TORUS

Transforming the Objective Real-world measUrement of Symptoms

WP5 NU Storyboard-led Study

The life-cycle of the TORUS system

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UKRI Engineering and Physical Sciences Research Council

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WP5 NU | Storyboard Study Description

TORUS system in a home-monitoring system to measure progression of Parkinson's symptoms during clinical drug trials. The system comprises cameras and a wearable band. The system will be deployed to people's homes that wish to participate to clinical drug trials, for a period of up to 3 months for the purpose of initial validation.

The storyboard features the life-cycle of TORUS system from proposition, to installation, to living with the system and eventually to the end of the trial and the system's deployment. The storyboard employs three fictional characters living with Parkinson's and the TORUS system and illustrates different scenarios for supporting system control, medication logging, data annotation and activities' validation.

You are invited to explore the storyboard and respond to an accompanying survey which poses questions to investigate the acceptability, useability and user experience of different suggested interactions. It is important for us to map your concerns and any additional questions you might have.

WP5 NU | Storyboard Study – The Characters

Robert, 58

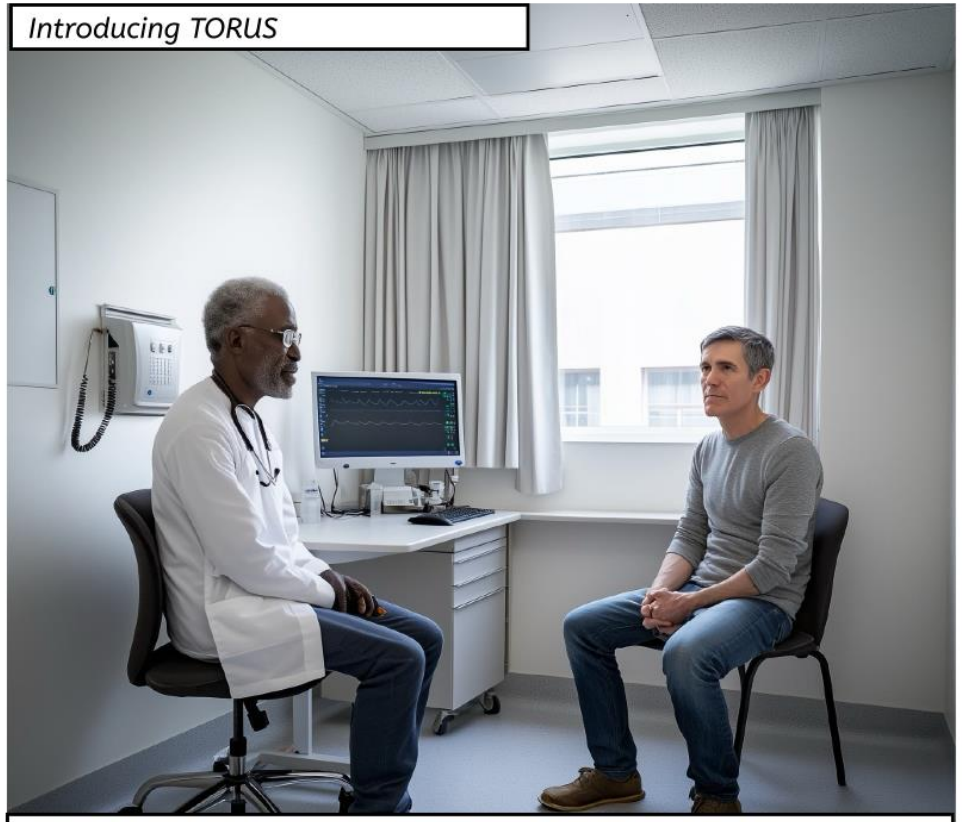
Jane, 73

David, 62

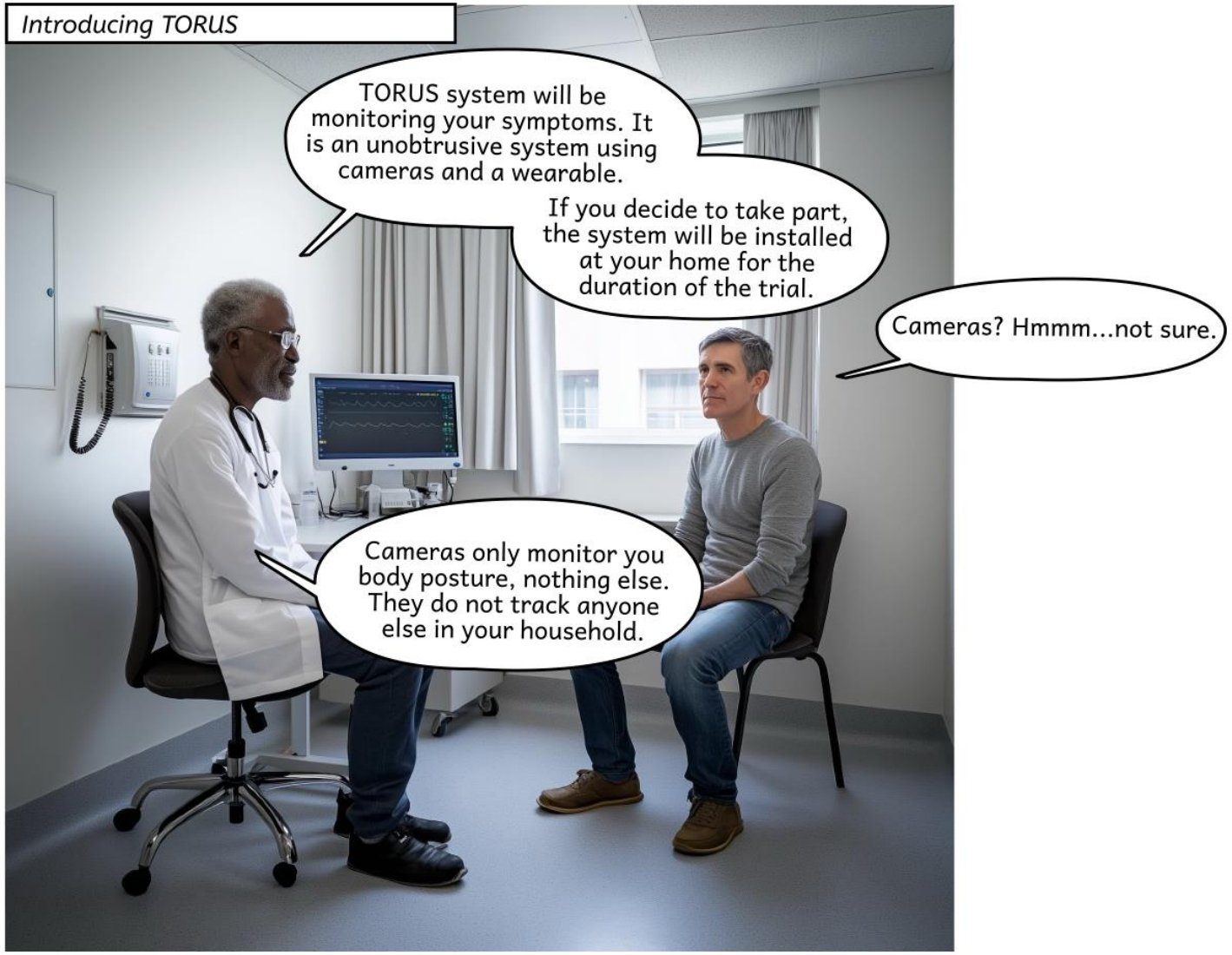
These three characters were generated with AI and the help of TORUS Patient Council members.

They represent people living with Parkinson's that took part in a clinical drug trial with TORUS system.

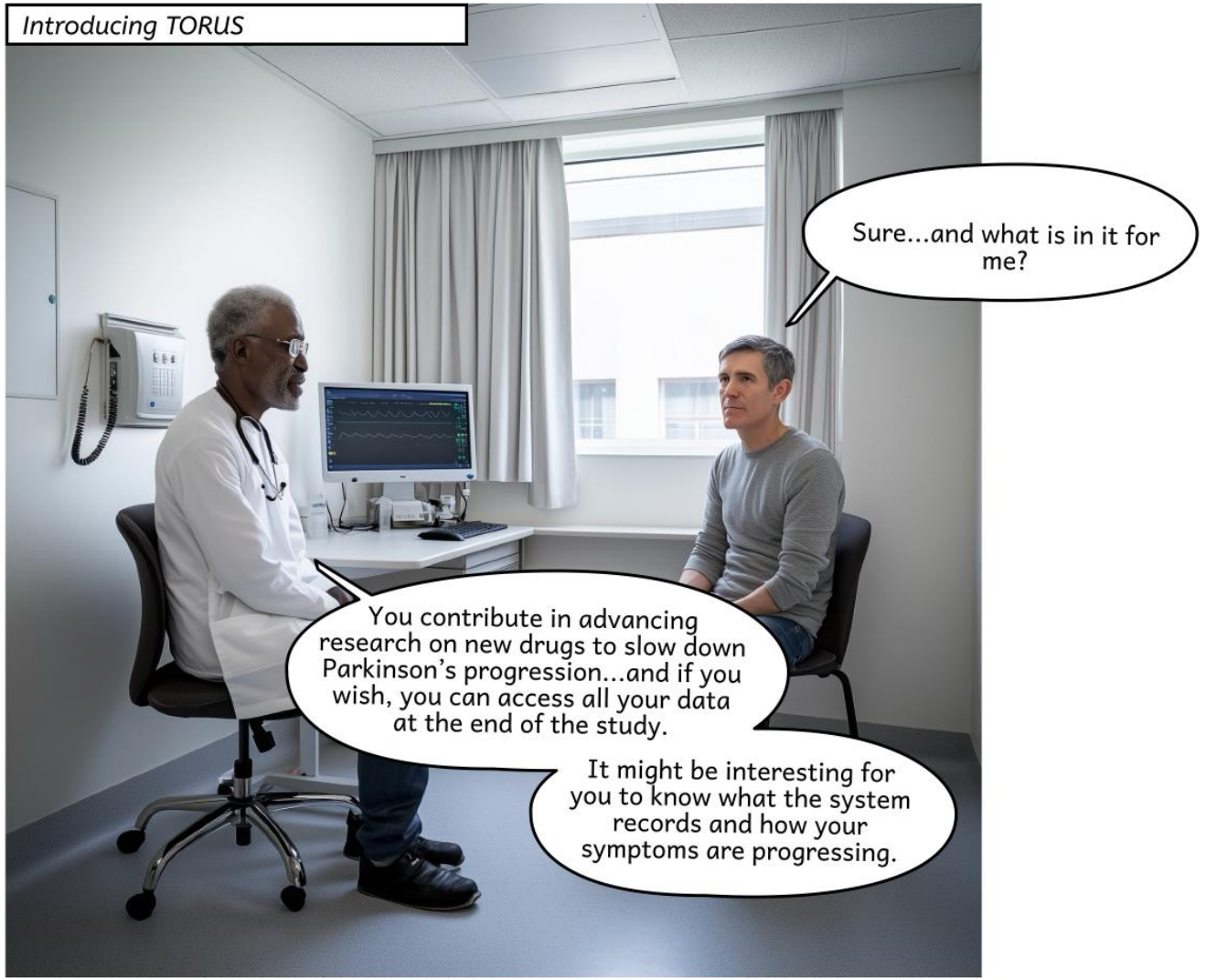
WP5 NU | Storyboard– TORUS Proposition



Robert has his planned appointment with a consultant doctor. At the end of his appointment, the consultant mentions a clinical drug trial supported by the TORUS system that was running, inviting Robert to take part. Robert asks to know more about the trial and the TORUS system, to make an informed decision about whether or not to take part.



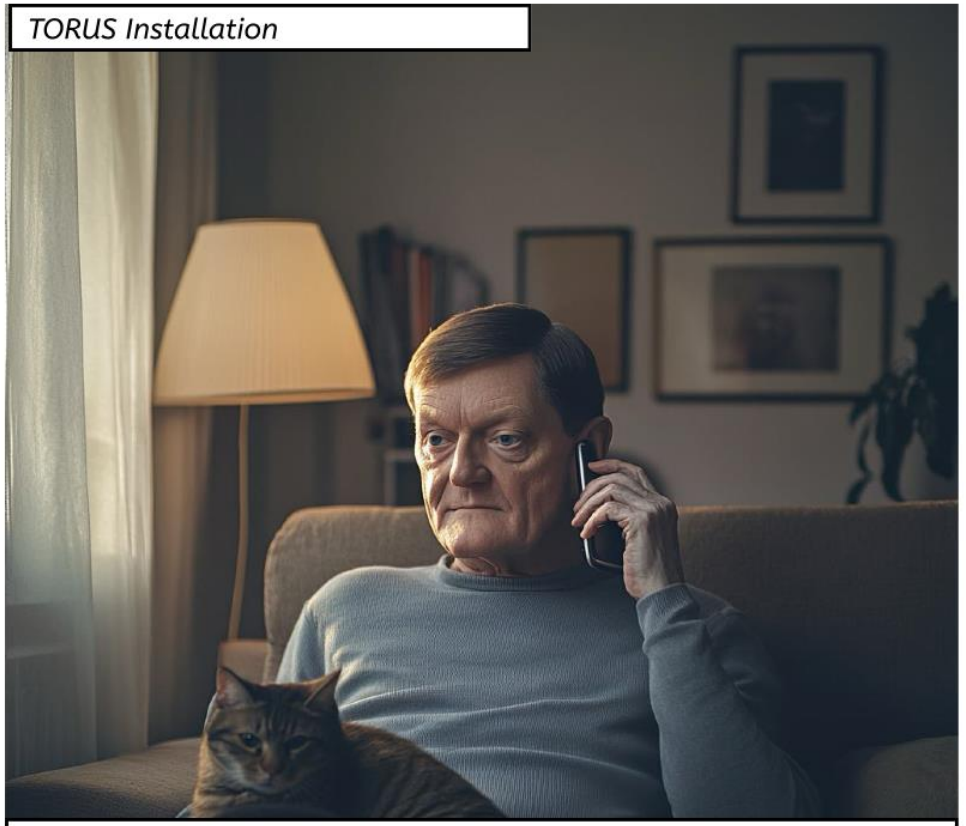
WP5 NU | Storyboard– TORUS Proposition



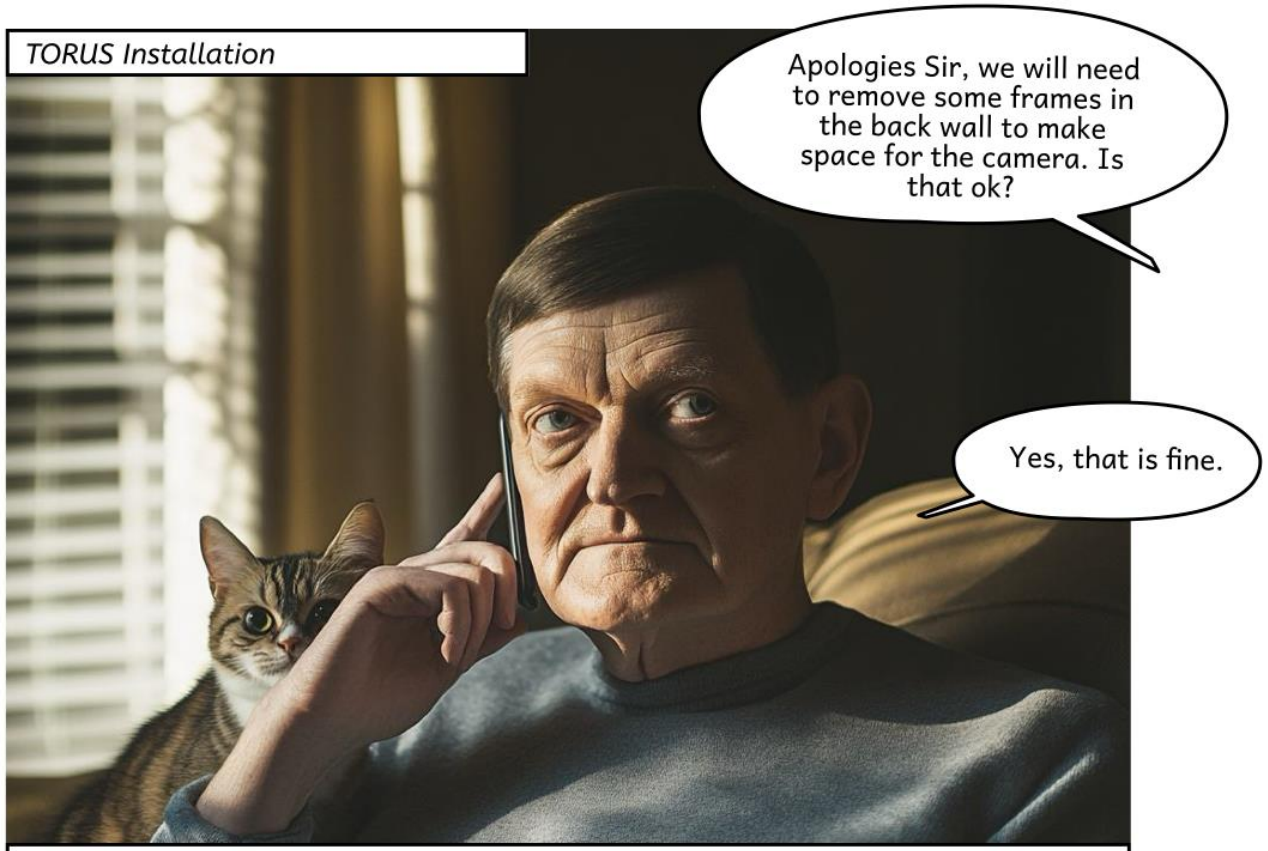
Questions

1. Do you find the presentation of the system appropriate?
2. What else would you find important to know before deciding to enroll in a clinical trial with the TORUS system?
3. What other questions would you have?

WP5 NU | Storyboard– TORUS Installation & Onboarding

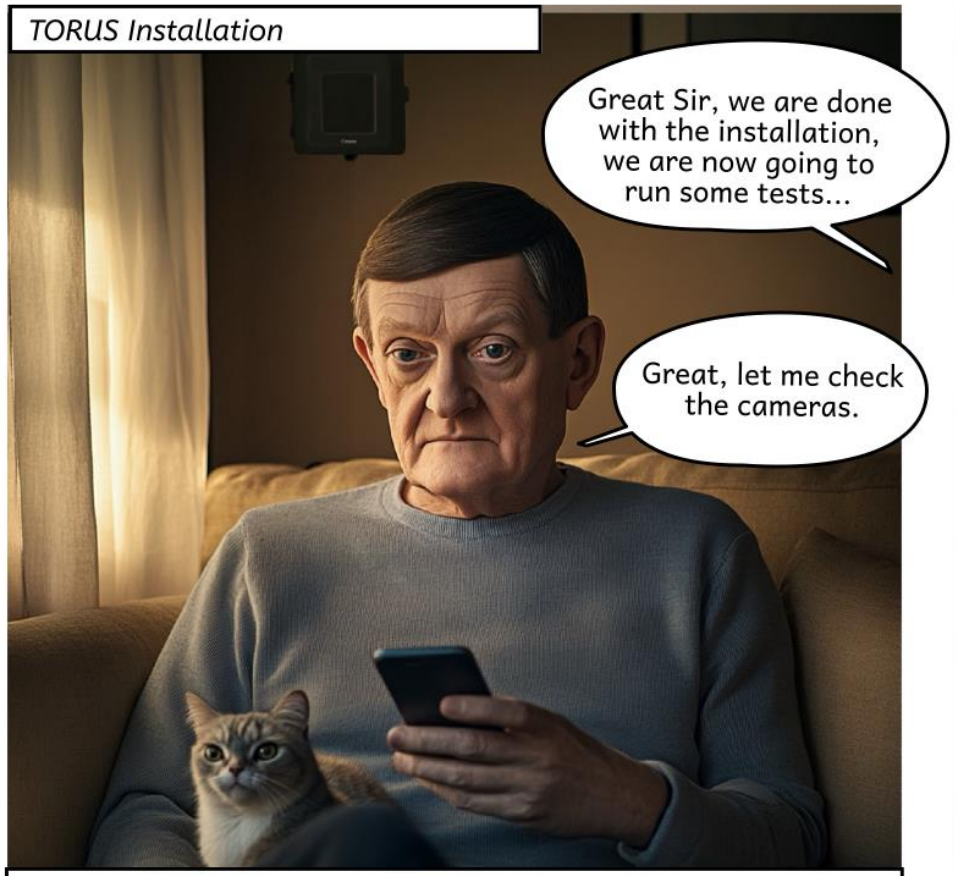


David has agreed to take part in a clinical drug trial that uses the TORUS system to record symptoms progression. Today is the day of the TORUS system installation at his home. David is sitting at his living room waiting for the technicians to arrive. He answers the doorbell on his phone. His wife lets the technicians in.

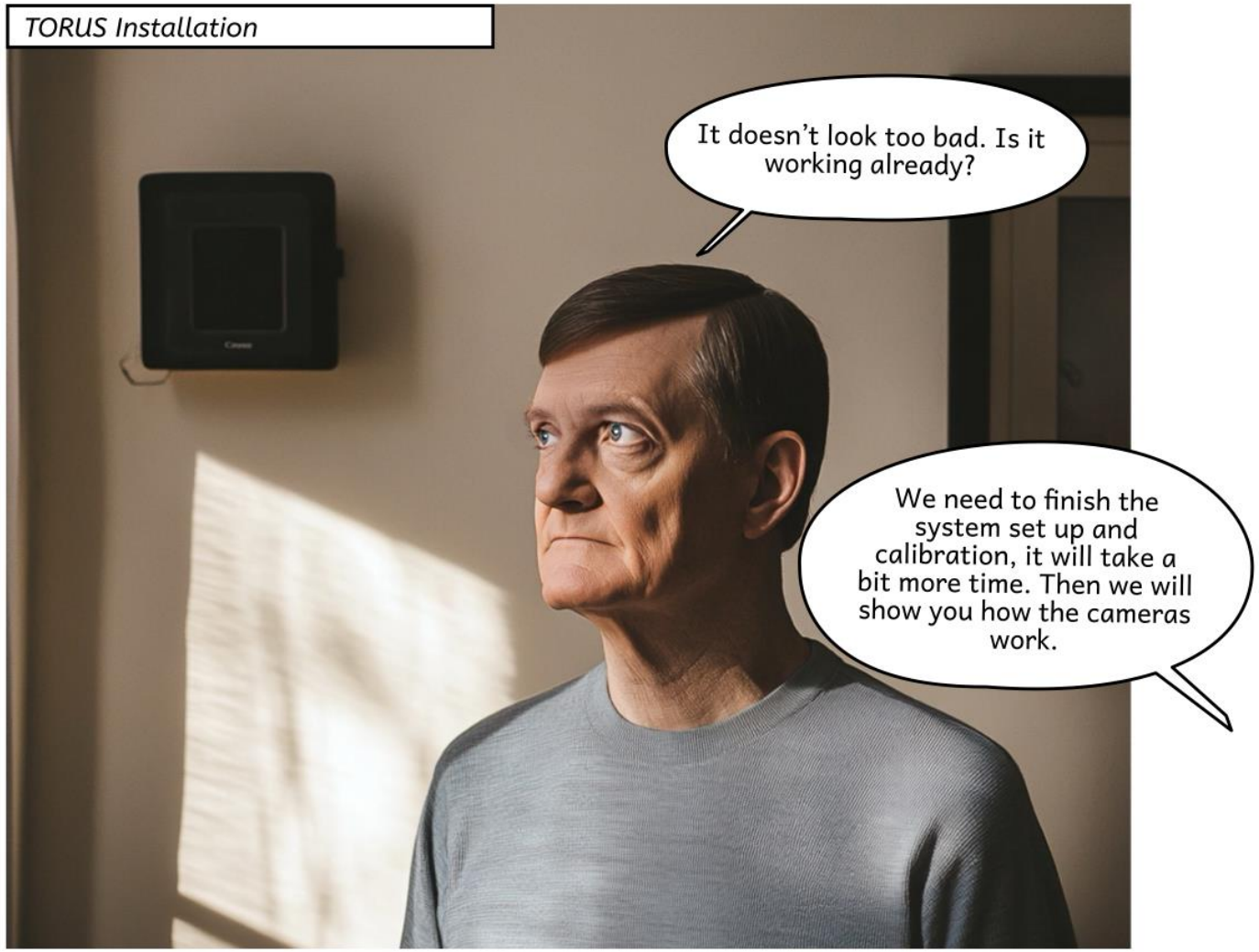


David has agreed to install three cameras in the communal areas of his house: one in the living room, one facing the front door, and one at the bottom of the stairs. These cameras will record David's posture and assess symptoms during walking, turning, and sitting or standing up. TORUS technicians will need to perform an assessment of the rooms' layout - i.e. test lighting in the rooms and remove potential obstacles to make sure the cameras will operate properly.

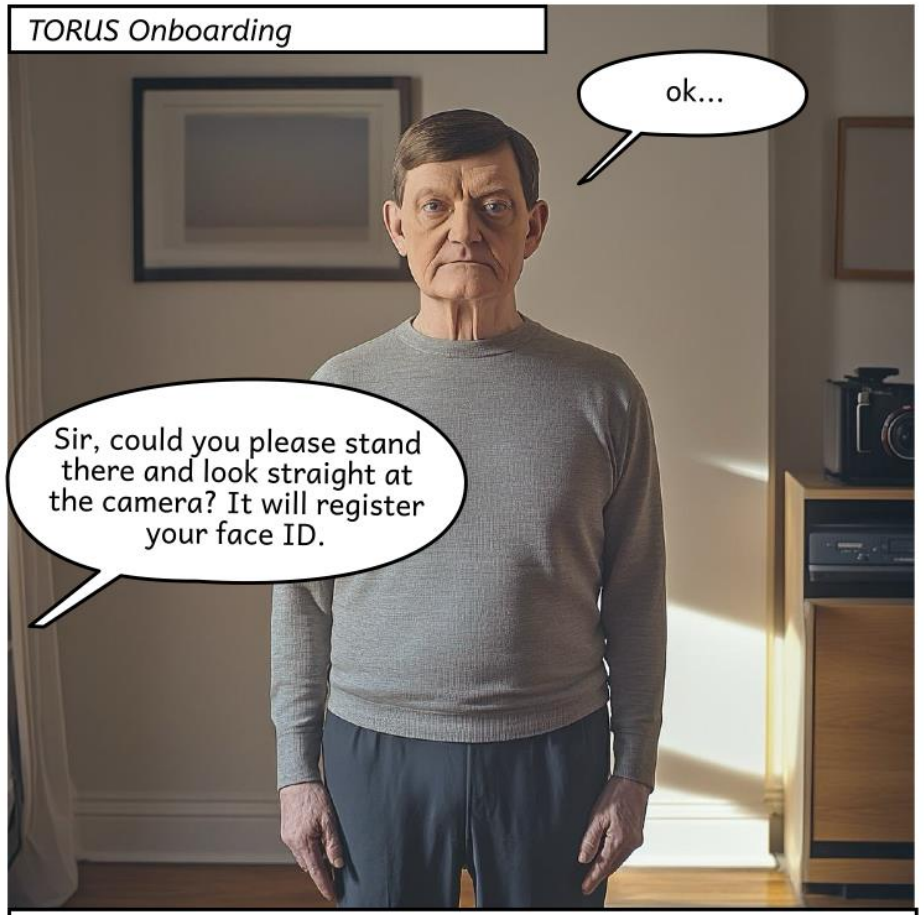
WP5 NU | Storyboard– TORUS Installation & Onboarding



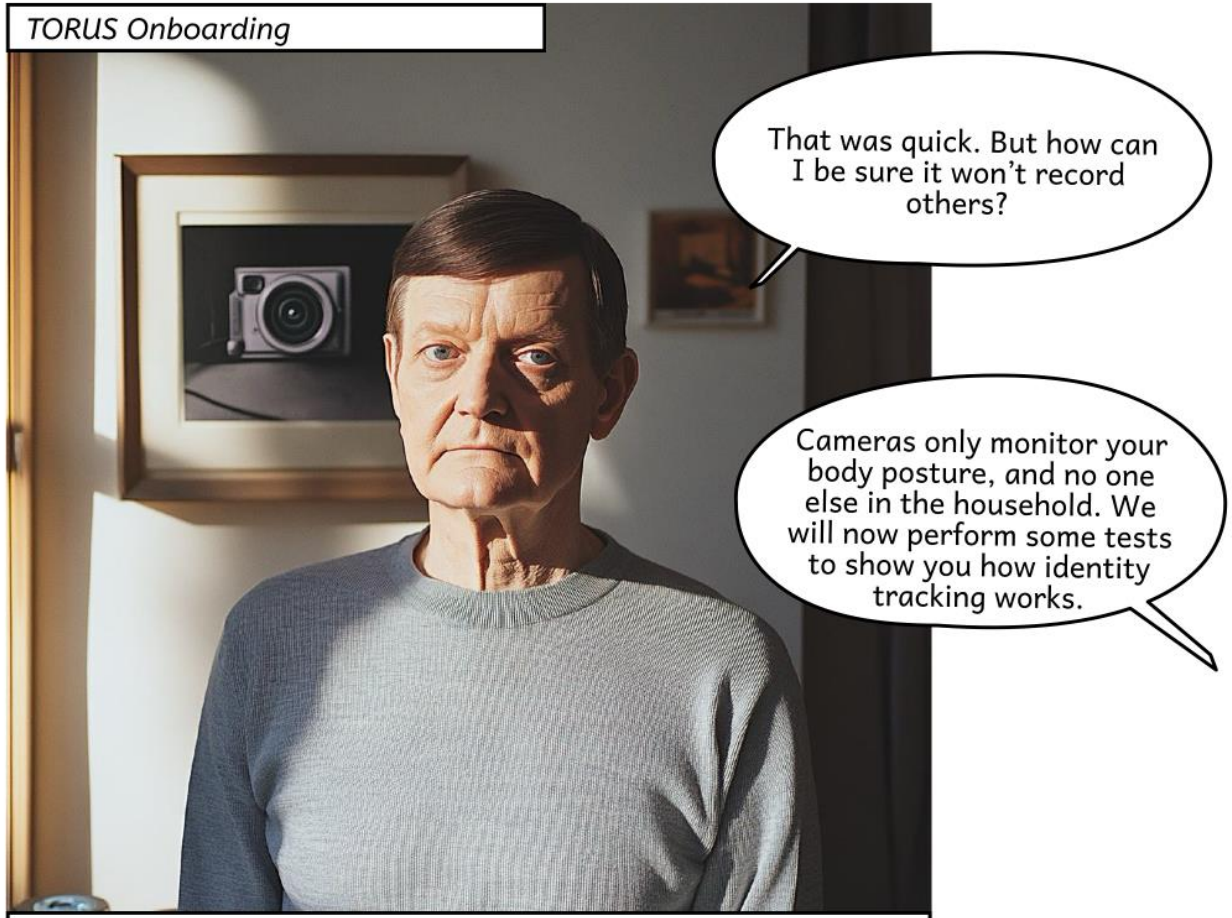
A couple of hours later, the installation of the cameras has finished. It is time to launch the system, calibrate it, and to make sure it works properly.



WP5 NU | Storyboard– TORUS Installation & Onboarding



It is time to activate the system and register David's identity. In that way, the system will only track David movements in the house and ignore everyone else. The system will not store any colour video, only stick figures representing different postures.



The identity registration was quick, but David has more questions.

WP5 NU | Storyboard– TORUS Installation & Onboarding

Testing the system

The technician shows a live recording from the camera in his tablet. The system has already scanned David's facial features and stored his ID, which appears written next to his live image. The technician performs multiple tests, with David going in and out of the room and bringing his wife in front of the camera, to test that the system accurately recognises only David. It all works smoothly.

Questions

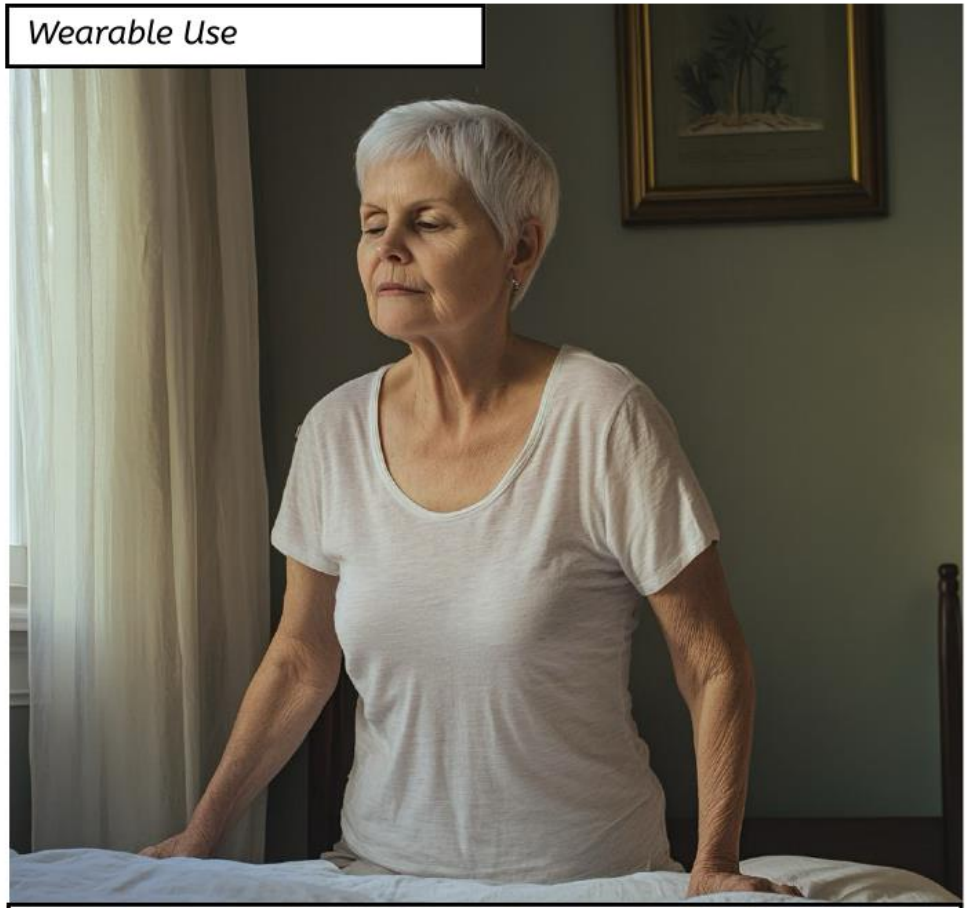
4. Would you be comfortable with this procedure?

5. What other information would you need to feel comfortable?

6. Would you have any concerns, and if so, what are they?

WP5 NU | Storyboard– TORUS Wearable Use

Wearable Use



Jane is participating in a clinical trial with the TORUS system. In the morning she takes her medication and gets ready for the day.

Charge Wearable

She is almost ready to leave the bedroom, but then she hears music in the background. It's a reminder to charge her TORUS band.

WP5 NU | Storyboard– TORUS Wearable Use

She goes to the docking station. She left one band charging overnight, while she was wearing the other one. The LED is green, indicating it is fully charged. She removes the one from her wrist and places it on the docking station. Then she picks the fully charged one.

Jane puts the charged band on, and gets ready to go down to have her breakfast.

Questions

7. Would you need a reminder to put on or to charge the band?

8. And if yes, what feedback from the docking station would be useful – i.e. light, noise.

9. Would you find swapping wearable bands to charge them useful?

WP5 NU | Storyboard– TORUS Medication & Symptoms Logging

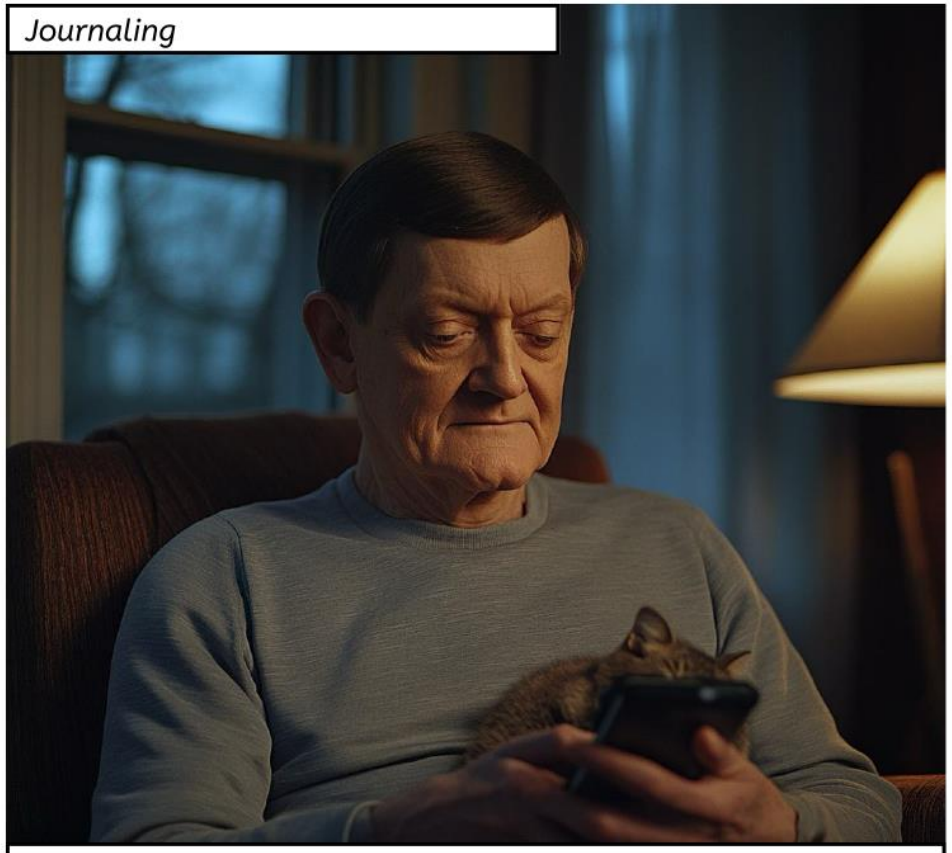
Medication Logging and Journaling

David drinks his morning cup of coffee in the kitchen. It is one hour post-medication, so he can soon have his breakfast with the company of his partner. As he sits there waiting for her to come over, he checks his tablet.

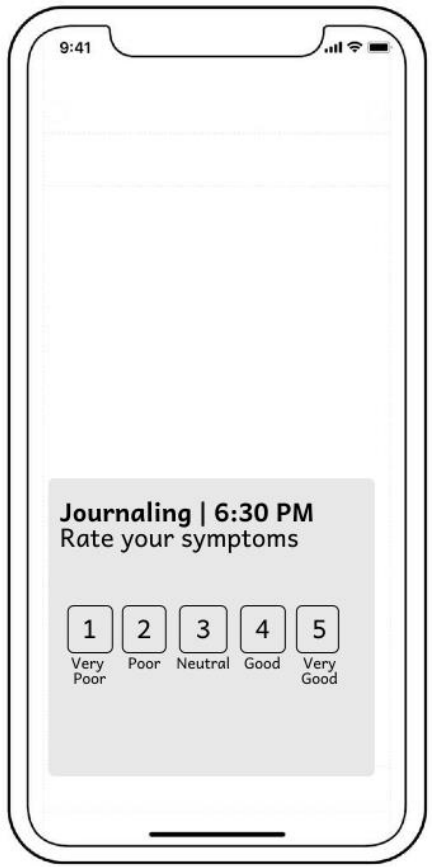
He has some notifications on his screen, to log his medication intake and rate his sleep. He presses a button to confirm he took his medication at 6:00AM. He provides a rating of his sleep: he logs a 4, which means good.

WP5 NU | Storyboard– TORUS Medication & Symptoms Logging

Journaling



Later that day, David goes over to his usual spot in the living room. He switches on the TV and lounges in his favourite chair with his cat on his lap. He waits for his wife to finish cleaning the kitchen to watch something together. He grabs his phone while waiting. He has some notifications on his screen, to rate his symptoms for the day and confirm his last medication intake.



Questions

10. Would you be happy logging and recording your medication and experience of symptoms manually (on a tablet/phone)?

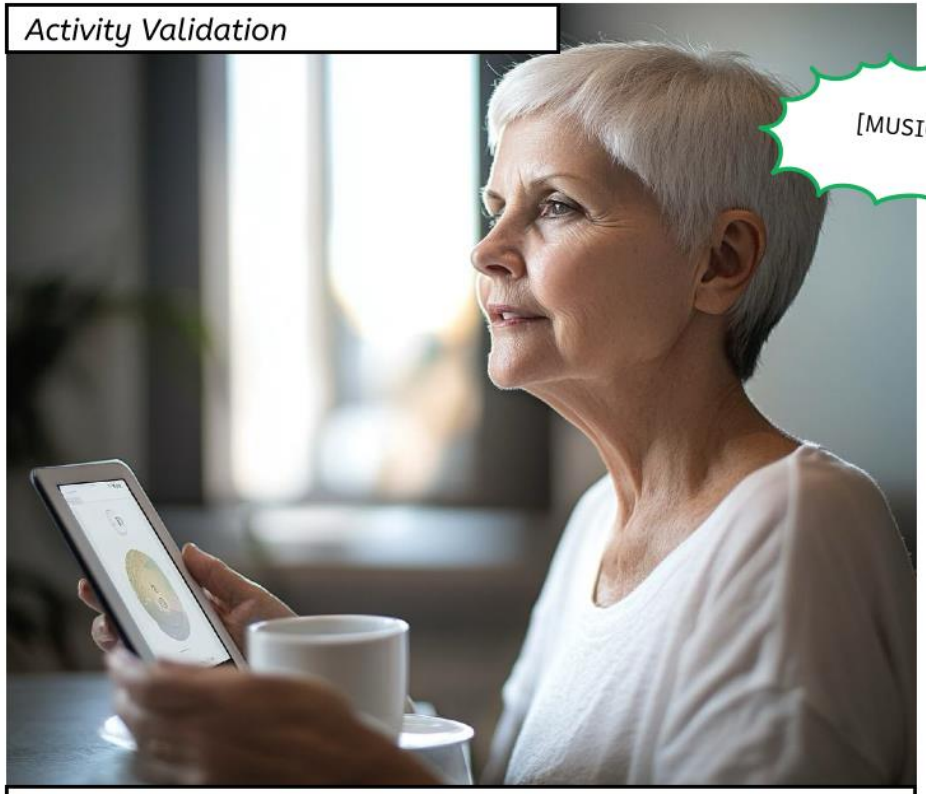
11. How often would you be willing to log them (e.g. more than daily, once a day, every few days, weekly etc.)?

12. What types of symptoms or experiences would you find meaningful to record?

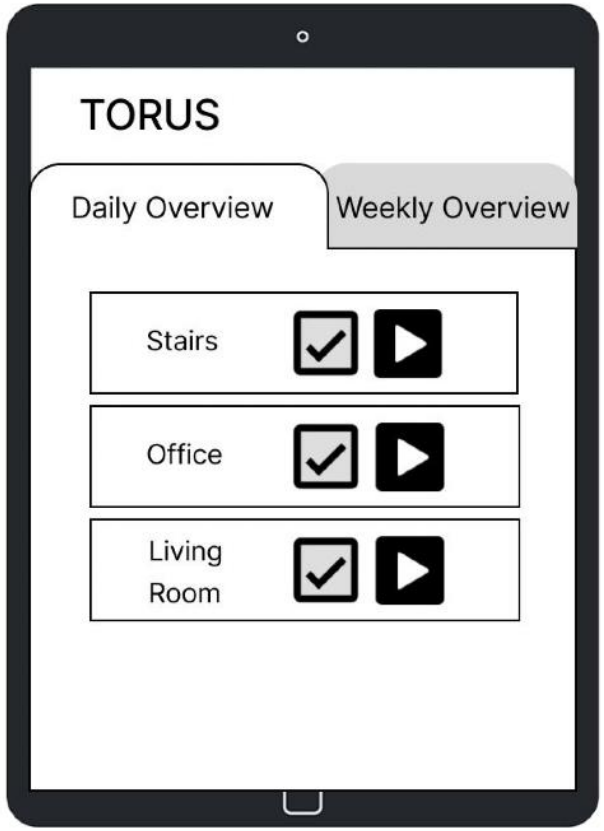
13. Would you be happy if somebody else was doing the recording (e.g. partner) for you?

WP5 NU | Storyboard– TORUS Activity Validation

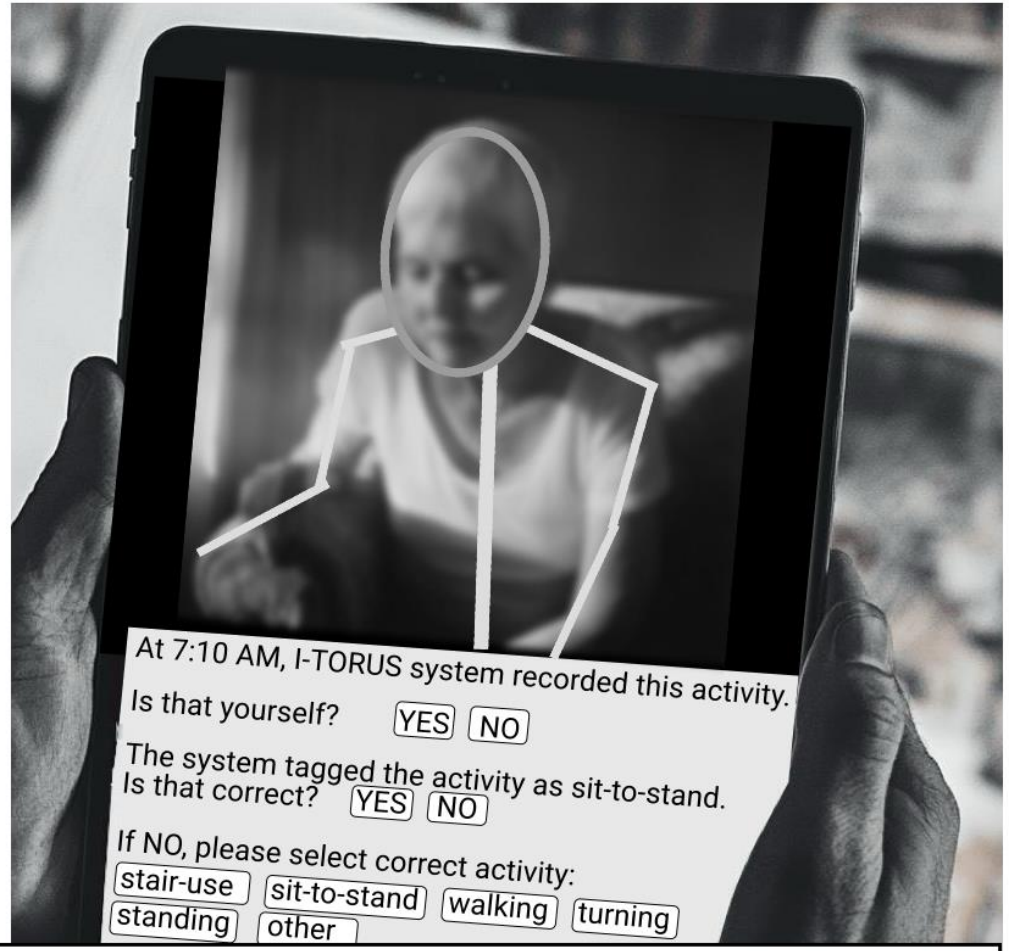
Activity Validation



Around lunchtime, Jane hears her tablet ringing. She opens the TORUS app on the tablet, and goes through her activities validation list. She has to review 10-15 short (10/15 second) blurred grayscale video-clips daily, to help the TORUS AI algorithms train. After she completes the review, the system deletes these video-clips. Jane tries to do most of them, but she often forgets or gets tired. Luckily, her partner helps her finish the task.



WP5 NU | Storyboard– TORUS Activity Validation



Jane watches the first video clip, showing her standing up from the sofa. For each of the video-clips, she has to validate that her identity is correct, and that the activity annotation provided by the system is correct. It doesn't take long, still, she leaves some for her husband to complete.

Questions

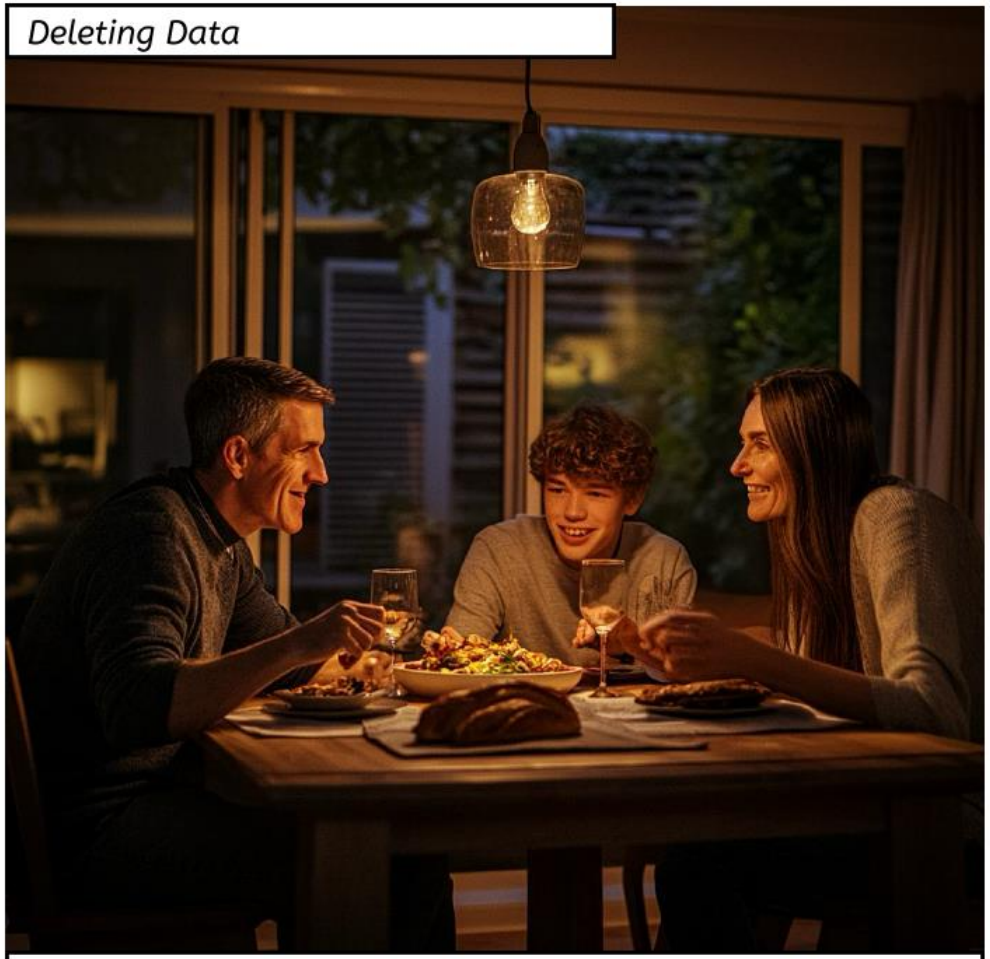
14. Would you be comfortable with this activity validation procedure?

15. How long for and how often would you be willing to do this validation activity (e.g. daily, every few days, weekly etc.)

16. Would you have any concerns about this procedure? If so, what are they?

WP5 NU | Storyboard– TORUS Data Deletion

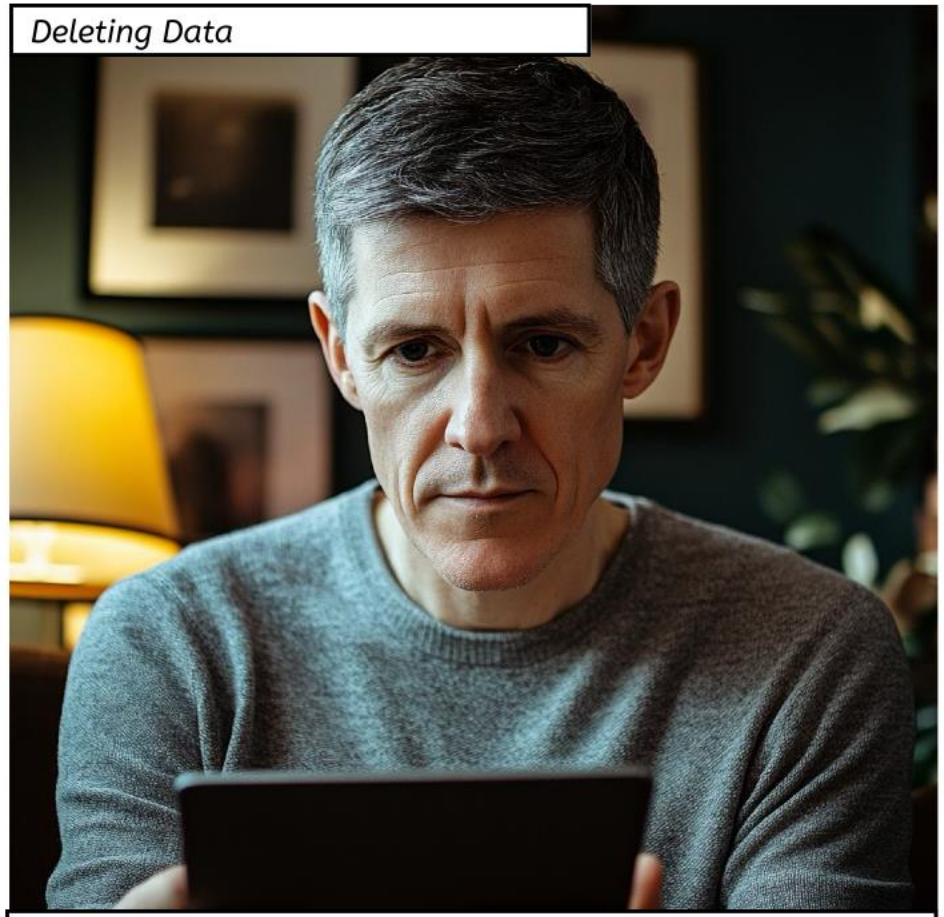
Deleting Data



Robert has dinner with his wife and son. He knows the camera doesn't record others, but he always feels uncomfortable when they are altogether and it is recording.

WP5 NU | Storyboard– TORUS Data Deletion

Deleting Data



After the dinner is over, Robert looks at his tablet. He has decided to delete the data captured during their dinner. He fills in a form stating the day-and-time interval he wishes to erase. He presses submit. He feels a bit better afterwards.

Questions

17. Would you want this functionality?

18. Would you consider this procedure to delete data as appropriate?

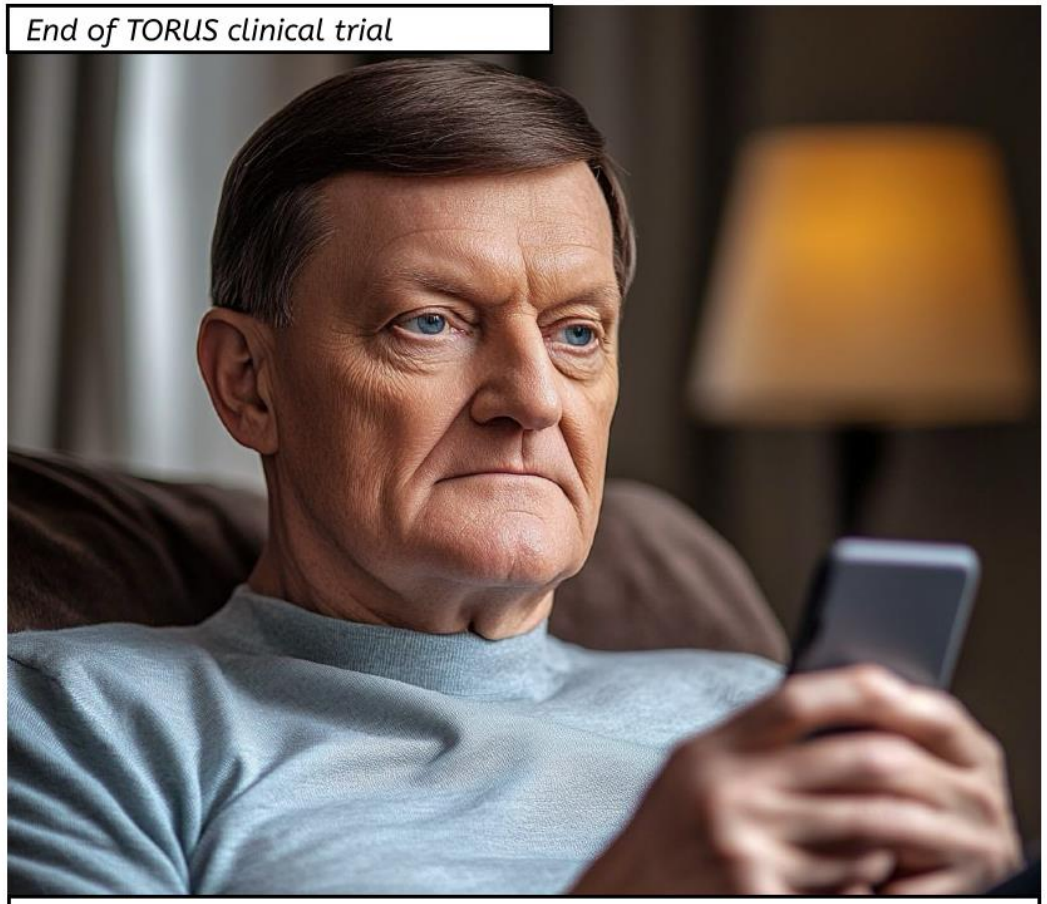
WP5 NU | Storyboard– TORUS End of Trial

David had organised for the equipment to be removed from his house at the end of the trial. This is completed quite swiftly. Only a few small holes remained on the walls, which were then covered by the picture frames that were hung back where they were originally.

David had requested his data to be shared with himself and a specialist consultant at the end of the trial. He would then receive a 20-minute phone call from the consultant to discuss his symptoms progression and the impact of medication. He was promised to also have access to his data file online. He is interested to see his own data charts.

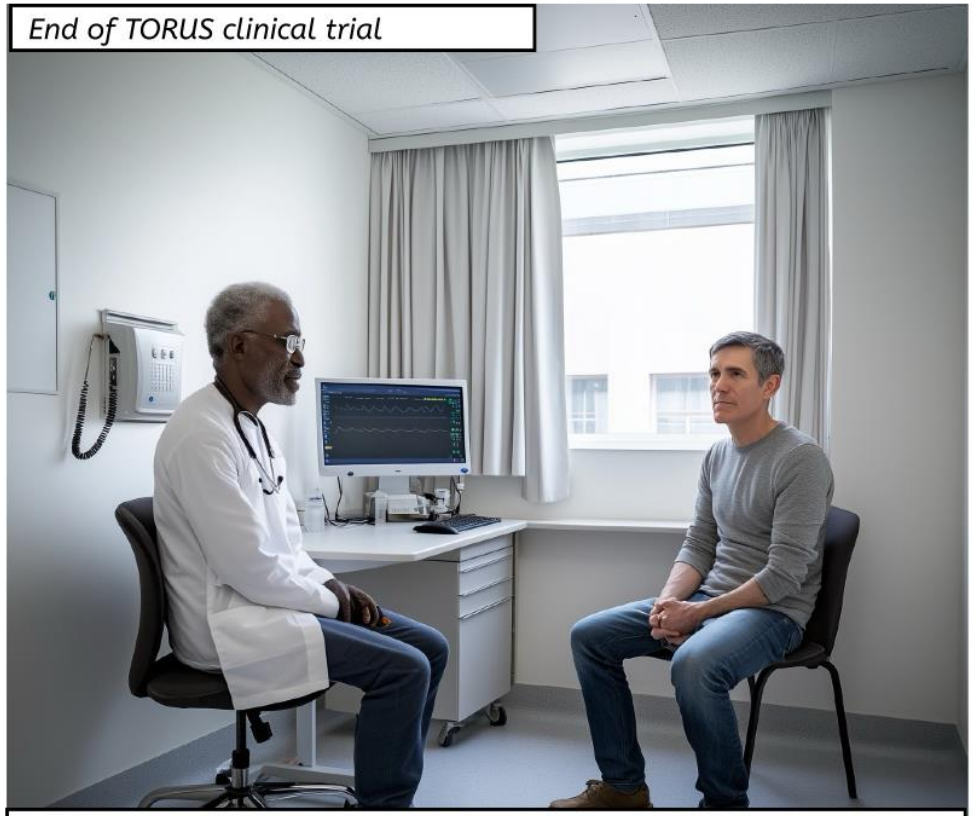
WP5 NU | Storyboard– TORUS End of Trial

End of TORUS clinical trial



David has been emailed a link to a file with a summary report and overview statistics based on the data the system has been collecting. He is interested to study it on his own, and use it for future reference when changing medication doses.

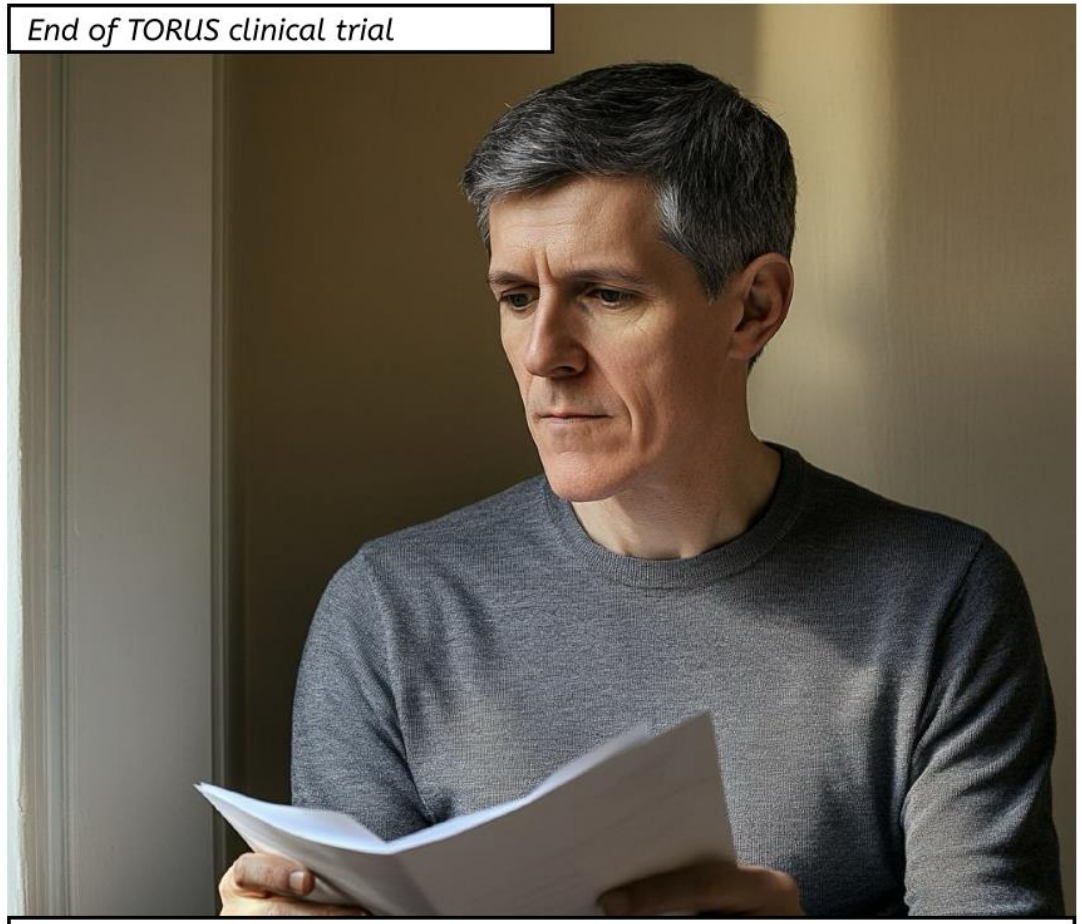
WP5 NU | Storyboard– TORUS End of Trial



After the end of the clinical drug trial, Robert had his planned appointment with a specialist.The specialist had access to the TORUS data prior to the appointment. During the appointment, they discussed Robert's progression and response to the medication, and future steps regarding medication dosing.

WP5 NU | Storyboard– TORUS End of Trial

End of TORUS clinical trial



Robert is handed a printed file with the overview statistics and monthly reports based on the data the system was collecting. Each month is represented in a different sheet of paper, with a graphic analysis of his symptoms progression. “I will study it thoroughly to get some insights on what to improve” he thought.

Questions

19. What would you be concerned about with removing the system from your home?

20. Would you be interested in a copy of your data? In what format?

21. What else would you wish for/expect at the end of TORUS trial?

22. Anything else that you would like to ask regarding ending TORUS trial?

Questions

23. What other questions do you have about taking part in a clinical drug trial using the TORUS system?

Thank you!

The following pages are intentionally left blank for you to complete if you wish to respond to the questions on paper.

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