing today except taking care of them. There is only one activity for that you need to do for today. Probably we have to do a surgery next week. So can you please discuss it with your partner and then make it clear when you are both ready for the surgery? You can highlight the days you can do it for next week and then , just take a picture and store it on your DC same way you did it yesterday.

See you tomorrow at the clinic, the event is in your outlook calendar, **Please do not forget to bring your DC.**

1- Highlight the days you can make them free on the calendar for supporting the patient (its hypothetical)
2-Take a picture of the page with your phone.
3- As already done before, simply scan the QR code on your DC.
3- Open the WhatsApp chat option.
4- Upload the image there.
5- As you are done sending them, The data will be stored in the flash memory inside your DC.

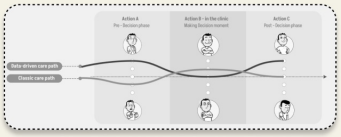
Note: The one who answers you on WhatsApp is the researcher (Kamran) . Im enacting the dataset AI admin. You can skip if you do not want to do this for any reason!

Day 4 - Action C

Good morning. Yesterday we had a perfect session for deciding the best treatment option. I'm so happy you were engaged in the process and you shared your concerns and values with me. Tomorrow is the day of your surgery, and I wanted to take a moment to share some info before we proceed.

How are you feeling? It's completely normal to feel nervous when your beloved one is taking a surgery like this. We do our best to make the best out of it.

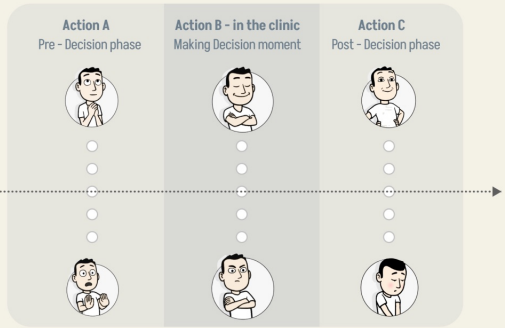
Now you have probably found some differences between the current data-driven care path compared to typical classic care path. I want to ask you to map out your emotions in different stages comparing these two. We want to see if you are feeling involved in making the decisions you made for the treatment of the patient



Your experience in this enactment! **Data-driven care path**

Your experience in real life! **Classic care path**

You can connect the dotes, following the lines in the left!



DESIGNING A DECISION SUPPORT TOOL FOR ONCOLOGY

SPECULATIVE ENACTMENT

THE SCENARIO OF DERMATOLOGIST

FOR A STORY ABOUT

MELANOMA

PARTICIPANTS NAME:

TU Delft

Erasmus MC

Day 1 - Action A

Lisette
data-scientist, EMC

Hey Doctor.

I am a member of the team responsible for implementing data-driven care at EMC. Recently, at Erasmus MC, we transitioned from the traditional care path to an innovative data-driven approach, leveraging the advantages offered by data libraries of clinical trials.

To streamline the data collection process, we are introducing new devices called Data Collectors (DC). Going forward, all the medical records you used to manually document on your PC regarding patients, tests, examination results, shared decision making session results, and check-ups will now be stored on these devices. Despite their small size, these devices are connected to cloud storage, providing you with unlimited space. So please don't underestimate their capabilities based on their size.

You will find a personal code alongside this message, which you can use to set up and personalize your own DC.

Thank you for your cooperation in this exciting transition towards data-driven care.

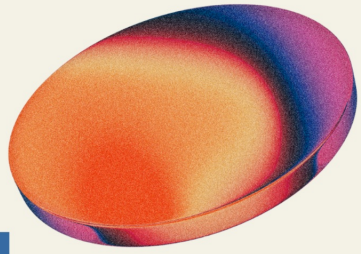
Medical ID number:
200-2563776-10

1- Simply scan the QR code on your DC.
2- Open the WhatsApp chat option.
3- Write down your hypothetical medical ID number.
4- As you send them, you will receive a text message that your device has been set up!

Note: The one who answers you on WhatsApp is the researcher (Kamran) . Im enacting the dataset AI admin. You can skip if you do not want to do this for any reason!

I am

and this is the scenario that I should enact.



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The sections highlighted with white text on colored boxes indicate that there are specific actions I need to take. This could involve completing an assignment or sending a submission to DC. These sections serve as clear indicators of tasks or requirements that require my attention and follow-through.

Day 2 - Action A

Jacob
laboratory
director, EMC

Dear doctor.

Yesterday, you sent us a sample of your patient's skin. It will take us a day to provide you with a pathological analysis of the tissue.

The result will be uploaded to your DC. For privacy purposes, we need to reassure that he/she is your patient. That's why Im kindly asking you to send the medical code of your patient to AI-admin. You can find the number in the patient information sheet.

1- Simply scan the QR code on your DC.
2- Open the WhatsApp chat option.
3- Write down your patient Medical ID number.
4- As you send them, AI-admin will upload the their result on your DC.

Note: The one who answers you on WhatsApp is the researcher (Kamran) . Im enacting the dataset AI admin. You can skip if you do not want to do this for any reason!

Day 3 - Action B

Dear doctor. Analyzing the tissue made it clear for us that the case is an stage-2 Melanoma. Further information, about the size and depth of the melanoma and regarding the melanoma spread to the nearby lymph nodes or other parts of the body are already loaded on your DC. If you need to be aware of the details of the result, just put your DC near to one of the medical displays in your clinic and enter patients medical number if you are already in the clinic.

Otherwise, you can go through the details tomorrow in your clinic.
Kind regards, Jacob | laboratory director, EMC

Hey doctor. Since the case with your patient turned to be serious, we have to fix an appointment for tomorrow. You will have a meeting with them in order to plan for the treatment. Please do not forget to bring your DC. I will put a calendar event for this on your outlook.

Kind Regards, Annemiek | Dermatology nurse practitioner, EMC

Briefly check next page for the medical status that you need to share with patients, you only have to be there in the clinic tomorrow with your DC.

Day 3 - Action B - **surgery procedure**

1. **Preoperative Preparation: Prior to the surgery, the patient will undergo a thorough examination and evaluation, which may include imaging tests and lymph node mapping (if necessary). The patient's overall health and any relevant medical conditions will be considered.**
2. **Anesthesia: The surgery is typically performed under general anesthesia, which means the patient will be unconscious during the procedure. In some cases, local anesthesia with sedation may be used.**
3. **Wide Excision: The surgeon will make an incision around the melanoma, ensuring that an appropriate margin of healthy skin surrounding the tumor is removed. The margin width will depend on the thickness and other characteristics of the melanoma, as determined by the pathology report.**
4. **Lymph Node Evaluation: If the melanoma is thicker or has other high-risk features, a sentinel lymph node biopsy (SLNB) may be performed during the same surgery. This involves the removal of one or a few lymph nodes that are most likely to be the first site of cancer spread. The removed lymph nodes are then examined for the presence of cancer cells.**
5. **Closure: Once the tumor and the required margin of healthy tissue are removed, the surgeon will close the incision using sutures or other closure techniques. The goal is to achieve optimal wound healing and minimize scarring.**
6. **Pathology Examination: The excised tumor and lymph nodes, if obtained, are sent to the pathology laboratory for further examination. The pathology report will provide important information about the characteristics of the melanoma, including its thickness, ulceration, mitotic rate, and any lymph node involvement.**
7. **Postoperative Care: After the surgery, the patient will be closely monitored during the recovery period. Pain management, wound care instructions, and any necessary follow-up appointments will be provided. The patient may also be advised on self-examination techniques and regular follow-up monitoring.**

DESIGNING A DECISION SUPPORT TOOL FOR ONCOLOGY

SPECULATIVE ENACTMENT

THE SCENARIO OF PATIENT

FOR A STORY ABOUT

MELANOMA

PARTICIPANTS NAME:

TU Delft

Erasmus MC Cancer Institute

Day 1 - Action A

Eva, GP

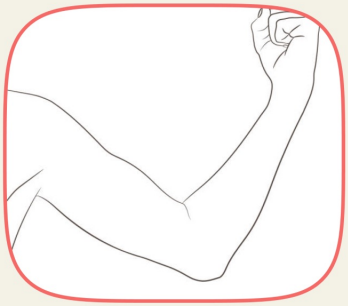
Hey there! Welcome to the first day.

I hope you're doing good. You came to our clinic yesterday because of those new moles on your left elbow. Since the mole got dark so fast (in 3 months), it looks like you might have skin cancer. But don't worry, we're not sure yet about it, and we just need to check the properties of your mole first. I will refer you to a dermatologist (that's a skin specialist doctor, by the way) and he/she can take a closer look.

Meanwhile, could you find the DC widget? It's going to help us gather data about your skin condition. Just wear it for an hour tonight and it starts to automatically scan your skin. You should put it on right over the mole and then the DC widgets, hypothetically collect data about your mole.

Tomorrow, you will visit your Dermatologist and he will help you with biopsy. A biopsy for analyzing a mole is a medical procedure performed to obtain a sample of tissue from a mole (also known as a nevus) for further examination under a microscope. The purpose of the biopsy is to determine if the mole is benign (non-cancerous) or if it shows any signs of malignancy (cancerous). You can find the instructions for Biopsy on the page below.

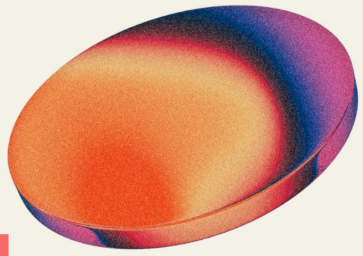
Can you please draw on the picture in the right side, where did you put your DC? That helps the dermatologist for prepration.



I am

.....

and this is the scenario that I should enact.



The parts written in black text are intended to assist me in immersing myself in my role and better understanding the character I am portraying. I do not need to perform any specific actions related to these parts. They are solely provided to enhance my ability to believe in and embody the character effectively.

The sections highlighted with white text on colored boxes indicate that there are specific actions I need to take. This could involve completing an assignment or sending a submission to DC. These sections serve as clear indicators of tasks or requirements that require my attention and follow-through.

Day 2 - Action A

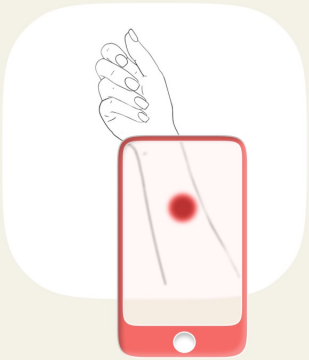
Put the bandage on your mole area.

Armin
Dermatologist

Hi . This is your dermatologist. Today you came to me for doing the biopsy, we removed a wide part of your skin around your mole. I hope you were not that much annoyed with the blade. We already sent the sample to laboratory for pathological analysis and it may take a day to receive the result. I can imagine waiting for the result will be an stressful time. But overthinking about it does not help. So be patient! You can do some assignments if you want:

A good practice would be to store some of your data in your DC. By providing this data, doctors will be able to offer you more personalized care and take into account your values, preferences, and concerns.

- **Fill out the next page, its a hypothetical smart page and whatever you write there, will be uploaded to your DC.**
- **Take picture of the mole area, and share it with AI-client using the QR code on the DC.**
- **If you have anything that you want to let your doctors know, (It can be your values, preferences or ..), you can write them there as well.**



Note: The one who answers you on WhatsApp is the researcher (Kamran) . Im enacting the dataset AI admin. You can skip if you do not want to do this for any reason!

Day 2 - Action A

Age: rather not say Sex: rather not say

I don't know

1. Symptoms and Duration:

a. When did you first notice the mole or skin lesion?

b. Has it changed in size, shape, or color since you first noticed it?

c. Have you experienced any itching, bleeding, or other symptoms associated with the mole?

2. Personal Habits and Sun Exposure:

a. How often do you expose your skin to the sun?

b. Do you use sun protection measures like sunscreen, hats, or protective clothing?

c. Have you ever used tanning beds or undergone excessive sun exposure?

3. Physical Examination:

a. Can you describe the mole or skin lesion in terms of size, color, shape, and border irregularities?

b. Does the mole exhibit any signs of asymmetry or uneven pigmentation?

c. Are there any other suspicious moles or skin lesions that concern you?

DC Share number: 153-297305-14

Day 3 - Action B

DC Share number: 153-117325-14

I don't know

1. Medical History:

- Have you had any previous melanomas or skin cancers?
- Do you have a family history of melanoma or other skin cancers?
- Have you had any previous treatments for melanoma or other cancers?
- Are you currently taking any medications or supplements?

2. Lymph Node Involvement:

- Have you noticed any swelling or changes in your lymph nodes?
- Have you experienced any unexplained weight loss or fatigue?
- Have you had any other symptoms that may indicate the spread of cancer?

3. Imaging and Diagnostic Tests:

- Have you had any imaging tests, such as ultrasound or MRI, performed on the melanoma or surrounding area?
- Have you undergone a biopsy or excisional biopsy to confirm the diagnosis of melanoma?
- Are there any additional tests or scans that need to be performed prior to surgery?

Day 3 - Action B

Annemiek
Dermatology nurse practitioner, EMC

Hi. This is Annemieke, I'm a dermatology nurse practitioner at EMC.

I received your test result today. Attached to this letter, you can find your test result. Im sorry but I have a bad news. Sadly, your case is an stage-2 Melanoma. A serious type of skin cancer. We need to start to plan for the treatment as soon as possible. I will set a time to visit your dermatologist tomorrow. Till then, you just have to load the test data on your personal DC.

See you in the clinic soon, you can find the place and time on your outlook calendar, please do not forget to bring your **DC**. Till then, please do the tasks below:

To load your biopsy test result to your DC, simply send the result share number to the WhatsApp chat with AI-admin. you will receive a confirmation as soon as the data is loaded on your DC.

Tomorrow you will have a meeting with your dermatologist and other medical provider. There, you will play a moment of shared decision making in year 2030 for planning a treatment considering your situation. In this session you will interact with other people and with a concept which predicts your future based on curtain type of care paths. This design concept helps us to provide you with personalized care. but for it to work, we need all the information you stored till now on your DC. So don't forget to bring the DC with yourself.

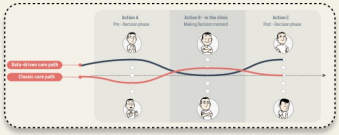
If you want to skip the waiting line tomorrow, you can already check in:) . It means that you can start answering the questions in the next page. When you are done, Your DC will save it.

Day 4 - Action C

Good morning. Yesterday we had a perfect session for deciding the best treatment option. I'm so happy you were engaged in the process and you shared your concerns and values with me. Tomorrow is the day of your surgery, and I wanted to take a moment to share some info before we proceed.

How are you feeling? It's completely normal to feel nervous before a surgery like this. I want you to know that our team is here to support you every step of the way. We've carefully planned and prepared for today, and we're committed to providing you with the best care possible with all the data you provided for us and the data that we collected from so many other patients.

Now you have probably found some differences between the data-driven care path that you experienced here in this speculation compared to typical classic care path. I want to ask you to map out your emotions in different stages. We want to see if you are feeling empowered about the decisions you made for the treatment plans.



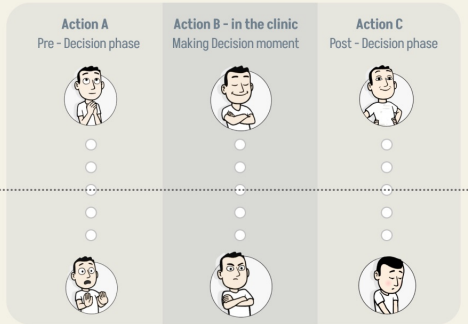
Your experience in this enactment!

Data-driven care path

Classic care path

Your experience in real life!

You can connect the dotes, following the lines in the left!



3. Co-Speculation Material

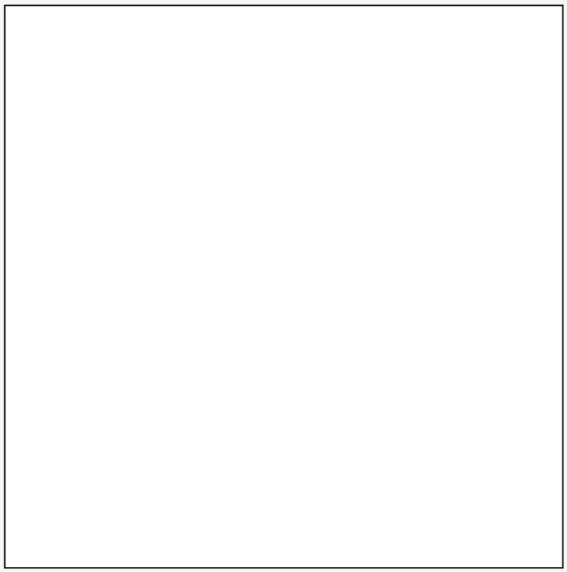
Hi. You can use the space below if you want to write down or draw anything while watching the video.

What do you think about living in this future? What are the things you like about it? What are the things you don't enjoy there?

Imagine you are a patient in this future. You are likely much more informed when you want to meet your doctor for the first time compared to the past. Do you think this state of being more informed helps you make better decisions?

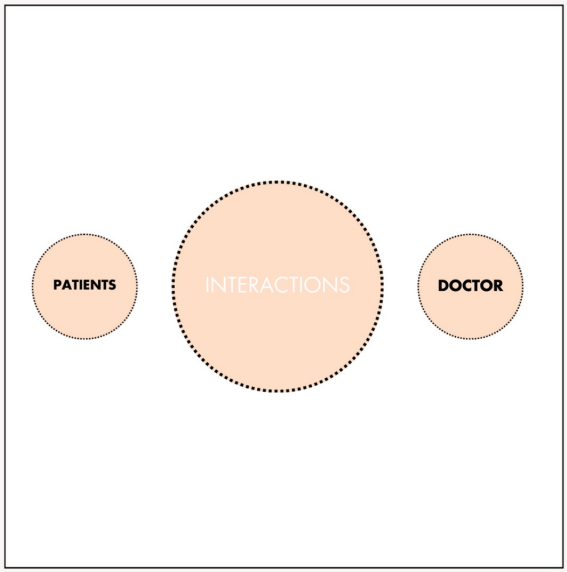
Imagine you are a doctor in this future, and you want to create a virtual version of yourself for certain tasks. How do you feel about cloning yourself? What should/should not the clone do in this context.

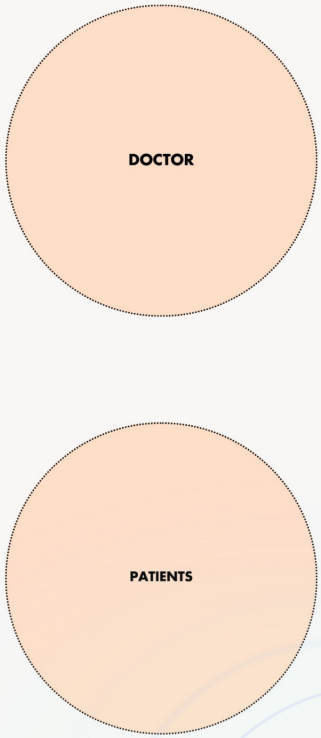
How do you feel about patients sharing data with a clone of a doctor? Do you think that helps the doctor to be more informed about the patients' preferences?



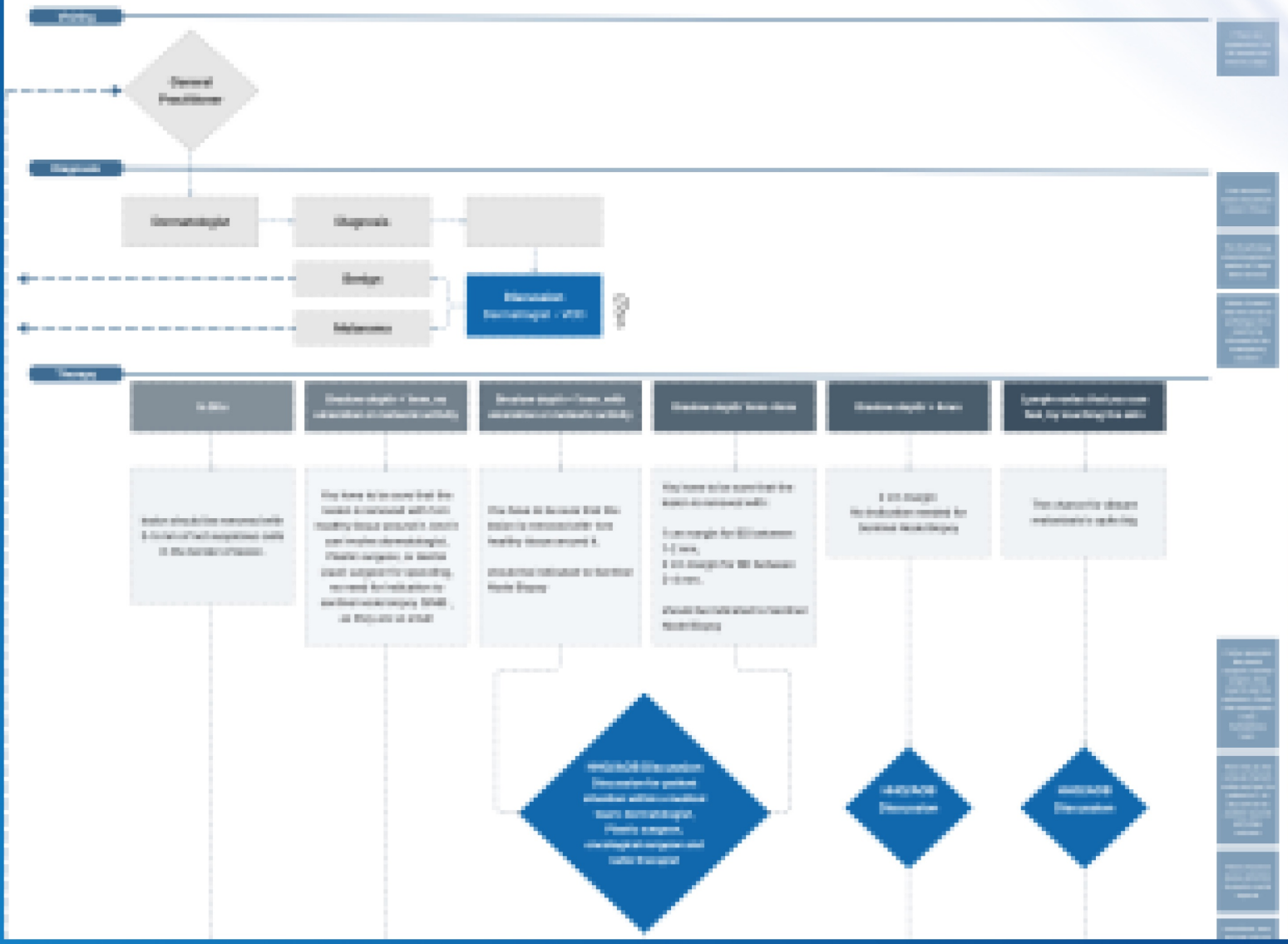
How do you fill about decisions made using a hybrid doctor/doctor's clone system. Do you think this switch is essential for making informed decisions?

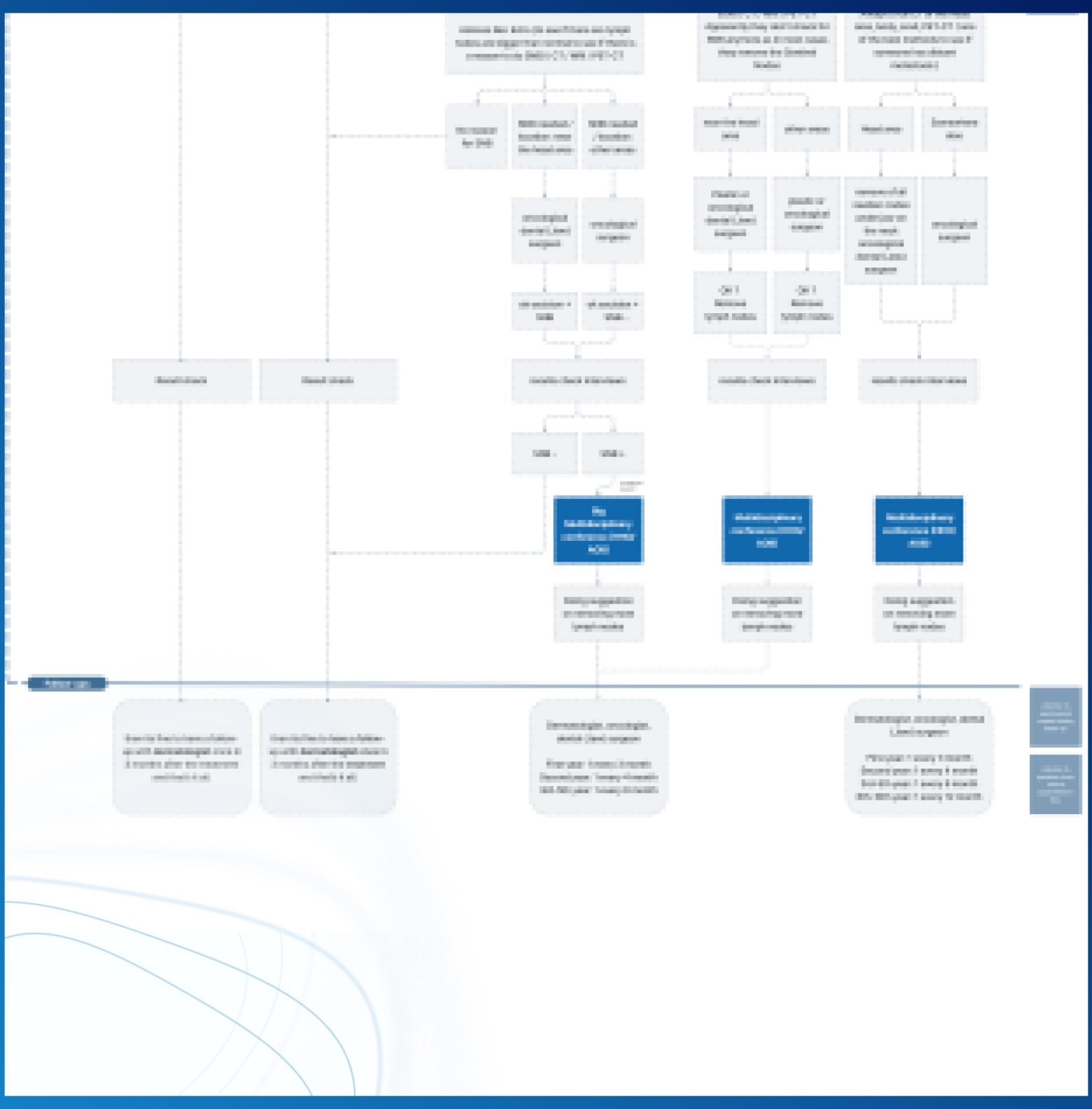
How do you think the interactions between the doctor and patients should look like in this future. How do **you** design this future? **You can use puppets to depict the future. The big puppets are the doctors and the small ones are the patienst.**



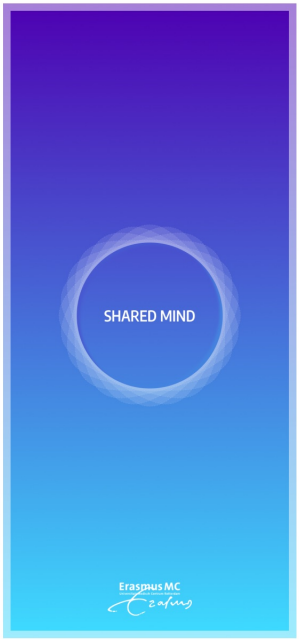


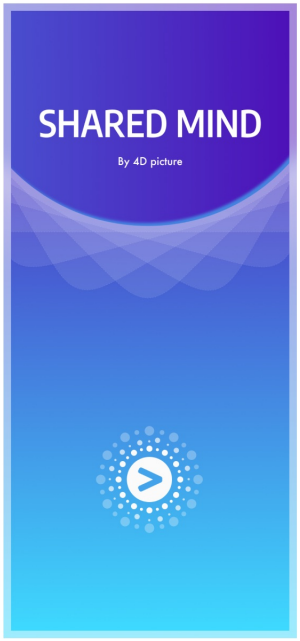
4. Melanoma Care-path

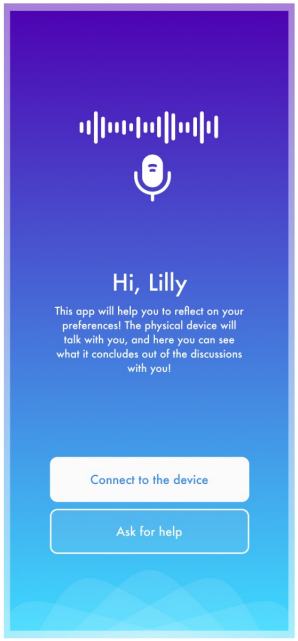


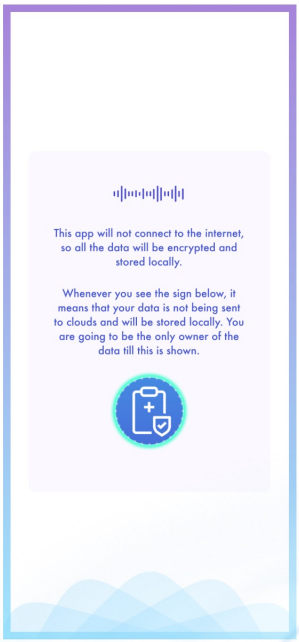


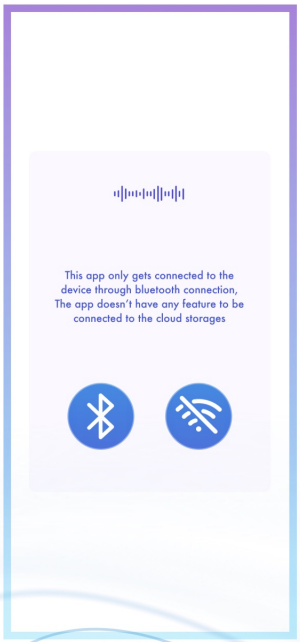
5. Preferences App and Cloning Software UI

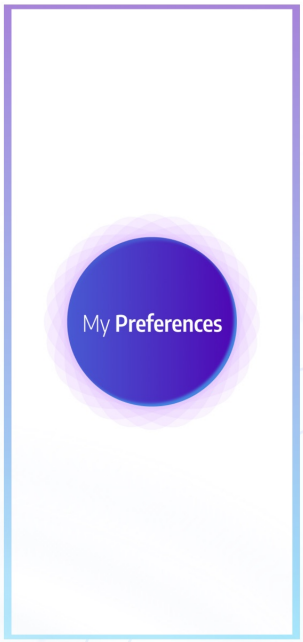


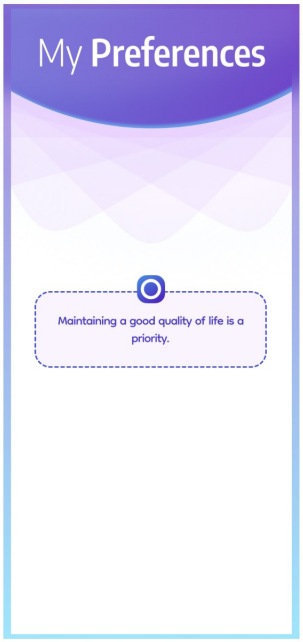






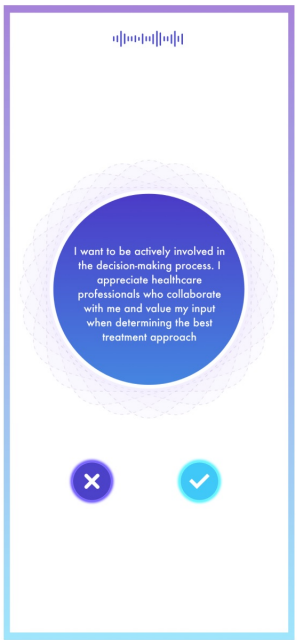


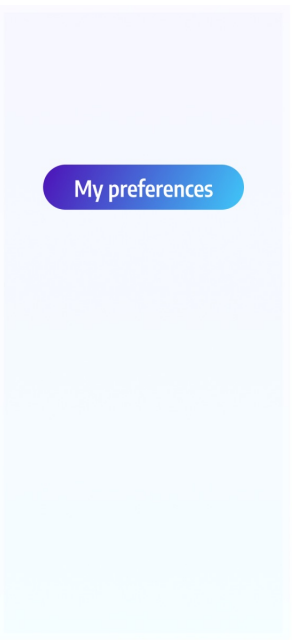


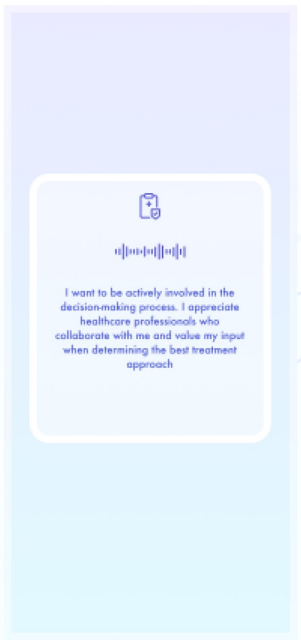

My Preferences
Maintaining a good quality of life is a priority.


My Preferences
Maintaining a good quality of life is a priority.
Supportive care is essential to me.

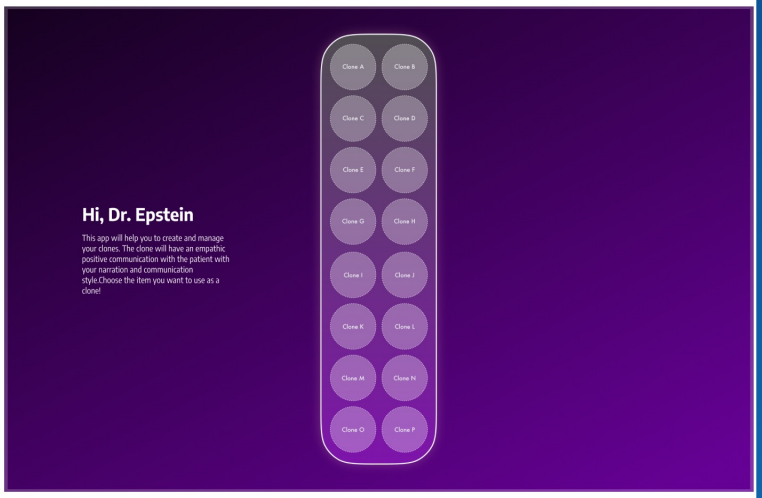

My Preferences
Maintaining a good quality of life is a priority.
Supportive care is essential to me.

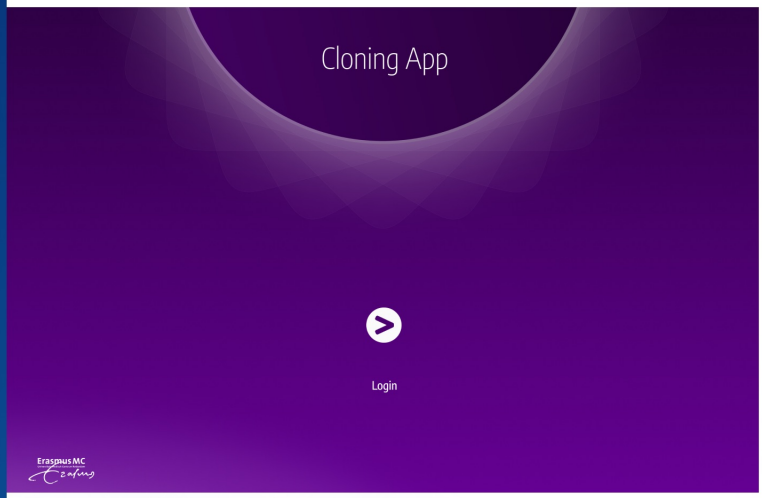

I want to be actively involved in the decision-making process. I appreciate healthcare professionals who collaborate with me and value my input when determining the best treatment approach

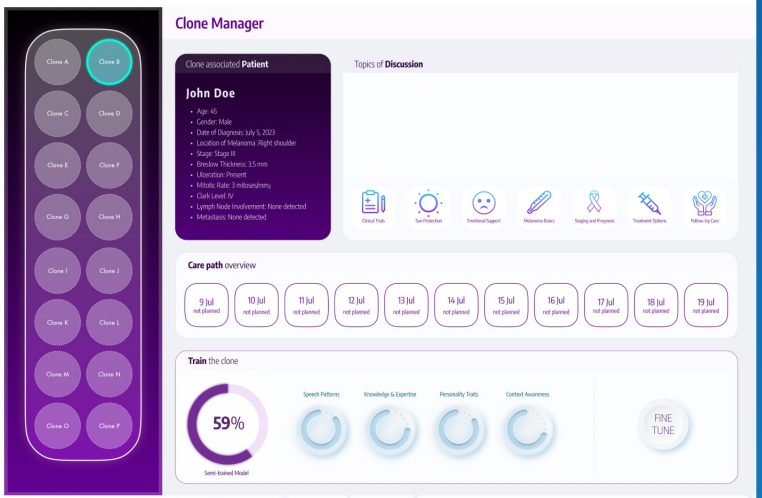

My preferences

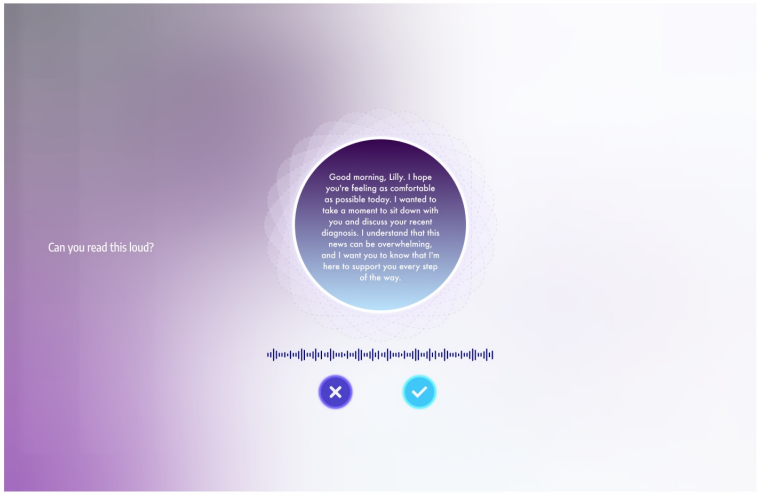

I want to be actively involved in the decision-making process. I appreciate healthcare professionals who collaborate with me and value my input when determining the best treatment approach

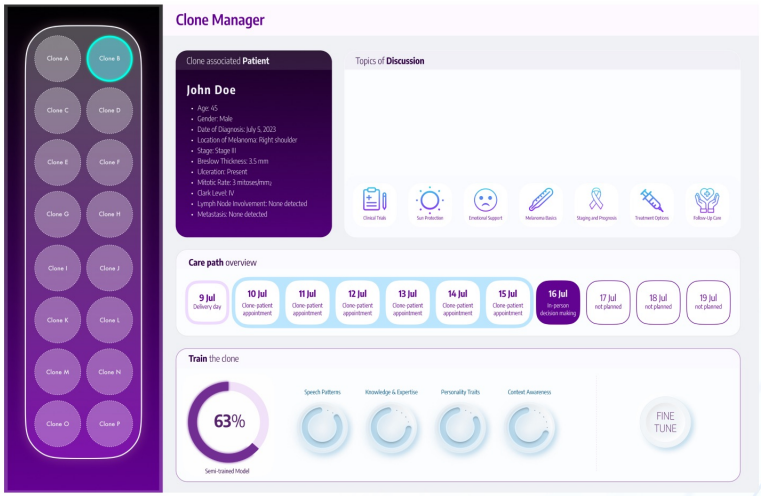

SHARED MIND
Erasmus MC
Cancer


Hi, Dr. Epstein
This app will help you to create and manage your clones. The clone will have an empathic positive communication with the patient with your narration and communication style.Choose the item you want to use as a clone!
Clone A
Clone B
Clone C
Clone D
Clone E
Clone F
Clone G
Clone H
Clone I
Clone J
Clone K
Clone L
Clone M
Clone N
Clone O
Clone P


Cloning App
Login
Erasmus MC
Cancer


Clone A
Clone B
Clone C
Clone D
Clone E
Clone F
Clone G
Clone H
Clone I
Clone J
Clone K
Clone L
Clone M
Clone N
Clone O
Clone P
Clone Manager
Clone associated Patient
John Doe
Age: 45
Gender: Male
Date of Diagnosis: July 5, 2023
Location of Melanoma: Right shoulder
Stage: Stage III
Breslow Thickness: 3.5 mm
Ulceration: Present
Mitotic Rate: 3 mitoses/mm²
Clark Level: IV
Lymph Node Involvement: None detected
Metastasis: None detected
Topics of Discussion
Clinical Trials
Sun Protection
Emotional Support
Melanoma Basics
Staging and Prognosis
Treatment Options
Follow-Up Care
Care path overview
9 Jul not planned
10 Jul not planned
11 Jul not planned
12 Jul not planned
13 Jul not planned
14 Jul not planned
15 Jul not planned
16 Jul not planned
17 Jul not planned
18 Jul not planned
19 Jul not planned
Train the clone
59%
Semi-trained Model
Speech Patterns
Knowledge & Expertise
Personality Traits
Context Awareness
FINE TUNE


Can you read this loud?
Good morning, Lilly. I hope you're feeling as comfortable as possible today. I wanted to take a moment to sit down with you and discuss your recent diagnosis. I understand that this news can be overwhelming, and I want you to know that I'm here to support you every step of the way.


Clone A
Clone B
Clone C
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Clone K
Clone L
Clone M
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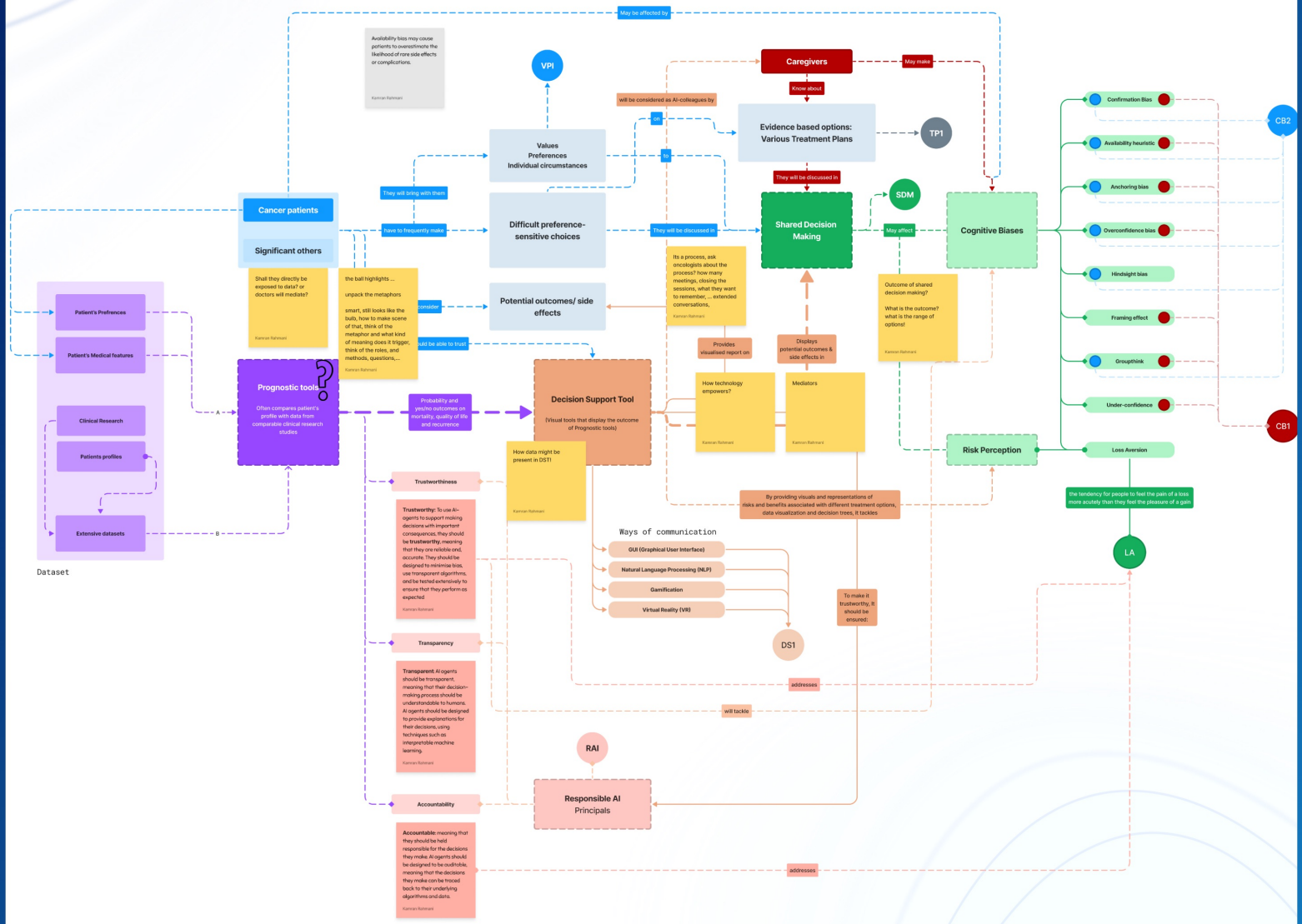
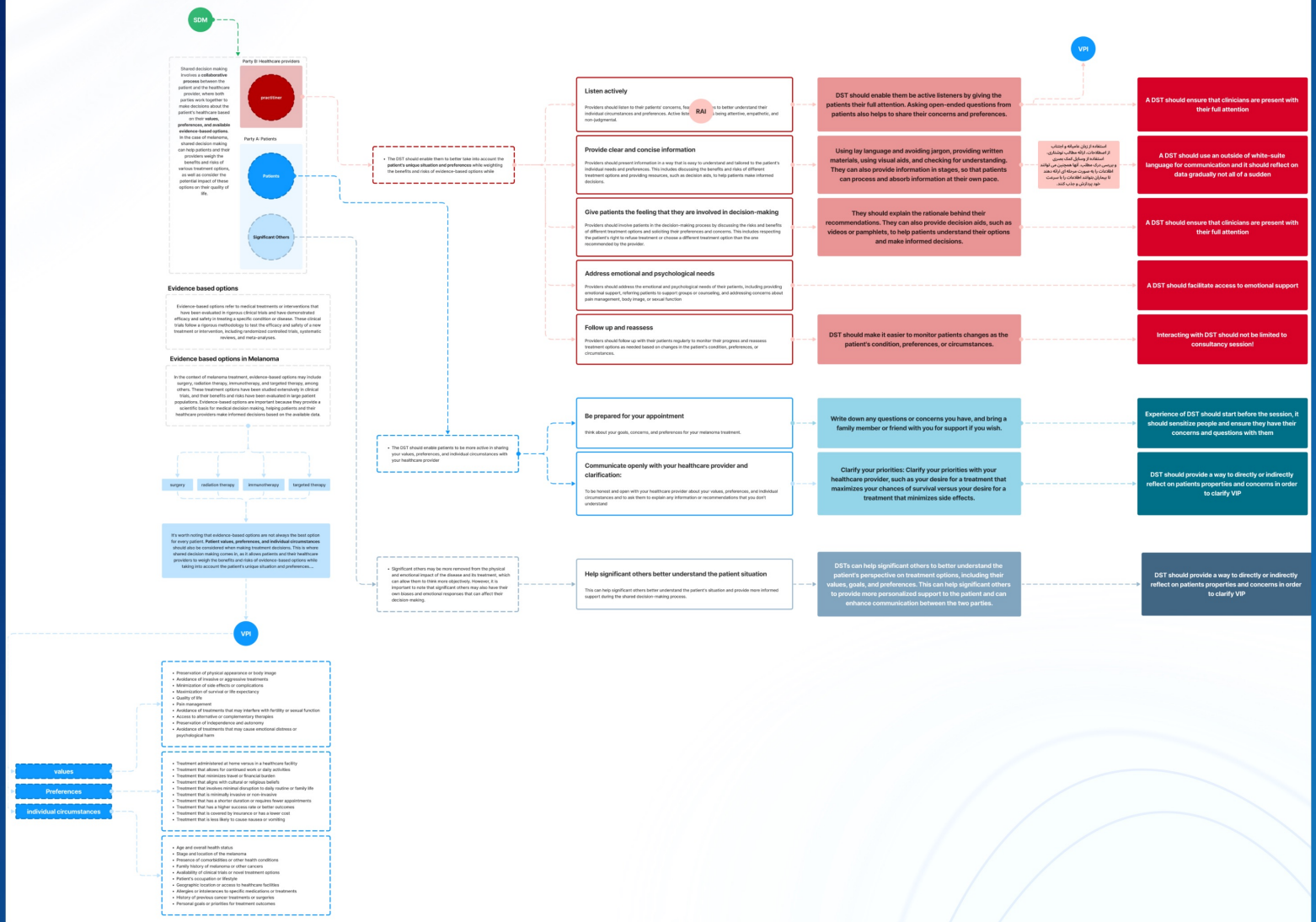
Staging and Prognosis
Treatment Options
Follow-Up Care
Care path overview
9 Jul Delivery day
10 Jul Clone-patient appointment
11 Jul Clone-patient appointment
12 Jul Clone-patient appointment
13 Jul Clone-patient appointment
14 Jul Clone-patient appointment
15 Jul Clone-patient appointment
16 Jul In-person decision making
17 Jul not planned
18 Jul not planned
19 Jul not planned
Train the done
63%
Semi-trained Model
Speech Patterns
Knowledge & Expertise
Personality Traits
Context Awareness
FINE TUNE

6. Project Concept Diagrams



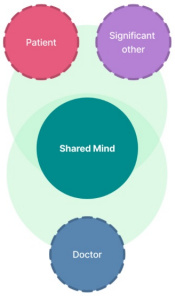

SDM
Party B: Healthcare providers
practitioner
Party A: Patients
Patients
Significant Others
Shared decision making involves a collaborative process between the patient and the healthcare provider, where both parties work together to make decisions about the patient's healthcare based on their values, preferences, and available evidence-based options. In the case of melanoma, shared decision making can help patients and their providers weigh the benefits and risks of various treatment options, as well as consider the potential impact of these options on their quality of life.
Evidence based options
Evidence-based options refer to medical treatments or interventions that have been evaluated in rigorous clinical trials and have demonstrated efficacy and safety in treating a specific condition or disease. These clinical trials follow a rigorous methodology to test the efficacy and safety of a new treatment or intervention, including randomized controlled trials, systematic reviews, and meta-analyses.
Evidence based options in Melanoma
In the context of melanoma treatment, evidence-based options may include surgery, radiation therapy, immunotherapy, and targeted therapy, among others. These treatment options have been studied extensively in clinical trials, and their benefits and risks have been evaluated in large patient populations. Evidence-based options are important because they provide a scientific basis for medical decision making, helping patients and their healthcare providers make informed decisions based on the available data.
surgery
radiation therapy
immunotherapy
targeted therapy
It's worth noting that evidence-based options are not always the best option for every patient. Patient values, preferences, and individual circumstances should also be considered when making treatment decisions. This is where shared decision making comes in, as it allows patients and their healthcare providers to weigh the benefits and risks of evidence-based options while taking into account the patient's unique situation and preferences. ...
VPI
values
Preferences
individual circumstances
• Preservation of physical appearance or body image
• Avoidance of invasive or aggressive treatments
• Minimization of side effects or complications
• Maximization of survival or life expectancy
• Quality of life
• Pain management
• Avoidance of treatments that may interfere with fertility or sexual function
• Access to alternative or complementary therapies
• Preservation of independence and autonomy
• Avoidance of treatments that may cause emotional distress or psychological harm
• Treatment administered at home versus in a healthcare facility
• Treatment that allows for continued work or daily activities
• Treatment that minimizes travel or financial burden
• Treatment that aligns with cultural or religious beliefs
• Treatment that involves minimal disruption to daily routine or family life
• Treatment that is minimally invasive or non-invasive
• Treatment that has a shorter duration or requires fewer appointments
• Treatment that has a higher success rate or better outcomes
• Treatment that is covered by insurance or has a lower cost
• Treatment that is less likely to cause nausea or vomiting
• Age and overall health status
• Stage and location of the melanoma
• Presence of comorbidities or other health conditions
• Family history of melanoma or other cancers
• Availability of clinical trials or novel treatment options
• Patient's occupation or lifestyle
• Geographic location or access to healthcare facilities
• Allergies or intolerances to specific medications or treatments
• History of previous cancer treatments or surgeries
• Personal goals or priorities for treatment outcomes
• The DST should enable them to better take into account the patient's unique situation and preferences while weighting the benefits and risks of evidence-based options while
• The DST should enable patients to be more active in sharing your values, preferences, and individual circumstances with your healthcare provider
• Significant others may be more removed from the physical and emotional impact of the disease and its treatment, which can allow them to think more objectively. However, it is important to note that significant others may also have their own biases and emotional responses that can affect their decision-making.
Listen actively
Providers should listen to their patients' concerns, fos ns to better understand their individual circumstances and preferences. Active liste g being attentive, empathetic, and non-judgmental.
RAI
Provide clear and concise information
Providers should present information in a way that is easy to understand and tailored to the patient's individual needs and preferences. This includes discussing the benefits and risks of different treatment options and providing resources, such as decision aids, to help patients make informed decisions.
Give patients the feeling that they are involved in decision-making
Providers should involve patients in the decision-making process by discussing the risks and benefits of different treatment options and soliciting their preferences and concerns. This includes respecting the patient's right to refuse treatment or choose a different treatment option than the one recommended by the provider.
Address emotional and psychological needs
Providers should address the emotional and psychological needs of their patients, including providing emotional support, referring patients to support groups or counseling, and addressing concerns about pain management, body image, or sexual function
Follow up and reassess
Providers should follow up with their patients regularly to monitor their progress and reassess treatment options as needed based on changes in the patient's condition, preferences, or circumstances.
Be prepared for your appointment
think about your goals, concerns, and preferences for your melanoma treatment.
Communicate openly with your healthcare provider and clarification:
To be honest and open with your healthcare provider about your values, preferences, and individual circumstances and to ask them to explain any information or recommendations that you don't understand
Help significant others better understand the patient situation
This can help significant others better understand the patient's situation and provide more informed support during the shared decision-making process.
DST should enable them be active listeners by giving the patients their full attention. Asking open-ended questions from patients also helps to share their concerns and preferences.
Using lay language and avoiding jargon, providing written materials, using visual aids, and checking for understanding. They can also provide information in stages, so that patients can process and absorb information at their own pace.
They should explain the rationale behind their recommendations. They can also provide decision aids, such as videos or pamphlets, to help patients understand their options and make informed decisions.
DST should make it easier to monitor patients changes as the patient's condition, preferences, or circumstances.
Write down any questions or concerns you have, and bring a family member or friend with you for support if you wish.
Clarify your priorities: Clarify your priorities with your healthcare provider, such as your desire for a treatment that maximizes your chances of survival versus your desire for a treatment that minimizes side effects.
DSTs can help significant others to better understand the patient's perspective on treatment options, including their values, goals, and preferences. This can help significant others to provide more personalized support to the patient and can enhance communication between the two parties.
VPI
استفاده از زبان ناخوانا و اجتناب از اصطلاحات. ارائه مطالب توضیحاری. استفاده از وسایل کمک بصری و بررسی درک مطالب. آنها همچنین می توانند اطلاعات را به صورت مرحله ای ارائه دهند تا بیماران بتوانند اطلاعات را با سرعت خود پردازش و جذب کنند.
A DST should ensure that clinicians are present with their full attention
A DST should use an outside of white-suite language for communication and it should reflect on data gradually not all of a sudden
A DST should ensure that clinicians are present with their full attention
A DST should facilitate access to emotional support
Interacting with DST should not be limited to consultancy session!
Experience of DST should start before the session, it should sensitize people and ensure they have their concerns and questions with them
DST should provide a way to directly or indirectly reflect on patients properties and concerns in order to clarify VIP
DST should provide a way to directly or indirectly reflect on patients properties and concerns in order to clarify VIP

Diagnosis	Staging	Treatment Planning	Surgery	Follow-ups	adjuvant therapies	Back to Normal Life
During this phase, Emily first noticed the irregular mole on her forearm and sought medical attention. The dermatologist conducted a thorough examination and recommended a biopsy, which led to her diagnosis of melanoma. This phase involved the initial shock of the diagnosis and the beginning of her journey towards treatment and recovery.	After her diagnosis, Emily underwent further tests and evaluations to determine the stage of her melanoma. This involved imaging scans, such as a CT scan or MRI, and potentially a sentinel lymph node biopsy to assess whether the cancer had spread to the nearby lymph nodes. Staging helps guide treatment decisions and provides valuable information about the extent of the disease.	Once the staging was complete, Emily met with her healthcare team to discuss the treatment options available to her. This phase involved shared decision making, where Emily, her significant others, and her healthcare providers discussed the potential benefits, risks, and side effects of various treatment approaches. They considered factors such as the stage of the melanoma, Emily's overall health, and her personal preferences and goals.	Emily underwent a wide local excision, which involved the surgical removal of the melanoma along with a margin of healthy tissue surrounding it. This surgical procedure aimed to completely remove the cancerous cells and reduce the risk of recurrence. The surgery phase included the operation itself and the subsequent recovery period, during which Emily focused on healing and regaining her strength.	Following her surgery, Emily entered a phase of regular follow-up appointments with her medical oncologist. These appointments involved physical examinations, monitoring for any signs of recurrence, and potentially additional imaging scans. The follow-up phase aimed to ensure early detection of any potential issues and to address any concerns or questions Emily had about her recovery.	Based on the staging and other factors, Emily and her medical oncologist decided to proceed with adjuvant therapy as an additional preventive measure. In this phase, Emily underwent immunotherapy to further reduce the risk of melanoma recurrence. This phase involved regular treatment sessions, monitoring for side effects, and ongoing communication with her healthcare team.	As Emily completed her treatment and her surveillance showed no signs of recurrence, she transitioned into a phase of returning to her normal life. This phase involved rebuilding her strength and confidence, resuming her daily activities, and embracing a new sense of appreciation for life. Emily's story became a testament to resilience and served as inspiration to others facing similar challenges.
Patient Upon receiving her melanoma diagnosis, Emily felt a range of emotions including fear, shock, and concern about what the future held. She leaned on her loved ones, including her boyfriend Sebastian, for emotional support during this challenging time. Emily sought out information to better understand her diagnosis and actively engaged with her healthcare team to gather all the necessary details about her condition.	**Patient** Throughout the staging phase, Emily felt a sense of anticipation and anxiety. She relied on Sebastian's presence for comfort and strength during medical appointments and tests. Emily actively participated in discussions with the healthcare team, asking questions and seeking clarity about the stage of her melanoma. She wanted to ensure she had a comprehensive understanding of her prognosis and treatment options.	**Patient** The patient actively participates in the treatment planning phase, discussing treatment options with the healthcare team. They may have questions about the benefits and risks of each treatment modality and the potential impact on their quality of life. The patient's emotions may range from hopefulness to concern as they consider the recommended treatment plan.	**Patient** Significant others may feel heightened concern and worry as the staging process helps determine the extent and severity of the melanoma. They may accompany the patient to appointments for imaging scans and other tests, offering emotional support throughout the process.	**Patient** The patient may go through a range of emotions, including shock, fear, and uncertainty upon receiving a melanoma diagnosis. They may rely on their significant others for emotional support during this time. The patient may have concerns about the implications of the diagnosis, the treatment process, and the impact on their daily life.	**Patient** The patient may experience heightened anxiety and anticipation during the staging phase. They may undergo various tests and procedures, which can be physically and emotionally demanding. The patient may have concerns about the potential spread of the melanoma and the implications for their treatment options and prognosis.	**Patient** The patient actively participates in the treatment planning phase, discussing treatment options with the healthcare team. They may have questions about the benefits and risks of each treatment modality and the potential impact on their quality of life. The patient's emotions may range from hopefulness to concern as they consider the recommended treatment plan.
Upon learning about Caroline's diagnosis of melanoma, Caroline's mom experienced a wave of shock and concern. She felt a deep sense of worry for her daughter's well-being and had many questions and fears about what the future held. She sought solace in gathering information and educating herself about melanoma, wanting to be as supportive as possible throughout Caroline's journey.	During the staging phase, Caroline's mom accompanied her to various medical appointments and tests. She provided emotional support, offering a comforting presence during the sometimes anxiety-inducing process. Caroline's mom actively listened and engaged with the healthcare team, seeking a clear understanding of the stage of Caroline's melanoma and what it meant for her treatment and prognosis.	1. Shared decision making became a crucial aspect of this phase for Caroline's mom. She actively participated in discussions alongside Caroline and the healthcare team, voicing her concerns, and asking questions about treatment options. Caroline's mom played an essential role in helping Caroline navigate the decision-making process, offering emotional support, and helping her evaluate the potential benefits and risks of different treatment approaches.	Caroline's mom was a pillar of strength for her daughter during the surgical phase. She provided practical assistance, ensuring that Caroline's pre-surgery preparations were in order, such as coordinating transportation and arranging necessary accommodations. During Caroline's recovery, her mom provided care and support, tending to her needs and ensuring a comfortable healing environment.	Accompanying Caroline to follow-up appointments, Caroline's mom offered moral support and acted as a second set of ears during discussions with the medical oncologist. She actively engaged in conversations, asking questions and seeking clarification about the surveillance plan and what signs of recurrence they should be vigilant for. Together, they celebrated each follow-up visit that showed no signs of cancer recurrence, providing reassurance and hope.	Throughout Caroline's adjuvant therapy phase, Caroline's mom played an integral role in providing emotional support and practical assistance. She accompanied Caroline to treatment sessions, offering a comforting presence and providing distractions to help make the experience more bearable. Caroline's mom also diligently monitored Caroline's well-being during treatment, providing care and assistance as needed, and ensuring Caroline followed the prescribed treatment regimen.	As Caroline transitioned back to her normal life, Caroline's mom celebrated this milestone with joy and relief. She recognized the strength and resilience her daughter had shown throughout the journey and embraced a renewed sense of appreciation for life's precious moments. Caroline's mom continued to be an unwavering source of support, offering encouragement and helping Caroline adjust to her "new normal" while remaining vigilant about sun protection and regular check-ups.
Clinician Upon diagnosing Emily with melanoma, the doctor recognized the importance of providing clear and accurate information while delivering the news in a compassionate manner. They understood the significance of this moment for Emily and her loved ones and took the time to address their concerns and answer their questions. The doctor provided guidance, explaining the next steps in the diagnostic process and outlining the importance of early detection and treatment.	During the staging phase, the doctor played a critical role in determining the extent of Emily's melanoma. They ordered and interpreted tests, ensuring accurate staging to guide treatment decisions. The doctor provided Emily with a comprehensive explanation of the staging results, discussing the implications and potential treatment options. They were empathetic, understanding the emotional impact this information could have on Emily and her support system.	The doctor engaged in shared decision making with Emily, actively involving her in the treatment planning process. They presented various treatment options, discussing the potential benefits and risks of each approach. The doctor considered Emily's preferences, values, and goals, ensuring her voice was heard. They provided guidance based on their expertise, helping Emily navigate the complexity of treatment decisions while considering her overall well-being.	During the surgical phase, the doctor led the surgical team responsible for removing Emily's melanoma. They ensured that Emily received appropriate pre-operative preparations, coordinating with other healthcare professionals involved in her care. During the surgery, the doctor skillfully performed the procedure, focusing on achieving optimal oncological outcomes while prioritizing Emily's safety. They communicated with Emily and her loved ones, providing updates and addressing any concerns that arose.	The doctor played a crucial role in Emily's follow-up care, monitoring her progress and assessing her response to treatment. During follow-up appointments, they conducted thorough examinations and ordered appropriate tests to detect any signs of recurrence. The doctor communicated the results clearly, offering explanations and addressing any questions or concerns that Emily and her loved ones had. They celebrated positive outcomes, providing encouragement and instilling a sense of confidence in Emily's ongoing care.	If adjuvant therapies were deemed necessary, the doctor guided Emily through this phase. They explained the purpose and potential benefits of adjuvant therapies, ensuring that Emily understood the treatment plan. The doctor closely monitored Emily's response to therapy, adjusting the treatment regimen as needed based on her progress and potential side effects. They provided ongoing support and addressed any concerns that arose during this phase.	As Emily transitioned back to her normal life, the doctor emphasized the importance of continued surveillance and follow-up care. They communicated the need for regular check-ups and reiterated the significance of sun protection and self-examinations. The doctor celebrated milestones with Emily, acknowledging her progress and providing guidance on maintaining a healthy lifestyle. They served as a source of knowledge and support, ensuring that Emily felt empowered and cared for during this phase of her journey.

Pre-consultation

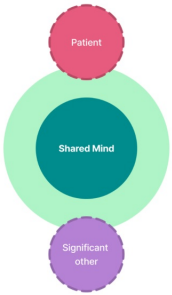
Patients usually struggle to be loaded with lots of information, all in once in a consultancy session, they prefer to know a bit more about basic knowledge prior to the consultation to be able to frame their questions and concerns

consultation

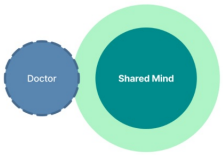


In stressful situations where doctors, patients, and significant others face a disease, they may forget to mention all their preferences due to uncertainty and stress, not because they do not want to, but because they are under emotional distress. To overcome this, DST create a immersive environment, come up with tailored topics based on ones unique properties, ask open-ended questions, provide information, and start to cluster them and visualize them in the shared mind space. one problem is that doctors are dealing with more patients, so it would be helpful to have diffrent shared minds.

Post consultation



Patients and SO can practice sharing their prefrences based on some offered topics in a chill home setting as well, they can develope the shared mind together and they can explore the possible optionbs in a chill setting. that may help them to be more



Meantime, doctors start to perceive more about the preferences, they can compare it with the outcome of DST based on the evidence based clinical trials regarding rate of compatibility considering survival, reassurance and quality of life.

TP1

Various Treatment Options

Surgery for melanoma
عمل جراحی برای ملانوما

Melanomas are surgically removed. This type of cancer rarely spreads through the body. If it does, the metastases usually occur in the lymph nodes, which will then have to be surgically removed as well. If the cancer has spread to other parts of the body, we will have to determine whether surgery is still an option for you. Other treatment options, such as drugs, may be more beneficial for you.

- Melanomas are usually removed under local anesthesia (بیهوشی).
- The surgery does not require hospital admission.
- Some people will need a skin transplant in order to cover up the wound.
- If your melanoma has spread to the lymph nodes and they have to be surgically removed, you will have to be admitted to the hospital.
- The removed **tissue**(بافت) will be tested at the laboratory.

Immunotherapy
ایمونوتراپی(تقویت سیستم ایمنی)

Immunotherapy is cancer treatment that enhances your immune system's ability to destroy melanoma cells and prevent their spread. These therapies **are key in treating advanced melanoma to help prevent its spread** — and even provide a cure, in some cases

Immunomodulators

- Aldesleukin
- Atezolizumab in combination with **vemurafenib** and **cobimetinib**)
- Interferon alfa-2b
- Ipilimumab
- pilimumab + Nivolumab
- Nivolumab
- Pegylatlerferon alfa-2b
- Pembrolizumabla

Oncolytic Virus Therapy
Injection of oncolytic viruses to tumours that regress or disappear.

- T-VEC...

Targeted therapy

Targeted therapy is a type of cancer treatment that halts the growth and division of cancer cells through medicine that blocks the specific molecules that cancer cells use for growth and survival.

Therapy with monoclonal antibodies.

Therapy using small molecule drugs that stop the signals inside of the cancer cells that regulate growth, cell division and survival. This kills the cancer cells, or stops their growth. The medicine works from inside of the cells.

T-VEC

T-VEC is a new and safe treatment type that can be used for metastases as a result of Melanoma. In this treatment, we will administer the virus responsible for cold sores (تبخال), adapted to destroy cancer cells and strengthen the immune system against cancer, into the metastases. These will shrink and disappear mostly or entirely.

Diagnosis Options

Care Path

Risk Factors for Melanoma

Some risk factors, like smoking and excess sun exposure, can be changed.

Some of them like your age or family history, can't be changed.

Risk factor:
Anything that raises your risk of getting a disease such as cancer. Different cancers have different risk factors.

Ultraviolet (UV) light exposure: The majority of melanomas have UV exposure as a major risk factor. UV rays are primarily produced by sunlight. Sunlamps and tanning beds are additional UV ray sources.

Moles: A mole is a benign (non-cancerous), pigmented tumor also known as a nevus. Moles rarely develop in newborns; instead, they frequently first show up in children and young adults. The majority of moles never cause any issues, but having numerous moles increases the risk of developing melanoma.

Fair skin, freckling, and light hair: African Americans have a much lower risk of developing melanoma than do White people. People who have blue or green eyes, red or blond hair, or fair skin that freckles or burns easily are more susceptible.

Family history of melanoma: If one or more of the first-degree relatives (parents, brothers, sisters, or children) have had melanoma, the risk of developing the disease is increased. 10% of all melanoma patients have a family history of the condition.

Personal history of melanoma or other skin cancers: A person who has already had melanoma is more likely to develop it once more. Melanoma risk is also higher in people who have had basal or squamous cell skin cancers.

Having a weakened immune system: The immune system of a person aids in the defence against skin and other organ cancers. Many different types of skin cancer, including melanoma, are more common in people who have immune systems that have been compromised (either by specific illnesses or medical treatments). For instance, medications that weaken the immune system are frequently given to organ transplant recipients to help them avoid rejecting the new organ. This raises their melanoma risk. Furthermore, HIV frequently weakens immune systems and puts people at higher risk for melanoma.

Being older: Melanoma is more likely to occur in older people, but it is also found in younger people. In fact, melanoma is one of the most common cancers in people younger than 30 (especially younger women). Melanoma that runs in families may occur at a younger age.

Being male: In the United States, men have a higher rate of melanoma than women, although this varies by age. Before age 50, the risk is higher for women; after age 50 the risk is higher in men.

Xeroderma pigmentosum: Xeroderma pigmentosum (XP) is a rare, inherited condition that affects skin cells' ability to repair damage to their DNA. People with XP have a high risk of developing melanoma and other skin cancers when they are young, especially on sun-exposed areas of their skin.

Melanoma

Melanoma is a type of skin cancer which happen melanocytes, the cells that give the skin its tan or brown color, start to grow out of control. When compared to other types of skin cancer, melanoma is far less common. Yet melanoma is more harmful because, if not detected and treated promptly, it is considerably more likely to spread to other bodily regions. Melanoma tumors are often brown or black because the majority of melanoma cells still produce melanin. Certain melanomas, however, do not produce melanin and might therefore appear pink, tan, or even white.

Types of Melanoma

Lentigo Maligna:
Melanoma in situ skin cancer on sun damaged skin on the head and neck

Its a type of melanoma so there is the chance that it can continue to grow wider into the skin

There is a chance **metastasize** (Spread through the body)

Surgery is typically recommended treatment option

Since the amount of margins needed to clear this type of melanoma may be larger, there are other options when surgery is not an option or not preferred

- Contraditions for surgery when there are other major comorbidities or conditions.
- Surgical excisions can lead to deforming surgery and necrosis action.
- Patients may have problematic reconstruction following excision due to...

https://www.cancer.org/cancer/melanoma-skin-cancer/about/what-is-melanoma.html

DESIGN FOR our future

TU Delft

IDE Master Graduation

Project team, Procedural checks and personal Project brief

This document contains the agreements made between student and supervisory team about the student's IDE Master Graduation Project. This document can also include the involvement of an external organisation, however, it does not cover any legal employment relationship that the student and the client (might) agree upon. Next to that, this document facilitates the required procedural checks. In this document:

- The student defines the team, what he/she is going to do/deliver and how that will come about.
- SSC E&SA (Shared Service Center, Education & Student Affairs) reports on the student's registration and study progress.
- IDE's Board of Examiners confirms if the student is allowed to start the Graduation Project.

USE ADOBE ACROBAT READER TO OPEN, EDIT AND SAVE THIS DOCUMENT

Download again and reopen in case you tried other software, such as Preview (Mac) or a webbrowser.

STUDENT DATA & MASTER PROGRAMME

Save this form according the format "IDE Master Graduation Project Brief_familyname_firstname_studentnumber_dd-mm-yyyy". Complete all blue parts of the form and include the approved Project Brief in your Graduation Report as Appendix 1 !

family name: Rahmani

initials: K. given name: Kamran

student number:

street & nr.:

zipcode & city:

country:

phone:

email:

Your master programme (only select the options that apply to you):

IDE master(s): ☐ IPD ★ DI ☐ SPD

2nd non-IDE master:

Individual programme: (give date of approval)

honours programme: ☐ Honours Programme Master

specialisation / annotation: ★ Medisign ☐ Tech. in Sustainable Design ☐ Entrepreneurship

SUPERVISORY TEAM **

Fill in the required data for the supervisory team members. Please check the instructions on the right !

** chair: Prof. dr. Rietjens, J.A.C. dept. / section:

** mentor: Dr. Ing. Rozendaal, M.C. dept. / section:

2nd mentor:

organisation:

city: country:

comments (optional):

Chair should request the IDE Board of Examiners for approval of a non-IDE mentor, including a motivation letter and c.v..

Second mentor only applies in case the assignment is hosted by an external organisation.

Ensure a heterogeneous team. In case you wish to include two team members from the same section, please explain why.

Personal Project Brief - IDE Master Graduation

TU Delft

Designing data-driven decision support tool for oncology (Melanoma) project title

Please state the title of your graduation project (above) and the start date and end date (below). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

start date 15 - 03 - 2023 11 - 08 - 2023 end date

INTRODUCTION **

Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money,...), technology, ...).

People with cancer and their loved ones often have to make complex decisions about different treatment regimens (like chemotherapy, radiotherapy, surgery - or even not doing any treatments). This complexity could be either due to logistical issues (such as waiting times for tests and the inability to obtain information from other hospitals) or a lack of understanding of the complete treatment trajectory (including unclear responsibilities and inconsistency in information provision to patients) considering different risk profiles, potential outcomes. Indeed, high levels of stress, fear, disempowerment, and unwanted dependence on healthcare professionals could happen due to this uncertainty (1).

Decision support tools (DST) are developed in accordance with the growing complexity of cancer treatment (2). They provide patients and caregivers with an overview of the available treatment options based on personal health information and evidence from clinical studies (3). Decision-support tools can be based on prognostic algorithms. This means that they support decision-making about cancer treatment by better predicting the outcomes of that treatment using the data that already exists. To produce and show information to clinicians and patients, these tools need person-specific data, computable biomedical knowledge, and genetic information besides taking into account the quality of life or individual preferences of patients (4,5).

The 4D PICTURE consortium, a multidisciplinary team comprised of individuals from nine European countries seeks to improve shared decision-making processes regarding cancer-related treatments by incorporating novel DSTs into the care path. They will anticipate treatment outcomes by building evidence-based, data-driven DSTs that use prognostic algorithms to forecast mortality, quality of life, and the likelihood of recurrence following certain treatments. This tool, which will be developed for patients with breast cancer, prostate cancer, and melanoma, should ideally be integrated into the communication between the patients and the doctors regarding the choice of treatment option while upholding the patient's preferences.

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introduction (continued): space for images

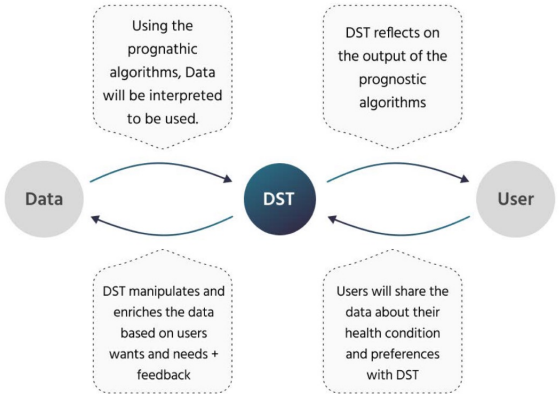


image / figure 1: Decision support tool (DST) in connection with the user and the data

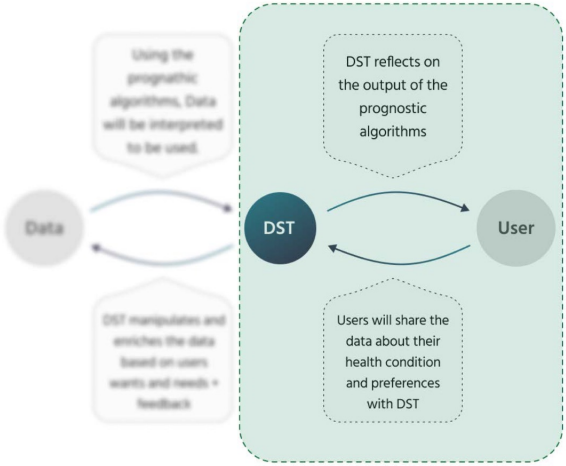


image / figure 2: potential design space for this project to develop the DST

Personal Project Brief - IDE Master Graduation

TU Delft

PROBLEM DEFINITION **

Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project.

While numerous decision-support tools have been developed to aid in the care path, these systems have not been widely adopted in clinical practice (6). One main reason noted is the lack of interaction design considerations in the design of these systems (7). Proper forms of human-computer interaction are needed to present clinical decision-support recommendations in a manner that supports clinicians and does not interrupt the workflow (8). Another main reason is sociocultural barriers like the healthcare professionals' idea of a loss of autonomy, the feeling of being replaced by the system, low computer literacy, lack of trust in the system, and failure to fulfill a perceived clinical need (9).
In many cases, the DTSs solely focus on accuracy as the statistical model has been extensively validated but the initial interface that allows public access had not been designed or tested for comprehension and usability (10). While the algorithms need to be statistically validated, they should also be easy to use, trustworthy, and produce outputs that are clear and useful to their users.
Even though the well-known design framework "human-centered design" is mentioned in various studies as a design strategy, the DSTs were not explicitly designed with the patients as the center (11). Focusing on human-centered design is critical to make such complex and emotionally difficult information available in a clear, perceivable, and unambiguous manner(12).
To effectively address these issues, DSTs should be applied to the care path in line with design interventions that ease the process of shared decision-making by accounting for non-medical determinants of health such as social determinants, patient-specific variables (e.g., patient history factors), comorbidities, and patient preferences and values (13) with an approach centered on both patients and clinicians. In other words, the envisioned tool should not only be adaptive to physicians' treatment pathways and time constraints, but it should also ensure that recommendations are tailored to the patient's unique circumstances and preferences.

ASSIGNMENT **

State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance: a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, ... In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

The purpose of this master's graduation project, in particular, is to iterate on an interactive tool for enhancing the shared decision-making process and the communication flow between clinicians and patients regarding cancer treatments. This tool should employ the results of prognostic algorithms, and then bring the preferences and values of patients to the middle to help the patient and doctor make the best decision they can.

Decision support tools have the potential to enhance cancer treatment decision-making, but how to correctly apply them to the context based on users' needs and wants is still unclear. Further better-designed interventions are required to ascertain the adaptability and effectiveness of DSTs(14). Current reviews reveal that in terms of audience, DSTs are either focused on clinicians or patients with different kinds of decisions and interactions. One is technical and medical, and the other is more about personal values and quality of life (8). So, investigations should be done on how these two different user groups come together, particularly how DSTs can enrich the relationship between patients and their medical care providers. Furthermore, we have to discover how this tool should be offered, how people should approach this tool and how should the interaction and communication flow take place within the context of use. The focus of this study will be on melanoma, which can affect people of different ages and sexes (15).
1- Get to know a better perception of the wants, needs, emotional state, and preferences of different stakeholders (patients, clinicians & significant others) by studying the literature, mapping the context(16), and designing by speculation and researching through design(17).2- Reflecting on the features of the envisioned interaction provided by an efficient decision-support tool 3- Make rough interactive prototypes and iterate as much as possible (considering the limitations of the project) on achieving the major and minor goals and the qualities of the interaction vision.4- Combine all the prototypes that were effective in achieving the aim into a robust whole and try to detail it to the point where we can test and elaborate on the degree to which we were able to meet the needs of the users.

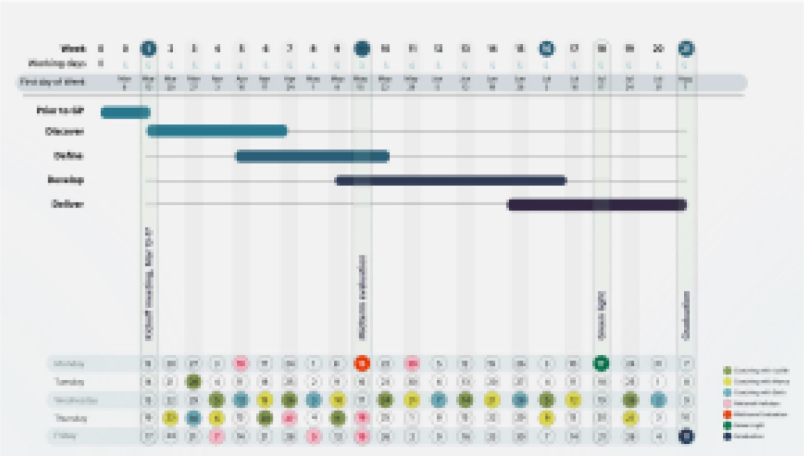
Initials & Name K. Rahmani Student number

Title of Project Designing data-driven decision support tool for oncology (Melanoma)

PLANNING AND APPROACH **

Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gant Chart by, for instance, explaining your approach, and please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any, for instance because of holidays or parallel activities.

start date 15 - 3 - 2023 11 - 8 - 2023 end date



Initials & Name K. Rahman Student number

Title of Project Designing data-driven decision support tool for oncology (Melanoma)

Personal Project Brief - IDE Master Graduation

TU Delft

MOTIVATION AND PERSONAL AMBITIONS

Explain why you set up this project, what competences you want to prove and learn. For example: acquired competences from your MSc programme, the elective semester, extra-curricular activities (etc.) and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge on a specific subject, broadening your competences or experimenting with a specific tool and/or methodology; .... Stick to no more than five ambitions.

Design is a multidisciplinary field, which is why I found it to be so exciting. When I first started looking for a graduation project, I had a plethora of ideas and keywords that I wanted to explore within my project. On one hand, I wanted to be focused on hands-on work, and I was sure I do not like to only do theoretical research. I wanted to prototype and iterate as much as possible and do the research through design. Indeed I always like it when you receive the main insights and takeaways while users interact with prototypes. On the other hand, I would prefer that this project make extensive use of the latest tools like artificial intelligence and machine learning. In fact, after thoroughly enjoying the Interactive Technology Design (ITD) course and learning the latest techniques for prototyping interactions, I wanted to establish those techniques in myself by employing them for addressing a real challenge. Furthermore, as I am planning to graduate with Medesign Specialisation, I was interested in a project focused on the medical field and that is how I ended up in the "4D picture" project.The statement that I always use to introduce myself as a designer is that I like to design on the border of tangible and digital. Indeed I like to make it possible to offer the complex capabilities of digital interfaces in a simple, less overwhelming, and understandable tangible form. As my previous master's took place in an Art school, being focused on how to shape and form products in a way that appeals to the user or evokes certain emotions, I consider my ability to develop concepts on how to offer a tangible platform to understand user wants and needs as what I bring to this project. And because of doing DR I was focused on the behaviors of users when approaching a product and the behavior of a product while being used by people, I want to consider the ability to establish a proper interaction flow between the user and the tool as my takeaway from this project.Another challenge that I want to take for my self-improvement is the fact that I want to become more confident in approaching people that can be the target user, initiate conversations with them and explore their desires. I want to step outside of my comfort zone and get to reach people and learn about their perspectives. I often felt I couldn't do this all on my one in most courses because we worked in teams, but this project will give me the opportunity to see if I can handle it on my own before starting a career. Indeed I want to keep my project user-centered, from the beginning to the end.

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FINAL COMMENTS

In case your project brief needs final comments, please add any information you think is relevant.

Due to space limitations, could not manage to put all the references in this document. They can be provided upon your request.

Initials & Name K. Rahmani Student number

Title of Project Designing data-driven decision support tool for oncology (Melanoma)