Appendix 1. Procedure of the discussions

Procedure
At the beginning of each session, participant information consent forms were first provided to the participants. For the participant from Headway, a copy of the consent form was sent ahead of time, printed by staff, and provided to her before the interview began. Participants were asked to read through and encouraged to ask any questions about the study, then invited to sign the consent forms if they were willing to participate. The participants were informed that the maximum length of time for the discussions would be 1.5 hours, however most focus groups and interviews did not last as long. A focus group and interview guide was used to direct the discussions. Concepts and themes started to repeat on the last interview and focus group, suggesting that data saturation has been reached.[1, 2]

Headway ABI
The participant from Headway had been voluntarily using Jintronix for 2 weeks at the time of the interview. The participant was shown the preliminary item bank of the PROM-PGHD for Kinect-based simulated rehabilitation technologies, previously developed following the PROM-PGHD Development Method.[3] Afterwards questions were asked intended to encourage the participant to comment on the clarity, suitability, relevancy, and comprehensiveness of the preliminary item bank. The participant was given the opportunity to suggest changes to or reduction of existing items. The participant was then asked about how accessing and using their PGHD from Jintronix had affected her health outcomes. Questions included what emotions or reactions the stroke survivor felt from seeing their PGHD; whether they felt more or less engaged after seeing their PGHD; and if any of their rehabilitation goals changed as a result of seeing the PGHD. All discussions were audio recorded.

Melbourne health service
Participants viewed a demonstration of Jintronix™. They were shown the log-in page, the patient-facing interface including launching exercises and activities that would be prescribed by an attending clinician, the scores shown briefly after completing an exercise game, and the days active on the home page. They were asked if they had any questions. Figure 1 shows an example exercise game, while Figure 2 shows a sample exercise game score stroke survivors see after completing an activity.

Figure 1. Sample exercise game that clinicians may assign patients to perform.

Figure 2. Sample exercise game score that patients will see after performing an activity.
Participants were then shown the clinician-facing interface, including the list of patients that would be assigned to a clinician, the types of assessments, exercises, and exercise games available, how to assign and modify activities to patients, and the data immediately available to clinicians, i.e., patient outcomes summary data, and detailed outcomes data. They were then asked again if they had any more questions. Figure 3 shows some of the activities that could be assigned to a patient, Figure 4 shows a sample patient outcomes summary data, and Figure 5 shows a sample patient detailed outcomes data.

Figure 3. Some of the activities that clinicians may assign to patients.

Figure 4. Sample patient outcomes summary data.

Figure 5. Sample patient outcomes detailed data.
The participants were then shown the preliminary item bank of the PROM-PGHD for Kinect-based simulated rehabilitation technologies, previously developed following the PROM-PGHD Development Method.[3] Afterwards they were asked questions intended to encourage them to comment on the clarity, suitability, relevancy, and comprehensiveness of the preliminary item bank. They were given the opportunity to suggest changes to or reduction of existing items.

Finally, in the stroke survivors’ focus groups, participants were asked to give their perspectives on how using the PGHD from Jintronix may affect their outcomes; while in the clinicians’ focus group, clinicians were asked for their perspectives on how PGHD use may affect the outcomes of stroke survivors. Questions included what emotions or reactions the stroke survivor may have from seeing their PGHD; whether they would feel more or less engaged after seeing their PGHD; and if any of their rehabilitation goals would change as a result of seeing the PGHD. All discussions were audio recorded.

Data Analysis
Approximately seven hours comprising three focus groups and three interviews were transcribed verbatim by GLD. All transcriptions were rechecked for accuracy, and de-identified. The transcriptions, data management, and coding were conducted using NVivo 11 (QSR International Pty Ltd, Melbourne, Australia).

Deductive thematic analysis was initially conducted independently by GLD, KG, and MM on a selection of transcripts. Themes were previously derived from the identified PGHD effects from the literature.[3] Papers from a major journal special issue on PGHD[4] were analysed inductively as an efficient way of targeting reported effects for this purpose.[5] The derived themes are a representative sample of PGHD utilisation effects from a variety of health information technologies, for different health conditions. In the coding process, the transcripts were read carefully to apply codes in the form of a paraphrase or label,[6] and these codes were grouped into the themes. Selective open coding was also conducted on the transcripts to help ensure that no relevant data, i.e., data about effects of PGHD utilisation, were missed. Selective open coding may be conducted in deductive studies to help obtain a more holistic impression of the data, and to identify and explain any interesting or unusual data.[6]

Once common understanding was achieved for how themes are applied, GLD proceeded to analyse the rest of the transcripts. GLD initially listened through the recordings again, while
simultaneously reading through the transcripts in order to familiarise himself with them. Throughout this process, codes were initially applied to texts, where relevant. Afterwards, GLD proceeded to go through the transcripts again to apply codes, and double-check the initial codes applied. A coding journal was used to clarify contentious quotes with KG and MM. Afterwards, all coded transcripts were independently checked by KG and MM. Any disagreements with the codes applied were discussed over 2 coding meetings, and subsequently resolved.
Full Discussion Guide for Patients

Moderator Introduction:
“Hi, my name is Gerardo Luis Dimaguila [introduce any other researcher/s or staff present]. I am going to lead the discussion we have planned for today. The aim of this study is to get your help with a survey that we are designing. This survey would let people like you to do routine reports. These reports would form a record of how you used information about your progress that you got directly from a system like Jintronix, in other words, how you used this information by yourself, for yourself. In first part of this session, I will be showing you a demonstration of Jintronix, a stroke rehabilitation system. For the next part of the session, we are going to ask you to take a few minutes to view a pilot version of our survey. Please feel free to ask questions throughout the process. Finally, we would ask you to discuss with us and with each other, not just about your answers, but about the survey questions themselves.

“We shall now proceed with the demonstration of Jintronix. We invite you to pay attention to the data Jintronix makes available.”

Proceed with demonstration:
1. Show the log-in page.

   ![log-in page]

2. Show patient-facing interface.
   a. Launches into Jintronix programme, which first shows calibration required.

   ![calibration required]

   b. Show list of activities assigned to them that they can choose (games or exercises).

   ![activities list]

   c. Show a sample exercise and game. Show feedback score provided at the end.

   ![sample exercise]

   Sample exercise:
Sample game:

Sample feedback:

d. Show performance outcomes summary data available to patients.

3. Show clinician-facing interface.
   a. Show list of patients of clinicians.

b. Show list of activities, exercises, and assessment tasks that can be assigned to patients.
c. **Show available settings that clinicians can customise for each activity and exercise.**

![Image of available settings](image1)


d. **Show detailed performance data available to clinicians.**

![Image of detailed performance data](image2)

“Do you have any questions about Jintronix?”

*Moderator to answer questions.*

“We are now going to view the survey. Please read through the questions, and reflect on them in the light of the features and available data of Jintronix, which you have just seen.”
Proceed with handing out the survey.

“We’ll now be talking about the survey questions you have just viewed. We want to be sure that the questions in a survey like this work well for anyone, anywhere, anytime, who is using any health technology system that gives patients direct access to their own health data. So be as critical and as creative as you can in talking to us about these questions now. We are going to use what you tell us to verify the appropriateness of the current items of our survey; and add, edit or remove items as necessary.”

Under the first section of the survey (Behavioural or attitude changes), there is a list of items you were asked to consider. After seeing the information about you that Jintronix may provide, what emotions or reactions did you have that are not included in the list?

*Follow up question (if not addressed during open discussion):*

After seeing the data that Jintronix may be made available to you, are there any other things you would say about possible changes in your behaviours or attitudes or actions?

Under the second section of the survey (Self-management of care), there is a list of items you were asked to consider. After seeing the information about you that Jintronix may provide you with, what views did you have regarding these data, views that are not included in the list?

*Follow up question (if not addressed during open discussion):*

Are there any other things you would say about whether seeing your rehabilitation data may help you understand your rehabilitation progress, and how?

Under the third section of the survey (Personalisation), there is a question you were asked to consider. After seeing the information about you that Jintronix may give you, what other data or information related to your rehabilitation would you have liked to see?

*Follow up questions (if not addressed during open discussion):*

What benefits, if any, do you think seeing all of your data have? What downsides do you imagine there could be?

How would you feel about being able to see all the same data about you that your therapists receive from Jintronix?

“Now we are going to try to get some ideas from you about items for our survey which did not have any questions in the one you just viewed.”

After seeing the available data Jintronix may provide you, in what ways did you feel more or less involved or engaged in your rehabilitation progress?

*Follow up questions (if not addressed during open discussion):*

How would you describe your involvement or engagement in your own rehabilitation if you had used Jintronix?

How would you describe your involvement or engagement in your own rehabilitation after seeing the available data Jintronix may provide you?
After seeing the available data Jintronix may provide you, what perceptions, if any, might you have on why your therapist might assign you particular exercise games to perform?

Follow up questions (if not addressed during open discussion):

After seeing the available data, what questions, if any, would you be prompted to ask your therapist?

After seeing the available data Jintronix may provide you, please comment on whether you would feel more or less confident in explaining your rehabilitation progress to loved ones, friends, or other people from the data.

Follow up questions (if not addressed during open discussion):

After seeing the available data, would you be prompted to contact a loved one or a friend to discuss your rehabilitation progress, or would you feel less like doing this?

What data, if any, would you like to share with loved ones or friends?

If you shared your data to loved ones or friends, what reactions or responses would you anticipate from them, or hope for from them?

After seeing the available data Jintronix may provide you, how do you think those data will aid in determining if you need further assistance or not?

Follow up questions (if not addressed during open discussion):

Would you like your data to be used automatically, to inform therapists of your need for further assistance, if so how would you like this to work; if not, why not?

Please comment on whether you liked or disliked seeing the available data Jintronix may provide you.

Follow up questions (if not addressed during open discussion):

What did you like best about seeing the data?

What did you NOT like about seeing the data?

What did you like least about seeing the data?

If you were to use Jintronix, what other data or information, if any, would you like to see?

Follow up questions (if not addressed during open discussion):

How would you like to see this information?

When would you like to see this information?

Who else would you like to see your data?

Who would you specifically NOT like to see your data?
“Thanks very much for your participation in this focus group today. That is all the questions we have for you. What happens next is that we analyse your ideas, and incorporate them into the way we use Jintronix with other groups of patients and the way we ask other patients to give feedback on what it is like for them to see and work with their own health data from a technology system. You will not be identifiable as an individual in any of this work. If you are interested to follow the progress of our work or to talk to us later on in our research, you are welcome to leave us your contact details.”
Full Discussion Guide for Clinicians

Moderator Introduction:
"Hi, my name is Gerardo Luis Dimaguila [introduce any other researcher/s or staff present]. I am going to lead the discussion we have planned for today. The aim of this study is to get your help with a survey that we are designing. This survey would let people like your patients to do routine reports. These reports would form a record of how your patients used information about their progress that they got directly from a system like Jintronix, in other words, how they used this information by themselves, for themselves. In the first part of this session, I will be showing you a demonstration of Jintronix, a stroke rehabilitation system. For the next part of the session, we are going to ask you to take a few minutes to view a pilot version of our survey. Please feel free to ask questions throughout the process. Finally, we would ask you to discuss with us and with each other, not just about your answers, but about the survey questions themselves.

"We shall now proceed with the demonstration of Jintronix. We invite you to pay attention to the data Jintronix makes available."

Proceed with demonstration:
1. Show the log-in page.

2. Show patient-facing interface.
   a. Launches into Jintronix programme, which first shows calibration required.

   b. Show list of activities assigned to them that they can choose (games or exercises).

   c. Show a sample exercise and game. Show feedback score provided at the end. Sample exercise:
d. **Show performance outcomes summary data available to patients.**

3. **Show clinician-facing interface.**
   a. **Show list of patients of clinicians.**
   
   b. **Show list of activities, exercises, and assessment tasks that can be assigned to patients.**
c. **Show available settings that clinicians can customise for each activity and exercise.**

d. **Show detailed performance data available to clinicians.**

"Do you have any questions about Jintronix?"

*Moderator to answer questions.*

"We are now going to view the survey. Please read through the questions, and reflect on them in the light of the features and available data of Jintronix, which you have just seen."
Proceed with handing out the survey.

“We'll now be talking about the survey questions you have just viewed. We want to be sure that the questions in a survey like this work well for anyone, anywhere, anytime, who is using any health technology system that gives patients direct access to their own health data. So be as critical and as creative as you can in talking to us about these questions now. We are going to use what you tell us to verify the appropriateness of the current items of our survey; and add, edit or remove items as necessary. “Under the first section of the survey (Behavioural or attitude changes), there is a list of items you were asked to consider. After seeing the information about your patients that Jintronix may provide, what emotions or reactions do you think they would have that are not included in the list?

Follow up question (if not addressed during open discussion):

After seeing the data that Jintronix may be make available to your patients, are there any other things you would say about possible changes in their behaviours or attitudes or actions?

Under the second section of the survey (Self-management of care), there is a list of items you were asked to consider. After seeing the information about your patients that Jintronix may provide them with, what views do you think they would have regarding these data, views that are not included in the list?

Follow up question (if not addressed during open discussion):

Are there any other things you would say about your patients seeing their rehabilitation data, and whether this may help them understand your rehabilitation progress, and how?

Under the third section of the survey (Personalisation), there is a question you were asked to consider. After seeing the information about your patients that Jintronix may give them, what other data or information related to their rehabilitation would you have liked them to see?

Follow up questions (if not addressed during open discussion):

What benefits would there be, if any, if your patients saw all of their data? What downsides do you imagine there could be?

How do you think your patients would feel about being able to see all the same data about them that their therapists receive from Jintronix?

“Now we are going to try to get some ideas from you about items for our survey which did not have any questions in the one you just viewed.”

After seeing the available data Jintronix may provide your patients, in what ways do you think they would feel more or less involved or engaged in their rehabilitation progress?

Follow up questions (if not addressed during open discussion):

How would you describe your patients’ involvement or engagement in their own rehabilitation if they had used Jintronix?

How would you describe your patients’ involvement or engagement in their own rehabilitation after seeing the available data Jintronix may provide them?
After your patients would see the available data Jintronix may provide them, what perceptions, if any, might they have on why their therapist might assign them particular exercise games to perform?

*Follow up questions (if not addressed during open discussion):*

After seeing the available data, what questions, if any, do you think your patients would be prompted to ask their therapist?

After seeing the available data Jintronix may provide your patients, please comment on whether you think they would feel more or less confident in explaining their rehabilitation progress to loved ones, friends, or other people from the data.

*Follow up questions (if not addressed during open discussion):*

After seeing the available data, do you think your patients would be prompted to contact a loved one or a friend to discuss their rehabilitation progress, or do you think they would feel less like doing this?

What data, if any, do you think they would like to share with loved ones or friends?

If your patients shared their data to loved ones or friends, what reactions or responses do you think they would anticipate from them, or hope for from them?

After seeing the available data Jintronix may provide your patients, how do you think those data will aid your patients in determining if they need further assistance or not?

*Follow up questions (if not addressed during open discussion):*

Do you think your patients would like their data to be used automatically, to inform their therapists of their need for further assistance? If so how do you think they would like this to work; if not, why not?

Please comment on whether you think your patients would like or dislike seeing the available data Jintronix may provide them.

*Follow up questions (if not addressed during open discussion):*

What do you think they would like best about seeing the data?

What do you think they would NOT like about seeing the data?

What do you think they would like least about seeing the data?

If your patients were to use Jintronix, what other data or information, if any, do you think they would like to see?

*Follow up questions (if not addressed during open discussion):*

How do you think your patients would like to see this information?

When do you think your patients would like to see this information?

Who else do you think your patients would like to see their data?
Who would you think your patients would specifically NOT like to see their data?

“Thanks very much for your participation in this focus group today. That is all the questions we have for you. What happens next is that we analyse your ideas, and incorporate them into the way we use Jintronix with other groups of patients and the way we ask other patients to give feedback on what it is like for them to see and work with their own health data from a technology system. You will not be identifiable as an individual in any of this work. If you are interested to follow the progress of our work or to talk to us later on in our research, you are welcome to leave us your contact details.”
REFERENCES


